

**‘It helps me stay healthy!’ Exploring the role of mHealth
(mobile technologies) in facilitating healthy lifestyle choices
in women with a mild intellectual disability**

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Abstract

Research findings indicate that in comparison with the general population, people with an intellectual disability experience higher rates of chronic health problems. Also, females with a mild intellectual disability and living independently or with family are more likely to be obese than others with intellectual disabilities. Mobile technology use has become a significant factor in engaging people in, and marketing, healthy lifestyle programmes. Research findings also indicate that women more than men are likely to use smartphones and health apps as part of a healthy lifestyle.

The aims of this research were to explore how women with a mild intellectual disability use mobile technologies and whether these mobile technologies play a role in facilitating healthy lifestyle choices among these women. Twenty-six female students of a specialist training and support service agreed to participate in this study. Following on from findings in ten individual semi-structured interviews and five focus group discussions with student participants indicating that parents play a significant role in daughters' lives, parents of participants were invited to participate. Five parents of student participants agreed to attend. Parents of non-participants were also invited to participate in semi-structured interviews and two parents agreed but only one was able to attend for interview. Overall, six parents participated in this study.

Findings from thematic analysis of the data based on the COM-B model of behaviour indicated that students are knowledgeable about mobile technology and are aware of, and sometimes use, apps and sites that are useful in making healthy lifestyle choices. Healthy lifestyle choices identified by students focused on diet, exercise, and sleep, on body issues such as epilepsy and food intolerance and on girls problems including the menstrual cycle. They spoke about how these issues impact on health

behaviours and on the opportunities they have in making healthy or unhealthy lifestyle choices. The role of parents as protectors/advisors was also highlighted as significant in influencing students' opportunities to engage in specific behaviours and in choices they make that relate, in particular, to diet and exercise.

What is unique about this study is that it adds student participants' experiences and opinions on how useful mobile technologies are, or can be, in facilitating healthy lifestyle choices in females with a mild intellectual disability.

1. Introduction

The following six sub-chapters provide, in the following order, a summary of the background to this study; an introduction to, and description of, the Behaviour Change Wheel (BCW) and the COM-B (capability, opportunity, and motivation) model of behaviour developed by Michie et al (2011) used in this study as a framework for understanding behaviour; definitions of intellectual disability that are recognised internationally; an exploration of the factors that facilitate healthy lifestyles; and an introduction to, and definition of, mHealth. The final two sub-chapters provide a description of the rationale for this study, and the aims and objectives of this research, respectively.

1.1 Background to Research

The principal researcher is employed as Regional Psychologist in National Learning Network (NLN), an organisation that provides training and education courses to over 5,000 students each year in 50 centres across Ireland. NLN is part of the RehabGroup, an international organisation that provides services to people with disabilities (physical, sensory, and intellectual), people with autism, people with acquired brain injury, people with mental health issues, older people, carers and others who are marginalised. Each year, more than 43,000 people and their families benefit from the services provided by RehabGroup's 3,500 staff in almost 250 locations across Ireland, the UK, the Netherlands, Poland, and Saudi Arabia (RehabGroup, 2017).

At NLN, students participate in programmes with core modules that include personal effectiveness, healthy lifestyle behaviours (diet, exercise, and sleep hygiene), and independent living skills (budgeting, shopping, cooking, and self-care), career planning, and IT skills. The psychologist is part of a team of professionals in each centre who work with students.

The role of the psychologist in NLN encompasses four key areas: providing a psychological assessment and intervention service to learners (to groups, and on a one-to-one basis), staff consultation, organisational consultation, and conducting psychological research (Table 1). In the context of providing direct support to students, the psychologist usually meets with each student on a one-to-one basis when that student has had an opportunity to settle into her/his programme (usually 6 weeks into the programme). The purpose of this meeting is to check in with each student to ensure that his/her strengths and needs are being accommodated within the programme. Other one-to-one sessions occur when students self-refer, or are referred by a tutor, to explore difficulties that impact on his/her ability to participate in training such as anxiety, depression, memory deficits, difficulties with focus and concentration, suicidal ideation, eating disorders, alcohol or drug abuse, and self-harm (Table 1).

Responsibilities of Regional Psychologists (RP)

Abuse	Any child protection or safeguarding issue. Includes all necessary paperwork and follow-up with staff, managers, other health care professionals, social workers, TUSLA, HSE Safeguarding teams, Gardaí, Probation Services etc.
Addiction	Including addiction issues relating to alcohol, drugs, gambling, sex, pornography, spending, and hoarding.
Anger & Aggression	Includes all types of aggression, violence, giving and receiving threats and any form of domestic violence.
Anxiety	Includes panic attacks, phobias and any form of OCD.
Assertiveness & Confidence	Includes all assertiveness and confidence building interventions.

Behavioural Issues	Includes all forms of challenging behaviours. Includes preparation of support plans and any necessary follow-up with staff, managers, family members and other professionals.
Bereavement	All forms of grief, loss, and dying. Includes loss of family members, friends, pets, jobs, divorce, separation, etc.
Clinical Risk Assessment	Includes any formal risk assessment outside of Intake assessment (which is considered part of the screening process). Clinical Risk Assessment includes RAMAS, information gathering, liaison with external health care professionals, and creation of risk management plans. A clinical risk assessment is necessary where new information comes to light after the person has started a program. This information may suggest the person may pose a risk to others. This additional information may arise during (but not limited to) a Child Protection or Safeguarding issue, during periods of aggressive, violent behaviour in the centre, or additional information received during the Needs Assessment interview. Risk to self is assessed under Suicide and Self Harm.
Concentration and Memory	Includes all memory & information processing interventions, strategies and support plans.
CPD Activities	Includes attendance at National RP meetings, attendance at conferences, workshops, or training courses. Reading psychological journals and materials, receiving training, and self-care activities.
Delivering Training to Learner	Includes all types of training and group psycho-education to learner's e.g. RSE, Boundary Management, Anti-bullying, Safe Navigation of Social Media etc.
Delivering Training to Staff	Includes delivery of all types of training to staff, e.g. Boundary Management, Child Protection Training, Safeguarding Training, Promoting a Positive

Behavioural Environment, Responding to Challenging Behaviours etc.

Depression Includes low mood, low or lack of motivation, and any attendance and time-keeping issues related to depression.

Developing Training All aspects of developing training or updating existing training delivered to staff and learners.

Evaluating Mental Health and / or Suitability for a Course Includes re-entry assessment meeting with learner following sick leave, check-in meeting relating to mental health stability, and wellness checks.

Family Includes all issues relating to adoption (current and historic), parenting, pregnancy, family relationships - does not include any Child Protection or Safeguarding issues that relate to family relationships. These will be addressed under abuse. Includes family intervention work and legal / court issues relating to separation, divorce, custody etc.

Frustration/ Complaint / Bullying Includes all formal and informal complaints raised by learners or staff / managers.

Intake Screening Interview Includes all meetings with applicants prior to starting the course for risk assessment and suitability for service and / or course. As per procedure all applicants with risk boxes ticked on the Health Report should have a screening interview prior to commencing the course. Managers and / or staff may also request a screening interview even if no risk boxes ticked.

Medication Includes all issues relating to medication, side-effects, emerging side-effects, queries, and non-compliance, and any issues with attendance and time-keeping relating to medication.

Offending and Criminal Behaviour Includes all issues relating to court appearances, previous or current convictions, liaising with Probation services.

Paranoia	Includes management strategies for paranoid thoughts and related interpersonal difficulties.
Physical Illness & Pain Management	Includes all aspects of pain management, coping with physical illness. Includes any impact on attendance and timekeeping
Professional Consultation with Organisation	Includes any and all consultation with Regional Operation Officers, Integration Service Managers, Senior Psychologist, Senior Social Worker, HR Business Managers, and other senior staff on managing psychological/clinical issues affecting the organisation. Includes attending workshops, participation on working groups etc.
Professional Consultation with Staff	Includes regular case management style meetings with staff e.g. meeting with instructors/tutors to review how each student is progressing. Any meeting with staff outside of the Individual Action Plan process where learner's needs/strengths are being discussed - includes consultation with the instructor/tutor, resource teacher, manager about rehabilitative strategies for improving the training environment - ensuring best practice. Does not include programme review style meetings e.g. discussing how to incorporate New Directions, Recovery etc.
Program Reviews	This includes all meetings with Programme Development Officers, instructors/tutors, managers, to review or update a programme e.g. New Directions, ETB Reviews.
Promoting Autonomy	Includes all aspects of independent living e.g. financial independence and accommodation, mobility etc.
Psychological Assessment	Includes Neuropsychological Assessment, Specific Learning Difficulties Assessment, and any other psychological assessment administered. Does not include Intake or Risk assessment.
Receiving Supervision	Includes receiving supervision, providing supervision to other psychologists and assistant psychologists e.g. attendance at peer supervision meetings, one to one supervision meetings and formal peer supervision. Does not include providing supervision to Rehabilitation Officers.

Referral for Counselling	Includes all aspects of making referral to any counselling agency or therapeutic service for learners, including paperwork, phone calls etc.
Relationships & Communication Difficulties	Includes issues with personal intimate relationships, issues with friendships, and all interpersonal communication difficulties. Does not include any family related relationship issues.
Research	All aspects including undertaking and participating in all forms of research. Includes presentation at conferences etc.
Sexuality	Includes any issues relating to sexual education (other than the RSE training), sexual issues, sexual identity, LGBT.
Sleep / Fatigue	Includes all issues with tiredness, sleep hygiene, and any related attendance and/or timekeeping issues.

Table 1. Responsibilities of Regional Psychologists in National Learning Network (2018)

In many of these circumstances the psychologist links the student with external supports within the community while also supporting the person through his/her training. The psychologist usually facilitates group sessions with students when delivering or facilitating training or workshops in areas such as bullying/cyber-bullying, safe navigation of social media, personal space (boundary management) workshops, relationships and sexuality training, study skill workshops, and WRAP (Wellness Recovery Action Plan) programmes (Table 1).

The main findings from a systematic review (Appendix A) of risk factors for obesity (an independent risk indicator for cardiovascular disease (CVD) and of an unhealthy lifestyle) in adults with an intellectual disability indicated that females classified with a mild intellectual disability and living independently, or with family, are more likely to be obese than others classified with an intellectual disability. What was also evident from the systematic review findings is that the majority of research

on health behaviours of individuals with an intellectual disability is taken from the perspective of carers or parents rather than from the perspective of those individuals, indicating a gap in existing knowledge in this area (Beail & Williams, 2014; Coons & Watson, 2013). The first main finding resonated with this researcher who noticed that many female students with a mild intellectual disability attending NLN services in the five centres in the south-east presented as being over-weight or obese.

The use of smartphones, health apps, and social media has become a significant part of the story of engaging people in healthy lifestyles practices and also in marketing diet and exercise programmes (Handel, 2011). Statistics from a large scale longitudinal study (Andone et al, 2016) with a sample size of 30,677 participants (16,147 of whom were male and 14,523 were female) indicate that females spend more time on their phones than males, spending a daily average of 166.87 minutes (SD = 91.95) in comparison to males who spend on average 154.26 minutes (SD = 92.78) per day. Andone et al indicate that women are more likely to use their phones for communication and social media and men are more likely to spend time gaming. Research findings from the US (Salesforce Marketing Cloud, 2014) indicate that women (72%) primarily use their phones for accessing social media/networks, and short message service (SMS) text messaging while a significantly higher number of males (54%) use smartphones for news alerts. Findings from the same source indicate that more females (30%) use social media on a daily basis than males (26%) and that greater numbers of females use the 'visual web' where, for example, more females (20%) use Instagram than males (15%). Also, Derbyshire & Dancey (2013) found that women are more likely than men to use health apps and sites that support a healthy lifestyle.

In conversation with tutors across the five NLN centres in the south-east of Ireland, they reported that students are constantly on their smartphones or tablets and stated that they have to remind students to put their phones or tablets away while working on specific assignments so as not to distract other students. These conversations prompted this researcher to question how, and for what purpose, students with an intellectual disability use mobile technologies. This researcher was unable to find any research in this area and set out to explore how female students use these technologies and whether they find them to be useful resources in everyday life, particularly in areas such as facilitating healthy lifestyle choices.

This would be more than just an information-seeking exercise; it would be an inclusive research where students would be facilitated in sharing their experiences of using mobile technologies in their daily lives. It would be an opportunity to explore whether mobile technologies have a role to play in supporting healthy lifestyle behaviour. It might also provide an opportunity for students and tutors to explore ways of using smartphones and mobile phones as part of healthy lifestyle modules.

1.2 Understanding Behaviour

In order to understand how mHealth may facilitate healthy lifestyle choices among women in this population it is necessary to have a model of behaviour that describes the factors that contribute to behaviour. There are numerous models of behaviour relevant to health psychology including the theory of reasoned action/theory of planned behaviour, the health belief model, social learning theory, and the transtheoretical stage model and while all of these models address some aspects of behaviour none offer a comprehensive or integrated framework for understanding behaviour (University College London, 2015).

The model of behaviour chosen for this study was the COM-B model developed by Michie et al (2011). Michie et al designed this model to be a central part of the Behaviour Change Wheel (BCW) (Figure 1). The BCW is a guide to designing behaviour interventions developed by Michie et al “not only to aid intervention design, but also to improve the process of intervention evaluation and theory development” (Michie et al, 2014; pp. 15-16). The BCW was developed from a review of 19 frameworks of behaviour change they identified across 83 theories. According to Michie et al (2014), none of these 19 frameworks offered a comprehensive approach to behaviour change nor were they “conceptually coherent or clearly linked to a model of behaviour change” (p. 16).

The role of the COM-B model of behaviour (Figure 2) in the BCW is to provide practitioners with a starting point where behaviours can be identified in the context in which they occur (Michie et al, 2014). The COM-B model of behaviour forms the core of the BCW that provides practitioners with a “systematic way of characterising interventions that enables their outcomes to be linked to mechanism of action, and it can help to diagnose why an intervention may have failed to achieve its desired goal” (p. 16). However, Michie et al (2014) point out that using the BCW is neither a “blueprint” nor a “panacea” for behaviour change; according to Michie et al it facilitates the best use of available resources and information to hand.

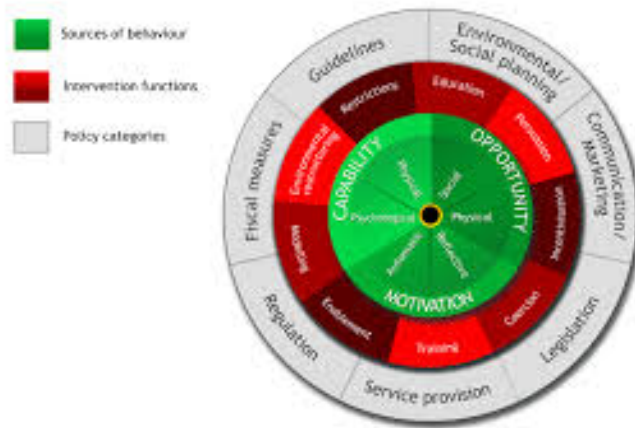


Figure 1. The Behaviour Change Wheel (Michie et al, 2011 – reproduced with permission of the author)

The BCW is comprised of three levels: at the centre of the wheel are the three components (capability, opportunity, and motivation) that make up the COM-B model of behaviour; surrounding this core is a circle containing nine intervention functions (education, persuasion, incentivisation, coercion, training, enablement, modelling, environmental restructuring, and restriction) that are dependent on the outcome of the COM-B analysis. The outer circle of the wheel provides seven policy options (environmental/social planning, communication/marketing, legislation, service provision, regulation, fiscal measures, and guidelines) that can be used to support delivery of the intervention functions (Michie et al, 2014). Lefevre (2016) described the BCW as a “framework that provides developers with a comprehensive, coherent, and universal toolkit for intervention design” (p. 1).

In the COM-B model, Michie et al describe *Behaviour* (B) as any action involving the interaction among the following three conditions; capability, motivation, and opportunity. *Capability* (C) is defined as the physical and psychological ability each individual has that facilitates his or her engaging in any activity. *Motivation* (M) is defined as the volitional and non-volitional mechanisms that energize and direct behaviour including automatic processes such as habitual

behaviour, impulsivity, emotional responses, and reflective processes involved in conscious decision-making and goal planning. *Opportunity* (O) is defined as contextual factors that lie outside the control of the individual such as physical opportunity afforded by environmental factors and/or social or cultural factors that influence an individual's way of communicating and being in the world. A behavioural intervention might change one or more components within this interactive system and according to Michie et al (2011) “*the causal links within the system can work to reduce or amplify the effect of particular interventions by leading to changes elsewhere*” (p. 4).

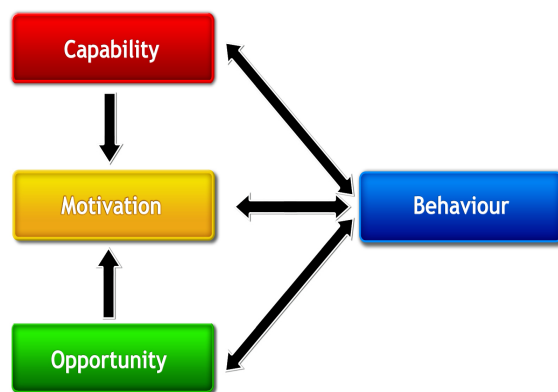


Figure 2. The COM-B Model of behaviour (Michie et al, 2011) (used with permission of the author)

Unlike the majority of models of health behaviour the COM-B model offers a broader framework for understanding behaviour by including context (opportunity) and automatic processing (motivation) among the components (Michie et al, 2011).

However, Ogden (2016) critiqued the development of the BCW and the COM-B model of behaviour describing it as an effort to reduce patient variability without taking into consideration the facts that patient variability is inevitable and that too many gaps exist that are not amenable to change. The gaps Ogden referred to include those between the patient's beliefs and behaviour, gaps between the patient's beliefs

and those of the health professional, and gaps between the health professional's behaviour and that professional's training. In other words, Ogden stated that there are too many gaps between the protocols as promoted within the BCW and the actual experience of the patient.

She further critiqued the development of the BCW as an attempt to remove the variability that exists within theories of behaviour within health psychology. She suggested that this striving to synthesise methods of engaging with individuals moves practitioners away from a professional role where professional opinion and ability to engage with the patient is an important part of the treatment protocol. This position is partly supported by Peters and Kok (2016) who, while they disagree with what they describe as Ogden's "somewhat fatalistic interpretations" of the consequences of relegating individual variability, stated that they agree with the importance of maintaining theoretical variability (p. 267).

This choice of using the COM-B model of behaviour was based on the ontological (critical realist) position and the epistemological (contextualist) position taken by this researcher. These positions are discussed in the methodology section in this study. The significance of the components in the COM-B model of behaviour to this study is explored later where themes are discussed.

1.3 Intellectual Disabilities & Healthy Lifestyles

The World Health Organisation (WHO, 2015) defines intellectual disability as:

A significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

According to the American Association on Intellectual Disabilities (AAID), *“intellectual disability is a disability characterized by significant limitations in both **intellectual functioning** and in **adaptive behavior**, which covers many everyday social and practical skills. This disability originates **before the age of 18**”* (2013 – bold as per original document)

The WHO also states that disability is context-based where environmental factors play a significant role in enabling/disabling the individual to participate in his/her community and be included in society (2015). It is estimated that approximately 2% of the UK population (Public Health England, 2013) and 1.4% of the population of the Republic of Ireland (Census, 2016) has an intellectual disability. According to the WHO (1999):

A healthy lifestyle is a way of living that lowers the risk of being seriously ill or dying early. Not all diseases are preventable, but a large proportion of deaths, particularly those from coronary heart disease and lung cancer, can be avoided. Scientific studies have identified certain types of behaviour that contribute to the development of non-communicable diseases and early death. Health is not only just about avoiding disease. It is also about physical, mental and social wellbeing .

According to Public Health England (2016), the major causes of premature death in the UK are cancer, cardiovascular disease, respiratory disease, and liver disease. All of these diseases are linked to behavioural risk factors such as tobacco use, excessive consumption of alcohol, lack of physical activity, nutrient poor diets, and also to factors associated with being obese or overweight. Public Health England (2016) describes obesity as an epidemic responsible for up to 30,000 deaths each year in the UK. They state that it is estimated that the NHS spent approximately £6.1 billion on overweight and obesity-related health problems among the general population in

England between 2014 and 2015. They point out that the annual amount spent on obesity and diabetes is greater than the combined costs of the police, fire, and judicial services.

A factor highlighted in research findings (Feldman et al, 2016; Robertson et al, 2014) is that adults with an intellectual disability experience significantly higher rates of age-related morbidity and mortality than their peers. According to Public Health England (2015a), mortality rates for people with an intellectual disability are approximately three times those of people in the general population. They also state that the rate of obesity among adults in this population is significantly higher than that of the general UK population. Their research findings indicate that females with an intellectual disability aged 18 to 24 have a BMI of 35.4% (a reading over 30% indicates obesity) compared to 15.4% (18.5% to 25% normal range) among females within the general population (Public Health England, 2015b). Figures for all ages indicate that obesity is more prevalent among females with an intellectual disability than females in the general population (2015b). Hsieh et al (2014) found that rates of morbid obesity among young adults (i.e., 18 to 39 years) with an intellectual disability were almost double those in the general population. According to Mitchell et al (2016) there is evidence to suggest that cardio-metabolic risk factors are present in adolescents with an intellectual disability thereby contributing to the greater disease burden among adults in this population.

The WHO (2015) defines overweight and obesity as ‘abnormal or excessive fat accumulation that may impair health’ and the World Heart Federation (WHF) (2011) state that being overweight or obese is a major risk factor for non-communicable diseases. Non-communicable diseases include cardiovascular disease (mainly heart disease and stroke which were the leading causes of death worldwide in

2012), diabetes mellitus, musculoskeletal disorders (especially osteoarthritis – a highly disabling degenerative disease of the joints), some cancers (endometrial, breast, and colon), gastric problems, tooth decay as a result of a diet high in sugar, gall bladder problems, excessive gasses and gastric bloating, liver problems, respiratory problems and sleep apnoea.

The WHF (2011) describe physical activity as a protective factor for non-communicable diseases and state that anyone, at any age, who engages in physical activity increases his/her protection against these diseases. They also state that diet plays a significant role in both the development of, and protection from, non-communicable diseases such as cardiovascular disease, and that a healthy diet is one of the key modifiable and protective risk factors that impacts on all other risk factors for cardiovascular disease. While the WHF acknowledges the many non-modifiable risk factors for non-communicable diseases such as age, gender, ethnicity, and socio-economic status, they emphasise the importance of managing modifiable risk factors such as diet, exercise, and weight.

Data from Public Health England (2015b) indicate that the risk factors for obesity in adults with intellectual disabilities include behavioural, environmental, and biological factors. Their findings support those of Slevin and Northway (2014) who described causative factors and barriers for health behaviours as genetic and physical factors, psychological factors, and social and cultural factors. In identifying health behaviours that positively or negatively correlate with a healthy lifestyle, Hsieh, Rimmer and Heller (2014) identified modifiable and non-modifiable risk factors for obesity. Non-modifiable ones identified were gender, age, severity and type of intellectual disability, and genetic syndrome. Modifiable risk factors they divided into personal risk factors and environmental risk factors. Personal risk factors included

medication that causes weight gain, diet, and physical activity while environmental risk factors included residential type.

One of the main findings from other studies in this area (Mikulovic et al., 2014; de Winter et al., 2012; Gazizova et al., 2012; Maaskant et al., 2009; Sohler et al., 2009; Bhaumik et al., 2008; Moran et al., 2005; Moore et al., 2004; Robertson et al., 2000) indicated that the non-modifiable risk factor of gender (being female) is a high risk factor both for obesity and poor health among people with an intellectual disability. Research findings also indicated (Hsieh et al, 2014; de Winter et al., 2012; Gazizova et al., 2012; Bhaumik et al., 2008; Robertson et al., 2000) an association between the non-modifiable risk factor of severity of intellectual disability and obesity; those with a mild intellectual disability are more likely to be obese than those classified with either a moderate or severe disability. However, Moran et al (2005) found no significant difference in prevalence of obesity between people with mild intellectual disability and the general population while Maaskant et al (2009) found that level of intellectual disability did not impact on weight status in their longitudinal observational study.

Living independently or with family members rather than living within more restrictive accommodation (e.g., residential services) was found to be a risk factor for unhealthy behaviours among adults with an intellectual disability, including physical inactivity and unhealthy eating habits leading to obesity (Koritsas et al 2016; de Winter et al., 2012; Bhaumik et al., 2008; Robertson et al., 2000). However, Hsieh et al (2014), Maaskant et al (2009) and Moore et al (2004) reported no significant difference between accommodation status and weight status in this population while Mikulovic et al (2014) found that people living within more restrictive accommodation had higher levels of unhealthy eating habits, lower levels of physical

activity and of obesity than those who were either half-boarders or living independently. However, Hsieh et al did make the point that those living in urban areas tend to have a higher risk of developing obesity than those living in rural areas, counter to findings in the general population as reported by Jackson et al (2005); they found a small significant difference in accommodation location rather than status. According to their findings, adults with an intellectual disability living in urban settings with less supervision spend significantly more time watching television, eat less fruit and vegetables, consume greater amounts of fast foods, sweetened beverages and salty snacks, smoke more, and consume greater volumes of alcohol than those in less supervised rural settings.

Physical inactivity as a risk factor for obesity was highlighted in several studies (Robertson et al., 2014; de Winter et al., 2012; Robertson et al., 2000). According to Koritsas and Iacono (2016), fewer young people and adults with an intellectual disability engage in recommended levels of physical activity than among the general population. Conversely, Mikulovic et al (2014) found higher levels of physical activity among overweight adults with intellectual disability than in the general population. In their study, Gazizova et al (2012) and Sohler et al (2009) recommended that level of physical activity be included in future studies in order to address risk factors for obesity at a behavioural level.

As well as physical inactivity, poor nutritional food choices also impact negatively on the health of adults with an intellectual disability. Jobling and Cuskelly (2006), cited in Caton et al (2012), reported that adults with an intellectual disability are capable of choosing healthy food options but actual food choices are based on preference. However, Curryer et al (2015) also made the point that overprotective parents and families may unintentionally deprive a family member with an intellectual

disability of opportunities for self-determination, i.e., to learn how to make competent decisions about healthy food choices and about exercise from personal experience.

Opportunities for self-determination are referred to by Wehmeyer (2003) as *'acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference'* (pp. 177). Curryer et al suggest that these opportunities for self-determination are limited in families where parents are convinced that they know what is best for family members. There is also evidence to suggest (Williden et al, 2006) that parents use highly dense caloric foods as a reinforcer for good behaviour thereby creating a link between specific food types and 'good' or 'bad' behaviour. Findings from studies (Koritsas et al, 2016; Hsieh et al, 2014; McGuire et al, 2007) based on data provided by care givers and family members (rather than directly by adults with an intellectual disability) also indicated that food choices made on behalf of many adults with an intellectual disability fall short of the recommended nutritional content.

1.4 mHealth

The unprecedented spread of mobile technologies as well as advancements in their innovative application to address health priorities has evolved into a new field of eHealth, known as mHealth. According to the International Telecommunication Union there are now close to 5 billion mobile phone subscriptions in the world, with over 85% of the world's population now covered by a commercial wireless signal. The penetration of mobile phone networks in many low and middle-income countries surpasses other infrastructure such as paved roads and electricity, and dwarfs fixed Internet deployment. The growing sophistication of these networks – offering higher and higher speeds of data transmission alongside cheaper and more powerful

handsets – are transforming the way health services and information are accessed, delivered, and managed. With increased accessibility comes the possibility of greater personalization and citizen-focused public health and medical care (WHO, 2011).

The number of mobile phone subscriptions worldwide is now close to 7 billion with mobile device usage in developing countries reaching 90% and a global reach of 96% (Voth, Oelke, & Jung, 2016). Smartphone usage by adults in the UK is at 85% with an expected usage of 90% by 2020 (Deloitte, 2017). Deloitte (2017) described the ongoing development of smartphone capability and availability as being strategically important to both the private and public sector. They also state that smartphones will be regarded as the primary method of communication and interaction both for services, such as health care services and public health services, and for people in general. This dramatic rise in the use of smartphone usage provides health care professionals with an opportunity to promote health behaviour change for groups and in peer-to-peer support for individuals (Kamel Boulos, Giustini, & Wheeler, 2016).

However, some researchers suggest that factors associated with smartphone and health app use are not yet fully understood (Emsting et al., 2017). In their population-based survey of German nationals aged 35 or over, Emsting et al (2017) found that while two-thirds of participants indicated that they owned a smartphone, only one fifth stated that they use health-related apps. They also found age-related, socioeconomic-related, literacy-related, and health-related disparities between those that used health apps and those that did not. Health app users were younger, less likely to be native German speakers, more likely to research health-related matters on the Internet, more likely to suffer with chronic health conditions, and more likely to engage in certain health behaviours. However, they stated that health app usage was

not reflected in positive health behaviours and suggested that usage may reflect motivation rather than actual performance.

Jantine Dute et al (2016) made the point that despite the rise in the use of smartphones by young people very few high-quality research studies are available about the potential use of mobile apps in health promotion for adolescents and students. They suggested that this may be due to the dynamic nature of the development of mobile technology contrasting with the often time-consuming processes involved in doing and publishing research. Rivera et al (2016) found that despite the proliferation of health apps for weight management the majority lack evidence-based strategies. Their findings also indicate that the rapid growth in the commercial market has resulted in a lack of appropriate scientific assessment of these apps, in the absence of input from health professionals, and a lack of evidence-based strategies for behaviour change.

In contrast to apps that may be found on the commercial market, Allman-Farinelli et al (2016) completed a nine-month randomised controlled trial of a 12-week multi-component mHealth intervention programme (TXT2BFiT) for prevention of weight gain in young adults. Findings from their study indicated modest weight loss at twelve weeks with further weight loss at nine months in 18 to 35 year-olds. This study indicates that mHealth technologies that offer multi-component factors, including personalised feedback on goal setting and review, tend to be more effective in promoting behaviour change than basic generic health apps that are commercially available.

These findings are further supported by research data from users of mobile health technologies (Miyamoto et al, 2016). This research data indicated that the following key design elements are essential in ensuring successful behaviour change;

apps must fit in with busy users' lifestyles, they must provide personal feedback, they must support social networks for sharing activities, for providing support, or for competition (gaming format), and they must provide professional health support (Miyamoto et al, 2016; Waterlander et al, 2014). In order for mHealth technologies to be effective their designers must create an interface that consistently re-engages the user (Miyamoto et al, 2016; Walsh et al, 2016).

According to Miyamoto et al (2016), findings from their research indicate that mobile diaries have been shown to engage patients in a focused way in tackling health behaviour activities; mobile displays are effective ways of communicating with users, as are reminder notifications by text or short-messaging service (SMS). Also Pfaeffli Dale et al (2016), in a systematic review of the effectiveness of using mobile technology in health behaviour change, found that the use of text messaging or short-message service (SMS) had significant positive effects on health behaviour change. These findings support those of Waterlander et al (2014) who stated that one criterion of successful mHealth weight management programmes is a personalised programme with immediate and informative text messages, with a preference among participants for at least one text message per day.

Haymes et al (2013) made the point that smart technology can be a useful resource for people with an intellectual disability in managing their healthcare needs. They stated that people with an intellectual disability would greatly benefit from access to accurate knowledge and real-time feedback in making healthy lifestyle choices. An important part of maintaining a healthy lifestyle within this population is access to smart technology, however research indicates that people with intellectual disabilities are less likely than those within the general population to access health information on the internet (Chadwick et al, 2013; Haymes et al, 2013).

The findings of Haymes et al (2013) are supported by those of Kagohara et al (2013) who reviewed 15 studies on the use of iPhones, iPad's, and iPods by students with an intellectual disability. Findings from these studies indicated positive results in acquiring targeted skills in academics, communication, employment, leisure, and transitions among students who used mobile technologies. Haymes et al suggested that these findings indicate that adults with an intellectual disability have the ability to engage with mobile health technologies as long as these technologies are user-friendly.

However, another factor that needs to be considered is the reality that some people with intellectual difficulties experience external and/or internal barriers to using the Internet. Sorbring (2017), Normand (2016), and Lussier-Desrochers, Caouette, and Godin-Tremblay (2016) indicate in their research findings that some people with intellectual disabilities experience barriers they described as ranging from the most basic barrier (*first barrier*) of gaining access to digital devices such smartphones and/or tablets through physical/sensory, cognitive, and/or technical difficulties that the individual may have through to the *fifth* and final barrier; understanding social and cultural norms/conventions when communicating online.

1.5 Rationale for this Research Project

Mobile technologies and access to the Internet are part of everyday life for the majority of people. People use the Internet and apps for keeping up-to-date on news items, weather, education, gaming, business, banking, socialising, maintaining friendships, and healthy lifestyle activities (Chadwick et al, 2013).

What is indicated in research findings is that despite the increased usage of the Internet and apps, there are many health apps created commercially with little evidence of scientific rigour involved in design and production. What is also indicated

in these findings is that there is little information on how people with an intellectual disability use the Internet and how they use apps. As stated earlier, research in the area of intellectual disability tends to focus on individuals as passive participants in their own lives (Coons & Watson, 2013) with research focused on data collected from carers and/or family respondents. This is despite the encouragement by the UK Research Governance Framework for Health and Social Care (Dept. of Health, 2005) to researchers to move from doing research on and about people with an intellectual disability to doing research with them. What this researcher also found was a paucity of research on the use of mobile health technologies by adults with an intellectual disability.

There is evidence from research findings to indicate that women use mobile technologies in support of healthy lifestyle choices in greater numbers than men. There is also evidence to indicate that females with a mild intellectual disability and living independently or with family are more likely to be obese and are, therefore, at greater risk of non-communicable diseases associated with obesity than others classified with an intellectual disability. These factors form the rationale for this study, which is an exploration of the role of mobile technologies in facilitating healthy lifestyle choices by women with a mild intellectual disability.

1.6 Aims and Objectives

The aims of this research project were to discover how female students use mobile technologies and whether they use them as a resource in making healthy lifestyle choices. These aims were broken down into the following objectives; the first objective was to discuss with student participants their use of mobile technologies, and the second was to discuss health issues that matter to them in order to understand if/how these health issues impact on their lifestyle choices.

2. Methodology

2.1 Research Methods

The method suited to an exploratory study such as this is qualitative; qualitative research is concerned with words and images and can be either experiential or critical (Braun & Clarke, 2013). Experiential qualitative research focuses on participants' interpretations of events in order to validate their experience and understand data from their perspectives. The role of the researcher is to organise data in an interpretative framework that reflects the personal and social context of participants' words. In other words, the analysis of data is not based upon the researcher's knowledge of participants but views participants as the experts on themselves (Braun & Clarke, 2013). Critical qualitative research, on the other hand, re-frames participants' stories in order to gain an understanding of how the language they use shapes their social realities (Braun & Clarke, 2013). Researchers using this approach view language as a means an individual has of creating reality rather than as a reflection of that individual's reality.

The approach taken by this researcher was an experiential one where participants' viewpoints were explored through semi-structured interviews and focus groups. Also included in this research are interviews with parents of students, including one parent of a non-participant student who gave her consent for her parents to share their experience. Parents were included as it became evident throughout the process that parents play a significant role in the health behaviours of the students who participated in this research.

2.2 Theoretical Framework & Approach

The methodology used in any qualitative research study is dependent upon the theoretical framework of the researcher. The researcher's theoretical framework is a

combination of that individual's ontological assumptions (i.e., the study of how individuals conceptualise reality; if they believe that social reality exists independently of human interpretation), and epistemological perspective (i.e., the study of knowledge, of what it is possible for individuals to know, and how they know what they know) (Braun & Clarke, 2013; Ritchie & Lewis, 2009).

Two ontological assumptions described by Braun & Clarke (2013) relevant to research are 'realism' and 'relativism'. Researchers who take a realist approach work on the assumption that there is only one truth out there in the world and this truth is accessible through the use of appropriate research methods. This is the approach most commonly used by quantitative researchers. Those who take a relativist approach describe multiple constructed realities that are influenced by environmental and personal factors. Braun and Clarke describe critical realism as being an in-between approach where reality exists as a backdrop to individuals experience but is not accessible to the researcher.

In this research project the ontological theoretical framework of the researcher is based on a critical realist perspective that assumes data can provide information about reality but can never 'mirror' reality (Beal & Williams, 2014). At the core of critical realism is the belief that ontology (what we 'know') cannot be reduced to epistemology (how we 'know') as human knowledge can only know a part of what is real in the world (Fletcher, 2017). According to Bhaskar (1975), acknowledging that our knowledge of reality is limited is not the same as saying there is no reality. Critical realists posit that at the heart of critical realism is realism about ontology - an inquiry into the nature of things. Ontological realism asserts that much of reality exists and operates independently of our awareness or knowledge of it. Reality does

not wholly answer to empirical surveying or hermeneutical examination (Archer et al, 1999).

Epistemological assumptions are based on what may be described as ‘legitimate knowledge’ (Braun & Clarke, 2013) and address the question of what it is possible for individuals to know. Epistemological positions are usually described as ranging from a positivist perspective to a constructionist perspective with a middle position being held by contextualists. Those holding a positivist (realist) perspective assume that reality can be directly observed using a scientific approach where confounding variables can be accounted for. On the other end of the spectrum, social constructionists (constructivism) state that there is no reality ‘out there’ to be discovered and that reality is a combination of ‘knowledge’s’ (Braun & Clarke, 2013); that *‘experiences are structured and understood through concepts and contexts, which are constructed by this subject’* (Flick, 2009, pp. 70).

Holding the middle ground are the contextualists who do not assume that a reality can be described without understanding contextual factors (Flick, 2009). Contextual research is an exploratory process that focuses on the ‘what’ and ‘how’ of the social world as experienced by participants (Richie & Lewis, 2009). The epistemological approach taken in this study is a contextualist one and is congruent with the ontological framework of the researcher described above.

The theoretical approach taken by this researcher in understanding behaviour is the COM-B model of behaviour because it emphasises the role of context in behaviour (Michie et al, 2011). This model fits very well with both a critical realist and contextualist approach to understanding human behaviour. Michie et al emphasise the importance of context when exploring ways of changing behaviour and suggest that this is the primary component in their model. According to Bhaskar (1989)

“social practices are concept-dependent; but, contrary to the hermeneutical tradition in social sciences, they are not exhausted by their conceptual aspect. They always have a material dimension” (pp. 4). Flick (2009) also made the point that behaviour can only be understood when contextual factors are included.

Applying a critical realist and contextualist approach to an analysis of women with a mild intellectual disability’s experience of the use of mHealth technologies facilitates an understanding of the individual’s perspective within the context of social, economic, cultural, and physical environmental influences.

2.3 Method of Data Analysis

Approaches to qualitative data analysis range from descriptive methods to interpretative methods (Braun & Clarke, 2013). Descriptive methods focus on giving voice to participants and treating their words as a reflection of their reality, whereas interpretative methods go beyond description seeking a more in-depth understanding of the contextual factors that impact on individuals’ experiences (Braun & Clarke, 2013).

Methods of data analysis suggested for qualitative research include Grounded Theory where in-depth analysis of data results in the *emergence* of a theory from the data. However, one criticism of the grounded theory approach is it assumes that the researcher is merely an observer and has no impact on the interpretation of data (Willig, 2008). Another method of in-depth analysis commonly used in qualitative research is Interpretative Phenomenological Analysis. This method was not considered appropriate for this study as it is most effective when used in exploring an individual’s experience of a specific phenomenon rather than exploring data across a group (Willig, 2008).

The method of data analysis used in this study was the six-step model of thematic analysis described by Braun and Clarke (2006). The six-step model begins with the researcher becoming familiar with the data, then moving on to coding the data, conceptualising themes, reviewing themes, classifying themes and sub-themes, and finally producing the report.

Thematic analysis acknowledges the active role of the researcher in identifying themes and patterns as opposed to the assumption of themes ‘emerging’ or ‘discovered’ within data (Braun & Clarke, 2006). It facilitates an analysis of “*the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of ‘reality’*” (Braun & Clarke, 2006; p. 84). Thematic analysis functions as a *contextualist* method within the theoretical orientation of critical realism and is used to facilitate the organisation, description, and interpretation of data in qualitative research. Braun and Clarke (2013) describe thematic analysis as a method for identifying, analysing, and reporting patterns or themes in data.

However, critics such as Biggerstaff (2012) and Willig (2008) suggest that while thematic analysis is a particularly useful method for categorising and summarising themes encountered in data collection it is too limited in scope to provide researchers with an opportunity for in-depth analysis of data.

2.4 Research Design

2.4.1 Participants

Students from a purposive sample were invited to participate in the study. The criteria were that participants be female, have a mild intellectual disability, be aged over eighteen, and live either independently or with family. Classification of mild

intellectual disability was identified through the Compass data-management system of the RehabGroup used to identify personal information about students including date of birth and diagnosis. While body image and obesity were factors identified in the research question this researcher thought it best to include all female participants to avoid focusing on those students who might already be self-conscious about their weight. All participants would be asked to self-rate on the Photographic Figure Rating Scale (PFRS) so that each person could self-identify with respect to weight and body image.

Twenty-six students agreed to participate in semi-structured interviews, and ten such interviews had been completed but not analysed prior to progression viva in May 2016. Post progression viva all twenty-six students agreed to participate in focus groups with follow-on agreed participation by six parents (five parents of student participants and one parent of a non-participant student), with consent from their daughters. All student participants were white and their ages ranged between 18 and 26 with an average age of 19 years. Of these twenty-six students, twenty-five were born in Ireland and one was born in the USA of white parents, one Irish and one American. Parental participants were mothers; all were white and ages ranged from late thirties to early fifties and all were born in Ireland.

The number of participants was considered sufficient for data collection in a study of this size (Braun & Clarke, 2013); recommendations for interviews being six to ten interviews, and two to four focus groups for small studies. Ten students participated in interviews and this complies with the recommendations as per Braun and Clarke (2013). Recommendations for numbers in focus groups vary (Krueger & Casey, 2009) and smaller groups of six to eight people are recommended when looking for in-depth discussion on a subject matter (Braun & Clarke, 2013; Ritchie &

Lewis, 2009). The drawback on very small groups (less than five participants) is that there may be a less diverse range of views among participants, plus smaller groups may lack some qualities that make a group a 'safe' environment (Ritchie & Lewis, 2009). The number of participants in focus groups in this study ranged from five to ten with an average number of eight. As no one group had less than five participants none of the negative factors associated with the use of small-numbered groups were relevant.

2.4.2 Data Collection

The original title of this study, *'The use of mHealth technologies by women classified with mild intellectual disabilities who self-rate on the Photographic Figure Rating Scale (PFRS) with regard to body image and obesity; An exploratory study'*, arose from findings of a systematic review of risk factors for obesity among adults with an intellectual disability completed by this researcher in 2015 as part of the requirements for the Professional Doctorate in Health Psychology (Appendix A). Ethical approval was received from both the RehabGroup (September 2015 – Appendix B) and the University of the West of England (January 2016 – Appendix C) for this study and this researcher began the data collection process in April 2016.

The method of data collection used was semi-structured interviews (Appendix D) plus participants were asked to identify body type on the Photographic Figure Rating Scale (Appendix E). The semi-structured interview format contained 13 questions, 11 of which were open-ended with the remaining two asking for participant's opinions on specific uses of mobile technology in relation to healthy lifestyle choices. The purpose of using focused questions was to discover if participants were open to the idea of using mobile technologies in very specific ways that would support a healthy lifestyle. This interview format was used as a guide

rather than as a list of questions to be adhered to throughout each interview. The format and content of the semi-structured interview was agreed with supervisors prior to usage.

It is common practice for students in NLN to be involved in different projects and activities on an on-going basis. In collaboration with tutors the researcher arranged that tutors introduce the project in a similar way to all other projects in which students voluntarily participate. Each tutor gave a small introductory talk to students about the nature of the interview. The purpose of this meeting was to allow students time to consider if they wanted to participate.

Students who expressed an interest to tutors in participating in the study were invited by the tutor to attend a meeting with the researcher. This researcher spoke about the role of the interview and the Photographic Figure Rating Scale (explaining to students that each participant would be asked to pick a figure that best fitted her view of self) in understanding how/whether they use mobile technology as a resource in making healthy lifestyle choices. The researcher then went through the Information Sheet and Certificate of Consent (Appendix F) with students who were assured throughout the process that if they chose not to participate their choice would not impact on services offered to them. Information sheets and consent forms were written in plain English for greater clarity.

Twenty-six students agreed to participate and all participants were informed that each interview would be electronically recorded and that all records would be confidential and stored in a fireproof cabinet. Participants were reminded of their right to withdraw from the interview at any time. They were also reminded that the information recorded was confidential and would not be shared with anyone outside the research team.

However, at Progression Viva in May of 2016 examiners suggested that the remit stated in the title created too broad a range of factors for exploration, thereby over complicating the research process. A further recommendation by examiners was that participants be given an opportunity to voice their opinions on health issues that matter to them, rather than assuming that participants shared the researchers opinion that obesity and weight issues were of primary importance in a healthy lifestyle. Prior to the progression viva ten semi-structured interviews had been completed in centres with student participants by this researcher and are included in this study (Appendix G). None of these interviews had been analysed prior to the Progression Viva in May 2016 and this researcher thought that including these interviews would add value to the study by giving the perspectives of individuals in contrast to data collected through the focus groups.

Subsequent discussions with supervisors resulted in agreement in a change in research focus away from obesity and towards a broader approach focused on how students conceptualise a healthy lifestyle. This change in focus resulted in a title change to: *'An exploration of the role of mHealth (mobile technology) in facilitating a healthy lifestyle among women with a mild intellectual disability'*. Post progression viva discussions with supervisors, with students, and with tutors also included a decision to change the method of data analysis from semi-structured interviews to focus groups (Appendix H). It was agreed among all that focus group discussions might provide individuals with an opportunity to discuss topics in a more supportive environment. It was also agreed that as the average timeframe for each interview was no more than twenty minutes focus groups would provide opportunities for more in-depth discussions.

The format for focus group discussion was guided by discussion with students, with tutors and with supervisors. It was agreed that participants take part in two focus group sessions; the first topic being the role of mobile technology in students' lives, the second being health issues that matter to students (Appendix I). Students suggested that a tutor co-facilitate each focus group with the researcher and while this was agreed among all participants it did not happen in one centre where the tutor was unavailable. At this discussion students were also informed of their right to leave the focus group if they so wished and that any concerns would be addressed after each session either by the researcher or by the tutor.

Information sheets and consent forms (Appendix J) were given to students and each student was given the opportunity to take the forms away to discuss with whomever they wished. Participants who had agreed to take part in the original part of this study also agreed to participate in focus groups. Immediately prior to each focus group meeting participants were reminded that personal issues could be discussed with the tutor or with the researcher after the session. Participants were also reminded that the group discussion was similar to ones they normally participate in, in that 'what is said in the room stays in the room'.

Five focus groups were held across three centres with numbers of participants in each group ranging from five to ten with an average of eight participants per group. All group discussions took place in NLN centres, were electronically recorded, and verbatim copies were transcribed by this researcher. All records (see samples in Appendix K) were kept in a locked fireproof cabinet in the researcher's private office. On completion of these focus group meetings with students, and post initial analysis for themes, discussion at supervision indicated that extra value could be added to data collected from students by including their parents. This factor arose as many

participants indicated that their parents play an important role in their lives. Ethical approval was sought for inclusion of parents from both the University of the West of England (Appendix L) and the RehabGroup (Appendix M) and was received in March 2017.

Letters of invitation with information and consent forms for parents (Appendix N) were handed to students who were requested to give their consent (Appendix O) for their parents to be included as participants; parents were requested in a covering letter to make contact if they were interested in becoming participants. This researcher, concerned that parents might not be available to participate, also spoke with students who were not part of the participant cohort and requested their permission to include their parents. Information sheets and consent forms (Appendix P) were handed to these students with covering letters for their parents. Two students gave their permission and their mothers agreed to participate. However, only one mother was able to participate as the other mother had too many commitments. In all, six mothers participated in semi-structured interviews where the focus ranged from their use of mobile technology to their roles in supporting their daughters in engaging in health behaviours.

At interview, each parent was assured of confidentiality and that names would be anonymised. They were also informed that no one else other than the senior psychologist in RehabGroup would have access to either the original recording or interview contents. Five interviews took place in centres while the sixth took place in the researcher's office in accordance with that parent's request. All interviews were electronically recorded (see sample of interviews in Appendix Q) and transcribed verbatim by this researcher; records were kept in a fireproof cabinet in the researcher's private office.

2.4.3 Quality Assurance

The concepts of reliability and validity were developed within the natural sciences (Ritchie & Lewis, 2003) to ensure that research practices were trustworthy. Reliability is concerned with the replicability of research findings and validity is concerned with the extent to which research findings match the purpose of research as claimed by the researcher (Willig, 2008). In the context of qualitative research, Beail and Williams (2014) made the point that the concepts of reliability and validity have greater applicability to quantitative research and stated that while quality assurance methods have been developed within qualitative research, not all qualitative approaches are inclusive of these methods. The method of qualitative analysis used in this research was Braun and Clarke's (2006) method of thematic analysis and they identified a checklist of fifteen criteria that they consider necessary for a good thematic analysis (See Table 2).

Transcription	1.	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2.	Each data item has been given equal attention in the coding process.
	3.	Themes have not been generated from a few vivid examples (an anecdotal approach) but, instead, the coding process has been thorough, inclusive and comprehensive.
	4.	All relevant extracts for all each theme have been collated.
	5.	Themes have been checked against each other and back to the original data set.
	6.	Themes are internally coherent, consistent, and distinctive.
Analysis	7.	Data have been analysed rather than just paraphrased or described.
	8.	Analysis and data match each other – the extracts illustrate the analytic claims.
	9.	Analysis tells a convincing and well-organised story about the data and topic.
	10.	A good balance between analytic narrative and illustrative extracts is provided.

Overall	11.	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12.	The assumptions about TA are clearly explicated.
	13.	There is a good fit between what you claim you do, and what you show you have done – ie, described method and reported analysis are consistent.
	14.	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15.	The researcher is positioned as <i>active</i> in the research process; themes do not just ‘emerge’.

Table 2. 15-point checklist of criteria for good thematic analysis (Braun & Clarke, 2006) (permission received through <http://www.tandfonline.com>)

This researcher used this checklist as a method of ensuring rigour throughout the analysis process. However, the process of analysis is also dependent upon the researcher’s ability to conduct a critical analysis and this can be captured in a reflective chapter where the researcher’s ontological perspective and epistemological approach on the research process is captured. Such a reflective chapter has been included in this study.

3. Analysis & Findings

3.1 Themes

Data from student participant semi-structured interviews, from student participant focus group discussions (see Table 3 for details of student participants) and from parental participants (Table 4) semi-structured interviews were analysed using the six-step model of thematic analysis described by Braun & Clarke (2006).

<u>Interviews/Focus Groups by Location</u>	<u>Number of participants</u>	<u>Participant codes (anonymised)</u>
Semi-structured Interviews in W*	5 participants	Listed from A to E
Semi-structured Interviews in C*	5 participants	Listed from A to E
First Focus Group in KK*	10 participants listed in order of participation	C, E, D, F, B, A, J, I, H, & K
Second Focus Group in KK*	8 participants listed in order of participation	A, C, B, D, M, E, F, & O
First Focus Group in W*	6 participants listed in order of participation	K, A, L, M, S, & E
Second Focus Group in W*	5 participants listed in order of participation	K, A, B, M, & O
Focus Group in C*	10 participants listed in order of participation	N, B, C, D, E, F, G, K, O, & R

Table 3. Student Participants (* denotes location anonymised)

Parental Participant	Mother of	Location
Parent B	Student Participant Focus Group	KK
Parent IC	Student Participant in Focus Group	KK
Parent T	Student Participant in Focus Group	KK
Parent M	Non-Participant	
Parent G	Student Participant Focus Group	KK
Parent IM	Student Participant Interview & Focus Group	C

Table 4. Parental Participants

The first step in this approach, familiarising self with data, involved the researcher listening to and transcribing taped interviews and focus group discussions. This was the foundation step for the next five steps; the second step involved the researcher generating codes, the third step the researcher searched for and conceptualised themes, the fourth step involved the researcher reviewed themes, the fifth step was the classification of themes and sub-themes, and the sixth and final step was the production of the report. The Initial themes and sub-themes were initially classified separately for student participants and parental participants as described in Table 5.

Student Themes	Student Sub-themes			
1. Role of Technology	1a. Knowledge, Skills, & Ability	1b. Compulsive Viewing		
2. Health Issues that matter	2a. Cravings	2b. Healthy Lifestyle	2c. Body Issues & Girls Problems	
3. Parental Role	3a. My Mam says ...			
Parental Theme	Parental Sub-themes			
What mothers say ...	The Positives & Downsides of Technology	Mother as Protector	Her Daughter's Voice	My daughter and I

Table 5. Student Themes and Sub-themes & Parental Theme and Sub-themes

Themes for student participants and parental participants were combined based on the idea that while both sets of themes seemed quite different from each other they shared similarities e.g., *My mam says* is an alternative perspective of *What mothers say*. The final conceptualisation of themes and subthemes is described in Table 6.

Three themes with sub-themes were identified in the data (Table 6):

- (1) **Mobile technology: positives and downsides**, with two sub-themes (1a) *Positives: Knowledge, skills and ability* and (1b) *Downsides: Privacy/security & compulsive viewing*;
- (2) **Health issues that matter**, with three sub-themes (2a) *Cravings*, (2b) *healthy lifestyle choices*, and (2c) *body issues & girls' problems*.
- (3) **What mothers' say/my mam says** with three sub-themes; (3a) *mother as protector & advisor*, (3b) *her daughter's voice*, and (3c) *my daughter and I ... she's her own person*.

“It helps me stay healthy!” An Exploration of the role of mHealth (mobile technologies) in facilitating healthy lifestyle choices in women with a mild intellectual disability

Themes	Sub-themes
1. Mobile technology: Positives & Downsides	1a. Positives: Knowledge, Skills, and Ability 1b. Downsides: Privacy/Security & Compulsive Viewing
2. Health issues that matter	2a. Cravings 2b. Healthy lifestyle choices 2c. Body issues & Girls' problems
3. What mothers' say/my mam says	3a. Mother as protector & advisor 3b. Her daughter's voice 3c. My daughter and I ... she's her own person

Table 6. Themes and sub-themes combined for students and parents

Titles of themes and sub-themes used reflected the language of student participants and parental participants whenever possible (e.g., positives and downsides, my mam says). Themes and sub-themes were conceptualised within the framework of the COM-B model of behaviour (Michie et al, 2011) and questions and topics for discussion used in both semi-structured interviews and in focus group discussions were guided by this model (see Appendices D, I, and Q). In the COM-B model, Michie et al conceptualise behaviour as a function of three components, namely; physical and psychological *Capability*, social and physical *Opportunity*, and reflective and automatic *Motivation*. The components of capability and motivation were emphasised in the first theme, *Mobile technology; Positives & Downsides*, where student participants exhibited their knowledge of the positives and negatives of using

mobile technology. All three components were in evidence in the second theme, *Health issues that matter*, with student participants describing the impact that physiological difficulties (capability) such as food intolerance and chronic illness have on making healthy food choices. They also spoke about cravings (non-volitional motivation) and their psychological capability in choosing alternative healthy options in food when faced with food intolerance. Michie et al emphasise the role of opportunity (context) in their model and describe it as the primary component of behaviour when creating behaviour change interventions. A primary example of the role of opportunity/context is reflected in the third theme, *What mothers' say/my mam says* described in Table 4 where opportunities to engage in behaviours are either enabled or blocked by parents.

3.2.1 Theme 1: Mobile Technology: Positives and Downsides

Students in focus group discussions shared their knowledge of social media apps and sites, about syncing smartphones and tablets, and about staying safe online. They spoke about the role that mobile technology plays in their lives; many students stated that they could not imagine life without their smartphones while others stated that they would be bored if they did not have unlimited access to their phones. They also spoke about apps that help them stay healthy and about sites that support a healthy lifestyle. Some parents spoke about the skills that their daughters learn online and others spoke about how being online is a positive aspect of their daughters lives.

On the downsides of using mobile technology students spoke about privacy and security issues that arise when using apps or sites where information is shared. They spoke about the impact that compulsive viewing has on their lives and how using smartphones late at night impacts on sleep. They discussed how compulsive viewing impacts on their relationships with others; they also spoke about the physical

isolation that can occur when spending too much time online. They spoke about being addicted to games such as Candy Crush, about binge watching television programmes and films online, and being addicted to watching online programmes.

Some parents spoke about their daughters spending too much time online, others spoke about the threats that being online may pose to their daughters, and about the actions they need to take to protect their daughters from online predators.

3.2. (1a) Subtheme: Positives: Knowledge, skills and ability

When students spoke about using mobile technology, they spoke about the important role that smartphones and tablets play in supporting and maintaining friendships and social groups. A (focus group in W) stated, in response to a question as to how useful mobile technologies are, that smartphones could be useful in helping to develop social and verbal skills. According to C (interview in C), *'Skype (Appendix T) is very handy to have on your phone 'cos it means you can keep in touch'*. She also stated that Messenger and Snapchat were her favourite apps (Appendix T) for keeping in touch with people as *'you don't have to send only pictures of yourself you can send pictures of things or places around you!'*

When asked about the usefulness or otherwise of smartphones as a way of creating a social group, A (interview in W) stated that:

Yeah, like, it is easier to get in contact with another person whatever apps that you use, and it, actually, also brings those people more together as they have that particular app to talk about, issues that bring people together in that app, or that particular phone, it is a social group area for that.

A's point is well made in that she suggested that individuals can come together in groups where interests are shared and this can provide people with social opportunities.

When asked by the moderator about the best way of using mobile technology for group chats, or linking in with other people, N (focus group in C) stated that *'Snapchat (Appendix T) is the main thing really!'* and she added that Instagram (Appendix T) is no good because *'you can't really talk'*. N indicated that what is really important in connecting with other people is using an app that facilitates conversation.

Mobile technology for many students is not just a way of sharing messages and photos with friends; it also provides opportunities for learning about healthy diets and the importance of exercise. Sites and apps such as Curves and Slimming World offer students a way of learning about healthy lifestyle choices. These apps and sites provide people with an opportunity to link in with others in a supportive environment both online and as part of a local group. A (interview in C), speaking about the Curves site (Appendix T), stated, *'I was quite surprised that the diet plans are very good, and that the exercise plans are very good'* while C (focus group in KK) described the Slimming World site (Appendix T) as *'a group Internet'* that *'shows people how to be healthy'*.

Showing her knowledge about how a healthy lifestyle app and site such as Slimming World works, K (focus group in C) said; *'there are people who do that, on Facebook, there is a website for Slimming World and people take pictures of their meals and put them up, like, their breakfasts, snacks, and whatever they are eating!'* N (focus group in C) added that:

They put it up on to the, eh, Slimming World page, and then what they do is, am, before they start Slimming World they take about four pictures of themselves and then a couple of weeks or months after they take another

couple of pictures and when they get to the weight they want to be they take another picture so just to show the difference!

N (focus group in C) stated that she got ideas from Slimming World on Facebook (Appendix T); *'that's what I do, it helps me a lot!'* Students showed that they had detailed information about Syns used in Slimming World where N (Focus group in C) stated that *'with Snapchat you can take a picture and put text with that ... you can just, it is just quicker to text, like, say porridge, how much you had and the Syn value and then just put it up on the website'*.

Sites suggested by participants that support healthy eating and exercise include YouTube where one student D (interview in W) stated that she used YouTube on a regular basis to learn football skills ... *'Just click on YouTube and use football skills and all good stuff comes up about things like kicking the football around, you know, and passing and all the good tricks!'* Participants in the focus group in the same centre as student D also suggested that smartphones could be used as an exercise diary (A, focus group in W), and for listening to music in the gym (M, focus group in W).

On the same theme of exercise S (focus group in W) stated that you could use *'apps for exercise for walking ... you can put one on that if you don't move for a time it will prompt you!'* Participants in the focus group in W also spoke about the usefulness of apps for monitoring and/or facilitating exercise routines and were very enthusiastic about using Pokémon Go (a gaming app) as a useful strategy for exercising. A in that group stated Pokémon G *'it's for fun but people don't realise that they are exercising, that they are keeping fit!'* She further stated that *'the reward is that you catch Pokémon! You are exercising and you don't know, it's a game!'* Also, A (focus group in W) stated that *'if you do it with others then it's lots of fun!'*

Participants were clearly aware that while Pokémon Go is a gaming app it has the added advantage of offering them a way of exercising with as little pain as possible!

A (focus group in C) also spoke about using the SHealth app (a fitness app from Samsung (Appendix T) for monitoring both her diet and exercise programme. N, a student in the same centre (focus group in C), also stated that *'I have SHealth; it counts how many hours you are awake and active. It helps me stay healthy! I can use it with other people if I wish'* (Appendix T) K (focus group in C) also added that the calorie counting app she has *'tells me how much is in each serving'*. These participants exhibited a thorough knowledge of the SHealth app and its advantages as a resource for making healthy lifestyle choices.

In the introductory part of the focus group meeting in C students were quick to correct the group moderator's lack of knowledge of mobile technology use with N stating *'yeah, you can now use your tablet to make calls!'* (focus group in C) and E adding *'Yeah, there is Viber and Messenger (Appendix T) that allow you'* make calls (focus group in C). The following conversation among these participants is a good example of their knowledge of Snapchat where N, speaking about sharing photos on Snapchat, stated:

So, now what you have to do with it is you have to go in to it and you have to screen shot it to save it, you can't just save it to your phone anymore, you have to screen shot it ... you can only download it off your own Snapchat, like if someone sent you a Snapchat, you cannot download that but if you screen-shot it

K finished the sentence stating that *'it tells the person that you are taking their photo!'* N stated in reply: *'Yeah, it comes up, em, that, it comes up (.) if K sent me on*

Shapchat, then it comes up on K's phone that I had screen-shot her picture! So, people know if someone is after taking their picture or not!

This conversation indicates that students in this group are very much aware of the complexities involved in using a social media app such as Snapchat.

On the topic of the positives of mobile technology, and in particular in relation to developing knowledge, skills and ability through the use of mobile technology, parent B stated about her daughter; *'I can see that this is probably making her wise to the world!'* She added that her daughter is *'learning new songs which is helping her (.) speak, use her voice'* plus *'she has learnt to play the drums and I see her downloading things regarding drums'*. Parent B also spoke enthusiastically about her daughter learning to play online chess and was also very animated when speaking about her daughter's ability to download, and follow through with, a 30 days fitness challenge.

Parent M stated in a positive way that her daughter, C, *'has become a tech savvy (.) you could nearly say recluse'* and M added *'that is her life! ... and she is very happy inside in that room'*. M's daughter has a diagnosis of Autism and prior to her attending the service she was very much a home person. Since attending she has become an often outspoken member of the group and asks to participate in all activities, particularly those that take her outside the centre. This suggests that C does not share M's perception of her being happy inside her room. It also suggests that C has limited opportunities to engage in activities that are not in line with M's perception of what is good for C.

Parent IC, on the other hand, framed her daughter's mobile technology skills in a negative way by expressing her concern that her daughter was taking unnecessary risks emailing *'people in America for information on the animation she is looking at'*.

Despite her protestation that she *'was absolutely shocked'*, IC's tone of voice suggested that she was quite proud that her daughter had sufficient initiative and capability to develop problem-solving skills. According to IC, her husband and she insisted that C consult with them before she take any similar action in the future, despite her daughter stating *'I'm not stupid!'*

An important message that is contained within this theme is that student participants have the knowledge, capability and the motivation to use mobile technologies in ways that are useful to them in supporting a healthy lifestyle. According to the COM-B model of behaviour, behaviour occurs as an interaction among three components; capability, motivation, and opportunity. For some students, opportunities to engage in specific behaviours are moderated by parents. Where opportunity is controlled or removed, capability is rarely tested and motivation to engage may be impacted negatively by this lack of opportunity to engage in decision-making or goal setting (Michie, Atkins & West, 2014).

3.2. (1b) Subtheme: Downsides: Privacy/security & compulsive viewing

Many student participants mentioned concerns about **privacy and security**. A (interview in W), for example, stated that a downside to using health apps is *'that someone is trying to, let's say hack your comp, your phone ... and they will hack all your apps and get all your information'*. She went on to say:

You really have to keep your eyes where you are going with apps because you really don't know where your apps are going or coming from, or if your apps are reliable, or, whatever, you have to keep your information safe but also, have fun with those apps, enjoy those apps ((laugh)) to make your life easier and you have to look and research them, yeah!

A's comments indicate that she takes a balanced approach to using mobile technology by being mindful of the need to be careful using apps; checking them for viruses while still managing to use them in a way that is both useful and enjoyable. R (focus group in C) also spoke about the importance of being vigilant when she stated that:

Messenger, Facebook, and you know (.) you know ones for viruses, some apps like exercise ones, there could be a virus with that, and the anti-virus one, once you download that it scans the app you have just downloaded and it lets you know if there is a virus and it clears it off.

O added that she does not have a Facebook page because her friend was bullied on Facebook but when her friend tried to close her page she was unable to do so and '*the page is still out there*'. When the co-moderator challenged this comment, N pointed out that while you think you have closed your Facebook account *it's not permanently gone!*' Again, this indicates that these participants have a good knowledge of specific social media sites that are commonly used but not always understood by those who use them.

D (focus group in KK) also spoke about the importance of being safe online and knowing who you are speaking with and mentioned the television programme Catfish. E in the group described Catfish as '*really good! It tells you about Internet dating and things that happen!*' When asked by the moderator if participants had learnt anything from this programme D replied '*a lot, like, be careful of what you say and how you say it!*'

On the same topic of privacy and security, A (focus group in W), in reply to the moderator's question as to what are the downsides of using smartphones and apps, stated that '*sex offenders! (.) You don't know who is talking!*' M in the group added, '*there are some people on Facebook setting up fake pages!*' In a similar vein, the

discussion about using Snapchat among the participants in the focus group in C indicated that sending photos or messages to people is very much about being able to trust the person and also taking personal responsibility. This was reflected in the comments made by G (focus group in C) when she stated that *'you usually don't send pictures that you shouldn't send anyway!'* and *'yes, there are people who when they get drunk expect others to take care of them!'*

These examples from student participants indicate that many are clearly aware of the risks that exist when using online sites and apps.

However, some of the comments made by parental participants indicate that they do not positively view their daughters' ability to safely use sites and apps. Parent IC, for example, stated that once she became aware that her daughter was emailing companies in America about downloading animation programmes she and her husband had to *'go through the safe use of the Internet with her'*. Despite her daughter stating that she was not *'stupid'*, IC replied that *'I'm not saying you're stupid C, you've got to be careful!'* According to IC, C replied that she knew that she needed to be careful and then showed them the original email and the reply from the company. IC's justified her response to C and stated *'we all know what goes on on the Internet (.) and people's accounts are hacked!'*

However, another parent, M, stated that her daughter *'likes to play games where she is alone, or she will play with someone on line that she doesn't (.) doesn't know'* which suggests that M is very comfortable with her daughter being online without being concerned about privacy or security issues.

On the topic of **compulsive viewing**, K (focus group in C) stated that *'I get into bed around 10 pm and watch my programmes until about 3 am (.) and then I am up with my son at 6 am (.) you get addicted!'* N responded to K by stating *'you have*

to tell yourself to stop!’ and cited her own situation where she described her time with her iPad as the only time she has for herself. She stated that:

It is the only time I have for myself, my son is usually asleep by 8:30 pm, then I am usually in bed by 9 pm or 10 pm. It is usually turned off by 12 and asleep by 1 am. I am reducing the time slowly ((laughs)).

The overall response from the group was that ‘you lose track of time, you watch about 45 minutes and then find that you have spent more than an hour’. The mixed responses among participants about compulsive viewing and the role of mobile technology indicates that while many use mobile technology as a way of relaxing, others are aware that mobile technology poses a threat to healthy lifestyle factors such as a good night’s sleep.

On the subject of gaming, which could be described as both a positive (e.g., Pokémon Go as an exercise app) and a downside (compulsive viewing) of mobile technology, C (interview in W) stated that she has Play Store from which she downloads gaming apps for free. She also stated that she prefers gaming apps but has been told by her mother ‘that one of the Candy Crush’s (Appendix T) has to be deleted’ and replaced with an exercise app. C said that she has no available storage for exercise apps with all the gaming apps. She added that she had not done anything as yet to delete any of the games and did not indicate that she had any intention of so doing any time soon. While C is clearly motivated to keep her gaming apps she shows no signs of being motivated to change her use of apps in accordance with what has been suggested by her mother. O (focus group in C) on the other hand stated, while smiling, ‘oh yeah, I’m addicted to Candy Crush (.) I play all the time!’ so no confusion exists as to where O stands and how she views her gaming habit.

When discussing the topic of the times at which individuals' turn their phones off E (focus group in KK) stated that she turns her phone off at 3 am because that is when *'people stop messaging!'* E's response, when asked what would happen if she turned her phone off at midnight, was that she would die of boredom. I (student in the same group) retorted; *'or you might get some extra hours sleep!'* E insisted that she could never spend a day with her phone off because *'I'd miss photos on Snapchat (Appendix T) that last only 24 hours! I'd feel left out! I wouldn't know what everyone else was doing!'* E's comments reflected the comments made by D who said that she would be *'lost'* without her phone. Both E and D were the most outspoken in the group about their need to be connected through their smartphones; others such as I, B and H stated that the only reason they leave their phones on all night is to use the alarm function.

On the topic of compulsive viewing, parent B stated that her *daughter 'spends too much time on that'* (phone) and stated that *'I would just love to take the whole thing off her and throw it out!'* However, these comments were part of a discussion where she stated that she believes that *'there is a good side and a bad side'* to her daughter using mobile technology.

IC stated that her daughter, C, when on holiday *'she'll sit by the pool but once there is Wi-Fi there she's fine!'* So, planning holidays must allow for C's wish to be online at all times! Parent M, when speaking about her daughter's use of technology, stated *'the only thing she is interested in is anything to do with technology'* and that *'her bedroom is like Games Stop! You name it, what console they sell in there she has it!'* M did not say this in a way that suggested that she saw this as a negative; her tone of voice suggested that she was quite pleased that C is surrounded by, and immersed in, technology.

As is the case in analysing responses from many participants who use mobile technology, student participants exhibit clearly that their behaviour is composed of a combination of capability, opportunity, and motivation as described in the COM-B model of behaviour. Their capability is reflected in the knowledge, skills and ability they demonstrate in using mobile technologies and their understanding of the positives and negatives of using these technologies. Opportunity is sometimes not such a straightforward matter for many students who have to negotiate their use of mobile technologies with their parents. Their ability to negotiate is evident in the efforts that some parents make to accommodate their daughters wish to use these technologies. Their motivation is reflected in how positively disposed participants are towards using mobile technologies and in the efforts each participant makes (including, for example, prioritising social media usage over sleep) in engaging with mobile technologies.

3.2.2 Theme 2: Health issues that matter

Many of the participants showed a good knowledge and awareness of their current health issues and discussed how some of these issues impact on their lifestyles choices, including choices they make about diet and exercise.

Student participants spoke about the role of medication in stabilising chronic health conditions, and shared their knowledge about non-communicable health issues and diseases such as obesity, heart disease, diabetes, cancer, stroke, and epilepsy. In some cases they spoke about how these issues affect themselves or family members. Students also spoke in great detail about healthy lifestyle choices and discussed the difficulties that can arise when having to plan meals around food intolerance issues or when making choices to eat healthy proteins and fats. They also spoke about cravings

and how these are linked, in some cases, to what they described as ‘girls’ problems’, giving the monthly cycle as an example.

These issues were also reflected in comments made by some parents who spoke about the difficulties that their daughters experience when food cravings impact negatively on healthy lifestyle choices. Parents also gave examples of how their own behaviour has impacted both negatively and positively on their daughters’ lifestyle choices.

3.2. (2a) Subtheme: Cravings

Some participants mentioned food cravings as a factor they struggle with, while others spoke about how they replace those cravings for unhealthy food options with healthy ones. In discussion about what might replace unhealthy foods that individuals crave, M (focus group in W) stated that *‘if I crave chocolate I go to the fridge and have a piece of fruit’* and she added that she only eats chocolate *‘once in a blue moon! It’s only when I get my yokes that I decide to have chocolate!’* K in the same group spoke about the plan she shares with her mother to lose weight. She described one of the difficulties she has in maintaining a healthy diet as follows; *‘I love chocolate and I can’t stop eating it, and I have a secret chocolate from the vending machine here!’* M’s advice to K was *‘instead of eating chocolate you could go to the shop and buy a piece of fruit and that would keep your mind off chocolate!’* M went on to say that her mam lets her eat a piece of chocolate on Friday.

When responding to the moderator’s request to identify other unhealthy foods, participants in the W group spoke about energy drinks such as Red Bull and Monster and about how much they like these drinks even though they know that they are unhealthy. They all agreed that these drinks have high levels of caffeine with lots of calories and that they get an energy boost when drinking them. While they were quick

to point out that there is one high energy drink that contains green tea they did agree that drinking too many of these drinks is unhealthy. M in the group stated that:

But you can't have too much because they make your heart race! That happened me when I had six cans of Red Bull! My mam had to bring me to hospital and they told me not to drink too much because they are bad for your heart!

Apart from M's personal experience, A in the group spoke of learning online about how energy drinks exacerbate the negative side effects of drug abuse. She stated, *I saw on YouTube a guy who had been taking drugs, drinking Red Bull and Monster (.) his heart was beating out here!* (Extends arm from chest).

From a parent's perspective, parent IC asserted that her daughter C is not addicted to caffeine drinks but stated *'you won't put C off coke!'* According to IC, C drinks the *'sugar free fat free one (.) and she'll have a glass with her dinner and a glass at night time'*. She went on to speak about her own 'addiction' to *'full fat coke'* (2.5 to 3 litres per day) and how she used it as a weight management strategy. She also described how this addiction was a significant factor in her experiencing two transient ischaemic attacks and stated that she thought that C, in witnessing these events, would not drink coke to excess. IC's comments on the relevance of her experience indicate that she believes that her negative experience provided C with an opportunity to adapt her behaviour accordingly.

In speaking about her daughter N, IM stated that she knows that *'N's downfall is chocolate! Downfall (.) absolutely chocolate, 100%!*' She also stated that N had successfully stopped drinking Lucozade at Christmas even though N had found *'she needed that extra boost coming up to her periods'*. Similar to IC in the previous example, IM spoke about the similarities between her own experience of being a *'late*

night binger’ when she would *‘love a Twix*’ and N’s craving for chocolate at night. According to IM, N would say, at about 8:30 or 9 at night, *“God, I’d love a square of chocolate!”* IM stated that N is particularly vulnerable *‘especially when she is getting her periods (.) the craving she would have would be doubled, just to get the sugar and the salt (.) do you know what I mean?’* and IM added, *‘but when she comes home and she has a craving (.) I feel sorry for her (.) it’s so difficult to get a craving out of your body!’*

These comments suggest that IM’s own experience of cravings impacts on how she responds to N’s experience of cravings. This is reflected in IM comments when she said: *‘... she would eat healthily but would eat the chocolate afterwards! But she is like the rest of us, when we are having a hard day some of us go for a cigarette, do you know, others for chocolate!’*

Within the COM-B model of behaviour, cravings can be described as a combination of capability (emotional response), opportunity (context) and motivation (automatic processing). For many participants eating chocolate can be described as an emotional response to physiological changes, or as a response to taste-driven choices that are both biological and emotional. Opportunity (context) is access that participants have to energy dense foods and drinks promoted through, for example, fast-food outlets (Visram et al, 2016; Ni Mhurchú et al, 2013; Breslin, 2013).

3.2. (2b) Subtheme: Healthy lifestyle choices

Students were very animated about healthy lifestyle choices with lots of comments reflecting their knowledge of what makes a healthy diet healthy, what works for them and what does not work. When parents were asked about healthy lifestyle choices made by their daughters, some spoke about their daughters’ initiatives, others described daughters whose behaviour was motivated by others (such as parents), and

others still spoke about daughters who are not particularly interested in engaging in a healthy lifestyle or daughters with limited capability or motivation.

According to E (focus group in KK), a healthy lifestyle *involves 'a balanced diet and exercise'*. A (focus group in KK) added *'sleep, not many people get a lot of sleep! You should get 8 hours sleep every night!'* B, in the focus group in W, stated that by not eating too many *'sweets'* or *'rubbish'* it is possible to maintain a healthy lifestyle. She described herself as *'a healthy person'* who maintains her health by *'exercising, I eat enough, enough dairy products, whatever, but that's about it! I do more exercise that keeps me healthy!'* A, in the same group, made the point that an important part of a healthy lifestyle is *'having it proportioned'*. M in the group stated that a healthy diet is based on knowing the food pyramid and that *'we did cooking in school and used the food pyramid! We did lunch and all for the teachers so we had to go down through the food pyramid to cook food!'* B (interview in W) stated that she keeps fit by *'exercising (.) keeping low balanced meals'*. These comments reflect a broad range of opinions that share an awareness of the importance of having a balanced diet, of having sufficient sleep, and of understanding the importance of food portions as significant factors in maintaining a healthy lifestyle. These comments also suggest that participants have had the opportunity to learn what works well in a healthy lifestyle.

When the discussion progressed to discussing healthy meals A (focus group in KK) stated that she has *'two boiled eggs and a glass of milk'* for breakfast while C in the same group stated that she has *'porridge and yogurt'*. In the discussion C stated that wholegrain cereal for breakfast is best while E stated that the suggested alternative by the co-moderator of wholegrain Cheerio's was not a good one, describing them as *'yuck! They taste of sugar!'* Her stated preference was Weetabix

that she described as being nutritionally better than other cereals, plus she would have brown bread to add to her healthy breakfast.

In response to a query from the co-moderator as to whether participants had tried foods such as falafels, B (focus group in KK) stated that *'I don't like chickpeas, they have no flavour! My mam sometimes puts them in what she calls a one-pot dinner!'* B indicated a difficulty that some people have with eating healthy foods; some healthy foods may challenge an individual's taste buds where other less healthy alternatives may have a satisfying taste.

A (focus group in W) spoke about the difficulties she experiences in maintaining a healthy diet in light of her food intolerance issues and stated *'I try to use calcium tablets rather than from milk, if I can't get protein from chicken I get it from fish'*. A's comments suggest that she is aware that she needs to plan her meals in order to maintain a healthy diet and is able to do so because she has a good idea of the range of options out there for her. In the same discussion M stated that *'we were in a chip shop one day (.) you see, mammy goes to him but I can't eat fatty food, but then he brought out a salad and he made a Panini for my mammy!'* In this comment M indicated her awareness of alternative food sources for proteins and fats that maintain a healthy diet. Also, this comment indicates that M's mother plays a direct role in supporting M when choosing food options.

Difficulties in maintaining a healthy lifestyle by using mHealth apps were highlighted by 'A' when speaking about using a health app on her smartphone. She stated: *'I used to have one of those on my phone and I had one where I had to put in my food I was eating, you had to be very specific'*. In response to a query from the moderator, A stated:

So, if I was having a burger I had to count the bread, the burger itself, the pickle, the onions, the tomato, the sauces, and the portion size of it as well! I had to count how many minutes that I walked, what speed (.) how many laps during that minute, how many times I did it!

The main difficulty that A described was her difficulty in *'remembering! You had to remember so much!'* When the moderator brought this difficulty to the group the general consensus was that they would also find the app too complicated. This, again, reflects the importance of app developers seeking user feedback and creating user-centred mHealth apps.

This important factor was also indicated in A's (interview in C) response to a question as to how user-friendly the SHealth app (Appendix T) was that she downloaded. While she stated that *'they are very useful for people who are trying to maintain their weight like me, or trying to lose a bit of weight, or shed weight, you know!'* she also stated that *'I wouldn't use them on a regular basis, I would use them from time to time, yeah!'*

When asked by the moderator about factors that might impact on an individual's ability to engage in activities on her own participants in the C focus group were able to describe factors that might impact negatively on individual motivation. N stated that a negative factor might be: *'Probably don't have enough confidence to do it by yourself'* while E suggested that an individual may have difficulty in maintaining interest and *'you could give it up easily'*. F made the point that *'if you have a group, they will push you to do it'*. All useful responses to consider when engaging in health behaviour change as motivation can be a reflective process based on personal opinions and knowledge, or it can be an automatic process influenced by needs, impulses and reflex responses (COM-B model of behaviour).

Student participants went on to discuss how useful Slimming World can be in providing individuals with opportunities in making healthy lifestyle choices. N (focus group in C) commented that *'you can see how others can do it'* and added that *'it helps me a lot'*. N did go on to point out that Slimming World recipes do not work for everyone and gave the example where *'there was one woman, she was doing, I can't think of what recipe they had, she was using the recipes and then another woman tried them and they didn't help her lose weight'* to which G replied *'just the way your body reacts to it'*. This conversation indicated a good knowledge among these participants of how useful online sites can be in facilitating healthy lifestyle choices. It also indicated awareness among participants of how individuals respond differently to the content of online diet and exercise sites. These comments suggest that participants have the knowledge and capability necessary to use these sites in a critical way.

Parents' responses to their daughters' healthy lifestyle choices were mixed. Parent B, for example, described her daughter C as quite an active person who makes good choices. B stated that C plays boccia, has learnt to play the drums on the Internet, and has downloaded a 30 days fitness challenge that she works on with her sisters. According to B, *'she is very disciplined in herself (.) although she might have a drawer full of rubbish she will keep it for a certain day ... she and her sister will say, "We'll eat these on Friday" (.) she might take an odd nibble during the week but normally she has good discipline'*.

Parent IC spoke at length about her daughter C and the difficulties that both she and C experience in negotiating a healthy lifestyle for C. IC described grocery shopping with C as follows:

I would get her Slimming World pasta sauce and I would get low fat mince and I would use passata and she'd love it (.) but then, she'd go off with a basket and she'd put stuff in it and I'd say, "That goes back ... that goes back" and she'd have a bit of a strop with me and I'd say, "C, if you are going to be like that you can go out to the car and sit in it or you put those back and you can hold on to one!" and she would say, "Yes, if that's what I have to do!" ... "Yes, that's what you have to do! I don't want to see you harming your health, so that's what you have to do!"

IC goes on to state that C:

Goes for a walk for, maybe, 40 minutes outside, in the fresh air ... she walks as far as the DG (park in local area) and she collects her Pokémon (Appendix T) and her points and she comes home then and she says, "Look, I'm after getting so many points" but she has got her walk in!

C's behaviour in the above examples suggests that her opportunities to eat what she desires are constrained within the family and this, perhaps, is reflected in her behaviour while attending NLN. Once she started on the programme in NLN she used the opportunity afforded to her to buy foods that she was motivated to eat in place of prepared Slimming World recipe dishes made by her mother. This suggests that C's food choices are taste-driven and focused on what is palatable rather than nutrient dense (Breslin, 2013).

C gained a lot of weight during her time on the programme. According to IC 'when people are in different environments they can "try it on" and they'll all have their ways and means to hide stuff, to go out during lunchtime and eat something before they come back, like C in Supermacs!' Citing an example of when she was in

town and met C leaving Supermacs (fast-food takeaway) even though IC had given her a packed lunch.

Parent T stated that her daughter S *'would be a very healthy eater! She is not a takeaway girl!'* She added that S must be the *'first person to go in (MacDonald's) and ask for carrots and potatoes!'* With regard to exercise T stated

I dropped her at the bottom of the street this morning; she thought it was hell on earth! She had to walk up, the whole way up the street, it would take her a minute or so! I think they are all like it (.) they think the world had ended. But she'll walk the dog at home! You know, now her dog (.) she walks her dog (.) she would now, yeah!

Perhaps this is more about S not wanting to go to the NLN centre rather than not wanting to walk. S has a diagnosis of dyspraxia and presents as a quiet and reserved person who is very conscious of how she appears to others. This may be the motivating factor behind her wish to be dropped at the door. Also, this is supported by the second part of T's comment when she states that S walks her dog.

Parent M, when speaking about her daughter C, stated that *'I think she has no interest in movement at all!'* She stated that C *'goes to archery on a Tuesday evening and that is about as far as she goes!'* M went on to acknowledge that *'I know that that sounds terrible!'* and then changed the subject and spoke about C being different to others in her group in NLN. M's daughter C has been diagnosed as being on the autistic spectrum and is over-weight. She is a friendly and sociable person in the centre and does engage in limited physical activity. However, the picture painted by her mother about C's home life is very much about a life *'that doesn't involve any movement, any exercise and she is very happy inside in that, in that room!'* This scenario suggests that C's home environment is not conducive to her engaging in any

physical activity, indicating that she does not have the opportunity to engage in any social or physical activities external to NLN. This comment also suggests that sedentary behaviour is encouraged within C's home environment. She may very well be capable and motivated to engage in activities outside her home but opportunities to engage are limited.

Parent G stated that her daughter S *'would come home from work, make a coffee and sit with the dogs all day!'* She went on to say that S *'is not the fastest at walking and tires quicker than most people (.) she can't run for nuts, and she runs like an elderly person with her feet turned out! And she would be genuinely tired but she goes!'* and G's advice was that what works best for S is to go at her pace. However, S does participate in activities organised by her mother and, therefore, has the capability to participate in healthy activities once given the opportunity, even if she needs some support in making choices.

Parent IM, speaking about N, stated that *'N loves swimming and is a member of the T leisure centre'* and that while N participates in exercise sessions in the centre any exercise she does in her own time is with her mother who stated *'we support each other!'* Again, while N has experienced many person difficulties she is capable of engaging when both the opportunity is provided and she is supported in her efforts.

In their COM-B model of behaviour Michie et al (2011) consider context (opportunity) an important starting point when considering behaviour change. This observation makes sense when considering the comments from students and their parents. Students' use of online apps and sites indicates that their capability in making healthy lifestyle choices is supported by sites and apps and that the most useful ones are those that are interactive and/or user-centred. Also both students and parents, but more so parents, indicated that opportunities to engage in healthy/unhealthy lifestyle

choices are in many cases mediated by mothers. A particularly interesting example is that of C who shows how capable she is in taking advantage of a change in environment (opportunity) when motivated to make alternative food choices. She eats what the family eats at home but when she is away from home her motivation to eat fast foods is facilitated by this change in environment.

3.2 (2c) Subtheme: Body issues & girls' problems

Participants spoke about personal health issues that impact on their lives; issues such as dealing with the impact of chronic health conditions such as epilepsy and thyroid disease. They also spoke about girls' problems such as managing the menstrual cycle and discussed how these issues impact on their daily lives and choices that they make.

K, participant in the focus group in W, named *'losing weight'* as a health issue that matters to her. A, in the same group, mentioned *'body issues (.) like, allergies and stuff!'* while M, also in the same group, stated that *'walking, exercise'* matter to her. M (focus group in KK) spoke about having to get regular blood tests (epilepsy) while E (diabetes) in the same group spoke about not having to go anymore *'cos I'm on the same medication for years'*. M (focus group in W) spoke about how she uses an app called iPeriod to track her menstrual cycle. According to M, *'when you get your yokes you count the number of days until the next month and you will know when to bring pads with you'*. E (focus group in KK) stated that she does not have to worry about tracking her monthly cycle as *'I don't have that anymore 'cos I got the bar'* and while it means that she does not have to worry about tracking her periods she stated that *'I still get the cramps though!'* K (focus group in W) stated that *'yeah! I get awful cramps with them'*. K went on to speak about the medication she needs to take *'for my thyroid problem'* and stated that while this health issue does not worry her *'it sometimes affects my mood though, so I can be a nuisance in class, talking rubbish,*

but I don't mean to!' K is overweight and an underactive thyroid is certainly a health issue that can impact on maintaining a healthy lifestyle.

C in the KK group mentioned obesity as a health issue that matters to her and stated that she goes to Slimming World sessions '*once a week*'. When asked if she found these useful she replied '*yeah, sometimes*'. C also spoke about '*lactose intolerance*', how this '*means that you can't have dairy products!*' and explained when asked, '*when I was young I watched a cartoon and one of the characters was lactose intolerant!*' C spends a lot of time online playing animation games and this is an example of where games can be a useful source of health information. A (focus group in W) spoke about her personal experience of being lactose and wheat intolerant when she said:

Yeah, I'm kind of lactose intolerant! Ever since I was 24 hours old, I can't take any milk, I can't digest it at all! My dad is on a special diet and I am on the same diet. It is really upsetting now that I am now allergic to wheat as well!

IM gave a parents perspective on the impact that body issues have on their daughters lifestyle when she stated that her daughter, N, is '*fighting a double battle*' with her weight. According to IM, the first part of this battle is N's battle with sugar/salt cravings, and the second is that N:

Does her best, during the day (.) to cut down on the bad stuff and go for the healthy option! But N puts on weight easily as she suffers from polycystic ovaries, do you know what I mean? ... Now, she is on the pill for that and has been since she was 14, but she would do her best (.) she would eat healthily but would eat the chocolate afterwards!

IM's comments indicate that N's capabilities in maintaining a healthy weight are limited by her having a physical health condition that impacts negatively on an individual's ability to lose weight (WebMD, 2017).

In the context of the COM-B model, girls' issues and body issues sometimes impact negatively on participants' capability and motivation in engaging in healthy lifestyle choices. A plus for participants is their can-do attitude and their capability in understanding the impact that issues beyond their control have on their behaviour.

3.2.3 Theme 3: What mothers' say ... my mam says

Student participants spoke about the role their mothers play in highlighting sites and apps that are useful for healthy lifestyle choices in diet and exercise. In some instances mothers' interventions were not welcome while in others they were passively accepted by students who shrugged their shoulders when speaking about their mothers wishes.

Mothers' responses generally reflected the 'protector' role they take in their daughters' lives. Some mothers' spoke about a desire to do the best by their daughters and others spoke about having to ensure that they protect their daughters' from possible harm. Daughters voices could be heard either in an outspoken way when they openly disagreed with their mothers' or passively when mothers made efforts to accommodate their daughters' needs in order to avoid conflict or resistance.

The idea of mothers and daughters as a team arose with mothers speaking about the efforts they make in encouraging their daughters to participate with them in making healthy lifestyle choices.

3.2 (3a) Subtheme: Mother as protector and advisor

This theme was a recurrent one throughout interviews and focus groups. In varying degrees mothers presented, or were represented by their daughters, as advisors and protectors.

Student B (interview in C), in response to a query from the interviewer about her diet, stated '*I mostly eat salads, like, I don't eat fast food ... I try to keep away from it ... I just like it sometimes, say every 2 to 3 months*'. When asked about the source of her knowledge on healthy lifestyle choices, B stated, '*ah (.) my mother gave me some advice ... and she would say go for that! I want to keep my fitness, I want to keep my body the way I am*'. These comments suggest that there is a good match between B's motivation to keep fit and maintain a healthy weight and her mother's ability to support her in her lifestyle choices.

C (interview in W) stated that her mother '*looks up stuff from Slimming World she looks up recipes*' and that C has to bake from these recipes because '*mammy stands there looking at me 'cos she gets fed up baking*'. C also made the point that her mother wants her to get fitness apps for her phone as she and her mother walk together:

I do around the block three times with mammy and then mammy does that and she has an app that counts the steps and she said to me to download that and it kept coming up that my storage was full and I have to get rid of some of my apps so that I can download that.

As already mentioned, C had not downloaded the app as this would mean she would have to delete one of her Candy Crush apps. In reply to a question as to what was stopping her downloading the app she stated '*nothing really*' so, perhaps, the question

is more about whether C's internal motivation to keep her gaming apps is greater than the opportunity to engage in healthy lifestyle choices provided by her mother.

D (interview in W) spoke about the difficulties she has in practising cooking skills. In response to questions about researching healthy recipes online D stated, *'I do, like, Google, helps you and I do (.) with healthy recipes, am ((pause)) I tried to ask my mam and she, like, said no, 'cos she thinks I'm going to burn the place down!'* D went on to say that when she asked her grandfather to help her *'he said all right, let's give it a go! But then he changed his mind saying, ah, we'll try it another time!'* Despite D's best efforts she was not given the opportunity at home to acquire the skills necessary, the capability, to cook for herself or for others.

In a similar vein, C (focus group in KK) spoke about attending Slimming World because *'my mam goes'* and A in the same group, speaking about using sites on the Internet for health issues, said that *'my mam looks up stuff about calories and stuff like that'*. M (focus group in W) stated, in reply to the same question, *'mammy does through Slimming World ... her diary is online, for when she fills out what she is eating and all!'* When speaking about healthy food choices many of these participants spoke about choices their mothers made rather than any specific personal preference.

The discussion moved on to healthy foods and E (focus group in KK) stated that *'my mother buys Manuka honey but I don't like it!'* and that when she has a salad *'my mam puts grapes in it'*. E added that her mother makes one-pot meals that have things like chickpeas (according to E chickpeas have no flavour) in them and that her mother buys *'brown bread, a mixture of grains mum gets'*. A joined in and stated that she eats *'bacon and potatoes and carrots and parsnips! I eat parsnips because they are good for you and because my mother will sit there until I have them eaten!'* M

(focus group in W) stated that *'we are not allowed Coke in the house anymore! Daddy is after banning it so we drink lots of water!'* M goes on to say that her mother allows her eat a piece of chocolate each Friday. C (Interview in W) stated that *'in the summer I like salads! And then we get a treat every so often, if we are good mammy gets us a take away, depends on how good we are!'* She went on to describe her favourite takeaway as *'meatballs, chips, rice and sweet and sour sauce!'*

It is evident from what student participants say that parents play an important role in their lives and in particular their diets. In many instances foods are defined as 'good' or 'bad' and in C's (interview in W) case takeaways are 'good' as they are described as rewards for good behaviour, indicating that healthy foods such as salads are to be endured. Opportunity to eat certain foods is either blocked or enabled by parents, thus impacting on participants' dietary behaviour (COM-B model).

From parents' perspectives, some described Pokémon Go as a useful exercise resource for their daughters as it encourages them to walk in seeking Pokémon Go characters. However, in response to a query from the interviewer as to whether M thought that Pokémon Go might be a useful exercise resource for her daughter, M stated that she knew that both her daughter, C, and her son were interested and:

I also know from going around in the car and having the hotspot on in my car that when they have their tablets on that they can actually play Pokémon as you drive around! So, walking isn't always necessary (.) and they are looking for the weird ones (.) they are not interested in the regular ones, they are always looking for the weird ones that are hard to find! But yes, you can drive and find Pokémon's!

In response to a query on how M thought that C might respond to a conversation about her taking part in exercise, M stated that *'the only thing she (C) is interested in*

is anything to do with technology!' This comment suggests that M believes that her daughter has no interest in exercise. As mentioned before, M tends to describe C as a passive participant in her own life. Yet, Pokémon Go would provide C with an opportunity to engage in physical activity. According to Niantic (2017), the makers of Pokémon Go, *'our goal is to create experiences that encourage healthy outdoor exploration and social gameplay'* and they discourage playing Pokémon Go in a car or on a bike for safety reasons (imposing a speed limit on collecting Pokémon). M's comments suggest that she facilitates C engaging in passive behaviour rather than facilitating her having the opportunity to actively pursuing Pokémon Go characters using her smartphone and her technical knowledge.

Opportunities, as per the COM-B model of behaviour, to make healthy lifestyle choices are facilitated in most cases by mothers while students are willing, on the most part, to take their mothers' advice. There are interesting exceptions where, for example, opportunities to learn are blocked for D in W, where opportunities to engage in physical activities appear to be discouraged by parent M, and where C in W's mother offers takeaways as 'treats' when encouraging C to eat healthily.

3.2 (3b) Subtheme: Her daughter's voice

While the story so far may suggest that student participants' voices are not always heard there is evidence to indicate that their voices do, indeed, impact on how parents interact with them. Having a voice indicates that daughters are capable of making choices even though those choices may not be regarded by parents as wise or healthy. When parent B spoke about her daughter C using the Internet, C's voice can be clearly heard. B stated that when she challenges C on the amount of time she spends on her laptop C responds saying *'I have this to do, mammy, I have that to do, mammy'*. It was interesting to note that C had helped prepare her mother for the

interview by giving her a list of things she uses mobile technologies for: *'What did she tell me this morning? I wrote down some of these things ((pause)) sports and basketball, she said that she plays darts online ... and she has started a 30 days fitness challenge!'*

Also, according to parent B, C creates her own opportunities in using mobile technologies as a way of maintaining a healthy lifestyle. These activities include her linking in with her sisters in taking on a 30 days fitness challenge. B stated that her daughter C is less likely to listen to her, and that C's healthy lifestyle practices are influenced by her sisters.

Parent IC stated that while her daughter C does listen when IC is giving her advice, *'the only advice she doesn't listen to is regarding food (.) what she should be eating and what she shouldn't be eating (.) the only thing that she doesn't listen to!'* While C will eat healthily at home (because she has little choice) her own voice is more significant than that of her mother when she is away from her home. It is evident from what IC and C both say that C has the motivation and capability, when given the opportunity, to use her voice in engaging in a lifestyle that she chooses.

With respect to food choices, C's lifestyle would appear to have two parts; the home one where she fits in with her mother's food choices and an external one where she makes her own food choices. C chooses low nutrient high energy dense foods and research findings indicate that there is a link between unhealthy eating habits and weight gain (Centers for Disease Control and Prevention, 2011). C has gained quite a bit of weight while attending the centre and even though she participates in a healthy lifestyle programme the food choices she makes for lunch are unhealthy ones.

In speaking about her daughter's S's voice, T gave an example of S using her voice when *'for the first time yesterday evening, for the first time I did oven chips and*

because I did not make them myself she said, “you’re joking!” T’s comment indicates that she has created high expectations for S in how she supports S in maintaining a healthy diet. S’s voice on healthy food choices is also indicated in T’s comments when she said that S *‘would be a good healthy eater, you know, no junk food!’*

In speaking about her daughter N’s voice, IM stated that when she suggests that N choose a yoghurt rather than a square of chocolate when she is hungry at night N’s response is *‘No’* and that is the end of that discussion. N’s very clear *‘No’* to a healthy option at a specific time may be indicative of environmental opportunities that mirror her mother’s behaviour who described herself as a *‘late night “binger” if that’s what you call it!’*

In the context of the COM-B model, daughters’ voices indicate that they are capable of making their wishes known to their mothers. C indicates to her mother that she is capable of making her own choices around Internet use and lifestyle choices. S does not hesitate in making her opinion known on her mother’s food choices; neither does N hesitate in letting her mother know that she will make her own food choices.

3.2 (3c) Subtheme: My daughter and I ... she’s her own person

There was strong evidence in all interviews to indicate that there is a close relationship between mothers and daughters who participated in this study. While many of these relationships may very well appear to be one-sided and about mothers’ needs and expectations, others have aspects that suggest a genuine ‘team’ effort where both parties work together in making healthy lifestyle choices.

C was very able to persuade parent B about the positives of using mobile technology, that being online was not all a negative experience and B could see that C used it in a way that was supportive of her learning new things. In the context of a discussion on the many things that C has achieved, plus the numerous things she is

working on, B stated that *'perhaps I don't give her enough credit for the things she does!'* and acknowledged that C does tend to follow through on her plans, an example being the 30 day fitness challenge. B further emphasised her understanding of C's way of doing things when she said *'she is very much her own person with her own opinions'*. B's comments indicate that C is a very capable person who is highly motivated to pursue ideas and plans and that B understands that she must provide C with the opportunity to follow-through on her plans as this facilitates C engage in behaviours that are of benefit to her. There was clear evidence from both B's and C's comments that their relationship is based on mutual respect.

IC's relationship with C is, perhaps, highlighted in the following comments made by C; *'but mammy won't let me have it!'* The conversation at that stage was focused on IC encouraging C to participate in Slimming World sessions and IC's discovery that, according to IC, C did not comprehend the purpose of these sessions. IC stated, *'it was the stuff she liked that she would talk about, not what she was supposed to talk about which is the stuff she should be eating!'* IC described C's comment about IC not letting her have what she wanted to eat as follows:

Yeah, and she blames us for not losing weight and when I asked her she said "you don't feed me!" and I said, "hold on (.) You have a meal in the evening time when you come home, you have something small in the evening time at around 6 or 7 o'clock!" but what she means is, we are not giving her the stuff that she wants!

IC went on to state that she makes a mistake in assuming that C understands less than she actually does: *'I assume that C hasn't the mental capacity to understand something'*. Her comment was made in the context of how C was able to persuade both her mother and her father that the reason she was not able to eat the Slimming

World meals prepared by her mother was because the microwave in the centre was not working. So, perhaps rather than her not understanding the purpose of attending Slimming World, it is likely that C did not want to attend Slimming World or eat Slimming World meals. C did say, in the focus group discussion, that she did not find attending Slimming World particularly useful. There is evidence from both IC and C that their relationship is fraught with difficulties, particularly with respect to healthy/unhealthy food choices. These difficulties reflect both IC's role as protector/advisor and C's as recipient of this advice. While there is little evidence of teamwork within this mother daughter relationship there is clear evidence of C's voice. While IC advised her to engage with Slimming World her motivation/voice was directed elsewhere and this is where she directed her capabilities (COM-B model).

G spoke about how she and S exercise together and stated that she sometimes has to make S exercise: *'I would make her go!'* When G was asked if she discussed options with S, G stated *'I would give her a choice! I would ask her, "do you want to go to BK woods or to M, or where?"'* The discussion moved on to what advice G would give other parents in supporting their daughters in maintaining a healthy lifestyle, G stated:

You can't force someone to eat food, if you aren't eating it yourself then you can't force them to eat it (.) and you need a breakout every week (.) you need some leeway on it! ... Do you know what I mean? You need to go at their pace, you can always go at your own pace tomorrow! Keep it simple!

G is clearly concerned that S engages in healthy lifestyle activities and describes her role as an enabler to S's role as passive participant. According to G, she is also very aware that S cannot be rushed and is mindful of the importance of modelling

behaviour rather than 'do as I say'. Yet, she does speak about having to make S exercise and this indicates that at time, perhaps, G is persuasive and at other times she pressurises S to participate. There is research evidence to indicate that parental influence may have a negative impact on adolescent behaviour particularly if that influence is based on pressure rather than persuasion (Lessard et al, 2010).

Parent IM spoke about how she and N work together as a team and how she encourages N by asking her to go walking with IM. IM stated: *'And I would ask her to come up with me and I would drive us there (.) and we would do two or three rounds of the EO track and we would come home'*. IM went on to say *'yes, we do something together every day! If I go, she goes, if she goes I go (.) we support each other!'*

These comments by students and parents indicate that opportunities to engage in health behaviours are a complex combination of both positive and negative contexts, with a hint of motivational resistance on the part of students (COM-B model).

4. Discussion

Introduction

The aims of this research project were to discover how female students use mobile technologies and whether they use them as a resource in making healthy lifestyle choices. These aims were broken down into the following objectives; the first objective was to discuss with student participants their use of mobile technologies, and the second was to discuss health issues that matter to them in order to understand if/how these health issues impact on their lifestyle choices.

Overall findings indicated that the majority of these female students do use mobile technologies on a daily basis and that they use them for a variety of purposes. These purposes range from using social media apps such as Facebook and Snapchat to keep in touch with friends and family, to gaming apps such as Pokémon Go. They also use apps and sites that support healthy lifestyle choices such as Slimming World, Curves, SHealth and Fitbit. Findings also indicated that students, similar to the general population, experience a variety of health needs including epilepsy, thyroid disease, and food allergies that in some cases impact on their healthy lifestyle choices.

Findings from discussions with students indicate that parents play a significant role in their daughters' lives and for this reason parents, with daughters consent, were invited to participate in interviews. Data from these interviews indicate that parents had mixed views on the benefits of their daughters using mobile technologies.

With regard to healthy lifestyle choices, again, most parents expressed mixed views about their daughters' choices and spoke about their role as advisor or team leader. Parents did express views suggesting that they are aware that their daughters have their own voices and that they sometimes underestimate their daughters capability.

There is evidence to indicate that the majority of students who participated in this study have the capability to use mobile technologies in a way that is supportive of them making healthy lifestyle choices. There is also evidence to indicate that opportunity to engage with mobile technologies is sometimes limited by parental supervision. Motivation to use mobile technologies in support of making healthy lifestyle choices can be influenced negatively by non-volitional factors such as compulsive viewing with a consequent negative impact on health behaviours such as sleep.

The following sections include an in depth discussion of findings under the aims of this study.

4.1 Aim 1: Students use of mobile technology

Sorbring et al (2017), Normand (2016), and Lussier-Desrochers, Caouette and Godin-Tremblay (2016) describe the barriers that people with intellectual disabilities experience in using the Internet as ranging from basic barriers to upper barriers.

The most basic barrier, the *first barrier*, ‘access to digital devices’, they describe as a financial one where an individual does not have the opportunity to acquire mobile technologies or to gain access to the Internet because of a lack of monetary resources. These factors are external to the individual and are described as ‘opportunity’ to engage in behaviour within the COM-B model of behaviour.

The *second barrier*, ‘sensory motor ability’, refers to the individual’s physical capability to use digital devices and includes sensory or motor capabilities in using smartphones or tablets. The *third barrier*, ‘cognitive ability’ and the *fourth barrier*, ‘technical ability’ they suggest may or may not be connected as smartphones and tablets have become an integral part of young people’s lives and using mobile technologies has identified them apart from previous generations; they have become a

‘digital nation’. These factors are internal to the person and are described within the COM-B model as ‘capability’; the psychological and physical ability that an individual has in engaging in behaviour. In this regard, Shaw et al (2015), in a systematic review of research findings about using social media as a health intervention in adolescent health, stated that adolescents (aged 12-24 years) are dynamic users of social media, that they are often the teachers for adults, and that when adults ‘catch up’ adolescents tend to move on to the next new technologies.

The *fifth barrier* identified is ‘understanding of social codes and conventions of the digital world’ (netiquette) and focuses on the difficulties that online connections can cause young people with intellectual disabilities who may face greater cognitive obstacles than other young people in identifying risky situations. From a COM-B perspective, this barrier is both external to the individual in that it exists within the online environment (opportunity) and internal to the individual (capability). Difficulties in both of these areas may impact negatively on that individual’s ability to engage in online communities. This negative impact may occur as a consequence of that individual’s motivation to communicate online without having the capability to understand the risks involved.

Student participants in this research indicated their cognitive and technical knowledge of mobile technologies when they described how smartphones and tablets function. None of these participants reported any sensory or motor issues in using mobile technology nor did they speak about financial barriers to using the Internet. These factors indicate that not only have participants got the physical, cognitive and technical capability to engage in using mobile technologies, they have financial access to these technologies. According to the COM-B model, students’ capability and motivation in using mobile technologies is evident, and opportunity to use these

technologies is facilitated by them having sufficient funds to acquire them plus access to the Internet.

Participants also indicated that as well as having detailed knowledge about the technical aspects of using mobile technologies they are also very aware of, and use on a daily basis, sites and apps that facilitate them engaging in social connections with young people of all abilities. They spoke about how they use smartphones and tablets as a way of keeping in touch with friends and family, and with their class colleagues. They spoke about Facebook and compared the pluses and minuses of Snapchat versus Instagram in facilitating social connections. They also spoke about the importance of abiding by the codes and conventions of Internet use (netiquette), for example, not sharing information that would compromise wellbeing such as sharing when drunk. All these factors suggest that students are capable of engaging within online communities in a responsible way; they articulated a clear understanding of the difficulties and possible dangers that exist in using apps and sites online.

These research findings are also indicative of how capable these participants are in engaging in behaviours that are supportive of a healthy lifestyle. Haigh et al (2013) identified that having positive relationships with family and colleagues is a significant factor in ensuring a healthy lifestyle for people with an intellectual disability. They also stated that social media apps facilitate relationships for people who might normally have difficulty in so doing. Research findings from recent studies in Sweden indicated that young people with an intellectual disability are striving for 'free zones' where they can hide from parental or adult oversight and, in turn, hide their disability from those with whom they connect (Lofgren-Martenson, Sorbring & Molin, 2015).

Similar findings by Shaw et al (2015) indicate that social media plays a central role in the lives of young people in general and *'provides young people with individual networks that can be used to promote and reflect the young person's individualism and community'* (pp. 2). Lussier-Desrochers et al (2017) stated that the use of information and communication technologies (ICT) by people with an intellectual disability facilitates their ability to communicate with others and engage in reciprocal social interactions in their communities. These findings mirror those of Valkenburg and Peter (2007) who found that not only can online communication be useful in building friendships it also impacts positively on wellbeing.

However, parental responses in this research indicate that some parents are less likely to take such a positive view of their daughters' online activities. Some parents discussed the benefits their daughters gained when using mobile technologies in learning new skills, in reading books online, or as a useful way of keeping their daughters occupied. Others spoke about the threat that mobile technologies pose to their daughters plus the efforts they need to put in place to ensure that their daughters remain safe. Some parents stated that they took the decision to use their daughters' passwords, without seeking their permission, to monitor and manage their social media activities including blocking access to dating sites and friend requests on Facebook. As has already been mentioned, social interaction and inclusion is central to student participants' way of using mobile technologies. Social interaction and inclusion has been found to be a useful way of engaging people in exercising such as, for example, students use of the gaming app Pokémon Go. Parental decisions to block or risk-manage opportunities for their daughters to engage in social interaction may impact negatively on their daughters. They may be excluded from social groups plus they may not acquire the skills necessary to use mobile technologies as a resource in

making healthy lifestyle choices. Lack of opportunity to engage may also impact negatively on an individual's ability to acquire the skills necessary to negotiate social media sites and apps (Blum-Ross, & Livingstone, 2016). Opportunities to engage are central to an individual's ability to engage in behaviours and this is highlighted in the COM-B model of behaviour.

Parental decisions can in part be explained by evidence from research findings that indicate that social media apps pose greater risks of exploitation and sexual predation for individuals with an intellectual disability than among the general population of adolescents (Lussier-Desrochers, 2017). Young people with intellectual disabilities may experience difficulties in interpreting and understanding social interaction on the Internet as there are fewer clues to others' intentions than in face-to-face communication (Lofgren-Martenson, 2008). This can lead to young people with an intellectual disability experiencing challenging and risky situations (Lofgren-Martenson et al., 2015).

Researchers such as Mitchell (2012), and Lindstrom et al (2007) made the point that a primary motivation for many parents taking an oversight approach may be a desire to protect young people from making life choices that could negatively impact on self and family. In an inclusive research project Cumming, Strnadova, Knox, and Parmenter (2014) found that using iPads increased the quality and quantity of social networks of participant female researchers with an intellectual disability. They also found that these female researchers had difficulties with support staff and with family where iPads were borrowed without permission and where family members confiscated them because they disapproved of what was being shared.

In the context of what has already been discussed it is realistic to suggest that the barriers to students making life choices identified by families include the vulnerability

of the individual to exploitation, limited decision-making capacity on the part of the individual, limited skill level, and lack of awareness of consequences (Curryer et al, 2016).

Barriers identified by families may very well reflect the stress that these families experience in caring for a child-to-adolescent with a disability. Seltzer et al (2010) found significant differences in cortisol expression between mothers of adolescents and adults on the autistic spectrum and mothers of age-matched adolescents in the general population. Mothers of those on the spectrum had significantly hypo-activated cortisol levels, especially those mothers of adolescents who present with challenging behaviours. These findings support those of Olsen and Hwang (2001) who found that mothers of young people on the autistic spectrum experienced higher levels of anxiety and depression than those mothers of young people with an intellectual disability. Olsen and Hwang also found that mothers of young people with an intellectual disability experienced higher rates of anxiety and depression than those in the general population.

These findings highlight both the difficulties that some young people with an intellectual disability experience in controlling their lives (Cumming et al, 2014) and the difficulties that parents experience in dealing with perceived risks and threats to both themselves and their young adult ‘children’.

What is concerning in these findings is the possibility that family members may very well be imposing their own perceptions of morality and choice on the individual with an intellectual disability in the name of keeping the person safe (Cumming et al, 2014). Many adults with an intellectual disability have identified the role of ‘parent as protector’ as a barrier to making choices and to self-determination (Curryer, et al., 2016; Haigh et al., 2013). When mothers spoke in interview some of

them mentioned the difficulties that their daughters create for them when they try to encourage them, while other mothers spoke about having to make holiday plans to suit their daughters' needs. Daughters in this research either took a passive role in sharing their objection to certain 'demands' or actively disagreed with parents.

Mitchell (2012) stated that parents and carers who take this 'paternalistic' approach do so in the belief that the vulnerability of people with intellectual disabilities translates into an inability to make wise life choices. Research (Reindl et al, 2016; Bjornsdottir et al, 2015; Mitchell, 2012) indicates that this approach is widespread among parents and carers of people with intellectual disabilities who struggle with finding a balance between a 'caring' approach and 'overseer' approach. They go on to state that those who take a paternalistic approach assume that allowing individuals with an intellectual disability make choices would be unwise as it could lead to them making 'wrong' or 'risky' decisions.

This approach is based upon an assumption that individuals with in intellectual disability lack decision-making capacity, an approach that has been replaced legally within many jurisdictions with a functional approach wherein it is assumed that the person has capacity (United Nations Convention on the Rights of Persons with Disabilities, 2006). One of the eight guiding principles of the UN Convention on the Rights of Persons with Disabilities is *'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'*. According to this principle, each person is entitled to make his/her own choices, and be assisted in doing so when necessary. These principles also enshrine the right of individuals to make choices that may be perceived by others to be unwise or risky. However, while many countries, including Ireland, have signed the UN convention not all have ratified it, including Ireland. While Ireland has passed the

Assisted Decision-Making Capacity Act (2015) moving the legal position from a paternalistic and ‘best interests’ approach towards persons with intellectual disabilities to a rights-based approach of choice, control and consent, Ireland has yet to enshrine in law the rights of people with disabilities to make their own choices. When these principles are enshrined in law and people with an intellectual disability are assisted in making choices, no matter how they are perceived within their families, then the work of those who support them as independent adults will have a more solid footing.

Interestingly, student participants indicated that they are capable of understanding the risks around privacy and security associated with using mobile technologies, and in particular using social media. Participants stated that they had downloaded apps for security to ensure that their smartphones were safe because they were aware of the consequences of their information being ‘hacked’. They talked about the importance of knowing where apps come from, whether apps are reliable and whether information shared on apps is safe. They spoke about the importance of sharing information only with people they know and trust when using social media apps such as Snapchat and Facebook and mentioned the fact that people open fake Facebook pages. In a similar vein, they spoke about the importance of being safe online by ensuring that they know with whom they are speaking. They made the point that just because a person closes a Facebook account it does not mean that the page disappears from the Internet. Students’ comments are supported by research findings (Dehling et al., 2015) on the development of mHealth apps that require detailed information from users. Those findings indicated that the majority of available mHealth apps lacked essential information privacy and security measures and

recommended that this be the focus of app developers as a way of fostering user acceptance and trust.

Students also spoke about compulsive viewing and expressed mixed views as to how this behaviour impacts on their lives. Where some participants were enthusiastic binge-watchers and Candy Crush gamers, others spoke about how this behaviour negatively impacts on their sleep and shared how they were making efforts to curb their compulsive viewing. Some students saw the positives in gaming apps such as Pokémon Go that encourages gamers to exercise as a way of completing tasks. This observation is supported in recent research where findings indicated that mobile apps combining gaming with physical activity lead to significant short-term increases in activity (Shameli et al, 2017; Althoff et al, 2016). The examples given above indicate that motivation and opportunity can either have a positive or negative impact on behaviour and this impact is dependent primarily on how an individual's capability is mediated by these factors (COM-B model).

Sleep disturbance was also the focus of a discussion on late night use by participants of smartphones and tablets. Some students stated that they were afraid that they might miss out on social activities if they turned their phones off at night, or at any time, while others stated that keeping phones on at night would impact negatively on hours slept. Those who spoke about feeling lost without their phones experience what is commonly called a 'fear of missing out' (FOMO) on incoming text messages and social media alerts, a fear of missing out on opportunities to engage with others, a fear of being excluded (Woods & Scott, 2016). In this instance, opportunity and motivation impact negatively on that individual's capability in engaging in health promoting behaviour resulting in negative health behaviours (COM-B model).

In the context of the pressure to be available twenty-four hours a day and seven days a week on social media, research evidence to date suggests that a relationship exists between social media use and adolescent mental health (Woods & Scott, 2016; Rosen et al, 2013). Woods and Scott (2016) found high levels of anxiety and depression among adolescents who use social media. The evidence from their research suggests that this relationship may not be a simple one where social media use can be identified as a source of anxiety or depression. Anxious adolescents may use social media to ease their anxiety, while depressed adolescents may use social media to regulate their moods. However, they found that night-time usage of social media significantly predicted poorer sleep quality than overall usage of social media.

4.2 Aim 2: Mobile technologies, conversations about health issues that matter, and healthy lifestyle choices

For many student participants, mobile technology plays an important role in their daily lives and provides opportunities for relaxing, watching favourite television programmes, for gaming, and for connecting with friends by sharing messages and photos. Access to the Internet also provides student participants with opportunities to learn new skills that benefit wellbeing, and learn about the role of diet and exercise in maintaining a healthy lifestyle. Student participants talked about using smartphone apps such as SHealth, Fitbit, and Pokémon Go as useful aids in maintaining a healthy lifestyle on a daily basis. The SHealth app is based on Samsung phones and is a standard commercial app as is Fitbit. The difficulty associated with standard commercial apps is that they lack evidence-based strategies that are critical to most clinical weight loss programmes (Rivera et al, 2016).

While research has yet to be conducted into the appropriate number and types of behavioural strategies necessary for an effective app, most commercial apps that employ goal-setting strategies are dependent on the participant being motivated

sufficiently to remember to input multiple types of data on a daily basis (Rivera et al, 2016). This was one of the critiques offered by student participants who expressed frustration at having to remember so many items to input on mHealth apps. According to the COM-B model of behaviour, this demand to remember lots of detail may not only poses a challenge to an individual's capability in using an app but may also be an obstacle to that individual's motivation.

In contrast to these health apps, Pokémon Go is a gaming app and research by Althoff et al (2016) found that the use of Pokémon Go increased physical activity among men and women across the general population of all ages with results that were significant enough to be recommended for use in public health programmes. Many participants in this study spoke about being positively motivated to use Pokémon Go as a way of exercising while one parent viewed it as a positive way of encouraging her daughter to take forty minute walks, searching for Pokémon Go characters.

Lee et al (2017) recommended mHealth app developers should '*consider gamification when developing mHealth services if their target users are healthy people. If they target the younger generation, they need to have a strategy that maximises the enjoyment factor by using not only gamification but also social interaction*' (pp. 9). As has been mentioned already, social interaction is at the centre of participants' use of the Internet and of their use of mobile technologies so they are well placed to benefit from such suitably developed apps. Also, research findings from Van Lippevelde et al (2016) recommended using a gamified monitoring app that uses reward-based learning incorporating individual differences as a way of motivating behaviour change in adolescent snacking behaviour. Motivation is a necessary requirement for engaging in any behaviour (COM-B) and Pokémon Go, as

described by participants in this study, provides individuals with both motivation and opportunity to engage in healthy activities.

Other student participants discussed the usefulness of Slimming World and Curves and stated that these sites provide opportunities for individuals to participate and become part of a group where support is available both face-to-face and online; useful motivating strategies in supporting diet and exercise routines. They were able to speak about Syns and how best to use the diet programmes offered on their app and online. Student participants in this study spoke about the usefulness of having visual options available on the online Slimming World site and on the app. Students also spoke about how their mothers keep visual diaries online on their member pages on Slimming World and stated that this method of self-monitoring was useful in maintaining a healthy diet. What was significant in these conversations was the role that mothers play in ‘encouraging’ them to download healthy lifestyle apps such as the free one offered through Slimming World. For some students, this encouragement provided an opportunity to participate in activities that promoted healthy eating and exercise routines. Perhaps this opportunity also contributed to participants’ capability to engage with a programme that they found to be user-friendly and that provides social support, factors described by Slimming World as important aspects in successful programmes (Slimming World, 2017). Opportunity and capability are also considered to be two important components of behaviour in the COM-B model of behaviour, opportunity/context considered to be a primary component as it is context that facilitates or obstructs an individual’s capability to engage in behaviour (Michie et al, 2011).

In a systematic evaluation of Internet and mobile interventions for improving diet, physical activity, obesity, tobacco, and alcohol use, Afshin et al (2016) found

that mobile interventions and Internet use were more effective in promoting physical activity if they used evidence-based behavioural change strategies based on psychological theories of behavioural change. According to the COM-B model of behaviour, behavioural change techniques are successful when behaviour is understood as a combination of three components, namely capability, opportunity, and motivation. The comments made by some students suggest that using online sites that provide social support and individual feedback (opportunity) and that require the participant to engage in a way that reflects personal ability (capability) facilitate motivation.

Student participants spoke about current *health issues that matter to them*, and in particular they spoke about how some of those health issues impact negatively on their lives. One student spoke about the necessity of having regular blood tests as part of maintaining a healthy lifestyle. Another spoke about hypothyroidism and the impact that this has on her ability to manage a healthy diet while dealing with cravings for ‘forbidden’ foods such as chocolate. Another student participant spoke about being lactose intolerant and about choosing alternative sources of protein to dairy products. Findings from research by Cooper et al (2015) indicated higher levels of co-morbidity within the adult population of people with an intellectual disability than in the general population. They stated that while co-morbidity increases with age it is highly prevalent at all ages within this population, with similarities experienced between those in the aged 20-25 and those aged 50-54. They also reported that women with an intellectual disability have higher rates of co-morbidity across all age groups. Their research findings support those of Caton et al (2012) and McGuire et al (2007) who found that a greater number of people with intellectual disabilities than those within the general population experience chronic health

problems and have an existing medical condition, or a physical or sensory disability, that impacts on their ability to maintain a healthy lifestyle. These examples provide evidence to support the idea that chronic health problems impact on those individuals' capability in making healthy lifestyle choices. These situations are further compounded by the reality that making healthy food choices is also dependent on what is available so, as per the COM-B model, opportunity is an important part of the equation. Also, motivation to consume energy dense foods negatively impacts on capability and opportunity and many of these foods are more readily available than healthy options thereby supporting taste-driven choices (Breslin, 2013).

In speaking about what a *healthy lifestyle* might involve students primarily spoke about eating healthy foods, about maintaining a balanced diet, exercising regularly, and about how their mothers recommend and buy healthy food options. Interestingly, Melville et al (2008), citing the work of Golden and Hatcher (1997), state that the results of a reliable questionnaire indicated a higher level of knowledge about nutrition among obese participants with an intellectual disability than among non-obese participants with an intellectual disability. These findings suggest that factors other than knowledge impact on levels of obesity within this population. According to the COM-B model, behaviour is a combination of capability, opportunity, and motivation. Knowledge is only one component in this dynamic process and is dependent upon the individual having both opportunity and motivation to engage. Perhaps an indication as to what one of those other factors may be can be found in the discussion that participants had about food cravings.

When speaking about food cravings, some students spoke about how unhealthy energy drinks are. One student was able to give a personal experience of drinking excessive amounts of these drinks in one sitting where her mother had to

bring her to hospital because of rapid heartbeat. Another gave an example of an incident she saw on YouTube where a person mixed illegal drugs and energy drinks and she described the negative consequence he experienced. Yet, they discussed personal preferences among brands and discussed the difficulties in being asked for ID when buying energy drinks because *'there are kids mixing them with alcohol, vodka and Red Bull!'* One student was able to verify this difficulty because, as she stated, *'Yeah, I should know, I do it all the time!'* According to Visram et al (2016) young people consume energy drinks because they taste good, because young people are influenced by branding and marketing and these drinks are well advertised on sites and apps used by young people and because these drinks are perceived to benefit performance. Taste-driven food choices have evolved and adapted within our environment and for many people their sense of taste (intrinsic motivation) may lead them to eat highly palatable foods that are low in nutrient content (Breslin, 2013). A second attraction of many of these foods is that they require little or no preparation and, therefore, are instantly available. There is research evidence that suggests a relationship exists between retail food environments and eating patterns and it is these environmental factors that create an opportunity for individuals to engage in unhealthy eating practices (Ní Mhurchú, 2013). Therefore, it can be stated that taste-driven choices are associated with both internal motivation (Breslin, 2013) and with external social factors such as brand loyalty (opportunity/context) that enhances participation (Visram et al, 2016). These findings suggest that participants are motivated to drink energy drinks because of brand loyalty and because these drinks taste good; opportunity and motivation would appear to have a stronger impact on students than their knowledge about the side effects of these drinks (COM-B model).

From parents perspectives on their daughters diets, two of the six mothers stated that they were satisfied that their daughters eat balanced diets, one mother did not mention her daughter's food preferences, two mothers' stated that their daughters would eat '*rubbish*' unless monitored, while the sixth stated that her daughter tries her best and that they support each other in trying to maintain a healthy lifestyle.

With regard to exercise as part of a healthy lifestyle, Hsieh et al (2015) reported that the majority of people with an intellectual disability do not engage in physical activity at sufficient levels to achieve or maintain optimum health levels. Findings from this study indicate that while some participants are motivated to engage in exercise, others do so when encouraged by their mothers. This encouragement provides some students with the opportunity to acquire the capability necessary to engage in health behaviours whereas without this opportunity they might engage in passive pursuits (COM-B model).

In this study, the majority of mothers spoke about the effort they put into encouraging their daughters to engage in exercise routines by ensuring that daughters' exercise with them. Some mothers spoke about the team effort and of a relationship of mutual support. All but two mothers expressed concern about their daughters' motivation to engage in exercise routines; of the two, one mother appeared to be quite happy with her daughter's level of inactivity while the other mother was happy that her daughter took the initiative in organising an exercise routine with her sisters. However, research findings from a longitudinal study of adolescent health behaviour showed no significant difference in weight loss between those with or without parental support (Pett et al, 2013). These findings may be a reflection of the nature of the relationship between parents and their adolescents, and whether parents used persuasion or pressure (Lessard et al, 2010).

In what might seem to be self-contradictory statements, all mothers expressed the view that they underestimate their daughter's ability and spoke in positive terms about the relationship that had developed between them.

4.3 Discussion Summary

Using the COM-B model of behaviour as an overarching framework for understanding participants' behaviour has facilitated an understanding of the factors that impact on participants' use of mobile technologies and also of the factors that influence their lifestyle choices.

Capability: There is evidence in findings from interviews and focus groups of students' capability in engaging in using mobile technologies and in negotiating their way through social media sites, the Internet, and apps that support healthy lifestyle choices. What is also evident is their capability in understanding the impact that health issues have on their choices, an understanding of the difference between healthy food choices and taste-driven choices, plus an understanding of how impulsive behaviours such as cravings have on healthy lifestyle choices.

Opportunity: What is also evident in this study is the important role that opportunity/context as described in the COM-B model, plays in choices participants make with respect to both using mobile technologies and in making healthy lifestyle choices. For many participants, their mothers mediate 'opportunity' to engage in certain behaviours without their knowledge or permission. This factor indicates that opportunity to engage in behaviour may be blocked by factors that are unknown to the individual who, perhaps, is motivated to engage in that behaviour. Some students' responses to mothers mediating as protectors or advisors was to take a passive role in including parents 'advice' in how they use mobile technologies or when making

healthy lifestyle choices, while others challenged their mothers either directly or indirectly.

Motivation: Many students spoke about the impact that automatic processes such as habitual behaviour (compulsive viewing), impulsivity (choosing high energy drinks despite knowing the negative consequences), and emotional responses (food cravings for chocolate, FOMO) have on their ability to engage in making healthy lifestyle choices. What was also evident was that mothers were motivated to protect and control their daughters' behaviour without, in many instances, trusting their daughters to acquire the necessary skills to engage responsibly.

Overall, the COM-B model has facilitated a broad understanding of the three components, both internal and external to participants, that impact on their behaviour. What is very significant about this model is that it includes contextual factors as well as motivational factors and as is evident in this study, these factors play an essential role in the lives of participants. What is also significant about the COM-B model is that it forms the hub of the BCW (Figure 1) and provides practitioners with a way of identifying how this interaction of components needs to be modified in order for behaviour change to occur. In the present study, examples of the components that need to be focused on for behaviour change to occur are *capability* (e.g., cravings), *occupational* (parental role) and *motivational* (e.g., cravings, and compulsive viewing) components. Surrounding this hub is the *functional intervention* ring (Figure 1) providing practitioners with a choice of interventions. Of these functional interventions, *persuasion* may be a useful intervention with parents when focusing on their role in facilitating the use of mobile technologies by their daughters. *Incentivisation* and *education* may be useful strategies in working with students in managing cravings and compulsive viewing.

The outer rim of the wheel (Figure 1) contains seven policy strategies that may be useful in supporting functional interventions. *Service provision* within NLN may be a way of supporting educational and incentivisation interventions with students who engage in compulsive viewing. *Communication/marketing* may also be a useful approach in support of educational interventions with students who experience cravings and who also engage in compulsive viewing.

5. Reflective Practice, Research Limitations, & Recommendations

5.1 Reflective Practice

I begin with the assumption that competent practitioners usually know more than they can say (Schon, 1983; pp. 8-9).

The purpose of this chapter is to share this researcher's reflection on her role in the research process, to explore overall limitations within this research project and to conclude with recommendations.

In identifying the gap between formal theory and professional practice Schon (1983) described 'reflective practice' as the ability to reflect on one's actions so as to engage in a process of continuous learning. The purpose of reflecting on practice is to be aware of how one is located within the research and how this impacts on the research process (Braun & Clarke, 2013; Fook, 2007). Reflective practice can help practitioners understand their own values, goals, purposes, and interests and enable them to work in challenging circumstances where power relations may be unequal, and where they may be working in emotionally and physically demanding environments.

From students' perspectives my role as psychologist in National Learning Network is to support them when they have issues around self-care and personal responsibility, when they need support around health behaviours that do not work for them, or when they need to talk about personal issues, or issues that arise in the centre that might impact on their ability to attend. This means that they come to me when they need help or advice and no matter how friendly or approachable I am, I am aware that there is a power imbalance in how our conversations are interpreted. In other words, I always hold the role of 'the expert' as I will never be in a position where I ask them for help on similar issues. I have an open door policy in each centre and

encourage students to drop in to chat when they are passing; this means that we do chat about lots of things not related to their needs, about what programmes they are watching, about the latest celebrity disasters, and about what they did at the weekend.

The idea to engage students in research on health behaviours was prompted by the fact that many of our students, despite participating in healthy lifestyle programmes, have diets based on fast food and takeaway options. Also, while they engage in exercise programmes in the centre many of them use creative reasons as to why they should not attend! The idea also came from findings of a systematic review I completed on risk factors for obesity among individuals with an intellectual disability. Again, the number of people who use our services that are overweight prompted the idea for the subject matter of this systematic review. The findings of this systematic review I completed in 2015 indicated that the main risk factors for obesity among adults with an intellectual disability were being female, having a mild intellectual disability, and living independently or with family. I hoped to expand on these findings, as I was aware that many of our students are avid smartphone users and I thought that this might be an area worth exploring. I also thought it a worthwhile idea to explore with them whether or not they use diet or exercise apps on their smartphones.

My supervisors and I debated how best to proceed and decided that I needed to include a reference to obesity, as this would be a follow on from the systematic review. While the main rationale for the study remained focused on the role of mobile technology in the lives of women with a mild intellectual disability, concerns arose among us as to how I could ethically explore the concept of obesity while not ‘fat shaming’ individuals. I came up with what I thought was an appropriate title (*The use of mHealth technologies by women classified with mild intellectual disabilities who*

self-rate on the Photographic Figure Rating Scale (PFRS) with regard to body image and obesity: An exploratory study) and study rationale that would respect each individual's perception of self by asking each person to rate self on an obesity scale that did not include BMI indicators. I received ethical approval for the title and rationale for this study in January 2016 and I began interviewing individuals in April 2016. The reason I chose to interview individuals was because I thought this would facilitate an exploration of issues in a way that might otherwise embarrass them in a group format.

I was quite anxious about inviting female students to participate in this study as a significant number of female students in NLN at that time had weight issues and I was concerned that they might think that I was focusing on them exclusively. I discussed with tutors how best to approach the research subject with students and I agreed with tutors that they would speak with each group of female students prior to my discussing the topic of my research with them. Tutors have a very relaxed approach to working with students, hence the rationale for this approach. I thought that this might facilitate students decide if they wished to participate without having to say 'no' directly to me. I then met with the students who agreed to participate and went through the whole process with them and asked if they had any questions. I described their participant role as a 'helping' one where their role was to help me understand how they use their smartphones and tablets and whether they might use them as part of a healthy lifestyle.

Prior to each interview I identified a visual representation of myself on the Photographic Figure Rating Scale (Swami et al, 2008) and then asked individuals to place themselves on the same scale. I thought that this might help participants relax into the process and this seemed to work for most participants. However, some

interviews were very short and I believe that this was due in part in how I framed questions, plus a wish on participants' part to give 'right' answers. I did reframe questions when I thought that participants might not understand what I was asking, plus I did check back my understanding of their replies with participants to ensure that I understood what they meant. Also, while I used the questions as a guide I found that sometimes I tended to move away from the points I wanted to focus on in an effort to engage with participants.

I found that I was not very comfortable with the overall process and I believe that this is because I have on-going issues with weight and managing my work-life balance. I find it difficult at times to balance work and study while making time for exercise and personal space and I am sure that this impacted on how I engaged with participants. I am also quite sure that my own difficulties in managing a work-life balance prompted my initial decision to explore the area of maintaining a healthy lifestyle with students. Perhaps my own experience of the difficulties I have had made me more aware of the difficulties that participants might also experience in their lives.

However, at viva progression in May 2016 I was questioned on the overall process including the rationale for my study. I was also questioned about what the examiners described as the unnecessary complexity of trying to explore too many factors. Also, they questioned whether obesity and weight should be the sole focus for a study rather than discussing healthy lifestyle issues. The point being made by examiners was that weight and obesity are not health behaviours. Taking a health psychology perspective should focus on healthy lifestyle issues that would facilitate a more useful conversation about health behaviours. I took this feedback on board, simplified the rationale for the study and decided to consult with students about health issues that matter to them rather than focus on weight and obesity. I also explored

with students whether they wished to participate in interviews or focus groups, as this was also a factor that examiners wished to see pursued.

Students chose focus groups and stated that they preferred that their tutors participate as co-moderators with this researcher within the focus groups. They stated that this would make them feel comfortable in discussing issues that are personal to them. I also found the idea of engaging with students in a focus group setting diluted my own difficulties in speaking about this subject on a one-to-one basis as I felt that this would be a more supportive environment for all participants. During the focus group discussions I thought that all went really well. There were lots of discussions on health issues that matter to participants, they discussed the positives and downsides of using mobile technologies and they also spoke about how mothers influence their lives. However, listening to the tapes of focus group discussions I thought that I spoke a lot and while I was aware that I needed to keep people on track I did sound as if I had a particular agenda, or that I was trying to 'force' particular ideas about using mobile technologies on students. Mind you, what also clearly came across was their ability to either ignore and not respond, or merely acknowledge my words with 'hmm'!

A theme that came up in all focus group sessions and one that I particularly became aware of was the theme of 'parental role'. In discussion with my supervisors it was agreed that it would be useful to interview parents to discover what their influence is and how they influence their daughters' behaviours. I was a bit concerned about engaging with parents as the ethos of our service is based on the belief that our students are independent adults. However, I did see that getting permission from students to speak with their parents would allow me the opportunity to understand the role that parents have in their lives. There would be no conflict between seeing

students as adults and speaking with their parents, getting the parents perspective on how useful or otherwise mobile technologies are in supporting young women with a mild intellectual disability in making healthy lifestyle choices.

Interestingly, only mothers agreed to participate and I interviewed six, five of whose daughters had participated in the first part of the study. I was particularly concerned with the opinions expressed by some mothers who were very much of the opinion that they are the experts on their daughters and entitled to monitor and control some of their daughters' behaviour, particularly with regard to their daughters' access to sites and apps that they considered inappropriate. However, I did not get the sense that these mothers did so for the 'wrong' reasons but that they thought that they needed to do this to protect their daughters, even though they stated that they did underestimate their daughters' abilities. I do believe that these parents have a difficult task in deciding when it is best to protect or enable their daughters. I also think that some of their behaviours, no matter how well intended, do impact on their daughters' human rights. I did not raise this issue with parents because I thought that this would interfere with their ability to be direct and honest. Also, as I had promised parents that our conversations were confidential I was not in a position to share their opinions with their daughters.

However, this whole process has made me more aware of our need as professionals to ensure that students with whom we work are reminded of their human rights and that we encourage them to exercise their personal boundaries with all, including their parents.

5.2 Research limitations

The purpose of the second part of this chapter is two-fold: firstly to reflect on the limitations of this research and, secondly, to suggest future areas for improvement or progression as in line with Schon's (1983) reflection-on-action.

The primary limitation of this study was that it focused on females that are participants in a supportive service where they are treated as independent adults with decision-making rights and responsibilities. There are females with an intellectual disability within our society who do not wish to, or are unable to, gain direct access to supportive services. That does not mean, however, that they are unable to make healthy lifestyle choices, nor that they would/could not use mobile technologies as a way of maintaining healthy lifestyles. It may mean that unless these females are known to the services it is highly unlikely that their voices will be heard. It would have been a useful exercise to try to invite participants from a wider population of women through social media. This would have had the advantage of making contact with people who use mobile technology as a way of engaging with peers and others; plus it may have provided a broader range of participants. Also, while all female participants across five centres in the south east of Ireland were invited to participate, of a total of forty who met the criteria those who agreed to participate were white, with all but one born in Ireland. Their ages ranged between eighteen and twenty-six with an average of 19, thus excluding the opinions of older females. This meant that opinions reflected a limited representation of the overall population of women with intellectual disabilities.

While one of the criteria was participants' be either living independently or with family, only two of the participants stated that they lived independently with the other twenty-four stating that they lived with family. Perhaps a more balanced mix of

participants would have provided a broader reflection of opinions, or maybe the mix of participants in this study is a reasonably accurate reflection of living accommodation for females within the age group who participated in this research. At the present time, of an overall population of 4,757,976 people who live in the Republic of Ireland, 458,874 adults over the age of 18 live in the family home and 41.4% of those are female (Census, 2016).

Another possible limitation of this study was the fact that interviews and focus group meetings with student participants were held in either classrooms or meeting rooms in centres rather than in neutral spaces. Participants were, of course, offered the opportunity to participate in alternative surroundings but stated that they were more comfortable in the NLN centre. Context (opportunity) influences behaviour and students in centre tend to act as students in classrooms with the same group dynamics reflected in discussions (COM-B model of behaviour). As was normal classroom practice among the various groups, students who were vocal during class were also vocal in the focus groups while others played their normal passive roles despite encouragement from both the moderator and co-moderator. There is nothing to suggest, of course, that group dynamics would change within a different context but the possibility cannot be discounted. The benefit of running group sessions in centres was ready access to participants who would all be in centres on the same day.

5.3 Recommendations

In exploring the usefulness or otherwise of mobile technologies as a resource for females with intellectual disabilities in making healthy lifestyle choices, findings from this research indicated that participants are prepared to engage with mobile technologies that have an interactive element. Many studies show that successfully meeting the health needs of individuals with intellectual disabilities involves the

development of health apps that are user-centred and user-inclusive (de Cock et al, 2017; Shameli et al, 2017; Haymes et al, 2013). This researcher suggests that one of the most effective ways of ensuring that these steps are progressed is to place this research in the area of public health promotion and intervention.

A first recommendation is that the relationship between parents and their daughters with a mild intellectual disability be further explored in the context of how the parental role of protector/advisor impacts on daughters' behaviours. This recommendation is based on findings from this study that indicate that daughters' capability is impacted both positively and negatively by mothers' monitoring and/or controlling daughters opportunities to engage in particular behaviours as indicated by the COM-B model of behaviour.

A second recommendation is that further research be undertaken where participants are invited to participate from a wider population of women through social media. This would have the advantage of making contact with people who use mobile technology as a way of engaging with peers and others.

A third recommendation, based on the COM-B model of behaviour, is that further research be undertaken on the role of mobile technologies in supporting opportunities for progression in education and training for students with a mild intellectual disability within the context of a service such as NLN. This research would include students as active participants working with tutors and with programme development officers in developing programmes and/or modules that both match students' needs and are in line with governmental expectations re outcomes for student progression.

A fourth recommendation is that an organisation such as the Health Research Board (an agency supporting and funding health research under the aegis of the

Department of Health in Ireland) leads research in the area of exploring how existing commercial health apps may be adapted as user-centred mobile health apps for people with intellectual disabilities. These apps should include a reward-based learning element similar to that used in gamification apps, which is supportive of people with intellectual disabilities making healthy lifestyle choices.

6. Conclusion

Mobile technologies play a central role in the lives of young adults in the general population (Ceobanu & Boncu, 2014) and as is evident from this research the same is true for females with a mild intellectual disability. However, this researcher was unable to find any literature that included the voices of women with a mild intellectual disability in research on the role of mHealth in health behaviours or in facilitating healthy lifestyle choices.

This research study explored the use of mobile technologies by women with a mild intellectual disability and whether they found these mobile technologies useful resources in facilitating healthy lifestyle choices. The theoretical model used was the COM-B model of behaviour that describes behaviour as a function of an individual's capability and motivation, factors influenced by environmental and social opportunities. This model was chosen because it provides a broad framework for understanding behaviour that is in line with the epistemological and ontological perspectives of this researcher. Themes were conceptualised in the research data using this model as a framework and findings were identified as follows:

Findings from this research indicated that women in this group are knowledgeable about the technical use of mobile technologies and that they primarily use their smartphones and tablets for social interaction with friends and peers. Research findings also indicate that some of them use apps on their smartphones as a resource in maintaining a healthy lifestyle. Difficulties in using mHealth apps identified within this research relate to the level of engagement required to input multifactorial levels of data. Also, very few of these apps provide users with an interactive experience unlike social apps such as Facebook and Snapchat where users are constantly invited to engage and participate. Findings also indicate that

participants' mothers play a significant role in monitoring and guiding their behaviour both online and in person. Some daughters challenge their mothers in a passive way; others challenge their mothers directly, again others accept their mothers' interventions.

What is unique about this study is that it adds student participants' voices on how useful mobile technologies are, or can be, in facilitating healthy lifestyle choices among females with a mild intellectual disability.

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Appendix A – Systematic Review

Risk factors for obesity in adults with intellectual disabilities: a systematic review of the evidence

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Risk factors for obesity in adults with intellectual disabilities: a systematic review of the evidence.

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Abstract

Background

There is a paucity of research in the area of risk factors for obesity in adults with intellectual disabilities – there are no systematic reviews in this area in the Cochrane Database.

Objectives

To understand to what extent biopsychosocial factors impact on levels of obesity in adults with intellectual disability.

Information Sources

English language electronic databases (1997-2015) plus hand-searched journals (2006-2014); databases searched – DOAJ, Informa Health Care, PsycINFO, Ssync Articles, JStor, BILD, ASSIDD, the UWE library. Google and Google Scholar were searched for non-government/government agency information. Hand-searched journals were Journal of Health Psychology, Health Psychology, Rehabilitation Psychology, Irish Journal of Psychology, European Psychologist, and British Journal of Health Psychology. Search terms included intellectual disability, mental retardation, learning disorders, learning difficulties, developmental disabilities, developmental disorders, obese, obesity, overweight, risk factors, gender, sex, adults, age, ethnicity, socioeconomic, lifestyle, biopsychosocial, physical, social, environmental, biological, genetic, weight status, weight measurement, fat measurement, and body mass index.

Eligibility Criteria

Types of studies included; cross-sectional, prevalence, and longitudinal studies.

Participants; Adults aged 18 or over with an intellectual disability (as defined by the WHO).

Intervention; studies evaluating quantitative or qualitative measures of risk factors for obesity in adults with intellectual disabilities.

Outcome; An understanding of risk factors for obesity in adults with intellectual disabilities.

Data Extraction

Data was extracted using a form adapted from a template from the Cochrane Collaboration Group – data were extracted by the lead researcher (AO'B) and reviewed by a second (MH).

Evaluation of Studies

The lead researcher assessed quality; methodological difficulties and issues with respect to missing statistical data meant that summary effects were not reported but effect measures odd ratios (OR) were worked out where sufficient data was provided.

Results

The diversity among methods and procedures within studies indicated that it would be beneficial to focus on each study separately. The findings from 9 of the 10 the studies indicated that gender (being female) was the highest risk factor for obesity in adults with intellectual disabilities.

Limitations

Inconsistencies in methodological quality, a lack of homogeneity in studies, missing statistical data, difficulties experienced in making contact with authors, were among some of the factors that crated limitations in this review.

Conclusions

Recommendations for refinement in qualitative and quantitative methods to better assess the impact of biological and sociocultural gender-specific risk factors for obesity in women with intellectual disabilities. Recommendation for adaptations in clinical practice to include biological and gender-specific factors in promoting healthy lifestyles.

Introduction

The WHO (2015) defines intellectual disability as:

A significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

While this definition may suggest that disability is within the individual, the WHO also states that disability is context-based where environmental factors play a significant role in enabling the individual participate and be included in society (2015).

It is estimated that approximately 2% of the UK population have an intellectual disability and according to Public Health England (2013) the rate of obesity among this population is significantly different from that of the general UK population (28.3% to 20.4%). The WHO (2015) defines overweight and obesity as “abnormal or excessive fat accumulation that may impair health” and state that being overweight or obese is a major risk factor for non-communicable diseases such as:

- Cardiovascular diseases (mainly heart disease and stroke), which were the leading cause of death in 2012;
- Diabetes mellitus;
- Musculoskeletal disorders (especially osteoarthritis – a highly disabling degenerative disease of the joints);
- Some cancers (endometrial, breast, and colon)
- Gastric problems – tooth decay as a result of a diet high in sugar, gall bladder problems, excessive gasses and gastric bloating, and liver problems;
- Respiratory problems and sleep apnoea.

Obesity is also linked to mental health difficulties such as depression and anxiety and a systematic review of longitudinal studies on the relationship between obesity and mental health indicated a positive correlation between depression and obesity; people who were obese had a 55% risk of experiencing depression while people with depression had a 58% risk of becoming obese (Luppino et al, 2010).

The standard measurement method used in many studies of overweight and obesity is Body Mass Index (BMI), which is a classification of body fat based on weight divided by the square of the height (kg/m^2). The WHO recommends that a BMI equal to or greater than 25 indicates a weight status of overweight while a BMI equal to or greater than 30 indicates a weight status of obesity. However, the WHO cautions that BMI should be used as a “rough guide” as it may not allow for differences of fat distribution among individuals. Slevin and Northway (2014) support this caution and point out that BMI correlates with, rather than measures, the amount of body fat in an individual. They suggest that BMI should be used as a screening tool rather than a diagnostic tool for weight status.

The WHO describes the primary cause of obesity and overweight as an energy imbalance between calories consumed and calories expended. According to data from WHO, global obesity levels have more than doubled in the years 1980 to 2014 in tandem with global changes in eating behaviours and habits. These changes occurred as a result of an increase in the availability and consumption of highly accessible calorie-laden and energy-dense foods high in saturated or trans fats, and/or unrefined sugar. These factors are further compounded by a decrease in physical activity associated with societal and environmental changes that arise from development unsupported by appropriate policies in areas such as health, transport, urban planning, environment, food processing, distribution, education and marketing

(WHO, 2015). The WHO also states “supportive environments and communities are fundamental in shaping people’s choices and preventing obesity” (WHO, 2015).

According to Public Health England (2013), the risk factors for obesity in adults with intellectual disabilities include behavioural, environmental, and biological factors. Women, people classified with a mild intellectual disability, people with genetic disorders such as Prader-Willi syndrome and Down’s syndrome, those taking prescribed psychotropic medication, and people who live independently are described as being at increased risk for obesity (PHE, 2013). Slevin and Northway (2014) describe causative factors and barriers as genetic and physical factors, psychological factors, social and cultural factors, and lower socio-economic status. Therefore, while the primary cause of obesity may be described as simply an imbalance between nutritional intake and energy consumption it is important to note that there are numerous causes and barriers to obtaining or maintaining a healthy weight for all populations (Slevin & Northway, 2014).

Despite the fact that data for people with intellectual disabilities are available through public health domains there is a paucity of research in the area of health determinants for this population. A search of the library of the University of the West of England and of the Cochrane Database of Systematic Reviews for reviews in this area was unsuccessful as no systematic reviews were found on the risk factors for obesity in adults with intellectual disabilities.

In light of the above this systematic review seeks to answer the following question:

- To what extent do biopsychosocial factors impact on levels of obesity in adults with intellectual disabilities?

Method

Protocol & Registration

There is no review protocol registered for this systematic review.

Information sources

English language electronic databases for the years 1997 to 2015 plus hand -searched journals for the years 2006 to 2014 were searched for studies in this systematic review. Electronic databases searched were as follows; DOAJ, Informa Health Care, PsycINFO, Ssync Articles, JStor, BILD, ASSIDD, and the UWE library. Google and Google Scholar were used to search for WHO reports, government reports and non-government agency reports. Hand searched journals were; Journal of Health Psychology, Health Psychology, Rehabilitation Psychology, Irish Journal of Psychology, European Psychologist, and British Journal of Health Psychology. Boolean search strategies were used to search for articles with the following terms; intellectual disability, mental retardation, learning disorders, learning difficulties, developmental disabilities, developmental disorders, obese, obesity, overweight, risk factors, gender, sex, adults, age, ethnicity, socioeconomic, lifestyle, biopsychosocial, physical, social, environmental, biological, genetic, weight status, weight measurement, fat measurement and body mass index.

Eligibility criteria

Types of studies: Types of studies included; cross-sectional/prevalence studies, and longitudinal studies.

Participants: Participants were adults aged 18 or over with an intellectual disability (as defined by the WHO).

Intervention: Intervention measures were studies evaluating quantitative and/or qualitative measures of risk factors for obesity in adults with intellectual disabilities.

Outcome: An understanding of risk factors for obesity in adults with intellectual disabilities.

Exclusion criteria: Studies that focused on children and adolescents; studies whose research protocols were based on factors other than risks for obesity; Public Health studies which reported data from diverse sources; studies focused solely on secondary issues such as physiological functioning; general obesity studies; studies focused solely on behavioural change; and studies focused on lifespan issues Figure 1 (Appendix A).

Data extraction

A standardised data extraction form, adapted from the Data Collection Form devised by the Cochrane Collaboration Group, was pilot-tested on an initial 5 studies after which it was revised (Appendix B). Data were extracted by the primary researcher (AO'B) and reviewed by a second (MH). Disagreements were resolved through discussion and it was agreed that areas of mutual difficulty be referred to a third party but this was not necessary.

Evaluation of studies

The lead researcher (AO'B) assessed the quality of included studies using the EPHPP tool developed by the Effective Public Health Practice Project, Canada. An assessment of heterogeneity of each study indicated that the quality evaluation should be focused on each study individually - details of this assessment are in Table 1 (Appendix C).

Summary effect measures were not reported but, where possible, effect measure odds ratios (OR) were worked out for each study where sufficient data were provided. As there was a small number of studies included in this review it was decided from a

clinical perspective and, indeed, from a research perspective that individual aspects of each study be explored and highlighted rather than summarised.

Results

Study Selection

A total number of ten studies that focused on the inclusion criteria of risk factors for obesity in adults with intellectual disabilities were selected for this systematic review; details with respect to exclusion criteria are given in Figure 1 (Appendix A). All the studies included in this systematic review were found by searching online databases – no articles that met the inclusion criteria were found through a hand-search of journals. Of the ten studies selected for the review, four took place in the UK, two in the Netherlands and in the USA, and one each in Australia and France. Full details of all studies are in Table 1 (Appendix 3).

Study Characteristics – study design factors

As stated above, ten studies that reported findings on risk factors for overweight and obesity in adults with intellectual disabilities were selected for this study. None of these studies were randomised control trials as most were described as cross-sectional, prevalence, or observational studies – two of these studies (Mikulovic et al, 2013; Robertson et al, 2000) described using random sampling but neither of these included a description of the sampling process.

Characteristics and Results of Individual Studies

Results of individual studies are included in Table 1 (Appendix C) and are summarised as follows:

Study 1:

Objectives

In their study, Bhaumik, Watson, Thorp, Tyrer, and McGrother (2008) sought to identify risk factors for overweight and obesity within a sample of people with intellectual disabilities, investigate inequalities in weight status between people with intellectual disabilities and those in the general population, and offer suggestions as to how these inequalities might be addressed.

Method

Participants in this study, 1119 in all aged 20 or over, were taken from the Leicestershire Learning Disability Register. A requirement of the study was that participants had a health check within two years of the date 1 July 1998 and had engaged in a home interview (with carers present) within three years of the health check. For comparison purposes, data for the general population was taken from the Health Survey for England 1998 (Department of Health, 1998) and this comparison was restricted to those aged 25 and over in order to comply with national statistics data.

Bhaumik et al performed a cross-sectional analysis of the data from the register and compared it with that of the general population, and they ran logistic regression on demographic, physical, mental health issues, and behavioural skills within the ID population sample to identify risk factors for obesity and overweight.

Results

The Standard Morbidity Rate (SMR) for obesity was lower for males (0.80; 95% CI 0.64-1.00) but the SMR for females (1.48; 95% CI 1.23-1.77) was higher than found in the general population. Adults living independently or with family were three times as likely to be obese as those in residential care (OR 3.28; 95% CI 2.12-5.08). Obesity

for females was almost three times that of males (OR 0.36; 95% CI 0.25-0.53) within this population. Overall, obesity was associated with living independently or with family, ability to drink/eat unaided, being female, hypertension, Down syndrome, and the absence of cerebral palsy.

Conclusions

The authors concluded that obesity is independently associated with both female sex and Down syndrome. They also include many recommendations for addressing organisational, political, and attitudinal barriers that exist within health services and within the whole area of health care.

Study 2:

Objectives

The objectives of the study by de Winter, Bastiaanse, Hilgenkamp, Evenhuis, and Echteld (2012) were to investigate the prevalence of overweight, obesity, and body fat percentage in older adults with intellectual disabilities. They also sought to identify any association there may be between overweight and obesity and demographic factors, health behaviours, activities of daily living (ADL), and treatment factors.

Method

Researchers in this study used BMI, waist circumference, waist-to-hip ratio (WHR), and skin-fold thickness in a regression analysis to measure body fat in adults with intellectual disabilities and compared findings with data within the general Dutch older population. They also used regression analysis to investigate associations between overweight and obesity with participant and treatment characteristics (gender, age, level of intellectual disability, Down's syndrome, autism, independent living, smoking, (instrumental) activities of daily living [(I) ADL], physical activity and use of atypical antipsychotic medication). Nine hundred and forty five

individuals with borderline to profound intellectual disability aged 50 and over and living in a variety of settings (central settings, community settings, and independently) receiving care or support from three organisations recognised as care-providers in the Netherlands.

Results

Overweight and obesity were highly prevalent among adults with intellectual disabilities. BMI measures of obesity were higher (26%) than in the general population (10%). Measures of obesity by waist circumference and WHR were 46% and 48% respectively –no comparison data was available for the general population (see Table 1, Appendix C). According to de Winter et al, characteristics such as gender (being female), Down’s syndrome, being older/of higher age, having a mild to moderate ID, autism, living independently, engaging in lower levels of physical activity, and use of atypical antipsychotics were associated with a greater risk for overweight and obesity.

Conclusions

The study authors state that their findings indicate a need for education in health behaviours in areas such as diet and exercise among people with intellectual disability, particularly those living independently. They also state that policy makers and clinicians need to be aware of the risks among this population so that they are best placed to address health care costs and quality of life issues.

Study 3:

Objectives

Gazizova, Puri, Singh, and Dhaliwal (2012) investigated the relationship between weight status and lipid levels of adults with intellectual disability and co-existing mental illness.

Method

They conducted a stepwise multiple regression analysis in order to allow for the investigation of semi-partial correlations in identifying predictor variables associated with BMI. Participants in this study were identified through the outpatient service in Hillingdon, England, and data collected were compared with that from the general population collected through the Health Survey of England (2008). Characteristics of data collected included BMI, age, gender, the presence of additional physical conditions, residential status, mental illness, and use of psychotropic medication. Analysis of lipid profiles included serum cholesterol, low-density lipoprotein, high-density lipoprotein (HDL), triglycerides and the serum cholesterol/HDL ratio.

Results

Findings indicated that 28% of patients were overweight and 41% obese. Of these, risk factors for obesity were associated with gender (being female), having mild intellectual disability, and high serum triglyceride levels – greater detail is contained in Table 1 (Appendix C). No statistical significant difference was found in either the mean serum cholesterol levels or the mean triglyceride levels between those taking and those not taking first-generation antipsychotics, second-generation antipsychotics, or anti-epileptic medication.

Conclusions

The authors state that their findings indicate higher rates of obesity within this population than was found in previous studies. They suggest that further studies include waist circumference and skin-fold thickness as well as BMI when measuring weight status. They also suggest that levels of physical activity, parental obesity, and socio-economic factors might be included in future studies.

Study 4:

Objectives

Maaskant, van Knijff-Raeven, van Schroyen Lantman-de Valk, and Veenstra (2009) studied the weight and weight status of individuals with intellectual disability (living in either institutional, residential, or community residential facilities) at two time points, namely 2002 and 2007, and to study differences in weight and weight status between these two time points. They also investigated the impact of various factors such as age, gender, level of intellectual disability, aetiology, and residential status/living conditions on weight and weight status within this timeframe.

Method

The authors measured BMI of 336 participants, clients of a Dutch service provider, and statistical analysis was performed using paired or unpaired *T-tests* where appropriate.

Results

Findings indicated a mean increase in BMI between 2002 and 2007 of 0.8 (2.2kg). In 2002 measures indicated that 36% of the study group was overweight/obese – however, this figure increased to 45% in 2007. Results from a linear regression indicated that none of the named characteristics – age, level of intellectual disability, gender, aetiology, living circumstances, or aetiology impacted on weight changes between 2002 and 2007. Findings from logistic regression analysis indicated that gender was a significant variable that impacted on weight change from normal to being overweight or obese – being female was shown to be a high risk factor for obesity and overweight (Appendix C).

Conclusions

The authors suggest that health promotion material be tailored to suit the abilities of people with intellectual disabilities. They state that in the main these materials are in written format and, therefore, are difficult for people with intellectual disability to understand. They also suggest that any health behaviour interventions should take into consideration contextual factors such as demographic factors, socio-economic factors, inter-personal factors as well as intra-personal factors.

Study 5:

Objectives

Mikulovic, Vanheist, Salleron, Marcellini, Compte, Fardy, and Bui-Xuan (2014), working on the initiative of the French Federation for Adapted Sports (FFSA), investigated the following factors in a sample of people with intellectual disability from French institutions; prevalence of overweight and obesity, health behaviours such as lifestyle, eating habits, physical activity, and perceptions of body image and health. Their second aim was to assess the relationship between metabolic disorders and potential predictive variables such as demographic factors.

Method

The authors collected data by using an adapted version of a questionnaire that had been developed for use with adolescents without intellectual disability, and then used with adolescents with intellectual disability. A total of 570 people (59% of whom were males) participated in this study, the majority of whom (57%) lived in institutions, 25% were half-boarders, and 18% lived within the community.

Results

Data were analysed through the use of descriptive statistics, and by running univariate and multivariate regressions. Findings indicated a mean BMI of 24.9 with 45.6%

overweight, 17.2% of whom were obese. According to the study, the greatest risk factor for obesity was gender (being female, $P < 0.0001$). Females (53.9%) were much more at risk of being overweight than males (39.9%) and obesity levels for females at 28.2% were significantly higher than those for males (9.5%). The authors made a point of noting that their findings on the relationship between weight status and living circumstances was in contrast to previous findings. They found that people living within institutions had higher levels of overweight and obesity (48.4%) than either half-boarders (41.2%) or those living independently within the community (34.0%). They also found that overweight adults with intellectual disability spent more time engaging in physical activities than the general population, a finding that the authors' state is not consistent with earlier reports. A significant association between weight status and obesity was also found within familial relationships ($P = 0.045$). They also found that 80% of participants were unhappy with body image and physical ability, apart from which they appeared to have a reasonably good opinion of themselves.

Conclusions

The authors recommend that an emphasis be placed on encouraging people to engage in physical activities and self-focused programmes that would help individuals work on those factors that are obstacles to healthy lifestyles.

Study 6:

Objectives

Moore, McGillivray, Illingworth, and Brookhouse (2004) aimed to investigate the weight distribution of adults with an intellectual disability in an Australian population sample by measuring BMI. Their second aim was to investigate weight distribution by sample split for gender, and then sample split for accommodation status. The third

aim of this study was to compare weight status classification for males between BMI and Kelly and Rimmer's (1987) Percentage of Body Fat (PBF) formula.

Method

Ninety-three participants, 51 females and 52 males, were recruited from four non-governmental agencies. Data on respondents indicated that 8% lived independently, 44% lived with parents, 21% resided in community residential units supported by outreach services, and 27% lived within fully supported environments.

Results

Data findings indicated gender (being female) to be a major risk factor for overweight and obesity where 41.4% of females were classified as overweight (compared to 30.8% for males) and 36.6% of females as obese (compared to 30.8% for males). Data comparisons between the general pop and this sample indicated higher levels of overweight (41.4% to 28.8%) in females with intellectual disability and higher levels of obesity within this population also (36.6% to 18.2%). Figures for males indicated no significant difference (61.6% ID to 63.7% gen pop). There were no significant differences found between accommodation status and weight status by BMI. However, significant differences were found in weight status between BMI and PBF where, according to PBF, 73% of males were obese.

Conclusions

Authors suggest that longitudinal research is indicated to assess changes in weight status over time, allowing for changes in residential status; also they suggest that health behaviours such as physical activity and diet be included as predictive risk factors.

Study 7:

Objectives

Moran, Drane, McDermott, Dasari, Scurry, and Platt (2005) stated that they were interested in discovering whether or not significant differences exist in weight status between people with intellectual disability and the general population and also whether changes occur in obesity levels across time.

Method

Authors used a retrospective observational study of medical records of 1806 people to identify people with intellectual disability (680) and those without, ensuring prospective participants were age-matched. Data on demographic factors such as age, gender, race, plus other medical conditions were also extracted. The authors highlighted the following caution – living accommodation for people in the sample was more likely to be flexible (205) rather than restrictive (120). They also note that there were a high percentage (27.1%) of people with a dual diagnosis of intellectual disability and severe mental illness. A further observation by the authors was that there were a lower proportion of females with ID in the sample than males, indicating that this is reflective of standard data findings.

Results

Data findings indicated a BMI of >30 in 33.1% of people without intellectual disability in comparison with 21% people with intellectual disability among those in the age group 20 to 29. Among those aged 50 to 59, 40.5% of people without intellectual disability and 35.2% of people with ID had a BMI of >30 . Females were at greater risk of being obese ($P = 0.0001$) than males and African Americans had greater obesity levels than whites ($P = 0.0001$) across the 20 to 60 age span. No significant difference was found in prevalence rates of obesity between people with

mild intellectual disability and those in the general population ($P = 0.083$). They also found that 15% to 40% of people with and without intellectual disability moved in and out of obesity between 20 to 60 years of age.

Conclusions

The authors emphasise that rather than being a chronic condition, obesity is transitional and therefore open to health behaviour interventions and that physicians should emphasise the importance of this among their patients.

Study 8:

Objectives

Robertson, Emerson, Baines, and Hatton (2014) investigated rates of obesity and health behaviours among British adults self-identified as having an intellectual disability and those without. They also investigated whether there was a relationship between socio-economic factors and differences in weight status between these populations.

Method

Authors ran a secondary analysis of de-identified cross-sectional data from the first two waves of Understanding Society, a longitudinal study of life experience of UK citizens. Five hundred and twenty people, aged between 16 and 49, participated in this study. It is important to note that socioeconomic factors were measured using a self-assessed hardship scale and a self-assessed scale of financial status – there is no indication as to how questions were agreed or or how these scales were measured for validity or reliability.

Results

The authors found that rate of obesity, physical inactivity, tobacco use, and alcohol use and poor diet were higher in adults with self-reported intellectual disability than in the general population. They also found no significant difference between populations when data was adjusted for age or gender – however, when risk factors of material hardship and financial status were adjusted for there was a consequent reduced risk found for self-reported intellectual disability in obesity, tobacco use, nutrition, and physical activity but not in alcohol use.

Conclusions

Authors suggest that their findings indicate a necessity to treat people with intellectual disability as a ‘vulnerable group’ who are particularly vulnerable to socioeconomic deprivation and that health inequalities need to be addressed at a policy level.

Study 9:

Objectives

Robertson, Emerson, Gregory, Hatton, Turner, Kessissoglou, and Hallam (2000) investigated risk factors (obesity, poor diet, physical inactivity, tobacco use and alcohol abuse) for poor health among adults with intellectual disability. They also investigated the prevalence of these factors among this population plus the variables that predict these factors.

Method

The authors used a cross-sectional analysis of data collected on 500 adults. The study population consisted of 3 samples of 30 adults randomly selected from 3 village communities, 5 samples of adults randomly selected from five residential campuses, and 10 samples of adults randomly selected from people living independently but

supported in dispersed housing schemes (no information was given in the study as to how samples were randomly selected).

Results

Authors reported that levels of physical inactivity and poor diet were higher in the sample than in the general population and, also, that levels of obesity among females within the sample were higher than in the general population. Risk factors for poor health were identified; poor diet, tobacco use, obesity, those who lived in less restricted environments and those with greater ability. Risk factors for obesity among those with less ability and more restrictive settings included physical inactivity. The authors made a point of stating that physical inactivity was the single most important risk factor for obesity among people with intellectual disability with 84% of males and 88% of females classified as physically inactive.

Conclusions

Robertson et al conclude by stating a recommendation that the single most effective way of improving health among people with intellectual disability is to introduce moderate levels of physical activity.

Study 10:

Objectives

Sohler, Lubetkin, Levy, Soghomonian, and Rimmerman (2009) describe the aim of this study as an investigation of obesity-related needs of adults with intellectual disability so as to inform practitioners who support them in primary health care settings.

Method

Sohler et al reported findings from data collected from a community-based speciality medical practice for people with intellectual disability in New York. Risk factors

identified were sociodemographic and clinical risk factors relating to hypertension, hypercholesterolemia, and diabetes mellitus among an ethnically diverse population – 291 people participated of whom 55.3% were aged under 30 and 72.5% were Black or Hispanic. Adults were included if they had a diagnosis of intellectual disability, lived either in the community with family/relatives or independently, received all their health care within the practice, and had attended the practice for one visit at least during the study.

Results

Findings indicated that of the total number of people; 126 were obese (43%), 58 (19.9%) had hypertension, 77 (26.5%) had hypercholesterolemia, and 13 (4.5%) had diabetes mellitus. They report that age, gender (being female), and BMI were the most consistent risk factors for poor health.

Conclusions

Authors suggest that practitioners need to use innovative strategies with a team focus on health care. They suggest that strategies should include modest changes in diet and physical activity for people and their families. Because of the focus of the article, the authors emphasise the role of social workers in the team process and give advice as to appropriate case management strategies.

Discussion

Summary of Evidence

One of the main findings from these studies indicates that gender (being female) is a high risk factor for obesity and poor health among people with intellectual disabilities (Bhaumik et al., 2008; de Winter et al., 2012; Gazizova et al., 2012; Maaskant et al., 2009; Mikulovic et al., 2014; Moore et al., 2004; Moran et al., 2005; Robertson et al., 2000; Sohler et al., 2009). The only study that did not find any association between

gender and obesity was Robertson et al (2014) where no significant difference was reported for gender or age.

Four studies also indicated an association between levels of intellectual disability and obesity where those with mild intellectual disability were more likely to be obese than those with either moderate or severe (Bhaumik et al., 2008; de Winter et al., 2012; Gazizova et al., 2012; Robertson et al., 2000). Conversely, Mikulovic et al (2014) found that those who were more able to live independently had lower levels of obesity than those with more severe disabilities living in supported institutional care. Moran et al (2005) found no significant difference in prevalence of obesity between people with mild intellectual disability and the general population while Maaskant et al (2009) found that level of intellectual disability did not impact on weight status in their longitudinal observational study.

Living independently or with family members rather than living within more restrictive accommodation was found to be a risk factor in some of these studies (Bhaumik et al., 2008; de Winter et al., 2012; Robertson et al., 2000). However, Moore et al (2004) and Maaskant et al (2009) reported no significant difference between accommodation status and weight status while Mikulovic et al (2014) found that people living within more restrictive accommodation had higher levels of obesity than those who were either half-boarders or living independently. However, they did make the point that a risk factor for obesity within this population was having a parent who was physically inactive, a factor that might indicate a connection between obesity levels and those living within family situations in other contexts.

Having a diagnosis of Down's syndrome was another risk factor for obesity identified by Bhaumik et al (2008) and Robertson et al (2000).

Physical inactivity as a risk factor for obesity was highlighted in several of these studies (de Winter et al., 2012; Robertson et al., 2014; Robertson et al., 2000). However, again conversely Mikulovic et al (2014) found higher levels of physical activity among overweight adults with intellectual disability than in the general population. In their study, Gazizova et al (2012) and Sohler et al (2009) recommended that level of physical activity be included in future studies in order to address risk factors for obesity at a behavioural level.

Many of the studies make recommendations for future clinical practice and research. The majority emphasise the importance of matching interventions for behavioural change with the ability of people with ID (Bhaumik et al., 2008; de Winter et al., 2012; Maaskant et al., 2009; Mikulovic et al., 2014; Robertson et al., 2000; Sohler et al., 2009). Many of these studies make recommendations for changing health care practice, attitudes, and policies (Bhaumik et al., 2008; Maaskant et al., 2009; Robertson et al., 2014; Sohler et al., 2009) while others suggest that demographic factors, inter-personal factors, intra-personal factors, and socio-economic factors be included as predictive risk factors (de Winter et al., 2012; Gazizova et al., 2012; Maaskant et al., 2009; Moore et al., 2004).

Gazizova et al also make a very specific recommendation for future research when they recommend that measures other than BMI, such as waist circumference and waist-to-hip ratio, be used when assessing body fat in people with disabilities in order to gain a comprehensive analysis. Moore et al (2004) make the point in their study that BMI does not reflect body fat percentage and that “body composition of persons who have an intellectual disability is different. Certainly they appear to have more abdominal fat than the general population” (p. 316). However, this statement is

made without any reference to supporting evidence and, therefore, must be viewed with caution.

Moore et al (2004) recommend that longitudinal research be encouraged in order to assess weight status over time. Moran et al (2005) also describe obesity as a transitional condition rather than a chronic condition and recommend that clinicians emphasise this to their patients as a way of encouraging behavioural change.

Limitations

Outcome level

The purpose of this review was to gain an understanding of the biopsychosocial factors that impact on levels of obesity in adults with intellectual disabilities. The preceding summary of evidence indicates that the main risk factor for obesity among people with intellectual disabilities is gender, namely being female. The lack of agreement among studies around all risk factors indicates the different approaches and objectives within these studies and supports the decision taken in the review to deal with each study separately.

Study & Review level

This study has many limitations that are in part due to the variation in the quality of the studies including inconsistencies in methodological quality and statistical analyses reported. The lack of homogeneity among studies, perhaps, is a reflection of the ethical and logistical difficulties associated with gaining access to vulnerable populations. However, there was also a difference in methodological quality among studies with many studies lacking clarity on issues such as:

- Informed consent;
- Ethical approval;
- Over/under-representation in samples e.g., ethnicity;

- Lack of clarity on randomisation protocol;
- Validity and reliability of measures used;
- Definition/description of level of intellectual disability;
- Protection of anonymity.

Issues also arose with regard to the interpretation of results/statistical analysis, such as; missing *P* values, missing SD values, effect sizes not quoted, and inconsistencies between statistical analyses quoted in text and tables – see Table 1 (Appendix C).

Other limitations of this review include the following; difficulties experienced in making contact with authors to gain clarity on both methods used and clarity on interpretation of statistical analyses; the fact that only English language articles were extracted meant that reviewers needed to be cognisant of the fact that these studies represent specific populations with a need to be cautious in extrapolating outcomes; reviewers were unable to locate qualitative articles that would, perhaps, have given depth to outcomes – it is noted that in some studies (Mikulovic et al., 2014; Moran et al., 2005; Robertson et al., 2014) researchers used an interview format as part of the methodological process, but none included qualitative information on personal experience from participants.

Conclusion

The most common risk factor for high levels of obesity found in these studies was gender, a finding that is supported by Public Health England (2013). However, some of the researchers pointed out that while gender is a significant risk factor for obesity there is also a need on the part of researchers and clinicians to be aware of social, economic, biological, and inter-personal factors as contexts for obesity (Maaskant et al., 2009; Robertson et al., 2014)

An interesting point to note for clinicians involved in health care, for those responsible for health promotion programmes and for policy-makers is the importance of understanding the distinction between ‘sex’ and ‘gender’. WHO defines sex as follows; sex “refers to the biological and physiological characteristics that define men and women”, while gender they state, “refers to the socially constructed roles, behaviours, activities, and attributes that a given society considers appropriate for men and women” (Kanter & Caballero, 2012). It is known that extremes in body weight are associated with sex hormones and hypothalamic function (Geliebter et al., 2013; Kennedy et al., 1997) and research in this area indicates that obese women experience greater affective neural responses associated with craving than obese men, which might be a contributing factor for higher levels of obesity among women (Geliebter, et al, 2013).

Studies of sociocultural factors and obesity have indicated that gender-based food preferences exist and that in many Western cultures men are more likely to consume protein-rich foods such as meat and drink a lot of alcohol, while women exhibit a preference for energy-dense foods such as biscuit bars or chocolate (Geliebter et al., 2013). Also, research indicates that women in Western cultures are more likely to consume greater amounts of dairy foods while expressing a preference for ‘healthy’ foods (Power et al., 2008; Mittendorfer et al., 2009; Kanter & Caballero, 2012; Geliebter et al., 2013; Krahn & Fox, 2013).

Recommendations for research in this area, particularly with respect to the experience of women with intellectual disabilities, might include a refinement of quantitative and qualitative research methods to better assess the impact of sociocultural gender-specific factors that may contribute to the high levels of obesity among women in this population. It would also be very relevant for research

practitioners to acknowledge the biological differences that exist between the sexes and how these differences impact on day to day functioning of women with intellectual disabilities – for example, there is very little research or information on the impact of the menopause on this population (Chou et al., 2013), Research indicates that the transition into menopause effects fat distribution in the body and therefore may exacerbate the effects of obesity on health (Kanter & Caballero, 2012).

Recommendations for clinical practice might include programmes or strategies that are informed by the fact that the causes of obesity are both biological and social and vary by sex and gender – for example, research indicates that sex differences exist in how adipose tissue is stored and metabolised (Power et al., 2008). Practitioners would also need to be aware of the impact of social and cultural factors in gender roles. Perhaps health strategies that are based on the differences between sexes might be more effective than those that focus on a general population of obese adults with intellectual disabilities. It would be important that these programmes be sensitive to existing inequalities for people with intellectual disabilities and not exacerbate these disparities.

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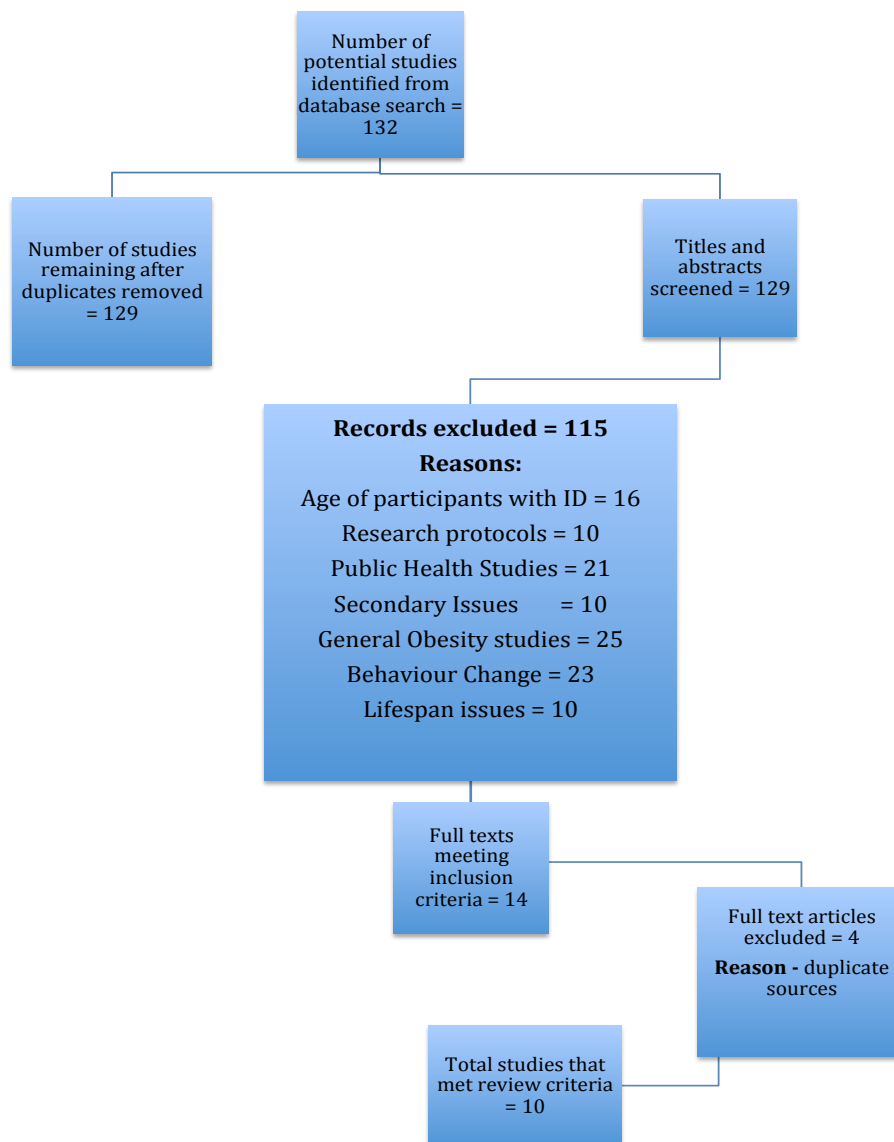
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APPENDIX A

Figure 1: Process of selection of studies for inclusion in review



Appendix B - Data Extraction Form

Notes:

- Be consistent in the order and style you use to describe the information for each report.
- Record any missing information as unclear or not described, to make it clear that the information was not found in the study report(s), not that you forgot to extract it.

Review title	Risk factors for obesity in adults with intellectual disabilities: a systematic review of the evidence.
Study ID (<i>surname of first author and year first full report of study was published e.g. Smith 2001</i>)	
Notes	

General Information

Date form completed (<i>dd/mm/yyyy</i>)	
Name/ID of person extracting data	
Reference citation (e.g. Medline)	
Study author contact details	
Publication type (<i>e.g. full report, abstract, letter</i>)	
Notes:	

Study eligibility

Study Characteristics	Eligibility criteria	Eligibility criteria met?			Location in text or source (<i>pg & ¶/fig/table</i>)
		Yes	No	Unclear	
Type of study	Experimental study including randomized controlled trials (RCTs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

	or cluster-randomized trials (CRTs).		
	Quasi-experimental studies including quasi-randomized trials, controlled before-after studies (CBAs) and interrupted time series studies (ITSs).	<input type="checkbox"/>	<input type="checkbox"/>
	Observational studies including cohort, case-control and cross-sectional studies.	<input type="checkbox"/>	<input type="checkbox"/>
Participants and setting	Adults aged 18 or over with a diagnosis/classification of intellectual disability.	<input type="checkbox"/>	<input type="checkbox"/>
Types of intervention	Quantitative/Qualitative analysis of risk factors for obesity in adults with intellectual disabilities.	<input type="checkbox"/>	<input type="checkbox"/>
Types of determinants	Determinants of concern are: 1) Biological factors; developmental factors associated with genetic inheritance or acquired through environmental factors such as prenatal environment. 2) Psychological factors – intrapersonal or interpersonal. 3) Social/environmental factors;	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>
INCLUDE <input type="checkbox"/>		EXCLUDE <input type="checkbox"/>	
Reason for exclusion			
Notes:			

DO NOT PROCEED IF STUDY EXCLUDED FROM REVIEW

Characteristics of included studies

Methods

	Descriptions as stated in report/paper	Location in text or source (pg & ¶/fig/table)
Aim of study		
Design		
Unit of observation (individual or groups)		
Start date		
End date		
Duration of participation <i>(from recruitment to last follow-up)</i>		
Ethical approval needed/ obtained for study	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear	
Notes:		

Participants

	Description	Location in text or source (pg & ¶/fig/table)
Population description <i>(from which study participants are drawn)</i>		
Setting and context		
Inclusion criteria		
Exclusion criteria		

Method of recruitment of participants (<i>e.g. phone, mail, clinic patients</i>)		
Informed consent obtained	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear	
Total no. of subjects		
Clusters (<i>if applicable, no., type, no. people per cluster</i>)		
Baseline imbalances (<i>if applicable</i>)		
Withdrawals and exclusions		
Results		
Statistical methods used and appropriateness of these methods.		
Number of missing participants and reasons.		
Results	Mean SD No of participants Effect	
Effect size – e.g. OR	Adjusted from stats quoted	
Number of missing participants and reasons.		
Authors' reported limitations of study's methods/results		

Scientific quality assessment (specify tool, e.g. modified EPHPP tool)		
Notes:		

Other information

Study funding sources <i>(including role of funders)</i>		
Possible conflicts of interest <i>(for study authors)</i>		
Key conclusions of study authors		
References to other relevant studies		
Correspondence required for further study information <i>(from whom, what and when)</i>		
Notes:		

Appendix B – Ethical approval from RehabGroup



RehabGroup

Investing in People, Changing Perspectives

Ailish O'Brien
National Learning Network
Regent House
William Street
Kilkenny

7th September 2015

Dear Ailish,

I note that you have submitted a formal proposal to National Learning Network to conduct research.

I am pleased to inform you that you have been granted ethical approval to proceed.

I stress that at all times, Rehab Group's policies and procedures must be adhered to, and draw particular attention to two policies and procedures, *Research*, (COR-OPS 002), and *Data Protection*, given the nature of the research to be undertaken and any subsequent revisions to these which are implemented during the project. Details in relation to confidentiality will be provided separately.

The following specific conditions also apply to your research:

1. The research must proceed as outlined in the proposal and any changes to this must be agreed in advance in writing with the designated Rehab contact person, Ursula Collins and me.
2. The research schedule must be agreed with National Learning Network through Ursula Collins.
3. All individual data will be kept by you, the researcher, at a secure location, outside the service. The data should be stored in an encrypted file format (Office 2007/2010/2013 or PDF) and password protected with a minimum of ten characters alphanumeric. The password should not be stored with the document.
 - In addition, the folder and /or any drive that the data is stored on (primary storage e.g. laptop, USB keys and backups) should be encrypted to AES256 or similar standards. To encrypt the data, please use BitLocker or equivalent built-in encryption technology provided by your Operating System.
 - You must ensure that you are using a supported Operating System e.g. Windows Vista or later. Please note that Windows XP is no longer supported.
 - Online storage of data using services such as DropBox must encrypt the data to a minimum of 256-bit AES encryption and should have two-step verification features available and enabled.

Rehab Group | Sandymount
Roslyn Park, Beach Road, Sandymount, Dublin 4, Ireland.

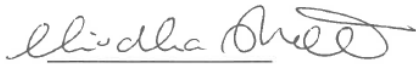
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The Rehab Group
Directors S Egan (Chairman), B Nevin (Vice-Chairman), J Brereton, N Hyland, A Kelly, K Marshall, M Martin,
S McHugh, K O'Higgins, F Ross, P Salinon (English), J Smith, D Tallon, D West, M Williams, S Wrigley-Howe (English)
Registered Office Roslyn Park, Sandymount, Dublin 4. Company limited by guarantee. Registered in Dublin, Ireland No. 14800
Rehab Group is a NGO in special consultative status with the Economic and Social Council (ECOSOC) of the United Nations.

4. Transmission of data must also be performed in a secure manner. Data should only be sent as an attachment i.e. not in the body of the email. The attachment should be in one of the secure file formats mentioned above. The password for the attachments must not be transmitted by email. Instead, you should call or text the recipient with the password. The email account used to send the data should allow for secure (https) login e.g. Gmail. It is recommended that the password used to secure the email account is strong (minimum 12 characters alphanumeric) and changed periodically. Two-step verification features (if available) should be enabled.
5. You will be required to provide brief updates to the Rehab Group Lead Director on Research policy on a three monthly basis, to inform internal reports on research activities.
6. The raw data gathered by you will be kept by you until the final research has been submitted to the University of the West of England in Bristol and National Learning Network. All raw data, taped and transcribed (including all onsite and offsite backups), will be destroyed no later than one year after the report has been completed and you will write to Rehab Group to confirm that this has been done.
7. Any resulting reports will be provided to National Learning Network. A copy of any research reports will be made available to the host organisation, National Learning Network. The researcher may be requested to present the report in the host centre and to any other forum within the wider organisation to which it may be of interest and to provide a synopsis of the report for information and use within the organisation.
8. In the event of approval for publication of the research by Rehab, the researcher will continue to adhere to the Rehab Group's policies and procedures and any revisions of same, with particular reference to the *Procedure on Dissemination and/or Publication of Research*, which refers to research commissioned by or conducted by Rehab and which would, for the purpose of any publication of this research, be considered to apply in full. This includes the requirement for sign off of the final document which will be given by Ursula Collins and final sign-off of the design and branding of the publication which will be given by Rehab's Communications and Public Affairs Team.

I would ask that you sign below to indicate your acceptance to these conditions, and return this letter to me at Rehab Group, Roslyn Park, Beach Road, Sandymount, Dublin 4.

Wishing you every success in your research,



Clíodhna O'Neill
 Director of Public Affairs and Communications
 Rehab Group

I, _____ have read and understood the terms outlined to me in the letter of 7th September 2015 regarding the conditions under which I may undertake my academic research within National Learning Network. I undertake to conduct my research in accordance with these terms.

Signed _____

Dated _____

Appendix C – Ethical approval from UWE

RE: FRDC Outcome - Ailish O'Brien RD1

Leigh Taylor <Leigh.Taylor@uwe.ac.uk> on behalf of
Research Ethics <researchethics@uwe.ac.uk>

Fri 05/02/2016 14:40

Research Project

To: Ailish O'Brien <Ailish2.Obrien@live.uwe.ac.uk>;

Cc: Julian Bath (Staff - SOLS) <Julian.Bath@uwe.ac.uk>; Rachel Gillibrand (Staff - SOLS) <Rachel.Gillibrand@uwe.ac.uk>;
mary.hughes@nln.ie <Mary.Hughes@nln.ie>;

Hi Ailish

UWE REC REF No: HAS.15.12.059

Application title: The use of mhealth technologies by women classified with mild Intellectual Disabilities who self-rate on the Photographic Figure Rating Scale (PFRS) with regard to body image and obesity: An exploratory study

Thank you for your response to the conditional approval. I can now confirm that you have full ethical approval.

Kind regards

Leigh

Leigh Taylor (Mrs)
Team Leader (Committee Services)
Research Administration
Research, Business & Innovation
University of the West of England, Bristol

Leigh.Taylor@uwe.ac.uk

Tel: 0117 328 1170

<http://rbi.uwe.ac.uk/resadmin.asp>

From: Ailish O'Brien [mailto:Ailish2.Obrien@live.uwe.ac.uk]

Sent: 30 January 2016 09:53

To: Research Ethics

Cc: Julian Bath; Rachel Gillibrand; mary.hughes@nln.ie

Subject: Re: FRDC Outcome - Ailish O'Brien RD1

Hi Leigh

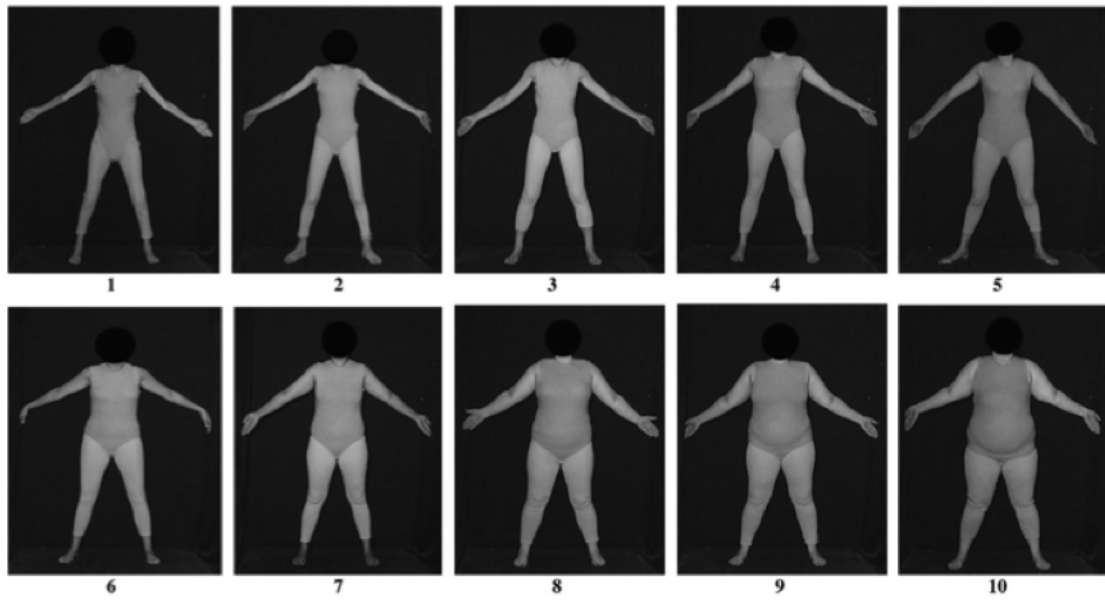
I attach amended ethics application form as requested.

Appendix D – Semi-structured interview for students

Semi-structured interview –

1. Do you have a computer/smartphone/tablet?
2. There are sites and apps on the Internet that give advice on diet and exercise. Have you ever looked at any of these sites and if so can you tell me what you found?
3. What was most useful about these sites?
4. What was least useful?
5. Have you downloaded any health apps and if so, why?
6. Where did you hear about these apps?
7. What did you find useful about these apps?
8. What was least useful about these apps?
9. Do you use any of these apps for information on diet and exercise?
10. Are these apps user-friendly – in other words, can/do you use them on a regular basis and if so how regularly?
11. As part of your healthy lifestyle classes do you use your phone for, say, everyday reminders and information such as:
 - a. A diary for class times or for new recipes?
 - b. As a way of keeping tabs on what you eat or drink or when you need to exercise?
12. Would you use your phone as a way of keeping a photo diary of meals you eat such as breakfast, lunch, snacks, and/or dinner? How would you do this?
13. Can you give me other examples of how you might use your phone as part of a healthy lifestyle?

Appendix E – Photographic Figure Rating Scale



Images used in the Photographic Figure Rating Scale (Swami, Salem, Furnahm & Tovee, 2008) arranged in ascending order of body mass index. (Permission received from author)

Appendix F – Information sheet and certificate of consent for student interviews

Informed Consent



University of the
West of England

Principle Researcher	Ailish O'Brien
Director of Studies	Julian Bath
2nd Supervisor	Dr Rachel Gillibrand
Supervisor at National Learning Network	Mary Hughes

The use of mhealth technologies by women with mild Intellectual Disabilities who self-rate on the Photographic Figure Rating Scale (PFRS), with regard to body image and obesity: An exploratory study.

This Informed Consent Form has two parts:

- **Information Sheet (to share information about the study with you)**
- **Certificate of Consent (for signatures if you choose to participate)**

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

My name is Ailish O'Brien – I am your regional psychologist and you know me from our meetings in the centre. I am exploring the use by female students of mhealth technology such as mobile phones, social media, and health apps, particularly in the area of healthy lifestyle. This is part of a research project I am working on as part of my studies in the University of the West of England, Bristol. I am going to give you information and invite you to be part of this research project. You do not have to decide today whether or not you will take part in the research. Before you decide, you might want to talk to someone you are comfortable with.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask me.

Purpose of the research

The purpose of this research is to discover whether you have found mhealth technologies such as mobile phones, health apps, and social

media sites useful for ideas about diet, exercise and being healthy.

Type of Research Intervention

This research involves you taking part in a semi-structured interview. This means I will ask you some questions about your experience of using mhealth technologies. I will also ask you to pick a figure of a woman's body that you think looks like your body shape from a row of pictures of women's body shapes. I am asking you to do this so that we can get an idea of how you see yourself – the right answer is the one you choose! Also, I will take a copy of our interviews on a recording device.

Participant Selection

You are being invited to take part because you are part of the Options group in this centre. You may be interested in giving your opinion on using mhealth technology.

Voluntary Participation

Your taking part in this research is entirely voluntary which means that you choose whether to take part or not. If you choose not to take part all the services you receive at this Centre will continue and nothing will change. You may change your mind about giving your consent during the first part of the study when your story is being recorded. I will check in with you to make sure that you are happy with your story being included in the study. However, once the study is completed you will not be able to withdraw your story.

Procedures

You will take part in an interview with me. In this interview you will choose the picture that you think is most like yours from the row of pictures of women's figures. While you are choosing your picture and when you are taking part in the interview we will sit in a comfortable place at the centre. If you prefer, we can do both in your home or a friend's home. If you do not wish to either choose a picture or to answer one or any of the questions during the interview, say so and I will stop. No one else but I will be present unless you would like someone else to be there. The information recorded is confidential. This means that only you, I and one other person who is Mary Hughes, Senior Psychologist, will know what you say. The entire interview will be electronically recorded so that I will be able to write exactly what you say. No one will be able to know the name of anyone on the recording because I will not say your name or write your name down. The recording will be kept in a fire proof locked cabinet in my office. The recording will be wiped clean once the study has been completed.

If you find any of the matters we discuss upsetting let me know either during the interview or later. If you need support we can then decide who is best placed to support you. If you do not want to speak with any people in your support team either in the centre or your supports outside the centre you can speak with Mary Hughes who is the Senior

Psychologist in National Learning Network. Mary knows what this study is about and her contact details are below.

Duration

The research takes place over 18 (say eighteen) months in total. During that time I will meet you once and each interview will last for about one hour.

Confidentiality

As already mentioned above, I will make sure that your name and details will be anonymous (your name will not be used and your details will be known by a number only) so that no one can know you from any information you share.

Sharing the Results

Nothing that you tell us will be shared with anybody outside the research team. This study may be published but this will not affect your right to confidentiality because your name will not be written down anywhere.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so. If you choose not to take part this will not affect your place in the centre. You may stop taking part in the interview any time that you wish. I will give you an opportunity at the end of the interview to listen to what you have said and have a look at notes I have taken. This will give us a chance to make sure that the recording is correct. You can also ask me to change parts of what I have written in case I did not understand you correctly.

Who to Contact

If you have any questions or concerns about the study you can ask them now or later. If you wish to ask questions later contact either Mary or me at the following numbers:

Ailish O'Brien	086 6072963	ailish.obrien@nln.ie
Mary Hughes	087 2412301	mary.hughes@nln.ie



University of the
West of England

Part II: Certificate of Consent

I have read the information sheet, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to take part in this study

Print Name of Participant

Signature of Participant

Date _____
Day/month/year

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Signature of witness _____

Date _____
Day/month/year

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the
consent _____

Signature of Researcher /person taking the consent

_____ Date _____

Appendix G – Sample of Student Interviews

160422 – C – A

A: Yes, I was looking at the Curves website, I was quite surprised that the diet plans are very good, and that the exercise plans are very good. They seem to be, to be very worthwhile seeing it on the Internet.

Interviewer: Great, great! And, am, that's the only one that you have looked at? Was there anything else?

A: Ahh (.) Slimming World, the recipes (.)

Interviewer: So there are pretty good recipes on Slimming World?

A: Yeah!

Interviewer: What was most useful about these sites?

A: What was most useful about these sites, ah, you can get recipes that are not sweet, they aren't sweet or sour, or anything like that, they are very good for you, in fact they are quite tasty!

Interviewer: And have you tried some of those recipes?

A: I have tried a few (.) in the centre here, mostly, yeah!

Interviewer: So what was least useful about those sites, do you think?

A: Am (.) I couldn't really think, to be honest,

Interviewer: ((overlapping)) they were pretty straight forward to get through and

A: ((overlapping)) they were, yeah.

Interviewer: Have you downloaded any health apps, and if so why?

A: Yes, the S Health app, I have downloaded that on my phone, I have downloaded it because I wanted to see how many steps I am getting in a day, how many walking steps I am getting in a day (.) how much water I am drinking, my water intake in a day, very important to me as well as the walking.

Interviewer: Where did you hear about these apps?

A: Where did I hear about these apps (.) I heard about these apps, I suppose, through friends, through friends of friends, that kind of thing!

160425 - W - A

Interviewer: Would you (.), what would you think would be the downside of having an app like that?

A: Ah (.) you could forget sometimes (.),

Interviewer: Mm

A: when you are someone who doesn't remember all of the time, to put the information in, but it also (.), the downside is that someone is trying to, let's say 'hack' your comp, your phone,

Interviewer: Mm

A: and they will hack all the apps and get all your information,

Interviewer: Mm

A: from your phone, from all the applications, so that is (.) kind of like a downside,

Interviewer: Mm. So (pause) what you are saying is, the downside was, first of all to remember to put in the calories of the food,

A: Yeah

Interviewer: and the second was if someone hacked in to it, or if someone got your personal information (pause), right. Would you think that your smartphone could be used (.) as a way of (.) working out a healthy lifestyle, you know?

A: ((intake of breath)) In a way, ah, I'm kind of split in the middle (.) as a help, and it is easier to have the smartphone to use it, as it can be less stress free,

Interviewer: Ah huh

A: also, we are not using our brains as a way, ah, to work, and it's just, we are not used to working our brains as we have them to do it for us.

Interviewer: Ok

A: I'm kind of fifty, fifty (.), it's just that they have something that is quick and easy and it is also, where it is like, we are also supposed to process, how we are supposed to work our brains properly if we have smartphones?

Appendix H – Amendment to Focus Groups

Amendment to Existing Research Ethics Approval

Please complete this form if you wish to make an alteration or amendment to a study that has already been scrutinised and approved by the Faculty Research Ethics Committee and forward it electronically to the Officer of FREC (researchethics@uwe.ac.uk)

UWE research ethics reference number:	HAS.15.12.059
Title of project:	Application title: The use of mhealth technologies by women classified with mild Intellectual Disabilities who self-rate on the Photographic Figure Rating Scale (PFRS) with regard to body image and obesity: An exploratory study
Date of original approval:	29 January 2016
Researcher:	Ailish O'Brien
Supervisor (if applicable)	Julian Bath

1. Proposed amendment: Please outline the proposed amendment to the existing approved proposal.

1a. I propose changing the title to: **An exploration of the role of mhealth (mobile technologies) in facilitating a healthy lifestyle among women with a mild intellectual disability.**

1b. I also propose changing the method of data collection from semi-structured interviews to focus groups.

2. Reason for amendment. Please state the reason for the proposed amendment.

1a. In light of recommendations I received in the Progression Viva I have changed the title to reflect amendments suggested in creating a clearer and more focused project.

1b. In order to collect relevant data for this project it is proposed to use focus

groups that will be recorded for thematic analysis. In my original application for ethical approval I stated that I would use semi-structured interview format but initial interviews that I ran indicate that this format will not provide sufficient material for my study. I consulted with students and asked for their advice as to the best method of engaging them in the project. They stated that they would be comfortable in discussing issues relating to health and mtechnology as part of a group and that they would like a tutor to be a co facilitator so that they would have two people to help them if any difficult issues arose. On their advice I intend running co-facilitated focus groups, two sessions with each group; the first session will focus on their use of mtechnology and the second on health issues that matter to them.

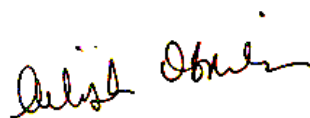
I have attached copies of relevant information sheets/consent forms plus copies of topics for discussion.

3. Ethical issues. Please outline any ethical issues that arise from the amendment that have not already addressed in the original ethical approval. Please also state how these will be addressed.

Ethical issues may relate to individuals sharing personal information within the group. The meetings being facilitated by two people will address this issue where one person will support an individual experiencing difficulties while the other will provide support for the group. Also, the already mentioned supports both within National Learning Network (NLN) and external to (NLN) will be in place.

To be completed by supervisor/ Lead researcher:

Signature:



Date:

14 June 2016

To be completed by Research Ethics Chair:

Send out for review:

Yes

No

Comments:

Since the revised documentation has been submitted as part of the amendment then this change raises no further ethical issues

Outcome:

Approve

Date approved:	<input type="checkbox"/> <i>Approve subject to conditions</i>
	<input type="checkbox"/> <i>Refer to Research Ethics Committee</i>
	<i>21.06.2016</i>
Signature:	<i>Dr Julie Woodley (via e-mail)</i>

Guidance on notifying UREC/FREC of an amendment.

Your study was approved based on the information provided at the time of application. If the study design changes significantly, for example a new population is to be recruited, a different method of recruitment is planned, new or different methods of data collection are planned then you need to inform the REC and explain what the ethical implications might be. Significant changes in participant information sheets, consent forms should be notified to the REC for review with an explanation of the need for changes. Any other significant changes to the protocol with ethical implications should be submitted as substantial amendments to the original application. If you are unsure about whether or not notification of an amendment is necessary please consult your departmental ethics lead or Chair of FREC.

Appendix I – Topics for Focus Group Discussion

Focus Group Discussion Topics – First Session



Introduce the overall topic of the session:

The role of mobile technology (mtechnology) in students' lives

Begin the session by reminding students that personal issues can be discussed with the tutor or with myself after the session.

- Sub-headings:
 - Do students use their smartphones/tablets on a regular basis?
 - What do they use their smartphones/tablets for?
 - How often do they use them?
 - Have they found any apps/sites that they find useful?
 - What are those apps/sites?
 - Are there any downsides of using apps/sites?
 - When do they turn their smartphones/tablets off?

Focus Group Discussion Topics – Second Session



Introduce the overall topic for the session:

Health issues that matter to students

Begin the session by reminding students that personal issues can be discussed with the tutor or with myself after the session.

- Sub-headings:
 - When I mention the words 'health issues' what do you think about?
 - What health issues matter to you?
 - How do you deal with these issues on a daily basis? (Link to healthy lifestyle)
 - Where do you look for help with these issues?
 - Have you ever looked for an app/internet site to help you when you need information about health issues? (Link to healthy lifestyle)

Appendix J – Information sheet and Consent form for Focus Groups

Informed Consent



Principle Researcher

Ailish O'Brien

Director of Studies

Julian Bath

2nd Supervisor

Dr Rachel Gillibrand

Supervisor at National Learning Network

Mary Hughes

An exploration of the role of mhealth (mobile technologies) in facilitating a healthy lifestyle among women with a mild intellectual disability.

This Informed Consent Form has two parts:

- **Information Sheet (to share information about the study with you)**
- **Certificate of Consent (for signatures if you choose to participate)**

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

My name is Ailish O'Brien – I am your regional psychologist and you know me from our meetings in the centre. I am exploring the use by female students of mhealth technology such as mobile phones, social media, and health apps, particularly in the area of healthy lifestyle. This is part of a study I am working on as part of a Professional Doctorate in Health Psychology in the University of the West of England, Bristol. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will take part in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask me.

Purpose of the research

The purpose of this research is to discover whether you have found mhealth technologies such as mobile phones, health apps, and social media sites useful in healthy living.

Type of Research Intervention

This research involves you taking part in focus group discussions, two sessions in all. The length of each session will depend on how the discussion goes but I imagine no more than an hour will be spent on each topic.

Participant Selection

You are being invited to attend because you are part of the Options group in this centre and you may be interested in giving your opinion on using mhealth technology.

Voluntary Participation

Your taking part in this research is entirely voluntary which means that you choose whether to take part or not. If you choose not to take part all the services you receive at this Centre will continue and nothing will change. You may change your mind about giving your consent during the first part of the study when the discussion is being recorded – I will check in with you to ensure that you are happy being included in the study. However, once the study is completed I will not be able to give you the opportunity to change your mind about taking part.

Procedures

You will take part in two group discussions with other female students in your group. The information recorded is confidential which means that only one I and one other person, Mary Hughes, Senior Psychologist, will read what I have written from the recording. The entire discussion will be electronically recorded and no one will be identified by name on the recording, all names will be deleted. The recording will be kept in a fire proof locked cabinet in my office. The information recorded is confidential, and no one else except Mary Hughes, Senior Psychologist, will have access to the recording. The recording will be destroyed once the study has been completed.

If you find any of the matters we discuss upsetting please let me know either during the meeting or later so that we can decide who is best placed to support you. If you do not want to speak with any people in your support team either in the centre or your supports outside the centre you can speak with Mary Hughes who is the Senior Psychologist in National Learning Network and knows what this study is about. Mary's contact details are below.

Duration

The research takes place over 18 (say eighteen) months in total. During that time, I will meet you twice and each discussion should take no more than an hour.

Confidentiality

As already mentioned above, I will ensure that your name and details will be changed so that no one can recognise you (your name will not be used

and your details will identified by a number only) from anything you say.

Sharing the Results

Nothing that you tell us will be shared with anybody outside the research team. This study may be published but this will not affect your right to confidentiality because your name will not be written anywhere.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so. If you choose not to take part this will not affect your place in the centre. You may stop taking part in the discussion any time that you wish. I will check in with you during the discussion to make sure that I understand you correctly. I will give you an opportunity at the end of the discussion to review your remarks. You can ask to change parts of what I have recorded or written if you do not agree with my notes or if I did not understand you correctly.

Who to Contact

If you have any questions or concerns about the study, as I stated above, you can ask them now or later. If you wish to ask questions later, you may contact either Mary or me at the following numbers:

Ailish O'Brien	086 6072963	ailish.obrien@nln.ie
Mary Hughes	087 2412301	mary.hughes@nln.ie



Part II: Certificate of Consent

I have read the information sheet, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to take part in this study

Print Name of Participant _____

Signature of Participant _____

Date _____
Day/month/year

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Signature of witness _____

Date _____
Day/month/year

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____
Day/month/year

Appendix K – Sample of transcribed Focus Group discussions

1st Focus Group K – 160516

- Moderator: Yeah (.) why don't you turn off your phones?
E: I might miss something on Snapchat!
D: Or on Facebook, or a phone call or a message!
A: I use it to help me fall asleep; I can't fall asleep (.)
Moderator: So you use it to help you fall asleep?
A: Yeah.
Co-moderator: And you would sleep well, then A, would you?
A: Yeah.
Moderator: That's a really useful one, helps you stay healthy!
Co-moderator: Would you use your phones (.) when would you stop messaging people?
E: 3am.
D: 2:30am.
J: 8:30pm.
Everyone talking at the same time ...
Moderator: What happens at 2:30am or at 3:am?
E: People stop messaging!
I: Oh you're having a laugh!
Moderator: So your phone decides what time you go to sleep?
E: ((laughs)) yeah!
Co-moderator: J said that she turns her phone off at 8:30; what about you F, what time do you turn your phone off?
F: 8:00pm.
Co-moderator: And you, H?
H: The only reason I leave my phone on at night is for the alarm, that's the only reason!
Co-moderator: What about you, B?
B: I'm the same as H, for the alarm.
Co-moderator: And what about you, C, would you be on your phone late?
C: Huh? I'd be on my phone; I'd turn it off when I got tired, about 11pm.
Co-moderator: So, phones *do* affect our sleep patterns, which is part of our health isn't it?
Moderator: So, E, what would happen if you turned your phone off at 12:00?
E: ((laughs)) I'd die of boredom!
I: Or you might get some extra hours sleep!
E: No I wouldn't! That's way too early!
I: No it's not!
Moderator: So what time do you wake up at then?
E: If I'm not coming in here I wake up at 3pm, but if I'm coming in here I wake at 8:30 or 8:45.

Moderator: Do anyone of you ever notice that if you stay up very late you feel extra tired or (.) that you have difficulty in concentrating when you are here?

Multi-response: Yeah!

Moderator: This is because sleep is important in processing what has happened during the day so that you have memories, sleep also allows you be able to focus and concentrate.

E: I never have difficulty in concentrating; I catch up on my sleep at the weekends!

Moderator: You may catch up physically but you still need to have a sleep pattern that starts before 3am!

Co-moderator: They always say that you should be in bed an hour before 12.

Moderator: Yeah (.) and using your phone as a way of helping you sleep is good because listening to music or a soft voice helps the brain sleep! Healthy lifestyle is more than what you eat or how your exercise, it is also about how you sleep! The odd late night is ok but regular late nights are bad for your brain!

Multi-response: ((laughs))

Co-moderator: I suppose stress comes into that, too, there are probably apps for stress and meditation (.) we have used some on the white board here, we have used a 5 minute meditation one, and one where you listen to a soft voice and closed our eyes (.) we've found them to be really good!

Moderator: So guys, anything else to add?

Co-moderator: Do you really like using, having smartphones and access to all these apps?

E: Yeah.

Moderator: Could you imagine life without your smartphones?

E: No, I'd be too bored!

Moderator: So, you'd be bored?

D: Lost!

Co-moderator: Do you think your phone is your friend?

E: Yeah!

D: Of course!

Moderator: What do you think is the most valuable thing about your phone?

E: Everything!

Moderator: Hm?

E: Everything; music and photos, your apps!

D: Snapchat!

Multi-response: ((laughs))

Moderator: Is an important part of your phone that it links you to other people?

Multi-response: ((pause))

Co-moderator: Do you think it difficult that you do not have face-to-face contact with people when you are messaging, that you feel a sense of isolation?

K: No!

I: Yeah, it can be difficult when you're not meeting person to person.

160830 – W – 2nd Focus Group

M: We were in a chip shop one day (.) you see, mammy goes to him but I can't eat fatty food, but then he brought out a salad and he made a Panini for my mammy.

A: There are also a few exercising apps on the phone, I used to have one of those on my phone and I had one where I had to put in my food I was eating, you had to be very specific!

Moderator: So, were you putting in different portions or what was on your plate?

A: What was on my plate! So, if I was having a burger I had to count the bread, the burger itself, the pickle, the onions, the tomato, the sauces and the portion size of it as well! I had to count how many minutes that I walked, what speed (.) how many laps during that minute, how many times I did it.

Moderator: That is a lot of information!

A: Yeah, it would tell me how many calories I need that day to stay healthy!

Moderator: Yes, A, and was that something that you felt that you could do on a daily basis!

A: Yes, it was something that you could do on a daily basis but the difficulty was the remembering! You had to remember so much!

Moderator: Ok!

A: That was kind of difficult!

Moderator: Ok, would anyone else find that a lot of information to remember, and to put together as A said?

Multi-response: Yeah!

M: Some people download Pokémon Go! 'Cos that helps you walk! 'Cos if you are in a car it will tell when it reaches 40 that you have to get out and walk!

Moderator: Right! So that's kind of a walking thing!

M: Right!

A: The reward is that you catch Pokémon! You are exercising and you don't know it! It's a game!

Moderator: Yes, is that a game that you do with someone else, that you don't do it on your own!

M: A whole bunch of you can do it!

A: Yeah, it's on your phone, it's a one-player game, but if you do it with others then it's lots of fun!

Moderator: And to people link in on social media, through Facebook and such?

A: People are losing weight!

Moderator: Is that something that you think would be an interesting way of doing exercise that you wouldn't be thinking about exercise, that you would be thinking about something else?

M: I don't have an excuse; I have to walk the dog!

Moderator: That's a good point!

A: I use Pokémon in the park!

M: That's cos it's next door to you!

K: I dance and your heart is beating and you go really fast! I don't like walking and I had to follow my cousins on Pokémon!

M: K, you are well able to walk!

A: You could do something else while you are walking!

K: Can I kind of tell you something that is confidential?

Moderator: No, K, we can talk about it later if you wish?

K: No, it's not that kind of confidential! Me and my mam have a plan of losing weight!

Moderator: Ah!

K: But my dad got a weighing scales and I weighed myself and my mam, and we have to be careful what we eat, so I find it hard to lose weight 'cos I love chocolate and I can't stop eating it, and I have a secret chocolate from the vending machine here.

M: Instead of eating chocolate you could go to the shop and buy a piece of fruit and that would keep your mind off chocolate!

K: But my mam does that!

M: I would just bring an extra piece!

K: But my mam doesn't know about it!

M: So you are a secret chocolate eater K?

K: Yes but I'm trying!

M: Yes, but my mam lets me eat a piece on Friday!

Moderator: That sounds nice! Anyone else have a day for a treat?

A: Yes, there is a diet with a bad day, it's not really taking you away from what you want, it is just giving you a day when you can have anything you eat!

Moderator: Is there anything else that you eat or drink that is bold!

M: Yeah, I like Red Bull!

K: I like Monster!

Multi-response: Yeah ... Monster!

Moderator: So, what's in all these drinks?

Multi-response: Lots of caffeine!

Moderator: So, they are not that good really!

Multi-response: No! But there is one that has green tea!

Moderator: So, any calories in these drinks?

Multi-response: Lots!

Moderator: Do you get a boost after drinking these?

Multi-response: Yeah!

M: But you can't have too much because they make your heart race! That happened me when I had 6 cans of Red Bull! My mam had to bring me to hospital and they told me not to drink too much because they are bad for your heart!

Appendix L – Ethical Approval from UWE to include parents

Amendment to Existing Research Ethics Approval

Please complete this form if you wish to make an alteration or amendment to a study that has already been scrutinised and approved by the Faculty Research Ethics Committee and forward it electronically to the Officer of FREC (*researchethics@uwe.ac.uk*)

UWE research ethics reference number:	HAS.15.12.059
Title of project:	Application title: An exploration of the role of mhealth (mobile technology) in facilitating a healthy lifestyle among women with a mild intellectual disability.
Date of original approval:	29 January 2016
Researcher:	Ailish O'Brien
Supervisor (if applicable)	Julian Bath & Rachel Gillibrand

1. Proposed amendment: Please outline the proposed amendment to the existing approved proposal.

1a. I propose to include interviews with parents/guardians of some of the participants, about 5 sets of parents/guardians in all. This proposal is dependent upon my receiving the consent of student participants.

2. Reason for amendment. Please state the reason for the proposed amendment.

1a. In light of recommendations from supervisors named above I intend broadening the scope of the exploration to include information from parents/guardians. The purpose of this further exploration is to discover the role that parents/guardians have in supporting health behaviour among the original participants.

1b. Parents/guardians will receive a written invitation to participate that will include all documentation including a cover letter, the information sheet, and a

consent form that I will hand to their daughters.

1c. In order to collect relevant data for this project it is proposed to use an interview format that will be recorded for thematic analysis.

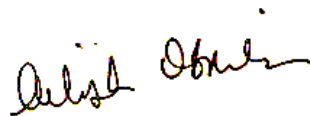
I have attached copies of relevant letters to parents, information sheets and consent forms.

3. Ethical issues. Please outline any ethical issues that arise from the amendment that have not already addressed in the original ethical approval. Please also state how these will be addressed.

Ethical issues may occur where parents/guardians may disclose information about student participants that is unrelated to this exploration. I will encourage parents/guardians to discuss any concerns that they may have around the content of the consent form. I will verbally remind parents/guardians when they attend of the importance of ensuring that they focus on the subject matter of the interview.

To be completed by supervisor/ Lead researcher:

Signature:



Date:

26 February 2017

To be completed by Research Ethics Chair:

Send out for review:

Yes

No

Comments:

This seems a sensible approach all ethics aspects associated with the amendment have been addressed

Outcome:

Approve

Approve subject to conditions

Refer to Research Ethics Committee

Date approved:

22nd March 2017

Signature:

Dr Julie Woodley (via e-mail)

Guidance on notifying UREC/FREC of an amendment.

Your study was approved based on the information provided at the time of application. If the study design changes significantly, for example a new

population is to be recruited, a different method of recruitment is planned, new or different methods of data collection are planned then you need to inform the REC and explain what the ethical implications might be. Significant changes in participant information sheets, consent forms should be notified to the REC for review with an explanation of the need for changes. Any other significant changes to the protocol with ethical implications should be submitted as substantial amendments to the original application. If you are unsure about whether or not notification of an amendment is necessary please consult your departmental ethics lead or Chair of FREC.

Appendix M – Ethical Approval from RehabGroup to include Parents

Research Approval-Ailish O'Brien

Audrey Lynch

Mon 03/04/2017 09:44

To: Ailish O'Brien <Ailish.O'Brien@nln.ie>;

Morning Ailish

This email is to inform you that the Research Panel reviewed your research proposal and are happy to inform you that your proposal has been approved with just the below change.

Just needs a "be" to be added to the confidentiality clause in the letter to the parents

We ask that you keep in contact during the research process and let us know how the project is getting on during the various phases of the research. You can communicate with Audrey Lynch at audrey.lynch@rehab.ie or 01 2057381 to send in any updates or if you have any queries.

Best of luck with the project.

Kind regards

Audrey

Audrey Lynch
PA to Director of Communications, Public Affairs and Fundraising
Rehab Group
Roslyn Park
Beach Road
Sandymount
Dublin 4
01 2057381

Appendix N – information sheet and Consent form for Parents of participants

Informed Consent



Principal Researcher

Ailish O'Brien

Director of Studies

Julian Bath

2nd Supervisor

Dr Rachel Gillibrand

Supervisor at National Learning Network

Mary Hughes

An exploration of the role of mhealth (mobile technologies) in facilitating a healthy lifestyle among women with a mild intellectual disability.

This Informed Consent Form has two parts:

- **Information Sheet (to share information about the study with you)**
- **Certificate of Consent (for signatures if you choose to participate)**

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

My name is Ailish O'Brien – I am the regional psychologist in National Learning Network in the South East.

I am exploring the use by female students of mhealth technology such as mobile phones, social media, and health apps, particularly in the area of healthy lifestyle. This is part of a study I am working on as part of a Professional Doctorate in Health Psychology at the University of the West of England, Bristol. I am inviting you to participate in this research as your daughter participated in the first part of this study and has given her permission for me to speak with you.

Purpose of the research

The purpose of this research is to discover whether women have found mhealth technologies such as mobile phones, health apps, and social media sites useful in healthy living.

Type of Research Intervention

This research involves you taking part in an interview that should take no more than 1 hour.

Participant Selection

You are being invited to attend because you are a parent of one of the females who participated in the first part of this study. I would like your opinion of the role of mobile technology in facilitating healthy lifestyle in young women and in particular how this relates to your daughter. I am also interested in your opinion of what works/does not work in maintaining a healthy lifestyle.

Voluntary Participation

Your taking part in this research is entirely voluntary which means that you choose whether to take part or not. If you choose not to take part all the services offered to your daughter will continue and nothing will change. You may change your mind about giving your consent during the first part of the study when the discussion is being recorded – I will check in with you to ensure that you are happy being included in the study. However, once the study is completed I will not be able to give you the opportunity to change your mind about taking part.

Procedures

You will take part in an interview with myself. During the interview I will sit down with you in a comfortable place at the Centre. If it is better for you, the interview can take place in your home. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else, except Mary Hughes, Senior Psychologist, will have access to the information documented during your interview. The entire interview will be electronically recorded, but no one will be identified by name on the recording. The recording will be kept in a fire proof locked cabinet in my office. The information recorded is confidential, and no one else except Mary Hughes, Senior Psychologist, will have access to the recording. The recording will be destroyed once the study has been completed.

Confidentiality

As already mentioned above, I will ensure that your name and details will be changed so that no one can recognise you (your name will not be used and your details will identified by a number only) from anything you say.

Sharing the Results

Nothing that you tell us will be shared with anybody outside the research team. This study may be published but this will not affect your right to confidentiality because your name will not be written anywhere. I appreciate your full and open co-operation and participation in this research project. Your privacy – and that of your daughter – is important to me. Please be assured that nothing in the written/published research material would lead to the identification of you, your daughter or your

family.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so. If you choose not to take part this will not affect your daughter's place in the centre. You may stop taking part in the interview any time that you wish. I will check in with you during the interview to make sure that I understand you correctly. I will give you an opportunity at the end of the discussion to review your remarks. You can ask to change parts of what I have recorded or written if you do not agree with my notes or if I did not understand you correctly.

Who to Contact

If you have any questions or concerns about the study, as I stated above, you can ask them now or later. If you wish to ask questions later, you may contact either Mary or me at the following numbers:

Ailish O'Brien	086 6072963	ailish.obrien@nln.ie
Mary Hughes	087 2412301	mary.hughes@nln.ie



Part II: Certificate of Consent

I have read the information sheet, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to take part in this study

Print Name of Participant _____

Signature of Participant _____

Date _____
Day/month/year

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Signature of witness _____

Date _____
Day/month/year

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Appendix O – Information sheet and Consent form from Students for parental participation

Informed Consent



Principal Researcher

Ailish O'Brien

Director of Studies

Julian Bath

2nd Supervisor

Dr Rachel Gillibrand

Supervisor at National Learning Network

Mary Hughes

An exploration of the role of mhealth (mobile technologies) in facilitating a healthy lifestyle among women with a mild intellectual disability.

This Informed Consent Form has two parts:

- **Information Sheet**
- **Certificate of Consent**

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

My name is Ailish O'Brien and I am your regional psychologist, you know me from our meetings in the centre and from taking part in this project. As you know, I am exploring the use by female students of mhealth technology such as mobile phones, social media, and health apps, particularly in the area of healthy lifestyle. This is part of a study I am working on as part of a Professional Doctorate in Health Psychology in the University of the West of England, Bristol.

I am asking for your permission to invite one or both of your parents to take part of this research. The reason I am asking this is to get your parents opinion on the usefulness or otherwise of sites, apps, and healthy lifestyle technology in promoting a healthy behaviour. I am also interested in their opinions on what works/does not work in promoting a healthy lifestyle.

You do not have to decide today whether or not you will ask your parents to take part in the research. Before you decide, you can talk to anyone you feel comfortable with about this.



Part II: Certificate of Consent

I have read the information sheet, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to take part in this study

Print Name of Participant _____

Signature of Participant _____

Date _____
Day/month/year

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Signature of witness _____

Date _____
Day/month/year

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____
Day/month/year

Appendix P – Information Sheet and Consent Form for parents of non- participants

Informed Consent



Principal Researcher

Ailish O'Brien

Director of Studies

Julian Bath

2nd Supervisor

Dr Rachel Gillibrand

Supervisor at National Learning Network

Mary Hughes

An exploration of the role of mhealth (mobile technologies) in facilitating a healthy lifestyle among women with a mild intellectual disability.

This Informed Consent Form has two parts:

- **Information Sheet (to share information about the study with you)**
- **Certificate of Consent (for signatures if you choose to participate)**

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

My name is Ailish O'Brien – I am the regional psychologist in National Learning Network in the South East.

I am exploring the use by female students of mhealth technology such as mobile phones, social media, and health apps, particularly in the area of healthy lifestyle. This is part of a study I am working on as part of a Professional Doctorate in Health Psychology at the University of the West of England, Bristol. I am inviting you to participate in this research as your daughter has given her permission for me to speak with you.

Purpose of the research

The purpose of this research is to discover whether females have found mhealth technologies such as mobile phones, health apps, and social media sites useful as part of a healthy lifestyle.

Type of Research Intervention

This research involves you taking part in an interview that should take no more than 1 hour.

Participant Selection

You are being invited to attend because you are a parent of one of the

female students in National Learning Network. I would like your opinion of the role of mobile technology in facilitating healthy lifestyle in young women and in particular how this relates to your daughter. I am also interested in your opinion of what works/does not work in maintaining a healthy lifestyle.

Voluntary Participation

Your taking part in this research is entirely voluntary which means that you choose whether to take part or not. If you choose not to take part all the services offered to your daughter will continue and nothing will change. You may change your mind about giving your consent during the first part of the study when the discussion is being recorded – I will check in with you to ensure that you are happy being included in the study. However, once the study is completed I will not be able to give you the opportunity to change your mind about taking part.

Procedures

You will take part in an interview with myself. During the interview I will sit down with you in a comfortable place at the Centre. If it is better for you, the interview can take place in your home. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else, except Mary Hughes, Senior Psychologist, will have access to the information documented during your interview. The entire interview will be electronically recorded, but no one will be identified by name on the recording. The recording will be kept in a fire proof locked cabinet in my office. The information recorded is confidential, and no one else except Mary Hughes, Senior Psychologist, will have access to the recording. The recording will be destroyed once the study has been completed.

Confidentiality

As already mentioned above, I will ensure that your name and details will be changed so that no one can recognise you (your name will not be used and your details will identified by a number only) from anything you say.

Sharing the Results

Nothing that you tell us will be shared with anybody outside the research team. This study may be published but this will not affect your right to confidentiality because your name will not be written anywhere. I appreciate your full and open co-operation and participation in this research project. Your privacy – and that of your daughter – is important to me. Please be assured that nothing in the written/published research material would lead to the identification of you, your daughter or your family.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so. If you choose not to take part this will not affect your daughter's place in the centre. You may stop taking part in the interview any time that you wish. I will check in with you during the interview to make sure that I understand you correctly. I will give you an opportunity at the end of the discussion to review your remarks. You can ask to change parts of what I have recorded or written if you do not agree with my notes or if I did not understand you correctly.

Who to Contact

If you have any questions or concerns about the study, as I stated above, you can ask them now or later. If you wish to ask questions later, you may contact either Mary or me at the following numbers:

Ailish O'Brien	086 6072963	ailish.obrien@nln.ie
Mary Hughes	087 2412301	mary.hughes@nln.ie



Part II: Certificate of Consent

I have read the information sheet, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to take part in this study

Print Name of Participant _____

Contact Number _____

Signature of Participant _____

Date _____

Day/month/year

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Signature of witness _____

Date _____

Day/month/year

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Appendix Q – Semi- structured interview questions & Sample of interviews with parents

Semi-structured Interview Questions

1. What do you know about mobile technology, do you have/use a smartphone, tablet, iPad etc.?
2. Do you use apps/sites that focus on health behaviours such as exercise, healthy eating/health foods, etc.? If so, what ones have you found to be useful and why?
3. Do you share what you find with your daughter as a way of guiding her?
4. What other resources/methods have you found to be useful in guiding your daughter in how she takes care of her health? For example; exercise classes, attending Slimming World classes, walking together?
5. Does she listen to your advice?
6. In the context of what we have been talking about, how do you see your role in supporting your daughter?
7. What difficulties, if any, have you both experienced in working towards a healthy lifestyle?
8. What advice would you give other parents in supporting their daughters in maintaining/working towards a healthy lifestyle?

1st interview with parents

12 May 2017

Interviewer: Thank you for participating in this research piece, B, I really appreciate you doing this. As you know, this research is about the use by female students of mhealth technologies, smartphones, tablets ... iPad's ... also, it is about healthy lifestyles ... for example, Rosemary helps students shop and cook within a budget, they are given a budget and they have to go out and ... ah ... work within that budget ... so ... am ... and the kind of things we will be talking about today is your experience of what happens at home, the kind of things you get involved in with C ... alright? What do you know about mobile technology, B, and do you have a smartphone or tablet?

B: ((pause)) I have a phone ... but it's not a smartphone ... No ... it's an iPhone, I suppose ... I don't use it ... I use it to make calls ... now, as regards C ...

Interviewer: Mm

B: she has a separate phone and she uses it, too, to make calls. She has a laptop and an iPad ... and she spends a lot of time on those ... she tells me that she is doing typing ... or whatever it is called ...

Interviewer: Mm

B: and she is also on the laptop and she goes on You Tube and she downloads songs ... and, maybe there is an issue with that because she spends too much time on that, but there is also the positive side in that she is learning these songs which is helping her to ... speak, use her voice ...

Interviewer: Mm ... yeah!

B: and she is also aware of ... won't come to me now ... and she knows every song!

Interviewer: Yeah!

B: ah ... and the downside now is that she is into Home and Away, and Neighbours ... which I like to myself, sometimes ... and she watches them a lot ...

Interviewer: Mm

B: and she could become consumed by it, in a sense maybe too much, but it also makes her wise to the world!

Interviewer: Mm

B: ... to my horror, but that is probably a good side ... the bad side is that I cannot always tell her that she is looking at it too much ... 'cos she will come back with an answer "I have this to do mammy, I have that to do mammy" and I would just love to take the whole thing off her and throw it out! Like everything, as I said, there is a good side and a bad side ...

Interviewer: It's getting the balance between them ...

B: It's getting the balance ... and I haven't got that ...

Interviewer: And I'm wondering if it is possible to get a balance?

B: When I look at all the other members of the family ... I don't get a balance either ... because I have another lady who comes home ...

Interviewer: ((overlapping)) yeah ...

B: and she spends her whole time ...

Interviewer: ((overlapping)) yeah ...

B: and she's taking photographs and I'm saying, "Where are you sending that?" ... And they're at an age that they are just consumed by it ...

Interviewer: Yeah ...

B: and you'd hope that they'd know the right thing ...

Interviewer: And I think that for us there was more about conversations between people ...

B: Yeah ... and they are just connecting with each other by sending photographs ... or that's what they look like now ... or that's what they are doing now ...

Interviewer: ((overlapping)) yeah ...

B: and that's ((pause)) and that's just the way the whole thing has gone ...

Interviewer: Yeah ...

B: and they have brought them into the schools now and there's not turning back now!

Interviewer: Mm ... and you did say it is about getting the balance right and you did say that C learnt a lot from it ...

4th interview with parents
19 May 2017

Interviewer: Do you think ... does C get involved in any exercise or anything at home, is there anything like that that she is interested in?

M: The only think she is interested in is anything to do with technology! She goes to archery on a Tuesday evening and that is about as far as she goes! She has become a tech savvy ... you could nearly say recluse.

Interviewer: Mm ...

M: Her bedroom is like Games Stop ... you name it, what console they sell in there, she has it ... and that is her life! It doesn't involve any movement, any exercise and she is very happy inside in that, in that room!

Interviewer: Mm ... that's her own space ...

M: Yeah ... that's her own space! And you know, she is fantastic on phones, on tablets on games ... she doesn't even have to read the instructions ...

Interviewer: Mm ...

M: She knows what to do! It's amazing!

Interviewer: So, do you think that there is something in that that could be useful, for, say ... could a conversation happen where she might be interested in doing something small, or do you think that she would not be interested in anything that would involve her moving?

M: Honestly? I don't think ... I think she has no interest in movement at all ...

Interviewer: At all ...

M: At all ... I know that that sound terrible ... like, I see her friends that she is in National Learning Network with and I have, have her passcode to her Facebook page, and she's not on

WhatsApp, she's not on ... Oh, she is on WhatsApp, she's not on Snapchat, she's not on Twitter ...

Interviewer: Mm ...

M: She's not on any of those ... she has a Facebook page that the centre set up for her, she didn't set it up ... and her passcode is the same for everything, for her tablet, her phone, so I can go in and have a look and I can see by how many notifications that she does not go on Facebook and she is different from the other girls in her group, I can see this when I go in to have a look at their pages from hers ... and they sometimes send me friendship requests ... just to have a nosey as to what is going on in their lives in comparison to hers! Her life is completely different to theirs, they are so active on social media it's unbelievable ... everything they do, everything they eat, everything they drink! They even take pictures of their teachers!

Interviewer: Mm ...

M: You name it; it's out there! But she's not like that!

Interviewer: Mm ...

M: She has no interest in socialising with other people... so if you have no interest in socialising with other people then Facebook is not something that is important to you!

Interviewer: Mm ...

M: She likes to play games where she is alone, or she will play with someone on line that she doesn't ... doesn't know.

Interviewer: Mm ...

M: They could be anywhere in the world ...

Interviewer: So, her connection is 'once removed', there is no physical connection there is a connection shared through the game?

M: Yes, yes!

Interviewer: She always strikes me as someone who is comfortable in her own skin!

M: Very comfortable, so comfortable! I would ... if I could be somebody for a day I would like to be her, just to feel what it feels like just to accept yourself, what it feels like to be happy in your life!

Interviewer: Mm ...

M: With not a worry in the world!

Interviewer: Mm ...

M: And I think, social media when you are so active on it can, kind of you know like, interrupt your life because all the others are going in to town, meeting guys, and if I was that active on social media I might feel that I was missing out!

Interviewer: Mm ...

5th interview with parents
26 May 2017

Interviewer: She would have spoken about meals that you cook and this is why I am speaking with parents as many girls spoke about what their mother's did ...

G: I would walk a lot ... I am after doing the 4 peaks challenge for Epilepsy Ireland about a fortnight ago ...

Interviewer: Right!

G: So, I suppose ... yeah, I had lost weight and put back on more ... I had gone to the Mothers and Baby commission because I had two children adopted and when that came up I went to make statements ... I didn't have to go, but I felt that if I didn't do that now when would I ever go? So I did it and when it finished I got very sick and then I started eating and put on the weight ... and while I had eaten healthily and had kept the weight off, I stopped walking ... and I said, "I can't put that weight back on!" so I joined Slimming World and lost it ... then I left after about 6 months ... I didn't lose it all ...

Interviewer: Mm ...

G: But I got a kick in the behind to kick- start my healthy eating and walking again!

Interviewer: Do you think that it is more what you do rather than what you say that influences S?

G: Probably! She would come shopping ... she doesn't like grocery shopping, but yet at the same time ... I don't know ... maybe so! I know if she had a chance she would buy rubbish ...

Interviewer: When we were speaking in the focus group S was very able to speak about the healthy choices you make at home ...

G: Mm ...

Interviewer: Do you think that she takes your advice?

G: At times, yes ... and I think it depends either on her frame of mind or whether it involves my friend or something that might go against her ... it might be something that she doesn't want to do ... she would make a face at you and would go off in a huff muttering as she went!

Interviewer: And she is still an adolescent, of course!

G: You think? She would never think of doing something off her own bat at home! No ... she would come home from work, make a coffee and sit with the dogs all day!

Interviewer: Do you think she spends too much time on the phone?

G: Too much! Too much! Too much! Absolutely too much! I have stopped them bringing their phones to the table, just like I stopped them bringing ... SK is a devil ... she would read all day ... and I would say "SK no book!" and you would be terrified saying things like that that you would turn them off it ... but the bloody phone, no!

Interviewer: Do you see a similarity between how we see smartphones now and how people saw books in the past?

G: Yes I do! I do, I absolutely do ... and she could read a book off her phone and she has a tablet and I tell her to read from the tablet ... I don't know why she won't read from the tablet, she prefers to read from her phone! It's either Facebook or a game ... do you know what I mean?

Interviewer: Right ...

G: So, yeah!

Interviewer: So, she really does not get involved in exercise?

G: No, no ... I went to T to walk the dunes before I did the challenge, right? And I brought ... there are 3 of our dogs that are fast walkers ... but Benjy is such a good walker, he goes slow ... so I would say you walk the back strand and I will go through the dunes and I would have gone through the dunes and she would not have gone half way ... but, yeah ...

Interviewer: So, you would bring her walking?

G: Yeah, but I would have to go slow!

Interviewer: But she goes with you?

G: Right ... I bring her to up to BK woods ... not every week, like ... but I would bring her up ... I would make her go!

Interviewer: You would ask her to go?

G: Well, I would give her a choice! I would ask her, "Do you want to go to BK woods or to M, or where?" I would give her the option of where! So it's not a case of ... we are going there!

Appendix R – Professional Skills Essay

Reflective Report

Introduction

In this reflective report I give a critical account of my development as a professional practitioner across the competencies of the Prof Doc in Health Psychology programme. I begin this report with a description of models of reflective practice and how these can be combined for effective practice. I then provide the context for my professional practice in National Learning Network (NLN). I follow this with examples of the development of my professional practice under the BPS competency headings and end with a conclusion paragraph.

Reflective Practice

Reflective practice has been described by Dewey as “the active , persistent and careful consideration of any belief or supposed form of knowledge in the light of the grounds that support it” (1910, p. 6). This suggests that we practitioners ought to take a questioning approach to tasks. The purpose of taking such an approach is to allow us reframe situations and problems in a way that facilitates us taking a new perspective. Schon (1983) describes the processes involved in reflective practice as reflection-in-action and reflection-on-action. The former is where practitioners engage this questioning approach in the here-and-now of practice, while the latter is after-the-fact questioning.

Atkins and Murphy (1993), describe the skills necessary *to engage* in reflective practice in their model (Figure 1).

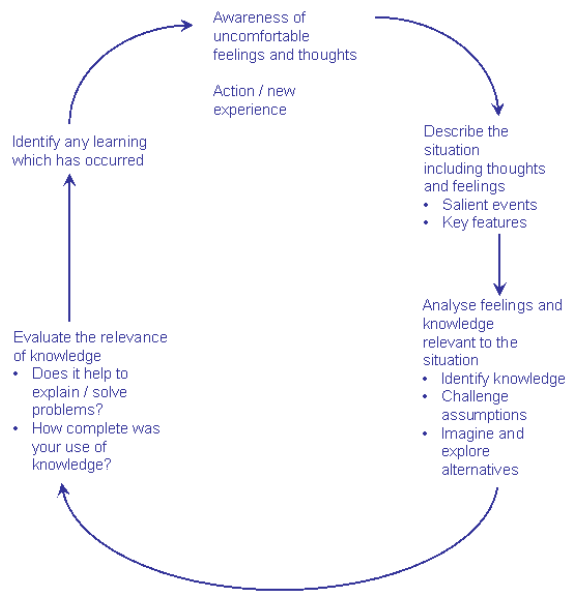


Figure 1. Atkins & Murphy (1993) Model of Reflective Practice (permission received from Royal College of Nursing)

The ‘how’ of reflective practice is very neatly described by Rolfe, Freshwater, and Jasper (2001) in their reflective practice model (Figure 2).

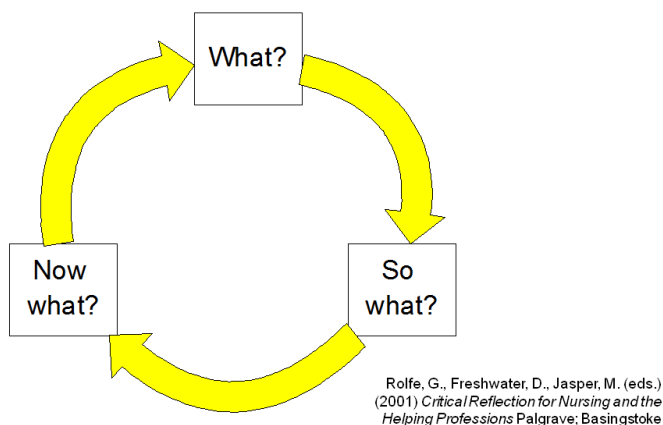


Figure 2. Rolfe et al (2001) Reflective Model (permission received from author and Palgrave Macmillan)

While the Rolfe et al (2001) model appears to be simple it facilitates a comprehensive critical reflective process when using the skills described by Atkins and Murphy (1993) as a framework. The first three stages of Atkins and Murphy’s model, namely,

self-awareness and *describe the situation* and *analyse feelings* can be mapped onto the ‘what’ of Rolfe et al.’s model. The fourth part, *evaluate the relevance of knowledge* can be mapped on to the ‘so what’ stage of the model, while the final part, *identify any learning which has occurred* can be mapped on to the ‘now what’ stage.

A recommendation from the Rolfe et al model is that a simple action plan be put in place with key ideas indicating what you will do and how this change will improve your practice.

Context

My role in NLN is Regional Psychologist and I work as part of many interdisciplinary teams providing support for students with intellectual, physical, and/or mental health difficulties located in our five centres in the South East of Ireland. I also provide support for staff in those centres, and am part of the regional management team in NLN in the South West/Mid West/South East (Appendix A).

Consultancy Competence

As part of my role I facilitate the use of appropriate interventions, training modules, and workshops for students and staff. As part of the consultancy competence I put together workshops on Workplace Boundary Management and Workplace Stress Management for students participating on a Health Care Support programme contracted to NLN.

In reflective dialogue post-workshops, the co-facilitator and I agreed that the ‘what’ per Rolfe et al (2001) was not consulting students prior to workshops. Therefore, I was reliant on the information I received from their tutor as to difficulties they wanted addressed. This meant that we did not have sufficient time to facilitate more in-depth work with students even though this was what they requested during

the workshops. This meant that we were not fully prepared to deal with the actual issues that students' needed us to prioritise.

The 'so what' was that the allocation of a half day rather than a full day for each module would have been of greater value to students and that workshops would have benefited from student participation through, say, focus group discussions. We also thought that it would have been beneficial for us to engage students in a follow-on session/group discussion about one to three months post workshop so that we could assess whether they had had an opportunity to put into practice skills they had learnt. However, I had not factored this in to our workshops and I was not in a position to re-negotiate the terms of the contract post-workshops.

The 'now what' of this situation was that I needed to ensure that in future I arrange meetings with students to facilitate student-focused workshops. I also needed to follow this up with meetings with tutors and managers to ensure that these workshops go ahead without clashing with other factors.

However, despite the difficulties that arose on the day re meeting students' immediate needs, the day went very well with lots of student involvement and questions and was positively assessed by both students and tutor.

Teaching & Training

As part of the teaching and training competency I co-facilitated with a tutor, who acted as my supervisor, a series of workshops on sexual health education with students. In reflective dialogue post-workshops, my supervisor and co-facilitator stated that I appeared to be hesitant in engaging with students in initial workshops. Using Schon's (1983) reflection-in-action process and in the 'what' of Rolfe et al.'s (2001) model, I feel that my hesitation was in response to the sometimes-puzzled expressions on students faces re concepts being discussed. In the 'so what' of the

model I wanted to create a learning pace and space that matched students' needs and strengths so that no one of the student group would be, or feel, excluded.

In the 'what now' with regard to the future I decided that it would be best to check in with students during the workshop so as to ensure that we are all 'on the same page'. I successfully used this learning in follow-on workshops when I was able to respond to students by changing the structure of workshops. In one workshop, for example, I discontinued a YouTube clip when I queried their understanding of the story line. This facilitated a discussion on the subject that focused on what students wanted to know rather than what I thought they wanted to know.

Rita was a good resource in guiding how I could adapt my way of working 'with' rather than 'to' students, and how best to maintain eye contact and motivation. I found these meetings with Rita useful as, in the context of Rolfe et al.'s (2001) reflective model (Figure 2), they gave me an opportunity to focus on the 'What?'

- What is the problem/difficulty/ reason for being stuck/reason for feeling bad?
What was my role in the situation? What am I trying to achieve? What actions did I take? What was the response of others?

The 'So what?'

- So what does this tell me/teach me/imply/mean about me/my class/others/our relationship? So what was going through my mind as I acted? So what did I base my actions on? So what other knowledge can I bring to the situation? So what broader issues arise from this situation?

The 'Now what?'

- Now what do I need to do in order to make things better/stop being stuck/improve my teaching/resolve the situation? So what broader issues need

to be considered if this action is to be successful? So what might be the consequences of this action? (Rolfe, G., Freshwater, D., Jasper, M., 2001)

Behaviour Change Competence

I initially established a private practice as part of a multidisciplinary team in a GP service. I now work independently of this practice on a part-time basis on one evening per week, usually Friday, plus Saturday's. As part of the behaviour change competence I began working with D on facilitating him deal with work-related stress. D was referred to me in July 2015 by his GP who, according to D, was unable to find any physiological reason for episodes of dizziness and blackouts that he had been experiencing for some months. D stated that he had had numerous tests and scans and nothing was found that could explain his physical symptoms. He stated that his doctor had spoken with him about his work and home life and had suggested that he make an appointment with me so that I could assess his situation.

I used a solution-focused approach working with D and in the overall context of facilitating D create solutions and find exceptions to what does not work there were times when I felt that the work had become 'stuck'. In the context of the reflection-on-action per Schon (1983), and the 'what' of Rolfe et al (2001), I used Milner and O'Byrne's (2002) suggestion. They suggest that this may indicate that the therapist is working to his/her own agenda, or that the therapist is working too hard at suggesting solutions.

The 'so what' was a sense of frustration I experienced when I perceived that D was waiting for answers rather than using the skills and techniques for taking personal responsibility that we had discussed. The 'now what' response in light of the Milner and O'Byrne's suggestion was that I gave the conversation, and responsibility, back to D by asking him to clarify for me how we might re-focus sessions and get us back

on track. This worked well as D had tended to look for solutions outside his own skills rather than use his skills. As a result of using reflective practice on my own, and engaging in reflective dialogue in peer supervision, I was able to identify the source of difficulties and how best I could facilitate change.

Generic Professional Competence

Part of my role, in ensuring best practice, is to communicate with the Senior Psychologist about matters that may impact on best practice with respect to ethical and legal factors. She also acts as supervisor for each member of the psychology team, and I am also lucky to have her as my NLN supervisor on the Prof Doc in Health Psychology. I believe that we have formed a positive work relationship throughout the Prof Doc, particularly in light of the fact that I am working my way through this while also being fully engaged in all aspects of NLN. I am always positively disposed to any challenge and am able to negotiate honestly and with passion when supporting the rights and responsibilities of students.

In this regard I put myself forward for conferences and workshops that I believe add to my professional practice as a psychologist, and particularly as a health psychologist. I have attended conferences that inform with respect to the legal aspects of professional practice, such as the conference on the Assisted Decision-making Capacity Act (2015). I have subsequently given presentations to the National Management Team of NLN informing them of the most up to date legal position for our students and staff and for those who attend the extended services of the Rehab Group.

I also attend conferences presented both by the Psychological Society of Ireland (PSI), and by combined teams from the PSI and the BPS that provide me with the most up-to-date information in the field of health psychology. Many of our

students present with physical health needs relating to drug and alcohol abuse, relating to chronic illness, pain management, and relating to acquired brain injury and it is my responsibility to ensure that I have sufficient knowledge to engage both with our students and with other professionals in a way that is supportive of the needs of our students.

I do believe that all of these factors contributed to my being chosen as the most appropriate psychologist to chair an investigation of an allegation of sexual abuse by a person who is engaged in one of our services, against an employee of that service. This investigation began in August 2014 and was completed in May 2016. My role was to ensure that all matters were dealt with in an ethical and professional manner and that the findings would be based on the balance of probabilities. A significant part of being able to manage the difficulties associated with investigating such an allegation is very much dependent upon the ability of the individual to reflect on practice. During interviews, for example, I found that I was reflecting-in-action and wondering ‘what’ issues were playing out for me and for the interviewee. I was always very much aware that the ‘so what’ of what was going through my mind might be more about my expectations and biases rather than about anything to do with the interviewee. Also, I found that that ‘now what’ was tempered with a wish to engage with people without projecting my perceptions and to remain focused on the subject matter. In the ‘now what’ phase I used my self-awareness and my ability to critically analyse and incorporate new learning with existing knowledge to manage problems or difficulties that arose during the process of the investigation.

While I was working on this investigation a senior manager within NLN, through a recommendation from the senior psychologist, requested me to work as the Interim Designated Liaison Officer at national level for RehabCare (part of the Rehab

Group with a focus on community and social care). Mary Hughes, Senior Psychologist asked me if I would be interested in taking this post for a period of seven months beginning in November of 2015. I was delighted as this gave me the opportunity to engage with other professionals in a lead role at a national level in ensuring that clients of the service be treated with dignity and respect and that their voices be heard in cases where concerns of abuse were raised.

It also gave me an opportunity to step outside my normal remit for an extended period and utilise my professional practice in an unfamiliar context. I took responsibility for ensuring that the person who replaced me was appropriately qualified and supported by myself in her role. I am always conscious of the responsibility each one of us has in relation to self-care and managing workloads and this is why I was very careful in ensuring that I would retain a small portion of my workload while ensuring that students were appropriately supported in my absence.

My main responsibility as Interim Designated Liaison Officer was advising and supporting the Regional Managers in RehabCare, (the Designated Officer's) in all matters relating to allegations of child abuse and concerns raised in safeguarding vulnerable adults. I am very pleased to say that I got very positive feedback from all people with whom I worked, including the Director of RehabCare who stated that she was very grateful for the very practical support and advice I shared with her and with her team.

Also, as part of this role, under the guidance of the Director of Quality and Governance, I was appointed chair of a three-person team responsible for writing the first draft of the updated version of Rehab Vulnerable Adult Protection policy and procedures (April 2016) and submitting this draft to the Director of Quality and Governance. Unfortunately, I discovered that the final copy would mention the three

of us as a footnote and that full credit would be allocated to the Directorate of the service. I was a bit disappointed, as I had put a lot of work in the project, ensuring that it was written in plain English so that it could be read by our students – these policies tend to use legal terminology that excludes rather than includes! However, I am pleased that the main parts of the document are being included and that the language is being kept as plain as possible.

Research Competence

My research project in the University of the West of England is an exploration of the use of mhealth technologies as part of a healthy lifestyle by females with intellectual disabilities. I think the most challenging part of the journey so far was the Progression Viva. On reflection-on-action, I was not prepared for the discussion that took place (the ‘what’) and while I had prepared supporting evidence for my work I feel that I was unable to provide a clear argument on the detail of my project (‘so what’). My plain (‘now what’) from that meeting was to go back to the initial question as I realised that I had complicated my question with too much detail. I also came to the realisation that I need, once again, to engage with students as to whether they wished to participate in an interview or focus group format, rather than referring to expert knowledge.

Conclusion

I believe that a significant part of my success in relation to the roles I was offered and that I accepted over the past two years is attributable to my progression as a student on the Prof Doc in Health Psychology. I have been challenged in many of the competencies and have stepped outside my comfort zone in meeting these challenges.

I am able to share my learning and knowledge with other professionals within NLN. An example of this is where I used Go to Meeting to present a narrated power

point presentation by webinar on the Biopsychosocial Model of Stress to other professionals within NLN. Not only did I use my knowledge from health psychology to share information with staff but I also learnt how to use an alternative method of facilitating workshops. I also share what I have learnt with my peers at our quarterly peer supervision meetings. I organised these meetings to ensure that we would engage in reflective dialogue and maintain professional practice CPD in a format accredited by PSI.

I have also used the knowledge I gained through the competencies in changing how I work with students and staff. I now use lesson plans for workshops with students that are based on what students stated needs.

I thank the programme for the practical knowledge that I have gained in taking a biopsychosocial approach to all my work, whether that is in NLN or in my private practice. The biopsychosocial model allows us see that an individual has a biological profile, a psychological profile, and a social/cultural profile. Once we take this perspective of another it ensures that we are taking a holistic approach rather than a dualistic one.

Word count 3020

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Appendix S – Dissemination of findings: Copy of poster presented and merit received - Psychological Society of Ireland Conference November 2017

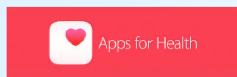
'It helps me stay healthy!'

Exploring the role of mhealth (mobile technology) in facilitating healthy lifestyle choices in women with a mild Intellectual Disability

Ailish O'Brien
Professional Doctorate in Health Psychology Programme, University of the West of England, & RehabGroup Ireland

1. Introduction

Research findings indicate that people with an intellectual disability experience higher rates of chronic health problems in comparison with the general population and that females with a mild intellectual disability and living independently or with family are more likely to be obese than others with intellectual disabilities. Mobile technology use has become a significant factor in engaging people in, and marketing, healthy lifestyle programmes. Research findings also indicate that women more than men are likely to use smartphones and health apps as part of a healthy lifestyle. The aims of this research were to explore if women with an intellectual disability use mobile technologies, how they use them, and if these mobile technologies play a role in facilitating healthy lifestyle choices among these women.



2. Method

Twenty-six female students of a specialist training and support service participated with follow-on participation by 6 parents. All students were white, and their ages ranged between eighteen and twenty-six. Of these twenty-six students, twenty-five were born in Ireland, one born in the USA. Parental participants were mothers; all respondents were white and born in Ireland, ages ranged from late thirties to early fifties. Students participated in semi-structured interviews and focus groups, parents participated in semi-structured interviews. Data were analysed using Thematic Analysis (Braun & Clarke, 2013).

Analysis was based on the COM-B model of behaviour (Michie et al, 2011) that describes behaviour as any action that a person engages in as a response to internal and/or external factors involving the interaction among three conditions (see Figure 1). **Capability** – physical and psychological ability to engage in any activity. **Opportunity** – external factors such as environmental or social factors that impact on behaviour. **Motivation** – volitional and non-volitional mechanisms that energise and direct behaviour.



Figure 1. The COM-B model of behaviour

3. Results

Three themes with sub-themes were conceptualised in the data (see Figure 2):
(1) Mobile technology: positives and downsides, with two sub-themes *Positives: Knowledge, Skills & Ability* and *Downsides: Privacy & security, & Compulsive viewing*;
(2) Health issues that matter, with three sub-themes *Cravings, Healthy lifestyle choices, and Body issues & girls' issues*.
(3) What mothers' say/my mam says, with three sub-themes; *Mother as protector & advisor, Her daughter's voice, and My daughter and I ... she's her own person*.

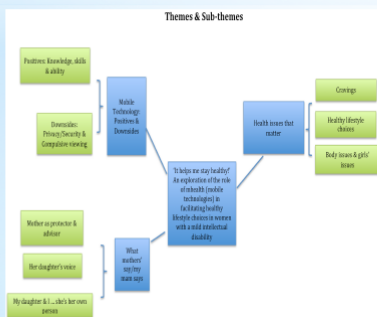


Figure 2. Themes & Sub-themes combined for Students & Parents

4. Overview of Themes & Subthemes:

Theme number 1: Mobile Technology: Positives & Downsides



Subthemes: (1) *Positives: Knowledge, Skills & Ability*



(2) *Downsides: Compulsive Viewing*

& *Privacy & Security*

Theme number 2: Health Issues that matter



(3) *Body issues &*



Subthemes: (1) *Cravings,*

(2) *Healthy Lifestyle Choices,*

Girls Issues

Theme Number 3: What mother's say/my mam says



Subthemes: (1) *Mother as protector & advisor,*

(2) *Her daughter's voice,*

(3) *My daughter and I ... she's her own person*

Thematic analysis of the data indicated that students were knowledgeable about mobile technology and aware of apps and sites that are useful in making healthy lifestyle choices, such as Slimming World who, according to one student, 'have an Internet site that shows people how to be healthy!'. The majority of students used mobile technology for connecting with friends, for gaming, or watching favourite programmes while others used it for learning new skills, 'social skills, verbal skills'. Students were vocal about health issues that matter to them including difficulties with food cravings, 'I find it hard to lose weight 'cos I love chocolate and I can't stop eating it, and I have a secret chocolate from the vending machine here'. The role of parents, particularly mothers, as protectors/advisors was also highlighted as significant in influencing students' having access to opportunities and choices. It was evident from what students and mothers said that mothers play a directive role in their daughters lives where, for example, one student stated that her mother does not allow her cook as she 'might burn the house down!' Mothers spoke about exercising with their daughters where one mother stated that 'I would bring her up to BK woods ... not every week, like ... but I would bring her up ... I would make her go!'. a comment that also reflected the behaviours of other mothers interviewed.

5. Conclusion

This study indicates that the majority of student participants are capable of using mobile technology and that they use it primarily for social media apps, for gaming, and some use healthy lifestyle apps. As per the COM-B model, opportunities to engage in healthy lifestyle choices for most students were moderated by mothers while others used gaming apps such as Pokémon Go as a way of keeping fit. Motivation to engage in healthy lifestyle choices was facilitated by knowledge gained from the internet, from information received in school, and from advice from mothers. Motivation for making healthy food choices was hampered by factors such as food cravings. Motivation for making healthy lifestyle choices was also hampered by compulsive viewing using mobile technologies that impacted on sleep. Motivation to engage in healthy lifestyle choices by using mobile technology was moderated by how user-centred health apps were perceived by participants. A recommendation was made that a public health intervention be put in place through the Health Research Board to encourage researchers develop user-centred mobile health apps that would support people with an intellectual disability in making healthy lifestyle choices.

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Cumann Síceolaithe Éireann

Student Poster Merit

This certificate is presented by
The Psychological Society of Ireland
to

Ailish O' Brien, Julian Bath, Rachel Gillibrand & Mary
Hughes

for the presentation of

*An exploration of the role of mhealth (mobile technologies)
in facilitating a healthy lifestyle among women with a mild
intellectual disability*

10 November 2017
at the Annual Conference of
The Psychological Society of Ireland

Michèle Boyle

President



Appendix T – Table of Apps/Sites used by Students

Apps/Sites used by Students

Participants by location*	<u>Skype</u>	<u>Messenger</u>	<u>iPeriod</u>	<u>Snapchat</u>	<u>Instagram</u>	<u>Viber</u>	<u>Facebook</u>	<u>Candy Crush</u>	<u>Pokémon Go</u>	<u>Curves</u>	<u>Slimming World</u>	<u>You Tube</u>	<u>SHealth</u>
A interview in C										✓			✓
C interview in W								✓					
O focus group in C								✓					
C focus group in C	✓	✓		✓									
E focus group in C		✓				✓							
N focus group in C				✓	✓		✓				✓		✓
K focus group in C				✓									
G focus group in C				✓									
E focus group in KK				✓									
R focus group in C							✓						
A focus group in W									✓				
C focus group in KK									✓		✓		

	Skype	Messenger	iPeriod	Snapchat	Instagram	Viber	Facebook	Candy Crush	Pokémon Go	Curves	Slimming World	You Tube	SHealth
A focus group in C													✓
M re her daughter, C (non-participant)									✓				
M focus group in W			✓										
D interview in W												✓	

*NLN centre location