Cancer Experiences in People with Intellectual Disabilities

Thesis submitted in accordance with the requirements of the University of Chester
for the degree of Doctor of Philosophy

by Samantha Elizabeth Flynn BSc.
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Declarations

The material being presented for examination is my own work and has not been submitted for an award in this or another Higher Education Institute. Where research pertaining to the thesis was undertaken collaboratively, the nature and extent of my individual contribution has been made explicit.

Signed:

Date: 28th August 2018

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Samantha Elizabeth Flynn –

Cancer Experiences in People with Intellectual Disabilities

People with intellectual disabilities are increasingly being diagnosed with cancer due, in part, to increases in life expectancy for this population. Despite the growing number of people with cancer and intellectual disabilities, the cancer-related experiences of people with intellectual disabilities are under-researched. Person-centred approaches to research are needed to better understand the needs and psychosocial outcomes of people with cancer and intellectual disabilities.

This thesis aims to better understand the cancer-related experiences of people with intellectual disabilities, and the impact on the people who support them. The thesis comprises four related studies: (1) a systematic review of psychosocial experiences of cancer in people with intellectual disabilities; (2) a qualitative study of cancer experiences in people with intellectual disabilities using thematic analysis informed by grounded theory; (3) a survey of UK oncology nurses' attitudes and care perceptions towards people with intellectual disabilities; and (4) a feasibility study of an intervention to improve healthcare professionals' perceptions of communicating with people with cancer and intellectual disabilities.

Five themes emerged from the ten papers included in the systematic review: delayed diagnosis; information, communication, and understanding; negative psychological consequences; negative physical consequences; and social support. Six of the ten papers included data from the same ethnographic study of 13 people, highlighting a paucity of empirical research regarding the psychosocial cancer experiences of people with intellectual disabilities. The qualitative study indicated that people with intellectual disabilities were often excluded from conversations about their diagnosis, treatment, and ongoing care, and expressed confusion and anxiety about their cancer. Attempts to protect them from distress inhibited communication, but where additional support was offered, participants engaged more meaningfully in their experience and this should, therefore, be encouraged. In the qualitative study, oncology nurses were reported to be important figures in the care of patients with intellectual disabilities. The survey of oncology nurses highlighted that caring for cancer patients with intellectual disabilities may intensify their already difficult role; however, previous experience may ameliorate negative consequences. This sample identified their need for training about communicating with people with intellectual disabilities. The first three studies informed the development of a novel, brief, online, video-based intervention for healthcare professionals working with people with intellectual disabilities and cancer. The feasibility trial of this intervention indicated that there were problems with recruitment, high attrition, and intervention adherence. These problems were, most likely due to participants finding the content and delivery method to be unacceptable. It is clear that the intervention is not feasible in its current format, and that further theoretical and modelling work is needed before the intervention is feasibility tested again ahead of a definitive trial.

This body of work has demonstrated that people with intellectual disabilities and cancer face multiple barriers to accessing cancer care, including informative and understandable communication with healthcare professionals. With appropriate support, psychological and physical outcomes can be improved for people with intellectual disabilities and cancer, but caring for people with cancer and intellectual disabilities can be challenging for paid and informal carers, and oncology staff. Difficulties with communication are bi-directional, and improving communication might be an appropriate first step to improving cancer experiences for this population, but developing effective interventions presents numerous feasibility challenges.

Chapter 1. An Introduction to Cancer and Intellectual Disabilities

Chapter Overview

Increasing numbers of people with intellectual disabilities are being diagnosed with cancer (Hanna et al., 2011; Tuffrey-Wijne, Hogg, & Curfs, 2007); this is partly attributable to increasing life expectancy (Hanna et al., 2011). Research suggests that cancer death rates are proportionally lower in people with intellectual disabilities compared to people without intellectual disabilities (Emerson & Baines, 2011); however, the needs and experiences of this population are equally important, and there is a lack of published literature about the cancer experiences of this population. We do know that people with intellectual disabilities face multiple barriers when accessing healthcare (Ali et al., 2013), and are more likely than people in the general population to have inadequate health knowledge (Turk et al., 2012a); such disparities may lead to poorer physical and psychological health outcomes for this population. There are parallels between the disparities in healthcare for people with intellectual disabilities and our limited understanding of how this population experiences cancer care.

Considering the paucity of research within this specific population, this thesis will identify the cancer experiences of people with intellectual disabilities, and the impact of this diagnosis on the people who support them. This will be achieved through first ascertaining the extent of current literature, and subsequently by investigating the cancer-related experiences of this population from a multiple-stakeholder perspective. This approach will provide the basis for the generation of further research questions and hypotheses to extend knowledge within this currently sparse literature. Further to this, this thesis will explore the perceptions of oncology nurses about providing care to people with intellectual disabilities and cancer, and test the feasibility of an intervention aiming to improve some of these perceptions in a cross section of oncology professionals. Understanding these perceptions, and ways to improve them where necessary, is essential to providing high-quality and equitable cancer care to people with intellectual disabilities.

This introductory chapter provides necessary context to the thesis, and aims to outline the need for further understanding of the cancer experiences of people with intellectual disabilities.

The Prevalence and Impact of Cancer

Cancer Prevalence and Survivorship Outcomes in the General Population

Cancer is one of the most prevalent chronic illness diagnoses according to the Eastern Region Public Health Observatory (ERPHO, 2008), with 2.56% of people in the United Kingdom (UK) receiving a diagnosis of cancer (all cancer types) between 2003 and 2008. In addition to being a highly prevalent disease, cancer is also one of the most common causes of death in the UK; the World Health Organization (WHO, 2011) estimates that 27% of deaths in the UK are as a result of cancer.

Early diagnosis of cancer is essential for the successful treatment of the illness, and can decrease morbidity rates (WHO, 2016). The National Awareness and Early Diagnosis Initiative (NAEDI) (Cancer Research UK, 2017)—a partnership between the Department of Health, National Cancer Action Team, and Cancer Research UK—aims to promote early diagnosis of cancer to improve survivorship outcomes for all. Specifically, this initiative has led to the development of national *Be Clear on Cancer* campaigns (launched in 2012), and is committed to improving access to primary care diagnostic pathways. Several studies have examined the impact of the *Be Clear on Cancer* campaigns on screening uptake and early diagnosis of bowel (Peacock et al., 2013), urological (Hughes-Hallett et al., 2015), and breast cancer (Mazari, Holt, & Azmy, 2017). Using retrospective designs, all three studies found increases in the number of screening referrals, but no improvements in the early diagnoses of these cancers. These studies only pertain to data collected in three specific regions of the UK (one per study); thus the national impact of the campaigns cannot be determined from these studies alone. Furthermore, these studies examined the immediate and short-term impact of the campaign over a period of three (Peacock et al., 2013) to 10 months (Hughes-Hallett et al., 2015), therefore the longer term impact of these campaigns is unknown. Based on this limited evidence, the efficacy of these campaigns is questionable, as the financial costs of the media campaign and increased burden on the National Health Service (NHS) far outweigh the intended benefits in these cases. Having said this, there have been significant improvements in the time to diagnosis between 2006 and 2013, with fewer emergency referrals being made and more diagnoses being made through GP referrals (Public Health England, 2015). Early diagnosis initiatives (e.g., *Be Clear on Cancer*) are likely to increase cancer awareness among the general population, and contribute to the earlier diagnosis of cancer in the long-term.

After diagnosis, with continual advances in treatment being made, more people are living longer with cancer; the five-year survival rate for six common cancers (breast cancer [women], testis and prostate cancer [men], Hodgkin lymphoma, melanoma, and thyroid cancer) is now above 80% (Office for National Statistics, 2016). The ten-year survival rates for these cancers remain at a similar level (above 80%) (Quaresma, Coleman, & Rachet, 2014). This is not universal, as other commonly diagnosed cancers have far lower five-year survival estimates; this is particularly pertinent to lung cancer, which has a five-year survival rate of 10%, reducing to 5% at 10 years (Quaresma, Coleman, & Rachet, 2014). Nonetheless, cancer is now commonly considered to be a chronic illness (WHO, 2011) with a clear focus on self-management (Foster et al., 2015). Such a shift will have significant implications for illness management and support.

Cancer continues to be a priority for the NHS, as outlined in the NHS's *Five Year Forward View* (2014). NHS England established an Independent Cancer Taskforce comprising a multi-disciplinary team of medical professionals, research organisations, and patients, to make recommendations to improve four key areas: (1) fewer preventable cancers, (2) better survival rates, (3) more positive experiences of care, and (4) better long-term quality of life. Since establishing the Cancer Taskforce, NHS England (2017) report improved cancer survival rates, a reduced number of smokers, and more efficient cancer check-ups. Future improvements between 2017 and 2019 include a further improvement in cancer survival rates; more efficient tests, results, and treatments; and national access to the most effective cancer treatments. Importantly, this initiative has been extensively planned and boasts outstanding transparency, enabling members of the public to establish accountability for specific actions (NHS England, 2016a). This initiative follows on from the government policy document *2010-2015 Long Term Health Conditions* (Department of Health, 2013a) which outlined strategies for improving outcomes for people with long term health conditions (including cancer) in a similar vein to the National Cancer Survivorship Initiative (NCSI) document *Living With and Beyond Cancer* (NCSI, 2013).

Cancer in People with Intellectual Disabilities

A definition of intellectual disabilities. There are upwards of one million people with intellectual disabilities in the UK (Emerson et al., 2014) and a recent meta-analysis estimated global prevalence at 10.37/1000 population (Maulik et al., 2011). Intellectual disabilities are characterised by impairments in intellectual functioning (typically an IQ of below 70) and adaptive functioning (including skills required for independent daily living, for example communication, self-care, and social skills), with onset during the developmental period (Diagnostic and Statistical Manual (5th edition) [DSM-V]; American Psychiatric Association [APA], 2013). People with intellectual disabilities are, by nature, a heterogeneous sample, with no specific personality or behavioural traits being attributable to onset (APA, 2013). Predisposing factors can include: heredity, chromosomal development, environmental factors, complications during pregnancy, and general medical conditions acquired in infancy or childhood (APA, 2013). Descriptions of the degrees of severity of intellectual disability are detailed in Table 1.1.

Table 1.1. Degrees of severity of intellectual disabilities. Adapted from DSM-V (APA, 2013)

DSM Code	**Degree of Severity**	**IQ Level**	**Proportion**	**Further Description**
317	Mild	55 to 70	85%	Generally able to learn social and communication skills from a young age. With appropriate support, able to live successfully in the community, either independently or in supervised settings.
318.0	Moderate	40 to 55	10%	Most people in this group are able to acquire communication skills during early childhood. During adolescence, difficulties in recognising social conventions may interfere with peer relationships. Adapt well to life in the community, usually in supervised settings.
318.1	Severe	25 to 40	3-4%	Usually acquire little or no communication skills during early childhood, though these are sometimes learnt during the school-age period. May be able to perform simple tasks in closely supervised settings during adult years. Most adapt well to life in the community, in group homes or with their families.
318.2	Profound	Below 25	1-2%	Most people with this diagnosis have an identified neurological condition that accounts for their intellectual disability. Motor development, self-care and communication skills may improve if appropriate training is provided. Some can perform simple tasks in closely supervised and sheltered settings.
319	Severity Unspecified	Unspecified		This category is used when there is a strong presumption that the person has an intellectual disability but their intelligence cannot be tested by standard means. For instance, those who are too impaired or uncooperative, or with infants.

Previous literature uses interchangeable terminology to describe intellectual disabilities. These include: *learning disabilities, mental handicap, intellectual difficulties, learning difficulties,* and *mental retardation*; however the latter is no longer routinely used. Mental retardation was previously included in the DSM-IV-TR (APA, 2000), but was replaced by *intellectual disability* in the DSM-V (APA, 2013). The shift in terminology was driven by the fact that mental retardation held negative connotations for many individuals (Finlay & Lyons, 2005; Snell & Voorhees, 2006), and intellectual disability more appropriately represented the construct being described. It also aligned well with international shifts in terminology (Schalock et al., 2007).

Some international distinction exists for some terms; thus whereas learning disability is used in the UK to describe intellectual disabilities, it is synonymous with *specific learning difficulties* (e.g., dyslexia, dyspraxia, dyscalculia) in the USA. The term learning difficulty is commonly used in the UK to describe people who have specific educational difficulties, such as dyslexia. Similarly, differences in preference of terminology exist between groups in the UK, with some people with intellectual disabilities preferring to use the term learning difficulty (Holland, 2011) as a description of their disability. The term intellectual disability is more commonly used internationally (e.g., in the USA and Australia), but is being increasingly used by UK-based researchers instead of learning disability (e.g., Bowring et al., 2017; Emerson et al., 2016; Beadle-Brown et al., 2016). Despite the more common use of intellectual disability in UK literature, the NHS still uses the term learning disability to describe this population (NHS Choices, 2015). Due to interchangeable use of these terms, both internationally and nationally, it is important that researchers and policy makers alike clearly define the construct and describe the population to ensure that findings are applied to the intended population. The term intellectual disabilities will be used throughout this thesis, encompassing all variants, as the term is more progressive and consistent with international literature.

As outlined above, one of the diagnostic criteria for intellectual disabilities is that a person has deficits in intellectual functioning, categorised as an IQ of below 70. This concept is contentious, as this key diagnostic criterion is the product of a social construction of intelligence (Rohleder, 2012). This construction has permitted the categorisation of people based on a unidimensional construct, which has in turn given rise to stigma and exclusion of a proportion of society who differ from the norm

(Rohleder, 2012). Further to this, Schalock et al. (2007) outline the ecological perspective of intellectual disabilities whereby the interaction between the individual and their environment is emphasised. Shalock et al. cite a movement towards a more social-ecological construct of disability and intellectual disability by both the American Association on Intellectual and Developmental Disabilities (AAIDD) and WHO. This movement highlights that individualised programmes of support and reasonable adjustments can improve the functioning of people with intellectual disabilities (Schalock et al., 2007), potentially leading to equitable opportunities for this population.

Cancer prevalence and survivorship in people with intellectual disabilities. The life expectancy of people with intellectual disabilities is steadily increasing (Emerson et al., 2014), with research suggesting that people with mild intellectual disabilities (with the exception of people with Down syndrome or severe or multiple disabilities) now have a life expectancy similar to the general population (Coppus, 2013). Suggestions have been made that as life expectancy of people with intellectual disabilities increases so too will the prevalence of cancer (Hanna et al., 2011; Tuffrey-Wijne, Bernal, Butler, Hollins, & Curfs, 2007). This relationship may be causal, in that as a population ages the likelihood of receiving a diagnosis of chronic or life-altering illness is increased (Christensen et al., 2009; Majeed & Aylin, 2015), and we are seeing a growth in the number of elderly people with intellectual disabilities. Proportionally, cancer deaths are lower in people with intellectual disabilities than in the general population (12-18% vs. 26%) (Emerson & Baines, 2011), although missed diagnoses may partially explain this discrepancy (Tuffrey-Wijne & Davies, 2006). Whilst there are some indications that life expectancy and cancer diagnoses are on the rise, data on either exact or estimated prevalence is currently unknown.

The prevention of avoidable deaths from cancer is a priority of the Independent Cancer Taskforce (2015), and whilst this does not specifically mention people with intellectual disabilities, the implications of this priority should extend to this population nonetheless. Furthermore, the *NHS Outcomes Framework 2015/16* (Department of Health, 2015) specifically seeks to reduce premature death in people with intellectual disabilities. People with intellectual disabilities often have poorer health knowledge than people without intellectual disabilities (Turk et al., 2012a), which can make early and effective symptom identification less likely. To ensure that serious health concerns are identified within this population, increasing numbers of people with intellectual disabilities are now receiving annual health checks (2008/9: 23%; 2009/10: 41%) (Department of Health, 2009). The increase in cancer diagnoses in this population could partly be explained by the introduction of annual health checks, which have been found to be both beneficial (Robertson et al., 2014) and well received among people with intellectual disabilities (Perry et al., 2014). Although uptake of these services is limited and annual health checks are not offered to all eligible people with intellectual disabilities (Buszewicz et al., 2014; McConkey et al., 2015). People who are most often missing out on annual health checks are usually younger and/or live in socially deprived areas with family members or independently (McConkey et al., 2015). This is likely to amount to a substantial proportion of the population being excluded from an effective system for the early identification of health conditions, such as cancer, that is known to lead to better survival outcomes (WHO, 2016).

Understanding the Impact of Cancer for People With and Without Intellectual Disabilities

Psychosocial impact of cancer. Of all chronic illnesses, cancer is perhaps the best understood from a psychosocial perspective, and many recent initiatives are working to better support this non-physiological aspect of illness. A recent systematic review defined psychosocial needs as a “requirement for help or support that underlies a person’s emotional and psychological wellbeing.” (Swash et al., 2014, p.1131). Such needs, for example, support, practical, psychological, physical, or information needs, are essential aspects of one’s psychological and social well-being in relation to healthcare provision (Thewes et al., 2004).

Cancer diagnoses have a profound impact on daily living, including necessary changes to lifestyle (e.g., diet, routine, and/or medication) required to self-manage the illness (McCorkle et al., 2011), and increased monitoring of health status (Riegel, Jaarsma, & Strömberg, 2012). Foster et al. (2015) highlight that there is an increasing expectation that cancer survivors self-manage their illness and after-care; thus it is imperative that they receive appropriate support to enable self-management. Self-management support in general population cancer survivors is most needed for fatigue, distress, and specific symptoms (including discomfort) (Foster et al., 2015).

There is no reason to expect that the needs of people with intellectual disabilities would be any different to those of the general population. McCorkle et al. (2011) established that self-management interventions are effective in empowering cancer patients, and their families, to care for themselves. Empowerment outcomes are particularly important for patient groups who are often marginalised (Goodrich & Cornwell, 2008), including people with intellectual disabilities (Jurkowski & Paul-Ward, 2007; Tuffrey-Wijne et al., 2007).

Effective self-management can conserve primary and secondary care resources by reducing patient need for these services (Lorig et al., 1999; Lorig et al., 2001); thus, from a health economics perspective, interventions seeking to improve cancer patients' self-management skills and self-efficacy would be beneficial. These studies (Lorig et al., 1999; Lorig et al., 2001) presented data from large samples representing a cross-section of patients with chronic illnesses, and demonstrated significant savings after two years, highlighting the long-lasting effect of self-management interventions. Notably though, they do not include people with intellectual disabilities.

Self-management may be more difficult for people with intellectual disabilities, and other specific patient populations (e.g., the elderly or people with mental health problems) and additional efforts may be required to understand the needs of these groups and what, if any, reasonable adjustments can be made. The Equality Act (2010) clearly outlined the legal duty of healthcare services to make reasonable adjustments for people with disabilities if omitting them would leave the individual substantially disadvantaged. The provision of training for healthcare providers is considered to be best practice, including making reasonable adjustments to routine care and promoting involvement in shared decision-making. Such adjustments are necessary to ensure equitable health outcomes for people with intellectual disabilities as part of cancer care pathways.

The National Cancer Patient Experience Survey (Quality Health, 2016) reported that 78% of cancer patients indicated that they were appropriately involved in decisions about their care and treatment; this indicates that shared decision-making (e.g., 'No decision about me, without me' [Department of Health, 2012]) is indeed the norm in practice. However, this is not always the case for people with intellectual disabilities. Often, protectionist attitudes, for instance that people with intellectual disabilities are incapable of understanding the complexities of health related decisions, or should be protected from truthful disclosure about their illness (Bernal & Tuffrey-

Wijne, 2008; Tuffrey-Wijne, Bernal, & Hollins, 2010), can lead to people with intellectual disabilities not being supported to actively engage in fully-informed healthcare decisions (O'Regan & Drummond, 2008). Being excluded from decision making in this way is distressing and disempowering for people with intellectual disabilities (Tuffrey-Wijne et al., 2009). In many cases, with appropriate support, people with intellectual disabilities would be able to engage in decision-making processes. Promoting self-determination in healthcare (e.g., enabling people with intellectual disabilities to be involved in their own healthcare decisions) is a key recommendation of the Health Issues Special Interest Research Group (Scheepers et al., 2005), and may contribute to more equitable cancer care experiences.

Further to the potential disruption to daily living, people in the general population who are diagnosed with cancer experience varying degrees of distress, with estimates ranging from 35.1% (Zabora et al., 2001) to 75% (Jacobsen, 2007). Evidence suggests that distress can be persistent throughout the illness trajectory (Lam et al., 2012). Cancer patients in the general population are more often prescribed psychotropic drugs than a demographically similar (e.g., similar in age, gender, and socioeconomic status) group of people without cancer (32.9% vs. 21.2%) (Ng et al., 2013), suggesting a higher prevalence of mental health problems within this population than in the non-cancer population. This is comparable to international prevalence estimates from a recent meta-analysis of mental health problems in cancer patients (31.7%) compared with a general population sample (20%) (Singer, Das-Munshi, & Brähler, 2010). Statistics on the prescribing rate for people with intellectual disabilities and cancer are not known. We do, however, know that people with intellectual disabilities are generally heavily medicated for mental health and behavioural problems (Sheehan et al., 2017; Lunsky et al., 2017; Perry et al., 2018).

In 2010, the International Psychosocial Oncology Society (IPOS) introduced the *Standards and Clinical Practice Guidelines in Cancer Care Statement* recommending that psychosocial needs must be integrated into routine care for quality cancer care to have been provided. This statement also proposed that distress is considered as a sixth vital sign and should be measured accordingly, in addition to blood pressure, pain, respiratory rate, temperature, and pulse. In the UK, the British Psychosocial Oncology Society, Breast Cancer Care, and Macmillan Cancer Support all endorsed this statement. The statement and subsequent endorsements signalled a move towards a more holistic focus, reflecting patients' desire and need for attention to be paid to psychosocial outcomes. A further IPOS publication, the *Lisbon Declaration: Statement of Psychosocial Care as a Basic Human Right* (2014) proposed that psychosocial oncology professionals and related stakeholders should collaborate to ensure that psychosocial cancer care is recognised as a fundamental human right, and that work is undertaken to encourage governments and policy makers to appropriately address the psychosocial needs of cancer patients.

Oncologists and cancer nurses are primarily responsible for identifying clinically significant psychological comorbidities (e.g., anxiety) in their patients (Stark & House, 2000); however, psychological comorbidities are often not identified during routine consultations, with oncologists only identifying 11/30 severely distressed patients in some studies (e.g. Söllner et al., 2001). The full psychological impact of the diagnosis may increase for patients whose distress goes unnoticed. Based on these data, current estimates of psychological comorbidities for cancer patients could be inaccurate. Further complications may arise for people with intellectual disabilities who might not display emotions in a familiar way (Adams & Oliver, 2011) leading to greater difficulty identifying distress in these patient groups. This will be explored in more detail within the study in Chapter 3.

The growing focus on the psychological well-being of cancer patients is being met with the increasing use of interventions for psychological comorbidities. As such, guidelines for these treatments have been developed for the general population (e.g., the National Institute for Health and Care Excellence [NICE, 2009] guideline for recognising and managing depression). These guidelines enable healthcare professionals to take a stepped care approach to the provision of a suitable intervention based on the severity of depression, and on whether the person has benefited from a previously provided intervention. Interventions which have the strongest evidence bases for reducing mental health problems (including distress) in cancer patients include:

- medication for anxiety and depression (Ng et al., 2013);
- Cognitive Behavioural Therapy (CBT) for distress and pain (Tatrow & Montgomery, 2006), insomnia (Espie et al., 2008; Garland et al., 2014; Fleming et al., 2014), and fatigue (Espie et al., 2008; Fleming et al., 2014; Montgomery et al., 2014);

- Mindfulness-Based Stress Reduction (MBSR) for stress, anxiety and depression (Zainal, Booth, & Huppert, 2013), and fatigue (Reich et al., 2017); and
- Acceptance and Commitment Therapy (ACT) for low mood, distress, and quality of life (Feros et al., 2013).

Whilst there are indications that these interventions are effective for reducing the impact of psychological comorbidities, it must be noted that a high proportion of intervention studies are undertaken with samples of breast cancer patients thereby limiting the generalisability of these findings to other cancer populations, particularly male cancer patients. Furthermore, these studies do not include people with intellectual disabilities and, as such, findings cannot be extended to this population of cancer patients. There is a growing evidence base supporting the use of CBT and mindfulness-based interventions for people with mild or moderate intellectual disabilities and anxiety or depression (Idusohan-Moizer, Sawicka, Dendle, & Albany, 2013; McCabe et al., 2006; McGillivray et al., 2008; Unwin et al., 2016), although their efficacy for people with severe or profound intellectual disabilities is unknown (Vereenooghe et al., 2018). Such findings indicate that these interventions may also be effective for people with mild or moderate intellectual disabilities and cancer.

Disparities in cancer care for people with intellectual disabilities. Whilst there is a density of literature that explores the impact of cancer, and interventions to support patients within the general population, such literature is sparse for people with intellectual disabilities. There are, however, indications that inequalities exist in cancer care for this population. A recent Cancer Patient Experience Survey report (Quality Health, 2016) indicated that, whilst cancer patients were generally satisfied with their care, inequalities were apparent for some patient groups. Notably, cancer patients from an ethnic minority, people with intellectual disabilities, people who are lesbian, gay, or bisexual (LGB), younger patients, and female patients responded less positively than their counterparts did. These differences are also apparent in the empirical literature, and represent a disparity for these patient groups: ethnic minorities (Ashing-Giwa et al., 2004; Fazil et al., 2015); LGB people (Fish & Williamson, 2018; Hill & Holborn, 2015; Hulbert-Williams et al., 2017); and younger patients (Kornblith et al., 2007; Thewes, Butow, Girgis, & Pendlebury, 2004).

Interestingly, the psychosocial needs of these patient groups are often similar to those of cancer patients overall, but it can be more difficult for these sub-groups of patients to access appropriate information and support (e.g., Hill & Holborn, 2015; Hulbert-Williams et al., 2017). It is important to understand these experiences within patient groups who receive inequitable cancer care, hence the rationale for this thesis.

Within the *Improving Outcomes: A Strategy for Cancer - Second Annual Report* (Department of Health, 2013b), it was reported that people with intellectual disabilities are more likely to feel as if they are being treated as “a set of cancer symptoms” (p.73) than is reported by people without intellectual disabilities. This suggestion of an impersonal approach to cancer care for people with intellectual disabilities is in direct opposition to the principles of the IPOS (2010) statement outlining the need for a more holistic approach to cancer care, and appears to be a more significant concern for people with intellectual disabilities. This difference is indicative of disparate cancer care experiences between these two patient groups, adding further weight to Emerson and Baines (2011) who identified that health inequalities are present across chronic illness diagnoses. The second annual report (Department of Health, 2013b) also noted that the National Cancer Equality Initiative (set up in 2008) was working to continue to highlight issues surrounding inequality in cancer care, including those related to people with intellectual disabilities, and to share best practice with Cancer Networks; however, no other specific recommendations regarding people with intellectual disabilities were made within the report. The third (Department of Health, 2013c) and fourth (Department of Health, 2014) annual reports following up on outcomes from *Improving Outcomes: a Strategy for Cancer* (Department of Health, 2011), omit any information about the experiences of people with intellectual disabilities and/or recommendations for their improved cancer care. This is, perhaps, indicative that the needs and experiences of people with cancer and intellectual disabilities may not be a consistent or high priority for the Department of Health or NHS (Michael, 2008), and highlights the difficulties of translating policy into practice for this patient group.

More recently, the *Five Year Forward View* (NHS England, 2016b) and the Cancer Taskforce’s *Equality Impact Assessment* (2015) have outlined plans to reduce inequalities in cancer care and outcomes for multiple populations, including people with intellectual disabilities. The Cancer Taskforce describes the need to improve patient experiences, and acknowledges that some adjustments will be needed for people with intellectual disabilities; this strategy is running until 2020 so it is not possible to establish its impact at present.

The *Five Year Forward View* (2014) is pre-dated by several documents highlighting the healthcare disparities faced by people with intellectual disabilities (e.g., *Valuing People*: Department of Health, 2001; *Healthcare for All*: Michael, 2008; *Valuing People Now*: Department of Health, 2009). Together, these documents made recommendations to improve general health outcomes, reduce inequality of healthcare experiences, and prevent avoidable deaths in people with intellectual disabilities, including:

- improvements in training for healthcare professionals to support and communicate with people with intellectual disabilities (Department of Health, 2009; Michael, 2008);
- employing health facilitators to support people with intellectual disabilities to access appropriate healthcare (Department of Health, 2001);
- developing Health Action Plans (a personalised document outlining details about the person's health and support needs) for all people with intellectual disabilities (Department of Health, 2001); and
- greater involvement of people with intellectual disabilities and their families in planning services (Department of Health, 2009).

More recently, the Independent Cancer Taskforce (2015) have highlighted that the needs of people with intellectual disabilities and cancer are a priority for the NHS: "Recommendation 48: NHS England should ask NIHR (National Institute for Health Research) and research charities to explore the needs of people with serious mental illnesses or learning difficulties when they have cancer." Whilst it is encouraging that the needs of people with intellectual disabilities and cancer are a current priority for the NHS, it is disappointing that this has not been presented as a priority in its own right, instead being categorised together with people who have serious mental illness. The needs of these two distinct populations are likely to be very different. Furthermore, mental health awareness is more widespread than intellectual disabilities awareness, and the needs of people with intellectual disabilities might not be considered as much as they would be if this patient group were considered as a priority in their own right. A recent progress report by Public Health England (2017) provides further evidence that the needs of cancer patients with intellectual disabilities are not being appropriately addressed: whilst updates are provided on the experiences of people with a mental illness, the report does not highlight that any progress has been made to explore the needs of people with intellectual disabilities and cancer. Thus, whilst an intention to prioritise the needs of this patient group has been outlined, little progress has been made since *Healthcare for All* (Michael, 2008). It is, therefore, imperative that work is undertaken to better understand the experiences of people with cancer and intellectual disabilities.

The recognition of health inequities for people with intellectual disabilities was, historically, an important step towards reducing the disparity, but this must be followed up with research and service development. Health inequalities are evident across chronic illness diagnoses for people with intellectual disabilities (Emerson & Baines, 2011), and can stem from communication difficulties or other barriers to accessing appropriate and timely healthcare. Cancer Research UK, one of the primary policy influencers in the UK, published a policy document in 2008 (*Inequalities in cancer experienced by those with learning disabilities)* that specifies ways of improving the cancer experience of people with intellectual disabilities. In this document the charity identified that in order to reduce disparities in cancer care it was important to provide understandable and individualised cancer information, and to evaluate the understanding of cancer symptom awareness. They also highlighted that the confidence of health professionals to communicate with this population needed to be established, and that training should be offered where necessary. Overall, this document highlights that further research is required to understand the cancer experiences and outcomes of this population. The Cancer Taskforce (2015) repeated this same sentiment seven years later, further highlighting the stagnation in translating policy into practice for people with cancer and intellectual disabilities. In addition to the suspected inequality in outcomes experienced by people with intellectual disabilities, the fact that we do not have empirical evidence to prove (or disprove) this hypothesis is yet further evidence of unequal treatment and a lack of consideration of the needs of this group in cancer care and cancer research.

Thesis Rationale and Overview

In summary, enhancements in medicine, and public health initiatives, have led to more people with intellectual disabilities living longer lives, which is contributing to an increasing number of people with intellectual disabilities receiving cancer diagnoses. At present, there is limited literature that explores the psychosocial cancer experiences of people with intellectual disabilities but, given population growth, the importance of research in this area is ever more apparent. Several recent policy documents and national initiatives over the past decade have outlined the importance of examining the needs and experiences of this population; however, little has changed in almost ten years. It is imperative that research drives our understanding of the experiences in this population, and that this evidence is then used to inform policy and practice regarding the cancer care of people with intellectual disabilities. This thesis aims to undertake a broad exploration of the cancer-related experiences of people with intellectual disabilities, and the people who support them, to extend this understanding.

To establish what is already known about the first-hand experiences of people with intellectual disabilities and cancer it was necessary to first conduct a systematic review of the literature, and this follows in Chapter 2. The overarching aim of this review was:

1. **To systematically review the literature surrounding the psychosocial cancer experiences of adults with intellectual disabilities, and to identify the current status of, and gaps in, research evidence.**

From undertaking this review (Chapter 2), it became evident that there is a paucity of literature exploring the cancer experiences of people with intellectual disabilities. This informed the empirical aims of the remainder of this thesis (Chapters 3-5).

2. **To investigate, in detail, the overall psychosocial experience of cancer diagnosis, treatment and survivorship in adults with a diagnosed intellectual disability.**

To address this aim, a qualitative study of the cancer experiences of adults with intellectual disabilities, and those who support them, was undertaken (Chapter 3). As the literature pertaining to such experiences is sparse, this study was a qualitative study of cancer experiences in people with intellectual disabilities using thematic analysis

(Braun & Clarke, 2006), and was informed by grounded theory (Glaser & Strauss, 1967) in the hope that this approach, and the findings from this study, would lead to a deeper understanding of the experiences in this population and stimulate further research and discussion. Findings from this study showed that participants were often excluded from conversations about their diagnosis and treatment, and expressed confusion and anxiety about their cancer. Increased involvement and empowerment seemed to reduce cancer-related distress, and the importance of the role of oncology nurses in helping participants to understand their diagnosis and treatment was evident.

Given the important role that oncology nurses play in cancer care (Rieger & Yarbro, 2003), and the likelihood that this population may already be experiencing psychological stress in undertaking this professional role (Escot et al., 2001; Gomez-Urquiza et al., 2016; Toh, Ang, & Devi, 2012), a survey of UK oncology nurses was next required to address the third thesis aim:

3. **To investigate the knowledge, awareness, and experiences of oncology nurses regarding the care of adults with a diagnosed intellectual disability and cancer.**

For this study, 83 oncology nurses were recruited and data collected about their attitudes and perceptions of providing care to cancer patients with intellectual disabilities, in comparison to patients without intellectual disabilities (Chapter 4). Results indicated that these participants felt uncomfortable and unconfident in their abilities to care for this specific population, and that further training to support successful communication with this patient population would be helpful. Such interventions have the potential to improve psychological and physical outcomes for people with intellectual disabilities (Arora, 2003; Zolnierek & DiMatteo, 2009). This led to the final thesis aim:

4. **To establish the feasibility and acceptability of a bespoke intervention to improve oncology healthcare professionals' perceptions of providing cancer care to people with intellectual disabilities.**

A brief online training intervention was developed based on the earlier findings in this thesis, and a thorough review of communication literature. This was then tested

(Chapter 5) to establish the acceptability of the study design and intervention content, and the feasibility of a full-scale randomised controlled trial (RCT) being undertaken using this study design.

The final thesis discussion chapter (Chapter 6) then draws together key findings from these interlinking studies to develop a series of thesis recommendations and implications for both research and practice. As part of this discussion, this chapter also evaluates the mixed-methods approach which underpinned the design of studies within this thesis, and reflects upon the challenges that were encountered during this PhD.

Chapter 2. Cancer Experiences in People with Intellectual Disabilities: A Systematic Review of the Literature

Chapter Overview

As discussed in Chapter 1, increased life expectancy has led to an increase in cancer diagnoses in people with intellectual disabilities; despite this increase, research exploring the psychological impact of such a diagnosis is rare. This chapter presents the findings from a systematic review aiming to explore the psychosocial experiences of cancer in adults with intellectual disabilities, revealing potential predictors and influencing factors of these experiences. In doing so, this addresses the first thesis aim, which was to identify the current status of research into the cancer experiences of adults with intellectual disabilities. Online databases were systematically searched to identify relevant literature, using predefined inclusion and exclusion criteria.

Of the 33,877 titles identified, ten papers met inclusion criteria. Narrative synthesis of the data identified five themes related to psychosocial cancer experiences and unmet needs, namely: (i) delayed diagnosis, (ii) information, communication and understanding, (iii) negative psychological consequences, (iv) negative physical consequences, and (v) social support. Of the ten papers included, six reported on the same sample of 13 participants, and so the generalisability of the findings is questionable. As so few studies were identified, it is clear that further empirical work is needed to understand the psychosocial experiences of people with intellectual disabilities diagnosed with cancer, and in turn how we can appropriately support this group.

Background

Receiving a diagnosis of, and living with, cancer is distressing (Zabora et al., 2001). In comparison with the general population, people with cancer are more likely to suffer from depression and anxiety (Hinz et al., 2010). Findings from the general population have highlighted that many people diagnosed with cancer experience psychological comorbidities such as anxiety, distress, and depression (Zabora et al., 2001; Jacobsen, 2007; Lam et al., 2012), and can face additional practical burdens, including financial and employment worries (Butow et al., 2012). Furthermore, cancer patients commonly report having unmet psychosocial needs (Harrison et al., 2009; Swash et al., 2014). Fear of recurrence is commonly reported by cancer survivors (Olesen et al., 2015; Koch et al., 2014; Dahl et al., 2013; Sekse et al., 2010), and can be detrimental to well-being and quality of life (Koch et al., 2014). The literature exploring cancer experiences in people without intellectual disabilities is ever increasing; however, there has been a relative paucity of research examining these important psychosocial needs and outcomes in people with intellectual disabilities.

People with intellectual disabilities often have impairments in key skill areas, including interpersonal communication skills, personal care, reading and knowledge (APA, 2013). These difficulties may disadvantage people with intellectual disabilities when accessing healthcare services, potentially leading to delays in symptom presentation and diagnosis, and resulting in poorer health and well-being outcomes. This may make their experience of cancer care even more psychosocially problematic. In the general population, cancer care generally follows a self-management framework (McCorkle et al., 2011). Self-management frameworks depend upon the person with cancer to self-administer medication and to manage their illness to prevent further complications. Whilst annual health checks for people with intellectual disabilities have been shown to be beneficial (Robertson et al., 2012), the self-management framework may not always be successful as people with intellectual disabilities may not be aware of, or may ignore, their symptoms to a greater extent than the general population (Turk et al., 2012a). Uptake for health screening appointments, for example, is lower for people with intellectual disabilities compared with the general population (Osborn et al., 2012). Osborn et al. found that uptake for cervical screening was particularly poor, with the sample of people with intellectual disabilities being 45% less likely to be screened than people without intellectual disabilities.

Study Purpose

Few empirical studies have explored the psychosocial impact of cancer on people with intellectual disabilities. However, research of this kind is important to inform policy and service provision for this population. Systematic reviews are helpful to prioritise research gaps and further direction in specific areas of study (Petticrew & Roberts, 2006). This review was designed to identify, evaluate and synthesise the literature exploring the psychosocial experiences of cancer in adults with intellectual disabilities (including pre-diagnosis, diagnosis, treatment, survivorship, and self-management phases). As a secondary research question, the review aimed to extract information on factors which may predict or ameliorate these experiences (e.g., social support, and communication impairments) to identify where additional appropriate support could be offered.

Methodology

Systematic reviews identify, evaluate and synthesise all relevant empirical evidence, meeting the researchers' own predefined inclusion criteria (Higgins & Green, 2011). As such, systematic reviewers must follow rigorous guidelines to reduce researcher bias and ensure the inclusion of all relevant papers, with procedural transparency maintained throughout. This is so that a systematic review carried out by one research team could be precisely replicated by another, independent, research team (Egger, Davey Smith, & Altman, 2001).

The protocol for this systematic review was designed in accordance with guidance published by the Cochrane Collaboration (Higgins & Green, 2011), and two systematic review handbooks (Petticrew & Roberts, 2006; Torgerson, 2003). All members of the supervisory team reviewed and approved the protocol before the commencement of the searches.

From scoping searches performed at the start of this PhD, it was evident there was a paucity of literature concerned with the psychosocial experiences of people with intellectual disabilities and chronic illness. Systematic database searches were developed, therefore, to be sensitive rather than specific, ensuring maximum inclusivity of relevant articles (Petticrew & Roberts, 2006).

Initial searches were undertaken in December 2012 and updated in May 2017; these focused on identifying literature exploring the experiences of people with intellectual disabilities and chronic illness. Searches were updated again in January 2018 with an improved search strategy being implemented: due to a higher return of relevant literature than expected, the scope of the review was limited to papers focusing solely on cancer experiences in this group.

Search String Development

Three search strings were developed using the existing literature, among other sources (for terms included within the search strings please refer to Figure 2.1):

- *Chronic Illnesses:* Search terms were identified using the WHO (2011) chronic illness webpage and the International Classification of Diseases (ICD-10; WHO, 2010). WHO definitions were prioritised here to give the work international relevance and provide confidence and consistency in search terms. Initially, broad searches were undertaken, encompassing all chronic illnesses; however, the review was later limited to synthesise data only from papers on cancer experiences in people with intellectual disabilities, to give more focus.

- *Intellectual disabilities:* Terms for this search string were verified using Mencap (2012) guidance about intellectual disabilities. As the UK's leading charity working with people with intellectual disabilities, Mencap's guidance was considered the most comprehensive and reliable.
- *Psychosocial experiences:* As the area of psychosocial experiences is vast, it was decided that, to be inclusive, terms would be based on existing systematic reviews of the psychosocial needs and/or experiences of patients with a chronic illness (including cancer) (e.g., Harrison et al., 2009; Rutten et al., 2005; Swash et al., 2014). Additionally, search terms for emotional reaction to illness were extracted from the comprehensive work of Lazarus (1991).

Abstract("Chronic illness" OR "Chronic disease" OR "Non-communicable" OR "Cancer" OR Neoplas* OR "Cardiovascular" OR Diabet* OR Epilep* OR "Osteoporosis" OR "Cerebral palsy" OR "Chronic pain" OR "Hypertension" OR "Chronic renal failure" OR "Fibromyalgia" OR "Periodontal disease" OR "Autoimmune disease" OR "ulcerative colitis" OR "lupus erythematosus" OR "Crohn's Disease" OR "Coeliac Disease" OR "cerebrovascular disease" OR "heart failure" OR "ischemic cardiopathy" OR "Myalgic encephalitis" OR "Chronic hepatitis" OR "Chronic osteoarticular disease" OR "Osteoarthritis" OR "rheumatoid arthritis" OR "Chronic respiratory disease" OR "Asthma" OR "chronic obstructive pulmonary disease" OR "COPD" OR "pulmonary hypertension" OR Sickle Cell An?emia OR H?emoglobin disorder OR "Coronary heart disease" OR "cerebrovascular disease" OR "peripheral arterial disease" OR "rheumatic heart disease" OR "congenital heart disease" OR "deep vein thrombosis" OR "pulmonary embolism" OR "HIV" OR "AIDS" OR Visual impair* OR Blind* OR Deaf* OR Hearing impair* OR "Periodontitis")

AND

Abstract((mental OR learning OR intellectual adj1 (disab* OR impair* OR handicap* OR subnormal* OR deficien* OR retard*)) OR (subnormal* OR retard*) OR (autis*) OR ("Smith-Magenis" OR Rett* OR "Lesch-Nyhan" OR "Prader-Willi" OR Angelman OR "fragile X" OR "Cri-du-chat" OR "Cornelia de Lange" OR "de Lange" OR "Rubinstein-Taybi" OR velocardiofacial OR DiGeorge OR "22q11.2" OR Down* adj2 (syndrome)))

AND

Abstract((psychosocial OR practical adj2 (need* or experienc*)) OR (support* OR inform* OR communicat* OR understand*OR know* OR spiritual* OR psychologic* OR adjust* OR adapt* OR identity OR coping OR uncertain* OR panic* OR lonel* OR isolat* OR depress* OR accept* OR denial OR resent* OR worr* OR fear OR stress* OR distress* OR body image OR quality of life OR well-being OR wellbeing OR relationship* OR benefit finding OR positive growth OR post-traumatic growth OR anxi* OR anger OR fright* OR guilt* OR *shame* OR sad* OR jealous* OR disgust* OR happ* OR relie* OR hope* OR love* OR compassion* OR emoti* OR mental health OR mental illness OR mood OR need OR unmet need))

Limits: humans; English language; 1911-2018; journal article

Figure 2.1. Example search (PsycINFO: Ovid)

Database Searches

Appropriate online databases (CENTRAL, Web of Science [SCI and SSCI], Medline, PsychINFO and CINAHL) were searched using the three search strings, each adapted as necessary for the specific search engine. The online databases were selected in consultation with members of the supervisory team who were experienced in conducting systematic reviews, including for the Cochrane Collaboration (Edwards, Hulbert-Williams, & Neal, 2008). The databases were chosen to encapsulate psychology and health literature, ensuring a comprehensive return of search results. Final searches took place during January 2018, and a log of search results was kept (Table 2.1). All search results were imported to EndNote, whereby automatic and manual de-duplication and an initial inclusion assessment were undertaken.

Table 2.1. Database search log

Database	**Date Searched**	**Dates Covered**	**Limits**	**n**
CENTRAL	05/01/2018	1959-2018	Trials	395
SCI and SSCI	05/01/2018	1989-2018	English language; article	12812
Medline	05/01/2018	1974-2018	Humans; English language; journal article	8639
Embase	05/01/2018	1974-2018	Humans; English language; journal article	6823
PsychINFO	05/01/2018	1911-2018	Humans; English language; journal article	2957
CINAHL	05/01/2018	1983-2018	Humans; English language; journal article	14233
		Cumulative Total		**45859**

Inclusion and Exclusion Criteria

To narrow the scope of the review to focus on psychosocial experiences of adults with intellectual disabilities and cancer, the following inclusion and exclusion criteria were developed:

i. Participants diagnosed with cancer and an intellectual disability, or data provided by a proxy informant.

ii. Retrospective or current cancer experiences, defined as occurring at any time point, including: pre-diagnosis (e.g., routine screening), diagnosis, treatment, self-management, illness-free periods, progression, survivorship, palliative care, and end of life.
iii. Participants were required to be adults (over 18 years of age) at time of diagnosis.
iv. Both qualitative and quantitative studies were included.

Restrictions were not placed on date of publication as a comprehensive overview of all research, historic and current, was required. However, only English language publications were considered for inclusion, in line with the resources available (only four papers were excluded for this reason).

Review Strategy

From the searches, 45,859 results were returned (see Figure 2.2). Automatic and manual de-duplication was undertaken within EndNote. Post de-duplication, titles and abstracts of 33,877 studies were carefully screened for broad relevance by the researcher (Samantha Flynn). A total of 26 abstracts were identified for full assessment from the 95% of records which were reviewed by the researcher. A 5% random sample (1,691 abstracts) was also independently checked by another reviewer (PhD student: Dale Chandler). This is an accepted practice when a review is large and resources are restricted (Petticrew & Roberts, 2006), although it is acknowledged that this method is not ideal as there is potential for studies to be unknowingly excluded. From the 5% sample, the independent reviewer identified four papers, three of which were also found by the first reviewer and thus included. There were two disagreements which were discussed and resolved collaboratively, with one paper being subsequently included in addition to the three that had already been included. The inter-rater reliability for the title and abstract screening was good (kappa=0.75).

Both reviewers then independently assessed full manuscripts of these 30 shortlisted abstracts; articles that did not meet full inclusion criteria at this stage were discarded. Initially, nine papers were agreed upon for inclusion by both reviewers. There were three disagreements, but inter-rater reliability was within an acceptable range (kappa=0.64). After discussions to resolve these disagreements, the three papers were excluded, and the nine papers which were agreed upon were included in the review. A manual search of the reference lists of included articles was then undertaken *(*by one reviewer only: Samantha Flynn*)* to locate any relevant articles not identified by electronic searches, as is accepted practice to supplement database searching (Horsley, Dingwall, & Sampson, 2011). One article (Cresswell & Tuffrey-Wijne, 2008) was identified and subsequently included.

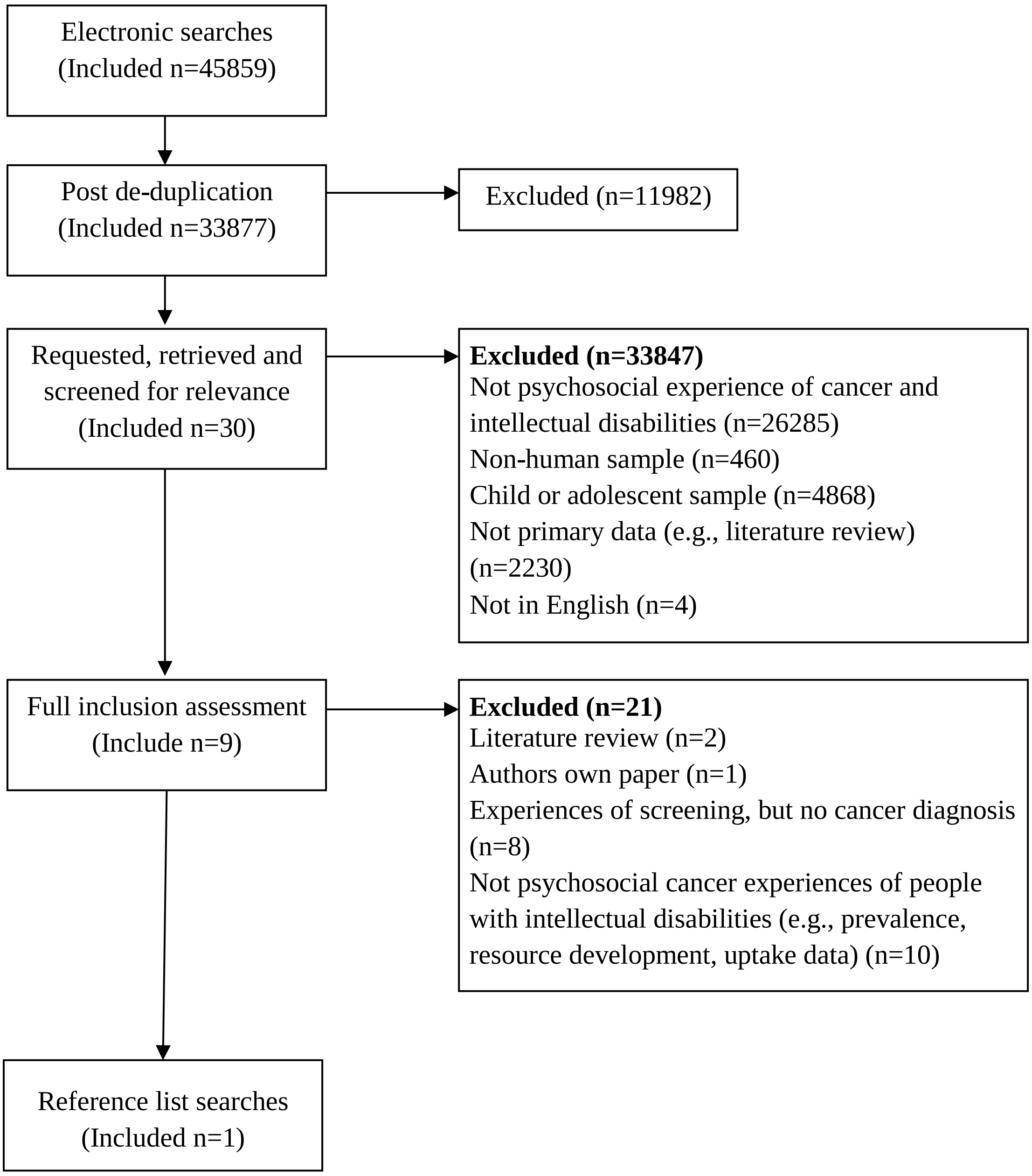

Figure 2.2. Flow chart indicating the narrowing of included papers

Data Extraction and Synthesis

Data extracted from included articles comprised: sample description (details of participants' intellectual disability and cancer diagnoses), study design, and key findings. Data was recorded using a standardised form (Appendix 1). Methodological quality assessments were also undertaken using the Framework for Assessing Qualitative Evaluations (FAQE; Spencer et al., 2003) (Appendix 2). Quality assessments are undertaken within systematic reviews to establish the methodological quality of the available studies; from this it is possible to establish the strength of evidence in any given field. This particular checklist was chosen as it provided a clear and extensive, evidence-based, framework to inform the evaluation of qualitative research. Unlike some other frameworks, the FAQE was developed following an extensive programme of preparatory work, including:

- a review of literature on qualitative research methods;
- a review of existing quality frameworks for qualitative research;
- interviews with qualitative researchers interested in quality assessment of qualitative research;
- a workshop to refine the initial framework; and
- a trial application of the framework.

A response of "yes", "partial", "no", or "not applicable" was given for each item on this standardised checklist. Each "yes" received a score of two, with responses of "partial" receiving a score of one and "no" receiving a score of zero. Each paper was then given a quality score from the summed totals. Articles score highly on the FAQE if it is clear how researchers reached their conclusions and findings were contextualized in relation to existing, and future, research. The quality of the discussion of limitations, study design rationale, sampling strategy, and how recruitment and data collection were carried out also impact the FAQE score. Finally, the FAQE outlines that it is important to have a clear narrative to the article, employing reflexivity and providing a clear explanation of the research process.

Some systematic reviews exclude poor quality studies (Higgins & Green, 2011) but, given the paucity of literature in this area, if a study met all inclusion criteria, a poor quality assessment did not warrant automatic exclusion from this review. Summaries of the included studies are presented in Table 2.2. Studies are numbered (see Table 2.2) and will henceforth be referred to by these numbers. A narrative literature synthesis was used to summarise findings textually as all included studies were qualitative in methodological design (Petticrew & Roberts, 2006). Best practice guidance by Popay et al. (2006), regarding conducting a narrative synthesis, was used throughout data synthesis to ensure a high standard of systematic review.

Table 2.2. Summary of included papers

Paper ID	Authors	Year	Country	N	Sample description	Design	Data analysis	Quality assessment score
[1]	Collins, K., McClimens, A., Mekonnen, S., & Wyld, L.	2014	UK	26	Twenty-six key stakeholders from national statutory and voluntary bodies who have contact with women with intellectual disabilities.	Qual	Framework approach	FAQE: 25/36 (69.4%)
[2]	Cresswell, A., & Tuffrey-Wijne, I.	2008*	UK	1	A 36-year-old woman with cerebral palsy and an intellectual disability (unspecified), diagnosed with non-Hodgkin's lymphoma six years previously (unspecified stage). She received chemotherapy, steroids and radiotherapy.	Qual	None presented	FAQE: 3/36 (8.3%)
[3]	Jones, A., Tuffrey-Wijne, I., Bernal, J., Butler, G., & Hollins, S.	2007	UK	4§	One woman with an intellectual disability who was diagnosed with cancer 8 months ago, and was probably in the terminal phase. Her husband, who also had intellectual disabilities, her support service manager, and her husband's support worker were also included in the study.	Qual	Not specified	FAQE: 24/36 (66.7%)
[4]	Kaushal, P., Smith, E. N., & Maddock, S.	2016	UK	1	A 47-year-old woman with a mild intellectual disability, diagnosed with bilateral breast cancer with bone and liver metastases: she received chemotherapy, tamoxifen, and monthly goserelin injections.	Qual	None presented	FAQE: 3/36 (8.3%)
[5]	Martean, M. H., Dallos, R., Stedmon, J., & Moss, D.	2013	UK	1	A 63-year-old woman with a learning disability (unspecified), diagnosed with breast cancer: she had a lumpectomy, radiotherapy, and chemotherapy.	Qual	Narrative analysis	FAQE: 34/36 (94.4%)

[6]	Tuffrey-Wijne, I., & Davies, J.	2006*	UK	1	A 44-year-old man with cerebral palsy and a mild intellectual disability, diagnosed with advanced penile cancer; he underwent surgery to remove his penis, bladder and bowel.	Qual	None presented	FAQE: 5/36 (13.9%)
[7]	Tuffrey-Wijne, I., Curfs, L., & Hollins, S.	2008*	UK	1	A 66-year-old with a severe intellectual disability and advanced lung cancer. When diagnosed, his disease was too advanced to receive any treatment.	Qual	None presented	FAQE: 3/36 (8.3%)
[8]	Tuffrey-Wijne, I., Bernal, J., Hubert, J., Butler, G., & Hollins, S.	2009*	UK	13	Thirteen people with intellectual disabilities (mild to profound) and cancer diagnoses (lung: n=2; lymphoma: n=1; penis: n=1; breast: n=3; testicle: n=1; primary unknown: n=1; stomach: n=1; bladder: n=1; bowel: n=1). They received a combination of chemotherapy (n=5), radiotherapy (n=5), and surgery (n=5), or no treatment at all (n=4).	Qual	Ethnography	FAQE: 32/36 (88.9%)
[9]	Tuffrey-Wijne, I., Bernal, J., & Hollins, S.	2010*	UK	13	Thirteen people with intellectual disabilities (mild to profound) and cancer diagnoses (lung: n=2; lymphoma: n=1; penis: n=1; breast: n=3; testicle: n=1; primary unknown: n=1; stomach: n=1; bladder: n=1; bowel: n=1). They received a combination of chemotherapy (n=5), radiotherapy (n=5), and surgery (n=5), or no treatment at all (n=4).	Qual	Ethnography	FAQE: 33/36 (91.7%)
[10]	Tuffrey-Wijne, I., Bernal, J., Hubert, J., Butler, G., & Hollins, S.	2010*	UK	13	Thirteen people with intellectual disabilities (mild to profound) and cancer diagnoses (lung: n=2; lymphoma: n=1; penis: n=1; breast: n=3; testicle: n=1; primary unknown: n=1; stomach: n=1; bladder: n=1; bowel: n=1). They received a combination of chemotherapy (n=5), radiotherapy (n=5), and surgery (n=5), or no treatment at all (n=4).	Qual	Ethnography	FAQE: 21/36 (58.3%)

* These papers presented data from the same core study (The Veronica Project) and the same sample of participants.

§ This study presented data from a mixed sample of people with and without cancer; only data from the person with an intellectual disability and cancer (and her supporters) has been included in this systematic review.

Results

When studies were synthesised by psychosocial experience (Table 2.3), five independent themes of experience emerged.

Table 2.3. Identification of themes within included papers

Paper	**Delayed diagnosis**	**Information, communication, understanding**	**Psychological consequences**	**Physical consequences**	**Social support**
[1]	✓	✓			
[2]	✓	✓	✓	✓	✓
[3]		✓			
[4]	✓		✓		
[5]			✓		
[6]	✓	✓	✓	✓	✓
[7]	✓	✓		✓	✓
[8]	✓	✓	✓	✓	✓
[9]		✓	✓		
[10]	✓	✓	✓	✓	✓

Delayed Diagnosis

Practitioners in one study [1] highlighted a lack of guidelines for looking after breast health, limited health-promotion activities, and inaccessible breast screening, and found this to be prohibitive of early diagnoses of breast cancer for women with intellectual disabilities. People with intellectual disabilities in three studies noticed a change in their health and sought advice from their general practitioner [2,6,8]. Physical symptoms prior to diagnosis were described; for example, the inability to eat properly due to the swelling tumour [2], a bad odour emanating from the tumour [6], coughing [7], and rapid weight loss [2,6,7]. In some cases, people were assured by healthcare professionals that their symptoms were innocuous [2,6,8]. One person [2] sought advice when the symptoms progressed; however, she was informed again that she was in good health. In contrast, another person [6] did not seek further medical attention despite the progressive symptoms, concealing his declining health from his family. Both people were eventually admitted to hospital in a critical condition [2,6]. People with intellectual disabilities are usually dependent on others for support, and this is also true for accessing health services; this dependence often led to delayed diagnoses as symptoms were ignored [7,8,10], or when carers thought that the person was attention seeking and that nothing was really wrong with them [8,10]. Delayed diagnoses in these studies led to poor prognoses or metastatic disease [4,6,7].

Information, Communication, and Understanding

The use of complex language by healthcare professionals when explaining diagnosis and treatment options was inhibitive to understanding and increased the levels of anxiety in people with intellectual disabilities, as reported by people with intellectual disabilities themselves and expressed during observations within the ethnographic studies [2,6,8,9,10]. Many people with intellectual disabilities were not told about their diagnosis [9,10], and if they were told, they were not sufficiently supported to understand the complexities of their diagnosis [9,10]. Support staff were concerned that greater understanding could lead to greater distress [3,7,8,9,10]; however, this was not usually the case [7]. Some people who were not told that they were dying eventually worked it out on their own and, from reports within the ethnographic studies, they seemed to accept this [8,9]. There was agreement between paid caregivers in included studies that someone close to the person with an intellectual disability should be involved in telling them about their diagnosis [3,7] due to medical staff being unconfident communicating with people with intellectual disabilities [7,8,10]. The extent to which people were told, and supported to understand, information about their cancer was largely dependent on the abilities of their intellectual disability support staff [8,10], including whether they felt confident enough to talk about cancer with the person.

Medical staff would often misunderstand what was being expressed by the people with intellectual disabilities [7,8], and this would further complicate communication. The use of accessible language both textually and verbally was conducive to understanding for the participants [2,3,6,9]. In one included study, women with intellectual disabilities received the same breast screening invitation letter as women without intellectual disabilities, and this led to confusion [1]. Some doctors accessibly explained the participant's diagnosis [6]; however, there was a general lack of accessible communication from hospital staff [6]. Reasonable adjustments were not seen as being a routine practice and, instead, compassionate and committed individuals within oncology and intellectual disabilities teams took it upon themselves to make changes to their practice [1]. Difficulties arose as reasonable adjustments had to be personalised to each person, and this was perceived as time consuming [1]. Often, medical professionals would rely on the opinions of carers to make treatment decisions, without seeking the opinion of the person with an intellectual disability themselves [8,10]; sometimes even carers were excluded from these treatment decisions [3]. Some carers made decisions based on their own opinions rather than in the best interests of the people with intellectual disabilities [7]; that this often included an appraisal of how painful or uncomfortable the treatments would be for the patient, without consulting them directly, is concerning.

Negative Psychological Consequences

Uncertainty was experienced by people with intellectual disabilities about their illness [2], and their mortality [2,6]. One person [6] reported that he concealed his emotions from his family. Another person reported being extremely lonely during his treatment, and that this led to him worrying; because of this, he sought emotional support from his friends and family [10]. Some paid intellectual disabilities carers were unsupportive of the people they worked with, and would disregard their emotions by telling them to cheer up when they had every right to be distressed [10].

Having religious faith [6] was reported to be associated with reduced negative psychological consequences. Another person reported being initially shocked about her diagnosis, but she was able to focus her energy on her treatment to lessen this shock [5]. One study [9] hypothesised from their data that people being in denial about their illness could have masked their level of understanding.

One study examined the impact of tamoxifen on the psychological well-being of a woman with an intellectual disability and breast cancer [4]. Her moods and behaviour deteriorated after two months of taking tamoxifen although this was not identified as the cause of her psychological deterioration until her sister highlighted it as a possibility following her own negative experiences of taking the drug some years before. The woman with an intellectual disability and breast cancer stopped taking tamoxifen after consultation with a psychiatrist, and her moods and behaviour improved after one month (she was also prescribed an antidepressant). Following treatment, one person reported being more confident after cancer and wanting to live her life to the fullest [5]. This type of resilience was also seen in people in another study [10], and this was partly attributed to the fact that they were used to facing adversity, and to being cared for.

Physical Consequences

Physical consequences of cancer or treatment were reported to be hair loss [2], altered sense of taste [2], and pain [10]; and included restrictions caused by the illness, such as undergoing physiotherapy to regain mobility post-surgery [6]. Due to the lasting physical effects of surgery, one person [6] was unable to climb stairs and was thus unable to continue living in his home. Another had to have his bed moved downstairs as he was too weak to climb the stairs [7]. These consequences are not unique to cancer patients with intellectual disabilities, but their experience of and reactions to them might be pertinent. People with intellectual disabilities and cancer would not always divulge their pain to their carers, choosing to hide it instead [10]; one person expressed that this was related to wanting to be an “easy” patient so their doctors liked them [5]. Pain medication was prescribed for some people; however, this was sometimes not correctly administered, as intellectual disability support staff were unsure about when they were able to administer additional pain relief, and what to do when the person was unable to swallow it [7,8].

In some cases, people with intellectual disabilities were not offered all standard treatment options [8], usually due to the assumption of medical and support staff that the person could not handle the treatment. Some carers believed that this was a discriminatory practice because of the person’s intellectual disability.

People with intellectual disabilities and cancer in these studies were concerned about how others perceived the effects of their treatment. For example, vomiting in public as a side effect of treatment raised concerns for one person that this could be misinterpreted as them being intoxicated [6]. Some people were placed in older age wards or homes [2,6], which in turn had negative consequences on them, as both people with intellectual disabilities in these studies felt that it was the wrong environment for them. One person [2] reported that another patient verbally abused her, as the other patient did not understand her disability. Additionally, other residents in shared houses were distressed by their housemate’s cancer, and about having to witness the deterioration in their health [7].

Social Support

Social support was considered to be important [8], with one person attending a community day centre for older people until the week that he died; his friends would also come to visit him and this was extremely important to him [7]. One person [6] had feared family members’ reactions to his diagnosis but since his diagnosis they were supporting him. Another person [2] was unable to see friends whilst she was undergoing treatment in case she got an infection, as her immune system was compromised due to her treatment; however, despite the lack of physical engagement with them, she still felt supported. The sister of one person with an intellectual disability and cancer did not go to see him while he was ill as she wanted to remember him as being healthy [7]; she is reported to miss him greatly, but the impact on the person with an intellectual disability was not explored within this paper. Some people with intellectual disabilities and cancer were aware that they were relying on other people, and so did not request further support from them even when their needs increased [10]. Some people enjoyed being around medical staff and were happy to have the company [8]. However, many people in these studies were extremely lonely during their illness [8,10], particularly as their routines changed dramatically.

Discussion

Review Findings in a Broader Context

Participants in included studies often experienced delays in symptom presentation and diagnosis. Poor symptom awareness and health knowledge/literacy may lead to the underreporting of pain and other symptoms, significantly affecting the likelihood of successful diagnosis and effective treatment (Janicki et al., 2002;

Tuffrey-Wijne & Davies, 2006; Ashing-Giwa et al., 2010; Turk et al., 2012a). Diagnostic delays can lead to psychological distress in the general population (Risberg et al., 1996) and it is reasonable to expect that this would also be distressing for people with intellectual disabilities. Regularly monitoring the health of people with intellectual disabilities (e.g., with annual health checks) may improve the likelihood of timely symptom identification, as behavioural or physical changes could signal pain or discomfort (de Knegt et al., 2013), among other symptoms.

One of the papers in this review highlighted that breast screenings can be inaccessible for women with intellectual disabilities [1]. Osborn et al. (2012) found that the screening rates between 1999 and 2009 for cervical, breast, prostate, and bowel cancers were much lower for people with intellectual disabilities in comparison with the general population. The largest disparities in the uptake of screening for people with intellectual disabilities were found for cervical screenings (45% less likely) and mammograms (35% less likely). This trend has been found in other studies for both breast (Davies & Duff, 2001; Piachaud & Rohde, 1998; Sullivan et al., 2004) and cervical (Biswas et al., 2005; Lewis et al., 2002a; Stein & Allen, 1999) screenings. Whilst less research has been conducted into sex-specific screening for men, limited findings suggest that men with intellectual disabilities are not advised about testicular screening (Hanna et al., 2011; Peate & Maloret, 2007). Perceptions that people with intellectual disabilities are asexual (Thomas et al., 2016), and taboos about discussing sex and relationships with people with intellectual disabilities (Sullivan et al., 2013; Winges-Yanez, 2014) may partly explain this. Unhelpful assumptions such as these could lead people with intellectual disabilities to feel ashamed about discussing intimate care and sexual topics with others. Embarrassment for people with intellectual disabilities (Turk et al., 2012a) and the people who support them (Turk et al., 2012b) can inhibit open communication about breast and reproductive cancers, leading to potentially avoidable delays in symptom presentation and diagnosis (Janicki et al., 2002). Cancer screening rates have improved for people with intellectual disabilities since the creation of the role of screening liaison nurses (Marriott et al., 2015); such findings are promising for the health promotion of people with intellectual disabilities and may lead to earlier diagnosis of cancers, thus improving survival rates.

Healthcare professionals can make false assumptions that symptoms are not due to a physical complaint but are instead due to the intellectual disability (diagnostic overshadowing) (Reiss et al., 1982). It is possible that this tendency was at play within several papers included in this review [2,6,8]. Diagnostic overshadowing can lead to avoidable deaths in people with intellectual disabilities, some of which were highlighted in *Death by Indifference* (Mencap, 2007); a report which highlighted severe health inequalities facing people with intellectual disabilities.

Cancer terminology is difficult to understand (Makaryus & Friedman, 2005), and for people with intellectual disabilities this is likely to be even more challenging, potentially leading to substantial misunderstandings and unmet information needs. This can exacerbate anxiety, fear and distress, particularly for people who had a greater capacity for understanding, as was the case within many of the included studies [2,6,8,9,10]. Accessible health information is not always available for people with intellectual disabilities; whilst there is a plethora of cancer information available in the public arena (e.g., leaflets, websites, and information centres), the information provided may not be accessibly written, leaving people with intellectual disabilities unable to understand it (O'Regan & Drummond, 2008; Ouellette-Kuntz, 2005; Wilkinson et al., 2011).

Accessible cancer information and communication can improve the understanding of people with intellectual disabilities [2,3,6,9]. Despite Easy Read cancer information becoming more readily available (e.g., Macmillan, 2017; Easy Health, 2017) it is still possible that it is not visible in hospital environments (Dinsmore, 2012). Moreover, people with intellectual disabilities are not always able to fully understand Easy Read information, which can be impacted by severity of intellectual disability, previous life experience, and how much they are supported to understand (Tuffrey-Wijne et al., 2006; Tuffrey-Wijne, Bernal, & Hollins, 2010). Reasonable adjustments can enhance communication and understanding for people with intellectual disabilities, and some suggestions from the wider literature for such adjustments include: using non-technical language (Turk et al., 2012a), equipment demonstrations (Tuffrey-Wijne et al., 2006), pictorial prompts (Nind, 2008; Turk et al., 2012a), simple pain screenings (Bromley et al., 1998; Donovan, 2002; McGrath et al., 1998; Turk et al., 2012a; Zwakhalen et al., 2004), and collaborative working between oncology and intellectual disabilities staff (Tuffrey-Wijne et al., 2010). On this final suggestion, Ali and Hassiotis (2008) suggest that suboptimal care is due to the lack of understanding of medical staff, and that effective communication between medical staff and patients who have intellectual disabilities is an issue that should be researched further.

Receiving a cancer diagnosis is distressing for people in the general population (Gunn et al., 2012; Musselman et al., 2003; Zabora et al., 2001), and this was also the case for participants in some included studies [2,4,6]. A review of psychological adjustment to cancer suggests that patients should engage in self-management strategies and express their emotions (de Ridder et al., 2008). However, this may not always be successful within an intellectual disabilities population, as people with intellectual disabilities can express emotions in an unfamiliar way (Adams & Oliver, 2011), and this may affect both their own psychological adjustment to a cancer diagnosis and the appropriate response by healthcare teams.

This review found that people with intellectual disabilities and cancer experienced negative physical, as well as psychological, consequences. Symptomatology is inevitably similar for those with and without intellectual disabilities; however, they may present particular problems for those with intellectual disabilities, for instance, not being offered the full range of treatments because of their intellectual disability, or the presumption that they would not cope with the treatment [8]. Whilst it is entirely possible that such issues may arise for people without intellectual disabilities, conclusions cannot be drawn without further exploration into this area. This issue, of people with intellectual disabilities not being offered the full range of cancer treatments, has been reported recently in the press (British Broadcasting Corporation [BBC], 2017), and represents a discriminatory and life-limiting practice. Further efforts must be made to involve people with intellectual disabilities in conversations about their illness and treatment, to improve adjustment to the diagnosis; an important stage in the illness trajectory which is related to psychological well-being (Karademas et al., 2009; Lewko et al., 2007).

Having a chronic illness can be stigmatising (Earnshaw & Quinn, 2012), for instance, if the person is required to self-administer medication in public (Schabert et al., 2013). Within this review, perceived negative social perceptions as a result of diagnosis and treatment side effects were apparent within two studies [2,6]. It is possible that there is an additional stigma present due to the person's intellectual disability (Beart, 2005; Cooney et al., 2006), and this stigma can be detrimental to the well-being of people with intellectual disabilities (Jahoda et al., 2010). It is not yet clear how the two forms of stigma might interact, or whether such stigma about having cancer is worse for people with intellectual disabilities than for the general population. These questions would benefit from more research attention.

Predictors and Influencing Factors

This review identified that people with intellectual disabilities were aware of their need for social support. Communication and social support are important moderators of cancer adjustment (Stanton et al., 2013). Discussion of cancer experiences has been found to be extremely useful in making sense of these experiences for people with intellectual disabilities, although this is not always possible (Tuffrey-Wijne et al., 2006; Tuffrey-Wijne et al., 2012). Whilst participants in three of the studies were receiving support, it was sometimes not sufficient [2], or increased their anxiety [6]. Social support is an important factor in psychological adjustment to cancer, often accessed through peer (Flynn et al., 2013) and/or online support groups (van Uden-Kraan et al., 2008). One of the included studies [2] found that the social support received was reported as being helpful in alleviating the impact of negative emotions, with the participant highly valuing the support she received. It is possible that such avenues of support are not as readily available or accessible to people with intellectual disabilities (Lippold & Burns, 2009), and this could lead to further feelings of isolation.

Methodological Summary and Critique of Included Papers

The final systematic search presented in this chapter identified only qualitative papers. Four [2,4,6,7] were purely descriptive accounts, in the case-study tradition, and did not present any substantial data analysis; such publications serve to highlight important issues and are often a first step in developing impetus in researching a topic within the field of intellectual disabilities (cf. Hulbert-Williams & Hastings, 2008). Whilst simply having data published in any form is of great importance, there are few robust conclusions to be drawn from these case study designs. Furthermore, the data presented in six of the papers [2,6,7,8,9,10] were from the same ethnographic study of 13 people with intellectual disabilities and cancer and, whilst this method draws attention to this under-researched area, it is an example of ‘salami slicing’ (Norman & Griffiths, 2008). Publishing research in this way can over-emphasise the results from one study, thereby limiting the generalisability of the findings within this systematic review.

The quality of the articles varied (see Table 2.2), with four articles [2,4,6,7] receiving scores of less than 30%. Had these articles been excluded (see Higgins & Green, 2011), only six would have remained in this study. This highlights a need not only for more studies on this topic, but for higher quality research to be conducted in this area. With quality comes an ability to draw increased confidence from the results of empirical research, and this allows more relevant conclusions, and implications for practice, to be drawn.

All included studies had small samples, particularly those which collected data about people with intellectual disabilities, rather than from intellectual disabilities staff. The largest of these was a sample of 13 participants with intellectual disabilities and cancer, which appeared in three papers [8,9,10], with the experiences of three of these participants being described in more detail in three further papers [2,6,7]. Whilst these findings do have clear implications for research, policy and practice, without substantial sample sizes and replication studies it is difficult to influence policy and practice in any persuasive way, or to make any practical use of the information gleaned from the research. Small sample sizes can also inhibit the extent of exploration within a study, as well as the generalisability of the findings to the wider population. Only three of the included papers [2,5,6] actively involved people with intellectual disabilities in the data collection process. The others presented data collected only from professionals [1,3], an ethnographic study [7,8,9,10], or from case notes [4]. Observational methods, as used in five of the included papers [4,7,8,9,10] are subject to observer bias, and should therefore be interpreted with some degree of caution. This limits the extent to which we can reliably conclude that the findings within this review accurately and thoroughly represent the experiences of people with intellectual disabilities.

Methodological Critique of this Systematic Review

Only ten studies were identified for inclusion in this review, with a total sample of 45 individual participants; whilst this is fewer than expected, and does limit the generalisability of the results from the review, it emphasises the need for more empirical research to be conducted within the area.

Studies reporting on the experiences of children and young people (under 18) with intellectual disabilities and cancer were not included in this review. This decision was taken with a view to informing the future chapters of this thesis, which solely focus on the experiences of adults (over 18). It is possible that this decision restricted the inclusion of papers with comparable experiences, but other systematic reviews about the health of people with intellectual disabilities regularly limit the population to either adults or children/young people (e.g., Anders & Davis, 2010; Oeseburg et al., 2011; Tuffrey-Wijne, Hogg, & Curfs, 2007; van de Wouw, Evenhuis, & Echteld, 2012). No papers pertaining to the psychosocial experiences of cancer in children with intellectual disabilities were identified from the search terms used within this review. This highlights an area for future research development. Children with Down syndrome have an increased risk of being diagnosed with acute myeloid leukemia (AML) and acute lymphoblastic leukaemia (ALL) compared with children in the general population (Hasle, Clemmensen, & Mikkelsen, 2000). There are multiple studies exploring the psychosocial experiences of children with AML or ALL (e.g., Abate et al., 2017; Mitchell et al., 2015; Willard et al., 2017; Zheng et al., 2017), and their parents (e.g., Cornelio et al., 2016; Muskat et al., 2017). This does not, however, appear to be the case for children with intellectual disabilities and AML or ALL.

The search terms were developed with attention paid to inclusivity of terms. Every effort was made to ensure maximised sensitivity so that all relevant terms were included within the search strings, and this sensitive search strategy led to a high return of papers to undergo title and abstract review. This method was piloted (December 2012 and May 2017) prior to searches being undertaken in January 2018, and the results of these searches informed the final searches presented in this chapter; throughout this process, the rigour of these searches was a priority. Whilst this decision substantially increased the workload of the review, it ensured that potentially relevant papers were not missed. Requests for relevant articles sent through intellectual research mailing lists provided additional means for the identification of relevant articles by researchers in the intellectual disability field. No additional articles were identified through this strategy.

The substantial number of papers identified through online searches practically precluded double-screening of all 33,877 titles and abstracts from the initial searches. Instead, a colleague who was a novice systematic reviewer, but who had recently received training and had undertaken non-systematic literature reviews, double-screened a random 5% sample of titles. It has already been noted that this is acceptable practice in large-scale reviews and, whilst the researcher took every possible precaution, it is possible that other potentially relevant titles were excluded due to this practice. Double-screening of all full text articles by two reviewers increased the methodological rigour at this stage of the process, exemplified by good inter-rater reliability statistics.

Recommendations for Future Research

Conducting a systematic review within an emergent field can call attention to an absence of research, facilitating further exploration (Petticrew & Roberts, 2006). This review highlights a substantial gap in knowledge about the psychosocial experiences of people with intellectual disabilities and cancer. Further exploration of this topic would be beneficial, particularly, studies exploring a comprehensive range of type and severity of intellectual disability. Where possible, it is essential that people with intellectual disabilities are actively involved (e.g., interviewed) as participants in the research to share their first-hand experiences, as this was not always the case within the included papers. For staff working in healthcare settings, research to better understand the specific needs of people with intellectual disabilities, and exploring whether the standard support received (e.g., health education, and clinical and social support) is fulfilling these needs, is important. Possessing a more coherent understanding will enable the provision of appropriate services and resources to meet the needs of people with intellectual disabilities and cancer.

Whilst research exploring the nature of psychosocial experiences in this population is always valuable, the articles within this review were of variable standard, making it difficult to fully appreciate these important findings. As such, it is imperative that high-quality research designs are employed in future research. It is essential that people with intellectual disabilities, and/or the people who support them, are involved in the design of studies to ensure that they are relevant and accessible (Nind, 2008). Researchers are involving people with intellectual disabilities in their projects as co-researchers (Flood et al., 2013; O’Brien, McConkey, & Garcia-Iriarte, 2014) and, more widely, the involvement of people with intellectual disabilities in service planning has been recommended by *Valuing People* (Department of Health, 2001) and *Valuing People Now* (Department of Health, 2008). However, this is not always pragmatically possible (e.g., where funding is limited).

Implications for Practice, Care, and Support Provision

Whilst few articles were identified within this review, new ideas and research questions are apparent. It is imperative that healthcare professionals ensure that all people are helped to fully understand their diagnosis, its implications, and available treatment options. With appropriate support (e.g., simple language and visual stimuli), many people with intellectual disabilities can be enabled to actively participate in their cancer experience. As a matter of standard practice, reasonable adjustments (e.g., accessible information and communication) should be made, to ensure that the experience is no more difficult than it would be for someone without intellectual disabilities (Equality Act, 2010).

It is evident from this review that the health-related quality of life of people with intellectual disabilities and cancer is a key issue. The Functional Assessment of Chronic Illness Therapy (FACIT) measurement system for the health-related quality of life of people with chronic illnesses (including cancer) has potential applications for people with intellectual disabilities and cancer. Key areas of this assessment are: physical well-being, emotional well-being, social/family well-being, and functional well-being; all of which were pertinent to the cancer experiences of the participants in this review. Webster et al. (2012) report that the FACIT is quick to complete, sensitive to change, and easy to interpret; all of which are beneficial within healthcare environments and increase the likelihood of it being used in routine practice. The FACIT questionnaires are written in language suitable for 9-10 year olds, which may make their use with people with mild intellectual disabilities possible. Efforts to improve the accessibility of this or similar measures of health-related quality of life for people with all levels of intellectual disability would ensure that the needs of this population are being accurately and appropriately assessed.

Rationale for Further Investigation

In summary, this review has highlighted the paucity of empirical research being conducted into the psychosocial experiences of people with intellectual disabilities and cancer. Such research is continually being conducted within general population samples; however, people with intellectual disabilities are often overlooked. In general-population psychosocial oncology, for instance, there is an emphasis on listening to the needs of the patient group and providing services dependent upon the findings (Corner et al., 2006). People with intellectual disabilities are under-represented and very little is known about their experiences of cancer. It is imperative that we understand such experiences from a first-hand perspective in order to provide a high standard of care to this population, as it has previously been found that information provided by caregivers is often inconsistent with the information from the participant themselves (Turk et al., 2012a). It is with this knowledge that this thesis now moves on to an in-depth empirical exploration of cancer-related experiences of people with intellectual disabilities. The goal of this study was to build on previous work by (1) taking a multiple stakeholder perspective, whilst (2) maintaining a focus on the first-hand experiences of people with intellectual disabilities and cancer, and (3) employing a rigorous methodology.

Chapter 3. “You don’t know what’s wrong with you”: An Exploration of Cancer-Related Experiences in People with Intellectual Disabilities

Work presented in this chapter has been published, in part, as:
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“You don’t know what’s wrong with you”: An exploration of cancer-related
experiences in people with an intellectual disability. *Psycho-Oncology, 25*(10),
1198-1205. doi:10.1002/pon.4211

Chapter Overview

As highlighted in Chapters 1 and 2, few empirical studies have explored the cancer-related experiences of people with intellectual disabilities, despite rising cancer incidence within this population. The research described in this chapter aims to better understand the experiences of this population from multiple perspectives, generating further research questions; as such, this chapter addresses thesis aim 2. Six people with intellectual disabilities and cancer, alongside twelve participants from their supportive networks (including family, social care and healthcare professionals), were interviewed, with transcripts being analysed using thematic analysis.

As will become clear, the results from this study showed that people with intellectual disabilities were often overlooked within cancer consultations and were often excluded from conversations about their care and treatment-related decisions. Caregivers (including ‘informal’ family carers and paid intellectual disability care teams) were relied upon to facilitate communication and understanding, and to supplement the knowledge of healthcare professionals. Caregivers’ attempts to protect the person with an intellectual disability from distress further inhibited communication, as participants suggest that increased involvement, and thus empowerment, ameliorated cancer-related distress. Further to this, people with intellectual disabilities wished to protect their caregivers from distress about their illness. Where healthcare professionals were reported to possess good patient-centred skills, and additional support was offered, people with intellectual disabilities were more likely to engage meaningfully in their cancer experience. In the clinical setting, patient involvement in healthcare decisions (despite problems associated with co-morbidity) is imperative in order to optimise engagement.

Background

As previously discussed (Chapter 2), people with intellectual disabilities and cancer experience difficulties in communicating with care teams and understanding their illness, leading to feelings of uncertainty, confusion, and distress. Additionally, this group might also face barriers when accessing healthcare, due to healthcare professionals’ limited knowledge about intellectual disabilities, and inhibitive staff perceptions (Ali et al., 2013). People with intellectual disabilities are likely to have poor symptom awareness, and may not seek medical assistance for potential health concerns (Turk et al., 2012a). Delays in symptom identification and diagnosis of cancer can have implications for physical and psychological outcomes; it is known, for example, that early presentation and diagnosis of symptomatic cancers (specifically, testicular, head and neck, colorectal, breast, and melanoma) can lead to overall increases in survival rates, and improvements in quality of life (Neal et al., 2015). Whilst we are aware that some barriers to effective healthcare exist for people with intellectual disabilities, there is little research exploring the psychosocial impact of cancer in people with intellectual disabilities (see Chapter 2). Any group of people with intellectual disabilities is, by nature, heterogeneous (as highlighted within Chapter 1), and it is therefore difficult to generalise results from specific studies to the population as a whole. This being said, it is imperative that research continues to highlight areas of concern for people with intellectual disabilities, so as to inform clinical policy and best practice.

In the context of the wider psychosocial oncology literature, few studies have been identified which focus on the first-hand psychosocial experiences of people with intellectual disabilities who have cancer. This highlights the need for further exploratory work to understand the cancer-related experiences of people with intellectual disabilities. The studies included in the systematic review (Chapter 2) suggest that people with intellectual disabilities and cancer face barriers to diagnosis and successful communication, and experience negative social, psychological, and physical consequences of their cancer diagnosis (Collins et al., 2014; Cresswell & Tuffrey-Wijne, 2008; Jones et al., 2007; Kaushal, Smith, & Maddock, 2016; Martean et al., 2013; Tuffrey-Wijne & Davies, 2006; Tuffrey-Wijne, Curfs, & Hollins, 2008; Tuffrey-Wijne et al., 2009; Tuffrey-Wijne, Bernal, & Hollins, 2010; Tufrey-Wijne et al., 2010). The included studies were often observational and/or did not present any analysis about the reported experiences, but included the narratives as standalone pieces. Considering this paucity of research, the current study aims to present a detailed account of the cancer-related experiences of people with intellectual disabilities, and to develop a greater understanding of these experiences that has relevance to both research and practice. This research will take a multiple-stakeholder approach to data collection. Importantly, the focus of data collection will be on the first-hand experiences of people with intellectual disabilities, with supplementary information being sought from other stakeholders where necessary. Interviews will be inclusive of all time-points (e.g., pre-diagnosis, diagnosis, treatment, and survivorship) in order to better understand how cancer is experienced by people with intellectual disabilities throughout the illness trajectory.

Methodology

Statement of Reflexivity

My assumptions, previous experience, and perspectives could have influenced data collection and analysis in this chapter. It is therefore important to outline these from the outset. Findings from the systematic review (Chapter 2) were sparse, with only ten papers included, six of which were drawn from the same ethnographic study of 13 people. Thus, no generalisable themes could be drawn from this research. I was keen, therefore, to include a broad range of questions in the interview schedule so as to establish the experiences of the participants within this research without giving greater weight to themes from the systematic review.

My interest in the subject was born of previous experience, both professional and personal, with people with intellectual disabilities. This was combined with personal experience of a healthcare system that did not cater for the needs of family members with diagnoses of high-functioning autism. As the participants in this population did not have diagnoses of high-functioning autism, I would not hold biases or make assumptions based on my previous experience, and I would instead be able to focus on the experiences of the participants with intellectual disabilities. In terms of research process, I believe strongly that the methodology used should suit the research question. Epistemologically, I consider myself a positivist, allowing for the combination of objective observation and logical interpretation to develop and answer research questions.

Study Design

Both qualitative and quantitative methods may prove to be problematic when undertaking research with people with intellectual disabilities. In quantitative research, it is often difficult to administer questionnaires due to comprehension difficulties (Nind, 2008). Qualitative methods are perhaps more suited to beginning to fill the gaps in the literature, as they offer a more flexible approach (Phellas, Bloch, & Seale, 2012) and are amenable to broader exploration of a relatively under-researched field. In light of the complexity of conducting research with participants who have intellectual disabilities, some researchers opt to conduct interviews solely with proxy participants (Nind, 2008). This method bypasses issues of communication, and capacity to consent, but there is a substantial disadvantage in that previous research suggests that proxy reports can be inaccurate (Turk et al., 2012a). Multiple-stakeholder research can be beneficial, as the person with an intellectual disability is the key informant and additional data are collected from a series of proxies to add depth and clarity to the initial interview. With this in mind, the present research adopts a qualitative methodology, enabling the research to be adapted to the needs of each participant and ensuring full understanding of research motives, procedures, and questions. Additionally, members of the participants' family, and their clinical and social care teams, will be recruited (where appropriate) to provide additional information about the participant's experiences.

Qualitative methods in psychological research have seen a resurgence in popularity over the past few decades, shifting from a primarily quantitative research base (Polkinghorne, 2005). Qualitative methods can be used to both generate and test hypotheses in a specific research area (Curry et al., 2009), and provide a wealth of rich data which might otherwise be overlooked by quantitative methods (Smith, 2008).

Thematic analysis (Braun & Clarke, 2006) was used within the present research as it is a flexible method that can be used within many different theoretical frameworks (Braun & Clarke, 2006). It is a method of identifying and analysing themes within the data. The thematic analysis presented in this chapter is a realist thematic analysis and, as such, reports on the experiences of participants. Grounded theory (Glaser & Strauss, 1965; 1967) was used to inform the present research as it is primarily used within emerging research areas where little literature exists (Goulding, 1999). This method is especially useful for researching the experiences of 'marginalised groups' (Tweed & Charmaz, 2012), such as people with intellectual disabilities and cancer. In line with grounded theory methodology, the themes in this analysis will be derived from the data itself rather than from any pre-conceived expectations of themes that may arise (Braun & Clarke, 2006).

Specific detail pertaining to how grounded theory was used to inform the data collection and analysis methods used within this study will be outlined in the Procedure and Analysis sub-sections below.

Study Development

Consultation with clinicians. Whilst developing the study, the views of intellectual disability professionals were sought about the materials and procedure. These professionals were primarily collaborators from four NHS trusts: the Black Country Partnership Foundation Trust, Northumberland, Tyne & Wear NHS Foundation Trust, Cheshire and Wirral Partnership Trust, and the Betsi Cadwaladr University Health Board. These collaborators also specifically advised on recruitment methods and anticipated recruitment rates within their trusts.

Feedback on the materials pertained to ensuring that the language used in information sheets and consent forms was appropriate for people with intellectual disabilities; one specific suggestion was that these should be read aloud to participants to assist those people who could comprehend verbal information better than written. This feedback was incorporated into the final materials.

Ethical considerations and research governance approval. During study development, particular attention was paid to ethical considerations when interviewing participants with intellectual disabilities. These included protection from undue distress and harm, capacity to consent, and enabling fully-informed consent; all of which will be explored in greater detail in the sections below.

Living with cancer is psychologically distressing (Mehnert et al., 2014; Zabora et al., 2001); thus, it could be expected that discussing such experiences with a researcher might be equally distressing. However, the opportunity to recount experiences in a relatively controlled environment can stimulate a positive and cathartic response for people with intellectual disabilities (Flynn et al., *under review*). Clearly, participants should enter the research with full knowledge of what will be asked of them, enabling them to fully prepare for the experience, and to withdraw should they feel that the experience would be too distressing. The opportunity to withdraw from the research was made clear to all participants, and was offered throughout the interview process.

The study was assessed by the University of Chester Psychology Department Ethics Committee before being submitted to the NHS North Wales (Central & East) Research Ethics Committee (REC) in December 2012 (confirmation of ethical approval is included in Appendix 3). The REC maintained that participants who were unable to give informed consent were to be excluded from the research; this decision should be informed by a capacity assessment that would be completed prior to the commencement of any research. This recommendation was subsequently incorporated into the project. The REC also requested clarification of the disclosure and distress policy should evidence of malpractice, unprofessionalism, or undue distress, become apparent. In response to this request, a clear distress screening and debriefing protocol was devised (Appendix 4) to be completed at the end of each interview. A policy for the disclosure of malpractice, unprofessionalism, or abuse was also developed in accordance with this recommendation (Appendix 5).

Further to these recommendations, the REC suggested that interviews should take place in a clinical setting, rather than in the participants' homes. The final recommendation required further consideration, including consultation with clinical collaborators and two experienced intellectual disability researchers, Professor Richard Hastings and Dr Darren Chadwick, about their own research practice related to this. The consensus was that returning to the hospital for an interview may induce additional distress, and would incur travel expenses for the participants. Furthermore, limiting data collection in this way may constitute a discriminatory practice, as people would not be able to participate should they not wish to attend the hospital. The reply to the REC therefore suggested that participants should determine the interview location. This was deemed acceptable, and a favourable opinion was obtained on 21st December 2012. Subsequent approval was acquired from local research and development departments in all four collaborating trusts.

Research Materials

Three versions of each information sheet (Appendix 6), consent form (Appendix 7), and debrief sheet (Appendix 8) were developed to incorporate the needs of all stakeholders: (1) the person with cancer and an intellectual disability, (2) the primary caregiver, and (3) additional stakeholders (e.g., other family members or health or social care professionals). Materials for people with intellectual disabilities were written to be accessible (e.g., Easy Read, font style, font size, etc.), and were checked by collaborators in intellectual disability services to ensure that they were appropriate. Written materials were to be read aloud to participants to ensure comprehension. A photograph of the researcher was included at the top of the invitation letter (Appendix 9) to develop familiarity ahead of the initial meeting; this technique is commonly used within intellectual disability services.

Semi-structured interview schedules (Appendices 10-12) were prepared using the existing psychosocial oncology literature, providing a guideline structure whilst maintaining participant freedom to talk about issues which were pertinent to them (Lewis, 2004). This would also allow the interview to be amended in line with the specific needs and communication difficulties of each interviewee (Finlay & Lyons, 2001). Prompts were included following each question, to enable the interviewer to lead the conversation in parts, if necessary.

Pictorial aids (examples in Appendix 13) were available within every interview to illustrate difficult or unfamiliar concepts (Goodsell & Scarborough, 2006; Nind, 2008; Tuffrey-Wijne & McEnhill, 2008), and included common oncology terminology (e.g., examination and treatment methods, hospital staff members, and side effects). Written explanations for the cards were based on the CHANGE (2013a; 2013b; 2013c) Cancer Series booklets. As with the information sheets, collaborators in intellectual disability services were asked for their feedback on the picture cards and, from this, amendments were made to include other pictures for medication, and to clarify the link between medication and fatigue.

Participants

Identification and recruitment of participants. People with intellectual disabilities may experience difficulties in comprehending research motives and procedures, as well as experiencing problems with time, hindering accurate recall of when specific events occurred (Finlay & Lyons, 2001; Tuffrey-Wijne & McEnhill, 2008). Harris (2003) suggests that it is possible that people with intellectual disabilities exhibit conditioned responses, and are generally unwilling to make a decision that will be unpopular, such as refusing to take part in research. This can make it difficult to ascertain whether a participant is able to comprehend the research purpose and procedure and is therefore voluntarily participating in the research, or whether they are simply acquiescing; this can present challenges for ascertaining whether a participant has the capacity to consent (Nind, 2008), but protocols can be developed to address this research challenge (Arscott, Dagnan, & Kroese, 1998; Department of Health, 2001; Hulbert-Williams et al., 2012; Mental Capacity Act, 2005).

No restrictions were placed on the type of cancer or intellectual disability diagnosis, other than that participants must have the capacity to consent, following reasonable adjustments. The means of obtaining informed consent is described later in this chapter. Participants were all over 18 years of age and had diagnoses of both intellectual disability and cancer. To be eligible, participants must have undergone some active cancer treatment so as to allow them time to adjust to their diagnosis and treatment.

To assist with participant recruitment, clinical facilitators were provided with recruitment information including inclusion/exclusion criteria (Appendix 14) and an initial consent form for sharing contact details with the researcher (Appendix 15). The team of facilitators comprised a number of learning disability nurses, a clinical psychologist working with people with intellectual disabilities, and a medical oncologist. Facilitators were asked to screen potential participants, discuss the study within routine appointments, and ascertain whether these people consented to their information being shared with the researcher. Facilitators kept records of their approaches to patients, and no approached patients declined consent at this stage.

Two information packs were sent in the post: one in an Easy Read format for the patient and another in standard format for their caregivers. After reading these information sheets, participants were asked to contact the researcher to arrange an initial interview.

Participant recruitment rates. Recruitment lasted for nine months, between June 2013 and February 2014 (recruitment information is presented in Table 3.1). In the initial stages, where recruitment was undertaken by intellectual disability services, recruitment was particularly slow, with only two participants being recruited in the first six months. Facilitators later acknowledged that they had overestimated likely recruitment rates. The recruitment strategy was therefore broadened to include cancer settings as well as intellectual disability services.

The limited identification of people with intellectual disabilities and cancer by these services meant that it was not possible to adhere to theoretical sampling as is required in grounded theory studies (Glaser & Strauss, 1967), thus purposeful sampling was used. Participants were also asked to identify other stakeholders who had played an important role in their experience (see Urquhart, 2013). This process was undertaken after both the initial and individual interviews.

Table 3.1. Recruitment information across all sites

ID	Recruitment site	Identified in	Initial consent	Participate	Additional information
1	Northumberland Tyne & Wear NHS Foundation Trust	June 2013	Yes	No	Progressive illness. Facilitator decided to exclude.
2	Black Country Partnership Foundation Trust	July 2013	Yes	No	Recurrent cancer. Facilitator decided to exclude.
3	Cheshire & Wirral Partnership Trust	July 2013	Yes	Yes	N/A
4	Betsi Cadwaladr University Health Board (BCUHB)	September 2013	Yes	Yes	N/A
5	BCUHB	September 2013	Yes	No	No response to follow-up calls.
6	BCUHB	December 2013	Yes	Yes	N/A
7	BCUHB	January 2014	Yes	Yes	Is happy to be interviewed alone.
8	BCUHB	February 2014	Yes	Yes	N/A
9	BCUHB	February 2014	Yes	Yes	Unaware that she had incurable cancer.

(Shaded rows indicate participants who were recruited to the study)

Participant demographic data. The sample included data from multiple participant groups, and some distinction is thus necessary. Throughout this chapter, the term *patients* will be used for people with intellectual disabilities who have been diagnosed with cancer. Family members or intellectual disability/social-care professionals will be referred to as *caregivers* whereas *healthcare professionals* refers to oncology professionals. Whilst these are not universally applicable definitions, their use is intended to aid brevity.

Nine people, all with a mild intellectual disability (IQ=55-70), were invited to participate, and six consented to be interviewed. Reasons for non-participation of those who did not consent are detailed in Table 3.1. Demographic characteristics are displayed in Table 3.2.

Table 3.2. Participant demographic details

Pseudonym and code	**Brief narrative**	**Cancer diagnosis**	**Treatment(s)**	**Related participant(s) also recruited**
Adam (1A)	53, lives with his aunt and uncle and is currently unemployed due to ill health. Both his mother and father died from cancer.	Plasma cytoma and bowel	Radiotherapy; surgery	Uncle (1B), aunt (1C), ID Nurse (1D)
Ben (2A)	35, lives with his mother and father and is in part-time employment.	Testicular and stomach	Surgery; chemotherapy	Mother (2B), father (2C), medical oncologist (2D)
Charlie (3A)	34, lives alone and is seeking part-time employment.	Testicular and stomach	Surgery; chemotherapy	Social worker (3B)
Daisy (4A)	76, lives in a residential home (10 residents) and attends a local college part-time. Her mother died from cancer.	Breast	Partial mastectomy	None
Elaine (5A)	64, lives alone (supported living) and is retired. Familial experience of cancer (cousin).	Breast	Lumpectomy; partial mastectomy; preventative double mastectomy; chemotherapy	Social worker (5B)
Freya (6A)	61, lives in a community group home (3 residents) and is retired. Her mother died from cancer.	Ovarian and lung	Chemotherapy (palliative)	Paid caregiver (6B), social worker (6C), health liaison nurse (6D), ID nurse (6E)

ID=intellectual disability

Procedure

Initial interview. After reading the information sheet (as described earlier) participants contacted the researcher to arrange an initial face-to-face meeting, within which an assessment of their capacity to consent (Appendix 16) was undertaken. The assessment required the participant to demonstrate comprehension of the study and of their rights as a participant, as well as their ability to retain and paraphrase the information read to them by the researcher (e.g., Arscott, Dagnan, & Kroese, 1998; Hulbert-Williams et al., 2012). Once capacity to consent had been established, fully-informed consent was obtained from the patient and from any caregivers who were also present within the initial interview. Patients, and caregivers if available, completed demographic questionnaires (Appendix 17) before participating in the initial interview. The initial interview (Appendix 18) allowed participants to become familiar with the interviewer and interview process, and established factual information for subsequent interviews. Pictorial communication aids were available for all participants should they have required them. During debrief, patients and caregivers were asked to participate in a subsequent interview (Appendix 19), and to identify any additional caregivers, or healthcare professionals who had played a significant role in their cancer experience, to be interviewed in conjunction with them. If such additional participants were identified, the researcher left an information pack for them, with an information sheet (Appendix 6), an invitation letter and a response form (Appendix 20) by which to indicate their willingness to be contacted about an interview.

Individual interviews. Individual semi-structured interviews were arranged with all consenting participants. Informed by grounded theory methodology, these were guided by each participant with the aim of establishing the patients' experiences of diagnosis, treatment, and survivorship (if appropriate). The purpose of the interview was explained again to participants, and the opportunity to withdraw was offered before each interview. Topics included relationships with healthcare professionals, emotional and practical support, being informed about cancer, and illness-related coping. As the study progressed, interview topic guides were further developed to integrate previous findings, as is the case in grounded theory studies (Glaser & Strauss, 1967). Interviews were audio recorded and transcribed verbatim. As part of a full debrief (Appendix 4) participants were briefly screened for distress. No signs of distress were apparent within any of the interviews but, in case of distress, the procedure was such that a referral would be made to a member of their clinical team for further support.

If not already identified, the interviewer enquired with participants about people mentioned within interviews who appeared to play a central role in their experience and who could extend findings within the emerging themes. The interviewer asked participants to enquire with these people as to whether they would be interested in participating in an interview.

Analysis

Informed by the principles of grounded theory, data collection and analysis were concurrent. This was occasionally not possible, and so interview tapes, notes about the interview, and any emerging themes were reviewed prior to undertaking the next interview (see Charmaz, 2006; Urquhart, 2013). Transcripts were read and reread before analysis began, to increase familiarity with the dataset. Transcripts were coded line-by-line, with relevant concepts and areas for further exploration being highlighted and added to subsequent interviews. The constant comparative method, whereby existing and emerging codes were compared to one another until meaningful themes were formed, was used throughout. Following initial coding, data were collated using the initial codes. These codes were grouped into initial themes, and were developed iteratively as more data were collected. When data collection ceased, emergent themes were checked for coherence within themselves and across the data set. Each theme was substantiated with data from the interviews to ensure that the emergent themes remained grounded in the data (Charmaz, 2006) and that they were prevalent across the data set (Braun & Clarke, 2006). Although not usually a necessary element of thematic analysis, attention was then paid to interrelationships and processual links, as is undertaken in some grounded theory studies (Strauss & Corbin, 1998).

Analysis was conducted by hand, rather than electronically, allowing full emersion and visualisation of the data, emergent codes and themes, as I felt that using a piece of software would sterilise the process. Memos and detailed descriptions of data collection and analysis were undertaken throughout the process to support my reflections. I undertook the analysis, with regular supervisory team meetings to audit and discuss the process and to validate both the process of analysis and emergent themes. This is considered good practice in qualitative research (Elliott, Fischer &

Rennie, 1999) to ensure transparency and validity. Data collection ceased when no new concepts were being found within the interviews that would develop the themes (Glaser & Strauss, 1967). This was agreed with the supervisory team.

Results

Coping with Cancer, or Just Cut Off?

The emergent themes centred around protective or empowering behaviours leading to positive or negative outcomes for patients; either they were truly coping, or they were being cut off from their experience. A more detailed overview is outlined below and is followed by an in-depth textual representation of the emergent themes.

Both caregivers and patients expressed their need to protect themselves and/or each other throughout the cancer experience. Patients were aware of the impact their diagnosis was having on family members, and sought to protect them from any distress by limiting discussions about their illness. Furthermore, caregivers clearly described their wish to protect the patient from their illness, perceiving that limited understanding was protective against distress and while it appeared that the patient was coping well there was no need to engage in discussions that might change this. This cycle of protection (patient protecting caregiver and caregiver protecting patient) was inhibitive of open communication, and led to the diversion of important, but difficult, conversations about emotions and existential concerns. The exclusion of patients from important conversations about their illness and treatment led to patients becoming cut off from their experience. Whilst caregivers expressed that this diversion of conversations was for the benefit of the patient, it also appeared to serve a second function, in that they were able to protect themselves from further distress and discomfort when having these conversations. Further complications arose when the healthcare professionals had limited knowledge about intellectual disabilities, as they relied on caregivers to facilitate communication and, in many cases, this inhibited open communication for the reasons that have been previously described. Healthcare professionals could, however, use good patient-centred skills (e.g., empathy, trust-building, and patience) to ameliorate some of this impact and to empower the patient to be involved in decisions and conversations about their illness and treatment, demonstrating that possessing these skills is more important than possessing concrete knowledge about intellectual disabilities. A full thematic chart is included in the Appendices (Appendix 21).

Protecting behaviours. Following diagnosis, some caregivers perceived that patients' limited understanding about their illness was protective against distress, as they were not as "aware of what it [cancer] does to a person" (Ben's mother; 61-62). *Caregivers expressed their need to protect patients from their illness,* and one of the strategies used was to avoid expressing their own emotions to protect patients

> "You do have your cry, your rant … but not in front of him. No, not in front of him … because I didn't want him to be worried; he's got to cope with enough." (Ben's mother; 754-758)

Caregivers perceived that patients were coping well, and often reported that they had been brave and complied with instructions without question or complaint. This apparent coping was evidenced by caregivers with an absence of expressed emotion, and caregivers wanted to ensure that they did not cause any unnecessary distress. It is, however, also possible that patients' emotional expression was constrained by their own perceptions of how their caregivers would react, thus *wanting to protect caregivers from their illness*, and any undue distress:

> Adam: "Well, more to [my uncle] cos [my aunt] gets a bit … thingy … [my uncle] understands it. Cos he used to go in you know … with us … to the place … "
> Interviewer: "So you're saying, not talking to [your aunt] so much?"
> Adam: "Well, it upsets her." (196-200)

Considering patients' perceptions of their caregivers' reactions, some patients modelled their behavioural and emotional responses to cancer on those of their caregivers:

> "I think he looked to us, actually … to see how we reacted to it … how he should, how he should take it. It's happening to him, obviously, but because he's so easy-going and may not [be] comprehending the serious of it, then he's

> looking to us to say ‘We need … we need to get … ’ He was picking up from us … how he … how he was gonna feel, almost.” (Ben’s father; 152-157)

This led to further inhibition of emotional expression, as caregivers reported avoiding congruent emotional expression in front of the patients; thus, by modelling their reactions on caregivers, patients were limiting their own emotional expression. The *emotional impact of cancer was rarely discussed* or described within the interviews, including their emotional reaction throughout their diagnosis and treatment. Considering the cycle of protection (caregiver protecting patient and patient protecting caregiver), and the inhibition of emotional expression that accompanied this need to protect, this is unsurprising.

In addition to the inhibition of emotional expression, *caregivers would often divert important, but difficult, conversations about the patient’s illness*. This is perhaps reflective of the perception that limited understanding was protective against distress. Whilst some attempts were made by caregivers to fully explain the illness to the patient, some caregivers would give up on difficult conversations after only minimal attempts, or would explicitly inform the patient that they did not wish to have the discussion:

> “Something will remind him about, say something we went on our walk ‘Do you remember that mum? I had that didn’t I?’ I said … ‘Yeah, but we’ve been there, we’ve done that. It’s all done now, ennit.’ … He’ll say ‘Oh yeah. I remember that.’ ‘But we don’t want bring that up, do we? That was a thingy time and erm … we’re fine now aren’t we?’ You know, we’re … put it away … and that’s … but we … so he still, you know … erm, things trigger it and he … not dwell on it … just say, ‘Remember that? I had that … remember those people who I went to … ?’ … So er yeah, so but … you know … that’s and that’s the way we deal with it … ” (Ben’s mother; 485-502)

Implicit strategies were also used to divert difficult conversations. Humour was commonly used as a communicative device and, in some cases, successful use by healthcare professionals put the patient at ease. However, in this data, use of humour by caregivers had a different function. Here, it mostly indicated the discomfort experienced by caregivers in having serious discussions with patients, and was thus used to diffuse tension:

> "Well I think she's quite concerned about the fact that she's becoming so thin. And I always say … 'Ooh, Freya, well look at me with this big fat tummy and a big fat bottom.' You know, 'And there's you like a supermodel!' And she laughs, but she is drastically losing weight." (Freya's Project Worker; 257-261)

The reluctance of caregivers to discuss cancer and death, or to offer full disclosure to patients, seems to be perceived by them as protecting the patient, but it may be hindering their ability to understand and process their experiences. What it does in fact do is *protect the caregiver from engaging in uncomfortable conversations with the patient*; this could be due to them wishing to avoid negative consequences for themselves, or indeed for the patient, or feeling that the patient would not cope with the information because they have an intellectual disability. Caregivers' self-protective behaviours and avoidant strategies, such as these, whilst potentially adaptive in the short-term, inhibited inclusion (which was greatly valued by patients), often leading to distress as patients became more aware of their exclusion from their own cancer experience. As difficult conversations were generally considered taboo, coping, support, and open communication in the long-term were constrained, for Adam, Ben, and Freya in particular.

Healthcare professionals. Further complications arose as *healthcare professionals often had limited knowledge about intellectual disabilities*. The interviewed healthcare professional reported not being educated about intellectual disabilities during medical training. In some cases, even when oncology staff were aware that the patient had an intellectual disability, they were not always supportive of the patient's needs:

> "There's all these drivers saying services need to, you know, break down barriers, they need to, you know, be putting easy read information things together. None of that was offered to us, even when I explained that this client, well Adam, had a learning disability." (Adam's Intellectual Disability Nurse; 264-268)

Considering these communication difficulties, *healthcare professionals would often rely on caregivers to facilitate communication* and patient inclusion, as they were viewed as the experts. However, this may in fact inhibit open communication, as caregivers and healthcare professionals alike were reluctant to offer full disclosure to patients, and would routinely *exclude patients from important conversations about their illness*:

> "When it was something that was a little bit, sort of … near the knuckle and important and they didn't want to distress Freya, erm … one of the members of staff would take her off to the café … and buy her a cream cake and a cup of tea while the others stayed and discussed the situation with the oncologist, then they could do a written report when they got back, and that was the best way. He would talk to her, but not go into any in … in depth which she perhaps wouldn't have been able to grasp or well it probably would have, erm … worried her really, so that's how we used to handle that." (Freya's Project Worker; 212-221)

As can be seen in the above quote, the exclusion of patients from important conversations is often expressed as a form of protection from distressing news about their illness. Throughout their treatment, patients were frequently not fully involved in conversations regarding their own illness and treatment. This was generally accompanied by ineffective communication strategies between healthcare professionals and patients, leading to patients having a limited understanding about their illness and treatments. This led to patients conveying confusion, anxiety, and frustration in their interviews:

> "You don't know … what's got wro … what's gone … what's wrong with you. Cos you can't … you can't … you you … I can't understand what they … the words that they're saying." (Adam; 349-351)

Although the lack of patients' expressed emotion was interpreted by caregivers as evidence of psychological coping, an alternative explanation might be that the cycle of protection led to *patients becoming <u>cut off</u> from their cancer experience*, and knowingly disengaging:

> "Confused a bit, yes. But, you see … I don't know how he does it but he can shut down. He'll like try and blank it out if he can." (Adam's uncle; 75-76)

Healthcare professionals who had little understanding about intellectual disabilities, but who reportedly *possessed good patient-centred skills* (e.g., patience, perspective-taking, friendliness, and compassion) were better placed to meet patients' needs, and support them throughout their experience. It appeared that empathy was a more important factor than was concrete knowledge about intellectual disabilities, and was valued by patients and caregivers. When a positive environment was fostered for the patients, the negative impact of treatment was ameliorated and *patients could be empowered to be involved in decisions and conversations*:

> "And they said that after I had chemo … after I got over that, I had to go back and see [the surgeon] and he said erm … he checked me over first and he said … 'soon you have to make your decision what you're going to do.' He said 'are you going …' he said 'are you going to have operation or not. Are you going to have it or not?' I said yes." (Elaine; 258-263)

Overall, the data suggest that caregivers' attempts to protect patients from negative emotional responses are misplaced. When patients were supported to have a good understanding about their illness and cope with the consequences of that level of understanding, they had no more difficulty coping than would be reasonable for anyone diagnosed with cancer:

> "No. I mean … it was major, major, surgery for Elaine and I really didn't know how she would cope with it. But she absolutely coped with it … fantastically, and in as much as I think if I ever had to go through it with anybody else, I'm sure she … if I asked her, she would … she would be quite a good source of erm … comfort or … erm, information for somebody else who'd been in a similar situation." (Elaine's Intellectual Disability Nurse; 253-258)

Patients, like Elaine, who were empowered by those supporting them to be involved in appointments, were better able to understand and participate meaningfully in their diagnosis and treatment, express their emotions, and subsequently to cope with psychological distress. In this way, it can be understood that *patients were being supported, and were coping with their cancer diagnosis,* rather than being cut off from it.

Discussion

This study aimed to present a detailed account of the cancer-related experiences of people with intellectual disabilities, and to develop an understanding that has relevance to both research and practice.

Healthcare professionals often had a limited understanding about intellectual disabilities and would therefore rely on caregivers to support communication. Caregivers, and patients alike, attempted to protect themselves and/or each other from cancer-related distress and, for caregivers, self-protection was often justified as a means to protect the patient from further distress. These protective and self-protective behaviours inhibited open communication with the patient, and eventually led to patients becoming cut off from their experience. Patients could be supported to cope with their illness, and to be involved in conversations and decisions about their cancer and treatment. This was supported by healthcare professionals who possessed good patient-centred skills, which were thought to be more important than concrete knowledge about intellectual disabilities.

Caregiver participants reported that they felt uncomfortable and ill-prepared to support the patient, often reporting that they were protecting the patient from some of the negative effects of cancer, by limiting truth-telling and by using humour to deflect uncomfortable conversations (c.f., Rodriquez et al., 2007). It is not unusual for caregivers and healthcare professionals to limit the discussion of sensitive topics with people with intellectual disabilities, and this practice is known to inhibit their understanding (Tuffrey-Wijne et al., 2006), and to negatively impact on their well-being (Tuffrey-Wijne, Bernal, & Hollins, 2010). Interestingly, within this data, it appeared that these strategies served to protect caregivers from some of the negative effects of cancer and, in doing so, left patients with a limited knowledge about their illness. It can, therefore, be hypothesised that many of the behaviours perceived by caregivers to be protective were predominantly self-serving and, whilst they did deflect distress in the short-term, they did not benefit patients in the long-term. Patients who were excluded in this way became cut off from their experience.

Evidence from within this study, and from wider research, demonstrates that the provision of clear and unambiguous information and communication can help people with cancer and intellectual disabilities to adjust, and is greatly valued by this population (Tuffrey-Wijne et al., 2006; Tuffrey-Wijne, Bernal, & Hollins, 2010). This sentiment extends to being included in healthcare discussions and decision making (Tuffrey-Wijne et al., 2007), and can support cancer patients with intellectual disabilities to cope with their illness. Considering the importance placed on involvement, the presented data raise concerns that people with intellectual disabilities who have the capacity to understand their prognosis and their own mortality are being excluded from the concept of having a "good death" (e.g., being involved in treatment decisions, dying in a preferred way and place, and having good emotional well-being at the time of death [Meier et al., 2016]). This level of exclusion of people with intellectual disabilities from a good death can be seen as a protection from upsetting news. However, the limited evidence in this area tentatively concludes that exclusion from discussion about their prognosis and existential concerns is upsetting in itself (Tuffrey-Wijne et al., 2009). The findings in this thesis support the wider literature, as, despite some caregivers considering the patient's intellectual disability to be inhibitive of understanding and, in turn, protective of further distress, most patients were willing to have conversations about their experiences, but were constrained by the reluctance of their caregivers.

Patients' emotions were rarely discussed in any detail by either the patient themselves or their caregivers, both during the interviews and throughout the patients' cancer diagnosis and treatment. When they were discussed, it appeared that the patient had coped remarkably well. An alternative explanation from within these data is that patients were disengaged from their experience due to limited understanding, a need to protect caregivers, or simply by modelling their own emotional expression on caregivers who were reluctant to express negative emotions with patients. This type of behavioural and emotional modelling might be inhibitive of congruent emotional expression, and further research should seek to address this. Whilst protecting people with intellectual disabilities from negative emotional events was often seen as the best course of action by caregivers, engaging in open and honest dialogue about cancer is often wanted by people with intellectual disabilities (Tuffrey-Wijne et al., 2006; Tuffrey-Wijne et al., 2012). This sentiment was expanded within the presented study, as appropriate support (including open and honest communication) led to better outcomes being experienced by patients (e.g., empowerment, involvement, adjustment, etc.).

It was also identified that the cycle of protection could inhibit patients' emotional expression and the support offered by caregivers, as patients' emotions could be overlooked by caregivers (Arthur, 2003). This might reflect caregivers' reluctance to engage in potentially difficult conversations; by not asking about emotions, the caregivers are not exposing themselves to a potentially difficult situation in which they don't know how to support or ameliorate problematic patient reactions. This can be understood as a method of self-protection for the caregiver, but is also justifiable, in their perception, as a method of protecting the patient's well-being.

To ensure wider patient inclusion, reasonable adjustments (including accessible information, understandable communication, and developing a care plan with the involvement and consent of the person with an intellectual disability) should be made, and these adjustments should be tailored to meet each person's needs (Department of Health, 2001; 2007). This patient-centred approach proved to be important to patients and their caregivers within this study, and led to patients being more meaningfully involved in discussions and decisions about their illness and treatment. This suggests that empowerment is important for patient engagement, and that this can be influenced by the actions of healthcare professionals and caregivers. When healthy people with intellectual disabilities are engaged in their own care and enabled to participate meaningfully in their own lives, their quality of life can be greatly improved (Lachapelle et al., 2005). The presented analysis demonstrates that this is also true of people with intellectual disabilities and cancer.

Study Evaluation

This study aimed to develop a detailed understanding about the cancer experiences of people with intellectual disabilities, and the emergent themes have been presented in this thesis chapter. This was generated based on the analysis and conceptualisation of the data, which has resulted in a novel, interesting, and workable thematic analysis that can be altered in line with future developments (Glaser & Strauss, 1967). Furthermore, the presentation of this analysis is easily accessible for healthcare professionals to apply to their own work with people with intellectual disabilities and cancer to promote positive adjustment and coping strategies within this population.

The qualitative study presented in this chapter was appraised using the same framework used to assess the quality of the studies in Chapter 2 (Spencer et al., 2003) and some of the key quality indicators of this appraisal framework will be discussed in the following paragraphs. Informed by grounded theory methodology, theoretical sampling (Glaser & Strauss, 1967) was the desired sampling strategy, but it was not possible to adhere to this, and so purposeful sampling was used. The implemented strategy of recruiting related participants (Urquhart, 2013) led to the development of a key finding, as it was possible to fully explore the functions of the protective behaviours of caregivers. It is possible that the emergent themes would have been different if the pool of participants were different, particularly if additional patients were recruited to the study. Related to this, had theoretical sampling been followed, patients who were not protected could have been theoretically sampled to extend the theme of coping, as the cut off element is better-saturated. With appropriate resources, the recruitment method could have been extended to be UK-wide, thus increasing the potential pool of participants and enabling theoretical sampling to be undertaken.

Importantly, the process of coding, and of the inductive construction of themes, was informed by grounded theory throughout the research, and the discovery of basic social processes in the data formed a key part of the emergent themes. Saturation was reached for the themes, and this coincided with a slowing recruitment rate. I decided, in consultation with my supervisors, that data collection should cease at this point.

On some occasions, interviews were limited by gatekeeping behaviours by caregivers (e.g., facilitators deciding what information to give to potential participants about the research, if any at all, and/or caregivers limiting discussion of certain topics within interviews). This specifically pertained to Freya, who had incurable cancer but was not aware of this. Gatekeeping behaviours were also present during recruitment, as two facilitators decided that they would not continue to support the recruitment of two participants who had recently received news that their cancer was progressive. These were the only two reported incidents of overt gatekeeping behaviour by facilitators, but this may have occurred on more occasions that were not reported. Both examples of gatekeeping behaviours, as described above, limit the extent to which we can explore the experiences of people with intellectual disabilities and cancer, particularly those with progressive cancer diagnoses, or those requiring purely palliative care. Only patients with a mild intellectual disability were interviewed (this was due to ethical restrictions that imposed the criterion that patients needed the capacity to consent to participate); however, it is reasonable to assume that similar (or worse) difficulties will be present and persistent for people with more severe intellectual disabilities. Nonetheless, any and all efforts to extend these findings within a wider demographic of people with intellectual disabilities would be beneficial.

In the previous chapter, the use of a rigorous research methodology was identified as a priority for future research and, in undertaking a rigorous thematic analysis, which was informed by grounded theory methodology, with some exceptions, this study has addressed this priority. This study has also addressed some of the limitations of existing literature (as presented in the previous chapter), in that people with intellectual disabilities were actively involved in data collection, rather than being the subjects of observational research methods. However, the sample of people with intellectual disabilities and cancer in this study was small (n=6) and geographically limited as all but one participants were recruited through facilitators working in the same health board. These limitations present issues of generalisability to the wider population of people with intellectual disabilities and cancer. These findings should now be tested with a broader sample of people with intellectual disabilities.

Intellectual disability professionals were consulted during the development of the project and provided valuable feedback on the study materials. Patient and public involvement (PPI) of this type is used by the National Institute of Health and Care Excellence (NICE, 2017) and the National Institute for Health Research (NIHR, 2017) to develop research in collaboration with patients, carers, the public, and professionals. It would have been beneficial to also have PPI from people with intellectual disabilities and cancer whilst developing the study, but involving this group in this way might have further limited the already small sample of potential participants.

Recommendations for Future Research

Protective behaviours by caregivers were ultimately detrimental to patients' involvement in their cancer experiences, and the function of these behaviours is arguably two-fold: protection and self-protection. Further research should test this hypothesis with both caregivers and patients, taking an initially open approach to gathering more data about this phenomenon, and could eventually lead to the testing of the effects of interpersonal interventions that enable caregivers to be more comfortable engaging in open communication with people with intellectual disabilities about their cancer and existential concerns. The findings presented within this chapter highlight that protection can be inhibitive of empowerment, leading to less-positive psychological and physical outcomes. It would also be beneficial to understand those factors that influence such protective behaviours in patients, caregivers, and healthcare professionals alike. Work can then be undertaken to counteract these so as to improve patient outcomes.

Patient empowerment was an indicator of good adjustment to cancer within these data. It is therefore of great importance that people with intellectual disabilities are being meaningfully involved in discussions and decisions about their diagnosis and treatment. Research should also seek to further understand the experiences of oncology professionals when caring for patients with intellectual disabilities, as only one such healthcare professional was recruited to this study. Such research could be qualitative, or could take the form of a quantitative survey of experience, using either previous or hypothetical experiences depending on whether or not the participant group has had previous experience of supporting a patient with an intellectual disability. Results from the present study indicate that patients and caregivers valued having the support of healthcare professionals who were person-centred, empathetic, and understanding. Potential interventions could focus on increasing healthcare professionals' knowledge, confidence, and communication skills in working with people with intellectual disabilities, particularly concerning difficult healthcare conversations and decisions.

Implications for Practice, Care, and Support Provision

Breaking down the barrier of caregivers' reluctance to engage in conversations about a patient's experience is essential to ensuring meaningful engagement in the experience, and is most likely to be achieved through intervening with the caregivers themselves, to enable more open and useful dialogue between the patient and their caregivers. Actively increasing an individual's knowledge, awareness, and involvement does not only improve the individual's understanding, but may also improve their physical and psychological outcomes, as was the case in this study. Such benefits could also stretch into cancer survivorship, as patients with lower awareness and involvement were less likely to remain vigilant in regard to potential future symptoms. Engagement in post-treatment care aims are related to survivorship outcomes in the general population (Jefford et al., 2013), and it is fair to assume that such engagement would serve the same purpose for people with intellectual disabilities. It is clear from these findings that cancer survivors with intellectual disabilities should be encouraged to remain engaged with cancer services, so as to ensure that they are receiving appropriate information and support.

As is the case in the general population (Kirk, Kirk, & Kristjanson, 2004; Leydon et al., 2000), some people with intellectual disabilities may not wish to know the full extent of their illness, and this should be respected. However, it is the responsibility of the oncology professionals to ensure that patients are supported to understand their illness, its ramifications, and the treatment options available. This extends to conversations about palliative care and death, as people with intellectual disabilities should not be excluded from having a ‘good death’ (see Meier et al., 2016 for a definition of a good death).

This study highlighted the importance of good patient-centred skills (e.g., empathy, patience, perspective-taking, friendliness, and compassion) in supporting people with intellectual disabilities and cancer, indeed, these skills may be even more important than concrete knowledge about intellectual disabilities. Efforts should be made to improve these patient-centred skills, either in parallel to intellectual disabilities knowledge or separately, so as to advance oncology professionals’ knowledge about intellectual disabilities. The heterogeneous nature of intellectual disabilities presents obstacles to full understanding by oncology professionals of the needs of this population, whereas improving patient-centeredness when caring for this population may be the most effective way forward, as these skills would be transferable between patients with different needs.

Conclusions

Whilst often adaptive in the short-term, caregivers’ protective behaviours led to patients becoming disengaged from their cancer experience. Many of these protective behaviours also served a second function, in that caregivers were also protecting themselves from the discomfort or distress of having difficult conversations with patients. Healthcare professionals could compound this, as they were often ill-prepared to work with patients who had intellectual disabilities. Healthcare professionals can use patient-centred skills to ameliorate some of these adverse aspects for people with intellectual disabilities and can therefore empower them to be meaningfully involved in their cancer experiences. This represents the basis of the presented thematic analysis, as participants can be supported to cope with their cancer diagnosis instead of being cut off from it. Future research should seek to establish the extent to which patient-centred skills can be used to support people with intellectual disabilities within consultations. In practice, healthcare professionals and caregivers must work together to empower people with intellectual disabilities to be meaningfully involved in their experience. Before this can be done, we must understand the perceptions of oncology professionals regarding the support of cancer patients who have intellectual disabilities.

Rationale for Further Investigation

It was clear from interviews with patients and caregivers that interactions with healthcare professionals were, in many cases, prohibitive, but could be encouraging and positive when healthcare professionals possessed patient-centred skills and worked to the needs of the patient. For most patients, the healthcare professionals who provided the most support in this way were oncology nurses. Generally, oncology nurses play a significant role in the treatment and care of cancer patients (Rieger & Yarbro, 2003) and have been found to feel significant stress when providing care to cancer patients (Gomez-Urquiza et al., 2016). This has been shown to lead to burnout (Barrett & Yates, 2002) and compassion fatigue (Yu, Jiang, & Shen, 2016) in oncology nurses. Little is known about the perceptions of oncology nurses when supporting patients who have intellectual disabilities, and whether they perceive this care to be significantly more demanding than caring for patients without intellectual disabilities. With appropriate support, some of which could be facilitated by oncology nurses, people with intellectual disabilities are better able to understand, and be involved in, their cancer experience, and increased meaningful involvement in their experience can lead to adaptive coping. Considering the positive impact that oncology nurses can have on an individual's cancer experience, it is important that their perceptions of providing cancer care to people with intellectual disabilities are more widely understood. The study presented in the next chapter of this thesis aims to better understand the care perceptions of UK oncology nurses, including their perceived stress, in caring for patients with cancer and intellectual disabilities.

Chapter 4. Caring for Cancer Patients with Intellectual Disabilities: Attitudes and Care Perceptions of UK Oncology Nurses

Work presented in this chapter has been published, in part, as:
Flynn, S., Hulbert-Williams, L., Bramwell, R., Stevens-Gill, D., and Hulbert-Williams, N. (2015). Caring for cancer patients with an intellectual disability: Attitudes and care perceptions of UK oncology nurses. *European Journal of Oncology Nursing, 19(5), 568-574. doi:10.1016/j.ejon.2015.03.002*

Chapter Overview

Work in the first two empirical chapters of this thesis clearly suggests the importance of cancer nurses being supportive by helping people with intellectual disabilities and cancer to adjust to and cope with their diagnosis. Caring for people with cancer or intellectual disabilities in isolation can be stressful: little is known about the combined impact of caring for cancer patients with intellectual disabilities, though this is expected to be especially challenging. This chapter describes a survey study which aimed to understand oncology nurses' perceptions of caring for patients with and without intellectual disabilities (thesis aim 3).

Eighty-three nurses, working in oncology or a related field (i.e., palliative care), were recruited. Their perceptions of caring for patients with and without intellectual disabilities were measured, alongside potentially confounding information about previous experience of intellectual disabilities, and perceived stress. Participants felt less comfortable communicating with patients with intellectual disabilities about their illness ($F(1,82)=59.52$, $p<0.001$), more reliant on a caregiver for communication ($F(1,82)=26.29$, $p<0.001$), and less confident that the patient's needs would be identified ($F(1,82)=42.03$, $p<0.001$) and met ($F(1,81)=62.90$, $p<0.001$). Participants also believed that caring for this patient group would induce more stress compared with patients without intellectual disabilities ($F(1,81)=31.592$, $p<0.001$). Previous experience of working with intellectual disabilities patient groups appears to mitigate some perceptions about providing care to this population.

Caring for cancer patients with intellectual disabilities may intensify what is already a difficult professional role. Through training and knowledge exchange, oncology nurses' confidence in communication, providing appropriate care, and positivity towards providing care to this patient group, may be improved.

Background

Oncology nurses are a frequent source of support for cancer patients (Reiger & Yarbro, 2003), but providing this support can be emotionally demanding (Emold et al., 2011), with oncology nurses being at heightened risk of emotional exhaustion (37%), job dissatisfaction (51% workload related; 47.5% pay related), and burnout ("feeling used up by the end of the workday": 35%) (Barrett & Yates, 2002). A meta-analytic review (Cañadas-De la Fuente et al., 2015) of 17 international studies (including Barrett & Yates, 2002) of burnout in oncology nurses corroborated these data. Strangely, this review did not include the Emold et al. study, thus casting some doubt on the inclusivity of this review. Toh et al. (2012) report that stress and burnout are heightened by perceived staff shortages, and this is a current crisis within the NHS (Glasper, 2016).

Caring for people with intellectual disabilities can also be particularly demanding for healthcare professionals (Mutkins et al., 2011; Skirrow & Hatton, 2007), with high potential for stress and burnout (Lin & Lin, 2013). Stress and burnout (depersonalisation and emotional exhaustion; Maslach, Jackson, & Lieter, 1996) for intellectual disability staff are often associated with incidents of challenging behaviour (Hensel et al., 2012; Mills & Rose, 2011). However, these kinds of study often rely on subjective measurement methods (e.g., self-rating by staff of the frequency of residents' challenging behaviour) across multiple services, and this can be unreliable. When these critiques are addressed, there is actually little evidence to suggest a relationship between objective exposure to challenging behaviour and well-being (Flynn et al., *in press*). Challenging behaviours often serve a function for people with intellectual disabilities, and can become more prevalent when verbal communication is restricted (e.g., if the person is non-verbal). Such behaviours can occur when a person is in pain, or has unrecognised physical health needs (NICE, 2015); thus it is likely that such behaviours would be presented in a clinical environment, presenting challenges for both the intellectual disability and healthcare staff.

In Chapter 3, barriers to effective communication led to feelings of frustration and confusion for people with intellectual disabilities, and oncology nurses were often relied upon to support communication outside of appointments. Communication difficulties are a barrier to providing appropriate healthcare for people with intellectual disabilities (Ali et al., 2013; Lennox et al., 1997). Whilst presenting valuable insights, the experiences of people with more severe intellectual disabilities is less evident in the literature, thus presenting difficulties in applying these findings to that specific population. Successful communication about cancer care between patients and healthcare professionals is vital; shared decision making, compassionate doctors, and satisfactory answering of patients' questions facilitate patient adjustment and well-being (indicated by less anxiety and depression, and better quality of life) (Arora, 2003). Similarly, good quality doctor-patient communication can increase adherence to medical treatment (Zolnierek & DiMatteo, 2009).

Time constraints (Hemsley et al., 2012), and presumptions that the information is too complex (Gibbs et al., 2008), can inhibit successful communication when caring for a patient with complex communication needs. In these instances, healthcare professionals (including oncology nurses) often prefer to talk to a family member or paid caregiver, rather than directly with the person with an intellectual disability (Hemsley et al., 2012; Gibbs et al., 2008; Ryan et al., 2011). These insights, however, are based on research in which sample sizes are generally small, or where healthcare professionals working within a small number of services have been interviewed; these results may, therefore, be due to the culture within individual services, and future research should sample more widely to substantiate these findings across multiple settings. Informal caregivers were often seen by healthcare professionals as facilitators to communication in the qualitative study (Chapter 3), and this could inhibit full participation of the person with an intellectual disability in consultations and care. Additionally, information provided by caregivers is not always congruent with information otherwise provided by the patient, as caregivers can report more symptoms than the person with an intellectual disability (Turk et al., 2012a). This reporting disparity could lead to inaccurate information for the healthcare professional and miscommunication between the patient and healthcare professional. Direct communication from healthcare professionals is known to decrease apprehension in people with intellectual disabilities and so should be encouraged (Gibbs et al., 2008).

Over time, more people with intellectual disabilities are being diagnosed with cancer, due in part to increased life expectancy (Hanna et al., 2011). Consequently, oncology nurses, among other healthcare professionals, are supporting more patients with additional needs and communication challenges. Given the important role that nurses have, and will continue to have, in cancer care, it is highly likely that this core group of healthcare professionals will also continue to have an important role in the cancer experiences of people with intellectual disabilities. Considering that caregiver stress is prevalent for cancer and intellectual disability professionals, it stands to reason that additional difficulties will arise when providing care for a cancer patient with an intellectual disability. Before this can be concluded, research is needed to understand the experiences of healthcare professionals when providing care to people with intellectual disabilities, and an important starting point for this should be research exploring the perceptions of oncology nurses in providing cancer care for this population.

This study aimed to undertake a survey of UK oncology nurses to compare perceptions of providing cancer care to patients with and without intellectual disabilities. The primary hypothesis was that participants would feel more confident and able to provide care to patients without intellectual disabilities. Secondary research questions were also explored: (a) whether providing care for patients with intellectual disabilities would be more stressful for participants than for patients without intellectual disabilities, and (b) whether there were differences in perceptions of their ability to communicate with patients with and without intellectual disabilities. Finally, this study aimed to undertake exploratory analysis to explore whether previous intellectual disability experience, or current levels of perceived stress, affected these differences.

Methodology

Initially a larger study was developed with a fellow postgraduate student (Ms Deborah Stevens-Gill) with the intention of gathering a large dataset from the same participant sample, which could then be separated between two theses with no duplication of data. A collaborative approach was adopted, and the study included additional demographic questions and stress-related measures that were relevant to the aims of Ms Stevens-Gill's work. This chapter focuses on reporting only those aspects of the study relevant to the aims of this thesis, and which resulted from the individual efforts of the researcher.

Study Design

To date, the hypothesis that there would be a difference in the perceptions of caring for cancer patients with and without intellectual disabilities has not been experimentally tested. As this was, therefore, the first study to test this hypothesis, a broad recruitment strategy was needed to capture data from different settings to ensure that setting-specific variables were not responsible for any observed differences.

Online research is becoming increasingly popular, with fewer financial and time-related costs for the researcher (Wright, 2005), and increased anonymity for the participants (Spears, Lea, & Postmes, 2007). Increased anonymity can lead to more truthful and congruent responses from participants (Bargh et al., 2002); this is especially beneficial in study designs where stigma or embarrassment may be problematic, thereby allowing for more reliable exploration of sensitive issues in healthcare research.

Vignettes are a description of a hypothetical situation which can be presented to participants (Braun & Clarke, 2013). Vignette research is a common and effective approach which allows researchers to gauge, with relative accuracy, the perceptions and beliefs of a participant group regarding a specific situation (Braun & Clarke, 2013). Vignette studies are of particular use within potentially sensitive research: being less direct than traditional questionnaires, the participant is encouraged to construct a realistic reaction to a hypothetical situation (Braun & Clarke, 2013). This method has applications to healthcare provision and nursing, for example in a study by Wandner et al. (2013) whereby biases (gender, age, and race) in pain-management decisions by healthcare professionals were investigated through the use of vignettes of virtual human patients. Vignettes are ideal to meet the aims of this study for these reasons, and the development and content of the vignettes used is described below.

Participants

Participants were nurses working in oncology or a related field (i.e., palliative care or haematology), and were members of the UK Oncology Nursing Society (UKONS). Using G*Power (Faul, Erdfelder, Lang, & Buchner, 2007) to determine the sample size, and based on a medium effect size (d=0.5; Cohen, 1988), it was concluded that 134 participants would be needed. Discussions with UKONS indicated that their membership stood at 2,309; therefore, to reach the required number of participants, it was necessary to achieve a 5.8% response rate.

Materials

Vignettes. The vignettes and accompanying care-perception questions used in this study were devised by the researcher, under the supervision of the supervisory team, to meet the aims of this research. Vignettes can be used to test theory (e.g., Landmann & Hess, 2017; Matosic et al., 2015), and to examine judgements on specific scenarios (Evans et al., 2015). The theory under examination in this study is that there is a difference in attitudes amongst oncology professionals about cancer patients with and without intellectual disabilities. This concept has been suggested in the literature in Chapter 2 (Sullivan et al., 2004; Tuffrey-Wijne et al., 2009; Tuffrey-Wijne et al., 2010; Turk et al., 2012b), and was evident in the early stages of the qualitative study presented in Chapter 3. Patients in the qualitative study (Chapter 3) were often not appropriately supported by healthcare professionals, who relied on caregivers to facilitate communication; this led to patients having difficulty understanding information, becoming confused and/or anxious, and eventually becoming cut off from their experience and emotions. All of these negative effects could be ameliorated to some extent by the healthcare professional being supported and trained to be able to take a patient-centred approach to their care.

Practical guidance about vignette development (Bradbury-Jones, Taylor, & Herber, 2014; Braun & Clarke, 2013) was followed. Bradbury-Jones et al. outline four key considerations for vignette development: (1) data sources; (2) vignette format; (3) capturing reality; and (4) vignette/participant congruence. These four considerations were taken into account in the development of this study. Before vignettes can be constructed, appropriate data sources must be chosen, and these can be previous research, literature reviews, and life experiences (Ulrich & Ratcliffe, 2008). The theoretical framework described above was central to the development of the vignettes and the related questions in the current study. The use of one’s own results from an earlier research phase is commonplace when developing vignettes for a new study (e.g., Bailey, 2008; Barter & Renold, 2000; Taylor, Bradbury-Jones, Kroll, & Duncan, 2011), and can improve the authenticity of the vignettes (Bradbury-Jones et al., 2014).

The vignettes created for this study were fictional composites (Spalding & Phillips, 2007) based on a range of participants’ experiences within Chapter 3, and findings from the wider literature (Chapter 2), thereby attending to consideration 3 by including authentic data from people with intellectual disabilities and cancer. Composite vignettes can sometimes be less authentic than portrait vignettes, defined as those which contain direct quotes from previous participants (Bradbury-Jones et al., 2014). However, if the process is performed with sensitivity to the original data and themes within, authenticity can be retained within composites (Bradbury-Jones et al., 2014). Regarding the format (consideration 2), vignettes were short descriptions of patients’ cancer experiences; this is common in vignette research (Bradbury-Jones et al., 2014), and served to limit the length of participation time for oncology nurses, which could influence participant propensity to drop out prior to completion. Further to vignette length, vignettes were also developed to be clear, with sufficient detail to enable participants to answer the questions following each vignette; this was intended to reduce the cognitive demand on participants, who were likely to be extremely busy (consideration 4).

Eight vignettes were used in total: these comprised two different versions of four "base" vignettes, a method advocated by Braun and Clarke (2013). Each vignette described a cancer patient, but additional information (e.g., "Jane is 53 and has breast cancer. She also has a moderate learning disability.") was included in one version of each to indicate that the patient had an intellectual disability (Appendix 22). Each participant was shown a partially random selection of four out of these eight vignettes, two describing a patient with an intellectual disability and two without an intellectual disability. For example, if the version of vignettes A and D used described a patient with an intellectual disability, the version of vignettes B and C used would describe a patient without intellectual disability.

Bradbury-Jones et al. (2014) note three further considerations for administering vignettes: (5) data collection; (6) presenting the vignette; and, (7) response perspectives. Vignettes can be used in individual and group research settings; both approaches hold advantages and disadvantages. Using vignettes within groups can provide a useful comparison of two groups' interpretation of an incident (Renold, 2002). Within the current study, data was collected from questionnaires, rather than focus groups, as this provided more quantifiable data and allowed for a broader geographical recruitment strategy than would be possible had focus groups been held (consideration 5). Questions following vignettes can be presented in a range of ways, including open-ended questions, unfinished sentences, and closed questions (Bradbury-Jones et al., 2014). Each of these methods has benefits for various purposes, and open questions or unfinished sentences can promote broader thought and reasoning about a particular topic (Barter & Reynold, 2000; Hughes & Huby, 2004). Questions in this study were mainly closed to enable the focussed and efficient collection of data on a range of variables (Gliner et al., 1999), although this could have prohibited participants from engaging more deeply with the subject matter (consideration 6). Questions were chosen to reflect the early themes from the data in Chapter 3, including knowledge, experience and training about intellectual disabilities, and perceptions about communicating with cancer patients with intellectual disabilities. This range of variables enabled a broad comparison of the perceptions of caring for cancer patients with and without intellectual disabilities. Responses to vignettes can take a number of perspectives; those of the vignette characters, of people or society in general, or of the participant (Bradbury-Jones et al., 2014). When the subject matter is particularly sensitive, responding as though from another person’s viewpoint can liberate participants from the perceived social desirability of certain responses, and lead to more honest responses (Hughes & Huby, 2004; Paddam et al., 2010). Participants in this study were asked to respond to the vignettes from their own viewpoint, as this study was interested in the perspective of oncology nurses rather than their perception of a third person’s perspective (consideration 7).

Care Perceptions Questionnaire. This measure was devised by the researcher, under the supervision of the supervisory team, to capture any differences in participants’ perceptions of providing care to patients with and without intellectual disabilities based on the patients described in the vignettes. The 12 questions that participants were asked to respond to after each vignette measured care perceptions and attitudes about caring for the patient in the vignette (detailed in Table 4.2). Responses were measured on a 5-point Likert scale, ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). This scale had high internal consistency in this study (α=.9).

Participants were then asked to consider more broadly how they feel about providing care to the patients described in the vignettes, by responding to two open-ended questions: “If you were unsure about how to provide the highest quality care for this patient, would you know where to go to for advice? Where would that be?” and “Are there any additional training needs you believe would be beneficial to help provide care to this person?”

Perceived Stress Scale. Developed by Cohen et al. (1983), the Perceived Stress Scale (PSS-10) (Appendix 23) is a 10-item self-report measure. Items such as “In the last month, how often have you felt nervous and ‘stressed’?” are responded to using a 5-point Likert scale (0: *never* to 4: *very often*). A total score is calculated by first reverse coding four positively framed items (items 4, 5, 7 and 8) and then totalling scores across all items; a high score indicates a high level of perceived stress. Within this study, the PSS-10 had high internal consistency (α=.84).

Procedure

Ethical approval was received from the Department of Psychology Ethics Committee at the University of Chester (confirmation of ethical approval is included in Appendix 24); the UKONS Board also approved the study for circulation to members. Following these approvals, an administrator at UKONS sent a standard recruitment email that included researcher contact details and a web-link to the online survey (Appendix 25) and an information sheet (Appendix 26) to all UKONS members. Data were collected and stored on the secure host-site (LimeSurvey); they were then transferred into SPSS (Statistical Package for the Social Sciences) version 21 for analysis.

Upon accessing the study webpage, participants read the information sheet and indicated consent by clicking through to the next page (Appendix 27); they subsequently completed a demographic questionnaire (Appendix 28). The questionnaires were then displayed in turn. Once the questionnaires were completed, participants were shown a debrief page (Appendix 29) which included signposts to further support if needed.

Randomisation of vignettes. It was imperative that a relatively even number of participants saw each vignette, and that this allocation was random; it was of equal importance that if a participant had viewed the intellectual disability version of a vignette, they did not see the non-intellectual-disability version of the same vignette. To meet this research need, a piece of JavaScript was written by a supervisor (Dr Lee Hulbert-Williams) which ensured that participants viewed four unique vignettes, but that only two intellectual disability (and two non-intellectual-disability) vignettes were viewed by each participant. As the allocation of vignettes was entirely random, both versions of each vignette were given a unique code, which participants were required to report after completion of the questions; this enabled a safety check for later analysis. This practice was successful, with even numbers of each vignette (and both versions) being reported by participants.

Counterbalancing. Questionnaires and vignette presentation were manually counterbalanced midway through the recruitment period; this coincided with a study reminder being issued, as it was noted that there was a relatively high dropout rate following the initial questionnaires. Thus, during month one participants completed the demographic questionnaire first, followed by the PSS-10, and then the vignettes and care perception questionnaire. During month two the vignettes and care perception questionnaire were presented before the PSS-10 whilst the demographic questions remained at the beginning of the questionnaire.

The initial email was sent to all 2,309 current members of UKONS on 26 February 2014, with a reminder sent in the *Breaking News Bulletin* on 25 March 2014. During the two-month data collection period, 138 people responded (6% response rate), with 83 participants fully completing the questionnaires (60% completion rate).

Analysis

Two mean scores were calculated for each item on the care perceptions questionnaire: one for the intellectual disability vignettes, and another for the non-intellectual-disability vignettes. A series of two-way within-participant Analysis of Variance (ANOVA) tests were then used to establish the main effects of vignette type (intellectual disability or non-intellectual-disability) on participants' care perceptions, thus testing the primary study hypothesis. Exploratory analysis was undertaken to identify any interaction effects with demographic or job-related variables, using 2x2 mixed measures ANOVAs. All analysis was conducted using SPSS version 21.

Responses to the two open-ended questions were analysed using Content Analysis (Cole, 1988). This method was deemed most appropriate as it was necessary to draw quantitative patterns from the qualitative data. The data were subsequently descriptively analysed to establish participants' additional training needs and advice-seeking suggestions.

Results

Participant Demographic Data

The majority of the 83 participants reported that they had some experience of working with people with intellectual disabilities (n=61). Participants had a mean Perceived Stress Scale score of 18.54; the maximum score is 40. Remaining demographic details are displayed in Table 4.1.

Table 4.1. Participant demographic details

	N (%)
Gender	
Female	81 (97.6)
Male	2 (2.4)
Age	
18-24	1 (1.2)
25-34	9 (10.8)
35-44	27 (32.5)
45-54	39 (47)
55-64	7 (8.4)
Highest Qualification	
Diploma	9 (10.8)
BSc/BA Degree	40 (48.2)
Graduate Diploma	9 (10.8)
MSc/MA Degree	20 (24.1)
PhD	3 (3.6)
Missing data	2 (2.4)
Employment Type	
Full-time	68 (81.9)
Part-time	14 (16.9)
Missing data	1 (1.2)
Employment Sector	
NHS	75 (90.4)
Private	5 (6)
Charitable Organisation	2 (2.4)
Research Organisation	1 (1.2)

Care Perceptions

As the question order was counterbalanced midway through the recruitment timeframe, analysis was undertaken to establish any differences between participants who completed the vignettes before or after the PSS-10. Significant differences were found between these two groups on two questions: (Q2) whether previous nursing experience would assist them in caring for the patient (*F*(1,81)=4.53, *p*=0.036), and (Q6) whether they would be dependent on the person accompanying the patient to communicate with them (*F*(1,81)=3.09, *p*=0.043). Mean scores for both questions were higher for participants who had completed the vignettes after the PSS-10 (Q2=1.65; Q6=3.97) than for participants who completed the vignettes before the PSS-10 (Q2=1.42; Q6=3.56). No significant differences were found for the other ten questions (*p* value range=0.098-0.967). This indicates that there was no significant global priming effect, but that participants appear to have given marginally different answers to two questions depending on the order of questionnaires.

Significant main effects of vignette type (intellectual disability versus non-intellectual-disability) were found for all 12 questions measuring care perceptions (see Table 4.2). Overall, these data indicate that participants felt more confident in their knowledge, training and experience, and better able to identify and meet the needs of, and communicate with, patients who did not have intellectual disabilities. Participants held more positive perceptions about caring for patients without intellectual disabilities and felt that caring for a patient with an intellectual disability would cause them to feel more stressed. Participants would be more reliant on the person accompanying the patient with an intellectual disability to the appointment to facilitate communication, compared with the patients without intellectual disabilities. The majority (11 out of 12) of these differences in care perception were found to have medium or large effect sizes (*d*=.51 to -1.05) (Cohen, 1988), indicating that the difference created by including information pertaining to the fictional patient’s intellectual disability resulted in substantially different care perceptions. The difference in responses to the question about “understanding the patient's circumstances” had a small effect size (*d*=-.46); thus the difference in means between vignette types was marginal.

Table 4.2. Mean scores, analysis of variance and effect sizes for care perception questions

Care Perception Question	**Mean scores (SD) for type of vignette**		**ANOVA**	**Effect size**
	ID	**Non-ID**	***F***	**(Cohen's d)**
I believe that I have the sufficient level of knowledge to provide care for this patient.	3.69 (.78)	4.20 (.59)	(1,82) 36.80*	-0.74
I believe that my previous nursing experience will assist me in providing care for this patient.	3.92 (.74)	4.42 (.46)	(1,82) 41.25*	-0.81
I believe that I have received sufficient training to provide the highest quality care to this patient.	3.34 (.94)	3.86 (.82)	(1,82) 42.76*	-0.59
I believe that I would be able to successfully communicate with this patient.	3.74 (.60)	4.33 (.52)	(1,82) 60.50*	-1.05
I feel comfortable talking to this patient about their illness.	3.79 (.70)	4.37 (.54)	(1,82) 59.52*	-0.93
I would be dependent on the person accompanying the patient to communicate with the patient.	2.70 (.84)	2.16 (.87)	(1,82) 26.29*	0.63
I feel confident that the needs of this patient would be identified.	3.43 (.74)	3.98 (.60)	(1,82) 42.03*	-0.82
I feel confident that the needs of this patient would be met.	3.38 (.69)	3.92 (.58)	(1,81) 62.9*	-0.85
I understand this patient's circumstance.	3.37 (.88)	3.79 (.93)	(1,81) 28.17*	-0.46
I feel positively about providing this patient with care.	3.85 (.64)	4.27 (.57)	(1,81) 39.54*	-0.69
I feel confident that I would be able to provide this patient with the appropriate care.	3.77 (.64)	4.22 (.58)	(1,80) 37.81*	-0.74
I believe that providing care for this patient would cause me to become stressed.	2.71 (.89)	2.26 (.88)	(1,81) 31.59*	0.51

* p<0.001. ID=intellectual disability

Interaction Effects

Significant interaction effects were found, whereby participants who had previous intellectual disability experience scored higher on items relating to possessing relevant knowledge (*F*(1,81)=7.670, *p*=0.007) and experience (*F*(1,81)=6.992, *p*=0.01) when providing care for patients with intellectual disabilities than did participants with no such experience. These participants were also more confident in meeting the needs of patients with intellectual disabilities (*F*(1,80)=4.314, *p*=0.041) and felt more positively about providing care (*F*(1,80)=11.458, *p*=0.001). Participants with previous experience felt more confident in providing appropriate care for patients with intellectual disabilities (*F*(1,79)=6.663, *p*=0.012) and believed that they would be less likely to become stressed when providing this care than did participants with no previous experience (*F*(1,80)=6.263, *p*=0.014).

Participants who reported having no previous experience with people with intellectual disabilities felt that they had received more appropriate training to care for patients without intellectual disabilities than they had to care for patients with intellectual disabilities. This difference was less evident for participants with previous experience of working with people with intellectual disabilities (*F*(1,81)=6.381, *p*=0.013). Additionally, participants with no prior experience felt that they were better able to understand the circumstances of patients without intellectual disabilities; this difference was less prominent for participants with previous intellectual disability experience (*F*(1,80)=4.928, *p*=0.029).

No statistically significant interaction effects were found for previous experience with people with intellectual disabilities and: successful (*F*(1,81)=3.606, *p*=0.061) and comfortable communication with the patient (*F*(1,81)=3.104, *p*=0.082), being dependent on the person supporting the patient (*F*(1,81)=0.245, *p*=0.662), or for identifying the patient's needs (*F*(1,81)=2.262, *p*=0.137). No significant interaction effects were found between PSS scores and care perceptions (*p* value range=0.298-0.987).

Free Text Responses: Seeking Advice and Training Needs

Seeking advice. Of 78 participants to answer this question, 64 participants made 107 suggestions regarding where they would seek advice when caring for a patient with an intellectual disability; these were coded into broad response categories (see Figure 4.1). One participant stated more generally that the specific circumstances and needs of the patient would determine where they would seek advice.

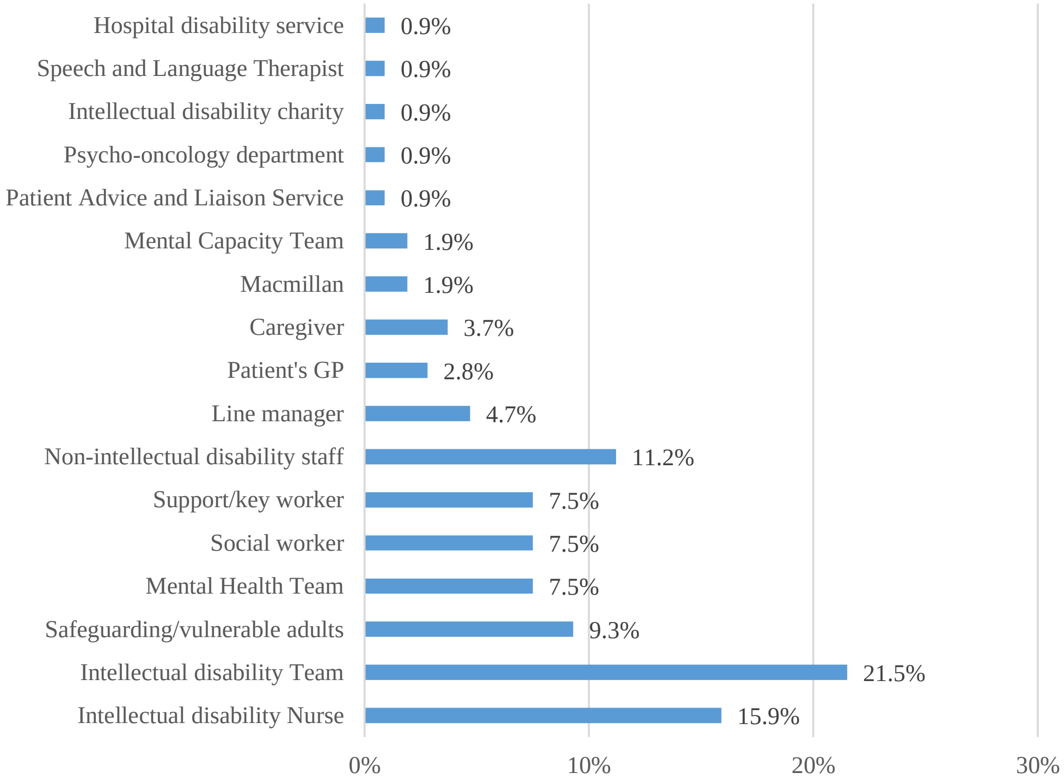

Figure 4.1. Participant-identified sources of advice when caring for patients with intellectual disabilities

Additional training needs. In total, 46 participants responded to this question, making 56 suggestions of additional training needs for providing care to a patient with an intellectual disability (Figure 4.2). The most frequent suggestions for specific training needs were intellectual disability communication training (33.8%) and general intellectual disability training (25%). The former suggestion is seemingly contradictory to the non-significant interaction between confidence in successful and comfortable communication and previous experience of intellectual disabilities.

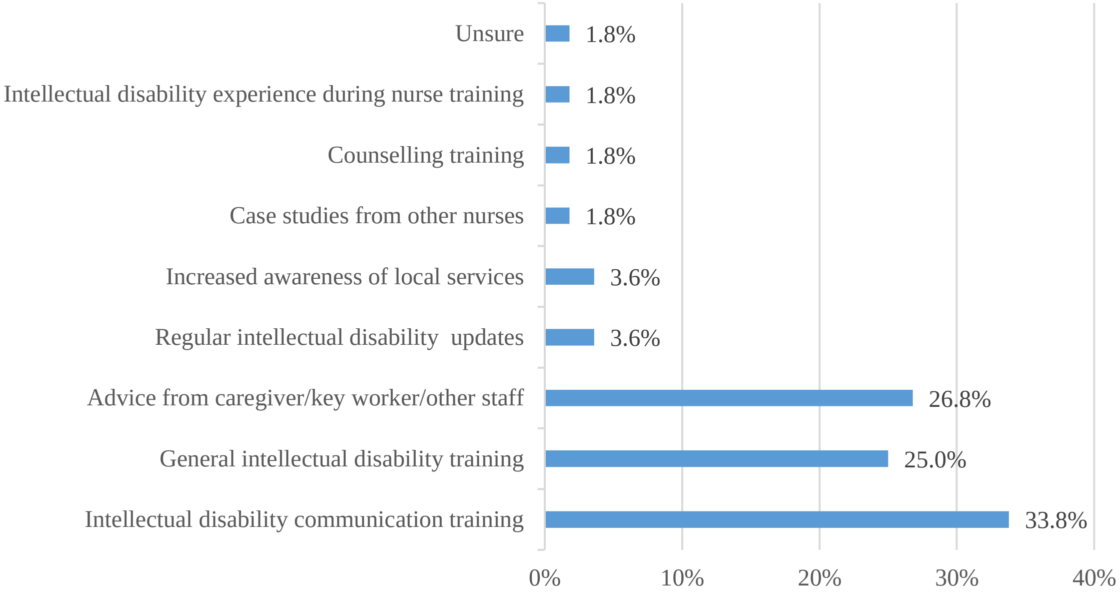

Figure 4.2. Participant-identified additional training needs for caring for patients with intellectual disabilities

As shown in Figure 4.1, oncology nurses would primarily seek advice from people or organisations (e.g., intellectual disability nurse/team, support/key worker, or caregiver) who would typically be in contact with a person with an intellectual disability at the time of a cancer diagnosis. They would also contact people who would potentially be able to provide additional support to the individual (e.g., safeguarding/vulnerable adults, or Macmillan). Regarding identified additional training needs, it is evident from Figure 4.2 that oncology nurses in this sample were keen to access organised training to supplement their knowledge when caring for an individual with an intellectual disability and cancer (e.g., general intellectual disability training, communication training, or counselling training). Participants' free text responses are included in Appendix 30.

Discussion

This study aimed to explore the perceptions held by oncology nurses about caring for patients with and without intellectual disabilities. The hypothesis, based on earlier work was that there would be a difference in the perceptions of caring for cancer patients with and without intellectual disabilities, but this was yet to be experimentally tested. Secondary aims were to undertake exploratory analysis to investigate whether participant demographics (e.g., previous experience with people with intellectual disabilities) interacted with these perceptions. Overall, participants felt more positively about providing care for patients without intellectual disabilities, and previous experience of caring for a person with an intellectual disability was the only significant variable within this exploratory analysis. These findings will be explored in more detail below.

Care Perceptions

As hypothesised, oncology nurses felt less positive and confident about providing care to patients with intellectual disabilities, including reporting having less relevant knowledge and experience of, or training in, caring for this patient group. This is reflective of the wider literature regarding palliative care staff’s lack of confidence in supporting and communicating about death with people with intellectual disabilities (McIlfatrick et al., 2011; Ryan et al., 2011; Stein, 2008). Cancer patients often have high expectations of oncology nurses’ roles (Sapir et al., 2000), and expect them to possess medical knowledge (e.g., cancer treatment, pain management, etc.) as well as strong interpersonal skills (e.g., reliability, patience, tact, and understanding psychosocial concerns). Particularly considering the latter expectation, oncology nurses will likely be expected to understand how to meet the needs of all patient groups; therefore, it is essential that they are able to access appropriate training to facilitate their understanding. This study provides a new and valuable insight into the confidence and care perceptions of oncology nurses when caring for patients with intellectual disabilities.

Stress and burnout for both cancer (Emold et al., 2011) and intellectual disability (Mutkins et al., 2011) care professionals is high; thus it is unsurprising that the participants felt that caring for cancer patients with intellectual disabilities would create additional challenges for them. The perceived shortage of knowledge, experience, and confidence when caring for this patient group may well have contributed to this, as has been found in the wider literature whereby accident and emergency nurses felt that they lacked the knowledge to care for patients with intellectual disabilities, leading to them being fearful of communicating with and caring for this patient group (Sowney & Barr, 2006).

Feeling less confident about communication skills can inhibit conversations (Travado et al., 2005), and this may lead to oncology professionals preferring to communicate with the person supporting the patient rather than with the patient themselves (Murphy, 2006; Sowney & Barr, 2006; Turk et al., 2012b), as was the case in this sample. Whilst carers are undoubtedly important figures for patients with communication difficulties, it is imperative that oncology nurses also feel able to converse with patients directly. The reliance on proxy reports, such as those from carers, can be problematic as this can often lead to a greater number of health problems being reported by carers than would be by the patients themselves (Turk et al., 2012a). Though it may be necessary to obtain supplementary information from a caregiver, it is best practice to speak directly to the person with an intellectual disability, involving and informing them as much as possible (Mental Capacity Act, 2005), using additional resources as appropriate (e.g., supported communication, Easy Read information, or additional time in consultations) to ensure that this can happen (Department of Health, 2001; Department of Health, 2007). Shared decision-making is an evidence-based best practice which is recognised worldwide (Kehl et al., 2015; Mead et al., 2013; Coulter et al., 2011). This practice can extend from the traditional physician-patient dyad to also include caregivers (Mead et al., 2013); this may benefit people with intellectual disabilities if used appropriately, so that people with intellectual disabilities are not being bypassed within appointments (as seen in Chapter 3).

Overall, oncology nurses in this sample felt that their previous experience, knowledge, and training was less useful when supporting cancer patients with intellectual disabilities than patients without intellectual disabilities. Nurses who perceived themselves to have limited previous experience of working with specific patient groups were more likely to report feeling unconfident when supporting that population (Lange, Thom & Kline, 2008; Söderhamn, Lindencrona, & Gustavsson, 2001). Providing opportunities for oncology nurses to experience caring for cancer patients with intellectual disabilities is important, and this will be explored in more detail below.

Previous Experience and Training Needs

Participants with previous experience of working with people with intellectual disabilities felt more positively about meeting patients’ needs, providing appropriate care, and feeling additional stress when providing care to this patient group, than did participants with no such prior experience. In the *Healthcare for All* report (Michael, 2008) it was recommended that all healthcare professionals should receive compulsory intellectual disability training; however, there is no evidence within the literature or in the data presented in this study to suggest that this recommendation is being implemented. Education courses can improve knowledge, self-perceived psychosocial care skills, and preparedness for nursing cancer patients (Steginga et al., 2005). Such interventions could be tailored to educate nurses about meeting the needs of diverse patient groups, including people with intellectual disabilities.

In the absence of actual clinical experience, simulated patients could be used to replicate essential aspects of caring for people with intellectual disabilities; this can prepare healthcare professionals for when they encounter similar situations within their practice (Hovancsek, 2007). Simulated experience can improve self-efficacy in nursing students to the same level as in nursing students who have clinical experience (Kimhi et al., 2016). Billon et al. (2016) found improvements in participants' knowledge, skills, and confidence to meet the healthcare needs of people with intellectual disabilities following simulation training, demonstrating the potential applicability of this method to healthcare professionals working with people with intellectual disabilities. The Billon study is novel, and should be replicated to further establish the potential utility of this method, and whether it could be specifically tailored to oncology professionals.

Increased familiarity and understanding of people with intellectual disabilities can reduce anxiety in university students when they later come into contact with people with intellectual disabilities (Li et al., 2012). A recent literature review (Ryan & Scior, 2014) of 24 studies aiming to improve medical students' attitudes towards patients with intellectual disabilities found that most interventions were effective. They note that self-selection bias could account for studies whereby no improvement was found, as participants were already reporting positive attitudes and may, therefore, have taken part because of a specific interest in supporting people with intellectual disabilities (e.g., Sinai et al., 2013). Having said this, given that the interventions reviewed in the Ryan and Scior (2014) paper were effective, even in a group who had no prior experience of working with people with intellectual disabilities, similar work exploring their efficacy in oncology nurses would be a valuable addition to the literature.

Most participants in this study reported that they would seek advice from another professional (e.g., intellectual disability team or charity, or their line manager) to supplement their own experience and knowledge in caring for and supporting a patient with an intellectual disability. Multi-Disciplinary Team (MDT) working is common within cancer (Rajan et al., 2013) and intellectual disability (Balogh et al., 2008) care, as both conditions are multi-faceted and often require input from different disciplines. Communication between intellectual disability teams and some oncology specialist teams (e.g., palliative care) can, however, be problematic (Ryan et al., 2010). This is one area of organisational development where a demonstrable difference could be made to the care of cancer patients with intellectual disabilities.

Many sources of inter-professional support would only be applicable in certain circumstances, for instance, making contact with a social worker would only be appropriate if the patient was already known to them, or had circumstances whereby their input was necessary. Nineteen participants in this study (22.9%) were either unsure of where to seek specific advice, or did not answer this question, and a small proportion of participants indicated that they would contact a mental health team. That these participants did not appropriately differentiate between intellectual disabilities and a mental health condition is concerning, as both uncertainty and seeking advice in the wrong place may lead to inappropriate or inadequate support being provided, further impacting on the healthcare experience of a patient during an already distressing time. There is a clear role for educational interventions being targeted at oncology professionals, not only in meeting the needs of patients with intellectual disabilities, but also in knowing how and where to seek advice when caring for patients with intellectual disabilities. None of the participants reported that they would consult the patient themselves about how best to support them, despite evidence that people with intellectual disabilities value involvement in their own healthcare decisions (Tuffrey-Wijne et al., 2007). This corresponds with another finding within this study that participants felt less confident communicating directly with patients with intellectual disabilities than they did with patients without intellectual disabilities.

Whilst no significant interaction was found between successful and comfortable communication with the patient and previous intellectual disability experience, 33.8% of participants suggested that specific training on how to communicate with people with intellectual disabilities would be helpful to them. This is not the only study to conclude that communication interventions would be helpful to improve communication confidence and reduce reliance on caregivers (e.g., Sowney & Barr, 2006; Tuffrey-Wijne et al., 2005). People with intellectual disabilities appreciate being communicated with, and find that it lowers their anxiety about what is going to happen (Gibbs et al., 2008). An intervention to support communication between healthcare professionals and people with intellectual disabilities would therefore be beneficial for multiple stakeholders. These findings indicate that work exploring the efficacy of interventions to improve care perceptions and to decrease the associated anxiety, uncertainty, and perceived difficulty reported by oncology nurses when caring for this population, would be a valuable addition to the literature.

Study Evaluation

Recruiting through a national society should have made it possible to reach a wide sample. However, as a proportion of registered UKONS members, the sample participating in this study is small. Additionally, not all oncology nurses will be members of UKONS, thus limiting the sample further as these nurses may have been unaware of the opportunity to participate in this research. The recruitment method is most likely responsible for this low recruitment rate as, without approaching each UK NHS trust directly, it would have been difficult to identify nurses who weren't members of UKONS to participate in this study.

The recruited sample size was initially considered sufficient on the basis of the *a priori* power calculation, but missing data led to the exclusion of some participants' responses from the final analysis. At this point, the analysed sample size fell below target. Whilst the sample was small, the effect sizes were, with the exception of one area of inquiry ("understanding the patient's circumstances"), all medium or large (higher than expected when the power analysis was undertaken). This indicates not only that the difference between participants' perceptions of caring for patients with and without intellectual disabilities in this sample is meaningful, but also that the sample size calculation might have been an over-estimate of that needed. Nonetheless, the small sample size has implications for the applicability and representativeness of these results, meaning that conclusions must be tentative. Demographic data pertaining to the age range of participants is relatively consistent with recent data from the Nursing and Midwifery Council (NMC, 2017); however, only 2.4% of the sample were male and this is an underrepresentation of male nurses in the UK (11.5% across disciplines) (NMC, 2017). We also cannot make assumptions about oncology nurses outside of the UK, particularly as the majority of participants worked within the NHS, which is a largely unique healthcare system, and results may differ in other countries' public and private healthcare systems. Replication work in larger samples, including those outside of the UK, would be beneficial, so as to lend further support to these novel findings.

Overall, counterbalancing the question order did not have a significant impact on participants' responses to questions, with the exception of two questions for which participants completing the vignettes after the PSS-10 had higher mean scores: (Q2) whether previous nursing experience would support them in caring for the patient, and (Q6) whether they would be dependent on the person supporting the patient to communicate. Participants may have been prompted to think about their current stress levels before answering the vignette questions, thus priming these participants to feel less confident in their abilities than participants who completed the vignettes first. For this study it was necessary to counterbalance the questionnaires, as completion rates in the first two weeks were poor and the vignette questions were positioned last within the package. This finding should be considered in future research questionnaire design to ensure that measures about perceptions are positioned appropriately in the questionnaire from the outset. From the data within this study, it appears advantageous to position perception measures before other measures that might prompt reflection on prior experiences, or that are emotionally charged.

Two questions in the questionnaire about care perceptions were negatively framed, and this may have led to an acquiescence bias as the majority of questions were positively framed (Salazar, 2015). The combination of positively and negatively framed questions can reduce the internal consistency of the scale (Salazar, 2015; Suárez-Alvarez et al., 2018), although this was not the case within this study. Conducting research into perceptions and attitudes can be difficult, not least because it is difficult to obtain frank and honest answers regarding sensitive subjects; vignette methodology enables researchers to explore such areas as it is less direct than being asked about personal experiences, and participants are able to express their care perceptions regardless of their previous experience (Braun & Clarke, 2013). Thus, it was possible to compare the perceptions of participants who had previous experience of working with patients with intellectual disabilities with those who did not. However, it would be valuable in future research to establish actual experiences of oncology nurses who have cared for this patient group, including complications they faced and how they resolved them. As an exploratory piece of work, qualitative methods might be best suited to begin to answer this question.

The use of a novel theoretical framework is common practice in vignette studies (e.g., Bailey, 2008; Barter & Renold, 2000; Taylor, Bradbury-Jones, Kroll, & Duncan, 2011), but it does give rise to questions of reliability, as the theoretical framework has not been further tested. Using findings from the systematic review presented in Chapter 2 added weight to the theoretical framework developed from an early version of the thematic analysis which was informed by grounded theory methodology. The theoretical framework used within this study is still reflective of the findings now presented in Chapter 3 but, like all theories, it is subject to development as new data emerge and as processes change (Glaser & Strauss, 1967). The internal reliability of the questionnaire related to the vignettes was high (α=.9), and this indicates that the items within the questionnaire were all measuring the same construct. Further psychometric testing (including construct and criterion validity, and test-retest reliability) could facilitate the wider applicability of this measure.

Recommendations for Future Research

Further research into the specific barriers to providing care to patients with intellectual disabilities and anxieties (e.g., time constraints and/or insufficient training in communication strategies) held by oncology nurses is warranted. It would also be beneficial to consider the experiences of a broader sample of oncology professionals, to fully research the most effective organisational approach to providing care to people with intellectual disabilities and cancer. Through a better understanding of how people with intellectual disabilities and cancer are typically supported, it would be possible to extend knowledge on barriers and facilitators to effective healthcare provision. It has been suggested within this chapter that caring for a patient with an intellectual disability and cancer may be an additional stressor to oncology nurses, and results from this research do go some way to supporting this; further research should extend this finding by identifying specific stressors when providing support to this population.

Regarding the finding that no participant would consult the patient themselves about how to best support them, it would be worthwhile to research the impact of more fully involving the patient in the support that they receive. Participants in this study expressed a need for additional training to support them to care for people with intellectual disabilities, and a particular area identified for development was in communicating with this population. Intervention research should, therefore, aim to improve perceptions of communicating with people with intellectual disabilities, and should be informed by the current literature, and by the perspectives of people with cancer and intellectual disabilities. Furthermore, it would be beneficial to understand the direct impact of such interventions on staff members, service provision, and patients alike.

Implications for Practice, Care, and Support Provision

Oncology nurses in this sample were more likely to communicate with the person supporting the patient, than with the person with an intellectual disability themselves, and this may be problematic for the patient's meaningful involvement in their own experiences (Chapter 3). It is, therefore, imperative that oncology nurses involve the person with an intellectual disability in conversations about their illness and treatment; it is likely that this population would benefit from additional support and training being made available to key professionals, to meaningfully involve people with intellectual disabilities in their own care.

Training to improve oncology nurses' perceived preparedness to provide care to patients with intellectual disabilities is required. The results of training to improve nurses' attitudes and care perceptions may not only benefit the patient, but also the well-being of carers and healthcare professionals. Burnout and occupational stress in nurses is often correlated with quality of patient care (Nantsupawat et al., 2016; Sarafis et al., 2016; Van Bogaert et al., 2014). Therefore, a healthcare professional who is less stressed, and has a better understanding of how to support a person with an intellectual disability, might be more likely to provide a better standard of care to this population. Furthermore, should this be the case, the person with an intellectual disability will be less likely to feel distressed and frustrated with their care, and their caregivers may also feel less strain in feeling they have to supplement healthcare that is not fully meeting the needs of the person with an intellectual disability (e.g., Gibbs et al., 2008).

Conclusions

This research has taken a novel approach to experimentally investigating the care perceptions of oncology nurses when providing cancer care for people with intellectual disabilities; a notable and important gap in the current oncology nursing literature. It is evident from these data that providing cancer care to patients with intellectual disabilities is perceived as being more difficult in many respects than to those without intellectual disabilities. However, previous experience and increased knowledge of working with this specific patient group acts as a protective factor against negative effects. Interventions to increase intellectual disability awareness, and the ability to communicate with people with intellectual disabilities, may be effective in reducing anxiety and may improve the perceptions and attitudes of oncology nurses when caring for this group of patients. However, before firm conclusions can be drawn, these effects should be replicated in larger, international, samples.

Rationale for Further Investigation

Participants in the qualitative study (Chapter 3) highlighted communication as potentially problematic, and this study has further clarified that care perceptions may be affected by lack of confidence in communicating with people with intellectual disabilities. This is supported by the wider literature (Sowney & Barr, 2006; Tuffrey-Wijne et al., 2005). Although there were many potentially interesting avenues for further research, the participants in this study specifically highlighted their need for training to support communication with people with intellectual disabilities. The potential impact of an intervention to improve communication with people with intellectual disabilities is far-reaching for both psychological and physical outcomes for the patient (e.g., Arora, 2003; Zolnierek & DiMatteo, 2009) and also for reducing the anxiety of the healthcare professional (Li et al., 2012). For the final empirical study in this thesis, therefore, an intervention was designed and feasibility tested. This training focussed on improving oncology professionals' perceptions of communicating with people with intellectual disabilities and cancer. The rationale and development of this intervention is described in detail in Chapter 5, as are the findings from the study.

Chapter 5. A Feasibility Study of a Novel, Brief, Online, Video-based Intervention to Improve Oncology Professionals' Perceptions of Communicating with People with Intellectual Disabilities

Chapter Overview

Oncology nurses can feel unprepared to care for and communicate with cancer patients with intellectual disabilities (Chapter 4). Participants in the UK nurse study (Chapter 4) highlighted their need for specific training to communicate with people with intellectual disabilities. This chapter will test the feasibility, acceptability, and indicative effectiveness of a novel, brief, online, video-based intervention to improve oncology professionals' perceptions of communicating with cancer patients with intellectual disabilities.

This study was a single-arm, pre- and post-test design with a six-week follow-up. Feasibility and acceptability were primarily measured by recruitment rates, retention, intervention adherence, completion of outcome measures, and qualitative perceptions about the effectiveness for practice.

Of 97 participants who completed the baseline questionnaire, 43 (44%) enrolled and engaged with the online training course. Of those, 16 (37%) completed the post-intervention questionnaire and 12 (28%) were retained to follow-up. Qualitative responses implied that participants who completed the intervention were generally satisfied with it, but modifications were suggested. There was some evidence of positive perceptions about the impact on practice from participants who completed the intervention, although this was a small sub-sample of the recruited participants.

Participants who completed the intervention perceived the intervention to be effective for their practice; however, taken as a whole, these results provide clear evidence that this intervention is not feasible in its current format. Problems with recruitment, high attrition, and intervention adherence indicate that further theoretical (pre-clinical) and modelling (Phase I) work (Medical Research Council, 2000) should be undertaken before this intervention is feasibility tested again.

Background

Effective doctor-patient communication (e.g., comprehensive, understandable, and patient-centred: Dowsett et al., 2000; Fallowfield & Jenkins, 1999; Hack, Degner, & Parker, 2005) can lead to better patient adjustment and well-being (Arora, 2003), and adherence to medical treatment (Zolneierek & DiMatteo, 2009). Whilst communicating with cancer patients without intellectual disabilities can present challenges (e.g., having limited experience, confidence, or time: Hemsley et al., 2012;

Travado et al., 2005; Weigel et al., 2007), effective communication can be especially difficult to achieve when a patient has an intellectual disability. People with intellectual disabilities can find some elements of communication difficult, including estimating the frequency and timing of events, comparing two or more events or sensations, identifying emotions, making generalised statements, discussing sensitive topics, giving relevant examples, and answering yes/no questions (Finlay & Lyons, 2001). Furthermore, people with intellectual disabilities can find unfamiliar information particularly difficult to understand (Finlay & Lyons, 2001; Lennox, Diggens, & Ugoni, 1997), and doctors can sometimes find it difficult to understand the speech of people with intellectual disabilities (Lennox, Diggens, & Ugoni, 1997) leading to miscommunication and misunderstanding. In Chapter 4 of this thesis, oncology nurse participants perceived communicating with, and caring for, patients with intellectual disabilities to be significantly more demanding than for patients without intellectual disabilities. Hospital nurses have also been found to hold more negative attitudes and emotions towards patients with intellectual disabilities, which may lead to poorer healthcare provision for these patients (Lewis & Stenfert-Kroese, 2010), including inadequate communication about their illness.

Whilst there is a plethora of research into communication skills training (CST) that attempts to address communication difficulties affecting patients without intellectual disabilities (e.g., Back et al., 2007; Bragard et al., 2010; Brown et al., 2009; Bylund et al., 2010; Epstein et al., 2017; Fallowfield, Jenkins, Farewell, & Solis-Trapoala, 2003; Fallowfield, Jenkins, Farewell, Saul, Duffy, & Eves, 2002; Grainger, Hegarty, Schofield, White, & Jefford, 2010; Han, Keranen, Lescisin, & Arnold, 2005; Schmitz, Schnabel, Stricker, Fischer, & Guttormsen, 2017; Shilling, Jenkins, & Fallowfield, 2003) there is a paucity of specific training, and research evaluating it, for people with intellectual disabilities. Participants in the survey of UK nurses (Chapter 4) highlighted this training as a professional development need. Although a UK Core Skills Training Framework (Skills for Health, 2017) is available, it is specifically targeted at employees within learning disability services rather than healthcare professionals in other services. Whilst oncology staff still receive essential communication skills training, they are not being routinely offered training about communicating with, and caring for, patients with intellectual disabilities.

Most CST is delivered over a number of days (e.g., Fallowfield et al., 2004; Shilling, Jenkins, & Fallowfield, 2005) and evidently improves oncology professionals' communication attitudes and behaviours (Barth & Lannen, 2011). CST can, however, be burdensome for participants, and the effectiveness of shorter-form training should be established, as these interventions are more likely to be feasible in practice than are lengthier alternatives (Barth & Lannen, 2011). Furthermore, Moore, Wilkinson and Rivera Mercado (2009) highlight that alternative methods of CST should be explored to reduce the resources needed for face-to-face training. Online training is a flexible method posing minimal disruption to time-critical tasks, such as patient consultations, allowing healthcare professionals to complete a course at their own pace (The Learning and Performance Institute, 2014). Online interventions (e.g., using virtual patients and non-face-to-face delivery) have been found to improve medical and nursing students' and medical residents' perceptions of communicating with people with intellectual disabilities (Boyd et al., 2008), and was effective as a stand-alone method when it was not possible to provide clinical experience as well.

Online interventions could make personal connection with the training material more difficult, and this may be a problem for training about communicating with people with intellectual disabilities as we know that having contact with people with intellectual disabilities can influence participants' perceptions of this patient population (Walker & Scior, 2015; McManus, Feyes, & Saucier, 2011). Specifically, McManus, Feyes, and Saucier found that, in an undergraduate sample, the quality of contact with people with intellectual disabilities was more strongly associated with positive attitudes than was the quantity of their contact with or knowledge about intellectual disabilities. Such contact, even if this is brief and indirect (Walker & Scior, 2013), can decrease anxiety about future interactions with people with intellectual disabilities (Hudson-Allez & Barrett, 1996) and may increase the likelihood of effective communication with this population (e.g., Hemsley et al., 2012; Travado et al., 2005).

Whilst the provision of online training limits the traditional methods that can be used to teach trainees (e.g., role play), video-based interventions have been successful in improving communication skills in oncology professionals (Schmitz et al., 2017) and other professional groups (Gartmeier et al., 2015; Harrison, Hayden, Cook, & Cushing, 2012). Video-based training allows trainees to reflect on difficult situations in a less pressured environment, compared to a practice setting (Harrison et al., 2012). Importantly, skills learned from fictional videos were found to transfer from training to practice in Harrison et al.'s mixed sample of teaching and medical students, highlighting the potential benefits of this method for doctor-patient communication. Video elements of training have long been relied on to provide context to key skills that cannot be demonstrated within face-to-face training sessions (Heaven, Clegg, & Maguire, 2011) and have recently been used to effectively demonstrate practical healthcare skills to lay people (e.g., hands-only Cardiopulmonary Resuscitation (CPR)) (Bobrow et al., 2011).

Considering budgetary restraints placed on the NHS and on third-sector cancer care organisations, it is possible that video-based online training can provide a practical solution as a cost-efficient and effective way to foster change. To date, neither the effectiveness of online CST nor video-based communication training has been used specifically to affect practice for cancer patients with intellectual disabilities. This feasibility study will aim to establish the feasibility, acceptability, and indicative effectiveness of this training method to oncology professionals.

Despite its extensive use in psychosocial oncology, CST for healthcare professionals is often born of expert opinion and is not evidence-based (Schofield & Butow, 2004). The implication of this is that CST is often implemented with little evidence regarding its efficacy (Moore, Rivera Mercado, Grez Artigues, & Lawrie, 2013) or the robustness of its development (Schofield & Butow, 2004). One way to ensure that CST packages are scientifically sound is to use the Medical Research Council’s (MRC, 2000) Framework for Development and Evaluation of RCTs for Complex Interventions to Improve Health, which recommends a phased approach to intervention development. This guidance was updated (MRC, 2008) to recognise that, whilst the development of complex interventions has several phases, they may not be implemented linearly. Nonetheless, each phase is essential when developing an intervention to ensure maximum efficacy and likelihood of implementation.

According to this guidance, the development phase (pre-clinical and Phase I) should ensure that appropriate groundwork has been undertaken to support novel interventions, providing a clear evidence-based rationale for intervention aims and content (MRC, 2008). This should draw on existing evidence, theoretical underpinnings, and how individual components of the intervention work (MRC, 2000; 2008). Once this has been undertaken, a feasibility study (Phase II) can be planned to test the intervention procedures and any other elements of the design that could present problems for a main trial (Phase III) (MRC, 2008; NIHR, 2013). Conducting feasibility studies ahead of definitive trials can reduce waste (of both time and money) in research, especially when the feasibility study finds that the intervention is infeasible (Morgan, Hejdenberg, Hinrichs-Krapels, & Armstrong, 2018).

Given the evidence provided elsewhere in this thesis (which forms the development phase), this study is best characterised as a Phase II feasibility trial (MRC, 2000; 2008), aiming to establish the feasibility, acceptability, and indicative effectiveness of a novel, brief, online, video-based intervention to improve oncology professionals' perceptions of communicating with people with intellectual disabilities. The feasibility questions for this study are:

1. Is it possible to recruit oncology professionals to this study?
2. Are the content and delivery method of the intervention acceptable to participants?
3. Is it possible to retain oncology professionals to follow-up, and do they complete the questionnaires?
4. Are the outcome measures suitable for what we wanted to measure?
5. Do participants perceive the intervention to be useful for their professional practice?
6. Can a reasonable estimate of effect size be established for a full-scale trial?

Methodology

Study Design

This was a single-arm, pre- and post-test, mixed-methods study with a six-week follow-up to test the feasibility, acceptability, and indicative effectiveness of a novel, brief, online, video-based intervention to improve oncology professionals' communication with cancer patients with intellectual disabilities.

Participants

Eligible participants were healthcare professionals (including oncologists, surgeons, nurses, other cancer centre staff, cancer charity staff, and hospice staff) who worked with cancer patients, had access to the internet, and had the ability to understand written and spoken English. No restrictions were placed on the country of residence or where participants were employed. Participants were made aware of the study through emails or newsletters sent out by collaborating organisations.

A formal sample-size calculation was deemed inappropriate for this feasibility study and, instead, a target sample size of 60 was chosen pragmatically, based on the resources available at the time and on sample sizes in the existing CST literature (e.g., Alexander et al., 2006; Butow et al., 2008; Heaven et al., 2006; Kruse et al., 2003).

Intervention Development

The evidence-base. Many established CST interventions are based on expert opinion rather than research evidence (Schofield & Butow, 2004). For this reason, two frameworks for developing CST training were used to guide the development of the intervention (Hulsman & Visser, 2013; Schofield & Butow, 2004) (see Appendix 31). In addition, this training intervention was developed using the findings from earlier empirical studies presented in this thesis (Chapters 3 and 4). Specifically, these studies showed that oncology professionals find communicating with people with intellectual disabilities more difficult than communicating with people without intellectual disabilities, and often choose to converse with the patients' caregivers instead. These communication behaviours can have a negative impact on the understanding, well-being, and experiential engagement of cancer patients with intellectual disabilities. Much of the broader CST literature has focussed on improving attitudes or perceptions of oncology professionals towards patients without intellectual disabilities, rather than on the types of challenging behaviour or care needs that might be evident in this specific population (e.g., Faulkner, Argent, Jones, & O'Keeffe, 1995; Klein, 1999; Razavi, Delavaux, Marchal, Bredart, Farvaques, & Paesmans, 1993; Wilkinson et al., 1998). Encouragingly, there is good evidence that it is possible to change attitudes. Wilkinson et al. (1998), for example, reported that challenging the negative attitudes of nurses caring for palliative patients (without disability) led to quantifiable increases in confidence and efficacy in communication in 90% of participants. However, interventions to improve attitudes and perceptions specifically pertaining to patients with intellectual disabilities have been overlooked.

The focus of this intervention is to change attitudes and perceptions regarding communication with people with mild to moderate intellectual disabilities, as this was the population for which earlier studies in this thesis have provided the most empirical evidence. Therefore, it was possible to use those earlier studies to develop composite vignettes of those participants to use in the intervention (Bradbury-Jones et al., 2014), which were an appropriate representation of the experiences of this patient population (Schofield & Butow, 2004).

A key outcome for this intervention is to improve communication perceptions and behaviours of healthcare professionals working with cancer patients with intellectual disabilities. Development work for this intervention therefore began with literature searches to find examples of perceived communication barriers (both general and cancer-specific). Widely accepted general guidance about communication difficulties for people with intellectual disabilities (Finlay & Lyons, 2001) was used alongside quotes from the interviews with participants in the qualitative study (Chapter 3) and resources about communicating about health, and about breaking bad news to people with intellectual disabilities (Breaking Bad News, 2016; Chew, Iacano, & Tracy 2009; intellectualdisability.info, 2016), to ensure that specific context was given to each video. These four resources, and the key themes extracted for use in development of this intervention, are outlined in more detail in Table 5.1.

Berkhof et al. (2011) reviewed four systematic reviews of CST interventions and, among other conclusions, they emphasised that CST should be a balance of didactic components and the opportunity to practise learned skills. This practise element is equally important in online training and Schmitz et al. (2017) found that video-based examples with corresponding explanations or feedback were effective in preparing final year nursing students for real conversations with patients. Upon completing the training, there were practise questions about a composite case study for participants to practise the techniques demonstrated in the videos by applying them to a relevant example, as recommended by Bradbury-Jones et al. (2014). The case study was developed using data from the study in Chapter 3 about communication barriers experienced by participants (e.g., Bailey, 2008; Barter & Renold, 2000; Taylor, Bradbury-Jones, Kroll, & Duncan, 2011). The practise questions were an optional addition to the main intervention, as it was thought that oncology professionals might not have time to undertake the practise questions as well as the intervention and, if the practise questions were compulsory, that this might lead to participants dropping out. Again, part of the analysis of data from this feasibility study aimed to explore uptake of each different element of this training intervention.

Table 5.1. Key recommendations from resources about communicating with people with people with intellectual disabilities

Finlay & Lyons (2001)	**intellectualdisability.info (2016)**	**Breaking Bad News (2016)**	**Chew, Iacano, & Tracy (2009)**
• Significant life events or other concrete events should be used as time markers if the patient has difficulty with estimating frequency or specific dates/times • Ask about events separately (e.g., pain now, pain last week), rather than asking for a comparison or a generalisation as this can be difficult • Patients should be asked to summarise the information to ensure they understand it • Simple language should be used to explain unfamiliar concepts • Open-ended questions might be useful when the subject is sensitive • Patients should be reassured about who will know about what they tell the healthcare professional • Healthcare professionals should ask a series of follow-up questions to ensure that they	• Healthcare professionals should introduce themselves at the start of every meeting, including giving information about their job • Healthcare professionals should use alternative communication strategies (e.g., picture books, diagrams, etc.) • Index events should be used to establish a shared timeline of events • Patients should be asked to repeat information in their own words to demonstrate understanding • Benefits and risks of treatment should be clearly outlined to enable informed decision making	• Approach the bad-news topic directly, and provide key information in stages to avoid information overload • People have the right not to be told bad news, if they so choose • Healthcare professionals should anticipate questions that might be asked • Healthcare professionals should be sure that they have understood the person • Honesty and avoidance of paternalism is essential • Healthcare professionals should avoid offering false hope or reassurance • Healthcare professionals should acknowledge the person’s emotions, and offer support if needed • People may need time to absorb the information • Healthcare professionals shouldn’t talk for too long	• Formal (e.g., pictures, communication boards, etc.) and informal (e.g., gestures, facial expressions, etc.) communication strategies should be used • Healthcare professionals should involve the patient in discussions, and communicate directly with them • Healthcare professionals might need to alter their communication style to meet the patient’s preference • Short sentences, with age-appropriate language should be used • Healthcare professionals should avoid patronising language • Patients should be asked to repeat information in their own words to demonstrate understanding • Healthcare professionals should be sure that they have understood the patient

have fully understood the patient’s answer and to make sure that it is a true reflection of their feelings/experience • Patients should be empowered to say that they don’t know the answer to a question or that they have not understood the question • Questions should be kept simple with limited technical language • Patients may discuss other things that are not relevant, the healthcare professional should validate the answer briefly and then move on		• Key information should be repeated, and this could be in different formats (e.g., pictures, reading written text aloud, models, etc.) • Multi-disciplinary working can be supportive	• Adequate time should be allocated for appointments • Additional information should be sought from caregivers (after obtaining the patient’s consent for this to occur)

Practical considerations. The intervention was developed using the University of Chester's external Moodle, which presented an opportunity to test the acceptability of the intervention using a low-cost delivery method. If acceptable, this delivery method could have implications for a financially conscious NHS (e.g., Dunn, McKenna, & Murray, 2016) and charity sector (e.g., National Council for Voluntary Organisations, 2016). To ensure that the survey site and intervention worked seamlessly together, the study was piloted with family and friends to check functionality in all web browsers. Videos did not play as embedded files in Mozilla Firefox and Chrome, and would not play at all in Safari. This was highlighted to all participants at the outset so that they could use an appropriate browser to view the videos.

To ensure that all relevant communication barriers were addressed, multiple videos were filmed to address each barrier in turn. Participants in a pilot project for a novel, brief, online, video-based communication training package with healthcare professionals (Harrison, Hayden, Cook, & Cushing, 2012) expressed a preference for short, succinct videos covering multiple topics. A similar approach was adopted for the videos in the current feasibility study. The intention was to use multiple-exemplar training techniques (e.g., Cooper, Heron, & Heward, 2007) whereby there would be some subtle overlap of behaviours in the videos to increase the chances of participants recalling previous techniques as they progressed through the videos. All of the videos contained positive examples of communication, and were intended to be used as positive modelling for participants (Cruess, Cruess, & Steinert, 2008).

Before each video, participants were informed of the problem to be addressed and the intended goal of the video. Throughout all of the videos the healthcare professional maintained eye contact with the patient and had a generally open posture, as both of these non-verbal behaviours have been shown to improve patients' perceptions about the quality of doctor-patient communication (Hillen et al., 2015; Marcinowicz, Konstantynowicz, & Godlewski, 2010).

Scripts for the composite video vignettes were informed by the data from interviews conducted in Chapter 3 with people with mild intellectual disabilities (see Bradbury-Jones et al., 2014) and by related literature (Breaking Bad News, 2016; Chew, Iacano, & Tracy 2009; Finlay & Lyons, 2001; intellectualdisability.info, 2016). Key insights from the data from Chapter 3 included the importance of patient-centred skills and alternative communication methods, the impact of explicit exclusion (e.g., talking to caregivers instead of the patient) and implicit exclusion (e.g., the use of complex terminology) from discussion and decisions (e.g., confusion about the diagnosis or procedures), as well as the emotional impact of a cancer diagnosis not being discussed, potential embarrassment about intimate procedures, and patients not remaining vigilant about potential future symptoms. The tone and content of the scripts were checked by a medical oncologist to ensure their relevance and accuracy (scripts are available in Appendix 32, and an outline of each video is provided in Table 5.2). Where possible, gender-neutral names for the person with an intellectual disability were used, to avoid any unconscious bias (Van Fleet & Atwater, 1997).

Colleagues in the Chester Research Unit for the Psychology of Health at the University of Chester were asked to act in the video vignettes as they possessed an understanding of the concepts to be portrayed within the videos. Neutral accents are often preferred by listeners (Lev-Ari & Keysar, 2010; Fuertes et al., 2012), so colleagues with non-regional accents acted in the video vignettes. To avoid any unconscious bias, two male and two female actors, with a range of ages, were chosen to portray the clinician. As an example of unconscious bias, it is possible that participants might identify more with someone they deemed to be similar to them and would be more willing to adopt this person's behaviours (Bandura, 1986) but, by having a range of ages, and actors of both sexes, this effect could be minimised. Ideally the video vignettes would also have included actors of ethnicities other than Caucasian, but this was not possible given that no staff who met this criterion were employed in the department at that time and the study was not sufficiently resourced to employ externally-sourced actors.

As there was also no funding available to employ an actor with an intellectual disability, and because it would have been extremely difficult for a person without an intellectual disability to inoffensively portray this role, it was decided that the voice of the patient would be distorted so that the speech was unrecognisable. Muting the voice of the patient would potentially be distracting as there would be periods of silence; distorting the voice instead ensured that they were still vocal during the video vignette, but that their speech was unrecognisable. As this has not yet been attempted or reported in the literature, this was a pragmatic design decision, and participant comments were used to evaluate whether this was effective as part of the feasibility study aims.

Being the observer of video cases involving other professionals, rather than those of one's own practice, can allow for deeper analysis and reflection (Kleinknecht & Schneider, 2013). The camera was therefore positioned so that there was a clear view of the actor playing the healthcare professional, with a view over the shoulder of the actor playing the patient (see Figure 5.1), enabling the participant to observe the consultations. This approach has been used successfully by Harrison, Hayden, Cook, and Cushing (2012) in their online video-based training package.

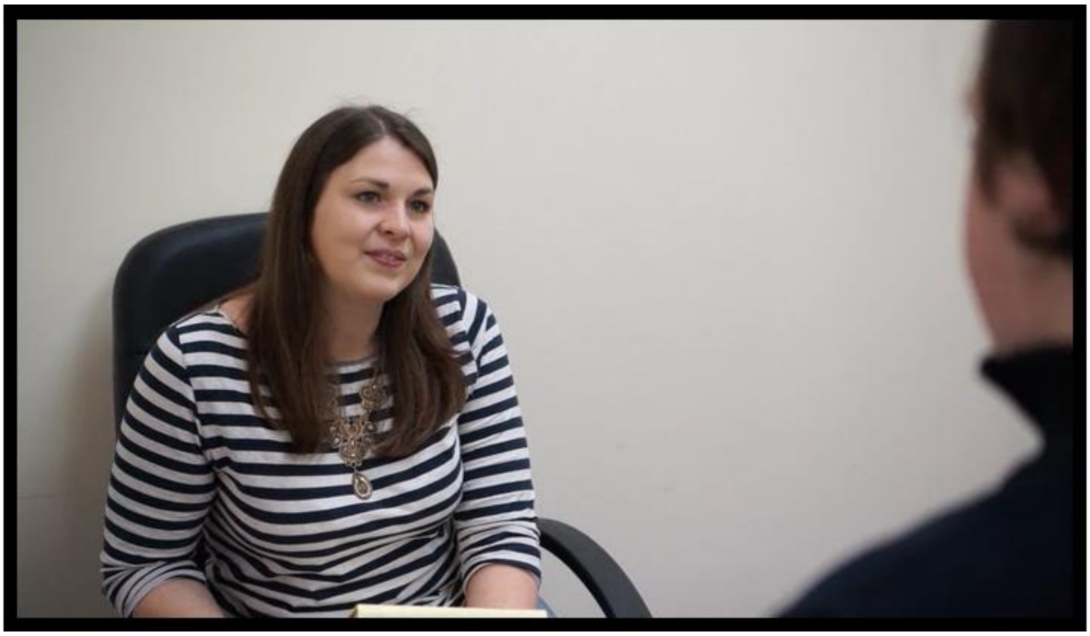

Figure 5.1. A video still to demonstrate the positioning of actors within the videos

Videos were ordered chronologically, with concepts to be used early in a consultation (e.g., "Taking time to get to know the person") at the beginning, and then others, which would tend to come later in the illness trajectory (e.g., "Encouraging continued engagement in experience"), at the end of the intervention. This decision satisfies a key recommendation of Hulsman and Visser (2013) in that CST should be situation-specific and based in a context which closely resembles practice (see Appendix 31 for a full list of recommendations).

Adobe Premier Pro and Audacity were used to produce and edit the video vignettes. Accompanying text was included to provide necessary context to each video; in most cases this was a sentence or two about the purpose of the video and a quote from a participant from Chapter 3. Seidel, Blomberg, and Renkl (2013) highlight the necessity of including some accompanying context to video vignettes to assist learners with their analysis. The final video files are available in the appendices (Appendix 33). To reduce the amount of information presented at any one time, each module (Table 5.2) was presented on its own page, and these pages were accessed from the homepage of the Moodle site for the training.

The Intervention

The intervention comprises 14 videos addressing key concepts to support communication with cancer patients with intellectual disabilities. An outline of the videos can be found in Table 5.2. Participants were provided with signposting information to external websites about intellectual disabilities, including the Australasian Society for Intellectual Disability, Mencap, and Palliative Care for People with Learning Disabilities. A diagram of the training process is presented in Figure 5.2.

Table 5.2. Overview of the training videos

Module	Problem to be addressed within the video	Intended goal of the video	Description of the video content	Sources of information
1. Taking time to get to know the person	In modern healthcare settings there is usually a significant demand on time. Failing to take at least a little time to try to build trust with a person with an intellectual disability can be counterproductive.	Building rapport and trust with the patient.	The healthcare professional introduces themselves to the patient, tells them what their job is and that they expect to see them often while they are having treatment. The healthcare professional asks the patient what they like to do, and has a short conversation about their interests. The healthcare professional indicates that they would like to know a bit more about it during the next appointment, before finishing that part of the conversation.	Data from Chapter 3 Chew, Iacano, & Tracy (2009) intellectualdisability .info (2016)
2. Don't assume prior knowledge	It is imperative to all future appointments, and for the understanding of the person with an intellectual disability, that cancer is explained from the very beginning.	Upon meeting a person with an intellectual disability and cancer, it would be worth asking them about their understanding, even if they were diagnosed some	The healthcare professional introduces themselves to the patient, and tells them what their job is. The healthcare professional then asks the patient if they know what cancer is and when the patient indicates that they are unsure, the healthcare professional then explains what cancer is; this is	Data from Chapter 3 Breaking Bad News (2016)

	But, in some cases, patients might not have been helped to fully understand their diagnosis within previous appointments.	time ago. It might be the case that they need some additional support to understand their diagnosis.	done gradually, with checking points along the way to ensure understanding. The healthcare professional tells the patient that they can ask questions about things that they don’t understand.	
3. Encouraging patient involvement	Many people with intellectual disabilities are not actively involved in conversations related to their healthcare decisions. This can lead to feelings of disengagement and confusion.	Healthcare professionals should try to actively involve the patient in discussions and decisions, rather than talking to the people who are supporting the patient.	The healthcare professional starts the appointment by telling the patient what they are going to talk about, and that they will be asking the patient questions. The healthcare professional then asks the patient what they will be talking about in the appointment, to gauge their understanding. The healthcare professional tells the patient that if they don’t know the answer to some of the questions then they could try to work it out together in a different way, or they could ask the person supporting the patient to help.	Data from Chapter 3
4. Structuring questions to enhance communication	Providing structure to questions is key, as some questions may not be perceived as they	A flexible approach to asking questions is a useful technique for healthcare professionals,	The healthcare professional asks the patient if they have had any pain since their last appointment, and where it was. They then ask the	Finlay & Lyons (2001)

	were intended, and answers might not be as informative as they could be.	and follow-up questions are necessary to establish experiences and to support the patient’s understanding of the question.	patient when it happened, and if it happened more than once, to establish generalisability. The healthcare professional asks about medication and the patient answers with some information that is not relevant to the appointment or their health. The healthcare professional briefly converses about the answer, and then asks the same question again. The healthcare professional asks a question that prompts an uncertain response, they ask some paraphrased follow-up questions to clarify the meaning and to enable the patient to more confidently answer the question.	
5. Fully explaining treatments and procedures to support informed consent	Without support to understand procedures and treatments, people with intellectual disabilities can find it difficult to know what they are consenting to. Similarly, healthcare	Accurate understanding of treatments and procedures can enable the patient to give their own informed consent and take a more active role in decision making.	The healthcare professional begins by highlighting the patient’s concern about a procedure (an injection). They then discuss that the patient is feeling unwell, so the healthcare professional explains that the injection will make the patient feel better. The healthcare professional also explains that it will be a bit sharp, but that it	Data from Chapter 3 Mental Capacity Act (2005) intellectualdisability .info (2016)

	professionals may wrongly assume that the patient is not able to provide informed consent.		will only last for a short time and after that they will feel better. After explaining the benefits and drawbacks, the healthcare professional asks for the patient’s consent to have the injection.	
6. Be careful when asking about time	Estimations of time can be difficult for people with intellectual disabilities.	Key events can be used as time prompts to narrow down broad estimates and to develop a shared timeline.	The healthcare professional asks the patient when something happened but the patient is unsure. The healthcare professional then uses Christmas and Easter as initial time prompts, and then asks whether it happened before or after the patient’s birthday. The patient and the healthcare professional are able to narrow down the estimate of when the event occurred.	Finlay & Lyons (2001) intellectualdisability.info (2016)
7. Don't assume sensitive topics are too difficult for someone with intellectual disability	It can be uncomfortable (for both parties) to discuss embarrassing or sensitive topics with a person with an intellectual disability.	Many cancers involve the discussion of sensitive topics, and may involve intimate procedures. Being open with patients about these, and being supportive will help to put them at ease.	The healthcare professional begins by telling the patient that they know that this might be an embarrassing procedure. They tell the patient that they see a lot of people with the same problems and that sometimes they feel embarrassed too. The healthcare professional tells the patient that part of their job, checking how they are, is to check some intimate areas. The healthcare	Data from Chapter 3 Finlay & Lyons (2001) Breaking Bad News (2006)

			professional asks if the patient would like someone else to be in the room when they check them. The patient asks to have someone present, and the healthcare professional reassures them that this will happen.	
8. Being clear when talking about diagnosis and procedures	Without an accurate understanding of their diagnosis it would be extremely difficult for the patient to fully participate in their healthcare decisions.	Supporting the patient to understand may also help them to engage meaningfully in discussions and decisions.	The healthcare professional asks the patient about their understanding of cancer and confirms that their understanding is correct. They then explain that some of their symptoms are because of the cancer. The healthcare professional tells the patient that they could have an operation and medication to remove the cancerous cells, and asks if the patient has any questions about this. The healthcare professional then tells the patient that they can talk to their family and friends about the operation and medication before they decide. They are also told that they can ask the healthcare professional questions after they have talked to other people.	Data from Chapter 3 Chew, Iacano, & Tracy (2009) Finlay & Lyons (2001) intellectualdisability.info (2016)

9. Taking time to explain difficult concepts	Unfamiliar information can be difficult to understand if the person with an intellectual disability is not supported.	Unfamiliar information and difficult concepts should be explained until the patient understands.	The healthcare professional says that the information they have just talked about might have been a bit confusing; the patient agrees. The healthcare professional shows the patient a picture to show the patient where their cancer is on their spine, and what will happen during the operation to remove their cancer. They then ask the patient if they would like to see some of the objects (plates and screws) that will be used in the operation, and tells them that this is what will help to support their back after the operation.	Data from Chapter 3 Finlay & Lyons (2001) Breaking Bad News (2016)
10. Regularly checking understanding	Patients may seem to have understood on the surface, but are actually confused and are unlikely to ask for clarification.	Taking time to assess their understanding, and re-engage them, is vital to ensuring that they are fully informed and aware of what is happening.	The healthcare professional begins by acknowledging that there was a lot of information, and asks the patient if they understood it. The healthcare professional then asks the patient to tell them what they heard, to make sure that the healthcare professional told them properly. The patient answers the question briefly, but the healthcare professional is not sure that the information was understood. The healthcare professional tells the patient that the information	Data from Chapter 3 Finlay & Lyons (2001) Chew, Iacano, & Tracy (2009) intellectualdisability.info (2016)

			might not have been clear, so they tell the patient the information in a different way.	
11. Using alternative communication methods	Without support, some communication can be too difficult for the patient to understand.	When communication is difficult, it is possible that alternative methods (e.g., picture books) might help.	The healthcare professional talks to the patient about a procedure (CT scan) that they are going to have, and asks the patient if they know what one is. The healthcare professional shows the patient a picture of the CT scanner, and describes what each bit does. This is to support the patient's understanding of the procedure, and to build familiarity with the scanner. The healthcare professional tells the patient what the purpose of the scanner is and asks if the patient has any questions.	Data from Chapter 3 Chew, Iacano, & Tracy (2009) intellectualdisability.info (2016)
12. Don't be afraid to ask about emotions	Emotions, and labelling them, can be tricky for people with intellectual disabilities.	Discussions about emotions should be broached in an understandable and reassuring way.	The practitioner starts by saying that there has been a lot of information in the appointment and asks the patient how they are feeling about it. The patient indicates that they are feeling worried about it, and that their treatment is distressing. The healthcare professional tells the patient that a lot of people feel the same about their treatment,	Data from Chapter 3 Breaking Bad News (2016)

			and says that they will try to help make it less worrying and distressing.	
13. The importance of asking non-leading questions	Leading questions can result in inaccurate information being recorded, as the patient may acquiesce.	Follow-up questions after a potentially leading question would help to ensure that no miscommunications occur.	The healthcare professional asks the patient if they are feeling OK, and the patient says that they are. The healthcare professional then asks a series of questions about anything that feels different, to establish whether the patient has any new symptoms and when they occur.	Finlay & Lyons (2001) Data from Chapter 3
14. Encouraging continued engagement in experience	Some patients will believe that once they have finished treatment that they no longer have to be vigilant.	Encouraging continued engagement may help to protect against this.	The healthcare professional tells the patient that their cancer has gone, but that they still need to check for signs that something might be wrong again. The patient is a bit worried about getting cancer again, so the healthcare professional reassures them that it doesn’t mean that they will have cancer again but that it is important to check themselves for signs that something might be wrong. The healthcare professional asks the patient if they remember how to check themselves, and suggests practicing it again together to remind the patient of what they need to do.	Data from Chapter 3

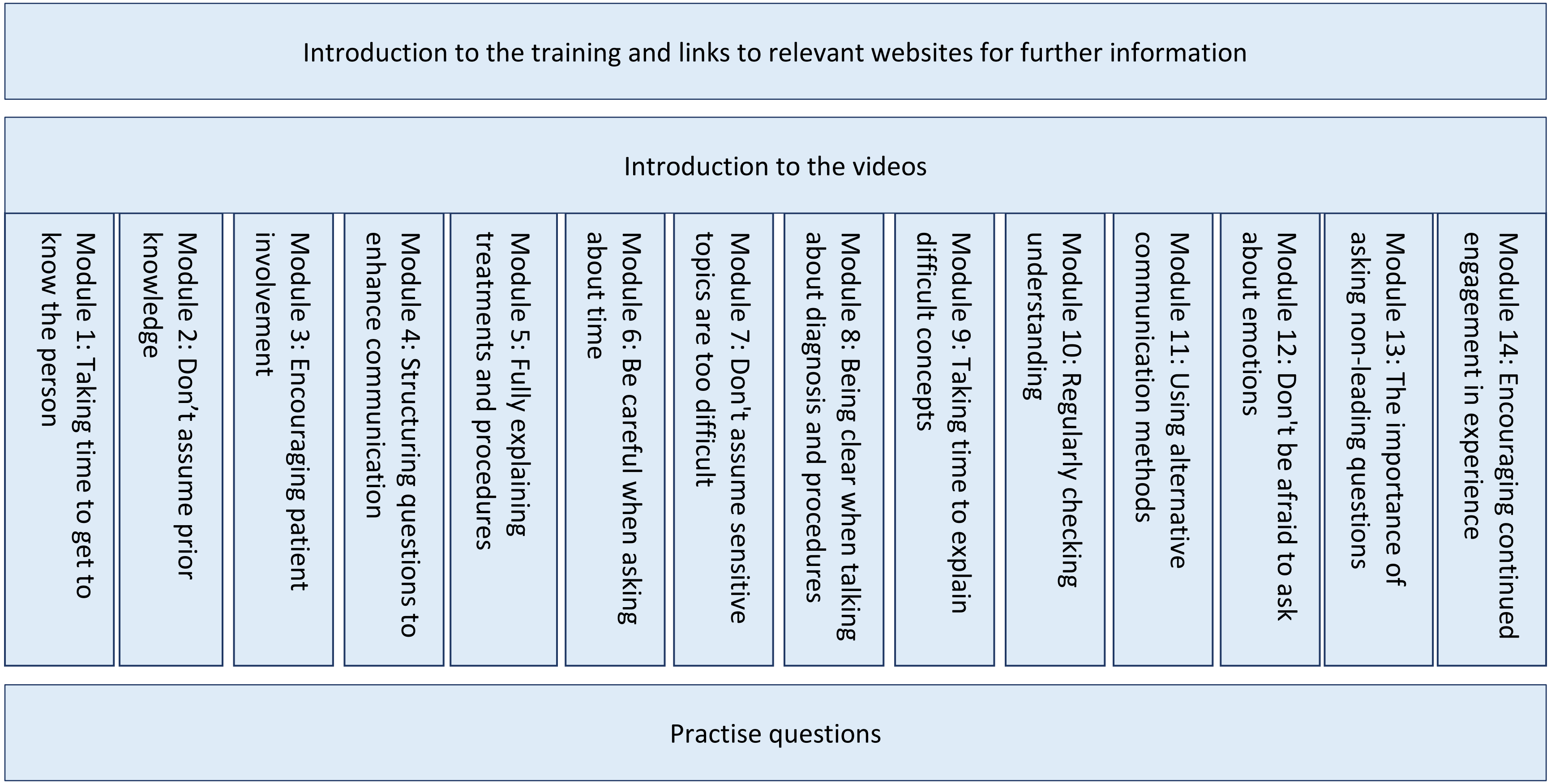

Figure 5.2. Structure of the training

Procedure

The intervention and feasibility study were approved by the Department of Psychology Ethics Committee at the University of Chester (confirmation of ethical approval is included in Appendix 34).

Organisations (e.g., cancer charities, professional societies, and hospices) were approached and asked to circulate a study invitation to their staff or members. Organisations with large or broad memberships were approached initially so as to advertise the study as broadly as possible; this recruitment strategy was then supplemented by approaching smaller organisations when it became apparent that the original recruitment strategy was not yielding the desired sample size.

Participants responded to an email or newsletter article about the intervention and associated study (Appendix 35) by clicking on a link to the survey site. Participants were fully informed about the study (Appendix 36) and asked for their consent to participate (Appendix 37). Baseline measures were then completed (Appendices 38-40) before participants received an URL invitation to the intervention (Appendix 41). Once enrolled, participants could complete the intervention at their own pace but were asked to watch the videos in the presented order.

After watching the videos and engaging in the (non-mandatory) supplementary practise questions (Appendix 42), participants were asked to complete the post-intervention questionnaire. Upon completion of the post-intervention questionnaire, participants were debriefed (Appendix 43) and were advised that they would be sent an invitation to the follow-up questionnaire (Appendix 44) in six weeks’ time. Once this was completed, participants were fully debriefed (Appendix 45) and were sent a study participation certificate (Appendix 46).

Email reminders were sent to participants who had not completed the post-intervention questionnaire two weeks after the baseline questionnaire and then, again, after four weeks. Additionally, participants who no longer wished to take part were asked, via a short online survey, why this was and whether they thought any improvements could be made to the study.

Outcome Measures and Analysis

Self-report data. Outcome measures are included in feasibility studies not as a test of intervention efficacy but to determine the acceptability of measures, completion rates, adherence to follow-up data-collection periods, and indicative effect sizes for later power calculations for a definitive trial (NIHR, 2013). Measures were chosen for this study to explore the key outcomes of behavioural intention to engage in communication with cancer patients who have intellectual disabilities, as well as the perceived ability and confidence of oncology professionals in communicating with this patient population, and indicative effectiveness of the intervention. These outcomes have been found to be important outcomes for CST for cancer patients in the general population (e.g., Faulkner, Argent, Jones, & O'Keeffe, 1995; Hemsley et al., 2012; Klein, 1999; Razavi, Delavaux, Marchal, Bredart, Farvaques, & Paesmans, 1993; Travado et al., 2005; Wilkinson et al., 1998), but this has not been applied to cancer patients with intellectual disabilities.

Behavioural Intention Measure. Participants' intentions to engage in treatment-related conversations with people with intellectual disabilities and cancer was an important outcome for this study. A measure for this outcome does not exist, therefore one was developed by the researchers for this study. The measure was developed with reference to Ajzen's (2006) guidance about intention items when constructing a theory of planned behaviour questionnaire. The theory of planned behaviour posits that beliefs and attitudes about a behaviour, as well as perceived behavioural control and subjective norms, will lead to intention to engage in the behaviour, and to subsequent engagement in the behaviour (Ajzen, 1985). This theory was deemed to be relevant to this project as it addresses the likelihood that an individual will engage in a certain behaviour, which is a key outcome of CST. Questions on this five-item self-report measure (Appendix 39) include "How willing do you feel to actively engage a person with an intellectual disability in treatment decisions?" and are scored on a 7-point Likert scale (1: *extremely unwilling* to 7: *extremely willing*). A high total score is taken to indicate a strong intention to engage in treatment-related conversations with this population.

Perceived Ability and Confidence in Communicating Measure. This measure (Appendix 40) was adapted from the one used in the study presented in Chapter 4 to include only information and model statements which pertained to communicating with people with intellectual disabilities. Vignettes were shortened, and became five brief statements, for example "A patient is accompanied to all appointments by a friend who tends to ask all of the questions for them. The patient does not seem to understand the full extent of what is happening." Following each statement there were five items (model statements) to assess perceptions of communicating with each patient. Items include: “I believe that I would be able to successfully communicate with this patient.” scored on a 5-point Likert scale (1: *strongly disagree* to 5: *strongly agree*). Model statements 2, 3, and 5 are reverse scored. The negative framing of these three model statements addressed a critique from Chapter 4, whereby only 2 out of 14 model statements were negatively framed.

A series of one-way repeated measures Analysis of Variance (ANOVA) tests were performed for both self-report outcome measures to ascertain whether participants perceived the intervention to be effective, and what the estimated effect sizes would be for a full-scale trial.

Evaluative questions. Participants were asked a series of open-ended evaluative questions about the usefulness of the training and whether they were able to implement the techniques into their practice (Appendix 47). In the post-intervention and follow-up questionnaires, participants were asked closed questions about the likelihood of using the learned techniques in their practice, and how useful they found the training to be. Participants who had not completed the post-intervention questionnaire two and four weeks after the baseline questionnaire were asked to complete a short online qualitative survey if they no longer wanted to take part. These questions pertained to the reasons for this and whether they thought any improvements could be made to the study (Appendix 48).

Feasibility and acceptability outcomes. Feasibility outcomes were assessed by exploring summary statistics (e.g., percentages) of recruitment rates, participant retention to follow-up, and questionnaire completion. Furthermore, Exploratory Factor Analysis (EFA) was conducted on participant responses to the baseline questionnaire for the Behavioural Intention Measure and the Perceived Ability and Confidence in Communicating Measure, to test the suitability (e.g., psychometric properties) of these self-reported outcome measures.

Acceptability was measured by evaluating adherence to the intervention and questionnaires, using summary statistics (e.g., percentages). Qualitative data pertaining to non-completion of the post-intervention questionnaire and the open-ended evaluative questions about the content, delivery method and indicative effectiveness of the intervention, were coded using Content Analysis (Cole, 1988). Categories were identified inductively within the raw data and subsequently described (Thomas, 2006) and analysed quantitatively using descriptive analysis.

The above are all outcomes of interest for feasibility studies according to MRC and NIHR guidance (MRC, 2000; 2008; NIHR, 2013). Other feasibility studies have used similar outcomes to establish the feasibility and acceptability of their interventions (Blok et al., 2017; Foster et al., 2016; Schenker et al., 2015).

Results

Participant Demographics

Participants were oncology and palliative care professionals, and those in related fields (e.g., psycho-oncology). The majority of participants were from the UK or Australia and worked in oncology or palliative care settings for either the NHS or a charitable organisation; this is largely reflective of the recruitment strategy. Participants' mean age was consistent across the three time-points, and they were predominantly female. One participant listed their country of origin as Tanzania at follow-up although they did not state this in any previous time-points; they participated at all three time-points but appear to have misread the question. Demographic details for participants are displayed in Table 5.3.

Table 5.3. Participant demographics at all three time-points

Variable	**Baseline** n=97	**Post-intervention** n=16	**6-week follow-up** n=12
Age (mean [SD])	46.96 [10.64]	44.87 [12.82]	44.58 [14.16]
Sex			
Female	92	14	10
Male	4	2	2
Missing data	1	0	0
Country of origin			
UK	40	9	8
Australia	39	4	1
South Africa	4	0	0
Sweden	3	1	1
New Zealand	3	0	0
Philippines	2	1	0
USA	2	1	1
Canada	1	0	0
Bosnia & Herzegovina	1	0	0
Barbados	1	0	0
Tanzania	0	0	1
First language			
English	90	14	11
Swedish	3	1	1
Tagalog	2	1	0
Afrikaans	1	0	0
Serbian	1	0	0
Specialism			
Oncology	37	7	4
Palliative care	25	3	3
GP/community nursing	11	0	0
Social work	5	1	1
Psycho-oncology	4	2	1

Psychology	3	0	0
Administration	2	1	1
Intellectual disabilities	2	0	0
Support	2	1	1
Diet	1	0	0
Health	1	0	0
Physiotherapy	1	0	0
Occupational Therapy	1	0	0
Chaplaincy	1	1	1
Speech pathology	1	0	0
Employment sector			
National Health Service	34	7	5
Charitable Organisation	31	7	5
Local Government	14	2	2
Private Healthcare	13	0	0
Public hospital	2	0	0
Hospice	1	0	0
University	1	0	0
Missing data	1	0	0
Years in current post (mean [SD])	4.76 [4.88]	3.72 [4.37]	2.99 [3.20]
Previous working experience of intellectual disabilities	92.78%	87.5%	83.33%

Feasibility Question 1: Is it possible to recruit oncology professionals to this study?

Of the 11 organisations approached, seven agreed to share the study invitation by email or in a newsletter. Twelve of the 89 UK hospices approached agreed to send emails to staff. Details of all organisations approached are in Table 5.4. The majority of organisations were either in the voluntary sector or were professional societies. An estimated 10,000 people were sent a study invitation in an email or newsletter. During the eight-month recruitment period, 97 people responded to the initial questionnaire, representing a recruitment rate of less than 1% of the total population who were sent an invitation. It is impossible, however, to provide an accurate response rate as we do not know how many people read the invitation.

Table 5.4. Invited organisations and outcomes

Organisation	Organisation population	Month approached	Method of recruitment	Month of recruitment (and follow-up)
Cancer Council Queensland, Australia	40 staff and 1,882 members of the Health Professional Cancer Network in Queensland	December 2015	Mass emails	July 2016 (October 2016)
Breast Cancer Care, UK	1,061 members of the Nursing Network	December 2015	Nursing Network newsletter articles	May 2016 (September 2016)
European Oncology Nursing Society (EONS), Europe	Approximately 2,000 members	December 2015	Mass emails	June 2016
Maggies, UK	N/A	December 2015	Unable to support due to limited capacity for external research	N/A
UK Oncology Nursing Society (UKONS), UK	3,736 members	December 2015 and October 2016	Newsletter article	November 2016
Mencap, UK	N/A	July 2016	Unable to support as they were currently piloting their own project	N/A
British Psychosocial Oncology Society (BPOS), UK	Approximately 100 members	September 2016	Newsletter article	October 2016

Macmillan, UK	Approximately 1,900 cancer professionals	September 2016	Newsletter articles	October 2016
Individual Hospices (n=89 hospices) throughout the UK	Unable to obtain figures, due to the number of individual hospices approached.	September 2016 to November 2016	Mass emails (n=12 hospices) Unable to support due to limited capacity, or no response to request (n=77 hospices)	October 2016 to December 2016
British Psychological Society Division of Clinical Psychologists, Faculty for Oncology and Palliative Care (SIGOPAC), UK	Unable to estimate figures.	September 2016	Online post	October 2016
Tenovus, Wales	N/A	October 2016	Unable to support as they only support Wales-based researchers	N/A
Royal College of Physicians, UK	N/A	November 2016	Unable to support due to a limited capacity for external research	N/A
Royal College of Radiologists, UK	N/A	November 2016	No response within recruitment window	N/A

Feasibility Question 2: Are the content and delivery method of the intervention acceptable for participants?

A key indicator of acceptability of the intervention is engagement, both with the overall training package and, differentially, across the individual modules. Only 37% of the 43 participants who began the training went on to complete it. Data pertaining to engagement in the intervention for all 43 participants recruited to the intervention and the 16 who completed the post-intervention questionnaire are presented in Figure 5.3. It was not possible to ascertain the total number of views for the practise questions but it was possible to obtain figures about whether participants had accessed them. It appears that some participants viewed some videos multiple times, which would seem to indicate that participants have re-watched them to ensure that they have fully understood the concepts within them. There is a progressive dropout rate throughout the training, and 27 participants did not go on to complete the post-intervention questionnaire.

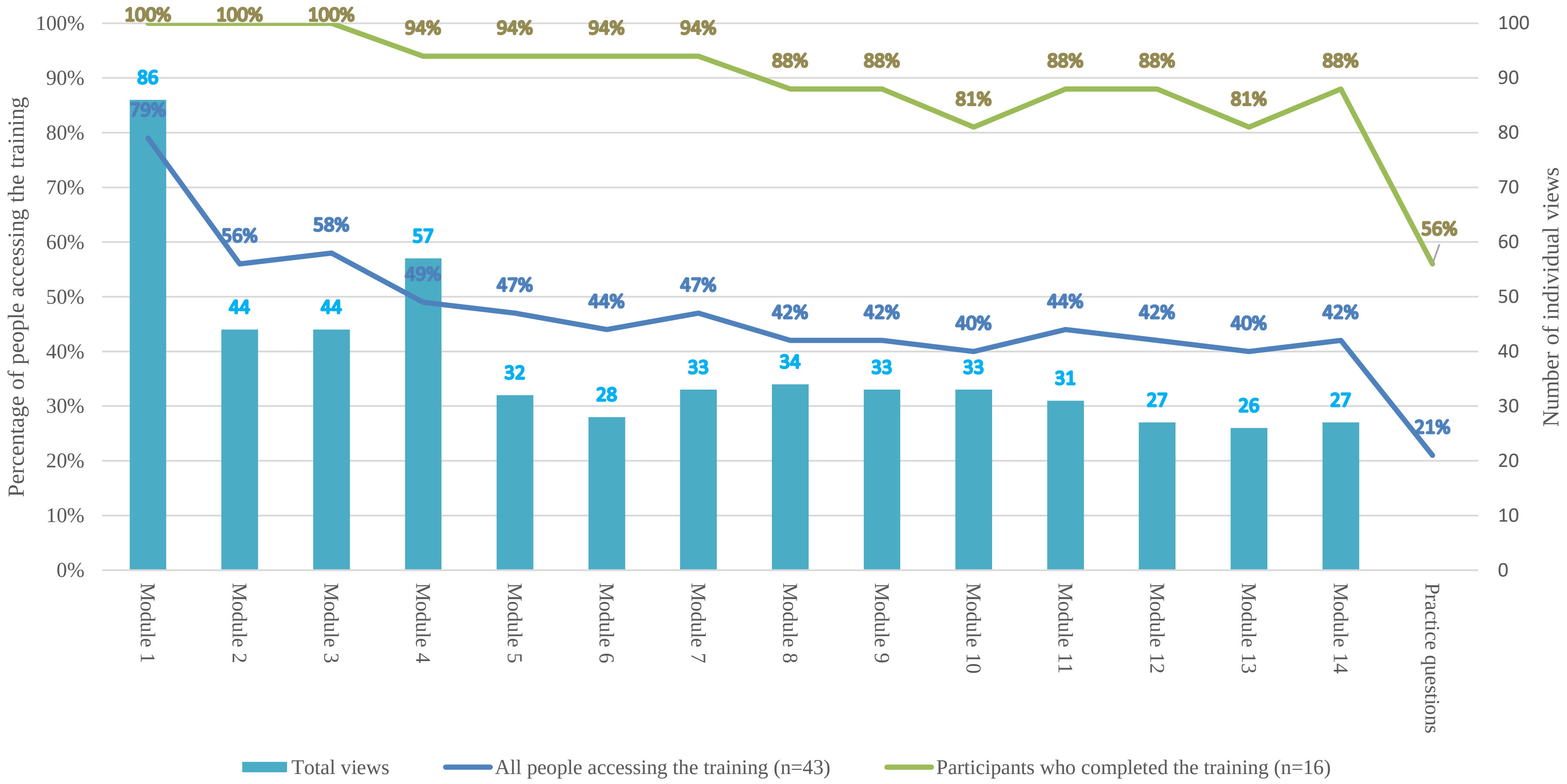

Figure 5.3. Participant engagement in training modules and practise questions (modules are numbered for brevity. Full module names are given in Table 5.2)

Using Chi-Square tests, no associations were found between intervention completion and participants’ sex (χ2(1)=3.4, p=.126), English as their first language (χ2(2)=1.344, p=.624), previous experience working with people with intellectual disabilities (χ2(1)=1.28, p=.585), contact with people with intellectual disabilities in the past month (χ2(2)=.762, p=.649), or whether such contact was in a professional capacity (χ2(1)=1.878, p=.265). Using t-tests, no significant differences were found between intervention completion and participants’ age (t(95)=.444, p=.176) or the length of time they had spent in their current post (t(94)=.935, p=.792). The use of statistical tests with small sample sizes in each comparator group can lead to an underpowered analysis, so these results should be interpreted with caution in the context of this small study.

Only participants who completed the full study reached the point at which free-text responses were invited (n=16). These participants made 27 comments about the usefulness of the intervention in the post-intervention questionnaire (Table 5.5). Full participant quotes are included in Appendix 49).

Table 5.5. A summary of participant feedback about the usefulness of the intervention

Participant feedback	***n***
The techniques in the training were very useful	8
The techniques in the training were useful	5
The training was a good reminder	2
It was good to see the techniques in action	2
I have learned new information from the training	2
The training was interesting	1
The training could also be used with people without intellectual disability	1
The techniques in the training were relevant to me	1
The techniques in the training were not useful	1
The techniques in the training were fairly useful	1
It gives a helpful starting point to plan my own consultations	1
I have learned some new information from the training, but it wasn’t all new to me	1
I didn’t learn anything new from the training	1

Participants (n=16) made a total of 19 specific comments about the most useful element and 18 comments about the least useful element (Table 5.6) in the post-intervention questionnaire.

Table 5.6. A summary of participant feedback about the most and least useful elements of the intervention

Most useful	***n***	**Least useful**	***n***
Seeing the techniques in context	6	Everything was useful	5
The effective strategies	1	Video buffering times	3
Confirming how much the patient understands	1	Practice questions could come after each video	2
Observing the "practitioners"	1	Website was not user friendly	1
A different approach to communication	1	Some videos were repetitive of others	1
It highlights common communication difficulties	1	More examples would be useful	1
Not using leading questions	1	Seeing techniques in context	1
Statements from support staff	1	Some videos were too staged	1
The structure of the techniques	1	Some videos were too short	1
Techniques are simple and easy to remember	1	Not being able to hear the patient respond	1
Nothing	1	Techniques will not lead to successful communication	1

Some participants (n=14) also commented on possible suggested improvements to the intervention (Table 5.7) in the post-intervention questionnaire (16 comments in total).

Table 5.7. A summary of participants' suggestions to improve the intervention

Participant feedback	***n***
Nothing	4
More examples	2
For training to be part of health service education	2
A technique sheet to print out	1
Video transcript	1
The site to be more user friendly	1
Tips about communication when carers are present	1
Would be better if actors didn't read from notes	1
Less repetition in videos	1
View videos one after another	1

Feasibility Question 3: Is it possible to retain oncology professionals to follow-up, and do they complete the questionnaires?

Of the 97 participants recruited, 43 enrolled on the intervention (44%), 16 (16.5%) completed the post-intervention questionnaire and 12 (12%) participants fully completed all three time-points. There were no responses to the two questions sent to all participants who had not completed the post-intervention questionnaire after two and four weeks, thus is it not possible to establish reasons for attrition. Figure 5.4 summarises loss of participants through the study. Demographic details for all time-points are displayed in Table 5.3.

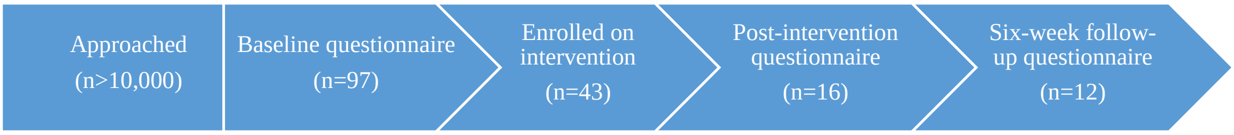

Figure 5.4. Participant process flow

Questionnaire completion rates at all three time-points were high, and only four participants had ≤5 missing values on the outcome measures. There was a substantial dropout by participants from Australia (90%). Both the mean number of years in post and the percentage of participants who had previous experience of working with people with intellectual disabilities reduced from baseline to post-intervention and follow-up, suggesting that participants who were less experienced in their role, and with working with the specific patient group, were more likely to complete the training and the associated evaluations (post-intervention and follow-up). This difference was not statistically significant, but that may be due to the small sample size.

Feasibility Question 4: Are the outcome measures suitable for what we wanted to measure?

Behavioural Intention Measure. A principal component analysis (PCA) was undertaken with the baseline data (n=97) on the five items of the Behavioural Intention Measure to determine the factor structure. Both the Kaiser-Meyer-Olkin (KMO) test of sampling adequacy (KMO=0.75) and Bartlett’s test of sphericity ($\chi^2(10)=222.62$, $p<.001$) indicated that the data were appropriate to undertake the analysis.

The Behavioural Intention Measure was a one-factor measure and explained 60.23% of the total variance. On the scree plot (Figure 5.5) this factor was the only one with an eigenvalue above 1 (Kaiser, 1970). Table 5.8 shows the factor loadings for this measure, all of which are higher than 0.4; the point at which they become statistically significant (Stevens, 1992). Furthermore, the Behavioural Intention Measure had good internal consistency ($\alpha=.82$) so is a reliable measure of behavioural intention to engage in conversations with people with intellectual disabilities about cancer. As the scale was unidimensional, a composite score will be used for the remainder of the analysis.

Figure 5.5. Scree plot for Behavioural Intention Measure

Table 5.8. Factor loadings for the Behavioural Intention Measure

Item	**Factor Loadings**
How willing do you feel to engage in a conversation with an individual with intellectual disability about their cancer, knowing that you might not be able to successfully communicate?	.88
How willing do you feel to use alternative communication strategies with an individual with intellectual disability about their cancer?	.86
How willing do you feel to engage in a conversation with an individual with intellectual disability about their cancer?	.81
How willing do you feel to actively engage an individual with intellectual disability in treatment decisions?	.70
How willing do you feel to sit with the feeling that you might not be successfully communicating with an individual with intellectual disability?	.60

Perceived Ability and Confidence in Communicating Measure. A PCA was also undertaken on the 25 model statements (5 model statements x 5 vignettes) of the Perceived Ability and Confidence in Communicating Measure, to determine whether they constituted a coherent measure. As the vignettes presented a different composite example of a person with an intellectual disability and cancer, these can be considered as different variations on the psychometric items. In the analysis, therefore, each combination of a model statement and the vignette about which it was asked was treated as a separate psychometric item, as these individual combinations were the stimuli to which participants were responding, and each of these were different. The data for this measure were also deemed adequate to undertake the analysis (KMO=0.81; Bartlett’s test of sphericity ($\chi^2(300)=1308.6$, p<.001)).

Six components with an eigenvalue of more than one were extracted which explained a combined 68.92% of the variance. However, as the first component explains more than 20% of the variance and the ratio between the eigenvalues of the first two components is 3.07, the decision was taken, following Reckase (1979), to retain only the first component. This is confirmed by scree plot (Figure 5.6). This one factor explains 32.27% of the variance. Factor loadings are presented in Table 5.9, all of which are statistically significant (Stevens, 1992). Within this study, the measure has poor internal consistency (α=.56). Considering the unidimensionality of this scale, a composite score will be used for the remainder of the analyses.

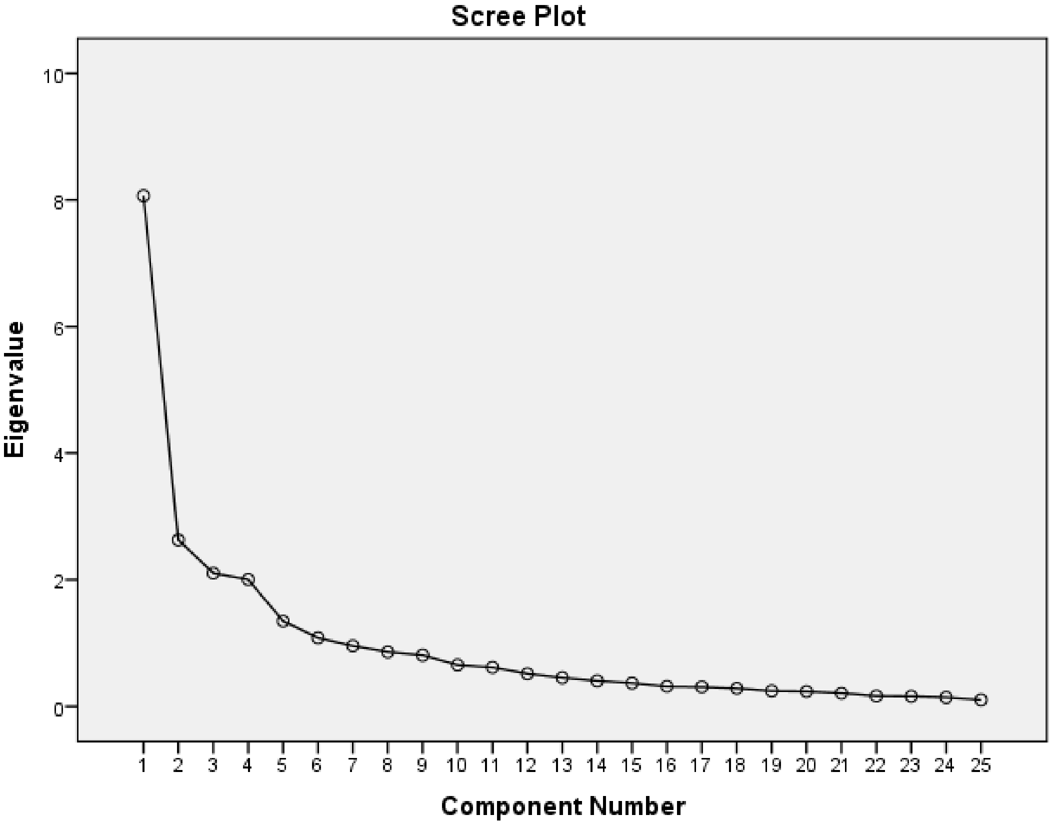

Figure 5.6. Scree plot for the Perceived Ability and Confidence in Communicating Measure

Table 5.9. Factor loadings for the Perceived Ability and Confidence in Communicating Measure

Vignette: Model statement	**Factor Loadings**
Vignette 3: "I feel confident that I would be able to identify and meet the needs of this patient."	.76
Vignette 2: "I feel confident that I would be able to identify and meet the needs of this patient."	.71
Vignette 5: "I believe that communicating with this patient would be stressful for me."	.67
Vignette 2: "I believe that communicating with this patient would be stressful for me."	.67
Vignette 1: "I believe that communicating with this patient would be stressful for me."	.62
Vignette 3: "I believe that communicating with this patient would be stressful for me."	.62
Vignette 5: "I feel confident that I would be able to identify and meet the needs of this patient."	.61
Vignette 2: "I would feel uncomfortable talking to this patient about their illness."	.60
Vignette 1: "I feel confident that I would be able to identify and meet the needs of this patient."	.59
Vignette 4: "I feel confident that I would be able to identify and meet the needs of this patient."	.57
Vignette 4: "I believe that communicating with this patient would be stressful for me."	.56
Vignette 2: "I believe that I would be able to successfully communicate with this patient."	.56
Vignette 3: "I believe that I would be able to successfully communicate with this patient."	.54
Vignette 3: "I would feel uncomfortable talking to this patient about their illness."	.53
Vignette 4: "I believe that I would be able to successfully communicate with this patient."	.52
Vignette 5: "I believe that I would be able to successfully communicate with this patient."	.51
Vignette 1: "I would be dependent on the person accompanying the patient to communicate with the patient."	.51
Vignette 1: "I would feel uncomfortable talking to this patient about their illness."	.43
Vignette 2: "I would be dependent on the person accompanying the patient to communicate with the patient."	.52
Vignette 1: "I believe that I would be able to successfully communicate with this patient."	.48
Vignette 3: "I would be dependent on the person accompanying the patient to communicate with the patient."	.49
Vignette 5: "I would be dependent on the person accompanying the patient to communicate with the patient."	.53
Vignette 4: "I would be dependent on the person accompanying the patient to communicate with the patient."	.49
Vignette 4: "I would feel uncomfortable talking to this patient about their illness."	.48
Vignette 5: "I would feel uncomfortable talking to this patient about their illness."	.52

The study design does not permit further examination of measure suitability, which was the ideal, as poor completion of the post-intervention and follow-up questionnaires was probably due to disengagement from the intervention.

Feasibility Question 5: Do participants perceive the intervention to be useful for their professional practice?

Evaluative feedback. Within the post-intervention questionnaire participants (n=16) were asked how likely they were to recommend the intervention to a colleague and to use their learning from the intervention in future interactions with people with intellectual disabilities. Responses for both questions are displayed in Figure 5.7.

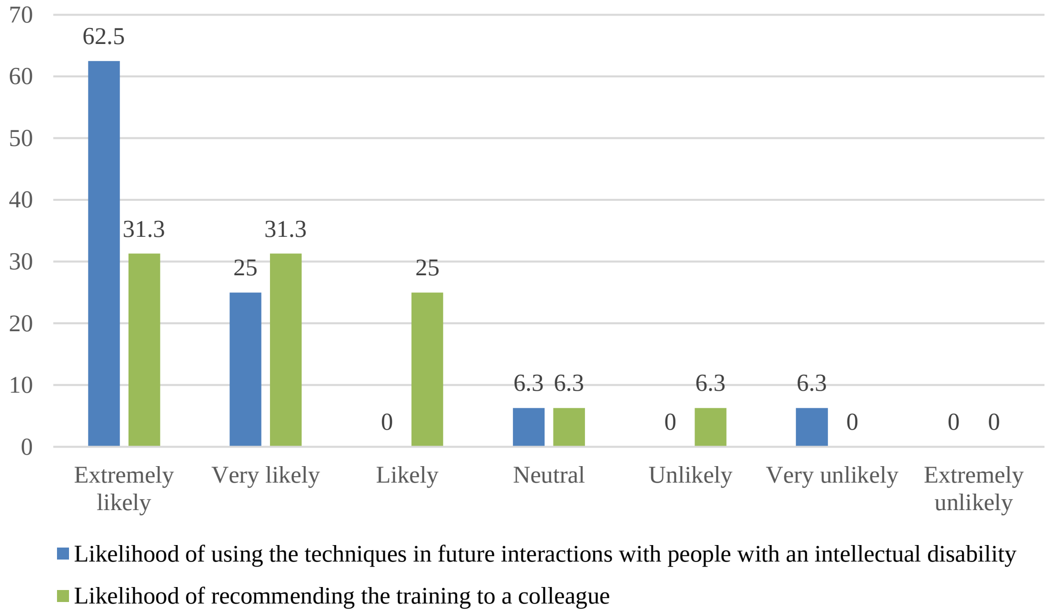

Figure 5.7. Likelihood (%) of participants (n=16) using the learned techniques in future interactions with people with intellectual disabilities and of participants recommending the training to a colleague

At follow-up, eight participants responded with 11 comments about how useful the intervention was for their interactions with people with intellectual disabilities (Table 5.10).

Table 5.10. Participants' evaluative comments at follow-up about the usefulness of the intervention

Usefulness of the training in interactions with people with intellectual disabilities	
Comment	***n***
Techniques were very useful	5
Have used techniques when communicating with patients	3
Techniques were helpful	1
Techniques reinforced current practice	1
Now have a good understanding about communicating with patients	1

Self-report outcome measures. There was a difference in sample size between participants who completed the baseline and post-intervention questionnaires only (n=16) and those who completed all three time-points (n=12). One-way repeated measures ANOVAs, were performed for the composite scores of both measures for the 16 participants who completed the baseline and post-intervention questionnaires only, and ANOVAs and pairwise comparisons were performed with the smaller sub-sample who completed all three time-points. The following results are indicative, as the sample size was small and should, therefore, be interpreted with caution.

Behavioural Intention Measure. There was a significant improvement in overall willingness to engage in conversations with cancer patients with intellectual disabilities ($F(1,15)=5.95$, $p=.028$, $\eta^2=0.08$) between baseline (M=26.25; SD=5.26) and post-intervention (M=29.00; SD=3.90) with a moderate effect size (Cohen, 1988).

There were also significant improvements in overall willingness for the 12 participants who completed all three time-points ($F(2,22)=3.54$, $p=.046$, $\eta^2=0.11$), with a moderate effect size (Cohen, 1988). Pairwise comparisons between all three time-points showed no significant differences for this sub-sample (Baseline and post-intervention: $p=.277$; Baseline and follow-up: $p=.140$; Post-intervention and follow-up: $p=1$). Descriptive statistics for these participants are displayed in Table 5.11.

Table 5.11. Descriptive statistics for the Behavioural Intention Measure for participants who completed all three time-points (n=12)

Time-point	**Mean (SD)**
Baseline	26.67 (5.57)
Post-intervention	29.25 (3.74)
Follow-up	30.00 (3.57)

Perceived Ability and Confidence in Communicating Measure. Significant improvements were found for the mean composite score on the Perceived Ability and Confidence in Communicating Measure ($F(1,15)=30.41$, $p<.001$, $\eta^2=0.25$) between baseline (M=15.61; SD=2.53) and post-intervention (M=18.80; SD=3.11). This was also the case for the 12 participants who completed all three time-points ($F(2,22)=19.73$, $p<.001$, $\eta^2=0.25$). Both of these results had a large effect size (Cohen, 1988). Pairwise comparisons indicate that there was a significant improvement between baseline and post-intervention ($p=.001$), and that this improvement was maintained at follow-up ($p=.003$). The difference between the post-intervention and follow-up scores was not significant ($p=1$). Descriptive statistics for these participants are presented in Table 5.12.

Table 5.12. Descriptive statistics for the Perceived Ability and Confidence in Communicating Measure for participants who completed all three time-points (n=12)

Time-point	**Mean (SD)**
Baseline	15.80 (2.41)
Post-intervention	19.05 (2.72)
Follow-up	19.30 (2.88)

A Pearson correlation was undertaken for the Perceived Ability and Confidence in Communicating Measure and the Behaviour Intention Measure at baseline (n=97); this was significant ($r=0.532$, $p<.001$), meaning that participants' intention to engage in communication with cancer patients with intellectual disabilities is significantly associated with their perceived confidence in their ability to do so.

Feasibility Question 6: Can a reasonable estimate of effect size be established for a full-scale trial?

Effect sizes from the Behavioural Intention Measure and the Perceived Ability and Confidence in Communicating Measure were moderate to large (η^2=0.08-0.25). These data were used in G*Power (Faul, Erdfelder, Lang, & Buchner, 2007) to determine the estimated sample size for a full-scale trial based on the smallest effect size (η^2=0.08) and a conservative alpha level of 0.005. For a full-scale trial, with two groups (intervention vs. control) and three time-points (baseline, post-intervention, and follow-up) and using a repeated measures ANOVA with within-between interaction effects, it was deemed that 66 participants would be needed. Based on the 12% retention rate to follow-up, this would indicate that the full-scale trial would need to recruit 550 participants at baseline.

Discussion

This study tested the feasibility, acceptability, and indicative effectiveness of a novel, brief, online, video-based intervention to improve healthcare professionals' perceptions of communicating with cancer patients who have intellectual disabilities. There were significant challenges with recruitment, retention, and adherence to the intervention. Despite the invitation being sent to over 10,000 people, the response rate was less than 1% and there was a sharp drop-off in participation between the baseline questionnaire and the intervention, and then, again, between the start of the intervention and the post-intervention questionnaire. Of 97 participants recruited to this study only 12 fully completed all time-points. More positively, participants who completed the intervention generally found it to be acceptable, and perceived it to be potentially effective in their professional practice. However, the high and consistent participant dropout rate indicates that these participants held the minority view. Results from this study indicate that the intervention is not feasible or acceptable in its current form.

It was possible to recruit oncology professionals to the study, but less than 1% of people who received an invitation were recruited, indicating that the recruitment method for this study was infeasible or otherwise ineffective. Oncology professionals surveyed in Chapter 4, and in the wider literature (Sowney & Barr, 2006; Tuffrey-Wijne et al., 2005), found communicating with people with intellectual disabilities to be particularly difficult. It is, therefore, surprising that the recruitment rate for this intervention was so low, particularly considering the diverse recruitment strategy. One potential reason for this is that it can be difficult to engage healthcare professionals in opt-in training, such as this intervention, whereas the provision of mandatory training may help unconsciously incompetent staff to recognise their need for skill development (Morell, Sharp, & Crandall, 2002). Unconsciously incompetent staff would be individuals who may have ignored the study invitation as they held a cognitive bias that they were already skilled in this area (Chapman, 2001). Whilst this may be the case, it is more likely that oncology professionals who felt that they were unskilled in this area were not confident that the intervention would help them to develop their skills, and so either ignored the invitation, or viewed the intervention and then disengaged from it when it did not meet their own perceived (or unperceived) needs.

It is possible that the advertising method was inappropriate for the intended population: online research, especially that which uses an unanticipated email request, often results in lower than expected response rates (Fan & Yan, 2010). Additionally, the advertising material was quite wordy, so, to address the aforementioned difficulties with online research (Fan & Yan, 2010), the advert in this study could have been more concise and more visually appealing to engage oncology professionals as they scrolled past the email or a section of a newsletter.

Retention of recruited participants was also challenging, and none of the participants who dropped out of the study responded to requests for data about the reasons for them dropping out and/or whether, in their opinion, any improvements needed to be made that might have made further participation more helpful to their own practice. This was intended to inform questions about the acceptability of the intervention content and method. Participants were aware that they would receive reminders to complete the intervention, and this survey was included within the reminders. It is very likely, therefore, that participants who had decided to disengage from the intervention did not open the email reminders and therefore did not see the survey requesting their feedback, or that they opened them and chose to ignore them. Researchers should consider this when designing trials, and could send requests for feedback separately, which could be conducted through different means (e.g., via the telephone, if participants consented to be contacted in this way).

High attrition rates are not unusual for online training courses and Long, Dubois, and Faley (2009) report that only 21% of employees who were enrolled on an online training course during a 14-month period completed it. Similarly, the Director of Learning for the Open University reported that attrition rates are often as high as 80% for eLearning courses (Flood, 2002). Although retention is a common problem for online training, it does raise questions about the feasibility of this training method for oncology professionals. Online delivery was considered to be a time- and cost-efficient training method (The Learning and Performance Institute, 2014) which is greatly needed in the NHS and charity sector (Dunn, McKenna, & Murray, 2016; National Council for Voluntary Organisations, 2016). It may be that online training is an effective method, but was just not suitable in this particular instance and, before any firm conclusions can be drawn about the suitability of this method, the opinions of oncology professionals should be sought. It may be possible to alleviate some of the barriers to online training engagement with this population by more thoroughly engaging a representative sample of the oncology professionals in the intervention development.

Although there is no objective data on why participants did not complete the intervention, there are many possible reasons for the high attrition rate (e.g., no time to complete it at work or home, it was non-mandatory training, or technical issues prevented engagement). However, high attrition may also indicate non-acceptability or non-suitability of the intervention content and/or delivery method. Participants who were more experienced were more likely to drop out of the study and not complete the intervention, indicating that more experienced professionals perceived the training to be less appropriate for their needs. It might be effective to engage medical trainees in this type of training from the outset, as they are receiving regular supervision with opportunities for the identification of unconscious incompetence and potential for skill development (Byrnes, Crawford, & Wong, 2012). This approach only accounts for a small percentage of practicing healthcare professionals and, as such, efforts must also be made to engage established healthcare professionals in this type of training to ensure that they recognise their need for development in this area. This finding in itself, that more experienced oncology professionals did not engage with the intervention, highlights that the content was not acceptable to all participants and this is a substantial flaw in the current work. Although participants who completed the intervention were generally satisfied with it, this point is somewhat overshadowed by the high attrition rate, which indicates that the majority view was that participants were, on the whole, dissatisfied with the intervention.

Both of the novel measures were unidimensional and explained a significant amount of variance. Completion rates for the measures were high across all three time-points, indicating that this element of the study was acceptable to participants. Although this study was not powered to detect changes following completion of the intervention, participants' behavioural intention and perceived confidence in communicating with cancer patients with intellectual disabilities improved from baseline to post-intervention and follow-up. This, along with participants' qualitative feedback in the post-intervention and follow-up questionnaires, indicates that participants perceived the intervention to be effective for their professional practice. Willingness to communicate with people with intellectual disabilities is correlated with their engagement in conversations about their life (Sowney & Barr, 2006) and in treatment decisions (as also found in Chapter 3 of this thesis). The findings from this feasibility study indicate that it is possible to improve the perceptions of communicating with people with cancer and intellectual disabilities and this correlates with behavioural intention to communicate with cancer patients with intellectual disabilities. We can be reasonably confident, therefore, that full engagement with an improved version of this intervention might improve communication practice. Findings from the wider literature also indicate that improved attitudes and perceptions can increase both the likelihood of difficult conversations taking place (Hemsley et al., 2012; Travado et al., 2005) and confidence and efficacy in communicating (Wilkinson et al., 1998). Increased willingness and confidence to have difficult conversations with people with intellectual disabilities about their cancer may have lasting effects on doctor-patient communication. In general population cancer populations, effective doctor-patient communication leads to better patient adjustment, well-being, and adherence to medical treatment (Arora, 2003; Zolnierek & DiMatteo, 2009). There is no reason to assume that this would be different in intellectual disabilities cancer populations.

It was possible to use the indicative effect sizes from this study to estimate the required sample size for a full-scale trial; however, when the retention rate was factored in to this it became clear that the figure was not feasible using the current study design considering the resources that were needed to recruit 97 people to the present study. However, modifying the intervention content might improve the dropout rate which could mean that a smaller sample will need to be recruited.

Study Evaluation and Suggestions for Future Development

It is clear from the results of this feasibility study that, despite some participants perceiving that it was effective for their practice, the vast majority of participants did not find the intervention to be acceptable and disengaged from it. It must therefore be concluded that this intervention was neither feasible nor acceptable in its current form. With this in mind, it was the right decision to undertake a feasibility (Phase II) trial initially, rather than conducting a Phase III RCT straight away. However, it has become apparent from the results that starting at the pre-clinical or Phase I stage would have been more appropriate. This Phase II trial was developed as it was presumed that there was enough insight and information from the scoping systematic review (completed before the systematic review presented in Chapter 2), the qualitative study (Chapter 3), and the survey of UK oncology nurses (Chapter 4), to start with a Phase II feasibility study. Having undertaken this feasibility study, it is clear that this foundation was not substantial enough and that it is necessary to further substantiate the theoretical and modelling elements and to refine the individual elements of the intervention (for both the content and the delivery method).

Although the experiences of people with intellectual disabilities were the basis for the development of this intervention, and a medical oncologist was consulted throughout the process, it has become apparent that this level of involvement was not substantial enough to facilitate the successful development of this intervention. Once redeveloped, the individual elements of the intervention should be tested and qualitatively evaluated using Patient and Public Involvement (PPI) (NIHR, 2017) with the target population (oncology professionals), and with people with intellectual disabilities and their caregivers, before another Phase II trial can be considered. This could include speaking to oncology professionals in different countries, as the attrition rate for Australian oncology professionals in particular was very high. A method akin to that of Foster et al. (2015) for developing their web-based RESTORE trial for fatigue self-management for cancer patients would be an appropriate starting point for the re-development of this intervention. To develop their intervention, Foster et al. (1)

undertook a systematic review of the empirical literature and guidelines, (2) conducted a scoping review to identify existing patient resources, (3) established a theoretical framework, (4) established a team of experts (including service users, academics, and clinicians) to design the intervention, (5) developed the prototype intervention, (6) user tested the intervention and undertook qualitative interviews, (7) refined the prototype intervention, (8) user tested the intervention again, and finally (9) refined the prototype ready to be tested in their exploratory RCT (Foster et al., 2016). The MRC (2008) identify that the steps necessary in developing an intervention are not always linear and may require some cyclical work, moving backwards and forwards through the phases to refine certain elements of the intervention before moving on. This is certainly a sensible recommendation on the basis of the findings from this feasibility trial.

Conclusions

The final study in this thesis aimed to develop an intervention to improve the perceptions of oncology professionals when communicating with cancer patients who have intellectual disabilities, and to subsequently test its feasibility, acceptability, and indicative effectiveness in this population.

The results of this study indicate that it was not feasible to recruit and retain oncology professionals to this study and that the content and/or delivery method were not acceptable to the vast majority of recruited participants. From the limited data available, participants who completed the intervention perceived that it was effective; this is not, however, enough to justify progressing to a Phase III RCT at present. Instead, it would be prudent to address the points of infeasibility through further pre-clinical and Phase I work before moving back to undertake another Phase II feasibility trial.

Chapter 6. Thesis Evaluation, Implications, and Conclusion

Chapter Overview

Considering the relative paucity of literature pertaining to the cancer-related experiences of people with intellectual disabilities compared with the general population (as reported in Chapter 2), the purpose of this thesis was to investigate the cancer experiences of people with intellectual disabilities, and those of the people who support them. As a body of work, this thesis aimed to develop a detailed understanding of their experiences (Chapters 3) and, through better understanding some of the difficulties of providing care for this population (Chapter 4), to develop and feasibility test an intervention to improve cancer experiences via improved communication between oncology professionals and people with intellectual disabilities and cancer (Chapter 5).

This concluding chapter will first address each thesis aim in turn with an overview of the findings of each study, and will outline how these findings have contributed to the development of subsequent studies and the wider literature. All four empirical chapters will then be discussed as a complete body of work, with associations being made between studies to support the assertion of four key messages from this thesis:

(1) Cancer patients with intellectual disabilities experience multiple difficulties in accessing equitable cancer care.
(2) Caring for cancer patients with intellectual disabilities is challenging for informal caregivers, intellectual disability staff, and oncology staff alike.
(3) With appropriate support, psychological and physical outcomes can be improved for cancer patients with intellectual disabilities.
(4) Improving communication might be an appropriate first step to improving cancer experiences for this population, but developing effective interventions presents numerous feasibility challenges.

Both personal and practical research reflections will be discussed in the closing sections of this chapter. Implications and recommendations for practice and research will then be provided, and a final conclusion drawn.

Thesis Summary and Evaluation

A summary of each chapter (Chapters 2-5) will be provided in this section, with particular attention being paid to how each study informed the development of subsequent studies, and to the value of the study in the wider psycho-oncology and intellectual disabilities literature.

Thesis aim 1: To systematically review the literature surrounding the psychosocial cancer experiences of adults with intellectual disabilities, and to identify the current status of, and gaps in, research evidence.

Systematic searches of online databases (in January 2018) identified 33,877 potentially relevant articles that were subsequently reviewed for inclusion in the review. Ten papers were included from these searches pertaining to the psychosocial cancer experiences of people with intellectual disabilities. Narrative synthesis of the included papers produced five themes: delayed diagnosis; information, communication, and understanding; negative psychological consequences; negative physical consequences, and; social support. Participants in these ten papers experienced delays in diagnosis due to inadequate information and care provision. Overall, these participants found the complex nature of cancer, and a general lack of understandable information, inhibitive of full understanding. They consequently felt uncertain, confused, and distressed about their diagnoses. Participants felt that their cancer was stigmatising, but the possible relationship between stigma about intellectual disabilities and stigma about cancer is not clear. Participants generally felt that social support was needed, but this was not always available and many people were lonely throughout their cancer experience.

The method used within this systematic review was rigorously tested and piloted on two occasions before the final search was undertaken, ensuring that the search terms were inclusive and that relevant research was returned. The paucity of research emanating from the broad and systematic searches supported the need for an in-depth exploration of the cancer experiences of people with intellectual disabilities. This was particularly pertinent considering that six of the ten papers presented data from the same ethnographic study of only 13 participants, indicating a limited representation of people with intellectual disabilities and thus raising questions about the generalisability of the review results. Further to this, nine papers were either purely descriptive accounts without formal analysis, or did not involve people with intellectual disabilities in data collection. The systematic review used a comprehensive search strategy and a robust methodology including searches of five online databases and the double-screening of records at both the screening and full inclusion stages. Although the searches were broad, and the inclusion criteria were inclusive, to maximise the number of included studies (Petticrew & Roberts, 2006), one key exclusion was that of children and young people (under 18). Whilst it is important to understand the experiences of this subgroup of people with intellectual disabilities, the diversity of cancer experiences between adult and child populations (CQC, 2014) was potentially too great to warrant the inclusion of a child/young person sample.

This systematic review was the first of its kind to be undertaken and serves to highlight the paucity of literature regarding the first-hand experiences of people with intellectual disabilities and cancer; from this we can begin to suggest some possible directions for future research. Suggestions for the direction of future research, based on the findings of the review, included:

- additional research to understand the experiences of people with intellectual disabilities who have a diagnosis of cancer, with a particular focus on such experiences for people with mild, moderate, severe, and profound intellectual disability (as opposed to only including people with mild intellectual disabilities);
- work to understand the information and support needs of people within this range of intellectual disabilities, and subsequently to identify whether these needs are being fulfilled;
- the undertaking of high-quality research with independent samples (many of the papers used the same dataset to draw their conclusions: Cresswell & Tuffrey-Wijne, 2008; Tuffrey-Wijne & Davies, 2006; Tuffrey-Wijne, Curfs, & Hollins, 2008; Tuffrey-Wijne et al., 2009; Tuffrey-Wijne, Bernal, & Hollins, 2010; Tuffrey-Wijne et al., 2010); and,
- the development and testing of interventions to improve the experiences of people with intellectual disabilities and cancer.

This evaluation of the published literature, and the suggestions for future research directions, were evident from undertaking pilot searches (in December 2012) and so the first empirical study was planned, in which an in-depth, rigorous, qualitative approach was used to establish the first-hand experiences of people with intellectual disabilities and cancer, whilst also including the perspectives of those who support them. This qualitative study built a foundation of research on which the remainder of this thesis was based.

Thesis aim 2: To investigate, in detail, the overall psychosocial experience of cancer diagnosis, treatment, and survivorship in adults with a diagnosed intellectual disability.

Six people with a mild intellectual disability and cancer were interviewed about their experiences of having cancer. These participants suggested an additional twelve people from their supportive network (including family, and social care and healthcare professionals) who were also interviewed to ensure a richness of data from multiple-stakeholder perspectives. As pilot searches for Chapter 2 had identified a paucity of relevant literature, objectivist grounded theory was used to inform the thematic analysis, as it is often used in research areas wherein little literature had been previously published. Although it was concluded in the systematic review (Chapter 2) that the experiences of people with all severities of intellectual disability should be examined in future research, it was not possible to do this within Chapter 3, as the NHS Research Ethics Committee (REC) stipulated that only participants with capacity to consent could be admitted to the study.

This study undertook a thematic analysis of psychosocial cancer experiences in people with intellectual disabilities, finding that people with intellectual disabilities could easily become cut off from their cancer experience but, with appropriate support, they could cope quite well with their illness. This has clear ramifications for healthcare professional-patient-caregiver communication and support provision and, ultimately, for patient engagement or disengagement with their cancer experience. People with intellectual disabilities in this study reported feeling overlooked within cancer consultations and/or excluded from conversations about their care and/or from treatment-related decisions. This perceived oversight led to feelings of confusion, anxiety, and frustration. Healthcare professionals often relied on caregivers to communicate with the patients, and this further inhibited honest or direct communication, as many caregivers professed a wish to protect patients from their illness. Strategies (e.g., humour or limited disclosure) appeared to be self-protective as caregivers were often uncomfortable engaging in conversations with patients and this could lead to patients becoming cut off from their own experience of cancer.

Further to this, patients often wished to protect caregivers from distress about their illness, thus increasing the barriers to meaningful engagement. Some healthcare professionals would often make additional efforts to involve people with intellectual disabilities in their own care and treatment, and some participants suggested that greater involvement and empowerment could lead to patients coping better with their illness than when this was not the case. Such areas of difficulty may be similar for cancer patients with and without intellectual disabilities, but the degree and incidence of difficulty appears to be greater for patients with intellectual disabilities, which is in line with previous findings about other health issues (Emerson & Baines, 2010).

Based on the findings from the systematic review (Chapter 2), this is the first study to undertake research informed by the principles of grounded theory to understand the cancer-related experiences of people with intellectual disabilities. This work was also the first of its kind to adopt a multiple-stakeholder design for data collection, enabling the broader reporting of experiences. As such, the current work made a valuable contribution to the literature. Although the thematic analysis was heavily guided by the principles of grounded theory, it was not possible to fully adhere to all aspects of grounded theory methodology and some pragmatic exceptions were made. Namely, it was not possible to adhere to theoretical sampling, and this deviation from grounded theory methodology may have influenced the developed thematic analysis as the “cut off” element is better-saturated than the “coping” element and this may have been different if theoretical sampling had been adhered to. It would have been beneficial to engage with people with intellectual disabilities during the development of this study; however, this could have further limited an already small sample of potential participants. It is for this reason that a thematic analysis informed by grounded theory was used, rather than a grounded theory study in its own right, as it was not possible to fully adhere to the implicit theoretical principles of grounded theory.

These novel contributions to the literature expanded our understanding of the cancer experiences of people with intellectual disabilities. Of particular pertinence to the findings from this study was the cycle of protection which fed into the role of caregivers in supporting people with intellectual disabilities, and highlighted the need to better understand strategies used by both caregivers and healthcare professionals in noticing and reducing potential psychological distress emanating from the cancer diagnosis, treatment, or prognosis. Another key implication for research from this work was the suggestion from patients and caregivers that healthcare professionals' patient-centred skills with people with intellectual disabilities and cancer were more important when supporting this patient population than was concrete knowledge about intellectual disabilities.

Oncology nurses were often reported as being a valued source of support for patients in this study, and this is reflected in the literature (Horrocks, Anderson, & Salisbury, 2002). Given that no oncology nurses were interviewed in the qualitative study, and considering the relative benefits that oncology nurses could have for the care of people with intellectual disabilities, and the evidence that this professional group are already stretched (Escot et al., 2001; Gomez-Urquiza et al., 2016; Toh, Ang, & Devi, 2012), it was necessary to come to a better understanding of their perceptions about caring for cancer patients with intellectual disabilities. Thus, the quantitative survey presented in Chapter 4 was developed to test the hypothesis that oncology nurses would perceive that providing care to people with intellectual disabilities would be more challenging than providing the same care to people without intellectual disabilities.

Thesis aim 3: To investigate the knowledge, awareness and experiences of oncology nurses regarding the care of adults with a diagnosed intellectual disability and cancer.

The perceptions of 83 nurses working in oncology or a related field (e.g., palliative care) about caring for patients with and without intellectual disabilities were measured alongside information about their previous intellectual disabilities experience and perceived stress. Participants responded to a series of vignettes (informed by the data from Chapter 3 and the wider literature in Chapter 2) which described cancer patients with and without intellectual disabilities, by indicating how they would feel about providing care to the described patients. They also provided information about where they would seek advice, and about any perceived additional training needs, to support them in providing care to people with intellectual disabilities.

Oncology nurses in this sample felt less confident and comfortable in providing care to patients with intellectual disabilities than they did providing the same care to patients without intellectual disabilities. Participants also believed that caring for this patient group would be more stressful than it would be to care for patients without intellectual disabilities. Sixty-one participants had previous experience working with intellectual disability patient groups, and exploratory analysis indicated that having previous experience of people with intellectual disabilities appeared to mitigate the negative perceptions of caring for this patient group. Participants also suggested that further training to support successful communication with patients with intellectual disabilities would be beneficial to the provision of care to this patient population.

This study added weight to the findings from Chapter 3 regarding healthcare professionals' communication with people with intellectual disabilities, particularly that oncology nurses in this sample found it difficult to know how to support this population, and were likely to communicate with the person supporting the patient rather than with the person with an intellectual disability. Research has previously been undertaken to examine the perceptions and experiences of oncology nurses caring for patients without intellectual disability (Emold et al., 2011), and the experiences of intellectual disability staff in supporting their client group (Mutkins et al., 2011; Skirrow & Hatton, 2007; Lin & Lin, 2013). However, the study presented in Chapter 4 is the first empirical study to examine the perceptions of oncology nurses about caring for cancer patients with intellectual disabilities, and thus makes a novel contribution to the literature. The use of vignettes allowed participants to express their care perceptions regardless of previous experience, as outlined by Braun and Clarke (2013), and the use of findings from previous research presented in this thesis and in the wider literature provided realistic and representative experiences for use within the composite vignettes (Bradbury-Jones et al., 2014). However, the small sample and limited participant pool (from one professional/academic society in the UK) limits the generalisability of findings from this novel study, and replication work in larger samples is warranted to extend the weight of these findings.

The findings from this study, particularly that oncology nurses felt less confident communicating directly with cancer patients with intellectual disabilities, and that they would value additional training specifically aimed at communication with people with intellectual disabilities, informed the final empirical study in this thesis. In developing and feasibility testing a novel, brief, online, video-based intervention to improve oncology professionals' perceptions of communication with people with intellectual disabilities and cancer (Chapter 5), it was intended that some of the negative experiences reported elsewhere in this thesis might be prevented, or at least minimised, in the future.

Thesis aim 4: To establish the feasibility and acceptability of a bespoke intervention to improve oncology healthcare professionals' perceptions of providing cancer care to people with intellectual disabilities.

The final study in this thesis involved the development and feasibility testing of a novel, brief, online, video-based intervention aimed at improving the perceptions of communicating with cancer patients who have intellectual disabilities. Ninety-seven participants completed a baseline questionnaire and 43 participants began the training; only 16 participants finished the post-intervention questionnaire, and 12 participants completed the 6-week follow-up questionnaire.

The results in this study indicate that it was not feasible to recruit and retain oncology professionals to this study, and that this was probably due to participants not liking the intervention content and/or delivery method, or not being confident that the intervention would benefit their practice. From the limited data available, it was evident that participants who completed the intervention perceived themselves to be more willing, confident, and able to engage in communication with patients with intellectual disabilities. This final point of feasibility is not, however, enough to justify progressing to a Phase III RCT at present; instead, it would be prudent to address the difficulties encountered in this feasibility trial through further Phase I work before moving towards undertaking another Phase II feasibility trial.

Patient-centred skills were deemed to be more important than concrete knowledge about intellectual disabilities by participants in the qualitative study (Chapter 3), and this study represents an important step in developing an intervention that specifically focusses on improving healthcare professionals' willingness and confidence to communicate with cancer patients who have intellectual disabilities. The development of the intervention was guided by the literature (Breaking Bad News, 2016; Chew, Iacano, & Tracy 2009; Finlay & Lyons, 2001; intellectualdisability.info, 2016), and by findings from the qualitative study in Chapter 3, to ensure the wider applicability of the techniques within the video vignettes. A broader recruitment strategy was adopted than the one used in Chapter 4, to include organisations from across the UK (e.g., Breast Cancer Care, British Psychosocial Oncology Society, etc.)

and some international organisations (e.g., Cancer Council Queensland and the European Oncology Nursing Society). It must be noted, however, that only English-speaking participants were able to participate and this may have limited the applicability of the training to some organisations outside the UK.

Overall Thesis Summary and Evaluation

This thesis extends empirical knowledge of the cancer-related experiences of people with intellectual disabilities, through the identification of the barriers to and facilitators of adaptive cancer-related experiences of people with intellectual disabilities and cancer, and through the development of a detailed understanding of these experiences (Chapter 3). The individual thesis chapters take different approaches in attempting to answer the overall question about the cancer-related experiences of people with intellectual disabilities and, in doing so, it is possible to ascertain alternative perspectives. This thesis culminates in four key messages, and these are:

1. *Cancer patients with intellectual disabilities experience multiple difficulties in accessing equitable cancer care*

This became apparent in the systematic review of cancer experiences (Chapter 2), and was confirmed by the participants (people with intellectual disabilities and their caregivers) in the qualitative study (Chapter 3). The survey of oncology nurses (Chapter 4) reinforced this finding as it was evident that oncology nurses felt unconfident and uncomfortable in providing care to cancer patients with intellectual disabilities, potentially inhibiting the meaningful engagement of people with intellectual disabilities in discussion and decisions about their treatment. Difficulties appeared at all stages of the illness trajectory (Chapter 3), and could go unnoticed as appropriate support was not always offered.

2. *Caring for cancer patients with intellectual disabilities is challenging for informal caregivers, intellectual disability staff, and oncology staff alike*

This was echoed throughout the qualitative study (Chapter 3) and the oncology nurse survey (Chapter 4), with all three groups (informal caregivers, intellectual disability staff, and oncology staff) finding this care to be challenging, and often outside of their skillset. Oncology professionals frequently relied on caregivers (family and intellectual disability staff) to facilitate communication with people with intellectual disabilities. This was not always effective, as caregivers sought to protect themselves and the person with intellectual disabilities from further distress. It was evident from the survey of oncology nurses (Chapter 4) that caring for this population was additionally challenging, compared with caring for cancer patients without intellectual disability.

3. *With appropriate support, psychological and physical outcomes can be improved for cancer patients with intellectual disabilities*

Some participants in the qualitative study (Chapter 3) were appropriately supported to understand and cope with their cancer diagnosis and treatment; it was these participants who reported that they had been able to adjust to their diagnosis better. This was also the case for participants in the studies included in the systematic review (Chapter 2) who were receiving social support throughout their experience. Barriers to appropriate support were often encountered by patients within their consultations and care, and included the reluctance to involve people with intellectual disabilities in discussions about their own cancer care (Chapters 2, 3 and 4).

4. Improving communication might be an appropriate first step to improving cancer experiences for this population, but developing effective interventions presents numerous feasibility challenges.

We know that effective doctor-patient communication can lead to improved physical (Zolnierek & DiMatteo, 2009) and psychological (Arora, 2003) outcomes in the general population, and from the data in Chapter 3 it is reasonable to assume that this would also be the case for people with intellectual disabilities. The study reported in Chapter 5 attempted to develop a novel, brief, online, video-based intervention aiming to improve healthcare professionals' willingness and confidence to engage in conversations with cancer patients with intellectual disabilities. Participants who completed the intervention perceived it to be beneficial for their practice; however, problems with recruitment and retention to this trial signal an infeasible study design, indicating that further development work is necessary before a full-scale trial can be undertaken. Once these challenges have been addressed, the likely benefits will be felt by healthcare professionals and people with intellectual disabilities alike.

Overall thesis evaluation. A recurring theme throughout the thesis was that sample size or sample homogeneity were limitations in all studies, although all study samples had their benefits. A strength of the research strategy within Chapters 3 and 5 was the development and implementation of a broader recruitment protocol midway through the research as it became clear that the current recruitment method was insufficient; this diversification led to more participants being recruited in both studies. Within Chapter 3, the sample of patients was small, but the addition of other stakeholders strengthened the interviews with people with intellectual disabilities. The heterogeneity of participants with a mild intellectual disability in this study was also a benefit, as male and female participants with a wide range of ages and cancer diagnoses were recruited. Nonetheless, these results are limited at present to people with mild intellectual disabilities. The exclusion of people who could not consent to research was a necessary ethical requirement, and future research could seek to explore the cancer-related experiences of people with more severe intellectual disabilities following this initial exploration. The sample size in the survey of oncology nurses (Chapter 4) was adequate, but it was recognised that this did not meet the a priori power calculation. Furthermore, a more geographically diverse sample would improve the generalisability of findings, as would including other oncology professionals. Finally, it was clear within the intervention study (Chapter 5) that participant recruitment and retention strategies limited the wider applicability of the findings, and indicated that the trial was infeasible. However, participants who completed the study did believe the intervention to be valuable to their everyday practice; therefore, further work should be undertaken to improve the feasibility and acceptability of this intervention prior to efficacy testing.

The disparity experienced by people with intellectual disabilities is likely to be reinforced by these difficulties in research, as numbers recruited to these studies were relatively small, even when recruiting internationally (Chapter 5). The difficulties experienced by participants in the three empirical studies did, however, echo those found in the systematic review (Chapter 2), and so this thesis has contributed by validating those small pilot studies where only small numbers of participants were recruited. Without a clear understanding of the cancer-related experiences of this patient group, and appropriate ways to support them, it will be difficult for oncology professionals to engage in fully evidence-based practice when providing cancer care to people with intellectual disabilities. This is important in the wider psychosocial oncology literature (Jacobsen, 2009), and should also be the case for people with intellectual disabilities. Groups for whom there is a have a potential disparity in healthcare experience compared with the general population are also generally those groups whose experiences are vastly under-researched, and this is likely to present a challenge to research that extends beyond intellectual disability populations (e.g., people who identify as LGBT [Fredriksen-Goldsen & Kim, 2017; Hulbert-Williams et al., 2017; Hughes & Cartwright, 2014] and those from ethnic minorities and migrant backgrounds [Bodewes & Kunst, 2016; Sze et al., 2015]). One of the key recommendations from the Cancer Taskforce (2015) is to ensure that the cancer experiences of people with intellectual disabilities is prioritised; this is reinforced by the Five Year Forward View (2014) and the Cancer Taskforce Equality Initiative (2015), to ensure that inequities in cancer care are identified and reduced. This thesis undertakes work that is integral to meeting those recommendations.

Personal Research Reflections

The process of undertaking this PhD has given rise to a number of challenges, and thus to opportunities for critical reflection. Some of these challenges have been addressed within previous chapters, and those most pertinent to my professional development have been included below.

The studies within this thesis were undertaken using a variety of methodologies, and there were advantages and challenges to undertaking a mixed-methods thesis. A key advantage of this method was that it was a pragmatic solution, and allowed me to use different research approaches based on how best to answer the research question at hand (Johnson & Onwuegbuzie, 2004). By first engaging in qualitative methods, and more specifically using grounded theory methodology to inform the thematic analysis (Chapter 3), it was possible to use both inductive and deductive methods to develop the themes and further research questions. Subsequent use of quantitative methods (Chapters 4 and 5) and deductive approaches enabled a series of research questions to be tested, further strengthening the assumptions within the qualitative study. The complexities presented by this mixed-methods thesis included the challenge of learning to proficiently use multiple methods, and ensuring that these were used to the advantage of the thesis, providing strength to the findings, rather than weaknesses. As most of my previous research experience was quantitative, I initially felt more confident with these elements of the thesis. I had previously used qualitative methodology, but had not undertaken any studies that used, or were informed by, grounded theory. To rectify this I was able to attend a grounded theory workshop at the beginning of my PhD, and learned how to effectively use this methodology for the purpose of my research. Learning how to use grounded theory was a time-consuming, but worthwhile, activity, as it gave me confidence in my ability and actions when undertaking the study in Chapter 3. Overall, the diverse methods used within this thesis have each enabled the appropriate examination of the research questions at hand.

During the course of this PhD (2012-2018), increasing national emphasis has been placed on involving relevant stakeholders in the development and undertaking of research (Patient and Public Involvement [PPI]; NIHR, 2017). Inclusive research ensures that studies remain relevant to the stakeholder groups for whom the research is about. This is particularly important for people with intellectual disabilities, as this group is often overlooked within research and healthcare policy (Durrell, 2016). PPI is a principle that I believe in strongly, but is a strategy that was not realised to its full potential within this thesis. This incongruence between principle and practicality is one that must be addressed within this concluding chapter. Involvement of oncology and intellectual disability professionals, and researchers, was planned for two of the empirical chapters in this thesis (Chapters 3 and 5). With hindsight, I could have sought the involvement of people with intellectual disabilities for both of these chapters; however, at the time of developing the work this was not considered to be a priority. On reflection, and with an improved understanding about the importance of PPI, the development of the empirical chapters in this thesis would have been strengthened by the active involvement of people with intellectual disabilities and the people who support them. It must be acknowledged that, without the involvement of people with intellectual disabilities, the studies presented in this thesis may have been biased towards a non-disabled viewpoint. However, I was constantly mindful of this possibility, and was guided by the data from the qualitative study in Chapter 3, thus engaging the viewpoints and experiences of people with intellectual disabilities in the development of the remainder of this thesis. PPI with people with intellectual disabilities is an area that I have gone on to practice in my subsequent research work (e.g., Richards, Williams, Przybylak, & Flynn, 2018), having developed my knowledge about the importance of this principle throughout my PhD.

The intervention that was developed and feasibility tested in Chapter 5 was a Phase II trial, based on the assumption that the information gathered from the previous chapters and from broader literature on communication skills training (CST), would provide a sufficient basis for developing the intervention (i.e. Phase I evidence). With hindsight, this was not the case as is demonstrated by the infeasibility of the intervention. In this way, I significantly underestimated the enormity of the task at hand when setting out to develop and feasibility test an intervention within this thesis. From this experience of developing and testing a novel intervention and from subsequent research assistant work on funded randomised controlled trials (Flynn et al., in preparation; Hastings et al., 2018; Hastings et al., in preparation), the scale of work to be undertaken before attempting a Phase II trial has crystallised. Whilst trial development can move between phases in a non-linear way (MRC, 2008), it is clear now that the groundwork for the feasibility trial in Chapter 5 was not substantial enough, and should have involved significantly more exploratory work with people with intellectual disabilities and with oncology professionals to better ensure feasibility and acceptability of the intervention content and delivery method.

The challenges inherent in recruiting and maintaining the engagement of healthcare professionals in research in the studies reported in Chapters 4 and 5 were particularly demotivating, and were the most difficult to overcome. Upon reflection about the recruitment strategies used within all chapters of this thesis, recruitment of people with intellectual disabilities to the qualitative study was also particularly challenging until I developed a working relationship with a Medical Oncologist through the Psychosocial Oncology Research Group at the University of Chester. This contact substantially improved recruitment rates for this study, which led to a more substantive and robust thematic analysis being undertaken. This highlights the benefits of such opportunities when developing and recruiting to a study, and what I learned from this was carried forward to the final empirical study in this thesis. Recruitment for the final study (Chapter 5) was primed by cold-calls to organisations where no working relationship existed, but was also enabled through existing relationships with researchers and professionals who I had met over the course of my PhD (e.g., people known to my supervisors, or my own contacts from previous research and national and international conferences). Although participant recruitment was difficult for the final study, there were seven organisations, as well as nine hospices, who were willing to disseminate the research invitation. With the exception of the hospices (who were cold-called), I had a working relationship with an individual from each of these organisations, which demonstrates the impact of developing working relationships with other research groups and organisations, and this personal approach could be implemented with participants as well. A more personal research strategy, such as face-to-face recruitment with verbal agreement from participants, can increase commitment (Gustafson et al., 1999), and therefore propensity to participate.

These challenges, whilst frustrating, have enabled me to develop a more rounded and practical approach to research. Problem-solving and a flexible approach to overcoming difficulties are two of the overarching skills that this PhD has imparted, both of which have continued to develop since completing the research within this thesis.

Having now completed the studies in this thesis, I have been able to reflect on my approach to research. I recognise that there are many ways to approach research into the psychosocial cancer experiences of people with intellectual disabilities, and the methods used in this thesis have been guided by those methods which were most appropriate to answer each thesis question in turn. I still believe that this positivist approach to research is the one that best suits my own epistemology. There is, however, a different direction that I would take were I to start this thesis again. Principally, having been able to further develop my skills and knowledge into grounded theory, I believe that I would now be able to follow grounded theory methodology, and the themes emerging from the data, more closely by persevering and undertaking theoretical sampling for people with intellectual disabilities and cancer. Although I still consider myself to be a mixed-methodologist, I think that my approach to the qualitative study and to my analysis of the data was too tentative and I could have followed the data more effectively. This more robust approach, as opposed to undertaking a series of smaller, mixed-methods studies, may have led to a theory emerging from the data which formed the entirety of this thesis.

Practical Research Reflections

Evidently, from the findings in this thesis, research into the cancer-related experiences of people with intellectual disabilities, and into how best to support this patient group, is greatly needed. People with intellectual disabilities may be experiencing a disparity in the level of difficulty they face in accessing and engaging in appropriate cancer care (Chapter 3) compared with the general population, and this is likely to have an impact on their short-term and long-term outcomes. This research is, however, difficult to undertake; there are difficulties in engaging people with intellectual disabilities in research, and some of these were encountered within this thesis, including:

- “gatekeepers” preventing full participation (Chapter 3);
- caregivers protecting the person with an intellectual disability from information about their diagnosis and/or prognosis (Chapter 3);
- ethics committees being reluctant to allow exploration of experiences with people who have more severe intellectual disabilities (Chapter 3); and,
- people with intellectual disabilities and cancer not being identified by services (Chapter 3).

There were two types of gatekeeping behaviour encountered during this thesis: (1) facilitators deciding not to approach or continue to discuss the research with potential participants after a change in their prognosis and (2) caregivers deciding what topics could be discussed with the participant with an intellectual disability. Both of these gatekeeping behaviours prevented full participation of people who had advanced and palliative cancer diagnoses. This has significant implications for the extent to which we can explore experiences of these advanced diagnoses in people with intellectual disabilities, thus limiting the development of policy and practice guidelines that are congruent with the experiences of this sub-population. By more-actively engaging facilitators and caregivers in the research process and explaining the importance of exploring the experiences of this sub-group, it may become less challenging to speak directly with people with intellectual disabilities and advanced cancer. Clearly, researchers would have to seek their fully-informed consent before such potential participants would be able to participate in any research, and people in this sub-group may decline the invitation to participate; but enabling people to make their own decision about participating in research would break down a significant barrier to understanding these experiences, and would ensure that they are recognised and represented in the literature, policy, and practice guidelines. One of the reasons behind the second type of gatekeeping behaviour was that caregivers were reluctant to fully disclose information about the person’s diagnosis or prognosis for fear of distressing them further. This extends beyond the importance of research being undertaken with people with intellectual disabilities, and becomes an issue of withholding information from people with intellectual disabilities, potentially preventing them from understanding, or accepting their illness. It was evident in Chapter 3 that people who were more fully involved in their cancer experience were better able to understand and adjust to their diagnosis, and were more actively involved in decision-making. Without changes in practice, including support for caregivers to share bad news with people with intellectual disabilities, this will continue to be a barrier to undertaking research with this population. Guidelines have been developed for this purpose (Breaking Bad News, 2016) and, if more widely disseminated, would be a valuable resource for oncology professionals working with people with intellectual disabilities.

Another barrier to fully understanding and representing the experiences of all people with intellectual disabilities is the reluctance of some ethics committees to grant approval to undertake research with people who lack the capacity to consent to participate in research. Whilst it is clear that additional measures are needed to ensure that people with intellectual disabilities who do not have capacity to consent are safeguarded from undue distress, it is important to understand their experiences in order to inform policy and practice. The British Psychological Society (BPS, 2008) published a guide for researchers wishing to undertake research with people who lack the capacity to consent to participate. This guide draws heavily on the Mental Capacity Act (2005). It recommends that, if a person is deemed not to have capacity to consent after reasonable adjustments (e.g., alternative communication methods) have been applied, they should be included in research if (1) the study has been approved by an appropriate ethical body (e.g., NHS Ethics Committee), (2) the researcher has consulted with other people who are not involved in the research about involving the person who does not have capacity, (3) the best interests of the person without capacity are considered above all potential benefits to others, and (4) signs of objection to the research are acknowledged. Consultations should be with a “trusted person” to the person without capacity, for example a relative or friend, but not a paid carer. When the research pertains to knowledge about a condition or care (as is the case with this thesis), there should be a negligible risk to participants when there is no direct benefit to them participating, and there should be no restriction of liberty or privacy, nor should the research be unduly invasive. This guide should be adhered to, and cited within ethics applications, to ensure that appropriate safeguards are in place to enable the participation of people who lack the capacity to consent. Additionally, it may be beneficial for researchers who are inexperienced in research with people without capacity to undertake theoretical and practical training before approaching research of this kind. Involving this sub-population of people with intellectual disabilities in research is likely to mean the adoption of alternative research methods (e.g., Talking Mats to allow people with significant communication impairments to express their views [Murphy, 1998]).

Challenges exist, and have been encountered within this thesis, when research has been undertaken with healthcare professionals, including:

- participant recruitment and retention difficulties in research (Chapter 4 and 5); and,
- low participant engagement and retention to training (Chapter 5).

Recruiting and retaining healthcare professionals into research was challenging within these research studies, and this was the case even when a larger number of organisations were approached about disseminating the study invitation to their staff or society members. It is possible that difficulties with recruitment were an artefact of the online recruitment method, as unanticipated requests for participation can result in low response rates (Fan & Yan, 2010). A more personal, but also more labour- and time-intensive, strategy would be to follow a multi-faceted recruitment method, with face-to-face or telephone recruitment being undertaken in an attempt to increase the propensity to participate through obtaining verbal agreement to participate (Gustafson et al., 1999). Members of the target participant population could be consulted about their preferred method for recruitment, as this could lead to more insightful and effective recruitment methods. Further to this, data collected from participants who drop out would be valuable in understanding the reasons for non-completion of questionnaires and non-adherence to interventions. This was the intention of the study reported in Chapter 5. However, no participants responded to requests for data about non-completion, which limited understanding of the barriers to taking part. Providing more opportunities for participants to share their reasons for disengaging with the research project could be effective (Salyers-Bull et al., 2004).

Similarly, engaging healthcare professionals in the intervention was particularly difficult. Upon examining the data from this feasibility study, it is most likely that the content and/or the delivery method were not acceptable to participants and so they disengaged from it. Some participants highlighted that they had technical issues with the intervention, and this is known to inhibit online course completion (Packham et al., 2004). Some participants were also displeased with the video staging and/or the content, and this is likely to have led to dropout for many of the participants who registered on the intervention but did not complete it. Although it was believed that there was sufficient understanding of the substantive area and practical considerations upon commencement of this study, it is apparent now that this was not the case. Many of these difficulties can be examined in more detail in subsequent pre-clinical and Phase I development work before the revised intervention undergoes feasibility testing.

Implications for Future Research

The experiences of people with intellectual disabilities were explored in depth in Chapter 3; however, some research questions were raised during the course of this study which were beyond the scope of this thesis, and these could be researched in greater depth in future research programmes.

One of these is the further quantitative study of perceived health inequalities in direct comparison with a general population sample, to establish where and why experiences demonstrate a disparity, and to begin to develop strategies to make them more equitable. The Cancer Patient Experience Survey (e.g., Quality Health, 2016) could be an opportunity to achieve this aim; however, the survey does not have a high recruitment rate for people with intellectual disabilities. This may be due to the format of the survey, and alternative formats should be developed in collaboration with people with intellectual disabilities, to ensure that they are accessible for people with different information needs.

Another initiative that could lend itself to research is the Check4Change (Macmillan, 2016) programme of work; evaluation of this peer-led workshop to improve symptom awareness in people with intellectual disabilities would provide a sound rationale for the wider roll-out of this service from Wales to the rest of the United Kingdom, and possibly beyond. This research project has relevance to the findings from this thesis as, in Chapters 2 and 3, it was clear that delayed presentation of symptoms was common, and one of the reasons for this delay was participants not knowing the signs and symptoms of cancer. One participant in the qualitative study

(Chapter 3) was taught to self-check, and this led to early presentation of symptoms and a subsequent early-stage diagnosis; the Check4Change seminars may increase the number of people for whom this is a possibility. The Check4Change seminars are practical and hands-on (with people learning practical checking skills using prosthetic breasts and testes), and this could be difficult for some people with intellectual disabilities as there is still a taboo about discussing intimate topics with this population (Sullivan et al., 2013; Winges-Yanez, 2014) and they may feel that they are not supposed to talk about them. However, as the sessions are peer led, potential barriers to engagement, caused by the presence of people who might be sensitive to such taboos about the discussion of intimate subjects, may be broken down. Engagement and perceptions of the seminars could be measured as part of the evaluation of the project.

Other programmes of work that seek to improve the self-determination and empowerment of people with intellectual disabilities and cancer should also be considered. This could include the development of a resource to promote active engagement in diagnosis- and treatment-related conversations for this population, as this was considered to be important by participants in the qualitative interviews. This was explored, to some degree, in the intervention study (Chapter 5) from a professional perspective, and research should continue to work to improve healthcare professionals' willingness, confidence, and ability to communicate with this population. Another way to do this would be to develop a resource for people with intellectual disabilities, and their caregivers, to use before attending appointments; this is becoming commonplace in non-intellectual-disability populations (e.g., Ask Share Know, 2013). The study could take the Ask Share Know approach by prompting people with intellectual disabilities, or their caregivers, to ask three key questions in each appointment. Doing so is likely to improve both the information given by healthcare professionals, and the likelihood that the healthcare professional would promote patient involvement (Shepherd et al., 2011). Alternatively, people with intellectual disabilities could be given a resource akin to the Talking Books developed by Smith et al. (2015). This resource provides written information, summaries, and pictures, in a book, and readers have the option of listening to the book instead of reading it, accounting for people with different levels of both functional literacy and health literacy. The Talking Books were developed for people with low health literacy, and not specifically intellectual disabilities; but, with PPI involvement, they could be adapted to suit the needs of this specific population.

Further exploration of the psychological aspects of cancer for people with intellectual disabilities is warranted, and the potential utility of the DisDAT distress screening tool (Regnard et al., 2007) could have been beneficial for participants in the qualitative study (Chapter 3). Distress screening in non-intellectual-disability populations is usually time-consuming, with 37.5% of surveyed clinicians (n=50) in a recent study believing that distress screening was impractical for routine use (Mitchell et al., 2012). The DisDAT is slightly longer than distress screening tools for people without intellectual disabilities, and this presents additional challenges to ensuring completion of the screening. A feasibility study exploring the barriers and facilitators to implementation would be a useful first step towards including distress screenings in routine appointments for people with intellectual disabilities and cancer.

Regarding the experiences of healthcare professionals, this thesis provides much-needed insight (Chapters 4 and 5), but additional research is required to establish whether any particular barriers or stressors exist when providing cancer care to people with intellectual disabilities. The survey study (Chapter 4) used vignette methods to examine perceptions of caring for this population, and further research should aim to interview oncology professionals with experience of working with people with intellectual disabilities to ascertain their experiences of caring for this patient group. This work would add to the knowledge base from this thesis, and would provide additional suggestions for improvements to the support of oncology professionals when caring for this population. Although the intervention content and/or delivery method, and the recruitment and retention strategy used in the feasibility study (Chapter 5), were not practicable, the intervention was perceived to be beneficial in practice for those participants who completed it. It would be beneficial to further develop the intervention as part of a future research strategy following guidance from the Medical Research Council (MRC, 2000; 2008).

This thesis has highlighted that there are difficulties in recruiting, and undertaking research with, people with intellectual disabilities (Chapters 2 and 3) and healthcare professionals (Chapters 4 and 5). These difficulties are a recurring theme in research in this area, and should be explored further to enable the development of appropriate strategies to reduce their impact.

Implications for Practice, Policy, and Support Provision

The ethos of ‘no decision about me, without me’, which is outlined in Improving Outcomes: A Strategy for Cancer (Department of Health, 2011), is particularly pertinent in light of the findings in this thesis. Participants in the qualitative study described the exclusion (both intentional and unintentional) of people with intellectual disabilities from discussions and decisions regarding their own cancer care. Enabling the meaningful engagement of this patient group will require some additional degree of expertise and effort from oncology professionals. The survey of oncology nurses which followed highlighted that oncology nurses felt uncomfortable and unconfident in communicating with, and providing care to, cancer patients with intellectual disabilities. This will potentially lead to exclusion from discussions and decision making, as participants in this sample indicated that they would be reliant on the person accompanying the patient to communicate with them, further highlighting the inherent difficulties for people with intellectual disabilities to be involved in conversations about their cancer. Whilst caregivers believed that they were protecting the patient from the negative impact of cancer, this protection was inhibitive of full and meaningful involvement in the cancer experience of the patient.

Successful doctor-patient communication has the potential to improve patient well-being (Arora, 2003) and adherence to medical treatment (Zolnierek & DiMatteo, 2009) in the general population, and it is reasonable to assume, from the findings presented in the qualitative study, that this would also be the case for patients with intellectual disabilities. Less reliance on caregivers is likely to lead to less stress and burden for this group. Finally, greater confidence in their skills may also benefit the oncology professionals themselves, as self-efficacy in communication ability is correlated with levels of burnout (Travado et al., 2005).

Promotion of independent and healthy lives through the NHS Outcomes Framework is extremely applicable to people with intellectual disabilities, as evidence of health inequalities indicates that there is still work to be done to achieve this for people with intellectual disabilities (Emerson & Baines, 2010). This is an important aim for the Cancer Taskforce (2015). The Be Clear on Cancer campaign’s work to improve early diagnosis of cancer (Cancer Research UK, 2017), however, was clearly ineffective for participants in the qualitative study (many of whom received a late diagnosis), despite the fact that intervening for this purpose is demonstrably easy and effective, as was shown by Elaine (Chapter 3), who was simply told to check her breasts for lumps which she then did. Through involving people with intellectual disabilities as much as is possible as partners in their own healthcare (e.g., Check4Change [Macmillan, 2016] as discussed above), and following reasonable adjustments, it may be possible to increase empowerment and engagement. This type of self-determination may also see increases in the well-being of this population (Lachapelle et al., 2005), and may lead to increased early symptom reporting and vigilance, and better psychological adjustment (as was seen in Chapter 3).

It has been demonstrated that people with intellectual disabilities could be more meaningfully involved in their cancer experience, and the recommendations of the Mental Capacity Act (2005) and the Equality Act (2010) could facilitate this. With appropriate support to comprehend information, and reasonable adjustments being made, people with intellectual disabilities will be better able to take an active role in their experience, and potentially access equitable healthcare. Strategies to support this involvement include:

- promoting open communication with this patient group to promote better understanding, adjustment, and meaningful engagement (Chapter 3; cf. Tuffrey-Wijne et al., 2009);
- providing peer-led programmes to enable self-checking for cancer symptoms for early diagnosis (Chapter 3);
- knowledge exchange between intellectual disability and oncology professionals (Chapter 4);
- the provision of training for oncology professionals to promote person-centred and appropriate care for this patient group (Chapter 5); and,
- active promotion of shared decision-making with the patient and with the people who are important to supporting them (Chapter 3).

The implementation of these strategies will not only benefit the physical and psychological well-being of the person with an intellectual disability and cancer (Arora, 2003; Zolnierek & DiMatteo, 2009), but also has the potential to improve the caring experience of healthcare professionals (Travado et al., 2005) and caregivers, leading to a better experience for all involved.

Conclusion

This chapter has drawn together the four studies from this thesis and, in doing so, four key messages have been identified:

(1) Cancer patients with intellectual disabilities experience multiple difficulties in accessing equitable cancer care.
(2) Caring for cancer patients with intellectual disabilities is challenging for informal caregivers, intellectual disability staff, and oncology staff alike.
(3) With appropriate support, psychological and physical outcomes can be improved for cancer patients with intellectual disabilities.
(4) Improving communication might be an appropriate first step to improving cancer experiences for this population, but developing effective interventions presents numerous feasibility challenges.

This thesis has demonstrated that challenges exist in the provision of high quality and equitable cancer care to people with intellectual disabilities, and that these challenges exist both for the patients themselves, and for those who support them. The findings from this thesis demonstrate the need for high-quality research in this area; little existing research was identified in the systematic review (Chapter 2), and what little there was included papers that were mostly derived from the same dataset. This thesis demonstrates that there are many barriers to conducting high-quality research in this area, particularly in identifying and engaging participants. These problems must be fully understood and addressed as we continue to research the cancer-related experiences of people with intellectual disabilities. Participants in the qualitative study (Chapter 3) described difficulties in understanding information, being meaningfully involved in their cancer care, and in being appropriately supported to cope with their illness, and these issues led to feelings of anxiety and distress. Some of these difficulties were also evident in the data from oncology nurses who participated in the survey (Chapter 4), and an intervention was developed and feasibility tested in Chapter 5 to attempt to address some of these difficulties. Although the intervention was found to be infeasible in its current form, the majority of participants who completed it perceived it to be beneficial to their practice and this demonstrates that this intervention, once further developed and tested, has the potential to improve the quality of communication with people with intellectual disabilities in clinical settings. Based on the findings from these empirical studies (Chapters 2-5), it is of the greatest importance that people with intellectual disabilities are supported to meaningfully engage in their experiences, but equally important that oncology professionals receive appropriate training and support to successfully engage this population.

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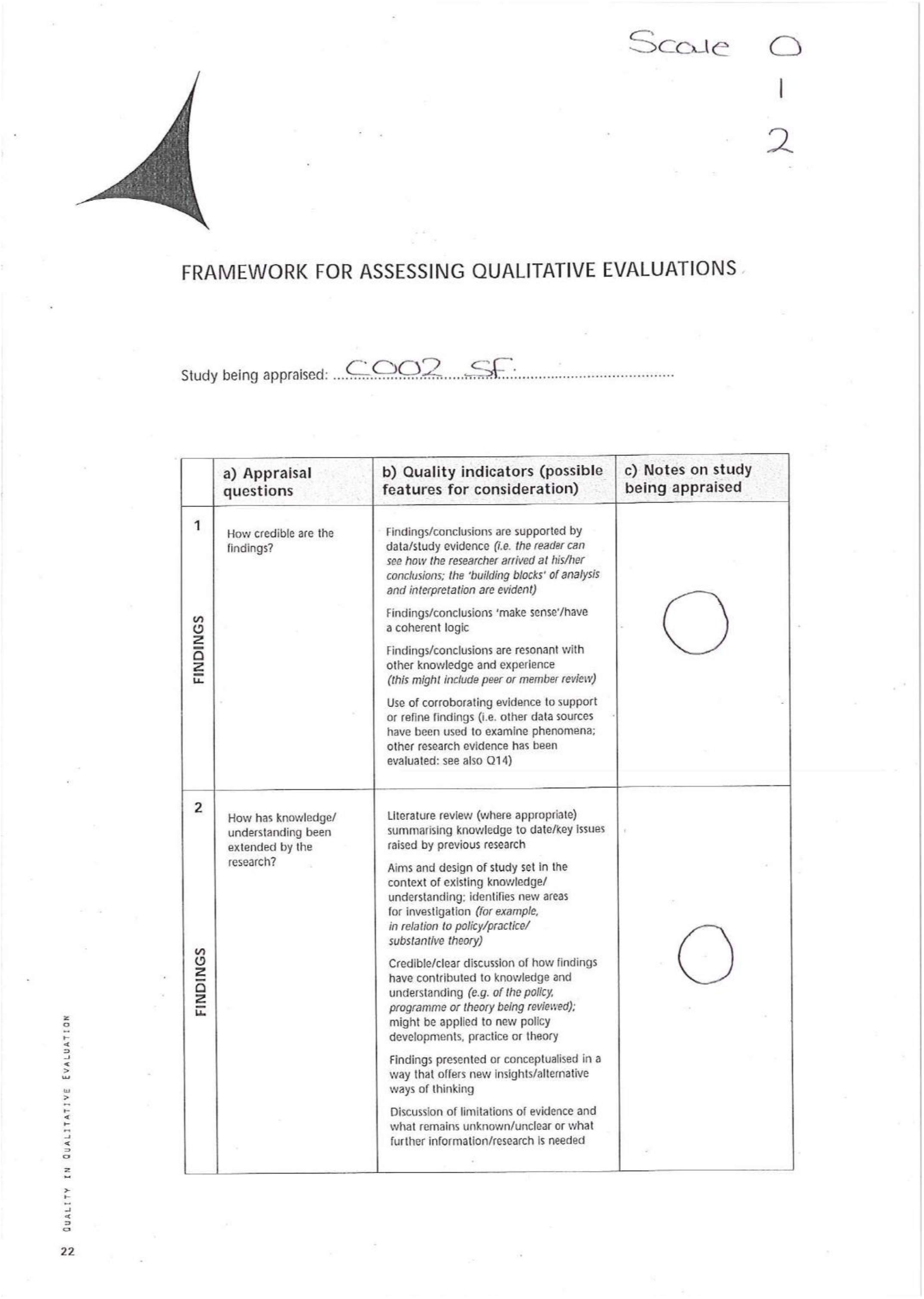
Appendix 1: Example data extraction form (Chapter 2)

Study ID	C002 SF
Main Author	Cresswell
Date	2008
Country	UK
Journal	British journal of learning disabilities
Title	The come back kid: I had cancer, but I got through it
Issue and page No.	

CATEGORY	DATA EXTRACTED
Participants:	
Total sample (n)	1
Intellectual disabilities represented?	Y – cerebral palsy and learning disabilities
Age	30
Response rate	1
Experiences:	
Experiences studied?	Y – Noticing something was wrong, diagnosis, treatment, life after cancer
Method of research? (e.g. questionnaire, observational)	One woman writing about her experiences
Qualitative/Quantitative ?	Qualitative
Outcome measures used?	None
Statistics?	None
Intervention:	
Type	None
Timing	None
Delivery	None
Facilitators (inc No., gender, and qualifications/training)	None
Clinical details:	
Chronic illness type	Cancer – non-Hodgkin’s lymphoma
Illness stage	Not stated
Any other illness present?	Not stated
Time since diagnosis	6 years
Length of Treatment	Not stated
Type of Treatment	Chemotherapy, steroids and radiotherapy
Summary of main findings	No findings as such – Main themes are: GP said there was nothing wrong No one at the first hospital would tell her what was happening, apart from one nurse First hospital were using language she didn’t understand Second hospital told her about her diagnosis on her own, without carers present Doctor explained everything in simple language and explained options

	Knew what chemotherapy was, doctor explained to her what would happen Not allowed to see friends in case she got an infection – described as her lowest time Would talk to her mum when she was upset (Mum is deceased) Received support from social worker, friends and carers Having faith helped her cope Very happy when told she was in remission Participant now teaches doctors and nurses about cancer experiences for people with learning disabilities It's really important for people to know about their cancer, told in a way which they can understand Participant would have liked someone to talk to Having cancer has made her stronger
Ethics and informed consent	Participant waived her right to anonymity, was approved by the Veronica Project Steering Group (including 3 advisors with learning disabilities) and by South East Multi-Centre Ethics Committee
Limitations	SF – One participant, cannot be generalised. No analysis of the monologue done.
Recommendations for future research	None
Author comments	None
Reviewer comments	Not sure if this should be included as there has not been any analysis undertaken on the data.

Appendix 2: Framework for Assessing Qualitative Evaluations (FAQE; Spencer et al., 2003) for qualitative studies (Chapter 2)



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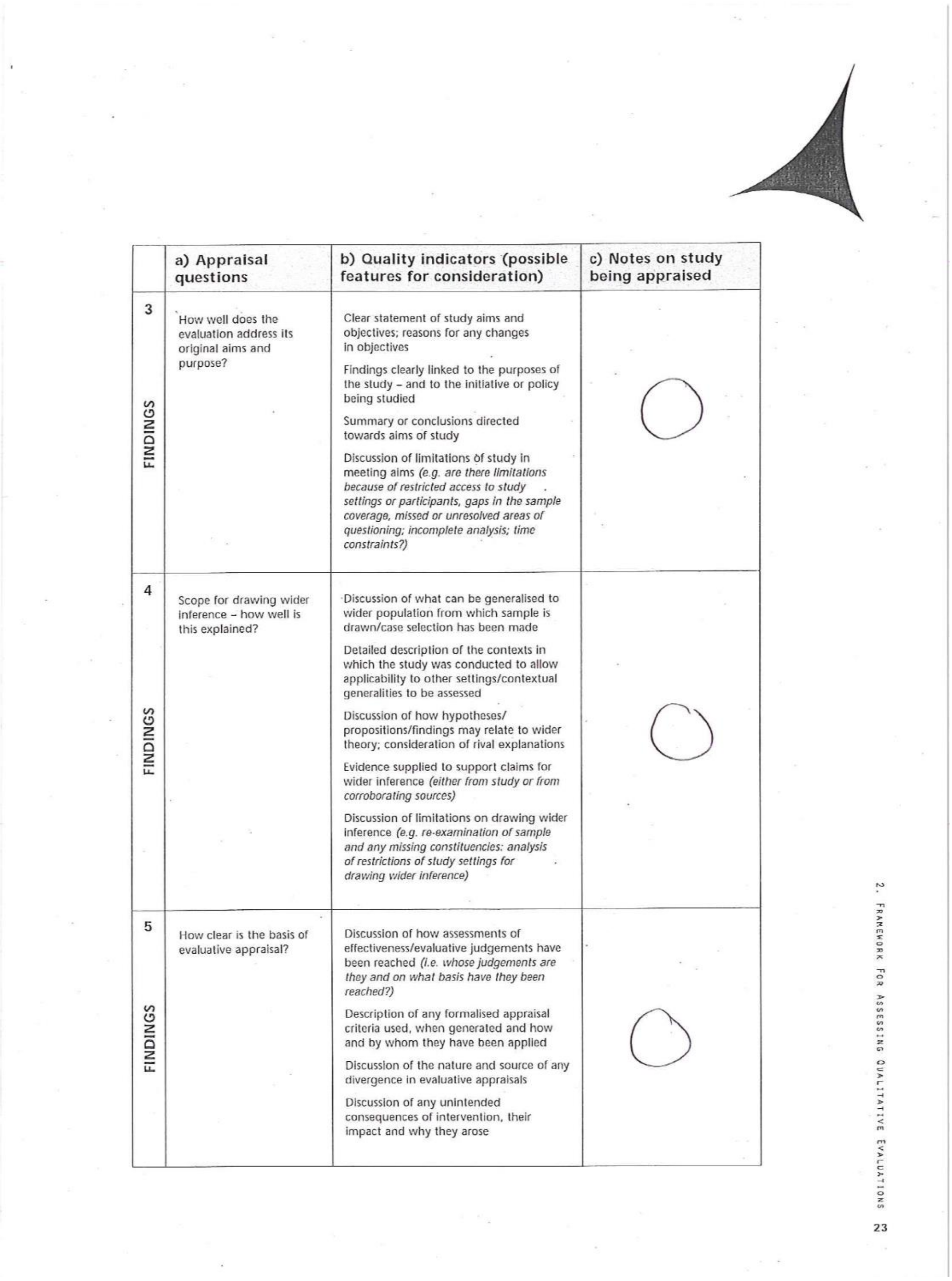
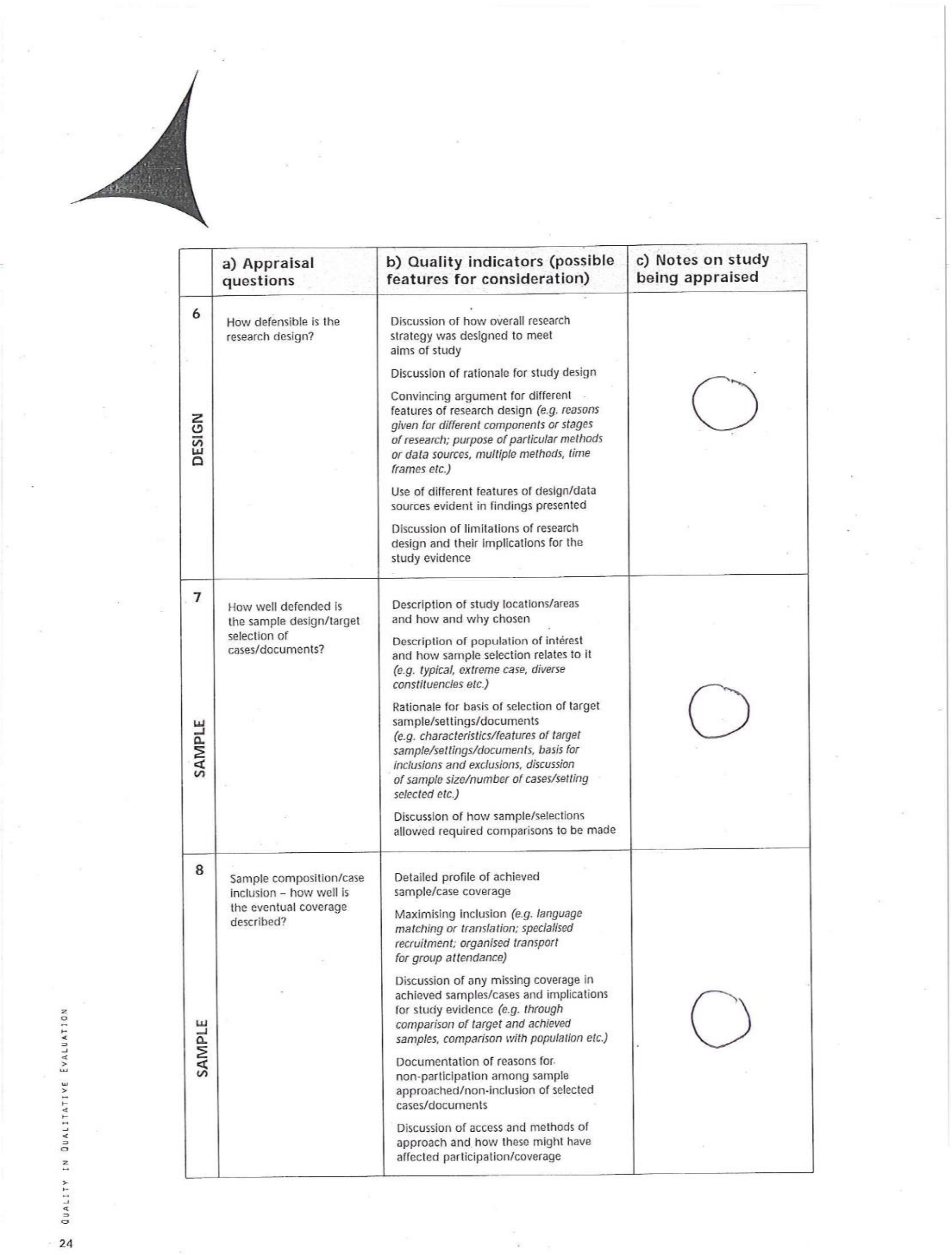
FRAMEWORK FOR ASSESSING QUALITATIVE EVALUATIONS

Study being appraised: C002 SF.

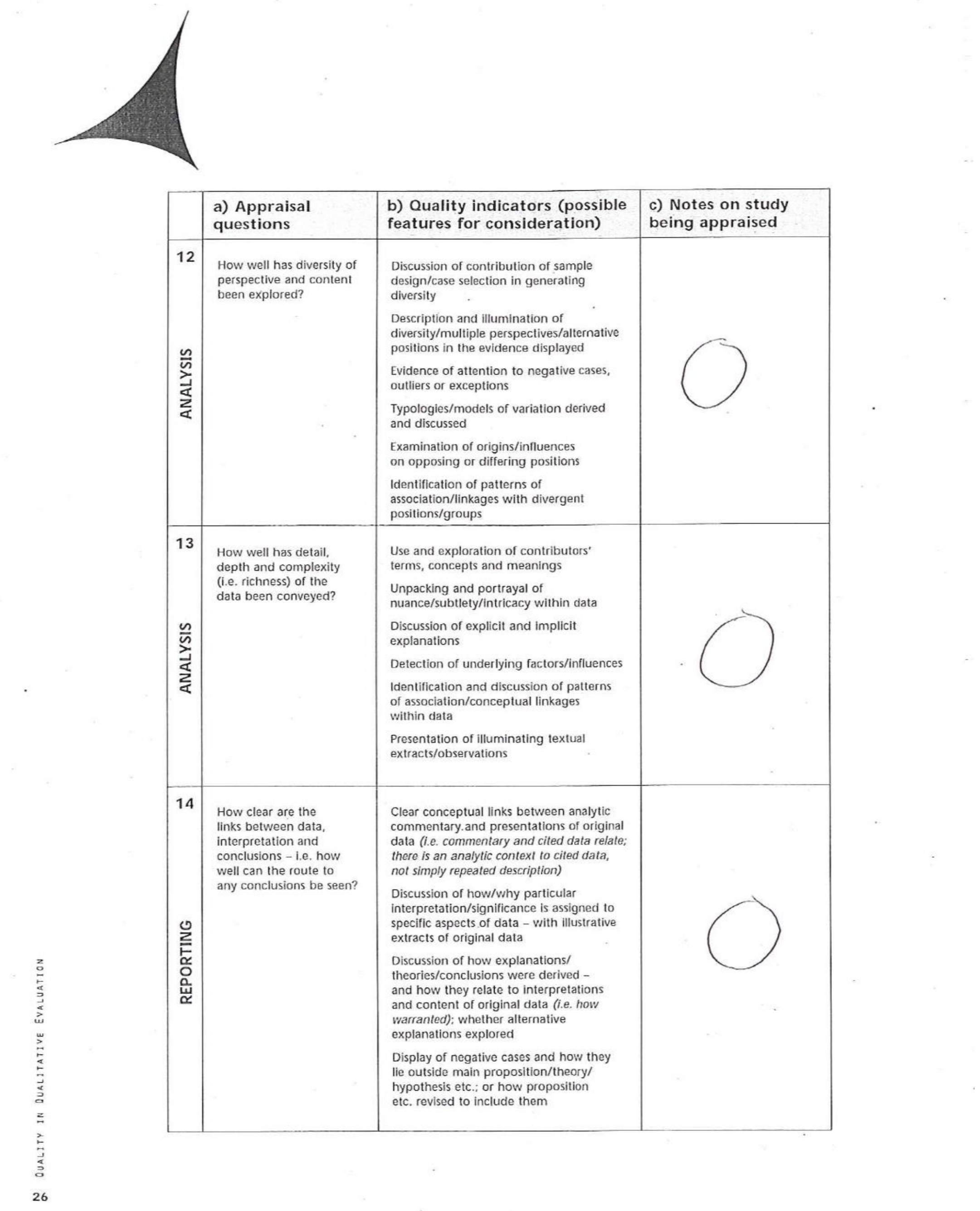
	a) Appraisal questions	b) Quality indicators (possible features for consideration)	c) Notes on study being appraised
1 FINDINGS	How credible are the findings?	Findings/conclusions are supported by data/study evidence *(i.e. the reader can see how the researcher arrived at his/her conclusions; the 'building blocks' of analysis and interpretation are evident)* Findings/conclusions 'make sense'/have a coherent logic Findings/conclusions are resonant with other knowledge and experience *(this might include peer or member review)* Use of corroborating evidence to support or refine findings (i.e. other data sources have been used to examine phenomena; other research evidence has been evaluated: see also Q14)	0
2 FINDINGS	How has knowledge/understanding been extended by the research?	Literature review (where appropriate) summarising knowledge to date/key issues raised by previous research Aims and design of study set in the context of existing knowledge/understanding; identifies new areas for investigation *(for example, in relation to policy/practice/substantive theory)* Credible/clear discussion of how findings have contributed to knowledge and understanding *(e.g. of the policy, programme or theory being reviewed)*; might be applied to new policy developments, practice or theory Findings presented or conceptualised in a way that offers new insights/alternative ways of thinking Discussion of limitations of evidence and what remains unknown/unclear or what further information/research is needed	0



	a) Appraisal questions	b) Quality indicators (possible features for consideration)	c) Notes on study being appraised
3 FINDINGS	How well does the evaluation address its original aims and purpose?	Clear statement of study aims and objectives; reasons for any changes in objectives Findings clearly linked to the purposes of the study – and to the initiative or policy being studied Summary or conclusions directed towards aims of study Discussion of limitations of study in meeting aims *(e.g. are there limitations because of restricted access to study settings or participants, gaps in the sample coverage, missed or unresolved areas of questioning; incomplete analysis; time constraints?)*	○
4 FINDINGS	Scope for drawing wider inference – how well is this explained?	Discussion of what can be generalised to wider population from which sample is drawn/case selection has been made Detailed description of the contexts in which the study was conducted to allow applicability to other settings/contextual generalities to be assessed Discussion of how hypotheses/ propositions/findings may relate to wider theory; consideration of rival explanations Evidence supplied to support claims for wider inference *(either from study or from corroborating sources)* Discussion of limitations on drawing wider inference *(e.g. re-examination of sample and any missing constituencies: analysis of restrictions of study settings for drawing wider inference)*	○
5 FINDINGS	How clear is the basis of evaluative appraisal?	Discussion of how assessments of effectiveness/evaluative judgements have been reached *(i.e. whose judgements are they and on what basis have they been reached?)* Description of any formalised appraisal criteria used, when generated and how and by whom they have been applied Discussion of the nature and source of any divergence in evaluative appraisals Discussion of any unintended consequences of intervention, their impact and why they arose	○



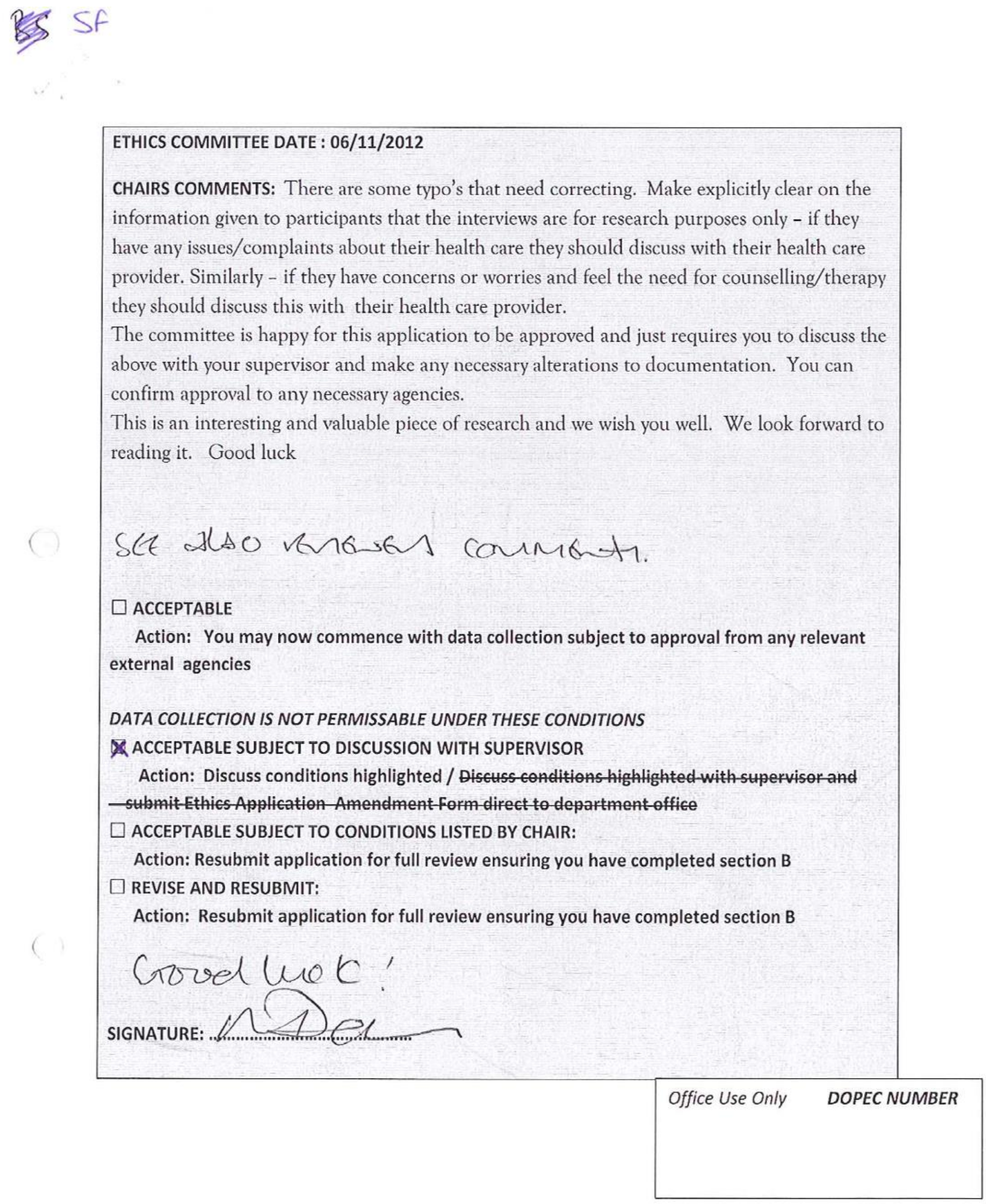
	a) Appraisal questions	b) Quality indicators (possible features for consideration)	c) Notes on study being appraised
6 **DESIGN**	How defensible is the research design?	Discussion of how overall research strategy was designed to meet aims of study Discussion of rationale for study design Convincing argument for different features of research design *(e.g. reasons given for different components or stages of research; purpose of particular methods or data sources, multiple methods, time frames etc.)* Use of different features of design/data sources evident in findings presented Discussion of limitations of research design and their implications for the study evidence	○
7 **SAMPLE**	How well defended is the sample design/target selection of cases/documents?	Description of study locations/areas and how and why chosen Description of population of interest and how sample selection relates to it *(e.g. typical, extreme case, diverse constituencies etc.)* Rationale for basis of selection of target sample/settings/documents *(e.g. characteristics/features of target sample/settings/documents, basis for inclusions and exclusions, discussion of sample size/number of cases/setting selected etc.)* Discussion of how sample/selections allowed required comparisons to be made	○
8 **SAMPLE**	Sample composition/case inclusion – how well is the eventual coverage described?	Detailed profile of achieved sample/case coverage Maximising inclusion *(e.g. language matching or translation; specialised recruitment; organised transport for group attendance)* Discussion of any missing coverage in achieved samples/cases and implications for study evidence *(e.g. through comparison of target and achieved samples, comparison with population etc.)* Documentation of reasons for non-participation among sample approached/non-inclusion of selected cases/documents Discussion of access and methods of approach and how these might have affected participation/coverage	○



	a) Appraisal questions	b) Quality indicators (possible features for consideration)	c) Notes on study being appraised
12 ANALYSIS	How well has diversity of perspective and content been explored?	Discussion of contribution of sample design/case selection in generating diversity Description and illumination of diversity/multiple perspectives/alternative positions in the evidence displayed Evidence of attention to negative cases, outliers or exceptions Typologies/models of variation derived and discussed Examination of origins/influences on opposing or differing positions Identification of patterns of association/linkages with divergent positions/groups	
13 ANALYSIS	How well has detail, depth and complexity (i.e. richness) of the data been conveyed?	Use and exploration of contributors' terms, concepts and meanings Unpacking and portrayal of nuance/subtlety/intricacy within data Discussion of explicit and implicit explanations Detection of underlying factors/influences Identification and discussion of patterns of association/conceptual linkages within data Presentation of illuminating textual extracts/observations	
14 REPORTING	How clear are the links between data, interpretation and conclusions – i.e. how well can the route to any conclusions be seen?	Clear conceptual links between analytic commentary and presentations of original data *(i.e. commentary and cited data relate; there is an analytic context to cited data, not simply repeated description)* Discussion of how/why particular interpretation/significance is assigned to specific aspects of data – with illustrative extracts of original data Discussion of how explanations/theories/conclusions were derived – and how they relate to interpretations and content of original data *(i.e. how warranted)*; whether alternative explanations explored Display of negative cases and how they lie outside main proposition/theory/hypothesis etc.; or how proposition etc. revised to include them	

	a) Appraisal questions	b) Quality indicators (possible features for consideration)	c) Notes on study being appraised
15 **REPORTING**	How clear and coherent is the reporting?	Demonstrates link to aims of study/research questions Provides a narrative/story or clearly constructed thematic account Has structure and signposting that usefully guide reader through the commentary Provides accessible information for intended target audience(s) Key messages highlighted or summarised	0
16 **REFLEXIVITY & NEUTRALITY**	How clear are the assumptions/theoretical perspectives/values that have shaped the form and output of the evaluation?	Discussion/evidence of the main assumptions/hypotheses/theoretical ideas on which the evaluation was based and how these affected the form, coverage or output of the evaluation *(the assumption here is that no research is undertaken without some underlying assumptions or theoretical ideas)* Discussion/evidence of the ideological perspectives/values/philosophies of research team and their impact on the methodological or substantive content of the evaluation *(again, may not be explicitly stated)* Evidence of openness to new/alternative ways of viewing subject/theories/assumptions *(e.g. discussion of learning/concepts/constructions that have emerged from the data; refinement restatement of hypotheses/theories in light of emergent findings; evidence that alternative claims have been examined)* Discussion of how error or bias may have arisen in design/data collection/analysis and how addressed, if at all Reflections on the impact of the researcher on the research process	0

Appendix 3: Ethical approval letters (Chapter 3)



~~BS~~ SF

ETHICS COMMITTEE DATE : 06/11/2012

CHAIRS COMMENTS: There are some typo's that need correcting. Make explicitly clear on the information given to participants that the interviews are for research purposes only – if they have any issues/complaints about their health care they should discuss with their health care provider. Similarly – if they have concerns or worries and feel the need for counselling/therapy they should discuss this with their health care provider.

The committee is happy for this application to be approved and just requires you to discuss the above with your supervisor and make any necessary alterations to documentation. You can confirm approval to any necessary agencies.

This is an interesting and valuable piece of research and we wish you well. We look forward to reading it. Good luck

See also reviewer comments.

☐ ACCEPTABLE

Action: You may now commence with data collection subject to approval from any relevant external agencies

DATA COLLECTION IS NOT PERMISSABLE UNDER THESE CONDITIONS

☒ ACCEPTABLE SUBJECT TO DISCUSSION WITH SUPERVISOR

Action: Discuss conditions highlighted / ~~Discuss conditions highlighted with supervisor and submit Ethics Application Amendment Form direct to department office~~

☐ ACCEPTABLE SUBJECT TO CONDITIONS LISTED BY CHAIR:

Action: Resubmit application for full review ensuring you have completed section B

☐ REVISE AND RESUBMIT:

Action: Resubmit application for full review ensuring you have completed section B

Good work!

SIGNATURE: ....

Office Use Only	***DOPEC NUMBER***

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

NISCHR
Gwasanaeth Moeseg Ymchwil | RES | Research Ethics Service

North Wales REC (Central & East)
G1/G2 Croesnewydd Hall
Croesnewydd Road
Wrexham Technology Park
Wrexham LL13 7YP

Telephone : 01978 726377

E-mail : tracy.biggs@wales.nhs.uk

Website : www.nres.nhs.uk

21 December 2012

Miss Samantha Flynn
PhD Student
University of Chester
Department of Psychology, Chritchley Building
Parkgate Road,
Chester
CH1 4BJ

Dear Miss Flynn

Study title:	**Cancer experiences in individuals with an intellectual disability.**
REC reference:	**12/WA/0364**
Protocol number:	**n/a**
IRAS project ID:	**113085**

Thank you for your letter of 18 December 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by a sub-committee of the REC at a meeting held on 20 December 2012. A list of the sub-committee members is attached.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Tracy Biggs, Tracy.Biggs@wales.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

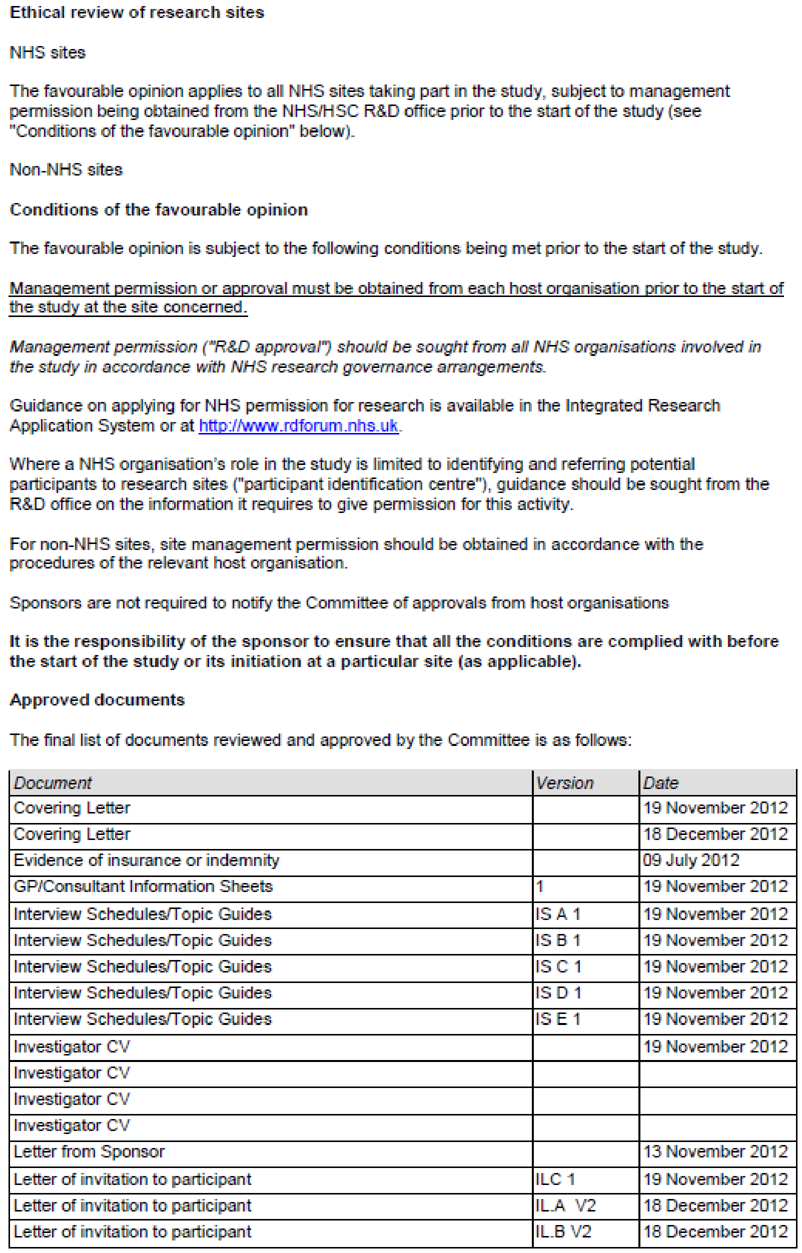
Following the clarification and confirmation provided by you that this section of the application had been completed and submitted in error the committee did not approve this research project for the purposes of the Mental Capacity Act 2005. The research may not be carried out on, or in relation to, a person who lacks capacity to consent to taking part in the project.

GIG Cymru NHS Wales | Bwrdd Iechyd Addysgu Powys | Powys Teaching Health Board

Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board

Ariennir gan Llywodraeth Cymru
Funded by Welsh Government



Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

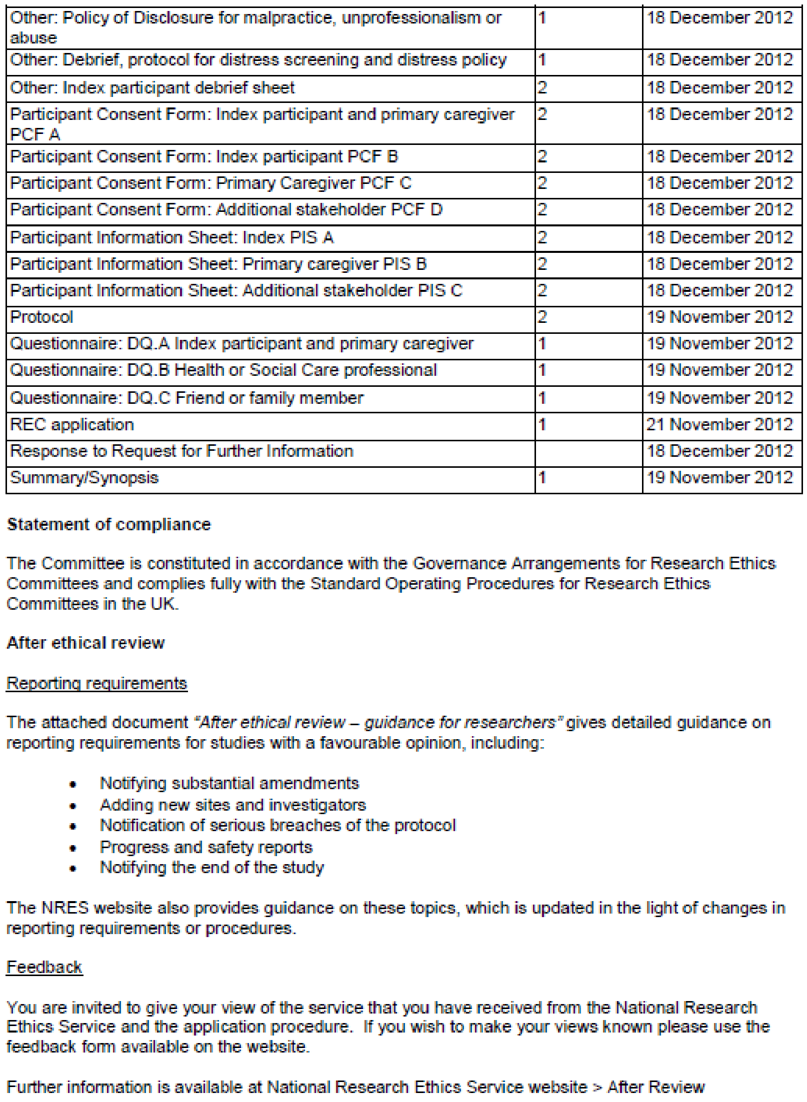
Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering Letter		19 November 2012
Covering Letter		18 December 2012
Evidence of insurance or indemnity		09 July 2012
GP/Consultant Information Sheets	1	19 November 2012
Interview Schedules/Topic Guides	IS A 1	19 November 2012
Interview Schedules/Topic Guides	IS B 1	19 November 2012
Interview Schedules/Topic Guides	IS C 1	19 November 2012
Interview Schedules/Topic Guides	IS D 1	19 November 2012
Interview Schedules/Topic Guides	IS E 1	19 November 2012
Investigator CV		19 November 2012
Investigator CV		
Investigator CV		
Investigator CV		
Letter from Sponsor		13 November 2012
Letter of invitation to participant	ILC 1	19 November 2012
Letter of invitation to participant	IL.A V2	18 December 2012
Letter of invitation to participant	IL.B V2	18 December 2012



Other: Policy of Disclosure for malpractice, unprofessionalism or abuse	1	18 December 2012
Other: Debrief, protocol for distress screening and distress policy	1	18 December 2012
Other: Index participant debrief sheet	2	18 December 2012
Participant Consent Form: Index participant and primary caregiver PCF A	2	18 December 2012
Participant Consent Form: Index participant PCF B	2	18 December 2012
Participant Consent Form: Primary Caregiver PCF C	2	18 December 2012
Participant Consent Form: Additional stakeholder PCF D	2	18 December 2012
Participant Information Sheet: Index PIS A	2	18 December 2012
Participant Information Sheet: Primary caregiver PIS B	2	18 December 2012
Participant Information Sheet: Additional stakeholder PIS C	2	18 December 2012
Protocol	2	19 November 2012
Questionnaire: DQ.A Index participant and primary caregiver	1	19 November 2012
Questionnaire: DQ.B Health or Social Care professional	1	19 November 2012
Questionnaire: DQ.C Friend or family member	1	19 November 2012
REC application	1	21 November 2012
Response to Request for Further Information		18 December 2012
Summary/Synopsis	1	19 November 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

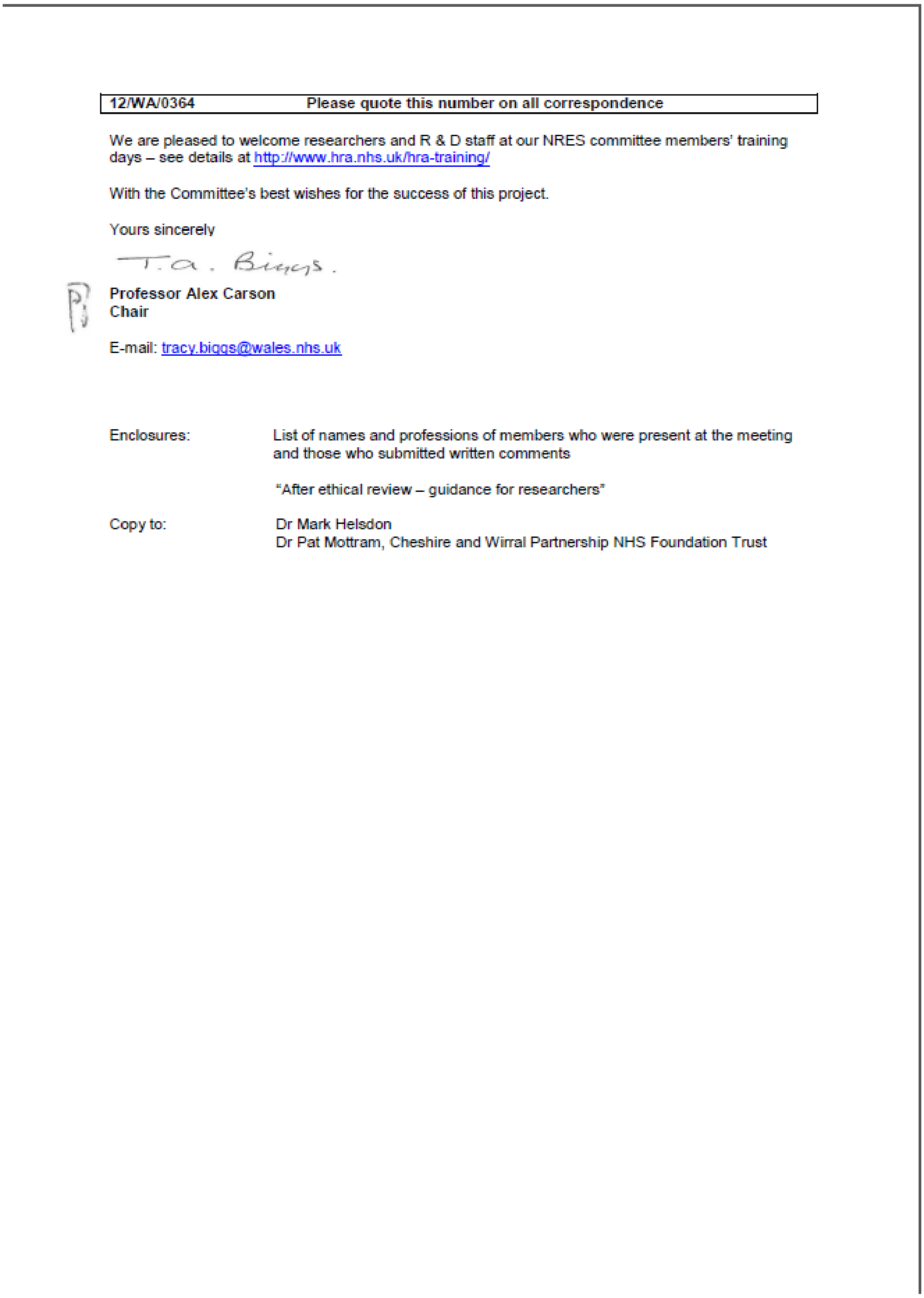
- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review



12/WA/0364 **Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

T.a. Biggs.

Professor Alex Carson
Chair

E-mail: tracy.biggs@wales.nhs.uk

Enclosures:	List of names and professions of members who were present at the meeting and those who submitted written comments
	"After ethical review – guidance for researchers"
Copy to:	Dr Mark Helsdon Dr Pat Mottram, Cheshire and Wirral Partnership NHS Foundation Trust

Appendix 4: Participant distress screening and debriefing protocol (Chapter 3)

University of Chester

NOTE: All text in bold will be read to the participant

Cancer and my life

Thank you for talking to me about your cancer and your life.

Here's a sheet for you so that you know what we've talked about.

What you have told me will help to make other people with intellectual disabilities experiences of cancer better.

All of your answers will be kept in a safe place.

If you feel a bit worried or confused about cancer and your life, you can talk to your doctor or nurse about it.

On this piece of paper, there are some numbers that you can call if you want to talk to someone about your worries, I've given them to (CAREGIVER'S NAME) as well.

Distress screening:

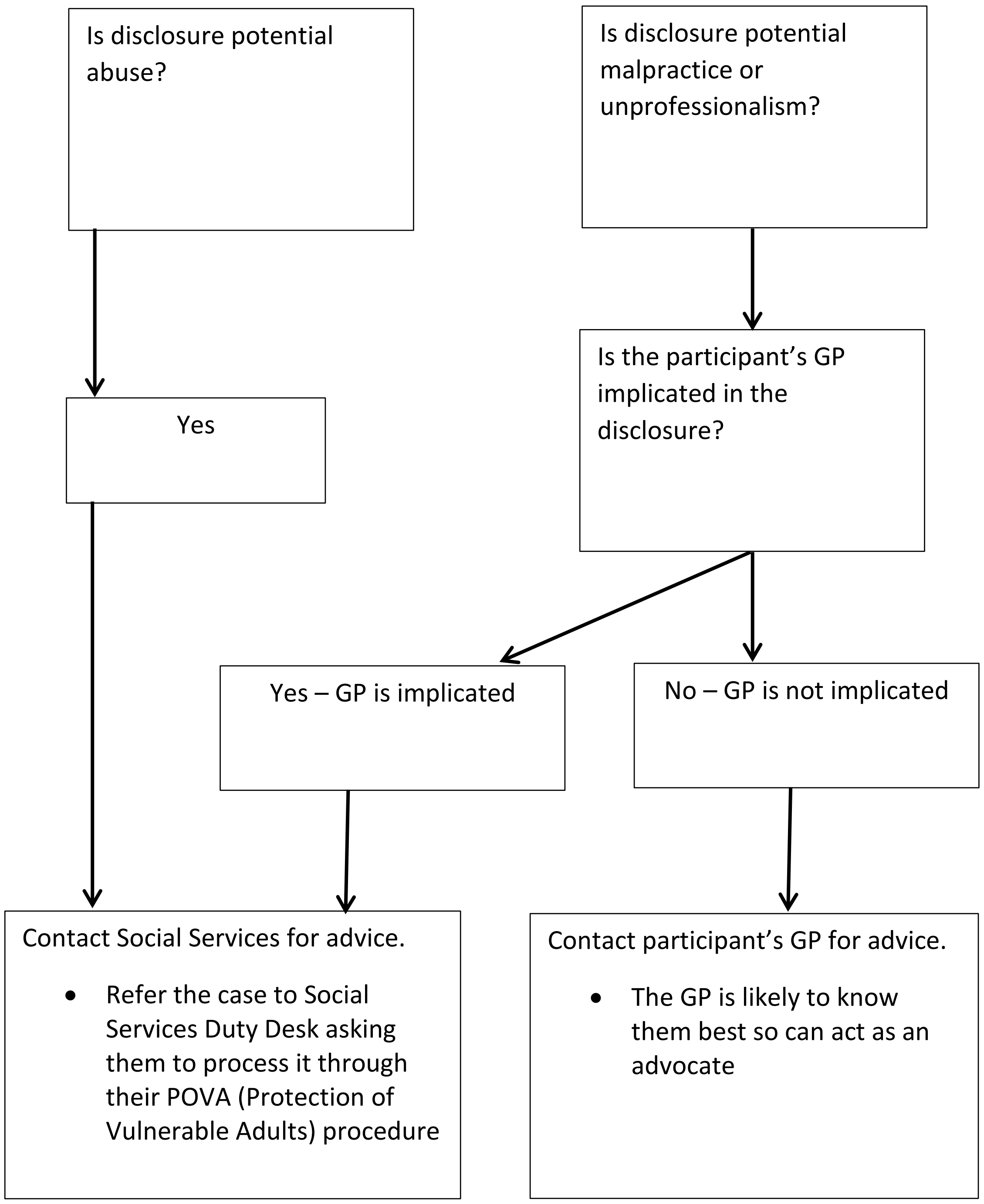
The interview is done now, was that OK?

Now that we've talked about your illness and how you're doing, do you feel OK?

If the participant responds negatively to either of these questions or there is a visible sign of distress I will refer them to a member of their clinical team for further psychological support.

Thank you again for talking to me.

Appendix 5: Policy for disclosure of malpractice, unprofessionalism or abuse (Chapter 3)



Appendix 6: Interview information sheets (patient, caregiver, and healthcare professional versions) (Chapter 3)

(To be spoken to participant)

University of Chester

Cancer and my life

Sometimes people can get poorly. Sometimes people have cancer. Some people who have cancer have an intellectual/learning disability too.

I want to talk to people who have an intellectual/learning disability like you and also have cancer like you do.

I want to talk to you about your cancer and your life. The things I want to ask you are:

- About your family
- When you've been in hospital
- How you feel about your cancer, if you're upset or confused
- Who has helped you with seeing doctors and nurses

I will let your doctor know that you are going to be talking to me, but I won't tell them what we talk about.

When I have finished, the answers I get from you will be kept in a safe place and I won't talk to anyone about what you have said.

I will come and talk to you at the [CLINIC NAME] so that there will be people who can help if we need them. If you want me to come and talk to you at your home then I can do this instead.

If you tell me anything that makes me think that you might be harmed then I will have to tell somebody. And if you tell me anything than makes me think that someone else might be harmed then I will have to tell somebody.

Remember that you do not have to say yes. If you do not want me to come and talk to you, just say no.

If you say yes, but then you change your mind that’s OK. Just tell me no later on. You won’t have to tell me why.

Thank you for letting me read this to you.

I would like to give you some time to think about it. If you do not want me to come and speak to you and [PRIMARY CAREGIVER], just tell me no.

PIS.B – Primary Caregiver Information Sheet

Research Study: Cancer experiences in individuals with an intellectual disability

Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done. Please take time to read the following information carefully and discuss it with friends, relatives or those in your medical care team. Ask me if there is anything that is not clear or if you would like more information.

Written information can be provided, upon request, in Welsh however all interviews will be held in English. If you require this information in Welsh please let me know using the contact details below.

Please can you read the information sheet 'Cancer and my life' to your dependant once you have read this information sheet.

Background and study purpose

The purpose of this study is to investigate the cancer experiences of individuals with an intellectual disability, as well as the experiences of those who care for them and ways in which both groups think their experience could be improved.

By asking you to take part in two interviews, we will ask you about your experiences of caring for someone who has an intellectual disability and cancer. We will ask you about how you think they have experienced the diagnosis and treatment and also how you have experienced it yourself.

We will audio record and analyse the conversation. The findings will inform future research and policy into improving the support that we can provide to cancer patients/survivors who have an intellectual disability and those who care for them. Findings will also form part of a PhD thesis and may also be utilised in a scientific article to publicise the work to a wider audience.

The interviews will take place within the clinic unless you would prefer to be visited at home; you can let the researcher know your preference when you are contacted. More support may be on hand if participants are interviewed in the clinical setting, however if this is not suitable for you then other arrangements can be made. You can elect a date and time most suitable for you to take part in the initial interview when the researcher contacts you.

Please note that the interviews are for research purposes only and are not intended to be used for therapeutic purposes.

Why have I been chosen?

You have been selected as a potential participant as you have been identified as caring for someone who has both an intellectual disability and cancer.

Do I have to take part? What happens if I don't take part?

No – you do not have to take part at all and you need not give a reason for this decision. You are also free to withdraw totally from the study at any point. If you withdraw from the study, this will not affect any care or medical attention either you or your dependant is receiving.

What will happen to me if I take part? What do I have to do?

If you, and your dependant, agree to take part, you are required to return the response form indicating this decision using the FREEPOST envelope. On the day of the interviews you'll be given another chance to read this information sheet and to ask any questions. After this the interview will begin. I'll record this using audio equipment. You should feel free to talk about anything that you think is relevant in the interview.

The initial interview will last for between 45 minutes and an hour and the secondary, individual interviews will both last for between an hour and 90 minutes. If at any point during the interviews you feel that you would like to take a break, then this can be arranged and won't be a problem.

Is there any potential harm from taking part in the study?

There are no directly harmful effects from taking part but some of the discussion may make you think about your experiences which may remind you of upsetting feelings or thoughts. You can always speak to Macmillan Cancer Support if this is the case (0808 808 0000).

How will I benefit from the study?

There are no immediate direct benefits to you as a caregiver. The results will be used to inform research and policy into improving the support that we can provide to cancer patients/survivors who have an intellectual disability and those who care for them. You may, however, indirectly benefit from the opportunity to express some of your feelings, thoughts, and emotions at this difficult time.

It is also possible that findings from this study will directly benefit you in the future, as they may be used to inform policies which improve the experience of individuals who have both an intellectual disability and cancer and those who care for them.

What if something goes wrong?

If you wish to make a complaint about any aspect of this research, or how you have been treated as a participant, please address it to the Head of Department, Department of Psychology, University of Chester, or to [INSERT DETAILS OF NHS COMPLAINTS CONTACT].

Confidentiality

The data provided by you will be used only for the purposes of this research. Information will be kept confidentially and securely, and you will remain entirely anonymous in any written reports, scientific papers, or study summaries. Data will be stored in accordance with the Data Protection Act and University Research Policies. Once analysis is complete, audio recordings of the interviews will be kept on a password protected DVD in secure archives held by the university; all other copies will be destroyed. Paper-based transcripts and study documents will also be kept in secure archives. Archived data will be confidentially destroyed after five years after study completion.

If the researcher becomes aware of any potential harm which has been done to either the participants involved or others, or malpractice or unprofessionalism by any professional involved, then there is an obligation to report this harm to the appropriate services.

We would like to be able to contact yours and your dependant's GP to inform them that you are taking part in this research; they will not be informed of the content of the discussions, just that you are taking part in the research and the title of the research. If you are happy for us to do this could you please provide us with their name and address on the questionnaire we will provide you with.

Other uses of the data

On the consent form you are asked to indicate whether you have objections to your data being included for use in publications and teaching sessions by the research team at the university. If you agree to this, the data will be anonymous and non-identifiable: we would simply be asking for your permission to provide students with transcripts from the interview for demonstration and practical work in research methods training. And to include anonymised quotations within publications of the work. You can participate in the study but choose not to permit the use of your data for teaching purposes.

What will happen to the results of the study?

We will write up the findings from this research as a research paper which will be submitted to intellectual disability, health psychology- and cancer- related scientific journals. Some results may also be presented at scientific meetings and conferences. In all results, all participants will remain anonymous. If you would like a summary of the results, please contact Samantha Flynn (see below).

Who is organizing and funding this research study?

The study is part of a PhD thesis being undertaken by Samantha Flynn, who is conducting the research under the supervision of Dr Nick Hulbert-Williams and Prof. Ros Bramwell at the University of Chester and Dr Lee Hulbert-Williams at the University of Wolverhampton.

Where can I get further information?

Please contact Samantha Flynn, Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ. Tel: 01244 513179; email: samantha.flynn@chester.ac.uk.

Please keep this Information Sheet for your future reference. Thankyou for taking part in this research.

PIS.C – Additional Stakeholder Information Sheet

Research Study: Cancer experiences in individuals with an intellectual disability

Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done. Please take time to read the following information carefully and discuss it with friends and family or colleagues and service managers. Please also ask me if there is anything that is not clear or if you would like more information.

Written information can be provided, upon request, in Welsh however all interviews will be held in English. If you require this information in Welsh please let me know using the contact details below.

Background and study purpose

The purpose of this study is to investigate the cancer experiences of individuals with an intellectual disability, as well as the experiences of health and social care professionals who come into contact with them for either their cancer or intellectual disability needs and ways in which both groups think their experience could be improved.

By asking you to take part in a telephone or face to face interview, we will ask you about your experiences of coming into contact with the previously mentioned individual who has an intellectual disability and cancer. We will ask you about your experiences of their cancer diagnosis and treatment.

We will audio record and analyse the conversation. The findings will inform future research and policy into improving the support that we can provide to cancer patients/survivors who have an intellectual disability and those who care for them. Findings will also form part of a PhD thesis and may also be utilised in a scientific article to publicise the work to a wider audience.

You can elect a date and time most suitable for you to take part in the interview when the researcher contacts you.

Why have I been chosen?

You have been approached as you have been identified by the individual mentioned on the invitation letter as having played a pivotal role in their cancer experience.

Do I have to take part? What happens if I don’t take part?

No – you do not have to take part at all and you need not give a reason for this decision. You are also free to withdraw totally from the study at any point. If you withdraw from the study, this will not affect your legal rights.

What will happen to me if I take part? What do I have to do?

If you agree to take part, you are required to return the response form indicating this decision, the consent form and demographic questionnaire using the FREEPOST envelope. On the day of the interview you'll be given another chance to read this information sheet and to ask any questions. After this the interview will begin. I'll record this using audio equipment. You should feel free to talk about anything that you think is relevant to your experiences of the previously mentioned individual in the interview, please note that it would not be ethical to discuss any other individuals within the interview.

Is there any potential harm from taking part in the study?

There are no directly harmful effects from taking part but some of the discussion may make you think about your experiences which may remind you of upsetting feelings or thoughts. You can always speak to Macmillan Cancer Support if this is the case (0808 808 0000).

How will I benefit from the study?

There are no immediate direct benefits to you. The results will be used to inform research and policy into improving the support that we can provide to cancer patients/survivors who have an intellectual disability and those who help to care for them. You may, however, indirectly benefit from the opportunity to express some of your feelings, thoughts, and emotions.

It is also possible that findings from this study will directly benefit you in the future, as they may be used to inform policies which improve the experience of individuals who have both an intellectual disability and cancer and those who help to care for them.

What if something goes wrong?

If you wish to make a complaint about any aspect of this research, or how you have been treated as a participant, please address it to the Head of Department, Department of Psychology, University of Chester, or to [INSERT DETAILS OF NHS COMPLAINTS CONTACT].

Confidentiality

The data provided by you will be used only for the purposes of this research. Information will be kept confidentially and securely, and you will remain entirely anonymous in any written reports, scientific papers, or study summaries. Data will be stored in accordance with the Data Protection Act and University Research Policies. Once analysis is complete, audio recordings of the interviews will be kept on a password protected DVD in secure archives held by the university; all other copies will be destroyed. Paper-based transcripts and study documents will also be kept in secure archives. Archived data will be confidentially destroyed after five years after study completion.

If the researcher becomes aware of any potential harm which has been done to either the participants involved or others, or malpractice or unprofessionalism by any professional involved, then there is an obligation to report this harm to the appropriate services.

Other uses of the data

On the consent form you are asked to indicate whether you have objections to your data being included for use in publications and teaching sessions by the research team at the university. If you agree to this, the data will be anonymous and non-identifiable: we would simply be asking for your permission to provide students with transcripts from the interview for demonstration and practical work in research methods training. And to include anonymised quotations within publications of the work. You can participate in the study but choose not to permit the use of your data for teaching purposes.

What will happen to the results of the study?

We will write up the findings from this research as a research paper which will be submitted to intellectual disability, health psychology- and cancer- related scientific journals. Some results may also be presented at scientific meetings and conferences. In all results, all participants will remain anonymous. If you would like a summary of the results, please contact Samantha Flynn (see below).

Who is organizing and funding this research study?

The study is part of a PhD thesis being undertaken by Samantha Flynn, who is conducting the research under the supervision of Dr Nick Hulbert-Williams and Prof. Ros Bramwell at the University of Chester and Dr Lee Hulbert-Williams at the University of Wolverhampton.

Where can I get further information?

Please contact Samantha Flynn, Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ. Tel: 01244 513179; email: samantha.flynn@chester.ac.uk.

Please keep this Information Sheet for your future reference. Thankyou for taking part in this research.

Appendix 7: Interview consent form (patient, caregiver, and healthcare professional versions) (Chapter 3)

(To be read to the participant)

<u>Corresponding information sheet: Cancer and my life (v2. 18/12/2012)</u>

Cancer and my life

Please read each sentence carefully and <u>tick in the box</u> if you agree with each sentence. You can ask someone to help you if you want to.

1. I have been told about the research and know what it is about and what I am going to do. ☐
2. I know that I can ask questions about it if I want to. ☐
3. I know that I can ask to stop talking if I want to. ☐
4. I know that my GP will be told that I am taking part in this study. ☐
5. I know that the person talking to me won't tell anyone what I have said. I agree with this. ☐
6. I know that my answers will be recorded on a voice recorder and this will be kept in a safe place. I agree with this. ☐
7. <u>I know that if I tell you something and you think that me or someone else might be harmed then you will have to tell somebody.</u> ☐
8. I know that some of my words might be used when the research is written up, but no one will know that it was me who said it. I agree with this. ☐
9. <u>I know that some of my words might be used to teach other people about cancer and disabilities, but no one will know that it was me who said it. I agree with this.</u> ☐

10. I want to take part in this study. ☐

Name of participant Date Signature

Name of caregiver (Witness) Date Signature

Name of researcher Date Signature

Consent form –Cancer experiences in individuals with an intellectual disability

<u>Corresponding information sheet: PIS.B - Cancer experiences in individuals with an intellectual disability (v2. 18/12/2012)</u>

<u>Please initial each box to indicate your agreement with each statement</u> and sign the form at the bottom once completed. If you have any concerns about doing so, please contact me:

1) I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions. ☐

2) I understand that my participation is voluntary and that if I decided I don't want to take part any more I can leave now, without giving any reason, without my legal rights being affected. ☐

3) I understand that my GP will be informed of mine and my dependent's participation in this study. ☐

4) I understand that in participating in this study my contributions to the interviews will be audio recorded but I have been assured that these will be dealt with in a secure, anonymous and confidential manner. ☐

5) <u>I understand that if my responses indicate that there may be any potential of harm to myself or others then the researcher is obligated to report this.</u> ☐

6) I agree to take part in the above study. ☐

Name of participant Date Signature

Name of researcher Date Signature

We would like to be able to use anonymised quotations from these interviews within publications of this research and <u>within teaching</u>. Please tick this box if you do not consent to this, you will still be able to take part in the research even if you wish for your data not to be used. ☐

Contact Details: Samantha Flynn
Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ
Tel: 01244 513179
Email: samantha.flynn@chester.ac.uk

Research Study –Cancer experiences in individuals with an intellectual disability

Corresponding information sheet: PIS.C - Cancer experiences in individuals with an intellectual disability (v2. 18/12/2012)

Please initial each box to indicate your agreement with each statement and sign the form at the bottom once completed. If you have any concerns about doing so, please contact me:

1) I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions. ☐

2) I understand that my participation is voluntary and that if I decided I don't want to take part any more I can leave now, without giving any reason, without my legal rights being affected. ☐

3) I understand that in participating in this study my contributions to the interviews will be audio recorded but I have been assured that these will be dealt with in a secure, anonymous and confidential manner. ☐

4) I understand that if my responses indicate that there may be any potential of harm to myself or others then the researcher is obligated to report this. ☐

5) I agree to take part in the above study. ☐

Name of participant Date Signature

Name of researcher Date Signature

We would like to be able to use anonymised quotations from these interviews within publications of this research and within teaching. Please tick this box if you do not consent to this, you will still be able to take part in the research even if you wish for your data not to be used. ☐

Contact Details: Samantha Flynn
Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ
Tel: 01244 513179
Email: samantha.flynn@chester.ac.uk

Appendix 8: Interview debrief sheet (patient, caregiver, and healthcare professional versions) (Chapter 3)

Cancer and my life

Thank you for talking to me about your cancer and your life.

What you have told me will help to make other people with intellectual disabilities experiences of cancer better.

All of your answers will be kept in a safe place.

If you feel a bit worried or confused about cancer and your life, you can talk to your doctor or nurse about it.

Here are some numbers that you can call if you want to talk to someone about your worries:

Macmillan Cancer Support:	0808 808 0000
Cancer Help UK:	0808 800 4040
The Samaritans:	08457 909090

Thank you again for talking to me,

Sam.

University of Chester

Research Study Debrief – Cancer experiences in individuals with an intellectual disability

I would like to thank you for taking the time to participate in my research study. You are not required to provide any more information nor to do anything else to participate in this study.

I am unable to provide individual feedback about the interviews, however, if you would like a written summary of the results, please do let me know and I would be happy to provide this for you. I will shortly be analysing the data and am confident that the information that you have provided will help us to improve the cancer experiences of individuals with an intellectual disability and those who care for them, in a way that will support and help many more cancer patients in the future.

I'd like to take this opportunity to remind you once again that anything discussed in the interviews will be treated as confidential. Similarly, in my study write-up, I'd like to assure you that I'll remove all personally identifying information so that you remain anonymous throughout.

Please feel free to contact me if you have any further questions about this study. If you have any queries about yours or your dependant's medical condition or the illness, we suggest that you refer these back to your GP or cancer team at the hospital where they are being treated.

Having cancer can be an upsetting and confusing time for some people. If you think you would benefit from talking to someone about your experiences, the following telephone numbers might be helpful:

Macmillan Cancer Support: 0808 808 0000

Cancer Help UK: 0808 800 4040

The Samaritans: 08457 909090

Once again, many thanks for participating in this research. I wish you the very best for the future.

Samantha Flynn.

University of Chester

Research Study – Cancer experiences in individuals with an intellectual disability

I would like to thank you for taking the time to participate in my research study. You are not required to provide any more information nor to do anything else to participate in this study.

I am unable to provide individual feedback about the interviews, however, if you would like a written summary of the results, please do let me know and I would be happy to provide this for you. I will shortly be analysing the data and am confident that the information that you have provided will help us to improve the cancer experiences of individuals with an intellectual disability and those who care for them, in a way that will support and help many more cancer patients in the future.

I'd like to take this opportunity to remind you once again that anything discussed in the interviews will be treated as confidential. Similarly, in my study write-up, I'd like to assure you that I'll remove all personally identifying information so that you remain anonymous throughout.

Please feel free to contact me if you have any further questions about this study.

Supporting people who have cancer can be an upsetting and confusing time for some people. If you think you would benefit from talking to someone about your experiences, the following telephone numbers might be helpful:

Macmillan Cancer Support: 0808 808 0000

Cancer Help UK: 0808 800 4040

The Samaritans: 08457 909090

Once again, many thanks for participating in this research. I wish you the very best for the future.

Samantha Flynn.

Appendix 9: Study invitation letter (Chapter 3)

IL.A - Invitation to a Research Study – Cancer experiences in individuals with an intellectual disability

My name is Sam and I'm completing my PhD within the Department of Psychology at the University of Chester, and I would like to invite you to take part in a new research study.

Written information can be provided, upon request, in Welsh however all interviews will be held in English. If you require this information in Welsh please let me know using the contact details below.

This research will investigate the cancer experiences of individuals with an intellectual disability and cancer, as well as the experiences of those who help care for them and ways in which both groups think their experience could be improved. The study will not affect the way in which participants involved receive treatment and support for their cancer and intellectual disability needs. You have been approached as you have been identified as the caregiver of an individual with both cancer and an intellectual disability.

If you decide to take part you will be required to take part in an initial interview with your dependant in order to discover key facts about their cancer treatment programme and establish a timeline of diagnosis and treatment. This initial meeting will also see that familiarity with the researcher and interview format will be established before the individual interviews take place. You will subsequently both be asked to take part in an individual interview, where the researcher will look to establish your experiences of the cancer diagnosis and treatment. The interviews will be audio recorded and the discussion analysed. Where necessary, additional measures (including the provision of flash cards and accessible language) will be taken to ensure that the interviews are accessible for both the caregiver and the dependant.

The initial interview should last approximately 45-60 minutes and the individual interviews are likely to last approximately 60 to 90 minutes. Whilst I appreciated that this is quite demanding on your time, I hope that you will be willing to take part so that I can establish a more complete understanding of cancer experiences of those with an intellectual disability and those who care for them. Please be aware that the interviews are for research purposes only and are not intended to be used for therapeutic purposes.

If you believe that this research is something that you would be interested in taking part in and would like to receive further information for both yourself and your dependent please complete the attached Consent to Share Personal

Information sheet and return to the person who approached you about this research.

If you do not wish to take part, you do not need to do anything. Your decision whether or not to participate in this study will in no way will affect the treatment of your dependant.

If you have any questions regarding this research please don't hesitate to contact me on 01244 513179 or samantha.flynn@chester.ac.uk.

With many thanks for your time

Samantha Flynn

Appendix 10: Patient interview schedule (Chapter 3)

Note: The format of these interviews is semi-structured and participant led, hence this list of questions should be used as a guide only. Not all questions and prompts will be used.

Hi, I'm Sam, we talked a while ago and I told you that I'm interested in talking to people who have an intellectual disability like you and also have cancer like you do. I'm going to be asking you some questions today about your life but if you don't want to answer some of them then you don't have to and if you want to take a break or stop talking then you just let me know and that is ok too. I've got the timeline we made last time to help us if we get stuck on when things happened and I've also got the flashcards like last time that we can use if you don't understand some of the words or can't remember some things, we don't have to use them but they're there again if we need them.

Rapport building:

1. So, how about you tell me a little bit about your life?
    a. Do you have a job?
    b. Do you have any pets?
    c. Who is in your family?
    d. Do you like sports?
    e. What are your favourite things to do?

Initial questions:

2. (INSERT NAME) told me that you have a learning/intellectual disability, is that right?
3. Could you tell me about it?
    a. Going to see a psychologist
    b. Getting help at home
4. (INSERT NAME) told me that you have cancer, is that right?
5. Could you tell me a bit about it?
    a. Being ill
    b. Hospital visits
    c. Doctors/nurses
    d. Treatments/examinations

Emotional Support:

6. Can you look at this card (SHOW FEELINGS FLASH CARD) and tell me if you feel the same as any of these pictures?
7. When people have a problem or something that makes them worry, they talk to people they know about it. Do you talk to people about having cancer?
8. Who do you talk to?
    a. Parents

   b. Brother/sister
   c. Friends
   d. Doctors/nurses
9. What do you talk to them about?
   a. Feelings/emotions/thoughts
   b. Pain/discomfort
   c. How to feel better
10. Does it make you feel better after you've talked to them?
    a. Less sad/more happy
    b. Less scared/angry
11. Some people like to think about their religion to help them feel better about life or when they are worried or poorly. Do you do this?
    a. Do you practice/go to church/temple etc.
12. Does it make you feel better when you think of your religion?
    a. Less scared/angry/sad

Learning about illness:

13. When people are poorly they sometimes like to ask questions about it to their doctor/nurse. Do you ask questions about it to your doctors and nurses?
    a. About being ill
    b. How to feel better
    c. About what's going to happen
    d. Treatments/examinations
14. Sometimes, doctors and nurses have books and leaflets, like this one (SHOW CHANGE CANCER SERIES: SYMPTOMS, SCREENING AND HEALTHY LIVING BOOK). Have you ever seen one of these before?
    a. Anything else like it, a leaflet/a website
15. If you have read something like this: Has it helped you to know what is happening?
16. Sometimes when doctors say things, it can be hard to know what they mean. Has this ever happened to you?
    a. What happened?
    b. Did someone else help you to know what they meant?

Switching focus from illness:

17. When people are worried about something, they sometimes do other things like playing a game or going for a walk so they can think about something else. Do you do this sometimes?
18. What sort of things do you try to do?
    a. Watch telly/film
    b. Play a game
    c. Go for a walk

    d. Talk to people

19. Does it make you feel better?
    a. Less angry/sad/scared
20. Some people think that when they feel happier, they can get better quicker. Do you think that this is right? Why?

Recurrence (If appropriate):

21. Sometimes people who have had cancer before get worried that they might get it again. Do you ever get worried that it might come back?
22. When people get poorly or have cancer they sometimes change things about their lives to try to make it better and to try to make sure it doesn’t come back. Have you changed anything about your life?
    a. Change of diet?
    b. Change of habit (e.g. smoking, drinking etc.)
    c. Increased exercise?

Ending as we began:

23. When we were talking earlier you were telling me about (ANSWER FROM QUESTION 1) and I’d really like to hear some more about it, could you tell me a bit more about it?

SF TO WRITE TOPICS FOR LATER DISCUSSION BELOW:

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

Thank you so much for talking to me today, all of your answers will be really helpful.

Appendix 11: Caregiver interview schedule (Chapter 3)

Note: the format of these interviews is semi-structured and participant led, hence this list of questions should be used as a guide only.

I'd really like to understand more about (INDEX PARTICIPANT)'s cancer experiences as well as your own experiences. So if we could start by talking a little bit about them and your life in general. If you don't want to answer some questions then you don't have to and if you want to take a break at any stage then just let me know and that's ok too.

Rapport building:

1. How about we start with you telling me a little bit about (INDEX PARTICIPANT)?
    a. Their hobbies/interests
    b. Jobs?
    c. Favourite things to do?
    d. Things they do with you?
    e. Their ID?

Proxy Participant/Dependant's experiences:

I'm going to ask you about how you think that (INDEX PARTICIPANT) has experienced their cancer diagnosis and treatment and how you think that it has affected them. If there are any questions that you'd rather not answer then just let me know and we'll move onto something else.

Emotional support:

2. Since their diagnosis, have you noticed any specific reactions which weren't there previously?
    a. Emotions: anger, sadness, confusion
    b. Behaviours: outbursts, introversion
3. Have they been getting any emotional support from others?
    a. Who do they get this from?
4. Do they talk to you or other family members or friends about their illness?
    a. What do they talk about: Practical things, emotions, questions
    b. How do they react to talking to others: Emotions, behaviours
5. How do they feel when they talk to doctors about their illness?
    a. Emotional changes?
    b. Behaviour changes?
    c. What usually happens during an appointment?
    d. What usually happens immediately after an appointment?
6. Have they turned to religion or other social support mechanisms to help them cope?

    a. Were they previously religious?
    b. Do they practice a religion regularly?
    c. Social support: community groups, forums
7. How do they react after they have done this?
    a. Behaviour changes?
    b. Emotional changes?

Learning about the illness:

8. Have they been asking other people about their illness and how they can feel better about it?
    a. Who have they been asking?
    b. What have they been asking?
    c. How do they respond to the answers?
        i. Behaviour changes?
        ii. Emotional changes?
9. There are a few cancer materials which are available and are targeted towards those who have ID and cancer. (SHOW CHANGE CANCER SERIES: SYMPTOMS, SCREENING AND HEALTHY LIVING BOOK). Do they read anything like this or try to learn about cancer?
    a. What do they do?
    b. Is it helping them to cope with it?
10. It’s difficult to understand everything that doctors and nurses tell us. Do you think that they have understood the questions asked and information the doctor has given them?
    a. Have they been helped to understand?
    b. Have they said when they don’t understand?
    c. If they don’t understand, do their emotions or behaviour change as a result?
11. Do you think that they have accepted their illness and what is happening to them?
    a. Have they spoken to you about it?

Switching focus:

12. Do they sometimes try to do other things to take they mind off of their illness?
    a. Hobbies/interests
    b. Films/telly
    c. Talk to people about other things
13. How positive do you think they feel about any aspect of life in general?
    a. Do they still enjoy doing things they used to do?
    b. Do they try to do more because of the diagnosis?

Recurrence:

14. Do they ever worry about recurrence or it getting worse?
15. Have they changed anything about their life to try to make their illness better or to make sure that it doesn't get worse or come back?
    a. Change of diet?
    b. Change of habit? (e.g. smoking, drinking)
    c. Increased exercise?

Own experiences:

Thank you for all of that. I'm going to ask you about your experiences of their cancer diagnosis and treatment now. Exactly as before, if there are any questions that you'd rather not answer then just let me know and we'll move onto something else.

Emotional support:

16. Have you been feeling any particular emotions since the diagnosis?
    a. Anger, sadness, confusion
17. Have you been getting any emotional support from others?
    a. Who do you get this from?
    b. What do you talk to them about? (Practical things/emotions)
    c. How do you feel after you've talked to them?
18. How do you feel when you talk to doctors about their illness?
    a. Confusion, sadness, positive and boosted?
19. Have you turned to religion or other social support mechanisms to help you cope?
    a. Were you religious before the diagnosis?
    b. Do you practice regularly?
    c. Social support: community centres/support groups

Learning about the illness:

20. Do you read and try to learn about cancer?
    a. What do you read?
    b. Is it helping you to understand?
    c. Is it helping you to cope?
21. Have you always understood the questions and information the doctor has told you?
    a. Do you ask questions when you don't understand?
    b. Have the doctors been helpful when either you or they don't understand?
22. Have you accepted their illness and what is happening to them?

Recurrence:

23. Do you ever worry about recurrence or it getting worse?

Meeting needs:

24. How do you feel when you’re trying to meet their needs?
    a. Positive/negative
    b. Do you have anyone who helps you?
25. How do you feel when you’re trying to meet own needs?
    a. Positive/negative
    b. Do you have anyone who helps you?

Making the experiences easier:

26. Do you think that this experience could have been made easier? If so, how?
    a. Communication
    b. Understanding
    c. More contact
    d. More support
    e. Better facilities
    f. Materials

Appendix 12: Other stakeholder interview schedule (Chapter 3)

FOR PROFESSIONALS

Note: the format of these interviews is semi-structured and participant led, hence this list of questions should be used as a guide only.

From my conversations with (INDEX PARTICIPANT), I understand that you have come into contact with them with regard to their cancer/ID needs. If there are any questions that you'd rather not answer then just let me know and we'll move onto something else. I'd also like to remind you that it would be unethical to discuss the experiences of any other individuals and we should only discuss (INDEX PARTICIPANT) and your general knowledge of cancer/ID.

Initial Questions – Oncology oriented professionals

24. Could you tell me about your knowledge of intellectual disabilities and how it can affect people's daily lives?
25. Were you aware of this before you came into contact with (INDEX PARTICIPANT)?
26. When did you first come into contact with (INDEX PARTICIPANT)?

Initial Questions – ID oriented professionals

1. Could you tell me what you understand about cancer?
2. Were you aware of this before you came into contact with (INDEX PARTICIPANT)?
3. When did you first come into contact (INDEX PARTICIPANT)?

Main body of questions:

4. Were you aware from the outset that they had an intellectual disability/cancer?
5. Could you recall a typical appointment with them?
    a. What happened?
    b. Were there any noticeable difficulties?
    c. How were these overcome?
6. Did you communicate with other professionals to assist with their treatment?
    d. For oncology professionals: ID professionals
    e. For ID professionals: Oncology professionals
7. Were you confident in your ability and knowledge when coming into contact with them?
8. Are there any changes which could be made that you believe would improve your experience of coming into contact with similar people in the future?

FOR FAMILY OR FRIENDS

Note: the format of these interviews is semi-structured and participant led, hence this list of questions should be used as a guide only.

I’m going to ask you about your experiences of (INDEX PARTICIPANT)’s cancer diagnosis and treatment now. If there are any questions that you’d rather not answer then just let me know and we’ll move onto something else.

Initial questions:

1. So, how do you know (INDEX PARTICIPANT)?
2. How have you been involved in their cancer experience?
    a. Offering emotional support?
    b. Taking them to appointments etc.?
    c. Providing respite care for them (Taking them out for the day etc.)?

Emotional support:

3. Have you been feeling any particular emotions since the diagnosis?
    a. Anger, sadness, confusion
4. Have you been getting any emotional support from others?
    a. Who do you get this from?
    b. What do you talk to them about? (Practical things/emotions)
    c. How do you feel after you’ve talked to them?
5. How do you feel when you talk about their illness?
6. Have you turned to religion or other social support mechanisms to help you cope?
    a. Were you religious before the diagnosis?
    b. Do you practice regularly?
    c. Social support: community centres/support groups

Learning about the illness:

7. Do you read and try to learn about cancer?
    a. What do you read?
    b. Is it helping you to understand?
    c. Is it helping you to cope?
8. Have you accepted their illness and what is happening to them?

Recurrence:

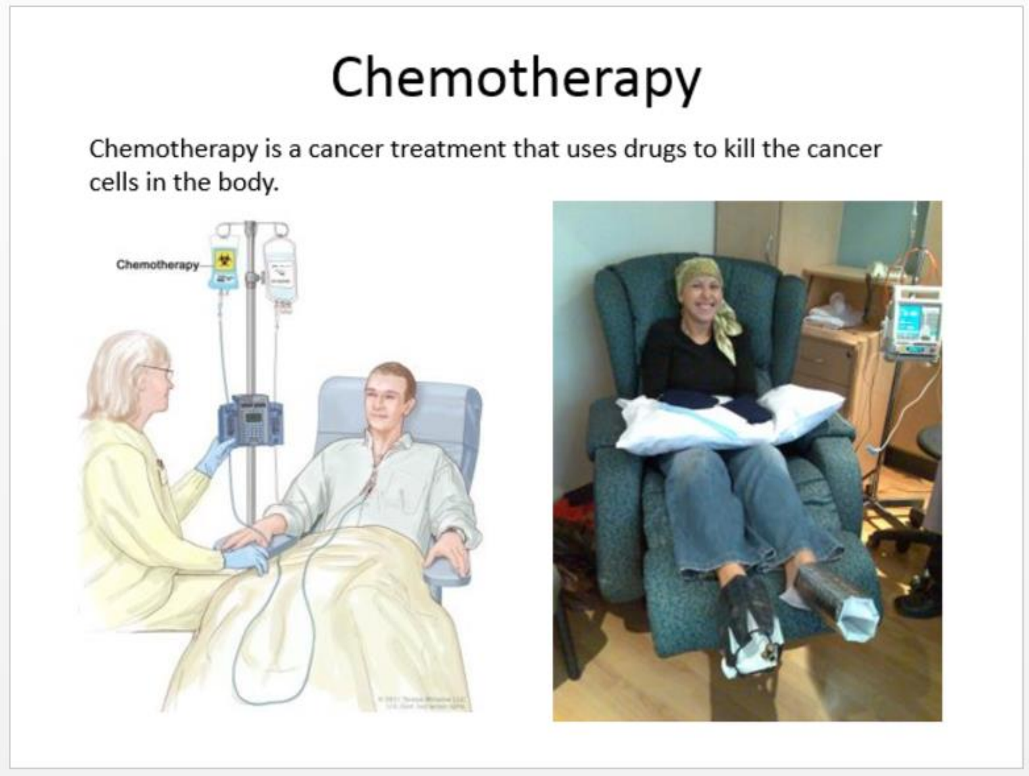
9. Do you ever worry about recurrence or it getting worse?

Making the experiences easier:

10. Do you think that this experience could have been made easier? If so, how?
    a. Communication

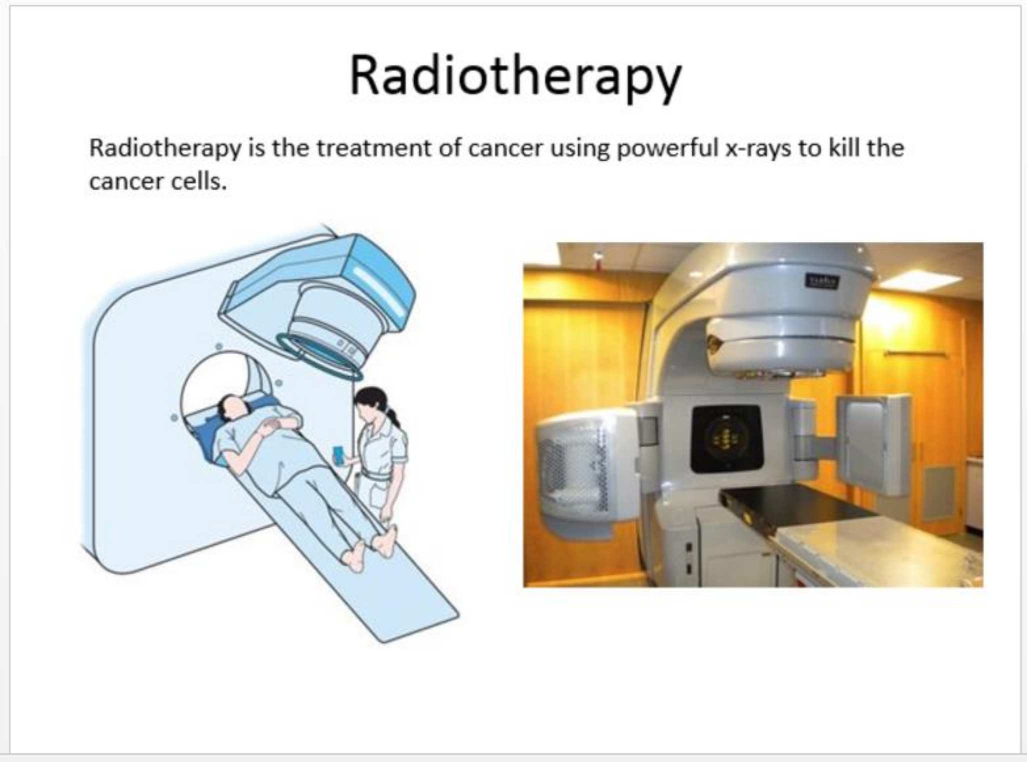
b. Understanding
c. More contact
d. More support
e. Better facilities
f. Materials

Appendix 13: Example of interview pictorial aids (Chapter 3)



Chemotherapy

Chemotherapy is a cancer treatment that uses drugs to kill the cancer cells in the body.



Radiotherapy

Radiotherapy is the treatment of cancer using powerful x-rays to kill the cancer cells.

Appendix 14: Recruitment information sheet and study inclusion/exclusion criteria (Chapter 3)

Research study - Cancer experiences in individuals with an intellectual disability

This study aims to gain a better understanding of the overall cancer experience of individuals with both an intellectual disability and cancer and the experiences of those who help to care for them. The information will then enable the development of a more coherent understanding. This will further our knowledge about where any issues may lie and what can be done to rectify them.

Once a more coherent understanding has been established, interventions may be developed and suggested to implement the recommendations made by the research in order to improve the overall experience.

Participants

Inclusion criteria for recruitment purposes are listed below. Both the individual with ID and cancer and their caregiver are to be contacted in first instance and asked whether they would be happy for their contact details to be passed to the research team.

Individual with ID and cancer (Index participant)

- Adults over the age of 18.
- Participants must have had a diagnosis of an intellectual disability with an onset before the age of 18.
- Participants must have had a diagnosis of cancer.
- Participants must have undergone assessment and some degree of active cancer treatment.
- Participants may have finished their treatment regime and no longer be undergoing active treatment.
- Participants must be able to give informed consent after specific considerations (including the provision of flash cards and accessible language) have been made. Researchers will conduct a consent test to ensure that all participants have the capacity to consent.

Their primary caregiver

- Adults over the age of 18.
- Participants must be informal caregivers for those in either group one.
- Participants must not be paid for their duties as caregiver.
- Participants must be able to give informed consent.

Procedure:

If you believe that individuals meet the above mentioned criteria, please provide them with the information sheet and consent form labelled ‘Invitation to a Research Study – Cancer experiences in individuals with an intellectual disability’.

Appendix 15: Initial consent forms for sharing contact information (Chapter 3)

Thank you for considering whether to take part in my research.

If you are happy, for both of you, to participate in my research, I will contact you once I have received this form and arrange a date and time for the interview which is suitable for you.

If both of you would like to participate in an interview, could you please return this form using the FREEPOST envelope provided. Alternatively, you can contact Samantha Flynn on 01224 513179 or samantha.flynn@chester.ac.uk

Name ……………………………………………………………………………………………………….

Address ………………………………………………………………………………………………………

……………………………………………………………………………………………………..

……………………………………………………………………………………………………..

Tel no …………………………………………………………………………………..

We would/would not* like to participate in an interview about our cancer experience.

**please delete as appropriate*

Appendix 16: Capacity to consent to interview protocol (Chapter 3)

1. Read Information sheet once to participant

Read the following part of the Information sheet:

“Sometimes people can get poorly. Sometimes people have cancer. Some people who have cancer have an intellectual/learning disability too. I want to talk to people who have an intellectual/learning disability like you and also have cancer like you do. I want to talk to you about your cancer and your life.”

2. Ask the participant: “Why do I want to come to speak to you?”.

Score 1 if the person gives an answer similar to “To talk to me about cancer” or “To talk to me about my life”.

Score 0 if the answer is irrelevant or too vague (eg “See me”).

3. Read the following part of the Information sheet:

“The things I want to ask you are: About your family. When you’ve been in hospital. How you feel about your cancer, if you’re, upset or confused. Who has helped you with seeing doctors and nurses.”

4. Ask the participant: “What do I want to ask you about?”.

Score 1 for any answer similar to “Me” or “When I was in hospital” or “When I’m angry or sad” or “My family”.

Score 0 if the answer is too vague or irrelevant.

5. Read the following part of the Information sheet:

“When I have finished, the answers I get from you will be kept in a safe place. Remember that you do not have to say yes. If you do not want me to come and talk to you, just say no.”

Ask the participant:

“Are you happy for me to ask you questions about your life and cancer?. Answers Yes or No.

6. Read the following part of the Information sheet:

“If you say yes, but then you change your mind that’s OK. Just tell me no later on. You won’t have to tell me why”

Ask the participant:

“What will you do if you change your mind?”.

Score 1 for any answer similar to “Tell you No”.

Score 0 if answer is irrelevant or too vague.

Overall Scoring

If the participant scores 0 to any of the questions under items 2,4 or 6, then the participant is assessed as not having the capacity to consent in this specific context and the researchers should follow the alternative route of seeking assent of the legal representatives. If the participant scores 1 in every question under items 2,4 and 6 then the participant is assessed as having the capacity to consent and s/he is indicating his wish to participate. If the participant scores 1 in every question under items 2,4 and 6 but answers “No” in either question 5, the participant is assessed as having the capacity to consent and is indicating his refusal to participate.

This protocol is based on the procedure followed by Arscott, Dagnan & Kroese, 1998.

Arscott, K., Dagnan, D., & Kroese, B.S. (1998). Consent to psychological research by people with an intellectual disability. Journal of Applied Research in Intellectual Disabilities, 11(1), 77-83.

And has been adapted from a material used by Dr Lee Hulbert-Williams in previous research.

Appendix 17: Patient and caregiver demographic questionnaire (Chapter 3)

Please complete the following questions about yourself.

1. Are you… Male
Female

2. Age (In years) ……………………….

3. Which best describes you (please tick one box only):

Employed full-time	☐	Employed part-time	☐
Self-employed	☐	In full-time education	☐
Retired	☐	Other (please specify below)	☐
Not employed (seeking work)	☐	Not employed (ill health)	☐
Not employed (not seeking work for other reason)			☐

……………………………………………………………………………………..

4. Would you describe yourself as having a ‘significant other’ (e.g. wife, husband, civil partner, etc.)?

Yes ☐
No ☐

5. Do you live with your ‘significant other’?

Yes ☐
No ☐
N/A ☐

6. Do you care for any dependants?

Under 18 ☐
18-65 ☐
Over 65 ☐

7. What is your relationship to the person with an intellectual disability and cancer?
………………………………………………

8. Are you…

White	☐	Black-African	☐
Black-Caribbean	☐	Asian-Indian	☐
Asian-Pakistani	☐	Asian-Bangladeshi	☐
Chinese	☐	Other (please specify)	☐

……………………………………………………………………………………..

9. What is your doctor's name and address?

GP Name: ………………………………………………………………………….
GP Address: ……….
……….

Please complete the following questions about your dependent.

1. Are they… Male
Female

2. Their age (in years) ……………………………….

3. Which best describes them (please tick one box only):

Employed full-time	☐	Employed part-time	☐
Self-employed	☐	In full-time education	☐
Retired	☐	Other (please specify below)	☐
Not employed (seeking work)	☐	Not employed (ill health)	☐
Not employed (not seeking work for other reason)			☐

4. Would you describe them as having a 'significant other' (e.g. wife, husband, civil partner, etc.)?

Yes ☐
No ☐

5. Where do they live?

Alone	☐	In a community group home	☐
With parents	☐	In a hospice	☐
With partner (eg. Wife/Civil Partner)	☐	Other (please specify) …………………….	☐
With other family members	☐		

6. Are they:

White	☐	Black-African	☐
Black-Caribbean	☐	Asian-Indian	☐
Asian-Pakistani	☐	Asian-Bangladeshi	☐
Chinese	☐	Other (please specify) ………………	☐

7. a. Do they have and intellectual disability? Yes/No
7. b. What intellectual disability do they have? ……………………………………
7. c. Do they have any additional disabilities? Yes ……………………………………/No

8. What type of cancer have they been diagnosed with? …………………………………….

9. What treatments have they had for their cancer? (e.g. Radiotherapy/surgery etc.)
……………………

10. What is their doctor's name and address?
GP Name: ………………………………………………………………………….
GP Address: ……….

Appendix 18: Initial interview schedule (Chapter 3)

Note: The format of these interviews is semi-structured and participant led, hence this list of questions should be used as a guide only. Not all questions and prompts will be used.

Hi, I'm Sam and I'm interested in talking to people who have an intellectual disability like you and also have cancer like you do. I'm going to be asking you some questions today about your illness but if you don't want to answer some of them then you don't have to and if you want to take a break or stop talking then you just let me know and that is ok too. I've got a timeline that we can fill out together so that we can see when everything happened and I know for our next interviews. I've got some flashcards we can use too if you don't understand some of the words or can't remember some things, we don't have to use them but they're there if we need them.

1. When did you first notice that something was wrong with your body?
   a. Was it in Spring, Summer, Autumn or Winter?
2. How long did you wait until you went to the doctor about it?
   a. Did you go straight away?
   b. Did you wait a while until you went to the doctor?
3. When were you diagnosed with cancer?
   a. Was it very long after you went to the doctor?
   b. Explain what a diagnosis is (Flashcard)
4. What cancer have you been diagnosed with?
5. What treatments have you had?
   a. Chemotherapy? (Flashcard)
   b. Radiotherapy? (Flashcard)
   c. Surgery? (Flashcard)
   d. Other?
6. When did you start your treatment?
   a. Was it very long after you were diagnosed?
7. Has your treatment finished?
8. When did that treatment finish?
9. What's the current status of your illness?
   a. Are you still having treatment?
   b. Do you still have to go to the doctor?
   c. Has your cancer gone away?
10. Have there been any other major changes which will be relevant to the subsequent interviews?
    a. With family/living situations?
    b. With doctors/hospital visits/stays?
    c. With your body?
    d. With your illness?

11. Is there anyone else, for example a health or social care professional or another family member, who has played a really big role in your cancer experience who I should interview about their experiences of (INDEX PARTICIPANT)’s cancer diagnosis and treatment?

Appendix 19: Initial interview debrief and invitation to a subsequent interview (Chapter 3)

University of Chester

Research Study Debrief – Cancer experiences in individuals with an intellectual disability

I would like to thank you for taking the time to participate in this element of my research study. You are both invited to take part in a second individual interview where we will talk about your cancer experiences.

All information about this next interview is provided on the information sheet which you have already been provided. You should read this again and discuss it with me if you have any questions or concerns.

I'd like to take this opportunity to remind you once again that anything discussed in the interviews will be treated as confidential. Similarly, in our study write-up, I'd like to assure you that we'll remove all personally identifying information so that you remain anonymous throughout.

Please feel free to contact me if you have any further questions about this study. If you have any queries about yours or your dependant's medical condition or the illness, we suggest that you refer these back to your GP or cancer team at the hospital where they are being treated.

Having cancer can be an upsetting and confusing time for some people. If you think you would benefit from talking to someone about your experiences, the following telephone numbers might be helpful:

Macmillan Cancer Support: 0808 808 0000

Cancer Help UK: 0808 800 4040

The Samaritans: 08457 909090

Once again, many thanks for participating in this element of the research.

Samantha Flynn.

Appendix 20: Additional stakeholder invitation letter and response form (Chapter 3)

Invitation Letter to a Research Study – Cancer experiences in individuals with an intellectual disability

Individual with an intellectual disability and cancer:
…………………………………………………………

I am completing my PhD within the Department of Psychology at the University of Chester, and I would like to invite you to take part in a new research study.

Written information can be provided, upon request, in Welsh however all interviews will be held in English. If you require this information in Welsh please let me know using the contact details below.

This research will investigate the cancer experiences of individuals with an intellectual disability and cancer, as well as the experiences those who help to care for them and ways in which both groups think their experience could be improved. You have been approached as you have been identified by the above mentioned individual as having played a pivotal role in their cancer experience.

If you decide to take part you will be required to take part in a telephone or face to face interview, where the researcher will look to establish your experiences of helping to care for someone with a has an intellectual disability and cancer. The interviews will be audio recorded and the discussion analysed.

I've included an information sheet that explains the study in more detail and you should take some time to read this thoroughly and ask any questions you have before agreeing to participate. You may also want to discuss this with your family, friends or colleagues, and that is fine for you to do so. The interviews can take place at your home, office or another private space will be made available on a date and time most suitable for you.

The interview is likely to last approximately 60 minutes. Whilst I appreciated that this is quite demanding on your time, I hope that you will be willing to take part so that I can establish a more complete understanding of cancer experiences of those with an intellectual disability and those who help to care for them. This research is being conducted with the view that a better understanding will make steps towards improving the support that we can provide to cancer patients/survivors who have an intellectual disability and those who help to care for them.

If after reading the information sheet you feel that you would like to take part, please complete the attached reply form, consent form and demographic questionnaire and return to the University in the enclosed FREEPOST envelope (please retain the information sheet for your records). If you do not wish to take part, you do not need to do anything. Your decision whether or not to participate in this study will in no way will affect your legal rights or the medical care of the individual with an intellectual disability and cancer.

If you have any questions regarding this research please don't hesitate to contact me on 01244 513179 or samantha.flynn@chester.ac.uk.

With many thanks for your time

Samantha Flynn

University of Chester.

Thank you for considering whether to take part in my research.

If you would like to participate in an interview, could you please return this form, along with the consent form and demographic questionnaire using the FREEPOST envelope provided.

If you have any questions you can contact Samantha Flynn on 01224 513179 or samantha.flynn@chester.ac.uk.

Individual with an intellectual disability and cancer: …………………………………………………

Your relationship to this individual: …………………………………………………

Your name ……………………………………………………………

Address …………………………………………………………………

…………………………………………………………………

…………………………………………………………………

Tel no …………………………………………………………………

I **would/would not*** like to participate in a **telephone/face to face*** interview about my experiences of the above mentioned individual who has both an intellectual disability and cancer.

**please delete as appropriate*

Appendix 21: Full categorical chart for the thematic analysis (Chapter 3)

THEORETICAL CONCEPT	QUOTE	LINE REF
Patient wants to protect their caregiver from their illness	1A: Well, more to (1B) cos (1C) gets a bit…thingy… (1B) understands it. Cos he used to go in you know…with us…to the place…see (INAUDIBLE). SF: So you're saying, not talking to (1C) so much? 1A: Well, it upsets her. SF: Yeah. 1A: It does sometimes (INAUDIBLE) doesn't it?	1A; 196-202
	1D: I think a lot of it was…was fright. I mean, (1A)…I think was frightened, well I could see he was frightened cos he…he was very pale, he was getting quite anxious. But his family members were very, very frightened as well, and he would pick up on that and he'd then start worrying about them as well, rather than just concentrating on himself. Erm, he…he's not a great one to show emotions, but he will show it in other ways….his behaviour, his anxiety. You know, and that sort of thing where we might just think we're frightened or nervous, (1A) might show it in a different way.	1D; 341-349
	1C: And I'm still really frightened of it. (PAUSES) You know, I'm probably more frightened that (1A) is.	1C; 278-279
	2C: He won't…he won't voice that. He won't say "Oh, I'm really disappointed, oh…" He won't have that…he won't have that reaction, no…he'll just…he'll just go along…	2C; 126-128
	3A: I just…myself…I just be'd myself. SF: Yeah? 3A: That's all you can be. SF: So you just relied on yourself. You didn't ask for any help or… 3A: Yeah, I just got through it.	3A; 140-144
	SF: OK. So did you talk to your family about anything else? 3A: No, because…that's it.	3A; 196-197
Caregiver wants to protect the patient from their illness	2B: So never in front of (2A) really, unless we were having one together, you know (LAUGHS) But it was only that time in that waiting room when he was…he got me a bit then and I thought "Don't	2B; 948-953

	cry!" (LAUGHS) "It's alright, you're fine. It's like a blinking hotel here, what are you worrying about?!" Keep it lighter like that, you know.	
	1C: You know, somebody else can…me turning a blind eye to cancer, you know, brushing it under the mat. I think helps him a little bit. I don't know.	1C; 155-157
	2B: you do have your cry, your rant and…then it's…but not in front of him. No, not if front of him, never erm…you talk about…you chat and say… "Oh for goodness sake, what are you up to again?" You know, I'll always "Ooh!" You know and…because I didn't want him to be worried, he's got to cope with enough	2B; 754-758
	2B: So never in front of (2A) really, unless we were having one together, you know (LAUGHS) But it was only that time in that waiting room when he was…he got me a bit then and I thought "Don't cry!" (LAUGHS) "It's alright, you're fine. It's like a blinking hotel here, what are you worrying about?!" Keep it lighter like that, you know.	2B; 948-953
	2B: No. That's the thing I think, d'you know…although it sounds strange to say it…I think (2A) being, erm…having the problem, the disability…helped him through the cancer, in as much, because he wasn't so aware…of what it does…to a person.	2B; 59-62
	2B: Oh yeah, I'm sure. I think, there was no…(2A) being (2A), there was never anything...that he thought something was gonna happen, I don't even think he thought on that wavelength because we wouldn't let him.	2B; 474-477
	2B: So we tried to play everything down, if we could, rather than…cos I don't want him to dwell on it, you know…	2B; 140-141
	2B: Where, (2A) just took it in his stride, really, you know…when I say took it in his stride…he doesn't display a lot of emotion…he's not a…he…yes, he does in his…he'll get…you can see he's getting upset about something, straight away in his face, but he coped with it remarkably well. Unbelievably well, and I think that it helped him, because probably…you know, he knew…cancer…you know, you see it on the TV and everywhere, so you know it was an illness but maybe he didn't understand…the depth of it…	2B; 68-76
	2B: Together, yeah…we wasn't weeping and wailing in front of (2A) all the time, I would be positive	2B; 621-622
	6B: Yes, but not…without all the…the…you know, the…the terminal bits, you know. We'd tell her all the other bits, that he was very pleased with her, and you know, that the problem with her tummy had got sli…no worse, and…you know, things like that. But we would say that the cancer was still	6B; 224-229

	there, it hadn't gone away but it was behaving itself at the moment, and she'd be quite happy with that.	
	6C: But again, she…you know…because she…she was very ill on the…on the maximum strength that…you know, that she…she made that decision, you know. So she mi…probably wasn't told, you know…like what, what that meant in terms of…you know, like the prognosis for her…but…I think that was sort of done you know, to sort of well…like I suppose it's getting that balance between sort of like…erm…involving her in the process as much as you can, but also…not scaring her…unnecessarily. Because at the end of the day, it's about quality of life, isn't it, so…erm…yeah.	6C; 93-102
	6D: So she was very aware, so as soon as she got told she had cancer she said "I'm gonna die like my mum." And nobody said yes or no to that, we all said. That was one of the reasons we had an MDT, because we were all going to sing from the same hymn sheet. So we all…We weren't going to say yes, we weren't going to say no, we weren't going to lie, we were just going to say "Everybody is individual, we're gonna give you the medicine and hopefully it will help." Which is what we all decided to do, and I found that that was a really good idea because, previous experiences…not particularly in cancer services, it's like "Oh, we won't tell them. Because they'll get so distressed that they'll die sooner." Or whatever. And it was like "Ooh, that doesn't sit right with me." People have a right to know. Erm, so that was…I…I found that was a good approach.	6D; 138-150
	6E: I understand that she…is aware she's had treatment, that no further treatment is being offered at the moment, because of all the issues she's had with the previous, erm…and occasionally she will say things like I'm not ready to die yet, so although she's got an understanding of cancer and the fact that she isn't well, I think it's something that we're trying to explain to her…in a positive way, that she is poorly, but also trying to give her the best quality of…of life. That her life doesn't revolve around medical appointments and clinic appointments and anything medical, that she has got a social life as…as well.	6E; 81-91
	2B: so he coped remarkably well with it. Erm, which I think…you know, may be because, I dunno whether it was to do with understanding or what but…you know, he does know what cancer does to people out there, cos you see it on TV enough and we've had people who…you know, passed away with it…so…but you know, he's well aware this is what…you know, but yeah so, you know…what was I saying?	2B; 83-89

	2D: And I think you know, they must have felt very, very protective over him and it must have been very, incredible difficult and I think they probably need, you know, parents in that situation, need a lot of support as well.	2D; 256-259
	2B: Er, no. I'd say no. I don't know what (2C) said. But, no. What he, you'd sort of…we would just, you know, when he said "Oh." We'd explain, like the nurse trying to get the…made a joke, couldn't get the, find the vein, you know, cos it's how we said well, no we had a chat about it, always knew what was coming. We said, you know "It's the only way. You've gotta have this, cos it kills off everything else there then, and be sure that it doesn't come back." So we'd explain to him, you…everything about what was happening, as long as he…we could tell him as much as we knew, and the doctors would explain everything to him, you know, it's not just "Oh well, do this" and erm, not tell him. They would talk, "Have to get you in (2A), that needs to go in" That w…and you know, and talk. Cos we were on the same with him, so as they're telling us, he's there listening to it all, so.	2B; 241-254
	6A: Just what he had to say, and afterwards I had a cake, I went down and had a cake while he was talking to them.	6A; 261-262
	6B: No, because when it was something that was a little bit, sort of…near the knuckle and important and they didn't want to distress (6A), erm…one of the members of staff would take her off to the café…and…loves a cream cake does our (6A)…and buy her a cream cake and a cup of tea while the others stayed and discussed the situation with the oncologist, then they could do a written report when they got back, and that was the best way. He would talk to her, but not go into any in…in depth which she perhaps wouldn't have been able to grasp or well it probably would have, erm…worried her really, so that's how we used to handle that.	6B; 212-221
Caregiver wants to protect themselves from discomfort and/or distress	2B: And he does know what it does…erm, but now something will remind him about, say something we went on our walk "Do you remember that mum? I had that didn't I?" I said "Yeah…" And then one of (2C)'s brothers "Yeah, but we've been there, we've done that. It's all done now, ennit." You know, and we… But he thinks about it, he don't forget a thing, he's remembered everything. "Remember when I had that, I was poorly weren't I?" Remember when I had that…" (Pause) Just can't…the things…something will remind him. He'll say "Oh yeah. I remember that." "But we don't want bring that up, do we? That was a thingy time and erm…we're fine now aren't we?" You know, we're…put it away…and that's..but we…so he still, you know…erm, things trigger it and he…not dwell on it…just say "Remember that, I had that…remember those people who I went to…" Just cos	2B; 485-502

	he remembers, very good memory. He'll still remember, probably, the bus we caught, number bus, you know what I mean. He's got a good memory. So er yeah, so but…you know…that's and that's the way we deal with it…	
	2B: Well you don't wanna be…you don't want to be reminded of it. It's a horrible time, you know, you don't erm…you do, sometimes you do…something will come up. But, you know, you forget it. Fine, dusted…done and dusted, all done, you know. But it er…sticks a long time, cos it's such a horrible…you know, someone who's been through it…it's not something...you know, when it hits you, it hits you. You know, knocks the stuffing out of you, it really does. But you learn to cope,	2B; 505-512
	6B: (6A) and I actually talked about it, you know, and she was asking me about (6B HUSBAND) and "Did (6B HUSBAND) get very thin like I'm getting thin?" And I said "Yes, he did. But he never turned into a supermodel like you!" And we'd have a bit of a laugh about it, you know…so…	6B; 67-71
	6B: Well I think she's quite concerned about the fact that she's becoming so thin. And I always say… "Ooh, (6A), well look at me with this big fat tummy and a big fat bottom." You know, "And there's you like a supermodel!" And she laughs, but she is drastically losing weight, cos I notice it…you know, if I'm off for a couple of days and I go back, believe it or not, I can see a difference. Erm, so I think that concerns her a bit…erm…and…I don't think she likes it very much, but you know…but she…she's alright	6B; 257-264
	6C: ...her home staff team, they have been really good at keeping her positive and sort of like, encouraging her to live her life, rather than sort of, preparing for death, you know. But equally, you know sort of like…being aware that…you know, she…like…if she does talk about things, you know…what…what the…you know…what sort of funeral she wants, and, you know…those sort of….using those…if those opportunities sort of happen naturally, to sort of take them on board, but not to sort of like…over-emphasize those kind of things…to sort of…really encourage her to…erm…do the things that she wants to do, you know…	6C; 180-190
	6C: Erm…I…well…(PAUSE) I…I think she, sort of…knows…what…you know…what is likely to happen in the future…erm…but I think…erm…(PAUSE) like…I do…I don't think she thinks that she's cured…I think she realises that, you know…that…I think…a lot of people thought that may be facing death at some point, it's nicer not to sort of think about it. And I think the sort of view, I…my view is that sort of…things will happen with (6A) naturally, whereas there'll be good points to sort of talk about different things, along the way…that it's not good to maybe bombard her with information and sort	6C; 105-117

	of scare her unnecessarily, but…equally…what the staff have been doing with her has been to sort of like ensure that if she wants to go on holiday, she can go on holiday and that her life carries on.	
	2C: Erm, I…er…no…I can't, I don…apart from you know "I've had cancer." You know, and you know, it was testicular cancer, and stuff like that and…a little bit of joking and banter about that but…and how terrible it was sometimes, you know how ill he felt. But I don…I don't think he actually talked as…as "Can you help me understand it?" I think when he talked, what he wanted was reassurance, that's all. "Everything's gonna be fine." I think it's on that level, you know…and, erm…which is what we all need I suppose	2C; 42-49
	3B: The staff there er…were not experienced er…in…in…in…the reaction was…again, unknown to (3A) that er…you know, er… "Is he dying?"…you know, that "Is he dying? Is he dying, will he die on us?" you know…that sort of thing. "What happens if I'm on shift if he dies?" And I said, having worked with terminal ill people myself, children…years ago…I said "There's no…in any case, he's having treatment and he's not going to die."	3B; 44-51
Healthcare professionals have limited knowledge about intellectual disabilities	1D: And, services, there's all these drivers saying services need to, you know, break down barriers, they need to, you know, be putting easy read information things together. None of that was offered to us, even when I explained that this client, well (1A) had a learning disability.	1D; 264-268
	5A: Oh, I did once. Oh god…(DOCTOR2) wanted see me…and I couldn't get taxi ambulance. I had to go in minibus and they took you all round area and I said "Excuse me…I've got appointment with (DOCTOR2)." They weren't bothered! SF: They weren't bothered? 5A: And then if I missed that appointment, I'd be in trouble! SF: And what did they say? (PAUSE) Oh really? They didn't want to know? 5A: Anyway, I saw (DOCTOR2) anyway and I said don't blame me! Blame them! SF: That must have been…what did that feel like, not knowing that you were going to get there? 5A: (PAUSE) I were a bit cross. SF: Yeah. 5A: Cos it…I knew she wanted to see me about something.	5A; 286-300
	6D: And likewise liaised very well with myself and the other members of the MDT, we had several MDT meetings…erm…multi-disciplinary team meetings, to erm…to decide how best to approach this	6D; 57-62

	with (6A) erm…and…they were very understanding and they made quite a few reasonable adjustments as well, to be fair to them. So, I was very impressed.	
	1D: So we put together a health action plan, which (1A) could then hand to…erm…whoever worked with him who could pick it up and would know (1A) from back to front because of the information that was there that was provided. So it looked at all, you know, his health issues, it looked how to communicate with him, to ask him if he was in pain cos he wouldn't actually…so it had information so you know, if he went to a ward or went to an appointment without me that information could be shared.	1D; 209-216
	1D: I think they really, really struggled. I think they didn't realise that (1A) had a learning disability. Cos (1A) would just nod and say the right sort of things, erm…they didn't really ask him if he wanted to ask any questions or ask him if he wanted anything explaining. They just presumed that he would have taken all this information. And the important thing with working with people with learning disabilities and information you give people, is you check whether they've understood or not and then trying to put ways of improving that.	1D; 241-249
	1D: I suppose people should have an awareness of people with learning disabilities, because there's a high proportion of people out there who've got an LD. And, services, there's all these drivers saying services need to, you know, break down barriers, they need to, you know, be putting easy read information things together.	1D; 262-266
	1D: I think services need to…I think…need to work collaboratively with people with, with learning disabilities.	1D; 319-320
	1D: I think other people need to get better at picking up an LD and not taking it for granted.	1D; 336-337
	1D: I think, the haematology now here is better, cos they know (1A) and I think they've put that he's got a mild learning disability and…erm…and often I'm, they know that I'm gonna be there as well.	1D; 353-355
	2B: "Why has he waited this long?!" You know, she must've said to him…you know, why, cos that's her reaction, you know. And he said "Well, he's got…the gentleman's got some learning disabilities and you know, his…" And, you know…fin…well it must've been on his notes	2B; 295-297
	2D: Erm, I think yes. I think that's just a general medical knowledge that you, you sort of learn as you go along and then with experience with working in psychiatry and things like that. I mean you do pick up, throughout your training, you do come into contact with, with different people. But I wouldn't say that it's ever been a specific subject that we've, we've learnt on, ok. So I think it's, it's	2D; 21-35

	the type of thing that you pick up, erm, through experience and…and there is, in Medical School we broached on subjects like that. But unless you're actually working in that environment you probably don't have a lot of exposure, your exposure comes from dealing with, with things that happen in the course of a normal medical job, yeah…so, I'd probably say, yes that basic knowledge was there, but then if you work with someone, particularly with a learning disability, things…things do obviously, erm, become clearer and…and I think you have to adjust to each person's disability.	
	2D: I think, if they are there in clinic, because this is not the first and it certainly won't be the last patient that goes through and…and I think, not only myself, but I think for other clinicians it's…it's something all of us know, not much…you know, in…in…experience with and I think it'll help, or you know, would have helped. I mean, we…we give them the general information but I guess that then would be more directed to family and carers and there's nothing p…you know, purely directed to the individuals in question and I think that it's much needed.	2D; 293-301
	3B: At this clinic. And she knew that (3A) had a learning disability, but chose to phone him up and tell him the date months ahead, and that was it! And then had the cheek to complain that he hadn't turned up…! And I thought, as well, luckily I got (LDCSN1) on his case, who is a learning disability nurse…er…to sort out this appointment and make it quite clear the need to have proper, organised…unbelievable! I..I mean, the whole…(3A) has got a learning disability, even somebody who's been through all that, was then told "September the 1st, 3 o'clock." It's not good enough, just simply not good enough.	3B; 83-92
	3B: I didn't feel, for example, that the organisation of appointments, the aftercare appointments were sufficient enough for (3A) to understand. The way they did it, by phone and this sort of thing…er…on the other hand, I didn't want (3A) treated any other way than…because he had a learning disability. I wanted it both ways. So what I'm saying is when a person is in a vulnerable position, with a learning disability or not	3B; 410-417
	3B: I would say, you know, really…I don't…I didn't want anything special for (3A)…but what we did need was communication.	3B; 428-430
	6C: the GP did sort of…and the district nurses initially did sort of have…like quite a negative erm…you know, attitude and I think we've sort of, like had to fight very hard to say…like, well, I suppose ultimately…erm…the…the…the management of (6A)'s treatment, from what we understand is fairly new, and I think that to be fair to the district nurses, their…they were used to	6C; 150-160

	sort of…the prognosis being…like quite…like, more or less, someone…erm…from er…diagnosis to death to…that time to be very short…erm…so I think they were sort of like, you know, planning things, you know, as if she didn't have very long to live.	
	6D: He was absolutely fantastic, he really was. Erm, when we started going to the oncology centre, erm…he was very patient, erm…(6A- does like the attention of professionals, erm…and she…she gave him hugs and kisses and she was really friendly with him, and he was very good, he wasn't sort of "Ooh!"… stand-off-ish or "Get away from me!" And he made sure that she understood what he was saying, erm, he took a long time with her…I think we had quite long appointments rather than the normal standard time.	6D; 40-47
	6D: Erm, but I must say the oncology nurses were very good, the specialist nurse was very good. Erm…very understanding, very erm, empathetic and erm…treated (6A) with dignity really.	6D; 54-57
	6D: But as time went on they understood more about the learning disability side, and part of my role is to help train up acute hospital staff members to understand how to work with people with learning disabilities.	6D; 76-79
	6D: And we use a lot of…well…of traffic light assessment, hospital assessment, and it's like a hospital communication passport. So we try to fill these in with the service users so it will tell the patient…er…the nurses on the wards or in any of the clinics how best to approach communication wise. And perhaps things you wouldn't do because it would upset them or cause a trigger for behaviour, so that was where…where my role really was…was facilitating the relationship between (6A) and the oncology staff.	6D; 79-87
	6D: the GP was...we…alleged to have said "There's nothing we can do for her…she's…you know…it's…it's not…not a good sign." Unfortunately one of the team members of the nursing team had let that slip to the staff members within the project, so that…although they didn't then…erm…say directly to (6A)…their behaviour changed…a very mollycoddling TLC type approach…erm…which er…we had…we ended up having an MDT and pulled the district nurses in and I wrote…did I write? Or did I phone? I contacted the GP and said "Look, we take the lead from the oncology centre. When they say enough's enough, then we take that. You don't say that to a nursing team who then gossip and change the whole approach." So that was…that was a particularly difficult situation.	6D; 168-180

	6E: I think possibly, erm…the GP. Now whether that's a cultural thing, or whether that's his lack of understanding of what learning disabilities all about, and his understanding of how able (6A) is and things like the mental capacity act, there have been issues there and it's something I've contacted like health liaison, cos I know they do a lot of work into GP surgeries. It's not a surgery I've previously had lots of experience, so I don't know whether this is unique to (6A) or whether, cos at some stages he felt that (6A) didn't have the capacity to make decisions whereas we know that she definitely did. But again, whether that's his understanding of learning disability, or whether he's not previously worked with people who are so able as (6A)…but I think there is some work to be done there.	6E; 125-136
Emotional impact was rarely discussed	2C: I think he looked to us, actually…to see how we reacted to it…to what…how he should, how he should take it. It's happening to him, obviously, but because he's so easy going and may not comprehending the serious of it, then he's looking to us to say "We need…we need to get…" he was picking up from us…how he…how he was gonna feel almost.	2C; 152-157
	6C: well she picked up right from the first meeting that, you know, that there was a possibility that she could die. Erm, and I think (CLINICAL PSYCHOLOGIST1) just sort of met with her and sort of like chatted to her around those issues, and sort of like, you know, her feelings, I think it was mainly her feelings around that.	6C; 36-41
	1B: Very quiet at time, yeah. Cos he's not able to express himself, how he feels.	1B; 44-45
	1B: Confused a bit, yes. But, you see…I don't know how he does it but he can shut down. He'll like try and blank it out if he can.	1B; 75-76
	1B: No, no he won't do that. He'll shut off.	1B; 196
	1B: He just seems to say, I don't know. He just seems to go blank, almost to say "That's it, nothing I can do about it."	1B; 202-203
	1C: And he was very, very brave. He never once tried to call on us for help, he stuck it himself. Marvellous.	1C; 33-34
	1C: But sometimes you know, I think he feels the word cancer, I think he fears it. But he won't say to you. He…he has got it locked up here I think and he won't come out with it. But he doesn't mopes, you know, he's very, very good.	1C; 95-98
	1C: But, no…he's a good lad and he's borne it very, very well.	1C; 216-217

	1C: Yes, that’s right. But (1A), we can’t get over how brave he’s been. He must have…you know, it must really have hurt him.	1C; 391-392
	1D: they heard the word cancer and…and (1A) didn’t show a lot of emotion	1D; 37
	1D: So it’s just, it’s just things in place, which I think…although (1A) didn’t show it, I could see it with his…his uncle the frustration and the worry then of these additional things that we had to take on board while we were there.	1D; 187-190
	2B: Cos (2A) won’t moan and groan, he gets on with it. The doctor said, he was a lovely Egyptian doctor at (HOSPITAL8) on the ICT…the Critical Care Unit. Erm, cos they’re always buzzing, there’s always a doctor there. And he said, he said “This young man is such a gentleman” he said, “he doesn’t complain.”	2A Initial interview; 332-336
	2A: Well, it didn’t feel very nice. It wa…it was horrible. Yeah, it was really…horrible. And I felt uncomfortable with it.	2A; 123-124
	2A: Well, I felt very…upset.	2A; 146
	2B: Where, (2A) just took it in his stride, really, you know…when I say took it in his stride…he doesn’t display a lot of emotion…he’s not a…he…yes, he does in his…he’ll get…you can see he’s getting upset about something, straight away in his face, but he coped with it remarkably well. Unbelievably well, and I think that it helped him, because probably…you know, he knew…cancer…you know, you see it on the TV and everywhere, so you know it was an illness but maybe he didn’t understand…the depth of it…	2B; 68-76
	2B: he was marvellous, I can’t say enough about him, really, er…how he coped with it.	2B; 190-191
	2B: And just affected him in as much, not that it made him upset or…erm, what’s the…just, you knew…you could tell, I can tell my (2A)’s features and how he was. You know, when somebody’s had chemo for three months, they grow to look really…the colour of my hair…you know, and thin, cos you know, it just, you try eating it’s, can’t…go the other way you know.	2B; 209-214
	2B: You know, but…but anyway, but you he, coped remarkably well so, and it was just like I said…he…wasn’t erm, he wasn’t…you…”Oh, I’ve had enough, go away, I don’t want any more of this!” and crying, nothing, none of that. He was just, accepted what he had, “You’ve gotta have this, you know that.” Yeah, you know, and that was it.	2B; 230-235
	2B: but he was fine, he went in with a smiling face	2B; 305

	2B: But that was the only time he felt sick, you know, that he expressed any…all through everything really	2B; 321-322
	2B: But erm…the only time, er, just thought of it…we went for a top up one day and it’s probably when he got a bit upset, but I think the chemotherapy made him upset, makes you upset and stuff, cos he didn’t used to be like that.	2B; 360-363
	2B: You know, and erm… “You’ll have to come in, we’ll have to admit you.” And he got upset then, funny enough, and I think it was the treatment was wearing down then, that’s why he got a bit upset.	2B; 369-372
	2B: But that was, I think the treatment…erm…he didn’t get emotional a lot, but it was just a reaction…and “OK, it’s alright, you can cry, I’m crying…” But you know, it was…that’s the only time I think I’ve seen him get…	2B; 378-381
	2B: He was alright with that, probably cos he’d got over the chemo then…yeah, cos that brought him down a lot and made him very emotional and upset. But it wasn’t like wailing…it was…it happened and it stopped, you know.	2B; 412-415
	2B: when you talk to (2A) “How were you (2A)?” “Oh, I didn’t feel well.” That was probably be what (2A) was saying to you, “Oh, I didn’t feel well.” But what erm…you know “Didn’t like it.”	2B; 863-865
	2C: No! (LAUGHS) Oh no, I think he was indifferent…yeah.	2C; 110
	2C: Yeah, yeah. I…I…he’d got to have an operation and that’s it	2C; 112
	2C: No…he’s very s…he’s very stable to be honest.	2C; 120
	4A: I was sad at first, but about the operation I was alright.	4A; 78
	6A: Yeah, that I had cancer, and it upset me. SF: Yeah. Can you remember what the doctor said? 6A: They said I’ve got cancer. SF: Yeah. OK. 6A: It upset me. SF: It upset you. 6A: Cos it were like my mum.	6A Initial interview; 5-11
	6A: No, cos I was too upset when I knew I’d got cancer at first.	6A; 48

	6B: Oh she was very upset, she was very distressed. Yeah, not happy at all, you know, and asking you know, when's it gonna stop and all that, you know…and erm…yeah, quite distressed about all that. Well we all would be, cos constant vomiting's not nice is it?	6B; 146-149
	6C: I think she's very, very positive. I think initially she was very scared, and…things were like, quite…negative.	6C; 178-179
	6C: She's a very cheerful person, erm…I suppose…I suppose that I'm saying that, but equally she's…she's a person that…when she's sad, she'll be sad…when she's happy, she'll be…show he happiness. You don't get the sense with (6A) that she's holding anything back, that, you know…I think there may possibly be some fears and that…that, you know…but I think she does talk to her team about that, you know…she erm…she doesn't say, appear to be holding, you know…holding anything in. She does seem to feel, be able to express everything.	6C; 249-258
	6C: Well that's it…if she's…sad, she'll start crying, you know. Like, and she'll say what it is that she'll…you know, she might take sort of a couple of minutes, and sometimes she might just go quiet and say she wants to go to her room, but if you sort of, you know, follow her there, she will…it does come out from her, so you know…	6C; 261-265
	6D: I know that she was fearful and that's why I involved the psychology services and our psychologist within the team visited and did a bit of anxiety related work.	6D; 153-155
Caregiver diverts important, but difficult conversations	3B: So then of course, knowing that you know, he had to go, so to speak and that and we talked that through didn't we, in our way…in a round about way…	3B; 38-42
	6B: (6A) and I actually talked about it, you know, and she was asking me about (6B HUSBAND) and "Did (6B HUSBAND) get very thin like I'm getting thin?" And I said "Yes, he did. But he never turned into a supermodel like you!" And we'd have a bit of a laugh about it, you know…so…	6B; 67-71
	6B: But she was adamant that it was…that she wasn't going to die like (6B HUSBAND). Erm…but I su…you know, as I said to her again "We all die eventually (6A). Nobody lasts forever do they?" Erm, but yeah…it was quite poignant really.	6B; 79-82
	6B: Oh yeah. And we always used to say, "If there's anything you want to ask us (6A), you know you can." And she'd "Yes, I know that." And you'd "Right…ok."	6B; 232-234
	6B: Well I think she's quite concerned about the fact that she's becoming so thin. And I always say… "Ooh, (6A), well look at me with this big fat tummy and a big fat bottom." You know, "And there's you like a supermodel!" And she laughs, but she is drastically losing weight, cos I notice it…you	6B; 257-264

	know, if I'm off for a couple of days and I go back, believe it or not, I can see a difference. Erm, so I think that concerns her a bit…erm…and…I don't think she likes it very much, but you know…but she…she's alright	
	6C: ...her home staff team, they have been really good at keeping her positive and sort of like, encouraging her to live her life, rather than sort of, preparing for death, you know. But equally, you know sort of like…being aware that…you know, she…like…if she does talk about things, you know…what…what the…you know…what sort of funeral she wants, and, you know…those sort of….using those…if those opportunities sort of happen naturally, to sort of take them on board, but not to sort of like…over-emphasize those kind of things…to sort of…really encourage her to…erm…do the things that she wants to do, you know…	6C; 180-190
	6B: I think they took it out (6A) because you don't have to have any more treatment, do you? 6A: No, no more treatment. SF: No more treatment? 6A: No, cos my hair's grown. 6B: So, there's no point in leaving the PIC line in, is there? 6A: No. 6B: And causing you discomfort, so they took it out. 6A: They took it out, yeah.	6A; 124-132
	6C: Erm…I…well…(PAUSE) I…I think she, sort of…knows…what…you know…what is likely to happen in the future…erm…but I think…erm…(PAUSE) like…I do…I don't think she thinks that she's cured…I think she realises that, you know…that…I think…a lot of people thought that may be facing death at some point, it's nicer not to sort of think about it. And I think the sort of view, I…my view is that sort of…things will happen with (6A) naturally, whereas there'll be good points to sort of talk about different things, along the way…that it's not good to maybe bombard her with information and sort of scare her unnecessarily, but…equally…what the staff have been doing with her has been to sort of like ensure that if she wants to go on holiday, she can go on holiday and that her life carries on.	6C; 105-117
	2C: Erm, I…er…no…I can't, I don…apart from you know "I've had cancer." You know, and you know, it was testicular cancer, and stuff like that and…a little bit of joking and banter about that but…and how terrible it was sometimes, you know how ill he felt. But I don…I don't think he actually talked as…as "Can you help me understand it?" I think when he talked, what he wanted was reassurance,	2C; 42-49

	that's all. "Everything's gonna be fine." I think it's on that level, you know…and, erm…which is what we all need I suppose	
	5B: Yeah, that she didn't dwell on it too much, I don't know. I can't quite answer that, you know, because she was never…you know, because she was never…I don't know if I remember her being really down, we had a couple of conversations where she sort of said "Oh you know I've been worrying about it. I'm frightened of dying and what if they don't get rid of it."	5B; 296-301
Patient is excluded from important conversations about their illness	1D: So, from my point of view, I highlighted that some of the things he was saying was too complicated and could he simplify it. And then he showed us the xray and there was a lot more…but without me being able to do that I think it would have been more difficult for yourselves to go.	1A Initial interview; 189-193
	1A: Well (PAUSE), words are hard 'cos I don't understand hard words.	1A; 322-323
	1A: I didn't understand what she…don't understand the doctors words. Can't understand them.	1A; 337-338
	SF: What do you think it would have been like if (1D) wasn't there? 1A: Ooh, I don't….I wouldn't know what was going on. I wouldn't know what he was saying cos I don't. Cos like long words that I can't understand.	1A; 369-372
	1D: I mean there was a few that I didn't go to because I was on leave and it was only, I suppose following that that (1A) and his uncle really struggled at those appointments.	1D; 105-107
	1D: And to help facilitate I think. To make sure, that also, that the consultants or the nurses who were working with them explained things better as well.	1D; 135-137
	1D: Very much so, it was as if they were talking to another consultant, cos even at times I had to ask can you actually put that a bit simpler cos I'm struggling, you know, some of the terminology they use.	1D; 139-142
	1D: So nothing was, you know, put in easy read, other than he did show us the x-ray, which made a big difference, so anything, you know, that small that made a big difference you think they'd be thinking like that but, they don't.	1D; 268-271
	6E: I've politely tried to explain that it might be good to involve (6A) in those, erm…discussions, and to invite her down for a consultation or even a home visit, if the GP feels that the medication needs to be reviewed. Erm, I've had the discussion that if it was anybody else I'm not sure that the GP would make those decisions without discussing it with the patient themselves, and I feel (6A) should be treated exactly the same.	6E; 143-149

	6A: Just what he had to say, and afterwards I had a cake, I went down and had a cake while he was talking to them.	6A; 261-262
	6B: No, because when it was something that was a little bit, sort of…near the knuckle and important and they didn’t want to distress (6A), erm…one of the members of staff would take her off to the café…and…loves a cream cake does our (6A)…and buy her a cream cake and a cup of tea while the others stayed and discussed the situation with the oncologist, then they could do a written report when they got back, and that was the best way. He would talk to her, but not go into any in…in depth which she perhaps wouldn’t have been able to grasp or well it probably would have, erm…worried her really, so that’s how we used to handle that.	6B; 212-221
	6E: I mean I have contacted the surgery a couple of times, cos I think they make decisions regarding (6A)’s mediation, pain relief, anti-sickness without discussion	6E; 139-141
	3A: They all speak a different language! SF: Yeah. 3B: Which is a very good point I think. SF: In what way? 3A: Just…they’re all speaking Welsh.	3A Initial interview; 45-49
	3B: Because (3A) wasn’t…didn’t feel that he was being included, you see, people were talking at the end of his bed in Welsh. (3A) can’t understand Welsh, so (3A) would ring up “They’re talking about me.” Well quite rightly he’d think that, if someone was standing at the end of my bed, perhaps glancing at me, I’d think they were talking about me even if they weren’t. So, if I didn’t understand their language and I did point that out to them, and they did stop and they did apologise.	3A Initial interview; 55-62
	SF: In (HOSPITAL9), and they would talk at the end of your bed in Welsh. And I just wondered how that made you feel? 3A: Didn’t understand a word that they were saying? SF: No? And what did that make you feel like? 3A: Didn’t bother. And… 3B: You rang me complaining, didn’t you? 3A: Yeah. SF: Yeah? So what did you…what…what did it make you think when they were talking in Welsh? 3A: Are they gonna speak Welsh to me?	3A; 46-60

	3B: And you thought that they were speaking about you, didn't you? 3A: Yeah. SF: Yeah? So what did…did that feel a bit, did that make you feel good or bad when they were talking in Welsh? 3A: Middle.	
	3B: He didn't understand what they were saying. The penny didn't drop with me, er…until I got there and I had a word with them about it and they they they they sorted…and in fairness, they did come to the bed and apologise. 3A: Yeah.	3A; 65-69
	SF: OK. So, when you didn't understand those words, you asked (3B). Do you think you might have asked them yourself, or did you go through (3B)? 3A: Hmm. 3B: I think you knew I was coming, didn't you? SF: OK. 3B: I'm sure you would have asked them if I wasn't coming, eventually. Yeah? SF: Yeah, you think you would? 3A: Yeah.	3A; 98-107
	5B: Erm…well it was arranged…actually…if I'm remembering now, with myself and (5A), there was…she had two…there were two oncology nurses that she saw, one particularly that she saw more…more than the other one…so she was always there in the room, and the consultant. And it was always discussed with (5A), he went through every step of what it would it would involve, what the options were and what he thought might be the right option for her, so…and then she could make that choice.	5B; 267-274
Healthcare professionals rely on caregivers to facilitate communication	1D: I found was that…the…the haematologist that gave us the diagnosis, I found, wasn't very clear in explaining what it actually meant. Erm, I acutally got him to write it down erm, so I was able then to go and try and put it into simpler terms.	1D; 33-36
	2D: And, erm, so I think we had an incredible about of help from…from his parents as such.	2D; 78-79
	2B: "It's a big op (2A), that blinking thing must have gone a bit further than we thought." You know, so…you know, "when he…when we took that bit out there, there's just a little bit up there, so they're gonna get that little bit there." It was just trying to explain it more, so he understood.	2B; 759-763

	6C: I think my role was…mainly around erm, her capacity to sort of understand the information she was given	6C; 26-27
	6D: Erm, and also facilitating the information, because the consultant…although he did try his best, used long, technical words, so we needed to break that information down and revisit it after the appointment so we could, erm…make sure that (6A) really understood what she was being told, so she could I…be informed on the decision whether she wanted treatment or not.	6D; 16-22
	6D: So I did a lot of background research myself, and erm…we used erm…a lot of pictorial information and erm…went on to the cancer website and there's an easy read website as well which helps people with learning disabilities to understand the processes. So, explaining what cancer is in the first place was quite difficult, so we would say "You…" erm "It's bad cells in your body. The bad cells are outweighing the good cells." Yeah, so that's an example.	6D; 26-33
	1D: I spose from my point of view, it's making other services aware that people have got a learning disability, that family members might have a learning issue. And when they're communicating that they need to make sure they've understood. That they do it in an easy way because I find that professionals throw a load of words to you, that I struggled with. I mean, I had to write down and then go and look things up myself. They're not that…I have to say that you know…some professionals are not user friendly when they're working with our client group…of putting things across simply enough.	1A Initial interview; 172-182
	2D: I mean, we…we give them the general information but I guess that then would be more directed to family and carers and there's nothing p…you know, purely directed to the individuals in question and I think that it's much needed.	2D; 298-301
	2D: they really tended to…to…to sort of guide you and look to you, and they also, erm probably made, you know…they…they sort of had an amount, an incredible amount of respect and they showed respect.	2D; 141-143
	1B: Didn't know what was going on. See, with (1D) she had that little bit of knowledge…and she understood (1A) so it helped.	1B; 622-623
	1D: Long hours. And, but, you know as I say, I felt that they need…probably needed me there to ask the questions that they…they couldn't think to ask.	1D; 122-124
	2D: But because his parents seemed to…they seemed to be the professionals and I think who could be better at advising us than the people who live with him and deal with him every day?	2D; 137-139

	1A: Oh, my Uncle asked all the questions. I just asked a couple and my Uncle asked the rest.	1A; 267-268
	1D: People with learning disabilities, they need to know, they need to be involved in the treatment and the discussions and I felt (1A), a lot of the time wasn't.	1D; 274-276
	1D: The difference from me is that I wanted to advocate for him and I wanted him to be more part of, I wanted things explaining so that he could understand what was going on.	1D; 281-283
	1D: I don't agree with that they tend to talk to me rather than (1A). I'll say "Talk to (1A) then I'll help you if you're struggling."	1D; 356-358
	2C: Erm, and it sounds as if we're saying about myself, you know, but it's not…I'd obviously make a decision in consultation with…with family, because (2A) is a grown man…you know, they weren't asking me "Can you sign the form?" They were asking (2A) "Can you sign the form?" Although, I think we had to sign as well…as…in case he didn't comprehend what's been said, we comprehended it on his behalf.	2C; 356-362
	2D: And then he explained it on his…erm…it was…just as a similar example, just recently…erm, his mum was quite concerned cos he had developed some swelling of the veins, and erm, you know, you'd say to him "How are you?" "No, I'm fine." And then his mum would say "What about the swelling behind your knee?" And he'd say "Oh yes, I've got something." And then she'd say "Are we going to show the doctor?"	2D; 161-167
	2D: we also try to speak to (2A) directly, erm…I guess it may be difficult if people can't speak, can't communicate, but with him he was able to give a good history and erm…I re…I do recall there, you know, there have been times where he's brought up things himself, like if he was feeling sick, or tired he…he would have indicated these types of things	2D; 175-180
Healthcare professionals can use good patient centred skills	1A: Yeah, she showed me like…she showed me a model. SF: A model? 1A: The sister did, to my Uncle…so we knew where it was and that. Because it sounded…made it easier for you..to understand it as well.	1A; 333-336
	1A: The model was good. I liked the model what the back was gonna do and all that. Without that I wouldn't have known what was going on.	1A; 341-343
	1B: Yeah, I couldn't see the x-ray, you see (INAUDIBLE). Er, but…she was there able to look at it and explain to us afterwards that what was happening. Same as at erm…(HOSPITAL 1), and we went there and the surgeon was trying to explain and I said "Well, I can't see the x-rays." So there was	1B; 321-335

	a…a theatre sister there, and she was going to, she was gonna be in the theatre with (1A). So what she did, she went and got me…erm…what she come back with was all these pieces of bones…well they were like plastic… But they were all locked into one another. And what she did then, she showed me what part goes into what and where they were gonna operate and what they were trying to take away from, say, this part. Well it was easier then cos, you've got…you seen a picture a lot, well an example of what the spine's like and what they're gonna do.	
	1B: And it made it a bit easier for him, cos all the back parts goin' into there, locks into there, that's what we're taking….	1B; 339-340
	1B: No, well doctors seem to be well…if you go to (HOSPITAL 1) and (HOSPITAL 3), the doctors have got that many patients…they can't have the time to explain everything to you. But if you get a sister on the ward and you ask her and she says "Well, I'll explain it to you" the best way she can. She understands you don't understand, well I'll say. As I said, she fetched me the diagram of the bones…well, the shapes that fit together, I wasn't struggling then.	1B; 675-681
	1D: And, the one at (HOSPITAL 5) in the end he actually showed us the MRI scan and was showing (1A) and that made more of an impact than all this verbal information that was obviously going over (1A)'s head.	1D; 142-145
	2D: It's like a child, if they trust you, erm…then…then you know, you, you…it makes it so much easier, and they tend to be able to do what you want them… if they are scared or if they get into a situation where they feel very anxious, it…it will make things very difficult.	2D; 267-271
	1D: You know, like showing him the picture of the x-ray made more sense than probably the appointments where they verbalised all these big words that didn't mean anything.	1D; 249-251
	2D: Because he probably didn't feel sick when he had the tumour, because it's very rare that testicular tumours give you any symptoms, and it's usually just a lump…and, and other than that he wouldn't have felt poorly at all. And he came in and we made him feel really poorly, and…and, you know, how much of that he understood and why it was happening, it…it was difficult to say. And I think you…you don't realise as much at the time, because for you the priority is to treat and…you know, and I think perhaps we should be looking into, at maybe our communication with them and making sure they do understand all the ins and outs. I think it is difficult in clinic situations especially, it's hard enough trying to deal with someone who's got full knowledge	2D; 234-245

	2D: you've got 20 minutes to try to see a patient, it can be tough, but I don't think that should exclude us from trying our best and perhaps spending the time as needed, or making different time and more time when people can come onto the ward to explain things. And again, I think it probably needs reiteration, because his parents also would not have had much knowledge about it and, for them it must have been a steep learning curve as well	2D; 247-253
	2C: And they offered professional sympathy, and you know…because they don't see a lot of…see a lot of people in the same situations and so they gave us all the information we needed to, to make proper decisions…as well as saying what their recommendations were. I felt…grateful for that…it was really good, I couldn't fault any of them for not taking our feelings into account in making the…you know, in making the right decisions, even though we weren't necessarily the best people to make the decisions, we got lots and lots of advice.	2C; 340-348
	2D: So, erm…and I think it's again something that can't be actually learnt, it needs to be adapted and you need to have…you know…good…I mean, good communication with the person in question as well as whoever is attending with them.	2D; 37-40
	2D: because you don't want to scare someone and make them uncomfortable because he always seemed quite comfortable coming in and you don't want to create a bad experience that he would then dread coming in.	2D; 116-119
	2D: I think perhaps it's also you feeling a bit unsure of yourself and…and you know, we've never had the guidance in you know, you just…you try to be professional and just get on with it, erm, but you're also trying to put someone at ease and it can often be a difficult situation.	2D; 125-129
	2D: Fantastic. No problems at all, our nursing staff have had…have had all sorts of experience with…with…many, many different patients, from patients who have got severe dementia to patients who are very elderly, very deaf, to patients who come from another country, who can't speak a word of English and I think they absolutely adored (2A). He was very, very, very popular.	2D; 196-201
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	2D: I think you always worry about how you're going to communicate, erm…and how to come across as friendly, that he trusts you. I think it's building up a trust, once…once someone trusts you, it's very, very easy.	2D; 264-267
	2D: So I guess the biggest concerns, erm…were communication and then putting people at ease and making sure they…they were comfortable and they were… And also perhaps erm, finding out how they were feeling, you know, because, if…if they're not very open and able to tell you exactly "I feel really sick" or "On this day, I…you know, I had a terrible headache." That can then influence how you treat them, because you may not be getting, you know, enough out of them to treat the side effects and that properly. So I think those were my biggest concerns, that we would…that the communication would result in not being able to give him the amount of medical support that we needed.	2D; 271-281
	3B: That was mainly… I have to say, with the…that was the…the nurse…the nurse's point of view, side…but the compassion wasn't there, and the understanding wasn't there…	3B; 97-99
	3B: (3A) is not a fool, you know…and…the…er…by talking to the health people there, and to remember that a person may have a learning disability…but they're not stupid, it's a different thing all together!	3B; 113-116
	3B: (CONSULTANT 1). Another…and…and he asked if we had any questions. And we'd ask…and he'd tell us. It was good wasn't it…he was a good man, wasn't he. You know. Liked him, didn't you? The Prof.	3B; 295-298
	6E: Erm…I think they've been absolutely fantastic! They've treated her just like anybody else, they've treated her just…as any other patient…possibly given her additional time in clinic to make sure she really has understood everything.	6E; 56-59
	5A: in A&E and one nurse had said "Is there anybody you want us to get?" I said "Yeah, (SURGEON2)!" SF: (LAUGHS) Did you like (SURGEON2)? 5A: Yeah. SF: Yeah, was he your favourite? 5A: Yeah. SF: Why was he your favourite? 5A: He's just kind and you know…	5A; 349-356

	5A: Anyway, he said “Oh my god!” he said (LAUGHS) “Hello trouble!” SF: Is that what he said to you? 5A: You know, teasing! He said “What you…what you done?” He said “What happened?” I said “I was in bathroom and I don’t know what happened, if I caught something or what.”	5A; 364-368
	5A: He said…he said…he said “You don’t want to…” This funny…one doctor in A&E put needle in there and when (SURGEON2) came in he said “Hey you, take it out! She’s going home!”	5A; 372-374
	5B: we didn’t have to sit for hours waiting in the queue quite often…the consultant would just take her through so she didn’t have to wait ages.	5B; 45-47
	5B: I mean she…she stayed in hospital for two weeks, which was unusual, but because she lived on her own, I think that was part and parcel of you know, the recovery for her…that she had that…erm…that place of where she felt safe afterwards and if there were any problems she wasn’t gonna be by herself. That she would have been on the ward, so they even facilitated that, which was great, and they all got on really well…I think she quite liked the social side…and….and then there was the chemo to follow, erm…and there were always the same nurses that saw to her.	5B; 181-189
	5B: And…she’d collect dolls, and even the consultant, she took them to see the consultant…he…he never rushed her through anything. He…he’d even sit and look at these dolls that she’d taken, you know.	5B; 192-195
	6A: I know (NURSE3) upstairs, she’s nice. SF: Is she? 6A: Yeah. SF: What does she say? 6A: “Oh, you’re here again?” SF: “Oh, you’re here again?” 6A: Yeah, yeah, yeah, yeah, yeah. She took me in the nice room. SF: So she jokes with you? 6A: Yeah. SF: And what’s that like to be joked with? 6A: Nice.	6A; 149-159

Patient can be empowered to be involved in decisions and conversations	1D: That’s it cos he was able to show, you know where the mass was and what they need the treatment, what we do shrinks it. So once you had that picture, I think it probably generated a bit more conversation as well.	1D; 147-150
	1D: So I think from, yeah, from his point of view I think it made a difference when things were broken down for him.	1D; 288-290
	3B: Those sorts of words. To do with, you know…procedures…which turned out not to be anything much in the end. And we thought, that’s a long word…I think one might have started with L…and we couldn’t understand what it was so just go and ask, you know. And I think I brought somebody in, didn’t I? Yes, that’s right…you were sitting in that room, that little room…that waiting room type place, the meeting room…and I got somebody and they came in and explained, didn’t they? She did, and fair play, didn’t she…yeah.	3B; 279-286
	SF: Did he? Oh, that’s really lovely. Did he explain everything to you? What was going to happen? 5A: He did. SF: Yeah. And did he make sure that you could understand everything that was happening? 5A: Yeah.	5A; 99-104
	5A: Yeah, they told me what they’d done. Taking the lump out.	5A; 136
	5A: Erm…I forget with that. I did have book on it. A file on it but I don’t know where it is now.	5A; 189-190
	6D: , we went to see the specialist nurse to tell us what sort of chemo it was, what side effects to expect…and, erm…that’s when I gave information, pictorial information about the side effects and how to look after your hair and…erm…you know, the things to expect.	6D; 109-113
	5B: They tried to explain things to her in a way that she…they thought she would understand. They tried to make sure that she understood what was being said to her…erm…that process was obviously followed up by my own reiterating what had been said so she didn’t forget.	5B; 36-40

	5B: Well I have to say that I thought that they were all absolutely marvellous with her, you know…they…they made her feel very comfortable, they were very honest with her. They tried to explain things to her in a way that she…they thought she would understand.	5B; 34-37
	5B: And…and…even when it came to looking at wigs and stuff like that, erm…they managed to get somebody else to come out who'd had the treatment done, and come out to (5A) and talk about their own experiences and they came to the house…and the…erm….they got somebody to come out and show her what the mastectomy would look like afterwards.	5B; 52-57
	5A: It just that you have to get on with it! SF: Who said that? 5A: Me. SF: You, yeah. Just have to get on with it. 5A: And then…I said go ahead and do it.	5A; 320-324
	5B: So she always took on board whatever you were trying to do with her.	5B; 364-365
	3B: Had a little bit of a disagreement, didn't we? Regarding the testical operation…do you remember? 3A: Oh. 3B: Cos I said that…cos I advised you to have a false one put in, didn't I? And you said no. And that was interesting! I couldn't understand that, why you said no. SF: Yeah, so did you go with your decision then? Did you stick to your decision? 3A: Yeah.	3A; 159-167
	SF: Yeah, but you had a conversation about it? 3B: Oh yes. SF: Was it a bit heated? 3B: Well he asked me what I thought. So I told him what I thought, if I was in his position I would have had the false one put in. Cos they…I'd been to the…I went to find out from the erm…surgeon. And the procedure was very simple, they could do it at the same time. So I did point that out. But no, for some reason, and still unknown to me, he disagreed. And his view of course was respected.	3A; 168-177
	3B: I think you did ask them, if I remember rightly, correct me if I'm wrong…that when they told you about having the testical operation…and…you…you…you…you seeked assurance that you wouldn't be getting any more chemo.	3A; 227-235

	3B: …(3A) would er…come to his own decision	3B; 41
	5A: I had operation first, then I had chemo. Then I had more operations, then I had last one…that I…when I decided to have it all off.	5A Initial interview; 79-80
	5A: Oh, I was told by one the doctors to check morning and night, so that was it.	5A Initial interview; 10-11
	5A: Well…it were hard, but you just had to make your own decision. But it was a hard thing to do, but I had to…	5A Initial interview; 87-88
	5A: They were good. Showed me about where I'd be in at (WARD2)…where I had chemo. And one thing you're not supposed to drink…sherry, beer, wine…	5A; 212-214
	5A: Try and not think about it. And they said that after had chemo…after I got over that, I had to go back and see (SURGEON2) and he said erm…he checked me over first and he said…soon you have to make your decision what youre going to do. He said are you going…he said are you going to have operation or not. Are you going to have it or not? I said yes.	5A; 258-263
	5A: He said it up to you what you want do.	5A; 272
Cut-off: Patient disengages from their experience, has a limited understanding, and feels confused, distressed, and frustrated	1A: You don't know…what's got wro….what's gone….what's wrong with you. Cos you can't….you can't...you you….I can't understand what they…the words that they're saying. That kind of word.	1A; 349-351
	1B: Well, he just used to seem to say to himself "Well I've got it and that's it." That's the way he seemed to be…look at it to me. And that was it then, he wouldn't say anything else. We tried to talk to him sometimes about it, but no. So I thought I'll leave it then, no use pushing it if he doesn't want to talk to it.	1B; 475-481
	3A: No, cos as far as I'm concerned. It looks like I have nothing wrong. 3B: It's in the past. 3A: In the past.	3A; 330-331
	3A: It's all gone, there's nothing really to talk about.	3A; 352

	3A: No, cos as far as I’m concerned. It looks like I have nothing wrong. 3B: It’s in the past. 3A: In the past.	3A; 330-333
	2C: Erm…I’m sure there’s a lot of things he didn’t understand. I’m not sure that I understood them all to be honest.	2C; 172-173
	4A: I talk to you, yeah. I talk to nobody else about it. SF: Nobody else. 4A: No. Nobody’s asked. SF: No? Would you talk to people if they did ask? 4A: Yes, I would. Yes, I would.	4A; 117-121
	4A: I talk to you, yeah. I talk to nobody else about it. SF: Nobody else. 4A: No. Nobody’s asked. SF: No? Would you talk to people if they did ask? 4A: Yes, I would. Yes, I would.	4A; 117-121
	SF: And do you know what he’s saying? 6A: Yeah, it’s in my ear. In my ear. SF: So do you understand exactly… 6A: Yeah, that I’ve got cancer. Yeah. SF: So does he say anything sometimes that’s a bit confusing? 6A: Yeah. SF: Yeah, what happens then? 6B: Well usually, usually, whoever’s gone with you explains it when you get home, really…don’t they? 6A: Yeah. SF: So does the doctor sometimes say things that are a bit confusing? 6A: Yeah, to explain it to the others.	6A; 57-69
	SF: OK, so do you talk to people about it? 6A: Not really. It’s private.	6A; 79-80

	6B: (PAUSE) To be perfectly honest, (6A)'s a very intelligent lady and I don't think she does…because…erm…she said to me a few weeks ago…erm… "(6B HUSBAND) died of cancer (6B), but I'm not going to am I?" I said "Oh…" I kept it very light and airy, I said "We all die eventually, (6A)." So, you know… "I'm sure you'll be ok." And just left it at that. But I know we were watching Holby City one night, and they were resuscitating somebody, and I said to her "Ooh, if I was really poorly…would you want that happening to you (6A)?" And she said "Yes, cos I want to live."	6B; 39-47
	1B: He panicked sometimes. You know about that, don't you, his panic…yeah.	1A Initial interview; 154-155
	1A: Slightly worried, cos you don't know what…what they mean.	1A; 356
	1A: Confused yeah, I don't know what the words are… what the words are about.	1A; 361-362
	1B: He'll get angry with himself sometimes, yeah. If he thinks he's not coping or he doesn't understand really. That's the problem, him understanding the situation.	1B; 97-99
	1D: Frightening, worrying, not knowing what, what was being said or what was expected of them.	1D; 111-112
	1D: And I think, you know, people with learning disabilities need to know what's going on, you know and how we can work with it, because…and then I think their outcome is a lot, a lot better then isn't it. So, it's nothing to be…it is a frightening process to go through, but knowing that the right support's there and you know, is gonna be helpful. But unless you explain that in a way that they're gonna understand, then it's not gonna be taken on board.	1D; 251-258
	2D: I guess, you know…it's just supposition, you know…(2A) may have been very protected and not had a clue what chemotherapy was. And it may have been very difficult to have needles stuck into him, and…you know, going back to the ward he knew that's going to happen again and then feeling tired.	2D; 227-231
	3B: You were very anxious about that. Very anxious about how many more after…after that operation. 3A: Yeah.	3A; 237-239
	3B: Yes, there was…at times, there was anxiety there. And there was also, I think, (3A) was conscious of…that people might be talking about him. And sometimes, they were talking about him but in their…in their…in their way.	3B; 158-161

	SF: Yeah, is it in your ovary? 6A: Yeah…it's a bowel cancer.	6A; 10-11
	6A: I were lying on the bed and she said, coming…why don't we take it out…get rid of it. SF: That's good, did he tell you why? 6A: No, he just said get rid of it.	6A; 111-114
	6A: Alright, I'm alright now. SF: Yeah. 6A: Yeah, I'm getting better.	6A; 235-237
	6B: Erm…no not really. She was quite…quite happy to speak to me about it, you know and she wasn't…she didn't seem distressed in anyway. You know. That's why I'm convinced that (6A) thinks, right, she's poorly, she's got to have some…but it's not necessarily gonna end the way we know it's gonna end any time, you know.	6B; 97-101
	6B: Well I think she understood it that…erm…she was…I think she thinks that because she's not having any more medicine, she's gonna…she's gonna be better. That's my impression anyway.	6B; 116-118
	6B: (PAUSE) I think she's quite happy in her own little world at the moment, because you know, she's sleeping a lot better, she's not in a lot of pain and I…I think she's feeling quite positive, cos at one point she was quite poorly.	6B; 121-124
	1B: I don't know if he has, but (1D) has tried to talk to him and explain it but he won't, no.	1B; 281-282
	1B: He wouldn't ask. SF: He wouldn't ask. 1B: No. SF: No. Would he let anybody know that he didn't understand? 1B: No, he'd just go quiet on the subject. SF: Yeah, OK. So, could you tell if he didn't understand? Could you… 1B: Yes, cos he'd seem to be a bit vacant then, but he wouldn't know.	1B; 347-355
	1B: Well, he just used to seem to say to himself "Well I've got it and that's it."	1B; 475-476
	1D: It's…I think from…knowing (1A), he probably would just go along with it.	1D; 280-281
	2B: Cos he'd just sort of sit there just you know, and he'd sit there and just let them, you know…but erm, we…so the 21st of September it started after about 3 months, the chemo wasn't it (2A)?	2A Initial interview; 153-155

	2B: But anyway, he…he was, like I said, it didn't affect him in as much that it made him a you know, horrible person, "I don't want that, get away, I don't…" you know, there was never any of that, just took it all, took it all.	2B; 206-209
	3A: I didn't know about it, so…didn't…that's all I know. 3B: He didn't know how serious it was, did you? SF: Yeah? So when the doctor said to you "It's cancer." What did you think? 3A: "Uh oh" He said it would go down more, it would. Just took whatever out of it and it was ok after that. SF: Yeah, so did you feel any like…did you feel worried, or… 3A: A little bit, not too much, but a little bit.	3A; 16-23
Coping: Patient engages in their experience, has a good understanding, and can be supported to cope with their illness	5B: We went for the false breasts and bras, and she tried them all on and she even had a laugh with the ladies and everything about it, you know. But then once she got home, you'd go and visit her and…(LAUGHS) she never used them! They never came out the box, I don't think! She said "Oh, no. I don't need them. I'm just quite comfortable how I am." That was it and I don't think she ever wore them, you know. I don't think she ever wore them, I don't think she's wore them to this day!	5B; 402-409
	3A: No, I understanded them. SF: Yeah. So did they tell you everything that was gonna happen? 3A: Yeah. SF: OK. And did they use any words that were just a bit too hard? 3A: No. SF: No? Cool. 3B: There were two words I think, (3A). Do you remember? You asked me to go and find out, but I didn't know either, so I went to ask them and they came back and told you, do you remember? 3A: Yeah. 3B: That was in (HOSPITAL6), wasn't it? SF: Oh, ok. So there were a couple of words that you didn't understand, and when doctors talk to me I don't always understand what they're saying, erm…and then (3B) went and found out for you? 3A: Yeah.	3A; 82-97
	SF: Why did you say yes? 5A: Cos I didn't want it come back.	5A; 264-268

	SF: OK. Did he tell you what was going to happen? 5A: Yeah, he…had erm…I said I think I will have it done, save cancer coming back and he said you made a hard decision there.	
	5A: Well I wanted it done. ... Try and stop cancer coming back.	5A; 328-330
	5A: Then I had go back and see (SURGEON2)…oh was it…oh hang on minute…was it (SURGEON2), or Dr…she came from (HOSPITAL8). SF: She came from (HOSPITAL8)? 5A: Oh no…that was it, I went to see (DOCTOR2) and she told me…she sent me for…erm…oh what is it…echo scan…that like checking your heart and that…then I had to go for scan, with all like polo thing… SF: The polo thing…is that what it looks like? 5A: Yeah. And then they inject dye into your arm. They give you injection, then they put the thing in…they careful…I don't know if it were there or there…anyway. I went, lie on table, then they inject some dye into thing…and then it show up. SF: Yeah, on the scan it shows up doesn't it? 5A: Yeah. And then it…that came out clear.	5A; 138-151
	5A: Well…it was trying to find out what…what…and tell you what cancer looked like, and er…then, it like a, like a (INAUDIBLE) long tube, like a round circle and like that…it had been shown on telly. SF: Yeah? So what about the chemo? Did they tell you what could happen, so about your water turning pink and about being sick? 5A: It supposed to stop cancer coming back.	5A; 171-176
	5B: She would get q…a little bit anxious before we went, so I hoped I alleviated that anxiety before going. Erm…she always had that port of…you know, call if she was worried about anything she knew to call me and I could always sort of liase with the nurses at…at (HOSPITAL11) and feed that back to her what they thought, you know and go and see her.	5B; 78-84
	5B: I think (5A)…she's very…sorry, I just said her name! She's very well known in the community and she's not one for keeping it all to herself anyway, she would talk to…I think she would talk to lots of people and perhaps people who had already had a similar experience.	5B; 123-127
	5B: she was just so positive all the way through and I think she's been in remission this long and erm…I don't think there was ever a conversation that was negative around the condition	5B; 166-169

	5B: Yeah, well…the anxieties I think were initially…at the initial stages of being diagnosed and I think once she got to know everybody and everyone was so friendly with her	5B; 175-177
	5B: No. I mean…it was major major surgery for (5A) and I really didn't know how she would cope with it. But she absolutely coped with it…fantastically, and in as much as I think if I ever had to go through it with anybody else, I'm sure she…if I asked her, she would…she would be quite a good source of erm…comfort or…erm, information for somebody else who'd been in a similar situation.	5B; 253-258
	5B: She, yeah…I…yeah, we did have conversations coming back in the car on a couple of occasions, that she was frightened that she might die if it didn't work, erm… (PAUSE) I…well, just as anybody else, I should imagine would be concerned	5B; 287-290
	5B: But she's always very sensible, and she always wanted to do everything right, and to make sure that every, you know, if you was advising her to do something, youd never go there and she hadn't done it.	5B; 359-362
	5B: Erm, and she did never…never ceased to astound me with her…with her optimism and her ability to cope with it really.	5B; 373-375
	5B: And I think she was always very honest about what she felt. And I think just having that access to be able to phone somebody up and it not be a problem	5B; 384-386
	5B: And…and…even when it came to looking at wigs and stuff like that, erm…they managed to get somebody else to come out who'd had the treatment done, and come out to (5A) and talk about their own experiences and they came to the house…and the…erm….they got somebody to come out and show her what the mastectomy would look like afterwards.	5B; 52-57
	5B: Completely, all the way down the line. Everything was discussed with her, completely. And of course…her learning disability's quite mild so she was able to consent anyway to…to everything and she understood what was going on. And if she didn't understand, she would always ask because…I think you have met her so you know that she's quite… I don't know how she found her information out from, but she just seems to…erm…she astounded me actually!	5B; 93-101
	5B: But…she would get…I mean she wouldn't even perhaps ask me the questions because she…she was quite fond of the consultant she was under, and so she would save those questions just for him. And I would think…"God! Where did that come from? I didn't know she was gonna ask that!" You know, but they were…they were perfectly…you know…great questions to ask really.	5B; 112-118

	5B: She’d even gone to the GP, and she’d made all that herself.	5B; 145
	5B: But she’s always very sensible, and she always wanted to do everything right, and to make sure that every, you know, if you was advising her to do something, youd never go there and she hadn’t done it.	5B; 359-362

Appendix 22: Patient vignettes (Chapter 4)

Using a facility within LimeSurvey, vignettes will be randomly assigned to participants; participants will each receive a series of four vignettes (2 LD and 2 non-LD). LimeSurvey allows the random assignment of questions; it is also possible to ensure that participants will see 4 different vignettes, 2 of which will be LD specific. It will also be ensured that if vignette A is used, vignette A^{LD} would not be used. An example of this randomisation is outlined below:

1	A^{LD}	B	C^{LD}	D
2	B^{LD}	A	D^{LD}	C
3	C^{LD}	D	A	B^{LD}
4	D^{LD}	C	B	A^{LD}

Providing care for someone with cancer can be difficult. Providing care for someone who has cancer and additional complex needs can sometimes be even more difficult.

Please can you read through the vignettes and indicate your agreement about the statements which follow. Please be honest in your answers and do not spend too much time thinking about any one question. There are no right or wrong answers.

Vignette A:

Rachel is 27 and has cervical cancer. She is very close with her mother and father. She is accompanied to all of her appointments by her mother, who seems very supportive and asks a lot of questions about Rachel's condition and treatment options. For the most part, Rachel is agreeable and sits quietly during appointments whilst her mother asks questions. Rachel is embarrassed and visibly uncomfortable during intimate examinations and procedures. Rachel's oncologist believes that she does not always fully communicate her thoughts and feelings; her behaviour is often perceived by other health care professionals as obstructive.

Vignette A^{LD}:

Rachel is 27 and has cervical cancer. Rachel also has a profound learning disability, she does not know about her diagnosis and her family are insistent that she should not be told as she will not understand. She lives with her mother and father and receives support from paid carers for her illness. She is accompanied to all of her appointments by her mother, who seems very supportive and asks a lot of questions about Rachel's condition and treatment options. For the most part, Rachel is agreeable and sits quietly during appointments whilst her mother asks questions. Rachel is embarrassed and visibly uncomfortable during intimate examinations and procedures. Rachel's oncologist believes that she does not always fully communicate her thoughts and feelings; her behaviour is often perceived by other health care professionals as obstructive.

Vignette B:

John is 31, has testicular cancer and lives on his own. His friend, Amanda, lives nearby and attends his appointments with him to offer emotional support, sometimes when John doesn't know what to say or is worried about the outcome Amanda asks questions for him. John worries a lot about his illness as his father recently passed away after a long battle with prostate cancer. Despite his worries, John is a good patient who is polite and considerate. John doesn't like to cause a fuss, so often does not inform health care professionals when he is feeling pain. During appointments, John prefers for diagrams, models and x-rays to be used to explain procedures and test results, rather than medical language.

Vignette B^{LD}:

John is 31 and has testicular cancer. He also has Down syndrome. He lives on his own and occasionally receives community support. His friend, Amanda, lives nearby and attends his appointments with him to offer emotional support; usually Amanda asks questions for him. John showed signs of anxiety and distress during his treatment, particularly about what all the machines did. John worries a lot about his illness as his father recently passed away after a long battle with prostate cancer; he believes that he will also die because of his cancer and does not like to discuss his diagnosis. Despite his worries, John is a good patient who is polite and considerate. John often does not inform health care professionals when he is feeling pain. John really struggles to understand during appointments, but is helped when diagrams, models and x-rays are used, rather than medical language.

Vignette C:

Jane is 53 and has breast cancer. Jane lives with her husband and her two dogs; she does not have any children. Her husband attends all of her appointments with her; he holds her hand and makes sure that she is OK throughout the appointment. Jane likes to make celebration cards in her spare time; she regularly makes cards for the staff to thank them for their care and support. Jane was not initially aware of her symptoms so received a delayed diagnosis, because of this she is very anxious about whether she will recover and often expresses this concern during her appointments. Jane sometimes seeks clarification on treatment side effects, as she has struggled to get her head around them.

Vignette C^{LD}:

Jane is 53 and has breast cancer. She also has a moderate learning disability. Jane lives with her husband and her two dogs; she does not have any children. Her husband, who has a mild learning disability, attends all of her appointments with her; he holds her hand and makes sure that she is OK throughout the appointment. Jane likes to make celebration cards in her spare time; she regularly makes cards for the staff to thank them for their care and support. Jane did not inform her GP of her symptoms straight away, so received a delayed diagnosis; because of this she is very anxious about whether she will recover and often expresses this concern during her appointments. Jane has not yet accepted her diagnosis, and finds hearing bad news very distressing. Jane does not fully understand the treatment side effects and often attributes them to other, unrelated, things.

Vignette D:

Paul is 48 and has colon cancer. He lives alone and is not married; he attends all of his appointments on his own as his family do not live close enough to help him. Despite this, he is a happy man who enjoys discussing sports with other patients and staff alike. He is determined to overcome his illness and doesn't moan about the treatments, even though it is apparent that he is experiencing some pain and discomfort. He asks questions during his appointments and seems to understand and accept the answers which are given to him, however some other health care professionals have highlighted that they are not sure whether he does fully understand everything that is said to him.

Vignette D^{LD}:

Paul is 48 and has colon cancer. He also has a mild learning disability. He lives alone and is not married; he attends all of his appointments on his own as his family do not live close enough to help him. Despite this, he is a happy man who enjoys discussing sports with other patients and staff alike. He is determined to overcome his illness and doesn't moan about the treatments, even though it is apparent that he is experiencing some pain and discomfort. Paul can struggle with some aspects of self-care; he has a paid carer who assists him twice a week. He seems to understand and accept the information which is given to him, however some other health care professionals have highlighted that they are not sure whether he does fully understand everything that is said to him. Paul sometimes gives an unrelated answer to questions asked by health care professionals; some colleagues have mentioned that it can be very difficult to find out important information.

Statements *(to come after each vignette)*:

1- Strongly disagree; 2 – Disagree; 3 – Neither agree or disagree; 4 – Agree; 5 – Strongly agree

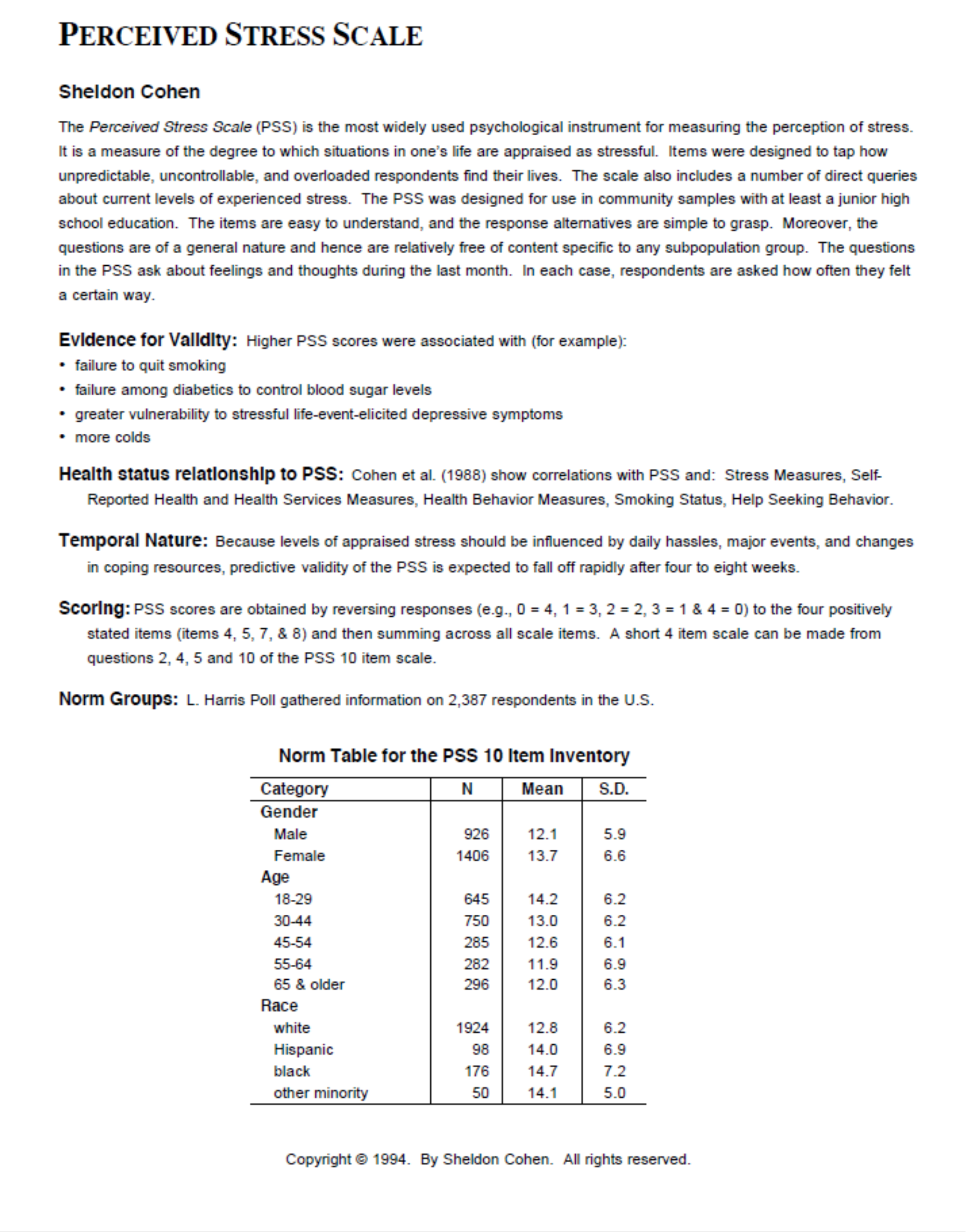
1. I believe that I have the sufficient level of knowledge to provide care for this patient.
2. I believe that my previous nursing experience will assist me in providing care for this patient.
3. I believe that I have received sufficient training to provide the highest quality care to this patient.
4. I believe that I would be able to successfully communicate with this patient.
5. I feel comfortable talking to this patient about their illness.
6. I would be dependent on the person accompanying the patient to communicate with the patient.
7. I feel confident that the needs of this patient would be identified.
8. I feel confident that the needs of this patient would be met.
9. I understand this patient's circumstance.
10. I feel positively about providing this patient with care.
11. I feel confident that I would be able to provide this patient with the appropriate care.
12. I believe that providing care for this patient would cause me to become stressed.

---Page break---

Now, thinking more generally, please consider that you are providing care for someone with a learning disability.

1. If you were unsure about how to provide the highest quality care for this patient, would you know where to go to for advice?
    a. Where would that be?
2. Are there any additional training needs you believe would be beneficial to help provide care to this person?

Appendix 23: Perceived Stress Scale (PSS-10; Cohen et al., 1983) (Chapter 4)



PERCEIVED STRESS SCALE

Sheldon Cohen

The *Perceived Stress Scale* (PSS) is the most widely used psychological instrument for measuring the perception of stress. It is a measure of the degree to which situations in one's life are appraised as stressful. Items were designed to tap how unpredictable, uncontrollable, and overloaded respondents find their lives. The scale also includes a number of direct queries about current levels of experienced stress. The PSS was designed for use in community samples with at least a junior high school education. The items are easy to understand, and the response alternatives are simple to grasp. Moreover, the questions are of a general nature and hence are relatively free of content specific to any subpopulation group. The questions in the PSS ask about feelings and thoughts during the last month. In each case, respondents are asked how often they felt a certain way.

Evidence for Validity: Higher PSS scores were associated with (for example):

- failure to quit smoking
- failure among diabetics to control blood sugar levels
- greater vulnerability to stressful life-event-elicited depressive symptoms
- more colds

Health status relationship to PSS: Cohen et al. (1988) show correlations with PSS and: Stress Measures, Self-Reported Health and Health Services Measures, Health Behavior Measures, Smoking Status, Help Seeking Behavior.

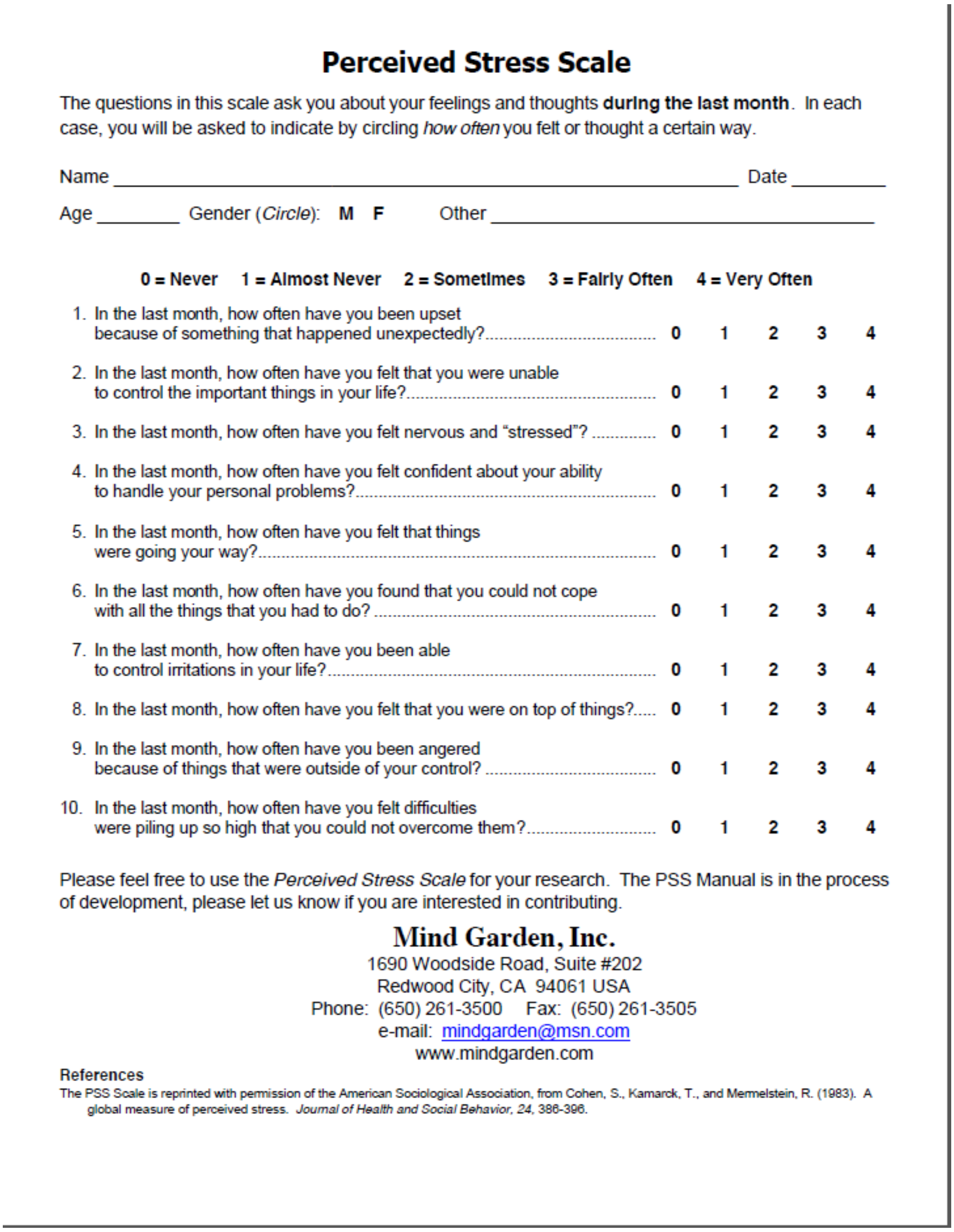
Temporal Nature: Because levels of appraised stress should be influenced by daily hassles, major events, and changes in coping resources, predictive validity of the PSS is expected to fall off rapidly after four to eight weeks.

Scoring: PSS scores are obtained by reversing responses (e.g., 0 = 4, 1 = 3, 2 = 2, 3 = 1 & 4 = 0) to the four positively stated items (items 4, 5, 7, & 8) and then summing across all scale items. A short 4 item scale can be made from questions 2, 4, 5 and 10 of the PSS 10 item scale.

Norm Groups: L. Harris Poll gathered information on 2,387 respondents in the U.S.

Norm Table for the PSS 10 Item Inventory

Category	N	Mean	S.D.
Gender			
Male	926	12.1	5.9
Female	1406	13.7	6.6
Age			
18-29	645	14.2	6.2
30-44	750	13.0	6.2
45-54	285	12.6	6.1
55-64	282	11.9	6.9
65 & older	296	12.0	6.3
Race			
white	1924	12.8	6.2
Hispanic	98	14.0	6.9
black	176	14.7	7.2
other minority	50	14.1	5.0



Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.

Name ____ Date _________

Age ________ Gender (*Circle*): **M F** Other ______________________________

0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?...................................	**0**	**1**	**2**	**3**	**4**
2. In the last month, how often have you felt that you were unable to control the important things in your life?..	**0**	**1**	**2**	**3**	**4**
3. In the last month, how often have you felt nervous and "stressed"?	**0**	**1**	**2**	**3**	**4**
4. In the last month, how often have you felt confident about your ability to handle your personal problems?..	**0**	**1**	**2**	**3**	**4**
5. In the last month, how often have you felt that things were going your way?...	**0**	**1**	**2**	**3**	**4**
6. In the last month, how often have you found that you could not cope with all the things that you had to do?	**0**	**1**	**2**	**3**	**4**
7. In the last month, how often have you been able to control irritations in your life?...	**0**	**1**	**2**	**3**	**4**
8. In the last month, how often have you felt that you were on top of things?.....	**0**	**1**	**2**	**3**	**4**
9. In the last month, how often have you been angered because of things that were outside of your control?	**0**	**1**	**2**	**3**	**4**
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?...........................	**0**	**1**	**2**	**3**	**4**

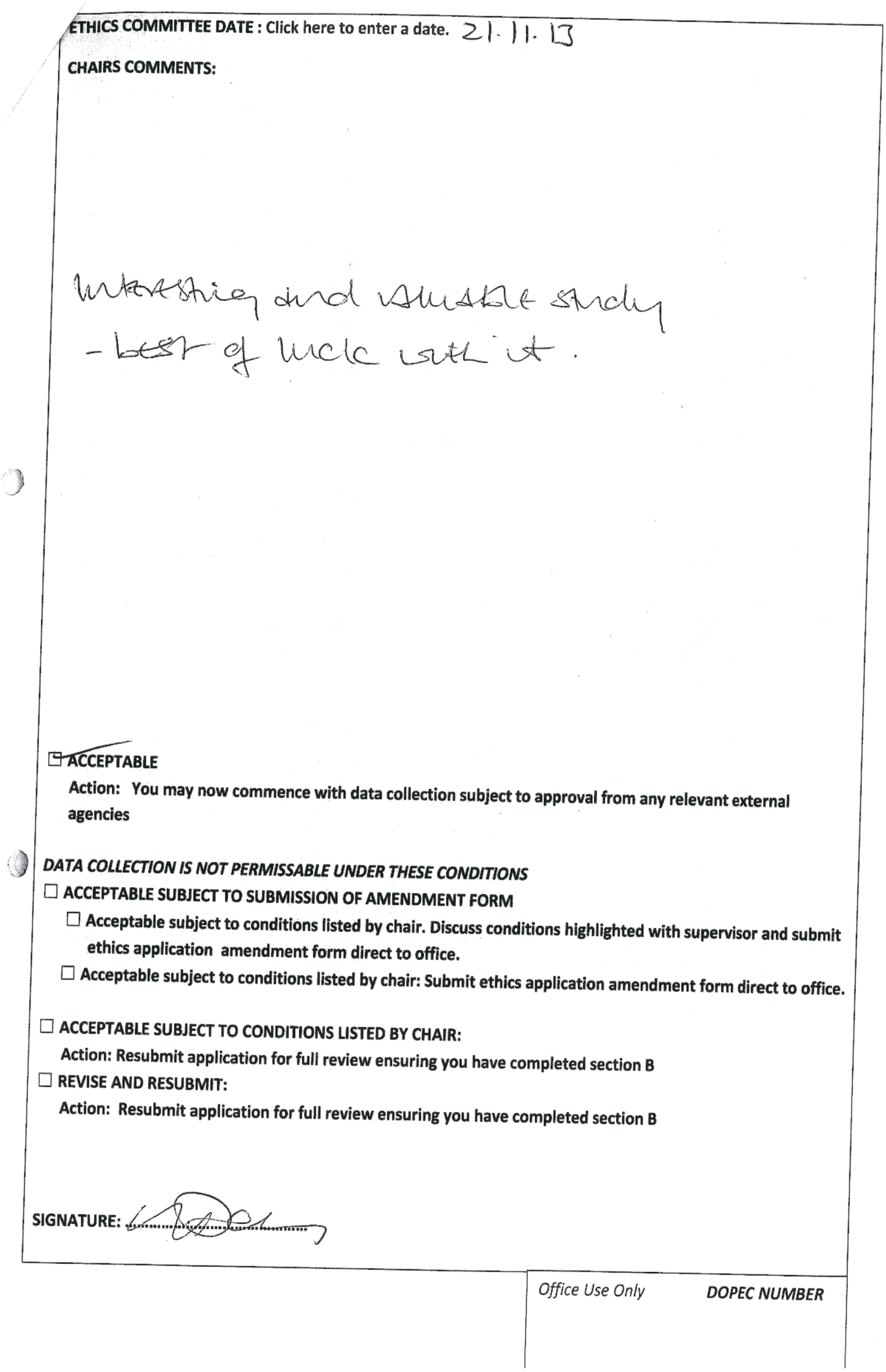
Please feel free to use the *Perceived Stress Scale* for your research. The PSS Manual is in the process of development, please let us know if you are interested in contributing.

Mind Garden, Inc.
1690 Woodside Road, Suite #202
Redwood City, CA 94061 USA
Phone: (650) 261-3500 Fax: (650) 261-3505
e-mail: mindgarden@msn.com
www.mindgarden.com

References

The PSS Scale is reprinted with permission of the American Sociological Association, from Cohen, S., Kamarck, T., and Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24*, 386-396.

Appendix 24: Confirmation of ethical approval (Chapter 4)



ETHICS COMMITTEE DATE : Click here to enter a date. 21.11.13

CHAIRS COMMENTS:

Interesting and valuable study
- best of luck with it.

☑ **ACCEPTABLE**

Action: **You may now commence with data collection subject to approval from any relevant external agencies**

DATA COLLECTION IS NOT PERMISSABLE UNDER THESE CONDITIONS

☐ **ACCEPTABLE SUBJECT TO SUBMISSION OF AMENDMENT FORM**

- ☐ **Acceptable subject to conditions listed by chair. Discuss conditions highlighted with supervisor and submit ethics application amendment form direct to office.**
- ☐ **Acceptable subject to conditions listed by chair: Submit ethics application amendment form direct to office.**

☐ **ACCEPTABLE SUBJECT TO CONDITIONS LISTED BY CHAIR:**

Action: Resubmit application for full review ensuring you have completed section B

☐ **REVISE AND RESUBMIT:**

Action: **Resubmit application for full review ensuring you have completed section B**

SIGNATURE: ……………………………………

Office Use Only	**DOPEC NUMBER**

Appendix 25: Participant recruitment email (Chapter 4)

Research study: Stress in oncology nurses: predictors and the particular challenge of caring for a patient with an intellectual disability

Hello,

Our names are Debbie Stevens-Gill and Samantha Flynn and we are researchers within the Department of Psychology at the University of Chester. The UKONS has kindly agreed to contact you on our behalf, as we would like to invite you to take part in our research study.

Our study aims to explore stress in oncology nurses and which specific factors might lead to oncology nurses feeling stressed. We are also interested in how confident oncology nurses are in providing care for people with additional complex needs. We have received full ethical approval for this study from the Department of Psychology Ethics Committee at the University of Chester. Our study is supervised by a team of academics at the University of Chester, Dr Nick Hulbert-Williams is the primary supervisor for both Samantha and Debbie. Nick has published widely in the field of psychosocial oncology and is the current chair of the British Psychosocial Oncology Society.

We appreciate that you may have some questions about this study before taking part, as well as about our other research interests, therefore if you wish to contact either of us, please feel free to do so on samantha.flynn@chester.ac.uk (Samantha) or 1021359@chester.ac.uk (Debbie). If you wish to contact our supervisory team, Dr Hulbert-Williams is contactable via n.hulbertwilliams@chester.ac.uk

Please follow the link below to take the survey. It takes about 30 minutes to complete.

http://goo.gl/Dh8bMQ

Sincerely,
Debbie Stevens-Gill and Samantha Flynn

{Clicking the link in the text will direct participants to the information sheet.}

Appendix 26: Participant information sheet (Chapter 4)

Research study: Stress in oncology nurses: predictors and the particular challenge of caring for a patient with an intellectual disability

You are being invited to take part in a research study. Please take time to read the following information carefully and decide whether you would like to participate.

Who is undertaking this research study?

The study is part of two PhD theses being undertaken by Debbie Stevens-Gill and Samantha Flynn, who are conducting the research under the supervision of Dr Nick Hulbert-Williams, Prof. Ros Bramwell & Dr Lee Hulbert-Williams at the University of Chester

What is the research about?

It has previously been found that oncology nurses can feel particularly stressed. We want to understand which specific factors may lead to feelings of stress in oncology nurses. We are also interested in how oncology nurses feel when providing care for someone with additional complex needs.

You will be asked to complete a quick series of questionnaires, some which ask you to and read some short statements and indicate how you would feel in that situation; in total, this should take no longer than 30 minutes. If there are some questions you do not feel comfortable answering, you may leave them out, but please be aware that this may mean we can't include your responses in our analysis.

How will my answers be used?

We will analyse the findings of the research. The overall findings will help us to better understand the experiences of oncology nurses who are feeling stressed, and more specifically the experiences of oncology nurses who provide care for patients with additional complex needs. The overall results of this analysis (i.e. the anonymous data from completed responses) will be written up as part of two PhD theses and may also be written up for publication in a scientific journal in order to present the research to a wide audience.

Do I have to take part?

You do not have to take part at all and you need not give a reason for this decision.

Should you wish to withdraw from the research before you have completed the survey, you can withdraw by closing the browser. Please note that your responses will be saved, but if you do not complete the survey, your responses will not be included in the analysis.

Please also be aware that once you have completed and sent your responses, it will not be possible for us to withdraw your responses as they will be pooled with all other responses and will not be identifiable.

Is there any potential harm from taking part in the study?

There are no directly harmful effects from taking part, but some of questions may make you think about your experiences which may remind you of upsetting feelings. If this is the case, please refer to your line manager for information on your department's support and guidance resources or make an appointment to see your GP. Alternatively you can seek information, support and guidance from the following sources:

- The Samaritans: 08457 90 90 90 (www.samaritans.org.uk) 24hrs
- Anxiety UK: 08444 775 774 (www.anxietyuk.org.uk)

How will I benefit from the study?

There are no immediate direct benefits to you, however by participating in this study, you will be helping us to gain a better understanding of stress within your profession.

Confidentiality

All information to be used in this study is strictly confidential and will only be used for the purposes of this research and subsequent publication. To reduce the risk of anyone seeing your responses you can exit the internet browser after you have sent your response. Some questions ask for personal information, so you might want to complete the questionnaire in private. Your responses will be stored in confidentially and securely, your responses will be pooled with the other responses, thus they will be unidentifiable. As your responses will be unidentifiable it will not be possible to remove your data once you have completed and sent your response.

Data will be stored in accordance with the Data Protection Act and University Research Policies. Once analysis is complete, data will be kept on a password protected DVD in secure archives held by the university; all other copies will be destroyed. Paper-based transcripts and study documents will also be kept in secure archives. Archived data will be confidentially destroyed five years after study completion.

What will happen to the results of the study?

We will write up the findings from this research as a series of research papers which will be submitted to relevant journals. Results may also be presented at scientific meetings and conferences. In all results, all participants will remain anonymous and individual responses will not be singled out. If you would like a summary of the results, please contact Debbie Stevens-Gill or Samantha Flynn (see below).

Complaints procedure

If you wish to make a complaint about any aspect of this research, or how you have been treated as a participant, please address it to:

Professor R. Bramwell, Head of Department, Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ.

Where can I get further information?

If you require further information, please contact either: Debbie Stevens-Gill or Samantha Flynn, Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ. Tel: 01244 513479/07825 853661; email: 1021359@chester.ac.uk / samantha.flynn@chester.ac.uk.

Please keep a copy of this Information Page for your future reference. Thank you for taking part in this research.

Appendix 27: Participant consent form (Chapter 4)

Research study: Stress in oncology nurses: predictors and the particular challenge of caring for a patient with an intellectual disability

Please read the following statements and click ‘Continue’ at the bottom of the page if you agree to take part in the research. If you have any concerns about doing so, please contact us:

Debbie Stevens-Gill or Samantha Flynn, Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ. Tel: 01244 513479/07825 853661; email: 1021359@chester.ac.uk / samantha.flynn@chester.ac.uk.

1) I confirm that I have read and understood the information sheet for the above study.

2) I understand that my participation is voluntary and that if I decide that I no longer wish to take part I can withdraw before completion of the survey, without giving any reason. I also understand that once I have completed and submitted the survey my responses will be unidentifiable, and I will therefore not be able to withdraw my responses.

3) I understand that in participating in this study my responses will be dealt with in a secure, anonymous and confidential manner.

4) I agree to take part in the above study.

Please click ‘Continue’ to indicate your agreement to the statements above, and your consent to take part in this research.

[CONTINUE]

Appendix 28: Participant demographic questionnaire (Chapter 4)

Research study: Stress in oncology nurses: predictors and the particular challenge of caring for a patient with an intellectual disability

Demographics

Please complete the following questions about yourself.

1. **Gender**:
   Male Female
2. **Age**:
   18 -24 25-34 35-44 45-54 55-64
   65+
3. **Marital Status**:
   Married Co-habiting Civil Partnered Divorced Single
   Widowed
4. **Highest Educational Qualification Achieved (*to date*):**
   Apprenticeship Diploma HND Degree (BSc/BA) Graduate diploma (or other CPD delivered at graduate level) Masters Degree (MSc/MA) MPhil PhD
5. **Employment Status**:
   Employed Unemployed
6. **Employment Type**:
   Full-time Part-time Bank Staff
7. **Number of Hours Worked per week**:
   <5 6-10 11-15 16-21 22-26 27-32 33-37 37+
8. **Specialism**:
   ……………………………………………………………
9. **As part of your role, do you come into contact with clients who**:
   Are: elderly young children
   Have: a learning disability a mental health condition
10. **How would you describe the sector you work in?**
    NHS Local Government Private Healthcare
    Charitable Organisation Research Organisation
    Other (please specify)………………
11. **Job Title (optional)**:
    ……………………………………………………………

Appendix 29: Participant debrief sheet (Chapter 4)

Research study: Stress in oncology nurses: predictors and the particular challenge of caring for a patient with an intellectual disability

We would like to thank you for taking the time to participate in our research study. You are not required to provide any more information nor to do anything else to participate in this study.

We are unable to provide individual feedback on what your scores were, however, if you would like a written summary of the overall results, please do let us know and we would be happy to provide this for you. We are currently analysing the data and are confident that the information that you, and your fellow participants, have provided will help us to better understand and begin to improve the experiences of oncology nurses.

We would like to take this opportunity to remind you once again that all answers provided within the study will be treated as confidential.

Please feel free to contact us if you have any further questions about this study, our contact details are provided at the bottom of this page. If you have any concerns about anything which was raised for you in this research, please seek advice from your GP, you may also find the following sources of information helpful:

- The Samaritans: 08457 90 90 90 (www.samaritans.org.uk) 24hrs
- Anxiety UK: 08444 775 774 (www.anxietyuk.org.uk)

Finally, if you would be happy to take part in future research of a similar nature, could you please provide us with your email address in the below text box. Please be assured that your email address will not be stored with the answers you have provided within the research, and will not be used for any other reason.

[TEXT BOX]

Once again, many thanks for participating in this research. We wish you the very best for the future.

Debbie Stevens-Gill and Samantha Flynn.

If you would like any further information about this research, please contact us: Debbie Stevens-Gill or Samantha Flynn, Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ. Tel: 01244 513479/07825 853661; email: 1021359@chester.ac.uk / samantha.flynn@chester.ac.uk.

Appendix 30: Participant free-text responses (Chapter 4)

If you were unsure about how to provide the highest quality care for this patient, where would you go to for advice?
…but I would know where to look
2 x specialist learning disability nurse in the Trust, community trust facilitation team. GP, mana
Additional needs worker
adult protection officer/learning disability officer
advice from learning disability liaison team and/or Macmillan
Approach specialists dealing with learning difficulties for assistance
care key provider/ social worker in firstinstance
carers & agencies
colleague who specialiszes in learning disabilities
Community learning disability team, hospital psycho-onc dept, safe guarding lead at the Trust
community mental health
Community team
Contact learning disabilities specialist nurse
contact their key worker
Expert resources either in the trust or outside tyhe trust. Vunerable adult leads
Imca and mental health partner ships
it would depend on the circumstances but initially I think I would approach our mental health team
Key worker
LD hospital based nursing team
Ld liason team with the trust
Lead Nurse - Vulnerable Adults
learning diisabilities team
learning dis nurse
learning disabilities nurse/vulnerable adults coordinator
Learning disabilities sister
Learning Disabilities specialist Nurses
learning disabilities team
learning disability cns
Learning disability CNS
Learning disability CNS
Learning Disability CNSs
learning disability liaison nurse
Learning disability nurse within the Trust
Learning Disability Specialist Nurse
Learning disability specialist nurse; patients key worker or social worker / carer
Learning Disability support team in hospital
Learning Disability team
Learning Disablities Team

Liaise with their community team, contact the Trust Safeguarding team, ask colleagues, their GP,
Line manager
Line manager, support Services in the area
Local learning disabilities team
local macmillan service
Manager and colleagues and Learning Disability support
Managers, peers, site specific clinical nurse specialists
MENTAL CAPACITY TEAM, SPEECH AND LANGUAGE THERAPIST, LEARNING DISABILITY NURSE
mental health support team
other colleagues, social worker
Other members of staff.
Other staff, specialist help
other teams,such as psycologist, psychiatric nurse,learning disability team
Our social work team, or the lead for learning disabilities in our trust
PALs /Social Services
patient's carer or support worker
Patients key worker.
phychololology team
Possiby the patients CPN o
Safe guarding team or learning disability nurse or social services
safeguarding professional within organisation
site specific nurses or learning disability team/consultant linked to patient
Social services, specialist nursing teams
Social Worker/GP services
Their care support worker or family
Trust lead for learning disability or community
Trust lead, their key worker in community, charity for related learning disability
Via hospital disability services
vulnerable adults team/patients specific care teams, learning disabilities team
We have a safegusrding adults advocate at the hospital
work collegue

Are there any additional training needs you believe would be beneficial to help provide care to this person?
yes.
Yes,there is a lack of training which is focused on oncology specific issues and locally organised sessions including informations on where we can contact for advice. Some post gaduate oncology courses i have attended covered this topic in some degree but not in the leve wchich gave me a confidence.
yes, care for the leaning disability person, dementia care ,mental health care etc.
Yes training on working with people with learning disabilities in a health care setting
Yes more training surrounding communication and interpretation of reactions of patients having a learning disability and how to cope with the outcomes .
Yes case discussion with the team

what resources are available to help explain procedures, medical terms and to assist patients identify their problems and communicate them to the health professionals.

We use LearnPro (an online module system) for a large part of additional training, a module specifically about working with, and supporting people with learning difficulties would help me feel more confident that I can help ascertain and address their needs and wishes

We have annual updates on vunerable adults; but if I was to be the key worker for a patient then as an MDT we would all need to idenify the needs of the patient and ensure care provided was holistic and suitable to the specific individual. If there was a very specific condition that was rare I would

Training on how to simplify information but ensuring they receive adequate information to give informed consent.

teaching sessions to be provided about communication methods that could be used to aid information giving to patients in this category.

spending some time with the learning disability team

REGULAR LEARNING DISABILITY UPDATESUPDATES RE MENTAL CAPACITY ACTADVANCED COMMUNICATION TRAINING

Regular educational updates in the Trust about capacity and safeguarding to keep this area of care in the forefront of healthcare professional minds.

Perhaps in house training from the learning disabilities specialist nurse to give advice on ways to communicate effectively in certain circumstances.

Perhaps in house training and awareness

Not really - this is covered up to a point as part of training. Specialist teams are there to deal with or offer advice on more complicated issues.

Not especially as would depend on knowing how best to communicate with them.

No, I would work in partnership with our specialist team for patients with additional needs and we would assess the patient and make a plan together with the carer and patient.

Needs team work. Have done many joint visits on such patients over the years with carers, professional and family.

Need to be aware of local services.

most patients I have cared for with a learning disability have advanced care plans which are very helpful in assisiting with care given.

More training around learning diabilities.

more mental health training and communication skills needed to improve care

mental health course for general oncology nurses

Mental capacity/ other support agencies who are able to provide help/resourcesCommunication with people with learning difficulties-other resourses available which would help

Managing communication difficulties with learning disability individuals

Key contacts/ Social workersCommunication skills adapation

It would depend on the particular person's learning disability/circumstance. I would seek advice from those close to him/her and relevant support organisations.

im not sure what that would look like

If having chemotherapy it would be essential to explain to the patient about the risks of sex and the need to use contraception.

I would discuss with carer or family members to determine what patient could understand. Get patient to tell me what they understand. (Communication study)

I worked as a support worker before my training in mental health and learning disabilties. I think all students should experience this and find there own ways of dealing with these patients, it would also make them aware of services acalible to signpost and bring primary and secoundry care closer

I don't think we have anough patients with the same learning disability issues to ensure training is appropriate, instead I think each person should be assessed and discussed within a wider team there needs discussed and an approach for dealing with them determined

I could not be specific as all patients are individual and not 'a condition'. I might very well seek advice from colleagues who are working with the patient as well.

Every patient is an individual, therefore I think its best to treat each case in such a way.However I think an experienced nurse will also know there own limitations and when and where they need to go for help if needed.

Ensure that the specialist disability nurse visits the patient when they have their treatment. Book training for nurses who feel unsure or unconfident to deal with this patient.

discussion of case studies from nurses who have experienced these situations with patientts with LD would be helpful

Different ways of communicating with individuals

Course to teach and support nurses to use appropriate Communication methods to patients with Learning Disabilities

Communications skills / counselling trainning would be useful

Communication courses - the Oncology Advanced Communication Course.

Breaking bad news to those with learning disabilities

Awareness raising and communication skills/techniques would be useful

Already have mandatory training in adult protection,learning disability,communication

All oncology staff should recieve communication training which should cover communication with patients with LD or cognitive Difficulties

additional strategies to support learning difficulties

A local directory of help that is available to patients with differing circumstances, although most patients would be known to specialist services and we would liase with them.

a care plan and documentation regarding background

Appendix 31: Frameworks for developing Communication Skills Training (Chapter 5)

Key Challenge	How this was addressed	Consideration	How this was addressed
[1] The training should be situation specific and goal related.	The training aims to improve the perceptions of communicating about cancer with people with intellectual disability.	[1] Identify the communication difficulties.	Communication difficulties were identified through a combination of findings within this thesis (Chapters 3 and 4) and from the wider literature (Finlay & Lyons, 2001; Intellectual Disability, 2016; Breaking Bad News, 2016; Chew, Iacono & Tracy 2009).
[2] The skills should gain relevance when it is possible to practice them with simulated patients who are largely representative of the target patient population.	Practice questions about communicating with a fictional patient were included for participants to practice their skills.	[2] Document patient and clinician views.	Clinician and patient views were included in previous chapters (3 and 4), and the wider literature was consulted to ensure wider generalizability.

[3] The training should be set in a practice context.	The intervention was set in a clinical environment.	[3] Identify helpful practices previously associated with better outcomes.	Communication practices were extracted from previous literature and from Chapter 3 of this thesis. Outcome measures were designed to specifically address the aims of this study.
[4] There should be a wider focus on other aspects of communication, including inter- and intra-personal dynamics.	Wider considerations about the inter- and intra-personal relationships between a clinician and patient with intellectual disability and cancer were made.	[4] Develop the evidence-based intervention based on [2] and [3].	This chapter describes the development of the intervention.
[5] Decision making is not solely based on rational processes, affect and intuition are also relevant processes.	The training promotes accessible and meaningful discussion of subjects that the participants may feel are too difficult for the patient with intellectual disability to comprehend.	[5] Test the effectiveness of the intervention in terms of the key outcomes.	Outcome measures were designed to specifically address the aims of this study. This chapter is a feasibility test of the effectiveness of the intervention.

[6] There should be an availability and use of context specific communication support tools to foster the transfer of skills into practice.	The intervention was clear and specific, the layout was easy to navigate, and the information was easy to understand.	[6] Disseminate the effective intervention.	This step will be addressed once an effective intervention has been developed and thoroughly tested.
[7] Guidelines which do not sufficiently meet the needs of trainees will likely be ignored.	The intervention was based on the findings from previous research, both contained within this thesis (Chapters 3 and 4) and from the wider literature.	[7] Broad adoption of the effective intervention.	This step will be addressed once an effective intervention has been developed and thoroughly tested.

Appendix 32: Intervention vignette scripts (Chapter 5)

1. *Using simple language to facilitate communication:*

(Displayed on the screen): *"You don't know…what's got wro….what's gone….what's wrong with you. Cos you can't….you can't...you you….I can't understand what they…the words that they're saying." (Adam)*

SF: It's important when talking with someone with an intellectual disability that you don't bombard them with complex words and overly long sentences. The following videos aim to highlight some common communication difficulties which might impact successful conversations with people with intellectual disabilities, and importantly, how you might be able to overcome them.

After watching each video conversation, spend a moment or two thinking about how you might be able to embed this technique into your own practice. This might be with a person with an intellectual disability, another communication difficulty, or neither of these.

2. *Structuring questions to enhance communication:*

(Displayed on the screen): *Providing structure to questions is key, as some questions may not be perceived as they were intended, and answers might not be as informative as they could be.*

SF: **"How have you been feeling since your last appointment?"** might be heard as simply **"How have you been?"** Often, the answer given could apply to both the actual and the assumed question. Without further prompting, an answer of **"fine"** or **"OK"** might lead to underlying **problems with treatment, or the person's health going unnoticed**. Asking **follow-up questions** related to the actual question will help to clarify the experience, enabling you to ascertain the true nature of their experience.

(Displayed on the screen): *On the other hand, answers might be far too specific, making it difficult to assess the frequency or generalisability of the event. Some additional prompting questions might be necessary.*

PRACTITIONER: Have you had any pain since your last appointment?
PWID: Yes.
PRACTITIONER: OK, where was it?
PWID: In my chest.
PRACTITIONER: (Touch upper chest) In your chest. When did that happen?
PWID: When I was walking.
PRACTITIONER: When you were walking, OK. Has it happened before?
PWID: It happened before.
PRACTITIONER: OK. What happened then?
PWID: It was when I was walking to the shop.
PRACTITIONER: So it was the same as the first time?
PWID: Yes.
PRACTITIONER: Does it happen every time you are walking?
PWID: Yes.
PRACTITIONER: Every time? What about when you are walking from the waiting room to see me? Does it happen then?

PWID: No, not every time.
PRACTITIONER: So just when it is longer distances. Ok. Let’s see what we can do about that.

(Displayed on the screen): *The answer might have no relevance to the appointment, their cancer, or their treatment. In such instances, it might be necessary to validate the answer briefly, and re-ask the same question, in a similar way as you did before.*

PRACTITIONER: Has the medicine been helping to make the pain better?
PWID: I went to the beach this weekend in Blackpool.
PRACTITIONER: Ah, OK. You went to the beach this weekend? That sounds lovely! I bet you had a good time.
PWID: Yeah, it was really nice.
PRACTITIONER: I was wondering if the medicine has been making the pain better?

(Displayed on the screen): *If you still haven’t had a related answer, it could be that the wording of the question is confusing, and could be paraphrased to offer some clarity as to what you are actually asking.*

PRACTITIONER: Does the pain go away when you have your medicine?
PWID: Erm. Yes.
PRACTITIONER: Hmm, OK. Have you been taking the medicine I gave you last time?
PWID: Yes, I have. Every morning.
PRACTITIONER: Yes, good. How does your shoulder feel after you take that medicine?
PWID: A little bit better.
PRACTITIONER: A little bit better. That’s good.

3. *Taking time to get to know the person:*

(Displayed on the screen):*“I think you always worry about how you’re going to communicate, erm…and how to come across as friendly, that he trusts you. I think it’s building up a trust, once…once someone trusts you, it’s very, very easy.” (Ben’s Medical Oncologist)*

In modern healthcare settings, there’s usually a significant demand on time. Failing to take at least a little time to try to build trust with a person with ID, however, can be counterproductive.

You could try something like this:

PRACTITIONER: Hello, Ben. My name is (FIRST NAME), and I am a cancer nurse. It’s great to meet you.
PWID: Hello.
PRACTITIONER: I’m going to be seeing you quite a few times over the next couple of years. (PAUSE) It’s my job to help you get better. How have you been today?
PWID: I’m ok.
PRACTITIONER: Yeah, that’s good. Have you done much this week?
PWID: Watching the tennis at home.
PRACTITIONER: Watching the tennis? I’ve missed most of it. Who do you think will win?
PWID: Andy Murray.
PRACTITIONER: I think he might do it too. Will you let me know what happens?

PWID: I’ll tell you next time.
PRACTITIONER: Yeah? Thank you.

4. *Don’t assume prior knowledge:*

<u>(Displayed on the screen):</u> *It is imperative to all future appointments, and for the understanding of the person with an intellectual disability, that cancer is explained from the very beginning. Upon meeting a person with an intellectual disability and cancer, it would be worth asking them about their understanding – even if they were diagnosed some time ago.*

PRACTITIONER: Hello Danny, my name is (FIRST NAME), and I am a cancer doctor. Do you know what cancer is?
PWID: I don’t know.
PRACTITIONER: Our bodies are made up of tiny cells. OK?
PWID: OK.
PRACTITIONER: Cancer is where some cells stop working and stop healthy cells from working too. So your cancer is sort of a lump, or a bump, that we can feel. Yeah?
PWID: Yeah, I can feel it there.
PRACTITIONER: That’s it. This is where all of the poorly cells have joined together.
PWID: Yeah.
PRACTITIONER: It’s my job to get rid of the poorly cells, and help the healthy cells to work properly again.
PWID: OK.
PRACTITIONER: If I say something that you don't know you can ask me questions. Is that OK?
PWID: Yeah, that’s ok.

5. *Encouraging patient involvement:*

<u>(Displayed on the screen):</u> *Many people with an intellectual disability are not actively involved in conversations related to their healthcare decisions. This can lead to feelings of disengagement and confusion.*

“I don’t agree with that they tend to talk to me rather than Adam. I’ll say ‘Talk to Adam then I’ll help you if you’re struggling.’” (Adam’s ID Nurse)

You should always try to involve the person in some way:

PRACTITIONER: Hello Adam. I’m going to ask you some questions in a minute. Is that OK?
PWID: That’s OK.
PRACTITIONER: I want to know how you have been feeling, and what has been happening. You know how you feel inside better than anyone else, don’t you?
PWID: Yes, I do.
PRACTITIONER: That’s right. So it would be good if you can answer them for me. What sort of questions might I ask you?
PWID: What’s happening and how I feel.
PRACTITIONER: That’s right. Some of the questions might be a bit hard. If you don’t know the answer, we can try another way or ask your mum and we can work it out together. Is that OK?
PWID: Yeah.
PRACTITIONER: So I’ll ask you first, and if you don’t know we could ask your mum.
PWID: OK.

PRACTITIONER: OK, great.

6. The importance of asking non-leading questions:

<u>(Displayed on the screen):</u> *Example problem - If given an example about their health difficulties, Chris will often reply with the example they were given. This makes it difficult to assess whether Chris' experience was in line with the example, or if they have simply repeated the example back.*

To ensure that no miscommunications occur in these instances, you could include some prompts following a potentially leading question, like this:

PRACTITIONER: Are you feeling ok today, Chris?
PWID: Yeah.
PRACTITIONER: OK? Has anything been feeling different than it did before?
PWID: Erm. I've been a bit dizzy.
PRACITIONER: You've been feeling dizzy?
PWID: Yeah.
PRACTITIONER: When does that happen?
PWID: Sometimes.
PRACTITIONER: So, what were you doing last time it happened?
PWID: Sitting down.
PRACTITIONER: You were sitting in the chair?
PWID: Yes.
PRACTITIONER: Were you doing anything as well, like reading or watching something?
PWID: I was watching the telly.
PRACTITIONER: You were watching something on telly? What were you watching?
PWID: Home and Away.
PRACTITIONER: Home and Away, OK, let's see what we can do about your dizziness then.

7. Regularly checking understanding:

<u>(Displayed on the screen):</u> *"They didn't realise that Adam had an ID. 'Cause Adam would just nod and say the right sort of things, erm…they didn't really ask him if he wanted to ask any questions or ask him if he wanted anything explaining. They just presumed that he would have taken all this information." (Adam's ID Nurse)*

Overloading a person with information can lead them to disengaging from the content of the appointment. Taking time to assess their understanding, and re-engage them, is vital to ensuring that they are fully informed and aware of what is happening. You could try something like this:

PRACTITIONER: I know that that was a lot of information. Did you understand what I just told you?
PWID: Yes.
PRACTITIONER: Good. Just to make sure that I told you properly, could you tell me what you heard?
PWID: I've got to have an operation.
PRACTITIONER: (Some nods) Hmm, thank you. I think something that I said wasn't very clear, so let me say it in a different way.

8. Taking time to explain difficult concepts:

<u>(Displayed on the screen):</u> *Example problem - Unfamiliar information can be really difficult for Jean to understand, and respond to within appointments so they tend to stay quiet when new information is being delivered.*

If you think the person with an intellectual disability and cancer has had difficulty understanding what you have said, trying to explain the difficult concept in a different way will be greatly beneficial. For example, you could try something like this:

PRACTITIONER: That might have been a bit confusing.
PWID: Yeah.
PRACTITIONER: But, I've got a picture here of the x-ray you had a couple of weeks ago. I can show you what we are going to do to take the cancer away. (TAKES OUT X-RAY PICTURE OF SPINE)
PWID: OK.
PRACTITIONER: This is your spine, it goes all the way down your back, and this is where the cancer is. (POINTS TO VERTEBRAE)
PWID: This bit, here?
PRACTITIONER: Yes, that bit there. So we have to take this bit away in the operation. Then we'll put in some metal plates and screws, like the ones on the table. Do you want to have a look at one?
PWID: Yeah.
PRACTITIONER: These will make your back strong again after the operation.

9. Be careful when asking about time:

<u>(Displayed on the screen):</u> *Example problem - When asked "When did this first start to happen?" Alex is usually unable to give a specific date, and has been found to really struggle with estimations and concepts of time.*

Including time prompts of key events might help to narrow down vague estimates of time, and develop a shared timeline:

PRACTITIONER: Alex, when did this start to happen?
PWID: I can't remember.
PRACTITIONER: Was it closer to Easter or Christmas?
PWID: Easter.
PRACTITIONER: OK, so it was close to Easter.
PWID: Yeah.
PRACTITIONER: Was it before your birthday, or after your birthday?
PWID: A few weeks before my birthday.
PRACTITIONER: It was a few weeks before your birthday? In May?
PWID: Yes, my birthday is 17th May.
PRACTITIONER: Does that sound about right?
PWID: Yeah. Before my birthday.
PRACTITIONER: Yes? OK. Thank you.

10. Using alternative communication methods:

<u>(Displayed on the screen):</u> *"But similar, and we used a communication book as well, with pictures in. Erm, but Freya is very able to verbalise so we didn't use it as much as needed really, but…yeah…we did…we did have those resources to hand." (Freya's ID Nurse)*

For people with an intellectual disability it might be necessary to include alternative forms of communication to ensure that they are fully aware of what is going to happen. You could try something like this:

PRACTITIONER: You've got to have a CT scan. Do you know what one of those is?
PWID: I don't know.
PRACTITIONER: OK. (TAKES OUT COMMUNICATION BOOKLET AND POINTS TO CT SCAN) It's a machine that looks a bit like a circle with a tray through the middle.
PWID: Like a Polo.
PRACTITIONER: A bit like a Polo, yes! You will lie really still on the bed in the middle, and the bed moves through the big circle. OK?
PWID: Yeah.
PRACTITIONER: The big circle is a scanner that will take a picture of your insides so we can see what is going on in there. Do you have any questions about it?

11. Being clear when talking about diagnosis:
<u>(Displayed on the screen):</u> *"The haematologist that gave us the diagnosis, I found, wasn't very clear in explaining what it actually meant. Erm, I actually got him to write it down erm, so I was able then to go and try and put it into simpler terms." (Adam's ID nurse)*

Using complex terms to explain diagnosis and key procedures will inhibit the amount of information that a person with an intellectual disability will understand. To try to improve their understanding, you could try something like this:

PRACTITIONER: We talked about what cancer is earlier, do you remember?
PWID: Poorly cells in my body.
PRACTITIONER: Yes, cells that have stopped working properly. You have some of those cells in your lungs. That is why you have been having pain and trouble breathing.
PWID: I am having pain.
PRACTITIONER: When we did a CT scan, we saw where all the groups of poorly cells are. OK?
PWID: OK.
PRACTITIONER: We can take them out in an operation, and then give you some medicine to get rid of any that are still there after the operation. Do you have any questions?
PWID: Not now.
PRACTITIONER: Not at the minute. You can talk to your family and friends about it, and if you have any questions you can ask me any time, OK?
PWID: OK.

12. Fully explaining treatments and procedures to support informed consent:
<u>(Displayed on the screen):</u> *Example problem - Ashley tends to refuse treatments and procedures – even blood tests and injections – before they have been fully explained. The initial pain or fear of the procedure remains in focus, rather than the benefits that it will have in the long term.*

Talking to the person about the procedure in a relaxed and relevant way might help to give some wider perspective to the issue, and help them in making a fully informed decision:

PRACTITIONER: Hi Ashley, I know that you are a bit scared of having this injection.
PWID: I don't want the injection.

PRACTITIONER: I know you don’t want it. But let me tell you about what it will do. You are feeling really sick at the minute, is that right?
PWID: I feel really sick all the time.
PRACTITIONER: Yeah? And you can’t stop being sick?
PWID: That’s right.
PRACTITIONER: That can’t be very nice.
PWID: It’s horrible.
PRACTITIONER: This injection will stop you feeling so sick.
PWID: OK.
PRACTITIONER: It might scratch a little bit for just a minute, but you will feel so much better after it’s done.
PWID: I won’t feel sick anymore?
PRACTITIONER: That’s right, you won’t feel sick anymore. You can squeeze someone’s hand while it happens, would that be OK?

Sometimes, of course, it might be judged that a person doesn’t have the capacity to consent to treatment. Still, it helps to maintain your relationship with the person if you take time to explain.

13. Don’t assume sensitive topics are too difficult for someone with an intellectual disability:

<u>(Displayed on the screen):</u> *“He had a testicular tumour, obviously that can be embarrassing, erm and it was quite often very difficult to broach that because…it’s very different if you have to feel someone’s tummy as oppose to if you have to examine them down below”(Ben’s Medical Oncologist)*

It can be uncomfortable to discuss embarrassing or sensitive topics with a person with an intellectual disability, however it is important that such topics are explored within appointments where necessary. Putting the person at ease is important, so you could say something like this:

PRACTITIONER: I know that this might be a bit embarrassing for you.
PWID: Yeah. It is.
PRACTITIONER: That’s ok. I see a lot of people with the same problem, and they sometimes feel the same way.
PWID: OK.
PRACTITIONER: It’s my job to check how you are, and that means having to check you down there. Do you want someone else to be here when I check you?
PWID: Yes, please. My mum.
PRACTITIONER: Yes. OK, we’ll make sure your mum is here too.

14. Don’t be afraid to ask about emotions:

<u>(Displayed on the screen):</u> *“But he’s…he’s very stable like that…he…he adjust really well, you know…it’s just that he, he won’t…he won’t voice that. He won’t say “Oh, I’m really disappointed, oh…” He won’t have that…he won’t have that reaction, no…he’ll just…he’ll just go along…” (Ben’s father)*

Emotions, and labelling them, can be tricky for people with an intellectual disability. However, asking in some way about emotions is key, even if it appears that they are coping well, they might have disengaged from their emotions, or be modelling their behavioural and emotional responses on those around them.

PRACTITIONER: There's been a lot of information to think about, hasn't there?
PWID: Yeah, a lot of information.
PRACTITIOENR: How are you feeling about it all?
PWID: It's ok. A bit scary.
PRACTITIONER: OK, a bit worried. So what sort of things have you been thinking about your treatment?
PWID: It makes me sad and tired after it.
PRACTITIONER: Yeah, so it's making you tired and a bit sad sometimes. A lot of people feel the same way.
PWID: Yeah?
PRACTITIONER: Let's see what we can do to make you feel less tired and sad after your treatment.

15. Encouraging continued engagement in experience:
(Displayed on the screen): *Some people will think that because they no longer have any symptoms, they can stop thinking about cancer – this can lead to them being less vigilant than we might like, for example:*

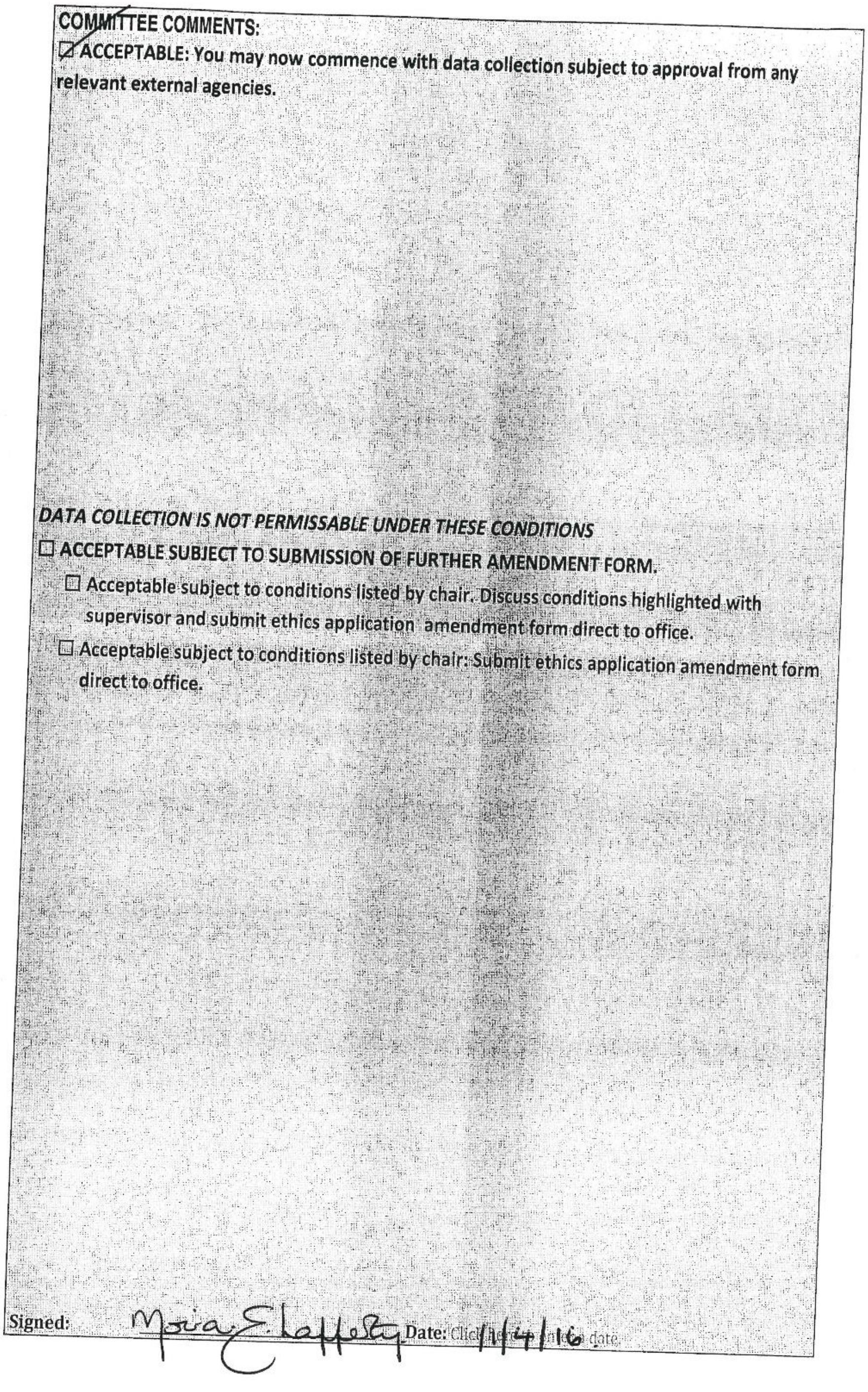
"No, because I knew it was a success so I didn't ask questions about it." (Daisy)
"No [I don't think about it much], cos as far as I'm concerned. It looks like I have nothing wrong." (Charlie)

It is important to highlight the necessity of remaining aware and being able to do a self-exam, but at the same time not alarming them unnecessarily:

PRACTITIONER: Your cancer has gone away.
PWID: They told me that just now.
PRACTITIONER: But you need to check for other signs that something might be wrong again.
PWID: If I get cancer again?
PRACTITIONER: It doesn't mean that you will have cancer again. But we know that sometimes people who have had cancer can have it again years later. OK?
PWID: OK.
PRACTITIONER: I'll keep seeing you for the next few years to make sure that you are still OK. Do you remember how we showed you to check yourself?
PWID: Yeah, I know.
PRACTITIONER: OK, why don't we go over it again together to make sure?

Appendix 33: Video files (Chapter 5)

Appendix 34: Confirmation of ethical approval (Chapter 5)



COMMITTEE COMMENTS:

☑ **ACCEPTABLE:** You may now commence with data collection subject to approval from any relevant external agencies.

DATA COLLECTION IS NOT PERMISSABLE UNDER THESE CONDITIONS

☐ **ACCEPTABLE SUBJECT TO SUBMISSION OF FURTHER AMENDMENT FORM.**

- ☐ Acceptable subject to conditions listed by chair. Discuss conditions highlighted with supervisor and submit ethics application amendment form direct to office.
- ☐ Acceptable subject to conditions listed by chair: Submit ethics application amendment form direct to office.

Signed: Moira E. Lafferty **Date:** Clic [illegible] date 1/4/16

Appendix 35: Recruitment text for an email or newsletter post (Chapter 5)

University of Chester

Chester Research Unit for the Psychology of Health CRUPH

**** Sent by (ORGANISATION) on behalf of Samantha Flynn ****

Free Online Training: Supporting Cancer Patients with an Intellectual Disability

Oncology professionals are invited to take part in online training which focusses on communicating with people with an intellectual disability. These skills may also be transferrable to your everyday practice. This training is certificated.

We are also evaluating the training – and have three short questionnaires to be completed before and after the training, and another six weeks later. We expect that, including all questionnaires and the training, the package will take you no longer than 3 hours. Participation is voluntary, and all data will be secure and confidential. If you want to find out more about this exciting project, please follow the link below:

https://chester.onlinesurveys.ac.uk/cpid1

Many thanks,

Samantha Flynn (samantha.flynn@chester.ac.uk)

Chester Research Unit for the Psychology of Health, University of Chester

Please note: The training site is best viewed in Internet Explorer. It also works well in Firefox and Chrome. The site is known not to work particularly well with Safari.

Appendix 36: Participant information sheet (Chapter 5)

University of Chester

Chester Research Unit for the Psychology of Health CRUPH

Training Package:
Supporting Patients with an Intellectual Disability

As an oncology professional, you are being invited to take part in a novel online training package and research project to improve wellbeing when caring for patients with an intellectual disability.

Please take time to read the following information carefully and decide whether you would like to participate.

Who is undertaking this research study?

This project aims to test an exciting new approach to training for communication skills and is being undertaken by Samantha Flynn under the supervision of Prof. Nick Hulbert-Williams, Dr Lee Hulbert-Williams and Prof. Ros Bramwell at the University of Chester.

What is the research about?

In our previous work, oncology nurses have reported that providing care to cancer patients with an intellectual disability is significantly more demanding than to cancer patients without an intellectual disability. Building on these findings, we are interested to discover the efficacy and feasibility of an online training package to improve perceptions of communication with cancer patients with an intellectual disability.

What is an intellectual disability?

An intellectual disability (sometimes referred to as a learning disability, or previously as mental retardation) is characterised by impairments in: *intellectual functioning* (typically an IQ of below 70), and *adaptive functioning* including skills required for independent daily living, with onset during the developmental period (American Psychiatric Association, 2013).

What will happen if I decide to take part?

You will be asked to complete an initial questionnaire (taking around 20 minutes), after which you will be transferred to the online training site where you will discover a series of videos and practice questions. You are able to do this at your own pace, and in your own time – we anticipate that you will be engaged with the content of the training for no longer than 2 hours.

Following completion of the training you will be asked to compete another questionnaire, and once again in around 6 weeks' time; both taking around 20 minutes each. After completion of the final questionnaire, you will be fully debriefed and we will arrange to send you a certificate of participation.

Do I have to take part?

You are not obligated to take part in this project and you need not give a reason for this decision.

Should you wish to withdraw from the project before you have completed the final questionnaire, you can do so by not submitting your answers and not responding to the follow-up email. Please note that your responses up until the point of withdrawal will be saved and potentially included in the analysis.

If you want all of your responses removed from the analysis you can request this by emailing Samantha Flynn (email address below) and quoting your username, you do not have to give a reason for this decision. You are able to request the removal of your responses until 2 weeks after you have submitted your last questionnaire – at this point usernames will be removed, data anonymised, and it will not be possible to withdraw your responses.

If there are some questions you do not feel comfortable answering, you may leave them out, but please be aware that this may mean we can't include your responses in our analysis.

Is there any potential harm from taking part in the study?
There are no anticipated harmful effects from taking part, but some of questions may make you reflect on your practice, and professional development. If this is the case, please refer to your line manager for information on your department's support, guidance and development resources.

How will I benefit from the study?
You will be receiving an online training intervention without charge to yourself or your employer. You will receive a certificate of participation following the final questionnaire. The skills learned will be transferrable between populations, so will be more widely applicable to your everyday practice.

You will also be helping to develop the training package, adding to current knowledge and potentially enabling the wider development and implementation of the training to other organisations.

Confidentiality
All information to be used in this study is strictly confidential and will only be used for the purposes of this research and subsequent publication. All responses will be stored confidentially and securely, prior to data analysis your responses will be pooled with the other responses, thus they will be unidentifiable to you.

Data will be stored in accordance with the Data Protection Act and University Research Policies. Once analysis is complete, data will be kept in secure archives held by the University; all other copies will be destroyed. Archived data will be confidentially destroyed five years after study completion.

What will happen to the results of the study?
We will write up the findings from this research as research papers which will be submitted to relevant journals. Results may also be presented at scientific meetings and conferences. In all results, all participants will remain anonymous and individual responses will not be singled out, thus it will not be possible to provide individual feedback. If you would like a summary of the results, please contact Samantha Flynn (see below).

Complaints procedure
If you wish to make a complaint about any aspect of this research, or how you have been treated as a participant, please address it to:

Chair of the Ethics Committee, Department of Psychology, University of Chester,
Parkgate Road, Chester, CH1 4BJ.

Where can I get further information?
If you require further information, please contact: Samantha Flynn, Chester Research Unit for the Psychology of Health, Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ. Tel: +44 (0)1244 511925; email: samantha.flynn@chester.ac.uk.

Please keep a copy of this Information Page for your future reference. Thank you for considering taking part in this research.

Appendix 37: Participant consent form (Chapter 5)

Training Package:
Supporting Patients with an Intellectual Disability

Please read the following statements and click ‘Continue’ at the bottom of the page if you agree to take part in the project. If you have any questions or concerns about doing so, please contact me:

Samantha Flynn, Chester Research Unit for the Psychology of Health, University of Chester, Parkgate Road, Chester, CH1 4BJ. Tel: +44 (0)1244 511925; email: samantha.flynn@chester.ac.uk.

1) I confirm that I have read and understood the information sheet for the above study.

2) I understand that my participation is voluntary and that if I decide that I no longer wish to take part I can withdraw before completion of the project, without giving any reason. I also understand that I am able to request the removal of your responses until 2 weeks after you have submitted your last questionnaire; after this time, my responses will become unidentifiable, and I will therefore not be able to withdraw my responses.

3) I understand that I can omit any question I do not wish to answer.

4) I understand that in participating in this project my responses will be dealt with in a secure, anonymous and confidential manner. Data will be pooled, and thus will not be identifiable.

5) I agree to take part in the above project.

Please click ‘Continue’ to indicate your agreement to the statements above, and your consent to take part in this training package and research project.

[CONTINUE]

Appendix 38: Participant demographic questionnaire (Chapter 5)

Please select a memorable, non-identifiable username.
e.g. Ferrari_Fan1; Wonder_Woman

You will use this username throughout the training, and for all subsequent questionnaires, so it is important that you remember it or write it down. (*There will be opportunities for you to anonymously retrieve your username through the training website – should you forget it).*

____

Please complete the following questions about yourself.

1. **Sex**: ______________ Prefer not to say
2. **Age**: ______________ Prefer not to say
3. **Specialism**: ______________
4. **As part of your role, have you come into contact with patients who**:
   Are: elderly
   children
   speaking English as a second language
   Have: an intellectual disability
   a mental health condition
   dementia
5. **How would you describe the sector you work in?**
   Public Sector Health Service (e.g. NHS, Medicare)
   Local Government
   Private Healthcare
   Charitable Organisation
   Research Organisation
   Other (please specify): ______________
6. **Job Title**: ______________
7. **Length of time in current post**: ______________

Appendix 39: Behavioural Intention Measure (Chapter 5)

Considering your current knowledge and experience of intellectual disabilities, please indicate the response which best reflects your intention to engage in the behaviour at present:

(*Extremely willing, very willing, somewhat willing, neutral, somewhat not willing, not very willing, extremely not willing*)

1. How willing do you feel to engage in a conversation with an individual with an intellectual disability about their cancer?

2. How willing do you feel to engage in a conversation with an individual with an intellectual disability about their cancer, knowing that you might not be able to successfully communicate?

3. How willing do you feel to use alternative communication strategies with an individual with an intellectual disability about their cancer?

4. How willing do you feel to actively engage an individual with an intellectual disability in treatment decisions?

5. How willing do you feel to sit with the feeling that you might not be successfully communicating with an individual with an intellectual disability?

Appendix 40: Perceived ability and confidence in communicating measure (Chapter 5)

Some situations that clinicians encounter may be difficult to handle. Please evaluate how you would feel about each of the following situations:

1. A patient is unaware of their cancer diagnosis, and their family are insistent that they are not told as they will not understand.

2. A patient is accompanied to all appointments by a friend who tends to ask all of the questions for them. The patient does not seem to understand the full extent of what is happening.

3. You have been told by colleagues that a new patient does not communicate their thoughts and feelings, and that their behaviour can be seen as obstructive during consultations.

4. You have become aware that a patient does not inform you when they are feeling pain or discomfort, and is not forthcoming about their symptoms.

5. It is clear that a patient does not fully understand the treatment side effects and is attributing them to other, unrelated, things.

Questions to come after each situation:

<u>1- Strongly disagree; 2 – Disagree; 3 – Neither agree or disagree; 4 – Agree; 5 – Strongly agree</u>

1. I believe that I would be able to successfully communicate with this patient.
2. I would feel uncomfortable talking to this patient about their illness.
3. I would be dependent on the person accompanying the patient to communicate with the patient.
4. I feel confident that I would be able to identify and meet the needs of this patient.
5. I believe that communicating with this patient would be stressful for me.

Appendix 41: Initial debrief and invitation to the training package (Chapter 5)

University of Chester

Chester Research Unit for the Psychology of Health CRUPH

Training Package:
Supporting Patients with an Intellectual Disability

Thank you for taking the time to complete this pre-training questionnaire.

You are now welcome to access the training package by following the link below:

****URL****

We would like to take this opportunity to remind you once again that all answers provided within the study will be treated confidentially. We are unable to provide individual feedback, however, if you would like a written summary of the overall results, please do let us know and we would be happy to provide this for you.

Please feel free to contact me if you have any further questions about this project (contact details are provided at the bottom of this page).

Some of questions may have led to you reflecting on your practice, and professional development. If this is the case, please refer to your line manager for information on your department's support, guidance and development resources.

Once again, many thanks for participating in this research. We hope that you find the training package interesting and useful.

If you would like any further information about this research, please contact: Samantha Flynn, Chester Research for the Psychology of Health, Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ. Tel: +44 (0)1244 511925; email: samantha.flynn@chester.ac.uk

Appendix 42: Case study and practise questions (Chapter 5)

David is 38 years old and has a mild intellectual disability. He was recently diagnosed with testicular cancer, and a secondary has been discovered in his stomach. He lives alone in a residential home. He often attends appointments with his social worker, however it is not unusual for him to come to routine appointments on his own.

Below are some communication difficulties which you, and your colleagues have found to be problematic during appointments. Please consider:

1. How this might practically impact the care David receives.
2. How this difficulty might emotionally impact David.
3. How you might be able to avoid or overcome this issue based on your current knowledge of David, and communication strategies.

If you are unsure, feel free to leave the box blank and move onto the next problem. Your answers to these questions are for your own practise only, and will not be read or assessed by any member of the research team.

Communication difficulty:

1. David often struggles to assess frequency of symptoms when he is asked if it occurs ‘all of the time’, ‘most of the time’, ‘some of the time’, ‘a little of the time’, or ‘none of the time’. His answers tend to substantially differ from compiled reports given by his social worker.

2. When asked “When did this first start to happen?” David is usually unable to give a specific date, and has been found to really struggle with estimations and concepts of time.

3. If asked about whether he is feeling better now than he used to feel, David can find it difficult to differentiate between the two events and give a conclusive answer.

4. David can struggle to express his emotions, or describe them. He finds it easier to talk about more concrete, rather than abstract concepts.

5. When asked what usually or generally happens, David will talk about one specific occurrence and it can be difficult to ascertain the frequency or generalisability of the occurrence.

6. Unfamiliar information can be really difficult for David to understand, and respond to within appointments so he tends to stay quiet when new information is being delivered.

7. David has appeared to be nervous when discussing sensitive topics during appointments, and has previously expressed concern about who will find out about what he tells you.

8. When asked questions such as: “How have you been feeling about your cancer?” David often answers the more general question: “How have you been feeling?” dropping the final clause from the question.

9. If given an example about his health difficulties, David will often reply with the example he was given. This makes it difficult to assess whether his experience was in line with the example, or if he has simply repeated the example back.

10. There are times when it is clear that David has not understood what has been said, however he will not explicitly state that he does not understand.

11. David has a tendency to reply positively to “yes-no” questions, even when the answer is contradictory to what might be anticipated. This makes it difficult to accurately understand how David is responding to treatment etc.

12. It is often the case that David will give apparently irrelevant answers during appointments, and often will talk about events and people who are of no direct relevance to the appointment, his cancer, or his treatment.

Appendix 43: Second participant debrief (Chapter 5)

University of Chester

Chester Research Unit for the Psychology of Health CRUPH

Training Package:
Supporting Patients with an Intellectual Disability

Thank you for taking the time to complete this post-training questionnaire.

Please provide your email address so that we are able to send the follow-up questionnaire in 6 weeks time. We would like to assure you that your email address will not be used for any other purpose, it will be stored separately from your answers and will be deleted immediately after the study has finished:

Email address: ___________________

Following completion of this questionnaire you will be asked for your preferred name and email address and will be sent a certificate of participation for completing the training package.

We would like to take this opportunity to remind you once again that all answers provided within the study will be treated confidentially. We are unable to provide individual feedback, however, if you would like a written summary of the overall results, please do let us know and we would be happy to provide this for you.

Please feel free to contact me if you have any further questions about this project (contact details are provided at the bottom of this page).

Some of questions may have led to you reflecting on your practice, and professional development. If this is the case, please refer to your line manager for information on your department's support, guidance and development resources.

Once again, many thanks for participating in this research. We hope that you have found the training package interesting and useful.

If you would like any further information about this research, please contact: Samantha Flynn, Chester Research for the Psychology of Health, Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ. Tel: +44 (0)1244 511925; email: samantha.flynn@chester.ac.uk

Appendix 44: Follow-up email (Chapter 5)

University of Chester

Chester Research Unit for the Psychology of Health CRUPH

Training Package:
Supporting Patients with an Intellectual Disability

Hello,

You recently completed an online training package aiming to improve practitioner perceptions of communicating with patients with an intellectual disability, and were asked to take part in a final follow-up questionnaire to evaluate the efficacy of this training.

Please follow the below link to take part in the final part of this project. It will take no longer than 20 minutes.

****URL****

If you have any questions about this project, please do not hesitate to contact me (email: samantha.flynn@chester.ac.uk; phone: +44 (0)1244 511925).

Many thanks, and best wishes,

Samantha Flynn
Chester Research Unit for the Psychology of Health, University of Chester

Appendix 45: Final participant debrief (Chapter 5)

University of Chester

Chester Research Unit for the Psychology of Health CRUPH

Training Package:
Supporting Patients with an Intellectual Disability

Thank you for taking the time to complete this final questionnaire. Your involvement in the project is now complete.

Please enter your name and email address in the spaces below to enable us to send you a certificate of participation. We would like to assure you that your name and email address will not be used for any other purpose, they will be stored separately from your answers and will be deleted immediately after the study has finished.

Name: ____________________
Email address: ____________________

The aim of this research is to determine the efficacy and feasibility of delivering a brief online training package to oncology professionals to improve confidence, perceived ability, and comfort in communicating with individuals with an intellectual disability. We are confident that the information you and your fellow participants have provided will help us to meet this aim.

We would like to take this opportunity to remind you once again that all answers provided within the study will be treated confidentially. We are unable to provide individual feedback, however, if you would like a written summary of the overall results, please do let us know and we would be happy to provide this for you.

Please feel free to contact me if you have any further questions about this project (contact details are provided at the bottom of this page).

Some of questions may have led to you reflecting on your practice, and professional development. If this is the case, please refer to your line manager for information on your department’s support, guidance and development resources.

Once again, many thanks for participating in this research. We hope that you find the training package interesting and useful.

If you would like any further information about this research, please contact: Samantha Flynn, Chester Research for the Psychology of Health, Department of Psychology, University of Chester, Parkgate Road, Chester, CH1 4BJ. Tel: +44 (0)1244 511925; email: samantha.flynn@chester.ac.uk

Appendix 46: Participant completion certificate (Chapter 5)

University of Chester

Chester Research Unit for the Psychology of Health
CRUPH

Certificate of Participation

____

Has completed the online training package:
Supporting Cancer Patients with an Intellectual Disability – Communication Skills and Strategies

Equivalent hours of learning: **3 HOURS**

Signed: ________________________

Date: _________________

Appendix 47: Evaluative questions (Chapter 5)

1. In the past month, have you had any interactions with an individual with an intellectual disability? (*Yes/No*)
2. If yes, were these interactions part of your professional practice? (*Yes/No*)
3. How would you describe these interactions? Consider any barriers and facilitators to successful communication. (*Free text*)

(Only in post-questionnaire):

4. How likely are you to use the learned techniques and strategies in future interactions with individuals with an intellectual disability? (*Extremely likely, very likely, likely, neutral, unlikely very unlikely, extremely unlikely*)

(In post- and follow-up questionnaires only):

5. How useful did you find the techniques and strategies in these interactions? (*Free text*)

(Only in post-questionnaire)

The following questions are being asked for the purposes of evaluating and improving the intervention for future implementation. Please be honest and comprehensive in your answers.

1. What was the most useful element of the training? (*Free text*)
2. What was the least useful element of the training? (*Free text*)
3. How likely is it that you would recommend this training to a colleague? (*Extremely likely, very likely, likely, neutral, unlikely very unlikely, extremely unlikely*)
4. How would you describe the training to a colleague? (*Free text*)
5. How would you like to see this training improved? (*Free text*)

Appendix 48: Survey about non-completion of the intervention/post-intervention questionnaire

Thank you for completing the first questionnaire for Supporting Cancer Patients with an Intellectual Disability. You are now able to complete the free online training package by following the link below If you haven’t already done so you will need to create an account (takes a few moments) and use the Enrolment Key ***Chester**** to access the site. (URL to training site)

If you have already completed the training, but have not yet submitted your post-training questionnaire please follow this link: (URL to post-training questionnaire)

If you no longer wish to complete the training we would be interested in knowing why. Please could you answer two brief questions on the following page.

If you have any questions about the training please contact Samantha Flynn at samantha.flynn@chester.ac.uk

Questions:

1. What were your reasons for deciding not to complete the training?
2. Is there anything we could have done differently which would have encouraged you to complete the training?

Appendix 49: Participant free text responses (Chapter 5)

Interactions with people with an intellectual disability (T0)	Interactions with people with an intellectual disability (T1)	Interactions with people with an intellectual disability (T2)
We work together with an information material about mammography in easy language. We talk about whats happening and tried to find pictures and text that explained the process. sometimes it was easy to find words that was right to use, I realized how easy it is to use "medical" words and how hard it is to "translate" them into easy language that still explain without making it children language.		
The lady was compliant and appeared to understand what we were doing - she asked questions / made comments to reinforce our opinions. Her carer accompanied her; she was happy that instructions and information had been understood.		
Writing information materials		
Need to get the whole patient history, change your approach for that individual person, take the time they need in a quiet area with out interruptions. barriers - time; interruptions;		

Had to use plain language and keep to the patients pace of understanding. Needed more closely observation than other patients. Relied on family members to help communicate as it made the patient feel safe.

A volunteer who has Fragile X syndrome works at our facility doing small housekeeping tasks under the supervision of his mother. Sometimes his mother is more of a barrier as she does not give him opportunity to talk directly to us. Sometimes one of the male volunteers who supervises him is better at guiding him and giving him opportunity to learn new things.Simple clear instructions work well. patients we have had recently over the last 6 months with intellectual disabilities do well once trust is established and clear open communication.

Positive - more lengthy process from a time perspective and probing required to obtain a clear picture and co-understanding

Limited by either staff or family influences/ perceptions/ attitudes, mu own limited understanding/ knowledge of communicating with this demographic and clinical setting barriers for engaging with this particular group.

they were wary of me at start, but once I was familiar to them, they were more comfortable. barriers were their understanding of their illness, and how much their mothers told them.
Good sometimes client agitated due to illness
Client goes out a lot and so have limited time to talk to them Group home so lots of others around
Staff unable to listen at times due to their workload

Working and taking care residents in the Dementia unit is a very challenging job, but once you know the residents well, their diagnosis, needs, behaviors and feelings. Everything will turn out right and things can be sort if any of the untoward behaviors arises.

Tricky but rewarding. They require more time alocated for a better outcome for the patient.

The longer i cared for the pt , the better i got at understanding if he was in pain or not feeling well by his actions. I soon realized i had to be the one speaking up on his behalf if i knew something was wrong.

Not able to remember important information relevant to their treatment. Pt needs regular contact throughout treatment
To effectively communicate and manage this patient setting aside time is imperative. Have an established professional relationship with this patient and see patient on his own, in an open treatment room. Discuss "how are you feeling today" " How have you been over the past few weeks" " Do you have any concerns or worries at the moment", "Can I help you with anything else?". No real barriers although I am aware that he is able to function "better" in the mornings so appts are tailored to meet this.

Limited until we established communication strategies through the assistance of main carer/or support person.   Barriers:Noise, unfamiliar surrounds, constant stream of new people. Using methods employed by family, eye contact, incorporate familiar loved items into communications.

Barriers is working with other team members not communicating well with the pt Talking over the phone is difficult not having access to a quite space with less environment stimulants Allowing more time assists and also drawing upon the experience of people who have a prior relationship with the pt re. how to effectively communicate with them

I have interacted with this person in an outpatient setting twice. I found the first time quite stressful and difficult as I did not get any feedback from this person. I had to avoid certain words that were imperative in explaining diagnosis and treatment. There was no eye contact and no signs of any participation with the conversation. however, the second time I saw this person they were much more inclined to make some eye contact and to interact with me. I still found it quite stressful as I still had to avoid essential key words, but we had begun to develop a system og communication that worked.

Facilitators- time, familiarity, continuity of care,
Barriers

Alot of patience is needed.. observations to their behaviours.. normal activities and responses.. body language facial expressions.. things outside of their normal character

The family did not want him to know of the terminal diagnosis therefore it was hard to know how much he actually understood.

client stressed due to different environment, unable to follow instructions.

listen carefully, encourage person to speak, helping them to find right world, asking short question, showing appathy and understanding, use body language

We have a volunteer who works at our facility. We have had clients with mental disabilities or intellectual disabilities. Our volunteer sees us weekly to assist with housekeeping chores. He has fragile X syndrome and is an absolute delight to have at our facility. He is supervised by the nurses and myself. He also attends fundraising functions with his mother, his carer.Successful communication is achieved in simple terms, with one of our other male volunteers and or mother facilitating communication, instructions, care. Some barriers have been his mother who means well but sometimes speaks harshly when he just wants to have a friendly chat.

Using clear, simple, consice language. If there is a carer with them include the carer in the discussion and instruction, as they know the individual best and their level of communication and understanding.

Engaging,   needed to adapt my use of language a bit so it was less complex.

Pt talked very loudly around other patients for attention but was easily distracted

I feel that I would like more skills and understanding when communicating. I work on a drop in basis so quickly need to assess and adapt communication natures and skills

challenging. Barriers are often associated with family members and the inability to allow/attempt the explanation to the individual with the challenge.

patient unresponsive but did appear to move eyes towards voices so talked and interacted as if she could hear

Lack of time is a significant barrier

Needed to be pitched at appropriate level of communication and understanding, taking the lead from the individual as to what they understood about their illness and using this as a basis to build on. Required easy read material and for any writing to be large print. Aim was reached by the end of the consultation.

Not always successful. It is difficult to discuss symptoms/problems etc to get a true picture of what is happening with someone who is confused/has diagnosis of dementia or other conditions

Instruction over the phone ,re telephone contact numbers . We took or time, as person found it hard to write quickly and needed to sound the number and check it with me We agreed to check their understanding of numbers given and who they were for at the sum up of this interaction

The patient in question was a patient with dementia and I made sure I had plenty of time to talk with them and tried to give them time to answer. I tried to not use too many open questions when communicating with them.

not recognising they haven't understood because they don't tell you, learning difficulty not formally diagnosed. family overspeaking and not giving you opportunity to explore issues with the patient. if a family member tells you the best way to communicate, which words to use/pictures and then gives you time to do this effectively. we have enough time in palliative care to have these discussions which I appreciate would take longer than an oncologist would have in clinic.

Difficulty ensuring true consent was gained prior to Radiotherapy treatment, therefore longer time needed for clinic appointments	Difficulty to provide informed consent for Radiotherapy	Difficulty gaining true informed consent
difficult as had to try and find numerous ways to get the point across and get some sort of reasoned response	it took several variations on a theme to get the patient to come to an understanding of sorts. now have a basis to build on.	Longer than normal Variable in content Issue led Scenario based tiring
	We have been writing information about mammography using easy language and pictures	
use of Makaton sign language facilitates communication		
For the most part, these encounters went moderately successful. As these clients were nonverbal, special consideration was made to the way in which communication was achieved. Facilitation was made through the use of communicative technology that allowed the client to express themselves in a verbal manner.	They went well enough, I believe had I known of some of these techniques in more detail ahead of time I would have done a better job at communicating with the client. As some were nonverbal, other communication strategies had to be put in place, such as electronic communication devices.	Overall, I would say that interaction went well for the most part. The client allegedly had little ability to comprehend some of the information that was being discussed; but I made sure that it was explained in terms that were easily understandable. In this manner, the client's guardian did help and acted as a facilitator. However, I feel that their attitude to the client's capacity to understand was unintendedly dismissive, and could also be potentially acting as a barrier.

This person had slight level of intellectual disability and was able to adequately communicate. I learnt that I needed to slow down, talk about one thing at a time, and be patient for a response.		
Challenging. Background noise distracting, hard of hearing difficult to communicate, usually pushed for time and no extra time given to reiterate on ongoing basis what is going on	using clear language, with words they are likely to understand, asking for info to be repeated Time restraints and having everyone else in hearing distance can be challenging	
In general the interactions made in the past were reasonably positive and constructive. Considering that there is a language barrier (my limited knowledge of Kiswahili language, only living in Tanzania for 6 months); I always try to utilise the assistance of other people: colleagues, friends and other health professionals in order to achieve the best possible outcomes for the person involved.	No problem at all. Very positive and constructive. I always ask for assistance from other people, colleagues, families and friends as well as other health professionals available.	There were occasions that the interaction were very challenging and moderately difficult. But overall, I was able to meet the needs required by the individuals with intellectual disabilities

These situations can be difficult but I try to communicate directly with the client while also being inclusive of any support people they may have. Communication can definitely be a barrier but using diagrams and illustrations and relating it back to something they have already experienced is often useful.	Difficult to work out the degree of understanding and retention. Family member kept interrupting.	
It can be difficult to ascertain a true understanding of their insight into the disease, prognosis, treatment and their true thoughts.	Sometimes difficult to ascertain their understanding, needs and thought process. Family/Carers can sometimes help	A lady with fluctuating capacity due to dementia. She had a very supportive husband and by making the communication simple she appeared to be able to process some of the information.
Some easier than others. One patient has complex difficulties and is deaf requiring a BSL interpreter which adds another person to the communication chain.	Mild intellectual disabilities are easier to deal with as long as the patient's understanding is repeatedly confirmed. Profound, multiple and complex disabilities offer more challenges to communication but a smile or extended hand is very rewarding. More knowledge, less fear and practice, practice, practice is the answer to successful communication.	Brief by nature of the situation Very positive - I took extra time to put my questions across to the patient
Previous patient cared for at the hospice. Struggled to understand the plan. Struggled to retain the information given and explained.		The gentleman unfortunately was for symptom control and end of life care. My first meeting he was rather sedated. My second meeting I could

Relative also had a similar condition and cared for the patient but better at retaining the information. Anxiety a main feature for both patient and relative. Took particularly long stay to manage symptoms because of this. Repetitive similar information given daily seemed to help.		talk about simple things like pain. He could explain pain killer helped and I could explain we would make it stronger. When he spontaneously asked questions I struggled to understand him at times. The relatives were very good at understanding him. My third meeting he was a little drowsy and I struggled to explain to him that I was changing one of his medications to an alternative. I think even if he had been more awake I would have struggled to get that concept across to him. Only meeting him on a few occasions and with limited exposure to patients with learning disabilities I did not feel I could explain he was getting more poorly as was unsure to what capacity he would be able to interpret this, as I did not want to distress him. Or put the pressure on the family as he found certain things like injections quite distressing.

How useful were the techniques? (T1)	Most useful element? (T1)	Least useful element? (T1)	Describe training to colleague? (T1)	Improvements to training? (T1)	How useful were the techniques? (T2)
Very useful, it is much easier to see them in action and then adopt what you feel will help in your service improvement and professional care	highlighting common communication difficulties that we see in everyday practice within the NHS	seeing the useful conversations and adopting the strategies to improve your own continuity of care	easy and not too time consuming but rewarding	n/a	very userful
helpful as starting points to try and plan a consultation of value	the statements from support staff	N/A	an interesting way of thinking to be asseded	N/A	very
Very useful, it was good to see someone using the tips not only read them	Seeing staff using the tips not only reading about them	can see any	useful tip in communication	I would like it to be a part of the nursing education, even here in Sweden	
i have completed a 3 day communication course and did not feel these short videos had anything extra to contribute to my learning	i didn't like the format at all	videos were very staged and i thought the participants wouldn't successfully engage with a person with intellectual disabilities			

Fairly useful.	The effectiveness of the strategies that were recommended were effective. Many of them were ones that were suggested to be used to me during my degree work.	The video buffering times proved to be very distracting and ruined the pacing of the information. The quality of the acting skills also took away from the immersion of how empathy and other effective communicative skills should be used when interacting with patients with an intellectual disability.	It is a good primer for people that are completely unfamiliar with working with clients or patients with intellectual or cognitive disabilities.	Perhaps provide a transcript of the interviews for those that are experiencing difficulties with the informative videos. As was previously said, I found it very irksome having to constantly stop and start the video.	They were helpful, and gave good entry level understanding with how to interact with a client that has intellectual or cognitive disabilities.
They seemed useful	Seeing the questions being asked in practice	Not being able to hear the response of the person	The training provides you with some tips on how to engage in people with an intellectual disability when talking about cancer	Some of the professionals looked like they were reading their next question. The videos where the professionals didn't look at their notes came across better. Maybe provide some more examples for each tip. Let us hear the responses. Develop a tip sheet that we can save or print out.	

Very. Most are not new, but a good reminder/refresher	seeing the videos, making the examples real	the emount of time it took to download each video/section, and navigation of the site very frustrating	interactive online self paced training	have videos available to view one after the other, with the corresponding text available	
Extremely valuable to my current profession.	The videos were valuable tool.	N/A	The training package will be a valuable tool in the health profession.	N/A	The techniques and strategies from the training were extremely useful to my interactions with individuals with intellectual disabilities. I utilised these techniques as tools and guidelines for my professional practice as well as personal day to day routine if necessary.
Useful in breaking it down to sound communication skills. Reminding us all not to make it too complicated and return to the basic skills which can be forget in busy clinics.	Use of vignettes demonstrating key skills	Would have like a larger number of examples and possibly questions after each scenario to complete/joy down how we would respond - to consolidate skills	Useful training which reinforces sound communication skills/techniques which can be used not only for those with a ID however people with lower levels of education and mental health problems.	Listed before - additional vignettes after introduction/demonstration of key skills to aid skill development and consolidation.	
Very useful	Looking at different ways of approaching different scenarios	A bit repetitive	A tool to develop our skills when talking to clients with disabilities	A little less repetitive	

Very useful - very simple and relevant.	Simple tips - quite logical things which are easy to remember. Not overly complicated so it's easy to see how they can be incorporated in to everyday practice.		Simple, helpful tips.	Maybe to see situations where carers/relatives are more prominent in sessions and how best this can be handled.	
Very interesting videos and useful tips which may enhance my assessment/communication skills.	The videos	N/A	Easy to retain and worthwhile engaging in.	N/A	Helpful as it is about understanding their understanding!
Very useful. As a former teacher I recognise the importance of breaking questions/concepts down into smaller sections.	Being able to observe the interviewers: I felt that facial expressions and body language played a big part in creating an atmosphere of trust		As an opportunity to learn new strategies in communication.		They reinforced my current practice
They were things I had not thought of before. It also gave more structure to techniques I had probably attempted before.	the structure of the 'tips' and being able to work through them	Some of the clips were very short and would have benefitted from a little more explanation	Useful to start thinking about communicating with patients who have intellectual disabilities. Practical with demonstrations	A little more detail in some of the clips.	

Very useful, good to see professionals adjusting their communication style to suit individual patients. And using less jargon which is good for all.	Watching actual examples of conversations to support the written tips	All was useful - thank you	How to communicate well with people with learning / communication disabilities particularly when explaining difficult to understand medical conditions and procedures.	I would like to see it available nationwide and compulsory for all health service professionals.	Very useful - I rephrased what I was trying to impart several times until I was sure that the patient understood
A lot of this felt like good communication skills to use with most patients regardless of IQ. Useful to highlight them though by these techniques. Also highlighting that patients with a learning disability struggle with time concepts was something I had not really thought about	Not to use leading questions and to confirm how much the patient understands	a lot of effort to download app that would convert wmv file to something my mac could use to watch the videos.	useful information that mainly covers good conversation skills but also highlights areas of the consultation patients with learning disabilities may struggle at.	easier to use video files	I thought of the online training whilst consulting the patient. I know other doctors had discussed one of his interests as a way to gain rapport. Mainly I kept questions simple and plans brief in explanation.