The Experience of Interval Scans for Adults living with Primary Malignant Brain Tumours

Sarah Elizabeth Rudkin

Submitted in accordance with the requirements for the degree of

Doctor of Clinical Psychology (D. Clin. Psychol.)

The University of Leeds

Division of Psychological and Social Medicine

June 2022

ACKNOWLEDGEMENTS

Firstly, I would like to thank all the participants who took part in this research, as well as any family members who supported them. I value the time that you gave to meet with me and feel privileged to have heard your personal stories and experiences. I would also like to thank my research supervisors, Dr Florien Boele, Dr Kate Absolom, Dr Thomas Booth and Dr Gary Latchford for sharing your research knowledge, and for your guidance, support, and feedback throughout. Thank you to Dr Helen Bulbeck, patient representative and director for the charity *brainstrust*, for your involvement and advice in the early stages of the project. I would also like to thank the neuro-oncology teams at Kings College Hospitals NHS Trust and Leeds Teaching Hospitals NHS Foundation Trust for helping me to identify and recruit patients. Finally, a big thank you to my family, fiancé and friends for all their ongoing support!

I dedicate this thesis to the memory of my brother, Jonathan. Thank you for always believing in me.

'If ever there is a tomorrow when we're not together, there is something you should always remember. You are braver than you believe, stronger than you feel, and smarter than you think.'

- *A. A. Milne*

ABSTRACT

Introduction: People living with primary malignant brain tumours (PMBT) face a complex and unpredictable illness. Throughout the disease course they undergo various treatments and follow-up with regular interval scans. There are potential burdens and benefits to interval scans, however there is no high-quality evidence to suggest interval scans are beneficial or whether scans alter outcomes of importance for people living with PMBTs. Yet, interval scanning may exacerbate issues such as uncertainty and anxiety, which impacts on patient quality of life. The aim of this study was to gain an in-depth understanding of how adults living with PMBTs experience and cope with interval scans.

Method: Twelve patients with a diagnosis of high-grade PMBT (glioblastoma n=10; ependymoma grade 3 n=1; solitary fibrous tumour of the dura grade 3 n=1) under the neuro-oncology teams at Leeds Teaching Hospital NHS Trust and King's College Hospital NHS Foundation Trust took part in the study. They were interviewed remotely about their experiences of interval scans, following a semi-structured interview guide. A constructionist grounded theory approach was used to analyse data.

Results: Six core categories and twenty subcategories were generated from the data. Core categories were: ‘Living with a PMBT: surviving’, ‘The interval scan process: varying levels of anxiety’, ‘The MRI scan: managing anxieties and accepting the discomfort’, ‘Waiting for the results: getting through the difficult times’, ‘The results: short-term relief vs ongoing anxiety’ and ‘Interval scans: provide a safety net’. Although most participants found interval scans uncomfortable, they accepted that they were something that they had to do and were using various methods to cope throughout the process. All participants said that the wait between their MRI scan and results was the most difficult time. Despite the difficulties they experienced, all participants said that they would prefer to have interval scans than wait for a change in their symptoms. Interval scans provided a ‘safety net’ for participants, by reducing uncertainty, giving them some sense of control, and a connection to their medical team.

Discussion: The present study shows that interval scanning is important and valued by some patients living with PMBT. Although interval scans can be distressing, they may help some people living with PMBT cope with the uncertainty of their diagnosis.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

CBTRUS- Central Brain Tumour Registry of the United States
CNS- Central Nervous System
CT- Computerised Tomography
GT- Grounded Theory
HGG- High grade glioma
HRA- Health Research Authority
KCH- King’s College Hospital NHS Foundation Trust
LGG- Low grade glioma
LTHT- Leeds Teaching Hospitals NHS Trust
MRI- Magnetic Resonance Imaging
MUIS-BT- Mishel Uncertainty in Illness Scale- Brain Tumour Form
NICE- National Institute for Health and Care Excellence
PBT- Primary brain tumour
PIS- Participant Information Sheet
PMBT- Primary malignant brain tumour
PRO- Patient-reported outcome
PTS- Post traumatic stress
PTSD- Post traumatic stress disorder
QoL- Quality of life
RT- Radiotherapy
SCM- Stress and Coping Model
SCTM- Social-Cognitive Transition Model of Adjustment
TCA- Theory of Cognitive Adaption to Threatening Events
TMZ- Temozolomide
UoL- University of Leeds
WHO- World Health Organisation

INTRODUCTION

Primary Brain Tumours in Adults: Diagnosis, Treatment, and Interval Imaging

In this section I will begin by discussing the different types of Primary Brain Tumours (PBT) in adults, as well as their incidence and common symptoms. I will also discuss PBT diagnosis, treatment, and follow-up care. Due to a lack of specific guidance on other tumour types, the guidelines I present will focus on glioma, the most common type of primary malignant brain tumour (PMBT) in adults. I will also share evidence on the use of interval scanning for brain tumour monitoring.

Primary Brain Tumours in Adults

Adults diagnosed with PBTs face an unpredictable and complex illness, with high symptom burden, invasive treatments, and ongoing monitoring (Lin et al., 2015). PBTs are a heterogenous group of tumours arising from cells within the Central Nervous System (CNS; Lin et al., 2013). According to the Central Brain Tumour Registry of the United States (CBRTUS; Ostrom et al., 2021) the average annual age-adjusted incidence rate of primary brain and other CNS tumours between 2014 and 2018 was 24.25 per 100,000. PBT's are relatively rare in terms of cancer diagnoses (De Robles et al., 2015). The incidence rate of brain metastases in adults is estimated to be around 10 times higher than PBTs (Nabors et al., 2020).

Classification of PBTs is made according to the World Health Organisation (WHO) CNS tumour grading system (Louis et al., 2021). PBTs were originally defined histologically and then assigned a grade of 1 to 4 in order of increasing aggressiveness (Lapointe et al., 2018). Grade 1 and 2 tumours are referred to as 'low-grade' tumours, grade 3 and 4 tumours are called 'highly-malignant or 'high-grade' tumours (Louis et al., 2021). Since 2016, PBTs have been classified based on their genotype (genetic alterations) and phenotype (physical observed characteristics; Louis et al., 2016). In this thesis, I define PMBT as "any primary intracranial mass classified as malignant or considered by the neuro-oncologist to be progressive over time" (Boele et al., 2022, p. 2060). Gliomas grow from the glial cells in the brain and are the most common PMBT in adults, representing around 75 per cent of all PMBTs (Lapointe et al., 2018). In adults, gliomas include astrocytoma, oligodendroglioma, glioblastoma (GBM) and ependymoma (Louis et al., 2021). More than half of gliomas in adults are grade 4 GBM (Lapointe et al., 2018). Glioma incidence usually increases with age, however oligodendroglioma and ependymoma incidence is highest in middle age, and there is a decline in the incidence of GBM in individuals over the age of 85 (Walsh et al., 2016). In a review by Ostrom et al. (2014) it was reported that gliomas are generally more common in men than women. Survival rates vary by grade and subtype; grade 1 pilocytic astrocytoma has the highest survival rate, as high as 100 per cent after 10 years following full resection (Lapointe et al., 2018; Ostrom et al., 2014). GBM has the poorest overall survival rates and is the cause of the greatest average loss of life-years among all cancers, with only 0.05-4.7 per cent of patients surviving five years following diagnosis (Ostrom et al., 2014). Age and level of functional impairment are important factors in terms of GBM survival, with younger and more functionally able patients surviving longer (Ostrom et al., 2014). This accounts for some of the variation in survival rates.

PMBTs can cause a wide range of physical, emotional and neurocognitive symptoms which can have a severe effect on a person's independence, activities of daily living and quality of life (QoL). The symptoms that someone living with a PMBT experiences depend on several factors, such as, the type and size of tumour, its location, the impact of any surgery and ongoing effects of treatment (Baker et al., 2016). According to a review by IJzerman-Korevaar et al. (2018), the most common symptoms across all stages of PMBT were "seizures, cognitive deficits, drowsiness, dysphagia, headache, confusion, aphasia, motor deficits, fatigue and dyspnea" (p. 490). The authors discuss how symptom burden is closer to that experienced in people living with a brain disease than the symptoms experienced by those with a diagnosis of cancer.

Diagnosis and Treatments

Computerised Tomography (CT) and Magnetic Resonance Imaging (MRI) can be used to diagnose PMBTs (Thompson et al., 2019). CT scans use x-rays to create images, whereas MRI scans do not use radiation. Instead, MRI scans use magnetic fields and radio waves to create detailed images of internal organs and structures (NHS, 2018). CT scans are less expensive, take less time, are more open in terms of the machine structure, and are quieter than an MRI scan (*brainstrust*, 2021; Cancer Research UK, 2019). However, in the diagnosis and follow-up of PMBTs, MRI scans are seen as the superior imaging technique because they provide higher resolution images and definition of tumours (Thompson et al., 2019). The following structural and procedural information about MRI scans is available for public access through the NHS (2018), Cancer Research UK (2019), *brainstrust* (2021) and RadiologyInfo (2021) websites. Traditional MRI machines are large cylinders surrounded by a magnet. The bore is narrow, with more recent machines having a bore of at least 70cm (Oztek et al., 2020). Some more recently developed 'short-bore' MRI machines are designed so that the magnet does not completely surround the patient, and some machines are open on the sides. These machines can be more comfortable, especially for those who experience claustrophobia. Typically, during an MRI head scan, the patient lies flat on a bed and a frame called a 'coil' is placed over their head to help create a better-quality image. The patient is then moved into the MRI machine head-first by a radiographer who sits at a computer in a separate room. The patient can talk to the radiographer through an intercom system and the radiographer can see the patient. During the scan the machine creates loud ‘hammering’ noises which vary throughout the procedure. These noises have been reported to reach as high as 130.7dB (Oztek et al., 2020). Due to this, patients are provided with earplugs or headphones to wear. For some MRI scans, patients require an injection of intravenous contrast dye. MRI head scans typically last for around 45 minutes, during which the patient must lie still to achieve high-quality images.

Once a tumour has been identified using imaging, it is either resected or biopsied to determine the diagnosis, and the individual is referred to a specialist multidisciplinary team for management of their tumour (National Institute for Health and Care Excellence; NICE, 2018). The treatment that a person is offered depends on the grading and type of tumour. In the management of low-grade glioma (LGG), NICE (2018) recommends consideration of surgical resection to remove as much tumour as possible and allow for diagnosis. Radiotherapy (RT) is considered post-surgery depending on age, tumour type and whether any residual tumour remains following surgery. For some very low-grade tumours, active monitoring may be considered alongside the other treatment options. For high-grade gliomas (HGG), NICE (2018) recommends that RT and chemotherapy, usually temozolomide (TMZ), are offered after surgical resection or biopsy. Treatment options depend on the person’s tumour type, age, and degree of functional impairment. For some people, surgery is not an option, and best supportive care alone will be considered. If a tumour recurs, then the individual may be offered further surgery, RT, chemotherapy, or supportive care alone. MRI scans are usually carried out at several points following diagnosis. They are used to determine the degree of remaining tumour after surgery and are repeated during treatment to measure response.

Follow-up and Interval Scanning

Following PMBT diagnosis and initial treatment, NICE (2018) guidelines recommend interval scanning using MRI as part of the regular follow-up schedule. They recommend interval scanning to assess for progression or recurrence of disease, and to guide treatment accordingly. Interval scanning involves scanning patients at set timings rather than waiting for a change in a patient’s symptoms prior to scanning (Thompson et al., 2019). However, changes in symptoms or clinical concern can also lead to investigation outside of the usual interval scan schedule (Booth et al., 2021). According to NICE (2018) guidelines, people diagnosed with a grade 1 tumour should have a scan at discharge, after 12 months and then at increasing intervals over the next 15 years, or every one to three years for the remainder of their lives, depending on whether the tumour is visible on imaging. Those with grade 2 to 4 tumours should have scans every 3 to 6 months for the first two years, every 6 to 12 months for the next two to four years, and then every 1 to 2 years for the remainder of their lives. The National Comprehensive Cancer Network recommends shorter scanning intervals (Nabors et al., 2020). They recommend interval scans for people diagnosed with LGG every 3 to 6 months for the first five years, then once a year for the remainder of their lives. People with a diagnosis of GBM are recommended interval scans every 2 to 4 months for the first three years, then every 6 months for the remainder of their lives.

According to NICE (2018) interval scans can be helpful; they may identify recurring disease and increase treatment options before the onset of symptoms, they may help to inform the patient about the course and prognosis of the disease, and some patients may find them reassuring. Having frequent follow-up appointments also allows any additional patient and carer needs to be identified and discussed, such as, the side effects of treatment or the need for emotional support. However, regular scans when someone is not experiencing a change in symptoms may cause anxiety (Booth et al., 2021; NICE, 2018; Thompson et al., 2019). Interval scans are also costly and time consuming for health services (NICE, 2018; Thompson et al., 2019). Interval scanning has other issues. For example, MRI scans can show pseudo-progression in the form of increased and enhancing tumour size; this is an early effect following treatment and can be difficult to discern from actual progression (Lin et al., 2013). Changes such as this, or other indeterminate results, can lead to increased uncertainty and anxiety for the person living with PMBT and their family member or carer (Lin et al., 2013).

Evidence for the use of Interval Scanning

The NICE (2018) guidelines on interval scanning are based on the clinical experience of the committee. They state that there is currently “no high-quality evidence that follow-up after treatment is beneficial, no high-quality evidence on the optimal frequency of imaging, and clinical uncertainty about whether such follow-up is likely to alter outcomes of importance to people with brain tumours (such as overall life expectancy or QoL)” (p. 41). According to NICE (2018) it is hoped that the early detection of changes may improve outcomes for people living with brain tumours, whereas missing changes could have severe negative consequences. However, the committee also discussed how patients may experience distress and anxiety from the ongoing interval scanning process. They emphasised the importance of scan results being explained as soon as possible to patients to try and reduce possible distress and anxiety. NICE (2018) recommend research to find out at what point the benefits of early identification of recurrence through interval scanning is outweighed by the burdens of interval scanning for those living with brain tumours.

Thompson et al. (2019) conducted a review to explore whether the timing of interval scans impact on survival for individuals living with glioma, which approach is best for identifying tumour changes, and which approach is most cost-effective for health services. They also explored the effects of interval scans on QoL, anxiety and depression. They discovered one retrospective, single-institution study that compared MRI imaging after surgery vs no imaging after surgery in persons with GBM (Mrowczynski et al., 2018). Thompson et al. (2019) report that this study showed little to no difference between the two groups and concluded that the study was high risk in terms of bias. Thompson et al. (2019) did not find any evidence evaluating the effectiveness of different imaging schedules, evidence of economic evaluations, or evidence of the impact of interval scans on patient QoL, anxiety or depression. They conclude that interval scanning has costs for both the health service and individuals, that interval scanning has not been evaluated economically or from a health perspective, and that there is a lack of evidence on the psychological impact of interval scans for people living with glioma.

In April 2019, experts in the field of interval scanning, data science, health economics, trial management of adult brain tumours, and patient representatives, met to review the evidence base on the use of interval scans for monitoring adult brain tumours. In their position statement, ‘The utility of Interval Imaging in Standard of Care Brain Tumour Management’, Booth et al. (2021) discusses the need for an evidence base around interval scanning practice. They report that this need is identified by researchers, and by patients and carers in terms of understanding the psychological impact they may face during the interval scanning process. Due to the lack of an evidence base, they question whether scans are cost-effective, meaning whether the resources required are justified by the health benefits, including survival and QoL. They recommend the need for research involving patients, carers and the healthcare system, to establish whether interval scanning is cost effective. They discuss the need for higher quality evidence using standardised tools in study design. However, they also share their dilemmas of addressing the evidence gap, including a lack of consensus around designing a randomised control trial to determine the value of interval scanning.

Summary

People diagnosed with PMBTs face an unpredictable and complex illness, with high symptom burden and invasive treatments (Lin et al., 2015). People living with PMBTs are routinely offered follow-up for the remainder of their lives using interval MRI scans. There are potential burdens and benefits to interval scans. They can inform important treatment decisions but may also heighten anxiety and uncertainty. There is currently no high-quality evidence to suggest whether interval scanning is beneficial or whether it alters outcomes of importance for people living with PMBTs (NICE, 2018; Thompson et al., 2019). Due to this, the costs of interval scanning to the healthcare system, and possible psychological impact to patients and carers, there is a need to develop an evidence base to determine the value of interval scans (Booth et al. 2021).

Psychological Impact of PMBTs

Any diagnosis of cancer can have major impact on a person's sense of self and threaten their hopes for the future (Brennan, 2004). In this section, I will discuss the psychological impact of cancer, including PMBTs. This will include a brief review of the literature on psychological distress, depression, anxiety and psychological trauma.

Psychological Distress

Psychological distress can be defined as "a state of emotional suffering characterised by symptoms of depression and anxiety" (Drapeau et al., 2012, p.105). In addition to the distress from the illness itself, people living with cancer also experience distress due to treatment and diagnostic scans (Bauml et al., 2016). Symptom burden and psychological distress in people living with PMBTs is high, has been related to lower QoL, and can significantly impact on prognosis and survival (Baker et al., 2016; Liu et al., 2018; Randazzo & Peters, 2016; Rooney et al., 2013). Risk factors for increased psychological distress include current and past mental health difficulties, a history or substance abuse, history of trauma or a comorbid physical illness with uncontrolled symptoms (Randazzo & Peters, 2016). In a qualitative study looking at the experiences of 17 patients living with PMBT, Sterckx et al. (2015) found that patients reported distress due to the shock of the diagnosis, ongoing uncertainty, anxiety and recognition of their own mortality, with many of their feelings reflecting those seen in the grieving process. Feelings of loss and grief were often related to how minor or absent initial symptoms were, and how the seriousness of the diagnosis did not really fit with how the patients were feeling.

Anxiety and Depression

The prevalence of anxiety in people living with PMBT is generally higher than rates for depression, with rates of anxiety ranging from 30 to 63 per cent (D'Angelo et al., 2008; Hao et al., 2020) and depression ranging from 30 to 50 per cent (Hao et al., 2020; Jiao et al., 2014; Rooney et al., 2011). However, prevalence rates are typically under-reported in people living with PMBT (Baker et al., 2016). In a narrative review, Rooney et al. (2014) reported that depression may appear following PMBT diagnosis, but this is often viewed as a normal reaction without the need for further investigation. Prevalence rates of anxiety and depression also differ depending on the measures used. For example, in a review Rooney et al. (2011) found that studies using measures which included somatic symptoms (e.g., the Beck Depression Inventory), reported higher clinically significant depression rates than those using measures which did not include somatic symptoms (e.g., the Hospital Anxiety and Depression Scale). Prevalence rates also depend on when measures for depression and anxiety are carried out, for example, in brain tumour patients, D'Angelo et al. (2008) found an increase in depression following resection surgery but no change in anxiety.

Depression and anxiety in PMBT can be caused by reactions to the diagnosis itself as well as poor prognosis (Hao et al., 2020; Jiao et al., 2014; Rooney et al., 2014), but can also be caused by the impact of the tumour on immune, neural and psychological systems in the brain (Hao et al., 2020). Survey studies have found that patients diagnosed with GBM report lower mood, depression and more illness intrusiveness than people living with other cancers and diseases (Edelstein et al., 2016; Randazzo & Peters, 2016). Garren et al. (2017) discuss how failing to recognise anxiety in brain tumour patients can lead to an increase in symptom burden and may impact on QoL. They found that anxiety was common among patients living with PMBT, especially when their tumour recurred. Most patients on psychotropic medication reported anxiety, and the authors discuss the need for better therapeutic interventions. In a meta-analysis by Shi et al. (2018) there was a positive association between depression and death in HGG patients, indicating lower survival rates for depressed vs non-depressed individuals.

Psychological Trauma

Many people experience significant psychological trauma due to their cancer diagnosis and treatment (Gibson & Graber, 2020). Cancer can be seen as an internal stressor with little chance of escape, with signs and symptoms acting as persistent reminders (French-Rosas et al., 2011). With ongoing periods of stress before diagnosis, during diagnostic tests, while waiting for test results, and while undergoing treatments, as well as the constant threat of recurrence, cancer is not a time-limited disease (French-Rosas et al., 2011; Leano et al., 2019). This ongoing stress can sometimes lead to cancer-related post-traumatic stress disorder (PTSD; Cordova et al., 2017; Leano et al., 2019). Most studies report a range of 4 to 6 per cent of current or lifetime cancer-related PTSD (French-Rosas et al., 2011). Risk factors for developing PTSD include advanced disease, younger age, having recently completed treatment, lower socioeconomic status, lower education level, history of trauma, history of mental health difficulties, poor social support and certain types of cancer (Gibson & Graber, 2020; Leano et al., 2019). There is evidence that individuals who experience prolonged, repeated, or multiple stressful events, develop more PTSD symptoms compared to individuals who experience single events (Kangas et al., 2002). Leano et al. (2019) discuss how PTSD can lead to distress and isolation due to avoidance. They talk about the importance of screening cancer patients for PTSD and, if needed, referring them on to psychological therapy services that can provide evidence-based treatments.

Many cancer patients will not meet the criteria for PTSD, however, many do report post-traumatic stress (PTS) symptoms including intrusive thoughts and images, flashbacks, emotional numbing, avoidance of reminders, hypervigilance, or physiological arousal (Jim & Jacobsen, 2008). Triggers for PTS symptoms may include medical settings, routine follow-up procedures and medical appointments (French-Rosas et al., 2011). These environments may act as a reminder of cancer (Cordova et al., 2017; Ghazali et al., 2013). A study by Kangas et al. (2012) looked at the effects of RT on psychosocial and cognitive function in 67 people living with brain tumours, 25 of whom were diagnosed with malignant brain tumours. Participants completed self-report questionnaires and neuropsychological tests before RT and at three months after RT. They found that individuals living with benign brain tumours had significantly elevated PTS and distress as well as lower QoL than those living with malignant brain tumours. However, those living with benign brain tumours showed a significant reduction in PTS symptoms and improved emotional wellbeing following RT. Whereas those with malignant brain tumours reported reduced social wellbeing and heightened social constraints post RT, indicating ongoing difficulties for them post-treatment.

Summary and Critique

Research has provided some evidence of the prevalence of psychological distress amongst people diagnosed with PMBTs, with symptoms of anxiety and depression being common features. Distress can have a significant impact on a person's symptom burden and QoL. Many people living with cancer experience symptoms of PTS, with medical procedures and follow-ups acting as potential triggers. Everyone will cope differently following a PMBT diagnosis, not everyone will develop anxiety, depression or experience PTS symptoms. For example, depression is not always certain following a diagnosis of GBM despite poor prognosis (Mugge et al., 2020). Also, some people living with low-grade PMBTs have been found to show positive psychological change and improvements in QoL in the face of the challenge of diagnosis, also known as post-traumatic growth (Li et al., 2019).

There are some limitations to the research into psychological distress. One of the main issues is that PMBT patients are often excluded from the research due to cognitive difficulties, however, PMBT which involves intrusive treatment and poor prognosis may cause more ongoing distress (Kangas et al., 2002). There is also little research on PTS in people living with PMBTs, and no research on the possible relationship between PTS and interval scanning. The study by Kangas et al. (2012) provides some evidence into the psychosocial issues that people living with brain tumours face. However, it was unclear as to what types of tumours participants were diagnosed with as the authors only describe participants as having 'malignant' or 'benign' brain tumours. Also, the sample of participants with malignant brain tumours was small, making it difficult to draw reliable conclusions about this group.

Psychological Impact of MRI Scans

After treatment, people living with cancer are left with uncertainties, such as the possibility of recurrence and the side effects of treatment (Louis et al., 2016; Thompson et al., 2010). These uncertainties can lead to anxiety which may increase around the time of a scan, also known as 'scanxiety' (Bauml et al., 2016; Booth et al., 2021). Research has found that people can experience anxiety prior to scans, during scans and whilst waiting for results (Tugwell et al., 2018; Van Minde et al., 2014). In this section, I will review the literature relating to scan anxiety in general and then focus more specifically on the impact of MRI scans and interval scans following a cancer diagnosis.

MRI machines are narrow, loud, and restrictive, and the scan can be a long process, all of which can contribute to an unpleasant experience and cause anxiety. (Mackenzie et al., 1995; Oztek et al., 2020; Van Minde et al., 2014). Moderate to high anxiety has been reported in up to 37 per cent of patients undergoing MRI (Eshed et al., 2007; Törnqvist et al., 2006b; Tugwell et al., 2018), with higher rates of anxiety reported in those entering the scanner headfirst (Dewey et al., 2007). Patients who experience anxiety before and during a scan sometimes end the scan early, and diagnostic accuracy may be reduced due to the physiological effects of anxiety or movement (Tugwell et al., 2018; Van Minde et al., 2014). Van Minde et al. (2014) measured stress and anxiety throughout the MRI procedure in 67 patients, 52 of whom were reported to be 'highly anxious'. They measured participants' heart rate and asked them to complete self-report questionnaires before and after the procedure. They found participants were most anxious prior to the MRI and when entering the scanner. In a retrospective study involving 95 patients that experience claustrophobia, Eshed et al. (2007) found that 59 patients ended their scan early. The number that ended their scan early was higher in women than men, higher for MRI head scans, and higher for those placed in supine position. In terms of repeating MRI scans over time, Chapman et al. (2010) found that anxiety levels were highest during the first scan but dropped to control levels by the second scan in healthy male volunteers, indicating that they had become habituated to the scan environment and procedures. However, in a study which looked at 500 patients' perceptions of MRI scans, Mackenzie (1995) found no difference in self-rated anxiety pre to post scans for those who had experience of scans vs those who had not. Although these studies are helpful in that they provide some understanding of anxiety and changes in anxiety associated with repeat MRI scans, they are not cancer or interval scan specific.

People undergoing cancer related scans and interval scans may experience heightened anxiety due to the possibility of diagnosis or tumour recurrence. In a cross-sectional survey, Bauml et al. (2016) measured scan associated distress using the abbreviated version of the Impact of Events Scale, and QoL using the Functional Assessment of Cancer Therapy-Lung. Participants included 103 patients with metastatic or recurring lung cancer. They reported that 83 per cent of participants experienced scan associated distress. They found that more severe scan distress was associated with poorer QoL and emotional wellbeing. Undetermined results requiring further testing, anxiety and waiting a long time for results were all associated with greater distress. Similar to those diagnosed with PMBT, interval scanning is carried out routinely for asymptomatic survivors of aggressive lymphoma (Thompson et al., 2010). However, rather than using MRI scans, CT scans are used. Thompson et al. (2010) discuss how the value of interval scanning for aggressive lymphoma has been questioned as relapses are often noticeable without a scan. They discuss how interval scans can also lead to false positives requiring further tests, further uncertainty and increased anxiety. The authors conducted a cross-sectional observational study of 70 long-term aggressive lymphoma survivors, measuring anxiety, the doctor-patient relationship as well as performing a qualitative interview. They found that 37 per cent of participants reported clinically significant anxiety symptoms and a fear of recurrence prior to an upcoming interval scan. They found that anxiety was highest prior to the scan and then reduced following results. Despite some participants experiencing clinically significant anxiety symptoms, some found scans reassuring. Whereas some reported them as ‘a big thing’ and one participant described them as ‘terrorising’. Participants reported that the wait for their results was a difficult time, and problems with the doctor-patient relationship was associated with higher anxiety rates. In terms of further issues with scanning, some participants found them to be an inconvenience, disliked the intravenous contrast, were worried about being exposed to radiation, felt they were over tested and felt that scans were a reminder of cancer. Scans were described as a "double-edged sword" in that they provided reassurance and relief when the news was positive, but they also caused anxiety and could lead to bad news, such as news of progression or recurrence.

In terms of brain tumour MRI scans, Tyldesley-Marshall et al. (2020) interviewed 14 families at Birmingham's Children’s Hospital. They wanted to build an understanding of children with brain tumours and their parents’ experiences of viewing their MRI images. They used grounded theory to analyse transcripts and created a model based on four core categories. The four categories were: ‘receiving results’, ‘emotional responses to MRI’, ‘understanding images’ and ‘the value of MRI’. None of the parents wished that they had not seen their child’s MRI results. Almost all parents reported distress or worry about scans, but many also reported relief, reassurance, and hope for the future from seeing results. In terms of receiving results, most children and parents found waiting for results to be a difficult time. Every parent mentioned that they were uncertain about the disease and their child’s future, and almost all children and parents mentioned anxiety related to the MRI scans and results. Preference to see the MRI results varied from always to never.

Most parents understood what an MRI could or could not show, however, most remember a time where they found them ‘confusing’. Many families found that seeing MRI scan images aided understanding, provided reassurance, made the problem more tangible, made parents feel more involved in their child's care, and some found that they aided acceptance. For some families, it gave them a sense of control in terms of what they were dealing with, whereas others felt that seeing an MRI image would not bring any benefit and only add to distress. Overall, having MRI scans and viewing scan images appeared to present both burdens and benefits to families.

Summary and Critique

Anxiety can heighten at different points throughout the scanning process, including before a scan, during a scan, and whilst waiting for scan results (Bauml et al., 2016; Tugwell et al., 2018; Van Minde et al., 2014). More severe scan-related distress has been associated with poorer QoL and emotional wellbeing (Bauml et al., 2016). Anxiety can be related to the MRI scan itself as well as related to the scanning process, due to fears as to what results might show or undetermined results (Dewey et al., 2007; Eshed et al., 2007; Törnqvist et al., 2006b; Tugwell et al., 2018; Van Minde et al., 2014). Although previous research is helpful, there are some limitations. Bauml et al. (2016) used measures that were not specific to scan-related distress, therefore distress reported may be due to other factors. This study was also cross-sectional so cause and effect relationships could not be established. The sample size was small and there was high heterogeneity in the sample due to differences in terms of prognosis. The authors report that it may have been helpful to measure other potentially relevant clinical variables, for example, treatments or the patient-doctor relationship.

The psychological impact of interval scans presents a particular issue due to the limited evidence base and the value of them being questioned in the management of PMBTs (NICE, 2018; Thompson et al., 2019; Booth et al., 2021). Research by Thompson et al. (2010) focused on the use of interval scanning in aggressive lymphoma, which is an understudied area. Although these patients were undergoing interval scans, aggressive lymphoma differs from PMBTs in that it has a high cure rate, and interval scans are carried out using CT rather than MRI. There were some limitations, such as interviews taking place around the time of a scan when anxiety may be higher, the study was cross-sectional, preventing researchers from concluding on cause and effect, and it was a small study from a single centre. The study by Tyldesley-Marshall et al. (2020) looked at children with brain tumours and their parents’ experiences of viewing their MRI images. This study did highlight burdens and benefits associated with MRI scans, including interval scans. Some participants found that images provided a sense of control and reassurance, whilst others thought that images would contribute to further distress. Although this study was specific to a brain tumour population, it focused on children and parents rather than adults, was concerned with the viewing of images rather than the scanning process and included those in active treatment as well as those undergoing interval scans. Other limitations included the fact that it was a single-site study, that the child and their parent were interviewed together, and that patients who had recently relapsed or received a poor prognosis were excluded. However, the sample did capture a range of responses and the authors reported that their categories reached theoretical saturation.

There is currently no research on the experience of interval scans for adults living with PMBTs. Adults living with PMBT may experience anxiety and distress around the time of their scan, which could impact on symptoms and QoL (Baker et al., 2016). The Response Assessment in Neuro-oncology (RANO) initiative recommend that well defined and reliable patient-reported outcome (PRO) measures are required to capture the impact of and prevalence of scan-related anxiety on people living with brain tumours, and to generate high quality evidence (Dirven et al., 2018). Due to a lack of prior research, qualitative research is needed to understand the impact of interval scanning before measures can be developed.

Uncertainty and PMBTs

In this section I will review the literature on uncertainty in illness and uncertainty following a diagnosis of PMBT. I will also discuss uncertainty in relation to interval scans. The Uncertainty in Illness Theory, Mishel (1988) states that uncertainty exists in illness when there is ambiguity, unpredictability, and lack of information. Although people with life-limiting illnesses frequently face uncertainty, this is understudied (Etkind et al., 2017), and clinicians may be hesitant to discuss issues like an uncertain prognosis for fear of alarming patients or destroying their hope (Barclay et al., 2011). However, unaddressed uncertainty can result in reduced psychological wellbeing, can lead to poor adaption to illness, adverse coping strategies and conflict with health professionals (Lillrank, 2003; Thorne et al., 2005; Wright et al., 2009). PMBTs are both complex and unpredictable which can lead to uncertainty (Lin et al., 2015). In a qualitative study by Ownsworth et al. (2011), one participant compared the diagnosis of PMBT to being on ‘death row’ due to the uncertainty they experienced about their future.

Lin et al. (2012) validated the Mishel Uncertainty in Illness Scale-Brain Tumour Form (MUIS-BT). Participants included 186 patients with brain tumour diagnosis, 143 of whom were living with PMBT. They were all adults and were at different treatment stages. The MUIS-BT demonstrated adequate validity and reliability in people living with brain tumours. Four factors were identified which triggered uncertainty in people living with brain tumours: ‘ambiguity or inconsistency of illness-related events’, ‘unpredictability of disease prognosis’, ‘unpredictability of symptoms or other triggers’, and ‘complexity of the disease process’. Using the same data, Lin et al.

(2013) found that perceived symptom severity for people living with brain tumours related to reported levels of uncertainty, measured by the MUIS-BT, and negative mood states, measured by the Profile of Mood States- Short Form. They found that the relationship between the severity of symptoms and uncertainty was mediated by mood states (i.e., the higher the levels of uncertainty, the more severe the symptoms and the more negative the mood states). The researchers discuss the importance of evaluating potential mediators between uncertainty and symptom severity to provide targets for intervention.

Due to uncertainty about disease progression, uncertainty and emotional responses to uncertainty may be worsened when people living with PMBT are awaiting scan results or receive undetermined results (Booth et al., 2021). A report by Lin et al. (2015) using the same data, investigated the predictors of uncertainty measured using the MUIS-BT in people living with brain tumours, including those with and without MRI review. They found that unpredictability was highest during treatment. Although worry was common prior to MRI for those on treatment, those that had an MRI prior to medical review were less uncertain than those that did not have an MRI review. They hypothesised that having an MRI result may give some people living with brain tumours a sense of control, allowing them to use more helpful coping strategies and reduce the impact of uncertainty. The authors recommend that the coping strategies used by people living with brain tumours should be considered in future studies. Although uncertainty can be difficult to tolerate, Newton & Mateo (1994) discuss strategies for coping with uncertainty when living with a PMBT. They talk about the need to maintain some uncertainty to create a sense of hope and help people to cope with a PMBT diagnosis. For example, although people living with PMBT experience uncertainty whilst waiting for MRI results, they can hold onto hope that the tumour has stabilised. The authors discuss how uncertainty increases and hope diminishes following progression of disease due to death becoming more of a certainty and the increasing fear associated with this.

Summary and Critique

There is a high degree of uncertainty for people living with a PMBT due to the nature of the disease. This uncertainty can cause ongoing stress which increases the severity of symptoms patients experience and impacts on their functioning and mood (Lin et al., 2012). There is some evidence that having an MRI prior to medical review whilst on treatment may reduce uncertainty (Lin et al., 2015). It is possible that having MRI scans will provide some people living with PMBT with a sense of control and hope (Lin et al., 2015; Newton & Mateo, 1994). However, the participants in the study by Lin et al. (2015) were still in the treatment stage, so may have experienced more hope and less fear of recurrence than those at the follow-up stages. Interval scans have not been researched in terms of their impact on uncertainty. Interval scans might increase uncertainty if a result is undetermined or shows pseudo progression (Lin et al., 2013). Uncertainty may also increase when patients are waiting for MRI results due to the unpredictability of the disease and fear of recurrence (Bauml et al., 2016; Booth et al., 2021).

The MUIS-BT (Lin et al., 2012) is a reliable and valid measure and provides clinicians with a way to measure uncertainty following a diagnosis of PMBT. This measure also allows researchers to assess the impact of uncertainty on physical, psychological, and QoL outcomes in people living with PMBT (Lin et al., 2012, 2013, 2015). Further research into uncertainty in people living with PMBT may help to shape future interventions which could improve coping and QoL (Lin et al., 2012). The original study by Lin et al. (2012) had a varied sample representative of the illness trajectory (e.g., different treatment approaches and time since diagnosis) and the sample size was relatively large. Despite this there were some limitations in that all participants were self-selected from a single hospital site and the study was cross-sectional. The reports by Lin et al., (2013, 2015) used secondary data from the Lin et al. (2012) study. The authors acknowledge that analysis of specific disease stages and additional demographic variables might be important when looking for further predictors of uncertainty (Lin et al., 2015).

In their position statement, Booth et al. (2021) offers some practical solutions to reduce uncertainty around interval scanning including ‘one stop’ neuro-oncology clinics. They also suggest that clinicians should provide reassurance following improvement, and clear management plans following scan results. However, they discuss the challenges of implementing these solutions in clinical practice, such as clinician availability. In keeping with the suggestions by the RANO initiative (Dirven et al., 2018) they recommend including PRO measures in study design so that uncertainty and any reduction in uncertainty associated with interval scanning can be measured.

Coping and Adjustment

How much someone is affected by cancer depends on several factors, one of which is how they cope and adjust following diagnosis (Brennan, 2001). In this section I will discuss the literature on coping and adjustment following a diagnosis of cancer, including PMBTs, as well as a review of the literature on coping with MRI scans.

Following a diagnosis of PMBT, people have been reported to use a number of different strategies to cope such as optimism and positive thinking, reappraisal, problem solving, trust, acceptance, distancing, self-control, distraction and avoidance (Goebel et al., 2012, 2018; Gustafsson et al., 2006; Keeling et al., 2013). In the qualitative study by Tyldesley-Marshall et al. (2020) almost all participants mentioned using strategies to cope with the difficult times of living with a brain tumour. Because mental health and psychological well-being are affected by coping, it's important that we understand the mechanisms used, how helpful they are and seek to find other useful interventions (Hulbert-Williams et al., 2012; Lin et al., 2015; Trejnowska et al., 2019). According to Mishel (1988), uncertainty in relation to illness might be viewed as a threat or an opportunity. If uncertainty is seen as a threat, then coping strategies are needed to reduce it, and if these are effective adaption should occur. People who are more optimistic about their diagnosis and become more actively involved in treatment, usually experience less psychological distress and are more likely to engage in the process of adjustment (Brennan, 2004). Psychological adjustment involves the psychological processes in response to illness and treatments which can have a significant impact on health (Dekker & de Groot, 2018).

Coping Theory

Folkman and Greer (2000) describe the Stress and Coping Model (SCM; Lazarus & Folkman, 1984) in their paper on ‘promoting psychological well-being in the face of serious illness’. They describe how the SCM involves both appraisal and coping. Following a change or stressor, the person appraises this in terms of personal significance and coping options. This appraisal is influenced by a person’s beliefs or values (primary appraisal). Coping includes the thoughts and behaviours that a person uses to regulate their distress, manage the problem that is leading to the distress, and maintain positive wellbeing. Coping depends on the extent to which the person believes that a situation can be controlled or changed (secondary appraisal). So, a cancer diagnosis may present itself as a harm, threat or challenge depending on the seriousness of the diagnosis, the individual and how they appraise it. This appraisal determines the intensity of emotions that accompany it and influences coping behaviours. If an individual feels they have a sense of control over the threat, then they are more likely to engage in problem-focused coping. This involves coping by actively finding ways to manage or alter the problem, such as planning, seeking information, problem solving and action. If an individual feels they have little control over a threat, then they are more likely to engage in emotion-focused coping. This includes ways of coping which aim to regulate emotions caused by the distressing situation, such as avoidance, distraction or accessing support from others.

Some revisions have been made to the SCM (Lazarus & Folkman, 1984) which may better describe some of the coping strategies that we see in people living with cancer. Endler and Parker (1990) proposed the addition of an avoidance coping style. This involves avoidance such as seeking out other people for support and engaging in other tasks. Temporary avoidance following a diagnosis of cancer is normal, it allows information to be filtered more slowly, lowers distress and anxiety temporarily, and can help someone to tolerate their difficulties (Brennan, 2004). However, prolonged avoidance, disengagement and feelings of helplessness or hopelessness have been related to higher psychological distress (Morris et al., 2018). Folkman and Greer (2000) describe an alternative third coping style called meaning-based coping. This coping style was introduced by Park and Folkman, (1997) and is likely to occur when people fail to resolve a problem using emotion or problem-focused coping. Following a recurrence of a serious illness or advanced cancer, Lethborg et al. (2008) explain how an individual may try to make sense of their situation by changing their perspective or reviewing their beliefs about their circumstances to fit their views. Individuals seek benefit wherever they can, resulting in positive affect, which can coexist with negative affect. This allows for gradual adaptation.

Social-Cognitive Theory

The concept of meaning-based coping fits with the Theory of Cognitive Adaption to Threatening Events (TCA; Taylor, 1983). According to this theory, individuals respond to threatening events through cognitive adaptation, or by engaging in cognitive efforts to control the situation and increase wellbeing. Cognitions can include 'illusions' based on unrealistically positive beliefs about a person that have no factual basis. The theory is based on three components: (1) search for meaning, (2) effort to gain mastery, and (3) attempts to enhance the self. Search for meaning includes, finding explanations for causes, or restructuring the meaning of life around the threatening event. The individual's belief that they have control over the threatening event and their use of that control during times of threat related to the event is referred to as effort to gain mastery or control. Attempts to enhance the self is where an individual views their experience as beneficial to them in some way, for example, they might compare themselves as being better off than someone less fortunate. Taylor (1983) interviewed 78 women patients living with breast cancer and found that no matter their prognosis or QoL, nearly all of them made some attempt to take control of their disease through the three issues outlined in the model. Stiegelis et al., (2003) supports the theory of cognitive adaption, they found that compared to a control group, cancer patients provided responses of high optimism and self-esteem. They found that psychological distress was predicted by lower levels of optimism and control.

Coping with Cancer and PMBTs

In terms of the literature on cancer and coping, Thomsen et al. (2010) reviewed 30 studies and identified potential factors that related to coping in people with advanced cancer. They identified seven potential factors: ‘creating meaning’, ‘support systems’, ‘minimising the impact of cancer’, ‘bodily and mental functioning’, ‘uncertainty’, ‘control’ (including loss of control and maintaining control) and ‘emotions’. They talk about how 'creating meaning,' 'control,' and 'emotions' are more emotion-focused strategies, whereas 'minimising the impact of cancer' can be seen as both problem-solving and emotion-focused because it includes both 'planning' and 'dealing with it'. Overall, they conclude that the majority of coping in people with advanced cancer is emotion-focused. The authors discuss the difficulties of categorising coping into the Lazarus and Folkman (1984) strategies and propose that meaning-based coping may offer a better description of the type of coping seen in people living with advanced cancer. They talk about how 'uncertainty' and 'bodily and mental functioning' may be more related to the appraisal process than the coping process, but they could not draw any conclusions on this. They discuss the importance of supporting emotion-focused as well as problem-focused coping in clinical practice.

There is little research on the coping strategies used by people living with PMBTs, and the results vary depending on whether the coping strategies are classified as emotion-focused or problem-focused. In a prospective cohort study of 18 patients with a diagnosis of a brain tumour, 10 of whom were diagnosed with GBM, Song et al. (2015) found that problem-focused coping techniques were utilised more frequently than emotion-focused strategies. Acceptance, active coping, using emotional support, and positive reframing were the most commonly used problem-focused strategies. Whereas distraction was the most commonly used emotion-focused coping approach by participants. In a qualitative study by Gately et al. (2020) which looked at the experiences of 10 long-term (>2 years) GBM survivors, emotion-focused coping was more predominant. In this study, emotion-focused coping included strategies of avoidance and distraction. The authors discuss how participants had become disconnected from their past, present and future selves, and they related this to long-term distress and poor adjustment. The authors question whether individuals ever really adjust to terminal diagnoses. The following model described by Brennan (2001) offers a cancer specific process of adjustment.

The Social-Cognitive Transition Model of Adjustment

In a review on adjustment to cancer, Brennan (2001) discusses the issues with the definitions of adjustment as well as issues with the theories of coping and adjustment for people living with a diagnosis of cancer. The author discusses how difficulties with psychological functioning should be seen as a normal part of the adjustment process due to the threat of a cancer diagnosis and the impact of symptoms. Brennan (2001) defines adjustment as "the processes of adaptation that occur over time as the individual manages, learns from and accommodates the multitude of changes which have been precipitated by changed circumstances in their lives" (p. 2). The author discusses how the diversity of threats following a cancer diagnosis are not usually reflected in the coping research due to its cross-sectional nature and the use of coping measures which focus on recent stressors. The author also talks about the diversity of outcomes in that, for some people, threatening life events can provide opportunity for personal growth not just distress. In this review an explanation is provided as to how coping theories, such as the SCM (Lazarus &

Folkman, 1984) and social cognitive theories, such as the TCA (Taylor, 1983) do not provide reasons as to why some people experience distress and others are able to adapt. The author also mentions how these theories do not consider the wider social context which impacts on adjustment.

Brennan's (2001) Social-Cognitive Transition Model of Adjustment (SCTM) provides an integration of coping theories, social-cognitive theories, trauma theories and cognitive theories of emotion. This model acknowledges that the effects of cancer are ongoing, and that people go through a normal process of adjustment that can result in both positive and negative outcomes. It explains how we form a "cognitive map" of beliefs about ourselves, others, and the world. Our cognitive map is constantly updated as a result of our experiences, social, and cultural context. Unexpected events cause us to re-evaluate our assumptions, whilst predictable experiences reinforce them, both of which help us forecast future events. Life-threatening experiences, such as the trauma of a cancer diagnosis, can cause disorientation, distress, and overwhelm because they challenge some of our underlying assumptions. Trauma-related symptoms such as heightened arousal, denial-avoidance, and intrusive thoughts may increase because of the threat's impact on our underlying assumptions; however, these symptoms are seen as part of the normal process of adjustment. As already discussed in terms of an avoidance coping style, short-term avoidance or denial can reduce distress and facilitate adjustment by allowing time for distressing information to be filtered so that it is not too overwhelming. This model also considers the interpersonal changes that occur and can impact distress and adjustment, such as the impact of a diagnosis on a person's family. It also looks at how all these changes occur within a broader social context, such as the healthcare system, which can have an impact on adaptation.

By drawing on a variety of models, the SCTM explains individual differences in terms of people's responses and the associated psychological impact of a cancer diagnosis. It also describes how people may adjust following a cancer diagnosis within a broader social and cultural context. For people living with PMBTs, it's important to consider the adjustment process and how interval scans may impact this. Together, an individual's life experiences, social and cultural environments will influence their perceptions of living with a PMBT and interval scans. Interval scans can confirm or disprove an individual's assumptions, which may have an impact on the person's level of distress, depending on how they and others around them deal with the information.

Coping with MRI Scans

In terms of coping with the MRI scan itself, studies have found that image quality and patient satisfaction improves when noise is reduced and the scanner is larger to allow more space for the patient (Katz et al., 1994; Oztek et al., 2020; Törnqvist et al., 2006a). In addition to changes to the scanning environment, controlled trials have been conducted to see if certain interventions can reduce patient anxiety during MRI scans and improve image quality in comparison to control groups (Grey et al., 2000; Lukins et al., 1997; Powell et al., 2015; Quirk et al., 1989; Tazegul et al., 2015; Tugwell et al., 2018). Past research has found that information before the scan such as procedural and sensory information, information on cognitive techniques to reduce anxiety, and discussions with the radiographer, all helped to reduce anxiety and improve image quality. Orientation to the scan environment, detailed temporal information and communication with staff were all helpful interventions on the day of the scan. Authors discuss the importance of offering such interventions into routine procedures for all patients to reduce discomfort and anxiety, especially when they are convenient and have minimal impact on clinician time.

Törnqvist et al. (2006a) interviewed 19 patients about their experiences of MRI scans. Participants had been scheduled for an MRI scan on different body parts. The scans were not cancer-specific, but they were all done with the participants' head inside the scanner. Participants' experience was described as 'being in another world' and included subthemes of 'threat to self-control', 'efforts to handle the situation', and 'need for support'. Threat to participants' self-control linked with the unusual environment and situation. Some felt no threat, while others felt panicked; this influenced the strategies used to deal with the situation, as well as their need for support. Common coping strategies included relaxation, breathing techniques, closing eyes, thinking about something else, visualisations, motivation in terms of reminding themselves of the importance of the scan, and seeking reassurance from staff. All participants found comfort in having some basic information about the scan, a buzzer to contact staff if needed and contact from clinicians during the scan. The more anxious someone was, the more they sought control through information, trust and reassurance from staff. Music was also helpful for these participants in terms of relaxing, timing and providing a sense of control. The authors concluded that information about the scanning procedure and patient-staff interactions have an important influence on patients' scanning experiences. They discuss the need for individualised approach to scanning depending on patients' experiences of threat to self-control.

As previously mentioned**,** in the qualitative study by Tyldesley-Marshall et al. (2020) almost all participants said that they had to find ways to cope with the difficult times of living with a brain tumour diagnosis. Although coping was not the focus of their research, in a separate report, Tyldesley-Marshall et al. (2021) explored the coping strategies that participants had mentioned around the topic of viewing MRI images. They identified four core categories: 'normalising', 'maintaining hope and sense of the future', 'dealing with an uncertain future' and 'seeking support.' In terms of normalising, participants used coping strategies to maintain their self-worth and some sense of normality. This was achieved through minimising any changes in their lives and through avoidance, for example, not taking images home. Participants’ sense of what was normal adapted over time, this included them seeing the process of having scans as normal. They maintained hope and sense of the future by focusing on the positives. MRIs seemed to serve as a sense of hope for the future in that participants could look back on earlier scans and see tumour reduction over time. Parents talked about how difficult treatment and symptoms could be at times, but that it was worth it to improve their child's QoL and life expectancy. Dealing with an uncertain future included attempts to reduce anxiety or fear of facing an unpredictable future. Participants dealt with this through becoming experts in their own illness, holding fatalistic views (e.g., belief that seeing images would not change the outcome) and using humour when sharing difficult memories. Seeking support included social support from family and friends, as well as social support from other families with children with brain tumour diagnoses. The authors discuss the importance of recognising MRIs as a potential aid for coping with a brain tumour diagnosis, as well as suggesting that families take their scan images home if appropriate. They discuss how MRI scan images can be used to remind families of positive progression and stability. This study provides some understanding as to how interval scans might relate to the processes of coping and adjustment following a brain tumour diagnosis.

Summary and Critique

How individuals cope and adjust following a PMBT diagnosis and during aspects of their care, such as interval scans, will depend on several factors. The SCM (Lazarus & Folkman, 1984) and adaptions to the model (Endler & Parker, 1990; Folkman, 1997) provide us with understanding of possible mechanisms through which people living with PMBT may cope. Coping strategies in the brain tumour literature vary, and this may be due to how information about coping is gathered, such as using self-rated questionnaires vs qualitative data from interviews. It also depends on which coping strategies are classified as emotion-focused or problem-focused, for example, 'seeking support' can relate to both. Avoidance and emotion-focused coping are common following cancer diagnosis, where people feel that they have little control over the situation (Folkman & Greer, 2000). However, meaning-based coping may offer a better understanding of the coping mechanisms used (Thomsen et al. 2010). The search for meaning and reappraisal of circumstances to fit with a person’s belief is described in the TCA (Taylor, 1983), and this theory has been applied to people diagnosed with cancer (Taylor, 1983; Stiegelis et al. 2003).

Although useful, these theories are more focused on the individual than on external factors and interactions. There are also challenges with this area of research in terms of accurately measuring coping and defining the term 'adjustment.' Some researchers question whether individuals ever adjust following a GBM diagnosis (Gately et al., 2020). Brennan (2001) provides a definition of adjustment which normalises the reactions people experience following a diagnosis of cancer. Their SCTM provides a broad perspective on the psychological effects of illness. It explains individual differences in responding to a cancer diagnosis in terms of the experiences of individuals themselves and the impact of their social environment. This is important because coping following a diagnosis of PMBT is likely to be driven by multiple factors. Although there is some research on coping with a diagnosis of PMBT, there is currently no research looking at how adults living with PMBT cope around the time of their interval scans. Appraisal of the situation and coping behaviours are likely to influence someone's experience of interval scanning. This may impact on their wider illness representations and influence how they adjust which has implications for mental health and psychological wellbeing.

There has been some research into how people cope with the MRI scan itself, including trials looking at the impact of focused interventions on anxiety and image quality. Inclusion of both procedural and sensory information, certain environmental adaptions, cognitive techniques and staff-patient communication have all been found helpful in reducing anxiety and helping people cope with scans (Grey et al., 2000; Lukins et al., 1997; Powell et al., 2015; Quirk et al., 1989; Tazegul et al., 2015; Tugwell et al., 2018). There are limitations with the intervention research in that many studies are not generalisable due to small sample sizes, scans are usually performed at one location, patients are all typically MRI "naive," they are not representative of the various reasons for scans that may impact anxiety (such as cancer-related scans), and some also discuss issues with blinding. There have also been issues with the application of interventions in clinical settings, however, some researchers discuss the feasibility of their tested interventions (Grey et al., 2000; Powell et al., 2015; Tazegul et al., 2015). Törnqvist et al., (2006a) discusses a need beyond general scan-related interventions and recommends a more individualised approach. The authors discuss how this may be time consuming at first, but that it will save time and money in the long-term through reduced patient anxiety and clearer images. People with a diagnosis of PMBT may experience and cope with scans differently to participants in the previous literature due to scans being repeated at set intervals, and due to the threat and uncertainty of PMBT.

The most similar research to the current research was carried out by Tyldesley-Marshall et al. (2021). They reported on the coping strategies that children with brain tumours and their parents discussed when sharing their experiences of viewing MRI images. As mentioned previously, this study differs from the current research in that it focuses on children with brain tumours and their parents' views. It also excluded children with no long-term chance of survival. Although the study was not intended to investigate coping, it did highlight the importance of coping after a brain tumour diagnosis because participants talked about it without being asked specific questions about it. A further limitation is that the research did not focus on coping, so it is unlikely that categories on the topic of coping reached theoretical saturation. It is, however, the first study to discuss coping and to highlight the importance of interval MRI scans in terms of their potential to aid coping.

Study Rationale

People living with PMBTs can experience high levels of psychological distress, uncertainty and lower QoL (Lin et al., 2015; Rooney et al., 2013). It is important to understand the experience of interval scans for adults living with PMBTs due to these scans being a life-long and potentially distressing procedure. According to Booth et al. (2021), NICE (2018), Thompson et al. (2019) there is currently no high-quality evidence to suggest whether interval scanning is beneficial or whether it alters outcomes of importance for people living with PMBTs. Therefore, the value of interval scans for people living with PMBT has been questioned. These authors recommend research to establish the benefits and burdens of interval scans for people with PBT, including the psychological processes involved.

Only one study (Lin et al., 2015) has included MRI scanning as a factor when looking at uncertainty measured by the MUIS-BT in the adult brain tumour population, however the MUIS-BT is not a measure that is specific to interval scanning. There has also been some qualitative research looking at children with brain tumours and their parents’ experiences of viewing their MRI images, which highlighted several associated burdens and benefits of MRI scans, including the potential for them to aid coping (Tyldesley-Marshall et al., 2020, 2021). Although there is some research as to how adults living with PMBTs cope with their diagnosis, and how people cope with MRI scans, there has not been any specific research into how adults living with PMBTs cope with interval scans. Coping and adjustment are important because they have implications for mental health and psychological wellbeing (Hulbert-Williams et al., 2012; Lin et al., 2015; Trejnowska et al., 2019), therefore it is important to understand the mechanisms that individuals living with PMBT use. We cannot make assumptions as to how adults living with PMBT experience interval scans, how they cope with this or the impact this might have on their life. Due to the potential for MRI scans to aid coping (Tyldesley-Marshall et al., 2021) and the value of scans being questioned (Booth et al., 2021; NICE, 2018; Thompson et al., 2019), research into the experiences of interval scans for adults living with PMBTs is important.

Due to the current lack of research in this area, it is important to begin by conducting qualitative research to gain a better understanding of adults’ experiences of interval scans and the psychological factors that influence them. The aim of this study was to gain an in-depth understanding of how adults living with PMBTs experience and cope with interval scans. This research is important because qualitative research and emerging theory can help to guide future research, which, for example, may look at measuring and understanding the impact of interval scans. It may also guide future research in the development of interventions for those undergoing interval scans. Understanding people's experiences also helps to inform current practice, such as informing patients of the potential burdens and benefits of interval scans, so they can make informed decisions about their care. This study also adds to the literature in terms of understanding how people with PMBT cope with an unpredictable and complex illness.

METHOD

In this section, I will discuss the research design and methodology rationale. In addition, I will discuss ethical considerations, data management, sampling, and participants. After that, I will provide an overview of the recruitment method, data collection, and analysis. Before concluding this section, I discuss quality control in qualitative research and Grounded Theory (GT), followed by a reflexive statement.

Research Question and Aims

Research Question

How do adults living with PMBTs experience and cope with interval scans?

Research Aims

The primary aim of this research was to gain an in-depth understanding of how adults living with PMBTs experience interval scans. The secondary aim of the research was to gain an understanding of how individuals cope during the interval scan process.

Research Design

Due to a lack of prior research in this area, a qualitative design was used. I gathered data from 12 people living with PMBTs using remote semi-structured interviews. I generated and analysed interview data using the constructivist GT approach outlined by Charmaz (2014).

Rationale for Methodology

Qualitative Research

To fully understand the impact of interval scans, we must first understand the experience of those undergoing them. Qualitative research aims to understand peoples’ experiences of events and how they make sense of the world around them (Willig, 2013). It enables researchers to gain insight into participants' inner thoughts and investigate areas that are understudied (Corbin & Strauss, 2015). It is flexible in terms of research design and allows for the collection of rich data (Snape & Spencer, 2003). Because there is currently no research on how adults with PMBTs experience and cope with interval scans, I chose to use a qualitative approach. I was able to obtain detailed accounts of participants' experiences of interval scans using semi-structured interviews, which provided knowledge and understanding of this under-researched area.

Grounded Theory

There are a variety of qualitative methodologies available, each with its own epistemological position (Willig, 2013). For this study, I decided to use a GT methodology. Other methodologies considered for this study were Interpretative Phenomenological Analysis (Smith, 1996), and Thematic Analysis (Braun & Clarke, 2006), but neither of them would have enabled the development of a theory or model that would provide explanations and a foundation for future quantitative studies. Glaser and Strauss developed GT as a method of qualitative research (1967). It is a widely used qualitative method that goes beyond describing and exploring phenomena of interest, instead attempting to explain them (Birks & Mills, 2015). A theory or model that describes a process or scheme related to a phenomenon is the goal of GT (Birks & Mills, 2015). It differs from other qualitative research in that the concepts that form the basis of the theory are derived from the data rather than being pre-determined (Corbin & Strauss, 2015). Second, research analysis and data collection are interrelated, which means that analysis takes place concurrently with data collection, and the data is constantly compared through a process known as ‘constant comparative analysis’ (Birks & Mills, 2015; Corbin & Strauss, 2015). Grounded theory is suitable when little is known about the topic of research, or when the development of a theory or model with explanatory power is a desired outcome (Birks & Mills, 2015). The theory or model developed as a result of GT provides a strong foundation for future studies using quantitative measures (Corbin & Strauss, 2015).

Earlier versions of GT took a positivist approach, assuming that reality can be objectively understood and emphasising the importance of theory being grounded in data (Glaser & Strauss, 1967); however, GT has undergone several revisions since then. When Glaser and Strauss parted ways, Glaser (1978) continued to use GT to look for theory grounded in the data, whereas Strauss and Corbin (1990,1998) used GT in a way that acknowledged GT researchers' prior knowledge. The constructivist method (Charmaz, 2006, 2014) offers an alternative perspective, in which the researcher constructs theory through their interaction with data (Willig, 2013). Every researcher brings their own perspectives, biases, and assumptions to the research process (Corbin & Strauss, 2015). The constructivist perspective acknowledges that the researcher's perspectives, privileges, positions, and interactions influence research, and emphasises the importance of reflecting on this as part of the ongoing research process (Charmaz 2006, 2014). Although Birks and Mills (2015) mention that it is not necessary to prescribe one version of GT throughout a study, I chose to follow constructivist GT as outlined by Charmaz (2014) for the following reasons:

- Following one approach provided some structure and guidance as a new GT researcher.
- The constructivist GT approach fits with my own ontological and epistemological position. Constructivist GT is rooted in the ontological position of idealism. This means that reality is viewed as subjective, and our experiences depend on our own history, values, and perspectives. The epistemological position of constructivist GT does not take an extreme

view as to how much reality exists. Instead, the researcher is seen as an ‘interpreter’, their interpretation is seen as one view and no single person's interpretation is necessarily correct (Charmaz, 2014).

- Charmaz (2014) discusses the importance of literature reviews, to create rationale and inform theory development. This was important because existing frameworks could be used to help me to make sense of the data.
- According to Charmaz (2014), memo writing is especially important for developing ideas, fine-tuning data collection, and engaging in critical reflexivity. This approach allowed space for reflection on my own perspectives and the impact of these on the research.

Ethical Considerations

Ethical Approval

I gained ethical approval for this research through the NHS and Health Research Authority (HRA) approval process. The research was approved by the Surrey Research Ethics Committee on 29 April 2021 (REC reference: 21/PR/0343). Leeds Teaching Hospitals NHS Trust (LTHT) and Kings College Hospitals NHS Foundation Trust (KCH) provided confirmation of capacity and capability for the research. Copies of HRA and NHS approval letters can be found in Appendices A and B.

Informed Consent

Prior to the interviews, I obtained informed consent from all participants. All eligible patients were provided with a copy of the participant information sheet (PIS) to read (see Appendix C for a copy of the LTHT PIS). They were given time to consider the information, as well as being provided with an opportunity to discuss the research with me and ask any questions. I gave patients as much time as they needed to decide whether they wished to participate. Once they had agreed to take part, I asked participants to sign a consent form (see Appendix D for a copy of the LTHT consent form) or provide consent verbally. When participants were providing consent verbally, I read through the statements on the consent form and asked participants to answer ‘yes’ or ‘no’ to each statement. I recorded verbal consent using a dictaphone.

The right of a participant to refuse participation without giving reasons was always respected. Participants remained free to withdraw from the study without giving reasons at any time until I had transcribed the data. I informed participants that after the transcription of their interviews, their individual data could no longer be withdrawn as the data had been anonymised and had already started to be analysed. I verbally re-visited aspects of the consent process pre and post interview to ensure that participants felt comfortable with what was happening and knew that they were free to withdraw at any time.

Anonymity and Confidentiality

All information collected during the study concerning individual participants was treated in the strictest confidence. Due to sensitive materials discussed and the depth of information participants provided, I ensured that I reminded all participants of their anonymity. All participants were assigned an ID code during transcription and have been given a pseudonym in this write up to ensure anonymity and protect confidentiality. I informed participants that I would only break confidentiality if they disclosed anything of serious concern about their own or others' health, safety, or wellbeing. I explained that if this happened, I would talk to them about it before contacting a professional. Prior to the start of the interview, I reminded participants of the limits of confidentiality in terms of risk. However, no breaches of confidentiality were necessary. All identifiable information was removed during the transcription process including, identifying information about family, friends, where participants lived and worked. Furthermore, all quotes in the results section were chosen to limit the amount of personally identifiable information that could be linked to participants.

Participant Risk, Burden and Benefits

This study was designed to reduce participant burden. Interviews were conducted in the most convenient manner for the participants, with them being able to choose a convenient time and date, as well as whether the interview was conducted via video call or telephone. I explained to participants that while their participation would not directly benefit them, it may help to inform future care and support for others living with PMBTs. Participants had all been diagnosed with a serious illness and were asked to share sensitive and personal information. As a result, there was a chance that during our interview discussions, participants would become upset or more aware of issues. I reminded participants that they were under no obligation to respond to any interview questions with which they were uncomfortable. I encouraged them to let me know if they needed to pause or end the interview. When participants became upset, I paused the interview and gave them time to process their feelings before checking in with them and asking if they wanted to continue. All the participants finished their interviews and were able to provide responses to all the questions.

Data Management

All the information collected during the study concerning individual participants was treated in the strictest confidence. I treated all data in accordance with the Data Protection Act (2018) and the University of Leeds (UoL) Information Protection Policy (Version 1.2). All the data for this study was held electronically and stored in a personal university storage area permitted for highly confidential data by the university's data protection policy, on the secure OneDrive of the UoL. A document containing patient contact details (including their name, phone number and email) was stored electronically using the above means. It was stored separately to the interview transcript and consent files and was deleted following the completion of data collection.

Recordings were made and stored in line with the UoL Data Protection Policy. Due to interviews being completed at home, an unencrypted dictaphone was used for all recordings. I ensured that the recordings were uploaded to the UoL secure OneDrive immediately following each interview and deleted from the recording device. Recordings of verbal consent were stored separately to the interview transcripts to maintain participant confidentiality. I asked the professional transcriber, who was employed by the UoL, to sign a confidentiality agreement in keeping with General Data Protection Regulations (2018). I used the UoL secure OneDrive to share audio files with the transcriber.

On completion of this research is agreed that all materials will be transferred to the research team so that they can access the data for future research. Consent forms, consent recordings and coded anonymised data will be stored for 10 years after study completion on password protected UoL computers with access restricted to the research team. I gained consent from participants for the use of data for future research and for their data to be stored for 10 years.

Patient Involvement

Patient input is important to ensure that the research captures patient experiences. A patient representative and director for the charity *brainstrust* (brain tumour specific, UK-based charity who provide advice and support to patients and carers) was involved in the research. The patient representative helped me to shape the project in the early stages. As someone that has been involved in research, they offered methodology advice and agreed that GT was the most appropriate qualitative approach. They also agreed on the importance of the area of research. They also reviewed my PIS and consent form to ensure the language used was lay friendly and acceptable.

Impact of COVID-19 on Research Procedures

The planning of the study and subsequent collection of data took part during the COVID-19 pandemic. Due to this, I planned procedures so that all recruitment and data collection could be carried out remotely, adhering to any COVID-19 restrictions. Due to the impact of cancer treatments on the immune system, people with cancer are at a higher risk of COVID-19 illness complications. As a result, following remote procedures was important for participant safety. Procedures followed included:

- Clinicians from the LTHT and KCH neuro-oncology teams identified most patients in clinic. In the later stages of the study, I was able to attend a clinic for recruitment. At this time, COVID-19 restrictions had been eased; I had been fully vaccinated and was wearing the appropriate personal protective equipment.
- I carried out all interviews remotely, either via phone or via Microsoft Teams depending on participants preference.

Recruitment

Inclusion and Exclusion Criteria

Inclusion Criteria

- Adults (>18 years of age)
- Diagnosis of a high-grade PMBT defined as, ‘any primary intracranial mass classified as malignant or considered by the neuro-oncologist to be progressive over time’. The research was limited to high grade PMBTs due to researcher capacity. High grade PMBTs were chosen over low-grade PMBTS due to them being more common and having a more uniform treatment and follow-up pathway.
- In the process of having interval scans, defined as ‘MRI scans at set intervals to monitor progression, following the completion of initial treatment’.
- Able and willing to provide informed consent
- Able to read and understand English. This was decided due to the amount of additional resource required to include participants that could not read and understand English.

Exclusion Criteria

Anyone with cognitive deficits of a severity that would preclude successful completion of study consent or procedures. This was determined by the treating doctor.

Sampling

Formal sample size calculations were not possible due to the descriptive and qualitative nature of the study. There is disagreement among grounded theorists about the amount of data required and, as a result, the number of participants needed (Charmaz, 2014). Some argue that in a homogeneous group, 12 participants should be enough to generate categories based on common experiences and viewpoints (Guest et al. 2006). Others discuss the need to gather enough data to go beyond identifying categories, and instead focus on having enough data to construct theory (Corbin & Strauss, 2008). According to Charmaz (2014), the number of participants is determined by the research's purpose and the level of analysis required. They state, for example, that when the topics are controversial or the analyses are complex, a larger number of participants may be required. I aimed to recruit between 10 and 15 participants, due to only focusing on individuals living with high grade PMBTs, and because their treatment and follow-up pathway is quite uniform. I started by collecting data using purposeful sampling. Purposeful sampling is a qualitative research technique that involves selecting information rich cases, which means selecting people who have a lot of knowledge or experience about the topic of interest (Palinkas et al., 2015). I then used theoretical sampling as the research progressed and gaps were identified.

Theoretical Sampling

Theoretical sampling is a core strategy in GT. It involves gathering data to further develop categories, or relationships between categories, through constant comparative analysis (Willig, 2013; Birk & Mills, 2015). It involves the researcher deciding who or what will provide the most information rich data to meet analytic requirements (Birks & Mills, 2015). After the initial categories have been formed, Charmaz (2014) discusses how theoretical sampling can be used to develop some of the initial categories. During the data collection and coding stages I identified some gaps in terms of my participant sample. The understanding of certain participant experiences was important to develop my emerging categories. Therefore, the following decisions were made:

- During some of the early interviews, participants made comparisons to others, stating that it might be more difficult to cope without others to talk to and support them. For example, one participant stated: *“I think it would be different if you didn’t have anyone else to talk to”.* Therefore, I ensured that I interviewed some individuals that lived alone and did not have support of their family members
- Some participants discussed how they coped well with scans due to being retired. For example, one participant stated: “*because we are both retired, these repeat MRIs are not as hard on us because we don’t have work limitations”.* Due to this, I interviewed some younger people that were still employed.
- The idea of scans becoming ‘normal’ and ‘getting used to scans’ was an emerging category, but the participants that I had interviewed in the early stages had already experienced a few years of scans. I tried asking them about their earlier experiences, but some found it difficult to reflect on these. As a result, I made sure that some of the participants were new

to interval scanning, with experience of having only one or two scans. This aided in the development of an emerging subcategory.

- My first eight participants all had a diagnosis of GBM. I wanted to make sure that I captured the experiences of people with high grade PMBT not just GBM, therefore I asked the team to focus on identifying some patients with a grade 3 diagnosis.

Theoretical Saturation

Data is collected until theoretical categories are 'saturated,' meaning that gathering data no longer generates new theoretical insights or properties of theoretical categories (Charmaz, 2014). In GT research we are not seeking ‘generalisability’ or ‘representativeness’, therefore the sample is seen as sufficient based on theoretical saturation rather than the size of the sample itself (Bowen, 2008). There are questions around whether saturation can ever truly be reached and Dey (1999) suggests the term ‘theoretical sufficiency’ rather than ‘saturation’. According to Willig (2013), theoretical saturation is more of an aim than a reality, in that, while we strive for saturation, it is always subject to change due to shifting views and category alterations. I continued interviewing and re-visiting transcripts until no new insights or properties emerged in this study. This was reached after interviewing 12 participants.

Recruitment Method

Participants were recruited from neuro-oncology follow-up clinics at two different sites: LTHT and KCH. Patients and clinicians meet in person or over the phone during their clinic appointments to discuss scan results and treatment. Prior to the clinics, professionals involved in their care identified eligible patients (e.g., treating consultant, clinical nurse specialist). It was essential that these professionals were involved, so that they could determine whether patients met the inclusion criteria. The number of patients identified from each clinic varied depending on eligibility, but also depending on the result of their scan. Professionals briefly introduced the study to eligible patients during their follow-up appointment and asked for their verbal consent to speak with me directly about the research. Once the patient gave verbal consent, I either met with them in person in the clinic (in the later stages of the research) or the professional would send me the patient's name and contact information via secure NHS email. I then contacted the patients, followed the consent procedures outlined in the 'informed consent' section, and scheduled the interview based on the preferences of the participant.

Data Collection

A total of 16 patients were identified as eligible and expressed an interest to take part in the research. In total, 12 of these patients agreed to participate. Interviews took place across an eight-month period, from July 2021 until February 2022. Willig (2013) discusses two different types of GT: the full version and an abbreviated version. In the full version of GT, the researcher alternates between data collection and analysis. Some data is obtained, analysed using initial coding, and initial links are created before the researcher collects more data to gradually inform theory development and achieve theoretical saturation (Willig, 2013). In the abbreviated version, the researcher works solely with the original data, which is then analysed using GT principles (Willig, 2013). I interviewed participants in groups of two or three at a time, analysed their data and then moved on to the next few interviews. The pacing of interviews depended on how many participants were recruited from each clinic. I tried to interview participants as soon as possible after their clinic appointment so that they could reflect on a recent scan and because of the potential progression of PMBT which may have impacted on their ability to consent and participate. Although this means that I did not adhere to the full version of GT, the research was not an abbreviated form of GT because I was able to collect and analyse some data simultaneously, which influenced theoretical sampling.

Semi-structured Interviews

Semi-structured interviews are a popular data collection approach in qualitative psychological research (Willig, 2013). Because the main topics for discussion are determined prior to the interview, semi-structured interviews allow for some focus and consistency (Corbin & Strauss, 2015). Semi-structured interviews also include flexible, open-ended, and in-depth questions that allows the researcher to investigate participant experiences, making them a useful technique in GT research (Charmaz, 2014). The participant-interviewer relationship is seen as important in constructivist approaches because the interview is a shared experience (Charmaz, 2014). Adams (2015) emphasises the importance of establishing rapport during the interview by beginning with simple 'ice breaker' questions before moving on to more directly relevant and difficult questions. Charmaz (2014) offers some suggestions for how interviews may change over time. They discuss how asking only a few questions at the start of an interview can allow the participant to share their story without being too directive or restrictive. To aid theory development, the interviewer may need to ask more directive 'how' and 'why' questions as they begin to make comparisons between the data and analysis.

Interview Procedure

Interviews were guided by a semi-structured interview guide (see Appendix E for a copy of the interview guide). The interview was designed in a way to build rapport. I aimed for interviews to be conversational and tried to help participants feel as relaxed as possible, whilst also making them feel listened to throughout the conversation. There were some 'ice breaker' questions at the start, as suggested by Adams (2015), to allow participants to share something about themselves and their story. The interview guide was designed with a few main questions to focus on specific topics, but it also allowed for flexibility and a space for participants to freely discuss their experiences. The guide was developed to address the research question, aims, and it was based on current research. In keeping with GT, the interviews progressed over time, with more 'what' and 'how' questions being asked in later interviews, for example, in addition to asking *"how have interval scans been beneficial to you?"* I also asked, *"what does the scan give you or provide you with?".* Because some of the participants had cognitive difficulties, I made sure that the questions were simple, that I explained questions when they were uncertain, and that I included several follow-up questions in case they needed more direction. Because the questions were sensitive, I made sure to check in with participants throughout the interview, giving them an opportunity to ask questions and share any additional information or feedback at the end.

Participants took part in one semi-structured interview. As discussed, all interviews were conducted remotely dependent on participant preferences. Two participants chose to participate via Microsoft Teams and the remaining 10 interviews took place via telephone. Interviews lasted between 30 and 75 minutes (with an average of 50 minutes). Participants were encouraged to interview alone so that they could freely discuss their views. However, participants were given the option of having a family member or carer present during the interview if they preferred. Two participants with one with moderate memory problems and one with moderate language problems chose to have their partner present during their interviews. Partners were told that they could assist the participant with answering questions, but that their views would not be included in the research. I audio recorded all the interviews using a dictaphone, following which they were transcribed verbatim. I transcribed two of the twelve interviews I conducted, while the others were transcribed by a professional transcriber. After receiving transcripts from the professional transcriber, I confirmed the accuracy of the transcripts against the original recording. I wrote memos after each interview, reflecting on how I thought the interview went, my interactions and relationship with the participant, and anything I wanted to modify before the next interview.

Data Analysis

I conducted data analysis using the GT methods outlined by Charmaz (2014). The first step in data analysis is coding, which Charmaz (2014) defines as the link between the data collected and the emerging theory that explains the data. Coding involves defining what is happening in the data and providing an understanding as to what it might mean. Coding is split into three main stages:

initial coding, focused coding and theoretical coding. These steps are revisited throughout the analysis as new data is gathered.

Initial Coding

Initial coding involves naming words, lines, or data segments. According to Charmaz (2014), during initial coding, we should stay as close to the data as possible. This allows us to explore links and processes from within the data, rather than trying to apply any pre-existing frameworks. Charmaz (2014) suggests coding data with 'gerunds,' these are words used to describe actions and can help us to focus on the data rather than forming assumptions. Initial codes are provisional and are open to change to best fit with the data we have. Initial coding can also help us identify any gaps in our data, which can be used to shape future data collection. I listened back to recordings and read the transcripts before working through transcripts line-by-line, labelling certain words or phrases with initial codes and trying to reflect actions where possible. During this stage I kept memos of anything of significance or any links and relationships that were emerging. An example transcription extract with initial codes can be found in Table 1. Appendix F contains another example of initial coding.

Table 1

Example transcription extract with initial and focused codes

Extract from transcript	***Initial coding***	***Focused coding***
Sophie: "*Every negative thought will be in my head so um... I'm not over superstitious, no more, no more than anybody else but it's like if I see a black cat, oh my god! That's bad luck. You know, I try mentally, try to push those thoughts away because, and every reasonable person will be the same, like, I don't know the result until I know the result so stop trying to guess it. Stop trying to guess it! But I find that really difficult. The longer away the results appointment is the worse it is. You know I'll get up one morning, usually when I get up in a morning, I'm a little bit blurry. It takes me a little while to um, sort of get with it during the day. Um, but then the next morning after the scan I'll get up I'll be a bit blurry and think 'Oh my god. The-the tumour must be growing. That's why I'm feeling like this or if I get a little twinge in my head or anything, anything is like negative.*" .	Waiting for results is difficult Experiencing negative thoughts Not usually superstitious Changing beliefs Trying to push thoughts away Normalising coping Can't guess the result Trying to stop herself guessing Avoiding is difficult Longer wait = worse Usually 'blurry' on a morning Takes time to get going After the scan thinking that what is normal might be a symptom/sign of recurrence	Waiting for results is a difficult time Increasing anxiety Avoiding thoughts Forecasting results Hypervigilance

Focused Coding

Focused coding, according to Charmaz (2014), involves comparing initial codes, identifying the most significant or frequent initial codes, and applying these to large amounts of data. Focused codes capture the initial codes that make the most sense analytically. Following the initial coding, I went over the transcripts again and started the process of focused coding. This process involved refining the initial codes and taking them to a more analytic level by 'coding the codes', which entailed thinking about questions such as 'what larger analytic story do these codes suggest?' and 'what processes do these codes indicate?' I also went back over memos to look for relationships between initial codes. Some examples of focused coding are shown in Table 1 and further examples of focused coding can be seen in Appendix F. In keeping with constant comparative analysis, I compared focused codes across interviews to see if there were any similarities or differences. To do this, I kept an excel document with the focused codes from each participant's interview, as well as memos about coding decisions. Appendix G contains an example of my focused coding table. Focused codes were added to the excel document each time an interview was conducted and analysed, and over time, I began to form initial ideas for categories and subcategories. When I noticed any similarities or differences, I added them to a separate table of core categories and processes, which allowed me to group codes together and refine the properties of subcategories and core categories over time. Examples of focused codes, subcategories, and core categories can be found in Table 2. After revisiting the data several times, a total of six core categories and 20 subcategories were generated. Appendix H contains a table of focused codes, categories, and processes.

Table 2

Examples of focused codes, subcategories and core categories

Focused codes	Subcategories	Core categories
Going along with it	Doing what it takes	Living with a PMBT: surviving
Using beach imagery during MRI scan	Passing the time	The MRI scan: managing anxieties and accepting the discomfort
Getting used to scans over time	Changes over time	The interval scan process: varying levels of anxiety
Avoidance of thoughts	Avoidance & distraction	Waiting for the results: getting through the difficult times
Good news = relief	Good news provides short term relief	The results: short-term relief vs ongoing anxiety
Scans provide reassurance	Reducing uncertainty	Interval scans: provide a safety net

Theoretical Coding

The aim of theoretical coding is to define the relationships between categories so that a theory can be developed to explain them (Birk & Mills, 2015). According to Charmaz (2014), theoretical codes are only useful when they are applied correctly; when they are applied incorrectly, such as through the use of a forced framework, they can cause wider processes to be missed. According to Charmaz (2014), for most projects, initial and focused coding is sufficient. At this advanced stage of coding, I used models, revisited memos, and reviewed previous literature to find patterns and relationships between the emerging categories. This was not a linear process, and each time I revisited the data I adapted and changed codes and categories to ensure that I did not miss any larger processes, and to ensure they captured a complete explanation of participant experiences. I added information about relationships and theoretical codes to the table of focused codes, categories and processes (see Appendix H). I also illustrate theoretical coding using a GT model which is presented in the results section alongside a description.

Memo Writing

According to Charmaz (2014), memo writing is important for developing ideas, fine-tuning data collection, and engaging in critical reflexivity. Memo writing is a core strategy in GT because it encourages us to examine our data and codes early in the research process. Memos are written notes of the researcher's thinking processes as they progress through the research, and they are created from the beginning (Birks & Mills, 2015). Memos can also assist researchers in identifying gaps, questions, and times when theoretical sampling is required. I engaged in memo writing throughout the research process. I kept memos about the interviews, coding decisions and broader thinking about the relationships of categories. Memos allowed me to reflect on my own feelings, thoughts, ideas, and insights, as well as and how these related to the process. Figure 1 shows an example of a memo I wrote during the early stages of coding. Appendix I contains additional memos related to model development.

Figure 1

Example of a written memo

Memo date: 04.12.21- focused coding David 'bad news'

"Um, I, I'd prefer to have more to be quite honest, but yeah, I, I, I, anticipate scans and I like, you know it's nice to know what's going on, basically, because you can't see anything. It's not like an injury or a condition where you can actually see something getting better or worse… you've no idea what's going on in there, and by the time you get some symptoms, or you get some change it could, there could've been a huge amount happening in your head that's irreversible, so yeah, I would definitely want to keep track of things."

David has had scans every 3 months but would prefer to have them more often if he could. He would prefer to know what is going on inside his head because he is unable to see what is happening. He talks about the difference between his brain tumour and other injuries or conditions that are visible. The idea that a 'huge' amount of change can happen before getting symptoms reflects the uncertainty of the disease, especially for him due to experiencing few symptoms prior to diagnosis. He seems to be worried that, without scans, change would be missed. He talks about too much change being 'irreversible' which may mean that treatment is not an option, or he may be relating this to physical damage to the brain (causing more symptoms). The interval scans seem to provide him with some answers and therefore reduce his uncertainty. Links with participants 1-6: all similar in that they would choose to have interval scans, many of them also discussed a lack of symptoms/non-specific symptoms prior to diagnosis and worries that without scans it might be 'too late' and progression might be missed. Although David received good news recently, he is the only participant so far that has received bad news and felt able to discuss it (Julie also had experience of bad news but did not discuss). For David, having interval scans had showed progression and lead to a change in treatment, which was followed by more positive results.

Note for future interviews- Look out for further examples of 'bad news' and try to explore this in relation to interval scans. Possible link between interval scanning and coping? Try to explore this further.

Diagrams and Modelling

In addition to verbal explanations, diagrams and models can provide concrete representations of our concepts as well as a visual representation of categories and their relationships (Charmaz, 2014; Birks & Mills, 2015). I used modelling to help shape my analysis, organise my categories, and make links between the core categories, in addition to tables and memos. Based on my reflections and discussions with my supervisors, I revised models over time to reflect evolving categories and processes until I arrived at a model that I felt provided the clearest visual representation of the emergent theory. Appendix I contains some examples of GT model development. In the results section, I present the final GT model as well as additional diagrams relating to core categories.

Quality Control

In GT studies, Charmaz (2006, 2014) proposes four main quality criteria: credibility, originality, resonance, and usefulness. To ensure quality in constructivist GT research, Charmaz and Thornberg (2021) provide an extended checklist. The methods I used to ensure quality in this GT study, as well as some additional qualitative quality procedures recommended by Elliott et al. (1999), will be discussed.

Methodological Self-Consciousness

To be methodologically self-conscious, the researcher needs to include details as to the reasons behind the chosen topic, methods, and methodology (Charmaz & Thornberg, 2021). I have discussed my philosophical position and how this guided the research process. Throughout the research planning, data collection, and analysis stages, I also kept memos detailing decisions made. At the end of this section, I provide a reflexive statement.

Originality

It is important that the researcher reviews the literature to establish a rationale for the study, to avoid repeating research and to increase their theoretical sensitivity. Research should be original in that it offers new insights or revises established ideas (Charmaz 2006, 2014). In the ‘introduction’ section of this thesis, I provide a detailed literature review in which I review and critique previous research relevant to the research question and aims. The study's rationale, as well as details about its originality, are also discussed in the ‘introduction’ section. Whilst writing up this research, I went back over the literature again, which gave me some new insights and increased my theoretical sensitivity. Theoretical sensitivity is “the ability to understand and define phenomena in abstract terms and demonstrate abstract relationships between studied phenomena” (Charmaz, 2014, p. 161).

Credibility

Charmaz (2006, 2014) discussed how having enough relevant data increases the credibility of the research. Relevant data includes rich data gathered by listening to the stories of people experiencing the phenomena of interest. Depending on the research question, what constitutes “enough” data changes. There needs to be enough data to draw relevant comparisons, analyse and construct categories, and convince readers of the importance of categories. This is achieved through theoretical sampling, and by aiming to reach theoretical saturation. These processes were described earlier in this section, under the heading ‘sampling’.

According to Elliott et al. (1999), there are a number of other ways in which researchers can ensure credibility in qualitative research. One way is by checking the quality of transcriptions. Following transcription, I listened to the audio recording of my interviews to ensure the transcriptions were accurate. This also gave me an opportunity to write down any further notes of reflections on the interview, as well as immersing myself in the data. Grounded theory researchers’ level of theoretical sensitivity increases as they become more immersed in their data (Birks & Mills, 2015). My research transcripts, coding, and categories were also shared with my supervisors via the secure UoL OneDrive. Elliott et al. (1999) also mentions a ‘verification’ step for researchers, in which they review their data for discrepancies and overstatements. This is something I carried out after the analysis and during the write up of the research.

Use of Constant Comparative Analysis

This is where the researcher goes back and forth between the data, comparing codes and emerging categories whilst also collecting data, allowing variation to be captured within emerging theory (Willig, 2013). This is a core GT procedure for ensuring that analytic categories are saturated (Charmaz & Thornberg, 2021). I treated my codes as provisional, asked questions about my data throughout the collection and analysis process, and made changes as new information became available.

Supervision

I was supervised by four members of the research team. All supervisors were experienced researchers; one was familiar with GT, and other supervisors were clinicians or researchers within the clinical area of the research. To ensure quality, each supervisor brought their expertise in various areas of the research. Throughout the research process, supervision took place on a monthly basis. Most supervision sessions were held online via Microsoft Teams due to the COVID-19 pandemic. In the analysis stages, I shared transcripts and files regarding my coding, categories and models prior to supervision. These were then discussed and refined during the session. We discussed any gaps in the analysis and considered how to collect the information needed to achieve theoretical saturation in accordance with theoretical sampling. I kept minutes from supervision sessions, these were shared with and reviewed by my supervisors following the session. I also used supervision to reflect on my experience of the research process and interviews, adding to the process of reflexivity.

Reflexivity

Reflexivity means to ‘recognise and take responsibility for one’s own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation’ (Berger, 2015, p. 220). It is important in ensuring credibility in research. By considering our assumptions, experience and how they influence our actions as researchers, our research becomes more credible (Charmaz, 2006, 2014; Charmaz & Thornberg, 2021). Personal characteristics and professional status, as well as any differences between the researcher and participants, should be discussed (Mays & Pope, 2000). It’s also important to consider the research’s impact on the researcher (Gentles et al., 2014). Based on the memos I’ve written throughout the research; I will now provide a reflexive statement:

I am a 32-year-old, white, British female from the Northwest of England. I am training to be a Clinical Psychologist at the UoL. Prior to training I had been working as an Assistant Psychologist in NHS memory assessment services. Therefore, I have worked with people who have a variety of cognitive and neurological difficulties. Because neuropsychology is my main area of clinical interest, I was initially drawn to a project in this area. The field of neuro-oncology interested me because it allowed me to learn about individuals with a condition that I was unfamiliar with. The idea for the topic of the research came from a discussion with a professional working within the neuro-oncology speciality. I was surprised by the lack of evidence regarding interval scanning, especially in understanding the impact on patients living with such a complex and uncertain disease. This is where my interest in the subject began. Understanding the perspectives of people going through a difficult time has always been important to me. I had previously conducted small-scale qualitative research studies using thematic analysis, but GT was a completely new methodology for me. GT fits my ontological and epistemological positions, as I’ve already stated in this section. During research planning and data collection, my experience of working with people with a variety of cognitive difficulties proved useful. I made sure that the information given to patients was simple and easy to understand, and I rephrased questions as needed, gave participants time to process information, and checked understanding during interviews. This provided a space for those with more moderate cognitive difficulties, who are often excluded from research, to share their stories and experiences.

Although I believe that my prior experience was beneficial most of the time, it did contribute to some difficulties. As a Trainee Clinical Psychologist, I provide psychological therapy to patients. During therapy, I reflect, summarise, make links, and ask questions. This was something I was perhaps too aware of during my first few interviews, which led me to refrain from asking more in-depth questions, allowing the participant to take control in some cases. After some thought, I realised this and made a conscious effort to change my approach during subsequent interviews. Keeping the power dynamic in mind, I kept the discussion flexible, gave participants a chance to tell their stories, and kept the interview as conversational as possible. However, I made sure to follow up on anything that of interest, such as asking, “Tell me more about that,” or revisiting interesting points that participants seemed to skip over. As a result, the data was much richer and more in-depth, and specific to the topic area.

In terms of differences between myself and the participants, I had never had an MRI scan before and therefore had no previous experiences to draw on. This, I believe, was beneficial because it allowed me to fully explore participant experiences without preconceived opinions. I asked the participants to help me visualise their scanning experience by giving me a detailed description of what it was like. But I was also aware that this revealed a difference between myself and the participants. I have never had an MRI scan and am I not living with a life-threatening condition, so I could not really draw on or relate to personal experiences in these parts of the conversation. Despite these differences, I was able to establish rapport with participants. Starting with simpler questions and gradually progressing to more difficult questions, as Adams (2015) recommends, may have aided this. Despite our differences, the COVID-19 pandemic was a shared experience that we often talked about during the initial stages of the interview.

Although I have no family history of PMBT, I have recent experience of family members being diagnosed with cancer and losing their lives. As a result, during supervision, my own well-being and ability to conduct interviews with people who have been diagnosed with a terminal illness were discussed at length. Despite the emotional challenges, I felt as though this research became even more important to me. I wanted to be able to hear individuals’ stories, make sense of their experiences and contribute to clinical practice and future research within this field. Interviews elicited strong reactions at times, which was unsurprising. I made sure to reflect on any reactions I had after interviews and that I had access to additional supervision if I needed it. I believe that having strong reactions strengthened my determination to ensure that participants’ experiences were shared in a meaningful and useful way.

I questioned if interviewing and recruiting people over the phone, rather than in person, created some emotional distance between myself and the participants. I went to St James’ Hospital in Leeds to recruit my final two participants. This was my first time meeting the neuro-oncology team and being in a medical setting while conducting this research. I met with my final participants in person before conducting phone interviews with them. These interviews were more emotionally difficult for me than previous interviews in which I had not met the participants in person. It made me think about different data collection methods and how they might impact research in terms of researcher-participant interaction. While phone interviews reduce nonverbal cues, they may also minimise ‘differences,’ resulting in a more balanced power dynamic and the sharing of more sensitive information (Azad et al., 2021). When writing memos, I asked myself questions such as, had noticing those differences made these interviews more difficult for me as a researcher? And how did this impact our interviews? However, after listening to the interview recording and reflecting on this, I did not feel that my emotional reaction had a significant impact.

In terms of the analysis, I found that choosing constructivist GT based on my philosophical position meant that it fit well with me in terms of my preferences for research. I found that having a structure to follow in terms of the core GT strategies and sticking to one approach was beneficial. However, as a new GT researcher, I found that Charmaz (2014)’s approach lacked some of the structure that other GT approaches, such as Corbin and Strauss (2015), provide. Charmaz (2014), for example, does not provide specific guidelines for conducting ‘theoretical coding,’ so I had to rely on supervisors and additional reading to gain a better understanding of the process and make my own decisions about how to proceed with this stage. I also discovered that I needed to take a step back to avoid creating ‘themes,’ as I had in previous thematic analysis research. Following some initial analysis, I discovered that trying to develop a theory narrowed my perspectives to the point where I was attempting to fit experiences into a model rather than allowing the theory to emerge from the data. Charmaz discussed this as one of the problems with theoretical coding (2014). However, once I realised this, I went back over the data and categories, making sure I looked for emerging processes that captured the broader experiences of the participants. As a result, two new core categories were created, as well as changes to the GT model. One of my original models, memos written after revisiting my analysis, and the first illustration of the new model that preceded the one presented in the results can all be found in Appendix I. Following Charmaz’s (2014) advice on keeping memos, conducting constant comparative analysis, and remaining open and flexible in the light of new information helped me think more process-driven and theoretically. I believe that the research has aided my personal and professional development by providing me with the opportunity to hear participant stories, learn about the topic area, and gain a better understanding and experience of GT.

RESULTS

In this section I start with a summary of participant information and pen portraits. Pen portraits provide a description of the participants, relevant background information, information about their diagnosis, treatments, and interval scans, as well as my reflections on their interviews. The GT model will then be presented alongside a description discussing the relationships between the core categories. Then, I will discuss each of the core categories and associated subcategories in more detail alongside diagrams and illustrative quotes.

Participants

Sixteen patients were identified as eligible for the study, and a total of twelve participants agreed to participate. Ten participants had a diagnosis of GBM (grade 4), one had a diagnosis of ependymoma (grade 3), and one was diagnosed with a solitary fibrous tumour of the dura (grade 3). Five participants were under the care of the neuro-oncology team at LTHT and seven were under the care of the neuro-oncology team at KCH. Participants were aged between 40 and 75 (median age of 54 years). Seven female and five male participants took part in the research. Their time since diagnosis ranged from less than one year to 10 years. Eight GBM patients had received the standard treatment for this type of tumour, which included surgical resection, RT with concurrent TMZ chemotherapy, followed by maintenance TMZ. Two of these participants had also received additional treatments, these included treatments related to research trials and private treatments. Two participants with GBM had inoperable tumours so only underwent RT with concurrent TMZ, followed by maintenance TMZ. The two participants with grade three tumours underwent surgical resection and RT. Nine participants were having MRI scans at three-month intervals, two were on three-to-four-month intervals, and one was having interval scans every six months. Ten interviews took place via phone, and two took place via Microsoft Teams. Table 3 provides a summary of participant information including their age group, gender, information about their diagnosis, treatments, approximate number of years since diagnosis, MRI scan intervals and the site they were receiving treatment at. Due to some participants having rare types of tumours, I used age groups to reduce the possibility of identification. The four patients that did not participate in the research included two patients that I was unable to contact on the day of the interview, one patient who decided they did not want to participate, and one patient who was feeling unwell on the day of the interview.

Table 3

Summary of Participant Information

Participant	Age group	Gender	Diagnosis (grade)	Treatments	Approximate years since diagnosis	Current scan interval (months)	Site
Anne	70-75	Female	GBM (4)	Standard	10	3	KCH
Julie	70-75	Female	GBM (4)	Standard plus additional	5	3-4	KCH
Ben	50-55	Male	GBM (4)	Standard plus additional	7	3	KCH
Sophie	50-55	Female	GBM (4)	TMZ & RT	4	3	KCH
James	50-55	Male	GBM (4)	Standard	<1	3	LTHT
John	70-75	Male	GBM (4)	Standard	2	3	KCH
David	40-45	Male	GBM (4)	TMZ & RT	1	3	LTHT
Hannah	40-45	Female	GBM (4)	Standard	1	3	LTHT
Emma	45-50	Female	Solitary fibrous tumour of the dura (3)	Resection & RT	6	6	KCH
Adam	50-55	Male	Ependymoma (3)	Resection & RT	8	3-4	KCH
Jane	55-60	Female	GBM (4)	Standard	<1	3	LTHT
Amy	40-45	Female	GBM (4)	Standard	<1	3	LTHT

Note. Standard treatment for glioblastoma (GBM) includes surgical resection, radiotherapy (RT) plus concurrent temozolomide (TMZ) chemotherapy, followed by maintenance TMZ. Additional treatments include research trial related treatments and private treatments. Sites include Kings College Hospital NHS Foundation Trust (KCH) and Leeds Teaching Hospitals NHS Trust (LTHT).

Pen Portraits

Anne

Anne lived with her husband and had three adult children. Anne had moved to the UK three years ago and had retired from work. She was diagnosed with GBM around 10 years before our interview. She was diagnosed after experiencing a seizure and being taken into hospital. She said that she did not experience any symptoms prior to the seizure. She followed the standard pathway of treatment for GBM. Since finishing treatment her MRI scan intervals had varied between three and six months. At the time of the interview, Anne was having interval scans every three months due to some undetermined results. I interviewed Anne via Microsoft Teams. She was supported by her husband during her interview due to her experiencing aphasia. At the start of the interview, Anne informed me that she was feeling a bit anxious, and that this could make her speech more difficult. I noticed that she did struggle at the beginning of the interview, perseverating on timeframes and struggling to express herself, but over time her ability to express herself improved. Although her speech improved it was clear that she experienced some discomfort during the interview, often laughing when discussing serious matters such as her life expectancy. Anne had undergone many MRI scans over the years and was able to share some her experiences with me. Her cognitive difficulties did limit her ability to answer more in-depth questions and reflect on some of her experiences, however she was able to share her worries about the future, including worries about how her husband might cope. Her husband reflected that it was the first time she had ever mentioned this.

Julie

Julie lived with her husband and had one adult child. She had retired from her work prior to her diagnosis. Julie was diagnosed with GBM around five years prior to our interview. She said that she had been feeling unwell at the time but that she had attributed this to stress. She was taken to A&E by her husband due to them suspecting that she might have had a stroke. Julie mentioned that she did not remember being informed of diagnosis until she woke up from surgery and was told that the tumours had been removed. She continued on the standard treatment pathway for GBM, but this was stopped early, and she was offered palliative care. Instead, she sought private treatment and started a new medication. Following this, her scans started to show tumour reduction. Since then, she had been having interval scans every three to four months and was on a research trial for artificial intelligence MRI scans at the time of interview. I interviewed Julie via phone. She experienced difficulties with her short-term memory, therefore her husband remained present in the room with her during the interview. Julie's husband did not need to support her until it came to recalling dates and timeframes. Julie was keen to share her story with me and for me to understand how her past experiences had influenced how she coped. She talked in-depth about her son's medical issues and losing him to cancer. She wanted to share her 'strength' and used a lot of war related terminology during the interview, such as, "*grenades going off". At times it was difficult to focus on her scan experiences because it was clear that she wanted to keep the conversation as positive as possible. She also used a lot of humour during the conversation and often laughed when discussing serious topics, such as receiving bad news following one of her earlier scans. Her husband mentioned that she has always coped well but that she does have *"quiet times"* around her MRI scans.

Ben

Ben lived with his wife and continued to work part-time for his own business. He was diagnosed with GBM around seven years before our interview. He said that he was diagnosed after experiencing a seizure during the night and being taken to hospital. He had followed the standard treatment pathway for GBM, following which he went onto a treatment related research trial which required him to have interval scans every two months. Since finishing the trial his scans had increased to three monthly intervals. He mentioned that he had experienced some sinus problems and headaches prior to diagnosis, but that he had related these to stress. I interviewed Ben via phone. He was open to discussing his experiences but had little to say about the interval scan process, therefore, his interview was much shorter than the first two participants. He said that he had never experienced any anxiety about the MRI scan itself, and although he talked about some anxiety whilst waiting for results, he said that had only ever been given good news. He apologised a few times for not being "*helpful*" with my research due to his lack of worry about the MRI scans.

Sophie

Sophie was divorced, with four adult children and family members living nearby. She was diagnosed with GBM about four years prior to our interview and she had stopped working following her diagnosis. Sophie told me that she had experienced intermittent symptoms prior to diagnosis, which included problems with her balance and ears. She had spent a few months going to and from the GP's trying to resolve her problems, and at times, felt that she was not taken seriously. After seeking private care, having an MRI scan and biopsy, she was given the diagnosis. Her brain tumour was inoperable, but she had accessed RT and TMZ treatments. She had been on three-monthly scan intervals since ending treatment. I interviewed Sophie via phone. She talked about the impact of symptoms on her day-to-day life and how she was being supported by her family. Sophie understandably found talking about her experiences difficult, especially when discussing her diagnosis, fears of the future and the impact this might have on her family. She was very open to discussing her feelings. In terms of interval scans, she experienced high levels of anxiety throughout the process. She shared her pre-scan anxieties due to claustrophobia, how she is unable to cope with a 'tube' shaped MRI scanner, and how she needs to be booked onto a less restrictive MRI scanner to be able to cope. She also talked in depth about her experiences of anxiety whilst waiting for scan results. This was one of the more emotionally challenging interviews for me due to her distress and the depth of our conversation.

James

James was divorced and had no children. He usually lived alone but was being supported by his sister at the time of the interview. He had stopped working several years ago due to mental health difficulties. He had past experiences of cancer in his family, losing his mum to a brain tumour when he was young. James was diagnosed with GBM less than a year before the interview. He had been feeling a bit "*run down*" but had related this to the stress and anxiety of not seeing anyone during the COVID-19 lockdown. He had been feeling more seriously unwell one day, was taken to hospital for further investigation and at this point was diagnosed. He started on the standard treatment pathway for GBM and, at the time of the interview, had just started to have interval scans every three months. I interviewed James by phone. Out of all the participants, he was the earliest on in terms of having interval scans. He only had experience of one interval MRI scan and had not yet had the results of this. This limited the interview in that he could not comment on questions relating to results. He did, however, share his expectations, reflected on some scan experiences, and talked about why he saw interval scans as important. James experienced memory problems and had prepared himself for our interview the night before. He mentioned that he did feel a bit anxious but seemed very open to discussing his experiences.

John

John lived with his wife and had two adult children. He said that he had retired prior to his diagnosis but that he had always kept himself very busy and active. John was diagnosed with GBM about two years prior to our interview. Before his diagnosis he had noticed some difficulties with driving, balance problems and pain in his neck. After his diagnosis, he followed the standard treatment pathway for GBM. Since finishing treatment he had been having interval scans every three months. He talked about the "*collateral damage*" he has experienced in terms of the ongoing issues he has had following treatment, including pain, fatigue and hearing loss. I interviewed John via phone. He was keen to talk and share his experiences, having had little difficulty with the interval scan process. He told me that he was involved in a serious accident when he was younger and said that he had always felt "*lucky*" to have survived. He compared his current experiences to this, mentioning that he had been through "*worse things*" in the past. He kept the conversations as positive as possible in terms of his ability to cope, often comparing himself to others that *"can't cope"*. He praised the clinicians and hospital staff and talked about wanting to make their lives as easy as possible. He did not always answer my questions and sometimes seemed a bit confused, possibly due to cognitive difficulties and additional problems with hearing. His wife was present in the room whilst he was on the phone and spoke to me at the end of the interview. She mentioned that he gets confused at times.

David

David lived with his partner and continued to work self-employed. Around one year prior to our interview he had started experiencing problems sleeping, headaches and sickness. After visiting his GP and trying painkillers with no success, he was sent for further investigations and was diagnosed with GBM. His tumour was inoperable; however, he had RT and was still on chemotherapy treatment. He had been having interval scans every three months. Recently, tumour progression had been seen on imaging, so his chemotherapy treatment was altered. He experienced a lot of symptoms including problems with mobility, pain, fatigue, and his memory. David mentioned that he had always enjoyed physical activities but could no longer participate in these due to his symptoms. I interviewed David by phone. He was very open to discussing his experiences and reflected on the difficulties that he had faced. He talked about his past experiences, including the loss of his dad to cancer when he was around the same age as David was at the time of our interview. David was the first participant that discussed the impact of receiving bad news after an interval scan, sharing how much of a shock this had been. I found this interview more emotionally challenging, perhaps due to David's age, the impact the diagnosis is having on his life and due to him discussing his experience of bad news.

Hannah

Hannah lived with her husband and baby, and she continued to work part-time. Just over a year before our interview, following the birth of her baby and whilst still in hospital, she started to experience headaches. These were thought to be related to post-natal depression, but after being sent for a scan she found out that she had a brain tumour and was immediately sent for resection surgery. She was diagnosed with GBM and continued on the standard treatment pathway. She was having interval scans every three months. Hannah's interview took place via phone. She was open to discussing her experiences but sometime contradicted herself. For example, she said that she did not feel anxious around scans but then talked about feeling claustrophobic and shared her worries regarding recurrence prior to results. She seemed very hopeful and appeared to be doing whatever she could to manage and cope with her diagnosis (e.g., taking supplements, changing her diet, breathing exercises).

Emma

Emma lived alone and worked self-employed. She had some support from family members, although they did not live nearby. She also had a supportive friendship network. Around six years prior to our interview, she experienced a seizure whilst she was out with friends. Following this she was sent for further investigations and was diagnosed with an adenoma, a slow growing brain tumour. A few months after this diagnosis she started to feel unwell, and after further investigations and scans showing progression, her diagnosis was changed to solitary fibrous tumour of the dura, grade 3. She had a surgical resection, but her tumour returned within a month. She then had further surgery and RT. Emma was having MRI scans at six months intervals. She also had a full body PET scan once a year to see whether her tumour had metastasized. Emma's interview took place via phone. She was the first participant that I had interviewed with a grade 3 tumour, and although her interval scanning experiences were similar to those with GBM, she presented quite differently. Although there was still high uncertainty, there seemed to be less threat associated with her diagnosis. She did not experience difficulties with the MRI scan itself, but she openly discussed the anxieties she experienced whilst waiting for results.

Adam

Adam lived at home with his wife, had three adult children and continued to work a full-time job. Around eight years prior to interview a defect was found in his visual field during his routine eye test, this was followed by him experiencing confusion at work. He visited his GP and was given a diagnosis of early onset dementia. After experiencing further confusion, he was sent for more investigations and was diagnosed with a grade 2 ependymoma. After progression was seen on scans and he underwent surgical resection, the diagnosis was changed to grade 3. He has had two further resections, RT and was having three to four monthly interval scans at the time of our interview. Adam's interview took place via Microsoft Teams. Adam had a background in research and showed interest in the work that I was doing. He talked in depth about his diagnosis and scanning experience, including receiving bad news. He talked about his relief of not having early onset dementia, but also discussed the uncertainty of his diagnosis and lack of information about prognosis due to his tumour being rare. He talked about how his anxiety related to having a recurring brain tumour, rather than anxiety related to the MRI scans themselves.

Jane

Jane lived at home with her husband and had three adult children. She had recently finished working due to her diagnosis. Around one year prior to our interview she had experienced some episodes of changes to her speech and difficulties with movement in her hand. She thought her symptoms were related to stress and anxiety due to the COVID-19 pandemic. However, her symptoms worsened, and she went to A&E after suspecting that she might have had a stroke. After having a scan, she was told she had a tumour, and GBM was confirmed following surgical resection. Further treatments were delayed due to her being unwell and spending time in hospital. She had since had RT, was still being treated with TMZ and had started having interval scans every three months. Jane was one of the participants that I met in hospital during recruitment. I then interviewed her via phone. She was early in on in terms of interval scans, having only had her second scan just before our interview. She experienced some difficulties with her speech, although this did not seem to limit her ability to express herself and share her experiences during our interview. She was open to discussing her feelings, including initial anxiety around scans and anxiety after receiving undetermined results. She seemed more anxious than some of the other participants, perhaps due to being early on in her diagnosis and new to the process of interval scans. I found this interview more emotionally challenging, perhaps because I had met with Jane in person.

Amy

Amy lived with her husband and two young children. Less than a year before our interview, after having her second COVID vaccine, she started to experience head and neck aches, problems with vision, and had difficulties concentrating at work. She was given painkillers by her GP, but these did not help. She went into hospital for a scan and was told she had suspected GBM, this was later confirmed following surgery. She had followed the standard treatment pathway for GBM and had started having interval scans every three months. I met with Amy in person, in hospital, during recruitment. Her interview took place via phone. Amy was open to discussing her feelings but understandably found it difficult to talk about her experiences, sharing her fears about the future and worries about her family. She was another participant that was early on in terms of interval scans, but she was able to reflect on the few scans she had experienced. She seemed more anxious and less hopeful than most participants. She talked about understanding the reality of her diagnosis due to her background in healthcare. This was another interview that I found more emotionally challenging. On reflection, I thought that this might be because I met with Amy in person, she was diagnosed at a young age, and seemed less hopeful and more distressed than some of the other participants I had interviewed.

Qualitative Results

In Figure 2, I present the GT model alongside a written description which details the relationships between the six core categories. I then discuss each of the core categories (see Table 4 for a list of core categories) and nineteen subcategories. Diagrams illustrating the relationships between core categories and subcategories, information on the number of participants who contributed to each category, and illustrative quotes, will be used in the discussions. Figure 3 will show the level of focused coding for core category 1, but due to space limitations in this thesis, the other core category figures will only illustrate the core categories and related subcategories.

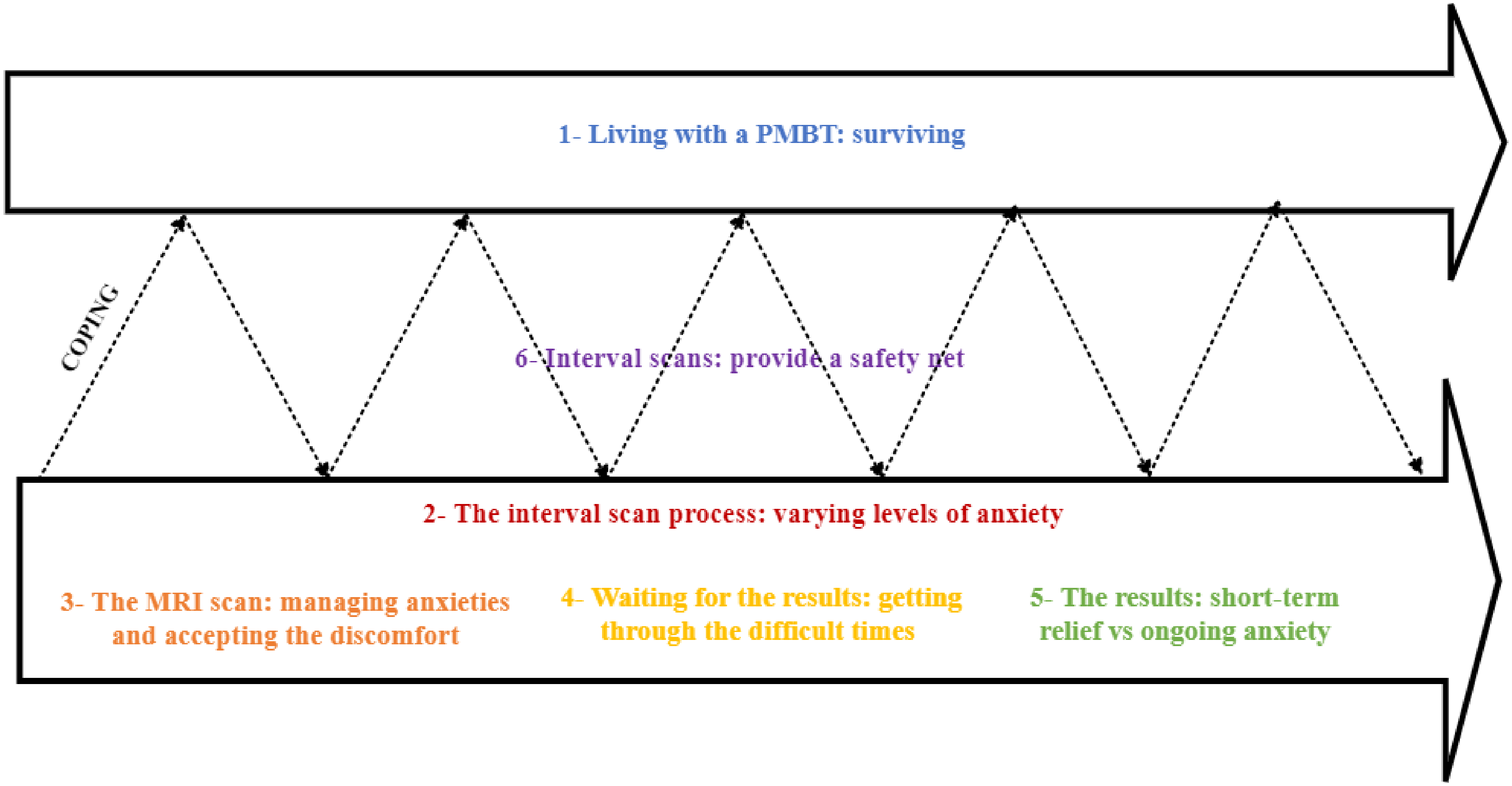
Table 4

Core Categories

Number	**Core category**
1	Living with a PMBT: surviving
2	The interval scan process: varying levels of anxiety
3	The MRI scan: managing anxieties and accepting the discomfort
4	Waiting for the results: getting through the difficult times
5	The results: short-term relief vs ongoing anxiety
6	Interval scans: provide a safety net

Figure 2

The Grounded Theory Model: Interval scans provide a ‘safety net’ for coping with living with a PMBT



Description of the Grounded Theory Model

Participants' experiences of being diagnosed with, and living with a PMBT, are captured in core category 1 'Living with a PMBT: surviving'. Participants discussed the uncertainty of living with a PMBT, shared their past experiences of illness and their access to support networks. Participants were also taking steps to manage their condition and ultimately survive; this is captured within the subcategory of ‘doing what it takes’. This subcategory relates directly to the interval scanning process because interval scans are recommended by professionals for monitoring disease progression and were viewed by the participants as something they ‘have to’ do. For the participants, having interval scans was seen as an essential part of living with a PMBT. The way participants coped with interval scans appeared to be influenced by their experiences of living with a PMBT, as well as other factors such as access to support from others and previous illness experiences.

Categories 2-5 all relate to the interval scanning process. Because interval scans are important for monitoring disease progression, all participants had developed strategies to cope with the process. Core category 2 ‘The interval scan process: varying levels of anxiety' describes how participants' anxiety levels varied throughout the interval scan process depending on a variety of factors. Only a small number of participants experienced anxiety relating to the MRI scan itself, and participants adapted to MRI scans over time. Most participants stated that they did not find the MRI scan difficult, but rather described them as being a 'discomfort'. Participants viewed interval scans as essential and therefore accepted the discomfort they experienced, found ways to ‘pass the time’ during the MRI scan and, if anxious, found ways to manage their anxieties. This is captured in core category 3, ‘The MRI scan: managing anxieties and accepting the discomfort’. Due to the uncertainty of living with a PMBT, nearly all participants found waiting for the results to be the most difficult part of the process. The coping mechanisms used by participants whilst waiting for their results are described in core category 4, 'Waiting for the results: getting through the difficult times.' Core category 5 ‘The results: short-term relief vs ongoing anxiety’ describes how interval scan results influenced how participants felt, with good news providing short-term relief and bad news or undetermined results causing ongoing anxiety.

Core category 6 ‘Interval scanning: provides a safety net’ relates core category 1 with core categories 2-5 by explaining why participants found interval scanning important and why they found ways to cope with the process despite it being difficult at times. Interval scans provided a ‘safety net’ because they helped reduce participants’ uncertainty and gave them some sense of control. Interval scans also provided participants with an ongoing connection to their medical team. Therefore, participants found ways to cope with the process of interval scanning because having scans at regular intervals helped them to cope with the uncertainty of living with a PMBT. This two-way coping process is illustrated in the GT model. I will now describe each of the core categories and related subcategories in more detail.

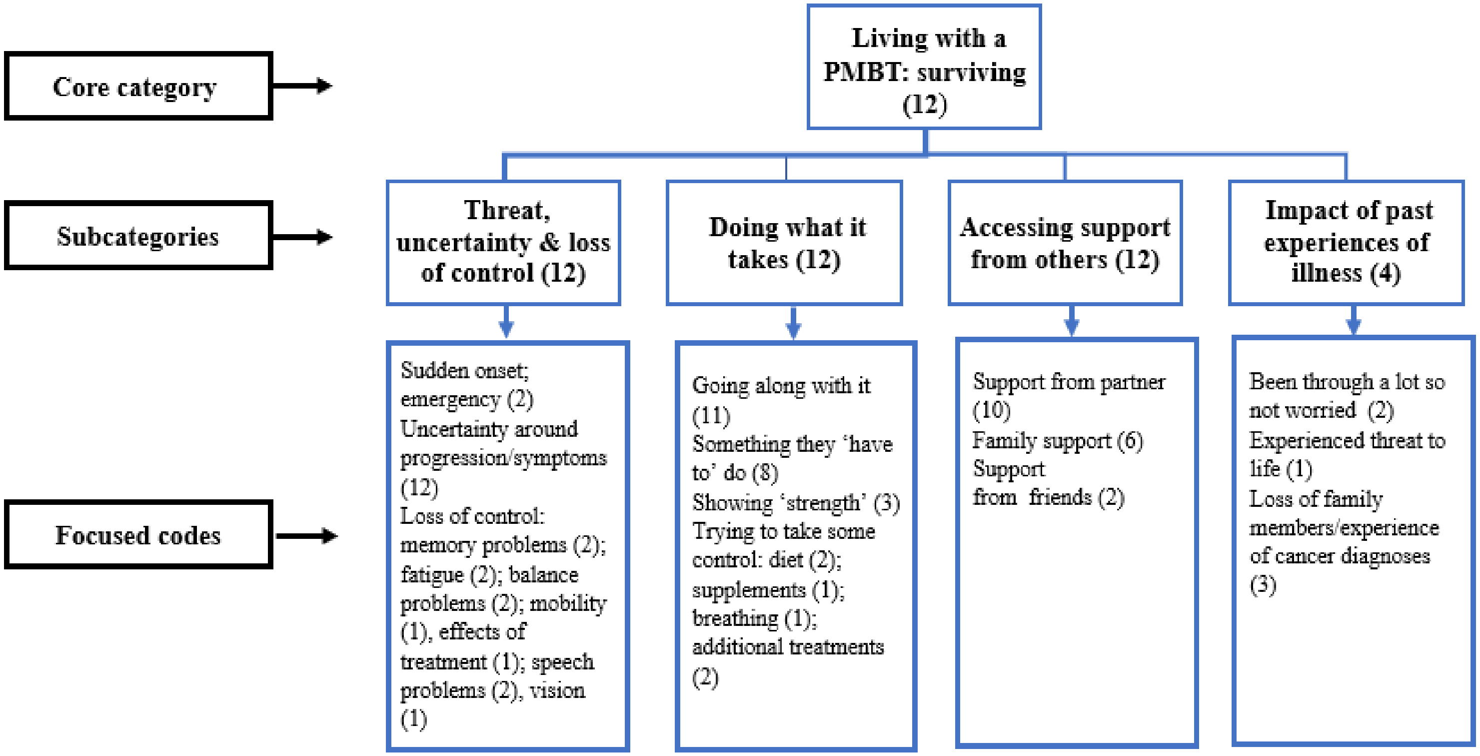
Core Category 1: 'Living with a PMBT: surviving'

Sources: 12

All participants shared their experiences of living with PMBTs. They were all suddenly confronted with a serious threat to their lives, as well as uncertainty around disease progression. This resulted in some loss of control over their lives due to their ongoing symptoms, the terminal nature of the disease and having to go through difficult treatments. They were all accessing support from others, as well as doing whatever it took for them to survive. There are four subcategories within this core category. Figure 3 shows the focused codes and subcategories related to core category 1. The number of sources is indicated by the numbers in brackets.

Figure 3

Core category 1: 'Living with a PMBT: surviving', related subcategories and focused codes



Subcategory 1a: 'Threat, uncertainty and loss of control'

Sources: 12

All participants shared their experience of their diagnosis. They were all faced with a sudden and serious threat to their lives. For many, based on their symptoms, there was a lot of uncertainty around their diagnosis. Eight participants talked about experiencing a few non-specific symptoms prior to diagnosis. Some of them had attributed these to other causes such as, stress, migraines or infections:

"I contacted the doctor and after a week they just said, oh, just take some paracetamol and try to rest… and then after two weeks I contacted them again and they said, well, look go into [hospital] it's probably nothing but just to check and then they did a CT and noticed a big shadow and then the MRI; it all kicked off from there basically." (David)

Some participants were diagnosed during the COVID-19 pandemic and thought that symptoms might be linked to the stress and anxiety of the situation:

"But at the time I'd been getting a bit forgetful, but I thought I were just rundown. Not many symptoms. I put it down to er, lockdown, you know with it being lockdown I couldn't get out y-y'know what I mean. I couldn't get out to see people I just put it down to part of me nerves and anxiety and all that, and stress really all of me other symptoms was basically a hangover." (James)

Three participants were diagnosed after having a seizure and being taken into hospital in an emergency. They described how they had no or few symptoms prior to their seizure:

"I was in a pub, and I suddenly sort of had a seizure, so, I was taken to A&E at [hospital] and obviously had to wait… and then I went in for a CT and they found a brain tumour so, obviously I was in huge shock because I hadn't displayed any, I wasn't symptomatic in any other way". (Emma)

Eleven participants described a loss of control over certain aspects of their life due to the physical, emotional, and neurocognitive effects of living with a PMBT and treatments:

"I can never remember... my short-term memory is in a petri dish if you want to go in and consult with that! Yes, yes, I do, even if I try really, really, hard I still can't remember". (Julie)

"The only difference is, or difficulty is my, my mobility is pretty bad now you know I have totally sore knees and ankles etcetera. And um, and then they don't, I've never really had a definite response; they're not sure. I can barely walk; I can't cycle anymore, can't rock climb, can't, you know do lots of what I used to". (David)

Participants also experienced threat, uncertainty, and loss of control over their lives due to the terminal nature of the condition. Some participants talked about their experiences of being told their prognosis at diagnosis:

"But when, when I got the pictures done um, it revealed this um, this growth inside me, and um, it was aggressive, and it was sort of growing. So, this lovely man that I saw, he said you've got about three months to live at the moment". (John)

Due to the sudden threat of the diagnosis, uncertainty and loss of control, all participants had to find ways to cope and survive.

Subcategory 1b: 'Doing what it takes'

Sources: 12

Due to the terminal nature of their disease, uncertainty related to their diagnosis, and loss of control over their lives, all participants were doing what they could to prolong their life and survive. All participants talked about following advice and accepting treatments that professionals recommended:

"I just went with what they advised me really." (Sophie)

"I just do whatever they tell me to do." (Jane)

Eight participants talked about 'having' to have treatments and scans. They saw the treatments and scans as essential and felt that they had little choice given their situation:

"I think it's probably because you know it's got to be done and you kind of just have to get on with it." (Jane)

"But the scanning itself is you know it's just a routine I have to go through." (Adam)

Some talked about having to cope with their treatments and scans for their family:

"There were times when I thought, I don't know if I can do this. Then I thought, don't be ridiculous, you've got to! You've got to do it; you've got to get through it, and you've got to get better. I thought, I can't die, my son will never cope." (Julie)

Many participants found their treatments difficult, but some talked about having to be 'brave' because they knew that it was something they had to do:

"*And I've been a brave little bunny. I just get on with it." (John)*

"The scans were just something I had to do, so, it was a case of 'big girl pants'; let's just get on with it." (Amy)

Alongside their treatments and interval scans some participants took additional steps to try and increase their chances of survival and maintain some sense of control over their lives. For example, two participants made changes to their diet and one participant sought additional private treatment:

"There's been protocol that people have done and there's been books on it, and they claim it helped them so I'm trying to do a combination of the supplements that they've taken. I've changed my diet as well. I've gone on a Ketogenic diet; there was a study on that that helps as well." (Hannah)

"After nine months they basically gave up on the treatment and we were put in touch with a hospice. Then we were advised to look into a thing called Sativex and we have been on that ever since." (Julie)

How participants coped with the threat of their condition and the difficult and invasive treatments they went through would have been partially influenced by their access to support from others and past experiences of illness.

Subcategory 1c: 'Accessing support from others'

Sources: 12

All participants were supported by members of their family or friends throughout their illness, treatments and follow-up. This helped them to cope with living with a PMBT. All participants had access to support from family:

"I've got a very supportive wife. She, she's a saint to put up with me, but you know but the thing is she knows I have to do something and er, we just shuffle along." (John)

"My husband always comes with me, he doesn't like me going on my own." (Hannah)

Only two participants talked about the support that they had received from their friends:

"And when people say to me, "how do you cope?" I tell them it's because I have the best friends, I do. If you are a friend of mine, you are a best friend." (Julie)

"I'm probably talking about it [diagnosis] more to friends and family." (Emma)

Subcategory 1d: 'Impact of past experiences of illness'

Sources: 4

Some of the participants talked about their past experiences of illness and how these influenced their ability to cope with living with PMBT. Four participants shared experiences of their own illnesses, accidents, or experiences of family members being unwell. One participant repeatedly talked about how positive her son had been following his cancer diagnosis and treatments, and how this had influenced her coping:

"And I can go through it because of the way he went through it. He always had a smile, never made a fuss, yes, yes, okay, okay. So, I thought, um, yep, that's it. And I am as good as I am because of [sons name]." (Julie)

One participant shared their experience of being in a serious accident, nearly losing their life and how this has helped him to cope:

"They didn't think I'd make it, but I must have been quite tough…you know I've been through quite big things in the past quite big things, so I know what to expect and just get on with it." (John)

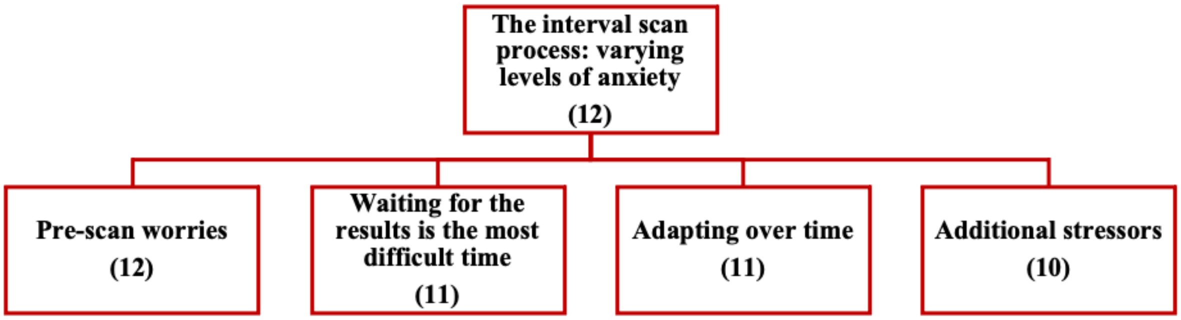
Core Category 2: 'The interval scan process: varying levels of anxiety'

Sources: 12

Throughout the interval scan process, participants' anxiety levels varied. Some participants were anxious before the scan, others were anxious during the scan, and many experienced anxieties while waiting for results. The majority of those who did experience anxiety discussed how they adapted over time. There were also some additional external stressors that had an impact on participants' anxiety levels and scan experiences. This is the first category that relates to core category 1 'Living with a PMBT: surviving,' because participants' experiences of living with a PMBT, access to support, and previous illness experiences appeared to influence how they felt during the interval scan process. It also relates to core category 1 because, no matter how difficult the MRI scanning process was for the participants, they believed it was something they had to do to survive. There are four subcategories within this core category. Figure 4 illustrates core category 2 and related subcategories.

Figure 4

Core category 2: ‘The interval scan process: varying levels of anxiety’ and related subcategories



Subcategory 2a: ‘Pre-scan worries’

Sources: 12

Some participants experienced worries prior to their scan. Four participants experienced claustrophobia and shared the anxieties they experienced pre-scan about the MRI scan itself:

“Oh, I do get really, really stressed. I’m claustrophobic.” (Sophie)

“The only thing is about those machines; I’m still a little bit claustrophobic inside them, and I have a few thoughts when I lie down that the machine’s going to stop working or it might crush me or something. But those thoughts quickly go away when the scan starts.” (Hannah)

Four participants worried pre-scan, not about the scan itself but as to what their results might show and the possibility of tumour recurrence. Two of these participants were new to having interval scans and two had received bad news in the past:

“I’m quite apprehensive. I-I’m expecting it to find, even though I know it’s only going to go one way, erm, but it’s still quite an anxious couple of days before and I then I feel intermittently better once it’s done, the day, once it’s done, and me and dad are coming back from [hospital] I’m like, phew! Glad that’s over.” (Amy)

“Um, but doing the scan makes me think about the tumour, which slightly raises my anxiety levels about the possibility of return, which is always there because I’ve got a kind of recurring brain tumour.” (Adam)

Five participants said that they did not experience any worries prior to having their interval scans:

"At the moment, I really don't even give it a second thought. I must have had, oh a dozen, 15 of them now so, it does, it does not bother me in the slightest, you know I have to admit that, and I don't know whether it ever did, to be honest." (Emma)

Subcategory 2b: 'Waiting for the results is the most difficult time'

Sources: 11

All but one participant, who had not yet received any results, reflected on their experiences of waiting for scan results. Eight participants talked about how this was the most difficult time for them. For those that experienced worries pre-scan, the wait for results was described as even more anxiety provoking:

"So that is the point of anxiety for me definitely; that wait in between." (Emma)

"I mean that's something the-the the most anxious period for me is in between the scan and getting the results; especially the lead up to getting the results because that's, you know I've had experience of that being a bad thing." (Adam)

Only two participants said that they did not feel anxious during this time. The two participants that said they did not feel anxious were those that talked in detail about the impact of their past experiences of illness on coping:

"It's not a big, the Sword of Damocles isn't hanging over my head. I'm not that sort of person. I don't worry about things." (John)

Whilst waiting for results, five participants described hypervigilance to sensations or symptoms which might indicate progression of their illness, such as, pain or headaches. Some participants talked about how they became worried about sensations and symptoms even though they knew they were normal:

"*You know I'll get up one morning, usually when I get up in a morning, I'm a little bit blurry. It takes me a little while to um, sort of get with it during the day. Um, but then the next morning after the scan I'll get up I'll be a bit blurry and think 'Oh my god. The-the tumour must be growing. That's why I'm feeling like this or if I get a little twinge in my head or anything, anything is like negative." (Sophie)*

Six participants discussed how waiting for results was difficult because they knew that their disease was terminal and that the scan result may confirm their biggest fear, that the disease has recurred or progressed. They worry about what this might mean for their future and how family members will cope:

"I think because I'm, I'm more now um, its um, it's more of an, know that what could happen to [husbands name] if something happened to me." (Anne)

"If I sit and think about it it's quite depressing, erm, only cause I've got little kids and I know I'll be leaving them soon. It's just that I know what's, well, I know what's coming. So, so, yeah. So, that, so, if I, if I let myself think about it then I just go into worry overdrive." (Amy)

Six participants shared their experiences of waiting for their scan results on the day that they received them. Most described anxieties, but others did not report any worries:

"My phone is in my hand all day because they give you a er, a large timeframe within which they'll ring so I think the last time was three till seven so, from 12 o'clock I've got my phone in my hand, and er, even before that in the morning cause my head is going overtime thinking. So, you know I'm glued to my phone. Um, er, and then it's just waiting and waiting and waiting." (Sophie)

"So, they ring me up and er, my oncologist rings me up and um, it's [name] I call her [name] and er, she rings up and tells me that everything's all right." (John)

Subcategory 2c: 'Adapting over time'

Sources: 11

Most participants had experienced a number of MRI scans prior to starting interval scans. They reflected on how the MRI scans got easier over time and became routine. Five participants described MRI scans as a procedure that had become routine over time:

"Yes. A regular procedure now; go there, get prepared, with my eyes shut because you know cause it's a tick box exercise." (Ben)

Five participants talked about how the procedure of having the MRI scan got easier for them the more that they had. This was mainly discussed by those that had disclosed more pre-scan worries or claustrophobia:

"*No, I got used to it the more they did it." (Anne)*

"Once I'm there and I know it's the right machine then I am a little bit calmer these days cause I've done it so many times." (Sophie)

Nine participants said that they did not see a need for any additional information about MRI scans prior to starting interval scanning because they already knew what to expect:

"Every time I get any appointment letters through, I do get a couple of pages of what to expect, to be honest I don't need to read it cause I know what to expect." (Emma)

Although some participants found that having the MRI scan itself got easier over time, many found that the wait for the results remained the same, with some expecting it to become more difficult:

"The process of having the scan has been easier but then that period from the scan to the results is always the same." (Sophie)

"It'll get harder because realistically there's only one way this is going." (Amy)

Subcategory 2d: 'Additional stressors'

Sources: 10

Participants described additional external stressors such as issues with appointments, issues with having their cannula fitted, issues with the MRI machine and the impact of COVID-19. All these additional stressors seemed to impact on participants' feelings during the interval scanning process. Five participants, all from one hospital site, described the additional stress and anxiety caused by issues with arranging their scan appointments:

"Instead of three months I had to wait four months. I just couldn't get through to them or MRI department. I need confirmation because they'd booked it and they'd put it in a different place to where it normally is; and then, of course, my anxiety is going through the roof you know are they going to put me in one of those tubes cause I can't do that." (Sophie)

Another stressor for four participants was issues with having their cannula fitted prior to their scan:

"But some people tend to struggle with it a little bit more, and it just, it just lengthens that anxiety process." (Amy)

Two participants had scans in mobile units and discussed how this felt isolated in comparison with going into the hospital:

"The last one I've done um; it's been in a mobile unit. I prefer to go in the hospital to have them done. You're kind of sat outside a little room on your own. . . first. Um, I don't know. I don't know why I prefer it really." (Jane)

Two participants had the experience of the MRI machine breaking down during their scan, which meant they had to endure a much longer scan than usual:

"And me last one the machine keeps on breaking down. I had an hour and a half of I just laid there; you know while they were trying to fix it yeah. I'll be honest, er, when, when they got it going, starting, at one point I were ready to well use the tap 'out' button." (James)

Some participants discussed the additional stress caused by COVID-19. Although COVID-19 did not impact them having interval scans, it did impact on travel to and from hospital, and the communication method for results. Some found their journey to and from hospital difficult:

"I guess the only other impact of COVID has been um, getting to and from the hospital. But because I've just trying to dodge any form of public transport or going into any shops or anything it's probably the only time that I've kind of felt a little nervous of being out and about cause I have to go." (Emma)

For some participants, their results moved from a face-to-face to telephone appointment. Some participants found this helpful, whilst others did not:

"Erm, it was nice meeting the people. I prefer to go in, I think, so I can speak to what they say to me." (Anne)

"It's that you know that waiting, and obviously that changed because it used to be a face-to-face appointment, um, and that was horrific you know in terms of it'd be a Monday clinic and you'd be in a massive waiting room with like a hundred other people and it would overrun significantly we're talking hours and hours. Now it's much easier on the telephone." (Emma)

One participant discussed the impact of PPE on receiving face-to-face results:

"*Um, it-it it's strange. You can't really, um, you can't see the-the-the um, consultant's face and you know it's not as easy to kind of get, gauge their um, you know um, whether it's going to be good or bad news basically just from clues around the eyes um, yeah, so that doesn't help." (David)*

Overall, there are individual differences in the amount of anxiety participants experience throughout the interval scanning process. This is impacted by both internal and external factors.

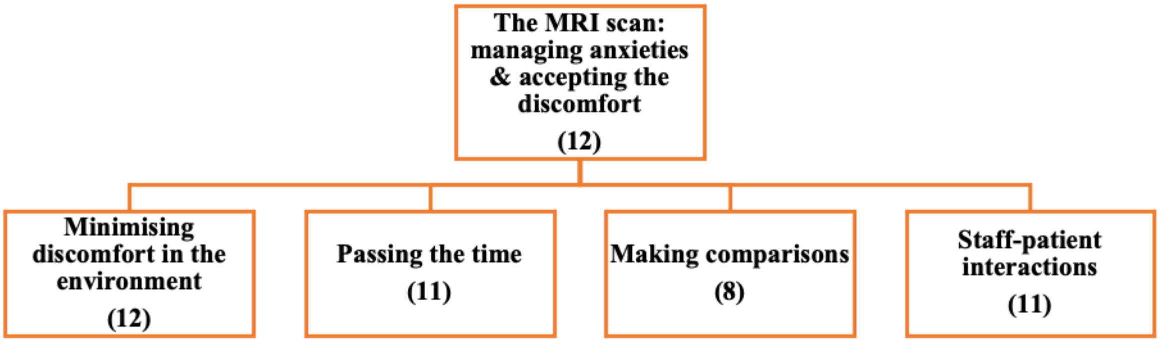
Core Category 3: 'The MRI Scan: managing anxieties and accepting the discomfort'

Sources:12

During the MRI scan, those participants that experienced anxieties due to the scan itself found ways to manage these. Most participants stated that they did not find scans difficult, but rather described them as a 'discomfort.' Participants used a variety of strategies to pass the time whilst they had their scans. Some participants coped by comparing themselves to others and interacting with staff during their scan appointment. This core category relates to core category 2, 'The interval scanning process: varying levels of anxiety,' because participants coped with the scan differently depending on their anxiety levels. It also relates to core category 1 ‘Living with a PMBT: surviving’ because interval scans were viewed as something participants ‘had to’ do, therefore they found ways to manage anxieties and accepted any discomfort experienced during the scan. There are four subcategories within this core category. Figure 5 illustrates core category 3 and its related subcategories.

Figure 5

Core category 3: ‘The MRI Scan: managing anxieties and accepting the discomfort’ and related subcategories



Subcategory 3a: ‘Minimising discomfort in the environment’

Sources: 12

All participants talked about their experience of having MRI scans. They discussed some of the discomforts of having a scan and how certain adaptions to the scan environment helped to reduce discomfort. Participants mentioned that the scan environment was cold, noisy, that the machine was narrow and that they had to lie still for an extended period:

“You’re not allowed to move your head or anything. I seize up if I’m in the same position for a long time... and, it is about an hour. I can't wait to move my legs and my feet when it finishes.” (Julie)

“It is really, really, noisy!” (Jane)

Most of the participants talked about how small adaptions in the MRI scan environment helped to reduce the discomfort. This included adaptions such as earplugs, music, a mirror, TV screens, being provided with a blanket and having a ball to hold and press if they feel the need to stop the scan:

"And they give you this ball to hang on to and if you get, something was to happen, you squeeze the ball, and it stops the machine." (John)

"The fact that there's a TV with anything... I was just like oh, that's nice you know takes your mind off it for a little bit." (David)

However, these adaptions were not always seen as helpful, with two participants experiencing worry during their scans after looking in the mirror and seeing staff viewing their scan images:

"So, sometimes there's a mirror that's at an angle and you can see back to the room, and I don't know if that's a good thing or a bad thing! because when I had the recurrence, I remember seeing them all crowding around you know the computer and I was like, that doesn't look good!" (Emma)

Subcategory 3b: 'Passing the time'

Sources: 11

Most participants talked about the various strategies that they used to pass the time that they spent in the MRI scanner. Three participants did not feel they needed to use any strategies and talked about passing the time by falling asleep or resting:

"I've fallen asleep in it before." (Ben)

However, most participants used coping strategies to help them pass the time. Four participants talked about the use of imagery, imagining they were on a holiday or on the beach and tuning into the sensory experience of this:

"I just shut my eyes and imagine that I'm on the beach. that's always one of my coping mechanisms with claustrophobia." (Sophie)

"Only way you do that is by zoning out. going to a nice place or somewhere or listening to music. I go to like holidays or somewhere, you know like Ibiza, sitting on beach wi-music in background, nice, warm. you know what I mean; it's like a happy place." (James)

Two participants talked about using timing and counting to help them pass the time:

"But what I do now is I count the bangs. I know how to count them on my fingers…the "boom, boom, boom". Yep. I do them in bursts of ten, that's my five fingers and one more because it's sixty

seconds to one minute and then I use my other hand for the minutes, one, two, three, four and five. And after about five, even though it's supposed to be 7, it usually stops." (Julie)

Whilst four participants talked about tuning into the noises the scanner made:

"I tend to kind of listen to the noise it's making and try figure out, right, that's one run of that part and one run of the other. Because you know the noise changes dramatically." (David)

Other strategies included focused breathing and thinking about other things:

"I often, I often think what's my dad up to cause he's usually the one that's taken me he's usually me taxi driver. I wonder where he is, you know is he all right has it got something to do." (Amy)

Subcategory 3c: 'Making comparisons'

Sources: 8

Participants compared the MRI scan to other medical procedures and compared themselves to people going through similar situations. Five participants mentioned that scans were not 'painful' and not as 'invasive' as other procedures they had been through:

"Well, the, they're not painful, you know what I mean it don't, it isn't as if er, you're cutting me open or anything like that. But . . .not. . . intrusive you know. Well, they are intrusive but you're not cutting me open or anything. It in't like an operation you know what I mean. They're not, they're not invasive." (James)

Six participants compared themselves to others in terms of how they cope with scans. Participants made downwards comparisons, seeing others as not coping as well as they do:

"You've just got to man up; you have to get on with it. Some people are squeamish about having things going over you but none of that bothers me." (John)

"You know compared to some other people I know I had, I've a friend who said she cried when she had her first MRI. I was like, really? And that was after I told her it would be absolutely fine; it was nothing. She came away and said it was awful". (Emma)

Two participants made downward comparisons regarding the support they received, seeing themselves as well supported compared to others:

"I could imagine it could be difficult for anybody who hasn't got anybody to take them. I'm lucky. My husband's self-employed so he can always take time off and get me, get me there." (Jane)

Two participants made downward comparisons in terms of their work situation, seeing themselves as being in a more supportive working environment than others:

"It might be different if I'd a full-time job and I was employed by someone and I couldn't get, you know it was a nightmare trying to get to and from the hospital in time to get to work." (Ben)

Subcategory 3d: 'Staff-patient interactions'

Sources: 11

Participants discussed their interactions with hospital staff during their scan appointments. Some described their scan as 'isolated' and 'lonely' and talked about the importance of having staff around to support them through the scan. They appreciated staff checking in with them during the scans, providing encouragement and informing them of timings:

"Just the fact that you're lying in a scanner that, you know you're all on your own it's quite isolating, it's quite lonely. So, just for them to say you're doing well, or you know we'll be in in a minute; last ten minutes, you know just something encouraging to make you think, oh okay I'm doing all right." (Amy)

"Sometimes it's just the way that they talk to you, you know, 'We're gonna do this. Are you okay with that?' and then while I'm in the machine, you know every, every five or ten minutes, 'Are you okay?" (Sophie)

Some talked about how staff are generally 'friendly,' 'caring' and 'competent':

"They're always incredibly friendly and just, yeah, it's a nice easy process." (David)

"They're always very good at that, competent, caring, but brisk almost like a production line getting you through, which is fair enough." (Adam)

Two participants talked about how they ensured they worked with the staff, to make it easier for them. This was something that John discussed repeatedly. He talked about how he 'stays strong' because he thinks that showing distress makes things more difficult for the staff:

"They've got a job to do and it, it doesn't need somebody like me getting weepy and upset about it... They've got a difficult job to do, and they don't need somebody like me giving them trouble. And I always tell them before they start how it's going to be. And they're so pleased because they don't need panics." (John)

Only one participant mentioned that staff differ in how helpful they are, with some staff not explaining things as well as others:

"Some are absolutely wonderful and, and some, huh! This is going to sound awful, but some need a bit more people skills cause some explain to you what they're doing and why they're doing it and other people just kind of do it." (Amy)

Overall, participants did not seem to find the MRI scan itself the most difficult part of the interval scan process.

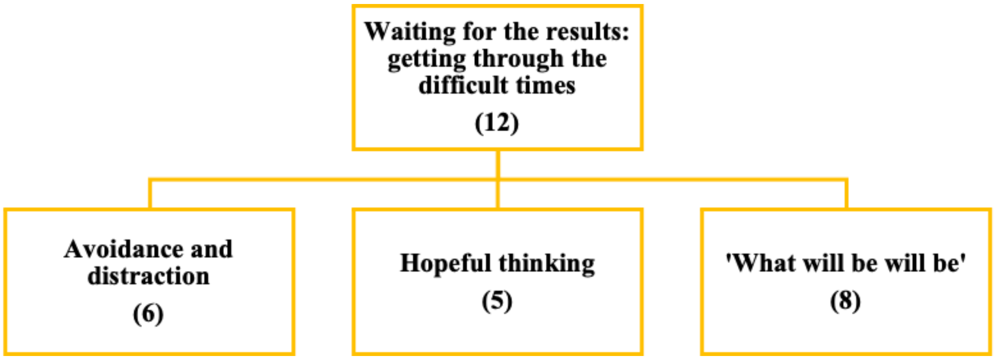
Core Category 4: 'Waiting for the results: getting through the difficult times'

Sources:12

As discussed in core category 2 'The interval scan process: varying levels of anxiety', waiting for the results was the most difficult time for the majority of participants. For these participants, their anxiety was heightened, and they seemed to experience an increased sense of uncertainty and lack of control. Participants described the different ways in which they got through this difficult time, often using emotion-focused and avoidance related coping strategies. Because coping seemed to be influenced by participants' past illness experiences, support from others, and experiences of living with a PMBT, this category is related to core category 1 'Living with a PMBT: surviving.'. There are three subcategories within this core category. Figure 6 illustrates core category 4 and its related subcategories.

Figure 6

Core category 4: 'Waiting for the results: getting through the difficult times' and related subcategories



Subcategory 4a: 'Avoidance and distraction'

Sources: 6

Six participants talked about getting through this time by avoiding thinking about the results, avoiding talking about them with others, or by distracting themselves from their thoughts. Four participants tried to avoid their thoughts:

"I, you know try mentally try push those thoughts away because, and every reasonable person will be the same like I don't know the result till I know the result. Stop trying to guess it. Stop trying to guess it! But it, I find that really difficult." (Sophie)

Two participants said that they avoided talking to others:

"I try not to expect anything and so when you know if my girlfriend kinda says, you know it's probably going to be dreadful and I'd stop her talking just so I'd rather not even think about it." (David)

Three participants talked about distracting themselves through work or other activities:

"Once I've, once I've started thinking about it then I need to like divert myself do something else; go out for a walk perhaps is usually a good one." (Amy)

Subcategory 4b: 'Hopeful thinking'

Sources: 5

Some participants remained hopeful. Some hoped for good news whilst others looked for signs that their results might be positive. Three participants talked about their hope for good news, these were the participants that said they experienced little anxiety throughout the interval scan process:

"But now the doctor will say "look at this, there is absolutely nothing". I take it for granted now. The doctor will be ringing me Thursday and he will be saying "it's all alright, it's all good", yeah." (Julie)

"I just think, oh, what are they going to say. Has it grown back or is there, has it, is there any shrinkage; and then I think oh maybe they're gonna tell me to go, I keep on imagining them saying oh, it's completely gone." (Hannah)

Two participants talked about trying to forecast whether their results were going to be good. They assumed that someone would contact them sooner if the news was bad:

“You're never gonna know until you get the results but like, I think also, I don’t know for sure, but I think if it is bad news . . .maybe they’d call me earlier.” (Ben)

Subcategory 4c: ‘What will be will be’

Sources: 5

Five participants acknowledged a lack of control over their illness and over what their results might be. They avoided being too hopeful, anxious or trying to guess their results:

“I try to think don’t worry about it because I can’t change anything; what will be will be.” (Jane)

“It’s just like a cup of tea. I'm quite, not interested in that because what will be will be.” (John)

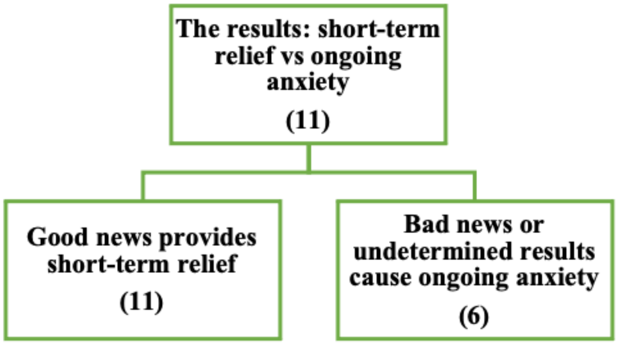
Core Category 5: ‘The results: short-term relief vs ongoing anxiety’

Sources: 11

Participants described how they felt following their results, depending on whether they were given good news, bad news or undetermined results. Depending on the result, they described feelings of relief or ongoing anxiety. This category relates to core category 1 ‘living with a PMBT: surviving’ because the results and participants’ feelings about the results appeared to influence how they coped with living with a PMBT, and how they reacted to future interval scans. There are two subcategories within this core category. Figure 7 illustrates core category 5 and its related subcategories.

Figure 7

Core category 5: ‘The results: short-term relief vs ongoing anxiety’ and related subcategories



Subcategory 5a: 'Good news provides short-term relief'

Sources: 11

All but one participant had experience of being told their results and receiving good news. At the point of being told their results, some participants described being at the peak of their anxiety. Being informed of good news provided them with a sense of relief:

"When they say you are okay, and everything is going to be fine you think, ah, phew, that's good, that's a good thing." (Anne).

"When there's good news it's just then I immediately lose that anxiety and just back to the general background anxiety rather than heightened." (Adam)

However, some participants discussed how they were aware that this relief was short-lived, knowing they had to go back through the same process in a few months' time:

"No, it's good. Good. And I usually feel on top of the world. And then, you know you do realise that you know you're gonna have to go through it all again in three months' time." (Sophie)

Subcategory 5b: 'Bad news or undetermined results cause ongoing anxiety'

Sources: 6

Only three participants had experience of bad news. One of these participants preferred to keep the conversation more positive and avoided discussion related to difficult experiences. Two participants were able to describe their experiences of bad news, sharing how they reacted to being told the news, the ongoing anxiety and loss of hope they experienced after:

"The, the silly thing is I was just kind of expecting standard, um, the MRI when they said it was bad news and there was another tumour... umm, I was just expecting, yeah, it's the same as it was, whatever, whatever, but it's, there's another one...it was like, oh wow, that's amazing, so, um, it-it it's strange". (David)

*"... and two times, s**t there is something to worry about better tell my partner and think about what we're gonna do! when it's you know a bad result then the heightened-the anxiety stays and I ponder about things; start noticing it a bit more about what the possibilities and the negative, what negative outcomes can occur from those sort of things they not, you know it makes you worried short term, it makes you think sort of feel a bit deflating because until then you hope that it might have gone away permanently and you won't have to worry about it again. But to be told that that hope has been dashed is deflating." (Adam)*

Four participants had experienced undetermined results. They discussed the ongoing anxiety they experienced until their scan was repeated and they had been given good news:

“They told me this, I have heard them say there is some difficulty. Then when they say ‘there's nothing serious, nothing to worry about’, then I’m alright. It makes you very, very tired. Um, yeah, I'm worried about it.” (Anne)

“Well, they-they said something about last one that the scan wasn’t the-the, they can see it but the nature of the machine; they want to send me on another machine and that’s when they send me to different department, a different scan machine cause they weren’t sure about something. I got a bit worried. I thought they’d found something, or you know it grew back or some-but it wasn’t that; they wanted to see something on a different machine.” (Hannah)

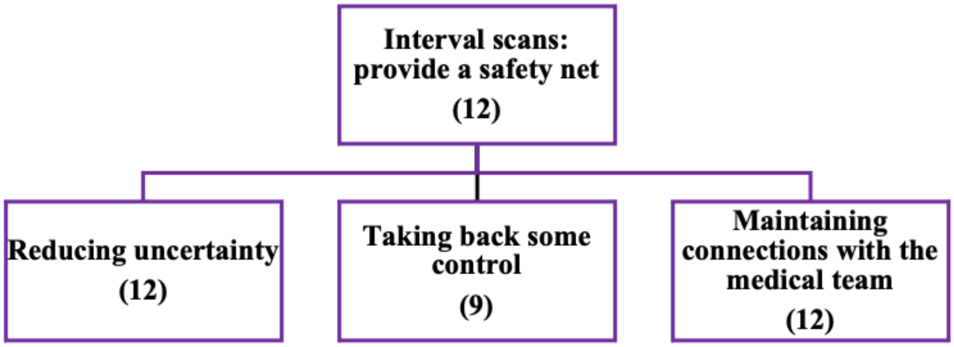
Core Category 6: ‘Interval scans: provide a safety net’

Sources:12

Core categories 2-5, which are all associated with the interval scan process, related to core category 6 because this core category explains why participants found ways to cope with the interval scan process despite the difficulties they faced. All the participants found scans to be beneficial in some way, and they all stated that they would rather have interval scans than wait for a change in their symptoms. They described how having the interval scans made them feel 'safer', as they feared that without this monitoring, their illness would progress, progression would be missed, and it would be 'too late' to access further treatment. They also valued the ongoing connection to their medical team, which gave them a sense of security. Some participants mentioned how having scans at regular intervals guided their treatment and helped them survive longer than they expected. Having scans at regular intervals also allowed some participants to plan ahead. As a result, interval scans provided some participants with a sense of control over their lives. Interval scans provided a ‘safety net’ for participants in that they helped them to cope with the uncertainty of their illness. Therefore, core category 6 is related to core category 1 ‘Living with a PMBT: surviving’. There are three subcategories within this core category. Figure 8 illustrates core category 6 and its related subcategories.

Figure 8

Core category 6: 'Interval scans: provide a safety net' and related subcategories



Subcategory 6a: 'Reducing uncertainty'

Sources:12

All participants talked about how interval scans helped to reduce their uncertainty. They reflected on the uncertainty of living with a PMBT in that it is something that they are unable to see, something that can progress with little signs or symptoms and how, depending on the amount of progression, treatment might not always be an option. All participants said that they would choose to continue to have interval scans, rather than only accessing scans following a change in symptoms:

"I would continue to have the scans if I had the choice. yeah. I wouldn't wait as it could be too late [coughs]. I think it's like bowel cancer, isn't it. One of those things that creeps up on you, you don't know. The next day you're dead! So, it feels safer to have the scans, just to check, you know." (Ben)

"I like, you know it's nice to know what's going on basically because you can't see anything. It's not like an injury or a condition where you can actually see something getting better or worse. You never know what's going on in there, and by the time you get some symptoms or you get some change it could, there could've been a huge amount happening in your head that's irreversible, so yeah, I would definitely want to keep track of things closer." (David)

"I'd definitely choose interval scans it just doesn't, it doesn't make sense to me to wait until it's big enough to damage your brain to find out you have to do something about it the last few times I would-I would not have known I had a tumour growing cause I didn't have any symptoms at all other than what I got for the first one so, there'd have been a tumour there growing, potentially,

you know metastasizing for all I know um, so, to know it's there and to be able to do something about it is much more reassuring than having to put it off just cause I don't want the scan." (Adam).

Subcategory 6b: 'Taking back some control'

Sources: 9

Having interval scans allowed some participants to hold on to some sense of control in their lives. Having scans means they were less uncertain about the progress of their condition and that they could plan ahead, whether this was planning with their family or friends, or whether this meant a plan in terms of their treatment:

"Whether that's, whether that's good or bad relieved cause I know I'm a planner, huh! I like to plan things and I like to be organised and I think once I know what, once I know again what I'm dealing with then I can, I can, take con-continue then." (Amy)

"So yeah, and that'll get dealt with if there are any changes, I'm hoping that they'll act on it accordingly, I suppose." (Jane)

Some participants talked about how interval scans had guided treatment and extended their lives, whilst also maintaining some QoL:

"Well, I've been lucky that the tumour's responded well to surgery each time and I've not headed into deterioration in quality of life because of it so again, that part of scanning helps with that because it enables them to get there. . .in time to ensure that I don't get any negative effects. If it wasn't for the scans, I'd probably be dead!" (Adam)

Subcategory 6c: 'Maintaining connections with the medical team'

Sources: 12

All participants mentioned how their medical team were always there. Having interval scans provided participants with a constant connection to their medical team, which added to their feelings of safety:

"Peace of mind; just a bit of security really that someone's there. They're gonna check things, not just leave me until I get symptoms, they wouldn't leave me but that's, that's how I'd probably feel" (Hannah)

"I think it's; it's reassuring that it's on that constant loop, that cycle. It's reassuring you know that generally knowing that it happens automatically. I feel confident that it's being monitored by them." (Emma)

As discussed in subcategory 1b ‘doing what it takes’, participants were putting their lives into the hands of the professionals and going along with their advice because they expect this to be their best chance to survive:

“They know what they’re doing, the consultants, and how often we should be scanned.” (Jane)

Summary

For the participants, interval scanning was viewed as an essential part of living and surviving with a PMBT. How participants experienced and coped with the interval scan process appeared to be influenced by their experience of living with PMBT, support network, and previous illness-related experiences. Some participants reported difficulties with the interval scan process, while others did not. Regardless of the difficulties they faced, they all found a way to get through the process because they saw it as beneficial. Interval scans provided a ‘safety net’ for participants because they helped to reduce their uncertainty, gave them some sense of control and provided them with a connection to their medical team. Participants found ways to cope with the process of interval scanning because having scans at regular intervals helped them to cope with the uncertainty of living with a PMBT.

DISCUSSION

In this section I will discuss the results within the context of the existing literature, outline the strengths and limitations of the research, followed by a discussion of the implications for clinical practice. I will also discuss some recommendations for future research.

Summary of the Research and Results

The aim of this research was to gain an in-depth understanding of how adults living with PMBTs experience and cope with interval scans. Twelve participants living with high-grade PMBT were interviewed and discussed their experiences of interval scans and coping. The GT model 'Interval scans provide a safety net for coping with living with a PMBT' was developed based on participants' experiences of interval scanning and related these experiences through processes of coping. The participants found ways to cope with the process of interval scanning because having scans at regular intervals helped them to cope with the uncertainty of living with a PMBT. Core categories, related subcategories and the GT model will now be discussed in relation to the existing literature.

Results in the Context of the Existing Literature

Living with a PMBT

All participants shared their experiences of being diagnosed with and living with a PMBT. They were all placed in a situation in which there was a sudden and serious threat to their lives. Participants described the physical, emotional, and neurocognitive symptoms they experienced as a result of living with a PMBT. These symptoms impacted on their abilities and independence, and alongside their shortened life expectancy, created a sense of loss. Previous research has described similar symptoms and feelings of loss in people living with PMBT and advanced cancer (Ijerman-Korevaar et al., 2018; Sterckx et al., 2015; Thomsen et al., 2010). In addition to loss, participants described the ongoing uncertainty that they faced as a result of living with a PMBT. According to the Uncertainty in Illness Theory (Mishel, 1988), uncertainty exists in illness when there is ambiguity, unpredictability, and a lack of information. Past research has described the unpredictability and complexity of PMBTs (Lin et al., 2015; Ownsworth et al., 2011; Sterckx et al., 2015). Participants in this study expressed uncertainty about their disease's progression, describing it as 'unknown' and 'unseen.' For many, this was based on their experiences of symptoms that were non-existent or non-specific prior to diagnosis or prior to being informed of progression. In a qualitative study of patient experiences of PMBT diagnosis, Walter et al. (2019) found that many patients experienced minor changes instead of specific symptoms. Sterckx et al. (2015) found that feelings of loss and grief were often related to how subtle or absent initial symptoms were, and how the seriousness of the diagnosis did not fit with how patients were feeling. Due to the threat, uncertainty, and loss of control over their lives, all participants in the current research were accessing support from others and doing what it took to survive, which included undergoing treatments and interval scans.

The Psychological Impact of Interval Scans

Past research has described the psychological impact of PMBTs, with high prevalence rates for both anxiety and depression which can impact on symptom burden and QoL (D'Angelo et al., 2008; Hao et al., 2020; Jiao et al., 2014; Rooney et al., 2011). For people with a diagnosis of cancer, anxiety can increase around the time of their MRI scans (Thompson et al., 2010; Bauml et al., 2016). PTS symptoms are common among cancer patients, with medical procedures and follow-ups acting as potential triggers (Jim & Jacobsen, 2008; French-Rosas et al. 2011; Cordova et al., 2017; Ghazali et al., 2013). Although this research did not measure the psychological impact of living with PMBTs, it did look at participants' experiences of interval scans including their feelings throughout the process.

Participants in this research reported varying levels of anxiety throughout the interval scan process. Some participants said they felt anxious at certain points during the process, while others said they did not. This is consistent with previous research, which found that people who had MRI scans for various reasons experienced anxiety before, during, and after the scan, as well as while waiting for results (Tugwell et al., 2018; Van Minde et al., 2014; Thompson et al., 2010; Tyldesley-Marshall et al., 2020). In terms of the scan itself, MRI head scans have been reported to be more of a trigger for anxiety than other scans, especially for patients that experience claustrophobia, due to the participant going into the confined space of the scanner headfirst (Eshed et al. 2007; Dewey et al., 2007). The participants that experienced claustrophobia in the current study reported feeling anxious prior to and during their MRI scans. All of them, however, managed their fears by utilising coping strategies before or during the scan. In previous research, a high number of patients with claustrophobia ended their scans early (Eshed et al., 2007); however, none of the participants in the current study mentioned having to stop a scan. Other participants in the current research experienced anxiety prior to their MRI scan, not due to the scan itself but due to the uncertainty of their disease and the high possibility of recurrence or progression. This was mainly reported by participants that had experience of bad news or undetermined results. In the study by Thompson et al. (2010) which investigated the psychological impact of routine CT surveillance scans in long-term survivors of aggressive lymphoma, participants also reported a fear of recurrence before their scans.

A finding from the current research, which offers a different perspective from the existing literature, is that participants reported that they had adapted to MRI scans over time. Most of the previous research on scan-related anxiety has typically focused on one-off scans that are not always cancer-specific. Most participants in the current research had undergone a high number of scans, including diagnostic, treatment-related, and interval scans. Several participants normalised the interval scan process, describing how it had become ‘routine’. This normalising was also reported by Tyldesley-Marshall et al. (2020, 2021), who researched the experiences of children with brain tumours and parents’ views of seeing their MRI images. They reported that participants perspectives changed over time, with the process of having scans becoming ‘normal’ for them. Some participants in the current research, including those with claustrophobia, said that their first few scans were difficult, but they became easier over time. Through repeated exposure, they appeared to get used to the scan environment and scanning procedure. Chapman et al. (2010) discovered that anxiety levels in healthy male volunteers decreased from the first to the second scan, indicating habituation. However, unlike the current research, Chapman et al. (2010) measured anxiety using self-report measures and heart rate across scanning sessions, and the participants did not have a life-threatening diagnosis. Therefore reasons why participants, in the current research, reported that their scans became easier over time, may not only be related to habituation to the scan environment itself. For example, participants discussed how they had undergone several difficult and invasive treatments prior to starting interval scans and reflected on how scans were less threatening than these. As a result, it's possible that their previous experiences, expectations, and coping strategies also helped them adapt to scans over time. However, because understanding this was not an aim of the current research, it was not explored in depth and conclusions cannot be drawn. Prior research has also looked at how procedural and sensory information, as well as information on cognitive techniques to reduce anxiety and discussions with the radiographer, all helped to reduce anxiety and improve image quality before an MRI scan (Grey et al., 2000; Powell et al., 2015; Quirk et al., 1989; Tugwell et al., 2018). However, participants in the current research mentioned they already knew what to expect and that additional procedural and sensory information was not helpful or necessary. Participants in the current research were not given any additional information about their MRI scan, such as information on cognitive techniques, so it's unclear whether they would have found this type of information useful.

Although MRI scans became routine or easier over time, most participants found the wait between scans and the results to be difficult. This was also found in previous research looking at interval scans (Thompson et al., 2010; Tyldesley-Marshall et al., 2020). Scan results were outside of the participants’ control and may have confirmed their fears, that the tumour had progressed beyond the point where it can be treated. Therefore, it was not surprising that whilst waiting for results, some participants described experiencing heightened anxiety and PTS-related symptoms (e.g., hypervigilance, intrusive thoughts, and avoidance), which are common after a cancer diagnosis (Brennan, 2001; Jim & Jacobsen, 2008). Uncertainty also appeared to heighten whilst participants waited for their results. According to research into the MUIS-BT, uncertainty can be triggered by inconsistency of illness related events and unpredictability of symptoms (Lin et al., 2012; Lin et al., 2013). In the current research, participants related uncertainty to the unpredictability of tumour progression and the lack of symptoms they had previously experienced. Although scans seemed to increase participants' anxiety and uncertainty at times, previous research found that patients who had an MRI scan before their clinical review were less uncertain than those who did not (Lin et al., 2015). Although some participants in the current research had difficulties with interval scans, having scans appeared to reduce their uncertainty overall, and provided them with some sense of control. However, the small number of participants who had experienced bad news and undetermined results, reported an ongoing increase in their anxiety and uncertainty. This is consistent with previous research which found that people living with aggressive lymphoma generally experienced relief and reassurance from interval scans, but experienced increased anxiety when news was bad or results were undetermined (Thompson et al., 2010). Newton and Mateo (1994) discuss strategies for dealing with uncertainty in PMBT, emphasising the importance of maintaining some sense of uncertainty to create a sense of hope, such as the hope that the tumour has stabilised. They do, however, talk about how as disease progresses, uncertainty grows, and hope reduces. Due to the small number of participants that experienced bad news in this study, understanding of this is limited. This will be discussed in terms of research limitations and future research.

Participants in the current research also discussed some additional stressors which seemed to impact on their interval scan experiences. Additional scan-related stressors, such as issues with the being cannulated, have been identified in the past literature (Thompson et al., 2010). In this research, some of the more practical issues, including problems with organising appointments, the MRI machine breaking down, and being in a portable scanner, added to participants' anxieties or discomfort. Unpleasant scan experiences were likely influenced by the fact that this study was conducted during the COVID-19 pandemic, a time of increased uncertainty and stress for many people, particularly cancer patients who were at a higher risk of illness-related complications. Although COVID-19 did not impact on participants' interval scans, it did impact on travel to and from appointments, as well as how results were communicated. Receiving results in person vs over the phone seemed to be an individual preference and was beyond the scope of the present study.

However, any additional stressors are important because of their potential to impact on scan experience and associated anxiety. For example, in a study looking at patients' perceptions of MRI scans, MacKenzie et al. (1995) found that unpleasant scan-related experiences, including issues such as discomfort related to the scan environment and parking or transport, were likely to lead to anxiety before future scans. Some of the additional stressors which participants shared in this research will be discussed in terms of clinical implications.

The results from the current research differed from the study by Thompson et al. (2010) which looked at interval scans in aggressive lymphoma survivors. None of the participants in the current study said that interval scans were an 'inconvenience', or said they felt they were 'over tested', as described by participants in the Thompson et al. (2010) study. However, there are some differences between aggressive lymphoma and PMBT. PMBT has no cure and progression is not always obvious without a scan, whereas aggressive lymphoma has a high cure rate and relapses are often noticeable without a scan. In the current research and in previous research involving brain tumour patients (Tyldesley-Marshall et al., 2020, 2021), interval scans presented both burdens and benefits. Following good news, interval scans provided a sense of relief and reassurance. They generally helped to reduce participants' uncertainty, provided them with some sense of control, and connected them to their medical team. However, interval scans could also present burdens because of the possibility of bad news or undetermined results, which could increase anxiety and uncertainty.

Interval Scans, Coping and Adjustment

Coping with Interval Scans

Coping and adjustment are important because they determine the psychological impact of an illness (Brennan, 2001). Due to PMBTs being such an uncertain and threatening illness, people living with PMBTs use a wide variety of strategies to cope (Goebel et al., 2012, 2018; Gustafsson et al., 2006; Keeling et al., 2013). Coping strategies used by people living with PMBTs in previous studies were also used by participants in this research during the interval scan process. Avoidance, distraction, seeking support, making comparisons, hopeful thinking, problem solving, and emotional control were all used as coping strategies. Participants described a sense of 'discomfort' about the MRI scan environment, such as it being noisy, cold, and the need to stay still. They discussed how certain aspects of the scan environment, such as having a buzzer to hold, a mirror to look out of, and music to listen to, generally helped to alleviate discomfort. Previous research on the impact of the scan environment on patients undergoing MRI found these features to be beneficial (Katz et al., 1994; Oztek et al., 2020; Törnqvist et al., 2006a). In keeping with the SCM (Lazarus & Folkman, 1984) there was evidence in this research of participants making appraisals about the MRI scan itself, with coping depending on whether the situation needed to be and could be changed. For example, if the MRI scan itself was a stressor, participants seemed to use more problem-focused coping to try and alter the stressor, such as ensuring they were booked onto a larger machine. During the MRI scan, participants recognised there was little they could do to control the situation, and instead, described their use of strategies to ‘pass the time’. Some participants used no strategies at all and just rested or slept, while others used more emotion-focused techniques like visualisations, breathing, thinking about other things, timing, listening to music, and seeking help from others. These strategies are similar to those discussed in previous research by Törnqvist et al. (2006) where patients were interviewed about their experiences of non-cancer related MRI scans.

The wait for scan results was another part of the interval scan process that participants felt they had little control over. As previously stated, the majority of participants said that this was the most difficult time for them. More emotion-focused and avoidance-related coping strategies were reported by participants during this time. For example, they attempted to avoid thinking about their results, avoided discussing their results with others, or distracted themselves by activities such as working or going for a walk. The coping strategies used by participants during this difficult time were similar to those used by people living with a PMBT in general (Goebel et al., 2012, 2018; Gustafsson et al., 2006; Keeling et al., 2013). Previous research found that people living with GBM used more emotion-focused coping (Gately et al., 2020), whereas people with both low- and high-grade brain tumours used more problem-focused coping (Song et al., 2015). However, as described in the ‘introduction’ section, categorising coping can be difficult (Thomsen et al., 2010). Participants' ongoing coping with their cancer diagnosis and interval scans may be better explained by the concept of meaning-based coping (Park &Folkman, 1997). This type of coping is likely to occur when people fail to resolve a problem using emotion or problem-focused coping (Park and Folkman, 1997). Individuals try to make sense of their situation and find benefit where possible, by changing their views or reviewing their beliefs about their circumstances to align with their perspectives (Lethborg, 2008). This could be useful in understanding how individuals cope after receiving scan results, especially when the results are undetermined, or they receive bad news.

The concept of meaning-based coping fits with the TCA (Taylor, 1983). According to this theory, individuals respond to threatening events through cognitive adaption, or engage in cognitive efforts to control the situation and increase their wellbeing. In keeping with this, participants seemed to be doing what they could to adapt, control their situation and increase their wellbeing where possible. In terms of interval scans we see examples of ‘efforts to gain mastery or control’ and ‘attempts to enhance the self’. Although the interval scans were difficult for some participants, they continued to have them. Having interval scans meant they were being ‘checked on’ by medical professionals in the hopes of detecting any changes before it was 'too late' for further treatment, thus reducing their uncertainty and maintaining some sense of control. This sense of control gained by having interval scans has been reported in previous research (Tyldesley-Marshall et al., 2020, 2021; Thompson et al., 2010). In terms of enhancing the self, some participants made downwards comparisons to others, believing that they were better off than others when it came to coping with scans. Social Comparison Theory (Festinger, 1954) links uncertainty and coping in that it discusses how individuals compare themselves to others in situations where they lack evidence or information (Umstead et al., 2018). When individuals see themselves as different to others who are in a worse situation, this can lead to positive feelings (Umstead et al., 2018; Van der Zee et al., 2000). This coping strategy has previously been discussed in the literature on brain tumours (Edvardsson & Ahlström, 2005; Salander et al., 1996). Some participants in the current study discussed the importance of 'working with' staff and controlling their emotions during scan appointments for the benefit of the staff. This was also found in a qualitative study by Byrne et al. (2002) where nearly all cancer patients shared a need to hide their distress to protect others, including staff and family. By controlling their emotions and seeming to cope better with scans than others, participants may have been provided with both a sense of control and self-enhancement. In the TCA (Taylor, 1983), cognitive adaption can also include ‘illusions’, these are unrealistic positive beliefs aimed at increasing the person’s sense of control over their situation and their wellbeing. Some participants in the current research seemed to have formed ‘illusions’ in that they were aware of the seriousness and terminal nature of their condition but were also very optimistic about their future. Over time these ‘illusions’ seemed to strengthen as participants repeatedly received good news which confirmed their beliefs. The confirmation or disconfirmation of beliefs may help us to understand how interval scans helped participants to cope with the uncertainty of living with a PMBT.

Interval Scans, Coping and Adjustment to living with a PMBT

Brennan's (2001) SCTM incorporates the coping and social-cognitive theories mentioned above (Lazarus & Folkman, 1984; Taylor, 1983), as well as trauma theories and cognitive theories of emotion. This model is useful for considering how interval scans helped participants to cope with the uncertainty of living a PMBT and provides a possible link between interval scans and adjustment. The model recognises cancer as presenting ongoing and multiple threats to the person living with the disease, something that previous research into scan anxiety and uncertainty has not always considered. According to the model, the anxiety and distress that someone experiences, such as that around the time of an interval scan, is a normal reaction to a potentially threatening event. Threats can cause distress, but they can also lead to personal growth. This model can help us to understand individual differences in anxiety and the coping strategies people use across the interval scanning process. For example, those who had hope from previous illness experiences seemed to report less anxiety and less need to find ways to cope with their situation. Each interval scan will likely contribute to the development of the participants' cognitive maps, either confirming or disconfirming their core assumptions. Some participants, for example, remained optimistic about their scan results because they assumed, based on previous medical experiences, that their consultant would call sooner if the news was bad. Others had received undetermined results at their last scan and assumed that they would be given bad news again. Good news sometimes appeared to confirm assumptions, for example, Julie stated, *"It confirms my belief that I am done with this"*. However, on the other hand, undetermined results or bad news sometimes appeared to disconfirm assumptions, for example, David said, "*I was just expecting, yeah, it's the same as it was, whatever, whatever, but it's, there's another tumour...it was like, oh wow, that's amazing"*.

According to the model, coping and adjustment also depend on social processes. Interval scans allowed participants to remain connected to their medical team following the ending of their treatment. This made them feel safer because they were being provided with trusted information about the progress of their condition and were connected to those who could provide treatment if needed. In the qualitative studies by Sterckx et al. (2015) and Ownsworth et al. (2011) patients with PMBTs expressed a need for information from professionals about what to expect and consequences so that they could feel prepared. Having accessible and available contact with the medical team was seen as essential. Although some people value information and choices, people living with PMBT may become overly reliant on medical staff and wish for them to take control and make decisions for them (Salmon & Young, 2017). This is consistent with attachment theory (Bowlby, 1979), which states that people are more likely to seek 'safety' and 'security' in times of fear and uncertainty. They are more likely to seek it from consultants they regard as 'experts' and who appear to be in control of the situation (Brennan, 2001). Although this was not addressed in the current study, a better understanding of the doctor-patient relationship is important because it will have implications for coping and adjustment.

In the current research interval scans appeared to have an impact on participants' assumptions, distress and coping, and may have also impacted on their adjustment to living with a PMBT. The idea of interval scans aiding coping was also discussed by Tyldesley-Marshall et al. (2021). In this study, having interval scans and viewing MRI images helped children with brain tumours and their parents deal with an uncertain future and maintain some sense of hope. Although not explored in this research, the SCTM does place coping and adjustment following a diagnosis of cancer within a wider social and cultural context. Interval scans were only one factor in participants' experiences of living with a PMBT; many other factors will have influenced how they have coped and adjusted following diagnosis.

The Importance of Interval Scans

All participants said they would prefer to continue having interval scans rather than accessing scans following a change in their symptoms. Following a scan, participants were informed that had a brain tumour, and while this was a difficult experience, many were grateful because it led to treatment that extended their lives. Participants hold the same hope for interval scans, in that they hope that they will detect progression so that it can be acted on as soon as possible. Many participants talked about how the uncertainty of living with a PMBT would be too difficult to manage without interval scans. They feared that without interval scans, their disease would progress without warning, that it would go unnoticed, and that this would have an impact on their survival. Although interval scans were difficult for some participants, they provided them with a 'safety net'. They helped to reduce participants' uncertainty and gave them some sense of control. Due to the small number of participants in the study, the full impact of receiving bad news is unknown; however, there was a sense that knowing rather than not knowing allowed participants to make plans, prepare, and seek treatment where appropriate. Interval scans also allowed participants to remain connected to their medical team following the ending of treatment which appeared to provide a sense of safety and security, as well as a space for support and information sharing. Participants found ways to cope with the process of interval scanning because having scans at regular intervals helped them to cope with the uncertainty of living with a PMBT. NICE (2018), Thompson et al. (2019) and Booth et al. (2021) discuss how there is currently no high-quality evidence to suggest whether interval scanning is beneficial or whether it alters outcomes of importance for people living with PMBTs. NICE (2018) and Thompson et al. (2019) recommended research to establish the benefits and burdens of interval scans for people with brain tumours, including the psychological processes involved. For the participants in this study, the benefits of interval scans outweighed the burdens of any distress caused by the process. The current study's strengths and limitations, as well as the implications for clinical practice and future research directions, will now be discussed.

Strengths and Limitations

Strengths

Usefulness of the Current Research

Issues regarding the lack of research on this topic have been described in the literature (NICE, 2018; Thompson et al., 2019; Booth et al., 2021). This research provides rich information based on participant experience in an understudied area. This is the first study to explore how adults living with PMBTs experience and cope with interval scans. This study adds to the literature around the psychological impact of MRI scans, specifically interval scans. It also contributes to the literature in terms of understanding how people with cancer and those living with PMBT cope with interval scans. It is also, as far as known by the author, the first study to discuss a relationship between interval scanning and wider coping and adjustment for adults living with a PMBT. This research provides insight into the burdens and benefits of interval scans for people living with PMBT. This research also helps us to start to understand the value of interval scans for people living with PMBT, which is important because the value of interval scans has been called into question. The findings have also been related to clinical practice and I discuss future research that will help to expand the body of knowledge in this area.

Quality and Grounded Theory Methodology

To ensure quality I followed the four main criteria for quality in GT studies outlined by Charmaz (2006, 2014). I also followed additional GT quality guidelines provided by Charmaz and Thornberg (2021), and qualitative research guidelines provided by Elliott et al. (1999). See the ‘method’ section for a discussion as to how I ensured methodological self-consciousness, originality, and credibility of the research. In the ‘method’ section I also describe how I followed the core processes of GT as identified by Willig (2013). I explained how I used theoretical sampling to ensure that I had sufficient data to develop categories and processes (Willig, 2013; Birks & Mills, 2015). This enabled me to carry out constant comparative analysis, in which I switched back and forth between data collection and analysis to make comparisons, refine codes, categories, and theory over time. Theoretical saturation is more of an aim than a reality, and it's possible it will never be fully reached (Dey, 1999; Willig, 2013). However, I made certain that collection of sufficient 'rich' and 'relevant' data continued until theoretical categories were saturated, meaning that no new insights or properties were emerging (Charmaz, 2014). By reviewing the current literature and immersing myself in the data, I was able to increase my theoretical sensitivity. Further to what was discussed in the ‘method’ section, I also compared the analysis and model with relevant research and theories from the evidence base. This gave me the chance to show how my research complemented and challenged existing research. The current research's usefulness was previously discussed under the heading ‘usefulness of the current research.'

Sample

Although the participant sample was small, it was varied in terms of age, gender, time since diagnosis, treatment options, number of interval scans and personal experiences. This ensured ensure adequate representation of the high-grade PMBT patient population and meant that the sample reflected some of the individual differences which may have impacted on interval scanning experiences. Research was also carried out across two sites which allowed similarities and differences between scanning experiences at the sites to be explored. Patients with cognitive difficulties are often excluded from studies, but this study included participants with mild-moderate cognitive difficulties, capturing a more representative sample of people with high-grade PMBT.

Limitations

Recruitment and Sampling Bias

In terms of recruitment bias, participants were asked whether they wanted to take part in the study during their neuro-oncology follow-up clinics. This is when they would typically receive the results of their most recent interval scan. Due to the impact that bad news could have on patients, clinicians only asked patients whether they were interested in taking part in the study if they had received good news from their most recent scan. This does bias the sample in that all participants reflected on their most recent scan experience and receiving good news, which is not representative of all scan experiences. Despite this, half of the participants did have previous experience of either bad news or undetermined results following an interval scan, and most were able to reflect on this.

There was also possible sampling bias in terms of who clinicians chose to mention the study to, and which patients chose to take part. Although having some longer-term GBM survivors in my sample was beneficial because they had a lot of interval scanning experience to share, they do represent a small percentage of GBM patients. According to Ostrom et al. (2014) only 0.05-4.7 per cent of GBM patients survive for five years following diagnosis, and three out of ten GBM participants in this research had survived five years or more. Two participants with rare tumours had a higher level of service involvement, and some participants were interested in research in general and had participated in trials and other studies. Therefore, these patients were perhaps easier for clinicians to approach, and more likely to agree to take part. Because clinicians were involved in inviting patients to participate in the study, some patients may have declined to participate if they had negative experiences or may have responded to interview questions in a more positive manner due to concerns that that their answers might negatively impact on their care.

Although the sample was varied for the reasons I have already described, due to the sampling method and limited numbers, the sample was not representative in terms of all types of PMBT, education level, socio-demographic background or ethnicity. Participants were excluded from the research if they did not speak English or if they had severe cognitive difficulties which would preclude successful participation in the interview study. As a result, the numerous factors that contribute to a person's identity and influence their experiences will not have been captured in this study. Although these are research limitations, it would not have been possible to include such a diverse sample with numbers limited due to the research project's time constraints. However, because we are not aiming for 'generalisability' or ‘representativity' in GT, the sample is considered sufficient based on theoretical saturation rather than sample size (Bowen, 2008).

Methodological Limitations

Due to conducting interviews in groups of two or three, I was unable to adhere to a full GT approach. In an ideal world, I would have conducted interviews one at a time, analysed them, and then theoretically sampled from one interview to the next. However, due to the method of recruitment from a follow-up clinic and the unpredictability of participants' diagnoses, I was unable to keep participants waiting for an extended period to be interviewed. If participants were kept waiting, their disease might have progressed, affecting their cognitive functioning and ability to consent. In keeping with the theoretical sampling method and as recommended by Charmaz (2014), it may have also been helpful to go back and re-interview people around the emerging categories and processes. This was not possible because the study had not been designed in this manner due to the nature of PMBT and its potential for progression. Although this was not possible, the theoretical sampling decisions made helped to refine categories and processes.

All interviews took place after participants had just received good news about their scan result. Although their scan and results were recent, making them easier to remember and reflect on, it is possible that this had an impact on their ability to recall previous scanning experiences, particularly those that were difficult due to bad news or undetermined results. Participants may not have wanted to discuss such difficult circumstances. Despite this potential issue, most participants were able to reflect on difficult times during the interval scan process. Gradually building rapport with participants, starting with easier questions before moving on to more difficult ones, and giving participants space when the discussion became difficult seemed to help me to facilitate more challenging discussions.

While capturing the experiences of those who did have some cognitive difficulties was beneficial, it did limit the amount of rich data gathered from some interviews. I asked participants to reflect on their previous interval scan experiences, so issues with their thinking abilities, such as memory issues, could have made this difficult. Another limitation of including participants with more moderate cognitive difficulties was that some were accompanied by a family member during their interview. According to the literature, some cancer patients try to 'stay strong' for family members, which may have influenced their responses (Molassiotis et al., 2010). In one interview, the participant's partner took part in the conversation and frequently answered questions on the participant's behalf. To try to mitigate this, I asked questions directed to the participant; however, their partner’s contributions may have influenced their responses in that they may have answered in ways that they would not have if interviewed alone.

Resonance

A further criterion for quality in GT outlined by Charmaz (2006, 2014) is resonance. This involves ensuring that categories and concepts are relevant to and represent participant experiences, as well as providing others with insight. Sharing the results of this research with the participants and asking for their feedback would have been beneficial. However, due to the unpredictable and terminal nature of PMBTs, it did not seem appropriate to ask participants at the time of the interview whether they consented to being sent the results in a few months’ time. As a result, these additional quality checks were not performed.

Impact of COVID-19

As already discussed in the ‘method’ section, the planning of the study and data collection happened during the COVID-19 pandemic. From the planning stages, the study was set up in a way which adhered to any COVID-19 restrictions. Most of the recruitment and all interviews took place remotely. In my reflexive statement, I included some thoughts on remote interviews. COVID-19 and the uncertainty it caused will have had an impact on some participants' experiences, even though interval scans continued as usual. Issues are described in the ‘additional stressors’ subcategory. Some participants were diagnosed during the pandemic; therefore all their interval scan experiences relate to this time. The impact of COVID-19 was not a focus of the research so will not be discussed any further, however it is important to acknowledge because it might have had some impact on participants’ experiences.

Researcher Bias

In constructionist GT (Charmaz, 2006), researcher bias is unavoidable, especially when conducting interviews where the researcher is a part of the interview process and product (Charmaz, 2014). There will always be some researcher bias, despite reflexivity and quality checks with supervisors. In my reflexive statement I reflected on the biases I noticed during the research process and discussed how I tried to adapt my approach accordingly.

Implications for Clinical Practice

The Value of Interval Scans

For the participants in this study, the benefits of interval scans outweighed the burdens. Interval scans provided a ‘safety net’ for participants. They helped to reduce participants’ uncertainty, gave some of them some sense of control and connected them to their medical team.

Although this research cannot be generalised, it does reflect the experiences of a group of participants living with PMBT and highlights the value of interval scans for these participants in terms of helping them to cope with the uncertainty of their illness. Participants remained hopeful that by having interval scans, progression will be detected before it is too late to do anything about it. Previous research has demonstrated the importance of instilling hope and having it protected by professionals (Sterckx et al., 2015; Salander, 1996).

Normalising Anxiety around the Interval Scanning Process

There is a tendency for anxiety to be viewed as a problematic emotion that should be avoided. However, scans when living with a PMBT are likely to cause anxiety for most people. This is a normal reaction to a difficult event. Some participants felt that they needed to ‘stay strong’ and be ‘brave’ in the presence of others. Byrne et al. (2002) discuss the importance of clinicians being aware of patients' protectiveness of others and how talk about 'strength' can prevent patients from discussing their emotional needs. Clinicians should be aware of this when working with patients who are having interval scans.

Improving Information about the Interval Scanning Process

Some of the differences between one-off MRI scans and interval scans were highlighted in the current research. Participants did not feel they needed information about the scanning procedure itself, however information about the interval scanning process might be helpful. This could include information around the potential burdens and benefits of interval scans, as well as general information about what to expect from the scanning procedure. It might be helpful to include quotes from others that have experienced interval scans to normalise anxiety about the process. Giving participants information about the burdens and benefits may provide patients with some sense of power and control in that they can see and weigh these up for themselves. It may also be helpful to include information about support groups so people can seek information from others going through similar experiences. Support from others going through similar experiences was not mentioned in this research, however in the report by Tyldesley-Marshall et al. (2021) which explored coping in children with brain tumours and their parents, the authors discuss how parents found support from others to be valuable.

Individualised Interval Scan Plans

As seen in this research, although most people will experience some anxiety during the interval scanning process, this differs widely between individuals. As suggested by Törnqvist et al. (2006a) it may be helpful that clinicians ask some targeted questions so that patients have an individualised plan around interval scanning procedures. This could include basic information about their difficulties, such as claustrophobia, as well as what they find helpful, such as staff communication throughout the scan. Patients could be referred on for support if needed, such as if they are experiencing intrusive thoughts and flashbacks, which could indicate PTSD. This discussion could also provide a space to ask patients about their preferences if there are options available. For example, asking whether patients prefer phone or face to face results. Providing patients with an individualised plan and choice around their interval scans may lead to empowerment and further feelings of control in their situation. It may be helpful for this plan to be reviewed with patients over time, to capture any additional needs or changes.

Minimising Discomfort and Additional Stressors

Although the MRI scan itself was not the most difficult part of interval scans for participants, it is still a part of a stressful and threatening process. Therefore steps should be taken to minimise discomfort and distress where possible. Some of these have already been discussed in terms of creating individualised plans with patients. However, there were some issues with organising scan appointments at one site. Participants would be provided with an appointment to get their scan results but would be left to arrange their own MRI scan appointment. Participants discussed how they had to "chase" appointments, and how they had difficulties getting through to the department via phone. This caused additional stress and anxiety for the patient and their family members. It would be beneficial to review this system to avoid this additional stress, especially given the ongoing threat of living with a PMBT. Services should also consider the MRI scan environment adaptions and make them available where possible. Additional practical ways to reduce scan anxiety during the scan itself have been identified in previous research, such as the provision of sensory and procedural information, information about relaxation techniques, and staff-patient interactions (Grey et al., 2000; Powell et al., 2015; Tazegul et al., 2015). As discussed by the authors of these studies, some changes of MRI procedures in services are feasible and should be implemented where possible to minimise discomfort, reduce anxiety and to improve image quality.

Future Research

Developing the Theory and Model

The theory and model discussed in this research is preliminary in terms of understanding the experiences of interval scans for adults living with PMBT and how they cope. By looking at a larger and more varied sample of participants, the properties and dimensions of categories could be further developed. The model could be expanded to include adults living with low-grade PMBTs, as differences in experiences and coping have been highlighted in the previous literature. There may also be some people with PMBTs who choose not to have interval scans or know their scan results.

It would be interesting to understand their experiences, perspectives on interval scans, and coping mechanisms. It would also be beneficial to gain some further understanding of people's experiences of receiving bad news and a larger, more varied sample might include more participants that have experience of this. By increasing understanding of this, avenues for support could be explored. As found in the study by Thompson et al. (2010), the doctor-patient relationship is also an important factor in people's interval scan experiences. This relationship will have implications for coping and adjustment and could also be explored in more detail to develop parts of the model regarding connections to the team.

Understanding the Impact of Interval Scans on the Family

This research focused on individual perspectives of interval scans. However, Fox and Lantz (1998) described PMBT a ‘family disease’. The SCTM (Brennan, 2001) discusses the involvement of others in adjustment. There is also a Social Cognitive Processing Model of Emotional Adjustment to Cancer proposed by Lepore (2001) which discusses how the social responses of others can impact on processing and adjustment. Although the MRI scan itself is an individual experience for the person living with PMBT, their family members are very much a part of the ongoing interval scan process. Family members may be able to provide insight into how the person living with PMBT copes, which the person themselves may remain unaware of. For example, Julie’s husband mentioned that Julie stayed quiet around the time of the scan, however, Julie on the other hand, did not mention this and expressed no anxiety. Family members will also have their own views and experiences to share about the interval scan process. Therefore, capturing their experiences could develop the theory.

Determining the Value of Interval Scans for Patients

The qualitative nature of this study meant that psychological distress was not measured across the scanning process. NICE (2018), Thompson et al. (2019) and Booth et al. (2021) all discuss the need to determine the value of the interval scan process, and the RANO initiative (Dirven et al, 2018) discuss the importance of PRO measures to do so. Because there is no specific instrument for measuring scan-related distress in people living with PMBT, and because distress experienced cannot be separated from the general distress that someone experiences while living with this disease, measuring scan-related distress in people living with PMBT is difficult. Participants in this research valued interval scans because they provided a sense of safety, helped to reduce their uncertainty, provided them with some sense of control, and connected them to their medical team. As a result, measuring patients' uncertainty and sense of control around interval scans could be beneficial. Booth et al. (2021) also recommended the inclusion of PRO measures of uncertainty in study design. Further understanding of the relationship between interval scans, coping and adjustment would also help to increase our understanding of the value of interval scans for people living with PMBTs. Additional qualitative information about patients' needs and the burdens and benefits of interval scans will also be important in shaping future research.

CONCLUSION

The value of interval scans for adults living with a PMBT has been questioned because there is currently no high-quality evidence to suggest whether interval scanning is beneficial or alters important outcomes for people living with PMBTs. The current research provides an understanding as to how some adults living with PMBTs experience and cope with interval scans. It also discusses the relationship between interval scanning and coping.

Participants’ experiences of living with a PMBT, and how they experienced and coped with interval scans, was generally consistent with previous research. When it came to the interval scanning process, experiences of anxiety varied, and participants coped in different ways. This appeared to be influenced by their experiences of living with a PMBT, as well as other factors. Although some found the MRI scan itself difficult, all participants found ways to cope. The wait for scan results was the most difficult part of the process due to the uncertainty of the disease. Unlike most other scan-related research, this study focused on interval scans rather than one-off MRI scans. Although participants used similar coping strategies to those reported in previous studies, this research found that most participants, whether anxious or not, adapted to scans over time.

For the participants in this study, the benefits of interval scans outweighed the burdens of any distress caused by the process. Interval scans were valued by participants because they provided them with a ‘safety net’. All the participants agreed that having scans rather than waiting for symptoms to change made them feel safer. Interval scans helped to reduce their uncertainty, provided them with some sense of control, and connected them to their medical team. Participants found ways to cope with the process of interval scanning because having scans at regular intervals helped them to cope with the uncertainty of living with a PMBT. This is important because others living with PMBT might have similar experiences, and coping, and associated adjustment, can determine the psychological impact of illness. The current research provides a preliminary GT model that illustrates these processes.

The anxiety experienced by most participants around interval scans was normal in that it reflected the uncertainty of their condition, and the threat of the situation they were in. Due to this, services should aim to reduce distress across the interval scan process where possible. Further understanding of the value of interval scans is likely to be determined by a combination of outcomes, such as sense of control and uncertainty, as well as further qualitative understanding of interval scan experiences and coping from a more diverse sample of participants.

REFERENCES

Adams, W. C. (2015). Conducting Semi-structured Interviews. In K. E. Newcomer (Ed.) *Handbook of Practical Program Evaluation* (pp. 492-505). John Wiley & Sons.

Azad, A., Sernbo, E., Svärd, V., Holmlund, L., & Brämberg, E. B. (2021). Conducting in-depth interviews via mobile phone with persons with common mental disorders and multimorbidity: The challenges and advantages as experienced by participants and researchers. *International Journal of Environmental Research and Public Health*, *18*(22), 11828. https://doi.org/10.3390/ijerph182211828

Baker, P. D., Bambrough, J., Fox, J. R. E., & Kyle, S. D. (2016). Health-related quality of life and psychological functioning in patients with primary malignant brain tumors: A systematic review of clinical, demographic and mental health factors. *Neuro-Oncology Practice*, *3*(4), 211–221. https://doi.org/10.1093/nop/npv042

Barclay, S., Momen, N., Case-Upton, S., Kuhn, I., & Smith, E. (2011). End-of-life care conversations with heart failure patients: A systematic literature review and narrative synthesis. *British Journal of General Practice*, *61*(582), 49-62. https://doi.org/10.3399/bjgp11X549018

Bauml, J. M., Troxel, A., Epperson, C. N., Cohen, R. B., Schmitz, K., Stricker, C., Shulman, L. N., Bradbury, A., Mao, J. J., & Langer, C. J. (2016). Scan-associated distress in lung cancer: Quantifying the impact of "scanxiety." *Lung Cancer*, *100*, 110–113. https://doi.org/10.1016/j.lungcan.2016.08.002

Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Birks, M., & Mills, J. (2015). *Grounded theory: A practical guide* (2nd ed.). SAGE Publications.

Boele, F. W., Weimer, J. M., Proudfoot, J., Marsland, A. L., Armstrong, T. S., Given, C. W., Drappatz, J., Donovan, H. S., & Sherwood, P. R. (2022). The effects of SmartCare© on neuro-oncology family caregivers' distress: a randomized controlled trial. *Supportive Care in Cancer*, *30*(3), 2059–2068. https://doi.org/10.1007/S00520-021-06555-5

Booth, T. C., Thompson, G., Bulbeck, H., Boele, F., Buckley, C., Cardoso, J., Dos Santos Canas, L., Jenkinson, D., Ashkan, K., Kreindler, J., Huskens, N., Luis, A., McBain, C., Mills, S. J., Modat, M., Morley, N., Murphy, C., Ourselin, S., Pennington, M., … Jenkinson, M. D. (2021). A Position Statement on the Utility of Interval Imaging in Standard of Care Brain

Tumour Management: Defining the Evidence Gap and Opportunities for Future Research. *Frontiers in Oncology, 11*(620070), 1–14. https://doi.org/10.3389/fonc.2021.620070

Bowen, G. A. (2008) Naturalistic inquiry and the saturation concept: A research note. *Qualitative Research, 8*(1), 137-152.

Bowlby, J. (1979). The Bowlby-Ainsworth Attachment Theory. *Behavioral and Brain Sciences, 2*(4), 637-638. doi:10.1017/S0140525X00064955

Brainstrust (2021, September 29) *Brain tumour symptoms and diagnosis.*

https://brainstrust.org.uk/symptoms/

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Brennan, J. (2001). Adjustment to cancer - Coping or personal transition? *Psycho-Oncology*, *10*(1), 1–18. https://doi.org/10.1002/1099-1611(200101/02)10:1<1::AID-PON484>3.0.CO;2-T

Brennan, J. (2004). *Cancer in context : a practical guide to supportive care*. Oxford University Press.

Byrne, A., Ellershaw, J., Holcombe, C., & Salmon, P. (2001). Patients' experience of cancer: evidence of the role of "fighting" in collusive clinical communication. *Patient Education and Counselling, 48*, 15-21.

Cancer Research UK (2019, March 05). *CT scan.*

https://www.cancerresearchuk.org/about-cancer/cancer-in-general/tests/ct-scan

Cancer Research UK (2019, July 24). *MRI scan.*

https://www.cancerresearchuk.org/about-cancer/cancer-in-general/tests/mri-scan

Chapman, H. A., Bernier, D., & Rusak, B. (2010). MRI-related anxiety levels change within and between repeated scanning sessions. *Psychiatry Research: Neuroimaging, 182,* 160–164. https://doi.org/10.1016/j.pscychresns.2010.01.005

Charmaz, K. (2006) *Constructing Grounded Theory: A practical guide through qualitative analysis.* SAGE Publications.

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). SAGE Publications.

Charmaz, K., & Thornberg, R. (2021). The pursuit of quality in grounded theory. *Qualitative*

Research in Psychology, *18*(3), 305–327. https://doi.org/10.1080/14780887.2020.1780357

Corbin, J. & Strauss, A. L. (2008). *Basics of Qualitative Research* (3rd ed.). SAGE Publications.

Corbin, J. & Strauss, A. L. (2015). *Basics of Qualitative Research* (4th ed.). SAGE Publications.

Cordova, M. J., Riba, M. B., & Spiegel, D. (2017). Post-traumatic stress disorder and cancer. *The Lancet Psychiatry*, *4*(4), 330–338. https://doi.org/10.1016/S2215-0366(17)30014-7

D'Angelo, C., Mirijello, A., Leggio, L., Ferrulli, A., Carotenuto, V., Icolaro, N., Miceli, A., D'Angelo, V., Gasbarrini, G., & Addolorato, G. (2008). State and trait anxiety and depression in patients with primary brain tumors before and after surgery: 1-year longitudinal study. *Journal of Neurosurgery, 108*(2), 281–286.

De Robles, P., Fiest, K. M., Frolkis, A. D., Pringsheim, T., Atta, C., St. Germaine-Smith, C., Day, L., Lam, D., & Jette, N. (2015). The worldwide incidence and prevalence of primary brain tumors: A systematic review and meta-analysis. In *Neuro-Oncology*, *17*(6), 776–783. https://doi.org/10.1093/neuonc/nou283

Dekker, J., & de Groot, V. (2018). Psychological adjustment to chronic disease and rehabilitation – an exploration. *Disability and Rehabilitation*, *40*(1), 116–120. https://doi.org/10.1080/09638288.2016.1247469

Dewey, M., Schink, T., & Dewey, C. F. (2007). Claustrophobia during magnetic resonance imaging: Cohort study in over 55,000 patients. *Journal of Magnetic Resonance Imaging*, *26*(5), 1322–1327. https://doi.org/10.1002/jmri.21147

Dey, I. (1999) *Grounding Grounded Theory: Guidelines for Qualitative Inquiry*. Emerald Group Publishing Limited.

Dirven, L., Armstrong, T. S., Blakeley, J. O., Brown, P. D., Grant, R., Jalali, R., Leeper, H., Mendoza, T., Nayak, L., Reijneveld, J. C., Rhun, E. Le, Walbert, T., Weller, M., Wen, P. Y., & Taphoorn, M. J. B. (2018). Working plan for the use of patient-reported outcome measures in adults with brain tumours: a Response Assessment in Neuro-Oncology (RANO) initiative. *The Lancet Oncology*, *19*(3), 173–180. https://doi.org/10.1016/S1470-2045(18)30004-4

Drapeau, A., Marchand, A. & Beaulieu-Prevost, D. (2012) Epidemiology of psychological distress. In L. L'Abate (Ed.) *Mental Illnesses–Understanding, Prediction and Control* (pp. 105-134). InTech.

Edelstein, K., Coate, L.,Massey, C., Jewitt, N. C., Mason, W. P., & Devins, G. M. (2016). Illness intrusiveness and subjective well-being in patients with glioblastoma. *Journal of Neuro-Oncology*, *126*(1), 127–135. https://doi.org/10.1007/s11060-015-1943-6

Edvardsson, T., & Ahlström, G. (2005). Illness-related problems and coping among persons with low-grade glioma. *Psycho-Oncology, 14*(9), 728–737. https://doi.org/10.1002/pon.898

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*(3), 215–229. https://doi.org/10.1348/014466599162782

Endler, N. S., & Parker, J. D. A. (1990). Multidimensional Assessment of Coping: A Critical Evaluation. *Journal of Personality and Social Psychology*, *58*(5), 844–854. https://doi.org/10.1037/0022-3514.58.5.844

Eshed, I., Althoff, C. E., Hamm, B., & Hermann, K. G. A. (2007). Claustrophobia and premature termination of magnetic resonance imaging examinations. *Journal of Magnetic Resonance Imaging*, *26*(2), 401–404. https://doi.org/10.1002/jmri.21012

Etkind, S. N., Bristowe, K., Bailey, K., Selman, L. E., & Murtagh, F. E. M. (2017). How does uncertainty shape patient experience in advanced illness? A secondary analysis of qualitative data. *Palliative Medicine*, *31*(2), 171–180. https://doi.org/10.1177/0269216316647610

Festinger, L. (1954). A theory of social comparison processes. *Human Relations, 7,* 117–140.

Folkman, S., & Greer, S. (2000). Promoting psychological well-being in the face of serious illness: when theory, research and practice inform each other. *Psycho-Oncology*, *9*(1), 11–19. https://doi.org/10.1002/(SICI)1099-1611(200001/02)9:1<11::AID-PON424>3.0.CO;2-Z

Fox, S. & Lantz, C. (1998). The brain tumor experience and quality of life: a qualitative study. *Journal of Neuroscience Nursing*, *30*(4), 245-52. doi: 10.1097/01376517-199808000-00005.

French-Rosas, L. N., Moye, J., Boston, V. A., System, H., & Naik, A. D. (2011). Improving the Recognition and Treatment of Cancer-Related Posttraumatic Stress Disorder. *Journal of Psychiatric Practice, 17*(4), 270-276. https://doi.org/10.1097/01.pra.0000400264.30043.ae

Garren, N., Acquaye, A. A., Vera, E., Lisa, B., Siegel, C., Park, D. M., Sull, J., Theeler, B. J., Wu, J., Crandon, S., Gilbert, M. & Armstrong, T. (2017). Evaluation of anxiety symptoms among brain tumor patients; are we providing appropriate, effective care? *Neuro-Oncology, 19*(6), 203–204. https://doi.org/10.1093/neuonc/nox168.823

Gately, L., McLachlan, S. A., Dowling, A., & Philip, J. (2020). Surviving glioblastoma and a sense of disconnection. *Journal of Clinical Neuroscience, 81*, 284–289. https://doi.org/10.1016/j.jocn.2020.10.012

Gentles, S. J., Jack, S. M., Nicholas, D. B., & Mckibbon, K. A. (2014). A critical approach to reflexivity in grounded theory. *The Qualitative Report, 19*(25), 1–14.

Ghazali, N., Cadwallader, E., Lowe, D., Humphris, G., Ozakinci, G., & Rogers, S. N. (2013). Fear of recurrence among head and neck cancer survivors: Longitudinal trends. *Psycho-Oncology*, *22*(4), 807–813. https://doi.org/10.1002/pon.3069

Gibson, A. W., & Graber, J. J. (2020). Distinguishing and treating depression, anxiety, adjustment, and post-traumatic stress disorders in brain tumor patients. *Annals of Palliative Medicine*, *9*(4), 77–77. https://doi.org/10.21037/apm-20-509

Glaser, B. G. (1978). *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory*. Sociology Press.

Glaser, B. G. & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine.

Goebel, S., Mederer, D., & Mehdorn, H. M. (2018). Surgery-Related Coping in Surgery Patients with Intracranial Tumors. *World Neurosurgery*, *116*, 775–782. https://doi.org/10.1016/j.wneu.2018.05.091

Goebel, S., Strenge, H., & Mehdorn, H. M. (2012). Acute stress in patients with brain cancer during primary care. *Supportive Care in Cancer*, *20*(7), 1425–1434. https://doi.org/10.1007/s00520-011-1225-6

Grey, S. J., Price, G., & Mathews, A. (2000). Reduction of anxiety during MR imaging: A controlled trial. *Magnetic Resonance Imaging*, *18*(3), 351–355. https://doi.org/10.1016/S0730-725X(00)00112-0

Guest, G., Bunce, A. & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability, *Field Methods, 18*(1), 59-82.

Gustafsson, M., Edvardsson, T., & Ahlström, G. (2006). The relationship between function, quality of life and coping in patients with low-grade gliomas. *Supportive Care in Cancer*, *14*(12), 1205–1212. https://doi.org/10.1007/s00520-006-0080-3

Hao, A., Huang, J., & Xu, X. (2020). Anxiety and depression in glioma patients: prevalence, risk factors, and their correlation with survival. *Irish Journal of Medical Science*, *190*, 1155-1164.

https://doi.org/10.1007/s11845-020-02374-5

Hulbert-Williams, N., Neal, R., Morrison, V., Hood, K., & Wilkinson, C. (2012). Anxiety, depression and quality of life after cancer diagnosis: What psychosocial variables best predict how patients adjust? *Psycho-Oncology*, *21*(8), 857–867. https://doi.org/10.1002/pon.1980

IJzerman-Korevaar, M., Snijders, T. J., de Graeff, A., Teunissen, S. C. C. M., & de Vos, F. Y. F. (2018). Prevalence of symptoms in glioma patients throughout the disease trajectory: a systematic review. *Journal of Neuro-Oncology*, *140*(3), 485–496. https://doi.org/10.1007/s11060-018-03015-9

Jiao, J., Jiang, C., Huang, J., Dai, M., Wang, C., Cheng, C., & Shao, J. (2014). Metabolic syndrome factors and risk of postoperative depression in high-grade glioma patients in a 1.5-year prospective study. *Medical Oncology*, *31*(10), 1–8. https://doi.org/10.1007/s12032-014-0234-y

Jim, H. S. L., & Jacobsen, P. B. (2008). Posttraumatic stress and posttraumatic growth in cancer survivorship: A review. *Cancer Journal*, *14*(6), 414–419. https://doi.org/10.1097/PPO.0b013e31818d8963

Kangas, M., Henry, J. L., & Bryant, R. A. (2002). Posttraumatic stress disorder following cancer: A conceptual and empirical review. *Clinical Psychology Review*, *22*(4), 499–524. https://doi.org/10.1016/S0272-7358(01)00118-0

Kangas, M., Tate, R. L., Williams, J. R., & Smee, R. I. (2012). The effects of radiotherapy on psychosocial and cognitive functioning in adults with a primary brain tumor: a prospective evaluation. *Neuro-Oncology*, *12*, 1485–1502.

Katz, R. C., Wilson, L., & Frazer, N. (1994). Anxiety and its determinants in patients undergoing Magnetic Resonance Imaging. *Journal of Behavior Therapy and Experimental Psychiatry*, *25*(2), 131–134. https://doi.org/10.1016/0005-7916(94)90005-1

Keeling, M., Bambrough, J., & Simpson, J. (2013). Depression, anxiety and positive affect in people diagnosed with low-grade tumours: The role of illness perceptions. *Psycho-Oncology*, *22*(6), 1421–1427. https://doi.org/10.1002/pon.3158

Lapointe, S., Perry, A., & Butowski, N. A. (2018). Primary brain tumours in adults. *The Lancet*, *392*(10145), 432–446. https://doi.org/10.1016/S0140-6736(18)30990-5

Lazarus, R., & Folkman, S. (1984). *Stress, Appraisal, and Coping.* Springer.

Leano, A., Korman, M. B., Goldberg, L., & Ellis, J. (2019). Are we missing PTSD in our patients with cancer? Part I. *Canadian Oncology Nursing Journal*, *29*(2), 141-146

Lepore, S. J. (2001). A social–cognitive processing model of emotional adjustment to cancer. In A. Baum & B. L. Andersen (Eds.), *Psychosocial interventions for cancer* (pp. 99–116). American Psychological Association.

Lethborg, C., Aranda, S., Bloch, S. & Kisane, D. (2008). The Role of Meaning in Advanced Cancer — Integrating the Constructs of Assumptive World , Sense of Coherence and Meaning-Based Coping. *Journal of Psychosocial Oncology, 24*(1), 27-42. https://doi.org/10.1300/J077v24n01_03

Li, J., Sun, L., Wang, X., Sun, C., Heng, S., Hu, X., Chen, W., & Liu, F. (2019). Are posttraumatic stress symptoms and avoidant coping inhibitory factors? The association between posttraumatic growth and quality of life among low-grade gliomas patients in China. *Frontiers in Psychology*, *10*, 1–11. https://doi.org/10.3389/fpsyg.2019.00330

Lillrank, A. (2003). Back pain and the resolution of diagnostic uncertainty in illness narratives. *Social Science and Medicine*, *57*(6), 1045–1054. https://doi.org/10.1016/S0277-9536(02)00479-3

Lin, L., Acquaye, A. A., Vera-Bolanos, E., Cahill, J. E., Gilbert, M. R., & Armstrong, T. S. (2012). Validation of the Mishel's uncertainty in illness scale-brain tumor form (MUIS-BT). *Journal of Neuro-Oncology*, *110*(2), 293–300. https://doi.org/10.1007/s11060-012-0971-8

Lin, L., Chiang, H. H., Acquaye, A. A., Vera-Bolanos, E., Gilbert, M. R., & Armstrong, T. S. (2013). Uncertainty, mood states, and symptom distress in patients with primary brain tumors: Analysis of a conceptual model using structural equation modeling. *Cancer, 119*(15), 2796–2806. https://doi.org/10.1002/cncr.28121

Lin, L., Chien, L. C., Acquaye, A. A., Vera-Bolanos, E., Gilbert, M. R., & Armstrong, T. S. (2015). Significant predictors of patients' uncertainty in primary brain tumors. *Journal of Neuro-Oncology*, *122*(3), 507–515. https://doi.org/10.1007/s11060-015-1756-7

Liu, F., Huang, J., Zhang, L., Fan, F., Chen, J., Xia, K., & Liu, Z. (2018). Screening for distress in patients with primary brain tumor using distress thermometer: A systematic review and meta-analysis. *BMC Cancer, 18*(1), 124. https://doi.org/10.1186/s12885-018-3990-9

Louis, D. N., Perry, A., Reifenberger, G., von Deimling, A., Figarella-Branger, D., Cavenee, W. K., Ohgaki, H., Wiestler, O. D., Kleihues, P., & Ellison, D. W. (2016). The 2016 World Health Organization Classification of Tumors of the Central Nervous System: a summary. *Acta*

Neuropathologica, *131*(6), 803–820. https://doi.org/10.1007/s00401-016-1545-1

Louis, D. N., Perry, A., Wesseling, P., Brat, D. J., Cree, I. A., Figarella-Branger, D., Hawkins, C., Ng, H. K., Pfister, S. M., Reifenberger, G., Soffietti, R., Von Deimling, A., & Ellison, D. W. (2021). The 2021 WHO classification of tumors of the central nervous system: A summary. *Neuro-Oncology*, *23*(8), 1231–1251. https://doi.org/10.1093/neuonc/noab106

Lukins, R., Davan, I. G. P., & Drummond, P. D. (1997). A cognitive behavioural approach to preventing anxiety during magnetic resonance imaging. *Journal of Behavior Therapy and Experimental Psychiatry*, *28*(2), 97–104. https://doi.org/10.1016/S0005-7916(97)00006-2

Mackenzie, R., Sims, C., Owens, R. G., & Dixon, A. K. (1995). Patients' perceptions of magnetic resonance imaging. *Clinical Radiology*, *50*(3), 137–143. https://doi.org/10.1016/S0009-9260(05)83042-9

Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *The British Medical Journal*, *320*(7226), 50-52.

Mishel, M. H. (1988). Uncertainty in Illness. *The Journal of Nursing Scholarship*, *20*(4), 225–232. https://doi.org/10.1111/j.1547-5069.1988.tb00082.x

Molassiotis, A., Wilson, B., Brunton, L., Chaudhary, H., Gattamaneni, R., & McBain, C. (2010). Symptom experience in patients with primary brain tumours: A longitudinal exploratory study. *European Journal of Oncology Nursing*, *14*(5), 410–416. https://doi.org/10.1016/j.ejon.2010.03.001

Morris, N., Moghaddam, N., Tickle, A., & Biswas, S. (2018). The relationship between coping style and psychological distress in people with head and neck cancer: A systematic review. *Psycho-Oncology*, *27*(3), 734–747. https://doi.org/10.1002/pon.4509

Mrowczynski, O. D., Zammar, S., Bourcier, A. J., Langan, S. T., Liao, J., Specht, C. S., & Rizk, E. B. (2018). Utility of Early Postoperative Magnetic Resonance Imaging After Glioblastoma Resection: Implications on Patient Survival. *World Neurosurgery*, *120*, 1171–1174. https://doi.org/10.1016/j.wneu.2018.09.027

Mugge, L., Mansour, T. R., Crippen, M., Alam, Y., & Schroeder, J. (2020). Depression and glioblastoma, complicated concomitant diseases: a systemic review of published literature. *Neurosurgical Review*, *43*(2), 497–511. https://doi.org/10.1007/s10143-018-1017-2

Nabors, L. B., Portnow, J., Ahluwalia, M., Baehring, J., Brem, H., Brem, S., Butowski, N., Campian, J. L., Clark, S. W., Fabiano, A. J., Forsyth, P., Hattangadi-Gluth, J., Holdhoff, M., Horbinski, C., Junck, L., Kaley, T., Kumthekar, P., Loeffler, J. S., Mrugala, M. M., … Darlow, S. D. (2020). Central nervous system cancers, version 3.2020, NCCN Clinical Practice Guidelines in Oncology. *Journal of the National Comprehensive Cancer Network*, *18*(11), 1537–1570. https://doi.org/10.6004/JNCCN.2020.0052

Newton, C., & Mateo, M. A. (1994). Uncertainty: Strategies for patients with brain tumor and their family. *Cancer Nursing*, *17*(2), 137–140.

National Institute for Health and Care Excellence. (2018). *Brain tumours (primary) and brain metastases in over 16s*. [NICE Guideline No. 99] https://www.nice.org.uk/guidance/ng99

Ostrom, Q. T., Bauchet, L., Davis, F. G., Deltour, I., Fisher, J. L., Langer, C. E., Pekmezci, M., Schwartzbaum, J. A., Turner, M. C., Walsh, K. M., Wrensch, M. R., & Barnholtz-Sloan, J. S. (2014). The epidemiology of glioma in adults: A state of the science review. *Neuro-Oncology*, *16*(7), 896–913. https://doi.org/10.1093/neuonc/nou087

Ostrom, Q. T., Cioffi, G., Waite, K., Kruchko, C., & Barnholtz-Sloan, J. S. (2021). CBTRUS Statistical Report: Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2014-2018. *Neuro-Oncology*, *23*(3), 1-105. https://doi.org/10.1093/neuonc/noab200

Ownsworth, T., Chambers, S., Hawkes, A., Walker, D. G., & Shum, D. (2011). Making sense of brain tumour: A qualitative investigation of personal and social processes of adjustment. *Neuropsychological Rehabilitation*, *21*(1), 117–137. https://doi.org/10.1080/09602011.2010.537073

Oztek, M. A., Brunnquell, C. L., Hoff, M. N., Boulter, D. J., Mossa-Basha, M., Beauchamp, L. H., Haynor, D. L., & Nguyen, X. V. (2020). Practical Considerations for Radiologists in Implementing a Patient-friendly MRI Experience. *Topics in Magnetic Resonance Imaging : TMRI*, *29*(4), 181–186. https://doi.org/10.1097/RMR.0000000000000247

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*(5), 533–544. https://doi.org/10.1007/S10488-013-0528-Y

Park, C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology*, *1*(2), 115–144. https://doi.org/10.1037/1089-2680.1.2.115

Powell, R., Ahmad, M., Gilbert, F. J., Brian, D., & Johnston, M. (2015). Improving magnetic resonance imaging (MRI) examinations: Development and evaluation of an intervention to reduce movement in scanners and facilitate scan completion. *British Journal of Health Psychology*, *20*(3), 449–465. https://doi.org/10.1111/bjhp.12132

Quirk, M. E., Letendre, A. J., Ciottone, R. A., & Lingley, J. F. (1989). Evaluation of three psychologic interventions to reduce anxiety during MR imaging. *Radiology, 173*(3), 759–762. https://doi.org/10.1148/radiology.173.3.2682775

RadiologyInfo (2021, February 08). *Head MRI.*

https://www.radiologyinfo.org/en/info/headmr

Randazzo, D., & Peters, K. B. (2016). Psychosocial distress and its effects on the health-related quality of life of primary brain tumor patients. *CNS Oncology*, *5*(4), 241–249. https://doi.org/10.2217/cns-2016-0010

Rooney, A. G., Brown, P. D., Reijneveld, J. C., & Grant, R. (2014). Depression in glioma: A primer for clinicians and researchers. *Journal of Neurology, Neurosurgery and Psychiatry*, *85*(2), 230–235. https://doi.org/10.1136/jnnp-2013-306497

Rooney, A. G., Carson, A., & Grant, R. (2011). Depression in cerebral glioma patients: A systematic review of observational studies. *Journal of the National Cancer Institute*, *103*(1), 61–76. https://doi.org/10.1093/jnci/djq458

Rooney, A. G., McNamara, S., MacKinnon, M., Fraser, M., Rampling, R., Carson, A., & Grant, R. (2013). The frequency, longitudinal course, clinical associations, and causes of emotional distress during primary treatment of cerebral glioma. *Neuro-Oncology*, *15*(5), 635–643. https://doi.org/10.1093/neuonc/not009

Salander, P., Bergenheim, T., & Henriksson, R. (1996). The creation of protection and hope in patients with malignant brain tumours. *Social Science and Medicine*, *42*(7), 985–996. https://doi.org/10.1016/0277-9536(95)00204-9

Salmon, P., & Young, B. (2017). A new paradigm for clinical communication: critical review of literature in cancer care. *Medical Education*, *51*(3), 258–268. https://doi.org/10.1111/medu.13204

Shi, C., Lamba, N., Zheng, L. J., Cote, D., Regestein, Q. R., Liu, C. M., Tran, Q., Routh, S., Smith, T. R., Mekary, R. A., & Broekman, M. L. D. (2018). Depression and survival of glioma patients: A systematic review and meta-analysis. *Clinical Neurology and Neurosurgery*, *172*, 8–19. https://doi.org/10.1016/j.clineuro.2018.06.016

Smith, J. A. (1996). Beyond the divide between cognition and discourse. *Psychology & Health*, *11*(2), 261–271.

Snape, D. & Spencer, L. (2003) The foundations of qualitative research. In J. Ritchie & J. Lewis (Eds.) *Qualitative Research practice: A Guide for Social Science Students and Researchers* (pp. 1-23). SAGE Publications.

Song, K., Amatya, B. & Khan, F. (2015). Advance care planning in patients with brain tumours: a prospective cohort study. *Journal of Cancer Research & Therapy*, *3*(7), 85–91. https://doi.org/10.14312/2052-4994.2015-12

Sterckx, W., Coolbrandt, A., Clement, P., Borgenon, S., Decruyenaere, M., De Vleeschouwer, S., Mees, A., & Dierckx de Casterlé, B. (2015). Living with a high-grade glioma: A qualitative study of patients' experiences and care needs. *European Journal of Oncology Nursing*, *19*(4), 383–390. https://doi.org/10.1016/j.ejon.2015.01.003

Stiegelis, H. E., Hagedoorn, M., Sanderman, R., Van der Zee, K. I., Buunk, B. P., & Van den Bergh, A. C. M. (2003). Cognitive adaptation: A comparison of cancer patients and healthy references. *British Journal of Health Psychology*, *8*(3), 303–318. https://doi.org/10.1348/135910703322370879

Strauss, A. L. & Corbin, J. M. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Technique*s. SAGE Publications.

Strauss, A. L. & Corbin, J. M. (1998). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (2nd ed.). SAGE Publications.

Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaption. *American Psychologist*, *38*(11), 1161–1173.

Tazegul, G., Etcioglu, E., Yildiz, F., Yildiz, R., & Tuney, D. (2015). Can MRI related patient anxiety be prevented? *Magnetic Resonance Imaging*, *33*(1), 180–183. https://doi.org/10.1016/j.mri.2014.08.024

The National Health Service (2018, August 09). *MRI scan.*

https://www.nhs.uk/conditions/mri-scan/

Thompson, C. A., Charlson, M. E., Schenkein, E., Wells, M. T., Furman, R. R., Elstrom, R., Ruan, J., Martin, P., & Leonard, J. P. (2010). Surveillance CT scans are a source of anxiety and fear of recurrence in long-term lymphoma survivors. *Annals of Oncology*, *21*(11), 2262–2266. https://doi.org/10.1093/annonc/mdq215

Thompson, G., Lawrie, T. A., Kernohan, A., & Jenkinson, M. D. (2019). Interval brain imaging for adults with cerebral glioma. *Cochrane Database of Systematic Reviews*, *12*. https://doi.org/10.1002/14651858.CD013137.pub2

Thomsen, T. G., Rydahl-Hansen, S., & Wagner, L. (2010). A review of potential factors relevant to coping in patients with advanced cancer. *Journal of Clinical Nursing*, *19*(23–24), 3410–3426. https://doi.org/10.1111/j.1365-2702.2009.03154.x

Thorne, S. E., Bultz, B. D., Baile, W. F., Hack, T., Degner, L., Brundage, M., Butler, L., Carlson, L., Davidon, J., Feldman-Stewart, D., Parker, P., & Tishelman, C. (2005). Is there a cost to poor communication in cancer care?: A critical review of the literature. *Psycho-Oncology*, *14*(10), 875–884. https://doi.org/10.1002/pon.947

Törnqvist, E., Månsson, Å., Larsson, E. M., & Hallström, I. (2006a). It's like being in another world - Patients' lived experience of magnetic resonance imaging. *Journal of Clinical Nursing*, *15*(8), 954–961. https://doi.org/10.1111/j.1365-2702.2006.01499.x

Törnqvist, E., Månsson, A., Larsson, E. M., & Hallström, I. (2006b). Impact of extended written information on patient anxiety and image motion artifacts during magnetic resonance imaging. *Acta Radiologica*, *47*(5), 474–480. https://doi.org/10.1080/02841850600690355

Trejnowska, A., Goodall, K., Rush, R., Ellison, M., & McVittie, C. (2019). The relationship between adult attachment and coping with brain tumour: the mediating role of social support. *Psycho-Oncology, 29*, 729–736. https://doi.org/10.1002/pon.5325

Tugwell, J. R., Goulden, N., & Mullins, P. (2018). Alleviating anxiety in patients prior to MRI: A pilot single-centre single-blinded randomised controlled trial to compare video demonstration or telephone conversation with a radiographer versus routine intervention. *Radiography*, *24*(2), 122–129. https://doi.org/10.1016/j.radi.2017.10.001

Tyldesley-Marshall, N., Greenfield, S., Neilson, S., English, M., Adamski, J., & Peet, A. (2020). Qualitative study: Patients' and parents' views on brain tumour MRIs. *Archives of Disease in Childhood*, *105*(2), 166–172. https://doi.org/10.1136/archdischild-2019-317306

Tyldesley-Marshall, N., Greenfield, S., Neilson, S. J., English, M., Adamski, J., & Peet, A. (2021).

The role of Magnetic Resonance Images (MRIs) in coping for patients with brain tumours and their parents: a qualitative study. *BMC Cancer*, *21*(1013), 1–10. https://doi.org/10.1186/s12885-021-08673-z

Umstead, K. L., Kalia, S. S., Madeo, A. C., Erby, L. H., Blank, T. O., Visvanathan, K., & Roter, D. L. (2018). Social comparisons and quality of life following a prostate cancer diagnosis. *Journal of Psychological Oncology, 36*(3), 350-363. https://doi.org/10.1080/07347332.2017.1417950

Van der Zee, K., Buunk, B., Sanderman, R., Botke, G., & Van den Bergh, F. (2000). Social comparison and coping with cancer treatment. *Personality and Individual Differences, 28*(1), 17–34. https://doi.org/10.1016/S0191-8869(99)00045-8

Van Minde, D., Klaming, L., & Weda, H. (2014). Pinpointing moments of high anxiety during an MRI examination. *International Journal of Behavioral Medicine*, *21*(3), 487–495. https://doi.org/10.1007/s12529-013-9339-5

Walsh, K. M., Ohgaki, H., & Wrensch, M. R. (2016). Epidemiology. *Handbook of Clinical Neurology, Gliomas, 134*(3), 3–18. https://doi.org/10.1016/B978-0-12-802997-8.00001-3 https://doi.org/10.1016/B978-0-12-802997-8.00001-3

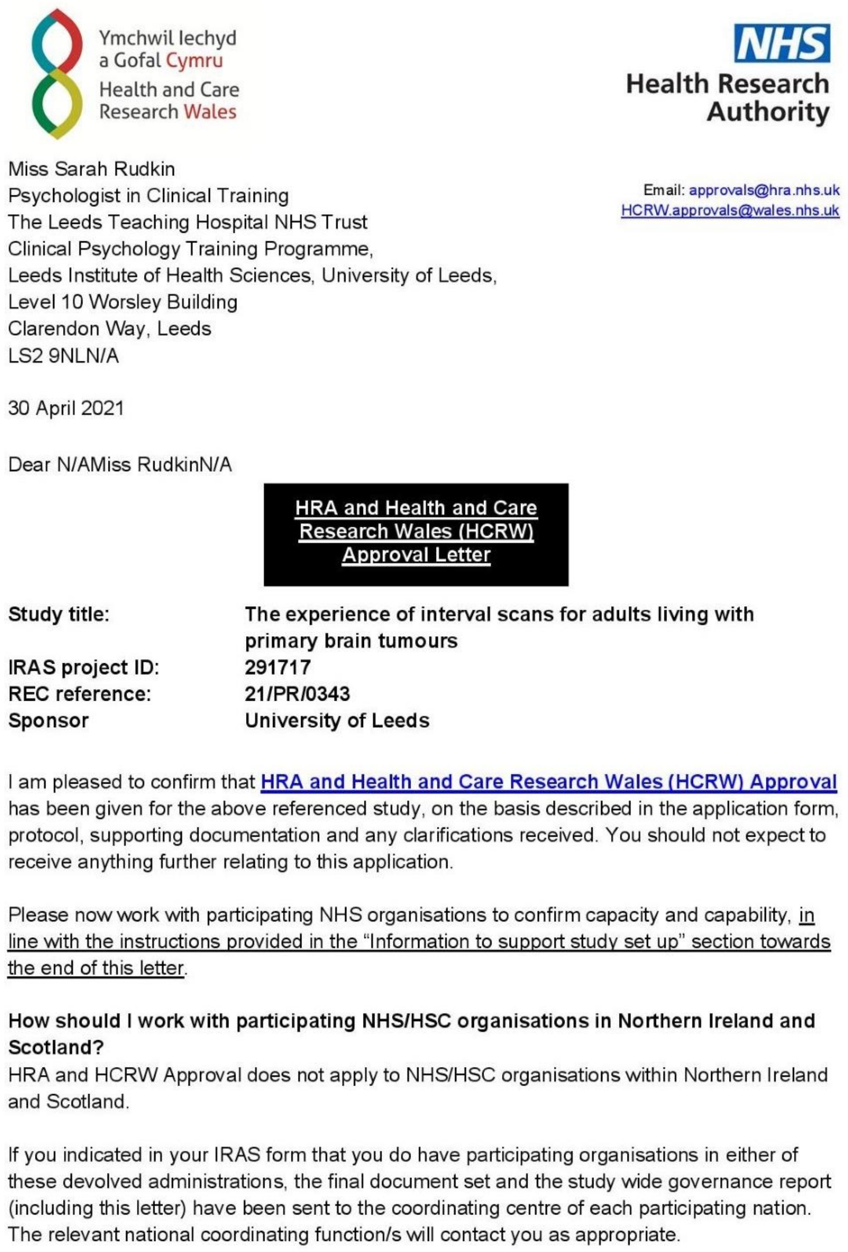
Walter, F. M., Penfold, C., Joannides, A., Saji, S., Price, S. J., Johnson, M., Watts, C., Brodbelt, A., Jenkinson, M. D., Hamilton, W., & Scott, S. E. (2019). Missed opportunities for diagnosing brain tumours in primary care: A qualitative study of patient experiences. *British Journal of General Practice*, *69*(681), 224–234. https://doi.org/10.3399/bjgp19X701861

Willig, C. (2013). *Introducing Qualitative Research in Psychology* (3rd ed.). Open University Press

Wright, L. J., Afari, N., & Zautra, A. (2009). The illness uncertainty concept: A review. *Current Pain and Headache Reports, 13*(2), 133–138. https://doi.org/10.1007/s11916-009-0023-z

APPENDICES

Appendix A: HRA Approval Letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Sarah Rudkin
Psychologist in Clinical Training
The Leeds Teaching Hospital NHS Trust
Clinical Psychology Training Programme,
Leeds Institute of Health Sciences, University of Leeds,
Level 10 Worsley Building
Clarendon Way, Leeds
LS2 9NLN/A

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

30 April 2021

Dear N/AMiss RudkinN/A

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The experience of interval scans for adults living with primary brain tumours**
IRAS project ID:	**291717**
REC reference:	**21/PR/0343**
Sponsor	**University of Leeds**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

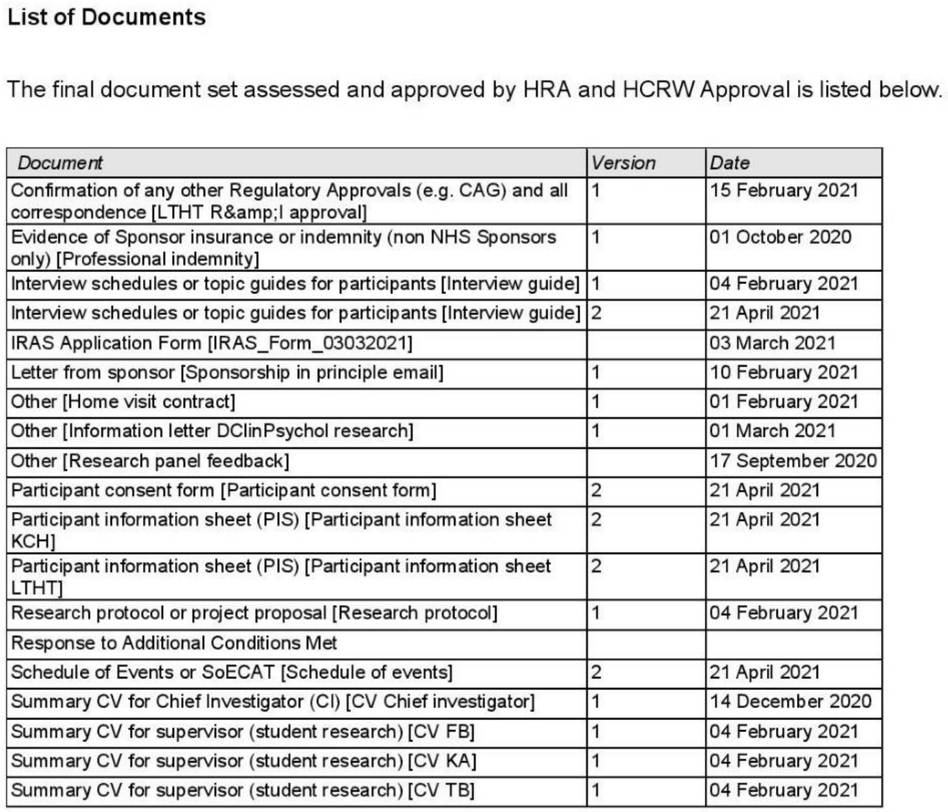
Your IRAS project ID is **291717**. Please quote this on all correspondence.

Yours sincerely,
Natasha Bridgeman

Approvals Specialist

Email: approvals@hra.nhs.uk

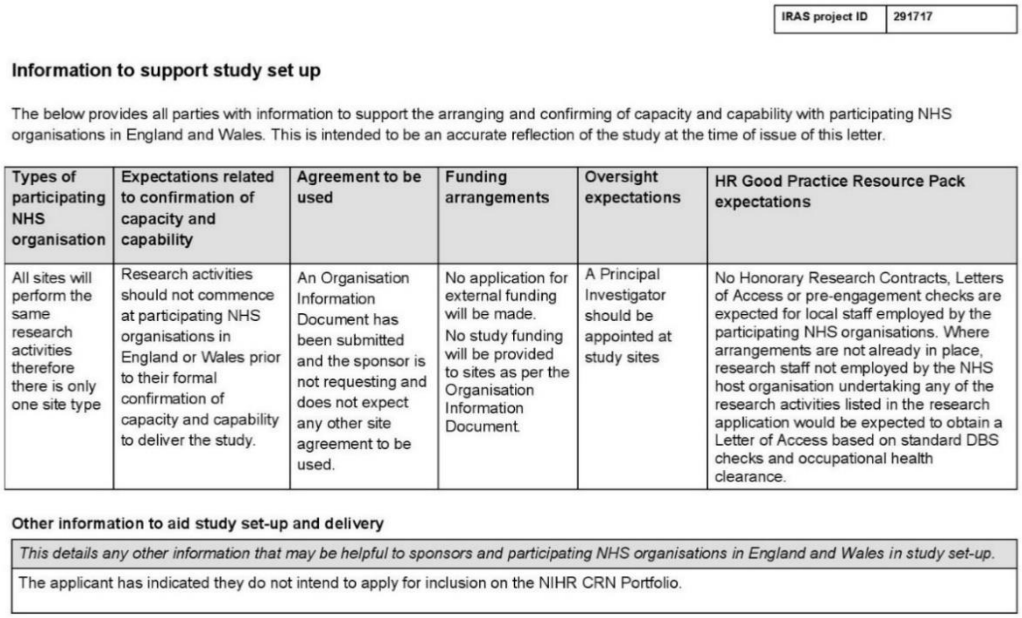
Copy to: *Ms Jean Uniacke*



List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [LTHT R&I approval]	1	15 February 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional indemnity]	1	01 October 2020
Interview schedules or topic guides for participants [Interview guide]	1	04 February 2021
Interview schedules or topic guides for participants [Interview guide]	2	21 April 2021
IRAS Application Form [IRAS_Form_03032021]		03 March 2021
Letter from sponsor [Sponsorship in principle email]	1	10 February 2021
Other [Home visit contract]	1	01 February 2021
Other [Information letter DClinPsychol research]	1	01 March 2021
Other [Research panel feedback]		17 September 2020
Participant consent form [Participant consent form]	2	21 April 2021
Participant information sheet (PIS) [Participant information sheet KCH]	2	21 April 2021
Participant information sheet (PIS) [Participant information sheet LTHT]	2	21 April 2021
Research protocol or project proposal [Research protocol]	1	04 February 2021
Response to Additional Conditions Met		
Schedule of Events or SoECAT [Schedule of events]	2	21 April 2021
Summary CV for Chief Investigator (CI) [CV Chief investigator]	1	14 December 2020
Summary CV for supervisor (student research) [CV FB]	1	04 February 2021
Summary CV for supervisor (student research) [CV KA]	1	04 February 2021
Summary CV for supervisor (student research) [CV TB]	1	04 February 2021



IRAS project ID	291717

Information to support study set up

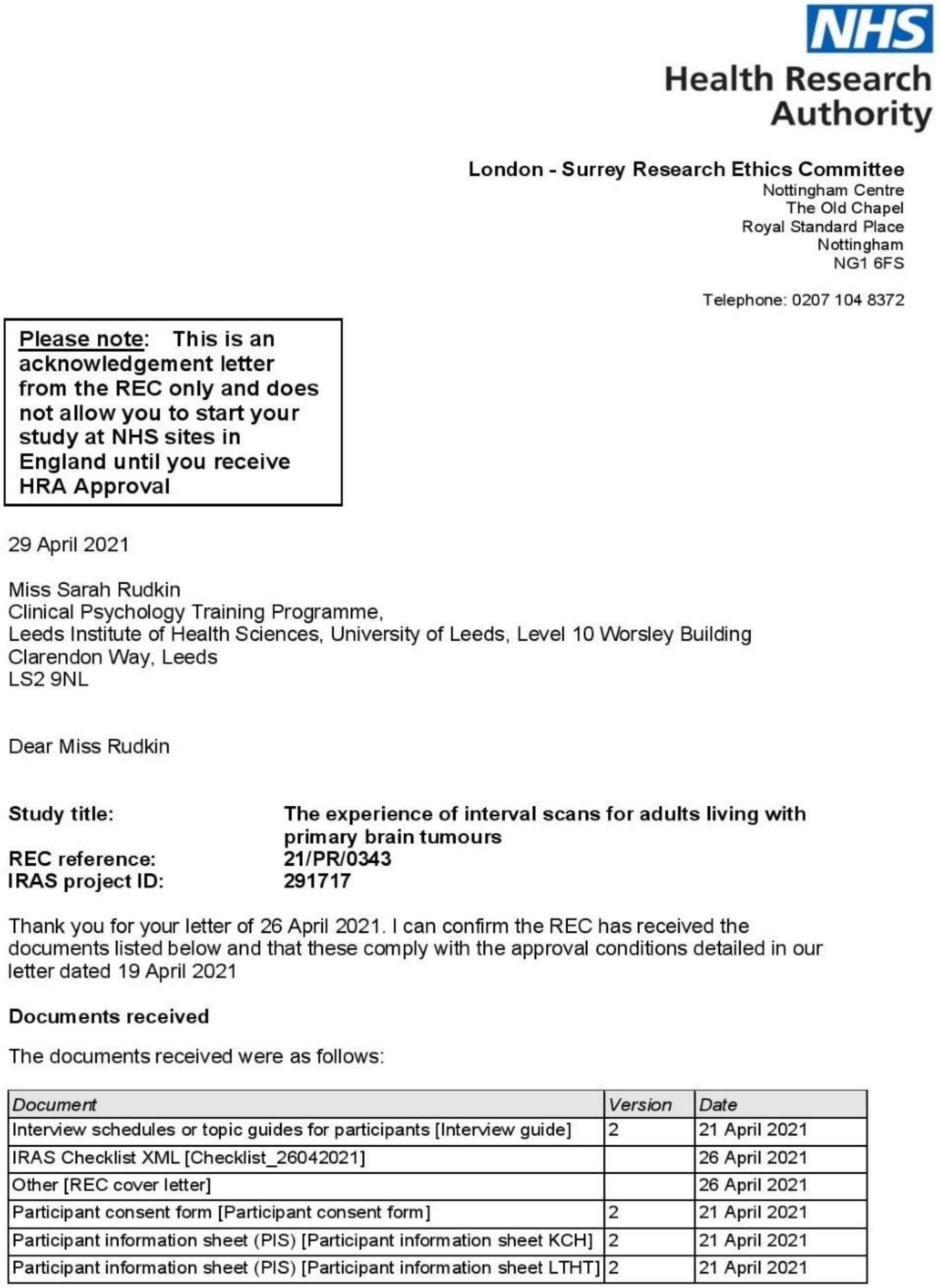
The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	**Expectations related to confirmation of capacity and capability**	**Agreement to be used**	**Funding arrangements**	**Oversight expectations**	**HR Good Practice Resource Pack expectations**
All sites will perform the same research activities therefore there is only one site type	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No application for external funding will be made. No study funding will be provided to sites as per the Organisation Information Document.	A Principal Investigator should be appointed at study sites	No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix B: NHS Ethics Approval Letter



NHS
Health Research
Authority

London - Surrey Research Ethics Committee
Nottingham Centre
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0207 104 8372

Please note: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

29 April 2021

Miss Sarah Rudkin
Clinical Psychology Training Programme,
Leeds Institute of Health Sciences, University of Leeds, Level 10 Worsley Building
Clarendon Way, Leeds
LS2 9NL

Dear Miss Rudkin

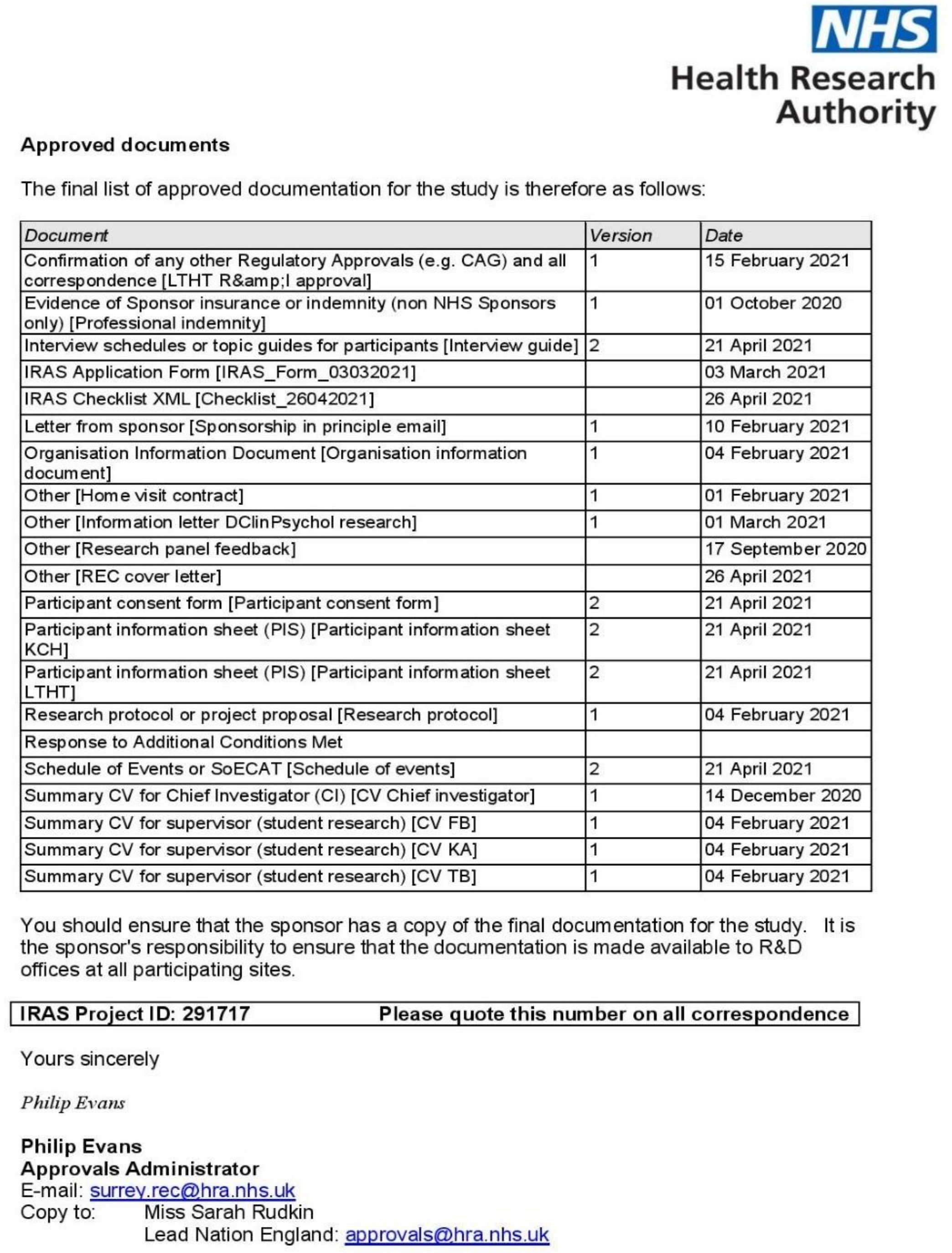
Study title:	**The experience of interval scans for adults living with primary brain tumours**
REC reference:	**21/PR/0343**
IRAS project ID:	**291717**

Thank you for your letter of 26 April 2021. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 19 April 2021

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Interview schedules or topic guides for participants [Interview guide]	2	21 April 2021
IRAS Checklist XML [Checklist_26042021]		26 April 2021
Other [REC cover letter]		26 April 2021
Participant consent form [Participant consent form]	2	21 April 2021
Participant information sheet (PIS) [Participant information sheet KCH]	2	21 April 2021
Participant information sheet (PIS) [Participant information sheet LTHT]	2	21 April 2021



NHS
Health Research
Authority

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [LTHT R&I approval]	1	15 February 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional indemnity]	1	01 October 2020
Interview schedules or topic guides for participants [Interview guide]	2	21 April 2021
IRAS Application Form [IRAS_Form_03032021]		03 March 2021
IRAS Checklist XML [Checklist_26042021]		26 April 2021
Letter from sponsor [Sponsorship in principle email]	1	10 February 2021
Organisation Information Document [Organisation information document]	1	04 February 2021
Other [Home visit contract]	1	01 February 2021
Other [Information letter DClinPsychol research]	1	01 March 2021
Other [Research panel feedback]		17 September 2020
Other [REC cover letter]		26 April 2021
Participant consent form [Participant consent form]	2	21 April 2021
Participant information sheet (PIS) [Participant information sheet KCH]	2	21 April 2021
Participant information sheet (PIS) [Participant information sheet LTHT]	2	21 April 2021
Research protocol or project proposal [Research protocol]	1	04 February 2021
Response to Additional Conditions Met		
Schedule of Events or SoECAT [Schedule of events]	2	21 April 2021
Summary CV for Chief Investigator (CI) [CV Chief investigator]	1	14 December 2020
Summary CV for supervisor (student research) [CV FB]	1	04 February 2021
Summary CV for supervisor (student research) [CV KA]	1	04 February 2021
Summary CV for supervisor (student research) [CV TB]	1	04 February 2021

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

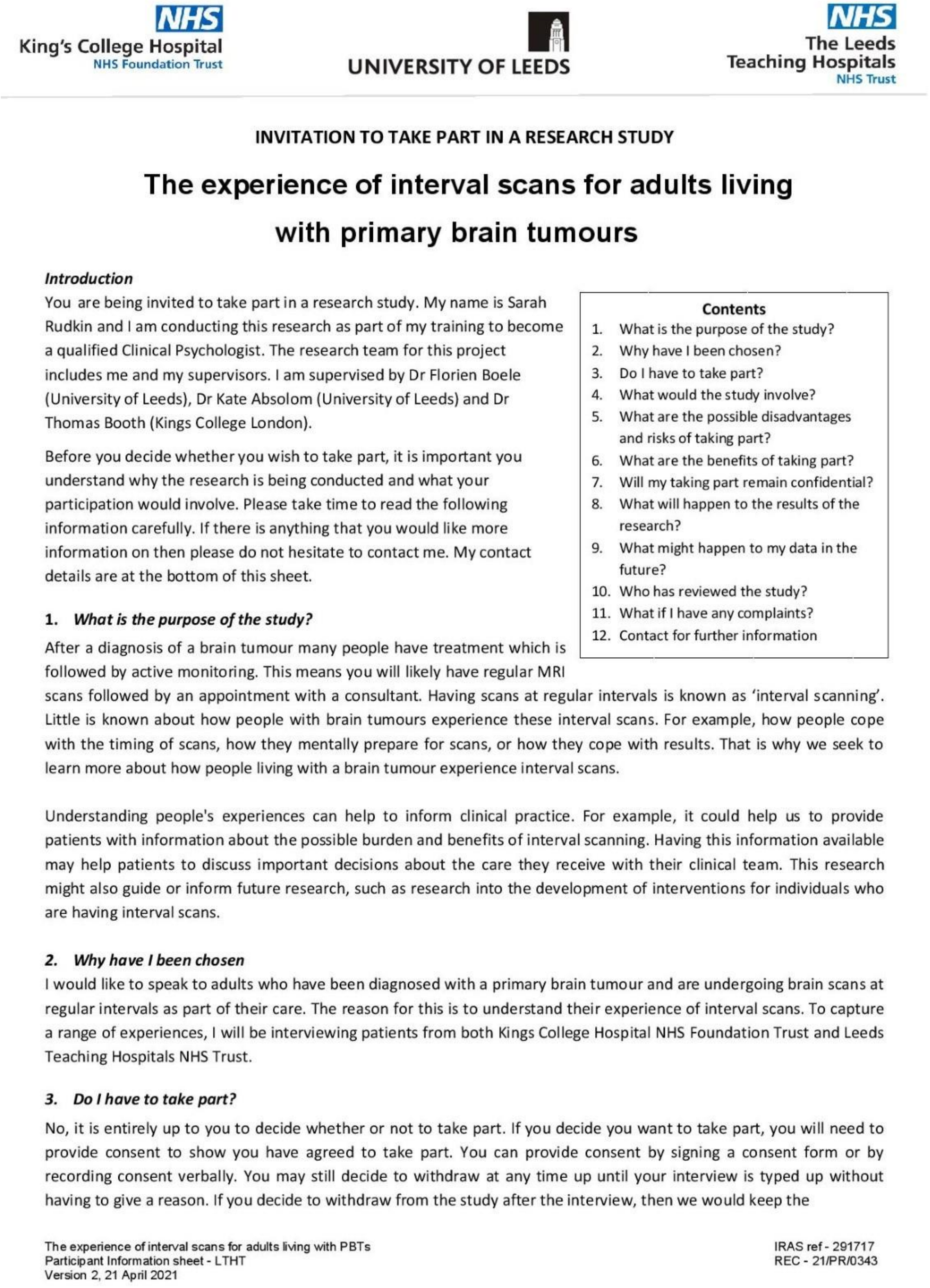
IRAS Project ID: 291717 **Please quote this number on all correspondence**

Yours sincerely

Philip Evans

Philip Evans
Approvals Administrator
E-mail: surrey.rec@hra.nhs.uk
Copy to: Miss Sarah Rudkin
Lead Nation England: approvals@hra.nhs.uk

Appendix C: Participant Information Sheet (LTHT version)



King's College Hospital
NHS Foundation Trust

UNIVERSITY OF LEEDS

The Leeds
Teaching Hospitals
NHS Trust

INVITATION TO TAKE PART IN A RESEARCH STUDY

The experience of interval scans for adults living with primary brain tumours

Contents

Introduction

You are being invited to take part in a research study. My name is Sarah Rudkin and I am conducting this research as part of my training to become a qualified Clinical Psychologist. The research team for this project includes me and my supervisors. I am supervised by Dr Florien Boele (University of Leeds), Dr Kate Absolom (University of Leeds) and Dr Thomas Booth (Kings College London).

Before you decide whether you wish to take part, it is important you understand why the research is being conducted and what your participation would involve. Please take time to read the following information carefully. If there is anything that you would like more information on then please do not hesitate to contact me. My contact details are at the bottom of this sheet.

1. *What is the purpose of the study?*

After a diagnosis of a brain tumour many people have treatment which is followed by active monitoring. This means you will likely have regular MRI scans followed by an appointment with a consultant. Having scans at regular intervals is known as 'interval scanning'. Little is known about how people with brain tumours experience these interval scans. For example, how people cope with the timing of scans, how they mentally prepare for scans, or how they cope with results. That is why we seek to learn more about how people living with a brain tumour experience interval scans.

Understanding people's experiences can help to inform clinical practice. For example, it could help us to provide patients with information about the possible burden and benefits of interval scanning. Having this information available may help patients to discuss important decisions about the care they receive with their clinical team. This research might also guide or inform future research, such as research into the development of interventions for individuals who are having interval scans.

2. Why have I been chosen

I would like to speak to adults who have been diagnosed with a primary brain tumour and are undergoing brain scans at regular intervals as part of their care. The reason for this is to understand their experience of interval scans. To capture a range of experiences, I will be interviewing patients from both Kings College Hospital NHS Foundation Trust and Leeds Teaching Hospitals NHS Trust.

3. Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to provide consent to show you have agreed to take part. You can provide consent by signing a consent form or by recording consent verbally. You may still decide to withdraw at any time up until your interview is typed up without having to give a reason. If you decide to withdraw from the study after the interview, then we would keep the

8. What will happen to the results of the research?

The results of the research will be written as a thesis report and published online, presented at conferences, and published in academic journals. Results will also be posted on the Patient Centred Outcome Research (PCOR) website where you may view them if you wish: http://pcor.org.uk/

9. What might happen to my data in the future?

University of Leeds is the sponsor for this study. The University will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The research team will keep identifiable information about you for ten years after the study has finished. The only identifiable information that will be kept is your signed consent form. All data collected from your interview will be kept and stored in a coded and anonymised way. Your rights to access, change or move your information are limited, as your information need to be managed in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally identifiable information possible. You can find out more about how we use your information by contacting the Data Protection Officer on dpo@leeds.ac.uk or at *https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf*.

The data from this research may be used by the research team in future research studies. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research. This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research and cannot be used to contact you or to affect your care.

10. Who has reviewed the study?

Before any research can happen, it has to be checked by a group of people called a Research Ethics Committee. This study has been approved by the Surrey REC on 29 April 2021 (REC reference: 21/PR/0343).

11. What if I have any complaints?

If you have a concern about any aspect of this study, then please contact me using the contact details below and I will do my best to answer your questions. If you remain unhappy you may wish to contact the Leeds Teaching Hospitals NHS Trust's Patient Advice and Liaison Service (PALS) - Phone: 0113 2066261 or 0113 2067168 Email: patient.relations@leedsth.nhs.uk.

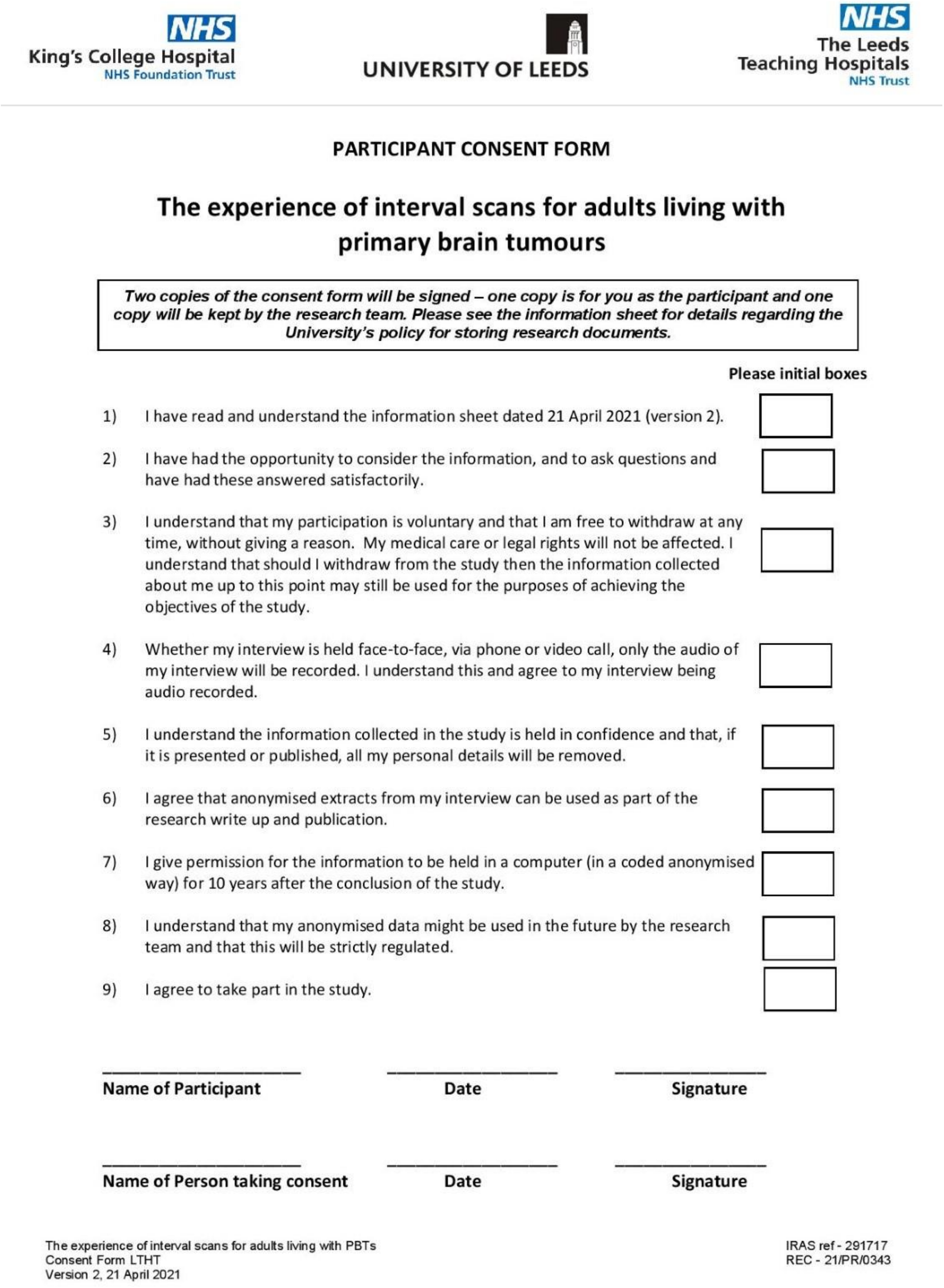
12. Contact for further information

If you have any concerns or questions about this study at any time, please contact me using the details below and I will get back to you as soon as possible.

Sarah Rudkin; Email: umser@leeds.ac.uk; Phone: 07708933667

Thank you for taking the time to read this information sheet

Appendix D: Participant Consent Form (LTHT version)



NHS
King's College Hospital
NHS Foundation Trust

UNIVERSITY OF LEEDS

NHS
The Leeds
Teaching Hospitals
NHS Trust

PARTICIPANT CONSENT FORM

The experience of interval scans for adults living with primary brain tumours

Two copies of the consent form will be signed – one copy is for you as the participant and one copy will be kept by the research team. Please see the information sheet for details regarding the University's policy for storing research documents.

Please initial boxes

1) I have read and understand the information sheet dated 21 April 2021 (version 2). ☐

2) I have had the opportunity to consider the information, and to ask questions and have had these answered satisfactorily. ☐

3) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason. My medical care or legal rights will not be affected. I understand that should I withdraw from the study then the information collected about me up to this point may still be used for the purposes of achieving the objectives of the study. ☐

4) Whether my interview is held face-to-face, via phone or video call, only the audio of my interview will be recorded. I understand this and agree to my interview being audio recorded. ☐

5) I understand the information collected in the study is held in confidence and that, if it is presented or published, all my personal details will be removed. ☐

6) I agree that anonymised extracts from my interview can be used as part of the research write up and publication. ☐

7) I give permission for the information to be held in a computer (in a coded anonymised way) for 10 years after the conclusion of the study. ☐

8) I understand that my anonymised data might be used in the future by the research team and that this will be strictly regulated. ☐

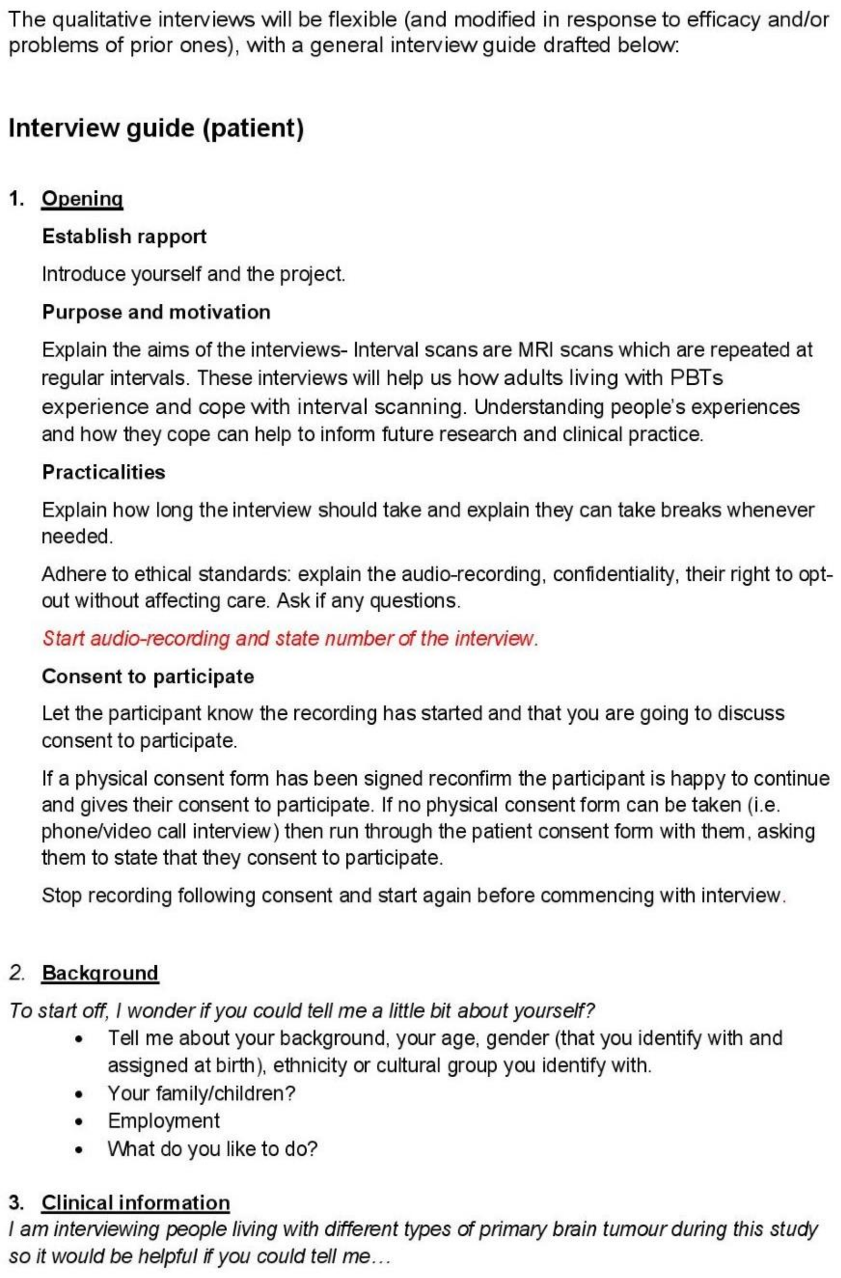
9) I agree to take part in the study. ☐

____________________	________________	______________
Name of Participant	**Date**	**Signature**
____________________	________________	______________
Name of Person taking consent	**Date**	**Signature**

The experience of interval scans for adults living with PBTs
Consent Form LTHT
Version 2, 21 April 2021

IRAS ref - 291717
REC - 21/PR/0343

Appendix E: Interview Guide



The qualitative interviews will be flexible (and modified in response to efficacy and/or problems of prior ones), with a general interview guide drafted below:

Interview guide (patient)

1. **Opening**

Establish rapport

Introduce yourself and the project.

Purpose and motivation

Explain the aims of the interviews- Interval scans are MRI scans which are repeated at regular intervals. These interviews will help us how adults living with PBTs experience and cope with interval scanning. Understanding people's experiences and how they cope can help to inform future research and clinical practice.

Practicalities

Explain how long the interview should take and explain they can take breaks whenever needed.

Adhere to ethical standards: explain the audio-recording, confidentiality, their right to opt-out without affecting care. Ask if any questions.

Start audio-recording and state number of the interview.

Consent to participate

Let the participant know the recording has started and that you are going to discuss consent to participate.

If a physical consent form has been signed reconfirm the participant is happy to continue and gives their consent to participate. If no physical consent form can be taken (i.e. phone/video call interview) then run through the patient consent form with them, asking them to state that they consent to participate.

Stop recording following consent and start again before commencing with interview.

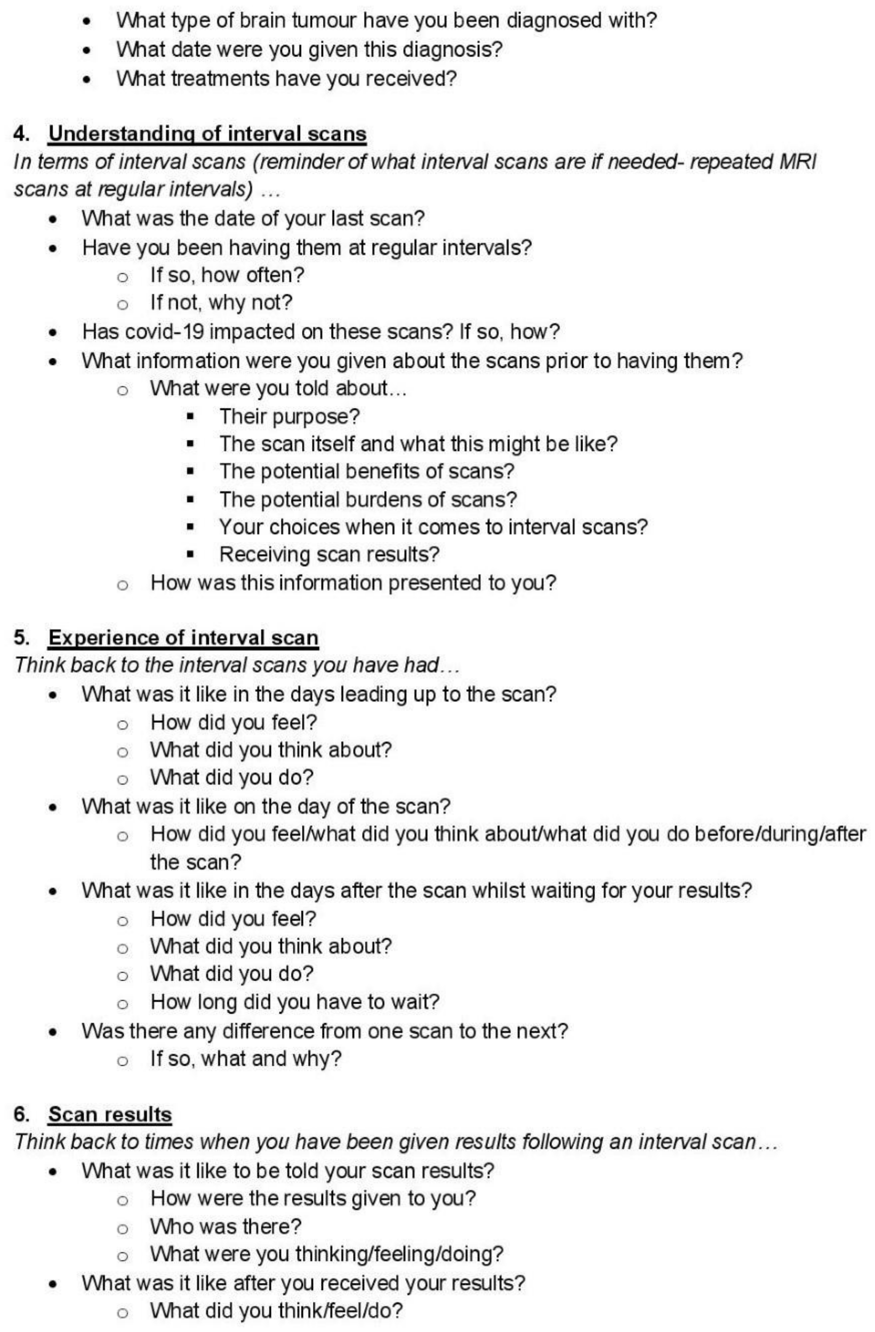
2. **Background**

To start off, I wonder if you could tell me a little bit about yourself?

- Tell me about your background, your age, gender (that you identify with and assigned at birth), ethnicity or cultural group you identify with.
- Your family/children?
- Employment
- What do you like to do?

3. **Clinical information**

I am interviewing people living with different types of primary brain tumour during this study so it would be helpful if you could tell me…



- What type of brain tumour have you been diagnosed with?
- What date were you given this diagnosis?
- What treatments have you received?

4. Understanding of interval scans

In terms of interval scans (reminder of what interval scans are if needed- repeated MRI scans at regular intervals) …

- What was the date of your last scan?
- Have you been having them at regular intervals?
  - If so, how often?
  - If not, why not?
- Has covid-19 impacted on these scans? If so, how?
- What information were you given about the scans prior to having them?
  - What were you told about…
    - Their purpose?
    - The scan itself and what this might be like?
    - The potential benefits of scans?
    - The potential burdens of scans?
    - Your choices when it comes to interval scans?
    - Receiving scan results?
  - How was this information presented to you?

5. Experience of interval scan

Think back to the interval scans you have had…

- What was it like in the days leading up to the scan?
  - How did you feel?
  - What did you think about?
  - What did you do?
- What was it like on the day of the scan?
  - How did you feel/what did you think about/what did you do before/during/after the scan?
- What was it like in the days after the scan whilst waiting for your results?
  - How did you feel?
  - What did you think about?
  - What did you do?
  - How long did you have to wait?
- Was there any difference from one scan to the next?
  - If so, what and why?

6. Scan results

Think back to times when you have been given results following an interval scan…

- What was it like to be told your scan results?
  - How were the results given to you?
  - Who was there?
  - What were you thinking/feeling/doing?
- What was it like after you received your results?
  - What did you think/feel/do?

- Have you ever had any undetermined results?
    - What was this like?
    - What did you think/feel/do?
- Has covid-19 impacted on receiving scan results? If so, how?

7. **Burdens vs. benefits**
    - Have interval scans been helpful or beneficial for you?
        - If yes, how?
        - If no, why not?
    - Have interval scans impacted on you or your day-to-day life in any way? (burdens)
        - If yes, how have they impacted?
        - If they experience distress- how do you manage this?
    - Given the choice, would you choose to continue having interval scans, or choose to only have scans following a change in your symptoms?

8. **End of the interview**
    - Is there anything else that you think we need to know?
    - Do you have any questions?
    - How have you found this interview?

Turn off audio-recorder.

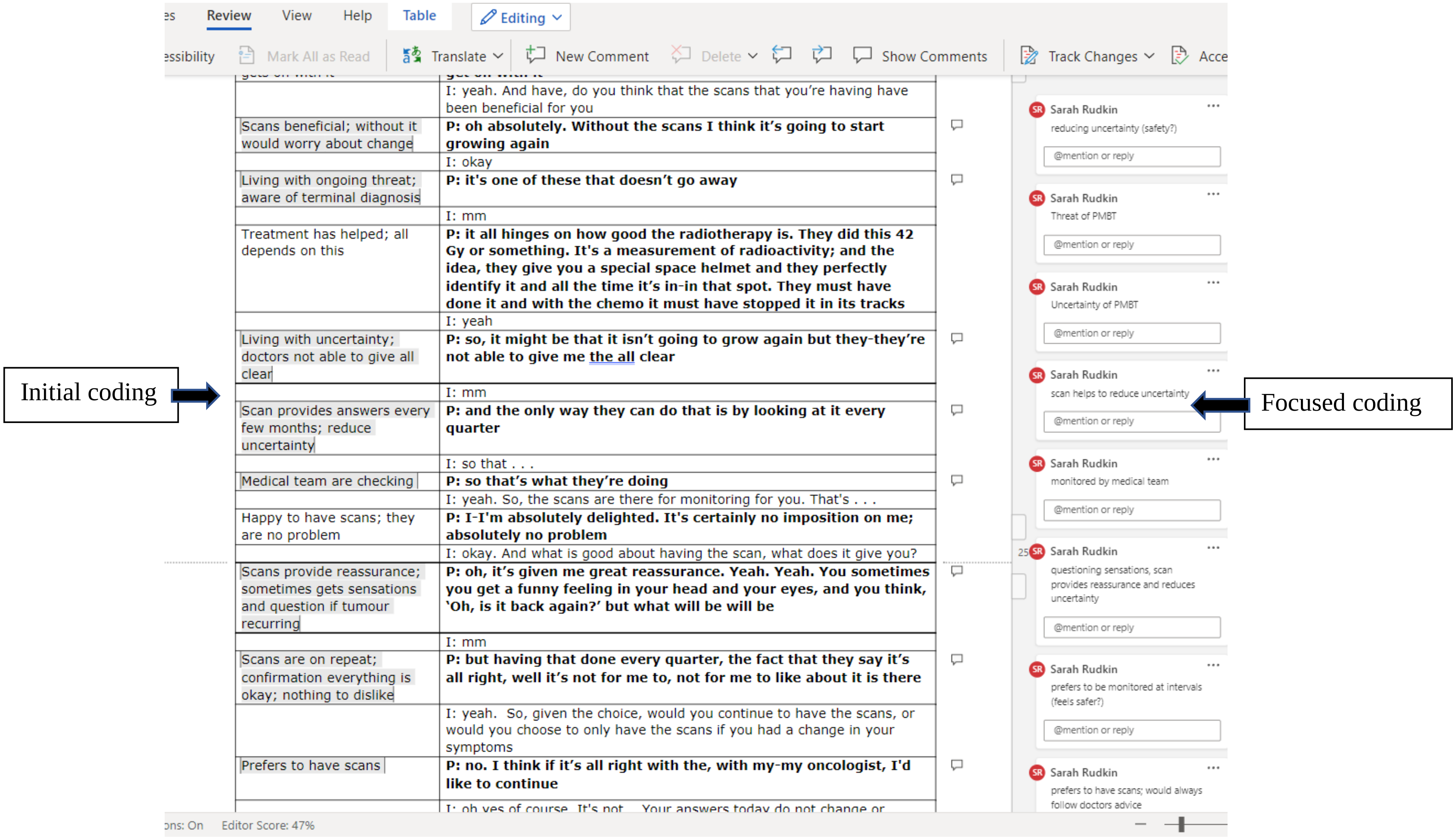
Explain following procedure. Provide contact information to contact us if anything is unclear or they need further information. Thank the participant for his/her time.

Note time end interview.

Standard follow-up questions

- What do you mean exactly?
- In what way?
- Could you explain that a bit more?
- What else can you tell me about that? There is no right or wrong, just tell me what you are thinking right now.
- Could you explain why (you feel like that)?
- Could you explain that further, in your own words?
- Is there anything else that pops up?

Appendix F: Example of anonymised transcript with initial and focused coding



	I: yeah. And have, do you think that the scans that you're having have been beneficial for you
Scans beneficial; without it would worry about change	**P: oh absolutely. Without the scans I think it's going to start growing again**
	I: okay
Living with ongoing threat; aware of terminal diagnosis	**P: it's one of these that doesn't go away**
	I: mm
Treatment has helped; all depends on this	**P: it all hinges on how good the radiotherapy is. They did this 42 Gy or something. It's a measurement of radioactivity; and the idea, they give you a special space helmet and they perfectly identify it and all the time it's in-in that spot. They must have done it and with the chemo it must have stopped it in its tracks**
	I: yeah
Living with uncertainty; doctors not able to give all clear	**P: so, it might be that it isn't going to grow again but they-they're not able to give me the all clear**
	I: mm
Scan provides answers every few months; reduce uncertainty	**P: and the only way they can do that is by looking at it every quarter**
	I: so that . . .
Medical team are checking	**P: so that's what they're doing**
	I: yeah. So, the scans are there for monitoring for you. That's . . .
Happy to have scans; they are no problem	**P: I-I'm absolutely delighted. It's certainly no imposition on me; absolutely no problem**
	I: okay. And what is good about having the scan, what does it give you?
Scans provide reassurance; sometimes gets sensations and question if tumour recurring	**P: oh, it's given me great reassurance. Yeah. Yeah. You sometimes you get a funny feeling in your head and your eyes, and you think, 'Oh, is it back again?' but what will be will be**
	I: mm
Scans are on repeat; confirmation everything is okay; nothing to dislike	**P: but having that done every quarter, the fact that they say it's all right, well it's not for me to, not for me to like about it is there**
	I: yeah. So, given the choice, would you continue to have the scans, or would you choose to only have the scans if you had a change in your symptoms
Prefers to have scans	**P: no. I think if it's all right with the, with my-my oncologist, I'd like to continue**
	I: oh yes of course. It's not . . . Your answers today do not change or

Sarah Rudkin
reducing uncertainty (safety?)
@mention or reply

Sarah Rudkin
Threat of PMBT
@mention or reply

Sarah Rudkin
Uncertainty of PMBT
@mention or reply

Sarah Rudkin
scan helps to reduce uncertainty
@mention or reply

Sarah Rudkin
monitored by medical team
@mention or reply

Sarah Rudkin
questioning sensations, scan provides reassurance and reduces uncertainty
@mention or reply

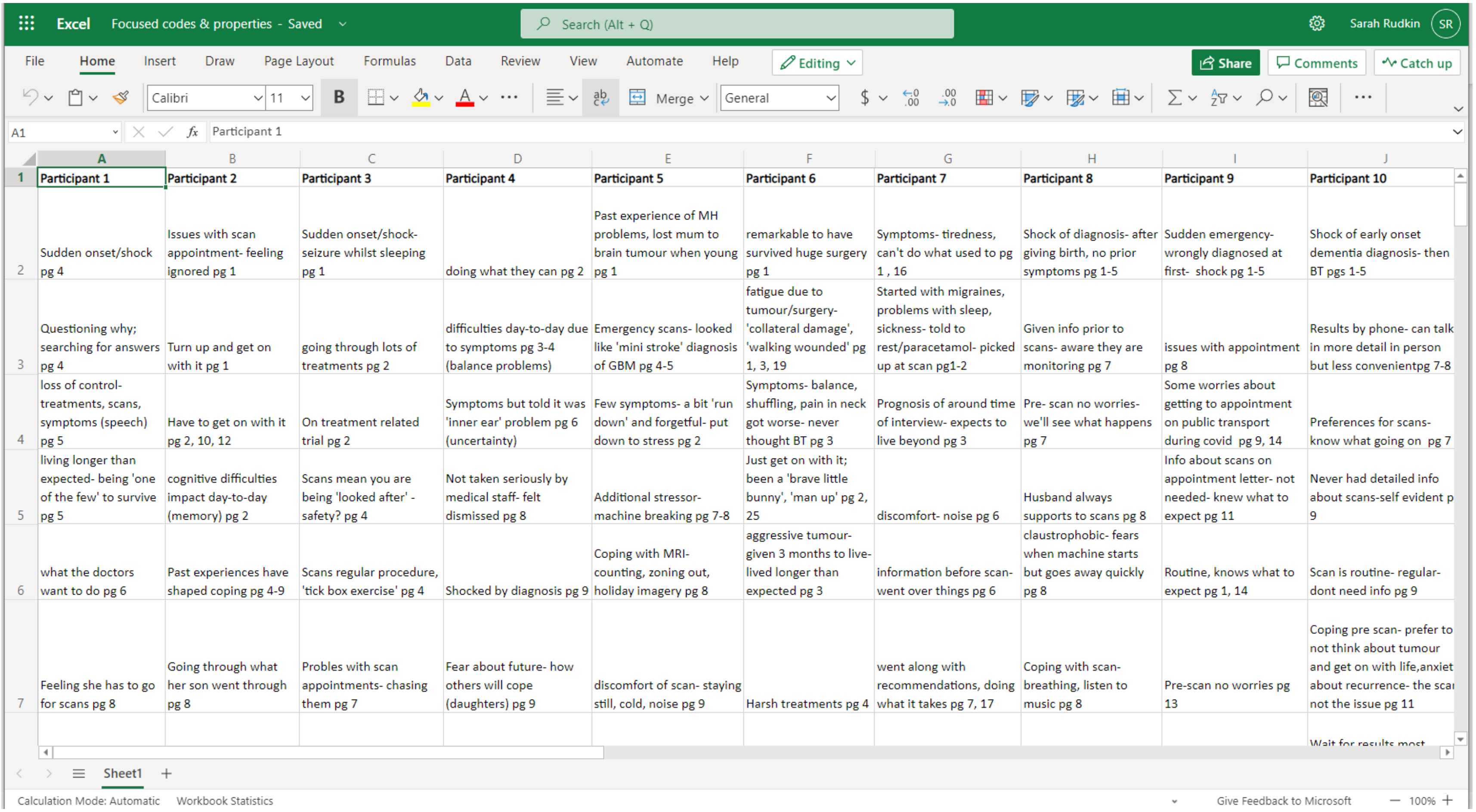
Sarah Rudkin
prefers to be monitored at intervals (feels safer?)
@mention or reply

Sarah Rudkin
prefers to have scans; would always follow doctors advice

Initial coding

Focused coding

Appendix G: Table of participant focused codes and their properties



	A	B	C	D	E	F	G	H	I	J
1	**Participant 1**	**Participant 2**	**Participant 3**	**Participant 4**	**Participant 5**	**Participant 6**	**Participant 7**	**Participant 8**	**Participant 9**	**Participant 10**
2	Sudden onset/shock pg 4	Issues with scan appointment- feeling ignored pg 1	Sudden onset/shock- seizure whilst sleeping pg 1	doing what they can pg 2	Past experience of MH problems, lost mum to brain tumour when young pg 1	remarkable to have survived huge surgery pg 1	Symptoms- tiredness, can't do what used to pg 1 , 16	Shock of diagnosis- after giving birth, no prior symptoms pg 1-5	Sudden emergency- wrongly diagnosed at first- shock pg 1-5	Shock of early onset dementia diagnosis- then BT pgs 1-5
3	Questioning why; searching for answers pg 4	Turn up and get on with it pg 1	going through lots of treatments pg 2	difficulties day-to-day due to symptoms pg 3-4 (balance problems)	Emergency scans- looked like 'mini stroke' diagnosis of GBM pg 4-5	fatigue due to tumour/surgery- 'collateral damage', 'walking wounded' pg 1, 3, 19	Started with migraines, problems with sleep, sickness- told to rest/paracetamol- picked up at scan pg1-2	Given info prior to scans- aware they are monitoring pg 7	issues with appointment pg 8	Results by phone- can talk in more detail in person but less convenientpg 7-8
4	loss of control- treatments, scans, symptoms (speech) pg 5	Have to get on with it pg 2, 10, 12	On treatment related trial pg 2	Symptoms but told it was 'inner ear' problem pg 6 (uncertainty)	Few symptoms- a bit 'run down' and forgetful- put down to stress pg 2	Symptoms- balance, shuffling, pain in neck got worse- never thought BT pg 3	Prognosis of around time of interview- expects to live beyond pg 3	Pre- scan no worries- we'll see what happens pg 7	Some worries about getting to appointment on public transport during covid pg 9, 14	Preferences for scans- know what going on pg 7
5	living longer than expected- being 'one of the few' to survive pg 5	cognitive difficulties impact day-to-day (memory) pg 2	Scans mean you are being 'looked after' - safety? pg 4	Not taken seriously by medical staff- felt dismissed pg 8	Additional stressor- machine breaking pg 7-8	Just get on with it; been a 'brave little bunny', 'man up' pg 2, 25	discomfort- noise pg 6	Husband always supports to scans pg 8	Info about scans on appointment letter- not needed- knew what to expect pg 11	Never had detailed info about scans-self evident p 9
6	what the doctors want to do pg 6	Past experiences have shaped coping pg 4-9	Scans regular procedure, 'tick box exercise' pg 4	Shocked by diagnosis pg 9	Coping with MRI- counting, zoning out, holiday imagery pg 8	aggressive tumour- given 3 months to live- lived longer than expected pg 3	information before scan- went over things pg 6	claustrophobic- fears when machine starts but goes away quickly pg 8	Routine, knows what to expect pg 1, 14	Scan is routine- regular- dont need info pg 9
7	Feeling she has to go for scans pg 8	Going through what her son went through pg 8	Probles with scan appointments- chasing them pg 7	Fear about future- how others will cope (daughters) pg 9	discomfort of scan- staying still, cold, noise pg 9	Harsh treatments pg 4	went along with recommendations, doing what it takes pg 7, 17	Coping with scan- breathing, listen to music pg 8	Pre-scan no worries pg 13	Coping pre scan- prefer to not think about tumour and get on with life,anxiet about recurrence- the scai not the issue pg 11
										Wait for results most

Appendix H: Table of focused codes, categories, and processes

Total Ppts	Focused codes (ppt numbers)	Subcategories	Properties	Core categories	Theoretical codes (processes/relationships)
12	Going along with it; following advice (all participants) Something they 'have to' do (1,2,4,5,6,10,11,12) Showing 'strength' (12,3,6) Trying to take some control- diet (6, 8); supplements (8); breathing (8); additional treatments (2)	Doing what it takes	From not mentioning it at all (ppts 9 and 10- grade 3) to having to do it vs doing it and remaining strong. Some ppts attempt to control their life through other means.	Living with a PMBT: surviving	Coping with a PMBT- directly links to interval scanning ('have to' have them)
12	Support from partner (1,2,3,6,7,8,10,11,12) Support from family (4,5,6,7,9,12) Support from friends (2,9)	Accessing support from others	All supported by family/partner throughout different stages of their illness- from general support to more specific support. Few mentioned friends.	Living with a PMBT: surviving	Coping with a PMBT
12	Sudden onset; emergency (1, 3, 9) Uncertainty around progression/symptoms (all participants) Loss of control- Memory problems (2, 5); fatigue (3, 6); balance problems (4, 9) mobility (7), effects of treatment (12); speech problems (1, 11) vision (10) Informed of prognosis (1, 3, 6, 7, 12)	Threat, uncertainty & loss of control	All participants talked about the sudden threat of their diagnosis- some were emergency situations; others were non-specific symptoms. They were met with a shortened life expectancy and ongoing effects of the illness and treatments.	Living with a PMBT: surviving	Experience of living with a PMBT- something they have to cope with
4	Been through a lot so not worried (2, 6) Loss of family members; experience of cancer diagnoses (2, 5, 7) Experienced threat to life (6)	Impact of past experiences of illness	Impact on coping/anxiety depending on what they have been through in the past	Living with a PMBT: surviving	Influences coping with a PMBT/interval scan
11	Getting used to scans over time (1,4, 8, 11,12) Scanning is routine (2,3,6, 9, 10) Additional information is not important (3,4, 6, 9, 8, 10, 7, 11, 12)	Adapting over time	Participants either found scans easy from the start and described them as 'routine' or found that they got easier over time. Told about purpose of scans but additional info not needed- used to it. Nothing mentioned by one ppt as new to interval scans.	Interval scan process: varying levels of anxiety	Coping with interval scans
12	No worries pre-scan (1, 3, 5, 6, 9) Worries pre-scan about results (7, 10, 11, 12) Heightened anxiety at the start of scan due to claustrophobia (2, 4, 8, 11) Worries about having the right scanner (4)	Pre-scan worries	From no difficulties to worries for a range of reasons e.g. 4,8,11 talk about claustrophobia; some discuss COVID and travel	Interval scan process: varying levels of anxiety	Individual differences- something people need to find a way to cope with

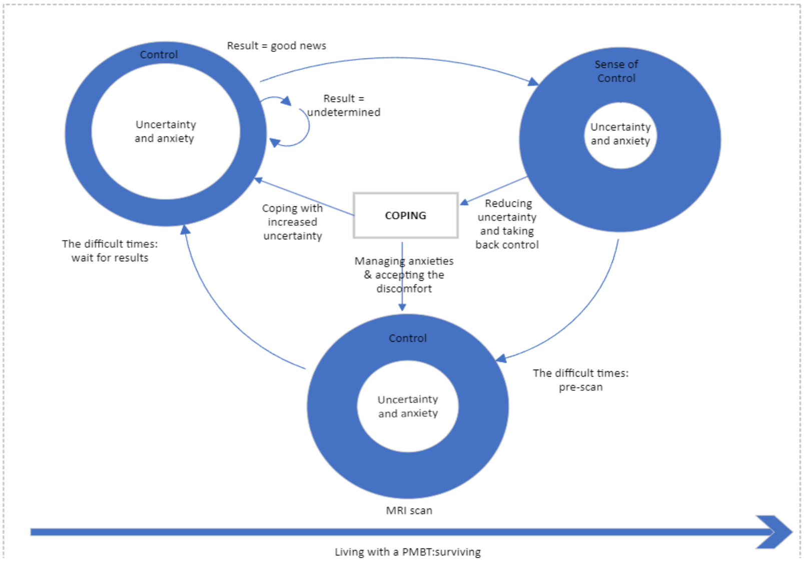
11	Waiting for the results is difficult; the most difficult time; high anxiety (1, 3, 4, 7, 9, 10, 11, 12) Fear about the future; fear of recurrence (1, 4, 9, 10, 11, 12) Hypervigilance (3, 12, 8, 9, 10) No fear during wait (2,6) Anxiety on results day (1 4, 11, 12) vs no anxieties discussed (2, 6)	Waiting for the results is the most difficult time	Ppt 5 had no experience of this; two ppts said they have no fear (hopeful, impact of past experiences)	Interval scan process: varying levels of anxiety	Individual differences- something people need to find a way to cope with
10	Issues arranging scan appointments (1, 2, 3 ,4, 9) Machine breaking down; prolonged anxiety (5, 11) Difficulties with cannula (1, 6, 7, 12) Issues with mobile scan unit (9, 11) Differences in results communication; face-to-face vs phone (1, 2, 9, 10); Impact of PPE (7) Worries about getting to hospital due to COVID-19 (1,4, 9)	Additional stressors	Some ppts had difficulties organising scan appts at one hospital site. Some had difficulties with having the cannula fitted or machine breaking down. Some ppts prefer going to hospital for scan rather than a mobile scanner. Impact of COVID was sometimes mentioned- impact on travel and communication of results	Interval scan process: varying levels of anxiety	Wider issues/issues outside of a person's control- something they have to cope with
12	Scan not painful; difficult; invasive; scary (2, 5, 6, 11, 9) Scans are uncomfortable: noise (1, 2, 5, 6, 7, 11, 12,10), lying still (2, 5, 11, 12), cold (2, 5), closed in (3, 4, 12, 8) Scan isolating (5, 7, 12, 9) Reducing discomfort: ear plugs (2, 6), mirror- not always helpful (4, 7, 12, 9, 10), being able to move (head and shoulder scan, 4) music (5,8, 9, 11, 12) ball (4, 6, 11,12, 9,8) screen (7) larger machine (8)	Minimising discomfort in the environment	Scanning not painful but is uncomfortable for most for many reasons- some factors help to reduce the discomfort.	The MRI scan: managing anxieties and accepting the discomfort	Coping with the MRI scan
8	Others struggle to cope (3, 4, 5, 6, 9, 12) Others may have difficulty coping due to lack of support (1, 11) Others may have difficulty coping due to their jobs (1, 3)	Making comparisons	Some people compare to others in terms of how they cope with the scan itself, or how they cope due to lack of support	The MRI scan: managing anxieties and accepting the discomfort	Coping with the MRI scan
11	Beach/holiday imagery (2, 4, 5, 11), counting bangs (2), counting (5) sleeping/resting (3,9,10) zoning out (5) listen to noises/tuning in (7, 12, 9,10) breathing (8) think about other things (12) daydream (9) staying still (6)	Passing the time	Ppt 1 did not talk about this- difficulties communicating. For others it was a sense of something they must do so they find ways of passing the time.	The MRI scan: managing anxieties and accepting the discomfort	Coping with the MRI scan
11	Staff caring, friendly, competent (1, 2, 4, 5, 6, 7, 8, 9, 10, 11, 12) Support from staff during scan (2, 4, 8, 11, 12)	Staff-patient interactions	Differences in that some people talk about staff being generally supportive, others give specific examples. Some talk about	The MRI scan: managing anxieties	Coping with the MRI scan

	Working with staff; making it easy for them (5, 6, 7) Some staff not as good as others (12)		working with the staff and making it easier for them. Only one ppt discussed issues.	and accepting the discomfort	
6	Avoidance of thoughts (4, 11, 10, 7) Avoidance of others (4, 7) Distraction (12, 9, 7)	Avoidance and distraction	Different ways of coping- some avoid, distract or do both- most people use a combination of strategies	Waiting for results: getting through the difficult times	Coping with wait for results
5	Forecasting (3, 11) Remaining hopeful (2, 6, 8)	Hopeful thinking	Different ways of coping- some avoid, distract or do both- most people use a combination of strategies	Waiting for results: getting through the difficult times	Coping with wait for results
5	Waiting to find out; not trying to guess; not worrying (6, 11, 12, 7, 10)	'What will be will be'	Different ways of coping- some avoid, distract or do both- most people use a combination of strategies	Waiting for results: getting through the difficult times	Coping with wait for results
11	Good news = reassurance; relief (1, 2, 3, 4, 6, 7, 8, 9, 11, 12) Short-term relief (4, 11, 12)	Good news provides short-term relief	All those that had received good news talked about feeling relieved or reassured. Some talked about knowing this was short-lived.	The results: short-term relief vs ongoing anxiety	Coping with result
6	Receiving bad news- hopeful thinking (2) ongoing anxiety (7, 10) seeking support from others (10) needing to prepare (10) Undetermined result- ongoing anxiety (1, 8, 10, 11)	Bad news or undetermined results cause ongoing anxiety	One ppt that received bad news did not want to discuss this/avoided talking about it. Others discussed prolonged anxiety, as did those with undetermined results.	Results: short-term relief vs ongoing anxiety	Coping with result
12	Prefer to have interval scans than wait for symptoms to change (all participants) Scans provide reassurance (1, 2, 3, 6, 7, 8, 9, 10, 11, 12) Changes might be missed (1, 3, 4, 5, 7, 8, 9, 10, 11, 12)	Reducing uncertainty	For all participants scans can (not always) reduce uncertainty- they let them know the unknown and make them feel safe/reassured	Interval scans: provide a safety net	Scans help them cope with PMBT
9	Scan guides treatment; planning (5, 6, 7, 10, 11, 12) Extended life expectancy; lucky to be alive (1, 2, 3, 6, 7, 10, 12)	Taking back some control	Not all participants discussed this, but it is important in terms of giving people control when they feel they have very little- if they can plan ahead or have treatment, they have a little control over their lives.	Interval scans: provide a safety net	Scans help them cope with PMBT
12	Checked/monitored by medical team (all participants) The medical team are experts (all participants)	Maintaining connections with the medical team	All participants talk about their connection to their medical team throughout which adds to feeling secure and safe.	Interval scans: provide a safety net	Scans help them cope with PMBT

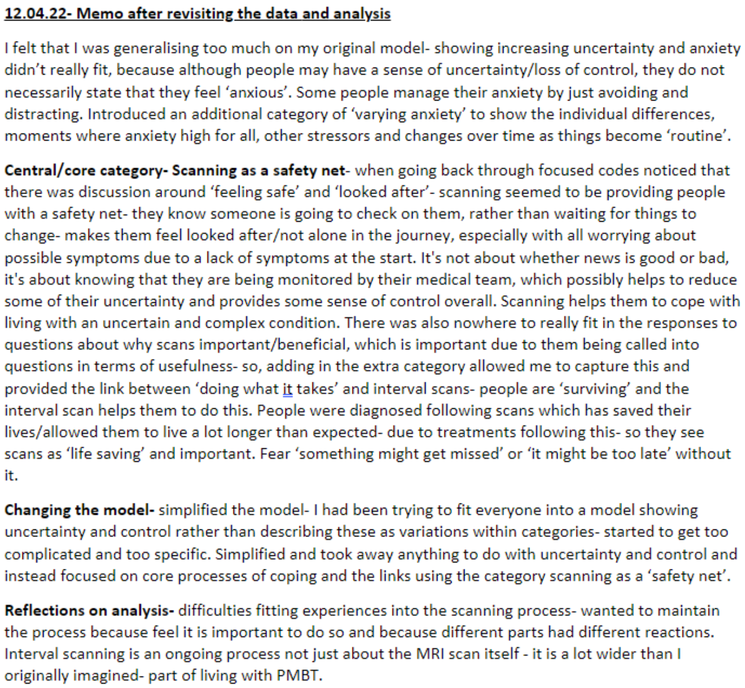
Note. *Coloured texts in this table represent the different core categories. Each correspond with the colours used in the GT model and diagrams presented in the results section.*

Appendix I: Examples of model development and memos

Model from March 2022:



Memo from April 2022:



12.04.22- Memo after revisiting the data and analysis

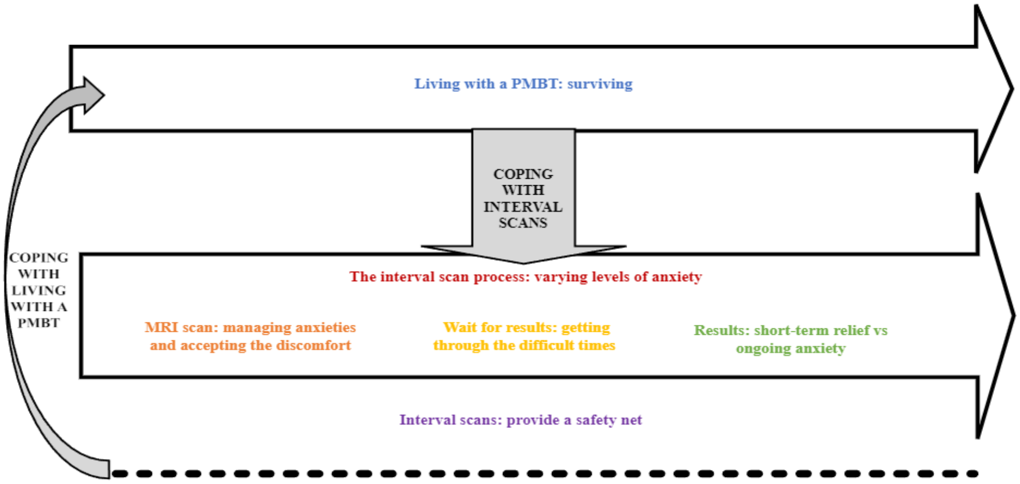
I felt that I was generalising too much on my original model- showing increasing uncertainty and anxiety didn't really fit, because although people may have a sense of uncertainty/loss of control, they do not necessarily state that they feel 'anxious'. Some people manage their anxiety by just avoiding and distracting. Introduced an additional category of 'varying anxiety' to show the individual differences, moments where anxiety high for all, other stressors and changes over time as things become 'routine'.

Central/core category- Scanning as a safety net- when going back through focused codes noticed that there was discussion around 'feeling safe' and 'looked after'- scanning seemed to be providing people with a safety net- they know someone is going to check on them, rather than waiting for things to change- makes them feel looked after/not alone in the journey, especially with all worrying about possible symptoms due to a lack of symptoms at the start. It's not about whether news is good or bad, it's about knowing that they are being monitored by their medical team, which possibly helps to reduce some of their uncertainty and provides some sense of control overall. Scanning helps them to cope with living with an uncertain and complex condition. There was also nowhere to really fit in the responses to questions about why scans important/beneficial, which is important due to them being called into questions in terms of usefulness- so, adding in the extra category allowed me to capture this and provided the link between 'doing what it takes' and interval scans- people are 'surviving' and the interval scan helps them to do this. People were diagnosed following scans which has saved their lives/allowed them to live a lot longer than expected- due to treatments following this- so they see scans as 'life saving' and important. Fear 'something might get missed' or 'it might be too late' without it.

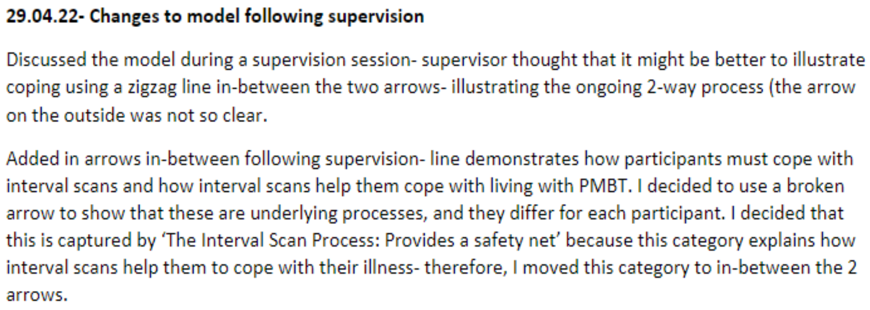
Changing the model- simplified the model- I had been trying to fit everyone into a model showing uncertainty and control rather than describing these as variations within categories- started to get too complicated and too specific. Simplified and took away anything to do with uncertainty and control and instead focused on core processes of coping and the links using the category scanning as a 'safety net'.

Reflections on analysis- difficulties fitting experiences into the scanning process- wanted to maintain the process because feel it is important to do so and because different parts had different reactions. Interval scanning is an ongoing process not just about the MRI scan itself - it is a lot wider than I originally imagined- part of living with PMBT.

Changes made to the model in April 2022:



Memo from April 2022 leading to the Grounded Theory model presented in the results:



29.04.22- Changes to model following supervision

Discussed the model during a supervision session- supervisor thought that it might be better to illustrate coping using a zigzag line in-between the two arrows- illustrating the ongoing 2-way process (the arrow on the outside was not so clear.

Added in arrows in-between following supervision- line demonstrates how participants must cope with interval scans and how interval scans help them cope with living with PMBT. I decided to use a broken arrow to show that these are underlying processes, and they differ for each participant. I decided that this is captured by 'The Interval Scan Process: Provides a safety net' because this category explains how interval scans help them to cope with their illness- therefore, I moved this category to in-between the 2 arrows.