THE EVIDENCE-BASED DEVELOPMENT OF AN INTERVENTION TO ADDRESS THE INFORMATION NEEDS OF ADULTS NEWLY DIAGNOSED WITH PRIMARY BRAIN TUMOURS AND THEIR CARERS

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THIS THESIS IS SUBMITTED FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

IN THE SCHOOL OF PUBLIC HEALTH AND INSTITUTE FOR HEALTH AND BIOMEDICAL INNOVATION,

QUEENSLAND UNIVERSITY OF TECHNOLOGY, 2011

KEYWORDS

brain tumours; patient information; doctor-patient communication; cancer; carers

ABSTRACT

Adults diagnosed with primary brain tumours often experience physical, cognitive and neuropsychiatric impairments and decline in quality of life. Although disease and treatment-related information is commonly provided to cancer patients and carers, newly diagnosed brain tumour patients and their carers report unmet information needs. Few interventions have been designed or proven to address these information needs. Accordingly, a three-study research program, that incorporated both qualitative and quantitative research methods, was designed to: 1) identify and select an intervention to improve the provision of information, and meet the needs of patients with a brain tumour; 2) use an evidence-based approach to establish the content, language and format for the intervention; and 3) assess the acceptability of the intervention, and the feasibility of evaluation, with newly diagnosed brain tumour patients.

Study 1: Structured concept mapping techniques were undertaken with 30 health professionals, who identified strategies or items for improving care, and rated each of 42 items for importance, feasibility, and the extent to which such care was provided. Participants also provided data to interpret the relationship between items, which were translated into 'maps' of relationships between information and other aspects of health care using multidimensional scaling and hierarchical cluster analysis. Results were discussed by participants in small groups and individual interviews to understand the ratings, and facilitators and barriers to implementation. A care coordinator was rated as the most important strategy by health professionals. Two items directly related to information provision were also seen as highly important: "information to enable the patient or carer to ask questions" and "for doctors to encourage patients to ask questions". Qualitative analyses revealed that information provision was individualised, depending on patients' information needs and preferences, demographic variables and distress, the characteristics of health professionals who provide information, the relationship between the individual patient and health professional, and influenced by the fragmented nature of the health care system. Based on quantitative and qualitative findings, a brain tumour specific question prompt list (QPL) was chosen for

development and feasibility testing. A QPL consists of a list of questions that patients and carers may want to ask their doctors. It is designed to encourage the asking of questions in the medical consultation, allowing patients to control the content, and amount of information provided by health professionals.

Study 2: The initial structure and content of the brain tumour specific QPL developed was based upon thematic analyses of 1) patient materials for brain tumour patients, 2) QPLs designed for other patient populations, and 3) clinical practice guidelines for the psychosocial care of glioma patients. An iterative process of review and refinement of content was undertaken via telephone interviews with a convenience sample of 18 patients and/or carers. Successive drafts of QPLs were sent to patients and carers and changes made until no new topics or suggestions arose in four successive interviews (saturation). Once QPL content was established, readability analyses and redrafting were conducted to achieve a sixth-grade reading level. The draft QPL was also reviewed by eight health professionals, and shortened and modified based on their feedback. Professional design of the QPL was conducted and sent to patients and carers for further review. The final QPL contained questions in seven colour-coded sections: 1) diagnosis; 2) prognosis; 3) symptoms and problems; 4) treatment; 5) support; 6) after treatment finishes; and 7) the health professional team.

Study 3: A feasibility study was conducted to determine the acceptability of the QPL and the appropriateness of methods, to inform a potential future randomised trial to evaluate its effectiveness. A pre-test post-test design was used with a non-randomised control group. The control group was provided with 'standard information', the intervention group with 'standard information' plus the QPL. The primary outcome measure was acceptability of the QPL to participants. Twenty patients from four hospitals were recruited a median of 1 month (range 0-46 months) after diagnosis, and 17 completed baseline and follow-up interviews. Six participants would have preferred to receive the information booklet (standard information or QPL) at a different time, most commonly at diagnosis. Seven participants reported on the acceptability of the QPL: all said that the QPL was helpful, and that it contained questions that were useful to them; six said it made it

easier to ask questions. Compared with control group participants' ratings of 'standard information', QPL group participants' views of the QPL were more positive; the QPL had been read more times, was less likely to be reported as 'overwhelming' to read, and was more likely to prompt participants to ask questions of their health professionals.

The results from the three studies of this research program add to the body of literature on information provision for brain tumour patients. Together, these studies suggest that a QPL may be appropriate for the neuro-oncology setting and acceptable to patients. The QPL aims to assist patients to express their information needs, enabling health professionals to better provide the type and amount of information that patients need to prepare for treatment and the future. This may help health professionals meet the challenge of giving patients sufficient information, without providing 'too much' or 'unnecessary' information, or taking away hope. Future studies with rigorous designs are now needed to determine the effectiveness of the QPL.

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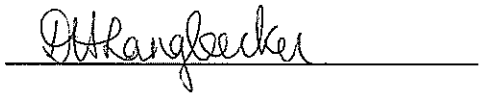
COMMONLY USED ABBREVIATIONS

AA	Anaplastic Astrocytoma
AACR	Australasian Association for Cancer Registries
AIHW	Australian Institute of Health and Welfare
CARES	Cancer Rehabilitation Evaluation System
CBI	Cancer Behavior Inventory
CCQ	Cancer Council Queensland
CI	Confidence Interval
DA	Decision Aid
DT	Distress Thermometer
ENRICHD	Enhancing Recovery in Coronary Heart Disease
EORTC	European Organisation for Research and Treatment of Cancer
FACT, FACT-G, FACT-Br	Functional Assessment of Cancer Therapy, FACT-General, FACT-Brain
GBM	Glioblastoma Multiforme
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HGG	High grade glioma
HREC	Human Research Ethics Committee
HRQOL	Health-related Quality of Life
ICC	Intra-class correlation coefficient
IES	Impact of Event Scale
KHOS/KHOS-I	Krantz Health Opinion Survey (- Information Subscale)
KPS	Karnofsky Performance Score
LGG	Low grade glioma
MCID	Minimal clinically important change
N; n	Number of cases
PAH	Princess Alexandra Hospital
PHR	Patient-held record
PN	Patient Navigator
QCR	Queensland Cancer Registry
QLQ-BN20	EORTC Brain Cancer Module
QLQ-C30	EORTC Quality of Life Questionnaire
QLQ-INFO25	EORTC Information module
QOL	Quality of Life
QPL	Question Prompt List
QUT	Queensland University of Technology
RBWH	Royal Brisbane and Women's Hospital
RCT	Randomised controlled trial
SD	Standard deviation
SEM	Standard error of measurement
SMOG	Simple Measure of Gobbledygook
WHO	World Health Organization

STATEMENT OF ORIGINAL AUTHORSHIP

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signature 

Date 27/09/2011

ACKNOWLEDGEMENTS

I would like to thank my principal supervisor, Monika Janda, for the knowledge, advice, and wisdom you have shared with me. You have been a great source of inspiration and support to me, even when you firmly asked me to rewrite a section once again! To my associate supervisor, Patsy Yates, thank you for your guidance and encouragement along this journey. I very much appreciate your insight and knowledge of this field, and the support and kindness you have shown me. Many thanks must also go to the Queensland University of Technology Faculty of Health, who provided me with a scholarship to undertake this research.

I would also like to thank my fellow students and colleagues, with whom I have shared the past few years. I have received an incredible amount of practical and emotional support from some amazing people – thank you so much. I would especially like to thank Loretta McKinnon and Abbey Diaz, who have shared in my greatest joys and sorrows, and always stood by my side. I would also like to thank Josie Auster, for your assistance with coding and thematic analysis, and helping me with participant follow-up. I do not think I would ever have ever completed my qualitative analysis without your help! And thank you to Angela Williamson for your assistance with readability testing, data entry, and many other tasks.

I am also very grateful to all of the patients, carers, and health professionals who participated in this research – thank you so much for giving your time and sharing your experiences. Your generosity of spirit is what makes research work, and to you we are all indebted. Thank you also to all of the health professionals who assisted with this research, especially Dr David Walker and Ms Vivien Biggs, who gave their time, knowledge, and energy to help me with each of my three studies.

Finally, thank you to my Mum for the many hours of editing and proofreading you have done over the past four years, and your unwavering love and support. To my brother Travis, thank you for your guidance and advice – I am very glad you did a PhD first! And to my partner Richard, thank you for listening to me talk about my thesis at all hours, for forgiving my single-mindedness, and for always making me smile.

1. INTRODUCTION

Primary brain tumours make up approximately one percent of incident cases of cancer, but are responsible for four percent of the cancer burden, due to high mortality and morbidity rates (Australian Institute for Health & Welfare (AIHW) & Australasian Association for Cancer Registries (AACR) 2010; AIHW 2010). Patients self-report significant levels of psychological distress and high levels of unmet supportive care needs, particularly with regard to information, communication and accessing ancillary services (Janda et al. 2006; Janda et al. 2008). Information seeking is highest in the period surrounding diagnosis, as attempts are made to understand recommended treatment and prognosis (Schubart et al. 2008).

Disease, treatment and support information is important for patients as it forms part of the continuity of their care, providing a 'common thread' between a multitude of providers and services (Reid et al. 2002). Appropriate, consistent, tailored and timely information provision allows patients and families to regain control as a person transitions to the often unexpected and unfamiliar situation of being a 'patient', and the ensuing change in status and control (Amato 1991; Street et al. 2009; Rodin et al. 2009). Conversely, patients who perceive that they have received inadequate information tend to experience increased levels of uncertainty, distress and anxiety (Diaz et al. 2009; Perks et al. 2009; Fallowfield et al. 1995).

Traditionally, information provision in the clinical setting has largely involved doctors and nurses verbally giving information to patients, supplemented by written patient materials (Vordermark 2010; Pander Maat & Lentz 2010). However, there has been increasing recognition that this approach does not meet the needs of many patients (Cutilli 2010; Degner et al. 1998; Kiesler & Auerbach 2006). A number of strategies to improve the provision of information to patients, and to assist patients and health professionals to better communicate with each other, such as treatment summary letters, provision of audio-tapes of consultations to patients and communication skills training for doctors, have been developed and evaluated for cancer patients in general, and specifically for patient groups with high needs (Clayton et al. 2007; Leighl et al. 2004). For brain tumour patients, information

seeking and comprehension may be hindered by cognitive, physical and/or emotional impairments caused by the brain tumour or treatment (Leavitt et al. 1996). Information processing may also be impaired for some of these patients due to difficulties coping with their diagnoses, particularly as the site of the tumour, the brain, is commonly seen to define the 'self' (Louis et al. 2000).

This dissertation details efforts to improve the provision of information for patients with brain tumours. As such, this study involved the evidence-based selection, development and feasibility testing of an intervention specifically designed for this patient group.

1.1. SCOPE OF THIS RESEARCH

The aim of this research program was to gain insight into how information provision could be improved for patients newly diagnosed with primary brain tumours and to apply this knowledge to select, develop, and assess the feasibility and acceptability of an intervention to improve the quantity and quality of information that patients receive. This study focused solely on the information needs of and strategies for improving information for adults (aged 18 years and over), rather than the needs of or care for children or adolescents. An examination of the research directed at these latter groups indicates that the information needs of the child/adolescent patient and parent/carer differ in many important respects from those of adults, and that children and adolescents are subject to different patterns of care (Zebrack 2009; Merchent et al. 2010).

This dissertation was concerned only with primary brain tumour patients, which, unlike secondary brain tumours, originate in the brain itself. Secondary brain tumours originate in another part of the body and metastasise to the brain (Ekman & Westphal 2005). Cancer treatments depend on histology (e.g. a lung cancer that has metastasised to the brain is still, histologically, lung cancer). Treatment pathways for primary and secondary tumours, and patients' ensuing information needs, are thus very different (Ostgathe et al. 2010).

However, this research program included patients with both malignant and benign primary brain tumours. Although no study has compared the information needs of

malignant and benign brain tumour patients, they are likely to be similar in many ways. Early in the disease trajectory, it is often uncertain whether a tumour is malignant or benign, and a specific diagnosis is made histopathologically, requiring a tissue sample obtained via biopsy or surgery (Rampling et al. 2004; Piepmeier & Baehring 2004). Many of the symptoms experienced by brain tumour patients result from intracranial pressure, or damage to specific structures in the brain by the tumour and/or treatment (Piepmeier & Baehring 2004; Rampling et al. 2004). Both malignant and benign primary brain tumour patients may undergo surgery and radiotherapy (Del Sole et al. 2001; Wentworth et al. 2009), and may experience a similar range of physical, cognitive, behavioural, and psychosocial impairments (Ownsworth et al. 2009; Weitzner 1999). Although the median survival is greater for patients with benign than malignant tumours, some benign tumours may be fatal due to their location in relation to blood vessels, structures and accessibility for surgery (Kalkanis et al. 2000). Benign and other less aggressive tumours may also progress to malignant or more aggressive tumours (Wrensch et al. 2002).

Patients with malignant or benign brain tumours consult the same group of health professionals, including neurologists, neurosurgeons, radiation oncologists and allied health professionals (Macarthur & Buxton 2001; Gabanelli 2005), and are able to avail themselves of similar support services. For example, the Cancer Council Queensland provides information for all brain tumour patients, regardless of malignancy (Cancer Council Queensland 2009).

1.2. RESEARCH AIMS

This study had three primary aims:

1) To select an appropriate intervention to improve the provision of information to patients with brain tumours.
2) To use an evidence-based approach to develop the chosen intervention.
3) To test the feasibility and acceptability of the intervention developed in Aim 2 with patients with brain tumours, to inform future intervention evaluation.

The research objectives related to each of these aims are outlined below.

Aim 1:

1a) Identify potential strategies to improve information provision based on the views of relevant health professionals, and quantify the perceived relative importance, feasibility and extent of current provision of each strategy;

1b) Describe the factors influencing the exchange of information between health professionals and patients and their families, as understood by health professionals;

1c) Integrate quantitative (1a) and qualitative findings (1b) to enable selection of an intervention for development and feasibility assessment.

Aim 2:

2a) For the intervention selected in Aim 1, use an evidence-based approach to establish content, reading level and design, based on the preferences of patients recently diagnosed with a brain tumour, their carers and health professionals.

Aim 3:

In preparation for a future randomised trial:

3a) Investigate the feasibility of recruitment strategies;

3b) Investigate the feasibility of evaluation strategies, particularly outcome assessment; and

3c) Investigate acceptability of the intervention among patients newly diagnosed with or undergoing treatment for a brain tumour.

1.3. SIGNIFICANCE OF THE RESEARCH

For the cancer patient, information about the disease, treatment, and prognosis is essential for coping and consequential psychological adjustment, to allow participation in treatment decision-making, make decisions about the future, and to ensure that appropriate care is provided, considering the patient's individual needs (Kitamura 2005; Haggerty et al. 2003; O'Leary et al. 2007). The preponderance of

unmet information needs and the importance of information provision for treatment adherence, physical and psychosocial wellbeing have been recognised in clinical practice guidelines developed for cancer patients overall (National Breast Cancer Centre & National Cancer Control Initiative 2003), and specifically for patients with brain tumours (Australian Cancer Network Adult Brain Tumour Guidelines Working Party 2009). A multitude of interventions to improve information provision or to improve doctor-patient communication (and thus facilitate information provision) have been developed. However, many interventions have not been developed using an evidence-based approach, and fewer still have been rigorously evaluated (Newell et al. 2002).

Recommendations for research to improve psychosocial care for cancer patients have emphasised the need for more intervention research. In particular, it has been recommended that intervention development should be clearly articulated, evidence-based, and include formal evaluation (Lewis 1997). Schofield and colleagues also emphasised the need for targeted research with high-need groups who are usually excluded from such studies, because of, for example, difficulties with recruitment and attrition (Schofield et al. 2006).

By detailing the process of developing and assessing the feasibility of an intervention, this study provides insight into the challenges of research with brain tumour patients, who experience high morbidity and mortality.

1.4. TERMINOLOGY

As this thesis concerns adults newly diagnosed with brain tumours, such persons have been referred to as 'brain tumour patients'. The term 'patient' has been criticised for its connotation of dependence, and some groups have advocated the use of other terms, such as 'customer', 'consumer', 'client', 'user', or 'survivor' (Herzberg 1990). However, others have found that the majority prefer the term 'patient' over such alternatives (Herzberg 1990; Elliot & White 1990). Patients may dislike terms such as 'customer', 'consumer' or 'client', because of their assumption of a 'market relationship', whereby health care is a commodity to be bought and sold (Deber et al. 2005; McLaughlin 2009). The term 'user' may also be disliked

because of its application to persons who use or misuse drugs, and resulting negative connotation (McLaughlin 2009; Herxheimer & Goodare 1999).

The term 'survivor' may be appropriate to some degree: the National Cancer Institute considers an individual a survivor "from the moment of diagnosis through the balance of his or her life", and includes friends, family members, and carers (2010, para. 2). However, 'survivorship' care and research most commonly targets the challenges facing individuals during and following the 're-entry' phase, in which persons who have completed treatment return to existing (or new) life patterns (Allen et al. 2009). In addition, the appropriateness of 'survivor' for persons newly diagnosed with a disease, particularly if their prognosis is poor, is not known. Thus, throughout this thesis, the term 'patient' has been used.

The term 'carer' has similarly been used to describe a patient's relatives, friends and neighbours, who provide informal regular help and support to the patient, regardless of their relationship with the patient, or whether they live with him or her (Heaton 1999). This term has also been criticised, labelled an unnecessary 'socio-political construct', as persons defined as 'carers' may not identify with the label, particularly if they do not provide physical care or receive welfare benefits (Netto 1998; Morris & Thomas 2001). In addition, 'carer' has been criticised for implying that providing care is burdensome, thus devaluing the care recipient (Molyneaux et al. 2011). However, other terms that denote the nature of the relationship between patients and carers (e.g. 'spouse', 'mother'), or that emphasise the sharing of experiences (e.g. 'companion') may not promote recognition of the physical, practical, psychosocial and emotional tasks that carers perform (Thomas et al. 2002; Netto 1998). The term 'carer' has been used in thesis to promote recognition of the needs of persons who provide care, with the acknowledgement that 'carers' are not 'extensions' of patients, but individuals who have their own health and social needs, separate from those of patients, and sometimes even at odds with the caring role (Heaton 1999).

For clarity, a distinction has also been made in this thesis between 'carers' and 'health professionals'. Although both groups provide care and may overlap to some degree, the relatives, friends and neighbours who provide care on an informal

and/or unpaid basis (regardless of the receipt of welfare benefits or allowances), have been referred to as 'carers', whilst persons who provide care as part of a professional, skilled, and/or paid capacity have been referred to as 'health professionals'. The latter term refers to persons from a range of disciplines, such as doctors, nurses, care coordinators, social workers, and support group staff. The disciplines or characteristics of particular health professionals have been specified where appropriate.

1.5. THESIS STRUCTURE

This thesis begins with a brief description of brain tumour epidemiology, morbidity, and quality of life (QOL) (Chapter 2), to provide context for understanding this thesis. The information needs, and provision of information to cancer patients and their carers, are reviewed in Chapter 3. Chapter 4 contains a critical analysis of the unmet information needs of brain tumour patients and carers, and strategies undertaken with this population to improve the provision of information. The theoretical framework for the mixed methods approach used in this study and methods to achieve rigour are described in Chapter 5.

This thesis has three main aims, each of which has been addressed in a separate study, with differing study populations, using a mixed methods approach. The results of research to address the first and second aims feed-in to the following aims. Thus, the methods and results for each aim (study) are presented within their own chapters, rather than in the traditional monograph structure of overall methods, results and discussion.

Chapter 6 presents the methods and results of the first study (aim 1), which utilised a 'concept-mapping' method with neuro-oncology health professionals to gather data with which to select an appropriate intervention to improve the provision of information to brain tumour patients and carers. Chapter 7 describes the iterative process used to develop the selected intervention, and presents the results of these analyses (aim 2). Existing information resources and extensive consultation with patients, carers and health professionals were utilised to determine the appropriate content, language and format for the intervention. Chapter 8 presents the methods

and results of a study undertaken to assess the feasibility and acceptability of the intervention and research methods for its evaluation (aim 3). Quantitative and qualitative findings from this quasi-experimental non-randomised control-group study are presented, along with recommendations for future evaluations of this intervention. Finally, a summative discussion combines all research findings, and describes recommendations for further research and practice (Chapter 9).

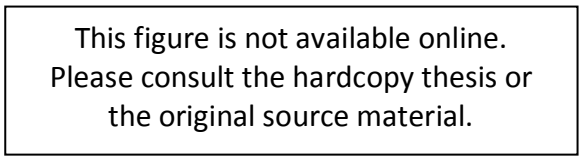
2. PRIMARY BRAIN TUMOURS

2.1. INTRODUCTION

This chapter provides contextual information about brain tumours that may be useful for understanding this thesis. The chapter describes the incidence and mortality of primary brain tumours in Australia, provides information about types of brain tumours and how they are diagnosed and treated. Morbidity and QOL issues of patients, and effects on carers, are described.

2.2. INCIDENCE AND MORTALITY

Based on data from 1998 to 2007, the AIHW and AACR (2010) estimated 1600 new cases of primary brain cancer and 1300 deaths in 2010. Primary brain cancers make up 1.4% of incident cases of cancer in Australia, with almost 1500 new cases diagnosed in 2007 (AIHW 2010). Primary brain tumours (referred to as 'brain tumours', except when distinguishing between primary and secondary tumours, or between all 'tumours' and cancer only) are more common among males (930/100,000) than females (660/100,000), and incidence increases at around 15-25 years (AIHW & AACR 2010). The incidence of brain tumours has not substantially changed over the last 25 years, as shown in Figure 2.1.



Source: (AIHW 2010)

FIGURE 2.1 AGE-SPECIFIC INCIDENCE (ASI) RATES FOR BRAIN CANCER, AUSTRALIA, 1982-2007

Overall, 1,123 persons (666 males and 457 females) died from primary brain cancer in Australia in 2007[1], and mortality has been relatively stable (Figure 2.2) (AIHW 2010). In addition to high mortality, brain cancer has high rates of disability: in 2008-9, brain cancer had the second longest average length of stay in hospital (excluding same-day hospitalisations) of all cancers, at 12.8 days per hospitalisation (AIHW & AACR 2010). The high incidence to mortality ratio, and high rates of morbidity, have led to brain cancer being the eighth leading cancer cause of burden of disease by disability-adjusted life years, for both males and females. Brain cancer is responsible for four percent of the cancer burden and one percent of the total burden of disease (AIHW & AACR 2010).

Source: (AIHW 2010)

FIGURE 2.2 AGE-STANDARDISED MORTALITY (ASM) DUE TO BRAIN CANCER IN AUSTRALIA, 1968-2007

2.3. AETIOLOGY AND CLASSIFICATION OF PRIMARY BRAIN TUMOURS

Most brain tumours are sporadic, with the exception of those associated with familial syndromes such as neurofibromatosis (Collins 2004). Spontaneous genetic alterations are currently thought to be partly responsible for the development of brain tumours, although as yet unknown environmental factors are likely to also play a role (Fisher et al. 2007; McKinney 2004). Evidence for involvement of environmental factors such as mobile phone use has been inconclusive, and high dose ionising radiation remains one of the few known environmental risk factors (McKinney 2004; Fisher et al. 2007). Unlike other cancers, brain cancers do not appear to be caused by potentially modifiable 'lifestyle factors' such as tobacco smoking or alcohol consumption (Fisher et al. 2007; Ohgaki 2009).

[1] National data on brain tumours reported by the AIHW does not include benign brain tumours.

Primary brain tumours may be intracerebral (i.e. occurring or situated in the brain) or extracerebral, such as meningiomas, which develop in the meninges surrounding the brain (Del Sole et al. 2001). There are over 125 different types of primary brain tumours, with nomenclature based on underlying cell type (McKinney 2004). A number of schemes have been used to classify brain tumours (Doolittle 2004). Since the 1970s, naming and categorisation of brain tumours has most commonly followed the World Health Organization (WHO) classification (Table 2.1), the International Statistical Classification of Diseases and Related Health Problems, tenth edition (ICD-10).

TABLE 2.1 CLASSIFICATION OF PRIMARY BRAIN TUMOURS ACCORDING TO THE WHO ICD-10

Tumour group	Common types of tumours *(not exhaustive)*
Tumours of neuro-epithelial tissue	Glioma, glioblastoma, astrocytoma, ependymoma, oligodendroglioma, mixed glioma
Tumours of the cranial & spinal nerves	Schwannoma, neurfibroma, perineuroma
Tumours of the meninges	Meningioma, mesenchymal non-meningothelioma, primary melanocytoma
Lymphomas & haematopoietic neoplasms	Malignant lymphoma, granulocytic sarcoma
Germ cell tumours	Teratoma, germinoma, choriocarcinoma
Tumours of the sellar region	Granular cell tumour, craniopharyngioma

WHO ICD-10: World Health Organization International Statistical Classification of Diseases and Related Health Problems, 10th edition. Source: (Louis et al. 2007).

The most common primary brain tumours, accounting for more than 90% of cases in persons over 20 years of age, are gliomas, which originate in glial cells (Del Sole et al. 2001). The three main types of gliomas are astrocytomas, oligodendrogliomas, and mixed oligoastrocytomas. Within astrocytomas, the WHO system classifies tumours by grade (I-IV), depending on cell features such as mitoses and necrosis, with increased grade indicating increased anaplasia (malignancy) (Kleihues et al. 2002; Behin et al. 2003). Glioblastoma multiforme (GBM), a grade IV tumour, is the most frequent astrocytoma subtype, comprising half of all gliomas (Behin et al. 2003; Del Sole et al. 2001; Kohler et al. 2011). Grade I and II or 'low grade' gliomas (LGGs) inevitably progress to 'high grade' (grade III and IV) gliomas (HGGs), with progression often occurring with five years (Del Sole et al. 2001). Together, HGGs make up 80-85% of all brain tumours in adults (Ohgaki 2009; McConigley et al. 2010).

Survival from brain tumours is influenced by tumour grade, histology, tumour localisation, age, functional status and treatments available (Lote et al. 1996; Louis et al. 2007). For patients with some brain tumours such as pituitary adenoma and meningioma, life expectancy following successful surgery is similar to population norms (Del Sole et al. 2001). Overall, patients with WHO grade II tumours typically survive more than five years, and those with grade III tumours, two to three years (Louis et al. 2007). In Queensland, from 2003-2007, for all persons with cancer of the brain, meninges and central nervous system, one-year relative survival was 46.0% (95% Confidence Interval (CI): 43.3-48.6%), and five-year relative survival was 23.5% (95% CI 21.4-25.7%) (Queensland Cancer Registry (QCR) and Cancer Council Queensland (CCQ) 2010). Relative five-year survival from a range of brain tumours by age group for 2000-2006, United States, is shown in Table 2.2.

TABLE 2.2 RELATIVE SURVIVAL FOR MALIGNANT BRAIN TUMOURS, 2000-2006: DATA FROM THE US SURVEILLANCE, EPIDEMIOLOGY, AND END RESULTS (SEER) DATABASE

	Relative 5 year survival (%) by age group		
Histology	20-39 years	40-64 years	65+ years
Pilocytic astrocytoma (grade I)	96.4	83.5*	
Diffuse (grade II) and anaplastic astrocytoma (grade III)	60.2	31.7	5.6
Oligodendroglioma	82.0	70.0	38.2
Embryonal/primitive/medulloblastoma	72.3	44.3*	
Mixed glioma	65.1	56.1	24.6
Neuroepithelial	65.1	26.6	4.6
Malignant glioma not otherwise specified	77.6	42.8	5.3
Glioblastoma (grade IV)	21.3	5.3	1.1

CNS: Central Nervous System. Source: (Kohler et al. 2011).

* Reflects relative survival for persons aged 40+ years

2.4. DIAGNOSTIC AND TREATMENT PATHWAYS

Diagnosis of a brain tumour generally follows the appearance of partial or general seizures, progressive focal neurological deficits (e.g. paresis, aphasia), cognitive dysfunction, or consequences of raised intracranial pressure (e.g. progressive headache, nausea, drowsiness) (Behin et al. 2003). Initial assessment includes radiological diagnosis, but a precise histological diagnosis (using samples from biopsy or resection) is needed to guide treatment decisions (Rampling et al. 2004).

Management of brain tumours is a multidisciplinary process, involving health professionals such as neurologists, neurosurgeons, medical and radio-oncologists, general practitioners (GPs), specialist nurses, care coordinators, psychologists, physiotherapists, occupational and speech therapists, and palliative care practitioners (Macarthur & Buxton 2001; Gabanelli 2005). Surgery may be used to obtain tissue for histological diagnosis, to attempt total macroscopic resection (i.e. the removal of all visually abnormal tissue), to reduce elevated intracranial pressure and associated symptoms, to enable delivery of adjuvant treatment (e.g. chemotherapy agents), or for palliation (Rampling et al. 2004). Radiotherapy may similarly be used for curative or palliative purposes. Prognosis following surgery and/or radiotherapy depends on factors such as age, performance score, tumour histology and extent of resection attainable (Rampling et al. 2004).

Historically, brain tumours have been considered resistant to chemotherapy (Bredel & Zentner 2002). However, research has shown that chemotherapy agents such as temozolomide, when used in addition to radiation therapy, improve clinical outcomes for glioma patients, and such agents have become part of the standard treatment protocol for glioma (Stupp et al. 2007). Chemotherapy is also a key part of a treatment regime for some chemo-sensitive brain tumours such as germ cell tumours, but selection of chemotherapy agents is limited by the agent's ability to penetrate the blood-brain barrier (Rampling et al. 2004). A number of novel anti-cancer treatments are under development, including strategies to modify genes, recruit the immune system and its components to attack the tumour, and utilise viruses or toxins to kill tumour cells (Rampling et al. 2004).

Supportive strategies are also necessary to control and prevent symptoms such as seizures, oedema, thromboembolic complications, medication side effects, fatigue, cognitive dysfunction and depression (Drappatz et al. 2007). Clinical guidelines for the management of adults with glioma, including diagnosis, imaging, treatment, rehabilitation, palliative care and psychosocial care have recently been published (Australian Cancer Network Adult Brain Tumour Guidelines Working Party 2009), highlighting the evidence available to guide the care of these patients.

2.5. MORBIDITY, IMPAIRMENT AND QUALITY OF LIFE

Although mortality has not significantly changed, the last thirty years have seen greater recognition of the morbidity of brain tumours (Oertel et al. 2005; AIHW & AACR 2010). To facilitate description, the sequelae of disease and treatment have been categorised as: physical; cognitive, behavioural and neuropsychiatric; depression and anxiety; speech and communication; and social and environmental issues. Relevant literature regarding the overall QOL of patients and carers has also been described and critiqued.

Many of these sequelae of tumours and treatments are linked with each other (for example, cognitive and memory problems may lead to communication problems) (Edvardsson & Ahlström 2005). Some symptoms also occur simultaneously (symptom clusters) with greater combined effect than each would have alone (Fox et al. 2007). These sequelae impact carers, as few cancer patients rely entirely on formal care and most are primarily cared for by family members and friends (Kim et al. 2006). As this role is usually unanticipated and undertaken without training, it may have negative impacts on carers' existing roles, and cause stress which can impact on QOL (Kim et al. 2006).

2.5.1. PHYSICAL SEQUELAE

A number of physical and functional sequelae of tumour and/or treatment have been documented. The most commonly reported include: fatigue; paresis, weakness and motor dysfunction; seizures; and pain; mobility and falls (Arber et al. 2010), changes in ability to perform activities of daily living (Ostgathe et al. 2010), changes in appearance (Batchelor & Byrne 2006), hair loss and itchy skin (Osoba et al. 1997) and visual disturbance (Heimans & Taphoorn 2002).

2.5.1.1. FATIGUE

A recent review highlighted fatigue as the most significant symptom for patients with high grade gliomas (HGGs) (Liu et al. 2009). Incidence of 'significant' fatigue has been reported among one third of newly diagnosed HGG patients, along with daytime somnolence rates of 20% (Brown et al. 2006). Among patients with recurrent HGG, 89% of patients with anaplastic astrocytoma (AA) and 94% of patients with GBM reported fatigue; 79% (AA) and 69% (GBM) reported drowsiness.

Tiredness was also reported by 67% of brain tumour patients accessing palliative care in Germany (Ostgathe et al. 2010).

Two known causes of fatigue for brain tumour patients are intracranial pressure, and neurological toxicity due to radiotherapy (Arber et al. 2010). For patients treated with radiotherapy, fatigue may also be part of a 'somnolence syndrome' described in patients receiving cranial irradiation for other conditions (Faithfull & Brada 1998). Somnolence syndrome usually appears five to six weeks after cranial irradiation. Its cause is not well understood, but it is speculated to occur due to transient demyelination of the nerve fibres (Woodford 2007).

2.5.1.2. PARESIS, WEAKNESS AND MOTOR DYSFUNCTION

Hemiparesis was identified among 17% and 34% of primary malignant brain tumour patients accessing palliative care services in the UK and Germany, respectively (Arber et al. 2010; Ostgathe et al. 2010). Motor dysfunction has been reported by 89% and 73% of recurrent GBM & AA patients (Osoba et al. 2000). In contrast, hemiplegia and/or weakness was a presenting symptom among 20% of patients with GBM (Yuile et al. 2006). Weakness of both legs has also been found to be less common among newly diagnosed patients than patients with recurrent disease (Osoba et al. 1997).

Motor dysfunction may result from focal neurologic deterioration (Liu et al. 2009), or occur because of steroid myopathy, a complication of steroid therapy that presents with muscle atrophy and weakness, particularly in the proximal lower extremities (Drappatz et al. 2007). Motor dysfunction is associated with lower QOL, especially in physical, role, emotional, and social functioning domains (Osoba et al. 1997).

2.5.1.3. SEIZURES

Approximately 35% of all primary brain tumour patients experience at least one seizure, but seizure activity is strongly associated with age (Drappatz et al. 2007), tumour histology (Smith et al. 1991) and location (Hildebrand et al. 2005). Seizures are more common among LGG patients (about 70%) than HGG patients (40-50%) (Klein et al. 2003). The mechanism behind seizures in brain tumours is not fully understood and may originate not from the tumour, but from adjacent brain tissue

(Klein et al. 2003). However, seizures are more commonly a manifestation of the brain tumour than epilepsy per se (Hildebrand et al. 2005). The impact on prognosis of seizures for brain tumour patients' survival is currently the focus of debate (Liu et al. 2009).

Seizure activity may be a source of fear for some patients and carers. Liu et al. (2009) found that 26% of LGG patients were afraid of having a seizure. Qualitative research has also found that many carers of primary brain tumour patients are afraid of (the patient having) seizures, and feel inadequately prepared to manage a seizure (McConigley et al. 2010). Seizures can be controlled by antiepileptic drugs in about half of all glioma patients (Klein et al. 2003). Antiepileptic drugs may cause depression, irritability, fatigue (Taillibert et al. 2004), and reduction in cognitive functioning, such as information processing speed (Klein et al. 2003). However, incompletely controlled seizures may themselves cause a decline in overall QOL (Klein et al. 2003).

2.5.1.4. PAIN

Pain, most commonly headache, has been reported by 30-70% of brain tumour patients (Taillibert et al. 2004; Ostgathe et al. 2010; Osoba et al. 1997; Osoba et al. 2000). Headache is also one of the most common presenting symptoms (Bell et al. 1998). Chronic headache may result from craniotomy; acute headaches from oedema due to radiotherapy and/or intracranial pressure due to the tumour (often accompanied by nausea and vomiting); while neuropathic pain may result from meningeal involvement (Taillibert et al. 2004; Bell et al. 1998).

2.5.2. COGNITIVE, BEHAVIOURAL AND NEUROPSYCHIATRIC SEQUELAE

A range of neurological impacts of brain tumours affecting cognitive function, behaviour and psychiatric function have been described.

2.5.2.1. COGNITIVE IMPAIRMENT

Cognitive impairment is defined as impairment(s) in the processes by which sensory input is elaborated, transformed, reduced, stored, recovered, or used (Neisser 1967). It is the most common impairment in patients with primary brain tumours (Tucha et al. 2000), and is significantly related to lower QOL, particularly in

functional domains (Gustafsson et al. 2006; Osoba et al. 1997). At diagnosis and prior to treatment, 91% of brain tumour patients had impairments in at least one area of cognition, 70% of patients had impairments in three or more areas, and one third of patients had impairments in eight or more areas. The most common deficits were of executive function (e.g. abstract thinking and concept formation), visuoconstructive abilities (e.g. three-dimensional drawing), attention (e.g. alertness, divided attention and processing speed), and verbal memory (e.g. recall, short-term memory), all impaired in at least 30% of patients (Tucha et al. 2000). Other studies have also indicated that memory loss, information processing and attention are commonly changed during and after radiation and chemotherapy (Weitzner 1999).

2.5.2.2. Neurobehavioural and neuropsychiatric symptoms

Brain tumour patients also may experience neurobehavioural symptoms and neuropsychiatric symptoms (i.e. tumour- or treatment-related behavioural and psychiatric symptoms). The most commonly reported behavioural changes include lack of insight and self-appraisal, disinhibition and lack of understanding of social cues, reduced motivation and inability to initiate activity, becoming demanding or distancing, having reduced empathy and personality change (Klein et al. 2001; Salander et al. 1999; Salander 1996; Australian Cancer Network Adult Brain Tumour Guidelines Working Party 2009). Cognitive impairments and neurobehavioural symptoms, particularly personality change, may lead brain tumour patients to feel a 'loss of self' (Fox & Lantz 1998). Other common symptoms include anxiety and depression, irritability, anger, apathy, hallucinations, mania, confusion and delusions, and are more frequent in patients with tumours in the frontal and temporal lobes (Filley & Kleinschmidt-DeMasters 1995; Scicutella 2007; O'Brien et al. 2006).

2.5.2.3. Mechanisms of effect and associated factors

Several mechanisms that may cause these changes have been recognised: invasion/displacement of brain tissue, disconnection of connections between brain regions, raised intracranial pressure, seizure activity, and/or changes in endocrine activity or function (Taphoorn et al. 1994). Biopsy or surgery to resect a tumour may

cause impairment as functional tissue is interspersed within tumour tissue (Giordana & Clara 2006). Focal cerebral radiation may cause necrosis in specific areas, while diffuse radiation injuries may result in dementia. Some chemotherapy drugs have also been linked with dementia-like symptoms (Giordana & Clara 2006), while corticosteroids and antiepileptic drugs have detrimental effects on cognitive function, depression and irritability (Klein et al. 2001). The relative effects of tumour progression and treatment factors have not been determined (Liu et al. 2009; Taphoorn et al. 1994). However, cognitive deterioration has been shown to precede tumour progression shown by MRI (Giordana & Clara 2006).

The magnitude of cognitive impairment is positively correlated with age and tumour volume (Tucha et al. 2000), and is worse among patients with recurrence, and those with more widespread oedema (Osoba et al. 1997; Giovagnoli & Boiardi 1994). Patients with left-sided lesions are more likely to exhibit impairments in verbal short-term memory, while patients with right-sided tumours more frequently exhibit visuospatial impairments (Tucha et al. 2000). Neuropsychiatric symptoms of anger, indifference and disinhibition are also associated with temporal (Andrewes et al. 2003) and frontal lobe lesions (Niki et al. 2009).

2.5.2.4. Impact on Carers

The impact of cognitive and behavioural changes on carers is also substantial. In one study, three of the four highest unmet needs for carers related to the patients' cognitive and behavioural impairments: adjusting to changes in mental and thinking ability of the brain tumour patient, managing difficult aspects of behaviour, and adjusting to the changes in the personality of the brain tumour patient (Janda et al. 2008). Carer distress has been linked with patients' personality, cognitive and behavioural changes (Cashman et al. 2007), and with neuropsychiatric symptoms in the care recipient (Sherwood et al. 2006).

Carers report fears that patients' may experience changes in or loss of individual control, cognition or consciousness, or personality (Ostgathe et al. 2010). A particular difficulty may stem from carers' lack of skills and knowledge to manage behavioural changes (Sherwood et al. 2004), and additional burden through decision-making responsibilities (McConigley et al. 2010).

2.5.2.5. CONSEQUENCES FOR HEALTH PROFESSIONALS

Cognitive, behavioural and neuropsychiatric impairments may interfere with a patient's ability to understand and participate in treatment decision-making, or give informed consent (Correa 2006). Many studies have found little relationship between objective test results for cognitive impairment and self-report measures (Taphoorn et al. 1992; Tucha et al. 2000; Taphoorn et al. 1994). Health professionals need to identify the nature and extent of any deficits present, to determine whether a patient is competent to make an informed decision (Australian Cancer Network Adult Brain Tumour Guidelines Working Party 2009).

Clinical observation has a low sensitivity, particularly for impairments of executive functions (Correa 2006), suggesting that objective assessment methods are needed. Tests should be short, repeatable, validated in the brain tumour population, and sensitive to the kinds of impairments experienced by these patients (Correa 2006; Weitzner & Meyers 1997). For example, the Mini-Mental State Examination (MMSE), which is commonly used to screen cancer patients for clinical trial participation, has limited sensitivity and specificity for detection of mild cognitive impairment, particularly impairments in abstract reasoning, executive functioning and visual perception, and impairments from right hemisphere lesions, common in brain tumour patients (Olson et al. 2008; Fox et al. 2006).

2.5.3. DEPRESSION AND ANXIETY

Prevalence of depression and anxiety depends greatly on the method of measurement used. Lower prevalence is generally shown by studies with clinician-administered structured psychiatric interviews, and higher prevalence by self-report (Catt et al. 2008; Litofsky et al. 2004). The prevalence of depression self-reported in three studies was 15-17%: 15% of 40 glioma or meningioma patients (Anderson et al. 1999), 16% of 105 recently diagnosed patients brain cancer patients (Pringle et al. 1999), and 17% of 70 brain tumour patients living in the community (Janda et al. 2008). Physicians also identified depression in 15% of 598 glioma patients in the postoperative period (Litofsky et al. 2004). However, using self-report questionnaires which conformed to criteria of the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV), Arnold et al. (2008) identified

depression in 41% of 363 brain tumour patients. Based on self-report and physician-reported measures, the prevalence of depression appears to decrease after surgery (Pringle et al. 1999), and to increase and stabilise at three and six months after surgery, respectively (Litofsky et al. 2004).

The prevalence of anxiety tends to be higher but similarly variable: five percent of 40 glioma or meningioma patients (Anderson et al. 1999), 30% of 70 community-based brain tumour patients (Janda et al. 2007), 30% of 105 brain cancer patients (Pringle et al. 1999), and 48% of 363 brain tumour patients, had clinically significant scores indicating anxiety on the various instruments used. Giovagnoli et al. (1996) suggest anxiety ratings are usually highest at initial diagnosis, and at the termination of therapy.

A recent descriptive study suggests the prevalence of depression and anxiety in cancer patients was around 18% and 21% respectively (Hinz et al. 2010). This suggests that the prevalence of depression may be similar in brain tumour patients as in cancer patients generally, but that brain tumour patients experience higher rates of anxiety than patients with other cancers.

A number of demographic, disease and treatment-related characteristics and impairments have been associated with depression and anxiety: being female, having a history of psychiatric illness, having a left-sided tumour, meningioma, or LGG (Pringle et al. 1999; Arnold et al. 2008) and physical disability (Anderson et al. 1999). Factors also associated with depression include lower education level (Arnold et al. 2008), a family history of psychiatric disorders (Wellisch et al. 2002), multifocal tumour sites, larger tumour size, use of glucorticosteroids, complications such as deep vein thrombosis, seizures, systemic infection, and adverse drug reactions (Litofsky et al. 2004), and worse cognitive function (Anderson et al. 1999). Associations between depression and shorter survival have also been found, although results are inconsistent (Litofsky et al. 2004; Mainio et al. 2005). Further research is needed to clarify the relative effects of disease, treatment, and psychological variables (Taphoorn et al. 1992; Anderson et al. 1999; Taillibert et al. 2004).

2.5.3.1. Anxiety and Depression among Carers

Caring responsibilities impose significant levels of stress, further impounded by factors unique to brain tumours (Horowitz et al. 1996; Sherwood et al. 2006). Although qualitative studies have described the stressful experience of caring in this setting (Sherwood et al. 2004; Schmer et al. 2008; McConigley et al. 2010), the prevalence of depression and anxiety among carers of brain tumour patients has not been widely assessed. Janda et al. (2007) found 40% of carers self-reported probable anxiety, scoring at least 11 points on the Hospital Anxiety and Depression Scale (HADS) anxiety scale; similar scores indicated 10% had probable depression.

Several factors have been found to be associated with worse psychological well-being among carers of brain tumour patients. A pilot study found that perceived stress was higher among carers of LGG (compared to HGG) patients, among men, and among younger carers (Keir et al. 2006). Another study showed that carers' psychological well-being for carers was significantly related to patients' level of functional (excluding cognitive) impairments, and that social support moderated this relationship (Ownsworth et al. 2010). A higher number of neuropsychiatric symptoms in brain tumour patients is associated with higher depressive symptom scores in carers (Sherwood et al. 2006).

2.5.4. Speech and Communication

Neurological damage to the language areas of the brain may result in dysphasia (also known as aphasia), which is an acquired language impairment characterised by impaired word selection, language production and comprehension, and which affects both spoken and written language (Beeson & Rapcsak 2006). Several other disorders can also impair communicative functions, such as apraxia, where motor programming for speech production is disrupted (Beeson & Rapcsak 2006), although dysphasia appears to be the most significant for brain tumour patients (Edvardsson & Ahlström 2005). Tumours in both the left and right hemispheres of the brain can result in communication deficits, although dysphasia most often results from left-hemisphere lesions (Beeson & Rapcsak 2006). In a review of five studies, the prevalence of dysphasia, language disturbance or slurred speech was 5-32% (Armstrong et al. 2004).

2.5.5. SOCIAL AND ENVIRONMENTAL SEQUELAE

A number of social and environmental sequelae to brain tumours have been identified, such as limitations in working and driving a car (Sherer et al. 1997), and corresponding increased dependency on carers (Halkett et al. 2010), limitations in social roles, especially in parenting, social opportunities, and education (Edvardsson et al. 2006), limitations in leisure activities, changes in relationships with family and friends (Edvardsson & Ahlström 2005), and financial difficulties (Bradley et al. 2009).

2.5.5.1. REHABILITATION

The sequelae of a brain tumour and treatment compromise the ability of many patients to live independently (Sherer et al. 1997). Similarities between the impairments suffered by patients with brain tumours and patients with traumatic brain injury suggest that brain tumour patients are good candidates for rehabilitation (Kirshblum et al. 2001). However, rehabilitation has not been commonly provided to brain tumour patients (Boake & Meyers 1993), probably due to neuro-oncology professionals' lack of awareness of services, rehabilitation professionals' unfamiliarity with brain tumour patients, and patients' poor prognoses (Kirshblum et al. 2001). Research investigating the effectiveness of rehabilitation programs for brain tumour patients suggests physiotherapy and occupational therapy improve motor functioning but not cognitive functioning (Catt et al. 2008), and lead to improvements in QOL (Sherer et al. 1997).

2.5.5.2. EMPLOYMENT

The majority of brain tumour patients do not return to work after diagnosis and treatment, most commonly because of cognitive impairment (Bell et al. 1998; Main et al. 2005). A study of 277 brain tumour patients and 224 carers in the US found that although 91% of patients were working before diagnosis, only 33% were working post-diagnosis, and almost two thirds of carers changed work patterns (Patterson 2007). Changes in employment for the patient and/or carer resulted in downward shifts in household income for 48% of respondents (Patterson 2007). The experiences of brain tumour patients are also likely to be similar to those of cancer patients in general, who often return to work with changed job responsibilities or decreased work hours (Main et al. 2005).

2.5.5.3. DRIVING

National regulations prohibit persons with certain conditions from holding an unrestricted private or any commercial driver's license in Australia (Australian Transport Council 2003). Relevant to this thesis, criteria prohibit driving by persons with evidence of residual malignant brain tumour, persisting visual field loss of half or a quarter of the eye or double vision, uncontrolled epilepsy, or impaired judgement. Clinical guidelines for the management of adult glioma patients recommend that persons wishing to resume driving after treatment undertake formal functional assessment to determine their safety to drive (Australian Cancer Network Adult Brain Tumour Guidelines Working Party 2009).

2.5.5.4. FINANCIAL ISSUES

The financial impact of brain tumours include costs to the patient, family and society, such as lost income, paid disability, decreased QOL, and loss of productivity to society (Weitzner & Meyers 1996). A US study of brain tumour patients found 47% incurred credit card debt, and 42% borrowed money from family and friends, to pay for expenses associated with their disease (Patterson 2007). Another qualitative study found most brain tumour patients had difficulties paying for medications and health care (Bradley et al. 2007). Although almost all studies that comprehensively assess the costs of brain tumours come from the US, similar findings regarding the high direct costs of brain tumour care, from studies conducted in Sweden (Blomqvist et al. 2000), Canada (Mendez et al. 2001), the UK (Latif et al. 1998) and Germany (Wellis et al. 2003), suggest these findings are not (entirely) a function of the American health care system.

2.5.6. QUALITY OF LIFE

The World Health Organization (WHO) defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" (The WHOQOL group 1995, p. 1405). Many other definitions of QOL have also been developed, generally emphasising that it is a subjective, multidimensional concept, although the dimensions measured vary across instruments (Heimans & Taphoorn 2002). The most common dimensions measured are: physical (e.g.

activities of daily living, symptom control); psychological (incorporating cognitive and emotional components); and social dimensions such as interpersonal relationships (Lovely 1998).

When measuring QOL in cancer, a range of patient-reported outcomes (PROs) such as symptoms and side-effects are usually measured (Figure 2.3). However, there is debate about which aspects should be measured or included as dimensions of health-related quality of life (HRQOL). Overall, however, there is agreement that QOL is a useful measure of the impact of disease and treatment for comparing groups of patients and/or different treatments, and that the choice of instrument and the dimensions measured should depend on the aspects relevant to the situation (King et al. 1996).

FIGURE 2.3 FACETS OF QUALITY OF LIFE (QOL) IN CANCER Source: (King 2007).

In the brain tumour setting, QOL may be a particularly important measure because the quantity of life is often so short (Cheng et al. 2009). QOL outcomes matter greatly to patients, and are used by patients and health professionals in treatment decision-making (Leavitt et al. 1996; Gilbert et al. 2000).

2.5.6.1. ASSESSMENT OF QUALITY OF LIFE IN NEURO-ONCOLOGY

Simple one-dimensional measures of physical functioning such as the Karnofsky Performance Scale (KPS) (Table 2.3) have been widely used as proxy measures of 'morbidity' or 'QOL' in the brain tumour setting (Bampoe et al. 1998; Lovely 1998).

However, the KPS is reported by health professionals, and so may not be a true reflection of QOL (Cheng et al. 2009). The KPS is also comparatively insensitive to neurologic impairments (Cheng et al. 2009), and to cognitive, emotional and social dimensions of QOL (Bell et al. 1998). Whilst highly sensitive to age, the KPS demonstrates a 'ceiling effect', in that improvements may not be evident among patients who are relatively well (KPS>80) (Mackworth et al. 1992). Despite these criticisms, the KPS and similar measures, such as the Eastern Co-operative Oncology Group (ECOG)/WHO clinical performance scale, are still commonly used, although now primarily as selection criteria or stratification factors, rather than as outcome measures (Cheng et al. 2009).

TABLE 2.3 THE KARNOFSKY PERFORMANCE SCALE (KPS) CRITERIA

Scale	
100	Normal; no complaints; no signs or symptoms of disease
90	Able to carry on normal activity; minor signs/symptoms of disease
80	Normal activity with effort; some signs or symptoms of disease
70	Cares for self; unable to carry on normal activity or to do active work
60	Requires occasional assistance, but is able to care for most of his/her needs
50	Requires considerable assistance and frequent medical care
40	Disabled; requires special care and assistance
30	Severely disabled; hospitalisation is indicated although death is not imminent
20	Very sick; hospitalisation necessary; active supportive treatment necessary
10	Moribund; fatal processes progressing rapidly
0	Dead

Source: (Schaafsma & Osoba 1994).

A number of multidimensional measures of QOL have now been developed for use in cancer populations, such as the Functional Assessment of Cancer Therapy-General (FACT-G), and the European Organisation for Research and Treatment of Cancer (EORTC) Core Quality of life Questionnaire (QLQ-C30). Brain tumour specific questionnaire modules such as the FACT-Brain (FACT-Br) and the EORTC Brain Cancer Module (QLQ-BN20), have also been developed to assess issues specific to brain tumour patients (Gilbert et al. 2000; Weitzner et al. 1995), and have been shown to be reliable and valid (Weitzner et al. 1995; Taphoorn et al. 2010; Osoba et al. 1996). The key features of these scales are described in Table 2.4.

TABLE 2.4 COMPARATIVE FEATURES OF THE FACT & EORTC QUALITY OF LIFE SUITES

	Functional Assessment of Cancer Therapy (FACT)	European Organisation for the Research & Treatment of Cancer (EORTC)
Generic instrument for cancer patients	FACT-General (FACT-G) 27 items, 4 subscales: • physical well-being • social/family well-being • emotional well-being • functional well-being	Quality of life in cancer: QLQ-C30 30 items, 6 domains: • physical functioning • role functioning • emotional functioning • cognitive functioning • social functioning • global quality of life 3 symptom scales: • fatigue • pain • nausea and vomiting
Brain tumour module	FACT-Brain (FACT-Br) 23 items: • overall domain only	Brain module (QLQ-BN20) 20 items, 4 domains: • future uncertainty • visual disorder • motor dysfunction • communication deficit
Features	More focus on psychosocial aspects	More focus on symptoms

Sources: (Taphoorn et al. 2010; Cheng et al. 2009; Weitzner et al. 1995; Mauer et al. 2008).

Two common problems in the assessment of QOL with brain tumour patients are selection bias and missing data. Selection bias occurs because a considerable number of patients cannot complete QOL measurements due to cognitive impairment, communication deficit, or distress (Cheng et al. 2009). Eligibility criteria in clinical trials also often specifically exclude patients with cognitive dysfunction, aphasia, or low KPS scores (Cheng et al. 2009). In longitudinal studies, missing data resulting from administrative failure, drop-outs, missed assessments, or refusal can similarly bias findings. Proxy ratings by carers or health professionals may be less reliable than patients themselves, because their ratings are likely to be influenced by their own perceptions and standards. However, research suggests carers' ratings are similar to those of patients (Brown et al. 2008; Hahn et al. 2003; Sneeuw et al. 1997). Using carers' proxy data in place of missing patient data may allow the inclusion of a broader range of patients, providing more accurate descriptions of the QOL of brain tumour patients (Cheng et al. 2009).

2.5.6.2. The Quality of Life of Brain Tumour Patients

The first study that used a multidimensional measure of QOL with brain tumour patients was published in 1989 (Trojanowski et al. 1989; cited by Lovely 1998). Since this time, at least 12 reviews have described the QOL of adults with primary brain tumours, many focusing also on cognitive or neuropsychiatric outcomes (Cheng et al. 2009; Efficace & Bottomley 2002; Heimans & Taphoorn 2002; Huang et al. 2001; Liu et al. 2009; Lovely 1998; Meyers & Weitzner 1995; Ownsworth et al. 2009; Palese et al. 2008; Taphoorn et al. 2010; Weitzner 1999; Weitzner & Meyers 1997). Early reviews reported that the studies therein were limited by small sample size, heterogeneous samples of different tumour types and locations, and a focus on functional status (Weitzner 1999), and called for more, better quality, longitudinal studies (Lovely 1998). More recent reviews echoed these calls (Taphoorn et al. 2010; Cheng et al. 2009; Ownsworth et al. 2009; Liu et al. 2009).

Overall, these reviews suggest that the QOL of brain tumour patients is a function of patient factors (demographic factors and comorbidities), tumour factors (tumour laterality, grade, size, location) and treatment factors (surgery, radiation, chemotherapy, concomitant medications) (Liu et al. 2009). Studies have variously found poorer QOL in patients with LGGs compared to HGGs and vice versa (Taphoorn et al. 2010; Ownsworth et al. 2009). Some studies suggest that patients with larger tumours, tumours in the nondominant hemisphere and tumours located anteriorly in the brain have poorer QOL (Taphoorn et al. 2010), while others have shown contradictory findings (Ownsworth et al. 2009). QOL may improve transiently after surgery, but decline with radiotherapy, although this has not been conclusively shown. Chemotherapy seems to have a negative impact on QOL that resolves shortly after treatment (Taphoorn et al. 2010). The most consistent findings suggest that poorer QOL is experienced by patients with poorer physical function or performance status (Ownsworth et al. 2009).

Few studies have compared brain tumour patients with other populations. The quality of life of HGG patients appears to be lower than that of healthy controls for the majority of newly diagnosed patients, but similar to that of patients with other neurological diseases of the central and peripheral nervous system and to those

with lung cancers (Taphoorn et al. 2010). However, brain tumour patients typically report more cognitive difficulties, communication problems, fatigue, activity limitations and neurological symptoms (Ownsworth et al. 2009).

2.5.6.3. The Quality of Life of Carers of Brain Tumour Patients

Research with cancer patients suggests that a carer's quality of life is related to that of the patient (Clark et al. 2006). This relationship has also been shown in one study with brain tumour patients and their carers (Janda et al. 2007). The quality of life of carers appears to be lower than that of population norms (Janda et al. 2007), and influenced by patients' functional and cognitive status (Sherwood et al. 2004). Qualitative studies have also confirmed the strain of caring, uncertainty and increased responsibility on carers of brain tumour patients and their need for support (Salander 1996; Leavitt et al. 1996; Madsen & Poulsen 2011).

2.6. Chapter Summary

Overall, despite their low incidence, the burden of disease caused by brain tumours is high because of their high morbidity and mortality. Fatigue and cognitive impairment are significant problems for patients, while carers need assistance to manage behavioural changes. Physical and cognitive impairments lead to changes in employment and mobility, and financial difficulties for many patients and carers. The volume of quality of life research has increased over the past 15 years, but many methodological issues remain. Understanding the multitude of influences on quality of life and its many dimensions is important to understand the needs of this population.

3. INFORMATION IN THE CANCER SETTING

3.1. INTRODUCTION

This chapter describes the role and complexity of information provision in cancer care. To understand these issues, the reasons information is important for cancer patients and carers are explained, and the most common unmet information needs are identified. Factors that influence information provision are examined. The success of interventions that have been undertaken to improve information provision are described, highlighting issues in their evaluation and implementation.

3.2. WHY IS INFORMATION OR ITS PROVISION IMPORTANT?

Information is important to patients and carers because it enables coping and psychological adjustment to the cancer diagnosis, allows participation in treatment decision-making and self-care, and facilitates continuity of care (Figure 3.1). This section expands on each of these reasons why information is needed.

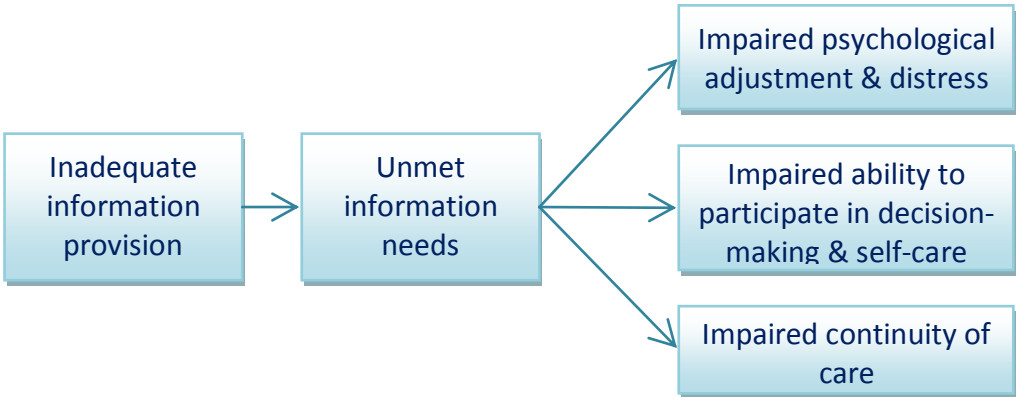


FIGURE 3.1 IMPACT OF INADEQUATE INFORMATION PROVISION ON PATIENT OUTCOMES

3.2.1. PSYCHOLOGICAL ADJUSTMENT AND DISTRESS

3.2.1.1. COPING THEORY

Lazarus and Folkman's (1984) model of coping may partially explain the relationship between information and psychological adjustment. In this model, coping is defined as "constantly changing cognitive and behavioural responses to demands that are appraised as taxing or exceeding the resources of a person" (Lazarus & Folkman 1984, p. 141). Coping is thus conceptualised as a dynamic process, dependent on both the person and environment. When a person encounters a stressor (such as a cancer diagnosis), the person makes an appraisal, or evaluative judgement about

the personal significance of the event. This appraisal involves estimating the potential of the stressor (e.g. to engender anger, or sadness, and to what degree), and the resources available to deal with the stressor, including the individual's resources, coping options available, and the probable result if options were applied (Livneh & Martz 2007).

Depending on the results of the appraisal, a person may select from many coping strategies, broadly categorised into problem- or task-focused strategies, and emotion-focused strategies. Problem-focused strategies seek to alter the external environment to decrease the stress, and include information seeking, seeking instrumental support, and problem solving (Manne 2007). For example, a problem-focused strategy in response to a cancer diagnosis may involve attempting to obtain more information about the problem and/or the options available to deal with it (information-seeking). In contrast, emotion-focused strategies aim to regulate emotions and/or adopt or accommodate oneself to the existing stressful environment, such as acceptance, positive reappraisal, distancing, cognitive or behavioural avoidance, and seeking emotional support. For example, an emotion-focused strategy in response to a cancer diagnosis may involve distancing oneself from the source of stress and avoiding information (information-avoidance) (Radnitz & Tiersky 2007).

Coping acts as a mediator between the appraisal and the emotional response. Folkman and Lazarus (1991, p. 209) defined emotions as "complex organised psychophysiological reactions, consisting of cognitive appraisals, action impulses, and patterned somatic reactions". Thus, the emotions that a person experiences depend on their appraisal and the coping strategies they use (Radnitz & Tiersky 2007).

Some studies have found that persons who used problem-focused strategies to deal with cancer had fewer symptoms of distress or anxiety than persons who used emotion-focused strategies (e.g. (Epping-Jordan et al. 1999; Ben-Zur et al. 2001)). However, most research has been observational and has been conducted with breast cancer patients, commonly in the early stages of disease (Manne 2007). It is

probable that both problem-focused and emotion-focused strategies may be adaptive or maladaptive, depending on the situation (Suls & Fletcher 1985).

Overall, Lazarus and Folkman's model of coping suggests that cancer patients may use information for coping in a number of ways. When patients experience a stressor such as a cancer diagnosis, they appraise the resources available to them, which includes information they have about their illness, and their information seeking or processing abilities. Patients and carers may also seek information as part of a coping strategy, increasing the resources available in further appraisals. As coping is the process of managing demands which exceed the resources of an individual, information may reduce the threat posed by a stressor and/or assist in the generation of less negative resultant emotions.

3.2.1.2. Other Uses of Information for Psychological Adaptation

Information may also be viewed as a tool to assist patients and their carers to regain a perception of control, psychologically adapt to diagnoses, and manage their disease (Ream & Richardson 1996). Following the model of coping modes, there are two fundamental dimensions of cognitive orientation towards situations of threat, one of which is vigilance, or the search for and processing of threat-related information in an effort to reduce subjective uncertainty (De Bruin et al. 2001). This theory is supported by studies which have shown that inadequate provision of information increased uncertainty, distress and anxiety in cancer patients (Fallowfield et al. 1995). Patients who wanted more information when leaving a consultation with their doctor tended to be less satisfied with the consultation than those whose information needs were met (Butow et al. 1997). This is significant as patients who are satisfied with their consultations demonstrate better psychological adjustment (Brown et al. 1997).

Provision of adequate levels of information has also been hypothesised to improve a patient's condition via increased acceptance of medical procedures and compliance with treatment, achieved through reduction of anxiety and improvement in psychological adjustment (Kitamura 2005). Information may generate feelings of safety and security, and assist patients to feel that they have control over their health (Ream & Richardson 1996; Pallson & Norberg 1995).

Although there have been suggestions that pre-operative anxiety may be beneficial in promoting recovery through hormonal responses, there have been conflicting findings with respect to relationship between preoperative anxiety and postoperative adjustment (De Bruin et al. 2001), and studies have been limited by ambiguous, short-term outcome measures and application to minor surgery situations (Salmon 1993).

3.2.2. DECISION-MAKING AND CARE

Information enables patients and their carers to participate in treatment decision-making, the right to which is emphasised by community attitudes and medical ethics (Butow et al. 1997; Brown et al. 1997). Although a shared model of decision-making has not been uniformly embraced or seen as appropriate for all situations, it has been recognised that choice of treatments consistent with patient preferences requires an understanding prognosis and potential therapies (Elkin et al. 2007). For example, patients require information about the possible effects of different treatments (risks and benefits) on their quality and quantity of life (Bruera 2006). Empirical studies have also shown that patients' need for information exists regardless of their decision-making preferences (O'Leary et al. 2007).

Regardless of the role taken in decision-making, information about what may or is likely to happen may enable patients to take actions to prepare. For example, information about impeding temporary or permanent intellectual disability may allow patients to settle outstanding affairs and arrange wills (Janda et al. 2006). Patients appropriately informed by health professionals may also engage in advance care planning, which documents their preferences for a surrogate decision maker (enduring power of attorney), and/or future use of specific life-sustaining therapies such as cardio-pulmonary resuscitation (CPR) (Back et al. 2008).

Information is also needed for patients to give informed consent to treatments, and to take appropriate actions to care for themselves. Information can help patients and carers to understand, report and respond to symptoms, access and comply with available services and undertake self-care (Carney et al. 2006; Cegala et al. 2000; Wrixon 2009). Carers also need information to develop competency in their caring responsibilities and learn ways to manage (Morris & Thomas 2002).

3.2.3. CONTINUITY OF CARE

Information may also be viewed as a 'common thread' linking care between providers or services, and over time, acting as a type of continuity of care (Haggerty et al. 2003; Reid et al. 2002). Reid and colleagues (2002) delineate three types of continuity: informational continuity (comprising transfer of information, and the accumulated knowledge of a patient), relational continuity (referring to ongoing patient-provider relationships and consistency of providers), and management continuity (involving consistency of services, particularly managing transitions).

In this framework, information on the patient's medical condition and his or her preferences, values and context, serves to ensure care is appropriate for the individual and responsive to his or her needs (Haggerty et al. 2003). A review of 32 clinical trials evaluating continuity interventions, 21 of which included interventions to improve informational continuity, found continuity of care is predictive of patient satisfaction with care and provider, compliance to treatment, and reduced resource consumption (van Servellen et al. 2006). Although this review was unable to distinguish the individual effects of improved informational continuity compared with other continuity elements, this and other studies suggest improving consistency of information has benefits for the patient and the health care provider (van Servellen et al. 2006; van Wersch et al. 1997).

3.3. INFORMATION NEEDS

3.3.1. DEFINITION AND MEASUREMENT OF INFORMATION NEEDS

As described in section 3.2, the adequate provision of information to meet patients' and carers' needs may have a number of positive consequences (Fallowfield et al. 1995; Kitamura 2005). However, an 'information need' is a difficult concept to define and operationalise. A common definition of a need is "the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being" (Foot 1996; cited in Sanson-Fisher et al. 2000, p. 227). An information need is thus defined when a person expresses a desire for information (Hyland et al. 2006).

The information needs of patients and carers have been estimated via assessment of a number of related concepts, such as knowledge or recall (Fortun et al. 2008), need or desire for more information (Davies et al. 2008), satisfaction with information and/or communication (Auerbach et al. 2005; Beaver et al. 2006), information-seeking behaviours (Feltwell & Rees 2004; Mayer et al. 2007), or use of different information sources (James et al. 1999; McCree et al. 2006). However, these concepts are not equivalent to information needs, although they may be related. For example, satisfaction with information received does not indicate if the information provided was wanted or adequate (Wen & Gustafson 2004; Iconomou et al. 2001), and does not identify areas not addressed by existing services (Sutherland et al. 2009). Information-seeking behaviours are also inadequate measures of information needs, as there are discrepancies between patients' intentions to seek information, and their actual behaviours (Friis et al. 2003; Carlsson & Strang 1998).

Furthermore, even within the concept of 'information need', variations in meaning exist. Many studies purporting to measure information needs have in fact measured perceived importance of information (Galloway et al. 1997), or the level of detail preferred (Jenkins et al. 2001). Such assessments do not assess the degree to which desires for information have been met. In this thesis, 'information need' is defined following the convention of Voogt and colleagues (2005), who concluded that a person's 'actual' need for information is dependent on the information he/she desired or expected, the information provided to them, and recall of the information given. Definition of an 'information need' thus involves a person's subjective assessment of the information that he/she desires and the extent to which this need has been met.

Instruments to assess 'information need' have similarly measured a variety of concepts. A recent systematic review found that almost half (47%) of studies of 'information need' used surveys specifically developed for their needs (Rutten et al. 2005). Among studies which used validated instruments, the most commonly used were the Krantz Health Opinion Survey (KHOS), which assesses information

preferences, and the Information Needs Questionnaire (INQ) or derivatives, which assess the perceived importance of information (Rutten et al. 2005).

Two instruments which assess 'information need' as defined by Voogt et al. (2005) are the Supportive Care Needs Survey (SCNS) and the EORTC information module, the QLQ-INFO25 (Table 3.1). The SCNS asks participants to select one of five response categories for each item, which are used to distinguish between respondents who have no need, who have an unmet need, and those whose need has been met (Sanson-Fisher et al. 2000). The second instrument, the EORTC QLQ-INFO25, was recently developed to evaluate the information received by cancer patients, but also acts as a measure of information need (Arraras et al. 2007).

TABLE 3.1 COMMON INSTRUMENTS USED TO ASSESS INFORMATION NEED

Instrument	Description	Features
Supportive Care Needs Survey (SCNS)	Multidimensional survey with 71 items. Items assess the level of need for help with 5 types of issues: psychologic, health system & information, physical & daily living, patient care & support, and sexuality	Assesses information needs as part of broader needs assessment
European Organisation for Research & Treatment of Cancer (EORTC) Information module (QLQ-INFO25)	26 item questionnaire, 4 scales & overall score: information about: the disease, medical tests, treatment, other issues. Also evaluates desire to receive more/less information, & helpfulness of the information received	Primarily assesses perception of information provided

Sources: (Sanson-Fisher et al. 2000; Arraras et al. 2007).

3.3.2. 'UNMET' INFORMATION NEEDS

Despite research suggesting positive effects from information provision, poor communication and inadequate information is one of the most common complaints made by patients with cancer (Smith 2000). A systematic review considered 14 studies which investigated the extent of agreement between information received and information desired in a particular medical consultation (Kiesler & Auerbach 2006). These studies were chosen as, unlike many others, the studies targeted a specific medical encounter, and participants reported the amount and/or type of information they preferred before the consultation and what they subsequently received. Findings from the review were mixed in the extent to which patients were dissatisfied with information; however, all studies found dissatisfaction with

information provision and a desire for more information. Overall, a median of 52% of patients (ranging from 26-95%) were dissatisfied with the information provided. Patients reported receiving inadequate on the nature of the disease, prognosis, treatment options and likely outcomes (Kiesler & Auerbach 2006).

Studies have similarly found that carers do not receive 'enough' information, and that this is a key area of unmet need (Morris & Thomas 2002; Rees & Bath 2000; Salminen et al. 2004; Soothill et al. 2001). Perceptions that information was 'adequate' for carers have ranged substantially, similarly to studies with patients. In a recent Australian study of the experiences of cancer patients and carers 4-10 months after discharge, almost half of all carers reported that they were not given any written information, approximately one fifth wanted more information, and the same proportion reported receiving conflicting information from different staff (Beckmann et al. 2009). A Finnish study showed varied opinions of spouses of breast cancer patients, with available information judged as 'sufficient' by 75% of carers of patients treated at one hospital, compared to 43% at another hospital (Salminen et al. 2004). In the UK, levels of satisfaction with information of carers of breast cancer patients were shown to vary by information source, with 84% of carers very satisfied with information received from the patient, compared with 67% with information received from the GP, and 27% with information from medical books (Beaver & Witham 2007). There is also some evidence that carers have greater unmet information needs than patients, perhaps due to greater difficulties in accessing information (Morris & Thomas 2002).

As with patient studies, most carer studies have been in the field of breast cancer. Studies have also frequently investigated carers as 'add-ons' to patients, have largely focused on spouses, or have investigated the experiences of bereaved carers, so results must be interpreted with caution (Morris & Thomas 2002).

3.3.2.1. Common Information Needs

In 1989, Degner and colleagues reviewed over 200 articles relating to cancer (mostly breast cancer) to develop a list of nine common information needs (Table 3.2) (Degner et al. 1989; cited in Luker et al. 1996). Since this time, a number of individual studies, and at least four systematic reviews, have confirmed findings, at

least for more recently diagnosed cancer patients (Mills & Sullivan 1999; Ankem 2005; Rutten et al. 2005; Parker et al. 2007).

TABLE 3.2 COMMON INFORMATION NEEDS OF CANCER PATIENTS

The extent of the disease
Likelihood of cure and the prognosis
How treatment will affect social activities
Effect on family/friends
Self-care and return to normal life style
Psychological effects of treatment
Types of treatment available and the advantages/disadvantages of each
Risk of other family members getting cancer
Side-effects of treatment.

Source: (Degner et al. 1989; cited in Luker et al. 1996).

Two reviews have reported that the information desired by carers is similar to that desired by patients (Morris & Thomas 2002; Rees & Bath 2000). However, some studies have found that carers want additional information to patients, about how to support and care for the patient, including information about pain, medications, and detecting deterioration (Morris & Thomas 2002; Rees & Bath 2000).

3.3.2.2. UNRECOGNISED INFORMATION NEEDS

While information needs related to diagnosis, prognosis and treatment are commonly recognised, the information needs relating to emotional, social, cultural, and practical issues may be less well recognised or addressed (Ramanadhan et al. 2007). Research suggests that health professionals are less likely to address the psychosocial information needs of cancer patients and carers, such as where to get psychosocial help, how to discuss the disease with their family or children (Ramanadhan et al. 2007), how to prepare for life as a cancer survivor (Bolderston 2008), financial aspects such as the cost of treatments (Kaser 2008), complementary and alternative medicines and therapies (Gertz & Bauer 2003; Tasaki et al. 2002), and body image, sexuality and fertility preservation (Hickey 2008; Hordern & Street 2007; Lintz et al. 2003; White 2008). In addition, although clinical trials may offer a number of benefits such as improved monitoring, information, and access to treatments otherwise not available, many health professionals do not discuss clinical trials with their patients, limiting patient accrual (Brown et al. 2011).

3.3.3. CHANGE IN INFORMATION NEEDS OVER TIME

Information needs are not stable, but change over the disease trajectory. The cancer trajectory has been described using phases through which patients and carers move, including: diagnosis and treatment, recurrence and further treatment, remission, and approaching death and dying (Lewis 1997). Information needs and provision have been most studied at diagnosis or during initial treatment, although some studies have taken a longitudinal approach (Mistry et al. 2010; Hawkins et al. 2008).

Overall, cancer patients' need for information relating to diagnosis and treatment seems to be highest at diagnosis or during treatment, but continue to exist during survivorship (Mistry et al. 2010; Rutten et al. 2005; Mills & Sullivan 1999; Squiers et al. 2005). While the prominence of these information needs declines, new needs develop: information related to how family and close friends may be affected by the disease, psychological effects of treatments (Mills & Sullivan 1999), risk of other family members getting cancer (Luker et al. 1996), information about support services and referrals (Squiers et al. 2005), helpful devices, food and diet, care settings, euthanasia (Voogt et al. 2005), health promotion, late-effects of treatment, interpersonal or emotional issues, insurance, and sexuality/fertility (Beckjord et al. 2007).

Carers also have been found to have changing needs over time relative to the disease trajectory. These depend on the needs and well-being of the patient, and the shifting nature of providing care, dubbed 'carerhood' (Morris & Thomas 2002). Similarly to patients, as carers move though the disease trajectory, they may experience additional information needs, such as for information to assess their own risk of cancer (Rees & Bath 2000). However, whilst the specific topics of information that is needed by patients or carers change over time, the provision of information required to meet their needs may not. Raupach and Hiller (2002) followed 266 women with breast cancer over a 25 month period. Women continued to report a high level of need for information about most issues over time; however, they reported receiving decreasing amounts of information and support.

3.3.4. INFORMATION SOURCES

Systematic reviews suggest that the most highly preferred sources of health information for cancer patients and carers are health professionals, most commonly physicians (Mills & Sullivan 1999; Ankem 2006). These are also the most widely used source for patients (Mills & Sullivan 1999), but carers generally rely more on the patient (Rees & Bath 2000). However, other sources such as family and friends, the internet, and the media, are also widely utilised, and most use a combination of information sources (O'Leary et al. 2007; Mills & Davidson 2002).

Differences in sources used between patients and carers may be due to the increased barriers to information that carers face compared to patients. Difficulties may occur because of concerns about the patient's privacy and the sanctity of the doctor-patient relationship (Morris & Thomas 2001), and it has been suggested that health professionals tend to ignore the information needs of carers (Salminen et al. 2004). Carers also tend to respect the information preferences of patients, and may avoid openly seeking information that they know the patient does not want to know (Rees & Bath 2000). It has also been shown that carers often appear reluctant to see their own needs as valid, and thus may be hesitant to approach health professionals (Morris & Thomas 2001; Morris & Thomas 2002).

A number of factors influence the information sources used, including patients' age, education level, and type of treatment (O'Leary et al. 2007). Younger patients were more likely to seek a second opinion, and educated patients were more likely to use a medical journal (O'Leary et al. 2007). Overall, 'people' sources were preferred to 'paper' sources of information (O'Leary et al. 2007). However, source preferences may change over time. Luker et al. (1996) found that while patients preferred verbal information from health professionals around diagnosis, mass media sources were preferred at 21 months post-diagnosis.

A number of studies have highlighted that the rise of the Internet has increased the amount of information available, and access to information (Cutilli 2010; Bylund et al. 2010; Helft et al. 2005; Lee et al. 2010). Most studies have found that the Internet is used primarily as an adjuvant information source (Cutilli 2010; Bylund et al. 2010; Carlsson 2000). Rates of internet use for information has also been found

to be low among patients, although this may reflect the older age of many cancer patients (Squiers et al. 2005; Rutten et al. 2005). However, carers have been shown to be much more likely to see information via the internet, and those who use it tend to value the information obtained from the internet very highly (James et al. 2007; Beaver & Witham 2007).

3.4. FACTORS INFLUENCING INFORMATION PROVISION & ITS SUCCESS

Patients' and carers' reporting of unmet information needs may in some part be due to misperceptions of the information they have received (e.g. lapse of memory or recall bias), or reflect the uncertainty of diagnoses or treatment choices. However, unmet information needs also reflect the nature and timing of the information provided. As Figure 3.2 shows, information is exchanged between patients and carers, and health professionals, within the health care system.

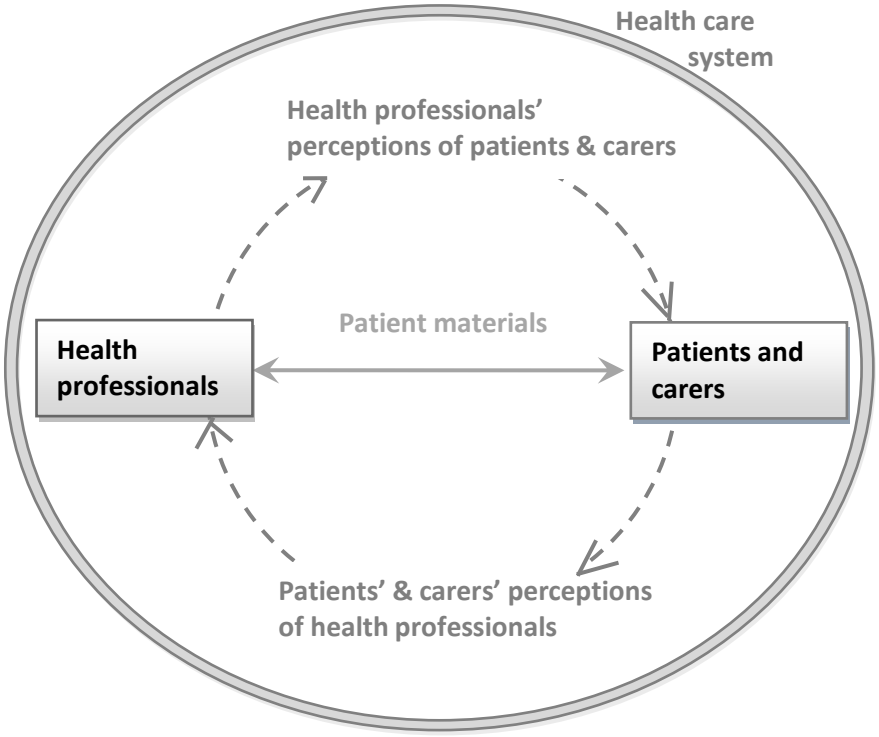


FIGURE 3.2 INFLUENCES ON THE PROVISION OF INFORMATION TO PATIENTS AND CARERS BY HEALTH PROFESSIONALS IN THE HEALTH CARE SYSTEM

Although, as previously discussed, information is derived from many sources, communication with the physician is the most commonly desired means of receiving information (Mills & Sullivan 1999). Furthermore, information received independently of health care professionals likely has the same limitations as information received within in the health care system (see patient materials, to follow). Factors which influence the success of information provision in meeting patients' and carers' information needs thus depend on the characteristics of health care professionals, the characteristics of patients and carers, the perceptions they hold of each other, the use and quality of patient materials, within the context of the health care system itself.

3.4.1. HEALTH PROFESSIONAL FACTORS

Health professionals may be seen as gatekeepers to information, supporting or impeding information provision either intentionally or inadvertently. Some theorists suggest that limiting information to patients is a way for practitioners to maintain power (Bensing & Verhaak 2004; Salmon & Hall 2003). However, with the growth of consumerism in health care and promotion of autonomy, patients are seen as having rights to information and participation in decision-making (Mills & Sullivan 1999). Some cultural norms discourage disclosure of cancer status, although it is unlikely that these widely apply in the Australian context (Rodriguez-Marin et al. 1996).

Health professionals may be reluctant to give negative information, or 'break bad news', for fear of extreme psychological reactions, causing undue distress, or causing distress which they feel poorly equipped to handle (Razavi et al. 1997; Espinosa et al. 1996; Butow et al. 2002). They may fear that giving patients *more* information, for example about the side effects of treatment, may cause anxiety (Gaston & Mitchell 2005). However, this is unconfirmed, as research has more commonly found psychological morbidity associated with *unmet* information needs, and that information given appropriately tends to ameliorate anxiety (Gaston & Mitchell 2005; Diaz et al. 2009; Brown et al. 2001; Thomas et al. 2000).

Giving information, particularly 'sad or bad' news, may also distress health professionals themselves, and be professionally and personally unrewarding

(Fallowfield 1993). Health professionals may fear being blamed for the bad news, feel like a failure for being unable to 'cure' the patient, and/or have a fear of death (Fallowfield 1993; Ong et al. 1995). Health professionals' information provision is also influenced by their personal beliefs, such as their role in dealing with patients' psychosocial concerns (Ryan et al. 2005).

Health professionals differ in their communicative behaviours, which influence the degree to which they effectively communicate. These communicative behaviours are generally divided into communicative skills (the ability to gather, synthesise and provide information, or to conduct and manage a consultation) and communicative style (the interpersonal processes that underlie behaviours and may reflect underlying relationships) (Anderson & Sharpe 1991). Two communicative styles are doctor-centred (in which the doctor is task-focused and exhibits high controlling behaviours) and patient-centred (in which the doctor shows more affective behaviours, such as empathy and openness, with greater patient participation) (Dowsett et al. 2000).

However, while communication skills and style influence the imparting of information and patients' receipt of such information, it has been argued that there is insufficient scientific evidence for effective communicative behaviours upon which to base interventions (Dowsett et al. 2000). Furthermore, it has increasingly been suggested that it is not doctor communicative style per se that is important, but the congruence between doctor communicative style and patient expectations and preferences (Kiesler & Auerbach 2006). Effective doctor-patient communication thus requires doctors to have the skills to identify patient's expectations and preferences, and to change their communicative style to match these preferences (Kiesler & Auerbach 2006). Health professionals may also be limited in their ability to communicate information effectively to patients or carers. They may not have the education or training needed to confidently deliver information to patients tailored at the level they desire (Mills & Sullivan 1999).

Mixed findings have been reported regarding the 'beneficial' effect of a carer being present in medical consultations (Eggly et al. 2006). Some studies have suggested that three-person or 'triadic' medical consultations (involving a health professional,

patient, and carer) are more difficult for health professionals, as they must recognise and respond to the (potentially differing) concerns and distress of carers as well as patients (Lienard et al. 2008). Health professionals appear to be able to adjust their communicative behaviours to the presence of a carer, but only to a slight degree (Delvaux et al. 2005).

3.4.2. PATIENT AND CARER FACTORS

Another difficulty in information exchange is that individuals differ in information needs. Although patients' and carers' most common information needs have been identified (see Table 3.2), these vary by demographic characteristics, disease subtype, and change over time (Ankem 2005). Patients also desire information to be tailored to their specific needs. Providing individually tailored information enables flexibility according to patient needs, and allows for feedback to be obtained (Schofield et al. 2003). Patients have been shown to adjust better upon receipt of specific rather than general information, which is consistent with the theory that information is used as a coping tool (Auerbach et al. 1983). However, some studies suggest that patients first require general information (for example, about cancer), before they are able to interpret more specific information (Mills & Sullivan 1999; Squiers et al. 2005).

Furthermore, although receipt of adequate information may increase a patient's ability to participate in treatment decision-making, preferences for such information, as well as for participation in decision-making, vary across patients and carers (Elkin et al. 2007). As described previously, information seeking may be performed as a technique to facilitate coping. However, as with denial and repression, the avoidance of information may also be used to reduce anxiety (Case et al. 2005). Miller (1995) conceptualises information seeking in situations of threat on two dimensions: monitoring (the extent to which someone searches for information) and blunting (the extent to which someone avoids information) in response to threat. Monitors thus attend to threatening information, while blunters avoid it. Just as providing too little information to a monitor may lead to dissatisfaction and anxiety, providing too much information to a blunter may similarly cause distress (Miller 1995). The Monitor-Blunter Style Scale (MBBS) and

Krantz Health Opinion Survey (KHOS) both assess information preferences (the KHOS also has a subscale to assess preferences for participation in decision-making) and have been validated in cancer populations (Miller 1995; Krantz et al. 1980).

To optimally provide patients or carers with information thus requires that information reflect their needs, be specific to their situation, and be offered at a level consistent with their coping style (information preference). However, another difficulty is that that the meaning sent is very rarely identical to the meaning received, especially when it is complex (Simonds 1995). Models such as the Source-Message-Channel-Receiver (SMCR) model of communication describe how the very process of communication may hamper information delivery. This model includes four main elements: a source (the person wishing to provide the information), message (the information to be sent), channel (the medium through which the information is sent, such as a one-to-one conversation or a printed booklet) and receiver (the person receiving the information) (Simonds 1995). A problem with any of these elements may impair communication; such as when the source encodes the message, or puts it into words or symbols, or the receiver decodes the message, or gives it meaning, based on his/her understanding or experience.

Thus, just as doctors' communication skills and style influence their sending of information, patients' characteristics influence their ability to actively participate in the consultation, and elicit the information they desire (Street 1991). More assertive, verbally active patients tend to acquire more information from doctors (Street 1991). In particular, patients' participation in the consultation, particularly in asking questions, making requests or expressing concerns, has been shown to increase doctor's provision of information (Street et al. 2007). The frequency with which patients ask questions is strongly related to doctors' provision of medical information, , and is widely used as a marker of patient participation (Street 1991). This is influenced by personal characteristics related to assertiveness and expressiveness such as education, income and age, and one's self-efficacy or confidence to interact with doctors in a medical consultation (Maliski et al. 2004; Street 1991).

Health literacy, or ability to access, understand, and use information to make health decisions (Peerson & Saunders 2009), is also important. Health literacy has been shown to have a significant influence on a person's ability to take action to improve their personal health (Peerson & Saunders 2009), correctly prepare for diagnostic studies or follow-up appointments, understand his/her test results, and comply with self-care or medication instructions (Manning & Dickens 2006). Patients with inadequate health literacy may have limited confidence and ability to participate in medical consultations, and find jargon, complex sentences, passive voice, and faster dialogue pacing particularly difficult (Amalraj et al. 2009). However, patients and carers with low health literacy are less likely to ask their physician to slow down or repeat information (Amalraj et al. 2009). They may also have limited capacity to know when or where to seek health information, and to process and retain information given (Jordan et al. 2010). This is likely to be further impeded by the stressful nature of consultations (Auerbach 2000). For example, patients are unlikely to recall information given directly after a diagnosis of cancer because of high levels of anxiety (Voogt et al. 2005).

Within a patient-carer dyad, differences between the information needs, preferences and participatory behaviours of patients and carers may also influence the receipt of information. As previously mentioned, carers tend to subjugate their information needs and preferences to those of patients, to avoid causing them distress (Rees & Bath 2000). In medical consultations, a carer may act as a 'watchdog', who monitors the interaction and interjects when he or she feels that issues need to be addressed (Street & Gordon 2008). Unsurprisingly, patients generally talk more in consultations than carers; however, carers' contributions are more likely to be active (e.g. questions, assertive behaviours) than patients' (Street & Gordon 2008). Although carers may assume the role of patient advocate, to assist patients to receive the information they desire (McIlfatrick et al. 2006), the influence of such behaviours on carers' own information needs has not been well studied.

3.4.3. HEALTH PROFESSIONALS' PERCEPTIONS OF PATIENTS AND CARERS

Although health professionals may try to tailor information to their patients' needs, studies suggest doctors generally underestimate both the type and amount of information that patients require (Fallowfield et al. 1995; Mills & Sullivan 1999). Health professionals may also under- or over-estimate the ability of patients and carers to understand the information they are providing, and provide information in a way that is difficult to assimilate (e.g. using technical terms) (Girgis et al. 1999; Mills & Sullivan 1999).

The information needs and preferences of patients have been found to differ depending on age, gender, education, time since diagnosis and stage of disease, although there remains disagreement as to whether some of these factors are influential (Degner et al. 1998; Ankem 2005). There is considerable variation within groups, and it is not possible for doctors to easily predict information needs or preferences (Mills & Sullivan 1999). However, studies have identified several patient characteristics as determinants of doctors' information provision (Street 1991). For example, a study in Alicante, Spain, found that among 24 general practitioners and 36 specialists, 72% considered the patient's intelligence level, 65% his/her emotional stability, 60% patient's expressed wish, and 43% patient age, in deciding to give information to cancer patients (Rodriguez-Marin et al. 1996).

While there has been a cultural shift emphasising patient autonomy, some health professionals may feel threatened or irritated by patients who conduct their own research (such as via the internet), or patients who ask 'too many' questions (Garfinkel 2008; Grain 2008). Some health professionals have reported a belief that the 'active' or 'informed' patient will question their advice or recommendations, or challenge their expert status (Chen & Siu 2001; Broom 2005). Such patients may also be seen as 'problematic' because of the perception that they will require longer consultations, although this perception appears to be inaccurate (see section 3.5.3) (Broom 2005; McMullan 2006).

3.4.4. PATIENTS' AND CARERS' PERCEPTIONS OF HEALTH PROFESSIONALS

Another source of difficulties in information provision stems from patients' and carers' perceptions of professionals. On a broad level, participation in the

consultation is influenced by norms and standardised behavioural expectations of the doctor-patient relationship, which have generally emphasised doctor authority and control, and patient passivity (Street 1991; Butow et al. 1997). The norm of the passive patient, receiving only 'required' information and participating little if at all in decision-making, has now largely been replaced with a model of shared decision-making, which emphasises patient autonomy and partnership in decision-making (Auerbach 2000). However, the extent to which patients, carers, and health professionals desire or practice this model is still being debated (Edwards et al. 2009).

Patients and carers are also influenced by their doctor's behaviour, from which they perceive cues as to the appropriate way to behave, and which may create or remove perceived barriers for interactions with doctors (Street 1991). For example, Hay et al. (2008) found that 87% of 120 patients looked up their symptoms or suspected condition prior to their first appointment, 62% of those via the internet. However, over 40% of patients who had conducted internet research did not mention this in the consultation, most commonly because they did not want to challenge their doctor or "come across as confrontational" (Hay et al. 2008, p. 579). Furthermore, several patients who did mention research reported that they perceived this behaviour as risky, and worried that the doctor perceived them as 'difficult'. A fear of being seen as 'difficult', and/or avoiding potentially 'confrontational' behaviours has been shown in other studies, although the extent of these attitudes and behaviours is unclear (Newnham et al. 2006; Kivits 2006; Sommerhalder et al. 2009).

Patients' and carers' disclosure of information to their doctor can also be influenced by their attitudes about the doctor's role, such as in relation to psychosocial issues (Ryan et al. 2005). Some patients, and perhaps even more carers, may believe that it is not the doctor's role to assist them with emotional issues (Morris & Thomas 2001), or may not raise this with their doctor (Ryan et al. 2005; Cox et al. 2006).

3.4.5. PATIENT MATERIALS

Whilst health professionals are the primary source of information for most patients, most health professionals supplement verbal information with patient materials,

including written information, videos, CDs, or websites (Mills & Davidson 2002). Information materials do not substitute for oral discussions, but allow the learning process to continue after the medical consultation (Thomas et al. 1999) and allow for self-paced learning (Hoffmann & Worrall 2004). However, patient materials suffer from a number of issues and limitations. Aside from the content and format of materials, health care systems require a structured approach to their provision (O'Donnell & Entwistle 2003). Such an approach should include: regular review to check that the information is up to date; ensuring adequate supply; clarification regarding who is responsible for offering materials, to whom and when; incorporation of information materials into routine practices; a method of checking whether information has been offered, and correcting if it has not; and a method of recording the details of information provided (O'Donnell & Entwistle 2003).

The content of patient materials may also be problematic. Patient materials need to be suitable for different age groups, intellectual backgrounds and cultures, and for both patients and carers (Carney et al. 2006). As written materials are targeted at a patient or population group (rather than designed for each individual person), their content necessarily is general, and may not meet the specific needs of individuals, which themselves change over time (Attfield et al. 2006; Thomas et al. 1999). Many materials have been judged 'inaccurate' because they do not provide sufficient information about possible treatment outcomes (e.g. potential risks and side effects), are not up to date, or give the misleading impression that there is complete certainty about the effects of treatments (O'Donnell & Entwistle 2003). Information materials may omit 'relevant' data by addressing the information needs that health professionals think are important rather than patients' most important needs (Coulter et al. 1999; O'Donnell & Entwistle 2003). Materials have also been criticised for adopting a patronising tone (Coulter et al. 1999).

The format of patient materials must also be considered. Information in formats such as video or audiotape may be needed to meet the needs of persons with visual or hearing impairment, but may also assist persons with low literacy or a cognitive impairment (O'Donnell & Entwistle 2003). Audiotapes are cheap, and can provide preformatted information on illness and treatment, and information in several

languages (Thomas et al. 1999). Videotaped information is also highly acceptable to patients and particularly welcomed by patients from ethnic groups (Thomas et al. 1999).

A number of studies have tested the usability of patient information materials (mostly written materials) and identified common problems. One of the most widespread problems is the readability of information. As previously mentioned, low health literacy may impair patients' ability to process information (Amalraj et al. 2009). Literacy itself is an important factor influencing patients' abilities to process information in written forms. At the simplest level, patients and carers who cannot read are unlikely to benefit from written materials. Even more widespread is the ability to read, but at suboptimal levels. In countries such as the UK, US and Australia, the average reading ability of adults is the sixth grade level, 3-6 years below the last grade attended at school (Freda et al. 1999). Current recommendations are thus that patient information materials should not require literacy skills exceeding sixth grade level (Davis et al. 1990; Weih et al. 2008; Sullivan & O'Conor 2001; Freda et al. 1999), however most current materials require higher literacy (Butow et al. 1998; Freda et al. 1999; Shieh & Hosei 2008). Readability is evaluated using mathematical formulas that measure the frequency of syllables in a word, sentence length, and related variables. Although different formulas yield different results, such results correlate highly with each other, and multiple formulas are commonly used (Freda et al. 1999).

In addition to readability, patient materials may not be 'clear' or usable. A review of the usability of three patient information leaflets in the Netherlands identified some common issues: the leaflets were long and the text structure unclear; the headings were not clear; the visual formatting of text did not reflect its structure; important information was 'hidden' in long text sections; and information regarding patient actions was often unclear (Pander Maat & Lentz 2010). In addition, presentation such as colours and illustrations, and timing of provision, influence patients' preference for, satisfaction with, and recall of information from written information booklets (Butow et al. 1998). To help address this issue, a number of guidelines have been provided which detail how to develop appropriate high-quality patient

materials, such as DISCERN (Charnock et al. 1999) and the National Health Service guide (O'Donnell & Entwistle 2003). However, organisations continue to create patient information leaflets with readability and usability problems, due to organisational politics and process issues (Gal & Prigat 2005).

3.4.6. HEALTH CARE SYSTEM FACTORS

A number of characteristics of the health care system influence provision of information. One factor is the shorter hospital stays of patients in recent years, which limits the amount of information that is provided to and assimilated by cancer patients (Luker et al. 1996). The economics of the health care system may also create barriers to information provision for carers. Although carers have identified the need for independent contact with health professionals for information (Janda et al. 2006), appropriate billing strategies for specialists when the patient is not present are unclear.

The ability of health professionals to provide information to patients and carers may also be limited by factors such as available time, workload or privacy in busy health care settings (Mills & Sullivan 1999; Razavi et al. 1997; Gaston & Mitchell 2005). The UK's National Health Service has been characterised as 'fast healthcare', whereby staff are pressured to deliver care with brevity, and there is 'no time to talk' (Crawford & Brown 2011). In addition, as care has become more specialised and delivered across multiple treatment centres, there may be confusion between health professionals with regard to who is responsible for providing patients with information (Smith 2000). Whilst information may be 'theoretically' available, health professionals may not timely manage the dissemination of information. Inappropriate dissemination of information may lead to inadequate receipt of information by cancer patients and carers. This situation, where there is an abundance of information, but patients and carers still report unmet information needs, has been termed the 'information paradox' (Smith 2000).

In summary, information needs can exist because of patient, carer, health professional and/or health care system factors and their interactions, and interventions may focus on one or several of these components.

3.5. IMPROVING INFORMATION PROVISION

Interventions aiming to improve information provision to cancer patients and carers have been grouped according to their aims and target:

- to improve the accessibility of information (e.g. audio-taped recordings of consultations);
- to increase health professionals' abilities to provide information (e.g. communication skills training);
- to increase patients' participation in consultations (e.g. question prompt lists); or
- to improve continuity of care or social support (e.g. care coordinator).

This review does not include clinical practice guidelines or standardised patient information materials mentioned previously (see section 3.4.5) such as written information or general audio- or video-tapes. Wherever possible, systematic reviews have been used to provide a 'snapshot' of the current nature of interventions and gaps in the research. This review assesses cancer settings in general, whereas brain tumour specific interventions are reviewed in Chapter 4.

3.5.1. INTERVENTIONS TO IMPROVE THE ACCESSIBILITY OF INFORMATION

Audio-taped recordings of consultations, treatment summary letters, websites and multimedia interventions are the most common information interventions. Both audio-taped recordings and treatment summary letters aim to provide patients and carers with a 'take home' resource to listen to or read after their consultation, based on the finding that many patients do not process information that they are provided in a consultation due to stress (Thomas et al. 1999). In newer iterations, websites and multimedia interventions aim to allow patients and carers to proactively choose the information to which they are exposed, and the format it is in, to suit their needs and interests (Loiselle & Dubois 2009). These interventions may be more effective than traditional 'one-size-fits-all' approaches, by allowing patients and carers to interact with the resource (Loiselle & Dubois 2009).

3.5.1.1. Audio-taped Recordings of Consultations

A number of systematic reviews have evaluated the provision of audio-taped recordings of consultations (Thomas et al. 1999; Scott et al. 2001; Ryan et al. 2008). Across studies, results show that patients provided a tape recording recalled more information than control participants (Thomas et al. 1999; Scott et al. 2001; Ryan et al. 2008). However, some studies suggest that patients' given poor prognosis in recorded consultations disliked having the audio-taped reminder (Scott et al. 2001).

Most research evaluating audio-taping consultations has been via randomised controlled designs, using outcome measures of knowledge, understanding or recall, and use of or satisfaction with the audio-tapes (McClement & Hack 1999). However, many instruments designed to measure knowledge, understanding or recall have not been validated (Ryan et al. 2008). Satisfaction may also be an inappropriate outcome measure as patients are generally reluctant to express dissatisfaction for fear that their response may influence their future care (Scott et al. 2001). Studies that have assessed psychosocial outcomes such as anxiety, depression or distress, have not shown significant differences between intervention and control groups (Scott et al. 2001; Thomas et al. 1999).

Further research may also be needed to determine the situations in which audio-taping the consultation is appropriate. Studies have been conducted with patients wide a wide variety of tumour types (Tattersall & Butow 2002), but mostly during medical oncologist appointments, and with initial meetings or specific 'bad news' consultations (Scott et al. 2001). Audio-taping consultations also has some practical issues. The taping process may interfere with the consultation for some patients (Thomas et al. 1999), and may influence the behaviour of patients, carers, or health professionals (Hawthorne effect) (Themessl-Huber et al. 2008). Australian doctors have also been unenthusiastic about allowing audio-taping of consultations, citing patient confidentiality and medico-legal concerns (McConnell et al. 1999; Tattersall & Butow 2002).

3.5.1.2. Treatment Summary Letters

Individual treatment summary letters have the same rationale as audio-taped recordings of consultations, and are generally well regarded by patients (Gaston &

Mitchell 2005), particularly for sharing with family and friends (Mills & Sullivan 1999). However, there is no evidence supporting their use for improving recall (van der Meulen et al. 2008). One study comparing audio-taped recordings of consultations and treatment summary letters showed that patients prefer audio-tapes to letters, perhaps due to its more personal nature, or the greater level of detail provided (Tattersall et al. 1994). However, only 3% of 154 oncologists and 4% of 55 surgeons said they offered patients an individualised summary letter in all or most cases, identifying in open-ended questions the beliefs that this practice would significantly increase their workload, be too costly, and may not be understood be patients (McConnell et al. 1999). Although these beliefs may change over time, this suggests that at present, summary letters may not be suitable in practice (Gaston & Mitchell 2005).

3.5.1.3. Websites and Multimedia Interventions

Websites and multimedia interventions are relatively new technologies, and their use enables the provision of information in a variety of formats, with the content accessed dependent on the patient's or carer's needs and preferences (Jefford & Tattersall 2002). The primary advantage of such interventions is their ability to provide information in a tailored or personalised manner (Loiselle et al. 2010; Jones et al. 1999). Clayman and colleagues (2008) described a website which patients may personalise by their tumour type, institution, and the names of their health care team. Most websites allow users to control the amount of information they are presented with by clicking on hypertext links (McPherson et al. 2001).

Web-based interventions present information in a variety of formats, such as via video, audio, pictures and text (Gautschi et al. 2010), narrative and didactic formats (Wise et al. 2008), and through a 'virtual' dialogue, in which pre-recorded answers to questions are supplied in response to user's spoken questions (Harless et al. 2009). As new technologies are varied, their effectiveness depends upon the specific media considered (Gysels & Higginson 2007). However, some general trends have been seen. Knowledge and understanding appear to increase with more tailored and interactive methods (Trevena et al. 2006). Probabilistic information such as risk is more easily perceived when presented as numbers rather

than words, and illustrations and graphs can increase comprehension (Trevena et al. 2006).

A review of six tailored website and multimedia interventions evaluated against written information found small but significant improvements in knowledge and satisfaction, without increases in anxiety (Gysels & Higginson 2007). However, many outcomes were adapted specifically to the material under investigation, with significant heterogeneity, limiting comparisons. Interestingly, Jones and colleagues (1999) found patients who received the computer-based tailored information felt they had received new and relevant information and were satisfied, compared with patients who received traditional written information brochures, who reported feeling overwhelmed with information.

However, there are significant areas in which more research is needed. Few studies have examined the costs of tailored or interactive systems, and some have been judged by investigators to be expensive (Gysels & Higginson 2007). Evaluation studies have frequently tested one or two components rather than entire multimodal systems (Loiselle et al. 2010). Although some programs have involved use of a hospital computer (Gautschi et al. 2010), computer training (Loiselle et al. 2010), or the provision of a computer and study-paid Internet access (Hawkins et al. 2010), websites or multimedia interventions may not be accessible to patients of low socioeconomic position. One study showed that regardless of intervention or control group, patients of high socioeconomic position reported better outcomes for all measures (Loiselle & Dubois 2009). However, studies of the Comprehensive Enhancement Support System (CHESS), showed greater use of and benefits for African American women with breast cancer than their Caucasian counterparts (Wise et al. 2008). This program, which includes the provision of a computer, study-paid internet access, and computer training, has also been successful when evaluated with low-income rural women with breast cancer, suggesting that such systems may be particularly beneficial for the medically underserved (Shaw et al. 2008). Overall, these studies suggest that new technologies offer a number of benefits, but research is needed to determine the most successful, cost-effective, and appropriate strategies.

3.5.2. INTERVENTIONS TO INCREASE HEALTH PROFESSIONALS' SKILLS

Communication training for health professionals has most frequently aimed to improve communication skills and/or to teach strategies to improve the therapeutic relationship, particularly in relation to patient-centred care (Butler et al. 2005). Training programs have most commonly consisted of seminars and workshops, although there have been some more long-term continuing education programs (Fallowfield et al. 2003; Butler et al. 2005). Content most commonly includes psychosocial issues, breaking 'bad news', issues related to dying and bereavement, history taking and assessment skills, treatment options, pain, anxiety and depression, sexual issues and ethical decisions (Butler et al. 2005).

The success of these programs in changing provider behaviours has been varied. Indicators used to measure program success have commonly been surveys with participant-report measures of change in knowledge, skills and attitudes (Butler et al. 2005), although some programs have used simulated patient scenarios, whereby a 'standardised patient' (either a real patient or an actor) was interviewed in a structured setting with feedback to the health professional (Siminoff et al. 2011). More recently, 'unannounced standardised patients' (USPs) have been used to capture health professionals' behaviours in clinical encounters where they do not know they are being observed. This methodology involves health professionals consenting in advance to a visit by a USP, which occurs at an unknown time. Although there are a number of barriers to such an approach, such as detection of the USP, the need to create an identify for a USP, difficulties obtaining 'undercover' audio-recordings of the consultation, and finance/medical insurance issues, this approach may allow more accurate assessment of health professional behaviours (Siminoff et al. 2011).

A further consideration is that whilst some evaluations may show changes in health professional behaviour (and many do not (Kruijver et al. 2000)), even fewer show improvements in patient outcomes (Uitterhoeve et al. 2010), and none have yet been successful in improving carer outcomes (Lienard et al. 2008). The most successful programs are generally long-term, involve a variety of methods, allow for rehearsal and feedback, and use skilled facilitators (Butler et al. 2005; Epstein &

Street 2007). Even the most successful, however, have a number of limitations, in that interventions need to be intensive, in small group environments, with a safe environment for learners to practice their skills (Butler et al. 2005). Interventions in medical school or residency are likely to have greater impacts than those delivered later, and only motivated clinicians tend to participate, thus missing those who need such programs the most (Epstein & Street 2007; Turner et al. 2011). Furthermore, the evidence for transferability of these research interventions into routine clinical practice is limited. Butler et al. (2005) suggests the relative lack of involvement of policy makers in communications research means that even effective interventions are unlikely to be implemented (Butler et al. 2005).

3.5.3. INTERVENTIONS TARGETING PATIENT PARTICIPATION

Interventions targeting patient[2] participation aim to increase information provision and knowledge and/or decrease decisional conflict (difficulty making decisions) (O'Connor et al. 2003). These interventions may be multifaceted (e.g. decision aids may aim to increase knowledge, assist patients to clarify their views, and consider how each treatment option aligns with their values) or focus on one particular behaviour (e.g. question prompt lists encourage patients to ask their doctors questions) (Kiesler & Auerbach 2006; O'Brien et al. 2009). Such approaches may increase patients' self-efficacy, assist them to meet their informational and/or decision-making goals or preferences, and improve psychological health (Shields et al. 2010). These methods may also be more feasible and cheaper than provider-focused interventions (Kiesler & Auerbach 2006).

However, such interventions have been criticised for enabling health professionals and institutions to take less responsibility (Salmon & Hall 2004), and for disempowering patients by inducing them to behave in ways that fit current cultural norms (e.g. participating in decision-making, taking control of their care) (Salmon 2005).

[2] These interventions have largely focused on patients rather than carers. Where appropriate, carer outcomes have been highlighted.

3.5.3.1. Decision Aids

Decision aids (DAs) have been defined as interventions designed to help people make specific and deliberate choices among options by providing information on the options and outcomes relevant to a patient's health (O'Connor et al. 1999). DAs generally contain at least two components: provision of information about available options and associated risks and benefits, and value clarification exercises (Sepucha & Mulley 2003). Other components may include information on the disease, opinions of others, and guidance or coaching regarding decision-making (O'Connor et al. 1999). DAs have been developed for a range of formats, such as using written, video and computer-based programs and interpersonal counseling (Jefford & Tattersall 2002; Kiesler & Auerbach 2006).

Three systematic reviews of decisions aids concluded that DAs increase knowledge, decrease decisional conflict, and increase patients' participation in decision-making, without increasing anxiety, with little variation across formats (O'Connor et al. 1999; Molenaar et al. 2000; O'Brien et al. 2009). However, some DAs have been criticised for neglecting to inform patients of all of their choices, which may influence decision-making (Sepucha & Mulley 2003). The appropriateness of these outcome measures has been debated (Entwistle et al. 1998; Bekker et al. 2003). Whilst anxiety is generally considered an undesirable response, most DAs are not designed to reduce anxiety, and its measurement has been inconsistent in timing across studies (Bekker et al. 2003). Increased levels of arousal may be expected in stressful situations, and it is not known if this leads to patients making better or worse decisions (Bekker et al. 2003). Entwistle and colleagues (1998) suggest that in addition to knowledge, decisional conflict, or other 'short-term' effects, health outcomes such as psychological well-being should be used to evaluate DAs, as their aim is primarily to improve patients' health (via short-term effects) (Entwistle et al. 1998).

DAs may also be insufficient if provided without associated support. Even if one's preferred decision is clear, a patient may not have the motivation or self-efficacy to carry out their decision (Sepucha & Mulley 2003). These patients may need additional support (O'Connor et al. 2003). However, many DAs are available via the

internet, and are used by patients without discussion with health professionals (Vordermark 2010).

Other research has suggested that the implementation of DAs requires further investigation (O'Cathain & Thomas 2004; Feldman-Stewart & Brundage 2004). One pragmatic DA trial found that some health professionals withheld DAs because they did not agree with the (evidence-based) content, held assumptions about patients' abilities to participate in decision-making, or as not all treatment options were available locally (O'Cathain & Thomas 2004). Structural barriers such as organisational issues and time must also be addressed (O'Cathain & Thomas 2004).

3.5.3.2. Question Prompt Lists, Coaching, and Patient Activation Materials

The most common type of intervention to increase patient participation in the medical consultation is a question prompt list (QPL). This is a structured list of questions for a patient or carer to ask a doctor should they desire (Clayton et al. 2003). QPLs are designed to encourage the asking of questions in the medical consultation, allowing patients to control the content, and amount of information provided (Bruera et al. 2003). Similarly to tailored patient materials, the success of these interventions may be because they assist patients to express their information needs, and obtain personally relevant information (van der Meulen et al. 2008). QPLs may assist persons who do not know what questions to ask, or do not know how to articulate their concerns, and also gives 'permission' to patients to ask questions of their doctor (Clayton et al. 2003).

QPLs are most commonly provided in paper or booklet form, although computer- or internet-guided QPLs have also been developed (Hartmann et al. 2007). QPLs have most commonly been developed for and evaluated in oncology consultations, although they have also been used in palliative care, surgery and general practice, asthma, and coronary artery disease (Brown et al. 1999; Brown et al. 2001; Clayton et al. 2007; Clayton et al. 2005; Clayton et al. 2003; Bruera et al. 2003; Hagerty et al. 2005; Butow et al. 1994; Hartmann et al. 2007; Ellis et al. 2004; Martinali et al. 2001; Tabak 1988; Glynne-Jones et al. 2006; Fleissig et al. 1999; Davison & Degner 1997; Butow et al. 2004; Butow et al. 2003).

Rather than providing a QPL, a similar intervention has involved asking patients pre-consultation to list questions that they may wish to ask during the consultation (Cunningham & Newton 2000; Newton & Cunningham 2003; Jones et al. 2002; Thompson et al. 1990; Wells et al. 2003; Little et al. 2004; Robinson & Whitfield 1985). Proponents of this less prescriptive approach to question encouragement argue that it is less paternalistic or patronising than the QPL, and also less likely to influence patients' agendas (Wells et al. 2003). However, unlike the QPL, this approach does not assist patients to formulate questions to ask, and requires patients to recognise and enunciate their information needs.

Coaching also has been used to increase patient involvement in the consultation. This approach usually involves a nurse or research assistant discussing patients' information needs and questions face-to-face before a medical consultation (Greenfield et al. 1985). The aim is to assist patients to identify and articulate concerns and questions, and may be include training, rehearsal and modelling (Roter 1977; Roter 1984; Sepucha et al. 2002; Kidd et al. 2004; Greenfield et al. 1985; Davison & Degner 2002). Although this approach showed early success in increasing question asking, it is resource-intensive and thus unlikely to be widely implemented (Roter 1977).

A final common intervention in this category is patient activation materials (also called patient empowerment materials), which encourage patients to take an active role in the medical consultation (Street et al. 1995). These are similar to the above interventions in encouraging question asking but also emphasise other aspects of patient involvement, such as patients' expressing their concerns and beliefs, or verifying the information they received (Frederikson & Bull 1995; McCann & Weinman 1996; Cegala et al. 2000; Street et al. 1995). Although these interventions have been found to increase question asking, results have been less supportive with regard to the expression of concerns or verification of information (Cegala et al. 2000).

The main outcomes used to assess the effectiveness of these interventions has been communication behaviours, usually evaluated using audio-taped recordings of consultations. The number of questions a patient asks is the most common

behavioural measure used, although patients' bids for clarification, or doctor's giving of information, have also been used (Ong et al. 1995). To allow identification, categorisation and quantification of communication behaviours, a number of interaction analysis systems have been developed (Ong et al. 1995), such as the Roter interaction analysis system (Roter & Larson 2002). This allows calculation of patient and doctor question-asking and information-giving behaviour, and calculation of a ratio of patient-centred to doctor-centred talk (Epstein et al. 2005).

Coding of communication behaviours has shown that QPLs and similar interventions increase question asking compared to controls (Brown et al. 1999; Brown et al. 2001; Clayton et al. 2003; Clayton et al. 2005; Clayton et al. 2007). Studies have mostly found that the intervention did not increase, or decreased, anxiety, and that patients in the intervention group found the QPL helpful. Overall, interventions encouraging question asking tend to cost-effective (Kinnersley et al. 2008). As with other types of interventions, those involving multiple or intense interventions have generally been more successful in improving outcomes (Kiesler & Auerbach 2006). The concern of some health professionals that question asking or other 'active' patient behaviours would increase consultation duration has also been largely disproved: a review of 17 randomised controlled trials in which consultation duration was measured showed increases in length in three studies, and no effect on length in 13 studies (Kinnersley et al. 2008).

However, using the number of questions asked by a patient as a marker of patient participation in the consultation may be overly simplistic (for example, patients may have already received adequate information). Measuring question asking also does not assess the degree to which patients are provided information; for example, in a consultation with a skilled communicator who enquired of a patient's information needs, a patient may not need to ask many questions; whilst, a patient may ask many questions from an unskilled communicator, yet not receive the information they need (Hebert et al. 2009). Better means to assess patients' receipt of information are needed in future evaluations.

Limited research to date has assessed if interventions are most effective in certain settings, or among certain patient groups (Kinnersley et al. 2008), or the optimal

timing of intervention provision, or method of involving health professionals (Gaston & Mitchell 2005; Hebert et al. 2009). In most studies (25/33 randomised trials in the most recent review), the intervention was provided just before the consultation (Kinnersley et al. 2008). However, the time provided to review the intervention may have been quite short (e.g. Clayton et al. (2007) estimated 20 minutes), and greater differences in question asking between intervention and control group patients may be seen if more time was given. Some studies have shown that QPLs are only effective when health professionals endorse the intervention, although it is unclear how best to encourage this behaviour (Butow et al. 2004; Brown et al. 2001). It has also been suggested that interventions may be more successful if, rather than being provided once just before a consultation, they were used in multiple consultations, where they were clearly part of usual care (Hebert et al. 2009; Kinnersley et al. 2008). This would allow change in the overall culture of the consultation, facilitating changes in the behaviour of patients and health professionals (Kinnersley et al. 2008).

In addition to changing the behaviours of patients and health professionals, information provision may also be improved by improving the coordination and continuity of information within the health care system, and increasing the social support available to patients and carers.

3.5.4. Interventions for Continuity of Care or Social Support

The National Health Priority Action Council identified an optimal cancer service as one in which cancer patients experience the cancer journey as "seamless and continuous care provided by one integrated service" (2004, p. 38). A lack of coordination or continuity in patients' care may lead to patients and carers receiving contradictory information from a variety of sources, exacerbating any anxiety that they may experience (Gysels & Higginson 2007). Health professionals may also find it difficult to provide care without appropriate access to information about a patient (Hayward 1998).

Social support, defined as an interaction between two or more people whose purpose is to promote awareness and education, provide emotional support, and assist with problem solving (Liu et al. 2006), may also facilitate information

provision. Social support buffers the impact of stressful experiences, and may be particularly pertinent for cancer patients and carers when offered by people have also experienced cancer, as peers can offer experiential empathy (Liu et al. 2006).

A number of interventions to improve continuity of care or social support have been developed, which may aim, in addition to other outcomes, to increase informational continuity. Given the focus of this thesis, evidence for the effects of these interventions is only briefly discussed.

3.5.4.1. CARE COORDINATOR

A number of approaches have been undertaken to improve continuity of care, many termed 'care coordination'. In Australia, the cancer care coordinator role evolved based on the specialist nursing care provided by Breast Care Nurses (BCNs) (Eicher et al. 2006). The BCN role combines four main elements: clinical, educational, research, and consultation, together with less well described, 'hidden complex work', such as care coordination (Hardie & Leary 2010). Care by BCNs is associated with better physical functioning, a reduction of depression and anxiety, and higher levels of patient satisfaction (Eicher et al. 2006). However, defining and scoping the BCN role has proved difficult, and the diversity of practices within the 'BCN' role have limited studies of its effectiveness for outcomes such as continuity of care (Eicher et al. 2006; Nutt & Hungerford 2010).

Similarly, there is no agreed definition of a 'care coordinator', and the exact roles of care coordinators tend to be unclear (Walsh et al. 2011; Mills & Sullivan 1999). Walsh and colleagues identified seven components of care coordination: organisation of patient care, access to and navigation through the health care system, the allocation of a 'key' contact person, effective communication and cooperation among the multidisciplinary team and other health service providers, delivery of services in a complementary and timely manner, sufficient and timely information to the patient and needs assessment (Walsh et al. 2011).

These seven components are somewhat similar to the patient-level outcomes identified by participants at a workshop held by the Clinical Oncological Society of Australia (2007). Their three patient-level outcomes were: that every patient is aware of their pathway of care; that the timing of treatment is efficient,

appropriate, and takes account of patient preferences; and that the patient experience is positive, with patients feeling valued, in control, and respected (Clinical Oncological Society of Australia 2007). Despite their differences, both definitions, and others, highlight that two key functions of care coordination is the provision of consistent, timely information appropriate to the patient's needs, across the disease trajectory, and a key contact person (Walsh et al. 2011; Clinical Oncological Society of Australia 2007; Yates 2004; Mills & Sullivan 1999).

Although there is a clear rationale for cancer care coordinators, only weak evidence exists that care coordinators improve care outcomes, because of difficulties evaluating the impacts of care coordination (Mills & Sullivan 1999). For example, an evaluation of cancer nurse coordinators (CNCs) in New South Wales surveyed patients, and found that patients whose care was coordinated (by a CNC or other health professional) were more satisfied than patients whose care was not coordinated (Thomas et al. 2009). More work is needed to identify appropriate outcome indices and measures, and to implement these measures.

Limited research has also been conducted to identify barriers to effective care coordination. Research with cancer patients, carers, and health professionals identified that confusion among patients and health professionals about the role of the care coordinator, and inadequate referral of patients to the care coordinator (Walsh et al. 2010). There was also initial resistance to coordinators in some situations, such as when GPs had had longstanding relationships with patients (Walsh et al. 2010). Both patients and health professionals may need to be made fully aware of the functions of care coordinators, for the role to function optimally.

3.5.4.2. Patient Navigators

The concept of patient navigation was initially developed to expedite access to care for individuals in marginalised communities, but has been expanded to address a wide range of systemic issues (Pedersen & Hack 2010). To some extent, the role of the patient navigator (PN) may overlap with that of the care coordinator. However, most PN interventions have been applied in screening and diagnosis, rather than in the treatment phase (Robinson-White et al. 2010). A review of the literature suggested that the most common PN roles were: facilitating access to care,

providing information and education, and providing links to resources (Pedersen & Hack 2010). The PN may serve as a central contact for patients across the disease trajectory, who can direct them to appropriate services (Pedersen & Hack 2010).

There is a lot of debate as to who should take on the PN role, such as a nurse, social worker, peer supporter, or lay individual (Pedersen & Hack 2010). Nurses may be required for positions in which PNs undertake assessments of patients' conditions or other clinical duties (Pedersen & Hack 2010), while persons with an in-depth knowledge and/or experience with the health care system, regardless of their formal skills, may be suitable for other PN roles (Gilbert et al. 2011). This debate underscores the diversity in PN roles and lack of a clear definition of patient navigation.

Limited research details the impact or effectiveness of patient navigation. A 2011 review included five studies, two of which were randomised controlled trials, two retrospective analyses and one programme evaluation (Gilbert et al. 2011). All studies had small sample sizes, and most were limited to a single institution. Patient navigation was associated with reduced time to diagnosis in two studies. Patient outcomes shown in single studies were: reduced anxiety, higher satisfaction, higher adherence to follow-up, and fewer missed appointments (Gilbert et al. 2011).

Patients who have received PN support value the supportive presence, the 'insider information', and the accompaniment to consultations and treatments (Yosha et al. 2011). Some negative experiences have also been identified, such as discomfort with having a male PN assigned to a female breast cancer patient, relational and actual distance between patients and PNs, and lack of accessibility, such as when PNs do not return calls promptly (Carroll et al. 2010). The PN approach as a whole has also been criticised for aiming to patch gaps in the system, rather than fixing the system (Pedersen & Hack 2010).

Overall, further research is needed to evaluate the effectiveness of PN, to evaluate different types or models of navigation, investigate PN costs relative to benefits (Gilbert et al. 2011), and to design tools to measure the efficacy of navigation (Pedersen & Hack 2010).

3.5.4.3. PATIENT-HELD RECORDS

Designed to facilitate continuity of care, patient-held records (PHR) may allow for a variety of information to be recorded, such as a summary of the patient's health history and treatments; advanced directives; patients' notes or diary; appointments, contact details, and medications, and instructions for use (Gysels et al. 2007). In some studies, actions were taken to encourage use of the PHR by patients and/or health professionals, while in others, no encouragement was given (Gysels et al. 2007).

Overall, most patients perceive PHRs to be useful, but randomised controlled trials show no benefits for most outcomes (Gysels et al. 2007; Ko et al. 2010). A number of elements have been identified that may act as facilitators or barriers to PHR effectiveness. Two studies described a preference for a smaller sized, informal record, and for provision of the PHR around the time of diagnosis (Gysels et al. 2007; Cornbleet et al. 2002). Providing the PHR early may be beneficial in that patients can gradually discover its benefits over time (Gysels et al. 2007). However, health professionals have a number of concerns about PHRs, such as fears that PHRs meant more paperwork, duplicate records (Cornbleet et al. 2002), intrude into patients' privacy, increase litigation claims (Williams et al. 2001), or upset patients (Gysels et al. 2007).

Because of unfamiliarity with the PHR, it is not always used in consultations, and its effectiveness is likely limited by low involvement and a lack of interest from health professionals (Gysels et al. 2007; Hayward 1998; Mills et al. 2008). There also appears to be a link between patients' and health professionals' use of the PHR: motivated health professionals led to patients with high opinions of the PHR (Lecouturier et al. 2002). In addition, in many studies, health professionals used the PHR as a way to communicate with other health professionals, or to keep up-to-date with the treatments a patient had received, overlooking its potential as a tool to assist patients (Lecouturier et al. 2002; Gysels et al. 2007).

Most studies evaluating PHRs have had recruitment problems, resulting in a lack of power to show an effect (Williams et al. 2001; Gysels et al. 2007; Mills et al. 2009). Many studies have also had a high risk of bias because of weak study designs (Ko et

al. 2010) and because unvalidated outcome measures were used (Mills et al. 2009; Gysels et al. 2007). There may be a difference in effectiveness between PHRs which seek to duplicate patients' medical record, and those which are unstructured and the content is 'patient-driven' (Finlay & Wyatt 1999). What served as a 'control' condition in some studies could be equivalent to the unstructured PHR of other studies (Ko et al. 2010). There is currently insufficient evidence for benefit of the PHR to recommend its implementation (Ko et al. 2010).

3.5.4.4. SUPPORT GROUPS

Surveys in the US suggest nearly one in four cancer survivors, particularly women, use support groups (Owen et al. 2007). Support groups enable patients and carers to seek social support and information (Jefford & Tattersall 2002). Descriptive studies of face-to-face, telephone, and internet support groups facilitated either by peers or professionals, have shown benefits such as receiving practical and emotional support, information, and encouragement, experiencing a sense of comfort or camaraderie, and decreasing uncertainty (Liu et al. 2006; Hoey et al. 2008; Weis 2003). However, relatively few high-quality studies have been published evaluating their effectiveness (Jefford & Tattersall 2002).

In randomised controlled trials, support groups have been shown to lead to increased self-efficacy and perceived availability of social support (Hoey et al. 2008), and improved psychological adjustment, anxiety or depression, although the effects were not present for all outcomes, and often transient (Weis 2003; Goodwin 2005; Hoey et al. 2008). Few studies assessed changes in informational outcomes, and many studies have had small sample sizes with the capacity to detect only moderate to large intervention effects (Hoey et al. 2008). Blinding is often not possible, and randomisation often not acceptable to participants (Weis 2003). Most studies also involved women with breast cancer, for whom there is a relative abundance of support (Hoey et al. 2008). Patients' and carers' motivation or the timing of the intervention may act as moderating variables on outcomes, but large-scale, rigorous studies are needed to obtain conclusive results (Weis 2003). Overall, support groups may be an important way of providing social support to patients

and/or carers, but little evidence supports their ability to meet their informational needs.

3.5.5. COMMON EVALUATION ISSUES

Many of the interventions reviewed suffer the same methodological issues. Most of the simpler interventions were evaluated using randomised controlled trials, although many were not blinded because of the nature of the interventions (Rodin et al. 2009). Self-report measures were commonly used, reflecting the subjective nature of informational, psychological and communicative outcomes. However, varied measures were used, making it difficult to compare the effects of interventions. The more complex interventions such as care coordinators and patient navigators have not been evaluated extensively (Jefford & Tattersall 2002; Dohan & Schrag 2005; Young et al. 2011).

Most studies have reported a single, short follow-up (Jefford & Tattersall 2002). In addition, almost all of the published work is from developed countries, describing the information needs and intervention effectiveness with English-speaking people (Jefford & Tattersall 2002). Research is also needed regarding the joint effects of interventions on patients and carers. Estimates vary widely but suggest that a family member or friend in is present in approximately 20% (Beisecker & Moore 1994) to 86% (Eggly et al. 2006) of all cancer consultations. As carers frequently assume information seeking roles, interventions that do not consider their needs or behaviours may be poor representations of reality. In addition, carers' information needs appear to be less well met than those of patients, suggesting carers should be targeted for interventions.

Research is also needed to identify the facilitators and barriers to intervention success, and to determine implementation requirements. Health professionals may not endorse interventions because of unfamiliarity, structural barriers, a lack of implementation support, or because of established practices that are perceived to be effective (Gaston & Mitchell 2005).

3.6. CHAPTER SUMMARY

In conclusion, cancer patients and their carers have numerous and complex information needs, which change over the disease trajectory. When health professionals do not recognise or address these needs, psychological adjustment and ability to participate in decision-making may be impaired. The provision of information is influenced by a number of factors, such as the views and behaviours of patients, carers, and health professionals. Despite the availability of information, barriers exist, leading to an 'information paradox'.

This chapter has shown that a range of interventions that may improve the provision of information to patients have been developed, and many interventions have been shown to be effective. For more complex interventions, research is needed to identify appropriate measures of effectiveness, identify factors associated with positive outcomes, and improve the implementation of interventions.

Research is also needed to determine the populations in which interventions are effective. This chapter has reviewed interviews across all cancer types; however, most research has been conducted with patients with common cancers such as breast cancer. The following chapter examines the evidence of the information needs and methods to improve information provision for primary brain tumour patients and their carers.

4. SYSTEMATIC REVIEW OF INFORMATION NEEDS OF BRAIN TUMOUR PATIENTS & CARERS

4.1. INTRODUCTION

This chapter brings together the foci of the previous two chapters in a systematic review of the literature regarding the provision of information to newly diagnosed primary brain tumour patients and carers. Although information is needed across the disease trajectory, this chapter focuses on the needs of brain tumour patients and carers early in the disease trajectory, from diagnosis to the completion of initial treatments. This period in the disease trajectory was chosen as the focus of this thesis because the need for information about diagnosis, prognosis, and treatment, is highest early in the disease journey (Mistry et al. 2010). Improvements in information provision achieved at this time – particularly those achieved by improvements to patients', carers', or health professionals' skills or behaviours – may be formative, and have long-lasting effects across the disease trajectory (Kinnersley et al. 2008).

This review thus aims to answer two questions:

1. How well met are the information needs of patients newly diagnosed with primary brain tumours and their carers? What are their unmet information needs?
2. How effective are actions or interventions at improving the provision of information for patients newly diagnosed with primary brain tumours and their carers?

To answer these questions, this chapter describes the techniques for searching the literature. The existing literature is examined and key methodological issues identified. Evidence to answer the research questions is synthesised, highlighting areas in which further research is needed.

4.2. SYSTEMATIC REVIEW METHODS

The scientific literature was reviewed via extensive searches of health- and psychology-related databases, including: Medline, PubMed, the Cochrane Library, CINAHL, PsycARTICLES, PsyBOOKS, PsycINFO, PsychEXTRA and Social Work Abstracts. General databases such as Academic Search Elite, Australia/New Zealand Reference Centre were also searched. Internet and database searching (via the Australasian Digital Theses Database and the Conference Papers Index) was undertaken to identify current and/or unpublished research from the grey literature, including government and institute reports, conference proceedings and abstracts, theses, newsletters and working papers. This was supplemented by the manual search for papers, sources, and authors from reference lists of papers found.

The search terms used to identify relevant citations included keywords and MeSH (Medical Subject Headings[3]) terms related to brain tumour patients and/or carers (e.g. glioma), terms related to information or communication (e.g. physician-patient relations), and terms related to interventions to improve information or communication (e.g. decision aid), shown in Table 4.1. To reflect current treatment and care for brain tumour patients, and the current culture in which autonomy and the right to be informed about one's own health status, searches were limited to articles published since 1990 (01/01/1990-01/03/2011). Searches were limited to papers published in the English language, or with at least the abstract available in English[4].

[3] MeSH is the controlled vocabulary thesaurus used for indexing articles for PubMed and Medline (National Library of Medicine 2009).

[4] Where only the abstract was available in English, only the abstract was used.

TABLE 4.1 SEARCH TERMS USED

Column A: participant term	Column B: outcome term	Column C: intervention term
(brain or central nervous system or CNS [a]) + (tumour or tumor or neoplasm)	information, knowledge, understanding, comprehension, awareness, or communication	written information or leaflets or pamphlets
glioma or glioblastoma	uptake and (service or information)	tape record* or audio-tap* or video-tap*
any of the above + carer, caregiver, partner family, spouse, relative	(physician-patient or nurse-patient or provider-patient) and relations or communication	patient information or patient education as topic
	(coherence or conflict*) and (communication or information)	help lines or telephone support or support group
	satisfaction with information	(patient or consultation) and (letter or summary)
		electronic sources or multimedia or CDs or DVDs or technology or internet or website or chat or web or blog or computer
		(tailor* or individual* or personal*) AND information
		(decision or communication) and (aid or tool)
		coach* or question prompt or question list
		specialist nurse or nurse coordinator or nurse support or care coordinator
		patient navigator or patient liaison

* indicates truncation of term, to identify all words using this root stem

[a] CNS: Central Nervous System

As the review was directed at newly diagnosed patients, interventions solely addressing palliative issues (e.g. for information about death and dying, advanced directives, etc) were excluded. However, studies with patients from different stages

in the disease trajectory were included, as these studies were expected to identify the needs or issues facing newly diagnosed patients. The inclusion and exclusion criteria applied are shown in Table 4.2.

TABLE 4.2 INCLUSION AND EXCLUSION CRITERIA APPLIED TO PAPERS

Category	Inclusion Criteria	Exclusion Criteria
Study type/ quality		excluding personal views or commentaries, descriptions of clinical practice, case studies, studies without the sample described
Participants	including studies for malignant and benign primary brain or central nervous system tumours, and/or their carers including studies for patients and/or carers of patients at any stage in the disease trajectory	excluding studies/interventions for children or parents of child patients
		excluding studies solely for patients or carers of patients with secondary tumours (studies included if considered both primary & secondary brain tumour patients, if can separate results for primary brain tumour patients)
Outcomes		excluding studies not reporting patient-reported outcomes
		excluding studies not assessing some measure of information or communication as either a primary or secondary outcome
		excluding studies in which 'information needs' were not identified by patients or carers[5]
Intervention evaluations	including interventions to improve doctor-patient communication targeting patients, health professionals, or patient information materials	excluding interventions without outcomes related to information
	including complex interventions of which information provision or communication is a part	excluding counseling as a therapeutic intervention, communication about clinical trial participation, interventions solely addressing palliative needs (e.g. to provide information about death or dying) or cognitive/behavioural management strategies
	including feasibility and pilot studies	

[5] Although a number of studies purported to identify information needs, such as (Guerrero 2005) or (Irvine and Jodrell 1999), these papers only identified information topics (in these cases, potential side-effects of cranial irradiation). As previously described, an 'information need' is subjectively defined by patients or carers. Studies that identified topics of information without reference to patients' or carers' needs were excluded.

Relevant clinical guidelines and systematic reviews were included to highlight common methodological issues and areas where further research is needed. Primary data sources were classified as identifying information needs or the prevalence of unmet needs (need studies), or as evaluations of interventions to meet information needs (intervention studies). Papers which described relevant interventions and satisfied the inclusion and exclusion criteria, but which did not include evaluation of outcomes relating to information, were included as need studies. Studies published as multiple papers (for example, with results for patients published separately from results for carers) were reported as a single study. Within 'need' studies, the evidence was examined to determine the prevalence of unmet information needs, the types or topics of information needed and differences between patients and carers, and particularly to focus on the evidence regarding the needs of patients and carers early in the disease trajectory.

Although it was intended to identify all relevant literature in the field, it is likely that projects associated with individual organisations have been overlooked, and that some unpublished studies were not found. However, it is unlikely that the inclusion of additional studies would substantially alter the conclusions of this review.

4.3. SYSTEMATIC REVIEW RESULTS

4.3.1. STUDY SELECTION

Overall, 1421 articles were identified, and 1299 excluded at the title/abstract stage. One hundred and twenty-two studies were retrieved, 71 of which were excluded as they did not meet the selection criteria (see Appendix A for a list of studies excluded at this stage and the reasons for their exclusion). The study selection process is shown in Figure 4.1.

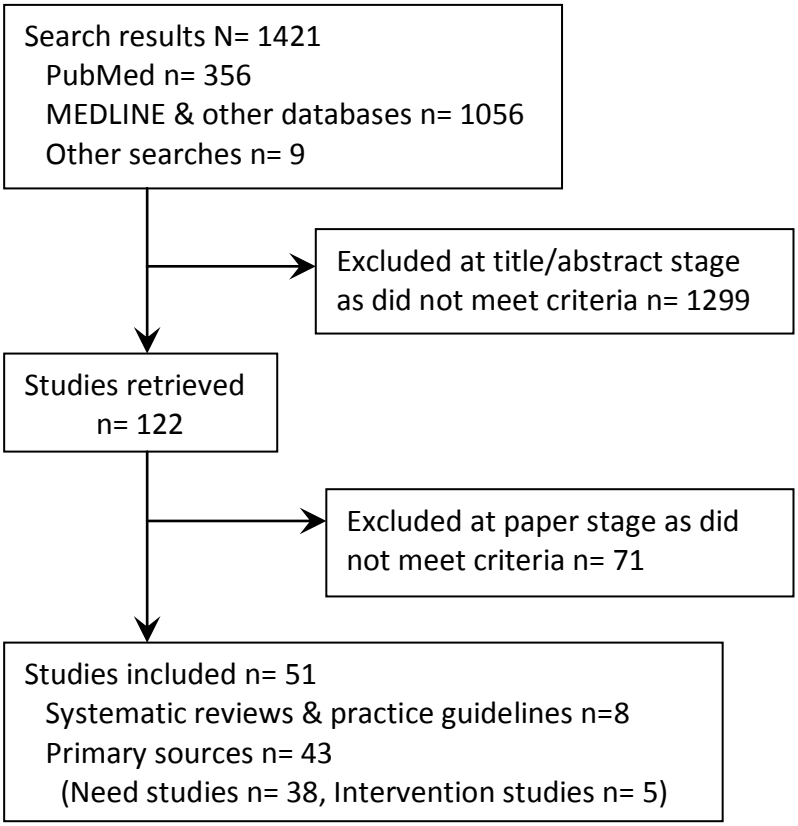


FIGURE 4.1 STUDY SELECTION PROCESS AND OUTCOMES

Fifty-one studies were included in this review. Of these, eight studies were systematic reviews or practice guidelines, and 43 were primary sources. Thirty-eight studies described information needs of primary brain tumour patients and/or carers, and five studies were evaluations of interventions aiming to improve information provision or related outcomes.

4.3.2. SYSTEMATIC REVIEWS AND GUIDELINES

Three clinical practice guidelines (Davies & Hopkins 1997; National Collaborating Centre for Cancer (NCCC) 2006; Australian Cancer Network Adult Brain Tumour Guidelines Working Party 2009) and five systematic reviews (Davies & Higginson 2003; Taillibert et al. 2004; Catt et al. 2008; Salander 2010; Madsen & Poulsen 2011) were identified (Table 4.3). Two of the three clinical practice guidelines (Davies & Hopkins 1997; Australian Cancer Network Adult Brain Tumour Guidelines Working Party 2009) focused on the needs of glioma patients. The third set of guidelines (NCCC 2006) targeted adults with brain and central nervous system tumours;

however, evidence for information and communication was based on studies with glioma patients only.

Four of the five systematic reviews focused on brain tumour patients, with varying focus on their relatives or friends (Davies & Higginson 2003; Catt et al. 2008; Salander 2010; Taillibert et al. 2004). A single review focused solely on the support needs of relatives of adult malignant glioma patients (Madsen & Poulsen 2011). Of the four reviews relating primarily to patients, one considered the needs of patients with any primary brain tumour (Taillibert et al. 2004), two focused on malignant gliomas (Davies & Higginson 2003; Salander 2010), and one on high grade gliomas (Catt et al. 2008). Only three (Davies & Higginson 2003; Salander 2010; Madsen & Poulsen 2011) of the five reviews described their search strategy and inclusion/exclusion criteria.

TABLE 4.3 SYSTEMATIC REVIEWS/PRACTICE GUIDELINES RELATING TO INFORMATION PROVISION FOR CANCER PATIENTS

Study	Review question	Summary of relevant findings	Additional information
Davies and Hopkins (1997) Study type: clinical guidelines based on literature & expert views Relevant* studies included: 9	To document consensus views about ways to improve patient care across several stages of illness, for adults with malignant cerebral glioma.	Diagnosis: identify when info needed; provide post-consult written summaries; tailor info to preference; provide written info; communications training. Follow-up: coordinate care e.g. specialist nurse. Care: record patients' concerns; provide info on potential impacts on patient & family. Support patient & carers: recognise non-medical info needs; develop info strategy. Transition between settings: provide GP with info. Palliative care: anticipate info needs, especially re impairments, personality change, communication difficulties; meet carers' needs.	Comment: inclusion criteria for studies not reported. Research gaps: appropriate model for breaking news & providing written info; nurse-led/phone clinics for follow-up; improve communication between settings; 'shared care record'; better ways to support patients & carers, understand impact of diagnosis on family, support needs & coping strategies used.
Davies and Higginson (2003) Study type: systematic review Studies included: 12 studies published as 16 papers	To identify: 1) is diagnosis/prognosis understood; 2) need for further info; 3) effective ways to break bad news; 4) effective ways of giving other info; 5) need for support; 6) evidence for specialist nurse; 7) effective educational interventions.	1) Nearly all patients aware of diagnosis, 25-48% aware of prognosis. 2) Unclear association: awareness & distress. Carers more distressed, more able to discuss prognosis. Tailor prognostic info. 3), 4) & 7) No data. 5) Need for support re: coping with the long haul of illness & family life changes; discussing CAMs with doctors; for carers, assistance to deal with patients' personality changes & cognitive problems. 6) 21 of 45 patients, 19 of 20 patients, & 36 of 45 patients satisfied with specialist nurse, others wanted follow-up by both a doctor & nurse. Nurses predict patients' needs during radiotherapy.	Comments: authors identified that there were relatively few studies, & many had methodological problems. Research gaps: how to best break bad news & educational interventions for this task, different methods of giving info, best combination of medical & nurse-led follow-up, influence of cognitive problems on patients' preferences & ability to retain info.

TABLE 4.3 CONTINUED

Study	Review question	Summary of relevant findings	Additional information
Taillibert et al. (2004) Study type: review of literature & experiences Relevant* studies included: 1	To update data on supportive and palliative care for adults with primary brain tumour.	Psychological aspects: 70% of patients worried about the future. Physicians & multidisciplinary teams: 38% of 60 patients complained of lack of info; 25% about the way health professionals communicated with them. Patients are afraid to ask questions, leading to unrealistic expectations. Physicians overly optimistic about prognosis. Carers: as patients are now treated as outpatients, carers' roles & burden have increased.	Comments: search strategy not reported. All evidence & recommendations for information or communication based on one study. Research gaps identified: none.
NICE (2006), NCCC (2006) & Linck et al. (2006) Study type: guidance & systematic review Relevant* studies included: 4	What is the optimum method for providing information to neuro-oncology patients who are not able to access information due to cognitive dysfunction, memory problems, etc?	There is only indirect & inconsistent evidence re how much patients want to know about their prognosis. Patients with brain & other central nervous system tumours have specific info needs, including: expectations re each stage of the disease journey, when & where such events will occur, & info on relevant clinical trials. Info needs to be provided in different formats. Need communications training for neuro-oncology health professionals.	Comments: search strategy not reported. Research gaps identified: none.

TABLE 4.3 CONTINUED

Study	Review question	Summary of relevant findings	Additional information
Catt, Chalmers et al. (2008) Study type: systematic review Studies included: 22 studies published as 25 papers between 2000 & 2007	To describe how the psychosocial & supportive care needs of adults with HGG can be met.	Active info seeking is coping strategy for both patients & carers. Info provision has been inconsistent. Nurse specialists are resource for patients & carers, improve continuity of care, reinforce info given & provide additional info. Prognosis: patients have varied awareness, less than carers; tailor to coping abilities & allow hope. Patients have high need for verbal & written info at diagnosis; need practical detailed info. Carers lack knowledge & skills to meet care needs at home, manage difficult behaviour, understand disease & its implications, financial info, access government agencies, info about the future. Carers defer to patients' info preferences but have different needs. Need extended access to info.	Comments: search strategy not reported & quality of papers not reviewed. Research gaps identified: interventions for cognitive problems & depression; communication skills re breaking bad news & prognosis; different methods of info delivery
Australian Cancer Network Adult Brain Tumour Guidelines Working Party (2009) Study type: clinical guidelines Studies included: 29	Section 2.3 'Specific communication issues: information provision' identifies the challenges at diagnosis & in discussing prognosis.	Initial consultation: check understanding/repeat, use communication aids, give info about support/info available. At each stage of care, describe relevant clinical trials. Breaking bad news: ask about family's adjustment & discussing prognosis with them. Tailor prognosis to needs, avoid jargon or euphemisms, give average/longest survival times. Treatment options & decision-making: provide adequate info for patients to make their own decisions, establish values & preferences for involvement, assist to express wishes while able to do so.	Comments: only 2 papers upon which guidelines are based are specific to patients with brain tumours and/or their carers. Research gaps identified: none

TABLE 4.3 CONTINUED

Study	Review question	Summary of relevant findings	Additional information
Salander (2010) Study type: Studies included: 15	To describe how different professional arenas can psychologically 'facilitate' adults with primary malignant brain tumours &/or their relatives.	Patient-physician relationship: info needs vary due to disease status, cognitive decline, preferences. Carers want separate opportunity to talk with physician. Specialist nurse: suitable for follow-up; most contact for info (treatment, side-effects, symptoms, practical day-to-day issues, medication); more carer calls. Support groups: provide info about the disease not provided elsewhere; increase patient well-being; helped carers with 'transition' through period of loss.	Comments: none. Research gaps identified: what aspects of the physician-patient relationship facilitate patient support, & what are the possibilities & limitations of group & internet connections for the families of brain tumour patients.
Madsen & Poulsen (2011) Study type: systematic review Studies included: 14	To review the everyday lives & need for support felt by relatives of adults with malignant cerebral glioma.	Carers' increased responsibility: for researching info; managing cognitive/psych sequelae. Living with uncertainty: constant, fear for future. Inconsistent re satisfaction with info received. Info missing/needed re: how to provide day-to-day care, manage psych problems at home, what to expect, what to tell children, life after the patient dies, the future. Hard to get info about experimental treatments from clinicians. End of life: many patients/spouses did not discuss the 'terminal' nature of disease or tell others. Friends & family: worked with the clinicians to obtain info. Clinicians: relatives believed most avoided answering questions about the future & prognosis Case manager: needed, provided chance to ask questions. Support groups: source of info & hope.	Comments: authors identified that relatively few studies were identified & studies were heterogeneous, sample sizes small, 6 studies did not identify relatives' characteristics, 75% of patients male, all but 3 studies were qualitative. Research gaps identified: impact of illness on parts of relatives' everyday lives; interventional research to assist relatives to handle difficulties at home when alone with patient; staff education re relative support.

* Relevant studies addressed information. CAM: Complementary & alternative medicine, info: information, NCCC: National Collaborating Centre for Cancer, NICE: National Institute for Health & Clinical Excellence, psych: neuropsychiatric.

The guidelines and reviews highlighted that few studies were available and/or had methodological problems. One review (Davies & Higginson 2003) quantitatively graded the rigour of study design and analysis. All quantitative studies were graded as evidence level IIIC (retrospective or observational studies with no comparison group, calculation of sample size, nor accurate/standard definition of appropriate outcome variable) (Higginson et al. 2002). In addition, only one qualitative study was graded as Grade A (good), while four were graded as Grade B (average) and three as Grade C (poor).

As all of the guidelines and reviews had different foci, only limited conclusions are possible. Most consistently, these papers emphasised the need for systematic information provision strategies that have been recommended for all cancer patients, such as providing written information, tailoring information to patients' and carers' needs, and providing a single point of contact with the health care system such as a specialist nurse. Studies suggest that nearly all patients were aware of their diagnosis, but there is inconsistent evidence regarding how much patients know, or want to know about their prognosis. On the whole, carers may have greater capacity for and want more detailed prognostic information than patients. However, both patients and carers need detailed, practical information to prepare them for the future, particularly regarding cognitive/neuropsychiatric impairments, management of difficult behaviour, and caring for the patient at home.

4.3.3. NEED STUDIES

4.3.3.1. STUDIES IDENTIFIED

Studies were classified by their primary research design or method (quantitative or mixed methods, versus qualitative) for ease in examination of study rigour. Sixteen quantitative or mixed methods studies and 22 qualitative studies were identified. As shown in Table 4.4, most studies focused on patients only (13 studies), or patients and carers (19 studies). Studies of carers only were predominantly qualitative (7 studies). The distribution of studies by location was fairly evenly spread, with more qualitative research published by groups in all locations except the UK. Most research has been published since 2005.

TABLE 4.4 DISTRIBUTION OF STUDIES ADDRESSING THE INFORMATION NEEDS OF BRAIN TUMOUR PATIENTS AND CARERS, 1990-2011

Characteristic	Quantitative & mixed methods studies (n=16)	Qualitative studies (n=22)
Sample composition		
Patients only	7	5
Carers only	1	6
Patients & carers	8	11
Study location		
UK	5	4
Other Europe	4	7
US/Canada	5	7
Australia	2	4
Year of publication[1]		
1990-1994	1	0
1995-1999	1	2
2000-2004	3	9
2005-2011	11	11

[1] where multiple papers were published on a study, refers to year of first publication

4.3.3.2. CHARACTERISTICS: QUANTITATIVE AND MIXED METHODS STUDIES

The sample sizes of the quantitative and mixed methods studies were mostly small, with the exception of an online survey in the US, which involved 709 patients and 702 carers (Spezeski 2009). The median number of patients over 13 studies was 75 (range 26-709); and the median number of carers was 68 (range 27-702). Only one study reported statistical calculation of sample size (Lidstone et al. 2003).

Study samples were relatively heterogeneous. Five studies recruited patients with any primary brain tumour (Lidstone et al. 2003; Janda et al. 2008; Parvataneni et al. 2011; Schröter et al. 2009; Spezeski 2009), three recruited patients with a malignant brain tumour (Jones et al. 2007; Mackenzie & Drummond 2010; Keir et al. 2006), and three recruited patients with high grade gliomas (Diaz et al. 2009; Steele et al. 1997; Davies et al. 1996). One study recruited carers of patients with high grade gliomas only. One study recruited only patients with acoustic neuroma (Orabi et al. 2005); no other study recruited only patients with benign tumours. The tumour type of participants was unspecified in three studies (Grimes 2000; Mursch & Behnke-Mursch 2003; Spezeski et al. 2007).

Only two studies reported including participants aged 75 years or older (Jones et al. 2007; Parvataneni et al. 2011), and only five studies reported patient samples with greater numbers of men than women, as would be expected in a representative sample (Davies et al. 1996; Diaz et al. 2009; Lidstone et al. 2003; Parvataneni et al. 2011; Steele et al. 1997). Of the eight studies which reported the socioeconomic position of patients/carers, six reported that participants had higher levels of education, income and/or employment than expected in a general population sample (Davies et al. 1996; Keir et al. 2006; Jones et al. 2007; Parvataneni et al. 2011; Schröter et al. 2009; Spezeski 2009). Only three studies reported the ethnicity of participants (Davies et al. 1996; Keir et al. 2006; Mackenzie & Drummond 2010; Spezeski 2009).

It is unclear how well represented were patients or carers of patients with a cognitive impairment. Two studies limited the inclusion of patients by KPS or WHO/ECOG performance scale (Keir et al. 2006; Steele et al. 1997). One study (Diaz et al. 2009) excluded five potential participants because of neurocognitive effects that limited their ability to understand information or make decisions, and another study (Davies et al. 1996) could not interview 13 patients 'in any depth' because of their disabilities. Another two studies listed inclusion criteria specifying ability to give informed consent or to complete questionnaires, although neither listed how this ability was tested (Jones et al. 2007; Parvataneni et al. 2011).

Studies were also limited by their sample selection. Nine studies recruited patients from a single hospital (Lidstone et al. 2003; Diaz et al. 2009; Keir et al. 2006; Jones et al. 2007; Parvataneni et al. 2011; Orabi et al. 2005; Steele et al. 1997; Grimes 2000; Mackenzie & Drummond 2010). Two of these studies were convenience samples (Keir et al. 2006; Jones et al. 2007). Another study recruited patients from seven neurosurgical and radiotherapy centres, but did not specify the number or characteristics of patients from each (Davies et al. 1996). Another four studies involved users of support services (Mursch & Behnke-Mursch 2003; Spezeski et al. 2007; Janda et al. 2008; Spezeski 2009).

Twelve studies were cross-sectional in nature (Diaz et al. 2009) (Jones et al. 2007; Mackenzie & Drummond 2010; Lidstone et al. 2003; Orabi et al. 2005; Janda et al.

2008; Keir et al. 2006; Parvataneni et al. 2011; Schröter et al. 2009; Spezeski 2009; Spezeski et al. 2007; Wasner et al. 2007). Another study involved two sequential, cross-sectional samples, whereby the same questionnaire was applied to two different samples of patients, at least six months apart (Grimes 2000). Two further studies involved the retrospective analysis of data collected over a period of time. Steele et al. (1997) analysed the content of 29 outpatient appointments involving 24 patients, and Mursch et al. (2003) analysed the content of an email mailing list over a six month period. Only one study followed the same group of participants over time (Davies et al. 1996).

No studies were directly comparable (for example, by using the same instruments). Table 4.5 lists the relevant findings of the quantitative and mixed methods studies.

TABLE 4.5 FINDINGS OF QUANTITATIVE/MIXED METHODS STUDIES EXAMINING THE INFORMATION NEEDS OF BRAIN TUMOUR PATIENTS AND/OR THEIR CARERS

Reference	Sample	Method	Results	Quality issues
Davies et al. (1993; 1996), Davies (1997; 1997)	75 patients with malignant glioma & 66 of their relatives, UK	Semi-structured interviews taped & transcriptions analysed	Awareness of prognosis: 19 patients & 44 carers fully; 24 patients & 16 carers partly, carers more aware than patients (kappa=0.20). 18 patients highly critical of coordination of care, 27 of lack of coherence in info.	Rating scales not validated, not reliable
Diaz et al. (2009)	26 patients with high grade glioma at time of discharge, Spain	Questionnaire: HADS, views re info & communication (not validated)	50% want all info, 23% only important, 27% only critical aspects. 36% fully comprehended info, 35% sufficiently comprehended, 31% only understood part. 15% wished to ask physicians more questions.	4 excluded (did not wish to know info), representativeness of 26 unknown
Grimes (2000)	30 patients with primary brain tumours (survey) & unknown no. (audit), UK	Unstructured interviews, audit (questionnaire) at baseline & 6 months	Problems: giving 'bad news' & out-patient services. Developed communications policy, communications training, reorganised systems. Audit of patients' views (baseline/6 months): clarity of explanation (48%/73%), enough time when results given (46%/70%).	Inadequate description of data collection & sample for audit
Janda et al. (2008)	75 brain tumour patients & 70 carers, Australia	Mailed survey (HADS, FACT-G & FACT-Br, FACT-GP, SCNS-SF, SCNS-P&C 44), 30% response	% unmet supportive care needs-patients: one staff member to talk to 38%; info on latest research 34%. Carers: access info on treatment benefits/side-effects 34%, manage difficult behaviour 34%.	Patients with high grade tumours under-represented, medical data based on self-report
Keir et al. (2006) - patients & Keir (2007) - carers	Convenience samples of 60 carers of brain tumour patients & 60 carers, US	Surveys (assessed stress using validated tool, validity of other items unclear)	86% patients/81% carers interested in stress reduction programs, 26%/65% wanted to receive info. % patients/carers want this info by: mail 32%/82%, email 32%/ 78%, flyer 24%/70%, computer program 24%/57%, in-person 27% /55%, phone 15%/48%.	Self-selection bias

TABLE 4.5 CONTINUED

Reference	Sample	Method	Results	Quality issues
Jones et al. (2007)	106 brain tumour patients, US	Mailed survey, 28% response rate, medical data via chart review	45% would have liked to get exercise program info during adjuvant therapy, 70% after. % want this info by: internet 48%, computer program 41% flyer 47%, email 49%, mail 55%, phone 24%, face-to-face 29%.	Low response rate. Self-selection bias, recall bias
Lidstone et al. (2003)	60 primary brain tumour patients, UK	Written questionnaire using Symptoms & Concerns checklist	Patients reported a problem due to issues: 38% due to a lack of info about illness/treatment, 70% concerns about the future, 25% the way in which doctors/nurses communicate with you	Sample size based on power calculations, validated tool
Mackenzie et al. (2010)	44 patients with malignant astrocytoma, Australia	Interviews using structured, standardised questionnaire	25% want info in other formats. 30% want only hear positive info; 70% want all info. 20% want info in simple language. 13% felt there was a need for central coordinator role to disseminate info.	POSTER ONLY
Mursch et al. (2003)	Emails sent via email mailing list (~ 380 members), Germany	Content analysis of 372 emails distributed over 6 months	Number of emails re topics: lack of sensitivity while giving diagnostic info (72), lack of communication between different therapists (21), lack of knowledge about alternative therapies (15).	Does not identify number of patients who sent/read emails
Orabi et al. (2005)	120 acoustic neuroma patients, UK	Mail survey of investigators' patients, 87% response rate	Info looked for via internet: 1) general, 2) treatment, 3) outcome, 4) alternative, 5) other. 97% reported close similarity between info provided by surgeons & Internet info. 10 found Internet info negative.	Validity of survey questions unclear, reporting of results unclear
Parvataneni et al. (2011)	83 patients & 83 carers (not participating as dyads), US	Survey during clinic visits or mailed back	% very important/% unsatisfied (p: patient, c: carer): cause info (p 60%/52%, c 49%/61%), foods/activities (p 55%/29%, c 65%/46%), phone access to health care provider knows me (p 68%/29%, c 82%/30%).	Questionnaire to identify needs was not validated

TABLE 4.5 CONTINUED

Reference	Sample	Method	Results	Quality issues
Schröter et al. (2009)	129 patients & 140 relatives, Germany	Survey completed on paper/online	Use of info sources (patients/carers): internet 80%/93%, print info 85%/86%, self-help groups 19%/23%, info meetings 62%/58%. 57%/58% dissatisfied with info provided by physicians.	Sample not representative: younger, more educated
Spezeski et al. (2007)	709 patients and 702 relatives/ friends, US	Online survey	% found it difficult to find info: on cognitive changes 59%, trials 52%, fatigue 49%. Carers unprepared for change: personality 33%, cognitive 33%, physical 32%.	Self-identification of patients & carers
Spezeski (2009)	75 callers (26 patients, 39 carers, 10 other) to neuro-oncology phone line, US	Retrospective telephone survey with sample of callers, 70% response rate	Callers sought information, support, or because of circumstances such as diagnosis or treatment options. 81% of callers received educational materials. Unmet needs included resources on long-term survivorship & the practical impact of diagnosis.	ABSTRACT ONLY
Steele et al. (1997)	36 patients with high grade brain tumours (GBM or AA), UK	Chart review & consultation topics logged	% of 29 consultations in which topics were discussed: scan results 14%, side effects of treatment 72%, symptoms of disease 90%, prognosis 7%, work/leisure 48%, housing 7%, interpersonal 10%, driving 24%	Relied on observer to characterise consultation content
Wasner et al. (2007)	27 carers, Germany	Written survey	48% felt sufficiently informed about the course of the illness.	ABSTRACT ONLY

AA: Anaplastic astrocytoma, FACT: Functional Assessment of Cancer Therapy, FACT-G: FACT-General, FACT-Br: FACT-Brain, FACT-GP: FACT-General Population, GBM: glioblastoma multiforme, HADS: Hospital Anxiety & Depression Scale, SCNS: Supportive Care Needs Survey, SCNS-SF: SCNS-Short form, SCNS-P&C44: SCNS-Partners & Caregivers, info: information, no.: number.

4.3.3.3. CHARACTERISTICS: QUALITATIVE STUDIES

The methodological characteristics of the 21 qualitative studies identified are shown in Table 4.6. Compared with the quantitative and mixed methods studies, the qualitative studies had smaller sample sizes, but were more likely to include patients with low-grade or benign tumours, and to involve follow-up over two or more time points.

TABLE 4.6 METHODOLOGICAL CHARACTERISTICS OF QUALITATIVE STUDIES OF THE INFORMATION NEEDS OF BRAIN TUMOUR PATIENTS AND/OR CARERS

	Studies with patients (n= 4)	Studies with patients & carers (n= 12)	Studies with carers (n= 5)
Patients' tumour type[1]			
low grade glioma only	0	1	0
high grade glioma only	0	4	0
malignant only	1	2	4
benign only	1	0	0
any primary	2	4	1
other	0	1	0
Time points/participant			
1	2	6	4
2	1	1	1
3 or more	1	5	0
Data collection			
Interviews	3	6	4
Written questionnaire	0	1	1
Observation	0	2	0
Combination/choice[2]	0	3	0
Data analyses[3]			
Content/framework	1	3	0
Thematic/other inductive	3	8	5

[1] Includes the tumour type of patients cared for by carer participants
[2] combination or choice of methods, e.g. interview and/or focus group
[3] excludes one study with patient & carers where the method of analysis was unclear (Barr 2003)

The median number of patients who participated in qualitative studies was 17 (range 3-41), and the median number of carers included was 21 (range 4-43)[6]. Study samples were mostly selected via purposive sampling, for maximum variation in characteristics such as phase of the disease trajectory (Schubart et al. 2008), and age, sex and ethnicity (Strang & Strang 2001). However, a number of studies involved convenience sampling (Durity et al. 2000) or the recruitment of

[6] Excluding the number of patients and carers who participated in studies in which only total numbers of participants (patients and carers) were reported (Curren 2001; Barr 2003).

consecutive patients and/or their carers at a hospital or clinic (Widenheim et al. 2002; Spetz et al. 2005; Salander 1996). Six studies sampled until saturation (Halkett et al. 2010; Janda et al. 2006; Strang & Strang 2001; Arber et al. 2010; Schmer et al. 2008; Schubart et al. 2008).

Eight studies did not report the age distribution of participants (O'Donnell 2005; Barr 2003; Curren 2001; Leavitt et al. 1996; Rosenblum et al. 2009; Strang & Strang 2001; Schmer et al. 2008; Sherwood et al. 2004). An additional two studies reported the age distribution of patients, but not of carers (Spetz et al. 2005; Widenheim et al. 2002). Five studies reported the participation at least one patient in his/her twenties (Rozmovits et al. 2010; Durity et al. 2000; Janda et al. 2006; Spetz et al. 2005; Widenheim et al. 2002), and nine studies reported the participation of at least one patient in his/her seventies or eighties (Edvardsson & Ahlström 2005; Molassiotis et al. 2010; Rozmovits et al. 2010; Durity et al. 2000; Janda et al. 2006; Halkett et al. 2010; Salander 1996; Spetz et al. 2005; Widenheim et al. 2002). Similarly, of the eight studies which reported the age range of carers, five included carers aged under thirty years (Durity et al. 2000; Edvardsson & Ahlström 2008; Salander 1996; Sherwood et al. 2011), and five included carers aged 70 years or over (Arber et al. 2010; Edvardsson & Ahlström 2008; McConigley et al. 2010; Salander 1996; Schubart et al. 2008).

Seven studies also did not report the gender of patients and/or carers (Schmer et al. 2008; Spetz et al. 2005; Widenheim et al. 2002; Barr 2003; Curren 2001; Rosenblum et al. 2009; Strang & Strang 2001). Of studies which did report gender, seven studies had the same or more male than female patients, reflecting the gender distribution of primary brain tumours (Edvardsson & Ahlström 2005; Molassiotis et al. 2010; Halkett et al. 2010; Salander 1996; Spetz et al. 2005; Widenheim et al. 2002; Lepola et al. 2001). All but one study (Durity et al. 2000) reported having more female than male carers.

Only five studies reported the ethnicity of participants, and all reported that participants were predominantly Caucasian (Leavitt et al. 1996; Sherwood et al. 2004; Sherwood et al. 2011) or born in the country in which the study was conducted (Rozmovits et al. 2010; Lobb et al. 2011). Five studies reported

participants' education or employment status (pre-diagnosis or currently) to some degree (Molassiotis et al. 2010; Durity et al. 2000; Janda et al. 2006; Leavitt et al. 1996; Lobb et al. 2011); the socioeconomic position of participants in two of these studies was clearly much higher than would be expected in the target population (Molassiotis et al. 2010; Leavitt et al. 1996).

Cognitive impairment was an exclusion criteria for seven studies (Lepola et al. 2001; Molassiotis et al. 2010; O'Donnell 2005; Edvardsson & Ahlström 2005; Lobb et al. 2011; Strang & Strang 2001; Widenheim et al. 2002). However, two studies did not specify how such impairments were identified (Molassiotis et al. 2010; O'Donnell 2005), and participation in three other studies required that patients be 'oriented to time and place' (Lepola et al. 2001), or that patients' cognitive or intellectual function was 'sufficient' to allow participation in interviews (Strang & Strang 2001; Widenheim et al. 2002). One study included patients with cognitive impairment (Salander et al. 1996); 11 of 30 participants had some level of neurological handicap, mental impairment and/or personality change.

In addition, six studies excluded patients on the basis of physical/functional impairment or prognosis: Molassiotis et al. (2010), excluded patients with a life expectancy of less than six months; O'Donnell (2005) excluded patients who scored less than 15 on the Coma Scale (15 indicates 'normal' consciousness (McCullagh et al. 2001)); Rozmovits et al. (2010) required that participants be 'ambulatory'; Strang et al. (2001) excluded patients with functional impairments that would impair participation in interviews; and both Salander (1996) and Spetz (2005) required patients to have a WHO performance status score of 0-2 (which indicates that a person is ambulatory, capable of all self-care, and not confined to bed or a chair for more than 50% of waking hours (Roila et al. 1991)).

Both patients and carers were predominantly recruited from a single hospital or clinic. In contrast, one study recruited patients from a cancer registry (Edvardsson & Ahlström 2005) and three studies recruited via support services (Barr 2003; Janda et al. 2006; Sherwood et al. 2004). In addition, one study involved observation of a support group over six, monthly sessions (Leavitt et al. 1996), and a further study analysed the content of a retrospective audit of calls made and received by a nurse

specialist (Curren 2001). Two studies did not describe how, where from, or why the sample was selected (O'Donnell 2005; Rosenblum et al. 2009). Relevant findings of each qualitative study are shown in Table 4.7.

TABLE 4.7 RELEVANT FINDINGS OF QUALITATIVE STUDIES OF THE INFORMATION NEEDS OF PRIMARY BRAIN TUMOUR PATIENTS AND/OR CARERS

Study	Sample	Aim	Methods	Relevant themes/findings	Theory base
STUDIES WITH PATIENTS ONLY					
Lepola et al. (2001)	8 brain tumour patients pre-surgery, Finland	To describe the experience of being a brain tumour patient & care in neurosurgery unit	Interviews, 2 time points (day before surgery, 3-7 days after surgery), thematic analysis	- after surgery, many patients had changed body image & fear for future - some needed more info before surgery, & many needed more info after	None reported
Molassiotis et al. (2010)	9 malignant brain tumour patients, UK	To understand the symptom experience & impact on daily life of a brain tumour	Interviews, 4 time points (diagnosis to 12 months later), framework analysis	- Misunderstandings due to medical jargon, inattention, shock. Anger re delivery of diagnosis & lack of preparation for symptoms experienced, communication problems, lack of sensitivity	Leventhal's self-regulation theory
O'Donnell (2005)	8 patients with a brain tumour, UK	To gain a better understanding of the info needs of brain tumour patients	Interviews, 1 time point (by 6 months post-diagnosis), phenomenological approach	- Understanding inconsistent, info needed - Organisational barriers to communication, procedural/physical need info dominated, limited info opportunities in hospital, family liaised with clinicians & found info	Not reported
Rozmovits et al. (2010)	25 benign brain tumour patients, Canada	To explore info needs of benign brain tumour patients who had had a craniotomy	Interviews, 1 time point, thematic analysis	- Amount of info wanted varies & is not limited to treatment options & risks - Patients consider compassion from their surgeon important & want direct communication post-operatively, when needs are greatest	None reported
STUDIES WITH PATIENTS AND CARERS					
Barr (2003)	34 members of a support Group[1], Australia	To describe initiating a brain tumour support group & info desired by attendees	Mail survey of group members, 1 time point, analysis not described	- Info desired: tumour types & causes; treatments & side-effects; research; deficits & their management; diet, herbs & lifestyle changes	None reported

TABLE 4.7 CONTINUED

Study	Sample	Aim	Methods	Relevant themes/findings	Theory base
Curren (2001)	402 patients or carers, post-diagnosis onward, UK	To describe the development & use of telephone service staffed by a neuro-oncology nurse	Retrospective audit of calls made & taken over 2 years, call topics logged[2]	Largest number of calls involved reinforcing info previously given or providing more info re treatment & side-effects. Other info needed: steroid dose reduction, dealing with steroid side-effects, seizures, financial & appointment advice.	None reported
Durity et al. (2000) & Wyness et al. (2002)	18 skull base tumour patients & 15 carers, Canada	To determine the pre-operative info needs of patients with skull-base tumours & carers	Interview/survey, 3 time points (2 pre- & 1 post-operative) content analysis & narrative method	Impact of hearing the news pervasive led to fear or resigned acceptance. 39% of patients & 93% carers became info-seekers. Both patients & carers wanted info re: tumour, surgery, post-operative experience, carers needed more detail	None reported
Edvardsson et al. (2005) & Edvardsson et al. (2008)	39 low grade glioma patients & 28 carers, Sweden	To describe low grade glioma patients' & carers' experiences, illness-related problems, & coping used in everyday life	Interviews, 1 time point, constant comparison & thematic analysis	- patients refrained from & avoided info (e.g. avoided contact with friends), gave & sought info & help (e.g. info seeking), & anticipated (e.g. prepared for future illness-related problems) - carers unprepared for post-surgery, uncertainty re relapse, treatment & future, felt invisible & neglected (e.g. insufficient info) & powerless in staff encounters, info helps feel secure & involved	Lazarus & Folkman's coping theory
Janda et al. (2006)	18 patients & 18 carers, Australia	To explore the experience with existing supportive care services & assess other needs	Focus group or telephone interview, 1 time point, framework analysis	- Need for info & coping with uncertainty, practical support, support to: return to responsibilities/self-care, deal with social isolation, organise respite, overcome stigma, discuss reduced life expectancy	None reported

TABLE 4.7 CONTINUED

Study	Sample	Aim	Methods	Relevant themes/findings	Theory base
Leavitt et al. (1996)	41 patients & 37 carers attending support group, US	To describe the needs of brain tumour patients & mechanisms of support groups	Observation of support group meetings (held over 6 months), grounded theory	- Not enough time to talk with doctors, confusion & conflicting advice, navigating between sites - Seeking & exchanging info: topics needed - Diminishing professional attention to non-life threatening problems	None reported
Lobb et al. (2011), Halkett et al. (2010), McConigley et al. (2010)	19 high grade glioma patients within 1 year of diagnosis & 21 carers, Australia	To describe the experience of being diagnosed with high grade glioma or being the carer of a patient diagnosed with high grade glioma, and their info & support needs	Interviews, 1 time point, grounded theory & constant comparative method	- given prognostic info while in shock - Uncertainty re prognosis, hope taken away - Communication with clinicians limited by barriers; & clinicians' lack of communication skills - Carers: many given specific prognostic info, needed to make changes & plans for future quickly; sought info re caring, difficult to find info	Maslow's hierarchy of needs
Rosenblum et al. (2009)	10 patients & 4 carers, Australia	To review the concept of hope as a way to support patients through the care continuum	Interviews, 1 time point, analytic method not described ('qualitative')	- Delivering diagnosis: calm fears, discuss science, address prognosis, build relationship, focus on preferences & needs - Ongoing care: maintain the relationship - Support: peer support, maintain hope	None reported
Salander (1996), Salander et al. (1996; 1998; 1999; 2002)	30 high grade glioma patients & 29 carers[2], Sweden	To describe pathways to care, how patient/carers cope, maintain hope & discuss disease	Interviews, up to 4 time points (discharge to after death), modified grounded theory	- Kept illusion of well-being by avoiding or reframing info, not discussing prognosis, patients more satisfied with info provided than carers, carers considerate of patients' info preferences but have own needs. Awareness of prognosis fluctuated & partial	None reported

TABLE 4.7 CONTINUED

Study	Sample	Aim	Methods	Relevant themes/findings	Theory base
Spetz et al. (2005; 2008)	16 high grade glioma patients & carers, Sweden	To describe how patients & families make use of the specialist nurse function	Interviews (every 3 months & after death), field notes logged all contacts, thematic analysis	- Personal, ongoing relationships facilitated info provision, removed barrier to care (e.g. steroids, routine), instrumental & relational support, both private & professional - Preparing for future important for carers	None described
Strang et al. (2001)	20 malignant brain tumour patients & 16 carers, Sweden	To explore how brain tumour patients & carers cope, understand & create meaning, & if spirituality assisted	Interviews, 1 time point, hermeneutic approach, inductive approach	- Comprehensibility: info decreased uncertainty & anxiety - Manageability: coping achieved by active info seeking, positive reinterpretation; lack of info & abrupt diagnosis delivery hamper coping, carers assume responsibility	Antonovsky's concept of sense of coherence
Widenheim et al. (2002)	3 high grade glioma patients & 5 carers, Sweden	To describe what it is like to live with a high grade glioma from a family perspective	Interviews, 2 time points (2-3 weeks post surgery, 3-6 months after diagnosis), inductive analysis for narrative text	- Info re illness & treatment correct, staff listened & answered questions, gave info on side effects, practical info, provide hope, inspire security, continuity (same doctor) - Problems: jargon & unclear meaning, 'unnecessary' info about future, 'forcing' info on carers re what could happen	None described
STUDIES WITH CARERS ONLY					
Arber et al. (2010)	22 carers of malignant brain tumour patients, UK	To identify carers' access to info & info on managing caring role	Interviews, 1 time point, constant comparative analysis & grounded theory	- Lacked info re: combine work & caring; finances; finding support groups; what to expect post-surgery; medications. - Difficulty with info post-surgery & at discharge - Searched for info via Internet re treatments & support groups	None reported

TABLE 4.7 CONTINUED

Study	Sample	Aim	Methods	Relevant themes/findings	Theory base
Schmer et al. (2008)	10 carers of malignant brain tumour patients, US	To explore carers' perspectives while the patient was receiving initial chemotherapy	Interviews, 1 time point (by 6 months post-diagnosis), phenomenological, inductive analysis	- Disclosure of diagnosis distressing, some kept from patient to protect, kept from others as they would not understand, to provide privacy, or prevent interference - Staff listened, explained & repeated	None reported
Schubart (2004) & Schubart et al. (2007)	25 carers of brain tumour patients, US	To describe the roles & needs of carers across the illness trajectory	Interviews, 1 time point, thematic analysis	- Info needs changed but seeking highest at diagnosis. Info aided coping. Physician most trusted info source, forgiven inadequate info provision, due to time & carers' fear of offending. Lack of formal support, info gained informally. Need info for future	Chronic illness manage-ment model
Sherwood et al. (2004)	43 bereaved carers of malignant brain tumour patients, US	To explore the positive & negative aspects of providing care for someone with a malignant brain tumour	Written open-ended questionnaire, thematic analysis	- Clinicians did not provide adequate info/support re managing symptoms/side-effects at home, cognitive/neuropsychiatric symptoms - Finding info re treatment, managing symptoms was difficult & took much time, but felt unprepared even when info given	Role adaption & role strain
Sherwood et al. (2011)	10 carers of malignant brain tumour patients, US	To examine how carers transition into the caring role & how their perceptions of this change over time	Interview, 2 time points (within 1 month of diagnosis & 4 months later), thematic analysis	- Between baseline & follow-up, carers became more interested in looking for peer support & for info, particularly re coping; needs became more specific; carers perceived support differently	Pittsburg Mind-Body Center's common pathways model

[1] distribution of patients and carers not reported, methods not fully described & only themes of results reported, thus grouped with qualitative papers
[2] Five papers were published on this sample with varying aims, some reporting on all patients & carers, some on a sample of them

4.3.3.4. Study Findings: All Need Studies

How well are the information needs of brain tumour patients and carers met?

Ten studies reported directly relevant data (Orabi et al. 2005; Wasner et al. 2007; Davies 1997; Rozmovits et al. 2010; Edvardsson & Ahlström 2008; Strang & Strang 2001; Arber et al. 2010; Schubart et al. 2008; Salander & Spetz 2002; Spetz et al. 2008). Only one study reported that patients believed that the information provided to them was comprehensive and adequate (Orabi et al. 2005). However, this study was undertaken by the participants' treating physicians, and participants may not have felt comfortable in reporting dissatisfaction with their care.

In all other studies, many patients and carers reported that they wanted much more, and more detailed information, and that they were not satisfied with the information than they had been provided (Arber et al. 2010; Davies 1997; Edvardsson & Ahlström 2008; Rozmovits et al. 2010; Schubart et al. 2008; Strang & Strang 2001; Wasner et al. 2007; Salander & Spetz 2002; Spetz et al. 2008). However, the extent of unmet information needs is unclear, as different instruments were used to assess these. Davies (1997) reported that 37% of patients and 39% of carers were critical of the lack of coherence of information, while Wasner et al. (2007) found that only 48% of 27 carers felt sufficiently informed about the course of illness. Diaz et al. (2009) assessed patients' satisfaction with information received about five topics, each on a scale from 1 (very satisfied) to 5 (very dissatisfied). When scores were combined, the mean global satisfaction with information score was 2.17, somewhere between neutral and somewhat satisfied.

The adequacy of information provision was also indirectly measured in studies which examined patients' and carers' awareness of diagnosis or prognosis, perceptions of accurate or conflicting information, misunderstandings of information provided, and difficulties in finding relevant information. Five studies reported patients' and/or carers' awareness of diagnosis or prognosis (Davies et al. 1996; Mackenzie & Drummond 2010; Molassiotis et al. 2010; Halkett et al. 2010; Salander et al. 1996). All patients were aware of their diagnosis in the study by Salander et al. (1996), and 95% of malignant glioma patients were reported to know that they had a brain tumour at diagnosis (Davies et al. 1996). However, Mackenzie

et al. (2010) reported that only 70% of patients knew what type of brain tumour they had been diagnosed with.

Awareness of prognosis was much lower, particularly among patients. Davies et al. (1996) classified patients' and carers' awareness of prognosis based on the concerns and level of distress expressed during semi-structured interviews. Based on this method, 25% of patients and 67% of carers were classified as 'fully aware', and 32% of patients and 24% of carers were classified as 'partly aware' at diagnosis (Davies et al. 1996). Salander et al. (1996) also categorised 30 HGG patients based on their statements about the severity of the disease at diagnosis, reporting that at least 37% understood that their disease may be fatal. These studies probably underestimated patients' and carers' awareness of prognosis, because they relied on participants' expressions of distress or severity of disease. However, qualitative studies have confirmed that at diagnosis, many patients were uncertain about their prognosis and how they would recover from surgery (Halkett et al. 2010; Molassiotis et al. 2010). Patients interviewed over multiple time points have also emphasised that they did not initially understand the terminal nature of their condition (Molassiotis et al. 2010).

Four studies reported patients' and carers' perceptions of the accuracy or coherence of information provided (Widenheim et al. 2002; Orabi et al. 2005; Rozmovits et al. 2010; Arber et al. 2010). Two studies found that patients believed that the information provided by health professionals about the illness and treatment was generally accurate (Widenheim et al. 2002; Orabi et al. 2005). However, 'inaccurate' information was reported by patients and carers regarding psychosocial issues in two studies. Arber et al. (2010) found that some carers received inaccurate and insensitive information from health professionals about combining work and caring responsibilities, while Rozmovits et al. (2010) reported that the most consistent point of misinformation was about how long recovery would take. While surgeons typically indicated that recovery would take '6-8 weeks', this period of time did not take into account the full range of physical, cognitive, and psychosocial problems that were relevant to patients, and recovery from which could which take six months to a year (Rozmovits et al. 2010). Although

such experiences may not be typical, they suggest that the information wanted by patients and carers covers far more than a narrow 'disease' perspective, a point which has been confirmed by other studies (Edvardsson & Ahlström 2008; O'Donnell 2005).

Five studies reported relevant data regarding misunderstandings of information (Diaz et al. 2009; O'Donnell 2005; Durity et al. 2000; Edvardsson & Ahlström 2008; Widenheim et al. 2002). O'Donnell (2005) and Widenheim (2002) found in qualitative studies that patients and carers had inconsistent understandings of their diagnoses, such as whether the tumour was malignant or benign. Patients and carers were also confused about the meanings of commonly-used terms, such as 'slow-growing', 'glioma', 'brain tumour', and 'cancer' (Widenheim et al. 2002). Similarly, Edvardsson et al. (2008) reported that many carers thought that patients were 'cured' when they were told by the surgeon that an operation was successful. Only later did carers realise that tumour cells were still present (Edvardsson & Ahlström 2008).

Two studies provided less rigorous evidence. Durity et al. (2000) reported that although all patients they interviewed knew that they would need more diagnostic tests, participants varied in their abilities to name the test, describe the reason for it, or outline what it involved. However, it is not clear if patients wanted to know this information, or thought it was important for them to know it. Diaz et al. (2009) reported that 35% of patients 'fully', 35% 'sufficiently', and 31% only partly comprehended the information they had been given. However, the questionnaire used to assess comprehension was developed for the purposes of the study and was not validated, and the meanings of 'fully', 'sufficiently' and 'partly' were not explained.

Finally, one quantitative study (Spezeski 2009) and one qualitative study (Sherwood et al. 2004) asked patients how easy or difficult it was to find information on selected topics previously shown to be relevant to patients and carers. In the quantitative study, approximately one-third of patients and carers reported that they found it 'somewhat difficult' and another one-fifth of participants 'very difficult' to find information on each of three topics: cognitive changes, clinical

trials, and fatigue (Spezeski 2009). These findings were supported by the qualitative study, in which carers reported that they found it very difficult and time-consuming to obtain information about cognitive and neuropsychiatric problems, experimental treatments, how to provide day-to-day care, and managing side-effects at home (Sherwood et al. 2004).

What are the types of topics of information needed by brain tumour patients and carers?

As described in the previous chapter, some studies that purportedly identified patients' and carers' information needs only assessed the perceived importance of information, and not the extent to which information needs had been met (Voogt et al. 2005). This review identified several studies which identified 'topics' of information that may or may not constitute unmet information needs (Table 4.8). Three studies identified topics of information that were provided to patients or carers (Steele et al. 1997; Davies 1997; Widenheim et al. 2002); six further studies identified areas in which patients or carers felt 'unprepared' (Sherwood et al. 2004; Molassiotis et al. 2010; Spezeski 2009; Lepola et al. 2001; Rozmovits et al. 2010; McConigley et al. 2010). Although these topics may suggest areas in which further information is needed, this may not be given in the level of depth or format needed (Fallowfield et al. 1995; Mills & Sullivan 1999). In addition, there is a gap between receiving information, and feeling prepared – some carers acknowledged that they had received information about issues they later did not feel prepared for (Sherwood et al. 2004).

TABLE 4.8 TOPICS OF INFORMATION THAT MAY BE NEEDED BY BRAIN TUMOUR PATIENTS & CARERS

Type	Topics identified
Information provided	Discussion of disease symptoms, treatment side-effects, work/leisure, driving, scan results, interpersonal issues, prognosis, housing (Steele et al. 1997)
	4 patients told of their duty to inform the relevant driving authorities of their brain surgery; most notes did not mention the impact of the disease on other elements of life (Davies 1997)
	Carers received information about: waiting times for surgery, how the treatments would be performed, effects and side effects of medication, how long treatment would continue, and what effects would be expected (Widenheim et al. 2002)
'Unprepared'	Carers felt unprepared to manage cognitive and neuropsychiatric changes at home (Sherwood et al. 2004)
	Patients were unprepared for tiredness (Molassiotis et al. 2010)
	Carers were unprepared to manage personality changes in the patient; cognitive changes in the patient; physical changes in the patient such as seizures, fatigue or driving limitations; to cope with changes in family roles (Spezeski 2009)
	Patients were not prepared for changes in their body image after surgery, such as their heads being shaven and the size of the surgical wounds; and symptoms after surgery such as being unable to speak, unilateral hemiplegia, and thrombosis (Lepola et al. 2001)
	Patients were unprepared for fatigue, psychological disturbance, and insomnia (Rozmovits et al. 2010)
	Most carers felt unprepared for their new role as 'carer', how to provide care and what to expect (McConigley et al. 2010)

Three studies quantitatively assessed patients' and/or carers' interest in receiving information about services (Keir et al. 2006; Keir 2007; Jones et al. 2007; Janda et al. 2008). Janda et al. (2008) reported the proportion of patients and carers extremely or very interested, Keir (2006) and Keir et al. (2007) reported the proportion of patients and carers somewhat or very interested, and Jones et al. (2007) reported the proportion of patients 'yes' or 'maybe' interested. However, as shown in Table 4.9, the proportions were comparable between studies. Patients were most interested in stress reduction programs, exercise programs, and improving physical activity, while carers were most interested in stress reduction programs, and learning how to cope with changes in the patient's behaviour.

TABLE 4.9 PATIENTS' AND CARERS' INTEREST IN INFORMATION ABOUT SERVICES

% of patients interested	% of carers interested
86% learn about stress reduction programs (Keir et al. 2006)	81% learn about stress reduction programs (Keir 2007)
70% receive information about exercise programs (after treatment finished) (Jones et al. 2007)	59% learn how to manage stress (Janda et al. 2008)
64% to improve physical activity (Janda et al. 2008)	56% learn how to cope with changes in the patient's behaviour (Janda et al. 2008)
60% to achieve healthier eating (Janda et al. 2008)	54% to achieve healthier eating habits (Janda et al. 2008)
46% to achieve weight control (Janda et al. 2008)	52% to improve physical activity (Janda et al. 2008)
45% learn how to manage stress (Janda et al. 2008)	36% to learn how to keep old and make new friends (Janda et al. 2008)
45% receive information about exercise programs (during adjuvant therapy) (Jones et al. 2007)	33% to achieve weight control (Janda et al. 2008)
44% learn how to keep old and make new friends (Janda et al. 2008)	26% to learn how to return to their usual activities (Janda et al. 2008)
43% return to usual activities (Janda et al. 2008)	
38% learn how to cope with changes in behavior (Janda et al. 2008)	

Unmet information needs were assessed quantitatively by three studies (Lidstone et al. 2003; Parvataneni et al. 2011; Janda et al. 2008). Lidstone et al. (2003) found that a lack of information about illness and treatment had been a problem for 38% of brain tumour patients in the previous week, a higher proportion than for patients from seven other tumour groups (breast, lung, gastrointestinal, gynaecological, urological, head/neck, lymphoma).

Janda et al. (2008) and Parvataneni et al. (2011) reported patients' and carers' information needs about a range of topics. Janda et al. (2008) reported the proportion of patients with a moderate to high need for help in three areas relating to information: 34% had a need for information on the latest development in research and treatment of brain tumours, 41% needed help with uncertainty about the future, and 34% help with fears about the tumour spreading. Carers' moderate to high needs for help were: 40% needed help addressing fears about the patient's

physical or mental deterioration, 34% with understanding the experience of the person with a brain tumour, and 34% with accessing information about the benefits & side-effects of treatments (Janda et al. 2008).

Parvataneni et al. (2011) identified topics which at least half of patients and carers thought were very important, and regarding which, at least 30% were dissatisfied. Using these criteria, three unmet information needs of patients and carers were identified: understanding what is covered by benefits/extended medical insurance (47% of patients and 55% of carers dissatisfied); knowing what foods & activities were good for the patient (42% of patients and 46% of carers dissatisfied); and information about what causes brain tumour (49% of patients and 61% of carers dissatisfied) (Parvataneni et al. 2011). Additional information needs of carers were: knowing what symptoms may occur and what to do about them (44% dissatisfied); knowing enough about the medications (35% dissatisfied); knowing enough about the side-effects of treatments (33% dissatisfied); and knowing how to help the person I am caring for to manage pain (32% dissatisfied) (Parvataneni et al. 2011).

The specific information needs assessed by these three studies differed, so results could not be directly compared. Overall, approximately 30-60 percent of patients and carers had not received sufficient information or wanted further help for each information need. However, these studies did not seek to assess unmet needs specifically at the time of diagnosis. Lidstone et al. (2003) recruited from outpatient cancer clinics, and 27% of brain tumour patients were currently receiving chemotherapy and/or radiotherapy, and 95% had advanced disease. Patients' time since diagnosis was not reported. Both Janda et al. (2008) and Parvataneni et al. (2011) recruited patients and carers from across the disease trajectory. Janda et al. (2008) reported that 46% of patients and 55% of carers were within 5 years of diagnosis, while the median time since diagnosis of patients and carers in the study by Parvataneni et al. (2011) was 1.6 years (range 0.02-28 years), and 9 months (0.02-15 years) respectively.

Unmet information needs were also identified in qualitative formats by 17 studies (Spezeski 2009; Lepola et al. 2001; Rozmovits et al. 2010; Barr 2003; Spetz et al. 2005; Durity et al. 2000; Orabi et al. 2005; Janda et al. 2006; Halkett et al. 2010; Schubart et al. 2008; Parvataneni et al. 2011; Sherwood et al. 2004; Spezeski et al.

2007; Widenheim et al. 2002; Arber et al. 2010; Sherwood et al. 2011; Edvardsson & Ahlström 2008). These information needs are summarised in Table 4.10. This typology of information needs was developed to reflect prominent themes, and is based on the typology developed by Rutten et al. (2005).

TABLE 4.10 TYPOLOGY OF BRAIN TUMOUR PATIENTS' AND CARERS' INFORMATION NEEDS

Category	Specific need	References
diagnosis and tumour information	brain tumours, type, benign/ malignant, slow- or fast-growing, grade, size, location, how long existed, explanation of terminology	(Orabi et al. 2005; Barr 2003; Durity et al. 2000; Lepola et al. 2001)
	relationship of tumour with symptoms	(Durity et al. 2000; Sherwood et al. 2004)
	causes of brain tumours (e.g. is it hereditary)	(Barr 2003; Durity et al. 2000; Lepola et al. 2001)
	diagnostic procedures & their results	(Durity et al. 2000)
prognosis & the future	prognosis and likelihood of recurrence & long-term survivorship	(Salander & Spetz 2002; Lepola et al. 2001; Durity et al. 2000; Spezeski et al. 2007)
	expectations re physical impairments, neuropsychological impairments, practical impacts	(Barr 2003; Schubart et al. 2008; Spezeski et al. 2007)
treatment-related information	treatments options including side-effects, risks, possible benefits & outcomes, statistics on success rates	(Spezeski 2009; Orabi et al. 2005; Rozmovits et al. 2010; Barr 2003; Durity et al. 2000; Halkett et al. 2010)
	actual procedure	(Durity et al. 2000; Rozmovits et al. 2010)
	surgeons' background, reputation and experience	(Rozmovits et al. 2010; Orabi et al. 2005)
	treatment schedule, appointment times, what happens next, department routines	(Salander & Spetz 2002; Arber et al. 2010; Widenheim et al. 2002)
	what happened during the treatment, problems, extent of treatment, why recovery slow or have complications	(Lepola et al. 2001; Rozmovits et al. 2010; Durity et al. 2000)
	expectations for recovery over both the short & long term (e.g. pain control, recovery time, expected abilities & limitations)	(Durity et al. 2000; Spezeski 2009; Lepola et al. 2001; Barr 2003; Rozmovits et al. 2010; Halkett et al. 2010)
	current research into new/ experimental treatments	(Barr 2003; Sherwood et al. 2004)
	diet, herbs and lifestyle changes, holistic treatments	(Barr 2003; Parvataneni et al. 2011; Lepola et al. 2001)

TABLE 4.10 CONTINUED

Category	Specific need	References
social and support needs & services	available support schemes and services, including welfare agencies, disability services, benefits, and how to access	(Janda et al. 2006; Davies 1997; Schubart et al. 2008; Halkett et al. 2010; Arber et al. 2010)
	physical therapy, occupational therapy, palliative care	(Parvataneni et al. 2011; Janda et al. 2006)
	employment issues & return to pre-treatment responsibilities	(Barr 2003; Spezeski 2009)
	information for patients who travelled for care (e.g. accommodation)	(Durity et al. 2000)
symptoms	symptoms to look for and symptom management (e.g. seizures), management of medications (e.g. chemotherapy drugs, anti-emetics, anticonvulsants, corticosteroids)	(Sherwood et al. 2004; Spezeski 2009; Barr 2003; Schubart et al. 2008)
info for carers	information about caring for the patient at home, including how to provide personal care, how to help the patient to recover, information to prepare for long-term care e.g. home-based nursing services, respite care	(Wyness et al. 2002; Janda et al. 2006; Halkett et al. 2010; Arber et al. 2010; Sherwood et al. 2004)
	Managing personality changes and challenging behaviours	(Sherwood et al. 2004; Arber et al. 2010; Spezeski 2009; Halkett et al. 2010; Barr 2003; Schubart et al. 2008)
	how to manage work and caring, how to cope with being a carer	(McConigley et al. 2010; Sherwood et al. 2011)
financial & legal issues	outstanding affairs, arranging for enduring power and wills, possible problems with insurance	(Janda et al. 2006; Sherwood et al. 2004; Schubart et al. 2008)
end of life issues	funeral arrangements, preparing for life after the patient dies, what to expect in the last days and hours	(Sherwood et al. 2004)

How do patients' and carers' information needs differ?

As Table 4.10 shows, some types of information were identified as being more needed by carers than by patients themselves. This may be because patients and carers need information for different reasons. Several studies showed that patients and carers both need information for some similar purposes, such as to cope with the illness, as Lazarus and Folkman's (1984) model of coping suggests, and to maintain a sense of control (Edvardsson & Ahlström 2005; Salander et al. 1999; Rozmovits et al. 2010). Both patients and carers also need information for decision-making and to make plans for the future, and to manage symptoms (e.g. what symptoms to look for, what to do in case of a seizure, and the management of medications) (Sherwood et al. 2004; Arber et al. 2010; Spezeski 2009; Halkett et al. 2010; Barr 2003; Schubart et al. 2008; Edvardsson & Ahlström 2005; Rozmovits et al. 2010). However, carers may need to take independent responsibility for these issues if a patient experiences short-term memory loss or other impairments, increasing their information needs (Sherwood et al. 2004; Arber et al. 2010; Halkett et al. 2010; Spetz et al. 2005).

Six qualitative studies suggested that carers also need three other types of information: information about how to provide personal care to a patient (e.g. how to shower, and toilet a person, and access nursing and respite services); information about how to cope with personality changes and to manage challenging behaviours; and information to meet their own needs, such as how to manage work and caring, and cope with becoming a 'carer' (Wyness et al. 2002; Janda et al. 2006; Halkett et al. 2010; Arber et al. 2010; Sherwood et al. 2004; Schubart et al. 2008).

Some evidence also suggests that carers may be more active information seekers than patients. Strang et al. (2001) found that carers felt a sense of helplessness from 'just standing by'. Schröter et al. (2009) found that, in addition to looking for information for other purposes, 80% of carers reported that they looked for information because they wanted to 'do more'. An audit of calls made and received by a specialist neuro-oncology nurse also showed that carers were more likely to contact the nurse specialist than patients, although the reasons for this were not investigated (Curren 2001). However, carers may have greater difficulty in obtaining information than patients, for example, if information is provided to patients with

memory problems when the carer is not present, or because of health care system requirements which emphasise patients' rights to privacy (Arber et al. 2010). Carers may also try to respect patients' information preferences, such as their desire not to know information about their prognosis, and seek information separately from their care recipients (Salander & Spetz 2002; Spetz et al. 2008).

Information needs early in the disease trajectory

Eighteen studies described the information needs of patients and carers at diagnosis or early in the disease trajectory to some degree (Janda et al. 2006; Rozmovits et al. 2010; Halkett et al. 2010; Schubart et al. 2008; Barr 2003; Widenheim et al. 2002; Molassiotis et al. 2010; O'Donnell 2005; Durity et al. 2000; Arber et al. 2010; Schmer et al. 2008; Keir et al. 2007; McConigley et al. 2010; Lobb et al. 2011; Strang & Strang 2001; Wyness et al. 2002; Edvardsson & Ahlström 2005; Leavitt et al. 1996; Orabi et al. 2005). This period of time was described as a period of immense shock, and the stressful nature of the experience impaired the ability of many patients and carers to process and assimilate information (Molassiotis et al. 2010; O'Donnell 2005; Durity et al. 2000; Lobb et al. 2011; Arber et al. 2010; Schmer et al. 2008). Some patients and carers later recalled that they had not understood the terminal nature of the diagnosis, or believed that they had not been provided information, because of shock and fear (Molassiotis et al. 2010; Durity et al. 2000; Lobb et al. 2011). Some patients and carers thus emphasised the need for written information that they could refer to if they could not remember what was said (O'Donnell 2005; Arber et al. 2010). On the other hand, difficulties with their vision, reading, or processing of written information, meant that written information was not appropriate for some patients (Halkett et al. 2010).

Many patients and carers reported that treatment decisions had to be made quickly, because of the very short time period between diagnosis and surgery (McConigley et al. 2010; Keir et al. 2007). Information was needed to assist in the making of treatment decisions, but could not always be provided because treatment was initiated so quickly after diagnosis (Janda et al. 2006; Strang & Strang 2001). Similarly, detailed prognostic information could not be provided in the

period after biopsy or surgery, until a histopathological diagnosis was made (Halkett et al. 2010; Widenheim et al. 2002).

Predominantly, patients and carers emphasised their desire for detailed information to be provided before treatment, or at least before discharge from hospital (Janda et al. 2006; Wyness et al. 2002; Rozmovits et al. 2010; Schubart et al. 2008). For example, carers in the study by Janda et al. (2006) said that patients should be offered information and advice about settling outstanding affairs and arranging for enduring power and wills should be offered very early in the treatment process, preferably before treatment initiation, because surgery may induce temporary or permanent intellectual disability. Some patients in the study by Wyness et al. (2002) reported that specific, detailed information provided pre-operatively about what would occur post-operatively, promoted confidence in the care they would receive. Rozmovits et al. (2010) reported that for the majority of patients, information needs were greatest after surgery, and that information about recovery was inadequate. Discharge was also particularly important because carers often need to perform specific tasks for the patient at home, for which they require training and support (Schubart et al. 2008). However, improved neurosurgical techniques have led to earlier discharge, such that only minimal support and information can be provided during hospitalisation (Barr 2003; Schubart et al. 2008).

Although information was needed for decision-making, the most prominent information need, emphasised in almost all studies, was information to prepare patients and carers for what was going to happen in the future (Halkett et al. 2010; Rozmovits et al. 2010; McConigley et al. 2010; Schubart et al. 2008; Edvardsson & Ahlström 2005; Janda et al. 2006; Strang & Strang 2001). Both patients and carers emphasised the importance of detailed, practical, individualised information about what to expect and eventualities, including potential symptoms, complications, and neurocognitive changes, before such events occurred (Rozmovits et al. 2010; Schubart et al. 2008; Janda et al. 2006; Halkett et al. 2010).

These studies also suggest that information about symptoms and changes that were not acute or immediately life-threatening, such as fatigue, pain control, medication side-effects, cognitive impairments, and seizure control, was not as well-provided as

information about acute issues (Leavitt et al. 1996; Rozmovits et al. 2010; Janda et al. 2006). This finding was supported by studies by Spezeski et al. (2009) and Sherwood et al. (2004), which showed that it was most difficult for patients and carers to find information about cognitive and neuropsychiatric problems, clinical trials, fatigue, providing day-to-day care and managing side-effects at home.

An additional difficulty with information about emergent issues is that they mostly will not be known at the time of consultations, such that patients and carers do not know 'what to ask' (Schubart et al. 2008). Patients and carers thus want health professionals to proactively provide this information (Janda et al. 2006). However, the need for information to be provided proactively, before changes occurred, must be tempered against the vulnerability of patients and carers at this time, and the need to preserve hope (Rosenblum et al. 2009; Halkett et al. 2010; Widenheim et al. 2002; Orabi et al. 2005; Lobb et al. 2011; Leavitt et al. 1996). While patients and carers wanted to be prepared for the future, they found it difficult to cope when 'too much' information was provided 'too soon' (Halkett et al. 2010). Some patients and carers also reported that 'unwanted' or 'unnecessary' information about 'preparing for the worst' or 'things that might happen' was forced upon them, causing distress and 'taking away' their hope (Widenheim et al. 2002; Orabi et al. 2005; Lobb et al. 2011).

How to provide accurate, realistic, proactive information to patients and carers without removing hope was not clear. Some patients and carers suggested that information be provided in incremental doses, and that positive factors be highlighted (Widenheim et al. 2002; Rosenblum et al. 2009; Lobb et al. 2011). The most detailed description of how to provide such information was tendered by Rosenblum and colleagues (2009), who reported that most patients wanted to know the typical survival (e.g. median survival), something about the bad things that could happen (e.g. side effects or recurrence), and plenty of examples of how things could go well (e.g. long term survival, remission, experimental treatments). However, whether patients and carers provided with prognostic information following this formula are any better informed has yet to be studied. Furthermore, how to proactively address other information needs has not been examined.

4.3.4. INTERVENTION STUDIES

Five evaluation studies of interventions (described in seven papers) were identified that met the review criteria, shown in Table 4.11 (Delaney et al. 2009; Byrne et al. 2007; Cashman et al. 2007; Rabow et al. 2010; Pan et al. 2002). One of these evaluations (Pan et al. 2002) was described only in an abstract form, so was excluded from this discussion. Of the remaining four studies, one targeted health professionals (Rabow et al. 2010), and three targeted patients and/or carers (Delaney et al. 2009; Byrne et al. 2007; Cashman et al. 2007).

4.3.4.1. SAMPLE SIZE AND PARTICIPANTS

All of the interventions targeted only patients with primary brain tumours, and/or their carers, or health professionals treating such patients. One intervention restricted sampling to high grade glioma patients (Delaney et al. 2009), and another to patients with grade II-IV glioma and their carers (Byrne et al. 2007). The other two studies targeted carers (Cashman et al. 2007) and health professionals (Rabow et al. 2010) respectively, regardless of the tumour type of the patients for whom they cared. All samples were non-random or self-selected.

Sample sizes ranged from 11-28 for studies with patients and/or carers (Delaney et al. 2009; Cashman et al. 2007; Byrne et al. 2007), and 61 health professionals participated in the intervention for which they were targeted. Only one study (Cashman et al. 2007) reported that the sample size was based upon power calculations. Twenty-four carers participated and 21 were needed to detect a difference of five correct test answers at a statistically significant level. Another study (Rabow et al. 2010) reported 'significant' changes based upon statistical significance; although the contextual significance of changes or power calculations were not reported.

TABLE 4.11 INTERVENTIONS TO IMPROVE INFORMATION PROVISION FOR PRIMARY BRAIN TUMOUR PATIENTS AND/OR THEIR CARERS

Study	Intervention	Sample	Design & follow-up	Outcomes	Comments
Pan et al. (2002), Canada	Five patient education support programs offered: brain tumour support groups, relaxation therapy, art therapy, resource library, OIES software on brain tumours.	28 brain tumour patients.	Retrospective, single group, structured interview/ questionnaire.	Mean overall satisfaction ratings (5=fully satisfied): brain tumour support groups 4.5, relaxation therapy 4.0, art therapy 4.9, resource library 4.0, OIES software 3.5.	Abstract only, inadequate data supplied to assess quality of methodology.
Byrne et al. (2007), Cher et al. (2009) & Matthews et al. (2009), Australia	Patient-held record (PHR) with awareness raising activities (posters, advertisements, letters).	11 patients & 8 carers provided PHR. GPs of 2 patients saw PHR.	Retrospective, single group (patients/ carers, GPs), written questionnaire.	10 patients/carers took booklet to all/nearly all visits. 13/18 agreed booklet improved communication: between self & clinician, 7/15 between clinicians. GPs thought PHR could be helpful if updated regularly & taken to every visit.	Pilot study. No questions validated. Self-selection of participants. Timing of provision of booklet varied & influenced results.
Cashman et al. (2007), Canada	Educational program held on 2 consecutive half-days on hospital campus, free & cost of parking covered.	24 carers of patients with a malignant glioma.	Prospective, single group, 3 written surveys (pre-test prior to program, post1 at end of program session, post2 4-6 weeks later).	Mean correct % knowledge scores sig. increased from pre-test to post1 ($p<0.05$) & remained sig. higher at post2 than baseline ($p<0.05$), despite decreasing from post1.	Sample size of 21 needed to see statistically significant different of 5 correct knowledge answers pre- to post-test. Measures not validated.

TABLE 4.11 CONTINUED

Study	Intervention	Sample	Design & follow-up	Outcomes	Comments
Delaney et al. (2009), Canada	Integration of pharmacist into neuro-oncology clinic, included initial visit & 2 follow-up calls (D1: next day, D5: 5 days after the start of treatment), designated point of contact for drug-related questions outside clinic hours.	11 of 13 newly diagnosed high grade glioma patients scheduled for chemotherapy & radiotherapy. 11 of 13 clinicians in team.	Prospective, single group, 1 survey by patients at end of study, 1 survey by clinicians; pharmacist logged all tasks or interactions performed.	Patients: 100% received useful information, 80% had additional drug-related questions answered by pharmacist to their satisfaction. Staff: 90% believed pharmacist available to answer drug-related questions. Most patient interaction between D1 & D5.	Feasibility study. Selection of sample size & validity of surveys not known.
Rabow et al. (2010), US	Screening of 48 minute documentary film 'The Caregivers' developed to reflect themes of focus groups & evidence.	61 health professionals in neuro-oncology.	Prospective, single group, 2 survey (pre-test prior & post-test after screening).	Changes pre- to post-viewing: more likely to agree "family caregivers greatly impact the health of patients", less likely to agree "supporting family caregivers is primarily someone else's job".	Quoted statistical significance, sample size not based on calculations.

Numerical inconsistencies reflect missing data, GP: general practitioner, OIES: Oncology Interactive Education Series, sig.: significantly

4.3.4.2. Intervention Types

The interventions implemented differed significantly, but all were evidence-based. Rabow and colleagues (2010) described the development and evaluation of a documentary film to educate health professionals regarding the needs and experiences of family carers of brain tumour patients. The contents of the film were based on themes identified in focus groups with the target population and carers of brain tumour patients. An Australian team (Byrne et al. 2007) developed and implemented a patient-held record (PHR) following a review of the literature. Based upon the results of this review, techniques such as posters and verbal and written instructions were implemented to increase awareness of the PHR and promote its use. The educational program for carers described by Cashman and colleagues (2007) was based on an earlier needs assessment, identifying aspects such the most appropriate format and location for the program, and the information most important to carers.

The integration of a pharmacist into a neuro-oncology clinic (Delaney et al. 2009) was perhaps the least evidence-based, having never previously been described. However, this intervention was chosen to meet an identified need (in this case, to meet the drug information needs of patients receiving chemotherapy and radiotherapy, and neuro-oncology staff), and pharmacists have the appropriate skill sets for such a role. In addition, the study described was a feasibility study, aiming to determine if the intervention was appropriate for the setting and needs of the target population.

Two interventions were short-term, involving a single session for the documentary film (Rabow et al. 2010), and two half-days for the educational program (Cashman et al. 2007). The integration of a pharmacist into a neuro-oncology clinic was perhaps the most intensive; it involved patients seeing the pharmacist an average of nine times (range 4-17) over a median of 30 days (range not supplied) (Delaney et al. 2009). The PHR was evaluated over the longest period, with patients asked to participate in the evaluation when provided with the PHR, then contacted to complete questionnaires at least five months later (Byrne et al. 2007).

4.3.4.3. Study Design

All studies involved a single group design without a control group. The PHR study collected data at one time point only (Byrne et al. 2007), while the pharmacist study surveyed patients at one time point, but logged all tasks and contacts over the study period (Delaney et al. 2009). Both the study of the documentary film for health professionals (Rabow et al. 2010) and study of the educational program for carers (Cashman et al. 2007) conducted pre- and post-intervention assessments. The latter study also involved conducting a second follow-up assessment with attending carers, to determine if improvements in knowledge persisted over time (Cashman et al. 2007).

4.3.4.4. Outcomes Assessed

Although the outcomes and measures used to assess each outcome varied across studies, positive outcomes were observed for all studies. The carers' educational program was evaluated primarily on improvements in knowledge, which were observed (Cashman et al. 2007). The PHR was evaluated with reference to participants' 'knowledge of its purpose', 'frequency of use', and 'perceived effects on communication' (Byrne et al. 2007). Perceived improvements in communication both between participants and health professionals, and between health professionals, were reported. Although only two GPs who had seen the PHR responded, their inclusion allowed study investigators to identify barriers to the use of the PHR, such as health professionals' lack of awareness of this resource.

The pharmacist study similarly sought the views of health professionals and patients, and collected data regarding the pharmacist's activities (Delaney et al. 2009). Patient indicators included 'the belief that one had received useful information', 'had questions related to medications answered satisfactorily', and that 'the pharmacist was useful to them'. Members of the neuro-oncology team answered questions regarding 'perceived efficiency', 'usefulness', and availability to 'answer drug-related questions'. Both patients and health professionals responded positively to these questions. Data regarding the number and timing of pharmacist contacts were prospectively collected, allowing the identification of timing issues (Delaney et al. 2009).

In contrast to the other studies, evaluation of the documentary film involved only health professionals, and included assessment of only one type of outcome, health professionals' attitudes towards family carers (Rabow et al. 2010). Of the seven attitude questions, 'significant' changes were reported in three between pre- and post-test.

4.3.4.5. Limitations of Studies

Although positive perceptions of interventions were reported, a number of factors limit the reliability of these findings. Study participants were not randomly selected, and may have attracted persons interested in the topic, or those with the capacity to respond to the intervention. Persons who most needed the interventions, such as patients or carers from different cultural backgrounds who experienced language or cultural barriers, or health professionals with entrenched attitudes towards family carers, may not have participated.

All interventions were evidence-based, and two studies (Byrne et al. 2007; Delaney et al. 2009) were conducted to inform future research. Three of the four studies reported assessment of implementation issues, such as awareness-raising for the PHR (Byrne et al. 2007), the 'identification of appropriate location, timing, and barriers to attendance', for the education program (Cashman et al. 2007), and analysis of 'the timing of patients' interactions with the pharmacist', to identify the most appropriate times for planned interactions (Delaney et al. 2009).

No studies investigated if the effects of the interventions were associated with other variables such as the tumour type, perhaps due to the small sample sizes. However, Rabow and colleagues (2010) reported differences in the attitudes of participants from different health professional groups at baseline. Qualitative responses regarding the timing of provision of the PHR also suggested that this may have influenced its use and benefit (Byrne et al. 2007).

All of the interventions were evaluated using questions developed for the purposes of the study, and the validity of study instruments was not reported. As described by Cashman and colleagues (2007), participants may have overstated the positive effects of an intervention because of a desire to please the health professionals who provided care for their relatives.

Overall, the studies reported represent a small portion of the types of interventions tested with other cancer groups (see Chapter 1). These studies suggest that the interventions may have the potential to improve outcomes, but only the educational program for carers had the methodological quality to show improvements, which were shown in knowledge (Cashman et al. 2007). Whilst knowledge is one aspect of information, further research is needed to determine if the knowledge gained was useful to participants, and if it met their needs. For the other interventions reviewed, further research is required using longitudinal study designs.

4.4. SYNTHESIS OF INFORMATION NEEDS AND INTERVENTIONS

This review brings together the evidence for information provision for all primary brain tumour patients, focusing on the needs of patients and carers early in the disease journey. Relatively few high-quality studies were identified by this review. Most quantitative studies were cross-sectional and had small sample sizes. This is likely due to the practical and ethical challenges of conducting longitudinal research with patients who can have physical, cognitive and neuropsychological impairments, and carers who experience significant burdens. More qualitative studies were identified, some of which followed patients and carers from diagnosis through to death; however, many studies reported information needs only as a peripheral aspect of the experience of patients and carers. The information needs of patients and carers early in the disease trajectory were mostly identified retrospectively, likely to be influenced by recall bias. Prospective assessment of information needs may be required to determine if these findings are valid. However, the identification of common themes across studies suggests that the findings are reliable.

Overall, this review shows that information needs are not sufficiently met for a significant proportion of patients and carers. Although differences in the measurement of need and the types of need assessed across studies limit quantitative conclusions, three studies showed that between 30 and 60 percent of patients and carers had unmet information needs (Lidstone et al. 2003; Parvataneni et al. 2011; Janda et al. 2008). As shown for cancer patients and carers more

generally in Chapter 3, these needs go beyond the narrow 'disease' focus of modern medicine, and include social, financial, and support needs (Edvardsson & Ahlström 2008).

This review also shows that brain tumour patients and their carers have information needs specific to brain tumours. As described in Table 3.2, common information needs of cancer patients include: the extent of the disease, likelihood of cure and prognosis, effect of treatment on social activities, effect on family and friends, self-care and return to normal lifestyle, psychological effects of treatment, types of treatment available and the advantages and disadvantages of each, risks of other family members getting cancer, and side effects of treatment (Degner et al. 1989; Luker et al. 1996). In contrast to patients with other cancers, many brain tumour patients face the uncertainty of progressive disease, and potential impairments to their physical, cognitive, and neuropsychological function, including their personality and behaviour. Compared to patients in the general cancer population, brain tumour patients may be more likely to need information about potential or actual physical, cognitive, or neuropsychological impairments, and the management of symptoms such as seizures (Schubart et al. 2008; Spezeski 2009). Because of the high morbidity and mortality associated with brain tumours, patients may be more likely to need information about social and support services, financial and legal issues, and end of life care (Janda et al. 2006). Carers of brain tumour patients may also be more likely to need information about caring for the patient at home, assisting the patient to recover, or preparing for long-term care (Arber et al. 2010; Sherwood et al. 2011).

Early in their disease trajectory, patients and carers want information to be provided to them proactively about what to expect, and what their future holds. Accurate information is needed so that patients and carers can hold realistic expectations and plan for future events. However, information needs to be provided in a way that allows patients and carers to hold hope for the future. From the current research, it is unclear how information can be provided to meet these disparate needs, particularly as the time between diagnosis and treatments or emergent impairments may be very limited.

Research is also needed to bridge the gap between information needs and information provision. Although information needs are subjective and should be based on the perceptions of patients and carers, the process of information provision involves a source (the health professional) and receiver (the patient and/or carer), as described in Chapter 1. Evidence exists for the unmet information needs of patients and carers, but not for how health professionals perceive their provision of information, and the barriers they experience in meeting patients' and carers' information needs.

Overall, very few intervention evaluations targeted at brain tumour patients and/or carers were identified. The paucity of the literature may reflect the dominant focus on descriptive and hypothesis-testing studies rather than interventional studies in behavioural research in quality of life and cancer (Lewis 1997). It is also likely to reflect the historical focus of neuro-oncology research on survival rather than quality of life outcomes (Whittle 1999). While it is hoped that improving information provision will have 'flow-on' effects on outcomes such as coping or QOL, assessment of these outcomes alone is not sufficient to determine if interventions improve information provision.

4.4.1. CONCLUSIONS

Overall, this review confirms the findings of the systematic review by Davies et al. (2003) that there is no 'gold standard' for providing information to patients with brain tumours and their carers. Health professionals face the challenge of providing 'sufficient', realistic, tailored information to patients and carers without taking away hope (Rosenblum et al. 2009). A proactive approach to address information needs before difficulties arise seems essential to increase the 'manageability' of issues, and patient's and carers' feelings of control (Janda et al. 2006). Further research is now needed to develop and evaluate targeted interventions specific to the emergent information needs of brain tumour patients and their carers.

5. METHODOLOGY

5.1. INTRODUCTION

This research program used a mixed methods research approach. The mixing of qualitative and quantitative methods has been criticised by some as being simply the fusion of the outputs of qualitative and quantitative techniques (Bryman 2007). However, when appropriately applied, the two approaches can offer different types of data to answer a research question, and provide a fuller and more complete understanding (Ritchie 2003).

Quantitative approaches can be used to measure and investigate relationships between constructs, while qualitative approaches can explore influences not amenable to more structured methods (Greene 2008). Use of the mixed-methods approach allows both quantification of outcomes and investigation of the processes by which the outcomes are achieved. It is thus expected that a combination of qualitative and quantitative approaches may provide a greater understanding and insight into research problems than either approach could alone (Creswell & Plano Clark 2007).

This chapter outlines the methodology selected to address each of the research questions of this thesis, and elaborates on the considerations that underpin the current research. As such, the chapter includes details of the methodological approach, the particular mixed methods approach used and how these methods best answer the research questions, and how rigour was achieved.

5.2. METHODOLOGICAL APPROACH

Historically, quantitative and qualitative approaches have been seen as diametrically opposed. Quantitative research is based on a positivist ontology, in which researchers are trying to discover natural laws and uncover the pre-existing (social) reality (Bergman 2008). Under this paradigm, only observable phenomena can be counted as knowledge, and scientific theories are tested empirically to see if they are supported (Snape & Spencer 2003). In particular, science is seen as value-free, in that values have no place or influence on objective 'facts' (Fossey et al. 2002). In contrast, qualitative research is traditionally based on an understanding of

reality as a social construction, and it is acknowledged as one or more realities that are subjectively interpreted and influenced by values (Fossey et al. 2002). This paradigm assumes that knowledge does not exist independently of human interpretation, and thus that many realities or constructions are possible (Ezzy 2002; Polit & Beck 2004).

The contrast between these viewpoints led to the positing of the 'incompatibility thesis', which holds that differences in the paradigms underlying qualitative and quantitative methods prevent the combination of these methods (Teddlie & Tashakkori 2003). Under this view, differences in concepts such as fact or truth, or the relationship between the investigator and the object of research, are so profound that research methods utilising these paradigms cannot be mixed (Howe 1988). As Guba (1987, p. 31) stated, adopting one paradigm precludes using another "just as surely as the belief in a round world precludes belief in a flat one".

However, the 'incompatibility thesis' has been largely overcome by both the reality that mixed methods research has been successfully conducted for many years, and by the emergence of the 'compatibility thesis' and 'pragmatism paradigm' (Teddlie & Tashakkori 2003; Howe 1988). In contrast to the 'incompatibility thesis', the 'compatibility thesis' holds that quantitative and qualitative methods *are* compatible, and that the 'purity' of qualitative and quantitative methods is overstated (Bergman 2008).

The philosophical divide between qualitative and quantitative research has been argued to have arisen from increased specialisation of disciplines, whereby researchers in a field become accustomed to and uncritical of their own methods and assumptions, and sceptical of those used by others (Hulme & Toye 2006). In addition, quantitative methods, previously seen as objective, have also been recognised to be influenced by values and thus not different in nature to qualitative research. For example, values influence the research question that is asked, the decision of a funding body to fund a study, the choice of research method within the quantitative paradigm, and the synthesis and generalisation of research findings (Bowling 2002; Johnson & Onwuegbuzie 2004).

As Bergman (2008) highlights, qualitative and quantitative methods represent overlapping families of methods, such that is it difficult to clearly distinguish the characteristics of one from that of the other. Recognition of the compatibility of methods and indeed to their complementarity (that is, that the use of more than one research paradigm allows a more complete understanding of the world), has led to the rise of 'methodological pragmatism' (Fielding 2008).

A pragmatic perspective allows the mixing of methods as needed to answer the research questions, embracing the "dictatorship of the research question" (Teddlie & Tashakkori 2003, p. 21). That is, the research question is more important than either the method or paradigm underlying the method (Teddlie & Tashakkori 2003). This perspective allows for multiple perspectives, avoiding the use of metaphysical concepts such as truth and reality, and sees inconsistencies between research findings obtained using different methods as opportunities for further exploration and thus improved understanding (Patton 2002).

5.3. MIXED METHODS USED IN THIS THESIS

There is still much debate on how to define 'mixed methods', with the term covering an umbrella of approaches (Bazeley 2004). This section clarifies the purpose for the use of mixed methods in this research and the specific 'mixing' of methods that occurs in this thesis.

One commonly used way of categorising mixed methods research is using Greene et al.'s framework (1989; 1997). This framework was initially generated from a theoretical review of 57 mixed-method evaluation studies and included five purposes (1989). This framework (Table 5.1) has been widely used to explain the use of mixed methods and show how mixed methods were used to achieve the research goals (Tashakkori & Teddlie 2008).

TABLE 5.1 FRAMEWORK FOR CATEGORISING MIXED METHODS RESEARCH BY PURPOSE

Purpose	Description
Triangulation	Seeks convergence or confirmation of results from different methods to increase the validity of constructs and results and to minimise bias inherent to specific methods. *For example, if results from qualitative and quantitative methods are similar, the 'truth' of the results is confirmed.*
Complementarity	Seeks clarification of results from one method by use of another method, to increase the meaningfulness and interpretability of results. *For example, qualitative methods are used to elaborate on or further explain quantitative results.*
Development	Results from one method are used to develop a second method, to increase the validity of results by using the specific strengths of specific methods. *For example, results from qualitative methods are used to inform the choice of measures used in a later quantitative study.*
Initiation	Seeks contradiction or new perspectives, to allow analysis of results from different perspectives or paradigms and thus increase the breadth and depth of the research. *For example, the research question may be re-framed based on contradictions found between results using different methods.*
Expansion	Seeks to increase the range of research questions that can be answered by choosing the most appropriate methods for each component of the research *For example, qualitative methods are used to answer questions best answered using these methods such as those requiring richness and thick understanding, and quantitative methods are used for method-appropriate research questions such as those requiring quantification of difference between groups.*

Sources: Greene et al. (1989), Caracelli and Green (1993), Teddlie and Tashakkori (2003), Onwuegbuzie and Leech (2004) and Tashakkori and Teddlie (2008)

Although other frameworks have also been developed (e.g. that of Tashakkori and Teddlie (2008)), Greene et al.'s framework (1989; 1997) provides a clear explanation of why mixed methods have been chosen in this research. As described in Chapter 1, this research project had three main aims: 1) to describe how health

professionals conceptualise information provision for brain tumour patients and thus identify an appropriate intervention to develop for these patients; 2) to systematically develop said intervention; and 3) to test the feasibility and acceptability of the intervention and its implementation/evaluation requirements. Each aim of this research project has been addressed in a separate, successive research phase, using the methods most appropriate to address the aim. As such, this research as a whole used mixed methods for **expansion**, in that each research aim was addressed using methods most appropriate to meet that aim. A variety of methods were also used within each research phase to best meet the research aims, again showing expansion.

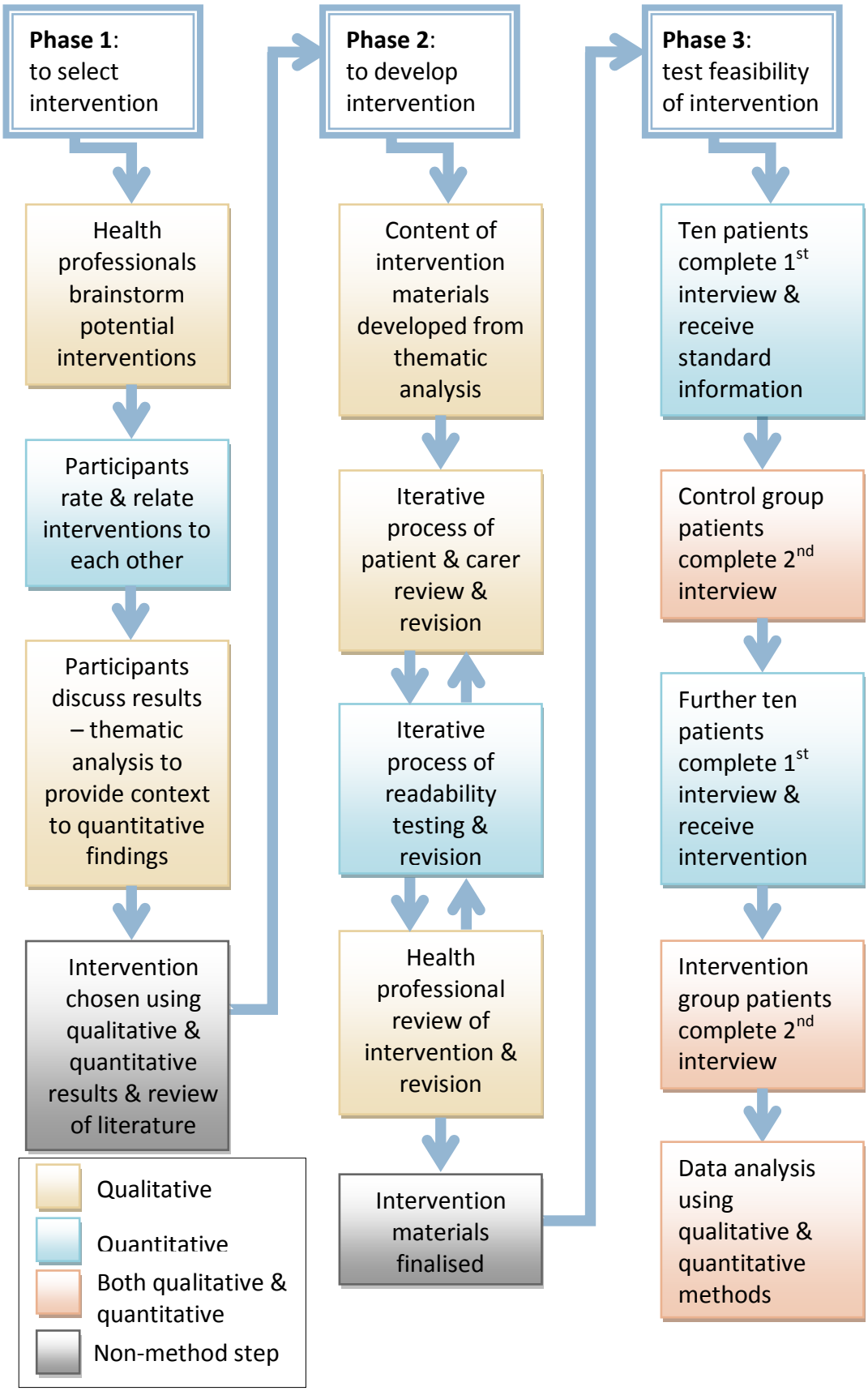


FIGURE 5.1 RESEARCH PROCESS FLOWCHART

As Figure 5.1 shows, Phase 1 of this research used both qualitative and quantitative methods. In this research phase, results from quantitative results were presented to participants for feedback and discussion, and thematic analysis conducted of the ensuing discussion transcripts. This **complementarity**, or use of results from one method to seek clarification of results from another method, allowed a more complete picture of information provision in the brain tumour setting to be obtained, and facilitated the choice on an appropriate and clinically acceptable intervention to be developed in Phase 2.

While the multiple mixing of methods within and between phases fits within the Green et al. model, it does not lend itself well to other classifications of mixed methods. However, Creswell's categorisation of mixed methods studies, based on whether quantitative and qualitative methods are used sequentially or concurrently, as well as the purpose of the mixing, most closely matches this study's methodological direction. In Creswell's system, there are three main types of mixed methods studies: 'sequential' (qualitative phase followed by quantitative, or vice versa, with separate analysis of each followed by overall interpretation), 'concurrent' (qualitative and quantitative methods applied to triangulate data in a single study), and 'transformative' (qualitative and quantitative data collected sequentially or concurrently, but with the study guided by a commitment to one theoretical perspective) (Creswell & Plano Clark 2007; Creswell et al. 2003).

Although this study consists of more than two research phases, it is, in essence, 'sequential', as distinct research phases with separate analyses are conducted, followed by an overall interpretation. This classification may also be seen by its inability to fit within Creswell's other categories: the study lacks the intent to triangulate and such cannot be truly classified as 'concurrent', and the commitment to a single theoretical perspective to be classified as 'transformative'. In this study, qualitative and quantitative approaches are used independently, and decisions are directed by the aims of the research, rather than by any overarching methodological or theoretical framework.

5.4. RIGOUR

One of the fundamental advantages of mixed methods research is that it allows a more complete picture of a topic to be generated. The techniques used to ensure the credibility of research differ between qualitative and quantitative research, however. For example, in qualitative research, techniques to ensure rigour may include remaining conscious of one's own biases with which one approaches the research, or in thematic analysis, two coders independently coding data and reviewing differences in coding to reach a joint agreed coding standard. In contrast, quantitative research may require the use of established statistical techniques, appropriate to the research question, such as the Fisher and Neyman-Pearson approaches to hypothesis testing (Lehmann 1993). Ultimately however, for any research design, rigour refers to the trustworthiness of the research, which is achieved via systematic and self-conscious research design, data collection, interpretation and communication (Mays & Pope 1995).

Six types of rigour can be considered:

1) theoretical rigour: consistency between the research strategy, including the research aims and methods, and the goal or purpose of the research;

2) methodological or procedural rigour: clear documentation of methodological and analytical decisions, designed to avoid overgeneralisation and enhance credibility;

3) interpretive rigour: gained when the interpretation accurately represents the understanding of participants and data;

4) triangulation: an external validation technique which assumes that greater clarity and precision can be gained through the inclusion of multiple information sources, researchers, theories and/or methods

5) evaluative rigour: requires consideration of the ethical and political aspects of research; and

6) rigorous reflexivity: examines the role of the researcher in the research (Liamputtong & Ezzy 2005; Lewis & Ritchie 2003).

These types of rigour are applicable to both qualitative and quantitative research (Dubois & Loiselle 2009; Moffatt et al. 2006; Tobin & Begley 2004), although the techniques may differ depending on the aim of the research and the approach taken. For mixed methods research, rigour is achieved when appropriate techniques are applied, and there is clear understanding of how and why qualitative and quantitative techniques are mixed (as described in section 5.3). In this thesis, each of these six types of rigour is considered and the strategies used to achieve them are described throughout subsequent chapters.

5.5. CHAPTER SUMMARY

This thesis used mixed methods, taking a pragmatic approach to allow the choosing of the research methods most appropriate to answer the research questions. The main purposes of mixing methods in this study, as defined by Greene et al.'s framework (1989; 1997) were expansion and complementarity, and research methods were mixed using a sequential method, according to Creswell's classification (2007; 2003). Rigour, or the trustworthiness of the research, was considered separately for each of the three research studies that together answer the research questions of this thesis. Rigour was also achieved via transparency and explanation of the mixing of each of the research techniques.

6. STUDY 1: EXPLORATION OF POTENTIAL INTERVENTIONS

6.1. INTRODUCTION

The review of the literature (Chapters 1-4) showed that adults with brain tumours have unmet information needs, and that meeting these needs may reduce uncertainty and distress and facilitate psychological adjustment. The level of unmet information need of cancer patients is determined by a number of factors, such as patients' demographics, their expectations and desire to participate in decision-making, and health professionals' communication skills and style. Brain tumour patients in particular experience additional challenges in seeking, obtaining and understanding information because of physical, cognitive and communication impairments. Together, this suggests that adult brain tumour patients may benefit from interventions to improve information provision and/or health professional-patient communication.

Evidence suggests that for interventions to be successful, researchers must take the social environment and practical limitations into account (Hoving et al. 2010). Previous research has shown that cancer patients predominantly nominate their doctor(s) as their preferred source(s) of information (Mills & Sullivan 1999), and this has also been shown for brain tumour patients (Schubart et al. 2008). Educational roles are also increasingly being undertaken by nurses and other allied health professionals (Hoving et al. 2010). Consequently, the views of doctors, nurses and other health professionals are likely to be instrumental in determining the success of an intervention. This research phase thus aimed to canvas the views of relevant health professionals to identify an appropriate and clinically and socially acceptable intervention to improve information provision.

6.1.1. CHAPTER ORGANISATION

This chapter presents the methods, results and conclusions of a structured group concept mapping study undertaken to identify an appropriate informational intervention for adults with brain tumours. The methods section describes the aims of concept mapping, recruitment of study participants, and procedures for data collection and analysis. Results of each of the data collection activities are

presented, with graphical displays used to facilitate understanding. To conclude, the strengths and limitations of this research, comparison with other studies, and relevance for intervention development in the neuro-oncology setting are presented.

6.2. METHODS

A structured concept mapping technique developed by Trochim (Shern et al. 1995) was used. This type of concept mapping is a participatory mixed methods approach that integrates qualitative and quantitative research methods to explore systems and organisations. It is designed to allow stakeholders to identify key elements or ideas and the relationships between them, and integrate this data using multivariate analyses (Johnsen et al. 2000). Results of these analyses are depicted visually as 'maps' that can be used as aids to facilitate the discussion of concepts (Trochim 1989). Concept mapping has been previously used in health research to understand stakeholder perceptions (Biegel et al. 1997; Lebel et al. 2011); identify appropriate intervention strategies (Ridings et al. 2011); and plan and/or evaluate programs (Galvin 1989; Poole et al. 2006).

This methodology was chosen for three reasons. Firstly, a participatory approach was desired to facilitate relationship-building with neuro-oncology health professionals. Commitment to the research process as a whole was desired both to identify facilitators and barriers to information provision in the neuro-oncology setting, and to encourage involvement in future research phases. Secondly, as described in Chapter 5, mixing of qualitative and quantitative methods allows greater interpretability and usefulness of results than either method could alone. This approach was chosen because it generates quantitative data that is then investigated for meaning by participants qualitatively. The third reason concept mapping was chosen was because it allows exploration of the relationship between concepts in a system (Sutherland & Katz 2005). Information provision is only one of many responsibilities of health professionals, and may 'compete' with other priorities (Hoving et al. 2010). Understanding how health professionals view information provision requires understanding of its role in relation to other clinical and psychosocial responsibilities. Together, these features of concept mapping

enabled the collection and interpretation of data needed to identify and evaluate information provision strategies, and to describe influences on information exchange in the neuro-oncology setting. In this way, concept mapping was an ideal vehicle for addressing the research question.

6.2.1. ETHICAL APPROVALS

This study received approval from the Human Research Ethics Committees (HRECs) of the Queensland University of Technology (QUT, approval number 0700000585), and UnitingCare Health (for the Wesley Hospital and St Andrew's War Memorial Hospital, reference 2007/56, see Appendix B).

6.2.2. PARTICIPANT RECRUITMENT AND SAMPLING

Health professionals with experience in the neuro-oncology setting including nurses, social workers, neurosurgeons, oncologists and allied health workers, from the hospital and community settings, were invited to participate in this research. Sampling was purposive, aiming for diversity in health professionals' roles and settings (public or private hospitals or health services, community settings). Several methods were used to recruit new participants: 1) word of mouth; 2) presentation of the proposed research at a glioma conference; 3) presentations about the research at St Andrew's War Memorial Hospital and The Wesley Hospital; and 4) snowball sampling, in which participants were asked to nominate other potential participants (see Appendix C for recruitment documents).

Interested health professionals or those nominated for participation were provided (in person, by post, or by email) a letter inviting their participation, accompanied with participant information and consent documents. All potential participants were followed up by mail, email or telephone one week later. Return of a signed participant consent form was required prior to participation.

Broad inclusion criteria were used, requiring only that a participant be: 1) adult aged 18+ years; and 2) a health professional involved in the treatment, support or care of persons with brain tumours. Overall, 45 health professionals were approached and 30 (67%) participated in at least one data collection activity.

6.2.3. DATA COLLECTION AND ANALYSIS

Following the concept mapping methodology, this research involved three predefined data collection steps, each with associated analysis, as shown in Figure 6.1.

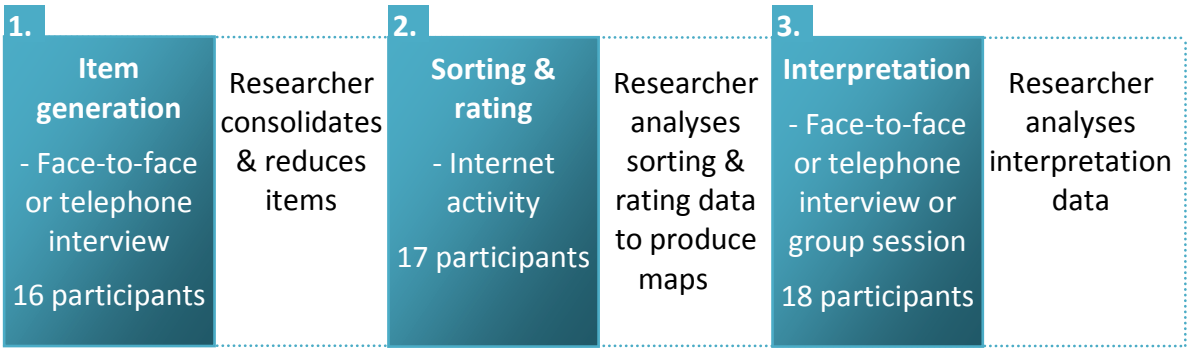


FIGURE 6.1 DATA COLLECTION AND ANALYSIS STEPS IN CONCEPT MAPPING

As the above diagram shows, the first and second data collection steps were conducted individually: the first together with the researcher (in face-to-face or telephone interviews), and the second via the internet. The third data collection step was conducted by the researcher with small groups or, where group sessions were not possible (for example, because of geography), with individuals.

6.2.3.1. PROCEDURAL ELEMENTS

Data collection took place from September 2007 to April 2008. All participants completed a brief questionnaire (see Appendix E; results reported in Table 6.1) to allow description of the characteristics of the sample. Data collection activities undertaken face-to-face or by telephone with the researcher were audio-taped with consent.

6.2.3.2. PARTICIPANTS

As recommended by Trochim and Kane (2005), participants in the first and/or second data collection steps were invited to participate in subsequent steps, to allow them to confirm or dispute the interpretation. However, not all participants were available for each step; different numbers of participants thus participated in each data collection step. The characteristics of participants overall, and in each data collection step, are shown in Table 6.1.

Overall, participants were most commonly female (87%), nurses (67%), and worked in the hospital setting (73%). Participants had spent a median of ten years (range 1-35 years) working with this patient group, and had cared for a median of 25 patients (range 0-135) in the previous year.

TABLE 6.1 CHARACTERISTICS OF PARTICIPANTS INVOLVED IN CONCEPT MAPPING: OVERALL AND IN EACH DATA COLLECTION ACTIVITY

	Overall (n=30)		**Item generation (n=16)**		**Sorting & rating (n=17)**		**Interpretation (n=18)**	
	n	%	n	(%)	n	(%)	n	(%)
Sex								
male	4	(13.3)	3	(18.8)	3	(17.6)	3	(16.7)
female	26	(86.7)	13	(81.2)	14	(82.4)	15	(83.3)
Profession								
nurse	20	(66.7)	8	(50.0)	10	(58.8)	10	(55.6)
social worker	3	(10.0)	3	(18.8)	2	(11.8)	3	(16.7)
support/advocacy group	2	(6.7)	2	(12.5)	2	(11.8)	1	(5.6)
neurosurgeon	1	(3.3)	1	(6.3)	1	(5.9)	1	(5.6)
radiation oncologist	1	(3.3)	1	(6.3)	1	(5.9)	0	-
general practitioner	1	(3.3)	0	-	0	-	1	(5.6)
other	2	(6.7)	1	(6.3)	1	(5.9)	2	(11.1)
Work setting								
public hospital only	9	(30.0)	6	(37.5)	7	(41.2)	3	(16.7)
private hospital only	10	(33.3)	0	-	0	-	10	(55.6)
both public & private hospital	2	(6.7)	2	(12.5)	2	(11.8)	1	(5.6)
private practice & hospital	1	(3.3)	1	(6.3)	1	(5.9)	1	(5.6)
area health service	2	(6.7)	1	(6.3)	1	(5.9)	0	-
nonprofit organisation	6	(20.0)	6	(37.5)	6	(35.3)	3	(16.7)

6.2.3.3. ITEM GENERATION

The aim of the first data collection step was to obtain a list of items (interventions, actions, resources or services) that health professionals thought could improve care of adults with primary brain tumours. In telephone interviews lasting 30-60 minutes, each of the 16 health professionals (53% of the 30 participants) who participated in this step responded to the following prompt: "I think a patient newly diagnosed with a brain tumour needs..." This prompt was selected to stimulate a comprehensive discussion of factors which influence information provision. Each participant could make as many responses to this prompt as warranted. Using participants' own words as much as possible, responses were compiled in a list.

This list was supplemented with brain tumour patients' and carers' suggestions, drawn from transcripts of focus groups and interviews of an earlier qualitative study. In that study, 18 brain tumour patients and 18 carers identified their unmet supportive care needs, including information needs (Janda et al. 2006).

The process generated a total of 649 items (including duplicates). Items were edited to correct grammar and provide consistent terminology without jargon. Reduction of items was conducted by the researcher as no more than 100 items (target 50 items for reasonable participant burden) can be used in concept mapping (Trochim 1989). Shown in Appendix D, reduction of items followed the principles outlined by Trochim and Linton (1986): 1) duplicate statements or obvious redundancies were removed (e.g. 'to provide a central contact point to help tie everything together' was similar to 'provide a central point of contract for patients'); 2) similar items (e.g. all items that referenced *distress*) were examined together to help identify nuances of meaning, and items selected on the basis of clarity and brevity; and 3) a random selection was made of items dissimilar to others. A final list of 42 items was generated, and numbered for use in the next step.

6.2.3.4. SORTING AND RATING

In this data collection step, health professionals individually sorted and rated the 42 items generated in the previous step, via a project internet site using usernames and passwords supplied by the researcher (see Appendix E for data collection

materials). Seventeen of the 30 participants (57%) participated in 'sorting and rating'.

Participants sorted the 42 items into categories following five instructions:

1) sort the items according to how similar they are, in a way that makes sense to you;
2) do not sort according to how important or feasible they are;
3) each item can only be placed in one category;
4) all items cannot be placed in the one category; and
5) each item cannot be placed into their own category.

Participants then rated each of the 42 items on a five-point Likert scale ranging from 1 (not at all) to 5 (extremely/fully) on three dimensions:

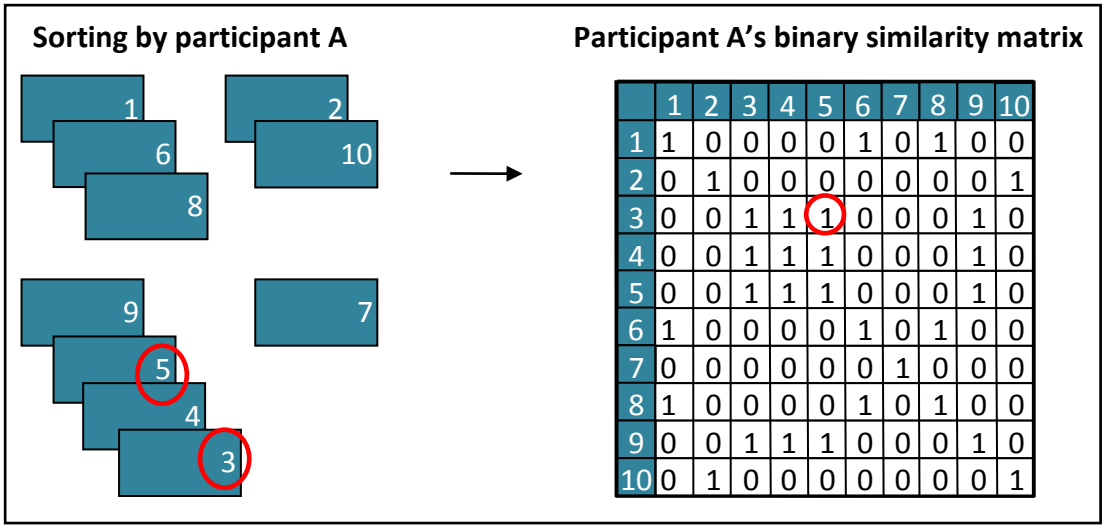
- importance (i.e. *How important is this?*);
- feasibility (i.e. *How feasible is it to provide this?*); and
- existence (i.e. *to what extent is this currently performed?*).

Sorting and rating data was analysed using Concept Systems software version 4.0.

Analysis of sorting data: point and cluster maps

Following the concept mapping methodology (Trochim 1989), the sorted data from each of the 17 participants were entered into a binary symmetric similarity matrix with 42 rows and 42 columns, corresponding to the 42 items. A value of *1* was assigned to a cell for those items sorted together in a category. A *0* was assigned to cells for those items that had not been sorted together. Because an item was always considered to be sorted with itself, the diagonal values of the matrix were each assigned a *1*. This resulted in 17 matrixes; one for each of the 17 participants. For example, Figure 6.2 (ten items only shown for simplicity) shows that if participant A sorted items 3 and 5 together, in Participant A's matrix, *1* would be entered into the cell in which row 3 and column 5 intersected[7].

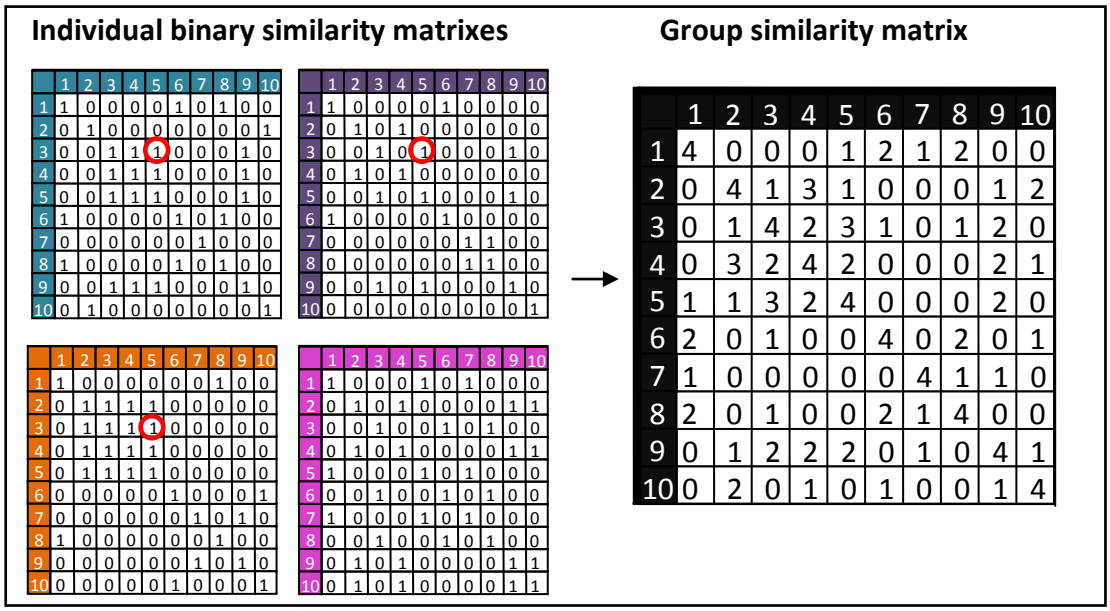
[7] As the matrixes are symmetrical, the values for row 3 and column 5 are the same as for row 5 and column 3 (i.e. participant A has a *1* in both these cells).



	1	2	3	4	5	6	7	8	9	10
1	1	0	0	0	0	1	0	1	0	0
2	0	1	0	0	0	0	0	0	0	1
3	0	0	1	1	1	0	0	0	1	0
4	0	0	1	1	1	0	0	0	1	0
5	0	0	1	1	1	0	0	0	1	0
6	1	0	0	0	0	1	0	1	0	0
7	0	0	0	0	0	0	1	0	0	0
8	1	0	0	0	0	1	0	1	0	0
9	0	0	1	1	1	0	0	0	1	0
10	0	1	0	0	0	0	0	0	0	1

FIGURE 6.2 EXAMPLE OF CREATION OF INDIVIDUAL BINARY SIMILARITY MATRIX FOR SORTING OF TEN ITEMS BY ONE PARTICIPANT

The individual matrixes were then combined into a group similarity matrix, which contained the same 42 columns and rows as the individual matrixes. The values for each cell were the number of participants who sorted these items together. For example, Figure 6.3 shows the group similarity matrix for four individual binary similarity matrixes. Three participants sorted items 3 and 5 together, so the group similarity matrix has a value of *3* for the cell in which row 3 and column 5 intersected. The group similarity matrix thus provided a relational structure for the 42 items, with higher values indicating the items that were sorted together by participants and thus were (theoretically) conceptually closer (Trochim 1989).



	1	2	3	4	5	6	7	8	9	10
1	4	0	0	0	1	2	1	2	0	0
2	0	4	1	3	1	0	0	0	1	2
3	0	1	4	2	3	1	0	1	2	0
4	0	3	2	4	2	0	0	0	2	1
5	1	1	3	2	4	0	0	0	2	0
6	2	0	1	0	0	4	0	2	0	1
7	1	0	0	0	0	0	4	1	1	0
8	2	0	1	0	0	2	1	4	0	0
9	0	1	2	2	2	0	1	0	4	1
10	0	2	0	1	0	1	0	0	1	4

FIGURE 6.3 EXAMPLE OF CONSTRUCTION OF A GROUP SIMILARITY MATRIX FOR FOUR PARTICIPANTS AND TEN ITEMS FROM INDIVIDUAL BINARY SIMILARITY MATRIXES

Nonmetric multidimensional scaling (MDS) is a multivariate analysis technique that represents the relative similarity of objects in terms of the relative distance between pairs of points on a map of any number of dimensions (Kruskal 1964). MDS analysis was used to transform the group similarity matrix into a set of X-Y values that were plotted in the form of a two-dimensional 'point map'. In this metric, the relative distance between items (shown as points) reflects the extent to which participants sorted items into the same category. A two-dimensional map was chosen as it is more easily understood (Kruskal & Wish 1978). The validity of the map generated by MDS was assessed via calculation of a 'stress value', which assesses the goodness-of-fit of the MDS results to the original data (Trochim 1993).

Hierarchical cluster analysis using Ward's algorithm of the X-Y values generated by MDS was performed to group items into clusters (Trochim & Kane 2005). Seven to sixteen clusters are commonly reported (Burchell & Kolb 2003). To determine the number of clusters, a cluster tree was generated showing all cluster solutions, and a cluster solution chosen such that each cluster had a distinguishable theme, and there were no redundant clusters (Burchell & Kolb 2003). Tentative names were given to each cluster by the researcher based on their constituent items. Figure 6.4 shows a point and cluster map constructed from the example group similarity matrix. Items more commonly sorted together (for example, items 3 and 5, sorted together by three participants) are closer to each other on the map, and thus more likely to be in the same cluster.

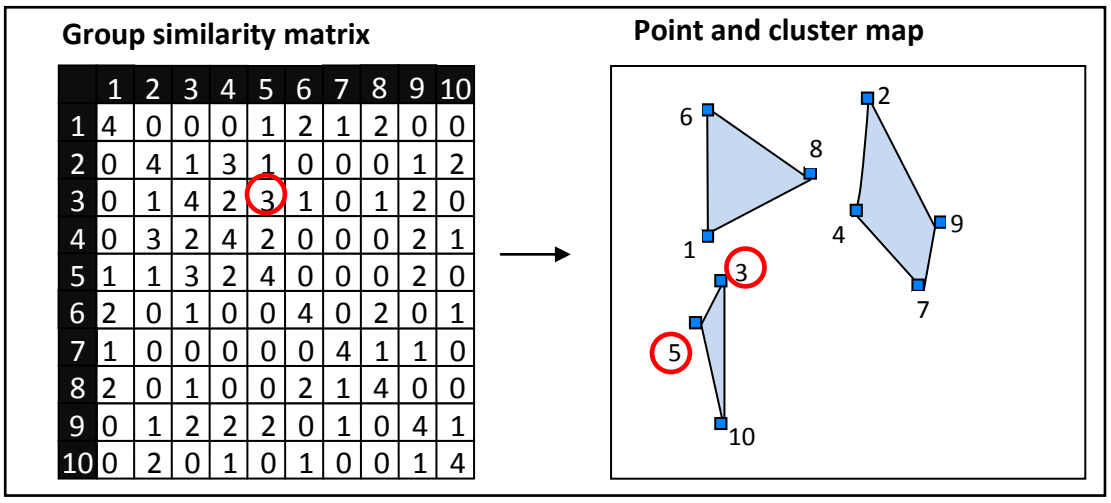


FIGURE 6.4 EXAMPLE OF A POINT AND CLUSTER MAP CONSTRUCTED FROM A GROUP SIMILARITY MATRIX

Analysis of rating data: average rating scores and go-zone graph

Mean rating scores were calculated for each item for each dimension (importance, feasibility and existence). Mean ratings were used to develop a go-zone graph, to compare items across two rating dimensions simultaneously. A go-zone graph is a bivariate plot of two rating dimensions, with the bivariate space divided into quadrants based on the average X and Y values (Trochim & Kane 2005). Figure 6.5 shows an example go-zone graph of the mean importance (X axis) and feasibility (Y axis) ratings for ten items. In this example, items 3 and 7 (yellow quadrant) were rated below average for both importance and feasibility. Items 1, 6 and 9 (purple quadrant) and 4 and 5 (orange quadrant) were rated above average for one dimension but below average for the other. In contrast, items 2, 8 and 10 (green quadrant) were rated as above average for both importance and feasibility. Such items may be most appropriate to select for interventions given their ratings (Trochim & Kane 2005).

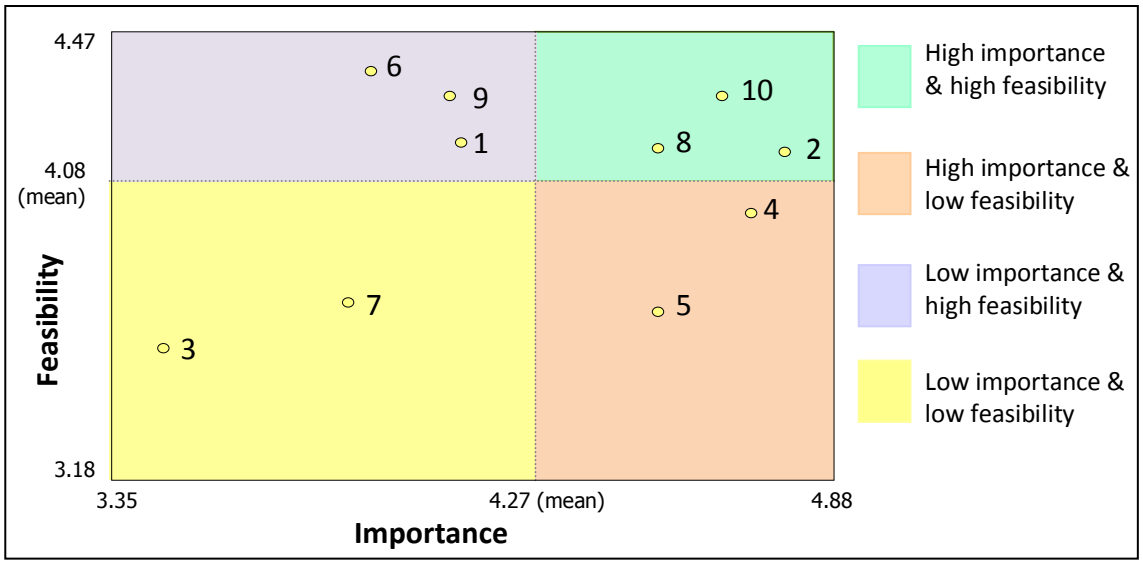


FIGURE 6.5 EXAMPLE GO-ZONE GRAPH OF MEAN IMPORTANCE AND FEASIBILITY RATINGS FOR 10 ITEMS

For ease of interpretation by participants, means were converted to ranks (i.e. the item with the lowest mean importance score ranked 1st and was categorised as 'very low' for importance). Categorisation of ranks used the classification: very low (ranks 1-9); low (10-16); medium (17-27); high (28-32) and very high (33-42). In addition to overall ranks, ranks for each dimension were generated for specific participant groups, based on occupation (nurses, other health care professionals),

setting (public hospital, nonprofit), years caring for brain tumour patients (10 (median) years or less, more than 10 years) and brain tumour patient workload (care for 26 (median) or fewer patients/year, or more than 26 patients/year). The highest and lowest ranks by participant group were presented together with the overall ranks. Items thus received a rank for importance, feasibility and existence, each with a range reflecting the variation in rankings.

6.2.3.5. INTERPRETATION

Once the analyses were complete, the results were fed back to participants in individual interviews or small group sessions lasting one to two hours. Eighteen of the 30 participants (60%) participated in interpretation, seven in individual interviews and 11 in one of three group sessions. Participants in group sessions were homogeneous (for example, one group consisted of nurses from a neurosurgical ward,) to encourage participants to feel comfortable expressing their opinions in front of others.

Interviews and group sessions discussed the items and their ratings, and the point and cluster maps. The aim of these sessions was to explore influences on information provision in the neuro-oncology context, and understand barriers and facilitators to the implementation of possible interventions. A summary of findings was provided to participants via a PowerPoint presentation (shown in person or emailed to participants, see Appendix E). For brevity, ratings were presented for 13 items only. These 13 items were selected for their high ratings (suggesting they may be suitable targets for intervention) and/or for having considerable variation in their rankings by different participant groups (for example, rated low by health professionals working in the community but high by hospital-based health professionals). Participants were prompted to discuss if and why an item would be a good target to intervene, facilitators and barriers to implementation, and who ideally would be responsible to implement the intervention. For items with variation between group ratings, participants were asked why they thought the ratings varied.

Point and cluster maps were presented to participants with explanations of how the analysis constructed the map, and the meaning of the proximal location of the

points. Participants examined each cluster and its items, to determine the appropriateness of the clustering and the cluster name. Participants discussed the validity of the clusters as elements of brain tumour care, and examined the map for patterns among clusters both adjacent to and opposite of each other.

Thematic analysis was undertaken to identify underlying themes of transcripts and notes of the interpretation data. This involved identifying the core categories of ideas from transcripts and notes, utilising open coding, axial coding and selective coding. This was initiated with several readings of the documents to enable familiarisation with the data. For open coding, participant responses were compared searching for similarities and differences. Conceptual labels were applied to group codes into categories (Strauss & Corbin 1998). In axial coding, the initial codes were scrutinised to ensure they were fully elaborated and developed. This process was completed independently by the candidate and a second researcher, JA. The codes developed by both researchers were then compared and discussed and a consensus reached on final codes. This process helped ensure important themes were not missed, and added breadth and completeness to the analysis. Finally, in selective coding, links between the codes were mapped to allow integration around central categories or themes. Themes were then grouped together, re-examined and refined. Throughout this process, the transcripts and notes were continually referred to, to ensure their meanings were not lost in the analysis.

6.2.4. HOW RIGOUR HAS BEEN ACHIEVED IN THIS STUDY

This study's design and implementation took into account each of the six techniques for ensuring rigour described in section 5.4. Theoretical rigour (consistency between research aims and strategy) was achieved through basing the aim of this research on gaps evident in the literature, and in choosing an methodology appropriate to answering the research question. Concept mapping enabled the collection and interpretation of rich qualitative and quantitative data with which to understand influences on information provision in the brain tumour setting, which may act as facilitators or barriers to intervention efficacy.

Methodological rigour (clear documentation of methodological and analytical decisions) was achieved by following established procedures for concept mapping. An audit trail was maintained, and all researcher interpretations reviewed by at least one consultant (supervisor, research assistant or health care professional) to minimise bias. For example, 649 items were generated by participants, reduced to 42 items following concept mapping methodology procedures. A second researcher, MJ, reviewed the processes and results of this reduction, to ensure that the breadth and completeness of items generated were not lost in the reduction.

Interpretive rigour is gained when the interpretation accurately represents the understanding of participants (Liamputtong & Ezzy 2005). In this study, recruitment and data collection for the two qualitative steps (item generation and interpretation) were continued together with data analysis until saturation was reached, to ensure that the data were rich enough and covered all the aspects raised by participants. Although the concept of saturation has been criticised for being unachievable or unrecognisable (Cutcliffe & McKenna 2002), a limited definition of data saturation permitted its use (Tuckett 2004). For this study, saturation was defined as occurring when no new information of significance for theorising was forthcoming, based on recurring patterns and themes that had been recognised in the data (Higginbotham et al. 2001; Patton 2002; Ezzy 2002). In practice, saturation was achieved in the item generation phase when the items generated by the latest participant were not dissimilar to previous items generated, and in the interpretation phase, when no new codes were generated in thematic analysis of two consecutive interviews.

The interpretation step also facilitated interpretive rigour, as it allowed quantitative results (such as average ratings and maps) to be presented to participants, who then discussed the validity of the findings and potential meanings of the results. In concept mapping, maps generated are not a conceptual 'reality', but rather act as tools to allow participants to discuss the system or context (Trochim & Linton 1986). Interpretive rigour was also demonstrated by using participants' own words in item generation, and by providing quotes from participants to illustrate the themes generated during the thematic data analysis.

Examination of the similarities and differences between qualitative and quantitative results allowed triangulation. In this study, quantitative results (such as the go-zone graph, which showed items rated highly by participants for importance and feasibility) were compared with results of thematic analysis of interviews and group sessions in the interpretation step. Whilst the quantitative data show which items may be most appropriate targets for intervention, the qualitative data show the difficulties perceived by health professionals in providing information, which may act as potential barriers to implementation of interventions.

Evaluative rigour requires consideration of the ethical and political aspects of the research. This study involved health professionals, but not patients and/or carers, and thus reflects only a partial understanding of the situation. Patients and carers were not included in this study because recent studies have examined brain tumour patients' desire for information and perceived barriers to receiving information (Janda et al. 2006; Janda et al. 2008). However, the views of patients and carers were obtained in later research phases (aims 2 and 3).

The sixth element, rigorous reflexivity, requires researchers to consider how their own feelings and assumptions, and their relationship with participants, may have influenced the research (Holloway & Freshwater 2007). This research aimed to be participatory, collaborating with, rather than doing research 'on', health professionals (Brown & Tandon 1983). Actions were taken to involve participants in all stages of the research, including analysis and dissemination of knowledge. Two participants acted as project consultants, with input on research design, recruitment and analysis. All participants received full and clear information about the aims of this research and the PhD program as a whole. Final research findings were disseminated to participants in the form of a study newsletter (Appendix F) and presentations at the hospitals involved.

Based on these considerations of rigour, the results of this research are presented.

6.3. RESULTS

Analysis of the sorting data by MDS obtained a stress value of 30% after nine iterations. Stress values range from 0-100%, and indicate the goodness-of-fit of the two-dimensional map with the original similarity matrix (Kruskal & Wish 1978). The value obtained for this analysis is within the range reported in a meta-analysis of stress values in previous concept mapping studies (20-36.5%), and suggests that the point map is a valid representation of the similarity matrix data (Kane & Trochim 2007; Trochim 1993).

The suitability of different cluster solutions was examined. An eight cluster solution (Figure 6.6) was selected as it preserved detail and made visual sense in terms of cluster size and interpretation. Within the eight cluster solution, no single cluster spanned half of the map, and none of the items within a cluster seemed too dissimilar, which would indicate that an increased cluster number solution was appropriate (Burchell & Kolb 2003). Clusters were given tentative names based on constituent items. As with the point map, clusters closer together may be interpreted as being more contextually similar, while more distant clusters represent less similar constructs.

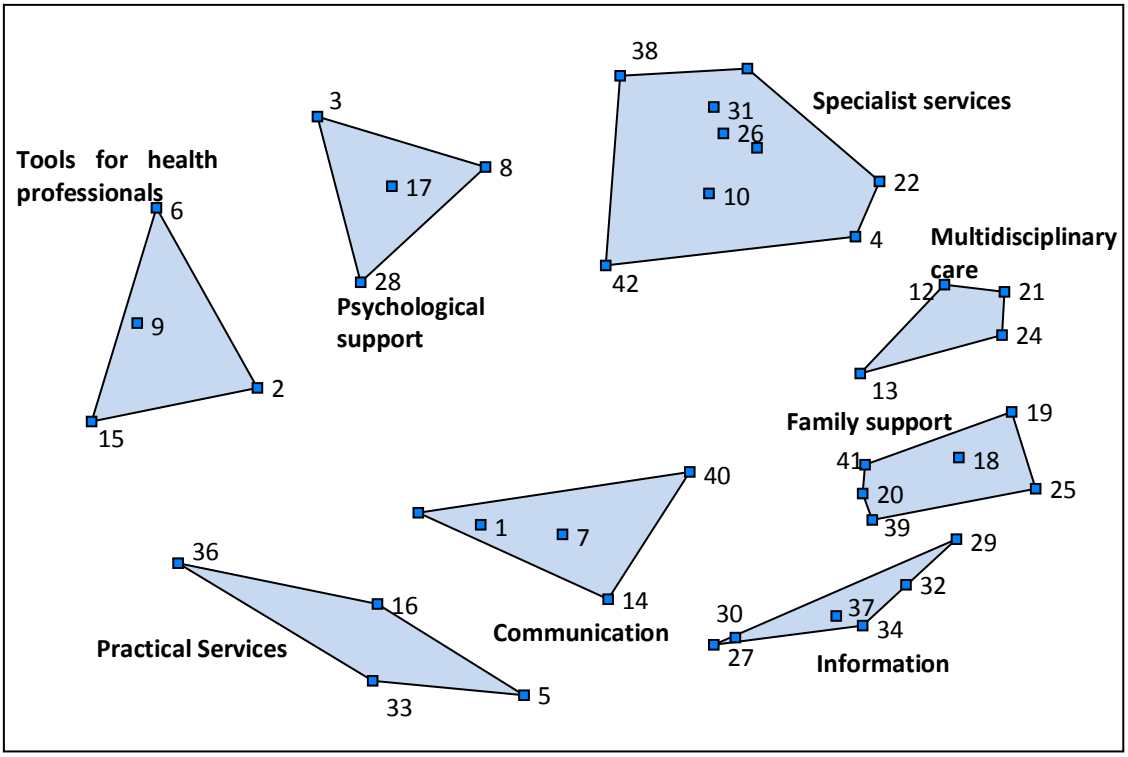


FIGURE 6.6 THE CONCEPT MAP: POINT AND CLUSTERS OF THE 42 ITEMS GENERATED BY PARTICIPANTS TO IMPROVE CARE FOR BRAIN TUMOUR PATIENTS

Table 6.2 presents the 42 items sorted by cluster, together with the mean rating scores for importance, feasibility and existence. Overall, importance and feasibility ratings were higher than existence ratings, suggesting participants perceive a need for interventions in this setting. The cluster *Psychological* support had the highest cluster ratings for all dimensions. The cluster with the lowest importance rating was *Communication* (mean importance rating: 4.11[8]); in the feasibility dimension, the lowest rated cluster was *Specialist services* (mean feasibility rating: 3.89); and in the existence dimension, the cluster *Tools for health professionals* (mean existence rating: 2.52) was rated lowest.

Of the individual items, a care coordinator (item 4) had the highest mean importance rating (4.88, SD 0.33). Information on driving (item 5), for prognosis to be discussed with the patient and family (item 8), and more information to be shared about the positioning of the tumour (item 24) achieved the highest mean feasibility scores (4.47, with SDs of 0.51, 0.80, and 0.72, respectively). For prognosis to be discussed with the patient and family also had the highest mean existence rating (4.25, SD 0.93). Use of a prompt or screening mechanism for distress (item 9) scored lowest for importance (mean 3.35, SD 0.79). Credentialing of brain tumour surgery (item 35) had the lowest feasibility (mean 3.18, SD 1.07) and existence ratings (mean 1.94, SD 0.93).

Two items relating to communicative behaviours, information to enable the patient or carer to ask questions (item 34), and for doctors to encourage patients to ask questions (item 17), had similar mean scores for each rating. Both had high importance (4.59 and 4.65 respectively) and feasibility ratings (each rated 4.24), suggesting health professionals value interventions to improve communication.

[8] Note: standard deviations are not presented for cluster means, as these are essentially an average of the average ratings given by participants. Standard deviations are not meaningful in this scenario.

TABLE 6.2 MEAN INFORMATION, FEASIBILITY AND EXISTENCE RATINGS OF THE 42 ITEMS BY CLUSTER

	Item	I	F	E
Cluster 1: Tools for health professionals	***Average value***	***4.13***	***3.96***	***2.52***
15	Maintain a patient-held record of their treatment	4.29	4.00	2.63
9	Use of a prompt or screening mechanism such as a distress thermometer to assess distress & emotional needs	3.35	3.53	2.06
6	Compilation & use of a central/shared directory of all services available & appropriate for brain tumour patients to enable easier referral	4.47	4.12	2.44
2	Use of a standardised information pack for health professionals to pull resources from	4.41	4.18	2.94
Cluster 2: Psychological support	***Average value***	***4.59***	***4.26***	***3.50***
3	A database of patient details to enable someone to keep in touch & monitor appointments	4.53	4.12	2.56
8	For prognosis to be discussed with the patient & family	4.59	4.47	4.25
17	For doctors to encourage patients to ask questions & help them feel comfortable asking questions	4.65	4.24	3.50
28	For a support person to be present whilst the diagnosis is received	4.59	4.24	3.69
Cluster 3: Specialist services	***Average value***	***4.31***	***3.89***	***2.57***
38	Training for non-specialist staff about how brain tumour patients are different from other cancer patients	4.47	3.76	2.44
35	Credentialing of brain tumour surgery as a subspecialty in neurosurgery	3.88	3.18	1.94
31	Staff to be trained on how to communicate	4.76	4.00	2.63
26	Referral to palliative care whilst receiving active treatment	3.94	3.94	3.00
42	Ascertainment of the medium most suitable for a patient to receive information during taking of patient history	4.00	3.76	2.56
22	Specialists to refer patients to advocacy groups & networks	4.29	4.00	2.29
10	Someone to assess how much or how well a patient understands information given to them during a consultation	4.00	4.18	2.44
11	Appropriate timely referrals across all disciplines	4.59	4.06	2.75
4	A care coordinator to follow patients, oversee their care, be a point of contact and someone to ask questions of	4.88	4.12	3.06
Cluster 4: Multidisciplinary care	***Average value***	***4.31***	***4.22***	***2.77***
12	To be provided with a pathway diagram representing all elements of care & health professionals involved	4.24	4.00	2.06
13	Strategic information provision - give appropriate information to patients at certain points on a pathway	4.24	4.00	2.63
21	For patients & families to be informed about the different staff members & roles so they can understand the system	4.29	4.41	3.13
24	More information shared about the positioning of the tumour & deficits that may occur because of its positioning	4.47	4.47	3.25

Abbreviations I: Importance (mean); F: Feasibility (mean); E: Existence (mean)

TABLE 6.2 CONTINUED

Item		I	F	E
Cluster 5: Family support	***Average value***	***4.21***	***4.10***	***2.91***
18	Australian versions of information for patients	3.94	3.82	3.29
19	Information re complementary and alternative therapies: what information to look for or questions to ask when checking information on a potential therapy	3.76	4.06	2.41
20	Modeling for carers on how to respond to challenging behaviours, & opportunities to practice these strategies	4.53	4.24	2.69
25	Information about clinical trials	4.00	4.06	2.94
39	Awareness/information days for patients, family & friends	4.41	4.18	3.35
41	A 'how to' manual for caregivers on dealing with mood swings, behaviour changes, cognitive deficits, physical deficits & on learning coping skills	4.59	4.24	2.75
Cluster 6: Information	***Average value***	***4.32***	***4.20***	***3.06***
27	Guidance for seeking information on the internet	4.12	4.35	2.88
29	Help with weighing up options & making treatment decisions	4.53	3.94	3.18
30	Information about what to do before having surgery (e.g. wills, bank accounts)	3.88	4.29	2.69
32	Information on how to ask for a second opinion	4.24	4.00	2.75
34	Information to enable the patient or carer to ask questions	4.59	4.24	3.44
37	Information on the process that is going to be undertaken while they are in hospital & after	4.59	4.35	3.44
Cluster 7: Communication	***Average value***	***4.11***	***3.99***	***2.88***
1	To be allowed to not know or not be informed about things if they do not want to be	4.00	3.65	2.94
7	Direction in how to get help in terms of community nursing	3.94	4.35	
14	Telephone support groups	3.76	3.59	2.47
23	A plan of action for what to do if something goes wrong	4.65	4.41	2.88
40	To be prepared for future events such as tumour recurrence	4.18	3.94	3.19
Cluster 8: Practical services	***Average value***	***4.15***	***4.18***	***2.78***
5	Information on driving, e.g. legality, contact with neurologists	4.41	4.47	3.38
16	Use of a checklist for patients covering things they may need to consider or do	4.12	4.24	2.38
33	Appropriate accommodation & respite services	4.24	4.06	3.19
36	Use of a checklist to assess the financial needs of the patient & family	3.82	3.94	2.19

Abbreviations I: Importance (mean); F: Feasibility (mean); E: Existence (mean)

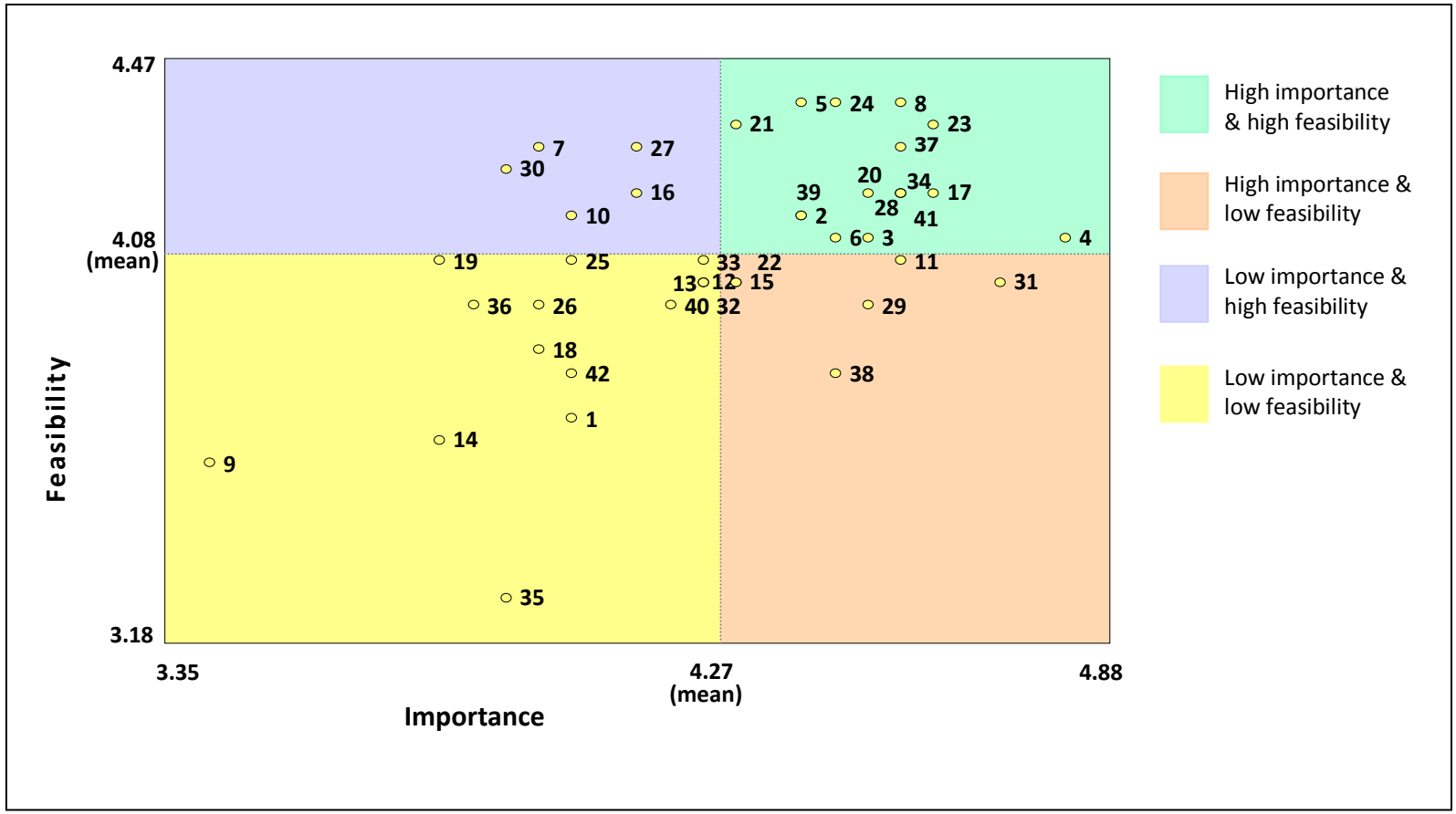


FIGURE 6.7 GO-ZONE GRAPH OF IMPORTANCE VERSUS FEASIBILITY OF THE 42 ITEMS GENERATED BY PARTICIPANTS

Mean rating scores for importance and feasibility were plotted on a go-zone graph (Figure 6.7). Of the 42 items, 16 items scored above the mean for both importance and feasibility.

As described in the methods, mean ratings were then used to rank items in order of importance, feasibility and existence (very low, low, medium, high, or very high). Ranks of mean ratings were compared across professional groups to determine the extent of consensus in ratings. For example, modeling for carers on how to respond to challenging behaviours (item 20) was ranked very high for importance (all participants). However, across professional groups its ranking ranged from low to very high, suggesting this item was not consistently viewed as an appropriate target for intervention by all professional groups. In contrast, a care coordinator (item 4) was ranked very high for importance, across all professional groups. This suggests that there is consensus that providing a care coordinator could be an appropriate intervention to test.

After the cluster maps, go-zone graphs and rankings were compiled, 13 items were selected for interpretation by participants (Table 6.3). These items were selected because either their ranks were high, or varied considerably between professional groups. The ranks, point, and cluster maps were presented to participants to facilitate discussion.

TABLE 6.3 PARTICIPANT RATINGS OF SELECTED ITEMS: OVERALL RATINGS AND THE RANGE OF RATINGS OF PROFESSIONAL GROUPS

Item		Importance	Feasibility	Existence
3	A database of patient details to enable someone to keep in touch & monitor appointments	high (low – v high)	medium (v low – v high)	low (v low – medium)
4	A care coordinator to follow patients and oversee their care	v high (all v high)	medium (v low – v high)	high (medium – v high)
6	Compilation & use of a central or shared directory of all services available and appropriate…	medium (low – v high)	medium (v low – v high)	v low (v low – low)
10	Someone to assess how much or how well a patient understands info given to them	low (v low – medium)	medium (v low – v high)	v low (v low – medium)
12	To be provided with a pathway diagram representing all elements of care and health professionals	medium (v low – medium)	low (v low – medium)	v low (all v low)
15	Maintain a patient-held record	medium (low – high)	low (v low – v high)	low (v low – medium)
20	Modeling for carers on how to respond to challenging behaviours	high (low – v high)	high (low – high)	medium (v low – high)
23	A plan of action for what to do if something goes wrong	v high (high – v high)	v high (medium – v high)	medium (low – v high)
25	Information about clinical trials	low (v low – low)	medium (v low – v high)	medium (medium – high)
30	Information about what to do before surgery (e.g. wills)	v low (all v low)	v high (medium – v high)	medium (v low – medium)
41	A 'how to' manual for caregivers on dealing with mood swings, behaviour changes	high (medium - v high)	high (low – high)	medium (low – medium)
42	Ascertainment of the medium most suitable for a patient to receive information	low (v low – high)	v low (v low – low)	low (v low – medium)

Categorisation of ranks: (v) very low: 1-9; low: 10-16; medium: 17-27; high: 28-32; (v) very high: 33-42.

Thematic analysis of transcripts of these discussions revealed five major themes as influencing information exchange: 1) health professional characteristics; 2) patient characteristics; 3) health professional perceptions of patients; 4) patient perceptions of health professionals; and 5) health system issues. The concept of individualised information provision was the central theme to emerge from the data (Figure 6.8).

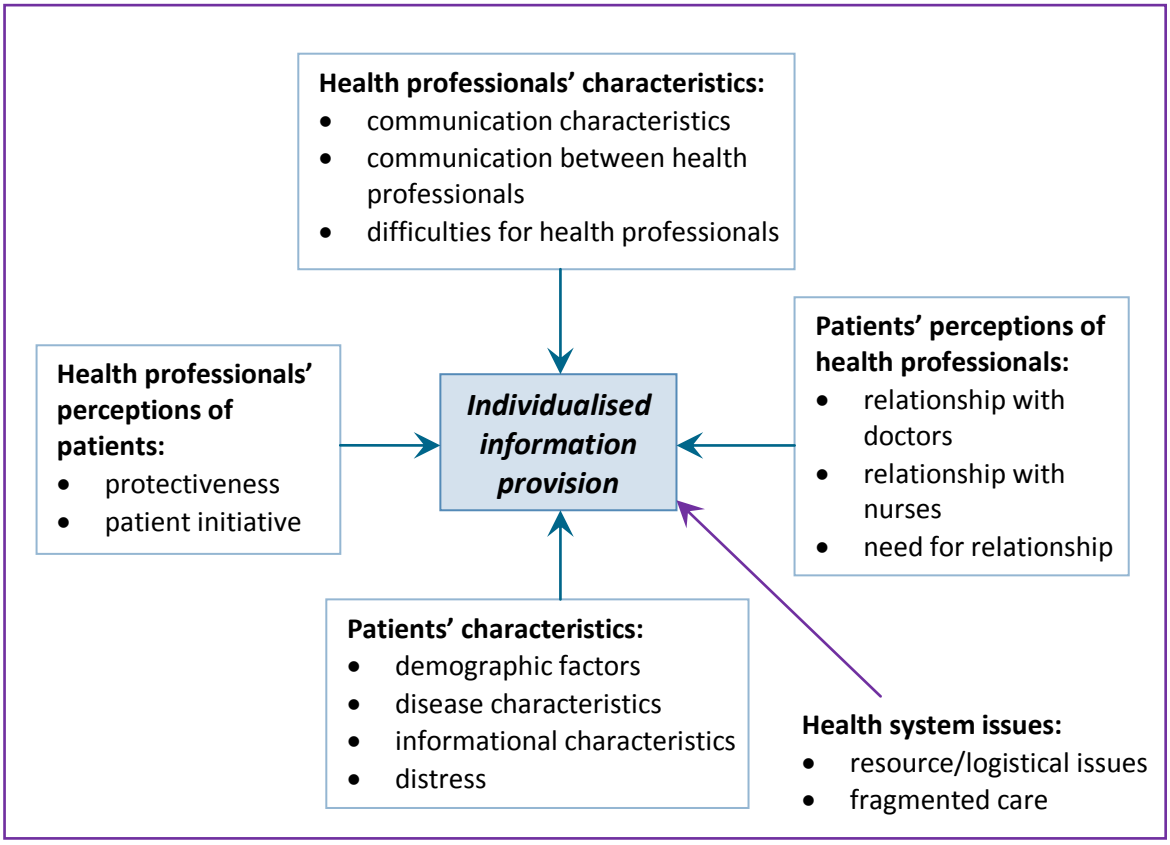


FIGURE 6.8 THE CENTRAL THEME OF INDIVIDUALISED INFORMATION PROVISION AND THE FIVE FACTORS INFLUENCING ITS PROVISION

6.3.1. HEALTH PROFESSIONALS' CHARACTERISTICS

Health professionals highlighted that their individual communication skills and style influenced how well they communicated with patients and their families, and how well they could adapt to meet an individual patient's needs. Effective communication was seen to depend on training received and early role models.

> *"I think you've got to know your patient and know when it's the right time. And I mean I think that most senior nurses would actually agree with that. But junior nurses tend to rush in there and just go for it, you know?"* (Person 5, #4).

Health professionals also indicated that the types and amount of information given to patients depended on the attitude of the health professional. Frequently, greater emphasis was given to symptoms and procedural aspects, compared to information about psychosocial or supportive care needs.

> *"A lot of medicos, because they have professional skills, they want to sell the idea of benefits of treatment, and don't want to give anything outside that."* (Person 1, #42).

Poor communication across health professional groups was also reported. Participants described difficulties in caring for and communicating with patients if they lacked information about the patients' condition. Within the hospital setting, nurses expressed frustration with not being provided with sufficient details about patients' illnesses and treatments.

> *"..if the doctor comes in and does a big spiel to the patient, then walks straight out and goes to write on the chart, then doesn't... you have no idea what's been said. ... You wouldn't have a clue and patients sometimes don't have a clue either so... And they ask you and you've got no idea."* (Focus group 3, Person B, #10).

Support for patients in the community was also seen as hampered by poor communication across health professionals and organisations. Participants emphasised the importance of adequate information to be provided to community nurses and general practitioners, who managed patients after hospital discharge.

Information exchange between health professionals was fostered by good relationships and team work. However, many allied health professionals felt that 'true' multidisciplinary care did not exist.

> *".. multidisciplinary has become multi-medical specialty and it doesn't have a range of disciplines – it has a range of doctors. .. So a true multidisciplinary should have everyone including occupational therapists, and speech pathologists, and a whole... then you'd know that the person's put on Dex*[9] *that he'd need to catch up with the dietician, because of the ah, increased intake of sweet things because of their Dex craving, so the same as if they've, you know, got aphasia and they need to be referred on ..."* (Person 1, maps).

Participants also described difficulties they had encountered in providing information, particularly for patients with cognitive or behavioural deficits. Many participants had experienced situations where they felt frustration at being unable to provide help.

> *"We've got a guy who's just finished treatment, he was a nursery worker, the guy with the tumour and his wife was a nurse. Of course they've retired now.*

[9] Dexamethasone – a steroid used to reduce intracranial pressure

But he … the moment he gets up in the morning, he gets dressed, has his breakfast and wants to go out in the car. He wants her to drive him around, all day. Now, if she doesn't drive him around, then he gets verbally aggressive, and pushes and shoves her! Because he wants to go out in the car. So yes… how do you?" (Person 1, #20).

Many health professionals felt distressed when they had to provide patients with information about potential negative outcomes, or witnessed patients' or families' distress when negative outcomes occurred that patients or families did not feel prepared for.

"Yes, I remember one of our clients – in the support group. The husband as saying that, 'I wish, I wish there would be information to tell us that how she's going to change' – the change, the possible changes that his wife had, and there was nothing. And at surgery she becomes – she survived – she's a survivor, but she's so cognitively impaired – that you know at times she's you know, wrong, in social settings. And I gather, you know, what is cognitive impairment, why is she like this, why is she changing so much, because she was a manager when well, a career woman, and then becomes really impaired – with significant changes in her, in her life, and I think I found it really hard that no one had given them the information that this could happen." (Person 2, #30).

6.3.2. PATIENT CHARACTERISTICS

"The reality is ... is everyone is different, all their spouse and family are different, and they're diagnosed at different times and they're going through different stages in their life." (Person 6, #20).

Health professionals reported that they tailored the information that they provided to patients to meet their individual needs, based on the patients' demographic, disease, and informational needs and preferences. In relation to demographic factors, health professionals indicated that older and/or less educated patients required less information about their condition, or information needed to be simplified to facilitate understanding.

"If you're telling a 75 year old, that they've got a glioblastoma, and their life expectancy is less than six months – because historically you know that they have a bad outcome – because they may be the person who hasn't had too much to do with the health system, how much are they going to take on board?" (Person 1, #42).

Health professionals also considered disease severity, progression and cognitive or behavioural deficits when providing information to patients. Many health

professionals reported providing more detailed information early on to patients with more aggressive tumours, or those whose disease was progressing more quickly, with information provision staggered over time to a greater extent for patients with less aggressive tumours or less severe symptoms. Health professionals also described the often short window of opportunity to provide information to patients before their symptoms progressed to a point where they were unable to effectively understand or communicate. This was balanced against patients' emotional comprehension or coping.

> *"I think at our point though it's just diagnosis in the acute phase, they don't – it's not what's going on in their head – they're just trying to get their head around what's happened to them so I would think maybe if it's a slower sort of moving tumour and you've got quite a while to think about it maybe later on – that coming back to the first year then they might make you think because really in our area I just don't think it's even in their thinking."* (Focus group 1, Person A, #30).

When patients' symptoms had progressed past the stage when they could communicate effectively, health professionals tailored information to the needs of family members. The type of information carers need in this situation was different to that needed when health professionals could communicate effectively with patients, and often related to patients' cognitive or behavioural deficits.

> *"The patient is sometimes cognitively impaired. So it's not the patient who's understanding the information, it's actually the carer. And the carer can talk to the patient, but the patient's there and listening. But she or he has got short term memory [loss] anyway; so it's going to go in one ear, and out the other. That's why we hate it when our doctor comes in and gives the patients the results on pathology, without having any member of family around. It's a waste of time. And the family really get upset, as you can imagine."* (Person 5, #10).

Health professionals were further influenced by patients' information needs, ability to understand information, information preferences, and their access to other information and services. Many health professionals stated that they assessed patients' ability to understand information informally, and would try alternative approaches if they thought the patient was not responding. However, time and resource constraints were frequently mentioned as influencing the use of alternative strategies for information provision, with one health professional

concluding that *"it would be a low priority - like just as long as you're giving the patient something."* (Focus group 2, Person B, #42).

Almost all health professionals reported recognising and responding to patients' information seeking preferences. If patients indicated that they did not want to receive information, health professionals respected this and provided little information. High information seekers were provided more information, and were also frequently cited as a useful source of information for health professionals themselves.

> *"Some patients do it [keep a treatment record] already – like they come in with their big plastic sleeve folder and it's really good because they have everything – you know all the consult notes, reports, you name it they have it in their little folder."* (Person 1, #15).

The manner of information was also tailored to patients' access to information and services, with patients who used the internet pointed to websites, and other patients provided printed information. Many health professionals reportedly spent significant time in locating services in rural areas, to link patients with local services.

> *"And we're talking about people from central coast who sometimes don't even have a bloody telephone that works! So they .. wouldn't be interested in looking up on the internet, that's why I photocopy the thing!"* (Person 5, #42).

Health professionals considered the level of distress exhibited by patients and families when providing information. Health professionals were very aware that patients may be overwhelmed by information, especially early in the disease journey, and that distress restricted information processing. Health professionals recognised that patients and families may have difficulties accepting their symptoms, and especially that changes might be permanent.

> *"Possibly they would freak out when they saw some of the potential changes that the patient may go through. Um because they naturally wouldn't want to accept that the person they love is going to become totally different. So they will probably cling to the hope that their family member is going to be the one exception to the rule."* (Person 1, #41).

6.3.3. HEALTH PROFESSIONALS' PERCEPTIONS OF PATIENTS

Health professionals highlighted the importance of protecting patients, particularly in terms of not creating false hope or expectations which could not be met. This was most clear with regard to clinical trials, which some nurse participants described as 'mercenary' and expensive, requiring patients to be 'guinea pigs' and offering little potential for cure.

> *"I think of particularly your oncologist who will make dying people think that this is going to rescue them and it never does! It's just completely dishonest."* (Focus group 3, Person C, #25).

Health professionals were also careful to avoid creating false expectations, and thus causing distress, with regard to information resources and referrals to services. For example, health professionals would not suggest counselling if a psychologist was not available, nor assess patients' preferences to receive information via alternative mediums (such as by video) if such materials were not available.

> *"It's all very well to be in constant contact, but if there's no one to refer them to, to meet their needs, it makes it really difficult to be that person. So I guess that's kind of what else is available – I mean if they need some sort of in depth counselling, it may not necessarily be that the care coordinator, given their case load, is in the position to provide that – but they could refer to psycho-oncology or someone else. But if there were none of those other people, it would also be very difficult, I'd imagine. Or that would create an expectation which couldn't be met which really is just – you know, more distressing."* (Person 4, #4).

Avoiding scaring or overwhelming patients with information was also important to health professionals. Participants reported wanting to give patients information they needed but avoiding giving additional or unnecessary information, especially if it could be distressing.

> *".. it definitely seems important that they know I guess the risks and the information that's needed – but yeah, it's hard to say that it's really important to give [information about what to do before surgery] to them because it's just additional information that's gonna well, one, probably terrify them and two, just too much to take in on top of everything else."* (Person 7, #30).

However, what information was classified as 'unnecessary' was highly contentious. Health professionals differed widely in their opinions of whether it was appropriate

to give patients information in relation to three specific topics: 1) pathways showing the different treatments they might receive; 2) information about what to do before surgery (for example, to prepare wills or advance health directives); and 3) information about possible cognitive/behavioural deficits that might occur. Health professionals who treated or supported patients later in the disease trajectory generally believed it was important to prepare patients and families for the future, which should include information about matters such as preparing wills. These professionals believed such measures should be discussed as part of routine practice, which could reduce any associated fear, and prevent later distress for families. Those who saw patients earlier in the disease trajectory however, were more likely to see such information as fatalistic and potentially distressing, taking away hope and suggesting to patients that they were likely to die.

> *"It's like, American car manufacturers didn't put seatbelts in 'til 15 years after Europeans did because, well, it sends a bad message! Cars might crash, you could get hurt, so we won't have a seatbelt. And then it will look all safe. .. maybe that's why it's not promoted – it's a message of the non-hopeful side of it."* (Focus group 3, Person C, #30).

> *"I almost see that as being fatalistic you know – 'oh before I go and have a procedure I'd better make sure my will's in order and that's done' and that I have to say that I don't think I'd see that as being the thing you need before, before the surgery."* (Focus group 1, Person C, #30).

A second sub-theme regarding health professionals' perceptions of patients related to patient initiative and capacity. Health professionals believed that patients should take the lead in the process by which they received information and support, and that patients were capable of and would ask for extra information if needed.

> *"They'll ask if they – if they want that information."* (Focus group 1, Person C, #42).

> *"I think health professionals, especially consultants – they, look, that they've got a 15 minute timeslot, or a half hour timeslot, and they want to basically tell them about the radiotherapy or the chemotherapy or side effects or whatever, and they – you know, it's not an ideal world, they've got too many patients! So they give them, sometimes patients get what I call – not even a drive through service, they get a take-away service. It's very quick. And then they will say 'oh look, when they come and ask me the questions, I'll deal with all of that then'."* (Person 1, #42).

Patients were also seen to exercise initiative by not asking for information or support.

> *"..some people don't want to know. Some people, I have got to chat to them at the moment they're going to have surgery, but will actually have asked us no more questions about what they're doing."* (Focus group 1, Person C, #42).

On the other hand, health professionals also acknowledged that many patients lacked the capacity to take initiative and control over their information needs, intellectually or due to distress, symptoms or side-effects of disease or treatment.

> *"And then if you look at people who end up in the emergency department all the time... we had someone brought in just before I went on leave, who kept having seizures – and his wife hadn't written anything down about any of the meds he was on, that he was having a seizure, what might have brought seizures on... when she was asked about um his surgery – cause he couldn't answer the questions – and about his chemo, she couldn't answer any of the questions, she was so stressed."* (Person 1, #15).

6.3.4. PATIENTS' PERCEPTIONS OF HEALTH PROFESSIONALS

Health professionals expressed the importance of building relationships with patients. Having a rapport and continuity enabled patients to be more open in their enquiries, to relax, and be more able to process information. The relationship also enabled the health professional to better understand patients' needs and to respond to these, even without patients specifically asking for information or support.

> *"So that is the advantage, I think, of having someone as a case coordinator who later on – cause of the consistency of their relationship can sort of – well, what they were told in their original, new patient consult with their specialist – then through I think some fairly, I think, simplistic communication with them – find out exactly what they have processed and what their understanding is. So the one person is consistent, then they'll pick up on that. If the one person isn't consistent, then they're not going to pick up on that at all."* (Person 1, #10).

However, some health professionals described the doctor-patient relationship as a power relationship, in that some patients were nervous talking to their doctors, believed doctors were 'too busy' to ask for information or resources, or needed to

be granted 'permission' before they would feel comfortable asking for further information from them.

> *"But to have permission that it's okay is really important. Because a lot of patients say, 'oh, the doctor's far too busy for me to ask my question'. And they sort of minimise their access to whatever it is they need."* (Person 4, #34).

Health professionals acknowledged that cultural changes in information seeking behaviours and doctor-patient relationships had occurred over time. Patients gained access to information from sources other than their doctors, (primarily the internet,) and thus became less intimidated by their doctors.

> *"I think it'll change with time – a lot of the older generation I think are still very much the manners, etiquette of society is just that like, you know, they're very well respected and you don't question – you believe, you have faith and trust in the doctor and therefore you don't have to question what they're saying. So it may be a generational thing."* (Person 3, #34).

Despite this, some health professionals believed some doctors were still restricting information from patients by ignoring their questions, thus perpetuating the power differential.

> *"They'll say, 'well, we asked so-and-so' and people say, 'well, I asked Dr So-and-so, and he never answered me – he just didn't respond. You know, I asked him and he just kept on writing'. You know, that sort of thing happens a lot."* (Focus group 3, Person D, #34).

The nurse-patient relationship was characterised by some participants as more personal and less intimidating. Health professionals, particularly nurses, believed patients felt more comfortable with nursing staff, and that seeing them repeatedly allowed them to cultivate a relationship.

> *"You're going to be there at night when they turn around and ask you questions – you know, pretty involved questions about things, and you know they might be comfortable with you too at that point."* (Focus group 2, Person D, #4).

6.3.5. HEALTH SYSTEM ISSUES

Issues surrounding resources and fragmented care were also believed by health professionals to impact information exchange. Many health professionals described the lack of information resources specifically suited to their needs. Resources were

often printed off the internet, or sourced from other countries. Although this patient literature was generally judged as high quality, many health professionals wanted current resources, in appropriate formats, tailored to Australian patients and their needs.

> *"You know, there is some good information about managing emotions and managing things with people with cognitive deficits on the internet. People tend to print those off and provide them. But it's on an ad hoc basis and you know, all of the professionals who work in this area are well aware of the cognitive deficits, especially the case managers, the doctors and things, and so they provide that information through what they experience and access, but there's like no document."* (Person 4, #41).

In addition, some participants believed there were appropriate resources and services that were not being used, because health professionals were not aware of them, or how to use them appropriately, and did not suggest them to patients.

> *"People don't know what our purpose is – or you know, if they haven't been given our number by somebody at hospital or one of their health care providers – a lot of people don't know about us or don't know what services we do provide."* (Person 7, #41).

Fragmented care also influenced information provided to patients. In Australia, many patients with brain tumours require surgery and/or radiation in tertiary treatment centres in metropolitan centres, while they may receive chemotherapy and supportive care services in local centres, and follow-up may be shared between centres. In this study, health professionals reported that patients did not always receive optimal care because of the lack of continuity. This occurred when patients received many different treatments, were treated by many different health professionals, and/or were treated in departments or hospitals that had different systems. The lack of continuity and coordination then led to a diffusion of responsibility, whereby it may not be clear to either health professionals or patients whose role it was to provide information to patients.

Health professionals also differed in how much responsibility they assumed for information exchange. Within the same system, different patients were provided different information.

> *"Cause I think the system we work in here creates confusion for patients because they're palliative, they'll often still come into visit under their*

> *treating specialist and quite often – well, probably half of the treating specialists actually – let go and the other half don't. And people are used to, 'For the last five years I've seen [name] every three months. And now do I ring [name] or do I ring you?' and they can't ring us, because we just do inpatient work. So you say, 'ring the GP' – 'oh, but I haven't seen the GP for five years'. So it's quite hard to construct a plan that actually works for them, because their network is fragmented and the responsibilities are taken to a varying degree by the different doctors."* (Focus group 3, Person C, #23).

These factors together led to health professionals conceptualising information provision in neuro-oncology as 'individualised'. The information provided by health professionals for patients depends on patients' needs and characteristics, the skills and beliefs of health professionals, and the system in which health professionals and patients interact.

6.3.6. MAP INTERPRETATION

Finally, health professionals used the maps displayed during the interpretation sessions to consider how information exchange formed part of brain tumour care, and as a tool to highlight opportunities for interventions. These were most evident with regard to a perceived lack of integration and coordination of services (health care system issues) and suboptimal communication between health professionals (health professional characteristics). Health professionals interpreted the concept map (Figure 5.6), as a suitable diagrammatic representation of brain tumour care, with all elements necessary for ideal care represented. However, most health professionals believed that, compared to the cluster map presented to them, the *Communication* cluster has a more central role, with other aspects of patient care such as information branching off communication (Figure 6.9).

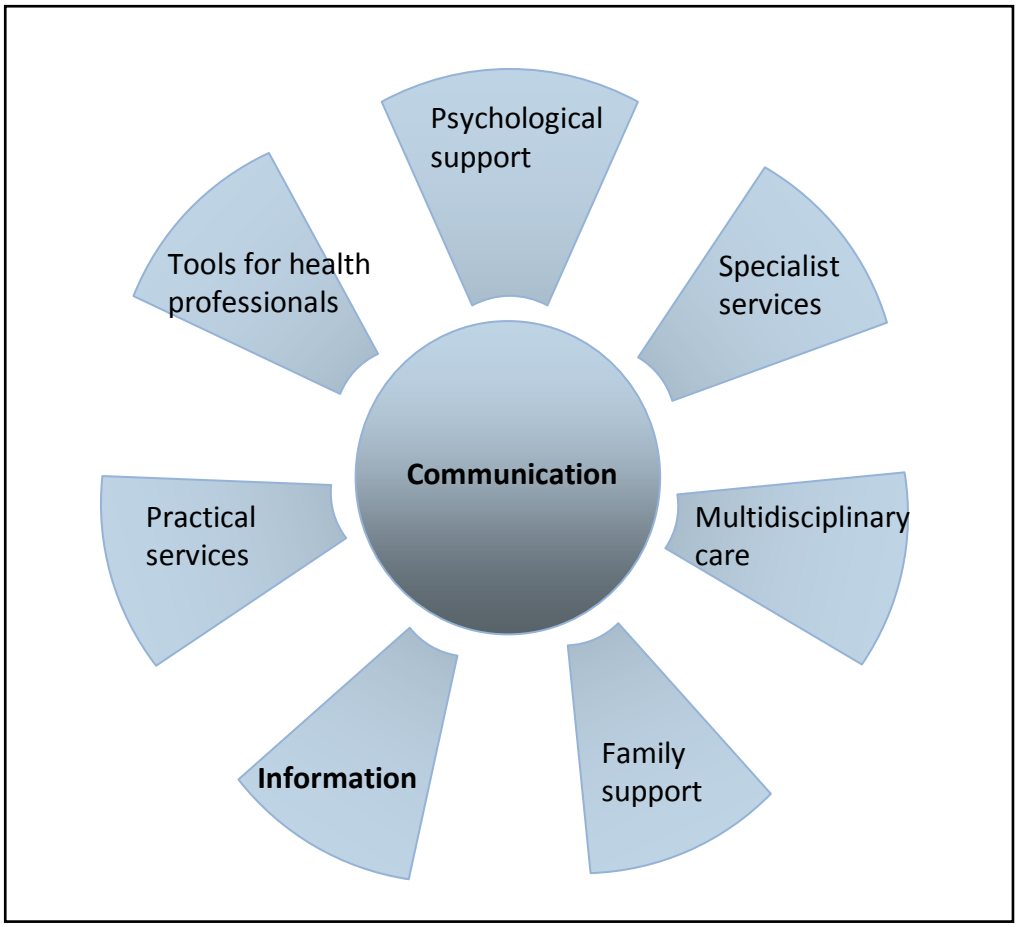


FIGURE 6.9 PARTICIPANTS' CONCEPTUALISATION OF THE ROLES OF COMMUNICATION AND INFORMATION IN IDEAL BRAIN TUMOUR CARE

Communication and information were thus seen as distinct entities, with communication serving both as a vehicle by which information was given to patients, and as a link or coordinating element between all other services. Participants believed communication between different health professionals, and between patients and health professionals, were of central importance in facilitating information exchange.

> *"Well your Communication [cluster] should be in the middle, really. I guess, um, because your communication is telling the family where they can go and get the services – Multidisciplinary Care, and the Psychological Support, and the Tools. And the Practical Services etcetera. So your Communication [cluster] really has to be – like the octopus – the centre, the nucleus."* (Person 5, maps).

6.4. DISCUSSION

The set of items generated by participants overlapped with several recommendations described in the Australian clinical practice guidelines for glioma (2009), such as for prognosis to be discussed with the patient and family (item 8), for a support person to be present whilst the diagnosis is received (item 28), and for early referral to palliative care (item 26). Other items, such as routine assessment of distress (item 9), have been recommended for cancer patients generally, and implementation is underway (Institute of Medicine 2008; Dudgeon et al. 2011). This suggests that the items generated are highly relevant and have the potential to improve the care of brain tumour patients.

Participants rated the importance of all 42 items above the half-way mark (≥3.0, on a 1-5 scale). The cluster *Psychological support* had the highest importance rating, suggesting it is seen as most important for brain tumour patients. Participants' feasibility ratings were all also above the half-way mark, suggesting participants believed it was feasible to implement the interventions they suggested. In contrast, 26 of the 42 items were rated below the half-way mark for existence. This may suggest that health care professionals are either not aware of services, or that services are not commonly available.

Overall, this study corroborates earlier findings that there is wide variability in how well information is provided to cancer patients (Edwards et al. 2009). Findings of the thematic analysis suggest that health professionals are aware that their communication skills, style and attitudes, as well as perceptions of patients, influence information provision. Health professionals also try to tailor the information they give to patients based on patients' information needs and information preferences. Congruence between the information provided and the information wanted has been shown to lead to higher levels of patient satisfaction and lower levels of distress and anxiety (Thomas et al. 1999). However, health professionals also reported tailoring information based on the patient's age, gender and prognosis. Whilst these factors may influence information need (for example, women and younger people generally seek more information than men and older people (Manne 2007)), they do not prescribe information need or preference.

Making judgements about categories or groups of people, and generalising these judgements is a common adaptive strategy to simplify the complex information and stimuli to which humans are exposed (van Ryn & Burke 2000). If the characteristics assigned to a group are automatically and unconsciously assigned to a specific individual, this process is referred to as stereotyping (van Ryn & Fu 2003). Given that stereotyping is a strategy used by all humans to simplify cognitive processing (Macrae et al. 1993), it is not surprising that it is used by health professionals who experience time pressure, task complexity and high emotional and cognitive load (van Ryn & Burke 2000). Previous studies have found that physicians use patient characteristics to predict patients' information requirements or desired involvement, including patients' age, socioeconomic position (Frojd et al. 2007), race (Street et al. 2007), perceived intelligence and number of dependents (Burton & Parker 1997). However, given that stereotyping may lead to incorrect perceptions of patients' needs, health professionals may need support and training to appropriately tailor information to patients' preferences.

Another factor was protectiveness, exemplified by some participants with regard to clinical trials. Previous studies have highlighted that structural or logistical factors (such as being unaware of open trials), and personal difficulties (such as concerns that the disclosure of uncertainty might affect the doctor-patient relationship), limit health professionals' recruitment of patients (Ellis 2000). Health professionals have also been found to adopt stringent criteria, often selecting only patients with far more favourable health status and prognosis than protocols demand, when determining which patients to approach about studies (Ford et al. 2011). However, the attitudes of health professionals towards research with patients with brain tumours in particular have not been well studied.

Some studies have examined doctors' attitudes towards recruiting 'vulnerable' patients for research. Kemeny et al. (2003) found decreased enrolment by physicians of patients who were older, with more advanced disease, or with comorbidity, even though they were potentially eligible. Although patients' views may play a part in this, health professionals have reported concerns regarding the effects of clinical trial treatments on their patients' comorbid conditions, the cost to

patients, and the burden of data collection on patients (Howerton et al. 2007). Clinicians also tend to be more concerned about the individual benefit for their patient, than about improving future therapies (Caldwell et al. 2005).

The views of other health professionals, who may not act as 'gatekeepers' to clinical trials, but who may clarify and interpret the information presented by physicians (Cheng et al. 2000), are less well known. Burnett et al. reported on the views of nurses in a US cancer centre towards clinical trials (2001). Although almost all nurses believed that clinical research was important to improve future standards of care, only half agreed that patients should be encouraged to participate in research. Most nurses also believed that patients participated in research with the expectation of cure, but again, only half thought patients were well informed when they chose to participate in a clinical trial (Burnett et al. 2001). Another study of physicians' and nurses' attitudes towards research with newborn babies found that nurses were much *less* likely than physicians to report that they would consent to enrol their own babies in research studies, and less likely to encourage other parent to enrol their babies in research studies (Singhal et al. 2004, p. 777).

The results of the current study and Burnett et al.'s research are consistent with the concept of nurses as patient advocates (Winslow 1984). Given that patients who participate in clinical trials receive promising new treatments, and often have greater monitoring and thus better outcomes than would be expected with standard treatment (Davis et al. 1985; Reiser & Warner 1985), education of health professionals of the aims, goals and ethical standards of clinical trials may be needed.

Protectiveness was also seen in discussions of what was 'unnecessary information' for patients. Health professionals who treated patients early in their disease were concerned that providing information to patients about potential future impairments or putting one's affairs in order in case of death or impairment would take away patients' hope. Avoiding discussion of 'bad news' for the perceived psychological benefit of patients has previously been described (Tuckett 2004). In Tuckett's typology of reasons for and against full disclosure of diagnosis and prognosis, discussion of 'bad news' may be avoided by health professionals because

it contravenes duties of benevolence and nonmaleficience, causes distress, pain and anger, and diminishes hope (2004). However, as health professionals who treated patients later in the disease journey reported, discussing the future enables the patient to make decisions and take action whilst he or she is able to. The difficulty of balancing truth telling and nurturing hope has been previously described in palliative care and advanced cancer settings (Porter 1999; Begley & Blackwood 2000; Clayton et al. 2005). For example, while several palliative care health professionals believed that it was important not to 'collude' with patients' unrealistic expectations (to avoid harm due to unpreparedness for death), while others believed denial was a valid coping mechanism that should be protected (Clayton et al. 2005).

Some health professionals characterised the doctor-patient relationship as an unequal power relationship although gradually weakening with improved access to information from sources such as the internet. Although these descriptions were given predominantly by nursing and allied health professionals, the power imbalance between patients and doctors has been well described (e.g. (Higgins 1994)). Patients' increased access to information via supportive care services or the internet may have a levelling effect on the power imbalance in the doctor-patient relationship (Bylund et al. 2007). Increased information may not eliminate that balance completely, because health professionals will still have technical competence unavailable to patients (2002). However, increased access to information may empower patients to become more active participants in their care (Bylund et al. 2010; Bylund et al. 2009).

In this study, health professionals expressed relying on patients to guide the process by which they received information and support, consistent with recommendations from professional education materials for health professionals, which emphasise "let patients lead you" and "they will tell you how much they want to know" (Towers 2007, p. 56). Studies have also shown that physicians provide more information to patients who ask questions, express concerns, and give opinions (Street 1991). Reliance on patients to guide information provision was also evident in participants' high ratings for both importance and feasibility for 'information to

enable the patient or carer to ask questions' (item 34) and 'for doctors to encourage patients to ask questions and help them feel comfortable asking questions' (item 17).

The final factor identified by participants as influencing information provision was health system issues, including resource and logistical issues and fragmented care. Fragmented care has been previously highlighted as a barrier to information-seeking by brain tumour patients (Leavitt et al. 1996), and may contribute to difficulties described by participants in communication across health professional groups. Together, these factors may diminish the 'continuity of care', or extent to which services are perceived as coordinated, coherent, connected and consistent with patients' needs (Woodward et al. 2004).

Together, the five main themes identified by this study suggest health professionals perceive that information provision for brain tumour patients is highly individualised, tailored to patient's needs and influenced by health professionals and the underlying connectivity of the system. These themes correspond to some extent with the speculative model of influences on information provision developed as part of the literature review (Figure 3.2, page 40). Applied to this model, this study suggests potential targets for intervention to address the information needs of brain tumour patients and carers, such as: modifiable characteristics or perceptions of health professionals or patients (e.g. communication skills; behavioural norms surrounding medical consultations), continuity and communication across the health care system (also shown in Figure 6.9), or patient materials.

6.4.1. SELECTION OF AN INTERVENTION

This study's quantitative and qualitative findings, and evidence from the literature, were considered to select an intervention appropriate to the brain tumour setting. From the quantitative findings, the intervention that was rated as most important by participants was for a care coordinator, and this item was rated above the mean for feasibility. Support for this item was shown in qualitative findings, in which health professionals identified that having continuity, and an ongoing relationship between a patient and health professionals, facilitated patients' expressions of

information need, and health professionals' understandings and response to these cues. As previously reported (section 3.5.4), coordination of care has been recommended to improve the provision of consistent, timely, appropriate information tailored to patients' needs, across the disease trajectory (Yates 2004; Walsh et al. 2011; National Cancer Control Initiative 2002).

However, care coordination may as yet not be the most appropriate vehicle to achieve visible improvements in information provision, because of difficulties evaluating its impacts. The most appropriate outcomes and indices for evaluation are still being debated, and only weak evidence exists that care coordination improves care outcomes (Mills & Sullivan 1999). When coupled with the financial and time requirements of a doctoral project, care coordination was not a suitable target for intervention.

The potential value of another intervention was suggested by qualitative findings. Overarching themes from this study concurred with evidence from the literature and clinical practice guidelines that recommend that information be tailored to the needs and preferences of patients and carers (Schrag 2005; Australian Cancer Network Adult Brain Tumour Guidelines Working Party 2009). Qualitative findings also showed that health professionals are concerned about overwhelming or scaring patients by providing information that was not needed or wanted, or that may cause distress (protectiveness), and that they rely on patients to express the information that they need and want (patient initiative).

A reliance on patients to express their information needs has been shown in other studies, which have found that physicians provide more information to patients who ask questions and express concerns (Kinnersley et al. 2008; Street et al. 2007; Butow et al. 2008). However, patients may not ask questions because they are afraid of taking up too much of their physicians' time, are afraid of appearing inadequate, feel uncomfortable (Li & Lundgren 2005), do not know what to ask, or how to articulate their concerns (Clayton et al. 2003).

A review of potential interventions relating to the asking of questions (section 3.5) revealed that question prompt lists (QPLs) have been successful in increasing question asking (Dimoska et al. 2008). As previously reported (section 3.5.3), a QPL

is a structured list of questions that a patient or carer can ask of health professionals if they wish, that is designed to encourage the asking of questions in medical consultations (Clayton et al. 2005; Bruera et al. 2003). A QPL is a low-cost intervention that may assist patients to express their information needs, and assist health professionals to determine how much, or what, information to provide (Kinnersley et al. 2008).

Support for interventions to encourage patients to ask questions was demonstrated in participants' above average ratings for the items 'information to enable the patient or carer to ask questions' and 'for doctors to encourage patients to ask questions and help them feel comfortable asking questions'. In addition, QPLs have not previously been developed for or trialled with brain tumour patients. Given the concordance of these findings, it was decided to develop a QPL aimed specifically at brain tumour patients.

6.4.2. STRENGTHS AND LIMITATIONS

The concept mapping process gains strength by utilising both individual and group-oriented activities (Trochim & Linton 1986). Participants worked independently during some data collection stages (i.e. sorting, rating), and thus were not required to share perceptions publicly, which may have avoided group problems such as conformity bias (Burke et al. 2005). The graphic representations of concepts and their relationships with each other were also easily understood, facilitating interpretation via individual and group discussion (Burke et al. 2005). Caution must be taken to view the point and cluster maps as tools, rather than as conceptual realities, but the triangulated design in which different qualitative and quantitative methods were combined contributes to the validity of the overall findings (Burke et al. 2005).

However, the results are partial, and reflect the views of participants at that time, rather than being 'generalisable'. Overall, a relatively small number of health professionals (n=30) participated in this study, and study participants were recruited using nonrandom sampling. Only a small number of medical specialists participated, which may have led to different results than would have resulted with greater recruitment of specialists. However, a meta-analysis of previous studies

using concept mapping suggests that at least ten participants are required for quantitative analyses, with greater clarity of results with increasing numbers up until a threshold of around 40 participants, at which points returns typically decrease (Kane & Trochim 2007). Recruitment was purposive, and included participants from a diverse range of disciplines and settings to allow the generation of new ideas (Higginbottom 2004). Recruitment was also conducted until saturation in each qualitative phase, suggesting that the participation of further health professionals would not have substantially changed the study conclusions.

Another potential limitation of this study relates to asking participants to assess the feasibility of potential interventions. The go-zone graph plotting importance versus feasibility (shown in Figure 6.7), shows items in the top right sector that were rated by health professionals as highly important and highly feasible. These items may be more appropriate and accepted targets for intervention than items rated of low importance and low feasibility, and more support may be offered by health professionals for their implementation. This is particularly relevant as part of the rationale for this study was to encourage the 'buy in' of relevant health professionals. However, this process relied on participants to understand the meaning of each item in a similar way, and divergent ratings may have resulted from different interpretations of items. This process may also have restricted the likelihood that more innovative or 'blue sky' ideas were supported.

This study also involved the examination of the ratings of specific health professional groups based on discipline and setting. Results from this analysis suggest that health professionals from different professional backgrounds, or who work in different settings, differ in the priority or value they place on potential interventions for brain tumour patients. However, these differences were not examined for statistical significance, and because of the small sample size, these conclusions should be interpreted with caution. Given that the intention of the analysis was not to test hypotheses but to explore the perspectives of health professionals, this does not significantly impact the study findings.

To strengthen the rigour of the study's findings, and to allow the exploration of meaning of the quantitative results, findings from the sorting and rating activities

were used as a tool for further discussion. The characteristics of participants varied across data collection steps, as shown in Table 6.1. Participants in the final interpretation phase were more likely to be female, nurses, and to work only in private hospitals, than participants in the previous data collection steps. The impact of these different characteristics on study findings is debatable. Trochim and colleagues (2007; Trochim 1989) state that the same participants, or same number of participants, are not required for each data collection step, as long as diversity is preserved and saturation reached in the two qualitative analyses.

Finally, this study considered only the views of health professionals, and patients and carers may suggest different potential interventions, and identify other factors that influence information provision. It may be argued that basing the choice of an intervention on the views of health professionals, rather than the views of patients and carers, could perpetuate inequities inherent in the system. This argument could be supported by the choice of a question prompt list, which aims to change the behaviours of patients, rather than health professionals (Salmon 2005). Although this criticism may be justified, continued exposure to increased question asking by patients and carers may ultimately result in improvements in information provision.

6.4.3. CONCLUSIONS

The primary purpose of this study was to identify a potential intervention suitable for implementation in the neuro-oncology setting. As previously highlighted, two items related to patient question asking were rated highly for importance and feasibility by health professionals. Qualitative findings supported the need for an intervention that promoted tailoring of information, the perceived need to 'protect' patients from unwanted information, and reliance on patients to guide the process of information provision, such as through question asking. The concordance of qualitative and quantitative results, support for QPLs in other cancer settings, lack of a brain tumour specific QPL, and the feasibility of developing a QPL within a doctoral program, contributed to the decision to develop a QPL for brain tumour patients and carers.

7. STUDY 2: QUESTION PROMPT LIST DEVELOPMENT

7.1. INTRODUCTION

The previous study suggested that health professionals may be better able to provide information to brain tumour patients who indicate their information needs and preferences, and thus 'lead' the process of information provision. Provider-patient communication and information exchange can be aided by patients asking their health care providers questions, and by doctors and other health professionals encouraging question-asking by patients. As described in Chapter 1, question prompt lists (QPLs) have been used to increase patient question asking in cancer settings. However, no such QPL has been developed for brain tumour patients. This chapter describes the development of a brain tumour-specific QPL. It thus consists of methods used to develop the QPL (including existing resources, participants, and data analysis techniques), results of these activities, and a brief discussion on the process and outcomes.

7.2. METHOD

The development of this QPL was guided by the principles offered by O'Donnell and Entwistle (2003) for producing health-care information for patients. As such, the development process was iterative, involving the elicitation and incorporation of feedback from relevant stakeholders (patients diagnosed with brain tumours and their carers, and health professionals who treat them), to ensure the final draft was understandable, usable and accessible.

Many resources which aim to inform persons diagnosed with brain tumours already exist. Thus, to minimise the burden on participants, we compiled an initial draft QPL, based on existing cancer and general QPLs, as well as brain tumour patient information materials. The initial draft QPL was further developed with feedback from stakeholders, with testing of the readability of the draft QPL, and redrafting as needed to improve readability, at each development stage. The development of the QPL progressed through five phases, as shown in Figure 7.1.

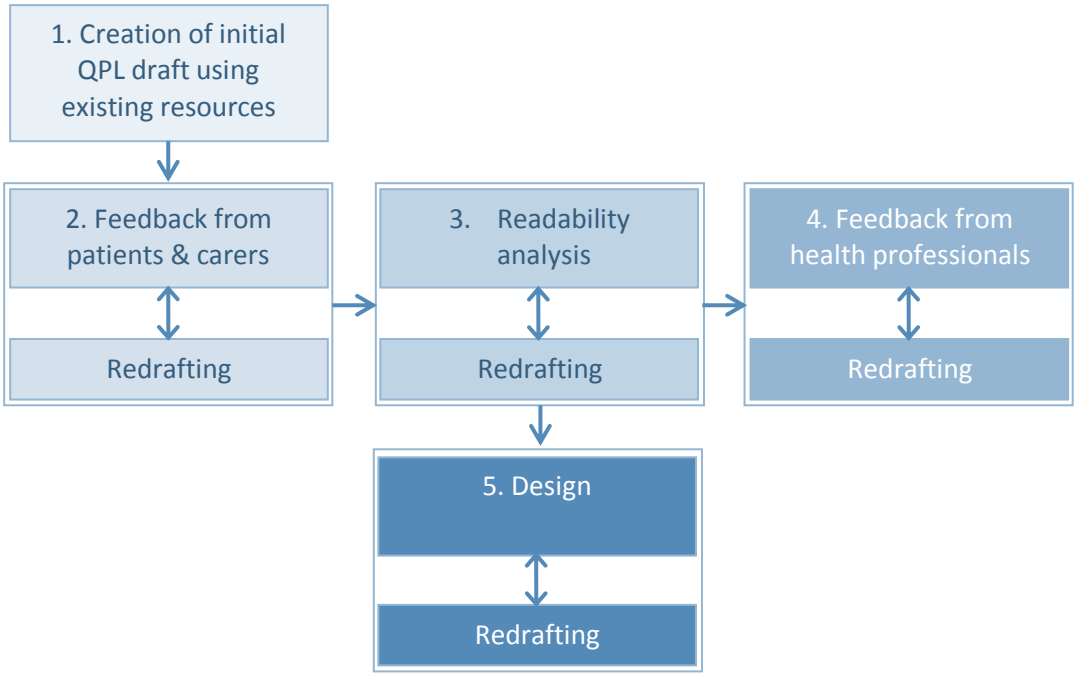


FIGURE 7.1 STUDY 2 PHASES

Each of these phases is elaborated on below. Ethical approval from the QUT HREC (approval no. 0800000079) and UnitingCare Health HREC (approval no. 200836) was received for this study (Appendix G).

7.2.1. PHASE 1: CREATION OF INITIAL QPL DRAFT USING EXISTING RESOURCES

7.2.1.1. SOURCES AND ANALYTICAL AIMS

The first phase comprised initial thematic analysis of four types of resources:

1) existing QPLs, comprising QPLs published in peer-reviewed journals and question lists from brain-tumour materials;

2) current information materials for patients with brain tumours available in Australia;

3) information recommendations outlined in 'Approach to the patient' from the draft Glioma Guidelines produced by the Australian Cancer Network[10] (2008); and

4) items pertaining to information needs suggested by health professionals in the previous study.

[10] These guidelines were in draft form at the time of the analysis; they have since been finalised and published.

The aims of this analysis were to identify common themes to form the structure of the QPL, and the breadth of questions or topics in each category.

Existing QPLs were retrieved from the peer-reviewed literature by searching Medline, PubMed, CINAHL, the Cochrane Library, Health Reference Center, PsycARTICLES, PsycINFO and PsycEXTRA with the search terms 'question prompt', 'question asking' and 'question list'. The inclusion criterion was that the QPL was presented (i.e. articles in which the QPL was not provided were excluded).

A comprehensive search of current information materials for patients with brain tumours was also conducted to identify two types of materials: QPLs, and brain tumour patient materials. The inclusion criteria applied were that brochures were: directed at patients with a brain tumour or their family or carer(s); not targeted solely at patients with a particular type of tumour (e.g. meningioma), parents of children with cancer or patients with brain metastases; not describing particulars of a single treatment modality; and available free of charge either through the internet or via mail.

Fourteen distinct QPLs were identified; nine from the peer-reviewed literature and five from current patient literature (Table 7.1). Four papers were excluded because the QPL was not provided (see Appendix H for exclusions). Five current brain tumour information brochures (also shown in Table 7.1) were randomly selected from the brain tumour patient education materials identified.

Of items suggested by health professionals (see Chapter 1), those containing 'information about', 'tell patient', 'inform patient', 'discuss with patient' or similar were selected. Items discussing changing patterns of care or structural items (e.g. for all patients to be discussed in multidisciplinary team meetings, or communications training for health professionals) were excluded. From the initial 649 items, 182 items were selected for analysis based on their relevance to patient information provision and/or health professional-patient communication (see Appendix H).

TABLE 7.1 EXISTING QUESTION PROMPT LISTS (QPLS) AND PATIENT MATERIALS USED TO IDENTIFY INFORMATION TOPICS VIA THEMATIC ANALYSIS

QPLs published in peer-reviewed journals (grouped by duplicates)
How to make the most of your time with the doctor (Brown et al. 1999; Brown et al. 2001; Butow et al. 1994)
Prompt sheet for breast cancer consultation (Bruera et al. 2003)
Asking questions can help: an aid for people seeing the palliative care team (Clayton et al. 2003; Clayton et al. 2005; Clayton et al. 2007)
An Evidence-based Question Prompt List (QPL) for Patients Seeing a Medical or Radiation Oncologist (Dimoska et al. 2008)
Questions you may want to ask the doctor (Fleissig et al. 1999; Glynne-Jones et al. 2006)
Frequently asked questions checklist (Martinali et al. 2001)
What you may want to know about your illness (McFarlane et al. 2008)
Question prompt list (McJannett et al. 2003)
Experimental treatment booklet (Tabak 1988)
QPLs from organisations
Questions to ask your doctor - The Cancer Council Qld
Cancer Answers: Common questions about everything from diagnosis to treatment and care - The Cancer Council NSW
Understanding Brain Tumours – Information Checklist - The Cancer Council NSW
Questions to ask your doctors from *Brain and spinal cord tumours: a guide for people with these tumours, their families and friends* - The Cancer Council Vic
Questions to ask your healthcare team from *The Way Ahead: a guide for those diagnosed with a brain tumour* - Schering-Plough
Current Brain Tumour Patient Information Materials
About brain tumours - The Cancer Council Queensland
Understanding brain tumours: a guide for people with brain or spinal cord tumours and their families and friends - The Cancer Council New South Wales
Living with a Brain Tumour - American Brain Tumor Association
Color Me Hope - Brain Tumor Society
Temodal Patient Support Resources - Schering-Plough

7.2.1.2. THEMATIC ANALYSIS

The thematic analysis was conducted in two parts. Firstly, themes common to existing QPLs were extracted. A second thematic analysis reviewed the other three sources (brain tumour patient materials, the relevant chapter of the draft glioma guidelines, and the list of items from interviews with health professionals), to identify additional topics specifically relevant to brain tumour patients.

The initial thematic analysis involved several readings of the selected QPLs to enable familiarisation with the data and subsequent identification of the core themes, utilising open coding, axial coding and selective coding. For open coding (see examples, Table 7.2), QPL questions were compared searching for similarities and differences, and conceptual labels applied to enable groupings into categories (Strauss & Corbin 1998). In axial coding, the initial codes were scrutinised to ensure they were fully elaborated and developed. Finally, in selective coding, links between the codes were mapped to allow integration around central categories or themes. Themes were then grouped together, re-examined and refined. Throughout this process, the questions from the initial sources were continually referred to, to ensure their meanings were not lost in the analysis.

The second thematic analysis reviewed the other three sources and applied the codes and themes from the QPL analysis to these documents. Where the documents contained topics not covered by the codes already developed, new codes were applied and themes developed, again using open, axial and selective coding. The new themes were integrated into the QPL analysis, leading to a final unification of information areas.

TABLE 7.2 EXAMPLE OF CODING IN THEMATIC ANALYSIS OF EXISTING QPLS

Text	Codes	Overall theme
What kind of cancer do/did I have?	type - diagnosis	diagnosis
Do members of my family have a greater risk of getting cancer?	family at risk – heritability – cause - diagnosis	diagnosis
Will it get better by itself?	improve by itself – natural history – what expect in future – prognosis	prognosis
If I have symptoms, what can be done to improve them?	options – improve symptoms – symptoms & problems	symptoms & problems
Is the treatment going to improve my chance of survival?	effect on symptoms & survival – benefits & risks – understanding treatment & choices - treatment	treatment
How long will I be on chemotherapy?	duration – treatment schedule – timing – practical/procedural – treatment	treatment
Is there someone I can talk to who has been through this treatment?	talk to someone been through this – peer support – support	support
How will I be followed up or monitored?	follow-up – plan for future – after treatment finishes	after treatment finishes
How will I know that my cancer has come back?	how know it has come back – recurrence – after treatment finishes	after treatment finishes
I would like to have a second opinion. Can you refer me to someone else?	refer – 2nd opinion – choice – members – health professional team	health professional team

7.2.1.3. FROM THEMATIC ANALYSIS TO DRAFT QPL

The overarching themes identified in the thematic analyses formed topics for the QPL. At least one question was written for each sub-theme of the QPL, with further questions written in areas with more codes, to allow more detail to be provided. Importantly, questions relating to unmet supportive care needs and/or topics reportedly difficult to talk about were included. For example, McFarlane and colleagues discussed that costs related to medical treatment is a notoriously difficult topic for patients to raise (2008). Questions were based on existing QPL items where these existed, or were written to elucidate information in the plainest language possible.

The wording, layout and visual appearance of the draft QPL was based on readability guidelines for patient information materials, particularly focusing on the needs of older adults, persons of low literacy, persons suffering cognitive impairment, and persons with aphasia. These included the use of: simple words and avoidance of jargon (Rose et al. 2003); 14-point font size, plain font type and white space to allow easy viewing (Arthur 1995; Rose et al. 2003; Weih et al. 2008); subtitles to break up text (Sullivan & O'Conor 2001); and short sentences (less than 20 words), to avoid undue reliance on memory (Weih et al. 2008).

The draft QPL was examined to ensure it only contained questions appropriate for newly diagnosed patients. For example, although end of life issues were a sub-theme of 'after treatment finishes', based on discussions with health professionals, direct questions about death and dying were excluded. This exclusion only covered questions directly about dying (e.g. about what death would feel like), rather than questions about the likelihood of death (prognosis), which were included. This decision was made because in-depth discussions about death are likely to arise at times of transitions (for example, transitions to palliative care), whilst detailed questions about the processes of death may be less common at diagnosis (Fagerlin et al. 2002). Furthermore, this topic is also already well covered by currently available materials, such as an Australian palliative care QPL (Clayton et al. 2005).

The draft QPL was then reviewed by the candidate's supervisors, a medical oncologist specialising in neuro-oncology, and three consumer advocates from The Cancer Council Queensland. These reviewers were specifically asked to consider whether there were any omissions.

7.2.2. PHASE 2: FEEDBACK BY BRAIN TUMOUR PATIENTS AND CARERS

Subsequent refinement of the draft brain-tumour specific QPL involved an iterative process of telephone interviews with patients recently diagnosed with a brain tumour (in the previous three years) and carers of recently diagnosed patients. Participants were asked to review appropriateness of topics, questions and language, and to comment on QPL length.

7.2.2.1. PARTICIPANT SAMPLING AND RECRUITMENT

A convenience sample of patients and carers was recruited using media strategies (see Appendix I for recruitment and data collection materials). A flyer advertising the study was included with a newsletter of The Cancer Council Queensland Brain Tumour Support Service, which is mailed to over 300 households across Queensland (Janda et al. 2006). The researcher informed to attendees of the July 1 2008 meeting of the Brain Tumour Support Service and invited them to participate in this research. A media release about the study was generated, which featured on the QUT news page and was picked up by some medical internet-based news pages.

To reach further potential participants, invitation letters were sent to twenty selected past patients of BrizBrain and Spine, a private neurosurgical clinic. Letters were sent by practice staff to adults aged over 18 years diagnosed with a primary brain tumour in the past 6-24 months who were not currently undergoing treatment, and were well enough to participate. Interested patients who returned the consent form were telephoned to answer any questions and arrange a telephone interview. Participants were asked to return a short demographic/tumour characteristic questionnaire by mail. Participants were also mailed a draft QPL for review prior to or during the telephone interview.

Recruitment of participants was planned to cease when informational redundancy was achieved. This was defined as occurring when no significant changes to the QPL (i.e. no new topics, and no questions deleted,) were suggested in four consecutive interviews.

7.2.2.2. DATA COLLECTION

Telephone interviews were utilised to enable participation by individuals unable to travel, or who lived outside the Brisbane metropolitan area. The use of telephone interviews is also known to enable participants to relax and discuss data that they may find difficult to disclose in face-to-face settings, including information about their perceptions of their medical care (Novick 2008; Zimney et al. 1980; Worth & Tierney 1993).

In the telephone interviews, open-ended questions were used to encourage participants to identify topics they thought a QPL for brain tumour patients should

include, focusing on questions they found difficult to ask, or information they wished they had received, or received later than desired (see Appendix I for the topic guide). Participants were then asked their opinion of the draft QPL they had been sent. This included discussion of their perceptions of the draft QPL's completeness, whether new informational areas needed to be added or whether they thought any questions were not relevant or inappropriate.

To allow continual refinement, changes suggested to the draft QPL were annotated by the candidate on the QPL during the telephone interviews. After the completion of the fourth interview, the draft QPL was modified and the next four participants were mailed the updated QPL. Changes to the QPL were then discussed by participants in subsequent discussions, leading to a gradual refinement of the list.

7.2.3. PHASE 3: READABILITY ANALYSIS

Analyses of the readability of the draft QPL were conducted following modification of the QPL in phases 2, 4, and 5, aiming for sixth grade level as recommended (Davis et al. 1990; Weih et al. 2008; Sullivan & O'Conor 2001; Freda et al. 1999).

Readability analyses generate mathematically derived ratings of the reading ease of written materials, and are influenced by factors such as vocabulary, sentence structure, and word density (Sullivan & O'Conor 2001). Three readability formulas were used: the Flesch reading ease formula/Flesch-Kinkaid grade level, the Statistical Measure of Gobbledygook (SMOG), and the Fry readability graph. These formulas produce slightly different results, but are each considered valid measures of readability, and the use of multiple formulas is recommended to ensure a thorough evaluation (Freda et al. 1999; Sullivan & O'Conor 2001).

7.2.3.1. THE FLESCH READING EASE FORMULA AND FLESCH-KINCAID GRADE LEVEL

The Flesch reading ease formula provides a score indicating readability from 0 (very difficult) to 100 (very easy) (Sullivan & O'Conor 2001). It is calculated using the formula:

Reading ease (RE) = 206·835 − 0·846 (wl) − 1·015 (sl)

where sl is sentence length in words, wl is number of syllables per 100 words

(Flesch 1948; Sullivan & O'Conor 2001).

The Flesch-Kincaid grade level converts the Flesch reading ease formula score, or raw data, into a grade-school level, which indicates the minimum school grade a person would require to be able to understand the document under review (Estrada et al. 2000). This grade level is calculated using the formula:

Grade level (GL) = 0.39 (sl) + 11.8 (wl/100) – 15.59
where wl is number of syllables per 100 words (Microsoft Corporation 2009).

Both these formulae have been incorporated into word processing programs such as Microsoft Word, enabling automated calculation (Sullivan & O'Conor 2001).

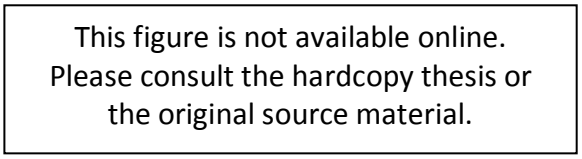
7.2.3.2. The Statistical Measure of Gobbledygook (SMOG)

The SMOG index is calculated based solely on the number of polysyllabic words (i.e. words of three or more syllables) in a document (McLaughlin 1969). To calculate the SMOG index, thirty sentences from the document (ten each from the beginning, middle and end of the document) were randomly selected, and the occurrence of polysyllabic words counted. The SMOG index, which also yields a grade level, is calculated using the formula:

SMOG grade = 3 + √(nearest perfect square to number of polysyllabic words)
(McLaughlin 1969).

7.2.3.3. The Fry readability graph

To calculate the grade level of readability using the Fry readability graph, the number of syllables and sentences, per 100 words, were calculated from three 100-word passages randomly selected from the text (Sullivan & O'Conor 2001). The average number of syllables and the average number of sentences per 100 words (across the three sections) were plotted on the Fry readability graph (Figure 7.2), to determine the grade level required to read each word passage (Fry 1969).



Source: (Browak 2007).

FIGURE 7.2 FRY READABILITY GRAPH

7.2.3.4. CHANGES MADE TO IMPROVE READABILITY

Guidelines for improving readability and understanding were applied to make changes to the QPL to improve readability. These changes included: reducing sentence length (Weih et al. 2008); replacing complex words with simpler alternatives (Rose et al. 2003); and removing words which may not be meaningful to readers (Sullivan & O'Conor 2001). Examples of changes made to the draft QPL to improve readability are shown in Table 7.3.

TABLE 7.3 EXAMPLES OF CHANGES MADE TO THE DRAFT QPL TO IMPROVE READABILITY

Change	Example
Shortening sentences	"Not all of these questions will be relevant to you, and the different sections of this brochure may be applicable to you at different times" *replaced with* "Not all questions will apply to you, or be important right now" (pp. 1-2)
	"What functions are controlled by that part of the brain?" *replaced with* "What does that part of the brain do?" (p 3)
Replacing complex words	"Is there someone who can help me cope with the changes my family and I are experiencing?" *replaced with "*Is there someone who can help me cope with the changes my family and I are going through?" (p 4)
	"What other tests will I need, and what is their purpose?" *replaced with* "What other tests will I need, and what for?" (p 9)
Removing non-meaningful words	"doctors and other health professionals" *replaced with* "doctors or other staff" (p 1)
	"Can you refer me to a vocational rehabilitation counsellor to help assist me to get back to work?" *replaced with* "Can you refer me to someone to help me to get back to work?" (p 27)
Removing words with strong emotional or cultural meanings	"What symptoms could I suffer from in the future?" *replaced with* "What symptoms may occur in the future?" (p 7)
	"On average, how many patients like me do you treat each year?" *replaced with* "On average, how many people like me do you treat each year?" (p 14)

As also recommended by Sullivan and O'Conor (2001), words which have strong emotional or cultural associations that may obscure the intended meaning were replaced with neutral alternatives. For example, some diagnostic labels (e.g. 'hysteria') which have been given to patients with medically unexplained symptoms have been perceived as offensive for implying that the patients were 'putting it on' (Stone et al. 2002). However, a change in the wording of a question to avoid potentially causing offense was only made if such a change would not obscure the meaning of the question (i.e. euphemisms were avoided) (Freeman 1994).

7.2.4. PHASE 4: REVIEW BY HEALTH PROFESSIONALS

After readability was optimised, the modified QPL underwent a verification process to ensure that health professionals expected the questions to elicit useful and highly important information during consultations. A purposive sample of health professionals (identified during the previous study) was invited to review the QPL. Feedback from these health professionals was then used to modify the QPL.

The readability of the QPL was subsequently assessed and modified as previously described.

7.2.5. PHASE 5: BOOKLET DESIGN

After all previous steps were completed, the text of the draft QPL was incorporated into a booklet format with appropriate font, graphics and illustrations. Besides its content, the design of patient materials also contributes to readability, particularly for persons with visual, language and/or cognitive impairments (Rose et al. 2003; Estrada et al. 2000; Weih et al. 2008). Four common design principles were followed:

- large, simple font (Rose et al. 2003; Weih et al. 2008);
- white space around the text (Rose et al. 2003);
- figures, pictograms or other appropriate illustrations (Estrada et al. 2000); and
- subtitles and/or lists to break up the text (Sullivan & O'Conor 2001).

Other measures incorporated to improve readability and suitability were:

- colour coding of different sections;
- clear page numbering and a table of contents;
- inclusion of illustrations of persons from a variety of ethnic and demographic backgrounds; and
- 'notes' pages so that patients or carers could write down answers received from health professionals, or additional questions.

Using the iterative method previously described, a further group of past patients and carers then gave feedback regarding the layout and design, and face validity of the QPL as a whole.

7.2.6. How Rigour was Achieved in this Study

Six techniques recommended to ensure rigour (see section 5.4), were considered in the design and implementation of this study: 1) theoretical rigour; 2) methodological or procedural rigour; 3) interpretive rigour; 4) triangulation; 5) evaluative rigour; and 6) rigorous reflexivity (Liamputtong & Ezzy 2005).

Theoretical rigour (consistency between research aims and strategy) was evident through this study's conception, in that it was developed from the results of the previous study. That study, together with a review of the literature, suggested that encouraging patients to ask questions of their doctors could improve information provision. To achieve the research aims, this study involved the use of existing materials (QPLs, patient literature and clinical guidelines), interviews with patients and carers (to allow for questions or topics not found in existing materials), assessment of readability (and redrafting as necessary), and review by health professionals (to ensure suitability of the final QPL for the medical consultation). These methods ensured the appropriateness of the QPL to both patients and health professionals, and evidenced theoretical rigour.

Methodological or procedural rigour (clear documentation of methodological and analytical decisions) was apparent through detailed documentation of the methods used, such as the thematic analysis undertaken. The practices used in this research were clearly defined, and all supporting documents (including the literature subjected to thematic analysis, recruitment documents, the topic guide used in interviews, and the development of codes and themes), were included for transparency (Appendices G-N), and to permit and external audit (White et al. 2003; Huberman & Miles 1983).

Interpretive rigour (which is gained when the interpretation accurately represents the understanding of participants and data,) was demonstrated in this research via the inclusion of primary texts (e.g. existing QPLs, patient literature, Appendix H). These allow evaluation of the authenticity of conclusions drawn (Liamputtong & Ezzy 2005). To further ensure that participants' meanings were preserved, their own words were used wherever possible as questions were rephrased during the QPL's refinement.

Triangulation is evident in this research through the use of multiple methods and analyses (e.g. two thematic analyses of literature, interviews) and different information sources (e.g. existing QPLs, brain tumour patient materials, clinical guidelines, past patients and carers, and health professionals). Consideration of the ethical and political aspects of research was also given to ensure evaluative rigour. These aspects were first addressed procedurally, in that ethical approval was gained and procedures for informed consent followed. Concern for participants' also shaped the research design, in that existing materials were used for initial QPL development to minimise participant burden.

Finally, the candidate has examined her role in the research, as part of efforts towards rigorous reflexivity. The initial QPL was drafted based on the emergent themes from the thematic analyses. These analyses were conducted by the candidate, and therefore were influenced by the candidate's preconceptions and ideas. The QPL was then refined via interviews with participants conducted by the candidate, which were also subject to the candidate's interpretation. However, the candidate's viewpoint reflects a belief in the importance of empowerment and autonomy, which is consistent with the aims of this study.

7.3. RESULTS

7.3.1. PHASE 1: CREATION OF INITIAL QPL DRAFT USING EXISTING RESOURCES

Seven main themes were identified from thematic analysis of existing QPLs: 1) diagnosis; 2) prognosis; 3) symptoms and problems; 4) treatment; 5) support; 6) after treatment finishes; and 7) the health professional team. Figure 7.3 summarises the overall themes and subthemes that emerged from this analysis.

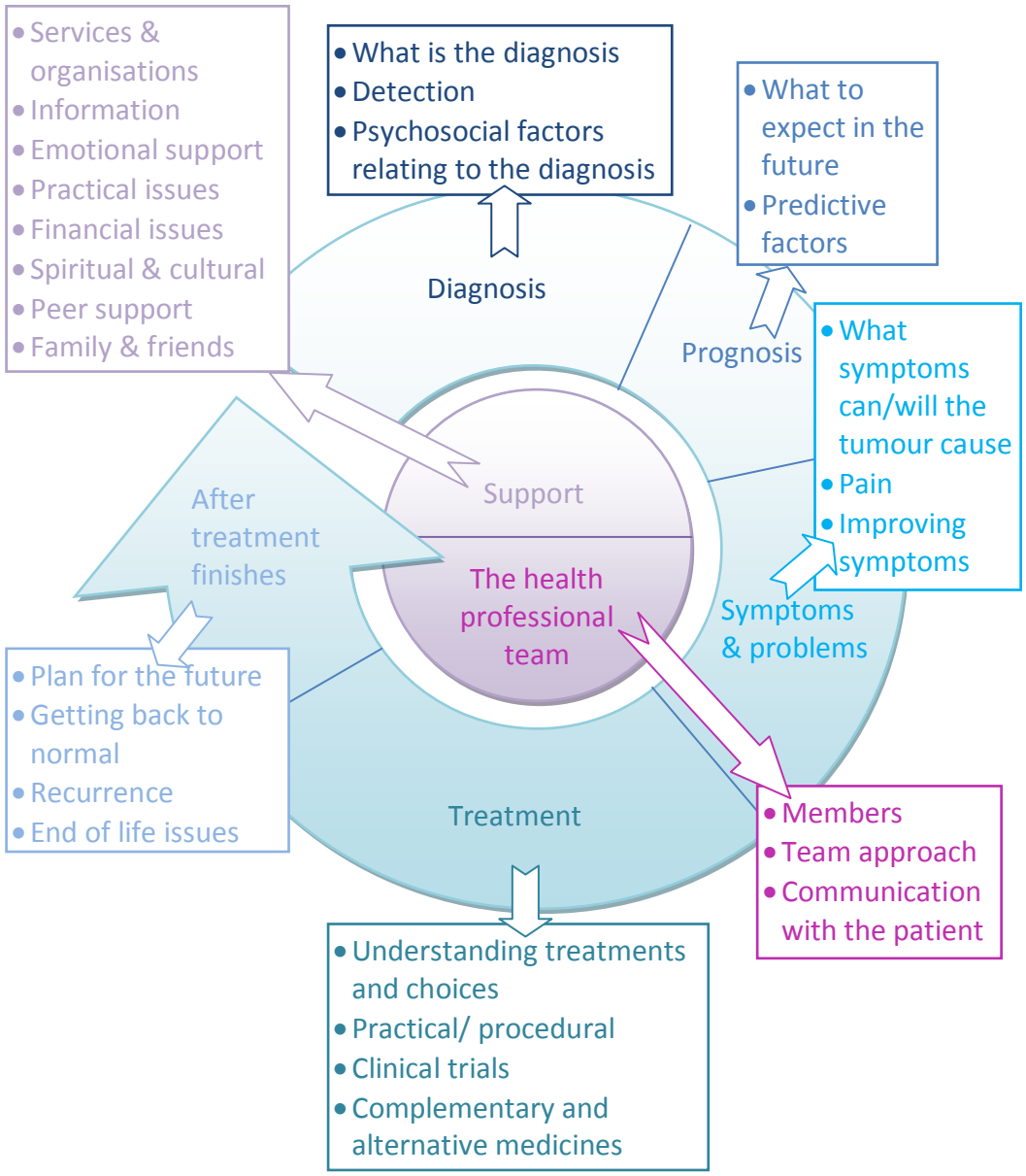


FIGURE 7.3 THEMES AND SUBTHEMES TO EMERGE FROM ANALYSIS OF EXISTING QPLS

Diagnosis

All QPLs included one or more question asking about the diagnosis.

> *"What kind of cancer do/did I have?"* (QPL 1)

Some QPLs contained more detailed questions about the tumour type, location and extent, and/or questions about its cause or heritability.

> *"Where is the tumour located in my brain?"* (QPL 14)
>
> *"If it is malignant, how extensive is my cancer? (How much cancer is there?)"* (QPL 15)
>
> *"Will my children have higher risk of getting cancer?"* (QPL 2)

Questions about the detection of the tumour were also covered, concerned with the purpose of tests, and procedural or experiential aspects, such as whether the test would hurt.

> *"What will I experience when having the test?"* (QPL 4)

Many QPLs also included a question regarding psychosocial elements of diagnosis, such as communicating the diagnosis to family members, or coping with the diagnosis.

> *"How do I tell my family and friends?"* (QPL 11).

Prognosis

The QPLs also contained questions about prognosis, although the depth of the questions varied from very basic to asking for details on probabilities.

> *"What is my outlook?"* (QPL 8)
>
> *"What is the expected survival for people with my type of cancer?"* (QPL 4)

In addition to questions about survival, questions were also identified that asked about quality of life issues.

> *"What can I expect to be able to do?"* (QPL 3)
>
> *"How will my life change?"* (QPL 9).

Symptoms & problems

Questions about symptoms that a patient may experience, and options for improving and/or controlling symptoms, were included in many QPLs.

> *"What cognitive/physical changes should I expect based on my tumour location?"* (QPL 14)

> *"What treatments are available to relieve my symptoms?"* (QPL 10)

Pain was a symptom that received significant attention, with many QPLs having a separate question about how pain would be treated.

> *"What if I have pain?"* (QPL 11)

Also significant as a sub-theme under symptoms and problems was understanding symptoms to watch for, and actions to undertake if these arose.

> *"Are there any problems I should watch out for?"* (QPL 13)

> *"What symptoms should I be alert for (i.e. fever, pain, etc) and what should I do about these symptoms?"* (QPL 2).

Treatment

The most significant theme, covered widely in terms of the number of sub-themes and codes in most existing QPLs, was treatment, particularly understanding treatment and choices. Most questions in this sub-theme asked about the purpose of treatment, choosing a treatment option, benefits and risks of treatment, and treatment side effects.

> *"What is the aim of each treatment? Is it to cure, control, prevent spread, prevent recurrence or relieve symptoms?"* (QPL 10)

> *"What are the risks and possible side effects of each treatment?"* (QPL 12)

In addition to highlighting the effects of the treatment on symptoms and survival, many QPLs also featured questions about the effects of treatment on a person's quality of life or lifestyle, or aimed to ascertain behaviours that a person should or should not engage in.

"What difference will this treatment make to my quality of life – can I work, have sex?" (QPL 10)

"How much activity or exercise is too much and how much is too little?" (QPL 3)

Practical and procedural questions were significant, asking about the timing of treatment (e.g. treatment schedule, duration, frequency), cost (out of pockets, insurance cover), location (e.g. public versus private hospitals, inpatient or outpatient treatment), and information on how treatment is given (e.g. how to manage medications, duration of hospital stay after surgery).

"How long will I be on chemotherapy?" (QPL 14)

"What is the cost of any new medication?" (QPL 3)

"Will I have to stay in hospital, or will I be treated as an outpatient?" (QPL 13)

"Will I have to have an injection?" (QPL 9)

Many QPLs featured questions about clinical trials, including understanding what they are, how to identify relevant trials, and how to decide whether or not to participate in a trial.

"What are clinical trials? Are there any that might be relevant for me" (QPL 4)

"What would I have to do as part of the clinical trial?" (QPL 10)

Questions about complementary and alternative therapies featured in some QPLs.

"What is the difference between complementary and alternative therapy? Can I use them?" (QPL 11)

"Are there any other complementary or alternative therapies that may help, e.g. acupuncture, naturopathy?" (QPL 14)

"If I am taking alternative medicine, can I still continue (herbs, natural foods, massage and chiropractic therapy, etc)?" (QPL 2).

Support

All QPLs contained questions about support. Many questions aimed to allow identification of specific services or organisations, including information about what they might offer, how they could be accessed, and costs involved.

> *"Are there support services I can access when I go home?"* (QPL 8)

> *"Where can I go for rehabilitation?"* (QPL 11)

Sources of information were also a topic of questions, including where to best get information about specific topics, information in different formats (e.g. books, pamphlets, videos, internet websites), and information for special groups (e.g. special needs, different languages, cultural groups).

> *"Do you have a video I could look at on this surgical procedure?"* (QPL 8)

> "*Can I get information on my cancer through the internet?"* (QPL 2)

> *"What resources are available for different cultural groups?"* (QPL 11)

Emotional support was covered, including how someone is likely to feel, and how people can cope.

> *"How am I likely to feel through this and what can I do to cope?"* (QPL 3)

Some QPLs contained questions about spiritual and cultural support, such as referral to someone for support, or to talk to someone from their own culture.

> *"I'm not religious, but I feel like I need something more meaningful in my life, especially now I have cancer."* (QPL 11)

> *"Can you arrange for me to talk with someone from my own culture, someone who may understand me better?"* (QPL 3)

Another sub-theme of support was peer support.

> *"Is there someone I can talk to who has been through this operation?"* (QPL 8)

> *"Do you know of any support groups I can join?"* (QPL 14)

QPLs also contained questions about support for and from family and friends, such as suggestions for how they could help, how support for them could be gained, and how to communicate with them.

> *"How can my partner and I help each other in the present situation; what should people in my direct environment do?"* (QPL 6)

> *"What should I say to my family and friends?"* (QPL 8)

Practical support was another topic of support-seeking questions. Questions asked for the identification of resources such as equipment, respite care, or help at home.

> *"Can you provide equipment to make every-day living easier at home?"* (QPL 3)

A significant sub-theme of many QPLs was financial support, including information about the costs of illness, information on differences between the public and private system, and identification of financial support for one's self or partner.

> *"What is the cost involved with seeing the palliative care team?"* (QPL 3)

> *"Am I eligible for government assistance?"* (QPL 14).

After treatment finishes

Although not evident in all QPLs, some covered care after treatment finishes, which comprised four sub-themes: plan for the future; recurrence; getting back to normal; and end of life issues.

Having a plan for the future was enunciated in a variety of ways, such as identifying future tests or treatments that might be needed, or understanding follow-up with different health professionals.

> *"Will I need to see you again and why?"* (QPL 5)

> *"Are future tests and examinations necessary and for what purpose?"* (QPL 6)

The possible recurrence of the tumour was raised in almost all QPLs. Questions asked about the likelihood of the disease returning, how it would be identified, if it could be prevented, and what would be done if the disease recurred.

"If we get rid of the cancer, what are the chances the cancer will come back?" (QPL 2)

"How will I know that my cancer has come back?" (QPL 11)

Questions about getting back to normal after the completion of treatment were identified in a significant minority of QPLs. Those that contained questions in this theme tended to ask about what kind of recovery to expect, or what people could do to assist their transition to recovery.

"Should I carry on as normal?" (QPL 11)

The depth of questions about end of life issues varied significantly between QPLs. Questions included legal matters such as making a will, planning future medical decisions such as Advance Medical Directives, and questions about dying, such as accessing palliative care and expectations during the last stages.

"Who can I talk to about the medical care that I want in the future when I am no longer able to speak for myself?" (QPL 3)

"How can I access palliative care?" (QPL 10).

The health professional team

Questions aimed at understanding and facilitating communication with the health professional team appeared in almost all QPLs. The topics covered by these questions could be sub-divided into the team members, the team approach, and communication with the patient.

In terms of the team members, questions asked for identification of the health professionals who the patient would see, their different roles, and choice of different health professionals. One common question in this theme asked for referral to another health professional for a second opinion.

"Who are the health professionals in my team?" (QPL 11)

"Is there another specialist who treats this type of cancer that you would recommend for a second opinion and would they have a different approach to you?" (QPL 8)

Understanding the multidisciplinary team approach was also a focus of some questions.

> *"Do you work in a multi-disciplinary team and what does this mean?"* (QPL 4)
>
> *"Does the palliative care team speak to or write to my GP and other specialists about my care?"* (QPL 3)
>
> *"Who will be responsible for my medical care?.. What do I do if I get conflicting information?"* (QPL 10)

Communication with the patient was another sub-theme. Questions in this sub-theme clarified who the patient should contact about different topics, and how and when they could or should contact a health professional.

> *"Which issues should I ask my medical oncologist about and which ones should I discuss with my GP?"* (QPL 14).

No additional themes were identified when the thematic analysis was expanded to include selected brain tumour patient brochures, information recommendations from the draft glioma guidelines (Australian Cancer Network 2008), and items generated by participants relevant to information from Chapter 6. However, as Figure 7.4 shows, additional subthemes became evident. These largely reflected inclusion of brain tumour specific concerns, such as cognitive impairments, seizures, or issues related to work or driving, and self-management, such as skin care, diet, exercise, seizure prevention, stress management and managing fatigue. A full list of codes from the initial and subsequent thematic analyses is available in Appendix J.

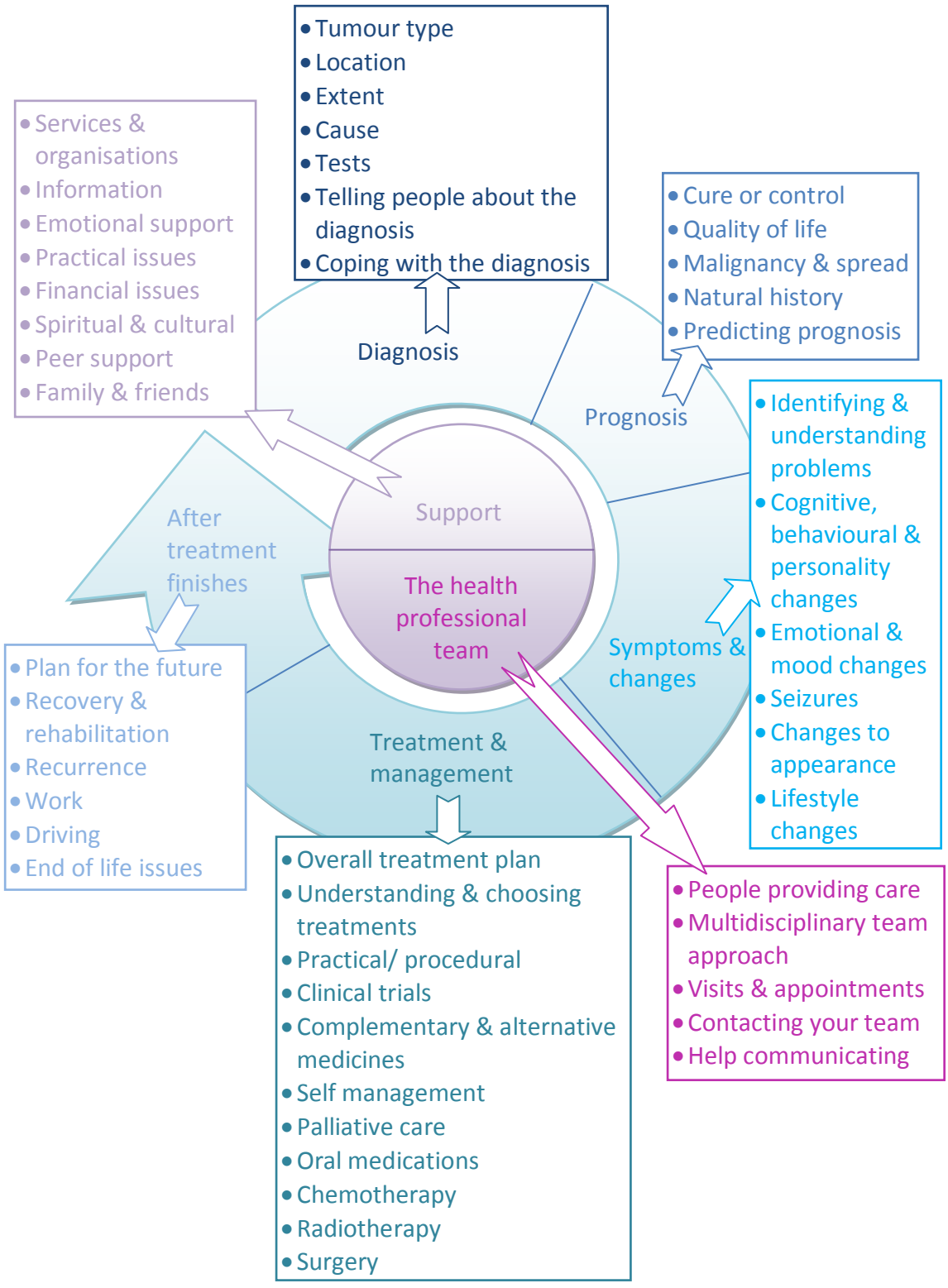


FIGURE 7.4 THEMES AND SUBTHEMES FOLLOWING INCLUSION OF BRAIN TUMOUR PATIENT MATERIALS

An initial draft QPL was developed upon completion of these thematic analyses, included in Appendix K.

7.3.2. PHASE 2 – FEEDBACK BY BRAIN TUMOUR PATIENTS AND CARERS

Thirteen patients and carers gave feedback in phase 2 of this study, and five patients and carers gave feedback in phase 5 (QPL design). The characteristics of the 18 patients and carers who participated in this study (across phases) are shown in Table 7.4. Just over half of participants (55.6%) were female, most (83.3%) were married or living together, and more than half (61.1%) were working as much as desired. Half of the tumours of patients and of the persons cared for by the carer participants were malignant, with the most common tumour types reported: meningioma (44.4%), followed by glioblastoma (16.7%) and oligodendroglioma (16.7%). All patients were treated with surgery, and the median time since diagnosis (of patients, and of the care recipients of carers) was 16.5 months (range 10-38 months). Four carers were spouses or partners, and two were a parent or child of a patient.

As described earlier, the draft QPL was sent to four participants, and changes made, then the modified QPL sent to the next four participants[11]. The first two QPLs sent were modified based on participant feedback from these nine participants, with some new questions suggested. No significant modifications (new topics, changes other than rewording) were suggested by the next four participants. All participants reported that they would have liked to have received the QPL when they, or the person they cared for, was diagnosed with a brain tumour.

[11] In each phase, one participant shared the draft QPL with his/her partner, and both provided feedback about the QPL, resulting in the uneven participant numbers.

TABLE 7.4 CHARACTERISTICS OF PATIENT & CARER PARTICIPANTS IN QPL DEVELOPMENT STUDY

	Patients (n=12)		Carers (n=6)	
Characteristic	Number	%	Number	%
Age, years: *median (range)*	53.5 (28-63)		56.5 (54-62)	
Sex				
Male	5	41.7	3	50.0
Female	7	58.3	3	50.0
Marital status				
Married or living together	10	83.3	5	83.3
Other	2	16.7	1	16.7
Education *(highest level completed)*				
Junior or senior high	4	33.3	2	33.3
Trade or certificate	4	33.3	0	0
University	4	33.3	4	66.7
Employment status				
Working as much as desired	7	58.3	4	66.7
Working less/not at all due to illness	2	16.7	0	0
Retired/home/caring duties	3	25.0	2	33.3
Months since diagnosis: *median (range)*[a]	18.0 (10-38)		14.0 (11-38)	
Tumour malignancy [a]				
Malignant	6	50.0	3	50.0
Benign	6	50.0	3	50.0
Tumour type [a]				
Meningioma	6	50.0	2	33.3
Glioma	5	41.7	3	50.0
Pituitary adenoma	1	8.3	1	16.7
Therapies used to treat the tumour [a] *(multiple responses allowed)*				
Surgery	12	100.0	6	100.0
Radiotherapy	7	58.3	3	50.0
Chemotherapy	4	33.3	2	33.3

[a] For carers, refers to the tumour and treatment characteristics of the person supported by the carer

7.3.3. PHASE 3 - READABILITY ANALYSIS

Initial readability analyses following the finalisation of the content of the QPL resulted in a Flesch reading ease score of 74.5, corresponding to a Flesch-Kincaid grade level of 5.5; SMOG grade level of 9; and Fry readability grade level of 7 (see Appendix L for details). As these results reflected a higher than desired 6th grade reading level, changes were made to the wording of the draft QPL, based on guidelines for improving readability and understanding outlined in the literature (see section 7.3.3).

The Flesch reading ease score improved to 77.8, corresponding to a Flesch-Kincaid grade level of 4.8; SMOG grade level of 8; and Fry readability grade level of 3-4. Although the SMOG score was still higher than desired, it was likely due to the inclusion of words with more than three syllables. A review of these words showed that most were commonly used and understood words such as 'medicines' and 'therapies'. Previous studies have shown that familiarity with words that are commonly used and understood may increase reading ease, even when the words are long (Meade & Smith 1991). Furthermore, research has highlighted the need to avoid simplifying patient education materials to an exaggerated degree as they may appear childish (Rose et al. 2003). Thus, although these words could be changed to lower the SMOG score, these changes may reduce QPL acceptability. As such, it was decided not to further modify the QPL.

7.3.4. PHASE 4 – REVIEW BY HEALTH PROFESSIONALS

The modified QPL was sent to eight health professionals (four nurse/brain tumour care coordinators, one oncologist, and three social workers,) who commented on the questions' abilities to elicit useful or relevant information, and overall appeal of the brochure. The most common suggestion provided by reviewers was to reduce the number of questions, and to remove some problematic questions. Twenty-eight of the 219 questions were removed by examining similarities or redundancies. Potentially problematic questions were removed, and suggested rewording of selected questions was integrated.

Some suggestions made by reviewers, however, were not integrated. For example, one reviewer suggested dividing the QPL into sections of questions to ask specific health professionals (e.g. questions for a neurosurgeon, questions for a social worker, etc). However, treatment pathways in Australia are diverse, and patients in different systems may or may not see different health professionals. Another suggestion made by a reviewer was to include further questions about end of life issues. However, as previously mentioned, a decision was made previously not to emphasise this topic, and a separate palliative care QPL is available.

7.3.5. PHASE 5 - DESIGN OF BOOKLET

Following the integration of feedback from health professionals, the draft QPL was sent to the production department and designed. To maximise its usability, sections were colour coded, and the colour of each section shown in the table of contents. The QPL was printed on a colour printer, and sent to four past patients/carers for feedback. Although it was planned that this would be an iterative process, no significant changes were suggested by these participants. All commented that it was comprehensive and that the questions were clear. No further changes were thus made to the QPL.

Following professional printing of the QPL (funded by the QUT School of Public Health), all patients, carers and health professionals who had participated in the QPL development and/or refinement were mailed a study newsletter (Appendix M) and a copy of the QPL (Appendix N).

7.4. DISCUSSION

This study used a rigorous, evidence-based approach to develop a QPL for patients diagnosed with primary brain tumours and their carers. Consultation with patients, carers and health professionals, was undertaken to optimise the acceptability of the QPL, and its ability to meet patients' needs. Readability analysis and the modification and design of the QPL were also undertaken to maximise the usability of the QPL to patients with low health literacy, or with visual or cognitive impairments.

The readability of patient materials was identified in the literature review as one of six factors influencing information provision, as shown in Figure 3.2 (page 40). However, the potential effects of a QPL may be more far reaching. It could be expected that, if the asking of questions results in the provision of timely, appropriate information, and thus the facilitation of coping, patients' and carers' self-efficacy to seeking health information in the future may increase (Shields et al. 2010).

Changes may also occur in the behaviour of health professionals exposed to patients or carers who use QPLs. These may include short-term changes in

behaviour (e.g. the provision of information in response to direct questions), but also longer-term changes, such as changed attitudes towards their role in relation to the provision of information, or confidence that they can provide information without causing undue distress. This 'reciprocal determinism' is predicted by social cognitive theory, which suggests that individuals, their behaviour, and environment continuously interact and influence each other (Bandura 1978). Although long-term effects would most likely result from a combination of different factors, an acceptable and valid QPL has potential for influence.

7.4.1. STRENGTHS AND LIMITATIONS

By developing the initial format of the QPL using existing materials, the potential burden on participants was reduced. However, including patients and carers ensured their concerns were identified. Recruitment did not result in a representative sample of the brain tumour population, and may have led to an over-representation of patients with longer survival and less physical and cognitive impairments. However, carers are likely to have recalled many of the information needs and concerns of their care recipients.

The research findings may also have been influenced by recall bias, in that participants may not have accurately remembered their information needs and concerns from the time of diagnosis (on average, 16.5 months, range 10-38 months, prior). However, it is likely that the most prominent concerns, or unaddressed information needs, were remembered. While some clinicians may have suggested to add more direct questions related to distress, anxiety or depression, the wording chosen in the QPL was that suggested by patients and carers. Future studies need to carefully examine if this is appropriate to encourage help-seeking for psychological issues, especially among patients and carers with high levels of distress.

Readability testing, and modification of the QPL to meet the required sixth grade level, was conducted to increase the 'usability' of this booklet to patients and carers. Verification of the appropriateness of questions by health professionals may also promote the acceptability of the QPL to health professionals. Further research is needed to determine the impact of the QPL on health professionals'

communication practices, and on related factors that are important to health professionals, such as consultation time.

7.4.2. CONCLUSIONS

In conclusion, this study produced a brain tumour specific QPL whose appropriateness and face validity have been confirmed by past patients, carers, and health professionals. Further research is needed to determine the acceptability of the QPL to patients who are newly diagnosed or undergoing treatments. Such research should consider how the QPL is used and whether its use leads to increased information provision. The next chapter of this thesis describes a feasibility study undertaken to investigate some of these outcomes.

8. STUDY 3: QUESTION PROMPT LIST FEASIBILITY STUDY

8.1. INTRODUCTION

The aim of this research was to test the acceptability of the QPL and the feasibility of its implementation and evaluation among patients newly diagnosed with or undergoing treatment for brain tumours. Assessment of the feasibility and acceptability of the QPL rather than effectiveness was chosen because: 1) the feasibility of recruiting patients undergoing treatment for brain tumours for a QPL trial was not known; 2) the best way to assess the QPL's effectiveness had not been demonstrated among the target population; 3) its acceptability had not been shown; and 4) its best manner of implementation (e.g. timing) was uncertain. A feasibility study thus allowed the collection of data about each of these elements to inform the design of a future randomised controlled trial (RCT) to evaluate the QPL.

In the past, so-called 'pilot' or 'feasibility' studies were often thought of as 'small-scale versions' of larger proposed studies, and studies that failed to achieve adequate sample size for publication have been inappropriately labelled as 'pilot' studies (Beebe 2007; Thabane et al. 2010; Arain et al. 2010). However, more recently, guidelines for 'pilot' and 'feasibility' studies have rigorously described their aims: to determine the feasibility of study elements (including intervention acceptability and implementation requirements) and to estimate study parameters such as effect size (Craig et al. 2008; Arain et al. 2010).

Some authors have distinguished between 'pilot' and 'feasibility' studies, defining 'pilot' studies as miniature but exact versions of a main study run to test whether all study components can work together; and 'feasibility' studies as research designed to test the suitability of (some) study elements (Arain et al. 2010; Lancaster et al. 2004). For example, a 'pilot' study for an RCT would be randomised, although a 'feasibility' study for the same trial may not, if the investigators do not seek to test randomisation procedures (Lancaster et al. 2010). Using this terminology, we sought to conduct a feasibility study to evaluate the acceptability of the QPL among the target population, and to guide the design of a future RCT to test the effectiveness of the QPL.

8.1.1. RESEARCH QUESTIONS

The research aims for this phase were thus:

1. To investigate the feasibility of strategies for recruitment.
2. To investigate the feasibility of evaluation strategies, particularly outcome assessment.
3. To investigate acceptability of the QPL among patients newly diagnosed with or undergoing treatment for a brain tumour.

8.1.2. CHAPTER ORGANISATION

To clarify the methods, the research design, participants, and recruitment strategy is described, and data collection procedures, instruments and variables are defined. Procedures used for data management and analysis techniques for each research question are explained. This chapter then presents results for each of the research questions, followed by a discussion of the strengths and limitations of the study, and the meaning of the findings in relation to other research.

8.2. METHODS

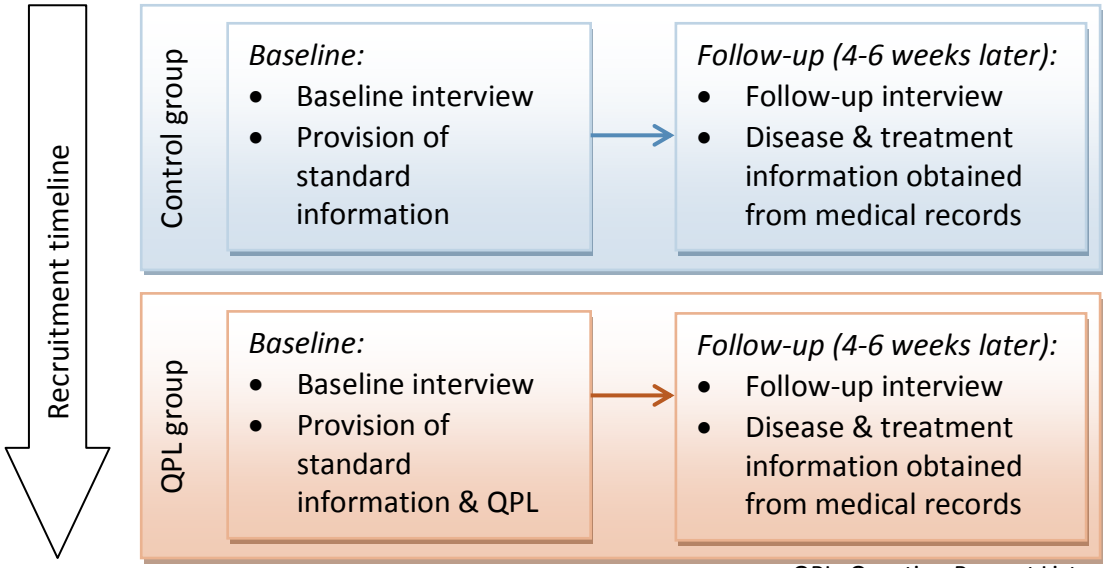
8.2.1. ETHICAL APPROVAL

This research project was approved by the Queensland University of Technology Human Research Ethics Committee (HREC) (approval no. 0800000549), the UnitingCare Health HREC, for the Wesley Hospital and St Andrew's War Memorial Hospital (approval no. 200841), the Royal Brisbane and Women's Hospital HREC (reference no. HREC/09/QRBW/55) and the Princess Alexandra Hospital HREC (reference no. 2009/075) (Appendix O).

This feasibility study was prospectively registered with the Australian and New Zealand Clinical Trials Registry. Public registration of pilot and feasibility studies has been recommended to reduce publication bias (Beebe 2007; Arnold et al. 2009; Laine et al. 2007).

8.2.2. RESEARCH DESIGN

This study used a non-randomised time-series design with control group (Figure 8.1). As this figure shows, the allocation of participants to control or intervention group (referred to as 'QPL group') was not random. The first 10 participants who were recruited were assigned to the control group, who were provided with standard information brochure after the baseline interview. The subsequent 10 participants who were recruited were assigned to the QPL group, and received the standard information brochure and the QPL after the baseline interview.



QPL: Question Prompt List

FIGURE 8.1 RESEARCH DESIGN: PRE- AND POST-INTERVENTION DESIGN WITH NON-RANDOMISED ALLOCATION TO CONTROL OR INTERVENTION GROUP

This staggered allocation to control or QPL groups was chosen to allow recruitment to commence while developing the QPL, reducing the timeframe of the overall research program, and facilitating study completion in the doctoral time frame. Non-randomised allocation to control or intervention groups was appropriate, as the research questions did not necessitate the inclusion of a control group. However, including a control group allowed the research questions to be answered in a more rigorous way. For example, participants reporting their perceptions of the QPL may report positively because the research team gave them this booklet (approval bias). Comparisons of the views of participants given the standard information brochure and those given the QPL allowed assessment of bias, and thus a better understanding of the acceptability of the QPL to participants.

However, the non-random allocation of participants to control or intervention groups means that any difference between the intervention and control group participants cannot be attributed to the intervention. Because of the staggered recruitment, the characteristics of control group and QPL group participants were expected to differ at baseline. Differences between groups at follow-up may thus be due to sampling bias or other confounding factors. For this reason, the follow-up scores of participants for outcome variables (e.g. information received, psychosocial variables) were not compared by control/QPL group allocation.

8.2.3. POPULATION AND SETTING

The target population for this study consisted of adults diagnosed with primary brain tumours undergoing treatments such as neurosurgery, radiation and/or chemotherapy in Brisbane. 'Undergoing treatments' was defined as a time during which a patient was discussing, planning or receiving treatment, as any of these would allow interaction with health professionals and thus opportunity for the QPL to be used and/or information to be provided to the participant by a health professional. This definition also allowed for recruitment of brain tumour patients who did not have surgical treatments (for example, those with tumours unsuitable for resection), and those who did not have adjuvant treatments (such as patients with benign tumours).

The target population (and thus the eligibility criteria) included patients with malignant or benign tumours, as these patients – especially early in the disease trajectory – undergo similar diagnostic and treatment pathways (Del Sole et al. 2001; Wentworth et al. 2009; Piepmeier & Baehring 2004; Rampling et al. 2004), experience a similar range of physical, cognitive, behavioural and psychosocial impairments (Ownsworth et al. 2009; Weitzner 1999), and consult similar health professionals, such as. neurologists, neurosurgeons, radiation oncologists, allied health professionals (Macarthur & Buxton 2001; Gabanelli 2005). Although no study has specifically compared the information needs of patients with malignant versus benign brain tumours, both groups have been found to have significant and similar unmet information needs (Rozmovits et al. 2010; Parvataneni et al. 2011; Lidstone et al. 2003; Janda et al. 2008). The QPL may thus be useful for both patient groups.

Although the QPL may have been used by and/or benefited both patients and carers, impacts on patients only were assessed in this evaluation, to keep within the budget and resources of the doctoral candidate.

8.2.3.1. INCLUSION AND EXCLUSION CRITERIA

Inclusion and exclusion criteria were the same for control and intervention participants. Patients must:

(1) have been diagnosed with a primary brain tumour, and either newly diagnosed or undergoing treatment for their tumour;
(2) have received their diagnosis of a brain tumour from a doctor;
(3) have not previously received a cancer diagnosis (except for skin cancer, if applicable);
(4) be able to speak and read English sufficiently to read the QPL or standard information;
(5) be 18 years of age or older;
(6) be able and well enough to read the QPL or standard information and complete interviewer−administered questionnaires; and
(7) be recommended for participation by their doctor.

All patients were thus screened for participation by their treating neurosurgeon, oncologist or care coordinator. Patients who had previously had cancer were excluded because they may be systematically different (e.g. in information-seeking behaviour, knowledge of cancer treatment) from patients without cancer history. Skin cancers were excluded from this criterion due to their prevalence: two in three Australians will be diagnosed with skin cancer by the age of 70 years (Staples et al. 2006).

8.2.3.2. SAMPLE AND SAMPLE SIZE

As the target population for this study were patients in the receipt of treatment, participants were recruited from healthcare settings. It was initially planned that the entire study sample would be recruited from the private Brisbane neurosurgical practice BrizBrain and Spine. This practice had a brain tumour nurse coordinator, who evaluated each patient, organised their treatments, referrals and admissions, and acted as a central point of contact for brain tumour patients. The brain tumour

nurse coordinator estimated that the four doctors at the practice saw approximately 70 new brain tumour patients each year. Based on an estimated recruitment rate of 50%, we expected to be able to recruit 30 patients in a 12 month period. Sample size was based on numbers reported by other feasibility studies, rather than formal calculations (e.g. (Clayton et al. 2003)). A target was set to recruit 30 patients in one year, with a minimum of 20 participants.

Seven participants were recruited in the first six months of the recruitment period, necessitating an expansion of the recruitment setting. Following ethical and site-specific approvals, the recruitment setting was expanded to include persons treated at two other (public) hospitals. Recruitment from these hospitals was expected to allow accrual of the minimum target of 20 participants within a further six to twelve months. However, it was also acknowledged that expanding the recruitment setting may lead to increased diversity of participant characteristics, as public and private patients have differential access to a care coordinator and other supportive care services. As the main aim of the study was not to determine intervention effectiveness but acceptability and feasibility, this risk was deemed acceptable.

8.2.3.3. RECRUITMENT STRATEGY

A two-stage recruitment strategy was used. Firstly, brain tumour patients were identified and screened by a health professional. Recruiting health professionals approached potential participants, provided them with a study brochure, and sought verbal or written permission from the patient for the candidate to contact them about the study. To allow for recruitment rates to be calculated, recruiting health professionals were asked to note each time they identified a potentially eligible patient, approaches made to such patients to give study information, and when such potential participants gave consent to be contacted by the candidate. Characteristics of non-participants (e.g. demographics, reason for refusal) were not recorded as the QUT HREC refused collection of this data.

Contact was then made with the patient by the candidate via telephone. The candidate explained the purpose and requirements of the study and answered any questions. Potential participants were provided with a Participant information sheet and consent form, which they read and signed prior to participation. Once

consented, arrangements were made to conduct the initial interview within one week of consent.

The recruitment period of the project lasted approximately 15 months (BrizBrain and Spine: November 2008 - January 2010; RBWH and PAH: April 2009 - January 2010). Recruitment documents and consent forms are provided in Appendix P.

8.2.4. INTERVENTION AND STANDARD INFORMATION

As described in Chapter 7, the QPL consisted of a 33 page A5 booklet (Appendix N). To determine when best to provide the QPL to participants, procedures from previous QPL studies were reviewed. As described in section 3.5.3.2, most intervention trials provided QPLs to patients shortly prior to consultations, while they were waiting for appointments (Hagerty et al. 2005; Clayton et al. 2003; Butow et al. 2003; Butow et al. 1994; Bruera et al. 2003). Providing the QPL when patients arrive for a consultation allows emergent information needs to be quickly addressed and thus anxieties allayed (McJannett et al. 2003). Alternatively, providing patients with more time to consider the QPL and discuss it with their family may enable it to have a greater impact (Butow et al. 2004). Interventions may also be more useful to patients early in the disease/treatment journey, as this is when information seeking is highest (Schubart et al. 2008; Lewis 1997).

The question prompt list was thus provided to participants as soon as possible in the research process, immediately following the baseline interview.

8.2.4.1. STANDARD INFORMATION

Permission was received by the Cancer Council Queensland (CCQ) to use their booklet, “About brain tumours” as standard information for this study. This twelve page booklet (Appendix Q) provides basic information about brain tumours, such as diagrams explaining the anatomy of the brain, common symptoms, suggestions for coping, information about the Brain Tumour Support Service of the CCQ, and contact details for the CCQ helpline, and is commonly available at the recruiting hospitals. All participants were provided with this booklet.

8.2.5. DATA MANAGEMENT

8.2.5.1. DATA COLLECTION PROCEDURES

Data were collected by interviewer-administered questionnaire (Appendix R) at two time points. Conducting interviews rather than asking participants to complete written questionnaires was chosen to allow the participation of persons with visual, motor or any other disabilities that could hinder completion of written questionnaires, and to identify questions that were problematic. Baseline interviews were conducted by the candidate either face-to-face in hospital or by telephone; follow-up interviews were conducted by telephone in all cases.

Follow-up interviews were planned for four to six weeks after the baseline interview, to allow the participant time to read and use the QPL. However, in some cases follow-up interviews were conducted more than six weeks after the initial interview, due to physical, cognitive or emotional reasons of participants or because of difficulties contacting the participant.

Participants' medical data were obtained from their medical records using standard forms (Appendix R).

8.2.5.2. DATA SAFETY AND STORAGE

Hard copies of the questionnaires and medical record abstraction forms were stored in a locked filing cabinet, and all electronic study information was kept on a password-protected network drive, to which only the candidate had access. All data was collected in a de-identified form, with each participant assigned a unique identifier that was used on both hard and soft copies of the data. A separate spreadsheet was kept with the patient identifier, name, address and telephone number.

8.2.6. DATA MEASUREMENT

Data were collected to assess the feasibility of recruitment (e.g. demographic characteristics), the feasibility of evaluation strategies (e.g. interview duration), and the acceptability of the QPL (e.g. views regarding the information brochure provided). Table 8.1 shows the data collected during this study, the measurement tool used, and the methods of collection (e.g. baseline or follow-up questionnaire,

or via medical record abstraction). In addition to these questions, notes were taken on any difficulties participants had during the interview (for example, if they could not recall response categories or could not answer a question), to assess the suitability of the measurement instruments.

TABLE 8.1 DATA COLLECTED: VARIABLES, MEASUREMENT INSTRUMENTS AND COLLECTION METHOD

		Method(s) of collection		
Variable	Measurement instrument	Base-line	Follow-up	Medical record
Information received	EORTC QLQ-INFO25	✓	✓	
Most prominent source of information	New question		✓	
QOL: general & brain	EORTC QLQ-C30 & QLQ-BN20	✓	✓	
Information & participation preferences	2 items from Cassileth Information Styles Questionnaire, Krantz Health Opinion Survey Information subscale	✓		
Self-efficacy in coping with cancer	Cancer Behavior Inventory	✓		
Social support	ENRICHD Social Support Instrument	✓		
Problems communicating with health professionals	Cancer Rehabilitation Evaluation System (CARES) Medical Interaction Subscale		✓	
Psychological adjustment & distress	Impact of Event Scale, Distress Thermometer, 2 single questions	✓	✓	
History of depression/anxiety	2 single questions	✓		
Acceptability & use of brochure	17 questions sourced from previous QPL study or new		✓	
Demographics		✓		
Experiences of information	Open-ended		✓	
Duration of interviews	Time at commencement & completion of interviews	✓	✓	
Disease & treatment information				✓

ENRICHD: Enhancing Recovery in Coronary Heart Disease, EORTC: European Organisation for Research & Treatment of Cancer, QLQ-BN20: Brain tumour specific tool, QLQ-C30: Quality of life tool, QLQ-INFO25: Information module, QOL: Quality of life, QPL: Question Prompt List

8.2.6.1. Proposed Primary Outcome: Information received

Selection process

As described in the literature review (see section 3.5.3), QPLs have been most commonly evaluated by counts of the number of questions asked, and/or other communicative behaviours (e.g. bids for clarifications), determined by audio-taping medical consultations (Zimmermann et al. 2007; Ong et al. 1995; Kinnersley et al. 2008). However, the number of questions asked by patients may not be the most appropriate measure, as it does not take into account differences in individuals' information needs or preferences (Gaston & Mitchell 2005), or the degree to which health professionals provide information (Hebert et al. 2009).

Furthermore, whilst audio-taping consultations also allows the determination of consultation duration, which has been used as a secondary outcome measure (Brown et al. 2001), audio-taping consultations may not be acceptable to patients or health professionals, and may alter the consultation process (McConnell et al. 1999).

Other outcomes previously used to evaluate QPLs include: recall (Brown et al. 2001; Butow et al. 1994), achievement of patient's information preferences (Clayton et al. 2007) or decision-making style (Butow et al. 2004), satisfaction with the consultation or care provided (Tabak 1988; Clayton et al. 2007), or psychological adjustment, depression, anxiety, or fear of recurrence (Clayton et al. 2007; Butow et al. 1994; Shields et al. 2010). Physician outcomes, such as their satisfaction with communication during the consultation, or perceived success in meeting patients' information needs, have also been reported (Butow et al. 2004; Dimoska et al. 2008).

These outcomes may be subject to a number of limitations, such as limited consistency with the intervention aims (e.g. recall, achievement of decision-making style), and social desirability bias (e.g. achievement of information preferences). The distal nature of psychological outcomes, and the multiple influences on these outcomes, may limit their responsiveness to QPL interventions,

To try to overcome some of the limitations associated with these outcomes, an alternative outcome measure was identified. The European Organisation for

Research and Treatment of Cancer (EORTC) QLQ-INFO25 is designed to assess the quality and quantity of information received by cancer patients at different stages of their disease, for use in both research and clinical practice (Arraras et al. 2004; Arraras et al. 2007; Arraras et al. 2010). This outcome measure allows participants to indicate whether they wish to receive more information (suggestive of unmet needs), and/or wish they had not received some information (suggesting that the information given was not consistent with their preferences) (Arraras et al. 2004). Differences between intervention and control participants, and over time, in the magnitude of information received, could also thus reflect effect of the QPL well.

Characteristics of outcome measure

The QLQ-INFO25 is a module designed to be used in conjunction with the QLQ-C30, which assesses QOL. Patients' responses to the 25 items of the QLQ-INFO25 are collated into four subscales: information about the disease, information about medical tests, information about treatments, and information on other services (Arraras et al. 2007). Single items assess whether or not participants have received written information, or information on CDs or tape/video, satisfaction with the amount of information, desire for more information, desire for less information, and helpfulness of information. Participants complete two open-ended questions to address what further information they desire, and what information they have received that they did not want; the former may be used as a measure of 'information need', while the latter may demonstrate divergence between the information wanted and information received (Arraras et al. 2007).

A validation study of this questionnaire was published during this study's data analysis phase (Arraras et al. 2010). Two changes to the questionnaire's structure resulted from the validation study: item 39, "information on non-medical treatments (e.g. herbal remedies, homeopathy, relaxation)" was removed[12] as it did not correlate with other questionnaire items (item-own-scale correlation $\rho=0.32$)[13] (Arraras et al. 2010). Secondly, the use of an overall score was suggested as the

[12] In this study, this question was kept and used as a single item question, although excluded from the overall score as per the recommendations discussed above.

[13] The removal of this question led to a change in the questionnaire name, from the QLQ-INFO26 to the QLQ-INFO25 (Arraras et al. 2010). For consistency, the latter name has been used.

internal consistency of the entire questionnaire was very high (Cronbach's alpha of 0.91) (Arraras et al. 2010). These adaptations were incorporated into the analysis of the present study.

Based on the data from the validation study, the QLQ-INFO25 has high internal consistency overall and across all subscales (Cronbach's α>0.90) and good test-retest reliability (intraclass correlations for each scale and item over time ranged from 0.71 to 0.91) (Arraras et al. 2010).

However, whilst the questionnaire has been reported to detect increases in information received about other services/places of care, the sensitivity to change of the questionnaire of other scales and items requires further testing (Arraras et al. 2010). Furthermore, although the QLQ-INFO25 has been used in mixed cancer patient samples (e.g. (Adler et al. 2009)), its use with brain tumour patients has not been reported to date.

Variable derivation

All the EORTC questionnaires use a four-point Likert scale of responses: 1 'not at all', 2 'a little bit', 3 'quite a bit' and 4 'very much', with respondents asked to select the answer that best applies to them, most commonly during the past week. A few questions use Likert scales from 1 to 7 (e.g. "rate your overall health during the past week", QLQ-C30), or dichotomous response categories (yes/no) (e.g. "have you received written information?", QLQ-INFO25). Scales and subscales were scored and summarised per the EORTC scoring manual (Fayers et al. 2001), and standardised to 0-100 to allow comparison across scales. As per the EORTC scoring manual, when a participant answered at least 50% of the items in a multi-item scale, missing scale items were imputed with the participants' mean of items present across the scale, and the scale prorated by the number of items answered (Fayers et al. 2001).

8.2.6.2. Other Proposed Outcome: Information Source

It was hypothesised that participants prompted to ask questions of health professionals by the QPL may be more likely to nominate a health professional as their primary information source, than other sources. Other participants may be more likely to nominate other sources, such as written information or the internet.

To assess this, the following open-ended question was designed by the research candidate: “People receive information about their illness from a lot of different sources. From whom or where have you received the most information about your illness?” Participants’ first response to this question was recorded, and qualitatively coded, and codes grouped to develop common themes. The frequency of each theme was then reported.

8.2.6.3. Proposed Independent or Explanatory Variables

Data was collected on variables that may influence the use of the QPL (e.g. distress, language), and/or that may influence the quality or quantity of information received (e.g. self-efficacy, problems communicating with health professionals, information preferences). Data was also collected on demographic and disease and treatment information to allow the description of the sample, and to assess the representativeness of the sample compared with normative data.

Quality of life

As the EORTC QLQ-INFO25 was used to assess information received, other EORTC instruments were also used to assess QOL (QLQ-C30) and brain-tumour specific QOL (QLQ-BN20). These QOL measures were included as aspects of the well-being of participants (e.g. cognitive impairments, speech impairments) may influence use of the QPL, and thus information received.

The EORTC QLQ-C30 is a 30-item questionnaire developed to measure multiple dimensions of quality of life. The QLQ-C30 yields an overall score, scores for five multi-item scales (physical, role, cognitive, emotional, and social), and six single items to assess other symptoms or problems commonly reported by cancer patients (dyspnoea, appetite loss, sleep disturbance, constipation, diarrhoea, and the perceived financial impact of the disease and its treatment) (Aaronson et al. 1993). It can be self-completed by participants, and has been validated for use with cancer patients.

The QLQ-BN20 Brain cancer module assesses topics not covered by the QLQ-C30, with 20 questions yielding four scales: visual disorder, motor dysfunction, communication deficit and future uncertainty, and seven individual items covering disease symptoms (e.g. headaches, seizures) and treatment toxicities (e.g. hair loss)

(Osoba et al. 1996). The questionnaire module has been validated with an English-speaking sample of 105 brain cancer patients, showing adequate internal consistency reliability (Cronbach's α=0.73-0.86) and expected responses to known group comparisons (e.g. fewer problems among patients with recently-diagnosed cancer than those with recurrent disease) (Osoba et al. 1996). Validation with a multinational, multi-lingual sample of 891 brain cancer patients found similar internal consistency reliability (Cronbach's α=0.70-0.90), that all items correlated more strongly with their own scale than other scales ($\rho > 0.70$), and that future uncertainty, motor dysfunction, drowsiness, visual disorder and bladder control were responsive to change over time (all $p<0.005$) (Taphoorn et al. 2010).

Information and Participation Preferences

Participants' preferences for information and for participation in consultations are likely to influence the amount of information they require, and the use of the QPL. To measure these variables, two items from the Cassileth Information Styles Questionnaire, and the Information subscale of the Krantz Health Opinion Survey (KHOS) were used.

The Cassileth Information Styles Questionnaire was developed to measure the extent to which patients wish to be informed about, and to participate in, their medical care (Cassileth et al. 1980). Two questions from this questionnaire are commonly used to assess patients' preferences for information and participation in decision making (Butow et al. 1997; Clayton et al. 2007; Brown et al. 1999).

The questions used were:

1) Which statement best describes your point of view:
    a. I prefer to leave decisions about my medical care and treatment up to my doctor, or
    b. I prefer to participate in decisions about medical care and treatment;
2) Which statement best reflects your attitude towards information about your illness:
    a. I want only the information needed to care for myself properly,
    b. I want additional information only if it is good news, or
    c. I want as much information as possible, good or bad.

The KHOS is a validated questionnaire with two subscales measuring a) preferences for information, and b) preferences for participation in decision-making (Krantz et al. 1980; Auerbach 2000). This study used only the information subscale (KHOS-I), which contains seven questions that evaluate desire to be informed about, and to ask questions about their care, yielding a subscale score. This subscale is frequently used alone, and has been shown to have excellent convergent validity with information specificity (Auerbach et al. 1983). That is, patients with a high preference for information showed much better adjustment when they received specific, rather than general information. In contrast, patients with a low preference for information adjusted slightly better to general, rather than specific information (Auerbach et al. 1983).

Initially developed for dichotomous responses (agree, disagree), a six-point Likert scale (strongly agree, agree, slightly agree, slightly disagree, disagree, strongly disagree) has been used with the KHOS-I to increase the ability to discriminate between respondents, without significantly changing the subscale reliability (α=0.76) (Garvin & Kim 2000; Woodward & Wallston 1987; Smith et al. 1984). This approach was used in this study, although it was found that several participants interviewed by telephone could not remember all six response categories despite their repetition by the researcher. In this case, participants were offered the choice to 'agree' or 'disagree' with the statements only, and all KHOS-I responses were dichotomised to 'agree' or 'disagree' for consistency.

Scoring the KHOS-I (dichotomously) yields a score from zero to seven, with higher scores representing a more favourable attitude towards seeking information (Krantz et al. 1980). The scale developers (Krantz et al. 1980) initially divided participants into three categories based on KHOS-I score, using pre-defined cut-points[14], and this approach was adopted by many early users of the questionnaire (e.g. Hilzenrat, Yesovitch et al. (2006)). However, many other studies have dichotomised the scale into higher versus lower scores (e.g. Auerbach, Martelli et al. (1983), Leino-Kilpi, Heikkinen et al. (2009)). This approach was also used here, with categorisation

[14] Cut-points were: 0-2: information avoider; 3-5: neutral; 6-7: information seeker (Krantz et al., 1980).

based on the median, to allow categorisation of participants as 'high' and 'low' information seekers whilst preserving degrees of freedom. The median scale score was 4.5 (range 0-7), so participants were categorised into low information seekers (score 0-4.5) or high information seekers (score 4.6-7).

Self-efficacy in coping with cancer

Self-efficacy in coping with cancer was assessed using the Cancer Behavior Inventory (CBI). This 33-item questionnaire asks participants to indicate their confidence in being able to perform behaviours that may help to cope with cancer, on a scale from 1 (no confidence) to 9 (highly confident) (Merluzzi et al. 2001). By summing responses, the CBI provides an overall score and scores for seven subscales: maintaining activity and independence; seeking and understanding medical information; stress management; coping with treatment-related side effects; accepting cancer/maintaining a positive attitude; affective regulation; and seeking support (Merluzzi et al. 2001).

The five-item CBI subscale relating to seeking and understanding medical information seemed particularly important to the present study as it assesses the confidence participants have to ask questions of various medical personnel, and their ability to understand the information provided (Merluzzi et al. 2001). Self-efficacy is likely to directly influence patients' information seeking behaviour. The CBI has excellent internal validity (Cronbach's α=0.94), and reliability (one week test-retest reliability coefficient=0.74) (Merluzzi et al. 2001).

Social support

The ENRICHD[15] Social Support Instrument is a seven-item questionnaire which assesses the degree to which the participant has functional and emotional support (Vaglio et al. 2004). Six of the questions use a five-point Likert scale from 1 (none of the time) to 5 (all of the time), and the seventh question asks whether the participant is married or living with a partner. Higher scores on the questionnaire indicate that a participant has more positive social support available to them. The

[15] 'ENRICHD' stands for Enhancing Recovery in Coronary Heart Disease (The ENRICHD investigators 2000). This questionnaire was developed from the Medical Outcomes Survey for a clinical trial of a cognitive-behavioural treatment for depression and low social support in patients who had experienced a myocardial infarction (Mitchell et al. 2003).

ENRICHD Social Support Instrument has been shown to have excellent internal consistency (Cronbach's α=0.88 (Vaglio et al. 2004) – 0.93 (Steginga et al. 2008)) and reliability (intra-class correlation coefficient=0.94 (Vaglio et al. 2004)).

Problems communicating with health professionals

The Medical Interaction subscale of the Cancer Rehabilitation Evaluation System (CARES) was used to assess whether participants had problems interacting with and/or communicating with doctors and nurses, as these problems may explain lower levels of QPL use and/or lower scores for the amount of information received.

CARES lists 139 problems that may be experienced by cancer patients, and assesses the degree to which patients experience each problem on a five-point Likert scale (Schag & Heinrich 1990). The Medical Interaction subscale contains 11 items and is one of five summary scales, specifically assessing three constructs: (a) the degree to which the participant felt they had problems obtaining information from their doctors and nurses; (b) difficulty communicating with the medical team; and (c) control of the medical team. The CARES-Medical Interaction subscale has been shown to be reliable, valid and internally consistent (Schag and Heinrich, 1990). When the scores are summed, higher scores indicate more problems (Collie et al. 2005).

Psychological adjustment and distress

Psychological symptoms were assessed because these could influence information seeking, although a recent review also showed that five studies have used depression or distress as distal outcome measures in QPL evaluation studies (Dimoska et al. 2008). Psychological symptoms were measured by three scales: 1) the Impact of Event Scale (IES); 2) the Distress Thermometer; and 3) two single-item questions about depression and anxiety. Although it is unlikely that a future evaluation study would include all three measures, these questionnaires may differ in their appropriateness for brain tumour patients because of their length, or language used. Their inclusion in this study thus could provide data to inform the selection of the most appropriate outcome for a future study.

The 15-item IES is commonly used to assess the psychological impact of a traumatic event, such as the diagnosis of cancer (Horowitz et al. 1979). Participants indicate

how frequently they experienced symptoms with respect to their brain tumour over the past week, on a four-point Likert scale. Higher scores indicating greater stress symptoms (Horowitz et al. 1979). According to the questionnaire manual, two subscale scores were calculated: 1) intrusion, characterised by unbidden thoughts and images, strong waves of feelings and troubled dreams; and 2) avoidance, characterised by denial of event meanings or consequences, numbness and blunted sensation (Horowitz et al. 1979).

This questionnaire was chosen as intrusion and avoidance may be more sensitive measures of psychological distress for cancer patients than other, more generalised measures (Epping-Jordan et al. 1994). The IES has been validated and shown to be a reliable, sensitive and responsive index of subjective distress, suitable for repeated measurements over time (Horowitz et al. 1979; Sundin & Horowitz 2002).

The single-item Distress Thermometer (DT) rapid screening tool asks participants to indicate "the number (0-10) that best describes how much distress you have been experiencing in the past week, including today" (Gessler et al. 2008', p. 539). The DT has been shown to be comparable to longer and more comprehensive instruments such as the Hospital Anxiety and Depression Scale (HADS) (receiver operating characteristic curve area under the curve of DT relative to HADS cut-off = 0.80) (Jacobsen et al. 2005). However, the DT has the advantages of being rapid, of being acceptable to patients as it does not pathologise distress, and being suitable for use in telephone interviews (Hawkes et al. 2010). DT scores were dichotomised using a cut-off score of 4 (score <4 or ≥4) as patients in a general cancer population with scores ≥4 have been shown to be more likely to report problems with depression ($p \leq 0.05$) and emotional problems ($p \leq 0.05$) (Jacobsen et al. 2005).

Two single items were also used. One question from the Patient Health Questionnaire (Kroenke et al. 2001', p. 613) was used to assess depressive symptoms: "Over the past two weeks, have you ever felt down, depressed or hopeless?". A similarly worded question was used to assess symptoms of anxiety: "Over the past two weeks, have you ever felt nervous, anxious or fearful?". These questions were measured on a Likert scale including 'not at all', 'a little', 'moderately', 'very' and 'extremely'.

Although these single-item questions cannot measure depression or anxiety in the true clinical sense, and are not as comprehensive as other instruments, they may be suitable as screening tools (Tambs & Moum 1993). The use of a single item question has been shown to adequately replace longer instruments when there is a need to reduce the burden on participants completing lengthy questionnaires (Davey et al. 2007). The depression question was shown to be 93% sensitive (95% CI 86-97%), and 62% specific (95% CI 58-67%), compared with the National Institute of Mental Health Quick Diagnostic Interview Schedule (Whooley et al. 1997). A single item Likert scale anxiety question also strongly predicted scores on the State-Trait Anxiety Inventory (STAI) in a study of 350 Australian breast cancer patients (Davey et al. 2007). Prediction graphs showed that scores obtained via the Likert scale question showed good comparability with STAI scores, with a correlation of 0.75 (95% CI 0.70-0.79), although the Likert scale item resulted in loss of sensitivity (Davey et al. 2007).

History of depression/anxiety

Self-reported history of anxiety and depression were assessed as a previous history of psychological problems has been associated with distress during cancer (Nordin et al. 2001). This information was collected by self-report using two yes/no questions: “Have you ever been diagnosed with depression by a physician?” and “Have you ever been diagnosed with anxiety by a physician?”. The self-reported history of depression question has been shown to be a valid measure compared with the DSM-IV (Sanchez-Villegas et al. 2008). The anxiety question was similarly constructed, although has not yet been validated.

Demographics

Demographic characteristics collected by self-report included age, sex, marital status, income, education, usual work situation, suburb and postcode. Participants were asked if they had ever worked in a health care or a medical-related job, and what language they usually spoke at home, as it was expected that these factors may influence their ability to seek and use medical information (David & Rhee 1998; Carnevale et al. 2009; Brach et al. 2005; Wilson et al. 2005; Bachmann et al. 2007; Fortun et al. 2008).

Disease and treatment information

Disease and treatment information for each individual was extracted from participants' medical records at the end of the recruitment period, to allow description of the sample, and to assess the comparability of control and intervention groups, and representativeness of the sample compared with the target population. The data extracted was:

- tumour type, hemisphere, lobe, grade, stage at diagnosis, whether the tumour type was confirmed histologically;
- treatment procedures received (yes/no): biopsy, surgical debulking, radiotherapy, chemotherapy, other (specify);
- Karnofsky Performance Scale (KPS) score; impairments (yes/no) in: speaking or understanding speech; abstract reasoning; attention or concentration; memory; visual function; motor function, other (specify);
- previous cancer diagnosis (if yes, specify);
- likely prognosis (weeks or months, years, or normal life expectancy); and
- date of first neurosurgical consultation.

8.2.6.4. Other Variables Collected

Feasibility of evaluation strategies

To assess the suitability of these outcomes, notes were taken on any difficulties participants had during the interview (for example, if they could not recall response categories or could not answer a question). The time taken to complete each questionnaire was also recorded as a measure of study process.

Acceptability of the QPL

Participants also completed 17 questions (shown in Table 8.2) to assess the acceptability of the QPL to participants, and how it was used. Several of these questions were sourced from a study examining the acceptability of a QPL for the palliative care setting (Clayton et al. 2003), to allow comparison with these findings. Other questions were designed for this study.

To allow some assessment of response bias, such as participants reporting positive assessment of information given to them to try to please the researcher, both

control group and QPL group participants were asked the same questions, which referred to 'the brochure/booklet we gave you'. As QPL group participants were provided with both the QPL and standard information materials, these participants were asked to specifically comment only on the QPL.

TABLE 8.2 QUESTIONNAIRE ITEMS RE OPINIONS ABOUT AND USE OF THE INFORMATION BROCHURE

Question/Statement	**Response Categories**
I found the brochure to be helpful The brochure made it easier to ask questions There were questions in the brochure that were useful to me The brochure helped me to put some of my questions or concerns into words I found it overwhelming to read the brochure I think the brochure will be useful to me in future The brochure was easy to understand	(Likert scale) Agree completely Agree somewhat Neither agree nor disagree Disagree somewhat Disagree completely
What is your view on the length of the brochure? Was it...	The right length Too long Too short
Did you have enough time to read the booklet before your consultations? Would you have preferred to receive the booklet at a different time?	Yes No Unsure
Have you read the booklet again since first receiving it?	Several times, 1-2 times, Not at all
Did the booklet prompt you to ask your neurosurgeon any questions? Did the booklet prompt you to ask your radio-oncologist any questions? Did the booklet prompt you to ask your medical oncologist any questions? Did the booklet prompt you to ask questions of any other members of your team?	Yes No Unsure Did not see (this professional)
Did anyone else read the booklet (i.e. carer/relative or friend)?	Yes No Unsure
If yes → Was the booklet helpful to them?	Very helpful A bit helpful Not helpful Not sure

Experiences of information during the current illness

Participants were also asked to describe their experience in receiving information through the course of their disease, in their own words. This short qualitative section used the following topic guide (Table 8.3), which covered information sources, strategies, QPL content and the research process.

TABLE 8.3 TOPIC GUIDE FOR PARTICIPANTS TO REFLECT ON THEIR INFORMATION-SEEKING AND THE QPL OR STANDARD INFORMATION PROVIDED

Topics/prompts
A lot of people diagnosed with tumours talk about difficulties getting the information they need or want. What information has been most important to you?
How do you think we can help people in your situation be better informed?
What did you do to try and find information?
Who have you talked to about your tumour?
How do you think someone in your situation can get the information they need?
Did you write down any questions for yourself to ask your doctor or nurse?
Can you suggest how we could improve the brochure to make it more useful?
Are there any other comments you would like to make about the brochure we gave you?
How has this experience of participating in research been for you?
Would you like to suggest any changes to our questionnaires to make this process easier for people, for when we do more research in the future?

8.2.7. DATA ENTRY, CLEANING AND VERIFICATION

The questionnaires and medical data abstraction forms were designed simultaneously with the coding manual and datasheet. Codes were assigned for all quantitative data (a list of variables, their type, and measurement is provided in Appendix S). The candidate initially entered all quantitative data into the statistical program, Statistical Package for the Social Sciences (SPSS), Version 16. A research assistant re-entered all data collected from five randomly selected participants (one quarter of the sample). Discrepancies or queries in entry coding were clarified by the candidate and recorded for future reference. Data entered by the candidate on five participants and 300 variables (all variables but string variables, to allow for expected differences in sentence case and punctuation), were compared with data re-entered by the research assistant. Five discrepancies were found, equating to

one error per 300 data entered (i.e. 99.67% accurate). Thus the original data entry was accepted.

Data were extensively checked for correct codes, outliers, extreme values and inconsistencies between questions, comparing entered data against questionnaires as needed. However, inconsistencies in responses to variables asking about the information that participants had received were not corrected. For example, if a participant indicated that they had received very much information about the diagnosis of their disease at time of first interview, but no information at all about diagnosis at follow-up, their responses were *not* altered. Although not necessarily logical, these answers reflect the subjective view of the participant. For example, this may reflect a response shift, such that what is previously seen as a large amount of information is later interpreted as so little to not be registered or valued (Sprangers & Schwartz 2010).

The interviews were not tape-recorded; however, the researcher entered all answers in the written forms and took notes of participants' responses to semi-structured questions.

8.2.8. Analytical Methods

8.2.8.1. Variable construction and transformation

Transformation of Postcodes into Areas

Based on road distance to and size of service hubs, the ARIA+ (modified Accessibility/Remoteness Index of Australia) methodology assigns an index value (0-15) to each one square kilometre area of Australia, from which geographical categories of remoteness are determined using the Australian Standard Geographical Classification (ASGC) (University of Adelaide 2011; AIHW 2004; Department of Health and Aged Care 2001). Using this method, participants' postcodes were transformed into ASGC areas (major city, inner regional, outer regional, remote, or very remote). These have previously been shown to correspond to differences in brain cancer incidence and survival in Australia (Baade et al. 2005).

Construction of a Brochure Acceptability Index

A simple summative index was created from the first seven items which asked participants' views of the QPL or standard information brochure (see Table 8.2). These items were scored using a five-point Likert scale, and the index summed scores after the reversal of the single negatively phrased question ("I found it overwhelming to read the brochure"). Index scores could range from 7-35, with higher scores indicating more positive views of the QPL or standard information brochure. The index had adequate reliability (Cronbach's alpha=0.764).

8.2.8.2. Variable Descriptions and Associations

Categorical variables were summarised using numbers and proportions where appropriate. Response categories were collapsed into fewer categories based on clinical cut-offs, groupings used in previous research, or based on the distribution of the variable in the current dataset (e.g. using quartiles).

Normality of continuous variables was assessed to determine the correct summary statistic to present and the correct statistical tests to conduct. The criteria used to determine if a variable was approximately normal were:

1. Mean within 10% of the median
2. Skewness coefficient between -3 and +3
3. Kurtosis coefficient between -3 and +3
4. Mean ± three SDs approximates the minimum and maximum values
5. Histogram approximates a normal distribution (bell shaped and roughly symmetrical)
6. And for variables scaled from zero (i.e. negative values are not possible), standard deviation less than or equal to half of the mean.

This set of criteria seeks to assess adequate symmetry and spread, to ensure means are an unbiased measure of central location and standard deviation an appropriate summary of spread (Battistutta 2008). Continuous variables that met these criteria were summarised using means and standard deviations, and parametric tests were applied. A failure to meet any of the above criteria was considered evidence that the variable was not adequately normally distributed to be used in this manner.

Three options were available in this case:

- the variable was transformed (e.g. using logarithm, square root, etc) to approximate a normal distribution, and parametric tests were used; or
- medians and ranges were used to summarise the variable and non-parametric tests were used; or
- the variable was categorised into meaningful groups and used as a categorical variable.

8.2.8.3. Statistical and Contextual Significance

As this study was a feasibility study with a small sample size, statistically significant results were not expected, and may not be easily interpreted, given that the size of the sample was not based on power calculations. Statistical tests of significance were consequently not applied. However, clinically significant results are possible without statistical significance (Beebe 2007). For this study, contextual or clinical differences were used to highlight potentially important results. Contextual or clinical significance was defined using the following criteria:

- for associations between continuous and categorical variables: an absolute difference of 10% in the continuous values between categories;
- for associations between two continuous variables: scatterplots showed evidence of a linear relationship;
- for associations between two categorical variables: the proportion of participants differed by at least 20% across groups;
- or clinical significant as defined from the literature. For example, a 10 point difference in QOL, measured by the EORTC QLQ-C30, indicates a moderate clinically important difference (Osoba et al. 1998).

8.2.8.4. Analysis for research question 1

RQ1. To investigate the feasibility of recruitment strategies.

The feasibility of recruitment strategies was examined via the Consolidated Standards of Reporting Trials (CONSORT) statement, showing the number of eligible patients, and the number of patients recruited (Moher et al. 2010). The characteristics of the sample were described, in terms of: sociodemographic,

disease and treatment characteristics; QOL; information and decision-making preferences; information received; psychological well-being; social support; and self-efficacy in coping with cancer. Participants' reported problems communicating with health professionals were also described.

As recommended by Arnold et al. (2009), the effect and success of eligibility criteria on recruitment was examined. The representativeness of the sample compared with the target population was also examined to highlight selection and/or recruitment biases, using data collected by the Queensland Cancer Registry (QCR), which unlike national registries, includes benign brain tumour cases (QCR & CCQ 2009).

To be able to draw causal inferences in non-randomised cohort designs, a key assumption of quasi-comparability between treatment and non-treatment groups must be met (Happ et al. 2008). This study was not designed to recruit comparable groups because of the staggered recruitment of control and QPL group participants. However, assessments of group comparability were made, as comparability would have facilitated the comparison of outcome data. These comparisons also allow the assessment of the suitability of summary statistics for comparisons.

8.2.8.5. Analysis for Research Question 2

RQ2. To investigate the feasibility of evaluation strategies, particularly outcome assessment.

Reliability analyses were performed to determine the suitability of scaling the data collected into the planned scales and/or subscales. This involved the calculation of the mean and standard deviation of scores for each scale and subscale, and the derivation of correlation matrixes for item-item correlations and item-total correlations. Results were summarised using Cronbach's alpha coefficient.

Interview duration and missing data were examined, and associations with longer interview duration identified. Initially, factors which may be associated with longer interview duration were identified on a theoretical basis (e.g. interviews with persons with speech difficulties may take longer). These associations were then tested using bivariate analyses. Questions that were problematic for participants, and/or that had the most missing data, were highlighted.

Descriptive statistics for the proposed primary outcome variable, the QLQ-INFO25, and secondary outcome variable, information source, were reported. For the QLQ-INFO25, the *a priori* assumption that scale validity requires fewer than 15% of participates to score at the scale ceiling[16] was examined (McHorney & Tarlov 1995). Change scores were computed by subtracting baseline scores from follow-up scores, and from these, the proportion of participants who achieved improvements or deteriorations in scores of five and 10 points were identified. These values were chosen as potential estimates of a minimal clinically important difference (MCID), as they have been used for other quality of life instruments, including EORTC scales (Osoba et al. 1998; King 1996; King 2001; Barrett et al. 2005). These estimates were used pending the identification of validated MCIDs, which can only be determined in consultation with patients, carers, and health professionals. Further analyses undertaken to determine the sensitivity to change of the QLQ-INFO25 and the appropriateness of the estimates of MCID are included in Appendix T.

The sample size required for an RCT to show statistically significant changes in QLQ-INFO25 overall scores in the estimated MCIDs between control and intervention groups was calculated. Given the uncertainty in parameters (e.g. MCID, clustering by recruitment sites, standard deviation in change scores[17]), a sensitivity analysis was conducted using a range of values for uncertain parameters. Although QLQ-INFO25 scores in this sample were not normally distributed, the normality assumption may be met in future studies. Sample size calculations were therefore conducted using the t-test (which assumes normality of the outcome variable) and the Mann-Whitney test[18] (which does not require normality), and both of which assume homogeneity of variances and independence of observational units.

These statistical tests require an estimate of the SD of change for the population of interest. Using the SD of change from pilot or feasibility study participants may underestimate sample sizes for given levels of type I and type II errors (Shiffler &

[16] It is usually recommended that no more than 15% of participants score at either the item floor or ceiling, to allow for significant decreases and increases (respectively) in scores. However, given the QLQ-INFO25 assesses cumulative amount of information received, allowing for decreases is not needed, so only item ceilings were examined.

[17] Due to the small sample size, the SD is unlikely to adequately estimate the SD of a larger sample.

[18] In application of the Mann-Whitney test, a double exponential distribution is assumed, as it has the highest asymptotic relative efficiency compared to the t-test (Ahmad 1996).

Adams 1987; Muller & Benignus 1992). As recommended by Browne (1995), an 80% upper one-sided confidence limit (UCL) of the sample SD was used for tests involving 80% power, and 90% UCL of the sample SD used for tests in which 90% power was planned, to overcome this risk and increase the chance of achieving the planned power.

To initial approximations of sample size, design effects were applied to adjust for sampling participants via hospitals (clusters) (Bowling 2002). Design effect (DEFF) is based on the intraclass correlation coefficient (ICC), and indicates the extent to which standard errors may be underestimated if adjustment was not made for clustering (Katz & Zeger 1994). The ICC for the change in information received represents the proportion of the 'between cluster' (hospital) variance in information scores to the total variance in these scores, and was calculated using an analysis of variance (ANOVA) test. ICC and DEFF were calculated using the formulae:

$$ICC = \frac{MSB - MSW}{MSB + (m-1)* MSW}$$

$$DEFF = 1 + ICC*(m-1)$$

where ICC is intraclass correlation coefficient, MSB is the mean square between cluster, MSW is the mean square within cluster or individual variation, m is the number of clusters, and DEFF is design effect.

(Smeeth & Ng 2002).

However, the ICC that may result in a larger study may be different from that of the feasibility study, as the average number of participants in each cluster in our sample was roughly equal to the number of clusters, resulting in a small ICC. In larger studies conducted over longer periods of time, there is often a substantial difference between the number of participants recruited per cluster and the number of clusters. Published estimates of ICCs for QOL and morbidity variables for participants recruited from 106 general practices (median cluster size: 281.5, range 35-772) ranged from <0.01 (low) to approximately 0.05 (large), similar to other ICCs published for the primary care setting (Smeeth & Ng 2002; Bland 2000). Design effects were therefore estimated using ICCs of 0.01 (low level), 0.03 (moderate level), and 0.05 (high level effect), and using estimates of the average number of participants per cluster (where is a cluster is a hospital or practice) of 10, 25 and 50.

To the initial sample sizes, estimates of non-response (30%), attrition (30%) and inflation for multivariable modeling (20%) were applied (Patel et al. 2003; Hulley et al. 2001; Walker et al. 2003; Taphoorn et al. 2005; Scotland et al. 2009; Hsieh et al. 2003; Battistutta 2006). Sample size calculations were performed using PASS (Power Analysis and Sample Size Software) version 11 (Hintze 2011).

8.2.8.6. Analysis for Research Question 3

RQ3. To investigate acceptability of the QPL among patients newly diagnosed with or undergoing treatment for a brain tumour.

Participants' responses to questions about the helpfulness and use of the QPL (QPL group) or standard patient information brochure (control group) were compared to allow assessment of the perceived usefulness of the QPL, controlling for social desirability bias. Brochure acceptability index scores (variable construction described in section 8.2.8.1) were reported for all participants, and for control group and QPL group participants separately.

To determine the suitability of timing of QPL provision, participants also answered two questions: 'Did you have enough time to read the booklet before your consultations?' and 'Would you have preferred to receive the booklet at a different time?' Results for brochure timing were presented for all participants, by participant group, and by time since diagnosis.

This quantitative data was augmented with qualitative data from the semi-structured interview referring to the usefulness of 'brochure' provided, including timing issues. As qualitative data were sparse, formal analysis of this data was not undertaken; rather, all relevant data were presented.

8.2.9. Study Close-out

Following the completion of analyses, recruiting health professionals and participants[19] were sent a newsletter describing the results found (Appendix U), and for control group participants, a copy of the QPL.

[19] The status of participants (i.e. alive) was determined with reference to obituaries and checks with health professionals.

8.2.10. How Rigour has been Achieved in this Study

Although the six techniques for ensuring rigour described in section 5.4 are more commonly applied to qualitative or mixed methods studies, they are equally applicable to this study. Theoretical rigour, which requires consistency between research aims and strategy (Liamputtong & Ezzy 2005), was demonstrated by the clear relationship between the research purpose and aims. The primary objective of this study was to assess the acceptability of the QPL and the feasibility of strategies for its evaluation. This study thus involved the collection and analysis of data required to examine the acceptability of the QPL, and the feasibility of study strategies (e.g. recruitment, problematic questionnaire items, sample size planning).

Methodological rigour, or clear documentation of methodological and analytical decisions, was gained through the keeping of detailed records (e.g. see Appendix S for the study codebook), and via description of variations to the original study plan (e.g. see section 8.2.3.2 for a description of changes in sampling undertaken when initial strategies did not yield a sufficient number of participants).

Interpretive rigour is gained when the interpretation accurately represents the understanding of participants and data (Liamputtong & Ezzy 2005). To evidence interpretive rigour, the conclusions drawn are clearly supported by results shown in tables and figures. Although statistical tests were not applied in this study, this reflects a desire to avoid 'over-interpreting' the findings, such as reporting values for statistical significance that have no meaning when clinical significance is not known and/or the study is not powered to detect such results.

Triangulation involves confirmation of results and/or minimisation of bias from different theories, methods, strategies, researchers, and/or sources (Jones & Bugge 2006). Of the three studies that make up this thesis, this study was the least multi-method, with predominantly quantitative data collection and analysis. However, participants answered open and closed questions to describe their views about the QPL, enabling comparisons across methods and strengthening conclusions drawn.

Evaluative rigour, or consideration of the ethical and political aspects of the research (Liamputtong & Ezzy 2005). The estimated MCIDs and resulting sample

sizes are only tentative indicators, or 'starting points' for further research. As with other patient-reported outcomes, the EORTC QLQ-INFO25 is a subjective measure, and patients' input is needed to determine whether the estimates used as MCIDs actually indicate 'meaningful' change (Swartz et al. 2011).

The final type of rigour is rigorous reflexivity, which involved critical reflection of how the researcher's feelings and assumptions, and his/her relationship with participants, influenced the research (Dowling 2006). During contact with participants, the candidate was asked by patients to give advice or clarify conflicting information, which may suggest that the candidate was viewed as a source of health information. Following ethical principles, appropriate information and support (excluding medical advice) was provided, and participants were referred to the Cancer Council Queensland telephone help line and website[20]. The candidate's willingness to assist participants may also have facilitated the research process, assisting participants to feel comfortable disclosing their experiences. However, the 'inside knowledge' displayed by the candidate may have led some participants to characterise the candidate as an 'expert' or 'outsider'. Such characterisation may have led participants to conceal difficulties that they encountered in interacting with health professionals.

[20] The candidate also clarified her position as a researcher, and not a health professional, although the nature and purpose of this distinction may not have been apparent to all participants.

8.3. RESULTS

This section presents the results for research questions 1-3 on the feasibility and acceptability assessment of the question prompt list.

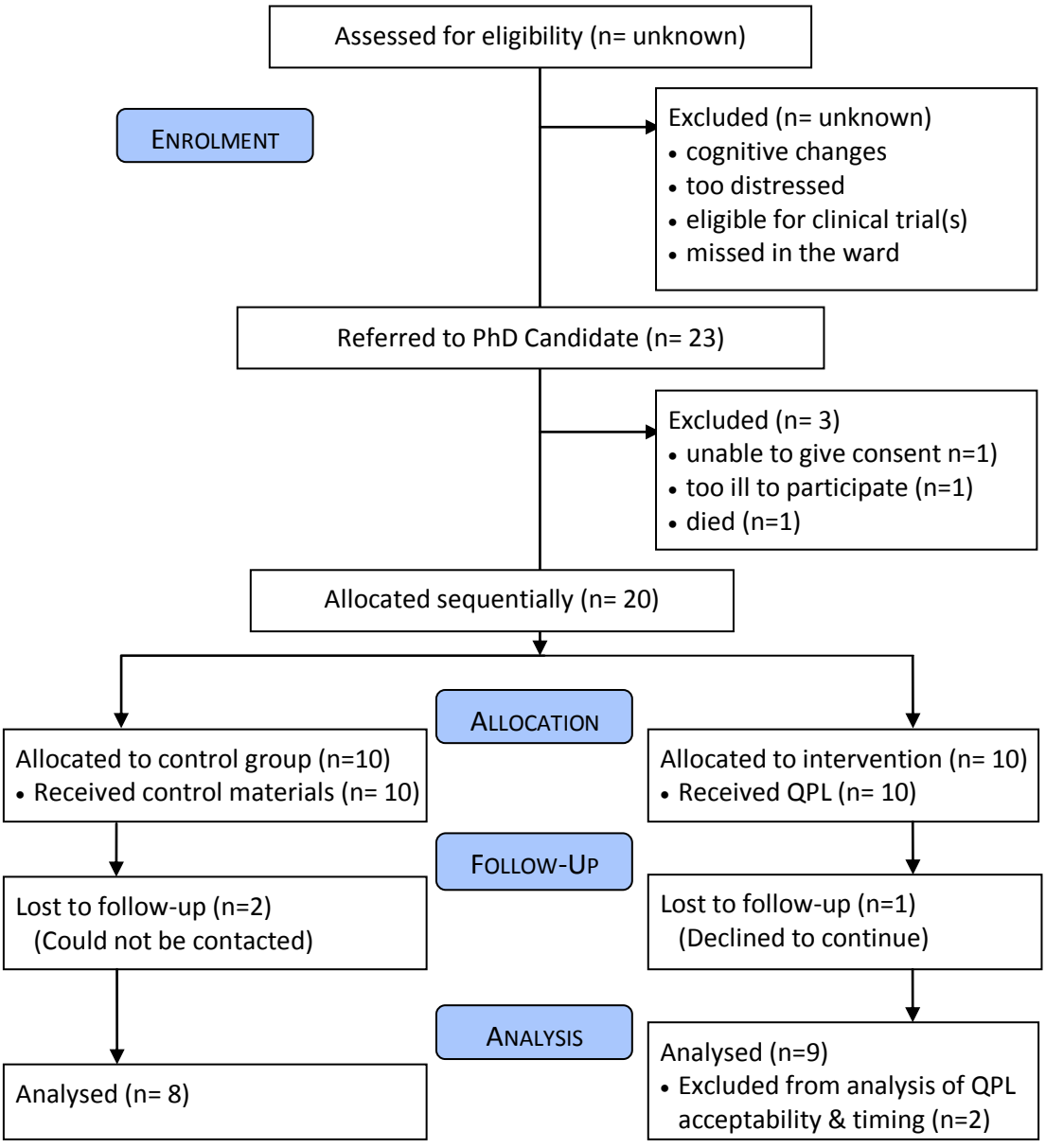
8.3.1. RESULTS FOR RESEARCH QUESTION 1

8.3.1.1. RECRUITMENT OUTCOMES

Twenty individuals were recruited from four Brisbane hospitals over a 14 month period. As shown in Figure 8.2, the number of persons eligible to participate over the recruiting period is unknown, as health professionals did not keep sufficient records and acknowledged that many persons eligible to participate were not identified or were identified but not approached. Reasons for not identifying and/or not approaching potential participants regarding study participation were: time pressures; health professionals' lack of interest in the study; changes in personnel or delegation of recruitment role to other personnel who did not fully understand the role; patient distress; lack of clarity as to when to approach patients; and perceived burden for persons eligible for participation in other research studies, particularly clinical trials of pharmaceuticals.

The lack of adequate data means accrual rates cannot be calculated; given the factors above these are likely poor and may have resulted in selection bias. However, they are probably typical for studies with vulnerable populations.

All other recruitment data was complete. Twenty-three eligible persons were referred to the PhD candidate, who invited each of these persons to participate. Three of these persons were excluded, one as he lacked understanding of his condition and was thus unable to give consent, and two who reported that they were too ill to participate at the time of the study, one of whom died during the study period. All twenty remaining persons gave informed consent and were allocated to control group (first ten participants) or intervention group (next ten participants). Overall, three persons were lost to follow up: two of the control participants could not be contacted in the four-month period following their initial interview, and one intervention participant declined to complete the follow-up interview.



QPL: Question Prompt List

FIGURE 8.2 CONSORT (CONSOLIDATED STANDARDS OF REPORTING TRIALS) DIAGRAM 2010 SHOWING FLOW OF STUDY PARTICIPANTS

Two of the 17 participants (from the QPL group) did not complete questions about the QPL[21].

8.3.1.2. PARTICIPANT CHARACTERISTICS

The median age of study participants was 51 years (range 28 to 72 years). The median time since diagnosis at baseline was 1 month (range 0-46 months); 60% of participants were male, 75% were married, and 50% were usually employed full-

[21] One participant did not read the QPL and another did not remember it (see Missing Data, page 156).

time; 70% of participants were from a major city, and 60% were treated in a private hospital (Table 8.4).

TABLE 8.4 DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS AT BASELINE (N=20)

Characteristic		n (%)
Sex	Male	12 (60.0)
	Female	8 (40.0)
Marital status	Married	15 (75.0)
	Living together	3 (15.0)
	Divorced	1 (5.0)
	Never married	1 (5.0)
Education	Junior high	7 (35.0)
	Senior high	4 (20.0)
	Trade certificate, technical college, diploma	3 (15.0)
	University degree	6 (30.0)
Usual employment status	Full time	10 (50.0)
	Part time or casual	4 (20.0)
	Full time home duties or home carer	4 (20.0)
	Retired	2 (10.0)
Household income	<$40 000	4 (20.0)
	$40 000 - < $80 000	6 (30.0)
	$80 000 +	9(45.0)
	Don't know	1 (5.0)
Worked in health care		5 (25.0)
Spoke a language other than English at home		2 (10.0)
Treated in a private hospital		12 (60.0)
Location (ARIA+) [a]	Major city	14 (70.0)
	Inner regional	2 (10.0)
	Outer regional	4 (20.0)

[a] ARIA+: Australian Remote Index for Areas classification (no participants were from remote or very remote locations) of home (not treatment) location

Glioblastoma (40%), oligodendroglioma (20%), and meningioma (15%) were the most prevalent tumour types (Table 8.5). All participants were treated surgically, 65% had radiotherapy, and 50% had chemotherapy.

TABLE 8.5 DISEASE AND TREATMENT CHARACTERISTICS OF PARTICIPANTS

Characteristic		N (%)
Hemisphere	Anterior right	9 (45.0)
	Posterior right	2 (10.0)
	Anterior left	5 (25.0)
	Posterior left	1 (5.0)
	Other	3 (15.0)
Tumour lobe	Frontal	4 (20.0)
	Parietal	3 (15.0)
	Temporal	5 (25.0)
	Other	8 (40.0)
Tumour type	Glioblastoma	8 (40.0)
	Meningioma	3 (15.0)
	Astrocytoma	1 (5.0)
	Oligodendroglioma	4 (20.0)
	Pituitary adenoma	1 (5.0)
	Ependymoma	2 (10.0)
	Mixed glioma	1 (5.0)
Tumour type confirmed histologically		20 (100.0)
Tumour stage at diagnosis	I	3 (15.0)
	II	4 (20.0)
	III	4 (20.0)
	IV	8 (40.0)
	grade unknown	1 (5.0)
Treatments received *(multiple responses allowed)*	Biopsy	4 (20.0)
	Surgery	20 (100.0)
	Radiotherapy	13 (65.0)
	Chemotherapy	10 (50.0)
	Clinical trial [a]	2 (10.0)
Impairments *(multiple responses allowed)*	Speaking/understanding speech	5 (25.0)
	Attention/concentration	6 (30.0)
	Abstract reasoning	1 (5.0)
	Memory	7 (35.0)
	Visual	3 (15.0)
	Motor	7 (35.0)
	Other (e.g. seizures, loss of sensation)	3 (15.0)
Previous cancer diagnosis		4 (20.0)
Likely prognosis	Weeks or months [b]	2 (10.0)
	Years	11 (55.0)
	Normal life expectancy	4 (20.0)
	Not available	3 (15.0)

[a] specific clinical trial(s) are not specified to preserve the confidentiality of participants
[b] includes one patient who died within weeks/months of participation

The most common impairments noted in participants' medical records were memory (35%), motor function (35%), and attention or concentration impairments (30%) Table 8.5). The baseline QOL of participants, measured using the EORTC QLQ-C30, is shown in Figure 8.3. The mean scores for all participants (higher scores indicate better QOL) were: global QOL: 66.46 (SD 23.20); physical functioning: 91.67 (SD 13.49); role functioning: 66.67 (SD 31.06); emotional functioning: 63.33 (SD 26.41); cognitive functioning: 71.67 (SD 23.01); and social functioning: 69.17 (SD 20.43).

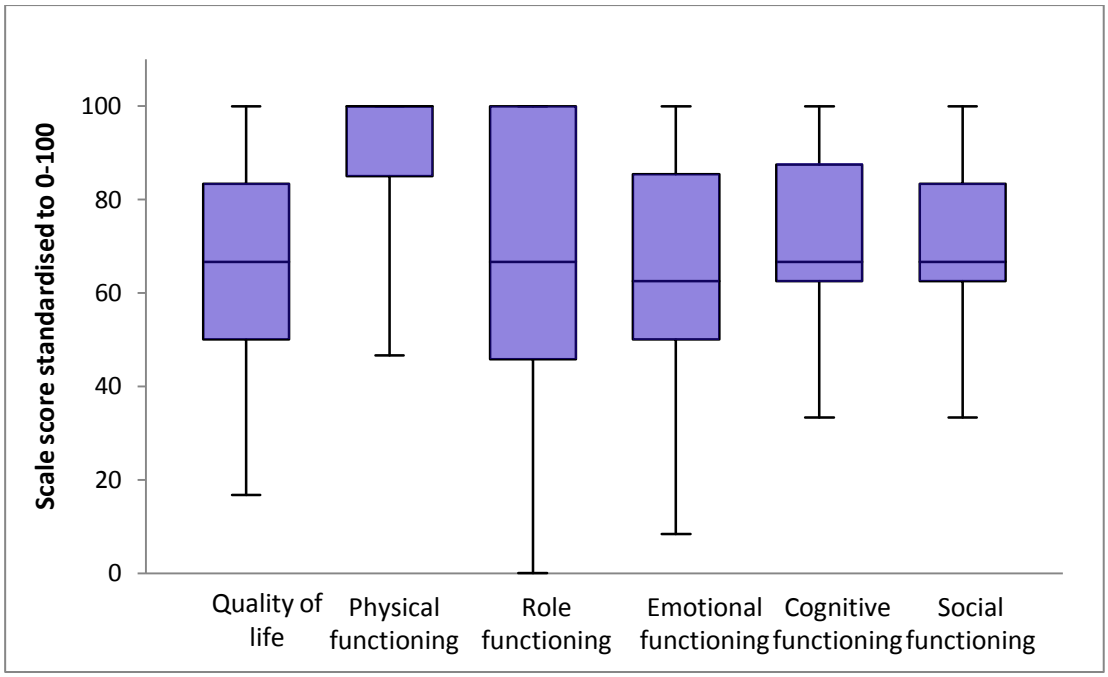


FIGURE 8.3 BASELINE QUALITY OF LIFE OF PARTICIPANTS: OVERALL SCORE AND SCORES FOR EACH FUNCTIONAL SCALE

The symptom scales from the QLQ-C30 (Figure 8.4) showed highest median scores (higher scores indicate more symptoms) for fatigue (median 33.3, range 0-100), nausea and vomiting (median 8.33, range 0-66.67), and pain (median 8.33, range 0-83.33).

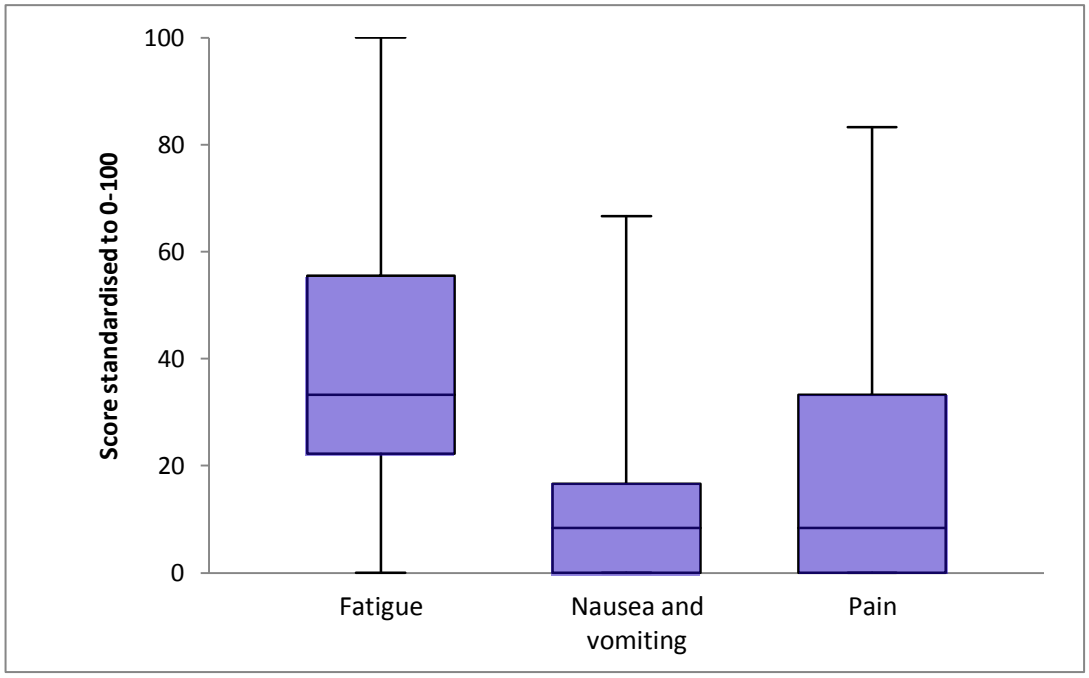


FIGURE 8.4 BASELINE SYMPTOM SCALES OF PARTICIPANTS ASSESSED BY THE QLQ-C30

Of the single item symptoms assessed by the QLQ-C30, the most prevalent symptoms experienced (to any degree) were insomnia (60%) and financial difficulties (55%). The most prevalent symptoms experienced (to any degree) that were assessed by the EORTC Brain tumour module, the QLQ-BN20, were drowsiness (70%), and headaches (55%), as shown in Table 8.6.

TABLE 8.6 QLQ-C30 AND QLQ-BN20 SYMPTOM SCALES: PROPORTIONS OF PARTICIPANTS EXPERIENCING SYMPTOMS (TO ANY DEGREE) OF AT BASELINE

Proportion [a] of participants experiencing any degree of:			
Dyspnoea	6 (30.0)	Headaches	11 (55.0)
Insomnia	12 (60.0)	Seizures	2 (10.0)
Appetite loss	5 (25.0)	Drowsiness	14 (70.0)
Constipation	8 (40.0)	Hair loss	3 (15.0)
Diarrhoea	1 (5.0)	Itchy skin	6 (30.0)
Financial difficulties	11 (55.0)	Weakness of legs	5 (25.0)
		Bladder control	3 (15.0)

[a] Symptoms reported as a proportion of patients experiencing them as scale distribution skewed

Four brain tumour specific scales were assessed by the QLQ-BN20 (Figure 8.5). At baseline, the highest median score (with higher scores meaning more symptoms) was for visual disorder (median 83.89, range 0-100).

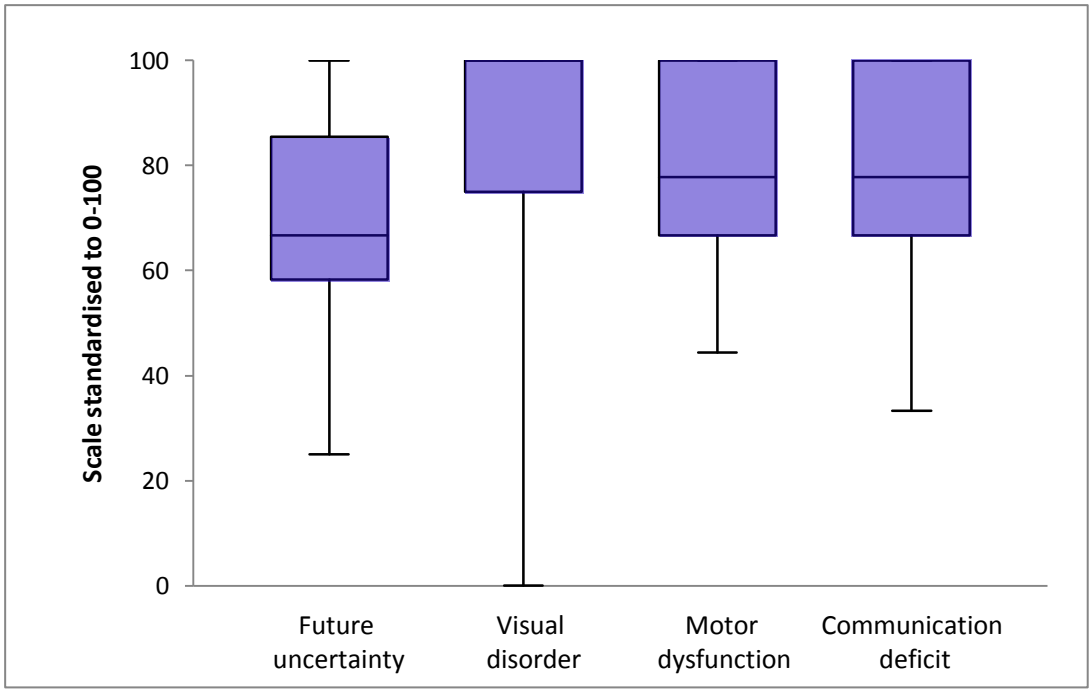


FIGURE 8.5 BASELINE BRAIN TUMOUR QUALITY OF LIFE OF PARTICIPANTS: QLQ-BN20 SCALES

The information and decision-making preferences of participants at baseline are shown in Table 8.7. Most participants said that they preferred to participate in decisions (70%), and that they wanted as much information as possible about their illness, good or bad (85%). Participants were categorised as 'low' or 'high' information seekers based on the median KHOS-I score (4.5).

TABLE 8.7 INFORMATION AND DECISION-MAKING PREFERENCES OF PARTICIPANTS (N=20)

Characteristic	N (%)
Attitude towards participation in decision-making: [a]	
Prefer to leave decisions about medical care & treatment up to doctor	6 (30.0)
Prefer to participate in decisions about medical care & treatment	14 (70.0)
Attitude towards information about illness: [a]	
I want only the information needed to care for myself properly	1 (5.0)
I want additional information only if it is good news	2 (10.0)
I want as much information as possible, good or bad	17 (85.0)

[a] from Cassileth Information Styles Questionnaire

A summary of EORTC QLQ-INFO25 scale scores is shown in Table 8.8. Median scores were highest (indicating more information received) for information about medical tests (median 61.1, range 33.3-100), and about treatment (median 58.3, range 16.7-88.9). Most (85%) participants said they had received written information, 25% had received information on CD, tape or video; 60% wanted more information; and no participants reported that they wished they had received less information.

TABLE 8.8 BASELINE SCORES FOR INFORMATION RECEIVED ASSESSED BY THE QLQ-INFO25 (N=20)

Characteristic	Score (0-100) median (range)
Amount of information received about:	
Disease	45.8 (16.7-83.3)
Medical tests	61.1 (33.3-100)
Treatment	58.3 (16.7-88.9)
Other services	20.8 (0-75.0)
Overall:	
Satisfaction with info received	66.7 (0-100)
Overall extent to which info was helpful	100 (0-100)
Overall QLQ-INFO25 score	46.0 (16.0-68.0)

QLQ-INFO25: Information module

The amounts of information received by participants about other topics measured by the QLQ-INFO25 are shown in Figure 8.6. For both non-medical treatments, and different places of care, more than half of participants reported that they received no information at all. Almost half of participants reported receiving 'a little bit' of information on "things to do to help yourself get better".

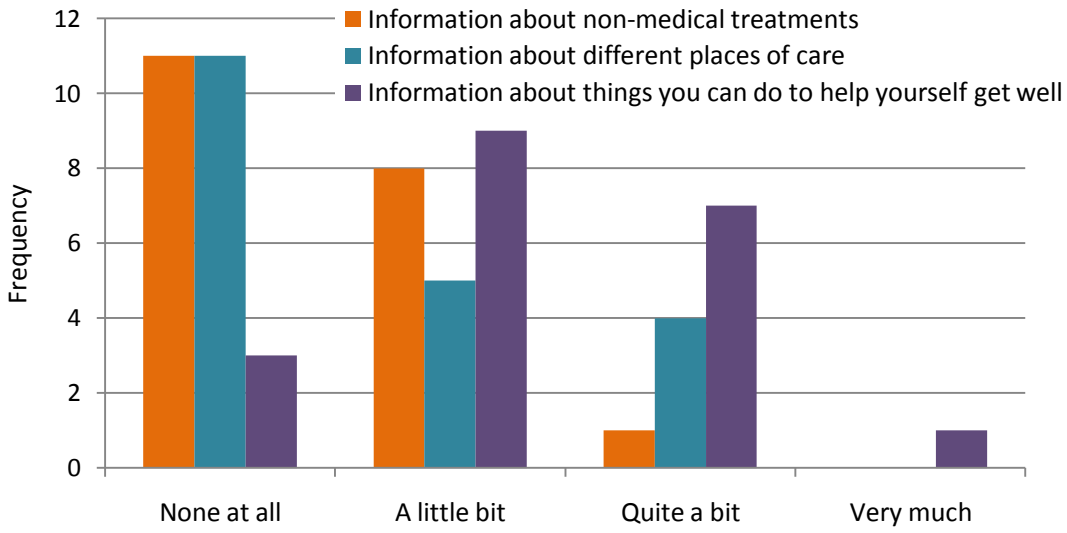


FIGURE 8.6: PARTICIPANTS' RESPONSES AT BASELINE REGARDING INFORMATION RECEIVED ABOUT THREE TOPICS (N=20)

Seven participants (35%) indicated that they had 'ever' been diagnosed with depression by a physician and six (30%) that they had 'ever' been diagnosed with anxiety. Using the recommended cut-point of 26 for the IES total score (Horowitz et al. 1979), 10 participants (50%) had mild levels of distress, and 10 (50%) exhibited moderate/severe distress at baseline (Table 8.9). Depressive symptoms and

symptoms of anxiety to the degree of 'moderately, very or extremely' were each reported by 45% of participants over the previous two weeks. The median distress thermometer score was 4.5 (range 0-10), and 60% of participants scored 4 or over, indicating a 'significant' level of distress.

TABLE 8.9 BASELINE PSYCHOLOGICAL WELL-BEING & SOCIAL SUPPORT OF PARTICIPANTS (N=20)

Characteristic	median (range)
Impact of event scale	
Overall score	26.0 (2-60)
Intrusion subscale score	13.5 (0-25)
Avoidance subscale score	11.5 (0-36)
Social support score	30 (25-34)
	n (%)
Have felt down, depressed or hopeless over the past 2 weeks	
Not at all or a little	11 (55.0)
Moderately, very or extremely	9 (45.0)
Have felt nervous, anxious or fearful over the past 2 weeks	
Not at all or a little	11 (55.0)
Moderately, very or extremely	9 (45.0)

Self-efficacy for coping with cancer was measured using the Cancer Behavior Inventory (CBI) (Table 8.10). Participants' scores were highest for the subscales 'Accepting cancer/maintaining a positive attitude' (median 8.1, range 6.2-9) and 'Seeking and understanding medical information' (median 8.0, range 4.3-9).

TABLE 8.10 PARTICIPANTS' SELF-EFFICACY IN COPING WITH CANCER AT BASELINE (N=20)

Characteristic	median (range)
Overall score	243.0 (180.5 - 281.0)
Mean subscale score: [a]	
Maintenance of activity & independence	7.7 (5.0-9.0)
Seeking & understanding medical information	8.0 (4.3-9.0)
Stress management for medical appointments	7.3 (3.2-9.0)
Coping with treatment related side-effects	6.9 (3.8-9.0)
Accepting cancer/maintaining a positive attitude	8.1 (6.2-9.0)
Affective regulation	6.2 (3.4-7.8)
Seeking support	7.0 (4.3-9.0)

[a] Mean scores were used to allow comparison between subscales with different numbers of items.

The median score for problems communicating with and/or interacting with health professionals, assessed using the CARES Medical Interaction Subscale, was 43 (range 27-55 points). The potential range of this instrument is 11-55, with lower scores indicating more problems.

8.3.1.3. Eligibility Criteria

This study had seven eligibility criteria, six of which addressed suitability for the study (e.g. diagnosis with a primary brain tumour), and informed consent (e.g. persons must be able and well enough to participate). The remaining study eligibility criterion specified that persons had 'not previously received a cancer diagnosis, except for skin cancer'. Data from medical records showed that all persons met the six eligibility criteria relating to suitability and informed consent. However, two persons had previously been diagnosed with cancer other than skin cancer: one with prostate cancer and one chondrosarcoma. As data from medical records was not gathered until after final interviews were completed, the ineligibility of these participants was not revealed until this time. Given the small sample, it was decided to include data from these persons for analysis.

8.3.1.4. Representativeness of the Sample

As Table 8.11 shows, men comprised 60% of study participants and 60% of persons diagnosed with brain, meninges and other central nervous system (CNS) tumours in Queensland in 2003-2007. The most populous age ranges for males and females in both our sample and the QCR data were 40-59 years and 60-79 years. However, compared with population data, our sample had a higher proportion of persons aged 20-39 years, and no participants aged 80 years or older.

Table 8.11 Comparison of Participants with Incident Cases of Brain, Meninges and Other Central Nervous System Cancers, Queensland Cancer Registry Data 2003-2007

Characteristic		Sample (n=20) n (%)	Population [ab] (n=263) %
Males	Aged 20-39 years	3 (15.0)	7.2
	Aged 40-59 years	7 (35.0)	25.5
	Aged 60-79 years	2 (10.0)	22.8
	Aged 80+ years	0 (0)	4.5
Females	Aged 20-39 years	2 (10.0)	6.1
	Aged 40-59 years	3 (15.0)	14.8
	Aged 60-79 years	3 (15.0)	13.3
	Aged 80+ years	0 (0)	5.7

[a] Sourced from (QCR & CCQ 2009).

[b] Incident cases of cancers of the brain, meninges or other central nervous system, persons aged 20+ years.

Based on QCR data, the most prevalent tumour type in Queensland over 20 years was astrocytoma (25.6%). In contrast, only 5% of study participants had astrocytomas. The most common tumour type in our sample was glioblastoma (40%) (Table 8.12). Meningioma was also far more common among our participants (15%) than among prevalent cases (2.8%).

TABLE 8.12 COMPARISON OF TUMOUR TYPE OF PARTICIPANTS WITH 20 YEAR PREVALENCE OF BRAIN TUMOURS IN QUEENSLAND (QLD)

Type of tumour	Participants (n=20) [a]		QLD prevalence (n=416) [b]	
	n	%	n	%
Glioblastoma	8	40.0	83	20.0
Meningioma	3	15.0	9	2.8
Astrocytoma	1	5.0	106	25.6
Oligodendroglioma	4	20.0	75	18.1
Ependymoma	2	10.0	34	8.2
Other	2	10.0	109	26.3

[a] Reported in participant medical records
[b] Data provided by the Queensland Cancer Registry, cited in (Janda et al. 2008).

8.3.1.5. COMPARABILITY OF CONTROL AND QPL GROUPS

This section highlights key differences between participants in the control and QPL groups at baseline (full analysis, Appendix T). Although control group participants were recruited prior to QPL group participants, and it was not expected that their baseline characteristics would be similar, comparisons were made to examine this assumption[22].

Median age was higher among the QPL group (55.5 years, range 28-68) than control group (48 years, range 30-72). Males represented 70% of the QPL group and 50% of the control group. Twenty percent of QPL group participants reported a yearly pre-tax household income of $80,000 or more, compared to 70% of control group participants, and 30% of the QPL group, compared with 90% of the control group, were treated in a private hospital.

[22] These comparisons were made because if, by chance, the baseline characteristics of control group and QPL group participants were similar, comparison of follow-up scores between groups may have been valid. For transparency, comparisons of change in QLQ-INFO25 scores between groups have also been included in Appendix T (Arnold et al. 2009). However, the uneven distribution of baseline characteristics and small sample size mean that any differences cannot be interpreted as showing the effectiveness of the QPL or standard information.

Compared with control group participants, QPL group participants tended to be diagnosed longer ago (median 2 months, range 0-46, compared with 0, range 0-12), have more aggressive tumours (60% versus 20% glioblastoma), more treatments (90% versus 40% radiotherapy, 70% versus 30% chemotherapy), more impairments (impairments to 50% versus 10% for attention, 60% versus 10% for memory), and a worse prognosis (0% versus 40% normal life expectancy predicted).

QPL group participants reported significantly better (10 points or more) quality of life than control group participants for global quality of life, cognitive functioning, fatigue, nausea and vomiting, pain, and communication deficit. However, control group participants reported significantly better physical functioning.

Subjective stress, measured using the Impact of Event Scale, was higher among control group participants (median score 29, range 2-58) than QPL group participants (median 21.5, range 2-60). Scores from the Cancer Behavior Inventory suggested QPL participants had higher self-efficacy in coping with cancer. Differences between groups were greatest for the subscales 'seeking and understanding medical information' (15.6% difference) and 'affective regulation' (10% difference).

Eighty percent of QPL participants said that they preferred to participate in decisions about medical care and treatment, compared with 60% of control group participants. Information preferences were oppositely distributed across groups: 70% of control group participants were high information seekers (scoring at or above the median KHOS-I score), compared with 30% of QPL group participants.

Information received at baseline

As shown in Table 8.13, QPL group participants reported lower QLQ-INFO25 scores at baseline for information about the disease, information about medical tests, and information about treatment, than control group participants. In contrast, 50% of QPL group participants, and no control group participants, reported receiving information on tape, video or CD.

TABLE 8.13 INFORMATION RECEIVED BY CONTROL GROUP AND QPL GROUP PARTICIPANTS AT BASELINE: MEDIAN SCORES

Characteristic	Control group (n=10)	QPL group (n=10)
	median (range) [a]	
Amount of information received about:		
Disease	58.3 (16.7-83.3)	33.3 (16.7-62.5)
Medical tests	61.1 (33.3-100)	55.6 (33.3-100)
Treatment	52.4 (14.3-61.9)	50.0 (23.8-81.0)
Other services	16.7 (0-14.7)	29.2 (16.7-75.0)
Overall:		
Satisfaction with info received	66.7 (0-100)	83.3 (0-100)
Overall extent to which info was helpful	100 (0-100)	83.3 (0-100)
Overall score	43.3 (16.0-61.3)	50.3 (29.3-68.0)
	n (%)	
Types of information received:		
Written information	8 (80.0)	9 (90.0)
Tape/video/CD	0 (0)	5 (50.0)
Wish to receive more information	5 (50.0)	7 (70.0)
Received information about different places of care		
Not at all	8 (80.0)	3 (30.0)
A little bit	1 (10.0)	4 (40.0)
Quite a bit	1 (10.0)	3 (30.0)
Received information about things you can do to help yourself get well		
Not at all	3 (30.0)	0 (0)
A little bit	2 (20.0)	7 (70.0)
Quite a bit	5 (50.0)	2 (20.0)
Very much	0 (0)	1 (10.0)

[a] Score standardised to 0-100, with higher scores indicating more information was received

8.3.2. RESULTS FOR RESEARCH QUESTION 2

The aim of this research question was to investigate the feasibility of evaluation strategies, particularly the characteristics of the proposed outcome variable, the QLQ-INFO25.

8.3.2.1. RELIABILITY ANALYSES

Cronbach's alpha determines the internal consistency of a scale, or homogeneity of items, by measuring the average correlation of items in a survey instrument (Streiner & Norman 2008). Cronbach's alpha normally ranges between 0 and 1, although there is no actual lower limit and negative scores are possible (Gliem & Gliem 2003). The closer Cronbach's alpha is to 1, the greater the internal consistency of the scale.

A Cronbach's alpha score of at least 0.7 generally indicates that the internal consistency of the scale or subscale under examination is adequate (Nunnaly 1978). However, α=0.6 has also been accepted by many researchers, particularly for scales constructed of 2-3 items, as the value of alpha is dependent on the number of items in the scale (Santos 1999; Streiner & Norman 2008). Within the present study, 19 scales/subscales met the criterion of Cronbach's alpha $\geq$ 0.7, and a further six scales ranged between 0.6 and 0.7 (Table 8.14). Five scales had scores for Cronbach's alpha that were less than 0.6. This could result from the small sample size of this study, or because the sample had characteristics different from the population from which the scale was developed. Rather than using the items from these scales individually, these scales were used 'as is' with appropriate cautionary warnings. This both reduces the random measurement error of single items (which 'average out' when combined into a multi-item scale (Gliem & Gliem 2003)), and allows comparison of the study sample with other populations using these scales.

TABLE 8.14 INTERNAL CONSISTENCY OF SCALES & SUBSCALES

Scale or subscale	number of items	score range	median (min, max) [ab]	Cronbach's alpha of sample [b]	Cronbach's alpha from literature	
Information received (QLQ-INFO25) [c]						
Overall score	25	0-100	46.0 (16.0-69.0)	0.799	0.91	(Arraras et al. 2010)
Info about the disease	4	0-100	45.8 (16.7-83.3)	0.604	0.76, 0.73, 0.75	
Info about medical tests	3	0-100	61.1 (33.3-100.0)	0.739	0.87, 0.86, 0.83	
Info about treatment	6	0-100	58.3 (16.7-88.9)	0.643	0.81, 0.8, 0.8	
Info about other services	4	0-100	20.8 (0-75.0)	0.359	0.7, 0.73, 0.73	
Quality of Life (QLQ-C30) [c]						
Global quality of life	2	0-100	66.7 (16.7-100.0)	0.829	0.86, 0.89	(Aaronson et al. 1993)
Physical functioning	5	0-100	100.0 (46.7-100.0)	0.719	0.68, 0.71	
Role functioning	2	0-100	66.7 (0-100.0)	0.815	0.54, 0.52	
Emotional functioning	4	0-100	62.5 (8.3-100.0)	0.789	0.73, 0.80	
Social functioning	2	0-100	66.7 (33.3-100.0)	0.168	0.68, 0.77	
Cognitive function	2	0-100	66.7 (33.3-100.0)	0.729	0.56, 0.73	
Nausea & vomiting	2	0-100	8.3 (0-66.7)	0.491	0.65, 0.73	
Pain	2	0-100	8.3 (0-83.3)	0.750	0.82, 0.76	
Fatigue	3	0-100	33.3 (0-100.0)	0.911	0.80, 0.85	
Brain tumour specific quality of life (QLQ-BN20) [c]						
Future uncertainty	4	0-100	66.7 (25.0-100.0)	0.703	0.70, 0.83	(Osoba et al. 1996)
Visual disorder	3	0-100	100.0 (0-100.0)	0.823	0.72. 0.82	
Motor dysfunction	3	0-100	77.8 (44.4-100.0)	0.691	0.74, 0.83	
Communication deficit	3	0-100	77.8 (33.3-100.0)	0.692	0.87, 0.86	
Krantz Health Opinion Survey Information Scale	7	0-7	4.3 (1.84)	0.535	0.76	(Smith et al. 1984)

TABLE 8.14 CONTINUED

Scale or subscale	number of items	score range	median (min, max) [ab]	Cronbach's alpha of sample [b]	Cronbach's alpha from literature	
Cancer Behavior Inventory (CBI)						
Total score	33	33-297	243.0 (180.5-281.0)	0.868 [d]	0.94	(Merluzzi et al. 2001)
Maintenance of activity & independence	5	5-45	38.5 (25.0-45.0)	0.796	0.86	
Seeking & understanding medical info	5	5-45	40.0 (21.5-45.0)	0.863	0.88	
Stress management for medical appointments	5	5-45	36.5 (16.0-45.0)	0.803	0.86	
Coping with treatment related side-effects	5	5-45	34.5 (19.0-45.0)	0.827	0.82	
Accepting cancer/ maintaining a positive attitude	5	5-45	40.5 (31.0-45.0)	0.680	0.86	
Affective regulation	5	5-45	31.0 (17.0-39.0)	-0.125 [d]	0.81	
Seeking support	3	3-27	21.0 (13.0-27.0)	0.622	0.80	
ENRICHD Social Support score	7	8-34	30.2 (2.70)	0.632	0.88	(Vaglio et al. 2004)
CARES Medical Interaction Scale	11	11-55	43.0 (27.0-55.0)	0.836	0.85, 0.87	(Schag et al. 1991)
Impact of Event Scale (IES)						
Total stress score	15	0-75	26.0 (2.0-60.0)	0.923 [e]	not reported [d]	
Intrusive subscale	7	0-35	13.5 (0-25.0)	0.847 [e]	mean 0.86 (0.72-0.92) [f]	(Sundin & Horowitz 2002)
Avoidance subscale	8	0-40	12.0 (1-35.0)	0.864	mean 0.82 (0.65-0.90) [f]	

[a] Medians (minimum, maximum) are shown for all variables except for the KHOS Information scale & the ENRICHD social support score, which were normally distributed
[b] For variables measured at two time points, baseline data is presented for simplicity
[c] QLQ-C30, QLQ-BN20 & QLQ-INFO25 scores are shown standardised to 0-100 for consistency.
[d] Cronbach's alpha is based on 16 values
[e] Cronbach's alpha is based on 19 values
[f] Mean and range of Cronbach's alpha from 18 studies from review study, Cronbach's alpha presented for each subscale only as is commonly reported
Abbreviations: ENRICHD: Enhancing recovery from coronary heart disease, CARES: Cancer rehabilitation evaluation system

8.3.2.2. Interview Duration

The median time to complete the baseline interview was 34 minutes (range 21-60). Nine baseline interviews were conducted face-to-face in the hospital setting, with the remaining 11 conducted via the telephone. Face-to-face interviews were slightly shorter in duration than telephone interviews (median 31 minutes versus 34 minutes), as shown in Figure 8.7.

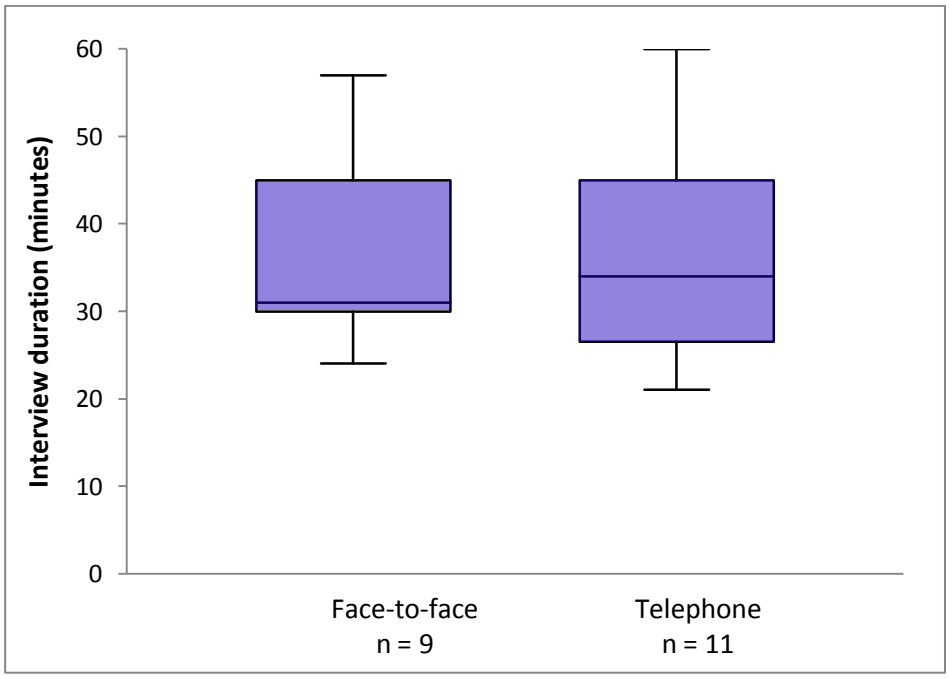


Figure 8.7 Baseline Interview Duration for Face-to-face versus Telephone Interviews

Three sociodemographic factors, two self-reported impairments, two tumour variables, and four impairments reported in medical records, were found to be associated with baseline interview duration, and are listed in Table 8.15.

Baseline interview duration was also positively correlated with self-reported visual disorder score[23] (spearman's correlation coefficient, ρ=0.307), and negatively correlated with self-reported communication deficit score (spearman's ρ=-0.324).

[23] Impairment scores refer to scores standardised from 0-100, with higher scores indicating greater impairment.

TABLE 8.15 RELATIONSHIPS BETWEEN DEMOGRAPHIC, DISEASE AND TREATMENT FACTORS AND BASELINE INTERVIEW DURATION (N=20)

Characteristic	Minutes duration: median (range)
Sex	
male	38.5 (21-60)
female	30.5 (24-45)
Education	
Junior or senior high school	34.0 (21-57)
Trade, technical certificate or diploma	45.0 (34-51)
University degree or equivalent	27.5 (24-60)
Language spoken at home	
English	34.0 (21-60)
Other	42.5 (28-57)
Tumour type [a]	
glioblastoma	32.5 (24-57)
other gliomas (astrocytoma, oligodendroglioma, mixed glioma)	46.0 (24-60)
meningioma	41.0 (21-45)
other (ependymoma, pituitary adenoma)	31.0 (25-42)
Tumour lobe [a]	
frontal	32.0 (21-57)
parietal	45.0 (24-51)
temporal	34.0 (24-47)
other (including multifocal, multi-lobular)	36.0 (25-60)
Visual impairment [a]	
Present	41.0 (24-42)
Absent	34.0 (21-60)
Memory impairment [a]	
Present	42.0 (28-60)
Absent	31.0 (21-51)
Attention impairment [a]	
Present	42.5 (28-60)
Absent	32.5 (21-57)
Motor impairment [a]	
Present	42.0 (21-60)
Absent	34.0 (24-57)

[a] reported in medical record

Median duration of the follow-up interview was 33.0 minutes, ranging from 19 to 51 minutes (n=17).

8.3.2.3. MISSING DATA

Twelve participants had no missing data, and six participants had one or two missing values, resulting from difficulties understanding or responding to questions (Table 8.16). The Karnofsky Performance Score was missing from the medical records of seven participants, and a likely prognosis was missing from four participants' files.

TABLE 8.16 DISTRIBUTION OF MISSING DATA ACROSS VARIABLES

Item & variable	Number of participants	Reason for missing data	Mitigating action or result
Baseline interview			
QLQ-INFO25 item 'Results of medical tests you have already received'	1	Participant reported that they had not received any medical results yet	QLQ-INFO25 overall score & subscale calculated as mean of existing items [a]
IES item 'Any reminder brought back feelings about it'	1	Participant found thinking about feelings distressing, declined to answer this item	IES overall score & subscale calculated as mean of existing items [a]
Household income	1	Participant reported they did not know	Observation excluded
Medical record			
Tumour stage at diagnosis	1	No grade available	Observation excluded
Karnofsky performance score	7	Not available	Variable not used in analysis
Patient's likely prognosis	4	Not available	Variable not used in analysis
Follow-up interview			
QLQ-C30 item 'Trouble taking a long walk'	1	Participant reported 'did not know' as had not tried to take a long walk	QLQ-C30 overall score & subscale calculated as mean of existing items [a]
QLQ-INFO25 item 'Results of medical tests you have already received'	1	Participant reported that they had not received any medical results yet	QLQ-INFO25 overall score & subscale calculated as mean of existing items [a]
QLQ-INFO25 'Expected effects of the treatment on disease symptoms'	1	Participant did not understand question	QLQ-INFO25 overall score & subscale calculated as mean of existing items [a]
IES	1	Participant found thinking about feelings distressing; declined to answer last 2 items	IES overall score & subscale calculated as mean of existing items [a]
Questions about the brochure [b]	2	One participant did not read the brochure; one did not remember it	Observations excluded

[a] Mean of existing values only used when at least half of scale & subscale items answered

[b] 'Brochure' refers to standard information given to control group participants and question prompt list given to QPL group participants

IES: Impact of Event Scale, QLQ-INFO25: Information Module

8.3.2.4. PROBLEMATIC QUESTIONS

Note was also taken of any questions that were upsetting, confusing or otherwise problematic for participants. The most common problems related to response categories or difficulty understanding the question or item.

Too many, too few or inconsistent response categories were problematic for participants when completing the KHOS, CARES, CBI, QLQ-C30 and IES. For the KHOS, two participants wanted to choose a 'neutral' score[24], and one participant had difficulty with the six response categories, and was only able to answer using a dichotomous 'agree' or 'disagree' format. Two participants had difficulties remembering the five categories of the CARES questionnaire, and responses were truncated into three categories (agree, neither, or disagree). The nine-point score of the CBI was problematic for three participants who wanted to choose a range (e.g. 5-6), rather than a single number. For the QLQ-C30, three participants wished to use half-points (e.g. 3.5) to score questions where integers were required.

These problems were resolved with repetition of the items and response categories and/or reduction of the number of response categories, as specified previously.

Nine participants had difficulty understanding the meaning of at least one questionnaire item. The CBI was the most difficult for participants to understand how to answer. It requires participants to score items from 1-9 indicating how 'confident' they are to perform the behaviours listed (Merluzzi et al. 2001). Three items from the 'Affective regulation' subscale of the CBI were most difficult: "Using denial", "Ignoring things that cannot be dealt with" and "Finding an escape". Two participants expressed difficulties understanding how to respond (e.g. "I'm not in denial so I don't know how to answer that")[25]. Difficulty understanding these questions, and thus responding differently than anticipated by scale developers (and discordantly compared with other subscale items), may have resulted in the negative Cronbach's alpha for this subscale (-0.125), reflecting negative average covariance among items (Table 8.17).

[24] KHOS response categories: strongly disagree, disagree, slightly disagree, slightly agree, agree, and strongly agree.

[25] Repetition of the question and the scoring instructions was provided and elicited a response.

TABLE 8.17 CORRELATIONS BETWEEN ITEMS OF THE AFFECTIVE REGULATION SUBSCALE OF THE CANCER BEHAVIOR INVENTORY

Items		1	2	3	4	5
1	ρ	1.000	.070	-.101	-.032	.381
	p-value		.769	.672	.895	.097
2	ρ		1.000	.001	-.527	-.005
	p-value			.997	.017	.982
3	ρ			1.000	-.273	-.159
	p-value				.245	.503
4.	ρ				1.000	.372
	p-value					.106
5	ρ					1.000
	p-value					

ρ: spearman's correlation coefficient, p-value for two-sided test of significance
Items: 1: Finding an escape
2. Ignoring things that cannot be dealt with
3. Using denial
4. Expressing personal feelings of anger or hostility
5. Expressing negative feelings about brain tumours

Examination of scale statistics showed the negative average covariance among items could be rectified by the removal of the "Using denial" item (Cronbach's alpha if item deleted = 0.139). Removal of both "Using denial" and "Ignoring things that cannot be dealt with" from the scale could further increase the Cronbach's alpha to 0.447.

Some questions of the EORTC QLQ-INFO25 were also problematic. Most participants spoke about the information they had received before assigning a category. This may reflect participants' need for time to think about their answer, or a desire to avoid reflecting negatively on their doctors or other health professionals. Participants sought further clarification from the interviewer as to the meaning of three items of the QLQ-INFO25:

- the wording of "expected effects of treatment on disease symptoms" was confusing for two participants, and resulted in missing data in one case;
- one participant asked what 'written information' was, and six of the seventeen respondents reported that they had not received written

information at follow-up, despite being given the standard brain tumour information by the candidate; and

- when asked how much information they had received on "results of medical tests that you have already received", two participants said they had not received any results from medical tests at all, and that they consequently could not answer this question. One participant gave this response at follow-up despite previously responding in the affirmative when answering this item at baseline.

One participant experienced distress at answering the items of the Impact of Event Scale (IES), and did not answer one item from the IES at baseline and two items at follow-up because of their distress.

8.3.2.5. Potential Secondary Outcome Variable: Information Source

All 17 participants who completed follow-up interviews reported at least one prominent information source including: doctors (n=6), hospital or practice (n=4), internet (n=3), other health professional (e.g. care coordinator, nurse, n=2), and other (n=2 participants). The 'other' category included 'friends', and a 'drug company'.

8.3.2.6. Potential Primary Outcome Variable: Information Received

Descriptive statistics for the EORTC QLQ-INFO25 at follow-up (n=17) are provided in Table 8.18. Participants reported that they received more information about medical tests than any other topic at both baseline and follow-up, followed by information about treatments. At least half of participants reported receiving no information at all, at either baseline or follow-up, on: non-medical treatments, or different places of care.

Significant ceiling effects, in which more than 15% of participants scored the highest possible scores (McHorney & Tarlov 1995), were observed for the satisfaction with information received (40% at ceiling at baseline and 29% at follow-up), and perception of helpfulness of the information overall (55% at ceiling at baseline and 35% at follow-up).

TABLE 8.18 DESCRIPTIVE STATISTICS FOR THE QLQ-INF26 SCALES AND ITEMS
(FIRST ROW: BASELINE ASSESSMENT, N=20; SECOND ROW: FOLLOW-UP ASSESSMENT, N=17)

	Mean [a]	SD	Median	min, max	% Ceiling [b]	% Floor [c]
Whole questionnaire [d]	47.0	12.5	46.0	16.0, 68.0	0	0
	45.3	13.4	48.0	21.3, 68.0	0	0
Information about the disease	45.4	19.4	45.8	16.7, 83.3	0	0
	49.5	21.7	41.7	25.0, 100	5.9	0
Information about medical tests	62.2	20.5	61.1	33.3,100	10	0
	59.8	24.8	55.6	22.2, 100	11.8	0
Information about treatments	48.1	15.4	50.0	14.3, 81.0	0	0
	39.2	18.2	33.3	9.5, 71.4	0	0
Information about treatments scale [d]	53.3	16.6	58.3	16.7, 88.9	0	0
	42.5	19.5	38.9	11.1, 83.3	0	0
Information about other services	26.3	18.2	20.8	0, 75.0	0	5
	29.9	18.4	25.0	0, 58.3	0	11.8
Information about non-medical treatments	16.7	20.2	0	0, 66.7	0	55.0
	19.6	23.7	0	0, 66.7	0	52.9
Information about different places of care	21.7	27.1	0	0, 66.7	0	55.0
	19.6	26.5	0	0, 100	5.9	52.9
Information about things you can do to help yourself get well	43.3	26.7	33.3	0, 100	5.0	15.0
	51.0	29.1	66.7	0, 100	11.8	11.8
Satisfaction with information received	70.0	32.3	66.7	0,100	40.0	10.0
	66.7	28.9	66.7	0, 100	29.4	5.9
Overall the information has been helpful	76.7	32.6	100	0,100	55.0	10.0
	72.5	24.3	66.7	33.3, 100	35.3	0
			n (%)			
Written information			17 (85.0%)			
			11 (55.0%)			
Information on CD, tape or video			5 (25.0%)			
			4 (23.5%)			
Wish to receive more information			12 (60.0%)			
			13 (76.5%)			
Wish had received less information			0 (0%)			
			1 (5.9%)			

Abbreviations: CD: compact disc, SD: standard deviation, min: minimum, max: maximum
[a] Scores for scales and items range from 0-100; higher scores indicate more information received
[b] Percentage of respondents at ceiling (maximum value)
[c] Percentage of respondents at floor (minimum value)
[d] Statistics given without item 'non-medical treatments'

8.3.2.7. Baseline to Follow-up Change Scores

The average and range of change scores were calculated for each item and scale (Table 8.19). Mean and standard deviation have been presented, consistent with scoring techniques of the scale developers (Arraras et al. 2010). Median and range have also been presented to provide more accurate representations of highly skewed scores. For dichotomous items, the number and proportion of participants whose responses changed from baseline to follow-up were presented.

Table 8.19 Change in QLQ-INFO25 Scores from Baseline to Follow-up (N=17)

	Change [a]			
	mean	SD	median	min, max
Whole questionnaire [e]	-3.08	14.18	-1.33	-36.00, 18.56
Information about the disease	3.18	21.73	8.33	-58.00, 25.00
Information about medical tests	-5.56	26.93	-11.11	-44.44, 44.44
Information about treatments	-9.57	18.72	-9.52	-38.10, 33.33
Information about treatments scale [b]	-11.76	20.78	-11.1	-38.89, 38.89
Information about other services	2.94	28.10	8.33	-58.33, 41.67
Information about non-medical treatments	3.92	30.92	0	-33.33, 66.67
Information about different places of care	-5.88	33.82	0	-66.67, 33.33
Information about things you can do to help yourself get well	5.88	33.82	0	-66.67, 66.67
Satisfaction with information received	-5.88	29.43	0	-66.67, 33.33
Overall the information has been helpful	-5.88	31.70	0	-66.67, 66.67
	n (%) [c]			
Written information	6 (35.3%)			
Information on CD, tape or video	4 (23.6%)			
Wish to receive more information	7 (41.2%)			
Wish you have received less information	1 (5.9%)			

Abbreviations: CD: compact disc, min/max: minimum/maximum, SD: standard deviation
[a] Change scores may range from -100 to +100; negative scores indicate more information at baseline
[b] Statistics given without item 'non-medical treatments'
[c] number & proportion of participants whose response changed presented for dichotomous items

Given that single items are likely to be of limited use in determining sample sizes, further analysis were confined to multi-item scales. The distribution of change in multi-item scales is shown in Figure 8.8.

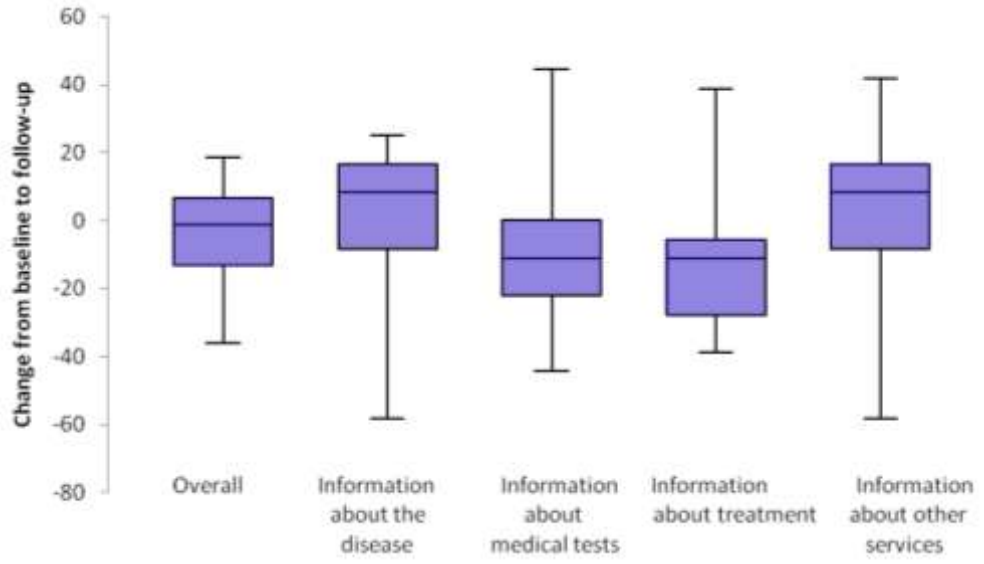


FIGURE 8.8 DISTRIBUTION OF CHANGE IN INFORMATION RECEIVED BETWEEN BASELINE AND FOLLOW-UP: QLQ-INFO25 MULTI-ITEM SCALES (N=17)

As described in the methods, five and 10 points were used as estimates of MCID, to benchmark potentially 'significant' change in QLQ-INFO25 scores. The number of participants whose change in QLQ-INFO25 scales would be classified as 'significantly' increasing or decreasing (or not significantly changing) based on these cut-points is shown in Table 8.20.

TABLE 8.20 CATEGORISATION OF PARTICIPANTS BASED ON 'SIGNIFICANT' CHANGES IN QLQ-INFO25 SCORES FROM BASELINE TO FOLLOW-UP (N=17)

	5 point cut-off			10 point cut-off		
	decrease	no change	increase	decrease	no change	increase
Overall score	5	7	5	5	10	2
Information about the disease	5	3	9	2	8	7
Information about medical tests	10	3	4	10	3	4
Information about treatments	13	2	2	10	5	2
Information about other services	6	0	11	4	6	7

8.3.2.8. Estimation of Sample Size for Future Evaluation Studies

As previously reported, the change in overall QLQ-INFO25 was not normally distributed, suggesting the Mann-Whitney test is an appropriate statistical test for sample size planning. However, the normality assumption may be met with a larger sample, so the t-test was also applied. By convention, sample size calculations were based upon α=0.05, where α is the probability of Type I error, and two commonly used levels of power (80% and 90%). As described in the methods, the sample SD was adjusted to prevent underestimation of sample size: for tests aiming for 80% power, 80% UCL of the sample SD (18.587) was used; for 90% power, 90% UCL (20.102) was applied.

For the purpose of sample size calculations, the following assumptions were made:

- study design: randomised controlled trial;
- primary outcome variable: change over time in overall QLQ-INFO25 score, with MCID of 5 or 10 points;
- sampling: by clusters (hospitals or clusters);
- random allocation: at the individual (not cluster) level, assuming that contamination is not significant, and that random allocation to control or intervention groups is made at the individual (not cluster) level; and
- as required by the statistical tests: independence of observational units; equal group size; homogeneity of variances between groups; and for the t-test, normality of the distribution.

The ICC of the sample for the overall QLQ-INFO25 was -0.161, which suggests that there was more variation within, than between, clusters (Sullivan 2010). This result may have occurred because the average number of participants per cluster (five) was similar to the number of clusters (four). A range of theoretical design effects were therefore applied.

Base sample size estimates were inflated to allow for non-response (30%), attrition (30%), and adjustment for covariates via multivariable modeling (20%), as described in the methods. Table 8.21 summarises these analyses[26].

[26] For ease of presentation, inflation for non-response, attrition and multivariate modeling is shown prior to application of a design effect.

TABLE 8.21 SAMPLE SIZE PER GROUP NEEDED TO DETECT 5 AND 10 POINT DIFFERENCES IN CHANGE IN QLQ-INFO25

Difference	Power	Test	SD	N	N inflated [a]	N per group for ICC and average participants/cluster [b]			
						ICC	10/cluster	25/cluster	50/cluster
5	80%	t-test	18.587	236	479	0.01	523	594	714
						0.03	609	824	1184
						0.05	695	1054	1653
5	80%	Mann-Whitney	18.587	150	305	0.01	333	379	455
						0.03	388	525	754
						0.05	443	671	1053
5	90%	t-test	20.102	357	724	0.01	790	898	1079
						0.03	920	1246	1789
						0.05	1050	1593	2498
5	90%	Mann-Whitney	20.102	227	461	0.01	503	572	687
						0.03	586	793	1139
						0.05	669	1015	1591
10	80%	t-test	18.587	60	122	0.01	133	152	182
						0.03	155	210	302
						0.05	177	269	421
10	80%	Mann-Whitney	18.587	38	78	0.01	86	97	117
						0.03	100	135	193
						0.05	114	172	270
10	90%	t-test	20.102	91	185	0.01	202	230	276
						0.03	235	319	457
						0.05	269	407	639
10	90%	Mann-Whitney	20.102	58	118	0.01	129	147	176
						0.03	150	203	292
						0.05	172	260	408

Abbreviations: SD: standard deviation, N: sample size needed; ICC: intraclass correlation coefficient

[a] inflated for non-response, attrition and multivariable modeling

[b] inflated for non-response, attrition and multivariable modeling and adjusted for design effect; n/cluster: n indicates average number of participants/cluster

Sample size per group required ranged from 78 to 2498, the latter of which is clearly unfeasible. This analysis may be useful, however, for future investigators, as it shows that even if the expected ICC is high, the design effect may be minimised by selecting more clusters with fewer average persons per cluster, rather than by selecting more participants from each cluster. An example of interpretation of these results is shown in Table 8.22.

TABLE 8.22 INTERPRETATION OF SAMPLE SIZE CALCULATION

To detect a minimum difference of *10 units* in change in QLQ-INFO25 scores between baseline and follow-up between control group and intervention group participants at a statistically significant level (two-tailed hypothesis at *5%* level of significance), with *80% power*, would require that 60 persons per group, or 120 persons overall, complete baseline and follow-up measures.
This number assumes independence of observations, *normality* of the distribution of scores, homogeneity of variances, equal numbers of participants per group, and is based upon the feasibility study standard deviation (adjusted for underestimation) of *18.587 units*.
Assuming a design effect (based on an inter-cluster correlation of *0.01*, with an average of *10* participants/cluster), and assuming that *30%* of those approached will not participate, *30%* of those who respond will be lost to follow-up, and allowing *20%* margin for multivariable modeling, would require that 266 persons be approached for participation.

Further publication of studies reporting on the QLQ-INFO25 (especially if ICCs are reported) may assist in selection of the most appropriate sample size.

8.3.3. RESULTS FOR RESEARCH QUESTION 3

Research question 3 concerns the acceptability of the QPL among patients with primary brain tumours. The results of this section are derived from multiple-choice and open questions focusing on participants' views of the brochure and its usefulness in assisting them to ask their doctors questions and obtain information. As it was expected that participants may exhibit a response bias, positively assessing any information given to them by the research team, both control group and QPL group participants were asked these questions, which referred to 'the brochure/booklet we gave you'. As QPL participants were given standard information materials and the QPL, they were asked to answer these questions about the QPL only. An equal positive response amongst both QPL and control group participants could suggest the QPL was no better than standard information; and differences between responses could indicate that the QPL was more or less useful than standard information.

All QPL participants agreed (either 'somewhat' or 'completely') that the brochure was 'helpful', and six out of seven agreed that it 'made it easier to ask questions' (Table 8.23). All seven participants agreed that there were questions in the brochure that were 'useful' to them, and six that the brochure helped them to 'put some of their questions or concerns into words'. Only one participant found it overwhelming to read the brochure.

Responses from control group participants about the standard information were also predominantly positive. However, control group participants were less likely than QPL group participants to 'agree completely' with positive statements about the brochure. In addition, three of the eight control group participants reported that it was overwhelming to read the brochure.

TABLE 8.23 QPL GROUP AND CONTROL GROUP PARTICIPANTS' VIEWS ABOUT THE QPL AND STANDARD INFORMATION

	QPL group: opinions about the QPL (n=7)					Control group: opinions about standard information (n=8)				
	agree completely	agree somewhat	neither agree or disagree	disagree somewhat	disagree completely	agree completely	agree somewhat	neither agree or disagree	disagree somewhat	disagree completely
I found the brochure to be helpful	4	3				2	5		1	
The brochure made it easier to ask questions	4	2	1				6	1	1	
There were questions in the brochure that were useful to me	3	4				1	6			1
The brochure helped me to put some of my questions or concerns into words	3	3	1			1	6		1	
I found it overwhelming to read the brochure	1			2	4		3		3	2
I think the brochure will be useful to me in future	4	1		2		1	6		1	
The brochure was easy to understand	7					1	6		1	

A simple summative index of 'brochure acceptability' was constructed from these seven questions to allow quantitative comparison of scores between groups. Construction of this index has been described in the methods; briefly, the index yielded possible scores from 7-35 (higher scores are more positive). Overall, the median score was 29, ranging from 15-34. As shown in Figure 8.9, scores were higher among QPL group participants (median 31, range 27-34) than control group participants (median 28, range 15-31).

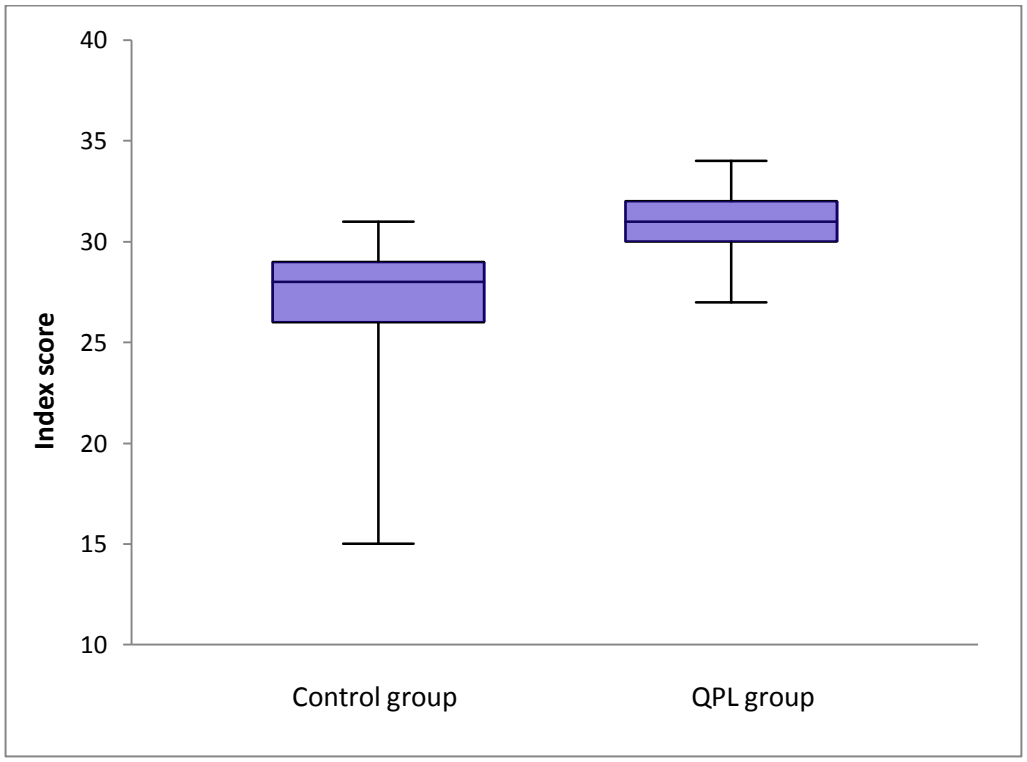


FIGURE 8.9 BROCHURE ACCEPTABILITY INDEX SCORE FOR CONTROL GROUP PARTICIPANTS (N=8) AND QPL GROUP PARTICIPANTS (N=7)

Results for the remaining brochure usefulness scores for the QPL group and control group are shown in Table 8.24, indicating that the QPL was the 'right' length and used during consultations.

TABLE 8.24 QPL GROUP AND CONTROL GROUP PARTICIPANTS' VIEWS ON AND REPORTED USE OF THE QPL AND STANDARD INFORMATION

	QPL group: opinions re QPL (n=7)	Control group: opinions re standard information (n=8)
Views on the length of the brochure		
Right length	6	7
Too short	1	1
Have you read the booklet again since first receiving it?		
Several times	2	2
1-2 times	2	3
Not at all	3	3
Did the booklet prompt you to ask your neurosurgeon any questions?		
Yes	2	1
No	4	4
Unsure	0	1
Did not see doctor	1	2
Did the booklet prompt you to ask your radio-oncologist any questions?		
Yes	4	0
No	2	2
Unsure	0	1
Did not see doctor	1	5
Did the booklet prompt you to ask your medical oncologist any questions?		
Yes	5	0
No	1	2
Unsure	0	1
Did not see doctor	1	5
Did the booklet prompt you to ask questions of any other members of your health care team?		
Yes	2	3
No	4	4
Unsure	1	0
Did not see doctor	0	1
Did anyone else read the booklet (i.e. carer/relative/friend)?		
Yes	5	4
No	2	3
Unsure	0	1
If anyone else read the booklet, was it helpful to them? [a]		
Very helpful	3	1
A bit helpful	2	1
Unsure	0	2

[a] Responses only for persons who said 'yes' to 'Did anyone else read the booklet?'

Qualitative data from the semi-structured interviews with participants confirmed their overall positive perception of the QPL, and the greater perceived usefulness of the QPL over the standard information (Table 8.25).

TABLE 8.25 FEEDBACK ABOUT THE QUESTION PROMPT LIST (QPL) AND STANDARD INFORMATION

Comments about the QPL	Comments about standard information
"[The] brochure was great to help get an overview and prepare for what was ahead. [I] had difficulty with talking with doctors beforehand." (participant 880)	*"[The] brochure was very hard, macabre, gave worst case scenario, lots of statistics"* (participant 764)
"[The] brochure covered it all" (participant 398)	*"The brochure was quite adequate"* (participant 501)
"Loved the brochure, showed it to my GP, and he was very impressed. [He] said they should make one for all cancer types. My daughter read it – she said, 'where are the answers?'" (participant 631)	*"Some stuff in the brochure [was] too simplistic, but it prompted me to go somewhere else to look. Covers a wide range, hard to be specific. Brought up things and prompted to look for more if want"* (participant 102)
"[The] brochure didn't answer enough of what [I] needed to know, but I liked to be able to take it and ask doctors" (patient 987)	*"Good to know there is something out there; the brochure verified info [I've been] given"* (participant 916)
"I gave the brochure to my sons to read, even my 15 year old had no problems, it was easy to understand" (participant 164)	
"*I can't concentrate and read. Put [the] brochure in plain English – some people don't understand, and are ashamed to ask"* (participant 940)	

8.3.3.1. TIMING

Both groups were provided standard information materials and QPL group participants received the QPL immediately after the baseline interview. During the follow-up interview, participants were asked both quantitative and qualitative questions about the timing of the booklet delivery. Overall, fifteen participants (eight from the control group and seven from the QPL group) answered these questions[27]. Of the fifteen participants who responded, eleven (73.3%) reported

[27] One participant did not remember the brochure and another did not read it.

that they had enough time to read the booklet before their consultations, while four indicated that they did not have enough time.

A larger proportion of control group participants (7 out of 8, 87.5%) than QPL group participants (4 out of 7, 57.1%) reported that they had enough time to read the brochure before their consultations. Furthermore, as Figure 8.10 shows, control group participants received the brochure at an earlier time since diagnosis than QPL group participants, suggesting differences in response by group may be due to confounding by time since diagnosis.

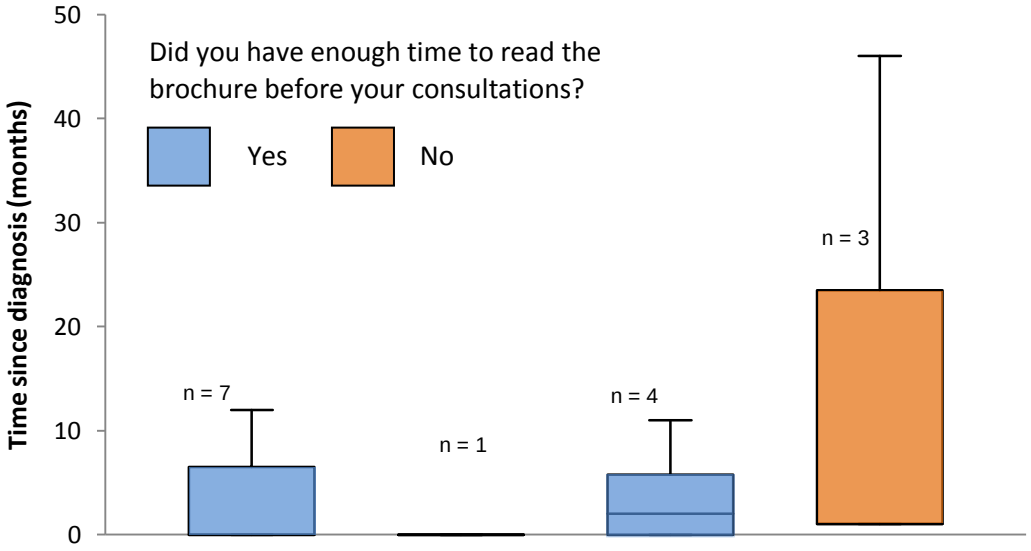


FIGURE 8.10 CONTROL GROUP AND QPL GROUP PARTICIPANTS' VIEWS ON BROCHURE TIMING BY TIME SINCE DIAGNOSIS

Six of the fifteen participants reported that they would have preferred to receive the booklet at a different time. On average, time since diagnosis was greater in participants who would have preferred to receive the booklet at a different time (median 6.5 months, range 1-46) than others (median 0 months, range 0-12). Four participants talked about timing of delivery of the brochure in semi-structured interviewing. All four of these participants said they would have liked to receive the brochure when they were first diagnosed. For example, one of these participants said that they would have liked to receive the QPL "before initial contact with doctors, or at least before the first outpatient department visit – before you get stuck in the system" (participant 880).

Fifty-seven percent of QPL group participants reported that they would have liked to receive the booklet at a different time, compared to 25% of control group participants. However, as previously presented, median time since diagnosis was higher in QPL than control group participants.

8.4. DISCUSSION

This study demonstrates the difficulties involved in recruiting brain tumour patients to research studies. The choice of hospitals as the recruitment setting was initially intended to allow the recruitment of patients early in the disease trajectory, and to maximise the likelihood of obtaining a representative sample. Barriers identified included health professionals' lack of interest and staff turnover, time pressures, perceived burden on patients involved in other studies, patient distress, and a lack of clarity as to when to approach patients, which have been reported in previous studies (Nichols et al. 2004; Ott et al. 2006; Lovato et al. 1997; Lancaster et al. 2010; Townsley et al. 2005; Chang et al. 2002). Whilst not reported, the timing of recruitment may have also been an issue. The diagnosis of a brain tumour is generally a very stressful time, and treatment decisions often need to be made quickly after diagnosis. Some patients and health professionals approached at this time may view research as an additional, unnecessary burden (Newberry et al. 2010).

Other recruitment options to be considered include recruitment from cancer registries, community outreach, or social marketing. However, recruitment through cancer registries involves considerable time, labour, cost, and complexity (Threlfall 2005), and are unlikely to result in sufficient recruitment of ethnic minorities (Yancey et al. 2006). Lijovic and colleagues (2008) recruited women newly diagnosed with breast cancer via the Victorian Cancer Registry, with low refusal rates. However, the average delay between diagnosis and notification to the cancer registry was 5 months. Another study which recruited lung cancer patients through cancer registries found that approximately 40% of eligible patients had died before initial contact was attempted, even though rapid case ascertainment methods were used (Cabral et al. 2003). This approach is therefore unlikely to allow brain tumour

patients to be identified early enough in the disease trajectory for optimal timing of QPL provision.

Community outreach (via support groups, community forums, professional and community organisations), and social marketing (e.g. media, mass telephone calls, mass mailings) have been used in many studies (Lloyd et al. 2010; UyBico et al. 2007; Ott et al. 2006; Nichols et al. 2004; Lijovic et al. 2008). Although the convenience samples obtained may be more socioeconomically advantaged than random samples drawn directly from the target population (Hultsch et al. 2002), these approaches may provide patients with greater autonomy and may overcome the low referral rates by clinicians (Clinton-McHarg et al. 2011). A recent development is the establishment of patient registries by charities such as the National Breast Cancer Foundation, and these may become a viable recruitment source in the future (Wei et al. 2004; Fellows et al. 2008), particularly for patients with rare diseases such as brain tumours (Gliklich & Leavy 2011).

If recruitment must involve health professionals' making an initial approach to patients, the use of dedicated research nurses, and/or further training and education may help overcome some barriers, such as the lack of clarity as to when to approach patients. Hoffman and colleagues (described in (Newberry et al. 2010)) attempted to alleviate physician-related barriers by having a recruiter known to staff on call 24 hours a day, every day of the year. However, as recruitment would likely need to be from a number of different clinics to achieve a sufficiently large sample, either of these approaches may involve a considerable resource investment (Clinton-McHarg et al. 2011).

The burden placed on health professionals may also need to be reduced. We asked health professionals to screen patients to ensure that they were 'well enough' to participate. Although this approach is common to prevent causing undue harm to frail patients, health professionals may find vague parameters difficult to interpret, and they may enrol fewer patients than if specific impairments or assessment processes were specified (Townsley et al. 2005). A more suitable approach may be to obtain neurosurgery and neuro-oncology clinic schedules at the beginning of each week. Health professionals could be asked to indicate patients who were

ineligible from this list, enabling research staff to approach eligible potential participants during clinic or hospital visits (Hricik et al. 2011).

It may also be useful to consider the choice of health professionals who are asked to recruit patients. Health professionals with a research background, and interest in the research topic, may be more motivated (Umutyan et al. 2008). Lancaster and colleagues (2010) have suggested considering the priority given to the research question in relation to other issues, and in retrospect, some of the clinicians asked to recruit patients may not have been the most appropriate choices. Lloyd and colleagues (2010) also found that most referrals of stroke patients came from physiotherapists and a stroke liaison officer.

Health professionals were also asked in our study not to approach patients with previous malignancy, but four patients were recruited who had previously had cancer. This exclusion criterion was planned because these patients' knowledge of the health care system may differ from cancer-naïve patients, but these patients were included due to low recruitment rates. The relevance of this eligibility criteria may be questionable, as the experience of a brain tumour is unique (Fox et al. 2006), and unlike that of other cancers which do not affect cognitive performance. This criterion, although commonly applied in cancer trials, may be criticised because there is little evidence that a previous, inactive cancer will affect almost any type of study-related outcomes (Townsley et al. 2005).

One aspect of recruitment that was successful in our study was the high consent rate of potential participants once contacted by the candidate. Of the 23 patients referred by health professionals, all 20 who were eligible consented. The lack of patient refusals may be due to patients being 'pre-screened' by referring health professionals. However, attrition rates were also low (2 participants were lost to follow-up and one withdrew), confirming suggestions from other studies that brain tumour patients desire to participate in research (Newberry et al. 2010; Scotland et al. 2009).

Our sample included patients with high grade tumours (e.g. 40% of sample had GBM), and patients with visual, cognitive, and speech impairments, suggesting these conditions themselves are not barriers to recruitment. However, patients

aged 20-39 years were over-represented, and no patients aged 80 years or over were recruited. Additional barriers to the recruitment of older adults in research have been noted, such as co-morbidities, lower educational attainment, and less exposure to, or understanding of clinical trials, and additional strategies may be needed to reach older adults (Kemeny et al. 2003; Townsley et al. 2005; UyBico et al. 2007). Stratified sampling (by age, gender, and tumour type) may be useful to recruit a more representative sample of patients.

We were also concerned that our sample may be biased in some important way, such as towards people who utilise information seeking as a coping strategy (Timmermans et al. 2007; Miller 1995). To determine whether these selection biases exist, we compared the characteristics of our sample with other studies. Eighty-five percent of participants reported wanting to know as much information as possible, consistent with the 87% of 394 cancer patients reported by Cox et al. (2006), and 87% of 2331 cancer patients reported by Jenkins et al. (2001).

Sixty percent of our sample scored four or above on the distress thermometer scale at baseline, the cut-off for 'caseness' associated with high levels of physical, emotional, practical, or family problems (Donovan et al. 2004; Keir et al. 2007). This proportion is higher than that reported for brain tumour patients in two previous studies (28% (Kvale et al. 2009) and 52% (Keir et al. 2007)), but lower than the 74% reported by Goebel et al. (2011). Together, these results suggest that our sample were unlikely to self-select on the basis of higher information seeking preferences, or lower levels of distress.

As expected, due to the staggered recruitment of control group and QPL group participants, and the expansion of recruitment to additional (public) hospitals mid-way through the study, the characteristics of the two groups were not comparable. Groups were especially different in terms of age, gender, education, time since diagnosis, and attendance at a private or public hospital. Given these differences between groups, outcome measures for intervention effectiveness (i.e. information received, and most prominent information source) were not compared between groups.

However, the pooled sample provides information useful for understanding the experiences of participants. Clinical practice guidelines recommend that all patients be provided with written information, and recommend the use of other media (Turner et al. 2005; Australian Cancer Network Adult Brain Tumour Guidelines Working Party 2009). At baseline, 85% of participants reported that they had received written information, and 25% information on CD, tape or video. These results suggest that improvements can be made in the provision of written information, and certainly information in alternative formats. The use of alternative strategies for the provision of information may be particularly useful for patients with impairments, which were noted in the medical records of patients in relation to speaking or understanding speech (25%), visual function (35%), memory (30%), and attention or concentration (35%).

Participants' ratings of the amount of information provided, and their desire for more information also suggest that information provision can be improved. Sixty percent of participants reported a desire for more information at baseline. The median score for information received at baseline was highest for information about medical tests (61.1, range 33.3-100), and lowest for information about other services (20.8, range 0-75.0). More than half of participants also reported receiving "no information at all" about non-medical treatments, or different places of care. These scores may reflect patients' current stage in the treatment trajectory (e.g. receiving tests and treatments, rather than practicing self-care), but could also reflect health professionals' greater comfort with providing biomedical information rather than information about psychosocial elements of care (Rozmovits et al. 2010; O'Donnell 2005; Edvardsson & Ahlström 2008).

Participants' desire for more information was higher at follow-up (75%) than baseline (60%). This is consistent with research that has found that over time, patients continue to require information about their disease, treatment, and prognosis, but experience increased need for information about psychological effects, support services, health promotion and the risk of disease for family members (Mills & Sullivan 1999; Rutten et al. 2005; Squiers et al. 2005; Luker et al. 1996). Raupach and colleagues (Raupach & Hiller 2002) also found that whilst

breast cancer patients followed over a 25 month period expressed a consistently high need for information over time, they perceived that the amount of information they were given decreased over time.

Participants' expressed views regarding the QPL were positive in almost all aspects, and more favourable compared to the standard information booklet. One interesting finding is that six of seven participants reported that the QPL was the 'right length'; this was also reported by seven of eight participants about the standard information booklet. This was despite the booklets' different lengths (QPL has 33 pages, standard information brochure has 11 pages).

Overall, comparisons between participants' views of the QPL and the standard information booklet were mostly different in degree, rather than in direction. For example, four QPL group participants 'completely' agreed that the QPL made it easier to ask questions, two 'somewhat' agreed, and one 'neither agreed or disagreed'. Of the eight control group participants, six 'somewhat' agreed that the standard information booklet made it easier to ask questions, one was neutral, and one 'disagreed'. Questions in which QPL group and control group participants' responses were quantitatively different were in respect to whether the 'booklet' prompted the participant to ask questions of health professionals. For each of these questions, the majority of control group participants answered to the negative, whilst between two and five (out of seven) QPL group participants answered affirmatively. This may suggest that both booklets were seen as useful, but that only the QPL encouraged question asking.

Many of the questions asked of participants about their views of the QPL were similar to those used by Clayton et al. (Clayton et al. 2003) in a preliminary evaluation of a QPL about palliative care for patients with advanced cancer. Similar proportions of our participants, compared with the 20 patients in the sample reported by Clayton et al. (2003), reported that the QPL was helpful (7/7 [our sample] versus 19/20 [advanced cancer]), that it made it easier to ask questions (6/7 versus 17/20), that there were questions in the QPL that were useful to them (7/7 versus 19/20), and that the QPL was easy to understand (7/7 versus 19/20).

Clayton and colleagues (2003) reported that far more participants reported asking questions of their doctors than was reported in our study. However, Clayton et al. (2003) gave participants the QPL immediately before a planned medical consultation. Furthermore, clinicians in Clayton et al.'s study (2003) were asked to endorse and refer to the QPL during the consultation, whilst such strategies were not integrated into this study.

Such endorsement has been found to increase patients' asking of questions (Brown et al. 2001). Health professionals' endorsement and referral may give patients 'permission' to use the QPL and help them feel comfortable using it (Dimoska et al. 2008). In previous research, some patients have reported that they felt it was 'risky' to discuss research they did on the internet with their doctors (Sommerhalder et al. 2009; Newnham et al. 2006). Similar concerns, such as being labelled a 'difficult' patient, may be held by some patients regarding asking questions, or using a QPL. Endorsement of the QPL by health professionals may overcome such barriers.

Other measures may also be needed to overcome perceived barriers to QPL use by patients, carers, and health professionals. Health professionals may be concerned that QPLs could increase the duration of consultations (Kinnersley et al. 2008). However, two recent reviews suggest the effects on duration, if they exist, are very small (Dimoska et al. 2008; Kinnersley et al. 2008). Dimoska and colleagues (2008) reviewed QPLs evaluated with cancer populations, reporting five studies which assessed the effect on consultation duration. Three studies showed no effects (Butow et al. 2004; Bruera et al. 2003; Butow et al. 1994); one study showed an average decrease of five minutes when doctors endorsed the QPL (Brown et al. 2001); and one study reported an average increase of seven minutes (Clayton et al. 2007). Kinnersley and colleagues (2008) reviewed 'pre-consultation' interventions aimed at helping patients to address their information needs, including QPLs and coaching sessions, and with cancer and other populations. Of 17 studies in which consultation duration was assessed, 13 studies showed no statistically significant change in consultation duration; one study showed mixed findings (depending on which consultation was targeted for intervention), and three studies showed statistically significant increases in consultation length of 0.9 (Middleton et al.

2006), 1.2 (McCann & Weinman 1996), and 6.8 minutes (Hornberger et al. 1997). A meta-analysis combining these results revealed no statistically significant increase in consultation duration (Kinnersley et al. 2008).

Another important issue for QPL implementation is timing. In previous studies, QPLs have been most commonly provided to patients immediately before (e.g. 20 minutes prior to) (Clayton et al. 2003), or a few days or more before consultations (Butow et al. 2004). QPLs have also been often evaluated with patients' initial consultations (Butow et al. 1994), of for one of their first three consultations, with a specified health professional (e.g. oncologist or palliative care physician) (Clayton et al. 2005). Whilst no study has directly compared these timings, patients tend to ask more questions (Butow et al. 2004), and consultations tend to be shorter (Kinnersley et al. 2008) when QPLs are given further in advance, perhaps as this allows patients greater time to consider their needs and to identify, prioritise, and rehearse questions (Kinnersley et al. 2008).

In our study, four of 15 participants reported that they had not had enough time to read the 'brochure' (QPL or standard information) before their consultations, and six would have preferred to receive the 'brochure' at another time. Participants dissatisfied with the timing of QPL provision were recruited later in the disease trajectory, and participants frequently reported wanting the QPL when first diagnosed. The provision of the QPL soon after diagnosis may enable patients to discuss potential symptoms and changes with their health professionals before these changes occurred, consistent with the desire for information about emergent issues reported in the literature (Wyness et al. 2002; Janda et al. 2006; Schubart et al. 2008; Rozmovits et al. 2010).

Unlike other studies (Dimoska et al. 2008), we encouraged patients to use the QPL at multiple consultations and with a range of health professionals. Use of QPLs in multiple consultations may increase patients' comfort with the QPL and actively participating in consultations, changing behavioural norms (Street 1991). As information needs change over the disease trajectory, longitudinal research is needed to investigate whether opinions of and use of QPLs evolve over time, and how QPLs can best meet changing needs (Dimoska et al. 2008).

Future research should also expand seek to optimise evaluation strategies. We administered questionnaires verbally, allowing participants with impairments to participate. Problematic questionnaire items were identified, and will be communicated to the designers of these questionnaires. Verbal administration of questionnaires may also have minimised missing data, which is a significant issue in psychosocial research (Walker et al. 2003). However, previous research suggests that participants report better health-related and overall QOL in verbally administered compared to self-completed questionnaires, perhaps because of social desirability bias (Buskirk & Stein 2008). This may make it difficult to compare to other studies and must be considered if participants were offered a choice of questionnaire administration modes.

The main outcome measure proposed for the assessment of the effectiveness of the QPL was patients' perceptions of the information that they received, assessed using the QLQ-INFO25. As previously described (Chapter 3), QPLs have been most commonly evaluated via a count of the number of questions a patient asks, following audio-taping of consultations. However, audio-taping consultations may influence its content (Elkin et al. 2007), and question asking does not take into account patients' information needs or preferences, or the effect of question asking on information received. Furthermore, it has been suggested that, in terms of impact on patient behaviour and health outcomes, perception of communication may be more important than actual communication (Elkin et al. 2007).

For change in information received by patients over time, and between QPL group and control group participants, to be used as the primary comparison in a future RCT, would require that the QLQ-INFO25 be sensitive to change. In a phase IV international validation study, Arraras and colleagues (Arraras et al. 2010) reported that only one item from the QLQ-INFO25 ("information about different places of care") had a positive difference in scores over time that was statistically significant at the $p<0.001$ level, and thus sensitive to change. Negative average change scores were interpreted as indications of non-responsiveness of scales to change, assuming that participants' levels of information could only increase over time. However, statistical significance does not necessarily imply a clinically meaningful

difference, and no *a priori* minimum clinically important difference was specified, nor used to determine the sample size for the study (Cocks et al. 2008). A difference of as little as 1.1 points on a 0-100 scale was reported as statistically significant, although this is unlikely to be clinically meaningful (Arraras et al. 2010).

We therefore examined the distribution of participants' baseline, follow-up and change scores. Similar to Arraras and colleagues (Arraras et al. 2010), we found that the median change score was positive for two scales, but negative for three others. A number of reasons may explain why patients reported lower scores (indicating 'less' information received) at follow-up than baseline. Firstly, underreporting about any given event increases rapidly with the time since the event, such that people tend to base their assessments of events over a given timeframe on the events that have occurred most recently (response bias) (Cannell & Henson 1974). People may not be able to accurately recall all the information that they have received across the entire disease trajectory, as the QLQ-INFO25 requires. More accurate data may be obtained by asking participants to report how much information they have received in the previous two weeks, similar to other EORTC QOL questionnaires (Aaronson et al. 1993). Successive data collections using the QLQ-INFO25 could thus be used to determine the amount of information received by patients at different points in the disease trajectory.

Participants' lower QLQ-INFO25 scores at follow-up than baseline may also reflect a response shift, whereby participants' perceptions of how much information is needed, or should be provided, changed over the disease trajectory. A response shift is the process whereby patients reinterpret their QOL (or other subjective concept) because of changes in their internal standards, values, or conceptualisations of a concept during their illness (Sprangers et al. 2002). It has been suggested that response shifts are most probable when the disease experience is "new, intense, and pervasive" (Sprangers et al. 2002, p. 568).

Although it has been suggested that response shifts may render assessments completed over time incomparable, as the 'units' of comparison have changed, by their very nature, all subjective measures reflect participants' internal standards, which differ between participants and may not be static over time (Sprangers et al.

2002). Methods have been developed to assess response shift (Lowy & Bernhard 2004), and the integration of these methods into future studies is recommended to determine if response shifts occur, and if so, the nature of their effects and potential impact on results.

Overall, if the QLQ-INFO25 is shown to be sensitive to change, and MCIDs are confirmed with research with patients, carers, and health professionals, the QLQ-INFO25 may be a suitable instrument to assess differences between control and intervention group participants in perceptions of information received. Single items of the QLQ-INFO25 which assess a person's desire for more information, or a wish that they had not received some information, although broad, may also be useful evaluation tools. The QLQ-INFO25 could be combined with traditional evaluation tools such as counts of questions asked, to further reveal relationships between patients' and health professionals' communicative behaviours and the satisfaction of patients' information needs.

Other, more distal, outcomes that may be suitable measures of QPL effectiveness may be suggested by the model showing the effects of inadequate information provision (Figure 3.1). Patients with unmet information needs may experience impaired psychological adjustment and distress (Lazarus 1999), reduced ability to participate in decision-making (Elkin et al. 2007) and practice self-care (Wrixon 2009), and may perceive their care as more fragmented, reducing satisfaction with their providers (van Servellen et al. 2006).

Psychological outcomes have been widely used as outcomes for studies evaluating informational interventions, although many have failed to demonstrate effectiveness for these outcomes (McPherson et al. 2001), for which there may be several reasons. A bidirectional relationship may exist; for example, stress may impair a patient's ability to seek and assimilate information (Auerbach 2000); while increased information provision may reduce anxiety levels (Gaston & Mitchell 2005). Even if a suitable aspect of psychological well-being is measured, the appropriate timing of assessment may be uncertain, and the indirect effects of a QPL or other informational intervention on psychological states may not be easily demonstrated (McPherson et al. 2001). Satisfaction (e.g. with a consultation,

provider or care), although widely used, is particularly susceptible to social desirability bias (Giebel & Groeben 2008; Burroughs et al. 2005), determined by a multitude of factors (Bertakis et al. 1991), and not strongly related with the fulfilment of patients' needs (Brown & Siminoff 2005), suggesting it is a poor outcome measure.

Some outcome measures may be developed relating to rights or practices deemed 'important' by community standards, such as whether patients believe they have received sufficient information to give informed consent, or participate in decision-making to the degree desired. A potentially 'objective' marker of the receipt of 'important' information may be patients' participation in advanced care planning, although this may be governed by perceived threat of death, and spiritual or cultural beliefs (Ditto & Hawkins 2005). Furthermore, these measures are based on the assumption that patients want the information relevant to these measures; however, negative outcomes may not only reflect insufficient information but also patients' underlying values, cultural beliefs or information needs.

The effect of the QPL may also be assessed using patient QOL, although these outcomes are influenced by a wide range of physical, emotional, cognitive, and social factors, potentially diluting intervention effects (De Bruin et al. 2001), and requiring a larger sample size to show a clinically significant improvement. Assessment of improvements in distal clinician outcomes such as stress and burnout are also desirable, although similarly may show modest, if any, effect because of their many determinants (Schofield & Butow 2004).

For the immediate future, research with the QPL should include determining its acceptability to carers and health professionals. Patients' and carers' use of the QPL may differ as they have different needs and face different barriers in acquiring information; the use of a QPL in a joint consultation may also reflect a variety of influences not yet identified. The acceptability of the QPL to health professionals is also necessary for its effectiveness, and the identification of facilitators and barriers to its use by health professionals would be informative.

8.4.1. STRENGTHS AND LIMITATIONS

Perhaps the most significant limitation of this study was its small sample size. For this reason, these findings cannot be generalized to the broader brain tumour community. Comparisons with population-based data suggest our sample was relatively representative with respect to age, gender, and tumour type, and comparisons with other studies suggest our patients were no more likely to use information as a coping strategy. However, different findings may have resulted from a larger sample.

Our sample was also relatively heterogeneous, particularly in terms of time since diagnosis. The QPL was expected to be most beneficial for patients newly diagnosed. However, it was highly acceptable, even to patients later in the disease trajectory, and their inclusion added weight to the voices of newly diagnosed patients who suggested the QPL should be given soon after diagnosis.

Ideally, the views of patients, carers, and health professionals would have been collected, but only patients were recruited due to resource and time limitations. As carers themselves often have unmet information needs, and as they tend to take on information-seeking and decision-making responsibilities, especially when patients are no longer able, it is crucial to understand their opinions of the QPL. Health professionals are also instrumental, as their information provision in response to questions determines whether QPL use is effective in meeting patients' needs. The views of a range of health professionals who are consulted by brain tumour patients must be canvassed, such as neurosurgeons, oncologists, GPs, nurses, social workers, psychologists, and care coordinators.

Another limitation of this study was the lack of data to determine response rate, a key element of recruitment. Although data collection was planned to allow its calculation, monitoring of documentation was insufficient, and the number of potentially eligible participants who were not approached is not known. This study therefore cannot be used to determine recruitment timelines for future research.

The MCID for the QLQ-INFO25 is not known, so sample size calculations were based upon estimates which may not be supported by future research. However, these

analyses suggest that the number of patients required to show a contextually significant difference in information received, at a statistically significant level (at least 78 participants per group) may be achievable, pending determination of the MCID. Research is now needed with patients, carers, and health professionals to determine the appropriateness of the estimated values, and thus the validity of the estimated sample sizes.

Despite these limitations, the evidence from qualitative and quantitative data collection suggest that the QPL was perceived as helpful and easy to understand, and that it prompted patients to ask questions, as was its aim. The inclusion of the control group, provided with a standard information brochure, suggests that these positive appraisals are not merely a reflection of social desirability bias, supporting the acceptability of the QPL.

8.4.2. CONCLUSIONS

Overall, as a feasibility study and with a small sample size, this study was not powered to show that a brain tumour-specific QPL improves information exchange for patients and carers in a medical consultation. However, it has shown that the QPL is acceptable to patients with brain tumours, and has demonstrated the recruitment and evaluation obstacles that must be overcome to enable further research. This feasibility study has provided insight into the challenges of achieving and assessing change, and as such, provides valuable insights to inform future evaluations of the QPL.

9. OVERALL DISCUSSION AND CONCLUSIONS

9.1. REVIEW OF RESEARCH PROGRAM

This research program endeavoured to provide evidence regarding how the provision of information to meet the needs of primary brain tumour patients and carers can be improved. The three-stage program harnessed the views of health professionals involved in the treatment and care of brain tumour patients to select an intervention appropriate to patients, and to understand the challenges of providing information in this setting. Thirty health professionals participated, and results confirmed suggestions from previous studies that information is provided in a largely unstructured manner (Grimes 2000). Information provided by health professionals was found to be dependent on the needs and preferences of patients, and sensitive to their levels of distress, as recommended by psychosocial guidelines (Australian Cancer Network Adult Brain Tumour Guidelines Working Party 2009).

Health professionals also conveyed that information provision was reflective of the individual perspectives and skills of health professionals. The need for a balance between proactive information provision about what may happen in the future, to allow preparation, with the provision of information in such a way that hope can exist, has been previously described from the perspective of patients (Rosenblum et al. 2009; Salander et al. 1996). However, this study has shown how health professionals struggle with this issue, and may indicate the need for engagement with both patients and health professionals, to develop detailed guidelines around this issue.

Based on the results of study 1, within study 2 it was decided to develop a brain tumour specific question prompt list (QPL), to assist patients to ask questions and obtain specific, personalised information to meet their information needs. An iterative process was used to develop the QPL. A thematic analysis of patient materials, question prompt lists developed for other settings, and guidelines for the psychosocial care of glioma patients identified the need for information in seven areas: 1) diagnosis; 2) prognosis; 3) symptoms and problems; 4) treatment; 5) support; 6) after treatment finishes; and 7) the health professional team. Consistent

with studies showing that health professionals focus more on the physical aspects of care than the informational aspects (O'Donnell 2005), existing QPLs were found to place emphasis on the biomedical model of illness, whilst patient materials followed a biopsychosocial model of health (not illness). Interviews with 18 adults who had been diagnosed with a brain tumour in the past two years, or carers of such patients, were used to refine the content and format of the QPL. Consultation with health professionals showed areas in which the QPL could be improved, and changes were made, particularly in terms of reducing the number of questions, based on their opinions.

After development of the QPL, study 3 was undertaken to inform future evaluation studies. The review of the literature undertaken for this thesis showed that few interventions have been evaluated with brain tumour patients, and that those that existed had a number of methodological challenges. This study was thus undertaken to assess the acceptability of the QPL with brain tumour patients, and to assess the feasibility of proposed recruitment, implementation, and evaluation strategies.

Twenty adults diagnosed with brain tumours in the previous six months, or undergoing treatment for their brain tumour, were recruited. The feasibility study highlighted barriers to recruitment, particularly in terms of the limited capacity of health professionals to recruit patients in addition to their already busy schedules, and the competing priorities of research with clinical practice. Study participants endorsed the QPL, and suggested it would be most useful when provided early in the disease trajectory. Given that the median length of time since diagnosis of participants was one month, the QPL may be ideally given to patients at or around diagnosis. A number of participants also reported that the QPL had encouraged them to ask questions of various health professionals. These findings suggest that, particularly early in the disease journey, patients have the capacity to participate in consultations. This is significant given that health professionals wanted the patients to lead discussion, but many patients may be limited by physical and cognitive impairments, and speech and communication difficulties. Once these impairments become more pronounced, such participation may not be possible, and carers may take over these responsibilities. Ideally, future studies would include both patients

and carers, and follow their use of the QPL and well-being across the disease trajectory, to test this hypothesis.

The feasibility study also suggests that the EORTC QLQ-INFO25, which measures the amount and type of information received, and need for information, may be sensitive to change, but ideally may be modified to reduce recall bias, and improve the understanding of some questionnaire items. In particular, the questionnaire may cause recall bias by asking patients to describe the amount of information they have received about their illness, rather than specifying, for example, information received in the last two weeks. However, based on potential values of 'significant' change over time, power calculations showed that, dependent on other parameters such as design effects, the number of patients needed to show differences over time between control and QPL groups (at least 78 per group), should be feasible for future studies.

9.2. STRENGTHS AND LIMITATIONS

Overall, this research program gains strength from mixing qualitative and quantitative methods both within and between studies. This approach allowed the selection of the most appropriate methods to answer the research questions, and facilitated triangulation, strengthening the veracity of findings.

This study also utilised an evidence-based approach to select, develop, and assess the acceptability and feasibility of evaluation of an intervention. Health professionals' views of potential interventions, and facilitators and barriers to information provision, are not the only possible lenses that may be used to understand information provision; however, these views have not been extensively explored. The insights of health professionals, when applied to the body of research regarding ways to improve information provision, suggested the potential appropriate of a QPL for the brain tumour setting.

An evidence-based process was also used to develop the QPL, considering the opinions of patients, carers, and health professionals, to optimise its appropriateness. Readability analyses and subsequent modification of the QPL were undertaken to maximise the likelihood that the language used would not prevent its

use by persons of low literacy or for whom English is not their first language. However, the acceptability of the QPL has not been (specifically) assessed with such a sample, so the achievement of this aim is unclear.

The feasibility study was also part of an evidence-based process, in that it involved conducting the preliminary steps required before effectiveness can be assessed. However, like the first two studies of this research program, the sample size was small, and findings are suggestive rather than conclusive.

Together, the three studies that make up this research program provide evidence for the value and acceptability of the brain tumour specific QPL, and suggest potential avenues for its evaluation.

9.3. FUTURE DIRECTIONS

9.3.1. IMPLICATIONS FOR RESEARCH

This research program has contributed to psycho-oncology research by describing facilitators and barriers to the implementation of an informational intervention, and describing the use of a relatively new measurement tool to assess such an intervention. However, more intervention research is needed, particularly involving patients of less common tumour groups such as brain tumours. A number of informational interventions have been evaluated with patients with common cancers, and research is needed to evaluate their suitability for brain tumour patients and their carers.

The evaluation of the brain tumour specific QPL developed as part of this research program is desired to determine if the QPL assists patients to ask questions, and thus to increase information provision to meet patients' unmet information needs. The EORTC QLQ-INFO25 shows promise as an outcome measure, but more methodological research is required, particularly to determine its sensitivity to change, and minimal clinically important difference for change over time and between groups.

Future research could combine subjective (e.g. patients' perception of information received) and objective assessments (e.g. counts of question asking obtained via audio-taping consultations), to overcome some of the limitations of each approach.

Assessment of the effects of QPL use on both patients and health professionals over a number of consultations is also needed, to understand its 'real world' effectiveness. Patients who use the QPL repeatedly with positive results may gain self-efficacy in asking questions, leading to improved outcomes even without the QPL. However, patients who are prompted to questions by the QPL, but who do not receive the information they need (e.g. due to health professionals' communication skills, or because an answer is not possible), may not use the QPL again.

Health professionals may act differently following repeated exposure to the QPL (e.g. providing more psychosocial information to patients as part of standard practice). Although this could be considered a measure of QPL success, this may mask an intervention effect, or make it difficult to identify some less desirable outcomes (e.g. if even with the QPL, patients still find it difficult to ask some questions). It is also possible that in response to repeated exposure to the QPL, health professionals may begin to rely on patients' asking questions, and provide less information, unless asked for more. Evaluation of the QPL must therefore include the assessment of potential negative outcomes.

Research is needed to identify, and if possible, address barriers to QPL use. Some patients may have reduced capacity to use the QPL (e.g. persons of low literacy, from a non-English speaking background, or with visual deficits). In the future, the QPL may be provided in different formats, such as video or multimedia, or translated into different languages, overcoming such barriers. Provision of the QPL via a computer program or the internet could expand the audience to whom it is available, and allow the integration of features to increase its usability. For example, hyperlinks could allow patients and carers to view limited sections of the QPL (avoiding exposure to questions they do not feel ready for); link to other websites (e.g. support services); or to select, save, print, or email questions of interest (e.g. to their doctor prior to their next consultation).

A QPL is a low-cost intervention, with primary costs involving development, printing and delivery, and further actions taken for implementation. If the effectiveness of the QPL is established, randomised controlled trials should be used to determine

the comparative effectiveness and cost-effectiveness of the QPL and other interventions such as patient held records, to determine best clinical practice.

9.3.2. IMPLICATIONS FOR CLINICAL PRACTICE

This research has shown the diversity and complexity of patients' information needs, and strategies to assist health professionals to identify and respond to these needs are needed. Information provision is one of the areas in which there is still not a structured, systematic approach. There is consensus that information should be tailored to the needs of the individual patient. However, a structured approach may help ensure that patients do not have unmet information needs that impair their ability to cope, care for themselves, or participate in decision making including. Such an approach could include repeated assessment of patients' unmet needs and information preferences, the provision and documentation of information desired, and the use of evidence-based interventions. This approach may assist health professionals who do not know what information to give or what has previously been given, or worry about providing unwanted information, and thus distressing or overwhelming patients.

Such an approach may be particularly needed regarding information to prepare for the future. Clinical practice guidelines recommend that the provision of information should be consistent with patients' preferences, respecting for example, a patient's right 'not to know' (Australian Cancer Network Adult Brain Tumour Guidelines Working Party 2009). However, this study suggests that the provision of information about topics such as wills, enduring power of attorney, and potential impairments, depends also on the views of health professionals, and whether they feel it this information is important, or could 'take away' hope. Education programs may be needed to increase health professionals' knowledge (e.g. about what information to provide), skills (e.g. how to identify and respond to patients' preferences, determine appropriate timing) and to address barriers (e.g. fear of death, fear of causing distress) to optimise information provision.

9.4. CONCLUSION

Improvements in information provision are needed to facilitate coping, inform decision-making, and to ensure that appropriate care is provided. Few interventions targeting information provision have been developed for, or evaluated, with patients with brain tumours. This research program provides a platform on which further research can be undertaken to find new and innovative ways to address brain tumour patients' and carers' unmet information needs.

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11. APPENDICES

APPENDIX A.

LITERATURE REVIEW: STUDIES EXCLUDED AND REASONS FOR EXCLUSION

Reference	Reason for exclusion
(Amato 1991)	Expert opinion
(Anderson, Taylor et al. 1999)	Does not identify information needs, only associations between mood disorders and awareness of prognosis
(Arber, Faithfull et al. 2010)	Does not address information
(Brada and Guerrero 1997)	Does not identify information needs
(Brain Tumour Alliance of Australia 2011)	Does not identify information needs or evaluate the care coordination
(Bransdon, Fowler et al. no date)	PowerPoint presentation only
(Bunston, Mings et al. 1998)	Does not describe information needs
(Carlson-Green 2009)	Relates to adult survivors of paediatric brain tumours
(Catt, Anderson et al. 2011)	Audited follow-up services, but did not assess information need or evaluate the intervention
(Chappell 1997)	Personal story of spouse of brain tumour patient
(Chung, Ng et al. 2009)	Relates to secondary brain tumour patients
(Clark 2003)	Describes neuro-oncology nurse role, but does not identify information needs or evaluation
(Clifford, Sharpe et al. 2009)	Examined patients' experiences of Gamma Knife therapy, did not identify information needs
(Davies and Bannon 1999)	Described pilot of proforma to use to audit patient records
(El-Jawahri, Podgurski et al. 2010)	Intervention dealt with end-of-life care only
(Erharter, Giesinger et al. 2010)	Quality of life monitoring in brain tumour care; not for purposes of improved information provision or communication
(Faithfull 1991)	Does not address information needs or difficulties
(Firth, Simpson et al. 2009) & (Simpson, Wright et al. 2009)	Cognitive-behavioural intervention to improve management of challenging behaviours; information materials developed were not evaluated

Reference	Reason for exclusion
(Fox and Lantz 1998)	Included patients with primary and metastatic tumours, could not separate findings related to primary brain tumour patients
(Guerrero 2002)	Commentary
(Guerrero 2005)	Does not address information needs or difficulties
(Hargrave, Hargrave et al. 2006)	Related to paediatric brain tumours
(Horowitz, Passik et al. 1994)	intervention not evaluated with respect to information
(Horowitz, Passik et al. 1996)	Intervention; outcomes related to information not evaluated
(Irvine and Jodrell 1999)	Does not address information needs or difficulties
(Jackson 2008)	Report of clinical practice only
(James, Guerrero et al. 1994)	Intervention of nurse follow-up by telephone; not evaluated in terms of information
(Jones, Guill et al. 2006)	Exercise intervention for brain tumour patients; does not describe information provision or communication
(Junck 2004)	Does not address information needs or difficulties
(Khalili 2007)	Case study
(Keir 2010)	Intervention; targeted quality of life but not information specifically
(Kilbride, Smith et al. 2007)	Included patients with both primary and metastatic brain tumours, did not examine differences by groups
(Leboeuf 2000)	Case study
(Lipsman, Skanda et al. 2007)	Only considered attitudes towards death & dying, and needs and attitudes at end of life
(Lucas 2010)	Does not relate to information
(Lyons 1996)	Does not identify information needs
(Mackenzie, Drummond et al. 2009)	Describes the development of guidelines
(McNamara 2008)	Review of palliative care issues
(Menkes, Davison et al. 2005)	Cannot distinguish views of brain tumour patients/carers from those of patients with vascular malformations
(Newton and Mateo 1994)	Does not identify information needs
(None given 2000)	Advertising about new video
(None given 2005)	Media release about brain tumour support group
(North 1997)	Personal story of spouse of brain tumour patient

Reference	Reason for exclusion
(Pace, Metro et al. 2010)	Deals only with medical management & palliative care, not information
(Passik, Malkin et al. 1994)	Does not address information needs
(Patterson and Lovely 2007)	Conference abstract says evaluation results will be presented, but results are not included in the abstract
(Perks, Chakravarti et al. 2009) & (Perks 2008)	Cannot distinguish between patients with brain tumours and those having craniotomy for other diagnoses
(Pickering, Pelletier et al. 2007)	Does not identify information needs or issues
(Sardell, Sharpe et al. 2000)	Evaluation of nurse led telephone clinic; information not evaluated
(Seyama and Kanda 2010)	Does not identify information needs
(Sherwood, Given et al. 2004)	Theory building only
(Sherwood, Given et al. 2004)	Does not identify information needs
(Strang, Strang et al. 2001)	Does not identify information needs
(Sze, Marisette et al. 2006)	Relates to secondary brain tumour patients & carers
(Swartz and Keir 2007)	Did not address information needs
(Taphoorn, Sizoo et al. 2010)	Does not provide evidence for brain tumour patients
(Tepper 2003)	Described plan for program for brain tumour patients and carers, but did not evaluate program
(Tivoli, Sanchez et al. 2005)	Described how patients receive a cancer diagnosis, did not evaluate information provision
(Van der Molen 2000)	Unable to distinguish needs of brain tumour patients from other cancer patients
(Verhoef, Hagen et al. 1999)	Does not identify information needs
(Ward-Smith 1997)	Looks at patients' experiences with Gamma Knife therapy, not information needs
(Wright, Langford et al. 2005; Wright 2006)	Describes project to start a support group; results of evaluation not included in conference abstract
(Weitzner 1999)	Not related to information

Reference	Reason for exclusion
(Western & Central Melbourne Integrated Cancer Service 2008)	Discusses information provision as part of a audit of supportive care provision, but results are provided across tumour streams & not specifically for brain tumour care
(Whiting, Simpson et al. 2009)	Although interventions piloted aimed to address challenging behaviours after brain tumour, evaluation assessed knowledge of psychological strategies rather than relating to information per se
Wright (2007)	Sample not described
(Zanchetta and Bernstein 2004)	Described experience of Gamma Knife/craniotomy only, not information needs
(Zwinkels 2008)	Described role of a specialist nurse; commentary

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APPENDIX B.

STUDY 1 HUMAN RESEARCH ETHICS COMMITTEE APPROVALS

University Human Research Ethics Committee
HUMAN ETHICS APPROVAL CERTIFICATE
NHMRC Registered Committee Number EC00171

Dear Dr Monika Janda

A UHREC should clearly communicate its decisions about a research proposal to the researcher and the final decision to approve or reject a proposal should be communicated to the researcher in writing. This Approval Certificate serves as your written notice that the proposal has met the requirements of the *National Statement on Research involving Human Participation* and has been approved on that basis. You are therefore authorized to commence activities as outlined in your proposal application, subject to any specific and standard conditions detailed in this document.

Within this Approval Certificate are:

* Project Details
* Participant Details
* Conditions of Approval (Specific and Standard)

Researchers should report to the UHREC, via the Research Ethics Officer, events that might affect continued ethical acceptability of the project, including, but not limited to:

(a) serious or unexpected adverse effects on participants; and
(b) proposed significant changes in the conduct, the participant profile or the risks of the proposed research.

Further information regarding your ongoing obligations regarding human based research can be found via the Research Ethics website http://www.research.qut.edu.au/ethics/ or by contacting the Research Ethics Coordinator on 07 3138 2340 or ethicscontact@qut.edu.au

If any details within this Approval Certificate are incorrect please advise Research Ethics within 10 days of receipt of this certificate.

Research Ethics Officer _____ Date 9/7/2007
(on behalf of the Chairperson, UHREC)

Project Details

Category of Approval:	Human Ethics Level 1	Confirmed Low Risk by Chair
Approved Until:	28/06/2010	
Approval Number:	0700000585	
Project Title:	Conceptualising health professionals' perspectives on services for patients with brain tumours	
Project Chief Investigator:	Dr Monika Janda	

Other Project Staff/Students:
Ms Danette Langbecker , Prof Patsy Yates , Dr David Walker , Ms Vivien Biggs

Experiment Summary:
Explore staff perceptions of ideal elements of care for persons with brain tumours and gaps between current and ideal services, as well as providing an understanding of the role of staff in the making of treatment decisions.

Participant Details

Participants:
10-20 participants including any health care professional involved in the treatment, support or care of persons with a brain tumour

Location/s of the Work:
Royal Brisbane and Women's Hospital, the Wesley Hospital, and BrizBrain and Spine, St Andrew's Place

RM Report No. E801 Version 2

University Human Research Ethics Committee

HUMAN ETHICS APPROVAL CERTIFICATE

NHMRC Registered Committee Number EC00171

Conditions of Approval

Specific Conditions of Approval:
No special conditions placed on approval by the UHREC. Standard conditions apply.

Standard Conditions of Approval:

The University's standard conditions of approval require the research team to:

1. Conduct the project in accordance with University policy, NHMRC / AVCC guidelines and regulations, and the provisions of any relevant State / Territory or Commonwealth regulations or legislation;

2. Respond to the requests and instructions of the University Human Research Ethics Committee (UHREC);

3. Advise the Research Ethics Officer immediately if any complaints are made, or expressions of concern are raised, in relation to the project;

4. Suspend or modify the project if the risks to participants are found to be disproportionate to the benefits, and immediately advise the Research Ethics Officer of this action;

5. Stop any involvement of any participant if continuation of the research may be harmful to that person, and immediately advise the Research Ethics Officer of this action;

6. Advise the Research Ethics Officer of any unforeseen development or events that might affect the continued ethical acceptability of the project;

7. Report on the progress of the approved project at least annually, or at intervals determined by the Committee;

8. (Where the research is publicly or privately funded) publish the results of the project is such a way to permit scrutiny and contribute to public knowledge; and

9. Ensure that the results of the research are made available to the participants.

Modifying your Ethical Clearance:

The University has an expedited mechanism for the approval of minor modifications to an ethical clearance (this includes changes to the research team, subject pool, testing instruments, etc). In practice this mechanism enables researchers to conduct a number of projects under the same ethical clearance.

Any proposed modification to the project or variation to the ethical clearance must be reported immediately to the Committee (via the Research Ethics Officer), and cannot be implemented until the Chief Investigator has been notified of the Committee's approval for the change / variation.

Requests for changes / variations should be made in writing to the Research Ethics Officer. Minor changes (changes to the subject pool, the use of an additional instrument, etc) will be assessed on a case by case basis and interim approval may be granted subject to ratification at the subsequent meeting of the Committee.

It generally takes 7 -14 days to process and notify the Chief Investigator of the outcome of a request for a minor change / variation.

Major changes to your project must also be made in writing and will be considered by the UHREC. Depending upon the nature of your request, you may be asked to submit a new application form for your project.

Audits:

All active ethical clearances are subject to random audit by the UHREC, which will include the review of the signed consent forms for participants, whether any modifications / variations to the project have been approved, and the data storage arrangements.

End of Document

UnitingCare Health
ABN: 87 842 457 440

Human Research Ethics Committee

1st Floor Moorlands House, The Wesley Hospital
451 Coronation Drive, Auchenflower Q 4066

PO Box 499 Toowong Q 4066
Phone: 3232 7500 Facsimile: 3232 7109
Email: ethics@uchealth.com.au

2nd November 2007

Please quote our reference: 2007/56

Danette Langbecker
QUT School of Public Health
Victoria Park Road
KELVIN GROVE QLD 4059

Dear Ms Langbecker

RESEARCH PROPOSAL: *Conceptualizing health professionals' perspectives on services for patients with brain tumour*

Participant Information Sheet and Consent Form Version 1.3 dated 23/08/07
Cover letters for potential participants (mailed and emailed)Version 1.2 dated 23/08/07
Telephone script for follow-up call Version 1.2 dated 23/08/07
Telephone script to reinvite participation in organisation phase Version 1.2 dated 23/08/07
Cover letters to reinvite participants in Ideas phase to participate in organisation phase Version 1.2, 23/08/07
Telephone script to reinvite participants to participate in interpretation phase Version 1.2 dated 23/08/07
Card for reinviting participants to interpretation phase (mail and email) Version 1.2 dated 23/08/07

I am pleased to advise that the UnitingCare Health Human Research Ethics Committee reviewed the abovenamed research proposal at its meeting on 25th October 2007 and granted ethical approval.

It is a strict condition of approval that any departure from the protocol detailed in the proposal submitted for approval be reported immediately to the Committee. If there is any change to the status of the project, this should be reported.

Approval for the project is given subject to your agreement to UnitingCare Health requirements for the monitoring of research, which have been based on the Australian Health Ethics Committee guidelines, a copy of which is enclosed. Please note the requirement to submit a report annually or at the completion of the project, as appropriate.

With best wishes

Yours sincerely

UNITINGCARE HEALTH HUMAN RESEARCH ETHICS COMMITTEE

Information for Researchers Gaining Ethical Approval for Research Projects

Monitoring of Research

The Australian Health Ethics Committee now requires institutional ethics committees to monitor research projects to which they have given ethical approval. The principal reason for the monitoring of research projects is to ensure that their conduct does not jeopardize the rights and interests of those who have consented to take part as subjects in them. By monitoring the projects to which approval has been given, Ethics Committees will also be helping to ensure that researchers are practising responsible science and that the good reputation of the institution that is the setting for the research is maintained.

UnitingCare Health Hospital Requirements

Within UnitingCare Health, researchers who have approval from the Human Research Ethics Committee for their respective projects will undertake the following:

1 A report on the approved project will be provided at least annually. This does not preclude the Ethics Committee from asking for a report at more frequent intervals.

2 Provision of relevant reports will be the responsibility of the applicant. In the case of multi-centre research, a report from the principal investigator may suffice. However, it is the applicant within who is responsible for submitting the report to the Ethics Committee.

3 The report should provide details of the following:

- 3.1 Status of the project (completed/in progress/abandoned/not commenced).
- 3.2 Compliance with the conditions of ethical approval, including security of records and procedures for consent.
- 3.3 Compliance with any special conditions stated by the Ethics Committee as a condition of ethical approval.

4 Applicants (or principal investigators) are responsible for notifying the Ethics Committee immediately of matters that might affect continued ethical acceptability of the project including:

- 3.1 Adverse effects of the project on subjects and of steps taken to deal with these
- 3.2 Changes in the research protocol, together with an indication of ethical implications (if any)
- 3.3 Other unforeseen events.

Where the above requirements are not adhered to, the Ethics Committee may withdraw ethical approval for a project.

Douglas Killer MBBS FRACP
Executive Officer

APPENDIX C.

STUDY 1 RECRUITMENT DOCUMENTS

QUT PARTICIPANT INFORMATION for QUT RESEARCH PROJECT

"Conceptualising health professionals' perspectives on services for patients with brain tumours"

Research Team Contacts	
Principal Investigator: Monika Janda Postdoctoral Research Fellow 07 3138 5817 m.janda@qut.edu.au	Co-Investigator: Danette Langbecker Master of Applied Science (Research) scholar 07 3138 5817 d.langbecker@qut.edu.au

Description

The purpose of this project is to explore staff perceptions of ideal elements of care for persons with brain tumours and gaps between current and ideal services, as well as provide an understanding of the role of staff in the making of treatment decisions.

The research team requests your assistance because although wide variations in patterns of care and recognition of unmet patient needs have led to a number of recommendations for service improvements and reorganisation, few studies have described how those currently providing services for these patients view essential elements of care, and how responsibility for meeting such elements is shared among the multidisciplinary team.

This project is being undertaken as part of a postgraduate research project for Danette Langbecker. The project is funded by the Queensland University of Technology (QUT). The funding body will have access only to aggregated results of the project.

Participation

Your participation will involve a combination of one or more activities depending on your availability, including:

- partaking in a group brainstorming activity (30 mins),
- completion of an individual activity at a time of your choosing [may be completed online] (40 mins), and/or
- contributing to a discussion of the findings of the first two activities [this will be audio recorded] (roughly 90 mins).

These activities will be held at The Royal Brisbane and Women's Hospital, The Wesley Hospital, St Andrew's Place and a private neurosurgery clinic.

All participants will also be asked to complete a short questionnaire regarding basic demographic information and information on their patient group.

Your participation in this project is voluntary. If you do agree to participate, you can withdraw from participation at any time during the project without comment or penalty. Your decision to participate will in no way impact upon your current or future relationship with QUT (for example your grades) or with the funding body. You will be informed in a timely manner of any changes to the research protocol that may affect your willingness to continue your participation.

Expected benefits

It is expected that this project will not directly benefit you. However, some participants may find it rewarding to participate in activities with the aim to improve services delivered. It may also benefit patients newly diagnosed with brain tumours, by allowing the identification of perceived gaps in service delivery in order of priority. When paired with existing research on patient needs, this will allow the planning of interventions to attempt to address such inconsistencies.

Risks

There are no risks beyond normal day-to-day living associated with your participation in this project.

Confidentiality

All comments and responses are anonymous and will be treated confidentially. The names of individual persons are not required in any of the discussion contributions. The audio recording of the discussion activity will not be verified by participants prior to final inclusion, and will be destroyed after the contents have been transcribed. They will not be used for any other purpose, and will not be accessible to members outside of the research team. If you would like to participate in this project without being recorded, please participate in one or both of the non-recorded activities.

Consent to Participate

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate, or will accept the return of a completed participant questionnaire as an indication of consent.

Questions / further information about the project

Please contact the researcher team members named above to have any questions answered or if you require further information about the project.

Concerns / complaints regarding the conduct of the project

QUT is committed to researcher integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Officer on 3138 2340 or ethicscontact@qut.edu.au. The Research Ethics Officer is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

CONSENT FORM for QUT RESEARCH PROJECT

"Conceptualising health professionals' perspectives on services for patients with brain tumours"

Research Team Contacts	
Principal Investigator: Monika Janda Postdoctoral Research Fellow 07 3138 5817 m.janda@qut.edu.au	Co-Investigator: Danette Langbecker Master of Applied Science (Research) scholar 07 3138 5817 d.langbecker@qut.edu.au

Statement of consent

By signing below, you are indicating that you:

- have read and understood the information document regarding this project
- have had any questions answered to your satisfaction
- understand that if you have any additional questions you can contact the research team
- understand that you are free to withdraw at any time, without comment or penalty
- understand that you can contact the Research Ethics Officer on 3138 2340 or ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project
- agree to participate in the project and to be contacted again should further questions about this project arise
- understand that parts of the project will include audio recording.

Name . . . . . .

Signature . . . . . .

Witness . . . . . .

Date . . . . / . . . . / . . . . . .

My preferred day-time telephone number is _____

Cover letter for potential participants to be sent with participant information sheet and consent form (mailed letter):

<QUT letterhead>

<date>

<address details of letter recipient>

Dear <name>

Current research has identified that patients diagnosed with primary brain tumours have high levels of unmet supportive care needs, particularly with regard to information, communication and accessing ancillary services, and often express difficulties navigating the medical system. To identify how we can improve care for such patients, we (Danette Langbecker, Master of Applied Science (Research) student, Dr David Walker, neurosurgeon, Dr Monika Janda, public health researcher and Vivien Biggs, brain tumour nurse coordinator) are undertaking a research study to explore staff perceptions of ideal elements of and flow of care for persons with brain tumours.

We would like to invite you to take part in this research. We need participants with a wide range of expertise and opinions.

Attached is a participant information sheet further explaining this project and outlining what your participation would involve. If you would like to participate in this project, please sign the consent form and return in the stamped envelope provided. Your decision to participate in this study (or not) will not influence your working relationship or relationship with QUT in any way.

Please do not hesitate to contact me (phone 07 3138 5817 or email d.langbecker@qut.edu.au) or my supervisor, Monika Janda (phone 07 3138 9674 or email m.janda@qut.edu.au) if you have any questions about this research project.

Kind regards,

Danette Langbecker

Cover letter for potential participants to be sent with participant information sheet and consent form (e-mailed letter):

Subject: Invitation to participate in research study

Dear <name>

Current research has identified that patients diagnosed with primary brain tumours have high levels of unmet supportive care needs, particularly with regard to information, communication and accessing ancillary services, and often express difficulties navigating the medical system. To identify how we can improve care for such patients, we (Danette Langbecker, Master of Applied Science (Research) student, Dr David Walker, neurosurgeon, Dr Monika Janda, public health researcher and Vivien Biggs, brain tumour nurse coordinator) are undertaking a research study to explore staff perceptions of ideal elements of and flow of care for persons with brain tumours.

We would like to invite you to take part in this research. We need participants with a wide range of expertise and opinions.

Attached is a participant information sheet further explaining this project and outlining what your participation would involve. If you would like to participate in this project, please either print and sign the consent form and return to the below address by fax or post, or provide your written address or fax number by return email, and an information package will be sent to you. Please also provide your preferred day-time telephone number to enable us to contact you about the research. If you do not wish to participate or be contacted again about this project, please also indicate your wishes by return email.

Please do not hesitate to contact me (phone 07 3138 5817 or email d.langbecker@qut.edu.au) or my supervisor, Monika Janda (phone 07 3138 9674 or email m.janda@qut.edu.au) if you have any questions about this research project.

Kind regards,

Danette Langbecker
School of Public Health
Queensland University of Technology (QUT)
Victoria Park Rd
Kelvin Grove Q 4059

Phone: 07 3138 5817
Fax: 07 3138 3130
Email: d.langbecker@qut.edu.au

Cover letter for distribution by Nursing Unit Managers to nurses to be sent with participant information sheet and consent form:

<QUT letterhead>

<date>

For the nurses of <department>,

Current research has identified that patients diagnosed with primary brain tumours have high levels of unmet supportive care needs, particularly with regard to information, communication and accessing ancillary services, and often express difficulties navigating the medical system. To identify how we can improve care for such patients, we (Danette Langbecker, Master of Applied Science (Research) student, Dr David Walker, neurosurgeon, Dr Monika Janda, public health researcher and Vivien Biggs, brain tumour nurse coordinator) are undertaking a research study to explore staff perceptions of ideal elements of and flow of care for persons with brain tumours.

We would like to invite you to take part in this research. We need participants with a wide range of expertise and opinions.

Attached is a participant information sheet further explaining this project and outlining what your participation would involve. If you would like to participate in this project, please sign the consent form and return in the stamped envelope provided. Your decision to participate in this study (or not) will not be disclosed to your unit manager or influence your working relationship or relationship with QUT in any way.

Please do not hesitate to contact me (phone 07 3138 5817 or email d.langbecker@qut.edu.au) or my supervisor, Monika Janda (phone 07 3138 9674 or email m.janda@qut.edu.au) if you have any questions about this research project.

Kind regards,

Danette Langbecker

Telephone script for follow-up call for potential participants sent cover letter and participant information sheet and consent form:

Good morning, my name is Danette Langbecker and I am a research student at the Queensland University of Technology. I am hoping to speak to … about a research study that we are currently undertaking. Is this an appropriate time?

<Arrange different time to call if suitable>

Thank you. I am calling with regard to a research study I am undertaking as part of my Research Masters to explore the perceptions of health professionals involved in treating or caring for or supporting persons with brain tumours about ideal elements of care, and gaps between current and ideal services. I sent a letter about this study a week or so again, can I ask if you received it?

<Discuss if received, resend if not & follow-up one to two weeks later>

Do you have any questions about this study?

<Answer any questions; provide further information if needed>

Would you like to participate in this study?

<If decline…> *Okay, thank you for your time, we won't contact you again.*

<If indicate willingness to participate…> *Great, thank you. Do you have the information sheet and consent form we sent you or would you like me to send you another?* <Arrange to send another information sheet and consent form if needed> *If you could sign this and fax or mail it back to me, I will then contact you with details for when we are getting started. Alternatively, you can just send me an email with your preferred telephone number stating that you are willing to participate. Thanks again.*

<End call>

Telephone script to reinvite participants to participate in Organisation phase of the research project:

Good morning, my name is Danette Langbecker and I am a research student at the Queensland University of Technology. I am hoping to speak to … about a research study that we are currently undertaking. Is this an appropriate time?

<Arrange different time to call if suitable>

Thank you. I am calling with regard to the research study exploring how to improve care for persons diagnosed with brain tumours. I really appreciate your participation in our brainstorming activity, and I was wondering if you would consider participating in our next phase of research? It would involve completing an individual activity where you sort patient needs or services into categories, and rate each item as to how much it is needed, or how feasible it is and the like. You can complete it online at a time suitable for you, or I can send written materials out if you like. Would you like to participate in this phase?

<If decline…> *Okay, thank you for your time.*

<If indicate willingness to participate…> *Great, thank you. Would you like to participate online or would you like me to send you written materials?*
<Arrange materials as desired> *Thanks again.*

<End call>

Telephone script to reinvite participants to participate in Interpretation Phase of the research project:

Good morning, my name is Danette Langbecker and I am a research student at the Queensland University of Technology. I am hoping to speak to … about a research study that we are currently undertaking. Is this an appropriate time?

<Arrange different time to call if suitable>

Thank you. I am calling with regard to the research study exploring how to improve care for persons diagnosed with brain tumours. I really appreciate your participation in the study so far, and I was wondering if you would consider participating in our next phase of research? It would involve attending a group session where I am going to present the results from this study. I'm going to be presenting our results as maps, and I need to ascertain that they are an accurate representation of ideal care, and then need group participants to help me put these results into context. Would you like to participate in this final phase?

<If decline…> *Okay, thank you for your time.*

<If indicate willingness to participate…> *Great, thank you.* <Arrange time to participate> *Thanks again.*

<End call>

APPENDIX D.

STUDY 1 REDUCTION OF IDEAS GENERATED

Reduction and editing of brainstormed ideas

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
	2nd opinion		
1	2nd opinion	assistance to transfer to a different hospital or see staff in a different hospital	
2	2nd opinion	give patients the option to and encourage them to have second opinions (in a different hospital or centre if desired)	
3	2nd opinion	info on how to ask for a second opinion	
4	2nd opinion	knowledge that they have a right to a second opinion	
	accommodation/respite		
7	accommodation	more appropriate accommodation for patients who need to travel from the country, that is suitable for the needs of people not fully independent (eg mobility, the need for assistance, having someone with them)	
9	accommodation	travel and accommodation information	
10	accommodation	user-friendly affordable and available accommodation for those travelling for treatment	
503	respite	access to appropriate respite care	
507	respite	direct in how to get access to respite	
511	respite	in-home respite services to enable carers to go out	
516	respite	short term respite if the carer gets sick	
	assess needs		
11	assess needs	all new patients flagged when first appointment is made for assessment of deficits and needs before first appointment with oncologist	
12	assess needs	flag patients and carers with psychosocial needs to ensure these are addressed	
15	assess needs	patients see allied health worker for assessment of need before discharge following surgery	
17	assess needs	sharing of patient history, deficits and needs, and referrals made, with relevant health professionals whom patients will see	
	children		
29	children	help for children in dealing with changes in a parent following diagnosis of a brain tumour	
30	children	information about supportive care available in the school setting	
33	children	link to childcare services	
34	children	literature for small children about brain tumours	
36	children	provide patients with kids with information about Canteen, which can provide children of patients with brain tumours with help coping, caring, bereavement	
	cognitive/behavioural		
39	cognitive/behavioural	“how to” manual for caregivers on dealing with mood swings, behaviour changes, cognitive deficits, physical deficits	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
41	cognitive/behavioural	access to neuropsychology	
42	cognitive/behavioural	access to services for patients who have aggression or other issues that make them less desirable to be involved with	
45	cognitive/behavioural	assistance relearning skills	
47	cognitive/behavioural	for carers, model how to respond to challenging behaviours and give an opportunity to practice	
56	cognitive/behavioural	more information shared with patients about the positioning of the tumour and the deficits that may or may not occur because of the positioning of the tumour in a particular lobe	
57	cognitive/behavioural	patients see neuropsychologist for cognitive function testing, especially for younger people, who want to return to work, or those whose families need help understanding their cognitive changes	
58	cognitive/behavioural	staff to be trained in how to cope with cognitive and behavioural problems	
	continuity		
61	continuity	continuity of care	
63	continuity	patients allowed to stay in the same hospital ward throughout a hospital stay so can build relationship, trust and rapport with staff	
64	continuity	primary nurse to attend doctors' visits with a patient and be a contact person for them	
65	continuity	primary nursing – the same nurse to see a patient when on shift to allow consistency and to build a relationship and rapport	
66	continuity	same team support patients in hospital and following discharge	
	coordinator		
68	coordinator	all patients diagnosed with a brain tumour have someone who follows them and oversees their care, is a point of contact and someone for them to ask their questions of	
69	coordinator	brain tumour nurses in specific neurosurgical units or practices with an interest in brain tumours	
70	coordinator	cancer nurse coordinator informs doctors and allied health of updates in patient's condition and care	
72	coordinator	care coordinator to let people know about counseling and support services	
73	coordinator	care coordinators specifically related to brain tumours who can be involved at an early stage, be a point of reference and a link for the patient and family as they travel from one specialist to another	
76	coordinator	central person as a key point of contact	removed "/care coordinator"
79	coordinator	database of patient details to enable someone to keep in touch and monitor appointments	
84	coordinator	non-tumour specific cancer nurse coordinators in rural areas who are linked with metropolitan services to provide continuous ongoing support to patients from the country (both in the city and once they return home)	
93	coordinator	someone to arrange appointments and explain things after the neurosurgeon has left	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
94	coordinator	someone to be the liaison officer for different organisations	
	decision making		
111	decision making	a person to talk to patients and family about treatment options before surgery	
112	decision making	assistance to make informed decisions	
114	decision making	guidance on when to stop treatment	
115	decision making	help with weighing up options and making treatment decisions	
116	decision making	information about both survival and long term effects of different treatments	
117	decision making	information about new treatments	
118	decision making	information about potential impacts of procedures, drugs and drug interactions	
119	decision making	information about the tumour and types of treatment the doctor suggests	
120	decision making	let people know all their treatment options	
122	decision making	people given time to consider their treatment options and organise things before treatment commencement without pressure	
	disclosing diagnosis		
124	disclosing diagnosis	after telling a patient that 'this is what we think it is', then tell them that this was confirmed or not	
127	disclosing diagnosis	discuss prognosis with patient and family	
128	disclosing diagnosis	do not keep patients in the dark as to their condition	
132	disclosing diagnosis	encourage patients to take someone with them to medical appointments	
135	disclosing diagnosis	information about the uncertainty surrounding diagnosis and the future	
136	disclosing diagnosis	keep patients in hospital after surgery/treatment until diagnosis is confirmed to allow easier access to specialists and support	
137	disclosing diagnosis	more time taken to tell patients of their diagnosis	
140	disclosing diagnosis	patients given written information about their diagnosis, including pronunciation of the tumour type, and professionally developed diagrams showing tumour location	
141	disclosing diagnosis	patients not informed of their diagnosis over the telephone	
144	disclosing diagnosis	someone to come to the home and talk with the family after someone is diagnosed	
145	disclosing diagnosis	support person present whilst receiving diagnosis	
146	disclosing diagnosis	to have somewhere to go in the hospital to sit quietly and come to terms with a diagnosis	
	distress/emotional		
149	distress	for health care providers to not pathologise distress patients experience	
151	distress	use a prompt or screening mechanism such as a distress thermometer to assess distress and emotional needs	
153	emotional	do things to give control back	
154	emotional	hope	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
156	emotional	the health system to be less desensitised	
157	emotional	understanding from others	
	expectations		
160	expectations	information about what is coming up and what to expect	
162	expectations	information for patients on feelings they may experience and what to expect	
167	expectations	prepare patients and families who need to travel from the country for possible delays in returning	
168	expectations	prepare patients for future events such as tumour recurrence	
169	expectations	prepare people for what to expect at the end of life and how it is going to unfold	
170	expectations	someone to tell patients what they have been through and what they are likely to face after they've come through surgery	
172	expectations	tell patients that there is a possibility that they may fit and what to do after and about their anticonvulsants	
	family involvement		
176	family involvement	family fully informed and involved in the care plan	
178	family involvement	family present when receiving diagnosis	
179	family involvement	involve family from the word go, not waiting until have diagnosis, etc	
180	family involvement	involve the patient and their family in discussions about their care	
	finance		
182	finance	access to financial assistance if money from Centrelink takes time to come through	
185	finance	better financial assistance for patients who need to travel from the country	
187	finance	checklist to assess financial needs of patient and family	
188	finance	disability funding for patients in chronic states	
189	finance	financial advice	
191	finance	financial help for families to be able to care for patients at home	
192	finance	give patients the option of whether to go public or private	
194	finance	help accessing superannuation	
195	finance	info about Centrelink and what they are entitled to and how to access	
200	finance	make patients aware of the possible costs under private or public hospital treatment before treatment commences	
201	finance	practical help for families. eg assistance arranging Centrelink payments	
202	finance	support for home assistance	
	info access		
210	info access	access to information for carers	
211	info access	allow patients to not know or be informed about things if they do not want to be	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
212	info access	information for carers or family about what was going on, even if the patient does not want to know	
213	info access	patients given information in a timely fashion	
214	info access	patients treated at more than one site (eg those travelling for surgery from a rural area then back to a local hospital) given comprehensive information	
	info content		
220	info content	explain useful ways for dealing with issues, eg fatigue	
221	info content	explain what is normal, eg re fatigue	
222	info content	give info specific to patients' needs	
225	info content	give people information about existential issues	
226	info content	good info about tests and what tests mean	
227	info content	info on how to get back to driving eg legality, contact with neurologists	
229	info content	information about how doctors plan to operate if desired	
232	info content	information about organ donation if desired	
236	info content	information on brain tumours' likely progression	removed "and affects"
237	info content	information specifically for people with benign tumours	
239	info content	make patients aware of the legal ramifications of driving once diagnosed	
240	info content	make sure patients with cancer are aware that they have it	
241	info content	someone to give an overview of the process at the beginning	
242	info content	tell carers possible symptoms and what to look for	
243	info content	tell patients of resources available	
244	info content	tell people where they can look for information	
638	who to call	contacts and phone numbers for services people might need	
18	CAMs	good clear information about complementary and alternative therapies	
20	CAMs	information about what patients can do for themselves to get healthy	
21	CAMs	information for patients with respect to complementary and alternative therapies: what information to ask, or look out for, when you're checking information on that particular topic	
	info format		
252	info format	ascertain which medium is most suitable for patients to receive information during taking of patient history	
253	info format	books for patients and families to read about what they are diagnosed with and potential treatments	
254	info format	checklist for patients covering things they may need to consider or do	
255	info format	DVD for patients newly diagnosed about brain tumour treatment	
256	info format	easily accessible and readable information	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
258	info format	give info about support services and medical care separately to help break it down	
259	info format	give patients options as to how they receive information, eg for someone with the visual centre of their brain affected, offer options other than written materials	
260	info format	information booklets with info and contact details	
262	info format	library of information and books for patients	
263	info format	maintain a patient-held record of their treatment	
273	info format	several sets of information that can be given out at different times, or patients and families made aware they can be sent to them when they are ready	
274	info format	someone to go through written information with patients before they leave hospital	
276	info format	strategic information provision – give patients appropriate info at certain points on a pathway	removed "so not overwhelmed by too much info"
123	info format	ability for patient and family to later read transcript of consultation with specialist when diagnosed as it is often all a blur	
278	info format	tape consultations so patients and families can re-listen to them and go back over what's going on, and also so they can share with family, so they don't have to constantly re-tell the story	
280	info format	treatment summary letters	
281	info format	user-friendly but not over-simplistic information given to patients, avoiding assumption that patients should not be given "too difficult" or "too complicated" information	
525	share/standardise	Australian versions of information for patients	
527	share/standardise	sharing of resources between health professionals	
528	share/standardise	standardised information pack for health professionals to pull resources from for patients	
294	internet	dedicated email discussion group for brain tumour patients and carers to bridge the geographical gap and allow people to seek support and discuss personal issues while "once removed"	
295	internet	guidance for patients seeking information on the internet	
298	internet	internet access at the hospital in a quiet room to enable family to research things	
299	internet	internet-based resource for patients about what to do, who to call, etc	
300	internet	specialist/organisation to moderate email discussion group postings and raise a red flag if misleading content is posted	
301	internet	specialists to tell patients of websites where they can have online support	
303	internet	use email to facilitate communication to patients in a timely manner	
	communication		

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
287	inter communication	improved access to medical and allied health teams	
288	inter communication	improved communication between specialists and patients	
290	inter communication	patients given opportunity to communicate with their neurosurgeon, not just the registrar, after surgery	
291	inter communication	regular two-way communication between patients and doctors	
292	inter communication	specialist make time to sit down with the patient and family and discuss the care plan with them	
310	intra communication	less conflicting advice and information	
312	intra communication	phone, email or text communication between doctors	
313	intra communication	relevant information shared across campuses and health care providers	
316	jargon	help trying to make sense of the terminology	
317	jargon	information particular to brain tumours to explain to children about it and what it is like in a language that they can understand	
319	jargon	someone to assess how much or how well a patient understands information given to them during a consultation	
	link to support/referral		
326	link to support	complete list of services and support groups and information sources given to patients at each neurology or radiation oncology ward	
329	link to support	encourage patients to seek help if they need it	
330	link to support	improve access to allied health services such as social workers and counselling for those in the private system	
335	link to support	making sure everyone who is diagnosed is able to access services	
338	link to support	provide avenues to link initial crisis support to ongoing support services	
339	link to support	support system set up in hospitals so that people can easily access them	
455	referral	a social worker specifically for one department, eg oncology	
457	referral	access to a welfare officer	
458	referral	access to good social work support	
460	referral	access to OT	
462	referral	allied health services for patients as home visits	
463	referral	allied health services for people to receive as outpatients (after no longer eligible for access to hospital services)	
464	referral	appropriate timely referrals across all disciplines	
466	referral	better links to health professionals and support groups for people in the country	
467	referral	central or shared directory of all services available and appropriate for brain tumour patients to enable easier referral	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
468	referral	connection to a GP who feels comfortable managing someone with a brain tumour for ongoing care and support, eg diabetes, job loss, financial concerns, not being able to drive	
471	referral	dietetics service provision	
475	referral	help get the ACAT team in if needed	
476	referral	hydrotherapy	
477	referral	involvement of speech pathologist specialising in or interested in speech impairments following brain tumours	
480	referral	physiotherapy	
482	referral	referral of patients to allied health even if expected lifespan is short	
485	referral	specialists to refer patients to allied health services	
488	referral	timely referral of patients to allow them to be seen on the same day as they have other appointments or very soon after	
22	referral	referral to naturopaths	
491	rehabilitation	access to appropriate rehabilitation services	
98	counseling	access to family counseling	
100	counseling	counselling for carers of brain tumours	
101	counseling	diagnosis counseling	
102	counseling	emotional support following initial crisis period	
103	counseling	explain how to access counselling services	
107	counseling	quicker and less financially burdensome access to a counsellor or health professional with counselling skills	
108	counseling	relationship counseling if needed	
	multidisciplinary		
347	multidisciplinary	coordinator in multidisciplinary care to coordinate all members of a team	
356	multidisciplinary	multidisciplinary team meetings after treatment is decided to keep involved professionals involved and up-to-date with care	
353	multidisciplinary	multidisciplinary team approach to managing patients across disciplines and locations, involving neurosurgeon, radio-oncologist, medical oncologist, pathologist, nurses, allied health, OT, physiotherapist, psychologist, etc	
357	multidisciplinary	multidisciplinary team meetings to decide best course of treatment	
522	role confusion	inform patients and families about the different staff members and their roles - what they do and why they do it, so they can understand the system	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
523	role confusion	provide each patient with a pathway - a diagram representing all elements of care and health professionals involved - and go through it with them in the initial consultation, to pave for who staff are and what they'll be doing later	
	non-aged		
359	non-aged	access to home help for those who do not qualify under aged care assessment	
360	non-aged	access to specialised services for patients under 65 years who don't classify as aged care	
363	non-aged	more suitable accommodation for young patients who need nursing care so they do not have to move to a facility for older persons	
413	non-aged	care with basic living needs able to be accessed by those who aren't elderly	
505	non-aged	day respite for younger people	
	organisations		
365	organisations	for families to call the Epileptic Foundation, who will come out to their home and give them a demonstration of what to do if the patient has a fit	
366	organisations	give patients the name of Brain Tumour Australia	
368	organisations	organisations such as Brain Tumour Australia make themselves more known	
369	organisations	provide patients with written information about the Cancer Council	
370	organisations	specialists to refer patients to advocacy groups and networks	
371	organisations	tell carers to get help from carers' associations	
372	organisations	tell people about what the cancer council offers in terms of counselling, equipment hire, other supports	
373	organisations	tell people with benign tumours that they can access the Cancer Council	
	palliative care		
390	palliative care	24hr palliative care service for patients to use as backup at home if they need it and continued contact	
391	palliative care	access to GPs trained in palliative care	
392	palliative care	explain what palliative care is and how to access it	
393	palliative care	guidance on when to access palliative care	
396	palliative care	referral to palliative care whilst receiving active treatment	
	plan		
398	plan	case management plan in place for patients (utilising services from radio/medical oncology treatment centre, as this is where patients have their longest association)	
399	plan	give info on the process that is going to be undertaken while they are in hospital and after – the stages of diagnosis, surgery, radiotherapy & chemotherapy	
401	plan	give patients a plan of action for what to do if something goes wrong	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
402	plan	information about what to do next after the current phase of treatment	
403	plan	preoperative clinic to go through steps involved and demystify process, raise flags for issues to follow up with	
270	plan	provide patients with a written care plan	
	practical		
404	practical	access to equipment	
408	practical	assistance fitting the house out with railings, etc	
410	practical	assistance to re-establish personal care and household routines	
411	practical	basic information about the city and how to go about doing the things you do for those who must travel for treatment	
412	practical	basic living needs	
414	practical	carer to help with medications	
415	practical	direct in how to get help in terms of community nursing	
416	practical	encourage people to seek practical help (eg driving to appointments) from their church, family and community, as people often want to help	
417	practical	general help maintaining the house and garden	
419	practical	help for family to work out what is going to happen to the rest of the family (eg in terms of work, the future)	
420	practical	help getting medication	
425	practical	info on legal aspects such as how to organise wills and power of attorney	
429	practical	personal care workers	
430	practical	plan with carers to ensure they can get parking, attend patients' appointments, etc	
431	practical	provide patients with information about what to do before they have surgery (eg wills, bank accounts)	
432	practical	provide patients with written information about what to do about their dylantin levels	
434	practical	someone to show patients around and orientate them	
436	practical	structures to enable carers to set up care for a patient after they no longer can	
437	practical	tell patients about mouth care	
24	carer help	help carers deal with changes in their roles	
25	carer help	help for the carer after the patient has passed away	
595	teach carers	course for patients and carers to develop coping skills for themselves and to help the other person cope	
597	teach carers	practical help for families to teach them to care for patients at home	
598	teach carers	preoperative education sessions for patients and families diagnosed early enough to educate about services available and what to expect	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
600	teach carers	workshops for carers on how to assist your disabled relative to live more independently	
627	transport	access to affordable transport (not just to and from medical appointments)	
628	transport	help people work out how to get to hospital, treatment centres, etc	
632	transport	tell people about transport services available	
646	work	assistance in gaining some form of employment	
647	work	counseling to help people make decisions about work	
648	work	help for carers to go back to work	
649	work	info on how to get back to work	
	questions		
438	questions	2nd appointment with doctor shortly after first to enable them to ask questions and discuss options	
440	questions	doctors encourage patients to ask questions and help them feel comfortable asking questions	
442	questions	if a doctor cannot answer a question, for them to look into it	
443	questions	information to enable you to ask the right questions	
444	questions	invitation for patients to go away and write down questions and come back and ask them	
445	questions	nurse to regularly pop back and spend time with patients to give them the opportunity to ask questions without having to wait for the next doctor appointment	
446	questions	patients able to call a person/team to ask questions regarding medications, side effects, etc, and appropriate staff member re-contacts them	
450	questions	patients given the opportunity to ask questions of their doctors	
453	questions	teach doctors to give patients time and opportunity to ask questions when diagnosed	
	research		
495	research	an updating service to let people know of the latest medical developments in the field	
496	research	dedicated clinical trials coordinator	
497	research	for patients to be involved in research	
499	research	improved access to international trials	
500	research	information about clinical trials	
501	research	ongoing active research program	
502	research	treatment by those involved in research	
	specialisation		
530	specialisation	access to a neuroscience or neuro-oncology nurse	
533	specialisation	credentialing of brain tumour surgery as a subspecialty in neurosurgery	
535	specialisation	ongoing education among the general public about where or who to go to get good treatment for brain tumours	
536	specialisation	patients educated about how to identify specialists with an interest in brain tumours	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
537	specialisation	patients treated by those with a special interest in brain tumours to ensure they get the latest most up-to-date treatment, are exposed to all the options, and to research projects	
538	specialisation	specialised brain tumour centre or unit	
540	specialisation	subspecialisation in oncology so patients treated by neuro-oncologists	
	support group/telephone		
541	support group	assistance for health professionals to start a tumour group	
542	support group	brain tumour support group newsletters for those who can't or don't wish to attend meetings	
544	support group	brain tumour support service offering peer support	
545	support group	brain tumour-carer specific telephone support group	
546	support group	encourage patients and carers to attend support groups	
547	support group	let people know there are different types of support, such as attend a support group, telephone group, other types of support	
548	support group	more frequent brain tumour support group meetings	
551	support group	personal invitation to attend a support group from someone who already attends	
553	support group	support group for carers of brain tumour patients	
556	support group	telephone support groups for brain tumour patients	
558	support group	tumour-specific telephone support groups	
559	support groups	make readily available support groups in a person's area	
563	support groups	specialists to tell patients of support groups	
601	telephone	24 hour contact to enable someone to ring up if they are worried	
602	telephone	answering service for carers who want counseling	
603	telephone	conference calls to link brain tumour patients for support	
605	telephone	provide patients with written information about conference calls available for patients and for carers	
610	telephone	telephone counselling service	
612	telephone	telephone support group for carers	
376	other patients	brain tumour network to link patients and families with others who can offer companionship and understanding	
377	other patients	Brain Tumour Support visitors	
380	other patients	hopeful stories about patients who have/have had the tumour	
382	other patients	matching people to others who have gone through treatment already to enable them to share ideas and seek support	
383	other patients	national phone based service with database to connect patients and carers to someone of similar age who has already gone through a similar diagnosis	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
385	other patients	opportunity for families to talk to someone who knows something about the strange world they have been catapulted into, who is not a doctor or health worker	
205	for patients	meditation or relaxation classes	
206	for patients	outings for patients to allow some enjoyment	
635	volunteers	Volunteer Support Program	
636	volunteers	volunteers available to be a companion for someone if they want to go out (if concerned about seizures, confusion, etc)	
637	volunteers	volunteers to sit with people who do not want to be alone	
246	info events	awareness/information days for patients, friends and families to obtain information and support	
248	info events	events/sessions held on weekends to increase accessibility to people who can't attend things during the week	
250	info events	information events scheduled more frequently so can access info about something before it happens	
	system		
564	system	an advocate to ensure patients are not let down by the system	
565	system	better access to specialists and new techniques not available in Australia	
566	system	dedicated specialists to care for patients who are "in between" supportive care teams, eg waiting for pathology results	
567	system	equitable access to services regardless of location	
568	system	follow the glioma guidelines	
571	system	post monitoring	
572	system	preferential opportunities to make appointments quickly if brain tumour suspected	
573	system	protocols and procedures for stopping and changing anti-epileptic medication	
574	system	reduce the length of time between diagnosis and treatment	
576	system	someone to advocate for patients	
577	system	specific data based on a doctor's own files or experience, rather than average national or global data	
578	system	transition between hospital units be informed by patient needs as well as resources	
579	system	tumour collaboratives involving all interested medical and allied health professionals to investigate ways of improving care and instigate changes	
	talk to		
580	talk to	at the beginning, have an opportunity to go over what has been said	
582	talk to	informal support from the nurses at the hospital	
583	talk to	patients called back within two weeks to see how they are travelling and see if they have processed the diagnosis a bit more and are open to linking in with support	

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
585	talk to	somebody in the medical field, but not necessarily a nurse or a doctor, to come along and talk to patients	
586	talk to	someone for the carer to talk to	
587	talk to	someone to ask the family of the patient who they are going, if they are comfortable, able to eat, drink and sleep	
591	talk to	someone to talk to about what is going on	
593	talk to	spend as much time with patients as they want	
	training drs		
614	training drs	adequate training for non-specialist staff about how brain tumour patients are different from other cancer patients	
616	training drs	better education for GPs and other allied health professionals about where to refer patients with brain tumours	
621	training drs	teach doctors sensitivity in giving patients their diagnoses	
622	training drs	train staff on how to communicate	
624	training drs	training for non-tumour specific cancer nurse coordinators about brain tumours	
625	training drs	training for nurses about different aspects of treatment for patients with brain tumours, to allow them to better support patients. eg nurses on the neurology ward who are interested given information about chemo or radiotherapy so can answer patients questions on these topics	
626	training drs	training for staff in hospices to appropriately care for brain tumour patients given their specific needs	
	redundant items		
560	support groups	patient support groups specific to brain tumours to provide regular social events in addition to education	same as 206
561	support groups	specialists to recognise the value of support and support groups	same as 563
283	inter communication	communication to help people understand when nothing can be done	same as 114
284	inter communication	doctors working together with patients and keeping them involved	same as 291
285	inter communication	for patients and families to be heard	same as 291
345	link to support	tell people with benign tumours about information and services available	same as 335
531	specialisation	attitudinal change in the neurosurgical and neurological community about the need for specialisation in brain tumour care	same as 533
594	teach carers	carer workshops	generic
596	teach carers	extra support for the patient and family who cannot receive treatment to cope or learn coping skills	same as 595
32	children	let schools of patients' children know what is happening	same as 30

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
35	children	provide information for families about how to talk to your kids about a parent's cancer	same as 29
37	children	service go to schools of children of patients with brain tumours and explain to the kids about cancer and how it is not contagious	same as 30
38	children	someone to talk with children of a patient and encourage them to talk about their feelings	same as 29
46	cognitive/behavioural	assistance understanding limitations and coming to terms with disabilities suffered as a result of the tumour	same as 56
346	link to support	tighten things up so people don't slip through the net	same as 335
469	referral	database of all support services available	same as 467
327	link to support	doctors or specialists to make patients more aware of support services	same as 485
328	link to support	each patient linked with a support person or a gateway person	same as 72
472	referral	easier access to counsellors and social workers for patients who go through the private system	same as 330
50	cognitive/behavioural	increased awareness of the role of neuropsychology	same as 41
59	cognitive/behavioural	strategies for managing memory loss	same as 46
53	cognitive/behavioural	involvement of OT to help with memory and cognitive problems	same as 460
618	training drs	educate neurosurgeons about how to communicate with patients	same as 622
620	training drs	more and more experienced staff and more training for staff	generic
99	counseling	counseling	same as 101/103
106	counseling	psychological care at the time of diagnosis	same as 101
110	counselling	suggestions about how to cope	same as 102
630	transport	someone to organise the travel and accommodation for those who need to travel	same as 628
208	for patients	social support to get the patient out and about	same as 206
406	practical	access to social worker at an early stage to help with anxiety and practical issues such as cash flow	same as 182
407	practical	assist carers to take patients home and nurse them at home if desired (training)	same as 597
264	info format	offer patients information in different formats, such as pictures, movie, audiotapes	same as 280+278+255
267	info format	provide a treatment summary booklet	same as 263
268	info format	provide education via different avenues - ongoing group, telephone group and internet forum	same as 542+556
269	info format	provide information in an ongoing way	same as 273/276
289	inter communication	patients given opportunity to communicate with their neurosurgeon to find out about their case to the extent desired before surgery	same as 137

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
311	intra communication	neurosurgeons to inform nurses of a patient's diagnosis and what they have done, so that nurses can help the patient understand	same as 306
306	intra communication	improved communication between different care providers	same as 313
334	link to support	let patients who go through the private sector know about what services are available	same as 330
344	link to support	tell people who the key "gatekeepers" are to contact	same as 328
320	jargon	specialists to realise that patients and families don't always understand what they are talking about	same as 317+319
478	referral	link with local support services for patients who need to travel for surgery or other specialist care	same as 466
487	referral	tell people you can organise to have blood tests taken at home	same as 462
378	other patients	for men, male visitors	same as 377
321	link to support	advocate to ensure patients are linked in with support	same as 335
581	talk to	for nurses to talk to patients to see how they are travelling, even if they don't have answers	same as 582
588	talk to	someone to help patients along their journey	same as 591
589	talk to	someone to ring each week to see how a family to going	same as 591
322	link to support	allow newly diagnosed patients to have ready access to resources	same as 335
323	link to support	better access to ancillary support once have gone through surgery	same as 335
324	link to support	better access to support services for people in rural areas	same as 335
325	link to support	community support	
331	link to support	improve knowledge and access to services that can be accessed after discharge	same as 335
332	link to support	inform people of the resources and services that are available	same as 327
341	link to support	tell patients in private sector what to ask to get access to allied health services	same as 330
459	referral	access to occupational therapy at home	same as 462
358	multidisciplinary	realisation among neurosurgeons, oncologists and neurologists that multidisciplinary care is best	generic
519	role confusion	explain to patients who is in charge of different aspects of their care	same as 522
422	practical	help to get affairs in order	same as 425
426	practical	information on practical issues such as where to park	same as 430
479	referral	patients referred to as many people who can help as possible	same as 485
483	referral	social worker	same as 458
484	referral	someone to meet patients at the hospital and introduce them to a counsellor, a neuroscience person, oncology social worker	same as 458+
490	referral	treatment team aware of and refer to linkages needed in addition to treatment	same as 485
44	cognitive/behavioural	assistance for families to help them understand that their loved one may never ever resume their pre-tumour function	same as 56
48	cognitive/behavioural	give advice about how to cope with behavioural changes	same as 39

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
51	cognitive/behavioural	info for carers/family on how to deal with changes in behaviour, mood, concentration, memory in a patient	same as 39
52	cognitive/behavioural	information about memory testing	same as 41+50
54	cognitive/behavioural	more information for carers about cognitive impairment and how to manage patients at home	same as 39
55	cognitive/behavioural	more information for patients about potential for problems with memory, behaviour changes, mood swings	same as 56
62	continuity	for the different departments of a hospital to work together	same as 306
104	counseling	give patients information about counsellors	same as 103
105	counseling	provide initial crisis support for those newly diagnosed	same as 106
121	decision making	more information about all the possibilities and dangers involved of treatments	same as 118
125	disclosing diagnosis	be informed on the prognosis	same as 127
126	disclosing diagnosis	compassion when delivering diagnosis	same as 621
131	disclosing diagnosis	emotional support during diagnosis	same as 106
133	disclosing diagnosis	for neurosurgeon to inform family of a patient about their likely prognosis with precision (but also realistic hope)	same as 127
134	disclosing diagnosis	give information about prognosis and what to expect	same as 127
139	disclosing diagnosis	patient accompanied by a nurse during consultations with a doctor to allow the nurse to review info with the patient later and support them	same as 145
142	disclosing diagnosis	patients supported when receiving diagnosis	same as 145
152	emotional	deal with issues holistically	same as 12
158	expectations	explain whilst in hospital about the functions of the affected lobe and prepare for what could possibly happen with it being disrupted	same as 56
165	expectations	prepare carers for potential changes in the patient's behaviour	same as 56
166	expectations	prepare carers for what to expect, what could happen, dealing with side effects	same as 116
175	expectations	tell people what to look out for and be concerned about	same as 242
209	info access	access to info and support through all stages	same as 269
217	info content	detailed info about the tumour and treatment	same as 119
218	info content	education about medication – what does it do, what are possible side effects	same as 118
219	info content	ensure patients are fully informed about their diagnosis	same as 140
223	info content	give information about side effects of the drugs and treatment	same as 118
224	info content	give information on the process of end-of-life issues	same as 169
228	info content	information about bereavement and what you need to do	same as 169
231	info content	information about nutrition	same as 471

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
235	info content	information about whether a tumour could grow again, whether it could become malignant, and how long side effects would last	same as 236
238	info content	information to prepare patients for the side effects of radiation	same as 160
261	info format	information pack with generic info and support details, with more specific info added as more is known	same as 276
272	info format	ready access to printed materials about brain tumours	same as 140
277	info format	support and information pack for patients	same as 260
5	accommodation	affordable accommodation close to the hospital to stay for those from the country	same as 7
6	accommodation	appropriate accommodation if need to travel for treatment	same as 7
8	accommodation	supported accommodation for people from the country who do not require a hospital bed but need a bit more care than provided by independent accommodation	same as 7
16	assess needs	recognise what patients needs are	same as 14
19	CAMs	information about alternative medicines	same as 18
23	carer help	follow up for family after someone has passed on	same as 25
26	carer help	see that the whole family is taken care of	same as 419
27	children	brochures with ideas on how to approach kids (of patients) with the knowledge they need to know and what they may or may not understand	same as 35
28	children	childcare	same as 33
31	children	information on how to deal with it with the children – how much info at their age they could understand, and what would be fair for them	same as 35
40	cognitive/behavioural	access to neuropsychological testing before returning to work	same as 57
43	cognitive/behavioural	appropriate timely information for families of patients with frontal lobe tumours about potential deficits and changed behaviours to assist them in understanding that there may be some deficits that never right themselves	same as 56
49	cognitive/behavioural	help for family members to cope with cognitive impairment and challenging behaviour	same as 47+48
60	cognitive/behavioural	tell carers/family about potential memory problems and brain injury	same as 55/56
67	coordinator	a central person patients can contact and doctors (and anyone else referring) can contact to advise about what services are around	same as 76
71	coordinator	care coordinator to act as main contact person	same as 76
74	coordinator	case coordinator who can find out information from all specialists	same as 73
78	coordinator	coordination of all the services that are available	same as 95
80	coordinator	introduction of a cancer nurse coordinator role	same as 76
83	coordinator	neuro-oncology care coordinator	same as 95

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
87	coordinator	point of contact for people to call for information about brain tumours	same as 76
88	coordinator	provide a central contact point to help tie everything together	same as 76
89	coordinator	provide a central point of contact for patients	same as 76
90	coordinator	role of the brain tumour support nurse in enabling consistent information and support	generic
97	coordinator	someone who meets patients before they leave hospital and keeps in touch after to see how they are and what help they need	same as 96
109	counseling	tell people how to cope with the shock of diagnosis	same as 101
113	decision making	counseling to help make treatment decisions	same as 112
129	disclosing diagnosis	doctors to give patients time when being told bad news to let the news sink in, and to spend time with them	same as 137
130	disclosing diagnosis	doctors to tell patients bad news in a quiet space with a nurse present	same as 145
138	disclosing diagnosis	nurse stay with a patient when they receive their diagnosis	same as 145
143	disclosing diagnosis	patients to have someone else with them during consultations	same as 145
147	distress	address emotions in an ongoing way	same as 148
150	distress	staff to be non-judgemental of patients and families in crisis	same as 149
155	emotional	hope, even when things are grim	same as 154
161	expectations	information about what to expect	same as 160
171	expectations	someone with information about what to expect	same as 160
173	expectations	tell patients what to expect to make it easier for them to cope	same as 160
174	expectations	tell people what to expect when they go for treatment	same as 160
181	family involvement	involvement of family	same as 176
184	finance	assistance dealing with Centrelink	same as 195
186	finance	better funding for families who must travel to seek care	same as 185
190	finance	financial help	same as 189
193	finance	guidelines for what you need to enquire about and what to do to get Centrelink assistance	same as 195
196	finance	info on financial assistance	same as 189
199	finance	link to financial assistance	same as 189
203	finance	tell patients and families about the carer's allowance	same as 195
204	finance	tell people that they are eligible to Centrelink payments, for the patient and carer	same as 195
207	for patients	relaxation for patients	same as 205
215	info access	tell relatives as well as patients what is available	same as 210
216	info content	access to information about the type of tumour	same as 217
230	info content	information about how to deal with possible side effects of medication	same as 223
234	info content	information about what was happening after surgery, such as side effects	same as 223

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
245	info content	tumour specific information	same as 217
247	info events	educational events for patients and families about topics such as radiotherapy, oncology, research, epilepsy	same as 246
249	info events	information courses on relevant info	same as 246
251	info events	information nights and events for patients and families to get exposure to other opinions and meet other patients	same as 246
257	info format	feed people bits and pieces as they are able to take it	same as 276
265	info format	option to receive info via videos or info in other formats	same as 264
266	info format	other ways of receiving info for people not comfortable with computers or the internet, who are affected by the flicker of the computer screen, or whose concentration is affected	same as 259
271	info format	provide patients with written information about who to depend on	same as 260
275	info format	someone to walk through necessary information with patients, rather than leave them to read it on their own	same as 274
279	info format	tape record consultation and give to patients	same as 278
282	info format	written information to supplement oral info	same as 272
286	inter communication	good communication with the specialist	same as 288
293	inter communication	time spent with the specialist	same as 292
296	internet	guidance on websites that are reliable	same as 295
297	internet	information on navigating information on the internet	same as 295
302	internet	tell people where they can look for credible internet-based information	same as 295
307	intra communication	improved communication between different facets of care	same as 307
308	intra communication	improved communication between disciplines	same as 307
309	intra communication	improved communication between specialists	same as 307
314	jargon	avoid speaking in jargon	same as 317
315	jargon	do not expect patients to know or understand diagnosis	same as 320
318	jargon	not assuming patients understand the information they are given about their condition	same as 320
333	link to support	knowledge about what government services are available	same as 332
336	link to support	patients informed of the support services available	same as 332
340	link to support	tell patients about services and that they are entitled to them	same as 332
342	link to support	tell people what is out there and what might be available to them	same as 332
343	link to support	tell people what services are available	same as 332
348	multidisciplinary	multidisciplinary care	same as 353
349	multidisciplinary	multidisciplinary care teams to help manage patients, eg work out where is best for patients to go to after they leave hospital and what support they need at home	same as 353

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
350	multidisciplinary	multidisciplinary case management	same as 353
351	multidisciplinary	multidisciplinary meeting involving the doctors, physios, OT	same as 353
352	multidisciplinary	multidisciplinary team	same as 353
354	multidisciplinary	multidisciplinary team includes all health professionals involved in care, including psychologists, OTs, etc	same as 353
355	multidisciplinary	multidisciplinary team meetings	same as 353
82	multidisciplinary	multidisciplinary team approach for neuro-oncology patients, to enable different professionals to talk about the patients that are coming up, how to manage them, what else they need, all aspects of the patient's and the family's needs	same as 356+357
361	non-aged	appropriate facilities to accommodate people with deficits who are not of old age	same as 363
362	non-aged	identified allied health services for younger people	generic
364	organisations	all patients given TCCQ helpline card	same as 369
367	organisations	information about The Cancer Council Queensland	same as 369
374	other patients	ability to mix with others who have had similar cancer experiences	same as 382
375	other patients	able for carers to talk to someone else who has gone through what they have	same as 382
379	other patients	help patients to get in touch with one other person who has survived a brain tumour who they can relate to, to help support them	same as 382
381	other patients	link people to those who have been through it before	same as 382
384	other patients	opportunities for patients to talk to others who have also had a brain tumour	same as 382
386	other patients	opportunity to speak to someone who is a success story	same as 382
387	other patients	patients given opportunity to talk to someone who has been through a similar situation	same as 382
388	other patients	sharing of strategies between patients	same as 382
389	other patients	to be able to talk to other people in a similar situation	same as 382
394	palliative care	information about palliative care	same as 393
395	palliative care	refer patients to palliative care early for symptom control and relief and psychosocial support	same as 396
397	palliative care	someone to explain to patients what palliative care offers and who is eligible	same as 392
400	plan	give information about the plan of treatment	same as 270
405	practical	access to home help	same as 417
418	practical	give people info about practical issues	generic
423	practical	help with grocery shopping, cooking	same as 412
427	practical	legal advice	same as 425
428	practical	parking at hospitals	same as 428
433	practical	someone to come and show the carer/family different ways of looking after a patient	same as 407
435	practical	someone to tell people where to park, where to stay when travelling for treatment, where they will go	same as 411

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
439	questions	after a patient receives a diagnosis, they are visited a second time by their doctor to give them the opportunity to ask questions and further discuss once the news has sunk in	same as 438
441	questions	doctors to encourage patients to ask questions after receiving bad news	same as 441
447	questions	patients given opportunity to ask questions about their tumour and care throughout the course of their illness	same as 450
448	questions	patients given opportunity to ask relevant questions of health care providers (eg timeframe of life, manner of death, other options)	same as 450
449	questions	patients given pen and paper following their doctor visit and encouraged to write questions down to ask when see them next	same as 444
451	questions	patients given time and opportunity to ask questions of their doctor at diagnosis	same as 450
452	questions	questions to ask to empower patients	same as 453
454	questions	to have your questions answered	same as 453
456	referral	access to a speech pathologist	same as 477
461	referral	access to physiotherapy at home	same as 462
465	referral	better access to professional help for patients from rural areas	same as 466
470	referral	dietary advice	same as 471
473	referral	every patient have contact with an oncology social worker	same as 483
474	referral	faster access to social workers and support services for those in crisis	same as 488
481	referral	referral for OT, physiotherapy, speech pathology, rehabilitation, etc	same as individual items
486	referral	speech pathology	same as 477
489	referral	timely referrals based on patient need	same as 488
492	rehabilitation	access to rehabilitation	same as 491
493	rehabilitation	rehabilitation program	same as 492
494	rehabilitation	specialised timely rehabilitation for patients in the community	same as 491
498	research	government initiatives to fund research	funding specific
509	respite	encourage carers to go out now and then	same as 509
512	respite	respite available	same as 503
513	respite	respite care	same as 503
514	respite	respite for the family	same as 503
515	respite	respite to support carers	same as 503

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
517	respite	someone to look after the patient for a few hours so a carer can go out	same as 510/511
518	role confusion	explain to patients and families the different medical professionals and their roles	same as 522
520	role confusion	help navigating through the health system, with all the different health professionals	same as 522/523
521	role confusion	help understanding the difference between all the health professionals	same as 522/523
524	role confusion	staff to explain their role and why they are involved	same as 522
526	share/standardise	more opportunities for service providers to interact and share resources	same as 527
529	share/standardise	use the same patient resources throughout Australia	same as 528
532	specialisation	brain tumour patients treated by people who are interested in brain tumours	same as 537
539	specialisation	staff specialised in brain tumours with in-depth knowledge to talk to patients	same as 537
543	support group	brain tumour support groups to show patients that there are other people in their situation who are surviving and doing well	same as 544
549	support group	opportunities for carers to meet externally from their environment to give them time out	same as 553
550	support group	peer support for carers	same as 553
552	support group	support group	same as 544
555	support group	support groups to enable people to share their stories and learn from each other, facilitated by a counsellor	same as 544
562	support groups	specialists to support support groups	same as 563
569	system	government funding for a specialised brain tumour centre	funding
570	system	more resources to reduce waiting times for treatment	funding
575	system	services to be more easily available to those in rural and outer-metropolitan areas	same as 567
584	talk to	patients given the opportunity to talk about their situation if they want	same as 591
590	talk to	someone to talk to	same as 591
599	teach carers	teaching of personal care skills, etc	same as 597
604	telephone	phone counseling services	same as 610
606	telephone	provide phone contact support	same as 606
607	telephone	someone to ring about symptoms or just to get some reassurance	same as 601
609	telephone	support of having someone to talk to over the phone	same as 601
611	telephone	telephone service patients can call for information and support	same as 601
613	telephone	telephone support service to assist patients with poor mobility or other issues	same as 601
615	training drs	awareness among non-specialised staff of what a brain tumour can do and how it affects you and how people can help	same as 615

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
623	training drs	training for neurosurgeons and others about how to they should convey bad news	same as 621
634	transport	transportation	
639	who to call	ensure carers know who to call if they have questions or need information	same as 639
640	who to call	ensure they know they can call someone	same as 639
641	who to call	information about where to go for help and support	same as 639
642	who to call	provide patients with written information about who to call	same as 639
643	why not what	improve how we give information	generic
644	why not what	information and support to get the sense of control back	generic
645	why not what	information right at the beginning to enable coping	generic
13	assess needs	identify problems family may face early on	same as 12
14	assess needs	improve psychosocial assessment to ensure needs of patients are identified	same as 12
75	coordinator	case manager	same as 68
77	coordinator	continued contact with cancer nurse coordinator from diagnosis through and after referral to palliative care	same as 73
81	coordinator	liaison person for brain tumour patients to be able to contact separate from doctors	same as 68
85	coordinator	one person to be accountable to	same as 68
86	coordinator	ongoing management following initial crisis	same as 68
91	coordinator	someone at point of diagnosis to be an advocate and conduit for the project management	same as 68
92	coordinator	someone to “project manage” a patient’s care	same as 68
95	coordinator	someone to coordinate patients’ care, including surgery, radiotherapy, oncology, physio, OT, psychology, neuropsych, etc, and ensure nothing is missed	same as 68
96	coordinator	someone to meet new patients and have continued contact with them afterwards	same as 68
148	distress	consider the emotional, spiritual and psychosocial issues of patients	same as 12
159	expectations	inform people about what you might expect about radiotherapy and chemotherapy	same as 160
163	expectations	information to know how to deal with seizures, what it would be like and what to expect	same as 172
164	expectations	patients provided with information about what to expect and what is “normal”	same as 160
177	family involvement	family kept up to date with necessary information so they can focus on the plan for the patient and do not push them in different directions	same as 176
183	finance	advice about how to deal with financial pressures	same as 189
197	finance	information about the ongoing costs of doctors, appointments, medicines	same as 200
198	finance	information about what is covered by insurance and what is not, and what is and is not covered by Medicare	same as 200
233	info content	information about seizures and their management	same as 172
304	intra communication	brain tumour nurses to communicate with patients’ GPs	same as 70

Statement ID	Codeword	Something that I think would improve the situation for patients with brain tumours is…	Notes
305	intra communication	for GPs to be informed of their patients' diagnosis, treatment and care	same as 70
337	link to support	personal invitation to support services and counseling to normalise it	same as 551
409	practical	assistance for caring for patients	same as 407
421	practical	help going back to living a normal life	same as 410
424	practical	home nursing services	same as 415
504	respite	access to respite specifically for people with brain tumours	same as 503
506	respite	develop strategies to improve access to care placements for patients	same as 503
508	respite	enable carers to do things for themselves knowing the patient is being looked after	same as 507
510	respite	excursions to give the patient and carer respite	same as 206
534	specialisation	media coverage to educate people about good brain tumour treatment centres	same as 535
554	support group	support group specifically for a tumour type	same as 558
557	support group	telephone support groups for carers	same as 612
608	telephone	specialists to tell patients of telephone support groups	same as 563
592	talk to	specialist nurse for patients to talk to – if, but and when they want to	same as 530
617	training drs	educate GPs about where to refer patients with brain tumours through publications and fliers	same as 616
619	training drs	GP education days to educate GPs about where to refer patients with brain tumours	same as 616
629	transport	improved transport for patients from outer metro areas not entitled to assistance or covered by hospital or community services	same as 627
631	transport	tell people about taxi vouchers	same as 632
633	transport	transport service to take patients to treatments	same as 627

APPENDIX E.

STUDY 1 DATA COLLECTION MATERIALS

QUT

PARTICIPANT QUESTIONNAIRE

"Health professionals' perspectives on services for patients with brain tumours"

Demographic questions

Name: . . . . . Age: _____ Sex: _____

Profession: ☐ Neurosurgeon ☐ Oncologist ☐ Radiologist
☐ Nurse ☐ Social worker ☐ Other, please specify . .

Years of experience in treating, caring for or supporting patients with a brain tumour: ____

Questions about your patient group

Approximately how many patients newly diagnosed with primary brain tumours did you treat, care for or support in the previous 12 months? ___

Approximately what proportion of your patients newly diagnosed with primary brain tumours are aged 18 years or older? ___%

Please indicate your usual places of work:

	Primary	Secondary	Tertiary
Royal Brisbane & Women's Hospital	☐	☐	☐
St Andrew's War Memorial Hospital	☐	☐	☐
Wesley Hospital	☐	☐	☐
Private Practice	☐	☐	☐
Non-profit organisation	☐	☐	☐
Other (please specify): _____	☐	☐	☐

We really appreciate your participation in this phase of the research project.

Your ongoing participation is important to us.

If you are interested in participating in subsequent steps of this research project, please provide your contact details.

Email: . . . .

Phone: . . . .

Thank you for your participation!

Version 1.2, 23/08/2007
Page 1 of 1

Concept Systems GLOBAL

hide menu | signed in as **danette** | sign out | save | cancel | home | help

Health professionals' perspectives on services for patients with brain tumours:

Welcome to our project, which aims to explore staff perceptions of elements of care for persons with brain tumours.

Thanks to those who have already participated in brainstorming elements of care. If you are new to this project, welcome.

This project involves 3 short activities. Firstly, please complete the 5 simple demographic questions to allow us to describe our participants. (Please note, these will not be used to identify individual participants). The second activity involves sorting elements of care into categories based on meaning or similarity. The third activity involves rating each element as to how important and feasible it is and the extent to which it currently is offered to patients.

We expect these activities to take a maximum of 45 minutes to complete in total. You can complete these activities in one session or over many, but please don't forget to save your work. The '**save**', '**cancel**', '**home**' and '**help**' keys at the top right of the screen as well as the menu on the left will help you find your way.

If you have any difficulties or questions about this project, please contact Danette Langbecker via phone: (07) 3138 5817 or email: d.langbecker@qut.edu.au.

Please click the '**Accept**' button below to indicate that you consent to participate in this project. Your participation is voluntary and your input confidential.

Accept Reject

Project Administrator: Danette Langbecker
Organization: School of Public Health, Queensland University of Technology
Address: Kelvin Grove
Address 2: Queensland
City State Zip: Ph: (07) 3138 5817 na 4059
E-Mail Address: d.langbecker@qut.edu.au

Project Home

Basic demographic questions
status: *OPEN*

Sorting
status: *OPEN*

Rating: Importance
status: *OPEN*

Rating: Feasibility
status: *OPEN*

Rating: Existence
status: *OPEN*

My Account

Edit Profile

Change Password

Sign out

Health professionals' perspectives on services for patients with brain tumours: Home

You have accepted this project.

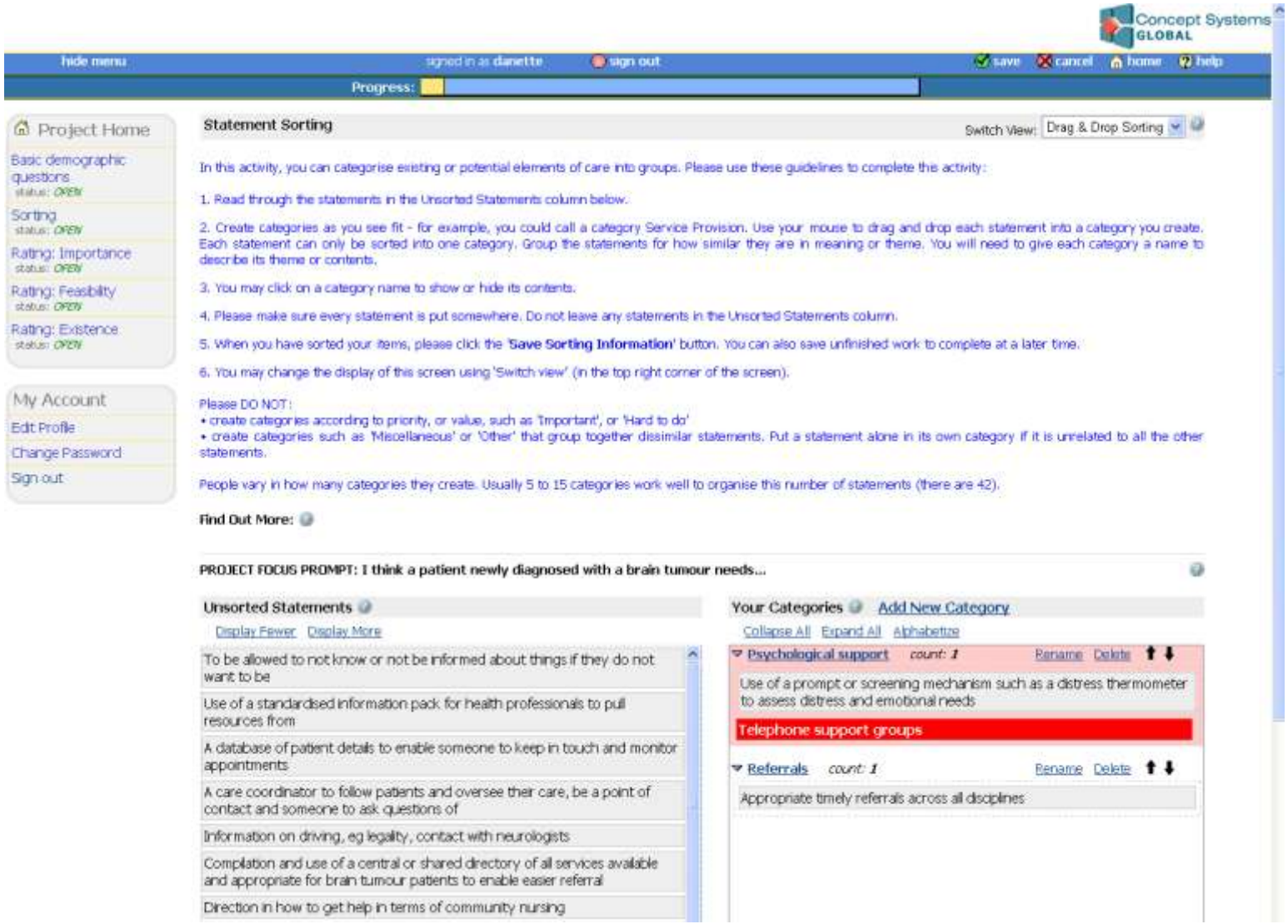
This page lists your project activities and shows you what activities are left to be completed. You can return to this screen at any time using the '**home**' key at the top right of the screen. Please save your anwers before returning to this page.

If at any stage you are unsure what to do, click on the circled question mark on the top right hand corner of the screen for help.

When you see no activities remaining, you have completed this phase of the research project - thank you! We will be in touch about further research activities and results.

NEXT STEPS:

1. Basic demographic questions
2. Sorting
3. Rating: How important is this service element?
4. Rating: How feasible is this service?
5. Rating: To what extent is this already provided?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signed in as danette
sign out
save
cancel
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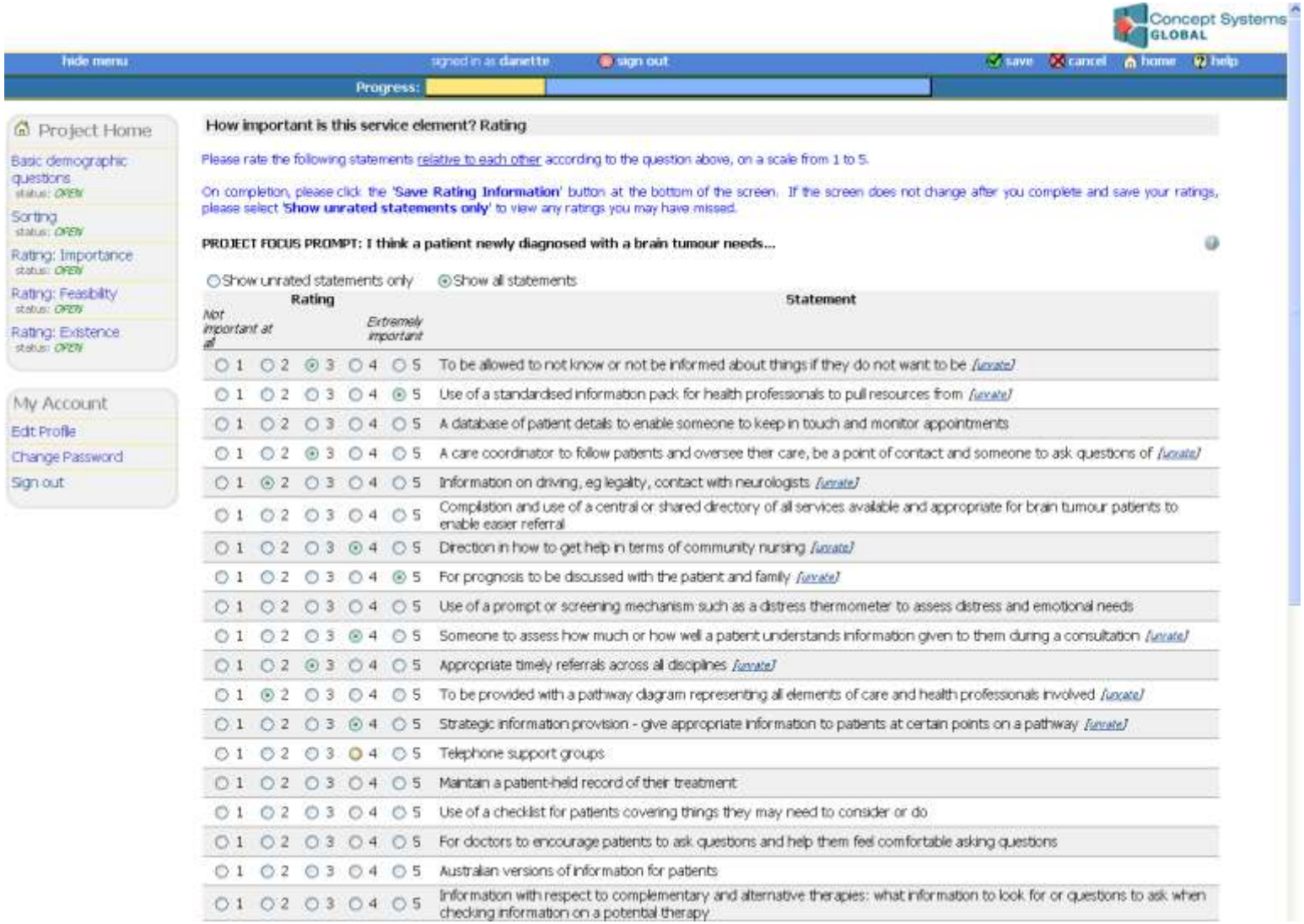
help
Progress:
Project Home
Basic demographic questions
status: OPEN
Sorting
status: OPEN
Rating: Importance
status: OPEN
Rating: Feasibility
status: OPEN
Rating: Existence
status: OPEN
My Account
Edit Profile
Change Password
Sign out
Statement Sorting
Switch View: Drag & Drop Sorting
In this activity, you can categorise existing or potential elements of care into groups. Please use these guidelines to complete the activity:
1. Read through the statements in the Unsorted Statements column below.
2. Create categories as you see fit - for example, you could call a category Service Provision. Use your mouse to drag and drop each statement into a category you create. Each statement can only be sorted into one category. Group the statements for how similar they are in meaning or theme. You will need to give each category a name to describe its theme or contents.
3. You may click on a category name to show or hide its contents.
4. Please make sure every statement is put somewhere. Do not leave any statements in the Unsorted Statements column.
5. When you have sorted your items, please click the 'Save Sorting Information' button. You can also save unfinished work to complete at a later time.
6. You may change the display of this screen using 'Switch view' (in the top right corner of the screen).
Please DO NOT:
• create categories according to priority, or value, such as 'Important', or 'Hard to do'
• create categories such as 'Miscellaneous' or 'Other' that group together dissimilar statements. Put a statement alone in its own category if it is unrelated to all the other statements.
People vary in how many categories they create. Usually 5 to 15 categories work well to organise this number of statements (there are 42).
Find Out More:
PROJECT FOCUS PROMPT: I think a patient newly diagnosed with a brain tumour needs...
Unsorted Statements
Display Fewer
Display More
To be allowed to not know or not be informed about things if they do not want to be
Use of a standardised information pack for health professionals to pull resources from
A database of patient details to enable someone to keep in touch and monitor appointments
A care coordinator to follow patients and oversee their care, be a point of contact and someone to ask questions of
Information on driving, eg legality, contact with neurologists
Compilation and use of a central or shared directory of all services available and appropriate for brain tumour patients to enable easier referral
Direction in how to get help in terms of community nursing
Your Categories
Add New Category
Collapse All
Expand All
Alphabetize
Psychological support count: 1
Rename
Delete
Use of a prompt or screening mechanism such as a distress thermometer to assess distress and emotional needs
Telephone support groups
Referrals count: 1
Rename
Delete
Appropriate timely referrals across all disciplines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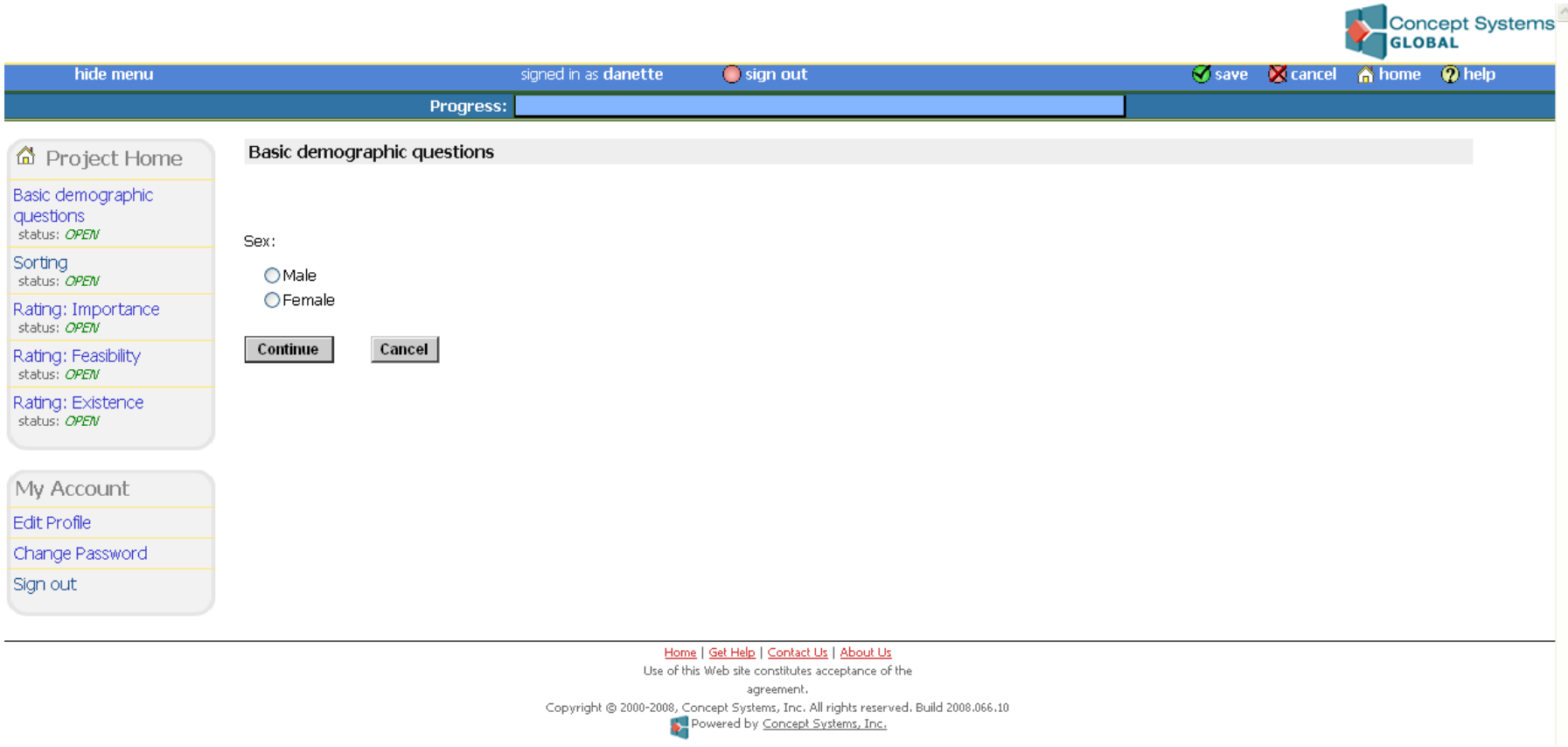
Progress:
Project Home
Basic demographic questions
status: OPEN
Sorting
status: OPEN
Rating: Importance
status: OPEN
Rating: Feasibility
status: OPEN
Rating: Existence
status: OPEN
My Account
Edit Profile
Change Password
Sign out
How important is this service element? Rating
Please rate the following statements relative to each other according to the question above, on a scale from 1 to 5.
On completion, please click the 'Save Rating Information' button at the bottom of the screen. If the screen does not change after you complete and save your ratings, please select 'Show unrated statements only' to view any ratings you may have missed.
PROJECT FOCUS PROMPT: I think a patient newly diagnosed with a brain tumour needs...
Show unrated statements only
Show all statements
Rating
Not important at all
Extremely important
Statement
1 2 3 4 5 To be allowed to not know or not be informed about things if they do not want to be [unrate]
1 2 3 4 5 Use of a standardised information pack for health professionals to pull resources from [unrate]
1 2 3 4 5 A database of patient details to enable someone to keep in touch and monitor appointments
1 2 3 4 5 A care coordinator to follow patients and oversee their care, be a point of contact and someone to ask questions of [unrate]
1 2 3 4 5 Information on driving, eg legality, contact with neurologists [unrate]
1 2 3 4 5 Compilation and use of a central or shared directory of all services available and appropriate for brain tumour patients to enable easier referral
1 2 3 4 5 Direction in how to get help in terms of community nursing [unrate]
1 2 3 4 5 For prognosis to be discussed with the patient and family [unrate]
1 2 3 4 5 Use of a prompt or screening mechanism such as a distress thermometer to assess distress and emotional needs
1 2 3 4 5 Someone to assess how much or how well a patient understands information given to them during a consultation [unrate]
1 2 3 4 5 Appropriate timely referrals across all disciplines [unrate]
1 2 3 4 5 To be provided with a pathway diagram representing all elements of care and health professionals involved [unrate]
1 2 3 4 5 Strategic information provision - give appropriate information to patients at certain points on a pathway [unrate]
1 2 3 4 5 Telephone support groups
1 2 3 4 5 Maintain a patient-held record of their treatment
1 2 3 4 5 Use of a checklist for patients covering things they may need to consider or do
1 2 3 4 5 For doctors to encourage patients to ask questions and help them feel comfortable asking questions
1 2 3 4 5 Australian versions of information for patients
1 2 3 4 5 Information with respect to complementary and alternative therapies: what information to look for or questions to ask when checking information on a potential therapy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Project Home
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Sorting
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Rating: Importance
status: OPEN
Rating: Feasibility
status: OPEN
Rating: Existence
status: OPEN
My Account
Edit Profile
Change Password
Sign out
Basic demographic questions
Sex:
Male
Female
Continue
Cancel
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How can we improve information delivery for patients newly diagnosed with brain tumours?

Danette Langbecker

A little about me…

B Health Science (Public Health),
Master of Applied Science (Research) Scholar

Interested in cancer recovery & survivorship

Involved in earlier study needs of brain tumour pts

And about this study…

From the study with patients & carers → information

Thought it important to investigate the views of those involved in caring for this patient group

Have collected ideas from you – now let's choose a target to start at

The story so far

Brainstorming:

"In your opinion, what might improve the situation for someone newly diagnosed with a brain tumour?"

For each idea:

3 ratings - scale of 1 – 5:

- "how important is this service?"
- "how feasible is this service?"
- "to what extent is this service currently provided?"

And finally…

"Sort the ideas into categories in a way that makes sense to you"

What are we going to discuss today?

Rating scores
- why do the rating scores for some ideas vary so much?
- what might be a barrier/facilitator to implementation?

Map showing how the ideas fit together
- what does this tell us about how information relates to other elements of care?

Rating scores – Importance vs feasibility

Rating scores

A plan of action for what to do if something goes wrong (# 23)

Average rating scores
- importance: v high
- feasibility: v high
- existence: ranged from low to v high

Rating scores

A care coordinator to follow patients & oversee their care, be a point of contact & someone to ask questions of (# 4)

Average rating scores
- importance: v high
- feasibility: ranged from v low to v high
- existence: high

Rating scores

Someone to assess how much or how well a patient understands information given to them during a consultation (# 10)

Average rating scores
- importance: low
- feasibility: ranges from v low to v high
- existence: v low

Rating scores

To be provided with a pathway diagram representing all elements of care & health professionals involved (# 12)

Average rating scores
- importance: medium
- feasibility: low
- existence: v low

Rating scores

Information about what to do before having surgery (eg wills, bank accounts)
(# 30)

Average rating scores

- importance: v low
- feasibility: v high
- existence: medium

Rating scores

Ascertainment of the medium most suitable for a patient to receive information during taking of patient history
(# 42)

Average rating scores

- importance: ranged from v low to high
- feasibility: v low
- existence: low

Rating scores

A 'how to' manual for caregivers on dealing with mood swings, behaviour changes, cognitive deficits & on learning coping skills
(# 41)

Average rating scores

- importance: high
- feasibility: high
- existence: medium

Rating scores

Modeling for carers on how to respond to challenging behaviours, and opportunities to practice these strategies
(# 20)

Average rating scores

- importance: ranged from low to v high
- feasibility: ranged from low to high
- existence: ranged from v low to high

Rating scores

Maintain a patient-held record of their treatment
(# 15)

Average rating scores

- importance: ranged from low to high
- feasibility: v low
- existence: low

Rating scores

A database of patient details to enable someone to keep in touch & monitor appointments
(# 3)

Average rating scores

- importance: ranged from low to v high
- feasibility: ranged from v low to v high
- existence: low

Rating scores

Compilation & use of a central or shared directory of all services available & appropriate for brain tumour patients to enable easier referral
(# 6)

Average rating scores

- importance: ranged from low to v high
- feasibility: ranged from v low to v high
- existence: v low

Rating scores

Information about clinical trials
(# 25)

Average rating scores

- importance: low
- feasibility: ranged from v low to v high
- existence: medium

Rating scores

Information to enable the patient or carer to ask questions
(# 34)

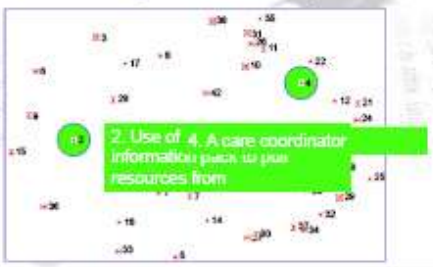
Average rating scores

- importance: high
- feasibility: ranged from low to v high
- existence: v high

And now for something completely different!

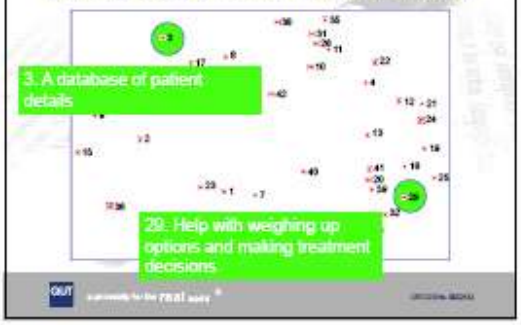
But before we move on,
are there any other ideas
anyone would like to discuss?

Sorting of ideas → map



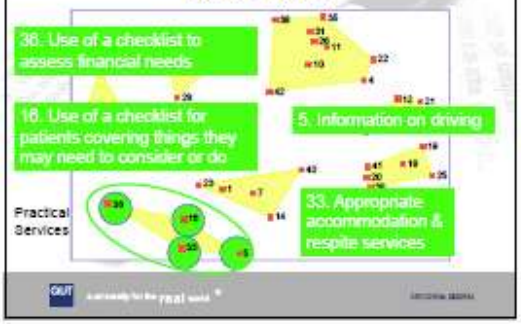
Conceptually *similar* ideas are close

Conceptually *different* ideas are distant



Similar ideas can form groups or *clusters*

Name clusters



How does info relate to other clusters?

Thank you so very much for your time & input!

Cluster: Tools for health professionals

15. Maintain a patient-held record of their treatment
9. Use of a prompt or screening mechanism such as a distress thermometer to assess distress & emotional needs
6. Compilation & use of a shared directory of all services available & appropriate for brain tumour patients to enable easier referral
2. Use of a standardised information pack for health professionals to pull resources from

Cluster: Psychological support

3. A database of patient details to enable someone to keep in touch and monitor appointments
8. For prognosis to be discussed with the patient & family
17. For doctors to encourage patients to ask questions and help them feel comfortable asking questions
28. For a support person to be present whilst the diagnosis is received

Cluster: Specialist services

38. Training for non-specialist staff about how brain tumour patients are different from other cancer patients
35. Credentialing of brain tumour surgery as a subspecialty in neurosurgery
31. Staff to be trained on how to communicate
29. Referral to palliative care whilst receiving active treatment
42. Ascertainment of the medium most suitable for a patient to receive information during taking of patient history
22. Specialists to refer patients to advocacy groups and networks
10. Someone to assess how much or how well a patient understands information given to them during a consultation
11. Appropriate timely referrals across all disciplines
4. A care coordinator to follow patients and oversee their care, be a point of contact & someone to ask questions of

Cluster: Multidisciplinary care

12. To be provided with a pathway diagram representing all elements of care & health professionals involved
13. Strategic information provision - give appropriate information to patients at certain points on a pathway
21. For patients and families to be informed about the different staff members and their roles – what they do & why they do it - so they can understand the system
24. More information shared about the positioning of the tumour & the deficits that may occur because of its positioning

Cluster: Family support

18. Australian versions of information for patients
19. Information with respect to complementary and alternative therapies: what information to look for or questions to ask when checking information on a potential therapy
20. Modeling for carers on how to respond to challenging behaviours, & opportunities to practice these strategies
25. Information about clinical trials
39. Awareness/information days for patients, family and friends
41. A "how to" manual for caregivers on dealing with mood swings, behaviour changes, cognitive deficits, physical deficits and on learning coping skills

Cluster: Information

27. Guidance for seeking information on the Internet
29. Help with weighing up options & making treatment decisions
30. Information about what to do before having surgery (eg wills, bank accounts)
32. Information on how to ask for a second opinion
34. Information to enable the patient or carer to ask questions
37. Information on the process that is going to be undertaken while they are in hospital & after

Cluster: Communication

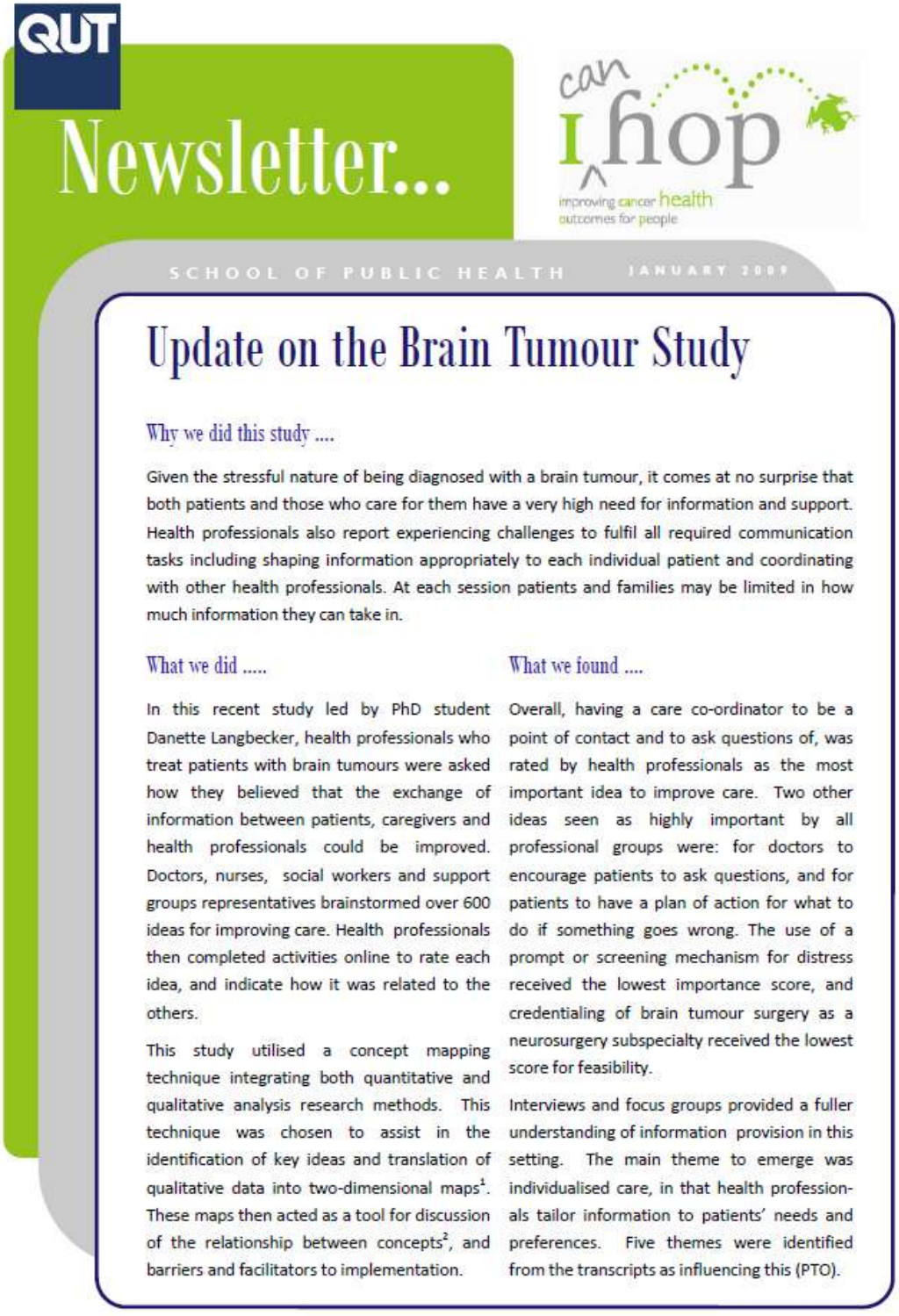
1. To be allowed to not know or not be informed about things if they do not want to be
7. Direction in how to get help in terms of community nursing
14. Telephone support groups
23. A plan of action for what to do if something goes wrong
40. To be prepared for future events such as tumour recurrence

Cluster: Practical services

5. Information on driving, eg legality, contact with neurologists
16. Use of a checklist for patients covering things they may need to consider or do
33. Appropriate accommodation & respite services
36. Use of a checklist to assess the financial needs of the patient and family

APPENDIX F.

STUDY 1 PARTICIPANT NEWSLETTER



QUT

Newsletter...

can I hop

improving cancer health outcomes for people

SCHOOL OF PUBLIC HEALTH JANUARY 2009

Update on the Brain Tumour Study

Why we did this study ....

Given the stressful nature of being diagnosed with a brain tumour, it comes at no surprise that both patients and those who care for them have a very high need for information and support. Health professionals also report experiencing challenges to fulfil all required communication tasks including shaping information appropriately to each individual patient and coordinating with other health professionals. At each session patients and families may be limited in how much information they can take in.

What we did .....

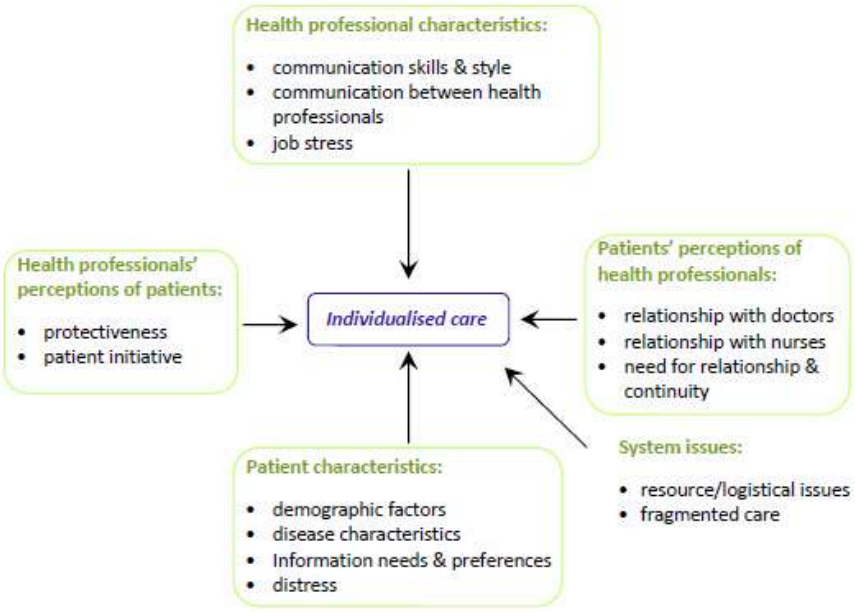
In this recent study led by PhD student Danette Langbecker, health professionals who treat patients with brain tumours were asked how they believed that the exchange of information between patients, caregivers and health professionals could be improved. Doctors, nurses, social workers and support groups representatives brainstormed over 600 ideas for improving care. Health professionals then completed activities online to rate each idea, and indicate how it was related to the others.

This study utilised a concept mapping technique integrating both quantitative and qualitative analysis research methods. This technique was chosen to assist in the identification of key ideas and translation of qualitative data into two-dimensional maps[1]. These maps then acted as a tool for discussion of the relationship between concepts[2], and barriers and facilitators to implementation.

What we found ....

Overall, having a care co-ordinator to be a point of contact and to ask questions of, was rated by health professionals as the most important idea to improve care. Two other ideas seen as highly important by all professional groups were: for doctors to encourage patients to ask questions, and for patients to have a plan of action for what to do if something goes wrong. The use of a prompt or screening mechanism for distress received the lowest importance score, and credentialing of brain tumour surgery as a neurosurgery subspecialty received the lowest score for feasibility.

Interviews and focus groups provided a fuller understanding of information provision in this setting. The main theme to emerge was individualised care, in that health professionals tailor information to patients' needs and preferences. Five themes were identified from the transcripts as influencing this (PTO).



Where to from here?

Although a care coordinator was rated as the most important idea to improve information by participants, the potential of interventions to assist doctors to encourage question asking was also highlighted. This idea has been chosen for further development given its lower resource requirements. As such, this study has led to the planning of a brain tumour specific question prompt list (QPL). A QPL is a list of questions that patients can use as a guide, to suggest questions that they may wish to ask their doctors and other health professionals. This can assist patients to communicate their information needs and preferences to their treating team, who can then better individualise the information they provide. This can also be used by doctors and other health professionals to help patients to feel comfortable asking questions. The development of such a resource is now underway.

The ihop Research Team

From left (back): Josie Auster, Sheree Harrison, Danette Langbecker, Melissa Newton, Loretta McKinnon, Monika Janda, Abbey Hamilton, Linda Finch. (Front): Sandi Hayes, Tracey Di Sipio.

References...

1. Johnsen, J. A., D. E. Biegel, et al. (2000). "Concept mapping in mental health: uses and adaptations." Evaluation & Program Planning 23: 67-75.2).

2. Trochim, W. (1989). "An introduction to concept mapping for planning and evaluation." Evaluation & Program Planning 12(1): 1-16.

APPENDIX G.

STUDY 2 HUMAN RESEARCH ETHICS COMMITTEE APPROVALS

University Human Research Ethics Committee
HUMAN ETHICS APPROVAL CERTIFICATE
NHMRC Registered Committee Number EC00171

Dear Ms Danette Langbecker

A UHREC should clearly communicate its decisions about a research proposal to the researcher and the final decision to approve or reject a proposal should be communicated to the researcher in writing. This Approval Certificate serves as your written notice that the proposal has met the requirements of the *National Statement on Research involving Human Participation* and has been approved on that basis. You are therefore authorized to commence activities as outlined in your proposal application, subject to any specific and standard conditions detailed in this document.

Within this Approval Certificate are:

* Project Details
* Participant Details
* Conditions of Approval (Specific and Standard)

Researchers should report to the UHREC, via the Research Ethics Officer, events that might affect continued ethical acceptability of the project, including, but not limited to:

(a) serious or unexpected adverse effects on participants; and
(b) proposed significant changes in the conduct, the participant profile or the risks of the proposed research.

Further information regarding your ongoing obligations regarding human based research can be found via the Research Ethics website http://www.research.qut.edu.au/ethics/ or by contacting the Research Ethics Coordinator on 07 3138 2340 or ethicscontact@qut.edu.au

If any details within this Approval Certificate are incorrect please advise Research Ethics within 10 days of receipt of this certificate.

Research Ethics Officer _____ Date 19/3/08
(on behalf of the Chairperson, UHREC)

Project Details

Category of Approval:	Human Ethics Level 1	Confirmed Low Risk
Approved Until:	18/03/2011	
Approval Number:	0800000079	
Project Title:	It's okay to ask: development of a question sheet to help patients diagnosed with brain tumours and their families	
Project Chief Investigator:	Ms Danette Langbecker	

Other Project Staff/Students:
Dr Monika Janda , Prof Patsy Yates

Experiment Summary:
Develop a brain tumour specific question prompt lists (QPLs) to establish desired content, language and format for adult patients newly diagnosed with a brain tumour and their caregivers, and determine preferred timing and methods for QPL distribution.

Participant Details

Participants:
Approximately 40 (20 patients and 20 cargivers)

Location/s of the Work:
QUT

RM Report No. E601 Version 2

University Human Research Ethics Committee

HUMAN ETHICS APPROVAL CERTIFICATE

NHMRC Registered Committee Number EC00171

Conditions of Approval

Specific Conditions of Approval:
No special conditions placed on approval by the UHREC. Standard conditions apply.

Standard Conditions of Approval:

The University's standard conditions of approval require the research team to:

1. Conduct the project in accordance with University policy, NHMRC / AVCC guidelines and regulations, and the provisions of any relevant State / Territory or Commonwealth regulations or legislation;

2. Respond to the requests and instructions of the University Human Research Ethics Committee (UHREC);

3. Advise the Research Ethics Officer immediately if any complaints are made, or expressions of concern are raised, in relation to the project;

4. Suspend or modify the project if the risks to participants are found to be disproportionate to the benefits, and immediately advise the Research Ethics Officer of this action;

5. Stop any involvement of any participant if continuation of the research may be harmful to that person, and immediately advise the Research Ethics Officer of this action;

6. Advise the Research Ethics Officer of any unforeseen development or events that might affect the continued ethical acceptability of the project;

7. Report on the progress of the approved project at least annually, or at intervals determined by the Committee;

8. (Where the research is publicly or privately funded) publish the results of the project is such a way to permit scrutiny and contribute to public knowledge; and

9. Ensure that the results of the research are made available to the participants.

Modifying your Ethical Clearance:

The University has an expedited mechanism for the approval of minor modifications to an ethical clearance (this includes changes to the research team, subject pool, testing instruments, etc). In practice this mechanism enables researchers to conduct a number of projects under the same ethical clearance.

Any proposed modification to the project or variation to the ethical clearance must be reported immediately to the Committee (via the Research Ethics Officer), and cannot be implemented until the Chief Investigator has been notified of the Committee's approval for the change / variation.

Requests for changes / variations should be made in writing to the Research Ethics Officer. Minor changes (changes to the subject pool, the use of an additional instrument, etc) will be assessed on a case by case basis and interim approval may be granted subject to ratification at the subsequent meeting of the Committee.

It generally takes 7 -14 days to process and notify the Chief Investigator of the outcome of a request for a minor change / variation.

Major changes to your project must also be made in writing and will be considered by the UHREC. Depending upon the nature of your request, you may be asked to submit a new application form for your project.

Audits:

All active ethical clearances are subject to random audit by the UHREC, which will include the review of the signed consent forms for participants, whether any modifications / variations to the project have been approved, and the data storage arrangements.

End of Document

UnitingCare Health

Human Research Ethics Committee

ABN: 87 842 457 440

1st Floor Moorlands House, The Wesley Hospital
451 Coronation Drive, Auchenflower Q 4066

PO Box 499 Toowong Q 4066
Phone: 3232 7500 Facsimile: 3232 7109
Email: ethics@uchealth.com.au

29th August 2008

Please quote our reference: 200836

Ms Danette Langbecker
Queensland Institute of Technology
IHBI School of Public Health
Victoria Park Road
KELVIN GROVE QLD 4059

Dear Ms Langbecker

RESEARCH PROPOSAL: *It's okay to ask: development of a question sheet to help patients diagnosed with brain tumours and their families*

I am pleased to advise that the UnitingCare Health Human Research Ethics Committee has reviewed the abovenamed research proposal and, at its meeting on 28th August 2008, granted ethical approval, subject to changes requested by the Committee to the Patient Information Sheet and Consent Form. Thank you for your response to those requirements. I am now able to confirm approval.

If your project involves inpatients or the use of hospital facilities, it will be necessary for you to obtain the approval of the Director of Medical Services before commencement.

It is a strict condition of approval that any departure from the protocol detailed in the proposal submitted for approval be reported immediately to the Committee. If there is any change to the status of the project, this should be reported also.

Approval for the project is given subject to your agreement to UnitingCare Health requirements for the monitoring of research, which have been based on the Australian Health Ethics Committee guidelines, a copy of which is enclosed. Please note the requirement to submit a report annually or at the completion of the project, as appropriate.

With best wishes

Yours sincerely

Douglas Killer MBBS FRACP
Executive Officer

APPENDIX H.

STUDY 2: SOURCES USED FOR OR EXCLUDED FROM THEMATIC ANALYSIS

QPLs not used in study 2 and reasons for exclusion

Hagerty, R., P. Butow, and M. Tattersall, *A pilot of a question prompt list to facilitate communication about prognosis in first and second oncology consultations.* Asia-Pac J Clin Oncol, 2005. **1**(Suppl): p. A26.
- abstract only

Ellis, P.M., S. Dimitry, G. Browman, and T.J. Whelan, *Cancer patients and the Internet: a randomized controlled trial (RCT) evaluating an intervention to facilitate physician and patient information exchange from the Internet.* Journal of Clinical Oncology, 2004. **22**(14S): p. abstr 6139.
- abstract only

Butow, P., R. Devine, M. Tattersall, M. Boyer, S. Pendlebury, and M. Jackson, *Preparing patients for oncology consultations: a randomised controlled trial of patient activation materials.* Proc Am Soc Clin Oncol, 2003. **22**: p. 2004 (abstr 2109).
- abstract only

Davison, B.J. and L.F. Degner, *Empowerment of men newly diagnosed with prostate cancer.* Cancer Nurs, 1997. **20**(3): p. 187-96.
- QPL not included

Source used in thematic analysis for study 2:

Selected ideas relevant to patient information from Study 1

Method of identifying relevant ideas (those relevant to patient information):

- Ideas that said 'information about', 'tell patient', 'help patient understand', 'inform patient', 'discuss with patient' or similar were included;
- Ideas that discussed changing patterns of care (for example, referring patient to a type of health professional, or inclusion of a care coordinator) or structural items were excluded'
- In situations of uncertainty, items were discussed with a second researcher (JA), and agreement reached.

Relevant ideas that were subjected to thematic analysis for study 2:

- ❖ information on navigating information on the internet
- ❖ information for patients with respect to complementary and alternative therapies: what information to ask, or look out for, when you're checking information on that particular topic
- ❖ help trying to make sense of the terminology
- ❖ help understanding the difference between all the health professionals
- ❖ information on practical issues such as where to park
- ❖ inform people of the resources and services that are available
- ❖ tell people what to expect when they go for treatment
- ❖ tell people what to look out for and be concerned about
- ❖ tell people who the key "gatekeepers" are to contact
- ❖ tell patients of resources available
- ❖ someone to tell people where to park, where to stay when travelling for treatment, where they will go
- ❖ patients given opportunity to ask relevant questions of health care providers (eg timeframe of life, manner of death, other options)
- ❖ patients given written information about their diagnosis, including pronunciation of the tumour type, and professionally developed diagrams showing tumour location

- more information shared with patients about the positioning of the tumour and the deficits that may or may not occur because of the positioning of the tumour in a particular lobe
- more information for patients about potential for problems with memory, behaviour changes, mood swings
- appropriate timely information for families of patients with frontal lobe tumours about potential deficits and changed behaviours to assist them in understanding that there may be some deficits that never right themselves
- assistance for families to help them understand that their loved one may never ever resume their pre-tumour function
- "how to" manual for caregivers on dealing with mood swings, behaviour changes, cognitive deficits, physical deficits
- help for children in dealing with changes in a parent following diagnosis of a brain tumour
- patients able to call a person/team to ask questions regarding medications, side effects, etc, and appropriate staff member re-contacts them
- patients provided with information about what to expect and what is "normal"
- patients informed of the support services available
- make patients aware of the possible costs under private or public hospital treatment before treatment commences
- give patients the option to and encourage them to have second opinions (in a different hospital or centre if desired)
- let people know all their treatment options
- do not keep patients in the dark as to their condition
- after telling a patient that 'this is what we think it is', then tell them that this was confirmed or not
- guidance for patients seeking information on the internet
- information for patients on feelings they may experience and what to expect
- inform people about what you might expect about radiotherapy and chemotherapy

- for neurosurgeon to inform family of a patient about their likely prognosis with precision (but also realistic hope)
- provide patients with written information about what to do about their dylantin levels
- provide patients with written information about who to call
- provide patients with written information about who to depend on
- provide patients with written information about the Cancer Council
- provide patients with written information about conference calls available for patients and for carers
- give patients the name of Brain Tumour Australia
- provide patients with information about what to do before they have surgery (eg wills, bank accounts)
- tell patients and families about the carer's allowance
- give patients information about counsellors
- for families to call the Epileptic Foundation, who will come out to their home and give them a demonstration of what to do if the patient has a fit
- tell patients that there is a possibility that they may fit and what to do after and about their anticonvulsants
- provide information for families about how to talk to your kids about a parent's cancer
- provide patients with kids with information about Canteen, which can provide children of patients with brain tumours with help coping, caring, bereavement
- tell carers to get help from carers' associations
- make patients aware of the legal ramifications of driving once diagnosed
- encourage people to seek practical help (eg driving to appointments) from their church, family and community, as people often want to help
- tell patients about mouth care
- books for patients and families to read about what they are diagnosed with and potential treatments
- guidance on websites that are reliable
- help for family to work out what is going to happen to the rest of the family (eg in terms of work, the future)

- discuss prognosis with patient and family
- prepare patients for future events such as tumour recurrence
- explain to patients and families the different medical professionals and their roles
- more information for carers about cognitive impairment and how to manage patients at home
- practical help for families to teach them to care for patients at home
- tell people how to cope with the shock of diagnosis
- information on how to deal with it with the children – how much info at their age they could understand, and what would be fair for them
- brochures with ideas on how to approach kids (of patients) with the knowledge they need to know and what they may or may not understand
- guidelines for what you need to enquire about and what to do to get Centrelink assistance
- checklist for patients covering things they may need to consider or do
- information about bereavement and what you need to do
- information about palliative care
- contacts and phone numbers for services people might need
- tell people that they are eligible to Centrelink payments, for the patient and carer
- advice about how to deal with financial pressures
- literature for small children about brain tumours
- information particular to brain tumours to explain to children about it and what it is like in a language that they can understand
- someone with information about what to expect
- information about whether a tumour could grow again, whether it could become malignant, and how long side effects would last
- doctors or specialists to make patients more aware of support services
- tell people you can organise to have blood tests taken at home
- information about the tumour and types of treatment the doctor suggests
- information about how doctors plan to operate if desired
- information about supportive care available in the school setting

- information about what is coming up and what to expect
- information about the ongoing costs of doctors, appointments, medicines
- information about both survival and long term effects of different treatments
- tell people what services are available
- be informed on the prognosis
- information about organ donation if desired
- legal advice
- tell people what is out there and what might be available to them
- information about alternative medicines
- information about what patients can do for themselves to get healthy
- information about how to deal with possible side effects of medication
- dietary advice
- specific data based on a doctor's own files or experience, rather than average national or global data
- tell carers/family about potential memory problems and brain injury
- tell carers possible symptoms and what to look for
- a person to talk to patients and family about treatment options before surgery
- information to know how to deal with seizures, what it would be like and what to expect
- information about nutrition
- information about what was happening after surgery, such as side effects
- tell people about taxi vouchers
- detailed info about the tumour and treatment
- more information about all the possibilities and dangers involved of treatments
- information to prepare patients for the side effects of radiation
- information about what to do next after the current phase of treatment
- information about where to go for help and support
- information about seizures and their management
- suggestions about how to cope
- information right at the beginning to enable coping

- information about The Cancer Council Queensland
- information about memory testing
- complete list of services and support groups and information sources given to patients at each neurology or radiation oncology ward
- someone to explain to patients what palliative care offers and who is eligible
- education about medication – what does it do, what are possible side effects
- strategies for managing memory loss
- financial advice
- knowledge about what government services are available
- prepare patients and families who need to travel from the country for possible delays in returning
- information on brain tumours' affects and likely progression
- information about potential impacts of procedures, drugs and drug interactions
- travel and accommodation information
- information about what is covered by insurance and what is not, and what is and is not covered by Medicare
- prepare carers for what to expect, what could happen, dealing with side effects
- plan with carers to ensure they can get parking, attend patients' appointments, etc
- ensure carers know who to call if they have questions or need information
- inform patients and families about the different staff members and their roles - what they do and why they do it, so they can understand the system
- staff to explain their role and why they are involved
- provide each patient with a pathway - a diagram representing all elements of care and health professionals involved - and go through it with them in the initial consultation, to pave for who staff are and what they'll be doing later
- provide patients with a written care plan
- information booklets with info and contact details
- tell people about transport services available
- help people work out how to get to hospital, treatment centres, etc

- counseling to help people make decisions about work
- basic information about the city and how to go about doing the things you do for those who must travel for treatment
- preoperative education sessions for patients and families diagnosed early enough to educate about services available and what to expect
- give people information about existential issues
- give people info about practical issues
- let patients who go through the private sector know about what services are available
- tell patients in private sector what to ask to get access to allied health services
- tumour specific information
- improve knowledge and access to services that can be accessed after discharge
- tell patients about services and that they are entitled to them
- ensure patients are fully informed about their diagnosis
- make sure patients with cancer are aware that they have it
- information about what to expect
- information about the uncertainty surrounding diagnosis and the future
- access to information for carers
- access to information about the type of tumour
- information about new treatments
- information about clinical trials
- information specifically for people with benign tumours
- communication to help people understand when nothing can be done
- tell people with benign tumours that they can access the Cancer Council
- tell people with benign tumours about information and services available
- tell people where they can look for information
- tell people where they can look for credible internet-based information
- specialists to tell patients of support groups
- specialists to tell patients of websites where they can have online support
- specialists to tell patients of telephone support groups
- good info about tests and what tests mean

- let people know there are different types of support, such as attend a support group, telephone group, other types of support
- good clear information about complementary and alternative information
- give info on the process that is going to be undertaken while they are in hospital and after – the stages of diagnosis, surgery, radiotherapy & chemotherapy
- give information on the process of end-of-life issues
- prepare people for what to expect at the end of life and how it is going to unfold
- give information about prognosis and what to expect
- give information about the plan of treatment
- give patients a plan of action for what to do if something goes wrong
- explain to patients who is in charge of different aspects of their care
- give information about side effects of the drugs and treatment
- explain what is normal, eg re fatigue
- explain useful ways for dealing with issues, eg fatigue
- explain how to access counselling services
- tell people about what the cancer council offers in terms of counselling, equipment hire, other supports
- direct in how to get help in terms of community nursing
- direct in how to get access to respite
- info on financial assistance
- info about Centrelink and what they are entitled to and how to access
- info on legal aspects such as how to organise wills and power of attorney
- info on how to get back to work
- info on how to get back to driving eg legality, contact with neurologists
- info for carers/family on how to deal with changes in behaviour, mood, concentration, memory in a patient
- give advice about how to cope with behavioural changes
- explain whilst in hospital about the functions of the affected lobe and prepare for what could possibly happen with it being disrupted
- explain what palliative care is and how to access it

- guidance on when to access palliative care
- guidance on when to stop treatment
- info on how to ask for a second opinion
- knowledge that they have a right to a second opinion

APPENDIX I.

STUDY 2 RECRUITMENT AND DATA COLLECTION DOCUMENTS

The following article appeared in the June 2008 newsletter of the Brain Tumour Support Service of The Cancer Council Queensland

Research Update

A care coordinator who knows the ins and outs of a patient, oversees their care, is a point of contact and someone to ask questions of, may be one way to greatly improve the care of someone newly diagnosed with a brain tumour, a researcher from the Queensland University of Technology says.

PhD student Danette Langbecker conducted brainstorming, online activities and interviews with 30 health professionals who treat, care for or otherwise support people diagnosed with brain tumours and their families. Danette was interested in understanding how they thought care for patients with brain tumours could be improved.

Doctors, nurses and social workers were enthusiastic of this topic and initially suggested over 600 ideas. Of those, three ideas were ultimately seen as most important to improve care and the most feasible to put into practice. Danette, who is based at the University's School of Public Health, said overall, health professionals rated a care coordinator as the most important idea for improving care. Two other ideas seen as highly important by all professional groups were for doctors to encourage patients to ask questions and help them feel comfortable asking questions, and for patients to have a plan of action for what to do if something goes wrong.

"Patients and their families have long identified a need for information and support. Often it is difficult to communicate their concerns to health professionals," Danette said. "But health professionals themselves are also experiencing communication difficulties, both between different professionals, and between health professionals and the people who they treat."

“Especially when someone is newly diagnosed, there is a lot of information to give and take in, and doctors and nurses worry about burdening a patient with too much information too fast. It is difficult for both patients and staff.”

Danette now plans to develop a question prompt list to facilitate communication between people newly diagnosed with a brain tumour and their doctors.

“A question prompt list is a list of questions that patients might want to ask their doctors,” Danette said. “Having a list of questions other people have found useful can make it easier to put your concerns into words, and help make sure you can find out what you want and need to know at each consultation. It helps you to plan ahead and gives you some guidance when going into your next discussion with a doctor.”

Danette is now seeking people who were diagnosed with a brain tumour and their families to participate in discussion groups in an effort to develop a question prompt list.

Adults aged 18 years and over who were diagnosed with a brain tumour in the past two years, or family or friends who provided support to such a person, are invited to participate in the discussion groups.

Contact Danette Langbecker on 3138 5817 or at d.langbecker@qut.edu.au

Asking questions during medical meetings

- Were you or a family member/friend diagnosed with a brain tumour in the last two years?
- Are you interested in attending a discussion meeting or speaking to me on the telephone to talk about the information you needed when first diagnosed?

People with other illnesses have found it helpful to have a list of questions to take to medical appointments. Your participation will help us develop a list of such questions for people newly diagnosed with a brain tumour and their families.

If you or someone you support/have supported was diagnosed with a brain tumour in the last two years, we would value your insight.

Would you like to know more?

Please contact Danette Langbecker on 07 3138 5817
Email: d.langbecker@qut.edu.au

This advertisement appeared as a flyer mailed out to members of the Brain Tumour Support Service of The Cancer Council Queensland together with their June newsletter in mid-June.

Copy of email sent to staff and postgraduate students at QUT in health-related domains (02 June 2008).

Flyer attached mentioned below is same as the advertising flyer that was mailed with the Brain Tumour Support Service Newsletter, together with the Participant information sheet.

Hi all,

Adults diagnosed with a primary brain tumour in the past two years, and family members or friends who provided support to such persons, are sought to participate in a new study that may improve communication between patients, families and their doctors.

The project seeks to develop a question prompt list, or list of questions that patients might want to ask their doctors. To develop this resource, participants are invited to share their ideas as to what information is needed or valuable in the period shortly after diagnosis.

Participation will involve one discussion group lasting about an hour, and the completion of a one-page questionnaire. Telephone interviews may also be arranged.

Participation in confidential and **all responses will remain anonymous**. Ethical clearance for this study has been granted (0800000079).

Please read the attached flyer or for more information, contact Danette Langbecker.
Phone: 3138 5817
Email: d.langbecker@qut.edu.au

Thank-you for all your help.

Danette Langbecker | PhD Scholar | School of Public Health/IHBI
Queensland University of Technology | Victoria Park Road, Kelvin Grove QLD 4059 Australia
ph: 07 3138 5817 | fax: 07 3138 3130 | email: d.langbecker@qut.edu.au
CRICOS No. 00213J

Letter sent to past patients of BrizBrain and Spine (printed on their letterhead), sent by their Brain Tumour Care Coordinator:

Dear Name,

I am writing to tell you about new research that aims to improve information available to people with brain tumours. Researchers at the Queensland University of Technology found that often patients newly diagnosed with a brain tumour would have liked to receive more and/or better information. These researchers now wish to develop a question prompt list, which lists common questions patients with a brain tumour may have asked if they had known more at the time of diagnosis. To compile this list, the researchers need your help.

The researchers would like to speak with people who have been diagnosed with a brain tumour in the past two years, and also family or friends who have provided support to the patients. Interested people can speak to the researchers in a discussion group or over the telephone.

Further information about this study is provided in the following documents. I know the researchers would very highly value your insight, and would like to kindly invite you to participate. I would also like to reassure you that your privacy and confidentiality will be respected, whether or not you choose to participate in this study. If you do not wish to participate, this will not affect your medical care in any way.

If you would like to know more, or to volunteer to participate in this study, please contact Danette Langbecker on 07 3138 5817.

Kind regards,

Vivien Biggs

QUT PARTICIPANT INFORMATION for QUT RESEARCH PROJECT

It's okay to ask:
development of a question sheet to help patients diagnosed with brain tumours and their families

Research Team Contacts

Ms Danette Langbecker
PhD Scholar
Phone: 07 3138 5817
Email: d.langbecker@qut.edu.au

Dr Monika Janda
Research Fellow
Phone: 07 3138 9674
Email: m.janda@qut.edu.au

Description

When diagnosed with a brain tumour there is a lot to take in about the tumour, treatment and where to get help. Many patients and families find it difficult to get the information they need. People with other illnesses have found it helpful to have a list of questions to take to medical appointments, to remind them of questions they may want to ask their doctor or nurse.

The purpose of this project is to develop such a question prompt list for people diagnosed with a brain tumour and their families. The research team requests your assistance to identify questions to appear on such a resource.

This project is being undertaken as part of a PhD project for Danette Langbecker. The project is funded by the Queensland University of Technology (QUT). QUT will not have access to individual data.

Participation

Your participation will involve a one-hour focus group and short questionnaire. Focus groups will involve patients or family members at a local public venue. Telephone discussions will also be arranged if needed.

Your participation in this project is voluntary. If you do agree to participate, you can withdraw from participation at any time during the project without comment or penalty. Your decision to participate will in no way impact upon your current or future relationship with QUT (for example your grades), or your current or future relationship with, care from or access to your healthcare providers. You will be informed in a timely manner of any changes to the research protocol that may affect your willingness to continue your participation.

Expected benefits & risks

It is expected that this project will not directly benefit you. However, it may benefit people diagnosed with a brain tumour and their families in the future.

This study involves discussing information requirements for patients and families. Some people may feel distressed or uncomfortable when discussing this topic, while others have found it a valuable experience. QUT provides for limited free counselling for research participants of QUT projects, who may experience some distress as a result of their participation in the research. Should you wish to access this service please contact the Clinic Receptionist of the QUT Psychology Clinic on 3138 4578. Please indicate to the receptionist that you are a research participant. The Cancer Council Queensland also provides a free helpline staffed by trained professionals who have knowledge about cancer and cancer care. They are there to help you with information, support and referrals to services throughout the state, and can be contacted on 13 11 20.

Confidentiality

All comments and responses are anonymous and will be treated confidentially. The names of individual persons are not required in any of the responses. You will not be required to verify your comments from the group session prior to inclusion in the final question sheet.

Consent to Participate

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate. Please post this to the research team in the envelope supplied or bring to your focus group.

Questions / further information about the project

Please contact the research team named above if you have any questions or would like further information.

Concerns / complaints regarding the conduct of the project

QUT is committed to researcher integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Officer on 3138 2340 or ethicscontact@qut.edu.au. The Research Ethics Officer is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

CONSENT FORM for QUT RESEARCH PROJECT

It's okay to ask:
development of a question sheet to help patients diagnosed with brain tumours and their families

Research Team Contacts

Ms Danette Langbecker
PhD Scholar
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Statement of consent

By signing below, you are indicating that you:

- have read and understood the information document regarding this project
- have had any questions answered to your satisfaction
- understand that if you have any additional questions you can contact the research team
- understand that you are free to withdraw at any time, without comment or any penalty in treatment and care
- understand that you can contact the Research Ethics Officer on 3138 2340 or ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project
- agree to be contacted again if further questions arise
- agree to participate in the project.

Name . . . . . .

Signature . . . . . .

Date . . . / _____ / . . .

I am a ☐ brain tumour survivor (please tick)

☐ support person of someone who has/had a brain tumour

Preferred contact telephone number(s) _____

Questionnaire: for persons diagnosed with a brain tumour

The following questions ask a little about you, and about your illness. Please choose the answer that best describes your situation.

About you

1. **Please indicate your gender:**
   - ☐ Male
   - ☐ Female

2. **What was your age at your last birthday?** _____ years

3. **Please indicate your marital status:**
   - ☐ Married or living together
   - ☐ Divorced
   - ☐ Separated
   - ☐ Widowed
   - ☐ Single (never married)

4. **What is the highest level of education you have completed?**
   - ☐ Not completed primary
   - ☐ Primary
   - ☐ Junior high
   - ☐ Senior high
   - ☐ Trade or certificate
   - ☐ University

5. **Please indicate the category that best describes your work status:**
   - ☐ Working as much as desired
   - ☐ Unable to work due to illness
   - ☐ Looking for work
   - ☐ Retired
   - ☐ Student
   - ☐ Home or caring duties
   - ☐ Other, please specify: _____

---------- Please turn over ----------

About your illness

6. **When were you first told you had a brain tumour?** _____ (month) _____ (year)

7. **Is the tumour malignant (cancer)?**
   - ☐ Yes
   - ☐ No
   - ☐ Don't know

8. **Is the tumour primary (originating in the brain) or secondary/metastatic (meaning it spread from another area)?**
   - ☐ Primary
   - ☐ Secondary/metastatic
   - ☐ Don't know

9. **Please indicate the type of brain tumour:**
   - ☐ Meningioma
   - ☐ Glioblastoma
   - ☐ Astrocytoma
   - ☐ Oligodendroglioma
   - ☐ Neuroma
   - ☐ Pituitary adenoma
   - ☐ Ependymoma
   - ☐ Other, please specify: _____
   - ☐ Don't know

10. **Which of the following therapies have been used against the brain tumour? (Tick all that apply)**
   - ☐ Surgical debulking (to remove part or all of the tumour)
   - ☐ Radiotherapy
   - ☐ Chemotherapy
   - ☐ None of the above
   - ☐ Don't know

Thank you for completing this questionnaire.

Questionnaire: for support persons of brain tumour patients

The following questions ask a little about you, and about the illness of the person you support. Please choose the answer that best describes your situation.

About you

1. **Please indicate your gender:**
   - ☐ Male
   - ☐ Female

2. **What was your age at your last birthday?** _____ years

3. **Please indicate your marital status:**
   - ☐ Married or living together
   - ☐ Divorced
   - ☐ Separated
   - ☐ Widowed
   - ☐ Single (never married)

4. **What is the highest level of education you have completed?**
   - ☐ Not completed primary
   - ☐ Primary
   - ☐ Junior high
   - ☐ Senior high
   - ☐ Trade or certificate
   - ☐ University

5. **Please indicate the category that best describes your work status:**
   - ☐ Working as much as desired
   - ☐ Unable to work due to illness
   - ☐ Looking for work
   - ☐ Retired
   - ☐ Student
   - ☐ Home or caring duties
   - ☐ Other, please specify: _____

---------- Please turn over ----------

About the person you support

6. **What is your relationship to the person diagnosed with a brain tumour?**

- ☐ Spouse/partner
- ☐ Parent/child
- ☐ Other relative
- ☐ Friend
- ☐ Other, please specify: _____

7. **When were they first told they had a brain tumour?** _____ (month) _____ (year)

8. **Is the tumour malignant (cancer)?**

- ☐ Yes
- ☐ No
- ☐ Don't know

9. **Is the tumour primary (originating in the brain) or secondary/metastatic (meaning it spread from another area)?**

- ☐ Primary
- ☐ Secondary/metastatic
- ☐ Don't know

10. **Please indicate the type of brain tumour:**

- ☐ Meningioma
- ☐ Glioblastoma
- ☐ Astrocytoma
- ☐ Oligodendroglioma
- ☐ Neuroma
- ☐ Pituitary adenoma
- ☐ Ependymoma
- ☐ Other, please specify: _____
- ☐ Don't know

11. **Which of the following therapies have been used against the brain tumour? (Tick all that apply)**

- ☐ Surgical debulking (to remove part or all of the tumour)
- ☐ Radiotherapy
- ☐ Chemotherapy
- ☐ None of the above
- ☐ Don't know

Thank you for completing this questionnaire.

It's okay to ask:
development of a question sheet to help patients diagnosed with brain tumours and their families

Topic Guide for Focus Groups/Telephone Interviews

When you were told you had a brain tumour for the first time, there must have been many things you wanted to know. What were some of the questions you asked, or things you wanted to know about?

Were there questions you wished you had asked, but didn't get to ask, or did not know about at the time? What were these?

Thinking back, are there any other questions you think would be helpful for people to ask at during their consultation, to ensure their needs are met?

Some questions can be difficult to ask, but may be important. For example, you may be interested in what is likely to happen in the future, or complications that may result from your treatment. What sort of questions do you think are important to ask about these issues?

A question sheet, or question prompt list, is a list of possible questions that patients and families may wish to ask. I have started putting together a question prompt list for patients with brain tumours, based on information from brochures that are available and things health professionals have suggested to me. In these groups that I'm holding, I'm asking people if they would like to see questions on any of these topics, and if any topics are not relevant. *<Show list of information needs/draft QPL>* What do you think about these topics as relevant for someone newly diagnosed?

I'm also inviting people to write questions for each of these topics. The questions you see here were suggested by participants in earlier groups I've held. What do you think about how useful some of these questions would be for people with brain tumours?

Should any of these questions be rephrased? Are they clear?

Are there other questions we could add?

Some questions can be difficult to ask, or make us uncomfortable. Were there any questions you found difficult to ask? What would make it easier for you to ask such questions?

Should any of the questions here be removed, or moved to a different section? What do think of the order of the topics?

Do you think it would be helpful to be given the question sheet?

Acknowledgements:
These questions are adapted from those used in:
McJannett, M., P. Butow, M.H. Tattersall, and J.F. Thompson, *Asking questions can help: development of a question prompt list for cancer patients seeing a surgeon.* Eur J Cancer Prev, 2003. **12**(5): p. 397-405.

Forms for Health professionals:

PARTICIPANT INFORMATION for QUT RESEARCH PROJECT

It's okay to ask:
development of a question sheet to help patients diagnosed with brain tumours and their families

Research Team Contacts

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Description

When diagnosed with a brain tumour there is a lot to take in about the tumour, treatment and where to get help. Many patients and families find it difficult to get the information they need. People with other illnesses have found it helpful to have a list of questions to take to medical appointments, to remind them of questions they may want to ask their doctor or nurse.

The purpose of this project is to develop such a question prompt list for people diagnosed with a brain tumour and their families. The research team requests your assistance to identify questions to appear on such a resource.

This project is being undertaken as part of a PhD project for Danette Langbecker. The project is funded by the Queensland University of Technology (QUT). QUT will not have access to individual data.

Participation

Your participation will involve providing feedback as to the suitability of potential questions (suggested as useful by patients and caregivers) for inclusion on a question sheet for patients newly diagnosed with brain tumours. This is estimated to take no more than 30 minutes to complete. Modifications to the questions will be made based on your feedback. The revised question sheet will then be provided to you again for comment. You will also be asked to complete a short questionnaire regarding demographic information. All participation will be via documents sent and received by mail or email.

Your participation in this project is voluntary. If you do agree to participate, you can withdraw from participation at any time during the project without comment or penalty. Your decision to participate will in no way impact upon your current or future relationship with QUT (for example your grades).

Expected benefits & risks

It is expected that this project will not directly benefit you. However, it may benefit people diagnosed with a brain tumour and their families in the future.

Confidentiality

All comments and responses are anonymous and will be treated confidentially. The names of individual persons are not required in any of the responses.

Consent to Participate

You may verbally or by email indicate your consent to participate. Provision of feedback on the question sheet to the research team will also be accepted as an indication of your consent to participate in this project.

Questions / further information about the project

Please contact the research team named above if you have any questions or would like further information.

Concerns / complaints regarding the conduct of the project

QUT is committed to researcher integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Officer on 3138 2340 or ethicscontact@qut.edu.au. The Research Ethics Officer is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Health professional participation – data collection

As can be seen from our research outline, the development of the question prompt list (QPL) will be an iterative process:

1. Existing items (questions useful to ask) will be identified from other QPLs and patient/research literature;
2. Patients and caregivers will identify items they feel are useful to ask; and
3. Health professionals will be given the draft version and asked to comment.

Therefore, the form below is preliminary only and will change slightly along the way. However, the example provided should give a good indication of what is expected from health professionals.

Each of the QPL items will be listed, and a space provided below each item for health professionals to write feedback, as the example below shows.

Sample question: Where can I get help with finances and accessing Centrelink payments?

Please comment as the suitability or appropriateness of this question:

Sample question: Is radiotherapy likely to extend my lifespan, and will it decrease my quality of life?

Please comment as the suitability or appropriateness of this question:

Sample question: What should I tell my children about my tumour and treatment?

Please comment as the suitability or appropriateness of this question:

Submit by Email | Print Form

Questionnaire:
for health professionals involved in brain tumour care

Name:

Profession
(e.g. social worker):

Current role
(e.g. support coordinator):

Where do you work?
(e.g. Prince of Wales Hospital)

How many years have you treated, cared for or supported patients with a brain tumour?

Thank you for completing this short questionnaire.

Please submit by email using the button in the top right-hand corner.

Alternatively, you may print this questionnaire and fax/send your response to:

Danette Langbecker
School of Public Health, QUT
Kelvin Grove Campus
Victoria Park Rd
Kelvin Grove Qld 4059
Fax: 07 3138 3130

APPENDIX J.

STUDY 2 THEMATIC ANALYSES

Themes identified from thematic analysis of existing QPLs

Overarching theme	→	→	→	→	→	most basic code
Diagnosis	what	type	prevalence			
			slow or fast growing			
		location				
		extent	stage			
			spread			
		seriousness				
		cause	preventability			
			heritability	family at risk		
			mechanism of disease			
	detection	detected earlier				
		tests	what needed	purpose	what info get	
					how influence tx	
			any others	confirm diagnosis		
				further needed	purpose	
					frequency	
			benefits & risks			
			reliability			
			procedural	what involved	pain	
				where have		
			results	when get		
				how receive		
				who talk to about		
	psychosocial	how cope with diagnosis				
		how tell friends & family				
Prognosis	what expect in	cure or control	curable or not			

Overarching theme	→	→	→	→	→	most basic code
	future		chances			
		survival	life expectancy			
			am I dying			
		QoL	will it get worse			
			best & worse case scenarios			
		spread	will it spread			
			will tx alter spread			
		natural history	improve by itself			
			get worse if not treated			
	what factors look at to predict how I will do					
Symptoms & problems	what symptoms can/ will tumour cause	what should I watch for	what do if these occur	any situations when go hosp/ambulance		
		what should I do if they arise				
		cause				
		cognitive changes	what expect based on tumour location			
			need seizure meds			
			will behaviour be affected			
		changes in appearance	how cope with			
	improve symptoms	options				
	pain	occurrence				
		control	options	morphine	addictive	
					body adapts	

Overarching theme	→	→	→	→	→	most basic code
			side effects			
			ways of taking			
Treatment	Understanding treatment & choices	purpose	cure or control intent			
			how necessary			
		choosing	opinion re best for me	why		
			any new txs			
			if tx doesn't work			
			if none, why not			
			help making decisions	how choose right tx		
			evidence base	guidelines		
				how do we know benefits & harms		
			how long to make choice			
		benefits & risks	effect on symptoms & survival	short- & long-term		
				how know it's working		
				how long til know it's working		
				response rates		
			effects on my life	social life		
				family	how remain close to partner	
				work	if/when return	
				sexual life	birth control	
				driving		
				fertility		
				other activities	holiday/trip	
				body image		

Overarching theme	→	→	→	→	→	most basic code
				what can/should do	diet	alcohol
					travel by plane	
					rest	how often
						how much
					activities to enjoy life more	
					exercise	how much
		side effects	what may have	pain		
				short- & long-term	how long after tx ends	
				risk		
			prevention			
			control			
		mechanism of effect				
		what could change the planned tx				
	Practical/ procedural	timing	tx schedule	duration		
				frequency		
				when start		
				number		
			waiting	what if have to wait	when tx needed?	
				why have to wait		
				can reduce rate if pay?		
		cost	out of pockets			
			insurance	Medicare		
				private		
				denials		
		location	where	advantages		
			public vs private	adv & disadv		

Overarching theme	→	→	→	→	→	most basic code
			in- or out-pt			
		how tx given	injection needed			
			medications	what are tbts for		
				how & when take		
				how mge taking		
				access meds		
				effect of new meds on current meds/condition	any tbts not take on this med	
					are old tbts still needed	
			surgery	who will do it		
				need blood		
				how long in hosp		
				what bring to hosp		
				tumour left after surg	where is it	
					why not all gone	
	Clinical trials	what are they				
		any relevant to me	how decide to do	why important		
			what involves	effect on care		
			risks & benefits	side effects		
				cost		
	CAMS	diff C & A				
		continue usual during tx				
		any helpful				
		any to avoid				
		tell dr about				
Support	Services & orgns	who/what	what offer	rehab		
				coping		
				physio, OT		

Overarching theme	→	→	→	→	→	most basic code
			where	in country		
		how access	in- & out-pt			
		cost				
	information	topics	about surgical procedure			
			surgical aftercare			
		what available	formats	written info		
				videos		
				internet websites		
		contact orgns				
		for special needs, languages, cultural groups				
	emotional	how likely feel				
		what can do to cope	cope depression			
			cope body changes			
	spiritual & cultural	refer to someone				
		someone to talk to own culture				
	peer support	talk to someone been through this				
		support groups	what offer			
			how find			
	family & friends	how they help?				
		support for	coping			
		help communicating with				
	practical	disability parking				

Overarching theme	→	→	→	→	→	most basic code
		volunteers to help				
		equipment	wig			
		respite care				
		help at home				
	financial	costs in illness	cost of hps			
		someone to talk to				
		help for self or family	govt pensions	eligible		
			help with meds, equipment, tests, tx, hosp			
		public vs private				
After treatment finishes	Plan for future	what is our plan				
		future txs needed	what			
			when			
		future tests	what			
			frequency			
			purpose			
		follow-up	when			
			frequency			
			what involve			
			with whom			
	Recurrence	chance				
		how know it has come back				
		can stop it returning?				
		what do if comes back				
	Getting back to normal	what is survivorship				
		what kind of recovery	how long feel tired after			

Overarching theme	→	→	→	→	→	most basic code
		expect	tx ends			
		what do to assist recovery	diet			
		how help others				
	End of life issues	legal affairs	will			
		planning medical decisions	Advanced medical directive			
			enduring power of attorney			
		dying	palliative care	how access		
				options		
			caring for someone	skills needed		
				assistance		
			expect/ experience			
			coping	as become dependent		
				for carer	with bereavement	
			place - options			
Health professional team	members	who				
		roles				
		choice	2nd opinion	refer		
				what do if get conflicting info		
			of hosp, hp or team	change hp		
				how choose right dr	do you specialise in this	
					tx performed by dr specialising in CNS tumours	
					see many pts like me	

Overarching theme	→	→	→	→	→	most basic code
					how often done this surgery	
				concerns about care		
	team approach	do you use				
		advantages				
		what expect from team				
		meet other members				
		who is in charge of my care				
		what if I get conflicting info				
		communication between team	who communicates with GP			
			how communicate with each other			
	communication with pt	who contact	first			
			re certain things	explain jargon		
				discuss qs		
				have concerns		
		how contact	after hours			
			emergency			
			in- & out- pt			
		when can/should I contact	will I see you again & why			
			frequency			
		help with qs for other drs				
		how remember what dr				

Themes following inclusion of additional information sources

Overarching theme	→	→	→	→	→	most basic code
Diagnosis	tumour type	prevalence				
		slow or fast growing				
		common characteristics of tumour type				
		common names				
		malignancy	tumour grade			
			slow or fast growing			
		primary or secondary				
	location	what lobe of brain does/controls				
	extent	stage				
		spread				
	seriousness					
	cause	preventability				
		heritability	family at risk			
		mechanism of disease	cells involved			
	tests	purpose	to confirm diagnosis or monitor tumour			
			what info will test give	how info influences		

Overarching theme	→	→	→	→	→	most basic code
				treatment/care		
			how test works			
			further needed			
		risks				
		procedural	what involved	pain		
			where, when, how often			
			surgical approach for biopsy			
		results	when get			
			reliability			
			how receive			
			who talk to about			
			2nd opinion interpreting findings			
			continue routines til get results?			
	telling people about the diagnosis	how to tell family & friends	telling children	sample explanations for different ages		
				how children may react or behave		
	coping with the diagnosis	suggestions for coping for self & family	how to help children cope	support available		
			info seeking & record keeping			
		emotional feelings & reactions	counseling			
			effect on relationships	support available		
			impact on family &	new responsibilities &	caregiving	

Overarching theme	→	→	→	→	→	most basic code
			friends	roles	responsibilities	
Prognosis	cure or control	likelihood of recurrence				
		curable or not	chances of cure			
		life expectancy	average survival time			
			longest survival time			
	QoL	will it get worse				
		best & worse case scenarios				
	malignancy & spread	can the tumour grade change				
		will it spread				
		will tx alter spread				
	natural history	improve by itself				
		get worse if not treated				
	predicting prognosis	how certain is prognosis				
		what factors look at to predict how I will do				
Symptoms & changes	identifying & understanding problems	normal vs concerning symptoms	what do if have certain symptoms?	any situations when go hosp/ambulance		
			what is normal?			
			what symptoms should I tell my dr about?			
		what expect based on tumour type, size & location	likelihood of occurrence			
		cause	tumour or treatment			

Overarching theme	→	→	→	→	→	most basic code
		temporality	temporary, permanent or late effect			
	cognitive, behavioural & personality changes	permanence of changes				
		occurrence				
		changes in behaviour				
		changes in memory or attention				
		neuropsychological assessment				
		help managing changes				
		help coping				
	emotional & mood changes	depression	counseling			
		grief & loss				
	seizures	likelihood of occurrence				
		lived experience	what it looks like			
			what it feels like			
		what to do if have a seizure	when to call for emergency help			
		triggers & advance notice				
		types of seizures				
		control	seizure medications	blood tests to monitor medication levels		
	changes to appearance	lose hair?				
	lifestyle changes	work	work during treatment			
		recreation	activity levels			
		driving	allowed	effect on insurance		

Overarching theme	→	→	→	→	→	most basic code
				reporting		
		relationships	talking to people about your illness			
			changes in sexual desire			
Treatment and management	Overall treatment plan	pre-treatment planning	financial planning	bank account access		
				unable to make financial decisions		
			legal planning	will		
			medical decisions	power or attorney		
				advanced care directive		
				family involvement		
				end or life planning		
				placement issues		
			planning with family			
		the treatment plan	changing the plan	what could change the plan		
			stopping treatment			
			what next			
			combining treatments	why		
	Understanding & choosing treatments	purpose & expected benefits	effect on symptoms & survival	response rates	drs own rates	
					factors influencing response	
				cure or control intent		
			mechanism of effect			
			necessity of treatment			
		how know treatment is working	how long til see effects			
			follow-up tests			

Overarching theme	→	→	→	→	→	most basic code
		decision making	opinion re best for me	why		
			help making decisions	how choose right tx		
			evidence base	guidelines		
				how do we know benefits & harms		
			how long to make choice			
		other options	any new treatments	at this or other locations		
			options if chosen treatment doesn't work			
			2nd opinions	purposes		
				procedure	referral	
					medical records	
				cost		
		choices re treatment provision	specialist			
			public vs private			
			in- or out-pt			
			where have treatment			
		risks & effects	what are the possible effects	physical effects	pain	
					fatigue	
					sexual activity	
					fertility	options to protect or manage
					body image	
				effects on my life	social & family life	how remain close to partner

Overarching theme	→	→	→	→	→	most basic code
					work	if/when return
						work during tx
					driving	
					other activities	holiday/trip
			temporality of effects	short-term, long-term, late	how long continue after end of tx	
				when start		
				when worst		
			prevention			
			control	other hps who might help		
			likelihood of occurrence			
	Practical/ procedural	timing	tx schedule	duration		
				frequency		
				when start		
				number		
			waiting	what if have to wait	when tx needed?	
				why have to wait		
				can reduce rate if pay?		
		cost	out of pockets			
			insurance	Medicare		
				private		
				denials		
		location	where	advantages		
			public vs private	adv & disadv		
			in- or out-pt			
		how tx given	injection needed			
	Clinical trials	what are clinical trials	why done			

Overarching theme	→	→	→	→	→	most basic code
		choosing to participate in a trial	any relevant to me			
			how decide to do participate	why important		
			what involves	effect on care		
			risks & benefits	side effects		
				cost		
		during a trial	who contact if have a problem			
	Self-management	work & usual activities	driving			
			work during treatment			
			rest & activity levels			
		preventing & managing seizures	triggers, advance warning			
			sleep, nutrition, stress management			
		managing fatigue	exercise			
		diet	supplements			
			alcohol			
			dietician			
		overall health	routine med appts			
	CAMs	CAM use	why people use			
			common CAMs used			
		what are CAMs	untested nature			
			diff C & A			
		choosing CAMs	how to evaluate	sources of info about		
				safety & efficacy		
			recommendations	any helpful		
				any to avoid		

Overarching theme	→	→	→	→	→	most basic code
		combining CAMs with conventional treatments	continue usual CAMs during treatment			
			interactions with drugs or treatments			
			tell dr about	CAM practitioner communicate with dr		
	Palliative care	what offer				
		access	referral			
			in- or out-pt			
		who can provide				
	Oral medications	purpose				
		dosage	will it change			
			ceasing meds			
		taking meds	with food			
			difficulties taking			
			how & when take			
		accessing meds				
		interactions with other drugs or conditions	with existing meds or condition			
	Chemotherapy	what drugs involved				
		how given				
		safety	protecting others from bodily fluids			
		protocol	dosage			
			frequency			
			length of protocol			
		fertility & birth control	impact on fertility	options to protect or manage		

Overarching theme	→	→	→	→	→	most basic code
			birth control needed	why		
				how		
				for how long for		
	Radiotherapy	type of radiotherapy	machines involved			
		planning beforehand	scans & tests			
			mask			
			marking skin			
		protocol	technique			
			dosage			
			frequency			
			use of radiosensitiser drugs			
		self-care	caring for skin			
	Surgery	plan for surgery	surgical approach			
			need blood			
			to remove how much tumour			
			operability of tumour	if not, why not		
		what take to hospital				
		surgeon	experience			
		expectations after surgery	length of hospital stay			
			what experience			
		results of surgery	tumour all removed or left	where left		
				why		
			follow-up, tests & monitoring			
Overarching theme	→	→	→	→	→	most basic code

Overarching theme	→	→	→	→	→	most basic code
Support	Services & orgns	who/what offer	rehab			
			coping			
			physio			
			OT			
			social worker			
			neuropsychologist			
		for specific groups	children			
			carers			
			pts with benign tumours			
			people with special needs, languages, cultural groups			
		access	in- & out-pt			
			in the country			
			referrals			
			cost			
	information	what available	formats	written info		
				videos		
				internet websites		
			topics			
		contact orgns				
		for specific groups	people with special needs			
			in diff languages			
			for diff cultural groups			
			for carers			
			for benign tumour pts			

Overarching theme	→	→	→	→	→	most basic code
	emotional	how likely feel				
		what can do to cope	depression			
			body changes			
	spiritual & cultural	refer to someone				
		someone to talk to own culture				
	peer support	talk to someone been through this				
		support groups	what offer			
			how find			
		telephone & online support				
	family & friends	support for	for children	school support		
			coping			
		help communicating with				
	practical	travel	parking	where to park		
				disability parking		
			taxi vouchers			
			accommodation			
		caring	home nursing care			
			respite care			
			caring skills			
		everyday life	help at home			
			volunteers			
			Meals on wheels			
			equipment	wig		

Overarching theme	→	→	→	→	→	most basic code
	financial	understanding costs	insurance	public vs private		
				what is covered		
				denials		
				documentation		
				out of pockets		
			direct costs	cost of hps		
			indirect costs			
			tracking costs			
		help for self or family	what available	help with meds		
				govt pensions		
				superannuation		
				equipment, tests, treatment, hospital		
				help with transport & accommodation		
				help from non-profits		
			help accessing			
			someone to talk to			

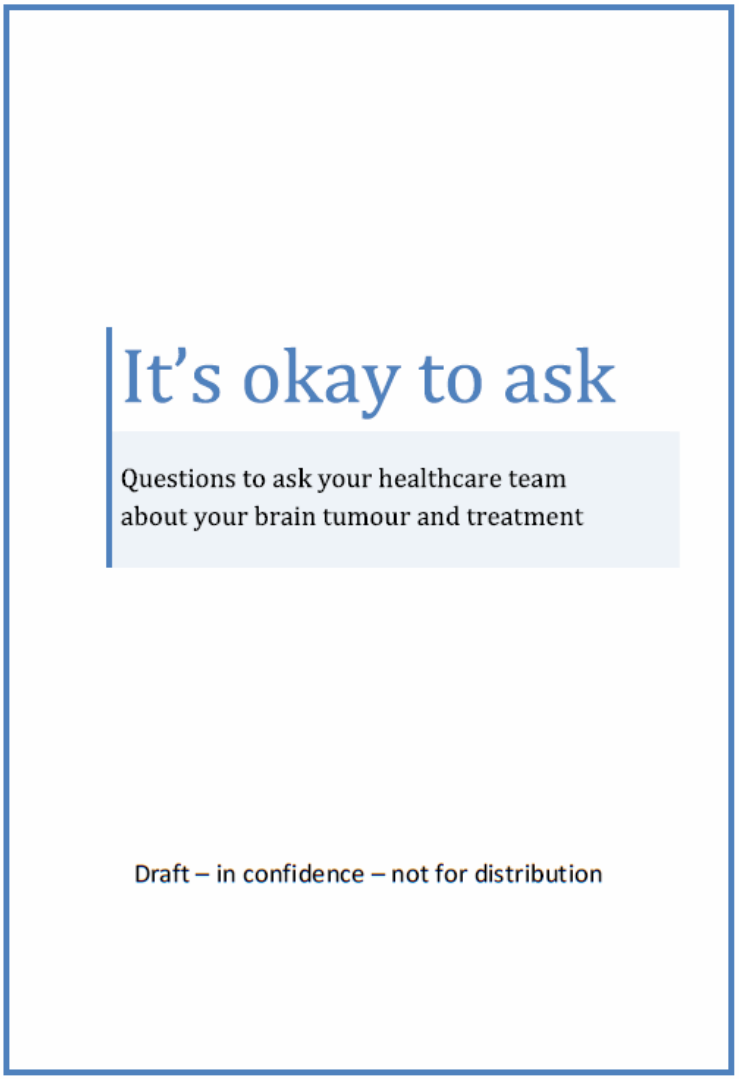
Overarching theme	→	→	→	→	→	most basic code
			counsellors			
			workplace assistance			
		issues to consider	partial, continuing recovery			
			nature of job			
		talking to employer				
	Driving	inability	reporting			
			insurance			
		restarting	assessment			
			when			
	End of life issues	help coping				
		caring				
		timeframe				
		place				
		what experience				
Health professional team	people providing care	who & what is their role	meet them?			
		what other services are available	access			
			referral			
		who is in charge of my care				
		choice	2nd opinion	refer		
				what do if get conflicting info		
			change hp			
			choice of hospitals			
			how choose right dr	do you specialise in this		

Overarching theme	→	→	→	→	→	most basic code
				see many pts like me		
			concerns about care			
	multidisciplinary team approach	do you use				
		advantages				
		what expect from team				
		communication between team	who communicates with GP			
			how communicate with each other			
	visits and appointments	when, who, how often				
	contacting your team	who contact	first			
			if get conflicting info			
			to explain jargon			
			discuss qs			
			if have concerns			
			if have a seizure			
			re medications			
		how contact	after hours			
			emergency			
			in- & out- pt			
	help communicating	interpreter services				
		culturally & linguistically diverse professionals				

APPENDIX K.

STUDY 2 DRAFT QUESTION PROMPT LISTS

Initial draft of QPL sent to Patient/carer Participants:



It's okay to ask comprises a list of questions that you may want to ask your doctors and other health professionals about various issues relating to your brain tumour and treatment. It aims to provide you with a starting point, and suggests questions that have been helpful for others in your situation.

Not all of these questions will be relevant to you, and the different sections of this brochure may be applicable to you at different times. You may feel that you don't want to know the answers to some of these questions, and that's okay.

This booklet has been developed with the assistance of both brain tumour survivors and their families, and doctors and nurses who treat patients with brain tumours. In this way, it has led to a list of questions that both patients and doctors think are useful.

You may want to read this booklet all at once, or refer to different sections as you need.

This booklet contains questions about seven different topics:

- diagnosis
- prognosis
- symptoms and changes
- your health professional team
- treatment and management
- support
- after treatment finishes.

Space is also provided for you to write additional questions or to note the answers you are given.

Diagnosis

Can you spell my tumour's name?

Are there any other names my tumour is known by?

Is it a slow- or fast-growing tumour?

Where is it in my brain? What functions are controlled by that part of the brain?

How extensive is the tumour? How much tumour is there?

What caused this tumour? Is my family likely to be at greater risk of developing a brain tumour?

Tests

What other tests will I need, and what is their purpose?

What information will this test give us? How will this information influence my treatment or care?

What is involved with having the test? Will it hurt?

When will I get the results of my test, and who will tell me my results?

Can I have a copy of my test results?

Should I continue my usual activities or routines until we receive the test results? Is there anything I should do or not do?

I'm not sure how to tell my child(ren) about this – can you suggest an explanation appropriate for their age(s)?

Is there someone I or my family can talk to, to help us cope with this?

Other questions or notes:

Prognosis

What are the chances of curing my tumour?

Is my tumour likely to come back after it has been treated?

If the tumour is likely to return, how long will I have before it returns?

What are the average and longest survival times for people diagnosed with this type of tumour?

Could my tumour become more aggressive in the future?

Will my tumour spread?

Could my tumour improve by itself? Will it get worse if it is not treated?

What factors will you look at to predict how I will do?

If my tumour cannot be cured, what can I expect in the future? What will my best and worst days be like?

Other questions or notes:

Symptoms & changes

What symptoms may occur in the future?

What changes are normal and to be expected?

Are there any problems that I should look out for, and what do I do if they occur?

How likely I am to experience these symptoms?

How long will the symptoms last for? Are they permanent?

What symptoms or changes is it important for me to tell you about?

Changes in thinking, behaviour and personality

In what ways are my thinking, my behaviour and my personality likely to change based on my tumour's location?

Can you refer me to be assessed for changes in thinking?

How will I be able to recognise if my thinking changes?

Will my physical appearance change?

Am I still going to be able to work?

Is it okay for me to drive? Do I need to tell driving authorities about my tumour?

Will I be able to do the same things I did before? Do I need to rest, or will I still have energy?

Will my sexual life be affected?

How can I deal with feelings of grief and loss?

Seizures

Am I likely to have seizures?

What do I do if I have a seizure?

In what situations should I go to hospital or call an ambulance?

What does it look like to have a seizure? What does it feel like?

Are there warning signs for a seizure?

What could trigger a seizure to occur?

Will you prescribe medications to prevent seizures?

Other questions or notes:

Your health professional team

What different types of doctors and other health professionals will be involved with my care?

When will I meet the different people involved in my care?

Who is in charge of my care?

On average, how many patients like me do you treat each year?

What other services are available for me? If I need to access other services, do I need a referral?

Who do I contact if I have concerns about my care?

Do I have a choice of hospitals? Can I receive treatment from the same doctors in a different hospital?

Will someone communicate with my GP about my tumour and treatment?

Can we arrange an interpreter to help us communicate more effectively?

Can I talk to a health professional from my own culture?

Multidisciplinary Teams

Do you work as part of a multidisciplinary team?

What does it mean for me if my treatment is by a multidisciplinary team?

How will the team members coordinate my care?

Contacting your doctors and health professionals

Who should I contact if I have questions about my treatment?

Who can I talk to if I receive conflicting information or advice?

Who is my first point of contact?

What issues should I talk to my GP about, and what should I discuss with my medical oncologist?

Who should I talk to if I have a seizure?

Can I talk to someone about managing my medications?

How can I get in touch with you out of hours, or in case of an emergency?

Do I contact the same people when I'm an outpatient as when I'm in hospital?

Doctors' visits

Who will I see next, when and where?

When will I see you again?

How often will I see you?

Other questions or notes:

Treatment & management

In your opinion, what treatment is best for me? Why?

Are there any guidelines for how to treat people with my kind of tumour?

Are there any new or experimental treatments that might benefit me, here or at other hospitals?

How long do I have before I need to decide what treatments to have?

What are my options if my treatment doesn't work?

Is there a point when I should consider stopping treatment? How will I know when I'm at this point?

What is my overall treatment plan? What will happen next after my current treatment?

What could change my treatment plan?

How can I guide those closest to me to make medical decisions for me if I am no longer able to do so for myself?

Other than the direct cost of treatments, what will I have to pay for? What will my insurance cover and what out-of-pocket costs will I have to pay?

Second opinions

Can I get a second opinion about my treatment options, even if I want to stay with my initial doctor for treatment?

How do I get access to my medical records to enable another doctor to offer a second opinion?

Can you refer me to someone you trust for a 2nd opinion?

Questions about each treatment option

How will this treatment affect my symptoms and chances of survival?

What will the treatment involve and what will I experience?

How will we know the treatment is working?

How long until I see some effects of the treatment?

What follow-up tests will I need during/after treatment?

Where will I have the treatment? Can I have it at a location closer to home? Can I have it as an outpatient?

Who will administer the treatment? Will it be someone specialising in this treatment or in treating brain tumours?

How will I receive the treatment? Will I have an injection, or medications?

Will this treatment impact on my fertility? What options do I have to protect or manage my fertility?

What physical effects will I experience during or after treatment? How likely are these effects?

How long will the effects last? Will they continue after I finish treatment?

How will having this treatment influence my everyday activities? Will I be able to work/ travel/ drive?

Can we prevent the side effects of treatment? What will we do to control or manage treatment side effects?

What will be my treatment schedule? Eg when, for how long, how many and how often?

How much will this specific treatment cost me?

Surgery

Will my surgery be done by a specialist neurosurgeon?

How will you do the surgery?

Do you expect to remove the whole tumour, or part of it?

Is there anything that could change your plan for my surgery?

Will this surgery cure me, or will it help control my symptoms?

What do I need to take into hospital with me?

How long will I be in hospital after surgery?

What will I experience when I come out of surgery?

What tests or follow-up will I need after the surgery?

How long until we know if the surgery has been successful?

After surgery

Did you remove the entire tumour? Why or why not?

If there is still some tumour left, how much is left and where is it?

Chemotherapy

What drugs will be given to me in my chemotherapy regimen? In what doses?

How will my chemotherapy be administered?

Will I need to take any measures to protect myself or others during or after my chemotherapy?

What is my treatment schedule – how often will I have treatment, and how many treatments will I have?

Do I need to use contraceptives (birth control) while I am receiving chemotherapy?

Will the chemotherapy impact my fertility?

Radiotherapy

What type of radiotherapy will I receive?

What sort of procedures will I have to undergo before the radiotherapy?

How often will I have radiotherapy, for how long each time, and for how many treatments overall?

How can I care for my skin while I am having radiotherapy?

What are the common side effects?

Will radiotherapy affect my thinking?

What can I do to stay well during radiotherapy?

Oral medications

What are these tablets for?

What do I do if I miss a dose, or bring it up (vomit it)?

What can I do if I have problems taking the pills?

How long do I have to keep taking the medication?

Should I keep taking my existing medication whilst I am on these medications?

Will these medications have any effect on my existing medical conditions?

Can I get these tablets from my usual chemist?

Should I buy all the repeats up front, or could my prescription or dose change?

If I have a seizure, should I keep taking my seizure medication? Should I change the dose?

Self-management

Can I continue to drive while I'm having treatment?

If I want to keep working during treatment, what issues should I think about and how can I manage symptoms and side effects at work?

How can I manage my fatigue? Should I rest, or could exercise help?

Can I do anything to prevent having seizures?

Are there any supplements or changes to diet that could help me stay healthy during treatment?

Complementary and alternative medicines/therapies

Are there any complementary or alternative medicines or therapies that you would recommend to help manage the symptoms or side effects I am experiencing? Are there any that I should avoid?

How do I know if an alternative medicine or therapy is legitimate and safe?

Do you know of any reputable sources of information or websites about alternative therapies?

Can I continue my usual herbal medicines (or other therapies) during my treatments?

Could any of the other medicines or therapies I use interact with my medical treatment and cause problems?

Do I need to tell you about other medicines, supplements or therapies I am using?

Can my alternative therapist contact you to discuss my care?

Clinical trials

What are clinical trials?

Are there any clinical trials that might be relevant to me?

What would my participation in the trial involve?

What costs will I have to pay if I enrol in the trial?

Who do I contact if I have problems while I'm enrolled in a trial?

Palliative care

What is palliative care?

What can palliative care offer me?

Can I get help from the palliative care team as an outpatient?

Other questions or notes:

Support

What services are available to help me through my illness and treatment?

Is there someone who can help me cope with the changes my family and I are experiencing?

How do I access support services when I go back home?

What organisations provide support for people with benign tumours?

What will it cost me to access rehabilitation services such as physiotherapy, speech therapy or occupational therapy?

Can you put me in touch with organisations which provide information and support for people like me?

What should I say to my family and friends?

Should I let my children's school know of my illness? How can they support my children while I'm ill?

What if I am not coping or feel depressed?

Is there anyone I can speak to about my spiritual or religious needs?

Could you arrange for me to talk to someone from my culture, someone who may understand me better?

Who can help me make a will and/or advanced medical directive?

Information

Do you have a video I can watch of the treatment procedure?

Could you recommend reputable websites about my tumour or treatment?

Do you have information in languages other than English?

Do you have any information I could give my family or children?

Practical issues

Where should I park when I come in for treatment?

Am I eligible for a disability parking permit? How do I obtain it?

Can I get taxi vouchers if I can no longer drive?

Where can I or my family stay if we have to travel for treatment?

Can I get Meals on Wheels once I go home?

Am I eligible for services to help me out at home or in the garden, or for some home nursing care?

Is there anyone who can teach my family how to look after me at home?

Is there any equipment you would suggest to make everyday living easier at home?

Where can I borrow or hire equipment to help me at home?

Where can I get a wig?

Financial issues

How much will my medical appointments cost and what will I get back?

How would my treatment or care differ in the public or private system? How would my out of pocket costs differ?

What documentation do I need to keep for my health insurance?

What do I do if my private health insurer refuses to pay for a certain treatment?

How can I keep track of all the costs of my illness?

Is there someone I can talk to about financial matters?

Is there any way I can get medications at a cheaper price?

Is there any assistance I can get with the costs of tests or treatments?

Are my family or I eligible for government support or benefits?

Can you help me complete the paperwork to get access to government pensions?

Can I access my superannuation to help cover the costs of my illness?

Do any other organisations offer financial help for people in my situation?

Peer support

Do you know of any support groups I could attend? What could they offer me?

Can you put me in touch with someone who has been through this?

What telephone or online support groups or services can I use?

Other questions or notes:

After treatment

What tests will I need to have in the future and why? When or how often will I need to have these tests?

Will I need to have more treatments in the future? What for?

What doctors will I continue to see after finishing treatment? How often will I see them?

What will my follow-up visits involve?

Recovery and getting back to normal

What can I expect in terms of my recovery?

How long will it take for me to get back to normal?

Will any of the symptoms or changes I have experienced be permanent?

What can I do to help with my recovery?

What issues should I consider when thinking about returning to work?

Can you refer me to a vocational rehabilitation counsellor to help assist me to get back to work?

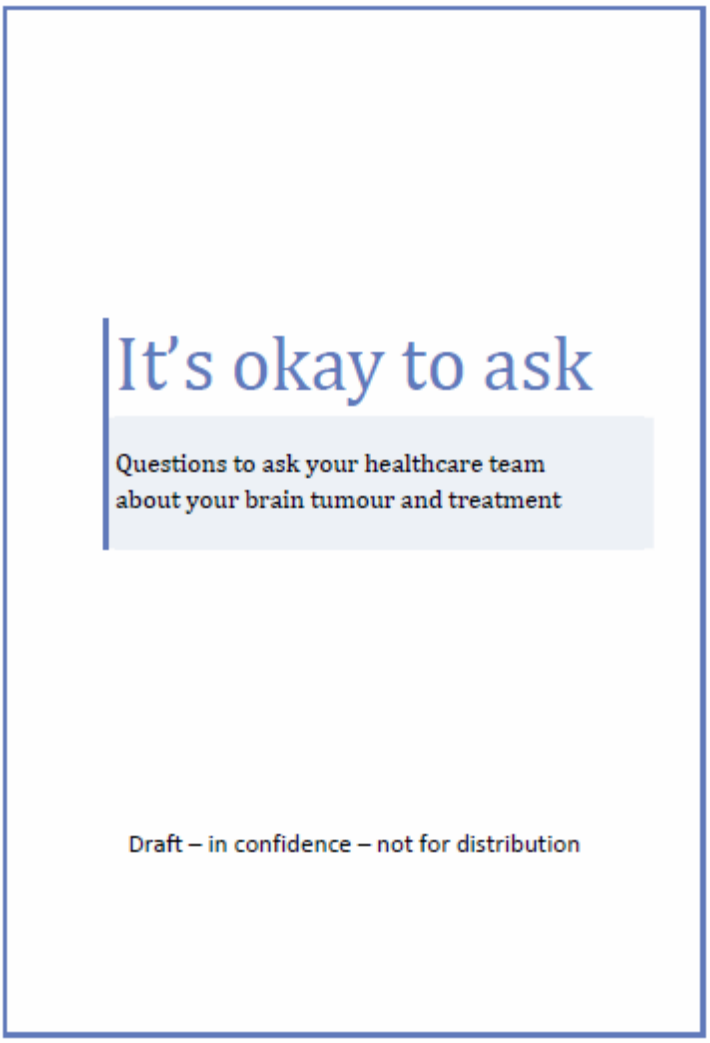
What should I tell my employer about my illness?

When will I be able to start driving again?

Will I need a specialist assessment before driving?

Other questions or notes:

Initial draft of QPL sent to Health Professional participants:



It's okay to ask

Questions to ask your healthcare team about your brain tumour and treatment

Draft – in confidence – not for distribution

It's okay to ask contains questions that you may want to ask your doctors or other staff about issues relating to your brain tumour and treatment. It was written with the help of brain tumour survivors and their families, and doctors and nurses who treat them. It aims to give you a starting point by listing questions that both patients and doctors think are useful.

The first few pages of this booklet have questions that might be useful to you at the start. Further questions are then listed about:

- diagnosis
- prognosis (what to expect in the future)
- symptoms and changes
- the health professional team
- support
- treatment and management, and
- after treatment.

Not all questions will apply to you, or be important right now. You may not want to know the answers to some of these questions, and that's okay. You may also have other questions not listed here. There is room to write your own questions or notes.

Initial questions you may wish to ask

Diagnosis

Can you write down the name of my tumour?

Where is it in my brain? What does that part of the brain do?

I'm not sure how to tell my family or child(ren) about this – how I can explain it?

What seems to have worked for others to deal with the stress of this diagnosis?

For further questions, see page 9.

Prognosis (what to expect in the future)

What are the chances of curing my tumour?

Could my tumour improve by itself? Will it get worse if it is not treated?

For further questions, see page 11.

Symptoms & changes

What symptoms may occur in the future?

Is how I am feeling at the moment normal for my condition?

Will I be able to do the same things I did before? Do I need to rest? Will I still have the same energy?

For further questions, see page 12.

The health professional team

Who is in charge of my care?

What other services are available for me? If I need to access other services, do I need a referral?

Who should I contact if I have questions about my treatment?

For further questions, see page 14.

Support

What services are available to help me through my illness and treatment?

Is there someone who can help me cope with the changes my family and I are going through?

Could you recommend trustworthy websites about my tumour or treatment?

Who can tell me about what government support or benefits my family or I may be eligible for?

Can you put me in touch with someone who has been through this?

For further questions, see page 16.

Treatment & management

In your opinion, what treatment is best for me? Why?

Are there any new or experimental treatments that might help me, here or at other hospitals?

Can you refer me to someone you trust for a second opinion?

How will having this treatment influence my everyday activities? Will I be able to work/ travel/ drive?

Surgery

Do you expect to remove the whole tumour, or part of it?

What will I experience when I wake up after the surgery? What tubes or drips will I have in?

Oral medications

What are these tablets for?

What do I do if I miss a dose, or bring it up (vomit it), or take too many pills?

Living healthily

What should I think about if I want to keep working during treatment? How can I manage symptoms and side effects at work?

Are there any supplements or changes to diet that could help me stay healthy during treatment?

Complementary & alternative medicines/ therapies

Are there any complementary or alternative medicines or therapies that you have seen help manage the symptoms or side effects I am experiencing? Are there any that I should avoid?

For further questions, see page 20.

After treatment

Will I need to have more treatments in the future? What for?

What can I do to help with my recovery?

For further questions, see page 27.

Further questions

Further questions are listed on the following pages. These might be useful if you'd like further details or information. However, some questions may not apply to you, as different tumours have different effects and treatments. There may also be some questions or topics that you don't want to read about right now. A table of contents is on the next page so you can look at the headings first before reading on.

Topic *Page*

Diagnosis

Are there any other names for my tumour?

Is it slow- or fast-growing?

How extensive is it? How much tumour is there?

What does the tumour look like?

What caused this tumour? Is my family likely to be at greater risk of developing a brain tumour?

Is there someone I or my family can talk to, to help us cope with this?

Tests

What other tests will I need, and what for?

What information will this test give us? How will this information influence my treatment or care?

What is involved with having the test? Will it hurt?

How old is the test equipment? When was it last tested or used?

When will I get the results of my test, and who will tell me my results?

Can I have a copy of my test results?

Should I continue my usual activities or routines until we receive the test results? Is there anything I should do or not do?

Other questions or notes:

Prognosis

How do you think I am going?

Is my tumour likely to come back after it has been treated?

If the tumour is likely to return, how long will I have before it returns?

What is the average survival time for this type of tumour? What is the longest you know of?

What are my chances of surviving this?

Could my tumour become more aggressive in the future?

Will my tumour spread?

What factors will you look at to predict how I will do?

If my tumour cannot be cured, what can I expect in the future? What will my best and worst days be like?

Other questions or notes:

Symptoms & changes

What changes are normal and to be expected?

Are there any problems that I should look out for, and what do I do if they occur?

How likely I am to experience these symptoms?

How long will the symptoms last for? Are they permanent?

What symptoms or changes do I need to tell you about?

Changes in thinking, behaviour and personality

In what ways are my thinking, my behaviour or my personality likely to change based on my tumour's location?

Can you refer me to be assessed for changes in thinking?

How will I know if my thinking changes?

Will my physical appearance change?

Am I still going to be able to work?

Is it okay for me to drive? Do I need to tell driving authorities about my tumour?

Will my sexual life be affected?

How can I deal with feelings of grief and loss?

Seizures

Am I likely to have seizures?

What should I tell my family to do if I have a seizure?

In what situations should I go to hospital or call an ambulance?

What does it look like to have a seizure? What does it feel like?

Are there warning signs for a seizure?

What could trigger a seizure to occur?

Will you prescribe medications to prevent seizures?

Other questions or notes:

The health professional team

What different types of doctors and other staff will care for me?

When will I meet the people involved in my care?

On average, how many people like me do you treat each year?

Who can I talk to if I'm worried about my care?

Do I have a choice of hospitals? Can I see the same doctors in a different hospital?

Will someone talk with my GP about my tumour and treatment?

Can someone get an interpreter to help us?

Can I talk to a doctor or staff member from my own culture?

Multidisciplinary Teams

Do you work as part of a multidisciplinary team?

What does it having a multidisciplinary team mean for me?

How will the team coordinate my care?

Contacting doctors and other health professionals

Who can I talk to if I receive conflicting information or advice?

Who is my first point of contact?

What issues should I talk to my GP about, and what should I discuss with my oncologist?

Who should I talk to if I have a seizure?

Can I talk to someone about managing my medications?

Do I contact the same people when I'm an outpatient as when I'm in hospital?

How can I get in touch with you out of hours? What about in case of an emergency?

Doctors' visits

Who will I see next, when and where?

When will I see you again?

How often will I see you?

Other questions or notes:

Support

How do I access support services when I go back home?

What organisations provide support for people with benign tumours?

Can you put me in touch with organisations which provide information and support for people like me?

What should I say to my family and friends?

How can I help my family to support me?

Should I let my children's school know of my illness? How can they support my children while I'm ill?

What if I am not coping or feel depressed?

Is there anyone I can speak to about my spiritual or religious needs?

Could you arrange for me to talk to someone from my culture, someone who may understand me better?

Who can help me make a will and/or Advance Medical Directive?

Information

Do you have a video I can watch of the procedure?

Do you have information in other languages?

Do you have any information I could give my family or children?

Practical issues

Where should I park when I come in for treatment?

Am I eligible for a disability parking permit? How do I get it?

Can I get taxi vouchers if I can no longer drive?

Where can I or my family stay if we have to travel for treatment?

Can I get Meals on Wheels once I go home?

Am I eligible for services to help me out at home or in the garden? Can I receive home nursing care?

Is there anyone who can teach my family how to look after me at home?

Is there any equipment you would suggest to make everyday living easier at home?

Where can I borrow or hire equipment to help me at home?

Where can I get a wig or bandana?

Peer support

Do you know of any support groups I could attend? What could they offer me?

What telephone or online support groups or services can I use?

Financial issues

How much will my appointments cost and what will I get back?

How would my treatment differ in the public or private system? How would my out-of-pocket costs differ?

What do rehabilitation services such as physiotherapy or occupational therapy cost?

What documentation do I need to keep for my health insurance?

What can I do if my private health insurer refuses to pay for something?

How can I keep track of all the costs of my illness?

Is there someone I can talk to about financial matters?

Is there any way I can get medications more cheaply?

Can I get help with the costs of tests or treatments?

What financial assistance is available for me and my family if we travel for tests or treatment?

Can you help me complete the paperwork to get government (Centrelink) pensions or benefits?

Can I access my superannuation to help with the costs of my illness?

Do any other organisations offer financial help for people in my situation?

Other questions or notes:

Treatment & management

Are there any guidelines for how to treat people with my kind of tumour?

How long do I have before I need to decide what treatments to have?

What are my options if my treatment doesn't work?

Is there a point when I should consider stopping treatment? How will I know if I'm at this point?

What is my overall treatment plan? What will happen next after my current treatment?

What could change my treatment plan?

How can I guide those closest to me to make medical decisions for me, if I am no longer able to do so for myself?

Other than the direct cost of treatments, what will I have to pay for? What will my insurance cover and what out-of-pocket costs will I have to pay?

Second opinions

Can I get a second opinion about my treatment options, even if I want to stay with you for my treatment?

How do I get access to my medical records to enable another doctor to give a second opinion?

Questions about each treatment option

How will this treatment affect my symptoms and chances of survival?

What will the treatment involve? What will I experience?

How will we know the treatment is working?

How long until I see some effects of the treatment?

What follow-up tests will I need during/after treatment?

Where will I have the treatment? Can I have it somewhere closer to home? Can I have it as an outpatient?

Who will perform or give me the treatment? Will it be someone specialising in this treatment or in treating brain tumours?

How will I receive the treatment? Will I have an injection, or medications?

Will this treatment impact on my fertility? What options do I have to protect or manage my fertility?

What physical effects will I see or feel during or after treatment? How likely are these effects?

How long will the effects last? Will they continue after I finish treatment?

Can we prevent the side effects of treatment? What can we do to control or manage treatment side effects?

What will be my treatment schedule? Eg when, for how long, how many and how often?

How much will this specific treatment cost me?

Surgery

Will my surgery be done by a specialist neurosurgeon?

How will you do the surgery?

Will you put my head in a frame to hold it still while you operate?

Where will you make the incision? How big will it be?

Is there anything that could change your plan for my surgery?

Will this surgery cure me, or will it help control my symptoms?

What do I need to take into hospital with me?

How long will I be in hospital after surgery?

What tests or follow-up will I need after the surgery?

How long until we know if the surgery has been successful?

After surgery

Did you remove the entire tumour? Why or why not?

How much tumour is left? Where is it?

Oral medications

What can I do if I have problems taking my pills?

How long do I have to keep taking these medications?

Should I keep taking my existing medicines whilst I am on these?

Will these medications have any effect on my existing medical conditions?

Can I get these tablets from my usual chemist?

Should I buy all the repeats up front, or could my prescription or dose change?

If I have a seizure, should I keep taking my seizure medication? Should I change the dose?

Chemotherapy

What drugs will be given to me in my chemotherapy regimen? In what doses?

How will my chemotherapy be administered?

Will I need to take any measures to protect myself or others during or after my chemotherapy?

What is my treatment schedule? How often will I have treatment? How many treatments will I have?

Do I need to use contraceptives (birth control) while I am receiving chemotherapy?

Will the chemotherapy impact my fertility?

Radiotherapy

What type of radiotherapy will I receive?

What sort of procedures will I have to undergo before the radiotherapy?

Will I need to wear a mask during radiotherapy? How will you make it?

How often will I have radiotherapy? For how long each time? For how many treatments overall?

Can you teach me relaxation or visualisation techniques to help during my treatment?

How can I care for my skin while I am having radiotherapy?

What are the common side effects?

Will radiotherapy affect my thinking?

What can I do to stay well during radiotherapy?

Living healthily

Can I continue to drive while I'm having treatment?

How can I manage my fatigue? Should I rest? Could exercise help?

Can I do anything to prevent having seizures?

Complementary and alternative medicines/therapies

How do I know if an alternative medicine or therapy is safe?

Can you recommend any trustworthy sources of information or websites about alternative therapies?

Can I take my usual herbal medicines (or other therapies) during my treatments?

Could any of the other medicines or therapies I use cause problems with my medical treatment?

Do I need to tell you about other medicines, supplements or therapies I am using?

Can my alternative therapist contact you to discuss my care?

Clinical trials

What are clinical trials?

Are there any clinical trials that might be relevant to me?

What would being in the trial involve?

What would I have to pay if I went in the trial?

Who do I contact if I have problems while I'm in a trial?

Palliative care

What is palliative care? What can it offer me?

Can I get help from the palliative care team as an outpatient?

Other questions or notes:

After treatment

What tests will I need to have in the future? What for? How often will I need to have them?

Who will I continue to see after finishing treatment? How often will I see them?

What will my follow-up visits involve?

What should I do if I am worried about my tumour coming back?

If my tumour comes back, what treatments can I have?

Recovery and getting back to normal

What can I expect in terms of my recovery?

How long will it take for me to get back to normal?

Will any of the symptoms or changes I have had be permanent?

Who can I talk to about coping with the changes in my life as I get better?

What should I consider when thinking about returning to work?

Can you refer me to someone to help me to get back to work?

What should I tell my employer about my illness?

When will I be able to start driving again?

Will I need a specialist assessment before driving?

Other questions or notes:

APPENDIX L.

STUDY 2 READABILITY ANALYSES

SMOG assessment

To perform the SMOG assessment, thirty sentences were selected from the QPL (10 each from the beginning, middle and end). The passages chosen are displayed below. Words of three or more syllables were highlighted and counted.

Box 1: First passage of 10 sentences

It's okay to ask comprises a list of questions that you may want to ask your doctors and other health professionals about various issues relating to your brain tumour and treatment. It aims to provide you with a starting point, and suggests questions that have been helpful for others in your situation.

This booklet has been developed with the assistance of both brain tumour survivors and their families, and doctors and nurses who treat patients with brain tumours. In this way, it has led to a list of questions that both patients and doctors think are useful.

Not all of these questions will be relevant to you, and the different sections of this brochure may be applicable to you at different times. You may feel that you don't want to know the answers to some of these questions, and that's okay.

This booklet contains an initial few pages of questions that might be useful to you at the start. Further questions are then listed about seven different topics:
(list omitted)

You may want to refer to different sections of this booklet as you need. Space is also provided for you to write additional questions or to note the answers you are given.

Number of polysyllabic words in first passage: 18.

Box 2: Second passage of 10 sentences

What different types of doctors and other health professionals will be involved with my care?

When will I meet the different people involved in my care?

On average, how many patients like me do you treat each year?

Who do I contact if I have concerns about my care?

Do I have a choice of hospitals? Can I receive treatment from the same doctors in a different hospital?

Will someone communicate with my GP about my tumour and treatment?

Can we arrange an interpreter to help us communicate more effectively?

Can I talk to a health professional from my own culture?

Multidisciplinary Teams *(title ignored)*

Do you work as part of a multidisciplinary team?

Number of polysyllabic words in second passage: 13.

Box 3: Third passage of 10 sentences

What is palliative care?

What can palliative care offer me?

Can I get help from the palliative care team as an outpatient?

After treatment *(title ignored)*

What tests will I need to have in the future and why? When or how often will I need to have these tests?

What doctors will I continue to see after finishing treatment? How often will I see them?

What will my follow-up visits involve?

What should I do if I am worried about my tumour recurring?

If my tumour recurs, what are my options for further treatment?

Number of polysyllabic words in third passage: 8.

The total number of polysyllabic words in the three passages 39 (18 + 13 + 8). As per SMOG assessment guidelines, the nearest square was found and three added to the square root to give the grade level (McLaughlin, 1969). In this case, the nearest square to 39 is 36, with the square root of 6, and three is then added to give a grade level of 9.

Fry readability graph

The Fry readability graph requires analysis of three randomly selected passages, each 100 words long. The average number of syllables and sentences for each passage are counted, and reference made to the Fry readability graph to determine grade level for each passage (Fry 1969). This process is demonstrated below.

Box 4: First passage for Fry testing

It's okay to ask comprises a list of questions that you may want to ask your doctors and other health professionals about various issues relating to your brain tumour and treatment. It aims to provide you with a starting point, and suggests questions that have been helpful for others in your situation.

This booklet has been developed with the assistance of both brain tumour survivors and their families, and doctors and nurses who treat patients with brain tumours. In this way, it has led to a list of questions that both patients and doctors think are useful.

Not all of

Total number of sentences: 4

Total number of syllables: 144

Box 5: Second passage for Fry testing

How do you think I am going?

Is my tumour likely to come back after it has been treated?

If the tumour is likely to return, how long will I have before it returns?

What are the average and longest survival times for people diagnosed with this type of tumour?

What are my chances of surviving this?

Could my tumour become more aggressive in the future?

Will my tumour spread?

What factors will you look at to predict how I will do?

If my tumour cannot be cured, what can I expect in the future? What

will my best and

Total number of sentences: 9

Total number of syllables: 134

Box 6: Third passage for Fry testing

What can I do if I have problems taking my pills?

How long do I have to keep taking these medications?

Should I keep taking my existing medication whilst I am on these medications?

Will these medications have any effect on my existing medical conditions?

Can I get these tablets from my usual chemist?

Should I buy all the repeats up front, or could my prescription or dose change?

If I have a seizure, should I keep taking my seizure medication? Should I change the dose?

Chemotherapy *(title ignored)*

What drugs will be given to me in my chemotherapy regimen? In what doses?

Total number of sentences: 10

Total number of syllables: 147

Averages were then calculated:

Average number of sentences = (4 + 9 + 10)/3 = 7.67

Average number of syllables = (144 + 134 + 147)/3 = 141.67

Finding the intersection of these averages on the Fry Graph (see Chapter 7) yields a grade level of approximately 7.

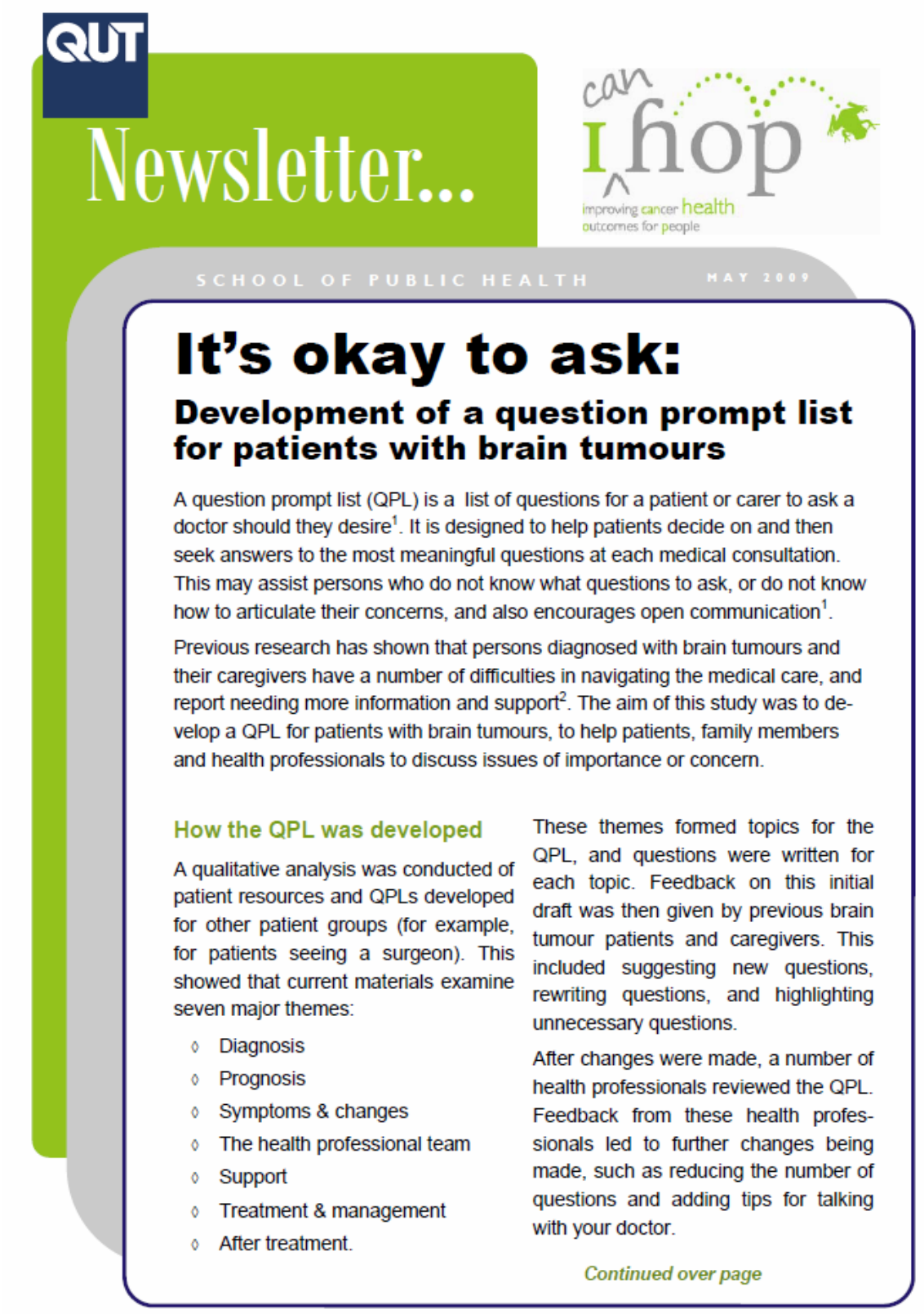
Reference List

Fry, EB (1969). "The Readability Graph Validated at Primary Levels." The Reading Teacher 22(6): 534-538.

McLaughlin, GH (1969). "SMOG grading - a new readability formula." Journal of Reading 12(8): 639-646.

APPENDIX M.

STUDY 2 PARTICIPANT NEWSLETTER



QUT

Newsletter...

can I hop

improving cancer health outcomes for people

SCHOOL OF PUBLIC HEALTH MAY 2009

It's okay to ask:

Development of a question prompt list for patients with brain tumours

A question prompt list (QPL) is a list of questions for a patient or carer to ask a doctor should they desire[1]. It is designed to help patients decide on and then seek answers to the most meaningful questions at each medical consultation. This may assist persons who do not know what questions to ask, or do not know how to articulate their concerns, and also encourages open communication[1].

Previous research has shown that persons diagnosed with brain tumours and their caregivers have a number of difficulties in navigating the medical care, and report needing more information and support[2]. The aim of this study was to develop a QPL for patients with brain tumours, to help patients, family members and health professionals to discuss issues of importance or concern.

How the QPL was developed

A qualitative analysis was conducted of patient resources and QPLs developed for other patient groups (for example, for patients seeing a surgeon). This showed that current materials examine seven major themes:

- Diagnosis
- Prognosis
- Symptoms & changes
- The health professional team
- Support
- Treatment & management
- After treatment.

These themes formed topics for the QPL, and questions were written for each topic. Feedback on this initial draft was then given by previous brain tumour patients and caregivers. This included suggesting new questions, rewriting questions, and highlighting unnecessary questions.

After changes were made, a number of health professionals reviewed the QPL. Feedback from these health professionals led to further changes being made, such as reducing the number of questions and adding tips for talking with your doctor.

Continued over page

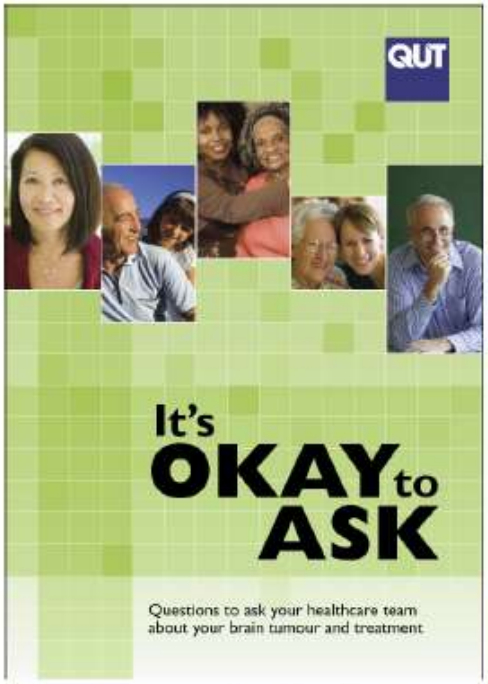
How the QPL was developed

Continued from page 1

The QPL was then analysed to determine its 'readability', or the grade level someone would need to have completed in school to be able to easily read the QPL. It is recommended that patient materials be written at the sixth grade level, to allow persons of low literacy to understand them[3]. To achieve this, further changes were made, such as using simpler language and shorter sentences.

The QPL was then professionally designed, and the final draft was again reviewed by past patients & caregivers.

Overall, twelve past patients, six family members and eight health professionals provided feedback to help develop the final QPL (right).



Front cover of the final QPL

Where to from here?

The QPL is now being tested with patients newly diagnosed with brain tumours in several Brisbane hospitals. This will allow us to find out if providing the QPL helps people to ask questions of their doctors, and to have their questions answered.

This pilot testing of the QPL will also allow us to make further changes if needed, before distribution to interested health professionals, patients and carers.

References

1. Clayton J, et al., Asking questions can help: development and preliminary evaluation of a question prompt list for palliative care patients. *British Journal of Cancer*, 2003. 89(11): pp. 2069-77.
2. Janda M, et al., Supportive care needs of people with brain tumours and their carers. *Supportive Care in Cancer*, 2006. 14(11): pp. 1094-1103.
3. Davis, TC., et al., The gap between patient reading comprehension and the readability of patient education materials. *Journal of Family Practice*, 1990. 31(5): 533-8.

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APPENDIX N.

STUDY 2 QUESTION PROMPT LIST

Please see separate file, ‘It’s okay to ask’.

It's OKAY to ASK

Questions to ask your healthcare team about your brain tumour and treatment

This booklet is called **It's okay to ask**. It contains questions you may want to ask your doctors or other health staff. It was written with the help of brain tumour survivors and their families, and doctors and nurses.

This booklet aims to help you get the information and support you need. It may give you a starting point by listing questions that both patients and doctors have found helpful.

The first few pages of this booklet have questions that might be useful to you at the start. These are printed on yellow pages. More detailed questions are then listed about:

- diagnosis
- prognosis (what to expect in the future)
- symptoms and changes
- the health professional team
- support
- treatment and management, and
- after treatment.

You may only want to look at these topics if they are of particular interest for you right now.

Not all questions will apply to you or to the type of tumour you have. You may not want to ask some of these questions, and that's okay. Everyone is different. Some people want to know a lot of details. They feel more in control when they know all of the facts. Others want only small amounts of information. They get upset when they are told too many details. They may want simple directions – what pill to take or what their treatment will be, and when it will be done. Don't be afraid to tell your doctor how much or how little you want to know.

You may have other questions not listed here. There is room to write your own questions or notes. You may also find that for some questions, there are no easy answers. Answers may take time to be found, or there may be no answer at all, except to wait and see. However, talking to your doctors and nurses can allow them to help you deal with your concerns.

Handy hints for talking to your doctor

- Let your doctor know at the beginning of your visit that you have questions. If you have a lot of questions or concerns, ask for a longer time with the doctor when making your appointment.
- Ask your doctor who else might be able to give useful information. This may be other members of the treatment team, local support groups, or other health professionals in your area.
- Take a trusted friend or family member to your doctor's visit. Another set or ears may help. Everything is new to you. People often need to hear new information a number of times.
- Unless you tell your doctor that you don't understand something, he or she will probably think that you do. It's important to tell your doctor if you don't understand.
- Remember – asking questions is an important part of your visit to your doctor. By asking questions, your doctor can clear up doubts, concerns or worries. It is an important way to get things straight.

Initial questions you may wish to ask

Diagnosis

1. Can you write down the name of my tumour?
2. Where is it in my brain? What does that part of the brain do?
3. I'm not sure how to tell my family or child(ren) about this – how I can explain it?
4. What seems to have worked for others to deal with the stress of this diagnosis?

For further questions, see page 11.

Prognosis (what to expect in the future)

5. What are the chances of curing my tumour?
6. Could my tumour improve by itself? Will it get worse if it is not treated?

For further questions, see page 13.

Symptoms and changes

7. What symptoms may occur in the future?
8. Is how I am feeling at the moment normal for my condition?
9. Will I be able to do the same things I did before? Do I need to rest? Will I still have the same energy?

For further questions, see page 14.

The health professional team

10. Who is in charge of my care?
11. What other services are available for me? If I need to access other services, do I need a referral?
12. Who should I contact if I have questions about my treatment?

For further questions, see page 16.

Support

13. What services are available to help me through my illness and treatment?
14. Is there someone who can help me cope with the changes my family and I are going through?
15. Could you recommend trustworthy websites about my tumour, treatment or for support?
16. Who can tell me about government support or financial assistance my family or I may be eligible for?
17. Can you put me in touch with someone who has been through this?

For further questions, see page 18.

Treatment and management

18. In your opinion, what treatment is best for me? Why?
19. Are there any new or experimental treatments or clinical trials that might help me, here or at other hospitals?
20. Can you refer me to someone you trust for a second opinion?
21. How will having this treatment influence my everyday activities? Will I be able to work/travel/drive?
22. How is my progress assessed?

Surgery

23. Do you expect to remove the whole tumour, or part of it?
24. What will I experience when I wake up after the surgery? What tubes or drips will I have in?

Oral medications

25. What are these tablets for?
26. What do I do if I miss a dose, or bring it up (vomit it), or take too many pills?

Living healthily

27. Can I keep working during treatment? How can I manage symptoms and side effects at work?

28. Are there any supplements or changes to diet that could help me stay healthy during treatment?

Complementary and alternative medicines and therapies

29. Are there any complementary or alternative medicines or therapies that may help me? Are there any that I should avoid?

For further questions, see page 21.

After treatment

30. Will I need to have more treatments in the future? What for?

31. What can I do to help with my recovery?

For further questions, see page 27.

Before you read on ….

Further questions are listed on the following pages. These may be useful to you if you'd like to ask more questions about a topic.

However, some of the questions may not apply to you, as different tumours have different effects and treatments. There may also be some questions or topics that you don't want to read about right now, or that might be upsetting to think about. You may want to decide which topic is important for you right now before reading on.

The table of contents on the next page lists the headings of these sections. These are colour-coded to match the tabs on the sides of the pages to make them easy to find. For example, if you are interested in Support look for the **red** colour coded pages.

Table of Contents

Diagnosis

- Are there any other names for my tumour?
- Is it slow – or fast-growing?
- How extensive is it? How much tumour is there?
- What caused this tumour? Is my family likely to be at greater risk of developing a brain tumour?
- Is there someone I or my family can talk to, to help us cope with this?

Tests

- What information will this test give us? How will this information influence my treatment or care?
- What is involved with having the test? Will it hurt?
- How old is the test equipment? When was it last tested or used?
- When will I get the results of my test, and who will tell me my results?
- Can I have a copy of my test results?
- Should I continue my usual activities or routines until we receive the test results? Is there anything I should do or not do?

Other questions or notes

Prognosis

- How do you think I am going?
- Is my tumour likely to come back after it has been treated?
- If the tumour is likely to return, how long will I have before it returns?
- What is the average survival time for this type of tumour? What is the longest you know of?
- What are my chances of surviving this?
- Could my tumour become more aggressive in the future?
- What factors will you look at to predict how I will do?
- If my tumour cannot be cured, what can I expect in the future? What will my best and worst days be like?

Other questions or notes

Symptoms and changes

- What changes are normal and to be expected?
- Are there any problems that I should look out for, and what do I do if they occur?
- How long will the symptoms last for? Are they permanent?
- What symptoms or changes do I need to tell you about?

Seizures

- Am I likely to have seizures?
- What should I tell my family to do if I have a seizure?
- In what situations should I go to hospital or call an ambulance?
- What does it look like to have a seizure? What does it feel like?
- Are there warning signs for a seizure?

- Will my physical appearance change?
- Am I still going to be able to work?
- Is it okay for me to drive? Do I need to tell driving authorities about my tumour?
- Will my sexual life be affected?
- How can I deal with feelings of grief and loss?

Changes in thinking, behaviour and personality

- In what ways are my thinking, my behaviour or my personality likely to change based on my tumour's location?
- Can you refer me to be assessed for changes in thinking?
- How will I know if my thinking or behaviour changes?

Other questions or notes

The health professional team

- What different types of doctors and other staff will care for me?
- When will I meet the people involved in my care?
- On average, how many people like me do you treat each year?
- Who can I talk to if I'm worried about my care?
- Will someone talk with my GP about my tumour and treatment?
- Can someone get an interpreter to help us?
- Can I talk to a doctor or staff member from my own culture?

Multidisciplinary teams

- Do you work as part of a multidisciplinary team?
- What does having a multidisciplinary team mean for me?
- How will the team coordinate my care?

Contacting doctors and other health professionals

- Who can I talk to if I receive conflicting information or advice?
- Who is my first point of contact?
- What issues should I talk to my GP about, and what should I discuss with my oncologist?
- Can I talk to someone about managing my medications?
- Do I contact the same people when I'm an outpatient as when I'm in hospital?
- How can I get in touch with you out of hours? What about in case of an emergency?

Doctors' visits

- Who will I see next, when and where?
- When will I see you again?
- How often will I see you?

Other questions or notes

Support

- How do I access support services when I go back home?
- Can you put me in touch with organisations which provide information and support for people like me?
- What should I say to my family and friends?
- How can I help my family to support me?
- Should I let my children's school know of my illness? How can they support my children while I'm ill?
- What if I am not coping or feel down?
- Is there anyone I can speak to about my spiritual or religious needs?
- Who can help me make a will and/or Advance Medical Directive?

Information

- Do you have information in other languages?
- Do you have any information I could give my family or children?

Practical issues

- Where should I park when I come in for treatment?
- Am I eligible for a disability parking permit? How do I get it?
- Can I get taxi vouchers if I can no longer drive?
- Where can I or my family stay if we have to travel for treatment?
- Am I eligible for services to help me out at home or in the garden? Can I receive home nursing care?
- Is there anyone who can teach my family how to look after me at home?
- Where can I borrow or hire equipment to help me at home?
- Where can I get a wig or bandana?

Financial issues

- How much will my appointments cost and what will I get back from Medicare?
- How would my treatment differ in the public or private system? How would my out-of-pocket costs differ?
- What documentation do I need to keep for my health insurance?

- What can I do if my private health insurer refuses to pay for something?
- Is there someone I can talk to about financial matters?
- Is there any way I can get medications more cheaply?
- Can I get help with the costs of tests or treatments?
- What financial assistance is available for me and my family if we travel for tests or treatment?
- Can I access my superannuation to help with the costs of my illness?
- Do any other organisations offer financial help for people in my situation?

Peer support

- Do you know of any support groups I could attend? What could they offer me?
- What telephone or online support groups or services can I use?

Other questions or notes

Treatment and management

- Are there guidelines for how to treat people with my kind of tumour?
- How long do I have before I need to decide what treatments to have?
- What are my options if my treatment doesn't work?
- Is there a point when I should consider stopping treatment? How will I know if I'm at this point?
- What is my overall treatment plan? What will happen next after my current treatment?
- What could change my treatment plan?
- How can I guide those closest to me to make medical decisions for me, if I am no longer able to do so for myself?

Second Opinions

- Can I get a second opinion about my treatment options, even if I want to stay with you for my treatment?
- How do I get access to my medical records to enable another doctor to give a second opinion?

Questions you could ask about each treatment option

- How will this treatment affect my symptoms and chances of survival?
- What will the treatment involve? What will I experience?
- How long until I see some effects of the treatment?
- What follow-up tests will I need during/after treatment?
- Where will I have the treatment? Can I have it somewhere closer to home? Can I have it as an outpatient?
- Who will perform or give me the treatment? Will it be someone specialising in this treatment or in treating brain tumours?
- Will this treatment impact on my fertility? What options do I have to protect or manage my fertility?
- What physical effects will I see or feel during or after treatment? How likely are these effects?
- How long will the effects last? Will they continue after I finish treatment?
- Can we prevent the side effects of treatment? What can we do to control or manage treatment side effects?

Surgery

- How will you do the surgery?
- Will you put my head in a frame to hold it still while you operate?
- Where will you make the incision? How big will it be?
- Is there anything that could change your plan for my surgery?
- Will this surgery cure me, or will it help control my symptoms?
- What do I need to take into hospital with me?
- How long will I be in hospital after surgery?
- How long until we know if the surgery has been successful?

After surgery

- Did you remove the entire tumour? Why or why not?
- How much tumour is left? Where is it?

Oral medications

- What can I do if I have problems taking my pills?
- How long do I have to keep taking these medications?
- Should I keep taking my existing medicines whilst I am on these?
- Will these medications have any effect on my existing medical conditions?
- Can I get these tablets from my usual chemist?
- Should I buy all the repeats up front, or could my prescription or dose change?
- If I have a seizure, should I keep taking my seizure medication? Should I change the dose?

Chemotherapy

- What drugs will be given to me in my chemotherapy regimen? In what doses?
- How will my chemotherapy be given?
- Will I need to take any measures to protect myself or others during or after my chemotherapy?
- Do I need to use contraceptives (birth control) while I am receiving chemotherapy?

Radiotherapy

- What type of radiotherapy will I receive?
- What sort of procedures will I have to undergo before the radiotherapy?
- Will I need to wear a mask during radiotherapy? How will you make it?
- Can you teach me relaxation or visualisation techniques to help during my treatment?
- How can I care for my skin while I am having radiotherapy?
- Will radiotherapy affect my thinking?

Living healthily

- Can I continue to drive while I'm having treatment?
- How can I manage my fatigue? Should I rest? Could exercise help?

Complementary and alternative medicines and therapies

- How do I know if an alternative medicine or therapy is safe?
- Can you recommend any trustworthy sources of information or websites about alternative therapies?
- Can I take my usual herbal medicines (or other therapies) during my treatments?
- Could any of the other medicines or therapies I use cause problems with my medical treatment?
- Do I need to tell you about other medicines, supplements or therapies I am using?
- Can my alternative therapist contact you to discuss my care?

Clinical trials

- What are clinical trials?
- Are there any clinical trials that might be relevant to me?
- What would being in the trial involve?
- What would I have to pay if I went in the trial?
- Who do I contact if I have problems while I'm in a trial?

Palliative care

- What is palliative care? What can it offer me?
- Can I get help from the palliative care team as an outpatient?

Other questions or notes

After treatment

- What tests will I need to have in the future? What for? How often will I need to have them?
- Who will I continue to see after finishing treatment? How often will I see them?
- What should I do if I am worried about my tumour coming back?
- If my tumour comes back, what treatments can I have?

Recovery and getting back to normal

- What can I expect in terms of my recovery?
- How long will it take for me to get back to normal?
- Will any of the symptoms or changes be permanent?
- Who can I talk to about coping with the changes in my life as I get better?
- What should I consider when thinking about returning to work?
- Can you refer me to someone to help me to get back to work?
- What should I tell my employer about my illness?
- When will I be able to start driving again?

Other questions or notes

It's OKAY to ASK

Published by

The School of Public Health,
Queensland University of Technology, 2008.

APPENDIX O.

STUDY 3 HUMAN RESEARCH ETHICS COMMITTEE APPROVALS

University Human Research Ethics Committee

HUMAN ETHICS APPROVAL CERTIFICATE

NHMRC Registered Committee Number EC00171

Dear Ms Danette Langbecker

A UHREC should clearly communicate its decisions about a research proposal to the researcher and the final decision to approve or reject a proposal should be communicated to the researcher in writing. This Approval Certificate serves as your written notice that the proposal has met the requirements of the *National Statement on Research involving Human Participation* and has been approved on that basis. You are therefore authorized to commence activities as outlined in your proposal application, subject to any specific and standard conditions detailed in this document.

Within this Approval Certificate are:

* Project Details
* Participant Details
* Conditions of Approval (Specific and Standard)

Researchers should report to the UHREC, via the Research Ethics Officer, events that might affect continued ethical acceptability of the project, including, but not limited to:

(a) serious or unexpected adverse effects on participants; and
(b) proposed significant changes in the conduct, the participant profile or the risks of the proposed research.

Further information regarding your ongoing obligations regarding human based research can be found via the Research Ethics website http://www.research.qut.edu.au/ethics/ or by contacting the Research Ethics Coordinator on 07 3138 2340 or ethicscontact@qut.edu.au

If any details within this Approval Certificate are incorrect please advise Research Ethics within 10 days of receipt of this certificate.

Research Ethics Officer _____ Date 16/9/08
(on behalf of the Chairperson, UHREC)

Project Details

Category of Approval: Full Application

Approved Until: 16/09/2011

Approval Number: 0800000549

Project Title: It's okay to ask: pilot evaluation of a tool to facilitate information exchange for adults with brain tumours

Project Chief Investigator: Ms Danette Langbecker

Other Project Staff/Students:
Dr Monika Janda , Prof Patsy Yates , Dr David Walker , Ms Vivien Biggs

Experiment Summary:
Conduct a preliminary evaluation of the brain tumour specific QPL (question prompt list) among newly diagnosed patients with brain tumours and their health professionals.

Participant Details

Participants:
Approximately 40, including 30 brain tumour patients and 5-10 health professionals

Location/s of the Work:
St Andrew's War Memorial Hospital and The Wesley Hospital

RM Report No. E801 Version 2

University Human Research Ethics Committee

HUMAN ETHICS APPROVAL CERTIFICATE

NHMRC Registered Committee Number EC00171

Conditions of Approval

Specific Conditions of Approval:
No special conditions placed on approval by the UHREC. Standard conditions apply.

Standard Conditions of Approval:

The University's standard conditions of approval require the research team to:

1. Conduct the project in accordance with University policy, NHMRC / AVCC guidelines and regulations, and the provisions of any relevant State / Territory or Commonwealth regulations or legislation;

2. Respond to the requests and instructions of the University Human Research Ethics Committee (UHREC);

3. Advise the Research Ethics Officer immediately if any complaints are made, or expressions of concern are raised, in relation to the project;

4. Suspend or modify the project if the risks to participants are found to be disproportionate to the benefits, and immediately advise the Research Ethics Officer of this action;

5. Stop any involvement of any participant if continuation of the research may be harmful to that person, and immediately advise the Research Ethics Officer of this action;

6. Advise the Research Ethics Officer of any unforeseen development or events that might affect the continued ethical acceptability of the project;

7. Report on the progress of the approved project at least annually, or at intervals determined by the Committee;

8. (Where the research is publicly or privately funded) publish the results of the project is such a way to permit scrutiny and contribute to public knowledge; and

9. Ensure that the results of the research are made available to the participants.

Modifying your Ethical Clearance:

The University has an expedited mechanism for the approval of minor modifications to an ethical clearance (this includes changes to the research team, subject pool, testing instruments, etc). In practice this mechanism enables researchers to conduct a number of projects under the same ethical clearance.

Any proposed modification to the project or variation to the ethical clearance must be reported immediately to the Committee (via the Research Ethics Officer), and cannot be implemented until the Chief Investigator has been notified of the Committee's approval for the change / variation.

Requests for changes / variations should be made in writing to the Research Ethics Officer. Minor changes (changes to the subject pool, the use of an additional instrument, etc) will be assessed on a case by case basis and interim approval may be granted subject to ratification at the subsequent meeting of the Committee.

It generally takes 7 -14 days to process and notify the Chief Investigator of the outcome of a request for a minor change / variation.

Major changes to your project must also be made in writing and will be considered by the UHREC. Depending upon the nature of your request, you may be asked to submit a new application form for your project.

Audits:

All active ethical clearances are subject to random audit by the UHREC, which will include the review of the signed consent forms for participants, whether any modifications / variations to the project have been approved, and the data storage arrangements.

End of Document

UnitingCare Health

Human Research Ethics Committee

ABN: 87 842 457 440

1st Floor Moorlands House, The Wesley Hospital
451 Coronation Drive, Auchenflower Q 4066

PO Box 499 Toowong Q 4066
Phone: 3232 7500 Facsimile: 3232 7109
Email: ethics@uchealth.com.au

15th October 2008 *Please quote our reference:* 200841

Ms Danette Langbecker
Queensland Institute of Technology
IHBI School of Public Health
Victoria Park Road
KELVIN GROVE QLD 4059

Dear Ms Langbecker

RESEARCH PROPOSAL: *It's okay to ask: pilot evaluation of a tool to facilitate information exchange for adults with brain tumours*

I am pleased to advise that the UnitingCare Health Human Research Ethics Committee has reviewed the abovenamed research proposal and has granted ethical approval, subject to changes requested by the Committee to the Patient Information Sheet and Consent Form. Thank you for your response to those requirements. I am now able to confirm approval.

If your project involves inpatients or the use of hospital facilities, it will be necessary for you to obtain the approval of the Director of Medical Services before commencement.

It is a strict condition of approval that any departure from the protocol detailed in the proposal submitted for approval be reported immediately to the Committee. If there is any change to the status of the project, this should be reported also.

Approval for the project is given subject to your agreement to UnitingCare Health requirements for the monitoring of research, which have been based on the Australian Health Ethics Committee guidelines, a copy of which is enclosed. Please note the requirement to submit a report annually or at the completion of the project, as appropriate.

With best wishes

Yours sincerely

Douglas Killer MBBS FRACP
Executive Officer

UnitingCare Health Human Research Ethics Committee

Information for Researchers Gaining Ethical Approval for Research Projects

Monitoring of Research

The Australian Health Ethics Committee now requires institutional ethics committees to monitor research projects to which they have given ethical approval. The principal reason for the monitoring of research projects is to ensure that their conduct does not jeopardize the rights and interests of those who have consented to take part as subjects in them. By monitoring the projects to which approval has been given, Ethics Committees will also be helping to ensure that researchers are practising responsible science and that the good reputation of the institution that is the setting for the research is maintained.

UnitingCare Health Hospital Requirements

Within UnitingCare Health, researchers who have approval from the Human Research Ethics Committee for their respective projects will undertake the following:

1 A report on the approved project will be provided at least annually. This does not preclude the Ethics Committee from asking for a report at more frequent intervals.

2 Provision of relevant reports will be the responsibility of the applicant. In the case of multi-centre research, a report from the principal investigator may suffice. However, it is the applicant within who is responsible for submitting the report to the Ethics Committee.

3 The report should provide details of the following:

- 3.1 Status of the project (completed/in progress/abandoned/not commenced).
- 3.2 Compliance with the conditions of ethical approval, including security of records and procedures for consent.
- 3.3 Compliance with any special conditions stated by the Ethics Committee as a condition of ethical approval.

4 Applicants (or principal investigators) are responsible for notifying the Ethics Committee immediately of matters that might affect continued ethical acceptability of the project including:

- 3.1 Adverse effects of the project on subjects and of steps taken to deal with these
- 3.2 Changes in the research protocol, together with an indication of ethical implications (if any)
- 3.3 Other unforeseen events.

Where the above requirements are not adhered to, the Ethics Committee may withdraw ethical approval for a project.

Douglas Killer MBBS FRACP
Executive Officer

Royal Brisbane and Women's Hospital
Health Service District

Queensland Government

Queensland Health

Enquiries to: Dr David Alcorn, A/Executive Director
Phone: 07 3636 1575
Fax: 07 3636 4481
Ref:

Ms Danette Langbecker
School of Public Health
QUT
Victoria Park Road
KELVIN GROVE. QLD. 4059

Danette

Dear Ms Langbecker

Re: Protocol HREC/09/QRBW/55: It's okay to ask: pilot evaluation of a tool to facilitate information exchange for adults with brain tumours

Thank you for submitting an application for authorisation of the above research project. I am pleased to inform you that authorisation has been granted for this study to take place at the Royal Brisbane and Women's Hospital.

If you have any questions relating to this authorisation please contact the Research Support Officer on 3636 8579. In addition to the conditions of approval imposed by the Human Research Ethics Committee, you are required to submit any amendments to the Research Support Officer, as well as to the Human Research Ethics Committee. Amendments may include changes to the protocol, budget, information sheets, consent forms, clinical trial agreements and any other research-related documentation.

I wish you every success with your research.

Yours sincerely

David Alcorn

Dr David Alcorn
A/Executive Director
29/04/2009

c.c. Dr Robyn Cheuk, Consultant Radiation Oncologist, Cancer Care Services, RBWH

Royal Brisbane and Women's Hospital
Metro North Health Service District

Office of the Human Research Ethics Committees

Queensland Government
Queensland Health

Enquiries to: Odette Petersen Coordinator
Phone: 07 3636 5490
Fax: 07 3636 5849
Our Ref: HREC/09/QRBW/55
E-mail RBWH-Ethics@health.qld.gov.au

Ms Danette Langbecker
School of Public Health
Queensland University of Technology
Victoria Park Road
Kelvin Grove Q 4059

Dear Ms Langbecker,

Re: Ref Nº: HREC/09/QRBW/55: It's okay to ask: pilot evaluation of a tool to facilitate information exchange for adults with brain tumours

Thank you for submitting the above project for ethical and scientific review. This project was considered at the Royal Brisbane & Women's Hospital Human Research Ethics Committee (HREC) meeting held on 16 March, 2009.

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. Attached is the HREC Composition with specialty and affiliation with the Hospital *(Attachment 1)*.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the District CEO or Delegate of that site has been obtained.

A copy of this approval will also be sent to the District Research Governance Office (RGO). Please ensure you submit a completed Site Specific Assessment (SSA) Form to the RGO for authorisation from the CEO or Delegate to conduct this research at the Royal Brisbane & Women's Hospital Metro North District.

I am pleased to advise that the Human Research Ethics Committee has granted approval of this research project on 30 March, 2009. HREC approval is valid for three (3) years from the date of this letter. The documents reviewed and approved include:

Document	Version	Date
Application: NEAF Online Form	2.0	
Covering Letter: Submitting Research Application		23 February 2009
Interview Schedules / Topic Guides: Initial Interview		
Interview Schedules / Topic Guides: Follow-Up Interview		
Investigator CV: Danette Langbecker		
PAH Information Sheet	1	20 February 2009
RBWH/PAH Permission to Contact	1	20 February 2009
PAH Patient Brochure	1	20 February 2009
RBWH Patient Brochure	1	20 February 2009
Letter of Approval from UnitingCare Health Human Research Ethics Committee		15 October 2008
QUT Human Ethics Approval Certificate	2	16 September 2008
Health Professional Participants Semi-Structured Interview: Topic Guide	1	05 August 2008
Resource Funding Schedule: Estimated Costs		
Ethics Addendum		
Information Booklet - "About Brain Tumours"		
References List		
Medical Record Abstraction Form		
Protocol: Research Protocol	2	27 March 2009
Questionnaire: Guide to Questionnaires	2	20 February 2009
Response to Request for Further Information: Answers to HREC questions		27 March 2009
Patient Information Sheet/Consent Form: Consent Form for QUT Research Project	3	24 March 2009
Patient Information Sheet/Consent Form: RBWH Participant Information Sheet	2	24 March 2009
Patient Information Sheet/Consent Form: Health Professional Information Sheet	2	20 February 2009
Patient Information Sheet/Consent Form: Consent Form for QUT Research Project: Health Professionals	3	24 March 2009

Please note the following conditions of approval:

1. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
    - Unforeseen events that might affect continued ethical acceptability of the project. Serious Adverse Events must be notified to the Committee as soon as possible. In addition, the Investigator must provide a summary of the adverse events, in the specified format, including a comment as to suspected causality and whether changes are required to the Patient Information and Consent Form. In the case of Serious Adverse Events occurring at the local site, a full report is required from the Principal Investigator, including duration of treatment and outcome of event.

2. Amendments which do not affect either the ethical acceptability or site acceptability of the project (e.g. typographical errors) should be submitted in hard copy to the HREC Coordinator. These should include a covering letter from the Principal Investigator providing a brief description of the changes and the rationale for the changes, and accompanied by all relevant updated documents with tracked changes.

3. Proposed amendments to the research project which may affect both the ethical acceptability and site suitability of the project must be submitted firstly to the HREC for review and, once HREC approval has been granted, then submitted to the Research Governance Office.

4. Amendments to the research project which only affect the ongoing site acceptability of the project are not required to be submitted to the HREC for review. These amendment requests should be submitted directly to the Research Governance Office (by-passing the HREC).

5. Amendments to the research project which may affect the ongoing ethical acceptability of a project must be submitted to the HREC for review. Major amendments should be reflected in a revised online NEAF (accompanied by all relevant updated documentation and a covering letter from the Principal Investigator, providing a brief description of the changes, the rationale for the changes, and their implications for the ongoing conduct of the study). Hard copies of the revised NEAF, the cover letter and all relevant updated documents with tracked changes must also be submitted to the HREC Coordinator as per standard HREC SOP. Further advice on submitting amendments is available from http://www.health.qld.gov.au/cpic/documents/ethics/researcher_userguide.pdf

6. The HREC will be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.

7. The Principal Investigator will provide an Annual Report to the HREC and at completion of the study in the specified format.

8. The District Administration and the Human Research Ethics Committee may inquire into the conduct of any research or purported research, whether approved or not and regardless of the source of funding, being conducted on Hospital premises or claiming any association with the Hospital, or which the Committee has approved if conducted outside Royal Brisbane & Women's Hospital Metro North Health Service District.

Should you have any queries about the HREC's consideration of your project please contact the HREC Coordinator on 07 3636 5490. The HREC terms of Reference, Standard Operating Procedures, membership and standard forms are available from http://www.health.qld.gov.au/cpic/ethics/reagu_homepage.asp

Once authorisation to conduct the research has been granted, please complete the Commencement Form *(Attachment II)* and return to the office of the Human Research Ethics Committee.

The HREC wishes you every success in your research.

Yours sincerely,

Dr Conor Brophy
Chairperson RBWH Human Research Ethics Committee
Metro North **DISTRICT**
01/04/2009

Princess Alexandra Hospital
Health Service District

Queensland Government

Queensland **Health**

Office of the Human Research Ethics Committee

Enquiries to: Ethics Manager
Phone: (07) 3240 7672
Fax: (07) 3240 7667
Our Ref: 2009/075
E-mail PAH_Ethics_Research@health.qld.gov.au
Date 20 April 2009

Ms Danette Langbecker
School of Public Health
Queensland Univirsity of Technology
Victoria Park Road
Kelvin Grove 4131

APPROVAL LETTER – PRINCESS ALEXANDRA HOSPITAL

Dear Ms Langbecker

Research Protocol: 2009/075

It's ok to ask: pilot evaluation of a tool to facilitate information exchange for adults with brain tumours	
NEAF:	**Version 2.0**
Participant Information and Consent Form: **PAH Patient Brochure** **RBWH Patient Brochure** **RBWH / PAH Permission to contact** **PAH Patient Information Sheet** **RBWH Patient Information Sheet** **Patient Consent Form** **About Brain Tumours**	 **Version 1, dated 20 February 2009** **Version 1, dated 20 February 2009** **Version 1, dated 20 February 2009** **Version 1, dated 20 February 2009** **Version 1, dated 20 February 2009** **Version 2, dated 20 February 2009**
Research Protocol:	**Version 1, dated 23 February 2009**
Questionnaires: **Patient Initial Interview** **Patient Follow-up Interview** **Medical Record Abstraction Form** **Health professional participant semi-structured interview** **Guide to Questionnaires**	 **Version 3, dated 20 February 2009** **Version 3, dated 20 February 2009** **Version 1, dated 4 August 2008** **Version 1, dated 5 August 2008** **Version 2, 20 February 2008**
Health Professional Information and Consent Form: **Health Professional Information Sheet** **Health Professional Consent Form**	 **Version 2, dated 20 February 2009** **Version 2, dated 20 February 2009**

At a meeting of the Princess Alexandra Hospital Human Research Ethics Committee (PAH HREC) held on 7/04/2009, the Committee reviewed the above research Protocol. The Princess Alexandra Hospital Human Research Ethics Committee is duly constituted, operates in accordance and complies with the current

National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research 2007.*

On the recommendation of the Human Research Ethics Committee approval is granted for your project to proceed. This approval is subject to researcher(s) compliance throughout the duration of the research with certain requirements as outlined in the *National Statement on Ethical Conduct in Human Research 2007 and Australian Research Code for the Responsible Conduct of Research.*

The following links have been provided for your convenience:
http://www.nhmrc.gov.au/publications/synopses/_files/e72.pdf
http://www.nhmrc.gov.au/publications/synopses/_files/r39.pdf

Some requirements are briefly outlined below. Please ensure that you communicate with the PAH HREC on the following:

- ***Protocol Changes:*** Substantial changes made to the protocol require HREC approval.
- ***Problems and SAEs:*** The HREC must be informed of any problems that arise during the course of the study which may have ethical implications. Serious adverse events must be notified to the HREC as soon as possible.
- ***Lapsed Approval***: If the study has not commenced within twelve months approval will lapse requiring resubmission of the study to the HREC.
- ***Annual Reviews:*** All studies are required by the NHMRC to be reviewed annually. To assist with reporting obligations an Annual Report template is available on the PAH HREC website. This form is required to be completed and returned to the HREC within the 12 month reviewing period.

As this research involves the recruitment of patients from the Princess Alexandra Hospital Health Service District (PAHHSD), it is my responsibility to remind you of your ongoing duty of care for all people recruited into projects or clinical trials whilst public patients. All conditions and requirements regarding confidentiality of public information and patient privacy apply. You are required to comply at all times with any application requirements of Australian Law including the Health Services Act, the Privacy Act and other relevant legislation, ethics obligations and guidelines which may be applicable to the PAHHSD from time to time including, without limitation, any requirement in respect of the maintenance, preservation or destruction of patient records.

When the study involves patient contact, it is your responsibility as the principal investigator to notify the relevant consultant and request their approval.

Should you have any problems, please liaise directly with the Chair of the HREC early in the program.

A copy of this letter should be presented when required as official confirmation of the approval of the Princess Alexandra Hospital Human Research Ethics Committee.

We wish you every success in undertaking this research.

Yours sincerely

David Theile

Dr David Theile Snr
DISTRICT CHIEF EXECUTIVE OFFICER
METRO SOUTH DISTRICT

6/5/09

Office	Postal	Phone	Fax
Princess Alexandra Hospital Health Service District	Ipswich Road Woolloongabba Q 4102	61 7 3240 7672	61 7 3240 7667

APPENDIX P.

STUDY 3 RECRUITMENT DOCUMENTS

To meet the requirements of the Human Research Ethics Committees of the hospitals involved, the study information booklet, participant information sheet and consent form were specific to each hospital or service. To avoid duplication, documents are shown for St Andrew's War Memorial Hospital and the Wesley Hospital. Documents for the other hospitals varied only in the details of hospitals and Human Research Ethics Committees involved.

General Study Information sheet supplied by Health professionals:

For more information about
It's okay to ask
contact Danette Langbecker at the Queensland University of Technology on 07 3138 5817 during office hours.

This project has been approved by the Queensland University of Technology Human Research Ethics Committee and by the ethics committees of St Andrew's War Memorial Hospital and The Wesley Hospital.

The Project Team

This study is being conducted by researchers from ihop (Improving Cancer Health Outcomes for People) at the Queensland University of Technology in collaboration with BrizBrain and Spine.

Patient brochure, Version 1, 06/08/2008.

QUT

BRIZBRAIN & SPINE RESEARCH FOUNDATON

It's okay to ask

Better meeting the needs of people newly diagnosed with brain tumours

can ihop

About the study

The diagnosis and treatment of a brain tumour is a difficult time for many people. Patients have reported difficulties finding out all they need and want to know.

With the help of doctors, nurses, patients and their families, researchers from the Queensland of Technology are developing a resource to help you get the information and support you need. Now we'd like to know if it helps.

How will the study do this?

We need assistance from men and women recently diagnosed with a brain tumour. By talking with people who receive our new resource, and those who don't, we will be able to see if it is useful to people in your situation.

improving cancer health outcomes for people

What will I be asked to do?

You will be asked to complete two interviews, a few weeks apart, to answer questions about your information needs, what information you have received, and whether this helped you. The researcher will come to see you in hospital or call you by telephone. These interviews will take about 45 minutes each. We would also like to ask your doctor about your disease and treatments.

How do I become involved?

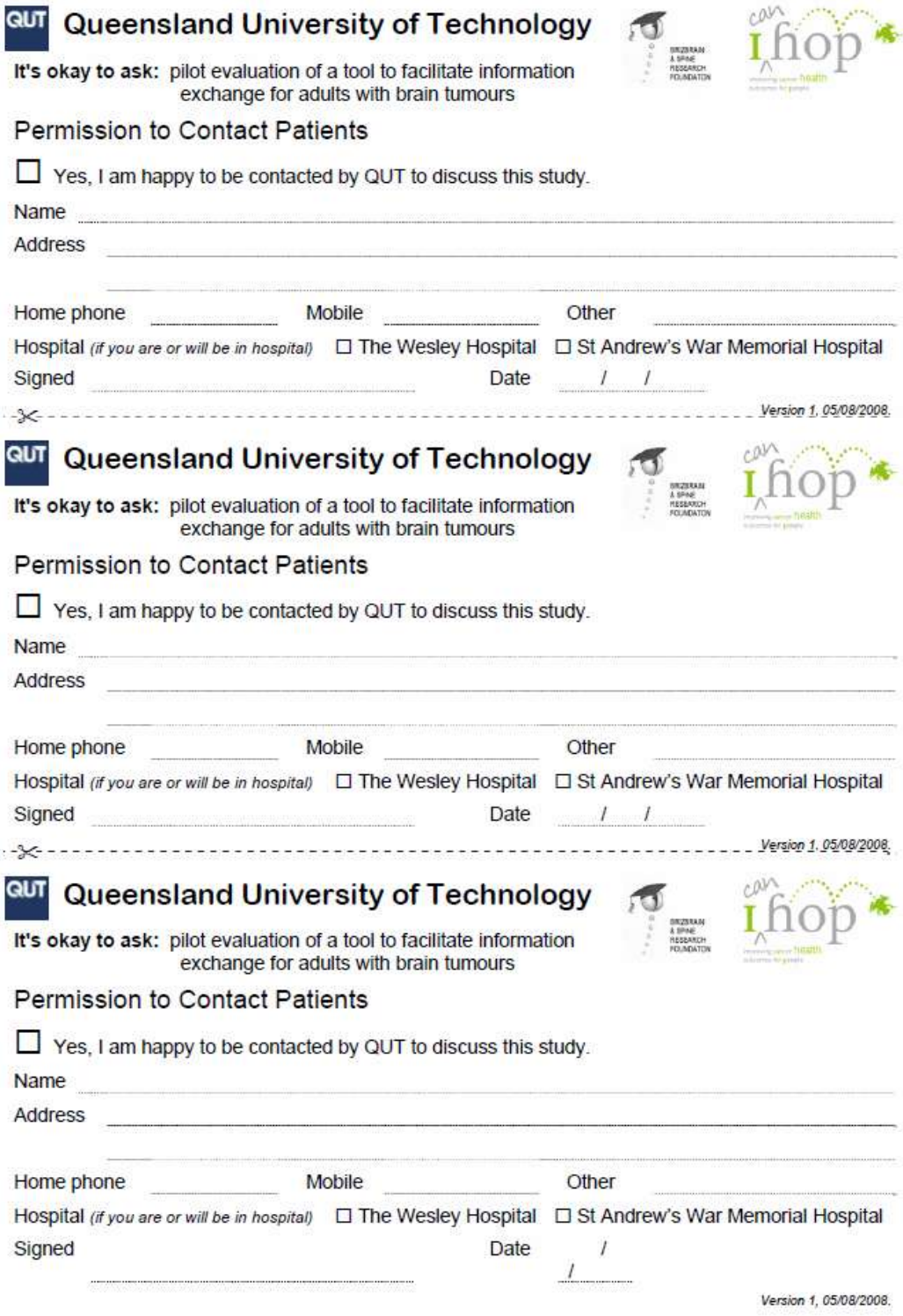
If you would like to know more, simply complete the attached form and leave it with your doctor or nurse. We will then contact you to explain the study in more detail.

Do I need to take part?

It is important for you to know that participating in this study is entirely voluntary. If you do not wish to participate, this will not affect your medical care in any way.

However, by participating you will be helping us to develop better resources for people with brain tumours in the future.

Form for patients to indicate consent to be contacted:



Queensland University of Technology

It's okay to ask: pilot evaluation of a tool to facilitate information exchange for adults with brain tumours

Permission to Contact Patients

☐ Yes, I am happy to be contacted by QUT to discuss this study.

Name .....

Address .....

Home phone ..... Mobile ..... Other .....

Hospital *(if you are or will be in hospital)* ☐ The Wesley Hospital ☐ St Andrew's War Memorial Hospital

Signed ..... Date ..... / ..... / .....

Version 1, 05/08/2008.

Queensland University of Technology

It's okay to ask: pilot evaluation of a tool to facilitate information exchange for adults with brain tumours

Permission to Contact Patients

☐ Yes, I am happy to be contacted by QUT to discuss this study.

Name .....

Address .....

Home phone ..... Mobile ..... Other .....

Hospital *(if you are or will be in hospital)* ☐ The Wesley Hospital ☐ St Andrew's War Memorial Hospital

Signed ..... Date ..... / ..... / .....

Version 1, 05/08/2008.

Queensland University of Technology

It's okay to ask: pilot evaluation of a tool to facilitate information exchange for adults with brain tumours

Permission to Contact Patients

☐ Yes, I am happy to be contacted by QUT to discuss this study.

Name .....

Address .....

Home phone ..... Mobile ..... Other .....

Hospital *(if you are or will be in hospital)* ☐ The Wesley Hospital ☐ St Andrew's War Memorial Hospital

Signed ..... Date ..... / ..... / .....

Version 1, 05/08/2008.

Participant Information Sheet:

Confidentiality

All comments and responses are anonymous and will be treated confidentially. The names of individual persons are not required in any of the responses.

Questions or further information

Please contact the researcher team members named on the front page of this brochure to have any questions answered or if you require further information about the project.

Concerns or complaints

QUT is committed to researcher integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Officer on 3138 2340 or ethicscontact@qut.edu.au. The Research Ethics Officer is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Information sheet, Version 1, 06/08/2008.

QUT

BRIZBRAIN & SPINE RESEARCH FOUNDATON

It's okay to ask

Participant information for QUT Research Project

Research Team Contact Details:

Danette Langbecker, PhD student
(07) 3138 5817
d.langbecker@qut.edu.au

Dr Monika Janda, Senior Research Fellow
(07) 3138 9674
m.janda@qut.edu.au

can I hop

About the study

This research aims to determine if we can help adults diagnosed with primary brain tumours better access the information they need and want. With the help of doctors, nurses, patients and their families, researchers from the Queensland of Technology are developing a resource to help you get the information and support you need. Now we'd like to know if it helps.

This project is being undertaken as part of a PhD project for Danette Langbecker. The project is funded by the Queensland University of Technology (QUT). QUT will not have access to individual data.

Your participation

You will be asked to complete two interviews, a few weeks apart, to answer questions about your information needs, what information you have received, and how you are coping. The researcher will come to see you in hospital or call you by telephone. These interviews will take about 45 minutes each. You will receive a brochure (either an existing brochure or our new resource) after your first interview to read if you wish. We would also like your permission to ask your doctor about your disease and treatments.

Consent to participate

Participation is voluntary and you can withdraw from participation at any time during the project without comment or penalty. Your decision to participate will in no way impact upon your current or future relationship with QUT (eg your grades) or with BrizBrain and Spine. If you do not wish to participate, this will not affect your medical care in any way.

We would like you to sign a consent form to confirm your agreement to participate.

Expected benefits and risks

Participating in this research may help you receive information and support, and you may benefit by sharing your journey and helping future patients.

We do not expect that you will be subject to any risks, although some people may become distressed when discussing their experience. The Cancer Council Queensland (phone 13 11 20) offers free support for people with brain tumours (whether cancer or not) and their families. QUT also provides limited free counselling for participants of QUT projects who experience distress as a result of their participation. To access this service, please contact the QUT Psychology Clinic on 3138 4578 and indicate you are a research participant.

It's okay to ask:
pilot evaluation of a tool to facilitate information exchange for adults with brain tumours

Consent Form for QUT Research Project

Statement of consent

By signing below, you are indicating that you:

- have read and understood the information document regarding this project
- have had any questions answered to your satisfaction
- understand that if you have any additional questions you can contact the research team
- understand that you are free to withdraw at any time, without comment or penalty
- understand that you can contact the Research Ethics Officer on 3138 2340 or ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project
- agree to participate in the project
- agree to be contacted again should further questions arise

Name _____.

Signature _____

Date _____ / _____ / _____.

APPENDIX Q.

STANDARD INFORMATION BROCHURE

The brochure ‘About brain tumours’ is not available online.

Please consult the hardcopy thesis or consult The Cancer Council Queensland to view this brochure.

The brochure ‘About brain tumours’ is not available online.

Please consult the hardcopy thesis or consult The Cancer Council Queensland to view this brochure.

The brochure ‘About brain tumours’ is not available online.

Please consult the hardcopy thesis or consult The Cancer Council Queensland to view this brochure.

The brochure ‘About brain tumours’ is not available online.

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Please consult the hardcopy thesis or consult The Cancer Council Queensland to view this brochure.

The brochure ‘About brain tumours’ is not available online.

Please consult the hardcopy thesis or consult The Cancer Council Queensland to view this brochure.

APPENDIX R.

STUDY 3 DATA COLLECTION FORMS

It's okay to ask:

pilot evaluation of a tool to facilitate information exchange for adults with brain tumours

Initial Interview

Ref:

Version 3, 20/02/2009.

Today's date: . . . / . . / ____

Time interview commenced: . . . : . .

Due to copyright restrictions,
some parts of this questionnaire
are not available online.
Please consult the hardcopy thesis or
the original source material.

18. Just a few more questions about your feelings. This question can be answered "not at all", "a little", "moderately", "very" or "extremely".

	Not at all	A little	Moder-ately	Very	Extre-mely	No response
Over the past two weeks, have you ever felt down, depressed, or hopeless?	1	2	3	4	5	-1
Over the past two weeks, have you ever felt nervous, anxious or fearful?	1	2	3	4	5	-1

7

20.	Have you ever been diagnosed of depression by a physician?	**Yes**	**No**	No response
21.	Have you ever been diagnosed of anxiety by a physician?	**Yes**	**No**	No response

And now just some final questions about you, to help us describe our participants.

24. Gender: ☐0 Male ☐1 Female

25. How old are you? ..... years No response

26. What is your present marital status? No response

- ☐0 Married
- ☐1 Living together
- ☐2 Separated
- ☐3 Divorced
- ☐4 Widowed
- ☐5 Never married

10

27. What is the highest level of education you have completed? No response

☐0	Some primary school	☐1	Primary school
☐2	Junior high	☐3	Senior high
☐4	Trade certificate, technical college or diploma	☐5	University degree
☐6	Other, please specify		

28. Have you ever worked in healthcare or a medical-related job? No response

☐0 Yes, please specify ..... ☐1 No

29. What language do you usually speak at home? No response

☐0 English ☐1 Other, please specify _____

30. How would you <u>best</u> describe your usual work situation? No response

☐0	Employed full-time
☐1	Employed part-time or casual
☐2	Full time home duties or home-carer
☐3	Student
☐4	Unemployed or looking for work
☐5	Retired
☐6	Permanently ill/ disabled/ unable to work
☐7	Other, please specify .....

31. What is your yearly household income from all sources before tax is taken out? No response

☐0 < $40,000 ☐1 $40,000 - < $80,000 ☐2 ≥ $80,000

32. What is your postcode? ..... And what suburb is that? . . . . . .

Thank you, this questionnaire is now complete!

We recognise that it has taken some time and would like you to know we really appreciate your assistance.

Time interview completed: _____ : _____

It's okay to ask:

pilot evaluation of a tool to facilitate information exchange for adults with brain tumours

Follow-up Interview

Ref:

Version 3, 20/02/2009.

Today's date: . . . / . . . / _____

Time interview commenced: . . . : . . .

14. People receive information about their illness from a lot of different sources. From whom or where have you received the most information about your illness?

_____ No response

18. I'd now like to ask your views about the brochure we gave you. Can you tell me if you agree completely, agree, neither agree nor disagree, disagree, or disagree completely, with the following statements.

	Agree compl-etely	Agree some-what	Neither agree nor disagree	Disagree some-what	Disagree compl-etely	No response
I found brochure to be helpful.	1	2	3	4	5	-1
The brochure made it easier to ask questions.	1	2	3	4	5	-1
There were questions in the brochure that were useful to me.	1	2	3	4	5	-1
The brochure helped me to put some of my questions or concerns into words.	1	2	3	4	5	-1
I found it overwhelming to read the brochure.	1	2	3	4	5	-1
I think the brochure will be useful to me in future.	1	2	3	4	5	-1
The brochure was easy to understand.	1	2	3	4	5	-1

19. What is your view on the length of the brochure? Was it…

	the right length?	too long?	too short?	No response

20.	Did you have enough time to read the booklet before your consultations?	Yes	No	Unsure		No response
21.	Would you have preferred to receive the booklet at different time?	Yes	No	Unsure		No response
22.	Have you read the booklet again since first receiving it?	Several times	1-2 times	Not at all		No response
23.	Did the booklet prompt you to ask your neurosurgeon any questions?	Yes	No	Unsure	Did not see	No response
24.	Did the booklet prompt you to ask your radio-oncologist any questions?	Yes	No	Unsure	Did not see	No response
25.	Did the booklet prompt you to ask your medical oncologist any questions?	Yes	No	Unsure	Did not see	No response
26.	Did the booklet prompt you to ask questions of other members of your team?	Yes	No	Unsure	Did not see	No response
27.	Did anyone else read the booklet (ie carer/ relative or friend)?	Yes	No	Unsure		No response
	Was the booklet helpful to them?	Very helpful	A bit helpful	Not helpful	Not sure	No response

28. For this final section, we would like to understand your views in your own words.
(Please note, these questions are a guide only.)

A lot of people diagnosed with tumours talk about difficulties getting the information they need or want. What information has been most important to you?

How do you think we can help people in your situation be better informed?

What did you do to try and find information?

Who have you talked to about your tumour?

How do you think someone in your situation can get the information they need?

Did you write down any questions for yourself to ask your doctor or nurse?

How have you used the information you've been given?

Could you suggest how we could improve the brochure to make it more useful?

Are there any other comments you would like to make about the brochure we gave you?

How has this experience of participating in research been for you?

Would you like to suggest any changes to our questionnaires to make this process easier for people, for when we do more research in the future?

Thank you, this questionnaire is now complete!

We recognise that it has taken some time
and would like you to know we really appreciate your assistance.

Time interview completed: . . . . : . . . .

Ref:

It's okay to ask:
pilot evaluation of a tool to facilitate information exchange for adults with brain tumours

Medical record abstraction form

1. Tumour details

hemisphere(s): ☐0 anterior right ☐1 posterior right ☐2 diencephalic
☐3 anterior left ☐4 posterior left ☐5 subtentorial
☐6 Other, please specify: .....

lobe(s): ☐0 frontal ☐1 parietal ☐2 occipital
☐3 temporal

tumour type: ☐0 glioblastoma ☐1 meningioma
☐2 astrocytoma ☐3 oligodendroglioma
☐4 neuroma ☐5 pituitary adenoma
☐6 ependymoma ☐7 mixed glioma
☐8 Other, please specify: .....

Has the tumour type been confirmed histologically? ☐0 yes ☐1 no

tumour stage at diagnosis: ☐1 I ☐2 II ☐3 III ☐4 IV

2. Treatments & procedures performed

(Please tick all that apply)

☐0 Biopsy ☐1 Surgical debulking ☐2 Radiotherapy
☐3 Chemotherapy ☐4 Other, please specify: .....

3. Functional status

Karnofsky Performance Scale (KPS) score: _____

Impairments suffered: *(Please tick all that apply)*

☐0 speaking or understanding speech ☐2 attention or concentration
☐1 abstract reasoning ☐3 memory
☐4 visual ☐5 motor
☐5 Other, please specify:

Please turn over

1

4. Has the patient previously been diagnosed with cancer?

☐0 No ☐1 Yes, please specify: .....

5. Patient's likely prognosis: *(Please tick only one)*

☐0 Weeks or months ☐1 Years ☐2 Normal life expectancy

Thank you for your assistance!

Medical record abstraction form, Version 2, 24/03/2009.

APPENDIX S.

STUDY 3 CODING MANUAL

Variable	Type	Measurement
Hospital	categorical dichotomous	Public or private
Time taken for interview 1	continuous	Time in minutes
Data collection for interview 1	categorical	In person or via telephone
Global health status at time 1	continuous	Score 0-100 (worst to best)
Physical functioning at time 1	continuous	Score 0-100 (worst to best)
Role functioning at time 1	continuous	Score 0-100 (worst to best)
Emotional functioning at time 1	continuous	Score 0-100 (worst to best)
Cognitive functioning at time 1	continuous	Score 0-100 (worst to best)
Social functioning at time 1	continuous	Score 0-100 (worst to best)
Fatigue at time 1	continuous	Score 0-100 (no to severe symptoms)
Nausea and vomiting at time 1	continuous	Score 0-100 (no to severe symptoms)
Pain at time 1	continuous	Score 0-100 (no to severe symptoms)
Dyspnoea at time 1	categorical dichotomous	No versus any symptoms
Insomnia at time 1	categorical dichotomous	No versus any symptoms
Appetite loss at time 1	categorical dichotomous	No versus any symptoms
Constipation at time 1	categorical dichotomous	No versus any symptoms
Diarrhoea at time 1	categorical dichotomous	No versus any symptoms
Financial difficulties at time 1	categorical dichotomous	No versus any symptoms
Future uncertainty at time 1	continuous	Score 0-100 (no to severe symptoms)
Visual disorder at time 1	continuous	Score 0-100 (no to severe symptoms)
Motor dysfunction at time 1	continuous	Score 0-100 (no to severe symptoms)
Communication deficit at time 1	continuous	Score 0-100 (no to severe symptoms)
Headache at time 1	categorical dichotomous	No versus any symptoms
Seizures at time 1	categorical dichotomous	No versus any symptoms

Variable	Type	Measurement
Drowsiness at time 1	categorical dichotomous	No versus any symptoms
Hair loss at time 1	categorical dichotomous	No versus any symptoms
Itchy skin at time 1	categorical dichotomous	No versus any symptoms
Weakness of legs at time 1	categorical dichotomous	No versus any symptoms
Bladder control at time 1	categorical dichotomous	No versus any symptoms
Information received at time 1	continuous	Score 0-100 (no to very much info)
Information received about the disease at time 1	continuous	Score 0-100 (no to very much info)
Information received about medical tests at time 1	continuous	Score 0-100 (no to very much info)
Information received about treatment at time 1	continuous	Score 0-100 (no to very much info)
Information received about other services at time 1	continuous	Score 0-100 (no to very much info)
Information received about non - medical treatments at time 1	categorical dichotomous	No versus any info
Information received about different places of care at time 1	categorical dichotomous	No versus any info
Information received about self help at time 1	categorical dichotomous	No versus any info
Written information received at time 1	categorical dichotomous	Yes or no
Information on tape/video/CD received at time 1	categorical dichotomous	Yes or no
Satisfaction with information at time 1	categorical dichotomous	Score 0-100 (not at all to very satisfied)
Wish to receive more information at time 1	categorical dichotomous	Yes or no
With had received less information at time 1	categorical dichotomous	Yes or no
Helpfulness of information received at time 1	categorical dichotomous	Score 0-100 (not at all to very helpful)
Attitude towards participation in decision making	categorical dichotomous	Prefer to leave decisions about my medical care & treatment up to doctor or prefer to participate in decisions

Variable	Type	Measurement
Attitude toward information about illness	categorical	Want only the info needed to care for self, want additional info only if good news, or want as much info as possible, good or bad
Information seeking preference	categorical dichotomous	Low or high information seeker
Total stress (Impact of event) score at time 1	continuous	0-75 (lowest to highest)
Avoidance score at time 1	continuous	0-40 (lowest to highest)
Intrusiveness score at time 1	continuous	0-35 (lowest to highest)
Depression symptoms at time 1	categorical ordinal	Ranked categories of depressed feelings
Anxiety symptoms at time 1	categorical ordinal	Ranked categories of anxious feelings
Self-efficacy for coping with cancer	continuous	33-297 (low to high)
Self-efficacy re maintaining activity and independence	continuous	1-9 (low to high)
Self-efficacy re seeking and understanding medical information	continuous	1-9 (low to high)
Self-efficacy re stress management for medical appointments	continuous	1-9 (low to high)
Self-efficacy re coping with treatment-related side-effects	continuous	1-9 (low to high)
Self-efficacy re accepting cancer	continuous	1-9 (low to high)
Self-efficacy re regulating affect	continuous	1-9 (low to high)
Self-efficacy re seeking support	continuous	1-9 (low to high)
Diagnosed with depression	categorical dichotomous	Yes or no
Diagnosed with anxiety	categorical dichotomous	Yes or no
Distress at time 1	continuous	0-10 (no high distress)
Social support	continuous	8-34 (low to high)
Gender	categorical dichotomous	Male or female
Age	categorical ordinal	Ranked categories of age
Marital status	categorical	Marital categories
Education level	categorical ordinal	Ranked categories of highest level of education completed
Healthcare work	categorical dichotomous	Yes or no

Variable	Type	Measurement
Language spoken at home	categorical dichotomous	English or other
Usual work situation	categorical	Work appointment categories
Household income	categorical ordinal	Ranked categories of income
Australian Standard Geographical Classification area	categorical dichotomous	Major cities or Regional Australia
Time taken for interview 2	continuous	Time in minutes
Data collection for interview 2	categorical	In person or via telephone
Global health status at time 2	continuous	Score 0-100 (worst to best)
Physical functioning at time 2	continuous	Score 0-100 (worst to best)
Role functioning at time 2	continuous	Score 0-100 (worst to best)
Emotional functioning at time 2	continuous	Score 0-100 (worst to best)
Cognitive functioning at time 2	continuous	Score 0-100 (worst to best)
Social functioning at time 2	continuous	Score 0-100 (worst to best)
Fatigue at time 2	continuous	Score 0-100 (no to severe symptoms)
Nausea and vomiting at time 2	continuous	Score 0-100 (no to severe symptoms)
Pain at time 2	continuous	Score 0-100 (no to severe symptoms)
Dyspnoea at time 2	categorical dichotomous	No versus any symptoms
Insomnia at time 2	categorical dichotomous	No versus any symptoms
Appetite loss at time 2	categorical dichotomous	No versus any symptoms
Constipation at time 2	categorical dichotomous	No versus any symptoms
Diarrhoea at time 2	categorical dichotomous	No versus any symptoms
Financial difficulties at time 2	categorical dichotomous	No versus any symptoms
Future uncertainty at time 2	continuous	Score 0-100 (no to severe symptoms)
Visual disorder at time 2	continuous	Score 0-100 (no to severe symptoms)
Motor dysfunction at time 2	continuous	Score 0-100 (no to severe symptoms)
Communication deficit at time 2	continuous	Score 0-100 (no to severe symptoms)
Headache at time 2	categorical dichotomous	No versus any symptoms
Seizures at time 2	categorical dichotomous	No versus any symptoms

Variable	Type	Measurement
Drowsiness at time 2	categorical dichotomous	No versus any symptoms
Hair loss at time 2	categorical dichotomous	No versus any symptoms
Itchy skin at time 2	categorical dichotomous	No versus any symptoms
Weakness of legs at time 2	categorical dichotomous	No versus any symptoms
Bladder control at time 2	categorical dichotomous	No versus any symptoms
Information received at time 2	continuous	Score 0-100 (no to very much info)
Information received about the disease at time 2	continuous	Score 0-100 (no to very much info)
Information received about medical tests at time 2	continuous	Score 0-100 (no to very much info)
Information received about treatment at time 2	continuous	Score 0-100 (no to very much info)
Information received about other services at time 2	continuous	Score 0-100 (no to very much info)
Information received about non - medical treatments at time 2	categorical dichotomous	No versus any info
Information received about different places of care at time 2	categorical dichotomous	No versus any info
Information received about self help at time 2	categorical dichotomous	No versus any info
Written information received at time 2	categorical dichotomous	Yes or no
Information on tape/video/CD received at time 2	categorical dichotomous	Yes or no
Satisfaction with information at time 2	categorical dichotomous	Score 0-100 (not at all to very satisfied)
Wish to receive more information at time 2	categorical dichotomous	Yes or no
With had received less information at time 2	categorical dichotomous	Yes or no
Helpfulness of information received at time 2	categorical dichotomous	Score 0-100 (not at all to very helpful)
Most prominent source of information	categorical	Information sources
Total stress (Impact of event) score at time 2	continuous	0-75 (lowest to highest)
Avoidance score at time 2	continuous	0-40 (lowest to highest)
Intrusiveness score at time 2	continuous	0-35 (lowest to highest)
Depression symptoms at time 2	categorical ordinal	Ranked categories of depressed feelings

Variable	Type	Measurement
Anxiety symptoms at time 2	categorical ordinal	Ranked categories of anxious feelings
Medical Interaction problems	continuous	11-55 (higher scores indicate more problems)
Distress at time 2	continuous	0-10 (no high distress)
Brochure/QPL helpfulness	categorical	Agree/disagree/don't know
Brochure/QPL made it easier to ask questions	categorical	Agree/disagree/don't know
Brochure/QPL had useful questions	categorical	Agree/disagree/don't know
Brochure/QPL helped put concerns into words	categorical	Agree/disagree/don't know
Brochure/QPL was overwhelming	categorical	Agree/disagree/don't know
Brochure/QPL will be useful in future	categorical	Agree/disagree/don't know
Brochure/QPL was easy to understand	categorical	Agree/disagree/don't know
Brochure/QPL length	categorical	Right length, too long, or too short
Brochure/QPL time to read	categorical	Yes, no or unsure
Brochure/QPL timing	categorical	Yes, no or unsure
Brochure/QPL read again	Categorical	Several times, 1-2 times, not at all
Brochure/QPL prompted questions to neurosurgeon	categorical	Yes, no, unsure or not applicable
Brochure/QPL prompted questions to radio-oncologist	categorical	Yes, no, unsure or not applicable
Brochure/QPL prompted questions to medical oncologist	categorical	Yes, no, unsure or not applicable
Brochure/QPL prompted questions to other	categorical	Yes, no, unsure or not applicable
Anyone else read brochure/QPL	categorical	Yes, no, unsure or not applicable
Helpfulness of brochure/QPL to other person	categorical ordinal	Ranked categories
Tumour hemisphere	categorical	Left, right or other
Tumour lobe	categorical	Brain lobes
Tumour type	categorical	Types
Histological confirmation	categorical	Yes or no
Tumour stage at diagnosis	categorical	I, II, III or IV
Biopsy performed	categorical	Yes or no
Surgical debulking performed	categorical	Yes or no
Radiotherapy performed	categorical	Yes or no
Chemotherapy performed	categorical	Yes or no
Other treatment performed	categorical	Yes or no

Variable	Type	Measurement
Karnofsky Performance Score	continuous	0-100 (worst to best)
Impairment in speaking or understanding speech	categorical	Yes or no
Impairment in attention or concentration	categorical	Yes or no
Impairment in abstract reasoning	categorical	Yes or no
Impairment in memory	categorical	Yes or no
Visual impairment	categorical	Yes or no
Motor impairment	categorical	Yes or no
Other impairment	categorical	Yes or no
Previous cancer diagnosis	categorical	Yes or no
Prognosis	categorical	Weeks or months; years; normal
Time since diagnosis at time 1	continuous	Days

APPENDIX T.

STUDY 3 SUPPLEMENTARY ANALYSES

COMPARISON OF CONTROL GROUP AND QPL GROUP PARTICIPANTS

TABLE T.1: COMPARISON OF SOCIODEMOGRAPHIC CHARACTERISTICS OF CONTROL GROUP AND QPL GROUP PARTICIPANTS AT BASELINE

	Controls (n=10)	QPL participants (n=10)
Characteristic	N (%)	N
Age, years – median (range)	48 (30-72)	55.5 (28-68)
Sex		
Male	5 (50.0)	7 (70.0)
Female	5 (50.0)	3 (30.0)
Marital status		
Married or living together	9 (90.0)	9 (90.0)
Divorced	1 (10.0)	1 (10.0)
Never married	0	1 (10.0)
Education		
Junior or senior high	5 (50.0)	6 (40.0)
Trade certificate, technical college or diploma	1 (10.0)	2 (20.0)
University degree	4 (40.0)	2 (20.0)
Usual employment status		
Full time	4 (40.0)	6 (60.0)
Part time or casual	3 (30.0)	1 (10.0)
Full time home duties, home carer or retired	3 (30.0)	3 (30.0)
Household income [a]		
<$40 000	2 (20.0)	2 (20.0)
$40 000 - < $80 000	1 (10.0)	5 (50.0)
$80 000 +	7 (70.0)	2 (20.0)
Worked in health care	1 (10.0)	4 (40.0)
Speak a language other than English at home	0	2 (20.0)
Treated in a private hospital	9 (90.0)	3 (30.0)
Location (ARIA+) [b]		
Major city	6 (60.0)	8 (80.0)
Regional	4 (40.0)	2 (20.0)

[a] 1 person who did not know was excluded
[b] ARIA+: Australian Remote Index for Areas classification

TABLE T.2: COMPARISON OF TUMOUR AND TREATMENT CHARACTERISTICS OF CONTROL GROUP AND QPL GROUP PARTICIPANTS

Characteristic	Controls (n=10) n (%)	QPL participants (n=10) n (%)
Time since diagnosis, months *median (range)*	0 (0-12)	2 (0-46)
Hemisphere		
Anterior right	4 (40.0)	5 (50.0)
Posterior right	1 (10.0)	1 (10.0)
Anterior left	2 (20.0)	3 (30.0)
Posterior left	0	1 (10.0)
Other	3 (30.0)	0
Tumour lobe		
Frontal	1 (10.0)	3 (30.0)
Parietal	2 (20.0)	1 (10.0)
Temporal	3 (30.0)	2 (20.0)
Other	4 (40.0)	4 (40.0)
Tumour type		
Glioblastoma	2 (20.0)	6 (60.0)
Meningioma	3 (30.0)	0
Astrocytoma	0	1 (10.0)
Oligodendroglioma	2 (20.0)	2 (20.0)
Pituitary adenoma	1 (10.0)	0
Ependymoma	1 (10.0)	1 (10.0)
Mixed glioma	1 (10.0)	0
Tumour stage at diagnosis [a]		
I	3 (30.0)	0
II	3 (30.0)	1 (10.0)
III	1 (10.0)	3 (30.0)
IV	2 (20.0)	6 (60.0)
Treatments received *(multiple responses allowed)*		
Biopsy	0	4 (40.0)
Radiotherapy	4 (40.0)	9 (90.0)
Chemotherapy	3 (30.0)	7 (70.0)
Clinical trial	0	2 (20.0)
Impairments		
Speaking/understanding speech	0	5 (50.0)
Attention/concentration	1 (10.0)	5 (50.0)
Abstract reasoning	0	1 (10.0)
Memory	1 (10.0)	6 (60.0)
Visual	2 (20.0)	1 (10.0)
Motor	2 (20.0)	5 (50.0)

TABLE T.2 CONTINUED

Characteristic	Controls (n=10) n (%)	QPL participants (n=10) n (%)
Previously had cancer	0	4 (40.0)
Likely prognosis		
Weeks or months [b]	0	2 (20.0)
Years	5 (50.0)	6 (60.0)
Normal life expectancy	4 (40.0)	0

[a] excludes one participant (control group) for whom grade was not available
[b] 'weeks or months' category includes one patient who died within weeks/months of participation; 3 participants for whom info was not available were excluded from this analysis

TABLE T.3: COMPARISON OF QUALITY OF LIFE (FROM THE EORTC QLQ-C30) OF CONTROL GROUP AND QPL GROUP PARTICIPANTS AT BASELINE

Characteristic	Controls (n=10)	QPL participants (n=10)
Global quality of life [a]	62.5 (41.7-100)	79.2 (16.7-100)
Physical functioning [a]	100 (80.0-100)	90.0 (46.7-100)
Role functioning [a]	58.3 (0-100)	62.5 (16.7-100)
Emotional functioning [a]	62.5 (25.0-100)	62.5 (8.3-100)
Cognitive functioning [a]	66.7 (33.3-100)	83.3 (33.3-100)
Social functioning [a]	66.7 (33.3-100)	66.7 (33.3-100)
Fatigue [a]	38.9 (0-100)	27.8 (11.1-77.8)
Nausea & vomiting [a]	16.7 (0-33.3)	0 (0-66.7)
Pain [a]	16.7 (0-83.3)	0 (0-83.3)
Symptoms [b] – patients experiencing any degree of:		
Dyspnoea	2 (20.0)	4 (40.0)
Insomnia	7 (70.0)	5 (50.0)
Appetite loss	2 (20.0)	3 (30.0)
Constipation	4 (40.0)	4 (40.0)
Diarrhoea	0	1 (10.0)
Financial difficulties	4 (40.0)	7 (70.0)

[a] Score standardised to 0-100: median, range
[b] Calculated as % of patients with any symptoms rather than as a scale as distribution not normal (skewed)

TABLE T.4: COMPARISON OF BRAIN-TUMOUR SPECIFIC QUALITY OF LIFE (USING THE EORTC QLQ-BN20) OF CONTROL GROUP AND QPL GROUP PARTICIPANTS AT BASELINE

Characteristic	Controls (n=10)	QPL participants (n=10)
Future uncertainty [a]	70.8 (41.7-91.7)	66.7 (25.0-100)
Visual disorder [a]	100 (0-100)	94.4 (55.6-100)
Motor dysfunction [a]	83.3 (44.4-100)	77.8 (44.4-100)
Communication deficit [a]	88.9 (66.7-100)	72.2 (33.3-100)
Symptoms [b] – patients experiencing any degree of:		
Headaches	6 (60.0)	5 (50.0)
Seizures	1 (10.0)	1 (10.0)
Drowsiness	8 (80.0)	6 (60.0)
Hair loss	2 (20.0)	1 (10.0)
Itchy skin	2 (20.0)	4 (40.0)
Weakness of legs	3 (30.0)	2 (20.0)
Bladder control	1 (10.0)	2 (20.0)

[a] Score standardised to 0-100: median, range

[b] Calculated as % of patients with any symptoms rather than as a scale as distribution not normal (skewed)

TABLE T.5: COMPARISON OF INFORMATION PREFERENCES OF CONTROL GROUP AND QPL GROUP PARTICIPANTS AT BASELINE

	Controls (n=10)	QPL participants (n=10)
Characteristic	N (%)	N (%)
Attitude towards participation in decision making:		
Prefer to leave decisions about medical care & treatment up to doctor	4 (40.0)	2 (20.0)
Prefer to participate in decisions about medical care & treatment	6 (60.0)	8 (80.0)
Attitude towards information about illness:		
I want only the information needed to care for myself properly	1 (10.0)	0 (0.0)
I want additional information only if it is good news	0 (0)	2 (20.0)
I want as much information as possible, good or bad	9 (90.0)	8 (80.0)
Information seeking behaviour: [b]		
Low information seeker (scored 0-4)	3 (30.0)	7 (70.0)
High information seeker (scored 5-7)	7 (70.0)	3 (30.0)

[a] from Cassileth Information Styles Questionnaire

[b] from Krantz Health Opinion Survey Information subscale – median score was 4.5 (range 0-7)

TABLE T.6: COMPARISON OF INFORMATION RECEIVED (USING EORTC QLQ-INFO25) BY CONTROL GROUP AND QPL GROUP PARTICIPANTS AT BASELINE – MEDIAN SCORES

Characteristic	Score: median (range) [a]	
	Controls (n=10)	QPL participants (n=10)
Amount of information received about:		
Disease	58.3 (16.7-83.3)	33.3 (16.7-62.5)
Medical tests	61.1 (33.3-100)	55.6 (33.3-100)
Treatment	52.4 (14.3-61.9)	50.0 (23.8-81.0)
Other services	16.7 (0-14.7)	29.2 (16.7-75.0)
Overall:		
Satisfaction with info received	66.7 (0-100)	83.3 (0-100)
Overall extent to which info was helpful	100 (0-100)	83.3 (0-100)
Overall score	43.3 (16.0-61.3)	50.3 (29.3-68.0)

[a] Score standardised to 0-100, with higher scores indicating more information was received

TABLE T.7: COMPARISON OF INFORMATION RECEIVED USING THE EORTC QLQ-INFO25 BY CONTROL GROUP AND QPL GROUP PARTICIPANTS AT BASELINE - PROPORTIONS

	Controls (n=10)	QPL participants (n=10)
Characteristic	n (%)	n (%)
Types of information received:		
Written information	8 (80.0)	9 (90.0)
Tape/video/CD	0 (0)	5 (50.0)
Amount of information desired:		
Wish to receive more information	5 (50.0)	7 (70.0)
Wish had received less information	0 (0)	0 (0)
Received information on non-medical treatments		
Not at all	5 (50.0)	6 (60.0)
A little bit	4 (40.0)	4 (40.0)
Quite a bit	1 (10.0)	0 (0)
Received information about different places of care		
Not at all	8 (80.0)	3 (30.0)
A little bit	1 (10.0)	4 (40.0)
Quite a bit	1 (10.0)	3 (30.0)
Received information about things you can do to help yourself get well		
Not at all	3 (30.0)	0 (0)
A little bit	2 (20.0)	7 (70.0)
Quite a bit	5 (50.0)	2 (20.0)
Very much	0 (0)	1 (10.0)

TABLE T.8: COMPARISON OF PSYCHOLOGICAL CHARACTERISTICS OF CONTROL GROUP AND QPL GROUP PARTICIPANTS AT BASELINE

	Controls (n=10)	QPL participants (n=10)
Characteristic	n (%)	n (%)
Have felt down, depressed or hopeless over the past two weeks		
Not at all or a little	6 (60.0)	5 (50.0)
Moderately, very or extremely	4 (40.0)	5 (50.0)
Have felt nervous, anxious or fearful over the past two weeks		
Not at all or a little	5 (50.0)	6 (60.0)
Moderately, very or extremely	5 (50.0)	4 (40.0)
Diagnosed with depression [a]	4 (40.0)	3 (30.0)
Diagnosed with anxiety [a]	2 (20.0)	4 (40.0)

[a] Refers to been ever diagnosed by a physician

TABLE T.9: COMPARISON OF PSYCHOLOGICAL WELL-BEING OF CONTROL GROUP AND QPL GROUP PARTICIPANTS (N=20) AT BASELINE – MEDIAN SCORES

	median (range)	
	Control group	QPL group
Impact of event scale		
Overall score	29.0 (2-58)	21.5 (2-60)
Intrusion subscale score	15.5 (1-25)	12.4 (0-25)
Avoidance subscale score	13.5 (0-34)	8.5 (0-36)
Distress thermometer	5.0 (2-10)	4.0 (0-9)
Social support score	29 (26-32)	32 (25-34)

TABLE T.10: COMPARISON OF SELF-EFFICACY IN COPING WITH CANCER (ASSESSED USING THE CANCER BEHAVIOR INVENTORY) AMONG CONTROL GROUP AND QPL GROUP PARTICIPANTS AT BASELINE

Characteristic	Control group (n=10) median (range)	QPL group (n=10) median (range)
Overall score	227.0 (192.0 - 281.0)	257.0 (180.5 - 281.0)
Subscales: [a]		
Maintenance of activity & independence	7.1 (6.0-9.0)	8.3 (5.0-9.0)
Seeking & understanding medical information	7.5 (5.4-9.0)	8.6 (4.3-9.0)
Stress management for medical appointments	6.7 (5.0-8.6)	7.9 (3.2-9.0)
Coping with treatment related side-effects	6.5 (5.2-9.0)	7.3 (3.8-9.0)
Accepting cancer/maintaining a positive attitude	7.8 (6.2-9.0)	8.3 (6.2-9.0)
Affective regulation	5.6 (3.4-7.2)	6.5 (5.4-7.8)
Seeking support	7.0 (4.3-9.0)	7.3 (4.8-9.0)

[a] Mean score of items in this subscale, to allow comparison between subscales with different numbers of items.

CRUDE EFFECT OF INTERVENTION (BETWEEN-GROUP COMPARISONS)

Previous analyses demonstrated that the characteristics of the control group and QPL group were not similar. Change in information scores between baseline and follow-up likely depend on a number of variables and may not represent change due to allocation to the intervention or control condition. The following results must thus be interpreted with caution.

As shown in Figure T.1, the median change in information received between baseline and follow-up was higher for QPL group participants (median 2.7, range -24.0 to 18.6, n=9), compared with control group participants (median -2.0, range -36.0 to 9.3, n=8).

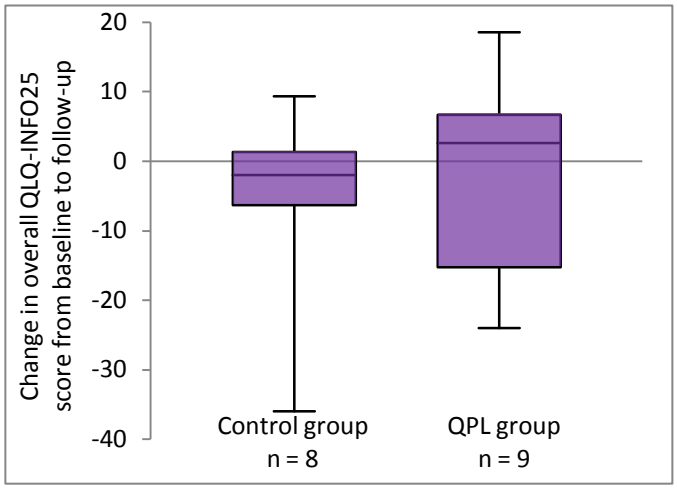

FIGURE T.1: CHANGE IN INFORMATION RECEIVED FROM BASELINE TO FOLLOW-UP AMONG CONTROL GROUP AND QPL GROUP PARTICIPANTS

As recommended for pilot studies with small sample sizes, the change scores of individual participants were also examined (Shih, Ohman-Strickland et al. 2004). Table T.11 shows the number of participants whose change in information received would be categorised as 'increased', 'stable' or 'decreased' for five and 10 point estimates of MCID.

TABLE T.11: NUMBER OF CONTROL GROUP AND QPL GROUP PARTICIPANTS WHOSE CHANGE IN INFORMATION RECEIVED FROM BASELINE TO FOLLOW-UP WOULD BE CLASSIFIED AS INCREASED, STABLE, OR DECREASED, BASED ON FIVE AND 10 POINT ESTIMATES OF MINIMAL CLINICALLY IMPORTANT DIFFERENCE

	5 point 'significant' change		10 point 'significant' change	
	Control group (n=8)	QPL group (n=9)	Control group (n=8)	QPL group (n=9)
Increased	2	3	0	2
Stable	4	3	6	4
Decreased	2	3	2	3

Increased: change of ≥ 5 or 10 points, decreased: change ≤-5 or -10 points, stable between values

VARIABLES ASSOCIATED WITH OVERALL QLQ-INFO25 SCORE AT FOLLOW-UP AND CHANGE BETWEEN BASELINE AND FOLLOW-UP

TABLE T.12 RELATIONSHIPS BETWEEN SOCIODEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS AT BASELINE AND OVERALL QLQ-INFO25 SCORES: FOLLOW-UP AND CHANGE SCORES

Characteristic	Overall QLQ-INFO25 score at follow-up median (min, max)	Change in overall QLQ-INFO25 score median (min, max)
Age, years		
20-39 years	45.33 (37.33, 61.33)	4.67 (-2.67, 9.33)
40-59 years	49.33 (22.67, 68.00)	0 (-24.00, 18.56)
60-79 years	40.28 (21.33, 60.00)	-15.22 (-36.00, 4.00)
Sex		
Male	49.33 (22.67, 61.33)	1.33 (-24.00, 18.56)
Female	37.33 (21.33, 68.00)	-1.33 (-36.00, 9.33)
Education		
Junior or senior high	44.14 (22.67, 68.00)	-2.67 (-24.00, 9.33)
Trade certificate, technical college or diploma	54.67 (37.33, 57.33)	12.00 (-2.67, 18.56)
University degree	45.33 (21.33, 61.33)	4.67 (-36.00, 9.33)
Usual employment status		
Full time	50.67 (22.67, 61.33)	4.00 (-24.00, 18.56)
Part time or casual	48.00 (21.33, 68.00)	-13.33 (-36.00, 9.33)
Full time home duties, home carer or retired	36.67 (30.67, 40.28)	-2.67 (-18.39, 1.33)
Household income [c]		
<$40 000	48.00 (30.67, 68.00)	2.67 (-1.33, 9.33)
$40 000 - < $80 000	42.67 (22.67, 61.33)	-13.33 (-24.00, 6.67)
$80 000 +	48.00 (21.33, 57.33)	-1.33 (-36.00, 18.56)
Worked in health care		
Yes	48.67 (22.67, 57.33)	7.33 (-24.00, 18.56)
No	48.00 (21.33, 68.00)	-1.33 (-36.00, 9.33)
Speak a language other than English at home		
Yes	31.47 (22.67, 40.28)	-21.19 (-24.00, -18.39)
No	48.00 (21.33, 68.00)	1.33 (-36.00, 18.56)
Treating hospital		
Private	48.00 (21.33, 68.00)	-1.33 (-36.00, 12.00)
Public	47.47 (22.67, 61.33)	2.67 (-24.00, 18.56)
Location (ARIA+) [d]		
Major city	41.47 (21.33, 60.00)	-0.67 (-36.00, 18.56)
Regional	56.00 (36.00, 68.00)	2.67 (-1.33, 9.33)

TABLE T.13: RELATIONSHIPS BETWEEN TUMOUR CHARACTERISTICS OF PARTICIPANTS AND OVERALL QLQ-INFO25 SCORES: FOLLOW-UP AND CHANGE SCORES

Characteristic	Overall QLQ-INFO25 score at follow-up median (min, max)	Change in overall QLQ-INFO25 score median (min, max)
Time since diagnosis, months		
less than 1 month	48.00 (21.33, 68.00)	-1.33 (-36.00, 9.33)
1-6 months	48.00 (22.67, 60.00)	4.00 (-24.00, 12.00)
≥ 6 months	37.33 (30.67, 61.33)	1.33 (-4.00, 18.56)
Hemisphere		
Left	42.67 (21.33, 52.78)	-15.22 (-36.00, 2.67)
Right	48.00 (22.67, 61.33)	1.33 (-24.00, 18.56)
Other	48.00 (37.33, 68.00)	9.33 (-4.00, 9.33)
Tumour lobe		
Frontal	46.67 (40.28, 54.67)	0.67 (-18.39, 18.56)
Parietal	46.67 (36.00, 57.33)	5.33 (-1.33, 12.00)
Temporal	48.00 (21.33, 52.78)	-15.22 (-36.00, -13.33)
Other	42.67 (22.67, 68.00)	2.67 (-24.00, 9.33)
Tumour type [a]		
Glioblastoma	48.00 (21.33, 60.00)	-15.22 (-36.00, 18.56)
Meningioma	50.67 (36.00, 68.00)	-1.33 (-1.33, 9.33)
Other gliomas	50.00 (37.33, 61.33)	4.67 (-2.67, 12.00)
Other	37.33 (30.67, 48.00)	1.33 (-4.00, 9.33)
Tumour stage at diagnosis [b]		
I	50.67 (36.00, 68.00)	-1.33 (-1.33, 9.33)
II	42.67 (37.33, 48.00)	2.67 (-2.67, 9.33)
III	57.33 (30.67, 61.33)	6.67 (1.33, 12.00)
IV	48.00 (21.33, 60.00)	-15.22 (-36.00, 18.56)
Previously had cancer		
Yes	47.72 (22.67, 60.00)	-6.28 (-24.00, 28.00)
No	48.00 (21.33, 68.00)	-1.33 (-36.00, 18.56)
Likely prognosis		
Reduced life expectancy [c]	48.00 (21.33, 61.33)	1.33 (-36.00, 18.56)
Normal life expectancy	44.00 (36.00, 68.00)	-1.33 (-4.00, 9.33)

[a] Other gliomas includes astrocytoma, mixed glioma, oligodendroglioma; other includes ependymoma, pituitary adenoma

[b] Excludes one participant (control group) for whom grade was not available

[c] Reduced life expectancy combines categories for 'weeks, months' and 'years', and includes one patient who died before the end of the study. Excludes 2 participants for whom information was not available.

TABLE T.14: RELATIONSHIPS BETWEEN INFORMATION PREFERENCES OF PARTICIPANTS AT BASELINE AND OVERALL QLQ-INFO25 SCORES: FOLLOW-UP AND CHANGE SCORES

Characteristic	Overall QLQ-INFO25 score at follow-up median (min, max)	Change in overall QLQ-INFO25 score median (min, max)
Information seeking behaviour: [a]		
Low information seeker	52.78 (36.00, 68.00)	2.67 (-18.39, 18.56)
High information seeker	37.33 (21.33, 57.33)	-2.00 (-36.00, 12.00)
Attitude towards participation in decision making:		
Prefer to leave decisions about medical care & treatment up to doctor	48.00 (21.33, 68.00)	-1.33 (-36.00, 9.33)
Prefer to participate in decisions about medical care & treatment	44.94 (22.67, 61.33)	0 (-24.00, 18.56)
Attitude towards information about illness:		
Want only information needed to care for myself properly, or want additional information only if it is good news [b]	40.28 (36.00, 54.67)	-1.33 (-18.39, 18.56)
Want as much information as possible, good or bad	48.00 (21.33, 68.00)	0 (-36.00, 12.00)

[a] categorised using score from Krantz Health Opinion Survey Information Scale (low: 0-4, high: 5-7)
[b] categories combined due to the small number of respondents in each category

TABLE T.1511: RELATIONSHIPS BETWEEN PSYCHOLOGICAL WELL-BEING OF PARTICIPANTS AT BASELINE AND OVERALL QLQ-INFO25 SCORES: FOLLOW-UP AND CHANGE SCORES

Characteristic	Overall QLQ-INFO25 score at follow-up median (min, max)	Change in overall QLQ-INFO25 score median (min, max)
Impact of event scale [a]		
Low (<26)	48.00 (21.33, 68.00)	1.33 (-36.00, 18.56)
High (≥26)	45.33 (36.00, 61.33)	-1.33 (-18.39, 6.67)
Distress thermometer [a]		
Low (<4)	52.78 (22.67, 61.33)	-4.00 (-24.00, 18.56)
High (≥ 4)	41.47 (21.33, 68.00)	0 (-36.00, 9.33)
Have felt down, depressed or hopeless over the past two weeks [a]		
Not at all or a little	51.72 (21.33, 68.00)	-2.67 (-36.00, 12.00)
Moderately, very or extremely	40.28 (30.67, 54.67)	1.33 (-18.39, 18.56)
Have felt nervous, anxious or fearful over the past two weeks [a]		
Not at all or a little	52.78 (21.33, 68.00)	1.33 (-36.00, 18.56)
Moderately, very or extremely	41.47 (36.00, 60.00)	-1.33 (-18.39, 9.33)
Diagnosed with depression [b]		
Yes	38.06 (30.67, 48.00)	-2.67 (-18.39, 2.67)
No	52.78 (21.33, 46.67)	4.00 (-36.00, 18.56)
Diagnosed with anxiety [b]		
Yes	41.47 (30.67, 61.33)	2.00 (-18.39, 9.33)
No	50.67 (21.33, 68.00)	-2.67 (-36.00, 54.56)

[a] Baseline score

[b] Refers to been ever diagnosed by a physician

TABLE T.16: RELATIONSHIPS BETWEEN SELF-EFFICACY IN COPING WITH CANCER (ASSESSED USING THE CANCER BEHAVIOR INVENTORY) OF PARTICIPANTS AT BASELINE AND OVERALL QLQ-INFO25 SCORES: FOLLOW-UP AND CHANGE SCORES

Characteristic	Overall QLQ-INFO25 score at follow-up median (min, max)	Change in overall QLQ-INFO25 score median (min, max)
Cancer Behavior Inventory (CBI) overall score [a]		
≤ 217 (n=6)	38.81 (30.67, 48.00)	-2.67 (-18.39, 2.67)
> 217-254 (n=7)	50.67 (21.33, 68.00)	6.67 (-36.00, 18.56)
> 254 (n=4)	55.06 (22.67, 60.00)	-5.61 (-24.00, 12.00)
CBI subscale: seeking & understanding medical information [ab]		
≤ 7.6 (n=8)	44.14 (36.00, 68.00)	-2.00 (-18.39, 18.56)
> 7.6-8.6 (n=5)	42.67 (21.33, 60.00)	2.67 (-36.00, 9.33)
> 8.6 (n=4)	55.06 (22.67, 61.33)	-4.28 (-24.00, 12.00)
ENRICHD Social support score [a]		
< 28 (n=4)	52.00 (36.00, 68.00)	4.67 (-1.33, 9.33)
≥ 28-32 (n=8)	37.33 (21.33, 50.67)	-3.33 (-36.00, 9.33)
> 32 (n=5)	54.67 (40.28, 60.00)	4.00 (-18.39, 18.56)
CARES medical interaction subscale score [a]		
≤ 42 (n=7)	48.00 (37.33, 68.00)	2.67 (-18.39, 9.33)
> 42-48 (n=6)	44.00 (30.67, 61.33)	-1.33 (-15.22, 6.67)
> 48 (n=4)	38.67 (21.33, 57.33)	-6.00 (-36.00, 18.56)

[a] Scale split into tertiles of approximately equal sizes to facilitate interpretation

[b] Mean score of items in this subscale, to allow comparison between subscales with different numbers of items.

TABLE T.17: RELATIONSHIPS BETWEEN SYMPTOMS [A] OF PARTICIPANTS AT BASELINE, AND OVERALL QLQ-INFO25 SCORES: FOLLOW-UP AND CHANGE SCORES

Symptoms	Overall QLQ-INFO25 score at follow-up median (min, max)	Change in overall QLQ-INFO25 score median (min, max)
Dyspnoea		
Any symptoms (n=5)	40.28 (30.67, 60.00)	1.33 (-18.39, 4.00)
No symptoms (n=12)	49.33 (21.33, 68.00)	-1.33 (-36.00, 18.56)
Insomnia		
Any symptoms (n=10)	43.07 (21.33, 68.00)	0 (-36.00, 9.33)
No symptoms (n=7)	52.78 (22.67, 61.33)	-1.33 (-24.00, 18.56)
Appetite loss		
Any symptoms	30.67 (21.33, 68.00)	1.33 (-36.00, 9.33)
No symptoms	49.33 (36.00, 61.33)	-1.33 (-18.39, 19.56)
Constipation		
Any symptoms (n=6)	38.14 (21.33, 48.00)	-7.33 (-36.00, 2.67)
No symptoms (n=11)	52.78 (22.67, 68.00)	4.00 (-24.00, 18.56)
Financial difficulties		
Any symptoms (n=9)	42.67 (21.33, 68.00)	1.33 (-36.00, 12.00)
No symptoms(n=8)	49.33 (36.00, 61.33)	-1.33 (-15.22, 18.56)
Headaches		
Any symptoms (n=10)	45.33 (21.33, 68.00)	2.00 (-36.00, 9.33)
No symptoms (n=7)	50.67 (36.00, 57.33)	-1.33 (-18.39, 18.56)
Drowsiness		
Any symptoms (n=12)	45.33 (21.33, 68.00)	0 (-36.00, 12.00)
No symptoms (n=5)	48.00 (22.67, 54.67)	-15.22 (-24.00, 18.56)
Hair loss		
Any symptoms (n=3)	54.67 (36.00, 68.00)	9.33 (-1.33, 18.56)
No symptoms (n=14)	45.33 (21.33, 61.33)	-2.00 (-36.00, 12.00)
Itchy skin		
Any symptoms (n=5)	40.28 (21.33, 57.33)	-18.39 (-36.00, 12.00)
No symptoms (n=12)	49.33 (30.67, 68.00)	2.00 (-15.22, 18.56)
Weakness of legs		
Any symptoms (n=5)	48.00 (36.00, 68.00)	-1.33 (-18.39, 9.33)
No symptoms (n=12)	45.33 (21.33, 61.33)	0 (-36.00, 18.56)
Bladder control		
Any symptoms (n=3)	40.28 (37.33, 60.00)	-4.00 (-18.39, 4.00)
No symptoms (n=14)	48.00 (21.33, 68.00)	0 (-36.00, 18.56)

[a] Diarrhoea & seizures not included as symptoms only reported by 1 & 2 participants respectively

TABLE T.18: CORRELATIONS BETWEEN QUALITY OF LIFE SCALES AND OVERALL QLQ-INFO25 SCORES: FOLLOW-UP AND CHANGE SCORES

	Overall score for QLQ-INFO25 at follow-up (Spearman's ρ)	Change in INFO25 overall score (Spearman's ρ)[a]
Quality of life	0.534	0.292
Physical functioning	0.184	-
Role functioning	0.308	-
Emotional functioning	0.274	-
Social functioning	0.206	0.223
Fatigue	-0.224	-
Nausea and vomiting	-0.221	-
Future uncertainty	0.257	0.161
Communication deficit	0.258	0.254

[a] Correlation coefficients not reported where scatterplots did not show linear relationships
ρ: Spearman's correlation coefficient

SENSITIVITY TO CHANGE AND MINIMAL CLINICALLY IMPORTANT DIFFERENCE (MCID)

As described in section 8.2.8.5, sensitivity to change is essential for the 'longitudinal validity' of an outcome measure (Revicki et al. 2006). If an instrument is sensitive to change, and if MCIDs have been determined through research involving patients, carers, and stakeholders, the MCID can be used to calculate the sample size required to show the MCID at a statistically significant level. However, sensitivity to change of the QLQ-INFO25 has not yet been shown, and the MCID for change over time is not known.

In this thesis, two values (five and 10 points) were used as estimates for the MCID for the QLQ-INFO25, to allow estimation of the sample size needed to use the QLQ-INFO25 as the primary outcome to evaluate the QPL. This section describes the analysis of participants' QLQ-INFO25 scores which were undertaken to assess the sensitivity to change of the QLQ-INFO25, and which were used to select these two values as MCID estimates for this instrument.

Methods

Estimation of MCID values

Three distribution-based techniques were applied to identify 'relevant' difference (i.e. difference greater than or unrelated to measurement error) in change scores (de Vet et al. 2001). These techniques relate differences over time and/or between groups to some measure of distribution of scores for an instrument, such as the standard deviation (Norman et al. 2001). Each of three techniques applied (Cohen's guidelines, constant proportions, and minimal detectable change) yielded at least one cut-point to categorise participants as achieving 'real' change over time.

Cohen's guidelines group changes into small (0.2), moderate (0.5) and large (0.8) effect sizes, and have been widely accepted as valid indicators of change (Samsa et al. 1999; Cocks et al. 2010). Effect size (ES) is calculated as the mean difference between groups divided by the standard deviation (SD); the difference between groups required for an effect of a certain size is thus:

Difference = ES x SD, where ES is effect size and SD is standard deviation.

The standard deviation used commonly in this equation is that of the sample at baseline, or of the control group (Streiner et al. 2008). For this calculation, the standard deviation of all participants (n=20) at baseline was used.

The second approach for benchmarking change used the constant proportions for change developed by Osoba et al. (1998). This group developed estimates for small (5-10 points), moderate (10-20 points) and large (>20 points) changes in scores for the QLQ-C30 using anchor-based methods. To develop these estimates, patients completed standard quality of life questionnaires at two points in time; at the second timepoint, they concurrently reported how much their quality of life had changed (anchor). Osoba et al. (1998) thus recommended that the MID be defined as 10% of the scale.

Other groups, using different techniques, have also estimated MIDs within 5-10% of the instrument range for quality of life instruments (King 1996; King 2001; Barrett et al. 2005), and suggest that this approach is at least as effective as other (anchor-based and distribution-based) measures (Ringash et al. 2007). Based on these findings, and given the similarity in scoring and interpretation of the QLQ-INFO25 to the QLQ-C30, changes of 5% and 10% in QLQ-INFO25 scales were used as benchmarks of 'relevant' change.

The third approach to interpreting 'relevant' change involved calculating the minimum detectable change (MDC), which is the magnitude of change required to be confident that the observed change reflects 'real' change and not just measurement error (Davidson & Keating 2002). The MDC is based upon the scale's standard error of measurement (SEM), defined as "the variability between an individual's observed score and the true score" (Guyatt et al. 2002, p. 381), and is expressed in the same units of the scale (de Vet et al. 2006). SEM is derived from the standard deviation and reliability of the scale, and reflect both the precision of the measurement tool and the variation in the sample (Guyatt et al. 2002; Wyrwich 2004).

As SEM depends upon the reliability of the scale, it is influenced by the measure of scale reliability used (i.e. internal consistency reliability or test-retest reliability) (Donner & Eliasziw 1987). However, participants were expected to change over time, so test-retest reliability would reflect both instrument precision and real change in participants' scores over time (Wyrwich et al. 1999; Wyrwich 2004; Nunnaly 1978). Internal consistency reliability in the form of Cronbach's alpha (α) at baseline was therefore used in the SEM calculation:

$$SEM = SD_{baseline} \times \sqrt{(1 - \alpha)}$$ (Streiner & Norman 2008).

The MDC was calculated using the SEM, based on a 90% confidence interval. This confidence interval indicates that 90% of stable patients (i.e. patients who do not change) demonstrated a random variation of less than MDC_{90} when tested on two occasions (Lin et al. 2009). The MDC was calculated using the formula:

MDC = z-score (for chosen confidence level) x SEM x √2
(de Vet et al. 2006).

Choice of MCID values

The results of these techniques were used in two ways. Firstly, similarities between benchmarks for change were used to select two values to approximate the MID upon which sample size calculations should be based. To determine which change scores to use, comparisons were made of the number of participants who would be categorised as achieving 'relevant' or 'real' change using each approach. Based on the theory of triangulation, similarities in actual cut-points (e.g. 5 points on the 0-100 scale), and/or in the number of participants categorised as 'changing', were used to identify one or more cut-points for 'relevant' change. Ideally, MID scores would reflect patient and expert definition of clinically or contextually important change (de Vet et al. 2006). However, until such data become available, cut-points for 'relevant' change identified using distribution-based approaches may act as temporary substitutes (de Vet & Terwee 2010).

Sensitivity to change using scale width

Recommendations for 'relevant' change were then applied to determine which QLQ-INFO25 multi-item scales had sufficient 'scale width', or capacity to adequately detect change in scores (Davidson & Keating 2002). As recommended by McHorney & Tarlov (1995), scale width was judged adequate if no more than 15% of participants had baseline scores within one 'change' of the theoretical upper or lower end of the scale, as this could prevent the detection of changes in their scores. As there was no theoretical justification for not including participants who were lost to follow-up (i.e. it was not expected that results would differ from those of participants who completed follow-up), all participants' baseline scores were used in the analysis. Together with the cut-points for change identified, this criterion allowed selection of QLQ-INFO25 scales which were sensitive to change.

Results

These three approaches yielded six cut-points for categorising participants as to whether or not they have changed, shown in Table T.19. The number of participants whose scores for each of the QLQ-INFO25 multi-item scales would be categorised as having 'significantly' changed (increased or decreased) using each of these cut-points is shown in Table T.20.

TABLE T.19: SCORES USED TO CATEGORISE CHANGE (BASELINE TO FOLLOW-UP) FOR QLQ-INFO25 SCALES

	Cohen's Effect Size (ES)			Constant Proportions		Minimal Detectable Change (MDC)
	Cohen's small (0.2) ES	Cohen's moderate (0.5) ES	Cohen's large (0.8) ES	5%	10%	MDC^{90} [1]
Whole questionnaire	2.51	6.27	10.03	5	10	13.078
Information about the disease	3.88	9.70	15.52	5	10	28.398
Information about medical tests	4.10	10.26	16.42	5	10	24.388
Information about treatments	3.31	8.28	13.25	5	10	23.017
Information about other services	3.64	9.10	14.55	5	10	33.884

[1] MDC_{90} Minimal detectable change with 90% confidence

TABLE T.20: NUMBER OF PARTICIPANTS CLASSIFIED AS HAVING 'SIGNIFICANTLY' CHANGED FROM BASELINE TO FOLLOW-UP FOR THE QLQ-INFO25 (N=17)

	Cohen's Effect Size (ES)						5% of scale		10% of scale		MDC_{90}	
	≥0.2 ES	≤0.2 ES	≥0.5 ES	≤0.5 ES	≥ 0.8 ES	≤0.8 ES	≥ 5%	≤ 5%	≥ 10%	≤ 10%	≥ MDC_{90}	≤ MDC_{90}
Whole questionnaire	7	7	5	5	2	5	5	5	2	5	1	5
Information about the disease	9	6	7	2	7	2	9	5	7	2	0	1
Information about medical tests	4	10	4	10	4	7	4	10	4	10	3	2
Information about treatments	2	13	2	10	2	7	2	13	2	10	1	5
Information about other services	11	6	7	4	7	4	11	6	7	4	1	2

ES: Effect size, MDC_{90}: Minimal detectable change for 90% confidence

Numbers refer to number of participants whose change scores (follow-up minus baseline) were at least as large as the specified cut-off, in the positive and negative directions respectively

For all five multi-item scales, the small ES yielded the lowest change needed for scores to be 'relevant', and the MDC_{90} yielded the highest. The MDC_{90} for 'information about other services' was more than twice the magnitude of the other cut-points for this scale, and larger than the MDC_{90} of other scales, likely because of this scale's much lower internal consistency than that of the other scales. The moderate ES scores were in the region of the 5% and 10% cut-points.

The number of participants categorised as having 'changed' using different cut-points was most consistent for the overall questionnaire score, with a difference of eight persons between the most disparate cut-points (six participants changed based on the MDC_{90}, and 14 changed based on the small ES). The greatest differences between disparate cut-points were for "information about the disease" and "information about other services". Variations can also be seen within each categorisation in terms of the direction of change. For example, the "information about other services" scale demonstrated inconsistency in direction of classification of change. More participants were categorised as having 'increased' rather than 'decreased' based upon the ES methods and 5% proportion, but fewer using the 10% proportion and MDC_{90} method.

Choice of MCID estimates

In the absence of knowledge, the 'relevant' cut-points calculated above provide a 'starting point' for interpreting change in QLQ-INFO25 scores. Given that a range of cut-points for 'relevant' change was calculated, and that they were not consistent in classifying participants as 'changed', multiple values were used to calculate sample size for each scale. For the overall QLQ-INFO25 score, the cut-points for 'relevant' change calculated were (in order of increasing magnitude): 2.5 (small ES), 5 (five percent of maximum score), 6.3 (moderate ES), 10 (10% of maximum score, also large ES), and 13.1 points (MDC_{90}). The smallest and largest values were disregarded as they may be more likely to reflect extreme changes than relevant. The value for moderate ES (6.3 points) was also disregarded as it similar to the 5 point cut-off. Five and ten point changes were thus chosen.

A similar process of examination was used for the other QLQ-INFO scales. The smallest and largest cut-points were disregarded. The number of participants who

would be categorised as 'changed' was then examined across cut-points, to identify similarities. When different cut-points would result in the same number of participants categorised as 'changed', the lower of the values was chosen. Cut-points were then rounded to the nearest integer. This process resulted in the recommendations for two values of 'relevant' change for each scale (shown together with further results in Table T.20TABLE).

Sensitivity to Change

As described in the methods, a scale is considered to have the 'scale width', or capacity to detect change over time, if no more than 15% of participants had baseline scores within one 'minimal relevant change' of the theoretical upper or lower end of the scale (McHorney & Tarlov 1995). For each scale, the two cut-points for 'relevant' change developed above were applied. Results of this analysis (Table T.21) suggest that for each cut-point used, the QLQ-INFO25 overall score, information about the disease scale, and information about treatments (QLQ-INFO25 scale) are appropriate measures of change in information for brain tumour patients. The information about medical tests scale failed this criterion for the higher value of change only, and the information about other services scale failed this criterion for both the scale floor and ceiling.

TABLE T.21: ESTIMATES OF MINIMAL CLINICALLY IMPORTANT CHANGE (MCID) & CAPACITY TO DETECT CHANGE OF QLQ-INFO25 SCALES

		MCID estimates and % of participants within this value of scale floor or ceiling	
Whole questionnaire	MCID	5	10
	% of participants	0%	0%
Information about the disease	MCID	10	16
	% of participants	0%	0%
Information about medical tests	MCID	10	16
	% of participants	10%	15%*
Information about treatments	MCID	8	13
	% of participants	0%	5%
Information about other services	MCID	10	15
	% of participants	20%*	20%*

* Indicates failed scale criterion (greater than or equal to 15% of the 20 participants)

Of the three responsive scales, the overall QLQ-INFO25 scale may be preferred, as it covers a diverse range of information needs. It is recommended that the overall score be used to assess change over time or within groups. This scale, together with the five and 10 point estimates of MCID, have been used to estimate the sample size needed to evaluate a QPL in a future trial.

Limitations of this Approach

The application of distribution-based statistical methods to QLQ-INFO25 change scores was conducted to estimate potential values of 'relevant' change, thus enabling the estimation of the sample size required for a future trial. It must be emphasised the estimates of MCIDs reflect the distribution of the sample (de Vet & Terwee 2010), rather than an assessment of the change in the amount of information received that patients would identify as meaningful, as the definition of minimal *clinically important* difference requires. Research using anchor-based methods should now be conducted with patients, carers and health professionals to identify the amount of change in QLQ-INFO25 scores that represents a 'meaningful' difference.

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APPENDIX U.

STUDY 3 PARTICIPANT NEWSLETTER

Better meeting the needs of people diagnosed with brain tumours

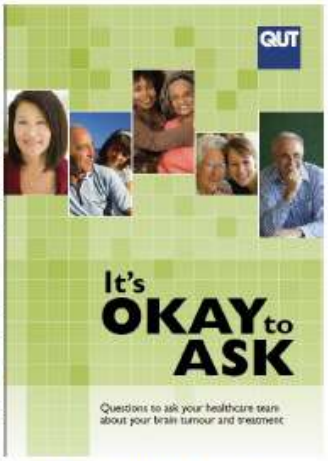
March 2011

Pilot evaluation of a tool to facilitate information exchange for adults with brain tumours

This newsletter reports on the results of a study aiming to help people with primary brain tumours to better access the information they need and want.

From late 2008 to early 2010, 20 adults with primary brain tumours participated in our research. As part of this, 10 people were provided with standard patient information. Another 10 were given a special brochure we previously developed, called "It's okay to ask".

This special brochure is called a "question prompt list" (QPL). A QPL is a list of questions for a patient or carer to ask a doctor should they desire[1]. It is designed to help people decide on and then ask the most meaningful questions at each medical consultation. This may assist persons who do not know what questions to ask, or do not know how to articulate their concerns, and also encourages open communication[1].



It's okay to ask: a question prompt list for people with brain tumours and their families

Why did we do this study?

Previous research has shown that persons diagnosed with brain tumours and their caregivers have a number of difficulties in navigating the medical system, and report needing more information and support[2].

We developed the QPL with the help of brain tumour survivors, caregivers, and health professionals. The aim of this study was to see if people currently undergoing treatment for a brain tumour thought that the QPL could help them to ask questions of their doctors, and so receive the information they want.

What did we look for?

- What did people think about the QPL? How helpful was it?
- Did the QPL help people to ask their doctors questions?
- Was the QPL any better than standard patient information?
- Is it feasible to conduct a larger scale study to determine if the QPL helps people with brain tumours to meet their information needs?

What did we find?

Fifteen of the 20 participants completed questions about the brochure they were given by the researchers (the QPL or standard patient information).

What did people think of the QPL?

All participants given the QPL found it helpful and easy to understand (see comments on right).

Did the QPL help people to ask questions?

For 6 out of 7 people, the QPL said it made it easier to ask their doctors questions.

The QPL prompted 2 people to ask questions of their neurosurgeon, 4 to ask questions of their radiation oncologist, and 5 to ask questions of their medical oncologist.

Was the QPL any better than standard patient information?

Participants given the QPL were more likely than those given standard patient information to strongly agree that the brochure:

- was helpful
- was easy to understand
- made it easier to ask questions
- contained questions that were useful to him/her
- helped the participant to put his/her questions or concerns into words
- will be useful to him/her in the future.

Is it feasible to conduct a larger scale study to determine if the QPL helps people with brain tumours to meet their information needs?

Based on the data from this pilot study, we think it is feasible to evaluate the QPL in a larger study. This larger study will assess if the QPL increases the information provided.

Participant's comments about the QPL:

"[The] brochure covered it all."

"[The] brochure was great to help get an overview and prepare for what was ahead. I had difficulty with talking with doctors beforehand."

"I liked to be able to take it [the QPL] away and ask doctors."

Where to from here?

This study's results will be presented to patients, carers and health professionals. We also hope to conduct a larger scale study to evaluate the QPL in the future. Until then, limited copies of the QPL are available to interested parties.

Thank you to all of the participants who assisted with this study.

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Any queries or comments

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