National Institute for Health and Care Excellence

Draft for Consultation

Brain tumours (primary) and brain metastases in adults

Evidence reviews for supporting people living with a brain tumour

NICE guideline <number>

Evidence Report D

January 2018

Draft for Consultation

These evidence reviews were developed by the National Guideline Alliance, hosted by the Royal College of Obstetricians and Gynaecologists

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ISBN:

Contents

Supporting people living with a brain tumour

This Evidence Report contains information on 3 reviews relating to supporting people living with a brain tumour. The Evidence Report is split into 3 sections:

- care needs of people with brain tumours, which contains 1 review on the care needs of people with a brain tumour
- neurorehabilitation assessment needs of people with brain tumours which contains 1 review on the neurorehabilitation assessment needs of people with brain tumours
- surveillance for late-onset side effects of treatment which contains 1 review on surveillance for late-onset side effects of treatment.

Care needs of people with brain tumours

Care needs of people with brain tumours

Review question

What are the health and social care support needs of people with brain tumours (primary) and brain metastases and their families and carers?

Introduction

The care needs of people living with brain tumours and those close to them are significant, and many are often hidden. Care needs can occur pre-diagnosis, at diagnosis, during routine monitoring, and during periods of stable disease as well as through treatment, recurrence and disease progression. The care needs of people with brain tumours are frequently different to people with other cancers because of the location of the tumour; brain tumours have the potential to significantly affect a person both physically and cognitively. The impact is also often individual, determined by the interplay of the tumour's location in the brain and the exact type of brain tumour the person has. Brain tumours also overlap 3 disease areas (rare cancer, rare disease, neurological disease). Feedback from patients, and surveys performed by support groups, suggest that there are high levels of unmet need and that some areas of difficulty are not routinely discussed. These tend to be areas that people find more difficult to articulate or feel ashamed mentioning, such as fatigue, memory problems or emotional problems.

This review is aimed at identifying what support needs people treated for brain tumours, their families and their carers may have. It will not identify what services help meet the identified needs.

PICO table

Table 1: Summary of the protocol (PICO table)

Population	Adults with an initial or recurrent brain tumour or brain metastases, including their families and carers. Populations which are a mix of people with tumours and people with other brain injury will be excluded unless brain tumour patient needs are explicitly identified
Intervention	Qualitative studies examining the health and social care support needs of the population above
Comparison	Not applicable
Outcome	Themes occurring in the context of health or social care support required by a person with a brain tumour and the family or carer of a person with a brain tumour. These themes will be identified from the literature, but may include: • loss of autonomy • financial support • healthy coping strategies (resilience)

	• psychological distress • driving/mobility • occupational support (vocational rehabilitation) • fatigue management • communication needs • neurocognitive impairment • advanced care planning (living will) • educational needs

For further details see the full review protocol in Appendix A.

Clinical evidence

Included studies

One systematic review including 21 studies with a total of 219 patients and 301 carers (Moore 2013) and a further 10 qualitative studies (Arber 2013, Cavers 2013, Coolbrandt 2015, Cornwell 2012, Edvardsson 2008, Nixon 2010, Ownsworth 2015, Sherwood 2011, Sterckx 2015, Wong 2011) were included in this review.

The studies examined health and social care support needs of the following populations:

- patients with malignant brain tumour (Moore, 2013; Nixon, 2010; Sterckx, 2015)
- patients with benign brain tumour, such as meningioma (Wong, 2011)
- carers of patients with malignant brain tumour (Arber 2013, Coolbrandt, 2015; Moore, 2013; Sherwood, 2011)
- carers of patients with benign brain tumour (Edvardsson, 2008)
- patients and carers of patients with malignant brain tumour (Moore, 2013)
- patients and carers of patients with benign brain tumour (Cornwell, 2012)
- carers of patients with either malignant or benign brain tumour (Ownsworth, 2015)
- patients and carers of patients with either malignant or benign brain tumour (Cavers, 2013).

The overall risk of bias of the published systematic review (Moore 2013) was considered to be low. The main concern noted was that no searches for unpublished or non-English language publications were conducted, which put the review at risk of publication bias. However, since the published review included only qualitative studies and one aspect of publication bias concerns the preferential publication of statistically significant results, the risk of publication bias in the case of Moore (2013) was likely to be reduced because qualitative studies are not subject to conventional significance testing (see Supplementary Material D for evidence tables containing the full quality assessment).

The main quality issues noted in the remaining 10 included studies were:

- the appropriateness of the recruitment strategy could not always be evaluated due to a lack of reporting
- the studies usually did not report anything about how/whether the relationship between the researcher and participants had been considered
- data saturation did not appear to be reached in a number of the studies according to the method sections of these studies (see also Table 3).

A summary of these studies is provided in Table 2, and the results along with the quality of the evidence for each outcome are listed in Table 3 and Table 4 below.

For further details, see also the study selection flow chart in Appendix C, the evidence tables for the individual studies in Supplementary Material D and the full GRADE tables in Appendix F.

Excluded studies

Full-text studies not included in this review with reasons for their exclusions are provided in Appendix K.

Summary of clinical studies included in the evidence review

Table 2: Summary of included studies: study characteristics

Study	Study aim	Participants	Brain tumour type	Method
Moore (2013) Published systematic review. Authors based in Australia, included studies conducted in Sweden (8), the USA (7), Japan (1), Australia (3) and the UK (2)	"What is the quality of evidence regarding the supportive and palliative care needs of patients with PMG and their carers, what are the key areas of our current knowledge, and what gaps exist?"	21 studies with a total of 219 patients and 301 carer	Primary malignant glioma	Systematic review of qualitative studies using structured, semi-structured and in-depth interviews and face-to-face or telephone questionnaires
Arber 2013 UK	"To explore the experience of family caregivers when caring for a person with a primary malignant brain tumour"	22 carers: 7 males/15 females; N = 17 aged < 60 years and, N = 5 aged ≥ 60 years.	Primary malignant brain tumour	Qualitative study using participant-guided interviews
Cavers 2013 UK	"To understand factors influencing the process of adjustment to a diagnosis of glioma"	26 patients: 14 males/12 females; mean age (SD, range) 50.7 (13.8, 21–76) years, and 23 relatives	Glioma multiforme (N = 15), astrocytoma grade (N = 2), brainstem glioma II (N = 1), anaplastic astrocytoma grade III (N = 2), oligodendroglioma	Qualitative study using participant-guided in-depth interviews

Study	Study aim	Participants	Brain tumour type	Method
			(N = 1), 'others' (N = 5)	
Coolbrandt 2015 Belgium	"[T]o explore the experience of family caregivers of patients with HGG and their needs related to professional care"	16 family care givers: 6 males/10 females; mean (range) age = 54.2 (31-68) years	High-grade glioma	Qualitative study using semi-structured interviews
Cornwell 2012 Australia	"[T]o understand how patients diagnosed with a non-malignant brain tumour and their carers experience the early discharge period after diagnosis and neurosurgical intervention, thereby provide insights into their perceived care and support needs"	9 patients: 3 males/6 females; mean age (range) = 55.9 (36-70) years 5 family carers: 2 males/3 females	Primary non-malignant brain tumour	Qualitative study using semi-structured interviews
Edvardsson 2008 Sweden	"[T]o explore the experience of being the next of kin of an adult person diagnosed with a low-grade glioma"	28 adult next of kin; 8 men/20 women, mean (range) age = 52.5 (25-77) years	Low-grade glioma	Qualitative study using semi-structured interviews
Nixon 2010 UK	"[T]o gain insights into the spiritual needs of neuro-oncology patients and determine their implications for practice."	21 patients age range = 18–69 years	Grade III or IV glioma (N = 19), anaplastic meningioma (N = 1), grade II glioma (N = 1)	Qualitative study using a Critical Incident Technique questionnaire
Ownsworth 2015 Australia	"1. How do caregivers perceive their support needs in the context of brain tumor [sic]?" This question examined both the support needs of the caregiver and of the person with a brain tumour. "2. How does brain tumor [sic] impact on the	11 caregivers; 6 males/5 females; mean (SD, range) age = 57.91 (12.62, 33–79) years	Benign or low-grade (N = 6); malignant (N = 5)	Qualitative study using In-depth semi-structured interviews

Study	Study aim	Participants	Brain tumour type	Method
	relationship between the caregiver and person with brain tumor [sic]?"			
Sherwood 2011 USA	"To examine how family members of patients with a primary malignant brain tumor [sic] transition into the caregiver role and how their perceptions of this transition change over time"	10 caregivers: 2 males/8 females: mean age (range) = 48 (21-63) years	Glioblastoma multiforme (N = 6), astrocytoma (grade I-III; N = 4)	Qualitative study using interview data
Sterckx 2015 Belgium	"[T]o better understand how patients with HGG experience life with a brain tumor [sic], and to explore their professional care needs"	17 patients: 10 males/7 females; mean (range) age = 50.5 (28-73) years	High-grade glioma	Qualitative study using semi-structured interviews
Wong 2011 Canada	"[T]o evaluate the supportive care and resource needs of patients undergoing craniotomy for benign brain tumours"	29 patients: 9 males/20 females; mean age 60.4 (20-88) years	Benign WHO grade I: meningioma (N = 25, N = 3 with recurrence), other (N = 4)	Qualitative study using semi-structured, face-to-face interviews

HGG high-grade glioma; PMG primary malignant glioma; SD standard deviation; WHO World Health Organization.

Table 3: Summary of included studies: themes and outline of different needs identified

Need	Studies
Patients with malignant brain tumour	
Information (e.g., about disease/treatment/future and about support available)	Moore (2013), Sterckx (2015)
Access to and availability of professionals (to help deal with questions, problems or insecurities; and for consideration and support)	Moore (2013), Nixon (2010; spiritual needs), Sterckx (2015)
Emotional support/need to talk/reassurance/share emotions and concerns (from professional caregivers)	Moore (2013), Nixon (2010; spiritual needs), Sterckx (2015)
Communication (timely so patients have the opportunity to express their desires and coordinate care plans early; supportive style; opportunities for [communication])	Moore (2013), Nixon (2010)

Need	Studies
Hope (not usually for cure, but to live well as long as possible; hopeful / encouraging communication from professional caregivers)	Moore (2013), Sterckx (2015)
Practical support	Nixon (2010)
Carers of patients with malignant brain tumour	
Information (about disease/symptoms/treatment/future and about support available, including benefits)	Arber (2013), Coolbrandt (2015), Moore (2013)
Time out from caring/respite	Arber (2013)
Access to and availability of professionals (to help deal with questions, problems or insecurities, and for consideration and support)	Arber (2013), Coolbrandt (2015), Moore (2013)
Specialist nurse access to assist in managing multiple care needs	Moore (2013)
Dedicated case manager/primary nurse to assist with uncertainty, social isolation and discussion around end-of-life issues	Moore (2013)
A relationship with the person providing care (for the patients)/consideration as a caregiver	Arber (2013), Coolbrandt (2015)
Support from others who have been in similar situations	Arber (2013), Sherwood (2011)
Patients with malignant brain tumour and carers (mixed population)	
Information (e.g., postoperative information to allow active involvement in care, disease and treatment information including about side effects and the effect of diagnosis on quality of life, medication management, prognosis information, proactive and understandable financial resources, information supporting the effective navigation of the health system, and information about resources such as access to support groups)	Moore (2013)
Investigation into the role of rehabilitation for patients, including specific interventions involving: family education and counselling, speech and occupational therapy and employment assistance	Moore (2013)
Neuropsychological assessment to support coping strategies, focusing in particular on managing difficult patient behaviours	Moore (2013)
Improved measure of cognitive change and psychological evaluation to enable increased responsiveness of services and appropriate counselling	Moore (2013)
Respite to reduce the burden of care, with the respite service providing additional support that includes competent seizure first aid, either in the home or inpatient setting	Moore (2013)
Hope	Moore (2013)

Need	Studies
Existential support (such as support with questions on the meaning and purpose of life, and support managing death anxiety)	Moore (2013)
Patients with benign brain tumour	
Access to formal support (e.g., support groups or counselling services)	Wong (2011)
Information (e.g., what to expect post-operatively, what symptoms mean, which activities the patient can undertake post-operatively)	Wong (2011)
Regular, long-term monitoring by physicians	Wong (2011)
Carers of patients with benign brain tumour	
Information (e.g., consequences post-surgery and for life together, rehabilitation, support available)	Edvardsson (2008)
Emotional support	Edvardsson (2008)
Communication style that allows the preservation of hope	Edvardsson (2008)
Accessible healthcare staff	Edvardsson (2008)
Broader professional teams in care	Edvardsson (2008)
Patients with benign brain tumour and carers (mixed population)	
Information (about availability of organised support services)	Cornwell (2012)
Organised support services (e.g., support group)	Cornwell (2012)
Support for the carers themselves	Cornwell (2012)
Home help/domestic cleaning	Cornwell (2012)
Carers of patients with benign or malignant brain tumour (mixed population)	
Information (about what to expect when caring for someone with a brain tumour, and support services available)	Ownsworth (2015)
Emotional support from healthcare professionals (e.g., through kind and caring manner)	Ownsworth (2015)
Patients with benign or malignant brain tumour and carers (mixed population)	
Professional reassurance and support by having a caring and emotionally supportive manner, being available, listening and providing information	Cavers (2013)
Hope	Cavers (2013)

Quality assessment of clinical studies included in the evidence review

The overall risk of bias of the systematic review by Moore (2013) was considered to be low (see the evidence tables in Supplementary Material D for the full quality assessment).

Table 4: Quality assessment of the included qualitative studies using the CASP checklist for qualitative studies

Quality item	Included qualitative studies									
	Arber 2013	Cavers 2013	Coolbrandt 2015	Cornwell 2012	Edvardsson 2008	Nixon 2010	Owns-worth 2015	Sher-wood 2011	Sterckx 2015	Wong 2011
1. Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Unable to tell	Unable to tell	Yes	Unable to tell	Yes	Unable to tell
5. Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6. Has the relationship between researcher and participants been adequately considered?	Unable to tell	Unable to tell	Unable to tell	Unable to tell	Unable to tell	Unable to tell	Yes	Unable to tell	Unable to tell	Unable to tell
7. Have ethical issues been taken into consideration?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

8. Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
9. Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
10. How valuable is the research?	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Recruitment until data saturation?	Yes	Yes	Yes	Yes	No	No	No	No	Yes	Yes

CASP critical appraisal skills programme; NA not applicable.

Economic evidence

The economic evidence search identified no studies that met the inclusion criteria for this review.

Resource Impact

No unit costs were presented to the committee as these were not prioritised for decision making purposes.

Evidence statements

Note that typically the number of participants in each study is more important than the number of studies. However for qualitative research the number of participants is less important than that the theme is commonly occurring. Therefore the number of studies per theme are recorded below, rather than the number of participants per theme. The quality ratings listed after each theme were derived using the ratings on the CASP checklist across studies taking into account any identified limitations as described in Table 4 and labelled as low (more than one study limitation identified), moderate (one study limitation identified) or high quality (no study limitations identified). All the themes contributed by the systematic review by Moore (2013) was rated of high quality as the systematic review contained a large number of studies and was at low risk of bias.

Patients with malignant brain tumour

- In patients with malignant brain tumour the following main health and social care support needs themes were identified: information (3 studies, high quality), access to and availability of professionals (3 studies, high quality), emotional support (3 studies, high quality), communication (2 studies, high quality), hope (2 studies, high quality), and practical support (1 study, low quality).

Carers of patients with malignant brain tumour

- In carers of patients with malignant brain tumour the following main health and social care support needs themes were identified: information (3 studies, high quality), access to and availability of professionals (3 studies, high quality), specialist nurse access to assist in managing the multiple care needs (1 study, high quality), dedicated case manager/primary

nurse to assist with uncertainty, social isolation and discussion around end-of-life issues (1 study, high quality), time out from caring/respite (1 study, moderate quality), a relationship with the person providing care for the patients (2 studies, moderate quality) and support from others who have been in similar situations (2 studies, low-moderate quality).

Patients with malignant brain tumour and carers (mixed population)

- In patients with malignant brain tumour and carers of such patients (mixed population) the following main health and social care support needs themes were identified (all in 1 study of high quality):
  - investigation into the role of rehabilitation for patients, including specific interventions involving: family education and counselling, speech and occupational therapy and employment assistance
  - neuropsychological assessment to support coping strategies, focusing in particular on managing difficult patient behaviours
  - improved measure of cognitive change and psychological evaluation to enable increased responsiveness of services and appropriate counselling
  - respite to reduce the burden of care, with the respite service providing additional support that includes competent seizure first aid, either in the home or inpatient setting)
  - hope
  - existential support (such as support with questions on the meaning and purpose of life, and support managing death anxiety)

Patients with benign brain tumour

- In patients with benign brain tumour the following main health and social care support needs themes were identified (all in 1 study of low quality): information, access to formal support and regular, long-term monitoring by physicians.

Carers of patients with benign brain tumour

- In carers of patients with benign brain tumour the following main health and social care support needs themes were identified (all in 1 study of low quality): information, emotional support, communication style that allows the preservation of hope, accessible healthcare staff and broader professional teams in care.

Patients with benign brain tumour and carers (mixed population)

- In patients with benign brain tumour and carers of such patients (mixed population) the following main health and social care support needs themes were identified (all in 1 study of moderate quality): information, organised support services, support for the carers themselves and home help/domestic cleaning.

Carers of patients with benign or malignant brain tumour (mixed population)

- In carers of patients with benign or malignant brain tumour (mixed population) the following main health and social care support needs themes were identified (all in 1 study of moderate quality): information and emotional support from healthcare professionals.

Patients with benign or malignant brain tumour and carers (mixed population)

- In patients with benign or malignant brain tumour and carers of such patients (mixed population) the following main health and social care support needs themes were identified (all in 1 study of moderate quality): hope and professional reassurance and

support in the form of a caring and emotionally supportive manner, availability, listening and provision of information.

Recommendations

D1. Be aware that the care needs of people with brain tumours represent a unique challenge distinct from other cancers, because (in addition to physical disability) the tumour and treatment can have effects on:

- cognition
- personality
- behaviour.

D2. Discuss health and social care support needs with the person with a brain tumour and their relatives and carers (as appropriate). Take into account the complex health and social care support needs people with any type of brain tumour and their relatives and carers will have (for example; psychological, cognitive, physical, spiritual, emotional).

D3. Set aside enough time to discuss the impact of the brain tumour on the person and their relatives and carers (as appropriate), and to elicit and discuss their health and social care support needs.

D4. Health and social care professionals involved in the care of people with brain tumours should address additional complex needs during or at the end of treatment and throughout follow-up. These include:

- the challenges of living with uncertainty
- maintaining a sense of hope
- changes to cognitive functioning
- loss of personal identity
- loss of independence
- fatigue
- potential for change in personal relationships
- the impact of brain tumour-associated epilepsy on wellbeing (see the NICE guideline on epilepsies: diagnosis and management).

D5. Provide a named healthcare professional with responsibility for coordinating the health and social care support for people with brain tumours and their carers, for example a key worker as defined in NICE guidance on improving outcomes for people with brain and other central nervous system tumours.

D6. Ensure information is given to the person with a brain tumour and their relatives and carers (as appropriate):

- in a professional and empathetic manner
- in suitable formats (usually meaning both written and spoken, with the information available to take away) following all principles as outlined in NICE guidance on patient experience in adult NHS services: improving the experience of care for people using adult NHS services
- at appropriate times throughout their care pathway.

D7. Explain to the person the implications of having a brain tumour on driving and any relevant legal consequences (for example if the person with the brain tumour has a responsibility to inform the DVLA).

D8. Provide and explain clinical results, for example imaging and pathology reports, to the person with a brain tumour and their relatives and carers (as appropriate) at the earliest opportunity.

D9. Offer supportive care to people with brain tumours and their relatives and carers (as appropriate) throughout their treatment and care pathway.

D10. If the person with a brain tumour is likely to be within the last year of their life, refer to the NICE clinical guidelines on end of life care for adults and, when appropriate, care of dying adults in the last days of life.

Research recommendations

No research recommendations were made on this topic.

Rationale and impact

Why the committee made the recommendations

The committee determined that people with brain tumours had very specific needs which were not being met. In particular they highlighted ways in which the care needs of people with brain tumours were different from the care needs of people with other types of cancers, such as the impact on the person's sense of self-identity or legal requirements related to driving. The committee believed that in doing this they would improve the support offered to people with brain tumours.

Impact of the recommendations on practice

The recommendations should improve care, and pre-empt the potential future needs of the person living with a brain tumour, and their relatives and carers. Forward planning is especially important if there is an expectation that a brain tumour will progress. It is likely that there will be a short-term resource impact of these recommendations in some geographical areas, as currently care for people with brain tumours is variable, with some areas offering very little support. The committee hoped that the recommendations will encourage an assessment of the wider health and social care needs alongside medical management with implications for investment in the individual's long-term future care and quality of life.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

As the review question was aimed at identifying the health and social care needs of people with brain tumours and their families and carers, the outcomes were the needs identified through the review and therefore not prioritised in advance of the review. Instead the needs identified by the evidence and by the expertise of the committee were discussed in depth and those agreed as the highest priority reflected in the resultant recommendations. For this, the committee anticipated a number of themes when developing the review protocol, such as;

loss of autonomy, psychological distress, driving/mobility issues, fatigue management, neurocognitive impairment, and educational needs.

Currently, supportive care pathways for patients and their families differ between hospitals, with significant regional variation in practice in this area, which will be a significant challenge for implementation.

The quality of the evidence

The evidence consisted of 1 published systematic review, which included 21 studies, and a further 10 qualitative studies. The included studies were critically appraised using the Risk of Bias for Sytematic reviews (ROBIS) checklist (for systematic reviews) and Critical Appraisal Skills Program (CASP) checklist (for qualitative studies). In the absence of a fully developed and agreed method for assessing the overall quality of the evidence for qualitative studies, the quality of the evidence for each identified need was determined based on an overall assessment taking into account the limitations identified for the individual studies based on the relevant checklist and the directness of the study aim and results relative to the review aim. The overall risk of bias of the systematic review was low and the quality of that was therefore high. The quality of the 10 qualitative studies ranged from low to moderate. The main quality issues noted in relation to the studies were:

- the appropriateness of the recruitment strategy could not always be evaluated due to a lack of reporting
- the studies usually did not report anything about how/whether the relationship between the researcher and participants had been considered
- data saturation did not appear to be reached in a number of the studies.

The committee determined that the evidence was consistent with their clinical experience, and consequently felt the limitations of the evidence would not prevent them from making recommendations.

Although there was no evidence found for people with brain metastases, the committee made recommendations that cover all relevant populations based on evidence showing similar needs across other subpopulations, as well as their clinical expertise.

Although the committee believed there was unmet care need for people with brain tumours, they did not think there was a significant knowledge gap around what care people with tumours valued. Therefore the committee did not choose to make a research recommendation.

Benefits and harms

Based on their experience, the committee believed that many clinicians mistakenly view brain tumours as a typical cancer. While the biological response of the tumours to clinical intervention might be typical of most cancers, the effect of the tumour and the treatment on the person with the disease is very atypical because it affects the brain in multiple and complex ways. This greatly increases the complexity of addressing the needs of people with brain tumours, both in a hospital setting and in the community (for example when general practitioners (GPs) address the needs of people with brain tumours after their initial treatment). The committee identified two themes from the evidence which highlighted this especially (cognition and behaviour) and supplemented this with one other theme they thought was important based on their experience but which was not taken from the evidence review (personality).

The committee recommended the many specific and often complex health and social care needs of people with brain tumours (and their families and carers) should be discussed and addressed with their care team. This is because the evidence suggests that an opportunity to discuss these needs is important to people with brain tumours. The committee added some examples of the sorts of thing people with tumours may need support with from their experience.

On the basis of their experience in discussing care needs, the committee added that discussing care needs can take significant time and expertise to do correctly, and so ensured that they made a recommendation that sufficient time be set aside to do this. The committee added that they believed sometimes clinicians were not spending enough time on this activity, which is why they chose to recommend something that should be ordinary clinical practice.

The committee outlined several areas of particular additional complex need on the basis of the evidence of its importance and their experience that the need is complex. The evidence confirmed that uncertainty, hope, cognitive function, independence, and changes in personal relationships were important to people with brain tumours and their carers, which was in line with the committee's experience. However the committee also highlighted other areas they believed from their experience were important to address but which were not covered by the evidence review.

The committee described how high quality qualitative evidence suggested that people with tumours would find it useful to have a healthcare professional with responsibility for coordinating health and social care support for them and their carers. This could be fulfilled through numerous models of care, and the committee noted that specific models of care were out of scope for this guideline. The committee described how one possible model of care they were familiar with from existing NICE cancer guidance was the 'key worker', and chose to cross refer into the guidance on improving outcomes for people with brain and other central nervous system tumours in order that these service delivery recommendations could be followed if appropriate.

The committee noted that there was high quality evidence that people with brain tumours and their carers valued information being provided to them during the course of their care. However the committee noted that the review was not set up to answer how to provide this information. They therefore made recommendations on the best way to provide this information on the basis of their clinical experience. The committee recommended making sure relevant information is provided in a timely and empathetic manner, and delivered in a style to suit the context of the person's needs and disease status. The committee stressed the importance of an individualised approach to providing information, facilitated by careful listening, based on their expert opinion – especially evaluating this approach at different time periods, as the needs of the person with a tumour are likely to be different at different times during the disease progression. Although this recommendation ought to already be followed in clinical practice, the committee's judgement was that information was inconsistently communicated and a recommendation was necessary to improve consistency.

Based on their expertise, the committee made several specific recommendations around areas of greatest confusion and anxiety for people with brain tumours; driving, waiting for scans and access to supportive care. These were not areas specifically identified by the evidence review, but the recommendations are thought by the committee to be helpful in reducing anxiety of those with brain tumours. Although there was no evidence on a patient need for information in these areas, the committee justified the strong recommendations on the basis that this information was, respectively, a legal requirement, required for informed consent for future treatment and an important equality issue if the person has any disabilities

or vulnerability. The committee therefore concluded that anything other than a strong recommendation risked underemphasising how significant the consequences of not communicating this information could be.

Some people with a brain tumour will be approaching the end of their life, and concern around this is reflected in the evidence which shows anxiety about end of life planning and existential questions is a need of people with a tumour. The committee recommended well considered and compassionate planning tailored to the individual needs of person with the brain tumour and their carers should be undertaken if appropriate. As NICE has existing guidance on providing this care, the committee cross-referred into this.

The committee agreed that the overall benefits of the recommendations would be that fewer health and social care support needs would be missed. This would be true for both people who have been diagnosed with brain tumours, and their families and carers. This would result in a better quality of life and less uncertainty about the many consequences of living with a brain tumour.

The committee described 2 potential harms of the recommendations. The first is that information may be imparted when it is not wanted, and that this may cause distress because once a person has the information it cannot be taken away - appropriately skilled professional support may do much to reduce the likelihood of this. The second is that if too many health and social care professionals become involved, care may become complicated and fragmented with multiple agencies. The committee discussed how the level of complexity of treating brain tumours could lead to people doubting their own ability to manage their condition. People requiring emergency treatment may require more timely guidance on the complex risks and benefits involved in treatment decisions. However the committee concluded that most people with brain tumours were comfortable refusing treatment if they did not want it, and therefore did not emphasise this as a potential harm.

The committee agreed that the benefits outweighed the potential harms.

Cost effectiveness and resource use

A literature review of published cost-effectiveness analyses did not identify any relevant studies for this topic.

The committee acknowledged there could be a large resource impact around recommendations made for this topic but it was decided it was not feasible to build a bespoke economic model given the largely qualitative nature of the clinical evidence base and wide variation around current practice.

Currently some areas have more comprehensive follow-up care and other areas offer very little support for people living with brain tumours, and their carers. In areas where little support is currently offered there is likely to be a need for additional healthcare professional time for discussing support needs and offering the care. There may also be significant resource use if additional accommodation is needed to provide these services.

The recommendations should, however, improve care through better planning of future treatment due to more joined-up care. This could lead to a reduction in suboptimal use of resources associated with prescribing ineffective treatments and treating associated adverse events. Having a good level of support for patients and their carers will also support development of appropriate strategies to manage the implications of the condition both practically and emotionally on an individual basis, and allow for people with brain tumours and carers to fully understand potential treatments and make informed decisions about care.

The recommendation on assigning a named individual to coordinate care is based on high-quality qualitative evidence. The committee discussed how they expected it to have only a small resource impact as currently care is coordinated by a large number of people throughout the treatment pathway of the person with the tumour. By redeploying the same number of people to coordinate care on an individual level the same resources should be used, only used in a different way so that there is no opportunity cost. In practice there may be a small impact from training and management needs. The cost effectiveness of 1 particular model of this coordinated care (key workers) is known to be acceptable to the NHS by the presence of other NICE guidelines on improving outcomes for people with brain and other central nervous system tumours.

It is difficult to say if these recommendations are cost effective given the wide variation in practice across England and consequently the large differences in potential resource use in implementing them. It was the committee's opinion that areas where large changes in practice would be needed would benefit from a large improvement in the care of people with brain tumours, and the experience of their carers, and would likely experience the largest increases in quality of life and associated quality-adjusted life years (QALYs). It was therefore deemed plausible that these recommendations would be cost effective.

Other factors the committee took into account

Although equality of access to services was not a theme discussed in any of the studies, the committee discussed this issue when making recommendations. In the view of the committee, access to and support with the complex needs presented by a brain tumour was not easily available to some black and minority ethnic (BAME) groups and especially non-English speakers. The committee described how their recommendations should make access to services easier, and therefore address this inequality. They did not make a specific recommendation on BAME populations because they agreed that their existing recommendations already improved access for this group.

The committee was aware of many online resources accessed by people with brain tumours and their carers. They emphasised that while some of the information is likely to be very valuable to people, in their experience some of it was very badly evidenced and potentially harmful. The committee suggested that people accessing online information could be reminded not to rely on the information as their only source. The committee also described how they believed this problem would lessen if information was being provided in a more complete and timely manner, as implied by the recommendations. Consequently the committee chose not to make a specific recommendation about online information, as the reliability of websites could change and it was difficult to make a judgement about exactly what sort of information was appropriate at different time periods. The committee added that certain topics appeared to be particularly prone to online misinformation (especially the effect of a brain tumour on driving).

The committee discussed issues around working with a brain tumour. They explained how many people had difficulty getting to work, and difficulty performing cognitively complex roles if the tumour or its treatment had damaged their cognition. In particular the committee highlighted that the effect of a brain tumour on cognition impacts on support needs and the effects on personal identity and sense of self, which is an extremely difficult aspect of the condition to manage. The committee was aware that NICE does not make recommendations that affect employment, but the care needs of someone with a tumour may include working with a brain tumour, and this should not be overlooked in discussion.

The committee also discussed how some people might experience difficulty accessing cancer support services because the language around brain tumours rarely uses the word 'cancer' for technical reasons. The committee drew attention to related NICE guidance on improving outcomes for people with brain and other central nervous system tumours which stressed that all brain tumours should be seen as cancer for the purpose of accessing support services, and that people with brain tumours should not be prevented from accessing such services even if the tumour is not malignant. By definition this means that it is classified as Specialised Commissioning for contracting and commissioning purposes.

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Neurorehabilitation assessment needs of people with brain tumours

Neurorehabilitation assessment needs of people with brain tumours

Review question

What are the facilitators and barriers to providing appropriate neurological rehabilitation assessment in people with brain tumours (primary) and brain metastases?

Introduction

Neurorehabilitation is an important part of the treatment pathway for a brain tumour. Since both the tumour itself and treatment for that tumour can have a negative impact on the nervous system of the person with the tumour, neurorehabilitation is needed to reduce or compensate for the negative impact of these effects on important functional outcomes such as limb weakness and sight impairment.

The committee noted the remit of the question was specifically about referral for neurorehabilitation assessment, and not how to carry out that assessment or the rehabilitation itself. This was because the committee was aware of a forthcoming NICE guideline on neurorehabilitation following traumatic brain injury or for a brain tumour, which might be applicable to people with brain tumours, and therefore reviewed a question on neurorehabilitation assessment in order to bridge to the forthcoming guideline. The committee also recognised that a person with a brain tumour may access specialist rehabilitation interventions from other generalist rehabilitation services, whose interventions may offer a reduction in the negative impact of symptoms.

Across the UK there is good provision of neurorehabilitation services as they are used extensively by those with other brain injuries. However there is variation across the UK in whether people with brain tumours can access these services, since many neurological rehabilitation centres do not accept referrals for people with brain tumours (or accept referrals only for certain kinds of brain tumour). There is also variation in how long and how intensively those diagnosed with a brain tumour can use services even areas where brain tumour patients are accepted into neurological rehabilitation pathways.

PICO table

Table 5: Summary of the protocol

Population	Adults with an initial or recurrent brain tumour or brain metastases, including their families and carers.
Intervention	Qualitative studies examining the neurological rehabilitation needs of the population above.
Comparison	Not applicable
Outcome	Themes occurring in the context of barriers to neurological rehabilitation assessment for a person with a brain tumour and the family or carer of a person with a brain tumour.

	These factors will be identified from the literature, but may include: • lack of awareness • difficulties not appreciated by staff • certain difficulties (i.e. mood-related difficulties) being considered a normal reaction and referrals are not made for support • uncertainty as to whether patients would be offered a neurological rehabilitation assessment, or what the referral criteria are • lack of awareness or availability of community neurocognitive rehabilitation services • the perception that patients may be too tired during treatment to cope with neurocognitive support or benefit from neurological rehabilitation.

For further details see the full review protocol in Appendix A.

Clinical evidence

Included studies

The clinical evidence search identified no studies that met the inclusion criteria for this review.

Excluded studies

Full-text studies not included in this review with reasons for their exclusions are provided in Appendix K.

Economic evidence

The economic evidence search identified no studies that met the inclusion criteria for this review.

Resource Impact

No unit costs were presented to the committee as these were not prioritised for decision making purposes.

Evidence statements

No evidence was identified.

Recommendations

D11. Consider referring the person with a brain tumour for a neurological rehabilitation assessment at diagnosis and every stage of follow-up.

D12. Offer people with brain tumours and their relatives and carers (as appropriate) information on accessing neurological rehabilitation, and on what needs it can help address.

Research recommendations

No research recommendations were made on this topic.

Rationale and impact

Why the committee made the recommendations

Based on their experience, the committee considered that neurological rehabilitation might be appropriate for many people with brain tumours. Given that neurological rehabilitation is time consuming and sometimes not appropriate, the committee agreed on the basis of their experience that referral for regular assessment was needed to identify which, if any, forms of rehabilitation would be appropriate. The committee therefore drafted recommendations to ensure that – if appropriate – referral for neurological rehabilitation assessment would be considered at every stage of the treatment and follow-up pathway.

Impact of the recommendations on practice

There are high quality neurological rehabilitation services across the entire UK. However, access of people with brain tumours to these services is variable, with variations in access to assessment being an especially important area of clinical variation. The recommendations may therefore mean a change in practice in some areas, as some people with brain tumours who would not have been referred for assessment for neurological rehabilitation before will now be referred for assessment. This will not require the provision of new services, however, as the referrals will be made into the existing neurological rehabilitation pathway.

People with a brain tumour make up a small percentage of people referred for neurological rehabilitation, so only a small increase in demand for these existing services may be expected. However, there should not be any increase in training needs for professionals involved as they would already have the knowledge and skills to provide the recommended services.

Despite being a small group relative to the numbers referred for neurological rehabilitation in general, people with brain tumours are unequally served by the current system and so these recommendations should increase equality.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

The objective of this review was to identify the most important facilitators and barriers to providing appropriate neurological rehabilitation assessment, and therefore how to design a service which will ensure appropriate assessment referrals take place. For this, the committee anticipated a number of themes such as: lack of appreciation of potential prognosis, clinical nihilism, provision of local rehabilitation teams and facilities, and shortage of clinical specialists required to perform the assessments.

As no evidence was identified, the committee based their recommendations on consensus informed by the experience and expertise of the members.

The quality of the evidence

The clinical evidence search identified no studies that met the inclusion criteria for this review.

The committee felt unable to make detailed recommendations on this topic as a result of the lack of evidence. However they did think it was appropriate to make general recommendations bridging the current implementation gap between a need for neurological rehabilitation assessment being identified (for example by a GP) and the rehabilitation being provided because in their experience this was an area of significant underprovision.

The committee was aware of a forthcoming guideline on the topic of neurological rehabilitation. For this reason they chose not to make any research recommendations.

Benefits and harms

The committee based these recommendations on opinion and clinical experience, as there was no evidence on the value of referral for neurorehabilitation assessment. The committee recommended referral to neurorehabilitation assessment as neurorehabilitation may be appropriate for all people with brain tumours during their care, regardless of type and grade of tumour or the stage of their treatment or follow-up, but that an assessment was the only way to determine this for an individual.

On the basis of their clinical experience, the committee believed that neurorehabilitation assessments could potentially be helpful to a person at every stage of follow-up (regardless of their diagnosis and prognosis), and so they did not limit this recommendation to any particular group of people with brain tumours. However because assessments are time consuming and potentially disruptive for the person with the tumour, they clarified that these referrals for assessment should only be made if they were consistent with the goals of the person with the tumour, for example a desire to return back to work or any existing neurorehabilitation goals from a previous stage of treatment.

In the experience of the committee, it could be difficult for people with tumours to know how to access neurorehabilitation assessment and so they recommended offering information on how to do this, especially if the person offering information was not also making a referral (for example if the specialist was talking to a person with a tumour about their follow-up care in the community). Although there was no evidence that offering information improved outcomes, there was high quality qualitative evidence from the review on care needs which identified that people with tumours value information and therefore the committee made this recommendation using this as indirect evidence. Since the committee had evidence on this topic (albeit indirect evidence) they felt justified in making a strong recommendation. This information could be on a number of different topics depending on the early and late side-effects associated with a particular treatment, for example it might be appropriate to offer information on some or all of; visual support, hearing support, neuropsychological support, speech and language therapy, occupational therapy or physiotherapy.

Cost effectiveness and resource use

A literature review of published cost effectiveness analyses did not identify any relevant studies for this topic.

The recommendations imply referral into services which already exist, and so therefore are not expected to carry significant one-off costs associated with setting up new services or hiring new staff. The recommendations will likely lead to a net increase in the number of assessments being undertaken and will therefore require an increase in healthcare professional time to provide this. While this topic specifically excludes consideration of the provision of rehabilitation services, a greater number of assessments may put greater pressure on such services, necessitating greater provision of services and potentially having a resource impact. People with brain tumours make up only a small minority of people requiring neurological rehabilitation and it may be that areas with already good neurological rehabilitation and neurological rehabilitation assessment facilities may be able to take on more referrals with limited resource impact.

Any increase in resource use will be counteracted by improved quality of life for patients through improvements in cognitive and neurological function, including improvements in mobility, talking, mood, sleep and other major determinants of good quality of life. The increase in QALYs resulting from implementation of the recommendations, through unquantified, was potentially large.

Other factors the committee took into account

Depending on when information is given or an assessment from a neurorehabilitation professional takes place, people with brain tumours may not fully understand the role of neurorehabilitation and that they have been assessed by a neurorehabilitation practitioner. For example, if the assessment is undertaken soon after neurological surgery a person may be more tired than normal, making it harder for them to recall information given verbally. The committee did not make specific recommendations about this issue, as they believed this was covered by recommendations made on information provision in the review on care needs. Nevertheless, they highlighted that information needs were important to address for neurological rehabilitation assessment as well as for other kinds of treatment on the basis of their experience.

In the experience of the committee, poor prognosis was one of the main barriers for an appropriate assessment, as it is often believed that recovery is not always guaranteed in rehabilitation. However the committee believed it was often possible to gain a higher quality of life and relief from some symptoms with appropriate rehabilitation interventions. Therefore the committee emphasised in their recommendation that consideration for assessment should happen at every stage of follow-up, including those stages with a poor prognosis.

The committee discussed how people with brain tumours may have fluctuating and varying neurological symptoms and problems at different points in the disease, and there is no one specific time where a patient needs neurorehabilitation – it can be appropriate at different times for different people. The committee discussed how there was perhaps a misunderstanding amongst some clinicians that neurological rehabilitation was considered only at the end of treatment, and that this could be improved on. To correct this misperception, the committee emphasised in their recommendations that referral for a neurological rehabilitation assessment should be considered at every stage of follow-up (including diagnosis).

References

The clinical evidence search identified no studies that met the inclusion criteria for this review.

Surveillance for late-onset side effects of treatment

Surveillance for late-onset side effects of treatment

Review question

What is the most effective surveillance protocol (including no surveillance) for detecting late effects of treatment for glioma, meningioma or brain metastases?

Introduction

People who are treated for glioma, meningioma, and brain metastases may develop side effects of treatment which occur months or even years later. These include neuropathy (including visual loss), cataracts, other causes of visual loss, hypopituitarism, cognitive decline, increased risk of stroke, and risk of secondary tumour. This is of particular importance for patients with glioma and meningioma who may survive decades after treatment. Surgical treatment generally causes immediate side effects though the impact of these may be lifelong; similarly, side effects from chemotherapy generally occur early after treatment (though some effects, such as infertility, may not be manifest until later). Radiotherapy differs from surgery in that the majority of significant side effects occur months or even years after treatment and the risks will vary depending on the technique used and the area of the brain treated.

Early identification of the potential late effects of treatment may allow the risk to be modified and the effect to be identified and treated promptly. This can increase length and quality of life for those people who have undergone treatment. The committee highlighted that post-treatment surveillance was very inconsistent in the UK and recommendations could help to improve this.

PICO table

Table 6: Summary of the protocol (PICO table)

Population	Adults who have received treatment for glioma, meningioma or brain metastases.
Intervention	Any surveillance protocol, which might include some combination of: • ophthalmology review • endocrine review (blood tests) • monitoring blood pressure and cholesterol • neurocognitive / neuropsychological testing • MRI.
Comparison	Any surveillance protocol No surveillance (wait until patient reports late effects).
Outcome	Critical: • stage and incidence of late effects (occurring from 12 months after treatment onwards): ○ stroke

	○ secondary cancer/tumour (in brain and body) ○ visual loss and cataract ○ hypopituitarism ○ neurocognitive decline ○ radio necrosis • severity of late effects: ○ stroke ○ secondary cancer/tumour (in brain and body) ○ visual loss and cataract ○ hypopituitarism ○ neurocognitive decline ○ radio necrosis • treatment of late effects: ○ stroke ○ secondary cancer/tumour (in brain and body) ○ visual loss and cataract ○ hypopituitarism ○ neurocognitive decline ○ radio necrosis • health-related quality of life.

MRI magnetic resonance imaging

For further details see the full review protocol in Appendix A.

Clinical evidence

Included studies

The clinical evidence search identified no studies that met the inclusion criteria for this review.

Excluded studies

Full-text studies not included in this review with reasons for their exclusions are provided in Appendix K.

Economic evidence

The economic evidence search identified no studies that met the inclusion criteria for this review.

Resource impact

Table 7: Resource impact and unit costs associated with surveillance for late-onset side effects of treatment

Resource	Unit costs	Source
Follow-Up Appointment	£188	NHS reference costs 2015-16 (WF01A)
MRI Scan	£145	NHS reference costs 2015-16 (RD01A)

Evidence statements

No evidence was identified.

Recommendations

D13. Be aware that people with brain tumours can develop side effects months or years after treatment, which can include:

- cognitive decline
- hypopituitarism
- epilepsy
- SMART (stroke like migraine attacks after radiotherapy)
- stroke
- hearing loss
- cataracts
- neuropathy (for example nerve damage causing visual loss, numbness, pain or weakness)
- infertility
- radionecrosis
- cavernoma
- secondary tumours.

D14. Assess the person's individual risk of developing late effects when they finish treatment. Record these in the written treatment summary and explain them to the person (and their relatives and carers, as appropriate).

D15. Encourage healthy lifestyle healthy lifestyle interventions such as exercise, healthy diet and smoking cessation advice in all those who have been treated with cranial radiotherapy to improve modifiable risk factors related to risk of stroke. See the NICE guidelines on obesity prevention, physical activity and smoking cessation.

D16. For people who are at high risk of stroke, consider checking blood pressure, Hba1c and cholesterol profile regularly.

D17. Consider ongoing neuropsychology assessment for people at high risk of cognitive decline.

D18. If a person has received a radiotherapy dose that has the potential to affect pituitary function, consider checking endocrine function regularly after the end of treatment.

D19. Consider ophthalmic review for people at high risk of visual impairment, for an eye examination.

D20. Consider referral to audiology for people who are at high risk of hearing loss, for a hearing test.

D21. Consider referral to stroke services if an MRI during active monitoring identifies asymptomatic ischaemic stroke.

Research recommendations

No research recommendations were made on this topic.

Rationale and impact

Why the committee made the recommendations

Based on their experience, the committee was aware that some people experience late effects after treatment for a brain tumour. With the possible exception of stroke risk it is unknown if these effects can be prevented, but the committee determined that the negative impact of these late effects could be managed through clinical vigilance and referral into appropriate specialist monitoring pathways. They therefore drafted recommendations to ensure that those at high risk of adverse outcome due to late effects could be monitored and managed appropriately.

Impact of the recommendations on practice

The recommendations should not significantly alter practice, as they are common clinical practice. However the committee noted that they might help empower people with tumours to ask about specific monitoring if they have not received it.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

The committee identified the following critical outcomes for this question; health-related quality of life, stage and incidence of late effects (occurring from 12 months after treatment onwards), severity of late effects and treatment of late effects. The latter 3 were identified as critical as they are all direct or proxy measures for the treatment of a late effect following management of a tumour. Health-related quality of life was also considered a critical outcome, as it was thought that the primary reason for treating late effects was to improve quality of life.

The committee added that some late effects were particularly prevalent (or otherwise important) and that these should be regarded as 'important' outcomes in their own rights. These effects were: stroke, secondary cancer/tumour (in brain and body), visual loss and cataract, hypopituitarism, neurocognitive decline and radionecrosis.

The quality of the evidence

The clinical evidence search identified no studies that met the inclusion criteria for this review.

Consequently the committee believed that they could offer recommendations based on their clinical experience, since the area was one they knew people with tumours needed advice and support with.

The committee was aware of the importance of surveillance for late effects, and consequently recommended a long follow-up period in all of their research recommendations. However they did not make a research recommendation on surveillance for late effects specifically because they believed this was likely covered in their existing research recommendations.

Benefits and harms

After treatment for brain tumours some people experience late effects. These can have a significant impact on the quality and length of life of the person treated, but identification of potential late effects of treatment may allow the risk to be modified and early detection can allow prompt treatment. The committee highlighted late effects which were particularly important for people with tumours to be informed about, in their clinical experience.

Specific features of the tumour can substantially alter the probability of late effects of treatment. For example, if the tumour was located near the optic nerve then visual impairment may occur, but this is very unlikely when treating a tumour remote from this area. Consequently the committee recommended assessing the specific risk for each individual, rather than consulting general tables of risk. This should be explicitly communicated to the person with the tumour, rather than relying on generic patient information leaflets. The written treatment summary will allow all those involved in the care of the patient to be aware of the risks, facilitating prompt referral and treatment as necessary. This was based on the committee's experience. Although the committee had no evidence, they chose to make a strong recommendation on the basis that this recommendation was critical in gaining informed consent for subsequent surveillance decisions, and consequently there was good reason to do it even in the absence of demonstrated clinical benefit.

Some population-based studies have shown an increased risk of stroke in people with brain tumour, particularly those in people a tumour next to central vasculature which has received radiotherapy. Consequently, the committee raised the importance of identifying and treating modifiable stroke-related risk factors. Based on their clinical experience, the committee described how clinicians should encourage the modification of lifestyle risk factors which may alter the risk of these late effects, such as exercise, smoking cessation and diet, with the person who has received radiotherapy for the tumour. In addition, the committee recommended considering blood pressure checks in appropriate groups on the basis of their clinical experience and judgement. They considered that given that treatment of high blood pressure reduces the risk of stroke in the general population there is a plausible biological pathway for blood pressure checks to help reduce post-treatment stroke in people with brain tumours.

Similarly the identification of those with diabetes (type 1 or 2) through HbA1c monitoring and those with an adverse cholesterol profile allows modification of these risk factors. The committee noted that such checks were less burdensome and costly than – for example – MRI scans, and preventing stroke was an important goal of post-treatment surveillance. The committee made these recommendations on the basis of clinical knowledge about the risk

factors for stroke, though they added that this knowledge was not brain tumour specific and therefore that the recommendation was based on indirect knowledge about the risk of stroke.

People with brain tumours often have a change in their cognitive function which frequently affects their activities of daily living. Both the tumour and its treatment can affect this. Neuropsychological assessment can identify this and assist with adaptations. Based on their clinical experience, the committee recommended ongoing neuropsychological review to try to identify early symptoms of cognitive decline in high-risk groups. Individual factors would determine the exact form and frequency of the review. The committee suggested that a review before treatment, a review 9-12 months after treatment, and additional reviews if new changes were noted would currently be considered best practice but added that there was no evidence on the best timing and so they could not make a more detailed recommendation.

The committee recommended checking of endocrine function to detect pituitary dysfunction since it is important for longer term survivors following cranial radiotherapy. This recommendation was made on the basis of the committee's clinical judgement and experience. Given the lack of evidence on the time and dose of radiotherapy that would require screening the committee was unable to give a detailed recommendation - the committee discussed how there was wide clinical variation at what level of radiation was appropriate (>=20Gy or >=30Gy) and on how long the screening should run for (10 years, 15 years, or lifelong). A dose of 30Gy or more can be associated with hormone deficiencies, but doses as low as 18Gy can cause growth hormone deficiency so the committee felt unable to make recommendations in enough detail beyond a general statement of the importance of the checks.

The committee recommended ophthalmic review for people at high risk of visual impairment on the basis of their clinical experience and judgement. The committee considered that the frequency of the ophthalmic review would need to be determined by the current symptomatology. Yearly review is often appropriate to screen for asymptomatic people but for those with visual impairment the person conducting the ophthalmic review would be better placed to recommend a timeframe for a follow up appointment. However, since the committee did not have any evidence on the best frequency of review they were unable to specify a frequency in their recommendation.

People with brain tumours can be at risk of hearing loss. The committee recommended audiological review for people at high risk of hearing loss on the basis of their clinical experience and judgement. The frequency of the audiological review will be determined by the level of the person's impairment. Yearly review may be suitable for asymptomatic patients but for those with impairment, after an assessment, the person conducting the audiological review would be better placed to recommend a timeframe for follow up appointment. However, since the committee did not have any evidence on the best frequency of review they were unable to specify a frequency in their recommendation.

Based on their experience, the committee noted that MRI scans obtained for the monitoring of tumour recurrence may identify an asymptomatic ischaemic stroke. In their experience, this could often be badly managed if not treated by a stroke specialist. They therefore recommended referral to a specialist as the most appropriate way to manage this finding.

The committee agreed that the overall benefits of the recommendations would be that more people who have been treated for brain tumours will have longer overall survival and higher quality of life because more late effects will be detected while they are still limited and easier to treat. However, the committee also recognised that increased surveillance is associated with psychological stress and anxiety for some people (including the risk of a false positive result and the worry of a possible true positive). There is also an additional potential harm of

discovering a post-treatment effect for which the risk cannot be modified, thus increasing anxiety in the person with a tumour for no clinical gain. Finally lifelong follow-up risks turning people into 'lifelong patients' which most people do not wish to become.

However, the committee agreed that the benefits of the recommendations outweighed the potential harms.

Cost effectiveness and resource use

A literature review of published cost effectiveness analyses did not identify any relevant studies for this topic.

Discussions about the future, including late effects should already happen at all centres after treatment of brain tumours. The committee did not believe that making recommendations about being aware of risk factors for late effects or encouraging lifestyle changes would increase demands upon on health practitioners' time and these things would already be discussed in the majority of centres. These recommendations were considered resource neutral.

While all centres will have some sort of follow up after treatment for the majority of brain tumour patients, the intensity and type (especially by types of specialists) varies widely across the NHS in England. Recommending specific types of follow-up and reviews, for example ophthalmic review, will lead to an increased number of appointments with these specialists and increased numbers of tests. While this would increase resource use in the short term it was thought that it would be offset significantly, if not totally, by identifying long-term effects earlier which would result in them being less complicated and less costly to treat.

Other factors the committee took into account

The committee chose not to make a recommendation on fertility. While the committee discussed that infertility was a common side effect of treatment, they considered that assessing fertility was only relevant when the person with a tumour might wish to have children. Consequently, surveillance of fertility would not usually form part of a routine assessment and so it was not recommended.

The committee discussed how in some people the ophthalmic review might require a consultant neuro-ophthalmologist (for particularly complex cases) but in others this level of review was too specialist and it could be performed by a local ophthalmologist or high-street optician, particularly if the person with a tumour did not have any visual symptoms and had a good relationship with their local ophthalmologist or optician. Therefore the committee did not specify who should conduct the review.

References

The clinical evidence search identified no studies that met the inclusion criteria for this review.

Appendices

Appendix A – Review protocols

Review protocol for review 5e – care needs of people with brain tumours

Field (based on PRISMA-P)	Content
Key area in the scope	Follow-up care after treatment for glioma, meningioma or brain metastases.
Actual review question	5e) What are the health and social care support needs of people with brain tumours (primary) and brain metastases and their families and carers?
Type of review question	Qualitative
Objective of the review	This review is aimed at identifying what support needs people treated for brain tumours, their families and their carers may have. It will not identify what services help meet the identified need.
Eligibility criteria – **population**/disease/condition/issue/domain	Adults treated for one of the following brain tumours and their carers and families: • brain metastases (single or multiple) • glioma (high- or low-grade) • meningioma • combinations of these Populations which are a mix of people with tumours and people with other brain injury will be excluded unless brain tumour patient needs are explicitly identified
Eligibility criteria – **intervention**(s)/exposure(s)/prognostic factor(s)	Themes occurring in the context of social or care support required by a person with a brain tumour and the family or carer of a person with a brain tumour. These themes will be identified from the literature, but may include: • loss of autonomy • financial support • healthy coping strategies (resilience)

Field (based on PRISMA-P)	Content
	• adapting to change • psychological distress • driving/mobility • occupational support (vocational rehabilitation) • fatigue management • communication needs and timeliness • neurocognitive impairment • advanced care planning (living will) • educational needs
Eligibility criteria – **comparator(s)/**control or reference (gold) standard	Not applicable – qualitative review
Outcomes and prioritisation	Not applicable – qualitative review
Eligibility criteria – **study design**	Only published full text English language papers Systematic reviews of qualitative studies Qualitative studies (any type) Date limit: 1990; as available care has changed significantly since then and by implications this will also be the case for the health and social care needs of adults with glioma, meningioma, or brain metastases and their carers and families
Other inclusion **exclusion criteria**	None
Proposed sensitivity/**sub-group analysis**, or meta-regression	Groups that need special attention Tumour type: • single metastasis • multiple metastases • high-grade glioma • low-grade glioma

Field (based on PRISMA-P)	Content
	• meningioma Age: • <70 years • >=70 years (as the guideline committee agreed the health and social care needs are likely to differ for these two age groups) Prognosis: • good prognosis (glioblastoma, grade III or II glioma, meningioma, metastases with extracranial disease with good prognosis) • poor prognosis (all others, including metastases where extracranial disease has poor prognosis)
Selection process – duplicate screening/selection/analysis	Duplicate screening/selection/analysis will not be undertaken for this review as it was not prioritised for it. This question was not prioritised as it had a qualitative design. Included and excluded studies will be cross checked with the committee and with published systematic reviews when available.
Data management (software)	CERQual, Excel and Word will be used to synthesise data from qualitative studies, if appropriate. STAR will be used for bibliographies/citations and study sifting. Microsoft Word will be used for data extraction and quality assessment/critical appraisal
Information sources – databases and dates	See Appendix B for full list of databases. Sources to be searched: AMED, Cinahl Plus, Medline, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Database of Abstracts of Reviews of Effectiveness, Health Technology Database, Embase, PsycINFO, Web of Science Social Science Citation Index Limits (e.g. date, study design). Limit to qualitative studies unless overall return is small Supplementary search techniques: No supplementary search techniques were used

Field (based on PRISMA-P)	Content
Identify if an update	Not an update
Author contacts	Developer: National Guideline Alliance (NGA-enquiries@rcog.org.uk)
Highlight if amendment to previous protocol	Not applicable.
Search strategy – for one database	For details please see Appendix B of the evidence review.
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as Supplementary Material D.
Data items – define all variables to be collected	For details please see evidence tables in Supplementary Material D of the full evidence guideline.
Methods for assessing bias at outcome/study level	Appraisal of methodological quality: The methodological quality of each study will be assessed using an appropriate checklist: • ROBIS for systematic reviews • the NICE quality appraisal checklist for qualitative studies will be used for this review. For details please see section 6.2 of Developing NICE guidelines: the manual
Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual
Methods for quantitative analysis – combining studies and exploring (in)consistency	Synthesis of data: Meta-analysis will be conducted where appropriate using CERQual, Excel and Word
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual. No explorations of publication bias will be undertaken as qualitative data are not subject to statistical inference testing which is one of the main concerns underlying publication bias.
Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual
Rationale/context – what is known	For details please see the introduction to the evidence review in the full evidence review/guideline.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by [add name of developer] and membership is given in Supplementary Material B in line with section 3 of Developing NICE guidelines: the manual.

Field (based on PRISMA-P)	Content
	Staff from the National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see Supplementary Material C.
Sources of funding/support	[add name of developer] is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Name of sponsor	[add name of developer] is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Roles of sponsor	NICE funds [add name of developer] to develop guidelines for the NHS in England.
PROSPERO registration number	Not registered in PROSPERO

1 *AMED Allied and Complementary Medicine Database; CERqual Confidence in the Evidence from Reviews of Qualitative research; PROSPERO International prospective*
2 *register of systematic reviews*

3 **Review protocol for review 6a – neurorehabilitation assessment needs of people with brain tumours**

Field (based on PRISMA-P)	Content
Key area in the scope	Referring adults with primary brain tumours or brain metastases for neurological rehabilitation assessment
Actual review question	6 What are the facilitators and barriers to providing appropriate neurological rehabilitation assessment in people with brain tumours (primary) and brain metastases?
Type of review question	Qualitative
Objective of the review	This review is aimed at identifying the most important facilitators and barriers to providing appropriate neurological rehabilitation assessment and neurological rehabilitation, and therefore how to design a service which will create appropriate assessment referrals
Eligibility criteria – **population**/disease/condition/issue/domain	Adults with an initial or recurrent brain tumour or brain metastases, including their families and carers: • brain metastases (single or multiple) • glioma (high- or low-grade) • meningioma • combinations of these Setting: • inpatient

Field (based on PRISMA-P)	Content
	• outpatient • community
Eligibility criteria – **intervention**(s)/exposure(s)/prognostic factor(s)/ Themes	Factors that facilitate an appropriate neurological rehabilitation assessment. Factors that are barriers to appropriate neurological rehabilitation assessment These factors will be identified from the literature, but may include: • consideration of most appropriate form(s) of assessment before referral for assessment made (e.g. neurocognitive, neuropsychological, neuromotor and sensory rehabilitation) • concurrent psychological care and support • early identification of the need for rehabilitation assessment • clinical specialities involved in assessment • presence (e.g. proximity, availability) of local rehabilitation assessment teams • presence (e.g. proximity, availability) of local rehabilitation teams and facilities • factors related to the person with a tumour (e.g. strong family support network, economic factors) • factors related to the tumour (site, progression etc.) • supportiveness and condition-specific knowledge of local primary care providers • presence of factors which assist employers to support their employees • clinical lack of knowledge /misunderstanding of prognosis
Eligibility criteria – **comparator(s)/**control or reference (gold) standard	Not applicable – qualitative review
Outcomes and prioritisation	These factors will be identified from the literature, but may include: • lack of awareness • difficulties not appreciated by staff • certain difficulties (i.e. mood-related difficulties) being considered a normal reaction and referrals are not made for support

Field (based on PRISMA-P)	Content
	• uncertainty as to whether patients would be accepted for a neurological rehabilitation assessment, or what the referral criteria are • lack of awareness or availability of community neurocognitive rehabilitation services • the perception that patients may be too tired during treatment to cope with neurocognitive support or benefit from neurological rehabilitation.
Eligibility criteria – **study design**	Only published full-text English language papers Systematic reviews of qualitative studies Qualitative studies (any type) Date limit of 1990, as neurological rehabilitation changed significantly around this time as improvement in primary treatment meant people with more advanced disease were surviving treatment.
Other inclusion **exclusion criteria**	• Children and young people (under 16 years old) The following (non-exhaustive) list of tumour types: • neuronal and mixed neuronal-glial tumours • tumours of the pineal region • embryonal tumours • tumours of the cranial and paraspinal nerves • melanocytic tumours • lymphomas • mesenchymal, histiocytic, germ cell, sellar originating and choroid plexus tumours.
Areas of focus/groups that need special attention	Groups that need special attention Tumour type: • high-grade glioma (HGG) • low-grade glioma (LGG)

Field (based on PRISMA-P)	Content
	• meningioma • 1-3 metastases versus 4 or more metastases Age: • <70 years • >=70 years (as the guideline committee agreed that health and social care needs are likely to differ for these two age groups)
Selection process – duplicate screening/selection/analysis	Duplicate screening/selection/analysis will not be undertaken for this review as it was not prioritised for it. This question was not prioritised as it had a qualitative design Included and excluded studies will be cross checked with the committee and with published systematic reviews when available.
Data management (software)	. • STAR will be used for study sifting. • CERQual, Excel and Word would have been used to synthesise data from qualitative studies.
Information sources – databases and dates	See Appendix B for full list of databases. Sources to be searched: AMED, Cinahl Plus, HMIC, Medline, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Database of Abstracts of Reviews of Effectiveness, Health Technology Database, Embase, PsycINFO, REHABDATA, Web of Science Social Science Citation Index. Date limit of 1990, as neurological rehabilitation changed significantly around this time as improvement in primary treatment meant people with more advanced disease were surviving treatment. Supplementary search techniques: No supplementary search techniques were used
Identify if an update	Not an update
Author contacts	Developer: National Guideline Alliance (NGA-enquiries@rcog.org.uk)

Field (based on PRISMA-P)	Content
Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual
Search strategy – for one database	For details please see Appendix B of the evidence review
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as Supplementary Material D of the full guideline. Data will be extracted to the point of saturation, i.e. when all needs have been detected and no new information is being found by the review team. From this point on, no more papers will be reviewed.
Data items – define all variables to be collected	Thematic data analysis will be conducted to identify all relevant needs of those with brain tumours and their family or carers. These needs will be separated by the groups with particular needs (as listed above).
Methods for assessing bias at outcome/study level	The NICE quality appraisal checklist for qualitative studies will be used for this review.
Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual
Rationale/context – what is known	For details please see the introduction to the evidence review in the full guideline.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by [add name of developer] and membership is given in Supplementary Material B in line with section 3 of Developing NICE guidelines: the manual. Staff from the National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see Supplementary Material C.
Sources of funding/support	[add name of developer] is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Name of sponsor	[add name of developer] is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Roles of sponsor	NICE funds [add name of developer] to develop guidelines for the NHS in England.
PROSPERO registration number	Not registered in PROSPERO

1 *AMED Allied and Complementary Medicine Database; CERqual Confidence in the Evidence from Reviews of Qualitative research; PROSPERO International prospective*
2 *register of systematic reviews*

1 Review protocol for review 5d – late effects of treatment

Field (based on PRISMA-P)	Content
Key area in the scope	Follow-up care after treatment for glioma, meningioma or brain metastases
Actual review question	5d What is the most effective surveillance protocol (including no surveillance) for detecting late effects of treatment for glioma, meningioma or brain metastases?
Type of review question	Intervention
Objective of the review	This review is aimed at identifying whether any surveillance protocol is significantly more effective than any other at detecting the late-onset effects of treatment.
Eligibility criteria – **population**/disease/condition/issue/domain	Adults who have received treatment for glioma, meningioma or brain metastases.
Eligibility criteria – **intervention**(s)/exposure(s)/prognostic factor(s)	Surveillance protocol (ophthalmology review; endocrine (blood tests); monitoring blood pressure and cholesterol; neurocognitive, neuropsychological testing; MRI). How frequently, for how long and by whom.
Eligibility criteria – **comparator(s)/**control or reference (gold) standard	• Any surveillance protocol • No surveillance (wait until patient reports late effects)
Outcomes and prioritisation	• Stage and incidence of late effects (occurring from 12 months after treatment onwards): o stroke o secondary cancer/tumour (in brain and body) o visual loss and cataract o hypopituitarism o neurocognitive decline o radio necrosis • Severity of late effects o stroke o secondary cancer/tumour (in brain and body) o visual loss and cataract o hypopituitarism o neurocognitive decline o radio necrosis • Treatment of late effects

Field (based on PRISMA-P)	Content
	○ stroke ○ secondary cancer/tumour (in brain and body) ○ visual loss and cataract ○ hypopituitarism ○ neurocognitive decline ○ radio necrosis • Health-related quality of life.
Eligibility criteria – **study design**	Only published full-text papers Systematic reviews RCTs Comparative observational studies
Other inclusion **exclusion criteria**	We will include papers that have more than 90% of patients who have been treated for glioma, meningioma or brain metastases
Proposed sensitivity/**sub-group analysis**, or meta-regression	• Surgery versus radiotherapy versus chemotherapy versus combinations of any of these • Age • Age at treatment
Selection process – duplicate screening/selection/analysis	Duplicate screening/selection/analysis will not be undertaken for this review as it was not prioritised for it. This question was not prioritised as the committee was not expecting to find significant evidence in this area. Included and excluded studies will be cross checked with the committee and with published systematic reviews when available.
Data management (software)	If pairwise meta-analyses undertaken, they will be performed using Cochrane Review Manager (RevMan5). 'GRADEpro' will be used to assess the quality of evidence for each outcome. STAR will be used for bibliographies/citations and study sifting. Microsoft Word will be used for data extraction and quality assessment/critical appraisal

Field (based on PRISMA-P)	Content
Information sources – databases and dates	See Appendix B for full list of databases. Sources to be searched: Medline, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Database of Abstracts of Reviews of Effectiveness, Health Technology Database, Embase. Limits (e.g. date, study design): limit to English language only (Medline and Embase). Limit to RCTs and systematic reviews and observational studies unless overall return is small. Date limit: 1990 (the relevant surveillance methods/MRI not available/comparable to present time before 1990) Supplementary search techniques: No supplementary search techniques were used.
Identify if an update	Not an update
Author contacts	Developer: National Guideline Alliance (NGA-enquiries@rcog.org.uk)
Highlight if amendment to previous protocol	Not applicable.
Search strategy – for one database	For details please see Appendix B of the evidence review.
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as Supplementary Material D.
Data items – define all variables to be collected	A standardised evidence table format will be used, and published as Supplementary Material D (clinical evidence tables) of the full guideline.
Methods for assessing bias at outcome/study level	Appraisal of methodological quality: The methodological quality of each study will be assessed using an appropriate checklist: • ROBIS for systematic reviews • Cochrane risk of bias tool for randomised studies • Cochrane risk of bias tool for non-randomised studies For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence will evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group
Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual

Field (based on PRISMA-P)	Content
Methods for quantitative analysis – combining studies and exploring (in)consistency	Synthesis of data: Meta-analysis will be conducted where appropriate using Review Manager. Minimally important differences Default values will be used of: 0.8 and 1.2 for dichotomous outcomes; 0.5 times SD for continuous outcomes, unless more appropriate values are identified by the guideline committee or in the literature.
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual. No evidence was identified. No explorations of publication bias were therefore undertaken.
Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual
Rationale/context – what is known	For details please see the introduction to the evidence review in the full evidence review/guideline.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by [add name of developer] and membership is given in Supplementary Material B in line with section 3 of Developing NICE guidelines: the manual. Staff from the National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see Supplementary Material C.
Sources of funding/support	[add name of developer] is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Name of sponsor	[add name of developer] is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Roles of sponsor	NICE funds [add name of developer] to develop guidelines for the NHS in England.
PROSPERO registration number	Not registered in PROSPERO

AMED Allied and Complementary Medicine Database; MRI magnetic resonance imaging; PROSPERO International prospective register of systematic reviews; RCT randomised controlled trial

Appendix B – Literature search strategies

Literature search strategy for review 5e – care needs of people with brain tumours

Date of initial search: 09/02/2017

Database: Embase 1974 to 2017 February 08, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

Date of re-run: 12/09/2017

Database: Embase 1980 to 2017 Week 36 & MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

#	Searches
1	exp Glioma/ use ppez
2	exp Glioma/ use oemezd
3	exp Astrocytoma/ use ppez
4	exp Astrocytoma/ use oemezd
5	Oligodendroglioma/ use ppez
6	exp Glioblastoma/ use ppez
7	(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*).tw.
8	or/1-7
9	Meningioma/ use ppez
10	Meningeal Neoplasms/ use ppez
11	exp Meningioma/ use oemezd
12	meningioma*.tw.
13	(mening* adj3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*)).tw.
14	or/9-13
15	exp Brain Neoplasms/ use ppez
16	exp Brain Tumor/ use oemezd
17	exp Cerebral Cortex/ use ppez
18	exp Brain Cortex/ use oemezd
19	exp Brain/ use ppez
20	exp Brain/ use oemezd
21	exp Meninges/ use ppez
22	Meninx/ use oemezd
23	or/15-22
24	exp Neoplasm Metastasis/ use ppez
25	metastasis/ use oemezd
26	24 or 25
27	23 and 26
28	exp Brain Neoplasms/sc use ppez
29	Brain Metastasis/ use oemezd
30	Meningeal Metastasis/ use oemezd
31	or/28-30
32	27 or 31
33	((brain or cereb* or intracranial or mening* or brainstem*) adj3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*)).tw.
34	32 or 33
35	Brain Neoplasms/co, px use ppez
36	Brain Tumor/co, rh use oemezd
37	35 or 36
38	8 or 14 or 34 or 37
39	exp Aftercare/ use ppez
40	"Continuity of Patient Care"/ use ppez
41	exp Aftercare/ use oemezd
42	Follow Up/ use oemezd
43	(followup or follow-up or follow up).ti,ab.

#	Searches
44	(aftercare or after-care or after care).ti,ab.
45	(after treatment or after-treatment or posttreatment or post treatment or post-treatment or post-therap* or post therap*).ti,ab.
46	(post-hospital* or post hospital* or posthospital* or after hospital* or follow* hospital*).ti,ab.
47	treated.ti,ab.
48	Transitional Care/ use oemezd
49	Patient Transfer/ use oemezd
50	periodic medical examination/ use oemezd
51	(re-examin* or reexamin or surveillance or monitor* or periodic examin* or regular examin* or checkup* or check-up* or check up*).ti,ab.
52	Watchful Waiting/ use ppez
53	Watchful Waiting/ use oemezd
54	exp Treatment Outcome/ use ppez
55	exp Treatment Outcome/ use oemezd
56	exp General Health Status Assessment/ use oemezd
57	exp Mental Function Assessment/ use oemezd
58	or/39-57
59	38 and 58
60	"Patient Care Planning"/ use ppez
61	Patient Care Planning/ use oemezd
62	"Health Services Needs and Demand"/ use ppez
63	health care need/ use oemezd
64	*Quality of Life/ use ppez
65	*"quality of life"/ use oemezd
66	Long-Term Care/ use ppez
67	Long Term Care/ use oemezd
68	Cancer Rehabilitation/ use oemezd
69	Social Support/ use ppez
70	Social Support/ use oemezd
71	Community Networks/ use ppez
72	Community Care/ use oemezd
73	"Community Health Planning"/ use ppez
74	Palliative Care/og, px, ut use ppez
75	Terminal Care/px, ut use ppez
76	Terminal Care/ use oemezd
77	(transmural adj (care or healthcare or service* or clinic*1)).tw.
78	(discharg* adj (plan* or patient*)).tw.
79	*Hospital Discharge/ use oemezd
80	care network*.tw.
81	community care.tw.
82	(social network* or social support*).tw.
83	exp Psychotherapy/ use ppez
84	Psychotherapy/ use oemezd
85	Psychosocial Care/ use oemezd
86	psychosocial support*.tw.
87	supportive care.tw.
88	exp Physical Therapy Modalities/ use ppez
89	exp Physiotherapy/ use oemezd
90	exp Physical Performance/ use oemezd
91	exp Motor Activity/ use ppez
92	Motor Activity/ use oemezd
93	(physical adj2 support*).tw.
94	Occupational Therapy/ use ppez
95	Occupational Therapy/ use oemezd
96	Independent Living/ use ppez
97	Independent Living/ use oemezd
98	Independence/ use oemezd
99	Activities of Daily Living/ use ppez
100	Daily Life Activity/ use oemezd
101	(daily adj (life or live* or living or activit* or difficult* or problem* or support*)).tw.
102	Lifestyle Modification/ use oemezd
103	Self Care/ use ppez
104	Self Care/ use oemezd
105	Automobile Driving/ use ppez
106	exp Car Driving/ use oemezd
107	(driv* adj1 (abilit* or inabilit* or difficult* or problem*)).tw.
108	Patient Education as Topic/ use ppez
109	Patient Education/ use oemezd
110	educat*.ti.

#	Searches
111	Personal Autonomy/ use ppez
112	Personal Autonomy/ use oemezd
113	Personal Value/ use oemezd
114	Personhood/ use ppez
115	Personhood/ use oemezd
116	((autonomy or mastery) adj2 (loss* or losing or personal or support* or abilit* or inabilit* or problem* or difficult*)).tw.
117	Individuality/ use ppez
118	exp Self Concept/ use oemezd
119	(self-esteem or self esteem or personhood).tw.
120	exp Adaptation, Psychological/ use ppez
121	exp Adaptive Behavior/ use oemezd
122	Life Change Events/ use ppez
123	attitude to change/ use oemezd
124	exp Behavioral Symptoms/ use ppez
125	Anxiety/ use ppez
126	Anxiety/ use oemezd
127	Patient Worry/ use oemezd
128	Resilience Psychological/ use ppez
129	exp Coping Behavior/ use oemezd
130	exp Stress/co, pc, rh use oemezd
131	((stress* or emotion* or orientat* or resilien* or coheren* or cope* or coping or chang*) adj2 (strateg* or support* or care* or difficult* or problem*)).tw.
132	Caregivers/px use ppez
133	Caregiver/ use oemezd
134	exp Family/px use ppez
135	exp Family/ use oemezd
136	exp Family Life/ use oemezd
137	Survivors/ use ppez
138	Cancer Survivor/ use oemezd
139	Interpersonal Relations/ use ppez
140	Human Relation/ use oemezd
141	Physician-Patient Relations/ use ppez
142	Doctor Patient Relation/ use oemezd
143	Nurse-Patient Relations/ use ppez
144	Nurse Patient Relationship/ use oemezd
145	exp Nursing Care/ use ppez
146	exp Nursing Care/ use oemezd
147	Financial Support/ use ppez
148	exp Financial Management/ use oemezd
149	((financ* or money or expenditure or bills) adj2 (support* or loss or personal or strateg* or difficult* or problem*)).tw.
150	exp Work/ use ppez
151	Work/ use oemezd
152	exp Employment/ use ppez
153	Employment/ use oemezd
154	Job Adaptation/ use oemezd
155	((work*or job* or employ* or profession* or occupation*) adj2 (return* or resum* or support* or adapt* or loss* or difficult* or problem* or abilit* or inabilit*)).tw.
156	Rehabilitation, Vocational/ use ppez
157	Vocational Rehabilitation/ use oemezd
158	Work Resumption/ use oemezd
159	Quality of Working Life/ use oemezd
160	Fatigue/px, rh use ppez
161	exp fatigue/rh use oemezd
162	exp Communication/px use ppez
163	Communication Skill/ use oemezd
164	Neurocognitive Disorders/ use ppez
165	cognitive defect/rh, si, th use oemezd
166	((neuroconiti* or cogniti*) adj (disorder* or dysfunct* or impair* or problem* or difficult*)).tw.
167	exp memory disorder/rh, th use oemezd
168	(memor* adj (loss* or disorder* or dysfunct* or impair* or problem* or difficult* or inabilit*)).tw.
169	amnesi*.ti,ab.
170	exp Advance Care Planning/ use ppez
171	*advance care planning/ use oemezd
172	Living Will/ use oemezd
173	(advance* directive* or living will* or power of attorney or ulysses contract* or psychiatric will* or right to die).tw.
174	or/60-173
175	59 and 174
176	limit 175 to english language

#	Searches
177	limit 176 to yr="1990 -Current"
178	Letter/ use ppez
179	letter.pt. or letter/ use oemezd
180	note.pt.
181	editorial.pt.
182	Editorial/ use ppez
183	News/ use ppez
184	exp Historical Article/ use ppez
185	Anecdotes as Topic/ use ppez
186	Comment/ use ppez
187	Case Report/ use ppez
188	case report/ or case study/ use oemezd
189	(letter or comment*).ti.
190	or/178-189
191	randomized controlled trial/ use ppez
192	randomized controlled trial/ use oemezd
193	random*.ti,ab.
194	or/191-193
195	190 not 194
196	animals/ not humans/ use ppez
197	animal/ not human/ use oemezd
198	nonhuman/ use oemezd
199	exp Animals, Laboratory/ use ppez
200	exp Animal Experimentation/ use ppez
201	exp Animal Experiment/ use oemezd
202	exp Experimental Animal/ use oemezd
203	exp Models, Animal/ use ppez
204	animal model/ use oemezd
205	exp Rodentia/ use ppez
206	exp Rodent/ use oemezd
207	(rat or rats or mouse or mice).ti.
208	or/195-207
209	177 not 208
210	exp Qualitative Research/ use ppez
211	exp qualitative research/ use oemezd
212	exp Surveys/ and Questionnaires/ use ppez
213	exp Questionnaire/ use oemezd
214	exp Health Services Research/ use ppez
215	action research/ use oemezd
216	Interview/ use ppez
217	exp interview/ use oemezd
218	Interviews as Topic/ use ppez
219	(interview* or qualitative or experience* or theme*).tw.
220	or/210-219
221	209 and 220
222	remove duplicates from 221

1 Date of initial search: 09/02/2017

2 Database: AMED (Allied and Complementary Medicine) 1985 to January 2017

3 Date of re-run: 13/09/2017
4 Database: AMED (Allied and Complementary Medicine) 1985 to September 2017

5

#	Searches
1	brain neoplasms/
2	(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*).tw.
3	meningioma*.tw.
4	(mening* adj3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*)).tw.
5	exp brain/
6	meninges.tw.
7	5 or 6
8	neoplasms/
9	7 and 8
10	neoplasm metastasis/

#	Searches
11	1 or 9
12	10 and 11
13	((brain or cereb* or intracranial or mening* or brainstem*) adj3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*)).tw.
14	12 or 13
15	1 or 2 or 3 or 4 or 14
16	exp general patient care/
17	(followup or follow-up or follow up).ti,ab.
18	(aftercare or after-care or after care).ti,ab.
19	(after treatment or after-treatment or posttreatment or post treatment or post-treatment or post-therap* or post therap*).ti,ab.
20	(post-hospital* or post hospital* or posthospital* or after hospital* or follow* hospital*).ti,ab.
21	treated.ti,ab.
22	"continuity of patient care"/
23	patient transfer/
24	patient discharge/
25	(re-examin* or reexamin or surveillance or monitor* or periodic examin* or regular examin* or checkup* or check-up* or check up*).ti,ab.
26	"Outcome and process assessment"/
27	(watch* adj wait*).tw.
28	exp patient assessment/
29	or/16-28
30	15 and 29
31	limit 30 to yr="1990 -Current"
32	limit 31 to english

1 Date of initial search: 09/02/2017

2 Database: Ebsco CINAHL Plus

3 Date of re-run: 13/09/2017

4 Database: Ebsco CINAHL Plus

5

#	Query
S107	S99 AND S106
S106	S100 OR S101 OR S102 OR S103 OR S104 OR S105
S105	TX (interview* or experienc* or theme*)
S104	(MH "Research, Nursing")
S103	(MH "Observational Methods+")
S102	(MH "Interviews+")
S101	TX qualitative
S100	(MH "Qualitative Studies+")
S99	S37 AND S98
S98	S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92 OR S93 OR S94 OR S95 OR S96 OR S97
S97	TX (advance* directive* or living will* or power of attorney or ulysses contract* or psychiatric will* or right to die)
S96	(MH "Advance Directives+")
S95	(MH "Advance Care Planning")
S94	TX amnesi*
S93	TX (memor* N (loss* or disorder* or dysfunct* or impair* or problem* or difficult* or inabilit*))
S92	(MH "Memory Disorders+")
S91	TX ((neuroconiti* or cogniti*) N (disorder* or dysfunct* or impair* or problem* or difficult*))
S90	(MH "Cognition Disorders")
S89	(MH "Communication+")
S88	(MH "Fatigue")
S87	(MH "Work Capacity Evaluation")
S86	(MH "Work Redesign")
S85	(MH "Rehabilitation, Vocational+")
S84	TX ((work*or job* or employ* or profession* or occupation*) N2 (return* or resum* or support* or adapt* or loss* or difficult* or problem* or abilit* or inabilit*))
S83	(MH "Job Accommodation")
S82	TX ((financ* or money or expenditure or bills or debt*) N2 (support* or loss or personal or strateg* or difficult* or problem*))

#	Query
S81	(MH "Financial Management+")
S80	(MH "Financial Support")
S79	(MH "Cancer Survivors")
S78	(MH "Family")
S77	(MH "Caregiver Support")
S76	(MH "Caregivers")
S75	TX ((stress* or emotion* or orientat* or resilien* or coheren* or cope* coping or chang*) N2 (strateg* or support* or care* or difficult* or problem*))
S74	(MH "Stress, Psychological+")
S73	(MH "Anxiety")
S72	(MH "Behavioral Symptoms+")
S71	(MH "Adaptation, Psychological+")
S70	TX (self-esteem or self esteem or personhood or self-concept or self concept or individuality)
S69	(MH "Individuality")
S68	TX ((autonomy or mastery) N2 (loss* or losing or personal or support* or abilit* or inabilit* or problem* or difficult*))
S67	(MH "Life Experiences")
S66	(MH "Personal Values")
S65	TI educat*
S64	(MH "Patient Education")
S63	TX (driv* N1 (abilit* or inabilit* or difficult* or problem*))
S62	(MH "Vehicle Operation+")
S61	(MH "Self Care+")
S60	(MH "Home Modification")
S59	(MH "Home Modification")
S58	(MH "Life Style Changes")
S57	TX ((daily or independen*) N2 (life or live* or living or activit* or difficult* or problem* or support*))
S56	TX (physical N2 support*)
S55	(MH "Motor Activity")
S54	(MH "Physical Therapy")
S53	TX supportive care
S52	TX psychosocial support*
S51	(MH "Psychotherapy+")
S50	(MH "Terminal Care+/PF/OG")
S49	TX (social network* or social support*)
S48	TX community care
S47	TX care network*
S46	(discharg* N (plan* or patient*))
S45	TX (transmural N3 (care or healthcare or service* or clinic*1))
S44	(MH "Community Health Services+")
S43	(MH "Support, Psychosocial")
S42	(MH "Activities of Daily Living+")
S41	(MH "Long Term Care")
S40	(MH "Quality of Life+")
S39	(MH "Health and Welfare Planning+")
S38	(MH "Patient Care Plans+")
S37	S18 AND S36
S36	S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35
S35	(MH "Long Term Care")
S34	(MH "Quality of Life+")
S33	(MH "Health Services Needs and Demand+")
S32	(MH "Physical Examination+")
S31	(MH "Functional Assessment+")
S30	(MH "Health Status+")
S29	(MH "Outcomes (Health Care)+")
S28	TX (re-examin* or reexamin or surveillance or monitor* or periodic examin* or regular examin* or checkup* or check-up* or check up*)
S27	(MH "Transitional Care")
S26	TX treated
S25	TX (post-hospital* or post hospital* or posthospital* or after hospital* or follow* hospital*)
S24	TX (after treatment or after-treatment or posttreatment or post treatment or post-treatment or post-therap* or post therap*)
S23	(aftercare or after-care or after care)
S22	TX (followup or follow-up or follow up)
S21	(MH "Continuity of Patient Care+")
S20	(MH "Holistic Care")
S19	(MH "After Care")
S18	S16 OR S17
S17	(MH "Brain Neoplasms+/PF/CO/RH/SS")

#	Query
S16	S3 OR S7 OR S15
S15	S13 OR S14
S14	TX ((brain or cereb* or intracranial or mening* or brainstem*) N3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*))
S13	S11 AND S12
S12	(MH "Neoplasm Metastasis+")
S11	S8 OR S9 OR S10
S10	(MH "Meninges")
S9	(MH "Brain+")
S8	(MH "Brain Neoplasms+")
S7	S4 OR S5 OR S6
S6	TX (mening* N3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*))
S5	TX meningioma*
S4	(MH "Meningeal Neoplasms+")
S3	S1 OR S2
S2	TX (glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*)
S1	(MH "Glioma")

1 Date of initial search: 09/02/2017

2 Database: The Cochrane Library, Issue 2 of 12, February 2017

3 Date of re-run: 13/09/2017

4 Database: The Cochrane Library, Issue 2 of 12, February 2017

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ID	Search
#1	MeSH descriptor: [Glioma] explode all trees
#2	MeSH descriptor: [Astrocytoma] explode all trees
#3	MeSH descriptor: [Oligodendroglioma] explode all trees
#4	MeSH descriptor: [Glioblastoma] explode all trees
#5	(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*)
#6	{or #1-#5}
#7	MeSH descriptor: [Meningioma] explode all trees
#8	MeSH descriptor: [Meningeal Neoplasms] explode all trees
#9	meningioma*
#10	(mening* near/3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*))
#11	{or #7-#10}
#12	MeSH descriptor: [Neoplasm Metastasis] explode all trees
#13	MeSH descriptor: [Brain Neoplasms] explode all trees
#14	MeSH descriptor: [Brain] explode all trees
#15	MeSH descriptor: [Cerebral Cortex] explode all trees
#16	MeSH descriptor: [Meninges] explode all trees
#17	{or #13-#16}
#18	#12 and #17
#19	MeSH descriptor: [Brain Neoplasms] explode all trees and with qualifier(s): [Secondary - SC]
#20	((brain or cereb* or intracranial or mening* or brainstem*) near/3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*))
#21	{or #18-#20}
#22	#6 or #11 or #21
#23	MeSH descriptor: [Brain Neoplasms] explode all trees and with qualifier(s): [Complications - CO, Psychology - PX]
#24	#22 or #23
#25	MeSH descriptor: [Aftercare] explode all trees
#26	MeSH descriptor: [Continuity of Patient Care] explode all trees
#27	(followup or follow-up or follow up)
#28	(aftercare or after-care or after care)
#29	(after treatment or after-treatment or posttreatment or post treatment or post-treatment or post-therap* or post therap* or follow* treatment or follow* therap*)
#30	(post-hospital* or post hospital* or posthospital* or after hospital* or follow* hospital*)
#31	treated
#32	(re-examin* or reexamin or surveillance or monitor* or periodic examin* or regular examin* or checkup* or check-up* or check up*)
#33	MeSH descriptor: [Watchful Waiting] explode all trees

ID	Search
#34	MeSH descriptor: [Treatment Outcome] explode all trees
#35	{or #25-#34}
#36	#24 and #35
#37	MeSH descriptor: [Patient Care Planning] explode all trees
#38	MeSH descriptor: [Health Services Needs and Demand] explode all trees
#39	MeSH descriptor: [Quality of Life] explode all trees
#40	MeSH descriptor: [Long-Term Care] explode all trees
#41	MeSH descriptor: [Social Support] explode all trees
#42	MeSH descriptor: [Community Networks] explode all trees
#43	MeSH descriptor: [Community Health Planning] this term only
#44	MeSH descriptor: [Palliative Care] this term only and with qualifier(s): [Organization & administration - OG, Psychology - PX]
#45	MeSH descriptor: [Terminal Care] this term only and with qualifier(s): [Organization & administration - OG, Psychology - PX]
#46	(transmural near (care or healthcare or service* or clinic*1))
#47	(discharg* near (plan* or patient*))
#48	care network*
#49	community care
#50	(social network* or social support*)
#51	MeSH descriptor: [Psychotherapy] explode all trees
#52	psychosocial support*
#53	supportive care
#54	MeSH descriptor: [Physical Therapy Modalities] explode all trees
#55	MeSH descriptor: [Motor Activity] explode all trees
#56	(physical adj2 support*)
#57	MeSH descriptor: [Occupational Therapy] this term only
#58	MeSH descriptor: [Independent Living] this term only
#59	MeSH descriptor: [Activities of Daily Living] this term only
#60	((daily or independen*) near (life or live* or living or activit* or difficult* or problem* or support*))
#61	MeSH descriptor: [Home Care Services] explode all trees
#62	MeSH descriptor: [Self Care] explode all trees
#63	MeSH descriptor: [Automobile Driving] explode all trees
#64	(driv* near (abilit* or inabilit* or difficult* or problem*))
#65	MeSH descriptor: [Patient Education as Topic] this term only
#66	educat*
#67	MeSH descriptor: [Personal Autonomy] this term only
#68	MeSH descriptor: [Personhood] this term only
#69	((autonomy or mastery) near (loss* or losing or personal or support* or abilit* or inabilit* or problem* or difficult*))
#70	MeSH descriptor: [Individuality] this term only
#71	(self-esteem or self esteem or personhood)
#72	MeSH descriptor: [Adaptation, Psychological] explode all trees
#73	MeSH descriptor: [Behavioral Symptoms] explode all trees
#74	MeSH descriptor: [Anxiety] this term only
#75	MeSH descriptor: [Resilience, Psychological] explode all trees
#76	MeSH descriptor: [Adaptation, Psychological] explode all trees
#77	((stress* or emotion* or orientat* or resilien* or coheren* or cope* or coping or chang*) near (strateg* or support* or care* or difficult* or problem*))
#78	MeSH descriptor: [Caregivers] explode all trees and with qualifier(s): [Psychology - PX]
#79	MeSH descriptor: [Family] explode all trees and with qualifier(s): [Psychology - PX]
#80	MeSH descriptor: [Survivors] explode all trees
#81	MeSH descriptor: [Financial Support] explode all trees
#82	((financ* or money or expenditure or bills or debt*) near (support* or loss or personal or strateg* or difficult* or problem*))
#83	MeSH descriptor: [Work] explode all trees
#84	MeSH descriptor: [Employment] explode all trees
#85	((work*or job* or employ* or profession* or occupation*) near (return* or resum* or support* or adapt* or loss* or difficult* or problem* or abilit* or inabilit*))
#86	MeSH descriptor: [Rehabilitation, Vocational] explode all trees
#87	MeSH descriptor: [Fatigue] explode all trees and with qualifier(s): [Psychology - PX, Rehabilitation - RH]
#88	MeSH descriptor: [Communication] explode all trees
#89	MeSH descriptor: [Neurocognitive Disorders] explode all trees
#90	((neuroconiti* or cogniti*) near (disorder* or dysfunct* or impair* or problem* or difficult*))
#91	(memor* near (loss* or disorder* or dysfunct* or impair* or problem* or difficult* or inabilit*))
#92	amnesi*
#93	MeSH descriptor: [Advance Care Planning] explode all trees
#94	(advance* directive* or living will* or power of attorney or ulysses contract* or psychiatric will* or right to die)
#95	{or #37-#94}
#96	#36 and #95 Publication Year from 1990 to 2017

Date of initial search: 09/02/2017

Database HMIC Health Management Information Consortium 1979 to November 2016

Date of re-run: 12/09/2017

Database: HMIC Health Management Information Consortium 1979 to May 2017

#	Searches
1	glioma/
2	(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*).tw.
3	meningioma*.tw.
4	(mening* adj3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*)).tw.
5	brain cancer/
6	exp brain/
7	exp meninges/
8	6 or 7
9	exp neoplasms/
10	8 and 9
11	((brain or cereb* or intracranial or mening* or brainstem*) adj3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*)).tw.
12	1 or 2 or 3 or 4 or 5 or 10 or 11
13	exp after care/
14	exp after care services/
15	(followup or follow-up or follow up).ti,ab.
16	(after treatment or after-treatment or posttreatment or post treatment or post-treatment or post-therap* or post therap*).ti,ab.
17	(post-hospital* or post hospital* or posthospital* or after hospital* or follow* hospital*).ti,ab.
18	treated.ti,ab.
19	patient transfer/
20	exp health checks/
21	(re-examin* or reexamin or surveillance or monitor* or periodic examin* or regular examin* or checkup* or check-up* or check up*).ti,ab.
22	exp outcomes/
23	exp assessment/
24	"continuity of patient care"/
25	or/13-24
26	12 and 25
27	limit 26 to english
28	limit 27 to yr="1990 -Current"

Date of initial search: 09/02/2017

Database: PsycINFO 1806 to January Week 5 2017

Date of re-run: 12/09/2017

Database: PsycINFO 1806 to August Week 36 2017

#	Searches
1	glioma/
2	(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*).tw.
3	1 or 2
4	meningioma*.tw.
5	(mening* adj3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*)).tw.
6	4 or 5
7	exp Brain Neoplasms/
8	exp Cerebral Cortex/
9	exp BRAIN/
10	exp Brain Stem/
11	meninges/
12	or/7-11

#	Searches
13	metastasis/
14	12 and 13
15	((brain or cereb* or intracranial or mening* or brainstem*) adj3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*)).tw.
16	14 or 15
17	3 or 6 or 16
18	exp brain neoplasms/
19	17 or 18
20	exp AFTERCARE/
21	"continuum of care"/
22	posttreatment followup/
23	(followup or follow-up or follow up).ti,ab.
24	(aftercare or after-care or after care).ti,ab.
25	(after treatment or after-treatment or posttreatment or post treatment or post-treatment or post-therap* or post therap*).ti,ab.
26	(post-hospital* or post hospital* or posthospital* or after hospital* or follow* hospital*).ti,ab.
27	treated.ti,ab.
28	client transfer/
29	exp outpatient treatment/
30	outpatients/
31	(re-examin* or reexamin or surveillance or monitor* or periodic examin* or regular examin* or checkup*).ti,ab.
32	exp monitoring/
33	(watch* adj wait*).tw.
34	"remission (disorders)"/
35	"recovery (disorders)"/
36	"relapse (disorders)"/
37	hospital discharge/
38	discharge planning/
39	exp measurement/
40	or/20-39
41	19 and 40
42	needs assessment/
43	exp health care delivery/
44	"quality of life"/
45	life changes/
46	exp life satisfaction/
47	exp lifestyle/
48	daily activities/
49	"activities of daily living"/
50	assisted living/
51	exp Well Being/
52	long term care/
53	palliative care/
54	terminally ill patients/
55	rehabilitation/
56	social support/
57	exp community services/
58	community involvement/
59	(transmural adj (care or healthcare or service* or clinic*1)).tw.
60	care network*.tw.
61	community care.tw.
62	(social network* or social support*).tw.
63	exp psychotherapy/
64	psychosocial rehabilitation/
65	psychosocial readjustment/
66	psychosocial support*.tw.
67	supportive care.tw.
68	physical therapy/
69	exp motor processes/
70	(physical adj2 support*).tw.
71	occupational therapy/
72	self-care skills/
73	adaptive behavior/
74	(daily adj (life or live* or living or activit* or difficult* or problem* or support*)).tw.
75	driving behavior/ or drivers/
76	(driv* adj1 (abilit* or inabilit* or difficult* or problem*)).tw.
77	client education/
78	educat*.ti.
79	"Independence (Personality)"/

#	Searches
80	Autonomy/
81	Self-Determination/
82	Personal Values/
83	exp Self-Concept/
84	((autonomy or mastery) adj2 (loss* or losing or personal or support* or abilit* or inabilit* or problem* or difficult*)).tw.
85	(self-esteem or self esteem or personhood).tw.
86	exp emotional states/
87	"resilience (psychological)"/
88	coping behavior/
89	"sense of coherence"/
90	exp stress/ or stress management/
91	((stress* or emotion* or orientat* or resilien* or coheren* or cope* or coping or chang*) adj2 (strateg* or support* or care* or difficult* or problem*)).tw.
92	caregivers/ or caregiver burden/
93	exp family members/
94	financial strain/
95	((financ* or money or expenditure or bills) adj2 (support* or loss or personal or strateg* or difficult* or problem*)).tw.
96	"quality of work life"/
97	exp occupational stress/
98	work-life balance/
99	work load/ or work scheduling/
100	working conditions/
101	occupational health/
102	((work*or job* or employ* or profession* or occupation*) adj2 (return* or resum* or support* or adapt* or loss* or difficult* or problem* or abilit* or inabilit*)).tw.
103	exp vocational rehabilitation/
104	fatigue/
105	exp communication skills/ or exp verbal communication/
106	neurocognition/
107	cognitive impairment/
108	((neuroconiti* or cogniti*) adj (disorder* or dysfunct* or impair* or problem* or difficult*)).tw.
109	exp memory disorders/
110	(memor* adj (loss* or disorder* or dysfunct* or impair* or problem* or difficult* or inabilit*)).tw.
111	amnesi*.tw.
112	advance directives/
113	(advance* directive* or living will* or power of attorney or ulysses contract* or psychiatric will* or right to die).tw.
114	or/42-113
115	41 and 114
116	limit 115 to english language
117	limit 116 to yr="1990 -Current"

1 Date of initial search: 09/02/2017

2 Database: Web of Science Social Science Citation Index (SSCI) 1990 to present

3 Date of rerun: 13/09/2017

4 Database: Web of Science Social Science Citation Index (SSCI) 1990 to present

5

#20	(#19 AND #18) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#19	(TS=(qualitative or interview* or experienc* or action research or questionnaire* or observational or participant observ* or theme* or thematic analys?s or grounded theor* or grounded stud* or grounded research* or grounded analys?s or field stud* or field research* or discourse analys?s or discurs* analys?s or narrative analys?s or nursing research methodology or ethnograph* or ethnonursing or ethnological research or phenomenol* or life stor*)) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#18	(#17 AND #16) AND LANGUAGE: (English) DocType=All document types; Language=All languages;

#17	(#5 OR #4 OR #3 OR #2 OR #1) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#16	(#15 OR #14 OR #13 OR #12 OR #11 OR #10 OR #9 OR #8 OR #7 OR #6) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#15	(TS=((health or function or status) SAME assess*)) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#14	(TS=treatment* outcome*) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#13	(TS=(watch* SAME wait*)) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#12	(TS=(re-examin* or reexamin* or surveillance or monitor* or periodic examin* or regular examin* or checkup* or check-up* or check up or check ups)) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#11	(TS=transition* care) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#10	(TS=treated) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#9	(TS=(post-hospital* or post hospital* or posthospital* or after hospital* or follow* hospital*)) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#8	(TS=(after treatment or after-treatment or posttreatment or post treatment or post-treatment or post-therap* or post therap*)) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#7	(TS=(aftercare or after-care or after care)) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#6	(TS=(followup or follow-up or follow up)) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#5	(TS=(primary brain cancer* or primary brain tumo?r* or primary brain neoplasm*)) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#4	(TS=((brain or cereb* or intracranial or mening* or brainstem*) NEAR3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*))) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#3	(TS=(mening* NEAR3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*))) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#2	(TS=meningioma*) AND LANGUAGE: (English) DocType=All document types; Language=All languages;
#1	(TS=(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*)) AND LANGUAGE: (English) DocType=All document types; Language=All languages;

Literature search strategy for review 6a – neurorehabilitation assessment needs of people with brain tumours

Date of initial search: 07/03/2017

Database: Embase 1974 to 2017 March 06, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

1 Date of re-run: 07/09/2017

2 Database: Embase 1980 to 2017 Week 36 2017 & MEDLINE(R) Epub Ahead of
3 Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid
4 MEDLINE(R) 1946 to Present

5

#	Searches
1	exp Glioma/ use ppez
2	exp Glioma/ use oemezd
3	exp Astrocytoma/ use ppez
4	exp Astrocytoma/ use oemezd
5	Oligodendroglioma/ use ppez
6	exp Glioblastoma/ use ppez
7	(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*).tw.
8	or/1-7
9	Meningioma/ use ppez
10	Meningeal Neoplasms/ use ppez
11	exp Meningioma/ use oemezd
12	meningioma*.tw.
13	(mening* adj3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*)).tw.
14	or/9-13
15	exp Brain Neoplasms/ use ppez
16	exp Brain Tumor/ use oemezd
17	exp Cerebral Cortex/ use ppez
18	exp Brain Cortex/ use oemezd
19	exp Brain/ use ppez
20	exp Brain/ use oemezd
21	exp Meninges/ use ppez
22	Meninx/ use oemezd
23	or/15-22
24	exp Neoplasm Metastasis/ use ppez
25	metastasis/ use oemezd
26	24 or 25
27	23 and 26
28	exp Brain Neoplasms/sc use ppez
29	Brain Metastasis/ use oemezd
30	Meningeal Metastasis/ use oemezd
31	or/28-30
32	27 or 31
33	((brain or cereb* or intracranial or mening* or brainstem*) adj3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*)).tw.
34	32 or 33
35	exp Brain Neoplasms/rh use ppez
36	exp brain tumor/rh
37	35 or 36
38	8 or 14 or 34 or 37
39	rehabilitation.fs.
40	Neurological Rehabilitation/ use ppez
41	neurorehabilitation/ use oemezd
42	(neurorehab* or neuro-rehab* or neuro* rehab*).tw.
43	40 or 42
44	exp Rehabilitation/ use ppez
45	exp rehabilitation/ use oemezd
46	Recovery of Function/ use ppez
47	rehabilitation care/ use oemezd
48	or/44-47
49	exp Health Services Accessibility/ use ppez
50	health care delivery/ use oemezd
51	exp Neurology/ use ppez
52	exp neurology/ use oemezd
53	Oncology Service, Hospital/ use ppez
54	cancer center/ use oemezd
55	oncology/ use oemezd
56	exp Ambulatory Care/ use ppez
57	exp ambulatory care/ use oemezd
58	Neuropsychology/ use ppez

#	Searches
59	neuropsychology/ use oemezd
60	exp "psychological phenomena and processes"/ use ppez
61	exp "psychological and psychiatric procedures"/ use oemezd
62	exp Neuropsychological Tests/ use ppez
63	exp neuropsychological tests/ use oemezd
64	exp Behavior Therapy/ use ppez
65	exp behavior therapy/ use oemezd
66	Physical Therapy Modalities/ use ppez
67	physiotherapy/ use oemezd
68	exp Primary Health Care/ use ppez
69	exp primary health care/ use oemezd
70	exp General Practice/ use ppez
71	general practice/ use oemezd
72	General Practitioners/ or Physicians, Primary Care/ or Physicians, Family/ use ppez
73	general practitioner/ use oemezd
74	exp Community Health Services/ use ppez
75	exp community care/ use oemezd
76	Inpatients/ use ppez
77	hospital patient/ use oemezd
78	Outpatients/ use ppez
79	outpatient/ use oemezd
80	exp Patient Care Team/ use ppez
81	Rehabilitation Nursing/ use ppez
82	Rehabilitation Nursing/ use oemezd
83	Oncology Nursing/ use ppez
84	exp oncology nursing/ use oemezd
85	Neuroscience Nursing/ use ppez
86	neuroscience nursing/ use oemezd
87	exp Home Nursing/ use ppez
88	exp home care/ use oemezd
89	exp Community Health Nursing/ use ppez
90	exp community health nursing/ use oemezd
91	exp Consultants/ use ppez
92	exp consultation/ use oemezd
93	Neurologists/ use ppez
94	neurologist/ use oemezd
95	Oncologists/ use ppez
96	exp oncologist/ use oemezd
97	Physical therapists/ use ppez
98	physiotherapist/ use oemezd
99	Occupational Therapists/ use ppez
100	occupational therapist/ use oemezd
101	speech language pathologist/ use oemezd
102	exp Family/ use ppez
103	exp family/ use oemezd
104	Caregivers/ use ppez
105	caregiver/ use oemezd
106	exp Employment/ use ppez
107	exp employment/ use oemezd
108	exp Work/ use ppez
109	exp work/ use oemezd
110	exp Rehabilitation Centers/ use ppez
111	sheltered workshop/ use oemezd
112	rehabilitation centers/ use oemezd
113	exp "Prostheses and Implants"/ use ppez
114	exp "prostheses and orthoses"/ use oemezd
115	exp Orthotic Devices/ use ppez
116	exp Neural Prostheses/ use ppez
117	exp neuroprosthesis/ use oemezd
118	or/49-117
119	48 and 118
120	rehab*.tw.
121	(neuro* or psycho* or oncolog* or cancer* or sensory or cogniti*).tw.
122	(physiotherap* or physical therap* or cognitive therap* or behavio?r therap*).tw.
123	(outpatient* or inpatient* or hospital* or home* or local* or communit* or famil* or carer* or caregiver*).tw.
124	((primary or family) adj (care* or healthcare or medical care or practi* or doctor* or physician* or clinician* or nurse*)).tw.
125	(general practi* or gp*1).tw.
126	(employ* or work* or occupation* or vocation*).tw.

#	Searches
127	(nurs* or consultant* doctor* or specialist* physician* or clinician* or health professional* or staff or therapist* or prosthe* or orthopti* or ortho* or speech or language).tw.
128	(multidisciplinary or multi-disciplinary or integrated or interdisciplinary or inter-disciplinary).tw.
129	(obstacle* or barrier* or obstruct* or facilitat* or takeup or "take up" or access*).tw.
130	or/121-129
131	120 and 130
132	39 or 43 or 119 or 131
133	exp "Referral and Consultation"/ use ppez
134	patient referral/ use oemezd
135	patient assessment/ use oemezd
136	(refer*1 or referr*).tw.
137	Symptom Assessment/ use ppez
138	symptom assessment/ use oemezd
139	exp Health Status/ use ppez
140	exp health status/ use oemezd
141	exp Health Status Indicators/ use ppez
142	exp health status indicator/ use oemezd
143	exp general health status assessment/ use oemezd
144	exp mental function assessment/ use oemezd
145	exp side effect assessment/ use oemezd
146	neurologic disease assessment/ use oemezd
147	exp Disability Evaluation/ use ppez
148	Program Evaluation/ use ppez
149	exp program evaluation/ use oemezd
150	"Predictive Value of Tests"/ use ppez
151	predictive value/ use oemezd
152	exp "Outcome Assessment (Health Care)"/ use ppez
153	outcome assessment/ use oemezd
154	(assess* or evaluat* or monitor*).tw.
155	or/133-154
156	38 and 132 and 155
157	limit 156 to english language
158	Letter/ use ppez
159	letter.pt. or letter/ use oemezd
160	note.pt.
161	editorial.pt.
162	Editorial/ use ppez
163	News/ use ppez
164	exp Historical Article/ use ppez
165	Anecdotes as Topic/ use ppez
166	Comment/ use ppez
167	Case Report/ use ppez
168	case report/ or case study/ use oemezd
169	(letter or comment*).ti.
170	or/158-169
171	randomized controlled trial/ use ppez
172	randomized controlled trial/ use oemezd
173	random*.ti,ab.
174	or/171-173
175	170 not 174
176	animals/ not humans/ use ppez
177	animal/ not human/ use oemezd
178	nonhuman/ use oemezd
179	exp Animals, Laboratory/ use ppez
180	exp Animal Experimentation/ use ppez
181	exp Animal Experiment/ use oemezd
182	exp Experimental Animal/ use oemezd
183	exp Models, Animal/ use ppez
184	animal model/ use oemezd
185	exp Rodentia/ use ppez
186	exp Rodent/ use oemezd
187	(rat or rats or mouse or mice).ti.
188	or/175-187
189	157 not 188
190	remove duplicates from 189

Review question:

Date of initial search: 08/03/2017

Database: AMED (Allied and Complementary Medicine) 1985 to March 2017, HMIC Health Management Information Consortium 1979 to January 2017

Date of re-run: 07/09/2017

Database: AMED (Allied and Complementary Medicine) 1985 to September 2017 & HMIC Health Management Consortium 1979 to August 2017

#	Searches
1	glioma/ use hmic
2	brain cancer/ use hmic
3	brain neoplasms/ use amed
4	(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*).tw.
5	meningioma*.tw.
6	(mening* adj3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*)).tw.
7	or/1-6
8	exp brain/ use hmic
9	exp brain/ use amed
10	exp meninges/ use hmic
11	meninges.tw.
12	or/8-11
13	exp neoplasms/ use hmic
14	neoplasms/ use amed
15	13 or 14
16	12 and 15
17	neoplasm metastasis/ use amed
18	7 or 16
19	17 and 18
20	((brain or cereb* or intracranial or mening* or brainstem*) adj3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*)).tw.
21	19 or 20
22	3 or 4 or 5 or 6 or 21
23	exp rehabilitation/ use hmic
24	exp rehabilitation services/ use hmic
25	rehabilitation/ use amed
26	exp rehabilitation centers/ use amed
27	exp rehabilitation modalities/ use amed
28	rehabilitation speciality/ use amed
29	rehab*.tw.
30	(neurorehab* or neuro-rehab* or neuro* rehab*).tw.
31	or/23-30
32	22 and 31
33	limit 32 to english language
34	remove duplicates from 33

Date of initial search: 08/03/2017

Database: EBSCO Host CINAHL Plus

Date of re-run: 13/09/2017

Database: EBSCO Host CINAHL Plus

#	Query
S21	S16 AND S20
S20	S17 OR S18 OR S19
S19	TX (neurorehab* or neuro-rehab* or neuro* rehab*)
S18	TX rehab*
S17	(MH "Rehabilitation+")

#	Query
S16	S3 OR S7 OR S15
S15	S13 OR S14
S14	TX ((brain or cereb* or intracranial or mening* or brainstem*) N3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*))
S13	S11 AND S12
S12	(MH "Neoplasm Metastasis+")
S11	S8 OR S9 OR S10
S10	(MH "Meninges")
S9	(MH "Brain+")
S8	(MH "Brain Neoplasms+")
S7	S4 OR S5 OR S6
S6	TX (mening* N3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*))
S5	TX meningioma*
S4	(MH "Meningeal Neoplasms+")
S3	S1 OR S2
S2	TX (glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*)
S1	(MH "Glioma")

1 Date of initial search: 08/03/2017

2 Database: The Cochrane Library, Issue 3 of 12, March 2017

3 Date of re-run: 12/09/2017

4 Database: The Cochrane Library, Issue 9 of 12, September 2017

5

ID	Search
#1	MeSH descriptor: [Glioma] explode all trees
#2	(glioma* or glioblastoma* or gliosarcoma* or astrocytoma* or astroblastoma* or oligodendroglioma* or oligodendrocytoma* or oligoastrocytoma* or GBM)
#3	ependymoma*
#4	(glial near/3 (neoplas* or cancer* or tumo* or carcin* or malign* or metasta*))
#5	{or #1-#4}
#6	MeSH descriptor: [Meningioma] explode all trees
#7	MeSH descriptor: [Meningeal Neoplasms] explode all trees
#8	meningioma*
#9	(mening* near/3 (neoplas* or cancer* or carcin* or tumo* or malign* or metasta*))
#10	{or #6-#9}
#11	MeSH descriptor: [Neoplasm Metastasis] explode all trees
#12	MeSH descriptor: [Brain Neoplasms] explode all trees
#13	MeSH descriptor: [Brain] explode all trees
#14	#12 or #13
#15	#11 and #14
#16	((brain or cereb* or intracranial or mening*) near/3 (metasta* or micometasta* or spread* or involvement or carcinosis or secondar*))
#17	#15 or #16
#18	#5 or #10 or #17
#19	MeSH descriptor: [Brain Neoplasms] explode all trees and with qualifier(s): [Rehabilitation - RH]
#20	#18 or #19
#21	MeSH descriptor: [Neurological Rehabilitation] explode all trees
#22	(neurorehab* or neuro-rehab* or neuro* rehab*)
#23	MeSH descriptor: [Rehabilitation] explode all trees
#24	MeSH descriptor: [Recovery of Function] explode all trees
#25	rehab*
#26	{or #21-#25}
#27	#20 and #26

6 Date of initial search: 08/03/2017

7 Database: PsycINFO 1806 to February Week 4 2017

8 Date of re-run: 12/09/2017

9 Database: PsycINFO 1806 to September Week 36 2017

#	Searches
1	glioma/
2	(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*).tw.
3	1 or 2
4	meningioma*.tw.
5	(mening* adj3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*)).tw.
6	4 or 5
7	exp Brain Neoplasms/
8	exp Cerebral Cortex/
9	exp BRAIN/
10	exp Brain Stem/
11	meninges/
12	or/7-11
13	metastasis/
14	12 and 13
15	((brain or cereb* or intracranial or mening* or brainstem*) adj3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*)).tw.
16	14 or 15
17	3 or 6 or 16
18	exp brain neoplasms/
19	17 or 18
20	exp Rehabilitation/
21	rehab*.tw.
22	(neurorehab* or neuro-rehab* or neuro* rehab*).tw.
23	or/20-22
24	19 and 23
25	limit 24 to english language

Date of initial search: 08/03/2017

Database: REHABDATA (http://www.naric.com/?q=en/SearchRehabdata)

Date of re-run13/09/2017

Database: REHABDATA (http://www.naric.com/?q=en/SearchRehabdata)

No save facility, so no search strategy recorded.

Keywords used: glioma, glioblastoma, astrocytoma, oligodendroglioma, meningioma, brain tumour/tumor, brain cancer, brain metastasis/metastases, brain neoplasms

Date of initial search: 08/03/2017

Database: Web of Science Social Science Citation Index (SSCI) 1900 to present

Date of re-run: 13/09/2017

Database: Web of Science Social Science Citation Index (SSCI) 1900 to present

#	Searches
8	#7 AND #6
7	(TS=(rehab* or neurorehab* or neuro-rehab* or neuro* rehab*)) AND LANGUAGE: (English) ;
6	#5 OR #4 OR #3 OR #2 OR #1
5	(TS=(primary brain cancer* or primary brain tumo?r* or primary brain neoplasm*)) AND LANGUAGE: (English)
4	(TS=((brain or cereb* or intracranial or mening* or brainstem*) NEAR3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*))) AND LANGUAGE: (English) ;
3	(TS=(mening* NEAR3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*))) AND LANGUAGE: (English)
2	(TS=meningioma*) AND LANGUAGE: (English)

#	Searches
1	(TS=(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*)) AND LANGUAGE: (English)

Literature search strategy for review 5d – late effects of treatment

Systematic reviews and RCTs

Date of initial search: 23/05/2017

Database: Embase 1974 to 2017 May 17, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

Date of re-run: 12/09/2017
Database(s): Embase 1974 to 2017 Week 36, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

#	Searches
1	exp Glioma/ use ppez
2	exp Glioma/ use oemezd
3	exp Astrocytoma/ use ppez
4	exp Astrocytoma/ use oemezd
5	Oligodendroglioma/ use ppez
6	exp Glioblastoma/ use ppez
7	(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*).tw.
8	or/1-7
9	Meningioma/ use ppez
10	Meningeal Neoplasms/ use ppez
11	exp Meningioma/ use oemezd
12	meningioma*.tw.
13	(mening* adj3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*)).tw.
14	or/9-13
15	exp Brain Neoplasms/ use ppez
16	exp Brain Tumor/ use oemezd
17	exp Cerebral Cortex/ use ppez
18	exp Brain Cortex/ use oemezd
19	exp Brain/ use ppez
20	exp Brain/ use oemezd
21	exp Meninges/ use ppez
22	Meninx/ use oemezd
23	or/15-22
24	exp Neoplasm Metastasis/ use ppez
25	metastasis/ use oemezd
26	24 or 25
27	23 and 26
28	exp Brain Neoplasms/sc use ppez
29	Brain Metastasis/ use oemezd
30	Meningeal Metastasis/ use oemezd
31	or/28-30
32	27 or 31
33	((brain or cereb* or intracranial or mening* or brainstem*) adj3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*)).tw.
34	32 or 33
35	8 or 14 or 34
36	exp disease surveillance/ use oemezd
37	exp medical examination/ use oemezd
38	Physical Examination/ use ppez
39	Neurologic Examination/ use ppez
40	neurologic examination/ use oemezd

#	Searches
41	exp neurologic disease assessment/ use oemezd
42	Monitoring, Physiologic/ use ppez
43	patient monitoring/ use oemezd
44	(surveillance or examination or assessment).tw.
45	exp Blood Pressure Determination/ use ppez
46	blood pressure monitoring/ use oemezd
47	exp Hematologic Tests/ use ppez
48	exp blood examination/ use oemezd
49	Hypercholesterolemia/ use ppez
50	cholesterol blood level/ use oemezd
51	((blood or h?ematolog* or h?emoglob* or platelet* or cholesterol) adj (test* or examin* or analys* or cytolog* or scintiscan* or smear* or review* or assess* or evaluat* or monitori*)).tw.
52	exp Diagnostic Techniques, Endocrine/ use ppez
53	exp endocrine system examination/ use oemezd
54	(endocrin* adj (test* or examin* or evaluat* or monitor* or assess* or review* or cytolog*)).tw.
55	exp Neuropsychological Tests/ use ppez
56	exp neuropsychological tests/ use oemezd
57	Vision, Ocular/ use ppez
58	(neuro* adj (test* or examin* or analys* or assess* or review*)).tw.
59	Ophthalmology/ use ppez
60	neuroophthalmology/ use oemezd
61	((opthalm* or ocular or vision or sight) adj (test* or examin* or evaluat* or monitor* or assess* or review*)).tw.
62	Neuroimaging/ use ppez
63	neuroimaging/ use oemezd
64	exp Magnetic Resonance Imaging/ use ppez
65	exp nuclear magnetic resonance imaging/ use oemezd
66	((MR or magnet*) adj2 (imag* or neuroimag* or scan* or spectroscop* or elastrogra* or examination*)).tw.
67	(MRI or MR*1 or NMR*1).tw.
68	exp Self-Examination/ use ppez
69	self examination/ use oemezd
70	self evaluation/ use oemezd
71	Symptom Assessment/ use ppez
72	symptom assessment/ use oemezd
73	((self or patient* or symptom*) adj (report* or review* or assess* or test* or examin* or evaluat* or monitor*)).tw.
74	((post-treat* or posttreat* or post-therap* or posttherap* or post-operat* or postoperat* or post-surg* or postsurg*) adj (report* or review* or assess* or test* or examin* or evaluat* or monitor*)).tw.
75	((after or complete* or finish* or following) adj (therap* or treat* or radiotherap* or surger* or chemo*) adj (report* or review* or assess* or test* or examin* or evaluat* or monitor*)).tw.
76	or/36-75
77	exp Treatment Outcome/ use ppez
78	outcome assessment/ use oemezd
79	((treat* or therap* or modalit* or surger* or resect* or operat* or radiothera* or chemo*) adj2 outcome*).tw.
80	exp Disease Progression/ use ppez
81	Late Onset Disorders/ use ppez
82	exp disease course/ use oemezd
83	Quality of Life/ use ppez
84	exp quality of life/ use oemezd
85	Disease-Free Survival/ use ppez
86	overall survival/ use oemezd
87	exp Stroke/ use ppez
88	exp cerebrovascular accident/ use oemezd
89	((cerebrovascular or brain vascular or cerebr* vascular) adj (accident* or apoplexy)).tw.
90	exp Vision Disorders/ use ppez
91	exp visual impairment/ use oemezd
92	exp Cataract/ use ppez
93	exp cataract/ use oemezd
94	(cataract* or lens* opac* or lens* cloud* or pseudoaphakia*).tw.
95	(((visual or vision or sight or eyesight or eye*) adj (loss* or impair*)) or (amauros* or blind*)).tw.
96	Neoplasm Metastasis/ use ppez
97	metastasis/ use oemezd
98	(second* adj (cancer* or tumo* or neoplas* or carcinoma*)).tw.
99	exp Hypopituitarism/ use ppez
100	hypopituitarism/ use oemezd
101	(hypopituitarism or ((sheehan or seldon or simmonds) adj (disease* or syndrome*))).tw.
102	((hypophys* or pituitar*) adj (insufficien* or deficien* or fail* or hypofunction*)).tw.
103	exp Neurobehavioral Manifestations/ use ppez
104	exp Neurocognitive Disorders/ use ppez
105	neurological complication/ use oemezd
106	(neuro* adj (declin* or disorder* or impair* or deficien* or insufficien* or complicat*)).tw.

#	Searches
107	radiation necrosis/ use oemezd
108	Radiation Injuries/ use ppez
109	Necrosis/ use ppez
110	(radionecrosis or radio-necrosis).tw.
111	((radiat* or irradiat* or radiotherap*) adj2 (necrosis or injur* or abnormalit* or destruct* or death)).tw.
112	or/77-111
113	35 and 76 and 112
114	limit 113 to english language
115	limit 114 to yr="1990 -Current"
116	Letter/ use ppez
117	letter.pt. or letter/ use oemezd
118	note.pt.
119	editorial.pt.
120	Editorial/ use ppez
121	News/ use ppez
122	exp Historical Article/ use ppez
123	Anecdotes as Topic/ use ppez
124	Comment/ use ppez
125	Case Report/ use ppez
126	case report/ or case study/ use oemezd
127	(letter or comment*).ti.
128	or/116-127
129	randomized controlled trial/ use ppez
130	randomized controlled trial/ use oemezd
131	random*.ti,ab.
132	or/129-131
133	128 not 132
134	animals/ not humans/ use ppez
135	animal/ not human/ use oemezd
136	nonhuman/ use oemezd
137	exp Animals, Laboratory/ use ppez
138	exp Animal Experimentation/ use ppez
139	exp Animal Experiment/ use oemezd
140	exp Experimental Animal/ use oemezd
141	exp Models, Animal/ use ppez
142	animal model/ use oemezd
143	exp Rodentia/ use ppez
144	exp Rodent/ use oemezd
145	(rat or rats or mouse or mice).ti.
146	or/133-145
147	115 not 146
148	Meta-Analysis/
149	Meta-Analysis as Topic/
150	systematic review/
151	meta-analysis/
152	(meta analy* or metanaly* or metaanaly*).ti,ab.
153	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
154	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
155	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
156	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
157	(search* adj4 literature).ab.
158	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
159	cochrane.jw.
160	((pool* or combined) adj2 (data or trials or studies or results)).ab.
161	or/148-149,152,154-159 use ppez
162	or/150-153,155-160 use oemezd
163	or/161-162
164	clinical Trials as topic.sh. or (controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or (placebo or randomi#ed or randomly).ab. or trial.ti.
165	164 use ppez
166	(controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or drug therapy.fs. or (groups or placebo or randomi#ed or randomly or trial).ab.
167	166 use ppez
168	crossover procedure/ or double blind procedure/ or randomized controlled trial/ or single blind procedure/ or (assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) adj blind*) or factorial* or placebo* or random* or volunteer*).ti,ab.
169	168 use oemezd
170	165 or 167

#	Searches
171	169 or 170
172	163 or 171
173	147 and 172
174	remove duplicates from 173

Observational studies

Date of initial search: 23/05/2017

Database: Embase 1974 to 2017 May 17, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

Date of re-run: 12/09/2017

Database(s): Embase 1974 to 2017 Week 36, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

#	Searches
1	exp Glioma/ use ppez
2	exp Glioma/ use oemezd
3	exp Astrocytoma/ use ppez
4	exp Astrocytoma/ use oemezd
5	Oligodendroglioma/ use ppez
6	exp Glioblastoma/ use ppez
7	(glioma* or glioblastoma* or GBM or gliosarcoma* or astrocytoma* or oligoastrocytoma* or oligodendroglioma* or oligo?astrocytoma* or xanthoastrocytoma*).tw.
8	or/1-7
9	Meningioma/ use ppez
10	Meningeal Neoplasms/ use ppez
11	exp Meningioma/ use oemezd
12	meningioma*.tw.
13	(mening* adj3 (neoplas* or cancer* or carcin* or tumo* or malign* or h?emangiopericytoma* or h?emangioblastoma*)).tw.
14	or/9-13
15	exp Brain Neoplasms/ use ppez
16	exp Brain Tumor/ use oemezd
17	exp Cerebral Cortex/ use ppez
18	exp Brain Cortex/ use oemezd
19	exp Brain/ use ppez
20	exp Brain/ use oemezd
21	exp Meninges/ use ppez
22	Meninx/ use oemezd
23	or/15-22
24	exp Neoplasm Metastasis/ use ppez
25	metastasis/ use oemezd
26	24 or 25
27	23 and 26
28	exp Brain Neoplasms/sc use ppez
29	Brain Metastasis/ use oemezd
30	Meningeal Metastasis/ use oemezd
31	or/28-30
32	27 or 31
33	((brain or cereb* or intracranial or mening* or brainstem*) adj3 (metasta* or micrometa* or macrometa* or spread* or carcinomatosis or carcinosis or secondar* or seeding or seeded or disseminat* or migrat*)).tw.
34	32 or 33
35	8 or 14 or 34
36	exp disease surveillance/ use oemezd
37	exp medical examination/ use oemezd
38	Physical Examination/ use ppez
39	Neurologic Examination/ use ppez
40	neurologic examination/ use oemezd
41	exp neurologic disease assessment/ use oemezd
42	Monitoring, Physiologic/ use ppez

#	Searches
43	patient monitoring/ use oemezd
44	(surveillance or examination or assessment).tw.
45	exp Blood Pressure Determination/ use ppez
46	blood pressure monitoring/ use oemezd
47	exp Hematologic Tests/ use ppez
48	exp blood examination/ use oemezd
49	Hypercholesterolemia/ use ppez
50	cholesterol blood level/ use oemezd
51	((blood or h?ematolog* or h?emoglob* or platelet* or cholesterol) adj (test* or examin* or analys* or cytolog* or scintiscan* or smear* or review* or assess* or evaluat* or monitori*)).tw.
52	exp Diagnostic Techniques, Endocrine/ use ppez
53	exp endocrine system examination/ use oemezd
54	(endocrin* adj (test* or examin* or evaluat* or monitor* or assess* or review* or cytolog*)).tw.
55	exp Neuropsychological Tests/ use ppez
56	exp neuropsychological tests/ use oemezd
57	Vision, Ocular/ use ppez
58	(neuro* adj (test* or examin* or analys* or assess* or review*)).tw.
59	Ophthalmology/ use ppez
60	neuroophthalmology/ use oemezd
61	((opthalm* or ocular or vision or sight) adj (test* or examin* or evaluat* or monitor* or assess* or review*)).tw.
62	Neuroimaging/ use ppez
63	neuroimaging/ use oemezd
64	exp Magnetic Resonance Imaging/ use ppez
65	exp nuclear magnetic resonance imaging/ use oemezd
66	((MR or magnet*) adj2 (imag* or neuroimag* or scan* or spectroscop* or elastrogra* or examination)).tw.
67	(MRI or MR*1 or NMR*1).tw.
68	exp Self-Examination/ use ppez
69	self examination/ use oemezd
70	self evaluation/ use oemezd
71	Symptom Assessment/ use ppez
72	symptom assessment/ use oemezd
73	((self or patient* or symptom*) adj (report* or review* or assess* or test* or examin* or evaluat* or monitor*)).tw.
74	((post-treat* or posttreat* or post-therap* or posttherap* or post-operat* or postoperat* or post-surg* or postsurg*) adj (report* or review* or assess* or test* or examin* or evaluat* or monitor*)).tw.
75	((after or complete* or finish* or following) adj (therap* or treat* or radiotherap* or surger* or chemo*) adj (report* or review* or assess* or test* or examin* or evaluat* or monitor*)).tw.
76	or/36-75
77	exp Treatment Outcome/ use ppez
78	outcome assessment/ use oemezd
79	((treat* or therap* or modalit* or surger* or resect* or operat* or radiothera* or chemo*) adj2 outcome).tw.
80	exp Disease Progression/ use ppez
81	Late Onset Disorders/ use ppez
82	exp disease course/ use oemezd
83	Quality of Life/ use ppez
84	exp quality of life/ use oemezd
85	Disease-Free Survival/ use ppez
86	overall survival/ use oemezd
87	exp Stroke/ use ppez
88	exp cerebrovascular accident/ use oemezd
89	((cerebrovascular or brain vascular or cerebr* vascular) adj (accident or apoplexy)).tw.
90	exp Vision Disorders/ use ppez
91	exp visual impairment/ use oemezd
92	exp Cataract/ use ppez
93	exp cataract/ use oemezd
94	(cataract* or lens* opac* or lens* cloud* or pseudoaphakia*).tw.
95	(((visual or vision or sight or eyesight or eye*) adj (loss* or impair*)) or (amauros* or blind*)).tw.
96	Neoplasm Metastasis/ use ppez
97	metastasis/ use oemezd
98	(second* adj (cancer* or tumo* or neoplas* or carcinoma*)).tw.
99	exp Hypopituitarism/ use ppez
100	hypopituitarism/ use oemezd
101	(hypopituitarism or ((sheehan or seldon or simmonds) adj (disease or syndrome))).tw.
102	((hypophys* or pituitar*) adj (insufficien* or deficien* or fail* or hypofunction*)).tw.
103	exp Neurobehavioral Manifestations/ use ppez
104	exp Neurocognitive Disorders/ use ppez
105	neurological complication/ use oemezd
106	(neuro* adj (decline or disorder* or impair* or deficien* or insufficien or complicat*)).tw.
107	radiation necrosis/ use oemezd
108	Radiation Injuries/ use ppez

#	Searches
109	Necrosis/ use ppez
110	(radionecrosis or radio-necrosis).tw.
111	((radiat* or irradiat* or radiotherap*) adj2 (necrosis or injur* or abnormalit* or destruct* or death)).tw.
112	or/77-111
113	35 and 76 and 112
114	limit 113 to english language
115	limit 114 to yr="1990 -Current"
116	Letter/ use ppez
117	letter.pt. or letter/ use oemezd
118	note.pt.
119	editorial.pt.
120	Editorial/ use ppez
121	News/ use ppez
122	exp Historical Article/ use ppez
123	Anecdotes as Topic/ use ppez
124	Comment/ use ppez
125	Case Report/ use ppez
126	case report/ or case study/ use oemezd
127	(letter or comment*).ti.
128	or/116-127
129	randomized controlled trial/ use ppez
130	randomized controlled trial/ use oemezd
131	random*.ti,ab.
132	or/129-131
133	128 not 132
134	animals/ not humans/ use ppez
135	animal/ not human/ use oemezd
136	nonhuman/ use oemezd
137	exp Animals, Laboratory/ use ppez
138	exp Animal Experimentation/ use ppez
139	exp Animal Experiment/ use oemezd
140	exp Experimental Animal/ use oemezd
141	exp Models, Animal/ use ppez
142	animal model/ use oemezd
143	exp Rodentia/ use ppez
144	exp Rodent/ use oemezd
145	(rat or rats or mouse or mice).ti.
146	or/133-145
147	115 not 146
148	Epidemiologic Studies/
149	Case Control Studies/
150	Retrospective Studies/
151	Cohort Studies/
152	Longitudinal Studies/
153	Follow-Up Studies/
154	Prospective Studies/
155	Cross-Sectional Studies/
156	or/148-155 use ppez
157	clinical study/
158	case control study/
159	family study/
160	longitudinal study/
161	retrospective study/
162	prospective study/
163	cohort analysis/
164	or/157-163 use oemezd
165	((retrospective$ or cohort$ or longitudinal or follow?up or prospective or cross section$) adj3 (stud$ or research or analys$)).ti.
166	156 or 164 or 165
167	147 and 166
168	remove duplicates from 167

1 Date of initial search: 23/05/2017

2 Database: The Cochrane Library, Issue 5 of 12, May 2017

3 Date of re-run: 12/09/2017

1 Database: The Cochrane Library, Issue 9 of 12, September 2017

2

ID	Search
#1	MeSH descriptor: [Glioma] explode all trees
#2	(glioma* or glioblastoma* or gliosarcoma* or astrocytoma* or astroblastoma* or oligodendroglioma* or oligodendrocytoma* or oligoastrocytoma* or GBM)
#3	(glial near/3 (neoplas* or cancer* or tumo* or carcin* or malign* or metasta*))
#4	{or #1-#3}
#5	MeSH descriptor: [Meningioma] explode all trees
#6	MeSH descriptor: [Meningeal Neoplasms] explode all trees
#7	meningioma*
#8	(mening* near/3 (neoplas* or cancer* or carcin* or tumo* or malign* or metasta*))
#9	{or #5-#8}
#10	MeSH descriptor: [Neoplasm Metastasis] explode all trees
#11	MeSH descriptor: [Brain Neoplasms] explode all trees
#12	MeSH descriptor: [Brain] explode all trees
#13	#11 or #12
#14	#10 and #13
#15	((brain or cereb* or intracranial or mening*) near/3 (metasta* or micometasta* or spread* or involvement or carcinosis or secondar*))
#16	#14 or #15
#17	#4 or #9 or #16
#18	MeSH descriptor: [Physical Examination] explode all trees
#19	MeSH descriptor: [Neurologic Examination] explode all trees
#20	MeSH descriptor: [Monitoring, Physiologic] explode all trees
#21	(surveillance or examination or assessment or monitor* or followup or follow-up)
#22	MeSH descriptor: [Blood Pressure Determination] explode all trees
#23	MeSH descriptor: [Hematologic Tests] explode all trees
#24	MeSH descriptor: [Hypercholesterolemia] explode all trees
#25	((blood or h?ematolog* or h?emoglob* or platelet* or cholesterol) near (test* or examin* or analys* or cytolog* or scintiscan* or smear* or review* or assess* or evaluat* or monitori*))
#26	MeSH descriptor: [Diagnostic Techniques, Endocrine] explode all trees
#27	(endocrin* near (test* or examin* or evaluat* or monitor* or assess* or review* or cytolog*))
#28	MeSH descriptor: [Neuropsychological Tests] explode all trees
#29	MeSH descriptor: [Vision, Ocular] explode all trees
#30	(neuro* near (test* or examin* or analys* or assess* or review*))
#31	MeSH descriptor: [Ophthalmology] explode all trees
#32	((opthalm* or ocular or vision or sight) near (test* or examin* or evaluat* or monitor* or assess* or review*))
#33	MeSH descriptor: [Neuroimaging] explode all trees
#34	MeSH descriptor: [Magnetic Resonance Imaging] explode all trees
#35	((MR or magnet*) near/2 (imag* or neuroimag* or scan* or spectroscop* or elastrogra* or examination*))
#36	(MRI or MR*1 or NMR*1)
#37	MeSH descriptor: [Self-Examination] explode all trees
#38	MeSH descriptor: [Symptom Assessment] explode all trees
#39	((self or patient* or symptom*) near (report* or review* or assess* or test* or examin* or evaluat* or monitor*))
#40	((post-treat* or posttreat* or post-therap* or posttherap* or post-operat* or postoperat* or post-surg* or postsurg*) near (report* or review* or assess* or test* or examin* or evaluat* or monitor*))
#41	((after or complete* or finish* or following) near (therap* or treat* or radiotherap* or surger* or chemo*) near (report* or review* or assess* or test* or examin* or evaluat* or monitor*))
#42	{or #18-#41}
#43	#17 and #42
#44	MeSH descriptor: [Treatment Outcome] explode all trees
#45	((treat* or therap* or modalit* or surger* or resect* or operat* or radiothera* or chemo*) near/2 outcome*)
#46	MeSH descriptor: [Disease Progression] explode all trees
#47	MeSH descriptor: [Late Onset Disorders] explode all trees
#48	MeSH descriptor: [Quality of Life] explode all trees
#49	MeSH descriptor: [Disease-Free Survival] explode all trees
#50	MeSH descriptor: [Stroke] explode all trees
#51	((cerebrovascular or brain vascular or cerebr* vascular) near (accident* or apoplexy))
#52	MeSH descriptor: [Vision Disorders] explode all trees
#53	MeSH descriptor: [Cataract] explode all trees
#54	(cataract* or lens* opac* or lens* cloud* or pseudoaphakia*)
#55	(((visual or vision or sight or eyesight or eye*) near (loss* or impair*)) or (amauros* or blind*))
#56	MeSH descriptor: [Neoplasm Metastasis] explode all trees
#57	(second* near (cancer* or tumo* or neoplas* or carcinoma*))
#58	MeSH descriptor: [Hypopituitarism] explode all trees
#59	(hypopituitarism or ((sheehan or seldon or simmonds) near (disease* or syndrome*)))
#60	((hypophys* or pituitar*) near (insufficien* or deficien* or fail* or hypofunction*))
#61	MeSH descriptor: [Neurobehavioral Manifestations] explode all trees

ID	Search
#62	MeSH descriptor: [Neurocognitive Disorders] explode all trees
#63	(neuro* near (declin* or disorder* or impair* or deficien* or insufficien* or complicat*))
#64	MeSH descriptor: [Radiation Injuries] explode all trees
#65	MeSH descriptor: [Necrosis] explode all trees
#66	(radionecrosis or radio-necrosis)
#67	((radiat* or irradiat* or radiotherap*) near/2 (necrosis or injur* or abnormalit* or destruct* or death))
#68	{or #44-#67}
#69	#43 and #68 Publication Year from 1990 to 2017

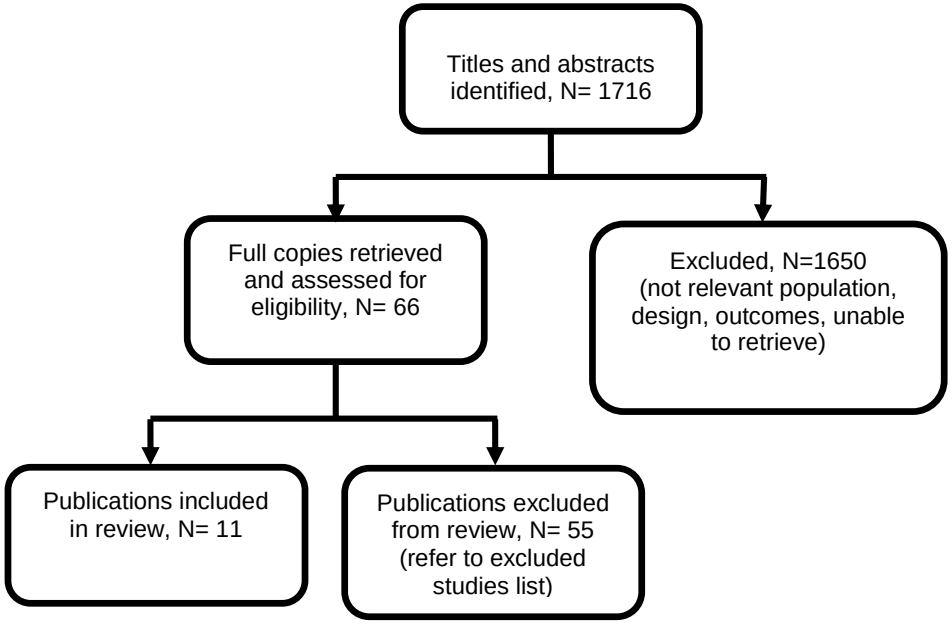
1

2

Appendix C – Clinical evidence study selection

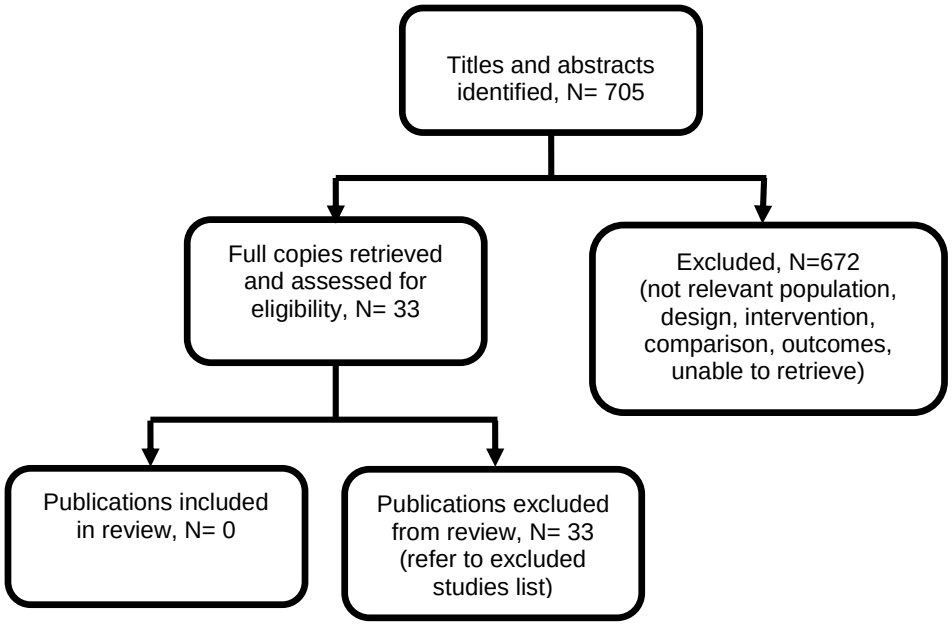
PRISMA flowchart for review 5e – care needs of people with brain tumours

Figure 1: Flow diagram of clinical article selection for review 5e – care needs of people with brain tumours



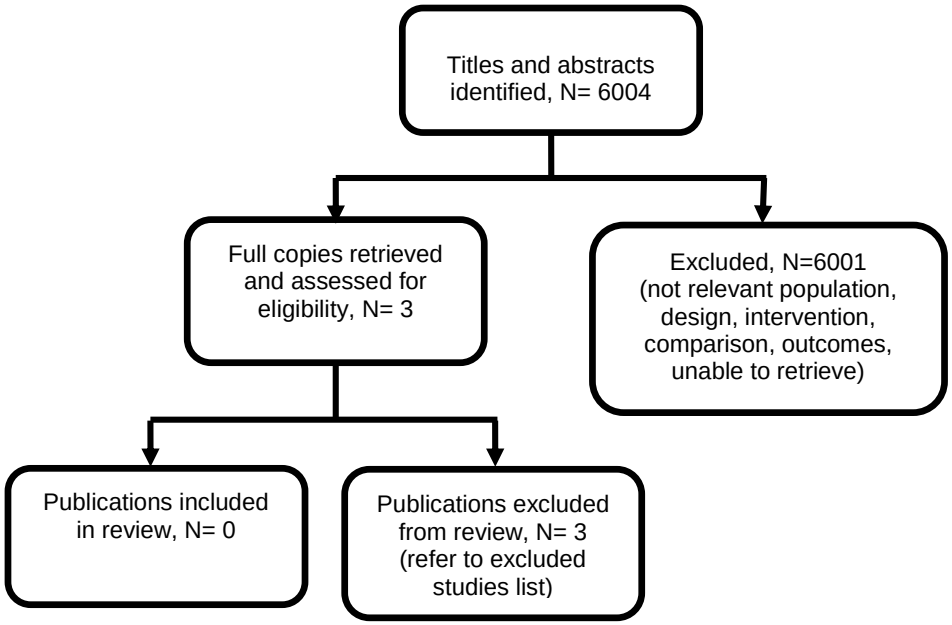
PRISMA flowchart for review 6a – neurorehabilitation assessment needs of people with brain tumours

Figure 2: Flow diagram of clinical article selection for review 6a – neurological rehabilitation needs of people with brain tumours



1 PRISMA flowchart for review 5d – late effects of treatment

2 Figure 3: Flow diagram of clinical article selection for review 5d – late effects of treatment



3

Appendix D – Clinical evidence tables

See Supplementary Material D.

Appendix E – Forest plots

Forest plots for review 5e – care needs of people with brain tumours

Not applicable – qualitative evidence cannot be meta-analysed.

Forest plots for review 6a – neurorehabilitation assessment needs of people with brain tumours

Not applicable - no evidence was identified.

Forest plots for review 5d – late effects of treatment

Not applicable - no evidence was identified.

Appendix F – GRADE tables

GRADE tables for review 5e – care needs of people with brain tumours

Not applicable – qualitative evidence not reviewed against GRADE criteria. See Supplementary Material D for information on quality assessment of these studies.

GRADE tables for review 6a – neurorehabilitation assessment needs of people with brain tumours

Not applicable - no evidence was identified.

GRADE tables for review 5d – late effects of treatment

Not applicable - no evidence was identified.

Appendix G – Economic evidence study selection

Economic evidence for review 5e – care needs of people with brain tumours

Economic study selection flowcharts are in Supplementary Material D.

Economic evidence for review 6a – neurorehabilitation assessment needs of people with brain tumours

Economic study selection flowcharts are in Supplementary Material D.

Economic evidence for review 5d – late effects of treatment

Economic study selection flowcharts are in Supplementary Material D.

Appendix H – Economic evidence tables

Economic evidence tables for review 5e – care needs of people with brain tumours

Not applicable – no economic evidence was identified.

Economic evidence tables for review 6a – neurorehabilitation assessment needs of people with brain tumours

Not applicable – no economic evidence was identified.

Economic evidence tables for review 5d – late effects of treatment

Not applicable – no economic evidence was identified.

Appendix I – Health economic evidence profiles

Economic evidence profiles for review 5e – care needs of people with brain tumours

Not applicable – no economic evidence was identified.

Economic evidence profiles for review 6a – neurorehabilitation assessment needs of people with brain tumours

Not applicable – no economic evidence was identified.

Economic evidence profiles for review 5d – late effects of treatment

Not applicable – no economic evidence was identified.

Appendix J – Health economic analysis

No de-novo economic analyses were carried out for these topics.

Appendix K – Excluded studies

Excluded studies for review 5e – care needs of people with brain tumours

Clinical studies

Excluded studies – 5e What are the health and social care support needs of people with brain tumours (primary) and brain metastases and their families and carers?	
Study	**Reason for Exclusion**
Aoun, S. M., Deas, K., Howting, D., Lee, G., Exploring the Support Needs of Family Caregivers of Patients with Brain Cancer Using the CSNAT: A Comparative Study with Other Cancer Groups, PLoS ONE, 10, 2015	Primarily quantitative study. The qualitative aspect of the study looks at the family caregivers' experiences in using the CSNAT (need screening instrument)
Bailey, L., Dunn, J., Eakin, L., Janda, M., Steginga, S., Troy, K., Walker, D., Supportive care needs of brain tumour patients and their carers, Australasian Journal of Neuroscience, 17, 23-23, 2006	Abstract only. Not enough information is available to extract study results or assess study quality
Bautista, C. A., Survivorship of a low-grade glioma brain tumor, Ph.D., 102 p-102 p, 2004	Unavailable
Boele, F. W., van Uden-Kraan, C. F., Hilverda, K., Reijneveld, J. C., Cleijne, W., Klein, M., Verdonck-de Leeuw, I. M., Attitudes and preferences toward monitoring symptoms, distress, and quality of life in glioma patients and their informal caregivers, Supportive Care in Cancer, 24, 3011-3022, 2016	Study focus not in PICO (not about what the supportive care needs are of patients/families/carers)
Catt, S. L., Anderson, J. L., Critchley, G. R., Patients' and staff's experiences of multidisciplinary follow-up for high-grade glioma after radical radiotherapy, Psychology, health & medicine, 16, 357-365, 2011	Study focus not in PICO (not about what the supportive care needs are of patients/families/carers)
Catt, S., Chalmers, A., Critchley, G., Fallowfield, L., Supportive follow-up for patients treated with radical intent for high-grade glioma, Psycho-Oncology, 22, 16-17, 2013	Abstract of Catt 2012 study, which was excluded
Catt, S., Chalmers, A., Critchley, G., Fallowfield, L., Supportive follow-up in patients treated with radical intent for high-grade glioma, CNS Oncology, 1, 39-48, 2012	Not a qualitative study

Excluded studies – 5e What are the health and social care support needs of people with brain tumours (primary) and brain metastases and their families and carers?	
Catt, S., Chalmers, A., Fallowfield, L., Psychosocial and supportive-care needs in high-grade glioma, 9, 884-91, 2008	Narrative review
Cavers, D., Erridge, S., Hacking, B., Morris, P., Murray, S. A., Acute distress even before the diagnosis is confirmed: A qualitative longitudinal study of people with malignant glioma and their relatives, Palliative Medicine, 1), S216, 2010	Abstract only. Not enough information is available to extract study results or assess study quality
Cavers, D., Hacking, B., Erridge, S. E., Kendall, M., Morris, P. G., Murray, S. A., Social, psychological and existential well-being in patients with glioma and their caregivers: A qualitative study, Cmaj, 184, E373-E382, 2012	Same participants as Cavers 2013, which is included and aimed more at the current review question. No further relevant data in Cavers 2012
Cavers, D., Hacking, B., Murray, S., Erridge, S., Distress across the illness: A qualitative longitudinal study of people with malignant glioma and their relatives, Neuro-Oncology, 12, i4, 2010	Abstract only. Not enough information is available to extract study results or assess study quality
Chabloz-Sussenbach, C., Schramm, M. S., Stoll, H., Spirig, R., "Don't let the world become too small" - How patients with advanced cancer and their significant others cope with transitions during the last year of life. A qualitative study, Pflege, 29, 171-181, 2016	In German with English abstract. Study focus does not appear to be in PICO (not about what the supportive care needs are of patients/families/carers)
Collins, A, Murphy, M, Gold, M, Sundararajan, V, Brand, C, Lethborg, C, Dowling, A, Moore, G, Staker, J, Philip, J, I-cope: Pilot testing an innovative model of supportive and palliative care for patients with high grade glioma and their carers, Asia-Pacific Journal of Clinical Oncology, 10, 169, 2014	Abstract only. Appears to be a quantitative study with a study focus not in PICO (not about what the supportive care needs are of patients/families/carers)
Collins, A., Lethborg, C., Brand, C., Gold, M., Moore, G., Sundararajan, V., Murphy, M., Philip, J., The challenges and suffering of caring for people with primary malignant glioma: qualitative perspectives on improving current supportive and palliative care practices, 4, 68-76, 2014	Unavailable
Curren, Jr, Support needs of brain tumour patients and their carers: the place of a telephone service, International Journal of Palliative Nursing, 7, 331-7., 2001	Not a qualitative study
Dagostino, N. M., Edelstein, K., Psychosocial challenges and resource needs of young adult cancer survivors: Implications for program development, Journal of Psychosocial Oncology, 31, 585-600, 2013	Population not in PICO/scope: 4 patients had a diagnosis of brain cancer aged > 16 years (tumour types: pineal cytoma, ependymoma, pineal blastoma, glioblastoma multiforme)

Excluded studies – 5e What are the health and social care support needs of people with brain tumours (primary) and brain metastases and their families and carers?	
Daniels, M., Kanter, C., Stone, A., Agostino, N. D., Edelstein, K., Brain tumor support groups: Patient and caregiver perspectives, Canadian Journal of Neurological Sciences, 1), S18, 2012	Abstract only. Not enough information available to extract relevant study data or appraise study quality
Davies, E, Higginson, I J, Communication, information and support for adults with malignant cerebral glioma: a systematic literature review (Structured abstract), Supportive Care in Cancer, 11, 21-29, 2003	No results reported directly relevant to the PICO/review question
Davies, Elizabeth, Patients' perceptions of follow-up services, 1997	Already included in Moore (2013) systematic review, which is included
Ford, E., Catt, S., Chalmers, A., Fallowfield, L., Systematic review of supportive care needs in patients with primary malignant brain tumors, Neuro-OncologyNeuro-oncol, 14, 392-404, 2012	Results checked and all relevant results/studies already included in Moore (2013)
Fraas, M., Balz, M., DeGrauw, W., Meeting the long-term needs of adults with acquired brain injury through community-based programming, Brain Injury, 21, 1267-1281, 2007	Population not in PICO
Golla, H., Ahmad, M. A., Galushko, M., Hampl, J., Maarouf, M., Schroeter, M., Herrlinger, U., Hellmich, M., Voltz, R., Glioblastoma multiforme from diagnosis to death: a prospective, hospital-based, cohort, pilot feasibility study of patient reported symptoms and needs, Supportive Care in Cancer, 22, 3341-3352, 2014	Outcomes not in PICO
Hsien, J. W. K., Rosewall, T., Wong, R. K. S., In their own words: A qualitative descriptive study of patient and caregiver perspectives on follow-up care after palliative radiotherapy, Journal of Medical Imaging and Radiation Sciences, 44, 209-213, 2013	Study focus not in PICO (not about what the supportive care needs are of patients/families/carers)
Janda, M., Eakin, E. G., Bailey, L., Walker, D., Troy, K., Supportive care needs of people with brain tumours and their carers, Supportive Care in Cancer, 14, 1094-1103, 2006	Already included in Moore (2013) systematic review, which is included
Kahalley, L. S., Wilson, S. J., Tyc, V. L., Conklin, H. M., Hudson, M. M., Wu, S., Xiong, X., Stancel, H. H., Hinds, P. S., Kahalley, Lisa S., Wilson, Stephanie J., Tyc, Vida L., Conklin, Heather M., Hudson, Melissa M., Wu, Shengjie, Xiong, Xiaoping, Stancel, Heather H., Hinds, Pamela S., Are the	Population not in PICO

Excluded studies – 5e What are the health and social care support needs of people with brain tumours (primary) and brain metastases and their families and carers?	
psychological needs of adolescent survivors of pediatric cancer adequately identified and treated?, Psycho-Oncology, 22, 447-458, 2013	
Kendall, M., Carduff, E., Lloyd, A., Kimbell, B., Cavers, D., Buckingham, S., Boyd, K., Grant, L., Worth, A., Pinnock, H., Sheikh, A., Murray, S., Multi-dimensional illness trajectories in people with cancer, organ failure or frailty: A synthesis of 8 qualitative longitudinal studies, Palliative Medicine, 30 (6), NP30, 2016	Abstract only. Not enough information is available to extract study results or assess study quality
Kloth, Mary A., The phenomenon of discussing family illness narratives: Living with pediatric brain tumors, Dissertation Abstracts International: Section B: The Sciences and Engineering, 67, 4713, 2007	Abstract only. Not enough information is available to examine study results or assess study quality
Lageman, Sarah K., Brown, Paul D., Anderson, S. Keith, Lachance, Daniel H., Yan, Elizabeth, Laack, Nadia N. I., Cerhan, Jane H., Exploring primary brain tumor patient and caregiver needs and preferences in brief educational and support opportunities, Supportive Care in Cancer, 23, 851-859, 2015	Not a qualitative study
Lang, D. A., Neil-Dwyer, G., Garfield, J., Outcome after complex neurosurgery: The caregiver's burden is forgotten, Journal of Neurosurgery, 91, 359-363, 1999	Not a qualitative study; outcomes not in PICO
Leavitt, M. B., Lamb, S. A., Voss, B. S., Brain tumor support group: content themes and mechanisms of support, Oncology Nursing ForumOncol Nurs Forum, 23, 1247-56, 1996	Study focus not in PICO (not about what the supportive care needs are of patients/families/carers)
Lepola, I., Toljamo, M., Aho, R., Louet, T., Being a brain tumor patient: a descriptive study of patients' experiences, Journal of Neuroscience NursingJ Neurosci Nurs, 33, 143-7, 2001	Outcomes/population not in PICO
Long, L. A., Wodrich, D. L., Levy, R., Etzl, M. M., Jr., Gieseking, A. T., Students with brain tumors: their post-treatment perceptions of teachers, peers, and academics and retrospective views on school during treatment, Journal of Child Health CareJ Child Health Care, 14, 111-25, 2010	Population not in PICO
Madsen, K., Poulsen, H. S., Needs for everyday life support for brain tumour patients' relatives: Systematic literature review, European Journal of Cancer Care, 20, 33-43, 2011	Results checked and all relevant results/studies already included in Moore (2013) [Horowitz 1996 checked, no formal methodology reported)

Excluded studies – 5e What are the health and social care support needs of people with brain tumours (primary) and brain metastases and their families and carers?	
McConigley, Ruth, Halkett, Georgia, Lobb, Elizabeth, Nowak, Anna, Caring for someone with high-grade glioma: A time of rapid change for caregivers, Palliative Medicine, 24, 473-479, 2010	Already included in Moore (2013) systematic review, which is included
Molassiotis, A., Wilson, B., Brunton, L., Chaudhary, H., Gattamaneni, R., McBain, C., Symptom experience in patients with primary brain tumours: A longitudinal exploratory study, European Journal of Oncology Nursing, 14, 410-416, 2010	Outcomes not in PICO
Newton, Polly, Supporting adults with a brain tumour, Journal of Community Nursing, 30, 24-24, 2016	Not a qualitative study
Norberg, A. L., Steneby, S., Experiences of parents of children surviving brain tumour: A happy ending and a rough beginning, European Journal of Cancer Care, 18, 371-380, 2009	Population not in PICO
Ownsworth, T., Hawkes, A., Steginga, S., Walker, D., Shum, D., A biopsychosocial perspective on adjustment and quality of life following brain tumor: a systematic evaluation of the literature, Disability & Rehabilitation, 31, 1038-1055, 2009	Not a replicable systematic review (e.g, no search strategy, very small search [N = 243]); superseded by systematic review by Moore 2013
Ozbayir, T., Malak, A. T., Bektas, M., Ilce, A. O., Celik, G. O., Information needs of patients with meningiomas, Asian Pacific Journal of Cancer Prevention: ApjcpAsian Pac J Cancer Prev, 12, 439-41, 2011	Not a qualitative study
Parvataneni, R., Polley, M. Y., Freeman, T., Lamborn, K., Prados, M., Butowski, N., Liu, R., Clarke, J., Page, M., Rabbitt, J., Fedoroff, A., Clow, E., Hsieh, E., Kivett, V., Deboer, R., Chang, S., Identifying the needs of brain tumor patients and their caregivers, Journal of Neuro-Oncology, 104, 737-44, 2011	Not a qualitative study
Pelletier, G., Husain, S., Determining the unmet needs of brain tumor patients barbara pickering, Psycho-Oncology, 18, S283, 2009	Abstract only. Not enough information is available to extract study results or assess study quality
Piil, K., Juhler, M., Jakobsen, J., Jarden, M., Controlled rehabilitative and supportive care intervention trials in patients with high-grade gliomas and their caregivers: a systematic review, BMJ supportive & palliative careBMJ support, 6, 27-34, 2016	Systematic review of quantitative studies

Excluded studies – 5e What are the health and social care support needs of people with brain tumours (primary) and brain metastases and their families and carers?	
Piil, Karin, Juhler, Marianne, Jakobsen, Johannes, Jarden, Mary, Daily life experiences of patients with a high-grade glioma and their caregivers: A longitudinal exploration of rehabilitation and supportive care needs, Journal of Neuroscience NursingJ Neurosci Nurs, 47, 271-284, 2015	Outcomes not in PICO (despite the title and aims, no needs after treatment appear to be included/reported in the results section)
Ramritu, P. L., Croft, G., Needs of parents of the child hospitalised with acquired brain damage, International journal of nursing studies, 36, 209-216, 1999	Population not in PICO
Ronan, L. K., Grigel, H., Wishart, H., Fadul, C. E., Patient decision support needs after initial diagnosis of malignant glioma, Annals of Neurology, 78, S71-S72, 2015	Abstract only. Not enough information to extract any relevant results or assess study quality
Scaratti, C., Leonardi, M., Saladino, A., Anghileri, E., Broggi, M., Lamperti, E., Fariselli, L., Ayadi, R., Tringali, G., Schiavolin, S., Needs of neuro-oncological patients and their caregivers during the hospitalization and after discharge: results from a longitudinal study, Supportive Care in Cancer, 25, 2137-2145, 2017	Quantitative study
Sherwood, P. R., Cwiklik, M., Donovan, H. S., Neuro-oncology family caregiving: review and directions for future research, CNS OncologyCNS Oncol, 5, 41-8, 2016	Not a replicable systematic review (e.g, no search strategy)
Sherwood, Pr, Given, Ba, Doorenbos, Az, Given, Cw, Forgotten voices: lessons from bereaved caregivers of persons with a brain tumour, International Journal of Palliative Nursing, 10, 67-75., 2004	Already included in Moore (2013) systematic review, which is included
Soanes, L., Hargrave, D., Smith, L., Gibson, F., What are the experiences of the child with a brain tumour and their parents?, European Journal of Oncology Nursing, 13, 255-61, 2009	Population not in PICO
Spetz, A., Henriksson, R., Bergenheim, A. T., Salander, P., A specialist nurse-function in neurooncology: a qualitative study of possibilities, limitations, and pitfalls, 3, 121-30, 2005	Already included in Moore (2013) systematic review, which is included
Spetz, A., Henriksson, R., Salander, P., A specialist nurse as a resource for family members to patients with brain tumors: an action research study, Cancer NursingCancer Nurs, 31, E18-26, 2008	Already included in Moore (2013) systematic review, which is included

Excluded studies – 5e What are the health and social care support needs of people with brain tumours (primary) and brain metastases and their families and carers?	
Sterckx, W., Coolbrandt, A., Dierckx de Casterle, B., Van den Heede, K., Decruyenaere, M., Borgenon, S., Mees, A., Clement, P., The impact of a high-grade glioma on everyday life: A systematic review from the patient's and caregiver's perspective, European Journal of Oncology Nursing, 17, 107-117, 2013	Results checked and all relevant results/studies already included in Moore (2013), or as individual study in this review (Nixon 2010)
Upton, P., Eiser, C., School experiences after treatment for a brain tumour, Child: Care, Health and Development, 32, 9-17, 2006	Population not in PICO
Wideheim, A. K., Edvardsson, T., Pahlson, A., Ahlstrom, G., A family's perspective on living with a highly malignant brain tumor, Cancer Nursing, 25, 236-44, 2002	Outcomes (results) not in PICO
Zelcer, S., Cataudella, D., Cairney, A. E., Bannister, S. L., Palliative care of children with brain tumors: a parental perspective, Archives of Pediatrics & Adolescent Medicine, 164, 225-30, 2010	Population does not appear to be in PICO (children: age 1-5 years (N = 3), 8-11 years (N = 3), 12-19 years (N = 11); no further information reported)

Economic studies

Not applicable – no economic evidence was identified.

Excluded studies for review 6a – neurorehabilitation assessment needs of people with brain tumours

Clinical studies

Excluded studies - 4. What are the facilitators and barriers to providing appropriate neurological rehabilitation assessment in people with brain tumours (primary) and brain metastases?	
Study	**Reason for Exclusion**
Alam, E., Wilson, R. D., Vargo, M. M., Inpatient cancer rehabilitation: a retrospective comparison of transfer back to acute care between patients with neoplasm and other rehabilitation patients, Archives of Physical Medicine & RehabilitationArch Phys Med Rehabil, 89, 1284-9, 2008	Narrative review
Alekseyev, K., Iannicello, A., Ozurumba, N. D., Bemanian, S. S., Rosenkranz, T. M., Amore, G., Ross, M., Cristian, A., Analysis of neurosurgical patients	Quantitative study

Excluded studies - 4. What are the facilitators and barriers to providing appropriate neurological rehabilitation assessment in people with brain tumours (primary) and brain metastases?	
acutely discharged (AD) vs non-acutely discharged (NAD) from an inpatient rehabilitation facility (IRF), PM and R, 8 (9 Supplement), S271-S272, 2016	
Anonymous,, Rehabilitation after brain cancer surgery, The Journal of Supportive OncologyJ Support Oncol, 5, 93, 2007	Abstract of a narrative review from the year 2007
Bartolo, M., Zucchella, C., Pace, A., De Nunzio, A. M., Serrao, M., Sandrini, G., Pierelli, F., Improving neuro-oncological patients care: basic and practical concepts for nurse specialist in neuro-rehabilitation, Journal of Experimental & Clinical Cancer ResearchJ Exp Clin Cancer Res, 31, 82, 2012	Narrative review
Bartolo, M., Zucchella, C., Pace, A., Lanzetta, G., Vecchione, C., Bartolo, M., Grillea, G., Serrao, M., Tassorelli, C., Sandrini, G., Pierelli, F., Early rehabilitation after surgery improves functional outcome in inpatients with brain tumours, Journal of Neuro-Oncology, 107, 537-44, 2012	Observational study (case-control)
Bayen, E., Wintrebert, G., Lieffroy, C., Velasco, L., Laigle-Donadey, F., Pradat-Diehl, P., Delattre, J. Y. E., Outpatient rehabilitation care services for patient with brain tumor, Annals of Physical and Rehabilitation Medicine, 56, e247, 2013	Narrative review
Bergo, E., Lombardi, G., Pambuku, A., Della Puppa, A., Bellu, L., D'Avella, D., Zagonel, V., Cognitive Rehabilitation in Patients with Gliomas and Other Brain Tumors: State of the Art, BioMed Research International, 2016 (no pagination), 2016	In this systematic review, only observational studies have been included
Campbell, C. L., Pergolotti, M., Blaskowitz, M., Occupational therapy utilization for individuals with brain cancer following a craniotomy: A descriptive study, Rehabilitation Oncology, 27, 9-13, 2009	Observational study
Campeau, M. L., Acute care considerations for physical therapists treating patients after brain tumor resection, Acute Care Perspectives, 18, 20-24, 2009	Narrative review
Catt, S., Chalmers, A., Fallowfield, L., Psychosocial and supportive-care needs in high-grade glioma, 9, 884-91, 2008	Narrative review
Chan, Vincy, Xiong, Chen, Colantonio, Angela, Patients with brain tumors: Who receives postacute occupational therapy services?, American Journal of Occupational Therapy, 69, 1-6, 2015	Observational study (retrospective cohort)
Cheung, L. L., Wakefield, C. E., Ellis, S. J., Mandalis, A., Frow, E., Cohn, R. J., Neuropsychology reports for childhood brain tumor survivors:	This study used a mixed-methods approach, however the qualitative section is focused on neuropsychology for childhood

Excluded studies - 4. What are the facilitators and barriers to providing appropriate neurological rehabilitation assessment in people with brain tumours (primary) and brain metastases?	
implementation of recommendations at home and school, Pediatric Blood & CancerPediatr Blood Cancer, 61, 1080-7, 2014	
Collins, A., Sundararajan, V., Brand, C. A., Moore, G., Lethborg, C., Gold, M., Murphy, M. A., Bohensky, M. A., Philip, J., Clinical presentation and patterns of care for short-term survivors of malignant glioma, Journal of Neuro-Oncology, 119, 333-341, 2014	Observational study
Davies, E., Hall, S., Clarke, C., Two year survival after malignant cerebral glioma: Patient and relative reports of handicap, psychiatric symptoms and rehabilitation, Disability and Rehabilitation, 25, 259-266, 2003	Not a qualitative study
Day, J., Gillespie, D. C., Rooney, A. G., Bulbeck, H. J., Zienius, K., Boele, F., Grant, R., Neurocognitive Deficits and Neurocognitive Rehabilitation in Adult Brain Tumors, Current Treatment Options in Neurology, 18 (5) (no pagination), 2016	Narrative review
Gabanelli, P., A rehabilitative approach to the patient with brain cancer, Neurological Sciences, 26, S51-S52, 2005	Narrative review
Gehring, K, Aaronson, Nk, Gundy, Cm, Taphoorn, Mj, Sitskoorn, Mm, Predictors of neuropsychological improvement following cognitive rehabilitation in patients with gliomas, Journal of the International Neuropsychological Society : JINS, 17, 256-66, 2011	Observational study
Gehring, K., Aaronson, N., Taphoorn, M., Sitskoorn, M., A description of a cognitive rehabilitation programme evaluated in brain tumour patients with mild to moderate cognitive deficits, Clinical Rehabilitation, 25, 675-692, 2011	Observational study
J, M., J, J., Piil, M. J. K., Rehabilitation for patients with high grade gliomas and their relatives-a feasibility study, Supportive Care in Cancer, 21, S64, 2013	Protocol for a mixed methods study
Kos, N., Kos, B., Benedicic, M., Early medical rehabilitation after neurosurgical treatment of malignant brain tumours in Slovenia, Radiology and Oncology, 50, 139-144, 2016	Narrative review
MacCartney, G, Stacey, D, Harrison, Mb, VanDenKerkhof, E, Symptoms, coping, and quality of life in pediatric brain tumor survivors: A qualitative study, Oncology nursing forum, 41, 390-8., 2014	Paediatric population, study does focus on symptoms that children and young people experienced after a brain tumour, but does not focus on neurorehabilitation
Moore, G., Collins, A., Brand, C., Gold, M., Lethborg, C., Murphy, M., Sundararajan, V., Philip, J., Palliative and supportive care needs of patients	Study focused on the care needs of patients diagnosed with a HGG. Does not include any theme about neurorehabilitation assessment

Excluded studies - 4. What are the facilitators and barriers to providing appropriate neurological rehabilitation assessment in people with brain tumours (primary) and brain metastases?	
with high-grade glioma and their carers: a systematic review of qualitative literature, Patient Education & CounselingPatient Educ Couns, 91, 141-53, 2013	
Mukand, J. A., Guilmette, T. J., Tran, M., Rehabilitation for patients with brain tumors, Critical Reviews in Physical & Rehabilitation Medicine, 15, 99-111, 2003	Narrative review and case study
Ownsworth, T., Hawkes, A., Steginga, S., Walker, D., Shum, D., A biopsychosocial perspective on adjustment and quality of life following brain tumor: a systematic evaluation of the literature, Disability & Rehabilitation, 31, 1038-1055, 2009	Observational study
Piil, K., Juhler, M., Jakobsen, J., Jarden, M., Daily Life Experiences of Patients With a High-Grade Glioma and Their Caregivers: A Longitudinal Exploration of Rehabilitation and Supportive Care Needs, Journal of Neuroscience Nursing, 47, 271-84, 2015	Study focused on prognostic information and changes in lifestyle after receiving the diagnosis, however it does not include any theme about neurorehabilitation assessment
Steinbach, J. P., Blaicher, H. P., Herrlinger, U., Wick, W., Nagele, T., Meyermann, R., Tatagiba, M., Bamberg, M., Dichgans, J., Karnath, H. O., Weller, M., Surviving glioblastoma for more than 5 years: the patient's perspective, Neurology, 66, 239-42, 2006	Observational study
Sterckx, W., Coolbrandt, A., Dierckx de Casterle, B., Van den Heede, K., Decruyenaere, M., Borgenon, S., Mees, A., Clement, P., The impact of a high-grade glioma on everyday life: A systematic review from the patient's and caregiver's perspective, European Journal of Oncology Nursing, 17, 107-117, 2013	Study focused on the experience of diagnosis in patient, however it does not include any theme about neurorehabilitation assessment
Strong, Nicole A., Love, Nicholas F., Toro, Franchesca Konig, Nickels, Jean L., A Comparison of Outcomes Between Glioblastoma Multiforme and Other Neurological Patients in the Acute Rehabilitation Setting, PM & R: Journal of Injury, Function & Rehabilitation, 8, S157-S158, 2016	Observational study
Thompson, K, Specialist occupational therapy for patients with brain tumour, European Journal of Palliative Care, 16, 58-61., 2009	This study summarises the reflection of a orthopaedist on a patient's case
Vargo, M, Brain tumor rehabilitation, American Journal of Physical Medicine and Rehabilitation, 90, S50-62., 2011	Narrative review
Vargo, M., Henriksson, R., Salander, P., Rehabilitation of patients with glioma, Handbook of Clinical NeurologyHandb, 134, 287-304, 2016	Narrative review

Excluded studies - 4. What are the facilitators and barriers to providing appropriate neurological rehabilitation assessment in people with brain tumours (primary) and brain metastases?	
Weitzner, Michael A., Meyers, Christina A., Cognitive functioning and quality of life in malignant glioma patients: A review of the literature, Psycho-Oncology, 6, 169-177, 1997	Narrative review
Wenstrom, I, Eriksson, Le, Ebbeskog, B, Living in a paradox-Women's experiences of body and life-world after, meningioma surgery, Journal of Advanced Nursing, 68, 559-68., 2012	The study analysed the experiences of women after being diagnosed with a high-grade glioma - unrelated to neurorehabilitation assessment

Economic studies

Not applicable – no economic evidence was identified.

Excluded studies for review 5d – late effects of treatment

Clinical studies

Excluded studies: What is the most effective surveillance protocol to detect late effects of treatment for glioma, meningioma or brain metastases?	
Study	**Reason for Exclusion**
Johannesen, T. B., Lien, H. H., Hole, K. H., Lote, K., Radiological and clinical assessment of long-term brain tumour survivors after radiotherapy, Radiotherapy & OncologyRadiother Oncol, 69, 169-76, 2003	Not surveillance protocol, non-comparative study
Khasraw, M., Lassman, A. B., Neuro-oncology: Late neurocognitive decline after radiotherapy for low-grade glioma, Nature Reviews Neurology, 5, 646-647, 2009	Narrative review
Kokshoorn, N. E., Appelman-Dijkstra, N. M., Neelis, K. J., Biermasz, N. R., Smit, J. W. A., Pereira, A. M., Pituitary dysfunction after long-term follow-up in adult patients after cranial radiotherapy for non-pituitary tumors, Endocrine Reviews. Conference: 93rd Annual Meeting and Expo of the Endocrine Society, ENDO, 32, 2011	Abstract, not enough information can be extracted to ascertain relevance, although it appears to be a non-comparative study

Economic studies

Not applicable – no economic evidence was identified.

Appendix L – Research recommendations

Not applicable – no research recommendations were made for the review questions presented in this report.