# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Executive Summary &amp; Recommendations</td>
<td></td>
</tr>
<tr>
<td>1.0</td>
<td>Current National Agenda</td>
<td>1</td>
</tr>
<tr>
<td>2.0</td>
<td>Commissioning Landscape</td>
<td>2</td>
</tr>
<tr>
<td>3.0</td>
<td>Regional Agenda</td>
<td>3</td>
</tr>
<tr>
<td>4.0</td>
<td>Clinical Commissioning Groups Strategic Priorities</td>
<td>4</td>
</tr>
<tr>
<td>5.0</td>
<td>Background to development of the Macmillan Brain &amp; CNS Cancer Improvement Programme</td>
<td>7</td>
</tr>
<tr>
<td>6.0</td>
<td>Brain &amp; CNS Cancer</td>
<td>11</td>
</tr>
<tr>
<td>7.0</td>
<td>Routes from Diagnosis and Brain &amp; CNS Cancer</td>
<td>12</td>
</tr>
<tr>
<td>8.0</td>
<td>Economic Impact</td>
<td>14</td>
</tr>
<tr>
<td>9.0</td>
<td>Emergency Presentation</td>
<td>15</td>
</tr>
<tr>
<td>10.0</td>
<td>Specialist Centre – Hull and East Yorkshire Hospitals NHS Trust (HEYHT)</td>
<td>18</td>
</tr>
<tr>
<td>10.1</td>
<td>Locality Services</td>
<td>18</td>
</tr>
<tr>
<td>10.2</td>
<td>Brain and CNS Multidisciplinary (MDT - Hull and East Yorkshire Hospitals NHS Trust (HEYHT)</td>
<td>20</td>
</tr>
<tr>
<td>11.0</td>
<td>Primary Care referral for patients with suspected Brain or CNS Tumour</td>
<td>21</td>
</tr>
<tr>
<td>12.0</td>
<td>Findings from Scoping Exercise</td>
<td>21</td>
</tr>
<tr>
<td>12.1</td>
<td>Patient and Carer Engagement</td>
<td>21</td>
</tr>
<tr>
<td>Section</td>
<td>Title</td>
<td>Page</td>
</tr>
<tr>
<td>---------</td>
<td>----------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>12.2</td>
<td>Clinical Mapping Session and Aspirations Event</td>
<td>22</td>
</tr>
<tr>
<td>12.3</td>
<td>Pre-diagnosis including Primary Care</td>
<td>23</td>
</tr>
<tr>
<td>12.4</td>
<td>Diagnosis and Treatment</td>
<td>24</td>
</tr>
<tr>
<td>12.5</td>
<td>Rehabilitation</td>
<td>25</td>
</tr>
<tr>
<td>12.6</td>
<td>Palliative Care</td>
<td>26</td>
</tr>
<tr>
<td>12.7</td>
<td>Self-care and Living with and Beyond Cancer</td>
<td>27</td>
</tr>
<tr>
<td>13.0</td>
<td>Evidence Base and Examples of Good Practice</td>
<td>28</td>
</tr>
<tr>
<td>14.0</td>
<td>Action Plan for Macmillan Brain Tumour and CNS Cancer Programme</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Appendices</td>
<td>44</td>
</tr>
</tbody>
</table>
Executive Summary

The aim of the Macmillan Brain Tumour and CNS Cancer Programme is to;

‘To promote excellence in the experience and outcomes of people affected by brain tumours and central nervous system cancer’.

Macmillan Cancer Support ambition is to ‘reach and improve the lives of everyone living with cancer and to inspire millions of others to do the same’. In order for Macmillan to achieve the degree of change required which is sustainable and cost-effective four areas of commitment have been identified and include; Building cancer teams for the future, Helping people take control, Inspiring millions of people to get involved and ‘Redesigning the System.’

This programme is part of Macmillan’s national ‘Redesigning the System’ programme which support organisations to make large-scale change, based on principles devised by Macmillan.

The primary aim of redesigning the system is to work with partners to change the cancer system to ensure all cancer services, in hospital and the community, providing medical, practical, emotional and financial support are joined up and designed around individual needs.

The Macmillan Brain Tumour and CNS Cancer Programme ‘Improving your cancer care together,’ is the first Macmillan redesign project to focus on a rare and complex form of cancer. The programme provides an opportunity to view the challenges across the whole care pathway from pre-diagnosis, treatment, impact of treatment, living with and beyond cancer and end of life care. The Programme also aspires to build on successful services which are already in place and share a commitment to address issues where they exist, especially at ‘transition’ points i.e. end of treatment to follow up, referral from local hospital to the specialist MDT within the pathway to ensure a positive experience for those affected by cancer.

The development of the Macmillan Brain Tumour & CNS Cancer Programme proposal was shared and agreed within the North Yorkshire and Humber Clinical Alliance. Yorkshire and Humber Commissioning Support also took the proposal to the Collaborative Clinical Commissioning Group and confirmation was agreed for the programme to commence.

Macmillan Cancer Support commissioned Yorkshire and Humber Commissioning Support to host and programme manage the Improvement Programme. This commenced in January 2014 with the appointment of a Programme Manager.

The implementation of the Macmillan Brain Tumour & CNS Cancer Programme is supported by Macmillan Cancer Support, Yorkshire and Humber Commissioning Support, North Yorkshire and Humber Commissioners, The Brain Tumour Charity
NHS England, NHS colleagues from local hospitals which refer patients to the Brain & CNS Multi-disciplinary Team at Hull and East Yorkshire Hospital Trust. There is also support the specialist team itself and patients and carers.

Primary Brain Tumours and CNS cancers are uncommon. However, Brain & CNS Tumour types are a disparate collection of tumour types with markedly different outcomes and treatment profiles. The most numerous are brain tumours and are said to account for 1.6% of cancers in England and Wales\(^1\).

Brain Tumours and CNS Cancers can have a significant impact on the individual affected and their family, friends and carers. They can effect on physical, psychosocial; cognitive and spiritual health, which can in turn affect the person, their families, vocational, environmental and financial situation. Therefore, the scoping exercise considers pre-diagnosis phase, treatment and on-going support of the individual affected by this cancer.

The survival outcomes for Brain & CNS patients vary greatly. Over half (55%) of the cancer patients included within the Routes from Diagnosis study with glioblastoma tumours did not survive past six months post diagnosis, showing similar short-term survival outcomes of lung cancer patients\(^2\).

In general Brain & CNS tumours have a poor prognosis and both their anatomical position and pathology play an important role in prognosis and decisions about appropriate investigation and treatment\(^3\).

The first phase of the redesign programme has been to conduct a scoping exercise. This was necessary in order to understand in more detail potential needs within the patient care pathway. This has included gathering intelligence through a number of experts, routes and exercises including; clinical and patient pathway mapping sessions; patient and carers’ feedback and experiences through focus groups and one to one interviews; an aspirations event with involvement and attendance from key stakeholders. Individual meetings took place with various providers of services from multi-disciplinary groups, to reflect the input and support received by patients along the continuum of the pathway; from early diagnosis through to living with and beyond cancer and end of life.

Commissioners and providers have been kept informed and involved during the scoping phase of the programme and will continue to be kept abreast of next steps and developments as they take place.

This report is the output of this initial scoping exercise and includes all the intelligence gathered during this phase with recommendations and associated action plan to be delivered over the next two years.


In order for the programme to succeed and deliver the suggested recommendations and delivery plan it will require the endorsement and support of our partners and stakeholders to achieve success and sustainable change and improvements.

Recommendations from the scoping phase include:

**Early Diagnosis**

- Earlier diagnosis of Brain and CNS Cancers including heightened awareness of presenting symptoms across primary care.
- Increased and equitable access to diagnostics for GP’s; which is appropriately managed.
- Influence the adoption of Brain Tumour & CNS Cancer in next phase of cancers to be included within the Macmillan Cancer Decision Support Tool and promote use.
- Design and implement ‘Education’ and support package for within Primary Care.

**Treatment**

- Improved information and communication with patients, carers, health, social care and voluntary sector professionals. This relates to all points within the pathway from early diagnosis to End of Life and Living with and Beyond Cancer. This is especially poignant at ‘transition’ points for patients and between health and social care professionals.
- Improved access to pre-treatment neuropsychological assessment
- Improved access to neurological services in primary and secondary care
- Enhanced pathway development to include access to appropriate support at appropriate time.
- Access to individual Holistic Needs Assessments & services required as an outcome of the assessment.
- To ensure patients who may continue to be ‘in-patient’ at ‘outlying wards’ receive equitable service.
- Access to care co-ordinator role as modelled with other cancer pathways
- Opportunity to develop nurse led clinics which operate in parallel with Holistic Needs Assessment.
- Patients to be at the centre of their care including the development of hand held records.

**Rehabilitation**

- Enhancement of rehabilitation offer to patients and balance between generic and specialist provision.
• Provision of equitable access to both generic and specialist services which meet the needs of patients with Brain & CNS Cancer.
• Design and implement a ‘rolling’ package of on-going education and support which addresses the interface between specialist and generic rehabilitation services.
• Need for high quality cost effective services from pre-diagnosis to rehabilitation which are available from the outset of presenting symptoms and continue until the person has reached their optimum potential in order to minimise the degree of a resulting disability.

**Palliative & End of Life**

• Undertake appropriate commissioning cycle activities to assess whether improved access to palliative and End of Life services are required.
• Undertake best practice/horizon scanning activities to support the development of optimum service provision for Brain & CNS Cancer patients.

It must be acknowledged the on-going action plan which is required to deliver the two year work programme needs to remain flexible and fluid. There is also a need to recognise the opportunities to embed elements of this programme within a wider programme of cancer service development; especially where there is reciprocal and mutual benefit.
1.0 Current National Cancer Agenda

Over the past few decades the UK has achieved significant progress in life expectancy, partly thanks to improvements in diagnosis, treatment, care and survival for serious conditions such as cancer. However, as Macmillan’s report Cancer in the UK 2014: State of the Nation, indicates there remains a huge gap to bridge in order to deliver the Macmillan Nine Outcomes for people with cancer by 2030¹.

Macmillan’s vision is that every person living with cancer will be able to say that the Nine Outcomes are true for them by 2030. These nine statements are what people with cancer have informed Macmillan they want to be able to say about their cancer experience². The Improving Outcomes: A strategy for Cancer (IOSC) was published in January 2011³. The focus of the strategy was to improve cancer survival through earlier diagnosis and improved access to the best possible treatment.

In the 2014 Annual Review of the IOSC there was an acknowledgement that much more needs to be achieved to maximise the scope to save lives, including improving patient outcomes for rarer cancers, preventing cancers developing in the first place, modernisation of cancer screening, early diagnosis of symptomatic cancers, improved access to treatment and better care for cancer patients and survivors⁴.

In January 2015 NHS England, on behalf of the six arm’s length Bodies (Care Quality Commission, Health Education England, Monitor, NHS England, Public

Health England and Trust Development Authority) announced the establishment of an independent taskforce to develop a five-year strategy for cancer services. The taskforce is charged with delivering the vision set out in the NHS Five Year Forward View, working across the entire health system, which will help improve survival rates and the experiences of people affected by cancer. The Five Year Forward view includes three main calls for cancer care and include;

- Better prevention
- Earlier diagnosis
- Better treatment, care and aftercare for all those diagnosed with cancer

The Statement of Intent: Cancer Strategy for England: 2015-2020 published by the Cancer Taskforce highlights that although there has been progress in improving survival for some types of cancer, there has been much less progress in others such as brain tumours. The report states that research efforts to address these needs must be maintained, both in the UK and internationally.

The Statement of Intent also suggests marginally lower rates of satisfaction for patients with rare cancers compared to more common cancers in patient experience and quality of life beyond diagnosis.

The National Cancer Survivor Initiative (NCSI) (2008-2013) was developed to ensure those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible.

Following on from the success of NCSI a new programme was launched in March 2013 named Living with and beyond cancer: Taking Action to Improve Outcomes Programme. The purpose was to develop and implement a transitional plan for the NCSI, aimed at embedding findings and recommendations into mainstream NHS commissioning and service provision.

The document identified a number of key interventions that could make an immediate difference, including the introduction of ‘The Recovery Package’ which includes:

- Structured Holistic Needs Assessment and Care Planning
- Treatment Summaries and Cancer Care reviews
- Patient education and support events
- Advice about and access to schemes that support people to undertake physical activity and healthy weight management

---


2.0 Commissioning Landscape

The Health and Social Care Act 2012\(^1\) introduced a number of key changes to the NHS in England. These changes came into effect on 1 April 2013. The changes created an entirely new commissioning framework for the provision of health care in England. Primary Care Trusts and Strategic Health Authorities were dissolved and in April 2013 and Clinical Commissioning Groups (CCG’s) and NHS England were established to take over their duties.

CCG’s are clinically led local organisations and became responsible for commissioning:

- Urgent and emergency care;
- Elective hospital care;
- Community health services;
- Maternity and new born

NHS England main aim is to improve health outcomes and deliver high-quality care for people in England by:

- Providing national leadership for improving outcomes and driving up the quality of care;
- Overseeing the operation of clinical commission groups (CCG’s);
- Allocating resources to clinical commissioning groups;
- Commissioning primary care and directly commissioned services (specialised services).

NHS England’s responsibilities are discharged through four regional teams (North, Midlands, East and South London) and 27 area teams. Out of the 27 area teams, ten have responsibility for specialised services.

Clinical Senates and Strategic Networks

CCG’s are expected to seek relevant advice from clinicians, patients, the third sector and others for the development of services. CCG’s may therefore approach bodies such as the clinical senates and strategic clinical networks, which hold sector, service and disease specific advice.

3.0 Regional Agenda

The regional Strategic Clinical Network (SCN) role is to support commissioning in strategic change and wide scale improvement activities that require joint work across professional and/or organisational boundaries.

The Yorkshire and Humber Cancer Improvement Programme themes are; Awareness and Early Diagnosis, Cancer Care Treatment, Living with and Beyond Cancer.

There are a number of programmes which are led by the Cancer SCN Team and include areas which are relevant to the Brain Tumour & CNS Cancer Programme i.e.

- Improving the stage at which cancer is diagnosed leading to improved survival and reduced human and health costs
- Improving equitable access to timely diagnostic assessment and treatment to improve patient outcomes
- Improving services for people living with and beyond cancer; promoting recovery and improving the way that people are supported to manage the consequence of treatment
- Improving primary care involvement in the cancer pathway
- Supporting the delivery of collaborative commissioning strategic objectives
- Supporting the delivery of NHS England Strategic objectives

4.0 Clinical Commissioning Group Strategic Priorities

Clinical Commissioning Groups (CCGs) Strategic Plans

The Clinical Commissioning Groups are required to have Strategic, Operational and Annual plans in place. These plans are different for each of the CCG’s, however detailed below are elements of those commitments within each of the CCGs plans which could have an impact on the Brain Tumour & CNS Cancer Programme. The full plans can be viewed through the hyperlinks.

Vale of York CCG

VoY Strategic Plan

The Strategic Plan 2014-2019 ‘My Health, My Life, My Say’ identifies lower outcomes than comparator and national average for a number of areas, one of which being higher mortality rates for cancer under 75 years of age. The plan identifies cancer prevention, diagnosis and treatment being a focus for the CCG and plan to undertake a review of the cancer pathways, in conjunction with primary care and specialist commissioning to ensure there is timely and effective routes to support diagnosis and treatment review identifies areas for improvement.
Scarborough and Ryedale CCG  
S&R Strategic Plan

The CCG Strategy concentrates on the key priority disease areas one of which being cancer. The plan identifies that there is a need to increase access to hospice care for all patient groups and to ensure this is available in a timely manner, in order to reduce admission to hospitals.

The CCG is committed to working with the Strategic Clinical Networks and specialist commissioners to secure and couple local commissioning responsibilities with that of national commissioning responsibilities; engage with Operational Development Networks regarding securing local pathways that interface with specialist services.

The CCG is committed to working with providers and the Strategic Clinical Network to develop new models of care which will deliver these elements of care and reduce the need for continued follow up.

East Riding of Yorkshire CCG  
ERoY Strategic Plan

The Strategic Plan highlights the need for better integration of local services to serve the holistic health and wellbeing needs of local people will also bring benefits including better referral pathways getting the right support at the right time in the right place.

The Health and Well Being Board strongly cite that good health and wellbeing for residents in the East Riding is best addressed by working with people in a holistic way, focusing on the individual with a whole system approach to addressing need.

The draft Operational Plan 2015-1016 identifies areas where more work has been identified through the Commissioning for Outcomes Pathways pack which includes a continued programme of cancer pathway review.

Hull CCG  
Hull Strategic Plan

The Hull CCG Strategic Plan 2014-2020 details the Hull 2020 Programme, which is based on 5 principles and include; integration, Care closer to home, Community hubs, Single care navigator, community designed and owned. Some activities for 2014/15 include the development and roll out of community hubs across Hull and creation of a single portal for people to access information about the services available to them.

North Lincolnshire CCG  
NL Strategic Plan

The five year strategic plan for the North Lincolnshire Unit of Planning sets of the vision for health services (2014/15-208/19). The plan includes a focus on improving early detection of cancer and reducing variations in referral patterns and the implementation of risk stratified follow-up pathways for people with cancer.
North East Lincolnshire
NE Lincs Strategic Plan

Part of the Strategy Embedding Transformation & Delivering Sustainability through Integration (2012-2015) includes the need to reduce dependency on services through self-care and community based care and ensure people have a positive experience of care.

Better Care Fund (BCF) Priorities within Clinical Commissioning Groups and Local Authorities

The Better Care Fund was announced in June 2013 to drive the transformation of local services to ensure that people receive better and more integrated care and support. The fund is deployed locally on local health and social care through pooled budget arrangements between local authorities and Clinical Commissioning Groups¹.

Scarborough and Ryedale Clinical Commissioning Group (CCG)
North Yorkshire Better Care Fund

Palliative Care Pathway- Integrated end of life and palliative care - ‘Hospice at Home’

The purpose of this service is the provision of an integrated palliative care service (provided in partnership between Saint Catherine’s Hospice and Marie Curie Cancer Care) across Scarborough & Ryedale CCG. The proposed model will provide an integrated solution for the provision of high quality end of life care for people identified as being in the last year of life. All such patients will be identified, have their needs assessed, care planned and provided for, to enable them to live well until they die, in their preferred place where possible.

Vale of York Clinical Commissioning Group
North Yorkshire Better Care Fund

‘Hospice at Home’ Scheme

The extended hours operation of the Hospice at Home will be a proactive and responsive care model for the population of the Vale of York which seeks to continually improve integrated health and care provision closer to or at service users usual place of residence.

All CCG’s in North Yorkshire
Re-ablement and Carers
North Yorkshire Better Care Fund

To harness the current programmes and schemes aimed at re-ablement and carers’ support and ensure they are aligned to support the ambition and goals of this North Yorkshire BCF plan and build capacity to support carers through the avoidance of duplication of activity and finding efficiencies through closer joint working. This will also ensure that support for carers is consistent, affordable and deliverable across North Yorkshire.

Hull CCG
Hull Better Care Fund

In relation to commitments within The Better Care Fund activities relate to avoidable emergency admissions and how effective collaboration across the health and care system can reduce emergency admissions

North Lincolnshire CCG

The Better Care Fund has focused plans related to preventative care, rehabilitation and integrated care.

North East Lincolnshire
North East Lincs Better Care Fund

A system wide programme of action Healthy Lives Healthy Futures Programme (HLHF) is being implemented to ensure local services are improved from a quality perspective as well as being able to continue to deliver for the needs of an increasingly frail population.
We want people to live independent, healthy lives, supporting one another and taking control of their own health. When they do need care however, they should have access to it by;

- Provision of services in the community, closer to the person, with reduced demand for hospital-based acute care;
- Provision of specialist and tertiary acute care, of sufficient scale to ensure safe, quality services.
- Access to Service 24/7 through the implementation of seven day working at a 24/7 single point of access.

East Riding
East Riding Better Care Fund

The role of the Better Care Fund (BCF) programme is to act as an enabler to accelerate the introduction of the vision and plans articulated within the Joint Health and Wellbeing Strategy and Clinical Commissioning Groups 5 year strategic plans. Due to the fact that the underlying principles of the BCF are inherent in local plans there are no service changes that would not occur if the BCF was not present, however the timescales would be longer and, therefore, the positive impact that we expect from the changes would be delayed.
We have a clear vision running through our BCF Plan, Joint Health and Wellbeing Strategy and Clinical Commissioning Group Strategic Plans which will deliver a systematic change in the way people access services, both in and out of hospital. Through a reduction in acute hospital based activity and an increased use of home based and community intervention these changes will not only deliver more integrated care, but also improve the experiences and outcomes for the East Riding population.

The BCF is providing a focused environment working at pace in which to progress our existing plans of work and details can be found on page 37 of the BCF Plan within the hyperlink above.

5.0 Background to development of the Macmillan Brain Tumour & CNS Cancer Improvement Programme

Primary Brain Tumours & CNS cancers are uncommon and are a disparate collection of tumour types with markedly different outcomes and treatment profiles. The most numerous are brain tumours and account for 1.6% of cancers in England and Wales.

Survival for people with Brain Tumours and CNS Cancers varies widely depending on which specific type of cancer they have. Fewer than 2% of people with glioblastoma will live for seven years or more, compared with almost two in three (64%) people with meningioma and more than four in five (87%) people with nerve sheath cancer.

The reasons for focussing on this rare cancer were multiple and included; concern over one and five year survival rates being the lowest in England; (with no increase since 2006) multiple areas of deprivation within the footprint; patients presenting late and often to A&E; rurality of the patch and access to services; patient treatment tending to focus on Acute Care and lack of access and inequality of provision of rehabilitation.

As a result of the Health and Social Care Act 2012, there have been organisational changes to the commissioning landscape, with different geographical footprints and the dissolution of Primary Care Trust. This coupled with the fact that there may well be potentially small numbers of patients within the CCG’s being diagnosed with a Brain Tumour or CNS cancer, data related to 1 year survival for specific CCG’s is not currently available.

However, the Brain & CNS Improvement Programme was agreed on the basis of concern of survival rates within the North Yorkshire and Humber clusters and these rates can be viewed below.

In summary, North Yorkshire and York and Humber clusters had lower one year survival rates than the England rate for 2005-2009 and the 1-year survival rate in

---

Humber cluster was significantly below the England rate. Although the NYY cluster has lower survival rates than England this is not significantly different.

Table 1: One Year Survival for cancer of Brain & CNS – all persons for 2001-05 to 2005-09

<table>
<thead>
<tr>
<th>Year</th>
<th>Humber cluster</th>
<th>NYY cluster</th>
<th>YH SHA</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001-05</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002-06</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2003-07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2004-08</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005-09</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Data source: UKCIS, March 2012

Table 2: Five Year Survival for Cancer of Brain & CNS – all persons for 1997-01 to 2001-05

<table>
<thead>
<tr>
<th>Year</th>
<th>Humber cluster</th>
<th>NYY cluster</th>
<th>YH SHA</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997-01</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1998-02</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1999-03</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000-04</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001-05</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Data source: UKCIS, March 2012

In summary the North Yorkshire and York cluster has lower five year survival rates than England but higher survival rates than the SHA region in 2001-2005. Humber cluster has lower five year survival rates than England and the SHA for the 2001-2005 period. However, despite lower survival rates, neither the North Yorkshire nor York or Humber cluster has significantly lower rates than England.

The Macmillan Brain Tumour and CNS Cancer Programme is the first Macmillan redesign project focused on a rare and complex form of cancer. The programme

---

provides an opportunity to view the challenges across the whole care pathway from pre-diagnosis, treatment, impact of treatment, living with and beyond cancer and/or end of life care. The Programme also aspires to build on successful services which are already in place and share a commitment to address issues where they exist, especially at ‘transition’ points within the pathway to ensure a positive experience for those affected by cancer.

The scope of the project is to provide a blueprint for commissioning services which improve the experience of people living with and beyond Brain Tumour and CNS Cancer, key features of the programme are:

- Improve patient experience, outcomes and quality of life
- Understand patient experiences and develop patient/user stories
- Formalise engagement activities and collect rich intelligence
- Develop a complete holistic pathway which is co-ordinated, costed and personalised
- Develop equity of services, which focus on closer to home support and considers preferred place of care
- Innovation of service development
- Working closely with Primary Care to ensure patients who present to their GP are diagnosed early to ensure optimum prognosis and reduce mortality
- Increase quality of life for both treatable and untreatable cancer
- Develop living with and beyond cancer services

It is anticipated that the outcomes of this programme will contribute to improving the experiences and outcomes of individuals with Brain Tumour & CNS Cancer. Whilst the initial focus will be on cancer pathways of care, there are areas of overlap with other pathways of care including early diagnosis, rehabilitation, palliative and end of life care and other diagnoses i.e. stroke, ABI, neurological conditions, mental health and other cancers.

Implementation will require close working with local and specialist commissioners, Local Authorities, Service providers and other stakeholders when developing a case for change or development during programme implementation.

The map below details the geographical footprint of the Programme and the various CCG’s, Hospitals and Local Authorities.
6.0 Brain Tumour & CNS Cancer

Approximately 6,500 primary Brain tumours and CNS cancers in those aged 15 years and older were registered annually in England and Wales between 1995 and 2000, of which 58% were classed as malignant. There is however evidence of significant under-registration of intracranial tumours in the UK, particularly low-grade tumours. Therefore, there may be individuals who need support who are not known to services.

Primary Brain Tumours and CNS cancers are uncommon. However, Brain & CNS Tumour types are a disparate collection of tumour types with markedly different outcomes and treatment profiles. The most numerous are brain tumours and are said to account for 1.6% of cancers in England and Wales (National Assembly for Wales, 2001). The variety of pathological tumours is large. The terms ‘high grade’ (Grades 3 and 4) and ‘low grade’ (Grades 1 and 2) are preferred terms to define in the World Health Organisation (WHO) classification, respectively a tumour that grows rapidly and is aggressive and a tumour that grows slowly, but which may or may not be successfully treated.

All Glioblastomas are highly malignant tumours, biologically aggressive, and are relatively resistant to both radiotherapy and chemotherapy. As they infiltrate the normal brain so widely they are almost impossible to completely remove surgically. They are consequently given the highest tumour grade in the WHO classification of
CNS tumours, WHO grade IV. The vast majority of meningiomas are WHO malignancy grade I, which means they do not invade the brain and can often be completely surgically removed.

The survival outcomes for Brain & CNS patients vary greatly. Over half (55%) of the cancer patients included within the Routes from Diagnosis study with glioblastoma tumours did not survive past six months post diagnosis, showing similar short-term survival outcomes of lung cancer patients.

In general Brain & CNS tumours have a poor prognosis and both their anatomical position and pathology play an important role in prognosis and decisions about appropriate investigation and treatment. The anatomical location influences symptoms that include physical, cognitive and psychological components. For this reason, adults with Brain & CNS pose a unique challenge to healthcare professionals; the patient may not be the best person to explain their symptoms and cognitive dysfunction may greatly increase the need for psychological/psychiatric, social and physical support.

In view of the poor survival of many patients, even with optimal treatment, an important aspect of improving outcomes is maximising quality of life.

7.0 Routes from Diagnosis and Brain & CNS Cancer

The Routes from Diagnosis report details a simplified framework to support the understanding of the distribution of patients into each Brain Tumour & CNS cancer type. This framework provides a consistent way in which to refer to and compare each cancer.

The graph in table 3 indicates:

- Patients with meningioma’s and nerve sheath tumours to have notably better outcomes, with the majority of patients living past 7 years.
- Higher percentage of meningioma patients did not survive past 12 months than patients with nerve sheath tumours (which may, in part, reflect the older age group profile of the meningioma patient group).
- Nerve sheath tumours are also mostly benign and appropriate treatment can lead to long term containment or cure.

---

### Table 3: Graphical view of simplified living with and beyond cancer outcome framework for the three most common Brain/CNS tumour types
(Adapted from Macmillan, 2014)

<table>
<thead>
<tr>
<th>Group</th>
<th>Limited survival</th>
<th>Limited–moderate survival</th>
<th>On-going survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>78.8%</td>
<td>4.7%</td>
<td>0%</td>
</tr>
<tr>
<td>2</td>
<td>1.1%</td>
<td>2.7%</td>
<td>3%</td>
</tr>
<tr>
<td>3</td>
<td>12.6%</td>
<td>2.6%</td>
<td>48.1%</td>
</tr>
<tr>
<td>4</td>
<td>6.0%</td>
<td>6.0%</td>
<td>38.1%</td>
</tr>
<tr>
<td>5</td>
<td>0.6%</td>
<td>1.4%</td>
<td>4.7%</td>
</tr>
<tr>
<td>6</td>
<td>0.6%</td>
<td>0.8%</td>
<td>2.6%</td>
</tr>
<tr>
<td>7</td>
<td>9.0%</td>
<td>4.9%</td>
<td>4.9%</td>
</tr>
<tr>
<td>8</td>
<td>22.7%</td>
<td>9.9%</td>
<td>9.9%</td>
</tr>
</tbody>
</table>

It is important to consider the living with and beyond cancer outcomes of Brain Tumour & CNS cancer patients in this way. For example it highlights the large percentage of patients with meningioma and nerve sheath tumours falling into Group 7, where there are major long-term health service demands.

The degree of variation in outcomes supports the need for stratification processes that helps to identify which care pathway is most suitable for each patient based on the level of care needed for the disease, the treatment and the patient’s ability to self-manage, and therefore what level of professional involvement required. This can then help health and social care identify and determine the on-going likely needs of each patient group.

---

8.0 Economic Impact

The Routes from Diagnosis report\(^1\) allows for an understanding of the variance of inpatient costs to living with and beyond cancer outcome group, which helps to build a complete cost of cancer and treatment. This also includes the cost of inpatient treatment in the living with and beyond cancer phase up to seven years after diagnosis.

Table 5: The average post-diagnosis cost of Brain & CNS patients split by phase, by simplified living with and beyond cancer outcome, with number of patients\(^1\)

This report highlights the average inpatient cost post-diagnosis for brain/CNS tumours being £13,200 over and above other cancer cohorts. Some of the highest in-patient costs are associated with moderate survival, rather than the longest period of survival. Overall, patients surviving one to seven years with cancer complications have the highest inpatient treatment costs post-diagnosis on average £26,147, followed by patients surviving more than seven years with cancer complications at £24,800.

\(^1\) Macmillan Cancer Support, 2014. Routes from Diagnosis: the most detailed map of survivorship yet, London: Macmillan.
Furthermore, for those patients who experienced moderate and continued survival, the costs associated with cancer complications are higher than those associated with inpatient co-morbidities, which are higher than those associated with no other inpatient morbidities.

It is noted that Brain/CNS patients costs continue to accumulate after the initial high treatment phase costs, with the exception of the patients who experienced no other morbidities. This implies:

- There is a high burden of acute illness in moderate to long-term survival due to cancer complications or morbidities.
- Approximately two thirds of all brain/CNS tumour patients (66%) experienced other inpatient morbidities.
- Highlights the very different living with and beyond cancer outcomes associated with the heterogeneous mixture of tumour types within brain/CNS tumour group¹.

9.0 Emergency presentation and impact on living with and beyond cancer

Rarer cancers are much more likely to be diagnosed through emergency presentation than the top four most common cancers. The Routes to Diagnosis report highlight that 63% of Malignant Brain cancer patients were diagnosed through emergency presentation².

One-year survival rates are lower for patients presenting as emergencies than for those presenting via other routes, including the Two Week Wait urgent referral route and routine outpatient appointments.

The table below highlights a proxy measure for emergency presentations for cancer by Clinical Commissioning Groups (CCG) over a 5 year period, which are included within the footprint of the Macmillan Brain & CNS Programme the programme. It can be noted that Hull CCG has the highest percentage of emergency presentations for cancer at 29.8% during January to December 2012 compared to the other CCG’s and the All England percentage of 20.6%

| Table 5: Proxy Measure for emergency presentations for cancer for All England and all CCG’s within footprint of Brain Tumour & CNS Cancer Programme (Jan 2008-Dec 2012)¹ |

The table below highlights the National Relative Survival rates estimates for Malignant Brain Cancer by routes for survival over several months up to 36 months from 2006-2010. It can be noted that those patients with the route of emergency presentation had 43% survival at 6 months compared to 61% survival rate if via a GP referral. It can also be noted that those patients surviving for 12 months presenting via A&E is 27% compared to 53% through other outpatients or 46% via GP referral\(^1\). Table 7 also demonstrates this in an alternative format.

The impact on survival rates due to the route to diagnosis is an important issue to consider. The figures are higher for Brain & CNS compared with many other cancers for example Brain & CNS cancer was 58% emergency presentation as the route to diagnosis compared with 4% for breast and 25% for colorectal\(^2\). This high rate is also reflected locally within the Brain & CNS MDT, with 105 patients being referred from Hull Royal Infirmary A&E to the MDT in 2014. It is also not clear if the referrals into the MDT from other hospitals also include patients who came via the A&E route, so the numbers could be higher than 105.

\(^1\)Cancer Commissioning Toolkit Accessed 18\(^{th}\) March, 2015 Available from:  https://www.cancertoolkit.co.uk

Table 6: Malignant Brain National Relative survival rates estimates by routes, for 1-month, 3-months, 6-months, 9-months, 12-months, 24-months, and 36-months post diagnosis 2006-2010

<table>
<thead>
<tr>
<th>Malignant Brain</th>
<th>All routes</th>
<th>Two Week Wait</th>
<th>GP referral</th>
<th>Other outpatient</th>
<th>Inpatient elective</th>
<th>Emergency presentation</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-month</td>
<td>87%</td>
<td>90%</td>
<td>90%</td>
<td>90%</td>
<td>90%</td>
<td>86%</td>
<td>90%</td>
</tr>
<tr>
<td>Confidence interval</td>
<td>87%</td>
<td>88%</td>
<td>89%</td>
<td>91%</td>
<td>89%</td>
<td>91%</td>
<td>94%</td>
</tr>
<tr>
<td>3-month</td>
<td>68%</td>
<td>82%</td>
<td>76%</td>
<td>79%</td>
<td>85%</td>
<td>61%</td>
<td>76%</td>
</tr>
<tr>
<td>Confidence interval</td>
<td>67%</td>
<td>66%</td>
<td>76%</td>
<td>87%</td>
<td>74%</td>
<td>77%</td>
<td>81%</td>
</tr>
<tr>
<td>6-month</td>
<td>51%</td>
<td>67%</td>
<td>61%</td>
<td>67%</td>
<td>70%</td>
<td>43%</td>
<td>60%</td>
</tr>
<tr>
<td>Confidence interval</td>
<td>50%</td>
<td>52%</td>
<td>59%</td>
<td>73%</td>
<td>59%</td>
<td>63%</td>
<td>65%</td>
</tr>
<tr>
<td>9-month</td>
<td>42%</td>
<td>58%</td>
<td>52%</td>
<td>59%</td>
<td>61%</td>
<td>34%</td>
<td>50%</td>
</tr>
<tr>
<td>Confidence interval</td>
<td>41%</td>
<td>43%</td>
<td>50%</td>
<td>65%</td>
<td>50%</td>
<td>54%</td>
<td>57%</td>
</tr>
<tr>
<td>12-month</td>
<td>35%</td>
<td>47%</td>
<td>46%</td>
<td>53%</td>
<td>53%</td>
<td>27%</td>
<td>45%</td>
</tr>
<tr>
<td>Confidence interval</td>
<td>35%</td>
<td>36%</td>
<td>40%</td>
<td>54%</td>
<td>44%</td>
<td>48%</td>
<td>51%</td>
</tr>
<tr>
<td>24-month</td>
<td>23%</td>
<td>21%</td>
<td>35%</td>
<td>40%</td>
<td>36%</td>
<td>15%</td>
<td>30%</td>
</tr>
<tr>
<td>Confidence interval</td>
<td>22%</td>
<td>24%</td>
<td>15%</td>
<td>28%</td>
<td>33%</td>
<td>37%</td>
<td>38%</td>
</tr>
<tr>
<td>36-month</td>
<td>19%</td>
<td>19%</td>
<td>31%</td>
<td>35%</td>
<td>29%</td>
<td>12%</td>
<td>26%</td>
</tr>
<tr>
<td>Confidence interval</td>
<td>18%</td>
<td>20%</td>
<td>13%</td>
<td>26%</td>
<td>29%</td>
<td>32%</td>
<td>33%</td>
</tr>
</tbody>
</table>

Number in cohort: 18,056

Cancer Commissioning Toolkit

Table 7: Malignant Brain National relative survival rates estimates by route, for 1 to 36 months post diagnosis 2006-2010

<table>
<thead>
<tr>
<th>Number of months</th>
<th>Percentage of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>All routes</td>
</tr>
<tr>
<td>3</td>
<td>Two Week Wait</td>
</tr>
<tr>
<td>6</td>
<td>GP referral</td>
</tr>
<tr>
<td>9</td>
<td>Other outpatient</td>
</tr>
<tr>
<td>12</td>
<td>Inpatient elective</td>
</tr>
<tr>
<td>24</td>
<td>Emergency presentation</td>
</tr>
<tr>
<td>36</td>
<td>0%</td>
</tr>
<tr>
<td>0%</td>
<td>20%</td>
</tr>
<tr>
<td>40%</td>
<td>60%</td>
</tr>
<tr>
<td>80%</td>
<td>100%</td>
</tr>
<tr>
<td>120%</td>
<td>120%</td>
</tr>
</tbody>
</table>

Cancer Commissioning Toolkit Accessed 18th March, 2015 Available from: https://www.cancertoolkit.co.uk
10.0 Specialist Centre – Hull and East Yorkshire Hospitals NHS Trust (HEYHT)

Hull and East Yorkshire Hospitals NHS Trust provide local, diagnostic and specialist Brain & CNS Cancer services for the population of Hull and the East Riding. HEYT also provide specialist cancer services to Scarborough and North East Yorkshire Healthcare NHS Trust, North Lincolnshire and Goole NHS Foundation Trust and York Teaching Hospital NHS Foundation Trust.

During 2013 the Brain & CNS MDT discussed 450 new cases and 1,023 follow up cases.

Each HEYT neurosurgeon has a weekly general neurosurgical clinic. In addition there are three joint Neurosurgeon and Oncologist clinic monthly, low grade glioma clinic jointly held by a neurosurgeon, neurologist and Specialist nurse. There is a joint pituitary clinic involving neurosurgeon and neuro-endocrinologist.

10.1 Locality Services

Northern Lincolnshire and Goole Hospitals Foundation Trust (NLGHFT) and York Teaching Hospital NHS Foundation Trust (YDHFT) provide local and diagnostic Brain & CNS Cancer services to their population. All patients diagnosed with Brain & CNS Cancers are referred to and discussed at the Specialist MDT based in Hull and East Yorkshire Hospital NHS Trust.

However, Vale of York and Scarborough and Ryedale Clinical Commissioning Groups may refer to Leeds, South Tees due to the geography of the region and patient choice.

There are named clinicians, at Consultant level for Brain & CNS Cancers for each locality trust, with specified time and a list of responsibilities for the role agreed by the trust cancer lead clinician.

There are no Brain & CNS Clinical Nurse Specialist posts in NLGHFT, YDHFT (including Scarborough). The referring Trusts do not provide any neuro-oncology clinics. This service is provided by HEYHT.

Table 8 highlights the numbers of patients referred from hospitals within the various localities to the Specialist Centre in 2013.
Table 8: Source of new referrals to MDT from January – December 2013

<table>
<thead>
<tr>
<th>Referral from Other Trusts</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>North Lincolnshire and Goole</td>
<td>140</td>
</tr>
<tr>
<td>York</td>
<td>56</td>
</tr>
<tr>
<td>Scarborough</td>
<td>40</td>
</tr>
<tr>
<td>Acute referrals from HEYHT</td>
<td>74</td>
</tr>
<tr>
<td>Consultant referrals from HEYHT</td>
<td>84</td>
</tr>
<tr>
<td>GP</td>
<td>37</td>
</tr>
<tr>
<td>GP 2 ww</td>
<td>09</td>
</tr>
<tr>
<td>Private patient</td>
<td>04</td>
</tr>
<tr>
<td>Other</td>
<td>06</td>
</tr>
<tr>
<td><strong>Total of new referrals</strong></td>
<td><strong>450</strong></td>
</tr>
</tbody>
</table>

Source: (Hull and East Yorkshire Hospitals NHS Trust, 2014)¹

10.2 Brain & CNS Multi-disciplinary Team (MDT) – Hull and East Yorkshire Hospitals NHS Trust

Table 9 highlights the number of patients seen by the Brain & CNS MDT during 2013, with the different tumour types reported. Over 33% of patients had a diagnosis of a high grade tumour, 5.6% a Low grade tumour, 17.6% a Metastatic tumour, 12.4% Meningioma, 9.2% Pituitary.

Table 9: Neuropathology reporting in 2013 (The numbers below include all tumours, including pituitary, spinal and skull base tumours)

<table>
<thead>
<tr>
<th>Tumour Type</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Grade (Grade 3 and 4)</td>
<td>83</td>
</tr>
<tr>
<td>Low Grade (Grade 1 and 2)</td>
<td>14</td>
</tr>
<tr>
<td>Metastatic</td>
<td>44</td>
</tr>
<tr>
<td>Meningioma (all grades)</td>
<td>31</td>
</tr>
<tr>
<td>Pituitary</td>
<td>23</td>
</tr>
<tr>
<td>Lymphoma/Myeloma</td>
<td>14</td>
</tr>
<tr>
<td>Schwannoma</td>
<td>11</td>
</tr>
<tr>
<td>Other</td>
<td>30</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>250</strong></td>
</tr>
</tbody>
</table>

Source: (Hull and East Yorkshire Hospitals NHS Trust, 2014)

As described in the Routes from Diagnosis report, it is important to consider the evidence which describes Brain & CNS Cancer and the cancer complexities, other morbidities and survival rates. This is important for patients on an individual basis to ensure services are in place which offer the appropriate support according to need. It is also a vital tool to consider when future planning of health and social care services. Stratification of patients according to potential needs can be a useful planning tool.

In order to understand the local position, a retrospective analysis of activity and stratification of patients within the MDT would be useful task to undertake.

When considering the idea of stratification of patients according to tumour type, the numbers below include all tumours, including pituitary, spinal and skull base tumours which were seen by the MDT during 2013. As noted the majority of patients had a high grade tumour, followed by those with Metastatic presentation. It is useful to consider the potential holistic needs of those patients locally according to tumour type and future service developments which may be required for those patients and their families.

---

11.0 Primary Care Referral for Patients with suspected Brain or CNS Tumour

People with certain types of rarer cancers are more likely to see their GP more than twice when compared to people with the most 4 common types of cancer. The Cancer Patient Experience Survey states that 39% of patients with Brain Tumour or CNS Cancer had to see their GP more than twice before they were diagnosed\(^1\). Patients with many types of rare cancer often experience vague but debilitating symptoms which could be attributed to causes other than cancer. They may therefore put off seeking help from their GP for some time and may not suspect cancer as a possible cause of their problem\(^2\).

The current Referral Protocol for Primary Care for suspected Brain Tumours can be seen in Appendix A.

12. Findings from Scoping Exercise

12.1 Patient and Carer Engagement

Patient engagement and involvement is a key feature and fundamental in both the development and on-going delivery of the Brain Tumour & CNS Cancer Programme.

As part of the scoping phase the Macmillan Involvement Co-ordinator developed an Implementation Plan to deliver patient engagement activities. To adhere to governance requirements, consent to contact patients was sought from providers of healthcare services. Where consent was sought, the Macmillan Involvement co-ordinator then approached patients to gain insight of their experience and understanding of where services/experiences could be improved.

A total of 19 patients and 8 carers have supported the programme to share their experiences, with varying diagnoses and from various localities within the patch. The engagement took the form of one to one interviews and focus groups; which concentrated on gathering rich information as to their experience through mapping the care pathway, from early diagnosis to living with and beyond cancer. There was a combination of patients involved who are either 5 years or over from initial diagnosis or under 5 years since initial diagnosis.

The patient consultation feedback within this report will be incorporated within each part of the care pathway.

---


12.2 Clinical Mapping Session and Aspirations Event

A Clinical Mapping session took place in September 2014, which was attended by a wide span of clinicians from across the care pathway. The aims of the day were to;

- Work together to acknowledge success and progress
- Identify gaps and barriers to success of future development
- Whole pathway approach
- Insights from patients

Identified Improvement related to Primary Care included;

- Improved communication and co-ordination between primary and secondary care
- Issues in that IT records are not linked to Primary Care/SystmOne and creates a time lag for information transfer
- Need for access for Dr to Dr communication
- Waits to liaise with GP e.g. CNS waits in surgery for GP to sign prescriptions
- Different needs at discharge and community services being made aware of the changed needs of the patient
- An Aspirations event was also held in November 2014

An innovative multi-agency workshop also took place to mark the end of the scoping phase of the programme. The aims of the event were to share with a wide range of stakeholders and delegates;

- Patient experience of pathway
- Scoping exercise outcomes to date
- Professionals understanding of what’s working well and where there is potential for improvement
- To start to shape and commit to future work programme

The format of the day consisted of key note speakers from various disciplines along the continuum of the pathway and interactive workshops. The keynote speakers highlighted aspects of the pathway which were working well, what could be improved and those interventions/services which were fundamental to provide, change or improve. Key note speakers from the day can be viewed at https://www.youtube.com/channel/UCS2ZH7t3nnMzS8aUdL1GEIA/videos.

The workshops provided the opportunity for both aspirational and realistic consideration of potential solutions for service improvement for the Brain Tumour and CNS pathway. This feedback has been triangulated with intelligence gathered during the scoping phase to develop the work programme.
12.3 Pre-Diagnosis including Primary Care

The majority of referrals from January to December 2013 into the Specialist Centre were from various hospitals within the localities described earlier. All patients referred with suspected cancer by their GP have a maximum wait of two weeks to see a specialist.

As can be noted within Table 8, only 9 patients from a total of 450 referrals to the Brain & CNS MDT came via GP’s thorough the Two Week Wait referral process. However, 37 referrals in total were received from GP’s outside of the Two Week Wait referral process.

From discussions with GP’s who work within the local areas within the footprint for this programme the emerging themes were;

- Inequity in access to diagnostics and direct access to MRI/CT/Radiologist across the footprint of the Brain & CNS Programme
- Inconsistency with referral including the 2ww referral criteria across the patch and need for guidance and support in diagnosis and when best to refer for GP’s
- Need to look at communication of patients plan of care from secondary care and shared interactions with Primary Care from Secondary Care and with patients
- Secondary care cite a large number of Two Week Waits referrals which don’t result in a Brain & CNS Cancer as the outcome
- An audit of the number of GP visits before diagnosis would be a useful piece of work and number of patients who presented with a headache
- GP significant event analysis to look at emergency presentation for Brain & CNS Cancer and links to the work SCN are conducting
- Differences in GP offer for EoL and Palliative Care patients
- Local rehabilitation is generic when specialist rehabilitation is required

Patient feedback has related to a number of themes of their experience within Primary Care and include;

- Numerous visits to the GP
- Optician appointments and then route/self-refer into A&E
- Multiple symptoms with multiple appointments to various specialists before diagnosis and therefore complicated routes to diagnosis
- Patients citing being referred by physiotherapist or opticians
- Experienced symptoms over a long period of time before they were taken seriously
- Long waits until patients can speak to someone about concerns; report up to two weeks
- Transition points difficult when waiting to access different parts of the pathway, with limited information/advice or support.

---

12.4 Diagnosis and Treatment

The themes from feedback from the scoping including the Clinical Mapping and Aspirations event relate to;

- Improved communication between primary and secondary care, including Acute hospital IT records not linking to SystmOne, which can lead to time lags in information being shared
- Complex patient pathway and not always sufficient resources to give patients time and space
- Can be different needs at discharge and need to ensure community services link are aware of the change.
- Significant pressures on neurosurgery to discharge patient and time can be limited for discussions about patients desires, wishes and future plans
- Improved access to pre-treatment neuropsychological assessment- assist in assessing the impact of the treatment on the patient and therefore any rehabilitation needs as a consequence of treatment.
- Improved access to secondary/tertiary clinics e.g. neurology (cross ref to Primary Care)
- Access to Holistic Needs Assessment and services required from outcome of assessment
- Ensuring patients on ‘outlying wards’ receive equitable service
- Ensuring Brain Tumour & CNS patients have access to critical care services as appropriate
- Access to ‘care co-ordinator’ ‘care navigator’ role
- Access to different models of secondary/tertiary service with the development of nurse led clinics
- Development of community based CNS role to provide ‘outreach’ services
- Establishment of Network Site Specific Group for Brain & CNS Cancer

Patient and Carers Perspective

Patient feedback provided insight into their experience once diagnosed and receiving treatment. Patients highlighted that once they were referred to secondary care, experiences seem to vary. Patients with a benign diagnosis report being given little in the way of information or support prior to and after surgery. The themes which emerged from patient engagement activities include;

Patients not fully aware of the consequence of treatment

Patients and carers also report not feeling like they fully understood the impact of the treatment on them, and how this would affect them in the future. They report being given little guidance or support offered to find ‘the new normal’.
Referrals to welfare and benefits are not routinely made

Over three quarters of patients and carers highlighted they had not been referred to benefits and welfare advice. They report that they had to find help for themselves, either via the voluntary sector organisations or information shared at support groups or online.

Patients with benign tumours not routinely offered psychological support

The issues reported were two-fold. Patients with benign tumours experience many of the same physical effects as those with malignant tumours; however they are not offered support to be able to deal with those effects and return to active employment and life. All patients also face the emotional rollercoaster of scans and waiting for the results on a regular basis, which makes moving on very difficult. There are also some issues around active monitoring of patients with benign or slow growing tumours and the way in which this is explained by clinicians. Patients report not feeling properly supported or cared as they are simply a set of scan results.

12.5 Rehabilitation

The themes which emerged from discussions with individuals focused on;

- Provision of equitable access to specialist and generic rehabilitation serviced which meet the needs of Brain & CNS patients
- All AHP who come into contact with Brain & CNS Cancer patients are aware of the specialist needs of the patient group and are supported to develop the appropriate skill set to support the patients/carers
- Need for specialist neurological knowledge and potential to use expertise of clinicians with this experience in the patch.
- Rehabilitation, Palliative Care and End of Life may need to run concurrently and need to improve the function for patients who are palliative
- Specialist rehabilitation and patient led rather than diagnoses led
- Opportunity to link with other appropriate pathways i.e. stroke, Acquired Brain Injury, Dementia, and other cancers.
- Patients placed and managed in services which best meets their clinical needs ‘Right patient, right service’ (UKROC)
- Existing local services such as leisure centres, vocational engagement, utilised to roll out community based programmes to help promote health and well-being
- Consideration of a ‘Hub and spoke’ model, which incorporates a three tier system, linked to each other, with the patient able to transverse and across any part of the pathway according to their needs
- Macmillan Brain & CNS Therapy Team provides specialist community therapy services for patients. There is extensive knowledge and the expertise within
this team and opportunities to share learning with local generic therapy services should be considered.

The unique nature of rehabilitation and re-ablement imply the necessity of close liaison with social services, especially with discharge co-ordination and provision of some accessible services for patient engagement in the community.

Patient experience feedback themes for Rehabilitation relate to;

**Positive Rehabilitation experience but inequalities exist**

Patients who used the Allied Health Professionals and counselling services report very positive experiences and it makes a difference to their recovery and quality of life. However, referrals to the services are inequitable depending on geography and diagnosis.

**Patient variation in support post treatment**

Over half the patients shared that they only found out self-help and support groups by chance, or via an online search. They also highlighted that there is little support available to help carers/family members cope emotionally and practically post diagnosis. Support feels like it ends as soon as treatment finishes and patient/carers report feeling very alone and out of the safety net of secondary or tertiary care.

Patients also report experiencing difficulties in knowing what kind of support is available once they are back in their own homes. They are unsure of who to go to with issues or where they can access support services for help with daily living.

**12.6 Palliative Care**

The gaps suggested below were identified within the scoping phase;

- Suggestion of a gap in care of patients after they have had their treatment but don’t meet palliative care criteria as there is no support available for them.
- When patients return from oncology support needed to manage the side effects of treatment and also support patients may need to manage, whether that is surgery, chemotherapy, radiotherapy.
- Learning from living with and beyond cancer package and how currently the key worker is not prescriptive/clearly identified
- Red book for patients undergoing chemotherapy treatment could be used for comprehensive information/care plan for patients
- Issues with access to patient data and the cost of licences to access IT system. Currently limited to small number of staff.
- Need to bridge the gap between community services and hospital
- Concerns about patient behaviour change and patients declining and the carers support which is needed to manage these changes
- Family problems and coping with the significant changes in their family member and access the Family Support Team in Hull useful support
• Access to palliative care services to improve the quality of palliative and End of Life pathway

There currently is limited involvement and feedback from patients and carers in relation to palliative care and End of Life support. This has been identified as a gap and as the programme develops will endeavour to gather more insight and understanding from the patient and carer perspective.

12.7 Self- Care and Living with and Beyond Cancer

The Oncology Health Centre at Castle Hill Hospital aim is to provide patients achieve the best possible health and quality of life during and after treatment. They offer a drop in service and can provide practical advice about treatment and its side effects.

As well as offering the opportunity to talk over matters with specially trained staff, they can also support with ‘self- help’ techniques. Family members and friends can also attend the centre.

- Patients report either not being informed of the services provided by the Oncology Health Centre or informed later within treatment about what the service offered. Once they knew about the service and accessed they found the support useful.
- Patients shared that they worry about their health whilst waiting for appointment for the next scan and they find the build-up to and follow up appointments stressful.

Following on from the success of The National Cancer Survivorship Initiative (NCSI) there is a new Survivorship Cancer Programme. This Programme is a two year partnership between NHS England and Macmillan Cancer Support to develop and implement a transitional plan for the National Cancer Survivorship Initiative, aimed at embedding findings and recommendations into mainstream NHS commissioning and service provision

The Programme Plan will focus on:

- Ensuring all cancer patients have access to holistic needs assessment, treatment summary, cancer care review and a patient education and support event – the ‘Recovery Package’;
- Developing and commissioning risk stratified pathways of post treatment management;
- Promoting physical activity;
- Understanding and commissioning for improved management of the consequences of treatment.

There is potential learning from this programme; with the opportunity to map locally and implement changes accordingly to meet the focus outlined in the Living With and Beyond Programme for patients with Brain Tumours and CNS Cancer.
13.0 Evidence Base and examples of Good Practice

The needs identified and potential solutions need to be considered in line with the evidence base, examples of good practice elsewhere; examination of interventions across the wider cancer agenda, and evidence which relates to generic support compared to more specialist support. Opportunities to consider innovative practice and interventions also need to be considered as part of the work programme.

There will need to conduct a comprehensive evidence review based on the needs highlighted and moving forward, those detailed in the Work Programme.

There are a number of initiatives taking place within Macmillan, which could be adapted or rolled out to meet the identified needs within this programme. Appendix B provides a flavour of some of those interventions taking place across the spectrum on the pathway. However, it must be acknowledged this is not a full review of initiatives taking place within Macmillan.

Other examples include;

Stratified Care Pathways

South Yorkshire Bassetlaw and North Derbyshire CCG’s have some of the highest levels of stratified care pathways to make the most of limited resources and deliver better outcomes for colorectal cancer patients, and launched a survivorship programme.

Stratified care pathways involve clinicians and patients deciding together what level of care and support best matches the patient’s needs. In addition to delivering a more tailored package of care, some evidence suggests stratified care pathways for people living with and beyond cancer can result in cost improvements if eligible patients with breast, colorectal or prostate cancer were moved to a supported self-management pathway. The project in this case study aimed to implement a comprehensive aftercare service for colorectal patients, using stratified care pathways in order to provide more individualised, holistic care and transform local health and social care systems. These new pathways are designed to enable patients to move to self-managed care where appropriate, whilst providing quick access back into hospital services when needed. By matching patient needs to the correct level of support, the programme aims to contribute to a reduction in emergency attendances and admissions.

Patient Centred Outcome Measures

Patient Centred Outcome Measures is a relatively new concept which involves putting patients, and their families and carers, at the heart of deciding which goals are most valuable for individuals with a range of health conditions, rather than clinician’s deciding what is best. In 2015 the DOH is focussing of developing PCOMs for children and young people.

To improve cancer outcomes, it is essential that all cancer patients receive the best treatments available at the highest quality standards. Huge improvements have been
made in treating cancer over the last few decades. This is partly the result of major radiotherapy commitments such as the Radiotherapy Innovation Fund and proton beam therapy (a different form of radiotherapy), and the success of the Cancer Drugs Fund.

Other factors are the growth of the enhanced recovery programmes, along with the continued importance of cancer peer review. There has also been a major increase in the use of effective new treatments approved by NICE, as well as reductions in waiting times.

**National Peer Review Report: Brain and CNS Cancer Services Report 2012/13**

Highlights examples of good practice to include:

- Radiotherapy techniques to ensure all patients receiving radical radiotherapy are planned using conformal techniques with image fusion using MRIs
- Use of treatment techniques including: awake craniotomies; motor cortical mapping and good recruitment into clinical trials
- Chemo-radiation toxicity and outcome audit demonstrating an overall survival rate comparable to published trials with low toxicity from treatment
- Dedicated palliative care support aligned to the brain service
- Building and opening of first dedicated inpatient unit for patients with brain tumours
- Establishment of a Vocational Rehabilitation Service for patients with brain tumours
- Expanding the remit of the Brain Tumour Unit office by offering patients direct telephone access to a CNS to triaging of symptoms, advice on medications and signposting to community services
- Introduction of a pre-operative assessment clinic to manage the patients and carers expectations in their care pathways and allows everyone in the team to meet the patient and start their care plan. This means that, particularly in relation to AHP support, the team can start to discuss patients’ needs with local services to ensure this is available in a timely way. This aids discharge and reduces length of stay as well as helping to avoid unnecessary/inappropriate admission to a neurosurgical bed.

**Ensuring better treatment**

**Waiting times**

Currently, all patients referred with suspected cancer by their GP have a maximum wait of two weeks to see a specialist. This also applies to all patients referred for investigation of breast symptoms, even if cancer is not initially suspected. Cancer patients should wait no more than 31 days from the decision to treat to the start of their first treatment. It is also expected that any subsequent surgical, drug or radiotherapy treatments will be delivered within 31 days. All patients should wait a maximum of 62 days from their urgent GP referral to the start of their treatment. This 62-day standard also includes all patients referred from NHS cancer screening programmes (breast, cervical and bowel) and all patients whose consultants suspect they may have cancer.
### 14.0 Action Plan for Macmillan Brain Tumour & CNS Cancer Programme

<table>
<thead>
<tr>
<th>Identified Needs/Concerns</th>
<th>Potential Solutions and Opportunities</th>
<th>Further Actions/ Options/ Thoughts etc…</th>
</tr>
</thead>
</table>
| **1 Early Diagnosis**     | **1.1 Training and Education for Primary Care** | ![To be informed by patient experience.](image)
<pre><code>                    | ✓ Link with cancer lead and Macmillan GP facilitators to champion Brain and CNS Early Diagnosis. | ![Benchmark current performance against regional and national performance. If there are differences – determine the nature, scope and impact of these differences and action plan accordingly.](image) |
</code></pre>
<p>|                           | ✓ Provide easily accessible information and data which verifies benefit from earlier awareness and diagnosis of Brain and CNS Cancers. | |
|                           | ✓ Design and provide an ‘education’ package including: | |
|                           | ✓ Referral protocol | |
|                           | ✓ Symptoms, features and multiplicity | |
|                           | ✓ Local referral routes | |
|                           | ✓ Patient experience/ feedback | |
|                           | ✓ Management of repeated visits. | |</p>
<table>
<thead>
<tr>
<th>Identified Needs/Concerns</th>
<th>Potential Solutions and Opportunities</th>
<th>Further Actions/ Options/ Thoughts etc…</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Early Diagnosis</strong></td>
<td><strong>1.1 Access to Diagnostics</strong></td>
<td>🌐 Consider the development of access to local diagnostic/ follow up services e.g. scans.</td>
</tr>
<tr>
<td></td>
<td>✓ Provide additional support to North Yorkshire and Humber wide Cancer Network to determine gap between demand and capacity for diagnostics,</td>
<td>🌐 Should MRIs be accessible by primary care and if so, under what circumstances. Are there any commissioning implications? Has this initiative been taken forward elsewhere?</td>
</tr>
<tr>
<td></td>
<td>✓ Work with commissioners and providers to improve access to MRI.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Foreshorten pathway between diagnostic and receiving diagnostic report.</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>1.2 Macmillan Cancer Decision Toolkit</strong></td>
<td>🌐 What are the plans, if any, for continued support of NSSG’s on a sub-regional basis?</td>
</tr>
<tr>
<td></td>
<td>✓ Develop and support Brain and CNS NSSG.</td>
<td>🌐 Would support for the Brain and CNS NSSGs set a precedent for either commissioners or providers which could not be realised?</td>
</tr>
<tr>
<td></td>
<td>✓ To develop agreement and joint working with GP’s, Consultants, CNS’s, diagnostic teams, service managers to agree to use guidelines, knowledge and diagnostic tools for cancer (NICE &amp; MCS and others) and develop and agree tests/ideas to improve diagnosis with clinicians.</td>
<td>🌐 Review outcomes for most recent peer review of this service. What the timescales for next internal/ external peer review?</td>
</tr>
<tr>
<td></td>
<td>✓ Design, develop adopt and promote the Macmillan Cancer Decision Toolkit.</td>
<td></td>
</tr>
</tbody>
</table>

**Early Diagnosis**

Improved access to diagnostics will:

- Reduce the period of uncertainty for clinician, patient and carer.
- Assist in the delivery of Cancer Waiting Time targets.

**Ensuring clinically appropriate referrals from primary to secondary care will:**

- Ensure patients are on the correct clinical pathways at the earliest possible opportunity.
<table>
<thead>
<tr>
<th>Identified Needs/Concerns</th>
<th>Potential Solutions and Opportunities</th>
<th>Further Actions/ Options/ Thoughts etc…</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2 Treatment</strong></td>
<td><strong>2.1 Improved access to neuropsychological assessments.</strong>&lt;br&gt; ✓ Audit level of compliance of compliance.&lt;br&gt; ✓ Review clinical pathway as appropriate.&lt;br&gt; ✓ Identify service/pathway gaps.&lt;br&gt; ✓ Seek commissioner and provider approval and actions to remove gaps.</td>
<td><img src="image" alt="How does this link to the rehabilitation programmes for individual patients? For example, how do the outcomes of the pre-treatment neuropsychological assessment feed into the rehabilitation prescription?" /></td>
</tr>
<tr>
<td>Improved access to pre-treatment neuropsychological assessment will:</td>
<td>✓ Assist in assessing the impact of treatment on the patient and therefore any rehabilitation requirements thereafter.</td>
<td><img src="image" alt="What other factors/referrals are influencing demand for neurology clinics?" /></td>
</tr>
<tr>
<td><strong>2 Treatment</strong></td>
<td><strong>2.2 Improved access to neurological services in primary and secondary care.</strong>&lt;br&gt; ✓ Monitor waiting times for patients into neurology services (York/Scarborough, Hull, Grimsby/Scunthorpe).&lt;br&gt; ✓ If appropriate, redesign and implement clinical pathways to reduce waiting time for patients (those on Cancer Waiting Time pathway and others).</td>
<td><img src="image" alt="Should a revised pathway (if considered) result in increased or decreased demand for these clinics." /> <img src="image" alt="Acknowledge the tension between early awareness treatments (access to diagnostics) versus improved access to neurology clinics." /></td>
</tr>
<tr>
<td>Improved access to secondary/tertiary clinics (e.g. neurology) will:</td>
<td>✓ Reduce the period of clinical and patient uncertainty.&lt;br&gt; ✓ Assist in achieving cancer waiting time targets.</td>
<td><img src="image" alt="What other factors/referrals are influencing demand for neurology clinics?" /> <img src="image" alt="Should a revised pathway (if considered) result in increased or decreased demand for these clinics." /> <img src="image" alt="Acknowledge the tension between early awareness treatments (access to diagnostics) versus improved access to neurology clinics." /></td>
</tr>
<tr>
<td>Identified Needs/Concerns</td>
<td>Potential Solutions and Opportunities</td>
<td>Further Actions/ Options/ Thoughts etc…</td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------------------------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td><strong>2 Treatment</strong></td>
<td><strong>2.3 Holistic Needs Assessment</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Undertake audit of sample of Holistic Needs Assessments.</td>
<td>Are the outcomes of Holistic Needs Assessments for Brain and CNS patients significantly different from those of other cancer patients – if so, how?</td>
</tr>
<tr>
<td></td>
<td>✓ Map services (statutory and voluntary sector) indicated by audit.</td>
<td>Are there generic outcomes of Holistic Needs Assessments of cancer patients which are being addressed in other work programmes (non-Brain and CNS).</td>
</tr>
<tr>
<td></td>
<td>✓ Consider access to these services (capacity/ accessibility/ appropriateness).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Confirm outcomes and potential way forward with PPI.</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>2.4 Patients as ‘outliers’ in secondary/ tertiary care.</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Determine the ‘size’ of the issue.</td>
<td>Are there any differences in patient experiences across the sub-region? For example, do patients experience different quality of services or access to different services depending on whether the patient is the responsibility of a different CCG?</td>
</tr>
<tr>
<td></td>
<td>✓ Determine the ‘impact’ of the issue.</td>
<td>If so, can these differences be evidenced?</td>
</tr>
<tr>
<td></td>
<td>✓ Tailor education, training and support packages for non-Brain and CNS staff (may need to do this across a number of cancer sites?).</td>
<td>If so, action plan accordingly.</td>
</tr>
<tr>
<td></td>
<td>✓ Consider any overlap with the model utilised by stroke services.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Access to Holistic Needs Assessment and services arising as a result of the Holistic Needs Assessment will:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Improve patient outcomes.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Improve quality of rehabilitation services.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Address patient needs.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Assist in the planning and development of services which address the generic and specialist needs of Brain and CNS patients.</td>
<td></td>
</tr>
<tr>
<td><strong>2 Treatment</strong></td>
<td><strong>Holistic Needs Assessment</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Undertake audit of sample of Holistic Needs Assessments.</td>
<td>Are the outcomes of Holistic Needs Assessments for Brain and CNS patients significantly different from those of other cancer patients – if so, how?</td>
</tr>
<tr>
<td></td>
<td>✓ Map services (statutory and voluntary sector) indicated by audit.</td>
<td>Are there generic outcomes of Holistic Needs Assessments of cancer patients which are being addressed in other work programmes (non-Brain and CNS).</td>
</tr>
<tr>
<td></td>
<td>✓ Consider access to these services (capacity/ accessibility/ appropriateness).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Confirm outcomes and potential way forward with PPI.</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Holistic Needs Assessment</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Undertake audit of sample of Holistic Needs Assessments.</td>
<td>Are the outcomes of Holistic Needs Assessments for Brain and CNS patients significantly different from those of other cancer patients – if so, how?</td>
</tr>
<tr>
<td></td>
<td>✓ Map services (statutory and voluntary sector) indicated by audit.</td>
<td>Are there generic outcomes of Holistic Needs Assessments of cancer patients which are being addressed in other work programmes (non-Brain and CNS).</td>
</tr>
<tr>
<td></td>
<td>✓ Consider access to these services (capacity/ accessibility/ appropriateness).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Confirm outcomes and potential way forward with PPI.</td>
<td></td>
</tr>
<tr>
<td>Identified Needs/Concerns</td>
<td>Potential Solutions and Opportunities</td>
<td>Further Actions/ Options/ Thoughts etc…</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>2 Treatment</td>
<td>2.5 Access to Critical Care Capacity</td>
<td>Link with sub regional Critical Care Co-ordinator</td>
</tr>
<tr>
<td>Ensuring Brain and CNS patients have access to critical care services as appropriate.</td>
<td>✓ Determine the ‘size’ of the issue. ✓ Determine the ‘impact’ of the issue.</td>
<td></td>
</tr>
<tr>
<td>2 Treatment</td>
<td>2.6 Care Co-ordination to manage patient pathways.</td>
<td>How does this role overlap with that of the specialist CNS?</td>
</tr>
<tr>
<td>2 Treatment</td>
<td>2.7 Development of Nurse Lead Clinics.</td>
<td>Would different tariff arrangements need to be discussed with NHS England/ Specialist Services? (See section 5.3).</td>
</tr>
<tr>
<td>Access to different models of secondary/ tertiary service provision – development of nurse led clinics.</td>
<td>✓ Horizons scan for best practice re nurse lead clinics generally (oncology) or Brain and CNS specifically. ✓ Undertake and cost and benefit analysis of the potential for this role of service provision. ✓ Dependent on outcome of cost benefit analysis and commissioner/ provider priority – implement role.</td>
<td></td>
</tr>
<tr>
<td>Identified Needs/Concerns</td>
<td>Potential Solutions and Opportunities</td>
<td>Further Actions/ Options/ Thoughts etc…</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------------------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td>2. Treatment</td>
<td>2.8 Improve the experience of patients who are not on active treatment</td>
<td>Which patients would be considered as ‘not being on active treatment’? For example, would this include all living with and beyond cancer and EoL/Palliative patients? If so, then need to consider overlap with sections 3 and 4.</td>
</tr>
<tr>
<td></td>
<td>✓ Map the pathways and experiences of patients who are not on active treatment.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Determine service gaps.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Action plan as appropriate.</td>
<td></td>
</tr>
<tr>
<td>2. Treatment</td>
<td>2.9 Development of community based CNS role.</td>
<td>Potential overlap with other community based clinical roles.</td>
</tr>
<tr>
<td></td>
<td>✓ Horizon scan for best practice re community based CNS.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Undertake and cost and benefit analysis of the potential for this role of service provision.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Dependent on outcome of cost benefit analysis and commissioner/provider priority – implement role.</td>
<td></td>
</tr>
<tr>
<td>Identified Needs/Concerns</td>
<td>Potential Solutions and Opportunities</td>
<td>Further Actions/ Options/ Thoughts etc…</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------------------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td>2. Treatment</td>
<td>2.10 Putting patients at the centre of care.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Assess current methods/ processes for putting patients at the centre of their care.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Assess where these methods/ processes fall short of patient expectations/ requirements. Action plan accordingly.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Development of hand held records (electronic or otherwise).</td>
<td></td>
</tr>
<tr>
<td>2 Treatment</td>
<td>2.11 Support for Brain and CNS NSSG</td>
<td></td>
</tr>
<tr>
<td>Provision of a Network Site Specific Group for Brain and CNS Cancer</td>
<td>✓ To provide the resource over the lifetime of the project to support the Brain and CNS NSSG for Humber sub region.</td>
<td>Potential to consider the advantages (or not) of supported NSSGs vs non-supported NSSGs.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Potential to set a precedent for an NSSG which could not be realised in the long term.</td>
</tr>
<tr>
<td>3 Palliative/ End of Life</td>
<td>3.1 Palliative/ End of Life Services.</td>
<td></td>
</tr>
<tr>
<td>Access to palliative care services (including beds) will improve the quality of palliative/ End of Life pathway for Brain and CNS patients.</td>
<td>✓ Undertake appropriate ‘commissioning cycle’ activities to assess whether improved access to palliative/ end of life services are required.</td>
<td>Need to link into local plans/ service developments regarding EoL and palliative care pathways.</td>
</tr>
<tr>
<td></td>
<td>✓ Undertake best practice/ horizon scanning activities to support the development of optimum service provision given the survival rates of Brain and CNS patients.</td>
<td>Are there any issues which are specific to Brain and CNS cancer patients which need to be addressed? If so, do we have the necessary evidence to support the development of these issues?</td>
</tr>
<tr>
<td>Identified Needs/Concerns</td>
<td>Potential Solutions and Opportunities</td>
<td>Further Actions/ Options/ Thoughts etc…</td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------------------------------------</td>
<td>------------------------------------------</td>
</tr>
</tbody>
</table>
| **4 Rehabilitation and living with and beyond cancer**  
All AHP who come into contact with Brain and CNS Cancer patients are aware of the specialist requirements of this cohort (e.g. reading skills, difficulty in concentrating for prolonged periods, recall etc.) | **4.1 AHP Input at sites other than the specialist/ tertiary centre**  
- Design and implement a ‘rolling package’ of education and ongoing support.  
- Design package to support the interface between specialist and generic rehabilitation services. | Education of generalists with regular meetings/ forums. |
<table>
<thead>
<tr>
<th>Identified Needs/Concerns</th>
<th>Potential Solutions and Opportunities</th>
<th>Further Actions/ Options/ Thoughts etc…</th>
</tr>
</thead>
</table>
| 4 Rehabilitation and survivorship | **4.2 Access to rehabilitation services**  
Provision of equitable access to specialist and generic rehabilitation services which meet the needs of Brain and CNS Cancer patients. | 😡 Disease overlap could include major trauma, stroke/ cardiovascular. |
|                          | ✓ Locality by locality, map access to generic and specialist rehabilitation services and pathways (commencing with ERY and NLincs?).  
✓ Research rehabilitation requirements of other disease areas in these localities and status of these work streams/ projects.  
✓ Determine areas of overlap and action plan accordingly.  
✓ Determine areas which are specific to Brain and CNS cancers and action plan accordingly.  
✓ Consider design and implementation of quality standards for rehabilitation services. | |
<table>
<thead>
<tr>
<th>Identified Needs/Concerns</th>
<th>Potential Solutions and Opportunities</th>
<th>Further Actions/ Options/ Thoughts etc…</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>5 Cross Cutting Theme: Share Learning</strong></td>
<td><strong>5.2 Address common themes/ issues in sub regional clinical networks which traverse DGH and Hub services.</strong></td>
<td></td>
</tr>
</tbody>
</table>
| Supporting shared learning across sub regional clinical networks for clinical pathways which traverse services provided in district general hospitals and specialist centres/ hubs. | ✓ Identification of services which may be of interest.  
✓ Research past/ current development work in these areas.  
✓ Consider potential benefit to Brain and CNS patients in supporting these pathways.  
✓ Action plan accordingly. | |
| **5 Cross Cutting Theme: Commissioning** | **5.3 Identifying/ securing commissioning responsibilities.** | |
| To determine respective commissioning responsibilities of local and national commissioners regarding care and treatment pathways of Brain and CNS patients – including funding mechanisms (e.g. block, tariff etc.). | ✓ Research how Brain and CNS activity is funded and aligned to commissioning responsibilities.  
✓ Explore if changes to these funding mechanism could have a positive influence on the care and treatment pathways of Brain and CNS patients. | |
<table>
<thead>
<tr>
<th>Identified Needs/Concerns</th>
<th>Potential Solutions and Opportunities</th>
<th>Further Actions/ Options/ Thoughts etc…</th>
</tr>
</thead>
</table>
| **5 Cross Cutting Theme: Information and advice**<br>Access to information and advice for patients and carers which give access to appropriate providers of support. | **5.4 Resource for Patients and Carers**<br> ✓ Develop a resource for information and advice, for patients and carers and designed by patients and carers to 'tap into' available services. | - Potential use of ‘Cloud’ – NHS or otherwise.  
- Different types of information/information packs may be required dependent on the patient position on the pathway (e.g. requirements of a newly diagnosed patient may be different from those of a patient who has received treatment and is receiving a range of rehabilitation services.)  
- Increased access to respite care for carers? (Probably a generic carer issue.)  
- Development of web based services for patients. |
| **5 Cross Cutting Theme: Communication**<br>Development of communication pathways | **5.5 Development of communication pathways**<br> ✓ Map communication pathways.  
 ✓ Identify those communication links which require redress.  
 ✓ Action plan accordingly. |  |
<table>
<thead>
<tr>
<th>Identified Needs/Concerns</th>
<th>Potential Solutions and Opportunities</th>
<th>Further Actions/ Options/ Thoughts etc…</th>
</tr>
</thead>
</table>
| 5 Cross Cutting Theme: Information Technology | 5.6 Information Technology | - Videoconferencing facilities for MDT and MRI results reporting.  
- Specialist information on the internet (e.g. neuro-oncology page).  
- NHS Cloud which patients can also access.  
- Improved access to System One.  
- Shared records.  
- Skype.  
- Airedale telemedicine model.  
- Patient website.  
- Texting as a tool for communication with patients. |

Information technology
<table>
<thead>
<tr>
<th>Identified Needs/Concerns</th>
<th>Potential Solutions and Opportunities</th>
<th>Further Actions/ Options/ Thoughts etc…</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 Cross Cutting Theme: Carers</td>
<td>5.7 Access to support services for carers</td>
<td></td>
</tr>
<tr>
<td>Carers of patients who have Brain and CNS Cancer are supported in to both deliver appropriate care and are supported to live a ‘normal’ life.</td>
<td>✓ Design and implement a package of information for Carers of patients with Brain and CNS cancers.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Map existing carers support services.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Ensure staff who come into contact with carers are aware of and can provide information to carers.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✓ Service design which proactively seeks to identify and support carers.</td>
<td></td>
</tr>
<tr>
<td>6 Area for further discussion/ exploration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single point of 24/7 access to information/ advice and support.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identified Needs/Concerns</td>
<td>Potential Solutions and Opportunities</td>
<td>Further Actions/ Options/ Thoughts etc…</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td><strong>6 Area for further discussion/ exploration</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Develop system within MDT for the patient to be ‘at the centre’ within the MDT with full support services through to GP &amp; MDT and back to patient</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix A: North East Yorkshire and Humber Clinical Alliance Clinical Expert Group Primary Care Guidelines (June 2012)

1. Referral Protocol: Brain Tumour

- **Symptom Complex**
  - Features suspicious of malignancy
    - Patients with headache, vomiting & papilloedema
      - New onset seizures characterised by one or more of the following:
        - Focal Seizures
        - Significant post-ictal focal deficit (excluding confusion)
        - Epilepsy presenting as status epilepticus
        - Associated inter-ictal focal deficit
        - Associated preceding persistent headache of recent onset
        - Seizure frequency accelerating over weeks or months

- **Headache**

- **Seizures**

- **Focal Neurological Deficit**
  - Sub acute progressive neurological deficit in the absence of previously diagnosed or suspected alternative disorders (e.g. multiple sclerosis)

- **Mental Health Changes**
  - Unexplained cognitive or behavioural changes

- **Acute Neurological Presentation**
  - Local Acute Trust
  - Local Imaging shows tumour

- **Referral route**
  - 2 week wait referral to Neurological Call centre.
    - Fax 01482 675505
    - Contact nMDT / cMDT Coordinator

  - Routine appointment in Neurology Clinic by CAB system. Letter to call centre

  - Neurological Registrar on call

- **If appropriate referral route is not clear please contact Neurologist on call to discuss**
## Appendix B: Current Macmillan Initiatives taking place

<table>
<thead>
<tr>
<th>Care Pathway</th>
<th>Current Macmillan Initiatives taking place</th>
</tr>
</thead>
</table>
| ACE Programme        | England lags behind comparable European countries when it comes to cancer outcomes including 1 and 5 year survival rates, and late diagnosis is one factor for poorer outcomes. Improving early diagnosis therefore has the potential to drastically improve cancer outcomes. The ACE Programme:  
  - **Accelerates** progress  
  - **Coordinates** implementation  
  - Consistently evaluates best practice and innovative approaches to early diagnosis of cancer.  
  It is an NHS England led Programme, which is supported by Cancer Research UK and Macmillan Cancer Support. It seeks to develop the knowledge base on early diagnosis in order to identify and evaluate good practice, which can reduce system delays and improve early diagnosis of cancer.  
  There was a call for projects in July 2014 and many NHS organisations across England submitted applications to have their projects included in the ACE Programme. In total 89 expressions of interest (EOIs) were received and 60 projects were accepted into the ACE Programme. |
| Electronic Cancer Decision Support (CDS) Tool | In 2013 Macmillan worked collaboratively with BMJ Informatica to develop and pilot an electronic cancer decision support (CDS) tool. The project aimed to help support GPs in their clinical decision making when referring for suspected cancer.  
  We tested the CDS tool with over 550 GP Practices across the UK to ascertain its usefulness and appropriateness to incorporate within a standard 10 minute GP consultation. The aim being to raise awareness of cancer risk among GPs and to get them to ‘think cancer’ whilst helping support their decision making in ‘low risk but not no risk’ consultation cases.  
  Using the tool and ultimately to diagnose cancer at an earlier stage  
  The risk calculated by the tool was different from the GP’s perceived level of risk 46% of the time  
  A fifth of all patients for whom we have evaluation data were referred for suspected cancer; nearly a quarter (23%) were intended for investigation; no action was taken for 47%  
  Of patients who were referred or intended for investigation, GP’s reported that in around 20% of these cases they would have taken no action without the software  
  The tools were welcomed by the majority of participants because they raised awareness of cancer symptoms and both |
reminded and altered GP’s to ‘think cancer’
The tool was useful in group practices where different GPs will see the patient
There were challenges in promoting and measuring usage of the software
Report CRUK executive summary of evaluation can be seen on their website
http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/EarlyDiagnosis/CDSExecSummary.pdf

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Macmillan one to one pilot – Forth Valley NHS Trust</th>
</tr>
</thead>
</table>
| Holistic Needs Assessment
Psychologists spent time with CNS and team members to upskill and teach them the assessment.
Offered to all patients – 53% took it up.
  - Patients complete “concerns checklist”
  - Care plan
  - MIDAS (electronic nursing record)
Carried out at first visit and at point of discharge. |

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Carers Support Programme</th>
</tr>
</thead>
</table>
| Support-line 9am-8pm Freephone 0808 8080000
Online community
Booklets specifically for carers
Macmillan LearnZone – Online and face to face training available – Information Centres can provide further details
Volunteering scheme – Volunteers provide support to carers on a range of areas.
Local authorities should all have a carer support service.
Currently around 1.1 million cancer carers in the UK – visit www.macmillan.org.uk/morethanamillion for more information |

<table>
<thead>
<tr>
<th>Living with and Beyond Cancer</th>
<th>Direct Services in your toolkit</th>
</tr>
</thead>
</table>
| Macmillan support line
  - free helpline
  - information and emotional support
  - clinical information
  - welfare rights and benefits
  - financial guidance
  - Translator available
Cancer information provided by specialist nurses based in Glasgow.
Welfare Rights information based in Shipley – can provide help completing forms – can even complete forms on |
behalf of patient.
Financial Guidance Team – Not able to give advice at regulatory level but are trained to that level.

Case study:
Worked with a mother of a child with cancer to produce a certificate for his sister for being so patient and supportive in partnership with creative branding team.
They also work in partnership with fuel companies, particularly npower to write off fuel debts.
Provide grants to people affected by cancer.

Macmillan support website:
- Can order booklets and leaflets about cancer information.
- 150 different booklets available
- Available in different formats and languages
- Accredited information
- written by experts

Online Community – message boards for all types of people affected by cancer. Macmillan mobile units – big green buses – 4 in country – set up at various places within a community setting.

The role of a cancer “team” in supporting people “living with the impact of cancer” – Velindre NHS Trust

Redesigned the care pathway.
- Working with people, not doing things for people – empowering patients in their own care pathway.
- Facilitating choice and control.
- Proactive from 1st conversation about patient choice e.g. activity and communication
- Preventative – financial
- Identify difficulties early/early intervention e.g. if suffering with fatigue sleep doesn’t help – education.
- Recognise patient’s existing coping strategies and resources – friends, family etc.
- Develop new coping strategies e.g. signpost to support groups and third sector providers. services
The role of a cancer “team” in supporting people “living with the impact of cancer” – Velindre NHS Trust

- 60% of people cope well with self-care
- 25% of people require targeted services
- 10-15% require complex case management
Everyone’s Death Should Matter to Someone – NHS Forth Valley

- Bereavement care is everyone’s responsibility – every department, not just bereavement services/palliative care – learning & development should be available to all
- Patient property bags introduced
- After death checklist
- Collaborative working – multi-agency
- Hand print of person dying given to children
- Partnership with Cruze Bereavement Care and Macmillan – Bereavement volunteers.
- Projects successful due to the Macmillan brand name – make the most of this!
- Bereavement care standards published May 2014 – all trusts should be working towards these. (Available to download On Macmillan Professionals website)