



Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Services

Brain and CNS Cancer Clinical Advisory Group (CAG)

Constitution

2025





VERSION CONTROL

THIS IS A CONTROLLED DOCUMENT. PLEASE DESTROY ALL PREVIOUS VERSIONS ON RECEIPT OF A NEW VERSION.

Please check the SWAG website for the latest version available <u>here</u>.

VERSION	DATE ISSUED	SUMMARY OF CHANGE	OWNER'S NAME
Draft 0.1	April 2016	First draft	V lyer / H
			Dunderdale
Draft 0.2	February 2017	Addition of	H Dunderdale
		Meningioma Pathway	
Draft 0.3	April 2017	Minor amendments	C Price, A Belisario, C
		and addition of	Fitzavon
		Glossary of Terms	
1.0	June 2017	Finalised	SWAG Brain & CNS
			CAG
1.1	April 2019	Rebranding from Site	H Dunderdale
		Specific to Clinical	
		Advisory Group	
1.2	28 th June 2019	Finalised	H Dunderdale
1.3	June 2022	Biennial update	H Dunderdale
1.4	April 2025	Biennial update	A Curry

This constitution was prepared by:

Venkat Iyer, Chair of the SWAG Brain and CNS CAG, Consultant Neuro Surgeon, North Bristol Trust

Helen Dunderdale, SWAG Cancer Clinical Advisory Group Manager

Anna Curry, SWAG Cancer Clinical Advisory Group Administrator



Brain and CNS CAG Constitution Contents

Section	Contents	Measures	Page
1	Statement of Purpose		5
2	Structure and Function		6
2.1		14.10.1011	
2.1	Network Configuration of the Brain and CNS MDTs	14-1C-101k	6
2.2	Configuration of Multi-	14-1C-102k	7
2.2	Disciplinary Clinics	14-1C-102K	,
3	Disciplinary clinics		8
3	The Network Group		8
3.1		14-1C-103k	8
	Network Group Membership		
3.2	Network Group Meetings	14-1C-104k	9
3.3	Work Programme and Annual	14-1C-105k	10
	Report		
3.4	Network Neuro-rehabilitation	14-1C-106k	10
	Lead		
4	Coordination of Care / Patient		10
	Pathways		
4.1	Clinical Guidelines	14-1C-107k	10
4.2	Chemotherapy Treatment	14-1C-108k	10
	Algorithms		
4.3	Treatment Pathways		10
4.4	Patient Pathway for Primary	14-1C-109 / 112k	11
	Brain, Spinal Cord and Other		
	Rare CNS Tumours		
4.5	Cerebral Metastases		12
4.6	Patient Pathway for Pituitary	14-1C-110k	13
	Tumours		
4.7	Patient Pathway for Skull Base	14-1C-111k	13
	Tumours		
4.8	Follow up pathway		13
4.9	Network Communication	14-1C-113k	13
	Framework		
4.10	Protocol for Emergency Surgical	14-1C-114k	14
	Interventions		
4.11	Operational Policy for Neuro-	14-1C-115k	15
	Rehabilitation		



	T	1	
4.12	Patient Pathways for Teenagers		15
	and Young Adults		
4.13	Cancer of Unknown Primary		15
	(CUP)Referrals		
5	Patient and Public Involvement		15
5.1	User Representative Input		15
5.2	Patient Experience	14-1C-116k	15
5.3	Charity Involvement	11101101	16
6	chartey involvement		16
	The National Personalised Care		
	and Support Initiative		
7			16
	Clinical Governance		
7.1	Clinical Outcomes / Indicators	14-1C-117k	16
	and Audits		
7.2	Data collection		16
8	Clinical Research		16
8.1	Discussion of Clinical Trials	14-1C-118k	16
9	Discussion of chinear trials	14 1C 110K	17
	Service Development		17
9.1	Enhanced Recovery Programme		17
9.2	Educational Opportunities		17
9.3	Sharing Best Practice		17
9.4	Awareness Campaigns		18
10			18
	Funding		
10.1	Clinical Commissioning Groups		18
10.2	Industry		18
11	A		19
11.1	Appendices		10
	Appendix 1 - Template Agenda		19
11.2	Appendix 2 - SWAG User Involvement Brief		21
11.3	Appendix 3 - SWAG Charity		21
11.5	Involvement Brief		
11.4	Appendix 4 - Pathway for the		22
11.4	Management of Malignant		
	Primary Brain Tumours in Adults		
11.5	Appendix 5 - Clinical Protocol for		23
11.5	the Management of Brain		25
	Tumours		
11.6	Appendix 6 - Referral and		24
	Management Pathway for Low		
L			





	Grade Intrinsic Brain Tumours in Adults	
11.7	Appendix 7 – Meningioma	25
	Pathway	
11.8	Glossary of Terms	26

1. Statement of Purpose

The Somerset, Wiltshire, Avon and Gloucestershire Cancer Network Brain and CNS Clinical Advisory Group (CAG) endeavours to deliver equity of access to the best medical practice for our patient population. The essential priorities of the CAG are to provide a service that is safe, high quality, efficient and promotes positive patient experiences.

To ensure that this statement of purpose is actively supported, the consensually agreed constitution will demonstrate the following:

- The structure and function of the service is conducted, wherever possible, in accordance with the most up to date recommended best practice, as specified in the Manual of Cancer Services, Brain and CNS Measures¹
- An CAG consisting of multidisciplinary professionals from across the Somerset,
 Wiltshire, Avon and Gloucestershire cancer services has been established and meets
 on a regular basis
- Network wide systems and care pathways for providing coordinated care to individual patients are in place. This includes the process by which network groups link to individual MDTs
- A process for ensuring that the CAG clinical decision making is in accordance with the most up to date NICE Quality Standards² (December 2014) is in place, as are local clinical guidelines that support the standards

¹ Manual for Cancer Services

² NICE Quality Standards





- There is a process by which patient and carers can evaluate and influence service improvements that supports the principle 'No decision about me without me'³
- Internal and externally driven routine risk related clinical governance processes are in place for evaluating services across the network, and identifying priorities for improvement
- The CAG has a coordinated approach to ensure that, wherever possible, clinical research trials are accessible to all eligible cancer patients
- Examples of best practice are sought out and brought to the CAG to inform service development
- Educational opportunities that consolidate current practice and introduce the most up to date practices are offered whenever resources allow
- Provision of advice to influence the funding decisions of the Cancer Alliance Board.

2. STRUCTURE AND FUNCTION

2.1 Network Configuration of the Brain and CNS MDTs (measure 14-1C-101k)

The Multi-Disciplinary Teams (MDTs) within the Brain and CNS CAG consist of consultant surgeons, clinical and medical oncologists, pathologists, imaging specialists and other health care professionals. They meet regularly to discuss and manage each individual patient's care.

All of the Trusts within the SWAG region, with the exception of Weston Area Health Trust, provide local and diagnostic Brain and CNS Cancer Services for a population of approximately 3 million adults and 5 million children.

All patients diagnosed with Brain and CNS cancer are referred to the Bristol Neuro-Oncology Group (BNOG) MDT based in Southmead Hospital, North Bristol NHS Trust.

Table 1 shows the CAG agreed list of MDTs, with their host hospital and Trusts.

-

³ Improving Outcomes: A Strategy for Cancer





Table 1

Name of MDT and Host Organisation	Type of MDT	Tumour type	Date and time of MDT	Contact details
Bristol Neuro- Oncology Group, North Bristol NHS Trust	Combined Neuroscience MDT and rehabilitation and non- surgical MDT	Brain and other rare CNS tumours, Spinal cord tumours	Wednesday, 9am	https://www.nbt.nhs. uk/bnog/about- bnog/contact-bnog
Bristol Neuro- Oncology Group, North Bristol NHS Trust	Combined Neuroscience MDT and rehabilitation and non- surgical MDT	Pituitary tumours, Acoustic Neuromas, Skull Base tumours	1 st , 3 rd and 5 th Thursday of the month at 12pm	https://www.nbt.nhs. uk/bnog/about- bnog/contact-bnog
Gloucestershire Hospitals NHS Foundation Trust	Rehabilitation and non- surgical MDT		Joins the MDT at NBT once a month	

The relationship between BNOG and its associated MDTs complies with the following ground rules for networking:

- The RNS MDT is the only RNS MDT for its catchment area for its tumour group
- The NS MDT is not in competition with another one for the same cancer type and for the same catchment area
- The neuroscience centre hosts an NS MDT for brain and other rare CNS tumours
- The NS MDT is associated with only one Neuro-Oncology Disease Site Group for the tumour groups with which it deals
- The NS MDT dealing with brain and other rare CNS tumours receive over 100 diagnosed cases of intracerebral tumours per annum.

2.2 Configuration of Multi-Disciplinary Clinics (measure 14-1C-102k)

Table 2

Clinic type	Location	Frequency
Brain, Spinal and other	Southmead Hospital,	Fortnightly on a Friday
rare CNS tumours	North Bristol NHS Trust	
Oncology	Bristol Oncology and	Every Monday afternoon
	Haematology Hospital,	
	University Hospitals	
	Bristol NHS Foundation	
	Trust	
Oncology	Royal United Hospital	Every Monday, Thursday,





	Bath NHS Foundation	Friday
	Trust	
Oncology	Gloucestershire Hospitals	Every Wednesday
	NHS Foundation Trust	
Pituitary and Skull Base	North Bristol Trust plus	Fortnightly on Thursday
Tumours	outreach clinics are held	afternoon
	in Bath, Yeovil,	
	Gloucestershire and both	
	Bristol Hospitals	
Neurofibromatosis	Southmead Hospital,	Quarterly
	North Bristol NHS Trust	

3. THE NETWORK GROUP

3.1 Network Group Membership (measure 14-1C-103k)

All participants at MDTs are welcome to attend the CAG meetings.

The SWAG Brain and CNS CAG consists of the following core members:

Table 3.

Trust	Name	Job Title
UHBW	Abby Sullivan	Clinical Nurse Specialist
NBT	Agdaliya Mikhalkova	Senior Clinical Fellow
NBT	Aimun Jamjoom	Neurosurgeon in training
NBT	Aled Daniels	Consultant Neuropathologist
UHBW	Alison Cameron	Consultant Clinical Oncologist
NBT	Amy Belisario	Neuro-rehabilitation AHP Lead
NBT	Angelo Pichierri	Consultant Neurosurgeon
SWAG	Anna Curry	Cancer Clinical Advisory Group Administrator
NBT	Becky Hunt	Consultant Radiologist
NBT	Belinda Coghlan	Neuro-Oncology Clinical Nurse Specialist
NBT	Bernice Hayles	Neuro-rehabilitation AHP Lead
NBT	Charlotte Granville	Neuro-surgery ANP
NBT	Charlotte Moran	Physiotherapist
Somerset FT	Christopher Price	Consultant Neurologist
Glos	Claire Harding	Neuro-Oncology Clinical Nurse Specialist
NBT	Constantinos Charalambides	Consultant Neurosurgeon
NBT	Danielle Kelly	Skull Base Nurse Practitioner



NBT	David Porter	Consultant Neurosurgeon
Somerset FT	Edward Fathers	Consultant Neurologist
NBT	Eleanor Shone	Neuro-Oncologist Clinical Nurse Specialist
YDH	Elena Bevan	Acute Oncology Clinical Nurse Specialsit
NBT	Fionnan Williams	Consultant Radiologist
NBT	Garry Pearce	Neuro-Oncology Cancer Support Worker
UHBW	Geoff Pye	Consultant Surgeon
UHBW	Georgina Casswell	Consultant Oncologist
NBT	George Malcolm	Consultant Neurosurgeon
Glos	Geraint Fuller	Consultant Neurologist
NBT	Harry Giles	Clinical Lead Physiotherapist – Neurosciences
	Hajira Mumtaz	PhD Student
UHBW	Hazel Boyce	Skull Base Radiographer
SWAG	Helen Dunderdale	Cancer Clinical Advisory Group Manager
NBT	Helen Marshall	Occupational Therapist
NBT	Helen Spear	Macmillan Neuro Oncology Speech and Language
		Therapist
NBT	Jane Ryan	Neuro-Oncology Clinical Nurse Specialist
NBT	Jayne Masters	Physiotherapist
Glos	Jessica Bailey	Consultant Oncologist
NBT	Jillian Davis	Consultant Neuropathologist
UHBW	Jodie Simmons	Occupational Therapist
UHBW	Karly Harris	Research Nurse
UHBW	Kate Falconer	Consultant Clinical Oncologist
NBT	Kathreena Kurian	Consultant Neuropathologist
NBT	Kathryn Urankar	Consultant Neuropathologist
NBT	Katarina Fraser	Speech and Language Therapist
NBT	Katrina Russell	Clinical Nurse Specialist
NBT	Kelly Caley	MDT Coordinator
NBT	Kirsty Reeve	Neuro-Oncology Clinical Nurse Specialist
UHBW	Lorna Hawley	Consultant Clinical Oncologist
NBT	Madeleine Farrow	Speech and Language Therapist
NBT	Marcus Bradley	Consultant Radiologist
RUH	Mark Beresford	Consultant Clinical Oncologist
NBT	Molly Cree	Speech and Language Therapist
NBT	Moya Kirmond	Neuro-Oncology Clinical Nurse Specialist
NBT	Neil Barua	Consultant Neurosurgeon
UHBW	Nicki Crew	Assistant Practitioner
RUH	Paul Lyons	Consultant Neurologist
NBT	Paul Smith	Consultant Radiologist
NBT	Rachael Sims	PhD Student





UHBW	Rachel Perrow	Neuro-Oncology Clinical Nurse Specialist
NBT	Raenette David	Specialist Registrar
NBT	Rosie Humphries	Prehabilitation Occupational Therapist
NBT	Rosalind Taylor	Advanced Neurosurgical Nurse Practitioner
Glos	Sam Guglani	Consultant Clinical Oncologist
RUH	Sarah Davis	Epilepsy Clinical Nurse Specialist
YDH	Sarah Levy	Neuro-Oncology Clinical Nurse Specialist
Glos	Sean Elyan	Consultant Clinical Oncologist
Glos	Sharon Nash	Neuro-Oncology Clinical Nurse Specialist
NBT	Shelley Renowden	Consultant Radiologist
UHBW	Sian Flower	Neuro-Oncology Clinical Nurse Specialist
UHBW	Sophie Allen	Research Nurse
UHBW	Suzanne Waldon-Smith	Neuro-Oncology Clinical Nurse Specialist
UHBW	Tania McGreene	Therapy Radiographer
UHBW	Tim Spencer	Consultant Oncologist
RUH	Tracy Langdon	Neuro-Oncology Clinical Nurse Specialist
NBT	Venkat Iyer	Consultant Neurosurgeon
NBT	Zoe Waller	MDT Coordinator
User	Andy Holness	User Representative
User	Carly Beasley	User Representative
User	Shaun Boycott-Taylor	User Representative
User	Anne Boycott-Taylor	User Representative

3.2 SWAG Cancer Services Network Group Meetings (measure 14-1C-104k)

The SWAG CAG will meet twice yearly. Agendas, notes and actions, and attendance records will be uploaded on to the SWAG website here.

Appendix 1 is the Template Agenda for the Brain and CNS CAG meetings, which is circulated prior to each meeting to ensure that all members are aware of who is required to attend and that all subject matters requiring discussion are identified.

Terms of Reference are agreed in accordance with the paper *Recurrent Arrangements for Cancer Alliance Clinical Advisory Groups (2019),* which is available on the SWAG website here.

The CAG meetings are also conducted in line with the Manual for Cancer Services, Brain and CNS Measures (Version 1.1):

http://www.cquins.nhs.uk/?menu=resources





3.3 Work Programme and Annual Report (measure 14-1C-105k)

The SWAG CAG will produce a Work Programme and Annual Report in discussion with the South West Cancer Alliance.

3.4 Network Neuro-rehabilitation Lead (measure 14-1C-106k)

There are named leads for neuro-rehabilitation for the network, who have recognised specialist clinical skills in oncology and neurological rehabilitation. They have specified time and a list of responsibilities for their role that have been agreed by the Chair of the CAG.

4. COORDINATION OF CARE / PATIENT PATHWAYS

4.1 Clinical Guidelines (measure 14-1C-107k)

The CAG refers to NICE guidance *Brain Tumours* (*primary*) and *brain metastases in adults* (*July 2018*). Further details of the local provision of the guidelines are within the Operational Policy produced by North Bristol Trust, which can be found on the SWAG website here. This is reviewed annually to ensure that any amendments to imaging, surgery, pathology, chemotherapy and radiotherapy practices are up to date.

4.2 Chemotherapy Treatment Algorithms (measure 14-1C-108k)

An agreed list of acceptable chemotherapy treatment algorithms is reviewed bi-annually and available to view in the Annual Report and on the SWAG website here.

4.3 Treatment Pathways

Treatment pathways depend on the outcome of the discussion at the neuroscience, skull base or pituitary MDT. All patients are discussed both pre and post-operatively, unless surgery had to be performed as an emergency before MDT discussion was possible (please see emergency surgery policy section). All surgery is performed at North Bristol Trust; radiotherapy and chemotherapy are delivered at University Hospitals Bristol, Royal United Hospitals Bath and Gloucestershire Royal Hospitals.

4.4 Patient Pathway for Primary Brain, Spinal Cord and other Rare CNS Tumours (measure 14-1C-109/112k)

Following discussion at the neuro-oncology MDT, patients with Brain and CNS malignancies may be managed with neuro-surgery, radiotherapy, chemotherapy, best supportive care or active surveillance. In the majority of cases, the treating clinician is present in the neuro-





oncology MDT and prompt arrangements for clinic review are made. In other cases, onward referral to other teams is arranged as detailed below.

Patients may be seen by:

- Neuro-oncology neuro-surgeon if surgery is being offered or active surveillance suggested. Neuro-surgical policy is that patients who are being offered surgery should be seen in clinic within 1 week of MDT discussion and operated on within 2
- Neuro-oncologist if the patient has already undergone surgery and further treatment with radiotherapy and / or chemotherapy is being recommended, or where patients are not felt to be surgical candidates but there are oncological management options e.g. palliative radiotherapy
- Local Palliative Care Specialist Team if patient is not well enough to come to clinic or
 is not a candidate for active treatment. It is recommended that best supportive care
 is delivered via the local teams. Referral to local palliative care is made by telephone
 by one of the MDT clinical nurse specialists or by a member of the palliative care
 team who was present at the MDT discussion. The formal neuro-oncology MDT
 minutes are also forwarded, and the neuro-oncology team remain available for
 ongoing telephone advice
- Lymphoma MDT if diagnosis of primary CNS lymphoma has been histologically confirmed, patients will be nominated for discussion at the Lymphoma MDT, details of which will be forwarded to the Lymphoma team with additional personal communication by one of the neuro-oncologists. Patients who are potentially suitable for intensive chemotherapy or clinical trial entry will be seen in the Lymphoma patient clinic; patients not well enough for chemotherapy will be seen in the neuro-oncology clinic by the neuro-oncology team to discuss radiotherapy or palliative care. Patients are managed in line with the national CNS Lymphoma Management Guidelines.

All new primary brain and spinal tumours patients are nominated for discussion at the Network MDT by the core members of that MDT who attend both meetings e.g. the CNSs or AHPs.

Cases are re-discussed in the neuro-science MDT and Network MDT at key points in their patient journey e.g. at relapse or if symptoms change. They are nominated for re-discussion by their treating clinician, keyworker or Allied Health Professional.





4.5 Cerebral Metastases

There are 3 subgroups of brain metastases patients for whom referral to the neuroscience MDT is appropriate:

1) Good prognosis patients who may benefit from surgical resection or stereotactic radiosurgery.

This group is defined as:

- Patients with solitary or less than 4 cerebral metastases, all measuring < 4cm
- AND who are of good performance status (KP > 70) i.e. independent and self-caring
- AND who have systemically controlled disease.
- 2) Patients with hydrocephalus or critically raised intracranial pressure, particularly from an obstructing cerebellar tumour
- 3) Patients with cancer of unknown primary site with no disease elsewhere in the body where neuro-surgical biopsy should be considered to obtain a histological diagnosis. All patients with brain metastases are managed in close collaboration with their treating site-specialised oncologists.

A stereotactic radiosurgery service has been available in the BHOC since October 2013. There are 4 possible outcomes for patients referred to the MDT for indication 1) above (< 4 small metastases in fit patients with systemically controlled cancer:

- 1) Suitable for neuro-surgical intervention: patients will be seen by a neuro-oncology neuro-surgeon
- 2) Suitable for stereotactic radiosurgery (SRS): Patients will be seen in the specialist SRS clinic at the BHOC by a neuro-oncologist
- 3) Suitable for either SRS or surgery: Patients will be seen jointly by a neuro-oncologist and a neuro-surgeon in the SRS clinic to discuss the pros and cons of each approach
- 4) Not suitable for either SRS or surgery: Referral back to treating oncologist via MDT minutes for consideration of palliative whole brain radiotherapy or best supportive care.

Patients referred to the neuro-science MDT who are to be offered surgery for brain metastases causing raised ICP or hydocephalus or for biopsy of CUP will be seen by a neuro-surgeon. In cases of obstructing hydrocephalus they may be transferred as an emergency.

4.6 Patient Pathway for Pituitary Tumours (14-1C-110k)





Pituitary tumour patients will be seen in a specialist clinic by an endocrinologist or surgeon associated with the pituitary MDT to discuss the recommended medical or surgical management, or active surveillance. If radiotherapy is being recommended, they are referred on to a clinical oncologist associated with the pituitary MDT. Patients are referred on to the Cancer Network MDT as required, at the discretion of treating clinicians and clinical nurse specialists.

4.7 Patient Pathway for Skull Base Tumours (measure 14-1C-111k)

Skull base patients will be seen in an out-patient clinic by a core member or the skull base MDT team to discuss active surveillance, surgery or radiotherapy, as per MDT advice. All treatment and follow-up is supervised by an MDT core member. Patients with supportive care or rehabilitation needs are referred on to the Cancer Network MDT, with liaison via their key worker.

4.8 Follow up pathway

Patients with primary brain and spinal cord tumours remain under long-term follow-up by the site-specialist MDT teams. Patients with primary brain and spinal cord tumours who have received radiotherapy or chemotherapy are never discharged. Almost all follow-up occurs in specialist clinics at North Bristol Trust; some pituitary patients may be followed up by endocrinologists at local acute Trusts working in conjunction with the specialist pituitary MDT. Frequency of visits and imaging follow-up is diagnosis-dependent; this is detailed in the CNS Management policy documents.

4.9 Network Communication Framework (measure 14-1C-113k)

The CAG, in consultation with the Trust Leads for Brain and CNS tumours and Lead Clinicians of the MDTs, aims to agree a policy for communications between providers of care for brain and CNS tumours, which fulfils the following framework:

- Patients with an initial imaging diagnosis of a CNS tumour should have been logged on to a dataset of the NSMDT within one week of the date of the image report
- A clinical summary from the clinician in charge of the patient at the time of the imaging diagnosis should have been received by the NSMDT within two working days of the date of the imaging report
- A written summary of the proposed management plan should be sent out from the NSMDT within one working day of the MDT meeting to the referring clinician, the RNS MDT and the GP





- The patient or their carers are informed of the diagnosis within one working day for inpatients and five working days for outpatients of the NSMDT meeting at which it is confirmed
- The patient or their carers are informed of the management plan by the NSMDT within one working day for inpatients and five working days for outpatients of the NSMDT meeting at which it is decided
- A referral for relevant patients is sent to the rehabilitation or palliative care service within one working day of the decision being made
- A referral of relevant patients for management by a member of the RNS MDT is sent out within two days of discharge from neurosurgical care
- Patients or their carers are informed of the identity and role of their key worker within one working day for inpatients and five working days for outpatients of the NSMDT meeting
- A referral back to the neuroscience MDT for further management of possible recurrence is sent from the multidisciplinary specialist clinic within one working day of the decision
- Should the assessment made by the MDT indicate that the diagnosis is more likely to be a cerebral abscess than a tumour, this should be communicated urgently to the referring hospital and arrangements should be made for urgent transfer.

4.10 Protocol for Emergency Interventions (measure 14-1C-114k)

The protocol for emergency surgical interventions in patients with a CNS tumour, for intra-CNS problems caused by the tumour or its treatment:

All emergency intervention is at NBT. Patients referred to the neuro-surgical on-call service who are felt to require emergency neurosurgical intervention due to critically raised intracranial pressure, rapidly progressive neurological symptoms and / or deteriorating level of consciousness will be transferred to NBT as an emergency and will be managed at the discretion of the neuro-surgical on-call team. In these circumstances it is accepted that brain tumour patients may be operated upon by surgeons other than core MDT. The aim of surgery is to stabilize the patient. The case is always discussed at the next MDT to determine the next steps in management. In the absence of critically raised intracranial pressure, rapidly progressive neurological symptoms and / or deteriorating level of consciousness, any issues with patients on treatment should be directed back to the treating team at NBT. The Neurosurgical on-call team can be contacted 24/7 via Southmead Hospital switchboard on 01179505050.





4.11 Operational Policy for Neuro-Rehabilitation (measure 14-1C-115k)

The CAG has produced an operational policy for in-patient and community neuro-rehabilitation facilities with regard to the treatment of patients with CNS tumours. The policy includes the specification that the facility should be open to patients whose rehabilitation needs are caused by their tumour or its treatment, and that they should not be excluded from the facility's scope of practice solely on the grounds of the diagnosis of a tumour.

4.12 Patient Pathways for Teenagers and Young Adults (TYA)

Details of TYA patient pathways for the SWAG CAGs can be found on the SWAG website:

TYA

4.13 Cancer of Unknown Primary (CUP) Referrals

All patients with a metastatic carcinoma of unknown origin are referred to the cancer of unknown primary MDTs within the network. Details of the CUP referral processes can be found on the SWAG website:

CUP

5. PATIENT AND PUBLIC INVOLVEMENT

5.1 User Representative Input

The CAG has two user representative members who contribute opinions about the Brain and CNS service at the CAG meetings. The NHS employed member of the CAG nominated as having specific responsibility for users' issues and information for patients and carers is the Cancer Network CAG Support Manager. The CAG actively seeks to recruit further user representatives. Appendix 3 contains the Patient/User involvement brief that is circulated for this purpose.

5.2 Patient Experience (14-1C-114i)

The results and actions generated from the National Patient Experience Survey within each Trust in the CAG will be reviewed in every other CAG meeting, and the progress of the agreed improvement programme monitored. Progress will published in the Annual Report.





5.3 Charity involvement

See Appendix 3

6. THE NATIONAL CANCER PERSONALISED CARE AND SUPPORT (PCS) INITIATIVE

The Brain and CNS CAG has agreed to conduct a review of patient follow up systems in line with the practices recommended by the National Cancer PSC Initiative. Due to the ever increasing population of patients living with and beyond cancer, the current follow up systems are not sustainable, therefore new follow up methods need to be established to provide the support that patients require to 'lead as healthy and active a life as possible, for as long as possible'⁴. The Brain and CNS CAG will work to ensure that all patients have access to the recommended *Recovery Package*. The *Recovery Package* consists of holistic needs assessments, treatment summaries and patient education and support events. The Brain and CNS CAG will also develop risk stratified pathways of post treatment management, promote physical activity and seek to improve management of the consequences of treatment.

7. CLINICAL GOVERNANCE

7.1 Clinical Outcomes, Indicators and Audits (measure 14-1C-117k)

In the course of their regular meetings, the CAG review the progress (or discuss the completed results, as relevant), of their associated MDTs' outcome indicators and audits. At least one network audit will be performed each year. The results of this are presented at the CAG meetings and distributed electronically to the group.

7.2 Data Collection

Patient data on diagnostics is uploaded to the Somerset Cancer Registry as part of a national initiative.

Version 1.4

SWAG Brain and CNS Cancer Clinical Advisory Group Constitution

⁴ http://www.ncsi.org.uk/





8. CLINICAL RESEARCH

8.1 Discussion of Clinical Trials (measure 14-1C-118k)

Members of the CAG discuss each MDT's report on clinical research trials within every CAG meeting. A list of all of the open trials on the Brain and CNS NIHR portfolio, and potential new trials, is brought to each CAG meeting by the West of England Clinical Research Network (CRN) Cancer Research Delivery Manager.

Due to the CRNs mapping with the Academic Health Science Networks, Taunton and Yeovil are in South West Peninsula CRN. The Cancer Research Delivery Manager from the Peninsula CRN will provide the CAG with the data for these Trusts. Information on clinical trial recruitment will be published in the CAG Annual Report. Potential new trials to open and actions to improve recruitment will be documented in the CAG Work Programme. The trials available in each Trust will be updated on the South West Strategic Clinical Network website at regular intervals so that CAG members can ensure, wherever possible, that clinical research trials are accessible to all eligible Brain and CNS oncology patients. The NHS staff member nominated as the Research Lead for the CAG is Consultant Clinical Oncologist Christopher Herbert.

9. SERVICE DEVELOPMENT

Regular review of major service developments and changes in treatment pathways are conducted at the CAG meetings.

9.1 The Enhanced Recovery Programme

The CAG will endeavour to provide an Enhanced Recovery Programme for all patients. The ERP is about improving patients' outcomes and speeding up a patient's recovery after surgery. The programme focuses on making sure that patients are active participants in their own recovery process. It also aims to ensure that patients always receive evidence based care at the right time.

9.2 Educational Opportunities

The CAG meetings will have an educational function. Continuous Professional Development (CPD) accreditation for meetings with multiple educational presentations will be sought by application to the Royal College of Physicians. This will involve uploading presentations and speaker profiles to the CPD approvals online application database. The approvals process takes approximately six weeks, and can be applied for retrospectively. The CAG members will be required to complete a Royal College of Physician's CPD evaluation form. Certificates





recording the CPD points that are allocated to meetings will be distributed to the CAG members.

9.3 Sharing Best Practice

Where best practice in Brain and CNS oncology services outside the SWAG CAG has been identified, information on the function of these services will be gathered to provide a comparison and inform service improvements. Guest speakers from the identified services will be invited to provide a presentation at the CAG meetings.

Where best practice in Brain and CNS oncology services within the SWAG CAG has been identified, information on the function of SWAG services will be disseminated to the other cancer networks.

9.4 Awareness Campaigns

In the event of a Brain and CNS awareness campaign, the CAG has an agreed process to manage the possible impact of increased urgent referral from primary care to the Brain and CNS oncology services. Information on clinical decision making when referring to colorectal services will be cascaded to General Practitioners via the primary care email bulletin and the SWAG website.

10. FUNDING

10.1 Clinical Commissioning Groups (CCGs) / Cancer Alliance Board

In the event that an insufficiency in the Brain and CNS oncology services relating to funding is identified, the CAG will gather evidence of the insufficiency via audit and research, together with feedback about how the provider Trusts have tried to address them. The consequences of the insufficiencies for patients will be listed so that all key issues are documented and the required actions made clear. This information will then be fed back to the Cancer Alliance Delivery Group to determine that action that needs to be taken and escalated to the SWAG Cancer Board if required.

10.2 Industry

The Government's paper *Improving Outcomes: A Strategy for Cancer* states that 'working together with other organisations and individuals, we can make an even bigger difference in the fight against cancer'. The CAG will forge relationships with pharmaceutical companies to





seek commercial sponsorship for the meetings in order to make savings that can be fed back into the CAG cancer services. The CAG Manager will comply with the various rules and regulations pertaining to the pharmaceutical companies' policies and with the NHS rules and regulations as follows:

- Completion of a register of interest form with the CAG support service host Trust,
 University Hospitals Bristol NHS Foundation Trust
- Declaration of any sponsorship offers
- Confirm with all sponsors that the arrangements would have no effect on purchasing decisions
- Ensure that all pharmaceutical companies entering into sponsorship agreements comply with the Code of Practice for the Pharmaceutical Industry (Second Edition) 2012
- Obtain advice from the Medical Director or Chief Pharmacist for sponsorship agreements in excess of £500.00
- Ensure that where a meeting is funded by the pharmaceutical industry, that this is documented on all papers relating to the meetings
- Ensure that the receipt of funding is approved by an Executive Director and recorded in the Register of Gifts, Hospitality and Sponsorship in advance
- Scrutinise contracts with the assistance of Financial Services prior to providing a signature.





11. APPENDICES

11.1 Appendix 1

Template Agenda

Network group membership to attend:

Chair, MDT core members: Clinical Nurse Specialists, Neurosurgeons, Neurologists, Endocrinologists, Clinical Oncologists, Medical Oncologists, Imaging Specialists, Neuropathologists, Patient Representatives, Administrative / Managerial Support. Any other relevant Allied Health Professionals are welcome.

- Chair to name nominated network group member responsible for users' issues and information for patients / carers
- Chair to name nominated network group member responsible for clinical trial recruitment function.
- 1. Review of last meeting report and actions:
- 2. Clinical opinion on network issues:
- Review of MDT membership changes / meetings / service.
- 3. Clinical guidelines:
- Review of any amendments to imaging, pathology, systemic anti-cancer therapy, radiotherapy, surgical practices.
- 4. Coordination of patient care pathways:
- Review hospital referral processes for TYA / varying indications / investigations and follow
- Review implementation of Primary Care referral pro forma / implementation of rapid diagnostic pathways
- Cancer Waiting Times breach example to discuss.





5. Patient experience:

- User representative input
- Review patient experience survey / identified actions
- QOL surveys
- Patient information
- CNS / keyworker support
- Addressing inequalities.

6. Personalised Care and Support:

- Holistic needs assessments
 - o To define when these should be performed
- Next steps (Health and Wellbeing events)
- Treatment summaries
- Risk stratified follow up.

7. Quality indicators, audits and data collection:

- Current audits / audit outcomes
- Audits in the pipeline Data collection issues.

8. Research:

- Current clinical trials / recruitment / actions to improve recruitment
- Clinical trials in the pipe line
- Regional referrals
- Developing early career researchers / addressing inequalities.

9. Service development:

- Sharing best practice
- Genomics
- Immunotherapy
- Early diagnosis
- Prehabilitation / enhanced recovery programme
- Training opportunities available
- Sharing best practice
- Innovation
- Awareness campaigns.

10. Any other business / date and time of next meeting:





11.2 Appendix 2

SWAG CAG Patient/User Involvement Brief

11.3 Appendix 3

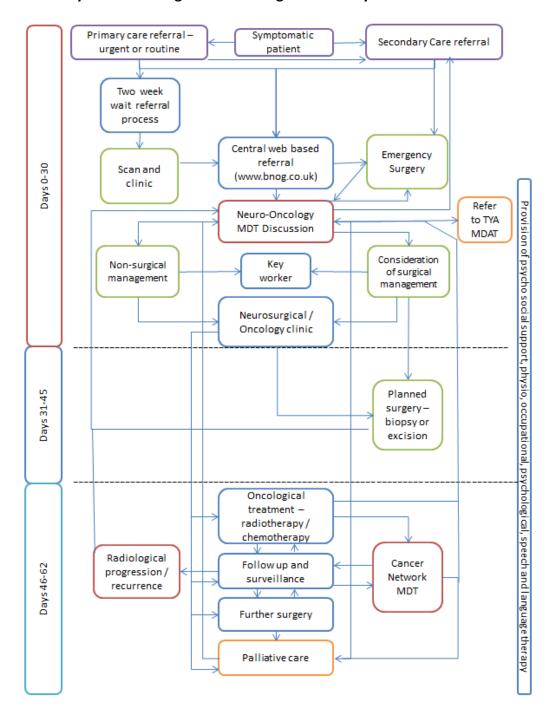
SWAG CAG Charity Involvement Brief





11.4 Appendix 4

Pathway for the Management of Malignant Primary Brain Tumours in Adults

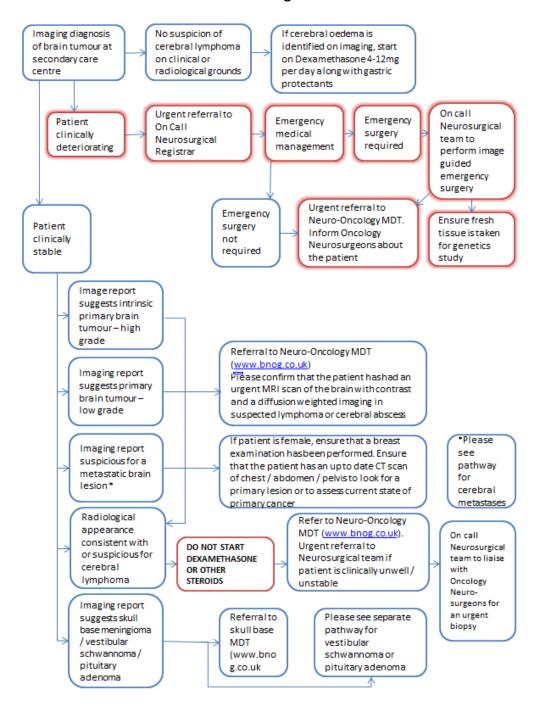






11.5 Appendix 5

Clinical Protocol for the Management of Brain Tumours

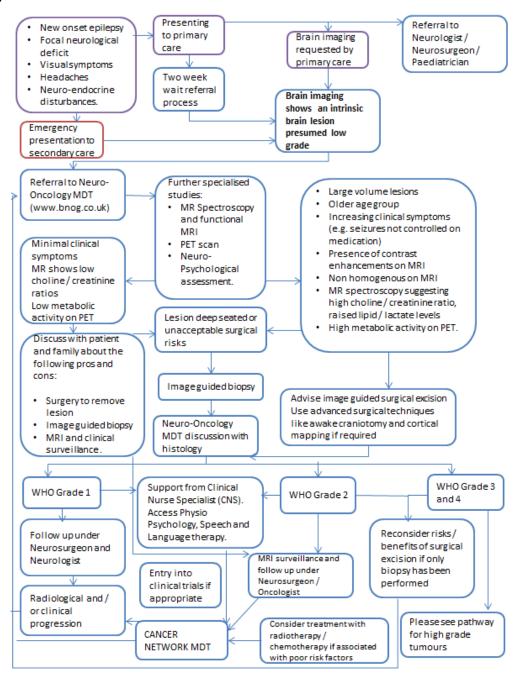






11.6 Appendix 6

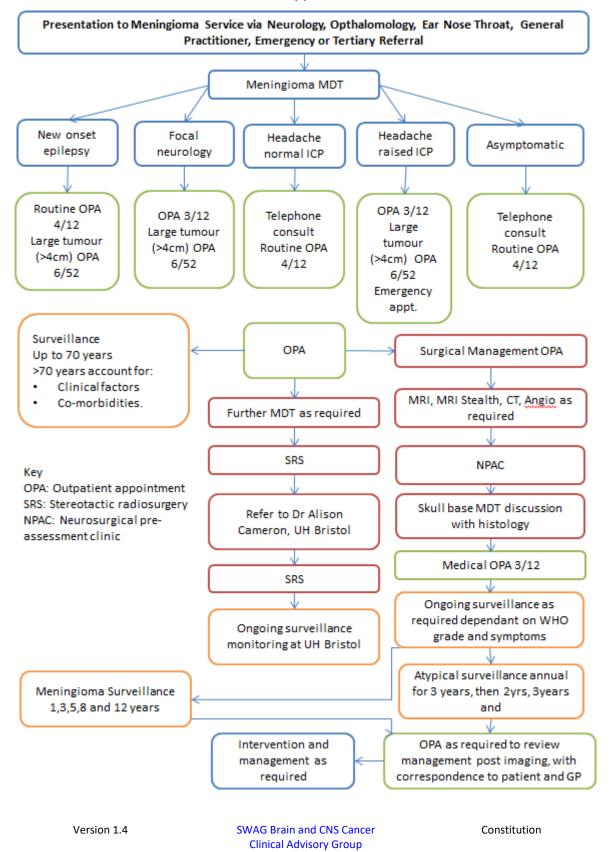
Referral, Diagnostic and Management Pathway for Low Grade Intrinsic Brain Tumours in Adults







11.7 Appendix 7







11.8 Appendix 8

Glossary of Terms

AHP	Allied Health Professional
ВНОС	Bristol Haematology Oncology Centre
BNOG	Bristol Neuro-oncology Group
CCG	Clinical Commissioning Group
CNS	Central Nervous System
CPD	Continual Professional Development
ICP	Intracranial pressure
MDT	Multi-disciplinary Team
NPAC	Neurosurgical pre-assessment clinic
NS MDT	Neuroscience MDT
CAG	Network Site Specific Group
OPA	Out-patient appointment
RNS MDT	Rehabilitation and non-surgery MDT
SRS	Stereotactic radiosurgery
SWAG	Somerset, Wiltshire, Avon and Gloucestershire