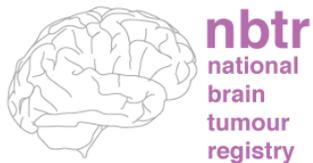


Brain Tumour Information Portal

NCIN Brain and CNS Workshop
26th March 2014

brain tumour PATIENT INFORMATION PORTAL



The Brain Tumour Information Portal

brain tumour
PATIENT INFORMATION PORTAL

Login ▾

Register

Please login or register to continue.

Welcome

The Brain Tumour Patient Information Portal is here to give patients the information they need to put them back in control following a brain tumour diagnosis.

This exciting pilot initiative gives you unprecedented access to your brain tumour pathology and imaging reports as well as treatment information.

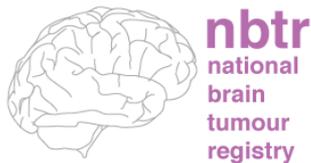
Developed by the National Brain Tumour Registry (NBTR) in partnership with brain tumour patients, dedicated brain tumour charity, brainstrust and Cancer Research UK.



Background

A disproportionate focus on surgical and oncological outcomes
National Peer Review 2012/13

The fight is so much harder than the diagnosis *Carer 2013*



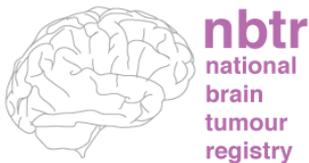
The patient information portal will...

- Give me greater involvement in my care
- Prepare me for what lies ahead
- Level the playing field
- Help me talk with my carers
- Help my carers talk to me
- Help avoid surprises
- Help others help me
- Help me explore all my options
- Help me ask the right questions.....
and get the answers

Benefits – the patients' view

Status

- Established systems and processes for secure, online access to records.
- Tested this with four pilot sites offering the portal to a limited number of brain tumour patients since June 2013 (4th from December 2013).
- Receiving initial feedback from users and clinical teams involved.
- Also conducted user testing of the portal site to improve and refine.



Current features



My brain tumour record

This is where you can see the information held about you by the National Brain Tumour Registry. You can add your own comments to the records, perhaps to define a technical term, or to remind yourself to follow something up with your clinical team.



My notes

This is your own personal space where you can **create and store notes** of any kind - your thoughts, observations, worries and hopes, or perhaps even your shopping lists.



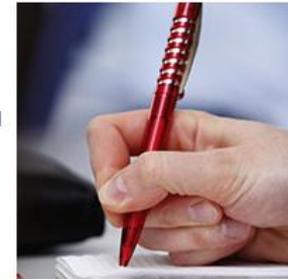
My quality of life

Use this **specially created survey** to assess your quality of life regularly so that you can compare how you felt last week, and how that correlates with the treatment you're receiving.



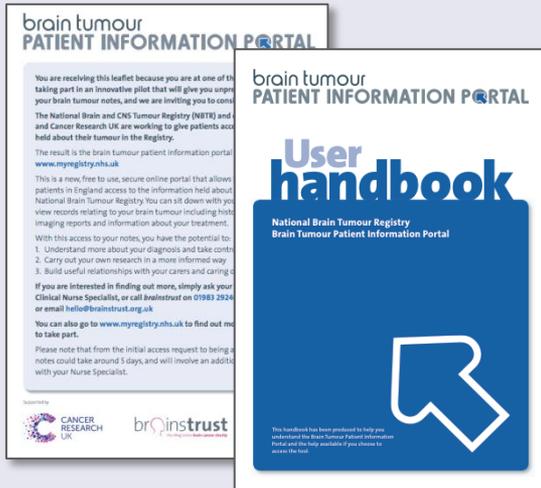
My contacts

A handy place to store all your **contact information** for your clinical team and any others involved in your treatment and care.



Role of clinical teams

1. Making the offer to patients: Opportunistically, mail out, patient led



brain tumour
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You are receiving this leaflet because you are at one of the following hospitals taking part in an innovative pilot that will give you unprocessed brain tumour notes, and we are inviting you to consent to the National Brain and CNS Tumour Registry (NBTR) and Cancer Research UK are working to give patients access to their tumour in the Registry.

The result is the brain tumour patient information portal www.myregistry.nhs.uk

This is a new, free to use, secure online portal that allows patients in England access to the information held about their brain tumour. You can sit down with your doctor to view records relating to your brain tumour including histology reports and information about your treatment.

With this access to your notes, you have the potential to:

1. Understand more about your diagnosis and take control
2. Carry out your own research in a more informed way
3. Build useful relationships with your carers and carers

If you are interested in finding out more, simply ask your Clinical Nurse Specialist, or call [01983 2924](tel:019832924) or email hello@brainstrust.org.uk

You can also go to www.myregistry.nhs.uk to find out more for take part.

Please note that from the initial access request to being able to access your notes could take around 5 days, and will involve an additional appointment with your Nurse Specialist.

brain tumour
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User
handbook

National Brain Tumour Registry
Brain Tumour Patient Information Portal

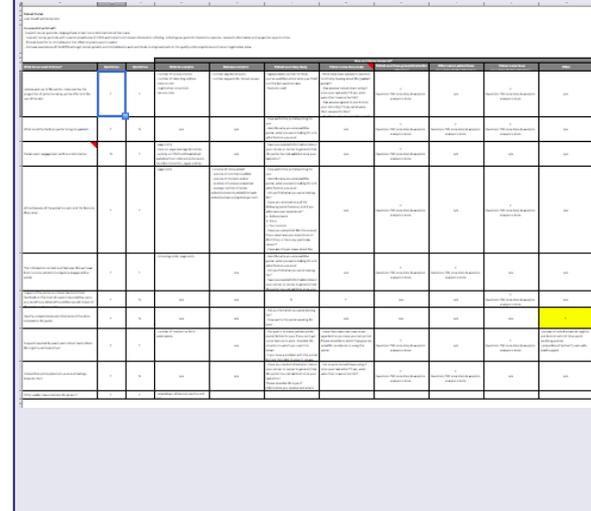
This handbook has been produced to help you understand the Brain Tumour Patient Information Portal and the way in which you can access the data.




2. Activating accounts and talking users through their records



3. Helping to evaluate and improve the pilot



Case ID	Age	Sex	Diagnosis	Grade	Location	Imaging	Pathology	Treatment	Outcome	Follow-up
1001	65	M	Low grade glioma	II	Frontal lobe	CT, MRI	Biopsy	Observation	Stable	12 months
1002	58	F	High grade glioma	III	Temporal lobe	CT, MRI	Biopsy	Surgery	Resected	6 months
1003	72	M	Meningioma	I	Supratentorial	CT, MRI	Biopsy	Surgery	Resected	18 months
1004	45	F	Pituitary adenoma	I	Sellar region	CT, MRI	Biopsy	Surgery	Resected	24 months
1005	60	M	Chordoid glioma	III	Optic chiasm	CT, MRI	Biopsy	Surgery	Resected	9 months
1006	55	F	Craniopharyngioma	I	Sellar region	CT, MRI	Biopsy	Surgery	Resected	30 months
1007	68	M	Metastatic disease	IV	Multiple sites	CT, MRI	Biopsy	Systemic therapy	Progressing	3 months
1008	50	F	Primary CNS lymphoma	III	Frontal lobe	CT, MRI	Biopsy	Systemic therapy	Stable	15 months
1009	70	M	Atypical meningioma	II	Supratentorial	CT, MRI	Biopsy	Surgery	Resected	21 months
1010	40	F	Diffuse intrinsic glioma	III	Frontal lobe	CT, MRI	Biopsy	Systemic therapy	Progressing	8 months

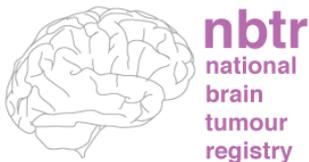
Patients see this as a step in the right direction but not for everyone

APPEALS TO:

- Patients in long term follow up;
- The information hungry;
- Carers and family members.

LESS ATTRACTIVE TO:

- High grade patients with poor prognosis;
- Patients immediately post diagnosis;
- Circumstances/condition prevent them from using the portal.



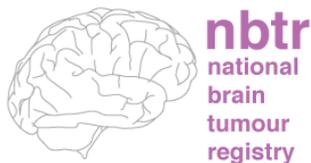
Challenges

DATA

- Complex, do not include everything patients would want (scan images and clinic letters) and take time to arrive.
- Will get timelier and more comprehensive, will stay complex.
- For now, we need to help people understand what is there.

NHS CAPACITY

- CNS time is at a premium and IT is a barrier.
- People are willing to help but we need to make this easy and useful for them.



We have shown that we can do this - what next?

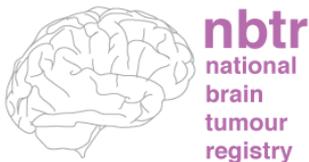
ASSESS UPTAKE RATE AND GET FEEDBACK FROM A LARGER NUMBER OF USERS:

- Work with existing pilot sites to offer the portal to more patients
- Explore options to offer the portal to brain tumour patients at more sites and for expanding to other tumour types.
- Allow patients at other sites to sign up, though not request access to records.

MAKE IMPROVEMENTS BASED ON FEEDBACK SO FAR:

- Making records more useful and engaging: Inline glossary and links
- Provide access to results of QoL survey to allow self monitoring and inform discussions with clinical teams.

WORK WITH NCRS TO STREAMLINE PROCESSES WHERE POSSIBLE.





THANK YOU!

cruk.org

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