

PATIENT PORTAL

NCIN CNS & BRAIN TUMOUR WORKSHOP

FEBRUARY 2015

Today

RECAP

- What we're doing and why
- Our approach
- Where we were in March 2014

PROGRESS SINCE MARCH 2014

- Improvements to the patient portal
- Early evaluation results

BEYOND BRAIN TUMOURS

- Expanding to more cancer types
- Next steps

What and why

We are offering patients with brain tumours access to their own records held by the NCRS to:

- Benefit patients through greater involvement in their care, increased feelings of control and better conversations.
- Benefit clinical teams by better informing patients.
- Understand quality of life following treatment.
- Improve the data held by the NCRS through patient feedback.
- Ensure transparency about what data are collected.

Please login or register to continue.

Welcome

The Patient Portal is here to give patients with cancer or a brain tumour better information about their diagnosis and treatment.

This innovative pilot initiative gives you unprecedented access to your pathology and imaging reports as well as a record of your treatment.

The portal has been developed by the National Cancer Registration Service (NCRS) in partnership with patients, Cancer Research UK and dedicated brain tumour charity *brainstrust*.



About the portal

Patients who choose to access their information can view records held about their tumour at the NCRS. They can also keep track of their care using online tools, and record their quality of life.

[Read more about the portal](#)



[Information for health professionals](#)



Supported by



The principles we are working towards

- Safety
- Value to patients and clinical teams
- Engagement
- Equity of provision and scalability
- Support to clinical teams
- Evaluation to inform our decisions

Where we were last time

When we last updated this group in March 2014, we had:

- 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).
- Received initial feedback from users and clinical teams involved.
- Conducted user testing of the portal site to improve and refine.

Progress since March

- Visible and invisible improvements
 - **Quality of Life:** More prominent, more important, more accessible.
 - **Account activation:** More straightforward, more flexibility
 - **Processes:** More of them. Better defined
 - **Security:** More important than ever
 - **Data:** More of it

15 Sep 2014



Survey

Submitted on 2014-09-15 13:46:20

[See my answers](#)

[Hide results](#)

Functional Measures

100 - Higher quality of life

Physical	53	Day to day	67
Cognitive	83	Emotional	50
Social	50	Overall	42

Symptoms

0 - Lower symptoms

Dyspnoea	67	Pain	33
Fatigue	56	Insomnia	0
Appetite loss	67	Nausea and vomiting	33
Constipation	0	Diarrhoea	33
Financial difficulties	0		

Progress since March

- **A virtuous circle:** Carefully refining the offer based on feedback.
1. Patience
 2. Trust
 3. Communication
 4. Careful and considered development

Thank you.

Early results

IT'S WORKING!

- Patients are able to access their records, though numbers are still small.

PATIENTS:

- Would generally recommend to others
- Value being able to access information in one place from their home as well as “being able to see exactly what was found”.
- Some expect to see more data or for information to be in ‘layman’s’ terms. Majority think it data needs to be richer and more timely.

CLINICAL TEAMS:

- Can fit this into workloads, but it is extra and slips off of the list.

NCRS:

- Receiving useful feedback that is contributing to improvements in data flows.

BRAINSTRUST:

- Only a handful of support calls so far. All operational rather than related to records.
- Some really interesting conversations with clinical teams
- Supportive patient community

The NCRS holds data for all cancer patients; small changes let us offer the portal more widely

Hospital Trust	Tumour Type
Leeds Teaching Hospitals NHS Trust	Brain
King's College Hospital NHS Foundation Trust	Brain
Norfolk and Norwich University Hospitals NHS Foundation Trust	Brain
Cambridge University Hospitals NHS Foundation Trust	Brain
Nottingham University Hospitals NHS Trust	Brain
Imperial College Healthcare NHS Trust	Brain
The Walton Centre NHS Foundation Trust	Brain
Southport and Ormskirk Hospital NHS Trust	Urology
Countess of Chester Hospital NHS Foundation Trust	Colorectal
Clatterbridge Cancer Centre NHS Foundation Trust	Prostate & melanoma

Welcome to the Cancer Patient Portal

This portal is a personal space for you to keep track of your cancer journey including notes on your experiences, on-going surveys of your quality of life, and access to your tumour records from the National Cancer Registration Service.

My cancer record
This is where you can see the information held about you by the National Cancer Registration Service. 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 survey to track your quality of life regularly and inform discussions with your clinical team.

My contacts
A handy place to store all your contact information for your clinical team and any others.

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THANK YOU

We would like to acknowledge:

- All of the patients who have contributed to the development of the patient portal and who have tested it during the pilot.
- The clinical teams at participating hospitals for supporting the pilot.
- *brainstrust*, Cancer Research UK and Public Health England (NCIN and NCRS) for funding and support.