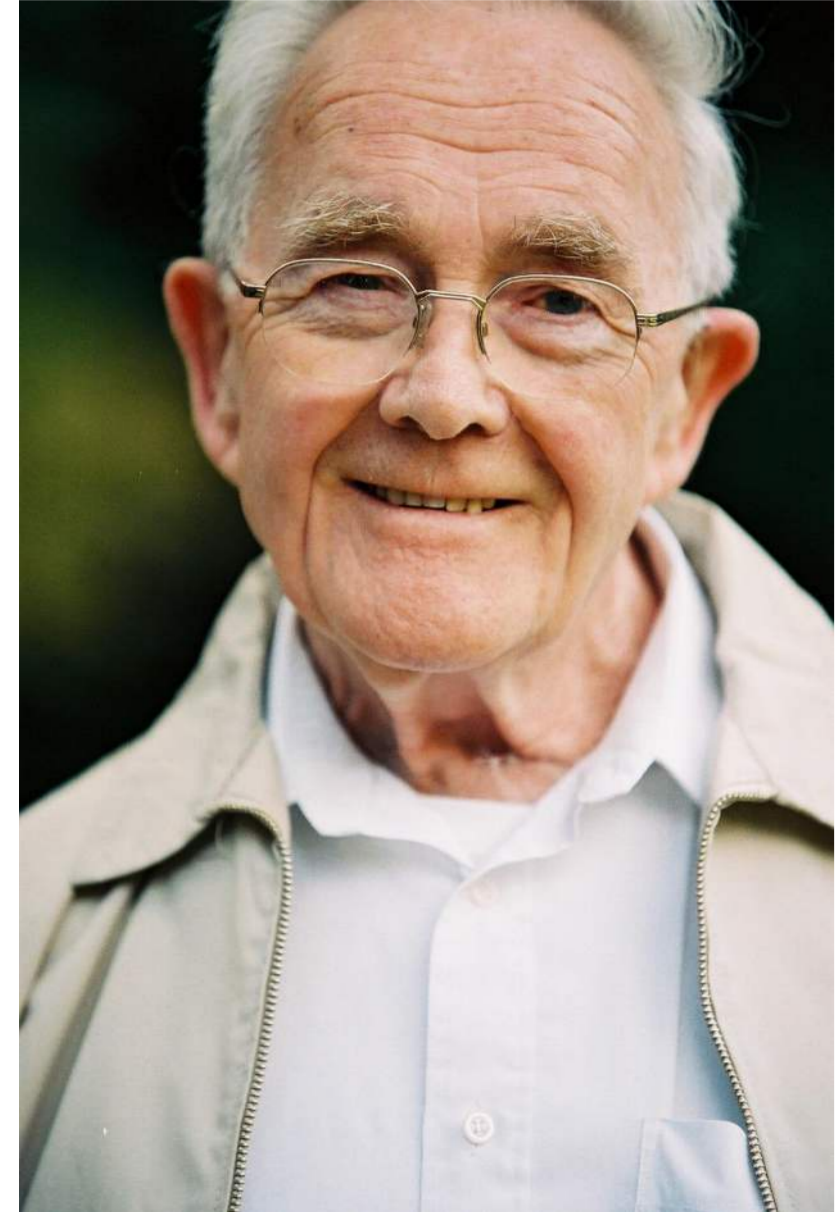


The Brain Tumour Information Portal: Piloting Patient Access To Cancer Registry Records

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Background



2011 I want to...

...be more involved in my care

...have better conversations with my clinical team and carers

...avoid surprises

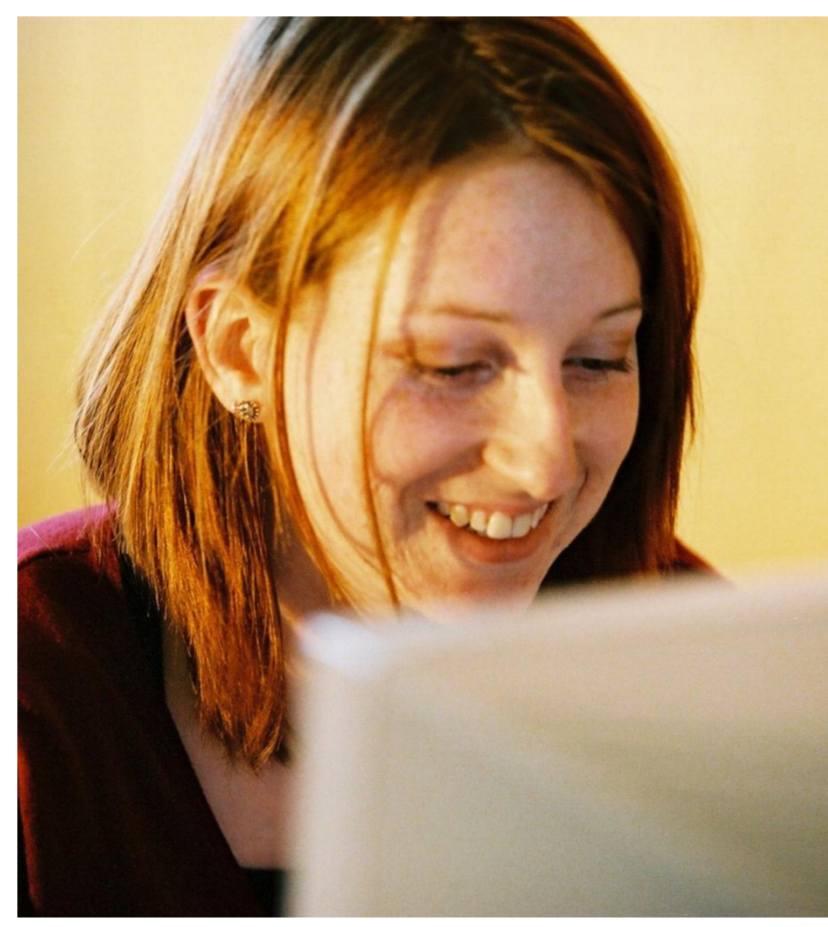
The Brain Tumour Information Portal (BTIP) aims to provide brain tumour patients with online access to the records held about them by the National Cancer Registration Service (NCRS) and to additional information and support. It is the first portal of its kind to offer patients access to their cancer registry records. Developed in conjunction with patients, their carers and clinicians, the initial pilot phase was a proof of concept to establish the secure infrastructure required. The pilot is running in four hospitals: Addenbrooke's Hospital in Cambridge, King's College Hospital in London, Norfolk and Norwich University Hospital in Norwich and St James's University Hospital in Leeds.

Methods

A mixed methods approach to the evaluation was adopted:

- Feedback from clinical teams was sought through meetings after a six month period.
- Clinical Nurse Specialists (CNSs) kept logs recording the number of offers and the reason for decline if a patient did not want to access the portal.
- The Portal records the number of registered users and how often they log in.
- Patient survey: patients who agreed to be involved in evaluation of the pilot were sent a questionnaire by email exploring their experience of using the portal. By the end of April a total of 15 patients opted in to the evaluation, 8 of whom had access to their records.
- 3 patients/carers responded to the questionnaire (20%). Feedback was also sought opportunistically through user testing with patients and through support groups.

2013/14 I can now...



...track how I am doing using the quality of life survey

...access my records when I want

...feel like I own my own information

I think...

... it's a brilliant idea

...that gaining access to records should be quicker and that more information could be included

Results

By the end of April 2014, 28 patients had requested access to their records and 15 had accessed them. This represented an overall uptake rate of 22% (95% CI: 13-32%) for the patients approached. Portal records showed that users log in frequently for a few months, but that this then drops off to only occasional use. Based on feedback from CNSs, the portal seems to appeal to patients with lower grade tumours and those who are in long term follow up. Carers and family members have also been interested in the opportunity to access the information. The small number of users means that only limited feedback has been received so far. Users are positive about the concept and the information provided, however all patients who responded wished to view their medical images which are currently unavailable on the portal.

Conclusion

We have developed a system to provide brain tumour patients at four hospitals with secure access to records held by the NCRS in a way that is scalable across England and to all cancer types. While the initial number of users is low, we have demonstrated that there is demand for this service from brain tumour patients. Clinical teams have found this manageable at a small scale within their existing workloads and are now expanding the number of staff and clinics involved with the pilot. Future work needs to investigate ways to reduce the burden on clinical teams.

We are now planning to expand the pilot to more tumour types and grow the number of users. This will allow for a more in depth evaluation of the way in which patients use the portal and any benefits that they receive.

Our vision: I can...



... share my information securely with whoever I wish to

... access the latest information about my particular cancer, my treatment and find out about trials

...enable researchers to access my information for research purposes if I wish

www.myregistry.nhs.uk

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. Your answers will also help us understand the impact of cancers on people during and after treatment.

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

Homepage: the landing page for the portal, enabling users to navigate to each section of the site.

My brain tumour record
This page shows you the information held about your tumour by the National Brain and CNS Tumour Registry. If you need any help interpreting these records you might find **this glossary** useful—or feel free to **contact us**.

Please note that viewing these records does not substitute discussion with your clinical team. Also note that the commenting feature is for your use and reference only—your comments will not be distributed to the clinical team via this system.

- 23 Apr 2012 Medical record
Type: Cytotoxic Chemotherapy
View detail Add comment
- 21 Feb 2012 Medical record
Type: Surgery
View detail Add comment
- 23 Apr 2012 Medical record
Type: RT - Teletherapy
View detail Add comment

Record: a display of the patient's NCRS records, listed in reverse chronological order. The records include pathology reports, summaries of imaging reports, and information about hospital attendances and treatment received.

| Functional Measures | | 100 - Higher quality of life | |
|---------------------|----|------------------------------|----|
| Physical | 11 | Day to day | 0 |
| Cognitive | 67 | Emotional | 33 |
| Social | 50 | | |

| Symptoms | | 0 - Lower symptoms | |
|------------------------|----|---------------------|-----|
| Dyspnoea | 67 | Pain | 50 |
| Fatigue | 67 | Insomnia | 67 |
| Appetite loss | 67 | Nausea and vomiting | 100 |
| Constipation | 0 | Diarrhoea | 0 |
| Financial difficulties | 33 | Future uncertainty | 67 |
| Headache | 33 | Visual disorder | 78 |
| Seizures | 67 | Motor dysfunction | 56 |
| Communication deficit | 50 | Drowsiness | 67 |
| Hair loss | 67 | Itchy skin | 33 |
| Weakness of legs | 33 | Bladder control | 33 |

Quality of life survey results: an example set of results for the quality of life survey. Patients can complete this as often as they like to track their progress over time.

We gratefully acknowledge the patients and carers who have contributed to the development of the BTIP and who have tested it during this pilot, the neuro-oncology teams at participating hospitals for supporting the pilot, and the funding and support received from the brainstrust, Cancer Research UK and Public Health England (NCIN and NCRS).