

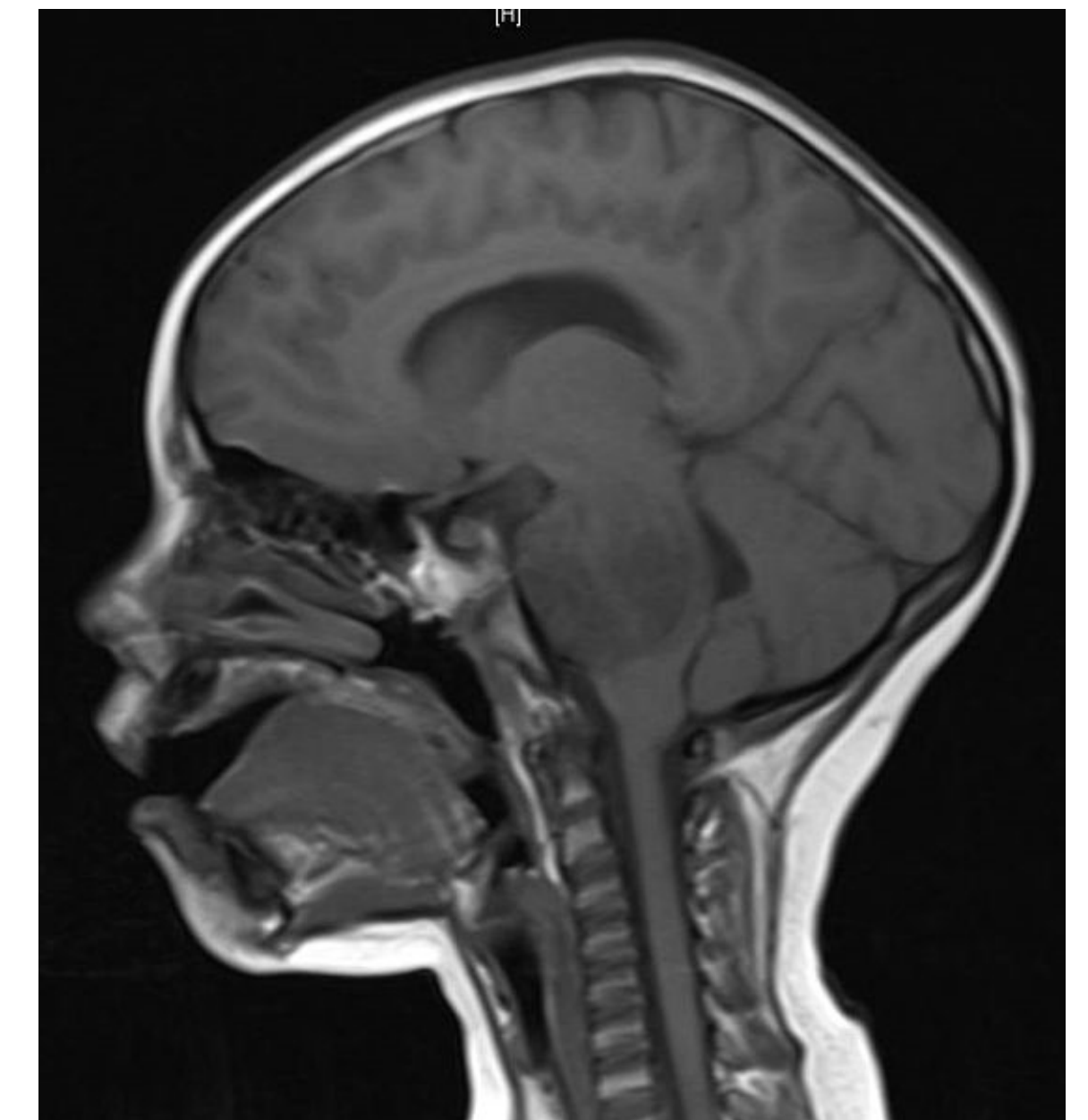
# “Get involved for the best possible outcome”: developing an information portal for brain tumour patients

Anne Swift<sup>1</sup>, Will Jones<sup>2</sup>, Jem Rashbass<sup>1</sup>

<sup>1</sup> Eastern Cancer Registration and Information Centre, Cambridge, UK <sup>2</sup> brainstrust, Cowes, UK

## Background

The UK National Brain Tumour Registry (UKNBTR, part of the National Cancer Registry) holds a significant amount of data about the care of individual patients with primary malignant brain tumours. Following consultation with brain tumour charities and clinicians, it is clear that these data constitute an important resource for cancer patients, their carers and their clinicians and that a mechanism should be developed for sharing of this data with patients: the Patient Information Portal.



A brainstem glioma in a four year old child  
MRI sagittal section without contrast

## The vision:

to provide all brain cancer patients in England with the opportunity to securely access data held about their care by the National Cancer Registry within an online supportive community, with the freedom to add to, comment on and share this information if they so wish

## Do patients want this?

Yes. The NBTR has been working closely with *brainstrust* and other charities to ensure that the Portal will fit patients' needs



## What information is available?

- Full text histopathology reports
- Abstracted information from imaging reports
- Details of specific treatments received
- Biochemical information such as receptor status, if relevant

## What will patients use the information for?

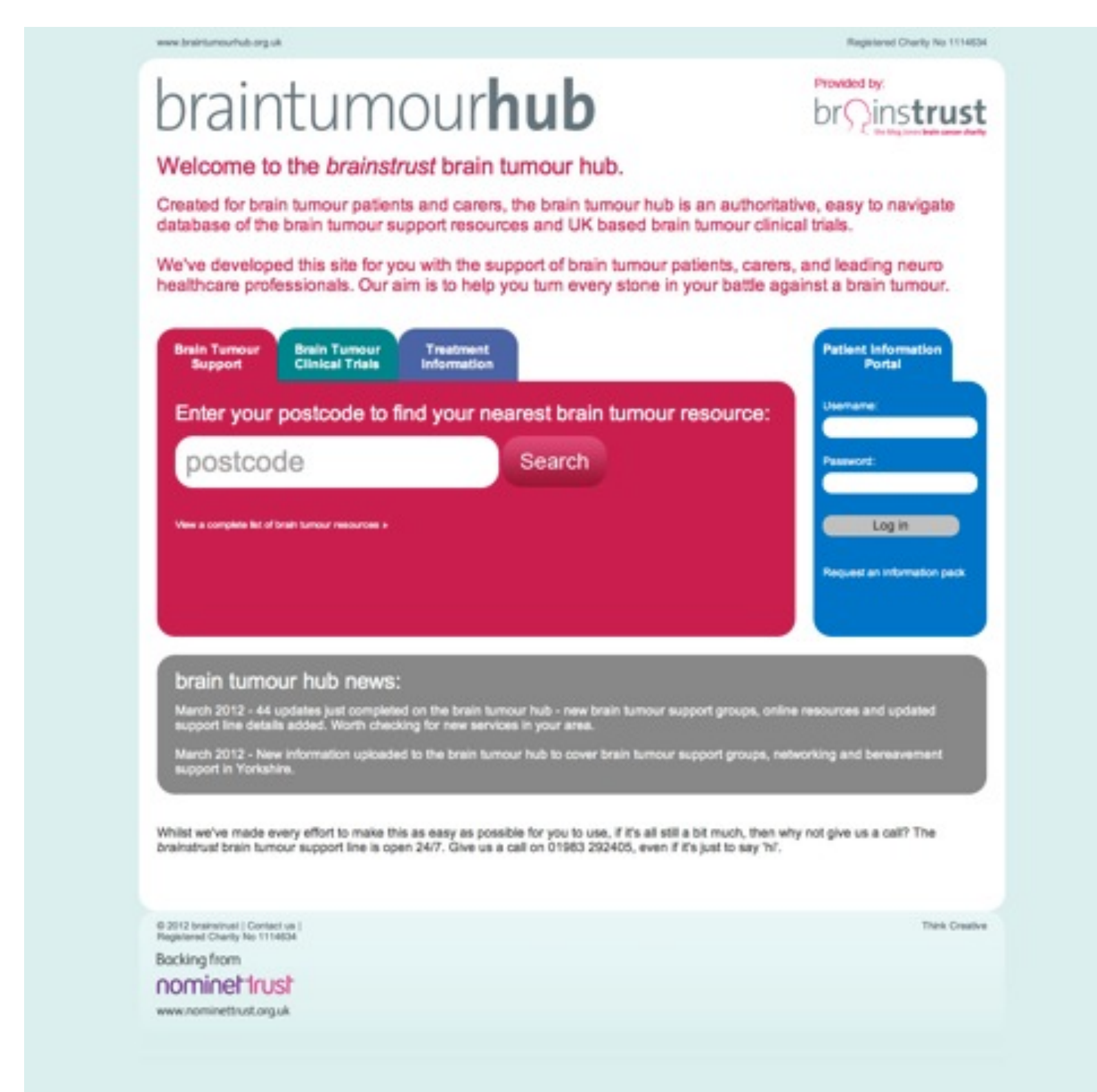
A consultation event in January 2012 generated insights into how access to their data will empower patients as informed partners in their care:

## How will patients access the Portal?

First-time access will be via a secure NHS N3 connection with a health professional at the patient's side.

Subsequent access will be through the web with high levels of security.

Access will be via [braintumourhub.org](http://www.braintumourhub.org) which provides comprehensive information on support available for patients, whether face to face, telephone or online



For more information,  
comments or questions  
please contact  
**[anne.swift2@nhs.net](mailto:anne.swift2@nhs.net)**

