



The Brain Tumour Patient Information Portal

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"With me, it was a case of 'this is what you're having'… no choice, no options… Actually I want to know what other choices there are"
"The attitude seemed to be, well yes, this information is about you but it's not yours, it's ours"
Shared decision making
"How is it so dangerous that you get the information that is about yourself?"
Making it easier for patients to access their own information

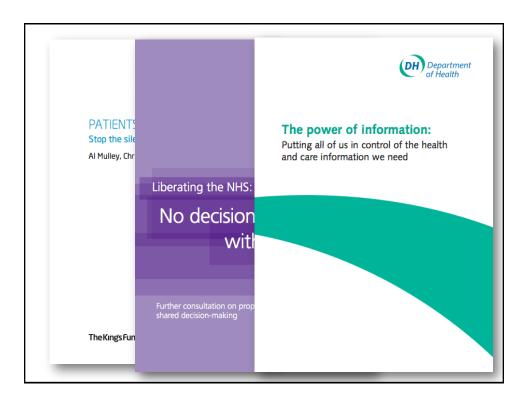
Why?

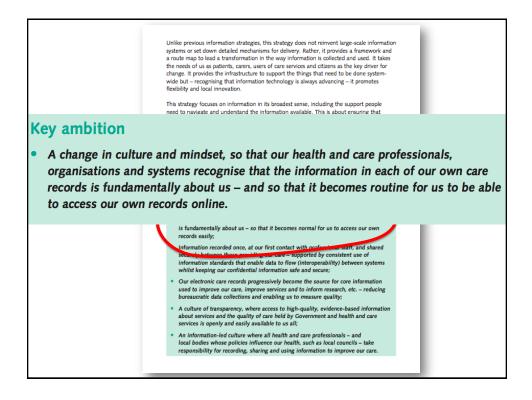
- Because this information belongs to the patient
- Because it can help
- Because patients want it

Patient objectives:

- To give me greater involvement in my care
- To help me ask the right questions
- To prepare me for what lies ahead
- To level the playing field
- To help me talk with my carers
- To help my carers talk to me
- To help avoid surprises
- To help others help me
- To explore all the options
- To help me ask the right questions, and get the answers





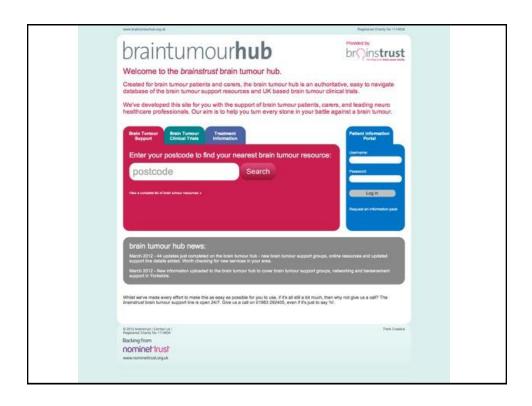


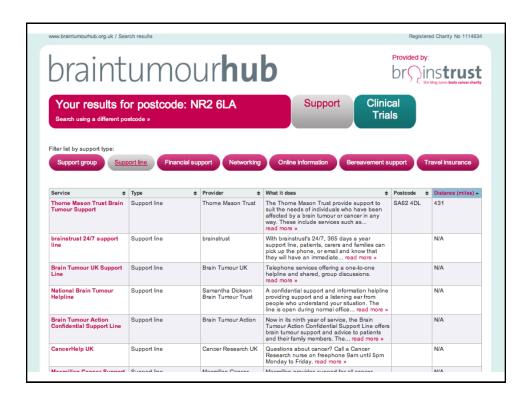
Outcomes from receiving full and clear information

- Improved knowledge and understanding
- Reduced anxiety
- Increased preparedness for events
- · Enhanced sense of control
- Enhanced compliance
- Increased satisfaction with treatment

National Institute for Clinical Excellence (2004). Improving supportive and palliative care for adults with cancer: the manual. Available from: http://www.nice.org.uk/csgsp

Information unique to the individual





Brain tumour registry data

- Just the facts!
- Full-text histopathology reports
- · Extracts from imaging reports
- Summaries of treatment information
 - Surgery
 - Chemotherapy
 - Radiotherapy

Does not include

- Clinic letters
- Clinical notes
- Information about other health conditions



Quality of life data

Key points

- Being developed in consultation with patients, neuro-oncology specialists, clinical nurse specialists and GPs
- First-time access alongside a health professional, within N3 network
- Full technical and patient / carer support available and clearly signposted
- Similar systems in other areas
- Pilot sites

Ultimately

- Simply another tool for patients and clinicians to use
- Most, if not all, of this information is already available – but patients have to work really hard to get it

"It's all about empowerment... some people don't want to know, but some people will want to know and investigate further. You can let people know, it's your choice...

...at the moment we haven't got a choice."

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