



The Brain Tumour Patient Information Portal

Anne Swift, National Brain Tumour Registry

Will Jones, *brainstrust*

Liberating the NHS:

An Information Revolution

A summary of consultation responses

The Government is committed to moving

- away from information belonging to the system, to information enabling **patients and service users to be in clear control of their care;**
- away from patients and service users merely receiving care, to **patients and service users being active participants in their care;**
- away from a culture in which information has been held close and recorded in forms that are difficult to compare, to one characterised by **openness, transparency and comparability;**
- away from the Government being the main provider of information about the quality of services to **a range of organisations being able to offer service information to a variety of audiences**

The Patient Information Portal

A way for patients and their nominated others to access the information held about them by the National Brain Tumour Registry

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
- Patient partnership and empowerment: get involved for the best possible outcome



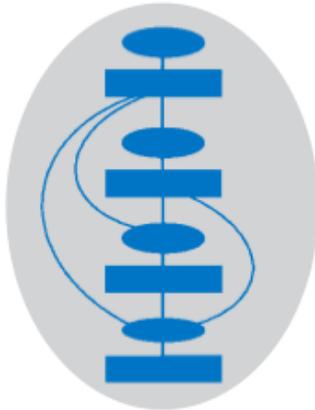
Why?

- Because this information belongs to the patient
 - HMG commitment to online access to GP records by 2015
 - DH Information Strategy
- Because it can help
- Because patients want it

Guidance on Cancer Services

Improving Supportive and Palliative Care for Adults with Cancer

The Manual



“[There is] ... strong evidence that patients and carers value – and benefit from – receiving accurate and relevant information.”

p70

Outcomes from receiving full and clear information

- improvement in knowledge and understanding,
- reduction in anxiety,
- increased preparedness for events,
- enhanced sense of control,
- enhanced compliance and
- 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>

“Patients... prefer information based on their own medical records, rather than general information.”

p71

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>

But mainly because it is what patients want

- 57 brain tumour patients and carers
- Geographically diverse (Sheffield and Winchester)
- Demographically diverse
- Different stages, conditions and situations



Having 2 Access points with
the necessary information, ~~with~~ ~~media~~
notes, contracts, organisations at
your fingertips without having to
data scattered in ~~several~~ ~~places~~
(i.e. internet, leaflets, organisations etc...)

check information you were given
if you've forgotten it.
second opinion
understanding of diagnosis

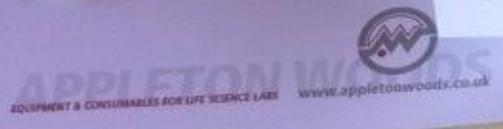
with data access which is
able to your needs.
information
Medication

to be able to find
information about
you was told in

understanding
YrTx +
disease
Using it for
a 2nd
opinion.

truth about
your
AND
PENIA
NAT
YOUR FAMILY. THE
ABLE TO TAKE/IN-
MAKE

able to get a second
opinion - if you want one!



challenges
a patient in

THE WHOLE PICTURE
Security
understanding the in-
and not misinterpreting
knowing too much detail
Finding out things you didn't know
about

Security
need to know

Understand
info given



What are the benefits of having access to your data?

- Closure
- Understanding
- Knowledge
- Reassurance
- Answers
- Empowerment
- Ability to ask, research any remaining questions
- Fill the gaps
- Access to 3rd parties for research

As a patient/carer, what are the challenges of having a patient information portal?

- Confidentiality
- Accuracy
- Clarity
- Security
- Stress, if it is bad news
- Who else sees this data?

What data would you want?

- All of it
- No jargon – layman's terms
- Prognosis
- Study data
- Scans
- Histology
- Links to research results

Where would you like to access this information?

- Via an app
- On the internet
- As a presentation (meeting or as a webcast)
- At home

Who would you like to discuss this information with?

- Family
- Doctor
- Neurosurgeon
- Advocates
- Anyone who will listen
- Relevant specialists
- Google/forums

What would you do if you didn't understand the information?

- Look it up on the internet
- *Ask brainstrust*
- Ask my GP
- Keep asking
- Feel uncertain
- Print it off and take it to the relevant specialist

There is a great thirst for information about diseases and treatments and most patients want more health information than they are usually given.

This includes honest assessments of treatment benefits, risks and side-effects. Many people express disappointment about the lack of opportunities to participate in decisions about their care.

While not everyone wants an active role, most surveys suggest that a majority do.

Flynn et al (2006). 'A typology of preferences for participation in health care decision-making'.
Social Science and Medicine, vol 63, no 5, pp 1158–69.

The patient information portal will...

- Give me greater involvement in my care
- Help me ask the right questions
- 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

“Get involved for the best possible outcome”



[Patient Transport Survey: Invitation 11 May 2012. More here](#)

...

[Aged between 15 and 25? Tell NHS Kidney care what it is like. Participate in Ipsos MORI research ...](#)

[RPV news update](#)

Welcome to Renal PatientView

Renal PatientView is a project of [RIXG](#) a UK group representing renal patients and the renal team. It aims to provide online information about renal patients' diagnosis, treatment, and their latest test results. Patients can share this information with anyone they want, and view it from anywhere in the world.

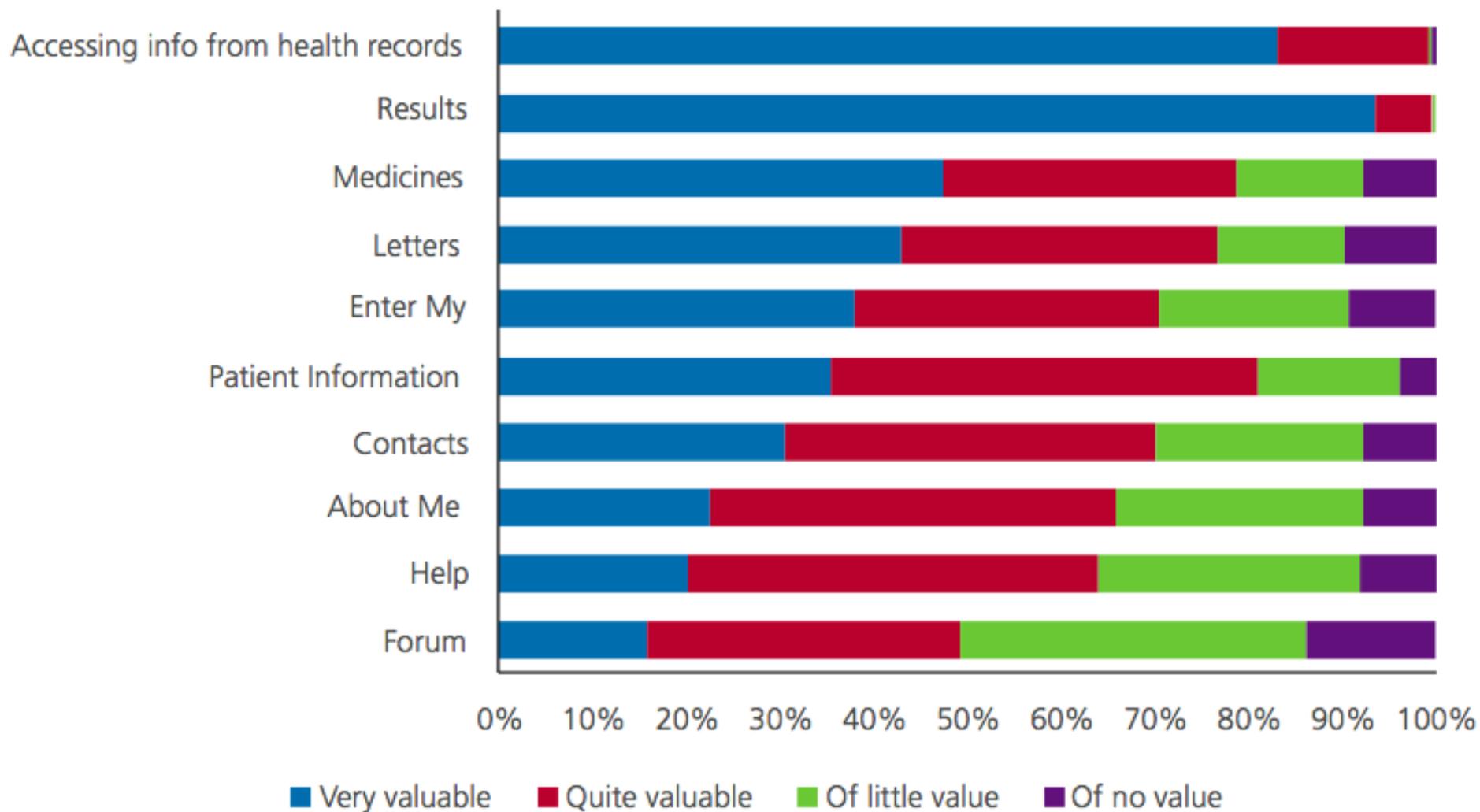
PatientView is only available from some UK renal units, and for patients who have chosen to participate. Here is a [list of units](#) involved so far. The information comes directly from existing databases within units, so if you suspect a mistake, you should check with your own unit. Links are provided after you log in.

You can view our [information links](#) without logging in.

You can view a [demo](#) as if you were a patient.

RPV is funded by contributions from renal units in England and Wales and by the Scottish Government in Scotland. Development funding has come from the Department of Health in England, Scotland and Wales, and from NHS Kidney Care.

Figure 1: Value of RPV to users

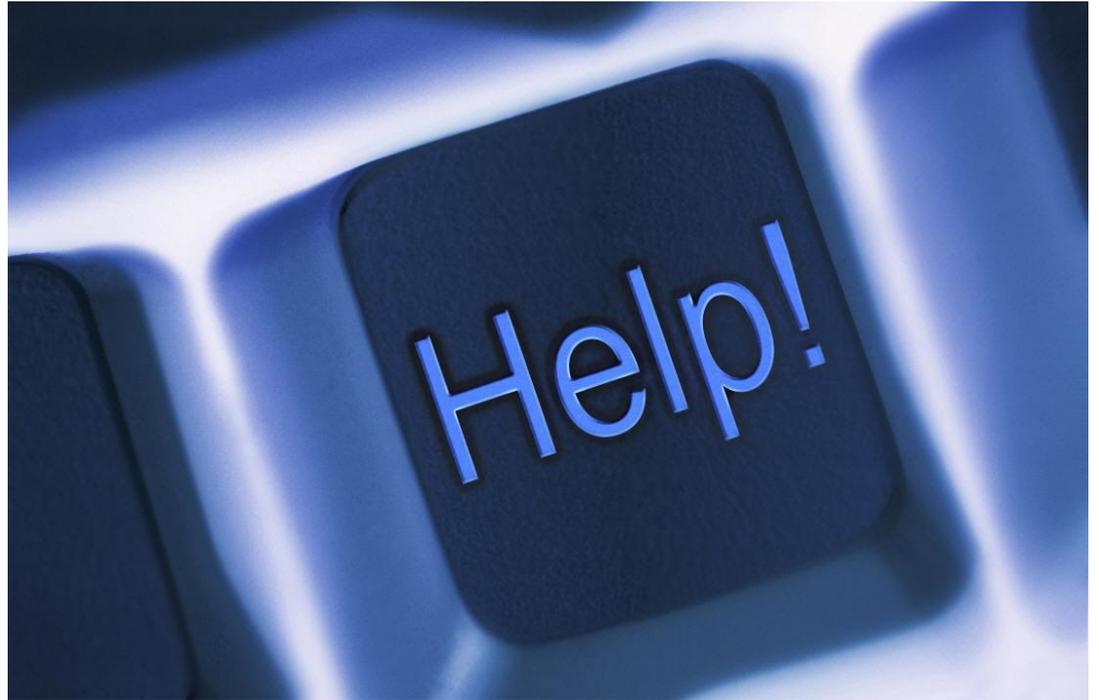


*“Patients and professionals were very enthusiastic about the empowering benefits of using RPV, and reported outcomes which included **improved patient involvement, ..., improved patient-professional communication, and improved patients’ sense of reassurance.**”*



Technical and patient / carer support

**The
supportive
community**



braintumourhub

Provided by
brainstrust
Charity (Brain Tumour Support)

Welcome to the *brainstrust* brain tumour hub.

Created for brain tumour patients and carers, the brain tumour hub is an authoritative, easy to navigate database of the brain tumour support resources and UK based brain tumour clinical trials.

We've developed this site for you with the support of brain tumour patients, carers, and leading neuro healthcare professionals. Our aim is to help you turn every stone in your battle against a brain tumour.

Brain Tumour
Support

Brain Tumour
Clinical Trials

Treatment
Information

Patient Information
Portal

Enter your postcode to find your nearest brain tumour resource:

[View a complete list of brain tumour resources >](#)

Username:

Password:

[Request an information pack](#)

brain tumour hub news:

March 2012 - 44 updates just completed on the brain tumour hub - new brain tumour support groups, online resources and updated support line details added. Worth checking for new services in your area.

March 2012 - New information uploaded to the brain tumour hub to cover brain tumour support groups, networking and bereavement support in Yorkshire.

Whilst we've made every effort to make this as easy as possible for you to use, if it's all still a bit much, then why not give us a call? The brainstrust brain tumour support line is open 24/7. Give us a call on 01963 292405, even if it's just to say 'hi'.

© 2012 brainstrust | Contact us |
Registered Charity No 1114024

Think Creative

Backing from
nominet trust
www.nominettrust.org.uk

Home
About us
How we can help
How you can help
News
Our campaigns
Little ships
Online shop
Contact us

Search the site

search

Community

We can't wait to meet you!

Remember that you are not alone on your brain tumour journey. This page is a gateway to all kinds of experienced based brain tumour support. Real world, or virtual world you can click on links, pick up the phone, type, talk text and share, but most of all, know that you are not alone. We can't wait to meet you!



Forum

Click here to go to the brainstrust forum - Let's grow something special, relevant and useful to people battling a brain tumour.



Email support

Click here to email brainstrust support specialists for confidential 24/7 brain tumour support.



Telephone support

Want to talk to someone? We've a dedicated team on hand to listen and help. **Open 24/7, you can call us on 01983 292405**



Meet ups

Taking the community into the real world. Click here to get involved in this popular and exciting project.



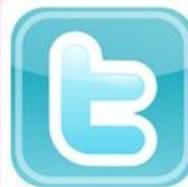
Brain Tumour Hub

Click here for a comprehensive list of UK brain tumour support services and brain tumour clinical trials.



Facebook

Click here to join over 1000 members of the brain tumour community.



Twitter

Join our community on twitter for a chat and for up to date brain tumour info.

Give today

Donate Now

Help us support brain tumour patients and their families in the UK
[Donate online](#)

Talk to us



Share photos and message other brainstrust fans on [facebook](#)



Follow us on [Twitter](#)

Stay in touch

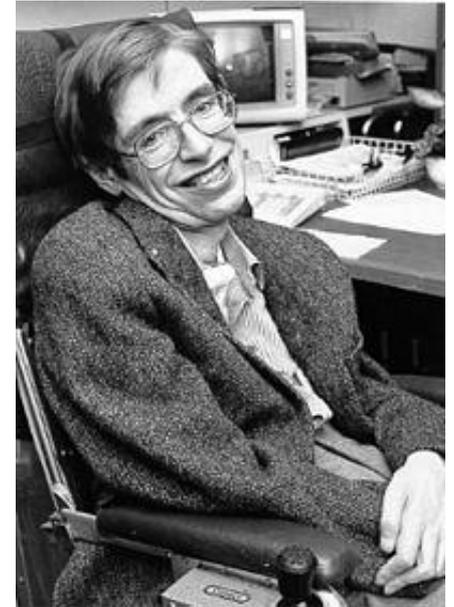
Sign up for the **DeckLog**, our entertaining newsletter.

First Name

Last Name

Email

Sign up!



All these people have built their own communities, on and offline with different 'levels' of discourse and engagement. Proof if ever there was that the existing support channels we have are suitable, nothing new is needed. But also demonstrative of the fact that we have a responsibility to promote and gently guide consumers towards the more educated and informed end of the spectrum. An opportunity!

Challenges

- Clinical time and workload
- Others

Benefits

- ...for patients
 - Empowered partners in their care
 - Useful for helping with difficult situations
- ...for clinicians
 - Work with informed patients to make the best decisions
- ...for the NHS
 - The information revolution
 - Shared decision making: “No decision about me, without me”



Please tell us what you think!

anne.swift2@nhs.net

will@brainstrust.org.uk

Thanks to Jem Rashbass, Sarah Stevens, Helen Bulbeck, Meg Hill and *the brainstrust*