

The Patient's Perspective

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Agenda

- The charity network - scale and reach
- Capturing patient/ family perspectives
- Ongoing concerns for patients and families
- Charity joint call for action - the Brain Tumour Manifesto
- Working together with Government

The charity network – scale and reach

- General cancer charities - large and small
- General neurological charities - large and small
- Dedicated brain tumour charities – larger and smaller and general/ tumour specific
- Person specific charities, in - charity groups and tribute funds
- Umbrella organisations

The charity network – scale and reach

Campaigning and lobbying through umbrella organisations:

Cancer 52

The Cancer Campaigning Group

The Rarer Cancer Foundation

The Neurological Alliance

National Voices

The National Council for Voluntary Organisations

and now also through.....



The charity network –scale and reach

..and now also through

The Brain Tumour Charity Coalition



SAMANTHA DICKSON
BRAIN TUMOUR TRUST

Head to head with brain tumours



Brain Tumour
Research



BRAIN
TUMOUR
UK



Capturing patient perspectives

Evidence based from:

Social networks, forums and blogs

Emails and helplines

On-line and off-line feedback and surveys

Patient stories and support groups

Focus groups

Conferences and information days

Ongoing concerns for brain tumour patients?

- Good data UK wide
- Information/ support, on/after diagnosis
- Late diagnosis/ missed diagnosis
- Best possible care, when and where needed
- Support for carers often coping alone
- Shortage of CNS nurses and care workers
- Post - treatment care in the community
- More clinical trials and research

The Brain Tumour Manifesto

A MANIFESTO FOR EVERYONE AFFECTED BY A BRAIN TUMOUR

This coalition of brain tumour organisations presents this manifesto on behalf of everyone diagnosed with a brain tumour in the UK each year, and their carers, families and friends.

We call on Governments throughout the UK to work in partnership with the UK's brain tumour charities to:

- 1** Ensure early diagnosis and treatment for everyone affected by a brain tumour.
- 2** Implement the best practice guidance for treating people with brain and CNS tumours.
- 3** Significantly increase Government investment in brain tumour research.

The Brain Tumour Manifesto

1 Ensure early diagnosis and treatment for everyone affected by a brain tumour

- Diagnosis of brain tumour often delayed
- GPs and A&E teams not requesting scans early enough
- Scans not referred to specialist neuro teams
- Misdiagnosis of headaches, nausea, migraines etc

Where are we now?

So.....

- Charities welcomed Government announcement of £25 million for early stage scans
- Look forward to hearing mechanism for allocation - who will authorise and neuro science team involvement

Meanwhile.....

- SDBTT action/ campaign May 2011
- Charity coalition will back
- We are collecting / using patient case studies

The Brain Tumour Manifesto

2. Implement the best practice guidance for treating people with brain and CNS tumours

- IOG published in 2006 for implementation over 3 - year period
- Late implementation barely begun by autumn 2010
- Ongoing postcode lottery in standards of treatment, rehabilitation and care
- Ineffective and unsupportive rehabilitation

Where are we now?

We:

- Warmly welcome self-assessments against IOG standards from April 2011 and follow up process in 2012
- Will keenly await feedback on challenges and concerns to identify areas where our pressure on government may help
- Are exploring how we might work with MDTs/social services within *The Big Society*

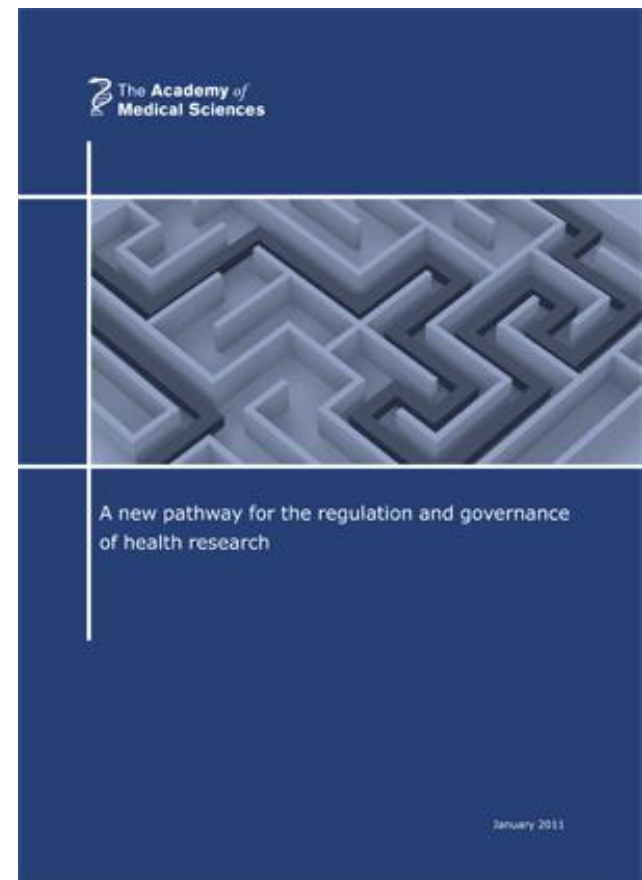
The Brain Tumour Manifesto

3. Significantly increase Government investment in brain tumour research

- Scientific research into brain tumours is underfunded
- Charities are working hard to increase research funding
- Belief that proportion of Government research funding remains proportionally low

Where are we now?

- Charities valued AMS report
- Existing statutory framework a major obstacle
- Welcome proposed new HRA
- Hope for early response



Where are we now?

We:

- We will be working to research/ publish a breakdown of site specific brain tumour research
- Are taking steps to ensure that by 2014 7.5% of adults are enrolled in randomised controlled clinical trials
- Are working with Professor Roy Rampling and his expert group on a strategic review of related issues and opportunities

Working together with Government

Wendy Fulcher