# Working with today's data for today's brain tumour community.





### New Research Paradigms

- A "flat" world, blending health and healthcare unbounded by place or time
- Lots of data, lots of things, everyone is "in"
- Challenges will be
  - Aggregating smaller data into Big Data (and back into personalised small data)
  - Analysing Big Data in appropriate clinical, social, environmental, etc. contexts
  - Drawing scientific conclusions, showing validity



- What data is there?
- What new work is happening today?
- What new questions do we have?
- What can we answer?
- What information is important to the community?



	AL CANCER INSTIT lance, Epidem		End Results Pi	ogram	Search SEER C
Cancer Statistics Statistical Summaries	Interactive Tools	Publications	For Researcher Datasets and Softwa		oport Our Registries and Research
<ul> <li>Colon and Rectum</li> <li>Endometrial Cancer</li> <li>Kidney and Renal Pelvis</li> <li>Leukemia</li> </ul>		Statistics at a Glance At a Glance			Show Less -
<ul> <li>Lung and Bronchus</li> </ul>		Estimated N Cases in 20		8]New Cases	Percent Surviving 5 Years
Melanoma of the Sk	homa			₩ Ó 6 -	
	homa	% of All Nev Cancer Case		a Peaths	
<ul> <li>Melanoma of the Sk</li> <li>Non-Hodgkin Lymp</li> <li>Pancreas</li> </ul>	homa →		15 220	Deaths	33.3%

Cancer Trends Progress Report

Did You Know? Video Series

**Glossary of Statistical Terms** 

**Other Statistical Resources** 

Software Used to Generate Statistics

[+] Defining Cancer Statistics

Resources

Tools 🖂 Email 📥 Print Page Number of New Cases and Deaths per 100,000: The number of new cases of brain and other nervous system cancer was 6.4 per 100,000 men and women per year. The number of deaths was 4.3 per 100,000 men and women per year. These rates are age-adjusted and based on 2008-2012 cases and deaths.

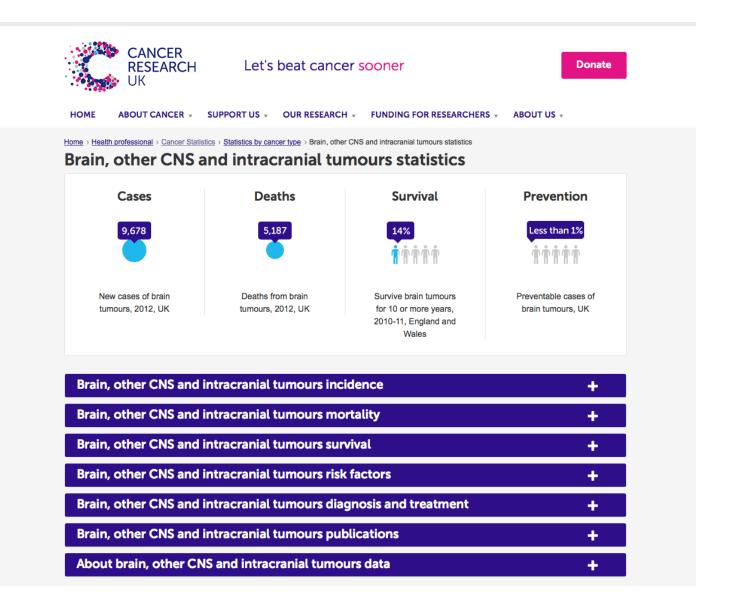
YEAR

Lifetime Risk of Developing Cancer: Approximately 0.6 percent of men and women will be diagnosed with brain and other nervous system cancer at some point during their lifetime, based on 2010-2012 data.

Prevalence of This Cancer: In 2012, there were an estimated 148,818 people living with brain and other nervous system cancer in the United States.

Survival Statistics	Show More +
Number of New Cases and Deaths	Show More +
Trends in Rates	Show More +
More About This Cancer	Show More +







#### The vision could be...

A responsive resource that gives access to data to help answer the important and relevant questions about the brain cancer patient journey in near real time.

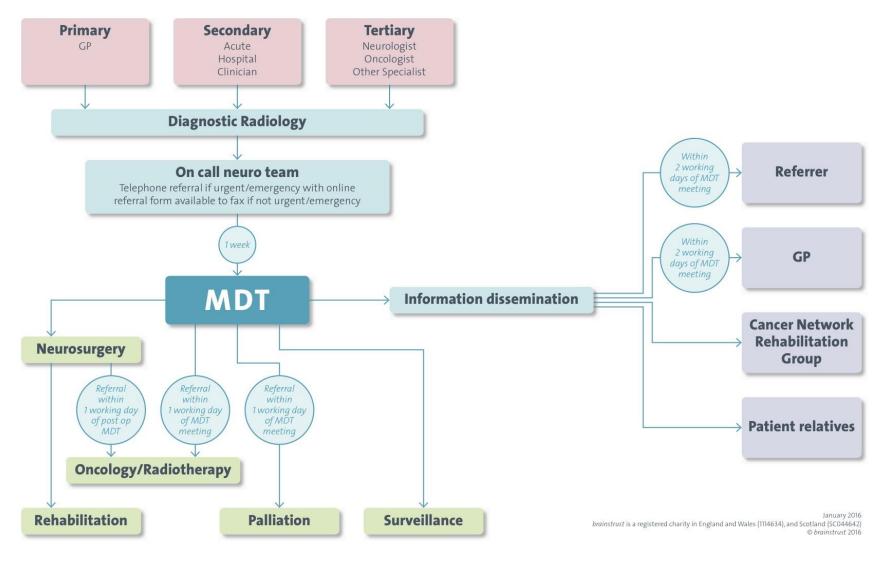
#### Additionality.

- Collaborative
- Progressive
- Positive
- •The whole pathway
- Robust
- Responsive
- Meaningful



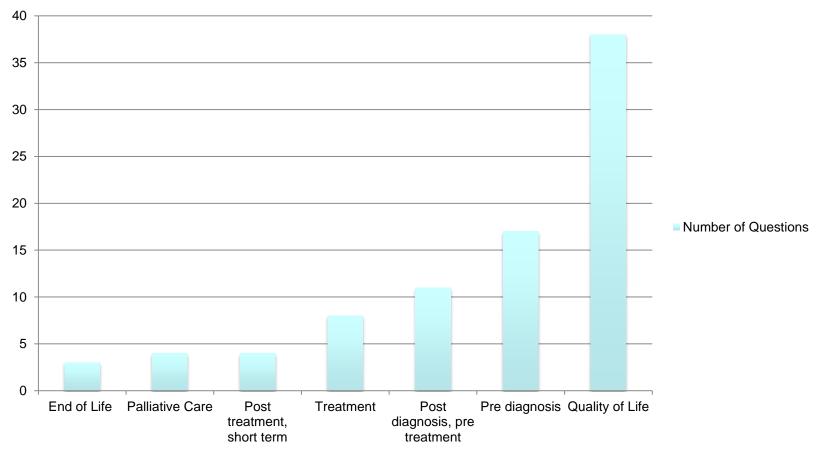
#### The patient's journey







#### **Number of Questions**





The (near) perfect storm:

•Patients want a better experience

•Carers want a better experience

•Clinicians understand the benefits

•3<sup>rd</sup> sector funders want to support a better experience for our community (but we still need to build a stronger case, with new data)

•Government understands it\* \*But isn't funding it yet, and probably wont on a site-specific level



## Improving the experience is *brainstrust's* focus and only priority

We raise funds to deliver resources, services and research that:

-Make you feel in control
-Help you feel less alone
-Help you become informed
-Make you less afraid





