Routes from Diagnosis

Brain/CNS Tumour SSCRG Meeting

26/03/14

WE ARE MACMILLAN. CANCER SUPPORT

Monitor Deloitte.

Agenda

- Introduction and context for Macmillan analytical programme
- Overview of RfD and a look at the brain/CNS tumour framework
- Questions

Why did we do this research?

- 2 million people living with cancer, will increase to 4 million by 2030.
- Survival rate improving, longer disease trajectory, seemingly unpredictable health outcomes. Long term-implications or the needs of this population?
- Responsibility to understand the health implications and ensure rational, informed planning and development of cancer services.
- Needs and issues of survivors identified through small interview based studies - expensive and time-consuming. Is there an alternative, and more powerful approach?
- Link and analyse routinely collected data i.e. HES and CRD, at the population level to describe the clinical journey people follow after their cancer diagnosis

The brain/CNS tumour RfD project is part of a broader Macmillan research agenda

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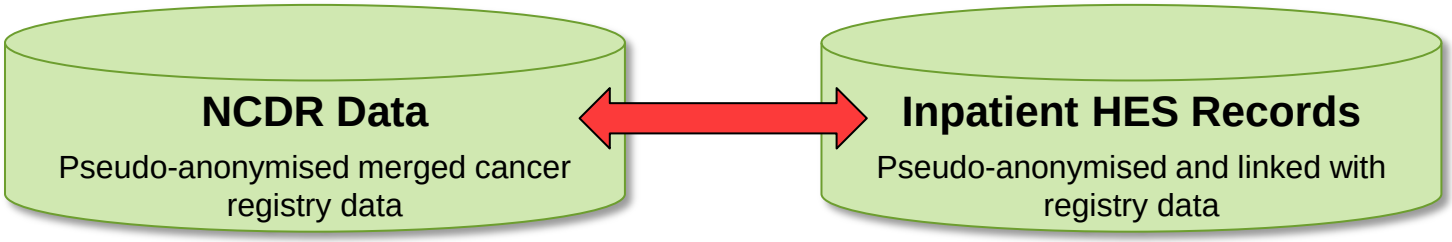
RfD uses anonymised NCDR and secondary care data linked at a patient and episode level….

Datasets linked by anonymised patient ID



- Patient level data
- Data include:
  - ONS survival data
  - Cancer stage & morphology
  - Demographic patient information

- Hospital episode level data
- Data include:
  - Dates of hospital admission
  - Type of hospital admission
  - Diagnosis codes (ICD-10)
  - Treatment specifications (OPCS)

Cohorts Studied

- **Core cohort** of analysis comprises of patients diagnosed with Brain or CNS tumours in **2003-2004**
- Analysis also conducted on patients from 2001-2002 and 2005-2006 to examine differences over time
- Hospital records of patients obtained from up to 8 years pre diagnosis until death or 7 years post diagnosis
- Period of cohorts studies mean that **some treatment advances e.g. Temozolomide aren't reflected** in the data presented

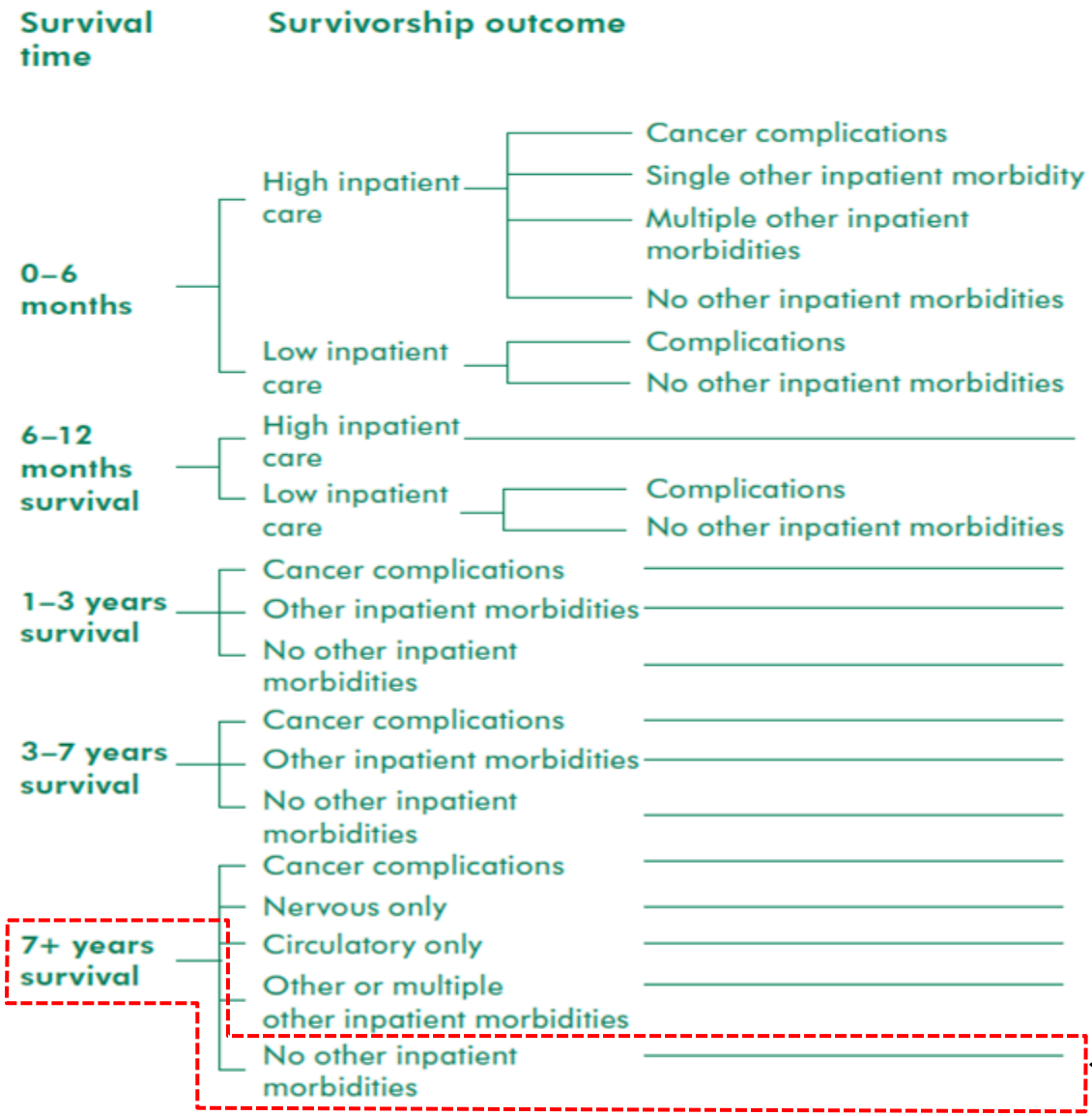
… to create the RfD framework which quantitatively describe the survivorship of historic cohorts

- **survival** + **meaningful pathway characteristics = 'survival + 1'**, (Survivorship Outcome Pathways)

- Survivorship Outcome Pathways can:

  - describe the burden of cancer

  - provide useful and applicable information for care providers and **commissioners**



One consolidated national level RfD Survivorship Outcome Framework has been developed for brain/CNS tumours under the expert guidance of the clinical team

i

- The team worked with **NCIN clinical experts** to determine
  - The most clinically appropriate way to group **survival,** e.g.,

0 – 1 mths	1 – 6 mths	6 – 12 mths	1 – 3 Years	3 – 7 Years	7+ Years

  - **'Survival + 1'** - The most clinically meaningful pathway characteristics, e.g.,

Cancer complications	Inpatient Morbidities	Inpatient experience
e.g., • Additional primary cancer • Recurrence	e.g., • Circulatory morbidities • Endocrine morbidities	e.g., • High proportion of survivorship spent in an inpatient setting

ii

- **Combinations** of survival and meaningful pathway characteristics were then identified which represented a **large number** of **clinically similar patients**, e.g.,

Survive 1 – 3 years + Inpatient Moribidity

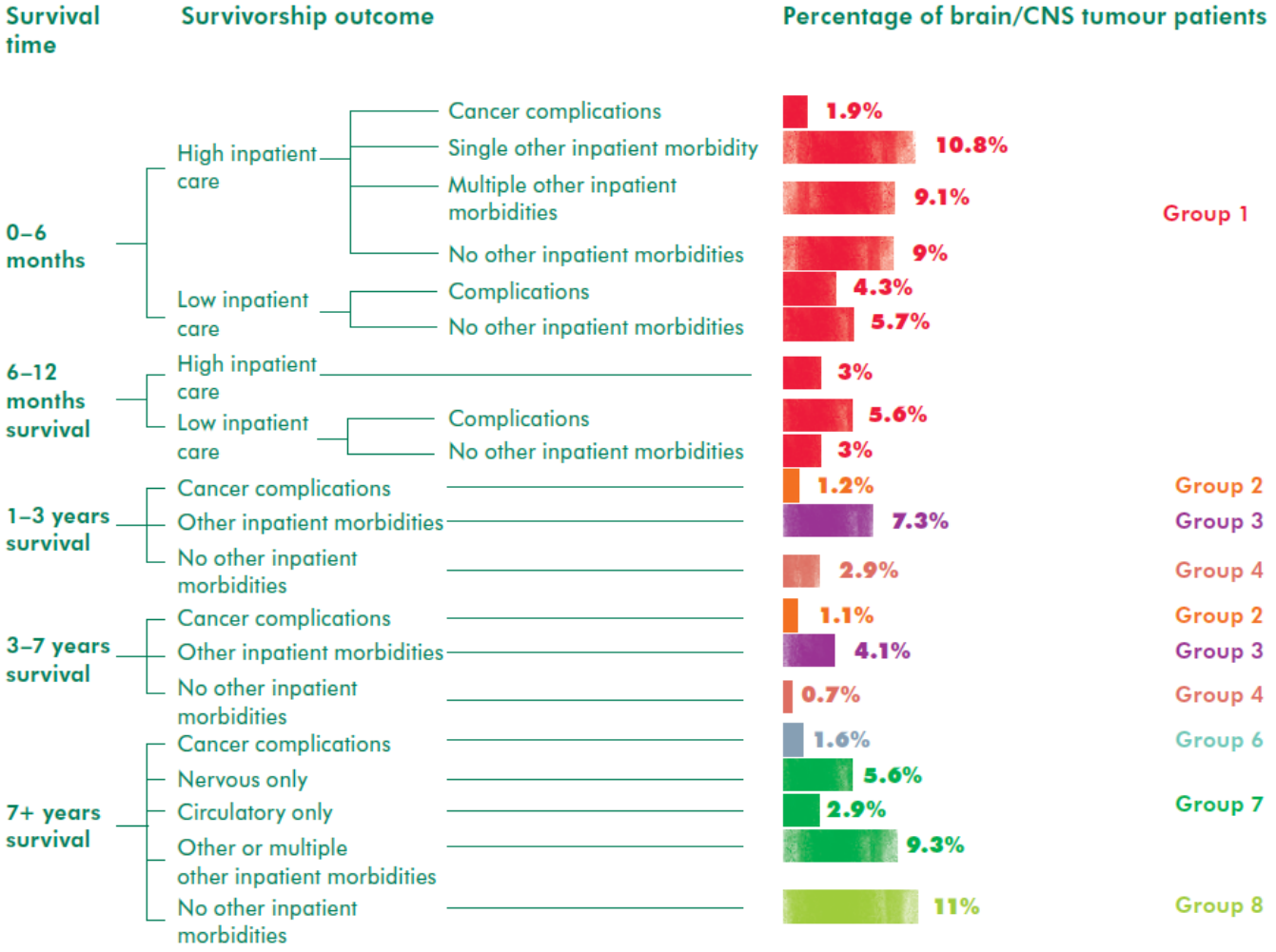
iii

- The clinically determined pathways were then **checked** so that each represented a **group of patients with similar resource usage**

Final Pathways

Developed with expert guidance of Professor Collins, Dr Greenberg & Mr Brodbelt

ii Combining survival and 'survival + 1', the brain/CNS tumour framework has 20 Survivorship Outcome Pathways

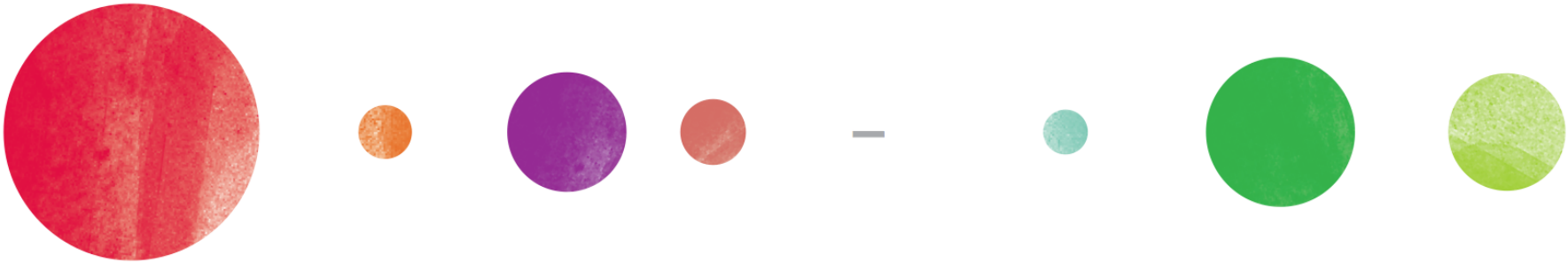


Note: Group 5 is not applicable to the brain/CNS tumour framework

Key
Cancer Complications: Recurrence or additional primary cancer
High inpatient care: Patient spent more than 25% of survival length in hospital
Low inpatient care: Patient spent less than 25% of survival length in hospital

Note: No complications indicates no identified complications as deemed relevant by a clinical panel; N = 8,762, 0% excluded

When you simplify the framework down to seven or eight groups you can begin to identify patterns of survivorship experience



52.4% 2.3% 11.4% 3.6% – 1.6% 17.8% 11.0%

Limited survival

- **Group 1**
  0–12 months survival

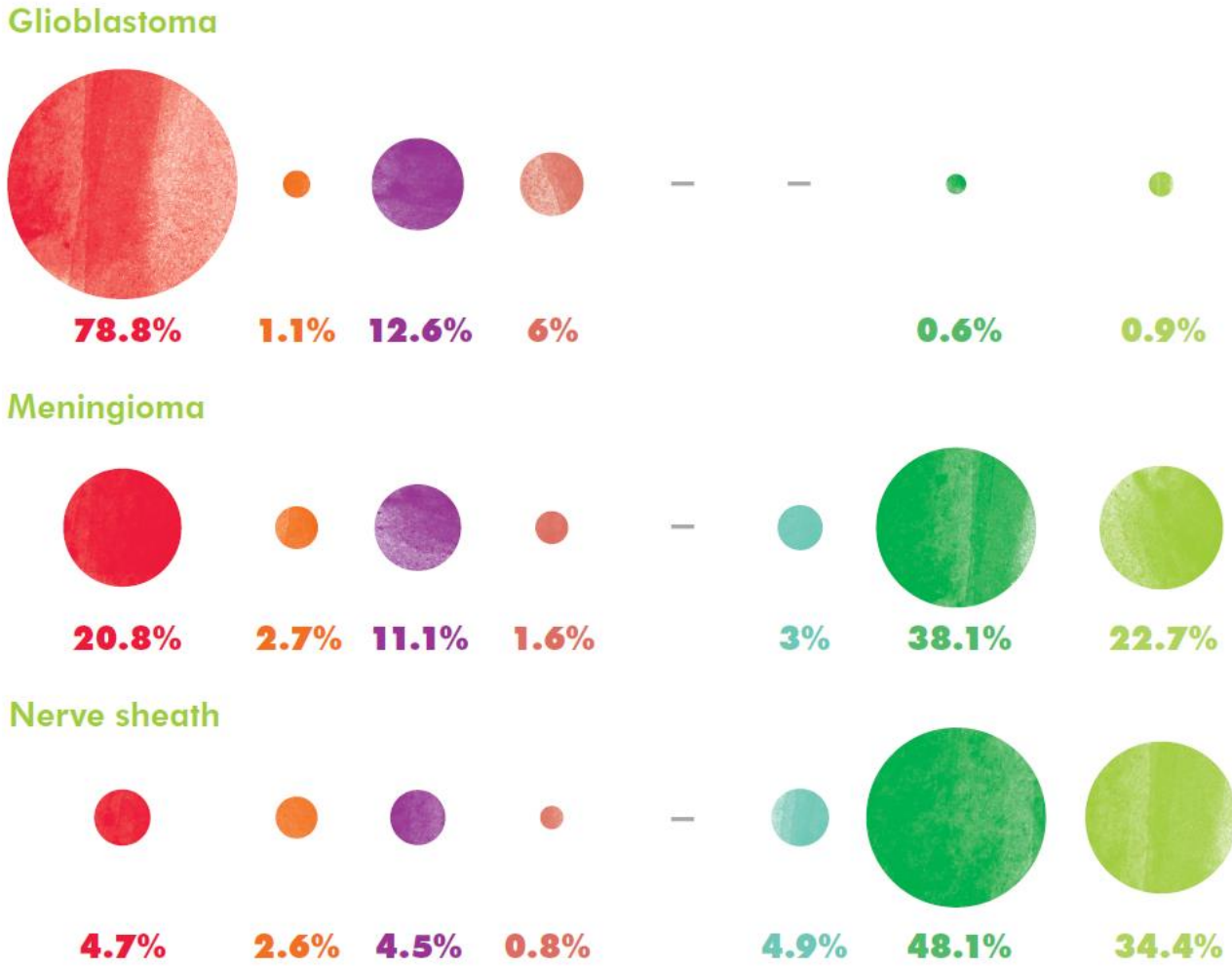
Limited–moderate survival

- **Group 2**
  1–7 years survival with cancer complications
- **Group 3**
  1–7 years survival with other inpatient morbidities
- **Group 4**
  1–7 years survival with no other inpatient morbidities

On-going survival

- **Group 6**
  7+ years survival with cancer complications
- **Group 7**
  7+ years survival with other inpatient morbidities
- **Group 8**
  7+ years survival with no other inpatient morbidities

Then by applying the framework to the different morphology groupings, we see clear differences in survivorship experience across them



Limited survival

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On-going survival

- **Group 6** 7+ years survival with cancer complications
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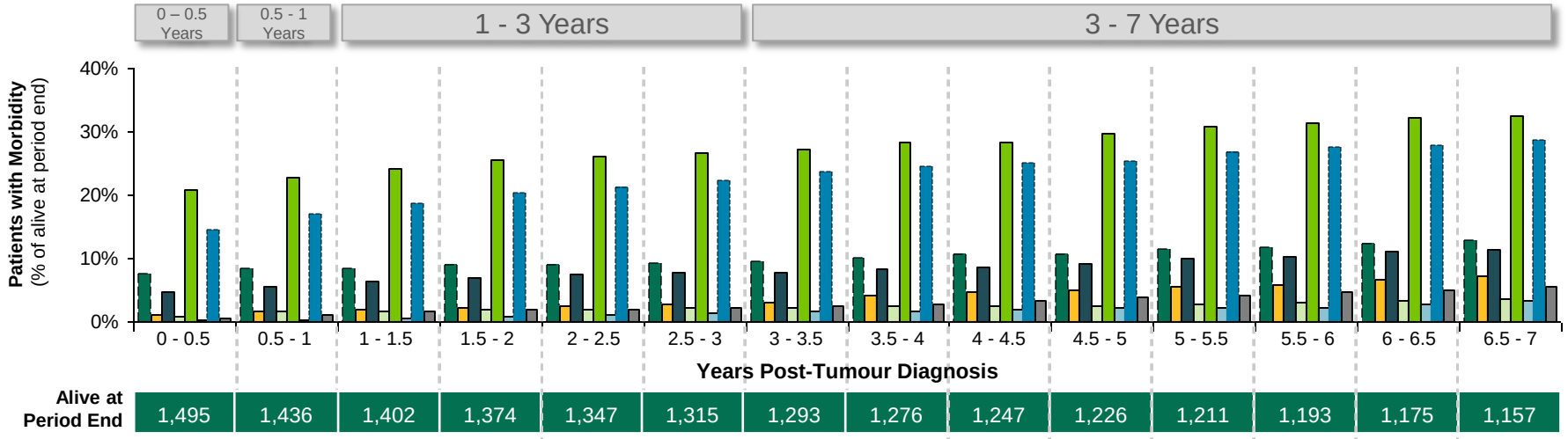
- **Group 8** 7+ years survival with no other inpatient morbidities

Note: Highlighted regions denote high patient populations; N = 8,762, 0% excluded

Meningioma patients seem to be particularly overindexed for endocrine and nervous system morbidities vs the comparison population

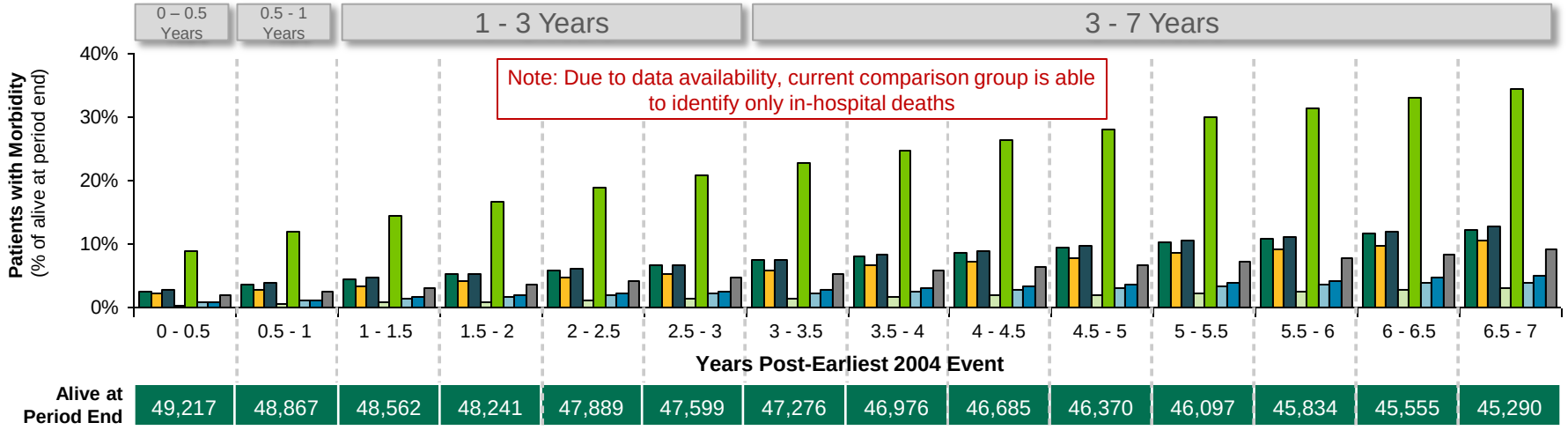
Meningioma

% of living *Meningioma Tumour Population* with a morbidity *in 0.5 Year Periods Post-Tumour Diagnosis (N = 1,812)*



Alive at Period End	0 - 0.5	0.5 - 1	1 - 1.5	1.5 - 2	2 - 2.5	2.5 - 3	3 - 3.5	3.5 - 4	4 - 4.5	4.5 - 5	5 - 5.5	5.5 - 6	6 - 6.5	6.5 - 7
	1,495	1,436	1,402	1,374	1,347	1,315	1,293	1,276	1,247	1,226	1,211	1,193	1,175	1,157

% of living *Comparison Population* with a morbidity *in 0.5 Year Periods Post-Earliest 2004 Event (N = 50,000)*

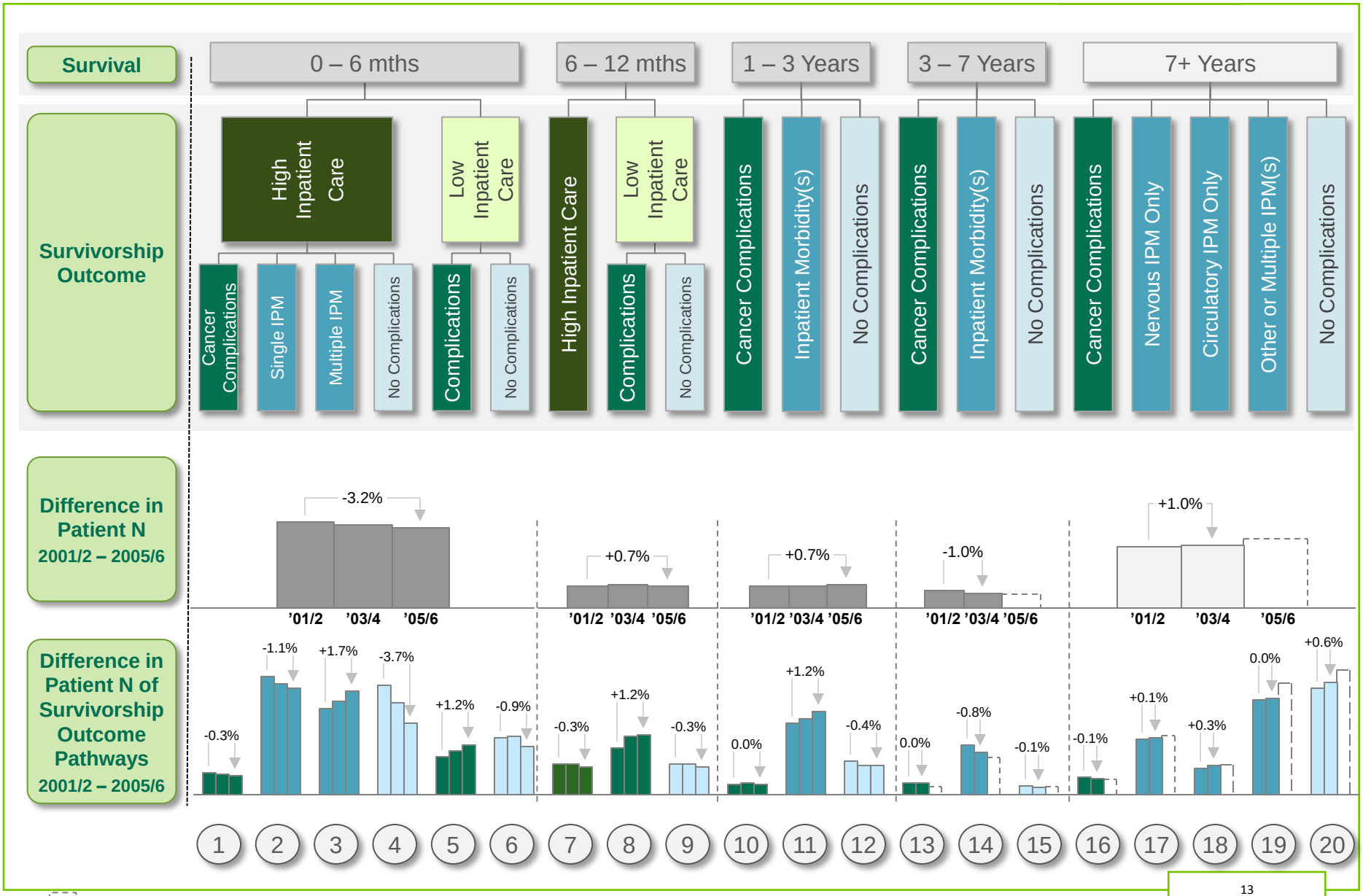


Alive at Period End	0 - 0.5	0.5 - 1	1 - 1.5	1.5 - 2	2 - 2.5	2.5 - 3	3 - 3.5	3.5 - 4	4 - 4.5	4.5 - 5	5 - 5.5	5.5 - 6	6 - 6.5	6.5 - 7
	49,217	48,867	48,562	48,241	47,889	47,599	47,276	46,976	46,685	46,370	46,097	45,834	45,555	45,290

KEY: **Patient stocks** Endocrine | Digestive | Respiratory | Musculoskeletal | Circulatory | Genitourinary | Nervous | New Primary Cancer

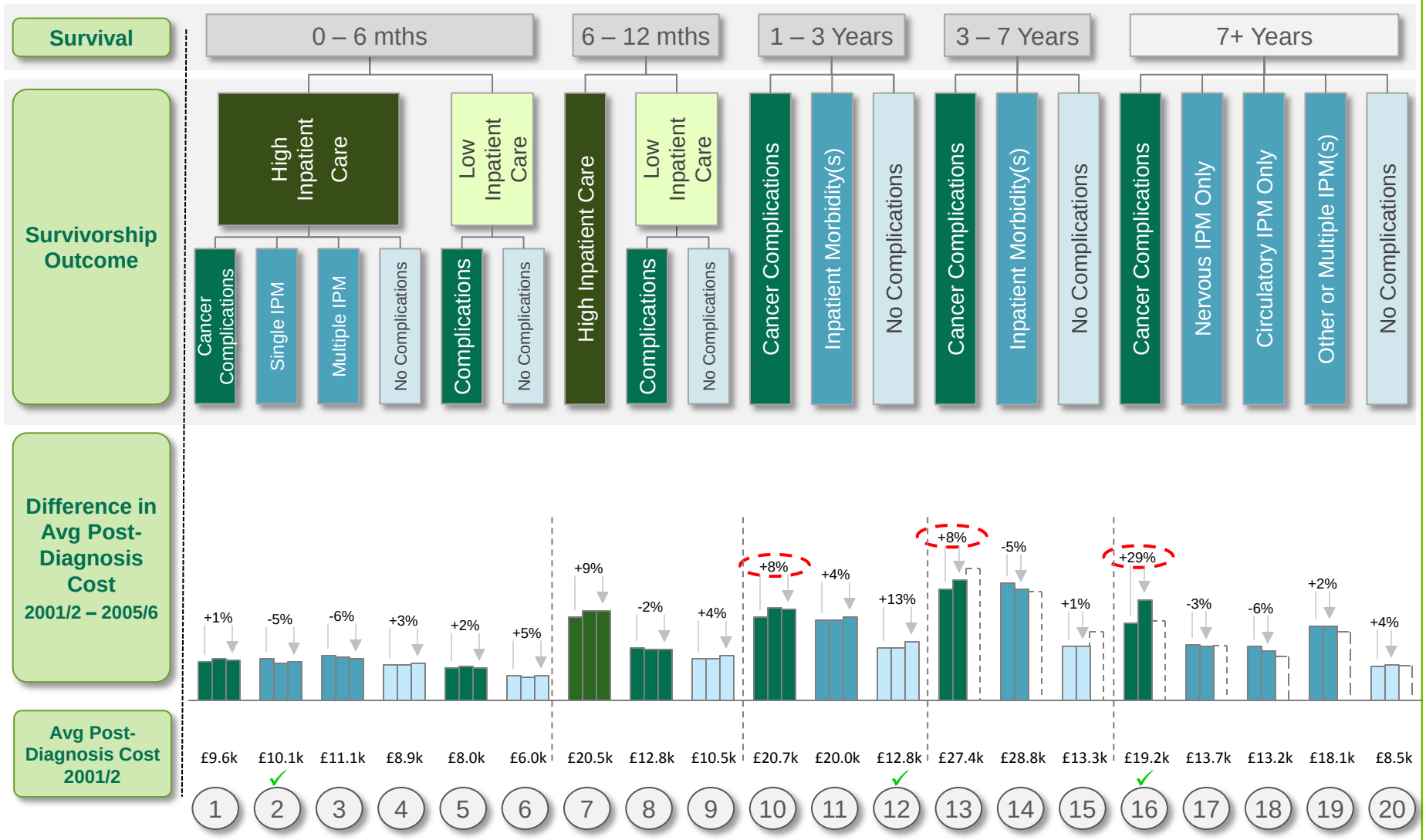
Note: Due to data availability, current comparison group is able to identify only in-hospital deaths, possibly inflating denominator in calculations
Source: HES Records 2003 - 2012

Applying the central framework to multiple cohorts shows us how general survival has been fairly flat over time with some limited improvements in later survival



Note: Cohort not valid for comparison based on length of available survival data; N for 2001/2 cohort = 8655 patients

For patients surviving longer, cancer complications are considerably more expensive in more recent years for brain/CNS tumours

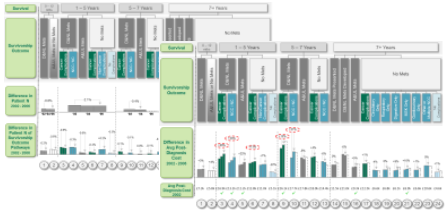


Note: ✓ indicates rejection of equality of means at p = 0.05 using 1-way ANOVA; ⬚ Cohort not valid for comparison based on length of available survival data; Post-diagnosis cost indicates cost from 90 days pre-diagnosis onwards; inpatient cost only; HRG 4.0 codes are costed using the 2011/12 National Tariff - costs are inpatient only and priced at the spell, rather than episode, level (in line with how commissioners pay providers); Non-tariff costs to the commissioner are approximated using publically reported non-tariff costs to providers

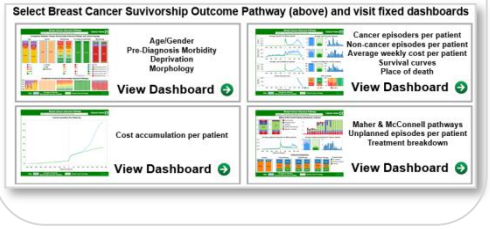
There are a broad swathe of different uses for the RfD framework …

Describing Survivorship Morbidity

Describing Pathway Evolution Over Time

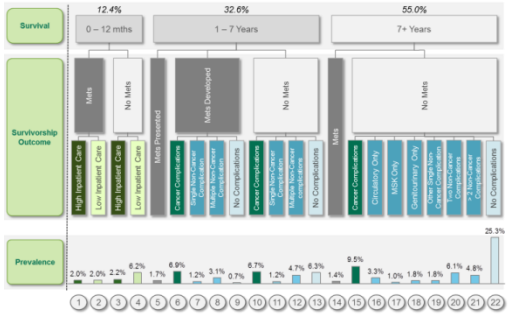


Describing Individual Pathway Experiences

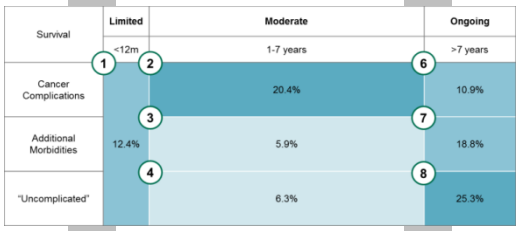


Descriptions

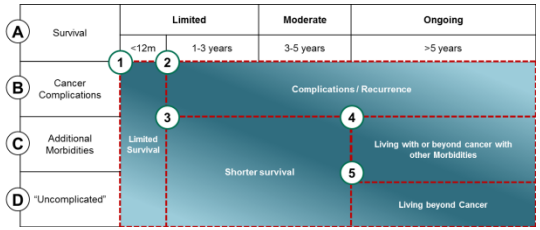
Detailed Survivorship Outcome Frameworks



Simplified Survivorship Outcome Frameworks

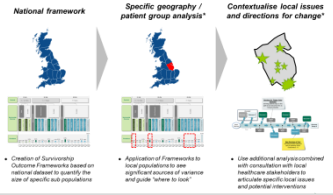


Pathways for Service Redesign

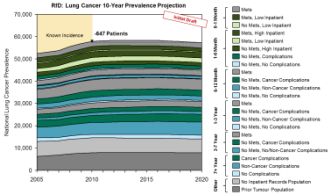


Applications

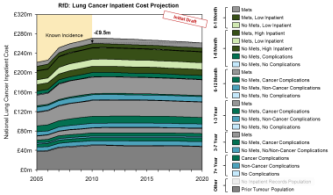
Diagnostic tool to Identify Local Variation



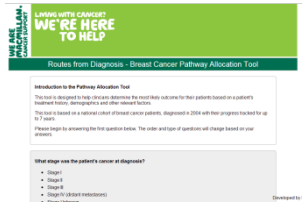
Understanding Prevalence



Costing a Cancer Population



Pathway Allocation Tool



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What are your reflections on RfD?

Returning to the guiding questions we introduced at the start of the session:

- **What** new insight does RfD bring that you did not have access to before?
- **What** about RfD remains tricky to understand?
- **Where** could you see an RfD approach being most helpful going forward?
- **How** could RfD add value to other ongoing NCIN projects?