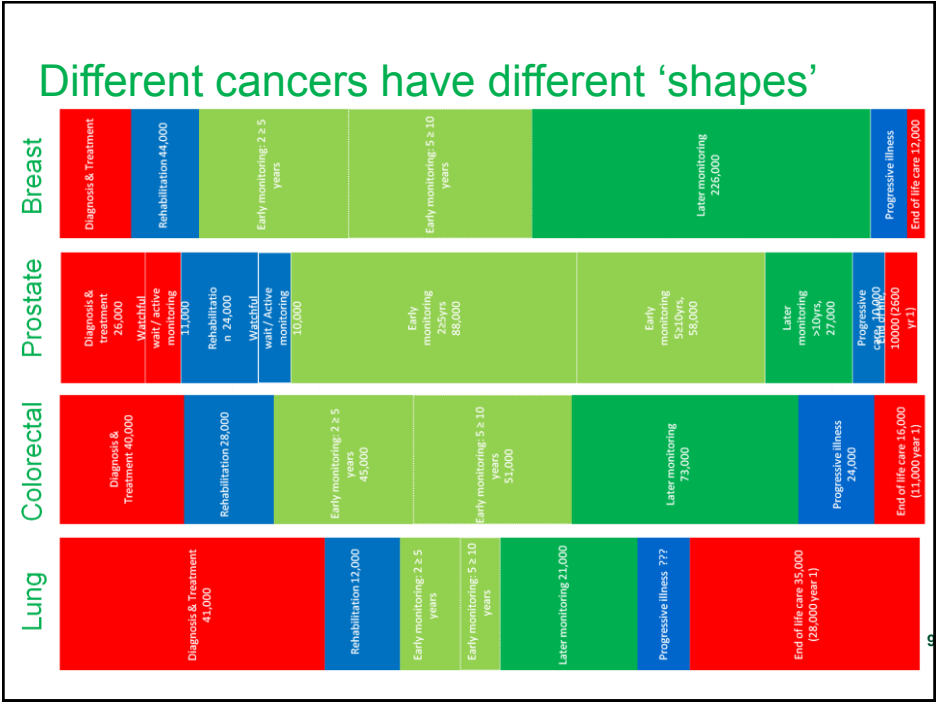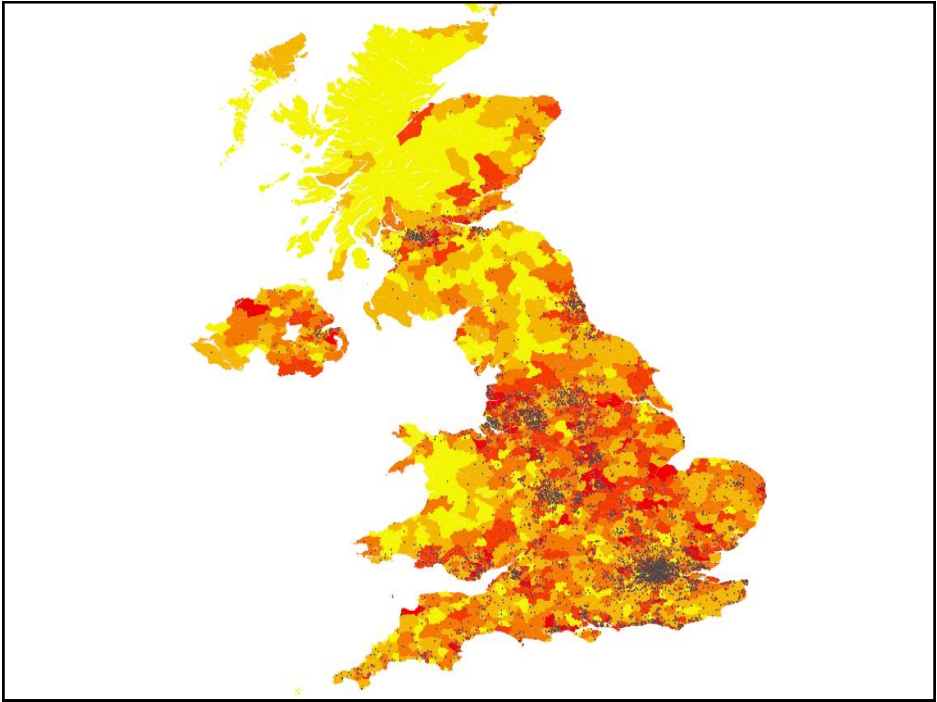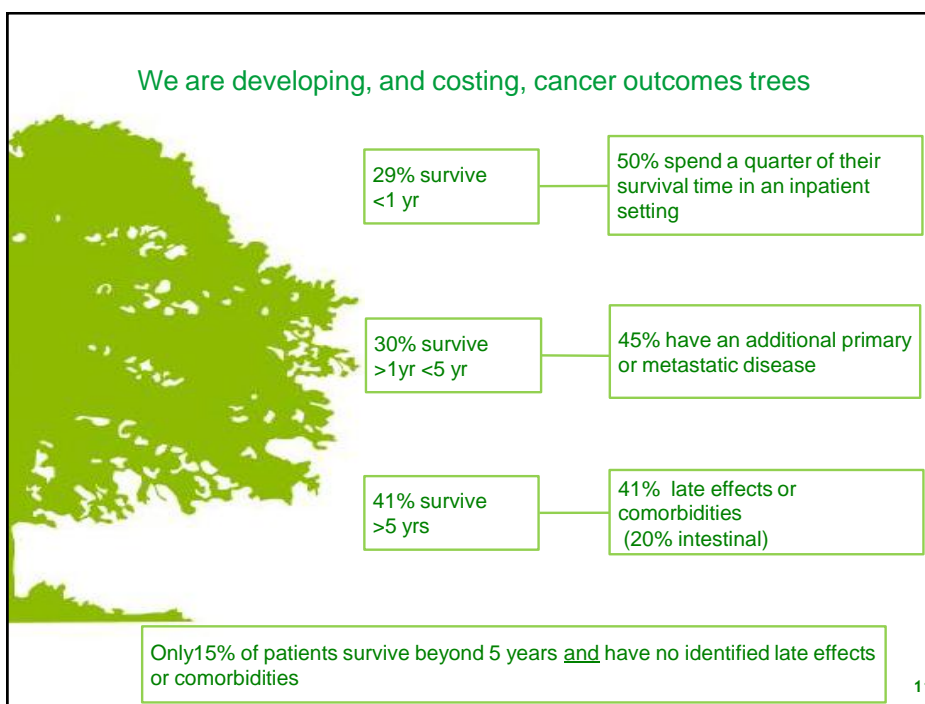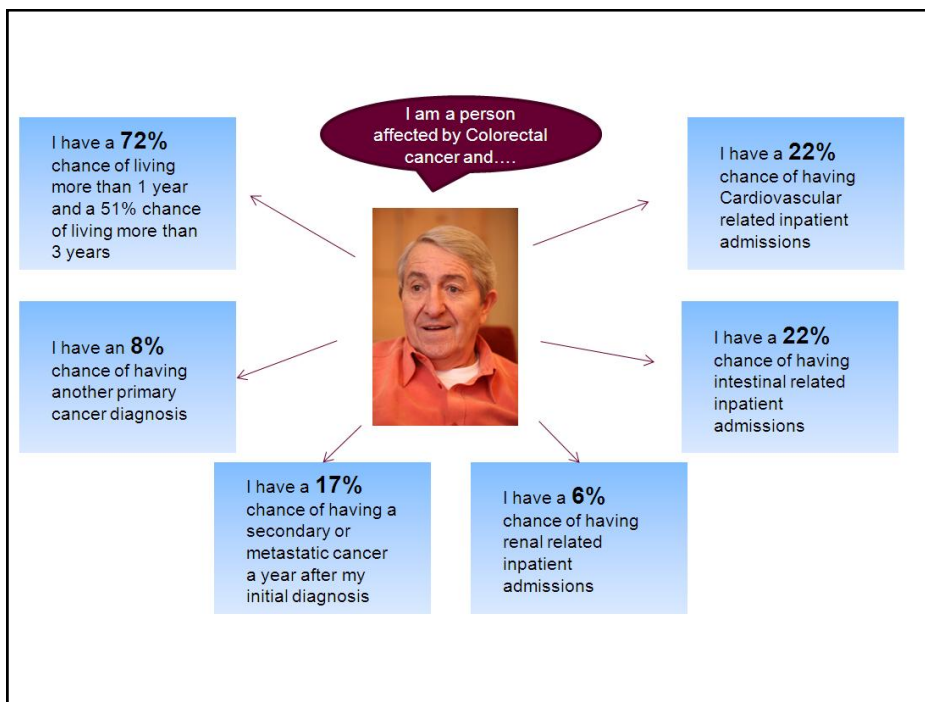**Are data really benefiting patients?**

Ciarán Devane
Chief Executive

WE ARE MACMILLAN. CANCER SUPPORT

2 MILLION

Different cancers have different 'shapes'
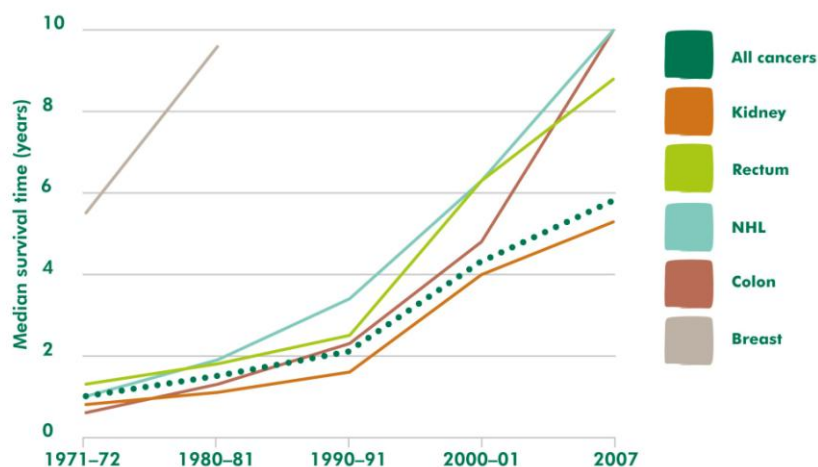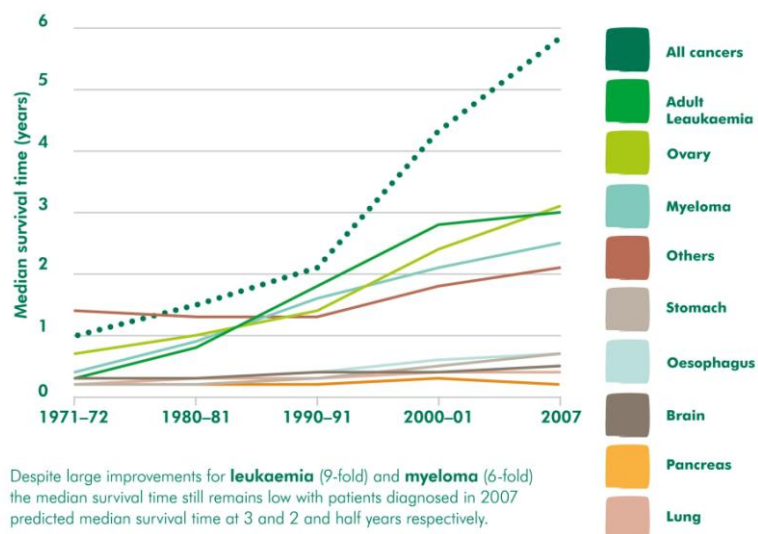

Breast
- Diagnosis & Treatment
- Rehabilitation 44,000
- Early monitoring: 2 ≥ 5 years
- Early monitoring: 5 ≥ 10 years
- Later monitoring 226,000
- Progressive illness
- End of life care 12,000

Prostate
- Diagnosis & treatment 26,000
- Watchful wait / active monitoring 11,000
- Rehabilitation 24,000
- Watchful wait / Active monitoring 10,000
- Early monitoring 2≥5yrs 88,000
- Early monitoring 5≥10yrs, 58,000
- Later monitoring >10yrs, 27,000
- Progressive illness 14,000
- 10000 (2600 yr 1)

Colorectal
- Diagnosis & Treatment 40,000
- Rehabilitation 28,000
- Early monitoring: 2 ≥ 5 years 45,000
- Early monitoring: 5 ≥ 10 years 51,000
- Later monitoring 73,000
- Progressive illness 24,000
- End of life care 16,000 (11,000 year 1)

Lung
- Diagnosis & Treatment 41,000
- Rehabilitation 12,000
- Early monitoring: 2 ≥ 5 years
- Early monitoring: 5 ≥ 10 years
- Later monitoring 21,000
- Progressive illness ???
- End of life care 35,000 (28,000 year 1)

I am a person affected by Colorectal cancer and….

I have a **72%** chance of living more than 1 year and a 51% chance of living more than 3 years

I have a **22%** chance of having Cardiovascular related inpatient admissions

I have an **8%** chance of having another primary cancer diagnosis

I have a **22%** chance of having intestinal related inpatient admissions

I have a **17%** chance of having a secondary or metastatic cancer a year after my initial diagnosis

I have a **6%** chance of having renal related inpatient admissions

We are developing, and costing, cancer outcomes trees

29% survive <1 yr

50% spend a quarter of their survival time in an inpatient setting

30% survive >1yr <5 yr

45% have an additional primary or metastatic disease

41% survive >5 yrs

41% late effects or comorbidities (20% intestinal)

Only15% of patients survive beyond 5 years <u>and</u> have no identified late effects or comorbidities

11

3

Median survival time (years), by period of diagnosis and cancer[1]

Source: Macmillan Cancer Support identified median survival times based on research by the Cancer Research UK Cancer Survival Group at the London School of Hygiene and Tropical Medicine. Incidence and mortality data for the survival analysis are originally sourced from the Office for National Statistics.

Median survival time (years), by period of diagnosis and cancer[1]

Despite large improvements for **leukaemia** (9-fold) and **myeloma** (6-fold) the median survival time still remains low with patients diagnosed in 2007 predicted median survival time at 3 and 2 and half years respectively.

Source: Macmillan Cancer Support identified median survival times based on research by the Cancer Research UK Cancer Survival Group at the London School of Hygiene and Tropical Medicine. Incidence and mortality data for the survival analysis are originally sourced from the Office for National Statistics.

Median survival time (years) by period of diagnosis, all cancers[1]

1 year	1971–72
1.5 years	1980–81
2.1 years	1990–91
4.3 years	2000–01
5.8 years	2007

Many of the patients diagnosed in 2007 will survive substantially longer than the predicted six years.

[1] Data are for adults aged 15–99 diagnosed in England and Wales. 2007 data are predicted survival estimates. Prostate and Bladder cancer are excluded. See Appendix 1 & 2 for full details.

Source: Macmillan Cancer Support identified median survival times based on research by the Cancer Research UK Cancer Survival Group at the London School of Hygiene and Tropical Medicine. Incidence and mortality data for the survival analysis are originally sourced from the Office for National Statistics.

Total Prevalence - now

| Diagnosis & treatment > 300,000 | Rehabilitation ~200,000 | Early monitoring 2-5 yrs ~380,000 | Early monitoring 5-10 yrs >400,000 | Later monitoring ~750,000 | Progressive illness >100,000 | End of life >150,000 |

Total Prevalence - 2030

| Diagnosis & treatment | Rehabilitation | Early monitoring 2-5 yrs | Early monitoring 5-10 yrs | Later monitoring | Progressive illness | End of life |

Quantifying the problem allows us to develop solutions.

Patient experience is best for breast cancer

Rank	Tumour
1	Breast
2	Skin
3	Prostate
4	Lung
5	Colorectal / Lower Gastro
6	Head & Neck
7	Upper Gastro
8	Gynaecological
9	Haematological
10	Urological*
11	Brain / CNS
12	Other
13	Sarcoma

Transparency will allow informed patients to make informed choices.

People write about cancer, a lot . . .

AIDS

Cancer

Tuberculosis
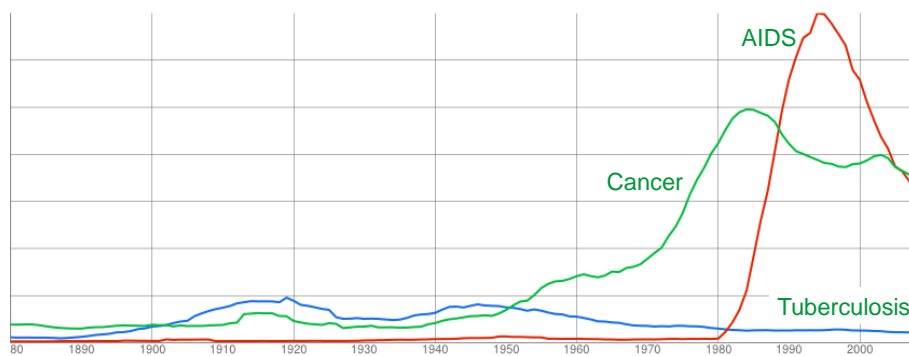
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… but the cancer story is changing, literally

Cancer Mortality

Cancer Survivorship

Cancer Survival
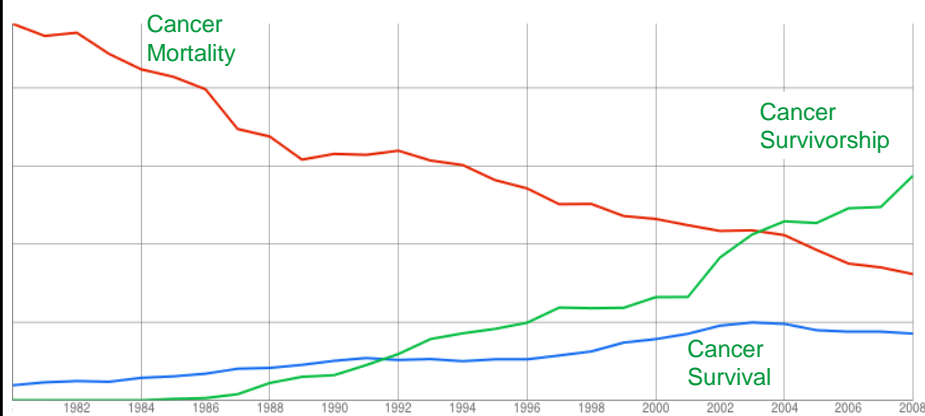
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Are data really benefiting patients?
Sizing services
Planning ahead
Quantifying & prioritising
Enabling decisions
Measuring change