

Using data to drive clinical improvements

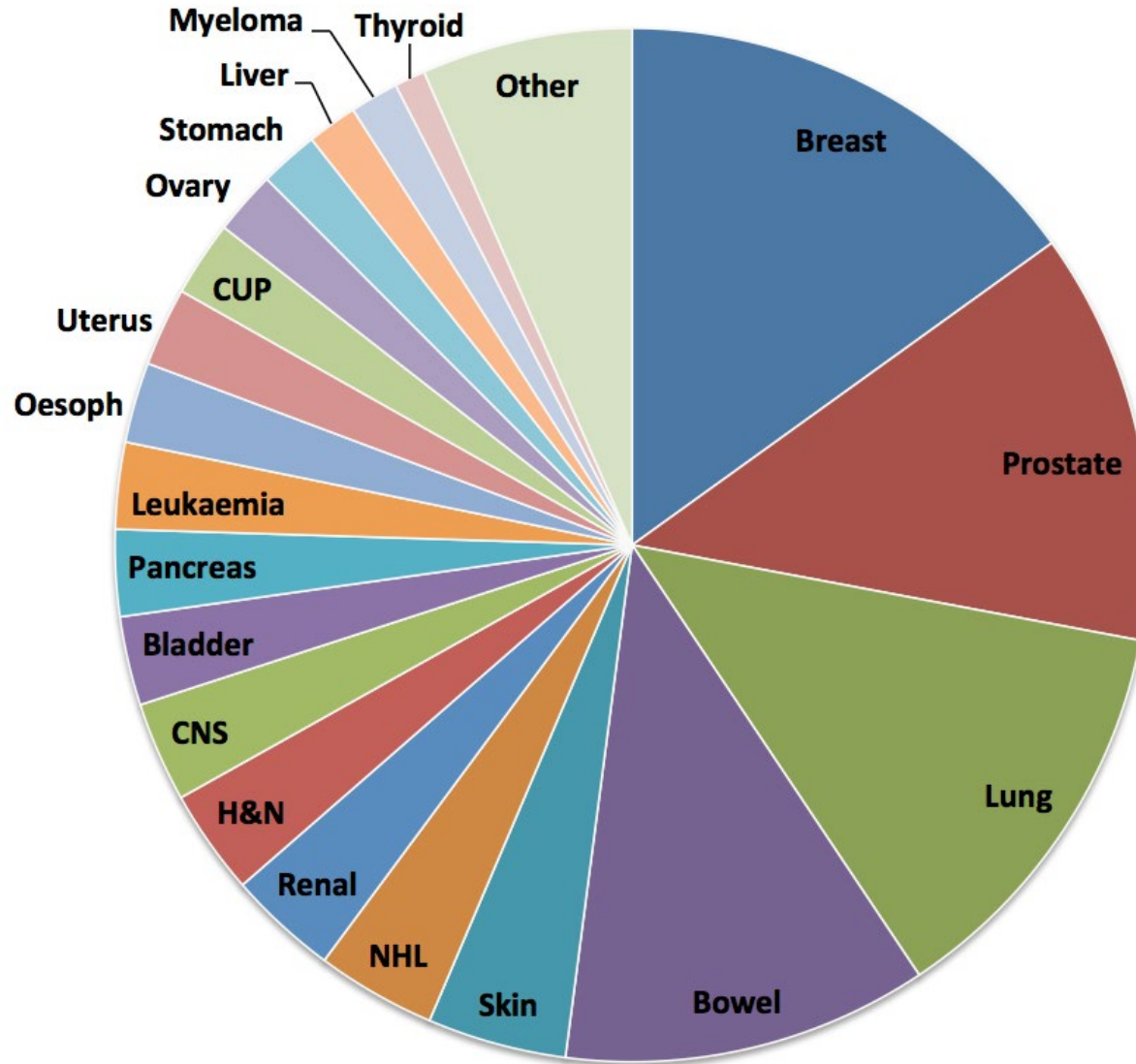
Dr Martin McCabe

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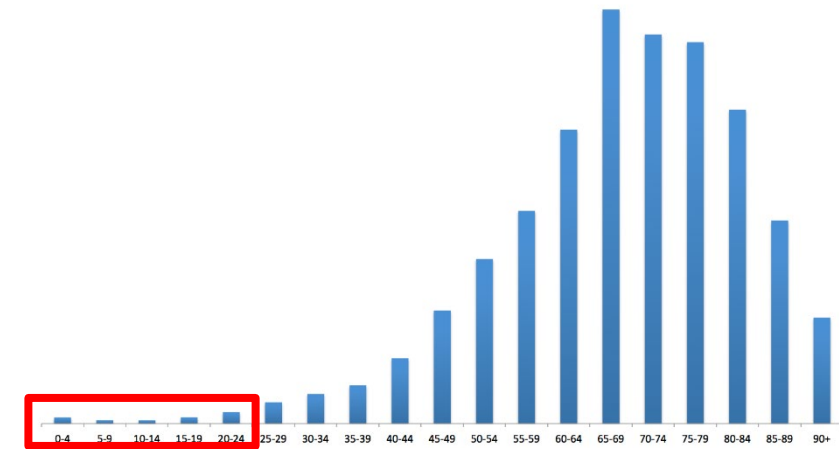
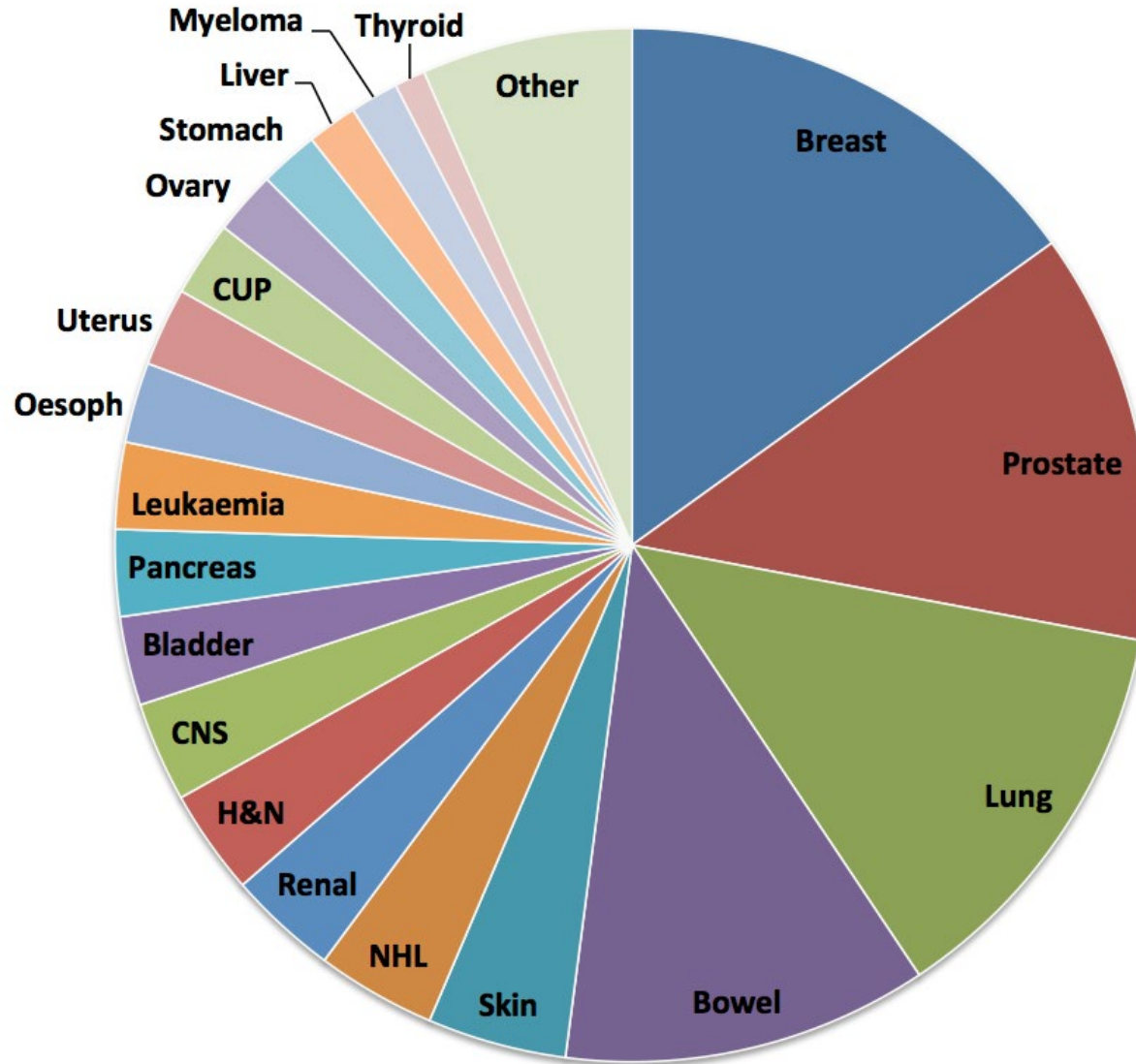
Clinical senior lecturer, University of Manchester

Hon consultant paediatric oncologist, The Christie NHS Foundation Trust

All cancers

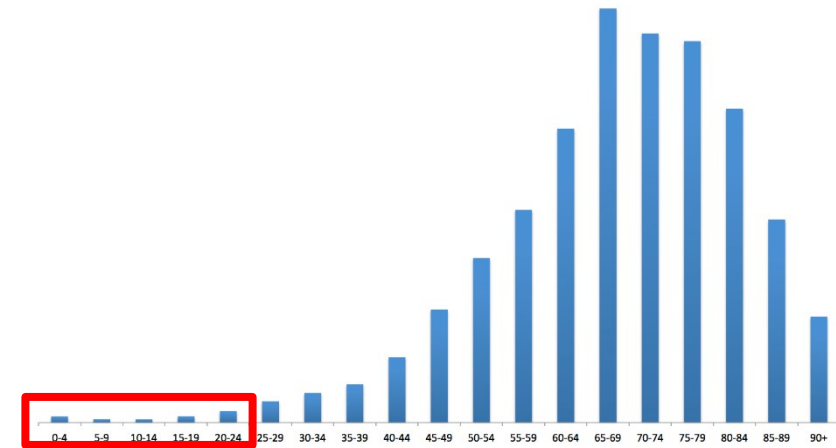
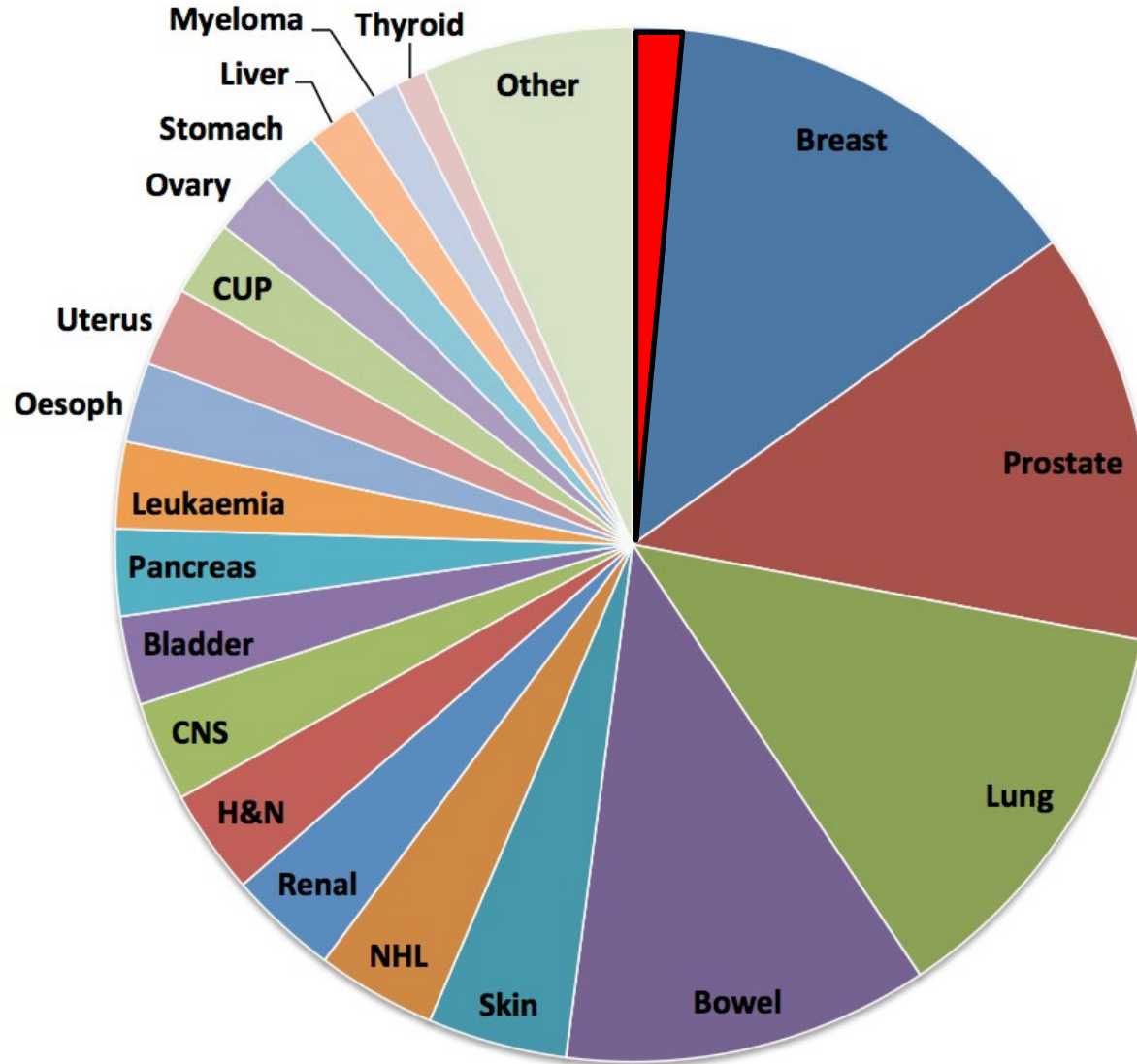


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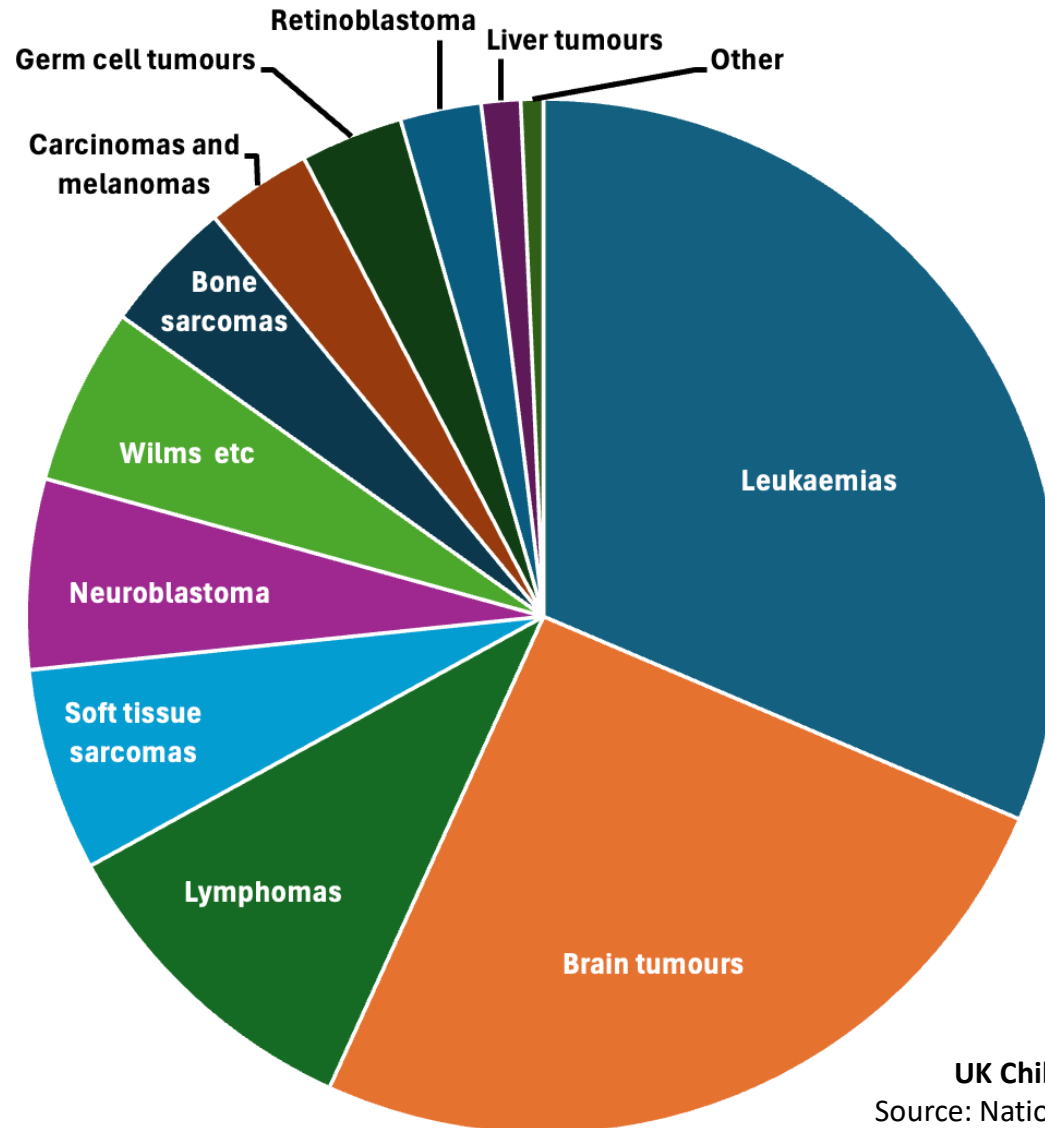


All cancers

Childhood & young adult $\approx 2\%$

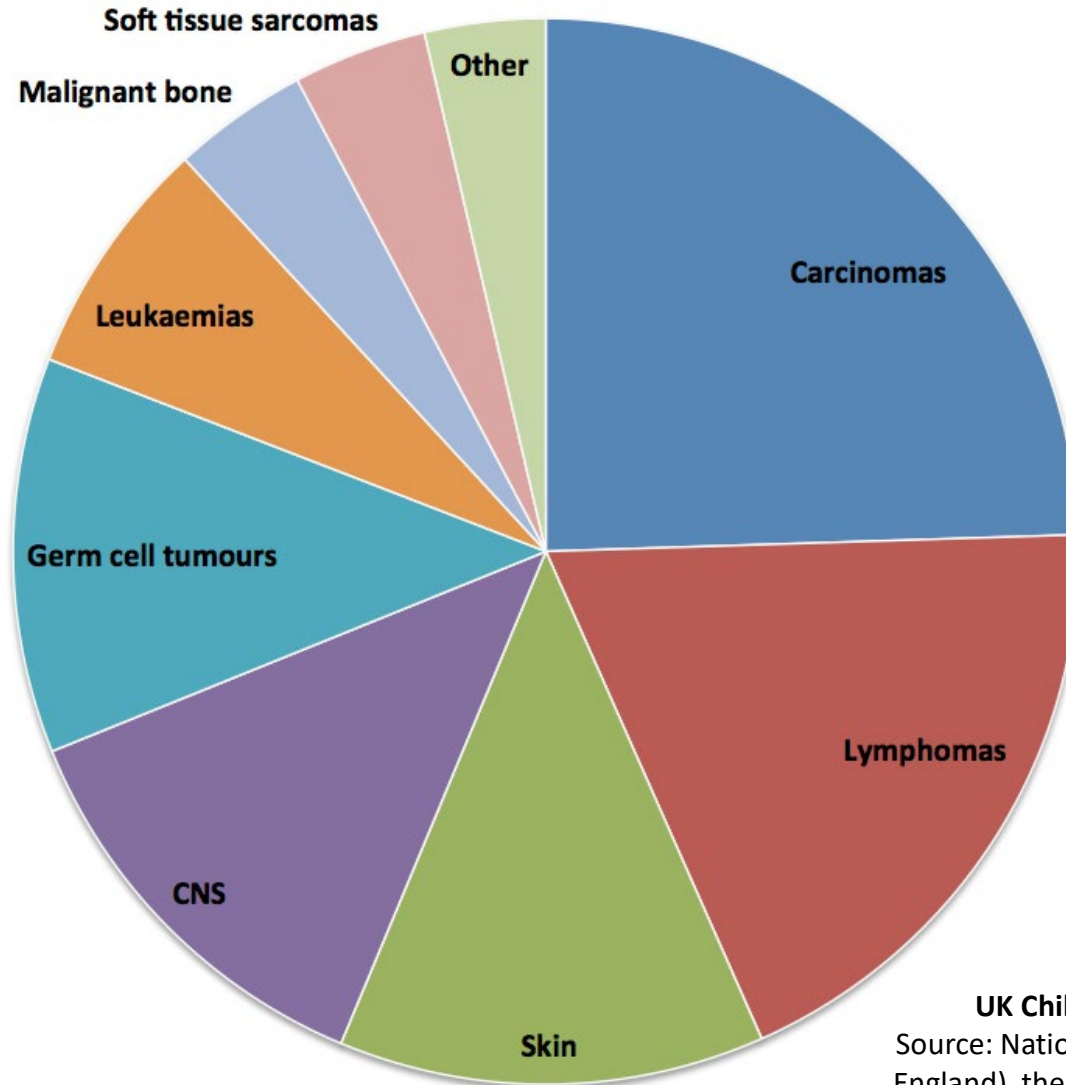


Childhood cancers



~1600 UK diagnoses per year
~250 deaths per year

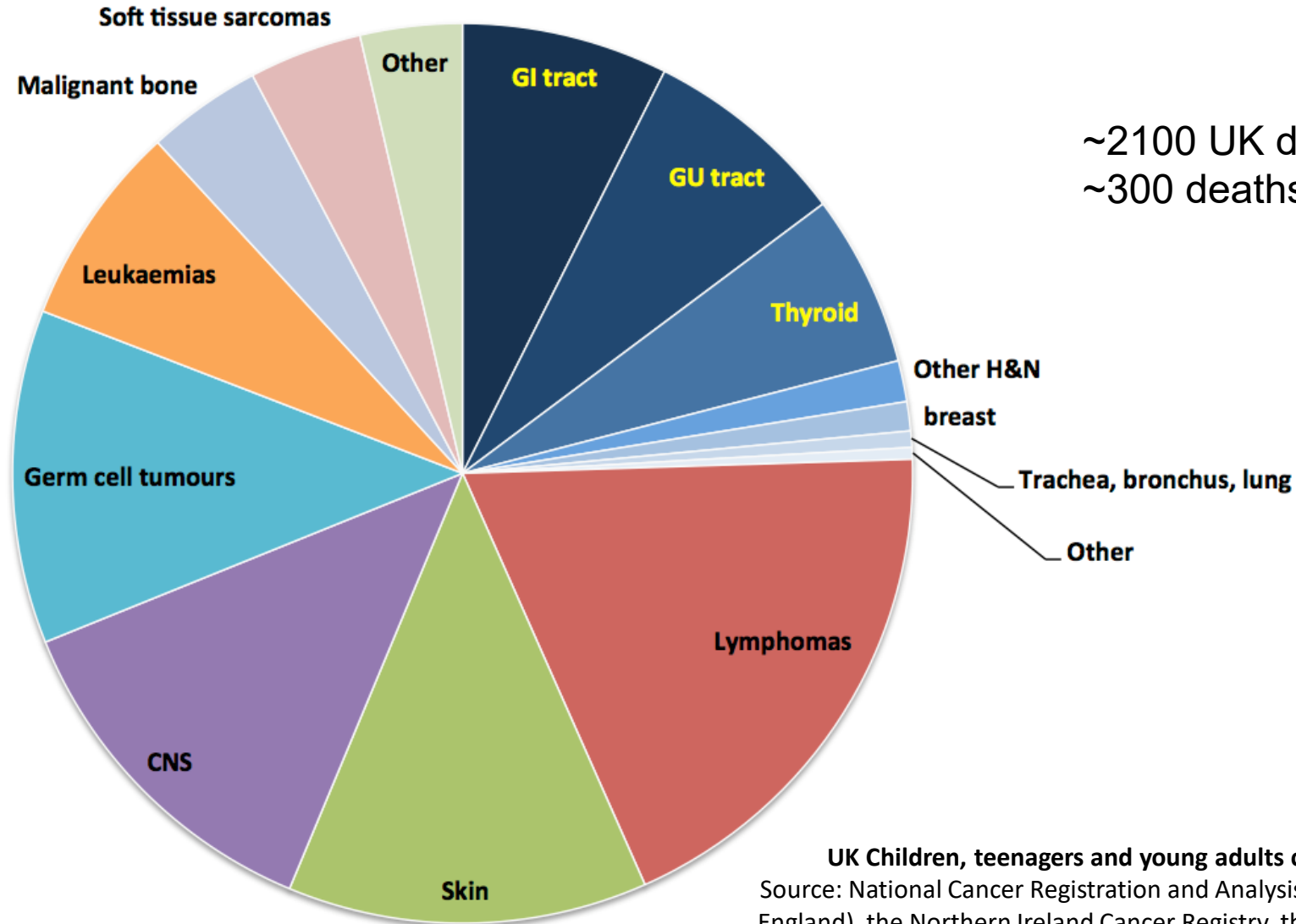
Young adult cancers



~2100 UK diagnoses per year
~300 deaths per year

UK Children, teenagers and young adults cancer statistics report 2021.
Source: National Cancer Registration and Analysis Service for England (Public Health England), the Northern Ireland Cancer Registry, the Scottish Cancer Registry, and the Welsh Cancer Intelligence and Surveillance Unit

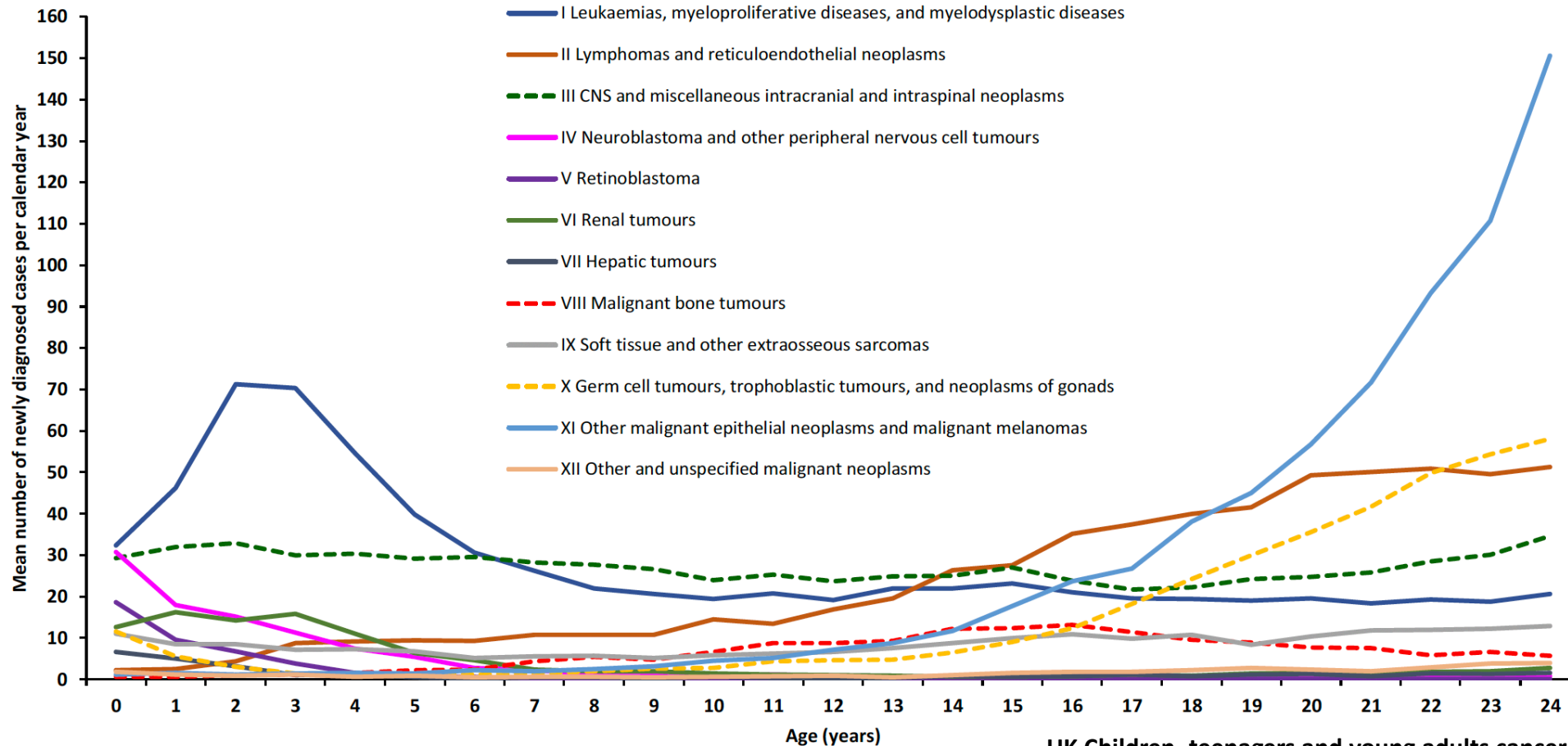
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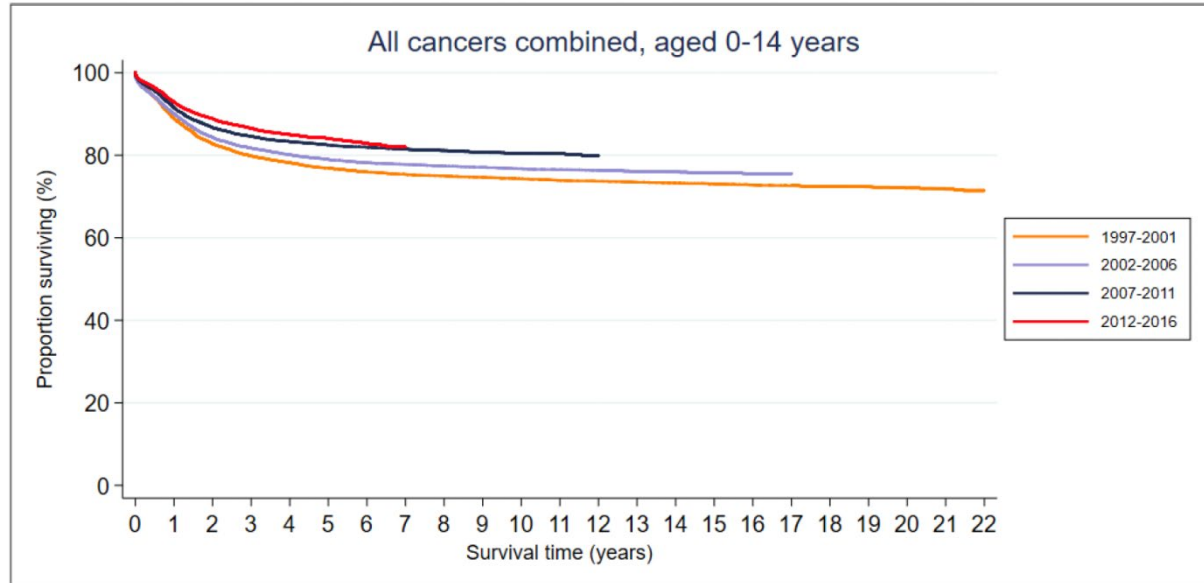
Cancer types change with age



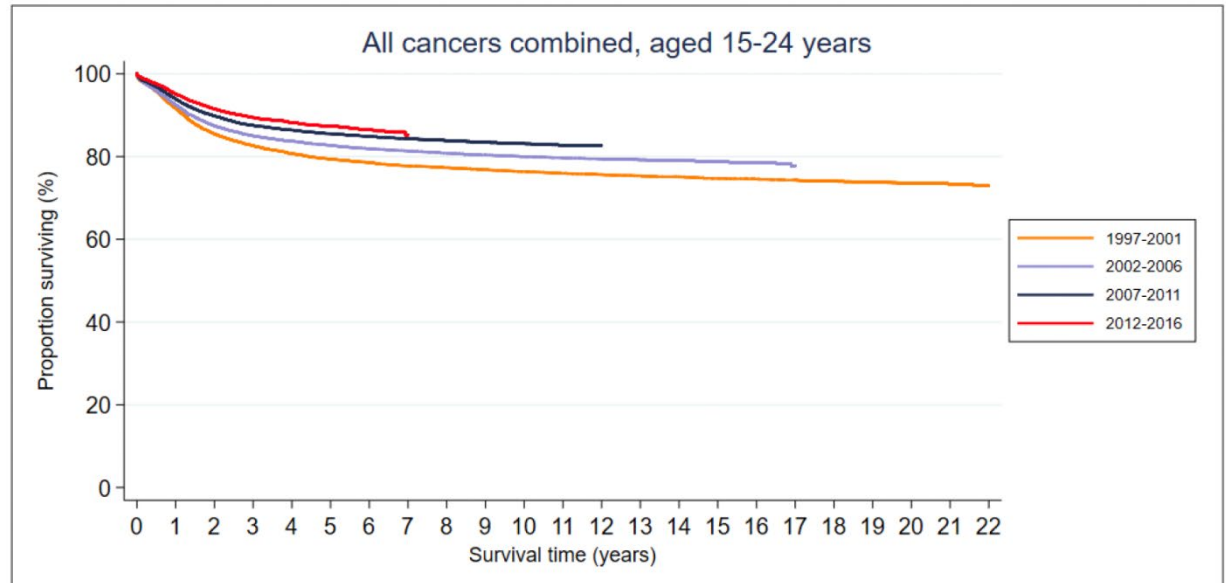
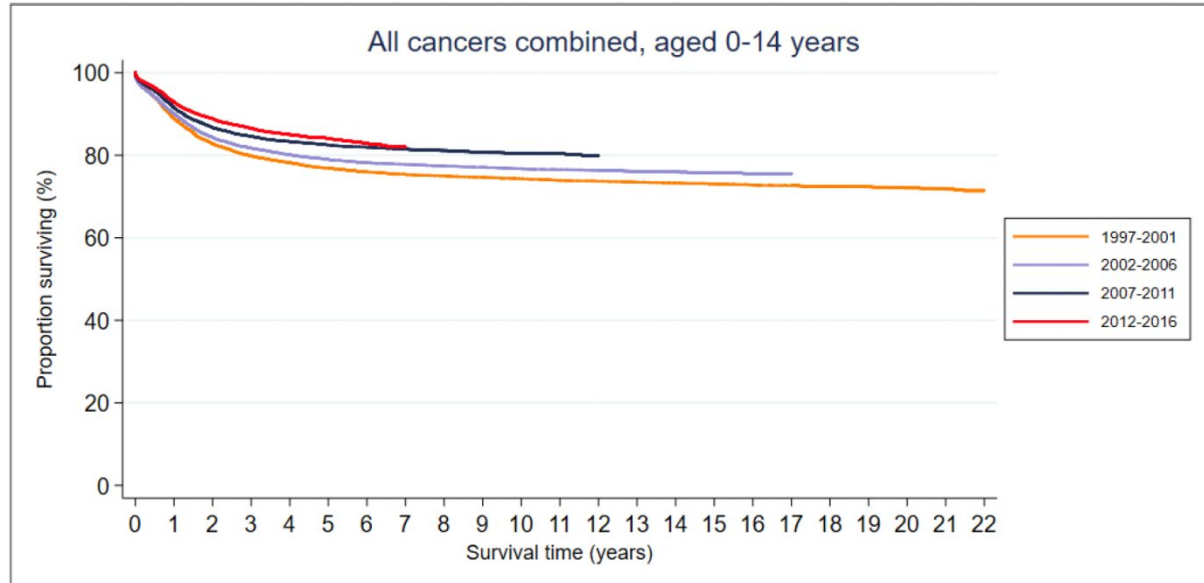
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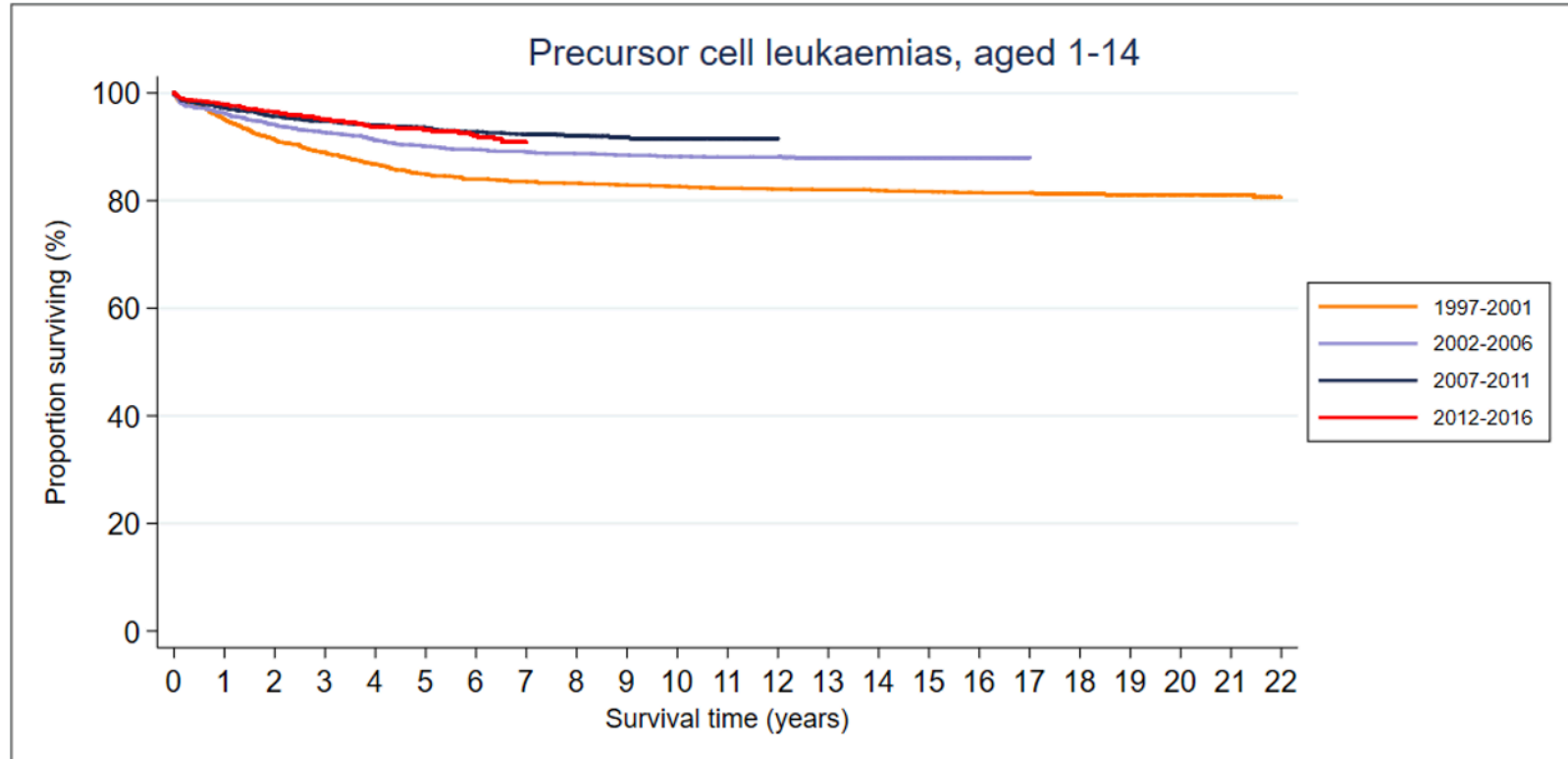
Survival is improving with time



Survival is improving with time

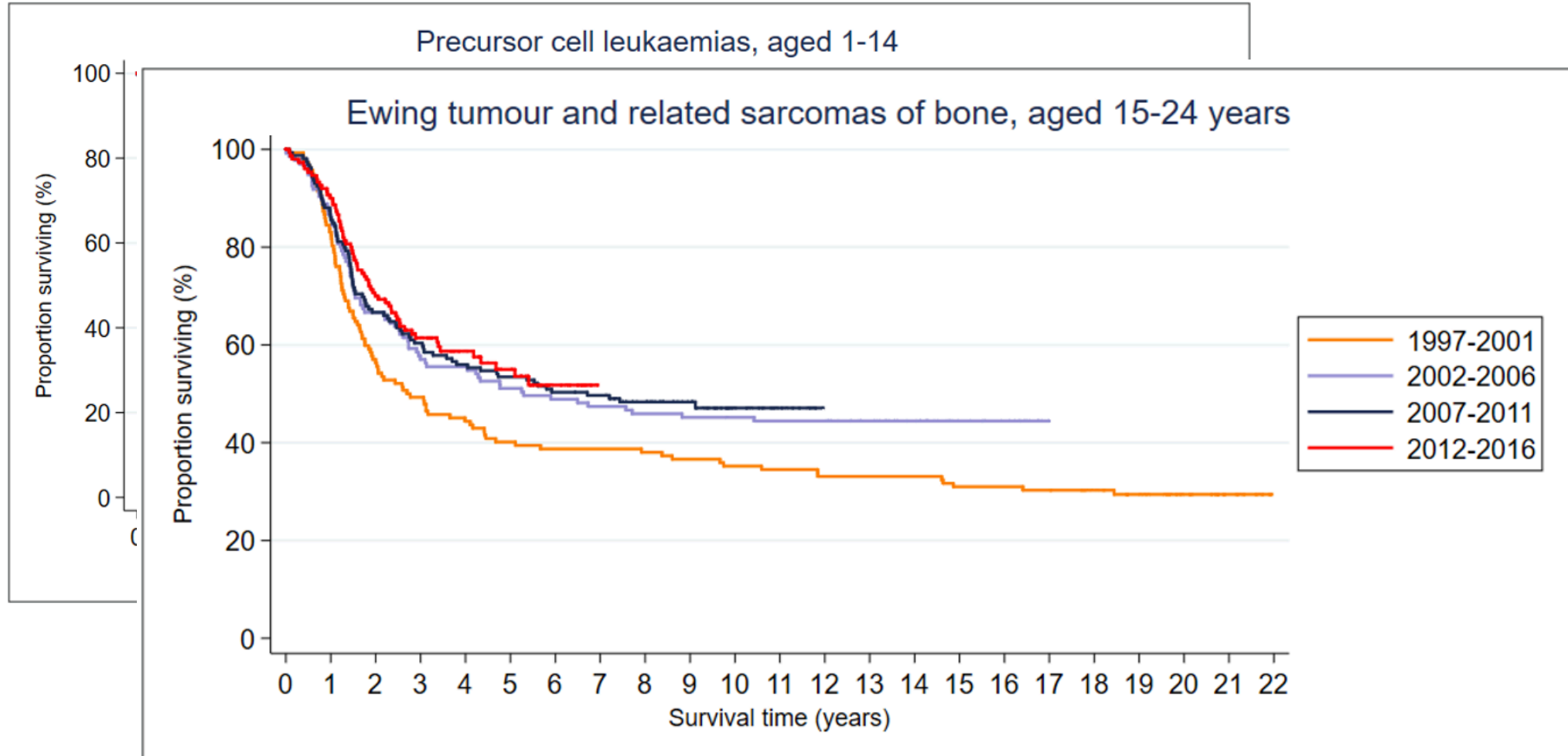


Some great success stories



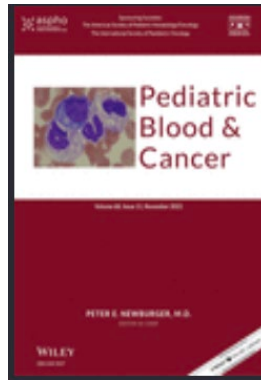
UK Children, teenagers and young adults cancer statistics report 2021.
Source: National Cancer Registration and Analysis Service for England (Public Health England), the Northern Ireland Cancer Registry, the Scottish Cancer Registry, and the Welsh Cancer Intelligence and Surveillance Unit

Some not-so-great stories



UK Children, teenagers and young adults cancer statistics report 2021.
 Source: National Cancer Registration and Analysis Service for England (Public Health England), the Northern Ireland Cancer Registry, the Scottish Cancer Registry, and the Welsh Cancer Intelligence and Surveillance Unit

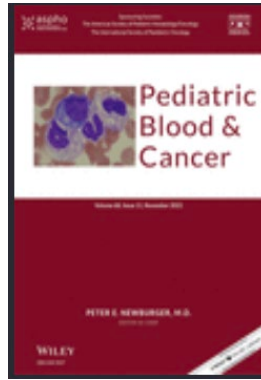
- Ideally we should recruit everyone to clinical trials to improve the number of children and young people who are cured.
- There often aren't clinical trials for patients to enter ...
 - ... particularly when their cancer returns after initial treatment
- Observational, 'real world' registry data are critical to understand whether our treatments are effective



Oral etoposide as a single agent in childhood and young adult cancer in England: Still a poorly evaluated palliative treatment

Jess Fraser^{1,2} | Lorna Wills¹ | Fahmina Fardus-Reid¹ | Lucy Irvine¹ |
Lucy Elliss-Brookes¹  | Lorna Fern³  | Alison L. Cameron⁴ |
Kathy Pritchard-Jones⁵  | Richard G. Feltbower⁶ | Jon Shelton² | Charles Stiller¹ |
Martin G. McCabe^{1,7} 

- Commonly used as a **palliative** treatment in childhood cancers
- When all else fails
- Because the parents and doctors want to keep trying
- Because it's important not to lose hope
- It's **well tolerated**.



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palliative, *adj.* and *n.*

A. *adj.*

1.

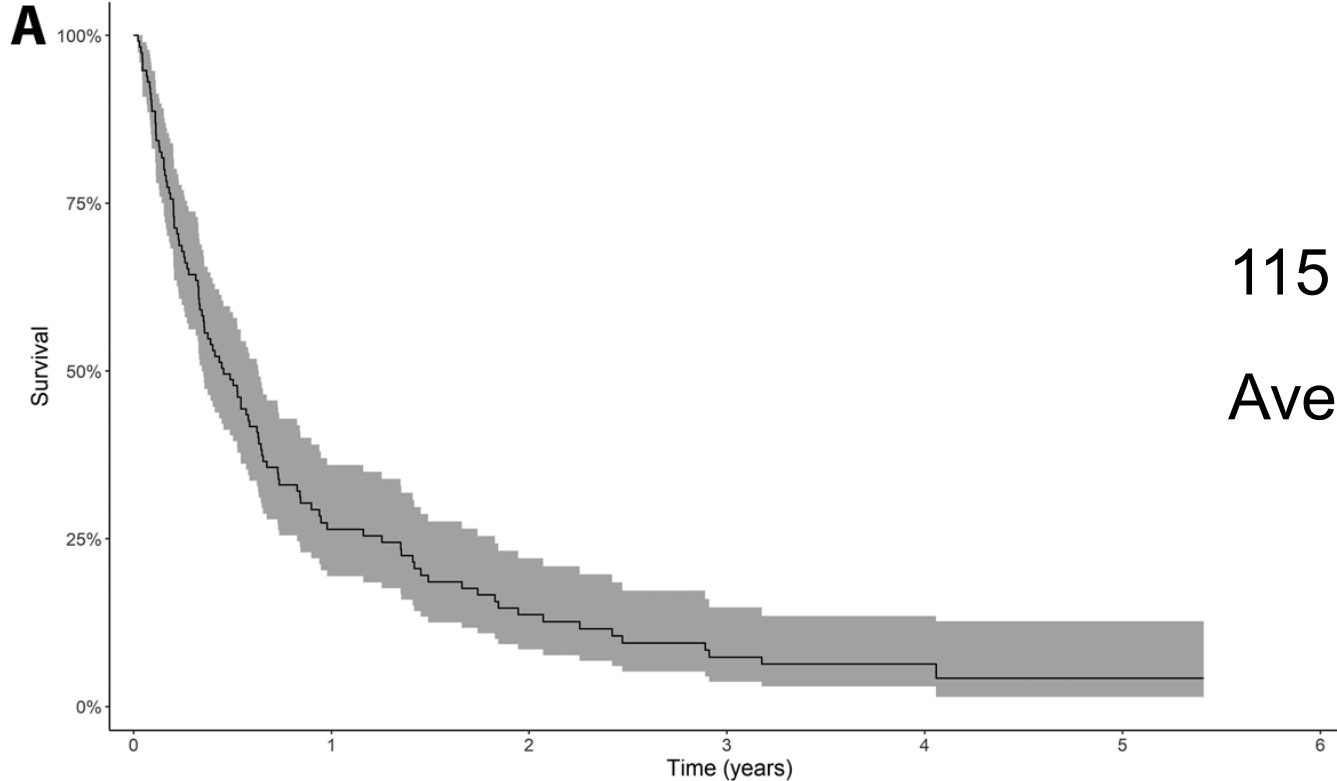
a. That relieves the symptoms of a disease or condition without dealing with the underlying cause.

b. In extended use: that mitigates emotional pain or other distress.



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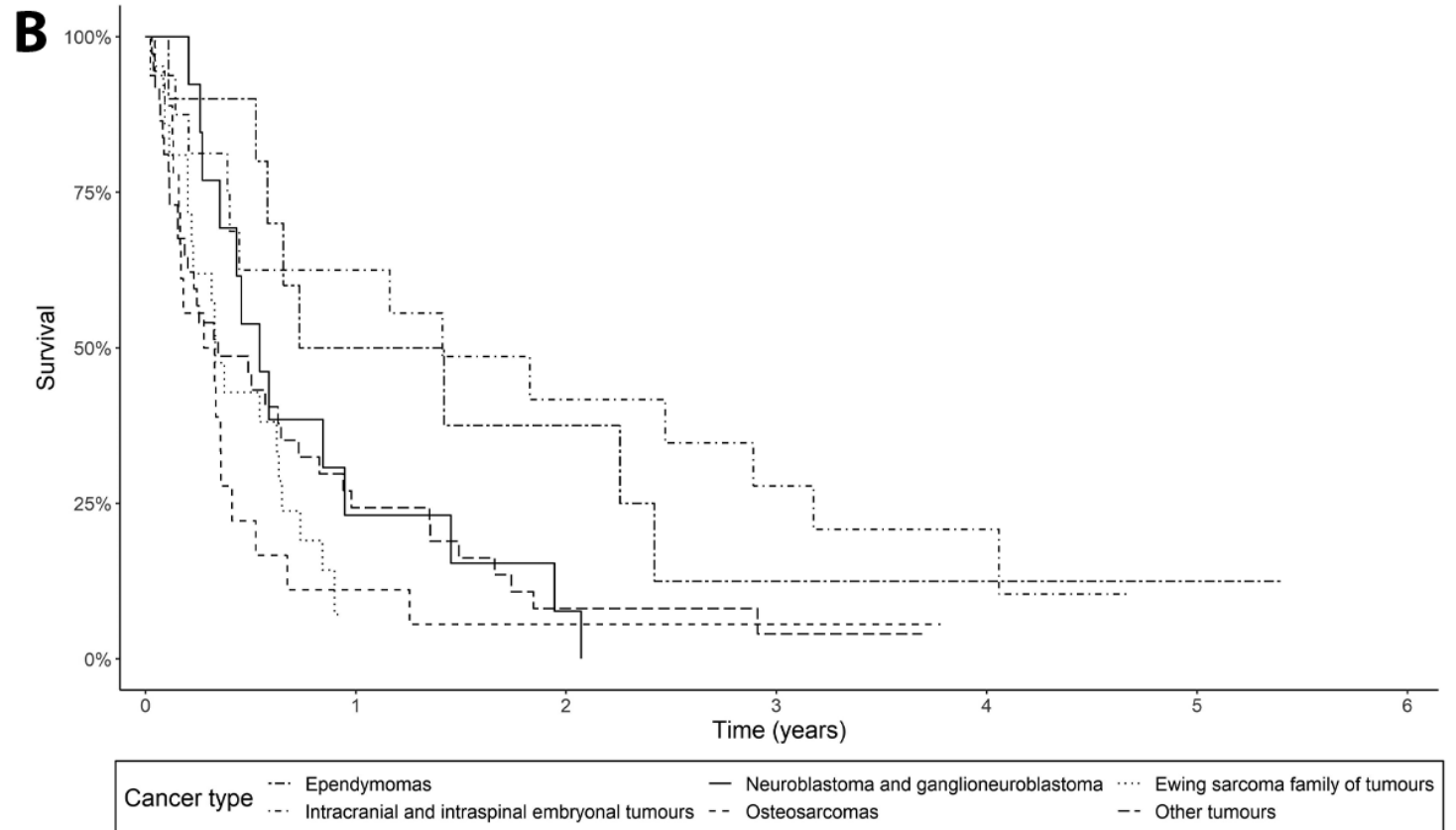
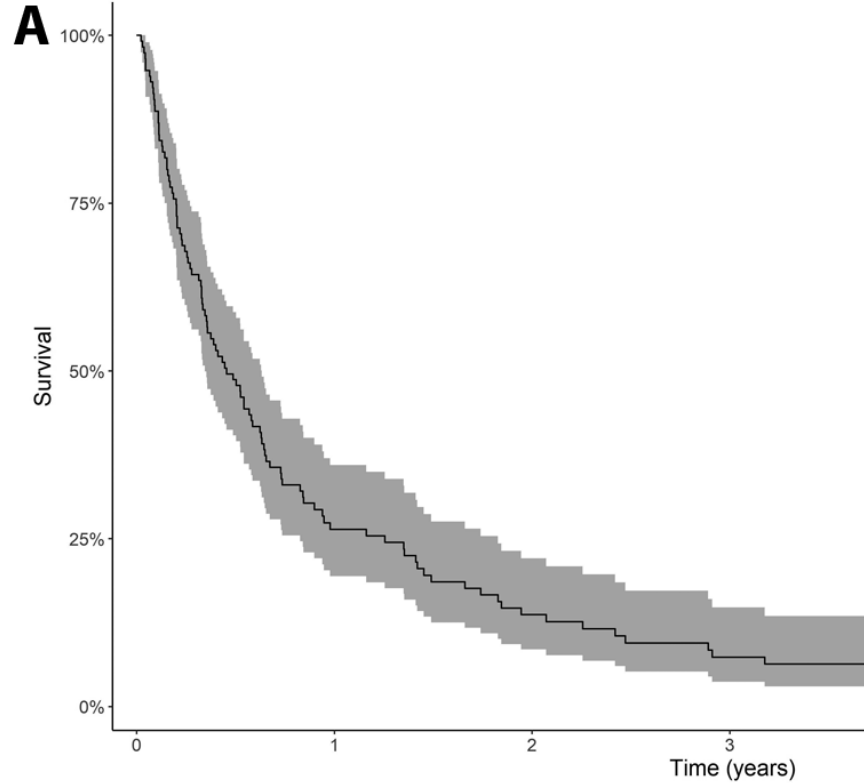


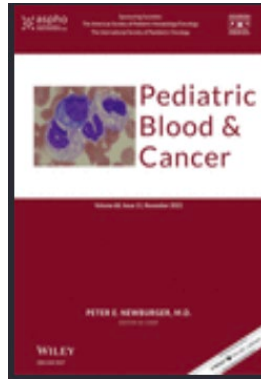
115 patients <25 over 6 calendar years
Average survival 5.5 months



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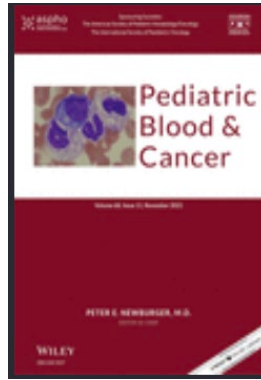




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1. >50% had only 1 cycle
2. >50% with bone sarcomas and 'other' cancers died within six months of starting treatment.
3. A handful of patients survived for several years.
4. Side effects in reported papers are not trivial.
5. Quality of life has never been reported
6. Symptom control is very poorly reported in the literature ... 5 patients of ~400
7. There have been no trials comparing oral etoposide placebo or another standard palliative treatment.



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Does oral etoposide:

1. relieve symptoms or otherwise mitigate distress ... ie is it useful as a palliative treatment?
2. prolong life?

I don't think we can answer either question despite it being in regular use for over 30 years.

Acknowledgements

Oral etoposide

Jess Fraser,
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Lucy Irvine,
Lucy Elliss-Brookes,
Lorna Fern,
Alison L Cameron,
Kathy Pritchard-Jones,
Richard G Feltbower,
Jon Shelton,
Charles Stiller

Data exemplar project

Pam Kearns
Lou Chesler
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