Cancer52

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Chair of Cancer52
And CEO, Teenage Cancer Trust

www.cancer52.org.uk

**"Representing the 'Rare' Majority
- a solution to improving national survival"**

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42 members

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Adam's Hats & Neuroblastoma Society
AMEND
Barrett's Oesophagus Campaign
Brain Tumour UK
Brainstrust
British Lymphology Society
Butterfly Thyroid Cancer Trust
Cancer Laryngectomee Trust
Cancer of Unknown Primary Foundation
Childhood Eye Cancer Trust
Children with Leukaemia
CLIC Sargent
CML Support Group
CORE
The Eve Appeal
International Brain Tumour Alliance
Jo's Trust
Kidney Cancer Support Network
Leukaemia CARE
Lymphoedema Support Network

Lymphoma Association
Maggie's Cancer Caring Centres
MDS Foundation
Meningioma UK
Mouth Cancer Foundation
Myeloma UK
Myrovlytis Trust
NET Patient Foundation
Oesophageal Patients Association
Oracle Cancer Trust
Orchid Cancer Appeal
Ovacome
Ovarian Cancer Action
Pancreatic Cancer Action
Pancreatic Cancer UK
Rarer Cancers Forum
Samantha Dickson Brain Tumour Trust
Sarcoma UK
Target Ovarian cancer
Teenage Cancer Trust
Wellbeing of Women
Wessex Urology Support Group

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C52 organisations by type
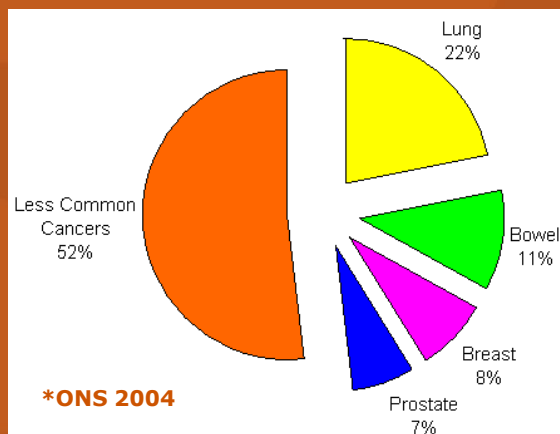
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- Brain
- Cervical
- Childhood cancer
- Connective tissue
- Endocrine
- Gastrointestinal
- Haematological
- Head and neck
- Kidney
- Male cancer
- Ovarian
- Pancreatic
- Rare cancers
- Supportive and palliative
- Teenage and young adult cancer
- Unknown primary
- Urology
- Women's cancer

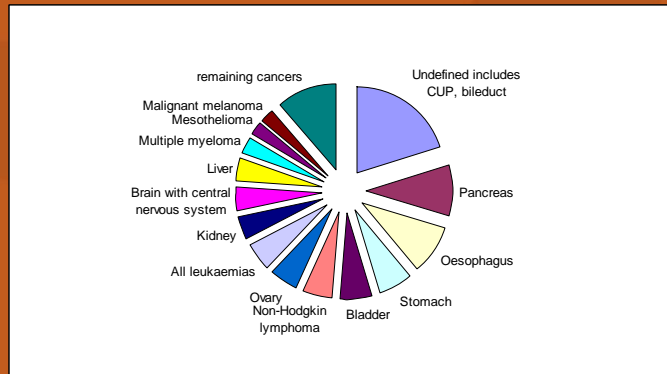**%** of cancer **deaths** due to less common cancers has **increased***

Although % incidence has decreased* (48.5% down to 46.5%*)
50.5% - 53.5% in England 1994/6-2005/7

UK Cancer deaths*

Lung 22%
Bowel 11%
Breast 8%
Prostate 7%
Less Common Cancers 52%

*ONS 2004

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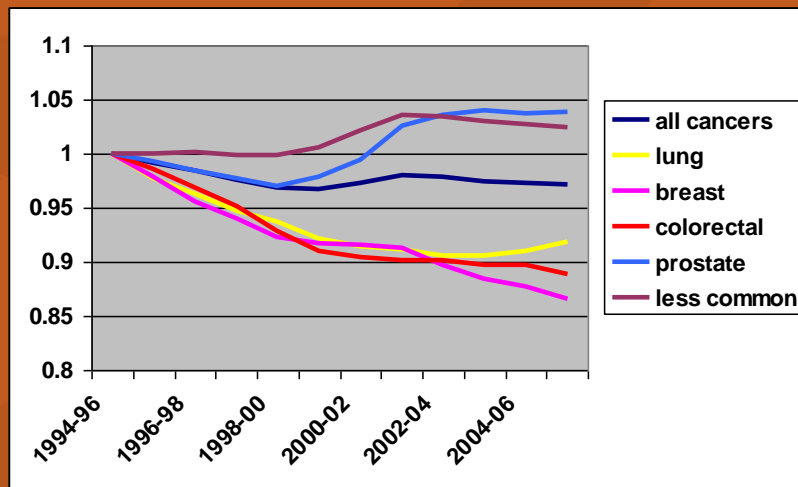
% of deaths, UK, 2008 less common cancers

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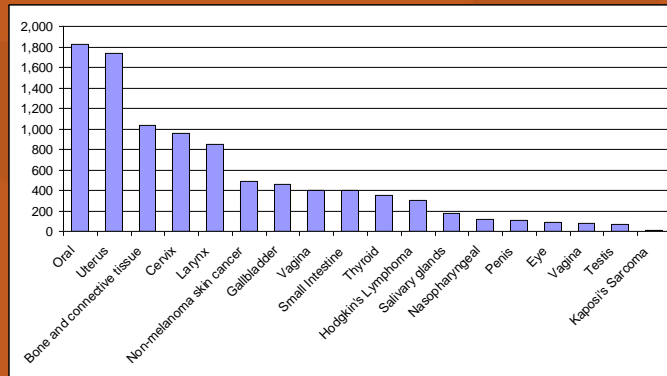## number of less common cancer deaths has increased since 1994-96

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Relative Change in Cancer Deaths In England since 1994-6

Legend:
- all cancers
- lung
- breast
- colorectal
- prostate
- less common

No of deaths, UK 2008 "remaining cancers"

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Latest report on number of deaths in 2008 (courtesy of CRUK) shows Cancer of Unknown Primary 4th (above prostate) and pancreatic cancer 6th

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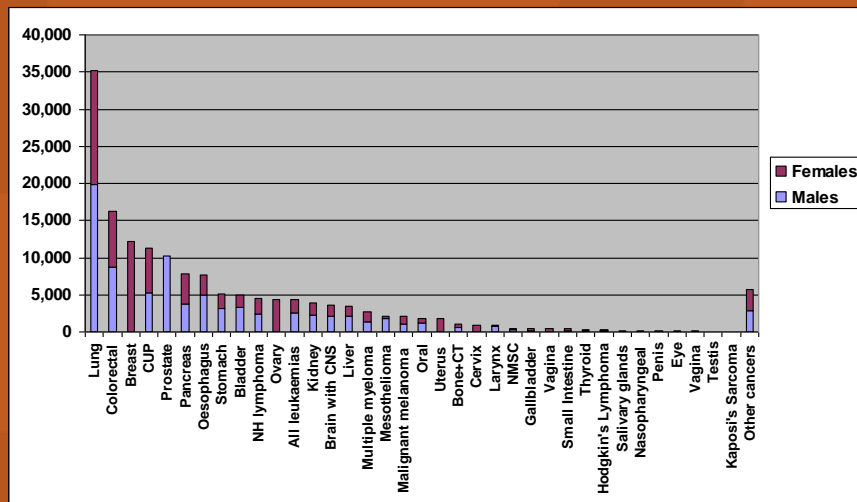
Variation in 5 year survival between networks*
*NCIN cancer atlas

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site	Min %	Max %	Variation %
breast	77.9	85	6
brain	13.4	25.9	93
bladder	48.5	70.1	45
cervix	60.6	76.1	26
colorectal	46.2	60.4	31
kidney	39.3	60.6	54
leukaemia	31.9	62.1	95
Malig. melanoma	77.1	91.8	19
NHL	51.1	60.8	19
oesophageal	7.1	14.9	110
ovary	30.4	49.4	63
pancreas	1.7	7.1	318
prostate	67.9	88.8	31
stomach	9	23.3	159
lung	5.8	10.5	81

Children (0-14)

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- **In the UK around 1,500 children (under 15) are diagnosed with cancer each year.**
  Average per year in UK during 2006-2008

	diagnosed	deaths(2008)
– Boys:	799	126
– Girls:	641	104

- **Leukaemia and brain tumours account for more than half of all cancers in childhood.**

- **In Britain childhood cancer incidence rates have increased by over 40% since the late 1960s. The reasons for this are poorly understood, though improvements in diagnosis and registration are likely to have played a part.**

Teenagers and Young Adults(15-24)

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- Like children, cancer is also relatively rare in teenagers and young adults

- In the UK during 2006-2008, average cases per year was

	diagnosed	deaths(2008)
– Males:	1,029	188
– Females:	921	117

- The most common cancer in young men is testicular cancer. Other common cancers for males in this age group include Hodgkin Lymphoma and Leukaemia.

- The most common cancers in young women are malignant melanoma, Hodgkin Lymphoma and Ovarian cancer.

Inequalities

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Intelligence
- Poor quality national information about less common cancers
- 100s of different cancers but statistics available for limited set
  - NCIN 16, CCT 13, NCIN stats 22, ONS 22, CRUK 27 and 35-49
  - some are grouped together and some missed eg CUP, bile duct
  - Hard to do long time series analysis, inconsistencies in different sources

Mortality ~53% of deaths
- % of deaths has increased despite % incidence decreasing
- No. of deaths increasing for LCC but decreasing for breast, lung, colorectal

Survival
- Large variation in survival across cancer networks – why?

Research
- Quality data needed to balance/ justify research spending
- Only 20% of research funding and clinical trials went to less common cancers

Reasons and Needs?

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- **Specialist Services**
  - Insufficient specialist services?
  - Paucity of specialist support particular at a community level?
  - Inexperienced treatment centres?
  - Need audit of treatments, demography, comorbidity, support, outcomes for all cancers

- **Diagnosis- late/misdiagnosis**
  - need Routes of Diagnosis analysis for less common cancers
    - Individual cancers
    - less common cancers as a whole
  - Need data to help build a greater understanding of misdiagnosis through patients pathways
  - Need information of stage at diagnosis for all cancers

- **Information**
  - What is the quality of reported information for less common cancers?
  - Is it reported as accurately?

Some Research Challenges

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- Low numbers

- Geographical spread

- Timing – right patient, right time

- Invasive to collect tissue samples

- Research criteria

- Health structures

- Clinician behaviour