



Public Health
England

Update from the TYA SSCRG analytical work programme

NCIN CTYA Workshop – December 11th, 2013



Public Health
England

Summary

- Highlights from current work programme
- Next year's work programme
- “Augmented registration system”



Highlights from current work programme

- Trends in survival for TYA with cancer in the UK
- International comparisons of TYA cancer mortality rates
- Radiotherapy use among TYA cancer patients in England
- Access to specialist care



Trends in survival for TYA with cancer in the UK

- Five-year relative survival
- 15-24 year olds
- 1992-1996, 1997-2001, 2002-2006
- 18 types of cancer



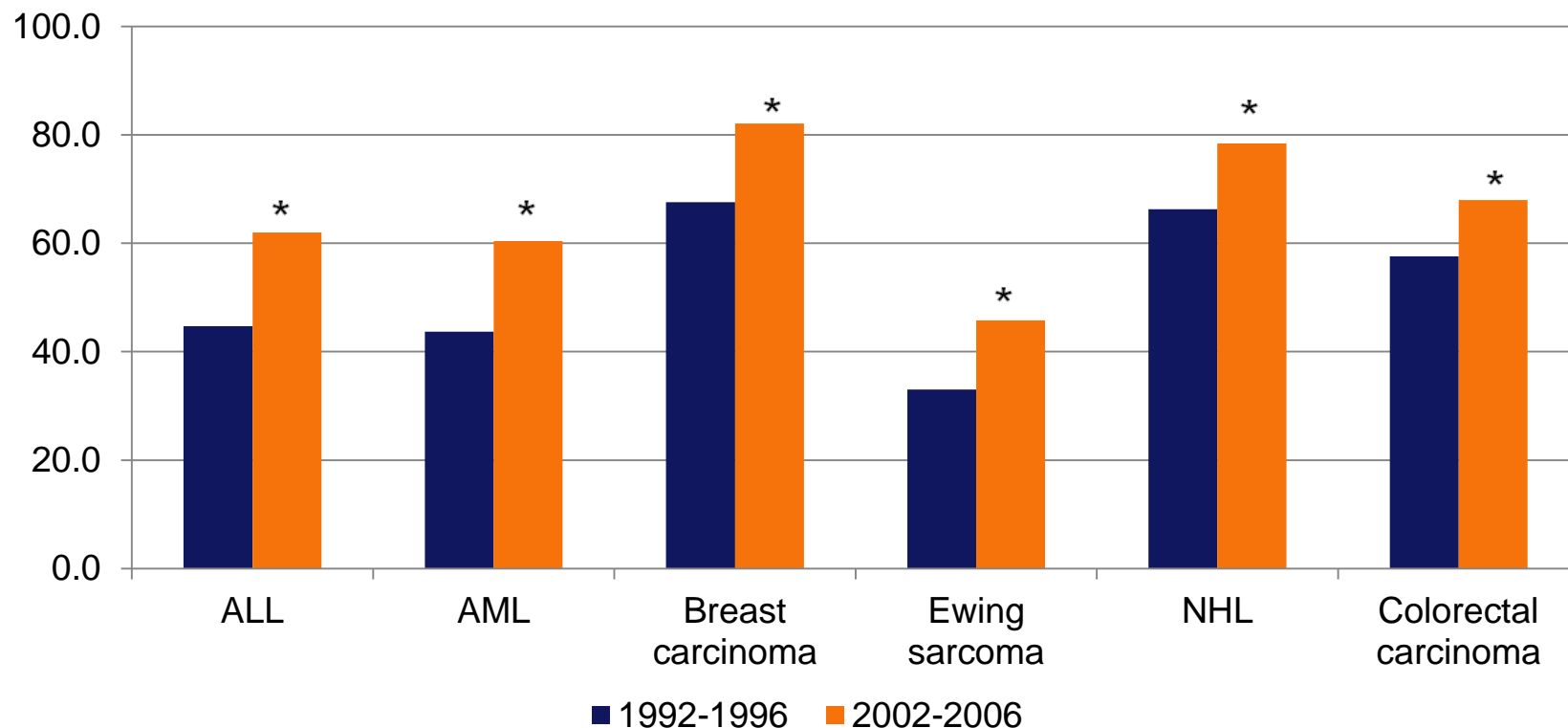
Five-year survival for all cancers combined

| Year | Males | | Females | | Persons | |
|-----------|-------|----------|---------|----------|---------|----------|
| | % | P value* | % | P value* | % | P value* |
| 1992-1996 | 73.5 | - | 78.2 | - | 75.7 | - |
| 1997-2001 | 77.0 | <0.001 | 80.6 | 0.005 | 78.6 | <0.001 |
| 2002-2006 | 80.6 | <0.001 | 83.9 | <0.001 | 82.2 | <0.001 |

*compared with 1992-1996



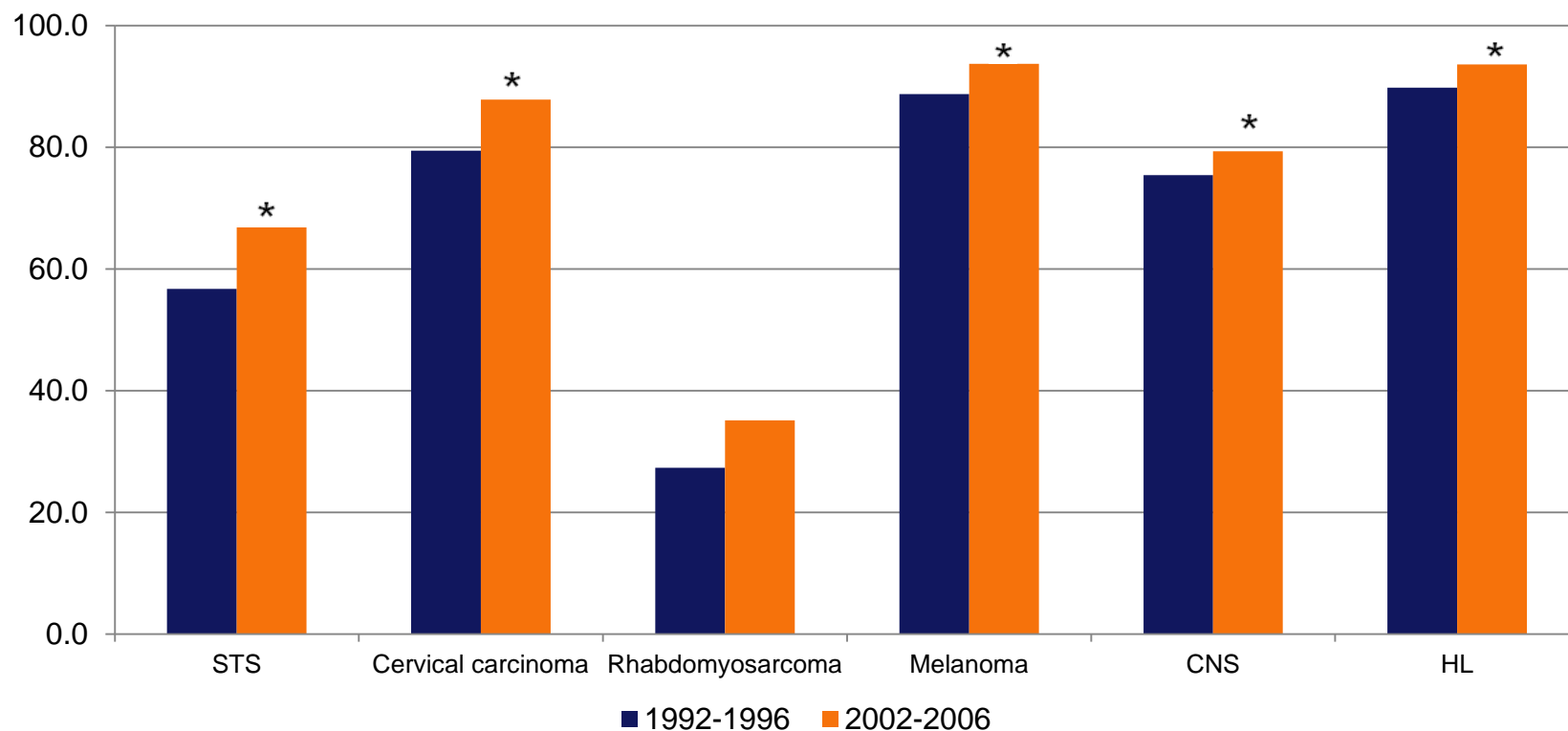
Five-year survival for 1992-1996 and 2002-2006 by cancer type



*statistically significant



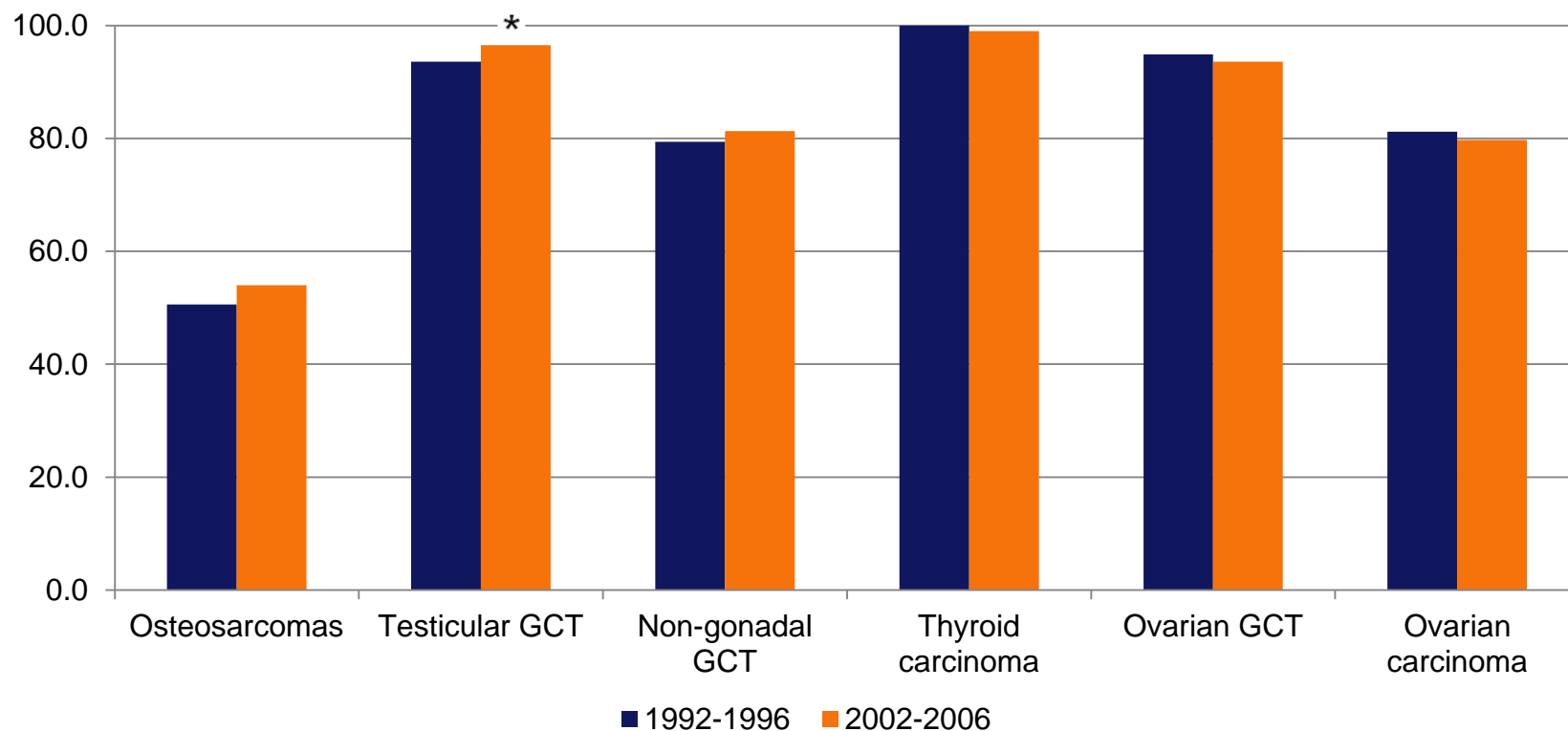
Five-year survival for 1992-1996 and 2002-2006 by cancer type



*statistically significant



Five-year survival for 1992-1996 and 2002-2006 by cancer type



*statistically significant



Public Health
England

Results from USA*

- SEER
- Diagnosed during 2000-2007
- Five –year survival
- 15-39 year olds

*A Bleyer JAYAO 2011: 37-41



Public Health
England

UK vs US

- 16 types of cancer
- Within 5% for 9
- UK higher: ALL, AML, CNS, cervical cancer
- US higher: osteosarcoma (11.8%), Ewing sarcoma (5.6%)



Osteosarcoma

- Small non-significant improvement in survival (3.4%)
- Lower survival than in US
- Lower survival than 0-14 and 25-49 year olds in UK (all bone)*

*Survival in teenagers and young adults with cancer in the UK. C O'Hara, A Moran. 2012 NCIN



Soft tissue sarcoma (STS)

- Survival 11% lower in males (not including Rhabdo)
- Lower survival than in 0-14 and 25-49 in UK (all STS)



International comparisons of TYA cancer mortality rates

- Mortality rates available for almost all countries
- Mortality determined by incidence and survival
- WHO mortality database



Age-specific mortality rates per 100,000 population for all cancers combined for 2006-2010 for males

| Rank Order | 15-19 | | 20-24 | | 15-24 | |
|------------|-------------|-----------------|-------------|-----------------|-------------|-----------------|
| 1 | Nordic | 3.3 | Australia | 4.2 | Australia | 3.9 |
| 2 | Canada | 3.4 | Germany | 4.6 | Nordic | 4.1 |
| 3 | Australia | 3.5 | Nordic | 4.9 | Germany | 4.1 |
| 4 | Germany | 3.6 | Canada | 5.1 | Canada | 4.3 |
| 5 | USA | 3.6 | UK | 5.2 (5*) | Netherlands | 4.5 |
| 6 | Netherlands | 3.6 | Spain | 5.2 | USA | 4.6 |
| 7 | France | 4.1 | Netherlands | 5.4 | UK | 4.7 (5*) |
| 8 | UK | 4.3 (5*) | USA | 5.7 | France | 5.1 |
| 9 | Italy | 5.2 | France | 6.2 | Spain | 5.5 |
| 10 | Spain | 5.8 | Italy | 6.6 | Italy | 5.9 |

*Rank order of UK for all cause mortality rates



Age-specific mortality rates per 100,000 population for all cancers combined for 2006-2010 for females

| Rank Order | 15-19 | | 20-24 | | 15-24 | |
|------------|-------------|-----------------|-------------|-----------------|-------------|-----------------|
| 1 | Canada | 2.4 | Germany | 3.1 | Germany | 2.9 |
| 2 | Germany | 2.6 | Canada | 3.3 | Canada | 2.9 |
| 3 | USA | 2.6 | Nordic | 3.3 | France | 3.1 |
| 4 | France | 2.7 | Netherlands | 3.5 | Netherlands | 3.1 |
| 5 | Netherlands | 2.7 | France | 3.5 | USA | 3.1 |
| 6 | UK | 3.0 (7*) | Australia | 3.7 | Nordic | 3.2 |
| 7 | Nordic | 3.1 | USA | 3.7 | UK | 3.4 (6*) |
| 8 | Australia | 3.1 | UK | 3.8 (6*) | Australia | 3.4 |
| 9 | Spain | 3.4 | Spain | 4.0 | Spain | 3.7 |
| 10 | Italy | 4.1 | Italy | 4.4 | Italy | 4.3 |

*Rank order of UK for all cause mortality rates



Public Health
England

Further work

- Comparisons for CNS, NHL, lymphoid leukaemia and bone
- Years of lives gained if cancer death rates in UK same as other countries



Public Health
England

Use of radiotherapy in TYA

- Variation in use of XRT by diagnosis, age, gender and region
- More detailed analysis led by Matt Williams



Public Health
England

Methods

- Record-match national radiotherapy dataset (RTDS) against the national cancer data repository (NCDR)



Access to specialist care

- “Notification of TYA with cancer to a PTC centre 2009-2010”
- Report published on the NCIN website in April 2013

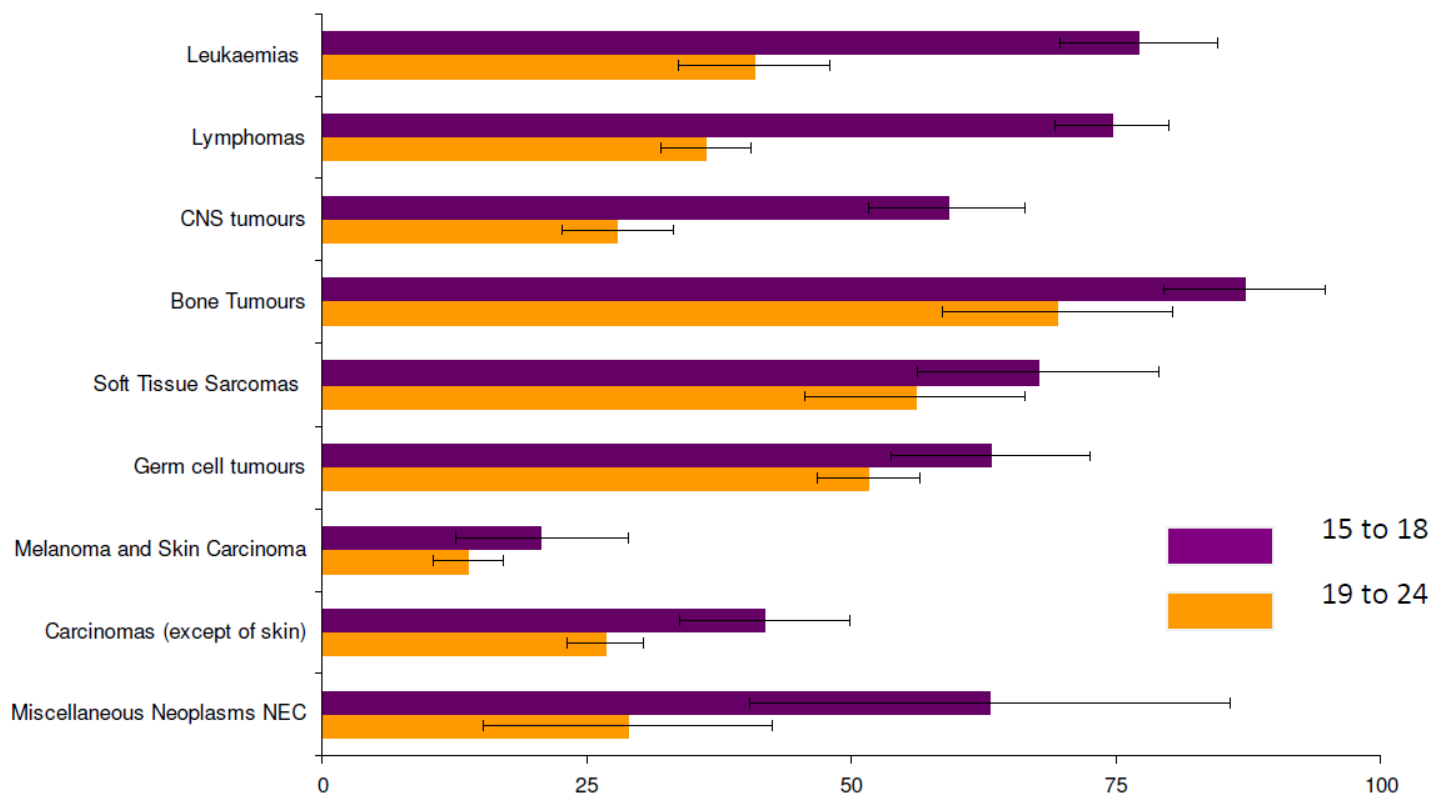


Methods

- PTCs send us form on all TYA patients notified to their TYA MDT
- Called the TYAC notification system
- Record-matched against NCDR
- Calculate % notified by diagnosis, age, gender and region
- Use HES and cancer waits to determine trust of treatment



Percentage of patients diagnosed in 2009-2010 who were notified by age group and diagnosis

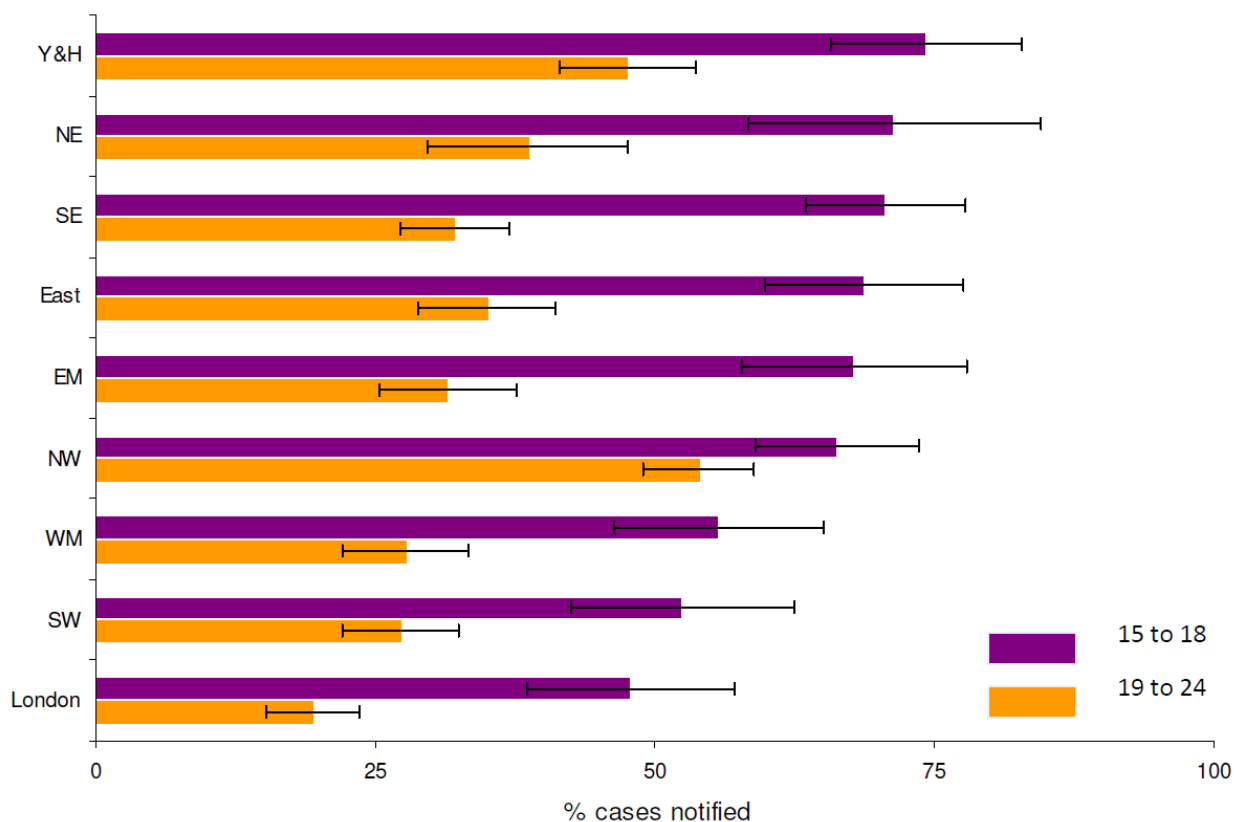


Error bars represent 95% confidence intervals

% cases notified



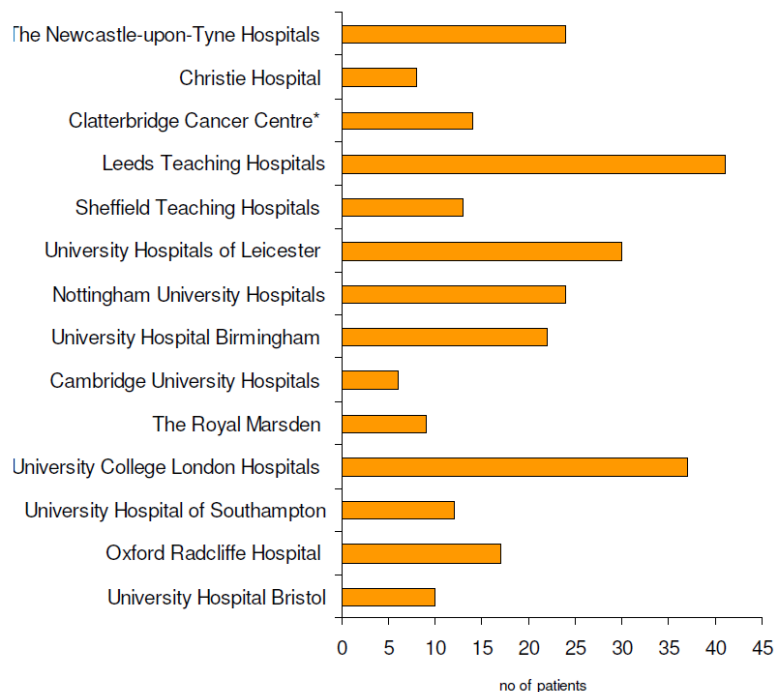
Percentage of patients diagnosed in 2009-2010 who were notified by age group and government office region (GOR) of residence



Error bars represent 95% confidence intervals



Number of patients aged 15 to 24 years diagnosed in 2009-2010 who were treated at each PTC and not notified



* includes Alder hey and The Royal Liverpool Hospital patients

† University of Leicester and Nottingham University Hospitals act together as the Teenage and Young Adult East Midlands Integrated Cancer Service

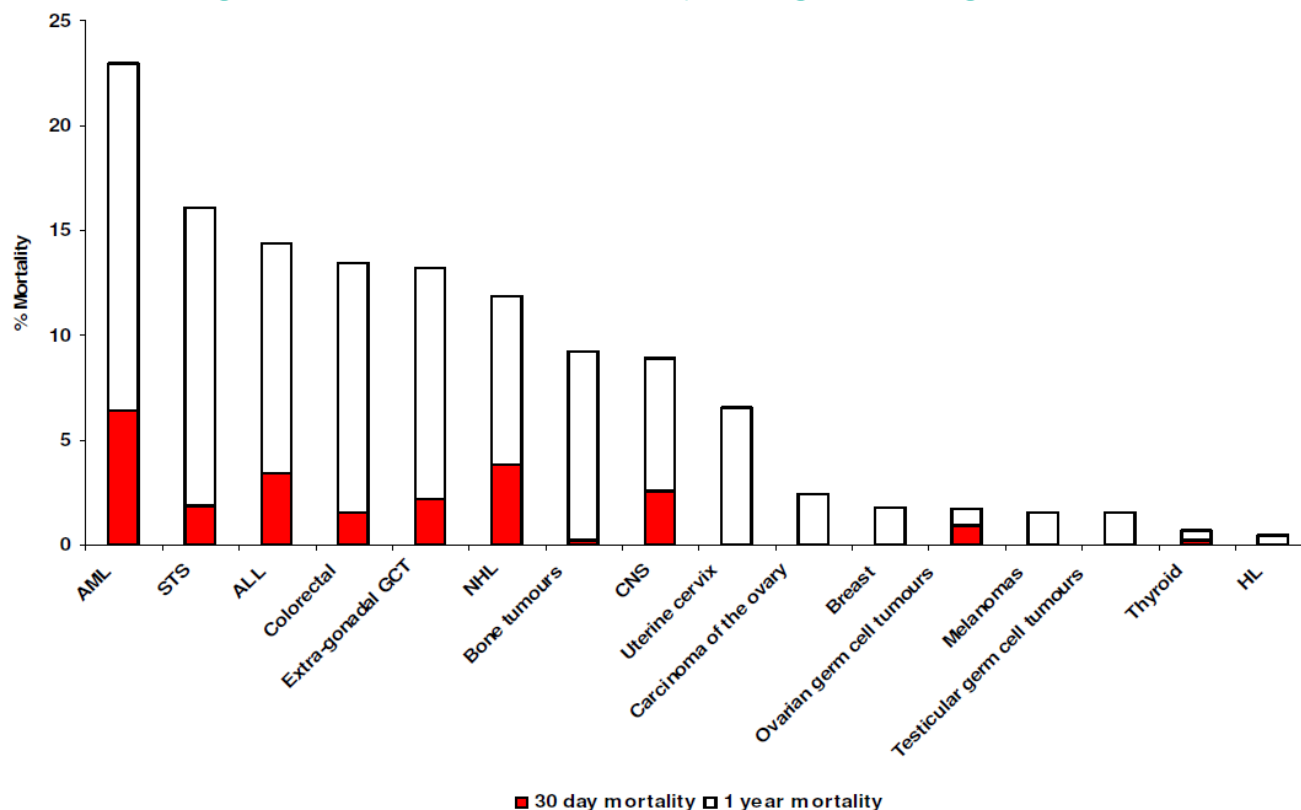


Next year's work programme

- Deaths within a year of diagnosis
- Survival by whether notified to a TYA MDT
- Variations in % of patients notified to a TYA MDT in 2009-2011



30 day and one year percentage mortality for individuals aged 15-24 diagnosed in England in 2005-2009 by diagnostic group*



*Pattern of deaths in the year following diagnosis in cancer patients aged 15-24 years in England. Tony Moran, Debasree Purkayastha, Catherine O'Hara. NCIN 2013



Deaths in first year in ALL in those diagnosed in 2005-2009

| Number of cases | Number of deaths | % of deaths |
|-----------------|------------------|-------------|
| 353 | 51 | 14.4% |



Record-match NCDR and UKALL2003 datasets

- % participating in trial
- One-year survival in those in and not in the trial
- Differences in pattern of deaths in first year
- Keeping the Haematology CRG informed



Possible further work

- Classifying deaths into due to (a) disease (b) complications of treatment
- Relate outcomes to where and how managed?
- Small numbers and political sensitivities



Survival by whether notified to a TYA MDT

- Compare one-year survival in those with and without a TYAC form
- Exploratory



Public Health
England

TYAC notification system

- Receive a form for 62% of 15-18 year olds and 34% of 19-24
- All data items on form are on COSD



Public Health
England

Usefulness

- Form received: indicator of access to specialist care
- Data on form
- Not used for routine statistics



Public Health
England

Way forward

- Check if COSD data of sufficient quality to stop
- Meantime?
- Devolved nations



Public Health
England

Our team

Sabrina Sandhu

Maria Khan

Debasree Purkayastha

Busani Ndlela