



Public Health
England

The Contribution of TYAC Registration 2009-2013

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TYAC Notification System

- Set up in 2008
- Need for more timely and more detailed data on TYA patients
- Proforma drawn up by TYAC and NCRI TYA CSG
- Funded by TYAC, TCT and CLIC-Sargent



How it works

- Data manager at each PTC completes form on patients notified to TYA MDT
- Sent to NW KIT (previously NWCIS)
- Put on database



Possible Criteria for assessing usefulness

- Proxy measure of access to specialist services
- More timely data
- More detailed data
- Raise profile of TYA cancers

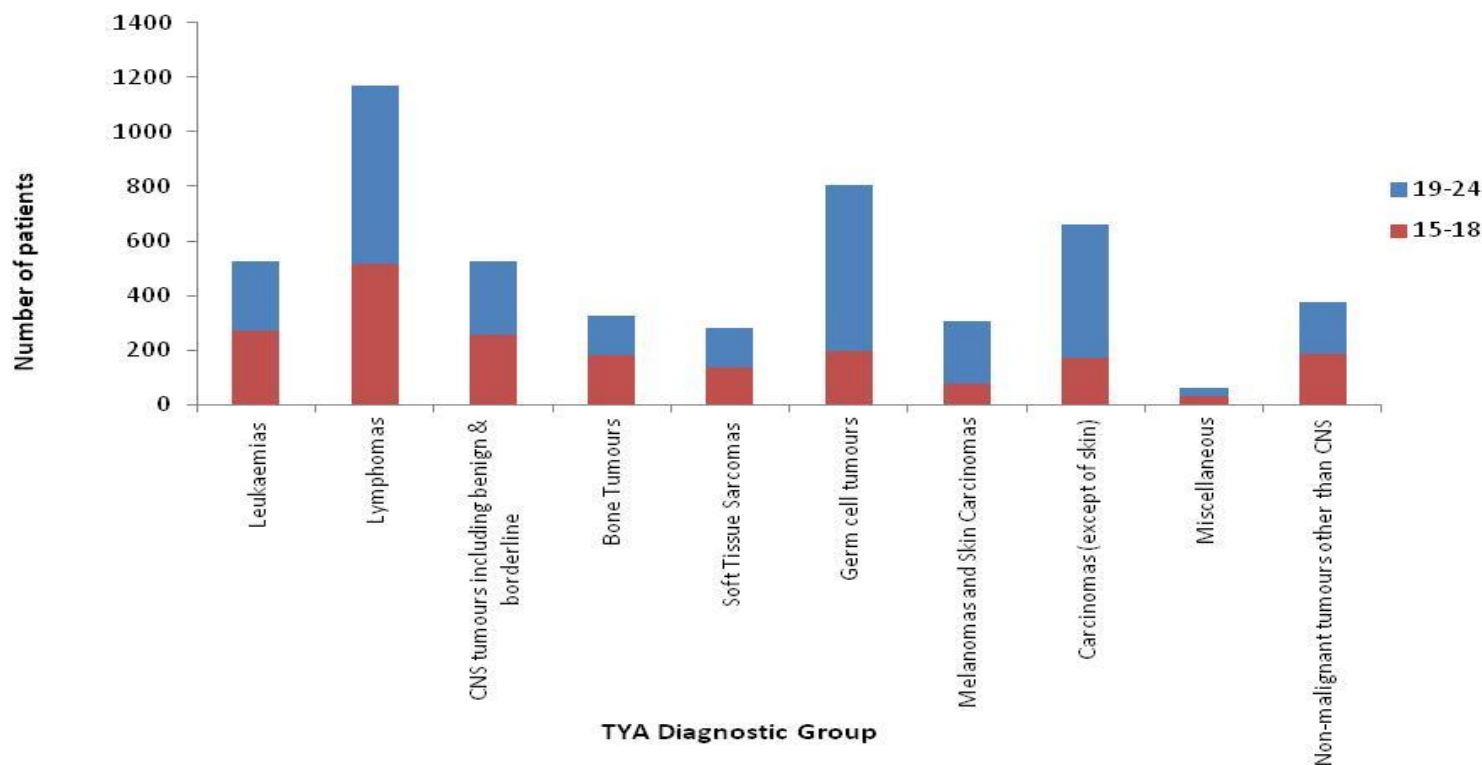


Number of Patients Reported by Year and Country

	2009	2010	2011	2012	2013	Total
England	597	911	1,001	1,115	1,098	4,722
Northern Ireland	1	1	0	2	0	4
Republic of Ireland	7	4	0	0	0	11
Scotland	13	15	61	13	43	145
Wales	24	29	56	34	12	155
Total	642	960	1,118	1,164	1,153	5,037



Number of patients reported in 2009-13 by diagnosis and age group



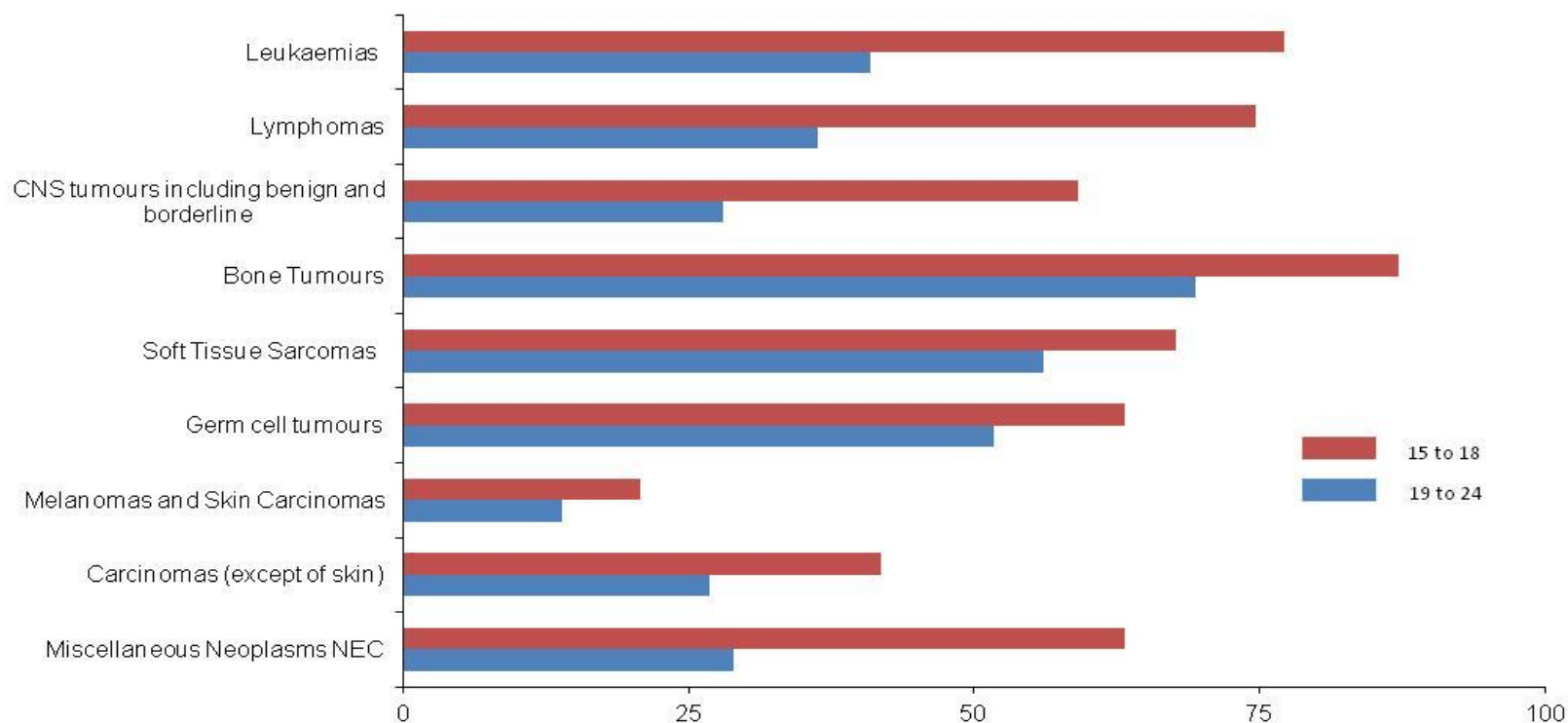


Percentage of Patients on Whom Form received

- England only
- 2009-10: matching against registry database
- 2011-2013: estimated using number of registrations in 2010



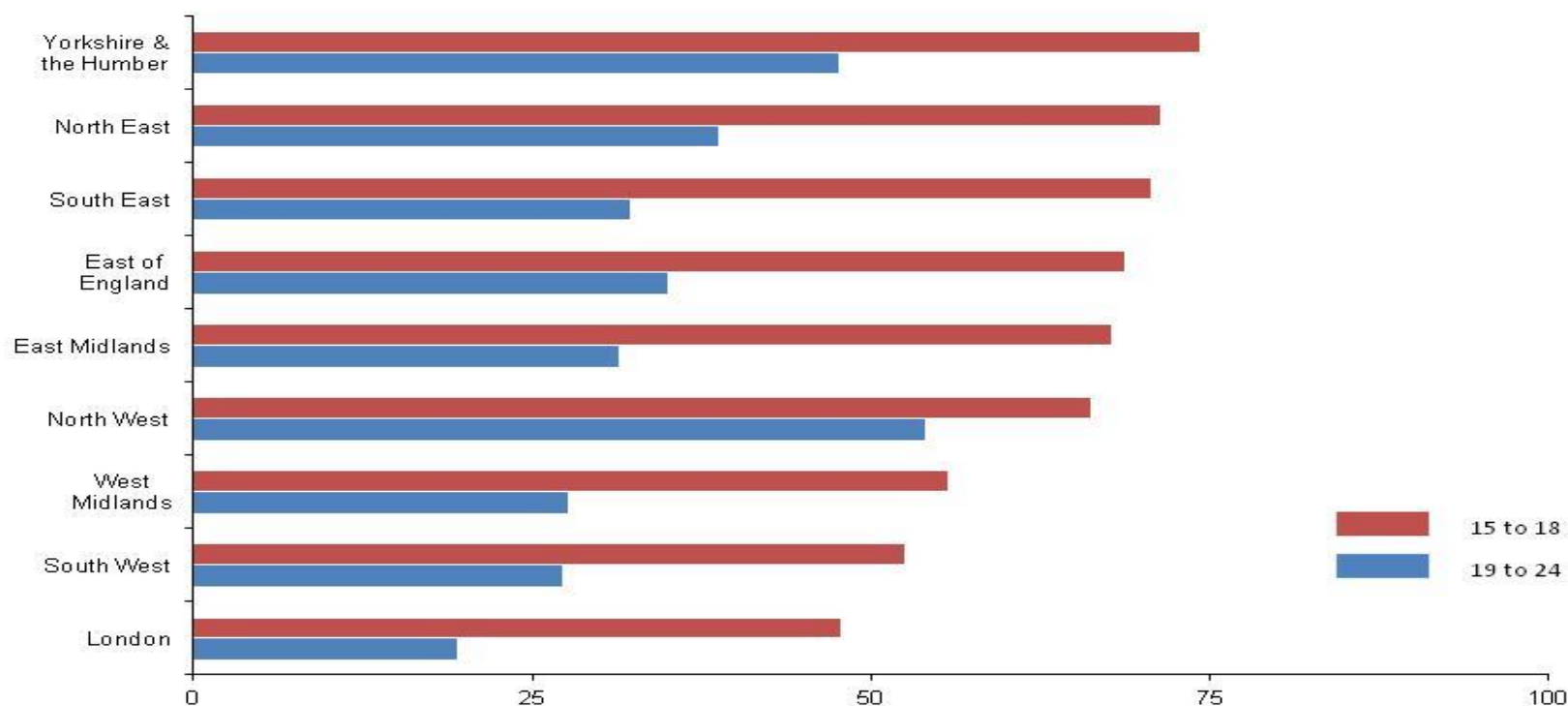
Percentage of patients diagnosed in England in 2009-2010 who were reported by age group and diagnosis*



*This figure has been taken from the report "Notifications of teenagers and young adults with cancer to a Principal Treatment Centre 2009-2010". Report can be found at :<http://www.ncin.org.uk/publications>



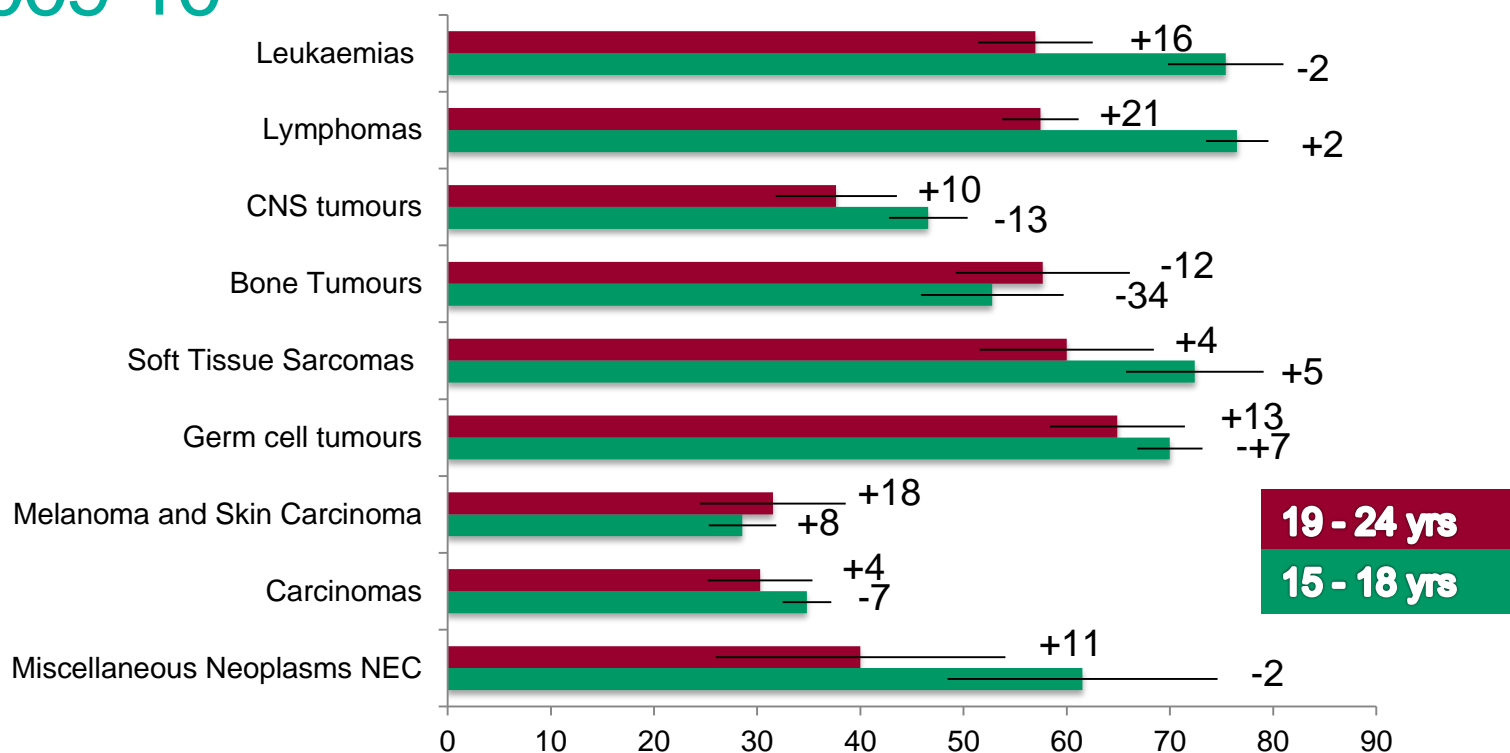
Percentage of patients diagnosed in England in 2009-2010 who were reported by age group and region of residence*



*This figure has been taken from the report "Notifications of teenagers and young adults with cancer to a Principal Treatment Centre 2009-2010". Report can be found at :<http://www.ncin.org.uk/publications>



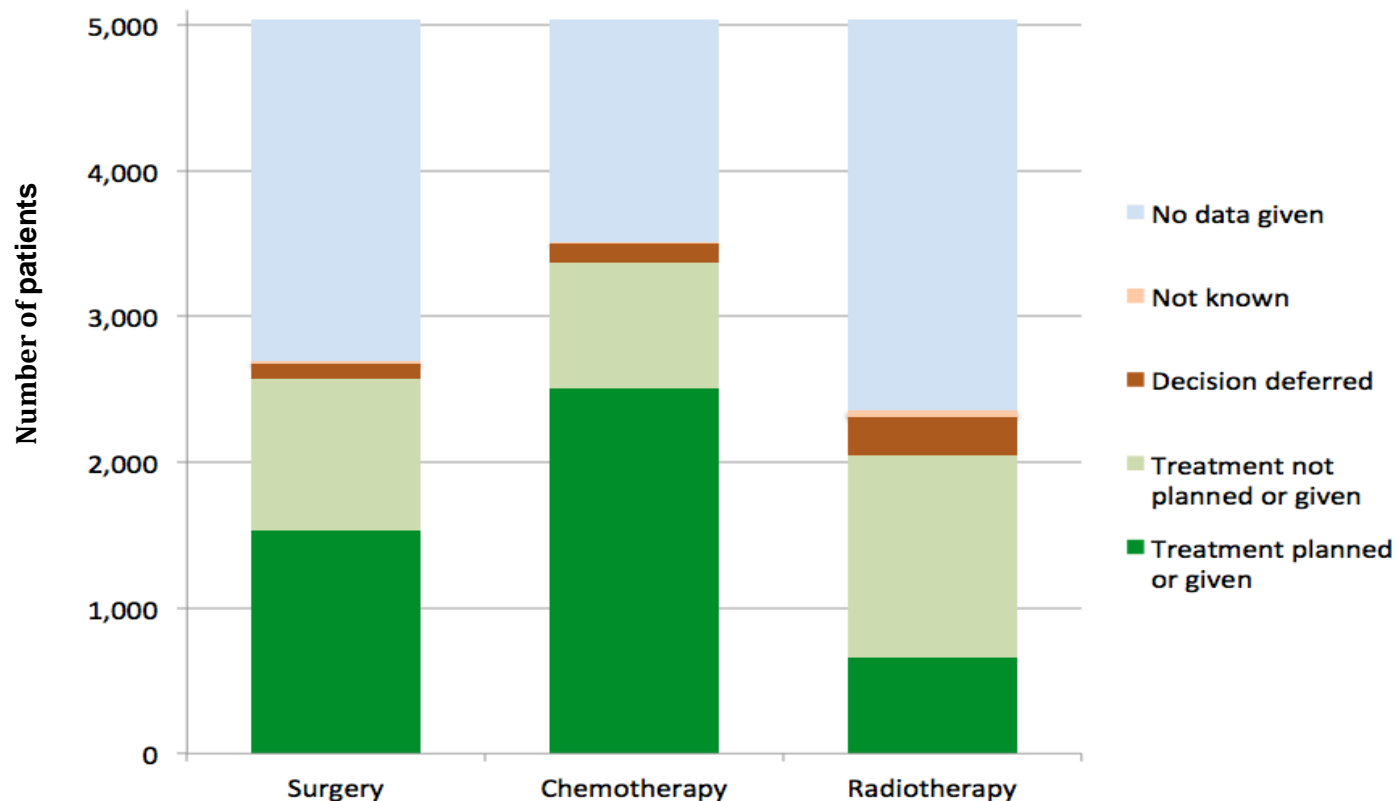
% of Patients reported in 2012 Showing Differences with 2009-10*



*This figure was taken from the presentation "Referral to and from specialist centres – how widespread is the practice and what is the outcome?" by Catherine O'Hara at NCIN meeting in June 2014



Answers on Forms regarding Decisions on Individual Treatment Modalities





Possible Criteria for assessing usefulness

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- More timely data
- More detailed data
- Raise profile of TYA cancers



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Update

- System stopped
- Funding ceased
- Replaced by COSD, SACT etc



Acknowledgements

Those who

- Set it up
- Funded it
- Completed the proformas
- Updated the database
- Undertook the analyses
- Produced the outputs