

National Cancer Intelligence Network
Variation in the uptake of radiotherapy
treatment in Teenagers and Young Adults
(TYA) diagnosed with cancer in England
in 2010

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Public Health England's mission is to protect and improve the nation's health and to address inequalities through working with national and local government, the NHS, industry and the voluntary and community sector. PHE is an operationally autonomous executive agency of the Department of Health.

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# The intelligence networks

Public Health England operates a number of intelligence networks, which work with partners to develop world-class population health intelligence to help improve local, national and international public health systems.

### **National Cancer Intelligence Network**

The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

### National Cardiovascular Intelligence Network

The National cardiovascular intelligence network (NCVIN) analyses information and data and turns it into meaningful timely health intelligence for commissioners, policy makers, clinicians and health professionals to improve services and outcomes.

### **National Child and Maternal Health Intelligence Network**

We provide information and intelligence to improve decision-making for high quality, cost effective services. Our work supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children's, young people's and maternal health

## **National Mental Health Intelligence Network**

The National Mental Health Intelligence Network (NMHIN) is a single shared network in partnership with key stakeholder organisations. The Network will seek to put information and intelligence into the hands of decision makers to improve mental health and wellbeing

## **National End of Life Care Intelligence Network**

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

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## Introduction

The Public Health England Knowledge and Intelligence Team, North West, (NW KIT) is the National Cancer Intelligence Network Site Specific Clinical Reference Group (NCIN SSCRG) lead intelligence team in England for cancer in teenagers and young adults. Cancer in teenagers and young adults (TYA) refers to diagnoses in those between 15 and 24 years of age.

Approximately 2,200 teenagers and young adults are diagnosed with cancer in the UK annually. Radiotherapy is an important part of the management of many children and young people with cancer. This type of therapy is used either alone or combined with surgery, chemotherapy in the curative or palliative treatment of cancers.

The Radiotherapy Data Set (RTDS) was set up in April 2009, in line with the recommendation of National Radiotherapy Advisory Group (NRAG) on formalising the collection of data on radiotherapy activity. This dataset should contain records on every patient treated with radiotherapy (more specifically teletherapy) in the NHS since April 2009 for England and 2010 for Scotland.

The purpose of this report is to calculate the proportion of TYA patients aged 15-24 who received radiotherapy treatment in England. The RTDS was used to determine which patients on the National Cancer Data Repository (NCDR) had received radiotherapy. The report focuses on TYA patients who were diagnosed in 2010 as this was the only full year for which both cancer registry and radiotherapy data were available.

## Methods

For this study, we extracted all patients aged 15 to 24 diagnosed in England with a diagnosis of malignant neoplasm or borderline and benign CNS tumours from the National Cancer Data repository (NCDR), a compilation of data, which includes details of all malignancies diagnosed in England during the period 1985 to 2010. We also obtained an extract of the radiotherapy dataset from NATCANSAT (the organisation which collects and collates radiotherapy data). This extract contains details of patients who received radiotherapy from June 2009 to the end of 2011 in England.

We first matched all patients on the RTDS extract we received against the full NCDR database to check the completeness of case ascertainment on the NCDR. All patients on the RTDS extract were identified on the NCDR.

For the purposes of calculating the percentage of patients receiving radiotherapy we limited our analysis to patients diagnosed in 2010, as this is the only full year for which registration and radiotherapy data are complete. We classified each tumour according to the TYA diagnostic groupings as described by Birch and colleagues (Birch et al. 2002) based on site of tumour and tumour histology (see appendix 1). We grouped patients into those diagnosed at 15-18 and 19-24 years, for further analysis.

# Data linkage

When the 1963 TYA patients recorded on NCDR as having been diagnosed with cancer in 2010 were matched against the RTDS extract, 338 were recorded on both datasets. Of these one received brachytherapy and the remaining 337 teletherapy (ie external beam radiation including total body irradiation), giving a percentage of 17.2% who received teletherapy.

# Results

Table I: Teletherapy by age group

Age group	Yes	No	Total
15-18	132 (23.4%)	432 (76.6%)	564
19-24	205 (14.7%)	1193 (85.3%)	1,398
15-24	337 (17.2%)	1626 (82.8%)	1,963

Table 2: Teletherapy by sex

Sex	Yes	No	Total
Male	183 (18.4%)	809 (81.6%)	992
Female	154 (16%)	817 (84%)	971
Total	337(17.2%)	1,626(82.8%)	1,963

Table 3: Teletherapy by England region of residence

UKACRGOR	N (%)	95% confidence interval	Total
A (North East)	20 (21.1%)	14.1 – 20.3	95
B (North West)	50 (16.3%)	12.6 – 20.8	307
D (Yorkshire and the Humber)	35 (17.3%)	12.7 – 23.1	202
E (East Midlands)	30 (17.8%)	12.7 – 24.2	169
F (West Midlands)	32 (15.0%)	10.8 – 20.8	214
G (East of England)	37 (19.5%)	14.5 – 25.7	190
H (London)	49 (19.0%)	14.7 – 24.2	258
J (South East)	47 (15.5%)	11.8 – 20.0	304
K (South West)	37 (16.6%)	12.3 – 22.0	223
Total	337		1,963

Table 4: Teletherapy by TYA diagnostic groups and subgroups

TYA groups	Yes	No	Total	% receiving teletherapy
Leukaemia	28	121	149	18.8
ALL	9	46	55	16.4
AML	15	43	58	25.9
Lymphoma	115	284	399	28.8
HL	93	201	294	31.6
NHL	22	82	104	21.2
CNS and Brain	77	174	251	30.7
Bone	24	54	78	30.8
Soft tissue	20	65	85	23.5
Germ cell	15	239	254	5.9
Testis	2	212	214	0.9
Melanoma & skin carcinoma	4	322	326	1.2
Carcinomas (except of skin)	49	341	390	12.6
Thyroid	2	102	104	1.9
Breast	5	16	21	23.8
Ovary	0	50	50	0.0
Uterine cervix	12	33	45	26.7
Colon & rectum	6	53	59	10.2
Miscellaneous specified	4	21	25	16.0
Unspecified	1	5	6	16.7
Total	337	1626	1963	17.2

<sup>\*</sup> As only the more common subgroups are included, the sum of the number of cases for several subgroups is less than the total for the relevant group.

## Comments

17.2% of TYA patients diagnosed with cancer in England in 2010 were recorded as having received teletherapy. Rates were higher for those aged 15-18 than for 19-24 year olds. Rates varied by type of cancer from 0.0% for ovarian carcinoma to 31.6% for Hodgkin lymphoma. The percentage receiving teletherapy varied by government region from 15.0% in the West Midlands to 21.1% for the North East, which has a considerably smaller population than the other regions and so values from the North East may be more prone to chance variation.

## **Appendix**

# Table 1: TYA Diagnostic Classification System (after Birch et al 2002 – updated to version 12)

### **Diagnostic Code Diagnostic Group**

#### GROUP 1: Leukaemias

- 1.1. Acute lymphoid leukaemia (ALL)
- 1.2. Acute myeloid leukaemia (AML)
- 1.3. Chronic myeloid leukaemia (CML)
- 1.4. Other and unspecified leukaemia (Other Leuk)
- 1.4.1. Other and unspecified lymphoid leukaemias

### **GROUP 2: Lymphomas**

- 2.1. Non-Hodgkin lymphoma (NHL)
- 2.1.1. Non-Hodgkin lymphoma, specified subtype
- 2.1.2. Non-Hodgkin lymphoma, subtype not specified
- 2.2. Hodgkin lymphoma (HL)
- 2.2.1. Hodgkin lymphoma, specified subtype
- 2.2.2 Hodgkin lymphoma, subtype not specified

# GROUP 3: Central Nervous System & other Intracranial & Intraspinal Neoplasms (CNS tumours)

- 3.1. Astrocytoma
- 3.1.1. Pilocytic astrocytoma
- 3.1.2. Other low grade astrocytoma
- 3.1.3. Glioblastoma and anaplastic astrocytoma
- 3.1.4. Astrocytoma not otherwise specified
- 3.2. Other gliomas
- 3.2.1. Oligodendroglioma
- 3.2.2. Other specified glioma
- 3.2.3 Glioma NOS
- 3.3. Ependymoma
- 3.4 Medulloblastoma and other primitive neuroectodermal tumours
- 3.4.1 Medulloblastoma
- 3.4.2 Supratentorial PNET.
- 3.5. Other specified intracranial and intraspinal neoplasms (Other CNS)
- 3.5.1 Craniopharyngioma
- 3.5.2 Pituitary tumours
- 3.5.3 Pineal tumours
- 3.5.4 Choroid plexus tumours
- 3.5.5 Meningioma

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- 3.5.6 Nerves sheath tumour of the brain
- 3.5.7 Other specified tumours
- 3.6 Unspecified intracranial and intraspinal neoplasms tumours
- 3.6.1. Unspecified malignant intracranial and intraspinal neoplasms
- 3.6.2. Unspecified non-malignant intracranial and intraspinal neoplasms

# GROUP 4: Osseous and Chondromatous Neoplasms, Ewing tumour and other Neoplasms of Bone (Bone Tumours)

- 4.1. Osteosarcoma
- 4.2. Chondrosarcoma
- 4.3. Ewing sarcoma
- 4.3.1 Ewing sarcoma of bone
- 4.3.2 Extraskeletal Ewing sarcoma
- 4.3.3 Ewing sarcoma of unknown site
- 4.4. Other specified and unspecified bone tumours (Other bone tumours)
- 4.4.1. Other specified bone tumours
- 4.4.2. Unspecified bone tumours

### **GROUP 5: Soft Tissue Sarcomas (STS)**

- 5.1. Fibromatous neoplasms (Fibrosarcoma)
- 5.1.1. Fibrosarcoma
- 5.1.2. Malignant fibrous histiocytoma
- 5.1.3. Dermatofibrosarcoma
- 5.2. Rhabdomyosarcoma
- 5.3. Other specified soft tissue sarcomas
- 5.3.1. Liposarcoma
- 5.3.2. Leiomyosarcoma
- 5.3.3. Synovial sarcoma
- 5.3.4 Clear cell sarcoma
- 5.3.5 Blood vessel tumours
- 5.3.6 Nerve sheath tumours
- 5.3.7 Alveolar soft part sarcoma
- 5.3.8 Miscellaneous specified soft tissue sarcoma
- 5.4 Unspecified soft tissue sarcomas

#### GROUP 6: Germ Cell & Trophoblastic Neoplasms (Germ cell tumours)

- 6.1 Gonadal germ cell & trophoblastic neoplasms
- 6.2 Germ cell & trophoblastic neoplasms of non- gonadal sites
- 6.2.1. Intracranial germ cell and trophoblastic tumours
- 6.2.2. Other non- gonadal germ cell and trophoblastic tumours

#### GROUP 7: Melanoma and Skin Carcinoma

7.1. Melanoma

#### 7.2. Skin carcinoma

### GROUP 8: Carcinomas (except of skin)

- 8.1. Carcinoma of thyroid
- 8.2. Other carcinoma of head and neck
- 8.2.1. Nasopharyngeal carcinoma
- 8.2.2. Carcinoma of other sites in lip oral cavity and pharynx
- 8.2.3. Carcinoma of nasal cavity, middle ear, sinuses, larynx and other ill- defined sites in head and neck
- 8.3. Carcinoma of trachea, bronchus, lung and pleura
- 8.4. Carcinoma of breast
- 8.5. Carcinoma of genito- urinary (GU) tract
- 8.5.1. Carcinoma of kidney
- 8.5.2. Carcinoma of bladder
- 8.5.3. Carcinoma of ovary
- 8.5.4. Carcinoma of cervix
- 8.5.5. Carcinoma of other and ill-defined sites in GU
- 8.6. Carcinoma of gastro- intestinal (GI) tract
- 8.6.1. Carcinoma of colon and rectum
- 8.6.2. Carcinoma of stomach
- 8.6.3. Carcinoma of liver and intrahepatic bile ducts
- 8.6.4. Carcinoma of pancreas
- 8.6.5. Carcinoma of other and ill-defined sites in GI tract
- 8.7. Carcinomas of other & ill- defined sites not elsewhere classified (NEC)
- 8.7.1. Adrenocortical carcinoma
- 8.7.2. Other carcinomas NEC

#### GROUP 9: Miscellaneous Specified Neoplasms NEC

- 9.1. Embryonal tumours NEC
- 9.1.1. Wilms tumour
- 9.1.2. Neuroblastoma
- 9.1.3. Other embryonal tumours NEC
- 9.2 Other rare miscellaneous specified neoplasms
- 9.2.1. Paraganglioma and glomus tumours
- 9.2.2. Other specified gonadal tumours NEC
- 9.2.3. Myeloma, mast cell tumours and miscellaneous reticuloendothelial
- 9.2.4. Other specified neoplasms NEC

### GROUP 10: Unspecified Malignant Neoplasms NEC

# National Cancer Intelligence Network

The NCIN is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

Sitting within the National Cancer Research Institute (NCRI), the NCIN works closely with cancer services in England, Scotland, Wales and Northern Ireland. In England, the NCIN is part of the National Cancer Programme.

The National Cancer Intelligence Unit will be hosted by Public Health England from 1st April 2013.

Our aims and objectives cover five core areas to improve the quality and availability of cancer data from its collection to use:

- promoting efficient and effective data collection throughout the cancer journey
- providing a common national repository for cancer datasets
- producing expert analyses, to monitor patterns of cancer care
- exploiting information to drive improvements in cancer care and clinical outcomes
- enabling use of cancer information to support audit and research programmes