

Analysing Long-term Patterns of Medical Care for the National Registry of Childhood Tumours (NRCT) Using Hospital Episode Statistics (HES)

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Background

About the NRCT

The NRCT is a population based register of malignancies and benign brain tumours diagnosed in children (less than 15 years of age) resident in England, Wales or Scotland at the time of diagnosis. Currently the database contains over 80,000 cases of childhood cancer, which are classified according to the International Classification of Childhood Cancer, 2nd edition (ICCC-2).

About HES

HES contains records of all patients admitted to NHS hospitals in England from 1989 (including private patients and patients resident outside of England), NHS outpatient attendances in England from 2003, patients living in England who were admitted to hospitals in Wales, and patients who received care from an NHS-funded treatment centre within England. Each record provides details about one care period.

Objectives

Pilot Study

This pilot study linked records for patients in the NRCT that were first diagnosed with cancer in 1999-2000 to the accumulated HES records up to 31/03/2004. The purpose of the study was to determine how successful linkage is and how HES might authenticate and supplement the NRCT.

Additionally, the pilot study will provide the CCRG with an idea of how many episodes of data each case will contribute each year. This will aid the CCRG in determining both the storage required for the data and how to present it.

Possible Benefits

- **Data validation** – confirm the NRCT data and find possible errors in the NRCT data
- **Provide missing data** – fill in gaps for data that the NRCT collects, but is missing for some cases, such as ethnic group
- **Provide additional data** – HES may supplement the NRCT in a number of ways:
 - provide information on non-cancer diagnoses
 - provide information on treatment
 - identify patients that died in hospital so their medical records can be obtained
 - provide information on second primary tumours and metastases

Methods

Data Sent to HES

A data file was created containing 'new' NHS number (a number used to identify a person uniquely within the NHS in England and Wales), birth date, sex, and supplementary identifiers for patients on the NRCT diagnosed in England between 1999 and 2000 (2387 cases). The file was sent to Dr Brian Cottier's team at Clatterbridge Hospital for record linkage to the HES data. 99% of the NRCT records for 1999-2000 have new NHS numbers, making linkage between the data possible.

Data Returned

HES data for 68,564 admissions at 289 Primary Care Trusts were matched to 89% of the supplied NRCT cases. The coding systems and field descriptions for the data were determined from HES Online's Data Dictionary (www.hesonline.nhs.uk) and the data were decoded using tables from HES Online and other sources. The data were extensively checked for duplicates, missing data, errors, and conflicting information. Conflicts and errors, such as those for NHS number, sex, and birth date, were corrected before analysis.

Preliminary Findings

Admissions and Discharges

- **Admissions per patient** – ranged from 1 to 544, mean 33, median 26, mode 2
- **Classification of patient when admitted** – majority were NHS patients; only 200 episodes for private patients and 35 unknown
- **Type of admission** – 51% day admissions, 46% ordinary hospital admissions, 3% regular day attendees, plus 3 episodes for mother / baby delivery
- **Discharge destination** – 94.2% of admissions ended with the patient discharged to usual place of residence, 0.3% to temporary residence, 2.6% to an NHS provider, and 0.1% to a non-NHS healthcare provider. For 2.7% of admissions, the patient died in hospital (9.2% of patients).

Most Frequent Medical Procedures*

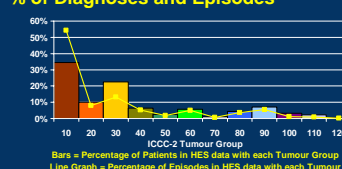
Treatment	Number	% of Procedures	% of Episodes	Patients	% of Patients
Intravenous chemotherapy	13746	23.6%	20.0%	1180	57.0%
Therapeutic spinal puncture	9038	15.5%	13.2%	749	36.2%
Blood transfusion	5078	8.7%	7.4%	983	47.5%
Diagnostic spinal puncture	4683	8.0%	6.8%	674	32.6%
Diagnostic puncture of bone	4261	7.3%	6.2%	1009	48.8%
Other vein related operations	3861	6.6%	5.6%	1456	70.4%
Blood withdrawal	3352	5.8%	4.9%	261	12.6%
Continuous infusion of therapeutic substance	2051	3.5%	3.0%	376	18.2%

*Note: This HES dataset does not include radiotherapy and stem cell transplant treatments

Selected Non-Cancer Diagnoses

Diagnosis	% of Leukaemia Patients	% of CNS Patients	Ratio of % of Leukaemia Patients to CNS Patients
Certain infectious & parasitic diseases	69.4%	26.7%	2.6 to 1
Mental & behavioural disorders	1.5%	6.0%	1 to 4
Nervous system diseases	9.9%	56.3%	1 to 5.7
Eye & adnexa diseases	8.6%	24.1%	1 to 2.8
Ear & mastoid process diseases	18.6%	9.2%	2 to 1
Circulatory system diseases	12.1%	4.3%	2.8 to 1
Respiratory system diseases	63.7%	25.6%	2.5 to 1
Digestive system diseases	52.5%	23.0%	2.3 to 1
Skin & subcutaneous tissue diseases	19.0%	7.1%	2.7 to 1

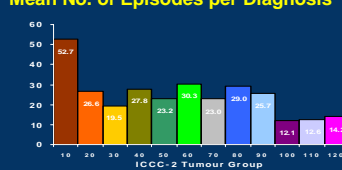
% of Diagnoses and Episodes



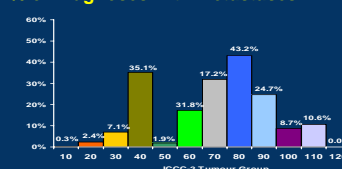
ICCC-2 Tumour Groups

- 10 – Leukaemia
- 20 – Lymphomas & Reticuloendothelial Neoplasms
- 30 – CNS & Misc. Intracranial & Intraspinal Neoplasms
- 40 – Sympathetic Nervous System Tumours
- 50 – Retinoblastoma
- 60 – Renal Tumours
- 70 – Hepatic Tumours
- 80 – Malignant Bone Tumours
- 90 – Soft Tissue Sarcomas
- 100 – Germ Cell, Trophoblastic & Other Gonadal Neoplasms
- 110 – Carcinoma & Other Malignant Epithelial Neoplasms
- 120 – Other & Unspecified Malignant Neoplasms

Mean No. of Episodes per Diagnosis



% of Diagnoses with Metastases



Conclusions

Assessment of Pilot Study

Linkage of the NRCT records to HES data was achieved with comparative ease and with a high percentage of completeness. Both datasets can be used to supplement each other. For example, HES provides treatment and episodes information for patients in the NRCT and the NRCT provides ICCC-2 tumour codes for patients in the HES dataset. Some additional data validation and manipulation is necessary for analysis involving surgery (data needs to be separated from other treatment data) and ethnic origin (conflicting data). The pilot was considered successful and CCRG will request HES data for other registration years.

Future Research

The exploration of the NRCT-HES linked data is ongoing. Planned analyses includes:

- Reasons for failure to link HES data to the NRCT
- Time from first admission (with cancer symptoms) to cancer diagnosis
- Correlation between treatment and subsequent episodes and outcome
- Geographical distribution of tumours
- Correlation between non-cancer diagnoses and tumour types
- Average number of operations for diagnosis
- Average number of episodes (factoring in age at diagnosis and mortality)

Extraordinary Data 687 patients admitted since 1999 had been waiting since 1582; operation codes erroneously in diagnosis field resulted in 2 patients admitted for chemotherapy diagnosed as 'victims of volcanic eruptions'

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