Cancer Registration

The Data Journey



THE PATIENT



DATA SOURCES

Histopathology



DATA SOURCES

Other



IMPORT



The data journey starts with the patient. Information is collected on the diagnosis and treatment of the patient's primary cancer. Primary cancer is the term used to describe where a cancer starts in the body. Data is collected on all treatments that take place in the twelve months following diagnosis



Approximately 90% of all new tumour registrations are registered from histopathology reports shortly after diagnosis.
Histopathology reports are also used to add extra information to existing registrations where appropriate. Most histopathology reports are provided to NCRI in electronic format



Other data sources such the Hospital In-Patient Enquiry system (HIPE), bespoke treatment systems such as radiotherapy, general hospital systems and medical charts are used to update existing registrations and register other tumours that were not notified to NCRI via histopathology



Electronic data is standardised, cleaned and coded during the import process into the NCRI's Advanced Cancer Enquiry System (ACES)



DATA LINKAGE



QUALITY ASSURANCE



ANALYTICS



OUTPUTS



Electronic data linkage and deduplication of registrations is performed using probabilistic matching software. All potential matches and possible duplicates are reviewed by a user. New registrations are created for non matches or existing registrations are updated. All electronic sources relating to a patient are linked and are available for the electronic Cancer Data Registrar (eCDR) to view and process within ACES



Quality assurance measures are implemented at every stage of the data journey, from import of electronic data into ACES, to tumour registration, to data extraction for analysis



Cancer registration is analysed for the following purposes:

- Assessing patterns and trends of cancer case numbers, risk, treatment and survival over time and in relation to factors such as age, cancer stage and geographic area
- Devising cancer policy and planning cancer services
- Supporting evaluation of the quality of cancer services and impact of cancer control measures
- Research on the causes and prevention of cancer



NCRI data is made available to researchers and the public through dissemination of reports (statistical, trends and projections), downloadable and custom datasets, factsheets, infographics, and educational material

