

NCCP Statement of Purpose for the collection of data

The NCCP is committed to implementing the national Cancer Strategies, particularly the *National Cancer Strategy 2017-2026* (Department of Health, 2017) and *A Strategy for Cancer Control in Ireland* (National Cancer Forum, Department of Health, 2006) which emphasised the central requirement for accurate, timely and relevant information in the development and the implementation of a national cancer control programme. Good information underpins appropriate decisions, whether by patients, health professionals, researchers, managers or policy-makers. Consistent availability and use of health information leads to better-informed patients and a better-informed public, improved service delivery, enhanced quality and efficiency and effective planning. Detailed and timely cancer data is needed for local audit, evaluation and risk monitoring, for national audit, evaluation and programme monitoring and for programme planning.

The National Cancer Control Programme (NCCP) collects information in order to ensure timely access for patients to evidence-based prevention, diagnosis and treatment for cancer in addition to ensuring cost effective care and facilitating audit of the services provided. This information collection also allows NCCP to ensure appropriate integration of cancer related data with hospital groups, individual acute hospitals, primary care services, other divisions of the HSE and appropriate national data registries in addition to service planning.

The information collected by NCCP includes demographic, clinical, financial, drug utilisation and administrative data from acute hospitals nationally, the Primary Care Reimbursement Service (PCRS), HIPE and other sources.

There are three key elements to the NCCP collection of data:

- i. The collection of key performance indicator (KPI) data commenced in 2009. It involves the collection of cancer service activity information from hospital computer systems, patient files and other sources in hospitals. These data are collected in order to inform cancer service planning, evaluation, audit and research. KPI data are collected for various site specific cancers in addition to general cancer management programmes.
- ii. The National Cancer Drug Management Programme, which is provided in conjunction with the Primary Care Reimbursement Service, commenced in 2012. It involves the collection of demographic, clinical and drug utilisation data by individual hospitals. These data are required to ensure that cancer services are provided in line with evidence-based treatment protocols and to ensure that cost-effective care is provided to eligible patients.
- iii. Determined by clinical priorities, the NCCP also occasionally conducts national audits of the quality and safety of particular services or tumour treatments. This requires access to an agreed random or opportunistic sample of individual patient data to enable the NCCP to scrutinise the care received by the particular cohort of patients. Data is anonymised by the hospital prior to transmission to the NCCP