



North Central London
Health and Care
Integrated Care System



North Central London Cancer Dataset Directory

The directory outlines the datasets, responsible organisations, content overview, typical publication timelines and provides easy access links to the datasets. The purpose of this dataset directory is to catalogue the wide variety of datasets available to healthcare professionals, commissioners and policymakers within North Central London.

The datasets listed in the directory contain a diverse range of critical metrics and information, such as population demographics, cancer incidence, treatment outcomes, patient experience, survival rates, and healthcare service efficiency.

Through analysing these datasets, stakeholders can transform data into actionable intelligence, fostering a comprehensive understanding of cancer care in NCL. This will enable the development of evidence-based strategies aimed at reducing inequities in patient access to cancer services and improving patient outcomes.

Dataset	Location	Content	Publication Timeline	Access	Link	Comments
National Cancer Registration and Analysis Service (NCRAS)	NHS England	Detailed cancer registration data, including patient demographics, tumour type, treatment, and outcomes.	Annual updates; data typically has a 12-18 month lag.	Open access for aggregate data; request required for individual-level data.	https://digital.nhs.uk/ndrs/	NCRAS is now part of the National Disease Registration Service (NDRS).
Getting It Right First Time (GIRFT) Cancer Dataset	NHS England, GIRFT Programme	Specialty-specific datasets aimed at improving care by identifying variation in clinical practices and outcomes. GIRFT provides detailed performance data at hospital and regional levels for cancer services.	Varies by specialty; typically published in annual or biennial reports.	Available via NHS platforms and through specific reports for various specialties.	https://gettingitrightfirsttime.co.uk/	
National Cancer Audits	Healthcare Quality Improvement Partnership (HQIP)	Disease-specific audits including lung, bowel, prostate, and breast cancer, providing clinical outcomes and quality improvement data. Key Audits: National Lung Cancer Audit (NLCA) National Prostate Cancer Audit (NPCA) National Bowel Cancer Audit (NBOCA) National Audit of Breast Cancer in Older Patients (NABCOP)	Annually, usually within 6-12 months of data collection	Reports publicly available, datasets can be accessed via request.	https://www.hqip.org.uk/a-z-of-nca/national-cancer-audit-collaborating-centre/	
Cancer Outcomes and Services Dataset (COSD)	NHS Digital	The main cancer data standard for capturing diagnosis, treatment, and outcomes for all patients diagnosed with cancer.	Monthly submissions with yearly aggregate data available	Data accessible via NHS Digital's services and reports.	https://digital.nhs.uk/ndrs/data/datasets/cosd	
National Cancer Patient Experience Survey (NCPES)	NHS England	Annual survey of cancer patients, focusing on their care experience and satisfaction.	Annual reports typically published in the summer	Publicly available survey results.	https://www.ncpes.co.uk/	
Cancer Waiting Times (CWT)	NHS England	Data on waiting times for cancer diagnosis and treatment against national standards (e.g., two-week referral, 31-day treatment target).	Monthly data releases.	Publicly available via NHS England.	https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/	
National Cancer Research Institute (NCRI) Cancer Research Database	NCRI	Funding data for cancer research in the UK, including breakdown by cancer type and research category.	Annual reports.	Publicly available.	https://www.ncri.org.uk/	The Charity is to wind down.
Cancer Registry Data (Scotland, Wales, Northern Ireland)	Scotland: Public Health Scotland Wales: Welsh Cancer Intelligence and Surveillance Unit (WCISU) Northern Ireland: Northern Ireland Cancer Registry (NICR)	Similar to NCRAS, these national registries collect data on cancer incidence, mortality, survival, and treatment in their respective countries.	Typically annual with 12-18 month lag.	Publicly available reports; individual-level data available on request.	https://phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/ https://publichealthscotland.scot/ https://www.qub.ac.uk/research-centres/nicr/	
National Disease Registration Service (NDRS)	NHS England	Broader disease registration, including cancer, rare diseases, and congenital anomalies.	Regularly updated.	Public and academic access available.	https://digital.nhs.uk/ndrs/	
Cancer Quality of Life Survey	NHS England, Quality Health	Survey to assess quality of life among cancer survivors after diagnosis and treatment.	Annual publication.	Reports publicly available; data can be accessed through NHS England on request.	https://www.england.nhs.uk/publication/cancer-quality-of-life-survey-summary-report-first-data-release-october-2021/	
UK Biobank (Cancer Data)	UK Biobank	Large-scale biomedical database with cancer data linked to patient outcomes, treatments, and genetic factors.	Continuous updates; large datasets released in batch updates.	Researcher access by application.	https://www.ukbiobank.ac.uk/	

New Hospitals Programme Data (Cancer Focused Projects)	NHS England	Data on cancer services and outcomes in hospitals built or upgraded under the New Hospitals Programme, focused on cancer service enhancement.	Ongoing as hospitals are developed or updated.	Data expected to be integrated with NCRAS and other national audits.	https://www.england.nhs.uk/wp-content/uploads/2022/10/item-7-public-board-meeting-new-hospital-programme.pdf	
Office for National Statistics (ONS) Cancer Mortality Data	ONS	Detailed statistics on cancer mortality by type, age, gender, and location.	Annual.	Publicly available.	https://www.ons.gov.uk/	
Clinical Practice Research Datalink (CPRD)	NHS Digital	Includes cancer-related data from primary care, linking to hospital episode statistics and NCRAS data.	Continuous data collection.	Available to researchers by request.	https://www.cprd.com/	
International Cancer Benchmarking Partnership (ICBP)	Cancer Research UK (CRUK)	Global comparisons of cancer survival and outcomes across multiple countries, focusing on lung, bowel, and breast cancer.	Irregular, based on research collaborations.	Publicly available	https://www.cancerresearchuk.org/health-professional/data-and-statistics/international-cancer-benchmarking-partnership-icbp	
Hospital Episode Statistics (HES)	NHS Digital	HES is a comprehensive database containing records of all inpatient, outpatient, and accident & emergency (A&E) admissions to NHS hospitals in England. For cancer, it provides valuable data related to hospital admissions, diagnoses, treatments, surgical procedures, and outcomes for cancer patients. HES Inpatient (IP): Tracks admitted patient care for procedures like surgeries and treatments for cancer. HES Outpatient (OP): Captures outpatient services, including follow-up appointments for cancer patients. HES Accident & Emergency (A&E): Tracks emergency admissions, including for complications due to cancer or treatment side effects.	Published annually and quarterly. Data typically has a 3-month lag for provisional data, with final data available 6 months after the period.	Aggregated data is publicly available; individual-level data can be accessed via request through the Data Access Request Service (DARS).	https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics	
NHS Payment Scheme (NHSPS)	NHS England	The National Payment Tariff sets prices and payment mechanisms for NHS-funded care, including cancer treatments. It outlines the payment structure for a range of services, from diagnostics to surgery and chemotherapy. The tariff defines how providers are paid for different procedures, including those related to cancer care. HRG Codes (Healthcare Resource Groups): For cancer care, specific HRG codes are used to classify patient treatments and episodes, which are linked to national tariffs. These include chemotherapy, radiotherapy, and complex cancer surgeries. Best Practice Tariffs: Includes incentives for providing care in line with clinical guidelines, often applied to cancer treatments and diagnostic pathways.	The tariff is updated annually, with an overview of proposed and final tariffs published in advance of the fiscal year.	Publicly available on NHS England's website.	https://www.england.nhs.uk/pay-syst/national-tariff/	2023/25 NHSPS came into effect on 1 April 2023

Cancer Survival in England	Office for National Statistics (ONS)	Provides cancer survival estimates by age, sex, and cancer type. This dataset focuses on one-year and five-year survival rates for common cancer types.	Published annually.	Publicly available via the ONS website	https://www.ons.gov.uk/
Surgical Workload and Outcomes (Including Cancer)	Royal College of Surgeons (RCS)	Data on cancer-related surgeries, including workload, outcomes, and complication rates. This data is important for specialties like oncology, colorectal surgery, breast surgery, and more.	Updated annually.	Publicly available in reports; some datasets require a request.	https://www.rcseng.ac.uk/
Systemic Anti-Cancer Therapy (SACT) Dataset	NHS England	Data on all patients receiving systemic anti-cancer therapies (such as chemotherapy, immunotherapy, and hormone therapy) in England. This dataset provides information on treatment regimens, drug usage, and outcomes.	Monthly submissions with yearly data reports.	Access is provided to researchers through NHS Digital and NCRAS.	https://digital.nhs.uk/ndrs/
Radiotherapy Dataset (RTDS)	NHS England	Captures data on patients receiving radiotherapy as part of their cancer treatment. RTDS provides data on treatment types, dosages, and outcomes.	Updated quarterly.	Accessible via NCRAS for researchers; summary statistics are available publicly.	https://digital.nhs.uk/ndrs/
Quality Outcomes Framework (QOF) - Cancer Indicators	NHS Digital	QOF data includes cancer indicators related to primary care, focusing on early diagnosis, screening, and ongoing care management for cancer patients.	Updated annually.	Publicly available data through NHS Digital.	https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/general-practice-data-hub/quality-outcomes-framework-qof
Cancer Incidence and Survival by Major Ethnic Group	NHS England	Provides cancer incidence and survival rates stratified by ethnic group. This dataset supports the study of cancer inequalities and disparities in treatment and outcomes among different ethnic groups in England.	Published irregularly, depending on analysis.	Publicly available via reports and datasets.	https://digital.nhs.uk/ndrs/
Public Health Outcomes Framework (PHOF) – Cancer Indicator	NHS England	A set of cancer-related indicators tracking outcomes related to cancer prevention, early diagnosis, treatment, and survival at a local level.	Updated annually	Publicly available via the PHOF tool.	https://fingertips.phe.org.uk/profile/public-health-outcomes-framework
Cancer Prevalence in England	Macmillan Cancer Support / Public Health England	Detailed prevalence data for people living with cancer in England, including breakdowns by cancer type, age, and region.	Published biannually.	Publicly available through Macmillan's reports.	https://www.macmillan.org.uk/about-us/what-we-do/research/cancer-statistics-fact-sheet
Genomic Data from Cancer Genomics England (C-GEN)	Genomics England	Provides genomic sequencing data for cancer patients as part of the 100,000 Genomes Project. This includes genomic information linked to clinical data for research purposes, enhancing precision medicine in oncology.	Ongoing.	Available to researchers via application.	https://www.genomicsengland.co.uk/
Primary Care Cancer Research Database (PCCR)	Cancer Research UK (CRUK)	Focuses on cancer data linked to primary care settings, including patient referrals, diagnoses, screening participation, and primary care interventions.	Ongoing updates based on studies.	Available to researchers through CRUK and partner institutions.	https://www.cancerresearchuk.org/health-professional/data-and-statistics/gp-practice-and-local-data
Cancer Screening Data (Breast, Cervical, Bowel)	NHS England	Data on national cancer screening programs (breast, cervical, bowel) tracking uptake rates, screening outcomes, and early detection rates.	Published annually, with quarterly updates for some metrics.	Publicly available through NHS Digital's data tools and reports.	https://fingertips.phe.org.uk/search/cancer%20screening
Cancer Registries in Other UK Nations	Public Health Scotland, Northern Ireland Cancer Registry, and Welsh Cancer Intelligence and Surveillance Unit (WCISU)	Similar to the National Cancer Registration and Analysis Service (NCRAS) in England, these registries capture cancer incidence, treatment, and outcome data for their respective regions.	Annual.	Publicly available reports and data; individual-level data can be accessed via request.	https://www.isdscotland.org https://phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/ https://www.qub.ac.uk/research-centres/nicr/

Cancer Drugs Fund (CDF) Data	NHS England	Data on patients receiving treatments funded through the Cancer Drugs Fund, which provides access to innovative new cancer therapies. Includes data on outcomes, treatment types, and patient demographics.	Updated quarterly.	Available through NHS England and NHS Digital; access for research purposes is via application.	https://www.england.nhs.uk/cancer/cdf/
Health Survey for England - Cancer-related questions	NHS Digital / ONS	Contains cancer-related questions as part of a national population health survey, including cancer awareness, screening participation, and risk factor data.	Annual.	Publicly available reports.	https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england
Data on Cancer Medicines from Blueteq	NHS England (Blueteq System)	Blueteq provides datasets on cancer medicines prescribed via the Cancer Drugs Fund, capturing use and outcomes of high-cost drugs and innovative treatments.	Ongoing data collection with regular reports.	Available through NHS England for specific requests.	https://blueteq.com/