NHS
North Central London
Cancer Alliance

Cancer clinical coding minimum dataset specification for primary care

Minimum dataset, technical SNOMED CT reference and audit standards — North Central London Cancer Alliance

Purpose and Scope

This minimum dataset (MDS) provides SNOMED CT coding recommendations for primary care across the cancer pathway. Developed by the North Central London Cancer Alliance and partners, it addresses known gaps and variation in cancer-related coding while aligning with current national and local requirements, including QOF, Local Commissioned Services (LCS), and the PRF1 patient registration framework.

The recommendations are based on analysis of current GP coding practice, prioritising widely used codes where possible, alongside stakeholder engagement and evolving Cancer Alliance priorities. The dataset is intended to complement, rather than replace, established coding standards such as cervical screening codes that are contractually mandated and linked to remuneration.

The MDS does not aim to capture every activity across the cancer pathway. Instead, it focuses on areas where coding gaps or variation exist and provides guidance on recommended coding, technical implementation, and audit standards. The dataset will continue to evolve in line with SNOMED CT developments, policy changes, and user feedback.

Policy Context

The dataset aligns closely with the PRF1 patient registration form, introduced on 1 November 2024, which expanded demographic and behavioural data collection beyond that previously captured through GMS1 registration forms. Data items aligned to PRF1 fields are identified within the specification.

Dataset Structure

The dataset follows the cancer pathway through 10 stages:

Section	Focus Area
Sections 1-3	Patient demographics & predisposing health factors
Sections 4-5	Screening and suspected cancer referrals
Sections 6-8	Diagnosis through to treatment monitoring
Sections 9-10	Personalised care and surveillance

Dataset Owners

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Updating the Dataset

Last Updated December 2025.

Annual review, assessment of proposed updates, changes, and publication in Quarter 1 (April/May/June) of each financial year.

Final v2.0 – January 2026 (specification); see Version Control for the full change history.

Implementation

The minimum dataset data items can be collected in North Central London using an EMIS template developed and maintained by the NCL ICB GP IT team that's available to all NCL GP practices. There are ongoing efforts to reduce the data collection burden by using Artificial Intelligence (AI), Automation, and Natural Language Processing (NLP) methods, and by improving data sharing from secondary care back to primary care.

Status	Task
Complete	The GP IT team will develop the EMIS MDS template
Ongoing	GP practices will pilot the template and refine workflows to allow for most efficient data capture
Complete	The Cancer Alliance will engage EMIS to confirm availability of SNOMED CT codes currently missing in the system
Ongoing	New SNOMED codes will be requested of the NHS Terminology and Classifications Delivery Service by the Cancer Alliance where there are coding gaps
Ongoing	Stakeholders (practice managers, coders) will be engaged to validate data collection workflows
Not Started	User-friendly workflows will be designed by the Cancer Alliance (e.g., auto-coding prompts) to align with practice routines
Not Started	Initial training will be provided by the Cancer Alliance along with a quick-reference guides for any rare scenarios identified in testing.
Ongoing	MDS uptake and data completeness will be monitored via a Power BI dashboard developed by the Cancer Alliance using GP data available via the One London Integrated Dataset (OLID).
Ongoing	Clear governance will be established in the Cancer Alliance and ICB for template maintenance and to manage updates to the MDS.

Audit Development for the MDS and Analytics Dashboard

Background

Our MDS (user guide and technical guide) was published on or website in April 2025. It covers demographics, diagnosis, staging, treatment & living with and beyond cancer related activity, and was built on, and aligned to, national priorities, incentives and frameworks e.g. QOF, PRF1 forms, NICPR.

In December 2025, an NCL wide MDS compliant template was built and released in by the NCL GPIT team for use in EMIS Web.

Following this, the NCLCA team have developed a draft MDS audit for future monitoring and quality assurance purposes, and to set aspirational but realistic targets for data completion across the MDS data items.

Dashboard: https://app.powerbi.com/groups/7cc050dc-acac-4ac6-b8bd-5e917f711ba0/reports/3964e9e5-d994-4194-9428-4c719b878c09/36e5192b7906890516a8?ctid=2f7a9b80-2e65-4ed6-9851-2f727effb3a1&experience=power-bi

Principles for target development and comparator denominators

- Anchor each data item to relevant national guidance or standards where available.
- Where no national standard exists, apply an evidence-informed consensus threshold (e.g. ≥95% for mandatory demographic fields such as ethnicity, main language, and smoking status; ≥70–80% for more complex clinical items such as cancer stage or treatment data).
- Apply a flexible, iterative approach using PDSA cycles, with thresholds and comparator denominators reviewed and refined as data quality, feasibility, or alternative data sources evolve.
- Recognise that some data items are static and require infrequent review (e.g. ethnicity, family history, cancer diagnosis), while others are dynamic and require regular refresh (e.g. smoking status, BMI, alcohol intake, carer status).
- Capture event-based data items at each relevant care episode (e.g. registration, referral decision appointment, cancer care review).
- Align screening and surveillance data items to relevant national or tumour-specific guidance.
- The unknown data denominator problem
    - Conditional Data / Subpopulation Data: When you only ask a subset (e.g., "only those with limited English"), the data collected is conditional.
    - Intentional Skips: In data management, these are specifically categorized as "good skips" where the missing value is expected, rather than "item non-response" (where a user skips a question they should have answered).

The audit targets, numerators and denominators below are presented alongside the corresponding coding recommendation and technical SNOMED CT reference for each data item, in the single reference table that follows.

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Minimum Dataset: Coding Recommendations, Technical Reference Guide, and Audit Standards

One row per SNOMED CT-coded data item. Columns combine: the coding recommendation and rationale (from the minimum dataset specification); the technical SNOMED CT reference, EMIS availability and policy alignment (from the technical guide); and the suggested audit target, numerator, denominator, and data period (from the audit and analytics dashboard framework). Colour-coding follows the key above.

Section	Data Item	Description	SNOMED CT Recommendation	EMIS Availability / Policy	Coding Rationale / Comments	Data Completeness Target and Rationale	Denominator	Source	Data Period
Demographics and Social Context	Ethnicity	Ethnic group classification, aligned with 2011 Census/QOF standards.	**Type:** Parent **SNOMED CT Code:** 976571000000100 Ethnic category - 2011 census England and Wales (finding) **Direct child codes:** 18	✅ Available **Policy alignment:** PRF1	Coding was aligned to the recommended SNOMED code and this aligns with QOF. Stable over time. Noted that different providers with coding. Note : Ethnicity is non-mandatory on the electronic PRF1 form	**Target:** 95% Core demographic field; alignment with PRF1 registration and QOF expectations.	All current NCL GP registered patients	GP Data (OLID)	Recorded ever
Demographics and Social Context	Main Language Spoken	Patient's primary spoken language.	**Type:** Parent **SNOMED CT Code:** 370157003 Main spoken language (finding) **Direct child codes:** 207	✅ Available	The parent code is the majority usage Conditional data - asked only if interpreter needed	**Target:** 85% Less routinely captured historically but essential for equitable care.	All current NCL GP registered patients	GP Data (OLID)	Recorded ever
Demographics and Social Context	Employment Status	Current work status (e.g., employed, retired, unemployed).	**Type:** Parent **SNOMED CT Code:** 365525008 Finding of employment status (finding) **Direct child codes:** 21	✅ Available	This parent code is most comprehensive. Working age spikes at around age 25 in the data. May affect cancer risk / survivorship	**Target:** 70% Social context data; allow stage-based improvement	Current NCL GP registered patients aged 25+	GP Data (OLID)	Captured within the last 4 yrs
Demographics and Social Context	Occupation	Stated occupation or job title.	**Type:** Parent **SNOMED CT Code:** 14679004 Occupation (occupation) **Direct child codes:** 28	✅ Available	Important demographic context to support equalities data analysis	**Target:** No target Not mandated via PRF1 or other data collection means and no obvious comparator dataset	Current NCL GP registered patients aged 25+	GP Data (OLID)	Captured within the last 4 yrs
Demographics and Social Context	Highest Education Level	Highest level of formal education completed.	**Type:** Parent **SNOMED CT Code:** 365461001 Finding of educational achievement (finding) **Direct child codes:** 11	✅ Available	Rarely changes	**Target:** 80% Often omitted, Useful for equity analyses	Current NCL GP registered patients aged 25+	GP Data (OLID)	Recorded ever
Demographics and Social Context	Main Religion/Belief	Stated religion, philosophy, or belief system.	**Type:** Parent **SNOMED CT Code:** 1400009 Spiritual or religious belief (religion/philosophy) **Direct child codes:** 50	✅ Available	Important demographic context to support equalities data analysis	**Target:** 90% For equitable care analysis	All current NCL GP registered patients	GP Data (OLID)	Recorded ever
Demographics and Social Context	Digital Exclusion	Identifies patients unable to access or use digital services.	**Type:** Child **SNOMED CT Code:** 1597941000000100 Unable to perform information and communication technology activities (finding)	✅ Available	Important demographic context to support equalities data analysis. Child codes include Unable to perform information and communication technology activities Unable to perform ICT (information and communication technology) activities	**Target:** No target Not mandated via PRF1 or other data collection means and no obvious comparator dataset	Current NCL GP registered patients aged 70+	GP Data (OLID)	Recorded ever
Demographics and Social Context	Reasonable Adjustments - Disability Impact on Daily Activity	Indicates if a patient reports an impairment with a substantial and long-term impact on day-to-day activities, under the Equality Act 2010.	**Type:** Child **SNOMED CT Code:** 1326341000000105 Impairment with substantial and long-term adverse effect on normal day to day activity (Equality Act 2010) (finding)	✅ Available **Policy alignment:** PRF1	In September 2023, the NHS published a that sets out what all NHS and publicly funded social care organisations in England are required to do to implement the Reasonable Adjustment Digital Flag in their services. The Information Standard Notice says that organisations must have processes in place to be able to identify, record, flag, share, meet and review and update people's reasonable adjustment needs on their systems. Question on PRF1 conflates patient & carer	**Target:** No target	All current NCL GP registered patients	GP Data (OLID)	Recorded ever
Demographics and Social Context	Reasonable Adjustments - Required	Identifies patients needing reasonable adjustments to access healthcare, as defined by the Equality Act 2010.	**Type:** Child **SNOMED CT Code:** 1108111000000107 Requires reasonable adjustment for health and care access (Equality Act 2010) (finding)	✅ Available **Policy alignment:** PRF1	In September 2023, the NHS published a that sets out what all NHS and publicly funded social care organisations in England are required to do to implement the Reasonable Adjustment Digital Flag in their services. The Information Standard Notice says that organisations must have processes in place to be able to identify, record, flag, share, meet and review and update people's reasonable adjustment needs on their systems. Question on PRF1 conflates patient & carer	**Target:** No target	All current NCL GP registered patients	GP Data (OLID)	Recorded ever
Demographics and Social Context	Reasonable Adjustments - Consent	Records if the patient has consented to upload reasonable adjustment information to the national digital flag.	**Type:** Child **SNOMED CT Code:** 1853771000000105 Consent given to upload data to Reasonable Adjustment Digital Flag (finding)	✅ Available **Policy alignment:** PRF1	In September 2023, the NHS published a that sets out what all NHS and publicly funded social care organisations in England are required to do to implement the Reasonable Adjustment Digital Flag in their services. The Information Standard Notice says that organisations must have processes in place to be able to identify, record, flag, share, meet and review and update people's reasonable adjustment needs on their systems. Question on PRF1 conflates patient & carer	**Target:** No target	All current NCL GP registered patients	GP Data (OLID)	Recorded ever
Demographics and Social Context	Reasonable Adjustments - Declined Consent	Records if the patient declined to upload reasonable adjustment information to the national digital flag.	**Type:** Child **SNOMED CT Code:** 1853781000000107 Declined consent to upload data to Reasonable Adjustment Digital Flag (finding)	✅ Available **Policy alignment:** PRF1	In September 2023, the NHS published a that sets out what all NHS and publicly funded social care organisations in England are required to do to implement the Reasonable Adjustment Digital Flag in their services. The Information Standard Notice says that organisations must have processes in place to be able to identify, record, flag, share, meet and review and update people's reasonable adjustment needs on their systems.	**Target:** No target	All current NCL GP registered patients	GP Data (OLID)	Recorded ever

Section	Data Item	Description	SNOMED CT Recommendation	EMIS Availability / Policy	Coding Rationale / Comments	Data Completeness Target and Rationale	Denominator	Source	Data Period
					Question on PRF1 conflates patient & carer				
Demographics and Social Context	Accessible Format Need	Indicates if the patient requires alternative communication formats (e.g., large print, Braille).	**Type:** Child **SNOMED CT Code:** 999002141000000102 Accessible information - requires specific information format simple reference set (foundation metadata concept)	✅ Available **Policy alignment:** PRF1	Indicates if the patient requires alternative communication formats (e.g., large print, Braille)	**Target:** No target Not on PRF1 form	All current NCL GP registered patients	GP Data (OLID)	Recorded ever
Demographics and Social Context	Interpreter Support	Flags the need for spoken language interpretation.	**Type:** Parent **SNOMED CT Code:** 315593009 Need for interpreter (finding) **Direct child codes:** 2	✅ Available **Policy alignment:** PRF1	Important demographic context to support equalities data analysis.	**Target:** 90%	All current NCL GP registered patients	GP Data (OLID)	Captured within the last 5 yrs
Demographics and Social Context	History Taking Declined	Indicates patient has declined to share demographic information.	**Type:** Parent **SNOMED CT Code:** 426544006 History taking declined by patient (situation) **Direct child codes:** 18	✅ Available	Important demographic context to support equalities data analysis. Supports 'missingness' analysis when patient does not share data	**Target:** No target Not mandated via PRF1 or other data collection means and no obvious comparator dataset. Important demographic context to support equalities data analysis.	All current NCL GP registered patients	GP Data (OLID)	Recorded ever
Demographics and Social Context	Has a Carer	Indicates patient has a nominated carer.	**Type:** Parent **SNOMED CT Code:** 184156005 Has a caregiver (finding) **Direct child codes:** 7	✅ Available **Policy alignment:** PRF1	Supports better care identification for patient. Carer status may change frequently. Noted young carers may not the captured.	**Target:** 80% Important for planning supportive care services	All current NCL GP registered patients	GP Data (OLID)	Captured within the last 12 months
Demographics and Social Context	Is a Carer	Indicates patient is themselves a carer.	**Type:** Parent **SNOMED CT Code:** 224484003 Patient themselves providing care (finding) **Direct child codes:** 15	✅ Available **Policy alignment:** PRF1	Supports better care identification for patient	**Target:** 80% Administrative/social role, relevant in survivorship pathways.	All current NCL GP registered patients	GP Data (OLID)	Captured within the last 12 months
Demographics and Social Context	Next of Kin Details	Details of patient's next of kin.	**Type:** Child **SNOMED CT Code:** 184142008 Patient's next of kin (observable entity)	✅ Available **Policy alignment:** PRF1	Supports better care identification for patient Safety-critical	**Target:** 90% Key for safety, contact, and care coordination	All current NCL GP registered patients	GP Data (OLID)	Captured within the last 12 months
Physical Characteristics	Body Weight	Recorded body weight.	**Type:** Parent **SNOMED CT Code:** 27113001 Body weight (observable entity) **Direct child codes:** 14	✅ Available **Policy alignment:** PRF1 QOF	Align with QOF codes QOF/Health Checks precedent	**Target:** 90% Often recorded in routine care / health checks	All current NCL GP registered patients	GP Data (OLID)	Captured within the last 12 months
Physical Characteristics	Height	Recorded height.	**Type:** Child **SNOMED CT Code:** 248333004 Standing height (observable entity)	✅ Available **Policy alignment:** PRF1 QOF	Align with QOF codes Doesn't change post-growth	**Target:** 90% Basic anthropometric measure	All current NCL GP registered patients	GP Data (OLID)	Captured within the last 12 months
Physical Characteristics	BMI	Calculated body mass index.	**Type:** Parent **SNOMED CT Code:** 60621009 Body mass index (observable entity) **Direct child codes:** 6	✅ Available **Policy alignment:** PRF1 QOF	Align with QOF codes Derived, time-sensitive	**Target:** 90% Derived from weight + height; important risk metric	All current NCL GP registered patients	GP Data (OLID)	Captured within the last 12 months
Predisposing factors to cancer	Smoking	Smoking status and behaviour.	**Type:** Parent **SNOMED CT Code:** 365981007 Finding of tobacco smoking behaviour (finding) **Direct child codes:** 13	✅ Available **Policy alignment:** PRF1 QOF	Align with QOF codes Dynamic risk factor Aligns with QOF	**Target:** 90% Many practices already high under QOF; good maturity baseline	Current NCL GP registered patients aged 18+	GP Data (OLID)	Captured within the last 12 months
Predisposing factors to cancer	Alcohol	Weekly alcohol units consumed.	**Type:** Child **SNOMED CT Code:** 1082641000000106 Alcohol units consumed per week (observable entity)	✅ Available **Policy alignment:** PRF1 QOF	Align with QOF codes Changes over time	**Target:** 80% Slightly lower target due to variable recording	Current NCL GP registered patients aged 18+	GP Data (OLID)	Captured within the last 12 months
Predisposing factors to cancer	Family History	Presence of family history of cancer.	**Type:** Parent **SNOMED CT Code:** 266883004 Family history of neoplasm (situation) **Direct child codes:** 13	✅ Available	Comprehensive existing code in SMOMED CT and currently no other databases are capturing this information. Static baseline	**Target:** 75% Dependent on patient disclosure; medium-term goal	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Environmental Exposure – General	Patient has documented exposure to harmful substances or environmental agents.	**Type:** Parent **SNOMED CT Code:** 418715001 Exposure to potentially harmful entity (event) **Direct child codes:** 28	✅ Available	Information is not consistently collected in any medical records. Systematic collection will support risk stratification and initiative-taking care Rarely changes Not collected via COSD – No other comparator source identified	**Target:** No target Challenging historically; set realistic early target	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Environmental Exposure – Radon	Documented patient exposure to radon gas.	**Type:** Child **SNOMED CT Code:** 16090491000119106 Exposure to radon (event)	✅ Available	Information is not consistently collected in any medical records. Systematic collection will support risk stratification and initiative-taking care Rarely changes Not collected via COSD – No other comparator source identified	**Target:** No target Challenging historically; set realistic early target	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Environmental Exposure – Arsenic	Documented patient exposure to arsenic.	**Type:** Child **SNOMED CT Code:** 16090531000119106 Exposure to arsenic (event)	✅ Available	Information is not consistently collected in any medical records. Systematic collection will support risk stratification and initiative-taking care Rarely changes Not collected via COSD – No other comparator source identified	**Target:** No target Challenging historically; set realistic early target	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Environmental Exposure – Asbestos	Documented patient exposure to asbestos.	**Type:** Child **SNOMED CT Code:** 699373005 Exposure to asbestos (event)	✅ Available	Information is not consistently collected in any medical records. Systematic collection will support risk stratification and initiative-taking care	**Target:** No target Challenging historically; set realistic early target	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever

Section	Data Item	Description	SNOMED CT Recommendation	EMIS Availability / Policy	Coding Rationale / Comments	Data Completeness Target and Rationale	Denominator	Source	Data Period
					Rarely changes Not collected via COSD – No other comparator source identified				
Predisposing factors to cancer	Environmental Exposure – Chemical Pollution	Documented patient exposure to chemical pollutants.	**Type:** Parent **SNOMED CT Code:** 102435003 Exposure to chemical pollution (event) **Direct child codes:** 2	✅ Available	Information is not consistently collected in any medical records. Systematic collection will support risk stratification and initiative-taking care Rarely changes Not collected via COSD – No other comparator source identified	**Target:** No target Challenging historically; set realistic early target	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Environmental Exposure – Artificial UV Light	Documented patient exposure to man-made ultraviolet light.	**Type:** Child **SNOMED CT Code:** 242537009 Exposure to man-made ultraviolet light (event)	✅ Available	Information is not consistently collected in any medical records. Systematic collection will support risk stratification and initiative-taking care Rarely changes Not collected via COSD – No other comparator source identified	**Target:** No target Challenging historically; set realistic early target	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Environmental Exposure – Sun	Patient has a history of overexposure to sun.	**Type:** Child **SNOMED CT Code:** 218201004 Overexposure to sun rays (event)	✅ Available	Information is not consistently collected in any medical records. Systematic collection will support risk stratification and initiative-taking care Rarely changes Not collected via COSD – No other comparator source identified	**Target:** No target Challenging historically; set realistic early target	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Hereditary Mutations	Genetic predisposition to cancer	**Type:** Parent **SNOMED CT Code:** 699346009 Hereditary cancer-predisposing syndrome (disorder) **Direct child codes:** 94	✅ Available	Relevant for cancer pathway/services. Data on hereditary information is not captured consistently. Static unless reclassified	**Target:** No target Rare domain; more aspirational baseline	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Hereditary Mutations - Lynch Syndrome	Patient has a confirmed or suspected diagnosis of Lynch Syndrome, a hereditary condition that increases the risk of colorectal, endometrial, and other cancers.	**Type:** Child **SNOMED CT Code:** 716318002 Lynch syndrome (disorder)	✅ Available	Relevant for cancer pathway/services. Data on hereditary information is not captured consistently. Static unless reclassified	**Target:** No target Rare domain; more aspirational baseline	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Hereditary Mutations - Familial adenomatous polyposis	Patient has a confirmed or suspected diagnosis of FAP, an inherited disorder that causes numerous polyps in the colon and rectum and significantly increases colorectal cancer risk.	**Type:** Parent **SNOMED CT Code:** 72900001 Familial multiple polyposis syndrome (disorder) **Direct child codes:** 5	✅ Available	Relevant for cancer pathway/services. Data on hereditary information is not captured consistently. Static unless reclassified	**Target:** No target Rare domain; more aspirational baseline	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Hereditary Mutations - BRCA1	Patient has a hereditary predisposition to cancer due to a BRCA1 mutation, associated with increased risk of breast, ovarian, and other cancers.	**Type:** Child **SNOMED CT Code:** 765057007 BRCA1 associated protein 1 tumour predisposition syndrome (disorder)	✅ Available	Relevant for cancer pathway/services. Data on hereditary information is not captured consistently. Static unless reclassified	**Target:** No target Rare domain; more aspirational baseline	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Hereditary Mutations - BRCA2	Patient has a hereditary predisposition to cancer due to a BRCA2 mutation, associated with increased risk of breast, ovarian, prostate, and pancreatic cancers.	**Type:** Child **SNOMED CT Code:** 766707003 Inherited cancer-predisposing syndrome due to biallelic BRCA2 mutation (disorder)	✅ Available	Relevant for cancer pathway/services. Data on hereditary information is not captured consistently.	**Target:** No target Rare domain; more aspirational baseline	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Hereditary Mutations - Peutz-Jeghers Syndrome	Patient has Peutz-Jeghers Syndrome, a genetic condition marked by polyps in the digestive tract and increased cancer risk.	**Type:** Parent **SNOMED CT Code:** 54411001 Peutz-Jeghers syndrome (disorder) **Direct child codes:** 1	✅ Available	Relevant for cancer pathway/services. Data on hereditary information is not captured consistently. Static unless reclassified	**Target:** No target Rare domain; more aspirational baseline	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Predisposing factors to cancer	Hereditary Mutations - Hereditary Pancreatitis	Patient has Hereditary Pancreatitis, a genetic disorder that increases lifetime risk of developing pancreatic cancer.	**Type:** Parent **SNOMED CT Code:** 68072000 Hereditary pancreatitis (disorder) **Direct child codes:** 2	✅ Available	Relevant for cancer pathway/services. Data on hereditary information is not captured consistently. Static unless reclassified	**Target:** No target Rare domain; more aspirational baseline	Current NCL GP registered patients aged 18+	GP Data (OLID)	Recorded ever
Screening	Cervical Screening - Non-Attendance	Patient did not attend scheduled cervical smear screening.	**Type:** Child **SNOMED CT Code:** 201761000000101 Did not attend cervical smear (finding)	✅ Available	Codes already set nationally GPs have advised us that this pathway works very well. Codes to capture activity is heterogenous but as the national team will search for all the varieties of codes GP uses – it does not have an impact. Prioritise DNA data and the recall data: There should be an agreement on cervical smear reminders, actions taken to recall.	**Target:** No target National programmes already have high completeness	Current NCL female GP registered patients aged 25 to 64	GP Data (OLID)	Per programme interval (5 years)
Screening	Cervical Screening - Declined	Patient declined cervical cancer screening.	**Type:** Child **SNOMED CT Code:** 112241000119107 Cervical cancer Papanicolaou smear screening declined (situation)	✅ Available	Codes already set nationally GPs have advised us that this pathway works very well. Codes to capture activity is heterogenous but as the national team will search for all the varieties of codes GP uses – it does not have an impact. Prioritise DNA data and the recall data: There should be an agreement on cervical smear reminders, actions taken to recall.	**Target:** No target National programmes already have high completeness	Current NCL female GP registered patients aged 25 to 64	GP Data (OLID)	Per programme interval (5 years)
Screening	Cervical Screening - Recall Issued	Patient was issued a recall for cervical smear screening.	**Type:** Parent **SNOMED CT Code:** 308417000 Cervical smear recall (procedure) **Direct child codes:** 3	✅ Available	Codes already set nationally GPs have advised us that this pathway works very well. Codes to capture activity is heterogenous but as the national team will search for all the varieties of codes GP uses – it does not have an impact. Prioritise DNA data and the recall data: There should be an agreement on cervical smear reminders, actions taken to recall.	**Target:** No target National programmes already have high completeness	Current NCL female GP registered patients aged 25 to 64	GP Data (OLID)	Per programme interval (5 years)

Section	Data Item	Description	SNOMED CT Recommendation	EMIS Availability / Policy	Coding Rationale / Comments	Data Completeness Target and Rationale	Denominator	Source	Data Period
Screening	Cervical Screening - First Recall Issued	Initial invitation sent to attend cervical screening following eligibility.	**Type:** Parent **SNOMED CT Code:** 185603003 Cervical smear - First recall (procedure) **Direct child codes:** 4	✅ Available	Codes already set nationally GPs have advised us that this pathway works very well. Codes to capture activity is heterogenous but as the national team will search for all the varieties of codes GP uses – it does not have an impact. Prioritise DNA data and the recall data: There should be an agreement on cervical smear reminders, actions taken to recall.	**Target:** No target National programmes already have high completeness	Current NCL female GP registered patients aged 25 to 64	GP Data (OLID)	Per programme interval (5 years)
Screening	Cervical Screening - Second Recall Issued	Second reminder issued after no response to the first cervical screening invitation.	**Type:** Parent **SNOMED CT Code:** 185604009 Cervical smear - Second recall (procedure) **Direct child codes:** 4	✅ Available	Codes already set nationally GPs have advised us that this pathway works very well. Codes to capture activity is heterogenous but as the national team will search for all the varieties of codes GP uses – it does not have an impact. Prioritise DNA data and the recall data: There should be an agreement on cervical smear reminders, actions taken to recall.	**Target:** No target National programmes already have high completeness	Current NCL female GP registered patients aged 25 to 64	GP Data (OLID)	Per programme interval (5 years)
Screening	Cervical Screening - Third Recall Issued	Final reminder sent following non-response to previous cervical screening recalls.	**Type:** Parent **SNOMED CT Code:** 185605005 Cervical smear - third recall (procedure) **Direct child codes:** 4	✅ Available	Codes already set nationally GPs have advised us that this pathway works very well. Codes to capture activity is heterogenous but as the national team will search for all the varieties of codes GP uses – it does not have an impact. Prioritise DNA data and the recall data: There should be an agreement on cervical smear reminders, actions taken to recall.	**Target:** No target National programmes already have high completeness	Current NCL female GP registered patients aged 25 to 64	GP Data (OLID)	Per programme interval (5 years)
Screening	HPV Self-Sampling - Offered	Patient was offered a self-sample test for HPV screening.	**Type:** Child **SNOMED CT Code:** 1091941000000105 Human papillomavirus self-sample screening offered (situation)	✅ Available	Emerging pathway in the NHS, Future proofing coding	**Target:** No target Emerging pathway in the NHS, Future proofing coding	Current NCL female GP registered patients aged 25 to 64	GP Data (OLID)	Per programme interval (5 years)
Screening	HPV Self-Sampling - Declined	Patient declined a self-sample HPV test.	**Type:** Child **SNOMED CT Code:** 1091931000000101 Human papillomavirus self-sample screening declined (situation)	✅ Available	Emerging pathway in the NHS, Future proofing coding	**Target:** No target Emerging pathway in the NHS, Future proofing coding	Current NCL female GP registered patients aged 25 to 64	GP Data (OLID)	Per programme interval (5 years)
Screening	HPV Self-Sampling - Positive	HPV self-sample test returned a positive result.	**Type:** Child **SNOMED CT Code:** 1091911000000109 Human papillomavirus self-sample test positive (finding)	✅ Available	Emerging pathway in the NHS, Future proofing coding	**Target:** No target Emerging pathway in the NHS, Future proofing coding	Current NCL female GP registered patients aged 25 to 64	GP Data (OLID)	Per programme interval (5 years)
Screening	HPV Self-Sampling - Negative	HPV self-sample test returned a negative result.	**Type:** Child **SNOMED CT Code:** 1091741000000108 Human papillomavirus self-sample test negative (finding)	✅ Available	Emerging pathway in the NHS, Future proofing coding	**Target:** No target Emerging pathway in the NHS, Future proofing coding	Current NCL female GP registered patients aged 25 to 64	GP Data (OLID)	Per programme interval (5 years)
Screening	Bowel Screening - Non-Responder	Patient did not respond to bowel cancer FIT screening invitation.	**Type:** Parent **SNOMED CT Code:** 373251000000108 No response to bowel cancer screening programme invitation (finding) **Direct child codes:** 1	✅ Available	Codes already set nationally GPs have advised us that this pathway works very well. Code heterogeneity is enabled as national team will search for all the varieties of codes GP uses. Prioritise DNA data and the recall data. There should be an agreement on bowel cancer screening	**Target:** No target Should align with national datasets	Current NCL GP registered patients aged 50 to 74	GP Data (OLID)	Per programme interval (2 years)
Screening	Bowel Screening - Declined	Patient declined bowel cancer screening.	**Type:** Child **SNOMED CT Code:** 294201000000109 Bowel cancer screening declined (situation)	✅ Available	Codes already set nationally GPs have advised us that this pathway works very well. Code heterogeneity is enabled as national team will search for all the varieties of codes GP uses. Prioritise DNA data and the recall data. There should be an agreement on bowel cancer screening	**Target:** No target Should align with national datasets	Current NCL GP registered patients aged 50 to 74	GP Data (OLID)	Per programme interval (2 years)
Screening	Bowel Screening - Advice Given	Bowel screening information or advice was provided to the patient.	**Type:** Child **SNOMED CT Code:** 382161000000102 Advice given about bowel cancer screening programme (situation)	✅ Available	Codes already set nationally GPs have advised us that this pathway works very well. Code heterogeneity is enabled as national team will search for all the varieties of codes GP uses. Prioritise DNA data and the recall data. There should be an agreement on bowel cancer screening	**Target:** No target Should align with national datasets	Current NCL GP registered patients aged 50 to 74	GP Data (OLID)	Per programme interval (2 years)
Screening	Bowel Screening - Phone Invitation	Patient received a telephone invitation for bowel cancer screening.	**Type:** Child **SNOMED CT Code:** 862011000000104 Bowel cancer screening programme telephone invitation (procedure)	✅ Available	Codes already set nationally GPs have advised us that this pathway works very well. Code heterogeneity is enabled as national team will search for all the varieties of codes GP uses. Prioritise DNA data and the recall data. There should be an agreement on bowel cancer screening	**Target:** No target Should align with national datasets	Current NCL GP registered patients aged 50 to 74	GP Data (OLID)	Per programme interval (2 years)
Screening	Bowel Screening - Not Eligible	Patient is recorded as not eligible for the bowel cancer screening programme.	**Type:** Child **SNOMED CT Code:** 758851000000101 Not eligible for bowel cancer screening programme (finding)	✅ Available	Codes already set nationally GPs have advised us that this pathway works very well. Code heterogeneity is enabled as national team will search for all the varieties of codes GP uses. Prioritise DNA data and the recall data. There should be an agreement on bowel cancer screening	**Target:** No target Should align with national datasets	Current NCL GP registered patients aged 50 to 74	GP Data (OLID)	Per programme interval (2 years)
Screening	Breast Screening - Offered	Breast cancer screening was offered to the patient.	**Type:** Child **SNOMED CT Code:** 512501000000109 Breast screening offered (finding)	✅ Available	Breast screen has most variability and absence of high-quality data on its activity. Codes are pragmatic matches to the Breast screening programme outcome codes	**Target:** No target Variable currently—target ambition while systems improve	Current NCL female GP registered patients aged 50 to 71	GP Data (OLID)	Per programme interval (3 years)

Section	Data Item	Description	SNOMED CT Recommendation	EMIS Availability / Policy	Coding Rationale / Comments	Data Completeness Target and Rationale	Denominator	Source	Data Period
Screening	Breast Screening - Declined	Patient declined breast cancer screening.	**Type:** Child **SNOMED CT Code:** 12275351000119103 Breast cancer screening declined (situation)	✅ Available	Breast screen has most variability and absence of high-quality data on its activity. Codes are pragmatic matches to the Breast screening programme outcome codes	**Target:** No target Variable currently—target ambition while systems improve	Current NCL female GP registered patients aged 50 to 71	GP Data (OLID)	Per programme interval (3 years)
Screening	Breast Screening - Normal Result	Breast screening result was normal.	**Type:** Child **SNOMED CT Code:** 171175005 Breast neoplasm screening normal (finding)	✅ Available	Breast screen has most variability and absence of high-quality data on its activity. Codes are pragmatic matches to the Breast screening programme outcome codes	**Target:** No target Variable currently—target ambition while systems improve	Current NCL female GP registered patients aged 50 to 71	GP Data (OLID)	Per programme interval (3 years)
Screening	Breast Screening - Cancer Detected	Breast cancer was detected through the national screening programme.	**Type:** Child **SNOMED CT Code:** 94361000000105 Breast cancer detected by national screening programme (disorder)	✅ Available	Breast screen has most variability and absence of high-quality data on its activity. Codes are pragmatic matches to the Breast screening programme outcome codes	**Target:** No target Variable currently—target ambition while systems improve	Current NCL female GP registered patients aged 50 to 71	GP Data (OLID)	Per programme interval (3 years)
Screening	Breast Screening - Non-Attendance	Patient did not attend scheduled breast cancer screening.	**Type:** Child **SNOMED CT Code:** 275981000000102 Did not attend breast screening clinic (finding)	✅ Available	Breast screen has most variability and absence of high-quality data on its activity. Codes are pragmatic matches to the Breast screening programme outcome codes	**Target:** No target Variable currently—target ambition while systems improve	Current NCL female GP registered patients aged 50 to 71	GP Data (OLID)	Per programme interval (3 years)
Screening	Lung Screening - Invitation	Patient was invited for a lung health check.	**Type:** Child **SNOMED CT Code:** 1771771000000105 Lung health check invitation (procedure)	✅ Available	**National would like Primary care to code -** 231003_TLHC SNOMED CT Codes - guidance for sites.pptx There are codes here across activities in this pathway. There are no incentives for primary care to use these codes/capture these.	**Target:** No target Emerging pathway; moderate early target	Current NCL GP registered patients aged 55 to 74	GP Data (OLID)	Per programme interval (where available)
Screening	Lung Screening - Declined	Patient declined lung cancer screening.	**Type:** Child **SNOMED CT Code:** 13015001000119105 Lung cancer screening declined (situation)	✅ Available	**National would like Primary care to code -** 231003_TLHC SNOMED CT Codes - guidance for sites.pptx There are codes here across activities in this pathway. There are no incentives for primary care to use these codes/capture these.	**Target:** No target Emerging pathway; moderate early target	Current NCL GP registered patients aged 55 to 74	GP Data (OLID)	Per programme interval (where available)
Screening	Lung Screening - Non-Attendance	Patient did not attend lung cancer screening.	**Type:** Child **SNOMED CT Code:** 1771781000000107 Did not attend lung cancer screening (finding)	✅ Available	**National would like Primary care to code -** 231003_TLHC SNOMED CT Codes - guidance for sites.pptx There are codes here across activities in this pathway. There are no incentives for primary care to use these codes/capture these.	**Target:** No target Emerging pathway; moderate early target	Current NCL GP registered patients aged 55 to 74	GP Data (OLID)	Per programme interval (where available)
Screening	Lung Screening - Signposting	Signposting patient to lung cancer screening service	**Type:** Child **SNOMED CT Code:** 1104521000000104 Signposting to lung health check (procedure)	✅ Available	**National would like Primary care to code -** 231003_TLHC SNOMED CT Codes - guidance for sites.pptx There are codes here across activities in this pathway. There are no incentives for primary care to use these codes/capture these.	**Target:** No target Emerging pathway; moderate early target	Current NCL GP registered patients aged 55 to 74	GP Data (OLID)	Per programme interval (where available)
Screening	Lung Screening - Cancer Detected	Lung cancer was detected through the national screening programme.	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	Future proofing No existing SNOMED code. To submit code requests to SNOMED CT.				
Screening	Multi-site cancer blood test screen	Participation in blood-based multi-cancer early detection screening.	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	Future proofing No existing SNOMED code. To submit code requests to SNOMED CT.				
Screening	Case Finding through healthcare record data	Using algorithms to identify individuals at higher cancer risk from electronic health records, instead of relying on symptoms or screening.	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	Future proofing No existing SNOMED code. To submit code requests to SNOMED CT.				
Suspected Cancer Referrals	Suspected Cancer Referral	Fast-track cancer referral by tumour site.	**Type:** Parent **SNOMED CT Code:** 199251000000107 Fast track cancer referral (procedure) **Direct child codes:** 14	✅ Available	Mandatory capture This is the preferred code and terminology. Fast track cancer referral is the parent code, and all the specific referrals sit under this. In London, all forms are centrally quality controlled. SNOMED codes are pre attached to the referral forms. Include Non-Site-Specific Symptoms pathway	**Target:** 95% Referrals should be fully coded; match Cancer Waiting Times data	Recorded Urgent Suspected Referrals	Electronic Referral Service (ERS) data	Captured over comparative time period
Suspected Cancer Referrals	Suspected Cancer Referral - Teledermatology	Fast-track Teledermatology cancer referral	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	This new pathway is used widely across the NHS. No existing SNOMED code. To submit code requests to SNOMED CT.				
Suspected Cancer Referrals	Direct Access Test	General direct access test requested directly by GP.	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	Ability to capture direct access tests as per NG12 is not available. No existing SNOMED code. To submit code requests to SNOMED CT.				
Suspected Cancer Referrals	Direct Access CT	CT scan requested directly by GP.	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	Ability to capture direct access tests as per NG12 is not available. No existing SNOMED code. To submit code requests to SNOMED CT.				
Suspected Cancer Referrals	Direct Access Ultrasound (US)	Ultrasound requested directly by GP.	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	Ability to capture direct access tests as per NG12 is not available. No existing SNOMED code. To submit code requests to SNOMED CT.				
Suspected Cancer Referrals	Direct Access MRI	MRI scan requested directly by GP.	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	Ability to capture direct access tests as per NG12 is not available.				
Suspected Cancer Referrals	Direct Access UGI Endoscopy	Upper Gastrointestinal endoscopy scan requested directly by GP.	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	Ability to capture direct access tests as per NG12 is not available. No existing SNOMED code. To submit code requests to SNOMED CT.				

Section	Data Item	Description	SNOMED CT Recommendation	EMIS Availability / Policy	Coding Rationale / Comments	Data Completeness Target and Rationale	Denominator	Source	Data Period
Cancer Diagnosis	Cancer Stage	Cancer stage (1–4, site-specific) — staging may be updated (upstaged or down staged) at any point following diagnosis or treatment; the most recent stage recorded will supersede any earlier entries.	**Type:** Parent **SNOMED CT Code:** 385356007 Tumour stage finding (finding) **Direct child codes:** 30	✅ Available	Parent code aligns well with COSD. Important outcome	**Target:** 80% Some patients may lack staging, but high aspiration	Patients with a cancer diagnosis and complete staging	Rapid Cancer Registration Data (RCRD)	Captured over comparative time period
Cancer Diagnosis	Metastases	Evidence of metastatic disease.	**Type:** Parent **SNOMED CT Code:** 128462008 Metastatic malignant neoplasm (disorder) **Direct child codes:** 45	✅ Available	SNOMED code matched Important outcome	**Target:** 80% Should be recorded when known	Patients with a cancer diagnosis and complete staging with M stage <> 0	Rapid Cancer Registration Data (RCRD)	Captured over comparative time period
Cancer Diagnosis	MDT Discussion	Flag for multidisciplinary team discussion.	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	No existing SNOMED code. To submit code requests to SNOMED CT				
Cancer Treatment	Surgery	Record of surgical cancer treatment.	**Type:** Parent **SNOMED CT Code:** 387713003 Surgical procedure (procedure) **Direct child codes:** 80	✅ Available	Maps to COSD Cancer Treatment Modality Code 01	**Target:** 95% Complex area: phased improvement expected	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Chemotherapy	Record of chemotherapy administration.	**Type:** Child **SNOMED CT Code:** 1255831008 Chemotherapy for malignant neoplastic disease using targeted agent (procedure)	✅ Available	Maps to COSD Cancer Treatment Modality Code 02	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Hormone Therapy	Administration of hormone therapy as part of cancer treatment.	**Type:** Parent **SNOMED CT Code:** 169413002 Hormone therapy (procedure) **Direct child codes:** 27	✅ Available	Maps to COSD Cancer Treatment Modality Code 03	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Hormone Manipulation	Hormone suppression or stimulation therapy.	**Type:** Child **SNOMED CT Code:** 309448001 Hormone manipulation (procedure)	✅ Available	Maps to COSD Cancer Treatment Modality Code 03	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Hormone Therapy - Gonadorelin Analogue Injection	Subcutaneous administration of gonadorelin analogue.	**Type:** Child **SNOMED CT Code:** 892651000000109 Subcutaneous injection of gonadorelin analogue (procedure)	✅ Available	Maps to COSD Cancer Treatment Modality Code 03	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Hormone Therapy - Estrogen Receptor Antagonist	Administration of therapy targeting estrogen receptors.	**Type:** Parent **SNOMED CT Code:** 1217003001 Administration of estrogen receptor antagonist therapy (procedure) **Direct child codes:** 2	✅ Available	Maps to COSD Cancer Treatment Modality Code 03	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Hormone Therapy - Tamoxifen	Administration of tamoxifen as part of cancer treatment.	**Type:** Child **SNOMED CT Code:** 724161009 Tamoxifen therapy (procedure)	✅ Available	Maps to COSD Cancer Treatment Modality Code 03	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Chemoradiotherapy	Combined chemo-radiation treatment.	**Type:** Parent **SNOMED CT Code:** 703423002 Combined chemotherapy and radiation therapy (procedure) **Direct child codes:** 9	✅ Available	Maps to COSD Cancer Treatment Modality Code 04	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	External Beam Radiotherapy (excluding Proton Therapy)	External beam radiation treatment.	**Type:** Parent **SNOMED CT Code:** 33195004 External beam radiation therapy procedure (procedure) **Direct child codes:** 23	✅ Available	Maps to COSD Cancer Treatment Modality Code 05	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Brachytherapy	Internal radiation therapy.	**Type:** Parent **SNOMED CT Code:** 152198000 Brachytherapy (procedure) **Direct child codes:** 30	✅ Available	Maps to COSD Cancer Treatment Modality Code 06	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Specialist Palliative Care	Palliative care involvement.	**Type:** Parent **SNOMED CT Code:** 395669003 Specialist palliative care treatment (regime/therapy) **Direct child codes:** 3	✅ Available	Maps to COSD Cancer Treatment Modality Code 07	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Active Monitoring	Monitored instead of immediate treatment.	**Type:** Child **SNOMED CT Code:** 413433006 Active monitoring (regime/therapy)	✅ Available	Maps to COSD Cancer Treatment Modality Code 08	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Radiofrequency Ablation	Use of RFA to treat cancer.	**Type:** Parent **SNOMED CT Code:** 879916008 Radiofrequency ablation (procedure) **Direct child codes:** 40	✅ Available	Maps to COSD Cancer Treatment Modality Code 10	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	High Intensity Focused Ultrasound	Use of HIFU for treatment.	**Type:** Parent **SNOMED CT Code:** 774001008 High intensity focused ultrasound ablation (procedure) **Direct child codes:** 15	✅ Available	Maps to COSD Cancer Treatment Modality Code 11	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Proton Therapy`	Receipt of proton beam therapy.	**Type:** Parent **SNOMED CT Code:** 10611004 External beam radiation therapy using protons (procedure) **Direct child codes:** 1	✅ Available	Maps to COSD Cancer Treatment Modality Code 13	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period

Section	Data Item	Description	SNOMED CT Recommendation	EMIS Availability / Policy	Coding Rationale / Comments	Data Completeness Target and Rationale	Denominator	Source	Data Period
Cancer Treatment	Immunotherapy	Administration of immunotherapy for cancer.	**Type:** Parent **SNOMED CT Code:** 76334006 Immunotherapy (procedure) **Direct child codes:** 12	✅ Available	Maps to COSD Cancer Treatment Modality Code 15	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Light Therapy	Photodynamic/light-based treatment.	**Type:** Parent **SNOMED CT Code:** 31394004 Light therapy (procedure) **Direct child codes:** 17	✅ Available	Maps to COSD Cancer Treatment Modality Code 16	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Radioisotope Therapy	Treatment using radioactive isotopes.	**Type:** Parent **SNOMED CT Code:** 399315003 Radionuclide therapy (procedure) **Direct child codes:** 13	✅ Available	Maps to COSD Cancer Treatment Modality Code 19	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Laser Treatment	Laser-based treatment delivered.	**Type:** Parent **SNOMED CT Code:** 35631009 Laser surgery (procedure) **Direct child codes:** 71	✅ Available	Maps to COSD Cancer Treatment Modality Code 20	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Radiosurgery	Precision external radiation (e.g., Gamma Knife).	**Type:** Parent **SNOMED CT Code:** 115959002 Stereotactic radiosurgery (procedure) **Direct child codes:** 9	✅ Available	Maps to COSD Cancer Treatment Modality Code 22	**Target:** 95% Where recorded, expect a high capture rate	Treatment Starts (First and Subsequent)	Cancer Waiting Times (CWT)	Captured over comparative time period
Cancer Treatment	Stem Cell Transplant	Patient received a stem cell transplant.	**Type:** Parent **SNOMED CT Code:** 1269349006 Transplantation of stem cell (procedure) **Direct child codes:** 2	✅ Available	Maps to COSD Cancer Treatment Modality Code 97	**Target:** No target Treatment not captured within CWT dataset		N/A	Recorded ever
Cancer Treatment	Hemopoietic Stem Cell Transplant	Patient underwent a hemopoietic stem cell transplant.	**Type:** Parent **SNOMED CT Code:** 234336002 Hemopoietic stem cell transplant (procedure) **Direct child codes:** 7	✅ Available	Maps to COSD Cancer Treatment Modality Code 97	**Target:** No target Treatment not captured within CWT dataset		N/A	Recorded ever
Cancer Treatment Monitoring	Cancer Treatment Monitoring	Patient currently under observation post-treatment.	**Type:** Child **SNOMED CT Code:** 719864002 Monitoring following treatment for cancer (regime/therapy)	✅ Available	In COSD these data fields are captured and more. These 3 would be most relevant to primary care.	**Target:** No target Includes follow-up, surveillance; moderate target initially		N/A	Recorded ever
Cancer Treatment Monitoring	Genomic Testing	BRCA or other cancer-related genomic testing completed.	**Type:** Child **SNOMED CT Code:** 252370006 Polymerase chain reaction analysis for genomic fingerprinting (procedure)	✅ Available	In COSD these data fields are captured and more. These 3 would be most relevant to primary care.	**Target:** No target Polymerase chain reaction analysis for genomic fingerprinting (procedure)		N/A	Recorded ever
Cancer Treatment Monitoring	Cancer Clinical Trials - Enrolled in Drug Clinical Trial	Patient is participating in a drug-based clinical trial.	**Type:** Child **SNOMED CT Code:** 713670002 Entered into drug clinical trial (finding)	✅ Available	In COSD these data fields are captured and more. These three would be most relevant to primary care.	**Target:** No target		N/A	Recorded ever
Cancer Treatment Monitoring	Cancer Clinical Trials - Follow-Up Visit	Patient attended follow-up visit related to a drug trial.	**Type:** Child **SNOMED CT Code:** 24171000000106 Clinical drug trial follow up visit (finding)	✅ Available	In COSD these data fields are captured and more. These three would be most relevant to primary care.	**Target:** No target		N/A	Recorded ever
Cancer Treatment Monitoring	Cancer Clinical Trials - Treatment Completed	Patient completed drug trial treatment.	**Type:** Child **SNOMED CT Code:** 430279008 Drug treatment stopped at end of clinical trial (situation)	✅ Available	In COSD these data fields are captured and more. These three would be most relevant to primary care.	**Target:** No target		N/A	Recorded ever
Personalised cancer care in community	Cancer Care Reviews - Support Information Given	Patient received information about cancer support services in primary care.	**Type:** Child **SNOMED CT Code:** 1239881000000109 Provision of information about cancer support services available in primary care (procedure)	✅ Available **Policy alignment:** QOF	Part of QOF Annual review for survivors	**Target:** 90% Already tracked via QOF in many systems	Patients with a new cancer diagnosis	Rapid Cancer Registration Data (RCRD)	Captured over comparative time period
Personalised cancer care in community	Cancer Care Reviews - Completed	Cancer care review conducted in primary care (typically at 3 or 12 months post diagnosis).	**Type:** Child **SNOMED CT Code:** 720006006 Cancer care review (procedure)	✅ Available **Policy alignment:** QOF	Part of QOF	**Target:** 85% Some patients may decline; aim high	Patients with a new cancer diagnosis	Rapid Cancer Registration Data (RCRD)	Captured over comparative time period
Personalised cancer care in community	Cancer Care Reviews -Care Plan Discussed	Cancer care plan discussed with the patient.	**Type:** Child **SNOMED CT Code:** 395673000 Cancer care plan discussed with patient (situation)	✅ Available **Policy alignment:** QOF	Part of QOF	**Target:** 85% Some patients may decline; aim high	Patients with a new cancer diagnosis	Rapid Cancer Registration Data (RCRD)	Captured over comparative time period
Personalised cancer care in community	Cancer Care Reviews -Care Plan Provided	Cancer care plan given to the patient.	**Type:** Child **SNOMED CT Code:** 25031000000106 Cancer care plan given (finding)	✅ Available **Policy alignment:** QOF	Part of QOF	**Target:** 85% Some patients may decline; aim high	Patients with a new cancer diagnosis	Rapid Cancer Registration Data (RCRD)	Captured over comparative time period
Personalised cancer care in community	Cancer Treatment Summary	Treatment summary sent from secondary care to GP.	**Type:** Child **SNOMED CT Code:** 1324891000000103 Cancer End of Treatment Summary Plan (record artifact)	✅ Available	QI of care	**Target:** 80% Critical handover item: aspiration to fully capture	CWT treatment starts – first and subsequent	Cancer Waiting Times (CWT)	Captured over comparative time period
Personalised cancer care in community	Holistic Needs Assessment	Flag for completed HNA.	**Type:** Child **SNOMED CT Code:** 787261000000106 Holistic needs assessment (procedure)	✅ Available	QI of care Once per phase (diagnosis, post-treatment, recurrence) Treatment starts used as a proxy denominator	**Target:** 80% Optional per patient, but should be offered	CWT treatment starts – first and subsequent	Cancer Waiting Times (CWT)	Captured over comparative time period
Personalised cancer care in community	Stratified Follow-Up	Patient on a risk-based follow-up pathway.	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	No existing SNOMED code. To submit code requests to SNOMED CT				
Personalised cancer care in community	Stratified Follow-Up - Prostate Cancer	Patient on a risk-based follow-up pathway for Prostate cancer.	**SNOMED CT Code:** No SNOMED code(s)	🔄 To Create	No existing SNOMED code. To submit code requests to SNOMED CT				

Section	Data Item	Description	SNOMED CT Recommendation	EMIS Availability / Policy	Coding Rationale / Comments	Data Completeness Target and Rationale	Denominator	Source	Data Period
Personalised cancer care in community	PIFU (Patient-Initiated Follow-Up)	Self-initiated follow-up by the patient.	**SNOMED CT Code:** No SNOMED code(s)	To Create	No existing SNOMED code. To submit code requests to SNOMED CT				
Surveillance	Barrett's Oesophagus Surveillance	Surveillance for Barrett's Oesophagus.	**SNOMED CT Code:** No SNOMED code(s)	To Create	No existing SNOMED code. To submit code requests to SNOMED CT.				
Surveillance	Lung Nodule Surveillance	Monitoring for detected lung nodules.	**SNOMED CT Code:** No SNOMED code(s)	To Create	No existing SNOMED code. To submit code requests to SNOMED CT.				
Surveillance	Bowel Polyp Surveillance	Surveillance pathway for bowel polyps.	**Type:** Child **SNOMED CT Code:** 293251000000107 Bowel screening polyp surveillance (regime/therapy)	Available	Picked up in colonoscopies – often fall out of surveillance follow ups. Code exists in SNOMED.	**Target:** No target Specialty surveillance pathways; realistic improvement goal		N/A	Recorded ever

NHS
North Central London
Cancer Alliance

Detailed Coding Change Log

Change Date	Section	Item Changed	Previous Code	New Code	Reason for Change	Author
18/05/2025	Screening	Lung cancer screening	No code	275981009	Relevant code found	GR
18/05/2025	Cancer Treatment	Proton Therapy	82371002	10611004	More appropriate code	GR
18/05/2025	Cancer Treatment	High Intensity Focused Ultrasound	310238002	774001008	More appropriate code	GR
18/05/2025	Screening	Bowel cancer screening	1101401000000107	373251000000108	More appropriate code	GR
20/05/2025	Predisposing factors to cancer	Environmental Exposure – Sun	315227004	218201004	More appropriate code	GR
20/05/2025	Predisposing factors to cancer	Hereditary Mutations - Lynch Syndrome	No code	716318002	Relevant code found	GR
20/05/2025	Predisposing factors to cancer	Hereditary Mutations - Familial adenomatous polyposis	No code	72900001	Relevant code found	GR
20/05/2025	Predisposing factors to cancer	Hereditary Mutations - BRCA1	No code	765057007	Relevant code found	GR
20/05/2025	Predisposing factors to cancer	Hereditary Mutations - BRCA2	No code	766707003	Relevant code found	GR
20/05/2025	Predisposing factors to cancer	Hereditary Mutations - Peutz-Jeghers Syndrome	No code	54411001	Relevant code found	GR
20/05/2025	Predisposing factors to cancer	Hereditary Mutations - Hereditary Pancreatitis	No code	68072000	Relevant code found	GR
20/05/2025	Screening	Bowel Screening - Non-Responder	1101401000000107	373251000000108	More appropriate code	GR
20/05/2025	Suspected Cancer Referrals	Direct Access UGI Endoscopy	No code	No code	Additional data item added	GR
04/06/2025	Screening	Cervical Screening - Recall Issued	No code	185603003	Additional code added	GR
04/06/2025	Screening	Cervical Screening - First Recall Issued	No code	185604009	Additional code added	GR
04/06/2025	Screening	Cervical Screening - Second Recall Issued	No code	185605005	Additional code added	GR
07/06/2025	Cancer Treatment	External Beam Radiotherapy (excluding Proton Therapy)	No code	33195004	Additional code added	GR
22/11/2025	Cancer Diagnosis	Curative - procedure intent (qualifier value)	373808002	No code	Removed from dataset	GR
22/11/2025	Cancer Diagnosis	Disease modification - intent (qualifier value)	905551000000108	No code	Removed from dataset	GR
22/11/2025	Cancer Diagnosis	Palliative - procedure intent (qualifier value)	363676003	No code	Removed from dataset	GR
22/11/2025	Screening	Signposting to lung health check (procedure)	No code	1104521000000104	Additional data item added	GR
22/11/2025	Cancer Diagnosis	Management Intent - Curative	373808002	No code	Removed from dataset	GR
22/11/2025	Cancer Diagnosis	Management Intent - Disease Modification	905551000000108	No code	Removed from dataset	GR
22/11/2025	Cancer Diagnosis	Management Intent - Palliative	363676003	No code	Removed from dataset	GR

Version Control

Version	Date	Author	Summary of Changes
0.1	18/05/2025	GR	Updates to suggested codes
0.1	20/05/2025	GR	Updates to suggested codes Based on feedback of alternative native codes in EMIS from ICB GP IT team
0.2	04/06/2025	GR	Updates to suggested codes Updated alignment of data items to MDS sections, including merger of Follow Up section into Personalised cancer care in community Updated data item descriptions
0.3	07/06/2025	GR	New code addition
1.0	20/06/2025	GR	First publication to NCL Website
2.0	22/11/2025	GR	Updated status of data items now available for capture in EMIS Removal of redundant data items Renaming of data items Second publication to NCL Website
3.0	06/08/2026	GR / JD	Merging of MDS specification, technical guide, and audit documents

References

GMS1 registration form guidance: https://www.gov.uk/government/publications/gms1

PRF1 registration guidance: https://digital.nhs.uk/services/register-with-a-gp-surgery-service/get-help-using-the-service/questions-asked

NHS Digital SNOMED CT Browser: https://termbrowser.nhs.uk/

Technical guide (v1.0, published NCL Cancer Alliance website): https://www.nclcanceralliance.nhs.uk/wp-content/uploads/2025/06/Cancer_Primary_Care_MDS_Technical_Guide_v1.0.pdf

Analytics dashboard (Power BI): https://app.powerbi.com/groups/7cc050dc-acac-4ac6-b8bd-5e917f711ba0/reports/3964e9e5-d994-4194-9428-4c719b878c09/36e5192b7906890516a8?ctid=2f7a9b80-2e65-4ed6-9851-2f727effb3a1&experience=power-bi

Missing-data guidance (unknown denominator problem): https://healthcaredelivery.cancer.gov/seer-cahps/researchers/missing-data-guidance.pdf