Public Health
England

Protecting and improving the nation’s health

Radiotherapy Data Set (RTDS)

Specification

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Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: @PHE_uk
Facebook: www.facebook.com/PublicHealthEngland

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Data Alliance Partnership Board

Acting on behalf of the Data Alliance Partnership Board (DAPB), which holds delegated authority from the Secretary of State for Health and Social Care, the Data Alliance Partnership Sub Board (DAPSB) has approved a change to an existing information standard for publication under section 250 of the Health and Social Care Act 2012.

Assurance that this information standard meets the requirements of the Act and is appropriate for the use specified in the specification document has been provided by the Data Standards Assurance Service (DSAS) and approved by the Data Alliance Partnership Board (DAPB).

This information standard comprises the following documents:

- Specification
- Implementation Guide
- Change Request.

An Information Standards Notice (DCB0111 Amd 84/2020) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled copies of these documents can be found on the NHS Digital website. Any copies held outside of that area, in whatever format (e.g. paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

Date of publication: 20 July 2021

Contents

Title	**PHE document**		
DAPB Reference	DAPB0111 Amd 84/2020		
Sponsor	Dr Brian Rous – Director of Tumour Classification	Status	Draft
Senior Responsible Officer	Sarah Stevens – Deputy Director	Versions	RTDS v6.0
Lead Developer	Andrew Murphy – Head of Cancer Datasets		
Author(s)	Andrew Murphy – Head of Cancer Datasets Catherine Roe – RTDS Project Lead Michael Sharpe – RTDS Project Manager	Version Date	20 July 2021

Amendment history

Version	Date	Brief Summary of Change	Editors
6.0 Final	15 June 2021	Final version for publication	Andrew Murphy

Approvals

This data set and subsequent changes and amendments have been approved by the senior RTDS development team. In addition, the changes were also discussed within the RTDS User Group (RUG) and Radiotherapy Information Strategy Group (RISG) following extensive consultation.

Executive summary

The purpose of this document is to provide instructions intended to support all NHS Acute Trust providers of radiotherapy services in England, private facilities where delivery is funded by the NHS or IT software developers (both in-house and commercial system suppliers), to prepare for the implementation of the Radiotherapy Data Set (RTDS) v6.0 from April 2022.

All documents (or links to them) can be found on either the RTDS or NHS Digital websites unless otherwise stated. These provide assurances that the proposed approach meets the business requirements identified in this document for DAPB0111 Amd 84/2020 and have been adequately researched and can be delivered.

This is an update to an existing information standard SCCI0111 Amd 13/2015 and is required to ensure that the data still meets the business objectives, scope and content of the standard and continues to be clinically accurate and relevant.

This version change structures the data requested into the pathways expected of a radiotherapy patient, including an episode, prescription, plan, exposure and attendance sections. This has in turn allowed the data set to be futureproofed, with the addition of SNOMED CT coding, unique radiotherapy coding (not currently found within SNOMED CT or OPCS), the accurate recording of radiotherapy beam type and the measurement type to support the prescribed and actual absorbed radiation dose.

Careful consideration was also made to introduce the recording of proton therapy, which is now being delivered in Manchester and will become operational in London from summer 2021. The ability to report clinical trials, treatment intent, route of admission and specialist radiotherapy treatments were forefront in the many considerations and decisions made throughout the development process.

Where a word or name is highlighted, this indicates that there is an embedded link that will take you to a webpage outside of this document or directs you to another page within this document that provides additional information. Please use this facility throughout the specification document, as this improves the accessibility for users with visual impairment or those using screen readers.

Introduction

Background

The RTDS standard (DAPB0111) is an existing standard that has required all NHS Acute Trust providers of radiotherapy services in England or private facilities where delivery is funded by the NHS, to collect and submit standardised data monthly against a nationally defined data set since 2009.

There are currently 51 NHS Acute Trusts delivering external beam radiotherapy in England, many of which are also delivering at least one form of non-external beam radiotherapy. In addition, there are approximately 40 NHS funded sites who do not deliver external beam radiotherapy but are known to be delivering molecular radiotherapy treatments.

The purpose of the standard is to collect consistent and comparable data across all English providers of radiotherapy or private facilities where delivery is funded by the NHS, to produce a timely and definitive analytical resource of radiotherapy services across England.

The standard continues to provide intelligence to underpin the strategic objectives for radiotherapy services defined in the NHS England/Cancer Research UK “Vision for Radiotherapy 2014 - 2024”.

The main recommendations of these reports are synthesised in the Achieving World Class Cancer Outcomes Strategy for England 2015 - 2020, which indicates the main areas where data and information can underpin the monitoring of outcomes and key dimensions of the future development of radiotherapy in England.

In addition, the RTDS will support through analysis the ambitions within the NHS ‘Five Year Forward View’, that patients will have access to sustainable high-quality, modern radiotherapy treatments wherever they live.

Who does RTDS apply to:

This standard specifies a data set for use at a local level, to inform national level analysis regarding radiotherapy treatment, to assist in achieving, supporting and monitoring the NHS Operating Framework, specialist commissioning and related policies.

All patients receiving radiotherapy in or funded by the NHS in England are covered by the standard. This includes adult and paediatric patients receiving radiotherapy, in acute inpatient, day-case and outpatient settings for solid tumours and haematological malignancies, including patients in clinical trials.

Radiotherapy treatment will be used as a term but includes all activity undertaken on external beam and brachytherapy machines or with radioisotopes not contained within an external beam and brachytherapy machine.

RTDS applies to the following key groups and organisations:

- NHS acute providers of radiotherapy services and all other providers of NHS commissioned radiotherapy services
- developers and suppliers of electronic systems for use within NHS acute providers of radiotherapy services
- organisations purchasing radiotherapy linear accelerator radiotherapy machines (LINAC) for use in NHS commissioned cancer centres and NHS acute providers of radiotherapy services

Data users of radiotherapy at both national and local levels, include:

At a national level:

- National Cancer Registration and Analysis Service (NCRAS)
- Department of Health and Social Care (DHSC)
- National Disease Registration Service (NDRS)
- NHS England and NHS Improvement
- Care Quality Commission (CQC)
- Public Health England (PHE)
- NHS Digital

At a local level:

- Radiotherapy Operational Delivery Networks (ODN's)
- commissioners and providers
- Cancer Alliances/Vanguards
- local NCRAS offices

Summary of changes

The new version of RTDS, version 6.0, was created after an extensive consultation process. Full details of this process, including those who were part of the consultation itself can be found in the ‘Consultation Summary Report’, and is available upon request from the RTDS helpdesk (rtds.helpdesk@nhs.net).

This revision allowed the data set to be clinically reviewed, validated and updated by experts in all fields of radiotherapy, and provides a clinically sound set of data to be collected from April 2022 onwards.

The changes to be made in this release are:

- the ability to structure the data requested into the pathways expected of a radiotherapy patient, including specific sections for:
    - an episode
    - the prescription
    - the plan
    - an exposure
    - an attendance
- clearer definitions and expanded formats to improve the quality of data submitted within the current data set
- the removal of the intention to change to xml reporting
- amendments to existing data items
- deletions where required
- new data items added, which have allowed the data set to be futureproofed with the addition of:
    - SNOMED CT
    - unique radiotherapy coding (not currently found within SNOMED CT or OPCS)
    - the accurate recording of radiotherapy treatment type
    - the measurement type to support the prescribed and the actual absorbed radiation dose
- changes, in response to careful consideration of improvements to the recording of:
    - proton therapy (within RTDS), which is now being delivered in Manchester and will become operational in London at the University College London Hospital (UCLH) in the summer of 2021
    - clinical trials that have a component of radiotherapy delivery included
    - treatment intent (in more granular detail)
    - route of admission
    - specialist radiotherapy treatments
- the addition of choices for linkage and radioisotope, enable clearer decision making and improves data quality

Other data have been given better descriptions, amended formats or updated attributes to help improve both the data quality, ascertainment and linkage of data through the data set.

Although there are only 4 data items deleted, there was a complete review of the additional 99 Commissioning Data Set (CDS) data items currently requested as supporting data for RTDS v5.0. The review concluded that many of these were no longer required, as they could be ascertained by linking to other high quality data sets or were duplicated. As such the content of RTDS will only include those items required to allow the accurate processing and patient matching of radiotherapy treatments. This has reduced the overall data set by 60 data items (48%), compared with the complied data set of RTDS v5.0.

This protects the data set moving forward and prevents the RTDS and CDS being out of sequence with each other's development cycles.

Implementation start and full conformance timeline

The following timeframe will be used to support the implementation, data collection and full conformance:

- implementation will be between 20 July 2021 and 31 March 2022 (8 months)
- data collection will start from 1 April 2022 (with a 3-month roll-out period between 1 April 2022 and 30 June 2022)
- full conformance from 1 July 2022

Supporting documents

All the documents referred to were submitted to the Data Standards Assurance Service (DSAS) for review under DAPB0111 Amd 84/2020.

Following acceptance by the Data Alliance Partnership Board (DAPB) and confirmation of authority to publish by the Department of Health and Social Care, the official Information Standards Notice (ISN) and related documents were published on the 20 July 2021.

This specification document should be read in conjunction with the following documents, available at the designated website:

http://digital.nhs.uk/isce/publication/dapb0111:

- Change Request
- Implementation Guide
- Information Standard Notice

http://www.ncin.org.uk/collecting_and_using_data/rtds:

- RTDS v6.0
- RTDS v6.0 User Guide
- RTDS v6.0 Technical Guide

https://nww.api.encore.nhs.uk/:

- RTDS v6.0 Portal User Guide

These documents are intended to support providers and developers who wish to identify and plan changes to their systems.

Please note that there is currently a new National Disease Registration Service (NDRS) website under construction and all RTDS publications will be accessible from there. Details of this launch and URL will be published in due course, RTDS will have a permanent section within this new website.

Related standards

The following should also be read in conjunction with this information standard:

DCB0084	OPCS Classification of Interventions and Procedures
DCB1521	Cancer Outcome and Services Data Set
DCB1533	Systemic Anti-Cancer Therapy Data Set
SCCI0021	International Classification of Diseases
SCCI0034	SNOMED CT

Contacts

RTDS has two main points of contact and queries regarding implementation should initially be raised with the RTDS helpdesk as follows:

- RTDS helpdesk email address – rtds.helpdesk@nhs.net
- RTDS helpdesk telephone number – 01865 458350

Health and care organisations

Requirements

All NHS Acute Trust providers of radiotherapy or private facilities where delivery is funded by the NHS **must**:

- read this document and Change Request documents in conjunction with the Implementation Guidance, to identify how the standard is applicable to them
- review their clinical services and confirm which areas of the standard apply to their clinical practice
- carry out a data mapping exercise to assess how well their existing systems align to the radiotherapy data set specification, and develop a plan for alignment if required
- submit data files to the RTDS portal on a monthly basis according to the staged programme defined in the Technical Guidance document
- submit downloads in either CSV or a spreadsheet format, as specified in the Technical Guidance document

A schedule for monthly submissions is published annually by the RTDS team (Appendix G).

NHS acute providers of radiotherapy services **must** include mandatory and where available required data items, which are part of NHS business rules (where applicable), otherwise files may be rejected. Data quality reports that are sent back to the data supplier **must** be reviewed and a resubmission may be required. It must be possible for the RTDS team to reconstitute details of each patient's sequential management from data supplied.

An experienced Head of Radiotherapy Services in each provider organisation **should** guide the service and system review, based on a good understanding of the scope, definitions and rules behind the data items (from the Implementation Guide).

Patients can opt-out of having their data collected and stored for cancer registration by clicking here, to be redirected to the NDRS opt-out page and following the instructions carefully.

Conformance criteria

Examples of reports available on the CancerStats2 platform to help providers monitor their conformance include:

- files submitted
- events (Attendances/Episodes/Prescriptions)
- radiotherapy machine reports
- intensity-modulated radiation therapy (IMRT)

Conformance is measured against the rules outlined in this document.

IT systems

It would be expected that all NHS acute providers of radiotherapy services have a service level agreement (SLA), with their system supplier to ensure future development needs are sufficient to meet changes to the standard.

This section is separated into three distinct parts:

- Trust
- Oncology Management System (OMS) Suppliers
- NDRS

Detailed and specific requirements and conformance criteria will be listed to inform and guide each of their responsibility in collecting, handling and reporting of data for RTDS.

Requirements – Trusts

The ability to transmit the data to the NDRS in XML format will no longer be a requirement for this data set, due to the additional burden this would cause developers and all parties financially.

Suppliers of radiotherapy systems or Cancer IT systems **should**:

- implement changes in accordance with their local contractual arrangements to enable all specified data items in the RTDS data set to be captured and extracted in compliance with the Specification and Implementation Guide
- collect each of the required data items, using the appropriate format and coding, for every patient receiving treatment of external beam radiotherapy (teletherapy), brachytherapy, proton therapy, radioisotope therapy (including radioiodine) and molecular radiotherapy using this data set
- submit a return of radiotherapy data by the 20th working day of each month, in line with the submissions schedule (Appendix G)

The RTDS requires data to be either extracted from the proprietary or in-house OMS or recorded directly in to one of the agreed submission formats – these will either be in the format of two complementary CSV files, or a single spreadsheet/CSV file as required.

A series of reports from the OMS and /or record and verify database tables, need to be extracted using the proprietary executive information software recommended by the OMS supplier or the in-house system to populate the data items.

Conformance criteria

The above requirements **must** be met, including the following:

Timeliness

Returns **must** be submitted in line with the submission schedule in Appendix G, including:

- a complete return of the data set is required for every month, where treatments were delivered
- RTDS benefits from being a complete data source for analytical purposes, so late submissions, although not sanctioned, are accepted and uploaded to the database at the next available monthly cycle
- providers who do not submit a monthly return by the date specified **would** be subject to an escalation policy that will be agreed with the Radiotherapy Information Strategy Group (RISG) and the standard sponsor

Quality assurance

Quality assurance tests are run on submissions upon receipt, during the data assembly process. Submissions which fail any of the critical tests are rejected and quality assurance reports are provided to submitters including details of their performance.

Returns **must** contain records for every treatment delivered, and the following data checks are applied:

- submissions are assessed for completeness upon receipt by NDRS
- submissions which appear to have missing data are queried with the submitter
- missing data is identified using the following criteria:
  - working days of the month omitted
  - a different number of radiotherapy machines than the previous month
  - a significantly different number of records than the previous month
- occasional audits of submissions against patient records and scheduling records are used to identify systematic omissions

NDRS will maintain communication with submitters to advise priorities for quality improvement.

Additional criteria

Providers of radiotherapy services to NHS patients in England **must** collect each of the required data items for the RTDS data set, ensuring:

- the appropriate format and coding are used for every patient receiving of external beam radiotherapy (teletherapy), brachytherapy, proton therapy, radioisotope therapy (including radioiodine) and molecular radiotherapy, given for treatment
- data is extracted directly from radiotherapy equipment software (record and verify systems, or radiotherapy management systems) for production of the standard
- data will be generated from the hospital oncology management and patient administration systems using agreed and tested extract processes

NDRS will continue to provide technical support to all radiotherapy providers who may require it, to consolidate the extraction and submission process. The data will be validated, quality assured, collated and reported on by NDRS within PHE, using an on-line submission and reporting portal.

Monthly data completeness and compliance reports are published on CancerStats2. These contain details of the degree of Provider compliance of RTDS data against expected levels. Regular reports are also published on this website, which highlight how the project is progressing so far as a whole.

Requirements – Oncology management system suppliers

Suppliers of radiotherapy systems or cancer IT systems **should**:

- ensure that the OMS are capable of recording the data required for the information standard
- support data extraction required for RTDS, this may be by the provision of standard reporting for extraction, or may be by the provision of user definable reporting
- liaise with NDRS regarding any changes to systems which may have an impact on RTDS and prior to implementation of extraction of RTDS from system

Conformance criteria

The above requirements **must** be met, including the following:

Overall

System suppliers are required to demonstrate that every field in the data set can be recorded and exported at the correct level of aggregation.

Using appropriate codes and formats, systems should:

- be tested by auditing real patient data against the expected outputs from the information standard
- include real patient data with multiple concurrent and consecutive prescriptions for treatment

Aggregation

OMSs must contain records stored at each level of aggregation as required by the RTDS (Patient, Episode, Prescription, Plan, Exposure and Attendance), in addition:

- system suppliers **must** provide an indication of a level of aggregation in the OMS, which is equivalent to: Patient, Episode, Prescription, Plan, Exposure and Attendance

Data items

OMSs **must** contain matching fields that will store defined data to support a defined extract. Each data item **must** be at the correct level of aggregation, in addition system suppliers **must**:

- provide an indication of a field in the OMS, which is equivalent to each of the fields specified in the defined extract, and that is held at the correct level of aggregation

Coding

OMSs **must** include every coded field, populated with a list of values which can be directly and unequivocally mapped to the codes in the NHS Data Model and Dictionary. In addition, system suppliers **must**:

- provide a list of codes used in their system in the fields which are equivalent to those in the OMS extract, and which are coded in the RTDS
- include each list of codes, detailing its direct or unequivocal mapping to the codes in the NHS Data Model and Dictionary

Formats

OMSs **must** include each field so that data can be entered and exported with the correct format (e.g. date).

In addition, system suppliers **must**:

- demonstrate that each field can be exported in the format specified in the OMS extract definition

Requirements – NDRS

Each of the data items submitted by providers will be subject to validation and quality assurance checks. The requirements Specification, Implementation Guide, Technical Guide and User Guide documents will be available to all providers, along with the data set. The Technical and User Guides will be maintained to continue to inform and underpin the extraction, submission and validation process.

When a file is uploaded through the submission’s portal, an instant report will be provided to the submitter. This will allow the provider to correct any errors that are identified or to re-submit the file within the agreed timetable.

Record level detail will be provided to providers to allow errors to be located on local systems and rectified.

NDRS will produce regular information reports on the data received from the radiotherapy providers. The range of reports will include:

National reports:

- number of LINAC’s in Use
- machine attendances per LINAC
- percentage of IMRT Episodes by Provider

Attendances:

- by Machine Type per Provider
- by Provider
- for Provider by CCG
- by Provider in Network

Episodes:

- by Network of Patient
- by Provider
- for Provider by CCG
- by Provider in Network

Machine attendances:

- by Machine
- by Machine Identifier and Day of Week
- by Machine Identifier in Network of Provider

Prescriptions:

- by Network of Patient
- by Provider
- for Provider by CCG
- by Provider in Network

Productivity:

- HRG Preparation Code
- HRG Treatment Code
- Working Day Profile of Linear Accelerator
- IMRT by Provider

Scope

Background

This document outlines the requirement for all NHS acute providers of radiotherapy services to collect and submit the RTDS to PHE. This is a continuation of the changes made in 2016, when responsibility and management for the RTDS service changed from the National Clinical Analysis and Specialised Applications Team (NATCANSAT) to PHE.

PHE now provides definitive national functions for the collection, quality assurance and analysis of cancer data across 154 NHS Acute Trust providers of cancer care. This already includes the 51 NHS Acute Trust providers of radiotherapy services and 40 NHS funded sites who do not deliver external beam radiotherapy but are known to be delivering molecular radiotherapy treatments.

PHE already manages major cancer data sets such as:

- Cancer Outcomes and Services Data set (COSD) DCB1521
- Systemic Anti-Cancer Therapy data set (SACT) DCB1533
- National Prostate Cancer Audit (NPCA)
- National Lung Cancer Audit (NLCA)

NPCA and NLCA data is collected as part of the COSD submission. This allows for greater integration of the management, collection, quality assurance and analysis of radiotherapy data alongside the other major national cancer data sets.

Submission and validation methods will continue to be through an on-line submission portal. Where necessary, on-site technical support will be provided by PHE to set up and ensure the timeliness and accuracy of data extraction and submission for RTDS.

Please refer to the governance section below for more information about the future of PHE after October 2021, and the ongoing commitment and obligations of NDRS.

In scope

This standard specifies a data set for use at both national and local levels to generate secondary uses information about radiotherapy treatments, to assist in achieving, supporting and monitoring the NHS Operating Framework, specialist commissioning and related policies.

All patients receiving radiotherapy treatment in or funded by the NHS in England are covered by the standard. This includes adult and paediatric patients receiving radiotherapy treatment, in acute inpatient, day-case and outpatient settings and delivery in the community for solid tumours and haematological malignancies, including patients in clinical trials.

Specifically, for radiotherapy this standard covers all radiotherapy which fall within the following treatment modalities:

- External Beam Radiotherapy (excluding Proton Therapy)
- Proton Therapy
- Radioisotope Therapy (including Radioiodine)
- Brachytherapy given using automated remote afterloading machines
- all other brachytherapy given for the treatment of malignant disease

The standard covers neoplasms coded within ICD-10 diagnosis codes range C00 - C97, D00 - D48 and E85.9. See Appendix B for list of mandatory registerable conditions.

Out of scope

It does not apply to the following groups of patients:

- radiotherapy delivered outside of England
- radiotherapy delivered in a non-NHS setting and not funded by the NHS
- non-therapeutic exposures delivered using a radiotherapy machine (e.g.: imaging)
- non-patient exposures (e.g.: dosimetry exposures, blood or tissues, animals)

Submission of data in XML format is now out of scope of this information standard, due to the additional financial cost and burden of implementation. As a ‘Secondary Uses’ data set, this standard does not define record level data to be used in the delivery of care. The data for RTDS should be derived from patient identifiable data, which are already recorded for the purpose of care management.

Data definitions

Details of the fields which comprise the RTDS data set, including their ‘Data Dictionary’ definitions, permissible values and other qualifying descriptions, are contained in the accompanying Implementation Guide, Change Request, data set version 6.0 and new User Guide documents.

RTDS has been carefully reviewed to support other major data sets and wherever possible, data items have been removed to reduce the burden of data collection.

In addition, discussions have taken place with other data set owners to refine data items where cross-over is possible, to maximise the clinical relevance and prevent multiple (similar) data being created with different meanings. This work is supported by the NHS Digital, Data Model and Dictionary Service and Terminology teams.

The Cancer Outcomes and Services Data set (COSD) has some overlapping content with the RTDS data standard. Where this occurs, field definitions are consistent to allow data to be interoperable. All remaining data items in the Cancer Waiting Times (CWT) data set have been removed through this version change.

Data set structure

Radiotherapy treatments are given over a prolonged period of time, comprising repeating and sequential elements. The patient may attend two or more providers during the course of treatment, potentially including simultaneous chemotherapy. In order to track the patient during treatment the data set must be capable of linking all the elements of care in a consistent and ordered way, including linking to the Systemic Anti Cancer Therapy (SACT) data set.

In order to achieve this, the data set requires a branching structure which links the initial data fields, which will remain constant during the treatment, with detail of each episode, prescription, fields and exposure prescribed. Examples of this are shown diagrammatically within Fig1.

Downloads from providers to the central repository will be in the form of monthly reports of current activity. It must be possible for the RTDS team to reconstitute details of each patient’s sequential management from these data.

Implementation and use

Submission of data

When a data file is ready for submission to RTDS, staff at the reporting organisation can connect using the NCRAS secure file upload system, which sits behind the English National Cancer Online Registration Environment (EnCORE) application programming interface (API) web portal.

Data sources

The data will be provided by all hospitals and health care providers treating patients with external beam radiotherapy (teletherapy), brachytherapy, proton therapy, radioisotope therapy (including radioiodine) and molecular radiotherapy using this data set. Collation of data will depend on local system implementation and configuration, for example:

- patient identifiers, demographics and details of the provider will be derived from existing patient administration systems and should be linked electronically, where these are in use
- details of the patient's clinical picture may also be derived from a variety of hospital systems or may need direct entry into the local reporting system
- details of specific radiotherapy treatments (teletherapy, brachytherapy and proton therapy), will be recorded in the course of clinical practice and will be derived either from a linear accelerator radiotherapy machine (LINAC) or other clinical databases

Approach and timelines

This is a new change to the RTDS information standard and builds on the excellent work done in previous versions, enabling clinically reviewed and agreed data to be collected at source and then made available for national analyses.

This version change is important in order to continue to meet the business objectives of the standard, and to ensure that all data requested are clinically accurate and relevant for the lifetime of the standard.

The RTDS has been designed to mirror the clinical decision making in delivering radiotherapy services, and is divided into five sections (excluding linkage and demographic details):

- radiotherapy episode
- radiotherapy prescription

- radiotherapy plan
- radiotherapy exposure
- radiotherapy attendance

Working practices

Implementation of the RTDS has implications for the skills and training of several staff groups. All groups require access to appropriate user guidance in electronic and/or paper form.

Please refer to the RTDS Implementation Guide, Technical Guide and the new User Guides created for version 6.0. These documents, along with the Specification and the radiotherapy data set itself, will support the process of implementation and upgrade.

It is preferable for local user guidance to be grafted seamlessly into that already provided for users of radiotherapy systems, either by system suppliers or local teams. This must be consistent with the RTDS information standard, but also system specific and tailored to the architecture and graphic interface of individual suppliers' systems.

It is recommended that all providers work closely with their software systems suppliers and internal IT departments. They will provide additional support on incorporating updates and any practical issues arising from the introduction of the RTDS information standard. Programming, early adoption and upgrades of existing systems is recommended as good practice.

RTDS v6.0 – Proposed relationship and key changes

The relationship diagram (fig 1) below is based on the changes for version 6.0 and should not be used in relationship with any other version. Please contact the rtds.helpdesk@nhs.net for any further information.

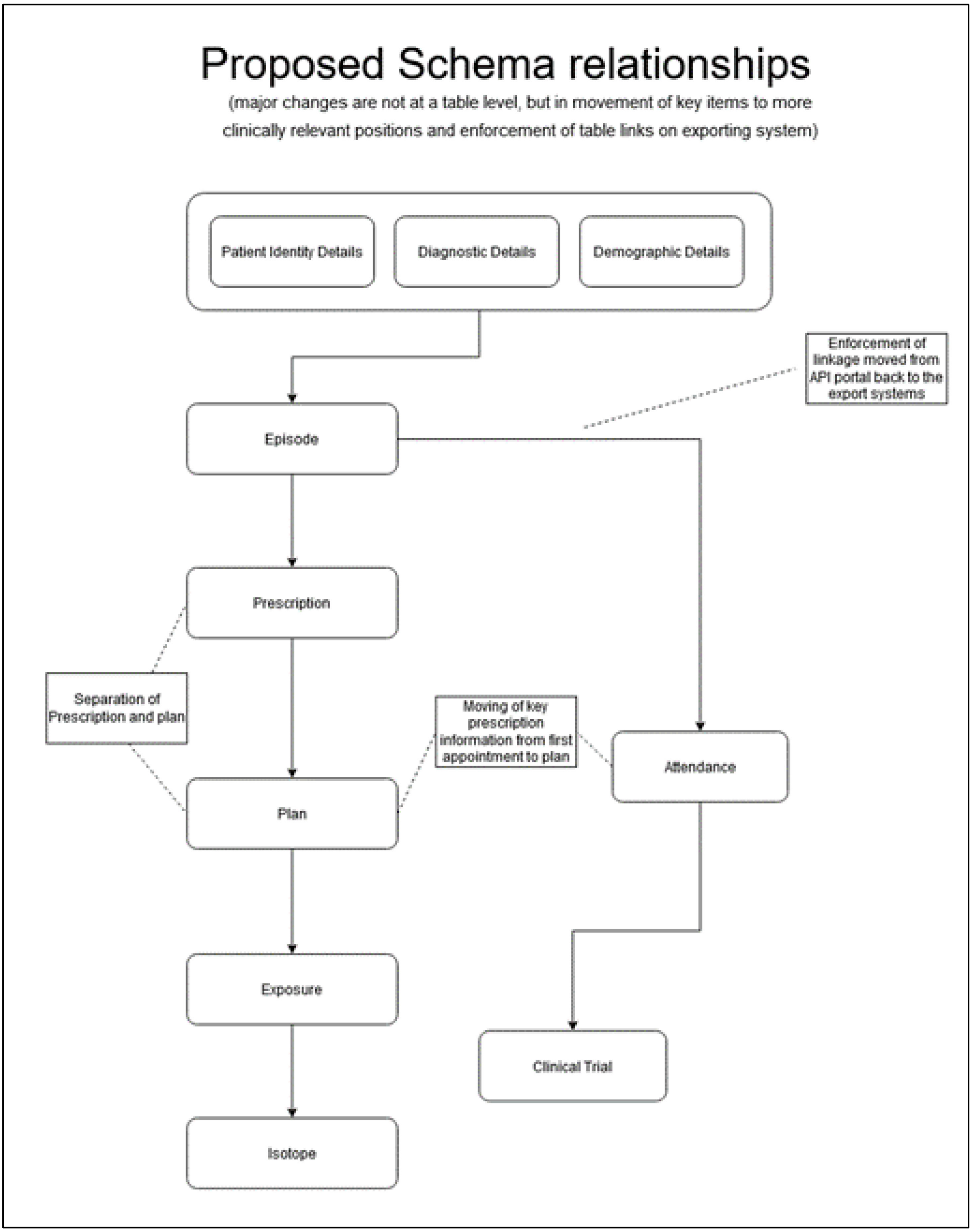

Fig 1: Relationship diagram for RTDS v6.0

Governance

Information governance, clinical safety and data protection

The primary purpose of the standard is for secondary uses only and will therefore have no direct impact on clinical safety and as such is not in scope of DCB0129. Consequently, a clinical safety case report is not required to support the standard.

NDRS is part of PHE which is an executive agency of the DHSC. The function of PHE is to fulfil the Secretary of State for Health's statutory responsibilities to protect and improve public health and reduce health inequalities. Running national data collections on a range of diseases, including cancer, is a vital part of this work. From October 2021 NDRS is expected to become part of NHS Digital, however all of its existing work programmes, functions and commitments will continue unchanged.

Section 251 of the NHS Act 2006 provides the statutory power to ensure that NHS patient identifiable information needed to support essential NHS activity can be used without individual patient consent. This power can be used only to support medical purposes and the interests of the public if seeking consent is not practicable and the use of anonymised information is not sufficient.

Under Regulation 2 of the Health Service Control of Patient Information Regulations 2002, NDRS is authorised to process "confidential patient information relating to patients referred for the diagnosis or treatment of neoplasia."

Permission to process these data is subject to annual review by the Confidentiality Advisory Group (CAG) of the Health Research Authority. The NDRS performance against national Information Governance (IG) standards for health data is assessed annually on the NHS Data Security and Protection Toolkit.

The NDRS must achieve at least a Level 2 score each year to continue to process patient identifiable information under Section 251. CAG advises the Secretary of State on whether to grant approval to continue to process based on its review and the toolkit score.

Under General Data Protection Regulation (GDPR) the lawful basis upon which the NDRS will process personal data is Article 6(1) (e) "processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority."

The NDRS receives health and genetics data in accordance with the conditions for “special category” data set out in GDPR Article 9(1) (h) “processing is necessary for the...provision of health care or treatment or the management of health...care systems and services.”

And GDPR Article 9(2)(i) “processing is necessary for reasons of public interest in the area of public health such as... ensuring high standards of quality and safety of health care... on the basis of [UK] law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy.”

Reported data will be managed by the NDRS where there is long standing expertise in managing large volumes of confidential data. Although the data items which are flowed to the NDRS have changed, the data flows (i.e. which organisations will be receiving the data in identifiable form) remain unchanged.

In compliance with the fair processing requirement within the Data Protection Act, provider organisations are expected to inform patients of this purpose for reporting their information and of the potential use of the information for service development, analysis and statistical research.

NDRS supports this process and provides privacy information to cancer patients in several ways. The NCRAS patient leaflet, for example:

- explains what cancer registration is, why it matters, where to go to find more information and how to opt-out
- was designed in partnership with patient groups and cancer charities and was approved by the Plain English Campaign
- is sent to Trusts’ cancer services, patient information centres, many site-specific Multi-Disciplinary Teams (MDTs), cancer charities and private health care providers
- is included in the Quality of Life (QoL) survey which people receive after they have had a cancer diagnosis
- is available on the NDRS patient facing website

In total, 166,000 copies of the leaflet were distributed in 2020 to 143 NHS Acute Trusts in England.

NDRS as part of PHE, complies with the DHSC’s Data Protection Act registration with the Information Commissioner's Office (ICO). The NDRS regularly reviews and harmonises its information governance policies to correlate them with those of PHE and aligning with multiple mandatory training requirements (annually) for its employees.

These policies inform for example:

- access controls of data
- server security and encryption
- data transfer procedures

All NDRS employees handling patient identifiable data (PID), are required to complete information governance, data security and responsible for information mandatory training. There is also a ‘Confidentiality Guidelines and Agreement’ document, which is an individual declaration for all employees and must be read and signed annually. This is monitored as part of their appraisal process.

Consent process

Where patients have requested their data are not shared, the provider organisation **must** ensure that their records are **not** included in the data downloads submitted to the NDRS. It is suggested that a dissent (i.e. the proactive expression by an individual from whom consent has not been obtained) or a similar flag **should** be provided in the provider organisation systems so that the record can then be omitted from the monthly upload.

The NDRS has published a Patient Information Leaflet (Appendix C) which explains that individuals have the right to access and have their own data held in the NDRS removed and explains the process.

If a patient discovers that their information has been uploaded to the NCRAS and they wish for this to be deleted, the requester can email their request to: optout@phe.gov.uk or write to the Director of NDRS, using the address in the patient leaflet. The NDRS will then, as far as is possible, remove the patient from the National Cancer Registration and Analysis Service (NCRAS) database.

Information for patients wishing to have their data removed, as far as possible, from the NCRAS database is available on the NDRS website.

Data retention

The NDRS holds data indefinitely, as without this facility accurate mortality and survival data cannot be calculated. If a patient wants their data removed at any point, then this facility is available as explained above.

Data disclosure

The NDRS adheres to the requirements of the Data Protection Act 2018 with regard to the receipt, storage and transfer of information relating to individuals. When releasing data to third parties, all NDRS offices strictly comply with the approval on the release of patient-identifiable and potentially identifiable information.

Recipients of such data are required to sign a declaration stating that they will protect the information they are entrusted with, use it only for the purpose for which it was supplied and make no attempt to identify information pertaining to particular individuals or to contact individuals. They are also prohibited from presenting any information that may identify an individual. This is also the case with publications produced by NDRS or NCRAS, which present aggregated data only.

As the NDRS is part of PHE, all such requests **must** be approved by the Office of Data Release (ODR).

Subject access requests

Subject access requests (SARs) are managed through PHE’s Public Accountability Unit, in line with PHE’s Data Protection Policy and the Data Protection Act.

For SARs, relating to cancer registration, there is a two stage information release process. This is designed to balance the needs of the individual with our statutory requirement to protect patient confidentiality.

At the first stage, we provide the subject with a summary report known as an “exemplar report”. This report contains information about data sources attached to the subject’s cancer registration, the date we received and the originating organisation. The report gives examples of the type of information these sources might contain and a glossary of terms.

Following this, if the subject requires more information, we also offer to send a copy of the actual records attached to the subject’s cancer registration to the primary care physician (the General Practitioner) or another clinician who knows the patient.

This allows the GP to verify that the data has been sent to the correct person and, because some of the information is quite technical, the recipient also has the opportunity to ask the practice staff to explain anything they may not understand.

All the information is reviewed by the NDRS’ own Caldicott Guardian before being released. Requests are fulfilled within the time periods required by the Data Protection Act.

There is a sample process map available in Appendix D.

Data quality

The RTDS has complex and interrelated content, so it is essential that data errors are eliminated to prevent corruption of sometimes complex analyses dependent on many disparate data elements.

PHE will receive, validate, quality assure and integrate the data received from across the 51 NHS Acute Trusts delivering external beam radiotherapy in England, many of which are also delivering at least one form of non-external beam radiotherapy. In addition, there are approximately 40 NHS funded sites who do not deliver external beam radiotherapy but are known to be delivering molecular radiotherapy treatments. This data is used to produce a timely and definitive analytical resource.

This will be linked vitally by PHE to data captured from other national cancer data sets, COSD (DCB1521) and SACT (DCB1533), to support key service metrics and to track progress in the provision of radiotherapy and other cancer services.

The added benefits of integrating the data collection and analytical functions will be cancer site-specific analyses of outcomes by patient and treatment variables, allowing for a better understanding and appreciation of the specific role of radiotherapy in improving outcomes compared with other treatment modalities.

When technical, coding and clinical errors have been corrected, the data will be released for the generation of a full range of analysis and reporting (using the CancerStats2) portal. This process runs in parallel with the clinical governance process above.

NHS providers

Each provider is responsible for ensuring the data submitted to the NDRS or submitted through other standard NHS routes, is of the highest quality and completeness possible, and accurately represents the service provided.

The NDRS provides a dynamic feedback process from the cancer registration system to providers. This will allow data quality assurance at a field level – with clinical teams given secure access to the data (via the api portal) that their organisation has submitted.

National Cancer Registration and Analysis Service (NCRAS)

One of the main roles of the NCRAS is to ensure data quality and consistency. The eight NCRAS regional offices use a single online processing system called (EnCORE). Working practices have been standardised with continuous performance monitoring and oversight of the entire NCRAS through PHE.

In 2016, NCIN became part of the NCRAS, which is part of PHE. This has enabled more efficient analysis of cancer data. Specific aspects of data quality are described in Appendix E.

CancerData is a publicly accessible portal to look at outcomes data for CCG’s and provider Trusts. This has been specifically released for the public as well as NHS organisations, and is a vital step forward in improving data quality, whilst producing as near-to real-time data analysis from the NCRAS.

There are several levels of RTDS reporting available from this portal:

- radiotherapy delivery in England by episode and attendance
- utilisation of intensity modulated radiotherapy in England
- radiotherapy COVID-19 dashboard

These reports allow the user to filter by many variables. In addition, CancerStats2 also provides a wide range of reports, however this is not available to the general public and is only accessible via the secure Health and Social Care Network (HSCN). HSCN is the data network for health and care organisations which replaced N3.

Demographic data

PHE needs the confidential data in the RTDS to ensure secure linkage of the details of radiotherapy plans and treatments to personal data already managed by PHE. This will ensure a full pathway of information on patients’ diagnosis, treatment and care. The full pathway data will allow clinical teams to understand better how radiotherapy treatment contributes to patient outcomes alongside other treatment modalities.

The cancer registration data is dynamic and individual tumour records are updated from numerous disparate data sources. Linkage of some of these sources across the NHS is not sufficiently good to allow accurate mapping of new data to existing items without patient-identifiable data.

An example could be when using only NHS Number. There is a risk that a typo could cause the wrong data to be inadvertently added to the wrong patient or a new record created to a patient who does not have cancer. Having additional patient identifiers helps to remove that possibility and provides an invaluable quality assurance process between the Trusts and the NCRAS.

Even once linked, retaining addresses and names remains important; the address stored by the NCRAS is that at the time of diagnosis of the tumour and is essential for cancer cluster analyses possibly many years later, when the patient may have moved. Without patient name, registries could not support genetic and follow-up enquiries made by clinicians who often only have limited information on the index case and possible relatives.

Nevertheless, it is NDRS practice to use pseudonymised or even anonymous (possibly still disclosive) data sets for analysis where patient identity is not needed. Access to identifiable and potentially disclosive data requires appropriate permissions from the Office of Data Release (ODR). This is a function of the National Disease Registration Service (NDRS) within PHE.

For details on how the NDRS processes deal with linkage and data discrepancies please see Appendix F.

Appendix A – glossary of terms

The following is a glossary of terms which relate to and are referenced within this specification document. The term is followed (in brackets) by the acronym, then below is the definition:

4D Adaptive radiotherapy (4D ART)

The ability to take account of the tumour shape in the three physical dimensions plus the fourth dimension of change with time. It can work well for tumours in areas of the body that may move during treatment, for example due to breathing.

Brachytherapy (BT)

Brachytherapy is the delivery of radiation using sealed sources which are placed close to the site that is to be treated. Isotopes used in brachytherapy can be applied directly to the tumour by surface applicators inserted into body cavities and tubular organs via specially designed delivery systems (intracavitary and intraluminal therapy) or inserted directly into a tumour (interstitial radiotherapy).

Burden

The Data Standard Assurance Service (DSAS) team within NHS Digital assess the burden on the NHS of all data collections as per the Health and Social Care Act 2012, on behalf of the Data Alliance Partnership Board. Anyone who collects data on a national scale from the service, needs to go through the Burden process to gain approval to collect the data.

Cancer

For the purposes of this standard the term ‘cancer’ is used throughout the standard and related documents to cover all conditions defined by the World Health Organization (WHO) and International Agency for Research on Cancer (IARC) Classification of Tumours.

Cancer Centres

Organisations which help people to live with, through and beyond cancer by bringing together specialist clinical and professional staff and communities of support.

Cancer Outcomes and Services Data set (COSD) DCB1521

The COSD is the national standard for reporting cancer in the NHS in England. It replaced the previous National Cancer Data set and includes the former Cancer Registration data set and additional site specific data items relevant to the different tumour types.

Cancer Registries

Organisations which exist internationally to collect, process, analyse and disseminate data on cancer patients in their local regions.

CancerStats2 Portal

Online resource that allows Trusts to review specific cancer data, submitted as part of the conformance framework.

Care Quality Commission (CQC)

One of the independent regulators of health and social care in England.

Chemoradiation

Chemoradiation is when chemotherapy and radiotherapy is given together. Chemotherapy may be given intravenously via a pump or orally during part of the radiotherapy course. Radiotherapy and chemotherapy treatments may also be alternated between each other.

Commissioners

Organisations that plan, purchase and monitor services to meet the health needs of their local population.

Data Coordination Board (DCB)

The Data Coordination Board meets monthly to review and approve the assurance of information standards and data collections (including extractions), known collectively as ICSE. Replaced by the Data Alliance Partnership Board, see below.

Data Alliance Partnership Board (DAPB)

The DAPB replaced the DCB in 2021, and continues to provide the same robust function.

Department of Health and Social Care (DHSC)

DHSC is a ministerial department, supported by 28 agencies and public bodies.

Expert Advisory Groups (EAGs)

A group of experts (at tumour site level) who advise NDRS on what data needs to be collected and what analyses are conducted.

Extensible Markup Language (XML)

Extensible Markup Language (XML) is a set of rules for encoding documents in machine-readable form.

Image Guided Brachytherapy (IGBT)

Image guided brachytherapy (IGBT) uses cross sectional image data to create 3D models. This allows clinicians to more precisely plan and deliver the radiation to the target while sparing surrounding health tissues.

Image Guided Radiotherapy (IGRT)

IGRT is any imaging at pre-treatment and delivery, the result of which is acted upon, that improves or verifies the accuracy of radiotherapy. IGRT encompasses the whole range of imaging from simple to more complex imaging that allows direct visualisation of the tumour and surrounding tissue. Using scanning during treatment enables verification of tumour position in relation to adjacent soft tissue organs.

Information Standard Notice (ISN)

Information Standards Notices (ISNs) are published to announce new or changes to information standards published under section 250 of the Health and Social Care Act 2012.

International Statistical Classification of Diseases and Related Health Problems (ICD)

A medical classification list for the coding of diseases, signs and symptoms, abnormal findings, complaints, social circumstances and external causes of injury or diseases, as maintained by the World Health Organization (WHO). The title is followed by the revision number, e.g. ICD10 is the tenth revision.

International Classification of Diseases for Oncology (ICD-O)

An extension of the ICD coding system used principally in tumour or cancer registries for coding site (topography) and histology (morphology) of neoplasms. The title is followed by the revision number, e.g. ICD-O-3 is the third revision.

Intra-operative Radiotherapy(IORT)

IORT is used (for example), for breast tumour treatments during surgery:
- the treatments are used directly after surgery to remove a tumour, prior to the excision site being closed
- the technique involves the precise application of a high dose of radiation to the target volume area or region of interest, with minimal exposure to healthy tissue, which can be displaced or protected during the procedure

Linear Accelerator (LINAC)

A radiotherapy machine capable of generating high energy penetrating photon and electron beams for the delivery of radiotherapy.

Magnetic Imaging Resonance (MRI)

MRI is a medical imaging technique, which makes use of the property of nuclear magnetic resonance (NMR) to image nuclei of atoms inside the body. This allows greater clarity of soft tissue structures.

Multi-Disciplinary Team (MDT)

The Multi-Disciplinary Team (MDT) is a group of experts who collectively make decisions about diagnostic tests required and the treatment management of patients suspected of or diagnosed with cancer.

MDT coordinator

The Multi-Disciplinary Team (MDT) coordinator is the person(s) responsible for facilitating the MDT meeting. They also have additional duties for collecting and recording information on patients as they pass through the Provider Trust, whilst on a cancer pathway. Sometimes known as a Patient Pathway Coordinator.

Molecular Radiotherapy (MRT)

MRT is the treatment of disease with radiopharmaceuticals. It delivers high radiation doses to a specific target and spares healthy organs from serious side effects.

National Clinical Analysis and Specialised Applications Team (NATCANSAT)

Previous owners of the data standard, and controllers of the RTDS data and reporting structure (up-to 2015).

National Cancer Registration and Analysis Service (NCRAS)

The NCRAS is the National Cancer Registration and Analysis Service for England, collecting cancer data from all NHS Providers of cancer care in England. The NCRAS is a function within the National Disease Registration Service within PHE.

National Cancer Waiting Times Monitoring Data set (NCWTMDS)

The Information Standard (DCB0147) used to monitor the time that patients with suspected and diagnosed cancer have wait for appointments, tests and treatments.

NHS Digital (NHSD)

NHS Digital is England's central, authoritative source of health and social care information for frontline decision makers, which builds upon the Health and Social Care Act 2012.

NHS England (NHSE) and NHS Improvement (NHSI)

NHS England is an executive non-departmental public body (NDPB) of the Department of Health and Social Care. NHS England oversees the budget, planning, delivery and day-to-day operation of the commissioning side of the NHS in England as set out in the Health and Social Care Act 2012.

From 1 April 2019, NHS England and NHS Improvement started working together as a new single organisation to better support the NHS to deliver improved care for patients.

Office of Data Release (ODR)

The ODR was established by the senior information risk owner to provide a systematic, risk-based approach to reviewing both internal and external requests to process PHE data for secondary purposes and to meet our obligations in line with data protection legislation, Common Law Duty of Confidentiality, Caldicott Principles and best practice set by the Information Commissioner's Office (ICO).

Office of National Statistics (ONS)

The UK's largest independent producer of official statistics and the recognised national statistical institute of the UK.

Oncology Management System (OMS)

A database associated with a radiotherapy machine, which verifies treatment to be delivered against present criteria and tolerances and records the details of treatment delivered.

OPCS Classification of interventions and procedures (OPCS)

The OPCS Classification of Interventions and Procedures is a fundamental information standard which is revised periodically. The classification is used by Health Care Providers and national and regional organisations. OPCS-4 is used to support operational and strategic planning, resource utilisation, performance management, reimbursement, research and epidemiology. It is used by NHS suppliers to build/update software to support NHS business functions and interoperability.

Patient Administration System (PAS)

A database which stores demographic, clinical, administrative details of patient's attending a hospital.

Positron Emission Tomography (PET)

PET scanning is a nuclear medicine imaging technique that produces a three-dimensional image or picture of functional processes in the body.

Proton Beam Radiotherapy

Proton Beam Radiotherapy uses a high-energy beam of protons rather than high energy photon to deliver a dose of radiotherapy. Proton beam treatment directs the radiation dose to precisely the depth where it is needed, with minimal damage to surrounding tissue. The treatment is therefore particularly suitable to complex childhood cancers.

Providers

Organisations that provide health services.

Public Health England (PHE)

Public Health England is an executive agency of the DHSC. Its role is protecting and improving the nation’s health and wellbeing and to reduce inequalities.

Radiotherapy Data Set (RTDS)

RTDS is a standard data set covering every patient treated with radiotherapy in the NHS in England.

Radiotherapy Information Strategy Group (RISG)

The main purpose of the Radiotherapy Information Strategy Group (RISG) is to provide expert clinical, commissioner, provider and lay advice to support the collection, understanding and effective use of radiotherapy data by all relevant stakeholders.

RTDS User Group

A formal group that meets quarterly to discuss the progress of RTDS and provides advice on the clinical application and practicalities of any changes proposed.

Stereotactic Ablative Body Radiotherapy (SABR)

SABR categorises any stereotactic plans delivered to the body excluding intracranial treatments, for example, for lung and oligometastatic lesions:

- the radiotherapy treatment plans account for any tumour motion and enhanced immobilisation devices may be used
- the dose distribution tightly covers the tumour with steep dose gradients away from surrounding tissues and organs
- SABR plans will be delivered using IMRT or VMAT technologies

Stereotactic Radiotherapy/Radiosurgery (excluding SABR) (excluding more specific definitions)

This categorises any plans delivered to the intracranial region excluding SABR body treatments, for example, for brain metastases and oligometastatic lesions:

- the radiotherapy treatment plans account for any tumour motion and enhanced immobilisation devices may be used
- the dose distribution tightly covers the tumour with steep dose gradients away from surrounding tissues and organs
- SABR plans will be delivered using IMRT or VMAT technologies

Systemic Anti-Cancer Therapy data set (SACT) DCB1533

SACT is the national collection of all cancer systemic anti-cancer therapy data in the NHS in England, which covers all solid tumour and haematological malignancies. This includes all adult and paediatric cancer patients, those in clinical trials, and covers acute inpatient, day case, outpatient and community settings.

United Kingdom and Ireland Association of Cancer Registries (UKIACR)

The UKIACR brings together organisations with an interest in developing cancer registration as a resource for studying and controlling cancer in the UK and Ireland.

XML schema

The documentation, definitions and descriptions required to enable the production and transmission of data for a specific XML.

Appendix B – mandatory registerable conditions

ICD 10	Description of neoplasm
C00 - C97	All malignant neoplasms
D00 - D09 (excluding D04)	All carcinoma in-situ (excluding all D04 in-situ skin cancers)
D32 - D33 D35.2 & D35.3 D35.4	Benign neoplasms of brain & other parts of nervous system Benign neoplasms of pituitary gland & craniopharyngeal duct Benign neoplasms of pineal gland
D37 - D48 (excluding D47.2)	All neoplasms of uncertain behaviour Neoplasms of unspecified nature of bladder Neoplasm of unspecified nature of brain Neoplasm of unspecified nature of other parts of nervous system & pituitary gland only (Excluding D47.2 Monoclonal gammopathy of undetermined significance (MGUS))
E85.9	Primary Amyloidosis

Please see RTDS user guide for full list of mandatory registerable conditions.

Although primary amyloidosis (E85.9) is listed as an E ICD code in the World Health Organization (WHO) disease classification, amongst clinicians it is widely acknowledged and subsequently treated as a cancer.

Appendix C – cancer registration leaflet

Below is the cancer registration leaflet (version 6), as of 6 January 2019.

Where can I find out more?

If you would like to find out why cancer registration is important or have any questions about the work we do, you can:

- visit us online at www.ndrs.nhs.uk
- talk to a member of the NHS cancer team treating you, or
- visit www.nhs.uk/your-data-matters to find out how the NHS uses information.

Public Health England
Protecting and improving the nation's health

NHS

Can I see the information you hold about me?

Yes, we can give it to a doctor (GP) who knows who you are, so they can share all the information with you.

Can I ask for my information not to be included in the cancer registry?

Yes, you have the right to opt out of cancer registration. This will not affect the personal care you receive from your healthcare team.

If you do not want your information included in the national cancer registry, you can contact us at **optout@phe.gov.uk** or write to:

Director
National Cancer Registry
Public Health England
6th Floor, Wellington House
133-155 Waterloo Road
London SE1 8UG.

For information on your rights and privacy visit www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy

This leaflet is available in alternative formats. Contact us at NCRASfeedback@phe.gov.uk for more information.

This leaflet is reviewed regularly.
If you have any comments, please email NCRASfeedback@phe.gov.uk.

PHE publications gateway number: 2018747. Version 6, January 2019.

Crystal Mark 22491 Clarity approved by Plain English Campaign

Cancer registration

Why it matters and what you need to know

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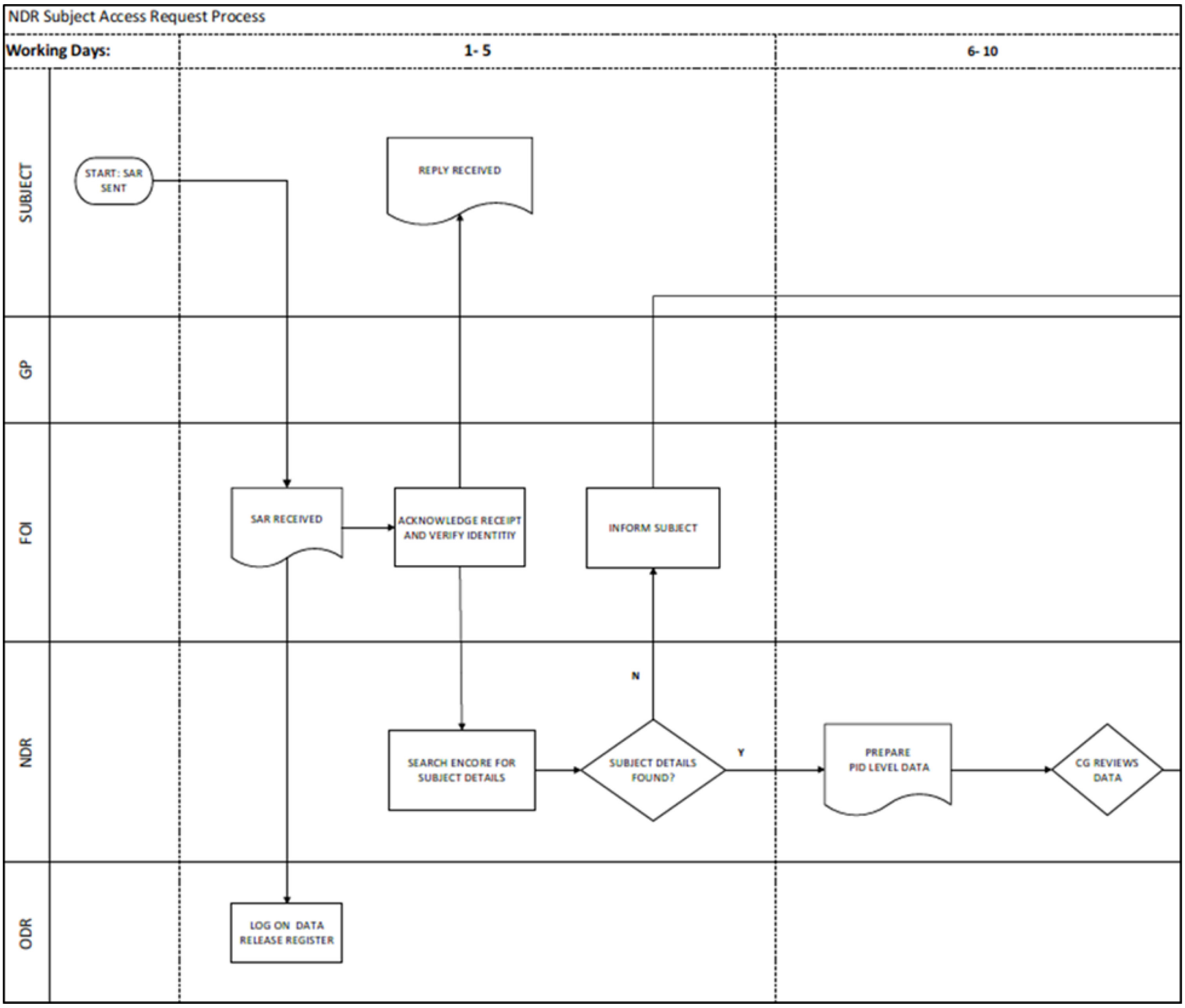
Cancer registration

Why it matters and what you need to know

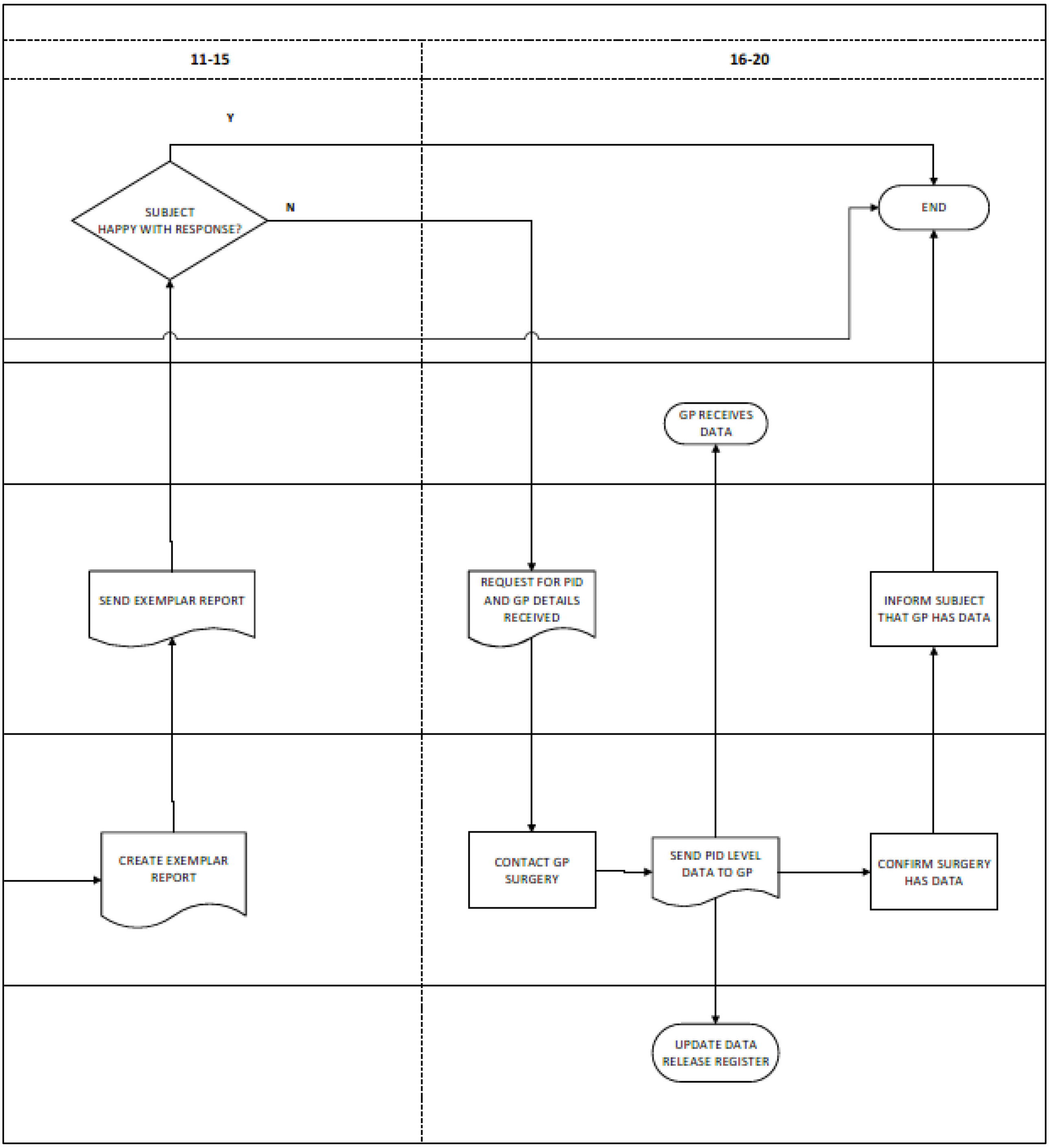
Appendix D – subject access request

The following are two flow diagrams of the subject access request process.

FOI days 1 to 5 and 6 to 10



FOI days 11 to 15 and 16 to 20



Appendix E – NCRAS data quality controls

Automated quality control

The data files submitted through the NCRAS data clearing house are subject to a wide range of additional validation rules to ensure that the data files and data within fields is consistent, as explained in the 5 sections below:

Batch tracing of all cases

All patient-identifiable electronic records are sent to the Demographics Batch Service for tracing against the NHS Spine, where discrepancies are identified, investigated and whenever possible reconciled.

This will not place any additional load on either the Personal Demographic Service (PDS) or Batch Tracing facilities, however the impact will be monitored by the NCRAS as the project progresses with any significant increase being brought to the attention of the RISG.

Use of multiple data sources

The quality of cancer registration relies upon the use of multiple independent data sources to ensure high ascertainment and cross validation, the EnCORE system automates much of the data linkage between the disparate sources - highlighting inconsistencies that can be further investigated.

Cancer registration staff

The National Cancer Registration and Analysis Service employs tumour registration staff at the local registries. These registration staff have considerable expertise in cancer coding and classification and spend much of their time quality assuring the electronic data sources and cases recorded at the registry. In some cases, cancer registration officers work in a local provider organisation, but all registries maintain very close contacts with the clinical teams.

Data feedback to clinical teams

Rapid feedback to the provider clinical teams, usually through the MDT provides an important process of data validation, the NCRAS uses secure web-based systems to deliver reports at a field-level on the completeness of individual data items.

Data quality audit

The UKIACR has developed a large number of performance metrics covering the process of data collection by registries, these performance metrics have been integrated into the new EnCORE system and will (where appropriate), form the basis of daily updates on the data quality and completeness of records held in the NCRAS.

Appendix F – data linkage and data discrepancies

Linkage

Linkage is a complex issue, which has become far simpler in recent years with the rollout in use of the NHS Number. Registries use different linkage methods according to the type of data which is available. In essence, the more data that is available, the more confident that linkage is correct. In fact, linkage comprises 2 parts; blocking and weighting.

Blocking

This takes an incoming record and uses a range of search criteria, determined by the incoming records content, to identify a series of possible matches in the database:

- where the NHS Number is available that is used, but other blocking is usually also applied
- in a manual context, these blocks tend to be sequential, but in an automated setting they tend to run consecutively, with all potential matches passing to the second stage, weighting

Weighting

Weighting can be simple, including:

- deterministic weighting which is used for NHS Number matching – but this is always augmented with at least one other identifier
- probabilistic techniques use a wider set of data matches – and are usually used when the NHS Number is not available on either the source record or the blocked record
- looking for the ‘commonness’ of the data value in the overall database, and then uses that to weight up or down based on a series of random control matches
- probabilistic weighting is a well-defined science, with robust methodologies, however it is used far less than in past years

Data discrepancies

The fundamental principle of cancer registration is that it relies on multiple sources of data. When dealing with multiple sources, many of which may contain a common item, there is likelihood that 2 sources will give different values for an item of data.

The technical design of the registration schema is such that multiple sources and multiple data values are held against the summarised registration record. Registration officers are trained to identify and deal with data discrepancy. This usually starts with some basic data checking with the source data supplier, but where conflicting data exists there are clear rules by which registry staff undertake this.

At no stage is any source data overwritten or lost, and regular checks are included in the registration practice to examine random sets of records as part of the standard QA built into registration practice over many years.

Appendix G – RTDS submission schedule

Data files are required to be submitted monthly, 20 working days after the end of the month for England. A full schedule of submission dates can be found on the RTDS web page.

All files containing data **must** be uploaded to the api portal and all errors on the file **must** be resolved by providers.