



Public Health England

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COSD News

Cancer Outcomes and Services Dataset

September 2019

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New helpdesk

Have a COSD related question?

Please contact the New COSD email address

COSEnquiries@phe.gov.uk

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If you are not on our mailing list or know a colleague, who should be, please

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and we will add you for next time.

Greetings!

Welcome to the latest COSD Newsletter for September 2019. As previously explained, we are not going to produce these on a monthly or quarterly timeframe, but only when we have enough news to warrant a newsletter. This way, we will distill communication to only messages that are vital for you to be aware of.

If you are not the correct person, or if you feel your colleagues would benefit from receiving a copy of this newsletter, please feel free to [forward a copy to them](#).

Warmest regards

Andrew Murphy
Head of Cancer Datasets

COSD Publication.

Following acceptance by the Data Coordination Board (DCB) and confirmation of authority to publish by the Department of Health and Social Care, the official Information Standards Notice (ISN) and related documents will be published in September 2019.

As of April 2020, COSD will go live for all patients diagnosed and treated within secondary care organisations. There will be a three-month rollout period for Trusts to work with their information systems suppliers in order to get the latest versions updated and tested locally. Full conformance is 1 July 2020 (September upload), all records from this point must be in COSD v9.0 and COSD Pathology v4.0 respectively. Any other submission will be non-compliant to the information standard.

It is important for Trusts to work with their information systems suppliers at the earliest possible point to arrange a timely upgrade of their systems, as per their service level agreement (SLA). All other Trusts must work with their local information teams to ensure a smooth transition between versions.

Documentation can be downloaded from the following websites to support the transition between versions:

www.digital.nhs.uk/isce/publication/dcb1521:

- change request
- implementation guide
- information standards notice
- COSD data set v9.0 schema pack
- COSD pathology data set v4.0 schema pack

- COSD data set v9.0
- COSD v9.0 user guide
- COSD v9.0 technical guide
- COSD pathology data set v4.0
- COSD pathology v4.0 user guide
- COSD pathology v4.0 technical guide

These documents are intended to support providers and developers that wish to identify and plan changes to their systems. The standard will be formally issued via DCB as an approved standard and additional documents (for example the data sets, user guides and technical guides), will be available to download via the NCIN website, where a new page for downloads will be created.

Additional support is available via the NCRAS Regional Liaison Managers:

Eastern: marianne.mollett@phe.gov.uk

East Midlands: simon.cairnes@phe.gov.uk

London & South East: katrina.sung@phe.gov.uk

Northern & Yorkshire: laura.prenton@phe.gov.uk

North West: paul.stacey@phe.gov.uk

Oxford: gemma.feeney@phe.gov.uk

South West: james.withers@phe.gov.uk

West Midlands: gemma.feeney@phe.gov.uk

What is coming in COSD v9.0 and COSD Pathology v4.0?

The new Information Standard will go live for data collection from 1 April 2020 with an agreed three month rollout as above to support Trusts and Information Suppliers update their local systems. All Trusts must be using the new versions for all new diagnoses from 1 July 2020 (September upload). It is important to understand that COSD v9.0 (the patient pathway) and COSD Pathology v4.0 have been formally separated within this version change.

Summary of changes

These 2 new versions of COSD (v9.0 and v4.0 for pathology), complete the changes started in 2017 and further updated in 2018. These additional changes were required in order to make the data sets clinically accurate, fully aligned with the Royal College of Pathologists (RC Path) Core data sets and also meet the recommendations within the Achieving World-Class Cancer Outcomes, A Strategy for England 2015 to 2020 (Cancer Taskforce Report)^[1]. This required changes to the standard which include:

- an improved mechanism for recording all 'Non Primary Cancer Pathway' to improve collection and data quality
- some relocation/restructuring of items within the data set
- new sections within the 'Core' to record diagnostic procedures and acute oncology
- the mandation of key data items to improve data quality and reduce the burden of data processing within NCRAS
- the addition of key new data within the Breast and Upper GI site specific sections
- the addition of a prefixed 'p' to all pathology data items along with the removal of all pathology data items from the COSD v9.0 data set, this reduces the potential in future versions of 2 or more data items having the same item number
- update of COSD pathology v4.0 data items to align with the RC Path 'Core' data sets
- a revision of the current schema specification, in order to continue to meet the business objectives of the standard

New data items have been added after an extensive (5-month) consultation was conducted with 40 key stakeholder groups and over 150 clinical experts, including:

- site specific Expert Advisory Groups (EAGs) within PHE

- experts from within the National Cancer Registration and Analysis Service (NCRAS)
- clinical support and advice from the chair of the Royal College of Pathologists Working Group on Cancer Services
- cancer charities (Cancer Research UK, AMMF - the Cholangiocarcinoma Charity, Breast Cancer Care, Living Beyond Cancer and MacMillan)
- patient groups and individuals through 'Use My Data' and the EAGs
- national cancer audits
- cancer and pathology system suppliers
- NHS England
- Cancer Waiting Times (CWT)
- quality surveillance
- cancer taskforce transformation board

This revision allowed the data sets to be clinically reviewed, validated and updated by experts in all fields of cancer, and provides a clinically sound set of data to be collected from April 2020 onwards.

However, it was recognised that there were still further improvements required within this release to improve data quality and to be more reflective of current and future changes in cancer treatments, outcomes and clinical care.

Mandating key data items was vital in this release: to improve data quality and reduce the burden of data processing within NCRAS. If a treatment record for example is submitted without a date or modality, it is of no use as a cancer registration event, however a registration officer would still have to review each incomplete record submitted, this multiplied by thousands of incomplete records per year was an unsustainable practice.

The data set can now be effectively implemented to improve the collection of specific data items within each Trust, by using one of 2 data sets (depending on the department responsible for each data collection process):

- **COSD v9.0** - this is the data set which the cancer services teams need to collect excluding pathology, by removing the pathology data items from their workload this could reduce their burden of data collection by up to 30% across the whole data set
- **COSD Pathology v4.0** - from April 2020, pathology data items will only be able to be reported via the pathology data set using the associated schema packs, this is mandated across all Trusts that supply these data in COSD XML directly from their pathology departments

Wherever possible duplication across the data set has now been removed and full explanations of how to collect these data within the new structure are provided within the change logs of each data set.

Finally, where there were data that are no longer part of a linked national data set (for example, the Royal College of Pathologists), these have also been removed from v4.0 of the COSD Pathology data set.

[1] <http://www.cancerresearchuk.org/about-us/cancer-strategy-in-england>

Changes to MDT pathway

NHS England and Improvement is producing guidance to support streamlining of Multi-Disciplinary Team Meetings. Streamlining is not mandatory but where it is implemented, the guidance must be followed. The guidance will provide information how the new data items in COSD should be completed. As a result COSD has updated and changed the way MDTs are recorded to support this new policy change. All queries regarding this policy change should be directed to the cancer policy inbox: england.cancerpolicy@nhs.net

FIGO staging

Following discussions with NCRAS, the British Association of Gynaecological Pathologists (BAGP) and BGCS Council, we have agreed that we should implement the transition for the purposes of cancer registration data from the 2009 to the 2018 FIGO staging systems for cervical cancer for all cases diagnosed on and beyond 1 January 2020.

This provides adequate time to implement changes to IT system capturing staging data including Infoflex and Somerset, as certain disease stages did not previously exist in the old staging system (e.g. cervical cancer IIIC1 and IIIC2).

In the meantime, we encourage MDTs to document and capture both the 2009 and 2018 FIGO stages for cervical cancers, and the 2018 system can be utilised for the purposes of clinical management. Please inform your

Cancerdata is the public facing web portal, this includes data on headline figures, survival, treatment, patient experience, quality of life, operational performance and cancer incidence and mortality data to be reviewed at population level.

Mandatory or Required - what's the difference (You Need To KNOW)



COSD was developed with a wide range of clinical advice to cover not just the registration data needed for epidemiology but also the clinical and pathway data needed to analyse services and outcomes. Only essential data items have been included in the dataset.

Mandatory items - must be included in the submission. Items marked as Mandatory are relevant to **all** cases and **must be submitted** in order for the XML file from MDT/Cancer Management Systems to pass validation. These are essential in order to identify and link patient and tumour records. For pathology XML files, a modified set of linkage items has been produced.

Required data - "If it's applicable". Not every data item is relevant to every case/tumour diagnosed, therefore we have marked these as "Required". These data items should be recorded for **all cases where they are applicable** and submitted as soon as possible in accordance with the schedule.

Pilot and Optional data items. These do not need to be submitted unless you are taking part in the pilot study or you choose to do so for local purposes.

Conformance. A number of key items are continually monitored for completion. Current completion rates by Trust can be seen on the COSD portal and the full conformance framework can be downloaded from the CancerStats Portal <https://cancerstats.ndrs.nhs.uk/>

For any COSD related enquiries, please email COSDenquiries@phe.gov.uk