

Cancer Outcomes Services Dataset (COSD) Combined Group Discussion Feedback

The following points were raised from colleagues from NHS Organisations (Primarily NHS Trusts), who currently either collect or are responsible for the collection and submission of COSD data.

These comments will help the Head of Cancer Datasets in Public Health England (PHE), and developer of the COSD, understand the issues within Trusts and guide the development of the next version change (v9.0) of COSD in 2020.

I have tried to group issues from across all the roadshows to help answer/highlight issues as follows:

Is there too much Clinical Information/not enough clinical support/Difficult to Collect?

Buy-in from clinical teams:

- No buy – in from clinicians
- Clinical buy-in and engagement is much easier for the tumour sites with specific national audits/datasets
- Awareness + buy in from clinicians
- Buy in at different MDTs - By lead affects ability to collect live at MDT
- Lack of MDT buy in makes collecting data difficult

Getting buy-in from the clinical teams is important at all Trusts in order to get the best data and validate the outputs. Throughout each process of updating COSD, I have worked with all the Site Specific Clinical Reference Groups (SSCRGs) to help understand what is required by each speciality. This reduces unnecessary collection of data that will not be used for national analysis and provides a direct link into current MDT practice.

NCRAS also has a team of Data Liaison Managers, who also work with Trusts and Clinicians to help engage them, improve buy-in, completeness and accuracy of data submitted.

Engagement at MDT:

- Difficult to engage clinical staff
- CTYA, Lack of clinical support
- Clinician engagement – Accuracy
- Clinical team support – or lack of – additional information requests, clinical time constraints
- Should be clinicians lead collection
- Clinicians time to forward information (staging)
- Clinicians not engaged
- Clinical team are more engaged if there is an audit
- Clinical engagement – Hard to get surgical margins – They want the outcomes
- Engagement from Exec + Clinical Team
- Some clinicians assume their data is perfect
- Clinicians doubt validity of data for multi-trust pathway
 - *Where there are multi Trust pathways, NCRAS would receive a record with varying levels of data in each. A series of highly trained registrars will then collate these together to form a national cancer registration record (at tumour level), and QA all the data for completeness. Any queries are taken back to the Trusts for clarity.*

- Clinical commitment , this is really difficult to achieve
- Clinicians don't always see any clinical value of COSD- Just receive performance based info on CWT. * Cancer Stats could help
 - ***NCRAS is not allowed to publish or link COSD with CWT***
- Clinicians not prepared to commit to P.S Because not seen patients
- How important do clinicians find this?
- Too much clinical information required
- Quality not quantity P/S , staging, More clinical support
- Staging too complex (not for administrators - Should be clinical function)
- Training the clinical team – understand the dataset and where to get in.
- Responsibility to collect data? Clinicians, CNS, MDT, and prioritisation of what to collect

We are working hard with every update to reduce the dataset (wherever possible) and reduce duplication where it exists. There is also ongoing work to engage clinicians all the time through the NCRAS Data Liaison Managers.

Engaging the clinicians to support the cancer services teams is very important, and we can do this in part by providing a dataset and reports that support their MDT, thus making them more likely to want to improve the data collection and accuracy of data submitted.

There needs to be a happy balance between the two and unfortunately I do not have a magic wand to fix this, however I am always listening to people to improve the dataset and for the next version change in 2020. I am planning to remove data that is simply not collected (for whatever reason – unless absolutely vital), and for these we will have a new push to improve them. Simplifying data collection is high on my priorities, and this work will be in part based on discussion we have had at this year's roadshow.

Clinical Champions:

- Demonstrate relevance of datasets to clinicians (national audits) to encourage ownership
- Data champions / leads + CHS buy in – encourage this both management + colleagues maintaining interest in spite of daily challenges
- Funding for clinical fellow as clinical champion

Ideally we would like to have clinical champions at every MDT who work closely with the MDT/Pathway coordinator to ensure that all data is accurate and complete. We do appreciate that is not always possible, but where this does happen we see an improvement in data submitted by the Trust. Indeed in some Trusts we have systems which will only allow the clinical teams to enter certain clinical data.

There is no national funding available for this, however it make be a good idea to approach your new Cancer Alliance to see if they can support this?

Other comments:

- Clinicians input is extremely useful
- Not sure clinicians/coordinators understand how best to give data
- How much do clinical teams engage with MDTs/help with data
- Clinical data by MDT co-ordinator
- Haematology – need to understand data requirements
- Mesothelioma staging – lung

- Training/Support
- Lack of training on CMS/Dataset-what teams must vs need to record
- Resources – no. of different people, different jobs/roles involved to produce a complete datasets
- MDTs – expectations too high. Clinical responsibility
- Smoking & Alcohol – needs to be collected in clinic OPA
- Knowledge – Specialist Areas, Trackers cover multiple sites. So can be difficult if their skills are lost or overburdened
- Lung Team have a template to collect at MDT
- How does COSD influence actual clinicians practice
- Not always recorded so have to dig for information, cross trust pathways difficult to get information
- Disagreement of provided stage clinically – feedback would be welcomed if issues when registration for COSD/cancer stats
- Skillset to use system/understanding of dataset not there always
- Too large – GOSH fields not relevant to PAEDS
- Extra data for audits/duplication

Wherever possible COSD has removed duplication and this includes linking with some of the audits too. Lung and over half of Prostate items are now collected and reported within COSD and work continues to try and refine all data with other audits, to enable collection once and then these data available to be mapped for different reporting requirements.

All these comments will refine the next version of COSD and in turn reduce the current burden of data collection upon Trusts.

We have already provide a series of staging sheets to support the MDT (via the CancerStats portal), including Mesothelioma.

Using the data collected through COSD and other cancer datasets (SACT, RTDS and some audits), NCRAS creates a unique and detailed picture of cancer both at a patient/tumour level but also at a local, regional and national level. By linking these to other factors (e.g. age, stage, deprivation and date of death etc.), we can use these data to improve future decision making around cancer treatments and outcomes.

The support of every MDT/Pathway coordinator and clinical team at all the Trusts who submit rapid and timely data through to NCRAS (via COSD), is very much appreciated. This is vital, high quality data that really does make a difference.