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:

General Discussion

Recurrence:

- Difficult data? Clarify over what is progression – not always clinical consensus but this is nothing COSD data collection can address its cons
- Is recording progression again a data burden?
    - ***By separating Progression, Transformation and Recurrence, it is hoped that data will be easier to collect. It is important to always seek clinical advice if uncertain, but this now provides a tool to record these three different pathways accurately***
- Clarification of scenarios of progression vs transformation
- Definition of recurrence
    - ***There are definitions of recurrences in the user guide starting from page 21, however you should always defer to the Clinician's opinion when recording this correctly (especially if not clear)***
- Recurrence recording potential problems –radical / treatment record to capture? MDT time constraints
- Recurrence addition is good, but need to be clear who completes – systems not set up to capture (not all patients will be discussed at MDT)
    - ***We accept this and this is why we do not use COSD as the only source of data in creating a cancer registration record on a patient. What COSD does now, is allows the Trust to accurately record a recurrence at the Trust if they have that information***
    - ***Every patient with a new diagnosis of recurrence and every recurrence must be recorded by the Trust. This is mandated and was a major part of the 'Achieving World-Class Cancer Outcomes (A Strategy for England 2015-2020)' report – Recommendation 90***

Feedback/Reports:

- Need responsive and relevant dashboards
- Feedback to and engagement with clinical teams re what is being done with the data and benefits of this could improve data completion and quality
- Is everything on COSD submission reports used?
- Where is the data items presented?
- Responsibility for ownership of data collection of feedback to Trust from Cancer Registry
- What impact is data on CancerStats having

- Show clinical teams the benefit of COSD
- Knowing the most important data items/high return
- Information in public domain engagement
- Responsibilities of data + sharing this out *being mandatory*
- Lack of info from team, use case studies of good practice
- Feedback to Trust when their data is used in reports on news etc.

NCRAS has for several years now been providing monthly reports on conformance, looking at staging, performance status and, Nurse Specialist (via the regional Data Liaison Manager). These have also been separated by overall Trust and then by MDT and ranked by top 25 and bottom 25 in the country.

We have however also recognised that these were not getting circulated to the clinical teams and MDT Leads, which is a shame as they could help drive up engagement. The data used for these reports comes from CancerStats and looks at the level 2 reports which the data is sent from each Trust in their monthly COSD submissions.

With CancerStats2 and the improved engagement with the NCRAS Data Liaison Managers, we hope to support Trusts even better. There will be graphical representations of the data and more information reviewed and analysed. The system will also allow us to tailor reports to individual's needs, so it is important for as many people (especially clinicians) to get access to this web portal.

In three years of the first CancerStats portal we saw staging go up dramatically, along with performance status. These data are used within regional, national and international benchmarking projects and a vital part of the cancer registration process.

Staging

- No staging on Radiology reports
- Inputting staging data is difficult in multi-provider pathways – who is responsible?

The staging for pre-treatment should be the MDT 'agreed' stage, which includes (where available) radiology, clinical and pathological staging combined (regardless where this took place). If the patient's care plan MDT is agreed at your Trust you are responsible for that stage. In v8, I have also added the Trust code along with the Date for the stage. Remember that you only have to report two stages (excluding the pathological one):

- ***Pre-treatment TNM - this is where after all the individual tests have been done (wherever they took place) and the MDT agrees that there is no more tests required to stage the patient and agree the treatment pathway, the pre-treatment TNM would be agreed here***
- ***Integrated TNM - this is after the first treatment where the first treatment is surgery, this would be the responsibility of the treating Trust to complete this***

Training and Resource

- Lack of training on CMS/Dataset-what teams must vs need to record
- Lack of resource – knee jerk reactions for resource allocation
- Need more education/resilience for MDT coordinators
- Support from National team clinical admin
- Overheads, clinical ownership and time available to collect data all issues raised
- No benefits/no incentives to impact data across 12 tumour sites

- MDT collection currently best placed but long term structure to be examined
- MDTC Training/recruitment/retentions issues
- Investment of time/hard work effort against length of time in use
- Training of new staff, Takes a long time to understand a site/ clinical info
- Understand pathway – Expecting tests etc. what is mandatory vs "nice to have"
- Understanding of where dataset come from and why being collected
- Changes increasing burden on staff with both COSD/ CWT – Same staff, no extra resource
- Collection – Skill and Knowledge (person)
- Manpower/grades of staff clinical buy in essential
- Is the cost worth the effort?
- Cancer resources are tight
- Being mindful of pressures in Trust
- Important to maintain momentum, keep interest
- Recognition of burden of work – allocate funds – need for IT rep in cancer services.
- Challenges with the Trust with work structure
- Accredited training/professional status for MDT coordinators would be helpful to develop and retain workforce
- Biggest barrier is people's time; Variance in resource
- Right time to collect

Most of these are local training issues. The User Guide helps explain at what point the data should be collected and gives a more detailed description of each item. The NCRAS Data Liaison Managers are also available to help and support Trusts with advice but we currently do not have any specialised MDT training packages you can hook into.

Unfortunately retention of staff and providing extra resources for you is not something that I have, however I can assure you that the work that you do and the data you collect, is an important part of cancer registration nationally. These data then go on to be part of many important analyses at regional, national and in some cases international benchmarking projects.

Together they provide an important understanding of cancer and its impact. 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.

<u>System Suppliers</u>

- Usage depends on Cancer MGMT system
- Linking PAS into Somerset – Other systems
- Automated systems – all dependent on manual input, "direct from source" entry
- Auto – populating of data from links systems would help
- Interfacing systems would be amazing but not if you are changing one type of admin for another (i.e., instead of copying data manually, selecting reports to link manually)
    - ***COSD is not providing any interfacing, certain information suppliers are working on this but these will be (paid-for add-ons), I believe. You would need to discuss with them the pros and cons for your service***

- Improve data sharing for patients with shared pathways
- Improvement integration of systems –within Trust and also between IPT – inter provider transfers
- Link for tertiary centres – electronic access
- Extraction of data complexities – functionality – overview as appeared to multiple views
    - ***This is a supplier issue and something the Trusts should engage with their Info Supplier to improve***
- Little support from DH on systems
    - ***Neither DH nor NCRAS can dictate or recommend one system over another as this could cause local legal challenges from suppliers if they did. This must be a locally driven decision, however discussions with a good performing regional Trusts is recommended to see how they have overcome challenges***
- Reliant on system providers to implement in timely manner. Someone has to be last so it is hard to train staff
- Lots of info to be recorded, lots of duplication in Somerset, Question of whether when low completion is it then worth completing? – Efforts could be focused on key data items
    - ***All data will be reviewed to address this very issue for v9***
- CNS making a big drive to improve at Chester CWS. Find Somerset is not very CNS friendly – don't find it easy to record. Use their hospital administration system to record instead. Bolton find it fairly easy to use
- Remove ability to record Data item in 3 or 4 places – not good when you spend a lot of time filling in but CS1 show completed
- Service/IT issues – Cost for info flex upgrades
- MDT lead meetings to - software developers – assist in making system more intuitive
- Somerset – Red, Green, Blue dots – where fields have all fields ticked are they necessary?
- Internal IT Issue – SCR upgrades
- Info flex reports not good enough locally
- SCR should be part of ALL referrals, Medications, etc., Private GP scans and reports
- Will SCR be ready?

Both SCR and Infoflex will be ready and have upgrades available for you to record data before the 30th June deadline for compliance, with all the changes coming in their spring upgrade (Mid May) along with the CWT change update too. It is important that all Trusts speak to them with some urgency to arrange their upgrade date.

If you have issues with certain functionality within your systems, talk to your system supplier. As a region if there are many Trusts using the same system, you have a bigger voice approaching them from a regional stand point. Perhaps working with your new Cancer Alliances or Vanguards will also help?

National Dataset/Audit Alignment

- Systems more aligned
- Roll out of cancer system – one source
- Realise if not collected in COSD well be in danger of spawning more audits
- 1 System (government mandate!) as an NHS organ
- Audit Data better
- Duplication due to multiple information systems
- NPCA submission separate to COSD file

- Too much duplications
- Start with purpose of dataset, clinicians interested in audit. Not COSD. Lost Networks so less clinical groups, less pressure at clinical events/conferences
- Poor engagement; Lack of understanding (Haem/Breast); Haem interest in trails datasets

The overwhelming discussion from every roadshow was around linking all the cancer datasets together e.g. COSD and all the cancer audits. This has huge benefits and we have seen from Lung, where there data does now get reported in real-time, the quality of data and ascertainment has improved substantially. In addition it also engages the clinicians too.

This is a long-term ambition of mine, but as the Audits are independently funded through HQIP, this is not an easy process. I am following this up with further discussions within Public Health England, on the back of the roadshows and your discussions.

I have removed wherever possible duplication within COSD, and I will again have this as my first priority when reviewing the dataset for v9. I do understand that there is duplication across datasets (COSD vs Audits). I have been working with the audits on this and also CWT, so hopefully many of the duplication you see now will disappear over the next 12 months.

Sexual Orientation/Gender

- Person specified Gender – unnecessary work, manual for every PT, doesn't link to ERS
    - ***Most Trusts data links to their PAS so this is only collected once at the point of record creation and not manually. I cannot comment if your system is different?***
- New field – sexual orientation, Why included? Will there be more like this? What does it mean?
- Sexual orientation – GP responsibility? Part of referral, what is the benefit

This is a new standard which every Trust in England will have to comply with. This is not a COSD item, but has been requested to be linked (though the PAS interface) as there is evidence that some LGBT people face difficulties accessing services or treatments for cancer. This has been set as optional until 2020 so Trusts can start reporting when their local systems are up-to-date.

IG Issues

- IG risk around certain demographics? Expectation/realisation of where it goes

There is no IG risk for supplying any data to NCRAS through COSD. NCRAS has section 251 approval so can collect these data without patient consent. In addition NCRAS complies with all the relevant UK and EU laws on IG, Data Protection and GDPR. Without this level of patient data and information security, we would not be able to provide many of the vitally important functions required of us by government.

MDT/Patient Pathway Concerns

- Moving to live Data collection
- Got to chase other Trusts – is this necessary
- Data not moving around sufficiently between Trusts
- CNS data – sometimes second Trust does this
- If patients are not treated within their Trust, they would like to be able to leave it blank – however currently it effects their compliance

- IT resource to help transfer data between systems
- Difficult to get surgical data for PTS referred out
- Collect duplicate data for tertiary PTS when referred out

Although these may (in the overview data submitted) be duplicated, the information is in many cases required at both Trusts to manage the patients pathway effectively. Within COSD, you can now state which Trust did each step of the process (including stage from v8). This will help understand the pathway easier through local, regional and national analysis.

Pathology and Dataset re-design

- Pathology Hub –Change of system
- Data not always available histology for example, Needs more "shop floor" representation from clinicians
- Concerns around the need to still collect path data for local reporting needs. Data burden – not removed
- COSD Pathology section being separated good thing – reduce chance of human error
- Removing path from MDT COSD doesn't remove for non-COSD audits

The suggestion here is to reduce the burden of data collection through COSD by not having to record and transpose very complex and difficult reports. If these reports can be sent directly from the pathology lab, then the data is more accurate. Sometimes some data is still required in local systems for patient management or as you say for other audits. COSD does not have control over these audits as they are independently funded by HQIP.

Other:

- Is there scope for Royal Colleges to promote use of the datasets/demonstrate their value?
- Data input is as good as what information is given to MDTC (Co-ordinators)
- Dataset never too big, but doesn't cover whole pathway
- Tangible effect on patient care
- Disparities about how to record – might mean lost data
- Equal representation across tumour sites
- Turn around for results + recording real time
    - ***There is already a 25 working day after the end of each month for recording and data can be collected and reported at each stage of the pathway to help with this***
- Are Senior Managers aware of the changes?
- Are Teams aware of ALL the changes?
    - ***All changes are circulated directly to Cancer Managers and as many people within the Trust as possible, via newsletters, regular contact with cancer teams by NCRAS Data Liaison Managers and roadshows. There is a reliance on the Cancer Manager to escalate changes within the Trusts, many senior managers attended the roadshows this year***
- Usefulness of data items locally
- Trust are not just cancer focussed - Needs to benefit the whole Trust or at least elsewhere (i.e.? up time in pathway)
    - ***I understand your point however we are only legally allowed to collect and store data on patient who have a registerable disease***
- Clearly see benefit of collection and importance – don't always see direct correlation.
- What is the value? Benefits for patients/pathways?

- Some Trusts on lower version of COSD, i.e., V6
- No repercussions for poor COSD completeness
    - ***There are potential penalties for non-compliance, but as yet these have not been applied. These are within the remit of each local CCG and their Trust and not within the remit of the COSD Governance Board***
- Must have CQUINS for focus, execs will pay attention then provide funding to meet
    - ***I agree and this is something we are going to have discussions about, although I cannot promise that they will be forthcoming***
- Site Specific data, SSCRG's to decide, but need to monitor actually using it
    - ***This is the current process, but I also consult with over 48 different organisations and individual groups before any version change and dataset is signed off***
- Hard to input a date when you only have the year of diagnosis to close the episode – now an issue when lacking at research
- Standing agenda items on Cancer Board Agenda – P.status; Stage; Recommended/Key points; Small datasets
- Expanding why and what used for
- Lack of awareness at senior level- focus on performance/CWT- no target *early stage performance
- How does Cancer data compare to diabetes?
- DI Team 1-2-1 visits are useful
- Lots of different fields – Definitions need to be more explicit especially for tertiary centres 'who is specialist first seen'?
- Increase in patient numbers with same or less staff?
- Clinical trials – Where will this data come from and what will it be used for? Is it useful and can the trials teams collect this? How is it going to be reported?

The working groups at the roadshows were incredible and created a huge amount of interest and important feedback for me. All these comments will refine the next version of COSD and in turn reduce the current burden of data collection upon Trusts.

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.