

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:

Reporting/CancerStats

Patient Level Data

- Give patients level data back to Trust
- PT level data/ Identify PT: Missing data

At this stage we are unable to get our data reported at patient level, but this is still something that is being looked at as a longer term project. Identifying missing data is difficult as many patients move between Trusts for investigations before and after diagnosis and treatments. CancerStats2 will give us a better platform and more data to look at and link.

Trust Level Data

- Start at Trust/tumour site level

CancerStats allows each user to set their own level of reporting through a series of menus, this does allow for Trust/Tumour site reporting.

Survival/Mortality Data

- Mortality rates at Trust level, more clinical engagement
- Trust Level mortality/Survival rates, Mortality by Trust will help to engage clinicians
 - *This is incredibly difficult to ascertain who is the responsible Trust? Is it the one who diagnoses the patient or the one where the patient died after treatment (within 30 days for instance where different)!*
- Ovarian Cancer would like to collect more data – mortality data
 - *This may already be available but not at Trust level. If specific work needed talk to your regional NCRAS Liaison Manager for added support*

Reporting and Feedback

- Compliance – Quarterly/monthly
- Poor update on analysis
 - *CancerStats produce monthly reports within 2 weeks for the data being submitted from the Trust (Level 2). In addition separate monthly reports are created and circulated to every Cancer Manager by the NCRAS Liaison Managers. NCRAS unfortunately cannot control the circulation of these reports within the Trust, but would recommend that everyone have a user account for CancerStats2 as all the reports will be in there from later this year*
- Improved feedback for data being sent in Audits being run in COSD/aligned to COSD reduced duplication
 - *Full reports already available to Trusts using CancerStats for NLCA and NPCA as well as COSD. Later this year the NABCOP will also be there*

- Feedback data – PHE cannot mandate data & not share the results
 - **All data is mandated through the standard and the data is shared through CancerStats and other sources with cancer managers and clinicians where requested. Please speak to your local NCRAS Liaison Manager for more information**
- Clinician engagement/buy-in with audits but not otherwise (generally) conformance data received but not feedback on tumour groups
 - **This level data is available within CancerStats and Trusts can tailor their reports**
- CancerStats – show benchmark against other European Countries
 - **This is not the purpose of CancerStats, however this work is done within Public Health England, and you can find some really interesting reports within the following webpages... <http://www.ncin.org.uk/publications/>**
- Value of conformance report?
- Feedback on more data that is submitted, Need more of the two-way process
- Feedback to teams – data compliance
- Better reports for clinicians
- Feedback with context and clinical relevance to local teams
- Who is doing the best at staging (current level 2 reports); please can we keep this going?

Overall there are many reports already on CancerStats which are not being used within the clinical teams. In addition monthly reports are created (at trust and MDT level) by NCRAS and send to the Cancer Managers at each Trust. In some cases it appears these are not being disseminated to the clinical teams and MDT leads.

CancerStats2 will help to improve this as these reports and many new ones will be available directly from the portal, therefore if the clinicians get themselves access or appoint a clinical champion, these reports will get to the very people who they are designed for and currently don't get them.

Ultimately the improvement of data ascertainment and quality is the goal and this in turn improves many national reports.

CancerStats2

- Cancer stats 2 promising
- Provide clinically relevant data not just “staging” at Trust level
 - **CancerStats2 will hopefully address this**
- Want nice easy reports for COSD – Matt’s presentation – need something easy to give back to clinicians
- Better ways of NCRAS feeding back analysis work to Trusts to see what goes towards
 - **CancerStats2 will do this for you, please get a log on to access these data**

What Do The Clinicians Get Back?

- Population level – needs Trust level and at clinician level
 - **This is difficult as I explained above. We are able to provide some data at Clinician level, please talk to your regional NCRAS Data Liaison Manager for more information and support**
- Reporting back to clinicians
- Not enough national reports made available to engage clinicians, PHE not good at this

- Improvements in data collection within Trusts can be made by sharing reports/data with clinical teams
- Clinician's buy-in/Headline data
- Clinical Validation

Providing more reports is our goal and CancerStats2 will improve this. There are many reports already available, which are not getting to the clinical teams, so we need to work with everyone to improve this.

If there are reports which people think would be useful but not available, talk to Matt Lynch or your regional Data Liaison Manager and we will see if they are possible with future development.

General Comments

- What impact is data on CancerStats having
 - ***There has been a huge improvement on staging and performance status across the country since CancerStats was first introduced to report on COSD data***
- What happens to the data? Reducing multiple systems for data collection – Are all results the same?
 - ***Sadly there are many audits and other cancer data collections within the NHS. Many major software suppliers and now trying to incorporating these within one system and I have been working with my colleagues across many audits to standardise data items. There is obviously still a lot of work to be done but this is a priority***
- Automated submission of data to NCRAS BUT must be confident data is QA'd before sending
- Improving validation processes - email reports for clinical sign off etc.
- Make data easier to extract from CMS
 - ***This must be a prerequisite of all data leaving a Trust to any national audit or data collection***
 - ***Again these should be done in house before submission and discussions with individual Trust cancer information system supplier would help with this***
- Staging from SMDT's – staging allocation performance in cancer stats
- Is local practice around staging reflected in National decisions, e.g., colorectal and dukes staging
- Insufficient time to collect cancer Stats
- Cancer stats is really helpful, v. timely and reasonably accurate
- Data Analyst resource, Is it available?; If available do they cover COSD/cancer services
- Access to Data views
- Risk factors – are clinicians interested in a 3 month history, Will this only be collected when it is significance. Can you get this from 1% care? On referral
- Is resource enough to collect datasets? Is the admin burden too much?
- Helps as a central reference point – needs to user-friendly

There are challenges in collecting the data for COSD, some of this is new within v8 and challenging. Saying that we should aspire to collect it or provide evidence why it cannot be collected. Reducing burden is always high on any developer's wish-list and this will be a high priority again within v9.

It is recognised what a fantastic job MDT and Pathway Coordinators do in collecting the data for COSD and other cancer datasets.

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.