<div align="center">

Cancer Outcomes Services Dataset (COSD)
Combined Group Discussion Feedback

</div>

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:

Things would you like to see added or removed?

Aligning to other Cancer Audit Datasets

- Importance of aligning datasets so stats for one trust are the same, (e.g. COSD/HES etc.) in all reports
- Integrating cancer audits in COSD is good
- Expanding COSD to include other audits such as NBOCAP, HANA, and NLCA etc.
- Joining all other audits, NBOCAP, NOGCA, HANA, NABCOP, Prostate
- Everything, incl. audits in COSD
- Integration of COSD/ audit is good
- All national datasets within COSD submissions
- Better attainment why site specific audit? These aligned with COSD more so
- Bring ALL the audits into COSD, No extra work. LUCADA – NLCA was the best thing to happen
- Why does COSD not feed all national audits, and the national audit be shut down?
- Audits through COSD (validations)
- Audit through COSD only combined data collection
- All audits should come through COSD
- Collect audits once and report to many sources, clinical team are more engaged if there is an audit
- All of the different audits/data feeds – merging then would be best
- All NCASP audits to be pulled from COSD (like lung & prostate)
- Integration of datasets
- Trusts would like all audits to be through COSD – duplications due to audits
- More national audits (able to plan, dedicated resources)

This is a strong message I have been given from every roadshow. Clearly Trusts would like to see all the clinical audits contained within COSD and submitted as a single monthly upload. This has great worth and would (if Lung is anything to go by), massively engage the clinical teams and improve both the ascertainment and quality of the data submitted.

This is not something that I can just do because the audits are funded by HQIP and managed by other leading colleagues etc., however saying that I will start the conversations and see where it takes us.

Risk Factors

- Vaping status
- Should we include diet and exercise levels?
- Smoking status is brilliant - To future proof should we include vaping (??) as separate options?
- What about "other" things smoked (i.e. marijuana)?
- Should we include a diet and exercise levels?

There are so many risk factors we could include, but I have to always try to understand the availability of these data and if they would be easily collectable. I do not want to increase the burden of data collection, but we can always tweak what we have.

Vaping has already been suggested by the Lung Audit, so I will be working with them to see how we add this. Other items like drug use is not a real option as people are very unlikely to admit to this and would be very difficult to collect for the clinical teams.

Diet and Exercise are also very difficult to collect and who would do this and where would this data be stored? I am not convinced that this would be easy to get without adding more burden, although I am always open to persuasion and we could add as a pilot, if there were centres who would like to prove it is possible?

Out of Scope Data

- Primary care data should be captured
- Vague symptoms – Presentations before??
- Diagnosed at GP But discussed at MDT

Currently we have no way of know if a patient was diagnosed by a GP as the dataset only affects secondary care. Most patients are diagnosed at the Trust following a referral from GP. Primary Care data is also collected in many (unstandardized) datasets across the country and this is not practicable to collect through COSD.

- Living with & beyond , Recovery package, Stratified Outcomes, Lost to follow-up
- COSD in the future? – Aspirational request but all the data items required for living with and beyond

These are not possible to collect trough COSD as the data is not available to the primary data collectors, and this would keep patients active on the patient list for months and years, without additional resource adding to the burden on the cancer services teams. These are better collected through PROMS

- Align with national KPI we asked about e.g. LOS
- Should link to pharmacies

LOS is better monitored within Trust using PAS data. There is a separate national project looking to see if pharmaceutical data can be collected and linked to cancer patients, early days on this though.

Other General Comments

- How does cancer data compare to diabetes or other long-term conditions?

- Could submission be quality so that validation and MDT buy in could be managed, better?
- Making readable referral forms to understand symptoms at diagnosis
- Relevant data items- why are we collecting?
- Not keen to add anything unless it has a clear purpose
- Care plan date, agreed date, validation in SCR?
- Information on importance of data items
- Maybe info about what work the data items have been used for

There are something that I cannot enforce but would be something that can be requested by the Trusts directly with Information Suppliers. We are working hard with CancerStats2 to improve the reporting and availability of these reports for the clinical teams.

I am not in a position to compare COSD with Diabetes or other data collections, Heart, Stroke etc., as the data are not really compatible. What I am doing is trying to make the data requested easier to collect and reduce the burden of data collection and duplication wherever I can.

What would you like see removed?

- Remove Pathology from COSD MDT
- Separation of pathology v Pathway data is good
- Duplication
- Reduction in size of COSD

Pathology will be removed from the main COSD extracts v9 (2020) to leave two distinct datasets; Patient Pathway COSD (334 data items) and Pathology COSD (155 data items). In addition I am already working with experts to review the current 'difficult data items' highlighted through these groups (Haematology, CTYA and Lab Results).

I have to mention again that it is recognised what a fantastic job MDT and Pathway Coordinators do in collecting the data for COSD and other cancer datasets. This work is hugely appreciated by me, the cancer registration community and the analysts who use these data.

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.