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 the Dataset too big?

Yes too big

- Dataset too big
- Should it be reduced?
- The data collection is too big, would be nice to have a category of importance so Trust know what to prioritise
- Yes not possible to collect all data items due to available resources, multiple computer systems - Investment in clinical time, MDT support, Cancer Services & engagement
- Dataset is to big – we don't have the man power to accurately and fully collect the data
- COSD – Too Big!
- Is data too big?, yes some data from tertiary difficult to collect If patient goes to more than a Trust staging problematic
- Too big? – Currently yes with lots of duplication, going forward hopefully not
  - *Most of the duplication has now been removed from COSD*
- Quite Big / complex. As a whole, difficult to ascertain what <u>Needs</u> to be completed
- Data set too big – No
- Dataset too big? – No, fit for purpose at the moment
- Dataset too big – removing data items & replacing with others is just "rearranging the furniture". To make it smaller you need to reduce data items and not replace
  - *In some sense that is true, however new items are only added if there is a clinical requirement for them, not just to keep the numbers at the same level*
- Too big – unrealistic expectations!
- MDT Co-ords – To many data items to complete everything
- Dataset is too big, find it impossible to complete everything, Trust focus is always on CWT

Lots of really constructive reasons why the dataset is too big. I agree it is large, but not all the data are required on all patients. The next plan is to remove pathology from COSD and have this as a stand-alone COSD dataset.

This reduces the overall dataset down from 489 to:

- *334 - COSD (Patient Pathway)*
- *155 - COSD (Pathology)*

I will then look to further reduce this if possible based on the feedback from the roadshows and also from the consultation with experts.

OK with changes
- Would like dataset to be as small as possible i.e. really meaningful and critical data items
- Good some things removed

Difficult to collect/resource issue
- Difficult to collect data, not all in one place, different systems to get data
- "priority" of data fields – reduction of burden – duplicating fields, Finite resource
- Need resource – as data get bigger (resource doesn't follow – no finance)
- Lack of input from all disciplines too many data items to collect – resource issues
- Relevant but resources to complete do not match workload
- Needs refining/streamlining
- Difficulty of collecting? – Availability of data/tertiary data/ multiple providers.
- Needs to be aligned with all audit to reduce duplication
- Difficult to go back and input missing information (time/capacity)

There is a resource issue I appreciate and with the new CWT changes, this will be further squeezed. I will be doing everything I can to make the collection process as easy as possible in the next review.

Pathology
- Pathology – Out…..Make it a separated entity
  - *This will be reviewed for v9*
- Need automated systems to populate e.g. pathology
- Imaging & Pathology difficult to collect - Do we go to cost effect of developing interfaces
  - *Some suppliers are looking at making this easier with interfaces, (but will not be free)*

Size OK
- Size ok, matches flow of patient pathway
- Size is fine but need to regularly review
- Dataset never too big, but doesn't cover whole pathway

There is only so far COSD can go in collecting the whole patient pathway. Looking at follow-up or events that may happen in the future, it is not practicable and should be covered in a dedicated Patient Reported Outcome Measure (PROM). Equally I have to ensure that something can actually be collected and understand who is going to do that collection.

Some clinical data should have the support of the clinical teams, consultants and nurses etc., but do not have to be completed by them, unless local systems and protocols are in place to allow this to happen. A good team, with good communication, with the data managed by a MDT/Pathway Coordinator are equally as good at returning excellent data.

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.