<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:

Fields most Trusts don't complete

CNS:

- CNS not well informed about COSD; concern CNS fields may not be completed – Training?
- CNS data – but now mapping (was system issue)
- A lot to fill in for CNS

We have recognised that there was confusion with some of the CNS items and we have worked hard with the major system suppliers to correct this. By grouping all the CNS together this gives ownership of these data and hopefully will engage the CNS teams in collecting the data.

I appreciate that I have added some new items in v8 which may be difficult to collect (Smoking Status on all patients and Alcohol consumption), but these are serious risk factors we need to understand more about. Also recording the height and weight of patients will allow us to understand the BMI and impact obesity may have on cancer too at a granular level.

Risk factors were prominent in the 'Achieving World-Class Cancer Outcomes (A Strategy for England 2015-2020)' report. I hope that we will be able to support national analysis through the excellent data we receive through COSD.

Performance status:

- Performance status can be difficult to compete
- Performance status – different places to enter data – only want to enter it in one place
    - *This is a local issue with your IT supplier*
- Performance status good but different
- Performance status – MDT Struggle to collect
- Performance status concerns, hard to collect – oncologists love this. They find performance status a bit too subjective – makes it wrong or inconsistent – this is probably worse than leaving it blank

To help keep this stable, COSD has always asked for performance status at diagnosis (and only reported once), rather than at the point of every treatment. This then allows for accurate analysis across all patients.

Haem Fields:

- Too many data points – Most data not easy to find. Not discussed at MDT
- Resources restrictions for data entry/integrated. IT systems, make it difficult

- Haem – All Ann Arbor, Binets & Rai Stage – Addenbrookes
  - ***Rai Stage was retired from COSD in v7 (Apr 2017) on the advice of the SSCRG***
- Haem Data - Too Complex, Requires lab data, Needs clinical analyse impact
- Haematology – especially diagnosis (concerns re: transformation/progressions)
- Haem Difficult to collect – Range of sites
- Haematology difficult to collect (knowledge)
- HAEM can be complex
- Haem difficult to collect data (staging)
- Haematology difficulty – accuracy of data
- Haem data – complex, difficulty in interpreting clinical information into ICD03 etc., which can then effect what is collected

It is understood that Haematology data is difficult to collect and in some cases can be complex. Return rates vary between item and Trust so a complete rethink is necessary for the next version change in 2020. I will be working with experts in this field (both clinical and analytical), together we will provide a better selection of data for collection.

Lab Results:

- LAB results not discussed at MDT
- Lab - sometimes the measurement on the local cab system is different to SCR

Lab results has for a long time been a difficult item to get. It is not as easy as just getting these from the path labs, as they are difficult to interpret (as you all know) and nationally we would be swamped with results if they are not effectively coded.

This was why originally it was decided that it would be the MDT who were best placed to discuss these and note what needed to be collected. I appreciate that the MDT's however are too busy to do all these tasks and effectively manage the patient's pathway.

I will be reviewing these along with the Haematology and CTYA data to try and improve this for v9

CTYA:

- CTYA, Lack of clinical support

I am meeting with senior clinical and analytical leads to discuss how we can improve CTYA data items being requested currently through COSD. Ascertainment for some data-items are incredibly low and this whole section needs reviewing.

Saying that, we need to keep some of these data as they are vital but we need to be more understanding around the issues in collecting these data first.

Other:

- M Stage: Difficult to collect in MDT meeting- Radiologist not reporting on notes
- Sarcoma staging, trouble getting staging from tertiary centre
- U/S, C/T before staging. Lengthy process. Need clinical lead buy in Not all at MDT
- Question – Why do we not get this? source
- Already being collected - can this be linked up?
- Info collected eventually, BUT only 1st MDT sent to COSD

It is never possible to get everything right in a dataset the size of COSD, nor can you satisfy every clinician that what is requested is really important and their support vital in this process. NCRAS through its teams of Data Liaison Manager are working directly with Trusts to try and bridge these areas.

Further work is ongoing in the background at a national level with system suppliers, clinicians and analytical teams to redefine the dataset to make it easier to collect and reduce the burden of data collection wherever possible. CancerStats2 will also help with better reports directed and tailored at the MDT and clinical teams.

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.