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Welcome

COSD Roadshow 2018

Taunton

28th February 2018



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Introduction

- Andrew Murphy (Head
- Your Local National Cancer
- Fire Alarms & Fire Exits
- Toilets
- Telephones – Please call
- Delegate Packs
- 5 minutes to introduce e
- Agenda for Today ➡

09:30	Reception, Coffee and Registration
10:00	Start Morning Session - COSD What's in COSD v8.0 (Q+A) – Andrew Murphy
10:50	<i>Comfort Break</i>
11:00	Round table discussion What works, what doesn't, future changes (Additions, Deletions + why)
11:30	Open discussion on suggestions from round table work
11:45	The New CancerStats2 Reporting Portal
12:10	National Cancer Audit Presentation (to be agreed)
12:30	Lunch + Networking
13:15	Start Afternoon Session - CWT The new CWT system System changes (incl. system demo) How to access data in the new system and reporting functionality (iView+) What is the National Cancer Waiting Times Monitoring Data Set v2.0? Dataset changes and additions Inter-Provider Transfers and breach allocation The 28 day Faster Diagnosis Standard What is the new Standard? Faster Diagnosis Standard items Implementation plan to 2020
14:15	Panel Q&A (with presenters of above sessions)
14:45	<i>Comfort Break</i>
15:00	Round table discussion What works, what doesn't, future changes (Additions, Deletions + why)
15:30	Open discussion on suggestions from round table work
15:45	Finish



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The Importance of Working Together

Andrew Murphy
Head of Cancer Datasets

National Cancer Registration and Analysis Service (NCRAS)
Public Health England



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Who are NCRAS

- NCRAS are the National Cancer Registration and Analysis Service.
- We collect data on every patient who is diagnosed with a registrable Tumour in England
 - 350,000 new cases registered each year
- We get data from COSD, Pathology, PAS, SACT, RTDS, HES, Cancer Audits and ONS (death certificates)
- This allows us to do some fantastic analysis at Trust, Regional and National level
- I'm here today to outline the changes to COSD v8, and hopefully encourage a closer working community, improving data completeness and quality



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Overview - COSD

- The Cancer Outcome and Services Dataset (COSD) is the largest 'Cancer Data' collection process in England covering all tumours diagnosed and treated in secondary care.
- The Dataset has been reviewed and wherever possible the agenda set by all the National 'Site Specific Clinical Reference Groups' (SSCRG's), National Cancer Intelligence Experts and the COSD Advisory Board (which includes Trust representation).
- The dataset has a CORE and Pathology section, which requires data to be collected on every patient and then 13 site specific tumour groups, which require data on specific tumours (but not on every patient).
- Certain data are monitored to improve data quality and completeness



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Clinical Support Essential

- MDT/Pathway Coordinator and Cancer Services provide a huge support to all the MDT's and submit data (collected in real-time) to the NCRAS
- Some data needs Clinical Support, via the MDT and clinical teams (including the Nurse Specialists)
- Ideally live data collection at the MDT is the best process, but we know this is not always possible. Therefore discussions and decisions made at MDT need to be clear and easy for data collection
- Cross dataset collaboration is required (including National Audits), to prevent duplication of data collection. Most Trusts use the same systems to collect data (Somerset/Infoflex) and then report these separately – Collect it once but report these across many datasets (COSD/Audits/CWT)



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←

https://www.cancerstats.nhs.uk/

CancerStats

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Constant Contact Mobile ... Google CancerStats CancerData NCRS Outlook NHSmail NCIN COSD - Data Dictionary SCCI1521 ISCE BAAS PHE-ESR PHE Farm ihtsdo.org SCR (2) International Classificatio... SACT Homepage the IG Training Tool Civil Service Learning

CancerStats Incidence Mortality Survival COSD NLCA NPCA RTDS Clinical Headline Indicators CCT

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Incidence > An incident case of cancer is a new case of cancer, counted once when the cancer is diagnosed. Base numbers of cases, crude and age standardised rates can be found by following the links below.

Base Numbers

Click here for numbers of new cases of cancer. Numbers can be presented for different cancer sites, different time periods, and different geographies. Numbers are useful when trying to estimate the burden of cancer - how many tumours have been diagnosed?

Go!

Crude Rates

Click here for crude cancer incidence rates. Rates can be presented for different cancer sites, different time periods, and different geographies. Crude rates are useful when trying to compare the incidence of cancer in two populations. Because of the strong link between age and risk of cancer, crude rates are often highest in populations with a high proportion of elderly people.

Go!

Standardised Rates

Click here for age-and-sex standardised cancer incidence rates. Rates can be presented for different cancer sites, different time periods, and different geographies. Standardised rates correct for the difference in incidence in cancer because of age and sex. They are useful for comparing underlying cancer risk in populations with different age/sex profiles.

Go!

Incident cases of cancer are counted for each separate primary tumour. One person may be diagnosed with more than one tumour, and would then appear twice in the incidence statistics. Recurrences of a previous cancer are not counted as new incident cases.

Incidence data for England is currently available to the end of 2014. The latest year for Northern Ireland, Scotland and Wales data is currently 2013.

Standardised rates are standardised according to the 2013 European Standard Population.

Data presented are taken from the National Cancer Registration Service Cancer Analysis System, snapshot CAS1602.

Populations data has been sourced from:

- England and Wales: [ONS Mid-2014 Lower Super Output Area Population Estimates](#), released 25/11/2015.
- Scotland: [National Records Scotland Population Estimates Time Series Data](#)
- Northern Ireland: [Northern Ireland Statistics and Research Agency Population and Migration Estimates 2014](#), released 04/06/2015.

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14/11/2016



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Challenge Your Data

- It is important that each MDT reviews their data submitted by the Trust to NCRAS, and having a clinical champion provides strong local leadership.
- Using the portal provides greater support and has already been adopted by other Audits?
- You can view:
 - Incidence, Survival and Mortality data (at population level)
 - COSD (at Trust, Tumour and element level)
 - NLCA (Lung)
 - NPCA (Prostate)
- Coming soon is 'CancerStats2'
 - and we have a presentation later this morning to demonstrate the amazing power of this new reporting portal.



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Next Phase

- COSD v8 has been reviewed for a launch in April 2018
- Careful consideration has been taken around removing any duplicated data item(s) throughout the dataset, or adding new data-item(s) that are required to support clinical audit dataset(s)
 - Examples here are:
 - pathology, where a data item has been removed from the Royal College of Pathologists (RC Path) core datasets, at Tumour level
 - where new data items are required to support e.g. National Lung Cancer Audit (NLCA) and National Prostate Cancer Audit (NPCA)
 - where staging or other fields are now outdated and require updating
- All these changes are required to ensure that COSD continues to be clinically accurate and relevant.



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Building on the work started in v7.0

- Extensive consultation was conducted over a 6 month period with 47 key groups or clinical experts including:
 - all the Site Specific Clinical Reference Groups (SSCRGs)
 - experts from within the National Cancer Registration and Analysis Service (NCRAS)
 - as well as Clinical Support and Advice from the chair of the Royal College of Pathologists Working Group on Cancer Services.
 - for the first time, cancer charities and patient groups were also consulted upon.
- This process completes the work started in 2016 and allowed the data set to be clinically reviewed, validated and updated by experts in all fields of cancer and provide a clinically sound set of data to be collected from 2018 onwards.
- This also meets crucial recommendations in the Achieving World-Class Cancer Outcomes, A Strategy for England 2015-2020 (Cancer Taskforce Report).



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COSD v8.0 Timeline

- Full stage submission = September 2017 DCB meeting acceptance
- ISN publication = 28th September 2017
- Implementation period = 28 Sept 2017 to 31 March 2018 = 6 months
- Start of new Data Collection – 1 April 2018
- Full Conformance (to allow rollout) = from 1 July 2018



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Exciting New Additions

- New pathway to record '**Non-Primary Cancer Pathway**':
 - new data items for Recurrences, Progression and Transformation
 - improved ability to record all metastatic sites
- New '**Person Sexual Orientation Code (at diagnosis)**' field
- Improved '**Nurse Specialist**' sections:
 - including 'Risk Factors'
 - 'Holistic Needs Assessment' becomes Required for all patients
- Improved '**Clinical Trials**' section
- Improved '**Staging**' section to allow for:
 - both UICC & AJCC TNM staging
 - ability to record the Trust which staged the patient



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The changes

Andrew Murphy
Head of Cancer Datasets

National Cancer Registration Service (NCRS)
Public Health England



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Quick Overview...

- **39 new data items have been added** most of these data are either collected already in cancer management systems or within the Multi-Disciplinary Team meeting (MDTm) and have been heavily consulted upon with the Site Specific Clinical Reference Groups. Of which:
 - **1 data item has been added**, which complies with the Information Standard SCCI2094 on sexual orientation.
 - **13 data items have been added**, to create a new section for the accurate collection of data for Liver tumours.
 - **3 data items have been added**, to create a new section for the accurate collection of risk factors.
 - **1 data item has been added**, which complies with the Information Standard SCCI0034 on SNOMED CT diagnosis.
- **92 data items have been deleted** of which 18 were to remove duplication within the data set, whilst 48 were to remove linked data collected in other national data sets. Of which:
 - **6 Pathology data items have been deleted** to reduce duplication or to align with revisions to Royal College of Pathologists (RC Path) core data sets.



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Quick Overview (continued)...

- **57 data items have been re-aligned or moved** within the data set. This ensures that data nests correctly within the XML and will help with data collection, quality and ascertainment.
- **51 data items have been amended** for better synchronisation across the NHS Data Model and Dictionary, to allow for changes in new staging systems and/or for clarification of descriptions and should improve the collection of the standard. Of which:
 - **11 data items have been updated** to meet the new requirement due to the new Health and Social Care Organisation Reference Data standard (ANANA) - SCCI0090.
- Implementation will be between 29/09/2017 and 31/03/2018 (6 months).
- Data collection will start from 01/04/2018 (with a three month roll-out period between 01/04/2018 and 30/06/2018).
- Full conformance from 01/07/2018 (reported in the July batch within the September upload).



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So What Does That Mean?

- I am now going to go through the dataset, outlining the changes in more detail.
- This afternoon, my colleagues from Cancer Waits will talk to you all about their changes and how they will affect you too.
- Extensive work have been continuing behind the scenes with system suppliers and Information Departments, to provide more support where needed to ensure the transition is a pain free as possible.
- A full set of documentation is available to help and support you with this including:
 - User Guides
 - Datasets (in excel format)
 - Xml schemas (with examples and change logs) to support development

- The first big change for v8 is around the addition of a new 'Non-Primary Cancer Pathway'

- | | | | | |
|--------|---------------------------|-----------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------|
| CR6500 | CORE - DIAGNOSTIC DETAILS | DATE OF NON PRIMARY CANCER DIAGNOSIS (CLINICALLY AGREED)* | <p>*For linkage purposes DATE OF PRIMARY DIAGNOSIS (CLINICALLY AGREED)
or
DATE OF NON PRIMARY CANCER DIAGNOSIS (CLINICALLY AGREED)
is required as mandatory.</p> <p>Record the date where the non primary cancer diagnosis was confirmed or agreed (This will normally be the date of the authorised pathology report which confirms this or if this is not available at the time it will be the date of the Multidisciplinary Team Meeting when the diagnosis was agreed)</p> | an10 ccyy-mm-dd |
|--------|---------------------------|-----------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------|

- | | | | | | | |
|--------|-----------------------------------------------|----------------------------|-----------------------------------------------------------------------------------|-----|----|----------------|
| CR6510 | CORE - NON PRIMARY
CANCER PATHWAY
ROUTE | NON PRIMARY CANCER PATHWAY | Indicate what pathway the patient is on if this is not the Primary Cancer Pathway | an2 | 01 | Recurrence |
| | | | | | 02 | Progression |
| | | | | | 03 | Transformation |



Main changes in 'CORE' (Continued)...

- If you select Recurrence, you can then specify what type of recurrence or metastatic disease

CR6520	CORE - NON PRIMARY CANCER PATHWAY ROUTE	RECURRENCE OR METASTATIC TYPE	Indicate the type of recurrence or metastatic disease diagnosed by the clinical team	an2	01	Local
					02	Regional
					03	Distant

- Finally you can also record the location of the metastatic spread

	Start of repeating item - Metastatic Site					
	Multiple occurrences of this item are permitted					
CR1590	CORE - NON PRIMARY CANCER PATHWAY ROUTE	METASTATIC SITE	The site of the metastatic disease, if any More than one site can be recorded	an2	02	Brain
					03	Liver
					04	Lung
					06	Multiple metastatic sites
					07	Unknown metastatic site
					08	Skin
					09	Distant lymph nodes
					10	Bone (excluding Bone Marrow)
					11	Bone marrow
					12	Regional lymph nodes
					98	Other metastatic site
					99	Other metastatic site
	End of repeating item - Metastatic Site					

– and you can record more than one



Main changes in 'CORE' (Continued)...

- Some of you would have also noticed the ability to record both Transformation and Progression within this section.

CR6510	CORE - NON PRIMARY CANCER PATHWAY ROUTE	NON PRIMARY CANCER PATHWAY	Indicate what pathway the patient is on if this is not the Primary Cancer Pathway	an2	01	Recurrence
					02	Progression
					03	Transformation

- This allows a Trust to record these data correctly, where they know the patients diagnosis is NOT a new diagnosis of cancer, but instead a progression or transformation of an existing disease...
 - and where the Trust has no record of the previous disease.
- Now you can record a new record as a Non-Primary Cancer Diagnosis, and for progression you can also add the new ICD code following the progression using:

CR6900	CORE - NON PRIMARY CANCER PATHWAY ROUTE	PROGRESSION (ICD)	Where a cancer has progressed, record the ICD10 code of the original diagnosis. This will normally be agreed at the MDT by the clinical team.
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Progression/Transformation changes (at Diagnosis)...

- However, if you already have a record of cancer on your local system, you can also now add any metastatic spread (at diagnosis), as well as the progression and/or transformation details to the original record as follows:

CR6960	CORE - DIAGNOSIS	METASTATIC TYPE	Indicate the type of metastatic disease diagnosed by the clinical team	an2	01	Local
					02	Regional
					03	Distant
	Start of repeating item - Metastatic Site					
	Multiple occurrences of this item are permitted					
CR6970	CORE - DIAGNOSIS	METASTATIC SITE	he site of the metastatic disease, if any, at diagnosis. More than one site can be recorded	an2	02	Brain
					03	Liver
					04	Lung
					06	Multiple metastatic sites
					07	Unknown metastatic site
					08	Skin
					09	Distant lymph nodes
					10	Bone (excluding Bone Marrow)
					11	Bone marrow
					12	Regional lymph nodes
					98	Other metastatic site
					99	Other metastatic site
	End of repeating item - Metastatic Site					

– you can add the Date of the progression

Start of repeating item - Progression				
CR6910	CORE - DIAGNOSIS	PROGRESSION DATE (PRIMARY PATHWAY)	The DATE the progression was agreed by the clinical team.	an10 ccyy-mm-dd
End of repeating item - Progression				



Transformation changes (at Diagnosis)...

- Using the following fields allows to you to accurately record the transformation...

Start of repeating item - Transformation						
CR7030	CORE - DIAGNOSIS	SNOMED VERSION (TRANSFORMATION)	The version of SNOMED used to encode MORPHOLOGY (SNOMED) PATHOLOGY and TOPOGRAPHY (SNOMED) PATHOLOGY Versions of SNOMED prior to SNOMED CT ceased to be licenced by The International Health Terminology Standards Development Organisation (IHTSDO) after April 2017 other than for historical content	an2	01	SNOMED II
					02	SNOMED 3
					03	SNOMED 3.5
					04	SNOMED RT
					05	SNOMED CT
					99	Not Known
CR7000	CORE - DIAGNOSIS	MORPHOLOGY (SNOMED) TRANSFORMATION	This is the TRANSFORMATION DIAGNOSIS using the SNOMED International / SNOMED CT code for the cell type of the tumour recorded as part of a Cancer Care Spell. This can be recorded as well as or instead of MORPHOLOGY (ICD03) TRANSFORMATION. Versions of SNOMED prior to SNOMED CT ceased to be licenced by The International Health Terminology Standards Development Organisation (IHTSDO) after April 2017 other than for historical content	min an6 max an18		
CR7010	CORE - DIAGNOSIS	MORPHOLOGY (ICD03)* TRANSFORMATION	The morphology code for the transformation of the cancer as defined by ICD-O-3. This can be recorded as well as or instead of MORPHOLOGY (SNOMED) TRANSFORMATION.	min an5 max an7		
CR7020	CORE - DIAGNOSIS	TRANSFORMATION DATE (PRIMARY PATHWAY)	The DATE the transformation was agreed by the clinical team.	an10 ccy-mm-dd		
End of repeating item - Transformation						

- We would expect a date within this section for each submission



Changes to Nurse Specialist 'CORE' data

- 'Clinical Nurse Specialist Indication Code' has been improved to include a new attribute...

Y5	Yes - Clinical Nurse Specialist not present when PATIENT given diagnosis but the patient was seen by a trained member of the Clinical Nurse Specialist team
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- These have also been moved into a new group called 'Core - Clinical Nurse Specialist + Risk Factor Assessment'
- this has allowed additional 'NEW' data to be added around 'Smoking Status'...

SMOKING STATUS	Specify the current smoking status of the patient.	an1	1	Current smoker
			2	Ex smoker
			3	Non-smoker - history unknown
			4	Never smoked
			Z	Not Stated (PERSON asked but declined to provide a response)
			9	Unknown

- and 'History of Alcohol' (Current and Past)...

HISTORY OF ALCOHOL (CURRENT)	Specify the current history of alcohol consumption for the patient (≤3 months) from date of diagnosis These are based on the UK Chief Medical Officers' Alcohol Guideline Review (Jan 2016)	an1	1	Heavy (>14 Units per week)
			2	Light (≤14 Units per week)
			3	None in this period
			Z	Not Stated (PERSON asked but declined to provide a response)
			9	Not Known (Not recorded)
HISTORY OF ALCOHOL (PAST)	Specify the past history of alcohol consumption for the patient (>3 months) from date of diagnosis These are based on the UK Chief Medical Officers' Alcohol Guideline Review (Jan 2016)	an1	1	Heavy (>14 Units per week)
			2	Light (≤14 Units per week)
			3	None ever
			Z	Not Stated (PERSON asked but declined to provide a response)
			9	Not Known (Not recorded)



Other changes to CORE...

- There are other changes within the CORE, where we have:
 - Improved the whole Clinical Trials pathway
 - adding dates when the patient agreed to the trail and when it started
 - Updated the Staging fields
 - allowing for both AJCC and UICC to be recorded as applicable
 - adding a new field to record the Trust/Organisation who did the staging
 - both at Pre-Treatment and Integrated Stage
 - adding new fields to record both the Edition and the Version number of the staging system used
- Added an Adjunctive Therapy Indicator...
- This compliments the updated Treatment Intent...

1	Adjuvant
2	Neoadjuvant
3	Not Applicable (Primary Treatment)
9	Not Known

01	Curative
02	Palliative
03	Disease Modification *
04	Diagnostic * *
05	Staging * *
08	Other
09	Not Known



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Site Specific Datasets Changes...

- You will notice across the dataset that **CTYA** items may have moved, either:
 - to the CORE, because on clinical advice we believe that these can be collected on more than just CTYA patients or
 - within their site specific parent (Sarcoma to Sarcoma) etc.
- **Breast** has a new item for recording the 'Menopausal Status'
- **Gynaecological** has an updated 'Consultant Grade'
- **Haematological** has an updated 'FLIPI 2 Index Score'
- **Head and Neck** has a new 'Speech and Language Therapist' date field
- There is a whole new section for '**Liver**'
- **Lung** has had two fields extend their format to allow for accurate data recording
- **Urological** has got three new fields aligning them to the NPCA submissions



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COSD - CORE Pathology

- Core pathology has had the least changes and continues to have its own dataset and schema.
- We will also investigate to see if it is possible within v9 to completely separate COSD Pathology from COSD Patient Pathway.
- Work is ongoing with the major pathology suppliers to have compliant LIMS available for Trusts to implement or upgrade to.
- The COSD Governance Board is aware of the delay, and difficulties in the transition to COSD xml reporting for pathology
- There are great benefits from reporting using COSD xml for pathology
 - reduced transcription errors
 - faster reporting of pathological outcomes (28 day targets)
 - ability to map to multiple datasets of accurate recording (interoperability)



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COSD - CORE Pathology (Continued)...

- There are only 13 changes to this dataset, of which 6 of these are deletions
 - these are primarily where we have grouped all pathology grade into one field '**Grade Of Differentiation (Pathological)**' (except colorectal)
- '**Service report Identifier**' and '**Pathology Observation Report Identifier**' have extended field lengths
- There are updated Staging fields to allow for:
 - both AJCC and UICC to be recorded as applicable
 - new fields to record both the '**Edition**' and the '**Version Number**' of the staging system used
- Colorectal pathology changes include:
 - an update to '**Response To Preoperative Therapy**'
 - a new field for '**Grade Of Differentiation (Colorectal Pathological)**'
- '**Sarcoma Surgical Margin Adequacy**' moved into Sarcoma pathology



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Finally...

- Although there were less changes this year, the challenges were equally as difficult and complex
- We now have a more balanced dataset, which better reflects current clinical practice, and allows for the accurate recording of recurrences, progression, transformation and the changes to the TNM staging systems from Jan 2018
- Our next challenge is to improve the completeness and ascertainment of data collected at Trust level
 - using CancerStats2 later this year will help you with this
- Again like last year, this is your challenge:
 - your opportunity to support the MDT and National Analysts
 - to improve data collection, accuracy and quality of data recorded
 - ultimately this whole process will improve the treatment pathways for patients



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Any Questions?



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Group Discussion

COSD - What works, what
doesn't and future changes
(Additions, Deletions and why)?



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Group Discussion...

- **30 Minutes**
- Is the dataset too big?
- What data are really difficult to collect and why?
 - laboratory results, CTYA, Haematology, other data or processes
- Should the dataset be reduced in size?
 - If so, what should we remove and why?
- What new things would you like to see in COSD in the future? Think about:
 - who is going to collect these?
 - how easy they are to collect?
 - what are they going to be used for?
- The next COSD change will be in 2020, so this is your chance to influence this change. **“Your opinions really matter”**