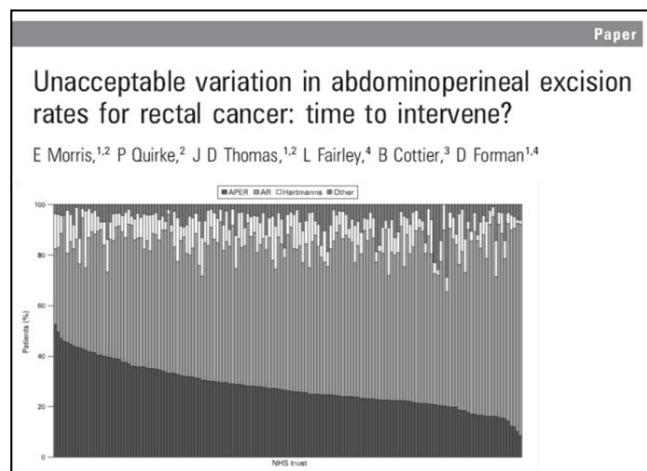
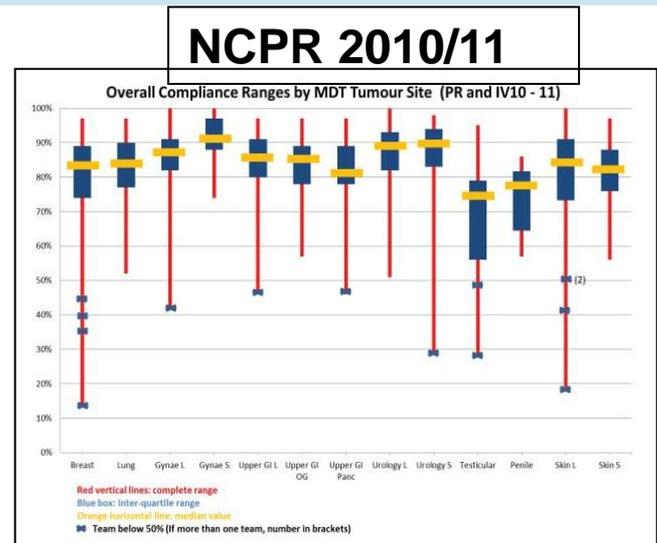
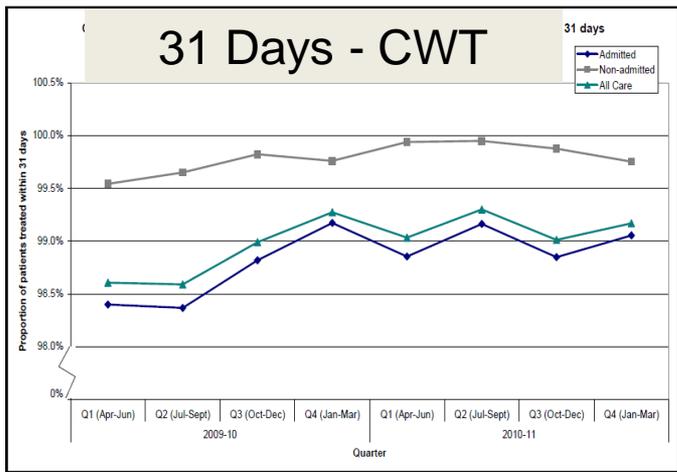


# Cancer Outcomes and Services Dataset

## What is COSD?

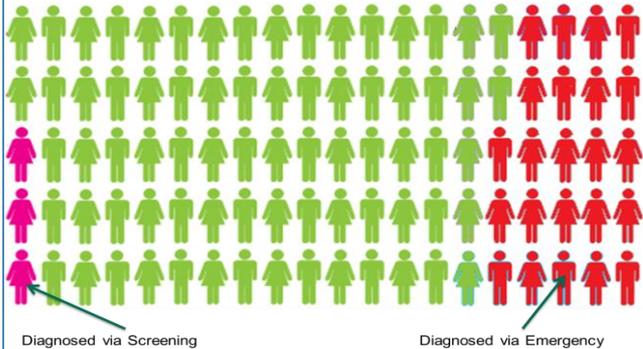
## Implications for Providers and Networks

# Why are we doing this – the impact of information?



# Why are we doing this – newer Information?

## Routes to Diagnosis



## Patient Experience Survey

The table displays patient experience survey results for various cancer types. The columns represent different metrics, and the rows represent different cancer types. The cells are color-coded: red for negative, yellow for neutral, and green for positive. The table is quite dense with data points.

### Older cancer patients 'denied surgery'

Bias helps to explain low survival rates

Sam Lister Health Editor

Thousands of cancer patients are being denied potentially life-saving surgery because of a cultural reluctance to operate on tumours in the middle-aged and elderly, an official study suggests.

The first research to track rates of cancer surgery across the country shows that the likelihood of patients having operations falls off markedly as they get older.

Doctors leading the study, to be published shortly but which has been seen by The Times, described the finding as a "striking indicator" of why England's cancer survival rates are poor by international standards.

The research, carried out by the National Cancer Intelligence Network (NCIN) set up by the Department of Health in 2005, suggests that a combination of poor access to specialist surgical expertise and a tendency within parts of the NHS to consider older patients as inappropriate for surgery are the main factors.

Miss Peake, who is based at Glenfield Hospital, Leicester, and led the study, said that, while it was not surprising that smaller numbers of the most elderly were undergoing surgery, the decline in rates among the middle-aged was particularly worrying.

Surgery remains the treatment with the best survival rates for most cancer types.

**Falling off the operating table**

— Bladder — Cervix — Kidney — Colorectal — Pancreas — Ovary — Stomach — Uterus — Thyroid — Breast — Prostate — Liver — Lung — Esophagus

100  
80  
60  
40  
20  
0

0-49 50-59 60-69 70-79 80-89

Survival NCIN, 2005/6

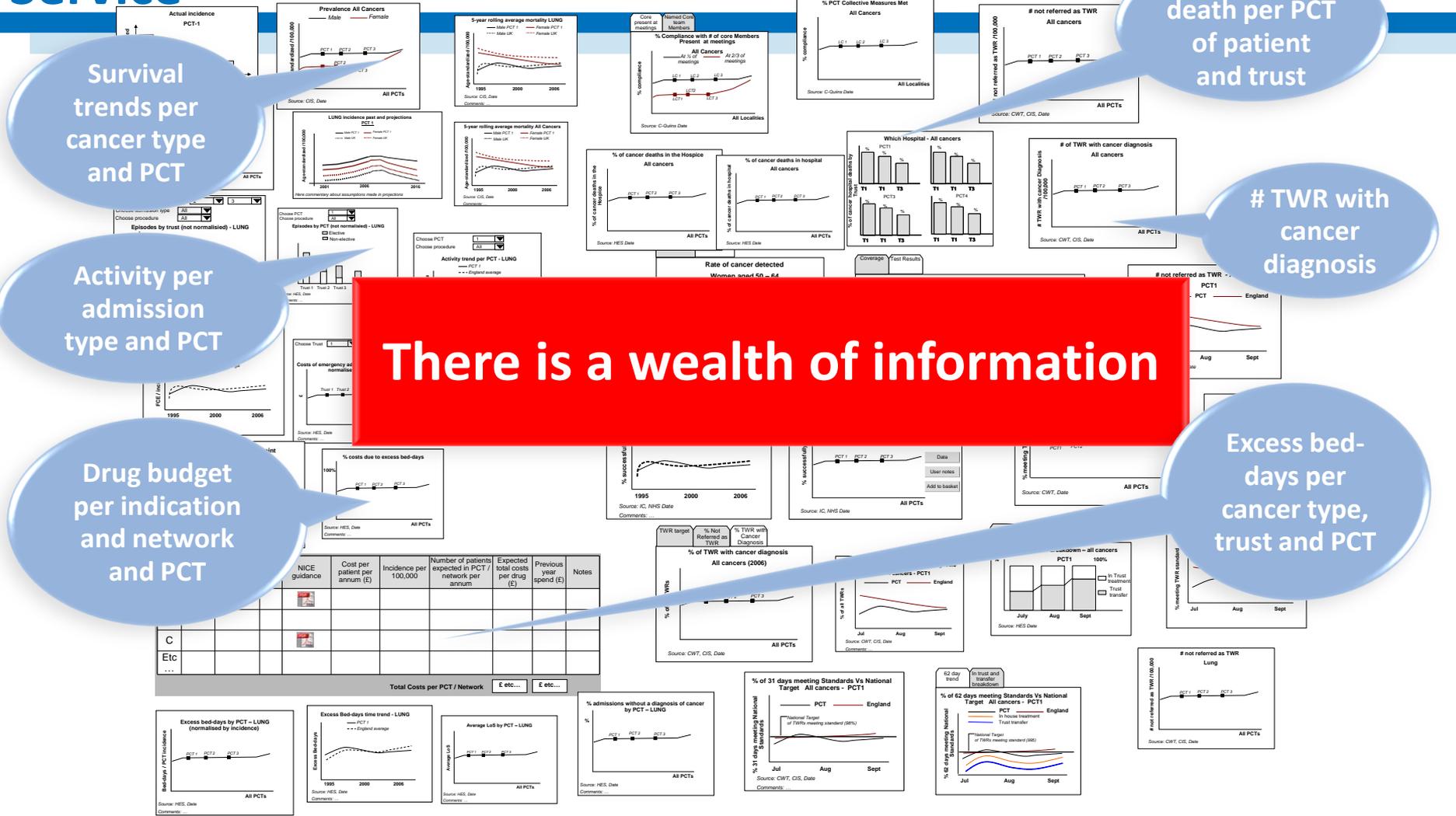
**I was lucky. Many aren't**

between 2004 and 2006, with follow-up in 2007, might not reflect recent improvements, Dr Peake said, but the trends held for the situation today.

While 9 per cent of patients aged 16-19 had surgery, the rate x

**15% OFF**

# There are 100s of aspects that must be taken into account when making decisions about a Clinical Service



**There is a wealth of information**

Survival trends per cancer type and PCT

Activity per admission type and PCT

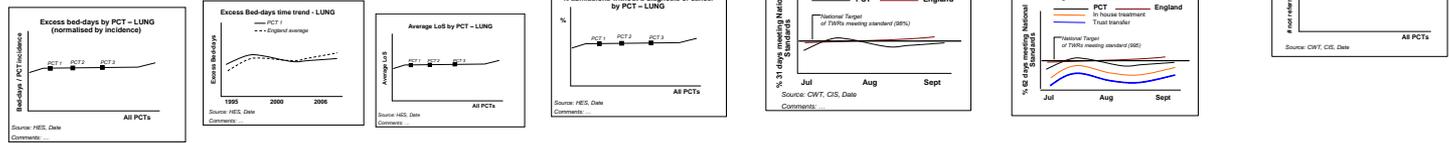
Drug budget per indication and network and PCT

Place of death per PCT of patient and trust

# TWR with cancer diagnosis

Excess bed-days per cancer type, trust and PCT

NICE guidance	Cost per patient per annum (£)	Incidence per 100,000	Number of patients expected in PCT / network per annum	Expected total costs per drug (£)	Previous year spend (£)	Notes
C						
Etc						



# 17 years ago....



...Cancer registration and careful monitoring of treatment and outcomes are essential...

*Calman-Hine 1995*

.....“Our aspiration is that England should achieve cancer outcomes which are comparable with the best in the world”

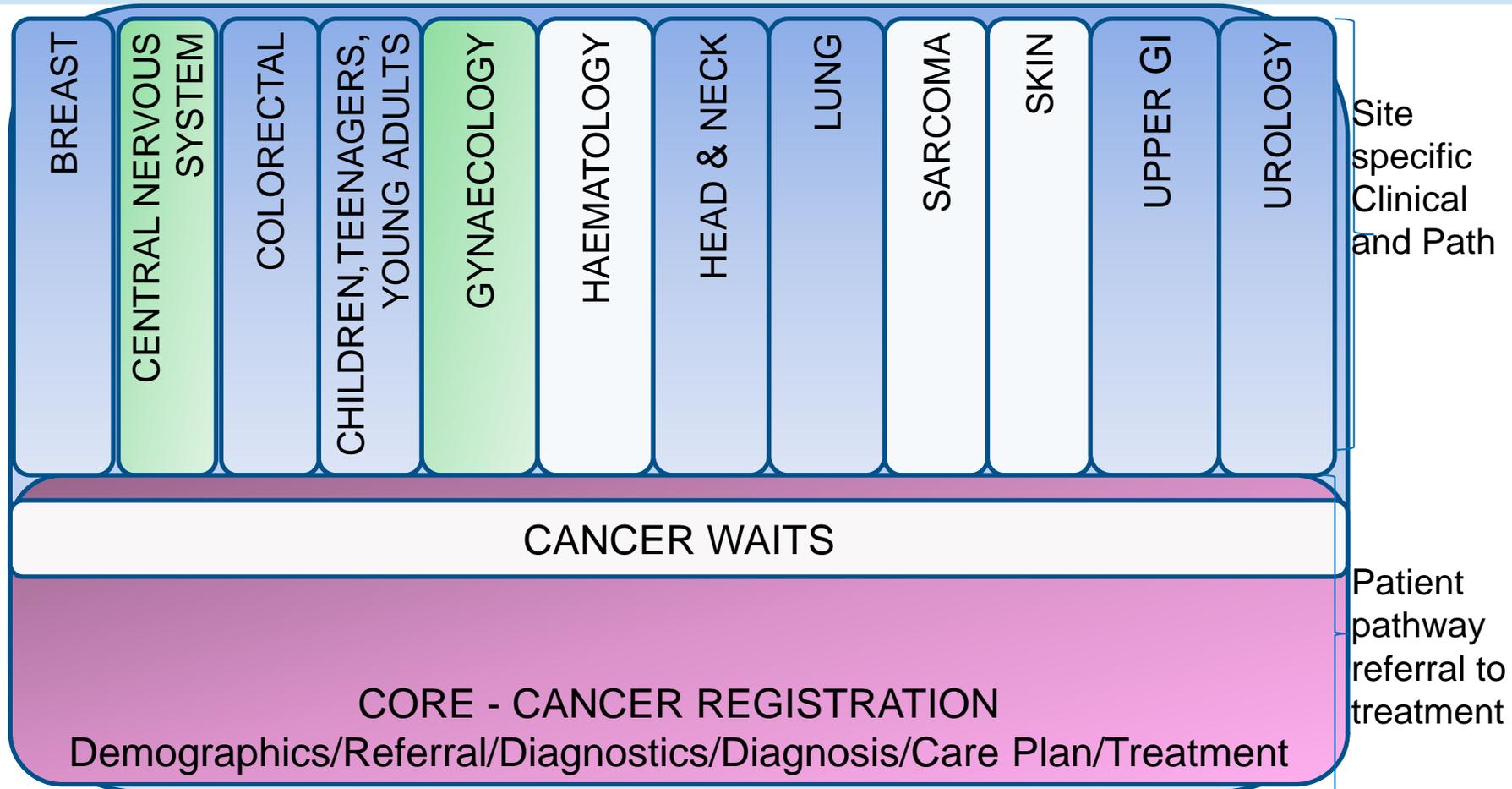
*Improving Outcomes: a Strategy for Cancer, 2011*

# What is COSD?



- **The new national cancer dataset**
- Cancer Outcomes and Services
- Aligned with patient management
- Proposed and supported by clinicians
- Incorporates previous cancer registration dataset
- Updated and aligned with other datasets
- Clarified definitions of data items, codes and values
- Specifies Provider submissions
- Compiled by registries from Providers and other sources

# COSD - Structure



# What's different about COSD? (1)



- Complete patient pathway
  - Referral details for all cases
  - All treatments
  - Includes palliative and supportive care
- Additional core data items including
  - Involvement of Clinical Nurse Specialist
  - Duration of symptoms
    - Mandatory for Children, Teenagers, Young Adults (CTYA), Optional for others
    - Year/Month/Day as appropriate or available
- All registerable conditions including
  - in situ bladder, in situ melanoma, benign brain tumours

# What's different about COSD? (2)



- Site specific data
  - Key site specific clinical items – patient management
  - Site specific stage
  - Stage components of RCPATH datasets
- Includes recurrences
  - Breast cancers to start with

# Site specific stage

TUMOUR GROUP	SITE SPECIFIC STAGE
BREAST	NPI
COLORECTAL	Modified Dukes
CTYA	Murphy (St Jude) Stage (NHL)
	Ann Arbor (Hodgkins Lymphoma)
	International Neuroblastoma Staging System
	Wilms tumour stage (Renal)
	TNM stage grouping (Non CNS Germ Cell)
	Chang staging (Medulloblastoma)
GYNAE	Final FIGO stage, Nodal status cervical cancer
HAEMATOLOGY	Rai stage, Binet stage (CLL)
	ISS stage (Myeloma)
	Ann Arbor (Hodgkins Lymphoma)
SKIN	AJCC Stage group
UROLOGY	(RMH) Stage group

# What will be collected?

	Total		
CORE	107		
BREAST	31		
CNS	15		
COLORECTAL	28		
CTYA	55		
GYNAE	35		
HAEMATOLOGY	35		
HEAD & NECK	25		
LUNG	20		
SARCOMA	11		
SKIN	22		
UPPER GI	25		
UROLOGY	32		
<b>TOTAL</b>	<b>441</b>		

# COSD Dataset

Data Item Name	Suggested System/Source
Primary Diagnosis (ICD)	[Green Box]
Multidisciplinary Team Discussion Date (Cancer)	
Cancer Care Plan Intent	
Performance Status (Adult)	
TNM Stage Grouping (Final Pre Treatment)	
Site Code (Of Imaging)	[Green Box]
Procedure Date (Cancer Imaging)	
Imaging Code (Nicip)	
Cancer Imaging Modality	
Imaging Anatomical Site	[Green Box]
Consultant Code	
Care Professional Main Specialty Code	
Procedure Date	[Green Box]
Primary Procedure (Opcs)	
Procedure (Opcs)	[Green Box]
Investigation Result Date	
Service Report Identifier	
Service Report Status	
Care Professional Code (Test Requested By)	
Organisation Site Code (Immunology Test Requested By)	[Yellow Box]
Cancer Treatment Event Type	
Treatment Start Date (Cancer)	
Cancer Treatment Modality	
Organisation Site Code (Provider Treatment Start Date (Cancer)	

Compilation into a single dataset (assembled by Registries – not by Providers)



**MDT**



**Radiology**



**PAS**



**Pathology**



**National Feeds – datasets and other sources e.g. CWT, RTDS, SACT, (ONS)**

# What does this mean for you?



- Monthly submission
  - Current cancer registry feeds expanded to include COSD items
  - 25 working days after diagnosis or treatment
  - Send updates as applicable
    - Aim for three months to complete initial record (to first treatment)
    - Final updates to first treatment within 6 months
    - Further treatments - submit 25 working days after treatment
- How to collect in “real time” ?
- Clinical ownership/sign off for
  - MDT extract
  - PAS extract
  - Path extract
  - RIS extract

# Key sources – MDT System



- Resources
  - Point of care recording
- Clinical sign off/Ownership
  - Review and revise processes
- Inter Provider pathways
  - Network wide implementation
  - Data collection agreements
- Alignment with national audits
  - Differences identified
  - Move towards integrated submission

# Key Sources – Pathology System



- Existing extracts continue
- Path items may also be recorded in MDT system
  - Can send from both systems
- Free Text Reports
  - Data items extracted by registries
- Direction of travel
  - Structured reporting
- Clinical oversight
  - Summary feedback reports

# Key sources – PAS

- Existing extract
  - Use SUS/CDS/PbR return
  - Check COSD data items included
  - Discuss with regional registry
- Process for Clinical oversight
  - Feedback reports

# Key sources – Radiology System



- How to identify cases
  - Can system identify cancer cases automatically
  - Can CWT be used to identify reports for cancer investigations
  - Identified by registries to request reports for specified cancer
  - Remote access to RIS for registries
  - IEP – future option?
  - Use of Diagnostic Imaging Dataset (DID)?
- Free Text reports
  - Data items extracted by registries
- Clinical oversight
  - Summary feedback reports
- Radiology items recorded in MDT system
  - Can send from both systems

# GAP Analysis – Conformance Checklist



PLEASE READ INSTRUCTIONS BEFORE COMPLETING				
Data Item Section	Data Item Name	Suggested System/Source	Item on system?	SYSTEMSOURCE
CORE - IMAGING	IMAGING REPORT TEXT	RIS	YES	RIS
CORE - IMAGING	LESION SIZE (RADIOLOGICAL)	RIS	YES	RIS
CORE - DIAGNOSIS	TUMOUR LATERALITY	MDT	YES	MDT
CORE - DIAGNOSIS	BASIS OF DIAGNOSIS (CANCER)	MDT	NO	MDT
CORE - DIAGNOSIS	MORPHOLOGY (SNOMED)	MDT	YES	MDT
CORE - DIAGNOSIS	MORPHOLOGY (ICD3)	MDT	NO	MDT
CORE - DIAGNOSIS	TOPOGRAPHY (ICD3)	MDT	NA	MDT
CORE - DIAGNOSIS	GRADE OF DIFFERENTIATION	MDT	YES	MDT
CORE - DIAGNOSIS	METASTASIS	MDT	YES	MDT
CORE - DIAGNOSIS	CANCER RECURRENT	MDT	YES	MDT
CORE - CANCER CARE PLAN	MULTIDISCIPLINARY DISCUSSION	MDT	YES	MDT
CORE - CANCER CARE PLAN	CANCER CONSULTANT	MDT	YES	MDT
CORE - CANCER CARE PLAN	PLANNED TREATMENT	MDT	YES	MDT
CORE - CANCER CARE PLAN	NO CANCER RECURRENT	MDT	YES	MDT
CORE - CANCER CARE PLAN	ADULT COUNSELLING EVALUATION	MDT	YES	MDT
CORE - CANCER CARE PLAN	PERFORMANCE (ADULT)	MDT	YES	MDT

LOCAL SYSTEMSOURCE (Completed from Conformance Checklist sheet)	IS THIS ITEM CURRENTLY COLLECTED ROUTINELY	IF NOT COLLECTED, WHO WILL RECORD IN FUTURE	IF NOT COLLECTED, WHEN WILL THIS BE RECORDED IN FUTURE	WHAT'S THE STATUS?
CORE - IMAGING	LESION SIZE (RADIOLOGICAL)	RIS	YES	
CORE - DIAGNOSIS	TUMOUR LATERALITY	MDT	YES	
CORE - DIAGNOSIS	BASIS OF DIAGNOSIS (CANCER)	MDT	YES	
CORE - DIAGNOSIS	MORPHOLOGY (SNOMED)	MDT	YES	
CORE - DIAGNOSIS	MORPHOLOGY (ICD3)	MDT	NOT REQUIRED	
CORE - DIAGNOSIS	MORPHOLOGY (ICD3)	MDT	NOT REQUIRED	
CORE - CANCER CARE PLAN	MULTIDISCIPLINARY DISCUSSION	MDT	MDT COORD	PPE MDM SCR
CORE - CANCER CARE PLAN	CANCER CONSULTANT	MDT		
CORE - CANCER CARE PLAN	PLANNED TREATMENT	MDT		
CORE - CANCER CARE PLAN	NO CANCER RECURRENT	MDT	MDT COORD	AT MDM SCR
CORE - CANCER CARE PLAN	ADULT COUNSELLING EVALUATION	MDT		
CORE - CANCER CARE PLAN	PERFORMANCE (ADULT)	MDT	MDT COORD	AT MDM SCR

HEADINGS	Number marked "Yes"	Number marked "No"	Number "Blank"	Number "NA"	TOTAL
Routinely collected?	9	5	449	0	463
Issues to be resolved	0	0	463		463

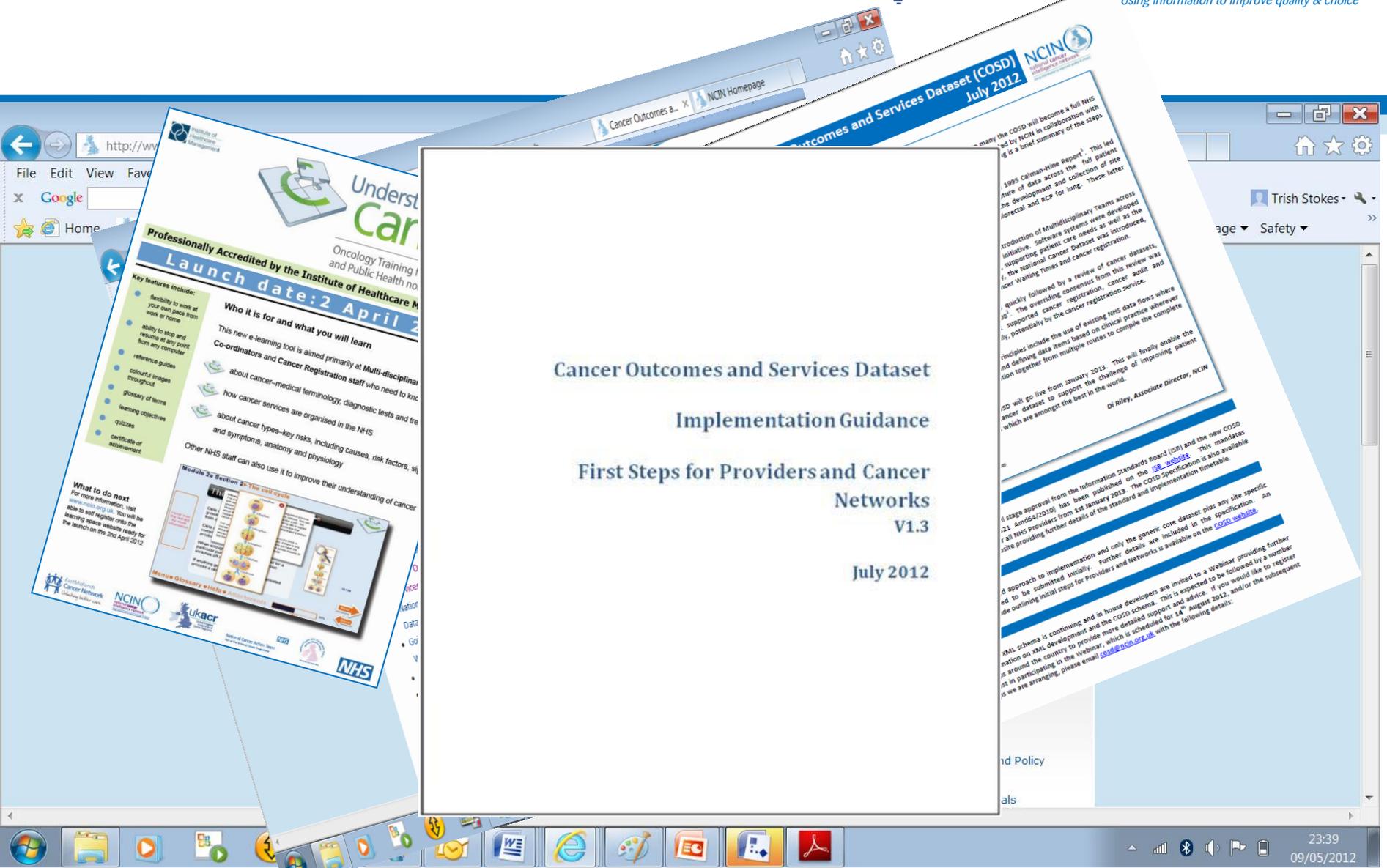
  

COLLECTION CHECKLIST	Summary sheet

Collection Issues

WHO WILL COLLECT?  
Select the person/role who will collect this in future.  
List can be amended in DATA SOURCES sheet, Column D

# Support



## Cancer Outcomes and Services Dataset Implementation Guidance First Steps for Providers and Cancer Networks V1.3 July 2012

### Understand Cancer

Professionally Accredited by the Institute of Healthcare Management  
Oncology Training and Public Health no.

**Launch date: 2 April 2012**

**Who it is for and what you will learn**

This new e-learning tool is aimed primarily at **Multi-disciplinary Co-ordinators and Cancer Registration staff** who need to know:

- about cancer-medical terminology, diagnostic tests and tests
- how cancer services are organised in the NHS
- about cancer types-key risks, including causes, risk factors, signs and symptoms, anatomy and physiology

Other NHS staff can also use it to improve their understanding of cancer

**Key features include:**

- flexibility to work at your own pace from work or home
- ability to stop and resume at any point from any computer
- reference guides
- colourful images throughout
- glossary of terms
- learning objectives
- quizzes
- certificate of achievement

**What to do next**

For more information, visit [www.ncin.org.uk](http://www.ncin.org.uk). You will be able to self register onto the learning space ready for the launch on the 2nd April 2012

Logos: Cancer Network, NCIN, ukacr, NHS

...many the COSD will become a full time initiative. Software systems were developed to support patient care needs as well as the development and collection of site data for the National Cancer Dataset (NCD) and the National Cancer Register (NCR). These latter two systems will be replaced by the COSD.

...1995 Calman-Hine Report. This led to the development and collection of site data for the National Cancer Dataset (NCD) and the National Cancer Register (NCR). These latter two systems will be replaced by the COSD.

...introduction of Multidisciplinary Teams across the country. This led to the development of the National Cancer Dataset (NCD) and the National Cancer Register (NCR). These latter two systems will be replaced by the COSD.

...supporting patient care needs as well as the development and collection of site data for the National Cancer Dataset (NCD) and the National Cancer Register (NCR). These latter two systems will be replaced by the COSD.

...quickly followed by a review of cancer datasets, the National Cancer Dataset (NCD) and the National Cancer Register (NCR). These latter two systems will be replaced by the COSD.

...principles include the use of existing data flows where supported, cancer registration, cancer audit and other data items based on clinical practice wherever possible, potentially by the cancer registration service.

...COSD will go live from January 2013. This will finally enable the use of existing data flows where supported, cancer registration, cancer audit and other data items based on clinical practice wherever possible, potentially by the cancer registration service.

...which are amongst the best in the world.

Dr Riley, Associate Director, NCIN

...stage approval from the Information Standards Board (ISB) and the new COSD (V1.3) has been published on the [ISB website](#). This mandates all NHS providers from 1st January 2013. The COSD Specification is also available on the [COSD website](#) providing further details of the standard and implementation timetable.

...approach to implementation and only the generic core dataset plus any site specific data to be submitted initially. Further details are included in the specification. An initial stage outlining initial steps for Providers and Networks is available on the [COSD website](#).

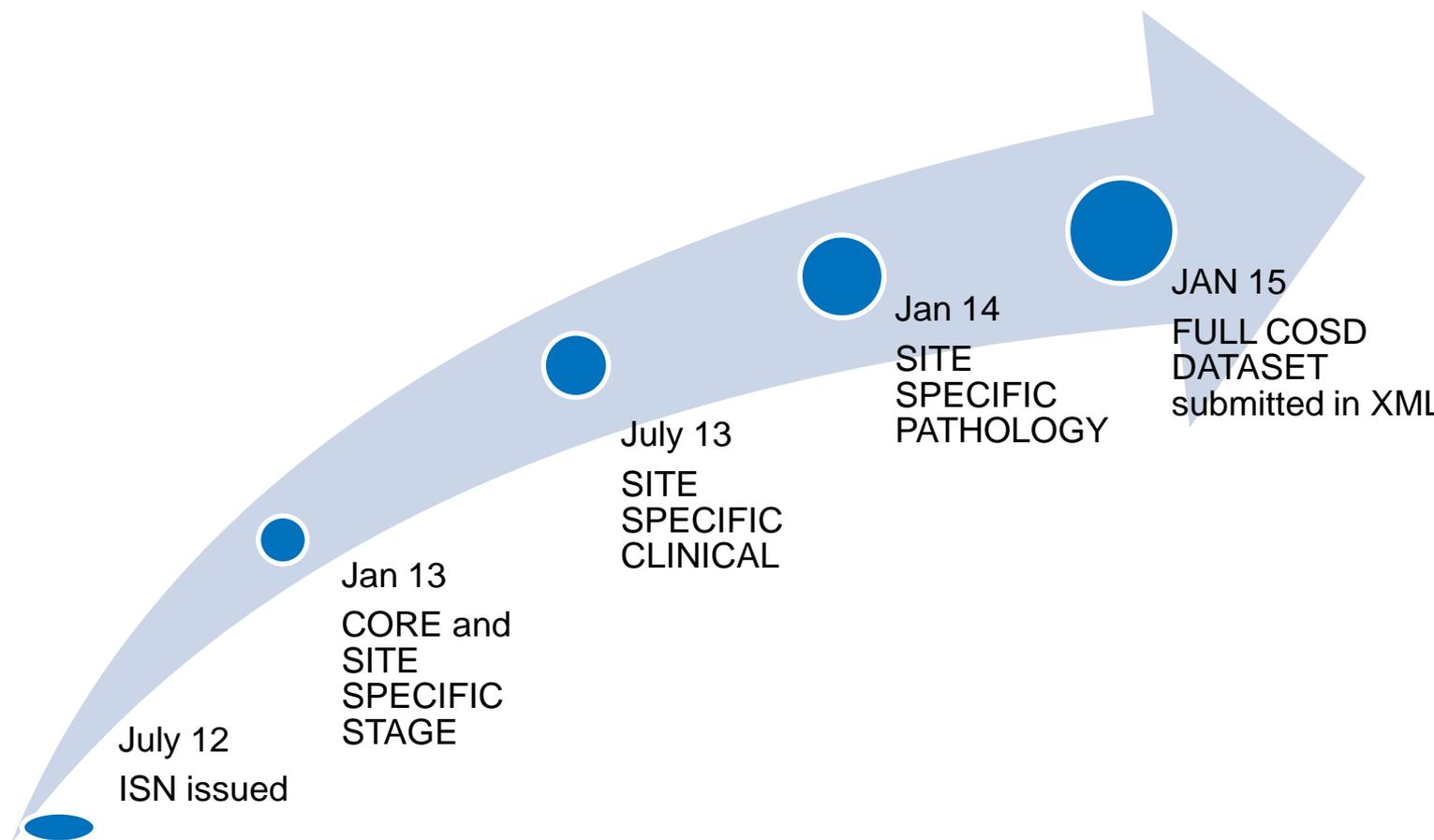
...XML schema is continuing and in house developers are invited to a Webinar providing further information on XML development and the COSD schema. This is expected to be followed by a number of Webinars around the country to provide more detailed support and advice. If you would like to register for this please email [cosd@ncin.org.uk](mailto:cosd@ncin.org.uk) with the following details:

# Conformance

- Simple criteria
  - Monthly feedback to Providers (raw data)
    - e.g. data submitted on time?
    - Staging data completeness
  - Quarterly and annual feedback to follow (processed data)
- Included in National Contract
  - Possible financial penalty
- Potential Escalation process
  - Informal discussions
  - Notification to CEO
  - Formal notification to commissioners
  - NHS Commissioning Board

# Implementation Timetable

**ISB Approval  
June 12**



# Thank you

[cosd@ncin.org.uk](mailto:cosd@ncin.org.uk)