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# Cancer Outcomes and Services Dataset:

## Implications for clinical teams


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Clinical Lead, NCIN

National Clinical Lead, NHS Cancer Improvement

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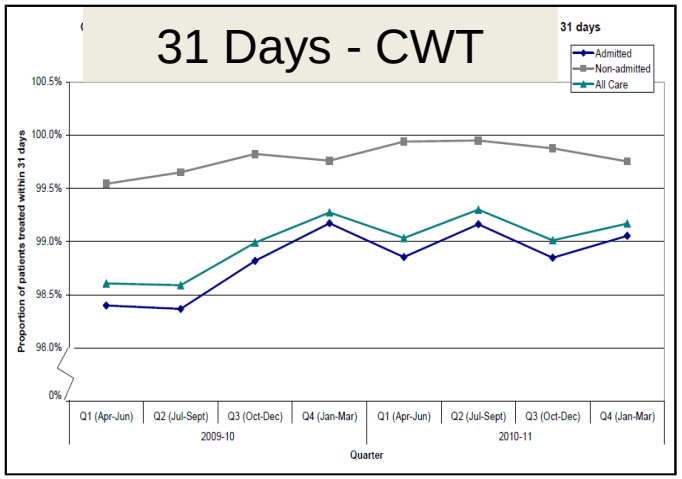
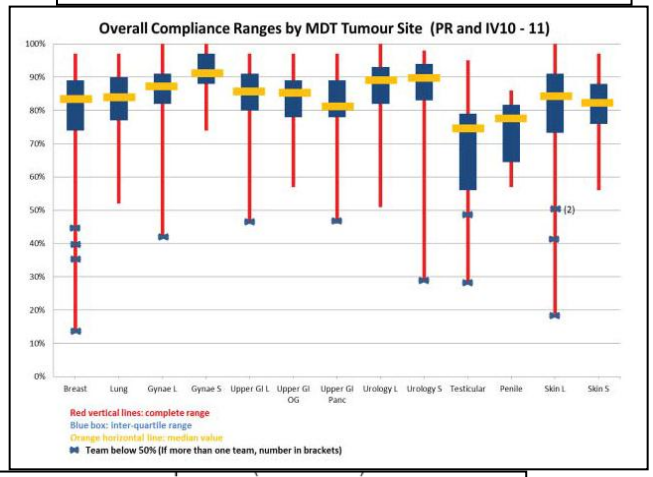
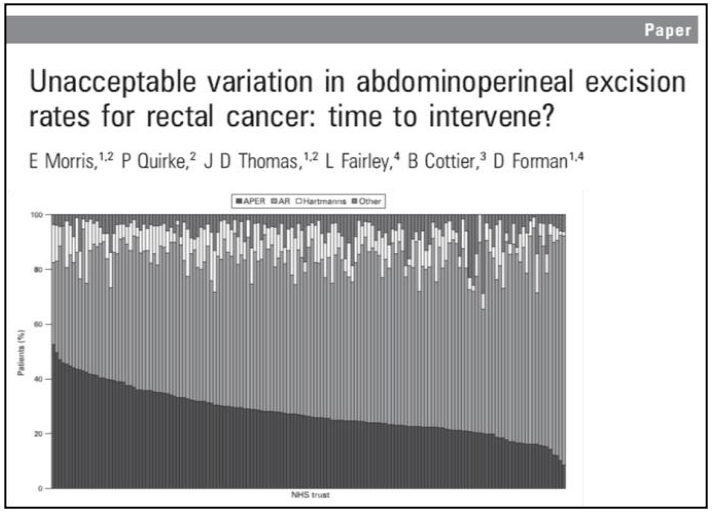
NCRI
National Cancer Research Institute

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




## Peer Review 2010/11

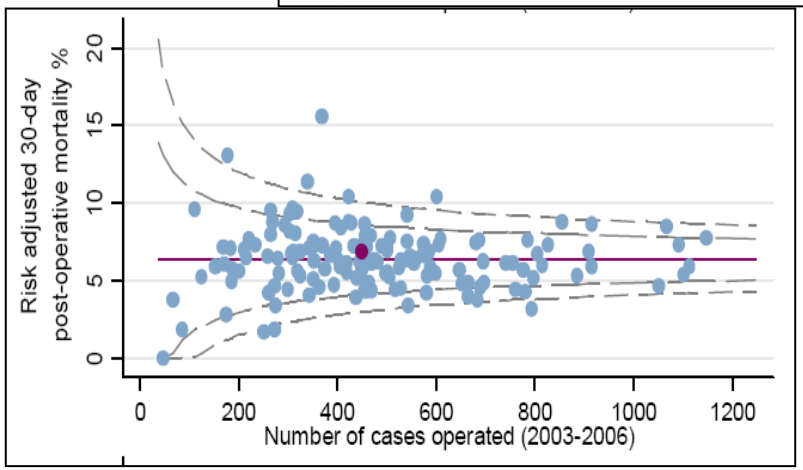




Paper

Unacceptable variation in abdominoperineal excision rates for rectal cancer: time to intervene?

E Morris,[1,2] P Quirke,[2] J D Thomas,[1,2] L Fairley,[4] B Cottier,[3] D Forman[1,4]





# Why are we doing this – newer Information?

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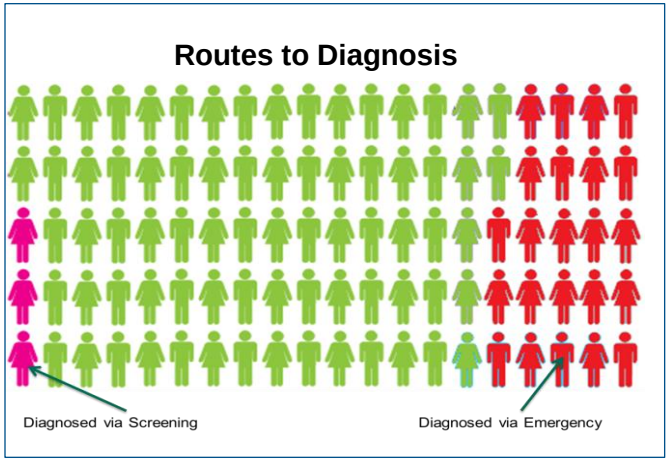


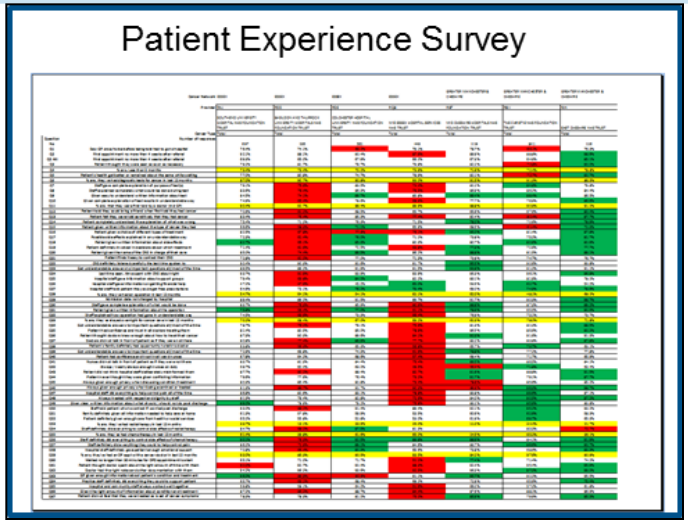


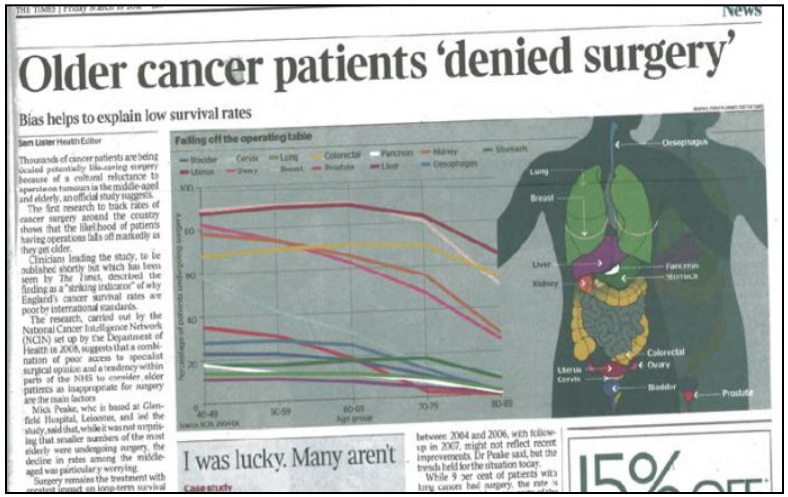

THE TIMES | Friday March 27 2009

News

## 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 around the country shows that the likelihood of patients having operations falls off markedly as they get older.

Clinicians 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 2008, suggests that a combination of poor access to specialist surgical opinion and a tendency within parts of the NHS to consider older patients as inappropriate for surgery are the main factors.

Nick 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 greatest impact on long-term survival

Failing off the operating table

Bladder, Cervix, Lung, Colorectal, Pancreas, Kidney, Stomach, Uterus, Ovary, Breast, Prostate, Liver, Oesophagus

Percentage of patients undergoing surgery

100, 80, 60, 40, 20, 0

40-49, 50-59, 60-69, 70-79, 80-89

Age group

Source: NCIN, 2009/08

Oesophagus, Lung, Breast, Liver, Kidney, Pancreas, Stomach, Colorectal, Ovary, Uterus, Cervix, Bladder, Prostate

I was lucky. Many aren't

Case study

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 with lung cancers had surgery, the rate is

15% OFF

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

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Place of death per PCT of patient and trust

Survival trends per cancer type and PCT

# TWR with cancer diagnosis

Activity per admission type and PCT

**There is a wealth of information**

Drug budget per indication and network and PCT

Excess bed-days per cancer type, trust and PCT

# 17 years ago....

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...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*

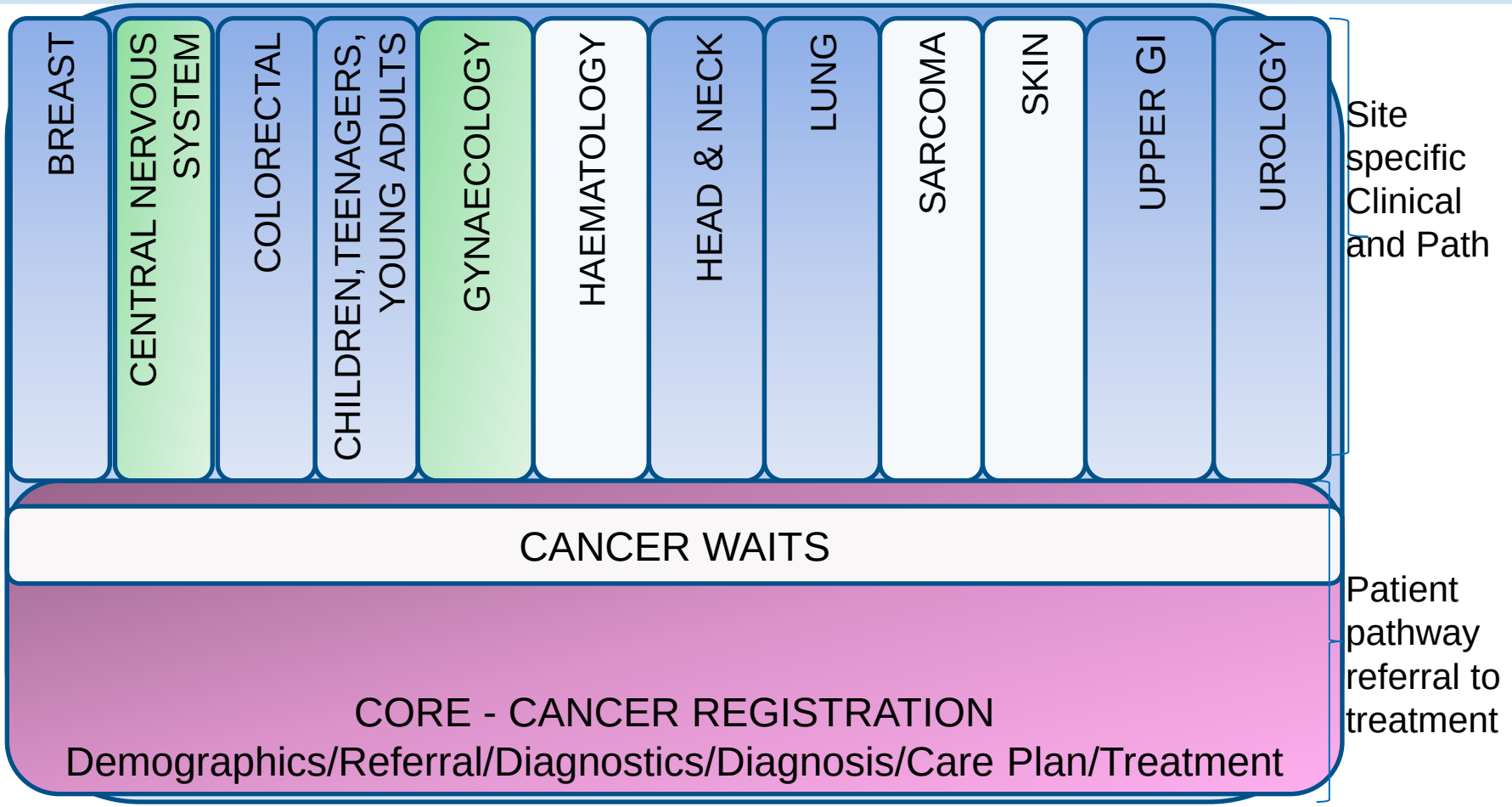
# What is COSD?

- **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

# Other data sets

- Radiotherapy Dataset (RTDS)
- Diagnostic Imaging Data Set (DIDS)
- Systemic Anti-Cancer Therapy Dataset (SACT)
- (UGI Audit)

# COSD - Structure



# What's different about COSD? (1)

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- 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)

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- Site specific data
  - Key site specific clinical items – patient management
  - Site specific stage (at the time of treatment decision)
  - Stage components of RCPath datasets
- Includes recurrences
  - Breast cancers to start with

# COSD Dataset

| Data Item Name | Suggested System/Source |
|---|---|
| Primary Diagnosis (ICD) | |
| Multidisciplinary Team Discussion Date (Cancer) | |
| Cancer Care Plan Intent | |
| Performance Status (Adult) | |
| TNM Stage Grouping (Final Pre Treatment) | |
| Site Code (Of Imaging) | |
| Procedure Date (Cancer Imaging) | |
| Imaging Code (Nicip) | |
| Cancer Imaging Modality | |
| Imaging Anatomical Site | |
| Consultant Code | |
| Care Professional Main Specialty Code | |
| Procedure Date | |
| Primary Procedure (Opcs) | |
| Procedure (Opcs) | |
| Investigation Result Date | |
| Service Report Identifier | |
| Service Report Stat | |
| Care Professional C Test Requested By) | |
| Organisation Site Cod ology Test Requested By) | |
| 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, Audits, RTDS, SACT, (ONS)

# Key sources – MDT System

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- 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

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- 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

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- 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

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

# Support

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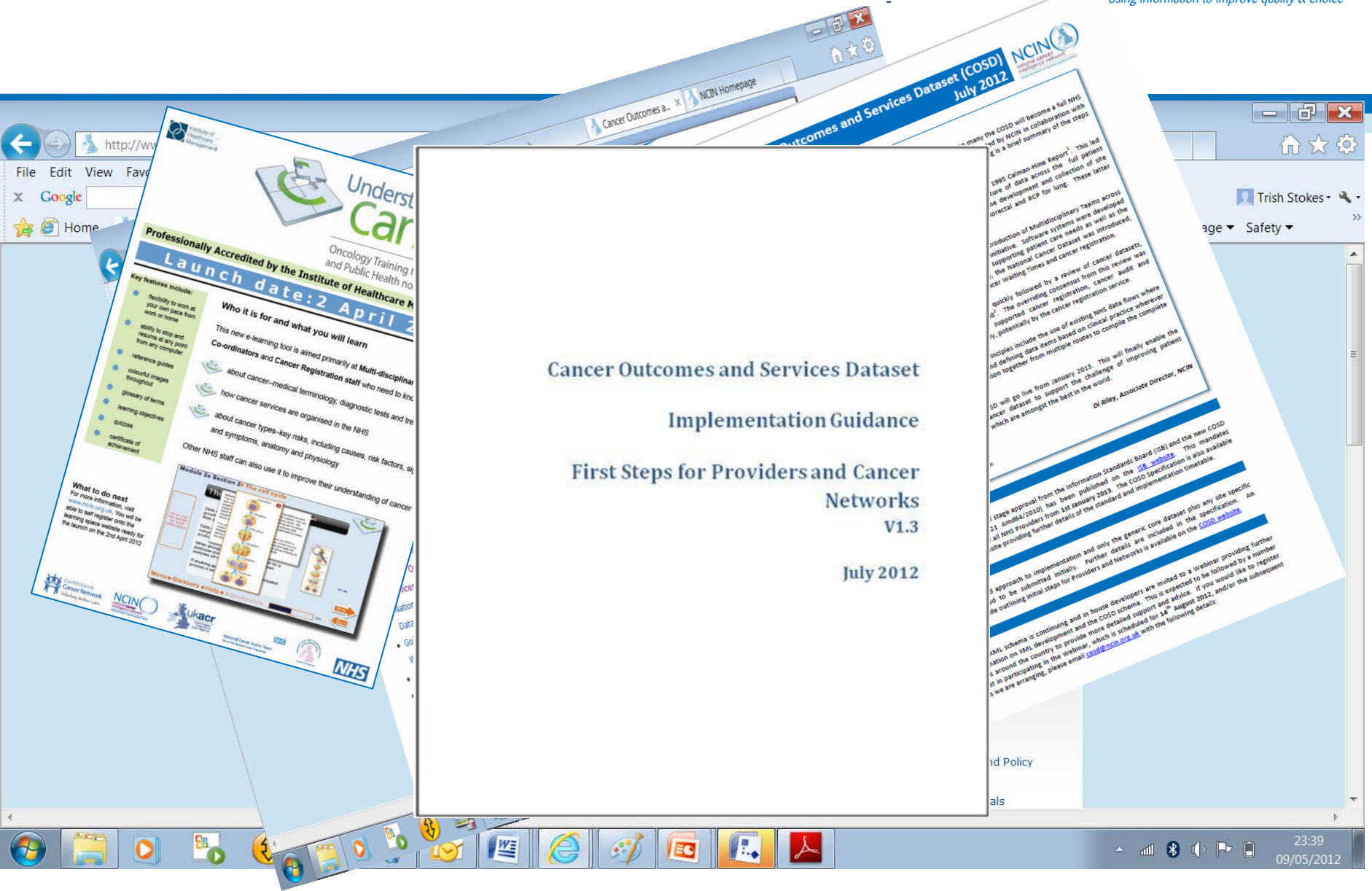

# Implementation Timetable

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**ISB Approval June 12**

July 12

ISN issued

Jan 13

CORE and SITE SPECIFIC STAGE

July 13

SITE SPECIFIC CLINICAL

Jan 14

SITE SPECIFIC PATHOLOGY

JAN 15

FULL COSD DATASET submitted in XML

# National Cancer Data Repository

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- The NCDR allows researchers to access linked datasets without the need to handle identifiable data
- Links records from the eight English cancer registries, death registrations and Hospital Episode Statistics (HES) data
- Over 8.5 million cancer registry records dating back to 1985
- Readily linked to other datasets such as SACT (chemotherapy) and RTDS (radiotherapy)

# Systemic Anti-Cancer Treatment (SACT) programme

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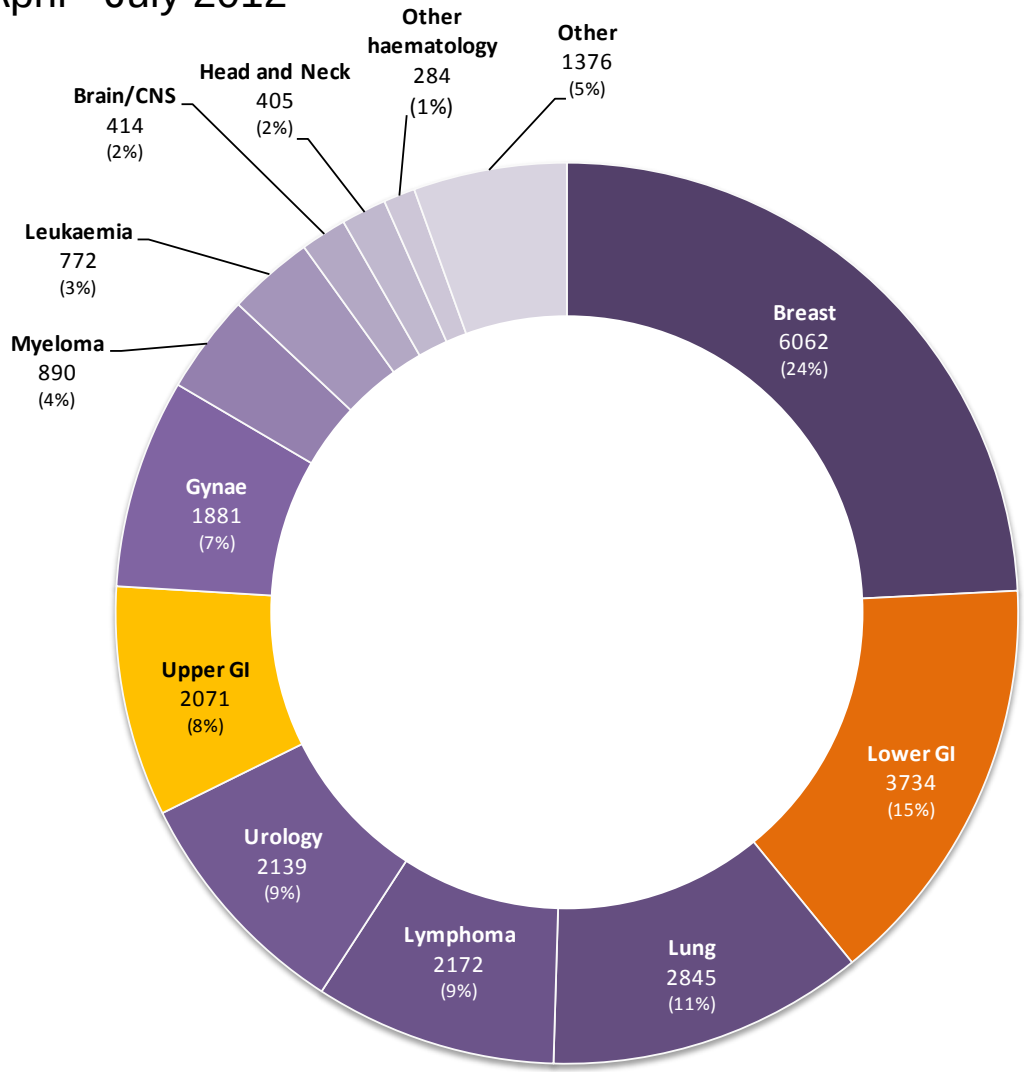
- Implementation April 2012 – April 2014
- Chemotherapy Intelligence Unit at Oxford CIU
- Covers all drug treatment for cancer in all settings
- Monthly upload from trusts; validation
- Three-monthly report of regimens by tumour site produced
- 97 out of 154 trusts supplying data to end September (63%)
- Database currently contains data on 46,595 patients

# Number of Patients by Diagnostic Group

All submitting trusts aggregated. Patients aged 16 and over.

Data received for April - July 2012



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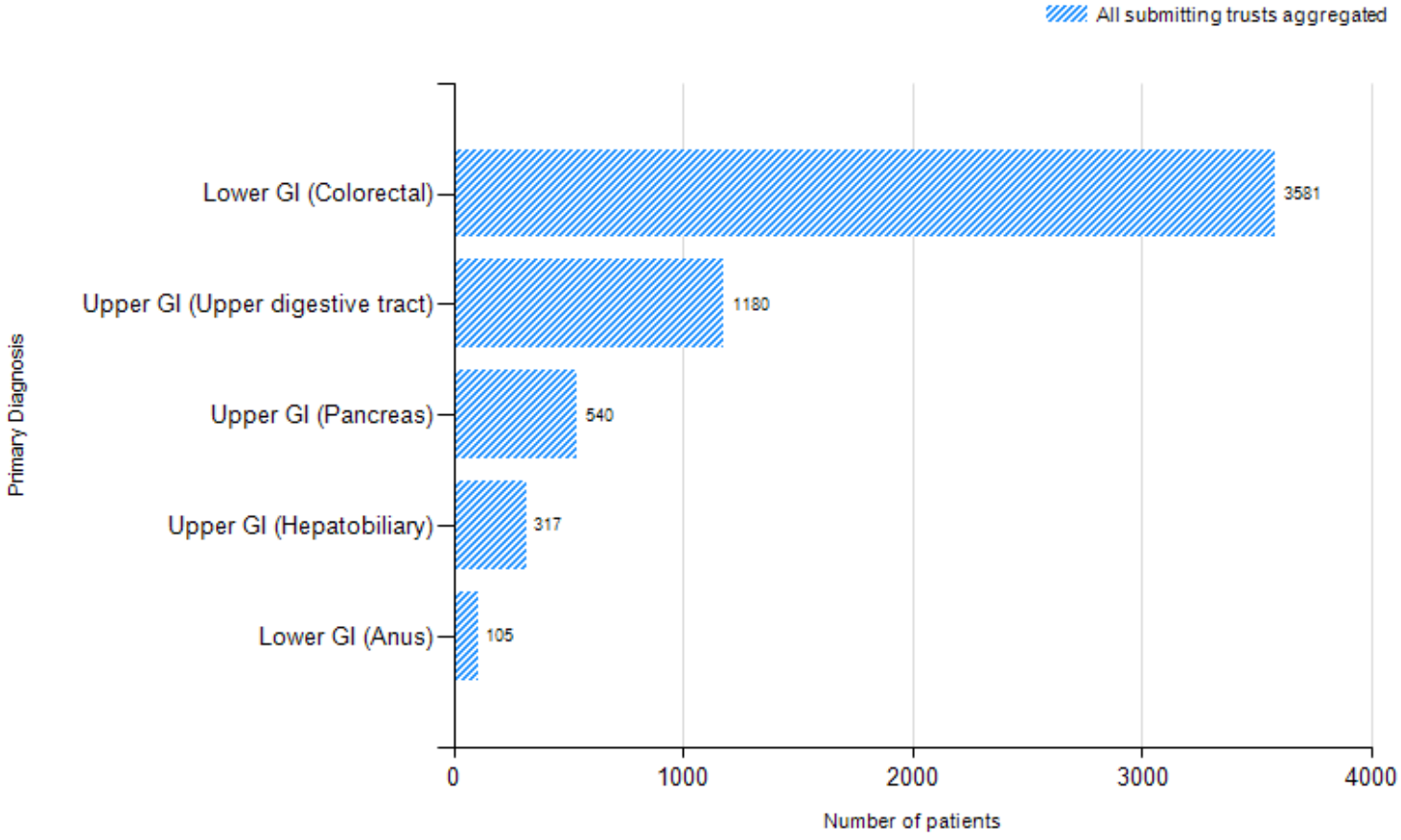
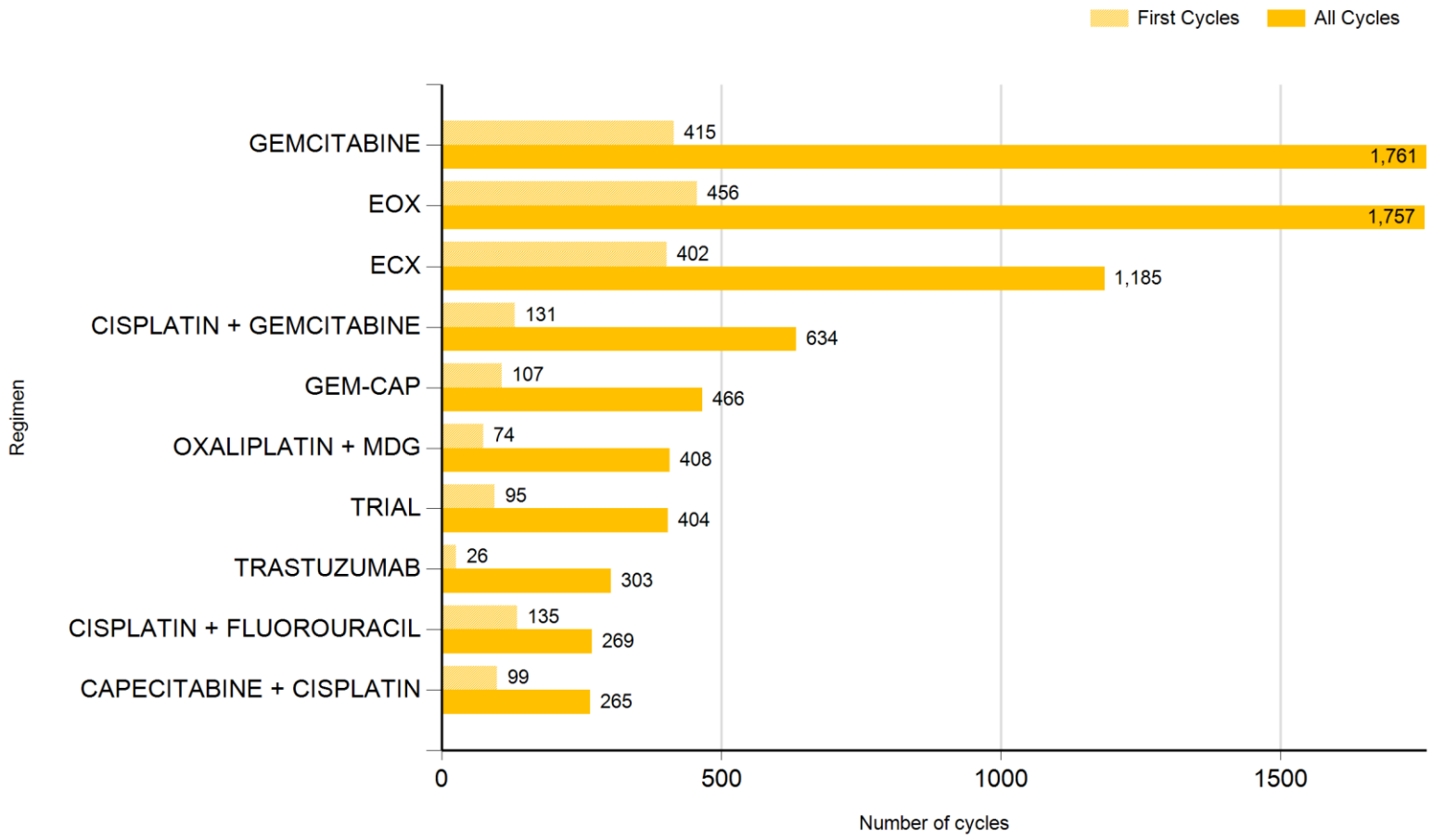


# Top Regimens by Diagnostic Group

## Upper GI †

All submitting trusts aggregated

Data received for April 2012 - September 2012. Patients aged 16 and over



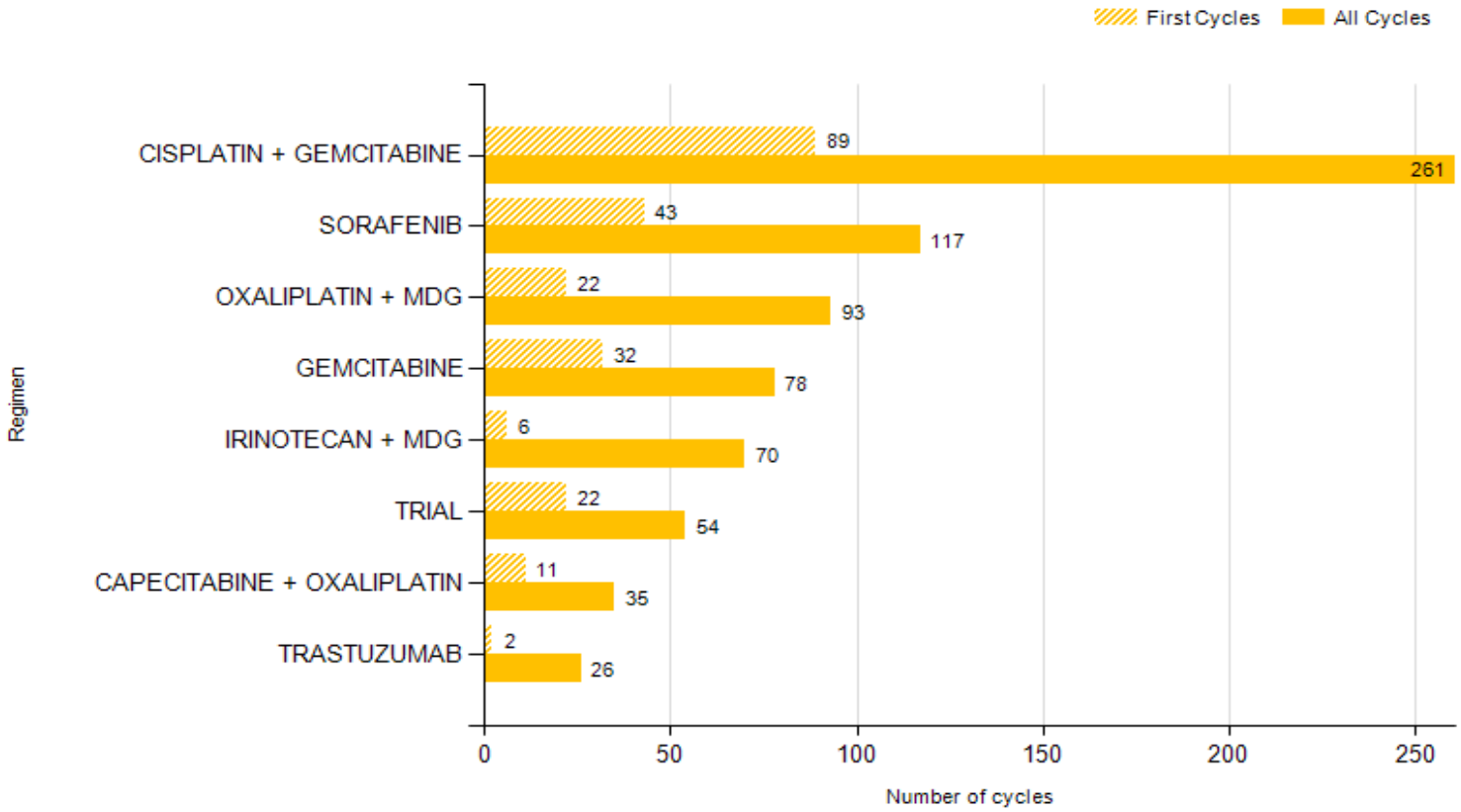
# Top Regimens by Diagnostic Group

## Upper GI (Hepatobiliary)

**ICD10: C22-C24**

All submitting trusts aggregated. Patients aged 16 and over

Data received for April - July 2012



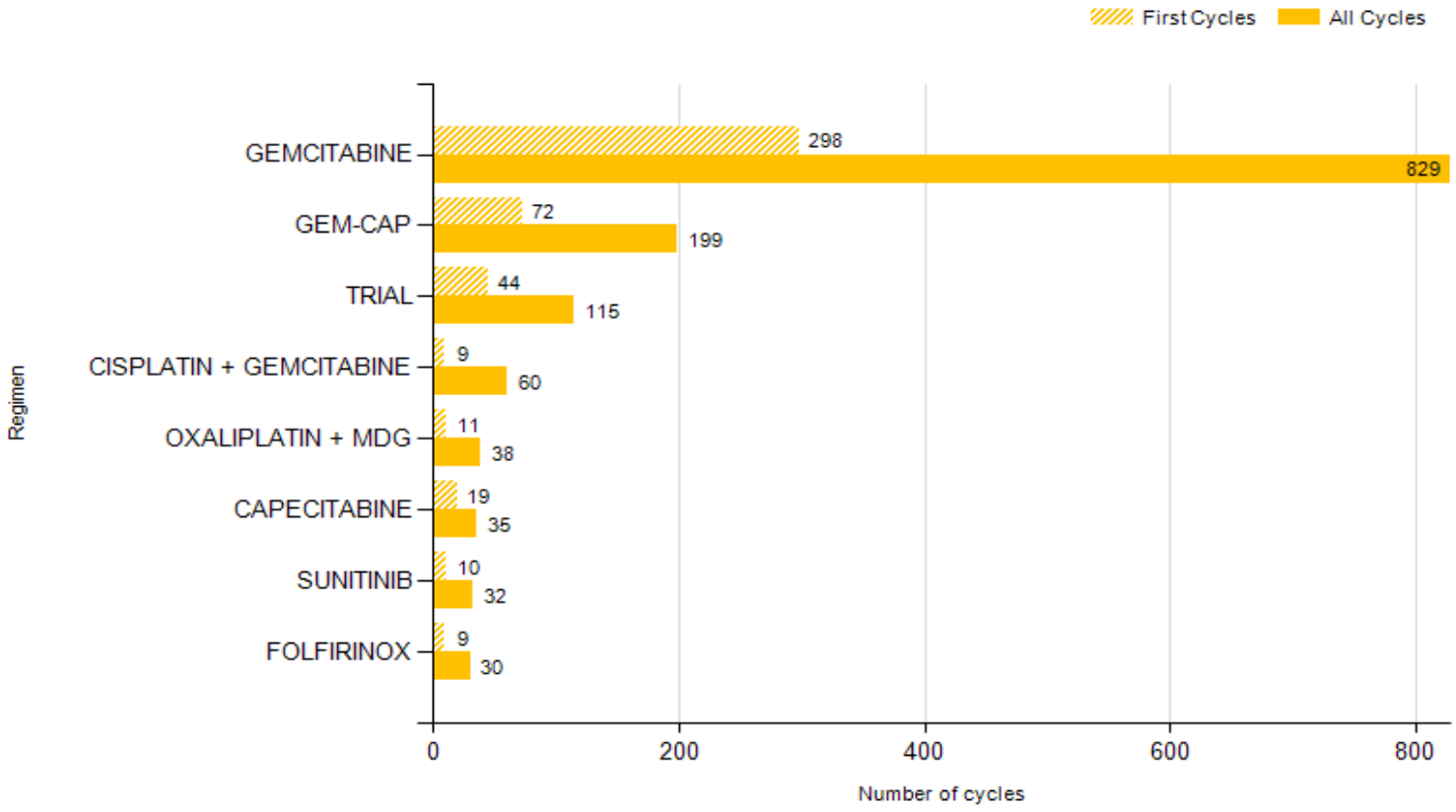
# Top Regimens by Diagnostic Group

## Upper GI (Pancreas)

**ICD10: C25**

All submitting trusts aggregated. Patients aged 16 and over

Data received for April - July 2012



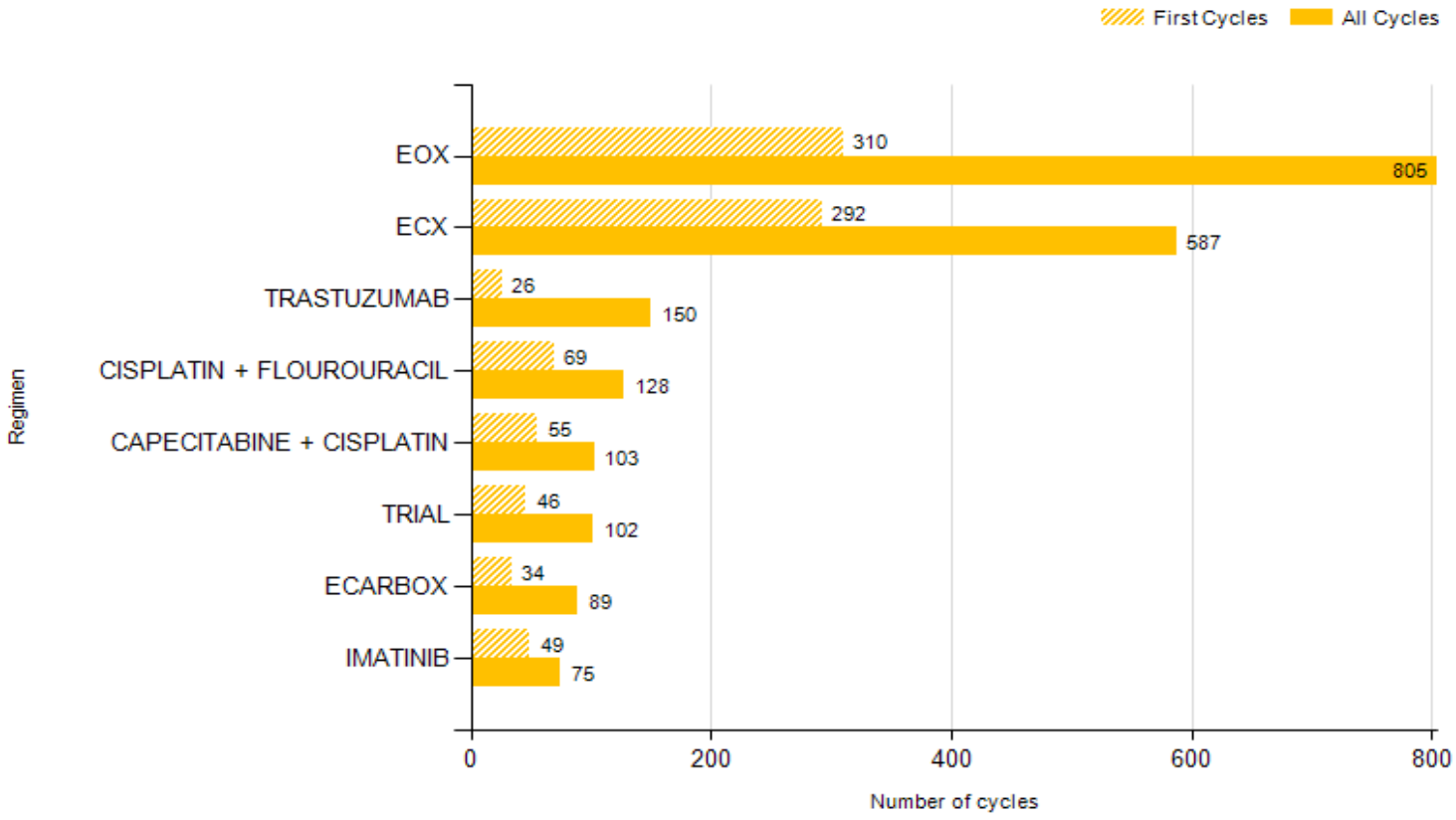
# Top Regimens by Diagnostic Group

## Upper GI (Upper digestive tract)

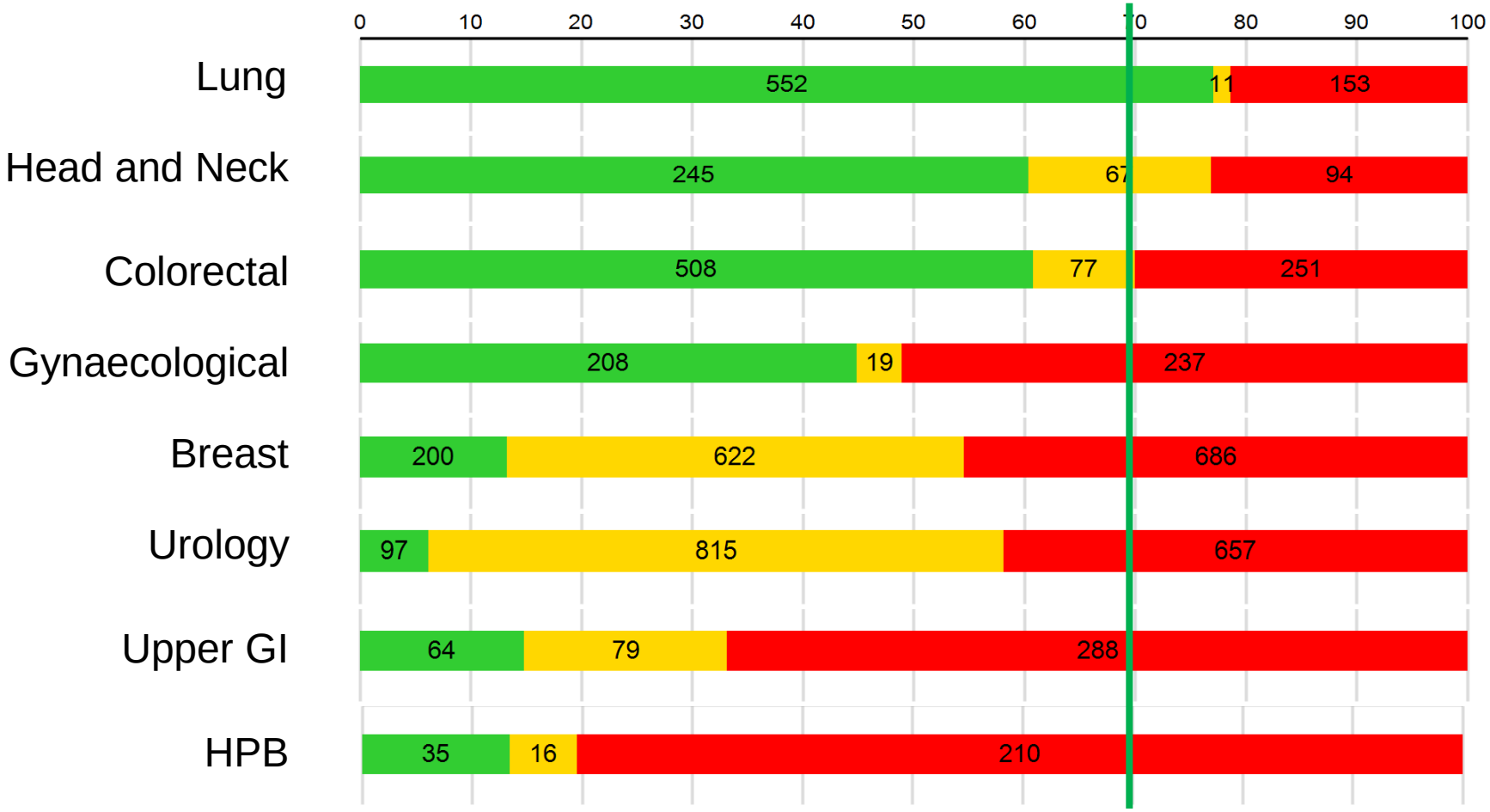
**ICD10: C15-C17**

All submitting trusts aggregated. Patients aged 16 and over

Data received for April - July 2012



# Staging Completeness (MDT) – 2011/12



# Summary

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- COSD is one of the key elements in a revolution in cancer data and intelligence
- Linked to other data sources will transform the range and timeliness of reports
- Data quality is key and clinical engagement leadership & leadership are vital

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www.ncin.org.uk

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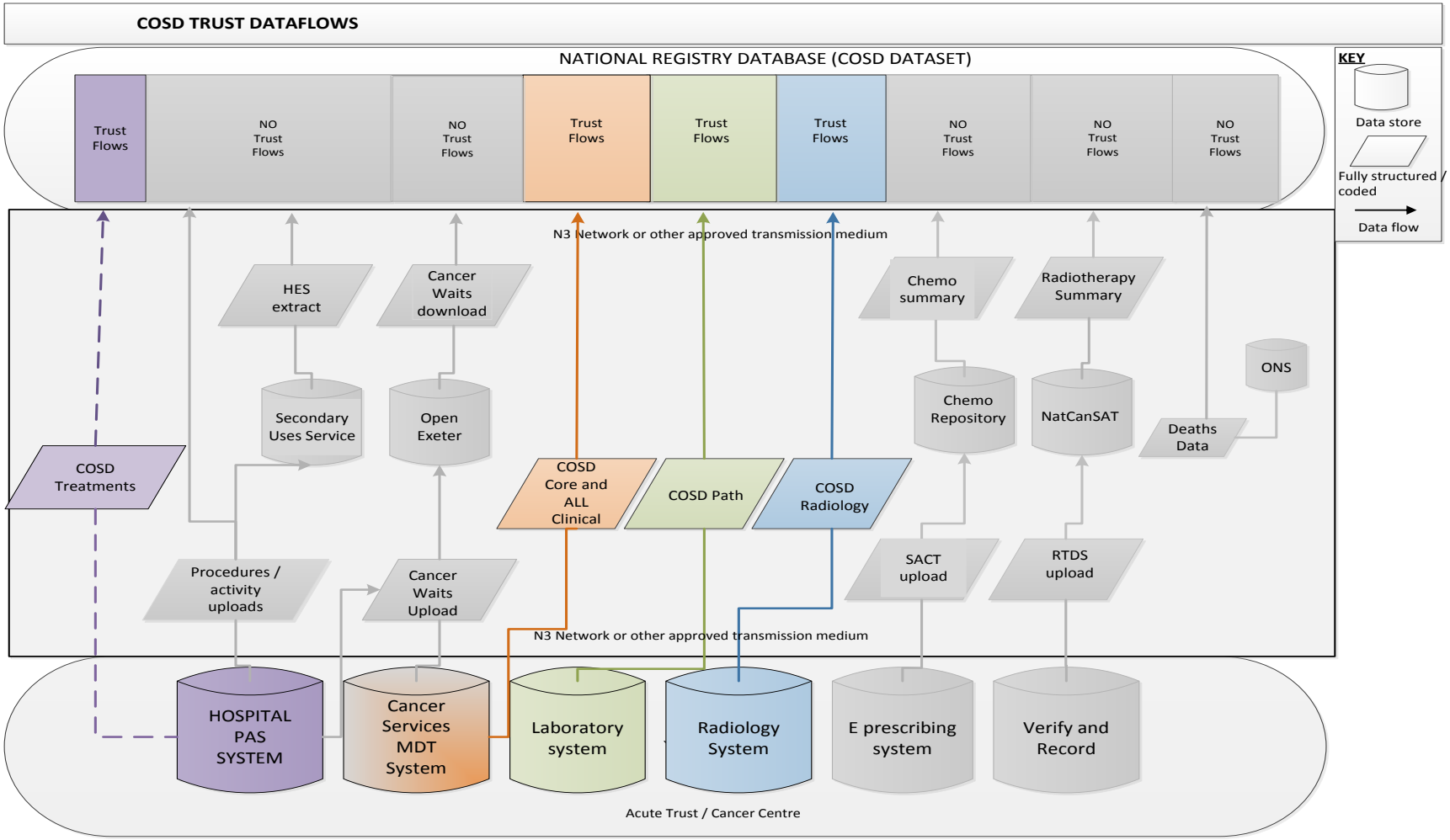
# Direct Provider data flows



# Information Governance (1)

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- S251 NHS Act exemption
  - All cancer registries covered – one annual application
  - Annual renewal through National Information Governance Board (NIGB) and corresponding statutory instrument
- Caldicott Guardian
  - sign-off required to allow transfer of data to and from organisations
  - existing signoff covers COSD

# Information Governance (2)

- Data Protection Act
  - All cancer registries are registered under the DPA.
  - Fair processing notices, including rights to withdraw consent, are provided through the UKACR Patient Information Leaflet
  - Leaflet available from:

www.orderline.dh.gov.uk/ecom_dh/public/home.jsf

ACR078 About Cancer Registration