Kent and Medway Cancer Network

Cancer data collection: The Kent and Medway Experience

National Cancer Intelligence Network Launch

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Background

Kent and Medway Cancer Network

- Kent and Medway Cancer Network established 2000
- NSSGs (Disease Orientated Groups/DOGs) established 2001/2
- Each DOG recognised the importance of understanding clinical outcomes
  - Major enthusiasm and commitment for the development of standardised cancer data sets across the network

Network house-keeping rules

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1. Common data set definitions across the network
2. NHSCDS compatible
3. Specialist data set compatible (e.g. ACP, BASO, BAUS)
4. NCASP compatible (where these existed)
5. OPCS procedure codes and disease site SNOMED codes to be embedded in data sets to facilitate improved and standardised coding

How?

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1. Multiple stand alone systems in existence
    - Data definitions defined by system rather than clinicians
    - Systems would not talk to each other
    - Data extraction difficulties

2. Agreement that a network wide platform was required

3. Market testing

Market testing

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Off the shelf

- You get what you pay for
- Generally used as a standalone system for one trust
- Developers implement the solution once for all client Trusts
- You know that the new datasets will be implemented and validated
- Standardised training/training materials/screen layouts
- You know it's going to work
- It's somebody else's problem
- All you have to do is roll out
- Depend on somebody else to decide on new features and how the system will operate
- Little say on developments at local level

Customisable

- You can use it for anything you want
- Can be used across multiple trusts/provider units
- Local data collection for interested clinicians
- Use can extend beyond the original spec
- Additional non-cancer uses, share cost of the system
- You can implement new datasets in the way that best works for your organisation
- You have totally flexibility
- Development overheads
- Flexible reporting and letters

We have a system managed from the Network but with individual Trusts able to make their own changes and customise the system.

InfoFlex agreed

First steps

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1. InfoFlex installed across the network
2. Arrival of 14, 31 & 62 day target monitoring
3. InfoFlex hijacked as monitoring tool
4. Disappointed clinicians as progress on clinical data collection takes a back seat
5. Not all bleak news…

Lung Cancer

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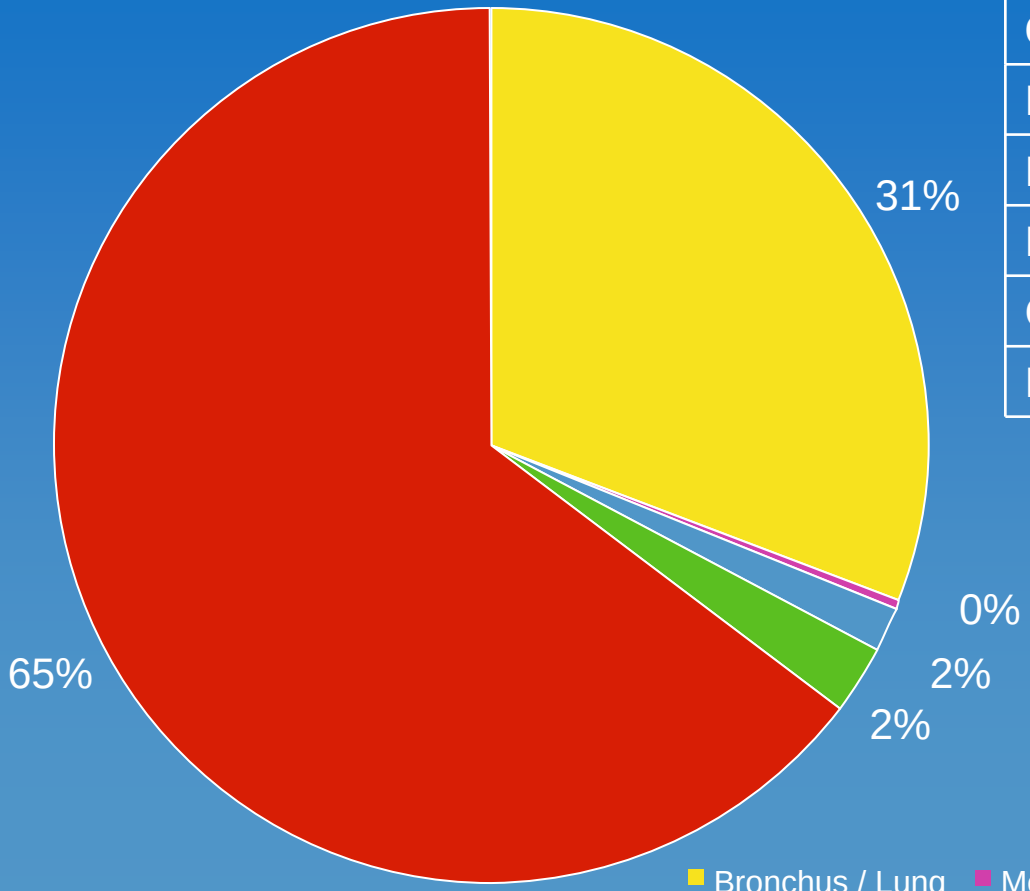
Two week wait referrals for the whole of Kent and Medway – for 2007



Cancer Type	Number of cases
Bronchus / Lung	346
Mediastinum	4
Mesothelioma	19
Other	27
Non cancer diagnosis	726

Lung Cancer

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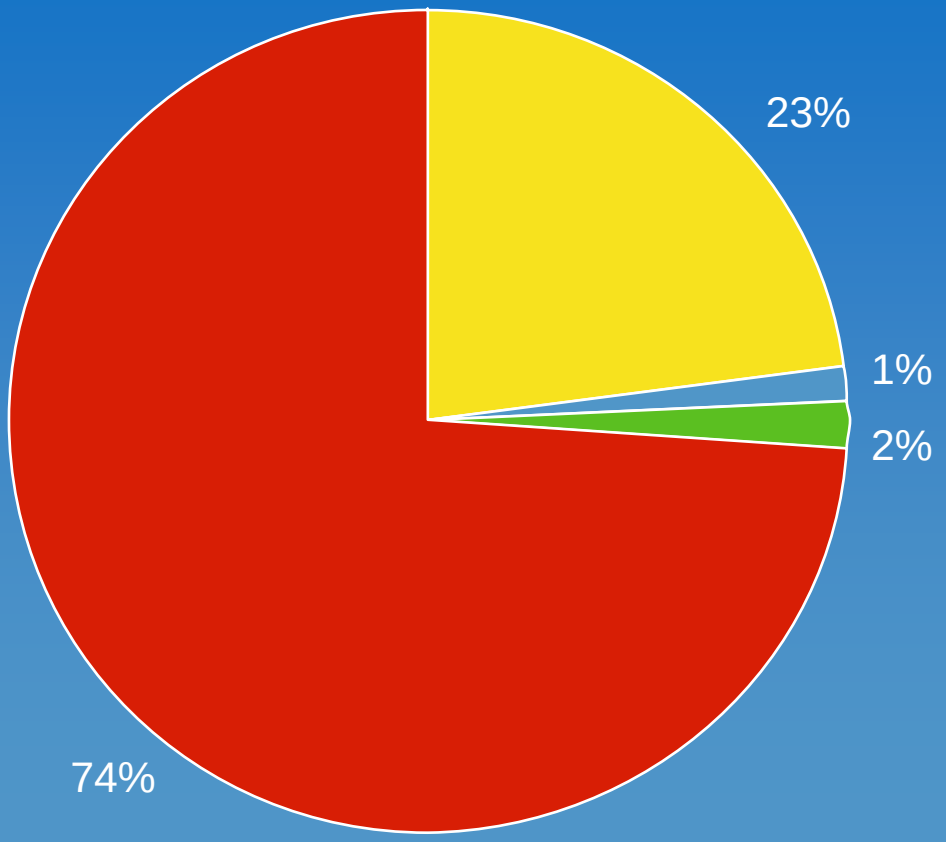
Two week wait referrals in Dartford – for 2007



Cancer Type	Number of cases
Bronchus / Lung	51
Mediastinum	0
Mesothelioma	3
Other	4
Non cancer diagnosis	164

Lung Cancer

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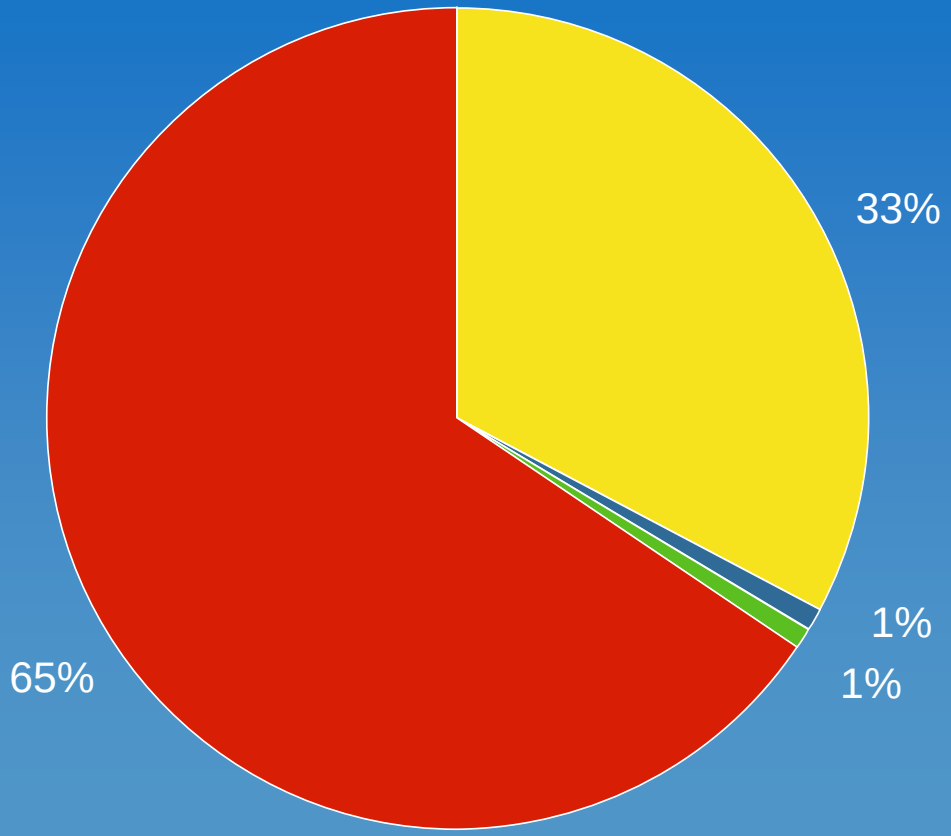
Two week wait referrals in East Kent – for 2007



Cancer Type	Number of cases
Bronchus / Lung	151
Mediastinum	0
Mesothelioma	4
Other	4
Non cancer diagnosis	302

Lung Cancer

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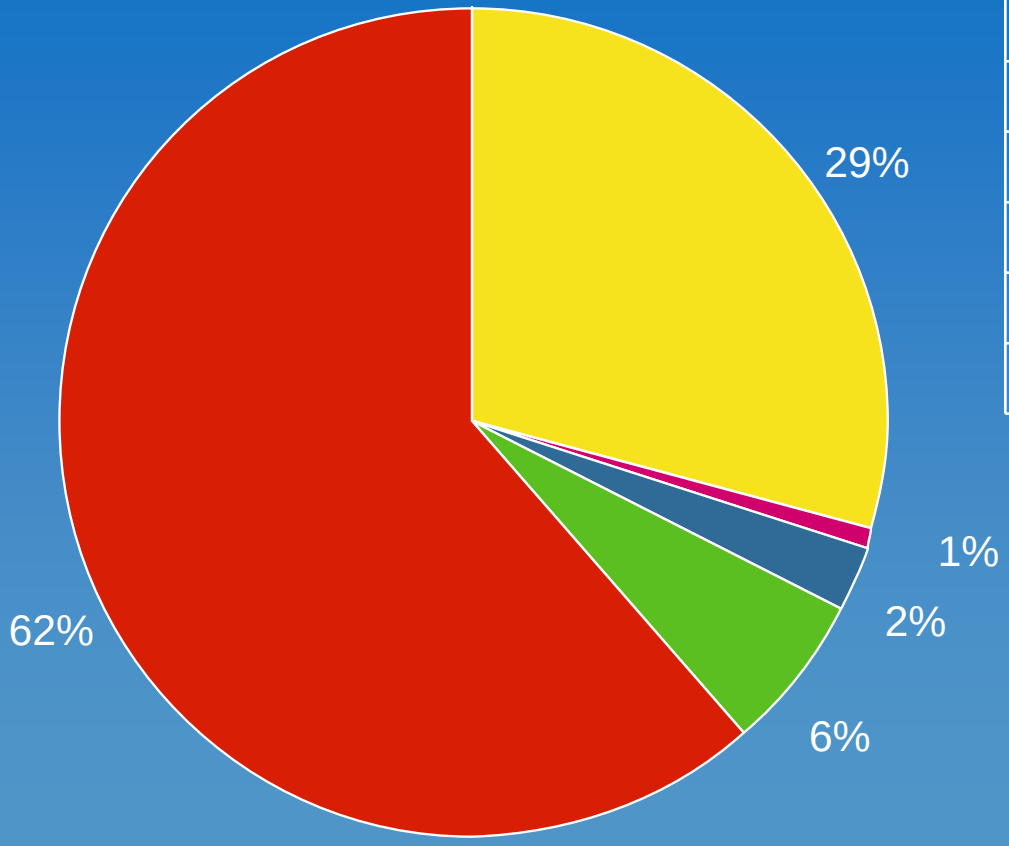
Two week wait referrals in Maidstone and Tunbridge Wells – for 2007



Cancer Type	Number of cases
Bronchus / Lung	346
Mediastinum	4
Mesothelioma	19
Other	27
Non cancer diagnosis	726

Lung Cancer

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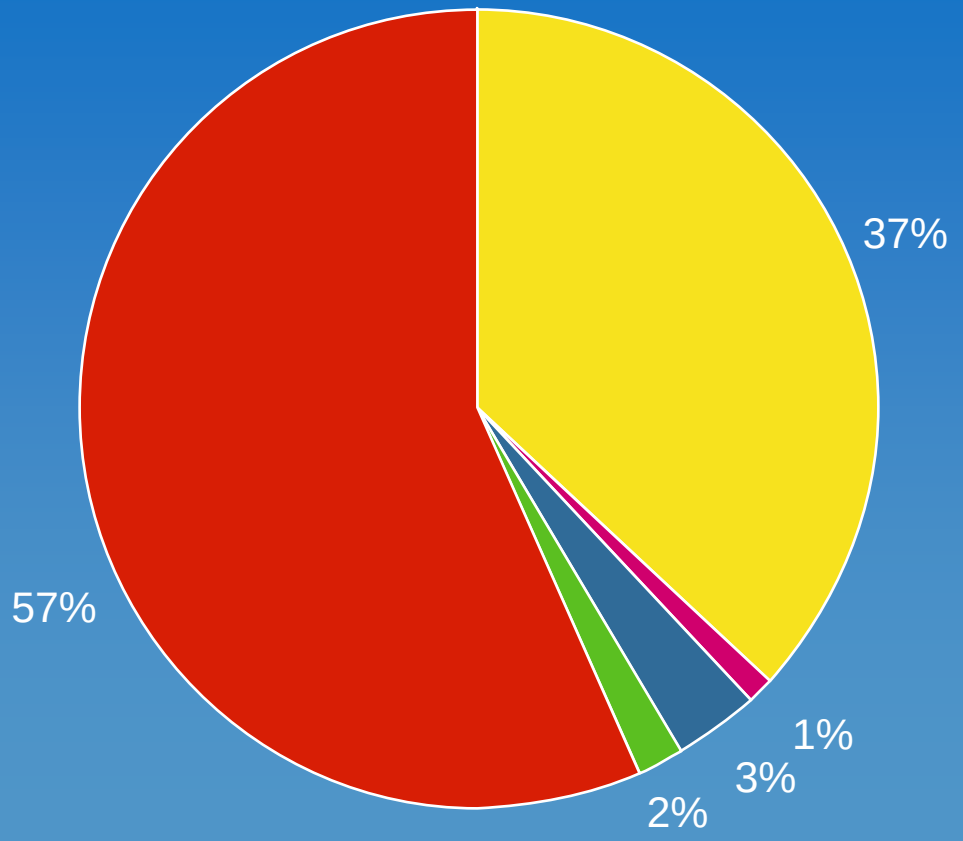
Two week wait referrals in Medway – for 2007



Cancer Type	Number of cases
Bronchus / Lung	70
Mediastinum	2
Mesothelioma	6
Other	4
Non cancer diagnosis	107

Upper GI Cancer

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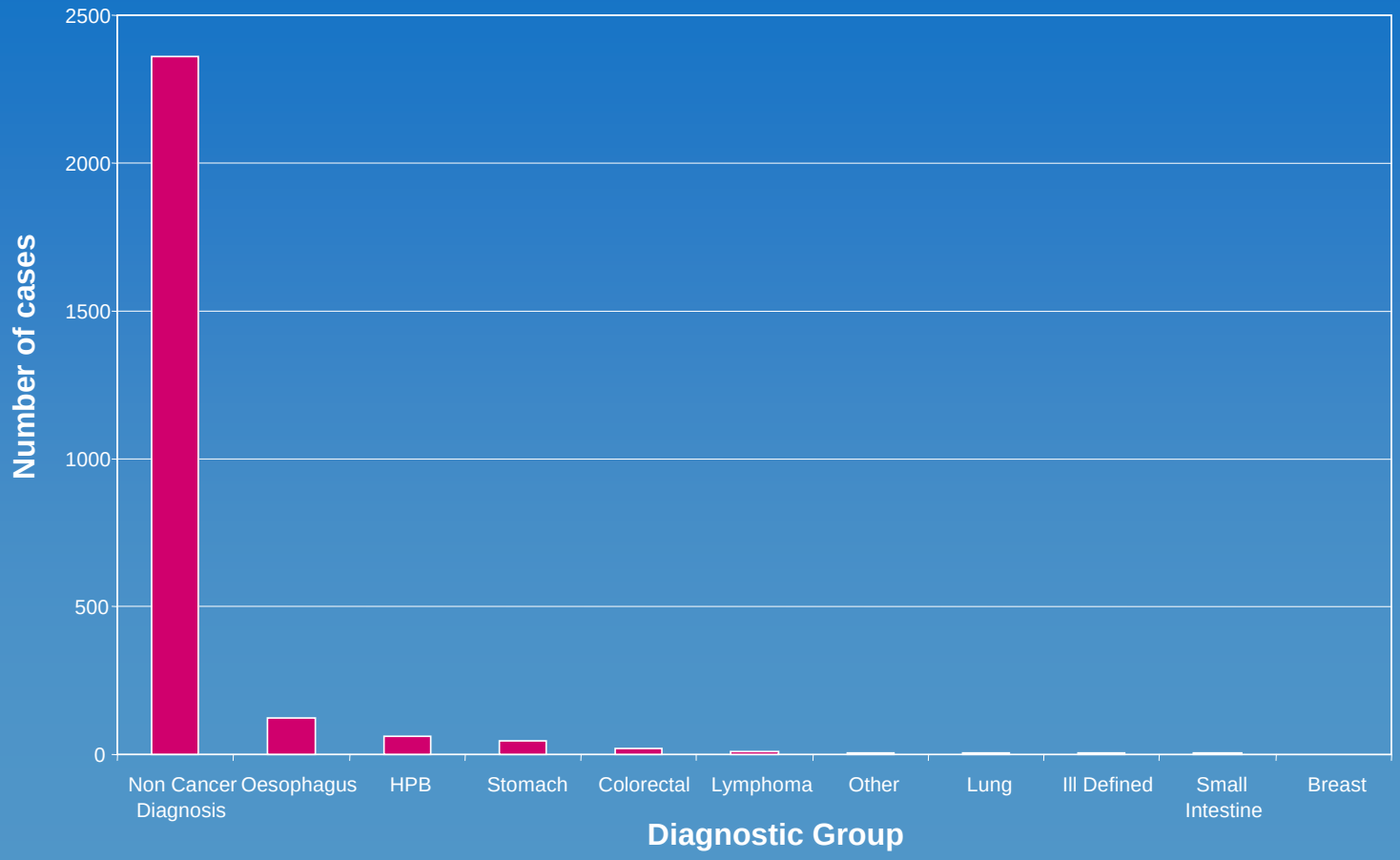
Two week wait referrals in Kent and Medway – for 2007



Diagnostic Grouping	Number of cases
Non Cancer Diagnosis	2359
Oesophagus	124
HPB	62
Stomach	48
Colorectal	21
Lymphoma	11
Other	7
Lung	6
Ill Defined	3
Small Intestine	3
Breast	1

Upper GI Cancer

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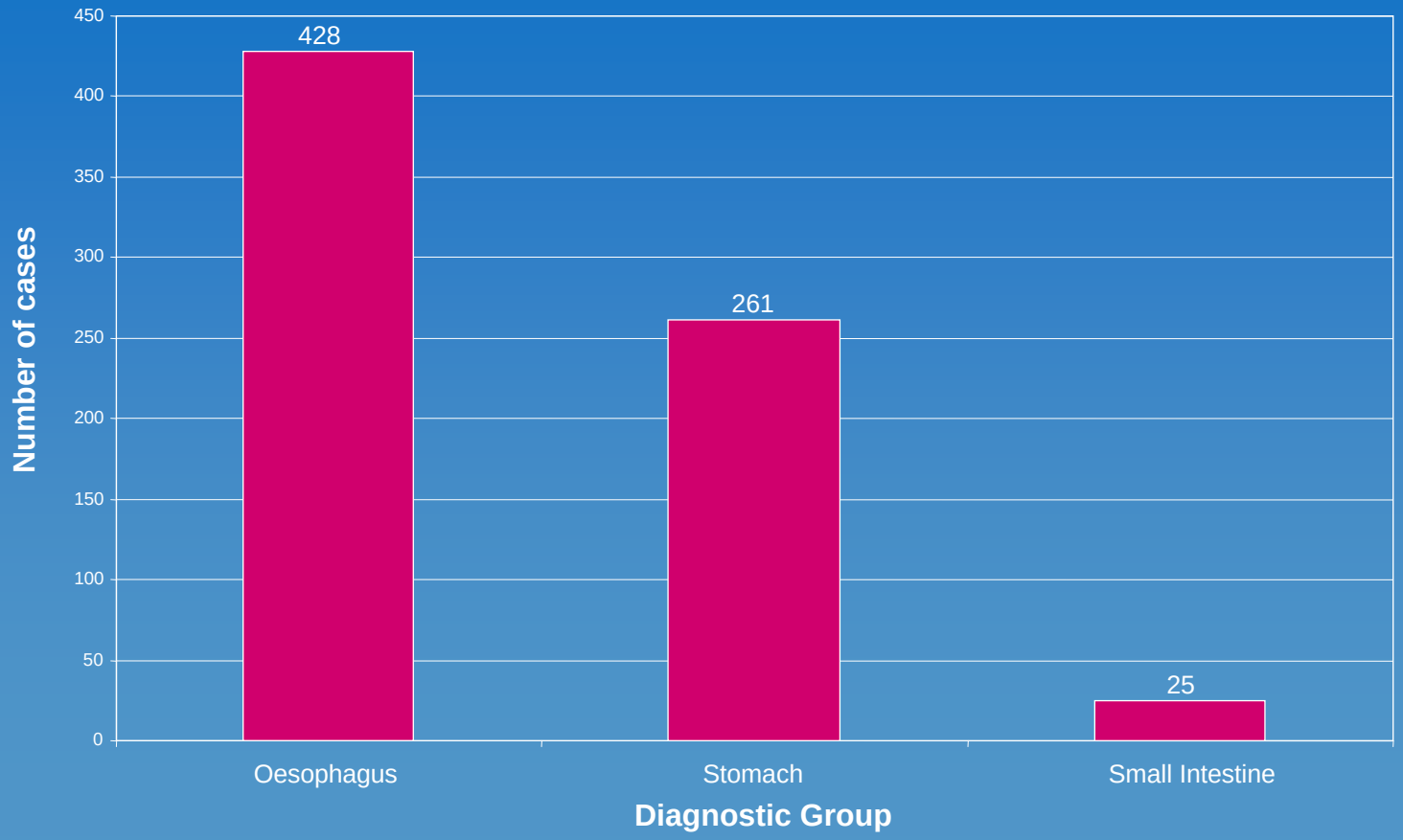
Non-urgent referrals in Kent and Medway – for 2007



Diagnostic Grouping	Number of cases
Oesophagus	428
Stomach	261
Small Intestine	25

Upper GI Cancer

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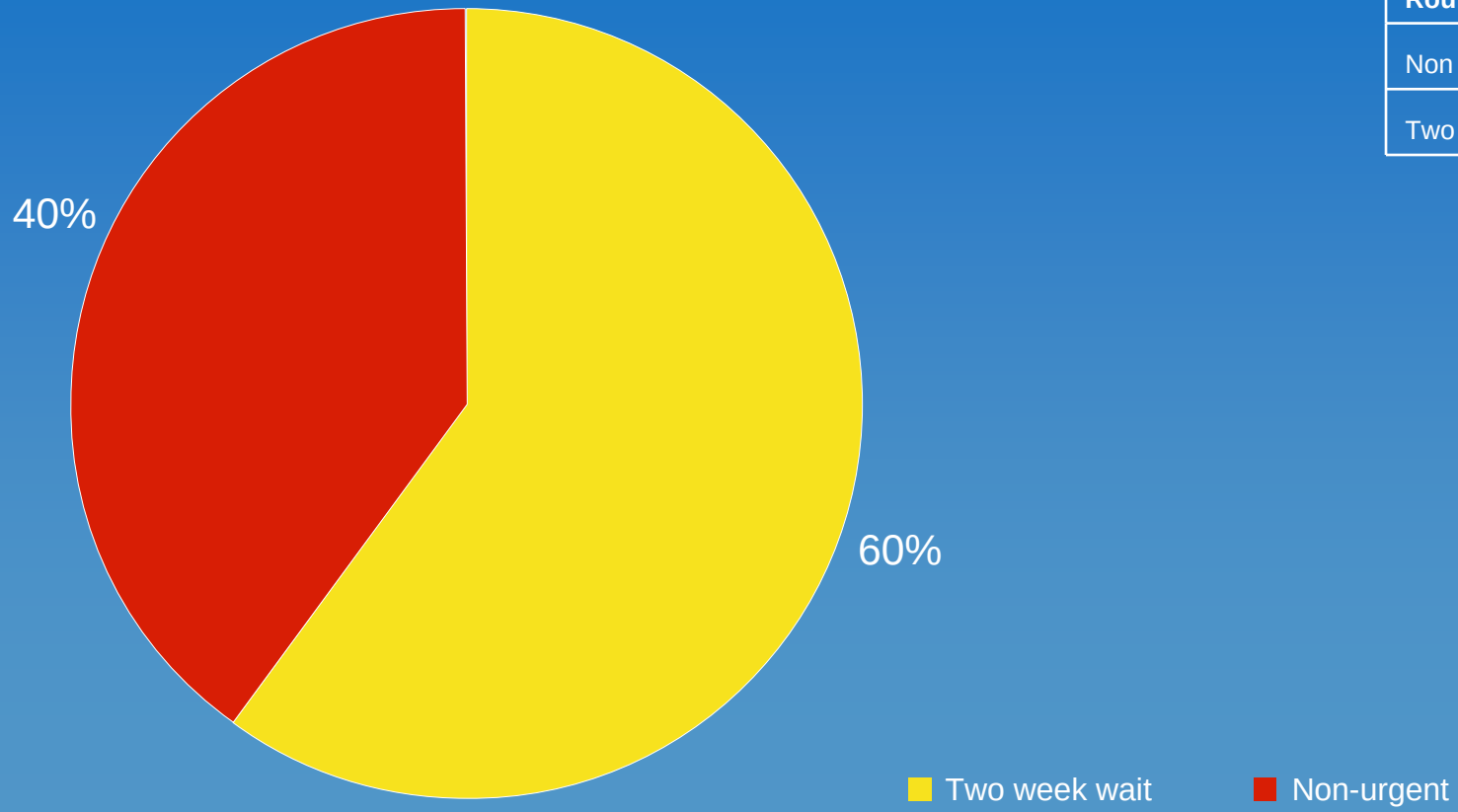
Positive Upper GI diagnoses in in Kent and Medway for 2007 ‘Non-urgent’ vs ‘two week wait’

Route	Number of cases
Non Urgent	188
Two week wait	286



Ovarian Cancer Referrals Showing Staging

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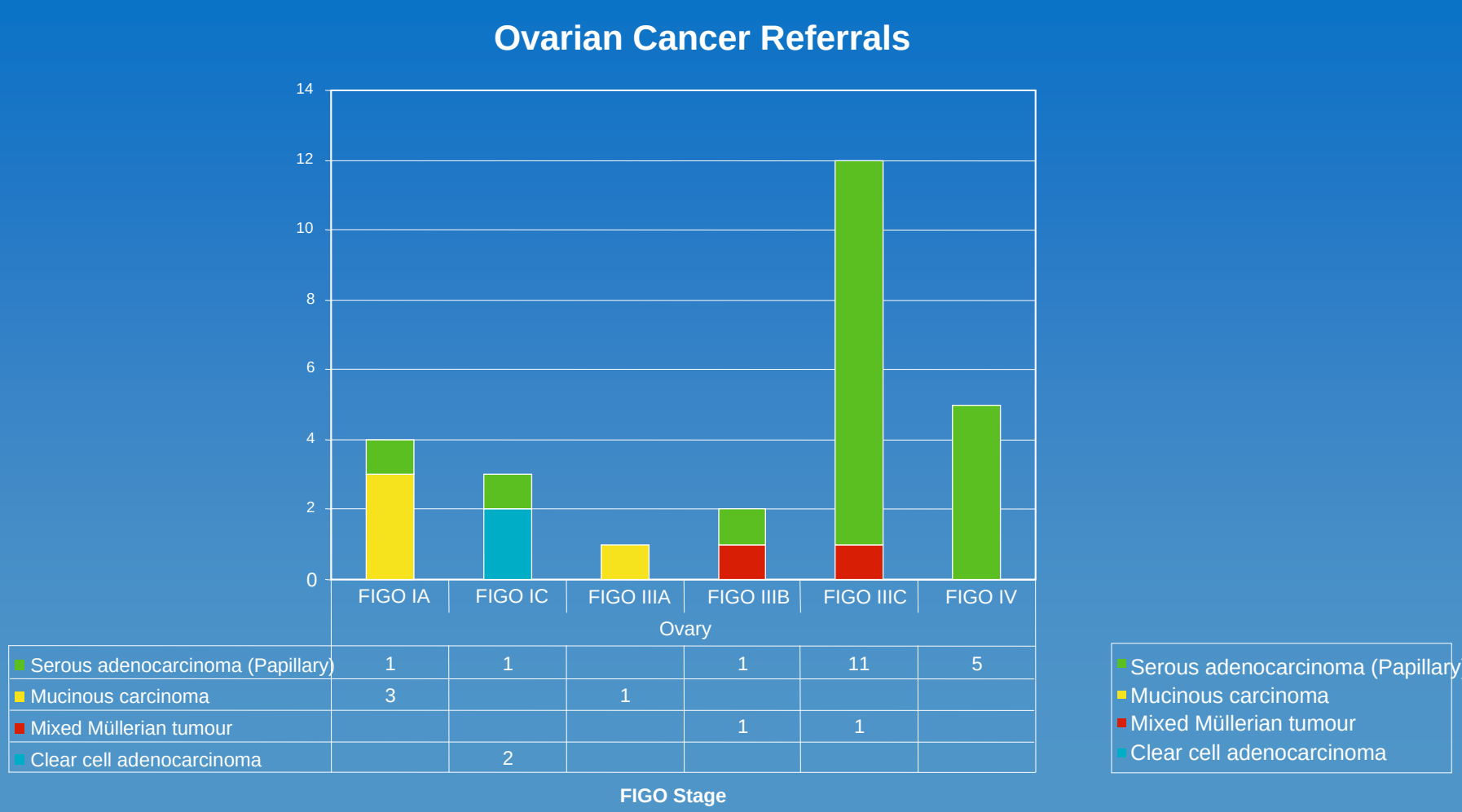

Progress 1

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1. Pilot programme to test electronic transfer of data to TCR
   - We know it works
   - Shelved for two years (staff changes!)
   - Now being resurrected
2. Target data set embedded across the network
3. Resume the focus to collect clinical data
4. Cancer Reform Strategy / NCIN levers for data collection
5. Re-engagement of clinicians
6. Data sets
   - Completely updated in line with new OPCS coding
   - Streamlined to highlight ‘must do’ core data items

Data Collection

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Data Collection

The MDT responsible for a particular element/episode of care along the patient pathway of care is the MDT responsible for the collection and validation of the data items associated with those elements/episodes. It is the responsibility of individual MDT lead clinicians and MDT co-ordinators to ensure that robust mechanisms for data collection and validation are in place.

This MDS has been designed so that if MDTs do not yet have access to the resource to collect agreed data items electronically it can be downloaded in hard copy format. A standard hospital “sticky label” can be applied to identify the patient; “tick boxes” have been provided for most other data items.

Every effort should be made to collect **RED** data items.

Items in **Bold GREEN** are Cancer Registry and NCIN Core Items, if no other data items are collected – these should be!

Items in **BLUE** need only be collected at the discretion of MDTs and/or the DOG and probably only then in response to collecting data for fixed term agreed audit projects.

Colorectal Data Sets

(& Gynae & UGI examples)

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Colorectal Data Sets	
Mandatory Fields (NCIN/TCR National Contract)	
Mandatory Fields	
Non mandatory fields (local interest/agreed specific audit)	
Patient Name	
NHS Number	**Hospital Number:**
Date of birth:	**Male / Female:**
Sticky label	

Challenges 1

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1. Agreed that clinical procedures would always be mandatory

2. Agreeing definitions for procedures difficult

3. OPCS does not cater for all definitions when finally clinicians do agree

4. Use of “fudge” codes – not universally accepted – variations across the country

Challenges 2

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1. “Block dissections” and “lymph nodes” - massive problem

2. OPCS does not mention some fairly common lymph node clusters

3. Use of “fudge” codes common in:
   - Head and neck
   - Upper GI
   - Gynae
   - Breast
   - Urology
   - Gynaecology

K&M Data Sets 1

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(Refer to Thyroid Excel Spread Sheet)

1. Note difficulties of trying to define procedures requiring block dissections
2. Potential inaccuracies of “named” procedures
   - “Shauta”
   - “Modified Radical Hysterectomy”
   - “Ivor Lewis”
   - “McKeown”

K&M Data Sets 2

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(Refer to UGI Excel Spread Sheet)

Next generation K&M data sets

1. Clinicians can pick from complete lists of procedures
2. Caters for complex surgical procedures
3. System will provide a “coding string” to define procedure – based on strict coding hierarchies

When used well (1)

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Data sourced:

- Demographics (2-WW offices – standard for all patients)
- MDT data (histology, stage, treatment options)
- Procedures (direct input in theatres)

Data output:

- GP letters
- Operation returns
- MDT records
- Referral letters to oncology

When used well (2)

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Requirements:

- Committed MDT leads and teams
  (Must be prepared to own data collection)
2. Data collection process mapping
3. Review of MDM working – “roles and responsibilities” / “trade-offs”

Honest current situation:

1. *Good data collection in many teams*
2. *Only used to the full potential described by a couple of teams*

Hurdles

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1. Trusts to take responsibility for data collection
   (CRS is a useful lever – now getting the message)

2. Reduction of manual data input:
   - Cell path results by download via interface engine – in the pipeline
   - Links to be developed to ChemoCare
   - Chemotherapy and radiotherapy “action sheets” direct from oncology system
   - “Blood science” results direct from pathology – in pipeline

3. Robust links with NCASP (always changing)

Have we cracked it?

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No!

But we're working at it.