NCIN national cancer intelligence network
Using information to improve quality & choice

An Update on Cancer Registration

Di Riley

NCRI National Cancer Research Institute

CRS, December 2007

.....Better information on cancer services and outcomes will enhance patient choice, drive up service quality and underpin stronger commissioning;

[Chapter 8]

High quality data on:

- Clinical outcomes, including survival
- adjustments for co-morbidity and stage of disease.

Collection of defined datasets

- all cancer patients
- mandated through the National Contract.
- PCTs responsible for ensuring delivery

How to Use Indicators and Data?

- Support Clinical Commissioning Groups to:
  - Understand ‘cancer burden’ (GP Profile)
  - Understand local services (Service Profile)
- Provide benchmarked information
  - Support Service Specifications
  - Identify Key Performance and Quality Indicators

Major Surgical Resections England, 2004-6

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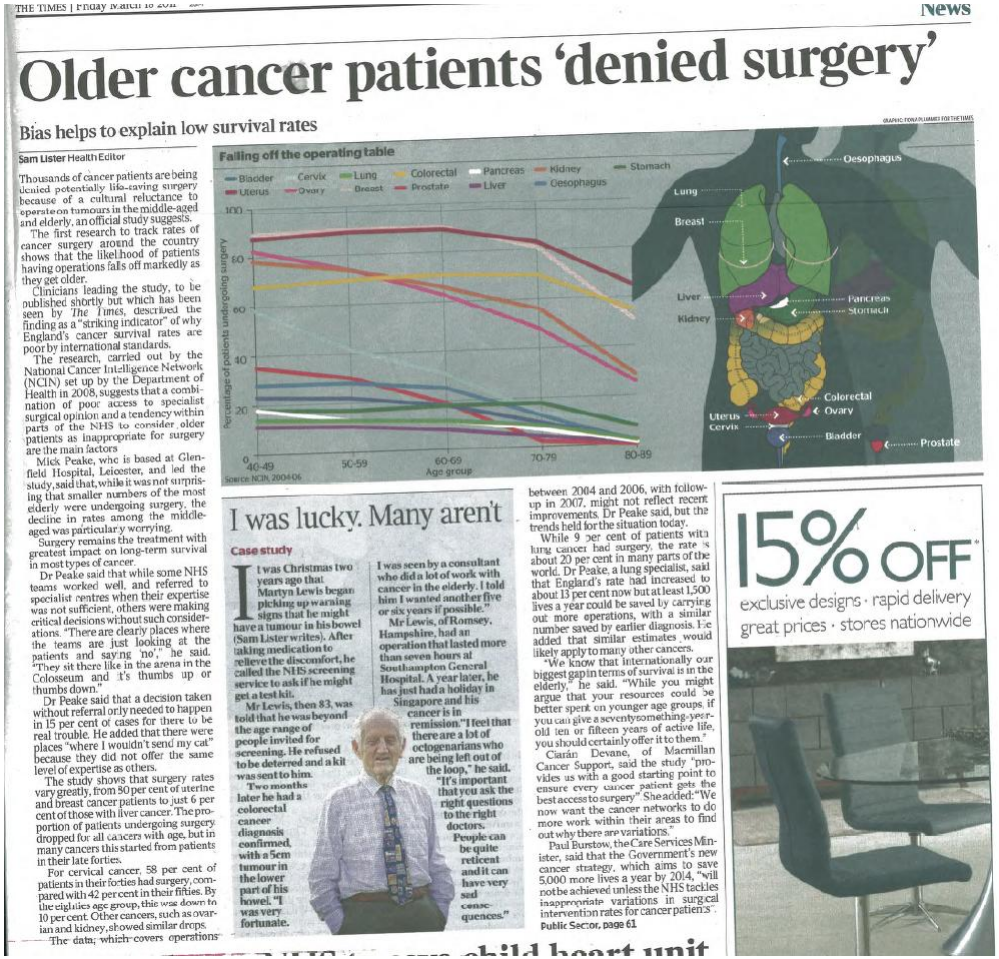


THE TIMES | Friday March 10 2011 News

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.

Mick 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 in most types of cancer.

Dr Peake said that while some NHS teams worked well, and referred to specialist centres when their expertise was not sufficient, others were making critical decisions without such considerations. "There are clearly places where the teams are just looking at the patients and saying 'no'," he said. "They sit there like in the arena in the Colosseum and it's thumbs up or thumbs down."

Dr Peake said that a decision taken without referral only needed to happen in 15 per cent of cases for there to be real trouble. He added that there were places "where I wouldn't send my cat" because they did not offer the same level of expertise as others.

The study shows that surgery rates vary greatly, from 80 per cent of uterine and breast cancer patients to just 6 per cent of those with liver cancer. The proportion of patients undergoing surgery dropped for all cancers with age, but in many cancers this started from patients in their late forties.

For cervical cancer, 58 per cent of patients in their forties had surgery, compared with 42 per cent in their fifties. By the eighties age group, this was down to 10 per cent. Other cancers, such as ovarian and kidney, showed similar drops.

The data, which covers operations 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 cancer had surgery, the rate is about 20 per cent in many parts of the world. Dr Peake, a lung specialist, said that England's rate had increased to about 13 per cent now but at least 1,500 lives a year could be saved by carrying out more operations, with a similar number saved by earlier diagnosis. He added that similar estimates would likely apply to many other cancers.

"We know that internationally our biggest gap in terms of survival is in the elderly," he said. "While you might argue that your resources could be better spent on younger age groups if you can give a seventy-something-year-old ten or fifteen years of active life, you should certainly offer it to them."

Ciarán Devane, of Macmillan Cancer Support, said the study "provides us with a good starting point to ensure every cancer patient gets the best access to surgery." She added: "We now want the cancer networks to do more work within their areas to find out why there are variations."

Paul Burstow, the Care Services Minister, said that the Government's new cancer strategy, which aims to save 5,000 more lives a year by 2014, "will not be achieved unless the NHS tackles inappropriate variations in surgical intervention rates for cancer patients".

Public Sector, page 61

Falling off the operating table

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

Percentage of patients undergoing surgery: 100, 60, 40, 20, 0
Age group: 40-49, 50-59, 60-69, 70-79, 80-89
Source: NCIN, 2004-06

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

GRAPHIC: TONY PLUMMER FOR THE TIMES

I was lucky. Many aren't

Case study

It was Christmas two years ago that Martyn Lewis began picking up warning signs that he might have a tumour in his bowel (Sam Lister writes). After taking medication to relieve the discomfort, he called the NHS screening service to ask if he might get a test kit.

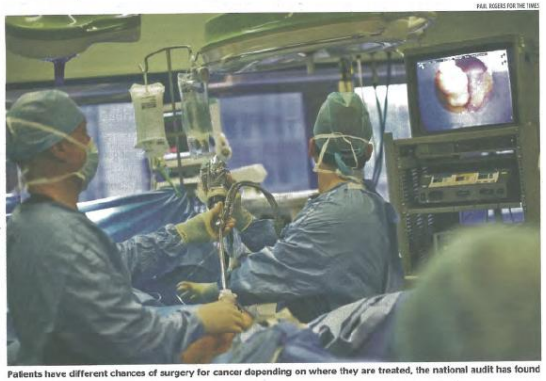
Mr Lewis, then 83, was told that he was beyond the age range of people invited for screening. He refused to be deterred and a kit was sent to him.

Two months later he had a colorectal cancer diagnosis confirmed, with a 5cm tumour in the lower part of his bowel. "I was very fortunate. I was seen by a consultant who did a lot of work with cancer in the elderly. I told him I wanted another five or six years if possible."

Mr Lewis, of Romsey, Hampshire, had an operation that lasted more than seven hours at Southampton General Hospital. A year later, he has just had a holiday in Singapore and his cancer is in remission. "I feel that there are a lot of octogenarians who are being left out of the loop," he said. "It's important that you ask the right questions to the right doctors. People can be quite reticent and it can have very sad consequences."

Beyond repair: how your age is a factor in the treatment of cancer

There are widespread inconsistencies over the decision to operate, a national audit found. **Sam Lister** reports



PAUL ROGERS FOR THE TIMES

Patients have different chances of surgery for cancer depending on where they are treated, the national audit has found

Mick Peake may be one of the country's leading chest physicians but he is refreshingly honest about episodes in his own career that show some of the shortcomings of his profession. When he was based at a district general hospital in Yorkshire he saw cancer patients who, he thought, could not be referred for surgery. The tumours were too complex or the patient too compromised by other health problems. Sometimes it might even have been that they were simply too old.

Years later, and now at Glenfield Hospital in Leicester, the veil has lifted. "I thought I knew, but now that I am in a big specialist centre I can see," Dr Peake says. "I know that there were patients I didn't refer on because I thought you couldn't operate on that sort of thing. But you can."

Understanding what others perceive can and can't be done in cancer has become something of a mission for Dr Peake. As clinical lead of the National Cancer Intelligence Network, he runs a groundbreaking research programme analysing patient data collected from hospitals and cancer registries throughout England, showing how people are treated for different problems. The variations are stark, signalling the inconsistencies in care that hold the key to why the country struggles with cancer. And no more so than when it comes to surgery.

When the results came through for the first national audit of surgical resections for cancer, seen by *The Times* and to be published shortly, several trends became clear. Patients could have the same complaint, such as bowel or ovarian cancer, and have dramatically different chances of surgery depending on where they were treated. It could vary widely between types of tumour and, most noticeably, it also appeared to be heavily dependent on the patient's age.

"When I first saw these statistics, it was the single fact that struck me most," Dr Peake observes. "The relatively young age at which the rates of surgery start to drop is dramatic. It is much earlier than you would expect." For the 13 key cancer sites around the body included in the analysis, the proportion of patients undergoing surgery decreased significantly as they got older — down to less than 7 per cent for half of these cancers in the over 80s. Yet this was not an issue simply for the very old, when other diseases and physical frailty play a greater part in decisions about surgery. The drop appears to be starting for those in their 50s.

Dr Peake believes that this reflects a culture in cancer care — and problems with how it is structured — that contribute to England's poor survival rates and thousands of potentially avoidable deaths every year. Surgery is the treatment that has the greatest impact on long-term survival in most types of cancer. It can also significantly improve symptoms, even in situations where life expectancy is not great. And yet some doctors in some places seem to view it as a no-go area.

"I have seen people in meetings stand up and say: 'My patients are all older, they are all sicker, they all come in having had a heart attack in the outpatients department.' There are always those excuses. There's an attitude out there," he says.

The culture is one that applies to patients who may not question their fate and take the line of "I've lived to 70, my dad lived to 70", Dr Peake accepts. But he also feels that too many doctors are seeing people without the background expertise on the possibilities and potential for surgery. A significant part of the problem lies with poor access to specialist surgical teams, he says. "There are some places I wouldn't want a member of my family anywhere near. There are some where I wouldn't send my cat."

While Dr Peake emphasises that there are not definitive "rights" or "wrongs" when examining the data — further analysis may reasons for low rates in areas, such as better ac therapy — the work questions about why standards and approaches fluctuate so much. He adds that the statistics from 2004 and 2006, with patient follow-up in 2007, may be slightly behind improvements in some areas but the key conclusions still hold.

Late diagnosis, which leaves some patients with tumours too advanced to tackle with a scalpel, remains a very important piece of the jigsaw. But the less widely acknowledged problem is patients referred to basic district cancer al hospitals around the country which, as Dr Peake experienced in Yorkshire, do not get the expert insights. Whether a patient came from a deprived community or not seems to have surprisingly little influence.

For Dr Peake and his team, the new data is a "treasure trove" that can enlighten and empower patients and hold doctors and health service managers to account.

"This research should make every network and NHS trust, every professional body that runs these specialties, look at their own data. They should want to really see what it means, to explain these variations and explore what we need to do to encourage best practice," he says.

Inside today
Thousands of elderly

Teamwork

- Contact with a multidisciplinary team is crucial for proper surgical assessment, and includes a physician, surgeon, anaesthetist, radiologist and nursing staff
- Poor performance in these roles can affect the decision making — for instance a poor radiologist may over-interpret imaging of the tumour, and carry out a surgical operation
- An effective system requires a robust "spoke and hub" model. While some hospitals may not have such expertise, they should have contact with a specialist "hub" to advise

Mick Peake is clinical lead of the National Cancer Intelligence Network

March 2011

How do outcomes vary between hospitals?

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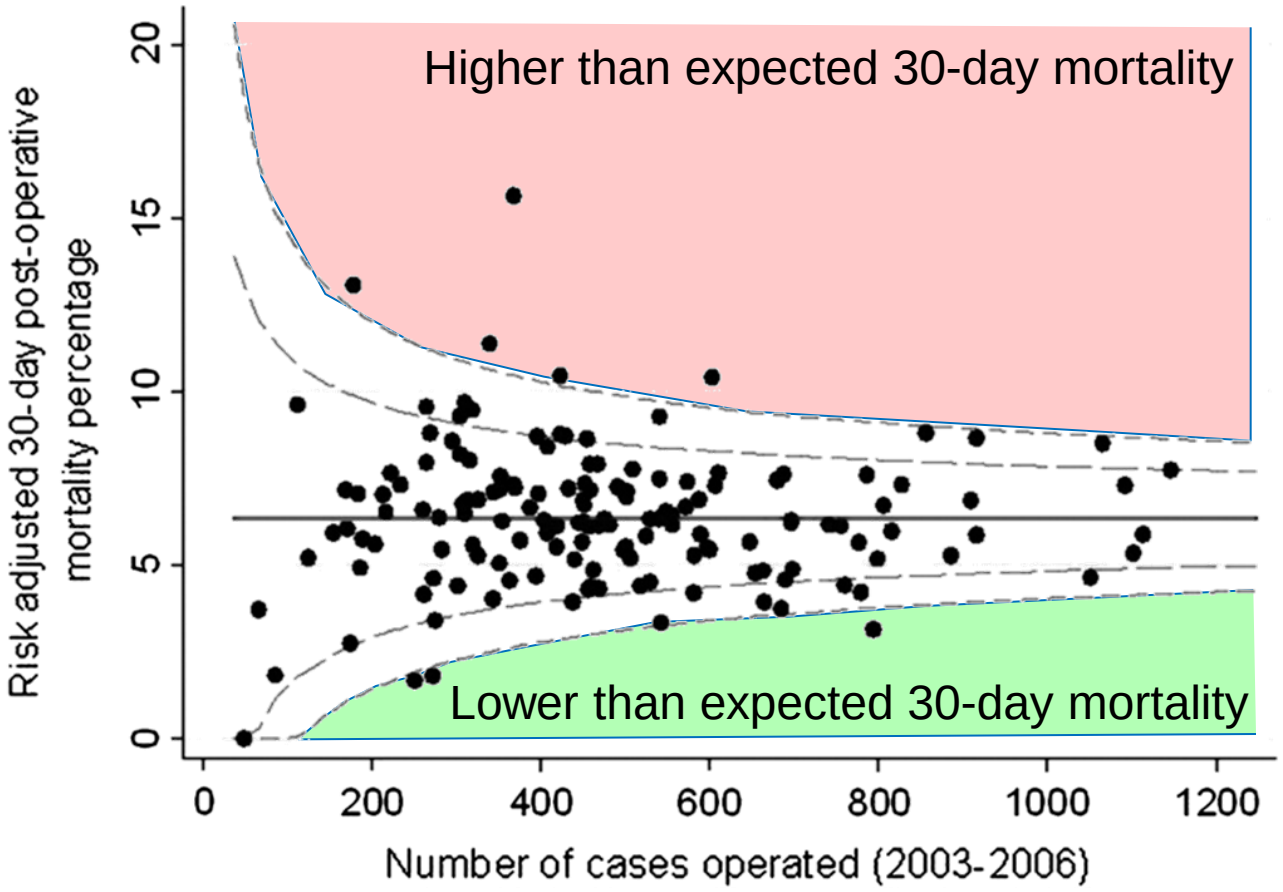


Morris *et al*. Gut, 2011

Issues?

- Timeliness and quality of data
  - Publish & polish OR
  - Polish & publish
  - Two years old TOO OLD!

- Are we collecting the correct data
  - Is it specific enough?
  - Can we support the requirements in IOSC?

Proposals and Solutions?

- Identify current information needs
- Collect data to support requirements
- Collate & make data available more timely
- Work together to a common vision
  - ‘revamp’ datasets
  - Work with MDTs and service providers
  - Modernise cancer registration

Key points – submitting the data

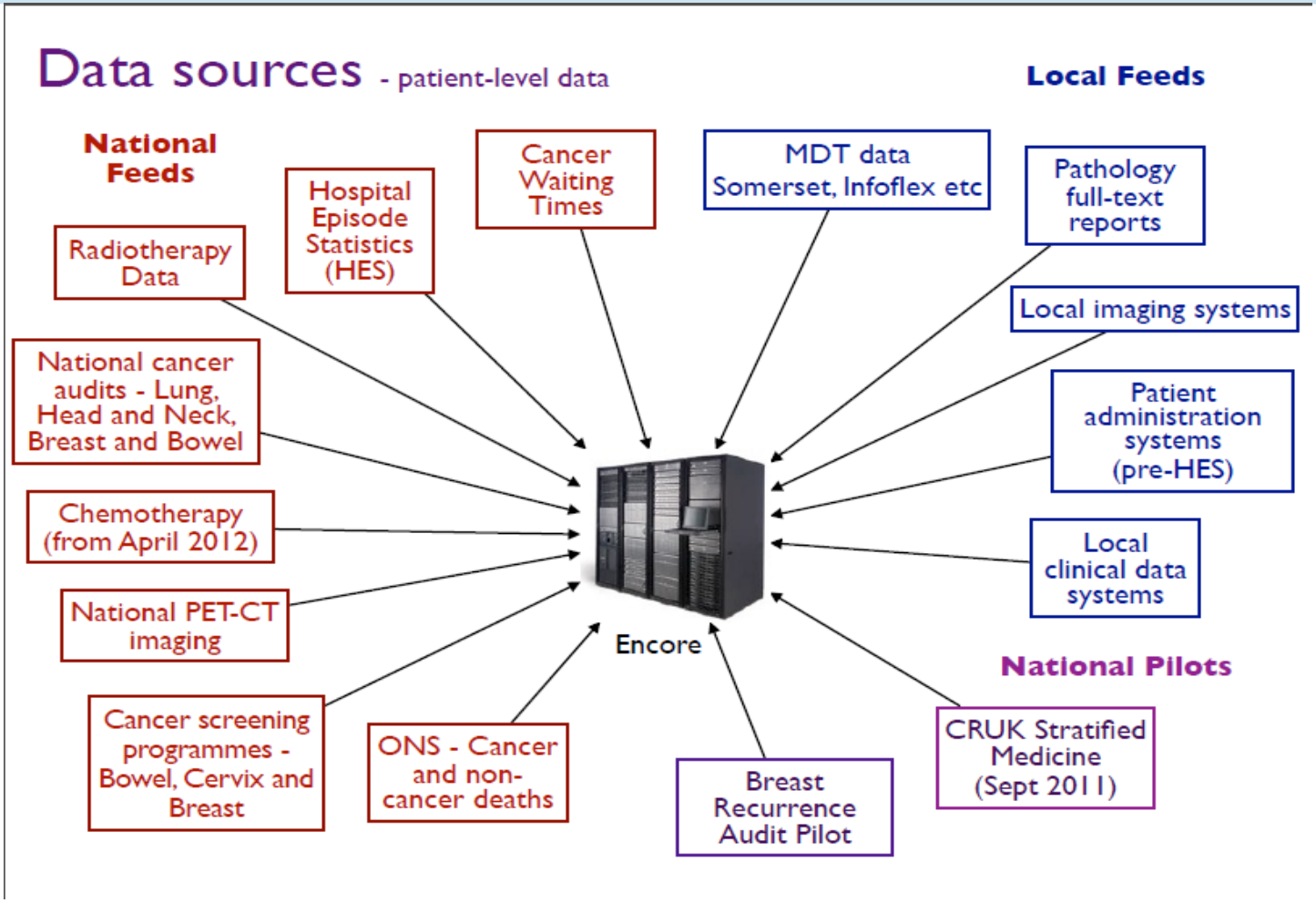
- COSD
  - replaces submission to cancer registries
  - trigger is new diagnosis/updates
  - can be submitted from different sources
  - submitted monthly
  - RCPath extracted from reports
  - Must get clinical support and ownership

GO LIVE END 2012

A single Cancer Registration Service for England

- Now need more timely, coordinated data collection
  - By 2013 ONE single Registry for England
  - Central processing, local links
  - More timely, increased quality
  - Closer relationships with local MDTs
  - More rapid feedback processes

Data Sources - 1



Data Sources - 2

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System	Number	Varieties	Live Feeds	Not live
Pathology	167	33	144	23
MDT	165	22	147	18
PAS♀	96	>12	96	63
Imaging	IEP/others	3	Pending	~20

♀TCR and SWCIS use Hospital Episode Statistics (HES) as source of data

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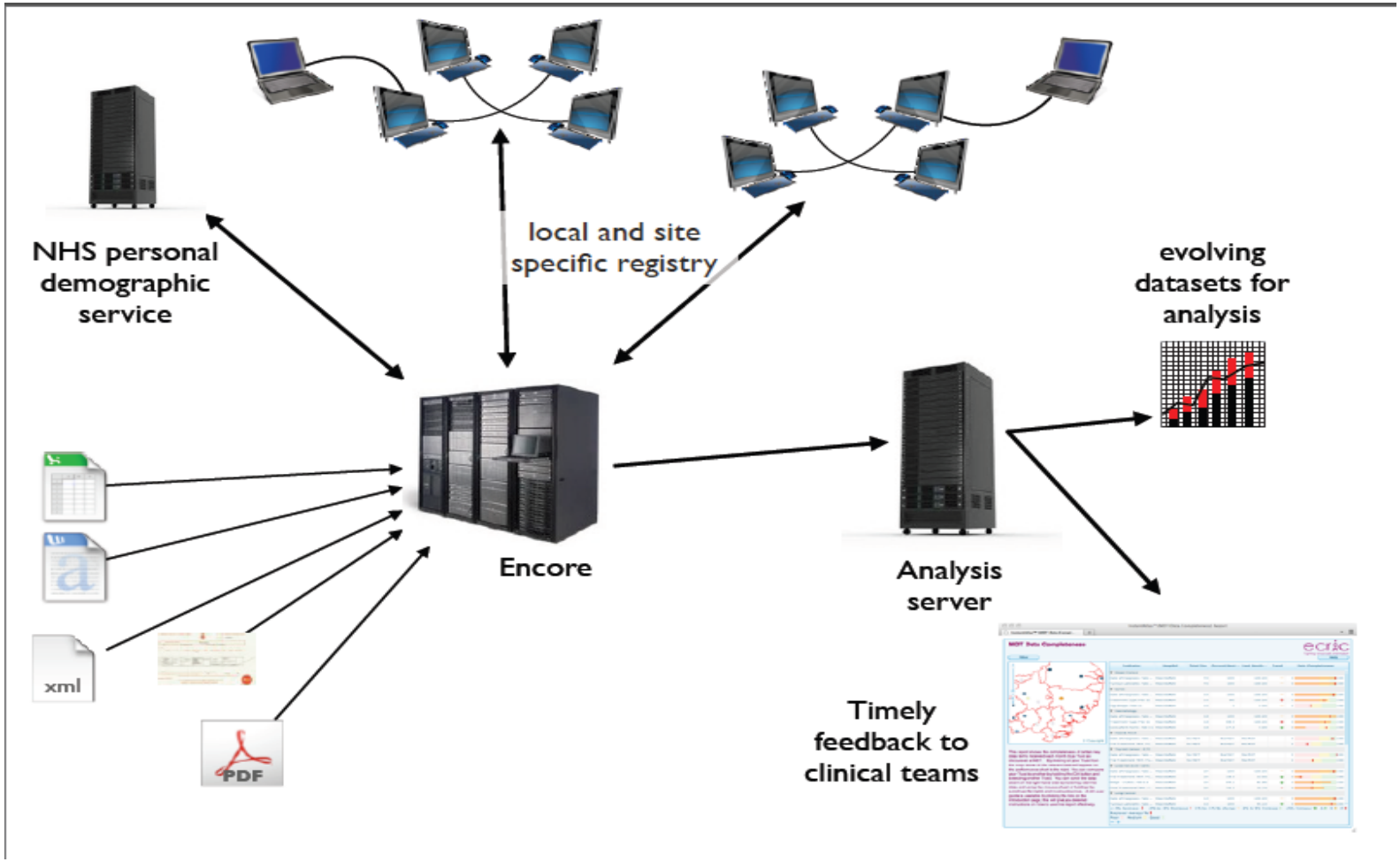
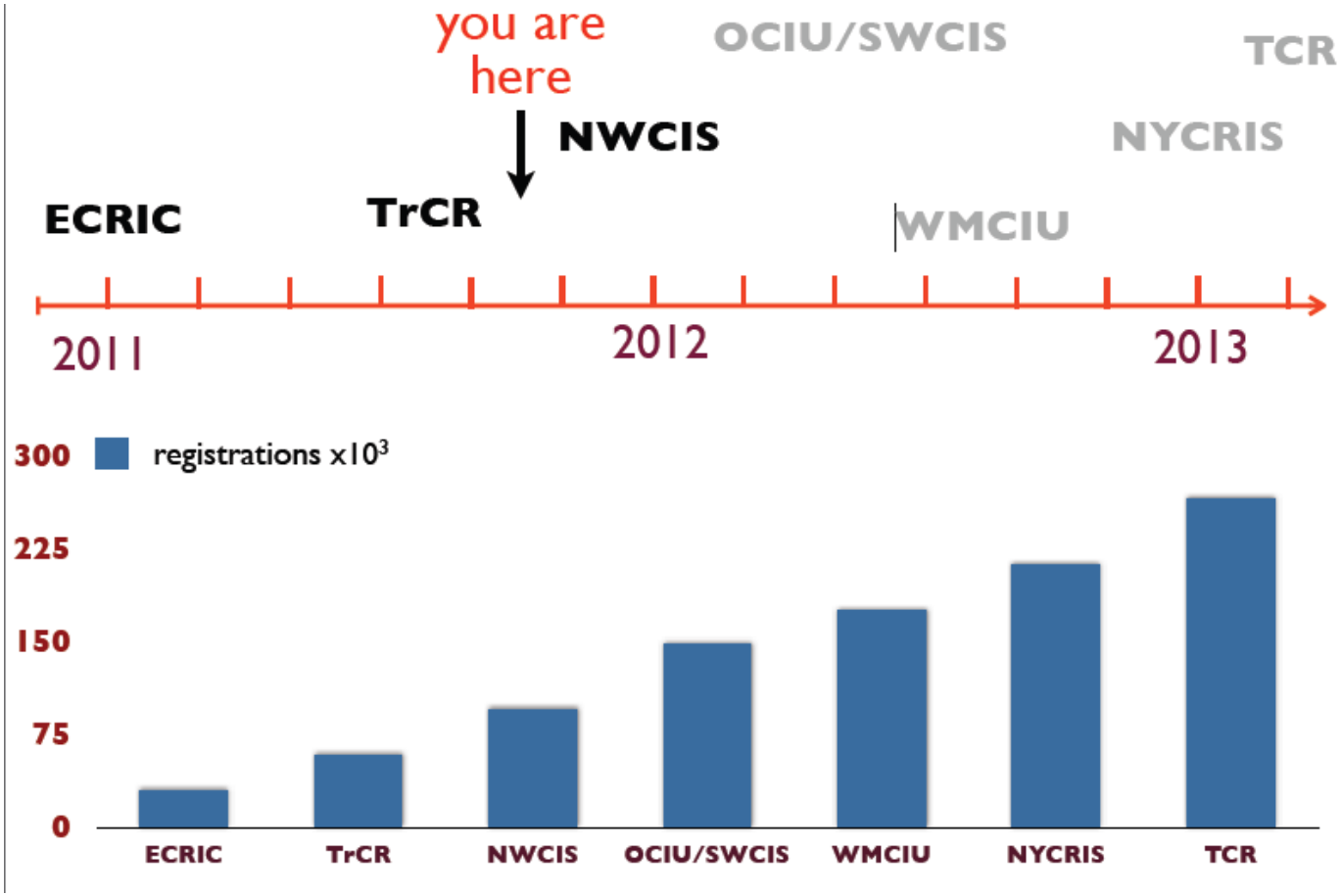


Migration Plan



In conclusion

To support, understand, improve services

- *COSD and the registry migration project:*
  - *Will transform cancer care, research and clinical practice in England*
  - *Will provide timely, consistent, accurate data on every patient*
- *BUT to succeed we need the engagement of all clinicians, providers, commissioners, patients and public*

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Thank you

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