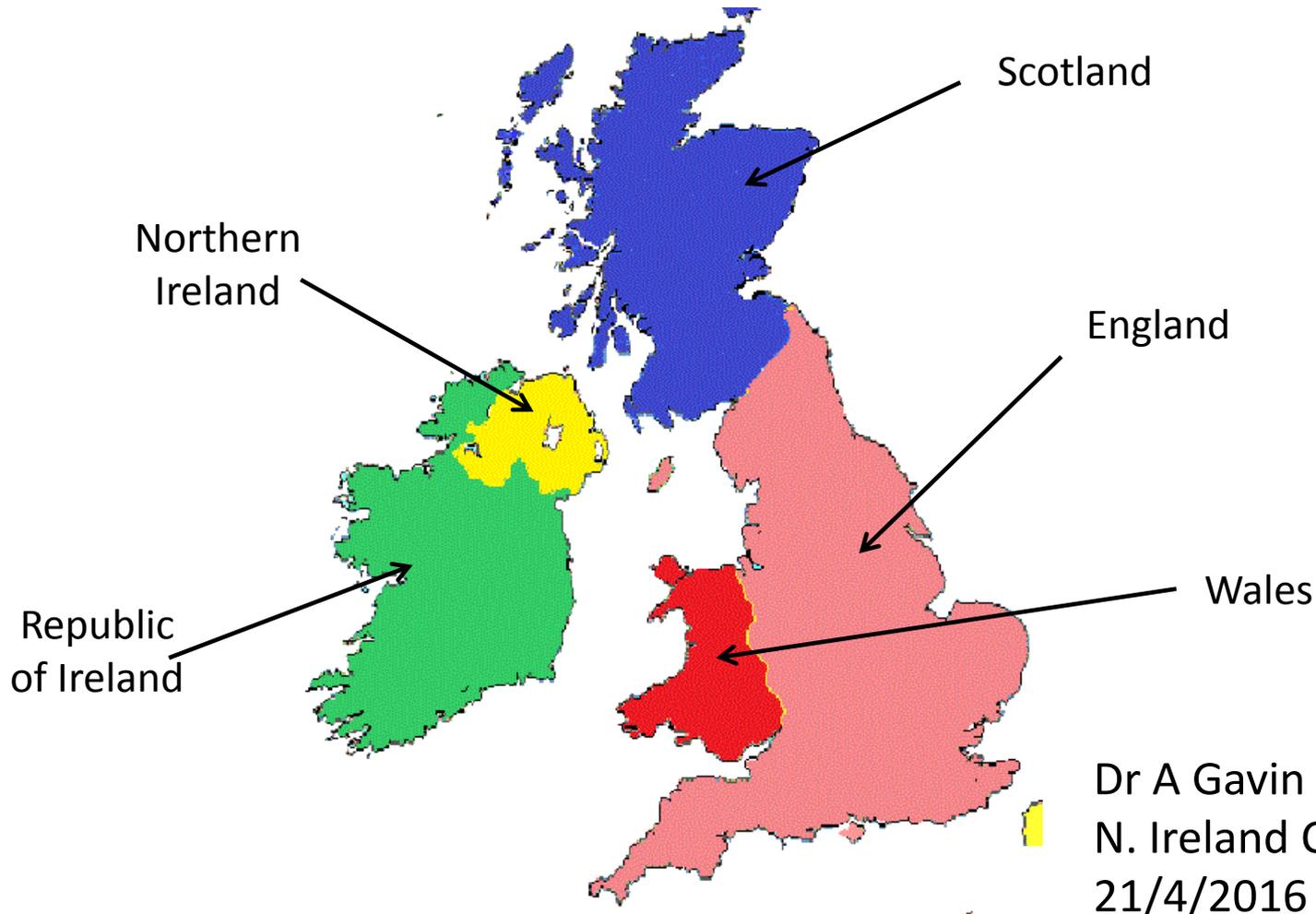


The Devolved Nations, Ireland & England – Contrasting Approaches to Patient Consent



Dr A Gavin
N. Ireland Cancer Registry
21/4/2016

Cancer Registries

Cancer Registries collect and analyse data relating to cancers diagnosed in population delivering timely, comparable and high quality data.

*Follow international guidelines for coding

500+ Cancer Registries
Internationally
4 in the UK
England, Wales,
Scotland &
N. Ireland



Patients Consent to Treatment/Intervention



- Consent – important part medical ethics & International law
- To be valid consent must be voluntary and informed (i.e. benefits & risks)
- The person must be capable of giving consent
- May be oral or written, usually written for interventions

Consent Not Necessary

Clinically

- Emergency treatment
- Severe mental health conditions
- Additional procedure required during surgery



Patient Consent – personal information

- In context
 - Cancer Registration
 - Audit
 - Research Studies- routine datasets
 - Research Studies – contacting patients or relatives

Today – we will consider

- What is personal health information;
- Why personal health information is needed, collected and held;
- What this information is used for, who it is shared with and why;
- What your rights are
- Highlighting similarities and differences between Scotland, Wales, N. Ireland, England and Ireland focusing on cancer data

What is personal health information?

- It is information that identifies you or me . It includes things like:
- name, address, date of birth and postcode;
- information about any care and treatment received and results of tests; and
- information about your health and lifestyle
- *Health records can be written on paper or held on a computer*
- *Used for our health, service functions, population health*



MY DATA and PRIVACY

- The right to [privacy](#) is a highly developed area of law in Europe. All the member states of the [European Union](#) (EU) are also signatories of the [European Convention on Human Rights](#) (ECHR). Article 8 of the ECHR provides a right to respect for one's "private and family life, his home and his correspondence

OECD' seven principles governing protection of personal data

- **Notice**—data subjects should be given notice when their data is being collected;
- **Purpose**—data should only be used for the purpose stated and not for any other purposes;
- **Consent**—data should not be disclosed without the data subject's consent;
- **Security**—collected data should be kept secure from any potential abuses;
- **Disclosure**—data subjects should be informed as to who is collecting their data;
- **Access**—data subjects should be allowed to access their data and make corrections to any inaccurate data; and
- **Accountability**—data subjects should have a method available to them to hold data collectors accountable for not following the above principles
- *(OECD) Organisation for Economic Co-operation and Development*

Europe -Data Protection Directive

- The **Data Protection Directive** 1995 (officially Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data) which regulates the processing of personal data within the European Union. It is an important component of EU privacy and human rights law.
- On 25 January 2012, the European Commission unveiled a draft European [General Data Protection Regulation](#) that will supersede the Data Protection Directive- **concerns re implications for cancer surveillance**

Consent

“any freely given specific and informed indication of his wishes by which the data subject signifies his agreement to personal data relating to him being processed.”

EC Directive 95/46/EC

The Data Protection Act 1998

Governs the use of personal information and gives you and me :

- the right to know how our personal health information is used .
- the right to object to use of this information. We can ask for the way information is used to be changed or restricted
- the right to access any personal information that may be held on us and
- If you think any of the information held is inaccurate, incomplete or out of date, we can ask to have this information amended.

Satisfying the DPA 98

- General awareness of uses of personal health data
- Good reasons for not obtaining consent
- Necessary for a legitimate “medical” purpose
- Data controller should be a medical practitioner or owe an equivalent duty of confidence to the data subject

Satisfying the common law duty of confidentiality

Personal data should only be disclosed

- with consent
- where the law requires it
- if it is in the public interest to do so

Cancer Registration

- Recognised as Integral for Cancer control
- Follow Guidelines from
 - Int Union Against Cancer UICC
 - Int Agency for Research on Cancer IARC
 - Int Assn of Cancer Registry IACR
 - World Health Organisation WHO
 - UK and Ireland Association of Cancer Registration

Personal data required for monitoring health including cancer

- Having this information means that the NHS can:
- look at how safe and effective a treatment is;
- check that the NHS is providing a good service and spending public money properly;
- plan how many beds, clinics and staff are needed;
- monitor particular illnesses or diseases;
- carry out public health or clinical research

Using identifiable data in the public interest for health Risk and benefit

Potential cost to individuals

- Some loss of autonomy
- Low risk of breach of confidentiality, and harm

Benefit to individuals and society

- Information on causes of disease – prevention
- Public health surveillance – protection
- Understanding outcomes – recurrence, survival

Registers need identifiable data

- To avoid double-counting



- To link cases over time - follow up eg survival
- For validation
- To link to other databases to better understand patterns eg effect of comorbidity on outcomes
- Cancer Registry
 - Genetic Advice Service
 - Recall exercises - patient safety
 - Research

- Informed consent is the fundamental principle governing the use of patient identifiable information within health or social/community care research. It is recognised that there are situations where
 - informed consent cannot be obtained.
 - not possible to use anonymised information
 - → Section 251 England and Wales,

England and Wales - section 251

- **Section 60** of the Health and Social Care Act 2001 -> **Section 251** of the NHS Act 2006

England and Wales - section 251

- **Section 60** of the Health and Social Care Act 2001 -> **Section 251** of the NHS Act 2006
- allows Secretary of State for Health to make regulations to set aside the common law duty of confidentiality for defined medical purposes
 - where not possible to use anonymised information and where seeking consent was not practical, having regard to the cost and technology available.

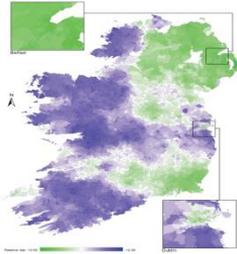
England and Wales - section 251

- **Section 60** of the Health and Social Care Act 2001 -> **Section 251** of the NHS Act 2006
- allows Secretary of State for Health to make regulations to set aside the common law duty of confidentiality for defined medical purposes
 - where not possible to use anonymised information and where seeking consent was not practical, having regard to the cost and technology available.
- The Regulations that enable this power = Health Service (Control of Patient Information) Regulations 2002.
- .The HRA responsibility for Section 251 since 2013, established the **Confidentiality Advisory Group** (CAG) function



Safeguards in Scotland

- Information services division (ISD) take advice now from the NHS National Services Scotland **Public Benefit Privacy Panel** on sharing information, which includes patients and doctors. This group helps ISD to make sure they protect personal information and meet their legal obligations of data protection and confidentiality.



Republic of Ireland

- Data protection ROI insist that patients give consent if the information is to be used for audit or research - even when these are patients of the doctor who is making the request
- Exception is where the doctor/hospital already has a registry or database which patients are aware of (i.e. that they have implicitly consented to the use of their data in research or audit). This rarely happens.
- – *they may be invited to complete a questionnaire and sign their consent on the form*

N. Ireland

- Health and Social Care (Control of Data Processing) Bill –Royal Assent on 11 April 2016 

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- Regulations to be drafted and consulted upon before being scrutinised and debated by the NI Assembly - practical aspects 1 – 2 years

Why not informed consent for public health research?

- Representativity & generalization
 - Avoid bias – selective loss
- Solid conclusions
 - Need for power and statistical strength
- Completeness
 - Few cases may determine risk
 - Loss in linkage may bias results
- All population
 - Disproportionate effort



Impact Of Requiring Consent N. Ireland Cerebral Palsy (CP) Population Based Registry

- Number smaller than cancer approx. 70 per year
- Numerous contacts with services
- When consent required 40% preliminary notifications remained unconfirmed
- Not parental refusal (2%) but professional involvement
- **Outcome** :Poor data quality meant removal from Multicentre Study - Does artificial reproduction increase risk CP



How is information kept secure?

- All ISD staff have a legal and contractual duty to keep personal information secure and confidential;
- ISD employs an individual known as a 'Caldicott Guardian' whose job is to make sure that information is handled properly;
- Access to personal health information can only be given with special authorisation, and use of that information is closely monitored by ISD;
- There are strict rules within ISD that govern how information should be managed e.g. to make sure names, addresses and any other information that might identify an individual are removed wherever possible.

Registry Security – only few staff have access to clinical data – separation of analysts for data staff

Physical

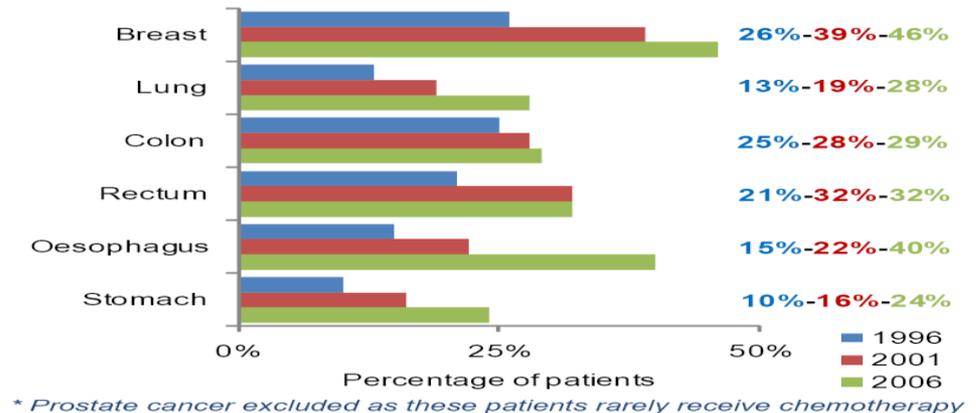
- Video Surveillance
- Locks/alarms
- Badges for visitors
- Clear desk
- Shredding

Electronic

- Passwords
- Fingerprint
- Audit trails
- Encryption
- Secure data transfer eg nhs.net
- Phones, email, letters, fax
- ISO27001

Levels of data

- Routine statistics



- Potentially identifiable eg NHS number used for linkages/ small numbers
- Patient identifiable

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Cancer survival rates in UK lagging behind, study finds



The scientific contribution of cancer registries

	Evidence of causality	Evidence of preventive activity	Availability of exposure indicators	Precancerous lesions	Decrease in incidence	Decrease in mortality
Tobacco smoking	YES	YES	YES	NO	YES	YES
Alcohol consumption	YES	YES	YES	YES/NO	YES	YES
HPV causality/ vaccinations	YES	YES	YES	YES	NOT YET	NOT YET
HBV causality/ vaccinations	YES	YES	YES	NO	NOT YET	NOT YET
Asbestos	YES	YES	YES	NO	NOT YET	NOT YET

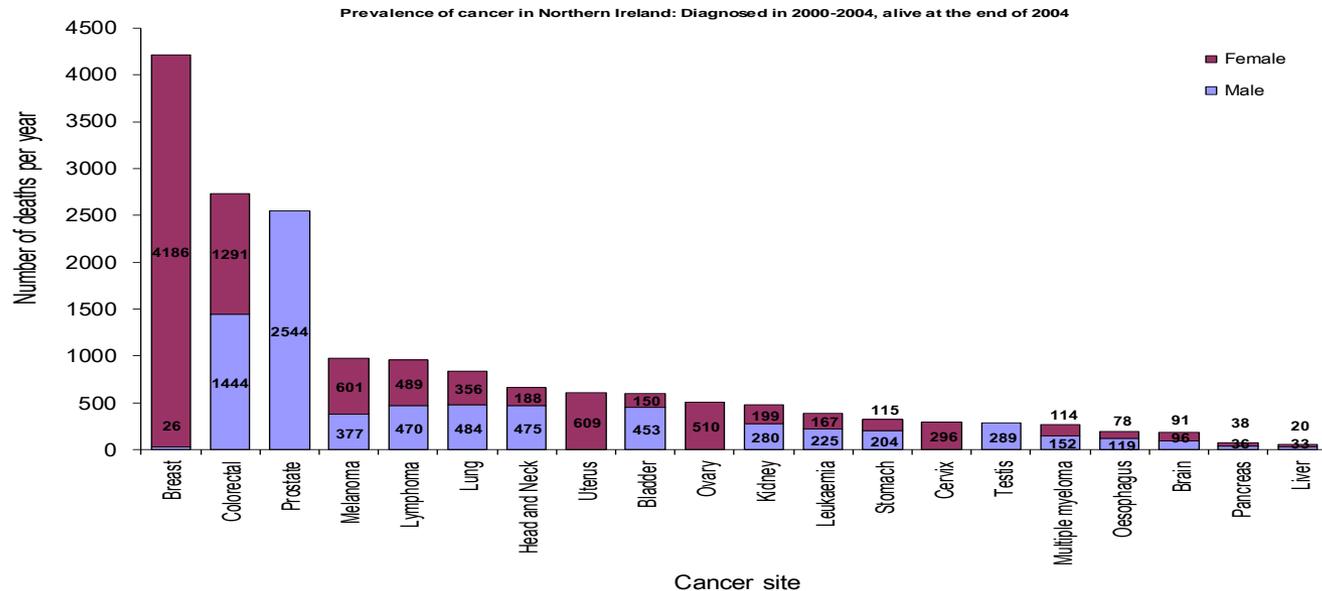
(Expected in a short)



Contribution from Cancer Registries

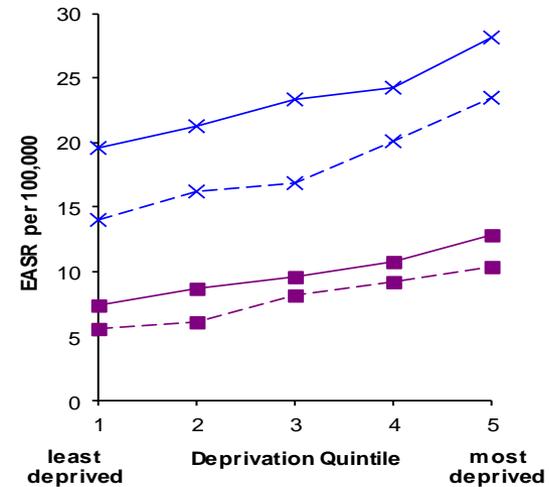
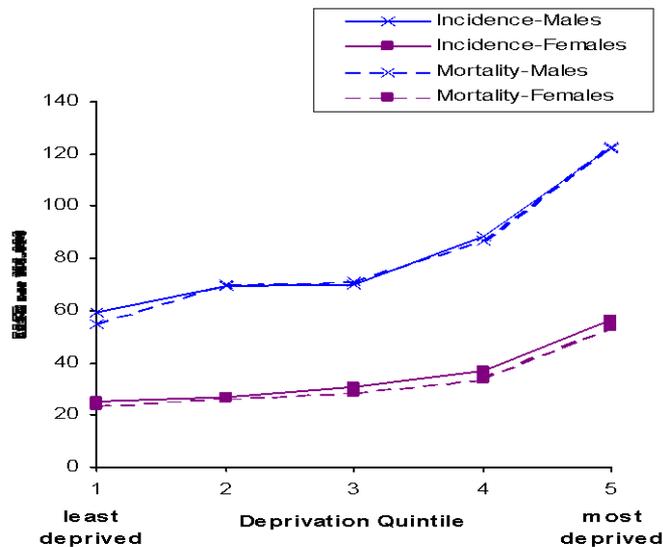
Routine Registry Data

- Requires accurate counting of cases without duplication.
- Provides information on trends, prevalence,

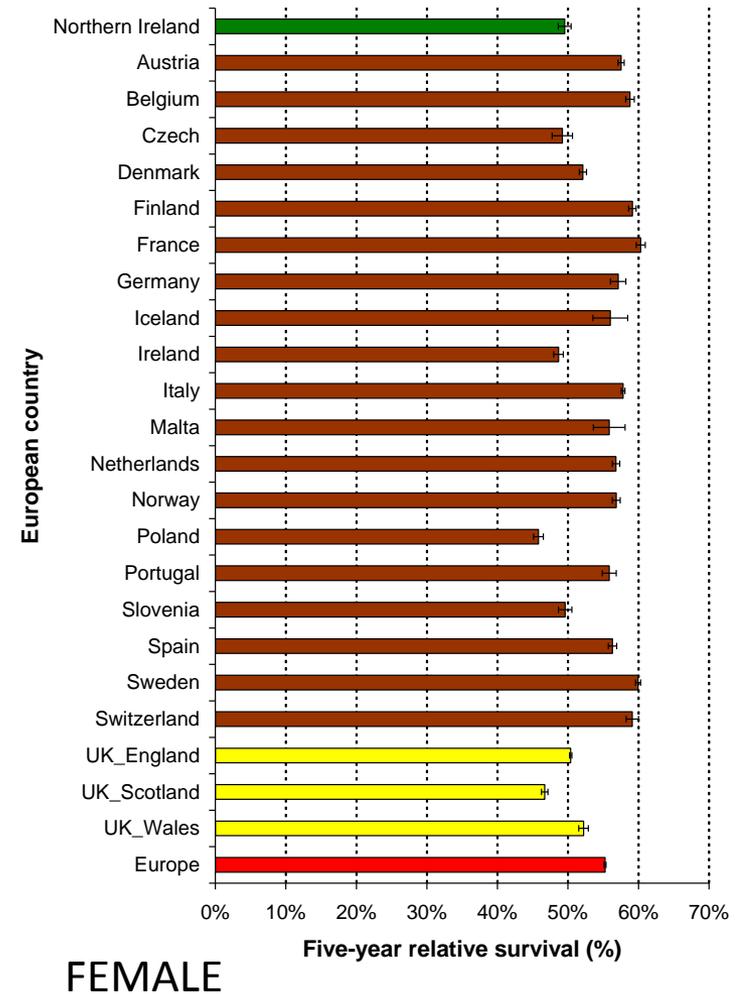
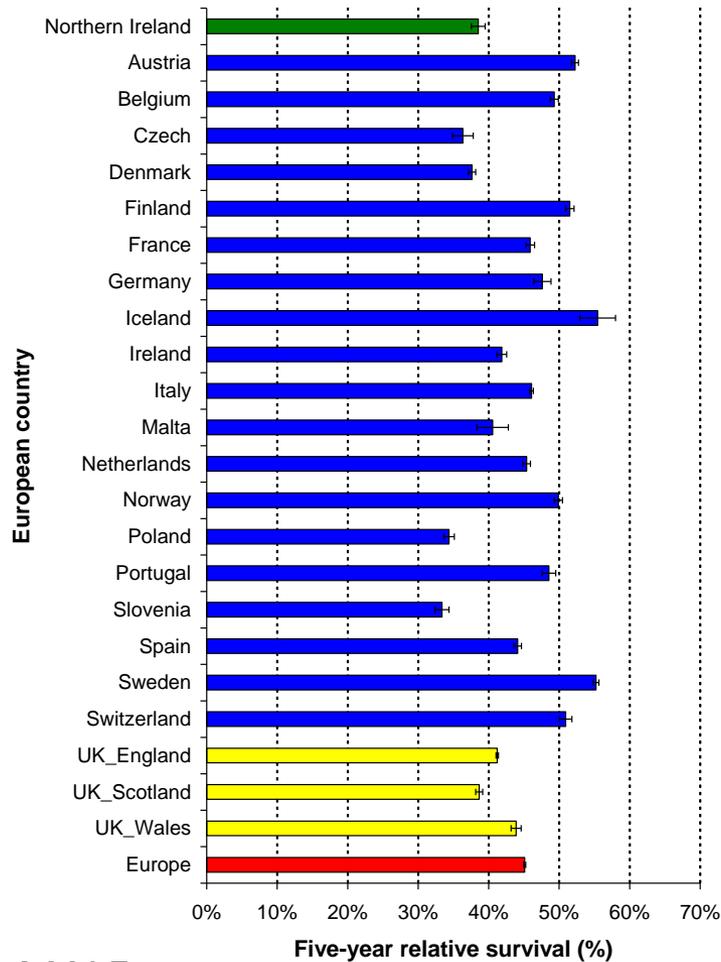


Routine Registry Data

- Requires accurate counting of cases without duplication.
- Provides information on trends, prevalence, socioeconomic differences, (lung/ stomach)

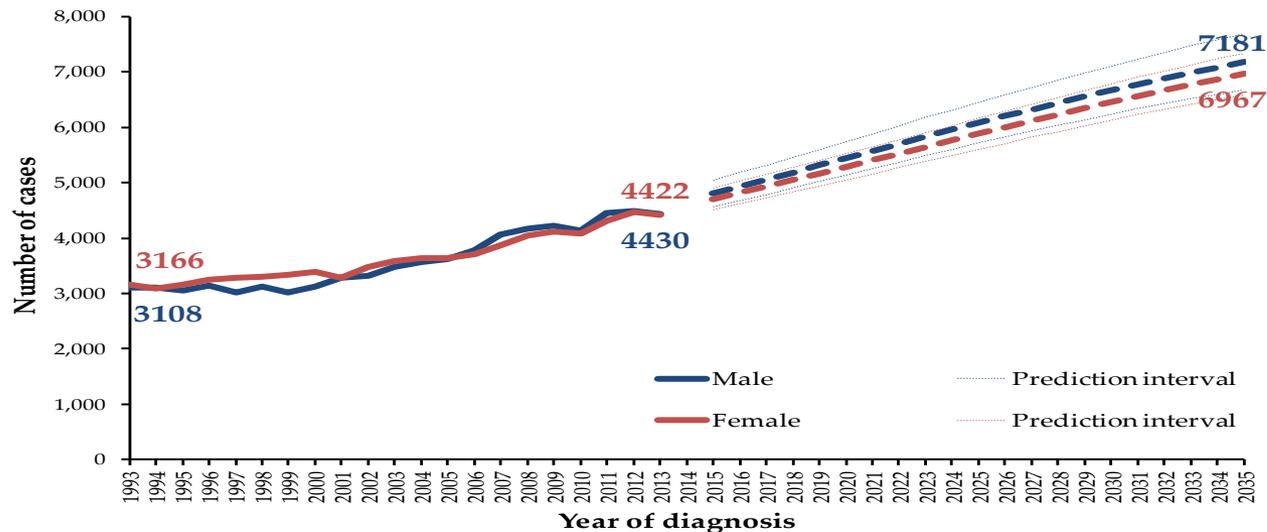


Eurocare-IV results – All Cancers



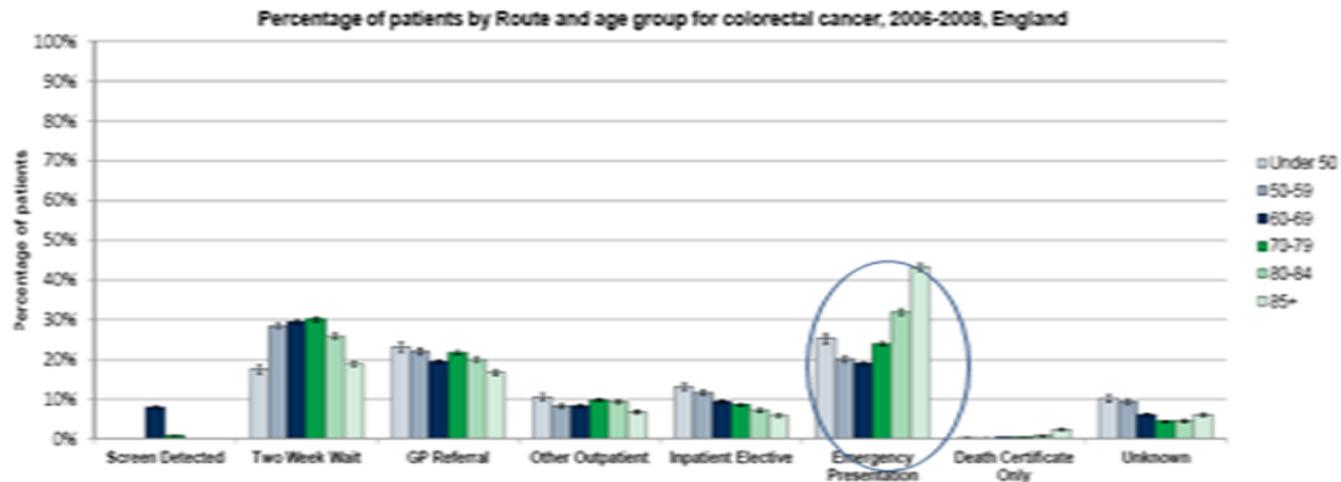
Routine Registry Data

- Requires accurate counting of cases without duplication.
- Provides information on trends, 66% increase predicted by 2035

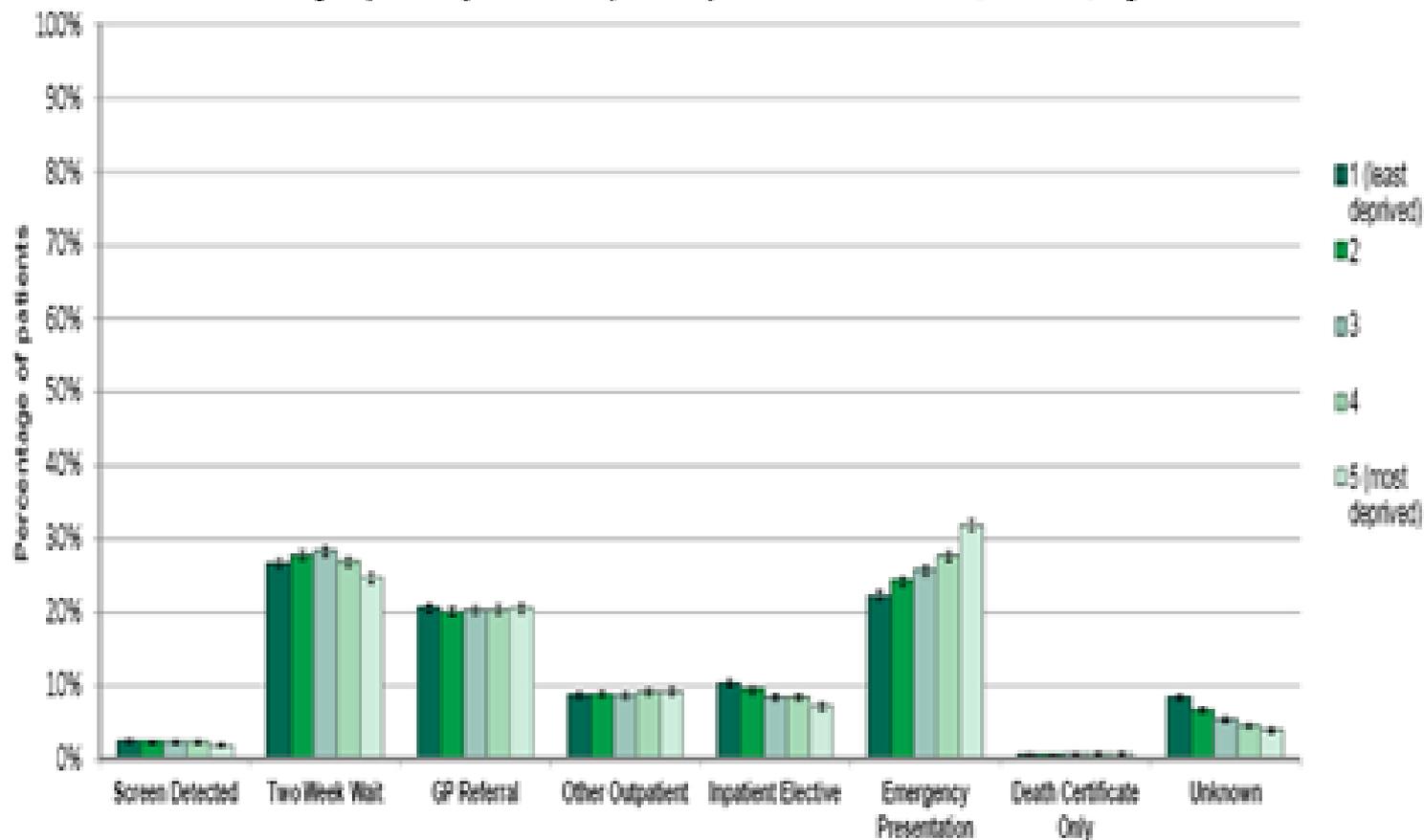


Routine Registry Data -

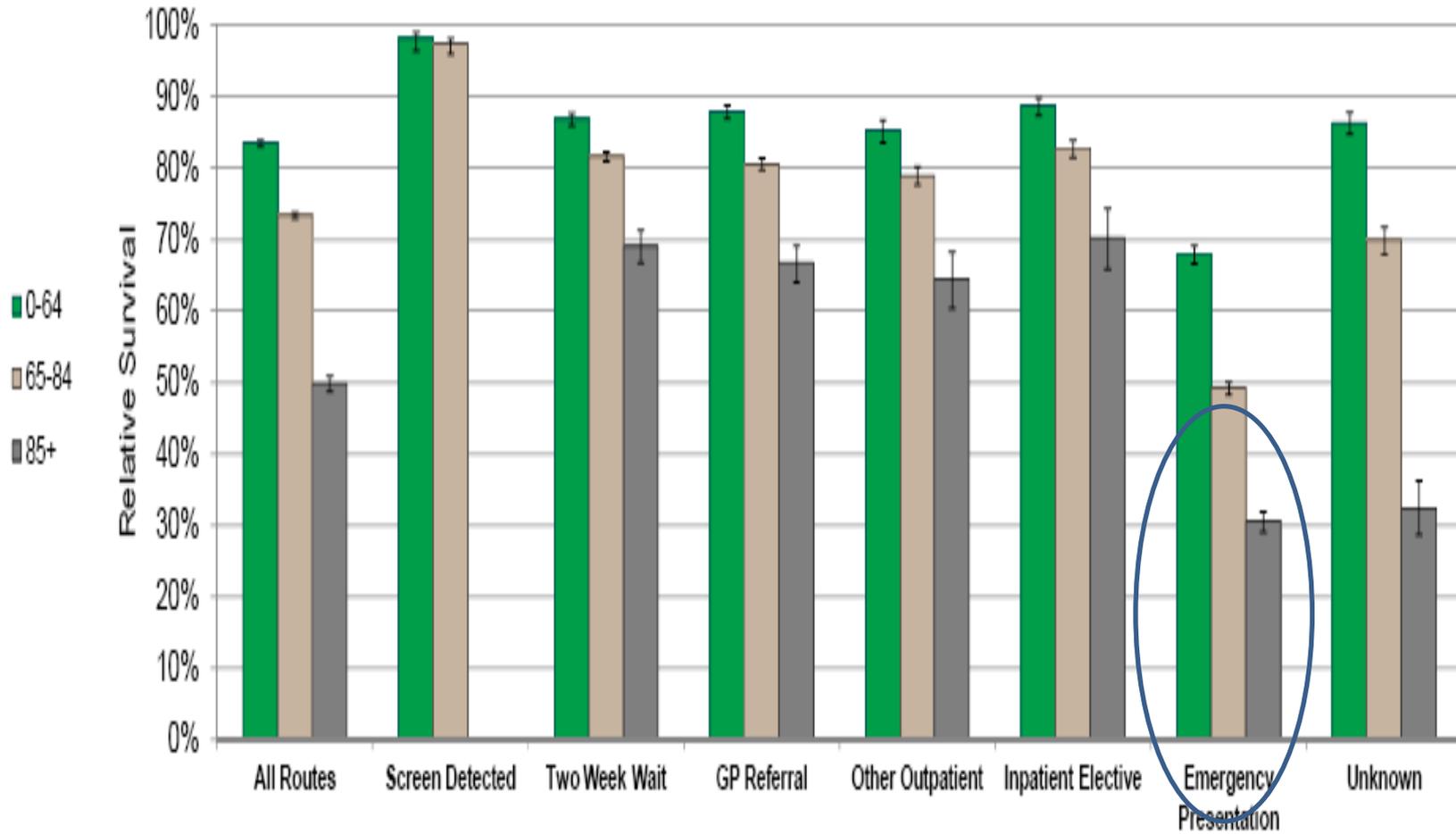
- Requires accurate counting of cases without duplication.
- Provides information on trends, prevalence, socioeconomic differences, **outcomes by routes to diagnosis**
739,667 records merged from various sources then anonymised



Percentage of patients by Route and deprivation quintile for colorectal cancer, 2006-2008, England



12-month relative survival estimates by Route and age for colorectal cancer, 2006-2008, England

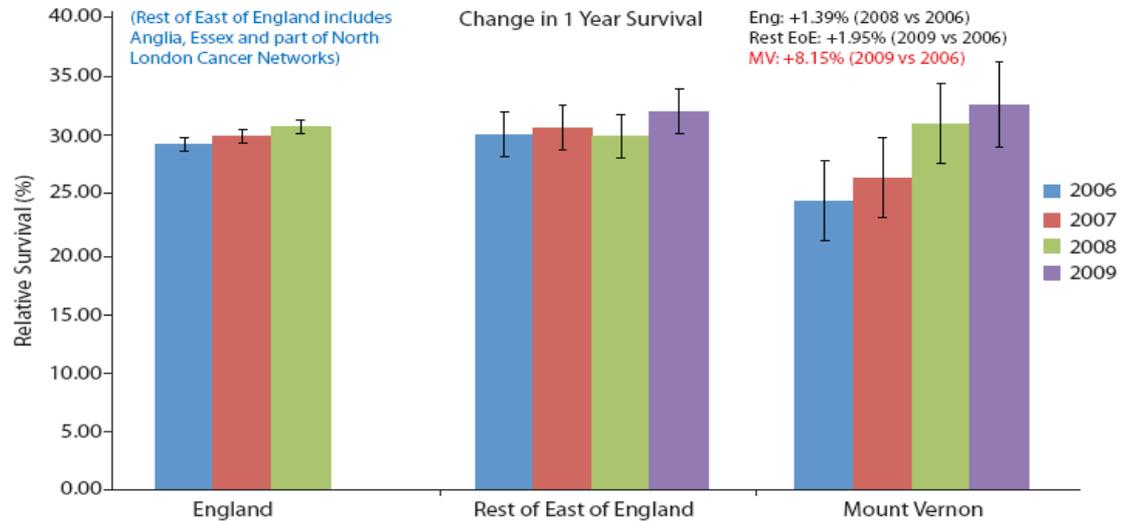


What clinicians want from data

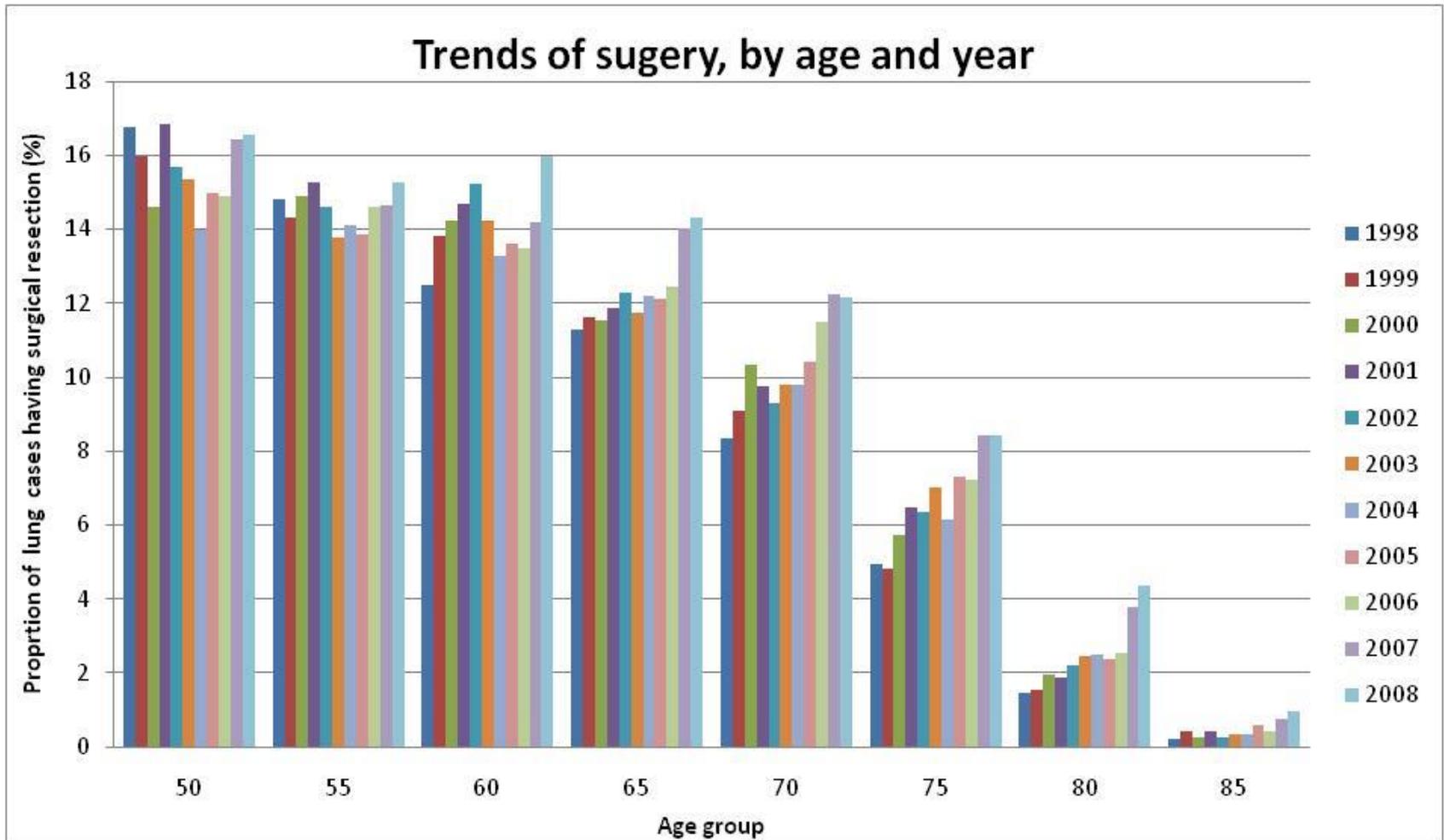
- **To support the answering of clinically relevant questions**
- **Clinically credible – though they have to take responsibility**
- **Ownership**
- **Timeliness**
- **Case-mix adjustment**
- **Reported ‘proportionally’ and with their knowledge**
- **Ongoing engagement with those that report data**

Audits

- LUCADA for lung cancer- personal data matched then anonymised for analysis
- **In lung cancer there was clear evidence of clinical behaviour change _ Mount Vernon**



Lung resection rate: trend by age



Source: Riaz et al; 2011;

Major Surgical Resections England, 2004-6

THE TIMES | FRIDAY 24 MARCH 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 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.

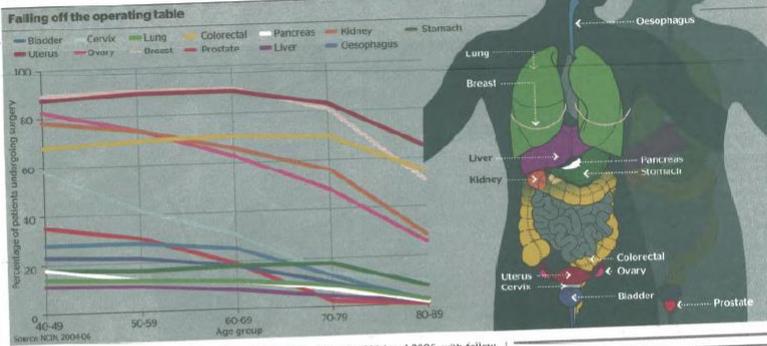
Surgery remains the treatment with greatest impact on long-term survival in most types of cancer. Dr Peake said that while some NHS teams worked well, and referred to specialist centres when their expertise was not sufficient, others were making critical decisions without such considerations. "There are clearly places where the teams are just looking at the patient and saying 'no', he said. "If 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 or if needed to happen in 15 per cent of cases for three to five years. He added that there were places "where I wouldn't send my cat" level of expertise as cities.

The study shows that surgery rates vary greatly, from 50 per cent of acute and breast cancer patients to just 6 per cent of those with liver cancer. The proportion of patients undergoing surgery many cancers this starts to fall 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 sixties age group, this was down to 10 per cent. Other cancers, such as stomach and kidney, showed similar drops.

The data, which covers operations



I was lucky. Many aren't

Case study

I was Christmas two years ago that Martyr Lewis began picking up warning signs that he might have a tumour in his bowel (Sam Lister writes). After talking 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 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."

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 22 per cent but 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. It is 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 see argue that your resources could be better spent on younger age groups, if old ten or fifteen years of active life, you should certainly offer it to them."

Casirán Devane, of Marmillan 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

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Be and 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

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 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, stalling 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's much earlier than you



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

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 2 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 further in their 50s.

Dr Peake believes that this reflects a culture in cancer care—the problems with how it is structured—that contributes 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 are all coming in having had a heart attack in the outpatient department. There are always these 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

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 areas can affect the decision making—for instance a poor radiologist may over-interpret imaging of the tumour, and a surgeon may not be prepared to carry out a major operation
- An effective system requires a robust "speak and hub" model. While some hospitals may not have such expertise, they should have contact with a specialist "hub" to advise

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 reveal reasons for low rates in areas, such as better or worse 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 England's profound bias against cancer 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.

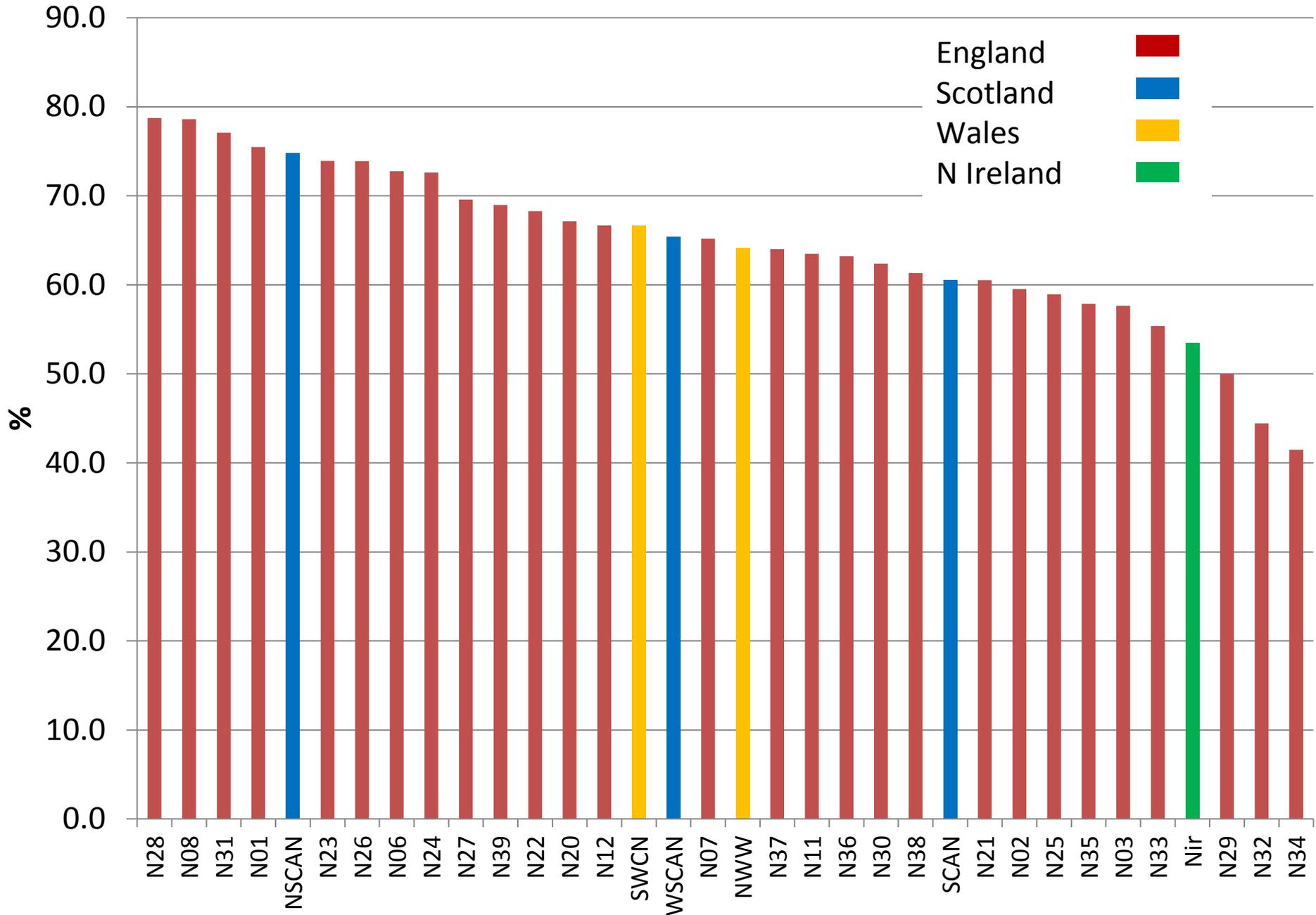
For Dr Peake and his team, the new data is a "treasure trove" that can enlighten and empower patients and hold doctors and health service managers to account.

"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.

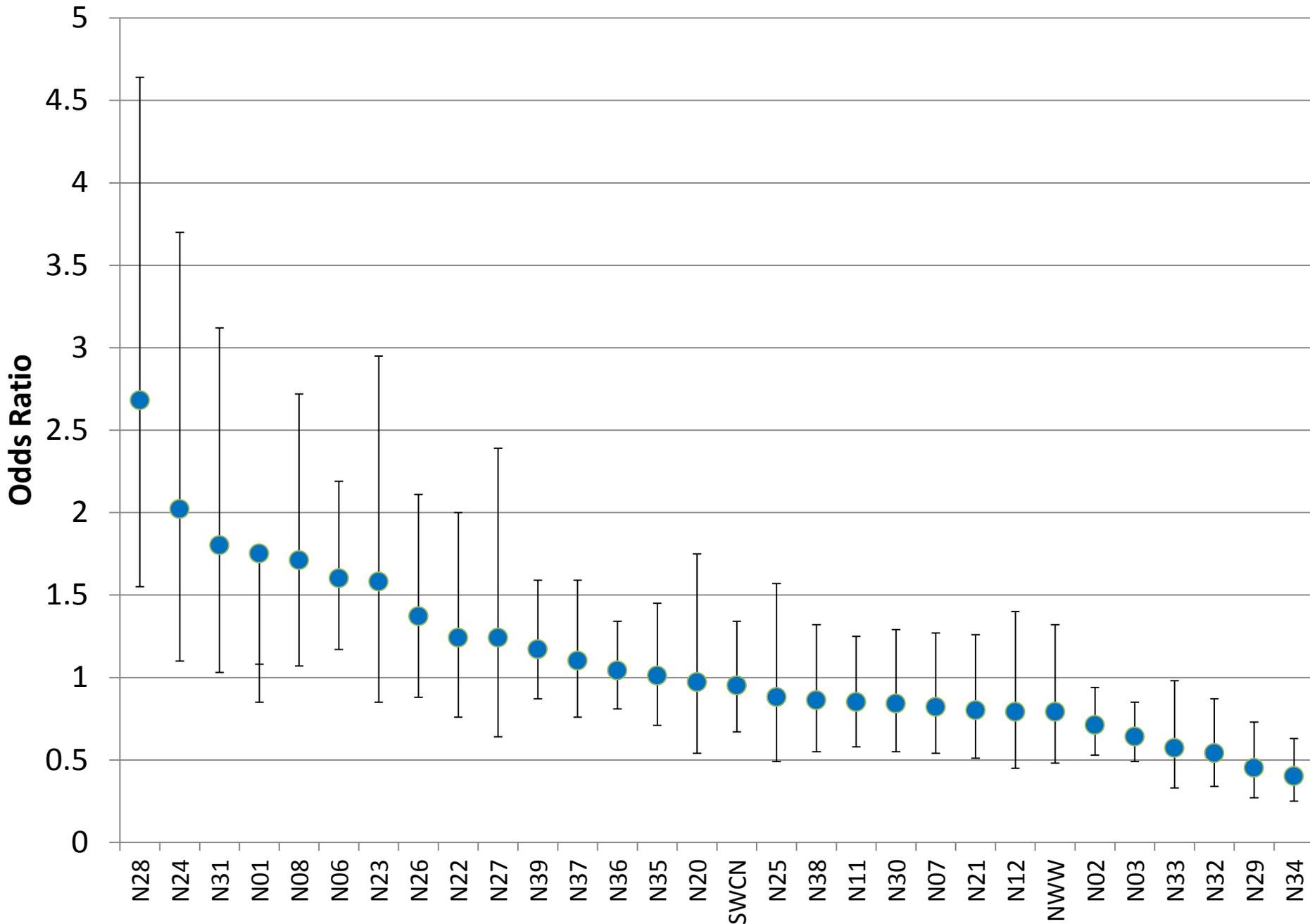
Inside today

Thousands of elderly

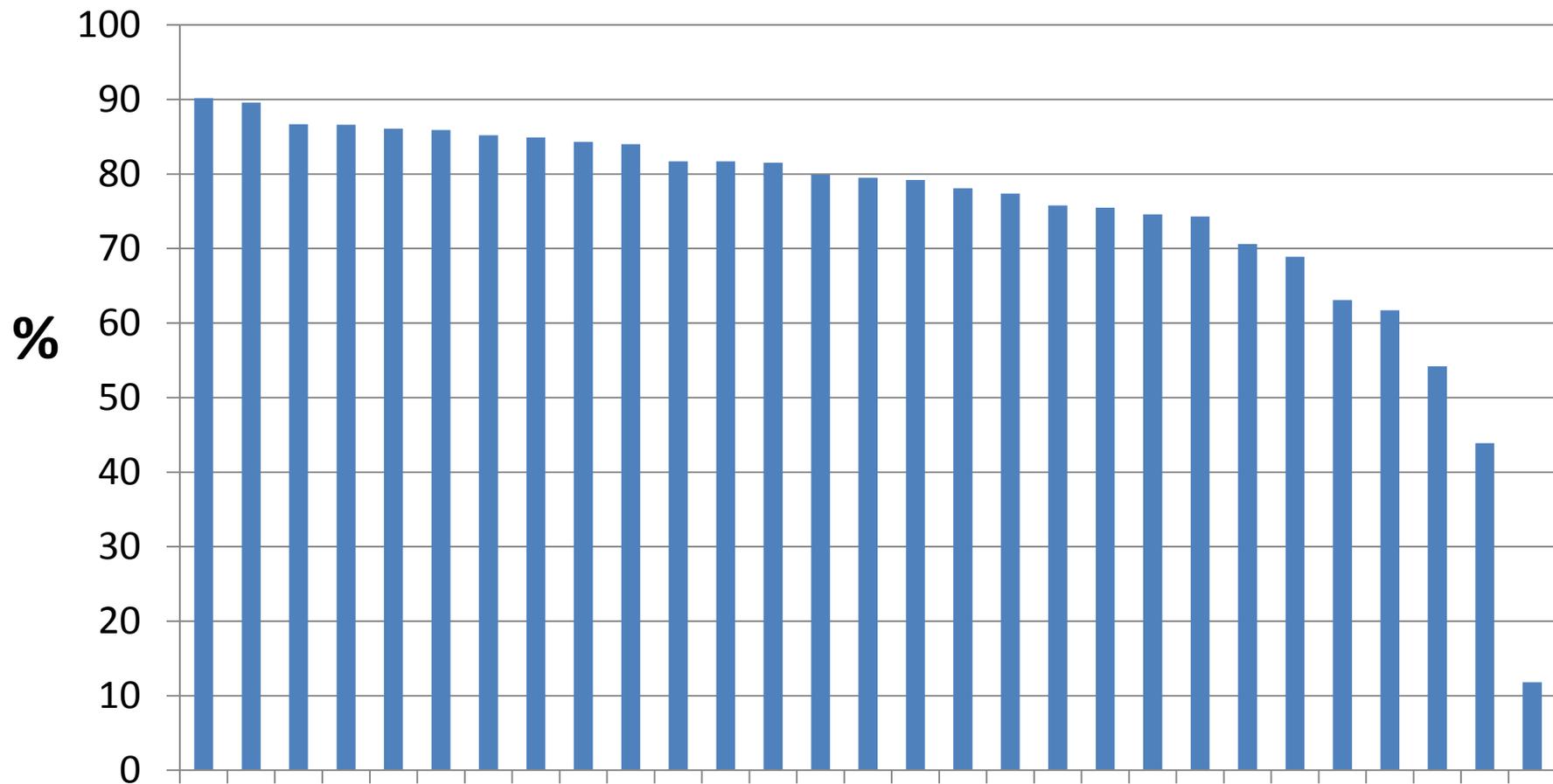
Lucada - Chemotherapy in SCLC (%)



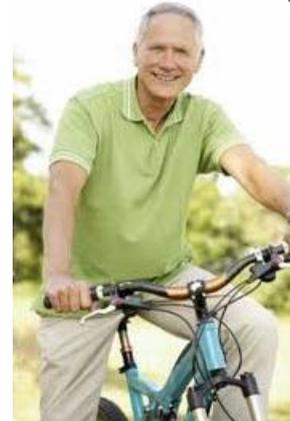
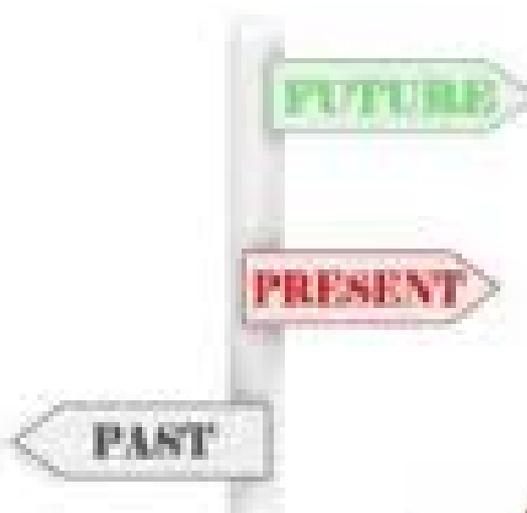
Chemotherapy in SCLC (England & Wales only)



Proportion of patients seen by Clinical Nurse Specialist by Cancer Network 2010 (% , E & W)



Life after a cancer diagnosis is different nowadays- but what is it really like?



Research contacting Patients

- Registries do not contact cancer patients or their relatives directly
- For ethically approved studies they work via the clinical team which taking account of patients health etc may or may not contact patients
- With multiple death checks to ensure only contacting live people

Will anyone contact me?

No one from the cancer registry will contact you. We sometimes release information to approved cancer researchers under strict conditions. For most cancer research, patients do not need to be contacted, but in some cases they do. **If researchers need to contact you, they will only ever do this with the approval of your own doctor.**

Do I have a choice?

Yes, you can object and this will not affect the care you receive. However, in order to work properly, the registration system needs to know about everyone with cancer.

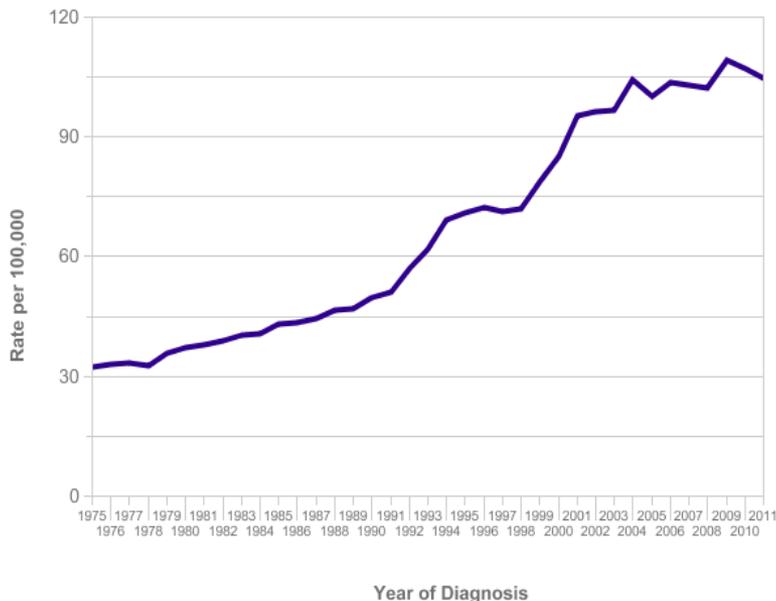
Information about your illness will help care teams to learn how best to treat cancer, make sure they provide the best care, and help to find out the causes of cancer. If you are concerned about your details being registered or any other issues in this leaflet, please talk to your doctor about this.



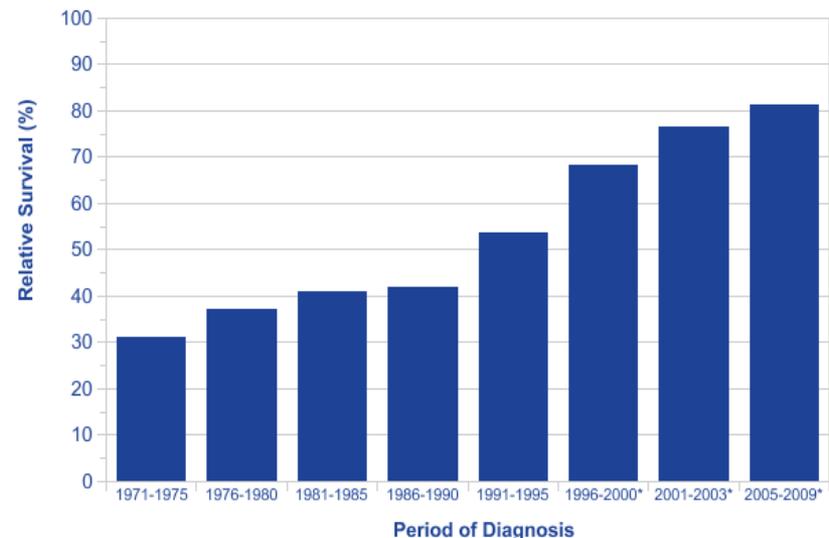
Prostate Cancer- most common cancer in males

- The number of newly diagnosed prostate cancer cases has more than doubled over the past 20 years
- The number of Prostate cancer survivors is growing steadily

European age-standardised incidence rates, prostate cancer, Great Britain, 1975-2011



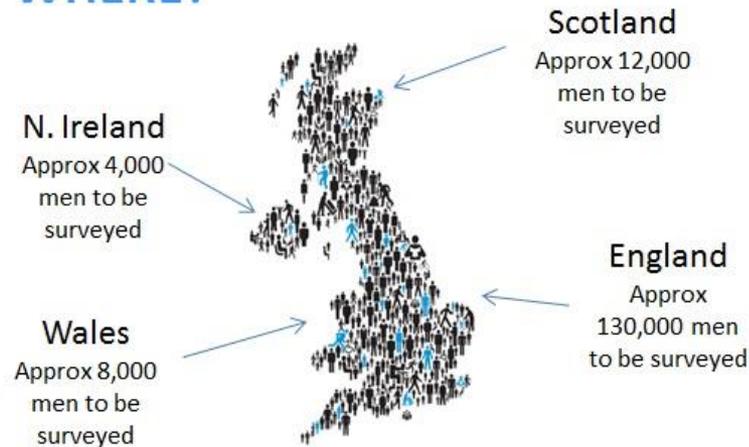
5-year age-standardised relative survival, prostate cancer, Great Britain, 1971-2009



Research

- Prostate PROMS UK wide (2014-2017)

WHERE?



- This will link with:
 - similar work in the Republic of Ireland and Australia and
 - the National Prostate Cancer Audit in England and Wales www.npca.org.uk

The route for consent after peer review for scientific quality, funding and Ethics – patient involvement++

- **England**- section 251, Confidentiality advisory Group, R&D approvals, Agreement from 111 separate Trusts (85%) for study and MDT leads to contact patients
- **Scotland** - Dept Health sponsorship, Public Benefit Privacy Panel, R&D each of 14 Health Boards- *Method*, matching of hospital records with Cancer registry to confirm diagnosis, send out on clinical headed paper,

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The route for consent after peer review for funding and Ethics – patient involvement++

- **England**- section 251, Confidentiality advisory Group (CAG), R&D approvals, Agreement from 111 separate Trusts (85%)for study and for letters to be sent from MDT leads to contact patients
- **Scotland** - Dept Health sponsorship, Public Benefit Privacy Panel, R&D each of 14 Health Boards- *Method*, matching of hospital records with Cancer registry to confirm diagnosis, invites to patients send out on clinical headed paper.
- **Wales** – section 251, R&D approvals from 7 Health Boards, CAG approvals, letters to patients from MDT leads
- **N. Ireland** – Health Trusts R&D, MDT leads inviting men to survey, nurses doing final checks re patient suitability. registry not sending names to Survey provider but postage from NICR as registry already know of men with prostate cancer

OECD' seven principles governing protection of personal data

- **Notice**—data subjects should be given notice when their data is being collected;
- **Purpose**—data should only be used for the purpose stated and not for any other purposes;
- **Consent**—data should not be disclosed without the data subject's consent;
- **Security**—collected data should be kept secure from any potential abuses;
- **Disclosure**—data subjects should be informed as to who is collecting their data;
- **Access**—data subjects should be allowed to access their data and make corrections to any inaccurate data; and
- **Accountability**—data subjects should have a method available to them to hold data collectors accountable for not following the above principles
- *(OECD) Organisation for Economic Co-operation and Development*

About Cancer Registration- informing patients leaflets



About Cancer Registration

Do I have a choice?

Yes, you do have the right to opt-out and this will not affect the care you receive.

However, in order to work properly, the registration system needs to know about everyone with cancer.

Your details help care teams to learn how best to treat cancer, make sure they provide the best care and help to find out the causes of cancer.

If you are concerned about your details being registered or any other issues in this leaflet, please discuss this with your Doctor or write to us at the National Cancer Registry in Wales:

E mail:

WCISU.enquires@Wales.nhs.uk

Post:

Director
Welsh Cancer Intelligence & Surveillance Unit
16, Cathedral Road
Cardiff
CF11 9LJ

Where can I get more information?

If you have any questions, you can get more information by:

- Asking your Doctor
- Visiting the national cancer registry for Wales website at www.WCISU.Wales.nhs.uk

- Visiting The United Kingdom and Ireland Association of Cancer Registries (UKIACR) website at www.ukacr.org

If you are a child with cancer or the parent of a child with cancer, you can get further information by visiting the Children's Cancer and Leukaemia Group's website at www.cclg.org.uk

This leaflet was adapted for use in Wales from the NHS "About cancer registration" leaflet which received the following awards:



About Cancer Registration
A leaflet for patients

ABOUT CANCER REGISTRATION

DO YOU KNOW THAT AS A CANCER PATIENT YOUR INFORMATION CAN HELP:

- Understand the causes of cancer and best treatments
- Plan and improve cancer services
- Measure cancer patients' care
- Monitor changing cancer levels in Northern Ireland since 1993
- Find out about cancer risk

Information is collected and managed confidentially by the medically led N. Ireland Cancer Registry

Pick up a Patient Information Leaflet to learn more or visit the Cancer Registry website: www.qub.ac.uk/nicr

Contact Details:

N. Ireland Cancer Registry,
Mulhouse Building,
Grosvenor Road,
Belfast, BT12 6DP
Tel: 028 9063 2573



The Northern Ireland Cancer Registry

Providing knowledge for cancer patients,
clinicians and policy makers



Queen's University Belfast

School of Medicine, Dentistry and Biomedical Science

N. Ireland Cancer Registry

search

The Registry

The N. Ireland Cancer Registry (NICR) is located in the Centre for Public Health, Queen's University Belfast and is funded by the Public Health Agency for Northern Ireland.

Home

About Us

News & Events

The Registry is responsible for the production of Official Statistics on cancer incidence, prevalence and survival in Northern Ireland and provides evidence to help inform decision making about cancer services. We collect patient information on their disease and the services they receive.

The Registry

Protection of patient information is a priority within the Registry and strict confidentiality rules are applied to prevent identification of individual patient details.

Aims & Objectives

To find out more about what we do and how we work you may wish to open our patient information leaflet (PDF, 645kb), cancer information poster and video (see below).

Confidentiality & Governance

The following video gives further information on the role and work of the Cancer Registry. Please do have a look at it.

Registry History

Staff

Links

Registry Databases

Frequently Asked Questions

Cancer Information

Publications

Research and Audits

A video player showing a red sign with white text. The sign says "Medical Library" with a white arrow pointing left, and "N. Ireland Cancer Registry" with a white arrow pointing up. The sign is in front of a brick building with arched windows. A white car is parked in front of the building. The video player has a progress bar at the bottom showing 0:20 / 4:00.

The Northern Ireland Cancer Registry

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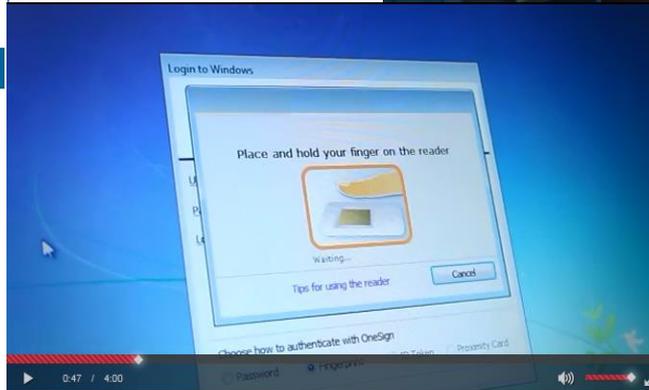
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HOUSE BUILDING

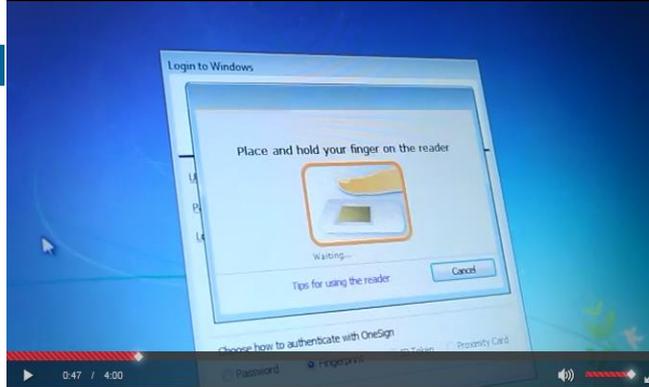
Medical Library

N. Ireland Cancer Registry



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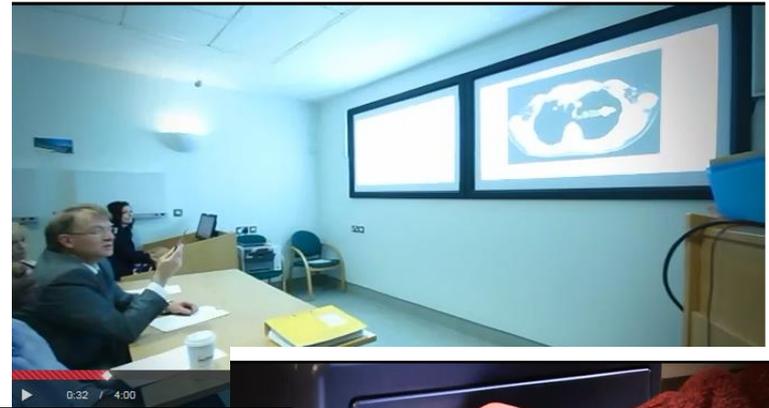
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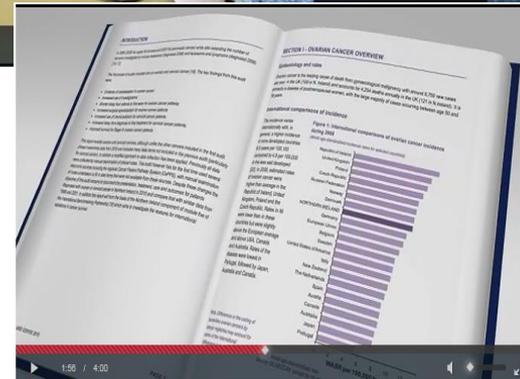
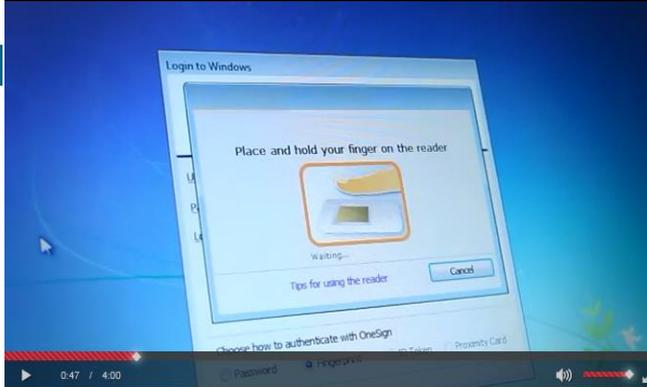
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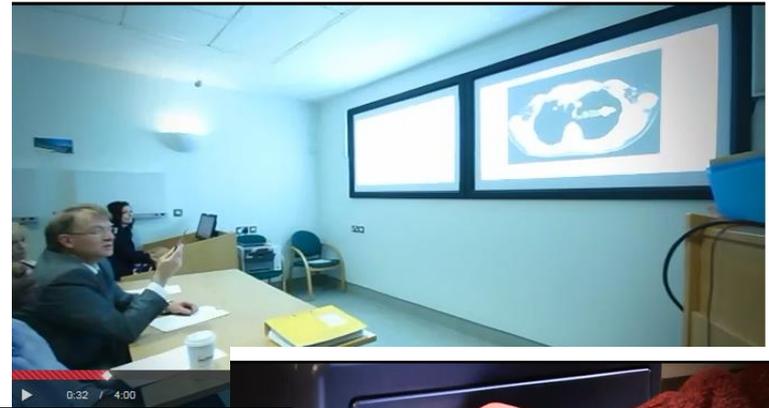
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N. Ireland Cancer Registry



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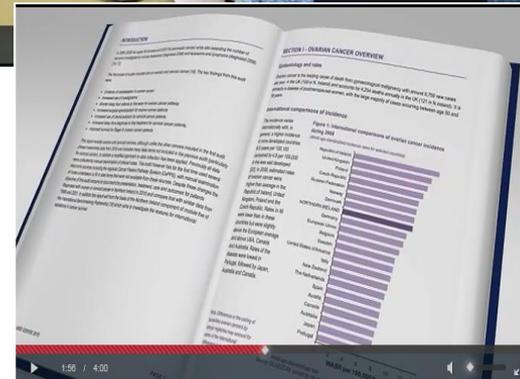
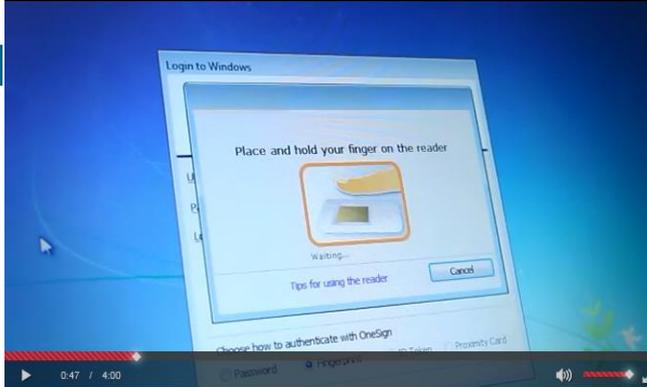
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Medical Library
N. Ireland Cancer



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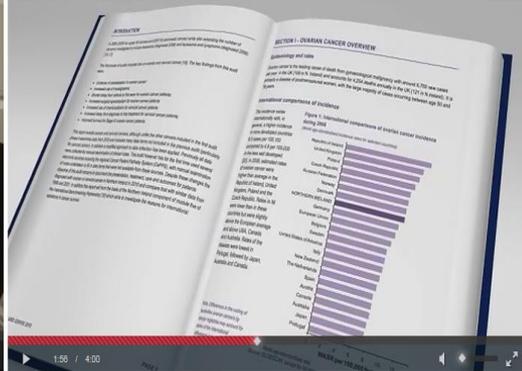
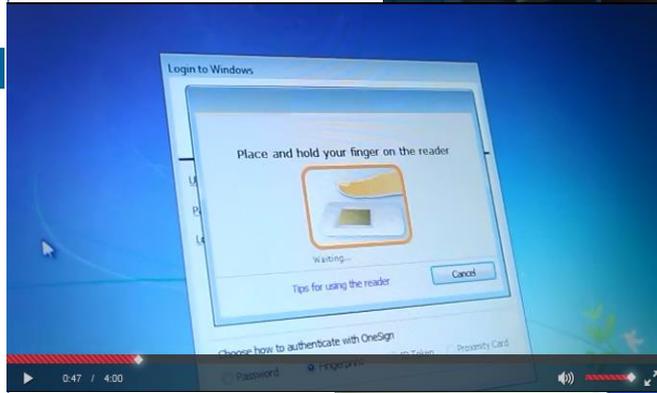
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Conclusions

- Cancer registries contribute to the monitoring of health for patient benefit, through identification of risks, monitoring of services, international benchmarking and research.
- They value the data and respect patient confidentiality, working in compliance with various legislations at European and local level.
- They hold the data securely and inform the public about their roles.
- While differences exist there are many similarities in the way Cancer Registries in the UK and Ireland deal with patient data and patient consent,