

Annual report 2005 - 2006

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Fighting cancer with information



Eastern Cancer Registration and Information Centre

In this report

Note from the director	4
Major challenges for 2005 / 2006	5
Introduction and background	6
Registration	7
Analysis	9
HES project	12
Boundary change	14
Budget and expenditure 2005 / 2006	15
Training	15
Quality assurance	16
Publications	17
Staff	18
Contacts	19

Note from the director

The last year has seen one of the most significant changes for the former East Anglian Cancer Registry with the transfer of the responsibility for registration and analysis for the entire population of Hertfordshire and Essex from the Thames Cancer Registry. The new Eastern Cancer Registry and Intelligence Centre now collect data for all cases in the entire 5.5 million population of the East of England Government Office.

Our information coverage is now for the first time coterminous with other Regional Intelligence organisations such as the QA Reference Centre for Breast and Cervical Screening and the Eastern Region Public Health Observatory.

The Registry is inevitably expanding and considerable work has been done on processing electronic data sources from across the Region. Our aim is to use these electronic sources to improve our efficiency in Cancer Registration so that we collect and process in a more timely and cost effective way. Where possible we will use automated techniques for registering cases, but only if this can be achieved without detriment to the traditional high quality data that the Registry collects. We are delighted that the National Performance indicators for Cancer Registries continue to show that the Registry is one of the best performing Registries in the UK with outstanding data quality.

Both the Analytical and Registration teams are now working closely with Trusts, PCTs, Cancer Networks and individual clinicians across the East of England. Registry has also made significant contributions to a wide range of national and international projects in service improvement and research.

In the coming year we will be further strengthening all of our teams and working closely on integration.



Dr Jem Rashbass
Director of ECRIC

Major challenges for 2005 / 2006

Boundary change

- Taking over Hertfordshire and Essex from Thames Cancer Registry
- Doubling of our resident population therefore, doubling our number of registrations
- No increase in existing staff numbers

Electronic data

- Custom design of an ECRIC Cancer Registration database
- All hospitals reporting electronically
- Introduction of a new path system
- Scanning of all paper records

HES linkage project

- Linkage of HES data with Cancer Registry data
- Data from 1999 to 2003



Boundary change

One of the most significant changes for ECRIC is the transfer of the responsibility for registration and analysis for the entire population of Hertfordshire and Essex from the Thames Cancer Registry from April 2006

Introduction and background

The Eastern Cancer Registration and Information Centre (ECRIC) registers all malignant tumours and some pre-cancerous lesions occurring in people resident in the East of England at the time of diagnosis.

Until 2004, ECRIC was known as the East Anglian Cancer Registry which was officially created in 1989 by amalgamation of the cancer registration bureaux in Cambridge, Norwich and Ipswich. However, data are available for the whole of the East of England from these bureaux from 1961. In 1994 the East Anglian and Oxford Regional Health Authorities (RHA) were merged, but the registries stayed separate. At the time of the merger, the county of Bedfordshire was transferred from North Thames RHA to the Anglia and Oxford RHA and from 1996 ECRIC data includes those from Bedfordshire.

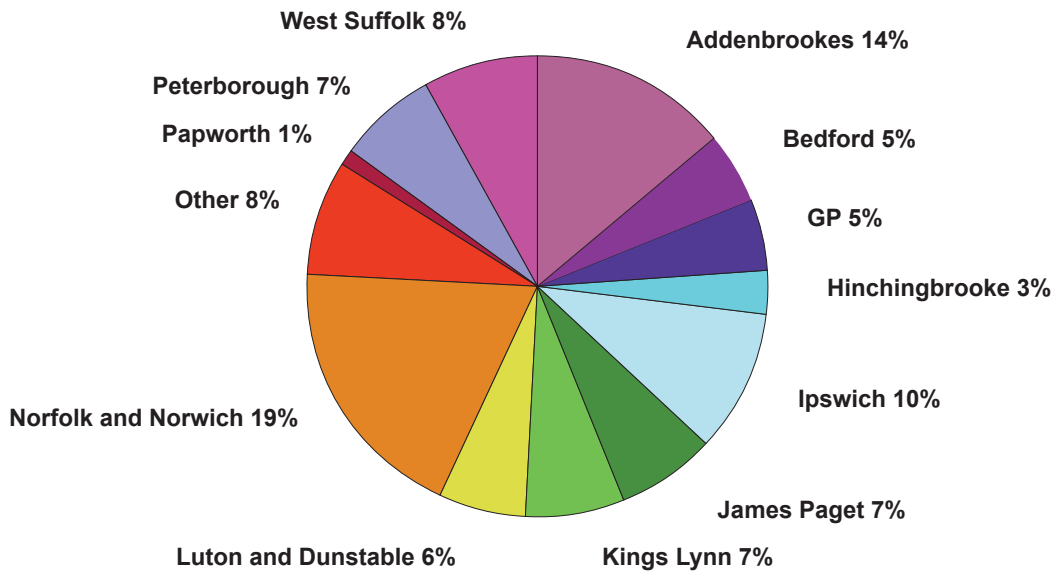
From April 2006 ECRIC took on Hertfordshire and Essex from Thames Cancer Registry. This increased the registry population to approx 5.5 million from 2.8 million. This meant that the ECRIC boundaries have become co-terminus with the East of England Government Office Region.

Currently the registry is based in Addenbrooke's hospital with registration staff based in the original offices in Ipswich and Norwich. We also have registration staff based in Colchester and Southend hospitals.

Registration

Registrations

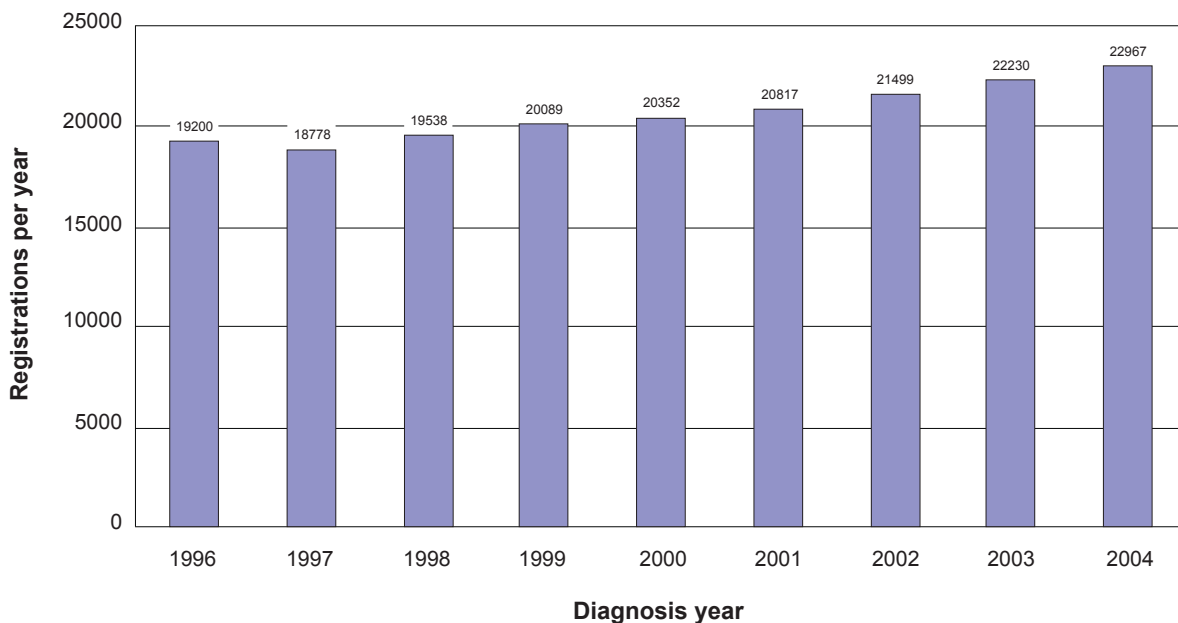
The annual number of registrations has increased by 13% since 2000 and will increase by a 100% in 2006 due to the increase in the population served. 2005/2006 has been challenging with the Boundary Change, use of electronic data, and in driving towards a 'paperless' Registry but we have succeeded in maintaining an enviable rate of 99% of registrations complete for the year.



Diagnoses by hospital for 2004

Scanning

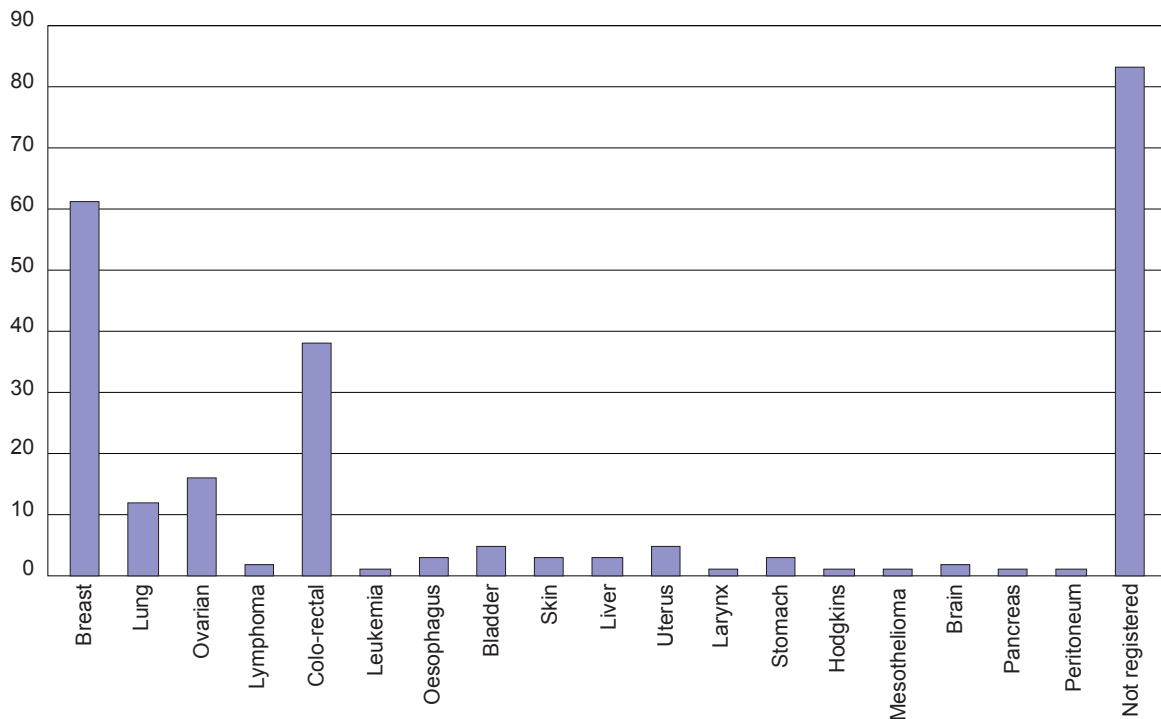
At ECRIC we have taken on the task of scanning in all our paper records going back to pre-1971 up to present day to try and become a paperless office. So far we have scanned over 110,000 records.



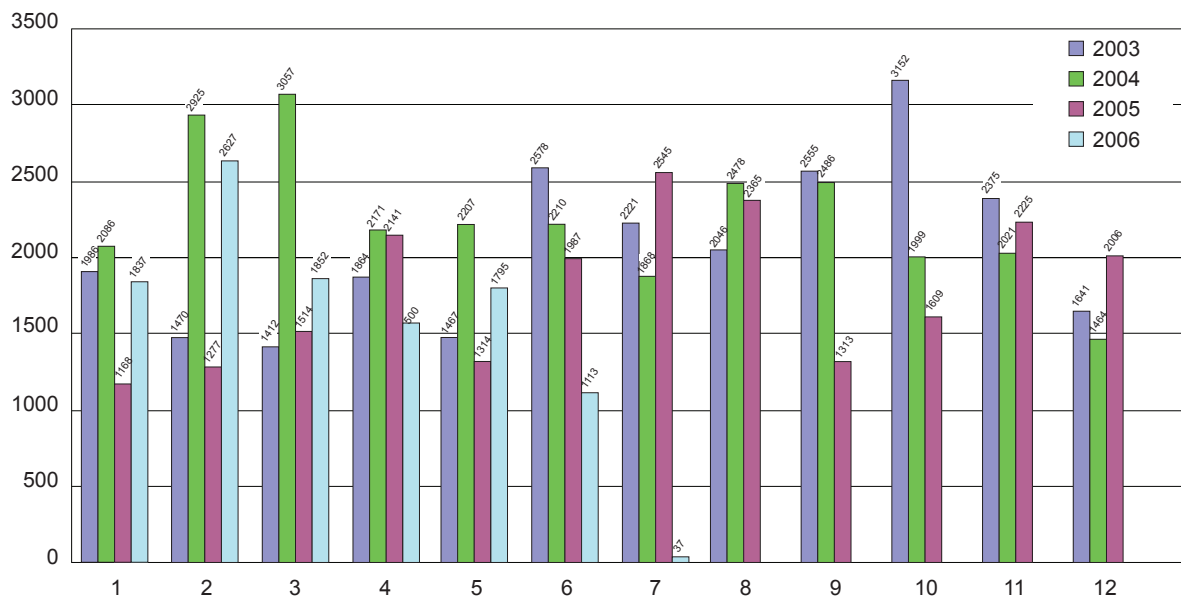
Total registrations by year

Genetic Enquiries

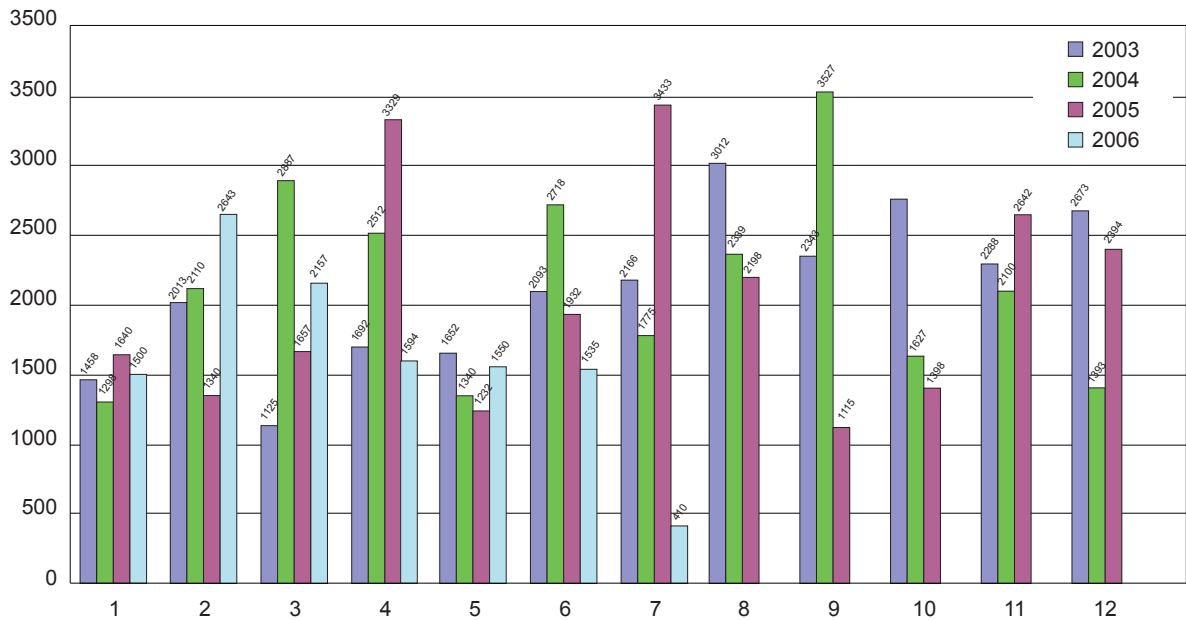
ECRIC responded to 242 Genetic enquiries in 2005/2006. Of these, 35% were not registered in our area. All replies were within the 10 day window, the majority within 5 days.



Genetic enquiries in 2005/2006



Total registrations by month 2003 - 2006 (all diagnosis years)

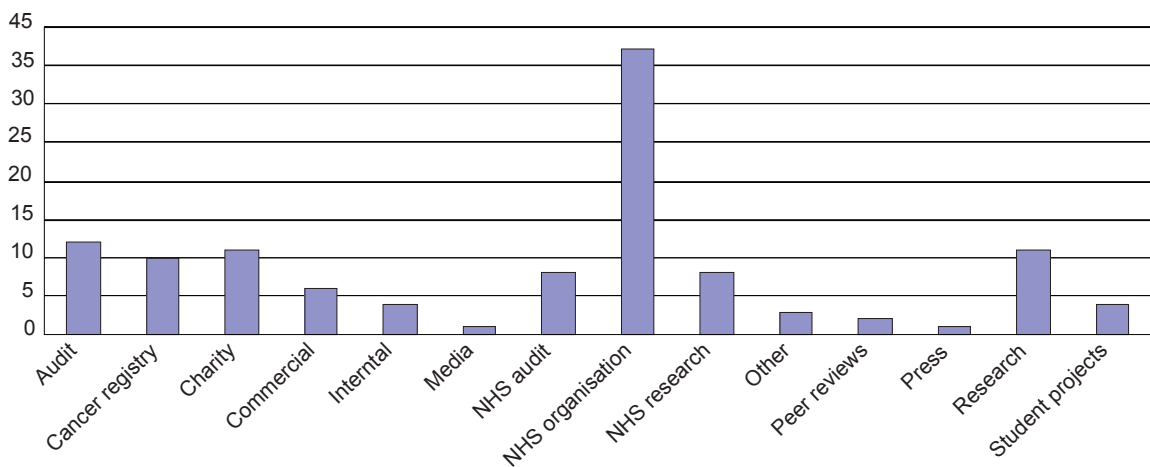


Data entry per month 2003 - 2006 (all diagnosis years)

Analysis

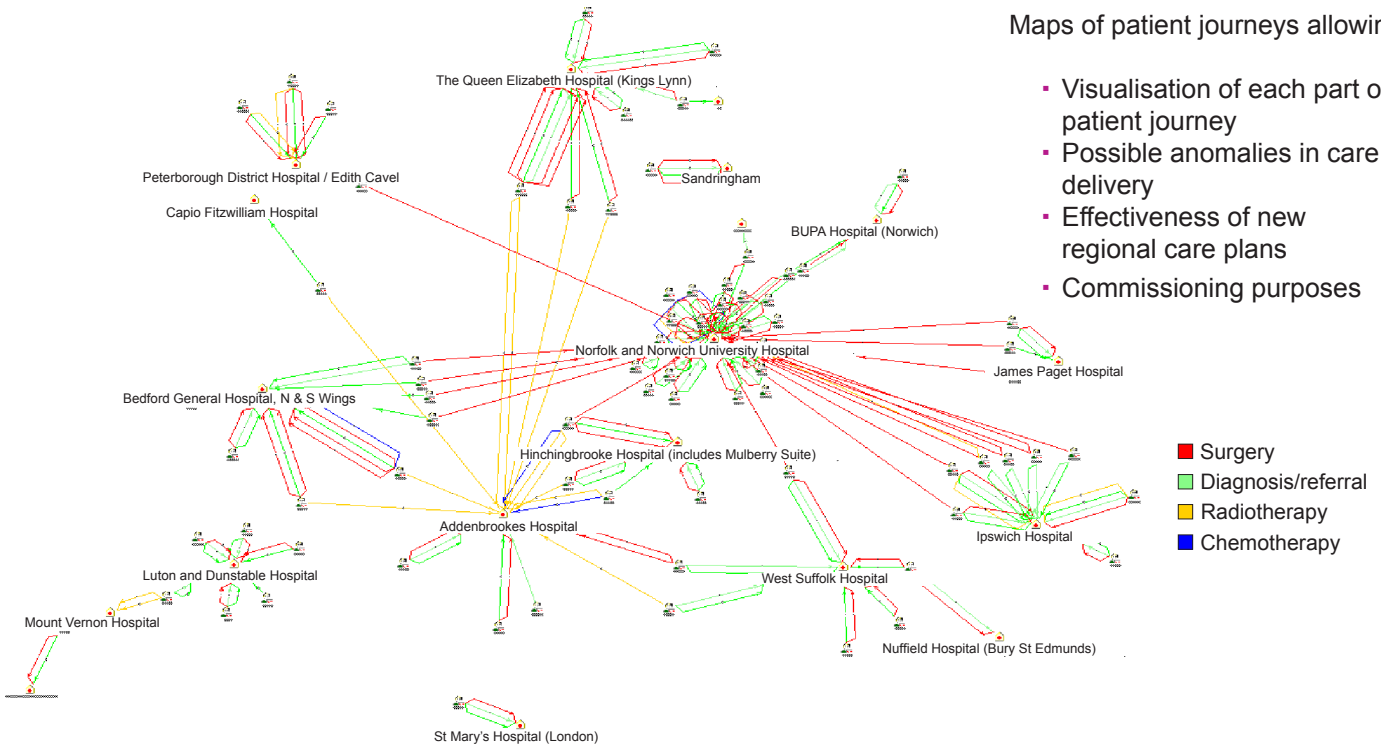
ECRIC’s analysis team extracts, analyses and interprets regional cancer statistics. Requests for data come from health professionals, researchers, national and regional organisations and the general public. Enquiries vary in their complexity from queries that require a simple extraction from the database to more complicated analyses, which may take several days.

In 2005/2006 the analysis team received and answered 118 queries from a variety of sources.



Number of queries April 2005 - March 2006

Maps of patient journeys allowing



Novel Patient Mapping software shows patients moving between hospitals with their treatments

Reports

On our website we have a number of reports looking at the different cancers. These include :

- General cancer Information
- All Cancers
- All Invasive
- All Bladder
- Bones and Articulate Cartilage
- All Breast
- All Colorectal
- Eye, Brain and CNS
- Head and Neck
- All Hodgkin's Disease
- All in situ Cervix
- All in situ of Breast
- All Kidney
- All Leukaemia
- All Melanoma
- All Mesothelioma
- Non Hodgkin's Lymphoma
- Non Melanoma
- Other haematological
- All Ovary
- All Prostate
- All Testis
- Trachea, Bronchus and Lung
- All Upper GI
- All Uterus

These reports were produced by the analysis team and by a summer student to the registry, Leo Culerier. The reports show -:

Cancer Statistics

Cancer affects all ages, however, is predominately a disease that affects the elderly; the rate of cancer in any age-group rises continuously in both males and females from about the age of 30.

The statistics presented here fall into three groups: Incidence, Mortality and Survival.

Incidence and Mortality are reported in three ways:

1. Number: this is simply the number of cases cancer in an area and will depend on the population of that area and on the age structure of its population as well as on the underlying rate of cancer.
2. Crude rate per 100,000 population: this is the number of cases of cancer in an area divided by the population of that area. This measure takes account of the size of that population, but not its age structure; it would tend to be higher in areas where the population is older.
3. Age standardised rate per 100,000 population: this measure adjusts the crude rate according to the age structure of the population. It estimates what the cancer rate would be if the age structure of the population was the same as that of a standard population (based on the whole European population). As this measure takes account of both population size and age structure, and can be used to compare the rates in different areas. The graphs of age standardised rates show 95% lower and upper confidence limits (95% LCI and 95% UCI); these are the levels between which it is 95% certain that the true rate of cancer will fall. These confidence limits become much wider as numbers become smaller, either when the area (and its population) is small, or when there are rare cancers with few cases.

Survival

Five-year relative survival rates of cancer patients diagnosed during the period 1995-1999 are shown. Relative survival, expressed as a percentage, is the ratio of the survival observed in a group of cancer patients to the survival that would be expected if they were subject to the same overall mortality rates as the general population.

See: <http://www.ecric.org.uk/reports.shtml>

HES project

Objectives

To match HES data with the cancer registry data to see if the combined linked data add value and enrichment to either set of data. Therefore allowing previously unknown and unidentified areas to be analysed and recorded.

Introduction/Background

Initial funding for the project was obtained from the University of East Anglia (UEA) for a project proposal from Jane Skinner. A proportion of the funding paid for an analyst at the Eastern Cancer Registration & Information Centre (ECRIC). This post was created to link the Cancer Registry data with the HES data, it was a joint piece of work between the UEA, ECRIC and the Eastern Region Public Health Observatory (ERPHO). The UEA provided funding, ECRIC provided the cancer registry data and an analyst and ERPHO provided the HES data extract for the years 1998 – 2003.

Initial Project Plan

- HES data imported onto stand alone machine into SQL server
- Initial manipulation of data to gain an understanding of HES data fields & structure
- Creation of a Cancer Registry table to be used in linkage
- Data cleansing to ensure data in correct formats (ie NHS number format, postcode format)
- Basic linkage practices
- First linkage on NHS number alone
- Creation of Access databases to store linked data for use by Jane Skinner
- Further linkage on sex, date of birth and postcode
- Look at data not found in HES when linked on NHS number
- IMD Scores

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Who is Missing from HES?

Cancer Registry to Hospital Episode Statistics Record Linkage

Authors: Jessica Pyle, Jan Fizzell, Jem Rashbass - Eastern Cancer Registration and Information Centre

BACKGROUND & INTRODUCTION

The Eastern Cancer Registration and Information Centre (ECRIC) had linked its entire cancer registry dataset with the East of England Hospital Episodes Statistics (HES) dataset for the years 1998 - 2002

The aim was to get a better understanding of the differences between records that linked and those that did not

We examined:

A) Differences between tumour types
B) Differences between treating organisation and between treatments registered
C) Differences over time

METHOD

The two datasets were linked using direct match linkage on NHS number Identified those which had not linked and studied these further

Three common and three rare cancers were compared

Patients who we would not expect to see in HES data were excluded

The table below shows excluded figures:

Cancer Group	Death Certificate Only	Private Hospitals / Non hospital healthcare	Hospitals out of Region
Breast	5	816	103
Colorectal	9	362	26
Lung (inc Testes)	4	113	42
Mesothelioma	0	8	0
Pancreas	3	54	13
Testicular	0	42	4
Total	21	1395	155

RESULTS

A) Proportion of Records Linked and Not Linked by Tumour Group

Percentage of non linked cases varied significantly between tumour groups (χ^2 test $p < 0.001$)

B ii) Treatments recorded by ECRIC in Unlinked Patients

There was a significant association between difference in treatments and tumour groups in unlinked patients (χ^2 test $p < 0.001$)

B i) Proportion of Cases Not Linked by Treating Trust and Tumour Group

Percentage of inpatient procedures being missed in HES varies significantly between hospitals (χ^2 test $p < 0.001$)

C) Time - Trends in Linkage over Time - All hospitals and Top 3 Hospitals With Poor Linkage Rates

The trend is for linkage to improve over the years, however this is not true for all hospitals. [Total ($r = -0.86$); $p < 0.025$], Hospital 1, ($r = -0.94$); $p < 0.05$], Hospital 2 ($r = -0.27$ (NS)), Hospital 3 ($r = 0.49$ (NS))]

CONCLUSIONS

If HES is being used as a primary system of ascertainment many cases may be missed

The quality of records available to link from HES varies significantly over time and between trusts

Unexpectedly, even patients registered as undergoing inpatient surgical procedures may be missing from HES data

Treatment data gained from HES may potentially under report treatment intensity significantly

LIMITATIONS AND FURTHER STUDIES

Linkage on NHS number only - future investigations will involve matching on procedures and dates of operation

Other tumour groups may show different patterns of linkage/non linkage

Further studies should be undertaken on rare cancers to ascertain the under-reporting of these tumours in HES

Acknowledgements:
We would like to thank the registration team at ECRIC without which none of this work would have been possible. We would also like to thank ERPHO for the permission to use the HES data and the University of East Anglia for the funding for the initial project. Thanks to the rest of the analysis team at ECRIC for their support and help.

**Abstract for the poster submitted:
Cancer registry to hospital episode statistics linkage; Who is missing from HES?**

Boundary change

The move of Herts and Essex from Thames Cancer Registry (TCR) to ECRIC, having been under intermittent discussion since 1990, went ahead on April 1st 2006.

Rationale

The main driver for this reorganisation was a desire for an alignment of the boundary of ECRIC with the Government Office of the Eastern Region.

Other key benefits for cancer registration in East Anglia include:

- Ensuring a strong and secure technical environment
- Economies of scale leading to a more cost effective operation
- Ensuring a robust governance and review framework

Learning Points

- The primary lesson to take away from this project is the importance of high level management buy-in
- The second factor is the need for a programme of relevant, targeted, up-to-date and ongoing communication
- Thirdly, do not overlook the importance of defining clear project boundaries and the usefulness of formal project management techniques
- A key factor in the success of the project was the commitment TCR had to making it work, despite the fact that they were “losing” catchment population
- Finally, pay near excessive attention to detail, including the breaking down of tasks to reasonable levels

Impacts

- A Cancer Registry boundary change has similar challenges to any other NHS organisational change. Dedicated project management is a necessary pre-requisite for any change of this size, but the process of change itself breaks down into easily identifiable tasks.
- Staff (training, TUPE regulations, resource planning, travelling)
- Data collection at hospitals
- Data Input at central office
- Automation and IT (including electronic feeds, transfer & merging of data, standing data & look-ups)
- Data analysis
- ONS and external reports
- Office procedures (including stationery, e-mail, equipment)

Finance

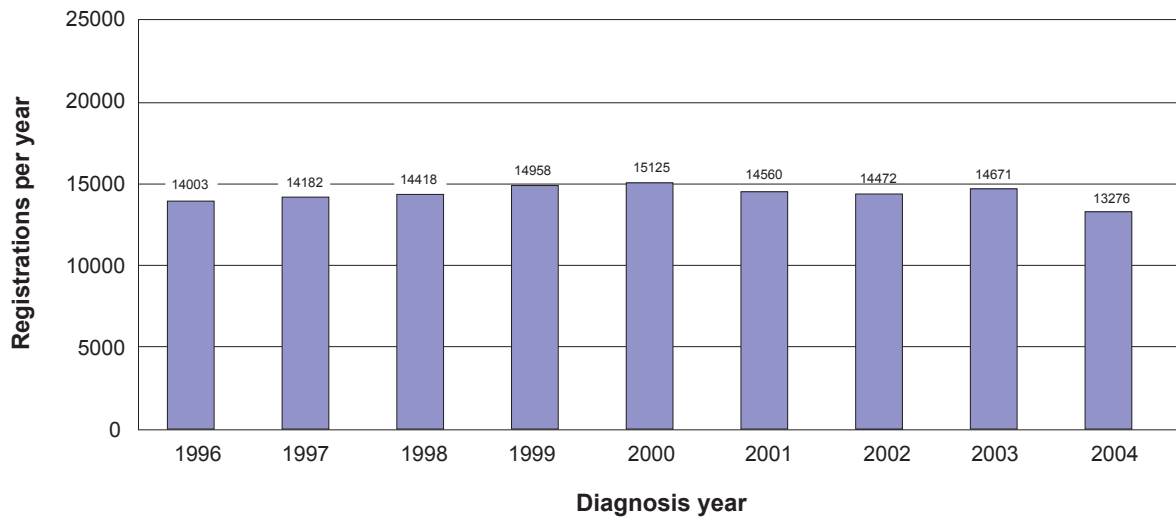
The costs of the boundary change are mainly those of resource required for the transfer of data, systems, and hospital processes. This can be reflected as: Total = £104k

Project Manager	15 months	£45k	Registry Officer	6 months	£10k
Software Developer	6 months	£15k	Admin Support	4 months	£8k
Data Quality Officer	6 months	£8k	Electronic Feed Manager	6 months	£18k

TCR will also have incurred costs in the above categories.

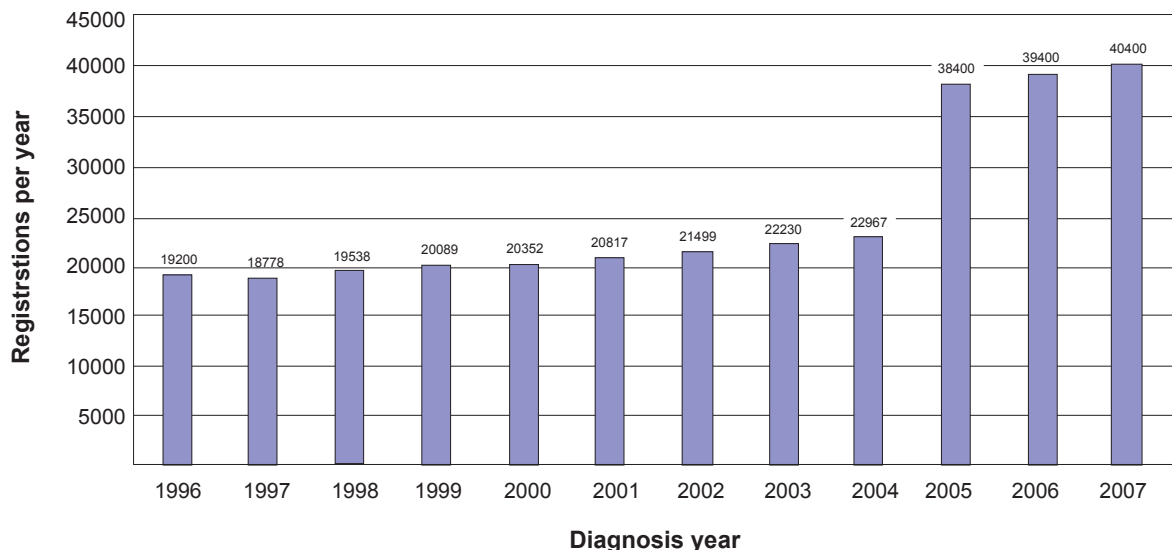
The change project itself, in terms of meeting milestones, targets and deliverables up to April 2006 was an agreed success. There has been no negative feedback from any of our hospital stakeholders.

The real success of the project will be judged on how ECRIC performs for Herts and Essex during our first year of responsibility. That is, on the evidence of the 2005 (registration year) figures and on the satisfaction of all our customers between now and July 2007.



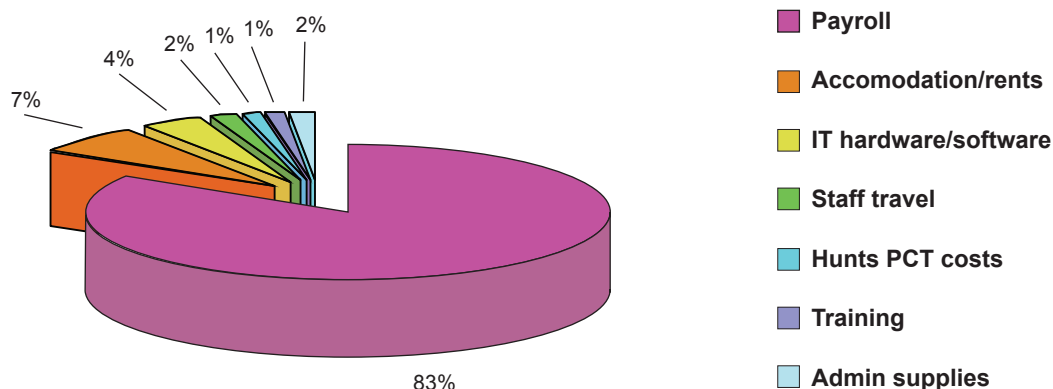
Registrations per year 1996 - 2004 (Hertfordshire, Essex)

The graph below shows the workload for the registry on the original catchment area for 1996..2004 together with the estimated workload for the area including Hertfordshire and Essex for the year 2005..2007. The predictions are based on the figure for 2004 for Beds, Cambs, Suffolk and Norfolk plus an increase of 500 cases per year, plus an approximate figure for Hertfordshire and Essex of 14500 for 2004 plus an additional 500 cases per year.



Predicted Registrations 2005 - 2007 (Herts, Essex, Beds, Cambs, Suffolk, Norfolk)

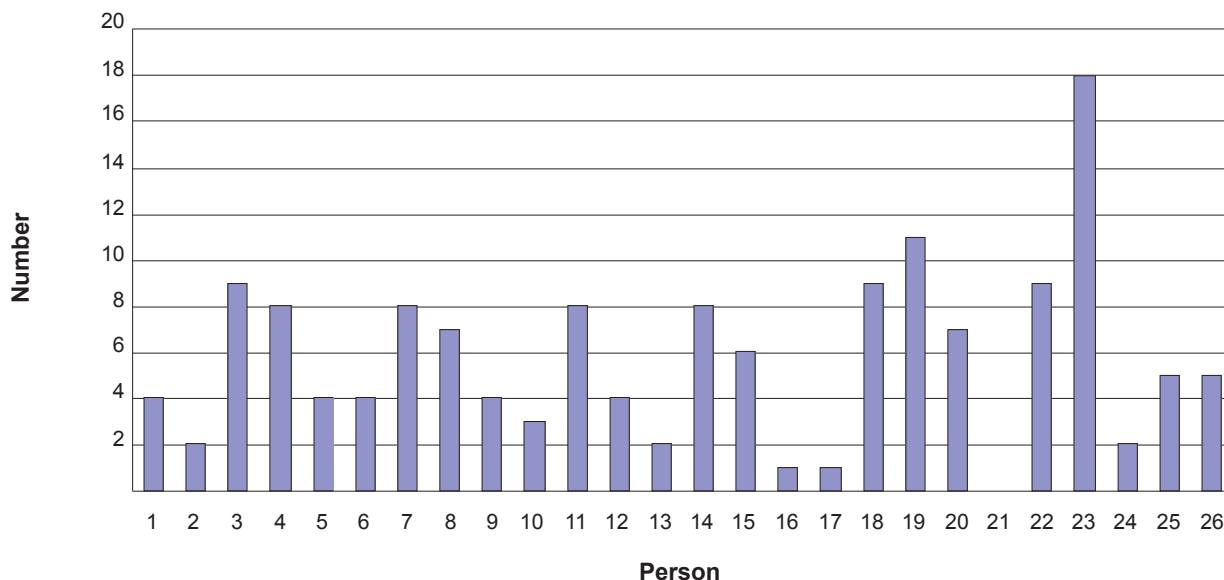
Budget and expenditure 2005/2006



Cost per 100,000 population = £221.00

Training

Within the registry we have a training manager who is in charge of recording and ensuring all members of staff have the required training to do their role.



Graph showing number of training courses attended by each member of staff in 2005/06

Quality assurance

Data collected for entry on to the Oracle database are subject to a number of validations, which are written into the data entry programme. It is not possible to include all possible validations so regular (monthly) checks are carried out on the finalised data.

The checks include a series of date validations to ensure that the hierarchy of dates are in the correct order (e.g. date of birth must be before date of diagnosis etc).

All Stageable sites are checked to ensure that a valid stage has been entered. Information which contributes to the determination of stage ie TNM, tumour size and number of nodes excised and number positive are scrutinised to ensure that they are meaningful.

There is an ongoing programme of de-duplication in place to ensure that no one is entered on to the database as two individuals.

Following the incorporation of data for Hertfordshire and Essex a comprehensive checking programme is underway to flag all case which have been registered by both ECRIC and Thames in the extra-regional data exchange system.

Immortal patients and patients with a missing NHS number are investigated using the NHS Tracing Service.

All invalid postcodes are checked and corrected.

All those cases which are registered from a death certificate (DCO) are thoroughly checked to ensure that they comply with the registration guidelines as laid out by the UKACR ie they must have zero survival, no other details entered other than those found on the death certificate and no treatment recorded.

Gender specific and childhood specific tumours are checked against sex, site and age.

A new database and data entry programme are currently under development, and it is planned to incorporate many of these checks in the database systems.

Publications

2006

Pashayan N, Powles J, Brown C, Duffy SW. **Excess cases of prostate cancer and estimated overdiagnosis associated with PSA testing in East Anglia.** British Journal of Cancer. 2006 Sep 4;95(5):660

Pashayan N, Powles J, Brown C, Duffy SW. **Incidence trends of prostate cancer in East Anglia, before and during the era of PSA diagnostic testing.** British Journal of Cancer. 2006 Aug 7;95(3):398-400

2004

Warren R, Allgood P, Hunnam G, Godward S, Duffy S; **East Anglian Breast Screening Programme. An audit of assessment procedures in women who develop breast cancer after a negative result.** Journal of Medical Screening. 2004;11(4):180-6

McCann J, Treasure P, Duffy S, **Modelling the impact of detecting and treating ductal carcinoma in situ in a breast screening programme.** Journal of Medical Screening. 2004;11(3):117-25

2003

Kaffashian F, Godward S, Davies T, Solomon L, McCann J, Duffy SW. **Socioeconomic effects on breast cancer survival: proportion attributal to stage and morphology.** British Journal of Cancer. 2003 Nov 3;89(9):1693-6

Published reports

Cancers diagnosed and treated in the West Anglia Cancer Network - ECRIC area 2003

Local or internal reports

Years of life lost due to cancer in East Anglia 1990-94 (circulated 1996)

Staff

Dr Jem Rashbass - Director
Dr Clement Brown - Medical Director
Mrs Sue Danson - Registry Manager
Mrs May Williams - Deputy Registry Manager
Mrs Jane Richardson - Operations Manager

Analysis Team

Dr David Greenberg - Senior Analyst
Miss Jessica Farrimond nee Pyle - Senior Information Analyst
Mrs Karen Wright - Quality Assurance & Information Officer
Dr Peter Treasure - Statistician

IT Team

Mr Warren Carmody - Senior Systems Developer
Mr Lee Robinson - Network and Systems Administrator
Mrs Elena Doyle - Systems Manager
Mr David Lawumni - Java Programmer

Boundary Change

Ms Dara Morefield - Boundary Change Manager
Mrs Kerry Gamble - Communications Manager
Mr Noel Younger - Cancer Action Programme Project Manager

Registration Staff / Clerical Staff

Mrs Claire Beattie - Senior Registration Officer
Mrs Christine Straughan - Quality Assurance & Training Officer
Mrs Karen Bull - Registration Officer
Mrs Karen Coppack - Registration Officer
Mrs Susan Court - Registration Officer
Mrs Liz Fisk - Registration Officer
Ms Lisa Godfrey - Registration Officer
Mrs Cheryl Reynolds - Registration Officer
Mrs Dawn Warren - Registration Officer
Mrs Jacky Tozer - Registration Officer
Mrs Lynda Fletcher - Registration Officer
Miss Jodie Barron-Johnson - Registration Officer
Mrs Christine Durrant - Lead Clerical Officer
Mrs Jenny Bates - Clerical Officer
Miss Linda Bullman - Clerical Officer

Contact

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