



**West Midlands
Cancer Intelligence Unit**

Cancer Registration, Information & Health GIS

Annual Report 2008/09

**Publication No. RO9/05
December 2009**

Table of Abbreviations

Abbreviation	Expansion
ASR	Age standardised rate
BCCOM	Breast Cancer Clinical Outcome Measures
C44	Non melanoma skin cancer
CBSA	Commissioning Business Support Agency
CIS	Cancer Information Service
CWT	Cancer Waiting Times
GIS	Geographical Information Systems
GP	General Practitioner
GRACE	Generic Registration and Cancer Epidemiology database
HES	Hospital Episode Statistics
LCI	Lower (95%) confidence interval
MDT	Multi-disciplinary team
NCIN	National Cancer Intelligence Network
NCIS	National Cancer Information Service
ONS	Office for National Statistics
RCPPath	Royal College of Pathologists
UCI	Upper (95%) confidence interval
UKACR	United Kingdom Association of Cancer Registries
WMCIU	West Midlands Cancer Intelligence Unit

WMCIU Annual Report 2008/09

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1.0 Executive Summary

This 2008/09 West Midlands Cancer Intelligence Unit (WMCIU) annual report covers the key strategic and operational achievements for the cancer registration activities carried out by the WMCIU in the 12 month period ending 20 June 2009.

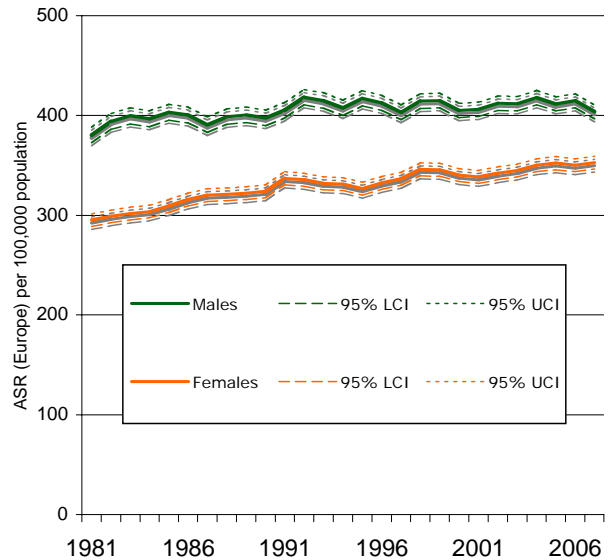
During 2008/09 the following key activities were undertaken:

- Completion of the UK Association of Cancer Registries Performance Indicators exercise which includes a review of the Cancer Peer Review targets on timeliness and data set completeness, and which demonstrated a 40% reduction in the number of Death Certificate Only cases
- Visits to all regional NHS Trusts to discuss the need for electronic data transfer and to agree action plans
- Appointment of a new Deputy Director of Cancer Registration
- Reorganisation of information provision, including the formation of the core information team and site specific teams for breast and gynaecological cancers
- The formation of the National Cancer Intelligence Network (NCIN) and the WMCIU's designation as lead registry for breast cancer and sarcoma

2.0 Cancer Registration

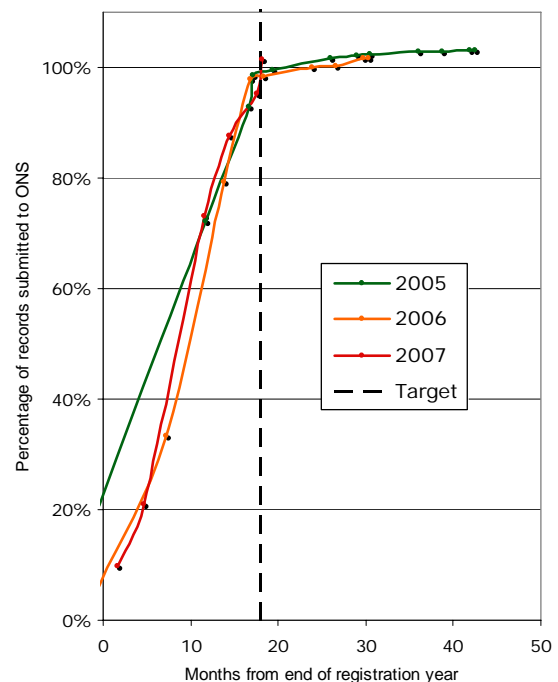
In 2007 40,677 new malignant (invasive and in-situ) cancers were registered in West Midlands residents. Of these, 26,259 were invasive tumours (excluding non-melanoma skin cancer, C44).

The age-standardised incidence rate (ASR) in the West Midlands in 2007 for all invasive malignancies (ex. C44) was 372 per 100,000 population. In males the ASR was 404 per 100,000 population and in females it was slightly lower at 352 per 100,000 population. The following figure shows how the annual ASRs in males and females have changed since 1981.



2.1 Timeliness of data submission

In 2007, the WMCIU achieved the Cancer Registry Measures target for submitting all data to the Office of National Statistics within 18 months of the end of the diagnosis year.



2.2 Data quality

The WMCIU continues to improve and automate the routine data quality checks that all data undergo after abstraction, and to increase the number of routine validations carried out at the time of data entry.

In 2007/08 problems with data submission from several of the region's Trusts were discovered, affecting the data quality of registrations for 2006 and 2007. These were primarily due to the introduction of new pathology laboratory computer systems which disrupted data flow to the WMCIU. The WMCIU has captured the back-log of missing cases, and has changed the monitoring process to enable issues to be addressed earlier in future.

2.3 Performance indicators

The WMCIU performed well in comparison to other UK cancer registries in the 2007 UKACR Performance Indicators exercise (submitted in June 2009). The key challenge remains the problems of obtaining further information on cases initially registered from a death certificate. However, the initiation of a tracing system via letters to GPs dramatically improved the WMCIU's Death Certificate Only rates for 2007 cases and the unit continues to work on ways to improve these rates.

Performance Indicators	WMCIU	UK Avg
Death Certificate Only cases (%)		
All sites (Male)	6.9	2.3
All sites (Female)	6.5	2.4
Microscopic verifications rates (%)		
All sites (Male)	84.3	84.4
All sites (Female)	86.1	85.9
Mortality:Incidence ratios		
All sites (Male)	0.55	0.53
All sites (Female)	0.50	0.50
Dataset Completeness (% complete)		
Postcode	99.9	99.9
Sex	100.0	100.0
Date of Birth	100.0	100.0
NHS Number	99.0	99.0
Ethnicity	78.9	50.0
Topography	95.8	96.4
Morphology	86.5	88.4
Breast staging	77.1	49.0
Cervix staging	77.4	64.7
Colorectal staging	71.9	68.8
Melanoma (Breslow)	95.8	77.9
Grade (breast only)	91.1	86.3

2.4 Training

The WMCIU continues to be an exemplary provider of training, both in-house and at regional and national levels. In-house training covers not only the initiation of new staff to the core cancer registration skills, but a broad programme of cancer site specific training designed to support the continued

development of experienced staff. The Training Manager works closely with the Data Quality team to identify coding issues so that they can be picked up at an early stage.

Sixteen external training workshops were held in 2008/09, aimed at non clinical staff such as multi-disciplinary team (MDT) co-ordinators, data collection officers, clinical coders and information staff. 244 delegates attended these sessions.

The Training Manager sits on national level UKACR training groups, and is part of the group working to provide a national level accredited training programme for MDT co-ordinators.

2.5 Electronic data transfer

The 2008/09 NHS Standard Contract for Acute Services gives a formal mandate for Trusts to provide electronic downloads of data to cancer registries.

In 2008/09 the WMCIU and the cancer networks met with cancer managers in Trusts throughout the region, to discuss the provision of electronic data. These meetings were very constructive, with key actions for each Trust identified to enable the WMCIU to move forwards on electronic data collection.

In 2008/09, good progress was made in obtaining electronic pathology data, which covered approximately 20% of the WMCIU's pathology workload by March 2009. This is expected to increase substantially in 2009/10 as test data supplied by further Trusts in the region are brought on line. Electronic radiotherapy data continue to be received from the three largest providers in the region.

2.6 GRACE 3

In 2008/09 the traditional Oracle based access screens used by registration staff to input data to the cancer registration database were replaced with a new windows based system capable of managing both automated and manual data processing. This not only improved the WMCIU's ability to deal with electronic data flows, but also provided an opportunity to review and improve format and processing methods.

2.7 Alternative data sources

In 2008/09, Cancer Waiting Times (CWT) and Hospital Episode Statistics (HES) data continued to be used to supplement GRACE, particularly for following up death certificate notifications. A successful pilot project was undertaken to automatically extract details on chemotherapy data from HES and this will be repeated for future years of data. The WMCIU also met with the Commissioning Business Support Agency (CBSA) to discuss the availability of more timely data on hospital admissions for cancer patients.

3.0 Information Provision

The WMCIU reorganised its research and information functions in 2008/09. A new Deputy Director of Cancer Registration was appointed, and the information team was restructured into three teams, to align more closely with the work of the WMCIU's Screening Quality Assurance Reference Centres. A Core Information Team was formed to co-ordinate the broad cancer registration information work in the WMCIU, with site specific queries being dealt with by newly formed Breast and Gynaecological Cancer Information Teams. This change has enabled the provision of well informed intelligence supported by detailed understanding of site specific issues.

3.1 Information requests

The WMCIU received 163 ad-hoc information requests in 2008/09. 136 were dealt with by the Core Information Team, 25 by the Breast Cancer Information Team, and 2 by the Gynaecological Cancer Information Team.

The Cancer Registry Peer Review Target states that 80% of requests should be dealt with within 20 working days. Only 74% of requests in 2008/09 were completed within the required timescale. This in part reflects the fact that 2008/09 was a year of major restructuring for the information team, with vacancies and new information managers in post. However, some delays were not due to the information team, but related to waiting for the requestor to send forms or data to the WMCIU. Better reporting and monitoring is now in place for 2009/10 with the aim of meeting the target in future years.

3.2 Network site specific reports

In 2008/09 the Core Information Team developed a template for site-specific cancer network reports. The reports covered key epidemiological statistics, including incidence, mortality, survival, Trust of referral, treatment patterns and place of death.

Three site specific reports were produced - stomach cancer, oesophageal cancer, and pancreatic cancer. As these reports looked at small numbers of cases by Trust, particularly around sensitive areas such as caseload and 30 day mortality, they were initially released in confidence to the cancer networks to allow discussion of data quality.

3.3 Other reports

The Core Information Team also produced a report on Incidence and Mortality in the West Midlands - Key Messages for PCTs and Cancer Networks. Reports on occasional operators in urology, upper GI and colorectal were produced for the Arden and 3 Counties Cancer Networks. Short factsheets on upper GI and prostate cancers were also published.

3.4 Cancer Information Service (CIS)

The regional CIS was overhauled in August 2008 to reflect the changes included in the National CIS system launched in October 2008. The registry is currently running the regional CIS in parallel with the national CIS, as the regional CIS has a large body of established users who would need to be migrated in a planned way, and because the regional CIS provides information not available on the national CIS. A review of the regional CIS is planned for 2009/10 to ensure minimum duplication.

3.5 Genetic enquiry services

In 2008/09 428 genetics requests were received at the WMCIU, requesting information on 4,341 patients. 96% were completed within 10 working days, exceeding the Cancer Registry Peer Review Target of 80%. 73% of patients were successfully traced. Those that could not be traced may have had insufficient or inaccurate information provided, or the person's cancer may have been registered in another area.

The WMCIU works in partnership with staff from the West Midlands Regional Clinical Genetics Service, who attend the unit on a weekly basis to extract the data they need.

4.0 Health Geographical Information Service (GIS)

The Health GIS service based at the WMCIU works to identify, develop and apply complex geographical analysis to address key public health policy needs.

In 2008/09 the Health GIS team developed a more sophisticated regional road network database, enabling measures of congestion and travel time to be taken into account. This work was applied to a number of regional initiatives, including measuring the accessibility of services to patients and the carbon footprint of patient travel.

The Health GIS team works closely with cancer registration and screening quality assurance reference centre staff to support the geographical side of information provision and to provide denominator populations. This role has also allowed the Health GIS team to support the development of the NCIS, providing population data, geographical data, and postcode look-ups. Two presentations at the annual UKACR conference were based on the work of the Health GIS team.

In 2008/09 the Health GIS service dealt with 70 ad-hoc requests from the WMCIU, other regional organisations, and national groups such as the UKACR.

5.0 Partnership Working

5.1 National Cancer Intelligence Network (NCIN)

June 2008 saw the launch of the National Cancer Intelligence Network (NCIN), bringing together cancer registries, clinical champions, health service researchers and a range of other interested parties. The NCIN's key aim is to "use information to improve quality and choice." This is underpinned by 5 core objectives

- Promoting efficient and effective data

- collection throughout the cancer journey
- Providing a common national repository for cancer datasets
- Producing expert analyses, to monitor patterns of cancer care
- Exploiting information to drive improvements in cancer care and clinical outcomes
- Enabling use of cancer information to support audit and research programme

The WMCIU plays a key role in the newly formed NCIN. The registry has submitted data to the national data repository, and gave oral and poster presentations at the first NCIN conference in June 2009.

5.2 Lead registry roles

As part of the creation of the NCIN, in 2008/09 the WMCIU was nominated to take on the national roles of the lead registry for breast cancer and for sarcoma. This presents a unique opportunity to work with national cancer registration data for the two cancer sites, and to combine these data with cancer waiting times, HES and the national clinical audit data, to produce the fullest possible picture of breast cancer and sarcoma care in England.

The role as lead registry for breast cancer is a natural extension for the WMCIU, which already co-ordinates the national NHS Breast Screening Programme audit of screen-detected breast cancer, the Breast Cancer Clinical Outcome Measures project, and the Sloane Project audit of non-invasive, screen-detected breast cancers.

The WMCIU was selected as the national lead on sarcoma, in part because of the unit's excellent links with the Royal Orthopaedic Hospital in Birmingham. Sarcomas are a rare and diverse group of tumours, and this will be the first opportunity to study their diagnosis, treatment and outcome at a national level.

The WMCIU secured funding from the NCIN to appoint two analysts to support the development of these lead registry roles in 2009/10.

5.3 Cancer registration study day

The annual cancer registration study day took place in November 2008, and was attended by almost 70 delegates. The study day invites staff from NHS Trusts in the region who are responsible for providing data to the WMCIU, in order to highlight how their data are used and to build relationships between the Trusts and the WMCIU. The themed session in the day focussed on bone and soft tissue sarcoma to reflect the registry's new national lead role.

5.4 UK Association of Cancer Registries (UKACR)

The WMCIU continued to take part in national level discussions about cancer registration, with representatives on the UKACR Executive, the Analysis Subgroup, the Registration Subgroup, the Coding and Classification Working Group, the Data Quality Working Group and the Training Working Group. In 2008/09 the WMCIU played a lead role in the review of UKACR subgroups to ensure that their scope was clear and that duplication was avoided. This review resulted in the establishment of a new subgroup structure for 2009/10.

5.5 Other collaborations

The WMCIU continues to work closely with the cancer networks in the West Midlands, attending Network Site Specific Groups as appropriate. In 2008/09 the WMCIU met with all Trusts in the region to discuss electronic data provision (as summarised in section 2.5). The WMCIU's Director is also involved in a number of national and international collaborations, including sitting on the RCPATH Working Group on Cancer Services, and attending meetings of EURO CARE. She is also the Regional Director of Quality Assurance for the cancer screening programmes; providing a vital link between cancer registration and screening QA activities at regional and national level.

6.0 Publications, Presentations and Research Activity

6.1 Reports and publications

WMCIU Cancer Registration & Health GIS Annual Report 2007/08. Publication no. R08/10, May 2008

Cancer Network Report series: Stomach Cancer. Publication no. R08/12
Cancer Network Report series: Oesophageal Cancer. Publication no. R08/13
Cancer Network Report series: Pancreatic Cancer. Publication no. R08/14
Prostate Cancer in the West Midlands. WMCIU Factsheet, July 2008
Upper GI Cancer in the West Midlands. WMCIU Factsheet, September 2008
D. Edwards. Health Geography. Key Health Data 2007/08
S. Jones. Comparing the 2004 and 2007 Indices of Deprivation. Key Health Data 2007/08
D. Edwards. Creating a Carbon Footprint of Radiotherapy Treatment for Breast Cancer in West Midlands in 1990 & 2004 – a case study. Cited in NHS Carbon Reduction Strategy 2008.

6.2 Lectures and oral presentations

D. Edwards, S. Jones, C. Lagord, C. Lawrence. The Carbon Footprint of Radiotherapy Treatment for Breast Cancer in the West Midlands. UKACR Annual Conference, September 2008
D. Edwards. GIS and Cluster Analyses. University of Wolverhampton.
D. Edwards. Use of Geographical Data in Cancer Registration, Cancer Registration Study Day, November 2008
G. Lawrence. The Work of the WMCIU. BSc(Hons) Radiotherapy, Birmingham City University, April 2008 and February 2009
G. Lawrence. Cancer Incidence and Mortality, Arden Cancer Network Board Meeting, June 2008
G. Lawrence. Cancer Registration – Surveillance in Practice. MSc in Evidence Based Healthcare and Health Technology Assessment, University of Birmingham, October 2008
G. Lawrence. NCIN and Sarcoma Data, South West Public Health Observatory Sarcoma Study Day, October 2008
G. Lawrence. Cancer Registration – Surveillance in Practice. Masters in Public Health and MSc in Health Promotion, University of Birmingham, December 2008
G. Lawrence. Initial analyses of sarcoma data in the West Midlands. Cancer Registration Study Day, November 2008

G. Lawrence. Update on Cancer Registration in the West Midlands. Cancer Registration Study Day, November 2008

G. Lawrence and R. Grimer. The National Cancer Intelligence Network: Capturing Data for Patient Benefit. British Sarcoma Group Conference, March 2009

V. Madurasinghe. Oesophageal Cancer in the West Midlands. Cancer Registration Study Day, November 2008

6.3 Posters

D. Edwards, C. Livings, S. Jones, V. Madurasinghe. The Effect of Deprivation Index on Lung Cancer Incidence. UKACR Conference 2008

N. Pearce, M. Porter, N. Wood, G. Barrett, C. Mellors. Automating Pathology Data – the WMCIU Experience. UKACR Conference 2008

C. Mellors, A. Macdonald, M. Porter. Death Certificate Notification – what is the best method of follow up? UKACR Conference 2008

C. Brooks, C. Mellors. Comparing OPCSIV codes in HES and the Cancer Registry Dataset. UKACR Conference 2008

7.0 Governance Arrangements

The WMCIU is accountable to the Cancer Registration Steering Group, which meets twice a year and is chaired by Dr Jammi Rao, the Deputy Regional Director of Public Health.

The current membership of the Steering Group is shown in the accompanying table. The WMCIU strives to have representation from all key stakeholders at Steering Group meetings, and is always receptive to suggestions for new members.

Member	Function
Dr Jammi Rao (Chair)	Deputy Regional Director of Public Health, DH (West Midlands)
Mike Attwood	Joint Chief Executive, Coventry tPCT
Linda Bentley	Birmingham Women's NHS Foundation Trust (Host Trust)
Mr Mark Chapman	Consultant Surgeon, Heart of England NHS Foundation Trust
Prof. Michel Coleman	London School of Hygiene & Tropical Medicine (External research)
Dr Bill Fuggle	Consultant Histopathologist, The Royal Wolverhampton Hospitals NHS Trust
Dr Beth Harrison	Arden Cancer Network Lead Clinician, Haematology
Dean Ironmonger	Health Protection Agency
Susan Jenkins	Lay Representative
Dr John Kemm	Director, West Midlands Public Health Observatory
Karen Metcalf	Director, Pan Birmingham Cancer Network
Jenny Millman	Requirements Manager, West Midlands SHA (Connecting for Health)
Dr Stephen Munday	Director of Public Health, Solihull Care Trust
Dr John Oxtoby	University Hospital North Staffordshire NHS Trust (Caldicott Guardian)
William Saunders	Non-Executive Director, Burton Hospitals NHS Trust
Dr Doug Wulff	Medical Director, Birmingham & North PCT
Dr Gill Lawrence	WMCIU Director
Sally Vernon	WMCIU Deputy Director
Paul Davies	WMCIU Registration Manager
Debbie Southall	WMCIU Business Manager

