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Fighting cancer with information



Eastern Cancer Registration and Information Centre
www.ecric.org.uk

**Analysis of the process &
outcome of all death card
notifications received by the
Eastern Cancer Registry in
2004 & 2005**

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Background To Report

Death Card Notifications Received in 2004 & 2005

General Information

This report has been produced to address questions raised by the UKACR performance indicator figures for the ECRIC.

The DCO rate is often used to monitor the efficiency of cancer registration. Figure 1 on page 4 shows the rates of all registries in the UK for 2004.

The target for all registries is a DCO rate of <2%. ECRIC has a DCO rate of <0.2% with some cancers having a DCO rate of zero.

This has led to questions of collection practices at ECRIC differing from those at other registries .

This report was to analyse all death card notifications received for 2004 & 2005 and how they have been processed by the registry.

Tumours registered by ECRIC

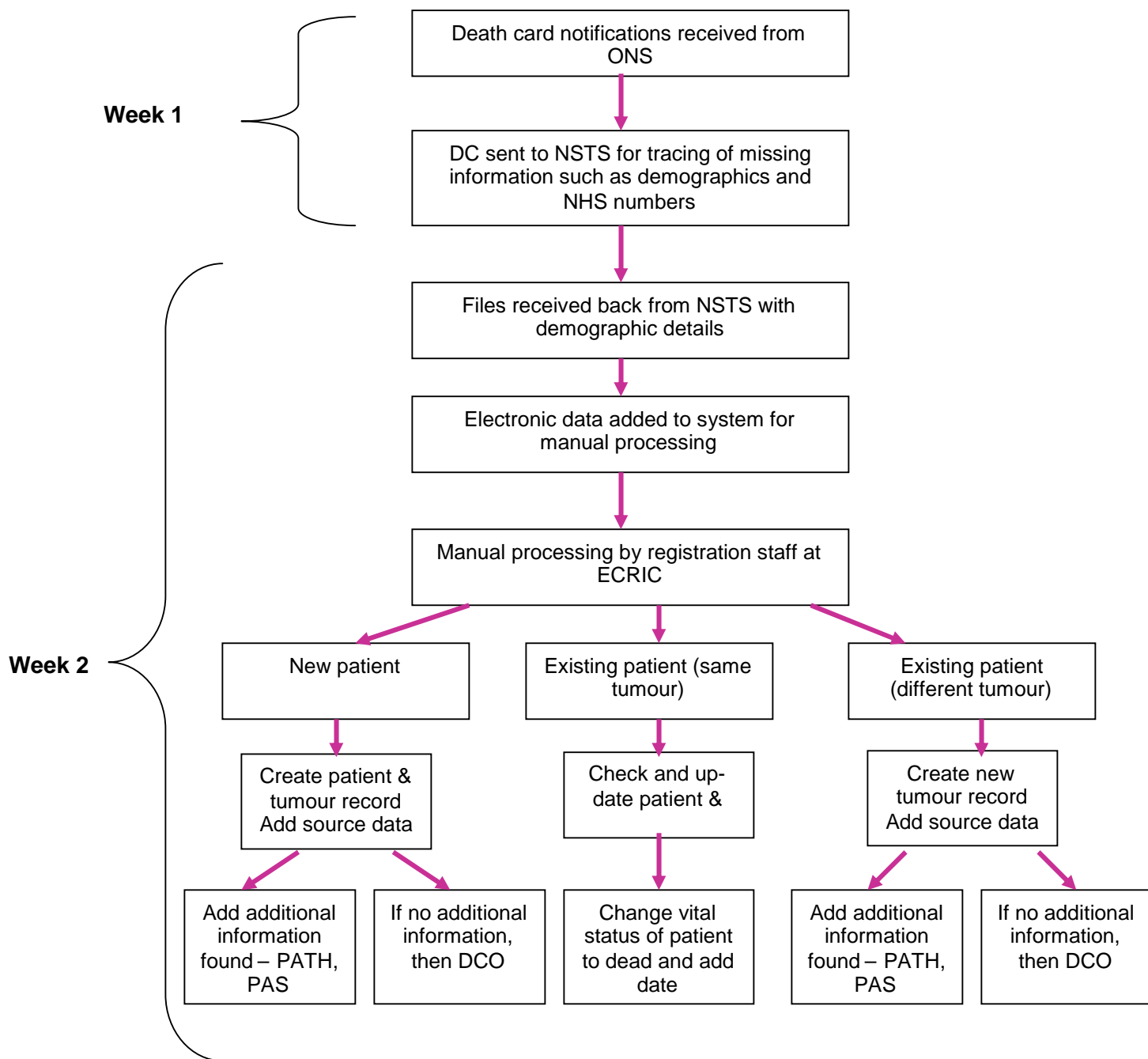
Tumours are coded using International Classification of Diseases 10th Revision (ICD-10). ECRIC uses the United Kingdom Association of Cancer Registries (UKACR) protocols for classification of tumours. ECRIC registers all cancers in the following ICD-10 C and D code ranges:

C00 to C97, D00 to D09, D32 to D33, D35.2 to D35.4, D37 TO D48. (all inclusive)

Figure 1—DCO rate for all registries in 2004

Registry	Year	Lung	Breast invasive	Cervix Invasive	Melanoma	Colorectal	Prostate	Bladder	Haem	Ill-defined sites	All sites** Males	All sites** female
England (average)		5.7	1.5	1.1	0.5	2.8	2.3	2.6	4.5	12.7	3.6	3.8
East Anglia	2004	0.0	0.0	0.0	0.0	0.2	0.1	0.5	0.0	0.7	0.1	0.1
North West (NWCIS)***	2004	6.7	1.7	1.0	0.4	3.3	2.7	3.9	7.4	12.2	4.7	4.5
NWCIS: Liverpool	2004	7.3	2.1	1.0	0.9	4.0	3.4	4.2	11.8	30.0	6.1	6.6
NWCIS: Manchester	2004	6.3	1.4	1.0	0.2	2.9	2.4	3.7	5.3	5.6	3.9	3.3
Northern & Yorkshire	2004	2.8	0.4	0.5	0.2	1.1	1.0	1.2	1.0	3.9	1.5	1.3
Oxford	2004	6.9	2.0	0.9	0.8	2.3	2.1	0.8	3.5	12.1	3.3	3.9
South & West	2004	6.2	1.4	0.9	0.5	2.7	2.0	2.4	2.8	16.2	3.3	3.6
Thames	2004	6.7	2.2	2.3	1.2	3.8	3.1	3.6	4.9	10.8	4.7	4.8
Trent	2004	5.2	2.2	1.2	0.4	3.0	2.9	2.7	4.5	8.5	3.4	3.7
West Midlands	2004	10.2	1.5	1.9	0.1	4.9	3.8	4.1	6.8	26.6	6.3	6.9
Scotland	2003	1.1	0.2	0.4	0.0	0.5	0.3	0.3	0.4	2.6	0.7	0.7
Wales	2004	6.2	2.2	0.0	0.2	2.9	1.7	0.8	2.8	13.0	3.1	4.1
Northern Ireland	2004	3.3	0.6	0.0	0.0	1.7	0.4	0.0	1.3	6.6	1.4	2.0
UK Average		5.2	1.3	0.8	0.4	2.5	1.9	2.0	3.8	11.4	3.2	3.4
Target :		2.0	2.0	2.0	2.0	2.0	2.0	2.0	2.0		2.0	2.0

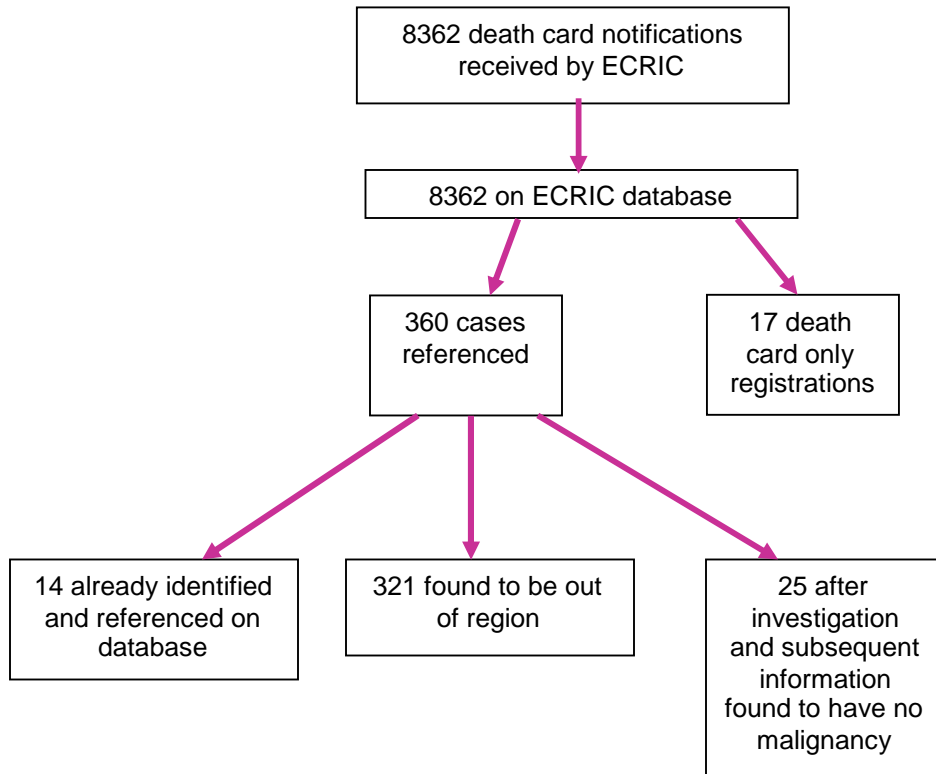
The method for processing death card notifications at ECRIC



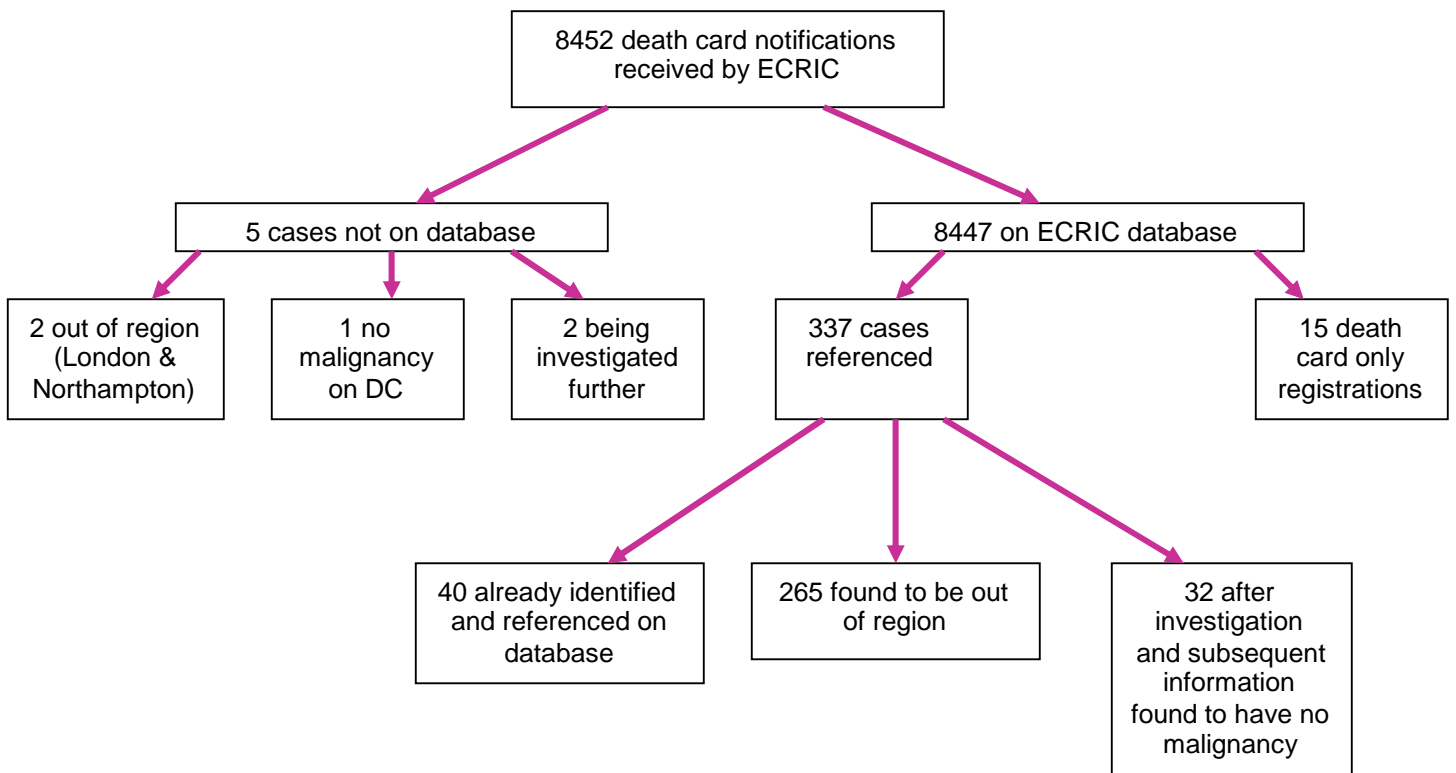
Referenced cases

Some patients on the ECRIC database appear as a reference only case. These are registrations which have been investigated and found not to be suitable for registration but have been kept as a source of information. The information stored allows users to follow the reasoning for decisions made. Some possible reasons may be that a patient is found to live outside our area at time of diagnosis, or malignancy was not confirmed.

Summary of death card notifications numbers in 2004



Summary of death card notifications numbers in 2005



Cancer groups (based on ICD codes) and year of diagnosis for 2004 notifications

The following table shows the death card notifications by their cancer grouping and year of diagnosis.

Cancer group	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	TOTAL
Bone & Cartilage	1	1	1		1			3	3	3	13
Brain			3	1	4	2	4	10	61	88	173
Breast	18	32	37	45	60	71	90	85	106	85	629
Breast in situ		2	2		1		1	1	1	1	9
CIN 3	1	1		1				1			4
Colorectal	13	15	16	36	32	54	78	139	270	364	1017
Female Gynaecological	5	8	6	13	13	27	39	66	112	114	403
Haematological	3	4	7	6	5	7	11	20	31	38	132
Heart									2		2
Hodgkins Lymphoma	1			2	2	2	3	2		9	21
Leukaemia	9	5	4	10	8	12	12	26	61	92	239
Lip, Oral Cavity & Pharynx	1	4	2	7	1	6	12	17	33	32	115
Liver						1	2	5	26	53	87
Lung	3	3	4	10	9	15	36	90	380	783	1333
Male Genital Organs		1					1				2
Melanoma in situ		1	1	1							3
Melanoma	3	1	7	7	3	6	10	18	24	4	83
Mesothelioma	1						5	12	50	49	117
NMSC	26	44	36	33	54	59	54	60	64	32	462
Non-Hodgkins Lymphoma	3	11	3	6	13	13	16	22	59	94	240
Other & ill Defined		1				2	4	8	100	386	501
Other Brain & Eye	1	1	2	2		1	2	4	1	1	15
Other D (Benign Neoplasms)	1	3	2		1	2	1	3	3	8	24
Other D (In Situ Neoplasms)		1	3	2	1		4	3	5	4	23
Other D (Uncertain Neoplasms)	8	9	7	14	15	22	27	39	50	78	269
Other Digestive Organ				1		4	5	11	26	52	99
Other Mesothelial & Soft Tissue		1		1	1	3	6	7	14	10	43
Other Respiratory		2	3	2	3	3	5	11	10	13	52
Other Thyroid & Endocrine									1	2	3
Pancreas							2	15	97	267	381
Penile						1		1	1		3
Prostate	23	42	30	42	50	71	92	121	121	104	696
Skin In situ	3	4	6	9	5	2	9	14	4	4	60
T-Cell Lymphoma			2	2	1		1	1	9	8	24
Testis					3	1		1	1	1	7
Thyroid		1		2		1	1	3	4	9	21
Upper GI	1	2	5	1	5	14	19	50	182	297	576
Urological	3	12	10	19	13	17	22	56	166	175	493
TOTAL	128	212	199	275	304	419	574	925	2078	3260	8374*

* Total different from 8362 due to multiple tumours

Cancer groups (based on ICD codes) and year of diagnosis for 2005 notifications

The following table shows the death card notifications by their cancer grouping and year of diagnosis.

Cancer group	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	TOTAL
Bone & Cartilage	1							4	3	3	4	15
Brain	2	1			3	1		6	10	59	102	184
Breast	25	42	30	36	68	65	69	96	96	98	89	714
Breast in situ		1	2	2		1	6	3	4	2	1	22
CIN 3	2					1	3		2			8
Colorectal	7	16	15	22	24	56	64	81	114	251	340	990
Female Gynaecological	5		10	14	15	14	25	35	73	101	129	421
Haematological	1		1	4	3	14	15	13	27	33	35	146
Heart										1	4	5
Hodgkins Lymphoma	1		1	1					2	5	10	20
Leukaemia	4	5	8	5	7	10	10	14	25	56	103	247
Lip, Oral Cavity & Pharynx	1	3	6	1		4	8	10	15	31	27	106
Liver	1					1	1		9	24	60	96
Lung	1	2	6	2	11	12	11	54	120	431	802	1452
Male Genital Organs										1	1	2
Melanoma in situ					3		2		2	1		8
Melanoma	2	4	5	2	4	8	10	10	23	25	9	102
Mesothelioma					1		2	2	19	37	50	111
NMSC	14	34	35	32	45	34	49	58	61	77	36	475
Non-Hodgkins Lymphoma	3	4	4	9	11	10	13	20	21	51	102	248
Other & ill Defined		2	1	2			4	4	16	88	363	480
Other Brain & Eye		2	1		2	2	1		2		1	11
Other D (Benign Neoplasms)	1	1	1	2	1		4	1		5	12	28
Other D (In Situ Neoplasms)			1	2	2	1	5	3	7	7	7	35
Other D (Uncertain Neoplasms)	3	5	12	13	13	15	29	34	37	57	59	277
Other Digestive Organ			1	3			1	5	13	31	75	129
Other Mesothelial & Soft Tissue	1	1	2	1	1	4	4	3	8	21	17	63
Other Respiratory	2	3	3	1	2	2	3	6	10	17	20	69
Other Thyroid & Endocrine						1	1		1	2	2	7
Pancreas		1			1	1	2	3	14	99	210	331
Penile		1	1				1	1	3	5	5	17
Prostate	14	32	30	42	51	57	72	116	128	126	95	763
Skin In situ	3	9	4	5	12	4	10	8	8	8		71
T-Cell Lymphoma		1	2	1		1		2	2	10	8	27
Testis				1				2	1	2	1	7
Thyroid		1	1		1	1	1	2		1	11	19
Upper GI	1	3		4	1	5	8	20	71	210	266	589
Urological	5	4	11	8	9	18	27	25	44	141	174	466
TOTAL	100	178	194	215	291	343	461	641	991	2117	3230	8761*

* Total different from 8447 due to multiple tumours

The status of the death cards (final registration, provisional or referenced)

The following table shows the death card notifications by their status of registration.

Status	2004 Count	2005 Count
Final	7975	7926
Provisional	27	184
Reference	360	337

Reasons for reference and if they were referenced before the death card was received.

The following table shows the death card notifications which have been referenced and whether they were referenced before the death card was received and where they were referenced based on the death card.

Reference Reason	2004 Count	2005 Count
Existing known referenced cases (known about => not DCO's)	14	40
After investigation found to live elsewhere, death card sent to alternate registry	321	265
After investigation or subsequent information available have found to have no malignancy	25	32
TOTAL REFERENCED	360	337

Basis of diagnosis for final registrations from death card notifications

The following table shows the basis of diagnosis for the final registrations from death card notifications

Basis of Diagnosis	2004 Count	2005 Count
Death Certificate Only	17	15
Clinical	1767	1603
Clinical investigation	1450	1527
Specific tumour markers	54	54
Cytology	491	579
Histology of a metastasis	466	463
Histology of a primary	4631	5004

Death Card Only records from the notifications received in 2004 & 2005

The following tables shows the cancer groups for the death card only cases

Cancer Group	2004 Count	Total Diagnosed	Percentage*
Breast	1	4494	0.02%
Colorectal	3	3377	0.09%
Female Gynaecological	1	1577	0.06%
Other & ill Defined	5	1320	0.38%
Other Digestive Organ	1	250	0.40%
Prostate	3	3418	0.09%
Upper GI	1	1387	0.07%
Urological	2	1574	0.13%

Cancer Group	2005 Count	Total Diagnosed	Percentage*
Breast	1	3060	0.03%
Colorectal	2	2750	0.07%
Leukaemia's	2	544	0.37%
Liver	1	216	0.46%
Lung	4	2877	0.14%
Non-Hodgkins Lymphoma	1	689	0.15%
Other & ill Defined	1	1081	0.09%
Other D (Uncertain Neoplasms)	1	1102	0.09%
Other Digestive Organ	1	244	0.41%
Pancreas	1	708	0.14%

*DCO Rate may vary from UKACR Performance Indicators value due to different grouping of cancer tumours in this report and due possible changes in data between writing this report and the time of the PI report.

Conclusions

This report has shown that within ECRIC we can trace and account for all death card notifications received.

In 2004 we received 8362 notifications, all of these were found on our database. In 2005 we received 8452 notifications, of these only 5 were not found on our database. Two of these five are being investigated further. The other three were found to be out of the East of England or to have no malignancy associated with the death card.

Further analysis of the 8362 notifications received in 2004 found on our database highlighted an area of interest in 360 cases which had been recorded as reference only. 25 of these were made a reference after significant investigation by our medical director and after further information following the medical certificate of death had found that there was no evidence of malignancy in the patient. 321 cases were out of region and the notification was then subsequently sent to the appropriate registry. The remaining 14 cases had already been made a reference case on earlier registration information, therefore these records are updated with the death details and kept as a reference only case.

Further analysis of the 8447 notifications received in 2005 found on our database showed a similar pattern with 337 cases being recorded as reference only. 32 of these were made a reference after significant investigation by our medical director and after further information following the medical certificate of death had found that there was no evidence of malignancy in the patient. 265 cases were out of region and the notification was then subsequently sent to the appropriate registry. The remaining 40 cases had already been made a reference case on earlier registration information, therefore these records are updated with the death details and kept as a reference only case.

Of all the death card notifications received in 2004 only 17 and in 2005 only 15 of these did not have further information found about them, therefore only 17 in 2004 and 15 in 2005 were death card only registrations. This figure gave us a dco rate each year of approx 0.2% which is less than the UKACR agreed national level of 2%.

Disclaimer

This report is compiled from data collected by the Eastern Cancer Registration and Information Centre. Although every effort has been made to ensure that the data is accurate and complete we can only report on the information that we hold.

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