Routes to Diagnosis

NCIN Data Briefing

Background

The overarching goal of the National Awareness and Early Diagnosis Initiative (NAEDI) is to promote early diagnosis of cancer and thereby improve survival rates and reduce cancer mortality. To help achieve this we need to better understand the different routes taken by patients to their cancer diagnoses, to examine what effect this has on overall outcomes.

For all patients diagnosed with cancer in 2007 we used existing routinely available data sources to work backwards through their cancer journey to examine the sequence of events that took them to that diagnosis. These routes to diagnosis included through inpatients, outpatients, screening and emergency presentation.

We then examined how the routes to diagnosis vary for different cancer types and by age, sex and deprivation, to highlight differences in relative one-year survival rates.

KEY MESSAGE:

23% of newly diagnosed cancer patients came through as emergency presentations. For almost all cancer types, one-year survival rates were much lower for patients presenting as emergencies than for those presenting via other routes.

Project approach

Cancer registration data from the National Cancer Data Repository is the core data source for the project. The results cover all English patients diagnosed in 2007 with malignant cancer; excluding non-melanoma skin cancer, in situ breast and cervical cancers, and patients with multiple tumours. Datasets were obtained for inpatient and outpatient activity from Hospital Episodes Statistics (HES), Cancer Waiting Times and from cancer registries for screening information.

The analysis takes as a starting point the date of cancer diagnosis. By working backwards from this point, retracing the patient journey through the data, a set of rules has been defined to identify the sequence of events that make up the different routes to diagnosis. From a patient perspective a series of appointments and investigations or procedures were the events that led up to the diagnosis of cancer, regardless of whether the diagnosis was as a result of a suspected cancer referral or an incidental finding.

There are clearly limitations using NHS data which was not specifically generated for this purpose, and a set of assumptions have been used within the algorithm which derives the route. It is important that when examining the results of this work, these factors are taken into account.

The eight routes to diagnosis were:

Screen detected	Flagged by cancer registry as detected via breast or cervical screening programme
Two Week Wait	Urgent GP referrals with a suspicion of cancer
GP/outpatient referral	Routine and urgent referrals where the patient was not referred under the Two Week Wait referral route
Other outpatient	An elective route starting with an outpatient appointment that is either a consultant to consultant referral, other referral, self-referral, dental referral or unknown referral
Inpatient elective	Where no earlier information can be found prior to admission from a waiting list, booked or planned
Emergency presentation	An emergency route via A&E, emergency GP referral, emergency consultant outpatient referral, emergency transfer, emergency admission or attendance
DCO	Diagnosis by death certificate only
Unknown	No data available from inpatient or outpatient HES or from cancer waiting times or screening

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Routes to diagnosis

Although there are potential limitations in the data and methodology to assign routes, the analysis shows the proportion of patients diagnosed through each route and the corresponding survival rates.

The table below highlights the wide variation across different cancer types in routes to diagnosis. Across all cancers, 25% of patients are being diagnosed through the Two Week Wait, whilst 23% are presenting as emergencies. The percentage of patients in the unknown route varies by cancer type. Some of these could be private patients and there could be data quality issues. This warrants further investigation.

Routes to diagnosis by cancer type for all malignant diagnoses, excluding C44 (non-melanoma skin cancer) and multiples, in England, 2007

All Persons	Screen detected	Two Week Wait	GP referral	Other outpatient	Inpatient elective	Emergency presentation	Death Certificate Only	Unknown	Total	Number of patients
Acute leukaemia		3%	17%	14%	4%	57%	0%	4%	100%	2,551
Bladder		32%	28%	15%	2%	18%	0%	4%	100%	7,665
Brain & CNS		1%	17%	14%	4%	58%	0%	6%	100%	4,147
Breast	21%	42%	12%	9%	0%	4%	0%	12%	100%	34,232
Cervix	14%	16%	25%	16%	2%	12%	0%	13%	100%	2,085
Chronic leukaemia		10%	30%	12%	2%	30%	1%	16%	100%	2,869
Colorectal		26%	24%	15%	4%	25%	1%	6%	100%	27,903
Kidney		20%	29%	18%	1%	24%	1%	6%	100%	5,172
Larynx		31%	32%	21%	1%	12%	0%	3%	100%	1,583
Lung		22%	20%	13%	1%	38%	1%	5%	100%	29,420
Melanoma		41%	29%	11%	1%	3%	0%	16%	100%	8,117
Multiple myeloma		13%	27%	15%	1%	38%	0%	6%	100%	3,145
Non-Hodgkin's lymphoma		16%	30%	17%	2%	28%	0%	7%	100%	7,777
Oesophagus		25%	21%	17%	10%	21%	1%	4%	100%	6,001
Oral		26%	28%	30%	1%	6%	0%	9%	100%	3,062
Other		14%	25%	15%	2%	36%	1%	7%	100%	27,730
Ovary		26%	22%	15%	1%	29%	1%	6%	100%	5,012
Pancreas		13%	18%	12%	2%	47%	1%	6%	100%	5,989
Prostate		20%	38%	16%	3%	9%	0%	14%	100%	28,362
Stomach		17%	21%	16%	7%	32%	1%	5%	100%	5,841
Testis		48%	14%	16%	2%	10%		10%	100%	1,569
Uterus		35%	31%	16%	1%	8%	0%	8%	100%	5,733
Total	**3%**	**25%**	**24%**	**14%**	**2%**	**23%**	**1%**	**8%**	**100%**	**225,965**

The table has been colour coded using a gradation in intensity to highlight data distribution and variation in the percentages, a darker colour indicates a higher value.

www.ncin.org.uk/databriefings

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Routes to diagnosis and outcomes

Having understood the proportion of patients through each route, it is also possible to calculate the relative one-year survival for patients first diagnosed through these routes. Relative survival looks at the ratio of the observed survival rate in a group of cancer patients to the expected survival rate in a similar group of people from the general population, where they have been matched by age and sex.

An example of the survival differences, for breast cancer, is shown in the graph below, highlighting the poorer survival for those patients diagnosed through the emergency presentation route, and for women aged 85 and over.

One-year relative survival (%) by diagnosis route and age group, malignant breast cancer, England, 2007
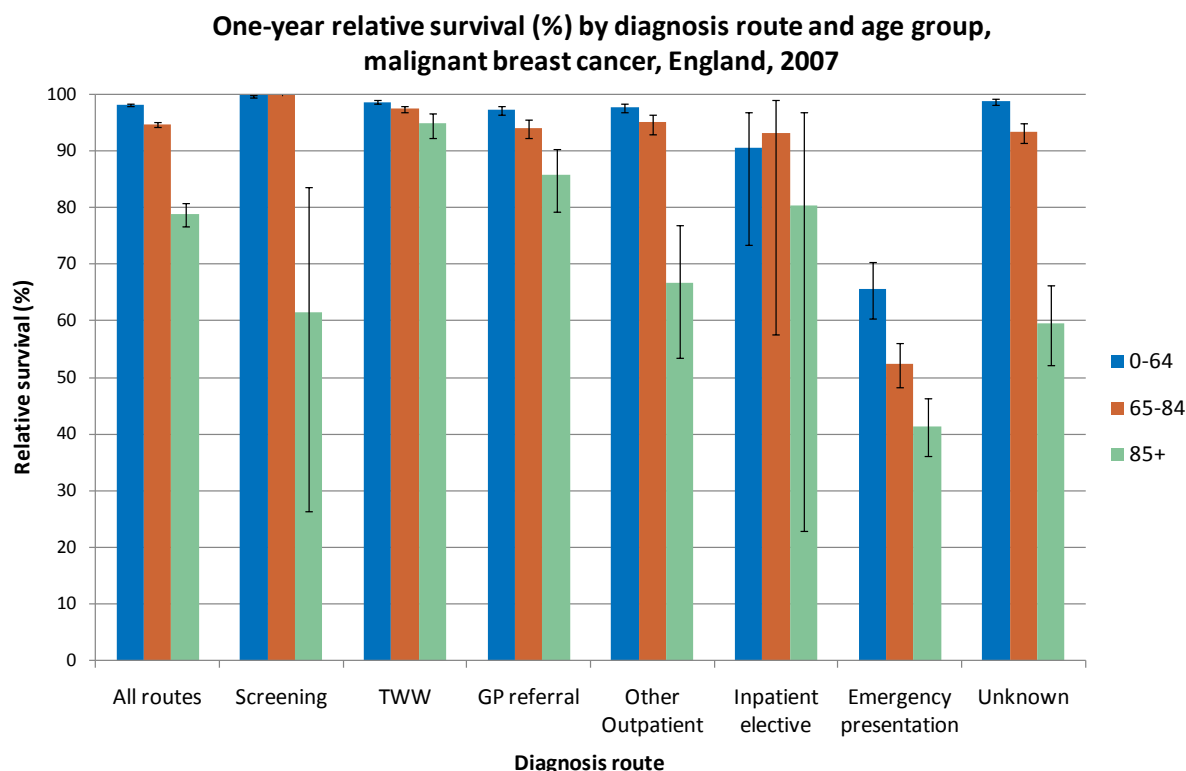
A series of more detailed analyses and results for a range of cancer sites will be available to download from the NCIN website (www.ncin.org.uk). Routes to diagnosis have been analysed by age band, sex, deprivation quintile and Cancer Network.

Conclusions and summary

These results show that nationally 23% of newly diagnosed cancer patients came through as emergency presentations. The proportion of emergency presentations varied widely between cancer types (e.g. melanoma 3%; brain and central nervous system 58%) and by age. Patients aged under 25 and patients over 75 were the most likely to present as emergencies. A socio-economic gradient was also observed, with more affluent patients being less likely to present as emergencies.

Importantly, for all cancer types apart from acute leukaemia, one-year relative survival rates were lower for patients presenting as emergencies than for those presenting via other routes, including the Two Week Wait urgent referral route and routine outpatient appointments.

Measurement of emergency hospital presentations of new patients with cancer, which correlates closely with poor one-year survival rates, provides a new indicator for the extent of early/late diagnoses in a population.

Recommendations

Because of the caveats highlighted earlier, it is recommended that an audit of patient-level data is carried out to quality assure the project methods and approach. It is also suggested that the results are updated for later years when these data become available. Recommendations for further analysis can be found in the Technical Supplement.

Data quality

A detailed Technical Supplement is available to accompany this national work, which was undertaken following piloting of the methodology in the South West. The project approach has relied on using multiple datasets which have their own strengths and weaknesses. The screening data were supplied by cancer registries and data coverage is not consistent across England and are likely to be under-recorded.

The matching of HES data to National Cancer Repository data is incomplete for some London Primary Care Trusts (PCTs). This has impacted on assigning the correct routes to diagnosis for nine PCTs. Investigations into why this happened are ongoing, and rather than publish results based on this data the particular PCTs where the problem existed have been excluded from the analysis.

The algorithm which derives each route uses new methods of data analysis, and can inevitably be improved with further, more localised data.

Detailed examination of data quality issues can be found in the Technical Supplement.

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FIND OUT MORE:

Results and Technical Supplement
Detailed results will be available to download from the NCIN website along with the Technical Supplement, which describes the methods, algorithms and data quality issues in more detail.

http://www.ncin.org.uk

South West Public Health Observatory
The South West Public Health Observatory is the lead cancer registry for urological and skin cancers.

http://www.swpho.nhs.uk

Other useful resources within the NCIN partnership:

Cancer Research UK CancerStats – Key facts and detailed statistics for health professionals

http://info.cancerresearchuk.org/cancerstats/

www.ncin.org.uk/databriefings

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