

Routes to Diagnosis: Comparing multiple studies

NCIN Short Report

Background

Improving cancer survival is a key challenge identified in *Improving Outcomes: A Strategy for Cancer*. Cancer survival estimates in England currently fall below those in many European countries. If cancer survival in England was comparable with the European average then 5,000 or more deaths within five years of diagnosis could be avoided per year. Identifying and categorising the routes taken by patients to their cancer diagnoses reveals significant survival differences across different presentation routes and helps our understanding of how patients with poor prognosis enter secondary care. This can inform targeted implementation of awareness and early diagnosis initiatives and enable assessment of their success.

Multiple studies have examined the proportion of cancers which present by various routes. The National Audit of Cancer Diagnoses in Primary Care (NACDPC) reported 13% emergency referrals while the Routes to Diagnosis project reported 24% overall emergency presentations (Table 1). The aim of this data briefing is to compare their results in the spirit of a sensitivity analysis which probes the strength of the apparent disagreement between them.

KEY MESSAGE:

Headline figures for the overall proportion of emergency presentations for cancer differ between the two largest studies conducted: 13% and 24%. However, we show that this difference is not necessarily a true one but reflects differences in classifications and methods of counting. Data collected in primary and secondary care have strengths and weaknesses that reflect their source.

NACDPC			Broad category	Routes to Diagnosis		
2 week	54%	65%*	All GP referral (not private or emergency)	63%	26%	Two Week Wait
Routine	15%				21%	GP Referral
Emergency	13%	10%	Other Outpatient			
Not referred by practice	7%	6%	Inpatient Elective			
Not known	7%	25%*	All Emergency	24%	24%	Emergency presentation
Private	5%					
Screening	0%	5%*	Screening	5%	5%	Screen Detected
					1%	Death Certificate Only

* NACDPC figures rescaled to add 5% screening cases

Table 1: Results from the NACDPC and Routes to Diagnosis study with figures aggregated into broader categories (figures may not sum to 100% due to rounding). Detailed definitions of the referral types can be found in the NACDPC report (Rubin et al, 2011) and Routes to Diagnosis paper (Elliss-Brookes et al, 2012).

Approach

The two largest studies, Routes to Diagnosis and the NACDPC, are compared directly, alongside a selection of smaller studies. The studies vary in many respects, including their study populations, study periods, case finding and categorisation of possible routes to diagnosis. We compare Routes to Diagnosis and the NACDPC by aggregating reported categories, as broadly as possible, to: emergency routes; non-emergency and non-private routes that are initiated by the GP; routes that do not involve NHS secondary care; and routes via the screening service. The NACDPC excluded screen detected cases (where these could be identified) so to enable a direct comparison these have been assumed to equal 5% and other proportions have been rescaled (for the figures for all cancers combined across males and females).

The choice of aggregation showcased might be seen as unsophisticated, with all routes aggregated to the broader category in which they most plausibly belong. It is however based on the reasonable assumption that missing or uncertain data in primary care indicates a secondary care route, and *vice versa*. For instance, it is judged that data about referrals from practices are well known to practices and hence missing referral data in the NACDPC indicates a non-practice and likely emergency presentation. Conversely, it is judged that emergency admissions are well known to secondary care and can be firmly linked to resulting diagnoses meaning that missing or uncertain data in Routes to Diagnosis is likely to indicate a GP referral as the start of the patient pathway.

Referral type	Place of presentation						Total	%
	Practice	Out patients	A&E	Walk-in centre	Other	Not Known		
2 week	9,663	109	84	17	264	38	10,175	54%
Routine	2,555	87	44	3	82	18	2,789	15%
Emergency	1,964	31	219	15	177	26	2,432	13%
Not referred by practice	285	344	317	9	315	53	1,323	7%
Not known	426	138	178	2	184	301	1,229	7%
Private	827	25	8	2	59	10	931	5%
Total	15,720	734	850	48	1,081	446	18,879	100%
%	83%	4%	5%	0%	6%	2%	100%	

Table 2: Cross tabulation showing the referral type by place of presentation, National Audit of Cancer Diagnosis in Primary Care.

Findings

The proportions of referrals reported in both the NACDPC and in the Routes to Diagnosis study are compared in Table 1. There is a good agreement in the proportions for the broadly aggregated routes.

A breakdown of the referral type by the place of presentation from the NACDPC is shown in Table 2. Ten per cent of patients (1,964) first presented at the GP surgery and were subsequently referred as an emergency - comparable to the figure from Routes to Diagnosis of seven per cent (NCIN 2013). Five per cent of patients (850) presented at A&E with the majority of these being classified as an "Emergency", "Not referred by practice" or "Not known" referral type.

Table 3 shows a wider comparison to other studies. The agreement between Routes to Diagnosis and the NACDPC seen across all cancers also holds reasonably well for individual tumour types, and both appear to agree well with other published studies.

Comparison of the Two Week Wait (TWW) and non-TWW GP referrals (as originally published) shows the Routes to Diagnosis figures at the lower end and the NACDPC at the upper end of those given by other studies.

Tumour Type	Study	Casefinding	n	GP referrals			All Emergency
				Non-TWW	TWW	All	
Bladder	Blick 2010	Secondary	100	38%	42%	80%	15%
	NACDPC	Primary	920	16%	59%	75%	20%
	Routes to Diagnosis		25,639	24%	30%	76%	19%
Colorectal	Barrett 2006	Primary	151		28%	74%	26%
	Neal 2007	Secondary	239		21%		
	NACDPC	Primary	2,566	16%	51%	68%	27%
	Thorne 2009	Secondary	1,679		33%		
	Routes to Diagnosis		91,416	20%	27%	65%	26%
Lung	Barrett 2008	Primary	246			61%	29%
	Neal 2007	Secondary	409		23%		
	NACDPC	Primary	2,014	8%	49%	57%	41%
	Routes to Diagnosis		96,735	17%	24%	55%	39%
Ovarian	Neal 2007	Secondary	95		24%		
	NACDPC	Primary	422	8%	47%	56%	36%
	Routes to Diagnosis		16,026	20%	23%	60%	32%
Prostate	Barrett 2005	Population	217			76%	11%
	Neal 2007	Secondary	146		32%		
	NACDPC	Primary	2,912	22%	56%	77%	18%
	Routes to Diagnosis		92,922	32%	26%	78%	10%
Upper GI	Thorne 2009	Secondary	498		34%		
	NACDPC	Primary	1,435	15%	47%	63%	33%
	Routes to Diagnosis		66,534	16%	21%	56%	37%

Table 3: Proportion of presentations by various routes by tumour type in the Routes to Diagnosis study, the NACDPC and other studies in the literature. "TWW" refers to Two Week Wait referrals, and All GP Referrals and All Emergency columns are defined as in Table 1, except that no rescaling for screening has been applied.

Discussion

Pathways taken prior to a cancer diagnosis can be complex - patients may move between primary and secondary care more than once on their route to diagnosis. This complexity is demonstrated by the variation of referral route with place of presentation in the NACDPC and shown in Table 2. Representing these complex pathways as summary figures demands that choices are made in operational definitions that may differ from study to study. In particular the categorisation of "Emergency Presentation" in Routes to Diagnosis is likely to be more inclusive than the "Emergency" referrals that the NACDPC uses. Also, for all studies there are multiple mechanisms by which under-ascertainment may occur, which differ between primary and secondary care. These could lead both to differences in case finding and in the completeness with which different data fields are collected. We should therefore accept that some degree of difference between different studies is to be expected.

The approximate agreement, 10% vs 7%, in the overall proportion of emergency referrals from GPs (i.e., excluding self-referrals via A&E) and the fact that these routes represent a minority of cases in Routes to Diagnosis but a majority in the NACDPC is suggestive: we can interpret this as evidence that many cases in the NACDPC are emergency presentations via A&E, as this would then make the two studies consistent.

The agreement in scale between private referrals in the NACDPC and the unknowns in Routes to Diagnosis is interesting and suggests that a large proportion of Unknown presentation routes in Routes to Diagnosis are in fact private referrals. This would explain the fact that 'Unknown' routes have 1-year survival is roughly equivalent to persons following known care pathways. It is also plausible that more affluent people, and those of working age, preferentially choose private referrals. This would also explain the socio-demographic variation in unknown routes observed in the Routes to Diagnosis study (NCIN 2012).

The nature of Inpatient Elective and Other Outpatient routes in the Routes to Diagnosis study was not fully explained. Broadly classifying them as a GP referral implies that a GP referral was the

action that ultimately started the route to diagnosis for these cases, though potentially via a complex pathway.

The aggregation we propose is simple but sensible and allows the results of the Routes to Diagnosis study to be seen as complementary to studies in primary care, as noted by Rubin *et al*, 2013. However, the aggregation of different operational definitions used here does not allow for incidental diagnoses or for referrals via (for example) walk-in centres. This indicates that further, more detailed, exploration of the subject is desirable.

In conclusion, what appears to be a difference between the NACDPC and Routes to Diagnosis is not necessarily a true one but one that reflects differences in classifications and methods of counting. Data collected in primary and secondary care have strengths and weaknesses that reflect their source. Great progress in further understanding the referral and diagnosis pathways would come from directly comparing primary and secondary care data at a patient level.

Acknowledgements

We thank Kathy Elliott, Professor Greg Rubin and Georgios Lyratzopoulos for permission to include data from the NACDPC and/or comments on the report.

References

- Barrett J and Hamilton W (2005) Pathways to the diagnosis of prostate cancer in a British city. A population-based study. *Scand J Urol Nephrol*, **39**: 267-270
- Barrett J, Jiwa M, Rose P and Hamilton W (2006) Pathways to the diagnosis of colorectal cancer: an observational study in three UK cities *BMC Family Practice* **23**: 15-19doi:10.1093/fampra/cmi093
- Barrett J and Hamilton W (2008) Pathways to the diagnosis of lung cancer in the UK: a cohort study. *BMC Family Practice* **9**:31 doi:10.1186/1471-2296-9-31
- Blick C, Bailey D, Haldar N, Bdesha A, Kelleher J, Muneer A (2010) The impact of the two-week wait rule on the diagnosis and management of bladder cancer in a single UK institution. *Ann R Coll Surg Engl* **92**: 46–50 doi 10.1308/003588410X12518836440207
- Elliss-Brookes L, McPhail S, Ives A, Greenslade M, Shelton J, Hiom S, Richards M (2012) Routes to Diagnosis for cancer - Determining the patient journey using multiple routine datasets. *BJC* **107**: 1220-1226
- Rubin G, Neal R, Abel G, and Lyratzopoulos G (2013) Integrated research efforts are needed to better understand how to reduce the proportion of patients with cancer who are diagnosed as emergencies. *BJC*, **108(7)**:1550-1
- NCIN (2012) Routes to Diagnosis 2006-2008 NCIN Information Supplement
<http://www.ncin.org.uk/view?rid=1629>
- NCIN (2013) Routes to Diagnosis: Exploring Emergency Presentations.
http://www.ncin.org.uk/publications/data_briefings/routes_to_diagnosis_exploring_emergency_presentations
- Neal R, Allgar V, Nasreen A, Leese B, Heywood P, Proctor G, Evans J (2007) Stage, survival and delays in lung, colorectal, prostate and ovarian cancer: comparison between diagnostic routes. *British Journal of General Practice* **57**: 212–219
- Rubin G, McPhail S, Elliott K (2011) National Audit of Cancer Diagnosis in Primary Care. Royal College of General Practitioners: London, England
- Thorne K, Hutchings H, Elwyn G (2009) The Two-Week Rule for NHS Gastrointestinal Cancer Referrals: A Systematic Review of Diagnostic Effectiveness. *The Open Colorectal Cancer Journal*, **2**: 27-33

FIND OUT MORE:

The NCIN developed the Routes to Diagnosis methodology:

http://www.ncin.org.uk/publications/routes_to_diagnosis.aspx

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

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

The National Cancer Intelligence Network is a UK-wide initiative operated by Public Health England. The NCIN coordinates and develops analysis and intelligence to drive improvements in prevention, standards of care and clinical outcomes for patients. This report has been produced in partnership between National Cancer Intelligence Network and Cancer Research UK.