Delays in the diagnosis of six cancers: analysis of data from the National Survey of NHS Patients: Cancer

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The aim of this paper is to describe and compare components of diagnostic delay (patient, primary care, referral, secondary care) for six cancers (breast, colorectal, lung, ovarian, prostate and non-Hodgkin's lymphoma), and to compare delays in patients who saw their GP prior to diagnosis with those who did not. Secondary data analysis of The National Survey of NHS Patients: Cancer was undertaken (65 192 patients). Breast cancer patients experienced the shortest total delays (mean 55.2 days), followed by lung (88.5), ovarian (90.3), non-Hodgkin's lymphoma (102.8), colorectal (125.7) and prostate (148.5). Trends were similar for all components of delay. Compared with patient and primary care delays, referral delays and secondary care delays were much shorter. Patients who saw their GP prior to diagnosis experienced considerably longer total diagnostic delays than those who did not. There were significant differences in all components of delay between the six cancers. Reducing diagnostic delays with the intention of increasing the proportion of early stage cancers may improve cancer survival in the UK, which is poorer than most other European countries. Interventions aimed at reducing patient and primary care delays need to be developed and their effect on diagnostic stage and psychological distress evaluated.

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There is good evidence that UK patients' cancers are diagnosed at a more advanced stage compared with patients in other European countries (Berrino et al, 2001); this may partly explain the poorer survival of UK cancer patients. Reducing diagnostic delays may increase the proportion of early stage cancers and improve survival. Delays may occur at different stages of the cancer diagnostic journey: 'patient delay' (from onset of symptoms to their first presentation); 'primary care delay' (from first presentation in primary care to referral for further care or diagnostic investigation); 'referral delay' (from referral for further care or diagnostic investigation to being seen in secondary care); and 'secondary care delay' (from being first seen in secondary care to diagnosis). Patients diagnosed through screening bypass patient and primary care delays. Current UK policy aimed at earlier detection of cancer by reducing delays concentrates mainly on treatment and referral delays (DoH, 2000a, b), although the evidence base for these policies has been questioned (Jones et al, 2001).

several common themes. With the exception of cancer registry studies, most of the studies report conflicting findings from relatively small numbers of patients; generalisation from these data is difficult. This is compounded by different healthcare settings,

The literature regarding the length of diagnostic delays has different methods of measuring delays, the potential confounding

inconclusive, shorter delays have been associated with earlier stage diagnosis for rectal but not for colonic tumours (Arbman et al, 1996; Kiran and Glass, 2002). In lung cancer, there is some evidence that early stage disease has better survival (Mountain, 1997), although there is wide variation in the findings of reported studies (Jensen et al 2002; Moody et al, 2004; Myrdal et al, 2004). In ovarian cancer, there is no evidence that delays in referral or diagnosis affects survival at 18 months (Kirwan et al, 2002), although women with earlier stage disease are diagnosed faster (Wikborn et al, 1996). We are not aware of any studies that have examined the effect on diagnostic delay of seeing the GP prior to a cancer diagnosis compared with not seeing the GP (whether by a screening, or in-patient diagnosis following an emergency admission or via A&E). For some cancers, especially lung, morbidity and psychological outcomes may be more important than mortality. Psychological distress correlates positively with total diagnostic delay (Risberg et al, 1996), itself a reason to minimise delays. The aim of this paper is to describe and compare the

effect of lead-time bias, and variations between cancers;

and is reflected in the conflicting findings from this literature.

Data from the literature relating to delays are shown in Table 1.

The effect of delays on clinical outcomes varies between cancers.

In breast cancer, delays of 3-6 months are associated with

poorer survival (Richards et al, 1999), although some patients

who present early may have poorer outcomes (Sainsbury et al,

1999). In colorectal cancer, delays have not been shown to have an

effect on survival (Roncoroni et al, 1999), and although somewhat

components of diagnostic delay (patient, primary care, referral,



Table I Diagnostic delays in six cancers – summary of findings from the literature

	Total delays	Patient delays	Primary care delays	Referral delays	Secondary care delays	Other
Breast	15 days (Arndt et al, 2003)	0 days (Jones et al, 1992) 4 weeks (Thongsuksai et al, 2000) 1/4 > 12 weeks (Thongsuksai, 2000) 1 Week (Thulesius et al, 2004) 14 days (Meechan et al, 2002) 16 days (Arndt et al, 2002) 13 days (Nosarti et al, 2000)	_	13 days (Sainsbury et al, 1999) 11 days (Jones et al, 1992) 9 days (urgent referrals) (Spurgeon et al, 2000) 14 days (nonurgent referrals) (Spurgeon et al, 2000) 13 days (Nosarti et al, 2000)	_	1/3 experience total pre-hospital delays of > 12 weeks (Richards et al, 1999) Provider delay of I Week (Thulesius et al, 2004)
Colorectal		60 days (Aithal and Tanner, 1996) 27.5 days (Thongsuksai et al, 2000) > 6 weeks (54%) (Robinson et al, 1986) 16.2 days (mean, rectum) (Holliday and Hardcastle, 1979) 12.7 days (mean, colon) (Holliday and Hardcastle, 1979) 20–66%) > 3 months (Graffner and Olsson, 1986)	47% > 6 weeks (Robinson et al, 1986) 15.3 days (mean, rectum) (Holliday and Hardcastle, 1979) 11.2 days (mean, colon) (Holliday and Hardcastle, 1979) 20-34% > 3 months (Holliday and Hardcastle, 1979)	16 days (Aithal and Tanner, 1996) 11 days (Jones et al, 1992) 13 days (urgent referrals) (Spurgeon et al, 2000) 27 days (nonurgent referrals) (Spurgeon et al, 2000)	15 days (Aithal and Tanner, 1996) 17 days (mean 52) (Potter and Wilson, 1999)	Mean delay to treatment delay: 244 days (Rectal), 149 days (colon) (Langenbach et al, 2003)
Lung	4.6 months (mean 5.8) (Myrdal et al, 2004) 189 days (Koyi et al, 2002) 109 days (Billing and Wells, 1996)	21 days (mean 43) (Koyi et <i>al</i> , 2002) 31 days (Jones et <i>al</i> , 1992)	33 days (mean 56) (Koyi et <i>al</i> , 2002)	7 days (Jones et al, 1992) 7 days (urgent referrals) (Spurgeon et al, 2000) 12 days (nonurgent referrals) (Spurgeon et al, 2000)		19 (8.6%) total delay > I year (of whom 18 had adenocarcinoma) (Yoshimoto et al, 2002)
Ovarian	55% <3 months, 26% >6 months, and 11% > 12 months (Goff et al, 2000) 56% <4 weeks, 30% >8 weeks, and 4% <4 days (Wikborn et al, 1996)	et al, 2002) 3.5 weeks (Thulesius	73% <4 weeks (Kirwan et al, 2002)	6 days (Kirwan et al, 2002) 70% < 2 weeks (Kirwan et al, 2002) 6 days (urgent referrals) (Spurgeon et al, 2000) 24 days (nonurgent referrals) (Spurgeon et al, 2000)	_	Mean total pre-hospital delay 95.3 days (s.d. 15.1 days) (Kirwan et al. 2002) Provider delay of 3.5 weeks (Thulesius et al. 2004)
Prostate	_	20 days (Jones et <i>al</i> , 1992)	_	15 days (Jones et al, 1992) 19 days (urgent referrals) (Spurgeon et al, 2000) 41 days (nonurgent referrals) (Spurgeon et al, 2000)	_	

All delays are medians unless other stated.

secondary care) for six types of cancer (breast, colorectal, lung, ovarian, prostate or non-Hodgkin's lymphoma), using patient-reported data from the *National Survey of NHS Patients: Cancer.* A secondary aim is to compare delays in those patients who reported seeing their GP prior to diagnosis with those who bypassed their GP, for whatever reason.

MATERIALS AND METHODS

Section 1 - National Survey of NHS Patients: cancer

The National Survey of NHS Patients: Cancer assessed quality of care of hospital patients in 172 Trusts in England (DoH, 2002).

Clinical Studies

Patients with one of six types of cancer (breast, colorectal, lung, ovarian, prostate or non-Hodgkin's lymphoma) discharged from hospital between July 1999 and June 2000, participated in the survey. From a total sample of 123 984 patients, 92 683 were sent a questionnaire, after excluding those patients whose death had been registered. Completed questionnaires were returned by 65 337 patients. This represented a response rate of 74%, after allowing for returned mail, patients whose death had been reported after mailing and ineligible patients. In the sample, 65 192 were diagnosed with one of six types of cancer: female breast cancer (25 627), colorectal (15 891), prostate (10 992), non-Hodgkin's lymphoma (5604), lung (4011) and ovarian (3067). A total of 145 male patients with breast cancer also participated in the survey but were not included in this analysis because of their small numbers. The data set was obtained from the Data Archive at the University of Essex in 2003. Part D of the questionnaire asked a series of questions devoted to 'finding out what was wrong with you' (Box 1).

Box I Questions analysed in this paper

- Q DI: When did you first notice signs or symptoms? (month and year) • Q D2: Had you visited a GP about this condition before you attended hospital? (Yes/No)
- Q D3: (if answered Yes to D2) After visiting the GP, how long did you have to wait before your first appointment with a hospital doctor (predetermined categories, including cannot remember)?
- Q D5: When did you first see a hospital doctor for your condition? (month and year)
- Q D9: Were you told what was wrong with you during this first hospital appointment, or was it before or after this first hospital appointment? If told after this appointment, then when? (predetermined categories including NA)?

Section 2 - Calculating components of delays, exclusions, and assumptions

Delays were calculated differently for patients who reported visiting their GP prior to diagnosis and those who had not, because of ways in which the questions were asked. This process is highlighted in Figure 1.

Total prehospital delay This was calculated as the number of days between the date of appointment with hospital doctor (Q D5) and the date that symptoms were first noticed (Q D1). These were both asked as month and year. The first of the stated month was used for calculations. Total prehospital delays could not be calculated for patients whose first appointment with a hospital doctor was before the date they first noticed symptoms, or if one or both dates were missing. For those patients who did not see their GP prior to diagnosis, the 'total prehospital delay' is equivalent to 'patient delay' since there were neither primary care nor referral delays.

Referral delay Referral delay was derived from Q D3, a categorical response variable, and was calculated by assigning a mid-point to the categories used (see Box 2). Referral delays could not be calculated for: patients who could not have had any referral delay because they did not see their GP prior to their diagnosis (i.e. answered no to Q D2, or did not answer Q D2); patients who had a delay of more than 1 year, since the categorisation did not permit calculation; and those who did not respond or could not remember.

Patient and primary care delay

For patients who saw their GP prior to diagnosis, patient and primary care delays were calculated by subtracting the referral

Box 2 Mid-point calculations for categorical variables

Referral	delay	Secondary care delay			
Category	Mid-point number of days	Category	Mid-point number of days		
Same or next day	I day	Before first appointment	Unable to estimate		
2 days-I week	5 days	Told at first appointment	0 days		
I−2 weeks	II days	I day to 2 weeks	7 day		
2 weeks-I month	21 days	2 weeks to I month	21 days		
I – 3 months	56 days	I month to 3 months	56 days		
3–6 months	126 days	3 months to 6 months	126 days		
6 months – I year	252 days	> 6 months	Unable to estimate		
> I year	Unable to estimate	'not been told'	Unable to estimate		

delay (as above), from the total prehospital delay (as above). Patient and primary care delays could not be calculated if the referral delay or the total prehospital delay was not available, or if the referral delay was longer than the prehospital delay, giving a false-negative patient and primary care delay. This arose because of the assumptions of mid-points and first of the month as described above.

Secondary care delay This was calculated from question Q D9 (a categorical response variable), which asked when the patient found out their diagnosis. As with Q D3, the number of days was calculated by assigning a mid-point to the categories (Box 2). Secondary care delays could not be calculated for patients who responded 'before first appointment' or 'more than 6 months', or those who 'had not been told' or did not answer.

Total diagnostic delay Total diagnostic delay was calculated by adding total prehospital delay to secondary care delay. As described above, this excludes patients who were diagnosed either before or more than 6 months after their first hospital appointment. Total delays could not be calculated if either secondary care delay or prehospital delay was missing.

Section 3 – statistics

Diagnostic delay between the six cancer groups were compared using Kruskall-Wallis tests; χ^2 tests were used for the categorical data. Mann-Whitney tests were used for comparisons within each cancer group between those patients who saw a GP and those who did not. A P-value of <0.05 was used to indicate statistical significance. All analyses were performed on SPSS (Version 11). The data are interval scale data; means and standard deviations (s.d.) are presented. However, due to the skewed nature of some of the distributions medians and interquartile ranges (IQR) are also presented for completeness. Confidence intervals around the means were calculated and are presented where appropriate in the figures. The large variation in delays resulted in some negative lower limits and large upper limits for some of the categories; these are not presented in the tables.

RESULTS

Numbers of patients seeing their GP prior to diagnosis

A total of 52 079 (80%) patients reported visiting their GP before their diagnosis, 12 074 (18%) reported that they had not, and 1039

Clinical Studies

For those who saw a GP (52079) First symptom Contact with GP Hospital doctor Diagnosis Q D1 (date) Q D2 (yes) Q D5 (date) Q D9 (date) Total prehospital delay (Q D1- Q D5) n= 44 028 Referral delay (Q D3) n=47 451 Secondary care delay Patient and primary care (Q D9) delay (Q D1- Q D5) - D3 n=42 221 n= 38 707 Total delay (Q D1- Q D5) + Q D9 n=37 063 В For those who did not see a GP (12 074) First symptom Contact with GP Hospital doctor Diagnosis Q D1 (date) (yes/no) Q D5 (date) Q D9 (date) Patient delay (Q D1- Q D5) n= 9743 Secondary care delay (Q D9) n=9827 Total delay (Q D1- QD5) + Q D9 n= 8164 For those who did not answer Q D2 (1039) Hospital doctor First symptom Diagnosis Q D5 (date) Q D9 (date) Q D1 (date) Total pre-hosp delays (either patient or patient + primary care delays) (Q D1- Q D5) n= 239 Secondary care delay (Q D9) n = 551

Total delay (Q D1– Q D5) + Q D9 n= 180

Figure I Individual components of delay in diagnosis.

(2%) did not answer this question. There was variation between the cancers, with 27% of breast cancer patients, but only 10% colorectal cancer patients, not seeing their GP prior to diagnosis (Table 2). In order to investigate this further, a sensitivity analysis was conducted, for breast cancer, to compare data for women within the screening age range (50-64) with women outside this age range. In all, 58% of the screening age women saw their GP, compared with 84% for those outside the screening age.

Main findings

The numbers of patients for whom different components of delay were calculated are shown in Table 3. Table 4 shows the mean (s.d.) and median (IQR) for each component of diagnostic delay by cancer type. There were significant differences for all the components of delay between the six site-specific cancers (Table 5).

Table 2 Number and percentage of patients seeing their GP prior to attending hospital

	Colore	ctal	Lur	ng	Ovar	ian	Prosta	ate	Non-Hodgkin'	s lymphoma	Brea	st	Tota	al
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Did see GP	14032	88	3246	81	2638	86	9159	83	4742	85	18 262	71	52 079	80
Did not see GP	1612	10	694	17	395	13	1560	14	791	14	7022	27	12 074	19
Not answered	247	2	71	2	34	1	273	3	71	I	343	- 1	1039	2
Total	15 891		4011		3067		10992		5604		25 627		65 192	

Table 3 Summary of the number of patients excluded, and those available for analysis for each component of diagnostic delay, by cancer type

	Colorectal	Lung	Ovarian	Prostate	NHL	Breast	Total
Number in the sample Total delay Secondary delay or total prehospital delay missing	15 89 l 11 385 (72%) 4506 15 89 l	4011 2669 (67%) 1342 4011	3067 2216 (72%) 851 3067	10 992 5840 (53%) 5152 10 992	5604 3537 (63%) 2067 5604	25 627 19 760 (77%) 5867 25 627	65 192 45 407 (70%) 19 785 65 192
Total delay (if 'yes' to Q D2) Secondary delay or total pre-hospital delay missing	10 248 3784 14 032	2235 1011 3246	1943 695 2638	4909 4250 9159	3049 1693 4742	14 679 3583 18 262	37 063 15 016 52 079
Total delay (if 'no' to Q D2) Secondary delay or total pre-hospital delay missing	1094 518 1612	420 274 694	267 128 395	896 664 1560	479 312 791	5008 2014 7022	8164 3910 12074
Total delay (if no response to Q D2) Secondary delay or total pre-hospital delay missing	43 204 247	14 57 71	6 28 34	35 238 273	9 62 71	73 270 343	180 859 1039
Total pre-hospital delay First appointment before had symptoms One or both dates missing	13 174 (83%) 453 2264 15 891	3260 (81%) 158 593 4011	2673 (87%) 65 329 3067	7759 (71%) 382 2851 10992	4650 (83%) 168 786 5604	22 494 (88%) 507 2626 25 627	54010 (83%) 1733 9449 65192
Total pre-hospital delay (if 'yes' to Q D2) First appointment before had symptoms One or both dates missing	11 835 388 1809 14 032	2706 134 406 3246	2330 53 255 2638	6563 320 2276 9159	4033 112 597 4742	16561 319 1382 18262	44 028 1326 6725 52 079
Patient delay (if 'no' to Q D2) One or both dates missing First appointment before had symptoms	1282 275 55 1612	535 135 24 694	336 48 11 395	1146 354 60 1560	605 130 56 791	5839 999 184 7022	9743 1941 390 12 074
Total prehospital delay (if no response to Q D2) First appointment before had symptoms One or both dates missing	57 10 180 247	19 0 52 71	7 I 26 34	50 2 221 273	12 0 59 71	94 4 245 343	239 17 783 1039
Patient and primary care delay (if 'yes' to Q D2) Referral delay or total prehospital delay missing False negatives	10 026 2959 1047 14 032	2361 675 210 3246	2036 407 195 2638	5369 3065 725 9159	3447 951 344 4742	15 468 2076 718 18 262	38 707 10 133 3239 52 079

Table 3 (Continued)

	Colorectal	Lung	Ovarian	Prostate	NHL	Breast	Total
Referral delay	12 527 (79%)	2950 (74%)	2453 (80%)	7877 (72%)	4242 (76%)	17 402 (68%)	47 451 (73%)
Answer 'no' to Q D2	16Ì2	694	395	1560	79 I	70 <u>2</u> 2	12074
No response to Q D2	247	71	34	273	71	343	1039
Can't remember (Q D3)	777	186	78	838	285	474	2638
Not answered (Q D3)	371	71	56	200	104	227	1029
> I year (Q D3)	357	39	51	244	111	159	961
	15 891	4011	3067	10992	5604	25 627	65 192
Secondary care delay	13 244 (83%)	3199 (80%)	2474 (81%)	7671 (70%)	4073 (73%)	21 938 (86%)	52 599 (81%)
Not answered	690	159	112	606	242	622	2431
Not told	166	26	20	95	47	68	422
> 6 months	266	38	30	173	68	137	712
Told before	1048	457	295	1251	420	1729	5200
NA	477	132	136	1196	754	1133	3828
Total	15 891	4011	3067	10992	5604	25 627	65 192
Secondary care delay (if 'yes' to Q D2)	11801	2633	2145	6393	3448	15 801	42 22 1
Not answered	505	95	83	390	164	385	1622
Not told	147	20	19	69	43	47	345
> 6 months	251	34	29	151	64	115	644
Told before	906	348	244	1112	343	981	3934
NA	422	116	118	1044	680	933	3313
Total	14032	3246	2638	9159	4742	18262	52 079
Secondary care delay (if 'no' to Q D2)	1314	532	308	1143	589	5941	9827
Not answered	90	39	19	115	51	134	448
Not told	18	6	1	24	4	19	72
> 6 months	12	4	1	21	4	21	63
Told before	133	98	48	119	72	722	1192
NA	45	15	18	138	71	185	472
Total	1612	694	395	1560	791	7022	12074
Secondary care delay (if no response to Q D2)	129	34	21	135	36	196	551
Not answered	95	25	10	101	27	103	361
Not told	1	0	0	2	0	2	5
> 6 months	3	0	0	Ī	0	Ī	5
Told before	9	ΙΪ	3	20	5	26	74
NA	10	i	Ō	14	3	15	43
Total	247	71	34	273	71	343	1039

1. Total diagnostic delay

Breast cancer patients experienced the shortest mean and median delays, followed by lung, ovarian, non-Hodgkin's lymphoma, colorectal and prostate. Delays were considerably shorter in all cancers for those patients who did not report seeing their GP prior to diagnosis (Figure 2). There was a significant difference in total diagnostic delay between those patients who saw their GP and those who did not for colorectal (t(11 340) = 6.9, P < 0.001), lung (t(2653) = 4.7, P < 0.001), ovarian (t(2208) = 2.9, P = 0.004), prostate (t(5803) = 4.2, P < 0.001), non-Hodgkin's lymphoma (t(3526) = 6.6, P < 0.001) and breast (t(19685) = 7.9, P < 0.001). In each case, those who saw their GP had a longer delay than those who did not.

2. Prehospital delays

Some patients in each cancer group reported no delay from first noticing symptoms until they saw a hospital doctor: breast 10601 out of 22494 (47%), lung 1177 out of 3260 (36%), ovarian 932 out of 2673 (35%), non-Hodgkin's lymphoma 1628 out of 4650 (35%), prostate 2391 out of 7759 (31%), and colorectal 3467 out of 13 174

(26%). There was a significant difference between cancer groups $(\gamma^2(5) = 1765.0, P < 0.0001).$

2a. Total prehospital delays The total prehospital delays were analysed by those who saw a GP prior to diagnosis and those who did not, since they are measuring different processes in each case (Figure 3). There was a significant difference in total prehospital delay between those patients who saw their GP and those who did not for all cancers: colorectal (t(13114) = 6.4, P < 0.001); lung (t(3239) = 3.9, P < 0.001); ovarian (t(2664) = 3.3, P = 0.001); prostate (t(7707) = 3.9, P < 0.001); non-Hodgkin's lymphoma (t(4636) = 4.3, P < 0.001); and breast (t(22398) = 8.7, P < 0.001). In each case, those who saw their GP had a longer delay than those who did not.

2b. Patient and primary care delays The shortest delays were experienced by patients with breast cancer, followed by lung, ovarian, non-Hodgkin's lymphoma, colorectal and prostate (Figure 4).

2c. Referral delays The shortest delays were experienced by patients with breast cancer, followed by lung, ovarian, non-

Table 4 Summary of the components of diagnostic delay by cancer type (all data in days)

	Colorectal	Lung	Ovarian	Prostate	NHL	Breast
(I) Total delay						
All patients						
Mean (s.d.)	125.7 (395.2)	88.5 (239.8)	90.3 (320.0)	148.5 (494.3)	102.8 (256.7)	55.2 (241.8)
Median (IQR)	61 (29–143)	38 (7-91)	37 (7-92)	61 (7-126)	51 (7-117)	30 (0-38)
GP patients	1244 (4125)	000 (0475)	077 (220 5)	1 (0 5 (427.7)	114 (272.2)	(2 (250.0)
Mean (s.d.)	134.4 (413.5)	98.3 (247.5)	97.7 (338.5)	160.5 (437.7)	114 (273.2)	63 (258.9)
Median (IQR) Non-GP patients	67 (30–151)	51 (21–99)	50 (7-99)	61 (30–150.5)	56 (21–122)	31 (0-56)
Mean (s.d.)	46.9 (124.5)	38.1 (190.5)	37.9 (113)	85.6 (733.5)	31.2 (74.8)	31.8 (176.9)
Median (IQR)	7 (0-52)	0 (0-31)	7 (0–31)	0 (0-31)	0 (0-31)	7 (0-31)
No response to D2	7 (0 32)	0 (0 31)	, (0 31)	0 (0 31)	0 (0 31)	7 (0 31)
Mean (s.d.)	62.6 (103.3)	31.4 (47.8)	20.5 (37.2)	75.1 (99.6)	98.2 (136.8)	76.4 (387.7)
Median (IQR)	21 (0-86)	7 (0-45)	0 (0-46.3)	31 (0-122)	7 (0-180.5)	7 (0-31)
(2a) Total prehospital delay	, ,	,	, ,	, ,	, ,	, ,
All patients						
Mean (s.d.)	116.7 (424.9)	79.1 (264.8)	83.1 (306.6)	141.7 (505.5)	99.7 (344.8)	52.2 (249.5)
Median (IQR)	59 (0-122)	31 (0-62)	31 (0-91)	31 (0-121)	31 (0-92)	29 (0-31)
GP patients	124.0 (440.0)	07 ((27 (0)	007 (225.4)	E E (A E / A)	1070 (2417)	(00 (27 E)
Mean (s.d.) Median (IOR)	124.8 (440.8) 61 (30-122)	87.6 (276.9) 31 (0-91)	90.7 (325.4) 31 (0-92)	151.5 (456.4) 61 (29-122)	107.9 (341.6) 31 (0-92)	60.8 (271.5) 30 (0-31)
Non-GP patients (= patient delay)	61 (30-122)	31 (0-71)	31 (0-72)	61 (27-122)	31 (0-72)	30 (0-31)
Mean (s.d.)	44.3 (234.5)	38.2 (193.6)	32.1 (102.4)	88.5 (730.2)	43.7 (361.5)	27.7 (167.5)
Median (IQR)	0 (0-31)	0 (0-30)	0 (0-31)	0 (0-30)	0 (0-29)	0 (0-30)
(2b) Patients & primary care delay (GP patients)						
Mean (s.d.)	80.4 (393.9)	51.8 (187.1)	58.1 (327.9)	97.5 (379.2)	58.6 (244.5)	40.4 (245.9)
Median (IQR)	20 (0-66)	10 (0-40)	10 (0-40)	10 (0-66)	10 (0-40)	9 (0-20)
(2c) Referral delay (GP patients)						
Mean (s.d.)	42.8 (54.7)	33.1 (48.6)	34.8 (51.4)	50.0 (57.1)	37.2 (53.1)	20.8 (30.7)
Median (IQR)	21 (11–56)	21 (5-56)	11 (5–56)	21 (11-56)	21 (5-56)	11 (5-21)
(3) Secondary care delay						
All patients						
Mean (s.d.)	11.9 (24.7)	11.5 (23.0)	8.7 (20.4)	11.3 (25.2)	13.2 (25.2)	5.4 (13.5)
Median (IQR)	0 (0-7)	0 (0-7)	0 (0-7)	0 (0-7)	0 (0-21)	0 (0-7)
GP patients	12.4 (2.4.2)	12 ((22.0)	0.2 (21.2)	12.2 (25.0)	145 (27.4)	E 0 (143)
Mean (s.d.) Median (IQR)	12.4 (24.2) 0 (0-7)	12.6 (23.9) 0 (0-21)	9.3 (21.2) 0 (0-7)	12.2 (25.9) 0 (0-7)	14.5 (26.4) 0 (0-21)	5.9 (14.3) 0 (0-7)
Non-GP patients	0 (0-7)	0 (0-21)	0 (0-7)	0 (0-7)	0 (0-21)	0 (0-7)
Mean (s.d.)	7.7 (20.4)	6.3 (16.5)	4.8 (13.8)	6.2 (19.6)	6.1 (15.8)	4.2 (10.4)
Median (IQR)	0 (0-7)	0 (0-7)	0 (0-7)	0 (0-0)	0 (0-7)	0 (0-7)
No-response D2	- (- ')	- ()	- (- ')	- ()	- ()	- (- /)
Mean (s.d.)	6.4 (14.3)	7.8 (23.6)	6.7 (17.1)	10.5 (27.2)	5.6 (13.8)	5.3 (17.9)
Median (IQR)	0 (0-7)	0 (0 – 2)	0 (0-0)	0 (0-7)	0 (0-5)	0 (0-0)

Table 5 Kruskall—Wallis statistical tests comparing the six cancer groups

Delay type	χ²	df	P-value
Total prehospital delay Patient, primary care and referral delay (GP patients only)	3859.9	5	< 0.00 l
	3172.5	5	< 0.00 l
Patient delay (non-GP patients only) Patient and primary care delay (GP patients only)	17.2	5	0.004
	1490.4	5	<0.001
Referral delay (GP patients only)	2910.0	5	< 0.00 l
Secondary care delay	572.9	5	< 0.00 l
Total delay	3632.0	5	< 0.001

Hodgkin's lymphoma, colorectal and prostate (Figure 5). Over 60% patients with breast cancer were seen within 2 weeks, compared with less than 30% prostate cancer patients.

3. Secondary care delay

These delays were considerably shorter than referral and prehospital delays (Figures 6 and 7). In all 9% found out their diagnosis prior to their first hospital appointment, but this varied significantly between cancer groups. Delays were shortest for breast cancer, followed by ovarian, prostate, lung, colorectal and non-Hodgkin's lymphoma. The median number of days was zero for all six cancer groups; the majority of patients found out their diagnosis at their first hospital appointment. Patients who saw their GPs prior to diagnosis had longer secondary care delays than those who did not. There was a significant difference for each cancer group: colorectal $(t(13\,113) = 6.6, P < 0.001)$; lung (t(3163) = 5.8, P < 0.001); ovarian (t(2451) = 3.6, P < 0.001); prostate (t(7534) = 7.5, P < 0.001); non-Hodgkin's lymphoma (t(4035) = 7.5, P < 0.001); and breast (t(21740) = 8.2, P < 0.001). In each case, those who saw their GP had a longer delay than those who did not.

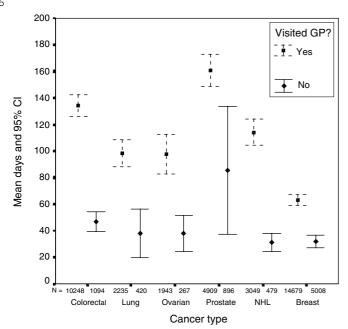


Figure 2 Total diagnostic delay (GP vs non-GP)

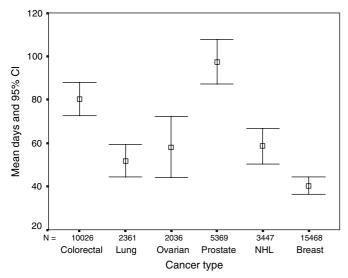


Figure 4 Patient and primary care delay.

Assessing the effect of assumptions made in main data analysis

Referral delay was greater than 1 year for 2% of the sample; these were excluded from the main analysis. Similarly, 1% of patients with a secondary care delay of greater than 6 months were excluded from the main analysis. In order to determine the effect of this on the analysis, we reanalysed the data, coding delays of greater than 1 year as 365 days and delays of 6 months as 168 days. This showed that the mean delay increased, as would be expected, but that the median delays remained the same for all except referral delay for ovarian cancer, where there was an increase from 11 days to 21 days

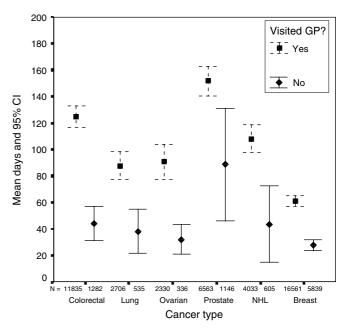


Figure 3 Total prehospital delay (patient, primary care and referral delay for GP patients and patient delay for non-GP patients).

DISCUSSION

Statement of principal findings

This paper reports findings from the analysis of a large data set of patients relating to their cancer diagnosis, and is the largest single comprehensive study of diagnostic delays in cancer. It is one of few studies to report delays in prostate cancer and the first to do so in non-Hodgkin's lymphoma. Total diagnostic delays remain long, particularly in some cancers. Breast cancer patients had the shortest delays compared with the other cancers. The mean delay of 8 weeks still suggests that the diagnostic process could be faster. Prostate cancer had the longest delays compared with the other cancers. Of more concern are the lengthy delays for colorectal cancer. Patients with lung cancer, ovarian cancer and non-Hodgkin's lymphoma also experienced considerable delays. Patient and primary care delays contributed to larger proportions of the total diagnostic delay than did referral delays and secondary care delays. Over a third of the sample reported no prehospital delays, either because there were no delays (i.e. cancer found by screening, or asymptomatic tumours found while under investigation for other problems) or because the symptom and the first hospital visit occurred within the same month. Large differences were found in all components of delay between patients who reported seeing their GP prior to diagnosis and those who did not (diagnosed through screening or diagnosed while an in-patient) with patients who reported seeing their GP experiencing longer

Strengths and weaknesses of the study All self-report questionnaires have to be interpreted with some caution. Sampling in 172 NHS Trusts in England ensured generalisability. There is the potential for bias in that different proportions of patients between the six cancer groups would have died prior to questionnaire administration; furthermore, these patients are likely to have had more aggressive disease and to have presented differently to those who survived. There is the potential for recall bias, especially given the time interval between diagnosis and survey completion, for at least some of the sample. Data were not collected relating to

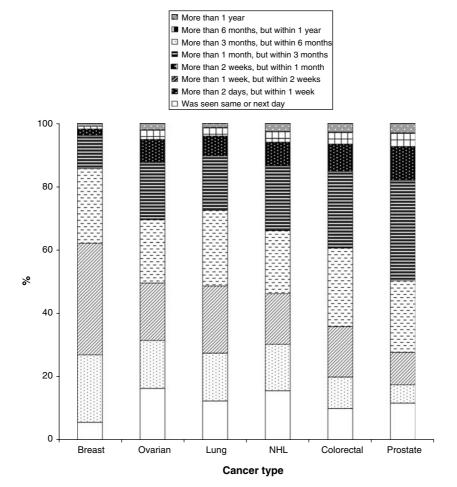


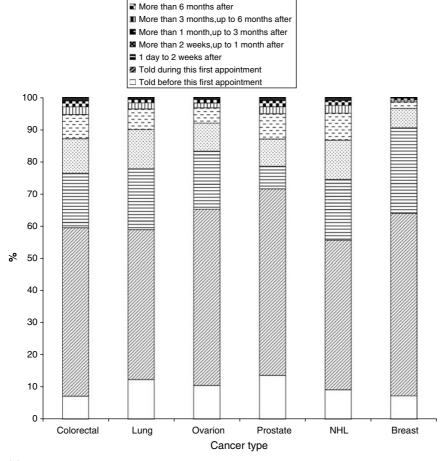
Figure 5 Referral delay.

diagnostic stage, comorbidity, histological type of cancer, or the natural history of the cancer; hence, we cannot be sure that the sample was representative of the 'cancer population', and cannot exclude the possibility of confounding as a result.

The ways in which questions were asked forced us to make assumptions about the data; these may have affected some of the analyses. For example, time was calculated by using the first of each month as the reference date for 'MM/YY' variables. If patients experienced symptoms during the same month that they were first seen at the hospital, this time duration would have been recorded as zero. However, this should give rise to a neutral effect because patients who experienced symptoms at the end of a month and were seen at the hospital at the beginning of the next month would have a time duration recorded as 2 months. As a result of 'open-ended' time categories, patients with referral delays of greater than 1 year and with secondary care delays greater than 6 months were excluded. This only affected a small number of patients and did not influence the main findings. There may be some differences between the actual date of 'tissue diagnosis' and the date perceived by the patients as the date that they were told 'what was wrong with them'. However, this would have been consistent across the data set. Our analysis divided patients who had reported seeing their GP for 'this condition' prior to diagnosis with those who did not. The survey did not ask patients about alternative routes into diagnosis, we are not therefore able to comment further on this. Lastly, the survey did not ask questions in such a way to permit patient and primary care delays to be calculated separately.

Strengths and weaknesses in relation to other studies, discussing important differences in results Compared with previous studies of diagnostic delay in cancer, this paper reports data from a very large data set. There is no standard tool for asking patients about their delays; hence, comparisons between all such studies must be undertaken with caution. In breast cancer, our data show that delays were longer than most previously published reports. For prostate cancer, there are no previous data with which to compare total delays, but our data on referral delays are in keeping with previous data. For colorectal cancer, our figures show that referral delays were longer than other published data, but secondary care delays were shorter. Our figures for lung cancer compare favourably with the literature, with total delays, referral delays and secondary care delays all being shorter. Our figures for referral delay in ovarian cancer show slightly longer referral delays. We are not aware of any other work that has compared delays between patients who saw their GP prior to diagnosis, with those diagnosed via alternative pathways.

Meaning of the study: possible explanations and implications for clinicians and policymakers Shorter delays in breast cancer compared with other cancers may occur because of a more straightforward presentation of signs and symptoms that are easily understood by patients and doctors, clear referral guidance, well-organised secondary care clinics, a national screening programme and a high public profile. Reductions in delays may improve survival. Longer delays in prostate cancer may occur because of



■ Have not been told what is wrong with me

Figure 6 Secondary care delay.

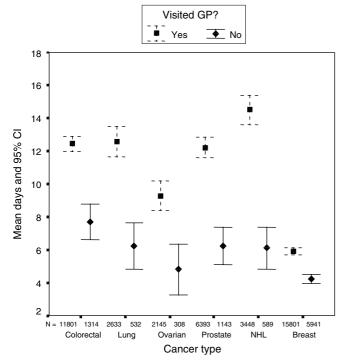


Figure 7 Secondary care delay by GP contact.

Table 6 Mean (s.d.) and median (IQR) delays after recoding referral and secondary care delay

	N	Number recoded	% N	Mean (s.d.)	Median (IQR)
Referral delay					
Colorectal	12884	357	3	51.7 (75.5)	21 (11.56)
Lung	2989	39		37.4 (61.2)	21 (5.56)
Ovarian	2504	51	2	41.5 (69.0)	21 (5.56)
Prostate	8121	244	3	59.4 (77.8)	21 (11.56)
NHL	4353	111	3	45.5 (73.5)	21 (5.56)
Breast	17561	159	I	23.9 (44.6)	II (5.21)
Secondary care	e delay				
Colorectal	13510	266	2	14.9 (32.7)	0 (0.7)
Lung	3237	38	- 1	13.3 (28.3)	0 (0.7)
Ovarian	2504	30		10.6 (26.7)	0 (0.7)
Prostate	7844	173	2	14.7 (33.8)	0 (0.7)
NHL	4141	68	2	15.7 (31.8)	0 (0.21)
Breast	22 075	137	I	6.44 (18.5)	0 (0.7)

the insidious onset of nonspecific symptoms, which may occur on top of preexisting urinary outflow symptoms. Delays may improve in the future with more opportunistic screening, although the effect of this on survival is unknown. The long delays in colorectal cancer may be for similar reasons; again the effects of the

introduction of a national screening programme are unknown. While there is insufficient evidence at present to prove that shorter delays are associated with better prognosis, there is considerable logic that this should be the case, given the potential for curative treatments. The effects of these delays for lung cancer, ovarian cancer and non-Hodgkin's lymphoma are unclear. There is clear potential to reduce delays with the anticipated outcome of improved survival.

The finding that patient and primary care delays were the longest suggests that while further reductions in referral delays and secondary care delays may result in better psychological outcomes, attempts to improve clinical outcomes (earlier stage diagnosis and improved survival), must be directed at patient and/or primary care delays.

The percentage of patients with cancer who bypassed their GP in their diagnostic journey varied considerably between the six cancers. This may have been for one of two reasons. First, because of diagnosis by screening. From the literature, it would be expected that a significant numbers of breast cancers would be screendetected (Banks et al, 2004). Our sensitivity analysis showed that for the female population in the age range for breast cancer screening, fewer patients saw their GP prior to diagnosis than those outside the age range, suggesting that screen-detected cancers were responsible for many of those apparently bypassing the GP. Second, through secondary care diagnosis following an emergency admission, by self-presentation to A&E or via an interspecialty referral. Such patients are likely to have varied presentations of often very advanced or rapidly progressing (and symptomatic) disease, and may, to a degree, confound the

The finding that patients who reported seeing their GP prior to diagnosis had longer delays than those who did not was an unexpected finding. Given that the referral delays were not prolonged, there are two potential explanations of this finding. Firstly, because earlier stage disease (usually less symptomatic) presents mainly to primary rather than secondary care, with later stage disease (with more aggressive symptoms) more likely to be presented to secondary care. Second, because there may be more 'system' delays in primary compared to secondary care (e.g. waiting times for primary care initiated diagnostics). Shorter secondary care delays in patients not seeing their GP prior to diagnosis are probably explained by quicker access to diagnostic tests for in-patients compared with outpatients. The effect of these longer diagnostic delays in patients seeing their GP prior to diagnosis on stage at diagnosis and survival remains unknown. The differences in delays by diagnostic pathway is an important finding and needs further work.

The implications of these findings, the methodological limitations notwithstanding are that there are significant opportunities to reduce diagnostic delay in order to potentially improve clinical outcomes, at least for at-risk groups for some of these six cancers, and to potentially reduce psychological distress caused by delays (Risberg et al, 1996). This is in keeping with the recent National Audit Office report recommendation to tackle diagnostic delays (National Audit Office, 2004). However, such interventions must be considered within the context of the overall presentation of suspicious symptoms in primary care, and the low positive predictive symptoms of suspected symptoms, and the processes of diagnostic reasoning (including watchful waiting) and appropriate thresholds for referral as a result. Our findings will provide a baseline for comparison of future surveys to measure progress in reducing diagnostic delays.

Unanswered questions and future research Prior to the development and evaluation of interventions to reduce delay (Jensen et al, 2002), further work needs to be performed in order to elucidate the separate contributions of patient and primary care delays to the overall delays. There may be variation between delays and sociodemographic factors, and local or regional variations; these need quantifying prior to intervention. Findings from the everincreasing evidence base on the reasons for patient delays in most cancers, and the smaller evidence base regarding primary care delays (Spellman et al, 1999) will inform the development of the interventions. Lastly, work is needed to further explore the reasons for and implications of longer delays in patients who reported seeing see their GP prior to diagnosis, compared with those who did not.

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