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

VL Allgar*1 and RD Neal2
1Centre for Research in Primary Care, University of Leeds, 71-75 Clarendon Road, Leeds LS2 9PL, UK; 2Department of General Practice, Wales College of Medicine, Cardiff University, Wrexham Technology Park, Wrexham LL13 7YP, UK

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.

British Journal of Cancer (2005) 92, 1959–1970. doi:10.1038/sj.bjc.6602587 www.bjcancer.com
Published online 3 May 2005
© 2005 Cancer Research UK

Keywords: delay; diagnosis; patient; primary care; secondary care; referral

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).

The literature regarding the length of diagnostic delays has 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, different methods of measuring delays, the potential confounding 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 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 components of diagnostic delay (patient, primary care, referral,
### Table 1 Diagnostic delays in six cancers – summary of findings from the literature

| Cancer          | 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) | —                   | 13 days (Sainsbury et al, 1999) | —                   | 1/3 experience total pre-hospital delays of > 12 weeks (Richards et al, 1999) Provider delay of 1 Week (Thulesius et al, 2004) |
| **Colorectal**  | —            | 60 days (Aithal and Tanner, 1996) | 47% > 6 weeks (Robinson et al, 1986) | 16 days (Aithal and Tanner, 1996) | 15 days (Aithal and Tanner, 1996) | 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) | 21 days (mean 43) (Koyi et al, 2002) | 33 days (mean 56) (Koyi et al, 2002) | 7 days (Jones et al, 1992) | 9 days (mean 33) (Koyi et al, 2002) | 19 (8.6%) total delay > 1 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) | 78% < 4 weeks (Kirwan et al, 2002) | 73% < 4 weeks (Kirwan et al, 2002) | 6 days (Kirwan et al, 2002) | — | 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 al, 1992) | —                   | 15 days (Jones et al, 1992) | — | — |
| **NHL**         | —            | —              | —                   | —              | — | — |

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).
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 reported before 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. From a total sample of 123 984 patients, 92 683 were sent a questionnaire, after excluding those patients whose death had been reported after returned mail, patients whose death had been reported after mailing and ineligible patients. 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 1 Questions analysed in this paper**

- Q D1: 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 delays 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 delay (as above), from the total prehospital delay (as above). Patient and primary care 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; $\chi^2$ 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
Delays in the diagnosis of six cancers
VL Allgar and RD Neal
British Journal of Cancer (2005) 92(11), 1959 – 1970
© 2005 Cancer Research UK

Figure 1 Individual components of delay in diagnosis.

A 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 (Q D9) n=42 221

Total delay
(Q D1–Q D5) + Q D9 n=37 063

B 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–Q D5) + Q D9 n= 8 164

C For those who did not answer Q D2 (1039)

First symptom Hospital doctor Diagnosis
Q D1 (date) Q D5 (date) Q D9 (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
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 range.

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

|                | Colorectal | Lung | Ovarian | Prostate | Non-Hodgkin's lymphoma | Breast | Total |
|----------------|------------|------|---------|----------|------------------------|--------|-------|
| Did see GP     | 14032      | 88   | 3246    | 81       | 2638                   | 86     | 9159  | 83    | 4742     | 85     | 18262  | 71   | 52079  | 80    |
| Did not see GP | 1612       | 10   | 694     | 17       | 395                    | 13     | 1560  | 14    | 791      | 14     | 7022   | 27   | 12074  | 19    |
| Not answered   | 247        | 2    | 71      | 2        | 34                     | 1      | 273   | 3     | 71       | 1      | 343    | 1    | 1039   | 2     |
| Total          | 15891      | 4011 | 3067    | 10992    | 5604                   |        |       |       |          |        | 25627  | 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           | 15891      | 4011 | 3067    | 10992    | 5604| 25627  | 65192 |
| Total delay                    | 11385 (72%)| 2669 (67%) | 2216 (72%) | 5840 (53%) | 3537 (63%) | 19760 (77%) | 45407 (70%) |
| Secondary delay or total prehospital delay missing | 4506 | 1342 | 851 | 5152 | 2067 | 5867 | 19785 |
| Total delay (if ‘yes’ to Q D2) | 10248 | 2235 | 1943 | 4909 | 3049 | 14679 | 37063 |
| Secondary delay or total pre-hospital delay missing | 3784 | 1011 | 695 | 4250 | 1693 | 3583 | 15016 |
| Total delay (if ‘no’ to Q D2) | 1094 | 420 | 267 | 896 | 479 | 5008 | 8164 |
| Secondary delay or total pre-hospital delay missing | 518 | 274 | 128 | 664 | 312 | 2014 | 3910 |
| Total delay (if no response to Q D2) | 43 | 14 | 6 | 35 | 9 | 73 | 180 |
| Secondary delay or total pre-hospital delay missing | 204 | 57 | 28 | 238 | 62 | 270 | 859 |
| Total pre-hospital delay       | 13174 (83%) | 3260 (81%) | 2673 (87%) | 7759 (71%) | 4650 (83%) | 24294 (88%) | 50104 (83%) |
| First appointment before had symptoms | 453 | 158 | 65 | 382 | 168 | 507 | 1733 |
| One or both dates missing      | 2264 | 593 | 329 | 2851 | 786 | 2626 | 9449 |
| Total pre-hospital delay (if ‘yes’ to Q D2) | 11835 | 2706 | 2330 | 6563 | 4033 | 16561 | 44028 |
| First appointment before had symptoms | 388 | 134 | 53 | 320 | 112 | 319 | 1326 |
| One or both dates missing      | 1809 | 406 | 255 | 2276 | 597 | 1382 | 6725 |
| Patient delay (if ‘no’ to Q D2) | 1282 | 535 | 336 | 1146 | 605 | 5839 | 9743 |
| One or both dates missing      | 275 | 135 | 48 | 354 | 130 | 999 | 1941 |
| First appointment before had symptoms | 55 | 24 | 11 | 60 | 56 | 184 | 390 |
| Total prehospital delay (if no response to Q D2) | 1612 | 694 | 395 | 1560 | 791 | 7022 | 12074 |
| First appointment before had symptoms | 57 | 19 | 7 | 50 | 12 | 94 | 239 |
| One or both dates missing      | 10 | 0 | 1 | 2 | 0 | 4 | 17 |
| Patient and primary care delay (if ‘yes’ to Q D2) | 10026 | 2361 | 2036 | 5369 | 3447 | 15468 | 38707 |
| Referral delay or total prehospital delay missing | 2959 | 675 | 407 | 3065 | 951 | 2076 | 10133 |
| False negatives                | 1047 | 210 | 195 | 725 | 344 | 718 | 3239 |

### 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).
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(19 685) = 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 10 601 out of 22 494 (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 7739 (31%), and colorectal 3467 out of 13 174 (26%). There was a significant difference between cancer groups ($\chi^2(5) = 1765.0, P < 0.0001$).

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(13 114) = 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(22 398) = 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-
Over 60% patients with breast cancer were seen within 2 weeks, compared with less than 30% prostate cancer patients.

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.

### Table 4

| Cancer Type | Colorectal | Lung | Ovarian | Prostate | NHL | Breast |
|-------------|------------|------|---------|----------|-----|--------|
| **(1) Total delay** | | | | | | |
| All patients | 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 | 134.4 (4115) | 98.3 (2475) | 97.7 (3385) | 160.5 (4377) | 114 (2732) | 63 (2589) |
| Median (IQR) | 67 (30–151) | 51 (21–99) | 50 (7–99) | 61 (30–150.5) | 56 (21–122) | 31 (0–56) |
| Non-GP patients | 46.9 (1245) | 38.1 (1905) | 37.9 (113) | 85.6 (7335) | 31.2 (748) | 31.8 (1769) |
| Median (IQR) | 7 (0–52) | 0 (0–31) | 7 (0–31) | 0 (0–31) | 0 (0–31) | 7 (0–31) |
| No response to D2 | | | | | | |
| 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) |

### Table 5

Kruskall–Wallis statistical tests comparing the six cancer groups

| Delay type | \(\chi^2\) | df | P-value |
|------------|------------|----|---------|
| Total prehospital delay | 3859.9 | 5 | <0.0001 |
| Patient, primary care and referral delay (GP patients only) | 3172.5 | 5 | <0.0001 |
| Patient delay (non-GP patients only) | 17.2 | 5 | 0.004 |
| Patient and primary care delay (GP patients only) | 1490.4 | 5 | <0.0001 |
| Referral delay (GP patients only) | 2910.0 | 5 | <0.0001 |
| Secondary care delay | 572.9 | 5 | <0.0001 |
| Total delay | 3632.0 | 5 | <0.0001 |

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.

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.
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 (Table 6).

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 delays.

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
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
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

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

| Cancer type | N   | Number recoded | %    | Mean (s.d.) | Median (IQR) |
|-------------|-----|----------------|------|-------------|--------------|
| Referral delay |      |                |      |             |              |
| Colorectal   | 12,884 | 357          | 3    | 51.7 (75.5) | 21 (11.56)   |
| Lung         | 2,989  | 39           | 1    | 37.4 (61.2) | 21 (5.56)    |
| Ovarian      | 2,504  | 51           | 2    | 41.5 (69.0) | 21 (5.56)    |
| Prostate     | 8,121  | 244          | 3    | 59.4 (77.8) | 21 (11.56)   |
| NHL          | 4,353  | 111          | 3    | 45.5 (73.5) | 21 (5.56)    |
| Breast       | 17,561 | 159          | 1    | 23.9 (44.6) | 11 (5.21)    |
| Secondary care delay |      |                |      |             |              |
| Colorectal   | 13,510 | 266          | 2    | 14.9 (32.7) | 0 (0.7)      |
| Lung         | 3,237  | 38           | 1    | 13.3 (28.3) | 0 (0.7)      |
| Ovarian      | 2,504  | 30           | 1    | 10.6 (26.7) | 0 (0.7)      |
| Prostate     | 7,844  | 173          | 2    | 14.7 (33.8) | 0 (0.7)      |
| NHL          | 4,141  | 68           | 2    | 15.7 (31.8) | 0 (0.21)     |
| Breast       | 22,075 | 137          | 1    | 6.44 (18.5) | 0 (0.7)      |
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 screen-detected (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 very often advanced or rapidly progressing (and symptomatic) disease, and may, to a degree, confound the findings.

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 socio-demographic factors, and local or regional variations; these need quantifying prior to intervention. Findings from the ever-increasing 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.

ACKNOWLEDGEMENTS

We thank the Data Archive at University of Essex. During planning stages of the work, RDN was funded by Macmillan Cancer Relief. The programme of work in primary care oncology at the University of Leeds receives funding from Macmillan Cancer Relief. We also thank Nefyn Williams and Clare Wilkinson for helpful comments on the draft.

REFERENCES

Aithal G, Tanner A (1996) Adjuvant treatment for colorectal cancer: reducing avoidable delays in establishing the diagnosis is also important. BMJ 312: 1417

Arbman G, Nilsson E, Storgen-Fordell V, Sjodahl R (1996) A short diagnostic delay is more important for rectal than for colonic cancer. Eur J Surgery 162: 899 – 904

Arndt V, Sturmer T, Stegmaier C, Ziegler H, Dhom G, Brenner H (2002) Provider delay among patients with breast cancer in Germany: a population-based study. J Clin Oncol 21: 1440 – 1446

Arndt V, Sturmer T, Stegmaier C, Ziegler H, Dhom G, Brenner H (2002) Patient delay and stage of diagnosis among breast cancer patients in Germany – a population based study. Br J Cancer 86: 1034 – 1040

Banks E, Reeves G, Beral V, Bull D, Crossley B, Simmonds M, Hilton E, Bailey S, Barrett N, Briers P, English R, Jackson A, Kutt E, Lavelle J, Rockall T, Wallis MG, Wilson M, Patrick J (2004) Influence of personal characteristics of individual women on sensitivity and specificity of mammography in the Million Women Study: cohort study. BMJ 329: 477

Berrino F, Gatta G, Sant M, Capoccia R (2001) The EUROCARE study of survival of cancer patients in Europe: aims, current status, strengths and weaknesses. Eur J Cancer 37: 673 – 677

Billing JS, Wells FC (1996) Delays in the diagnosis and surgical treatment of lung cancer. Thorax 51: 903 – 906

Department of Health (2000a) The NHS Cancer Plan. London: Department of Health.

Department of Health (2000b) Referral Guidelines for Suspected Cancer. London: Department of Health.

Department of Health (2002) The National Survey of NHS Patients: Cancer Survey. London: Department of Health (http://www.doh.gov.uk/nhspatients/cancersurvey/)

Goff BA, Mandel L, Muntz HG, Melancon CH (2000) Ovarian carcinoma diagnosis. Cancer 89: 2068 – 2075

Graffner H, Olsson S (1986) Patients’ and doctors’ delay in carcinoma of the colon and rectum. J Surg Oncol 31: 188 – 190

Holliday HW, Hardcastle JD (1979) Delay in diagnosis and treatment of symptomatic colorectal cancer. Lancet 1: 309 – 311

Jensen AR, Mainz J, Overgaard J (2002) Impact of delay on diagnosis and treatment of primary lung cancer. Acta Oncol 41: 147 – 152

Jones R, Rubin G, Hungin P (2001) Is the two week rule for cancer referrals working? BMJ 322: 1555 – 1556

The National Survey of NHS Patients: Cancer Survey

http://www.doh.gov.uk/nhspatients/cancersurvey/}
Kiran PR, Glass RE (2002) Duration of symptoms and spread of colorectal cancer: a short history does not mean early disease. *Ann R Coll Surg Eng* 84: 381–385

Kirwan JMJ, Tinchello DG, Herod JJO, Frost O, Kingston RE (2002) Effect of delays in primary care referral on survival of women with epithelial ovarian cancer: retrospective audit. *BMJ* 324: 148–151

Koyi H, Hillerdal G, Branden E (2002) Patient’s and doctors’ delays in the diagnosis of chest tumors. *Lung Cancer* 35: 53–57

Langenbach MR, Schmidt J, Neumann J, Zirngibl H (2003) Delay in treatment of colorectal cancer: multifactorial problem. *World J Surg* 27: 304–308

Meechan G, Collins J, Petrie K (2002) Delay in seeking medical care for self-detected breast symptoms in New Zealand women. *NZ Med J* 115: 257

Moody A, Muers M, Forman D (2004) Delays in managing lung cancer. *Thorax* 59: 1–3

Mountain CF (1997) Revisions in the international system for staging lung cancer. *Chest* 111: 1710–1717

Myrdal G, Lambe M, Hillerdal G, Lamberg K, Agustsson T, Stahle E (2004) Effect of delays on prognosis in patients with non-small cell lung cancer. *Thorax* 59: 45–49

National Audit Office (2004) *Tackling Cancer in England: Saving More Lives*. London: The Stationery Office

Nosarti C, Crayford T, Roberts JV, Elias E, McKenzie K, David AS (2000) Delay in presentation of symptomatic referrals to a breast clinic: patient and system factors. *Br J Cancer* 82: 742–748

Potter MA, Wilson RG (1999) Diagnostic delay in colorectal cancer. *J R Coll Surg Ed* 44: 313–316

Richards MA, Smith P, Ramirez AJ, Fentiman IS, Rubens RD (1999) The influence on survival of delay in the presentation and treatment of symptomatic breast cancer. *Br J Cancer* 79: 856–864

Richards MA, Westcombe AM, Love SB, Littlejohns P, Ramirez AJ (1999) Influence of delay on survival in patients with breast cancer: a systematic review. *Lancet* 353: 1119–1126

Risberg T, Sorbye SW, Norum J, Wist EA (1996) Diagnostic delay causes more psychological distress in female than in male cancer patients. *Anticancer Res* 16: 995–999

Robinson E, Mohilever J, Zidan J, Sapir D (1986) Colorectal cancer: incidence, delay in diagnosis and stage of disease. *Eur J Cancer Clin Oncol* 22: 157–161

Roncoroni L, Pietra N, Violi V, Sarli L, Choua O, Peracchia A (1999) Delay in the diagnosis and outcome of colorectal cancer: a prospective study. *Eur J Surg Onc* 25: 173–178

Sainsbury R, Johnston C, Haward B (1999) Effect on survival of delays in referral of patients with breast-cancer symptoms: a retrospective analysis. *Lancet* 353: 1132–1135

Spellman P, Smith I, Bruce E, Neal RD (1999) *The Cancer Journey to Secondary Care of Patients with Suspected Cancer of the Colon or Lung: A Perspective from General Practice*. Leeds: Nuffield Programme

Spurgeon P, Barwell F, Kerr D (2000) Waiting times for cancer patients in England after general practitioners' referrals: retrospective national survey. *BMJ* 320: 838–839

Thongsuksai P, Chongsuvivatwong V, Sriplung H (2000) Delay in breast cancer care: a study in Thai women. *Med Care* 38: 108–114

Thulesius HO, Lindgren AC, Olsson HL, Hakansson A (2004) Diagnosis and prognosis of breast and ovarian cancer – a population-based study of 234 women. *Acta Oncol* 43: 175–181

Wikborn C, Pettersson F, Moberg PJ (1996) Delay in diagnosis of epithelial ovarian cancer. *Int J Gynecol Obst* 52: 263–267

Yoshimoto A, Tsuji H, Takazakura E, Watanabe T, Haratake J, Kasahara K, Fujimura M, Nakao S (2002) Reasons for the delays in the definitive diagnosis of lung cancer for more than one year from the recognition of abnormal chest shadows. *Int Med* 41: 95–102