Ruth Swann, Sean McPhail, Jana Witt, Brian Shand, Gary A Abel, Sara Hiom, Jem Rashbass, Georgios Lyratzopoulos, Greg Rubin and the National Cancer Diagnosis Audit Steering Group

Diagnosing cancer in primary care:

results from the National Cancer Diagnosis Audit

Abstract

Background
Continual improvements in diagnostic processes are needed to minimise the proportion of patients with cancer who experience diagnostic delays. Clinical audit is a means of achieving this.

Aim
To characterise key aspects of the diagnostic process for cancer and to generate baseline measures for future re-audit.

Design and setting
Clinical audit of cancer diagnosis in general practices in England.

Method
Information on patient and tumour characteristics held in the English National Cancer Registry was supplemented by information from GPs in participating practices. Data items included diagnostic timepoints, patient characteristics, and clinical management.

Results
Data were collected on 17 042 patients with a new diagnosis of cancer during 2014 from 439 practices. Participating practices were similar to non-participating ones, particularly regarding population age, urban/rural location, and practice-based patient experience measures. The median diagnostic interval for all patients was 40 days (interquartile range [IQR] 15–86 days). Most patients were referred promptly (median primary care interval 5 days [IQR 0–27 days]). Where GPs deemed diagnostic delays to have occurred (22% of cases), patient, clinician, or system factors were responsible in 26%, 28%, and 34% of instances, respectively. Safety netting was recorded for 44% of patients. At least one primary care-led investigation was carried out for 45% of patients. Most patients (76%) had at least one existing comorbid condition; 21% had three or more.

Conclusion
The findings identify avenues for quality improvement activity and provide a baseline for future audit of the impact of 2015 National Institute for Health and Care Excellence guidance on management and referral of suspected cancer.

Keywords
cancer; clinical audit; diagnosis; investigations; morbidity; primary care.

INTRODUCTION

The timeliness of cancer diagnosis in patients who present with symptoms has long been a cause of public, professional, and political concern. The result has been an increasing focus on achieving earlier diagnosis,[1,2] supported by growing evidence for associations between time to diagnosis and clinical and patient experience outcomes,[3,4] and evidence of substantial variation in clinical primary care practice.[5] Differences in cancer outcomes between the UK and other comparable health systems are thought to partly reflect differences in diagnostic timeliness, and insights into processes that might underpin these differences have been generated through the International Cancer Benchmarking Partnership.[6]

Forming part of the National Awareness and Early Diagnosis Initiative,[7] the first English National Audit of Cancer Diagnosis in Primary Care (NACDPC) was undertaken in 2009–2010 in order to gain an understanding of the diagnostic process in primary care for patients subsequently diagnosed with cancer.[8] It included information on 18 879 patients diagnosed with cancer, identified from the registers of nearly 1200 practices, and provided detailed information on the primary care pathways to cancer diagnosis.

The *Achieving World Class Cancer Outcomes* cancer strategy 2015–2020 contained a commitment to a second national audit of cancer diagnosis, alongside specific recommendations for clinical practice and the organisation of diagnostic services.[9] It suggested that precautionary 'safety netting'[10,11] becomes more established and that direct access for GPs to diagnostic tests be increased, additionally including a target for achieving diagnostic resolution (cancer diagnosed or ruled out) in most patients within 28 days of referral.[9] Building on the 2009–2010 NACDPC, a National Cancer Diagnosis Audit (NCDA) was formulated as a collaborative initiative between the key UK agencies in cancer diagnosis.

The aim of the NCDA was to generate a detailed understanding of the diagnostic process for cancer in primary care for patients who were diagnosed during 2014. At a national level, it would provide a baseline against which the impact of large-

R Swann, PhD, senior analyst, National Cancer Registration and Analysis Service, Public Health England, London, and Cancer Research UK, London. **S McPhail**, PhD, senior analyst; **B Shand**, PhD, software developer; **J Rashbass**, MD, PhD, MRCPath, director, National Disease Registration, National Cancer Registration and Analysis Service, Public Health England, London. **J Witt**, PhD, project manager, Cancer Research UK, London. **GA Abel**, PhD, senior lecturer, University of Exeter Clinical School, University of Exeter, Exeter. **S Hiom**, BSc, director, Early Diagnosis and Cancer Intelligence, Cancer Research UK, London. **G Lyratzopoulos**, MD, MPH, FRCP, FFPH, professor of cancer epidemiology, National Cancer Registration and Analysis Service, Public Health England; Epidemiology of Cancer Healthcare and Outcome Group, University College London, London; Cambridge Centre for Health Services Research, University of Cambridge, Cambridge.

G Rubin, FRCGP, FRCP(E), professor of general practice and primary care, Institute of Health and Society, Newcastle University, Newcastle; National Cancer Diagnosis Audit Steering Group, Cancer Research UK, London,

Address for correspondence

Ruth Swann, National Cancer Registration and Analysis Service, Public Health England, Skipton House, 80 London Road, London, SE1 6LH, UK.

E-mail: ruth.swann@phe.gov.uk

Submitted: 30 August 2017; **Editor's response:** 30 September 2017; **final acceptance:** 17 October 2017.

This is the full-length article (published online 19 Dec 2017) of an abridged version published in print. Cite this version as: **Br J Gen Pract 2017; DOI: https://doi.org/10.3399/bjgp17X694169**

How this fits in

Unlike most previous studies, the National Cancer Diagnosis Audit has collected primary care referral data for a comparatively large and population-based cohort of patients with cancer. The audit aims to further understand the patient pathway from primary care to diagnosis, and to highlight where improvements can be made, shortening the time interval from presentation to diagnosis. It also provides a baseline for future audits to assess the impact of the 2015 National Institute for Health and Care Excellence guidelines on the recognition and referral of patients with suspected cancer. The authors summarise key methodological aspects of this project and its principal findings.

scale interventions, such as the revised 2015 National Institute for Health and Care Excellence (NICE) guidance for recognition and referral of patients with suspected cancer and the new national cancer strategy, could be re-audited in future.[9,11] At a practice level, the indicators selected would map to cancer standards and guidelines in order to support quality improvement initiatives.

METHOD

Data

After excluding non-melanoma skin cancer, all incident malignant cancer cases among England residents in 2014 (n = 296 231) were assigned to the general practice in which they were registered at the time of their cancer diagnosis, using information from the Hospital Episodes Statistics and Cancer Waiting Times datasets (which hold patient administration and cancer target compliance data, respectively).

Participation in the NCDA was voluntary and promoted through the Royal College of General Practitioners' (RCGP) website and e-newsletters to its members, and through Cancer Research UK and Macmillan Cancer Support primary care engagement processes. Once registered and verified, practices had access, via a secure web portal developed by Public Health England's (PHE) National Cancer Registration and Analysis Service (NCRAS), to a list of all patients who were diagnosed with cancer in 2014 while registered at their practice. Verified GPs and other practice health professionals could then enter primary care data on the patient's characteristics, place of presentation and symptoms presented, primary care-led investigations, the number of pre-referral consultations, the referral pathway, whether there was evidence of safety netting, and any diagnostic delays incurred. The audit portal remained open from September 2016 to February 2017.

Except for dates, all responses were selected from drop-down menus with predefined answers. Categories of avoidable delay were based on a taxonomy previously generated through analysis of free-text responses contained in the NACDPC.[12] Practices could verify screening-detection status but were not required to provide data on these cases. A payment of £10 per tumour record was given to participating practices that returned information on 95% or more of their NCDA patients (365 practices). Some clinical commissioning groups (CCGs) had encouraged participation through local incentive schemes before this funding became available and were later reimbursed.

Analysis

The authors describe key variables by sex, age group (0–24, 25–49, 50–64, 65–74, 75–84 and ≥85 years), and cancer site (for the 20 sites comprising >1% of the sample: bladder, brain, breast, cancer of unknown primary, colon, endometrial, leukaemia, liver, lung, lymphoma, melanoma, multiple myeloma, oesophageal, oral/oropharyngeal, ovarian, pancreatic, prostate, rectal, renal, stomach [all n ≥265]). The distribution of sex, age, stage at diagnosis, and cancer site of the NCDA cohort was compared with the 2014 national cancer registration statistics.[13] Similarly, participating and non-participating practices were compared in respect of their key characteristics, key aspects of patients' experience of primary care (access, continuity, satisfaction, and doctor communication) as reported by the 2013–2014 NHS General Practice Patient Survey (GPPS), https://gp-patient.co.uk, and rates of use of the 2-week wait (TWW) referrals for suspected cancer and related metrics (in England, clinical guidelines enable GPs to refer patients for specialist assessment within 2 weeks when certain symptoms are present and cancer is a suspected diagnosis).[11]

Primary care-led investigations were grouped into blood, urinary, imaging, endoscopy, and other tests. The number of pre-referral consultations and also the number of comorbidities were categorised as 0, 1, 2, and ≥3. The data from patients with screen-detected cancers are reported separately (given in tables as 'Screening', n = 1006).

The authors focus on three diagnostic intervals: the primary care interval (PCI), the diagnostic interval (DI), and the time from referral to the date the patient was

Table 1. Sample composition and referral type that led most directly to the cancer diagnosis (*N* = 17 042)

	Total of NCDA *n* (%)	TWW *n* (%)	Urgent[a] *n* (%)	Routine *n* (%)	Screening *n* (%)	Emergency[b] *n* (%)	To private care *n* (%)	Other *n* (%)	Not known *n* (%)
Total	17 042 (100.0)	8820 (51.8)	745 (4.4)	1346 (7.9)	1237 (7.3)	2818 (16.5)	315 (1.8)	1004 (5.9)	757 (4.4)
Male	8544 (50.1)	4482 (52.5)	436 (5.1)	829 (9.7)	145 (1.7)	1474 (17.3)	187 (2.2)	549 (6.4)	442 (5.2)
Female	8498 (49.9)	4338 (51.0)	309 (3.6)	517 (6.1)	1092 (12.9)	1344 (15.8)	128 (1.5)	455 (5.4)	315 (3.7)
Age group, years									
0–24	198 (1.2)	46 (23.2)	14 (7.1)	16 (8.1)	2 (1.0)	94 (47.5)	4 (2.0)	9 (4.5)	13 (6.6)
25–49	1705 (10.0)	951 (55.8)	73 (4.3)	162 (9.5)	113 (6.6)	208 (12.2)	67 (3.9)	59 (3.5)	72 (4.2)
50–64	4144 (24.3)	2144 (51.7)	153 (3.7)	318 (7.7)	561 (13.5)	509 (12.3)	107 (2.6)	201 (4.9)	151 (3.6)
65–74	4877 (28.6)	2532 (51.9)	228 (4.7)	423 (8.7)	473 (9.7)	655 (13.4)	73 (1.5)	313 (6.4)	180 (3.7)
75–84	4213 (24.7)	2274 (54.0)	198 (4.7)	326 (7.7)	79 (1.9)	797 (18.9)	42 (1.0)	281 (6.7)	216 (5.1)
≥85	1905 (11.2)	873 (45.8)	79 (4.1)	101 (5.3)	9 (0.5)	555 (29.1)	22 (1.2)	141 (7.4)	125 (6.6)
Cancer site									
Bladder	490 (2.9)	308 (62.9)	26 (5.3)	39 (8.0)	2 (0.4)	61 (12.4)	7 (1.4)	25 (5.1)	22 (4.5)
Brain	265 (1.6)	23 (8.7)	19 (7.2)	11 (4.2)	0 (0.0)	172 (64.9)	4 (1.5)	16 (6.0)	20 (7.5)
Breast	2714 (15.9)	1533 (56.5)	30 (1.1)	46 (1.7)	918 (33.8)	56 (2.1)	35 (1.3)	50 (1.8)	46 (1.7)
Cancer of unknown primary	400 (2.3)	137 (34.2)	21 (5.2)	20 (5.0)	3 (0.8)	160 (40.0)	3 (0.8)	25 (6.2)	31 (7.8)
Colon	1320 (7.7)	543 (41.1)	63 (4.8)	100 (7.6)	122 (9.2)	350 (26.5)	31 (2.3)	57 (4.3)	54 (4.1)
Endometrial	400 (2.3)	311 (77.8)	14 (3.5)	23 (5.8)	1 (0.2)	26 (6.5)	10 (2.5)	8 (2.0)	7 (1.8)
Leukaemia	470 (2.8)	96 (20.4)	30 (6.4)	79 (16.8)	4 (0.9)	165 (35.1)	9 (1.9)	45 (9.6)	42 (8.9)
Liver	272 (1.6)	87 (32.0)	14 (5.1)	23 (8.5)	7 (2.6)	86 (31.6)	4 (1.5)	32 (11.8)	19 (7.0)
Lung	2132 (12.5)	976 (45.8)	95 (4.5)	89 (4.2)	14 (0.7)	625 (29.3)	9 (0.4)	212 (9.9)	112 (5.3)
Lymphoma	739 (4.3)	347 (47.0)	57 (7.7)	81 (11.0)	2 (0.3)	143 (19.4)	21 (2.8)	53 (7.2)	35 (4.7)
Melanoma	836 (4.9)	611 (73.1)	22 (2.6)	113 (13.5)	2 (0.2)	4 (0.5)	16 (1.9)	45 (5.4)	23 (2.8)
Multiple myeloma	272 (1.6)	84 (30.9)	24 (8.8)	39 (14.3)	3 (1.1)	76 (27.9)	2 (0.7)	23 (8.5)	21 (7.7)
Oesophageal	447 (2.6)	281 (62.9)	19 (4.3)	35 (7.8)	8 (1.8)	65 (14.5)	5 (1.1)	17 (3.8)	17 (3.8)
Oral/oropharyngeal	268 (1.6)	160 (59.7)	12 (4.5)	20 (7.5)	0 (0.0)	17 (6.3)	9 (3.4)	19 (7.1)	31 (11.6)
Other	1582 (9.3)	728 (46.0)	93 (5.9)	194 (12.3)	72 (4.6)	240 (15.2)	32 (2.0)	130 (8.2)	93 (5.9)
Ovarian	332 (1.9)	192 (57.8)	15 (4.5)	11 (3.3)	1 (0.3)	81 (24.4)	7 (2.1)	11 (3.3)	14 (4.2)
Pancreatic	460 (2.7)	185 (40.2)	26 (5.7)	30 (6.5)	0 (0.0)	156 (33.9)	8 (1.7)	36 (7.8)	19 (4.1)
Prostate	2130 (12.5)	1398 (65.6)	92 (4.3)	258 (12.1)	4 (0.2)	112 (5.3)	72 (3.4)	103 (4.8)	91 (4.3)
Rectal	648 (3.8)	374 (57.7)	28 (4.3)	66 (10.2)	69 (10.6)	58 (9.0)	19 (2.9)	20 (3.1)	14 (2.2)
Renal	557 (3.3)	290 (52.1)	27 (4.8)	39 (7.0)	5 (0.9)	94 (16.9)	11 (2.0)	61 (11.0)	30 (5.4)
Stomach	308 (1.8)	156 (50.6)	18 (5.8)	30 (9.7)	0 (0.0)	71 (23.1)	1 (0.3)	16 (5.2)	16 (5.2)

[a]Urgent referrals are not for suspected cancer. [b]Includes instances of patient self-referral. NCDA = National Cancer Diagnosis Audit. TWW = 2-week wait, urgent referral for suspicion of cancer.

informed they had cancer, calculated for patients with available-date data. The PCI was defined as the number of days from first presentation with symptoms deemed to be relevant to the subsequent diagnosis of cancer to the date of first referral from primary care for suspected cancer, and the DI as the number of days from first relevant presentation to the date of diagnosis, as registered by NCRAS.

Interval times of <0 and >730 days were excluded, consistent with previous literature,[14] or 'interval' hereafter. The median (50th), together with the 25th and 75th centiles are described, along with the percentage of patients who had a primary care interval or diagnostic interval >60 or 90 days (for PCI and DI), or >28 days (for time from referral to the date the patient was informed).

RESULTS

The authors report key results in this paper, with more detailed tables provided at www.ncin.org.uk/collecting_and_using_data/.

Sample characteristics

A total of 439 practices submitted data during the audit period, representing 5% of all (approximately 8000) English practices. During quality assurance, 22 patient records were excluded, chiefly because they represented duplicates or pre-2014 diagnoses. The final sample included 17 042 patients (6% of all cancers diagnosed in 2014 in England). Of those, 50% of patients were male, the median age was 69 years, and the most numerous cancer sites were female breast (16%), lung (13%), prostate (13%), and colon/rectal cancer (12%) (Table 1). Completeness of

Table 2. Patient characteristics

	n	(%)
Union for International Cancer Control (UICC) cancer stage group[a]		
0	13	(0.1)
1	4255	(32.6)
2	2872	(22.0)
3	2412	(18.5)
4	3506	(26.8)
Not known	3984	
Ethnicity		
White	13 850	(95.0)
Asian	385	(2.6)
Black	156	(1.1)
Mixed	134	(0.9)
Other	49	(0.3)
Not known	1462	
Screening	1006	
Language		
Is a native English speaker	14 251	(95.3)
English is not the patient's mother tongue but they are very fluent in English	452	(3.0)
English not mother tongue and patient not fluent in English	154	(1.0)
English not mother tongue and communication only possible through translator	91	(0.6)
English not mother tongue but communication possible because of mother tongue concordance with GP	10	(0.1)
Is a native Welsh speaker	2	(0.0)
Not known	1076	
Screening	1006	
Communication difficulty		
No difficulty	*12 326*	*(89.6)*
Cognitive impairment	*495*	*(3.6)*
Hearing impairment	*440*	*(3.2)*
Vision impairment	*194*	*(1.4)*
Language barrier	*169*	*(1.2)*
Speech impairment	*97*	*(0.7)*
Learning difficulty	*94*	*(0.7)*
Severe longstanding mental illness	*86*	*(0.6)*
Other	*45*	*(0.3)*
Not known	*2276*	
Screening	*1006*	
Housebound status		
The patient is not considered housebound	12 997	(89.0)
The patient is considered housebound	1263	(8.7)
Lives in residential/nursing care home	340	(2.3)
Not known	1436	
Screening	1006	
Living arrangements		
Cohabiting	8749	(72.2)
Living alone	2834	(23.4)
In residential or nursing home	530	(4.4)
Not known	3923	
Screening	1006	
Number of comorbidities		
0	3801	(24.3)
1	4721	(30.2)
2	3756	(24.0)
≥3	3355	(21.5)
Not known	403	
Screening	1006	

... continued

Table 2 continued. Patient characteristics

Type of comorbidity		
No comorbidity	*3801*[b]	*(24.3)*
Hypertension	*5914*	*(37.8)*
Cardiovascular disease	*3230*	*(20.7)*
Arthritis/musculoskeletal disease	*2769*	*(17.7)*
Diabetes	*2463*	*(15.8)*
Chronic obstructive pulmonary disease	*2342*	*(15.0)*
Previous cancer	*1763*	*(11.3)*
Cerebrovascular disease	*1083*	*(6.9)*
Cognitive impairment	*688*	*(4.4)*
Severe longstanding mental illness	*385*	*(2.5)*
Longstanding physical disability	*257*	*(1.6)*
Other comorbidity	*3094*	*(19.8)*
Not known	*403*	
Screening	*1006*	

[a]UICC cancer stage group as recorded by NCRAS. [b]Values in italics are for variables where multiple answers could have been selected and the percentages will add up to more than 100%. Percentages are calculated after removal of 'not known' and 'screening' groups from the total (n = 17 042) in each category. NCRAS = National Cancer Registration and Analysis Service.

stage at diagnosis (0–IV) was 77%.

Most patients were white (95%) and native English speakers (95%). Among all patients, 23% were reported as living alone, 11%

Table 3. Comparison of key attributes of English general practices participating in the NCDA (*N* = 439) with non-participating practices

		Median (IQR)		
		NCDA participating practices	**Non-participating practices[a]**	***P*-value[b]**
List size (number of patients)		8318 (5370–11 174)	6197 (3703–9528)	<0.001
% of patients ≥65 years		16.9 (12.4–20.9)	16.9 (12.1–20.9)	0.697
% of patients ≥85 years		2.1 (1.5–3.0)	2.1 (1.4–2.8)	0.055
Number of GPs		6.5 (4–9)	4 (2–7)	<0.001
Number of GP FTE		5.6 (3.5–8.0)	3.8 (2.0–6.1)	<0.001
Patients per GP FTE		1466 (1253–1826)	1673 (1337–2119)	<0.001
Patient experience (GPPS scores)[a–f]	Access	85.0 (80.8–89.8)	85.2 (80.7–89.2)	0.671
	Continuity	66.2 (58.6–73.7)	67.8 (59.7–75.5)	0.002
	Doctor–patient communication	82.7 (79.9–84.7)	81.7 (78.7–84.2)	<0.001
	Satisfaction with primary care	84.7 (80.8–87.8)	83.8 (80.0–87.0)	0.001
Urgent (2-week-wait [TWW]) referrals for suspected cancer	TWW referrals for suspected cancer (per 100 000 population)	2758.1 (2009.1–3315.0)	2531.7 (1864.9–3278.6)	0.0136
	% of TWW-referred patients found to have cancer (conversion rate)	8.1 (6.3–10.4)	8.1 (5.9–10.6)	0.564
	% of treated cancer patients who were diagnosed after a TWW referral (detection rate)	47.5 (40.2–56.0)	47.8 (39.1–56.0)	0.737
		***n* (%)**	***n* (%)**	***P*-value[b]**
Practice population IMD score	1 — least deprived	82 (18.7)	1474 (20.1)	<0.001
	2	105 (23.9)	1450 (19.8)	
	3	111 (25.3)	1445 (19.7)	
	4	85 (19.4)	1470 (20.0)	
	5 — most deprived[g]	56 (12.8)	1499 (20.4)	
Setting	Urban	374 (85.2)	6367 (85.7)	0.792
	Rural	65 (14.8)	1067 (14.4)	

[a]Excluding practices with <1000 registered patients. The exact number of non-participating practices varies by the characteristic compared given different sources and operational definitions, but is generally >7000. [b]From Mann–Whitney U-test. [c]Based on GPPS item regarding ability to book an appointment. [d]Based on GPPS item about ability to see a preferred doctor (among patients who express such a preference). [e]Based on GPPS item about doctor's interpersonal skills. [f]Based on GPPS item about overall satisfaction with primary care. [g]From χ^2 test. FTE = full-time equivalent. GPPS = GP practice survey. IMD = index of multiple deprivation. IQR = interquartile range. NCDA = National Cancer Diagnosis Audit. TWW = 2-week wait.

Table 4. The distribution of the primary care interval (*n* = 10 493) and the diagnostic interval (*n* = 12 929) by patient characteristic and cancer diagnosis groups[a]

	Primary care interval *n* = 10 493						Diagnostic interval *n* = 12 929					
	n	25th centile	Median, days	75th centile	% >60 days	% >90 days	*n*	25th centile	Median, days	75th centile	% >60 days	% >90 days
Total	10 493	0	5	27	12.5	8.3	12 929	15	40	86	35.8	24
Male	5478	0	8	30	13.7	9.2	6768	21	47	96	39.9	26.6
Female	5015	0	1	21	11.2	7.3	6161	13	31	77	31.3	21.2
Age group, years												
0–24	112	0	5	34.2	14.3	7.1	170	6.2	26.5	68.5	28.2	17.1
25–49	1131	0	0	20	10.9	8.2	1326	13	30	81	32.7	23.0
50–64	2485	0	4	28	13	8.6	2954	17	42	87	37	24.1
65–74	2989	0	7	29	13	9.1	3610	19	44	92	38.8	25.7
75–84	2693	0	5	27	12.6	8	3378	16	41	89	35.8	24.7
≥85	1083	0	5	24	11.1	6.6	1491	13	30	71	30	20.2
Cancer site												
Bladder	344	0	6	28	13.7	9.6	405	35	56	97	44.2	26.7
Brain	85	0	3	19	12.9	9.4	221	10	29	67	27.1	16.7
Breast	1399	0	0	0	2.6	2.1	1534	10	14	19	7.2	5.0
Cancer of unknown primary	212	0	8	33	15.6	9	312	11.8	35	81.2	30.8	21.5
Colon	773	0	6	29	14.9	10.7	1010	21	49	105	41.5	29.1
Endometrial	317	0	0	14	7.6	6	335	14	34	86.5	34.3	23.9
Leukaemia	253	0	6	26	11.5	6.7	340	6	30	82.5	32.6	23.8
Liver	137	0	5	22	13.9	9.5	207	11	31	91	36.7	25.6
Lung	1148	2	14	45.2	17.9	10.8	1748	20	43	86.2	38.5	23.5
Lymphoma	473	0	11	35	14.8	9.3	581	23	50	100	41.1	27.7
Melanoma	649	0	0	3	6	4.8	723	14	32	56	22.4	14.5
Multiple myeloma	150	4.2	23.5	56.8	23.3	15.3	202	24	53.5	107.5	47.5	31.7
Oesophageal	327	0	1	32	12.8	7.6	383	12	28	65.5	28.5	18.0
Oral/oropharyngeal	158	0	1	27.2	15.2	7	189	17	39	74	33.9	20.1
Other	999	0	7	32.5	13.7	8.9	1212	24	56	114.2	46.9	33.1
Ovarian	240	0.8	13	28	9.6	6.2	285	29	55	85	45.6	22.8
Pancreatic	303	1	11	36	14.5	9.2	386	15	42.5	93	37.3	26.4
Prostate	1551	2	11	31.5	14.6	9.9	1678	29	55.5	126	46.4	33.4
Rectal	455	0	1	22	14.3	10.5	496	21	42	88.2	34.7	24.6
Renal	309	0	14	38	15.2	9.4	422	33.2	66	114	54.5	35.3
Stomach	211	0	11	38	19.4	15.6	260	17	42	89.2	37.3	24.6

[a]*Intervals are restricted to 0–730 days. Patients with a cancer diagnosed through screening are excluded. Primary Care Intervals and Diagnostic Intervals are available for patients where the relevant valid dates were entered. Any intervals that were not within 0–730 days were excluded.*

were housebound or lived in a care home, and 10% had communication difficulties. Only 24% of all patients had no recorded comorbidities before diagnosis, while 21% had ≥3. The most common comorbidities were hypertension, cardiovascular disease, and arthritis/musculoskeletal disease (38%, 21%, and 18%, respectively [Table 2]).

Patient and practice comparisons

Patients included in the NCDA were representative of the 2014 national incident cohort in respect of sex, age, and cancer site.[13] Participating and non-participating practices were similar regarding the age profile of registered patients, but participating practices were somewhat larger (median 8318 versus 6197 listed patients) and had slightly fewer patients per full-time equivalent GP (median 1466 versus 1673) (Table 3). There were relatively fewer participating practices in the least and most deprived quintiles. Participating and non-participating practices had similar patient experience scores, though differences were significant given the large sample size. The median rate of TWW referrals for suspected cancers (*n* per 100 000 population per year) was higher in participating practices compared with non-participating ones, though conversion and detection rates were similar.

Presentation, consultations, and referrals

Most patients (72%) first presented at the GP surgery or had a home visit. Of these patients,

Table 5. Avoidable delays (*n* = 15 369)[a]

	Avoidable delay,[b] *n* (%)	Not known, *n*
Total	3380 (22.0)	1673
Male	1839 (24.0)	897
Female	1541 (20.0)	776
Age group, years		
0–24	39 (22.9)	28
25–49	338 (21.6)	140
50–64	766 (20.3)	379
65–74	937 (21.2)	448
75–84	931 (24.6)	436
≥85	369 (22.2)	242
Cancer site		
Bladder	109 (24.4)	43
Brain	38 (16.9)	40
Breast	178 (6.9)	146
Cancer of unknown primary	95 (28.3)	64
Colon	339 (28.7)	139
Endometrial	92 (24.2)	20
Leukaemia	60 (14.7)	62
Liver	48 (19.5)	26
Lung	447 (24.0)	267
Lymphoma	171 (26.3)	90
Melanoma	151 (18.9)	38
Multiple myeloma	63 (27.3)	41
Oesophageal	112 (27.2)	35
Oral/oropharyngeal	63 (28.5)	47
Other	387 (28.2)	209
Ovarian	89 (29.6)	31
Pancreatic	129 (31.6)	52
Prostate	429 (22.0)	183
Rectal	177 (29.2)	41
Renal	110 (22.2)	61
Stomach	93 (34.4)	38

[a]If there was a perceived avoidable delay in the patient receiving their diagnosis, the following questions gathered information about the nature of that delay, considering three key dimensions: where it occurred, the stage of the diagnostic process during which it occurred, and to whom or what factor it was attributable. Delay was defined as an unnecessary prolongation of the time to reach a diagnosis that has potentially adverse consequences on outcomes. [b]Screening and not applicable cases are excluded from the avoidable delay category. Percentage values relate to observations with non-missing information (that is, excluding 'not-known'). This is to prevent under-reporting of the proportion of the known categories by assuming that the not known cases are missing at random and therefore evenly distributed among the known groups.

11 539 (94%) had at least one recorded symptom. A small proportion (*n* = 1176, 7%) of patients first presented to A&E.

Among patients with a consultation (*n* = 12 369, 73% of all patients), 74% had fewer than three consultations and 26% had three or more. The most common recorded reason for multiple (>3) consultations was symptoms suggestive of a different initial diagnosis (*n* = 1684, 11%) or comorbidity 'blurring the picture' (*n* = 851, 5%).

Approximately 52% of patients were referred through the TWW route: this percentage was lowest in the 0–24 age group (Table 1), and varied greatly by cancer site, ranging from 9% (brain cancer) to 78% (endometrial cancer).

In total, 2818 patients had an emergency referral (17% overall, but ranging from 0.5% for melanoma to 65% for brain cancer [Table 1]). Of those patients, 1326 (48%) had self-referred to A&E/hospital (26% of 2818 patients without any previous relevant GP consultations, 11% while waiting for referral/investigation arranged by the GP, and 11% having previously consulted the GP but not awaiting previously arranged tests or referrals) and 1286 patients (47%) were referred to A&E/hospital as an emergency by the GP or out-of-hours service (20% of 2818 patients without previous relevant GP consultations, 8% while awaiting to be assessed in hospital following referral, and 19% having previously consulted the GP but not awaiting previously arranged tests or referrals) (5% other reason). The results for the emergency referrals are not in a table within the main paper but will be supplied in the supplementary tables hosted on the following webpage: www.ncin.org.uk/collecting_and_using_data/.

Intervals and avoidable delays

The median PCI was 5 days (interquartile range [IQR] 0–27 days), with 8% of patients having a primary care interval longer than 90 days (Table 4). Females with breast cancer had the shortest PCI (median 0 days, IQR 0–0 days), whereas patients with multiple myeloma had the longest (median 23.5 days, IQR 4–57 days). The median DI for all patients was 40 days (IQR 15–86 days). Patients with breast cancer also had the shortest DI (median 14 days, IQR 10–19 days), whereas those with prostate cancer had a median DI of 55.5 days (IQR 29–126 days). The time from referral to being told the diagnosis of cancer exceeded 28 days in 54% of patients: 19% of patients with breast cancer having an interval longer than 28 days compared with 74% of melanoma patients.

For one in five patients the GP considered there to be an avoidable delay in the patient receiving their diagnosis, varying from 7% (breast) to 34% (stomach) (Table 5). Delays were most frequently attributed to the patient, primary/secondary care clinician, and system factors (26%, 28%, and 34%, respectively).

Investigations and safety netting

Primary care-led investigation before referral was used in 45% of all patients, ranging from 3% (breast cancer) to 76% (prostate cancer) (Table 6). For 44% of patients, there was evidence in the clinical record that safety netting had been used, with limited variation by patient

Funding

The National Cancer Diagnosis Audit (NCDA) received enabling support from Cancer Research UK, NHS England, and the National Cancer Registration and Analysis Service.

Ethical approval

This study uses data collected as part of a clinical audit and collated by the National Cancer Registration and Analysis Service under regulation 2 of the Health Service (Control of Patient Information) Regulations 2002.

Provenance

Freely submitted; externally peer reviewed.

Competing interests

The authors have declared no competing interests.

Acknowledgements

The authors would like to thank all GPs and health professionals who participated in the NCDA, and contributing Cancer Research UK staff, including Beccy Cummings, who managed the initial phase of the audit; the National Cancer Registration and Analysis Service, NHS England, the Royal College of General Practitioners, Macmillan Cancer Support, and Health Data Insight. Data for this audit are based on patient-level information collected by the NHS, as part of the care and support of cancer patients. The data are collated, maintained, and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England. National Cancer Diagnosis Audit Steering Group: Sue Ballard (patient and public representative), Patricia Barnett, David H Brewster, Cathy Burton, Anthony Cunliffe, Jane Fenton-May, Anna Gavin, Sara Hiom (chair), Peter Hutchison, Dyfed Huws, Maggie Kemmner, Rosie Loftus, Georgios Lyratzopoulos, Emma McNair, John Marsh (patient and public representative), Jodie Moffat, Sean McPhail, Peter Murchie, Andy Murphy, Sophia Nicola, Imran Rafi, Jem Rashbass, Richard Roope, Greg Rubin, Brian Shand, Ruth Swann, Janet Warlow, David Weller, and Jana Witt (NHS England representative). Ruth Swann and Sean McPhail have contributed equally as first authors, and Georgios Lyratzopoulos and Greg Rubin as last in the present manuscript.

characteristics, but substantial variation by cancer site.

DISCUSSION

Summary

About one in 20 English general practices participated in a major national audit initiative providing opportunities for targeted significant event analysis, reflective learning, and action planning, and additionally generating detailed information about how patients with cancer were diagnosed.

The findings provide the most detailed and accurate picture to date about the diagnostic process in a large, representative, nationwide population of patients with cancer. Overall, though, the median diagnosis interval was 40 days with a median primary care interval of 5 days.

Strengths and limitations

The key strength of the NCDA is the collection of detailed data on the diagnostic process by GPs, based on in-depth understanding of their patients, the detailed information included in the primary care patient record, and application of clinical judgement. The audit employed a population-based design, allowing for direct comparability of patients included with those not included in the audit. It linked rigorous case ascertainment and staging data with information unique to the primary care record and not available without direct extraction after expert clinical scrutiny.

Though both the included patients and participating practices were largely representative, participating practices may differ from non-participating practices in important aspects of the diagnostic process for which no comparative data exist (for example, in how often they use safety netting). Therefore, caution is needed when interpreting the findings as nationally representative, though comparisons of other characteristics of participating and non-participating practices are reassuring. Clinical judgement is inherently needed for certain data items (for example, to establish the date of the 'first consultation with relevant symptoms' for a patient subsequently diagnosed with cancer, particularly in patients with comorbidity). Therefore, the assignment of first relevant consultation (and related diagnostic intervals) can potentially contain errors. It should be acknowledged that clarity or vagueness of presenting symptoms may influence both the completeness and accuracy of how they are recorded in primary care records and the ability of auditing GPs to accurately extract and record this information. Validation studies (involving multiple raters) in sub-samples of patients would be merited. Another limitation is the degree of missing data, particularly regarding diagnostic interval measures and the assessment of whether delays have occurred (Tables 4 and 5).

Comparison with existing literature

This English (2014) NCDA builds on previous related initiatives in England (NACDPC 2009–2010),[8] Scotland (2006–2008),[15] and Denmark.[16] It is complemented by nearly synchronous audits in both Scotland and North Wales.

The findings presented here reaffirm previous evidence on key determinants of variation in the measures and markers of diagnostic timeliness, particularly in respect of cancer site, with patients subsequently diagnosed with cancers characterised by non-specific symptom signatures (for example, lung, colon, stomach, and multiple myeloma) typically having longer primary care intervals and higher percentage of multiple pre-referral consultations.[17–19] Furthermore, we demonstrate that this variation by cancer site also applies to the soon-to-be-implemented 28-day faster diagnosis standard (from referral to receipt of diagnosis)[9] and that performance in 2014 falls well short of the proposed 95% target for all sites.

The NCDA data provide information on referral type; this is analogous but not directly comparable with diagnostic route as described by the Routes to Diagnosis data.[20] Nonetheless, the proportion of patients with an emergency referral type in the NCDA was of similar order to that of patients being diagnosed through an emergency presentation according to the Routes to Diagnosis data for 2014 (17% and 20%, respectively).[21] In about one in four emergency referrals the patient had not previously consulted with a GP, a finding consistent with other evidence,[22,23] and 19% were missed opportunities for earlier diagnosis (associated predictor: no prior GP contact (OR = 3.89; 95% CI 2.14 to 7.09). In the NCDA population, 52% of all patients were diagnosed following a TWW referral. The total number of TWW referrals increased by 71% in the relevant 5-year period 2009/2010 to 2014/2015, though the proportion of those receiving a cancer diagnosis decreased from 10.8% to 8.2%.[24]

Implications for research and practice

For policymakers, this audit provides a baseline against which the impact of

Table 6. Number of primary care-led investigations ordered by the GP as part of the diagnostic assessment prior to referral

	Investigation group (*N* = 16 762, excluding not knowns)		Percentage of patients investigated by test type[a] (*N* = 16 762)				
	No investigations,[b] *n* (%)	Not known, *n*	Blood tests, *n* (%)	Urinary tests, *n* (%)	Imaging, *n* (%)	Endoscopy, *n* (%)	Other, *n* (%)
Total	9160 (54.6)	*280*	5795 (34.6)	212 (1.3)	3289 (19.6)	267 (1.6)	446 (2.7)
Male	3662 (43.7)	*156*	3773 (45.0)	152 (1.8)	1780 (21.2)	139 (1.7)	250 (3.0)
Female	5498 (65.7)	*124*	2022 (24.1)	60 (0.7)	1509 (18.0)	128 (1.5)	196 (2.3)
Age group, years							
0–24	131 (68.6)	*7*	38 (19.9)	0 (0.0)	31 (16.2)	1 (0.5)	6 (3.1)
25–49	1105 (66.4)	*40*	353 (21.2)	12 (0.7)	325 (19.5)	23 (1.4)	47 (2.8)
50–64	2362 (57.8)	*60*	1275 (31.2)	44 (1.1)	781 (19.1)	77 (1.9)	101 (2.5)
65–74	2465 (51.1)	*52*	1820 (37.7)	66 (1.4)	997 (20.7)	73 (1.5)	132 (2.7)
75–84	2079 (50.3)	*83*	1602 (38.8)	67 (1.6)	848 (20.5)	78 (1.9)	118 (2.9)
≥85	1018 (54.5)	*38*	707 (37.9)	23 (1.2)	307 (16.4)	15 (0.8)	42 (2.2)
Cancer site							
Bladder	208 (43.1)	*7*	171 (35.4)	61 (12.6)	60 (12.4)	4 (0.8)	58 (12.0)
Brain	192 (74.7)	*8*	50 (19.5)	4 (1.6)	24 (9.3)	1 (0.4)	3 (1.2)
Breast	2602 (96.8)	*26*	53 (2.0)	1 (0.0)	50 (1.9)	0 (0.0)	7 (0.3)
Cancer of unknown primary	190 (49.0)	*12*	164 (42.3)	0 (0.0)	97 (25.0)	6 (1.5)	8 (2.1)
Colon	624 (47.9)	*16*	621 (47.6)	7 (0.5)	168 (12.9)	52 (4.0)	31 (2.4)
Endometrial	247 (62.7)	*6*	72 (18.3)	3 (0.8)	82 (20.8)	4 (1.0)	25 (6.3)
Leukaemia	182 (40.0)	*15*	266 (58.5)	2 (0.4)	36 (7.9)	3 (0.7)	2 (0.4)
Liver	121 (44.8)	*2*	122 (45.2)	4 (1.5)	80 (29.6)	8 (3.0)	2 (0.7)
Lung	844 (40.1)	*29*	602 (28.6)	5 (0.2)	1100 (52.3)	16 (0.8)	50 (2.4)
Lymphoma	305 (42.4)	*19*	324 (45.0)	6 (0.8)	247 (34.3)	12 (1.7)	16 (2.2)
Melanoma	779 (94.3)	*10*	9 (1.1)	0 (0.0)	7 (0.8)	0 (0.0)	37 (4.5)
Multiple myeloma	89 (33.7)	*8*	162 (61.4)	1 (0.4)	72 (27.3)	4 (1.5)	10 (3.8)
Oesophageal	239 (54.4)	*8*	162 (36.9)	0 (0.0)	55 (12.5)	37 (8.4)	10 (2.3)
Oral/oropharyngeal	197 (75.8)	*8*	49 (18.8)	1 (0.4)	27 (10.4)	1 (0.4)	5 (1.9)
Other	839 (54.1)	*30*	395 (25.5)	15 (1.0)	452 (29.1)	26 (1.7)	61 (3.9)
Ovarian	100 (30.9)	*8*	170 (52.5)	6 (1.9)	159 (49.1)	4 (1.2)	11 (3.4)
Pancreatic	145 (32.2)	*10*	267 (59.3)	6 (1.3)	166 (36.9)	23 (5.1)	9 (2.0)
Prostate	503 (24.0)	*33*	1555 (74.2)	70 (3.3)	166 (7.9)	4 (0.2)	44 (2.1)
Rectal	360 (56.2)	*7*	260 (40.6)	2 (0.3)	27 (4.2)	28 (4.4)	19 (3.0)
Renal	262 (48.2)	*13*	174 (32.0)	17 (3.1)	175 (32.2)	5 (0.9)	32 (5.9)
Stomach	132 (43.6)	*5*	147 (48.5)	1 (0.3)	39 (12.9)	29 (9.6)	6 (2.0)

[a]Patients could have had >1 investigation. Each investigation group has been counted once, therefore multiple blood tests are counted as blood test x1. [b]Number of investigations include not applicable and screening patients. Percentage values relate to observations with non-missing information (that is, excluding 'not-known'). This is to prevent under-reporting of the proportion of the known categories by assuming that the not-known cases are missing at random and therefore evenly distributed among the known groups.

subsequent initiatives to improve cancer diagnosis, such as the 2015 NICE guidance on recognition and referral of suspected cancer[11] and the implementation of the *Achieving World Class Cancer Outcomes* Cancer Strategy 2015–2020,[9,25] can be assessed. It provides pointers to where implementation efforts might best be directed, for example, in achieving the 28-day standard from referral to diagnosis. It appears that, despite efforts since 2012 to increase access to specialist investigations such as imaging or endoscopy, these are not widely ordered by GPs for patients subsequently diagnosed with cancer, who are however investigated after a specialist referral.[26]

Individual practice feedback has already been provided along with quality improvement initiatives including the Quality Improvement toolkit from the RCGP and Cancer Research UK, specifically targeted at the NCDA,[27] and completion of cycles of audit. The novel methodology developed for this audit also permits continuous large-scale participation by practices in the future.

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