

NATIONAL CANCER ACTION TEAM and ROYAL COLLEGE OF GENERAL PRACTITIONERS

PRIMARY CARE CANCER AUDIT

GREATER MIDLANDS CANCER NETWORK

REPORT

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1. EXECUTIVE SUMMARY

- It is widely known that 1 in 3 of us will get cancer at some time in our lives and that 1 in 4 of us will die because of cancer.
- It is also known that outcomes for cancer patients in this country are not as good as in many European and North American countries.
- It is believed that late diagnosis is the explanation for most of the poorer outcomes in the United Kingdom. Studies are being carried out at present to confirm this belief.
- It is estimated that 7500 – 10000 lives are lost each year in this country due to late diagnosis.¹
- As well as these premature deaths, late diagnosis is costly in financial terms. It has recently been estimated that on a cumulative basis by 2020, total costs could be reduced by £10 billion and 71,500 lives could be saved if cancer services in England were improved to be among the best in Europe.²
- Just over 25% of the overall cost of cancer relates to the NHS. Greater Midlands Cancer Network (GMCN) covers approximately 4% of the population of England so this equates to a potential 2860 premature deaths avoided, and £100 million cost savings to be made locally over the next 10 years, if outcomes were improved to the level of other developed countries.
- Late diagnosis has three elements. Firstly, delays can be due to the patient not presenting early enough to their GP. There are several reasons for these delays that are discussed later in this report. The second element is delays in primary care, either doctor delay or system delay. The third element is delays in secondary care.
- Many of the delays in secondary care have been addressed following publication of the NHS Cancer Plan in 2000, although there is more to be done.
- The Cancer Reform Strategy of 2007 recognised that patient delay and primary care delay were also important, although little research had been carried out in these areas.
- The National Awareness and Early Detection Initiative (NAEDI) was developed the following year, and this Primary Care Cancer audit was the result of one of the NAEDI work-streams.
- GMCN is one of 18 networks across the country taking part in the audit and all the results will be analysed nationally, resulting in a national report and recommendations later this year.
- There were 3 parts to the audit:
 - For the first part, the patient journey from first symptoms through to referral to secondary care was recorded on a spreadsheet.
 - GPs were asked to complete significant event audit reports for 2 patients for the second part.
 - Finally the practice was asked to convene a practice meeting of clinical staff to discuss all the cases identified for the audit. Learning and action points were then produced in a report for the PCT.
- All eight Primary Care Trusts (PCTs) in GMCN participated in the audit. 161 practices completed the audit resulting in data for 1530 patients who had a new cancer diagnosed (some cancers were excluded) between October 1st 2008 and March 31st 2009.
- Section 2 of this report describes the background to this audit.
- Section 3 shows a summary of the findings from the spreadsheet.

¹ Abdel-Rahman M, Stockton D, Rachet B et al. What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable? Br. J. Cancer 2009 **101(S2)**:S115-S24

² The cost of cancer | Henry Featherstone & Lilly Whitham | www.policyexchange.org.uk Feb. 2010

- All the findings of the significant event audits are collated in section 4, and the outcomes of the practice meetings are reported in section 5.
- Section 6 is a discussion of the findings and section 7 lists a number of recommendations for the Network Board to consider.
- There is a lot of information included in sections 4 and 5 to emphasise the great deal of thought and effort that a lot of GPs have put into this audit.
- There is no doubt that the audit has caused much reflection amongst GPs, and it is expected that many practices will be changing some of their referral habits and in-house processes as a result of the audit.
- The results show that the majority of the delays are due to the patient not recognising that their symptoms could be due to cancer, or denying or ignoring such symptoms.
- Primary care delays do occur at times due to:
 - A few GPs having a poor knowledge of the National Institute for Health and Clinical Excellence (NICE) referral guidelines, or choosing to ignore them. Problems with locum Doctors and GP registrars were noted by a few practices in this respect.
 - The difficulties of separating cancer symptoms from the symptoms of benign disease.
 - The difficulties that can be caused by pre-existing medical conditions.
 - The lack of “safety-netting” processes in some practices, for dealing with the follow up of patients with unexplained symptoms, abnormal test results and ensuring that 2 week referrals are received by the local hospital.
- The audit wasn’t really about secondary care delays but several practices reported delays in secondary care. Many of these were about poor communication.
- A report for each PCT with the specific data and findings for that PCT has already been issued and shared with each of the eight PCTs.
- A series of recommendations are made at the end of this report including:
 - The setting up of a network Public Health and Primary Care steering group to oversee a Local Awareness and Early Detection initiative.
 - The use of the new GMCN website to act as a source of information for patients and GPs. GPs receive little feedback about their performance in the detection of cancer and the website should be used to provide this information. Examples of good practice regarding guidelines and in-house systems could be shared with other practices through the website.
 - Sharing of the findings of this report (and the next steps that should follow) with PCT commissioners and Hospital managers through the Cancer local implementation teams (LITs), to PCT Professional Executive Committees and with GPs through local education events.
 - Separate tumour-type specific reports can be prepared and shared with Network Site Specific Groups (NSSGs).
 - Two suggestions for sustaining the impetus of this audit and to involve those GP practices that did not participate in the audit.

2. INTRODUCTION

2.1 Background

The concept of this national Primary Care Cancer audit was first mentioned in the Cancer Reform Strategy (CRS) which was published in 2007 following the National Cancer Plan of 2000. *“A national audit in primary care of newly diagnosed cancers will be used to make decisions about how best to provide more support to primary care professionals to ensure the early diagnosis of cancer”*.

The National Awareness and Early Detection Initiative (NAEDI) was developed in 2008 following the publication of the CRS, and “Reducing Primary Care Delay” is one of the 8 NAEDI work streams. The audit presented in this paper is the main project arising from this work stream.

The audit spreadsheet was developed by Professor Greg Rubin and his colleagues at the University of Durham in association with the National Cancer Action Team (NCAT) and the Royal College of General Practitioners (RCGP). This spreadsheet was tested by a few Primary Care Trusts (PCTs), before being offered to all Cancer Networks in May 2009. The spreadsheet can be found by clicking on the link:

www.RCGP-NCATaudittemplateforcancerdiagnosisinprimarycare2009.xls

Greater Midlands Cancer Network (GMCN) made a successful bid for funding, to cover the costs of the audit.

2.2 Project Aims

- To identify any delays in patient pathways.
- To identify any potential groups of patients or tumour types which are particularly vulnerable to delay.
- To use the findings to plan interventions to improve early diagnosis for cancer patients in GMCN.
- To use the findings to address any health inequalities locally and develop a Local Awareness and Early Detection Initiative (LAEDI)
- To ensure that next steps are included in the commissioning intentions for each PCT.

2.3 The Audit Templates

On the audit spreadsheet, GPs were asked to record all new cancer diagnoses made between October 1st 2008 and March 31st 2009 excluding the following cases:

- a) Any cancer diagnosed through the national screening programmes.
- b) All non-melanotic skin cancers.
- c) Any case where the medical records were unavailable (i.e. the patient had moved practice or died).

GP practices had to record a minimum of 5 cases to be eligible for inclusion, and if the practice could not identify 5 cases in the above 6 month period, they were advised to search backwards through their records until they could identify 5 cases.

The spreadsheet captured the patient demographics and the first part of their cancer pathway.

The spreadsheet calculated the totals for each cancer type, the type of referrals (2 week wait, emergency, routine) and the number of potentially avoidable delays identified by GPs. The template also calculated (where the information was recorded) the number of days from the patient first noticing symptoms to their presentation to Primary Care, the number of days from presentation to referral, the number of days

from referral to being seen in Secondary Care, and the total number of days from symptoms first being noticed by the patient to being seen in Secondary Care.

Whilst we await the national team to analyse and report on the audit, GMCN produced an interim report of each PCT's data and this overarching network report.

The second part of the audit was for each GP practice to analyse 2 cancer cases in much more detail in the form of significant event audits (SEAs). Practices were asked to select a complex case, or a patient who had died, or a patient who suffered an apparent delay. The national SEA template used is attached as appendix 1.

Finally the practice was asked to convene a practice meeting with attendance of as many of the practice clinicians as possible. All the cases identified by the audit were to be discussed and learning points and actions recorded in a report.

A template was produced by GMCN to capture the SEAs and Practice meetings. This network report summarises all three parts of the audit, with comparative figures for the PCTs where it is deemed appropriate or of interest.

2.4 Finance

Practices would be paid £500 per practice which included the two SEA reports and the practice meeting report.

In addition, practices would be paid £30 for each line completed which then had to be validated by a PCT clinician and/or the GMCN GP adviser.

The audit was paid as a Local Enhanced Service (LES). The sums on offer were fixed and non-negotiable, so there was no need for PCTs to consult with Local Medical Committees (LMCs).

2.5 Process

It was unknown at the outset what the likely uptake from PCTs and GPs would be.

Initially GMCN requested that PCTs made a contribution to the cost of the audit, but few PCTs had any funds that could be committed in this way.

GMCN then decided to aim for a 60% uptake (similar to the figure achieved in one of the pilot PCTs) and fund the whole audit themselves.

PCTs were asked to provide administrative support, to act as communication channels between practices and the network, to encourage initial interest and to try and ensure delivery, and to collate all information and have it checked by a PCT clinician before returning the completed templates to GMCN for approval.

The full papers were sent to PCTs in early July with a request that interested practices should sign the LES by July 31st 2009. This deadline was later extended to August 31st and to September 11th for one PCT that was very slow in sending out the information to practices.

PCTs were asked to raise an invoice for the total number of practices signing the LES (at £500 per practice).

The original deadline of October 16th for completion of the audits was later extended to November 20th.

PCTs were asked to collate all the information from their participating practices and populate the master templates supplied. The deadline for the return of the completed templates was set at December 24th.

Once the returns had been approved by the Network GP Adviser, a "thank-you" e-mail and a very brief initial report was sent to the participating GPs via their PCT.

Once the number of approved cases was known the PCT could raise the second invoice at £30 per line.

The spreadsheet lines were entered on a Network master template prior to onward transmission to Professor Rubin for analysis at national level.

3 RESULTS OF AUDIT

3.1 Participating practices

Greater Midlands Cancer Network:	
Total population	2179100³
Population of audit practices	1050053⁴
% of population covered by audit	48.2⁵
Total number of Practices in Network	376
Number of Practices sent LES in July / August	372
Number of Practices who initially signed LES	225
Number of Practices eventually completing audit	161
Completed main audit template	161
Completed SEA	159
Held practice meetings & provided report/action points	152
% of practices participating in audit	42.8
Total number of audit lines approved by Network	1530

Table 1

Across the network, the range of participating practices was from 28.1% (South Staffs) to 60% (North Staffs). The population covered by the audit ranged from 34.4% (South Staffs) to 70.2% (Wolverhampton).

In total, 161 out of 376 practices (42.8%) participated in the audit covering a population of just over 1,050,000 patients (representing 48.2% of the network population).

It should be noted that a total of 64 practices, that had initially expressed an interest in taking part in the audit, didn't go on and complete it. Only 2 practices in total from North Staffordshire, Telford and Wrekin and Wyre Forest didn't complete the audit, having originally signed the LES. The other 62 practices were fairly evenly distributed across the remaining 5 PCTs, although 20 of the 47 South Staffordshire practices that originally wished to participate didn't complete the audit.

³ PCT total population taken from ONS. Estimated figure for mid 2008.

⁴ Population of audit practices provided by the Primary Care Trusts.

⁵ Network population includes just the Wyre Forest part of NHS Worcestershire population, but the whole of the South Staffs population is included although some of the South Staffs practices refer routinely to Hospital Trusts outside GMCN (these couldn't be identified).

3.2 Demographics

Age (range)	Number	Mean age (yrs)	Median age (yrs)
All (3y to 104y)	1530	67	68
Male (13y to 94y)	808	68	69
Female (3y to 104y)	714	66	67

Table 2

52.8% of the audit patients were male and 46.6% were female.
 8 patients (0.5%) had no gender stated.
 1 patient had no age stated.

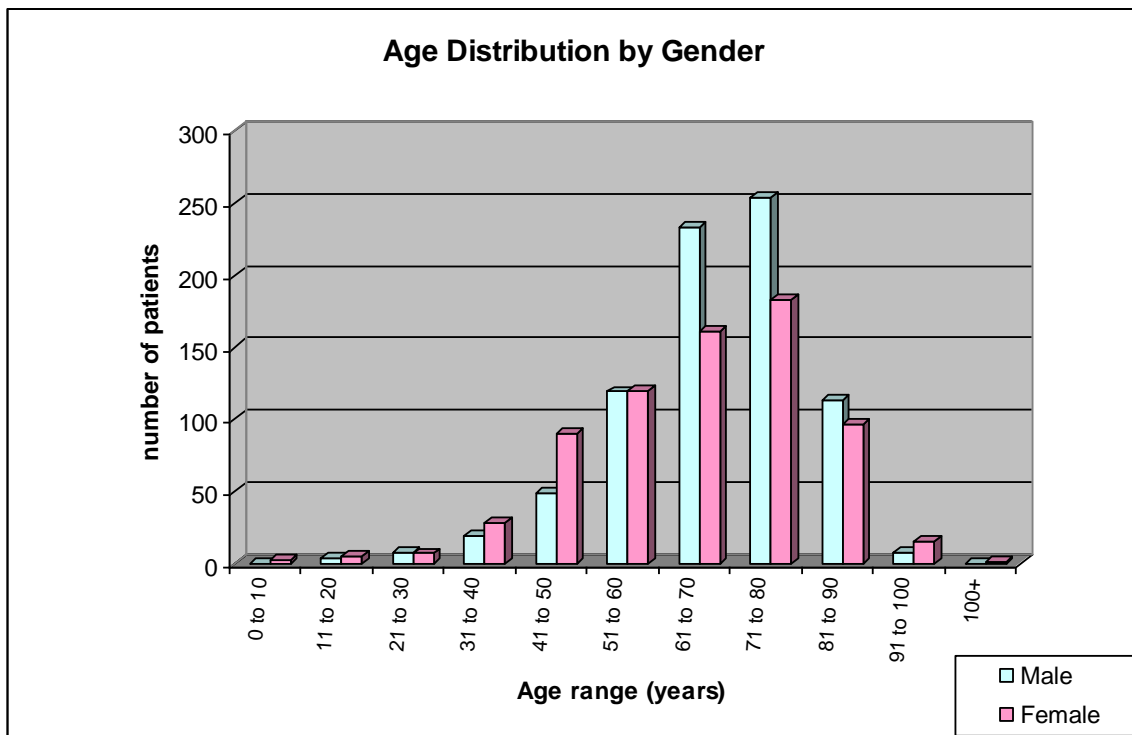


Chart 1

The age sex distribution of the audit patients is shown in Chart 1 above.

Ethnicity	Number	%
White British	1294	85
White Irish	6	<1
White Other	17	1
Black African	2	<1
Black Caribbean	11	<1
Black other	1	<1
Chinese	3	<1
Indian	18	1
Asian other	1	<1
Mixed white /Black Caribbean	2	<1
Mixed Other	1	<1
Other	11	<1
Not known	142	9
Not stated	20	1

Table 3

Country of Birth	Number	%
United Kingdom	1251	82
Western Europe	5	<1
Eastern Europe & Russia	8	<1
Asia	9	<1
Sub-Saharan Africa	2	<1
Middle East	2	<1
Indian sub-Continent	5	<1
Australasia	1	<1
Caribbean	6	<1
Other	3	<1
Not Known	197	13
Not stated	41	3

Table 4

85% of the audit patients were recorded as white British. It is likely that a significant proportion of the “not known” patients were also white British, as the majority of “not known” patients were recorded by a few practices predominantly in Shropshire and Wyre Forest. Some of these practices recorded “not known” for all of their audit patients, suggesting that the main audit template was completed by practice staff rather than the GP. The comments made regarding the group of “not known” patients also apply to Table 4 which records the country of birth of the audit patients

3.3 Communication and Access Difficulties

Patients recorded as having communication or access issues	<i>Number</i>
No communication issues	1409
Dementia	16
Language barrier	12
Learning difficulties	6
Mental Health	10
Poor hearing	20
Poor vision	3
Speech impairment	7
Other	6
Not known	23
Not stated	18
Patients recorded as being "housebound"	93

Table 5

One of the aims of this audit was to identify any potential groups of patients or tumour types which are particularly vulnerable to delay. The number of patients with communication issues, even when totalled across the eight PCTs, was still relatively small. It will therefore be left to the national team to analyse this information further, and to see whether there is a link between avoidable delay and this group of patients.

93 patients (6.1%) were recorded as being housebound. A further 22 were recorded as not known, and the information wasn't provided for 2 patients.

3.4 Diagnosis – cancer site

	<i>Number</i>	<i>%</i>
Prostate	267	17
Breast	250	16
Colorectal	238	15
Lung	132	9
Oesophageal	67	4
Bladder	65	4
Lymphoma	54	4
Melanoma	53	4
Leukaemia	45	3
Endometrial	39	3
Ovarian	39	3
Myeloma	31	2
Oropharyngeal	31	2
Renal	27	2
Pancreatic	24	2
Stomach	21	1
Brain	19	1
Testicular	15	1
Cervical	13	<1
Laryngeal	12	<1
Thyroid	11	<1
Unknown Primary	11	<1
Mesothelioma	10	<1
Liver	10	<1
Sarcoma	10	<1
Vulval	9	<1
Small Intestine	5	<1
Gallbladder	4	<1
Other	18	<1
Total	1530	100

Table 6

Table 6 records all the diagnoses for the 1530 patients. The 4 commonest cancers nationally (i.e. prostate, breast, colorectal, and lung) are, as expected, the 4 commonest cancers found in the network audit.

The individual PCT reports list the 10 commonest cancers for that PCT. Again the PCT data reflects the national and network findings, although lung cancer does not appear in the “top 4” for NHS Telford and Wrekin. However, Telford and Wrekin only reported on 81 patients in total, so this is not seen as significant.

More detailed analyses and reports of individual cancer sites will be produced for presentation to Network Site Specific Groups (NSSGs). It is expected that reports will be prepared for the Urology NSSG, the Breast NSSG, the Colorectal NSSG, the Lung NSSG and the Skin NSSG. Other reports can be produced on request for other NSSGs, but numbers are much lower for other cancer sites.

It is expected that the national report will identify if there are avoidable delays linked to specific tumour types.

3.5 Stage at diagnosis

	Organ (%)	Local spread (%)	Distant spread (metastases) (%)	Not known or not stated (%)
Prostate n= 267	167 (62)	53 (20)	30 (11)	17 (6)
Breast n= 250	115 (46)	81 (32)	20 (8)	34 (14)
Colorectal n= 238	104 (44)	62 (26)	41 (17)	31 (13)
Lung (inc mesothelioma ⁶) n= 141	38 (27)	45 (32)	43 (30)	15 (11)

Table 7

Table 7 above shows the staging of the 4 commonest cancer types as recorded in the GP medical records. Clearly patients whose cancers are diagnosed early (restricted to the organ of origin) are likely to have a better outcome than patients whose cancers have already spread (locally or more distant).

There is a wide variation between the PCTs for the staging of these four cancers which will be reported in more detail for the NSSG reports. A summary for stage 1 (organ only) shows:

Breast (250 cases)

Organ only – average 48.6% (PCT range 34 -72%)

Colorectal (238 cases)

Organ only – average 47% (PCT range 31 – 82%)

Prostate (267 cases)

Organ only – average 61.6% (PCT range 35 – 93%)

Lung (including Mesothelioma) (141 cases)

Organ only – average 29.5% (PCT range 14 – 45%)

⁶ 9 out of the 10 mesothelioma cases are included here, as most clinicians would regard them as a type of lung cancer. The 10th case was a peritoneal mesothelioma so has been excluded from this particular analysis.

COLORECTAL CANCER - STAGING

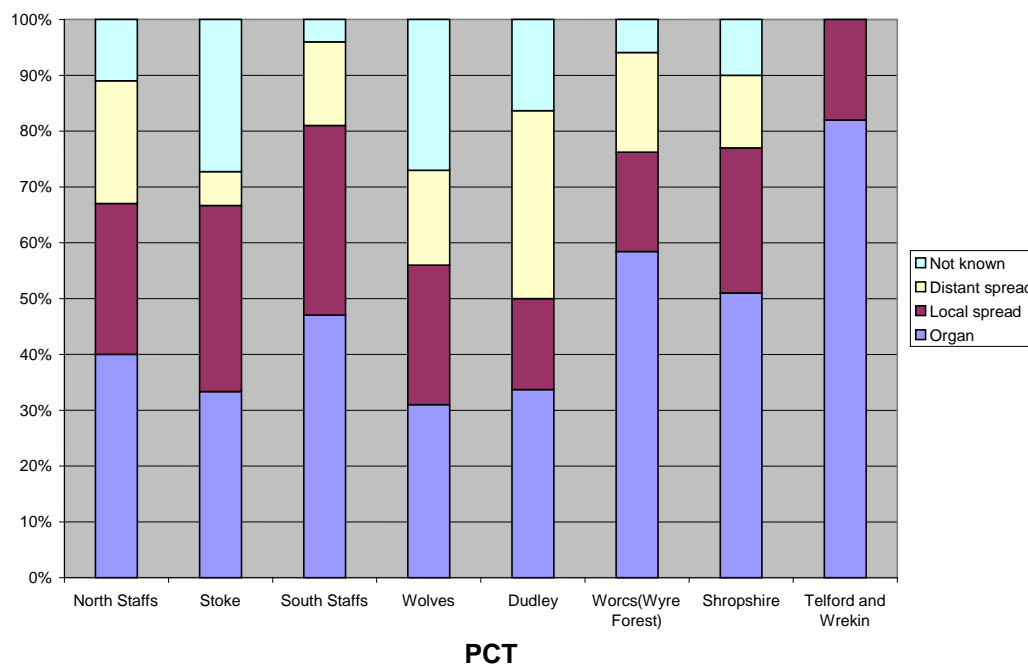


Chart 2

Chart 2 shows comparative information relating to colorectal cancer for the different PCTs. The “not known” column is high for Stoke and Wolverhampton which probably makes their figures look worse than they are in reality, but nevertheless there does seem to be a wide variation in PCT “performance”.

The staging data for colorectal cancer is the only chart reproduced here, but similar charts are available for the other cancers.

3.6 Referral type

	<i>Number</i>	<i>%</i>
Total number of patients reported upon of which were:	1530	100
Emergency referrals	186	12
2 week wait referrals	873	57
Routine referrals	230	15
Not referred by practice	117	7
Private	61	4
Not known	51	3
Not stated	12	<1
Number where avoidable delay identified	273	18

Table 8

Table 8 shows the breakdown of the type of referral made resulting in a diagnosis of cancer. During the 6 months of this audit, 57% of the cancers were diagnosed through the 2 week wait referral system.

The Cancer Reform Strategy Implementation – 2nd annual report published in December 2009 quoted figures between 38% (Telford and Wrekin) and 61% (Worcestershire) for cancers diagnosed through the 2 week wait referral system. This figure was for Q3 of 2008/9, but was for all the network practices, and included cancers diagnosed through the national screening programmes (which were excluded in this audit).

Across England as a whole, around 45% of cancers were diagnosed through the two-week wait referral route in Q1 2009/10.

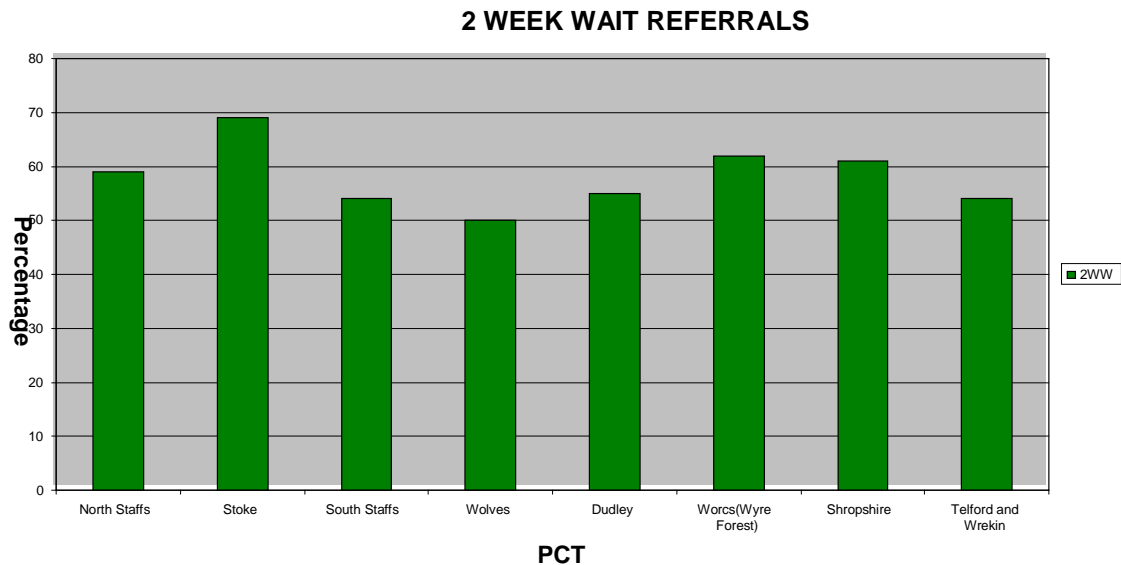


Chart 3

Chart 3 above shows the percentage of cancer diagnoses made via the 2 week wait referral route for each PCT. The range was 50% (Wolverhampton) to 69% (Stoke). Of course, a high number for this marker may just reflect late presentation by the patient.

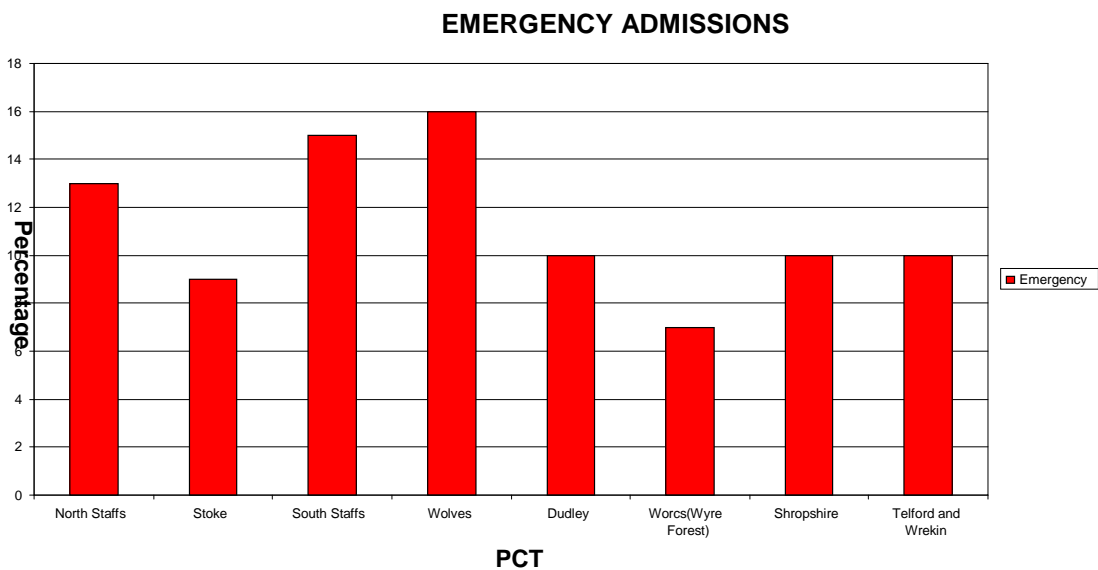


Chart 4

Chart 4 shows the percentage of cancer diagnoses made following emergency admissions for each PCT. The range was 7% (Wyre Forest) to 16% (Wolverhampton).

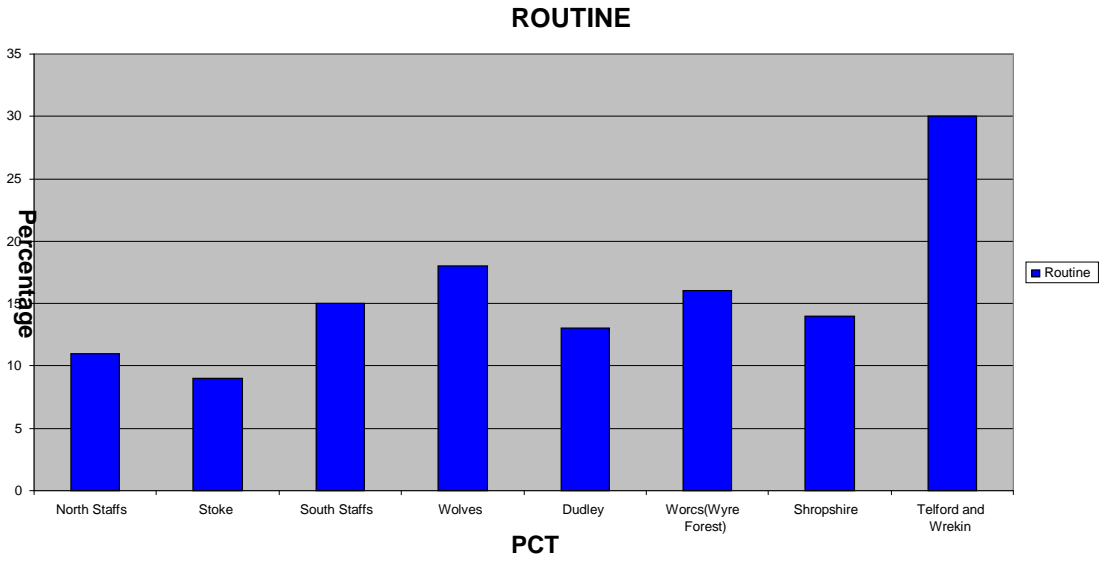


Chart 5

Chart 5 shows the percentage of cancer diagnoses made following routine referral for each PCT. The range was 9% (Stoke) to 30% (Telford and Wrekin).

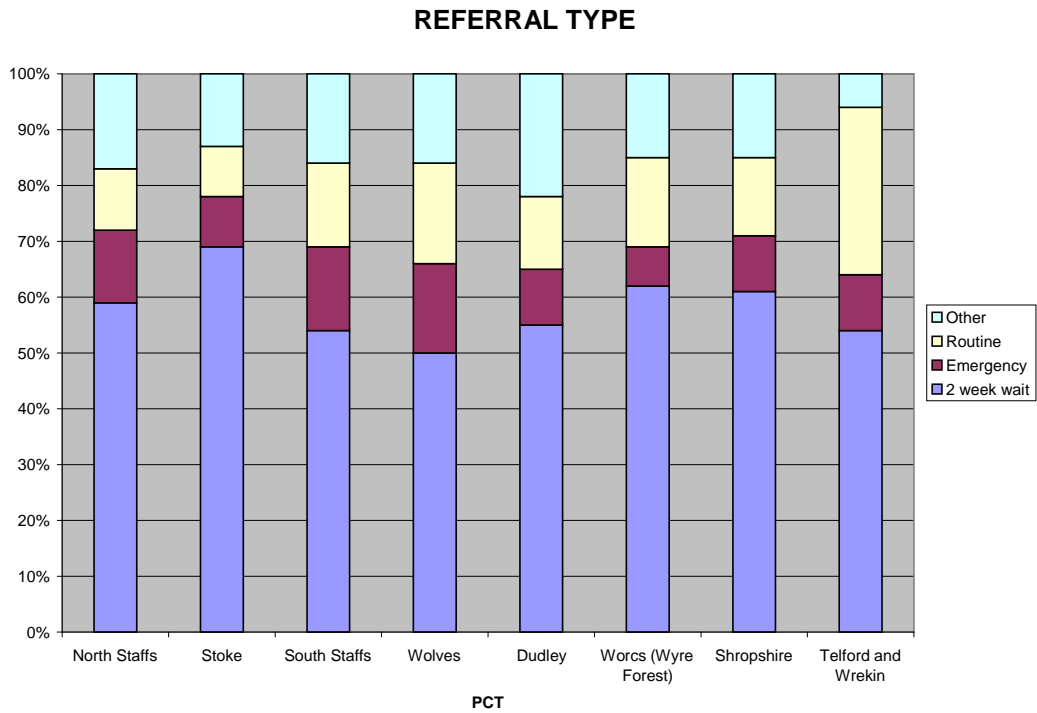


Chart 6

Chart 6 is a summary of all the referrals made. The “other” column includes patients “not referred by the practice” e.g. referrals from other hospital departments, private referrals and “not known”.

3.7 Pathway intervals

	<i>Min</i>	<i>Mean number of days</i>	<i>Median number of days</i>	<i>Max</i>
From first signs/symptoms to Primary care attendance	0	40	4	1487
From 1 st attendance to referral to Secondary care	0	26	1	2202
From referral date to date 1 st seen by Consultant	0	17	11	230
Total pathway - first signs/symptoms to seen by Consultant	0	80	37	2219

Table 9

Table 9 comes with a note of caution. The date that patients first note their symptoms is not always recorded in the GP records (in 314 instances across the network), or is recorded as the same date as the patient first presented to primary care (another 476 instances).

The latter zero figures would be entirely correct for patients presenting acutely with pain or bleeding, but this seems unlikely in all 476 instances. The empty boxes are excluded from the calculations but the others recorded as zero are included. The figures in the first row of the table (mean and median) are therefore likely to be too low in reality.

The longest delay for a patient presenting to their GP was a patient who had noticed increasing hoarseness for over 4 years. He was eventually diagnosed as carcinoma of the larynx which had spread locally.

The longest delay in primary care was a patient who had had nocturia for 6 years and was seen on 6 occasions before referral (this patient also had the longest total pathway). This patient's symptoms may, of course, have been due to benign disease initially.

The longest referral interval (GP to Consultant) is misleading as it refers to a patient who failed to attend on 2 occasions. The next longest (176 days) was a patient with back pain who was referred routinely to the physicians. She turned out to have metastatic breast disease.

The vast majority of 2 week wait referrals were seen within 14 days.

3.8 Pathway intervals for 4 commonest cancer sites

	<i>Min</i>	<i>Mean number of days</i>	<i>Median number of days</i>	<i>Max</i>
Total pathway – Breast	0	55	18	1052
Total pathway – Colorectal	0	91	62	731
Total pathway – Lung inc Mesothelioma	0	66	38	773
Total pathway – Prostate	0	90	35	1645

Table 10

- Breast** – 197 of the 250 patients (78.8%) presented with a breast lump but other symptoms included nipple changes or discharge, and breast pain. Most patients presented within a few days of finding a lump. 20 patients (8%) delayed between 3 months and 2 years, but a few of those delays were patients with symptoms other than a breast lump. 1 patient was male. 206 of the 250 patients (82.4%) were referred under the 2 week rule.
- Colorectal** – There were 238 colorectal cancers reported in this audit. Change of bowel habit was reported by 93 patients (39.1%), rectal bleeding by 63 patients (26.5%) and 42 (17.6%) had symptoms of anaemia. Other symptoms included abdominal pain, weight loss, abdominal swelling, loss of appetite, back pain, pruritus (itching), indigestion and vomiting. Some of the patients had more than one presenting symptom recorded. 117 of the 238 patients (49.4%) had some investigations arranged by the GP before referral. 126 patients (52.9%) were referred through the 2 week wait route, 46 (19.3%) were admitted as emergencies, and 46 (19.3%) were referred routinely. 40 patients (16.8%) appear to have had some delay during part of the patient journey, although most of these delays were due to the patient presenting late.
- Lung (including mesothelioma)** - A total of 141 patients (132 lung cancers and 9 patients with mesothelioma) were looked at for this section of the report. Patients with lung cancer and mesothelioma presented with a variety of different symptoms. Shortness of breath was the commonest main presenting symptom. 38 patients (27%) complained of this, and 31 patients (22%) presented with a persistent cough. Haemoptysis (coughing up blood) was reported in only 12 patients (8.5%). Recurrent or persistent chest infections, chest pain, back pain, shoulder pain, fatigue, weight loss, night sweats, hoarseness, and symptoms due to metastases were also recorded. Some patients had more than one presenting symptom noted. A few patients were found to have lung cancer as an incidental finding when having an imaging investigation for other reasons. 92 of the 141 patients (65.2%) had some investigations arranged by the GP before referral. A chest x-ray was usually (but not always) one of the investigations requested. 78 patients (55.3%) were referred through the 2 week wait route. 21 patients (14.9%) were diagnosed following an emergency admission and 11 patients (7.8%) were referred routinely. 16 patients (11.3%) appear to have had some delay during part of the patient journey, although most of these delays were due to the patient consulting their GP late.

- Prostate** – There were 267 cases of prostate cancer identified in this audit. 126 patients (47.2%) presented with urinary symptoms and a further 60 (22.5%) were diagnosed following referral for a raised Prostate specific antigen (PSA) found on routine or screening blood tests. Other, less frequently reported symptoms included haematuria (blood in the urine), abdominal pain, back pain, weight loss, and erectile dysfunction. 233 patients (87.3%) had some investigations (nearly always including a PSA) arranged by the GP before referral. 171 patients (64%) were referred through the 2 week rule, and 46 (17.2%) were referred routinely. 27 patients (10.1%) appear to have had some delay during part of the patient journey, although most of these delays were due to the patient consulting their GP late. Delay was difficult to identify in some of the cases of prostate cancer as some delays were planned (such as watchful waiting).

3.9 Number of times patients attended GP before referral

	<i>Number</i>	<i>%</i>
Number of times patient attended GP before referral	-	-
0	229	15
1 – 2	1010	66
3 – 4	156	10
5 +	49	3
Not stated	86	5

Table 11

81% of the audit patients were referred to secondary care after 2 or less visits to Primary Care.

3.10 Investigations and Communication

	<i>Yes (%)</i>	<i>No (%)</i>	<i>Not known or not stated (%)</i>
Did GP organise any Investigations before referral?	730 (48)	756 (49)	44 (3)
Would rapid access to Investigations have altered patient's management?	115 (8)	1320 (86)	95 (6)
Were there any delays in informing practice of diagnosis	94 (6)	1383 (90)	53 (3)

Table 12

In general GPs were more likely to request investigations when the presenting symptoms were vague, or co-morbidities were present. Investigations were more likely to be requested for symptoms later found to be due to upper gastro-intestinal or colorectal cancers, than for breast lumps, blood in the urine, or changing moles.

GPs stated that in 86% of cases (PCT range 76% to 93%), rapid access to investigations would not have altered their management of these cases. Rapid access to investigations for GPs is currently a top priority for the Government (announcement made last September). It is hoped that easier access to diagnostics will reduce the number of patients being referred to secondary care, as those patients shown not to have cancer would not then be referred through the 2 week wait system. This of course will be very welcome to those patients, but it remains to be seen whether quicker access to diagnostics will improve outcomes for patients subsequently found to have cancer.

DELAYS IN INFORMING PRACTICE OF CANCER DIAGNOSIS

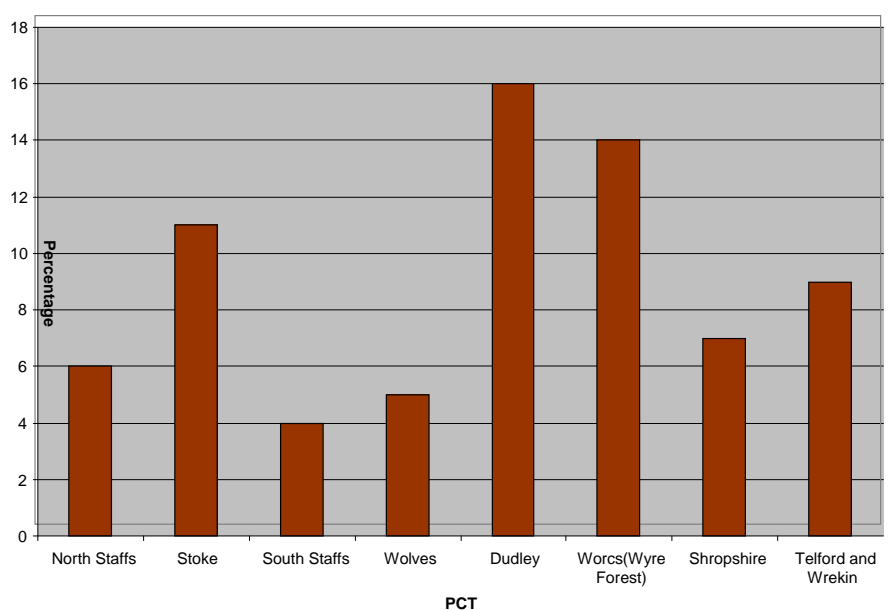


Chart 7

Chart 7 shows the percentage of cases per PCT where the GP felt there was a delay in informing the practice of a cancer diagnosis. The range was 4% (South Staffordshire) to 16% (Dudley).

3.11 Trusts referred to

	<i>Number</i>	<i>%</i>
Local Network Trust	1273	83
Out of Network Trust	165	11
Private provider	58	4
Not known/stated	33	2
Not referred	1	<1

Table 13

Table 13 shows the hospital trusts that the audit GPs referred to. More detail is available in the individual PCT reports.

3.12 Subsequent deaths

	Yes (%)	Not stated (%)
Number of patients stated as having subsequently died.	183 (12)	1347 (88)

Table 14

4 SIGNIFICANT EVENT AUDITS

The PCT Significant Event Audit reporting template was populated by comments lifted verbatim from the comments column in the main audit template, comments made in the analysis of the 2 significant event audits and comments made in the practice report that was produced following the practice meeting that was held to discuss all the cases diagnosed for the audit. All these comments were fed back to participating GPs in the initial feedback.

This report summarises the main themes reported by different GPs from each PCT. Anecdotal verbatim comments are quoted in italics with a few comments by the GMCN GP Adviser. Each individual PCT report detailed most of the comments made by that PCT's GPs, but only a selection have been reproduced for this report.

4.1 Any reasons found for delays in patients presenting to GP

- Fear or denial of a potential cancer diagnosis.
- Patients' lack of knowledge or understanding, of certain symptoms and their potential significance.
- The patient already having a chronic disease or illness and blaming the symptoms on that pre-existing condition.
- Problems caused by patients' underlying physical and mental health.
- Seeking advice from a family member or work colleague rather than the patient's GP.
- Problems noted with some patients new to the practice list and no/little access to previous medical records.
- Patient "too busy" with other priorities to attend GP.
- Patient choice.

"Patient admitted to a 12 month history of change in bowel habit with loose stool, occasional rectal bleeding and some weight loss". (Shropshire GP)

"Late presentation in teenage boy due to embarrassment of symptoms (scrotal swelling)". (North Staffs GP)

"Patient had 6 months of symptoms before presentation - he felt assured that they were related to previous problems which had been investigated". (Shropshire GP)

"Learning difficulties can lead to symptoms being missed or not recognized by the patient or carers". (Dudley GP)

"Patient very demented and unable to express symptoms". (Dudley GP)

"The patient consulting the practice they worked at for advice rather than the practice they were registered with, resulting in no investigations being requested for the symptoms".

(South Staffs GP)

"A letter from previous GP would have been beneficial whilst new practice was waiting for records to arrive. GP however isn't always aware that patient has left the practice".

(Telford and Wrekin GP)

"Patient had ignored symptoms for at least 6 months as father dying of colorectal tumour".

(Wolverhampton GP)

"The patient was a carer for her husband, and therefore was very busy looking after him, and rather neglected her own health". (Wolverhampton GP)

"The delay in this case was due to the lady's refusal to be referred for further investigation". (Wyre Forest GP)

4.2 Problems caused by GP initially not thinking of cancer as a possible diagnosis

- Cancers are uncommon in General Practice, and many cancers will present with symptoms of more common disease.
- The patient already having a chronic disease or illness, and the GP blaming the symptoms on that pre-existing condition.
- Absence of "red flag symptoms".
- Frequent attenders "crying wolf".
- Patients with mental health issues or learning disability can cause delay.
- The problems that can be caused by a mildly raised PSA.
- The necessity of good record-keeping, particularly if the patient is likely to see more than one Doctor at the practice.
- The importance of asking (and ensuring) patients return for review in cases of uncertainty.

"First reporting of rectal bleed was suggestive of piles and treated conservatively".
(Shropshire GP)

"Intermittent constipation and blood in stool 4-5 weeks. Proctoscopy showed bleeding haemorrhoids" (Carcinoma recto-sigmoid junction diagnosed 3 months later).

(Wolverhampton GP)

"Difficulty diagnosing new cancer in patients with ongoing medical problems and symptoms e.g. COPD, dyspepsia, IBS". (Several North Staffs GPs)

"Patient's symptoms were attributed to alternative diagnosis, Irritable Bowel Syndrome and Diverticular Disease of the Colon". (Shropshire GP)

"The difficulty in diagnosis of carcinoma bowel in a patient with a long history of bowel symptoms and a known diverticular disease. In the patient discussed, the significant feature was iron deficiency anaemia and the relevance of this as an alarm symptom was stressed". (Dudley GP)

"Unusual case of post menopausal bleeding as on injections that could affect periods, and early menopause age 41". (Shropshire GP)

"Absence of 'red flag' signs does not exclude cancer and benign conditions (e.g. Benign Prostatic Hypertrophy) can become malignant". (North Staffs GP)

"Delays in referral from primary care were due to the fact that the patients had not initially presented with any red flag symptoms". (South Staffs GP)

“This lady is a very anxious lady and has a high attendance rate, clearly a lady who is reliant on medical assurance. In the preceding three years she had a total of 123 consultations”. (This is included not because there was any delay in this particular case, but to act as a reminder that anxious patients can get cancer too.)

(Wolverhampton GP)

“Frequent attendees get ill and it becomes very difficult to spot the important symptom mixed in with everything else, especially as if we know them well our emotions cloud our judgment. If this is the case we need to refer or perhaps better, discuss it with other GPs in the practice to get a more objective outside view”. (South Staffs GP)

“Patient seeing different GPs therefore failure to have an individual GP managing the patient’s care”. (South Staffs GP)

“Patient had significant psychological/mental health issues which created a lot of “white noise” (Telford and Wrekin GP)

“PSA was mildly raised for over 2 years prior to referral”. (Wyre Forest GP)

“Patient seeing different GPs therefore failure to have an individual GP managing the patient’s care”. (South Staffs GP)

4.3 Problems caused by investigation results (normal and abnormal)

- The importance of doing simple investigations (bloods and chest x-ray).
- The importance of explaining to patients when to return for review, and for the GP to arrange follow up in certain cases, flagging the medical records where appropriate.
- The importance of having a robust system for handling abnormal results, including “safety-netting” for patients who don’t attend for review.
- Normal investigations (primary and secondary care) can be falsely reassuring
- The appropriate use of in-house diagnostics and treatments.
- The importance of having a policy for investigating iron-deficiency anaemia – following NICE guidance re 2 week referrals where appropriate.
- The importance of following national guidance for PSA testing.
- Patient choice.

“Lucky he had a FBC when he presented with gout”. (Wyre Forest GP)

“An earlier CXR might have picked up an effusion”. (Wolverhampton GP)

“12 day delay in getting blood test done in a pale-looking patient who turned out to have acute leukaemia”. (Shropshire GP)

“Another patient was asked to return in 7 days, and did not present for 3 months”. (Dudley GP)

“Importance of appropriate safety netting - to review patients even if investigations are normal”. (North Staffs GP)

“Patient failing to return for the follow-up appointment following the investigations”. (South Staffs GP)

“Had an essentially normal CXR a month before the definitive one”. (Wolverhampton GP)

“This patient had a normal mammogram and breast ultrasound and specialist breast clinic assessment only 8 months before diagnosis”. (Dudley GP)

“Another practice referred for in-house bowel investigations causing a 6 month delay when the referral route broke down”. (North Staffs GP)

“The importance of recognizing that iron deficiency anaemia can be a marker of serious disease and warrants prompt referral/investigations”. (South Staffs GP)

“Positive predictive value of iron deficiency anaemia in men over the age of 50 (primary care population) is >5%. All patients with this test result in this age-sex group should have malignancy excluded”. (North Staffs GP)

“PSA should be a part of routine investigations for patients presenting with prostate problem”. (South Staffs GP)

“Pt has not been keen on investigations all along. Patient delayed colonoscopy but did have endoscopy. She didn’t want an op whatever was found so didn’t feel investigation was worth it”. (Shropshire GP)

4.4 Issues relating to follow-up of patient and/or investigation results

- The importance of good communication at all stages of the patient pathway.
- The importance of GPs and hospital doctors explaining why patients should attend for investigations.
- The importance of having a robust system for handling abnormal results, including “safety-netting” for patients who don’t attend for review.
- Follow-up of unexplained weight loss.
- Patient choice.

“Patients not making follow up appointments”. (Stoke GP)

“Delay in letting patient know results. Surgery was waiting for patient to contact them and vice versa! Lack of communication!” (Shropshire GP)

“Staff not following up patients who have missed an appointment”. (Stoke GP)

“Patient arranged several tests as worked at the hospital. Took advice from GPs and the hospital consultant and then decided not to attend the practice for appointments. Had these tests have been arranged via the practice, the practice may have chosen to arrange further tests”. (Telford and Wrekin GP)

“Patient asked why she hadn’t returned – had some improvement following antibiotics and had not realized that serious pathology was a possibility” (29 year old patient who had squamous cell carcinoma of oral cavity). (Wyre Forest GP)

“No review of the lump carried out when the patient attended with other problems; there was no reminder easily visible on the computer screen to facilitate this”. (Wyre Forest GP)

However inappropriate notice was taken of the results of previous investigations which were now 1 and 3 years previously and no action was taken”. (Wyre Forest GP)

“Practice needs system to ensure that all investigation results and referrals are chased up if necessary”. (North Staffs GP)

Useful reminder to weigh patients regularly if they have unexplained abdominal symptoms, and to continue to review, investigate or re-test until the symptoms or findings can be explained”. (South Staffs GP)

4.5 Issues relating to referral processes including use of NICE guidelines

- NICE 2 week referral guidelines are only guidelines and do not cover all situations.
- However NICE guidelines are accepted best practice and are there to be used.
- Ensure all Doctors (including registrars and locums) working in the practice are aware of NICE referral guidelines, and the in-house procedures relating to those referrals.
- The importance of GPs explaining why patients are being referred, and that they can expect to receive an appointment within 2 weeks.

- The GP should check that the patient is available to attend hospital in the following 2 weeks.
- The practice should have a robust process for 2 week wait referrals. A proforma should always be used, which also acts as an aide-memoire for the 2 week referral criteria. The referrals should be faxed or sent through Choose and Book. A copy of the referral should be kept and a receipt requested from the cancer referral centre to ensure that the referral has been received.
- Making more than one simultaneous referral for the same patient/condition should be avoided. GP and/or practice staff should ensure that a NHS appointment is cancelled if the patient changes their mind and opts for private appointment.
- Misunderstandings can occur as to who is responsible for arranging further investigations/referrals.

“It highlighted the NICE guidelines for suspected cancer as a learning need for all clinicians”. (South Staffs GP)

“Not being referred through the 14 day pathway causing delay in diagnosis”. (Stoke GP)

“Doctors need to sometimes think outside of the NICE guidelines when they suspect that a patient may have cancer”. (South Staffs GP)

“Inappropriate referral by a locum- the need to train and support locum doctors was recognised and need to feedback” (North Staffs GP)

“Trainees and Registrars working in general practice need to be aware of referral pathways, and discuss referrals with colleagues”. (South Staffs GP)

“The importance of ensuring that patients know that they are being referred urgently, together with the reason. The GP and patient can then have an informed discussion if the patient wants to delay being seen”. (Dudley GP)

“We currently only have hard copies of referral criterion for cancer. These proformas need to be on our intranet for perusal”. (Shropshire GP)

“The process could have been quicker had the patient been referred immediately with haemoptysis, through the haemoptysis pathway, but unfortunately the patient saw a Locum rather than one of the regular doctors”. (Wyre Forest GP)

“There was some confusion regarding her gynae appt. She was seen again by another gynaecologist for the same problem on the next day, 10.7.08. The confusion could have been caused by the fast track referral in addition to the original referral but nobody picked up the double gynae appointments”. (Wolverhampton GP)

“No cross referral made to ENT at initial gastroenterology work up. Primary Care GP assumed patient had been referred to ENT by secondary care, this was not checked out” (Telford and Wrekin GP)

“Patient reported problems/symptoms to specialist rather than GP. Specialist then referred back to GP and advised further referral under 2 week rule” (Telford and Wrekin GP)

“It became clear in discussion that there seemed to be different approaches within the x-ray department as to when the follow-up test is organised by x-ray and when the GP is required to re-refer. From discussion it appeared that there are no clear guidelines on this matter and it may be worth trying to establish some”. (Wyre Forest GP)

4.6 Issues relating to delays in hospital investigations, treatment or communications

Although the audit was primarily about patient and primary care delays, several problems with secondary care were highlighted.

- Secondary care pathways can be slow – sometimes for good reasons, sometimes not.
- Waiting lists for investigations and surgery.

- Poor communication.
- Are hospital referral letters always read, and acted on appropriately?
- The process for internal Consultant to Consultant referrals needs to be clarified for Consultants and GPs.
- The problems that can arise when a patient is under the care of more than one Consultant.
- Misunderstandings can occur as to who is responsible for arranging further investigations/referrals.
- Delays caused by malfunctioning equipment.
- Patient choice.

“Over 8 month delay. Multiple endoscopies, staging tests, and fitness for anaesthesia tests – very slow”. (Wyre Forest GP)

“Lady for whom a delay in having a colonoscopy performed resulted in late diagnosis of colonic cancer over a 5 month period. (Barium enemas and blood tests had been done)”. (Dudley GP)

“Patient notes lost by hospital causing delay of 8 weeks” (Telford and Wrekin GP)

“Long delays, took 6 months from 2WW referral to surgery” (Wyre Forest GP)

“Lost to Urology follow up after MRI and notes went missing”. (Shropshire GP)

“The histology takes too long”. (Stoke GP)

“Lack of clear communication between secondary and primary care”. This was noted by 2 practices - one relating to UHNS, one referring to Macclesfield. (North Staffs GPs)

“Relatives/ patients informing general practice of their cancer diagnosis rather than communication from the hospital”. (2 North Staffs GPs)

“Secondary care – had they even read the original referral letter?” (NB patient referred following scan that showed ascites and liver metastases. Patient had normal endoscopy and then discharged.) (Wyre Forest GP)

“After endoscopy, referred back to primary care to organise scan”. (Shropshire GP)

“The issue of secondary care internal referrals needs to be addressed in that there has been a delay in this patient been seen”. (South Staffs GP)

“Delays in investigating anaemia, partly because of broken colonoscope”. (Shropshire GP)

“CT scanner broken down”. (Shropshire GP)

4.7 Other

- GP access.
- Patients presenting with multiple problems in a consultation can lead to abnormal results being missed.
- The increased number of QOF reminders on the GP computer screen can also complicate a consultation.
- The importance of clinical audit.

“The importance of appointments being available within 48 hours and on the same day is essential. The patient may have only just plucked up the courage to come to the GP”. (Wolverhampton GP)

“Also, when a diagnosis of cancer is received by the practice, the 2 week fax list will be cross checked and if the referral was not made by us then the details will be considered as a Significant Event Audit like this one looking at the circumstances leading up to the diagnosis looking for areas to address”. (South Staffs GP)

5. PRACTICE MEETINGS

As part of the audit, participating practices were asked to hold a multi-disciplinary meeting to discuss all the cases identified by the audit. Specific action/learning points were to be recorded in a practice report and shared with the PCT.

Some of the specific action/learning points are listed below grouped under headings. This part of the report shows many practices have put a lot of thought and reflection into their current practice, and shows a number of changes that will be made to their practice as a result of this audit.

By publicising these changes, it is expected that many other practices will adopt some of the ideas here.

5.1 Access

- Practice to provide more appointments within extended hours, to try and improve uptake of cervical sampling.
- Practice to actively target non-attenders for cervical cytology tests, especially in the younger and older age range.

5.2 Investigations

- Have a low threshold for checking Bloods (i.e. Full Blood Count & Liver Function Tests) for patients over 60 with new abdominal symptoms. Irritable Bowel Syndrome unlikely as a presentation in this age group.
- With many co-morbidities sometimes it is best not to investigate and treat if the investigation and treatment will not benefit the patient and they will actually be worse off.
- The difficulty of when to investigate very elderly patients was discussed particularly when faced by reluctance from patients or relatives to pursue invasive tests.

5.3 Records

- GPs are aware that clear detailed notes are important, particularly if patients are seeing different doctors. It is as important to list significant negatives – e.g. no hoarseness, as the positives in history and examination.
- The importance of ensuring all staff record comprehensive notes on the consultation screen for any patient contact.
- Practice needs to improve documentation of consultations.
- Documentation, stressed regarding Family History and its significance in certain cancers, to be improved overall.
- Practice now ensures that carer details are held for all learning difficulty patients.

5.4 In-house processes

- Short cuts for 2 week rule guidelines are on each desktop.
- Practice needs system to ensure that all investigation results and referrals are chased up if necessary.

- We decided that any patient who has a blood test requested must be asked his current telephone number at the time of being issued a blood test form.

5.5 Guidelines

- That we need clearer practice guidelines in relation to PSA testing.
- Guidelines for PSA testing in LUTS will be drawn up and shared within the team.
- Agreed on protocol that patients presenting with prostatism should have PSA/urine analysis/DRE/U & E.
- Anyone presenting with 2 episodes of painless haematuria where MSU are reported negative must be referred using fast track facilities to exclude malignancy. **(N.B. NICE recommends that patients of any age with painless macroscopic haematuria (i.e. first presentation) should be referred via 2 week rule).**
- New practice guideline written for follow-up/ management of microscopic haematuria noted on routine testing.
- Ask the patient more questions relevant to diagnosis of possible ovarian cancer in a patient presenting with urinary tract symptoms.
- The importance of follow up for undiagnosed lymphadenopathy and appropriate referral channels locally. As a result of this audit we have devised a practice protocol for the management of undiagnosed cervical lymphadenopathy, looking at presentation, investigation, and management.
- We will develop a protocol for weight loss.

5.6 Referral

- 2 week rule referral now to be used for ALL suspected cancer referrals and not referred as urgent.
- When referring a patient through the 2-week rule system, explain this to the patient, indicating likely timescales, and ask them to contact us in one week if they have not received an appointment.
- Care to be taken to avoid risk of over-referring under 2 week rule.
- We will keep a closer eye on Locum referrals in this situation and continue to monitor/chase patients with sinister symptoms who fail to re-appear for follow up or have tests done.
- When we fax off a 2 week referral, these are logged and checked that they have been delivered but we now ensure that the referrals are checked at 4 weeks to ensure that they have been acted upon.
- Any fast track referrals will be logged and chased. A fast track referral log book has now been put into place and relevant staff have been assigned to this to monitor all fast track referrals, any cancelled or missed appointments will be dealt with a.s.a.p. We have also planned to do an audit in six months.
- Any patient over the age of 55 presenting with altered bowel movements, can be referred as fast track and not routine, even though they do not have any red flag signs. Referral policy has been changed.
- All patients fulfilling the NICE guideline criteria for iron deficiency anaemia will be referred under the 2 week guidelines.
- We have a good awareness now of the significance of any haematuria in patients over the age of 40 and the need to investigate this immediately.

5.7 Follow up

- Make sure patients are seen for results and if patient do not attend appointments, then contact patients and make sure they are followed up.
- It was agreed that when results are suggestive of malignancy, or any condition that will necessitate urgent referral that the doctor actioning the report will not wait for the patient to arrange a review appointment, nor use the routine system for contacting those patients who fail to do so. Instead, they will contact the patient directly themselves or ask a receptionist to do so, to arrange for an urgent appointment.
- It would be prudent to ask patients to book an appointment for review anyway if unsure of diagnosis so that lack of resolution could be identified.
- We will add reminders when blood tests are requested to check that they have actually been performed i.e. that the patient has been for them, and that the results are checked and followed up.
- Abnormal blood results are monitored by staff and patients recalled in a timely fashion.
- Patients must be notified of abnormal results and asked to return for further discussion and examination and decision making.
- Change in practice process of follow-up of women who fail to respond to smear test invitations.
- Change in practice process for notifying patients about abnormal cervical cytology results.
- In future I will endeavour to keep an electronic “track” to alert if patients do not come back for intended procedure.
- GPs will follow up all painful testes, even when no lump present. It is up to the individual GP as to what recall system they use – one GP uses a book to recall those patients that he particular wishes to follow up.

5.8 Information

- Ensure all clinicians aware of cancer support networks/contact details.
- GPs need to be aware of services, support and information available to patients suffering from cancer.
- Need for in-house patient education leaflets to explain ‘red flag’ symptoms- might also use website and practice newsletter for this.
- At a practice level, we should promote breast awareness by making leaflets available in the waiting room and putting up a health promotion message through the Life Channel which is broadcast in the waiting room.
- We will consider running a poster campaign in the waiting room on the symptoms and signs of bowel cancer to raise public awareness.
- It was agreed that patients requesting screening tests would always be provided with written literature (by doctors, nurses and HCSW).
- Information being given to patients in different languages and interpretation services made more readily available – more awareness.

5.9 Communication

- Highlighted GPs’ responsibility to let secondary care know of patients’ deterioration and concerns.

5.10 Audit

- Impressed by template, Will use it in future for our cancer reviews. After completing this exercise we will adopt the data collection and Significant Event templates provided through this LES to use at our annual review of cancer diagnoses.
- We will review all 2 week wait referrals and audit all cancer diagnoses.
- It was suggested that an audit was carried out to check that the 14 day standard was being correctly applied to gastroenterology referrals.
- Perform audit of our 2 week referrals to ensure that we are following NICE guidance appropriately.
- Continue to monitor cancer diagnoses via the cancer register and identify any delays in order to feedback to clinicians.
- The practice now undertakes a regular audit of PSA results and ensures repeats requests of PSAs are done. Highlighted patients being missed to follow-up. Protocol changed to ensure regular testing.

5.11 Education

- We are trying to do more routine health checks and trying to engage families on cancer awareness.
- Education meeting (group learning event) planned on guidelines for suspected cancer.
- Consider further training for clinical staff such as nurse and pharmacist regarding red flag symptoms. Also update for doctors as part of routine process and Personal Development Plan.
- Formalisation of cancer meetings so that specific learning points can be taken from each meeting.
- Regular clinical meetings taking place – not ad-hoc.
- Considering inviting cancer link nurses to the practice to meet them.
- Education meeting planned around PSA testing.

5.12 Other

- It generated lot of discussion about how to manage patients with learning disabilities and ways to improve services for them.
- We aim to review our locum pack for GP so they are informed of local policies as well as national guidance of cancer referral.
- Create new list of suitable morbidity codes so that cancer diagnoses are correctly recorded, following identification of several patients coded with morphology codes which would not be picked up by Contract plus/ QOF.
- Inappropriate use of in-house procedures - (minor ops in patients with skin cancer and colonoscopy in patients who fit the colorectal 14 day guidelines): revision and review of use of minor surgery and review of skin cancer guidelines.
- Informed consent and the assessment of capacity to make a voluntary informed choice were discussed.
- A reminder that patients suffering from cancer receive free prescriptions.

5 DISCUSSION

- It is widely known that 1 in 3 of us will get cancer at some time in our lives and that 1 in 4 of us will die with it.
- It is also known that outcomes for cancer patients in this country are not as good as in many European and North American countries.
- It is estimated that 7500 – 10000 lives are lost each year in this country due to late diagnosis⁷.
- Studies are being carried out at present to determine why there is such a disparity, but it is thought that it is largely due to the diagnosis of cancer being made later in this country.
- A Cancer Research UK study of 2200 people in July 2009 found that if faced with symptoms that could be due to serious disease:
 - 40% wouldn't see their GP in case they were wasting the GP's time.
 - 37% wouldn't consult because they were too frightened.
 - 25% wouldn't consult because they were too busy.
 - 20% wouldn't consult because they were too embarrassed.
- This audit shows that many of the delays identified were due to the patient's reluctance to report worrying symptoms to their GP, so there seems to be something about the British psyche that needs to be overcome before early presentation becomes reality.
- Increasing cancer awareness in the general public lies outside the scope of this report, but it is worth noting that there is no evidence that increasing public awareness works, unless the awareness campaign is sustained.
- However, the general practice surgery waiting room may be an effective place to raise awareness of cancer with the practice patient population. This has been noted by several practices as a result of this audit. Poster campaigns, leaflets, video presentations and the practice website could all be useful in providing relevant information.
- The national screening programmes (cervical, breast and bowel) are important in diagnosing cancer early, but uptake is often less than 80%. The paper summarising the Cancer Reform Strategy Implementation 2nd annual report, that accompanies this report details the performance of the network PCTs.
- Although cancer is such an important diagnosis to make, and to make as early as possible, the diagnosis of a new cancer is relatively uncommon in general practice. A full-time GP would expect to see only 8 or 9 new cancers each year, of which ½ will be one of the 4 commonest cancers (breast, colorectal, prostate and lung). A GP would only expect to see a new ovarian cancer every 5-7 years, a brain tumour every 10 years and a cancer in a child or young person once in the GP's career. Many GPs do not work full-time these days, with the result that part-time GPs will see even less new cancers.
- As has been confirmed in this audit report, many cancers will present with symptoms explained by more common benign disease. Patients with pre-existing conditions that produce similar symptoms to cancer (e.g. chronic obstructive pulmonary disease, benign prostatic hypertrophy and irritable bowel syndrome) cause even more of a challenge when they present with similar symptoms that are due to a cancer that is unrelated to the underlying condition.
- The National Institute for Health and Clinical Excellence (NICE) did produce guidelines for referral criteria in 2005. Although no guideline can help detect all cancers, these guidelines are widely accepted as useful, and any patient fulfilling the criteria for an urgent referral should be referred under the 2 week wait referral pathway.
- However the GP also holds a role as gatekeeper for the NHS. Every GP knows that recognition is rarely given when a patient is correctly referred and diagnosed with cancer or for those very many patients who are (correctly) not referred because

⁷ Abdel-Rahman M, Stockton D, Ratchet B et al. What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable? Br. J. Cancer 2009 **101(S2)**:S115-S24

cancer has been excluded or considered highly unlikely. The GP also knows that a missed or late diagnosis can cause an avoidable death or serious morbidity and may result in a complaint or legal action. The risk of a headache being due to a brain tumour is about 1 in a 1000, so how does the GP identify that one early?

- This audit shows that the majority of patients present promptly and are referred along the correct pathway. Some cancers will only cause symptoms when they are well established and may then result in an emergency admission.
- Having said that, there were still a number of incidences where the GP did not follow NICE referral criteria causing a delay e.g. haematuria (blood in the urine), dysphagia (difficulty swallowing), iron-deficiency anaemia, raised PSA and changing moles.
- It is impossible to quantify, but if NICE guidance had been followed where the criteria clearly fitted the patient's symptoms then some delays would have been avoided and maybe some lives saved. This appears to be an educational need for a minority of GPs. NB 57% of the network practices did not participate in this audit, so we do not have the complete picture by any means. This audit may have been undertaken by the GPs most interested in cancer.
- As well as the problems associated with lack of awareness (patient and GP), a number of other issues were identified that have led to delays and will do so in the future if not rectified.
- These include:
 - The importance of good record keeping, particularly when the patient is likely to see more than one doctor in the practice.
 - The importance of using NICE guidance and referral proformas.
 - The importance of following national and local guidance for the management of iron-deficiency anaemia, abnormal PSAs, microscopic haematuria and cervical lymphadenopathy (enlarged neck glands).
 - The importance of ensuring all healthcare professionals in the practice (including locums) are aware of in-house referral processes and the provision of any in-house services such as minor surgery and sigmoidoscopy.
 - The importance of robust practice processes, including "safety-netting", for managing test results, particularly abnormal ones.
 - The importance of good communication at all times.
- The final section of this report describes a number of recommendations for the Board to consider.

6 RECOMMENDATIONS

1. A Network-wide Public Health and Primary Care steering group should be formed to oversee a Local Awareness and Early Detection Initiative (LAEDI).
2. GPs should be encouraged and supported by the network to provide information for their patients about cancer awareness. Information should be both in paper form (leaflets and posters) and electronic (through the practice website where available).
3. To facilitate recommendation 2, the GMCN website should be promoted to become the local cancer website of choice, providing a wide range of information for patients and healthcare professionals including:
 - a. Links to reliable patient information sites such as www.patient.co.uk www.cancerresearchuk.org.uk and www.macmillan.org.uk .
 - b. Regular information for GPs about their 2 week wait referral rates the number of 2 week wait referrals made outside NICE guidelines, and conversion rate of those referrals. The percentage of their cancer diagnoses that are made through the 2 week wait route, following an emergency admission, and following a routine referral should also be made available. This information should be at PCT level for the network website, but GPs should be able to access their practice and individual GP data from their PCT, hospital trust or GMCN GP Adviser.

- c. The full range of NICE referral criteria, any local referral guidelines and the full range of referral proformas.
 - d. National “Key messages” as developed by the National Cancer Action Team (NCAT).
 - e. National guidance on PSA screening and testing, so a consistent message is given to patients.
 - f. Any “helpful hints” produced by the NSSGs following consideration of the audit findings, over and above published guidelines.
4. The Network Board should endorse the use of referral proformas (that have been approved by Local Medical Committees) for ALL 2 week wait referrals.
 5. Network-wide proformas should be developed if and when NICE update their referral guidelines.
 6. GP practices to be asked by the network GP adviser and PCT cancer leads to share “good practice” ideas such as “safety-netting” for follow up of patients and abnormal investigation results, information for locums, guidelines, and “safe” referral processes. These would be published on the GMCN website with appropriate recognition of the practice supplying them.
 7. This audit and the national report, when published should be widely disseminated and considered at Cancer Local Implementation Team meetings and Professional Executive Committee (or equivalent) meetings.
 8. This report should be presented and discussed at local GP education meetings, in particular at protected learning time events, to reach a wide an audience as possible.
 9. The Board supports the network GP adviser approaching the NCAT with the suggestion that the main audit template be adapted and used as a “living document” to form part of the GP Quality and Outcomes Framework (QOF). Cancer is poorly represented in the QOF, and it is proposed that each new cancer is entered on the template as the diagnosis is made, recording the patient pathway from the time that the patient first noticed the symptoms through to diagnosis. The template could be further developed to incorporate the present palliative care register and to act as a check list for ensuring the patient’s wishes are recorded, that other agencies (e.g. out-of-hours, West Midlands Ambulance have been informed of the patient’s wishes), that the DS1500 claim form has been completed etc.
 10. If Recommendation 6 is not accepted at national level (impractical or lack of finance), then it is proposed that the Network develop an award system (Gold, Silver and Bronze – certificates not money) to recognise good cancer care in general practice. The awards would use criteria mentioned in this audit together with other markers.
 11. Primary Care Trusts should be asked to share GP practice manager e-mail addresses to facilitate direct electronic communication between GMCN and the network general practices. This will enable the network GP adviser to inform practices of website developments and additions, and to (hopefully) improve uptake of any future cancer audits.

Further information is available from:

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Greater Midlands Cancer Network



Royal College of
General Practitioners



National Cancer Action Team

**Cancer Significant Event Audit (2009)
REPORT TEMPLATE**

Diagnosis	
Date of diagnosis	
Age of patient at diagnosis	
Is the patient currently alive? (if not alive, please give date of death)	
Date of SEA meeting	

1. What happened?

Describe the process to diagnosis for the patient, including dates of consultations, referral and diagnosis. Consider, for instance, the key consultation at which diagnosis was made, consultations for this patient in the practice in the year prior to diagnosis and the referral process. How often had the patient been seen? Had he/she been seen by the out of hours service, at A&E or in secondary care clinics? Was there any delay on the part of the patient in presenting with their symptoms?

2. Why did it happen?

Reflect on the process of diagnosis. Was this as good as it could have been? If so, what were the factors that contributed to speedy and /or appropriate diagnosis in primary care? If there was some delay in diagnosis, what were the underlying factors that contributed to this? Were reasons for any delay acceptable or appropriate?

3. What has been learned?

Describe the discussion at the team meeting. Demonstrate that reflection and learning have taken place on an individual or team basis and that relevant team members have been involved in considering the process of diagnosis. Consider, for instance: a lack of education or training; the need to follow systems of procedures; the importance of team working or effective communication. Consider the role of the NICE Referral guidelines for suspected cancer and their usefulness to primary care teams.

4. What has been changed?

Outline the action(s) agreed and implemented, where this is relevant or feasible. Consider, for instance: if a protocol has been amended, updated or introduced; how this was done and who it will involve and how this change will be monitored. Are there things individuals or the practice will do differently. Consider both administrative and clinical issues.

What was effective about this SEA?

Some information about your practice

How many patients do you have? <2500 2500-5000 >5000

Which of the following best describes your practice? Urban Semi-rural Rural

Is your practice a training practice? Yes No

Do you teach medical students? Yes No