



# **Delayed Diagnosis of Cancer in Primary Care**

Complaints to  
the Health and Disability Commissioner:  
2004-2013



**HEALTH & DISABILITY COMMISSIONER**  
TE TOIHAU HAUORA, HAUĀTANGA

## **Feedback**

We welcome your feedback on this report. Please contact Natasha Davidson at [hdc@hdc.org.nz](mailto:hdc@hdc.org.nz)

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# CONTENTS

Contents.....	I
Commissioner’s Foreword.....	II
Executive Summary.....	III
Introduction.....	1
1. Cancer and cancer diagnosis.....	1
2. Using complaint data to investigate diagnostic error.....	3
3. The data used in this report.....	5
4. Objectives of this report.....	6
Complaints about Delayed Diagnosis of Cancer by GPs.....	7
1. Number of GPs complained about.....	7
2. Clinical characteristics seen in the complaints.....	10
3. Conclusion.....	17
Factors Contributing to a Delayed Diagnosis of Cancer by GPs.....	18
1. Describing and categorising delayed diagnosis.....	18
2. Delayed diagnosis factors in complaints.....	20
3. Delayed diagnosis factors in complaints, by cancer type.....	30
4. Conclusion.....	51
Reducing Delays in the Diagnosis of Cancer by GPs.....	52
1. Introduction.....	52
2. Learnings for GPs.....	53
3. How can patients help?.....	57
4. Conclusion.....	59
References.....	60
Appendix A: Methodology.....	62

# COMMISSIONER'S FOREWORD

Every complaint is an opportunity for learning. While those opportunities are invariably seized by providers who are the subject of such complaints, sharing those learnings and insights among providers can be more difficult. Where I find a provider in breach of the Code, publication of my investigation opinion may lead those who provide similar services to reflect on aspects of their own interactions with consumers. However, there is also much to be learned from complaints where no provider was found in breach of the Code, and from the trends and patterns that emerge in relation to particular types of complaint. We, at HDC, are working to ensure that those insights are not lost, but are reported back to the sector and to the general public in a way that supports quality improvement. That is what this report is all about.

The primary care sector is a critically important part of the New Zealand health system, with GPs performing around 15 million consultations per year. The vast majority of the time, the care provided by general practitioners is outstanding. Patients receive high quality and timely services that meet their needs. I am frequently impressed by the lengths that general practitioners go to in order to advocate for their patients, and to get the bottom of complex diagnostic issues.

Diagnosis is one of the key skills for any general practitioner but, because of the breadth of symptoms seen in general practice and the rarity of some conditions that present, it can be incredibly difficult to get right. Approximately 36% of all complaints received by my Office about general practitioners concern a missed or delayed diagnosis. With this in mind, we decided to look at those complaints, focusing particularly on the diagnosis of cancer, to see if we could discern any patterns or trends, both in terms of the complaints made and in terms of what appeared to have caused any diagnostic error.

The information presented in this report comes from the complaints made to my Office, and from the expert clinical advice we received in relation to the care provided. As you will see, certain trends are discernible, and are largely consistent with what one would expect given the aetiology of particular cancers and the results of international studies. A number of observations arise out of these trends though, and from the individual cases described, that I trust will prove useful for both general practitioners and for those who use their services. Most notable for me is how important it is, in general practice as well as in all healthcare interactions, to get the basics right – read the notes, ask the questions, talk to the patient.

As I noted at the outset, complaints are an opportunity for learning. My thanks to all those who have shared their experiences and, in doing so, have made this report and that learning possible.

Anthony Hill

**Health and Disability Commissioner**

# EXECUTIVE SUMMARY

This report analyses complaints made to the Health and Disability Commissioner in the last decade to investigate issues concerning delayed diagnosis of cancer by general practitioners (GPs) in New Zealand. During that period, 243 GPs were complained about in relation to this issue, with the number per year increasing significantly over that time. While this is consistent with general complaint trends, complaints about delayed cancer diagnosis now comprise a significantly larger percentage of all complaints about GPs than was the case a decade ago.

Colorectal and lung cancers were the cancers most commonly involved in the complaints to HDC about delayed cancer diagnosis, and the diagnostic delays were often lengthy. Complaints about the delayed diagnosis of breast cancer were found to be less common and involved shorter delays.

The factors found to typically contribute to the delayed diagnosis of cancer by GPs can be grouped into four main categories, depending on the stage at which they occur in the diagnostic process: consultation factors, diagnostic factors, follow-up and referral, and patient factors. Within these main categories are a number of subcategories of delayed diagnosis factors which may be at issue in any particular case. In the HDC complaints, the most commonly seen delayed diagnosis factors related to: the cancer presenting with non-specific or atypical symptoms, poor communication with secondary care, appropriate referrals not being made, inappropriate reliance on negative test results, and the GP failing to adequately take, review or consider relevant patient history.

The delayed diagnosis factors that were present in the complaints varied by type of cancer involved. However, for colorectal, lung, skin and breast cancers, the most common issue was the non-specific or atypical presentation of symptoms. Delayed colorectal cancer diagnosis was significantly associated with the failure to conduct an appropriate examination, and the treating of symptoms in isolation, compared to other cancer types. Issues of co-morbidities drawing focus, and inappropriate reliance on test results were characteristic of complaints relating to a delayed diagnosis of lung cancer. Delayed diagnosis of skin cancer was significantly associated with the patient not reporting their symptoms, and delay in prostate cancer diagnosis was strongly associated with the failure to follow-up test results.

There are various learnings that arise from the cases that may assist in decreasing diagnostic error among GPs. Some of these are things for GPs to focus on, while others may assist with patient engagement in the diagnostic process.

For GPs, the cases, and the trends and themes that emerge from them, suggest that additional focus could be given to:

- undertaking clinically indicated examinations and tests;
- examining patients in the context of their past history;
- ensuring comprehensive documentation is kept;
- being aware of limitations of diagnostic testing (e.g. false negative rates);
- considering all clinically relevant differential diagnoses;
- continuing to hold a suspicion for cancer despite co-morbidities;
- not treating symptoms in isolation;
- providing safety-netting advice to patients;
- having robust follow-up systems; and
- advocating for patients in the secondary care system.

For patients, diagnostic error, including length of any diagnostic delay may be lessened by ensuring:

- attendance at follow-up appointments;
- reporting all symptoms to the GP; and
- proactively following up on test results and referrals.

# INTRODUCTION

## 1. Cancer and cancer diagnosis

### Cancer in New Zealand

In 2011 there were 21,050 new registrations of cancer in New Zealand. This means 331 people in every 100,000 were diagnosed with cancer in 2011. In 2011 the most common cancer was colorectal cancer, followed by prostate cancer, breast cancer and melanoma.<sup>1</sup> The incidence of cancer in New Zealand is increasing. This has been attributed to population growth and an ageing population.<sup>1</sup>

Cancer is also the leading cause of death in New Zealand, accounting for 29% of all deaths.<sup>1</sup> In 2011 the most common cause of cancer death was lung cancer, followed by colorectal cancer, breast cancer and prostate cancer.<sup>1</sup>

Evidence shows that reducing delays in the diagnosis of cancer may improve survival rates as early treatment can greatly improve prognosis.<sup>2</sup> General practitioners (GPs) in New Zealand perform around 15 million consultations per year and will often be the first point of contact for patients with signs or symptoms of cancer. GPs also often act as gatekeepers to the secondary health care system, controlling access to diagnostic tests and cancer specialists. Consequently, GPs have an important role to play in improving cancer survival through early diagnosis.

Due to the important role of GPs in the early diagnosis of cancer, guidelines for the investigation and referral of suspected cancer in primary care have been developed in New Zealand and have been in place since 2009.<sup>3</sup> These guidelines are based on a systematic review of the literature and international guidelines. They aim to help GPs make timely and appropriate referrals by alerting them to features that should raise their suspicion for cancer.



## Delayed diagnosis

Delayed diagnosis is one of the most common forms of medical error. In the United States, it is the leading cause of malpractice claims,<sup>4</sup> and of preventable adverse events in hospitals.<sup>5</sup> There is also some evidence that delayed diagnosis leads to the most serious consequences for patients.<sup>6</sup>

In particular, delayed or missed diagnoses of cancer have been found to account for over half of the cases of diagnostic error identified in studies of malpractice claims.<sup>4</sup> Cancer misdiagnosis is also considered to be one of the most harmful and costly types of diagnostic error.<sup>7 8</sup>

Error can occur at different stages of the diagnostic process. Studies of cancer diagnosis often use four categories to measure delay in the cancer diagnostic pathway:

- Patient delay – time from onset of symptoms to first presentation to a health care provider.
- Primary care delay – time from first presentation to a GP to referral to secondary care for further diagnostic investigation.
- Referral delay – time from referral for further diagnostic investigation to being seen in secondary care.
- Secondary care delay – time from being seen in secondary care to diagnosis.

Studies investigating delays in cancer diagnosis have found that patient and primary care delays are often the longest.<sup>2</sup> In New Zealand, although only 1% of treatment injury claims made to ACC relate to a delay or failure to diagnose, a third of these diagnostic errors occur within a primary care setting (Accident Compensation Corporation. Treatment Injury: Delay or Failure to Diagnose. E-mail to Natasha Davidson 16 December 2014)

Diagnostic errors typically seen in primary care include the following:

- failure to initiate timely action in the presence of one or more established clues or indications for diagnostic workup;
- misinterpretation of signs, symptoms or test results;
- inappropriate formulating or weighing of differential diagnoses; and
- short-comings in the timely follow-up of abnormal test results.<sup>9</sup>

Minimising delayed diagnosis in primary care relies on patients presenting with potential symptoms of cancer and on GPs responding appropriately to these symptoms. However, cancer diagnosis can be difficult, with a patient often initially presenting with non-specific symptoms which can be attributed to a number of benign conditions. In addition, many patients will present with symptoms which may be indicative of cancer, but, in the vast majority of cases, cancer will be excluded. By the nature of their work, GPs manage a wide range of conditions through a few, often brief encounters, putting these providers at a higher risk for diagnostic error.<sup>10</sup>

## 2. Using complaints data to investigate diagnostic error

### Complaints to the Health and Disability Commissioner

The role of the Health and Disability Commissioner is to promote and protect the rights of health and disability services consumers. HDC does this by:

- resolving complaints;
- improving quality and safety within the health and disability sector; and
- appropriately holding providers to account.

The rights of consumers (and corresponding duties of providers) are set out in the Code of Health and Disability Services Consumers' Rights (the Code).

Anyone can complain to HDC about a health or disability provider that they consider may have breached the Code. The steps involved in assessing a complaint vary depending on the circumstances, but usually involve HDC:

- seeking a response to the complaint from the provider(s);
- gathering additional information related to the complaint, for example, HDC may ask the provider for a copy of the consumer's medical records; and
- seeking independent expert advice on the clinical aspects of the care received.

A range of resolution options is available to the Commissioner on the receipt of a complaint, including:

- referral to another agency, including a regulatory authority (for example, the Medical Council of New Zealand);
- referral to the provider;
- referral to advocacy; and/or
- commencement of a formal investigation.

The Commissioner may also decide, after giving regard to all the circumstances of a case, that any action or further action is unnecessary or inappropriate. There may be a number of reasons for deciding to take no further action on a complaint, such as:

- the independent expert clinical advice is that the care provided was of a reasonable standard;
- it is recognised that further inquiry will not resolve evidential issues;
- the allegation is not serious and the provider has taken appropriate action in response to the complaint (e.g. they have apologised and/or taken steps to improve their practice);
- the conduct departed from accepted practice only to a mild degree, and the provider recognises the need for specific improvement; and/or
- the provider has made significant changes to their practice or processes to avoid future errors.

Often a decision to take no further action will be accompanied by an educational comment or recommendations designed to assist the provider in improving future services.

## **The value of complaints for quality improvement**

Every individual complaint represents an opportunity for learning. Both local and sector-wide changes result from the assessment and/or investigation of what went wrong in a particular case, and how such events can be prevented in future.

Considered together, complaints can become an even more powerful tool for widespread quality improvement. Understanding trends and patterns in the complaints received, and what occurred in the clinical interactions, allows for the identification of common issues and possible solutions.

## **Using complaints to investigate delayed diagnosis**

The study of delayed diagnosis is challenging. Because diagnostic error is an error of omission, it is difficult to identify and often goes unreported. When these errors are identified, medical records rarely contain enough detail to allow for a causal analysis.

Internationally, malpractice claims and complaint data have been identified as potentially rich sources of data to study delayed diagnosis.<sup>4 11</sup> These data sets offer two main advantages for such analysis.

First, delayed diagnosis is a common allegation made by patients. In a study conducted in the United States, delayed diagnosis was found to account for over one third of malpractice claims directed at primary care.<sup>12</sup> A study of malpractice claims involving outpatient care in the United States found that 59% of such claims involved a delayed diagnosis, half of which related to the diagnosis of cancer.<sup>4</sup>

Secondly, the information collected when a complaint is assessed means that relatively thorough documentation is available regarding what happened. In the HDC context, this information usually includes:

- a complaint letter alleging what happened;
- medical records pertaining to the event;
- the provider's response to the complaint;
- expert clinical advice on whether a diagnostic error occurred and what may have caused that error; and
- the Commissioner's decision report which synthesises the above information to provide an analysis of what occurred, and whether or not the care provided in relation to the diagnosis was appropriate.

### 3. The data used in this report

The data analysed in this report comes from the HDC's current complaints database. That database contains information about all complaints received by HDC since 1 January 2004.

From that database, we extracted all complaints made about GPs between 1 January 2004 and 31 December 2013, and which contained reference to a missed or delayed diagnosis of cancer (the HDC complaints data). We identified **197** such complaints.

Complaints to HDC often involve more than one provider, and multiple GPs are sometimes involved in a single complaint about a delayed diagnosis of cancer. Due to the fact that different issues may arise in relation to each GP's contribution to the diagnostic error, we undertook a separate analysis of these factors for each GP. Therefore, our sample database was organised at the provider-level, rather than at the complaint-level. We identified **243** GPs who were complained about in relation to a delayed diagnosis of cancer.

## 4. Objectives of this report

In New Zealand, very little is known about the patterns of cancer misdiagnosis in the primary care setting. Despite GPs arguably having the most influence over timely diagnosis, few studies have investigated delayed diagnosis within that setting and few interventions have been identified addressing the factors responsible for delayed diagnosis in primary care.

As recognised internationally, complaints data represents a rich source of data to investigate delayed diagnosis. Accordingly, this report provides an analysis of the HDC complaints data in order to shed light on possible patterns of delayed diagnosis of cancer in New Zealand. Specifically, this report details an analysis of complaints made to HDC over a ten year period alleging the missed or delayed diagnosis of cancer by a GP.

Our primary objectives in analysing this data and reporting on these findings were as follows:

1. To understand the number of complaints about delayed diagnosis of cancer by GPs in the context of other complaints received by HDC.
2. To identify the clinical characteristics of complaints about delayed diagnosis of cancer by GPs in terms of cancer type, length of diagnostic delay and outcomes for the patient.
3. To investigate the factors that contributed to delayed diagnosis of cancer by GPs and the stage at which those issues typically arose, both overall and with reference to specific cancer types.
4. To compare our findings against existing literature.
5. To bring together the clinical recommendations made in the cases with a view to improving quality of care.

# COMPLAINTS ABOUT DELAYED DIAGNOSIS OF CANCER BY GPs

## 1. Number of GPs complained about

### Introduction

This section looks at the number of GPs complained about in relation to a delayed diagnosis of cancer, and sets that number in context, both in terms of general complaint numbers and in terms of trends over time.

### What does the HDC complaint data show?

Over the ten year study period, 243 GPs were complained about in relation to a delayed diagnosis of cancer. The number of such complaints has increased per year over that time, as reported below in Table 1 and shown in Figure 1.

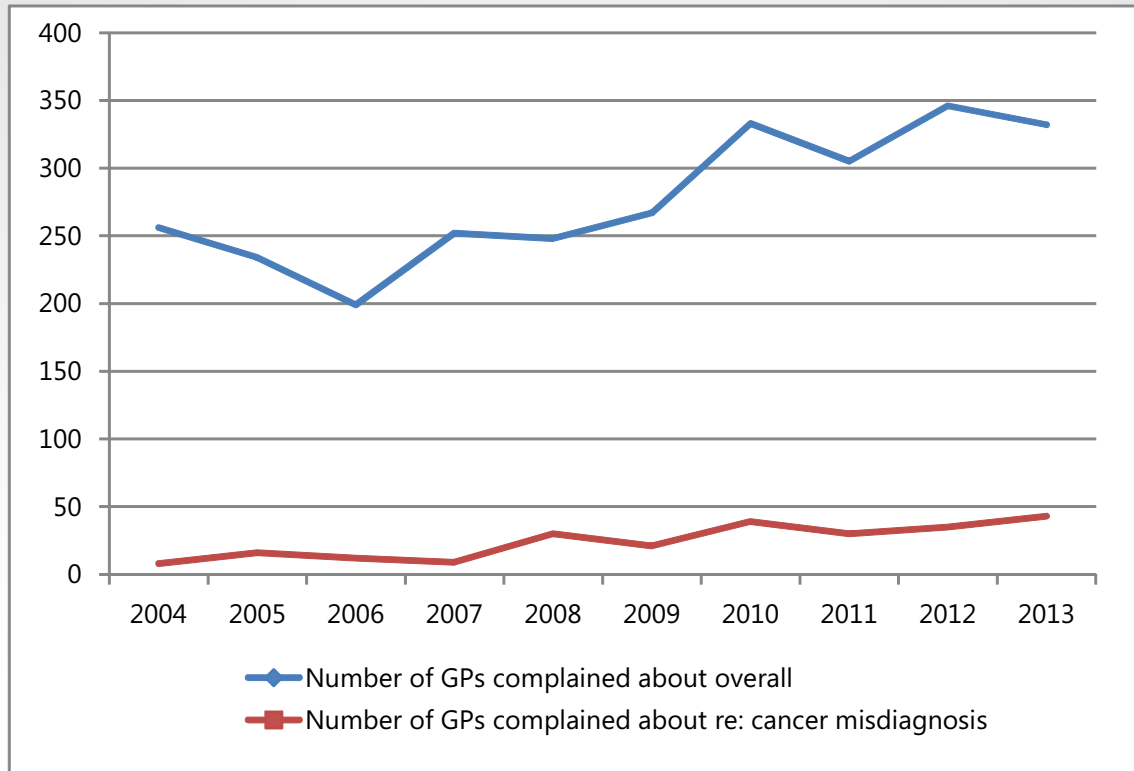
**Table 1.** Number of GPs complained about each year in relation to a delayed diagnosis of cancer

2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
8	16	12	9	30	22	38	30	35	43

In 2013, the number of GPs complained about in relation to a delayed diagnosis of cancer was over five times the number complained about in 2004. Analysis shows the increase to be statistically significant ( $r=0.80$ ,  $p<0.05$ ).

There has been a concurrent significant increase ( $r=0.72$ ,  $p<0.05$ ) in the overall number of GPs complained about to HDC (see Figure 1), with GPs consistently making up about 30% of all individual providers complained about in the last decade.

**Figure 1.** Number of GPs complained about each year



However, as shown in Table 2 below, the proportion of the complaints about GPs that have concerned a delayed diagnosis of cancer has significantly increased over that time ( $r=0.62$ ,  $p<0.05$ ).

**Table 2.** Proportion of GP complaints each year regarding a delayed diagnosis of cancer

2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
3%	7%	6%	4%	12%	8%	11%	10%	10%	13%

### What does this tell us?

The number of GPs complained about in relation to a delayed diagnosis of cancer has increased dramatically over the last ten years. The number of GPs complained about in relation to all issues has also increased, in line with the overall increase in the number of complaints to HDC in that period.

While all three indicators have increased over the last decade, the number of complaints received about GPs in relation to a delayed diagnosis of cancer has increased disproportionately over that period. As a result, the percentage of GP complaints concerning a delayed diagnosis of cancer has increased, from 3% in 2004 to 13% in 2013. The reason for this change in the profile of GP complaints is unclear, but illustrates the importance of cancer diagnosis in the care provided by GPs.



The increase in the number of complaints should be interpreted with caution. HDC does not have any evidence to suggest that any such increase is reflective of a decrease in health care quality. Rather, the growth is more likely to reflect the increasing profile of HDC, the improved accessibility of complaints processes and an increasing knowledge among the public of consumer rights. Increasing complaint numbers is a consistent trend internationally, both in the health care context and in other complaints jurisdictions.



## 2. Clinical characteristics seen in the complaints

### Introduction

This section looks at the types of cancers that were most commonly the subject of complaints about a delayed diagnosis by a GP, the length of the delay in diagnosis, and the outcome of the cancers for the patients.

Several studies have explored whether particular types of cancer are more prone to diagnostic error than other types of cancer, and what the reason for this might be. In 2005, Allgar and Neal<sup>2</sup> analysed diagnostic delay for six cancer types. They found that breast cancer had the shortest primary care delay, while prostate and colorectal cancers had the longest. They concluded that shorter delays may occur in breast cancer because the signs and symptoms of this cancer are straightforward and clearly understood by patients and providers, while longer delays may occur in prostate and colorectal cancers due to their insidious and non-specific presenting symptoms.

In 2011, an audit of primary care providers in England concluded that rarer cancers are more prone to error, and that this may be due to providers' lack of experience with those types of diagnoses.<sup>13</sup> Another, more recent, study of diagnostic delay in eighteen types of cancer found that patients with multiple myeloma and lung cancer experienced the longest delays in diagnosis and those with breast cancer and melanoma, the shortest.<sup>14</sup> This was seen as further support for the conclusion that cancers which present non-specifically typically have longer diagnostic delays.

Lung cancer has the highest mortality rate of all cancers in New Zealand, accounting for 19% of all deaths from cancer. Its 5-year survival rate is low, with only 11% of patients diagnosed with lung cancer living for 5 years or more. Colorectal is the second most common form of cancer death, with 63% of New Zealand patients surviving for five years or more following diagnosis. The third most common form of cancer death is breast cancer, followed by prostate cancer. However, the five-year survival rates for these cancers are high at around 90%. Skin cancer also has one of the highest five-year survival rates with it also being around 90%.<sup>15</sup>

### What does the HDC complaint data show?

This analysis only included cases which were considered by the HDC clinical expert advisor to have involved an actual delayed diagnosis of cancer. Fifteen GPs were, therefore, excluded for the purposes of this analysis, for the following reasons:

- The complaint file did not contain expert advice and therefore, it could not be ascertained whether diagnostic error had occurred.
- The consumer did not, in fact, have cancer.
- No delayed diagnosis was found to have occurred.

It should be noted that the data presented in this section is expressed in terms of number of complaints, rather than number of GPs, as the characteristics described remain stable regardless of the number of GPs involved in the delayed diagnosis.

### Type of cancer

As can be seen from Table 3 below, the most commonly appearing cancer type in the HDC complaint data was colorectal cancer (27%), followed by lung cancer (14%), skin cancer (11%), breast cancer (7%), prostate cancer (5%) and lymphomas (5%).

**Table 3.** Types of cancers in cases in the HDC complaints data

Type of cancer	Number of cases	Proportion of cases
Bladder	2	1%
Brain	5	3%
Breast	13	7%
Cervix	5	3%
Colorectum	54	27%
Kidney	6	3%
Leukaemia	4	2%
Lung	27	14%
Lymphomas	9	5%
Multiple myeloma	3	2%
Oesophagus	5	3%
Oral and throat	6	3%
Ovary	5	3%
Pancreas	7	4%
Prostate	10	5%
Skin	21	11%
Stomach	2	1%
Uterus	2	1%
Unknown primary site	2	1%
Other	9	
<b>TOTAL</b>	<b>197</b>	

The relationship between the incidence of types of cancer in the HDC complaint data, and the overall incidence of those types of cancer in New Zealand is reported below in Table 4. Statistical analysis shows that there is a significant over-representation of colorectal cancer in the HDC complaint data as compared to the national incidence rate ( $z=5.22$ ,  $p<0.01$ ). There is also a significant under-representation of breast cancer ( $z=-2.82$ ,  $p<0.01$ ) and prostate cancer ( $z=-3.63$ ,  $p<0.01$ ) in the HDC complaint data as compared to the national incidence rate.

**Table 4.** Percentage of cases in the HDC complaint data compared to percentage of cancer cases in New Zealand, by cancer type

Type of cancer	Percentage of cases in the HDC complaints data	Percentage of cancer cases in New Zealand <sup>1</sup>
Bladder	1%	2%
Brain	3%	1%
Breast	7%	14%
Cervix	3%	1%
Colorectum	27%	14%
Kidney	3%	2%
Leukaemia	2%	3%
Lung	14%	10%
Lymphomas	5%	4%
Multiple myeloma	2%	1%
Oesophagus	3%	1%
Oral and throat	3%	2%
Ovary	3%	1%
Pancreas	4%	2%
Prostate	5%	14%
Skin	11%	11%
Stomach	1%	2%
Uterus	1%	2%
Unknown primary site	1%	2%

### Diagnostic delay

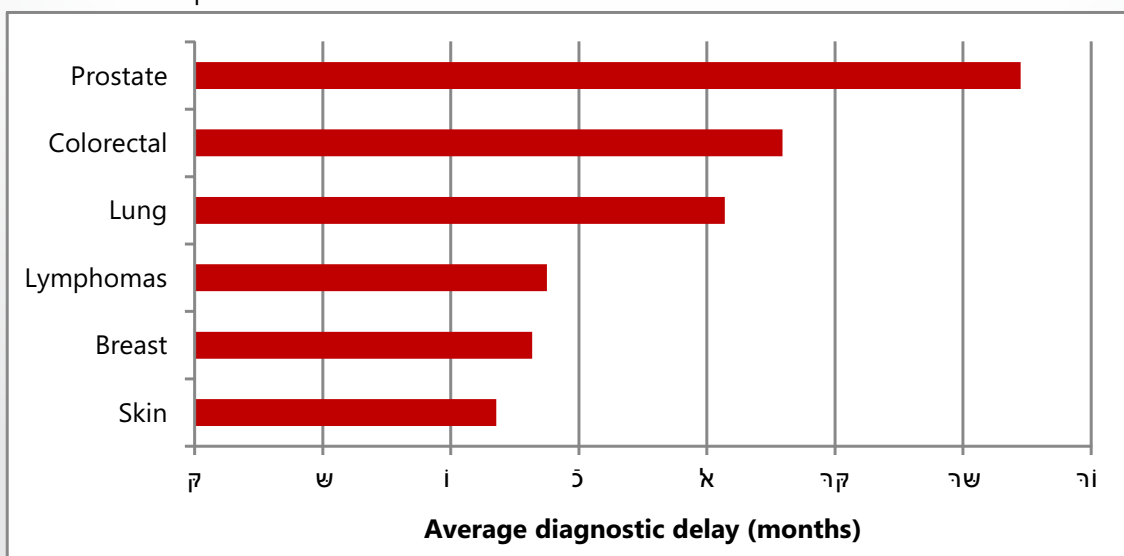
Diagnostic delay is defined as the time from when the patient presents with the first sign or symptom of cancer to when the cancer is diagnosed. As shown in Table 5 below, the length of diagnostic delay for cases in the HDC complaint data varied from less than one month to over two years. The average diagnostic delay seen in cases in the HDC complaint data was 8 months.

**Table 5.** Length of diagnostic delay in the HDC complaint data

Length of delay	Number of cases	Proportion of cases
Less than 1 month	3	2%
1-3 months	56	28%
4-6 months	46	23%
7-9 months	25	13%
10-12 months	28	14%
13-18 months	10	5%
19-24 months	6	3%
Over 24 months	11	6%
Unknown	12	6%
<b>TOTAL</b>	<b>197</b>	

The average length of diagnostic delay also varied by type of cancer, as shown in Figure 3 below.

**Figure 3.** Average length of diagnostic delay for the most common cancer types in the HDC complaint data



Prostate cancer cases had the longest average diagnostic delay (13 months) followed by cases of colorectal cancer (9 months), lung cancer (8 months), lymphomas (6 months), breast and skin cancer (5 months each). However, statistical analysis showed that no cancer type was associated with significantly longer or shorter delays than other cancer types.

### **Outcomes**

The outcomes for patients with cancer as seen in the HDC complaint data are shown in Table 6 below.

**Table 6.** Outcome of cancer in delayed diagnosis complaints

<b>Cancer outcome</b>	<b>Number of cases</b>	<b>Proportion of cases</b>
<b>Death/terminal illness</b>	127	64%
<b>Major physical harm</b>	11	6%
<b>Significant physical harm</b>	19	10%
<b>Minor physical harm</b>	40	20%
<b>TOTAL</b>	<b>197</b>	

For the majority of patients concerned, the cancer resulted in death or a terminal diagnosis (64%). However, as shown in Table 7, the outcomes varied according to the type of cancer concerned.

**Table 7.** Outcome of cancer for the six most common cancer types in the HDC complaint data

<b>Colorectal cancer</b>		<b>Lung cancer</b>		<b>Skin Cancer</b>		<b>Breast cancer</b>		<b>Prostate cancer</b>	
Death/terminal illness	72%	Death/terminal illness	96%	Death/terminal illness	43%	Death/terminal illness	69%	Death/terminal illness	20%
Major physical harm	2%	Major physical harm	0	Major physical harm	0	Major physical harm	0	Major physical harm	0
Significant physical harm	13%	Significant physical harm	0	Significant physical harm	10%	Significant physical harm	8%	Significant physical harm	40%
Minor physical harm	13%	Minor physical harm	4%	Minor physical harm	48%	Minor physical harm	23%	Minor physical harm	40%

Among the cases in the HDC complaint data, colorectal, lung and breast cancers were the most likely to result in the patient's death or a terminal diagnosis. Ninety six percent of cases involving the delayed diagnosis of lung cancer and 72% of cases involving the delayed diagnosis of colorectal cancer were eventually diagnosed as terminal. Whereas, skin cancer and prostate cancer were more likely to result in only minor physical harm for the patient.

Our statistical analysis showed that complaints concerning the delayed diagnosis of lung cancer were significantly associated with death/terminal illness (RR=17.8, p=0.002), while complaints concerning the delayed diagnosis of skin cancer were significantly associated with only minor physical harm (RR=4.4, p=0.01).

## **What does this tell us?**

Colorectal and lung cancers were the cancer types involved in the most complaints about delayed diagnosis by GPs. In particular, colorectal cancer was found to be significantly over-represented in the HDC complaint data given its incidence in the population. This finding is consistent with international literature which has found that colorectal and lung cancers are often more prone to a delay in diagnosis, due to their non-specific presenting symptoms making them more difficult to diagnose.

Our findings are also consistent with existing knowledge in New Zealand, that both lung and colorectal cancers are often diagnosed at a later stage than many other cancers.

Breast and prostate cancers were underrepresented in the HDC complaint data, as compared to the incidence of these cancers in the population. This is consistent with international literature which has found that breast cancer is often diagnosed in a more timely fashion as the symptoms are well-known to both GPs and patients. It should also be noted that New Zealand has a national screening programme for breast cancer which means that the diagnosis of this cancer often bypasses primary care.

While prostate cancers were underrepresented in the HDC complaint data, the cases that were present showed some of the longest diagnostic delays, with an average delay of 13 months across the ten cases.

Sixty four percent of patients represented in the HDC complaint data died from their cancer or were given a terminal diagnosis. Unsurprisingly, rates for these outcomes varied markedly by cancer type, with lung cancer having much worse outcomes than other types of cancer and skin cancer having more minor outcomes for patients. This finding is consistent with national cancer data trends which show that lung and colorectal cancer have low survival rates when compared to breast, prostate and skin cancers.

Death and terminal diagnoses are over-represented as an outcome of cancer in the HDC complaint data when compared to cancer outcomes in the national population. It must be noted that there are a number of factors which greatly limit our ability to make conclusions about this finding. Firstly, it cannot be known what impact delayed diagnosis had on the outcome for the patient as, in many cases, the nature of the cancer may have had a much greater impact on outcome.

Secondly, it may be that patients experiencing worse outcomes are more likely to complain about a perceived delay in the diagnosis of their cancer.

Overall, the clinical characteristics seen in complaints to HDC about delayed cancer diagnosis are as expected given what is known, in New Zealand and internationally, about cancer diagnosis. The HDC complaint data is consistent with established knowledge that colorectal and lung cancers are the most commonly misdiagnosed cancers, can be subject to lengthy diagnostic delays, and more frequently lead to patient mortality. In addition, the HDC complaint data is consistent with past findings that breast cancer is less commonly misdiagnosed and that any diagnostic delays tend to be shorter.



### 3. Conclusion

The number of complaints to HDC concerning a delayed diagnosis of cancer by GPs has increased markedly over the last ten years. While this is consistent with general complaint trends, complaints about delayed cancer diagnosis now make up a significantly larger percentage of total complaints to HDC about GPs than was the case a decade ago. It is unclear what is driving this shift.

Colorectal and lung cancers were the cancers most commonly at issue in complaints to HDC about delayed diagnosis, and the diagnostic delays were often lengthy. This is as expected given the nature of those cancers and the diagnostic difficulties they present. Complaints about the delayed diagnosis of breast cancer were found to be less common and involved shorter delays, again most likely related to the relative ease with which that cancer can be identified and diagnosed.



# FACTORS CONTRIBUTING TO A DELAYED DIAGNOSIS OF CANCER BY GPs

## 1. Describing and categorising delayed diagnosis

### Introduction

Diagnostic processes are complex and involve interactions between system factors and individual cognitive factors.

Cognitive factors may include:

- perception and thought processes, influenced by clinical training and experience;
- predisposition to cognitive and affective biases; and
- fatigue and/or stress.<sup>16</sup>

System factors refer to organisational processes and may include:

- poor communication;
- inadequate coordination of care;
- inadequate supervision;
- technology design;
- availability of resources and/or personnel; and
- negative culture regarding error reporting.<sup>16</sup>

Studies have found that when delayed diagnosis occurs there are often multiple identifiable root causes, representing a complex combination of individual cognitive factors and system factors.<sup>4</sup> Perhaps due to this, little is known about which diagnostic processes are the most vulnerable to error.<sup>10</sup>

This section describes the factors that appear to have contributed to each case of delayed diagnosis included in the complaint sample. These factors have been drawn from the things that the expert clinical advisor on each complaint considered to be the reasons behind the delayed diagnosis.

## Our coding methodology

In order to analyse the factors in the diagnostic delays in a systematic way, we created a coding methodology of 17 factors that have been found to contribute to the delayed diagnosis of cancer in primary care. These factors were then grouped into four over-arching categories according to the stage of the diagnostic process involved. The coding methodology is further explained and defined, with examples, in the box below.

### Factors that may contribute to the delayed diagnosis of cancer by GPs

#### Consultation factors

- Clinically indicated examination not conducted in response to symptoms e.g. **rectal exam not conducted in presence of rectal bleeding**
- Clinically indicated tests not conducted e.g. **chest x-ray not conducted in response to symptoms of lung cancer**
- Relevant patient history not taken/reviewed/given appropriate significance e.g. **family history of cancer, smoking history, symptoms at previous consultations etc.**

#### Diagnostic factors

- Co-morbidities drew focus e.g. **respiratory symptoms attributed to co-existing chronic obstructive pulmonary disease**
- Failure to consider differential diagnoses e.g. **bias towards one diagnosis led to failure to consider other clinically relevant causes despite persistent or evolving symptoms**
- Failure to acknowledge limitations of diagnostic testing e.g. **reliance on negative chest x-ray to exclude lung cancer despite persisting or evolving symptoms**
- Non-specific/atypical symptoms e.g. **lung cancer did not present with respiratory symptoms, colorectal cancer did not present with bowel symptoms etc.**
- Treated symptoms in isolation e.g. **treatment of iron deficiency anaemia without investigating cause**
- Multiple providers/poor inter-provider communication (between GPs) e.g. **patient's regular GP not aware of tests ordered by locum**
- Test interpretation error (by GP) e.g. **failure to interpret significance of blood test results**

#### Follow-up and referral

- Appropriate referral not made (in response to alarm symptoms, abnormal test results etc.) e.g. **did not make referral for colonoscopy despite alarm symptoms present for colorectal cancer**
- Inadequate follow-up of referral e.g. **failure to check if referral had been received by secondary care**
- Inadequate follow-up of symptoms e.g. **failure to ascertain whether symptoms resolved with treatment**
- Inadequate follow-up of test results e.g. **failure to take further action on abnormal test results**
- Poor communication with secondary care providers e.g. **failure to ensure patient was appropriately triaged by secondary care**

#### Patient factors

- Patient did not attend for consultations/investigations e.g. **did not return for follow-up review despite GP request to return**
- Patient did not report symptoms (indicative of cancer) to GP e.g. **failure to report development of alarm symptoms such as rectal bleeding, breast lump**

## 2. Delayed diagnosis factors in complaints

### Introduction

In 2013, a group of researchers from the United States published the results of a study in which they reviewed medical records in two primary care settings.<sup>10</sup> They identified that the majority of diagnostic errors involved breakdowns in processes during the patient–practitioner clinical encounter. Breakdowns also occurred in the domains of referral, test ordering and interpretation, follow-up, tracking of diagnostic information and patient-related factors. The most frequent process breakdowns in the patient-practitioner encounter were related to problems with history-taking, examination and the ordering of diagnostic tests. The researchers concluded that these findings reflected the need for primary care providers to focus on cognitive skills in diagnosis, particularly data gathering, thorough history taking and physical examinations, and the subsequent synthesis of that data.

A survey of primary care providers found that providers reported that the most common pathway to diagnostic delay was the attributing of symptoms to a commonly seen benign disease in patients who had an uncommon serious disease. Most providers reported that this error had led them to subsequently broaden their differential diagnoses and to ensure that they considered certain “don't miss” diagnoses for specific presenting symptoms.<sup>6</sup>

A review of diagnostic error studies in primary care also found that errors relate to the ways in which conditions present. Errors were more likely in cases of atypical or non-specific presentations, rare conditions and the presence of co-morbidities. These findings further support the conclusion that diagnostic error often represents a failure by clinicians to formulate an appropriate set of diagnostic hypotheses and to gather the right information to test these hypotheses.<sup>17</sup>

Studies of diagnostic error in cancer have typically investigated error within individual cancer types. However there are some factors which seem to contribute to error across all cancer types, including, symptom misattribution,<sup>18 19</sup> insufficient examination,<sup>20</sup> false negative test results,<sup>20 21</sup> <sup>22</sup> inadequate follow-up arrangements<sup>19 23</sup> and co-morbidity<sup>22 24</sup>.

This section looks at the HDC complaint data in order to investigate the factors that appear to have contributed to each case of diagnostic delay, and identify any patterns among those factors. Later in this section, we undertake an analysis by cancer type to ascertain whether there are any particular themes that arise in relation to particular cancers.

## What does the HDC complaint data show?

The delayed diagnosis factors identified for each GP complained about in relation to delayed diagnosis of cancer are reported below in Table 8.

It should be noted that this analysis was done by GP complained about rather than by complaint due to the fact that in some complaints more than one GP contributed to the delay in diagnosis. In addition, up to six factors were identified for each GP.

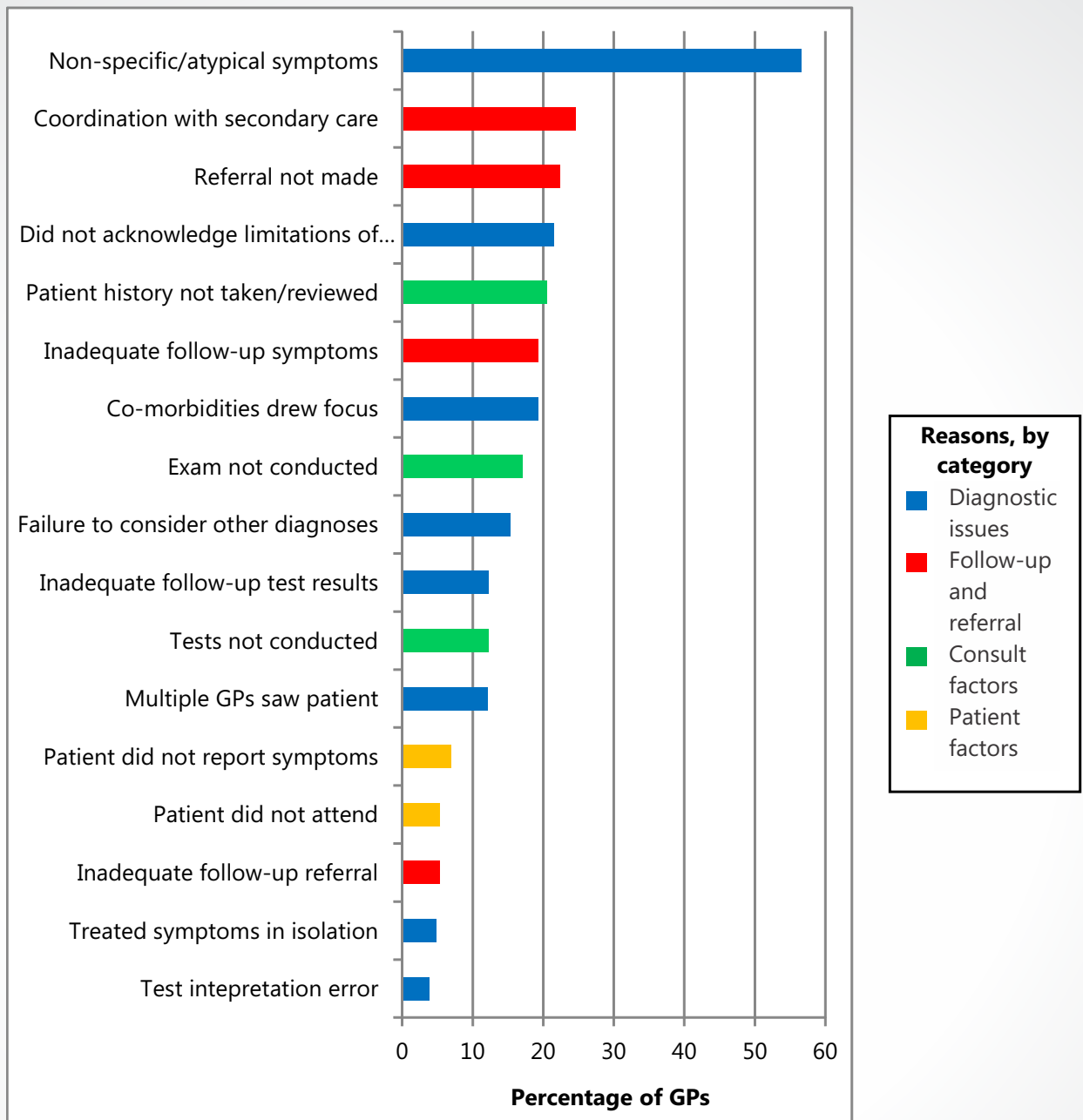
**Table 8.** Delayed diagnosis factors present in the HDC complaint data

Delayed diagnosis factors	Number of GPs for whom the factor was present	Percentage of GPs for whom the factor was present
<b>Consultation factors</b>		
Relevant patient history not taken/reviewed/given significance	47	21%
Clinically indicated examination not conducted	39	17%
Clinically indicated tests not conducted	28	12%
<b>Diagnostic factors</b>		
Non-specific/atypical symptoms	129	57%
Failure to acknowledge limitations of diagnostic testing	51	22%
Co-morbidities drew focus	44	19%
Failure to consider differential diagnoses	35	15%
Multiple providers/poor inter-provider communication	30	13%
Treated symptoms in isolation	11	5%
Test interpretation error	9	4%
<b>Follow-up and referral</b>		
Poor communication with secondary care	56	25%
Appropriate referral not made	52	23%
Inadequate follow-up of symptoms	44	19%
Inadequate follow-up of test results	28	12%
Inadequate follow-up of referral	12	5%
<b>Patient factors</b>		
Patient did not report symptoms	16	7%
Patient did not attend	12	5%

The most common factors identified as contributing to the delayed diagnosis of cancer were 'non-specific/atypical symptoms' (57%), 'poor communication with secondary care' (25%), 'appropriate referral not made' (23%), 'failure to acknowledge limitations of diagnostic testing' (22%), and 'relevant patient history not taken/reviewed/given significance' (21%).

The prevalence of each of these factors is further illustrated in Figure 5.

**Figure 5.** Delayed diagnosis factors present in the HDC complaint data



The most common delayed diagnosis factor seen in the HDC complaint data was 'non-specific/atypical symptoms' which contributed to delayed diagnosis for over half of the GPs concerned. A similar issue, that of the cancer mimicking the symptoms of a patient's co-existing illnesses, was a factor for 19% of the GPs.

These findings are consistent with the international literature which has found that diagnostic errors are affected by the way in which conditions present and are more common with atypical or non-specific symptoms. Cancer is known to be difficult to diagnose. It is an illness that often presents non-specifically, with symptoms which could be attributed to a number of benign conditions. This makes it difficult for GPs who must identify the patient who has cancer from the many who have the same symptoms but for whom the diagnosis will be benign.

## Case Example

### Non-specific/atypical symptoms

A woman in her thirties presented to her GP with frequent bouts of belching and nausea. The GP requested a stool sample and ordered an abdominal ultrasound, both of which returned normal results. A provisional diagnosis of gastritis was made and treatment was prescribed for this.

Seven months later the woman presented to the GP complaining of hard bowel motions, pain prior to defecation and urinary symptoms. Physical examinations were normal, but the woman's urine test was suggestive of infection. The GP made a differential diagnosis of constipation and urinary tract infection. Treatment was prescribed and the woman was told to return if her symptoms persisted or evolved.

Four months later the woman returned to the GP reporting a small amount of blood after a bowel motion. She stated that there had been no other changes to her bowel habits or any weight loss. Rectal and abdominal exams were normal. Taking into consideration that the episode of bleeding had only occurred once, and the lack of family history of bowel cancer, the GP adjusted the differential diagnosis to one of internal haemorrhoids.

A month later, the woman re-presented with a 24 hour history of un-wellness including fever, lower back pain and abdominal pain. She did not mention any rectal bleeding or change in bowel habits. The GP undertook a comprehensive physical exam and all findings were normal. Blood test results were consistent with a picture of inflammation and the GP formed a working diagnosis of inflammation of the gallbladder. Low iron levels were noted in the blood tests, but the GP attributed these findings to the woman's menstruation, and oral iron was prescribed.

The woman then moved to another region of the country where, three months later, she attended ED and was diagnosed with colorectal cancer.

The Commissioner's expert clinical advisor considered that the woman's cancer had presented atypically – her symptoms were intermittent with an absence of red flags for malignancy such as weight loss, persistent bowel change and rectal bleeding. The woman had no risk factors for colorectal cancer, being young with no family history of cancer and no history of drinking or smoking. According to the relevant guidelines nothing in the woman's presenting symptoms should have triggered a suspicion for an underlying colorectal malignancy or an urgent referral for further investigation.

The expert advised that the provisional diagnoses made by the GP were consistent with the woman's presenting systems and with the results of physical examinations and tests. The expert concluded that the major factor leading to delayed diagnosis was the atypical nature of the woman's tumour and clinical picture, rather than any omissions made by the GP. Therefore, the Deputy Commissioner decided to take no further action on this complaint.



However, the way in which cancer presented was not the only delayed diagnosis factor seen in the HDC complaint data. Consistent with the international literature, the HDC complaint data confirm that the ways in which GPs gathered and synthesised information during the diagnostic process also contributed to diagnostic delay.

### **Consultation factors**

Issues within the consultation process contributed to a delayed diagnosis for 36% of GPs in the HDC complaint data. The most common specific issues were 'relevant patient history not taken/reviewed/given significance' and 'clinically indicated examination not conducted'.

Again, these findings are reflective of the international literature, which asserts that breakdowns in the diagnostic process often occur within the patient-practitioner encounter. These issues reflect a failure to get the basics right - knowing when to conduct physical examinations, order the appropriate tests, and review the patient's history. Or, as often expressed by the Commissioner: "Read the notes, ask questions, talk to the patient." It is much more difficult for GPs to formulate a correct diagnostic hypothesis if these basics are not given due attention.

## Case Example

### History not taken/reviewed/given significance

A woman in her late 50s with a previous history of breast cancer presented to her GP with pain and reduced movement in her left shoulder. The GP diagnosed a rotator cuff injury and referred the woman for an X-ray and ultrasound.

The GP received and reviewed the woman's imaging report in which the specialist radiologist had commented that a full thickness tear of the supraspinatus tendon was evident, and there was a lytic lesion in the head of the humerus that was highly suspicious of a metastatic lesion. A bone scan and review by an oncologist was strongly recommended. After reviewing the imaging report, the GP recorded these findings in the Medical Centre's electronic patient management system (PMS) and arranged to see the woman later that day. However, at that appointment, the GP did not discuss the possibility of metastasis with the woman, instead only informing her of the tendon tear.

One month later, the woman returned to the GP complaining of a 10-day history of chest pain. He queried whether there was reduced air entry into her lung and arranged for the woman to be urgently admitted to hospital. Hospital admission resulted in a diagnosis of musculoskeletal pain. No reference was made to the woman's previous shoulder pain by the woman or the GP.

Another month later, the woman again presented to the GP with pain in her left shoulder. The GP referred the woman to an orthopaedic surgeon for review of her left shoulder. The referral letter made no reference to the possibility of metastasis being present, and referred to the woman's previous breast cancer only briefly. The orthopaedic surgeon, on reviewing the woman's X-rays, subsequently diagnosed the woman as having a metastatic lesion in her left shoulder, likely of breast origin given her medical history.

The Commissioner's expert clinical advisor stated that the GP's failure to discuss the possibility of metastatic disease with the woman, despite having acknowledged the imaging report just hours earlier, constitutes a severe departure from expected standards. It is evident that the GP failed to review his own notes regarding this imaging result during both this consultation and any of his subsequent consultations with the woman. The expert advised that had he done so, he would have been reminded of the possibility of metastatic disease.

The Commissioner commented that this case highlights the importance of doing the basics well – “read the notes, ask the questions, talk with the patient”. In this case a repeat presentation for continuing left shoulder pain failed to elicit the most basic of enquiries. The GP failed to read his own notes, even in relation to the woman's last presentation with shoulder pain, and apparently failed to reflect on the woman's history of breast cancer – which he nonetheless recorded in the referral letter. The Commissioner also emphasised the importance of effective and prompt communication of test results by providers to consumers. He considered the GP's failure to inform the woman of her imaging results to be of particular significance given the potential seriousness of the result in light of the woman's history of breast cancer.

The Commissioner, therefore, found the GP in breach of the Code for not arranging timely follow-up in response to the imaging report, failing to discuss the scan results with the woman and for not including sufficient information in his referral letter to the orthopaedic surgeon.

The Commissioner recommended that the GP:

- Provide a written apology to the woman's family.
- Review the relevant aspects of his practice in light of this report, particularly in relation to test result processes, and provide evidence to HDC of this review and the subsequent changes he has made to his practice.
- Undertake an audit of his clinical records to ensure that all patient test results he had received in the last two years had been appropriately followed up and communicated to patients.

The Commissioner also recommended that the Medical Practice develop an appropriate policy to ensure that tests results are actioned and referrals are made in an adequate and timely manner, including an appropriate alert system. These recommendations have been met by the GP and the Practice.

The Commissioner referred the GP to the Director of Proceedings for the purpose of deciding whether any proceedings (or legal action) should be taken.



### **Diagnostic factors**

Diagnostic factors was the most common category of delayed diagnosis factors present in the HDC complaint data. Diagnostic factors reflect the ways in which GPs synthesise and analyse the information they gather during a consultation.

Most common among the diagnostic factors observed was 'non-specific/atypical symptoms' (for 57% of GPs in the sample). The ways in which non-specific symptoms and co-morbidities can make diagnosis more difficult have been discussed above.

Other common diagnostic factors included 'failure to consider differential diagnoses' (present for 15% of GPs) and 'failure to acknowledge limitations of diagnostic testing' (22%). False negative test results have been found to considerably lengthen diagnostic delay. An over-reliance on test results to exclude certain diagnoses can become inappropriate in the presence of evolving or persisting symptoms and can represent the GP failing to consider the whole clinical picture.

It has been reported internationally that diagnostic error can reflect a need for GPs to broaden their set of diagnostic hypotheses. Formulating diagnostic hypotheses is the cornerstone of the diagnostic process. Not considering appropriate differential diagnoses may stem from incorrectly synthesising the information collected during the consultation. It may also stem from overconfidence in an original diagnosis, leading to tunnel vision where hypotheses are not formulated or discounted in light of persistent or evolving symptoms or test results.

### **Follow-up and referral**

Common delayed diagnosis factors relating to follow-up and referral included 'appropriate referrals not made' (present for 23% of GPs), 'poor communication with secondary care' (25%) and 'inadequate follow-up of symptoms' (19%). These findings are consistent with international studies which have reported that issues concerning follow-up and referral often contribute to diagnostic delay.

Referral and follow-up factors reflect GPs not formulating the appropriate actions in response to the diagnostic analysis undertaken. For example, not making the appropriate referrals is indicative of a failure to appropriately synthesise the information collected during the consultation and see that referral for further diagnostic testing or specialist intervention is warranted.

Inadequate follow-up has been found to be particularly associated with long diagnostic delays. Not following up with a patient regarding symptom resolution may reflect an inappropriate reliance on the patient's understanding of the significance of their persistent or evolving symptoms.

## Case Example

### Appropriate referral not made

A woman in her early 50s with an extensive history of smoking and a family history of lung cancer, presented to her GP on multiple occasions over a 20 month period with complaints of persistent coughing, chest and throat pain, fever and sweating, haemoptysis (coughing up blood), and shortness of breath. The woman also had a long-standing benzodiazepine dependency.

Over this 20-month period, the GP diagnosed the woman with recurrent respiratory tract infections and acute pharyngitis and prescribed the woman antibiotics and cough medicine. There is no record of the GP undertaking a physical examination of the woman during this period or of him taking any steps to investigate the cause of her respiratory symptoms.

The GP's notes were a combination of computerised and handwritten notes. His handwritten notes were, in places, illegible and incomplete. Most notably, the handwritten notes did not comprehensively and accurately document the woman's symptoms of persistent coughing and chest and throat pain, or what examinations, if any, were undertaken to diagnose the woman.

At the end of this 20-month period, the woman presented to hospital suffering from severe chest pain. During her admission she was diagnosed with primary lung cancer with extensive metastases.

The Commissioner's expert clinical advisor advised that the current relevant guidelines recommend urgent specialist referral for smokers, aged over 40 years with persistent haemoptysis, and an urgent chest X-ray if they have unexplained haemoptysis or more than three weeks of any unexplained chest/shoulder pain, shortness of breath, abnormal chest signs and cough. The expert considered that the woman's presentation fulfilled the recommended criteria for referral at the beginning of the 20 month period. The expert stated that the woman's late diagnosis of lung cancer was a direct result of a failure by the GP to consider this diagnosis, in a patient at significant risk and with a suspicious presentation, in a timely manner.

The expert was also critical of the GP's failure to undertake any physical examinations when the woman presented with significant respiratory symptoms. The expert further stated that the GP's notes were not only illegible and of poor quality and structure, but that there is a combination of handwritten and computerised notes which distracts from effective continuity of care. The GP also failed to comprehensively and accurately document the woman's presentations.

The Commissioner stated that this was a case of a doctor failing to discharge his duty of care to his patient. The GP's failure to get the basics right compromised the woman's safety and well-being. The woman presented repeatedly with history and symptoms that should have prompted enquiry. The GP should have been capable of managing the woman's drug dependency without overlooking the clear need to investigate her respiratory symptoms. The Commissioner, therefore, found the GP in breach of the Code for failing to physically examine the woman or refer her for an urgent chest X-ray. The Commissioner also found the GP in breach of the Code as his documentation did not meet professional standards.

The GP no longer holds a current practising certificate. However, the Commissioner recommended that, should he return to practice in the future, he first familiarise himself with the relevant guidelines and undergo additional training on clinical documentation. The Commissioner also recommended that the Medical Council undertake a competency review of the GP before issuing him a practicing certificate.

The Commissioner referred the GP to the Director of Proceedings for the purpose of deciding whether any proceedings (or legal action) should be taken.

## Case Example

### Poor communication with secondary care

A man in his late sixties with a family history of prostate cancer presented to the Emergency Department (ED) with lower urinary tract symptoms where, following review by a urologist, he was diagnosed with prostatitis. An elevated prostate specific antigen (PSA) level was noted. The urologist advised the man's GP that the man should receive regular blood tests to confirm that his PSA levels had returned to normal following resolution of the infection. The GP advised HDC that she did not receive this advice from the specialist. The man then self-referred to a private urologist for recurrent urinary symptoms. That urologist told HDC that although he requested that the man return for follow-up, he only saw him once. However, over the next few years, the man gave his GP the false impression that he was under the care of the private urologist. The GP never contacted the urologist directly.

Over the next two years, the man regularly requested PSA tests from the GP's practice. The GP said that she had been under the impression that the tests were being requested by the urologist. From May 2008 the results were slightly abnormal and from February 2009 the results were trending upwards. The GP advised HDC that she did not conduct any further examinations, such as a digital rectal exam (DRE), in light of these abnormal results because she felt reassured that the results were being managed by the urologist. However, the GP did not copy any of the test results to the urologist.

The man then saw a locum GP who noted his increasing PSA results, performed a DRE, and referred him to the urologist. The urologist diagnosed the man with prostate cancer. The GP explained to HDC that her reason for not contacting the urologist directly was that the man was protective of his privacy and wanted to control the flow of information between the GP and the urologist.

The expert clinical advisor expressed the view that, as the doctor ordering and receiving the results of the PSA tests, it was the GP's responsibility to ensure that these results were communicated to the specialist.

In making a decision on the complaint, the Commissioner noted that the introduction of specialist assistance does not mean that the role of the GP in a consumer's care comes to an end. Rather, it remains the GP's responsibility to ensure that the consumer receives quality and continuity of services. In the context of the man's increasingly abnormal PSA results, the GP should have taken responsibility for the co-ordination of the man's care by making enquiries of the man about the extent of the urologist's involvement and by contacting the urologist directly to discuss the man's results and a management plan. The Commissioner concluded that the GP's failure to proactively engage with the specialist contributed to the delayed diagnosis of the man's prostate cancer.

The Commissioner found the GP in breach of the Code for failing to:

- offer to perform a DRE;
- make specific enquiries about the extent of the urologist's involvement;
- arrange for the man's test results to be copied to the urologist; and
- request the man's consent to communicate with the urologist to ensure that his symptoms and rising PSA levels were being appropriately managed.

In light of these findings, the Commissioner recommended that the GP apologise to the consumer and review her practice in relation to co-ordination of care, review of test results processes, and communication with other providers, and provide evidence to HDC of the review and subsequent changes. The Commissioner also recommended that the Medical Council undertake a review of the GP's competence. These recommendations have been met.

### **Patient factors**

Research indicates that patient factors can cause considerable delays in the diagnostic process. Patient delay (time from onset of symptoms to first presentation to a health care provider) has been found to be one of the longest delays in the diagnostic pathway.<sup>3</sup> We did not find patient factors to be prominent in the HDC complaint data, at issue for only around 5% of GPs. This may be because patients who delay in attending appointments or reporting symptoms are less likely to subsequently complain about a delay in diagnosis.

### **3. Delayed diagnosis factors in complaints, by cancer type**

#### **Introduction**

Previous research has indicated that the factors involved in diagnostic error tend to differ depending on the type of cancer concerned. This section describes the delayed diagnosis factors identified in the HDC complaint data for each of the five cancer types seen most frequently in that data.

#### **Colorectal cancer**

##### **Introduction**

Research conducted in New Zealand has found that colorectal cancer is typically more advanced in New Zealand patients at diagnosis than is seen internationally, and that one-third of New Zealand patients are diagnosed after presenting acutely to ED.<sup>25</sup> These findings indicate that, by international standards, New Zealand has a low rate of early stage colorectal cancer diagnosis.

An international review of delay in colorectal cancer diagnosis conducted in 2008 found that the failure to appropriately examine the patient, and receiving false negative test results, were associated with delay across a wide number of studies.<sup>20</sup> Another study found that failures to follow-up or refer patients with iron deficiency anaemia was significantly associated with missed opportunities to diagnose colorectal cancer.<sup>26</sup>

Patients with colorectal cancer have also been found to experience the longest primary care diagnostic delays, a finding which has been attributed to the cancer's non-specific presenting symptoms.<sup>2</sup>

##### **What does the HDC complaint data show?**

As can be seen from Table 9 below, the most common delayed diagnosis factors identified in the HDC complaint data as contributing to diagnostic error in colorectal cancer were 'non-specific/atypical symptoms' (at issue for 44% of the GPs), 'clinically indicated examination not conducted' (33%), 'poor communication with secondary care' (30%) and 'inadequate follow-up of symptoms' (27%).

**Table 9.** Delayed diagnosis factors present for colorectal cancer in the HDC complaint data

Delayed diagnosis factors	Number of GPs for whom the factor was present	Percentage of GPs for whom the factor was present
<b>Consultation factors</b>		
Clinically indicated examination not conducted	21	33%
Relevant patient history not taken/reviewed/given significance	16	25%
Clinically indicated tests not conducted	7	11%
<b>Diagnostic factors</b>		
Non-specific/atypical symptoms	28	44%
Co-morbidities drew focus	15	24%
Multiple providers/poor inter-provider communication	15	24%
Failure to consider differential diagnoses	13	21%
Failure to acknowledge limitations of diagnostic testing	9	14%
Treated symptoms in isolation	6	10%
Test interpretation error	1	2%
<b>Follow-up and referral</b>		
Poor communication with secondary care	19	30%
Inadequate follow-up of symptoms	17	27%
Appropriate referral not made	15	24%
Inadequate follow-up of referral	9	14%
Inadequate follow-up of test results	7	11%
<b>Patient factors</b>		
Patient did not attend	4	6%

We found colorectal cancer to be significantly associated with 'clinically indicated examination not conducted' (RR=4.1, P=0.001), and 'treating symptoms in isolation' (RR=4.2, P=0.04), as compared to other cancer types.

### **What does this tell us?**

The most common delayed diagnosis factor we found in cases of diagnostic error in colorectal cancer was 'non-specific/atypical symptoms'. This is consistent with the international literature. Colorectal cancer is known to present with lower gastrointestinal symptoms, such as rectal bleeding and a change in bowel habit, which are common in the general population and which usually have a benign cause. These non-specific symptoms can make the diagnosis of colorectal cancer complex for GPs as it is necessary to determine whether the patient's symptoms warrant further referral for diagnostic testing or whether a 'treat (for benign illness) watch and review' approach is appropriate. Although this watch and review approach may often be appropriate in colorectal cancer diagnosis it must be done in the context of having gathered all of the required information.

Although 'non-specific/atypical symptoms' was the most commonly seen delayed diagnosis factor, it was the failure to undertake clinically indicated examinations and the treatment of symptoms in isolation that were particularly prevalent in the delayed diagnosis of colorectal cancer. Both delayed diagnosis factors were around four times more likely to appear in cases of colorectal cancer than for any other type of cancer considered.

The failure to undertake a rectal or abdominal examination in the presence of symptoms that might have been indicative of colorectal cancer was seen in many cases in the HDC complaint data. This demonstrates a failure to gather the information needed to make an appropriate diagnosis, as a rectal or abdominal mass found on examination would usually lead to urgent referral and an earlier diagnosis. However, it is acknowledged that an abdominal mass is present in only a minority of patients presenting with symptoms of possible colorectal cancer, and a rectal mass is palpable in only 24-56% of such patients.<sup>27</sup>



## Case Example

### Colorectal cancer: Clinically indicated examination not conducted

A 62 year old woman consulted her GP complaining of rectal bleeding and discomfort. No physical examinations were carried out by the GP. The GP provided the consumer with a prescription for Ultraproct cream for 'possible haemorrhoids'. The documentation from that consultation was limited with no reference to the reason for the consultation, symptoms, clinical findings or diagnoses.

Three months later, the woman re-presented to the GP requesting a change in one of her regular medications. The GP also prescribed a repeat of the Ultraproct cream. No physical examinations were carried out. Again, the documentation was very limited with no indication as to why a repeat of Ultraproct had been given.

Four months later, the woman consulted the GP again. The documentation for that consultation simply read "see referral letter". This was a letter referring the woman to a gastroenterologist for a colonoscopy. The letter noted that the woman had had diarrhoea for the past year and had lost five kilograms in the last four months. However, the referral was never sent.

Two months passed before the woman presented to hospital with severe bowel pain, resulting in a diagnosis of colorectal cancer.

The expert clinical advisor noted that, given the high incidence of bowel cancer in New Zealand especially in people aged over 50 years, the GP should have recorded some information about the woman's bowels when she presented with rectal bleeding. The expert stated that "it is not safe to assume rectal problems are always from haemorrhoids" and that a basic examination should have included a palpitation of the woman's abdomen and a DRE. The expert emphasised that examination findings are just as important as ordering tests, as the examination findings form the first part of the diagnostic process, without which it is impossible to take suitable and prompt action. The poor standard of the GP's documentation and her failure to both send and follow-up on the gastroenterology referral were also viewed with disapproval by the expert.

The Commissioner found the GP in breach of the code for failing to examine the consumer's abdomen and rectum at either of the first or second consultations. The GP was also found in breach of the Code for failing to have an appropriate system to alert her to referrals which had not been actioned, and for failing to meet professional standards in terms of her documentation.

The GP advised HDC that, as a result of the complaint, she had made changes to her practice. For instance, she reported that when a patient presents with gastro-intestinal related symptoms she will in future always perform and document a full examination and order appropriate tests to exclude other pathology and to ensure her diagnosis is correct. The GP also undertook an audit of all patients who had been prescribed haemorrhoid medication in the last 18 months and reviewed her notes for examinations and follow-up.

The Commissioner recommended that the GP enter into a mentoring relationship with another GP. The mentor was asked to report back to HDC to confirm mentoring had occurred and to give their evaluation of the GP's practice in the areas of concern identified by the complaint. This recommendation has been met.



Treating symptoms in isolation may also relate to a failure to gather the appropriate data. Although iron deficiency anaemia often has a benign cause and can be treated with iron tablets, it is also known to be a symptom of serious disease. A serious cause must be excluded before treatment is undertaken.

## Case Example

### Colorectal cancer: Treating symptoms in isolation

A woman in her mid-sixties consulted her GP with a general feeling of unwellness, shortness of breath and chest pain. Her cardiovascular exam was normal. The GP ordered blood tests which found low iron levels and the pathologist queried recent blood loss as a cause of the results. The GP diagnosed iron deficiency anaemia and prescribed iron supplements. Blood tests five months later showed improving iron levels.

After three more months, the woman presented with breathing difficulties, tiredness and a burning feeling in her chest. The GP did not carry out a physical exam, but diagnosed gastritis. Blood tests were ordered and showed decreasing iron levels. The GP advised the woman to increase her iron supplements. The GP then continued to prescribe iron supplements without further checks of the woman's iron levels. About four months later, the woman presented on multiple occasions during a two month period. She reported persistent chest tightness, lethargy and abdominal pain. Blood tests were taken and showed abnormal CRP levels indicative of inflammation. The GP did not, however, carry out any action to investigate the cause of that result.

The woman then went to another GP for a second opinion on her symptoms. The second GP found an epigastric mass on abdominal examination and referred the woman to a gastroenterologist who diagnosed colorectal cancer.

Expert clinical advice was that iron deficiency anaemia in postmenopausal women is commonly caused by gastrointestinal blood loss or malabsorption. Specifically, that anaemia is not a disease, but a symptom of an underlying condition. The expert considered that the woman's presentation was consistent with colorectal cancer given her family history, age, iron deficiency anaemia, and gastrointestinal symptoms. The expert viewed with severe disapproval the GP's treatment of the woman's symptoms of iron deficiency without undertaking any examinations or investigations to elucidate its cause. The expert concluded that had the woman been managed in accordance to accepted practice her cancer would have been diagnosed a year earlier than it was.

The Commissioner found the GP in breach of the Code for failing to:

- appropriately investigate and manage the woman's iron deficiency anaemia;
- examine the consumer's abdomen; and
- meet professional standards in terms of his documentation.

The Commissioner concluded that the management errors made in this case indicated significant gaps in what the expert considered to be basic GP knowledge. Therefore, the Commissioner recommended that the GP undergo additional training on clinical documentation and familiarize himself with the guidelines for the management of iron deficiency anaemia, and report back to HDC regarding the completion of this training and the steps taken to achieve improvements in the quality of his documentation.

The Commissioner also referred the GP to the Director of Proceedings who brought proceedings (or legal action) against the GP.

We also found that 'inadequate follow-up of symptoms' was a common issue in the delayed diagnosis of colorectal cancer, although not significantly associated with colorectal cancer compared to other cancer types. Often times, this may indicate that the "watch and review" strategy has not been carried out appropriately. It is important that GPs organise a review to ensure that the symptoms have resolved with treatment, as persisting or evolving symptoms can indicate a more serious cause for the symptoms. Patients may also be falsely reassured by treatment for a benign disease (such as haemorrhoids) and fail to return proactively to their GP for review.

## **Lung Cancer**

### **Introduction**

Much like colorectal cancer, lung cancer diagnosis has been found to be subject to one of the longest primary care delays, something that is also often attributed to its non-specific presenting symptoms.<sup>14</sup> A 2013 analysis of significant event audits in lung cancer diagnosis in the United Kingdom found that lung cancer frequently mimics the symptoms of other, less serious, diagnoses. The study concluded that providing patients with appropriate information about when to return for follow-up was vital to accurate diagnosis.<sup>19</sup>

Studies of lung cancer patients have also found that those with a false negative chest x-ray had a primary care delay up to six times longer than those whose x-rays raised suspicion for cancer, and that patients with atypical symptoms had a median delay of more than three months compared to a median delay of one month for patients with more typical symptoms.<sup>21</sup>

In New Zealand, lung cancer is the cancer with the highest mortality rate. This is generally attributed, at least in part, to the late stage at which lung cancer is often diagnosed. A 2010 audit of lung cancer diagnosis in New Zealand found that the majority of patients with lung cancer accessed secondary care through acute presentation to ED, rather than through primary care.<sup>28</sup> This is at odds with guidelines for the management of suspected lung cancer, which assumes that patients are referred to a respiratory specialist by their GP.<sup>3</sup> Over half of the patients presenting to ED were self-referred, despite the fact that many of them had seen their GP in the previous six months. Patients presenting to ED were also more likely to have terminal metastatic disease. Consistent with the international literature, the 2010 study also found that abnormal chest x-rays were an important trigger for referral and diagnosis, and that a normal chest x-ray resulted in substantial diagnostic delays.<sup>27</sup>

In 2012 a study of New Zealand GPs' views of lung cancer diagnosis was undertaken.<sup>29</sup> GPs reported uncertainty around which patients to investigate and refer as many patients presented with non-specific symptoms similar to other respiratory diseases, rather than with the more classic alarm symptoms (such as haemoptysis, chest pain and weight loss) outlined in "Suspected Cancer in Primary Care: Guidelines for investigation, referral and reducing ethnic disparities".<sup>3</sup> This diagnostic difficulty was reported as being further compounded by the fact that less than half of the GPs in the study had seen a lung cancer patient in the last year, but reported that respiratory symptoms were a common presentation. This led to GPs in the study carrying a low index of suspicion for lung cancer.

### **What does the HDC complaint data show?**

Table 10 shows the delayed diagnosis factors seen in the HDC complaint data in cases of lung cancer diagnostic error.

**Table 10.** Delayed diagnosis factors present for lung cancer in the HDC complaint data

<b>Delayed diagnosis factors</b>	<b>Number of GPs for whom the factor was present</b>	<b>Percentage of GPs for whom the factor was present</b>
<b>Consultation</b>		
Relevant patient history not taken/reviewed/given significance	10	33%
Clinically indicated tests not conducted	7	23%
Clinically indicated examination not conducted	2	7%
<b>Diagnostic</b>		
Non-specific/atypical symptoms	19	63%
Failure to acknowledge limitations of diagnostic testing	15	50%
Co-morbidities drew focus	11	37%
Failure to consider differential diagnoses	6	20%
Multiple providers/poor inter-provider communication	1	3%
Treated symptoms in isolation	1	3%
<b>Follow-up and Referral</b>		
Appropriate referral not made	7	23%
Inadequate follow-up of symptoms	6	20%
Poor communication with secondary care	6	20%
Inadequate follow-up of test results	2	7%

As can be seen from Table 10, the most common delayed diagnosis factors observed in cases of lung cancer were 'non-specific/atypical symptoms' (present for 63% of GPs concerned), 'failure to acknowledge limitations of diagnostic testing' (50%), 'co-morbidities drew focus' (37%), and 'relevant patient history not taken/reviewed/given significance' (33%).

We found that diagnostic error in relation to lung cancer was significantly associated with 'co-morbidities drew focus' (RR=2.9, p=0.01), and 'failure to acknowledge limitations of diagnostic testing' (RR=4.5, p<0.01), as compared to other cancer types.

### **What does this tell us?**

Our results are similar to what has been seen both internationally and within New Zealand. As can be seen from the literature, lung cancer is a difficult diagnosis for GPs to make.

As noted above, we found the issue of co-morbidities drawing focus to be twice as likely to occur in cases of lung cancer diagnostic error than for other cancer types. Lung cancer generally presents with respiratory symptoms, such as a cough, chest pain and shortness of breath, which are indicative of many respiratory illnesses, most of which are benign. Its symptoms also mimic the symptoms of other illness that those at a higher risk for lung cancer are more likely to suffer from, such as chronic obstructive pulmonary disease. This complexity of diagnosis also often leads GPs to take a 'treat, watch and review' approach to diagnosis. As for colorectal cancer, a delay in diagnosis may occur when this strategy is carried out without the right information or in a context where the information is not appropriately analysed.

## Case Example

### Lung cancer: Co-morbidities drew focus

A woman with a significant smoking history and a diagnosis of chronic obstructive pulmonary disease (COPD) presented to her GP with a productive cough. The GP assumed that the cough was due to an infective exacerbation of her COPD and treated her with antibiotics.

Two months later the woman had a comprehensive COPD review undertaken by a practice nurse. The woman reported shortness of breath on mild exertion and a cough. Respiratory tests were consistent with her diagnosis of severe COPD. A month later the woman saw the GP again; this time with a cough which produced a watery discharge and continuing shortness of breath. No abnormalities were found on respiratory examination. The GP queried a viral cause for the symptoms and noted that the woman would be started on antibiotics if her symptoms did not settle.

A week later the woman reported that her cough was persisting and that she had developed a sore throat. She was started on antibiotics for exacerbation of her COPD. However, the woman failed to improve and 10 days later she presented to the GP with lethargy, dark urine, and pleuritic right posterior thoracic pain. On examination, sounds could be heard in her right lung base. A blood test was ordered and results were suggestive of inflammation. Upon receipt of these results the GP organised for the woman to be admitted to hospital. Further tests during that admission indicated the woman may have pneumonia and she was treated accordingly. Six months later the woman became unwell again with weight loss, ongoing lethargy and shortness of breath. The GP attributed these symptoms to a relapse of the woman's pneumonia and she was readmitted to hospital. A chest X-ray was consistent with a diagnosis of pneumonia. When the pneumonia failed to resolve with treatment a CT scan and biopsy were undertaken, leading to a diagnosis of lung cancer.

The Commissioner's expert clinical advisor considered that overall the GP's management of the woman was consistent with expected standards and that the diagnostic delay was due to the symptoms of malignancy being masked by her pre-existing co-morbidities. The woman's symptoms, including weight loss, chronic cough, shortness of breath and lethargy, were masked by persistent lung infections and were as consistent with her diagnosis of severe COPD as they were with lung cancer. Given the consistency of those symptoms with the woman's pre-existing COPD, a chest X-ray was not indicated. When a chest x-ray was carried out its results were consistent with COPD and pneumonia, not malignancy.

Taking this advice into account, the Deputy Commissioner took no further action on the complaint. no further action was taken on the complaint.

The complexity of lung cancer diagnosis is further exacerbated by the fact that the primary diagnostic test used in primary care, the chest x-ray, is not always reliable. Studies have found that 23% of patients who had at least one chest x-ray requested by primary care in the year before lung cancer diagnosis had a negative result. Although chest x-rays can be used as a tool to trigger referral, a negative result may be an unsafe basis on which to exclude lung cancer.

Analysis of the HDC complaint data showed that, for 50% of GPs concerned, a negative chest x-ray contributed to the delayed diagnosis of lung cancer. It appears that the overreliance on negative chest x-rays was a significant cause of diagnostic delay for this type of cancer.



## Case Example

### **Lung cancer: Failure to acknowledge limitations of diagnostic testing**

A woman presented to her GP with chest pain and difficulty breathing. The woman had a history of smoking and a family history of lung cancer. A chest x-ray was taken and was normal. However, preliminary tests were suggestive of possible upper gastrointestinal tract issues and the GP referred her to a gastroenterologist. The gastroenterologist undertook a gastroscopy which showed chronic superficial gastritis.

Over the next 9 months, the woman continued to complain to various GPs at the clinic about gastric reflux, loss of appetite, weight loss and back pain. Blood tests and a spinal x-ray were all normal.

A year after her first presentation, the woman saw her GP with breathlessness and chest and throat pain which was affecting her swallowing. A chest x-ray was ordered and returned normal results. The GP urgently referred the woman to an ENT clinic.

A month later, the woman reported a cough, persistent throat and chest pain and continuing weight loss. The GP requested sputum samples, but the samples were judged as unsuitable for analysis. Blood tests were ordered and were normal.

The following month, the woman returned with a persistent cough and debilitating retrosternal pain. The GP referred her to the surgical outpatient clinic for further investigation of this pain.

The woman was seen by an ENT specialist who found no abnormalities on physical examination. An ultrasound and barium swallow were ordered and were normal. The specialist concluded that there was no ENT cause for her symptoms. The woman was then seen by a surgeon who made a provisional diagnosis of costochondritis.

The woman made repeated presentations to the clinic over the next two months and her general deterioration was noted. At the end of that time, the GP noted an enlarged lymph node and requested a CT scan and fine needle biopsy of the lymph node. This biopsy revealed lung cancer.

The Commissioner's expert clinical advisor noted that the GPs in this case were inappropriately reassured by specialist reports. He advised that the sensitivity of chest x-rays for the diagnosis of lung cancer is variable and CT scans are more specific. He stated that, in retrospect, given the woman's smoking history and family history of lung cancer, the woman's GPs made an error in not considering lung cancer to be a strong enough possibility to insist that specialist providers carry out a CT scan or to consider referral to a respiratory specialist to exclude a lung malignancy. However, it was also noted that the woman presented with a complex and atypical mix of symptoms, which were initially more consistent with a gastrointestinal diagnosis than a respiratory one. The clinicians in this case "went to some length" to try and find a cause for her symptoms, although they were unsuccessful.

Taking these mitigating factors into account the Deputy Commissioner decided to take no further action on this complaint. However, she did ask the GPs to reflect on the importance of "professional intuition" and the need for medical professionals to investigate further on suspicion of a possible differential diagnosis with timely referrals.

Relevant patient history not taken/reviewed/given' was found to have contributed to the delayed diagnosis of lung cancer for 33% of GPs concerned. However, this factor was not found to be significantly associated with lung cancer vis-à-vis other cancer types.

In many such cases, the GP did not correctly record or review the patient's smoking history. It has been suggested that, given smoking is such a strong risk factor for the development of lung cancer, GPs should have a much higher suspicion for lung cancer in patients with a smoking history who present with non-specific respiratory symptoms.

## **Skin Cancer**

### **Introduction**

Skin cancer often presents with very specific symptoms and providers usually hold a high suspicion for skin cancer on presentation of such symptoms. As a result, skin cancer tends not to be associated with long diagnostic delays.

### **What does the HDC data show?**

As noted earlier in this report, the percentage of cases in the HDC complaint data that concerned skin cancer was the same as the percentage of all cancer cases involving skin cancer in New Zealand generally. The delay in diagnosis in these cases was also relatively short (averaging five months, compared to eight months for all cancer types).

As can be seen from Table 11, the most common delayed diagnosis factors identified as contributing to a delayed diagnosis of skin cancer were 'non-specific/atypical symptoms' (present for 67% of GPs concerned), 'inadequate follow-up of symptoms' (29%), and 'patient not reporting symptoms' (25%).

The issue of patient not reporting symptoms was found to be significantly associated with skin cancer (RR=6.5,  $p < 0.01$ ), compared to other cancer types investigated.

**Table 11.** Delayed diagnosis factors present for skin cancer in the HDC complaint data

Delayed diagnosis factors	Number of GPs for whom the factor was present	Percentage of GPs for whom the factor was present
<b>Consultation</b>		
Relevant patient history not taken/reviewed/given significance	3	13%
Clinically indicated tests not conducted	2	8%
Clinically indicated examination not conducted	1	4%
<b>Diagnostic</b>		
Non-specific/atypical symptoms	16	67%
Failure to consider differential diagnoses	3	13%
Co-morbidities drew focus	1	4%
Failure to acknowledge limitations of diagnostic testing	1	4%
Multiple providers/poor inter-provider communication	1	4%
Test interpretation error	1	4%
<b>Follow-up and Referral</b>		
Inadequate follow-up of symptoms	7	29%
Appropriate referral not made	4	17%
Poor communication with secondary care	4	17%
Inadequate follow-up of test results	2	8%
<b>Patient factors</b>		
Patient did not report symptoms	6	25%
Patient did not attend	1	4%

**What does this tell us?**

This was the only cancer type in which patient factors seemed to play a role in delayed diagnosis, with the patient not reporting symptoms contributing to diagnostic delay for a quarter of the GPs concerned.

This may be due to the nature of skin cancer, where patients often present to GPs with moles or lesions, yet the incidence of melanoma diagnosis is low. Patients may be reassured by previous benign diagnoses and fail to report subsequent changes to a lesion or new lesions.

This result may also be linked to GPs not providing the patient with appropriate safety-netting advice, that is, not emphasising to the patient the importance of returning for review if they notice any other skin changes or the appearance of any new moles or lesions. This accords with our finding that the inadequate follow-up of symptoms was also a prominent delayed diagnosis factor for skin cancer.

## Case Example

### Skin cancer: Patient did not report symptoms

A man in his late twenties presented to his GP a number of times over a two year period for issues related to his eczema. At three separate consultations the GP carried out a review of the man's moles. No remarkable lesions were found during any of these examinations.

The man did not present to the GP again until three years later, when he presented with two lesions; one on his abdomen and one on his back. He complained that both these lesions had recently become inflamed and were bleeding. On examination, the GP thought that both lesions were most likely benign although there was some potentially abnormal variability in colouring. Therefore, he excised both lesions for histology. The histology report diagnosed the lesions as superficial spreading melanoma. The GP referred the man for further excision of the lesions. The man chose to see a private surgeon for this excision. The man later presented to this surgeon with a groin lump and was diagnosed with melanoma metastasis.

The man complained to HDC about the delay in his skin cancer diagnosis, reporting that he felt sufficiently reassured by the GP during previous skin checks to not be concerned about the irritation he then experienced from his moles.

The Commissioner's expert clinical advisor concluded that the GP's management in this case was not inconsistent with expected standards. There was no clinical documentation to support the man's contention that he had mentioned these lesions to the GP in earlier years. It was noted that the man was at a relatively low risk for melanoma – he was young and had no personal or family history of skin cancer. The expert further advised that it was certainly possible for the man's moles to have developed suspicious features between his first consultations and the consultation three years later, but the man did not consult with the GP over that period and there was therefore no opportunity for the GP to have reviewed the lesions.

Taking this advice into account, the Deputy Commissioner decided to take no further action on the man's complaint. However, it was highlighted to the GP that this case should serve as a reminder of the high incidence rate of melanoma in New Zealand and the importance of having a low threshold of suspicion for melanoma when patients present with concerns about lesions.

## Breast Cancer

### **Introduction**

Breast cancer is one of the cancers least affected by diagnostic delay. This is often attributed to the fact that it usually presents with specific symptoms that are well understood by both providers and patients.<sup>2 14</sup> In New Zealand, breast cancer is also often diagnosed via national screening programmes and so bypasses the primary care stage of the diagnostic journey. However, the literature does show that when patients with breast cancer present atypically, for example, a young patient or a patient without a breast lump, diagnostic delays can be substantial.<sup>17 18</sup> Other studies have also found that breast cancer can be prone to diagnostic delay where GPs choose an inappropriately long follow-up time in relation to the checking of test results or symptom resolution.<sup>11</sup>

### **What does the HDC complaint data show?**

The delayed diagnosis factors identified in the HDC complaint data in relation to the delayed diagnosis of breast cancer are reported in Table 12 below.

**Table 12.** Delayed diagnosis factors present for breast cancer in the HDC complaint data

Delayed diagnosis factors	Number of GPs for whom the factor was present	Percentage of GPs for whom the factor was present
<b>Consultation</b>		
Clinically indicated examination not conducted	3	21%
Clinically indicated tests not conducted	3	21%
Relevant patient history not taken/reviewed/given significance	3	21%
<b>Diagnostic</b>		
Non-specific/atypical symptoms	7	50%
Failure to consider differential diagnoses	3	21%
Failure to acknowledge limitations of diagnostic testing	3	21%
Multiple providers/poor inter-provider communication	2	14%
Co-morbidities drew focus	1	7%
Treated symptoms in isolation	1	7%
<b>Follow-up and Referral</b>		
Appropriate referral not made	5	36%
Inadequate follow-up of symptoms	5	36%
Poor communication with secondary care	2	14%
Inadequate follow-up of test results	1	7%
<b>Patient factors</b>		
Patient did not report symptoms	2	14%
Patient did not attend	1	7%

The most common delayed diagnosis factors identified for breast cancer were 'non-specific/atypical symptoms' (at issue for 50% of the GPs concerned), 'inadequate follow-up of symptoms' (36%), and 'appropriate referral not made' (36%). None of these factors were found to be significantly associated with breast cancer diagnosis as distinct from the other types of cancer in the HDC complaints data.

### **What does this tell us?**

Our findings are largely consistent with the literature. The high degree of contribution of non-specific/atypical symptoms to delayed diagnosis of breast cancer may indicate that GPs need to be made more aware of presentations of breast cancer that do not include a palpable lump. The cases also suggest that, in order to avoid diagnostic error, breast symptom resolution must be proactively followed up by GPs. Patients may be falsely reassured by the atypical nature of their symptoms and by receiving a benign initial diagnosis by GPs, and so may not return for follow-up. It is important that GPs communicate to patients the importance of follow-up if their symptoms persist.

## Case Example

### Breast cancer: Inadequate follow-up of symptoms

A pregnant woman in her early 40s visited her midwife for a routine check-up. The midwife found a lump in the woman's left breast and advised her to see her GP.

The woman presented to her GP two days later, reporting a three-day history of a painful lump in her breast. The GP noted that on examination there was a 3cm lump. He considered that this lump was most likely due to an infection of the breast tissue possibly caused by a blocked milk duct. The GP prescribed a 10-day course of antibiotics and documented his intention to refer the woman to a specialist if the lump did not respond to this treatment.

The woman re-presented a week later and advised the GP that there had been some reduction in the size of the lump and that it was not as painful as it had been previously. The GP did not perform a physical examination of the breast. The GP advised the woman to continue to take the antibiotics and that he would review her in three months following the birth of her child.

Two months later the woman moved to another city, where she told her new midwife that she had a lump in her breast. This resulted in the woman being immediately referred to the nearest breast screening service where she was diagnosed with breast cancer.

The Commissioner's expert clinical advisor advised that the initial diagnosis of a breast tissue infection and the decision to treat the infection and review the lump the following week was appropriate. However, the expert viewed the failure of the GP to conduct a breast exam at the second consultation with severe disapproval. The expert also stated that the decision to follow-up the woman in three months was completely unacceptable; advising that breast cancer in pregnancy is particularly aggressive and needs urgent management.

The Commissioner held that by not examining the woman at the second consultation, or scheduling timely follow-up, the GP did not provide the woman with services with reasonable care a skill and therefore, the GP was found in breach of the Code.

The Commissioner concluded that the management errors made in this case indicated significant gaps in the GP's knowledge of obstetric care and so referred the GP to the Medical Council for a competency review.

The Commissioner also referred the GP to the Director of Proceedings who brought proceedings (or legal action) against the GP.



## Prostate Cancer

### **Introduction**

Research suggests that diagnostic delays for prostate cancer can be long.<sup>2</sup> Such delay is often attributed to the fact that prostate cancer often presents with non-specific lower urinary tract symptoms (LUTS) which are most likely to have a benign cause.<sup>2</sup> However, it would be expected that the effect of these non-specific symptoms would be somewhat ameliorated by following the guidelines set out in the publication "Suspected Cancer in Primary Care: Guidelines for investigation, referral and reducing ethnic disparities"<sup>3</sup> which states that GPs should perform a PSA, a DRE and test for genitourinary infection for any man presenting to primary care with LUTS and that all men with a high PSA reading in the absence of infection and/or a mass on DRE should then be urgently referred to a specialist.<sup>3</sup> It should be acknowledged that, when applying these guidelines, there is a need to apply clinical judgement regarding factors such as the age of the patient, for example, a 22 year old man with LUTS is far more likely to have a sexually transmitted infection than a prostate problem, and therefore, a PSA and DRE may not be clinically indicated in this situation.

### **What does the HDC complaint data show?**

As can be seen from Table 13 below, the most common delayed diagnosis factor identified in the HDC complaint data as contributing to a delayed diagnosis of prostate cancer was 'inadequate follow-up of test results' (at issue for 64% of GPs concerned).

**Table 13.** Delayed diagnosis factors present for prostate cancer in the HDC complaint data

<b>Delayed diagnosis factors</b>	<b>Number of GPs for whom the factor was present</b>	<b>Percentage of GPs for whom the factor was present</b>
<b>Consultation</b>		
Clinically indicated examination not conducted	3	27%
Clinically indicated tests not conducted	1	9%
Relevant patient history not taken/reviewed/given significance	1	9%
<b>Diagnostic</b>		
Multiple providers/poor inter-provider communication	2	18%
Test interpretation error	2	18%
Failure to consider differential diagnoses	1	9%
Failure to acknowledge limitations of diagnostic testing	1	9%
Non-specific/atypical symptoms	1	9%
Treated symptoms in isolation	1	9%
<b>Follow-up and Referral</b>		
Inadequate follow-up of test results	7	64%
Appropriate referral not made	3	27%
Poor communication with secondary care	3	27%
Inadequate follow-up of symptoms	2	18%
Inadequate follow-up of referral	1	9%

On analysis, we found prostate cancer to be significantly associated with 'inadequate follow-up of test results' (RR=16.3,  $p < 0.01$ ) when compared to other cancer types.

### **What does this tell us?**

Surprisingly, given what is indicated in the literature, prostate cancer was one of the only cancers for which 'non-specific/atypical symptoms' was not one of the key delayed diagnosis factors. Rather, 'inadequate follow-up of test results' was by far the most common factor observed, arising for 64% of GPs concerned. In every instance, this related to the follow-up of abnormal PSA results. Diagnostic error due to 'inadequate follow-up of test results' was 16 times more likely to occur in relation to prostate cancer than in relation to any of the other cancer types. Here, a distinction needs to be made between the use of PSA monitoring in asymptomatic men as a screening test for prostate cancer versus the use of PSA as a diagnostic aid in men with LUTS or other symptoms suggestive of prostate cancer. However, detection of an elevated PSA on screening does require appropriate follow-up and a number of cases of failure to follow-up on abnormal results fell into this category.

## 4. Conclusion

The factors that typically contribute to the delayed diagnosis of cancer by GPs can be grouped into four main categories, depending on the stage at which they occur in the diagnostic process: consultation factors, diagnostic factors, follow-up and referral, and patient factors. Within these main categories are a number of subcategories of delayed diagnosis factors that may operate in any particular case.

In the HDC complaint data, the most commonly seen delayed diagnosis factors were 'non-specific/atypical symptoms' (at issue in the delayed diagnosis for 57% of GPs concerned), 'poor communication with secondary care' (25%), 'appropriate referral not made' (23%), 'failure to acknowledge limitations of diagnostic testing' (22%), and 'relevant patient history not taken/reviewed/given significance' (21%). These findings were broadly consistent with findings in relevant international studies.

The delayed diagnosis factors identified in the HDC complaint data varied by type of cancer involved. However, for colorectal, lung, skin and breast cancers, non-specific/atypical symptoms was the most common factor involved. This was not the case for prostate cancer.

Colorectal cancer was significantly associated with the appropriate examination not being conducted (usually a DRE) and the treating of symptoms (often anaemia) in isolation compared to the other cancer types. For lung cancer, diagnostic error was significantly associated with co-morbidities drawing focus (often COPD) and inappropriate reliance on test results (usually a chest x-ray). Skin cancer diagnostic error was significantly associated with the patient not reporting symptoms, and prostate cancer was strongly associated with the inadequate follow-up of test (PSA) results. Again, these findings sit comfortably within the international and national literature, and seem to make sense given the characteristics of the particular cancer types and their diagnosis.

# REDUCING DELAYS IN THE DIAGNOSIS OF CANCER BY GPs

## 1. Introduction

As illustrated by the case examples in this report, cancer can be difficult to diagnose. In particular, the HDC complaint data shows that a non-specific or atypical presentation of cancer contributed to the diagnostic error for 57% of GPs concerned. Additionally, the cancer mimicked the symptoms of a co-morbid disease 19% of the time. This makes it very difficult for GPs to choose which symptoms seen in primary care may be indicative of cancer and require further testing or referral for specialist involvement. Despite this, in the vast majority of cases, GPs identify and manage cancer diagnoses in a timely and appropriate fashion.

However, as also illustrated by some of the case examples in this report, there are instances where diagnostic error could have been prevented or, at least, the delay in diagnosis could have been shortened.

In many cases, it is appropriate for the GP to take a 'treat (for possible benign cause), watch and review' strategy, with referral for further testing being made if symptoms persist or evolve on review. However, in order to carry out this strategy appropriately, GPs must gather the necessary information, synthesise that information correctly, and take the appropriate actions. Many of the factors that led to a delayed diagnosis as identified in the HDC complaint data represent an error at some point in that process.

This section collates the lessons from our findings and from the case examples in this report, and applies those learnings to the various stages of the diagnostic process, and to other key interactions involved in cancer diagnosis. The aim is that we might assist GPs to recognise and address factors that contribute to diagnostic error in cancer diagnosis.

## 2. Learnings for GPs

### Consultation

Consultation with a patient is, at least in part, about data gathering. It is the key opportunity (and, in some cases, the only opportunity) for the GP to obtain information from which to form a diagnosis.

#### **Undertake clinically indicated examinations and tests**

We found that, in the HDC complaint data, 17% of GPs failed to undertake clinically indicated examinations, and 12% failed to undertake clinically indicated investigations.

Although the presenting symptoms of cancers may have many causes, physical examinations and tests can immediately provide the GP with important information regarding whether they should be suspicious for cancer. For example, in a patient presenting with rectal bleeding, the finding of a mass on DRE would indicate the need for urgent referral because of a high suspicion of malignancy as the underlying cause; in an older male patient presenting with LUTS, an elevated PSA test in the absence of infection may increase suspicion of a prostate malignancy underlying his symptoms.

Recommended examinations and tests for specific clinical scenarios are outlined for GPs in “Suspected Cancer in Primary Care: Guidelines for investigation, referral and reducing ethnic disparities”.<sup>3</sup>

Employing a “watch and review” strategy will generally only be appropriate if clinically indicated examinations and tests have first been conducted in response to the symptoms.

#### **Examine the patient in the context of their past history**

Twenty one percent of the GPs in the cases in the HDC complaint data failed to take/review/give significance to relevant patient history. Accurately taking and reviewing the patient's past history in the context of their presenting symptoms may indicate to the GP whether they need to carry a higher suspicion of cancer for that particular patient. For example, a chronic cough in an ex-smoker should raise more suspicion for lung cancer as the underlying cause than it might in a patient who has never smoked. It is, therefore, important to take an accurate smoking history and give this history significance when the patient presents with respiratory symptoms.

Giving due regard to a patient's history is one of the basic building blocks of the diagnostic process. It is important to do such basics well – to “read the notes, ask the questions, talk to the patient”.

### **Ensure comprehensive documentation is kept**

In order to form a comprehensive clinical picture that allows appropriate diagnostic strategies to be selected, it is vital that GPs document all examinations, test results, possible differential diagnoses, relevant history and symptoms. It can also be important to document the absence of symptoms. For example, in a patient who presents with a change in bowel habit without rectal bleeding, it can be just as important to document the absence of rectal bleeding as it is to document the presence of a change in bowel habit.

Detailed and thorough documentation also becomes important when the patient sees multiple GPs. We found that, in the HDC complaint data, poor inter-provider communication within primary care was a factor that contributed to diagnostic error for 13% of GPs.

## **Diagnosis**

The actual forming of a diagnosis, or a working diagnostic hypothesis, is at the heart of the diagnostic process. It involves the analysis of data and information, and should be sufficiently flexible to respond to changes in that information.

### **Be aware of the limitations of diagnostic testing (e.g. sensitivity and specificity of tests)**

An inappropriate reliance on negative test results contributed to diagnostic error for 22% of the GPs in the HDC complaint data. In the case of lung cancer, 50% of the GPs concerned were falsely reassured by a negative chest x-ray.

GPs should be aware of the limitations of diagnostic testing and be prepared to retain consideration of a diagnosis of malignancy in the face of negative investigations, especially if the symptoms continue to persist or evolve.

### **Consider all relevant differential diagnoses**

The failure to consider all relevant differential diagnoses contributed to diagnostic error for 15% of the GPs in the HDC complaint data. In the complaints where this was an issue, the GP tended to hold a cognitive bias towards their original diagnosis. This often led to tunnel vision and the GP becoming blind to persistent or evolving symptoms which did not fit with their original diagnosis. It is important for clinicians to be flexible enough to change their management plan and differential diagnoses in response to new or persistent symptoms.

Although cancer is an uncommon diagnosis in primary care, and although many of its symptoms are non-specific and more commonly have a benign cause, it is important that GPs remain alert to the possibility that particular presentations may be indicative of underlying malignancy.



### **Hold a suspicion for cancer despite co-morbidities**

A focus on co-morbidities was a particular feature of delays in the diagnosis of lung cancer in the HDC complaint data, with this contributing to diagnostic delay for 37% of the GPs concerned.

Although the diagnosis of cancer can be particularly hard to make when it mimics the symptoms of pre-existing disease, it is important to acknowledge that cancer may co-exist with other morbidities. For example, although the presence of haemorrhoids may explain rectal bleeding, colorectal cancer may co-exist with the haemorrhoids and the GP may need to continue to hold a suspicion for cancer, particularly in older patients who are at an increased risk of colorectal cancer.

### **Beware of treating symptoms in isolation**

We found treating symptoms in isolation to be a particular issue for colorectal cancer diagnosis. Although this factor only contributed to a delayed diagnosis of colorectal cancer for 10% of GPs, it caused substantial delays in all such cases and represented a departure from the guidelines set out in "Suspected Cancer in Primary Care: Guidelines for investigation, referral and reducing ethnic disparities"<sup>3</sup>. Symptomatic treatment for any symptom that may have a serious underlying pathology, particularly in the absence of structured follow-up, is not usually appropriate. For example, unexplained iron deficiency anaemia should not be simply treated with iron supplements, further investigation is required to exclude occult gastrointestinal blood loss as a possible cause.

## **Follow-up and referral**

Following up patients, and referring them as appropriate, will often be part of the sequence of the diagnostic process. Failures in these areas may be due to individual GP factors, or may arise as a result of system issues, such as computerised processes for sending and logging referrals or reviewing test results.

### **Provide safety netting advice**

Nineteen percent of GPs in the HDC complaint data failed to follow-up whether a patient's symptoms had resolved with treatment. This may represent a failure to undertake the review portion of a "watch and review" strategy.

This issue highlights the importance of providing patients with safety netting advice. Patients are often reassured when cancer is not immediately diagnosed as a cause for their symptoms and therefore, it is important for GPs to communicate to the patient the significance of persisting or evolving symptoms and the importance of returning for review. However, the GP should not generally rely on the patient alone to assess the significance of their symptoms and re-present as they may minimise on-going symptoms once reassured there is no immediate suspicion of underlying malignancy.

In some cases, it is important to pro-actively follow the patient up to ensure that their symptoms have resolved with treatment and no other concerning symptoms have appeared.

### **Utilise robust follow-up systems**

'Inadequate follow-up of test results' contributed to diagnostic error for 12% of GPs in the HDC complaint data, and this issue was the predominant reason for delays in the diagnosis of prostate cancer. We found that 'inadequate follow-up of test results' caused substantial diagnostic delays and provided a reason for why prostate cancer was subject to the longest diagnostic delays of all cancers investigated.

Inadequate follow-up of test results is often due to a failure of systems; it can represent a failure of the GP to correctly input the need for follow-up on test results into their system or a failure of the system to have good follow-up procedures in place. Being vigilant about having good systems and using those systems appropriately is vital in avoiding this delayed diagnosis factor.

### **Advocate for the patient in the secondary care system**

Poor communication with secondary care was one of the predominant issues identified in the HDC complaint data, contributing to diagnostic error for a quarter of the GPs concerned. In most of these cases the GP was not as effective as they could have been in advocating for their patient in the secondary care system.

It is the GP's responsibility to ensure that a patient gets referred for appropriate diagnostic workup and specialist intervention. This starts with the GP following the guidelines set out in "Suspected Cancer in Primary Care: Guidelines for investigation, referral and reducing ethnic disparities"<sup>3</sup> and making the appropriate referrals in response to a particular set of symptoms and/or test results. Twenty three percent of GPs in the HDC complaint data failed to follow those guidelines in making referrals.

Atypical presentations can pose dilemmas for GPs as there may not be enough 'red flags' or 'indicators' to meet the threshold for the referral to be accepted by the public health system. This puts increased onus on GPs to request tests and make referrals at clinically appropriate times. In these cases, GPs may need to be vigilant of changing clinical indicators to align referrals with the guidelines set out in the suspected cancer guidelines.<sup>3</sup>

When making a referral, GPs should ensure that they provide the specialist with the information needed to appropriately triage the patient, and should then follow-up on the referral to ensure that it has been received and appropriately triaged.

### 3. How can patients help?

There are also lessons within the findings of this report for patients. Our aim here is to empower patients in their interactions with GPs in order to help minimise the risk of diagnostic delay. If patients have an understanding of the diagnostic process and the errors that can occur within it, there may be actions they can undertake to mitigate the effects of such errors.

#### **Attend/make follow-up appointments**

Cancer can often mimic the symptoms of benign disease, and in most cases these symptoms will be due to benign causes which can be easily treated within primary care. However, if symptoms persist in the face of initial treatment or if new symptoms emerge it is important to communicate this to the GP. These persistent or evolving symptoms are what will lead to the GP holding a suspicion for cancer.

Given the non-specific and atypical ways in which cancer can present, "Suspected Cancer in Primary Care: Guidelines for investigation, referral and reducing ethnic disparities"<sup>3</sup> will often not recommend referral for diagnostic testing until symptoms can be considered persistent or until 'red flag' symptoms emerge. Within this context, attending follow-up or review appointments becomes vital to the diagnosis of cancer. For example, a cough and shortness of breath will commonly be indicative of a respiratory infection. However, if these symptoms persist for longer than three weeks then referral for a chest x-ray to exclude lung cancer may be required if persistence of the symptoms is unexplained, particularly if the patient is a smoker.

In this study, 'inadequate follow-up of symptoms' contributed to a delay in diagnosis for 19% of GPs. These cases often represented a failure by the GP to ensure that the patient returned for review or follow-up to ensure that their symptoms had resolved with initial treatment. In many cases, patients were reassured by the initial benign diagnosis of their symptoms and so would not recognise the significance of persistent or evolving symptoms and the need to re-present to their GP for further review.

#### **Report all symptoms to the GP**

The non-specific and atypical symptoms of cancer mean it can be difficult for patients to know which symptoms are significant enough to report to their GP. In the HDC complaint data patients not reporting significant symptoms contributed to delayed diagnosis for 7% of GPs.

International literature has found that patient delay is a significant contributor to misdiagnosis of cancer.<sup>2</sup> We consider it may be less prominent in our study because patients who did not report significant symptoms to their GP may be less likely to complain about a subsequent diagnostic delay.

Other studies have found that patients often delay in presenting to primary care with significant symptoms for a number of reasons, including; fear of embarrassment (that the symptoms are trivial or affect private areas of the body), fear of a cancer diagnosis, misinterpretation of symptoms, and a lack of knowledge of significant symptoms.<sup>20 22 33</sup> Studies in New Zealand have found that only two thirds of people surveyed could identify any common symptoms of lung cancer, and only 17% of people identified shortness of breath or chest pain as common symptoms.<sup>31</sup> Patients being too embarrassed to report the symptoms of colorectal cancer to their GP has also been named as a factor in the late diagnosis of this cancer in New Zealand.

Therefore, it is important that patients are both educated on what the common symptoms of all cancers are (rather than just the well-known ones, such as breast and skin) and that they feel as if they can report all symptoms to their GP. As noted above, it is especially important for patients to report any symptoms if they become persistent.

### **Proactively follow up test results and referrals**

In the HDC complaint data 'inadequate follow-up of test results' contributed to a delay in diagnosis for 12% of GPs and 'inadequate follow-up of referrals' contributed to diagnostic delay for 5% of GPs. When these errors did occur they were also often associated with longer diagnostic delays.

These errors often represent a failing of the systems and tools GPs use to ensure that follow-up occurs. For example, an abnormal test result may have been filed in the wrong location leading the GP to assume it was normal, or the appropriate alert may not have been put on a referral to ensure that it was sent. In these cases the GP is often not made aware of the error until the patient themselves proactively follows up the outcome of their test result or questions why their specialist appointment had not yet occurred. Therefore, the patient can play an important role in mitigating the effects of these errors by being aware that such errors can occur and proactively following up any tests results or referrals that they have not received.

## 4. Conclusion

Cancer can be difficult to diagnose. The way in which it presents makes delayed diagnosis an issue for both GPs and patients. Patients must decide which symptoms are worthy of presentation and GPs must decide which symptoms are worthy of further investigation. However, this study has identified some actions both GPs and patients can take to help protect against the the delayed diagnosis of cancer in primary care

For GPs, it is particularly important to:

- undertake clinically indicated examinations and tests;
- examine the patient in the context of their past history;
- ensure comprehensive documentation is kept;
- be aware of the limitations of diagnostic testing;
- consider all relevant differential diagnoses;
- hold a suspicion for cancer despite co-morbidities;
- beware of treating symptoms in isolation;
- provide safety-netting advice;
- utilise robust follow-up symptoms; and
- advocate for the patient in the secondary system.

For patients, it is helpful to:

- attend/make follow-up appointments;
- report all symptoms to your GP; and
- pro-actively follow-up on test results and referrals.



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# APPENDIX A: METHODOLOGY

## Setting

Data for this study came from the New Zealand Health and Disability Commissioner's current complaints database. This database contains all complaints received by HDC since 1 January 2004.

## Sample

From the complaints database we extracted all complaints received about general practitioners between 1 January 2004 and 31 December 2013. Keyword searches were run on these complaints to find those complaints which contained a reference to cancer. We then went individually through each of these complaints and extracted those which related to a consumer complaining about a missed or delayed diagnosis of cancer by a GP.

## Data collection

The variables of interest were: type of cancer, cancer outcome, length of diagnosis delay and what caused the delayed or missed diagnosis.

Type of cancer was derived from the clinical expert's advice. These types of cancers were then collapsed into categories in order to reflect the classifications used by The International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM). This allowed us to directly compare our data with that collected by the New Zealand Cancer Registry.

Cancer outcome was derived from the complaint letter, in which complainants often reported what effect the cancer had on their life. This outcome was then classified into one of four categories depending on the level of harm; whether it be minor, significant, major or death. These categories were taken from previous studies investigating harm in malpractice claims and were applied in the same way as in those studies<sup>1 2</sup>. These categories were:

- Minor physical harm (insignificant injury or minor temporary injury).
- Significant physical harm (major temporary or minor permanent injury).
- Major physical harm (significant permanent, major permanent, or grave injury).
- Death.

The length of diagnosis delay was taken from time of first presentation to the GP with an 'alarm symptom' to the final diagnosis being made.

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<sup>1</sup> Gandhi, T. K., Kachalia, A., Thomas, E. J et al. (2006). Missed and delayed diagnoses in the ambulatory setting: A study of closed malpractice claims. *Annals of Internal Medicine*, 145, 488-496.

<sup>2</sup> Phillips, R. L., Bartholomew, L. A., Dovey, S. M et al. (2004). Learning from malpractice claims about negligent, adverse events in primary care in the United States. *Quality and Safety in Health Care*, 13, 121-126.

What caused the delayed diagnosis was taken from what the expert clinical advisor articulated in their expert advice to the Commissioner. In order to construct a draft coding typology we reviewed the expert advice of 100 complaints and developed a list of categories for what the expert advisor had identified as causing the missed or delayed diagnosis. These categories were then discussed which led to further refinement and agreement on 17 factors, identified by an expert, which contributed to a delayed diagnosis of cancer by GPs. Up to 6 delayed diagnosis factors could be identified for each GP.

### **Data analysis**

The analyses for this study were descriptive. All analyses were conducted using STATA version 13 (StataCorp, College Station, Tex, USA).

Statistical analyses of cancer type were only carried out for the five most common types of cancer in our sample.

### **Number of GPs complained about**

We used simple linear regression in order to determine whether the number of GPs complained about overall and the number complained about in relation to a delayed diagnosis of cancer had significantly increased over time.

### **Clinical characteristics seen in the complaints**

This analysis was carried out at the complaint level. The cancer type and cancer outcome variables were dummy coded.

We used a z-test for proportions in order to determine whether there was a significant difference between the incidence of a type of cancer within the New Zealand population and the incidence of that same cancer within the HDC complaint data.

T-tests were used to test whether any cancer types were associated with significantly longer or shorter delays.

X<sup>2</sup> tests were used to test whether any cancer types were significantly associated with a particular cancer outcome. Where the sample size was less than five, Fisher's exact test was used. When a significant result was found, odds ratios were calculated to determine the odds of that outcome occurring for a specific cancer type relative to the other cancer types

### **Factors contributing to delayed diagnosis of cancer by GPs**

This analysis was carried out at the GP level. The cancer type and delayed diagnosis factor variables were dummy coded.

$X^2$  tests were used to test whether any cancer types were significantly associated with any delayed diagnosis factors. Where the sample size was less than five, Fisher's exact test was used. When a significant result was found, odds ratios were calculated to determine the odds of that factor occurring in the delayed diagnosis of a specific cancer type relative to the other cancer types.