POLICY BRIEF

The Royal New Zealand College of General Practitioners

THE ROYAL NEW ZEALAND COLLEGE OF GENERAL PRACTITIONERS

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Delayed diagnosis of cancer: in perspective

Some cancers are notoriously difficult to diagnose or need investigation of poorly differentiated symptoms, and diagnostic delays may be incorrectly attributed to poor professional performance.[1] The recent report by the Health and Disability Commissioner (HDC)[2] on delayed diagnosis of cancer in primary care has prompted the College to further examine the topic. This *Policy Brief* discusses the diagnosis of cancer in general practice and highlights key learnings for GPs from the HDC report.

Cancer in New Zealand

Cancer is the leading cause of death (28.9% in 2009) and a major cause of hospitalisation in New Zealand.[3] For Māori and people living in socioeconomically deprived areas, the burden of cancer is much higher. In 2011, 21 050 new cases of cancer were registered in New Zealand.*[4] It is expected that more New Zealanders will develop cancer and the effect of cancer will continue to increase as a result of population growth and people living longer.[5]

Internationally, New Zealand performs well in terms of overall cancer outcomes.†[5] The availability of treatment, quality of care, screening programmes, and public health initiatives are all likely to have had a role in improved survival rates.

However, a recent study has found that cancer survival in New Zealand was significantly lower than in Australia for male and female patients diagnosed in 2006–2010, suggesting that further improvements in the recognition, diagnosis, and treatment of cancer in New Zealand should be possible, particularly for Māori and low-income groups. Five-year relative survival ratios were 3.8% lower (61.3% vs 65.1%) for men and 4.2% lower (63.2% vs 67.4%) for women than in Australia.[6]

A diagnostic dilemma in general practice

The diagnosis of cancer is relatively rare for the individual GP, whose role has been described as sorting out the minority of patients needing urgent attention from the majority who are likely to have self-limiting disorders and where time can be used as a diagnostic and therapeutic tool.[7] The assessment of a classic 'textbook' presentation of cancer is relatively straightforward, but the more usual and difficult scenario is the patient with vague symptoms and comorbidity.[8]

Although cancer is often referred to as a single entity, there can be significant variation between types of cancer and even within types of cancer, leading to unpredictable differences in patterns of symptoms, speed of onset, and progression of symptoms.[9] A fast-growing tumour is likely to cause symptoms with more rapid progression, leading to a quicker diagnostic journey, but worse outcomes because of aggressive growth and spread. Conversely, a slower-growing tumour is likely to cause symptoms that develop more insidiously, take longer to diagnose, but have better outcomes with treatment offered.[9]

* The New Zealand Cancer Registry is a population-based tumour register of all primary malignant disease. Basal and squamous cancers arising in the skin are not required to be reported, except for those of the genitalia.

† The OECD uses breast, cervical, and colorectal cancer as indicators of how well countries are delivering cancer care.

Key messages

Cancer is an uncommon diagnosis in primary care, and many of the associated symptoms are non-specific, and more commonly have a benign cause.

Most patients subsequently diagnosed with cancer are referred to a specialist after one (50%) or two (30%) consultations.

The HDC has identified potential solutions to help address preventable diagnostic delays of cancer. These include:

- undertaking clinically indicated examinations and tests in response to symptoms and considering a 'watch and review' strategy only after they have been conducted.
- holding a suspicion of cancer despite comorbidities.
- being aware of the limitations of diagnostic testing and treating symptoms in isolation.
- being flexible enough to change the management plan and differential diagnoses in response to new or persistent symptoms.
- providing patients with safety-netting advice and using robust follow-up systems.

Around 90% of cancers present symptomatically.[10] However, most patients with cancer present to GPs with symptoms that have low or very low positive predictive values for cancer. Even alarm symptoms or 'red flags' (e.g. rectal bleeding, dysphagia, haemoptysis, and haematuria) have positive predictive values for cancer of less than 10% in men.[1,11] These values are up to twofold lower in women, and even lower for young adults and children (less than 1%).[1,12] This means the great majority of patients with these symptoms will not have cancer.[1]

The GP's dilemma is to keep vigilant for 'alarm symptoms' that are rarely caused by cancer, and to be aware that most potential cancer symptoms are very similar to those of common chronic or minor diseases.[9] While it can be argued that greater vigilance is needed, it is also important not to routinely over-investigate or make inappropriate referrals.[8] US surgeon and public health researcher Atul Gawande aptly describes overtesting as creating a new, anticipated problem of overdiagnosis – 'the correct diagnosis of a disease that is never going to bother you in your lifetime.'[13]

British research has found that the majority of patients subsequently diagnosed with cancer are referred to a hospital specialist after one (50%) or two (30%) consultations.[1,14,15] However, a substantial minority (20%) of patients with cancer visit a primary care doctor with relevant symptoms three or more times before referral. Cancers where most patients present with non-specific symptoms (e.g. back or abdominal pain) are more frequently associated with multiple consultations than those where most patients present with fairly specific symptoms (e.g. a palpable breast lump or a visible skin lesion).[1]

Multiple GP consultations prolong diagnostic intervals and potentially affect clinical outcomes and care experience. However, it has been argued that multiple GP consultations are more likely to stem from diagnostic difficulty and the need for investigation of poorly differentiated symptoms rather than suboptimal professional practice.[1]

Timely diagnosis of cancer

Cancer diagnoses are made on screening, as incidental findings, and following the presentation of symptoms. GPs play an important role in improving cancer survival through early diagnosis. However, diagnosis of cancer can be a complex process, often involving secondary health care.[8]

Reducing diagnostic delays may lead to diagnosis of cancer of an earlier disease stage and improved clinical outcomes.[9]

Delayed diagnosis can have a negative effect on quality of life, with the use of more toxic treatments when cancer is diagnosed at an advanced stage, and increased psychological distress.[8] However, it is difficult to quantify the effect of diagnostic delays on survival or mortality. Patients with rapidly progressive disease who present with advanced cancer may have poor outcomes despite prompt referral.[9]

Delays: patient, doctor and the health care system

Diagnostic delay considers the time from when the patient presents with the first sign or symptom of cancer to the diagnosis of cancer.[2] Delays can occur for many reasons and may occur at different stages of the cancer diagnostic journey.[8] Hansen and colleagues describe three categories of diagnostic delay of cancer:[16]

- Patient delay
- Doctor delay (primarily the GP)
- System delay (including primary health care, secondary health care, and treatment delay)

Patient delay is usually defined as the length of time a patient is aware of symptoms before they seek health care advice. The way patients interpret and label their symptoms influences help-seeking behaviour in cancer.[8] For instance, symptom appraisal may account for at least 60% of the total delay in seeking a medical diagnosis in women with breast and gynaecological cancer.[17] Fear of cancer or embarrassment and anxiety have also been identified as factors contributing to delay in patient presentation. Further, being older, and cultural and ethnic factors may also contribute to late presentation of cancer.[8] Notably, Māori and Pacific peoples often present with cancer at a later disease stage.[18] These themes highlight the importance of improving public information and awareness of relevant symptoms.

The literature highlights factors contributing to the doctor delay, i.e. the interval between the first consultation and referral for diagnostic tests or specialist assessment. These have included:[8]

- symptom misattribution
- no examination or investigation of cancer
- comorbidity
- patient characteristics (e.g. men experienced longer doctor delays).

System delay refers to the interval between referral and definite diagnosis or treatment. This includes waiting times for tests in secondary care, further investigations of symptoms in secondary or specialist care, and administration.[8]

The HDC report: learning from complaints

Patient complaints are a valuable source of insight into health care safety.[19] The HDC report analyses data from complaints about 228 GPs and actual delayed diagnoses of cancer that

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were made to the HDC between 1 January 2004 and 31 December 2013.‡ The learnings in the report are drawn from the trends and patterns emerging from the complaints at an aggregate level. This is in contrast to the more traditional approach of sharing lessons from an investigation opinion where the Commissioner has found an individual provider in breach of the Code of Health and Disability Services Consumers' Rights.

The HDC report provides a constructive analysis of delays that have occurred in the process of diagnosing cancer in primary care. The underlying patterns in the report are similar to international findings, confirming the value of the HDC's findings.

Clinical diagnostic errors or delays are often (and may be incorrectly) considered as failures linked to doctors' skills and training. It is important to note that while the complaints analysed involved an actual delayed diagnosis of cancer, the report provides no indication as to whether or not the delay reflected inadequate care provided by the GP.

However, it is worth noting caveats to the interpretation of complaints data. Data are prone to being skewed because complaints are 'refracted through the lens of patients' behaviour'.[20] The diagnosis of cancer, where outcomes (death and morbidity) tend to be more severe, is more likely to generate a disproportionately large number of complaints about a perceived or actual delay. Thus, quality concerns identified through complaints need to be interpreted carefully. Complaints cannot be used as a proxy for the incidence or prevalence of particular adverse events in health care systems.[20]

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While the report focuses on diagnostic delays in general practice, it should be stressed that the care provided by individual GPs comprises only one aspect of the diagnostic process. Improvements in the diagnosis of cancer requires a multifaceted approach including the patient, doctor and health care system. Creative solutions such as clinical decision support tools and natural language computer auditing programmes to alert GPs to 'red flag' patients warrant as much consideration.

Common issues and the HDC's potential solutions for GPs

Overall the HDC report suggests scope for improving the timeliness of diagnosis of cancer in general practice. Set out below are the HDC's findings on the factors contributing to a delayed diagnosis of cancer and the HDC's potential solutions to the problems identified. The recommended solutions have been derived from a robust process where expert advice was obtained from a number of GP clinical advisors. The College encourages GPs to reflect on their own practice in light of the potential solutions. The HDC also identifies the role of patients in minimising the risk of diagnostic delay.

Table 1 (page 4) sets out the common specific issues identified and the HDC's suggested solutions, in four categories:

1. Consultation factors
2. Diagnostic factors
3. Follow-up and referral
4. Patient factors.

The most common factors identified as contributing to the delayed diagnosis of cancer were:

1. non-specific/atypical symptoms (at issue in the delayed diagnosis for 57% of GPs concerned)
2. poor communication with secondary care (25%)
3. appropriate referral not made (23%)
4. failure to acknowledge limitations of diagnostic testing (22%)
5. relevant patient history not taken/reviewed/given significance (21%).

Non-specific/atypical symptoms was the most common factor involved for colorectal, lung, skin and breast cancers, but not for prostate cancer. Diagnostic errors were more common with atypical or non-specific symptoms.

Delayed diagnostic factors for five cancers most commonly appearing in the HDC complaint data are set out in Table 2 (page 5).

The most frequently complained about cancer types were:

- colorectal cancer (27% of cases in the HDC data) – a significant over-representation compared with the national incidence rate
- lung cancer (14%)
- skin cancer (11%)
- breast cancer (7%) – a significant under-representation compared with the national incidence rate
- prostate cancer (5%) – a significant under-representation compared with the national incidence rate
- lymphomas (5%).

Colorectal and lung cancers were more prone to a delay in diagnosis, due to their non-specific presenting symptoms. Breast cancer was often diagnosed in a more timely fashion as symptoms are well known to both GPs and patients.

‡ During the study period, 243 GPs were complained about, and in some complaints, more than one GP contributed to the delay in diagnosis. Fifteen GPs were excluded because the patient did not have cancer or no delayed diagnosis was found to have occurred as determined by the HDC clinical expert advisor.

Table 1. Contributing factors to the delayed diagnosis of cancer by GPs, and the HDC's suggested solutions

Delayed diagnosis factors	Common specific issues	The HDC's suggested solutions
Consultation factors	■ Relevant patient history not taken/reviewed/given significance ■ Clinically indicated examination not conducted	■ Accurately take and review the patient's past history in the context of their presenting symptoms. ■ Undertake clinically indicated examinations and tests in response to symptoms. Recommendations can be found in **Suspected cancer in primary care: guidelines for investigation, referral and reducing ethnic disparities**.[18] ■ Consider a 'watch and review' strategy only after clinically indicated examinations and tests have been conducted. ■ Document all examinations, test results, possible differential diagnoses, relevant history and symptoms.
Diagnostic factors	■ Non-specific/atypical symptoms ■ Failure to consider differential diagnoses ■ Failure to acknowledge limitations of diagnostic testing	■ Remain alert to the possibility that particular presentations may be indicative of underlying malignancy. ■ Acknowledge cancer may coexist with other morbidities. ■ Be aware of the limitations of diagnostic testing (e.g. sensitivity and specificity of tests). ■ Be prepared to retain consideration of a diagnosis of malignancy in the face of negative investigations, especially where symptoms persist or evolve. ■ Be flexible enough to change the management plan and differential diagnoses in response to new or persistent symptoms. ■ Avoid providing symptomatic treatment where serious underlying pathology might exist, particularly in the absence of structured follow-up.
Follow-up and referral factors	■ Appropriate referrals not made ■ Poor communication with secondary care ■ Inadequate follow-up of symptoms	■ Follow guidelines in **Suspected cancer in primary care: guidelines for investigation, referral and reducing ethnic disparities**[18] and request tests and make referrals at clinically appropriate times. ■ For atypical presentations, be vigilant of changing clinical indicators; align referrals with the suspected cancer guidelines. ■ Provide patients with safety-netting advice. ■ Avoid relying on the patient alone to assess the significance of their symptoms and to re-present (as they may have been falsely reassured). ■ Provide sufficient referral information so that the specialist can appropriately triage the patient. ■ Follow up on the referral to ensure that it has been received and appropriately triaged. ■ Have and use good systems for follow-up.
Patient factors	■ Patient delay	■ Educate patients on the common symptoms of all cancers. ■ Ensure patients can feel they can report all symptoms. ■ Make patients aware that errors can occur. Encourage patients to: ■ attend/make follow-up appointments. ■ report all symptoms to their GP, including if symptoms persist or new symptoms emerge. ■ proactively follow up on test results and referrals.

Table 2. Key factors in delayed diagnosis per cancer and the HDC's suggested solutions

Cancer	Key factors in delayed diagnosis	The HDC's suggested solutions
Colorectal	■ Non-specific/atypical symptoms ■ Clinically indicated examination not conducted –usually digital rectal examination (DRE)§ ■ Inadequate follow-up of symptoms ■ Treating symptoms (often anaemia) in isolation§ ■ Poor communication with secondary care	■ Gather all required information before adopting a 'treat (for benign illness) watch and review' approach. ■ Undertake clinically indicated examinations, e.g. rectal or abdominal examination. ■ Exclude a serious cause before commencing treatment. ■ Be aware of treating symptoms in isolation. ■ Organise a review to ensure that symptoms have resolved with treatment. ■ Watch for persisting or evolving symptoms which may indicate a more serious cause. ■ Note that patients may be falsely reassured by treatment for a benign disease (such as haemorrhoids) and fail to return proactively for GP review.
Lung	■ Non-specific/atypical symptoms ■ Failure to acknowledge limitations of diagnostic testing (usually chest X-ray)§ ■ Comorbidities drew focus (often COPD)§ ■ Relevant patient history not taken/reviewed/given significance	■ Take, review, and give significance to the relevant patient history. ■ Record or review the patient's smoking history and hold a much higher suspicion for lung cancer in patients with a smoking history who present with non-specific respiratory symptoms. ■ Gather and appropriately analyse the right information before adopting a 'treat, watch and review' approach to diagnosis. ■ Note that chest X-rays are not always reliable. Be aware of the over-reliance on negative chest X-rays.
Skin	■ Non-specific/atypical symptoms ■ Inadequate follow-up of symptoms ■ Patient not reporting symptoms§	■ Provide adequate follow-up of symptoms. ■ Provide the patient with appropriate safety-netting advice. ■ Emphasise the importance of returning for review if the patient notices any other skin changes or the appearance of any new moles or lesions.
Breast	■ Non-specific/atypical symptoms ■ Inadequate follow-up of symptoms ■ Appropriate referral not made	■ Be aware of presentations that do not include a palpable lump. ■ Proactively follow up breast symptom resolution (patients may be falsely reassured by atypical symptoms). ■ Communicate the importance of follow-up if symptoms persist.
Prostate	■ Inadequate follow-up of test results (PSA)§	■ Follow guidelines in **Suspected cancer in primary care: guidelines for investigation, referral and reducing ethnic disparities**[18] while applying clinical judgement. ■ Gather the necessary information, synthesise the information correctly, and take the appropriate actions before adopting a 'treat (for possible benign cause), watch and review' strategy, with referral for further testing if symptoms persist or evolve on review. ■ Perform a prostate-specific antigen (PSA), a DRE, and test for genitourinary infection in any man presenting with lower urinary tract symptoms (LUTS). ■ Make an urgent referral to a specialist for all men with a high PSA in the absence of infection and/or a mass on DRE. ■ Make a distinction between 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. ■ Ensure appropriate follow-up for the detection of an elevated PSA on screening.

§ Factors found by the HDC to be significantly associated with the specific type of cancer compared to other cancer types analysed.

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Further information:

Delayed diagnosis of cancer in primary care. Complaints to the Health and Disability Commissioner 2004–2013 (The Health and Disability Commissioner, 2015)

Suspected cancer in primary care (New Zealand Guidelines Group, Ministry of Health, 2009)

Suspected cancer in primary care: guidelines for investigation, referral and reducing ethnic disparities (New Zealand Guidelines Group, Ministry of Health, 2009).

The unequal impact of cancer (bpac^{nz}, 2008)

If you have any questions about this issue, or would like to express a view on this topic, please contact the College's policy team: policy@rnzcgp.org.nz

The Royal New Zealand College of General Practitioners is the professional body that provides training and ongoing professional development for general practitioners and rural hospital generalists, and sets standards for general practice.

PO Box 10440, The Terrace, Wellington 6134 | T +64 4 496 5999 | F +64 4 496 5997 | E rnzcgp@rnzcgp.org.nz | W www.rnzcgp.org.nz