



# Improving the efficiency of cancer care

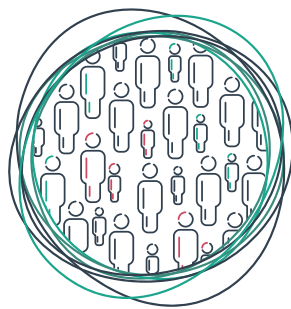
## A focus on diagnosis

### About this focus brief

This brief is the first of a series focused on four key themes emerging from the All.Can patient survey, which aimed to obtain patients' perspectives on where they encountered inefficiency in their care, looking at the entire care continuum as well as the broader impact of cancer on their lives. The survey was open to current or former patients with any type of cancer; caregivers were also able to fill in the questionnaire on behalf of the patient, if needed. Nearly 4,000 cancer patients and caregivers responded to the survey, providing insights into which aspects of their care could be improved. The survey used the All.Can definition of inefficiency, namely resources that are not focused on what matters to patients.

This document focuses on what respondents said about their diagnosis. For more information about the survey methodology and a full report on the survey findings, please visit <https://www.all-can.org/what-we-do/research/patient-survey/>





# Introduction

**Early diagnosis** – accurately identifying cancer without delay at the earliest possible stage and rapidly providing treatment – is recognised as a core component of quality cancer care.<sup>1,2</sup> It has been shown to result in improved survival and lower costs of care.<sup>1,3,4</sup>

**The ability to diagnose cancer early, and the associated benefits, vary by cancer type:** cancers that have clear signs and symptoms (for example: breast, endometrial or testicular cancer) are easier to diagnose than cancers that have non-specific symptoms.<sup>5</sup> For some cancers (e.g. breast, colorectal and cervical), population screening programmes offer a good opportunity to undertake early detection. However, even for cancers where population screening is not possible, there is good evidence that earlier detection can improve outcomes.

**In some cases, early diagnosis may only be of benefit if an effective treatment option exists.<sup>1</sup>** Some patients who have a rapidly progressive cancer and present for diagnosis at an advanced stage may still have poor outcomes despite prompt diagnosis and referral.<sup>5,6</sup>

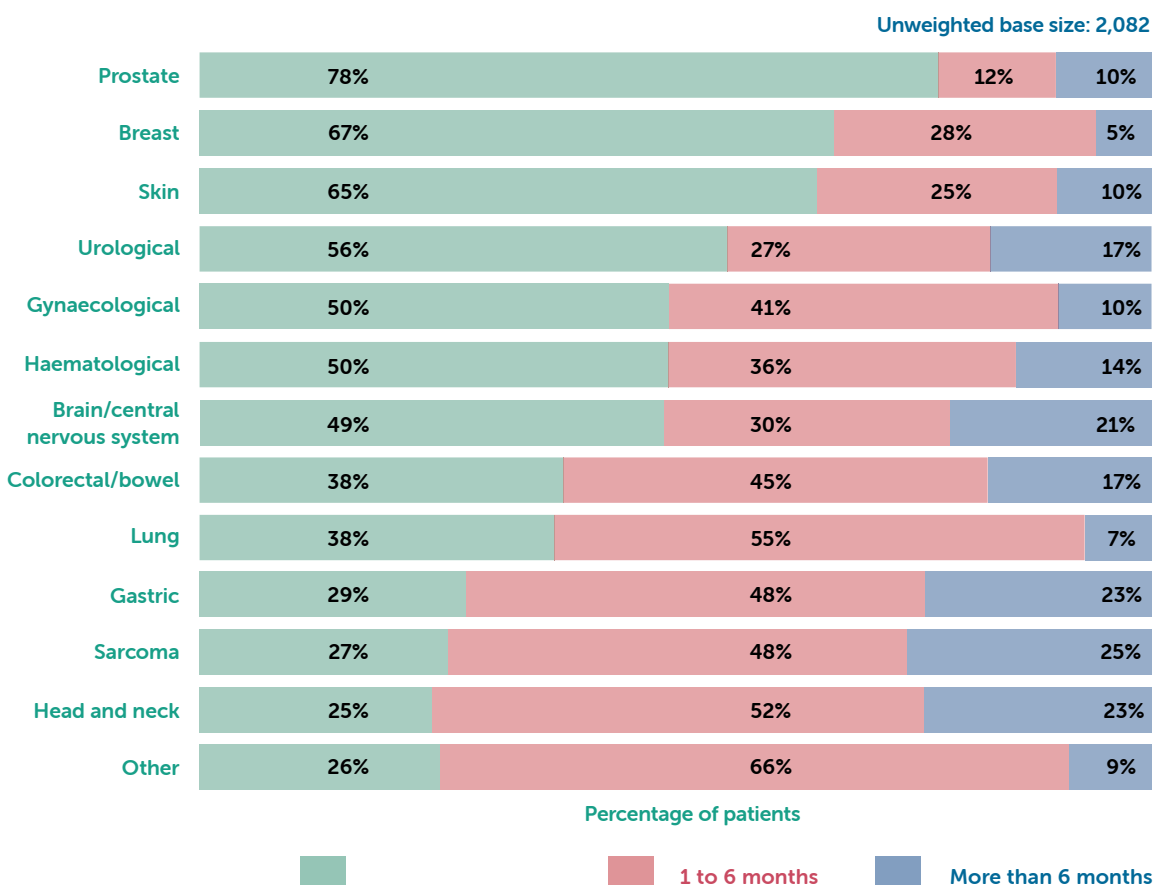
**In the All.Can patient survey, diagnosis was the area where patients felt there was the greatest inefficiency out of all aspects of their care.** One clear opportunity to improve efficiency from the patients' perspective is thus to ensure a swift, accurate and appropriately delivered diagnosis.

# What the survey told us about diagnosis\*

**Symptoms of cancer are not always recognised immediately.** Among respondents whose cancer was diagnosed outside of a screening programme, 32% reported that their cancer was diagnosed as something else (initially or multiple times). This varied by cancer type.

**Delays in diagnosis vary considerably by cancer type.** For example, nearly 80% of prostate cancer respondents said their cancer was diagnosed in less than a month, while for head and neck cancer respondents this figure was only 25% (Figure 1).

Figure 1. Time to diagnosis, by cancer type (among respondents whose cancer was detected outside of a screening programme)



\* All findings in this brief are from the full report of findings: All.Can. 2019. Patient insights on cancer care: opportunities for improving efficiency. Available from: [https://www.all-can.org/wp-content/uploads/2019/07/AllCan\\_international\\_patient\\_survey\\_findings.pdf](https://www.all-can.org/wp-content/uploads/2019/07/AllCan_international_patient_survey_findings.pdf)

**Delays in diagnosis can affect the entire experience of care.** For respondents whose cancer was detected outside of a screening programme, delayed diagnosis (>6 months) was associated with a more negative view of many aspects of care, information and support. Respondents who experienced delays more frequently stated that they were not sufficiently involved in shared decision-making than respondents with fewer delays. They also more frequently reported gaps in information on the signs and symptoms that indicate cancer might be returning or getting worse, and on available peer-support groups.

**The way diagnosis is communicated is important.** Some respondents reported a lack of empathy from healthcare professionals.



'Nothing would have changed the diagnosis, but the way I was treated and lack of communication made a difficult time horribly upsetting for me.'

Respondent from the United Kingdom

**Timing of delivering diagnosis also matters.** A number of respondents commented that healthcare professionals should make sure people are not alone when receiving their diagnosis and are immediately given a point of contact to address any questions that may arise – instead of having to wait several days to speak with a specialist about their cancer.



'A nurse called on a Friday and gave me the biopsy results and said a doctor wouldn't be available to speak to me until Monday. Worst weekend ever.'

Respondent from the United States

# How does early diagnosis contribute to greater efficiency in cancer care?

There are many benefits associated with early diagnosis, outlined below; however, not all cancer types will benefit equally.

## Better survival

Stage at diagnosis is a strong predictor of survival; delays in diagnosis can increase the risk of cancer progression and lead to fewer treatment options and poorer clinical outcomes.<sup>1,5</sup> For example:

- In melanoma, the five-year survival rate is estimated at 95% for stage I, compared to below 20% for metastasised tumours.<sup>2</sup>
- More than 80% of patients with lung cancer survive for at least one year if diagnosed at the earliest stage, compared to around 15% if diagnosed with the most advanced stage.<sup>7</sup>
- In ovarian, breast and colon cancer, 90% of women diagnosed at the earliest stage survive for at least five years. By contrast, only 5% of women with metastatic ovarian cancer, 15% of women with metastatic breast cancer and 14% with metastatic colorectal cancer survive for at least 5 years.<sup>7,8</sup>

## Reduced anxiety and psychological distress

A study of patients with endometrial and ovarian cancer found significant associations between time to diagnosis and patient-reported psychological distress – increased time to diagnosis was associated with a more negative quality of life.<sup>6</sup>

## Lower costs

It is generally less costly to treat cancer at an early stage than at a late stage. A UK report suggested the cost of treating colon, rectal, ovarian and lung cancer at stage IV was 2–3 times the cost of treating these cancers at stage I (see Table 1).<sup>3</sup>

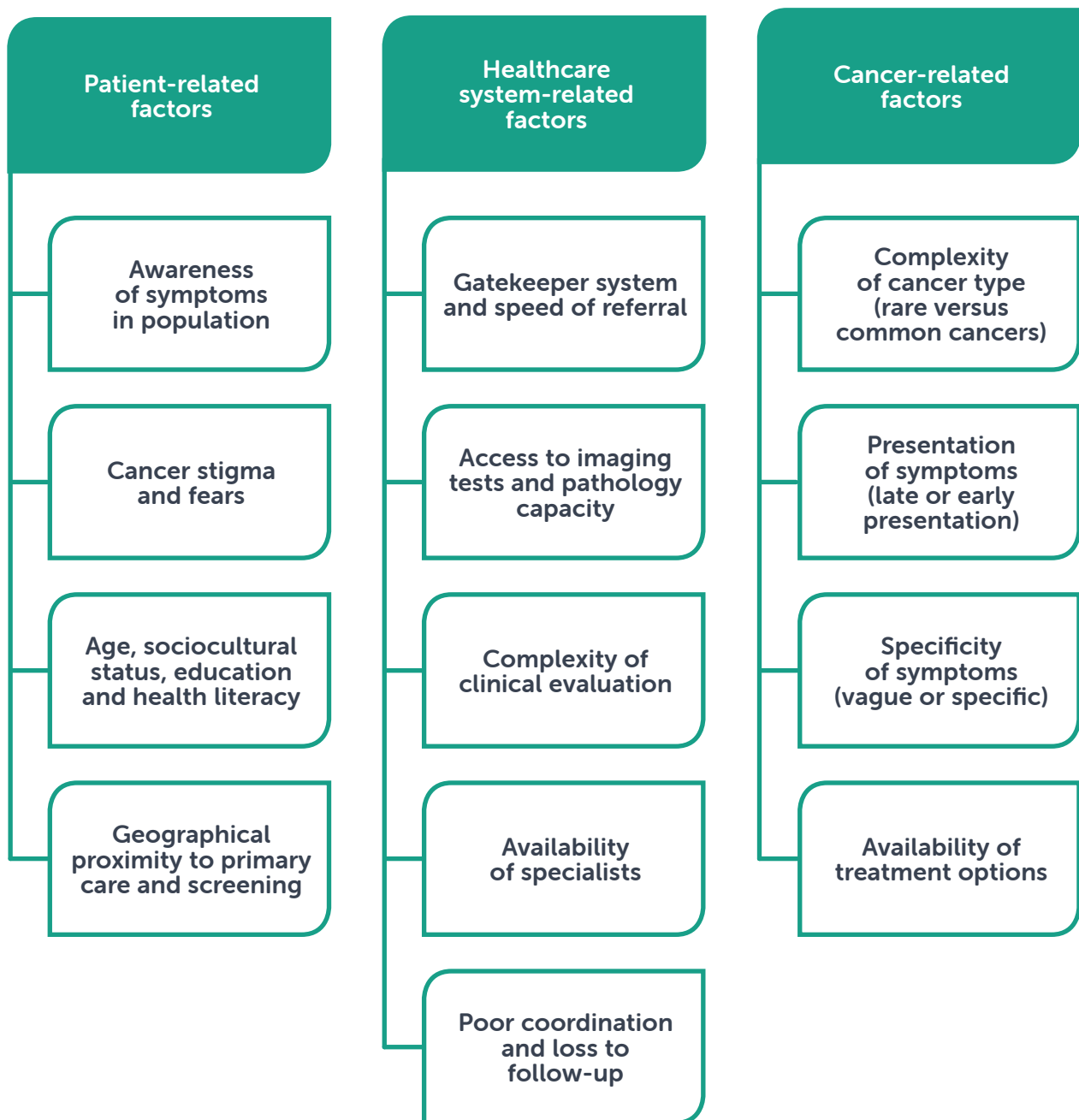
**Table 1. UK costs for treating four types of cancer at stage I and stage IV<sup>3</sup>**

Cancer type	Stage I cost	Stage IV cost
Colon	£3,373	£12,519
Rectal	£4,449	£11,815
Lung	£7,952	£13,078
Ovarian	£5,328	£15,081

# What can contribute to delays in diagnosis?

Delays in diagnosis are influenced by many factors and can occur at different stages in the diagnostic pathway. Causes for delays can be summarised largely as being a result of three main influences: patient-related, healthcare system-related and cancer-related (see Figure 2).<sup>1679</sup>

Figure 2. Factors contributing to delays in diagnosis



## Patient-related factors

**These factors can influence the speed of diagnosis as they may affect health-seeking behaviours.** Such factors include, but are not limited to, individuals' awareness of suspected cancer symptoms, fears and stigma associated with cancer, where they live in terms of access to primary care and screening, their age, sociocultural status, education and level of health literacy.

It is well established that age influences early diagnosis, with younger patients often experiencing more severe delays. Healthcare professionals may not suspect cancer in younger patients; younger people may also be ineligible for national screening programmes. In some instances, symptoms may not be taken seriously given a person's young age.<sup>10,11</sup> These influencing factors were reflected in the All.Can patient survey findings, with one respondent from Australia saying: **'After seeing multiple doctors, not one of them thought my symptoms could be related to cancer as I was 15 at the time and "too young" for a cancer diagnosis.'**

## Healthcare system-related factors

**These factors include the presence of a gatekeeper system, referral patterns from primary to secondary care, access and availability of diagnostic and staging tests, complexity of clinical evaluation and availability of specialists.** The speed of referral was a commonly mentioned issue among All.Can patient survey respondents, with many saying they had to press their doctors for a referral and that, as a result, it took too long to receive an eventual diagnosis.

## Cancer-related factors

**These factors include the complexity of cancer type, presentation of symptoms and availability of viable treatment options.** For example, backache is the most common symptom of myeloma, but only one in 1,000 adults reporting backache will actually have myeloma.<sup>6</sup> This illustrates the complexity in diagnosing certain cancer types. Accurate diagnosis may be particularly challenging in rare cancers due to their rarity of presentation and healthcare professionals' lack of familiarity with existing guidelines. Delayed diagnosis is known to contribute poorer five-year survival among rare cancers compared with more common cancers (47% compared to 65%).<sup>12</sup>

# What can be done to improve efficiency in early diagnosis?

**The importance of early and accurate diagnosis, combined with effective treatment options, has been widely recognised across the cancer community.** At the highest level, early diagnosis standards and good practices are outlined by the World Health Organization in a guide to early cancer diagnosis.<sup>1</sup> Early diagnosis is also a core component of national cancer plans, European Society for Medical Oncology (ESMO) clinical practice guidelines<sup>13</sup> and the Essential Requirements for Quality Cancer Care developed by the European CanCer Organisation (ECCO).<sup>2,14-16</sup>

Several countries have implemented programmes to help reduce diagnostic delays for cancer. Initiatives include:

- National screening programmes to detect cancer at an early stage – now implemented for breast, cervical and colorectal cancers at the population level in the majority of European countries<sup>16</sup>
- Targeted screening for high-risk populations (e.g. lung cancer in older smokers)<sup>16,17</sup>
- Educational campaigns to help raise awareness of cancer symptoms among the general population and avoid possible delays in presentation to a doctor<sup>6</sup>
- Rapid referral pathways, which have been implemented across many countries, including Australia, Canada, Denmark, Norway, Sweden and the UK.<sup>18-20</sup>

National guidelines and decision support tools are also said to be vital to optimise referral pathways and reduce the burden on specialist services.<sup>16</sup>

Some examples are presented as case studies below.



## **Case study 1. 'On the ball' campaign by Sarcoma UK: education packs for primary care physicians to recognise cancer symptoms**

The first sign of sarcoma is a lump on the body, and treatment is more effective if the cancer is detected when the lump is smaller than a golf ball. Sarcoma UK delivered more than 1,600 'On the ball' packs to primary care physicians across the UK to help them diagnose sarcoma more quickly. The packs contained golf ball keychains, diagnostic toolkits with clinical information and fact sheets about sarcoma, the red-flag signs and symptoms to be aware of and instructions for how to refer to specialist centres for diagnosis and treatment.<sup>21</sup>



### Case study 2. Cancer Patient Pathways in Denmark

Denmark has a higher cancer mortality rate than many other Western countries.<sup>22</sup> General practitioners (GPs) are often the first point of contact for people with potential cancer symptoms. These symptoms can be difficult to recognise, leading to delays in referral and diagnosis.<sup>23</sup> As a result, in 2008 the Ministry of Health introduced Cancer Patient Pathways (CPPs) – 32 cancer pathways linking GPs, hospitals and specialist diagnostic centres to improve the diagnostic process. When a GP suspects possible cancer, they can refer patients through one of the clear referral pathways based on the severity of symptoms. Shortly after the introduction of CPPs in Denmark, survival rates increased, excess mortality decreased and diagnosis waiting times shortened.<sup>24 25</sup>



### Case study 3. European Reference Networks for diagnosis and treatment of rare cancers

Rare cancers have an incidence of fewer than six cases per 100,000 people per year, making them difficult to research, diagnose and treat.<sup>12</sup> European Reference Networks (ERNs) were established to encourage collaboration between healthcare specialists in Europe on rare diseases, including rare cancers.<sup>26</sup> They are virtual networks that connect healthcare specialists across the EU through web-based clinical software and telemedicine tools.<sup>26</sup> This allows members to exchange information on diagnosis and treatment, laboratory procedures, real-world data collection and healthcare professional education.<sup>27</sup> The ERNs give patients and healthcare professionals access to important knowledge and expertise, without the need for patients to travel to other countries to access this specialist healthcare expertise.<sup>26 28</sup> Since the launch of ERNs in 2017, they have hosted more than 250 virtual clinical consultations.<sup>29</sup>



#### Case study 4. Find cancer early: public awareness campaign in Western Australia

Cancer outcomes for people living in rural and remote areas in Western Australia (WA) are worse than for those living in urban areas, and delayed presentation has been observed in this patient population.<sup>30</sup> The Government of WA Department of Health, in partnership with the Cancer Council of Western Australia, developed a public awareness campaign to provide the most up-to-date information on finding cancer early.

It provided information on its website to help people identify potential early symptoms of bowel, breast, lung, prostate and skin cancer, and guidance on what to do if they have these symptoms. The campaign focused on adults aged over 40 living in rural WA. The goal was to eliminate any barriers to early detection related to public knowledge of cancer signs and symptoms.<sup>31</sup>

The campaign was delivered in three regions, with two other regions acting as controls. It was promoted in local media and in the community. Following the campaign, populations living in these regions had higher knowledge of cancer symptoms compared to those in regions where there was no campaign. More than a quarter of people who had exposure to the campaign said they saw a GP as a result of their newfound knowledge of cancer symptoms.<sup>30</sup>

## Conclusion

Ensuring a swift, accurate, and appropriately delivered diagnosis is widely recognised as a core component of efficient cancer care. It is also a key area where respondents to the All.Can patient survey felt there were inefficiencies in their care, and represents an important opportunity for improvement.

Policymakers should consider these findings in future healthcare plans and investment decisions to ensure all patients who can benefit from early diagnosis are able to do so. Failure to act on these findings risks resulting in higher costs of care and worse patient outcomes, including poorer survival, for people who have been diagnosed with cancer.

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