



# Patient insights on cancer care: opportunities for improving efficiency

Findings from the international All.Can patient survey



Changing cancer care together

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# About All.Can

All.Can is an international, multi-stakeholder policy initiative aiming to identify ways we can optimise the use of resources in cancer care to improve patient outcomes.

All.Can comprises leading representatives from patient organisations, policymakers, healthcare professionals, research and industry, and consists of All.Can international, plus All.Can national initiatives currently established in 13 countries.

Members of All.Can international are:



**Matti Aapro**, Clinique Genolier, Switzerland; **Tit Albreht**, Institute of Public Health, Slovenia; **Neil Bacon**, International Consortium for Health Outcomes Measurement; **Kathleen Barnard**, Save Your Skin Foundation Canada; **Antonella Cardone**, European Cancer Patient Coalition (ECPC); **Szymon Chrostowski**, Polish Cancer Patient Coalition; **David Duplay**, healtheo360; **Alex Filicevas**, ECPC; **Pascal Garel**, HOPE (European Hospital and Healthcare Federation); **Stefan Gijsels**, Digestive Cancers Europe; **Rainer Hess**, GVG-Committee on Health Goals; **Matthew Hickey**, Intacare International Ltd; **Petra Hoogendoorn**, Goings-On; **Vivek Muthu**, Marivek Healthcare Consulting; **Kathy Oliver**, The International Brain Tumour Alliance; **Richard Price**, European CanCer Organisation; **Natalie Richardson**, Save Your Skin Foundation Canada; **Christobel Saunders**, University of Western Australia; **Thomas Szucs**, University of Basel; **Jan van Meerbeeck**, Antwerp University Hospital; **Lieve Wierinck**, Former Member of the European Parliament; **Andy Whitman**, Varian; **Titta Rosvall-Puplett**, Bristol-Myers Squibb; **Karin Steinmann**, Amgen; **Matthijs Van Meerveld**, MSD; **Aleksandra Krygiel-Nael**, Johnson & Johnson; **Shannon Boldon**, The Health Policy Partnership (secretariat); **Suzanne Wait**, The Health Policy Partnership (secretariat)\*

\* Baxter, Helspy and Roche joined All.Can international in July 2019 (in addition to the members listed here)



# Acknowledgements

This report was developed by All.Can international, with close input from Quality Health, along with All.Can national initiatives in Australia, Belgium, Canada, Italy, Poland, Spain, Sweden and the United Kingdom, and healtheo360 in the United States.

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All.Can international research and evidence working group

All.Can Australia

All.Can Belgium

All.Can Canada

All.Can Italy

All.Can Poland

All.Can Spain

All.Can Sweden

All.Can UK

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Cancer 52

Pink Ribbon Foundation

Maggie's

Womb Cancer Support UK

Womb Cancer Info

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# Glossary of terms

This glossary provides definitions of terms used throughout this report. These may be accepted definitions (referenced as appropriate), or All.Can's internal definitions of terms used in relation to the patient survey. **Where text is coloured light blue in the report**, it indicates that these terms are explained in the glossary.\*

## Active treatment

Any range of treatments intended to control or cure cancer (e.g. surgery, radiotherapy, chemotherapy, hormonal therapy or immunotherapy), as opposed to treatments patients may receive in addition to relieve symptoms or side effects of treatment (e.g. pain medication).<sup>1</sup>

## Allied health professionals

Health professionals other than those working in medicine, nursing or pharmacy who are involved with the delivery of health or related services. This includes, among others, dietitians, nutritionists, occupational therapists and physiotherapists.<sup>2</sup>

## Caregivers

'Any relatives, friends, or partners who have a significant relationship with and provide assistance (i.e. physical, emotional, medical) to a patient with a life-threatening, incurable illness.'<sup>3</sup>

## Inefficiency

The allocation of resources to anything that does not focus on what matters to patients.

## Integrated care

Care that is 'person-centred, coordinated, and tailored to the needs and preferences of the individual, their caregivers and family. It means moving away from episodic care to a more holistic approach to health, care and support needs, that puts the needs and experience of people at the centre of how services are organised and delivered.'<sup>4</sup>

\* Terms relating specifically to All.Can or the reporting of survey findings, such as 'inefficiency' and 'respondents', are not highlighted in light blue throughout the report.

## Multidisciplinary cancer care

Care used and implemented by multidisciplinary care teams, which are 'an alliance of all medical and healthcare professionals related to a specific tumour disease whose approach to cancer care is guided by their willingness to agree on evidence-based clinical decisions and to coordinate the delivery of care at all stages of the process, encouraging patients in turn to take an active role in their care.'<sup>5</sup>

## Out-of-pocket costs

The entirety of costs related to cancer that patients have to pay for themselves. This includes, for example, costs of diagnostic tests, treatment or care which are not covered by the patient's health insurance, travel costs associated with care, and the cost of childcare or household help.

## Palliative care

An approach to care 'that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering from pain and other problems, as well as psychosocial and spiritual support.'<sup>6</sup>

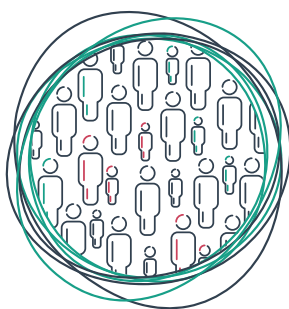
## Respondents

People who completed the All.Can patient survey. This may include both current and former cancer patients, as well as caregivers who completed the survey on behalf of patients who were themselves unable to do so or had passed away. The term is used in this report in relation to both weighted and unweighted data; for an explanation of data weighting please see **About this survey** (page 11).

## Shared decision-making

A process in which 'clinicians and patients work together to choose all aspects of care, based on clinical evidence, patient goals and informed preferences.'<sup>7,8</sup>

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# Executive summary

## Tackling inefficiency in cancer care: the patient perspective

**The prevalence, complexity and costs of cancer are rising** – yet, across healthcare, up to 20% of expenditure is thought to be spent on interventions that are deemed inefficient.<sup>9</sup> There is thus an urgent need to ensure that cancer care is delivered as efficiently as possible for the sustainability of our healthcare systems.

**All.Can defines efficiency as focusing resources on what matters to patients** – and our aim is to find practical solutions to improve the efficiency of cancer care. However, in order to tackle inefficiency from the patient's perspective, we believe that we need to gain a better understanding of where patients consider their care is not focused on what matters to them.

**The All.Can patient survey was designed with this purpose in mind.** It asked patients where they had encountered inefficiency across the entire continuum of cancer care, including diagnosis, treatment and care, ongoing support and the broader impact of cancer on their lives. The survey questionnaire made explicit our definition of inefficiency.

**Nearly 4,000 respondents from more than 10 countries participated in the survey from January – November 2018 – making this, to our knowledge, the largest international survey specifically aimed at obtaining patient perspectives on inefficiency in cancer care.**



### About this survey

The All.Can patient survey was conducted by Quality Health, with close input from the All.Can international research and evidence working group. It was disseminated via patient organisations and social media.

To find out more about the survey and to view additional materials, see [www.all-can.org/what-we-do/research/patient-survey/about-the-survey/](http://www.all-can.org/what-we-do/research/patient-survey/about-the-survey/)

## Key opportunities identified to improve efficiency in cancer care

Overall, the majority of survey respondents reported that their needs were sufficiently addressed during their care. However, the survey highlighted four crucial areas where respondents reported that they experienced inefficiency and where there are opportunities for improvement.

### 1. Swift, accurate and appropriately delivered diagnosis

Diagnosis was not always communicated to respondents in the most appropriate way. Respondents sometimes reported a **lack of empathy** from physicians, along with poor timing. For example, some were told they had cancer without a family member present, or had to wait several days to speak to a specialist after receiving their diagnosis.

When asked to select the one area of cancer care where they experienced the most inefficiency, **26%** of respondents chose diagnosis – more than any other area of cancer care.

Across all cancer types, **58%** of respondents had their cancer detected outside of a screening programme. As might be expected, this varied considerably by cancer type.

Among respondents whose cancer was detected outside of a screening programme, **delayed diagnosis** (>6 months) was associated with a more negative patient view of all aspects of care and support.

Time to diagnosis varied significantly by cancer type: nearly **80%** of prostate cancer respondents whose cancer was detected outside of screening said their cancer was diagnosed in less than a month, while for head and neck cancer respondents diagnosed outside of screening this was only **25%**.

Nearly a third (**32%**) of respondents whose cancer was detected outside of a screening programme reported that their **cancer was initially diagnosed as something different** – and, again, this varied considerably by cancer type.

### 2. Information, support and shared decision-making

In qualitative responses, **respondents said that they felt overwhelmed because too much information was given at once**, and they would have preferred to receive relevant information at appropriate points along the entire care pathway.

Nearly a third of respondents (**31%**) felt they were **not given adequate information** about their cancer care and treatment in a way that they could understand. Additionally, only half of respondents (**53%**) felt they were sufficiently **involved in making decisions** about their care.



Nearly two in five respondents (39%) felt they had **inadequate support to deal with ongoing symptoms and side effects**, both during and beyond active treatment. In particular, nearly a third (31%) felt that they lacked adequate information and care for dealing with the pain they experienced.

Respondents reported **a lack of information and support on what to expect** after their phase of **active treatment** was over. Specifically, more than a third of respondents (35%) felt inadequately informed about how to recognise whether their cancer might be returning or getting worse.

Gaps in information and support along the entire care pathway were more prevalent among those with more advanced cancers – reflecting similar findings in the literature that the support needs of these patients are often less well met than are those of patients with earlier-stage cancer.

### 3. Integrated multidisciplinary care

A common finding was that respondents felt there was sometimes a **lack of coordination** in their care – for example, they had no written care plan, nor a primary point of contact to whom they could direct questions.

Respondents stated that **cancer specialist nurses played a critical role** in filling this gap, acting as the respondents' companion and 'navigator' through the cancer care journey and helping them adapt all aspects of their lives to cancer – both during and after treatment.

Respondents wanted more **information about what they could do to support their treatment and recovery** in terms of diet, exercise and complementary therapies. In most countries, they had to pay for these services themselves. While three quarters (76%) felt that support from **allied health professionals** (dietitians, physiotherapists etc.) was always or sometimes available, nearly a quarter (24%) did not.

The majority of respondents (69%) said they **needed psychological support during or after their cancer care**, yet one in three (34%) of those who needed such support reported that it was unavailable. Even when psychological support was available, it was not always considered helpful. This may reflect the limited availability of specialist psycho-oncology services that are designed with the needs of cancer patients in mind.

In addition, respondents expressed **concerns about the impact of cancer on their families** and wanted psychological support for them as well.

More than two in five respondents (41%) were not given information at the hospital about available **peer-support groups**.

## 4. The financial impact of cancer

**Respondents frequently spoke of the financial impact that cancer had on their lives** – not just in terms of components of their care they may have had to pay for themselves, but also the cost of travel to medical appointments, childcare or household help, lost income from employment, and difficulties in getting insurance, mortgages or loans as a result of their cancer diagnosis.

More than half of respondents (**51%**) **paid for some part of their overall cancer care themselves**, either **out-of-pocket** or through private insurance. Respondents highlighted that this often created significant financial pressure for their families.

Apart from any possible care costs incurred, **36%** of respondents also referred to significant **travel costs** (i.e. to and from the hospital or clinic), and **26%** to **loss of employment income** – with those who were self-employed and caring for young children being especially vulnerable to financial insecurity due to their cancer diagnosis.

A recurring theme among respondents was that **the financial implications of cancer could last a lifetime**, in terms of people's ability to find or keep employment, reduced productivity for themselves and their **caregivers**, and an inability to get insurance or loans – even years after their treatment was finished.

## Conclusions

Findings from this survey identify some important areas where cancer patients have highlighted from personal experience that improvements are needed. They align with other findings from patient surveys in the literature, as well as the views of patient organisations in the All.Can network. These themes are intrinsically important as they represent respondents' perceptions of their care.

**As we strive to improve the efficiency of cancer care, we must ensure that the patient perspective is always central to our definitions and aims.** Each of the areas identified represents an opportunity to improve cancer care for patients. We need to give these issues due prominence in future cancer plans, policies and investment decisions to build truly patient-driven care. We need to develop integrated health and social policies to address the wide-reaching impact cancer can have on all aspects of people's lives.

**Making these changes could lead to real differences – to patients' outcomes, their experience of care and the financial impact cancer has on them, their families and ultimately on the health system and society as a whole.**





# About this survey

## Purpose

The aim of the survey was to obtain patients' perspectives on where they felt 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 questionnaire made explicit that we defined inefficiency as resources that are not focused on what matters to patients.

## Survey conduct and oversight

The design and conduct of the survey was led by Quality Health ([quality-health.co.uk](http://quality-health.co.uk)), a specialist health and social care survey organisation working with public, private and voluntary sector organisations to understand and improve patients' experience of their care and treatment. The All.Can international research and evidence working group provided close input and validation for all phases of the survey and analysis.

The survey was conducted internationally, with adapted versions in 10 countries ([Australia](#), [Belgium](#), [Canada](#), [France](#), [Italy](#), [Poland](#), [Spain](#), [Sweden](#), the [United Kingdom](#) and the [United States](#)).

## Survey development and patient interviews

The questions included in the survey were developed based on key themes that emerged from an international literature review and five exploratory pre-survey patient interviews. Iterative versions of the survey were revised based on input from the All.Can international research and evidence working group and other professional stakeholders where appropriate.

Country-specific versions of the survey were produced in relevant languages for each country and comprised both common questions and a maximum of five questions specific to the country. All surveys were developed with input from national All.Can initiatives (where they existed) and validated by patient representatives in each country. Additionally, an international 'generic' version of the survey was available in English, French, German and Spanish.

All versions of the survey were reviewed by the All.Can international research and evidence working group to ensure consistency between the different country versions. The survey asked respondents whether they would be willing to take part in a post-survey interview to provide more insights. These interviews were conducted in all participating countries except France, Spain and the United States (as there were no volunteers in those countries). Some of these interviews have been featured as patient stories throughout this report.

## Recruitment of respondents

The survey was made available online, with only a few paper copies distributed where they were requested. Respondents were predominantly recruited via patient organisations and social media (Facebook, Twitter and LinkedIn). A notable exception was in Australia, where the survey was also distributed by clinic staff in Western Australia; and the United States, where it was distributed via the *healtheo360* online platform. These methods of recruitment were chosen as they offered the most feasible and flexible approach to reaching a wide group of patients within the scope and budget of the project.

The survey was open to current and former cancer patients, irrespective of age and cancer type. Caregivers and former caregivers were also invited to respond on behalf of those patients who were unable to respond personally or who had passed away. Because caregivers were asked to complete the survey on behalf of patients, we use the term 'respondents' in this report when describing the survey results to refer to both patients and caregivers who completed the survey.

The survey ran from January to November 2018.

## Respondent characteristics

A total of 3,981 people completed the survey. The number of respondents by country is presented in **Table I**. Overall characteristics of respondents are presented in **Table II**.

**Table I. Overview of survey languages and responses (unweighted data)**

Country	Survey languages	Number of respondents*	% of total responses
Australia	English	861	22%
Belgium	French, Dutch, German	396	10%
Canada	English, French	342	9%
France	French	55	1%
Italy	Italian	97	2%
Poland	Polish	1135	29%
Spain	Spanish	50	1%
Sweden	Swedish	60	2%
United Kingdom	English, Welsh	360	9%
United States	English	513	13%
International 'generic' version	English, Spanish, German, French	112	3%
<b>Total</b>		<b>3,981</b>	<b>101%**</b>

\* The number of respondents for each country shown here represents the international grouping of respondents. Each country survey asked whether the respondent was a resident in that country; if the respondent said no, their response was added to the international sample but not the country-specific sample. Therefore, the number of respondents shown in each country profile (**Appendix 1**) may not match the number of respondents for each country shown here. For more information, please see the full survey methodology at [www.all-can.org/what-we-do/research/patient-survey/about-the-survey/](http://www.all-can.org/what-we-do/research/patient-survey/about-the-survey/)

\*\* This comes to a total of 101% due to rounding

**Table II. Characteristics of respondents (unweighted data)**

		Number	Percentage
<b>Respondents</b> (Age: mean 55 years; median 57 years)*	Patients (current or former)	3,450	89%
	Caregivers filling in the survey on behalf of a patient	432	11%
	Unspecified	99	n/a
<b>Gender distribution</b>	Male	787	20%
	Female	3,092	80%
	Unspecified	102	n/a
<b>Length of time since patients were first treated for this cancer, at the time they completed the survey</b>	Less than 1 year	964	25%
	1–5 years	1,706	44%
	More than 5 years	1,185	30%
	Don't know/can't remember	35	1%
	Unspecified	91	n/a
<b>Patients per cancer type</b>	Brain/central nervous system	97	2%
	Breast	1,656	42%
	Colorectal/bowel	216	6%
	Gastric cancers (oesophageal, stomach, pancreatic, liver or gall bladder)	123	3%
	Gynaecological	415	11%
	Haematological	362	9%
	Head and neck	161	4%
	Lung	167	4%
	Prostate	144	4%
	Sarcoma	72	2%
	Skin	203	5%
	Urological	186	5%
	Other**	115	3%
Unspecified	64	n/a	

\* The age distribution of survey respondents is similar to the age distribution of the general cancer patient population

\*\* For a full breakdown of cancer types included in these categories, please see the full methodology at [www.all-can.org/what-we-do/research/patient-survey/about-the-survey/](http://www.all-can.org/what-we-do/research/patient-survey/about-the-survey/)

## Reporting of quantitative findings

Quantitative findings from the survey are based on responses to the closed-ended questions in the survey. Percentages are calculated after excluding respondents who did not answer each particular question. All percentages are rounded to the nearest whole number, therefore the sum of percentages for all answers to a given question may not total 100%.

As the patient survey welcomed responses from all cancer patients (no quotas were set) in order to be as inclusive as possible, the relative volume of people responding to the survey varied between countries and cancer types. To correct for this, quantitative findings have been weighted by two factors:

- Representative cancer prevalence rates for each cancer type listed within each participating country
- General population statistics for each country as a proportion of the international total.

Where figures and tables in the findings section of this report state a base size, this is always the unweighted base size; however, all other data in these figures and tables have been weighted.



### To see the statistics used for these calculations

Please download a copy of the full methodology document at [www.all-can.org/what-we-do/research/patient-survey/about-the-survey/](http://www.all-can.org/what-we-do/research/patient-survey/about-the-survey/)

## Reporting of qualitative findings

Qualitative findings presented in the report are based on responses to open-ended questions. A thematic analysis was conducted of all qualitative responses to the survey, as well as the in-depth patient interviews. Final themes were agreed by consensus of the All.Can international research and evidence working group and Quality Health. The most relevant and illustrative quotes supporting these themes were then selected to substantiate each section in the report.

Qualitative responses were not quantitatively analysed due to the significant cost that translations and coding would have entailed on such a large sample. In addition, as not all respondents answered the open-ended questions, it would not be possible to give an accurate estimation of what proportion of all respondents might agree with each comment. Therefore, we have expressed these findings throughout the report as 'respondents' in the plural – without quantifying how many this concerned in each instance.

## Report structure

The report is organised into four themes that emerged from our findings. These themes closely mirror the closed-ended questions in the survey, which focused on specific areas known from previous research to be important to patient care. However, open-ended free-text questions allowed respondents to mention other areas of importance to them. As these responses were captured in the thematic analysis described above, they also contributed to our selection of the four themes highlighted in this report.

A selection of patient stories based on the post-survey patient interviews are also included throughout the report, providing more context and insights into the relevant sections. Names and some other identifying details have been changed to protect the anonymity of those respondents who shared their stories with us.

## Country-level findings

Country-level findings are reported in **Appendix 1**. These findings are unweighted and therefore not directly comparable between countries. Individual country reports were only developed where the survey had more than 50 responses, namely for Australia, Belgium, Canada, Italy, Poland, the United Kingdom and the United States. Country-level reports were not developed for France, Spain and Sweden.

## Limitations

Respondents participated in the survey voluntarily, therefore they are self-selected and represent the perspectives of patients who wanted to have their voices heard and were able to complete the survey. They do not necessarily reflect the perspectives of all cancer patients.

As the survey was primarily distributed online, it was limited to those who had access to the internet, were active on social media, or connected with a national or international patient organisation that shared the survey.

The survey was focused on patient experiences and processes of care and therefore did not include any questions regarding specific treatments or interventions.

Finally, it is important to mention that this report is focused on reporting the findings of the survey, and as such, we have not conducted an in-depth analysis of what improvements in health outcomes and overall efficiency of care could be achieved if the issues highlighted in this report were adequately addressed. All.Can is committed to exploring these questions further and it is our hope that this report may also encourage others within the research and policy community to do the same.



### For more information

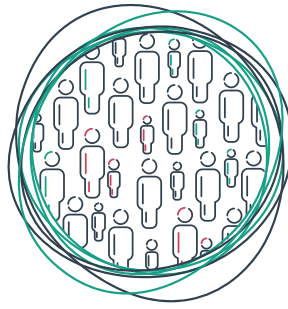
**The survey questionnaires and full methodology may be found on the All.Can website ([www.all-can.org/what-we-do/research/patient-survey](http://www.all-can.org/what-we-do/research/patient-survey)) along with other survey materials not included in this report – including further patient stories drawn from interviews conducted as part of the survey.**







# All.Can patient survey: findings



# Introduction

**The past decade has seen transformational advances in cancer care.** As the prevalence of cancer increases, governments and health systems around the world are struggling to fund these advances – and notions of value, efficiency and affordability have become increasingly important in the cancer policy debate. At least one fifth of total healthcare spending is thought to be wasted on inefficient care.<sup>9</sup> Moreover, removing wasteful or ineffective interventions could lead to a gain of approximately two years of life expectancy in industrialised countries.<sup>10</sup> Within this landscape, leading researchers and policy experts are trying to identify where inefficiencies lie, in order to pave the way for sustainable cancer care.<sup>11-13</sup>

**Unfortunately, the patient perspective is too often forgotten in current definitions of value and efficiency.**<sup>14</sup> Existing definitions are most often driven by health economists and healthcare professionals, with outcomes measures often based on processes that are easily measurable within healthcare systems, rather than on outcomes known to matter to patients.<sup>14 15</sup> Yet patients are, arguably, the only people who have full sight of the impact of their condition and care experience on their physical, emotional and mental wellbeing.<sup>14</sup> Their perspectives must, therefore, be built into any definitions of value and efficiency.

**All.Can defines inefficiency as the allocation of resources to anything that does not focus on what matters to patients.**<sup>16</sup> Our aim is to find sustainable solutions to improving cancer care. To guide these efforts, we need to gain a better understanding of where patients perceive their care is not focused on what matters to them – and find practical ways to remedy any gaps.

**The All.Can patient survey was designed with this purpose in mind:** we asked patients where they had encountered inefficiencies in their care, and where efforts were most needed to improve efficiency. We made our definition of inefficiency explicit throughout the survey.

**This report presents the main themes that have emerged from our findings.** While most respondents reported that their needs were sufficiently addressed, the findings also show that there is clear room for improvement. Each of the themes represents an opportunity for improving cancer care from the perspective of patients.

**Nearly 4,000 respondents from more than 10 countries participated in the survey – making this, to our knowledge, the largest international survey specifically aimed at obtaining patient perspectives on inefficiency in cancer care.** It is our hope that the insights gathered in this report may help guide patient-driven policies to improve the efficiency and sustainability of cancer care.

# Key opportunities

to improve efficiency from  
the patient perspective:

1. Swift, accurate and appropriately delivered diagnosis
2. Information, support and shared decision-making
3. Integrated multidisciplinary care
4. The financial impact of cancer



1

# Swift, accurate and appropriately delivered diagnosis<sup>i</sup>

## Key findings

- The way diagnosis is communicated was found to be important. Respondents reported a lack of empathy from physicians and poor timing – such as being told they had cancer without a family member present, or having to wait several days to speak to a specialist.
- When asked to select the one area of cancer care where they experienced the most inefficiency, **26%** of respondents chose diagnosis – more than any other area of cancer care.
- Across all cancer types, **58%** of respondents had their cancer diagnosed outside of a screening programme.
- Among respondents whose cancer was detected outside of screening:
  - Delayed diagnosis (>6 months) was associated with a more negative respondent view of all aspects of care and support
  - The speed of diagnosis varied significantly by cancer type
  - Nearly a third (**32%**) reported that their cancer was initially diagnosed as something different.



'No procedure was useless; everything happened very quickly and efficiently. Ultra-fast and professional support.' [Respondent from Belgium](#)



'Everyone was vague about my diagnosis. No one wanted to commit. I had to press the surgeon for a direct response. It took too long for a final diagnosis.' [Respondent from the United States](#)

<sup>i</sup> Please note that in this survey, patients were asked only about their experience of diagnosis from the moment they contacted the doctor or were seen as part of a screening programme.

# Overview of findings

## The way diagnosis was communicated was very important to respondents.

A theme that emerged from qualitative responses was that respondents<sup>ii</sup> sometimes felt that their instincts were not listened to by doctors – even when they themselves thought their symptoms may be related to cancer. This was mentioned particularly by younger respondents.



'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.'

[Respondent from Australia](#)



'I had delays in diagnosis, and, above all, I felt I was made a fool of about the symptoms I had – they were trivialised as an intestinal virus and anxiety.'

[Respondent from Italy](#)

In qualitative responses, respondents often reported a lack of attention and empathy in how doctors communicated the news of their diagnosis. Respondents said they would have liked more time to discuss things and digest information.



'Make the diagnosis in a softer way and take a little more time for it.'

[Respondent from Belgium](#)



'My GP just told me he would be surprised if I didn't have leukaemia as he looked at a blood test done for another issue... What was I supposed to do with that information?'

[Respondent from Canada](#)

Respondents also expressed concern that information was sometimes withheld from them – including the fact that they had cancer. There were comments indicating that the different steps in their diagnosis were not explained enough, or in an understandable way.

<sup>ii</sup> As explained on page 14 (About this survey), where this report refers to 'respondents' without a specific percentage, we are referring to qualitative findings. These findings cannot be quantified as not all respondents answered the open-ended questions, so it would not be possible to give an accurate estimation of what proportion of all respondents might agree with each comment.



'I wish I had been told the whole truth from the start instead of diminishing it. I was the one to use the word "cancer" for the first time.' [Respondent from Belgium](#)



'Nothing would have changed the diagnosis, but the way I was treated and lack of communication made a difficult time horribly upsetting for me, my friends and family.' [Respondent from the United Kingdom](#)

The timing of delivering the diagnosis is also key. Respondents commented that doctors should make sure people are not alone when receiving their diagnosis and are given a point of contact for any questions that will inevitably arise after they recover from the initial shock.



'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](#)

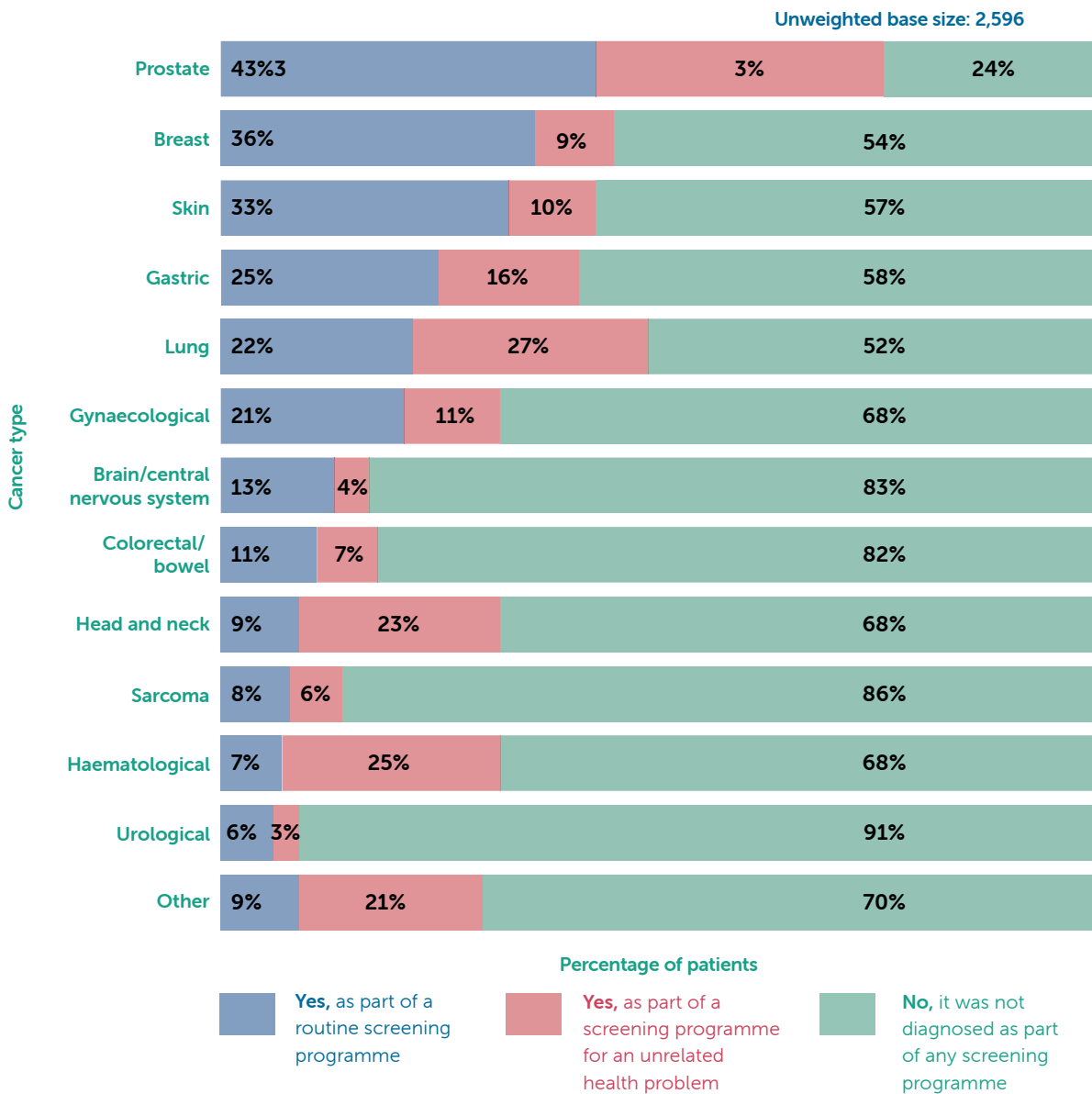


'I was told over the phone that it was melanoma and I was being booked with a surgeon, but wasn't given any other information, so it was extremely stressful.' [Respondent from Canada](#)

### **The proportion of respondents whose cancer was detected by screening varied by cancer type.**

Overall, **26%** of respondents recalled that their cancer was detected through a routine cancer screening programme and **17%** stated their cancer was detected through screening for a health problem unrelated to cancer. The remainder (**58%**) had their cancer detected outside of any screening programme (**Figure 1**).

**Figure 1. Was your cancer diagnosed as part of a routine screening programme, or as part of a screening programme for an unrelated health problem?**



**For all respondents, regardless of whether their cancer was detected through screening, diagnosis was one of the main areas where they reported the greatest inefficiency.**

When asked to select the one area of cancer care where they experienced the most inefficiency, **26%** of respondents chose diagnosis – more than any other area of cancer care. As might be expected, this was highest among respondents whose cancer was diagnosed outside of screening (**31%**), compared to **18%** among respondents whose cancer was detected through a routine cancer screening programme and **13%** among respondents whose cancer was detected through screening for an unrelated health problem.

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### During the whole of your cancer care and treatment, where do you feel there was most inefficiency?

(Respondents were asked to select one option only)

- **26%** my initial diagnosis
- **21%** dealing with the ongoing side effects
- **14%** getting the right treatment for my cancer
- **12%** dealing with the psychological impacts
- **10%** dealing with the financial implications
- **5%** the opportunity to take part in clinical trials
- **2%** access to patient support groups
- **10%** other\*

\* The most frequently reported 'other' sources of inefficiency included coordination between different elements of the healthcare system (e.g. general practice, social services and hospital), inefficiency around organising appointments, general delays, follow-up care, and getting the right information and communication.

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### For cancers detected outside of a screening programme, the speed of diagnosis had a major impact on respondents' experience across the entire care pathway.



'I lost valuable time having to wait three months to secure an appointment with the specialist after I noticed symptoms.' Respondent from Belgium



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#### Why it matters

For many cancers, early diagnosis can improve survival<sup>17</sup> – for example, a breast cancer study showed that patients who experienced short delays in diagnosis (under 3 months) had 7% better overall survival compared with those who had longer delays (3–6 months).<sup>18 19</sup>

Early diagnosis is associated with reduced treatment costs – the cost of treating colon, rectal, breast, ovarian and lung cancer at stage IV has been reported as 2–3 times the cost of treating these cancers at stage I.<sup>20</sup>



People whose cancer diagnosis took longer gave more negative scores on virtually every question in the survey, particularly in terms of information and support (Table 1).

**Table 1. Respondents' negative perceptions of information and support, by time taken to receive diagnosis**

Survey questions	Unweighted base size*	% of respondents who answered 'No' to each question**					
		Overall	Respondents whose diagnosis took...				
			< 1 month	1 to 3 months	3 to 6 months	6 months to 1 year	> 1 year
Were you involved as much as you wanted to be in deciding which treatment options were best for you?	3,124	15%	14%	16%	14%	22%	30%
Have you always been given enough information about your cancer care and treatment, in a way that you could understand?	3,650	31%	24%	38%	36%	44%	44%
Have you always been given enough information, in a way that you could understand, about signs and symptoms to look out for that your cancer might be returning/getting worse?	2,627	35%	30%	40%	31%	48%	51%
Were you given information about patient groups, charities and other organisations that might be able to support you through your diagnosis and care?	3,717	41%	40%	43%	41%	54%	52%

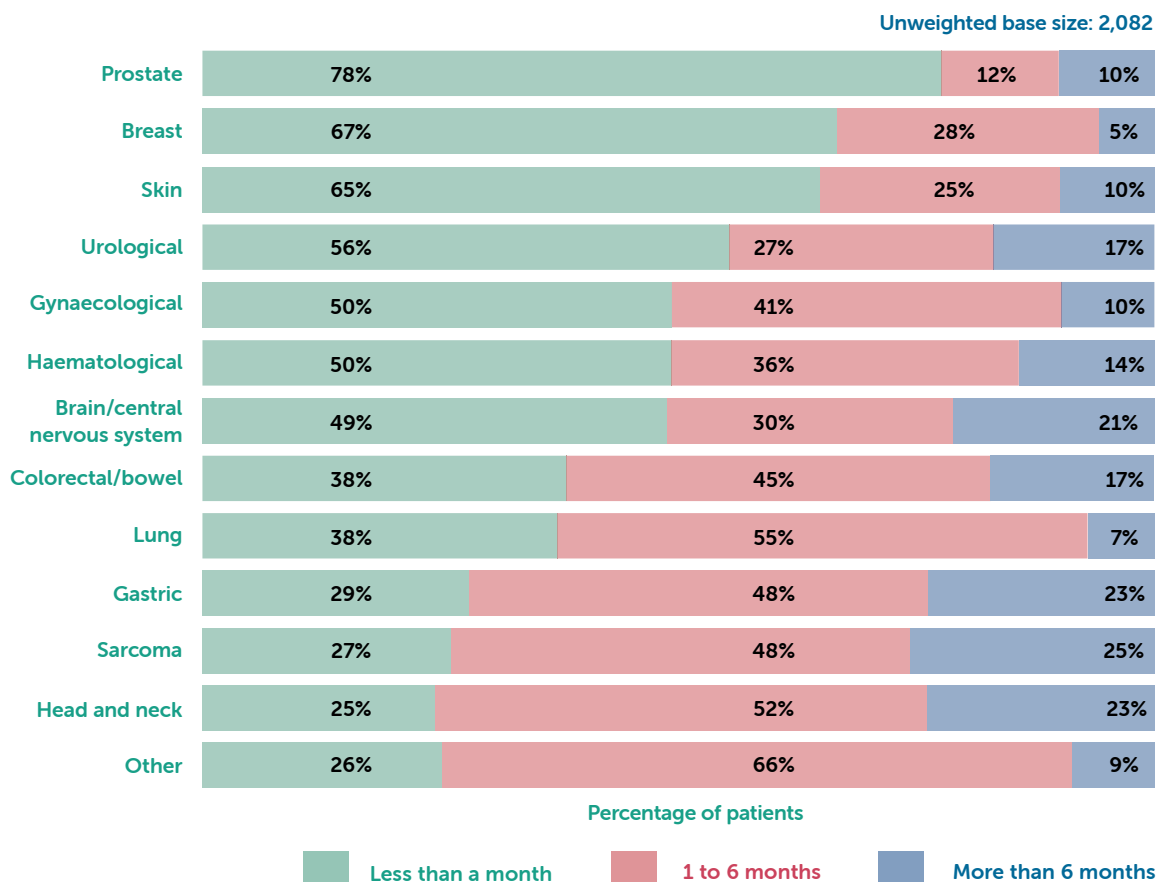
\* Total number of people who responded to each question

\*\* **Interpreting this table:** the 'Overall' column gives the proportion of all respondents who answered 'no' to each question in the first column, and the other columns are broken down by the time taken to diagnose the cancer. For example, 15% of respondents overall reported that they were not involved as much as they wanted to be in deciding which treatment options were best for them; for those diagnosed in less than one month, this figure was 14%, but for those whose diagnosis took more than one year, it was 30%.

### For cancers detected outside of a screening programme, the speed of diagnosis varied considerably by cancer type.

Nearly **80%** of prostate cancer respondents said their cancer was diagnosed in less than a month, while for head and neck cancer respondents this was only **25%** (Figure 2).

**Figure 2. Time to diagnosis, by cancer type (among respondents whose cancer was detected outside of a screening programme)**



### What we know

Late diagnosis and misdiagnosis are common in many cancers and can lead to delays in treatment or limited treatment options, poorer outcomes, lower likelihood of survival and higher costs of care.<sup>16,18</sup>

Diagnosis may be delayed for various reasons, including patient-related factors (e.g. lack of awareness of symptoms) and system-related factors, including availability of specialists, speed of referral, fast access to imaging, pathology capacity and other factors. The complexity of the process of clinical evaluation, diagnosis and staging may also vary by cancer type.<sup>18</sup>

Early diagnosis is not equally feasible for all cancer types. Cancers that have clear signs and symptoms and effective treatments (e.g. breast cancer) tend to benefit most from early diagnosis.<sup>18</sup>

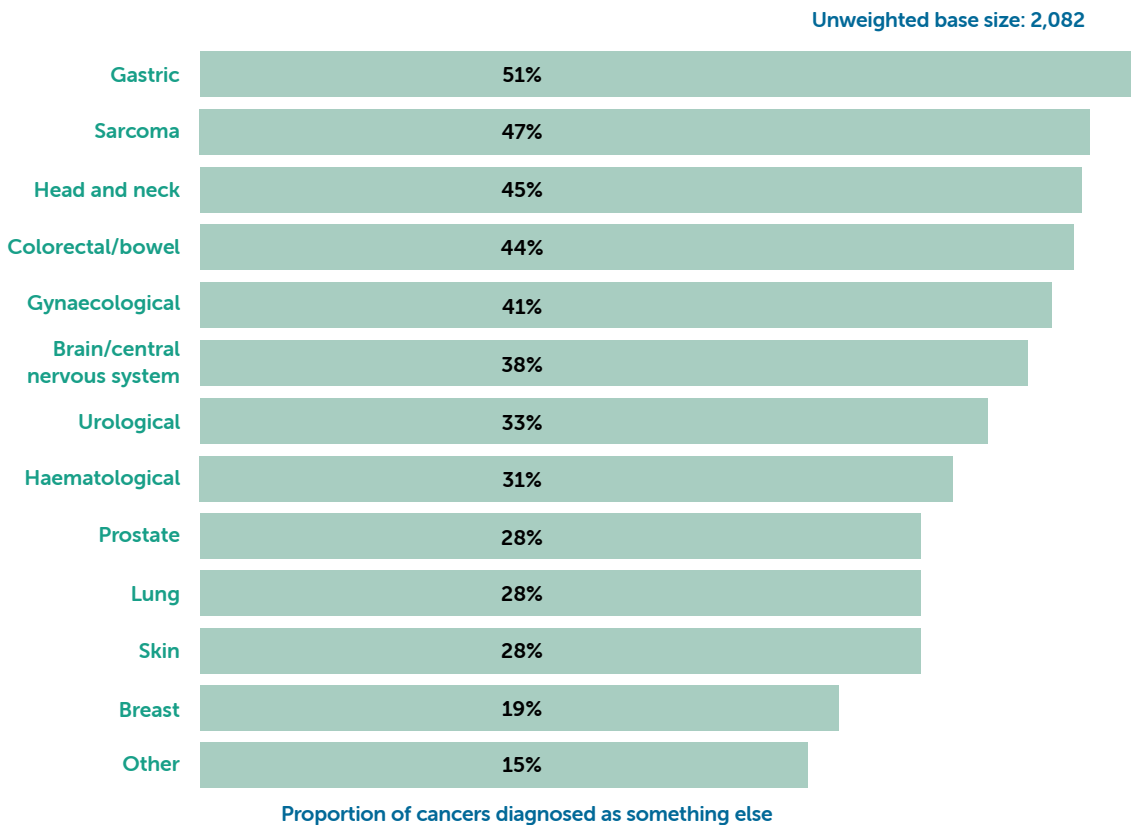
For some cancers (e.g. colorectal), early diagnosis – before symptoms start to show – is crucial to allow time for effective treatment options. This emphasises the importance of screening for early detection.

One reason for delays in diagnosis for respondents whose cancer was detected outside of a screening programme was that they were diagnosed with something else before eventually receiving a correct diagnosis of cancer.

- **32%** of respondents whose cancer was not detected through a screening programme reported that their cancer was diagnosed as something else (initially or multiple times).

This varied between cancer types, with over half (**51%**) of gastrointestinal cancer respondents having been diagnosed with something else, once or many times, whereas for breast cancer respondents this was significantly less at **19%** (Figure 3).

**Figure 3. Proportion of cancers diagnosed as something else, once or multiple times, by cancer type (among respondents whose cancer was detected outside of a screening programme)**





## Patient stories

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### Deborah\* (United Kingdom)

**I had random abdominal pain, which the GP thought was a kidney infection.**

When antibiotics didn't help, I was referred to gynaecology at my local hospital. They weren't expecting me when I arrived, and were very rude. I was in so much pain, and they thought I was making it up. The whole experience was horrendous.

**It took about a month to work out what it was, when I eventually had the right scan.** The doctor said, 'There's a mass near your kidney. There's nothing we can do about it now – it's Friday night. Don't worry about it. Go home and we'll be in touch next week.' He wrote my discharge summary, which obviously the patient isn't supposed to read. It said I had a 10cm tumour – potential lymphoma. I read that in the car on the way home with my children. That's how I found out that things were not good.

**The scan was in July, and I had to wait until the end of November before I had surgery.** I have a very aggressive form of cancer and to have to wait so long for surgery was completely unacceptable. It took them three months to get all the scans in order because it was the summer holidays.

**I had one appointment with my surgeon and the letter was never sent to me.** I got a phone call about five days after my diagnosis, asking why I wasn't at my appointment. The letter arrived three days after the appointment was supposed to happen. At that point, you feel like it is the end of the world.

**Ten weeks after my surgery, I had another scan.** The disease had spread to my bones. They found other tumours, including one in my liver.

**I had further major surgery.** Then I read about a new drug and proactively referred myself to a medical trial. Surgery is the main option for sarcoma, but you get to the stage where they cannot keep operating. I had to demand to see my oncologist. I never met her before that point – maybe if I had met her after my first surgery, my cancer might not have metastasised. Anyway, they were trialling the new drug at a hospital in another city and I asked if she could refer me. It took a while to get onto the trial. I would have started chemo a lot earlier if I had stayed at my first hospital, but it was definitely a good decision. When you have a rare cancer, you're going to have to travel. It's just what you do to get the best treatment. I was more than happy to go where I was referred.

**I was given amazing emotional support through the hospital's charity.** I'm having counselling, which I found out about through the research team. But this is the thing: there are all sorts of things available, but it is finding out about them. The counselling only came about from a nurse making a throwaway comment. Similarly, I found out there's an acupuncture team, but only because the radiologists mentioned it.

**I've had some hideous experiences – like being told my cancer had spread by someone I'd never met before.** Several times, I have been made to feel that I'm making things up. I've had to see doctors who know nothing about my disease and write incorrect follow-up notes. It takes weeks to unpick that sort of stuff – it's a waste of time and energy.

**The computer systems are ridiculous.** If I have to go into Accident & Emergency, I take a copy of all my scans and notes, as they won't be able to access them. They won't know what drug I'm on because they'll never have heard of it. I've seen about 50 people over the last year. It can't be that difficult to find someone to provide some continuity of care.

**Communication between departments shouldn't be siloed.** I once had genetic blood tests and they wouldn't fax the form from one hospital to another, so I had to physically drive to one hospital, pick up a piece of paper, drive to the other hospital, wait for two hours for a blood test – and then they lost the test, so I had to do it again. It's archaic – why can't they just email my doctor?

**It would have been better if I'd been listened to.** When people say you're making it up, and you know something is wrong, you almost need your GP, or someone who knows you, to speak for you. I know that some people do make things up, and they have to deal with that, but I had a 10cm tumour. They should take patients seriously. I was made to feel like I was nothing from the moment I walked into the hospital. I was shouted at! I can still remember the nurse who did it – she was clearly having a really bad day, but that was no excuse. When you go into this profession, you have to be professional. Be nice!

**They should treat patients like people – that's their biggest job.** That's what I would say to anyone coming into this: make them see you as a person.

\* Names and some other identifying elements have been changed to protect patients' anonymity.



2

# Information, support and shared decision-making

## Key findings

- Respondents reported that too much information being given at once was sometimes overwhelming, and they would have preferred to receive relevant information at appropriate points along the entire care pathway.
- Almost half of respondents (**47%**) did not feel sufficiently involved in deciding which treatment option was best for them.
- Nearly two in five respondents (**39%**) felt they had inadequate support to deal with ongoing symptoms and side effects.
- Close to a third of respondents (**31%**) felt that they lacked adequate support for dealing with pain.
- More than a third of respondents (**35%**) felt inadequately informed about how to recognise whether their cancer might be returning or getting worse.
- **41%** of respondents were not given information at the hospital about available peer-support groups.
- Gaps in information and support were more prevalent among people with more advanced cancers.



'The disconnect between the language my haematologist uses and common language has been frustrating.' [Respondent from Canada](#)



'I don't want more information, but better information.' [Respondent from the United States](#)

# Overview of findings

## Respondents often felt overwhelmed by the information they received.

A recurring theme in qualitative responses was that respondents felt overwhelmed by all the information they received at the point of diagnosis, and would rather have had information provided at each stage of their care.



'It would have been good to have access to resources at appropriate points during treatment i.e. before surgery, before radiation. I found I was given all the information at once, which was too much.' [Respondent from Australia](#)

Respondents also spoke of a disconnect between the language used by their doctors and what they could understand. They often did not know where to begin or what to ask, as the experience of cancer was new to them.



'How can you ask a question when you have never had chemotherapy before? It's like being given a lemon meringue pie and not knowing what it tastes like until you try it!' [Respondent from Australia](#)

There were also comments that the information provided was not always tailored to the patient's individual experience or stage of treatment.



'Some of the information was not relevant to my situation. To go through all the information was beyond what I was up for, so most of it remained unread.' [Respondent from Canada](#)



### What we know

Information needs vary from one patient to another and are influenced by many factors.<sup>21,22</sup> They also change along the care pathway.<sup>23</sup>

Many studies show that patients often do not fully comprehend what their diagnosis, prognosis and treatment mean. This can be due to them not fully understanding the terminology used, not receiving all relevant information or not being able to recall what they have been told during medical appointments.<sup>22, 24-26</sup>



## Why it matters

Part of quality healthcare delivery is understanding what patients want to know and providing that information at the right time in an understandable way.<sup>27 28</sup>

Information can help patients feel in control of their disease, reduce anxiety, create realistic expectations, and promote self-care and engagement in their care.<sup>22 23</sup> Fulfilling patients' needs for information is also associated with improved treatment adherence<sup>21 29 30</sup> and better clinical outcomes.<sup>22 30</sup>

## Respondents were often not sufficiently involved in decisions about their care or provided with enough information about their treatment options.

Almost half of respondents (47%) did not feel sufficiently involved in deciding which treatment option was best for them, and nearly a third (31%) felt they were not always given enough information about their treatment and care.

### Have you always been given enough information about your cancer care and treatment, in a way that you could understand?\*

- Yes: **69%**
- No, I was given information, but could not understand it all: **14%**
- No, I was not given enough information: **16%**

\* All percentages are rounded to the nearest whole number, so may not total 100%

### Were you involved as much as you wanted to be in deciding which treatment options were best for you?

- Yes: **53%**
- Yes, to some extent: **32%**
- No, I would have liked to be more involved: **15%**



'Options could have been explained a little better. I had a new procedure done and thought I was cured.'  
Respondent from the United States





## Why it matters

Studies have shown that **shared decision-making** is associated with improved patient outcomes.<sup>34</sup>

Treatment decisions can change after patients become well informed – with many choosing fewer treatments – and there is a substantial gap between the outcomes patients prefer and the outcomes that doctors think patients prefer.<sup>35</sup>

## Respondents needed more and better guidance on how to deal with ongoing side effects – especially after treatment was over.

Dealing with ongoing side effects was perceived as a major source of inefficiency, with **21%** of respondents saying it was the greatest source of inefficiency in their care. This was the second highest-reported area of inefficiency overall, after diagnosis (**26%**).



‘I think we do not take the aftermath into account enough. Treatments... help heal cancer but destroy other things. Life becomes different after and many “little sores” occur, with which one must live.’ Respondent from Belgium

In some comments, respondents said they had little warning of what the most common side effects were or how to deal with them – especially once they were no longer having **active treatment**.



‘The side effects are more than just a nuisance and need real recognition.’ Respondent from the United Kingdom



## What we know

Patient empowerment – including involving patients in **shared decision-making** and providing information to help them better understand their condition – is widely recognised as being an enabler of high-quality and sustainable healthcare.<sup>31-33</sup>

Shared decision-making should involve enquiring into patients’ goals for their treatment, providing **evidence-based information about treatment options**, and having systems for recording and implementing patients’ treatment preferences.<sup>7,8</sup>



‘Perhaps a clinician could go over the fine details on the usage of the drugs. I’m having to learn the do’s and don’ts via the internet rather than someone attached to my particular case.’ Respondent from Canada



### What we know

Evidence shows that, at the end of their treatment, cancer patients may be left to deal with consequences of treatment that could have been managed or avoided altogether.<sup>36 37</sup>

Long-term consequences and effects of having cancer and its treatment can include physical effects, chronic fatigue, sexual difficulties, mental health issues and pain. Problems can persist for up to 10 years after treatment, or even longer, and may lead to social isolation and financial difficulties due to disruption to work.<sup>38</sup>

### Respondents were not always given adequate information about pain management and palliative care.

- **31%** of respondents said they were never, or only sometimes, given enough information and care to deal with the pain they experienced.

Although **69%** of respondents said they received enough information and care to manage their pain, this was not the case for all respondents. Further, in the qualitative comments, respondents suggested that their worries or the pain they experienced were sometimes dismissed.



‘Although I kept saying that my pain was 7–8 out of 10, each time I returned to the room for chemotherapy, I was never advised or directed to solve this problem. I was the one to take charge... but it took (and still takes) a lot of energy.’ Respondent from France



### Why it matters

Without adequate assessment of patient needs – both during and after active treatment – suboptimal service use (overuse or underuse) may occur. This can have a negative impact on patient outcomes and costs incurred for healthcare systems.<sup>39</sup>

More individualised approaches to follow-up versus a one-size-fits-all approach may have benefits as well – for example, by supporting patients in self-managing their condition.<sup>37</sup>

In England, it is estimated that follow-up costs £1,554 per patient over a five-year period (equivalent to 4–5% of the total national cancer budget) but one study showed it may be possible to save up to £1,000 per patient through a stratified approach to follow-up, pathway efficiency and better management of comorbidities.<sup>37</sup>

Respondents who had access to comprehensive **palliative care** services reported great satisfaction with this aspect of their care. However, a number of respondents said that palliative care was not discussed with them as an option when they themselves thought it could be helpful.



‘I was referred to the palliative service, which provided much more supportive care than I had ever imagined I could receive. I was given support, counselling, specialist advice, which was invaluable.’ **Respondent from Australia**



## Why it matters

Early integration of **palliative care** can lead to improved symptom control and reduced distress through treatment and care delivery that matches patients’ preferences – and overall improvements in patient outcomes, quality of life and survival.<sup>42-44</sup>

It can also significantly improve patients’ understanding of their prognosis over time, which may impact treatment decisions about end-of-life care and lead to less aggressive treatment.<sup>44 45</sup>



## What we know

Many cancer patients experience unnecessary pain – studies suggest that one in three cancer patients do not receive pain medication appropriate to their pain level.<sup>40</sup>

**Palliative care** is often assumed to be solely focused on end-of-life care – but, in fact, it is much broader. The World Health Organization defines it as an approach that improves quality of life for people (and their families) with life-threatening illnesses – including pain relief and psychosocial support.<sup>6</sup>

Guidelines recommend that the need for palliative care should be built into treatment plans early in the course of illness, in conjunction with therapies that are intended to prolong life, such as chemotherapy or surgery.<sup>6 41</sup>



### What we know

Studies have shown that patients' information needs are often highest, and least well met, during the phase following active treatment.<sup>30</sup> An effective handover from secondary care to primary care, with regular and timely follow-up, is therefore necessary for all patients.<sup>39</sup>

### Respondents often lacked information about how to tell whether their cancer might be coming back.

Another important gap frequently expressed in qualitative comments was the lack of information on how to deal with possible signs and symptoms that cancer might be recurring. This led to significant fears for respondents, not knowing whether a symptom they experienced was harmless or a cause for greater concern.



'I don't think professionals really understand how much we fear recurrence.'

Respondent from the United Kingdom



'I would like to understand better how I will be able to monitor the risk of recurrence when I am no longer receiving regular follow-up after my hormone therapy.'

Respondent from Belgium



### Why it matters

Without appropriate follow-up after discharge, patients can feel lost or abandoned, and ill-prepared to manage their condition, after weeks of intensive treatment and frequent interactions with their care team.<sup>46</sup>

## Respondents were not always given information about available patient groups or peer support.

- **41%** of respondents said they were not given any information about patient advocacy groups, charities or other organisations that could support them.

In addition to information and support they may have received from their care team, respondents expressed the value of being able to speak to people who had been through a cancer diagnosis themselves.



'I would suggest that anyone with any type of cancer look for others that have that type of cancer, and help each other. Only those who are going through cancer, or have gone through it, really understand.'

Respondent from the United States



### Why it matters

Even with the support of family and friends, many people who have cancer find it helpful and comforting to talk with others who have already gone through the experience first-hand, to discuss all aspects of how to deal with cancer and its impact on life. Patient organisations often help provide this peer support to patients. They can fill important gaps in patients' needs, providing emotional support and financial advice, as well as valuable information about treatment options and available services.<sup>47</sup>

Not all healthcare professionals may feel comfortable or able to distribute patient support-group information. This presents a missed opportunity as doctors are usually the main source of information connecting patients to support groups.<sup>48</sup>

## Overall, gaps in information and support were found to be greatest for respondents whose cancers were diagnosed at an advanced stage.

Across almost all questions relating to information, respondents whose cancer was diagnosed at a more advanced stage reported gaps more often than those with earlier-stage cancer (**Table 2**).

**Table 2. Respondents' negative perceptions of information and support, by stage of disease at time of diagnosis**

Survey responses	Unweighted base size*	% of respondents who answered 'No' to each question**		
		Overall	Respondents whose cancer had not spread to other organs at diagnosis	Respondents whose cancer had spread to other organs at diagnosis
Were you involved as much as you wanted to be in deciding which treatment options were best for you?	3,124	15%	12%	22%
Have you always been given enough information about your cancer care and treatment, in a way that you could understand?	3,650	31%	26%	39%
Have you always been given enough information, in a way that you could understand, about signs and symptoms to look out for that your cancer might be returning/getting worse?	2,627	35%	31%	39%
Do you feel you have always been given enough support to deal with any ongoing symptoms and side effects, even beyond the phase of 'active' treatment (if applicable)?	3,623	39%	34%	54%

\* Total number of people who responded to each question

\*\* **Interpreting this table:** the 'Overall' column gives the proportion of all respondents who answered 'no' to each question in the first column, and the other columns are broken down by how advanced the cancer was at point of diagnosis. For example, 15% of respondents overall reported that they were not involved as much as they wanted to be in deciding which treatment options were best for them; for those whose cancer had not spread at diagnosis, this figure was 12%, but for those whose cancer had already spread by the time of diagnosis, it was 22%.



### What we know

There is evidence that support services available for cancer patients may not always be appropriate for patients with more advanced disease. For example, a comprehensive survey of breast cancer patients in Australia found that those with metastatic breast cancer found available support less adapted to their needs compared to patients with earlier-stage disease.<sup>49</sup>



## Patient stories

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### Julie\* (Belgium)

**Two weeks after noticing a lump in my breast, I saw my GP and was referred for a mammogram.** They told me it was probably benign but suggested I get it removed just in case. I had a biopsy, and the people at the research centre said everything looked OK and that I shouldn't be too worried about it – so I felt really reassured. When I got the results a few weeks later from my gynaecologist, he told me they'd found some bad cells in my breast. I didn't know what that meant exactly, but I knew there was something wrong. When I got emotional, he asked, 'Didn't you expect this?' The way he gave the diagnosis was very hard for me; I found it unprofessional and it felt like he didn't take me seriously.

**The breast care nurse was at the appointment and, after the conversation with the gynaecologist, she had all the time in the world to answer questions.** She was very understanding, gave us a lot of information and made me feel it was OK to be emotional. It still wasn't clear to me whether I had cancer or not, so the nurse had to tell me. Throughout my cancer treatment, the breast care nurses have always been a great support.

**I wasn't really involved in discussing my treatment plan.** They never gave me the option to choose an alternative location or seek a second opinion. Now, I know that I actually had a choice about certain things, but at the time I just trusted the doctors. It gave me a good feeling that my treatment plan was designed by a team of doctors. I've had various treatments: mastectomy, tissue expansion, radiation, anti-hormonal therapy, chemotherapy and a breast reconstruction. If I had the choice now, I wouldn't have had a breast reconstruction. I wasn't well informed about the rehabilitation. It's been very hard. I have a very tight tummy now, which makes walking difficult and causes heavy back pain. They also removed my lymph nodes, which gave me a very big arm. All these things cause me a lot of stress.

**My illness had a huge effect on my marriage, which ended in a divorce.** The emotional impact was huge. But I'm very happy with the psychological support I received from the breast care nurses and my friends. I practised mindfulness for cancer patients and my kids got support from the hospital as well.

**I had so many questions, but they all needed to be answered by different doctors.** It would have been nice to have an appointment with all the doctors at once, so I could ask all my questions at the same time. It would be less time-consuming and would have cost me less energy – energy I didn't have.

**I would like to tell other patients that you have a choice about certain treatments.** If you make your own decisions, you will probably feel a lot more in control – and that will make you feel stronger.

\* Names and some other identifying elements have been changed to protect patients' anonymity.



3

# Integrated multidisciplinary care

## Key findings

- Respondents commented that specialist cancer nurses had played a critical role – acting as their ‘navigators’ and helping them adapt all aspects of their lives to cancer – both during and after treatment.
- Nearly a quarter of respondents (**24%**) felt that support from allied health professionals (dietitians, physiotherapists etc.) was not always available.
- Respondents wanted more information about what they could do to support their treatment and recovery in terms of diet, exercise and complementary therapies.
- **69%** of respondents said they needed psychological support during or after their cancer care. However, of these, **34%** said it was not available.
- Many respondents expressed concern for the impact their cancer had on their families, and wanted psychological support for them as well.



‘There needs to be a plan made for each cancer patient, so a person doesn’t have to explain to each healthcare person what is going on and why the cancer patient needs help.’ [Respondent from Canada](#)



‘Psychological support should not just be offered in the form of a brochure stating, “If you need help, you can get it here.” Many people will say they are “coping” when, in reality, they need support readily at hand.’ [Respondent from Australia](#)



# Overview of findings

## Cancer nurses played a critical role in coordinating care for respondents.

Respondents often reported a lack of communication between their primary care physician and specialists – particularly in countries with a primary-care-led model (e.g. Canada, Australia and the United Kingdom). Respondents reported the impact of this lack of communication from diagnosis onwards – and again after they had left the hospital setting and were in the follow-up stage of care in the community setting.



'There needs to be more communication between healthcare providers... don't tell the patient to ask the surgeon, who then refers you back to your doctor, and this keeps going on and on.' Respondent from Canada



'I needed one central point of contact for everything but also one place to go for everything too. I have been under the care of three different hospitals with appointments for different procedures, tests etc. at different locations – it takes a lot of energy. I have had to become, in effect, a manager rather than a patient.' Respondent from the United Kingdom

Respondents commented that specialist cancer nurses had played a vital role in remedying these communication and coordination gaps – acting as the patient's companion and 'navigator' through all phases of care.



'The reference nurse in oncology has been very helpful and has always directed me to the appropriate specialist doctor without ever underestimating my problems. It is a real asset to have such a reliable person.' Respondent from Belgium



### What we know

In 2014, the European CanCer Organisation (ECCO) endorsed cancer nurse specialists as an essential part of the multidisciplinary care team.<sup>50</sup>

Ideally, a cancer nurse specialist acts as a central point of contact for patients, helping them navigate through diagnosis, treatment, follow-up and, if necessary, end-of-life care.<sup>50 51</sup>

Cancer nurses can help ensure clear communication with patients and their families and other healthcare professionals; they can address patients' emotional, psychological, financial and social needs and offer information, advice, support and reassurance.<sup>51 52</sup>



## Why it matters

Having a cancer nurse specialist has been shown to improve outcomes for patients and reduce associated costs of care, due to:

- reduction of symptoms<sup>53 54</sup>
- improved patient knowledge and self-management<sup>53 54</sup>
- improved management of chronic problems<sup>54</sup>
- faster care pathways, allowing more patients to be seen<sup>52</sup>
- reduced rates of emergency admissions and shorter hospital stays<sup>54-56</sup>
- fewer follow-up appointments.<sup>54</sup>

Data also suggest that this specialist role may bring overall savings to healthcare systems, with one report in the United Kingdom suggesting that introducing specialist nurses into the cancer care pathway could save about 10% of cancer expenditure.<sup>52</sup>

## Access to allied health professionals and complementary care was often perceived as inadequate by respondents.

Almost a quarter of respondents (24%) said they did not have access to support from **allied health professionals**. In qualitative findings, respondents commented that they would have liked to be told what role these different professionals or services could play in aiding their recovery.



'It was difficult to find a physiotherapist. The importance of this [role in my recovery] was not explained.'

Respondent from France



'They should actually involve additional specialists (i.e. dietitian, physiotherapist, psychologist) in the treatment of the patient from the moment of diagnosis. The content provided by all physicians should be consistent. I would avoid frightening a patient by focusing on how difficult and demanding their treatment is, and focus more on the goals to be achieved after treatment.'

Respondent from Poland

In addition, respondents reported that they were not always provided with enough information about how they could optimise their care through diet, exercise, mindfulness and complementary therapies. In many countries, respondents had to pay **out-of-pocket** for these services.



'I had to source my own information regarding complementary therapies... These were quite expensive, and yet they should be offered as part of cancer treatment, in my opinion.' [Respondent from Australia](#)



'I would have liked to know more about the food that should be eaten, the quality of life I could expect...' [Respondent from Spain](#)



### What we know

The added value of complementary therapies is widely recognised among international cancer societies. For example, the American Cancer Society recommends a selection of evidence-based complementary therapies as part of **integrated care**: music therapy, meditation, yoga and relaxation, massage, acupressure and acupuncture.<sup>57</sup>

Complementary approaches can be important for patients' care, wellbeing and recovery.<sup>58</sup> Doctors do not necessarily need to provide these components of care, but they should be able to signpost patients to relevant services.<sup>49</sup>

### Psychological support was often unavailable to respondents.

A recurring comment from respondents was that their psychological or emotional needs were not sufficiently addressed by their cancer care team. More than a third of respondents (**34%**) who wanted psychological support said it was unavailable to them.

- **69%** of respondents said they needed psychological support during or after their cancer care. But **34%** of these respondents said it was not available.



'I think the psychological involvement part is forgotten. It is true that the main thing is to survive, but it is also necessary to feel accompanied and understood.' [Respondent from Spain](#)

## Even when psychological support was available, it was not always felt to be helpful.

In qualitative comments, respondents mentioned being referred to professionals who did not have a sufficient understanding of cancer to provide any meaningful help to them or their families. In some instances, support was inappropriate or even hurtful to respondents.



'I needed someone to talk to; I was given written information.'  
Respondent from France



'On the emotional side, I had to deal with everything myself. A psychologist, in the hospital after an operation, reduced me to tears by asking questions like, "Do you know that you will be bald and may lose your job?" It sounds unbelievable, but it happened.'  
Respondent from Poland



### What we know

According to the International Psycho-Oncology Society, 40–60% of cancer patients and family members experience psychological distress that could benefit from intervention, but only a minority receive psychological support and care.<sup>59</sup> This is despite psychological distress screening being recommended for all cancer patients from diagnosis onwards.<sup>60</sup>

These figures are partly due to the fact that significant gaps exist in the availability of psycho-oncology services across the world. A 2015 survey across 27 countries in Europe found that only eight (30%) had nationally recommended psycho-oncology care guidelines, ten (37%) had budgets for psycho-oncology care, and six (22%) had official certifications for psycho-oncology care education.<sup>59 61</sup>



## Why it matters

Mental distress is common among cancer patients, and can result in difficulty in processing information, decisional regret about treatment choices, fear of cancer recurrence, chronic pain and difficulty with social reintegration.<sup>60</sup>

Cancer patients are three times more likely to suffer from depression compared with the general population. Cancer patients with depression have 39% higher mortality,<sup>62</sup> higher healthcare utilisation, and higher healthcare expenditure than patients who do not have depression.<sup>63</sup> For example, a study in the United States found that adult cancer survivors had an estimated 31.7% greater total expenditure compared to those without depression.<sup>63</sup>

A higher incidence of anxiety and depression is reported in adolescents and young adult cancer survivors compared with older populations. This can inhibit their ability to get an education and gain employment.<sup>64</sup> Furthermore, psychological care is especially crucial in the post-treatment phase, due to fears over not being able to conceive children, body image dissatisfaction and anxiety.<sup>64</sup>

## The impact of cancer on families and loved ones was a common concern for respondents.

In addition to needing psychological support themselves, respondents said that psychological support should be offered to their spouses and children. This comment was made by both patients and **caregivers** completing the survey.



'I wish more attention was given to the partners of cancer patients. It is often they who suffer most from the treatment.' [Respondent from Belgium](#)



'We, as a family, also felt broken. We had no previous cases of cancer in the family. I don't know if you know what it feels like, watching someone close to you for 12 months, knowing they are dying.'  
[Respondent from Poland](#)



## Why it matters

Many studies show the negative impact that parental cancer has on the lives of children and the whole family unit, including siblings, necessitating support for the entire family.<sup>65 66</sup>

**Caregivers** to people with cancer, in particular, have a unique burden placed on them – and their new role in providing practical, emotional and other support can negatively affect their own psychological, physical and financial health. Reasons for experiencing increased burden are multifaceted, and can be due to coping with the emotional impact of a loved one who is suffering, taking on this new ‘full-time job’ of providing care to a patient with cancer and/or taking on additional household responsibilities with no extra support. On average, these caregivers provide 8.3 hours of care each day for 13.7 months.<sup>3</sup>

As a result, caregivers can have high unmet needs.<sup>3</sup> They frequently report psychological issues, including fear, hopelessness and mood disturbances. Studies also show that rates of anxiety and depression among family caregivers are comparable to, or higher than, those of the patient for whom they provide care. Physical health complications are also common – including sleep difficulties, fatigue, cardiovascular disease, decreased immune function and increased mortality.<sup>3</sup>

In the United States alone, it is estimated that the annual economic value of caregiving is \$375 billion across all diseases.<sup>3</sup>



## Patient stories

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### Hanna\* (Sweden)

**I saw a doctor after discovering blisters on the roof of my mouth.** I had to fight to get an examination and was eventually sent to an ear, nose and throat clinic. It was easy for the doctor to spot the tumour and I was sent home; later, my doctor called me and told me it was malignant. I would rather have spoken face to face, so that I could have had someone to answer my questions.

**I was not given a clinical nurse or doctor after my diagnosis, and I had no one to talk to.** At the hospital they did not show much sympathy for me and I felt I was annoying when I was seeking information.

**I was never involved in any discussion about different treatments.** Everything went so quickly, and I had no other information – I had to search online for a lot of information about my diagnosis myself.

**After my surgery, my speech was very affected, which was a complete shock.** This might have been communicated to me, but if it was, it was not in a way that I was able to understand due to the circumstances. I had severe issues with swallowing and could only consume liquids. I had to contact a nutritionist myself as I became malnourished because I couldn't eat properly. I was given a speech therapist, who has been an enormous support.

**I wasn't given any psychological support at all after the surgery** – even my surgeon never found the time to see me afterwards – and I really needed someone because what had happened to my speech was so traumatic. Throughout my career, communication has been hugely important, and I am a very social person.

**The dates of my follow-up appointments are constantly changing,** which is very hard for me as I am very anxious and nervous before them – if it was once or twice it would have been fine, but it happens all the time.

**As I haven't been given any psychological support, it has affected my mental health.** I feel like I haven't been listened to; I have felt very lonely and not cared for. It has now been more than four and a half years, and I still haven't been offered any support at all. I am so grateful to my family and friends for their support – I don't know what I would have done without them. But I need someone to talk to outside of my friends and family. This is something that has never been discussed during my follow-ups.

**My treatment was very efficient** – everything happened so fast, from my first visit to the surgery, so that worked out very well. But if I could change something, it would be that I would have had someone to talk to. That's something I still need.

\* Names and some other identifying elements have been changed to protect patients' anonymity.



## Patient stories

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### Ray\* (United Kingdom)

**From the first time I saw my GP to being diagnosed with cancer took six months.** It's far too long – shockingly long.

**I think GPs' knowledge needs to be improved, and if they don't know they should send people for a biopsy.** A biopsy is zero inconvenience to me, but maximum efficiency for results. Looking back now, I should have demanded a referral. But I also think the doctor should say that they don't know what it is and send you to get a biopsy done.

**Unless you have been told the words – 'You've got cancer' – you have no idea what it means to hear them.** I can't even explain it now. It's everything you understand about life: you as a person, your whole existence, all your experiences – when you hear those words, 'you've got cancer', it just goes out the window. Everything. You can't hear anything else.

**I had surgery, but the cancer came back a few years later.** With my secondary cancer, I wasn't happy after treatment. Maybe I was a bit depressed – I wasn't in a good place. And then I found out about a holistic centre, where I had some psychology appointments. They were absolutely fantastic, and that turned my life around. It wasn't just psychology, there was reiki, aromatherapy and all sorts – all provided by volunteers. The thing that annoys me, though, is that I had to ask for it. No one told me this was available until I told them I needed someone to help me with my head. I wish I'd had it the first time around as well.

**The best emotional support I got in the hospital, the people that spent time with me to make me feel safe and secure, were the healthcare assistants.** They're worth their weight in gold. When I was crying in bed, they used to sit there and literally hold my hand. It's those small things that make so much difference.

**The main thing I would change about my cancer treatment would be the psychological side of things.** Your emotional needs are not acknowledged or addressed at all. And it shouldn't just be aftercare, it should be right the way through treatment.

**The National Health Service is fantastic at the clinical side of it – they do that brilliantly.** But we really need to concentrate on the psychological impact. It's not just medication, surgery and treatment. The psychological trauma of cancer is massive, but no one ever tells you that. It can only be supported through good psychological care, and that needs to be provided as part of your cancer treatment. I got it as part of my cancer treatment – but only because I asked for it.



**You do sort of get used to having cancer, and I have lived with it successfully, I think.** For the first five years I was running away from it, but I'm not running away anymore. It's part of me. I've learnt that if you call it a 'battle', it's almost like you're going to lose. It's not about winning or losing a battle; it's about living. I'm not scared of dying – I'm just scared of not living well. And living well doesn't mean it has to be hedonistic; it can just be sitting with your wife and kids watching TV, laughing, having quality of life, and feeling safe and secure.

**My health is not bad now.** You can't compare it, my pre-cancer life and post-cancer life. I've had lymph nodes and muscle removed, and blood clots in my lungs. Health-wise, physically, I'm probably 70% of what I used to be. I used to run a lot of marathons; I was lean. Now I'm a bit rotund, which upsets me a bit.

**Mentally, though, I'm the strongest I've ever been.** That's the positive side. But I've had to do that through psychology, just for myself as well. I can't stress that enough: people need to put the effort into their own heads. No one can make you feel happy apart from yourself, so you can be your own worst enemy. You've got to be your own best friend.

\* Names and some other identifying elements have been changed to protect patients' anonymity.

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# 4

## The financial impact of cancer

### Key findings

- Just over half of respondents (**51%**) paid for some part of their care, either out-of-pocket or through private insurance.
- Travel costs (**36%**) and loss of employment income (**26%**) were the most frequently reported non-treatment-related costs for respondents.
- Cancer had a negative, and often long-term, impact on productivity for respondents and their caregivers. In some cases, a diagnosis of cancer created lifelong financial insecurity.



'The running costs of cancer are generally ignored. There are a huge number of hospital visits involved in chemo and oncologist appointments, with travel costs (petrol and parking), as well as the dislocation and stress to the driver/carer's life.'

Respondent from the United Kingdom



'I was not really given any info about how long to recover from chemo or returning to work. I had to devise my own return-to-work plan.'

Respondent from Canada

# Overview of findings

## Many respondents were shocked by the dramatic financial impact cancer had on their lives.

Respondents were asked about the financial impact of cancer on their lives, and in the qualitative responses many reported that they had incurred significant costs due to cancer.

Even in countries with publicly funded healthcare systems, respondents frequently reported having to pay for some of their cancer care themselves. Reasons differed but included wanting to avoid delays or because a particular aspect of care was not covered by their insurance system.

‘I paid for several exams out of my own pocket to speed things up.’  
Respondent from Italy

‘I did the biopsy privately because the National Health Fund doctor said she did not see a reason to do it.’ Respondent from Poland

For some respondents, cancer continued to have a financial impact for many years after they had completed treatment, such as having to pay for complementary care not covered by their health insurance, or not being able to fully return to work.

The financial impact of cancer was sometimes devastating, as respondents had to make huge sacrifices to pay for their care and the associated travel.

‘I had to sell an investment property to pay for my cancer treatment, as I had to travel, and stay away, for seven weeks for radiation treatment.’  
Respondent from Australia



### What we know

There is growing evidence from different countries that many patients face a ‘cascade of financial burden’ due to cancer:

- An Australian study found that cancer patients may spend up to 15% of their lifetime income on their disease.<sup>67</sup>
- A study of working-age cancer survivors in the US found that one third had gone into debt, and 55% incurred costs of \$10,000 or more due to their cancer.<sup>68</sup>
- A French national study (VICAN 2) found that, two years after diagnosis, 25% of people living with cancer were below the poverty threshold, compared with 14% of the general population.<sup>69</sup>
- Patients living in rural or remote areas may be most affected by the financial impact of cancer due to the need to travel a long way to specialist centres.<sup>49</sup>
- Even when cancer patients are eligible for support, they may not be aware of financial assistance to which they are entitled, and navigating existing benefit systems can be difficult.<sup>70</sup>

**Travel costs and loss of employment were the most frequently reported non-treatment-related costs for respondents.**

**Were there any other financial implications of your cancer care and treatment?\***

- Travel costs: **36%**
- Loss of employment: **26%**
- Loss of insurance: **10%**
- Childcare costs: **8%**

\* This was a 'tick all that apply' question, therefore results do not equal 100%



'Cost of parking, especially when attending the hospital for appointments up to three times a week. Paying up to \$100 a week.'  
Respondent from Australia



**What we know**

With the growing number of cancer survivors, there is increasing recognition of the need for social policies to help former cancer patients return to work after their care and protect them from financial insecurity.<sup>71</sup>

In Italy, for example, there is a law allowing patients to switch from full-time to part-time work while undergoing treatment, and go back to full-time work as soon as they are able. It has been recommended that all countries implement similar measures.<sup>72</sup> The Netherlands, meanwhile, is one of the first countries with a government Plan of Action for 'Cancer & Work'.<sup>73</sup>

Unfortunately, not all countries have legal frameworks for the reintegration of cancer survivors into the workplace, although more countries are developing legislation to support and protect this right to return to work.<sup>72</sup>

**For some respondents, cancer had a negative, and often long-term, impact on productivity for them and their caregivers.**

Over a quarter of respondents (**26%**) reported that they had suffered financially due to loss of employment related to their cancer.

Respondents sometimes reported not only a loss of their own income, but reduced income for their **caregivers**, who had to assume greater responsibility by caring for a spouse with cancer alongside maintaining daily household tasks and often caring for children on their own. Self-employed respondents and caregivers felt the impact of this most strongly.



'My husband has cancer, and he's self-employed (no work means no money). I was denied paid leave (I'm a caregiver). I can't take unpaid leave (no work means no money).'

Respondent from Italy



'I have no family nearby and my husband's employers were not understanding. He had to take unpaid leave to take me for treatment and tests, and visit me during surgery and recovery. This not only caused financial strain but added to stress as he could have lost his job due to absences.'

Respondent from the United Kingdom



## Why it matters

Although many cancer patients are able to return to work after their care, this is not the case for all. Lost productivity due to cancer is estimated to cost €52 billion per year in the EU.<sup>74</sup>

People surviving cancer are 1.4 times more likely to be unemployed and three times more likely to receive disability benefits than the general population.<sup>75</sup> Based on the French VICAN 2 study, 22% of those aged 18–57 reported losing their job when their cancer was diagnosed, rising to 92% 15 months after diagnosis.<sup>69</sup>

A study in the United Kingdom found that almost one in three people living with cancer (30%) had a loss of income as a result of their diagnosis and lost £860 a month on average. A third of people (33%) stopped working permanently or temporarily.<sup>70</sup>

These data underline the need for social policies that protect patients from financial insecurity during and after their cancer care.

## A prior diagnosis of cancer created lifelong financial insecurity for some respondents.

In addition to the cost burden of cancer itself, respondents sometimes commented that having had cancer had a long-term impact on their ability to get a mortgage or affordable insurance – and many worried about their future financial security as a result.



‘It’s impossible to get a bank loan, however necessary at this moment... One is punished for being ill, and it all comes down to luck. In my case, I had never neglected my health.’ Respondent from Belgium



‘Cannot get a new mortgage insurance, new travel insurance or new life insurance. We have become outcasts in the eyes of insurance companies.’ Respondent from Canada



### What we know

**In France, research found that disclosure of a childhood cancer was associated with difficulties in obtaining insurance and loans later in life.<sup>76</sup>**

As a result of these findings, France put into place in 2016 the first anti-discrimination laws to relieve cancer survivors of having to disclose their history of cancer to insurers, as long as it had been at least five years since the end of their active treatment. These laws – called ‘The right to be forgotten’ (Le Droit à l’Oubli) – are now also being implemented in Belgium.



## Patient stories

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### Sofia\* (Italy)

**During one year, I consulted three specialists at my own expense.** After three negative medical opinions, I had peace of mind. But when I eventually saw another specialist, he immediately arranged an operation. A week later, he phoned to confirm that it was cancer, and that I needed a second operation. I considered that phone call a gesture of kindness; he wanted to inform me immediately, as I had asked. But the diagnosis could have been made a year earlier.

**I chose to do all the diagnosis and the surgical operations at my own expense,** because I found it difficult to get an appointment in a public hospital – especially at 8.30am to fit around work.

**Cancer treatments have had a heavy impact on my work.** My job required me to travel a lot and did not allow for long absences. After the first two operations to remove the primary cancer, I had another seven preventive operations. After each operation, I needed to be off work for two weeks.

**The psychological impact has also been very hard.** I had to face fears and make tough decisions. Each operation left marks on my body, which has been difficult to accept. During these years of analysis and examinations, I have never been offered any psychological support, nor had I been advised about patient support groups. I paid for psychological aid at my own expense.

**Through personal online research, I discovered support networks.** I have become an active member of an association that offers support. Meeting other patients, who understand and know exactly what you are experiencing, is of enormous importance.

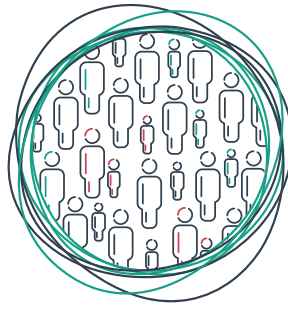
**The financial impact of my cancer has been significant.** At the time, I had private health insurance – an optional benefit of my job. It covered about 40% of the total expenses, and I paid the rest out of my own pocket.

**But after quitting my job, I had to subscribe to new health insurance.** It includes oncologic expenses in the case of primary tumours, but not any risks related to previously diagnosed cancer – unless you pay impossible premiums.

**The experience of having cancer in my 30s changed my perspective on life.** I decided to make a career change; now I work with my partner, so I can spend more time with him and I have a more peaceful approach to work. I began to ask myself: how do I want to live my life from now on? In my case, it led to a profound change of my priorities and a reorganisation of my life – to give more value to myself rather than other people's expectations.

\* Names and some other identifying elements have been changed to protect patients' anonymity.

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# Conclusions

**This report presents findings from nearly 4,000 respondents on where they felt inefficiency occurred in their care.**

These findings are intrinsically important, as they represent patients' perceptions about the efficiency of their care. Patients live the reality of healthcare delivery. Their insights are both unique and valuable. If we want to be true to our aim of delivering care focused on what matters to patients, we must consider these patient insights alongside economic and clinical data, and ensure that we account for them in our definitions of efficiency and inefficiency. From a policy perspective, we should not only be looking at health system reform; we should also look at how policies and societies need to adapt to adequately provide for people living with and beyond cancer.

The All.Can patient survey findings reflect similar findings from surveys and reviews in the literature<sup>38 49 77 78</sup> and reveal a number of opportunities where improvement is needed from the patient perspective:

- 1. Ensure swift, accurate and appropriately delivered diagnosis.** When asked to select the one area of cancer care where they experienced the most inefficiency, 26% of respondents chose diagnosis – more than any other area of cancer care. Even in countries where another area of cancer care was reported as most inefficient, diagnosis was always among the top three areas of inefficiency reported by respondents. For respondents whose cancer was diagnosed outside of a screening programme, speed of diagnosis had an impact on their entire experience of care.
- 2. Improve information-sharing, support and shared decision-making.** Respondents expressed the need for better information and support to help them feel more engaged in their care. Information on what to expect in terms of side effects and risk of recurrence, and what to do after the phase of active treatment was over, was particularly needed.



### 3. **Make integrated multidisciplinary care a reality for all patients.**

Respondents asked for more focus on the emotional and psychological impact of cancer and better integration of allied health and complementary services into their care. Cancer nurse specialists were often cited as playing an essential navigator role for respondents and their families.

### 4. **Address the financial implications of cancer.** Respondents commented on the significant and lasting economic burden often caused by cancer, and the need for greater support early in their care to facilitate their return to work and adapt their lives following cancer care.

Throughout the survey, respondents' comments underscored the wide-reaching impact cancer can have on all aspects of their lives. This is also reflected in economic data: social costs represent 60% of the total cost of cancer.<sup>74</sup> Integrated health and social policies that recognise the broad impact of cancer on individuals will be essential<sup>72</sup> if we are to curb the costs of cancer on our society.

Finally, we should not forget that simple solutions can often go a long way in improving efficiency – leading not only to economic gains but, most importantly, to better outcomes for patients.

## Find out more

All.Can is eager to continue working with others based on these survey findings. More patient stories will be posted on our website, and we would be happy to share further information about the survey. **To find out more, please contact us at [secretariat@all-can.org](mailto:secretariat@all-can.org).**

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# Appendix 1: country findings



United States



Canada



Belgium



Poland



United Kingdom

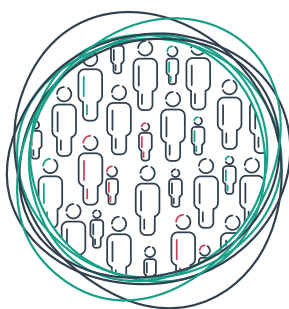


Italy



Australia





# Introduction

This Appendix contains overviews of findings of the All.Can patient survey in seven participating countries.

All.Can international and Quality Health worked with individual All.Can national initiatives and associated member organisations to develop tailored surveys for each participating country. Most questions remained the same across countries, but additional questions were added to suit local country contexts and at the request of each country. In some cases, the wording of questions was adapted to accommodate local differences. Surveys were produced in English, and then translated into local languages. All translations were verified by a representative of the country's national All.Can initiative. The surveys were hosted online, and links were distributed.

To download a copy of the survey questions used in each country, please visit the All.Can international website ([www.all-can.org/what-we-do/research/patient-survey/about-the-survey/](http://www.all-can.org/what-we-do/research/patient-survey/about-the-survey/)).

For more information on All.Can national initiatives involved in the patient survey, please visit <http://www.all-can.org/national-initiatives/>.

## Interpretation of findings

The survey was conducted in 10 countries: Australia, Belgium, Canada, France, Italy, Poland, Spain, Sweden, the United Kingdom and the United States. We have excluded findings from France, Spain and Sweden from this section due to small sample sizes (<50 responses each).

Country findings presented in this section are unweighted and therefore represent the actual responses from current and former cancer patients and/or caregivers who completed the survey in each country. As they represent different populations in each country, **the country findings in this Appendix must be considered independently and cannot be directly compared with those of other countries.** Further country comparisons will form part of the next phase of our research.

## For more information

For more detailed findings from each country, please contact the All.Can international secretariat: [secretariat@all-can.org](mailto:secretariat@all-can.org). Further country-level analyses will be disseminated by each All.Can national initiative throughout 2019.

# Australia



**1 in 2 Australians will be diagnosed with cancer by the age of 85 and, in 2019, it is estimated 145,000 new cases will be diagnosed and 50,000 deaths will occur.<sup>i</sup>**

## About this survey in Australia

The survey in Australia was conducted in partnership with All.Can Australia and the University of Western Australia. Data collection took place from 12 July – 30 November 2018.

**A total of 850 people took part in the Australian survey.**

### Respondent profile

- **Cancer type:** breast **68%**; lymphoma **7%**; prostate **5%**; other (various cancer types, all <5%) **20%**
- **Gender:** female **89%**; male **11%**
- **Age:** 0–24 **1%**; 25–64 **67%**; 65+ **32%**

Please note: as the majority of respondents in Australia were breast cancer patients, the key findings (page 67) consider the results for breast cancer patients against the results for all other cancer types. This applies only to the Australian findings.

### Where did inefficiencies occur most?

- My initial cancer diagnosis: **23%**
- Dealing with ongoing side effects: **19%**
- Dealing with the psychological impacts: **15%**



'My cancer nurse was, and still is, the most amazing support we could have asked for. She has a wealth of knowledge and helped us out and at any time of the day or night!'



'Some initial psychological assistance might be useful, even if the patient doesn't request it – sometimes one doesn't realise one needs it!'

<sup>i</sup> Cancer Council Australia. 2019. Cancer in Australia. Available online at <https://www.cancer.org.au/about-cancer/what-is-cancer/facts-and-figures.html>

## Australia: key findings

### Swift, accurate and appropriately delivered diagnosis

- **28%** of respondents whose cancer was detected outside of a screening programme said that their cancer was diagnosed as something different – either initially or multiple times. This occurred less frequently for respondents with breast cancer (**18%**) than for all other tumour types (**43%**)
- The largest difference between cancer types was expressed in diagnosis: **91%** of breast cancer respondents whose cancer was detected outside of a screening programme were diagnosed within three months, compared to an average of **69%** in all other tumour types
- **12%** of respondents whose cancer was detected outside of a screening programme waited more than six months to be diagnosed with cancer. In breast cancer this was **5%**, while the average across all other tumour types was **22%**

### Information, support and shared decision-making

- **35%** did not feel involved enough in deciding which treatment options were best for them
- **28%** were not given enough information (in a way they could understand) about their cancer care and treatment
- **50%** did not receive enough support to deal with ongoing symptoms and side effects – including beyond the active phase of their treatment
- **41%** did not receive enough information (in a way they could understand) about the signs and symptoms indicating that their cancer might be returning or getting worse
- **31%** were not given information about patient groups, charities and other organisations that might be able to support them

### Integrated multidisciplinary care

- **30%** did not have access to a specialist cancer nurse, either immediately after their diagnosis or during treatment
- **19%** said that supported from allied health professionals was not available when they needed it
- **63%** were not offered complementary therapies (e.g. massage, meditation, acupuncture, aromatherapy and/or other non-traditional therapies) as part of their cancer treatment
- **64%** reported that they needed some sort of psychological support during/after their cancer care but, of those, **35%** said it was not available

### The financial impact of cancer

- **79%** reported out-of-pocket costs, **32%** reported travel costs (**11%** had to travel for 1–2 hours to attend appointments or receive treatment, **7%** for more than 2 hours, and **9%** required an overnight stay because it was too far from home), **27%** reported a loss of employment, **8%** a loss of insurance and **4%** childcare costs

# Belgium



An estimated 3% of the Belgian population were living with and beyond cancer between 2004 and 2013.<sup>i</sup> There are over 70,000 new cases of cancer each year.<sup>ii</sup>

## About this survey in Belgium

The survey in Belgium was conducted in partnership with All.Can Belgium. Data collection took place from 28 August – 30 November 2018.

**A total of 391 people took part in the Belgian survey.**

### Respondent profile

- **Cancer type:** breast **47%**; haematological **9%**; bowel/colorectal **7%**; lung **7%**; other (various cancer types, all <5%) **29%**
- **Gender:** female **75%**; male **25%**
- **Age:** 0–24 **1%**; 25–64 **61%**; 65+ **34%**; not specified **3%**
- **Language:** Dutch **63%**; French **37%**; German **0.26%**

### Where did inefficiencies occur most?

- Dealing with ongoing side effects: **28%**
- My initial cancer diagnosis: **17%**
- Getting the right treatment for my cancer: **15%**



'My son's diagnostic process was very fast and efficient. Even after our first emergency visit, the follow-up (to make sure we did not stop the medical exams) was impeccable.'



'I had to ask for psychological help myself. This wasn't the priority of the treating physician, but I am very glad that I insisted. The doctor was not against it, but didn't think it was a priority!'

<sup>i</sup> Belgian Cancer Registry. Cancer burden 2004-2013. Available online at [https://kankerregister.org/media/docs/publications/BCR\\_publicatieCancerBurden2016\\_web160616.pdf](https://kankerregister.org/media/docs/publications/BCR_publicatieCancerBurden2016_web160616.pdf)

<sup>ii</sup> Belgian Cancer Registry. Annual tables. Available online at <https://kankerregister.org/default.aspx?PageId=643>

## Belgium: key findings

### Swift, accurate and appropriately delivered diagnosis

- **26%** of respondents whose cancer was detected outside of a screening programme said their cancer was diagnosed as something different – either initially or multiple times
- **13%** of respondents whose cancer was detected outside of a screening programme waited more than six months to be diagnosed with cancer

### Information, support and shared decision-making

- **45%** did not feel involved enough in deciding which treatment options were best for them
- **24%** were not given enough information (in a way they could understand) about their cancer care and treatment
- **42%** did not receive enough support to deal with ongoing symptoms and side effects – including beyond the active phase of their treatment
- **40%** did not receive enough information (in a way they could understand) about the signs and symptoms indicating that their cancer might be returning or getting worse
- **50%** were not given information about patient groups, charities and other organisations that might be able to support them

### Integrated multidisciplinary care

- **53%** always felt supported by those involved in their care (e.g. surgeons, oncologists, radiologists, nurses and other specialists)
- **11%** said that support from allied health professionals was not available when they needed it
- **71%** reported that they needed some form of psychological support during/after their cancer care but, of those, **23%** said it was not available
- **80%** of those who received psychological support found it helpful
- **6%** had to miss or cancel their own appointments three or more times at short notice, whereas **2%** reported this was done by their hospital or clinic

### The financial impact of cancer

- **21%** reported travel costs, **10%** a loss of employment, **2%** childcare costs, **2%** loss of insurance and **15%** other

# Canada



Cancer is the leading cause of death in Canada – responsible for 30% of all deaths. One in every two Canadians is expected to develop cancer during their lifetime, and one in four Canadians will die from cancer. In 2015, 2.1 million people in Canada (aged 12 and over) reported living with and beyond cancer.<sup>i</sup>

## About this survey in Canada

The survey in Canada was conducted in partnership with All.Can Canada, led by Save Your Skin Foundation. Data collection took place from 13 June – 30 November 2018.

**A total of 314 people took part in the Canadian survey.**

### Respondent profile

- Cancer type: breast **37%**; haematological **13%**; skin **11%**; other (various cancer types, all <5%) **39%**
- Gender: female **81%**; male **19%**
- Age: 0–24 **1%**; 25–64 **61%**; 65+ **37%**
- Language: English **87%**; French **13%**

### Where did inefficiencies occur most?

- My initial cancer diagnosis: **25%**
- Dealing with ongoing side effects: **17%**
- Dealing with the psychological impacts: **15%**



‘Having a Nurse Practitioner assigned to my case to help me through the initial trauma of a cancer diagnosis would have been very helpful. Doctors don’t always have time to provide patients with all the support they need.’

<sup>i</sup> Government of Canada. 2018. Fact sheet: Cancer in Canada. Available online at <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/fact-sheet-cancer-canada.html>

# Canada: key findings

## Swift, accurate and appropriately delivered diagnosis

- **27%** of respondents whose cancer was detected outside of a screening programme said that their cancer was diagnosed as something different – either initially or multiple times
- **14%** of respondents whose cancer was detected outside of a screening programme waited more than six months to be diagnosed with cancer

## Information, support and shared decision-making

- **44%** did not feel involved enough in deciding which treatment options were best for them
- **35%** were not given enough information (in a way they could understand) about their cancer care and treatment
- **48%** did not receive enough information (in a way they could understand) about the signs and symptoms indicating that their cancer might be returning or getting worse
- **43%** were not given information about patient groups, charities and other organisations that might be able to support them
- Of those who knew about patient groups, **62%** used them a lot, or some of the time
- **88%** would like their health data shared with larger data bodies for the purpose of research and the ability to track long-term patient outcomes

## Integrated multidisciplinary care

- **18%** said that support from allied health professionals was not available when they needed it
- **61%** reported that they needed some form of psychological support during/after their cancer care but, of those, **35%** said it was not available
- **27%** were left with unused medicine at the end of their treatment because they were given too much

## The financial impact of cancer

- **48%** paid for some part of their cancer care: **25%** for private insurance, **10%** for care not covered by the national health system, and **6%** to avoid delays
- **43%** paid for medicines, **38%** paid for alternative treatment and support (homeopathy, naturopathy, psychosocial support, physiotherapy) and **19%** paid for some part of their diagnosis not covered by a private or public insurance plan
- **46%** reported travel costs, **28%** reported loss of employment, **6%** reported loss of insurance, **5%** reported childcare costs and **18%** reported other non-care-related costs

# Italy



Cancer represents the second leading cause of death in Italy. In 2018, there were 3.3 million people living with and beyond cancer, and an incidence of 373,000 new cases that year.<sup>i</sup>

## About this survey in Italy

The survey in Italy was conducted in partnership with All.Can Italy. Data collection took place from 27 September – 30 November 2018.

**A total of 96 people took part in the Italian survey.**

### Respondent profile

- Cancer type: breast **25%**; urological **25%**; skin **22%**; other (various cancer types, all <5%) **29%**
- Gender: female **66%**; male **34%**
- Age: 0–24 **2%**; 25–64 **79%**; 65+ **17%**; not specified **1%**

### Where did inefficiencies occur most?

- Dealing with the psychological impacts: **25%**
- My initial cancer diagnosis: **24%**
- Dealing with ongoing side effects: **11%**
- Access to patient support groups: **11%**



'Cancer is a disease that must be addressed with a 360-degree view, and psychological support is necessary for the patient or for their partner.'

<sup>i</sup> AIOM, 2018. I numeri del cancro in Italia. Available online at [https://www.fondazioneaiom.it/wp-content/uploads/2018/10/2018\\_NumeriCancro-pazienti.pdf](https://www.fondazioneaiom.it/wp-content/uploads/2018/10/2018_NumeriCancro-pazienti.pdf)



## Italy: key findings

### Swift, accurate and appropriately delivered diagnosis

- **22%** of respondents whose cancer was detected outside of a screening programme said that their cancer was diagnosed as something different – either initially or multiple times
- **9%** of respondents whose cancer was detected outside of a screening programme waited more than six months to be diagnosed with cancer

### Information, support and shared decision-making

- **50%** did not feel involved enough in deciding which treatment options were best for them
- **32%** were not given enough information (in a way they could understand) about their cancer care and treatment
- **44%** did not receive enough support to deal with ongoing symptoms and side effects – including beyond the active phase of their treatment
- **59%** were not given information about patient groups, charities and other organisations that might be able to support them
- **94%** of those who used patient groups, charities and other organisations said they benefitted from them

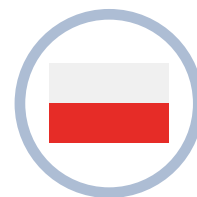
### Integrated multidisciplinary care

- **76%** were treated by a multidisciplinary team (e.g. surgeons, oncologists, radiologists, nurses and other specialists)
- **70%** saw a physician within 24 hours if any complications occurred during treatment
- **68%** reported that they needed some form of psychological support during/after their cancer care but, of those, **46%** said that it was not available
- Of those who received psychological support, **71%** received it in a hospital setting and **19%** from a voluntary organisation

### The financial impact of cancer

- **62%** incurred expenses because of their cancer: **57%** paid to speed-up waiting times, **9%** paid for private insurance, and **33%** for other reasons
- **48%** reported travel costs, **15%** a loss of insurance, and **13%** a loss of employment

# Poland



In Poland each year, over 163,000 people are diagnosed with cancer, and more than 100,000 people die from cancer.<sup>i</sup>

## About this survey in Poland

The survey in Poland was conducted in partnership with All.Can Poland. Data collection took place from 7 June – 30 November 2018.

**A total of 1,135 people took part in the Polish survey.**

### Respondent profile

- Cancer type: breast **39%**; gynaecological **14%**; haematological **8%**; other (various cancer types, all <5%) **39%**
- Gender: female **83%**; male **17%**
- Age: 0–24 **3%**; 25–64 **75%**; 65+ **22%**

### Where did inefficiencies occur most?

- Dealing with ongoing side effects: **27%**
- Dealing with the psychological impacts: **18%**
- My initial cancer diagnosis: **14%**



'There is always something to improve – definitely faster start of treatment from the first diagnosis, because undoubtedly the whole process takes too long. During this time, the patient and family do not know what to do with themselves, and the cancer progresses.'

<sup>i</sup> Najwyższa Izba Kontroli (NIK) 2018. How to prevent and cure cancer more effectively? Available online at <https://www.nik.gov.pl/plik/id,16371,vp,18897.pdf>

## Poland: key findings

### Swift, accurate and appropriately delivered diagnosis

- **27%** of respondents whose cancer was detected outside of a screening programme said that their cancer was diagnosed as something different – either initially or multiple times
- **12%** of respondents whose cancer was detected outside of a screening programme waited more than six months to be diagnosed with cancer

### Information, support and shared decision-making

- **52%** did not feel involved enough in deciding which treatment options were best for them
- **53%** were not given enough information (in a way they could understand) about their cancer care and treatment
- **63%** were not informed in a way they could understand about possible treatments, including those that were not reimbursed or available in other centres
- **69%** did not receive enough information on how to deal with pain
- **69%** did not receive enough support to deal with ongoing symptoms and side effects – including beyond the active phase of their treatment
- **75%** were not given information about patient groups, charities and other organisations that might be able to support them

### Integrated multidisciplinary care

- **50%** said that support from allied health professionals was not available when they needed it
- **89%** reported that they needed some form of psychological support during/after their cancer care but, of those, **41%** said it was not available

### The financial impact of cancer

- **47%** paid for some cancer care and treatment themselves: **33%** to avoid delays, **15%** for treatment not covered by the national health system, and **4%** for private insurance
- **63%** reported that they had to purchase additional medicines, **43%** reported an absence from work, and **43%** reported additional costs to fulfil family and social roles (i.e. running a home, taking care of children)

# United Kingdom



**1 in 2 people in the United Kingdom will be diagnosed with cancer in their lifetime.<sup>i</sup>** In 2015, it was estimated that more than 2.5 million people in the United Kingdom were living with cancer, and there were 359,960 new cases of cancer that year.<sup>ii iii</sup>

## About this survey in the United Kingdom

The survey in the United Kingdom was conducted in partnership with All.Can UK. Data collection took place from 31 January – 23 August 2018.

**A total of 322 people took part in the United Kingdom survey.**

### Respondent profile

- **Cancer type:** breast **28%**; gynaecological **20%**; bowel/colorectal **9%**; other (various cancer types, all <5%) **43%**
- **Gender:** female **79%**; male **21%**
- **Age:** 0–24 **1%**; 25–64 **62%**; 65+ **37%**

### Where did inefficiencies occur most?

- My initial cancer diagnosis: **36%**
- Dealing with ongoing side effects: **19%**
- Dealing with the psychological impacts: **15%**



‘In addition to support to manage the anxiety of having a life-threatening condition, I think that more needs to be done to support people [with cancer] managing at work, i.e. managing time off, talking to your employer, understanding your rights.’



‘I would like more information about mental health support. I asked repeatedly (oncologists, nurse and GP) and nobody was able to give me any information. I knew I had a problem, but it was extremely difficult for me to find professional support.’

i Cancer Research UK. **Lifetime risk of cancer.** Available online at <https://www.cancerresearchuk.org/health-professional/cancer-statistics/risk/lifetime-risk#heading-Zero>

ii Cancer Research UK. **Cancer incidence statistics.** Available online at <https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence#heading-Zero>

iii Macmillan Cancer Support (2015). **2.5 million people now living with cancer in UK.** Available online at [https://www.macmillan.org.uk/aboutus/news/latest\\_news/25millionpeoplenowlivingwithcancerinukmacmillanrevealstoday.aspx](https://www.macmillan.org.uk/aboutus/news/latest_news/25millionpeoplenowlivingwithcancerinukmacmillanrevealstoday.aspx)

## United Kingdom: key findings

### Swift, accurate and appropriately delivered diagnosis

- **40%** of respondents whose cancer was detected outside of a screening programme said that their cancer was diagnosed as something different – either initially or multiple times
- **21%** of respondents whose cancer was detected outside of a screening programme waited more than six months to be diagnosed with cancer

### Information, support and shared decision-making

- **52%** did not feel involved enough in deciding which treatment options were best for them
- **38%** were not given enough information (in a way they could understand) about their cancer care and treatment
- **58%** did not receive enough support to deal with ongoing symptoms and side effects – including beyond the active phase of their treatment
- **48%** did not receive enough information (in a way they could understand) about the signs and symptoms indicating that their cancer might be returning or getting worse
- **40%** were not given information about patient groups, charities and other organisations that might be able to support them

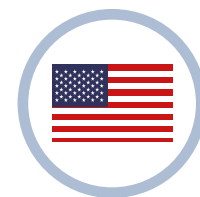
### Integrated multidisciplinary care

- **67%** reported that they needed some form of psychological support during/after their cancer care but, of those, **50%** said it was not available
- **34%** said they were given too much medication and therefore had excess amounts left over at the end of their treatment

### The financial impact of cancer

- **14%** paid for some or all of their cancer care themselves (either because the care and treatment they wanted was not available via the National Health Service, or because they wanted to avoid delays in treatment)
- **47%** reported travel costs, **27%** reported loss of employment, **12%** reported loss of insurance and **5%** reported childcare costs

# United States



In 2018, an estimated 1,735,350 new cases of cancer were diagnosed in the United States, with 609,640 people dying from the disease.<sup>1</sup>

## About this survey in the United States

Respondents were recruited through the health360 online platform. Data collection took place from 1 June – 17 August 2018.

**A total of 497 people took part in the United States survey.**

### Respondent profile

- Cancer type: breast **25%**; skin **11%**; gynaecological **11%**, head and neck **11%**; other (various cancer types, all <5%) **41%**
- Gender: female **63%**; male **37%**
- Age: 0–24 **1%**; 25–64 **87%**; 65+ **12%**

### Where did inefficiencies occur most?

- My initial cancer diagnosis: **31%**
- Dealing with ongoing side effects: **23%**
- Dealing with the financial implications: **15%**



'More follow-up care would be important. I ended up in a fairly serious bout of depression a year or so after my treatment ended. It came out of nowhere – luckily, I sought help from a therapist and was able to get through it with medication. The therapist said this is quite common in cancer patients – it would have been helpful to know this and to know what to expect'.



'Because I became too sick to work, I lost my job. Because I lost my job, I lost my health insurance'.

<sup>i</sup> National Cancer Institute. 2018. Cancer Statistics. Available online at <https://www.cancer.gov/about-cancer/understanding/statistics>

## United States: key findings

### Swift, accurate and appropriately delivered diagnosis

- **31%** of respondents whose cancer was detected outside of a screening programme said that their cancer was diagnosed as something different – either initially or multiple times
- **12%** of respondents whose cancer was detected outside of a screening programme waited for more than six months to be diagnosed with cancer

### Information, support and shared decision-making

- **41%** did not feel involved enough in deciding which treatment options were best for them
- **25%** were not given enough information (in a way they could understand) about their cancer care and treatment
- **31%** did not receive enough support to deal with ongoing symptoms and side effects – including beyond the active phase of their treatment
- **30%** did not receive enough information (in a way they could understand) about the signs and symptoms indicating that their cancer might be returning or getting worse
- **23%** were not given information about patient groups, charities and other organisations that might be able to support them

### Integrated multidisciplinary care

- **59%** reported that they needed some form of psychological support during/after their cancer care but, of those, **31%** said that it was not available

### The financial impact of cancer

- **68%** paid for some part of their cancer care: **55%** for private health insurance, **6%** for care and treatment not covered by insurance, and **4%** to avoid delays
- **44%** reported travel costs, **31%** reported loss of employment, **10%** reported loss of insurance and **9%** reported childcare costs



Changing cancer care together

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