Cancer Lived Experience Survey Report

2025

rare cancers
Australia

Survey and analysis
conducted by
So What?

Cancer Lived Experience Survey Report

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Introduction and methodology

Introduction

At Rare Cancers Australia (RCA), our vision is that every person impacted by rare and less common cancers will be supported from every angle, from the beginning. We do whatever it takes to change the story of a rare cancer diagnosis, through limitless support and relentless advocacy. We stand side by side with people diagnosed with cancer, and their families, with knowledge, energy and an unwavering determination to create a better world for people with rare cancers.

RCA commissioned the 2025 Cancer Lived Experience Survey to better understand what people with cancer and their carers go through. The survey provides insights into what is working well, and where services, supports and care pathways can be improved.

Nearly 2,500 people impacted by cancer completed the survey, sharing insights into what happened and how they felt before, during, and after their diagnosis, throughout treatment and beyond, and the impact on them and those close to them. Three-quarters of respondents had, or cared for someone who had, a rare or less common cancer.

We compare experiences between common and rare and less common cancers, because people we support consistently tell us they face additional challenges—longer diagnostic pathways, fewer treatment options, and greater difficulty navigating a system not always designed for them. This survey helps to identify and describe those differences at a national level and opportunities to learn from what is working better in common cancer pathways.

We sincerely thank the patients and carers who shared their time, insights, and deeply personal stories. They participated not only to be heard, but to contribute to a clearer understanding of the lived experience of cancer in Australia and drive improvement in care for others. Their contribution highlights the importance of consistently capturing and learning from patient-reported experience data to ensure cancer care is safe, person-centred, and equitable.

> “Thank you for the opportunity for allowing me tell my story, no one has ever been interested in my experience before.”

> “It’s a very good idea to have people give their experiences through a survey so that progress can be made towards better management of all areas of cancer.”

Survey overview

The Cancer Lived Experience Survey was conducted by So What? Research, a specialised healthcare market research agency, on behalf of RCA. The survey was designed as an exploratory study to identify unmet needs among people living with rare and less common cancers, as well as the carers who support them.

The survey was disseminated via email, social media, and through promotion by patient and healthcare organisations to maximise reach. Participation was voluntary, and all responses were anonymous.

Priority populations and future research

Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse backgrounds were eligible to participate in the survey. However, the survey design and distribution methods were not specifically tailored to these priority populations. As a result, representation from these groups is relatively low, and their perspectives may be under-represented in the findings. RCA recognises this as an important limitation and a priority for future research, including more culturally appropriate and accessible approaches to survey design and dissemination.

Children and adolescents (under 18 years) were excluded from this survey. Cancer care pathways, support needs, and decision-making processes for children and young people differ substantially from those for adults, and RCA considers that a dedicated survey, developed with appropriate ethics approval, would be required to accurately capture these experiences.

Eligibility and recruitment

Respondents were eligible to participate if they were adults (18+) living in Australia who either:

- currently had or previously had cancer; or
- were the primary carer of an adult with cancer (including carers of someone who had died from cancer).

A *primary carer* was defined as a non-professional caregiver—such as a partner, family member or close friend—who provided ongoing support.

Survey administration

Fieldwork took place between 21 March and 16 June 2025. To support accessibility, the survey was designed to be straightforward and user-friendly, taking approximately 20 minutes to complete online at a time and place chosen by respondents.

People diagnosed with cancer were asked a series of structured and open-ended questions about their experiences. Carers were asked about the experiences of the person they care(d) for as well as the impact of caring on their own lives.

The study received approval from the Bellberry Human Research Ethics Committee (Reference Number: 2025-02-121).

Analysis and reporting

Results are presented using counts and percentages to describe respondent characteristics and experiences. Base sizes are reported for each question and may vary, as not all questions were compulsory. Q Research software was used to identify statistically significant patterns within the data.

> Quotes are included throughout the report to illustrate respondents' experiences in their own words and to substantiate the findings.

Carer responses

Carers' responses about their own caregiving experience are shown separately in this report and appear on slides with dark pink backgrounds. Carer responses provided from the perspective of the person with cancer are not included in the analyses presented here but remain available for further exploration and to inform future work.

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Sample profile and analysis of results

Sample profile

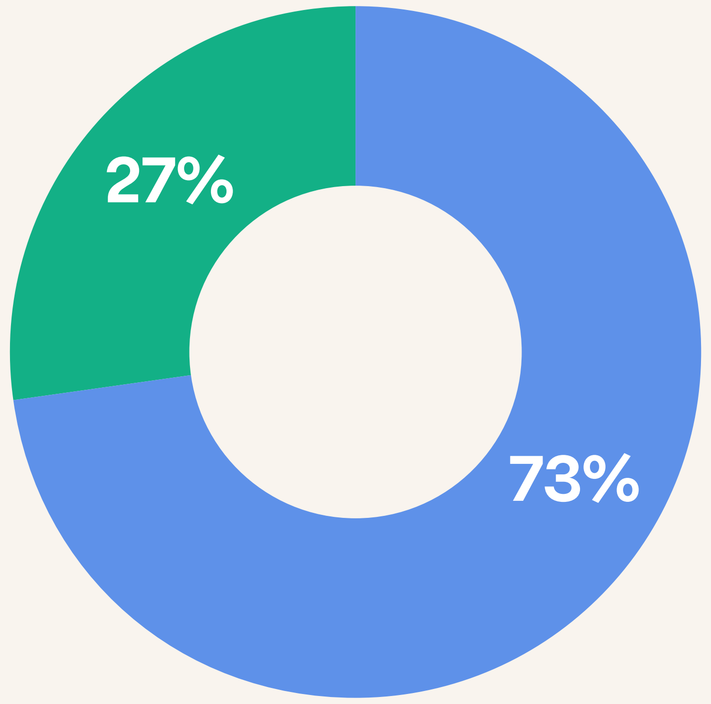
Cancer classification

Rare or less common (RLC) cancer

1,780 patients and carers
- **1,159** patients
- **621** carers

Common cancer

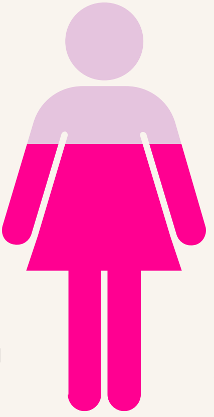
673 patients and carers
- **399** patients
- **274** carers



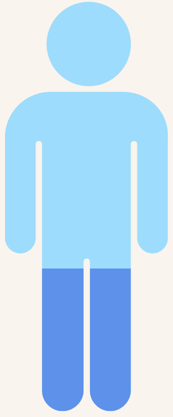
Refer to page 9 for definition of rare and less common cancers in this survey.

Gender

n=1 non-binary, n=1 prefer not to answer, n=1 Woman and non-binary



65% Women



35% Men

Sexual orientation

93%	2%	2%	2%
Straight (heterosexual)	Gay or lesbian	Bisexual	Prefer not to answer

n=10 different term (e.g., Queer)

Totals may be below or above 100% due to rounding

Country of birth

77% Australia	**3%** New Zealand
9% United Kingdom	**<1%** All other countries

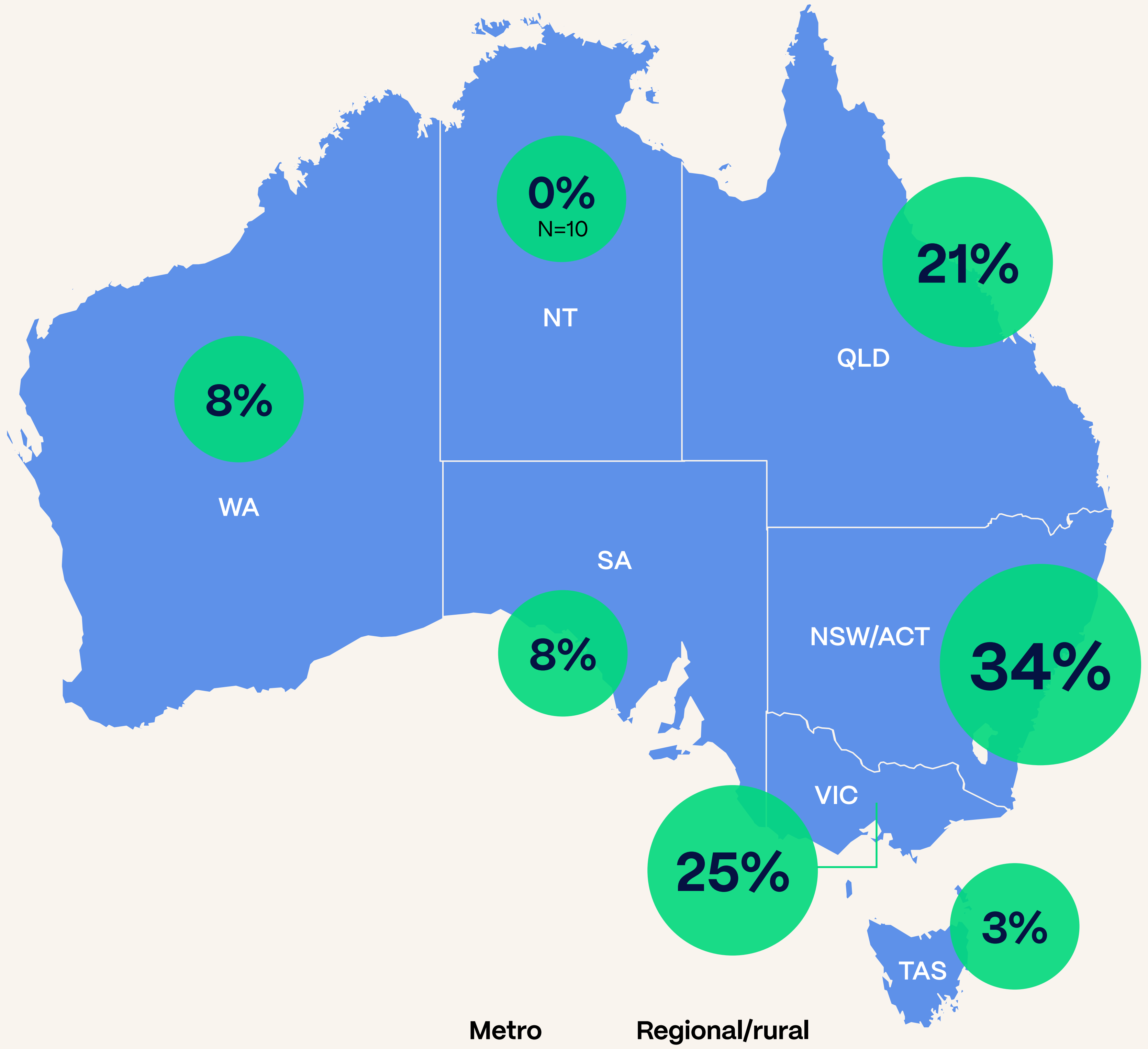
1% each
Netherlands, China, Germany, Italy, South Africa

Main languages spoken at home

98% English

6% Other languages
- **1%** Italian
- **1%** Greek
- **1%** Cantonese
- **4%** Other

Aboriginal or Torres Strait Islander descent



	Metro	Regional/rural
NSW/ACT	36%	28%
VIC	26%	24%
TAS	0%	10%
QLD	20%	22%
SA	9%	7%
WA	9%	7%
NT	0%	1%
Total	**66%**	**34%**

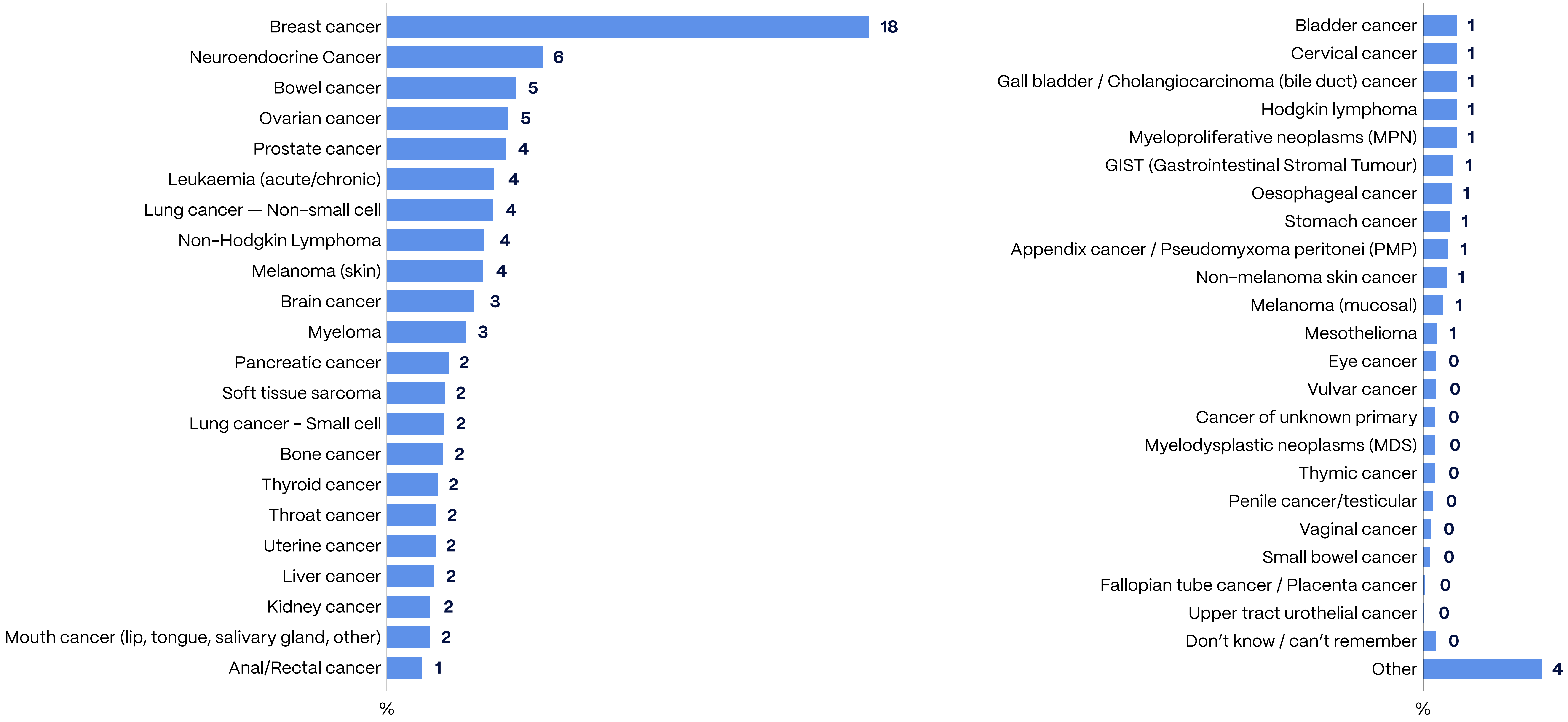
Cancer types represented in sample

Responses to:

What type of cancer were you most recently diagnosed with? What type of cancer was the person you are caring/have cared for most recently diagnosed with? **(2,460 responses)**

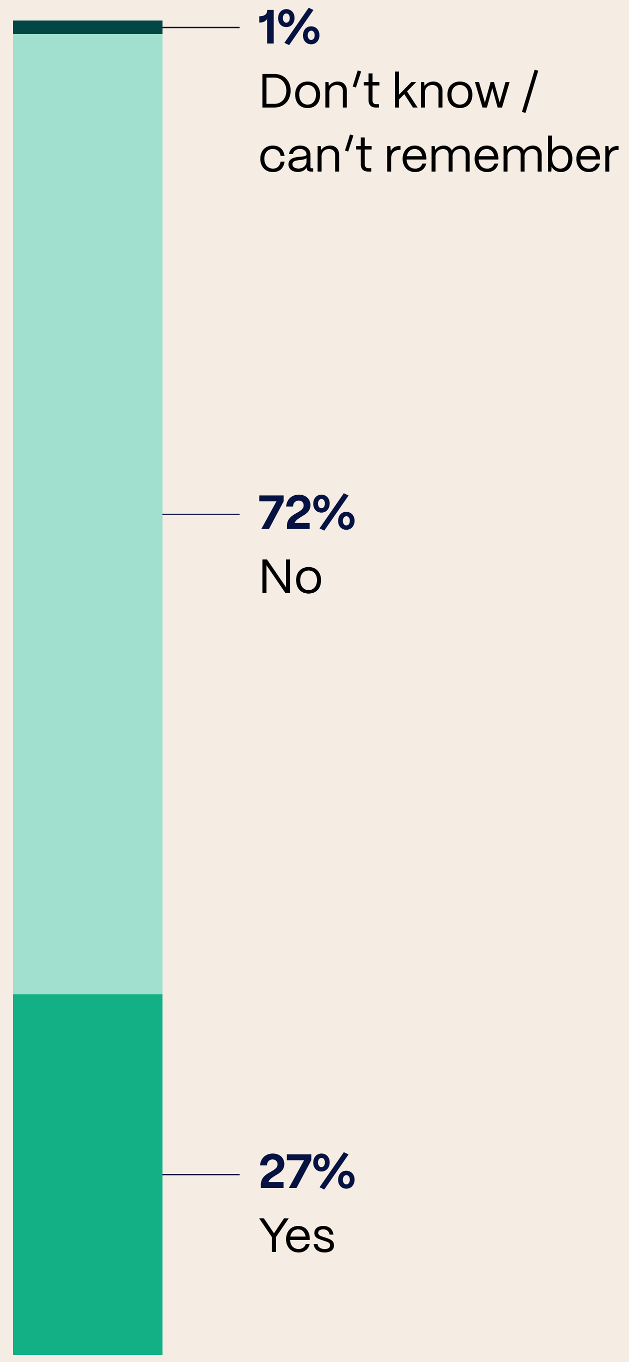
Have you ever been diagnosed with any other type(s) of cancer? **(1,779 responses)**

What type of cancer were you most recently diagnosed with?



Multiple cancer diagnoses

(same or other type)

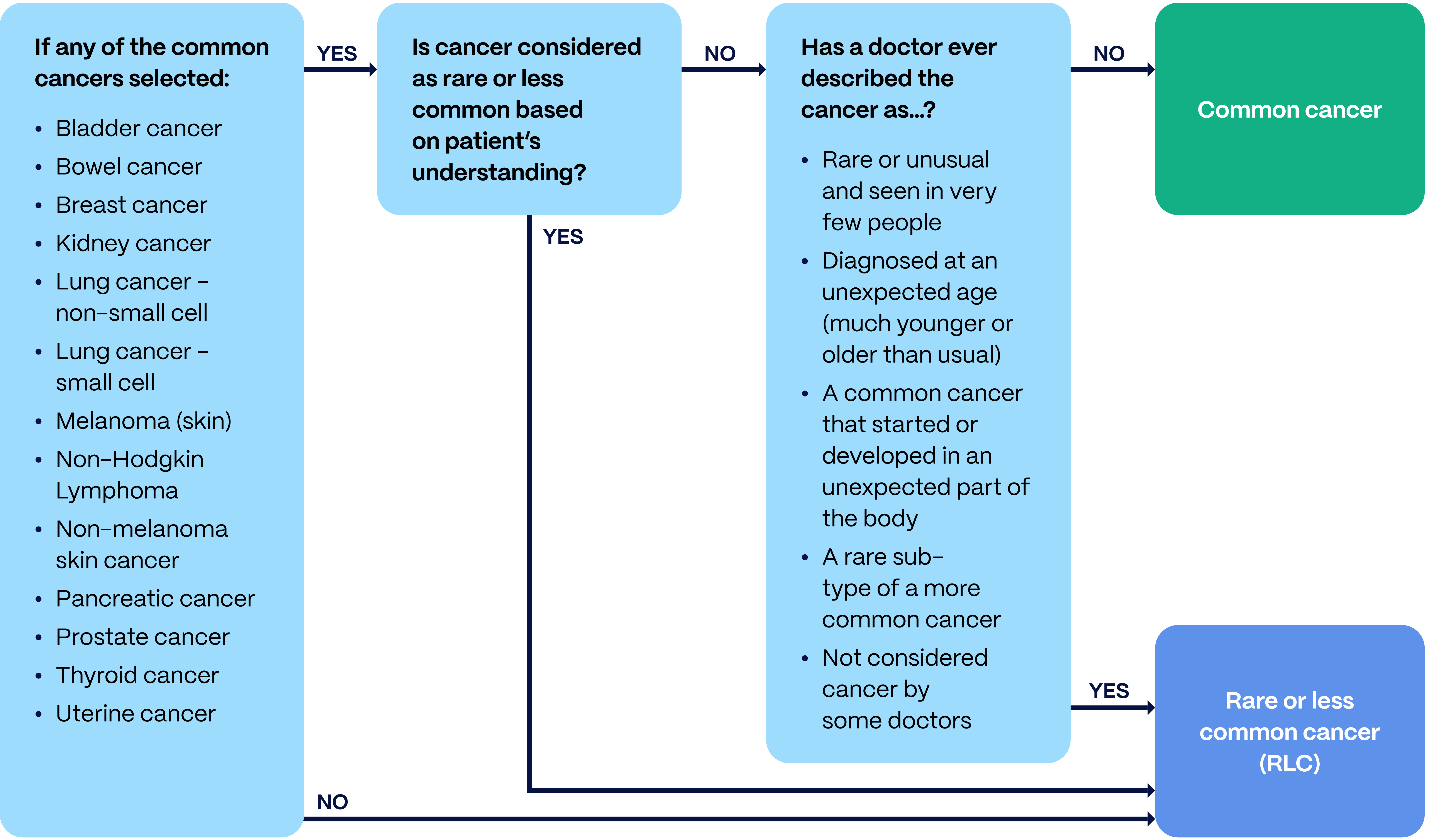


Percentages are rounded to the nearest whole number and may appear as zero where values are greater than zero.

Defining rare and less common cancers in this survey

In this study, rare and less common cancers were defined to capture rare subtypes of common cancers. This approach provides greater visibility of the experiences across the broader community that RCA supports, many of whom are not included in routine reporting.

This approach expands on the definition used by the Australian Institute of Health and Welfare (AIHW) definition, which currently classifies cancer rarity based on incidence rates using the International Classification of Diseases – Tenth Revision (ICD-10) that reflect the primary site of the cancer[1]. A rare cancer has an incidence rate of fewer than 6 cases per 100,000 people in the population. A less common cancer has an incidence rate of between 6 and 12 cases per 100,000.



If any of the common cancers selected:

- Bladder cancer
- Bowel cancer
- Breast cancer
- Kidney cancer
- Lung cancer – non-small cell
- Lung cancer – small cell
- Melanoma (skin)
- Non-Hodgkin Lymphoma
- Non-melanoma skin cancer
- Pancreatic cancer
- Prostate cancer
- Thyroid cancer
- Uterine cancer

Is cancer considered as rare or less common based on patient's understanding?

Has a doctor ever described the cancer as...?

- Rare or unusual and seen in very few people
- Diagnosed at an unexpected age (much younger or older than usual)
- A common cancer that started or developed in an unexpected part of the body
- A rare sub-type of a more common cancer
- Not considered cancer by some doctors

Common cancer

Rare or less common cancer (RLC)

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[1] AIHW (2025). Cancer Data in Australia. https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/overview

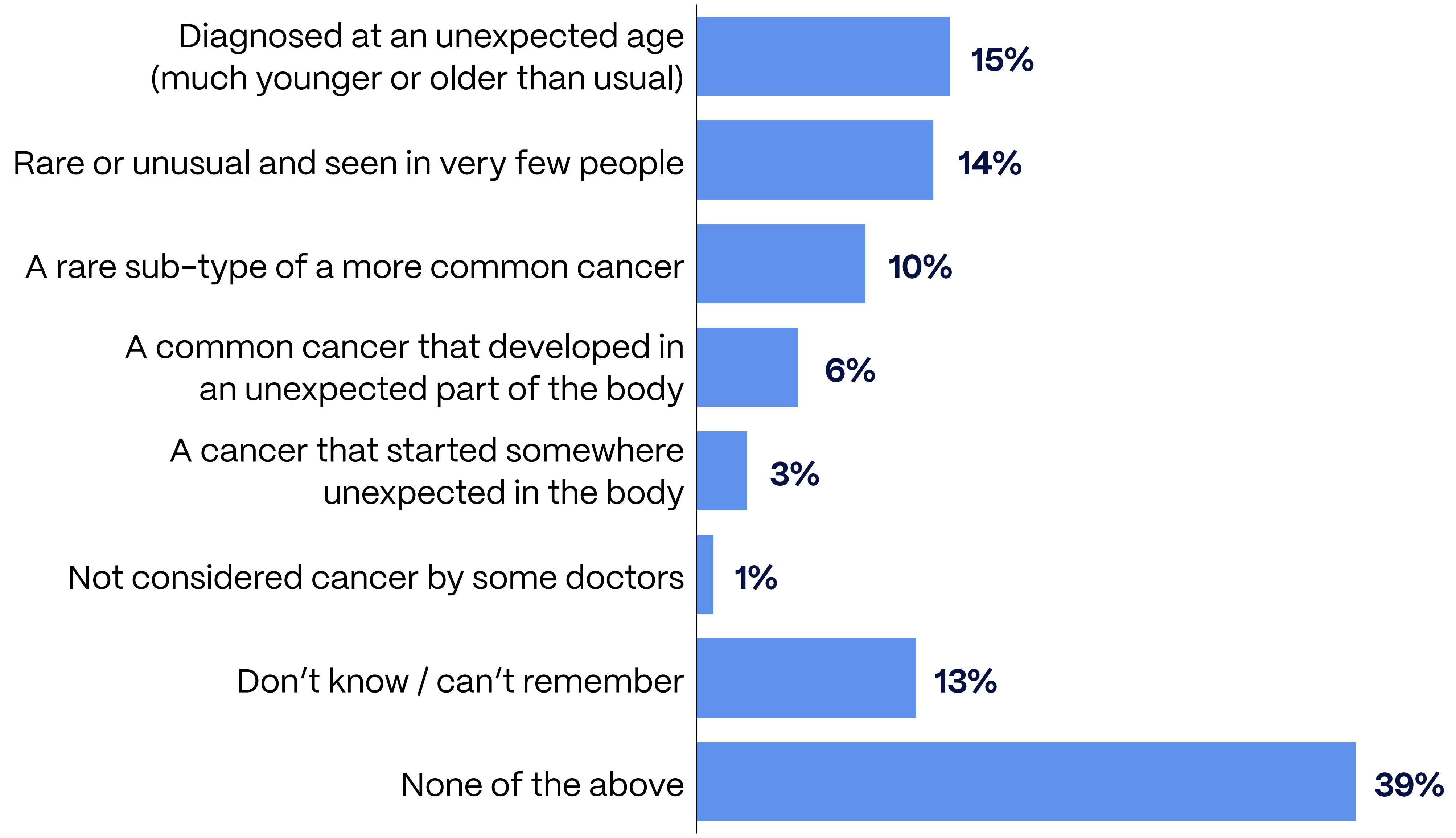
Common cancer diagnoses re-classified as rare or less common in survey analysis

Responses to:

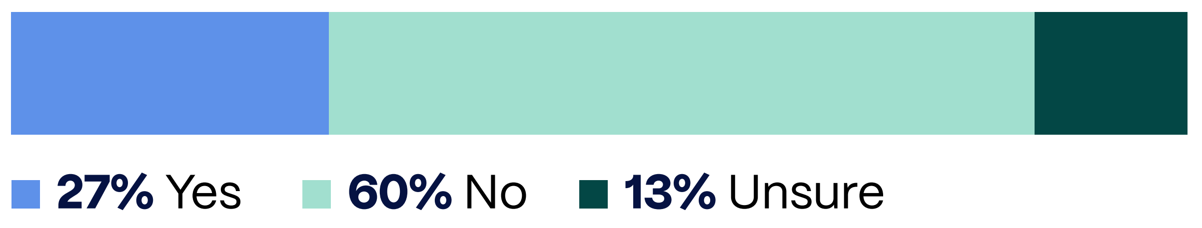
Has a doctor ever described your cancer as... Please select all that apply. Have you ever heard the person's doctor or care team, or the person with cancer describe their cancer in any of the following ways? Please select all that apply **(2,459 responses)**

Based on your understanding and experience, do you consider your type of cancer as rare or less common? Has the person you care(d) for ever referred to their cancer as rare or less common? **(2,460 responses)**

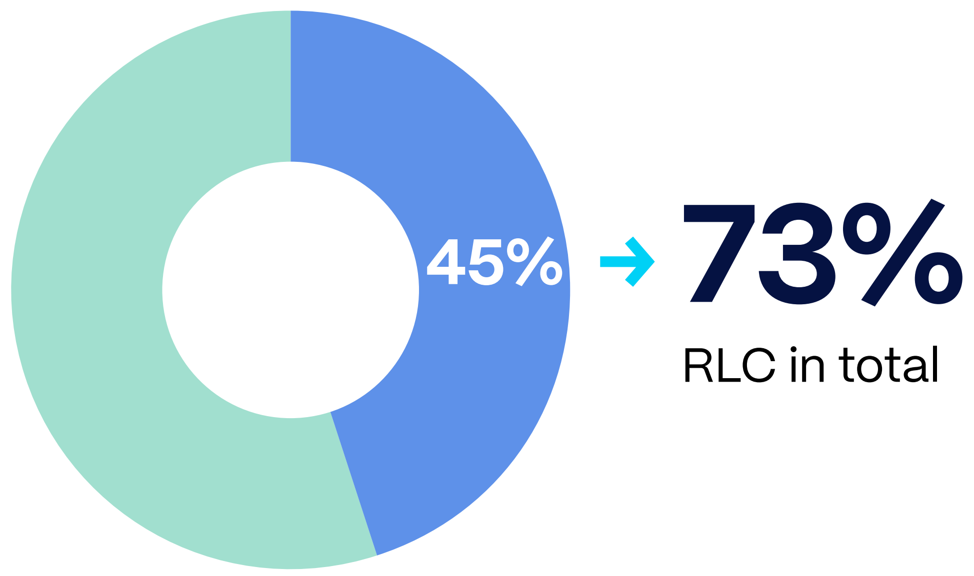
Has a doctor ever described your cancer as...?



Do you consider your type of cancer as rare or less common?



Common cancers classified as RLC



Any common cancers that fall into any of the categories in blue were re-classified as rare or less common for the purposes of this survey

45% of common cancers were re-classified as RLC based on these questions

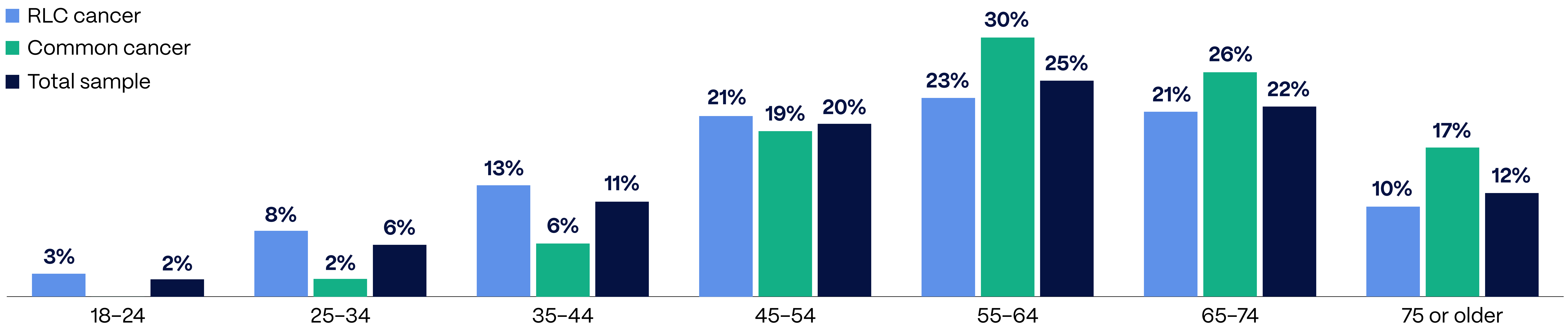
This results in a total of **73%** RLC cancers in the survey (**50%** selected a RLC cancer, plus **45%** of those who selected a common cancer)

Sample profile – Age and year of diagnosis

Responses to:

How old were you when you were diagnosed with this cancer? How old was the person you are caring for/have cared for when they were diagnosed with cancer?
(2,460 responses)

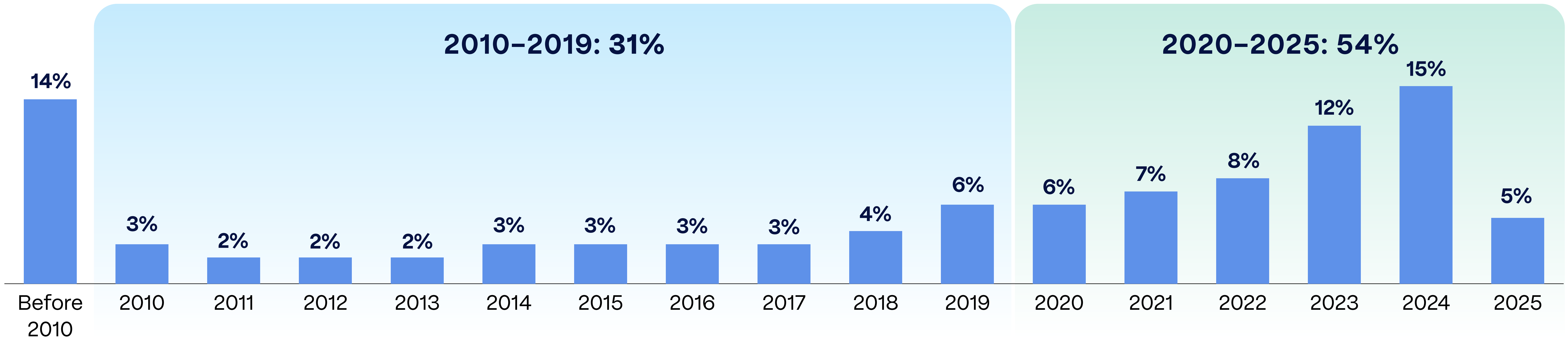
Age at diagnosis



Responses to:

In what year were you diagnosed with this cancer? In what year was the person you are caring for/cared for diagnosed with this cancer?
(2,459 responses)

Year of diagnosis



Limitations of survey data

	Cancer Lived Experience Survey		Australian population (2025)		
Geographical representation	NSW/ACT	**34%**	NSW/ACT	**33%**	Well-balanced across states with largest populations (NSW, VIC, QLD): these represent 80% of the national population and also 80% of our sample, showing strong geographic coverage. NT and WA underrepresented: below population norm, may affect generalisability for that region. TAS and SA slightly overrepresented, but within acceptable tolerance.
	VIC	**25%**	VIC	**26%**	
	QLD	**21%**	QLD	**21%**	
	WA	**8%**	WA	**11%**	
	SA	**8%**	SA	**7%**	
	TAS	**3%**	TAS	**2%**	
	NT	**<1%**	NT	**1%**	
Metro vs regional/rural	Metro: **66%** Regional/rural: **34%**		Metro: **70%** Regional/rural: **30%**		Small underrepresentation of people from metro areas (defined as Modified Monash Model 1), within acceptable tolerance.
Gender and sex	Female: **≈65%** Male: **≈35%** Gender diversity: **<1%**		Female: **≈51%** Male: **≈49%** Gender diversity: **<1%**		Females are overrepresented, which is common for large-scale voluntary health surveys and consistent with volunteer survey trends. Very low representation of gender diverse people, in range with comparable studies.
Age at diagnosis	Diagnosed at 45+ years: **80%**		Diagnosed at 45+: **92%**		Overrepresentation of people diagnosed at a younger age.
Indigenous status	**2%**		**≈3%**		Underrepresentation of Aboriginal and/or Torres Strait Islander people.
Cultural and linguistic diversity	Non-English as main language at home: **2%**		**≈23%** speak other languages		Survey only asked main language spoken at home. It is unclear what the total proportion of respondents is who speak a language other than English. However, culturally and linguistically diverse people are likely underrepresented.
Education level	**66%** post-school qualifications		**≈56%** post-school qualifications		Overrepresentation of higher education level. This reflects a known pattern in voluntary health surveys, where more educated individuals are more likely to participate. As a result, findings may underrepresent the experiences of those with lower health literacy or educational attainment.

3

Pre–diagnosis and diagnosis

Key findings – Pre-diagnosis and diagnosis

Respondents with rare and less common cancers were less likely to be diagnosed through screening and more likely to have their cancer picked up incidentally.

More than half (56%) of respondents were diagnosed with cancer after seeing a healthcare professional about symptoms.
One in four (28%) respondents with a rare or less common cancer were diagnosed incidentally during tests or treatment for another condition, compared with **15%** of those with a common cancer.
More than one third (34%) of respondents said they first became aware of their common cancer through routine screening. Just **9%** of respondents with a rare or less common cancer said they were diagnosed this way.

Respondents diagnosed with a rare or less common cancer were more likely to experience delays in diagnosis.

21% of respondents with a rare or less common cancer experienced delays of more than six months from first seeing a healthcare professional about symptoms to getting tested for cancer. **7%** reported that it took more than three years.
In comparison, **88%** of respondents diagnosed with a common cancer had tests within three months of seeing a healthcare professional about symptoms.

One in three (34%) respondents with a rare or less common cancer and **12%** of those with a common cancer attended four or more appointments to discuss their symptoms before receiving their diagnosis.

Key findings – Pre–diagnosis and diagnosis

One in four (26%) respondents with a rare or less common cancer said they were initially diagnosed with another condition. **Almost half (46%)** of people who were diagnosed with a rare or less common cancer after noticing symptoms felt that their symptoms were overlooked or associated with another illness or condition. In comparison, only **3%** of respondents with a common cancer reported being initially diagnosed with another condition.

People diagnosed with a rare or less common cancer were significantly less likely to understand which tests they were having and what they would tell them.

19% of people with a rare or less common cancer said they did not know what their diagnostic tests were for, compared with just **3%** of those with a common cancer.

People diagnosed with or caring for someone with a rare or less common cancer were more likely to seek and use information from websites and social media during the diagnostic phase than those diagnosed with or caring for someone with a common cancer.

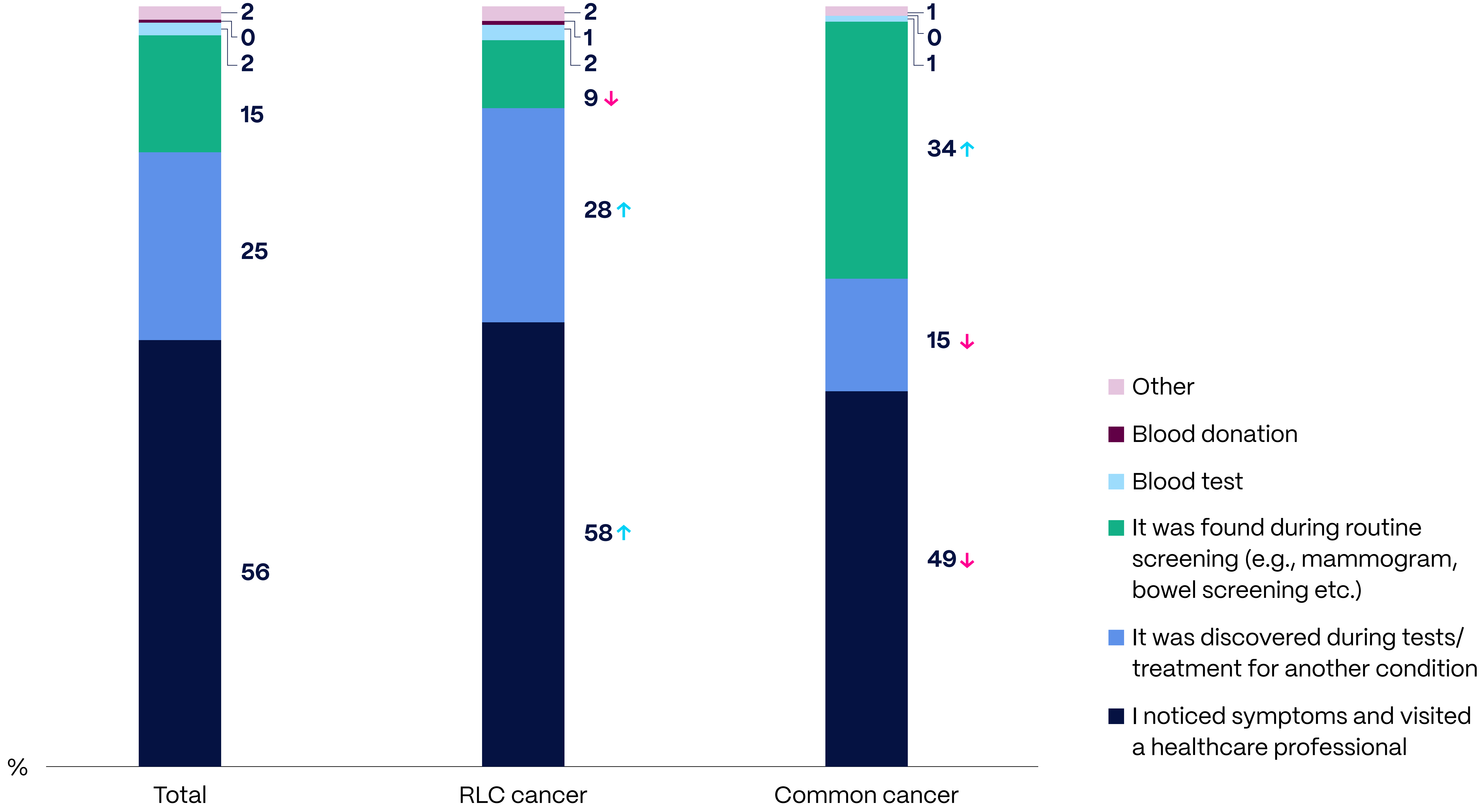
People with a rare or less common cancer were **more likely** to report having had genomic testing as part of their diagnosis (**36%** for rare and less common cancer compared with **18%** for common cancer). **One in five (19%)** respondents diagnosed with a rare or less common cancer had their care plan influenced by genomic testing.

People diagnosed with a rare or less common cancer were **more than twice** as likely as those with a common cancer to seek a second opinion about their diagnosis, and say that it was helpful or necessary (**14%** compared with **6%**).

Initial cancer awareness

Responses to:

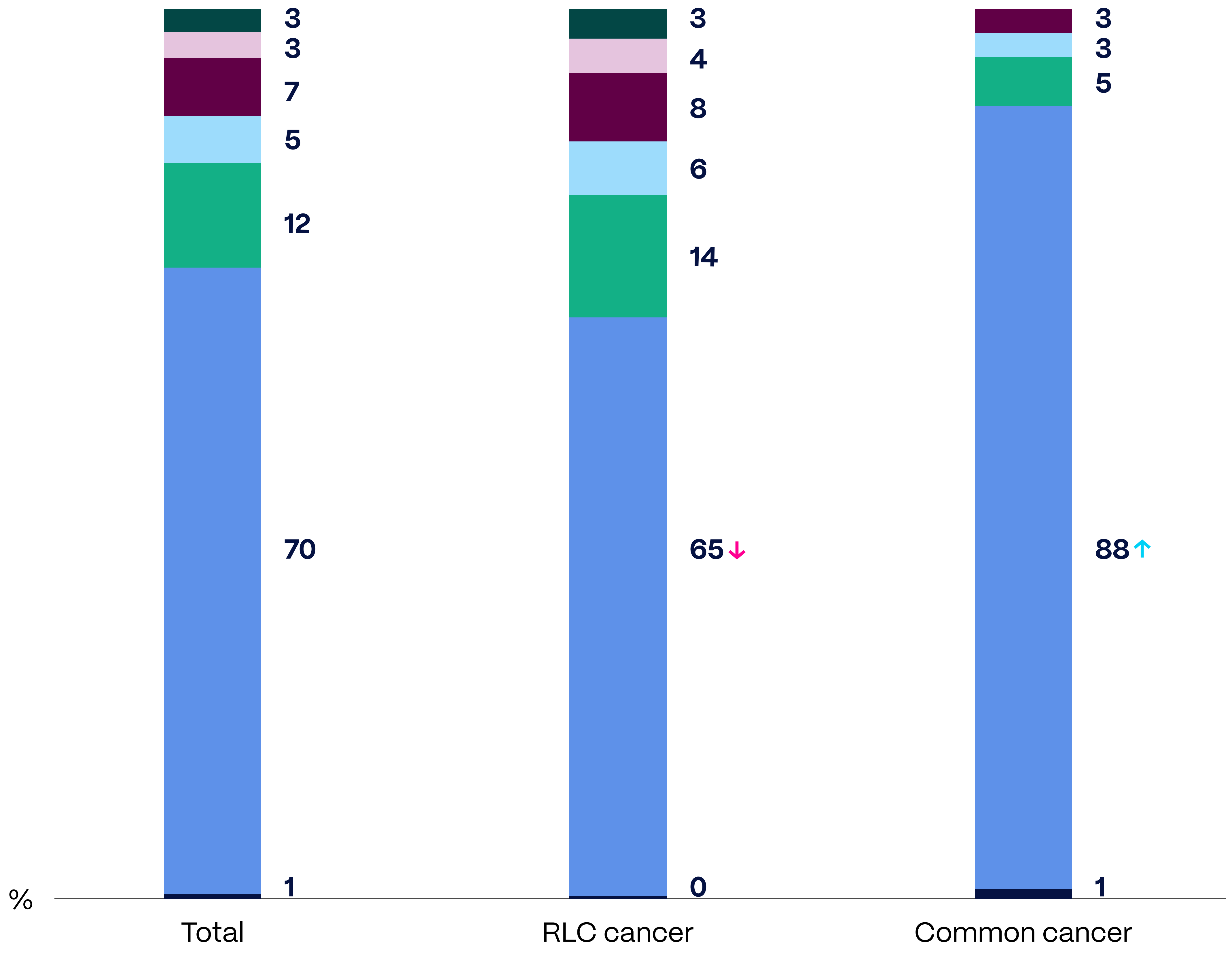
How did you first become aware of your cancer? **(1,547 responses)**



↑↓ Statistically significant difference

> Three doctors looked at my rash and dismissed my concerns – it was another six months before the cancer was diagnosed after the rash had spread significantly. I wish they had known how to identify my cancer type and acted sooner.

Time between first seeing a healthcare professional about symptoms and getting tested for cancer



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Responses to:

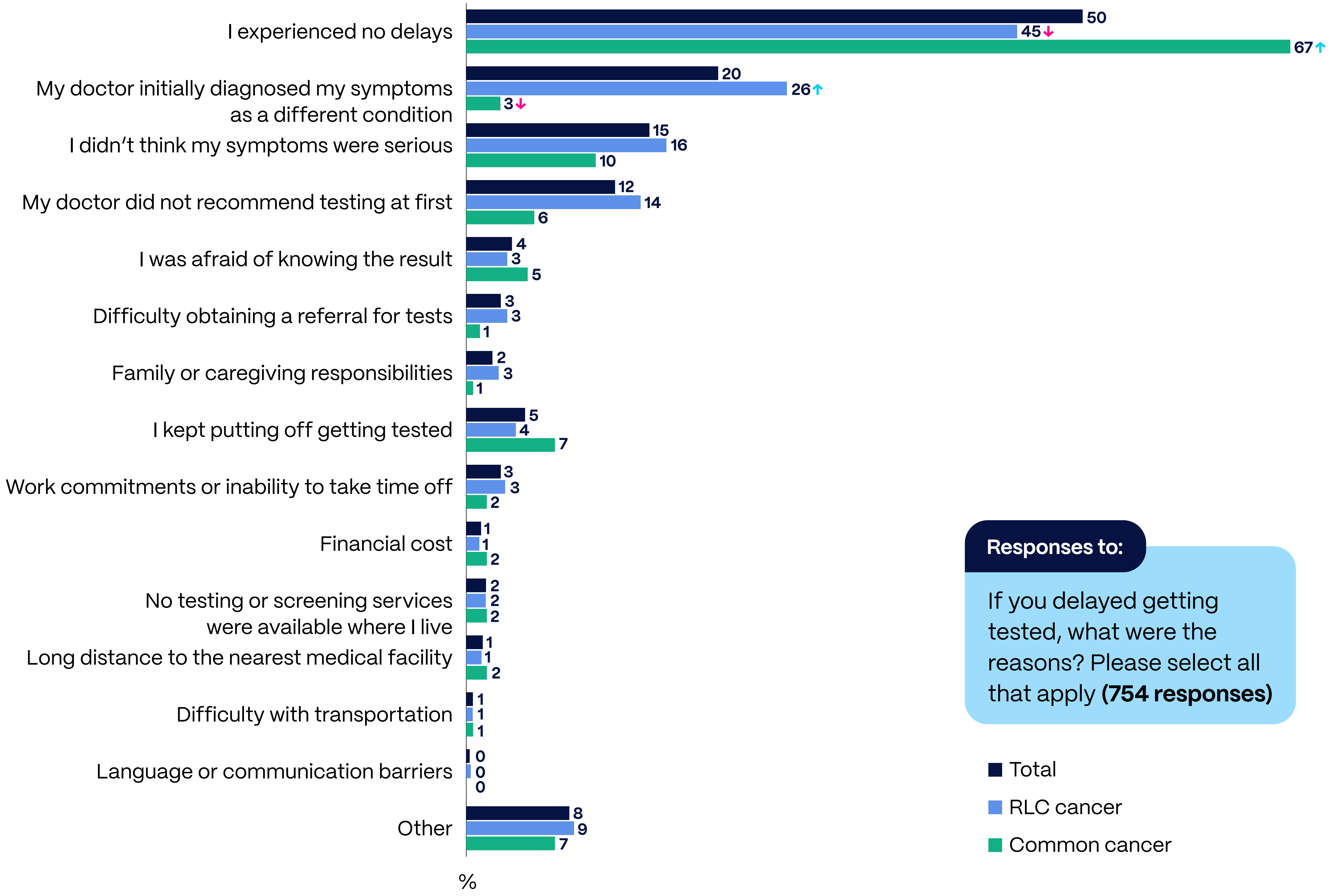
From first seeing a healthcare professional about your symptoms to getting tested for cancer, how long did it take? **(781 responses)**

- ■ More than 5 years
- ■ 3–5 years
- ■ 1–2 years
- ■ 7–11 months
- ■ 4–6 months
- ■ Less than 3 months
- ■ Don't know / can't remember

> Once I was able to get into a GP I was quickly referred for testing and able to get this done the following day.

> I was dismissed for 8 years by my GP who thought my symptoms were because of stress and menopause. She never put all the symptoms together to see the big picture nor did she refer me to a specialist physician to investigate further.

Reasons for delayed testing



Responses to:

If you delayed getting tested, what were the reasons? Please select all that apply **(754 responses)**

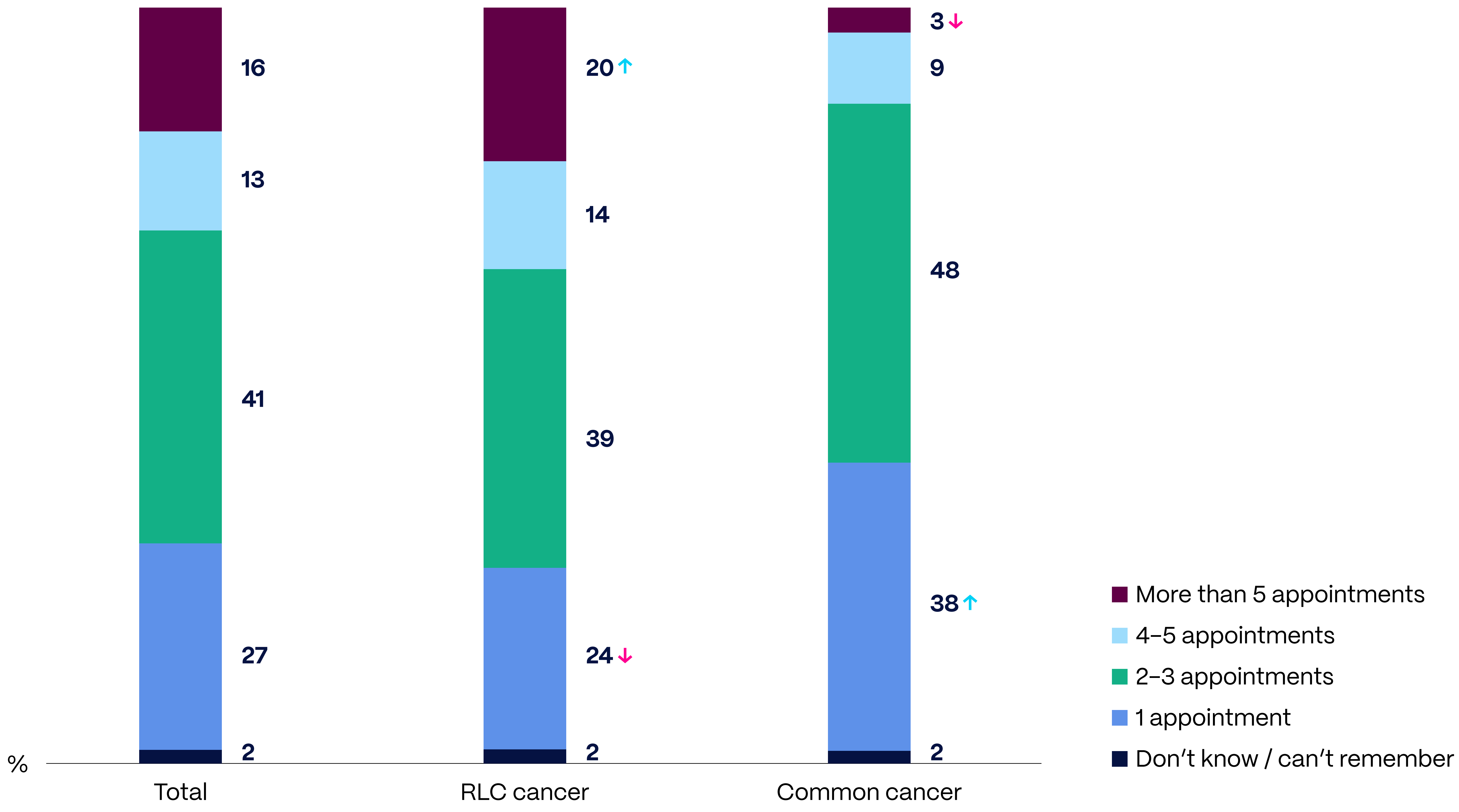
↑↓ Statistically significant difference

> My GP was excellent and continually followed up with further blood tests, but we found it difficult to access an ultrasound. It was also not considered during testing that the cause would be cancer, so this was a shock when I was finally able to get a CT scan privately.
>
> After an initial ED visit as an attempt to get an ultrasound (as my GP and rheumatologist knew something was up), the resultant appointment through the public system for an ultrasound would've been 5 months later. It was only because I had the ability to pay for private CT scans that I was diagnosed so quickly.

Number of appointments to discuss symptoms

Responses to:

Before receiving your cancer diagnosis, how many medical appointments did you attend to discuss your symptoms? **(776 responses)**



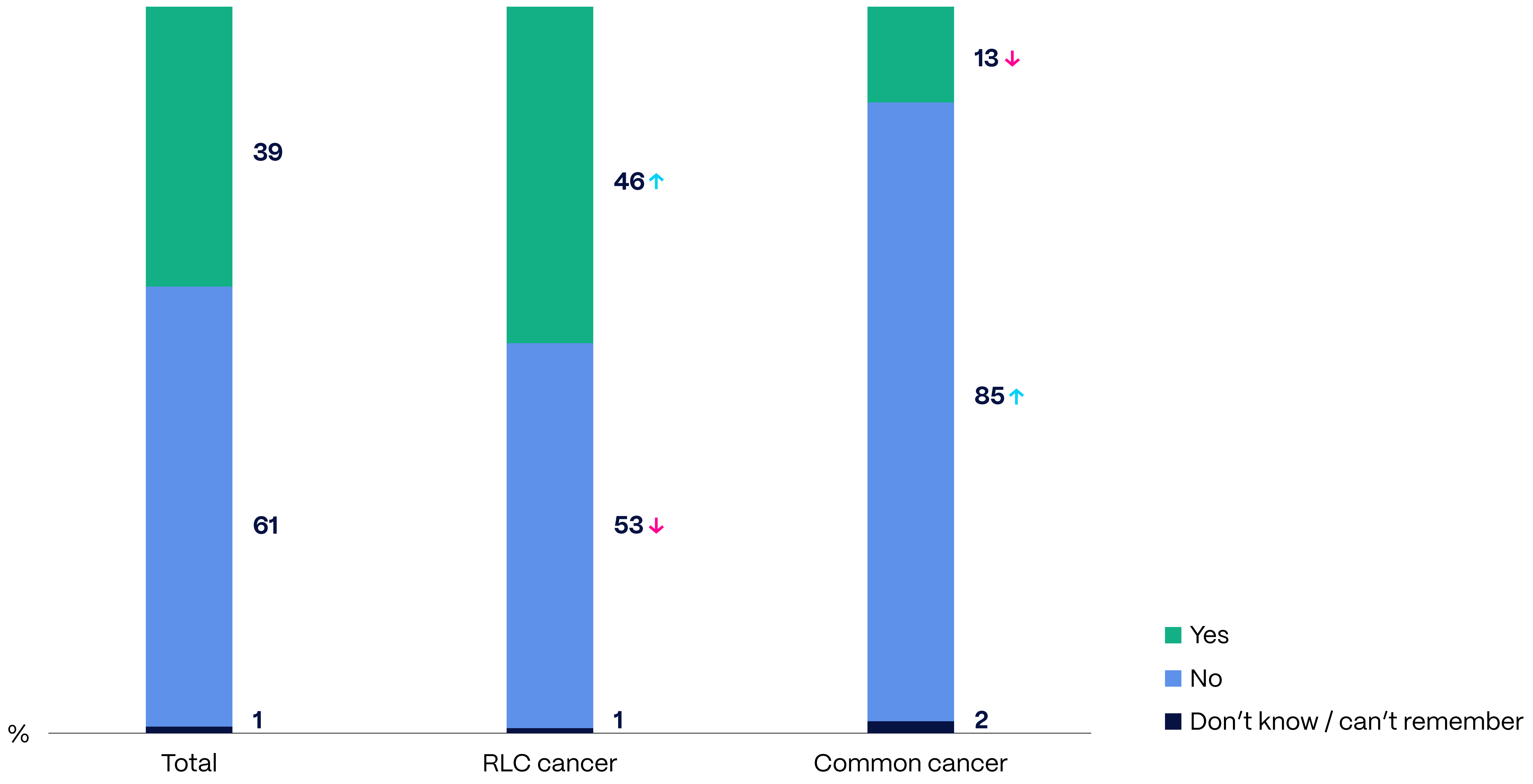
↑↓ Statistically significant difference

> Went to GP numerous times, sent to three specialists that had long waiting periods to get an appointment before I was actually diagnosed. Kept getting told I was "presenting as a healthy person" but knew that something wasn't right so persisted.

Perceptions of symptoms overlooked or misattributed

Responses to:

Did you feel your symptoms were overlooked or associated with another illness or condition? **(778 responses)**



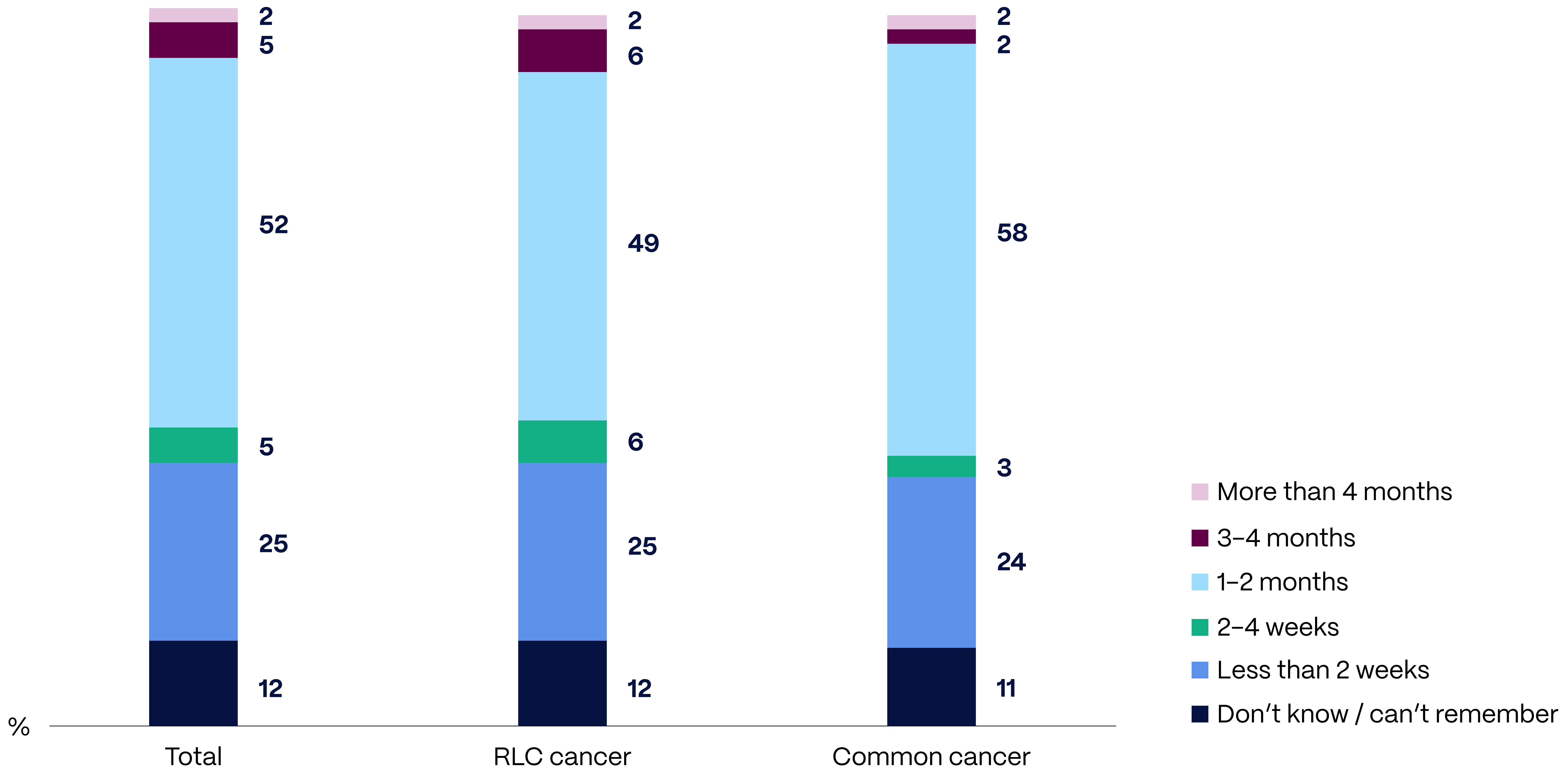
↑↓ Statistically significant difference

> I just wish someone had believed me that something was wrong in the first place. I wish it was detected earlier and not assumed it was something else.

Time between first tests for cancer and confirmed diagnosis

Responses to:

How long did it take from the first tests for cancer until you received your confirmed diagnosis (the specific type of your cancer)? **(1,544 responses)**



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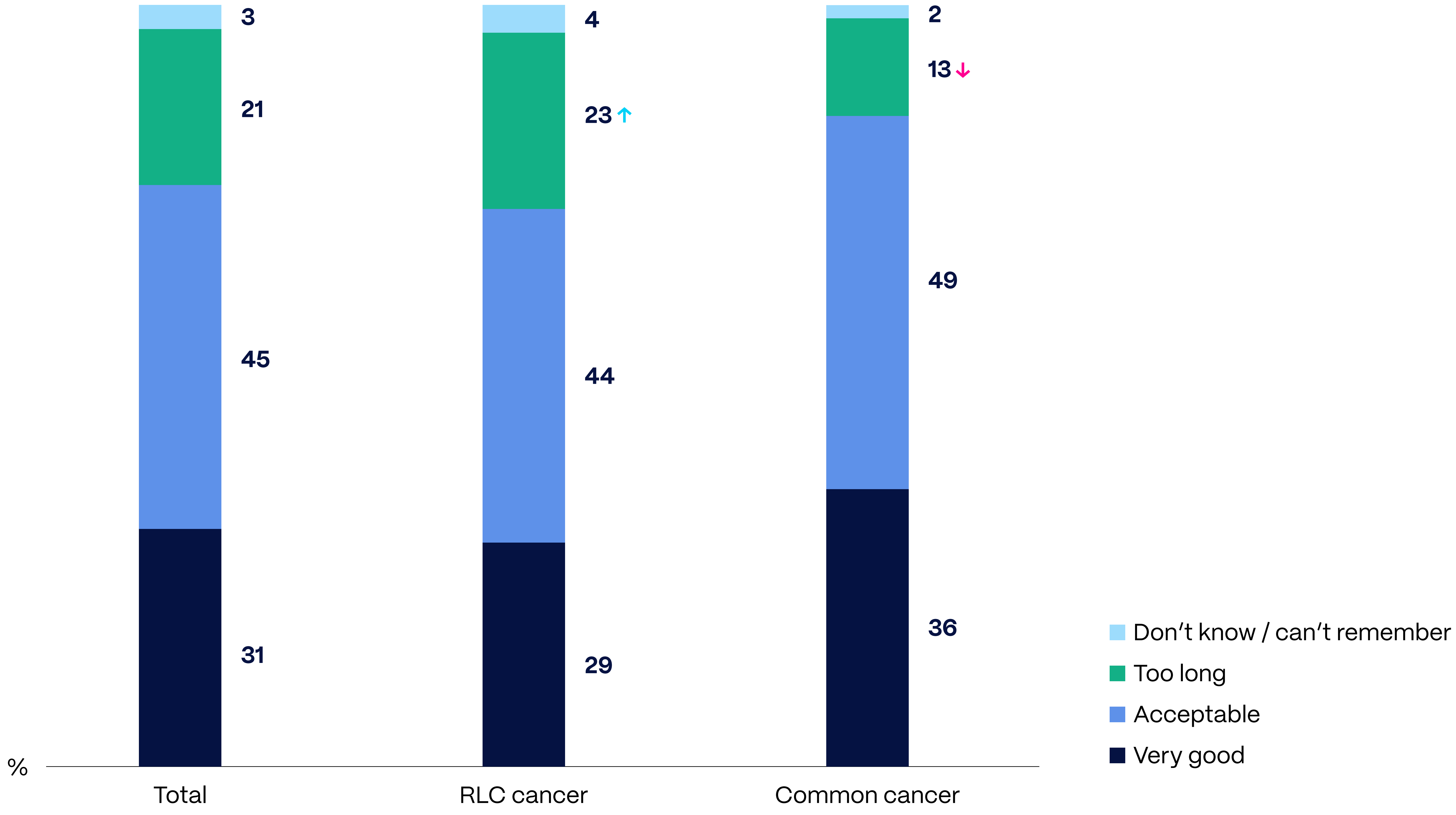
> Waiting for test results and not knowing is a very difficult period.

Waiting period for test results

Responses to:

How did you feel about the waiting period for your test results? **(1,551 responses)**



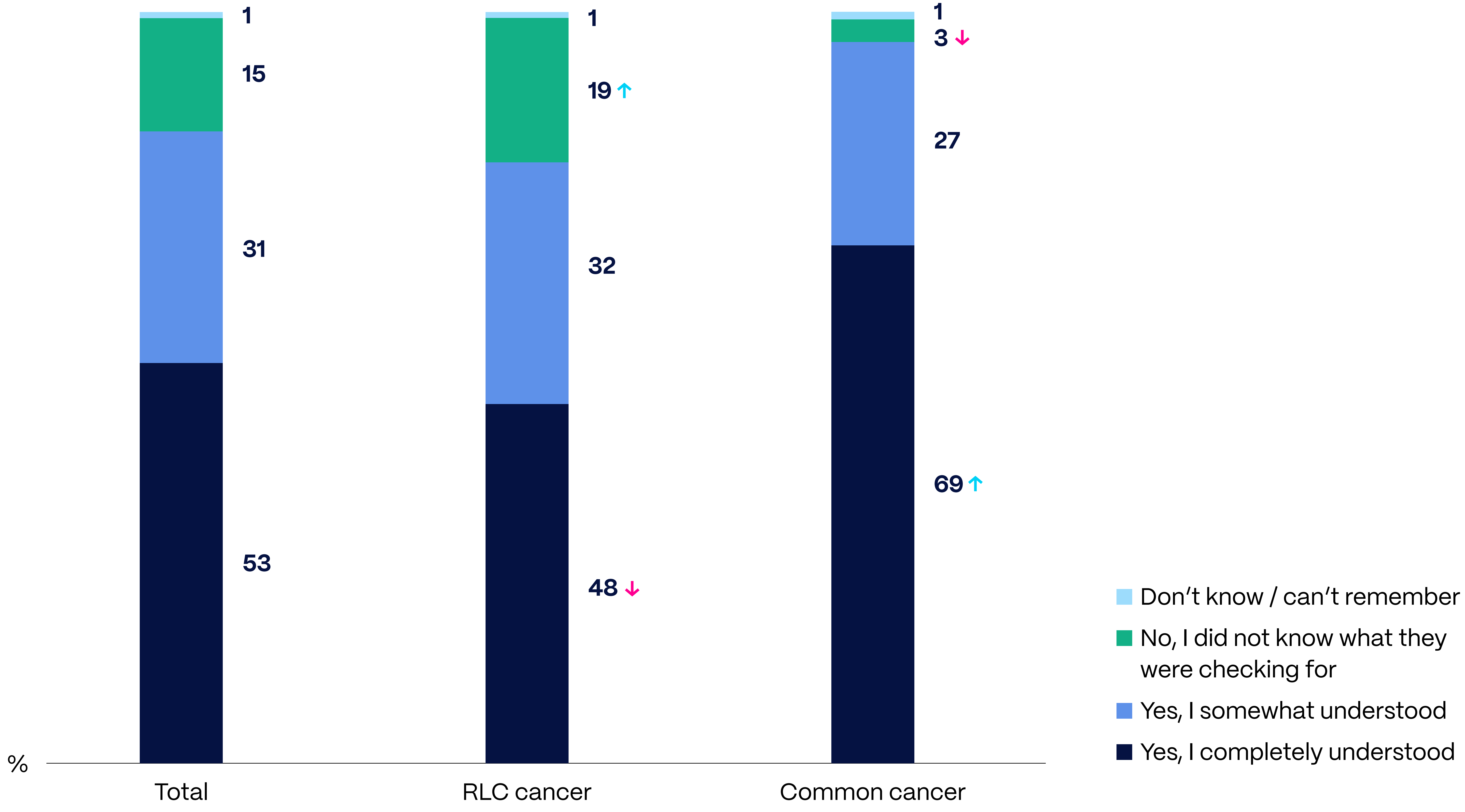
↑ ↓ Statistically significant difference

> There was no one to talk to as I did not understand what was going on. I was very confused and some doctors did not know anything about my cancer. I couldn’t believe it. It was very frustrating for a very long time.

Understanding of tests and outcomes

Responses to:

When you were tested for cancer, did you understand which tests you were having and what they would tell you? **(1,547 responses)**



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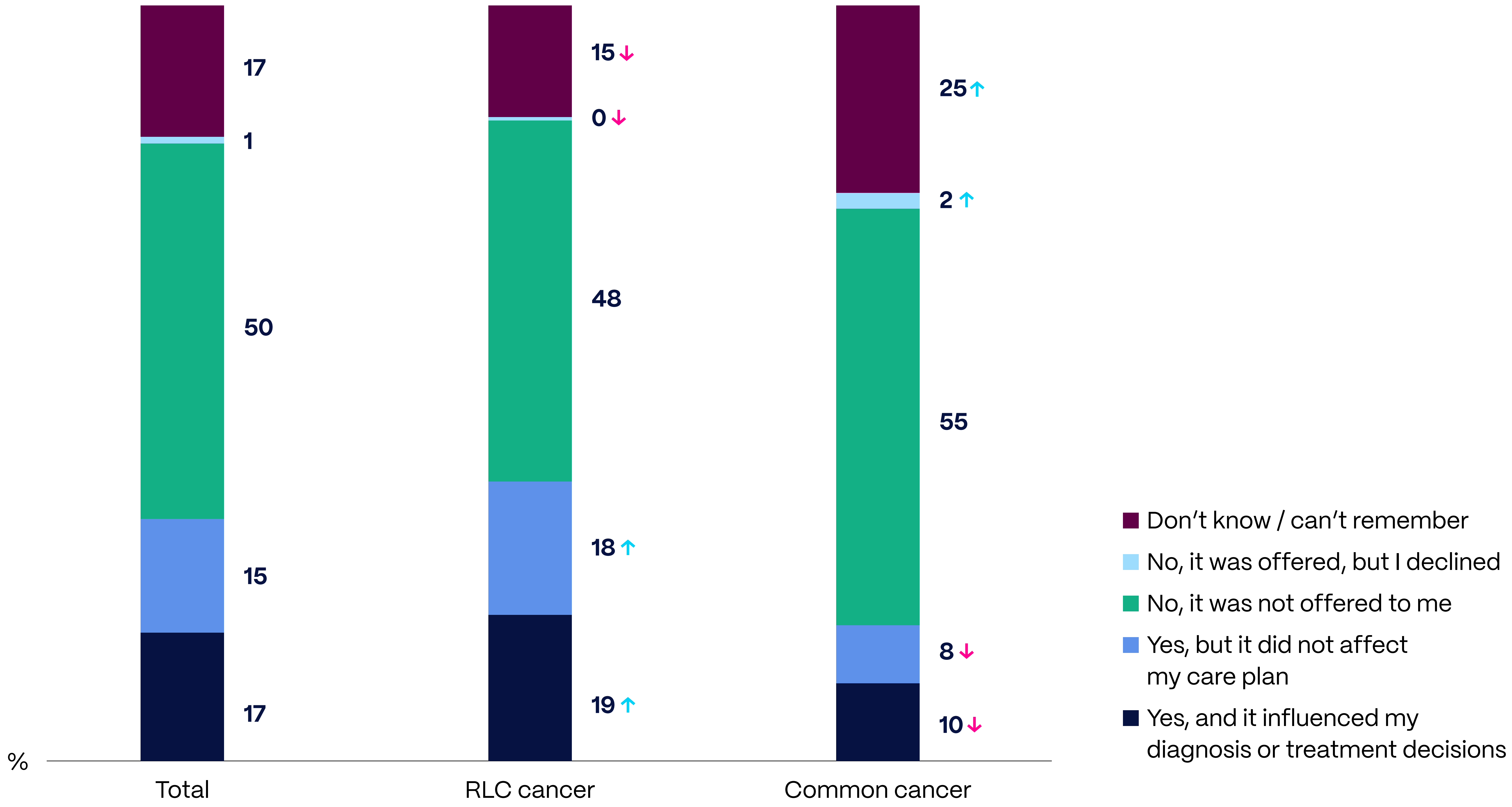
> At no time was I made aware that the GP was looking as to whether I had cancer, although I was guessing this was so. Nothing was said after the first test of the ultrasound which showed a lump in my neck, nor the CT scan and not before the biopsy. My GP did not lead me to believe that we were looking at something so serious.

Genomic testing as part of the diagnosis

Responses to:

Did you undergo genomic testing as part of your diagnosis? **(1,455 responses)**



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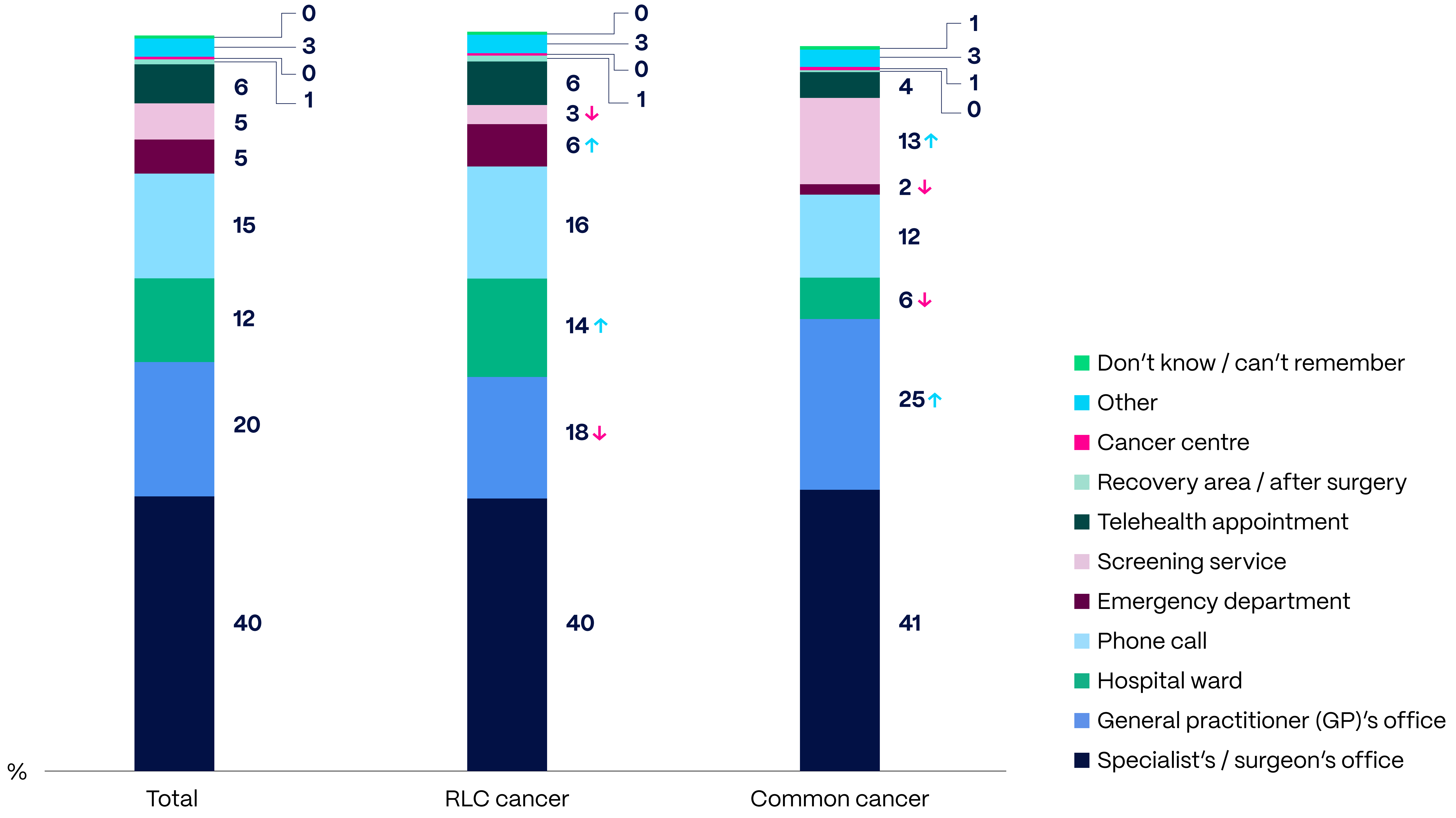
> Genomic testing was only performed much later after metastatic changes.

> The key thing for me was the genomic testing, the results of which only became available well into the treatment process […] so my treatment was able to move from a general treatment to a specific treatment.

Where cancer diagnosis was confirmed

Responses to:

Where were you when your cancer diagnosis was confirmed? **(1,542 responses)**



↑ ↓ Statistically significant difference

> My first awareness of my cancer diagnosis was after logging on to see my ultrasound/ mammogram and core biopsy results via an imaging service. I read the report which mentioned cancer. In retrospect, it would have been better to find out from a GP or specialist.

How cancer diagnosis was communicated

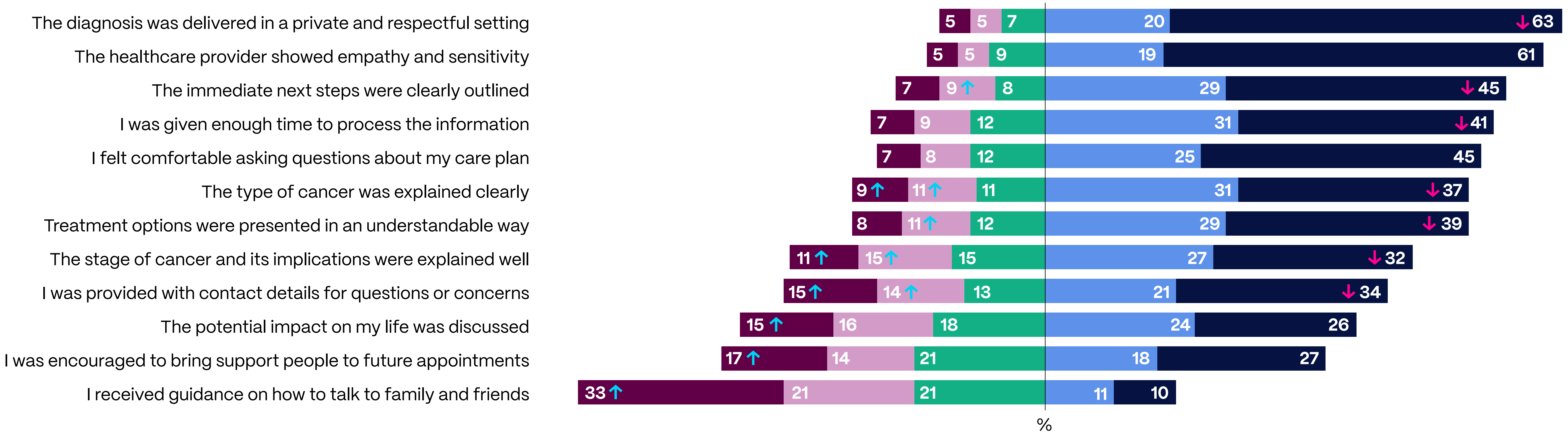
Responses to:

When you were informed of your cancer diagnosis, to what extent do you agree with the following statements? Please answer to the best of your recollection.

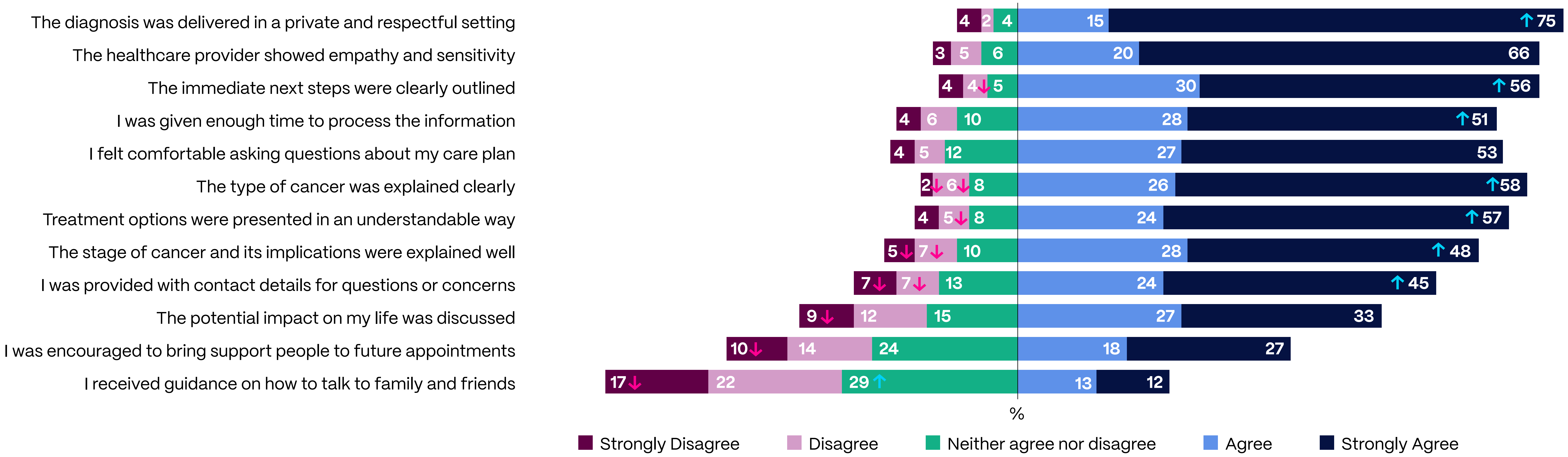
RLC cancer:
1,138 – 1,157 responses

Common cancer:
394 – 399 responses

RLC cancer responses



Common cancer responses



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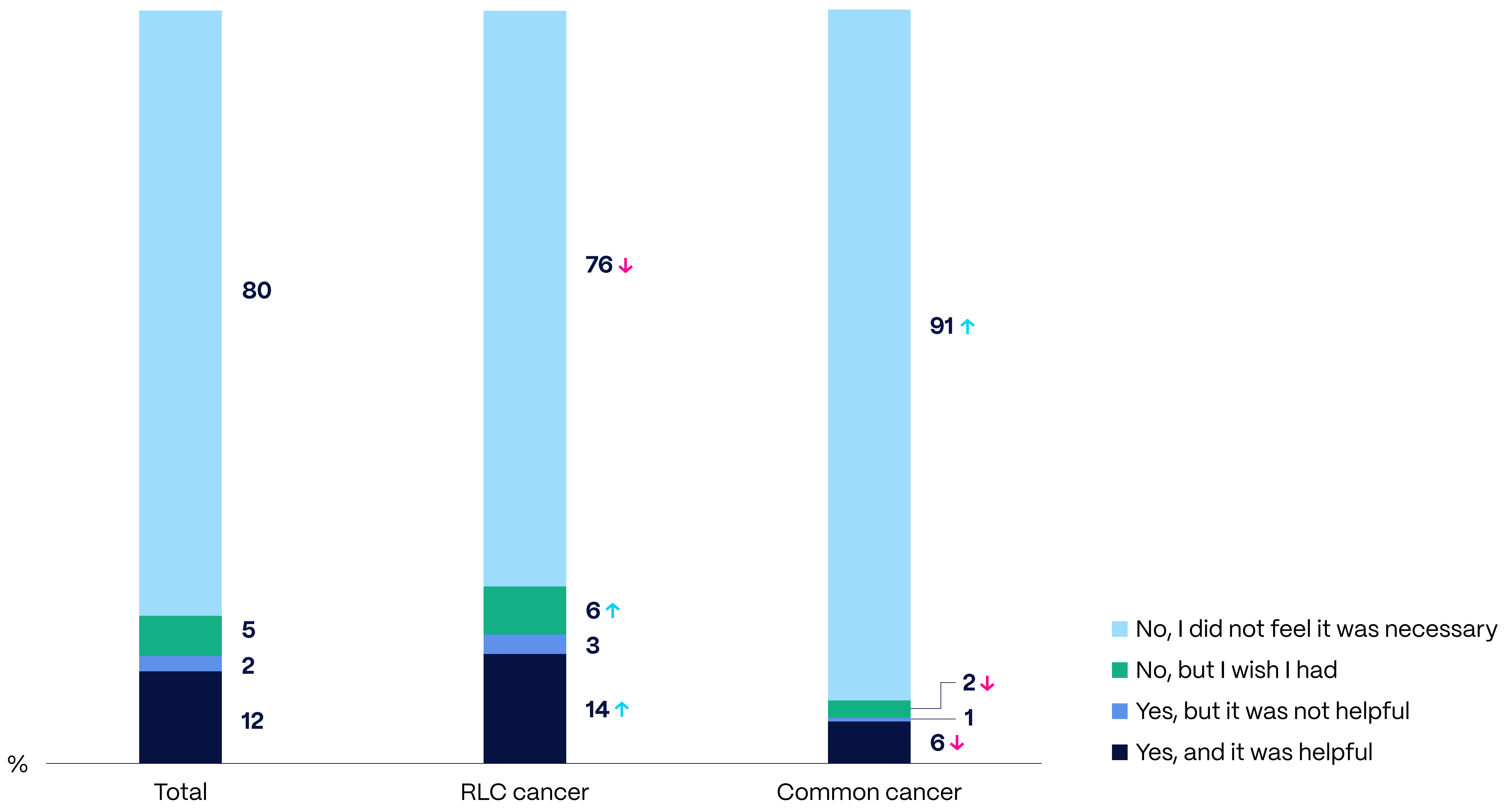
Seeking a second opinion about the diagnosis

Responses to:

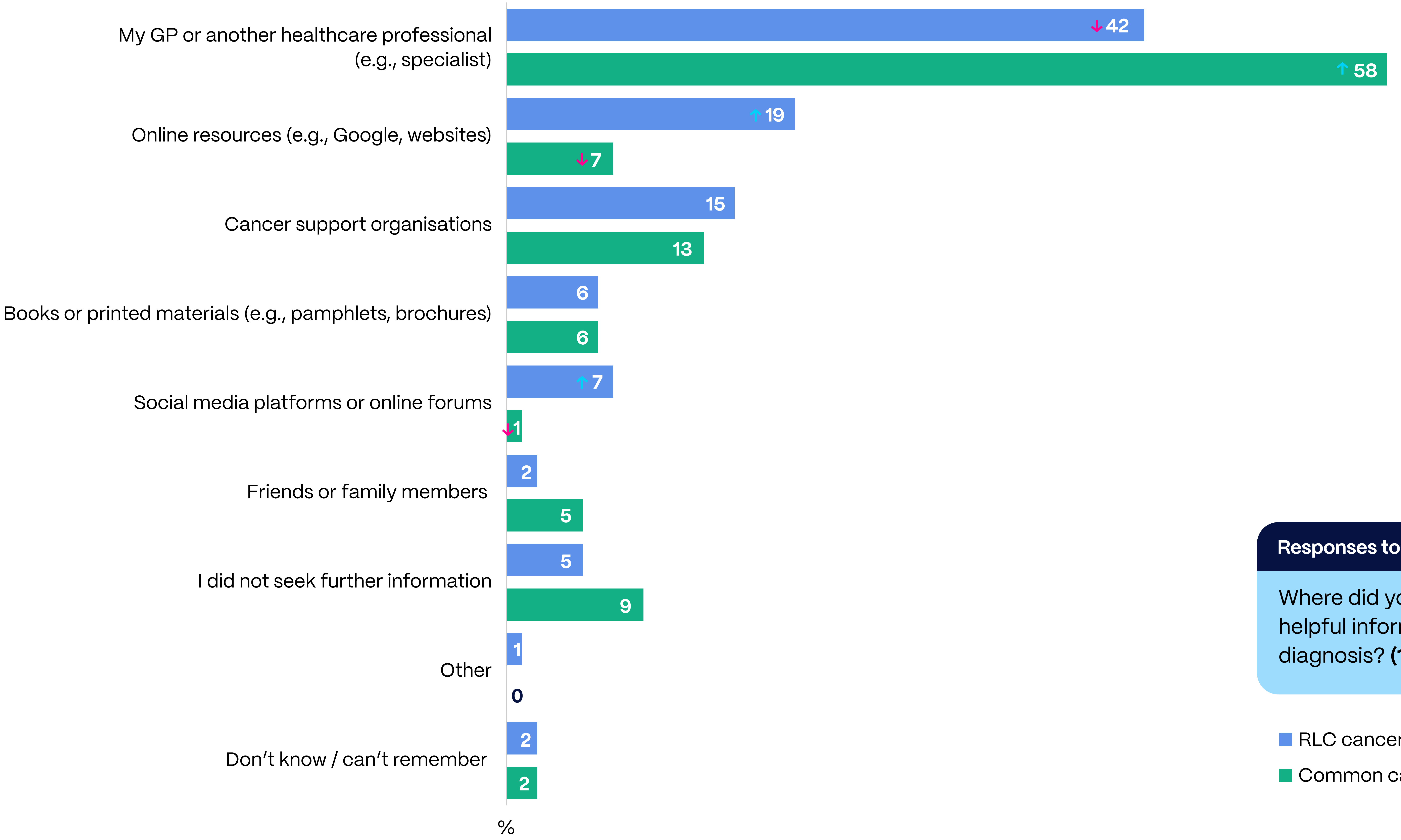
Did you seek a second opinion about your diagnosis? **(1,542 responses)**



↑ ↓ Statistically significant difference

> General advice is often to get a second opinion with a treatment plan. I found this to be awkward in reality, some doctors seem to be afraid of stepping on another doctor's toes by giving a second opinion.

Helpful sources of information after diagnosis



Responses to:

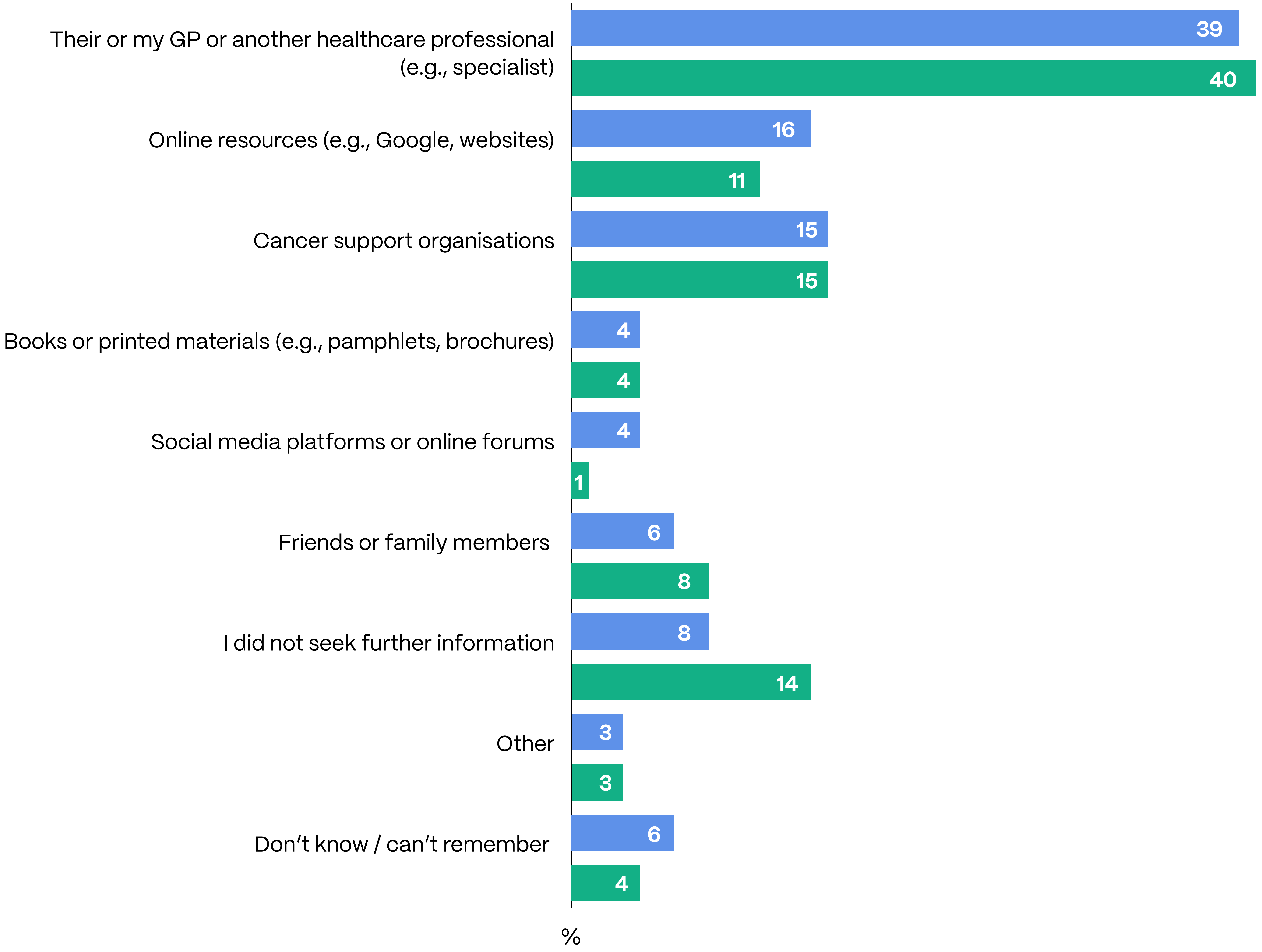
Where did you find the most helpful information after your diagnosis? **(1,456 responses)**

🟦 RLC cancer

🟩 Common cancer

↑↓ Statistically significant difference

Helpful sources of information after diagnosis



Responses to:

As a carer, where did you find the most helpful information after your diagnosis? **(878 responses)**

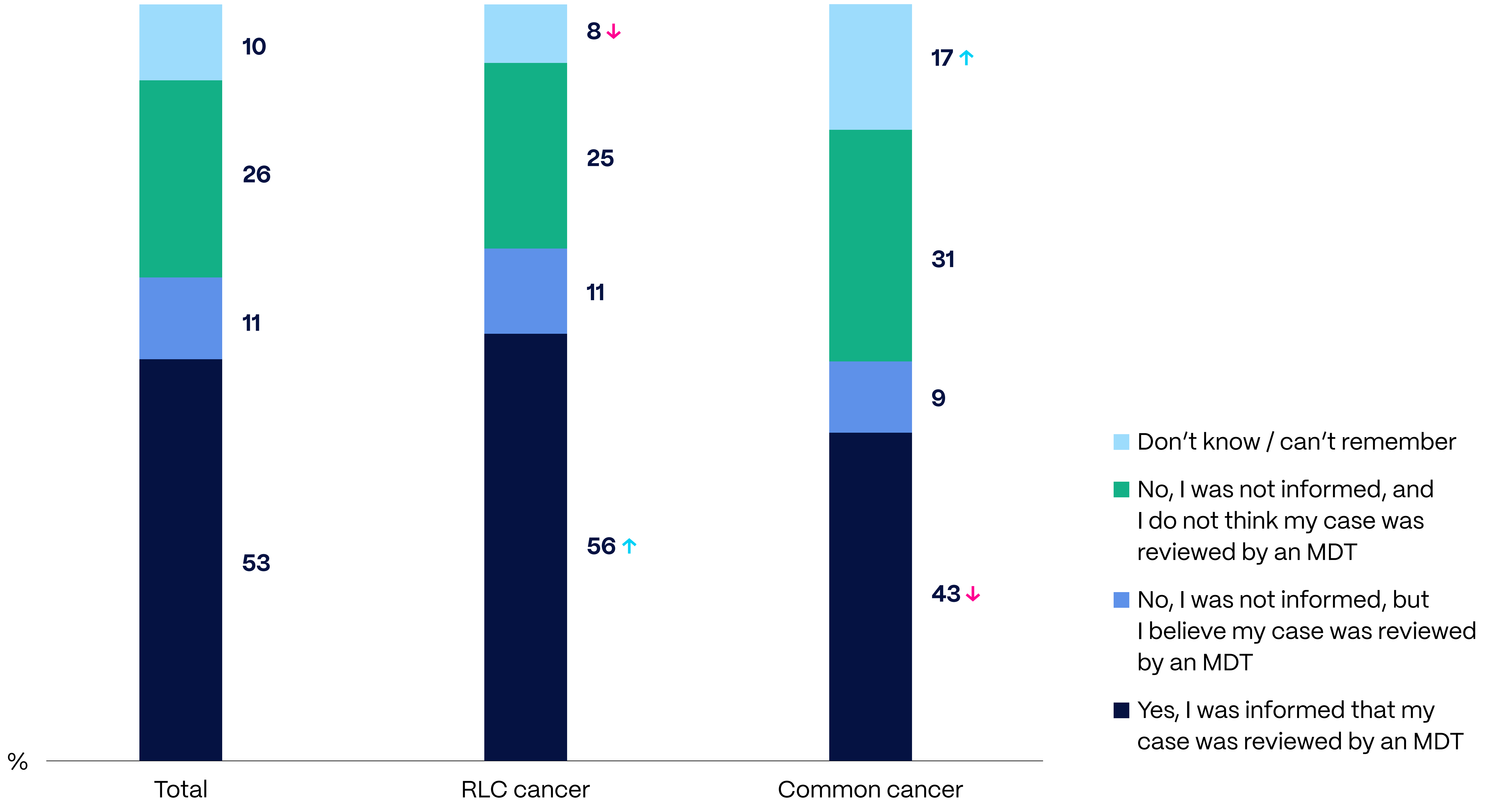
🟦 Carer – RLC cancer

🟩 Carer – Common cancer

Multidisciplinary team review

Responses to:

Were you informed about whether your case was reviewed by a multidisciplinary team (MDT)? **(1,526 responses)**



↑↓ Statistically significant difference

> We were lucky that we had an excellent doctor (surgeon) who was the one finding the cancer as part of another procedure. He practices at an excellent hospital and took all the time we needed to tell us everything we wanted to know. He also involved us very much in the decision on the best treatment approach and what the MDT recommended.

4

Treatment

Key findings – Treatment

Survival and maintaining quality of life were the most important treatment priorities for people with cancer, regardless of whether their cancer was rare, less common or common. **Nearly half (44%)** of respondents with a rare or less common cancer (**46%** of respondents with a common cancer) said achieving survival or cure was most important to them during their initial cancer treatment. Maintaining quality of life, including managing side effects, pain and physical changes, was most important for a further **one in four (24%)** respondents with a rare or less common cancer (**22%** of respondents with a common cancer).

One in ten (11%) respondents chose not to proceed with a recommended treatment, with no statistically significant difference between the responses of people with rare and less common cancers and those with common cancers. The most common reasons were:

- concerns about side effects, impact on quality of life, or physical changes **(56%)**
- treatment not being curative or improving survival **(33%)**
- cost of treatment **(7%)**
- limited ability to spend time with family and friends **(4%)**

Respondents with a rare or less common cancer were more likely to have had chemotherapy **(52%)**, immunotherapy including CAR T-cell therapy **(16%)**, a targeted therapy **(18%)** and/or a stem cell or bone marrow transplant **(5%)** compared with respondents with a common cancer.

Respondents with a common cancer were more likely to have had surgery **(78%)**, radiation therapy **(51%)**, and hormone therapy **(28%)**.

Key findings – Treatment

One in two (56%) respondents diagnosed with a rare or less common cancer were informed that their case had been reviewed by a multi-disciplinary team, compared with **42%** of respondents with a common cancer.

Respondents diagnosed with a rare or less common cancer were more likely to be told about clinical trials as a treatment option **(36%)** and to take part in one or more trials **(15%)**, than those with a common cancer (**23%** were told about trials and **11%** took part in one or more).

Respondents diagnosed with a rare or less common cancer were **three times more likely** to report that they experienced **discrimination**, **bias**, or **differential treatment** based on their age **(9%)** or where they live **(8%)** compared with respondents diagnosed with common cancers.

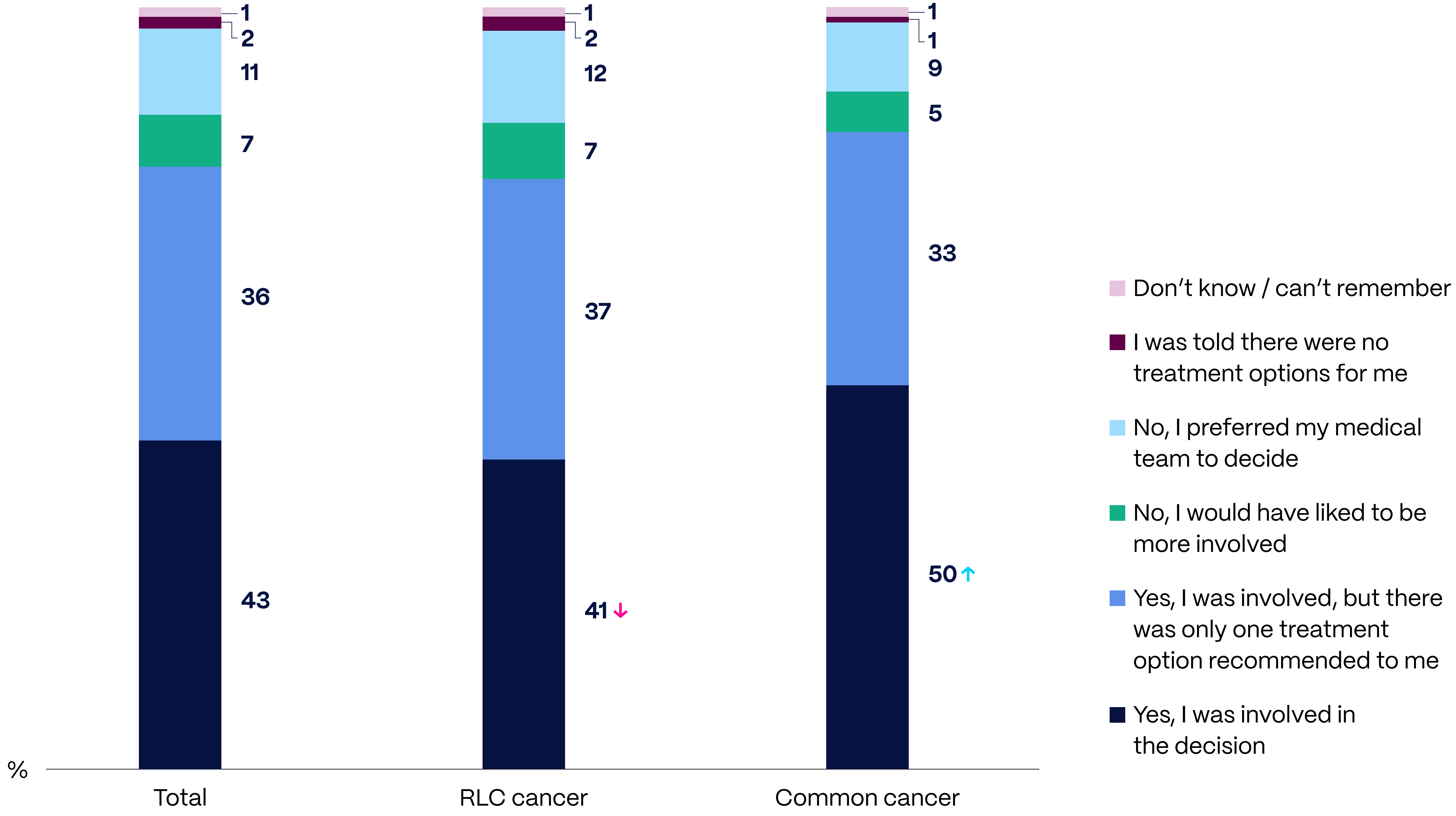
More than one in four carers (28%) said the person they cared for did not have access to end-of-life care that met their needs, with no statistically significant difference between the responses of carers for people with rare and less common cancers and those with common cancers.

Respondents diagnosed with rare or less common cancers were significantly less likely to feel that their care was well coordinated **(55%)** compared with those diagnosed with common cancers **(71%)**.

Patient involvement in treatment decisions

Responses to:

Did your treating team involve you in deciding which treatment options were best for you and when to start treatment? **(1,532 responses)**



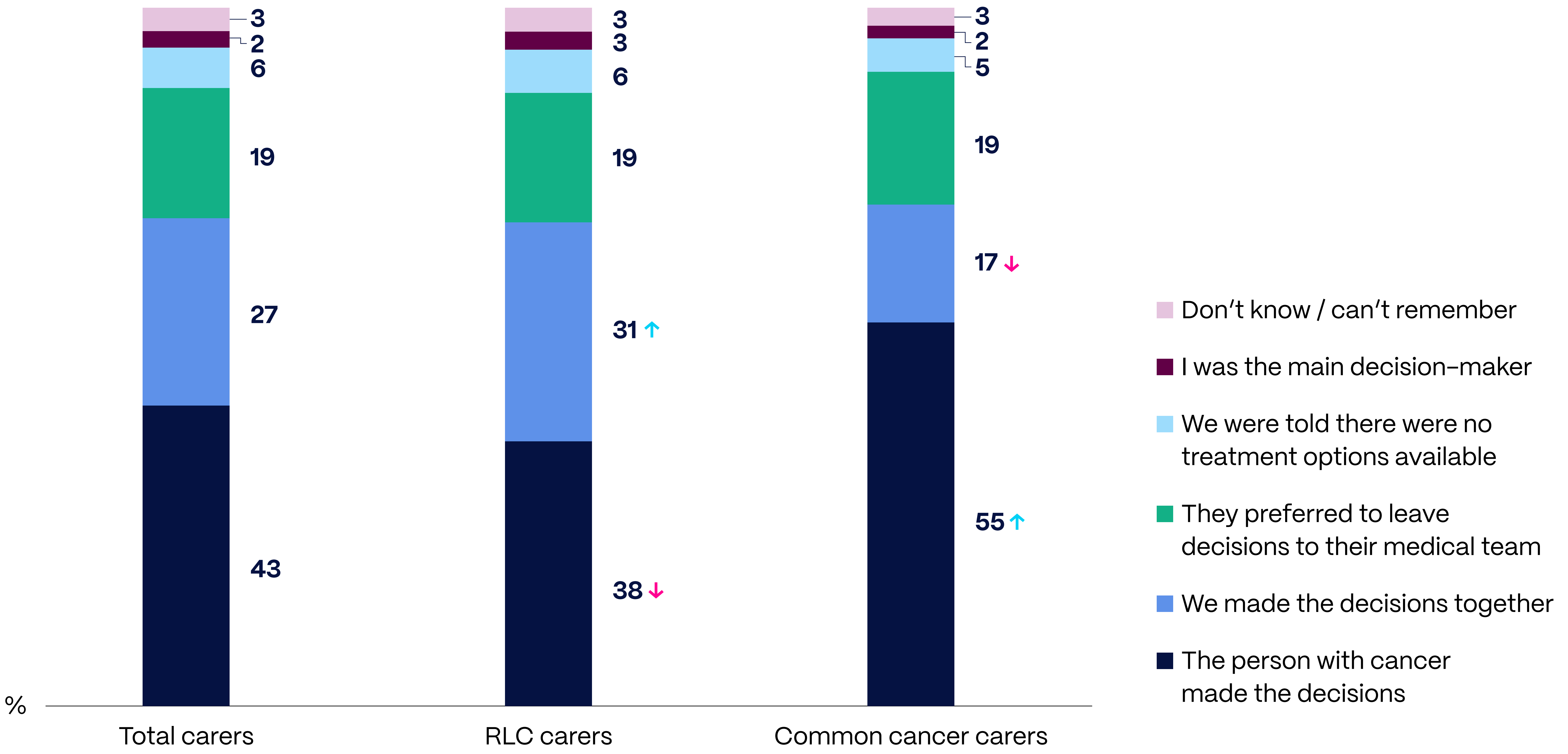
↑ ↓ Statistically significant difference

> I was treated with respect & kindness always. Trips back and forth were 2 hours each way so it was good to feel welcomed and part of "my team".

Carer involvement in treatment decisions

Responses to:

As a carer, how involved were you in decisions about which treatment options were best and when to start treatment? **(895 responses)**



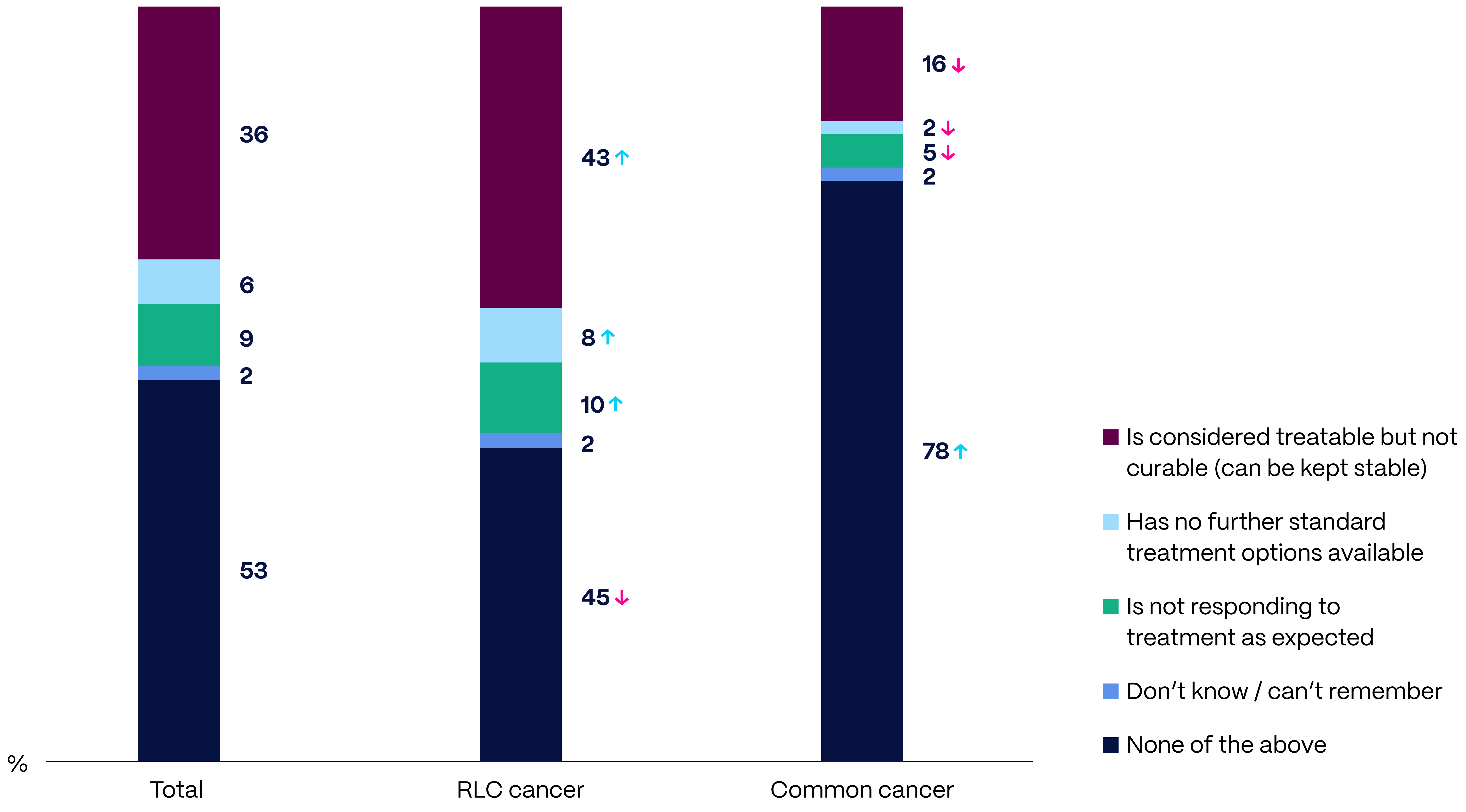
↑ ↓ Statistically significant difference

> I was there for support and when they were tossing up between chemo and radiation.

Treatment response

Responses to:

Has a doctor ever told you that your cancer... Please select all that apply. **(1,558 responses)**



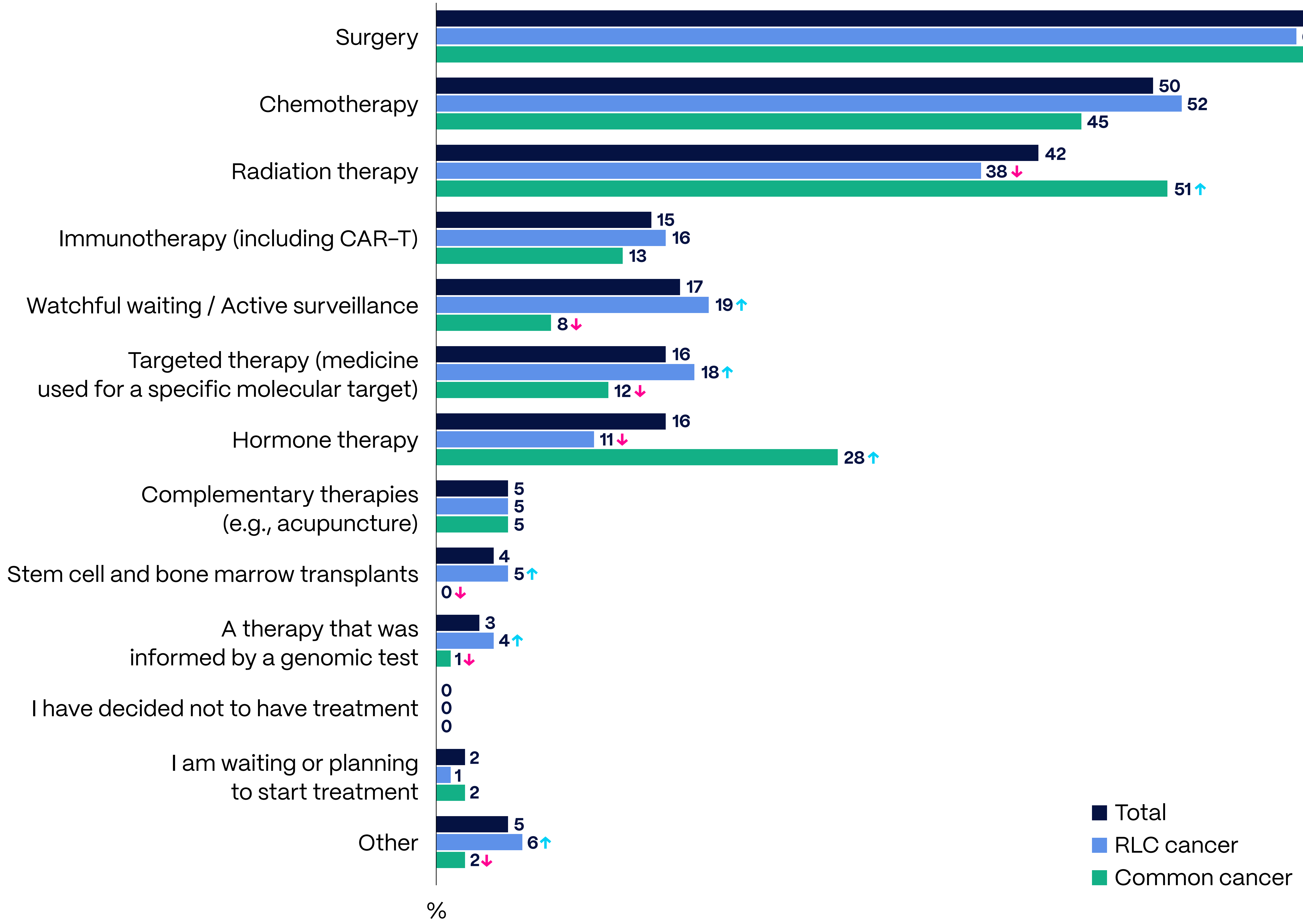
↑ ↓ Statistically significant difference

> I was very lucky it was found at an early stage.

> I have relapsed four times in five years, I have two young kids and was the primary financial provider. Now I am unable to work due to side effects from treatment and multiple surgeries and my wife is forced to work ungodly hours to keep a roof over our head.

Treatment modalities and number of treatments

Treatment modalities



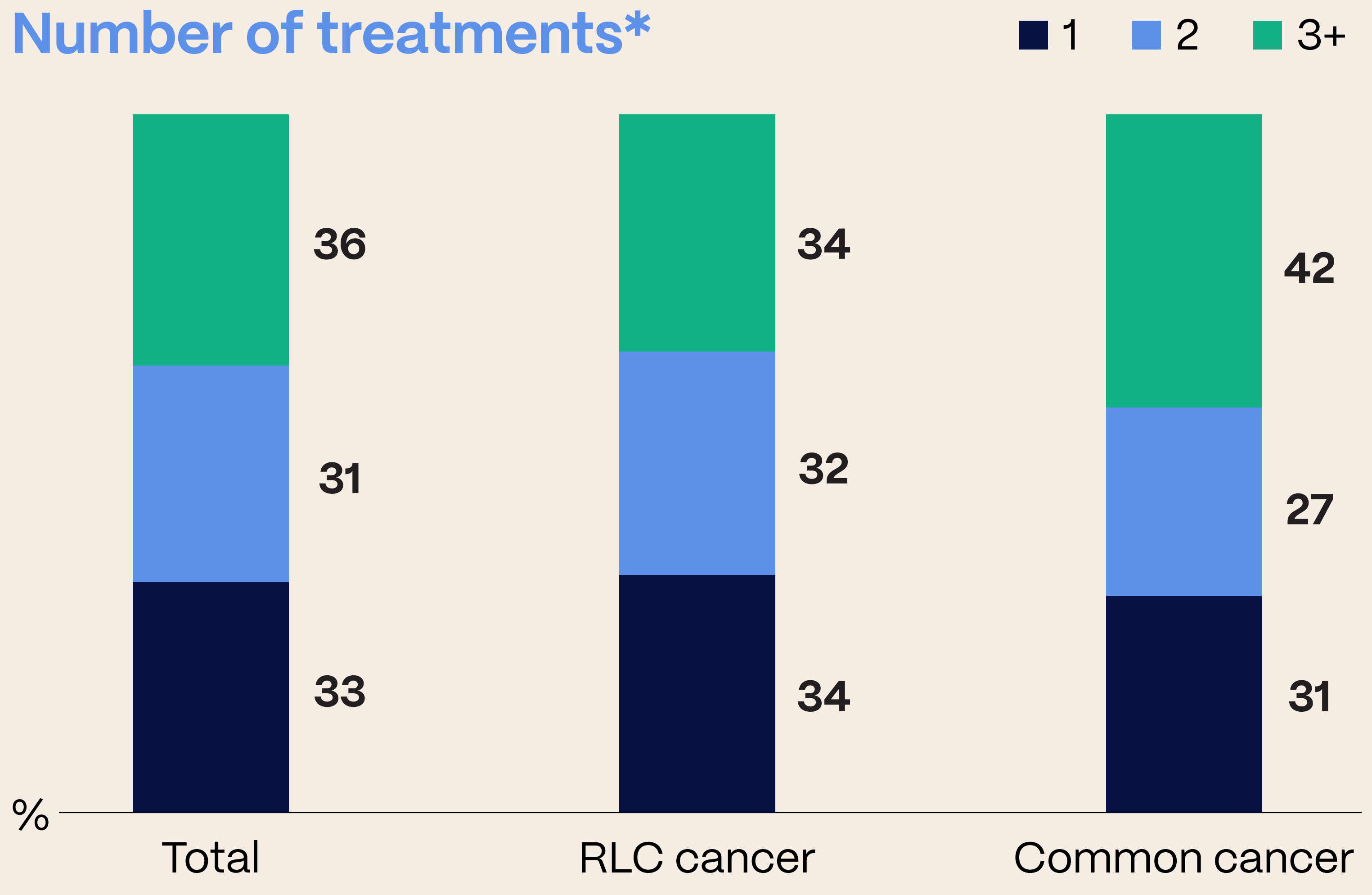
↑↓ Statistically significant difference

Responses to:

What types of treatment(s) did you receive for your cancer? Please select all that apply **(1,534 responses)**

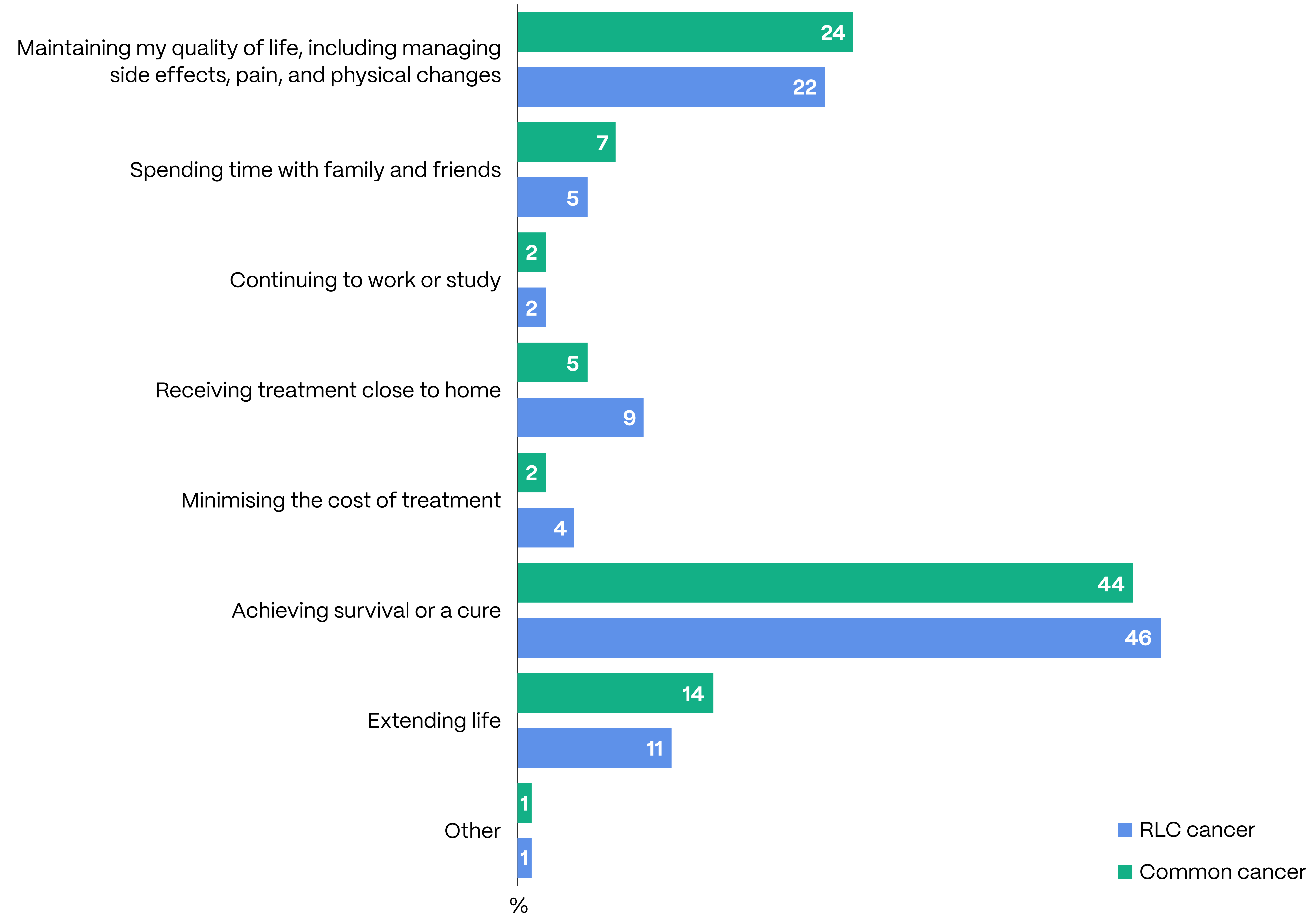
What types of treatment(s) did you receive for your cancer? More than 1 treatment* response chosen **(1,452 responses)**

Number of treatments*



* chemotherapy, surgery, radiation therapy, immunotherapy, targeted therapy, hormone therapy, stem cell and bone marrow transplants, therapy informed by genomic test

Priorities during initial cancer treatment



Responses to:

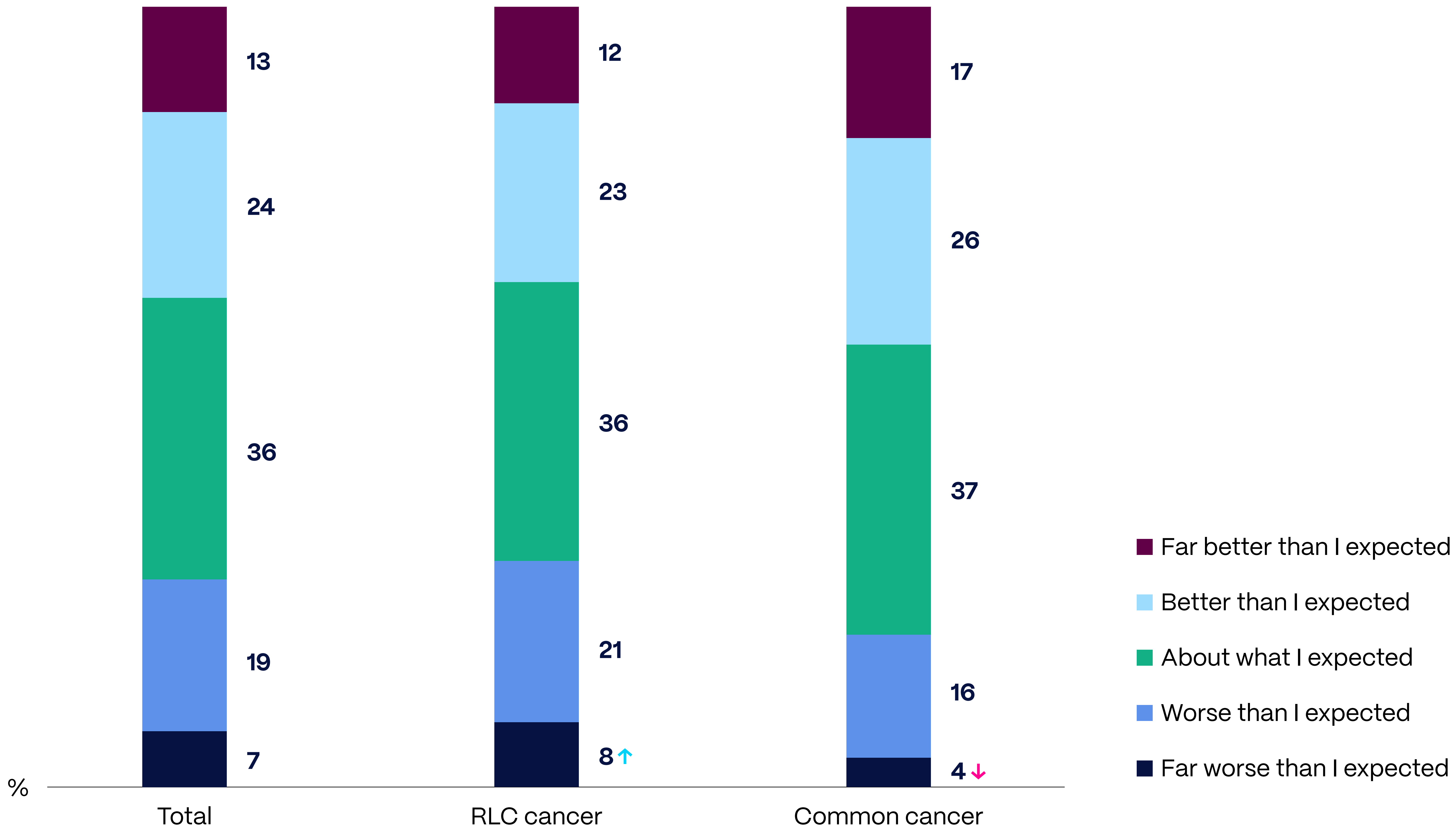
What was most important to you during your initial cancer treatment? **(1,438 responses)**

> The treatment decision was complex and took a few days. The Orthopaedic team and Radiation team worked together to decide a plan of action due to the instability of my [spine].

Treatment expectations

Responses to:

How well did your cancer treatment experience meet your expectations? **(1,482 responses)**



↑↓ Statistically significant difference

> I was very happy with my treatment experience. I honestly think my oncologist, with his expertise and experience, saved my life.

> Potential side effects were not discussed when I had radiation treatment.

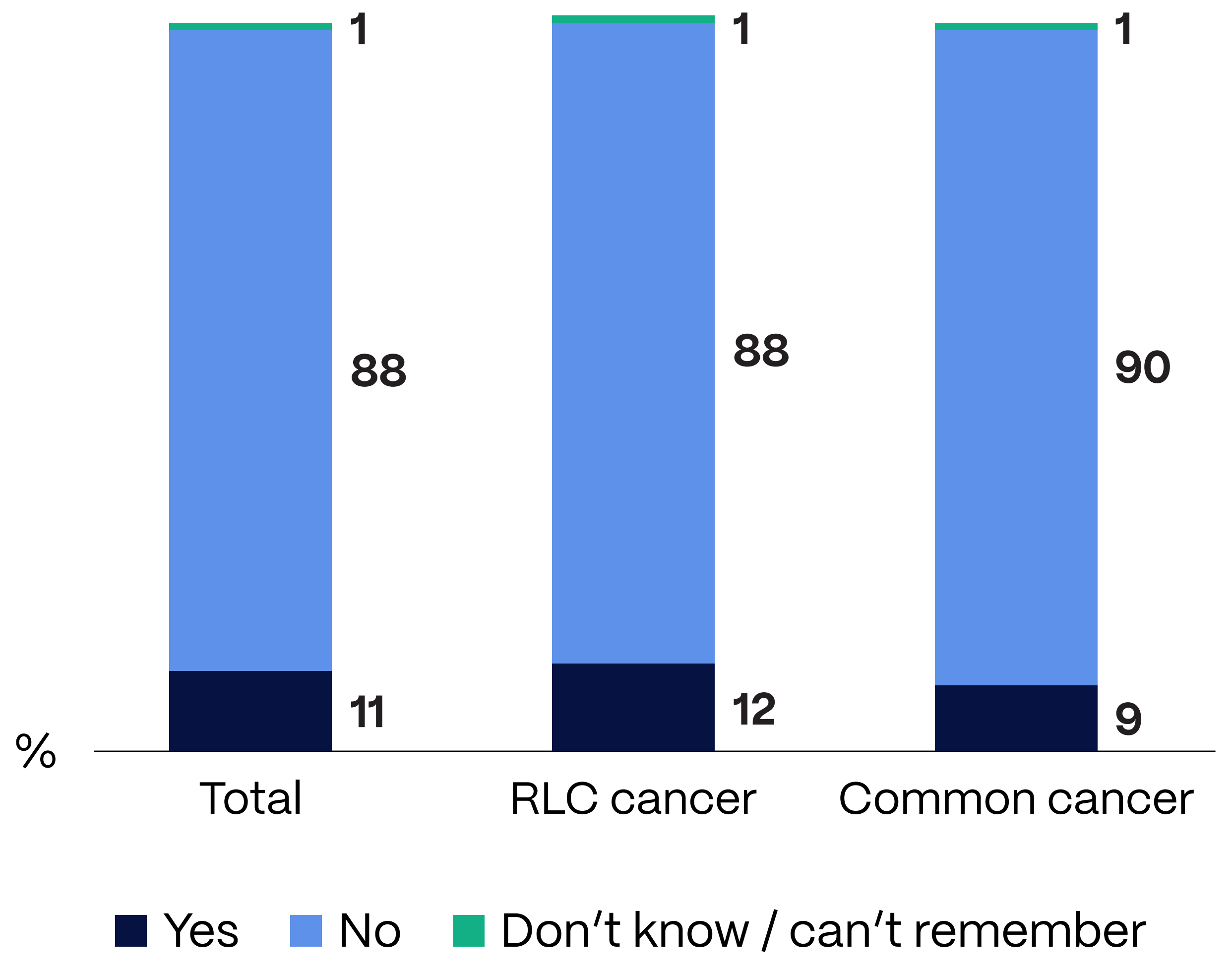
Barriers to treatment

Responses to:

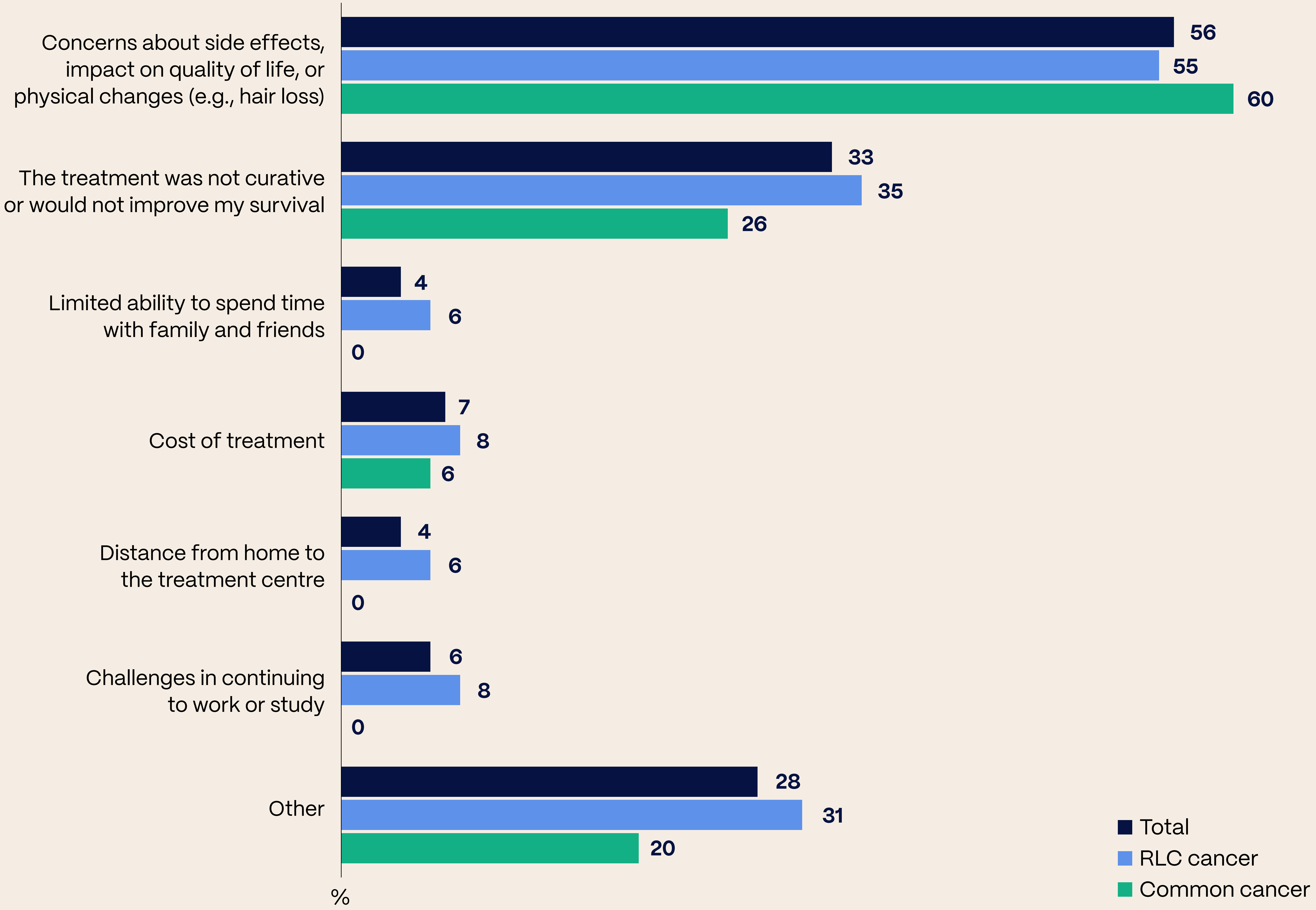
Have you ever chosen not to proceed with a cancer treatment that was recommended to you? **(1,543 responses)**

What were the reasons you chose not to proceed with the recommended treatment? Please select all that apply **(159 responses)**

Did you ever choose not to proceed with a recommended treatment?



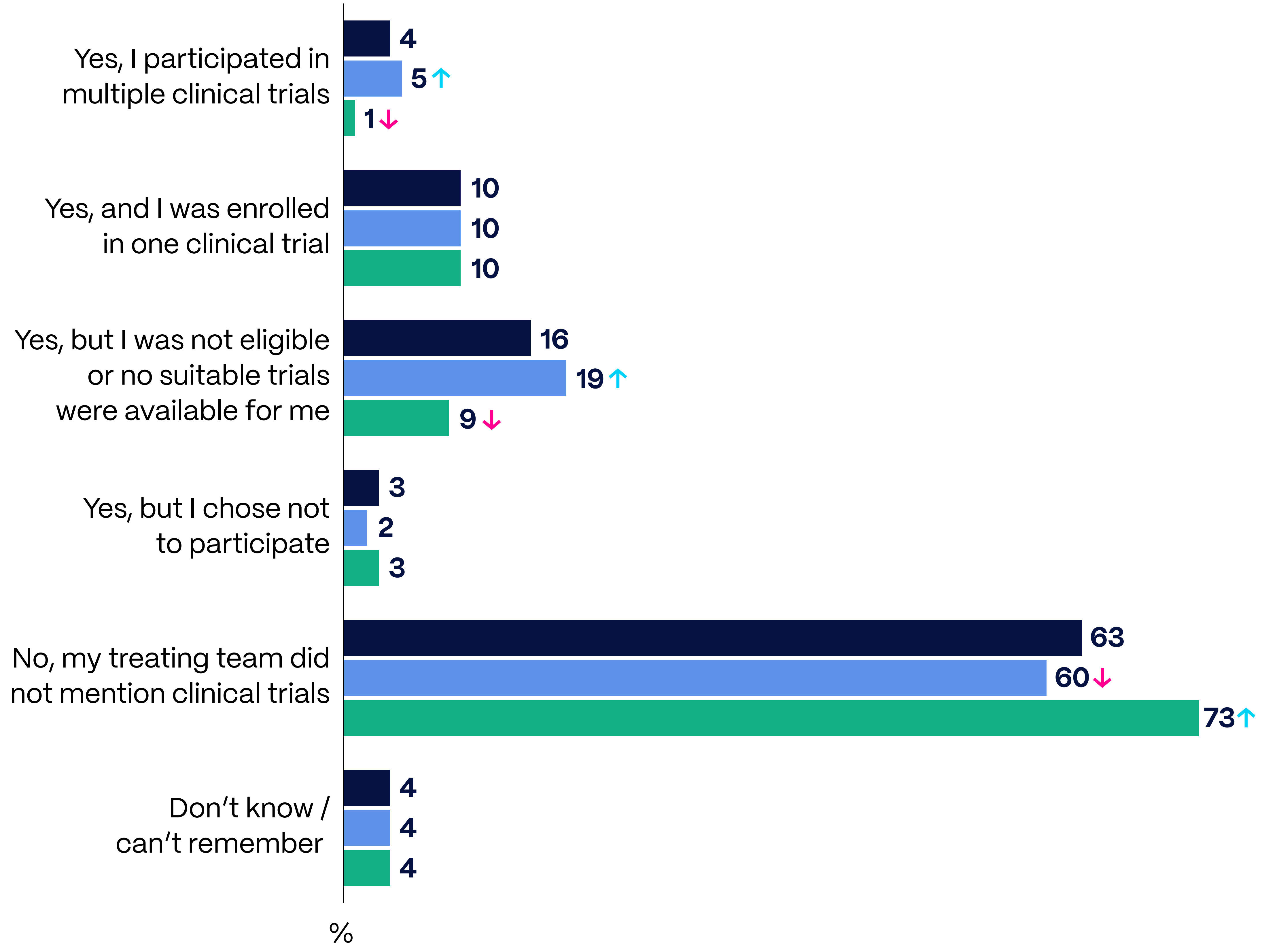
Why did you choose not to proceed with a recommended treatment?



Clinical trials as a treatment option

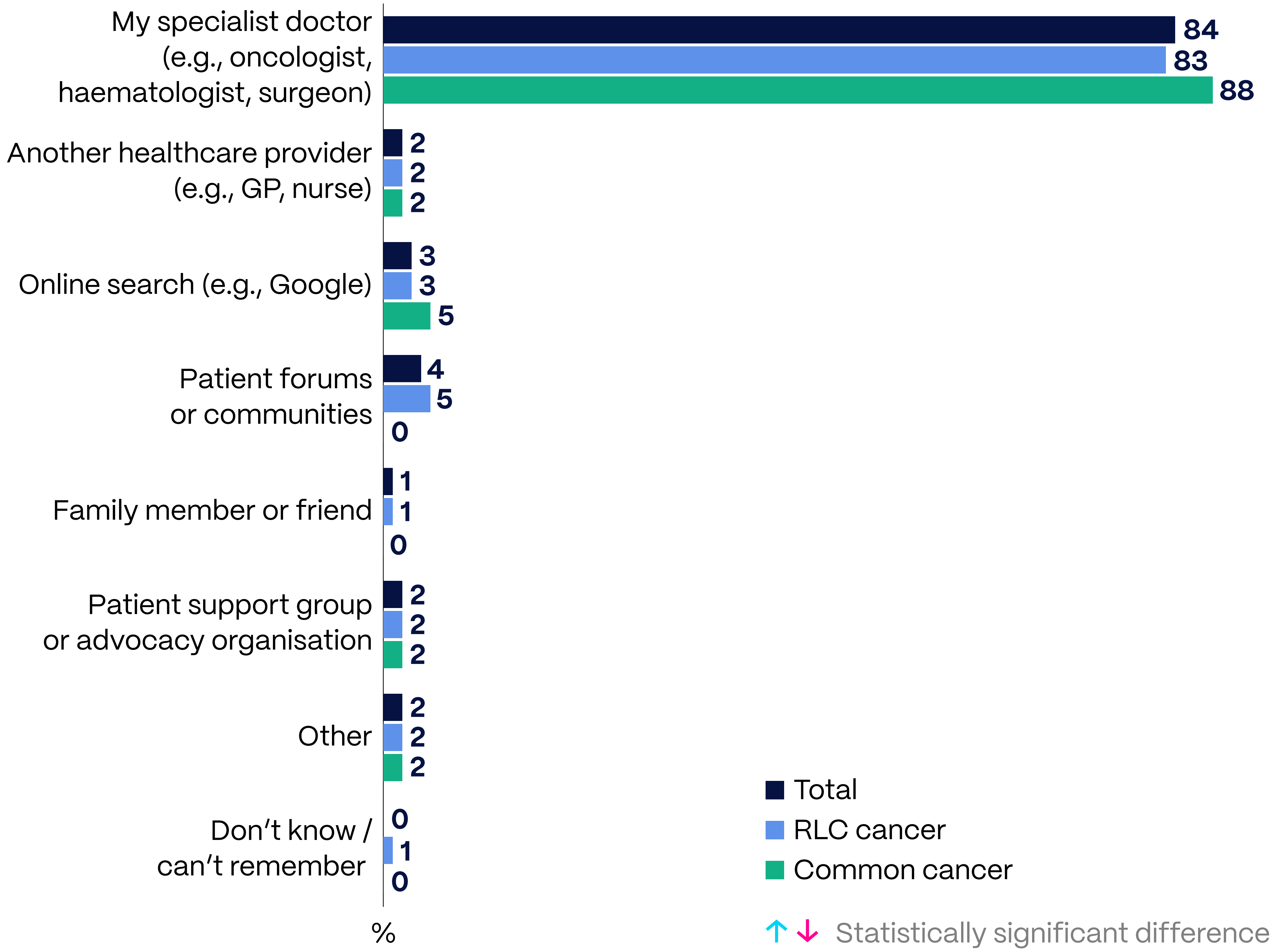
Responses to:

Did your treating team mention or discuss clinical trials as a treatment option for your cancer? **(1,535 responses)**



Responses to:

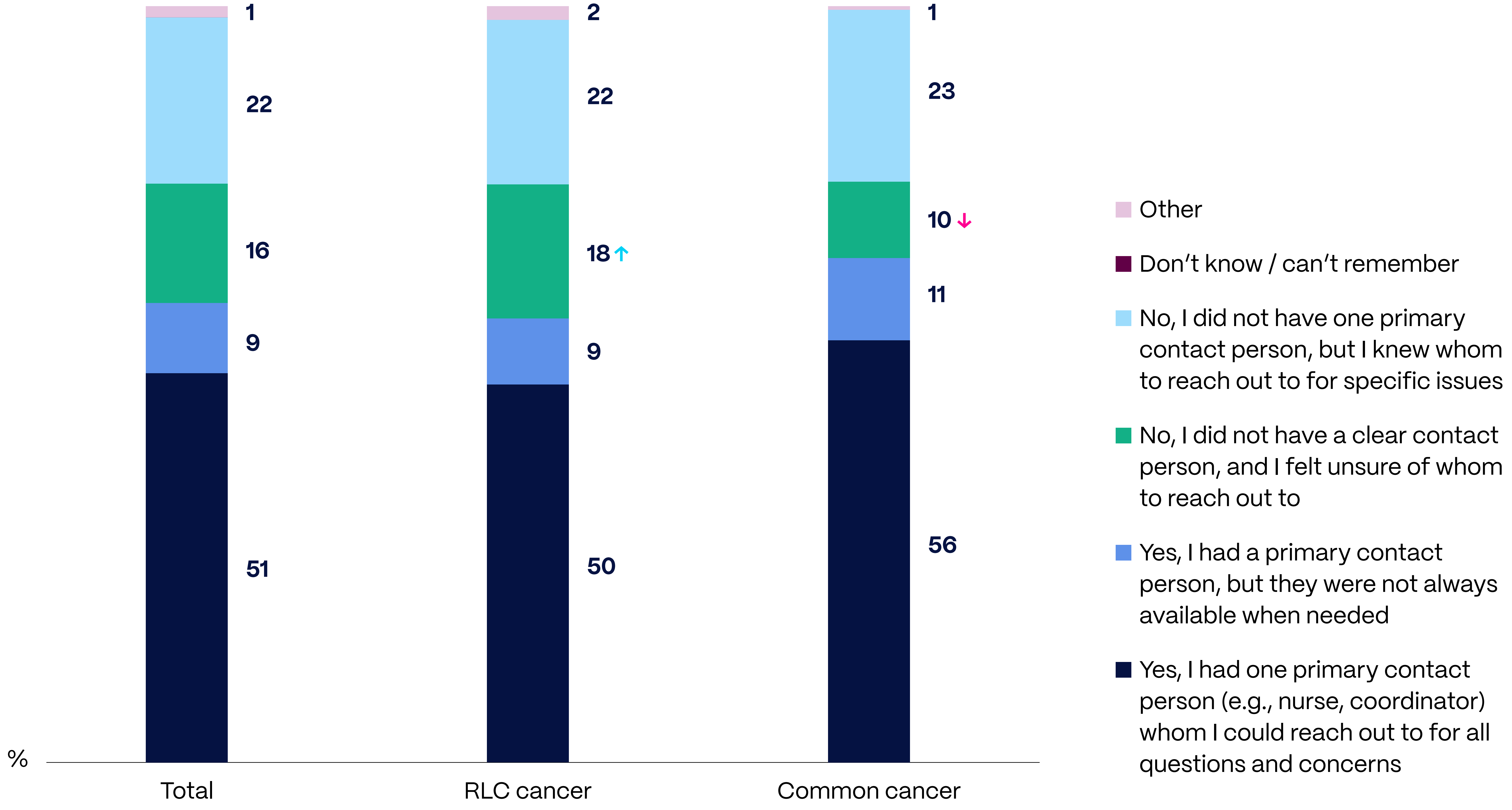
How did you first learn that clinical trials were a cancer treatment option for you? **(208 responses, prompted if participated in trial)**



Clear contact person for questions

Responses to:

Did you have a clear contact person for questions and concerns? **(1,541 responses)**



↑↓ Statistically significant difference

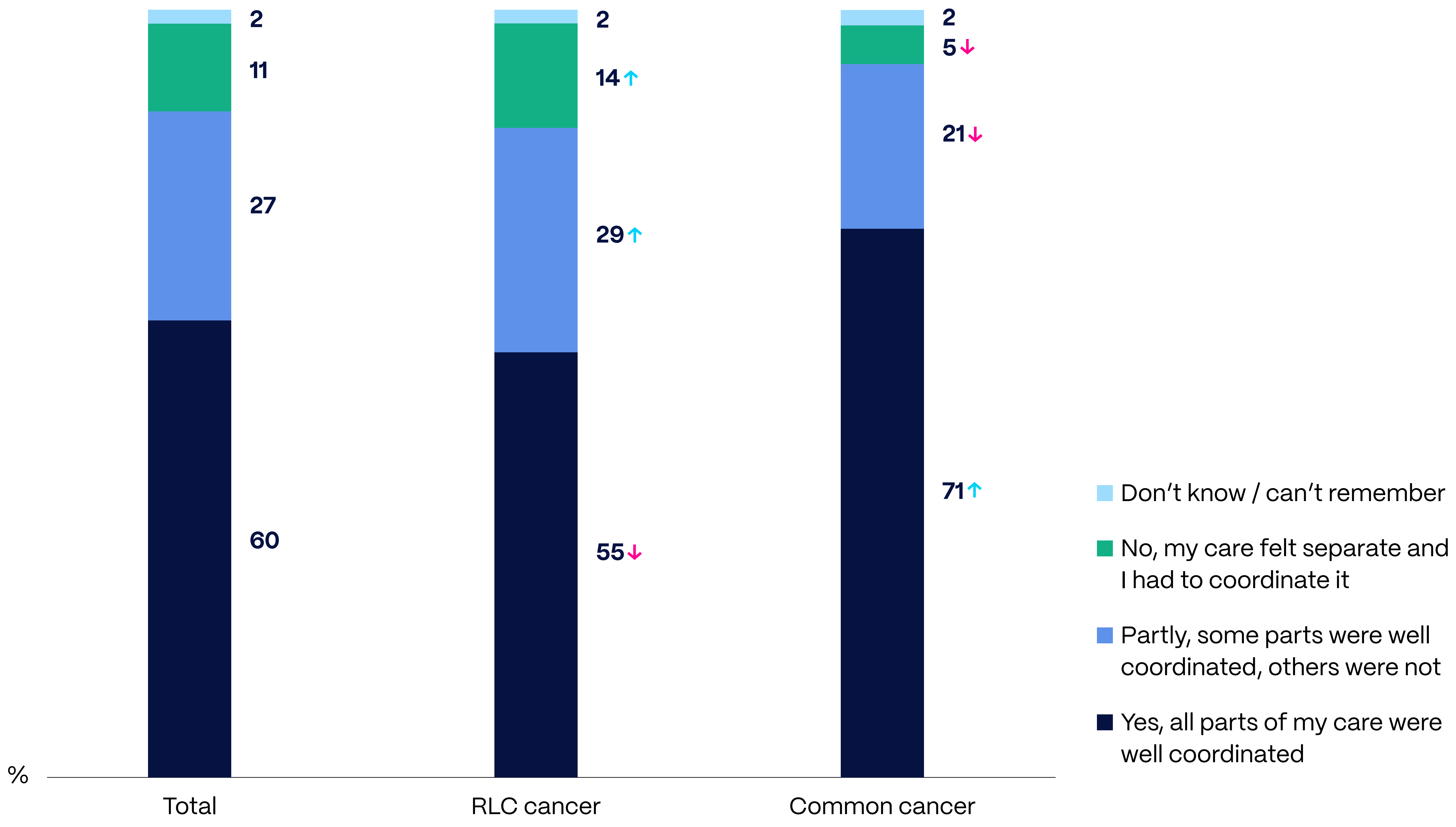
> Currently in regular contact with oncologist and he is very good.

> Follow up from a coordinator would have been positive. Whilst I knew I could contact this person, information was not always free flowing and contact was not necessarily encouraged.

Coordination of care

Responses to:

Did you feel your care was well coordinated and that different people and services were working together? **(1,534 responses)**



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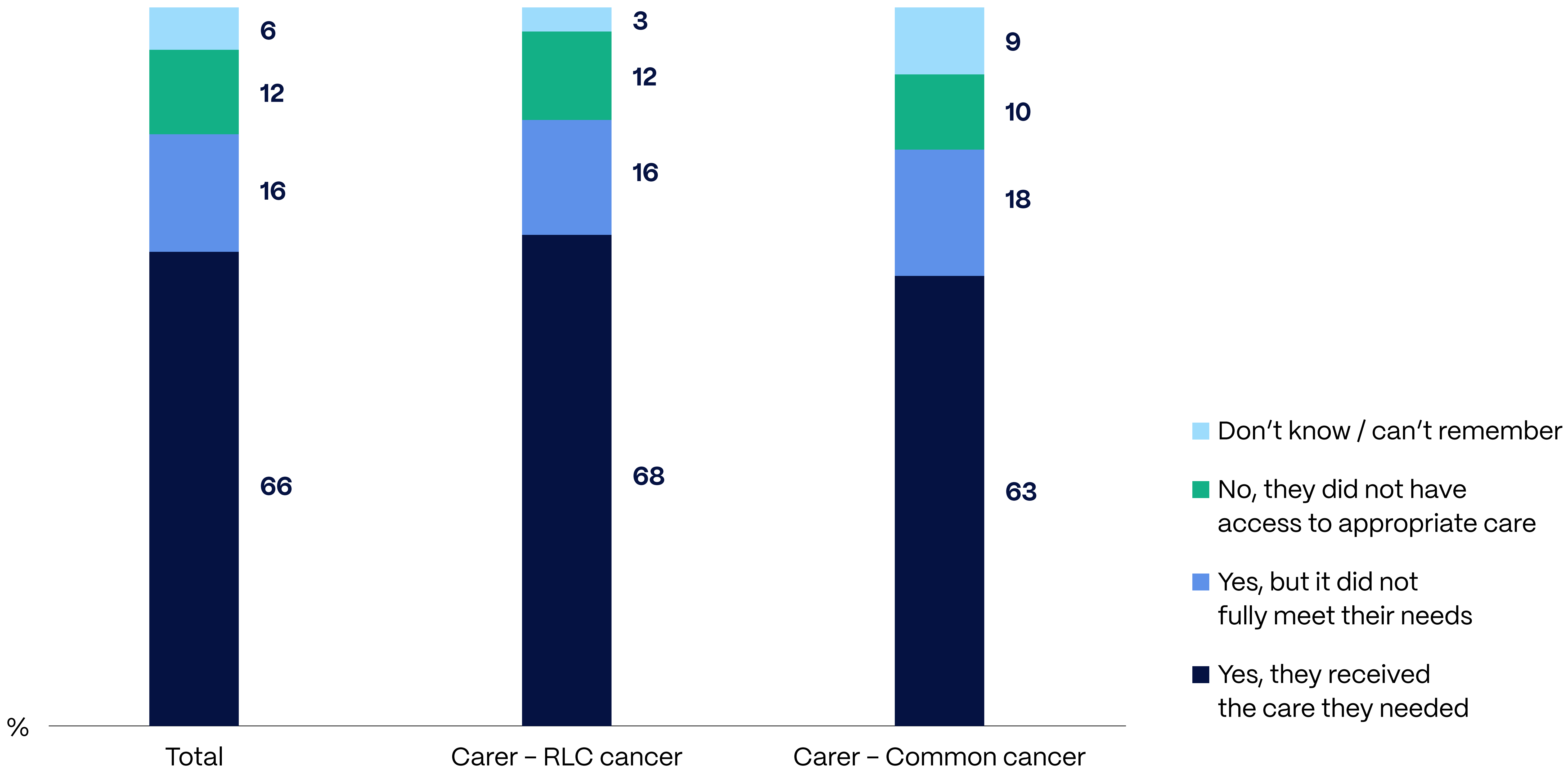
> My treatment was well coordinated and the patient care coordinator made contact with me on my first treatment and subsequently to check on me. Because I am a farmer and not comfortable with people and noise all around me, my care coordinator arranged a private room for my comfort and the convenience of my daughter who was my carer so that she could continue to work remotely during my treatment. My oncologist paid me a visit at every infusion. The nurses functioned as a team and were professional, courteous and respectful at all times.

Access to end-of-life care

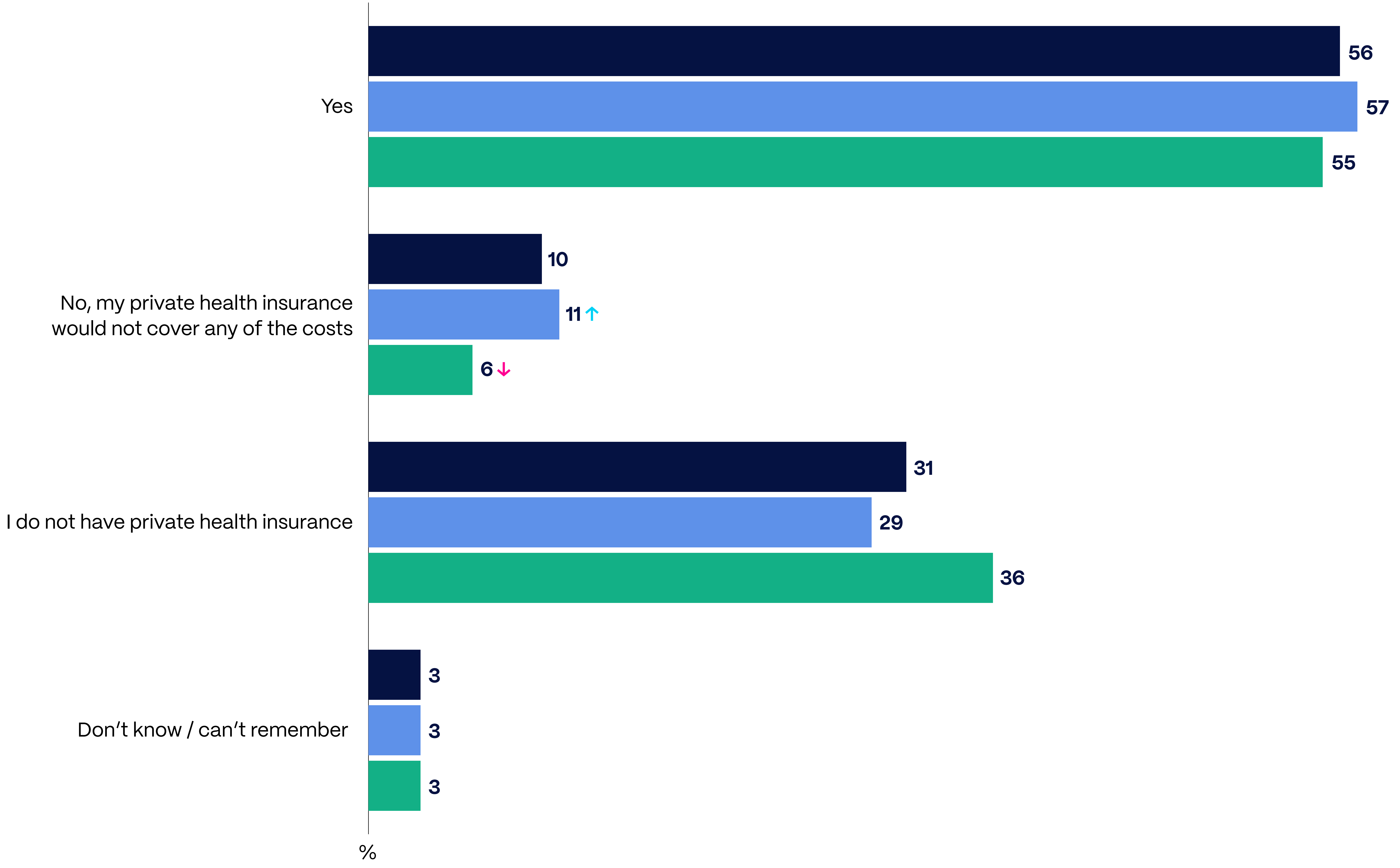
Responses to:

Did the person you cared for have access to appropriate end-of-life care (e.g., palliative care, hospice services, home-based support)? (**544 responses** from respondents who cared for someone who had cancer and has died)



> Despite all the negatives, I felt privileged that I could look after my husband from home and that we could have palliative care in the home.

Use of private health insurance



Responses to:

Have you used private health insurance to cover some of the costs of your cancer testing, scans, or treatment? **(1,538 responses)**

■ Total
■ RLC cancer
■ Common cancer

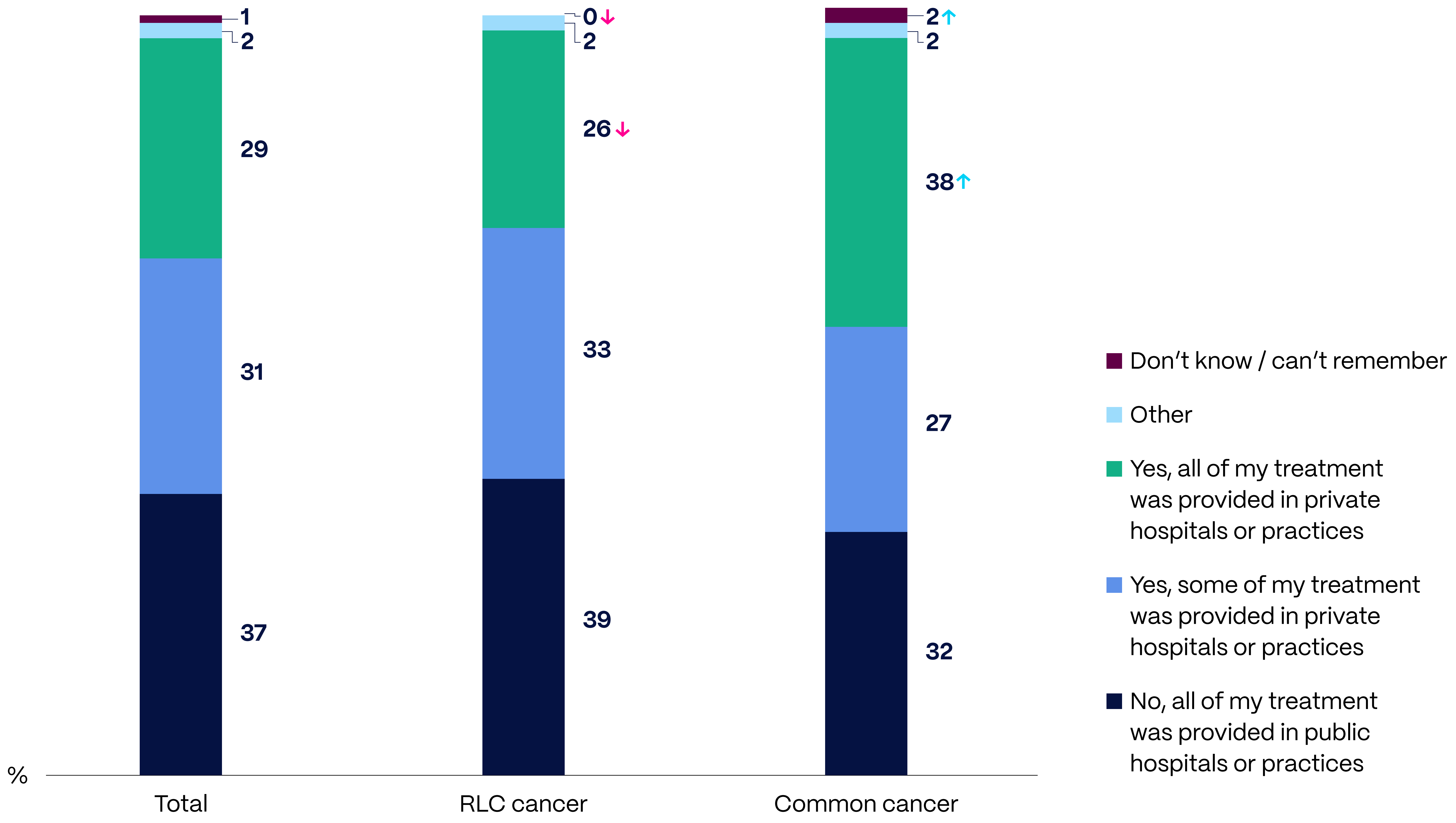
> The gaps for private health surgery and treatment was very expensive. It could be prohibitive for many others.

↑↓ Statistically significant difference

Treatment through the private healthcare system

Responses to:

Was any part of your cancer treatment provided through private hospitals or private practices (e.g. private hospital stay, specialist visits)? **(1,503 responses)**



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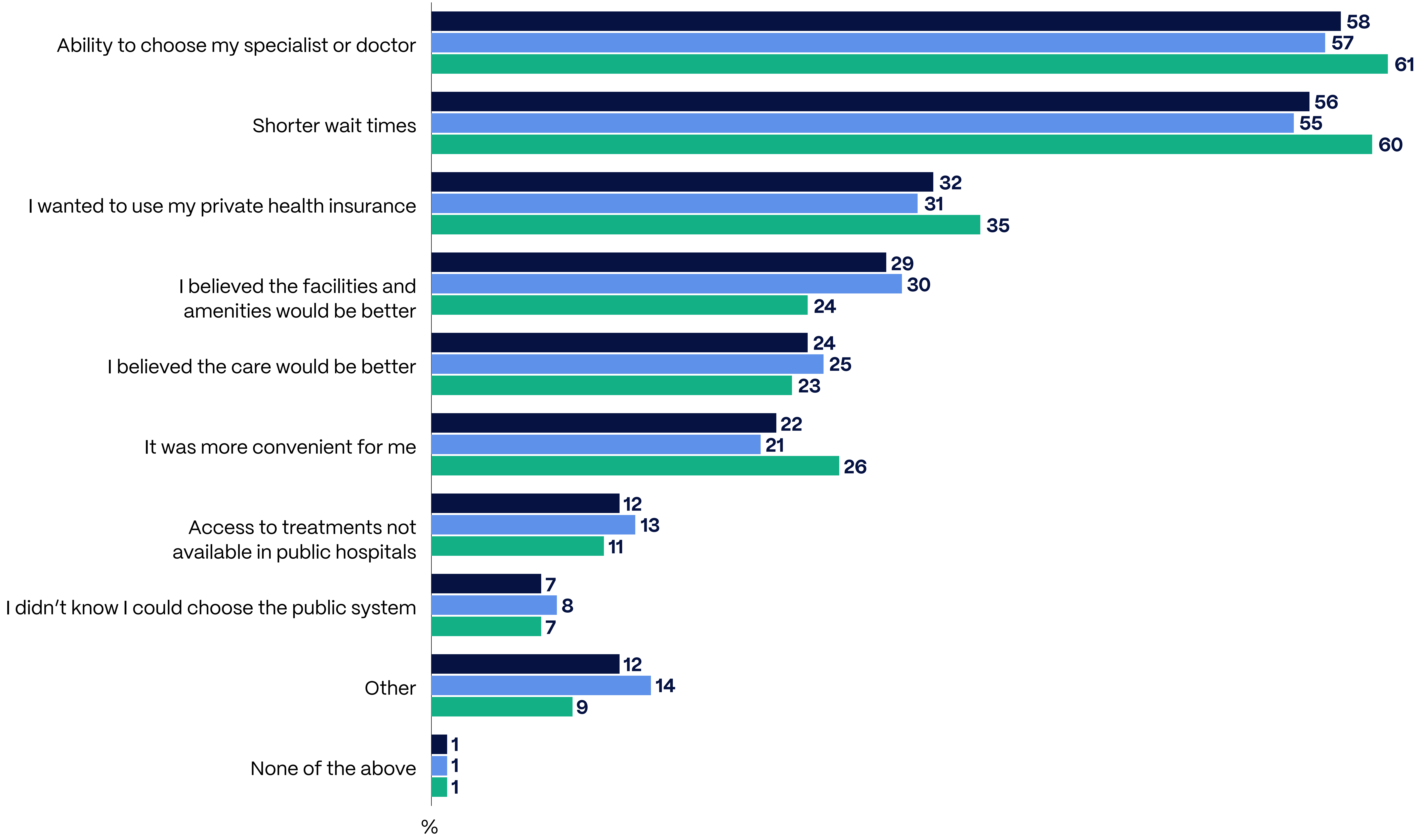
> The treatment I received was faultless but there's little to no support for private patients when you leave hospital or cease treatment. I felt like I'd fallen off a cliff.

Reasons for having treatment in the private system



Responses to:

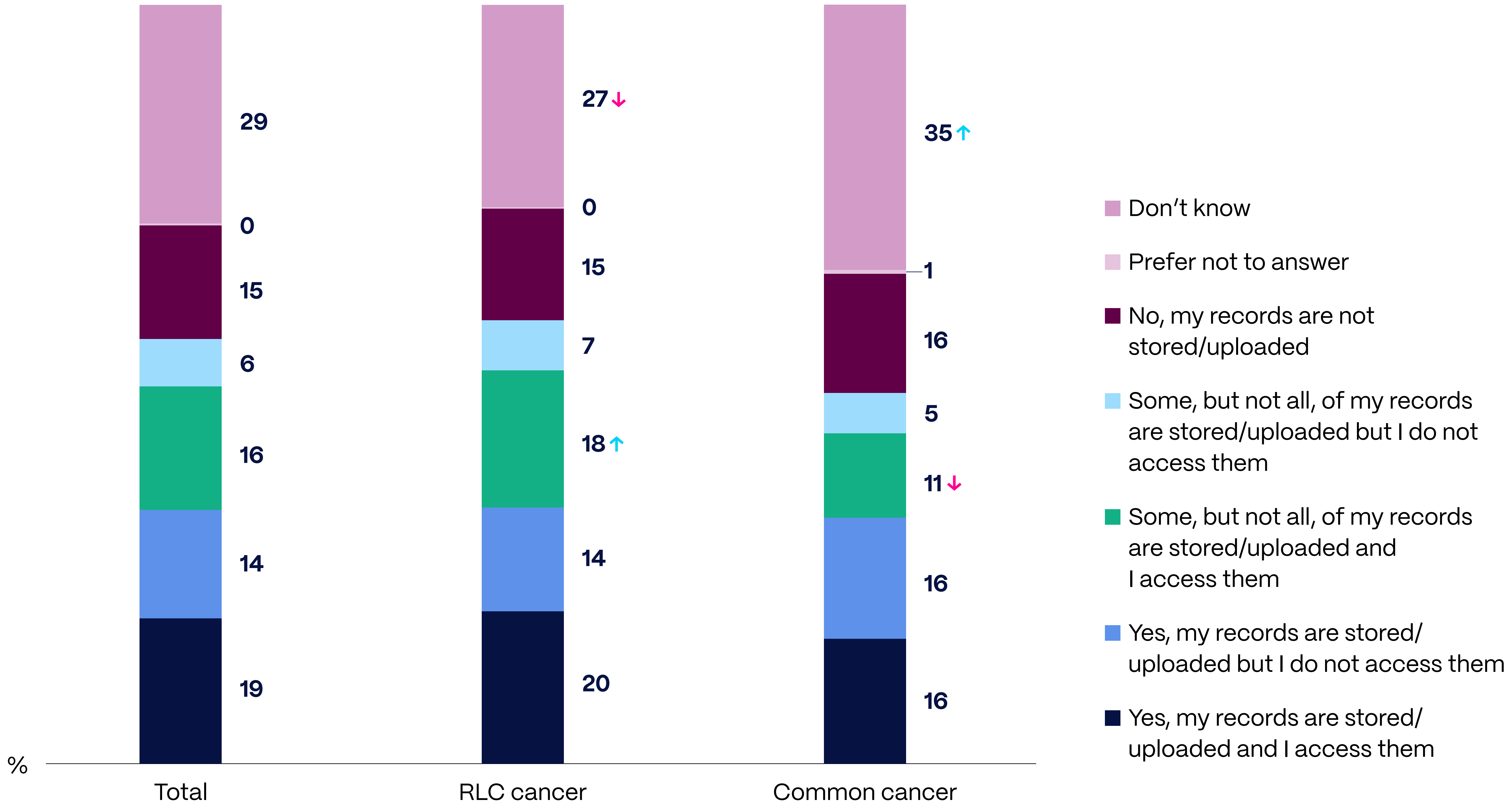
What were the main reasons you chose to receive some or all of your treatments in a private system? Please select all that apply **(881 responses)**

- ■ Total
- ■ RLC cancer
- ■ Common cancer

Use of My Health Record

Responses to:

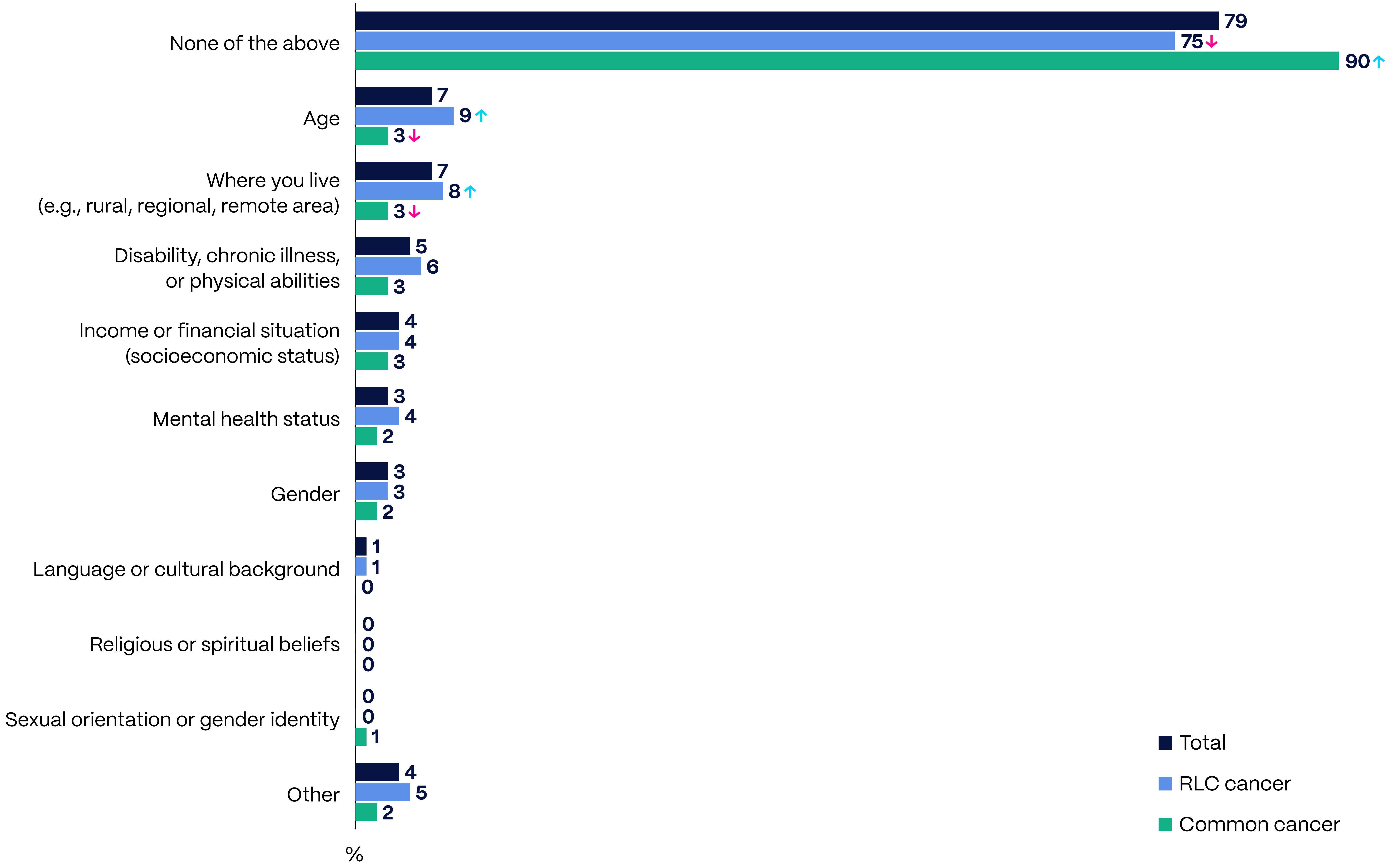
Are your medical records stored or uploaded on My Health Record, and do you access them for your own information? **(1,535 responses)**



↑↓ Statistically significant difference

> I wish all my records were uploaded to My Health Record, so when I do visit the hospital or doctors everyone can see my most recent scans and results, so when I am not well enough they can look at the results and not get me to go through it each time.

Perceived discrimination, bias, or differential treatment



Responses to:

During your cancer experience, did you feel you faced any discrimination, bias, or differential treatment due to any of the following? **(1,517 responses)**

> I was told over and over again that I was too young and didn't have any of the risk factors and therefore it couldn't be cancer.

5

Support and impact

Key findings – Support and impact

Mental health was the greatest unmet support need identified by respondents.

Nearly half (49%) of respondents with a rare or less common cancer (compared with **34%** of respondents with a common cancer) reported that their mental health needs could be better supported during their cancer experience.

One in four (26%) respondents with a rare or less common cancer (compared with **15%** of respondents with a common cancer) identified that they were not referred to mental health services but would have liked to be.

Respondents diagnosed with a rare or less common cancer identified significantly higher needs for access to supportive care.

Respondents diagnosed with a rare or less common cancer were significantly more likely to **access information or support** from patient advocacy or support organisations **(56%)** compared with those diagnosed with common cancers **(38%)**.

More than one-third (37%) of respondents with a rare or less common cancer would have liked to be referred to a **supportive care navigator** but were not. Overall need for access to supportive care navigators was nearly twice as high among people diagnosed with rare or less common cancers **(60%)** compared with common cancers **(34%)**.

Key findings – Support and impact

58% of respondents with a rare or less common cancer (**42%** of respondents with a common cancer) reported that their cancer experience made their household financial situation worse. Almost **one quarter (23%)** of respondents with a rare or less common cancer encountered out-of-pocket expenses in excess of $10,000.

More than one quarter (27%) of all carers reported that their financial situation became worse while caring for a person with cancer. Carers of a person with a rare or less common cancer were **more than four times** more likely to arrange financial support from family, friends, or crowd-funding for cancer treatment.

Carers reported significant unmet support needs in managing the psychological, informational, emotional, social and practical demands of their role.

Over one third (34%) of carers of a person with a rare or less common cancer said they were not referred to a carer support service but would have liked to be. **30%** said they would have liked to have been referred to a supportive care navigator but were not – almost two times higher than for those caring for someone with a common cancer **(16%)**.

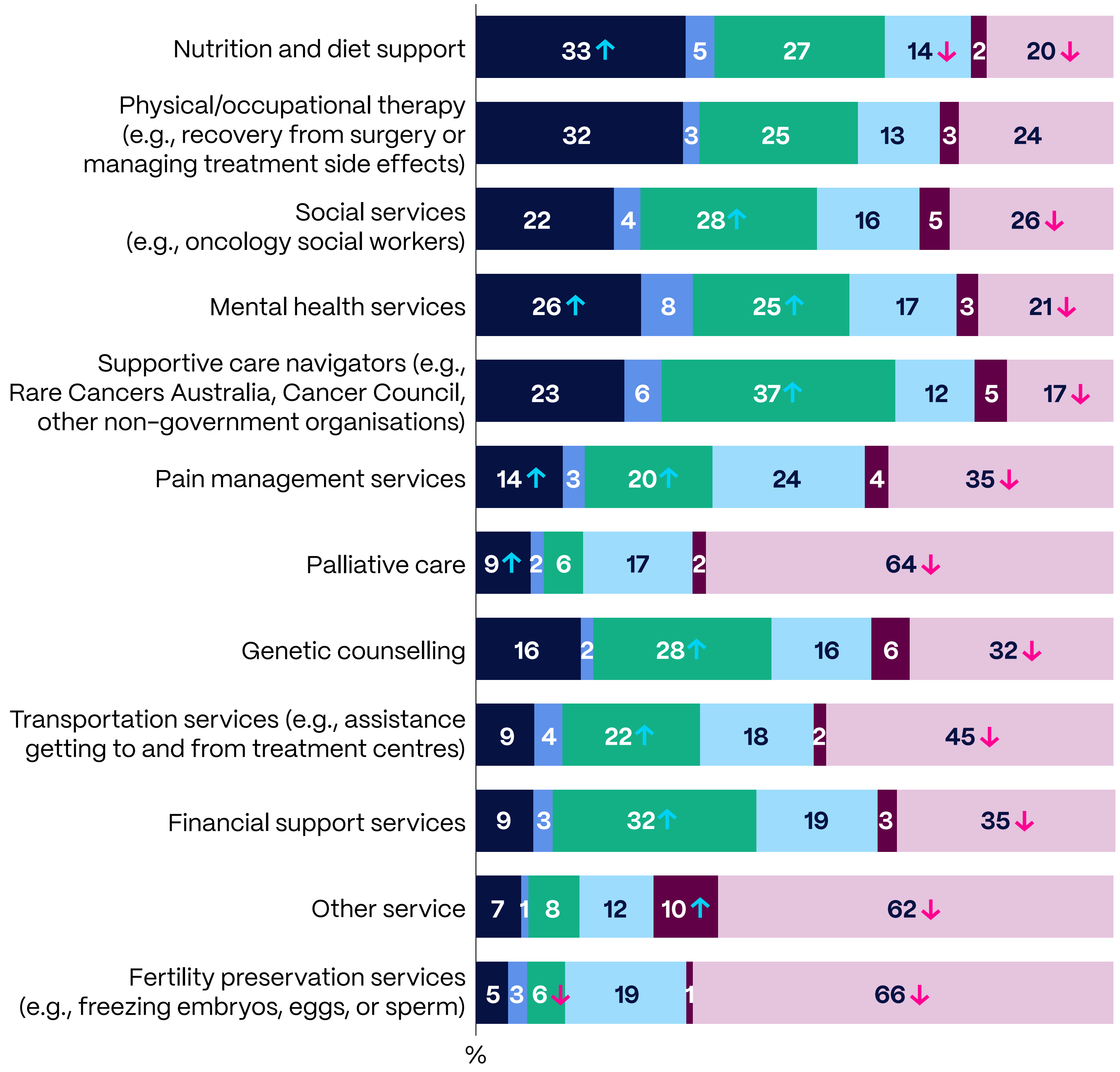
Significant gaps in support for carers during the end-of-life period were also identified. **More than 1 in 4 (29%)** carers said they did not feel very or at all supported during this time.

Access to support services

Responses to:

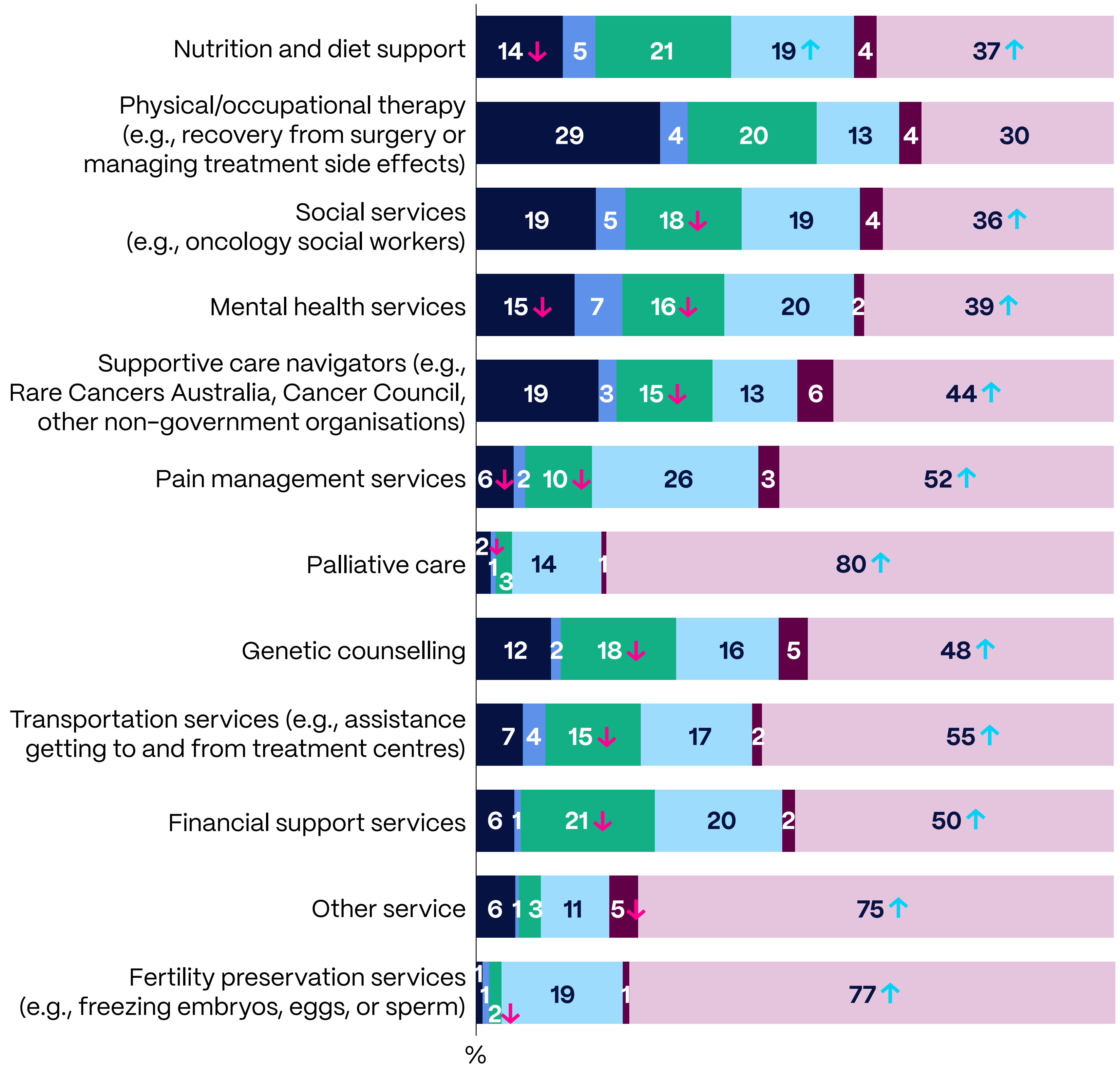
Were you referred to, and did you attend, any of the following services? **(RLC cancer: 1,046–1,133 responses, Common cancer: 371–395 responses)**

Respondents with a RLC cancer



Total need (%) RLC cancer
60↑
57↑
49↑
50↑
60↑
34↑
15↑
44↑
31↑
40↑
15
11↑

Respondents with a common cancer



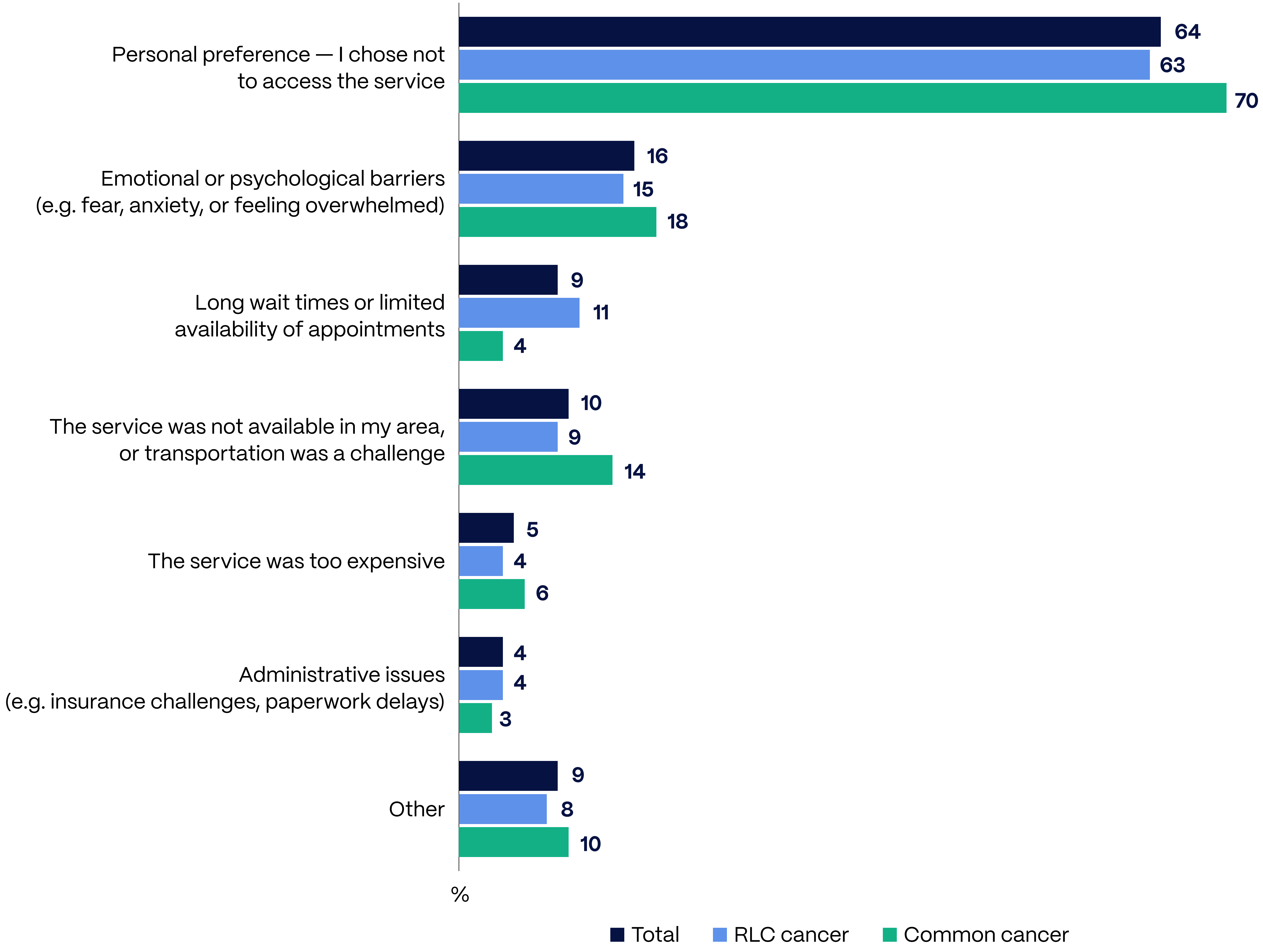
Total need (%) common cancer
35↓
49↓
37↓
31↓
34↓
16↓
5↓
30↓
22↓
27↓
10
3↓

■ Yes, referred and attended ■ Yes, referred but did not attend ■ No, not referred but would have liked to be ■ No, not referred and did not want to attend ■ Don't know / can't remember ■ Not applicable / needed

↑↓ Statistically significant difference

* Total need = Yes, referred and attended + No, not referred but would have liked to be

Reasons for not taking up supportive care referral



Responses to:

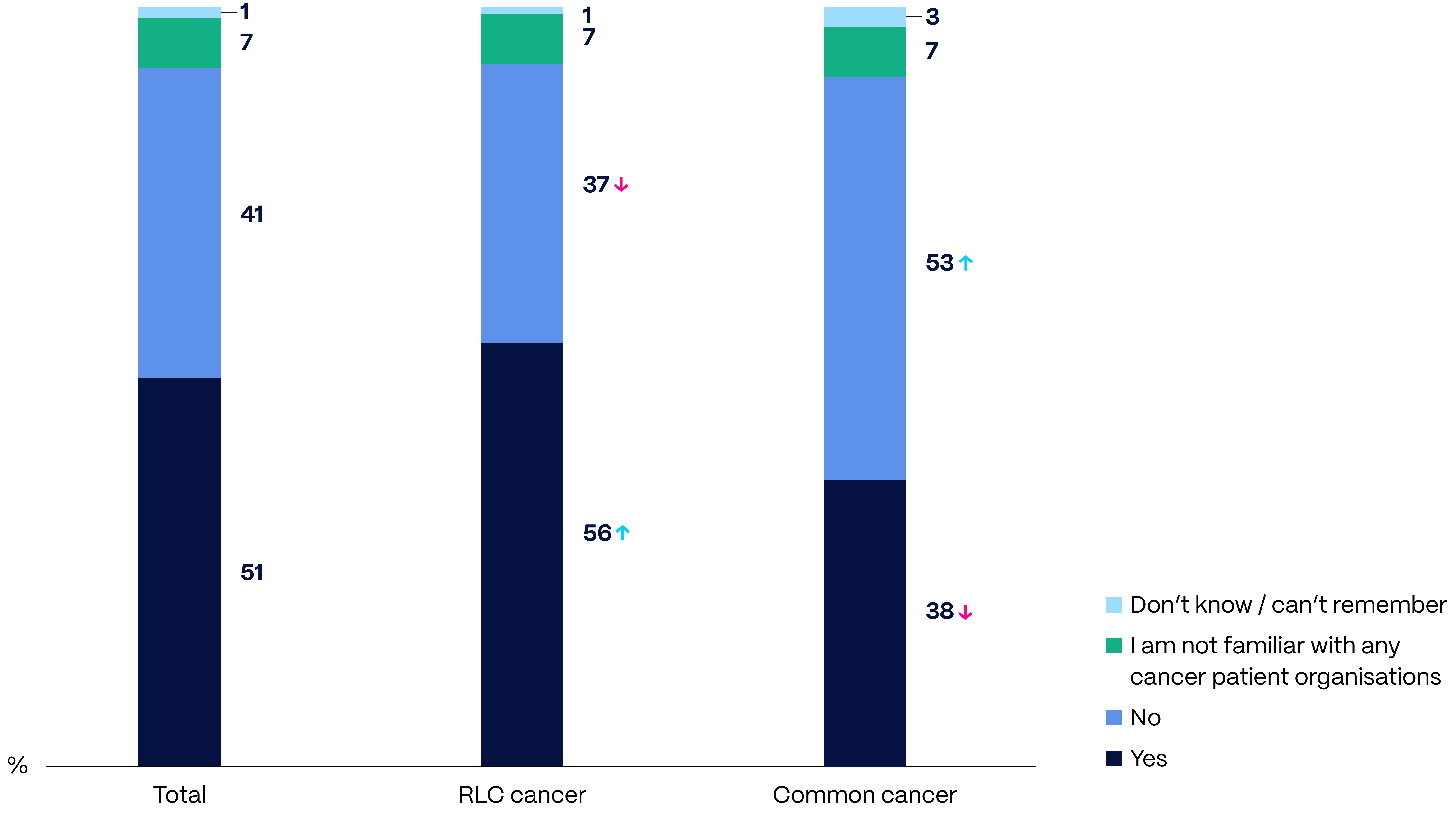
You said you were referred to at least one service but did not attend. What were the main reasons you did not access these services? Please select all that apply **(339 responses)**

> Massively out-of-pocket for medications, scans, private lymphoedema clinic and have not engaged other services such as a dietitian due to no access in public system and cost as a barrier privately.

Accessing patient advocacy or support organisations

Responses to:

Have you accessed information or support from any cancer patient advocacy or support organisations, such as Rare Cancers Australia, Cancer Council, etc? **(1,547 responses)**



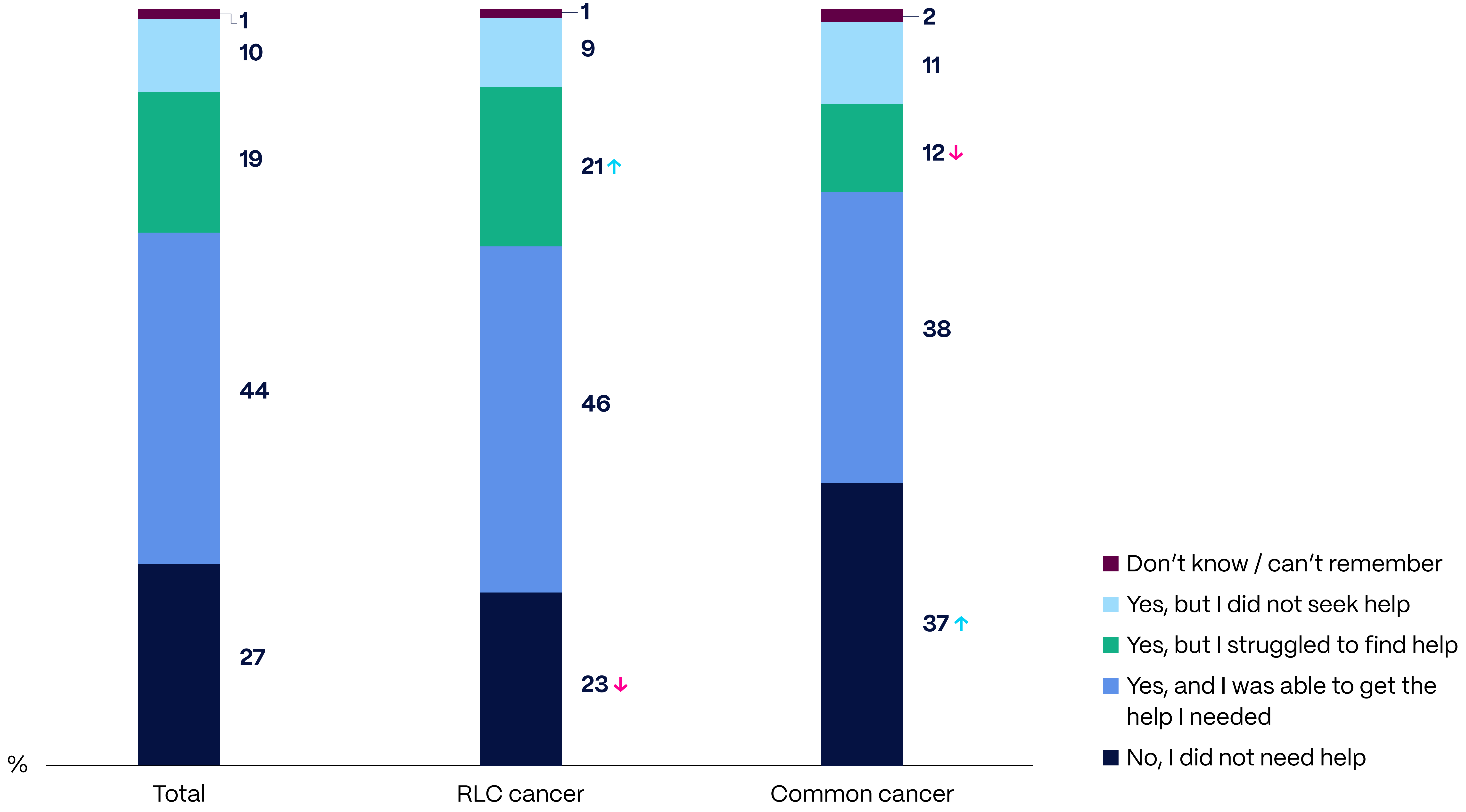
↑↓ Statistically significant difference

> There was very little information on my rare subtype, and I only found out it was rare through my [omitted] nurse who suggested I get in contact with Rare Cancers Australia.

Accessing help for symptoms and side effects

Responses to:

Did you need help managing your physical symptoms and side effects (such as pain and fatigue) during your cancer experience? **(1,542 responses)**



- 🟥 Don't know / can't remember
- 🟦 Yes, but I did not seek help
- 🟩 Yes, but I struggled to find help
- 🟦 Yes, and I was able to get the help I needed
- ■ No, I did not need help

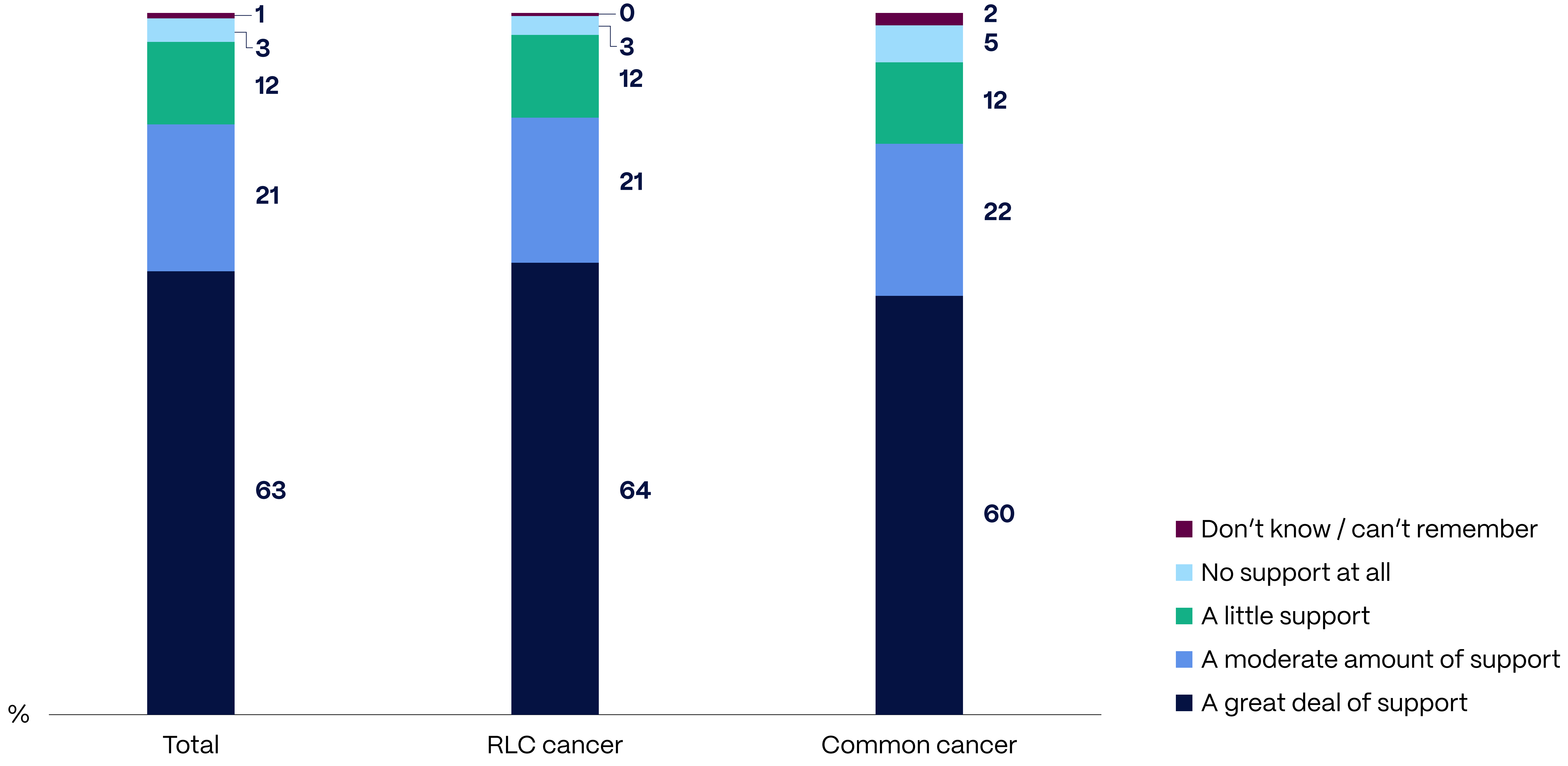
↑↓ Statistically significant difference

> I self referred or organised the support I needed (eg counsellor, exercise physiologist, lymphoedema physiotherapist). I did this using information I found in materials given to me by specialist nurses and on specialist NFP websites and forums.

Support from family, friends and social networks

Responses to:

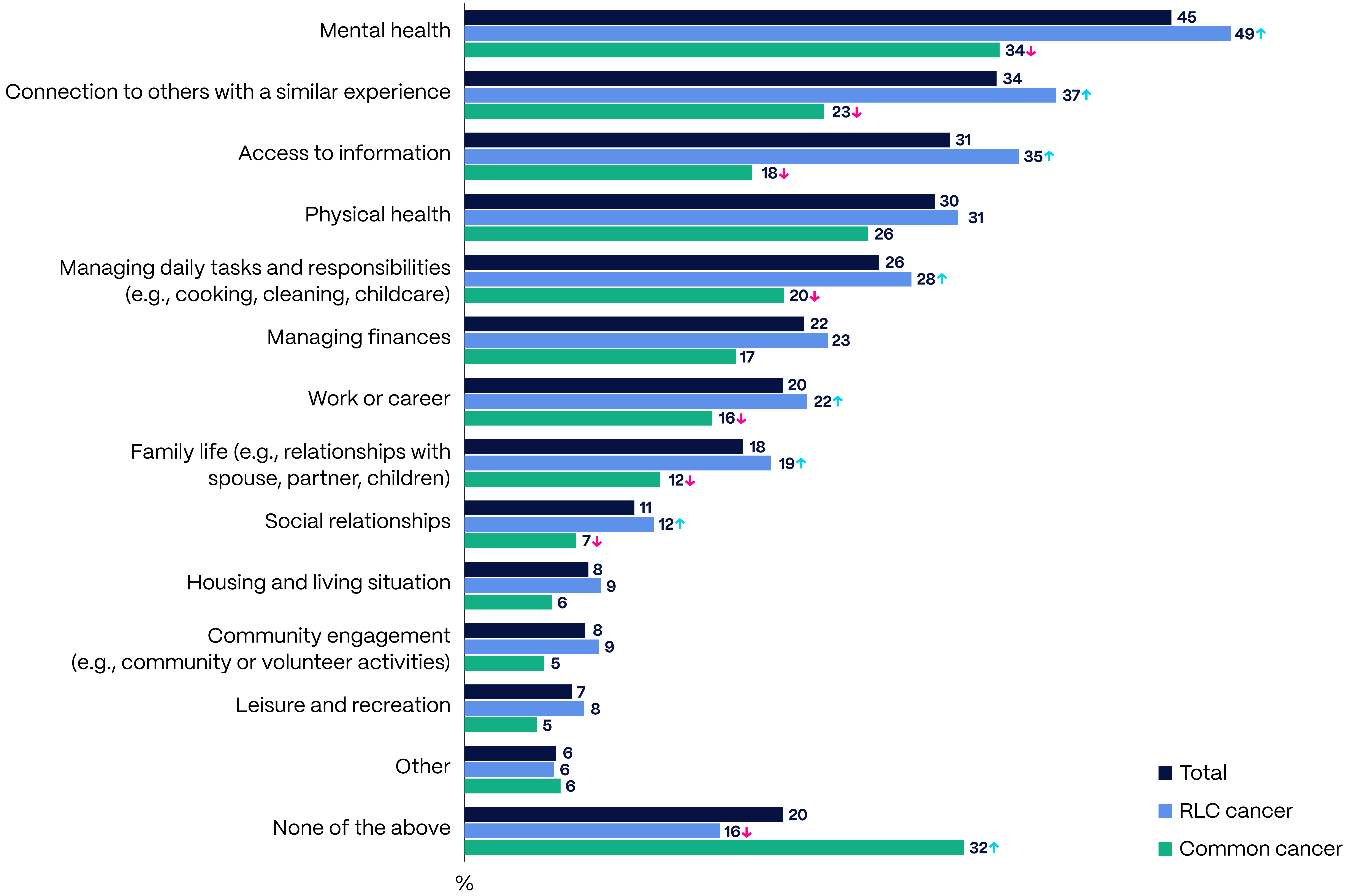
To what extent did your family, friends, or social support networks provide help during your cancer experience? This may include emotional, practical, or financial **(1,549 responses)**



↑↓ Statistically significant difference

> The emotional impact of my ever-worsening prognosis was very high. Most of my support to deal with this impact has come from my own resources and friends. I have requested emotional/therapeutic support from my team but that hasn't been offered yet.

Unmet support needs



↑ ↓ Statistically significant difference

Responses to:

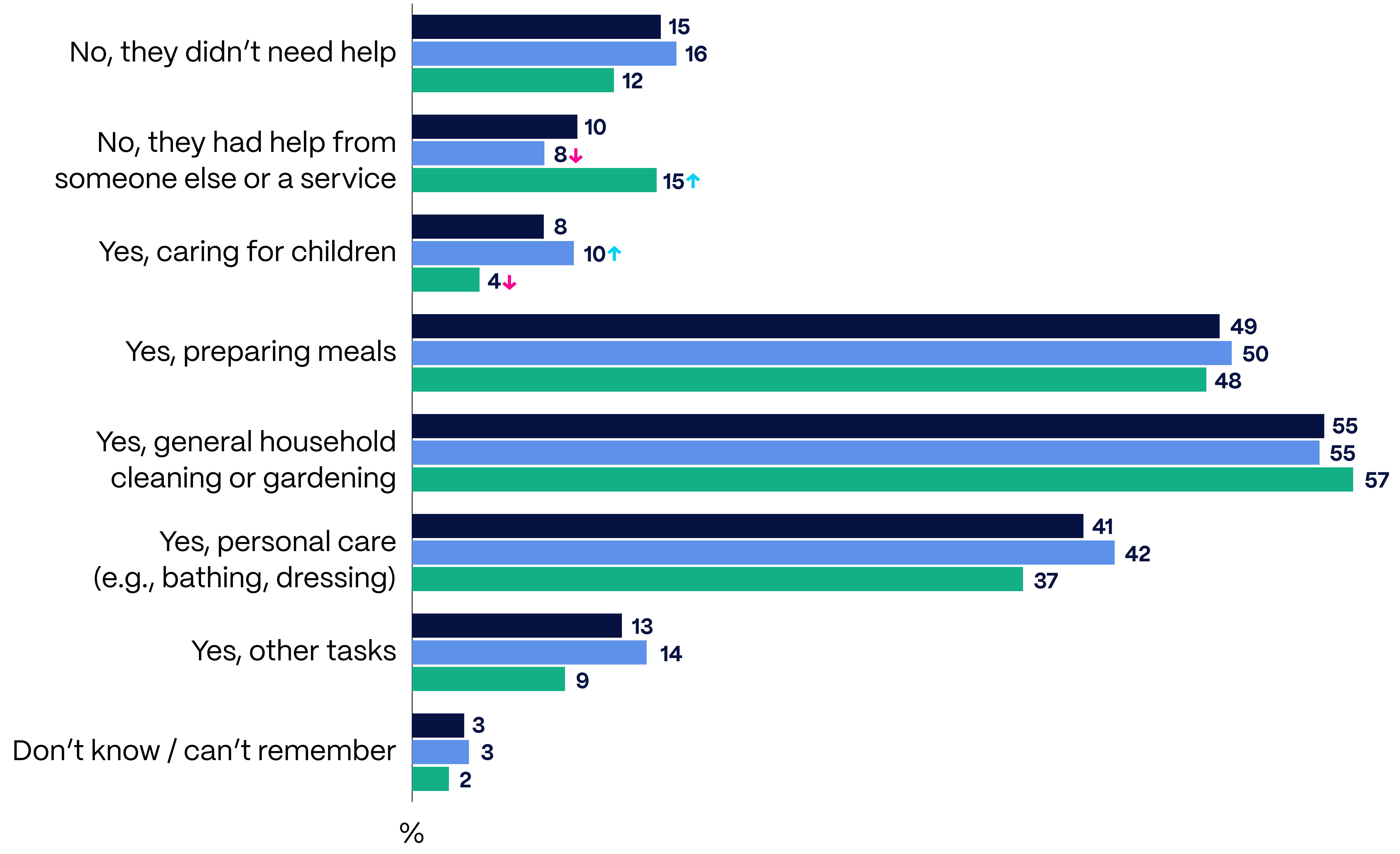
Regarding your cancer experience, what areas do you think could be better supported? Please select all that apply **(1,542 responses)**

> **Mental health support would be my most valuable support. I was already dealing with chronic illness when my cancer was diagnosed and coping was a daily mental challenge. My cancer has now metastasised and all avenues of treatment have been exhausted. At this stage mental health support would be more advantageous than usual.**

Practical care responsibilities and access to assistance

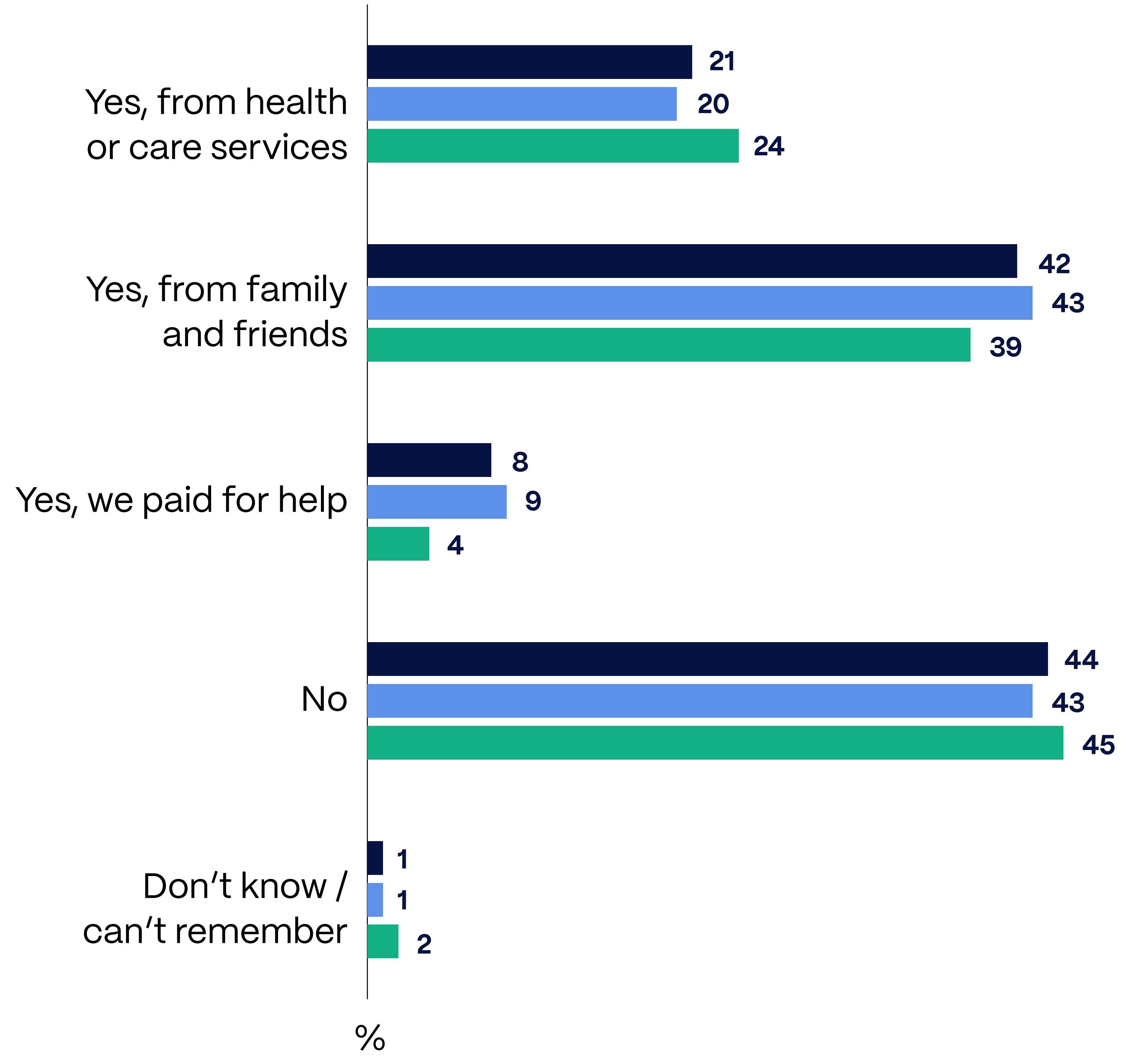
Responses to:

Did you need to help the person with any day-to-day tasks (e.g. bathing, shopping, cleaning) because of their cancer symptoms or side effects? Please select all that apply **(892 responses)**



Responses to:

If yes, did you have any help to support them with those day-to-day tasks? Please select all that apply **(638 responses)**



■ Total ■ Carer – RLC cancer ■ Carer – Common cancer

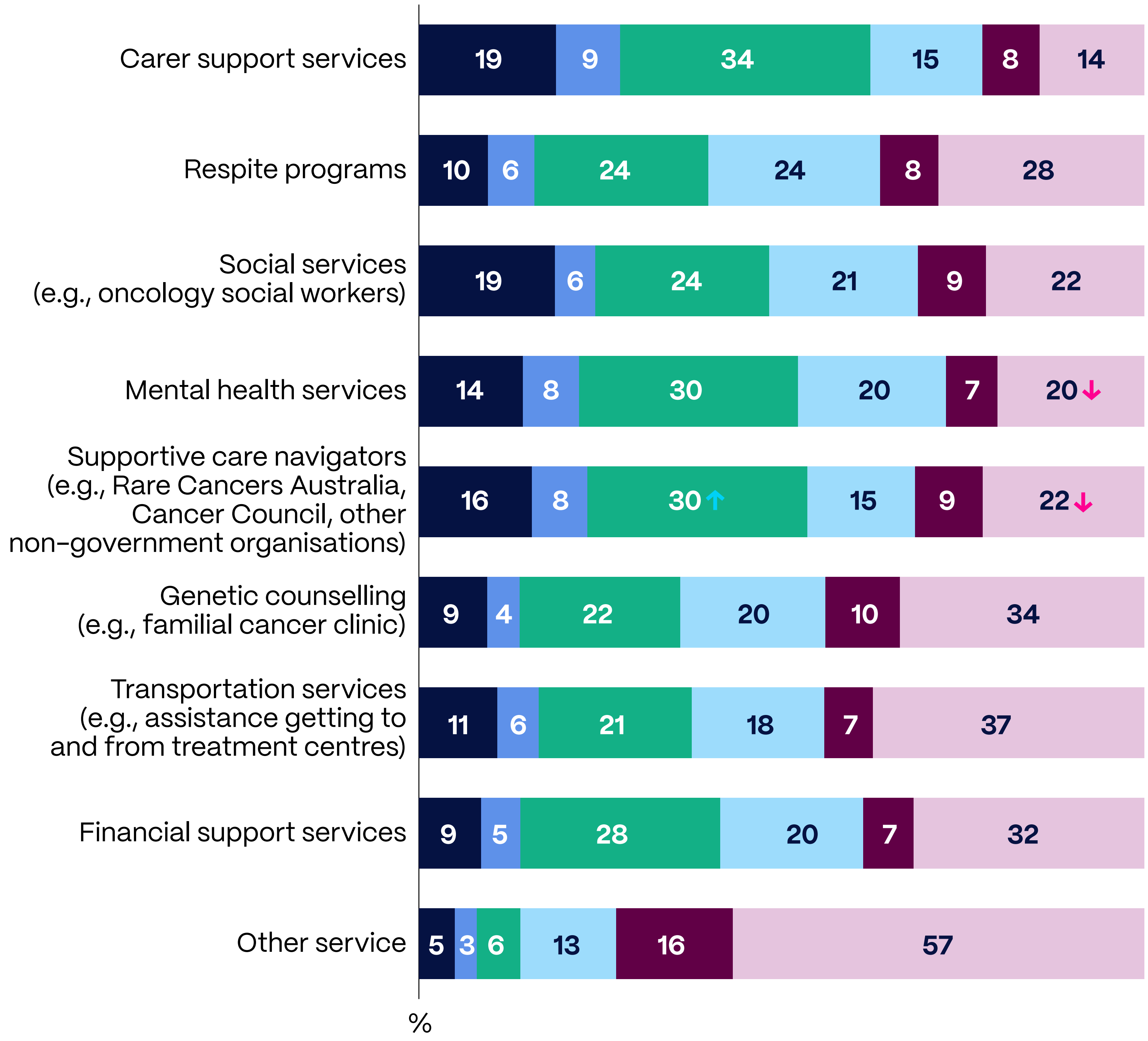
↑↓ Statistically significant difference

Access to support services

Responses to:

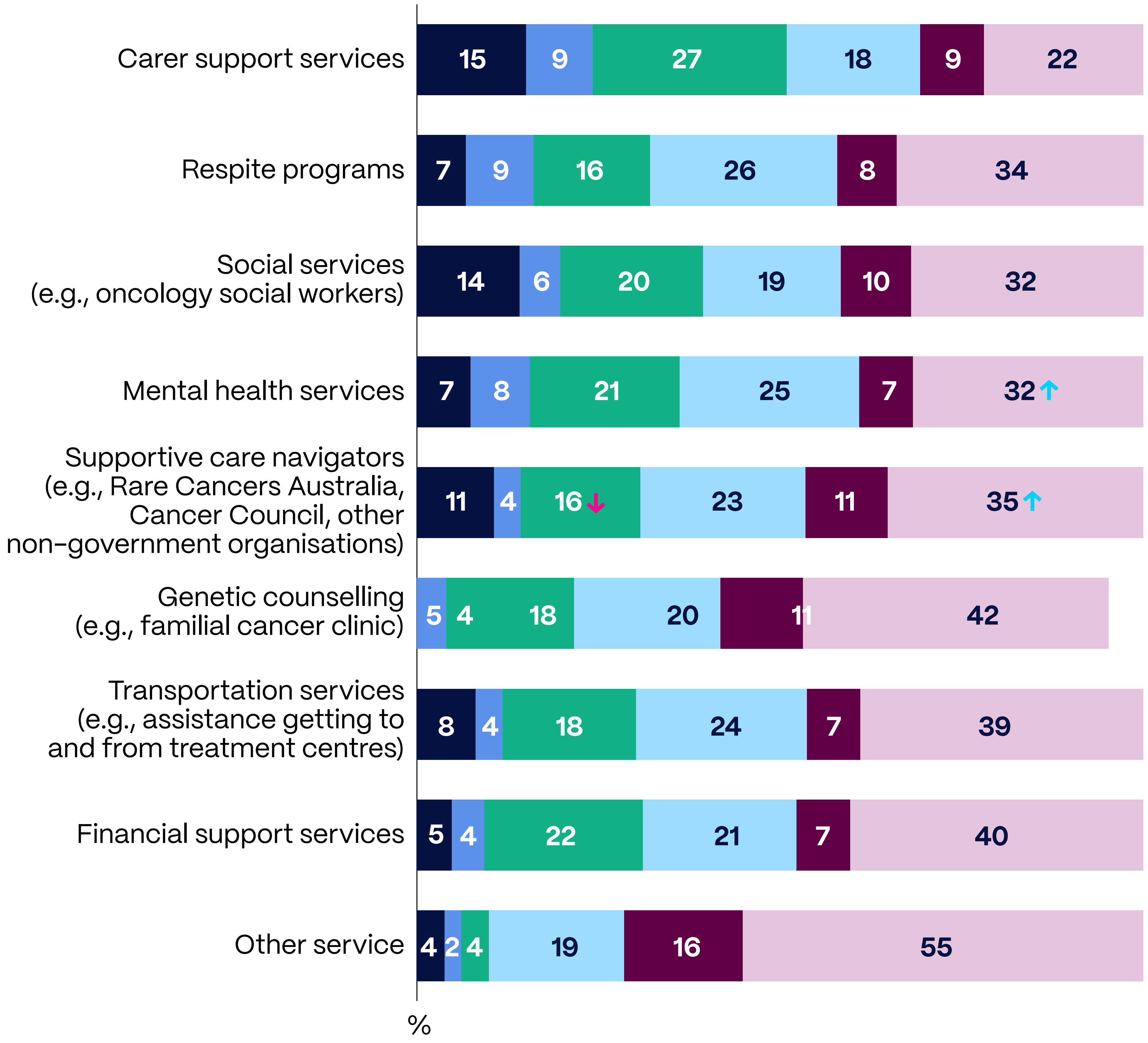
As a carer, were you ever referred to, and did you attend, any of the following services? **(RLC cancer: 566–612 responses, Common cancer: 263–273 responses)**

Carer access to support services – RLC cancer



Total need (%) RLC cancer
53 ↑
33 ↑
43 ↑
44 ↑
46 ↑
32 ↑
32
36 ↑
11

Carer access to support services – Common cancer



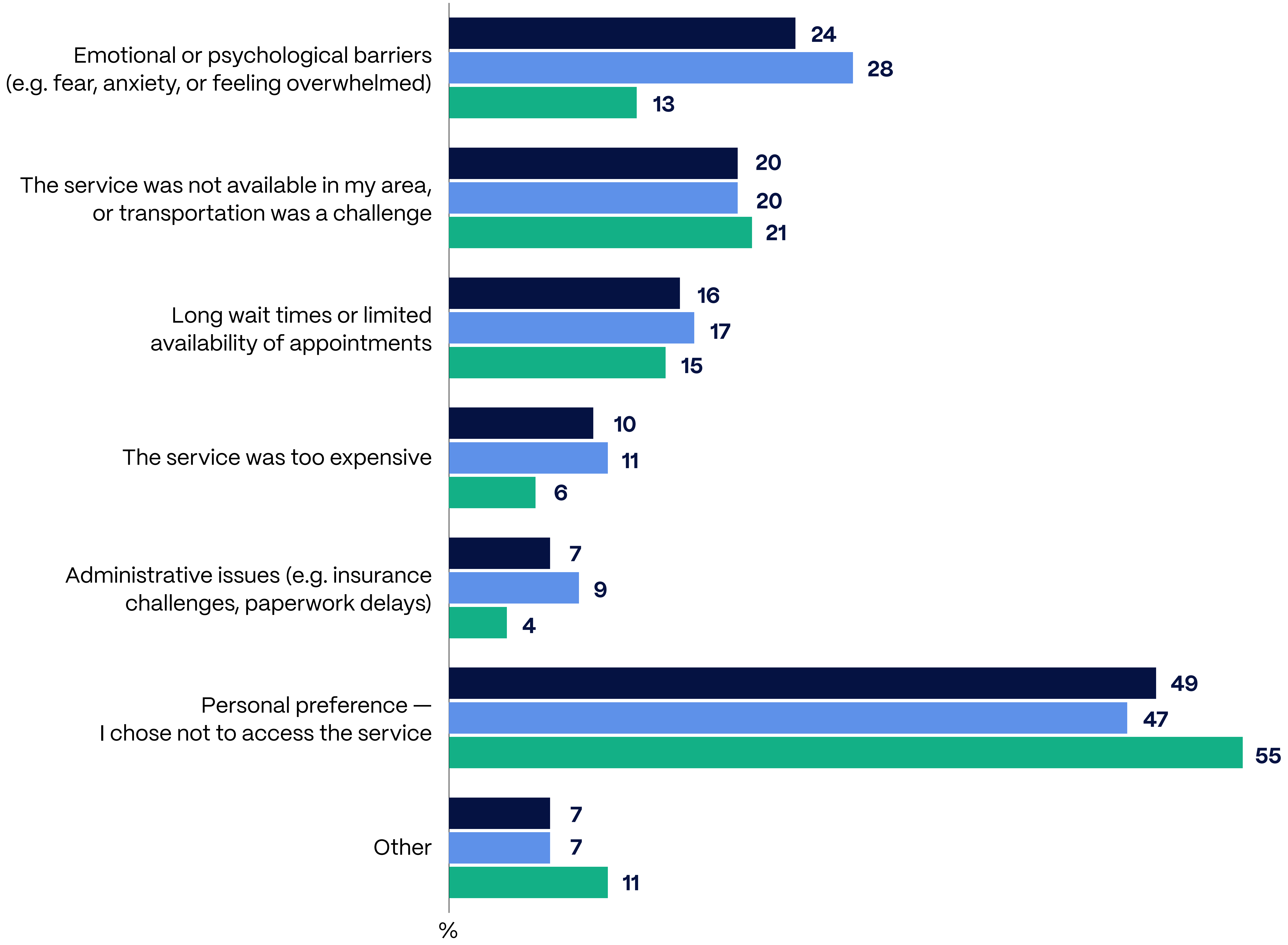
Total need (%) common cancer
42 ↓
23 ↓
34 ↓
28 ↓
27 ↓
22 ↓
26
27 ↓
8

■ Yes, referred and attended ■ Yes, referred but did not attend ■ No, not referred but would have liked to be ■ No, not referred and did not want to attend ■ Don't know / can't remember ■ Not applicable / needed

↑↓ Statistically significant difference

*Total need = Yes, referred and attended + No, not referred but would have like to be

Reasons for not taking up a support service referral



> Lack of carer support despite promises made. The nursing staff were amazing but other support such as social worker and psychologist made promises to support me but didn't follow up. It was a lonely journey.

Responses to:

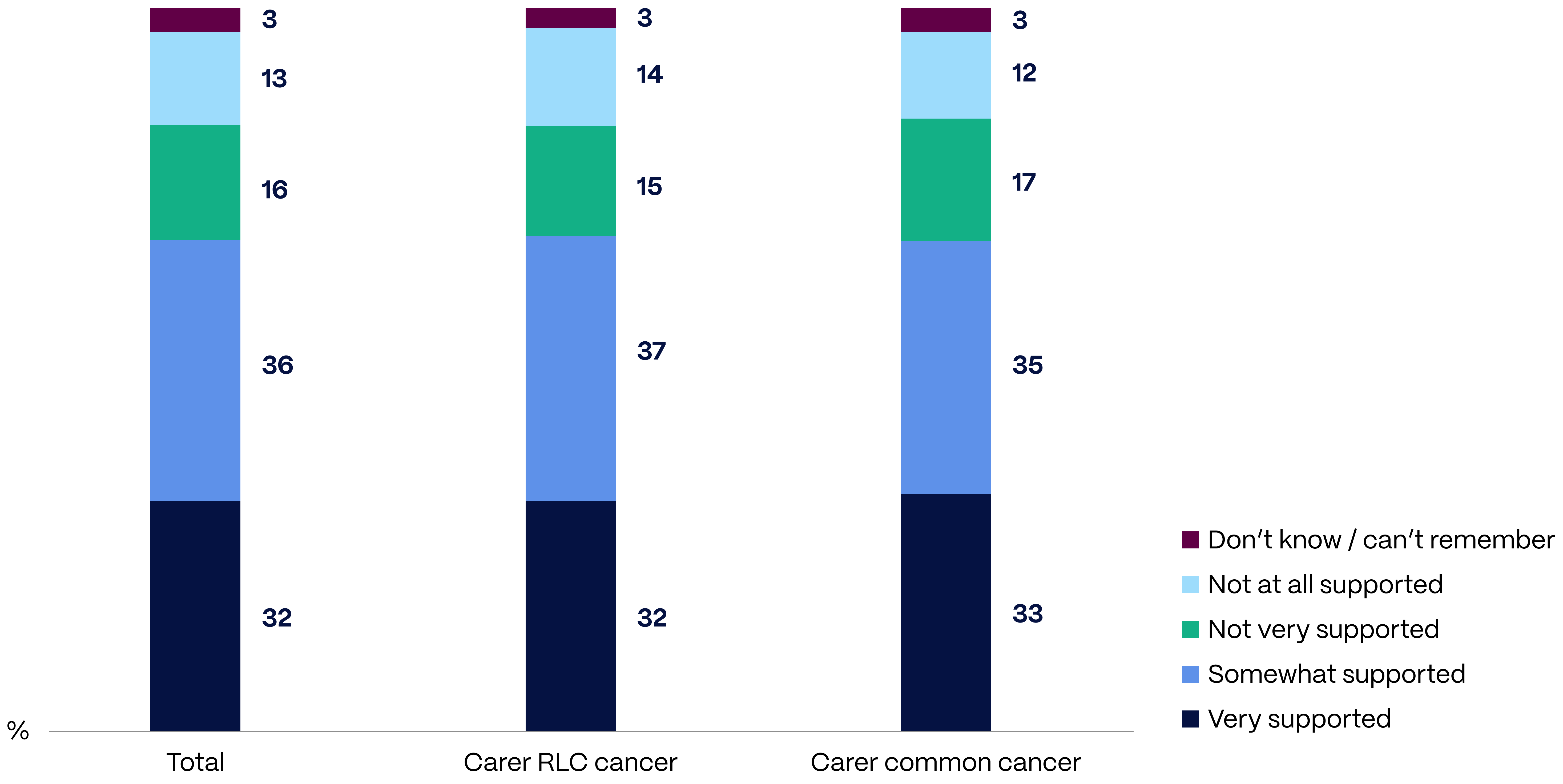
You said that you were referred to at least one service but did not attend. What were the main reasons you did not access these services? Please select all that apply **(187 responses)**

- ■ Total
- 🟦 Carer – RLC cancer
- 🟩 Carer – Common cancer

Carer experiences of support at end-of-life

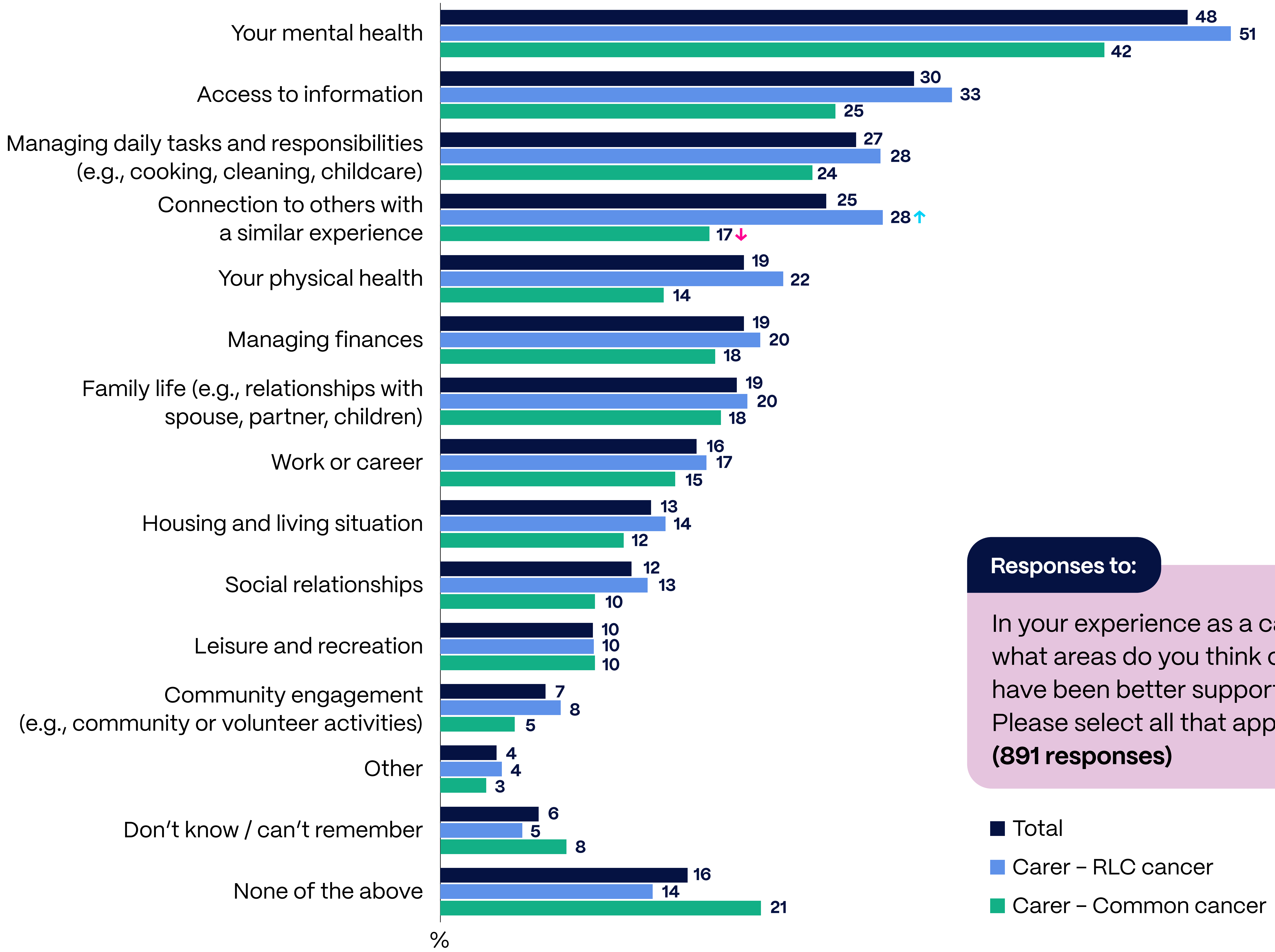
Responses to:

How supported did you feel as a carer during the end-of-life period? (**549 responses** from respondents that cared for someone who had cancer and has died)



> As a carer, I felt there was a lack of support services available to me, particularly during her palliative care phase. There was very little support and education provided and I did not know what to expect.

Unmet support needs



Responses to:

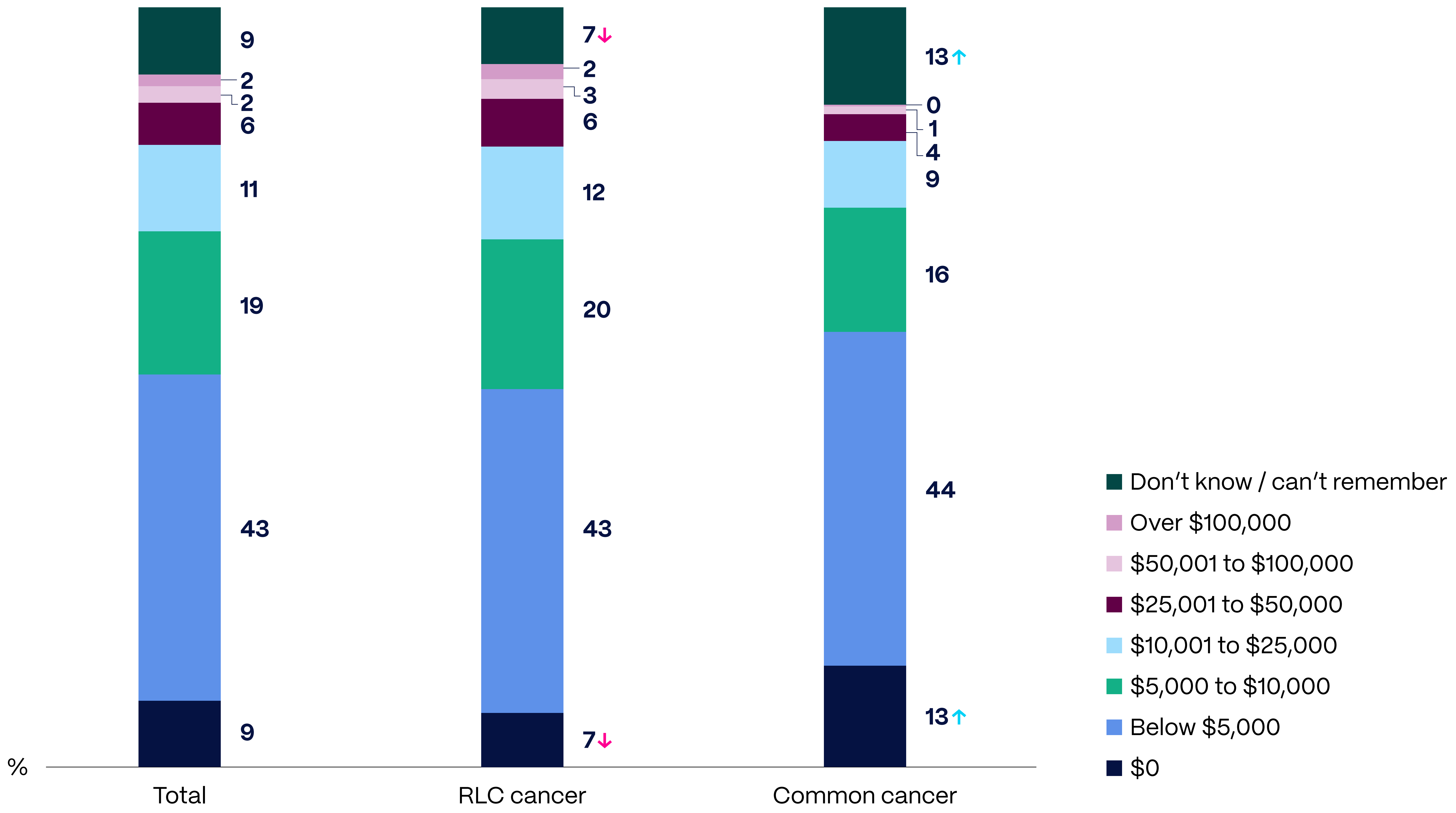
In your experience as a carer, what areas do you think could have been better supported? Please select all that apply **(891 responses)**

> Your world is upside down, you lose track of just about everything except when the next dose of radiation or chemotherapy is, running backwards and forwards to hospital. Seven days a week and nights, you're cleaning the house, washing the patient, cleaning the clothes, cooking the meals, trying to do your job as well and go to work. The whole thing just destroys your life and it's completely wrecked mine, I just have never been able to get back on the horse ever since.

Out-of-pocket expenses

Responses to:

Approximately how much have you spent out-of-pocket on cancer-related expenses? **(1,550 responses)**



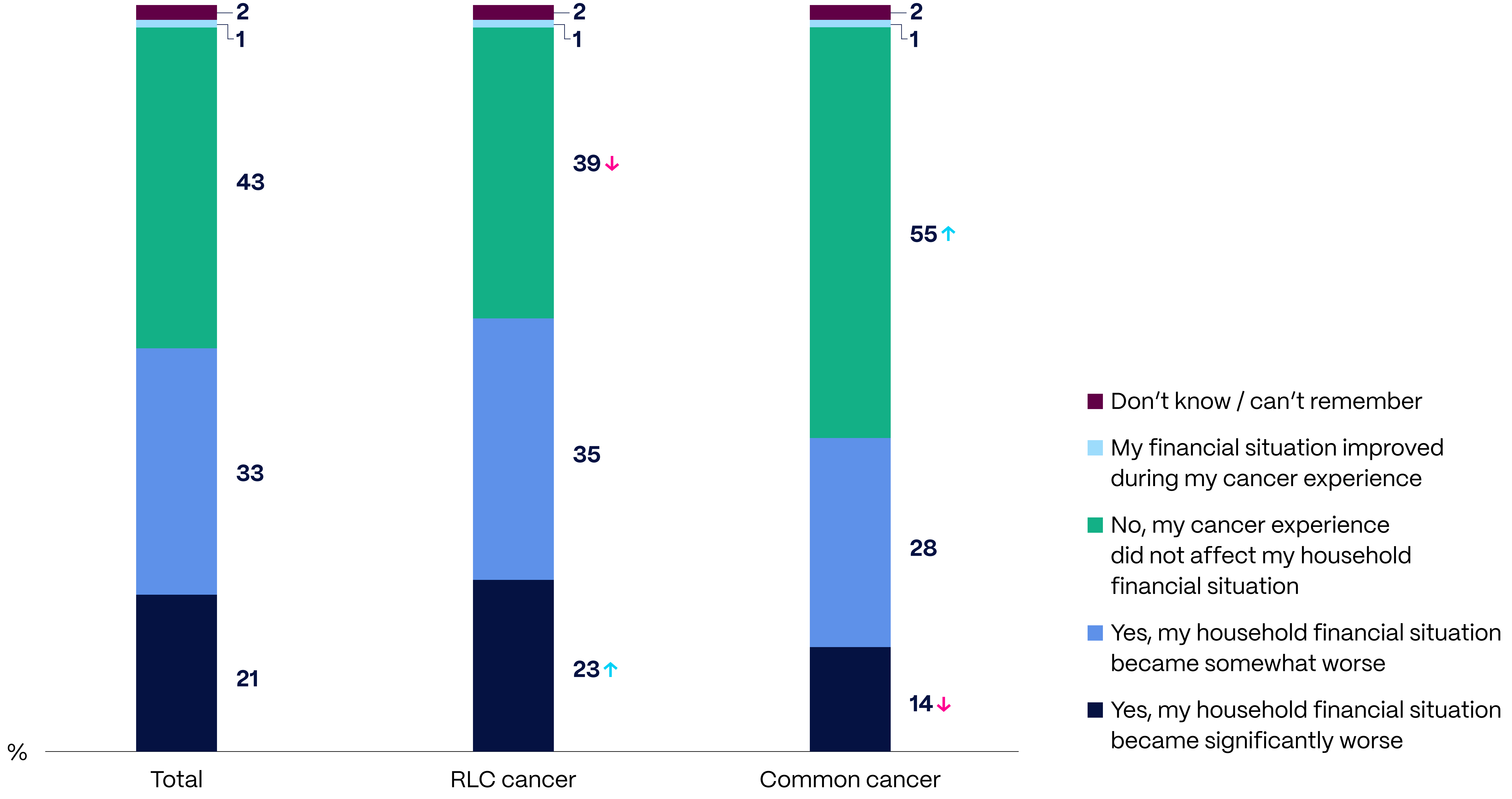
↑↓ Statistically significant difference

> My treatment was VERY expensive (even though we had private health insurance). It was very difficult to make all the payments and took me a long time to get over financially. I had to return to work way earlier than my body needed due to mounting expenses and the treatment and accommodation process being so expensive.

Impact on household financial situation

Responses to:

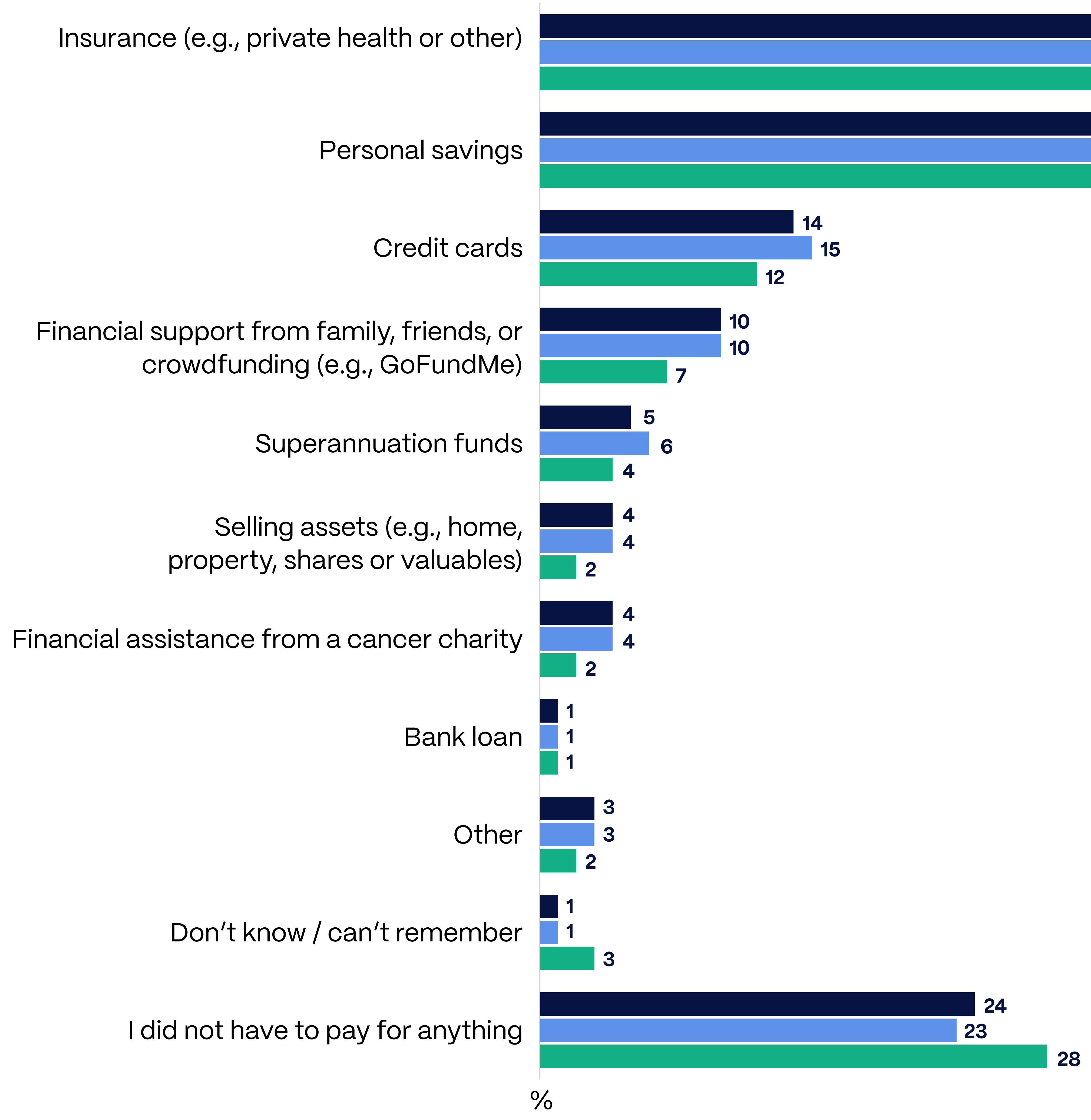
Did your cancer experience result in a change in your household financial situation? **(1,535 responses)**



↑↓ Statistically significant difference

> There is simply not enough financial help or assistance to support anyone who have been directly affected by an unexpected cancer diagnosis. When a person/couple/family is forced to reduce income/s and pay for additional expenses that they didn't have before plus all their usual lifestyle expenses (ie. House loans, electricity, insurances, groceries etc. that's just to name a few) the additional stress of having to think about how to navigate this in no way helps the person's physical and mental health or recovery.

How the costs of cancer treatment were covered



Responses to:

Did you use any of the following to pay for your cancer treatment(s)? Please select all that apply **(1,496 responses)**

■ Total
■ RLC cancer
■ Common cancer

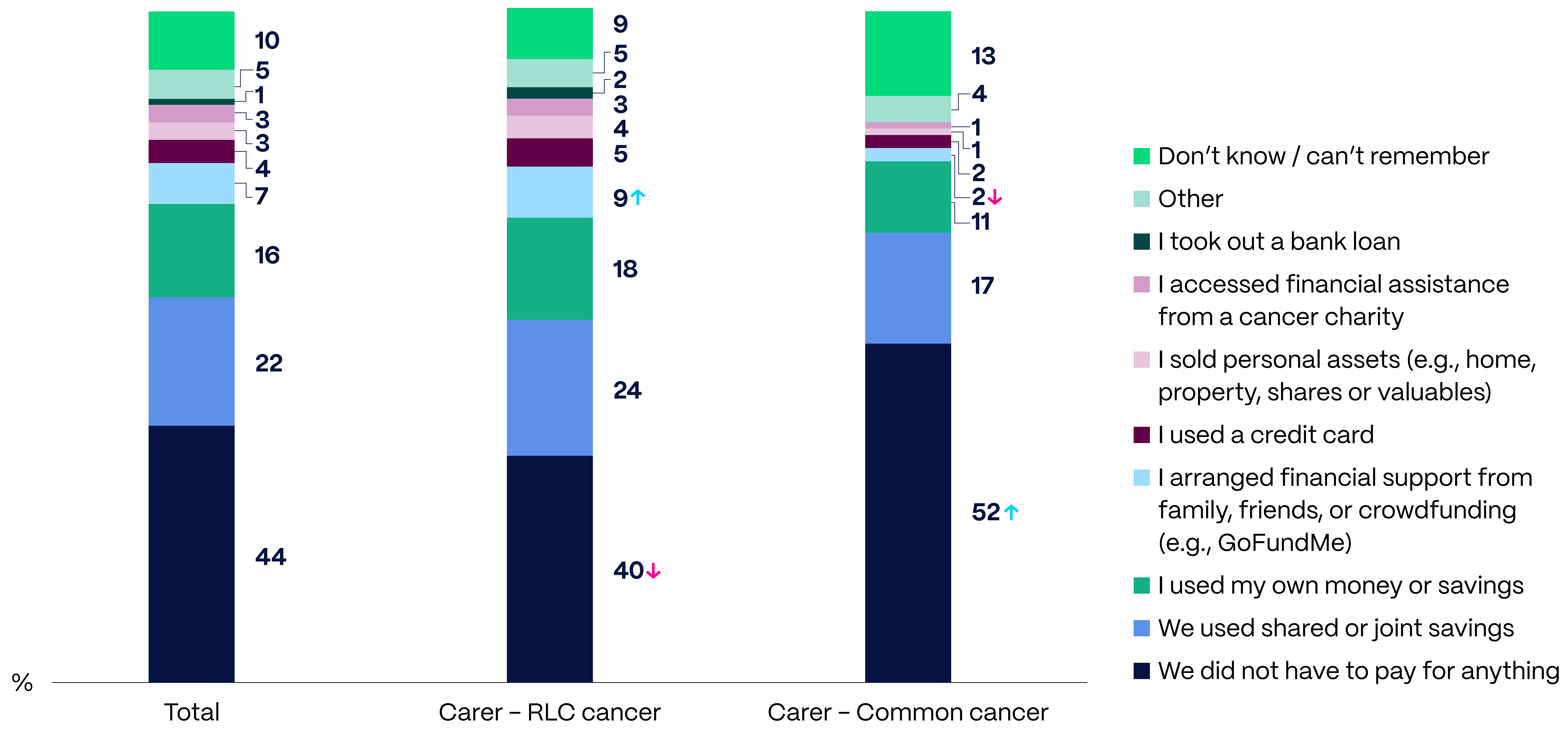
↑↓ Statistically significant difference

> Because of limited treatment options available to me and that the option best suited to my situation was not covered in any way by Medicare and therefore also my Private Health Insurance, I had to cover the cost of my treatment by drawing on Superannuation savings.

Contribution to treatment costs

Responses to:

Did you personally contribute or help arrange payment for the person's cancer treatment(s)? Please select all that apply **(826 responses)**



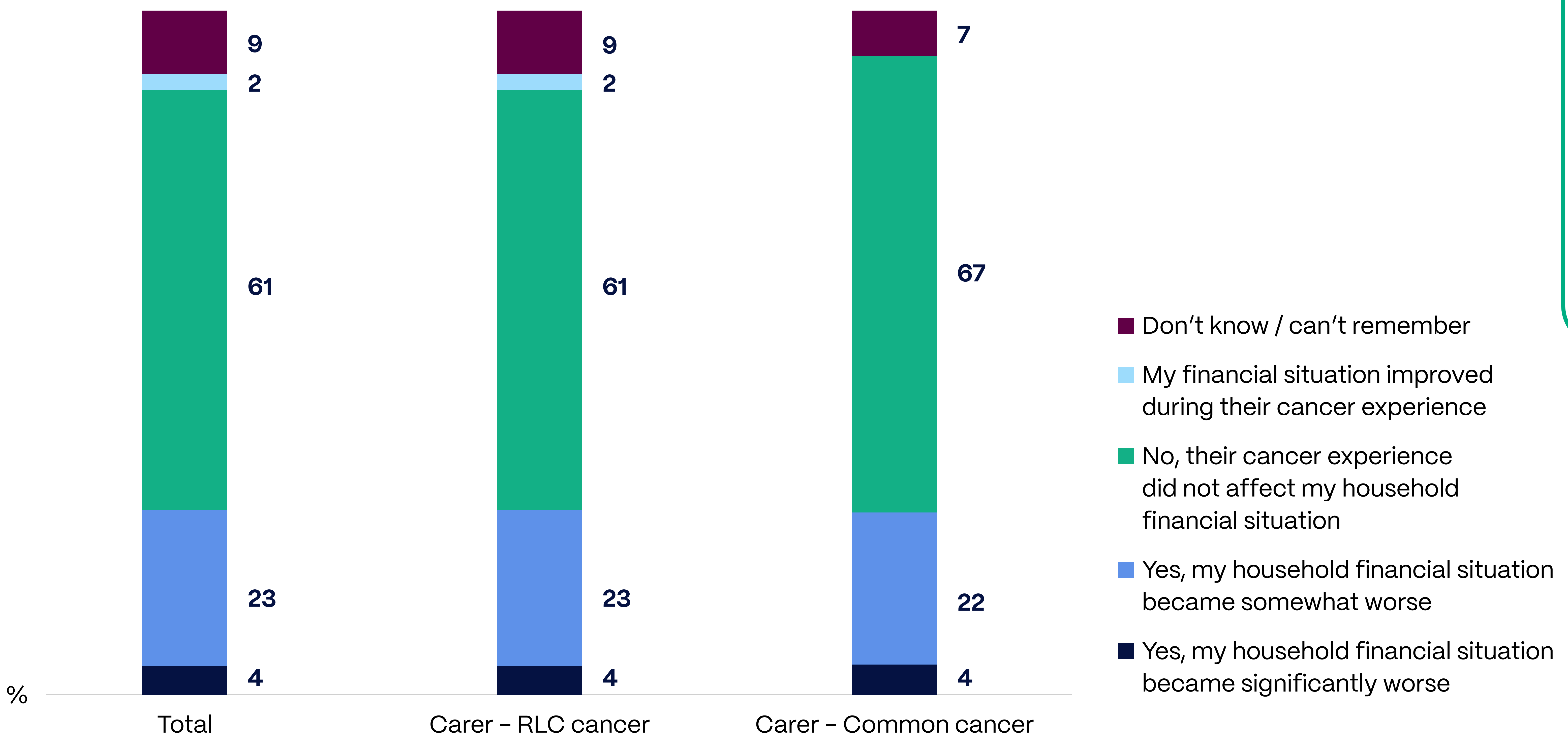
↑↓ Statistically significant difference

> Over two years since diagnosis and we are still impacted. My partner was working full-time and is now unable to work. I had to increase my hours from part-time to full-time. We are not eligible for financial support from Centrelink. We have had to spend our house deposit savings to keep afloat.

Impact on household financial situation

Responses to:

If yes, did their cancer experience result in a change in your individual household financial situation?
(351 responses)



↑↓ Statistically significant difference

> Taking all our savings, forcing us to go bankrupt and having to live my life financially, mentally, emotionally drained as I am working full–time and caring full–time for my husband.

6 Acknowledgements

We thank every person who completed the survey and so generously shared their time and reflections. Your insights are invaluable and will directly inform our own support services and advocacy.

We thank So What? Research for conducting the Cancer Lived Experience Survey on our behalf and for their collaborative approach throughout the project.

We also thank all those who helped to share the survey, including Australian Cancer Nursing and Navigation Program (ACNNP) partner organisations.

- Australian Gynaecological Cancer Foundation
- BEAT Bladder Cancer
- Breast Cancer Network Australia
- Bowel Cancer Australia
- Cancer Council Australia
- Cholangiocarcinoma Foundation
- GenesisCare
- Head and Neck Cancer Australia
- Inherited Cancers Australia
- Icon Cancer Centre
- Leukaemia Foundation
- Lung Foundation Australia
- Liver Foundation
- McGrath Foundation
- Melanoma Patients Australia
- Neuroendocrine Cancer Australia
- Omico
- Ovarian Cancer Australia
- Pancare
- Prostate Cancer Foundation of Australia
- PureProfile
- Ramsay Health Care

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