LYMPHOMA COALITION

GLOBAL PATIENT SURVEY ON LYMPHOMAS AND CLL



BELGIUM

Country Report

2026

Methodology

Questionnaire development

The survey was designed with consultation between Lymphoma Coalition, patient member groups and Picker. The 2026 GPS focused on the following themes:

- Patient and care partner demographics
- Lymphoma or CLL diagnosis
- Health care information
- Care from healthcare professionals
- Treatment
- Barriers to treatment
- Clinical trials
- Side effects of treatment, including fatigue
- Physical health and emotional wellbeing
- Impact on employment
- Understanding of palliative care
- Experience of care partners, friends and family members

The survey was cognitively tested to improve the validity of the questionnaire and respondent experience. Through online interviews, it was tested with four patients living with lymphoma or CLL, and two care partners. Following feedback from interviewees, amendments were made to questions (i.e., inclusion of additional response options). The cognitive interviewees were recruited by LC.

To enhance analysis, demographic questions were included that asked about country of residence, age, biological sex and gender, ethnicity, level of education, employment status and household composition. Care partner respondents were asked demographic questions about themselves, about their relationship to the person they care for, as well as length of time they have been providing care and support.

To improve respondent experience, question routing was used within the survey tool to ensure respondents were only shown questions that were relevant to them. Consequently, some questions were only asked of a subset of respondents.

LC member patient organisations in countries with 100+ responses to the 2024 LC GPS were invited to provide up to five country-specific questions to be included in the survey. These were standardised, translated, and asked only to residents from that country and reported only in the relevant country specific reports. Two subtype-specific member organisations were provided the same opportunity with data for these questions reported only in the cutaneous and Waldenstrom's macroglobulinemia subtype specific reports.

Methodology

Questionnaire development (continued)

The English questions were translated by an approved language translation service using native speakers to translate and proofread. Native-speaking LC members reviewed the final translations, with the exception of Arabic and Swedish. The survey was available online in the following 21 languages:

- Arabic
- Bulgarian
- Chinese (Simplified)
- Danish
- Dutch
- English
- Finnish
- French
- German
- Hebrew
- Hindi
- Italian
- Japanese
- Korean
- Lithuanian
- Portuguese
- Serbian
- Slovak
- Spanish
- Swedish
- Tagalog

Available in 21 languages

Data collection

The survey was hosted on the third-party online survey portal Qualtrics for a period of 10 weeks from 19 January 2026 to 31 March 2026. Respondents were eligible to complete the survey if they were aged 18 years and over and have been diagnosed with lymphoma or CLL, or if they care for somebody who has lymphoma or CLL.

There were no time constraints to answer individual questions. Respondents could complete the survey at their own pace within the 10-week period the survey was live. If a respondent had cookies turned on in their browser settings, they could leave the survey and return at the same place if accessing again on the same device and browser.

LC ensured privacy and confidentiality measures were respected and no participant identifiers were collected. Before starting the survey, respondents were informed of the purpose of the program; that completing the survey was voluntary and any feedback would be kept confidential; and how the results would be used. Considerations were taken to ensure that respondents could be as honest as possible without fear of repercussions.

LC created communication and marketing materials to promote the survey. The engagement and promotion of these materials were shared on the LC website and social media platforms such as X (Twitter), Instagram, and Facebook. Promotion materials were shared with LC member organisations and their networks, healthcare professionals, and scientific and community partners worldwide.

Methodology

Data cleaning and analysis

The data cleaning process included the following steps:

1. Partially completed surveys were removed from the dataset if respondents did not consent to having their responses included unless they fully completed the survey (Q3=2).
2. Responses that were not completed up to Q41 (inclusive) were removed from the dataset.
3. Surveys that were flagged by Qualtrics as potential bots were reviewed prior to data being aggregated.
4. Surveys that were identified as duplicate or fraudulent responses via response patterns were removed from the dataset.

In total, 4052 responses were removed from the dataset.

Data was categorised within Qualtrics before being exported to MS Excel and IBM Statistical Package for the Social Sciences (SPSS) v29 for visualisation into frequency tables and charts. No statistical analysis was performed; any reported differences cannot assume statistical significance.

Cross tabulations were used to investigate patterns in care experiences. Results were only reported where there were 20 or more survey responses (per individual question). For any sub-group analyses (e.g., lymphoma subtype, gender, age group etc.), data captured was not reported for groups with less than 20 responses.

Data presentation

Throughout this report, percentages have been rounded to 0 decimal places. This means that sometimes the total for a single-response question can be just below or above 100%.

Where data is reported as 0%, this may indicate either that no respondents selected that response option (n=0) or that the proportion of respondents was sufficiently small that the percentage has been rounded down to 0%.

Data <5% are not included in stacked horizontal bar charts to enhance readability.

The number of respondents to each question or response is indicated as n=(x), where x equals the number of respondents. Due to question routing within the survey, and because responding to all questions was not mandatory, the number of respondents to each question varies throughout the results.

Please note; analyses of free text comments to open-ended questions have not been included in this report.

Key learnings

Respondent demographics



- Belgium received 206 responses, 93% (n=192) were patients and 7% (n=14) were care partners.
- Respondents were most likely to live in Antwerp (21%, n=43), Flemish Brabant (15%, n=30) and East Flanders (14%, n=29).
- Respondents were most likely to be aged 66 to 75 (34%, n=60).
- Fifty-three percent (n=102) of patients were female, while 47% (n=90) were male.
- The most common subtypes were CLL / SLL (26%, n=54), Follicular (15%, n=31) and Diffuse Large B-Cell (DLBCL) (14%, n=28).
- Thirty-six percent (n=74) were in remission (with or without monitoring visits), 16% (n=32) were receiving treatment (including continual long-term treatment) and 15% (n=30) said treatment is not yet needed, and they were in active monitoring or watch and wait.

Diagnosis and symptoms



- Fatigue was the most prevalent symptom (64%, n=132).
- Pain had the greatest impact amongst the symptoms queried, with 77% (n=20) reporting a severe or very severe impact.
- Forty-four percent (n=64) were diagnosed within 1 month of first seeking medical attention.
- More than one-third (36%, n=75) of patients received one or more incorrect diagnoses before their lymphoma or CLL diagnosis was confirmed.

Shared decision-making



- More than two-thirds (68%, n=140) of respondents felt well or very well informed about the processes and stages of care as it relates to the lymphoma or CLL diagnosis.
- Seventy-seven percent (n=150) of respondents wanted to be involved in making healthcare decisions, while 22% (n=44) wanted decisions to be made by their doctor alone.
- Fifty-four percent (n=77) of patients were definitely involved as much as they wanted to be in decisions about their care and treatment, while 34% (n=48) felt involved to some extent and 1% (n=2) did not want to be involved.
- Forty-nine percent (n=58) said a joint decision was made between the doctor and the patient about which treatment was received for their most recent treatment.

Key learnings

Side effects and fatigue



- Fatigue was the most prevalent side effect from treatment (84%, n=96).
- Hair loss or thinning had the greatest severity amongst side effects queried, with 74% (n=34) reporting a severe or very severe impact.
- The majority (96%, n=24) of patients treated more than 5 years ago are still experiencing side effects they attribute to treatment.
- Of patients who experienced fatigue, 7% (n=10) had not discussed their fatigue with their doctor or other members of their medical team and 28% (n=38) were not provided any fatigue related information or support.

Wellbeing



- Symptoms and side effects were reported to have had the greatest negative impact on the patient's everyday activities that people their age can usually do (77%, n=105).
- At their last appointment, 78% (n=97) of patients reported their doctor asked questions that were relevant to their quality of life or wellbeing.
- Eighty-three percent (n=123) of patients experienced a negative emotional impact during the last 6 months as a result of the lymphoma or CLL diagnosis. Patients were most likely to experience anxiety / nervousness (49%, n=72).
- Conversely, 49% (n=72) of patients experienced a positive emotional impact during the last 6 months as a result of the lymphoma or CLL diagnosis. Patients were most likely to experience healthier lifestyle choices (eat better, smoke less, reduced alcohol consumption) (26%, n=38).

Role of nurses in lymphoma or CLL care



- Approximately one third (35%, n=40) said their nurse specialist is definitely involved as much as they want them to be in guiding their decision-making and during treatment. Thirty-eight percent (n=44) do not have a nurse specialist.
- Half (50%, n=57) of patients would be willing to have a registered nurse visit their home to take a blood sample before or after their treatment, so they don't need to travel to the hospital or clinic.

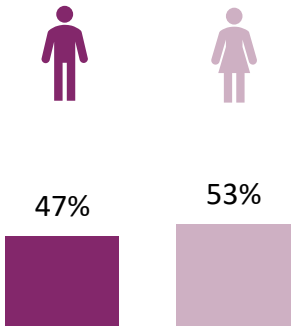
About survey respondents

206

Total respondents

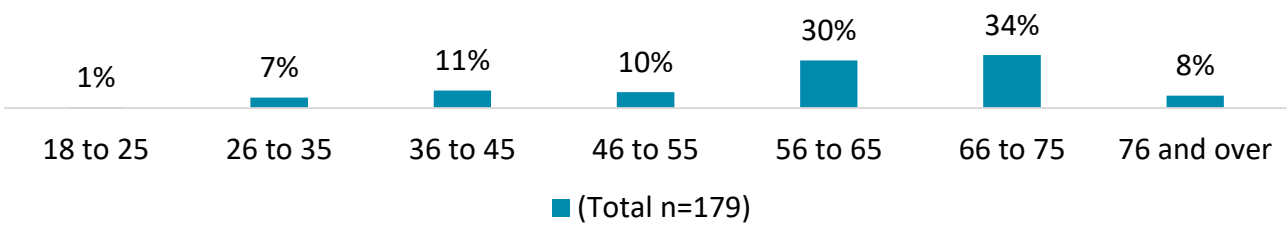
192 total patient respondents

14 total care partner respondents



Patient biological sex (n=192)

Age



Education level

- 1% (n=3) Primary (Elementary) or less
- 22% (n=45) Secondary (High-school)
- 6% (n=13) Trade school
- 50% (n=103) Post-Secondary (College / University)
- 17% (n=34) Postgraduate (Master's, PhD)

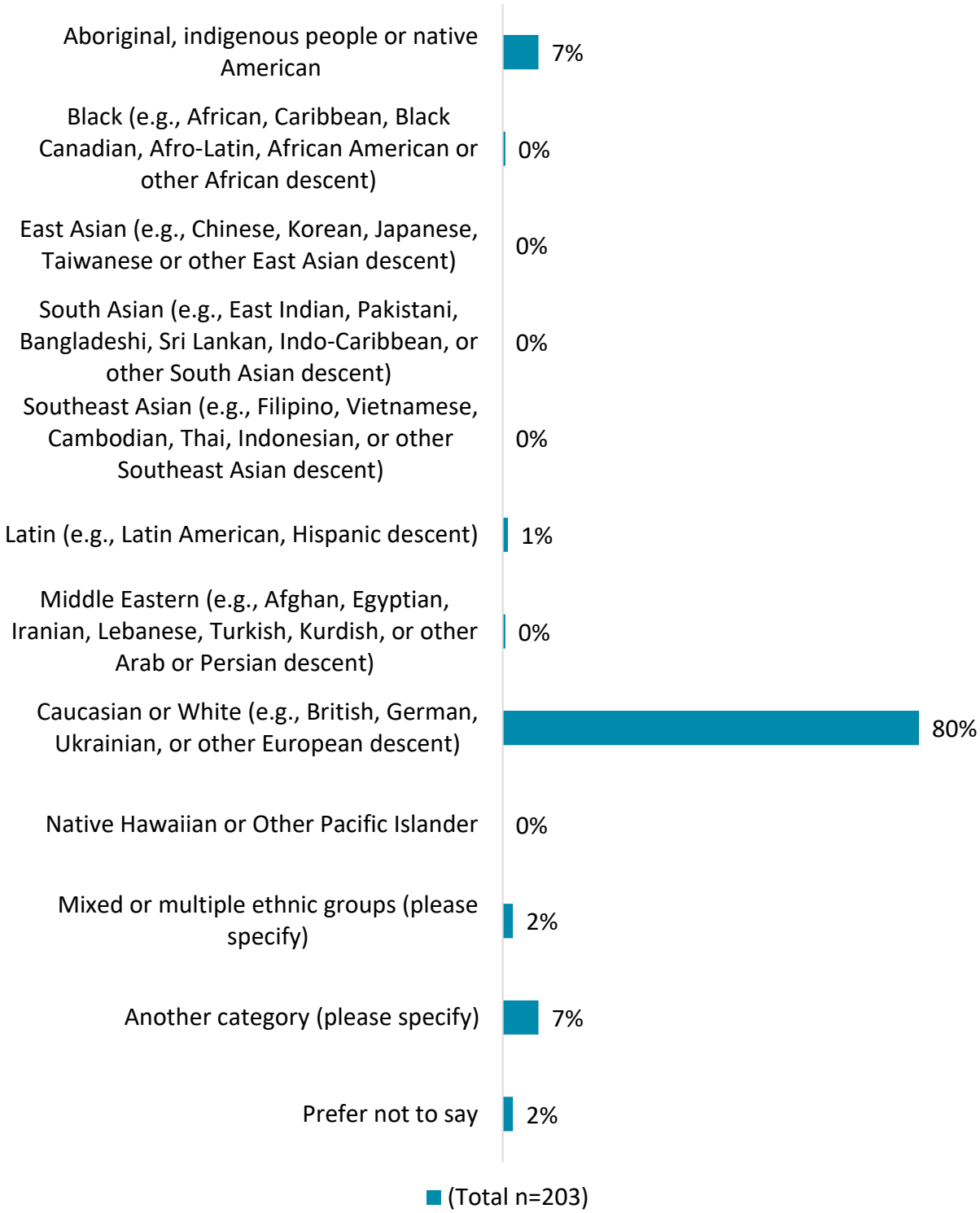
Household composition

- 15% (n=31) live alone
- 76% (n=157) live with their spouse or partner
- 12% (n=25) live with adult children (aged 18 and over)
- 13% (n=27) live with young children or teenagers (up to age 17)
- 3% (n=7) live with their parents
- 1% (n=2) live with other adults

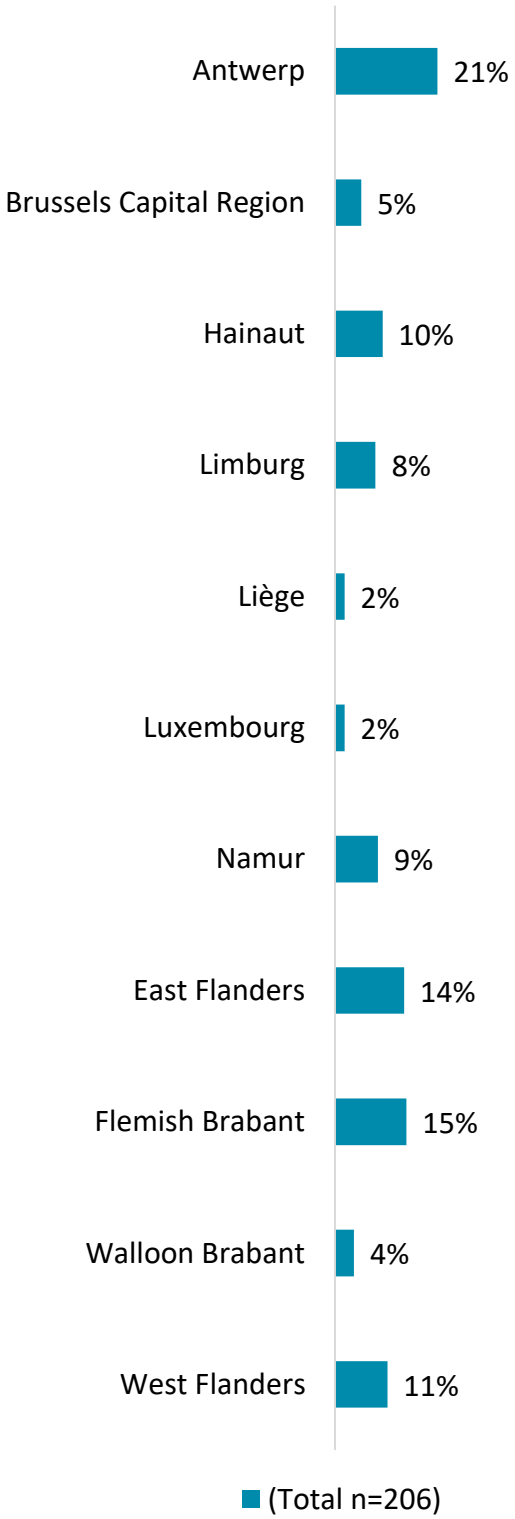
Residential setting

- 26% (n=54) City / urban area
- 35% (n=72) Suburbs or residential area
- 39% (n=80) Rural area

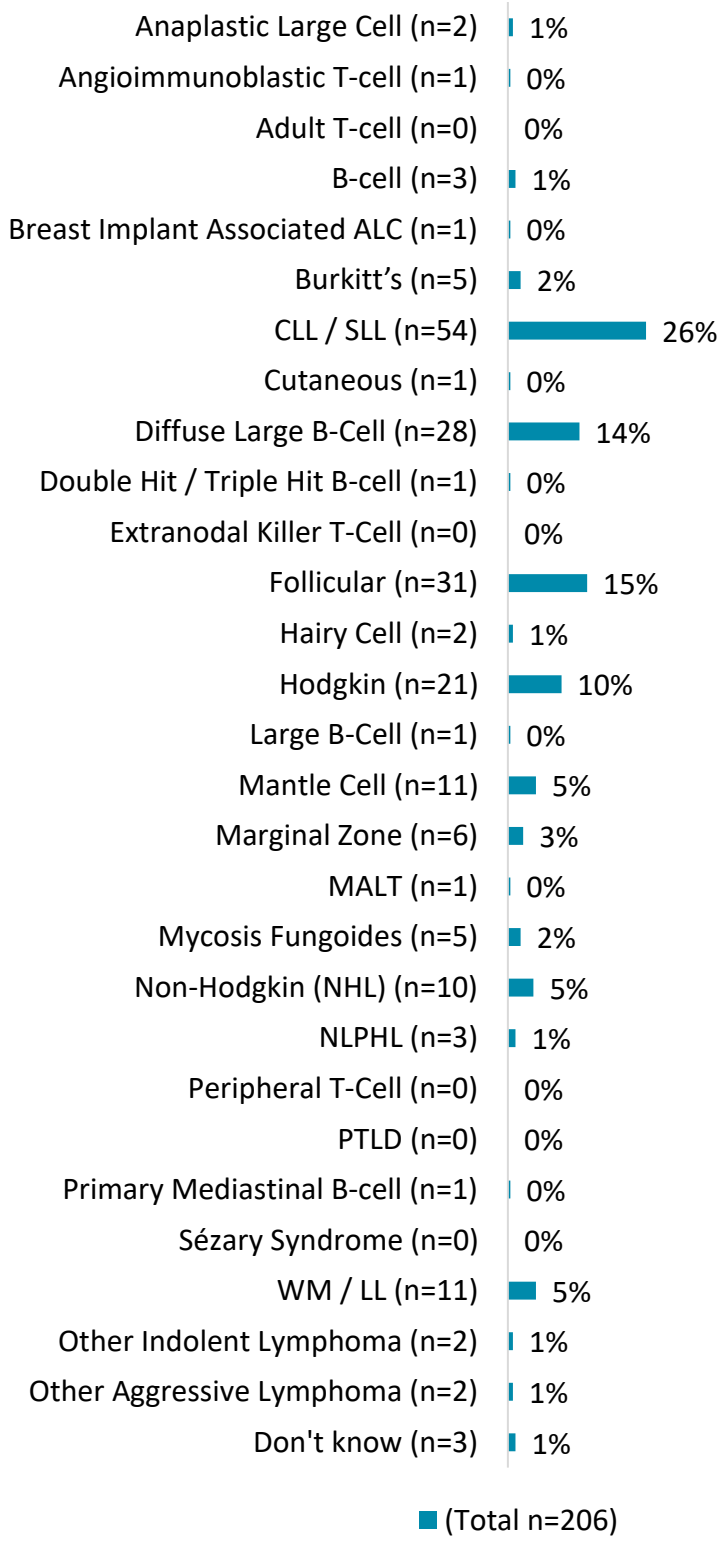
Ethnicity of survey respondents



Province or territory



Subtype



Breast Implant Associated ALC is Breast Implant Associated Anaplastic Large Cell; CLL is Chronic Lymphocytic Leukaemia; SLL is Small Lymphocytic Lymphoma; MALT is Mucosa-Associated Lymphoid Tissue; NLPHL is Nodular Lymphocyte Predominant Hodgkin; PLTD is Post Transplant Lymphoproliferative Disorder; WM is Waldenstrom's Macroglobulinemia; LL is Lymphoplasmacytic Lymphoma

Lymphoma information

Current status of disease



- 1% (n=2) Newly diagnosed and not yet sure of my treatment options
- **15% (n=30) Treatment is not yet needed (active monitoring or watch and wait)**
- 9% (n=18) Completed treatment and now back in active monitoring (watch and wait)
- **16% (n=32) Receiving treatment (including continual long-term treatment)**
- 12% (n=24) Finished treatment and on maintenance therapy
- 1% (n=3) Finished or stopped treatment but am not in remission (including stopping due to failure to improve / negative side effects)
- **36% (n=74) In remission (with or without monitoring visits)**
- 1% (n=2) Disease did not respond to treatment (called refractory) or has since recurred (called relapse) but am not currently being treated
- 0% (n=1) Palliative care only
- 10% (n=20) Other
- 0% (n=0) I am completing the survey on behalf of someone who passed away

Relapse status

14% (n=22) of patients had relapsed once, 9% (n=14) had relapsed more than once, 72% (n=110) had not relapsed, and 5% (n=7) didn't know or couldn't remember.

Length of time from diagnosis

- 6% (n=12) Less than 6 months ago
- 5% (n=11) 6 months to less than 1 year ago
- 14% (n=28) 1 year to less than 2 years ago
- 28% (n=58) 2 years to less than 5 years ago
- 29% (n=60) 5 years to less than 10 years ago
- 10% (n=20) 10 years to less than 15 years ago
- 3% (n=6) 15 years to less than 20 years ago
- 5% (n=11) More than 20 years ago
- 0% (n=0) Don't know / can't remember

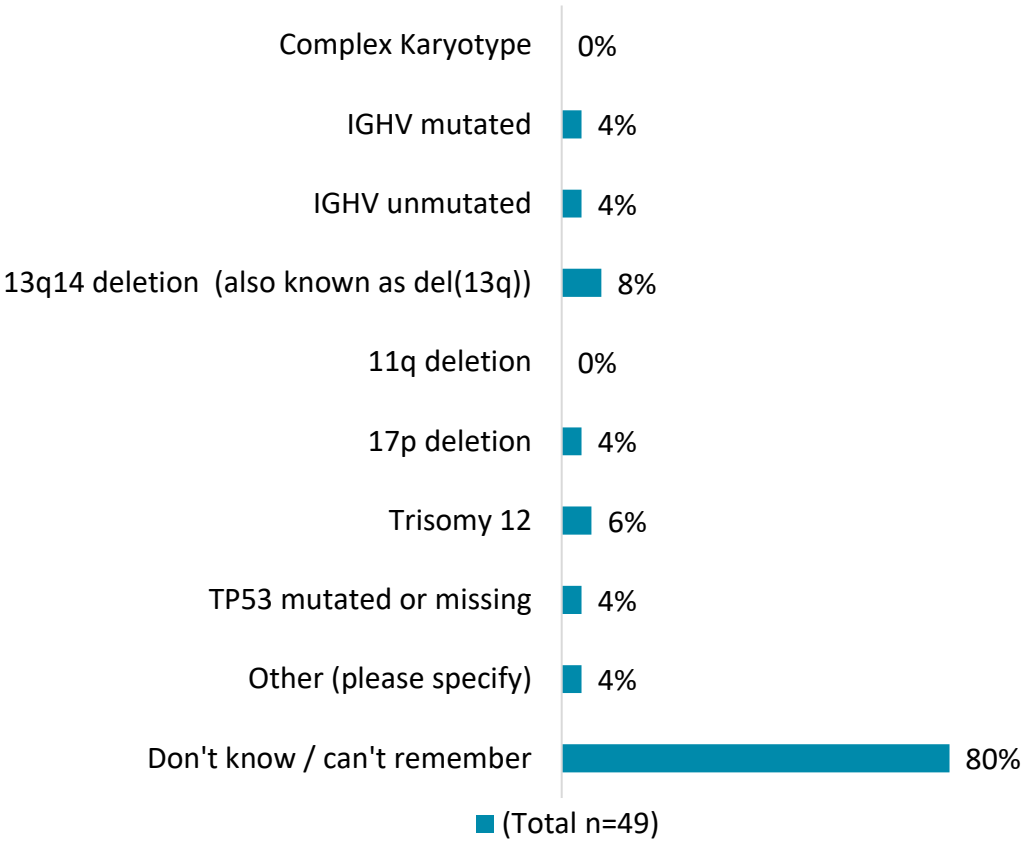
Stage

10% (n=13) Stage I
17% (n=23) Stage II
10% (n=13) Stage III
50% (n=67) Stage IV
14% (n=19) Don't know / can't remember



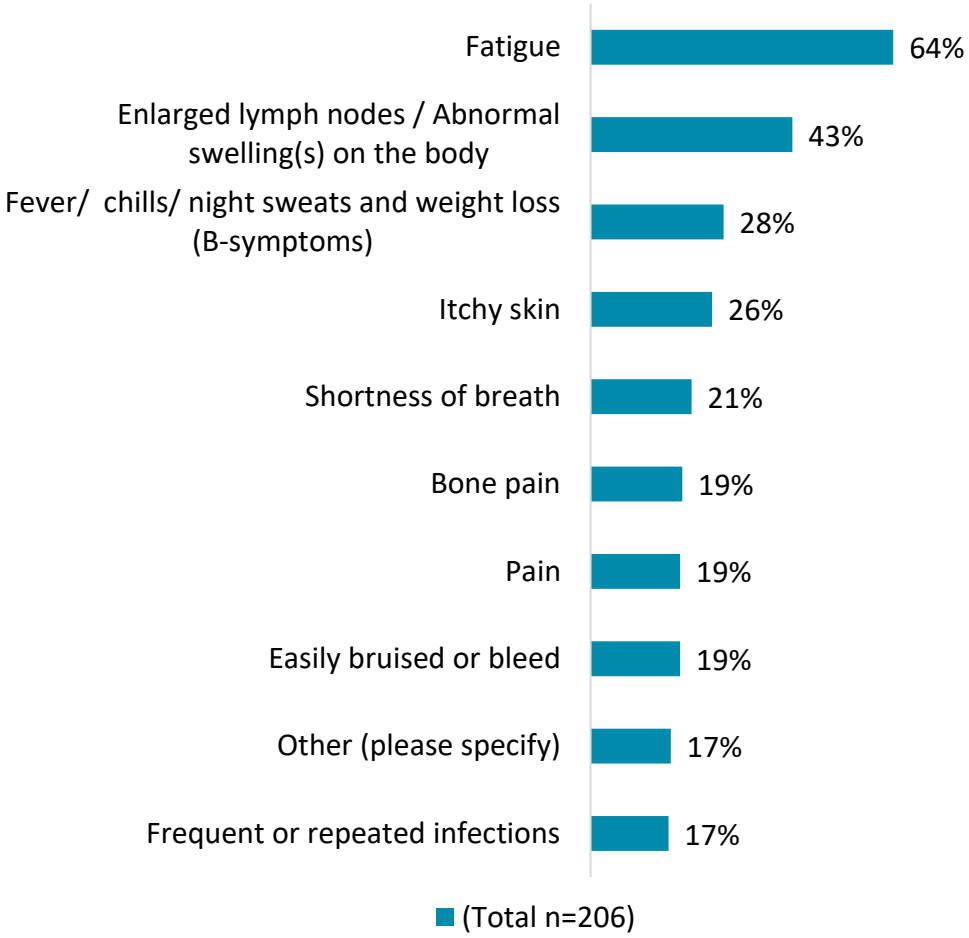
Testing for gene mutation status

Patients with CLL were asked if they knew if the following applied to their disease

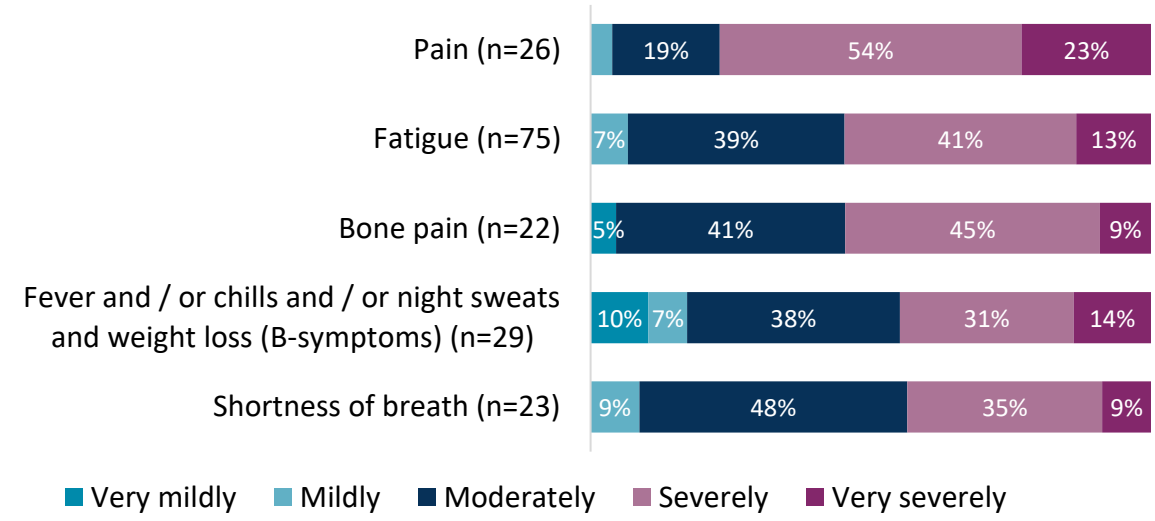


Symptoms

Top ten most commonly experienced symptoms



Top five most severely experienced symptoms



Prior to diagnosis

Length of time to seek medical attention from experiencing symptoms



24% (n=45) Less than 1 month
21% (n=39) 1 month to less than 3 months
10% (n=18) 3 months to less than 6 months
8% (n=15) 6 months to less than 12 months
15% (n=28) 12 months or more
10% (n=18) Did not seek medical care for their symptoms
12% (n=22) Don't know / can't remember

Length of time to diagnosis from first seeking medical attention



44% (n=64) Less than 1 month
18% (n=26) 1 month to less than 3 months
16% (n=23) 3 months to less than 6 months
5% (n=7) 6 months to less than 12 months
15% (n=22) 12 months or more
2% (n=3) Don't know / can't remember

Top three symptoms prompting patients to seek medical advice:

1. Fatigue (37%, n=44)

2. Enlarged lymph nodes / Abnormal swelling(s) on the body (30%, n=35)

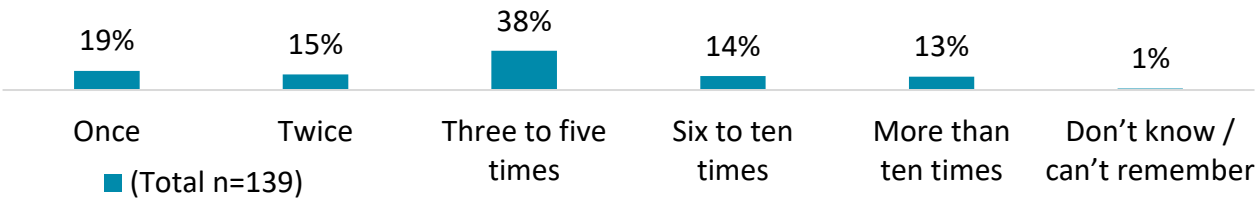
3. Pain (18%, n=21)

Top two factors that led to diagnosis without seeking medical advice for symptoms:

1. Blood test showed abnormal results (32%, n=12)

2. Doctor visit about another health condition (29%, n=11)

Number of visits to doctors about symptoms before receiving diagnosis



Receiving a diagnosis

Receiving the correct diagnosis



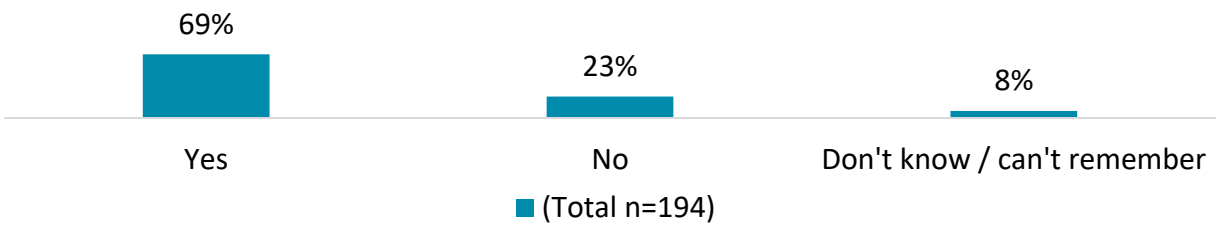
- 63% (n=129) of patients received a correct first diagnosis
- 19% (n=39) first diagnosis was incorrect, and the second diagnosis was correct
- 17% (n=36) received multiple incorrect diagnoses before the correct one

Receiving treatment, therapy or medication for an incorrect diagnosis



- 40% (n=29) received treatment, therapy or medication for the incorrect diagnosis and it did not help
- 10% (n=7) received treatment, therapy or medication for the incorrect diagnosis but it did help
- 47% (n=34) did not receive treatment, therapy or medication for any of the incorrect diagnoses

Proportion of patients who were told their lymphoma subtype or that they had CLL when first diagnosed



Explanation of diagnostic tests

- 62% (n=127) of patients said diagnostic tests and results were explained to them in a way that they could completely understand
- 29% (n=60) said they could understand to some extent
- 3% (n=7) did not understand the explanation they received about diagnostic tests and results

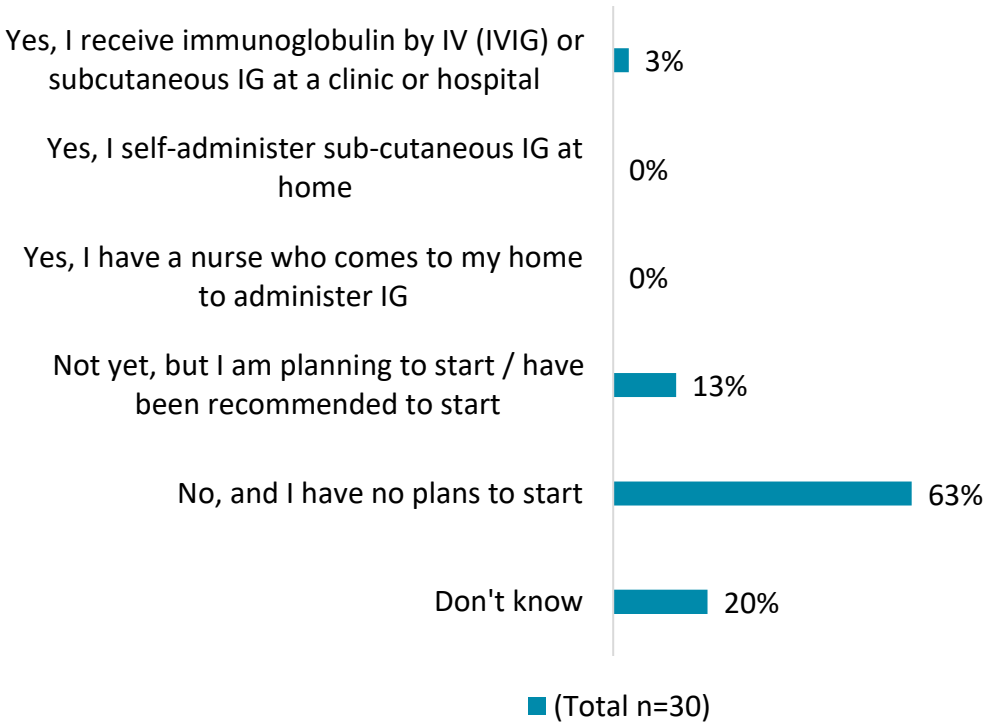
Active monitoring and immunoglobulin replacement therapy

Length of time in active monitoring



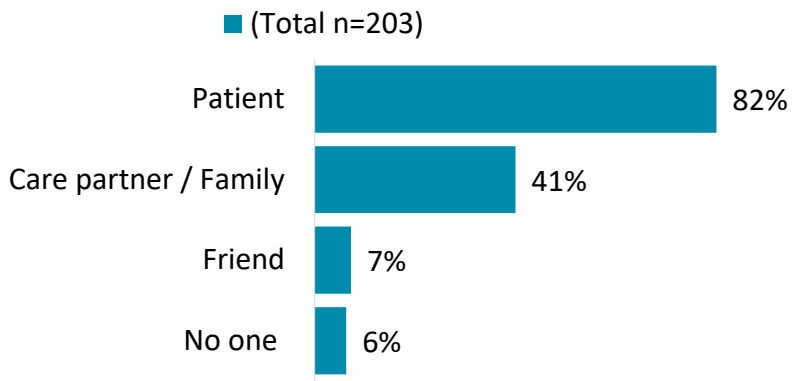
- 48% (n=23) Less than 2 years
- 27% (n=13) 2 years to less than 5 years
- 25% (n=12) 5 years or more

Receipt of immunoglobulin replacement therapy



Healthcare information

Who looked for information about the disease and potential treatments?



Top three preferred information sources

1. Conversations with my / the patient's healthcare staff (76%, n=155)
2. Booklets / written information (prints or digitals) / medical journals (56%, n=115)
3. Websites (47%, n=97)

Top information source

Respondents selected **conversations with my / the patient's healthcare staff** as their top information source (67%, n=119)

Healthcare information

When asked how informed they feel about processes and stages of their health care as it relates to their / the patient's lymphoma / CLL diagnosis (e.g., diagnosis, treatment, resources available for support and self-care)…

68% (n=140) of respondents felt well or very well informed



6% (n=5) of respondents **have not** used patient organisation information and support in the last 12 months.



Top five most accessed patient organisation information and support in the last 12 months

1. Conferences / patient meetings / webinars / symposium (58%, n=52)
2. Booklets or other written information, such as newsletters (54%, n=49)
3. Contact with other patients and / or care partners (36%, n=32)
4. Websites (including videos) (31%, n=28)
5. Social media channels (Facebook, X (Twitter), LinkedIn, Instagram) (24%, n=22)

Preferred websites and social media platforms

Top five preferred websites for lymphoma or CLL information

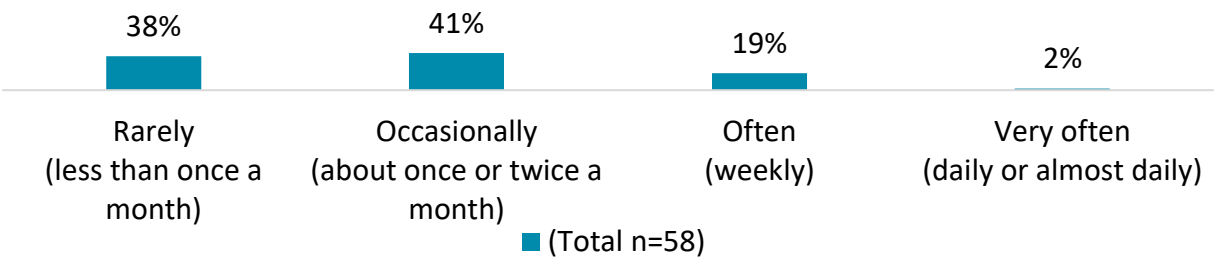
1. Search engines (e.g., Google, Bing, etc.) (87%, n=84)
2. Patient organisation websites (60%, n=58)
3. Hospital websites (55%, n=53)
4. Public health websites (47%, n=46)
5. Academic institution websites (e.g., university websites) (34%, n=33)

Top five ranked social media platforms used to access information on lymphoma or CLL

1. Facebook (66%, n=21)
2. YouTube (34%, n=11)
3. Instagram (16%, n=5)
4. Other (please specify) (13%, n=4)
5. X (Twitter) and / or Threads (3%, n=1)

Use of Artificial intelligence tools like ChatGPT, CoPilot or Gemini

Respondents who indicated they used AI tools to get information about lymphoma or CLL were asked how often they use them



Top five domains respondents used AI tools to support understanding:

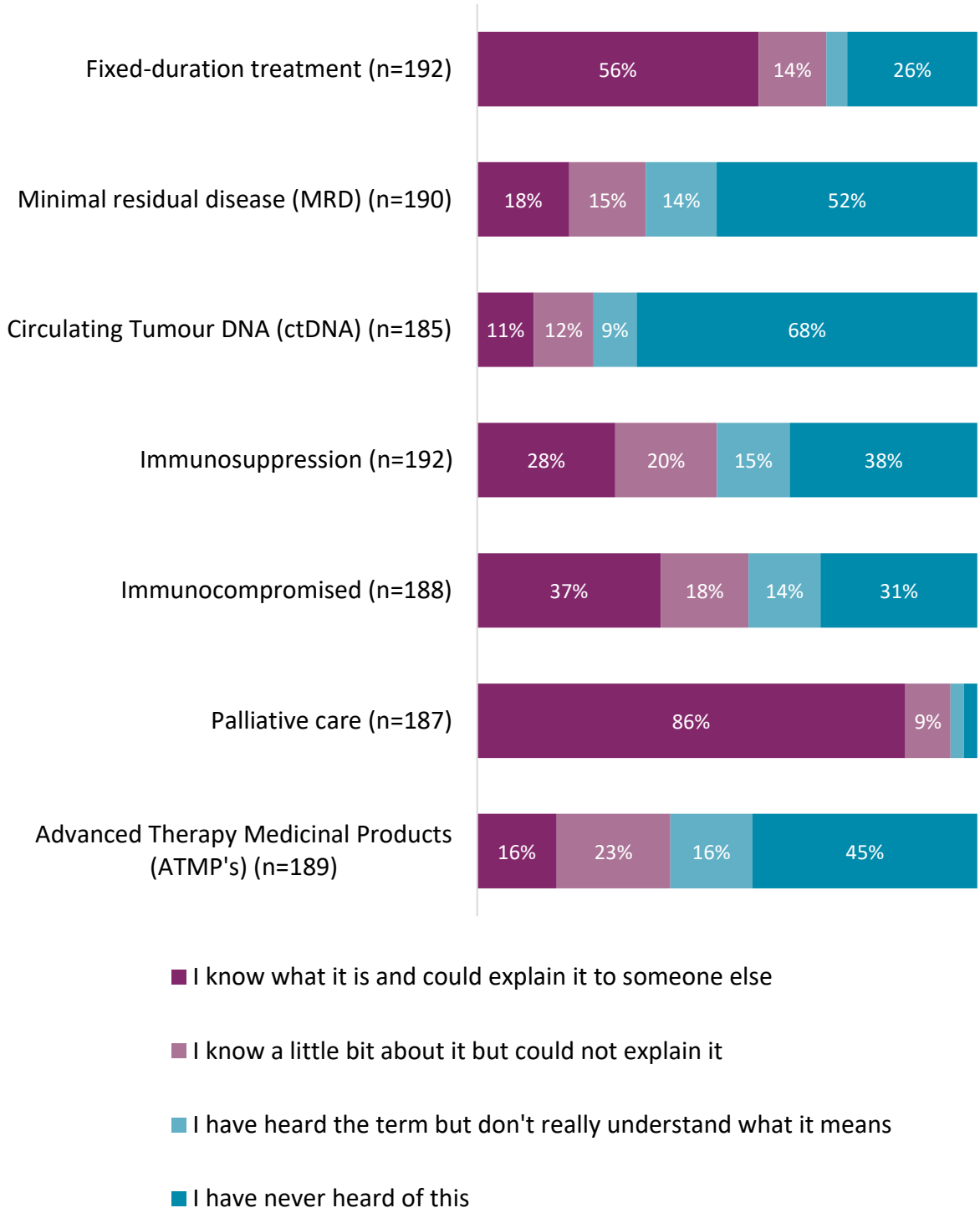
1. General information on lymphoma or CLL (72%, n=41)
2. Side effects caused by treatment (61%, n=35)
3. Treatments (60%, n=34)
4. Signs or symptoms of lymphoma or CLL (54%, n=31)
5. Interpret medical reports (including diagnostic tests) (47%, n=27)

When asked about using AI to increase understanding of lymphoma or CLL…

- ✓ 80% (n=45) agreed AI answers their questions in a satisfactory way
- ✓ 43% (n=24) agreed they trust what information is generated by AI
- ✓ 45% (n=25) agreed they confirm what they learn from AI with other patients or care partners
- ✓ 64% (n=35) agreed they confirm what they learn from AI with their / the patient's healthcare team
- ✓ 65% (n=35) agreed they confirm what they learn from AI with other sources of information
- ✓ 28% (n=15) agreed they share what they learn from AI with others
- ✓ 4% (n=2) agreed they / the patient's healthcare team recommends they use AI
- ✓ 14% (n=8) agreed when they have a question about their / the patient's health, they prefer to ask AI rather than their / their healthcare team

Understanding of medical terms

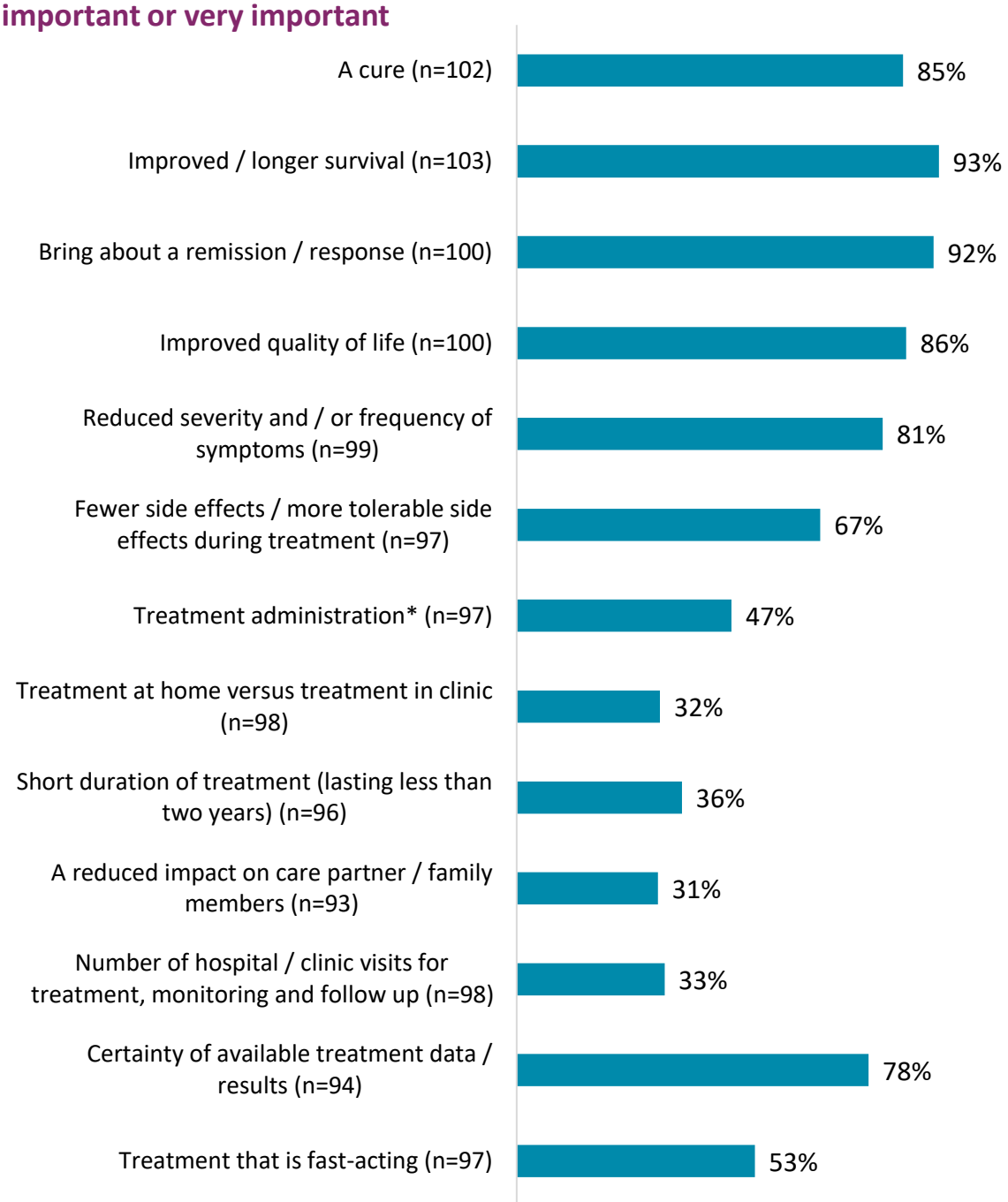
Respondents were asked how they would describe their understanding of the following terms.



Important aspects of most recent treatment

The most important aspect of treatment for patients was **improved / longer survival** (93%, n=96)

Proportion of patients rating aspects of their most recent treatment as important or very important



* e.g., Treatment administration (pill, through an IV, subcutaneous or under the skin, etc)

Involvement in care

Involvement in decision-making

- 54% (n=77) of patients were definitely involved as much as they wanted to be in decisions about their care and treatment, while 34% (n=48) felt involved to some extent
- 10% (n=15) would like to be more involved
- 1% (n=2) did not want to be involved

When asked who they would ultimately like to make healthcare decisions, the following proportion of patients preferred decisions to be made by:

15% (n=29) Patient alone
22% (n=44) Doctor alone
1% (n=1) Care partner alone
48% (n=95) Patient and doctor together
2% (n=4) Patient and care partner together
0% (n=0) Doctor and care partner together
11% (n=21) Patient, doctor and care partner together
3% (n=5) Other

22% (n=26) of patients were given more than one treatment option

84% (n=26) of patients reported they had an adequate amount of time to think about their treatment options before a decision was made about their current or most recent treatment

Involvement in care



When asked to think about their experience with lymphoma or CLL…

- ✓ 84% (n=116) agreed they have a treatment plan, and they understand it
- ✓ 89% (n=125) agreed they have confidence in their treatment plan and the doctor who is coordinating their care
- ✓ 67% (n=94) agreed their lifestyle and favourite activities were discussed with their doctor to maintain their quality of life as much as possible
- ✓ 84% (n=117) agreed they understand that past treatment may impact their choices for future treatment, if the disease comes back or progresses



When asked to think about doctor encouragement regarding participation in decision-making in the last 12 months…

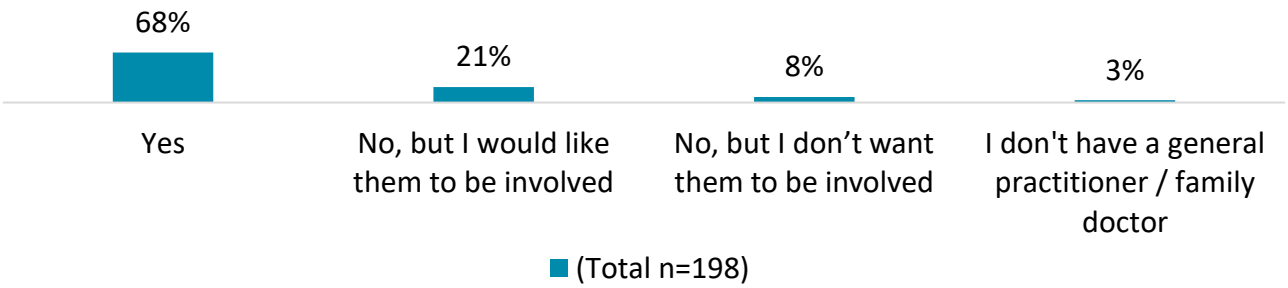
- ✓ 43% (n=61) said their doctor always encourages them to ask questions
- ✓ 52% (n=75) said their doctor always ensures they understand answers to their questions
- ✓ 69% (n=99) said their doctor always allows them to express themself without interrupting
- ✓ 75% (n=108) said their doctor always talks to them in a kind and sensitive way
- ✓ 72% (n=103) said their doctor always listens to them carefully

The following are the top six behaviours respondents said that it was important or very important that their doctor…

- ✓ Explains my treatment choices in an understandable way, including potential side effects and expected outcomes (99%, n=142)
- ✓ Tell the full truth about the diagnosis or test results when breaking difficult news (99%, n=141)
- ✓ Ask how much I want to be involved in decisions about my care and treatment (97%, n=138)
- ✓ Provide information or support so that I can confidently manage my lymphoma or CLL (e.g. cancer care plan, survivorship care plan) (96%, n=137)
- ✓ Understand what is important to me and / or my care partner when managing my care (96%, n=136)
- ✓ Help me understand the cost implications of treatment options (71%, n=100)

Involvement of general practitioner / family doctor

Is your general practitioner / family doctor involved as much as you want them to be in your follow-up care for your lymphoma or CLL?



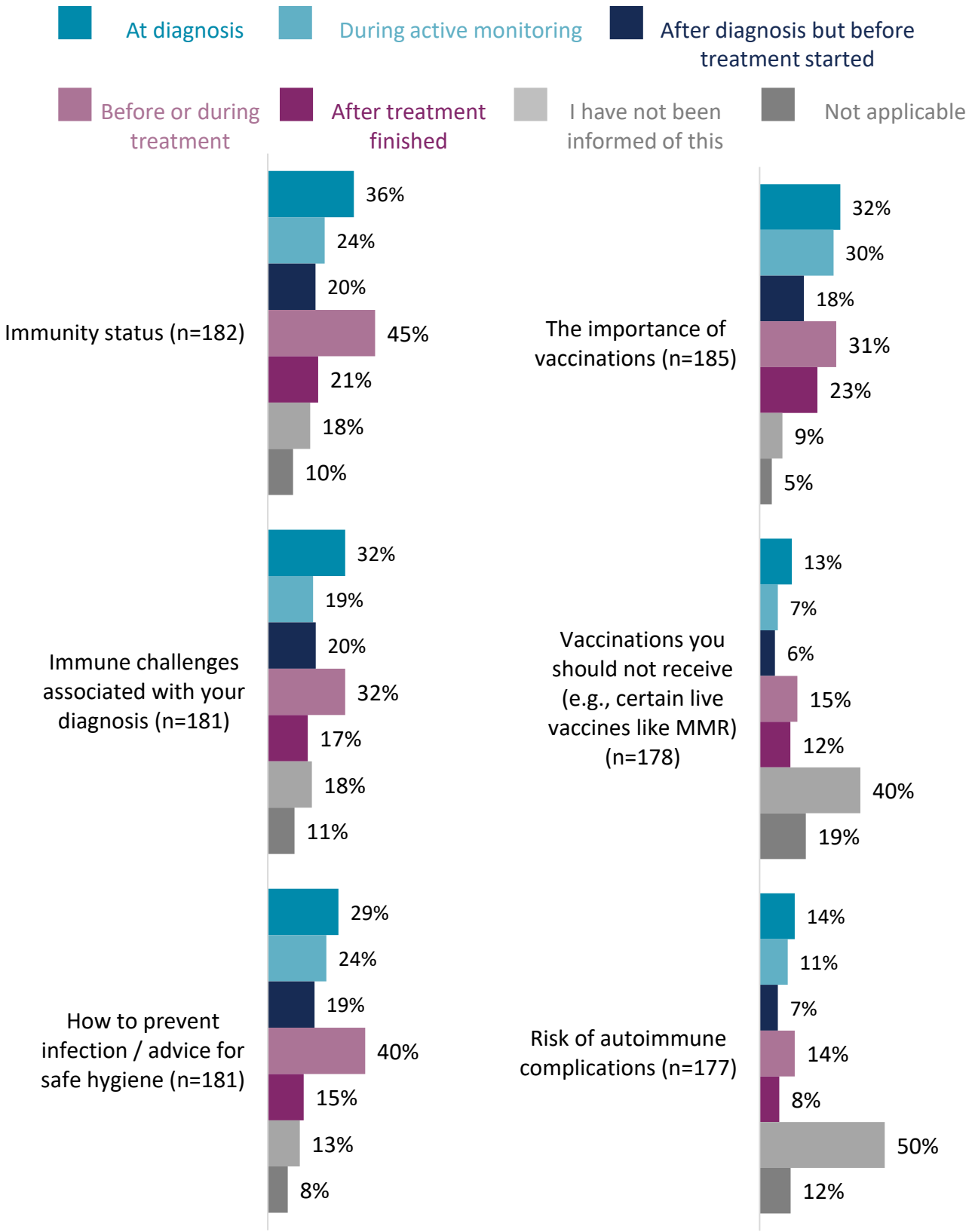


12% (n=23) reported that they have experienced difficulties in receiving support or care from their general practitioner / family doctor during their follow-up care for their lymphoma or CLL

When asked during which stage of care their general practitioner / family doctor would be most helpful in the follow-up and management of their lymphoma or CLL…

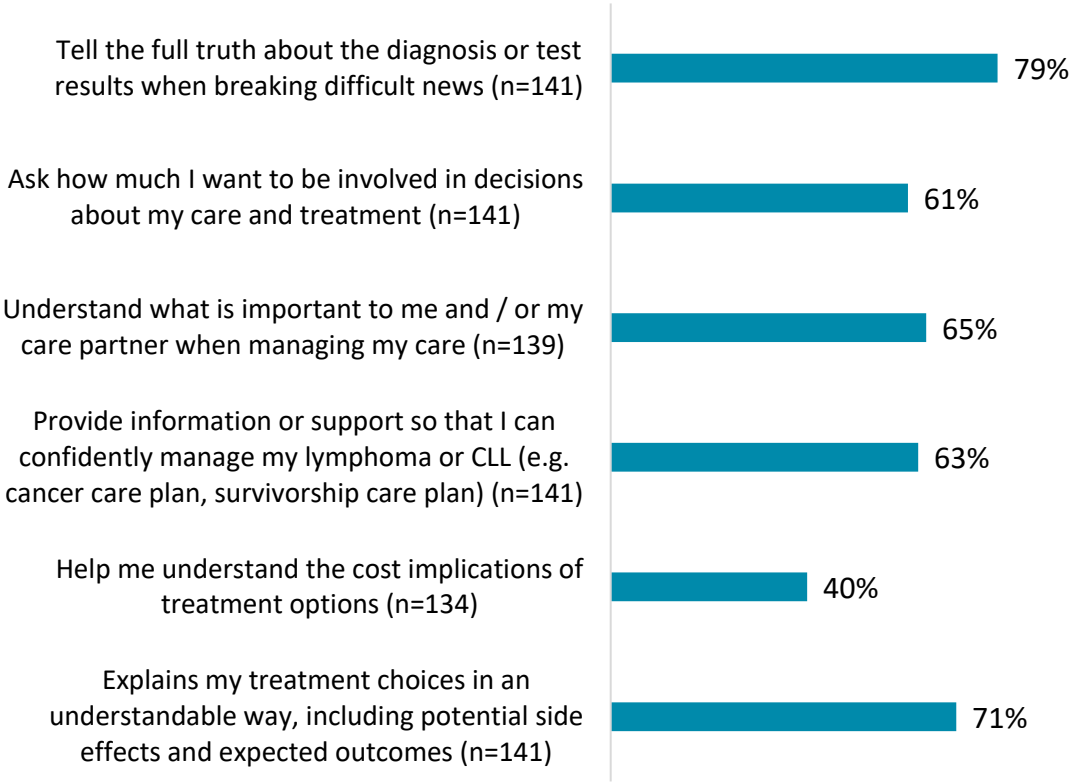
- ✓ 7% (n=13) said only during active monitoring (watch and wait)
- ✓ 2% (n=3) said only during treatment
- ✓ 10% (n=17) said only during follow up
- ✓ 67% (n=116) said at all stages of care

Proportion of respondents who received immune related information from healthcare team at each stage of care

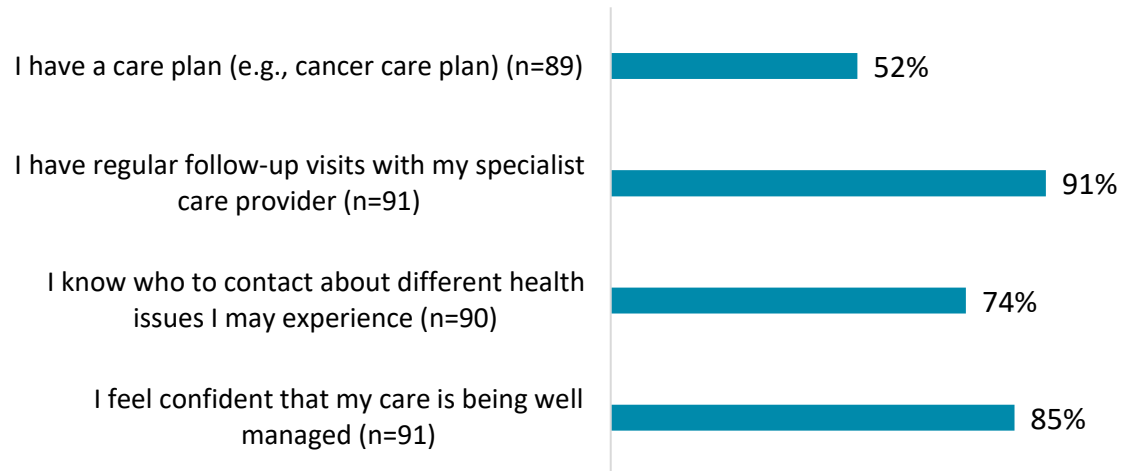


Relationship with primary doctor and care plans

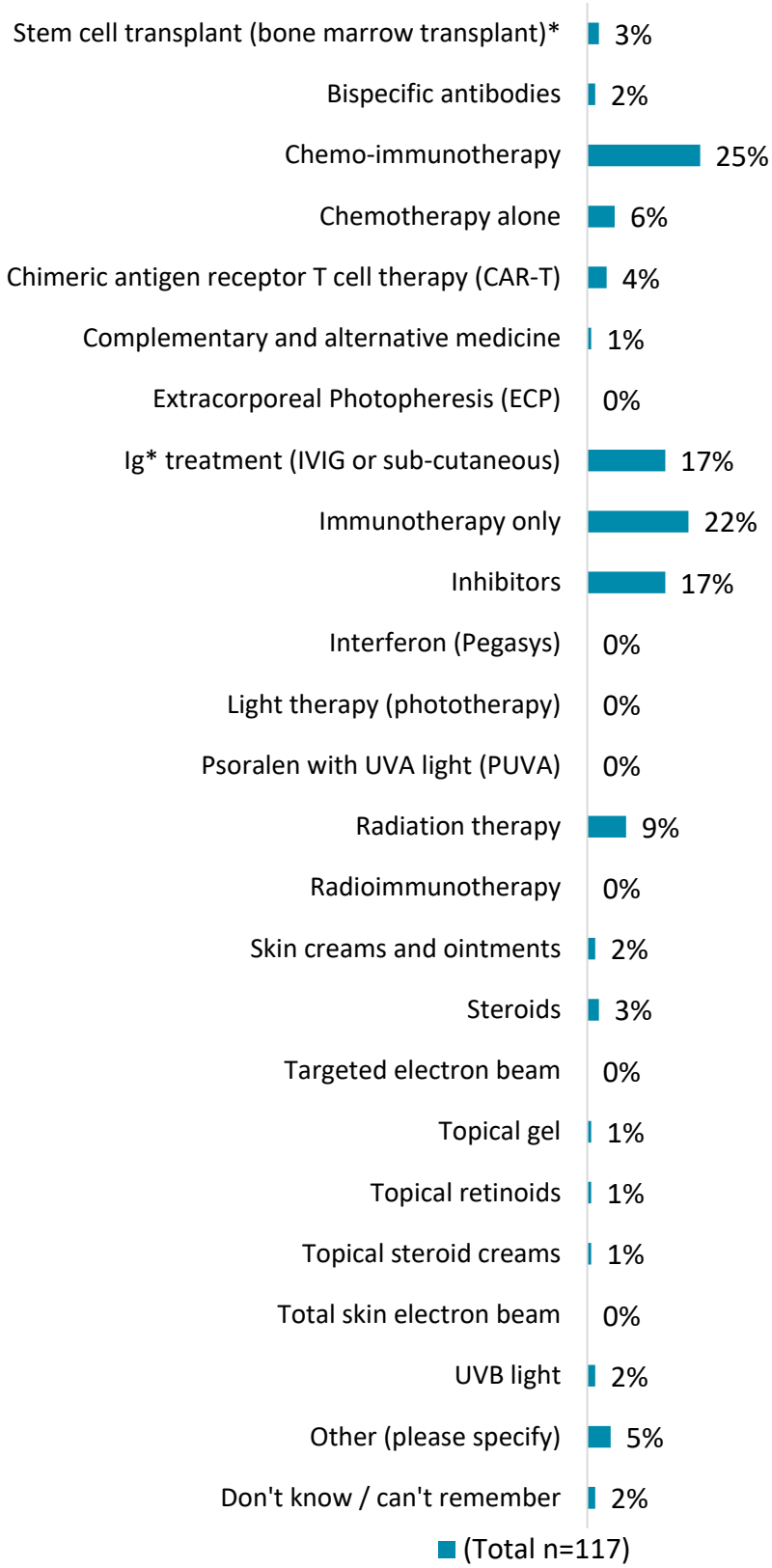
Below is the proportion of respondents who reported that their primary lymphoma or CLL doctor does the following very well or extremely well



Respondents who are in active monitoring (before and after treatment) and those who are in remission with their most recent treatment 5+ years ago were asked about their lymphoma or CLL care right now. The following proportion of respondents agreed…



Most recent treatments received



*Autologous or allogeneic; Immunoglobulin

Treatment

Who made the final choice on the most recent treatment received



- 41% (n=49) Doctor alone
- 1% (n=1) Patient alone
- 0% (n=0) Care partner alone
- 49% (n=58) Joint decision between the doctor and the patient
- 2% (n=2) Joint decision between the patient and care partner
- 8% (n=9) Joint decision between the doctor, patient and care partner

Number of regimens to date



- 47% (n=66) have had 1 treatment regimen
- 18% (n=26) have had 2 treatment regimens
- 9% (n=12) have had 3 treatment regimens
- 18% (n=25) have had 4 or more treatment regimens

Switching treatment

33% (n=45) of patients reported that they have had to switch their treatment. The top three reasons for switching were:

1. Significant side effects while taking the treatment (e.g., many side effects or severe side effects) (11%, n=15)
2. Treatment did not work (10%, n=14)
3. Other (please specify) (4%, n=6)

Fearfulness of in person appointments

11% (n=5) currently feel fearful of in person visits to healthcare providers because of the risk of contracting COVID-19 or another contagious illness

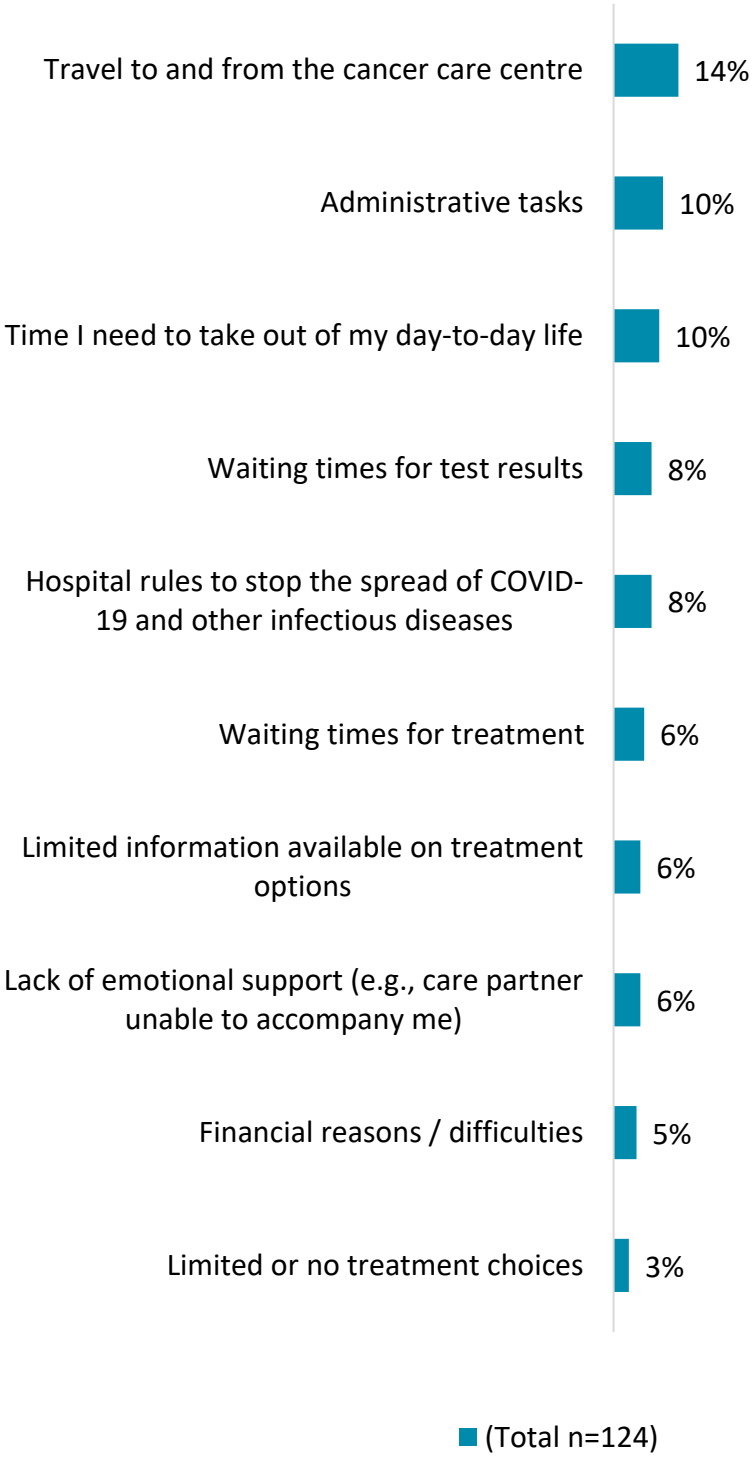
Delivery of treatment and / or follow-up appointments currently

60%	35%	4%	0%
In a medical centre close to where the patient lives (n=84)	In a medical centre not close to where the patient lives (e.g., in another region) (n=49)	At home (n=6)	Virtual / telehealth appointments (n=0)

Treatment barriers for patients

41% (n=51) of patients experienced a barrier that made getting their most recent treatment more difficult.

Top ten most commonly experienced barriers



Clinical trials

Awareness

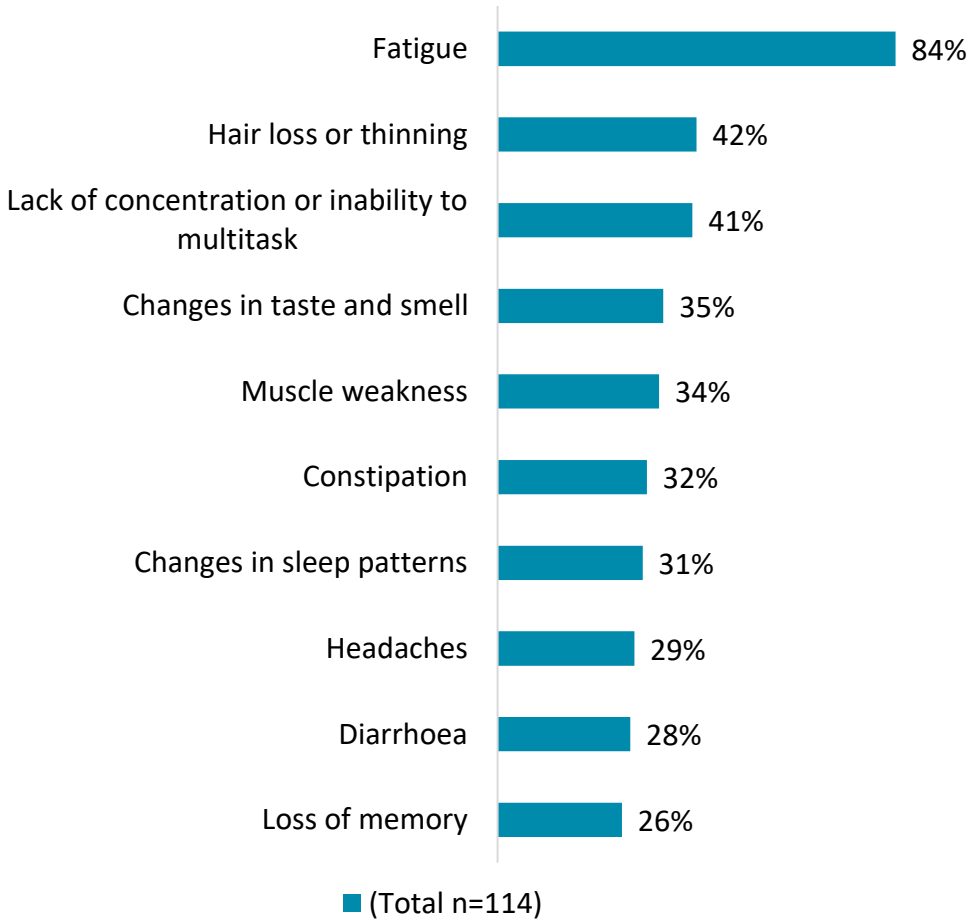
85% (n=159) of respondents were aware that participation in a clinical trial provides access to newer treatments (e.g., new drugs, CAR-T) with potentially better outcomes compared to standard therapy

Participation

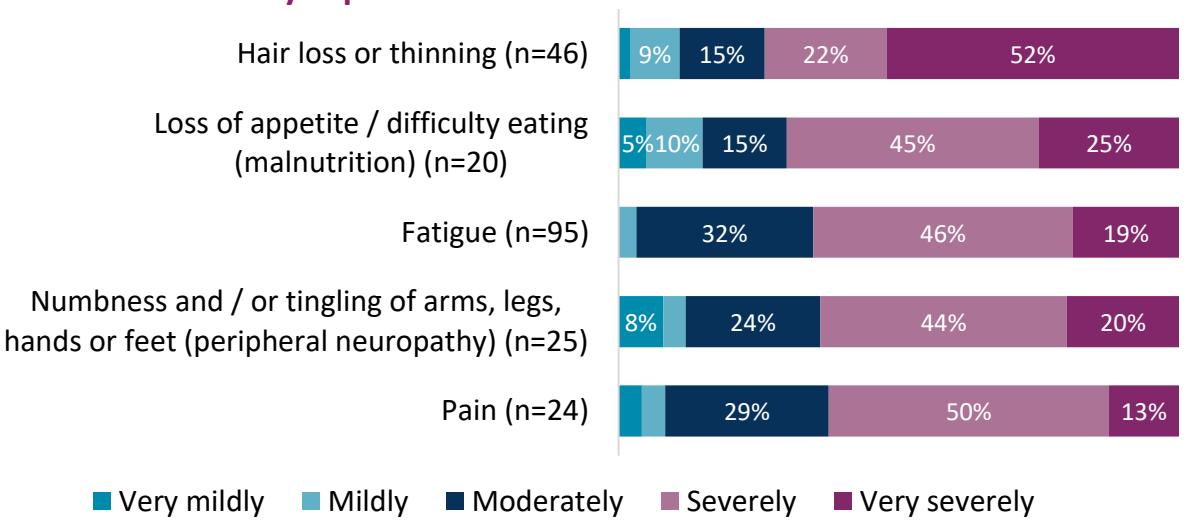
24% (n=32) of patients have participated in a clinical trial for their lymphoma or CLL in the past or presently

Incidence and impact of side effects on those treated within the last 5 years

Top ten most commonly experienced side effects



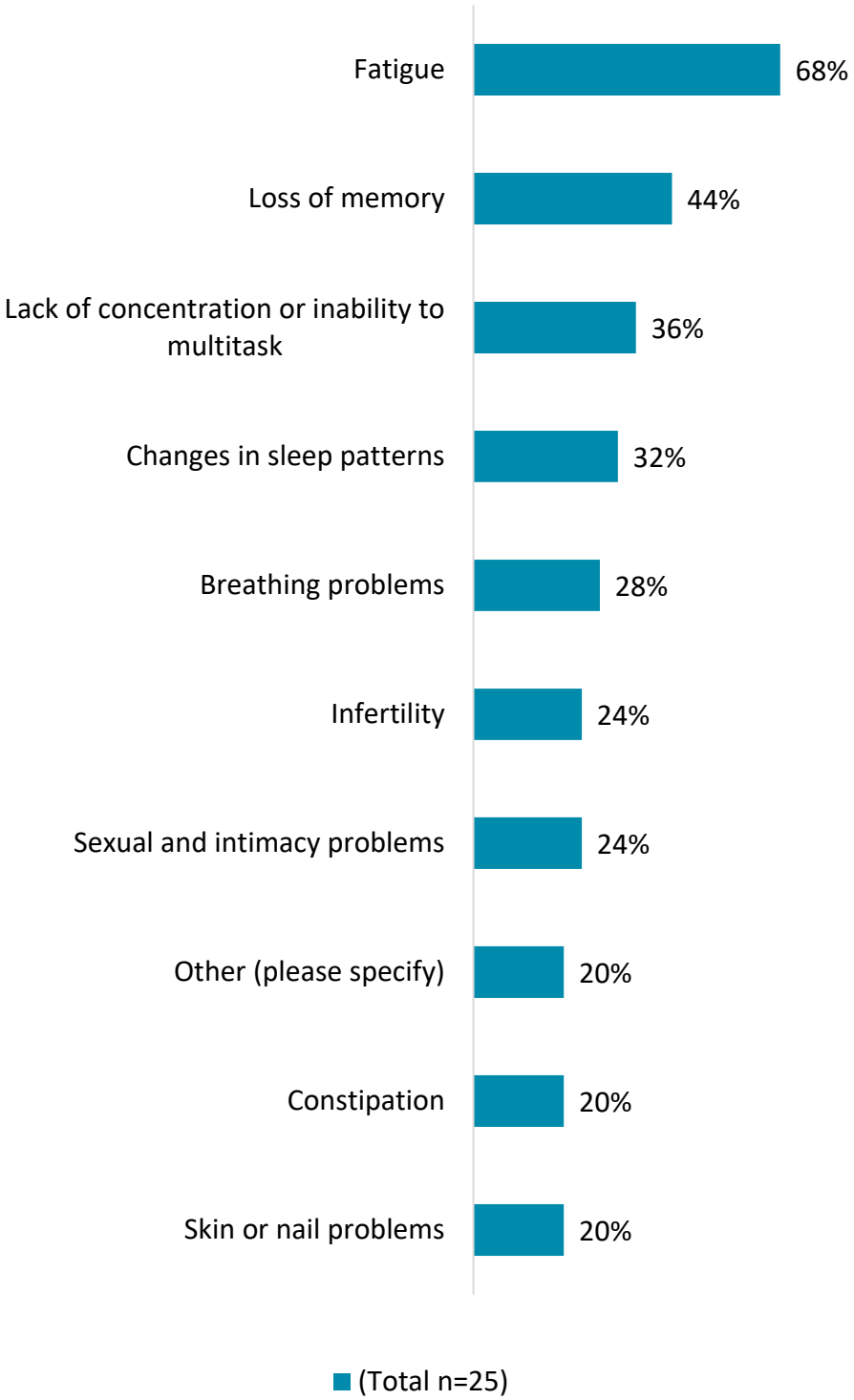
Top five most severely experienced side effects



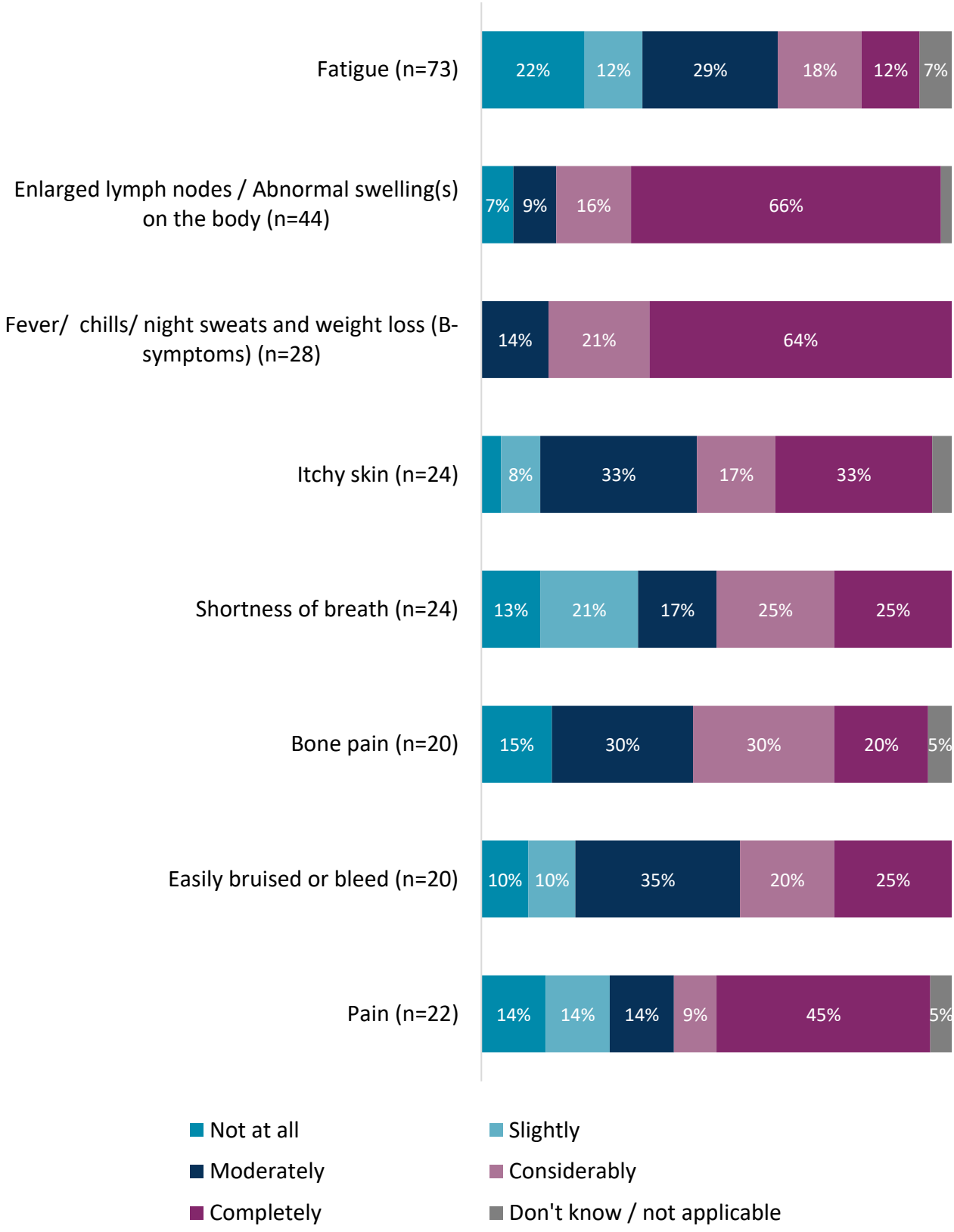
Incidence and impact of side effects of those treated more than 5 years ago

96% (n=24) of patients treated more than 5 years ago are still experiencing side effects they attribute to treatment.

Top ten most commonly experienced side effects



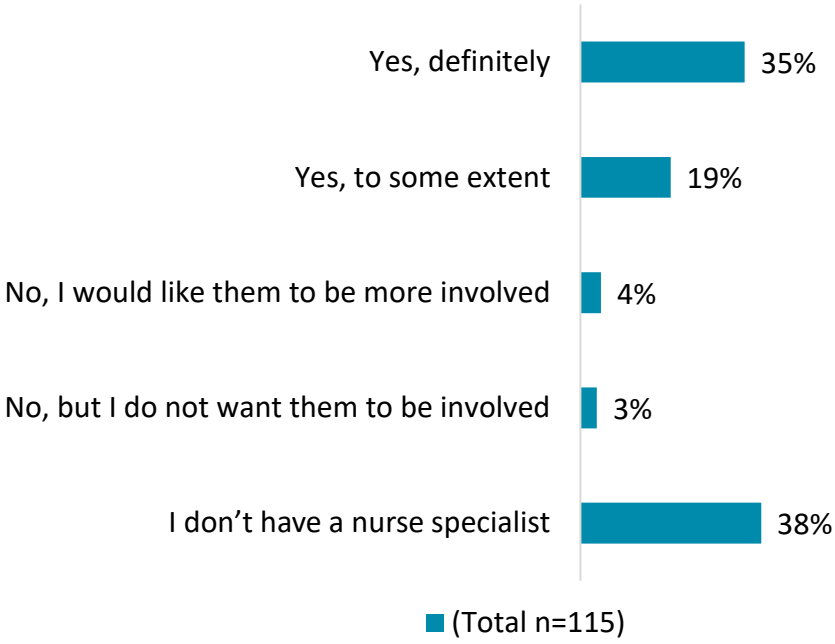
Effectiveness of treatments in managing symptoms



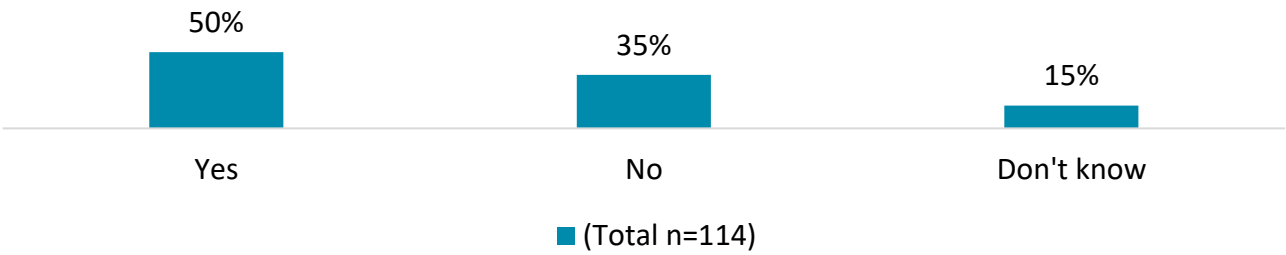
Role of nurses in lymphoma or CLL care

Is your nurse specialist involved as much as you want them to be in guiding your decision-making and during treatment?





Proportion of respondents willing to have a registered nurse visit their home to take a blood sample before or after their treatment, so they don't need to travel to the hospital or clinic

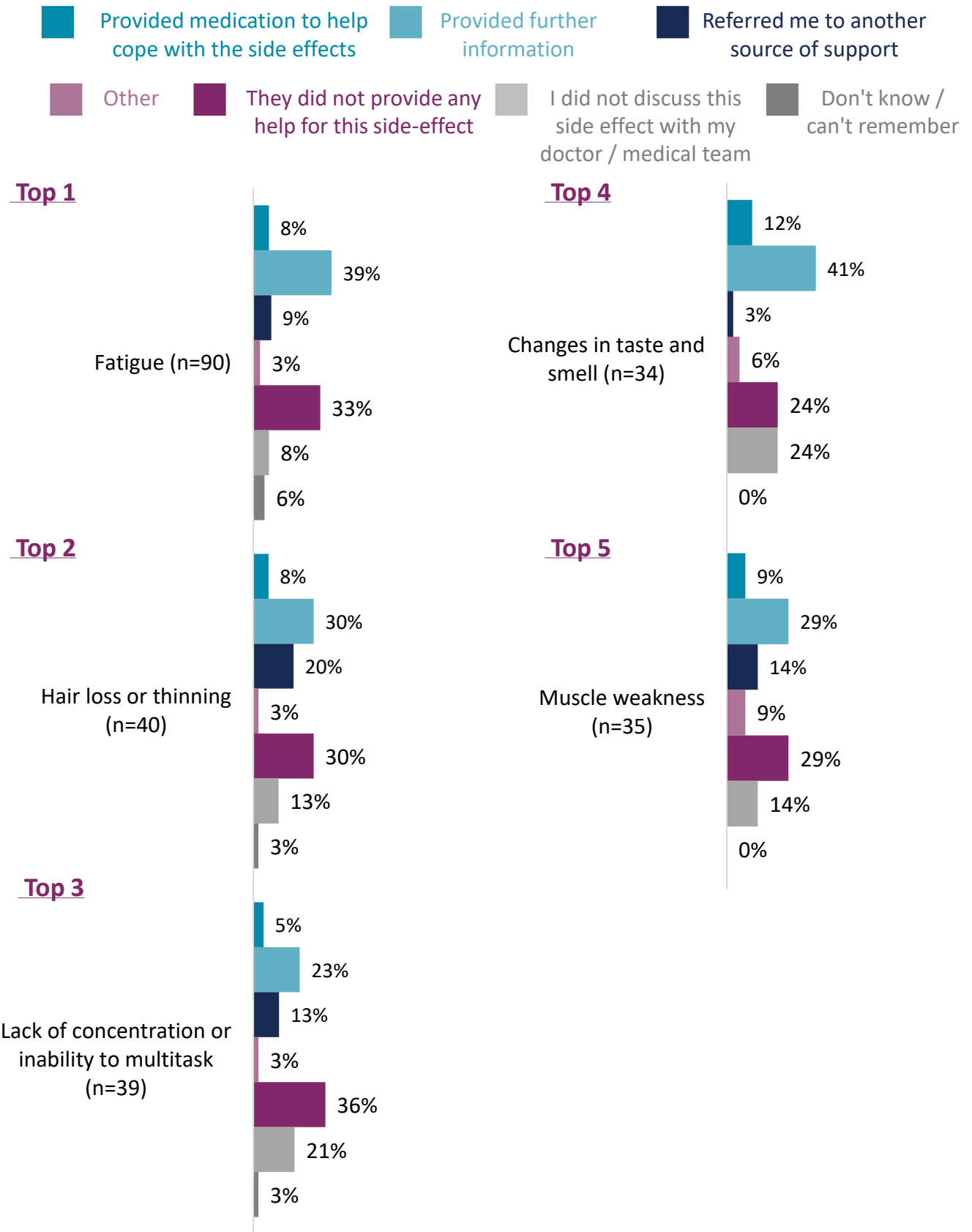


Information provision on impact of treatment on fertility

Respondents aged 50 years or less were asked if they received any information about treatment side effects on fertility and about fertility preservation opportunities before starting treatment

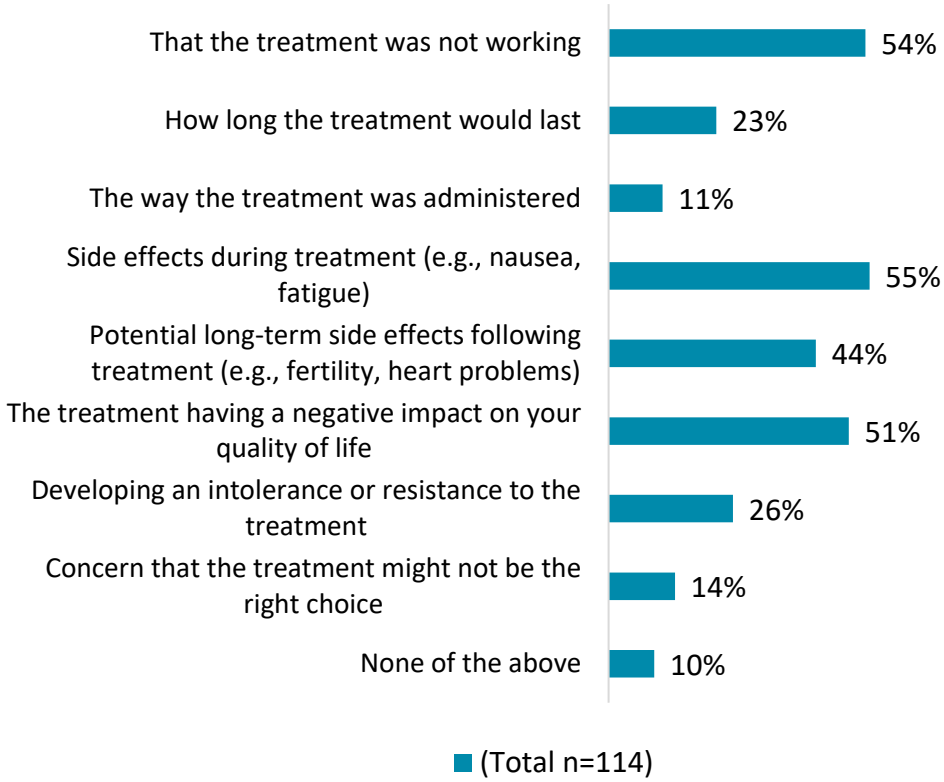
- 70% (n=19) wanted this information and received this
- 11% (n=3) did not want this information but received this
- 11% (n=3) did not receive this information but would have liked this
- 7% (n=2) did not receive this information and didn't want or need this
- 0% (n=0) didn't know or couldn't remember

Medical team support with side effects where last treatment was less than 5 years ago

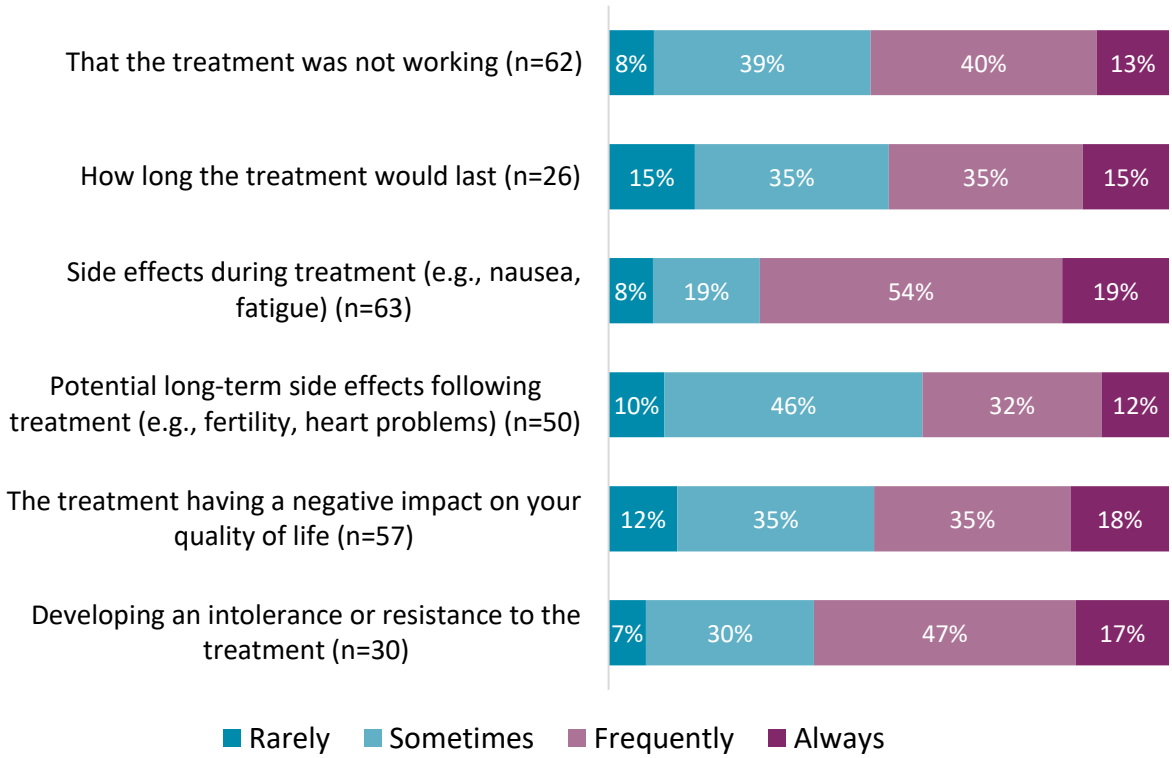


Concerns and worries during most recent treatment

Proportion experiencing concern or worry



Frequency of experiencing concern or worry

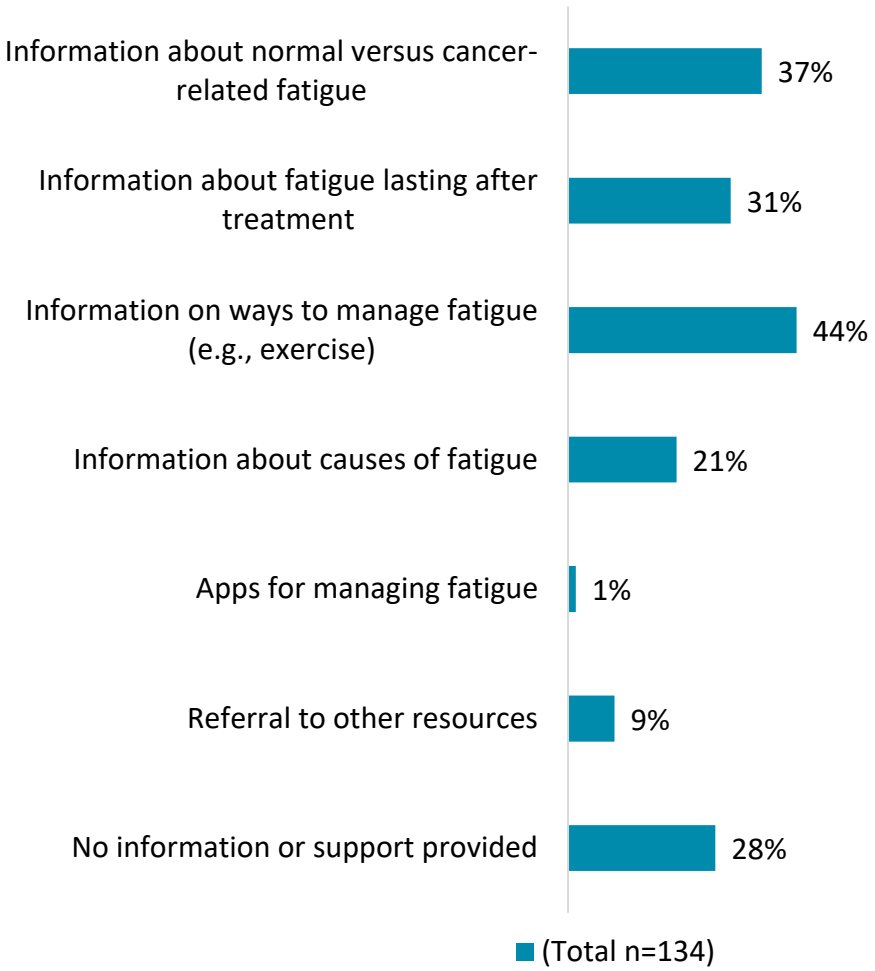


Support for fatigue from doctor

Thinking about the last 2 years…

Patients who received information / support on fatigue from their doctor or medical team were most likely to receive **information on ways to manage fatigue (e.g., exercise)** (44%, n=59).

71% (n=105) said they have discussed their fatigue with their doctor or other members of their medical team a great deal or to some extent

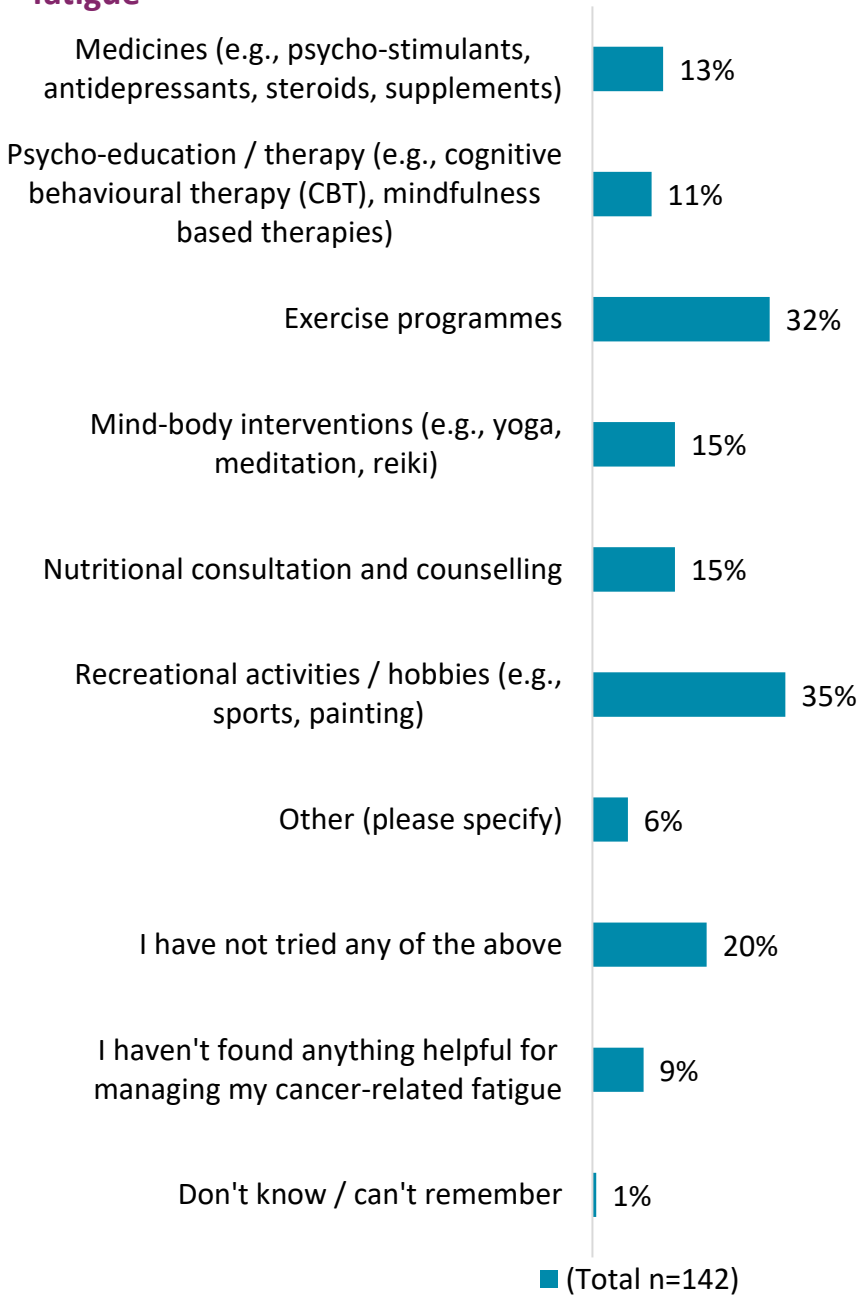


Managing cancer-related fatigue

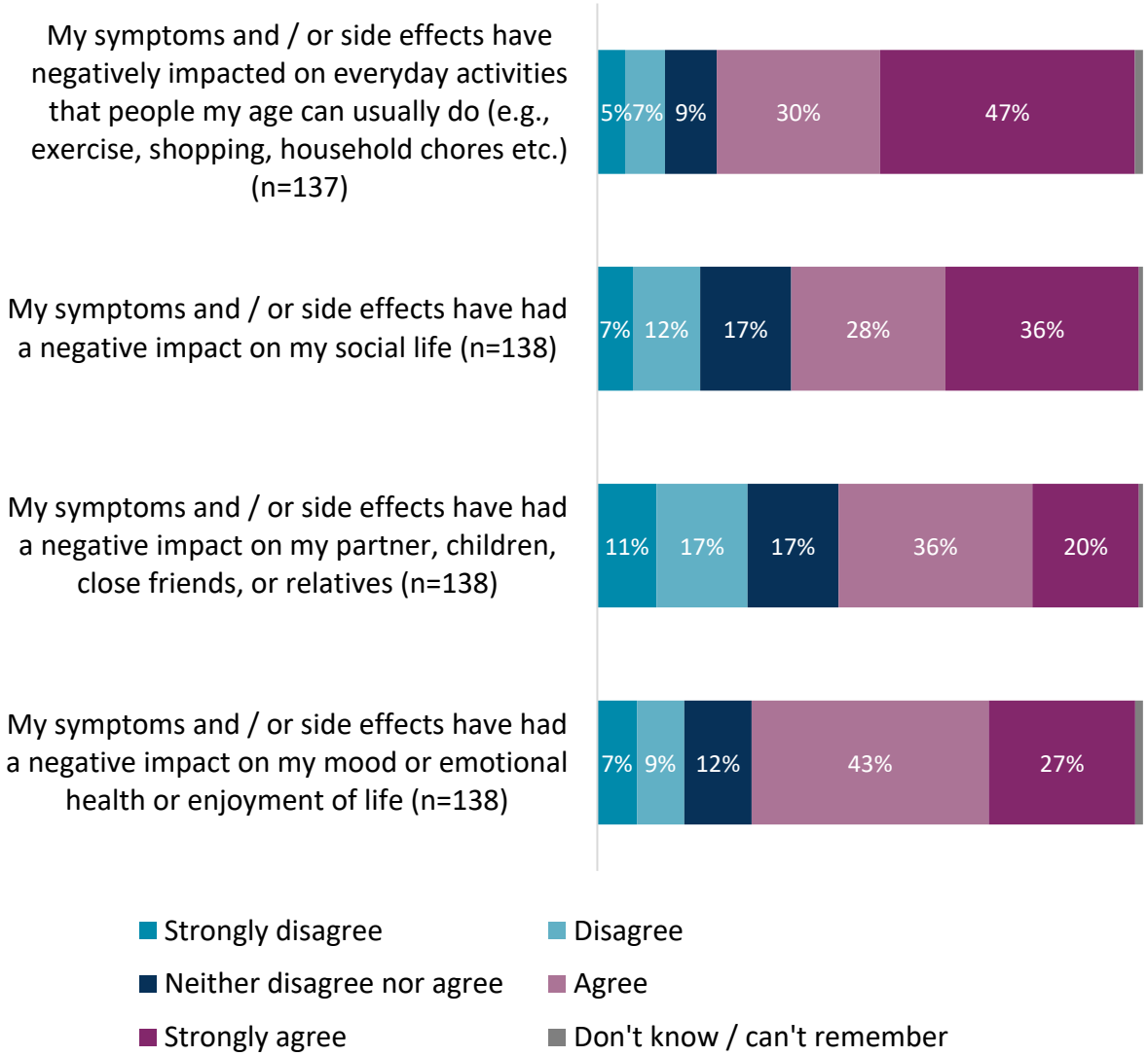


Patients were most likely to find **recreational activities / hobbies (e.g., sports, painting)** (35%, n=49) helpful in managing their cancer-related fatigue

Proportion of respondents who found methods helpful in managing cancer-related fatigue

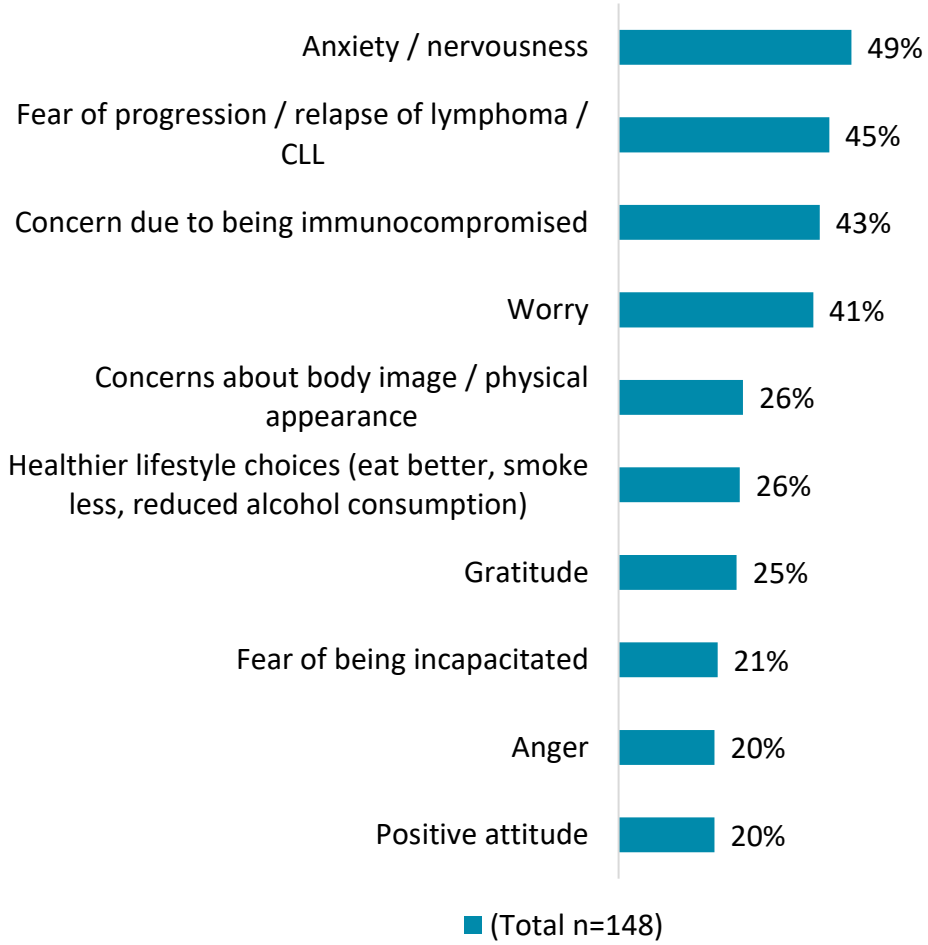


Impact of lymphoma or CLL symptoms and / or treatment side effects on patient

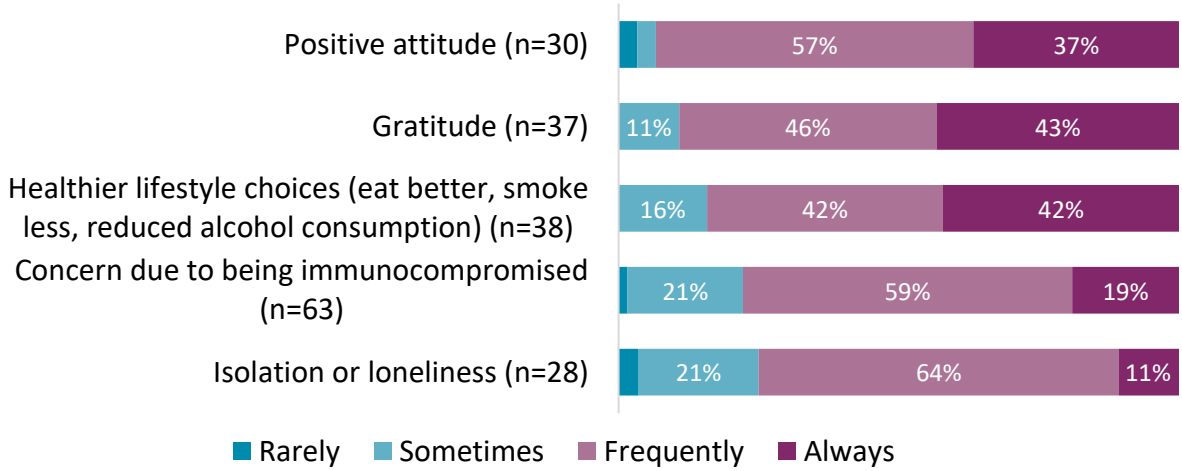


Emotional impact of lymphoma or CLL in last 6 months

Top ten most commonly experienced emotions

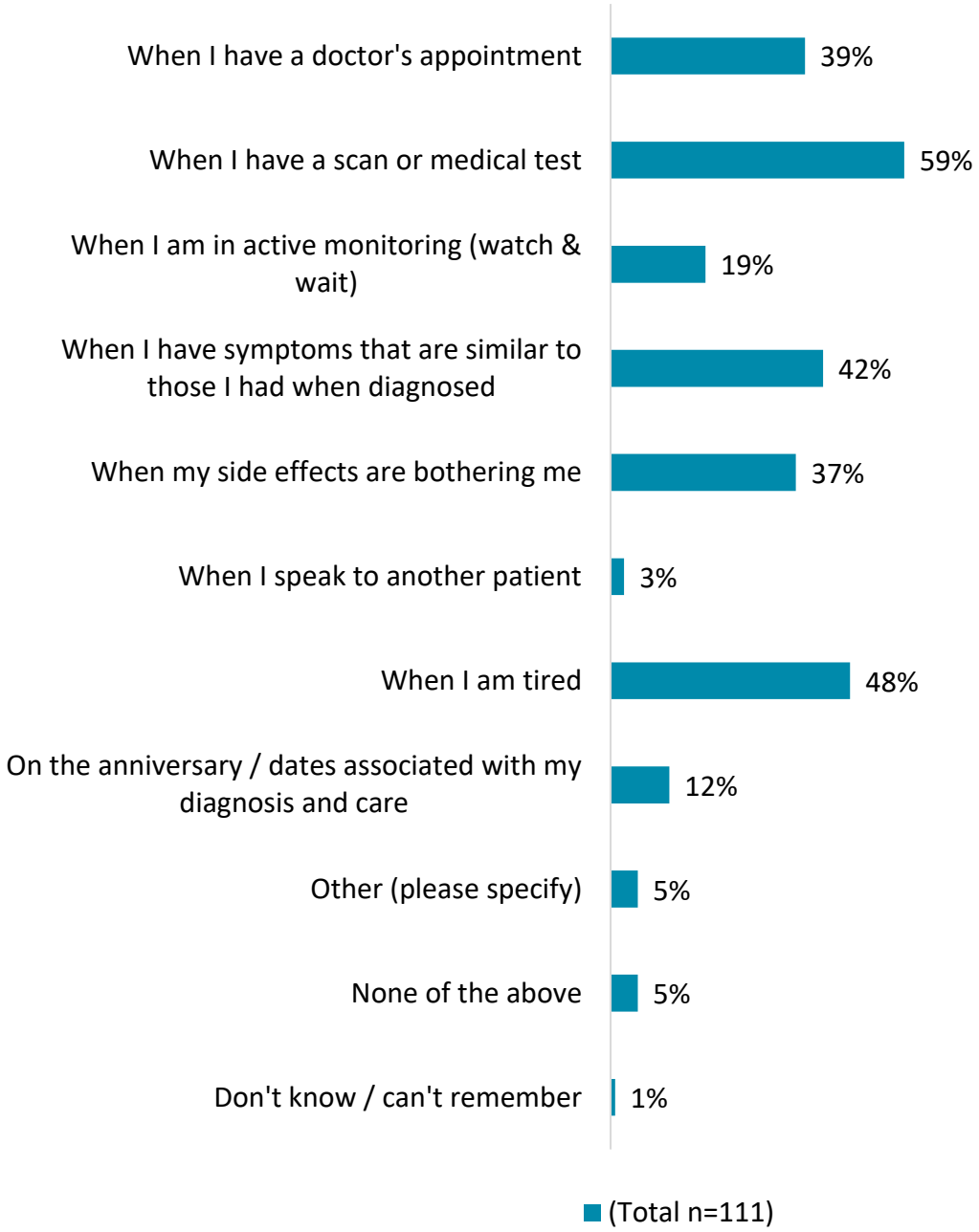


Top five most frequently experienced emotions

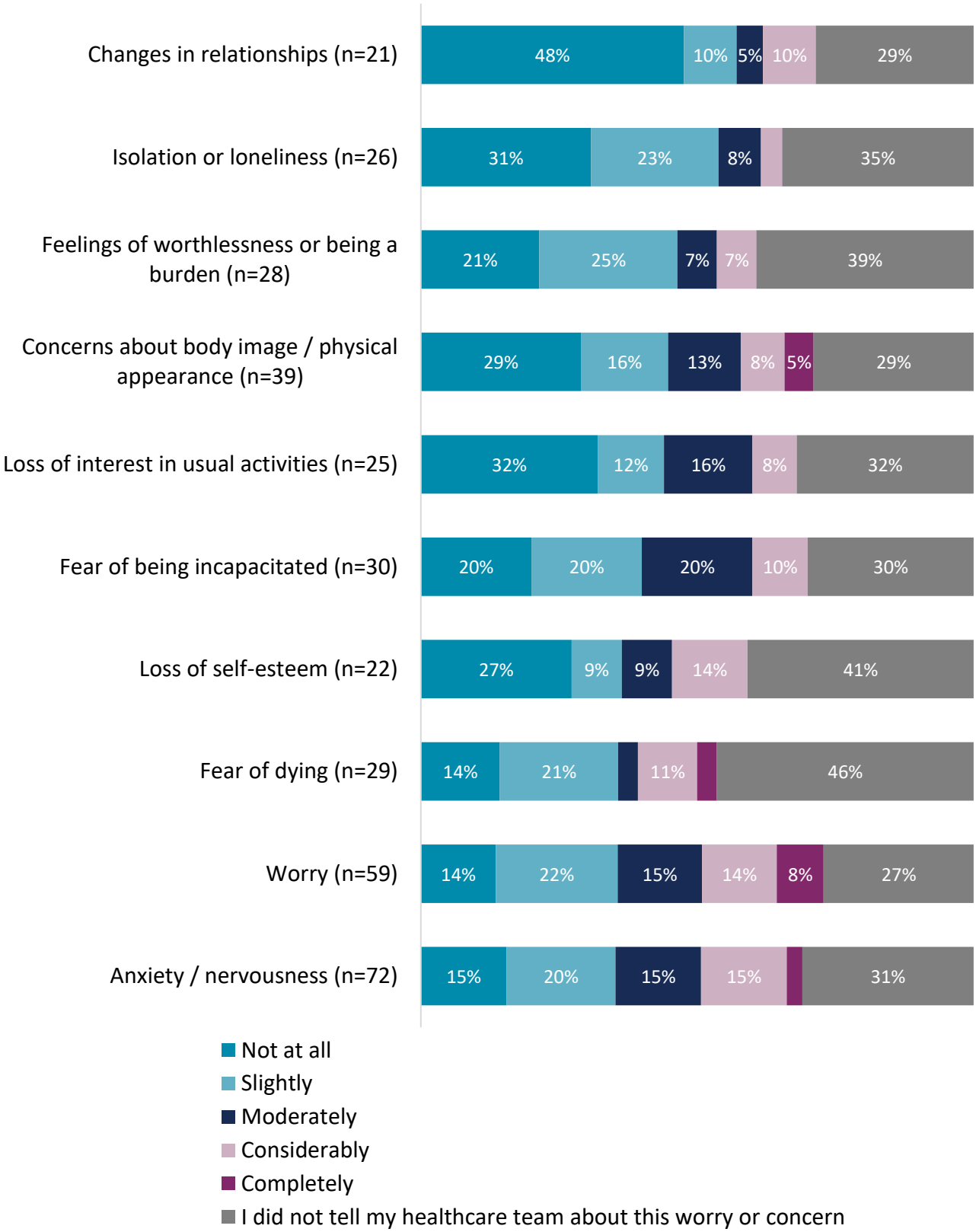


Factors that intensify emotional distress

Respondents who had experienced anxiety, depression, fear or worry in the last 6 months were asked when these feelings are increased or worsened…

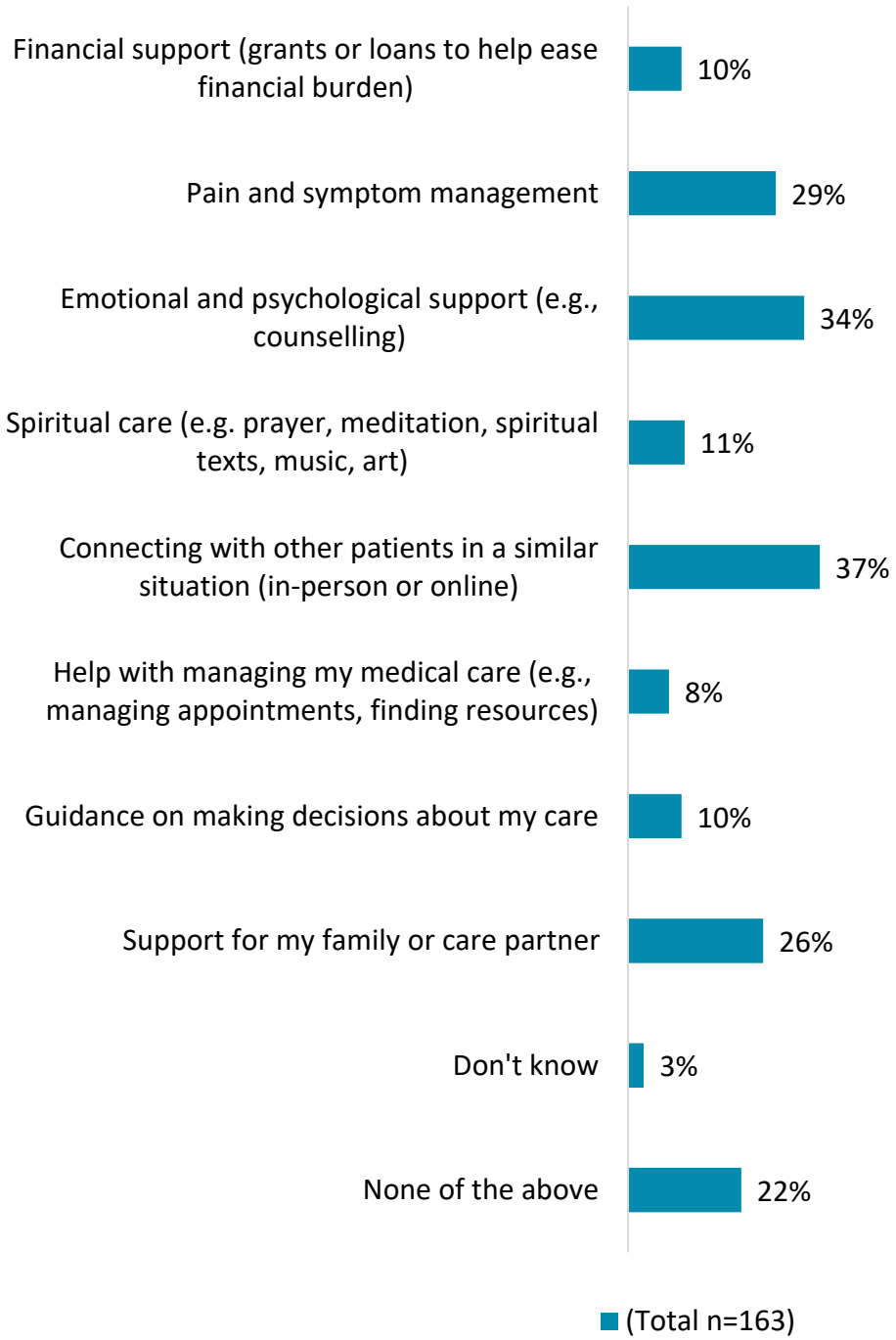


Helpfulness of care provided by medical team in managing emotional concerns



[Please note don't know/ can't remember has been removed from this analysis]

Services and resources that would be most helpful in life with lymphoma or CLL



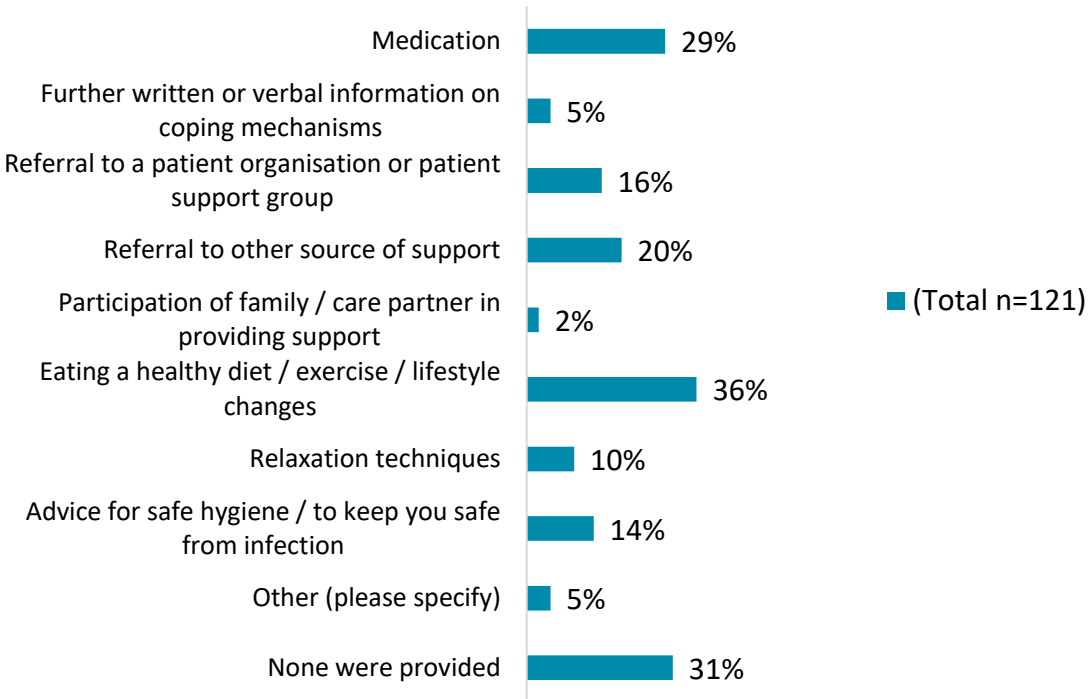
Management of patient wellbeing

At their last appointment, 45% (n=56) of patients reported their doctor definitely asked questions that were relevant to their quality of life or wellbeing. 33% (n=41) of patients said their doctor asked these questions to some extent.

When asked to what extent patients thought their doctor understands the impact of their lymphoma or CLL on their quality of life, 46% (n=58) said they understand a great deal, while 40% (n=50) said they understand to some extent.

2% (n=2) said their doctor does not ask about their quality of life.

Proportion of patients who received the following recommendations from their healthcare team to help with worries or concerns in the last 6 months



55% (n=45) of patients completely followed through on recommendations from their doctor regarding the issues that they were experiencing, while 33% (n=27) partially followed through.

61% (n=60) of patients reported their healthcare team did not follow up with them about the worries or concerns they were experiencing. 12% (n=12) of patients reported their healthcare team definitely followed up with them about the worries or concerns they were experiencing, while 21% (n=21) said their healthcare team followed up to some extent.

Impact on sexual life

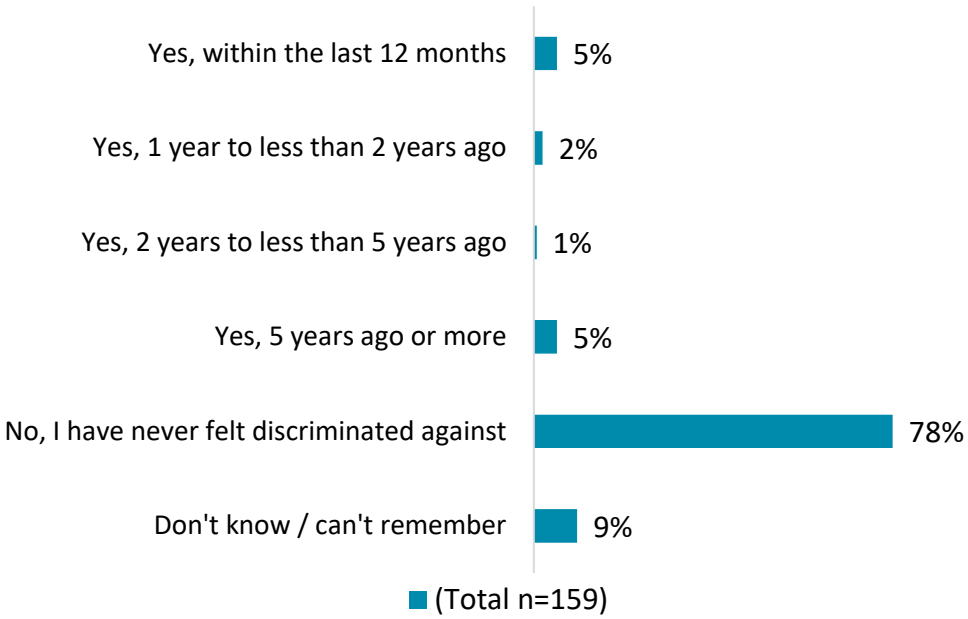


18% (n=31) of patients reported their diagnosis of lymphoma or CLL has had a great negative impact on their sexual life

29% (n=51) said it has had a negative impact to some extent

Financial discrimination due to lymphoma or CLL diagnosis

Proportion of respondents who felt discriminated against in accessing banking, credit or insurance services because of their lymphoma or CLL diagnosis



Employment

Patient's employment status



- 13% (n=22) Full time
- 11% (n=18) Part time
- 5% (n=8) Self employed
- 2% (n=3) Homemaker / Stay-at-home parent
- 0% (n=0) Student
- 50% (n=82) Retired
- 1% (n=2) Unemployed and seeking work
- 6% (n=10) Unemployed and unable to work for health reasons (NOT seeking work)

Early retirement

22% (n=18) of patient's retired earlier than they had planned to because of their lymphoma or CLL diagnosis or treatment

Ability to work



62% (n=43) of patients reported that their ability to work had been affected since they were diagnosed.

Patients whose ability to work had been affected, reported that they…

- 43% (n=30) had to stop working temporarily
- 6% (n=4) had to stop working permanently
- 22% (n=15) had to work reduced hours
- 0% (n=0) had to work additional hours
- 13% (n=9) needed workplace accommodations (e.g., flexible hours, remote work)
- 3% (n=2) changed to a different type of work

Returning to work

- 15% (n=12) of patients did not return to work following their diagnosis or treatment
- 13% (n=10) of patients did not stop working as a result of their diagnosis or treatment
- 18% (n=14) of patients were not working at the point of their diagnosis or treatment
- 16% (n=13) of patients did not experience difficulties upon returning to work following their diagnosis or treatment

Top three difficulties experienced by patients who stopped working during diagnosis and treatment upon returning to work include:

1. Concern of feeling well enough or having the energy to get through the work day (24%, n=19)

2. Concern about work ability being questioned or difficulty being promoted (14%, n=11)

3. Negative reaction of supervisor or co-workers when taking medical leave to attend treatment (8%, n=6)

The following proportion of respondents would like to see improvements for awareness in the workplace that people with lymphoma or CLL…

- May currently have health problems or be at high risk for health problems in the future (33%, n=19)
- May have decreased or different work ability due to their diagnosis and treatment (39%, n=22)
- May have decreased ability to perform daily tasks compared to their co-workers (32%, n=18)
- Can have their emotional behaviours and personality affected by lymphoma or CLL (30%, n=17)
- May have various limits in socialising or developing relationships with co-workers due to their diagnosis (21%, n=12)
- May need privacy or sensitivity when discussing their diagnosis or treatment at work (19%, n=11)

Palliative care



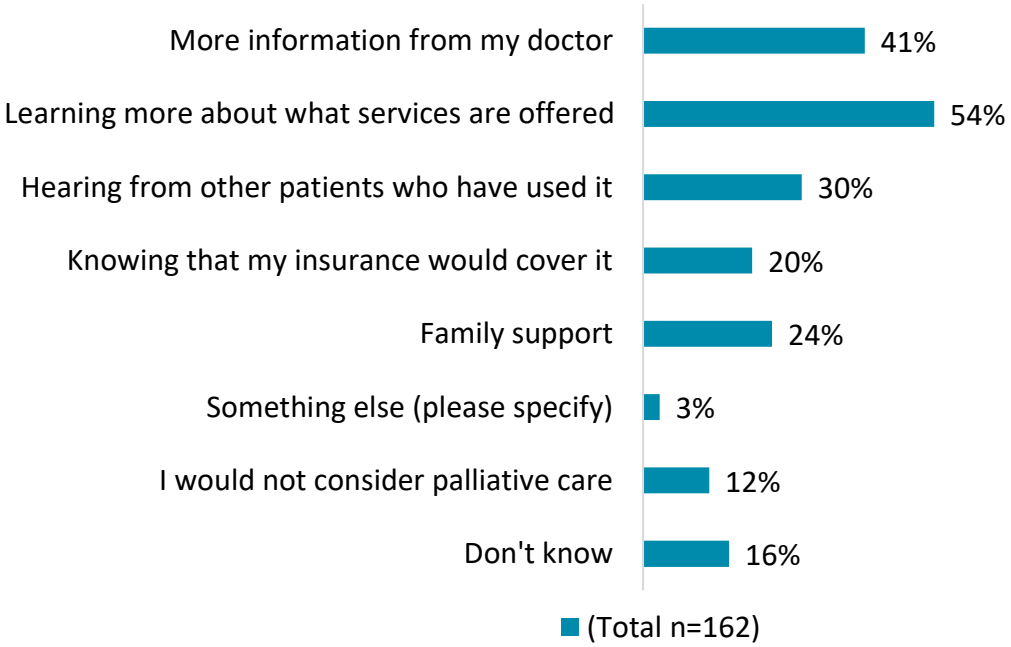
66% (n=110) of respondents thought that having palliative care means a patient is at the end of their life.

7% (n=11) of respondents have had a conversation with their / the patient's healthcare team about palliative care.

When asked about their own understanding of palliative care…

- 41% (n=66) agreed palliative care can be used at the same time as lymphoma or CLL treatments
- 63% (n=103) agreed palliative care helps people manage symptoms (e.g., pain, fatigue, nausea)
- 62% (n=101) agreed palliative care helps people with their emotional wellbeing (e.g., anxiety, depression, coping with their diagnosis or treatment)
- 21% (n=35) agreed that palliative care and palliative treatment are the same thing

When asked what would make them more comfortable to consider palliative care as an option, respondents said…



Lymphoma Coalition

Lymphoma Coalition (LC) is a worldwide network of patient organisations with a full or partial focus on providing support to those affected by lymphoma, including chronic lymphocytic leukaemia (CLL). LC was established in 2002 and has over 100 patient member organisations across more than 55 countries with an overarching goal to facilitate a community of patient organisations which support efforts to help patients with lymphoma or CLL, receive the care and support needed.

Our vision

A better future for everyone impacted by lymphoma.

Our mission

Lymphoma Coalition is the leading global coalition of patient organisations. We work together to generate and provide trusted information, knowledge, and best practice to influence and make possible equitable care. LC's current strategy is focused on five key priorities:

1. Influence policy to improve optimal care
2. Deliver usable evidence & information that leads to action
3. Develop exemplary patient opinion leaders and empower patient organisations to fulfil their missions
4. Connect diverse stakeholders to collaboratively advance care
5. Ensure impact globally, regionally and locally

For more information on Lymphoma Coalition and its work, please visit our website.

Picker

Picker is a leading international health and social care charity. We carry out research to understand individuals' needs and their experiences of care. We are here to:

- Influence policy and practice so that health and social care systems are always centred around people's needs and preferences.
- Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.
- Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

Picker Institute Europe has UKAS accredited certification for ISO 20252:2019 (GB08/74322) via SGS, as well as ISO 27001:2022 and ISO 27701:2019 (certificate number 23715) via Alcumus ISOQAR. We comply with Data Protection Laws including the General Data Protection Regulation, the Data Protection Act 2018, the Data (Use and Access) Act 2025 and the Market Research Society's (MRS) Code of Conduct.

For more information on the work Picker do, please visit our website.