Lymphoma Coalition 2024

Global Patient Survey on Lymphomas & CLL

2024 Global Patient Survey on Lymphomas & CLL

Belgium Report

LYMPHOMA COALITION

Methodology

Questionnaire development

The survey was redesigned with consultation between Lymphoma Coalition, patient member groups and Picker. The 2024 GPS focused on the following themes:

- Patient demographics
- Lymphoma or CLL diagnosis
- Health care information
- Care from healthcare professionals
- Treatment
- Barriers to treatment
- Clinical trials
- Side effects of treatment and fatigue
- Physical health and emotional wellbeing
- Impact on employment
- Experience of care partners, friends and family members
- Explicit emphasis on Health Related Quality of Life (HRQoL) and current performance status (ECOG) were included to provide clinical context for findings from the survey

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 one caregiver. Following feedback from interviewees, amendments were made to questions (i.e., to introduce a recall period). 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. Caregiver 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 2022 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 into 19 languages 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 languages:

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

Data collection

The survey was hosted on the third-party online survey portal Qualtrics for a period of 10 weeks from 2 February 2024 to 15 April 2024. 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 used unless they fully completed the survey (Q3=2).
2. Responses that were not completed up to Q52 (inclusive) were removed from the dataset.
3. Surveys that were flagged by Qualtrics as potential bots were reviewed prior to data being aggregated.

In total, 2,811 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. Data was then exported into reports for researcher interpretation and commentary. No statistical analysis was performed; any reported differences cannot assume statistical significance.

Cross tabulations were used to investigate patterns in care experiences between patient demographics, lymphoma subtypes and countries and regions of residence; cross-tabulations were also used to examine patterns between caregiver 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 for a response option as 0%, this may mean the percentage has been rounded down to 0%, not that it had zero respondents.

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

Demographics

- Respondent Demographics: N = 547 (89% patients, 11% caregiver); 50% patients female; 75% are over the age of 55; 59% have higher than secondary education.
- The top 4 subtypes are: Chronic Lymphocytic Leukaemia (24%), Hodgkin (16%), Follicular (12%), Diffuse Large B-Cell (type unknown) (12%).
- Majority (67%) diagnosed 2 or more years ago.
- Currently, 30% in remission, 24% receiving treatment, 13% finished treatment and are on maintenance therapy, and 11% treatment is not yet needed.

Symptoms and diagnosis

- Fatigue was the most prevalent symptom (63%) with 90% indicating at least moderate severity.
- Bone pain, frequent or repeated infections, and pain had the greatest impact amongst the symptoms queried.
- With regard to diagnosis, 1/2 of patients sought medical attention within less than 3 months of symptom onset. Additionally, 73% of patients received a diagnosis in less than 3 months of seeking medical attention.

Healthcare information

- Only 1% of patients did not want to be involved in their care decisions.
- Forty percent of patients wanted to share decision making with their doctor, while 17% felt confident in making the decisions on their own.
- Caregivers were more concerned about the certainty of available treatment data / results and duration of treatment than patients.
- Less than half of patients (45%) reported their doctor always encourages them to ask questions. Fifty-two percent report their doctor always ensures they understand answers to their questions.
- Almost all patients and caregivers (98%) want to be told the truth about the diagnosis.

Treatment and care

- Eighty-one percent of patients have had treatment with 55% of those indicating treatment was received close to where they live.
- The most common anti-cancer treatments received include chemo-immunotherapy, chemotherapy alone, immunotherapy only, and radiation therapy.
- Fatigue (80%), hair loss (51%), changes in taste and smell (42%), constipation (36%), muscle weakness (35%), and lack of concentration (34%) were the most common side effects.

Key learnings

Treatment and care (continued)

- 33% of patients did not have a choice of treatment options.
- Twenty-nine percent of patients who reported fatigue did not receive any information or support for their experienced fatigue.
- Sixty-eight percent of respondents reported no difficulties in obtaining treatment. However, 11% indicated travel to and from the cancer care centre was a barrier.
- 47% of caregivers experienced a barrier for their patient to obtain treatment with travel to and from cancer centre being most commonly reported.
- 1/3 of patients did not receive information on clinical trials and 82% were not offered the opportunity to enroll in a clinical trial.

Psychosocial impact

- Over 80% of patients reported some type of emotional impact attributable to their diagnosis with the most prevalent concerns being anxiety / nervousness followed by fear of progression / relapse.
- The severity of emotional impact was rated to be at least moderate for almost every domain with isolation or loneliness leading the way.
- For the emotional aspects queried (N = 17), on average, 33% of respondents did not communicate their emotional difficulties to their healthcare team.
- Supportive care from the healthcare team principally consisted of advice on eating a healthy diet with exercise, medication, and referrals to other sources of support.
- Over half (54%) of patients reported their healthcare team did not follow up with them about the worries or concerns they were experiencing.
- 1/5 patients reported their diagnosis of lymphoma or CLL has had a great negative impact on their sexual life. Only 13% reported they have discussed their sexual life with their doctor.
- Eighteen percent of patients reported they have felt discriminated against financially because of their lymphoma or CLL diagnosis.
- The vast majority of caregivers (91%) suffer emotional impacts due to the lymphoma diagnosis and only 47% of caregivers discussed their worries and concerns with a healthcare professional.

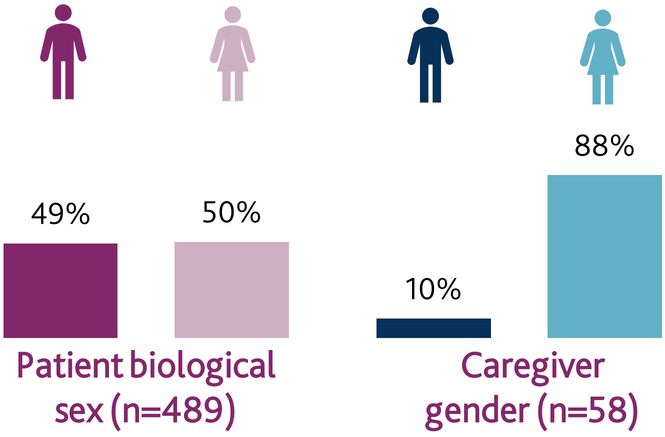
About survey respondents

547

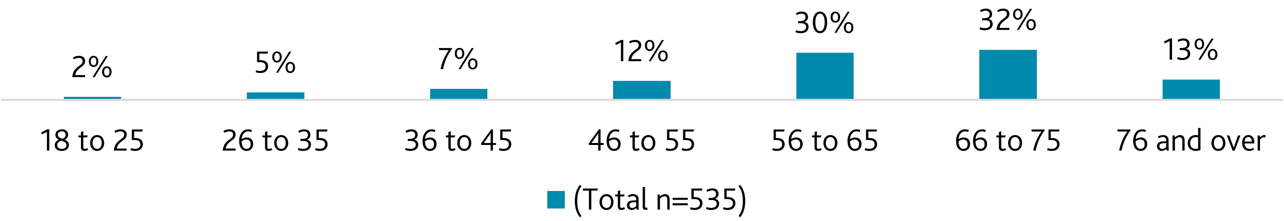
Total respondents

489 total patient respondents

58 total caregiver respondents



Age



Education level

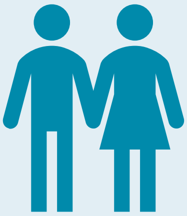
- 3% (n=13) Primary (Elementary) or less
- 35% (n=176) Secondary (High-school)
- 46% (n=231) Post-Secondary (College / University)
- 13% (n=66) Postgraduate (Master's, PhD)

Employment status

- 21% (n=115) Full time
- 11% (n=61) Part time
- 2% (n=13) Homemaker / Stay-at-home parent
- 1% (n=5) Student
- 50% (n=274) Retired
- 0% (n=2) Unemployed and seeking work
- 4% (n=21) Unemployed and unable to work for health reasons (NOT seeking work)

About survey respondents

Caregiver relationship to patient



- 62% (n=36) Spouse / Partner
- 12% (n=7) Parent
- 14% (n=8) Child
- 5% (n=3) Brother or sister
- 3% (n=2) Extended family member
- 2% (n=1) Friend
- 2% (n=1) Other

Length of time as a care partner

14% (n=8) Less than 6 months

17% (n=10) 6 months to less than 1 year

21% (n=12) 1 year to less than 2 years

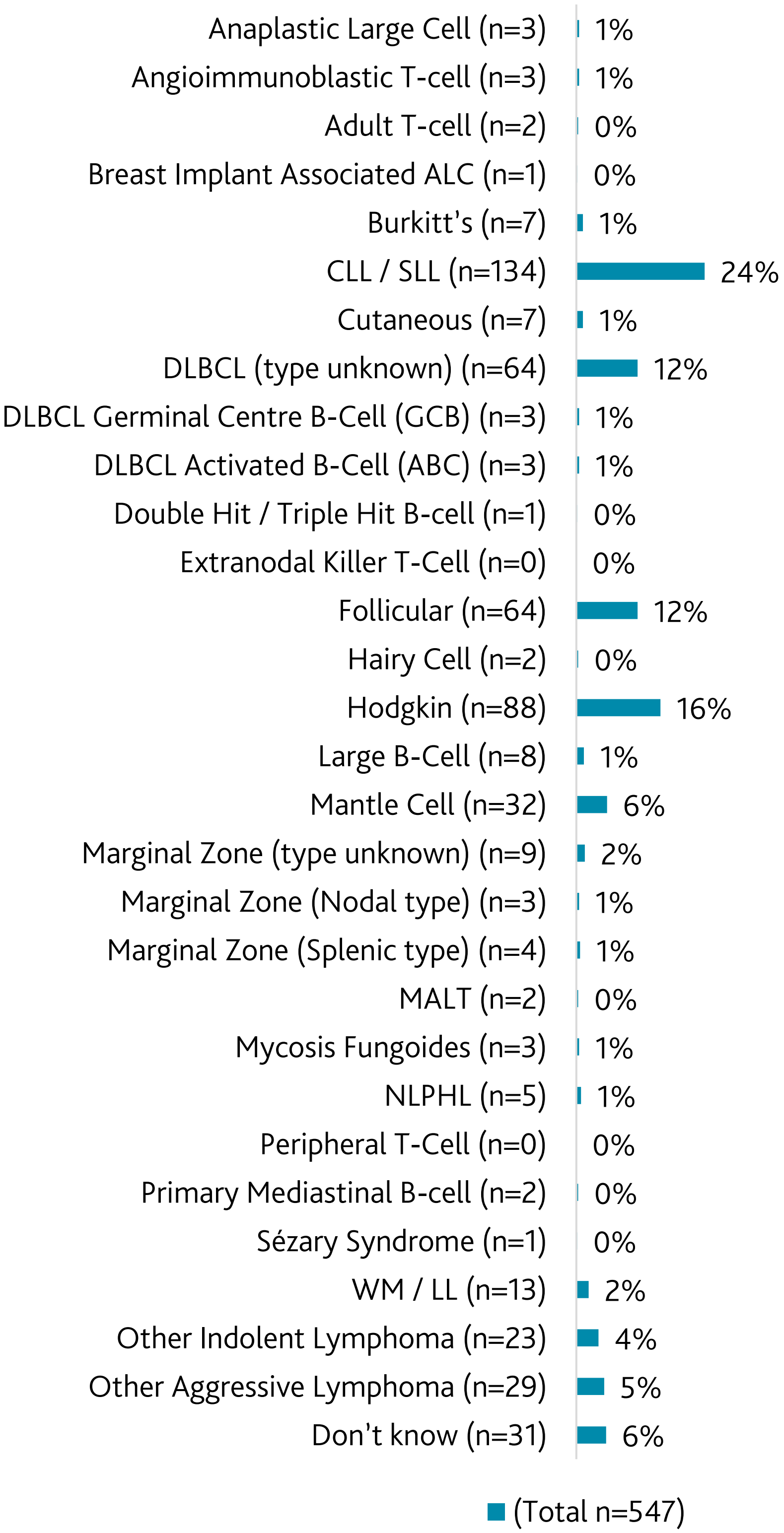
22% (n=13) 2 years to less than 5 years

10% (n=6) 5 years to less than 10 years

16% (n=9) More than 10 years

0% (n=0) Don't know / can't remember

Subtype



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

Lymphoma information

Current status of disease

- 1% (n=5) Newly diagnosed and not yet sure of my treatment option
- 11% (n=61) Treatment is not yet needed (active monitoring or watch and wait)
- 8% (n=42) Have had treatment and now back in active monitoring (watch and wait)
- 24% (n=129) Receiving treatment
- 13% (n=71) Finished treatment and on maintenance therapy
- 4% (n=23) Finished or stopped treatment but am not in remission
- 30% (n=162) In remission
- 1% (n=7) Relapsed or refractory disease but am not currently being treated
- 0% (n=2) Palliative care only
- 7% (n=40) Other
- 1% (n=5) I am completing the survey on behalf of someone who passed away

Relapse status

16% (n=74) of patients had relapsed once, 12% (n=58) had relapsed more than once, 67% (n=317) had not relapsed, and 5% (n=24) didn't know or couldn't remember.

Length of time from diagnosis

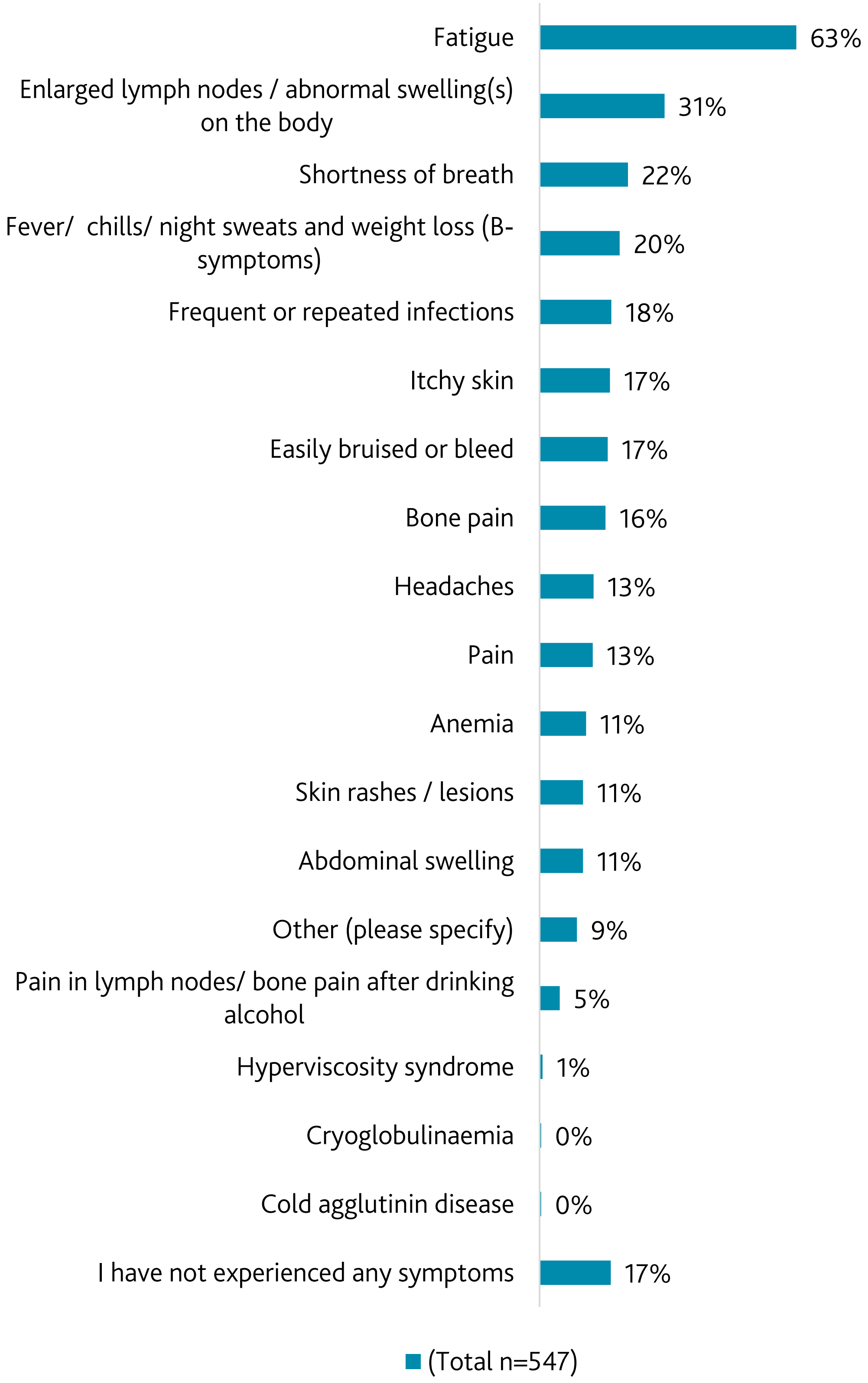
- 9% (n=47) Less than 6 months ago
- 9% (n=49) 6 months to less than 1 year ago
- 15% (n=80) 1 year to less than 2 years ago
- 25% (n=138) 2 years to less than 5 years ago
- 22% (n=123) 5 years to less than 10 years ago
- 20% (n=110) More than 10 years ago
- 0% (n=0) Don't know / can't remember

Stage

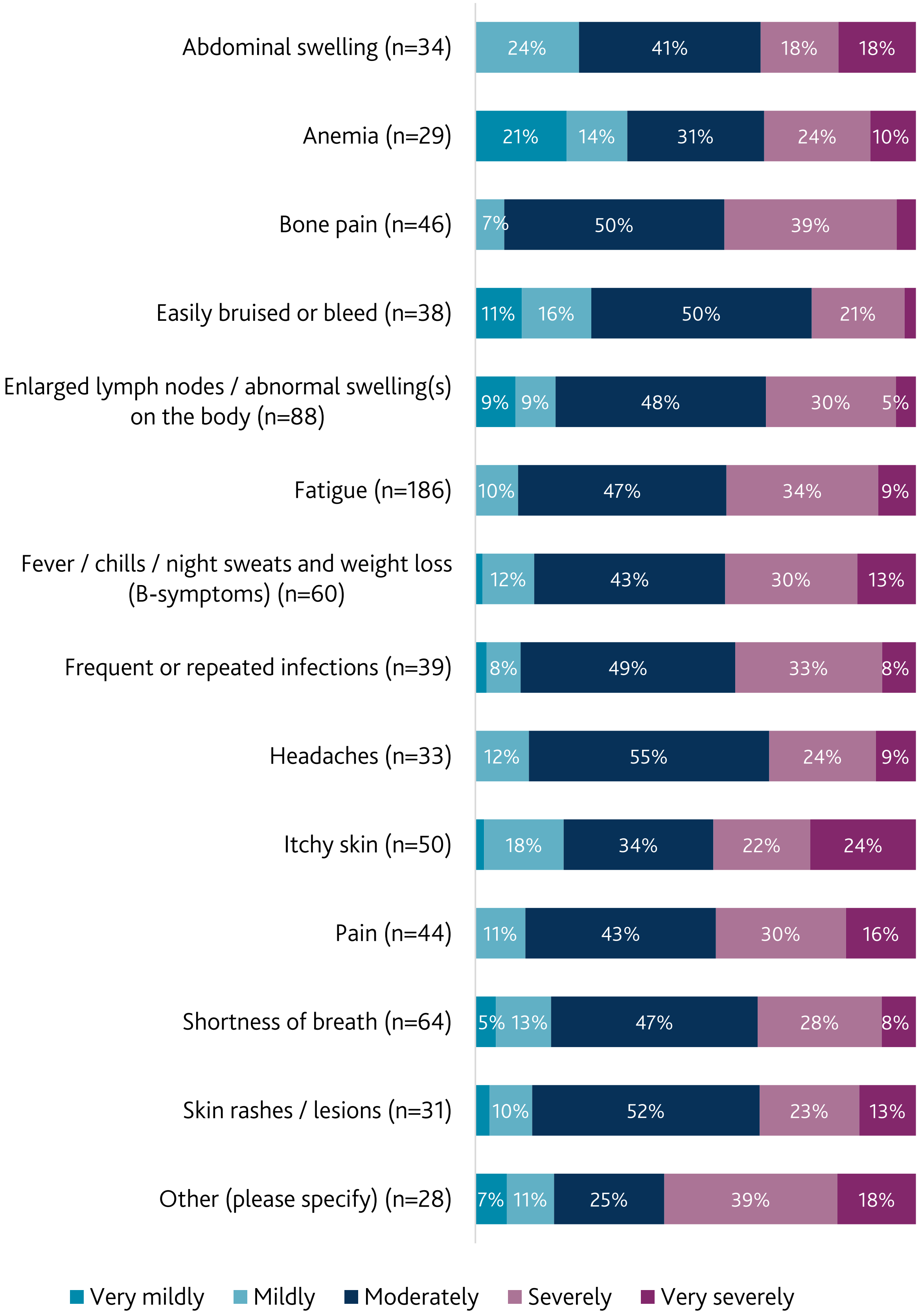
2% (n=6) Stage 0
9% (n=35) Stage I
15% (n=59) Stage II
17% (n=65) Stage III
35% (n=136) Stage IV
23% (n=88) Don't know / can't remember

Symptoms

Proportion of patients who experienced the following symptoms



Impact of symptoms



Diagnosis

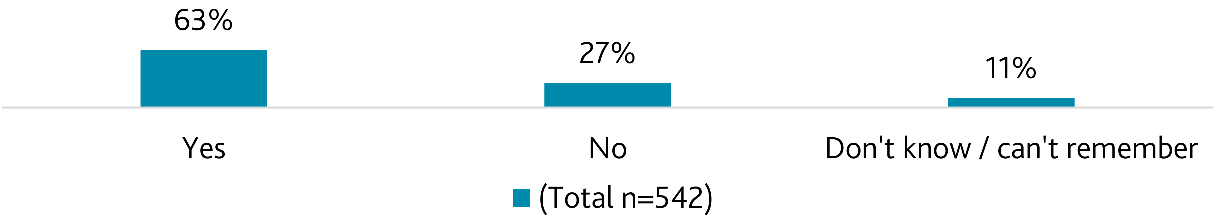
Length of time to seek medical attention from experiencing symptoms

25% (n=119) Less than 1 month
25% (n=118) 1 month to less than 3 months
14% (n=68) 3 months to less than 6 months
9% (n=42) 6 months to less than 12 months
13% (n=61) 12 months or more
13% (n=62) Don't know / can't remember

Length of time to diagnosis from first seeking medical attention

52% (n=252) Less than 1 month
21% (n=104) 1 month to less than 3 months
8% (n=37) 3 months to less than 6 months
6% (n=28) 6 months to less than 12 months
8% (n=37) 12 months or more
5% (n=26) Don't know / can't remember

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



Healthcare information

Who looked for information about the disease and potential treatments?

According to patients

78% (n=382) Patient
38% (n=183) Caregiver / family
10% (n=48) Friend
7% (n=32) No one

According to care partners

49% (n=28) Patient
88% (n=50) Caregiver / family
4% (n=2) Friend
5% (n=3) No one

Patients top 3 preferred information sources

1. Conversations with healthcare staff (79%, n=384)

2. Booklets / written information (prints or digitals) / medical journals (55%, n=265)

3. Websites (43%, n=207)

Caregivers top 3 preferred information sources

1. Conversations with healthcare staff (81%, n=47)

2. Booklets / written information (prints or digitals) / medical journals (57%, n=33)

3. Websites (41%, n=24)

76% (n=372) of patients

64% (n=37) of caregivers

felt well or very well informed 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)

Top information source

Patients selected **Conversations with healthcare staff** as their top information source (61%, n=215)

Caregivers selected **Conversations with healthcare staff** as their top information source (56%, n=24)

Healthcare information

28% (n=135) of patients, and 21% (n=12) of caregivers have not used patient organisation information and support in the last 12 months.

Most accessed patient organisation information and support in the last 12 months

Patients

1. Booklets or other written information, such as newsletters (38%, n=183)
2. Websites (including videos) (31%, n=150)
3. List of questions to ask doctors (22%, n=105)
4. Contact with other patients and / or caregivers (20%, n=95)
5. Conferences / patient meetings / webinars / symposium (18%, n=85)

Caregivers

1. Booklets or other written information, such as newsletters (43%, n=25)
2. List of questions to ask doctors (41%, n=24)
3. Websites (including videos) (33%, n=19)
4. Contact with other patients and / or caregivers (31%, n=18)
5. Social media channels (Facebook, X (Twitter), LinkedIn, Instagram) (24%, n=14)

Preferred internet sources to get lymphoma or CLL information

Patients

1. Search engines (e.g., Google, Bing, etc.) (67%, n=327)
2. Public health websites (33%, n=161)
3. Hospital websites (31%, n=152)
4. Patient organisation websites (27%, n=134)
5. I do not access the internet for this type of information (12%, n=60)

Caregivers

1. Search engines (e.g., Google, Bing, etc.) (71%, n=41)
2. Hospital websites (43%, n=25)
3. Public health websites (38%, n=22)
4. Patient organisation websites (36%, n=21)
5. Facebook (19%, n=11)

Involvement in care

Involvement in decision-making

- 50% (n=240) of patients were definitely involved as much as they wanted to be in decisions about their care and treatment, while 39% (n=185) felt involved to some extent
- 10% (n=46) would like to be more involved
- 1% (n=3) 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:

17% (n=89) Patient alone
27% (n=138) Doctor alone
0% (n=2) Caregiver alone
40% (n=209) Patient and doctor together
0% (n=2) Patient and caregiver together
0% (n=2) Doctor and caregiver together
10% (n=51) Patient, doctor and caregiver together
5% (n=26) Other

17% (n=68) of patients were given more than one treatment option

16% (n=65) of patients did not have treatment options

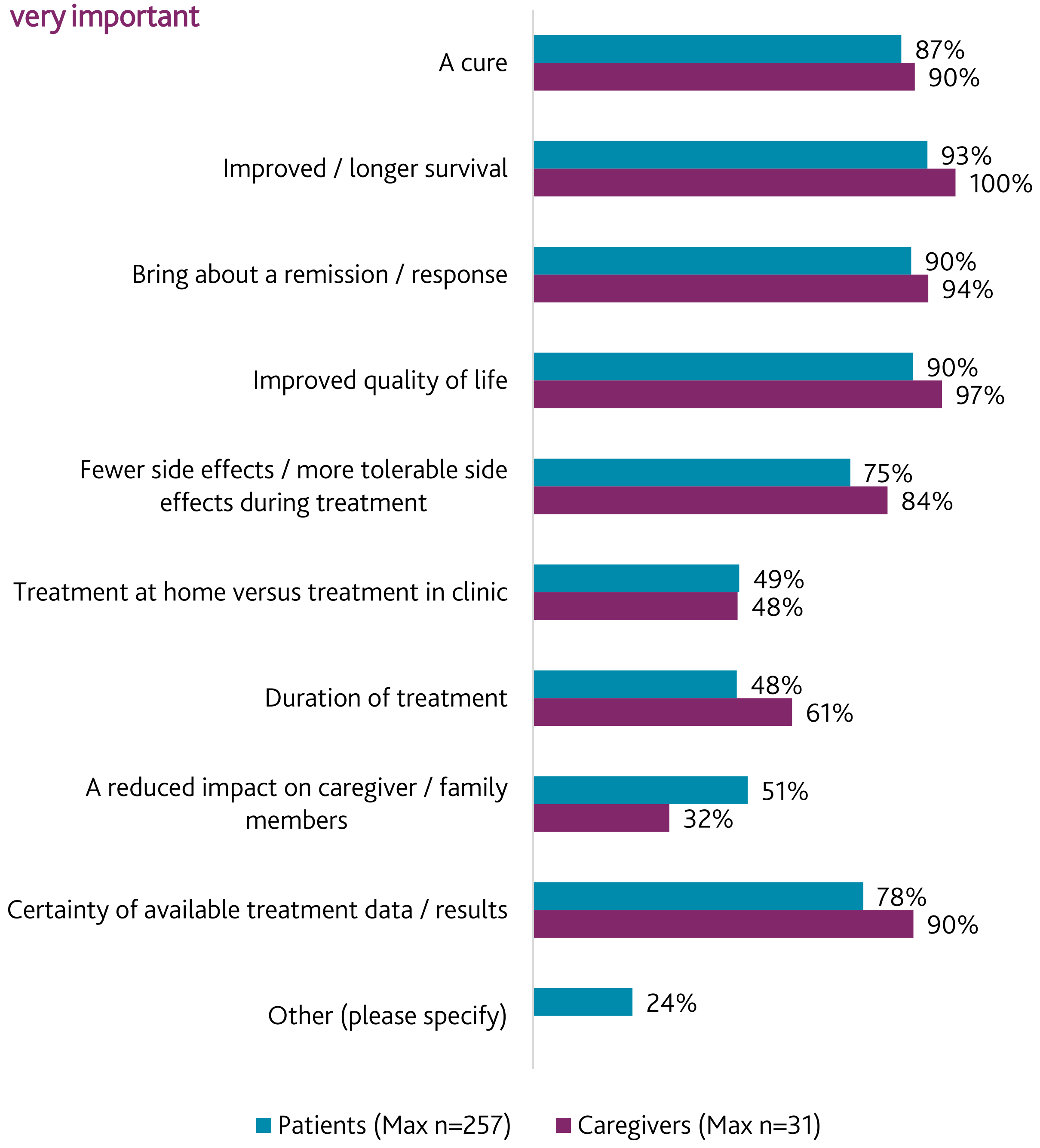
61% (n=247) of patients reported they had an adequate amount of time to think about their treatment options before a decision was made about their current or most recent treatment

Important aspects of treatment

The most important aspect of treatment for patients was **Improved / longer survival** (93%, n=238)

The most important aspect of treatment for caregivers was **Improved / longer survival** (100%, n=31)

Proportion of patients and caregivers rating aspects of treatment as important or very important



Involvement in care

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

- ✓ 85% (n=441) agreed they have a treatment plan, and they understand it
- ✓ 90% (n=470) agreed they have confidence in the doctor who is coordinating their care
- ✓ 74% (n=383) agreed their lifestyle and favourite activities were discussed with the doctor to maintain their quality of life as much as possible
- ✓ 75% (n=387) agreed they understand that past treatment may impact their choices for future treatment, if the disease comes back or progresses

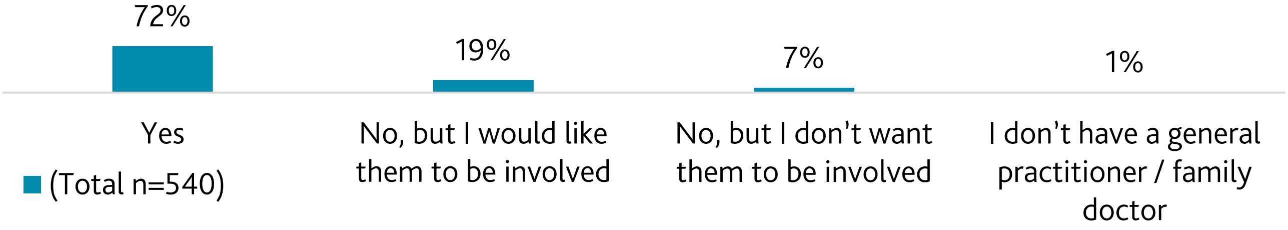
When asked to think about doctor encouragement regarding participation in decision-making…

- ✓ 45% (n=235) said their doctor always encourages them to ask questions
- ✓ 52% (n=267) said their doctor always ensures they understand answers to their questions
- ✓ 63% (n=326) said their doctor always allows them to express themself without interrupting
- ✓ 73% (n=373) said their doctor always talks to them in a kind and sensitive way
- ✓ 71% (n=367) said their doctor always listens to them carefully

The following proportion of respondents said that it was important or very important that their doctor…

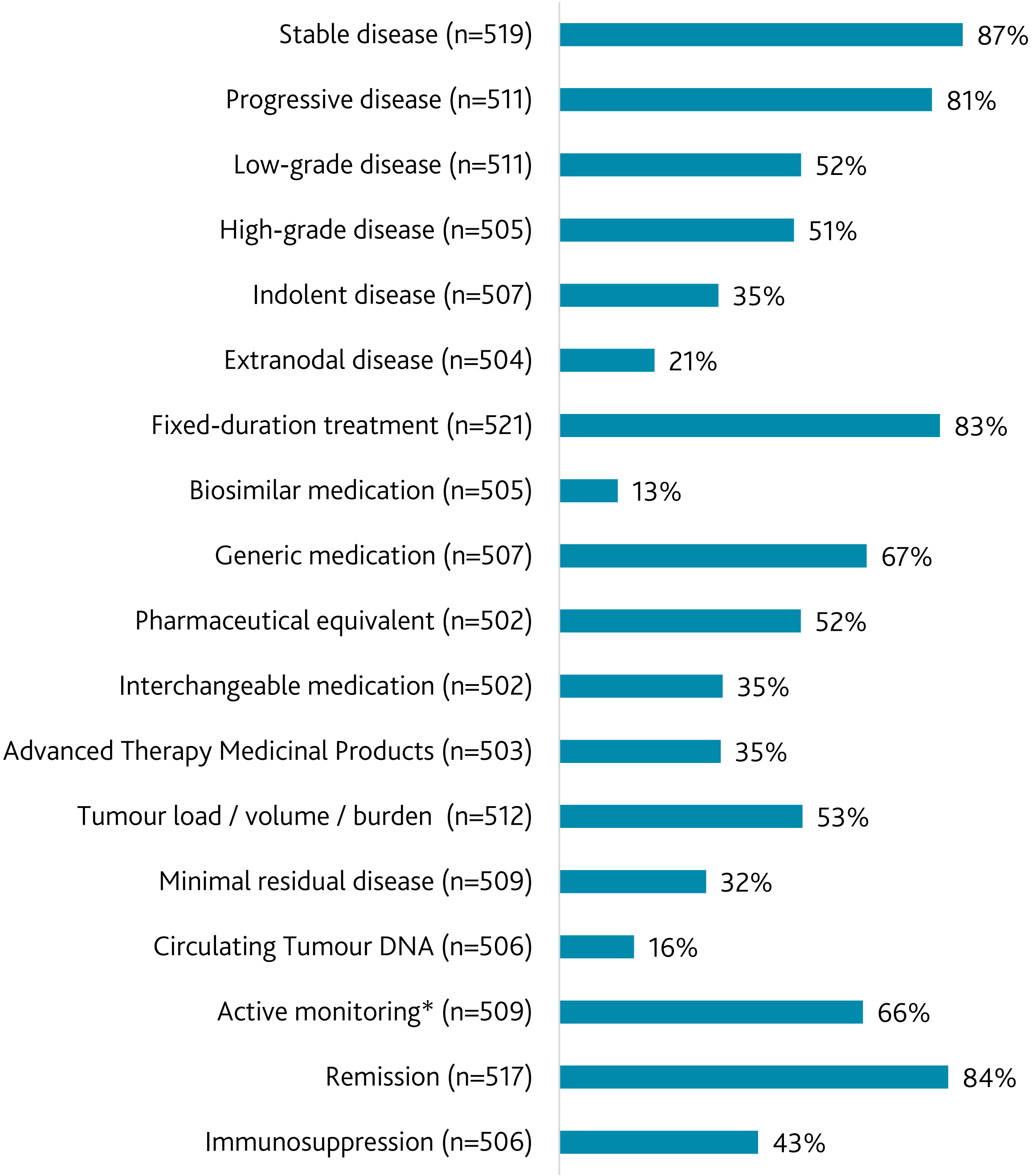
- ✓ Tells the full truth about the diagnosis or test results when breaking difficult news (98%, n=510)
- ✓ Asks how much they want to be involved in decisions about their care and treatment (96%, n=492)
- ✓ Understands what is important to the patient and/or their caregiver when managing their care (96%, n=487)
- ✓ Provides information or support so that they can confidently manage their lymphoma or CLL (95%, n=484)
- ✓ Helps them understand the cost implications of treatment options (78%, n=399)

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?



Understanding of medical terms

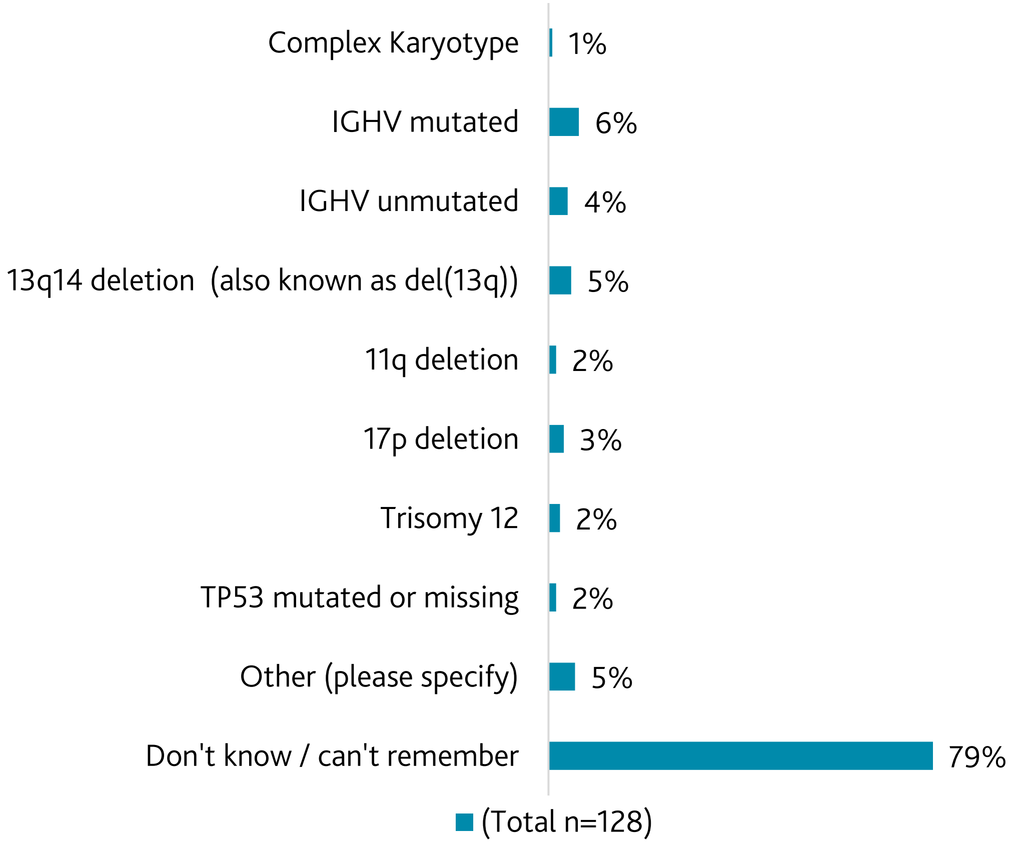
Respondents were asked to truthfully answer whether or not they understand the following terms doctors sometimes use to explain lymphoma / CLL to their patients. Below is the proportion of respondents who reported yes, they have enough understanding of terms relating to disease status, treatment options and possible treatment outcomes and phases



*or Active surveillance or Watch and Wait

Testing for gene mutation status

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



Treatment

Treatment experience

31%	23%	27%	19%
Are currently in treatment (n=158)	Had treatment within the last 2 years (n=120)	Had treatment more than 2 years ago (n=137)	Have not had treatment (n=100)

Location of treatment and / or follow-up appointments

- 55% (n=218) All in a medical centre close to where they live
- 32% (n=125) All in a medical centre in a region different from that of their residence
- 6% (n=25) Some care is being delivered partly in a medical centre in their region of residence, partly in a different medical centre
- 6% (n=25) Other (please specify)

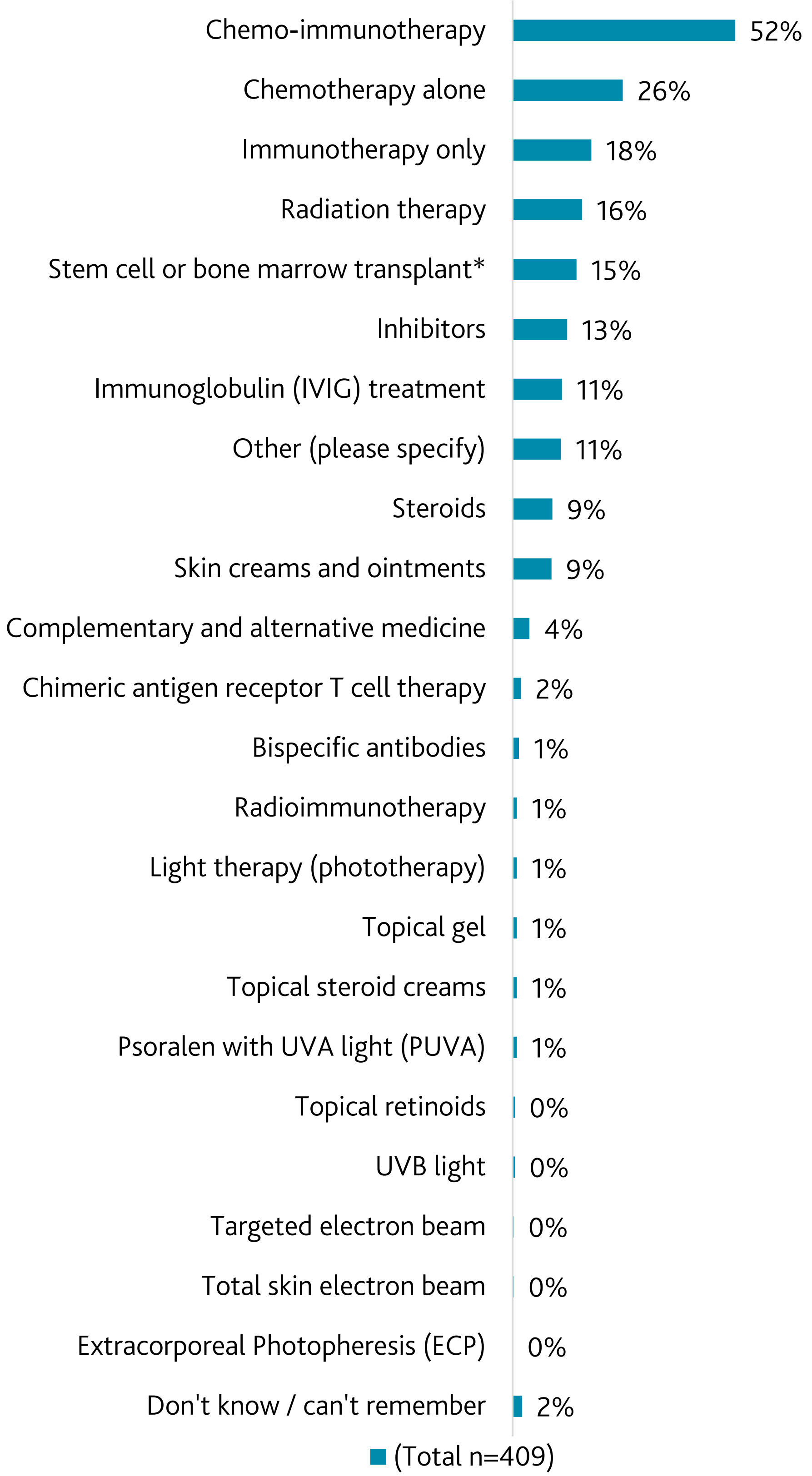
Number of regimens to date

- 40% (n=158) have had 1 treatment regimen
- 25% (n=98) have had 2 treatment regimens
- 9% (n=37) have had 3 treatment regimens
- 16% (n=62) have had 4 or more treatment regimens

Side effects from most recent treatment

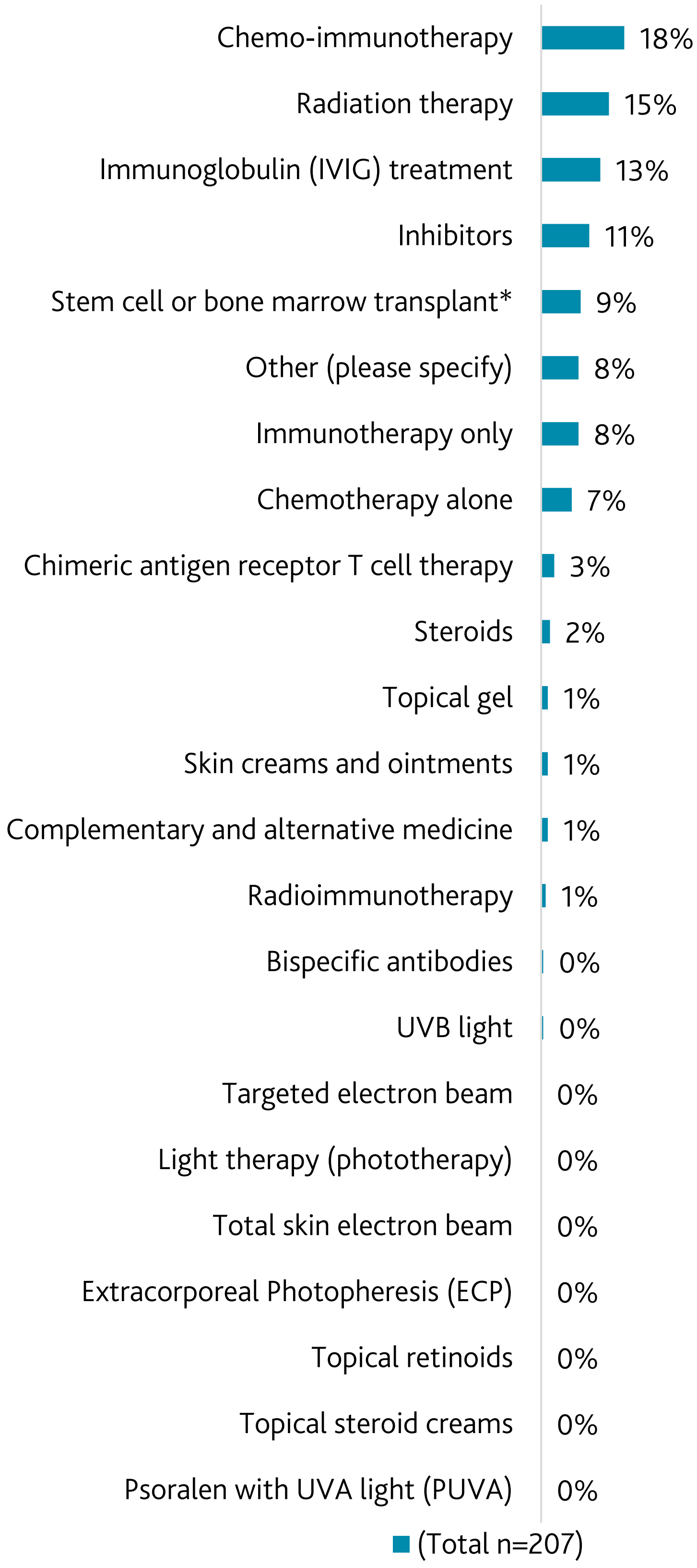
- 94% (n=366) experienced side effects from their most recent treatment
- 6% (n=23) did not experience side effects

Treatments received



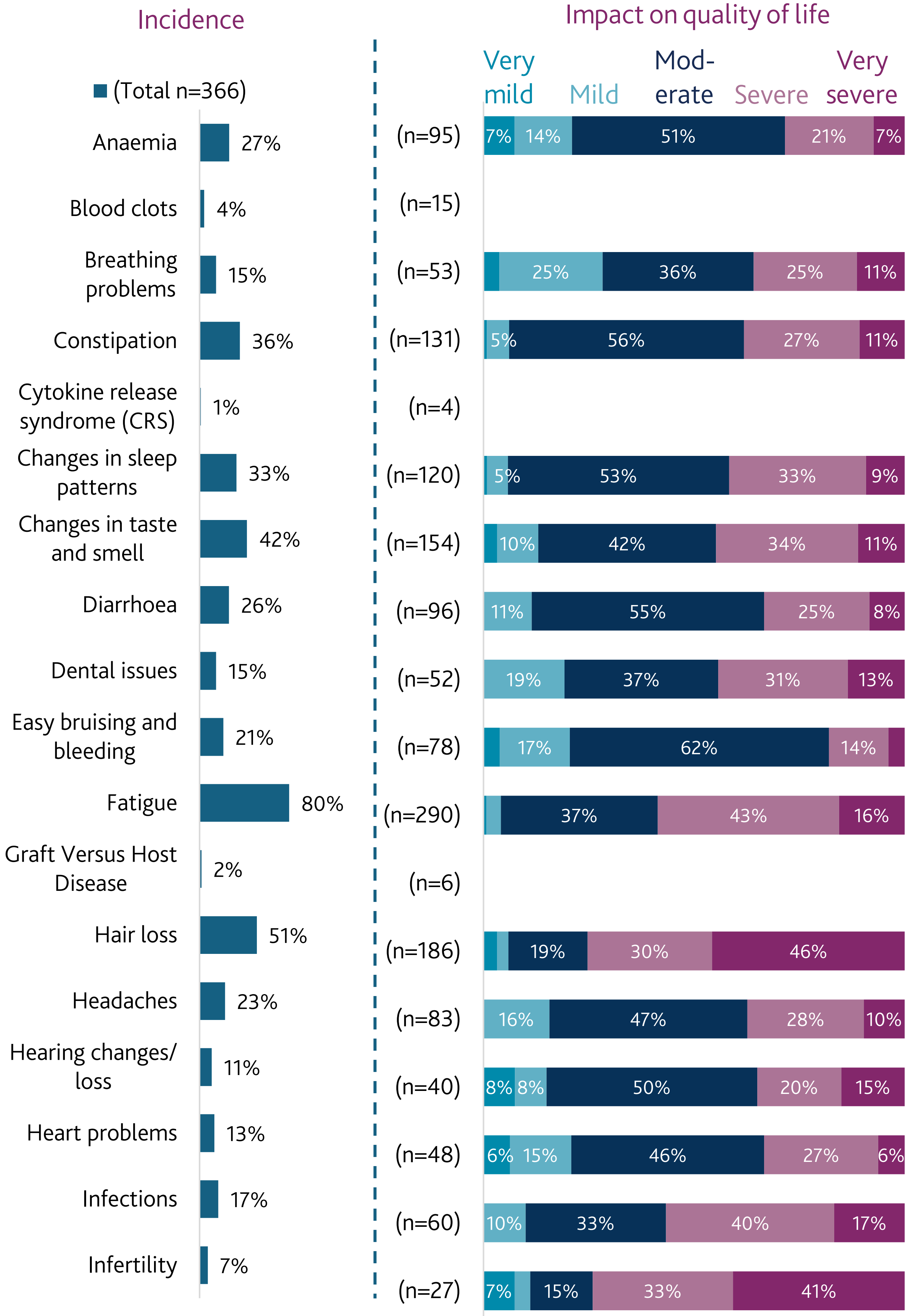
*Autologous or allogeneic

Most recent treatment received

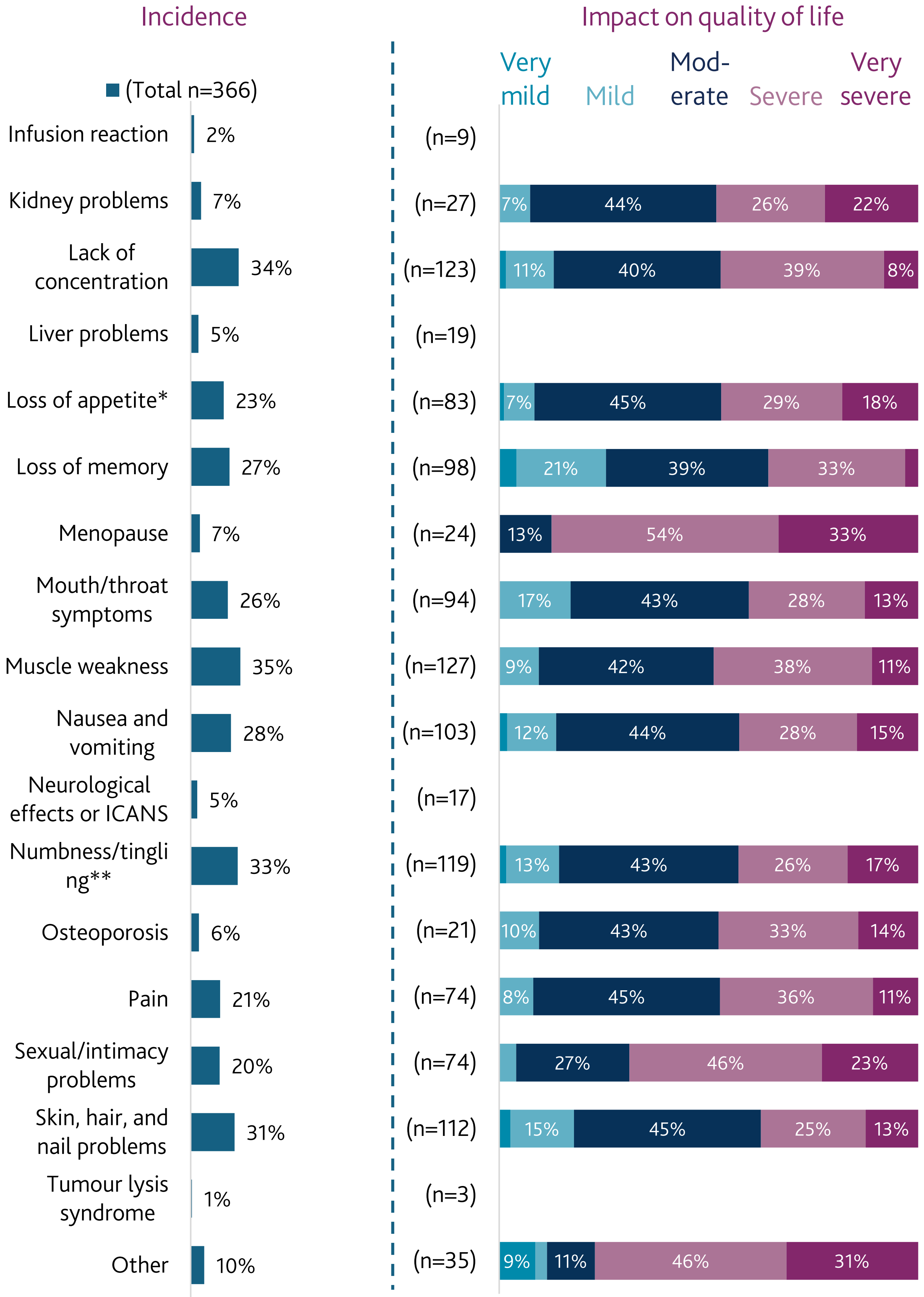


*Autologous or allogeneic

Incidence and impact of side effects

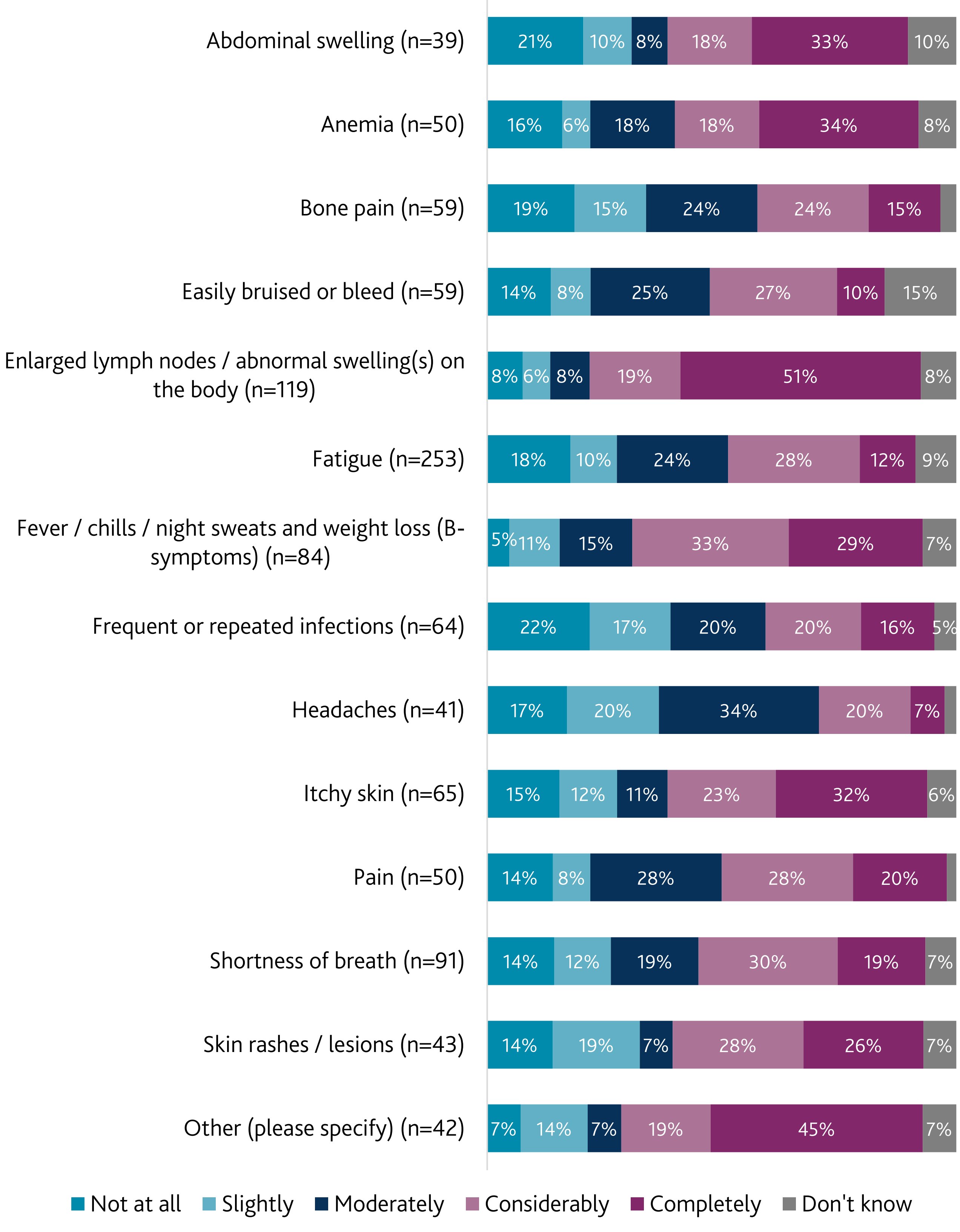


Incidence and impact of side effects



*or difficulty eating **of arms/legs/hands/feet

Effectiveness of treatments in managing symptoms

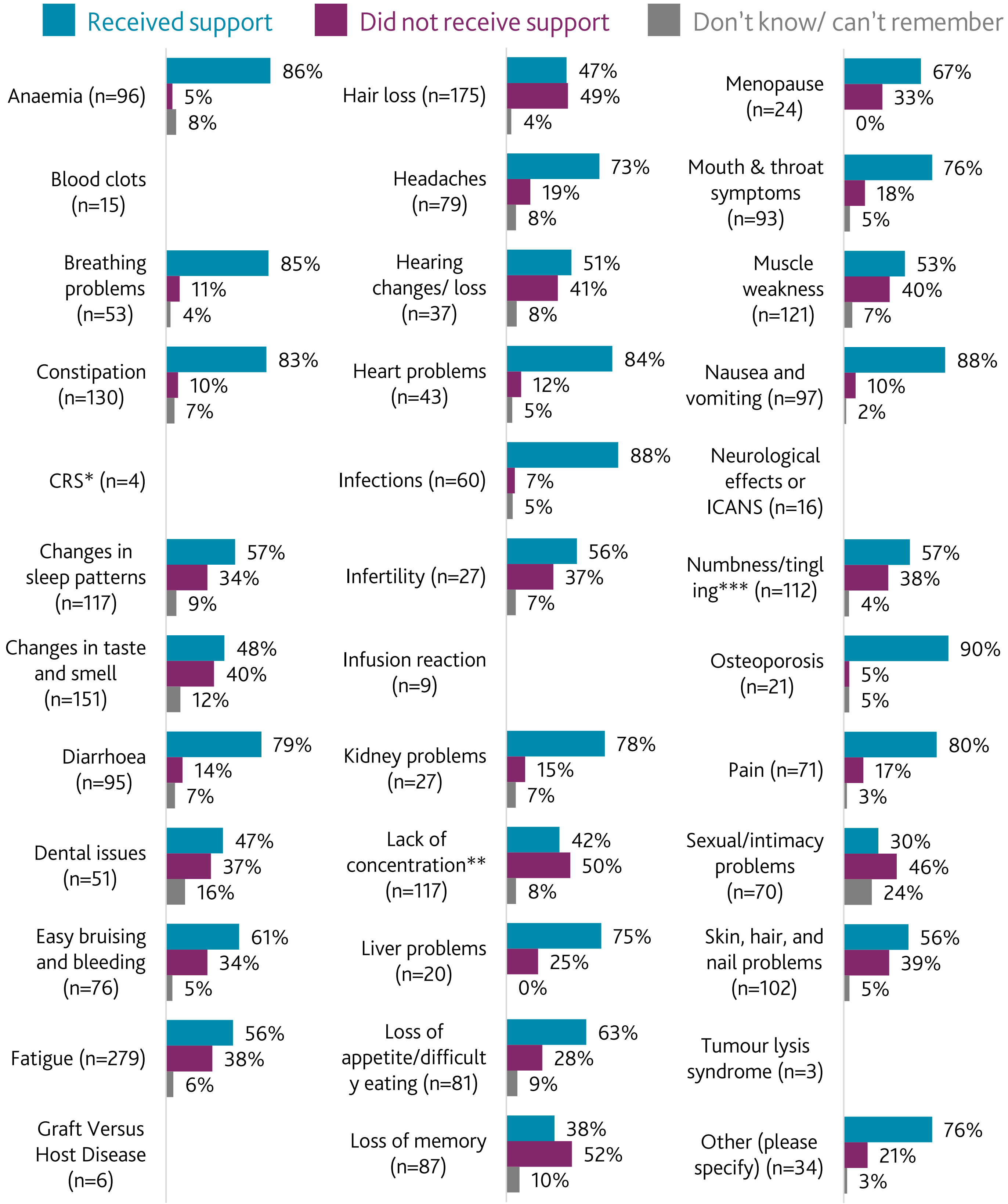


Information provision on impact of treatment on fertility

Respondents were asked if they received any information about treatment side effects on fertility and about fertility preservation opportunities before starting treatment

- 40% (n=161) wanted this information and received this
- 3% (n=13) did not want this information but received this
- 7% (n=26) did not receive this information but would have liked this
- 42% (n=169) did not receive this information and didn't want or need this
- 7% (n=29) didn't know or couldn't remember

Medical team support with side effects



*Cytokine release syndrome **inability to multitask ***of arms/legs/hands/feet

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Perception of treatment

55% (n=207) of patients would not have chosen a different treatment option

33% (n=123) of patients did not have a choice of treatment options

In hindsight, 6% (n=21) of patients would have chosen a different treatment option

Respondents who said they would choose a different treatment option said this was because of…

1% (n=5) long-term consequences

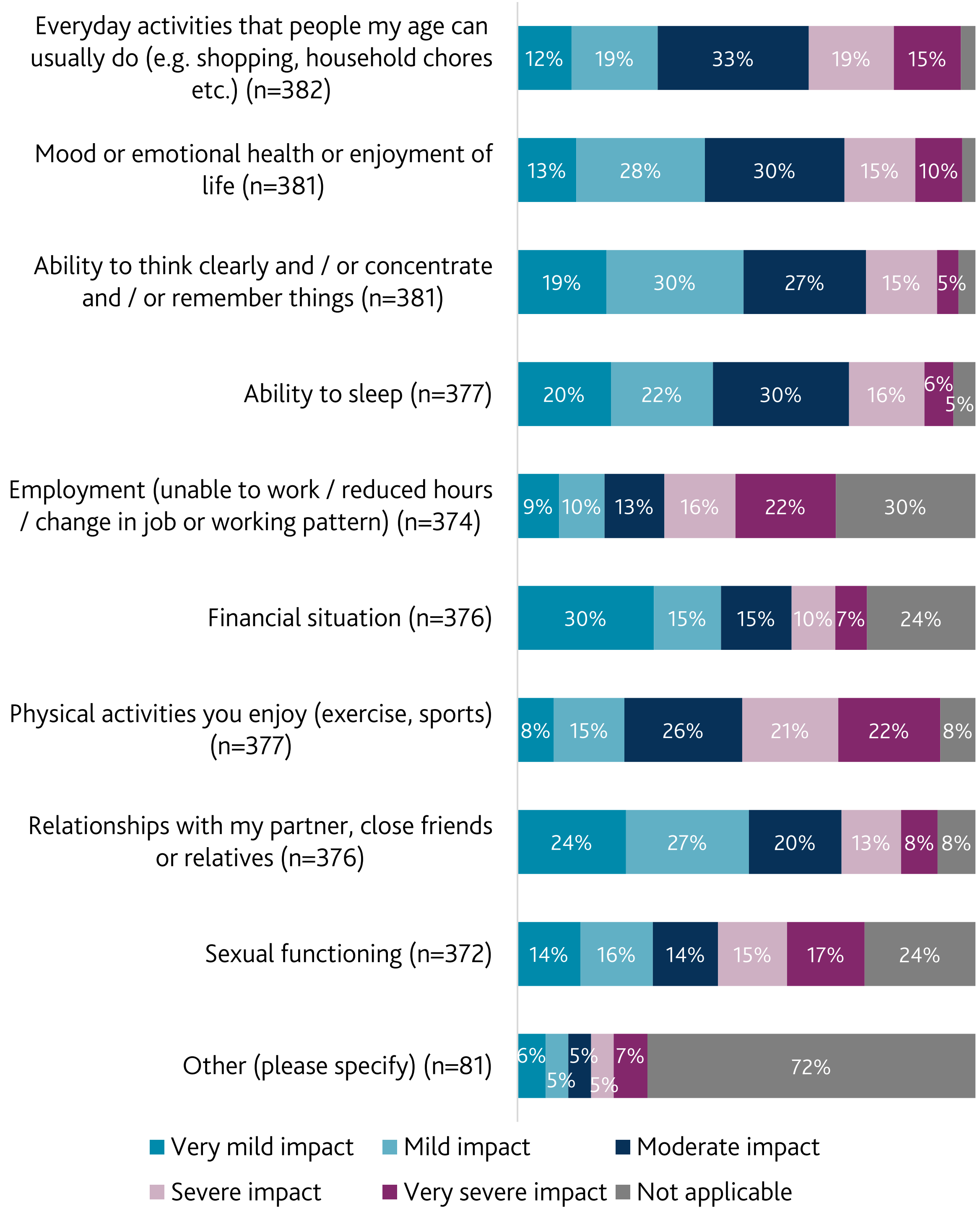
3% (n=10) impact on quality of life

1% (n=2) cardiovascular consequences

1% (n=4) neuropathy

Impact of fatigue

Patients experiencing fatigue were most likely to say their **relationships with their partner, close friends or relatives** (51%, n=190) was moderately, severely or very severely affected in their day-to-day life in the last week

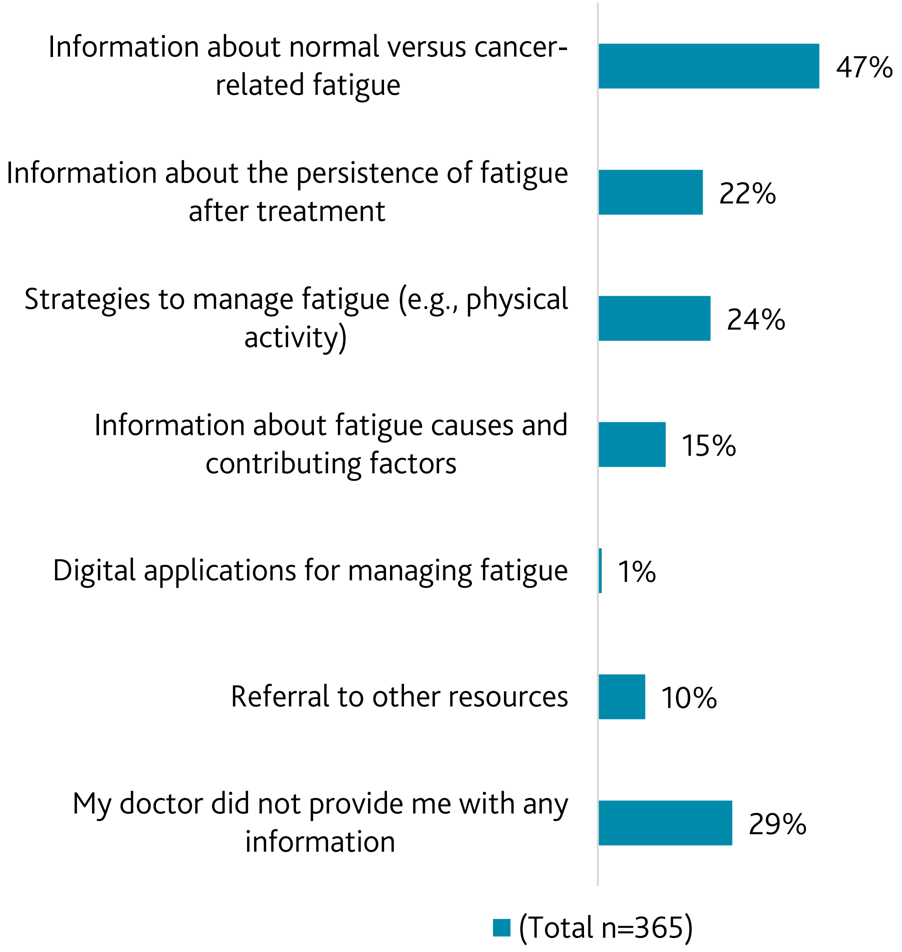


Support for fatigue from doctor

Thinking about the last 2 years…

Patients who received information / support on fatigue from their doctor were most likely to receive **Information about normal versus cancer-related fatigue** (47%, n=173).

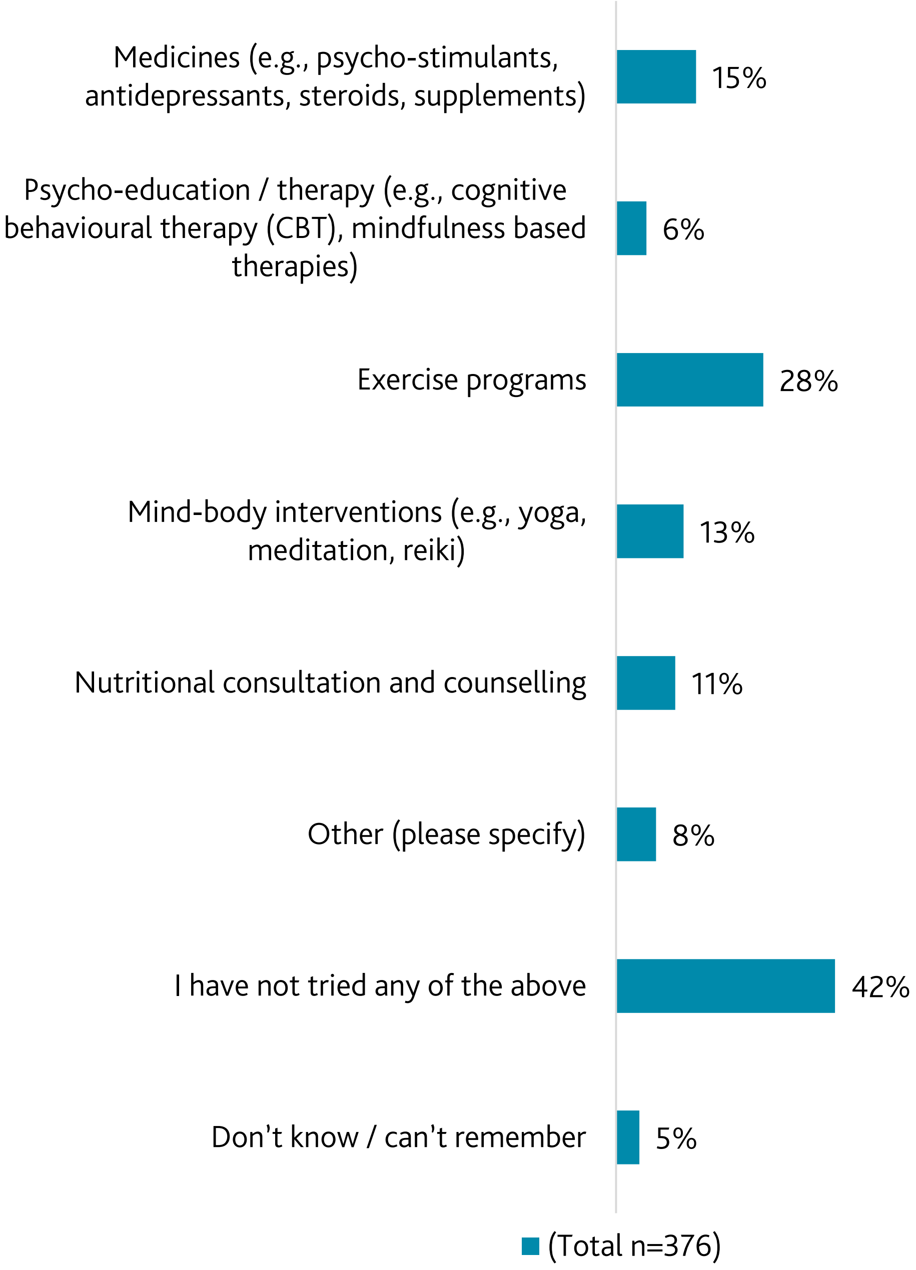
76% (n=271) said they have had the opportunity to discuss their fatigue with a doctor a great deal or to some extent



Managing cancer-related fatigue

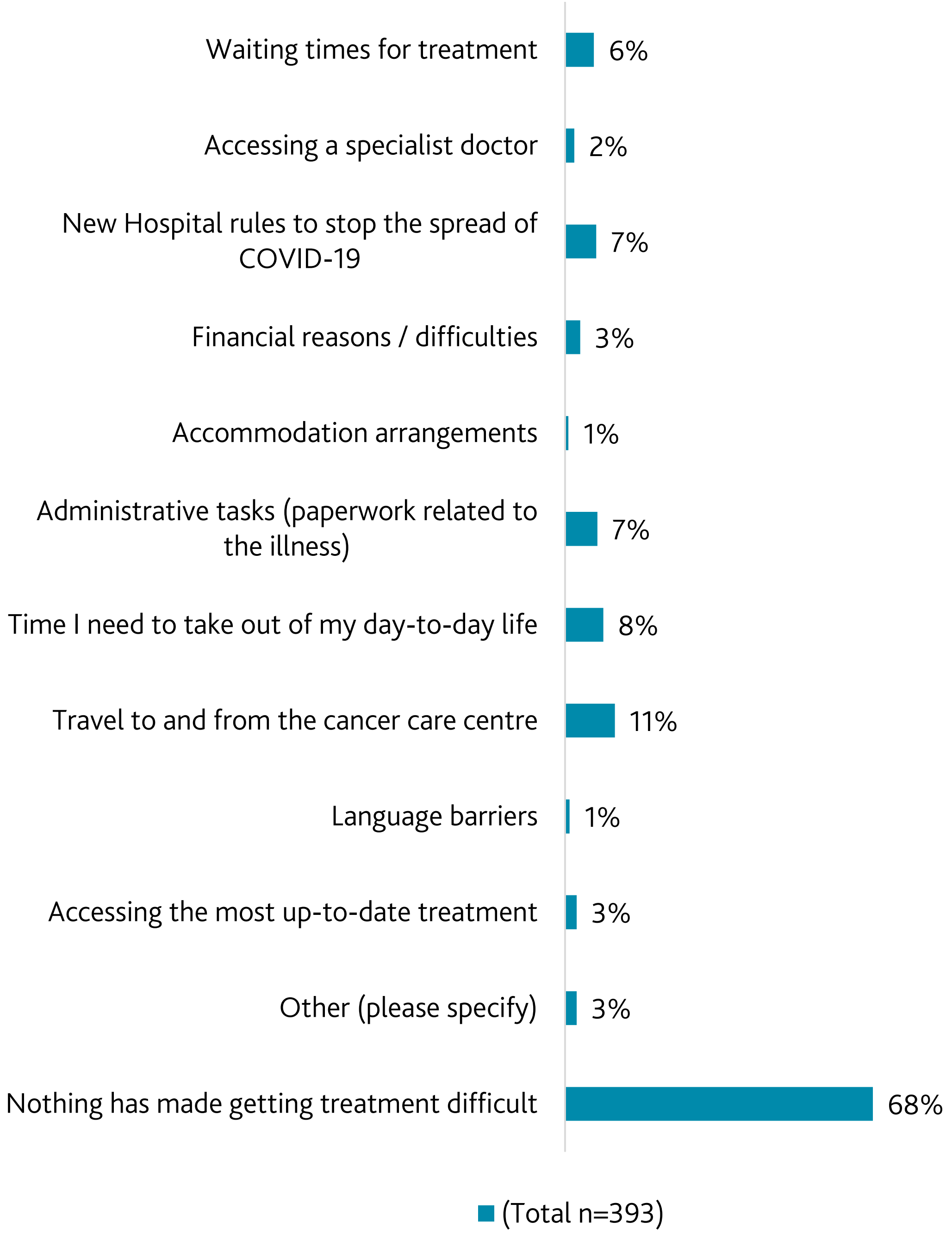
Patients were most likely to find **Exercise programs** (28%, n=107) helpful in managing their cancer-related fatigue

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

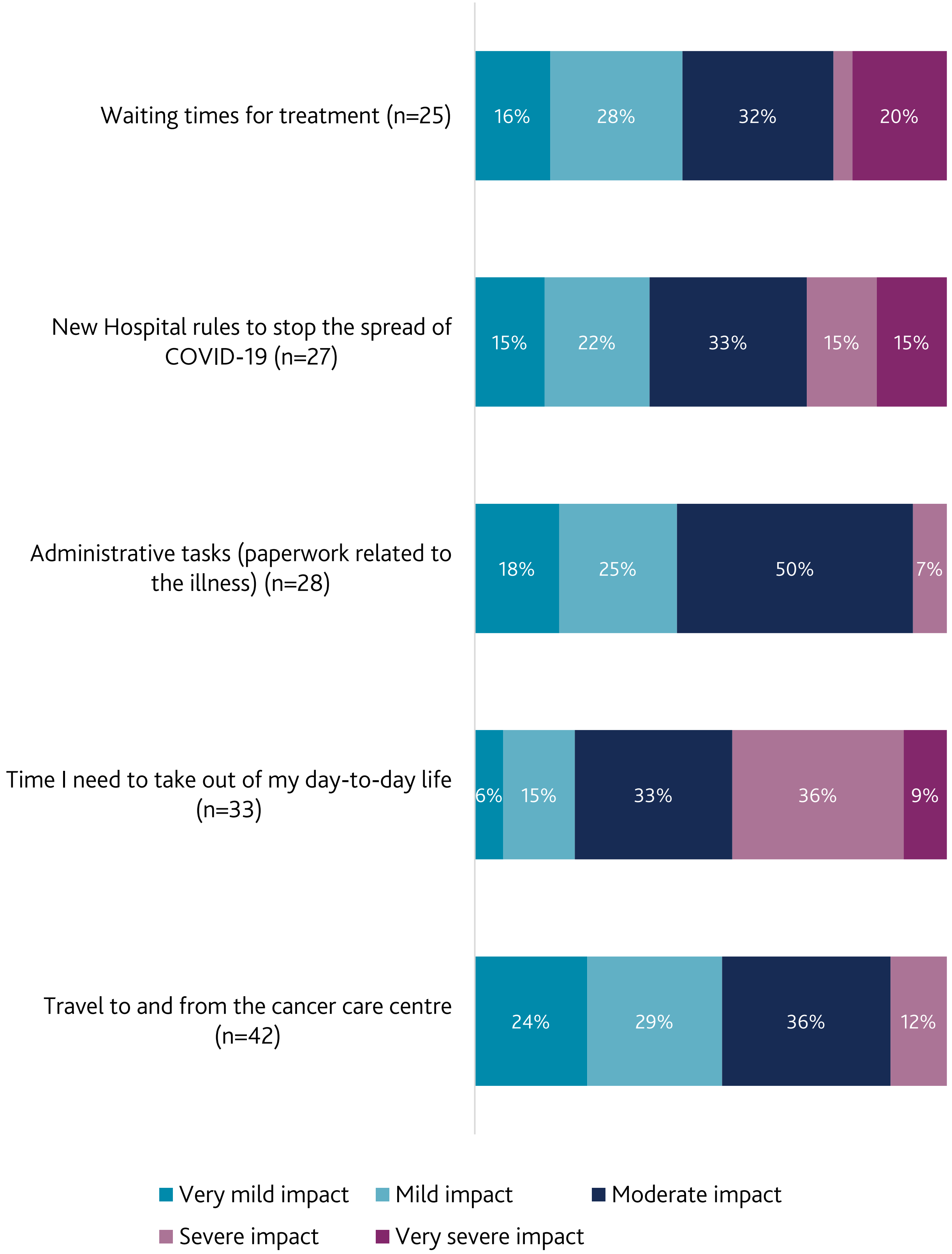


Treatment barriers for patients

32% (n=127) of patients experienced a barrier that made getting their most recent treatment more difficult.

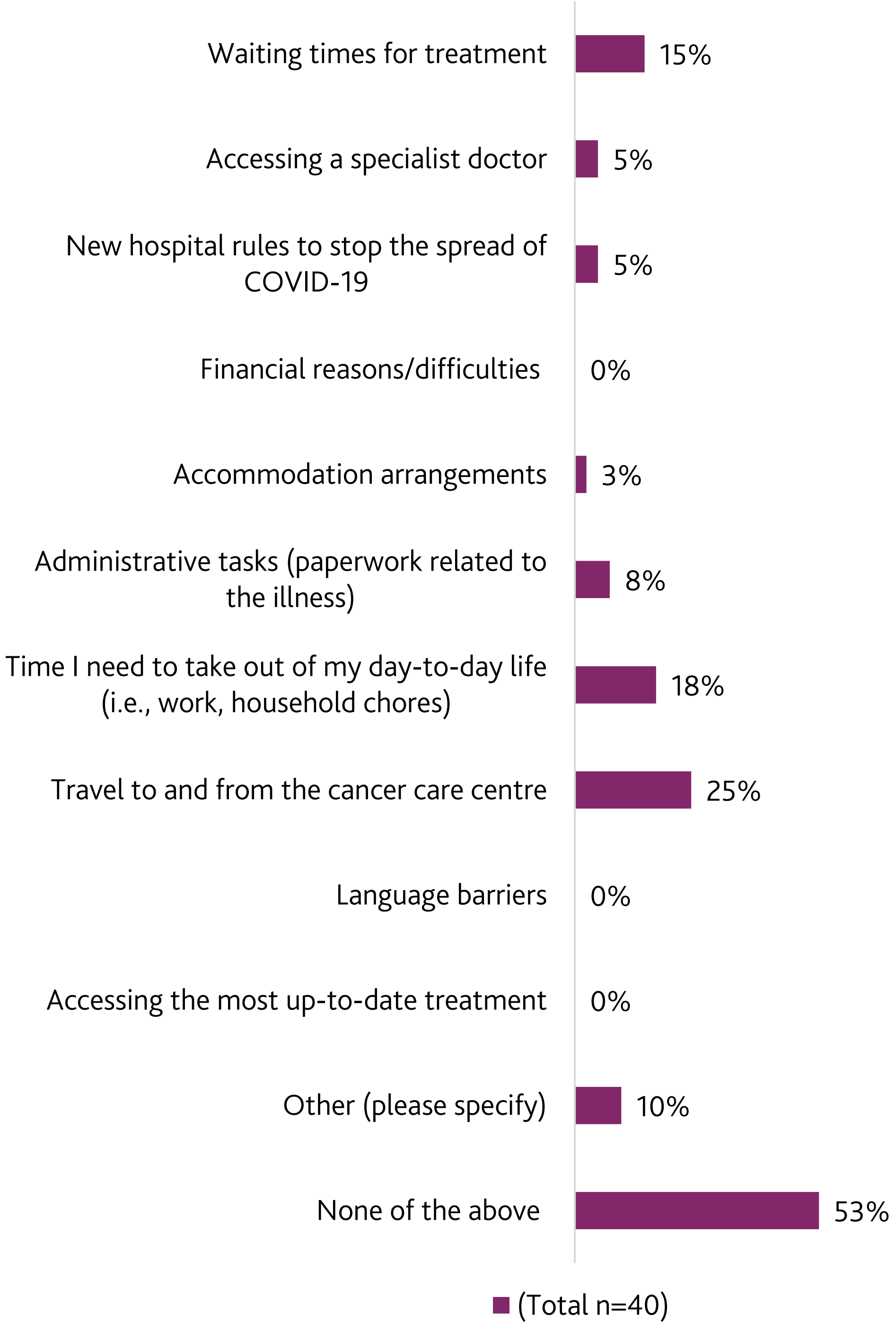


Impact of treatment barriers for patients



Treatment barriers for caregivers

48% (n=19) of caregivers experienced a barrier that made getting the patients most recent treatment more difficult.



Clinical trials

When asked about information provision related to clinical trial options…

- 29% (n=141) received this information from their doctor and understood their clinical trial options
- 2% (n=12) received this information but didn’t understand the information provided
- 8% (n=38) received this information but they were not related to the patients case
- 33% (n=158) did not receive any information about clinical trials
- 24% (n=116) did not receive this information as they needed to start treatment without delay

80% (n=386) of respondents were aware that participation in a clinical trial provides access to newer drugs with potentially better outcomes compared to standard therapy

21% (n=101) of patients have participated in a clinical trial for their lymphoma or CLL

Top 3 reasons for not participating in clinical trials

1. Never been offered to take part in a clinical trial (82%, n=302)

2. Fear of potential unknown side effects (7%, n=27)

3. Other (please specify) (7%, n=27)

Future participation

62% (n=302) are likely or very likely to participate in a cancer clinical trial if invited in future

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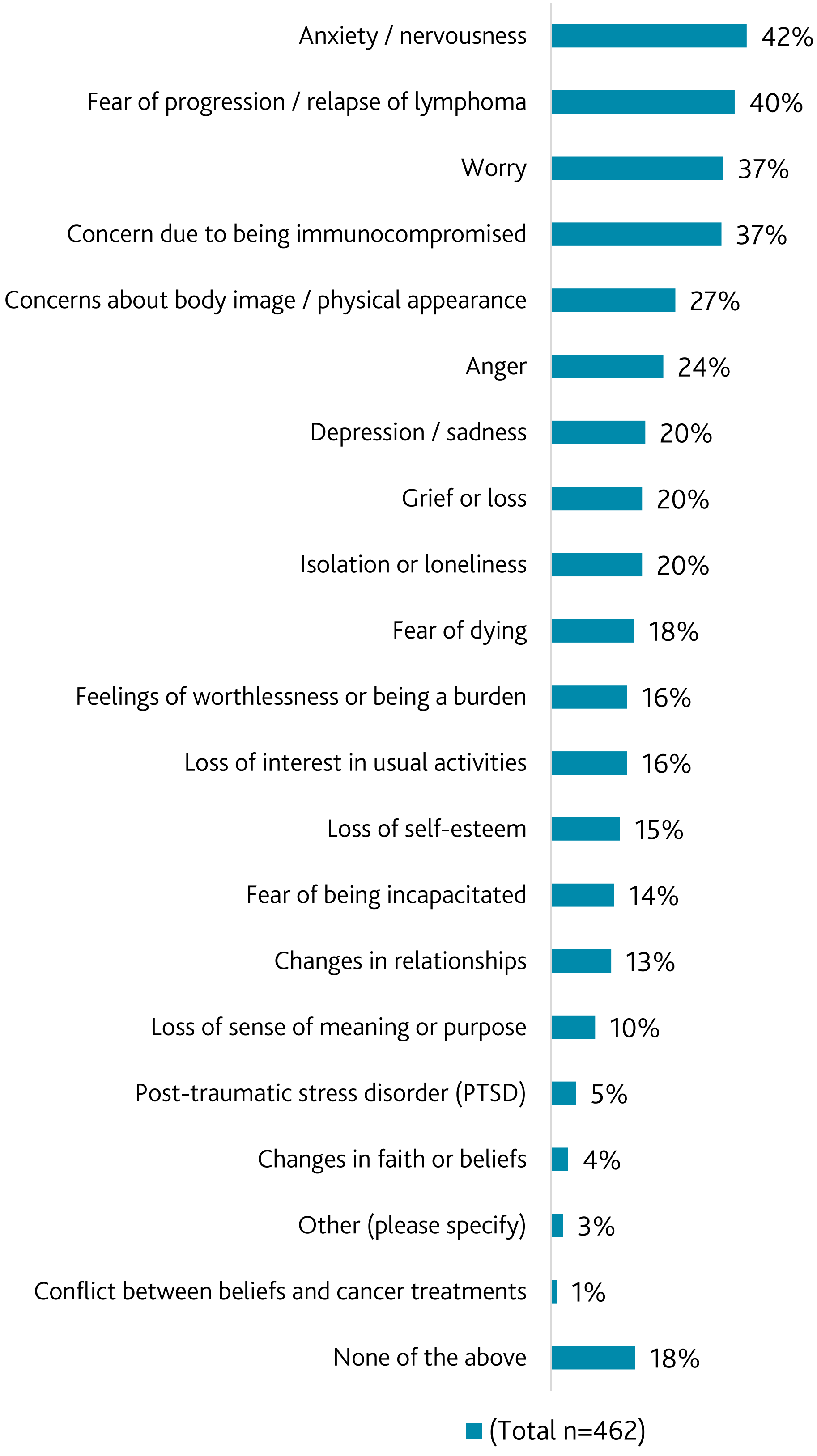
Emotional impact of lymphoma or CLL in last 6 months



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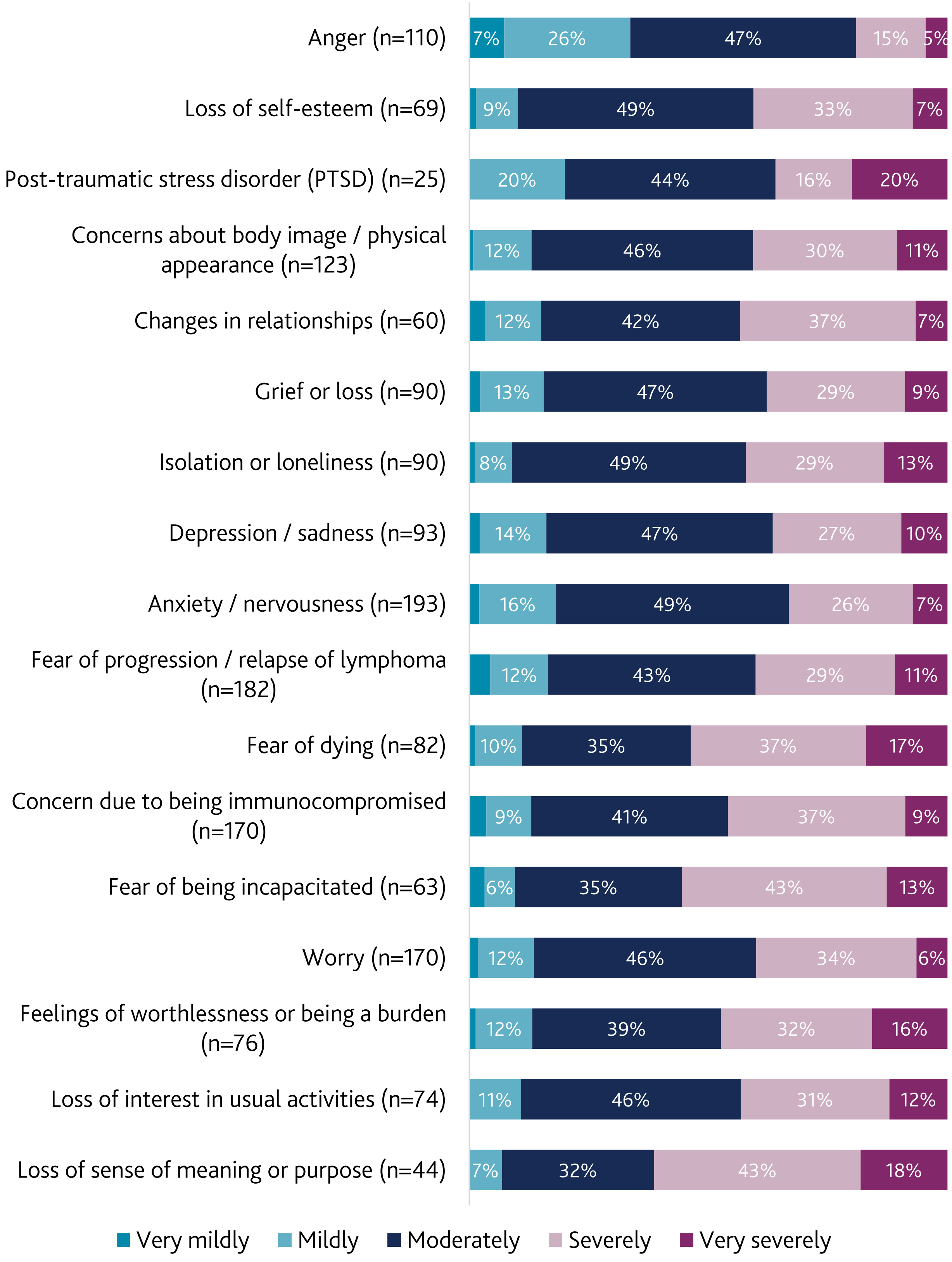
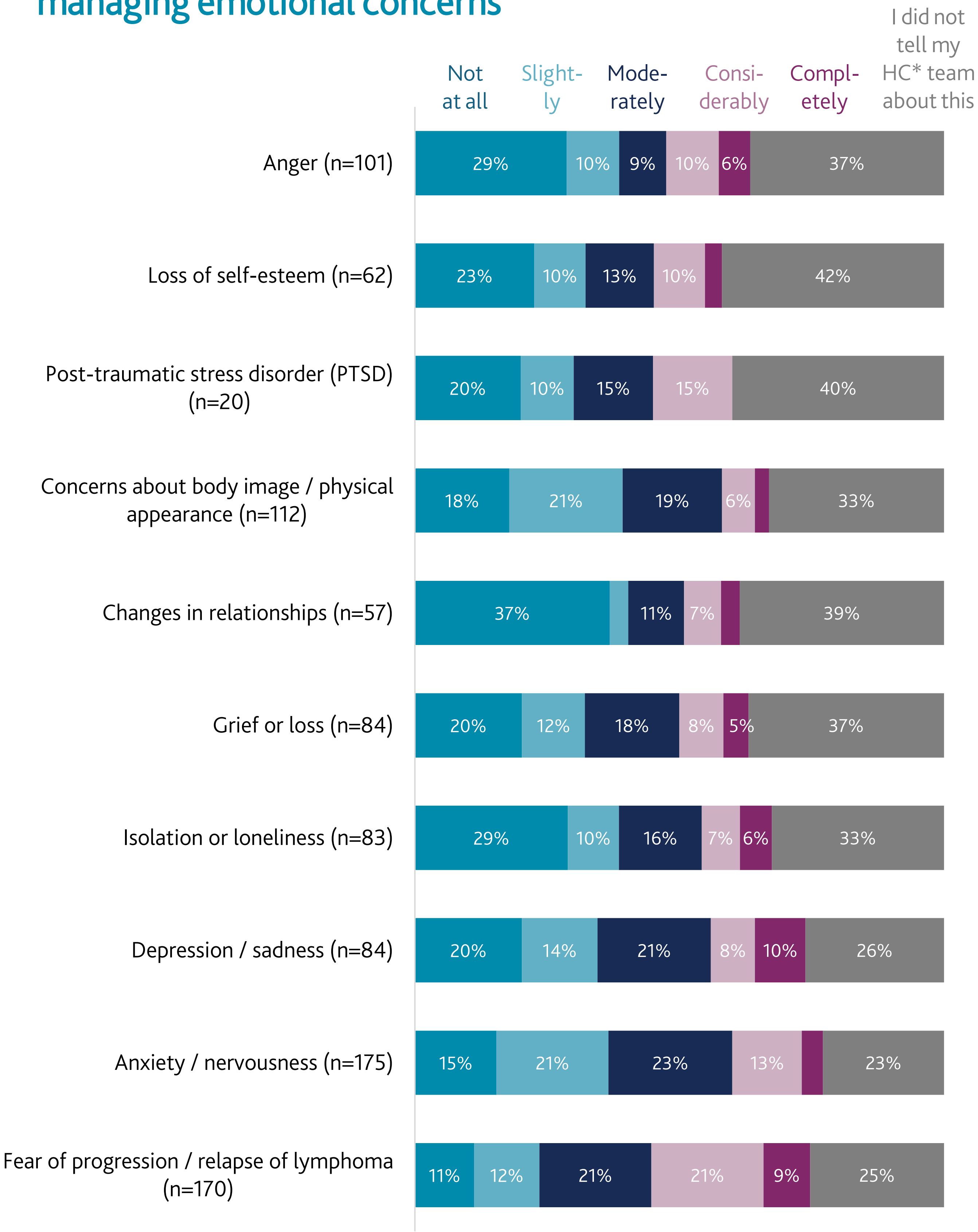
Extent of emotional impact of lymphoma or CLL in last 6 months



Helpfulness of care provided by medical team in managing emotional concerns



*healthcare

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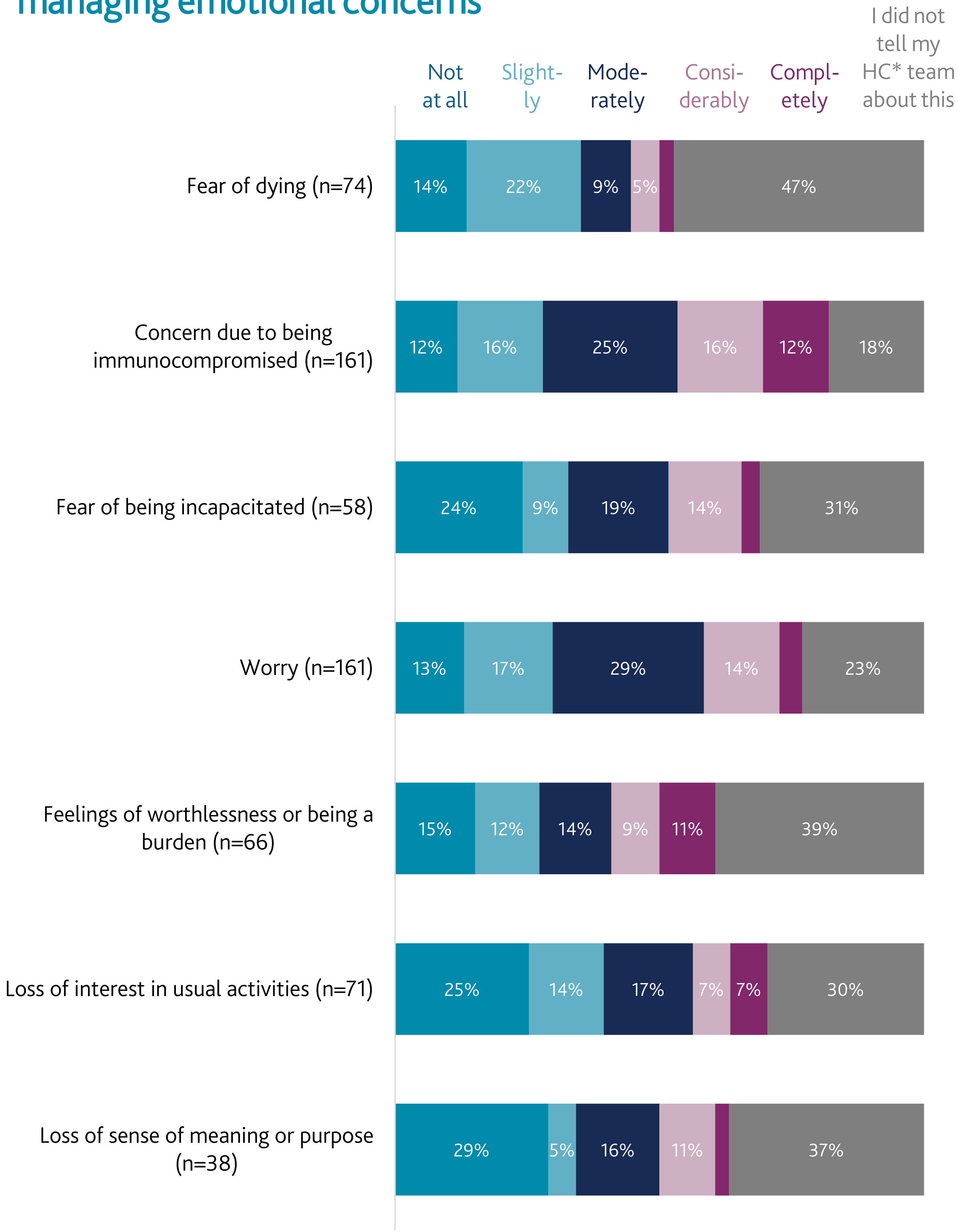
Helpfulness of care provided by medical team in managing emotional concerns



*healthcare

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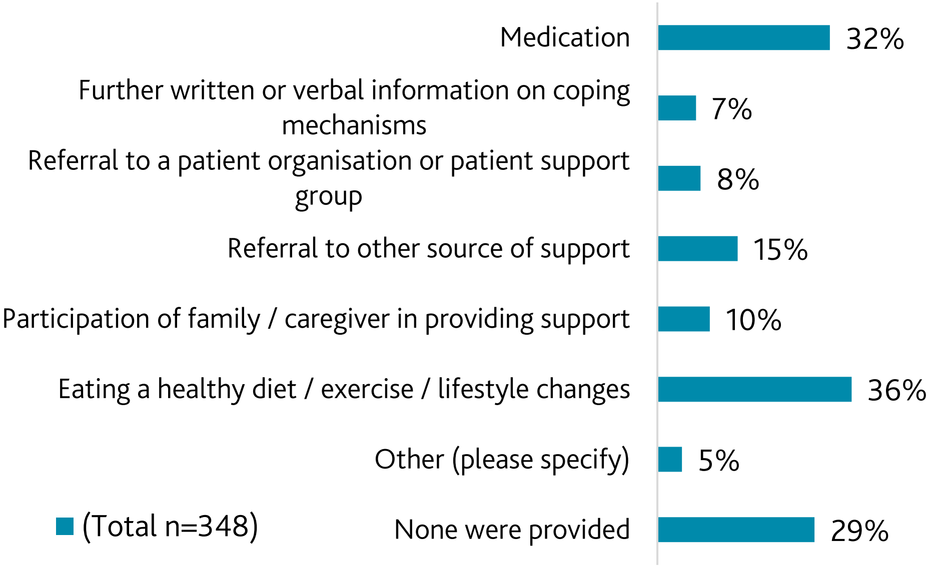
Management of patient wellbeing

At their last appointment, 47% (n=218) of patients reported their doctor definitely asked questions that were relevant to their quality of life or wellbeing. 30% (n=139) 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, 49% (n=227) said they understand a great deal, while 38% (n=177) said they understand to some extent.

3% (n=15) said their doctor does not ask about their quality of life.

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



56% (n=129) of patients completely followed through on recommendations from their doctor regarding the issues that they were experiencing, while 35% (n=81) partially followed through.

54% (n=154) of patients reported their healthcare team did <u>not</u> follow up with them about the worries or concerns they were experiencing. 15% (n=42) of patients reported their healthcare team definitely followed up with them about the worries or concerns they were experiencing, while 26% (n=75) said their healthcare team followed up to some extent.

Impact on sexual life

20% (n=96) of patients reported their diagnosis of lymphoma or CLL has had a great negative impact on their sexual life

28% (n=129) said it has had a negative impact to some extent

When asked about impact on their sexual life, the following proportion of patients reported they have experienced

- 20% (n=60) emotional distress
- 24% (n=69) stress
- 55% (n=162) fatigue
- 26% (n=76) lack of self-esteem / self-image
- 35% (n=104) sexual dysfunction (vaginal dryness, erectile dysfunction)
- 48% (n=141) lack of libido
- 4% (n=12) difficulty finding a sexual partner
- 11% (n=31) problems with their partner
- 4% (n=12) other (please specify)

13% (n=62) of patients reported they have discussed their sexual life with their doctor. 75% (n=346) have not and do not think this is necessary, and 6% (n=29) have not but would have preferred to have these discussions.

Impact on relationships and finances

Impact living with cancer has on relationships

- 30% (n=147) agreed they have lost friends who don't understand the nature of their cancer and what that means for them
- 74% (n=369) agreed their friends are supportive
- 80% (n=404) agreed their immediate family understand the nature of their cancer and support them
- 71% (n=356) agreed their extended family understand the nature of this cancer and support them

Financial discrimination due to Lymphoma or CLL diagnosis

- 82% (n=420) of patients reported they have never felt discriminated against financially because of their lymphoma or CLL diagnosis

- 4% (n=18) reported they have felt discriminated against in accessing banking, credit or insurance services because of their diagnosis and they are currently receiving treatment / therapy

- 14% (n=74) reported they have felt discriminated against in accessing banking, credit or insurance services because of their diagnosis and are not currently in treatment

Returning to work

- 16% (n=32) of patients did not return to work following their diagnosis or treatment
- 14% (n=28) of patients did not stop working as a result of their diagnosis or treatment
- 28% (n=57) of patients were not working at the point of their diagnosis or treatment
- 9% (n=19) of patients did not experience difficulties upon returning to work following their diagnosis or treatment

Patients who stopped working during diagnosis and treatment, most commonly experienced the following difficulties upon returning to work…

1. Concern of feeling well enough or having the energy to get through the work day (21%, n=42)

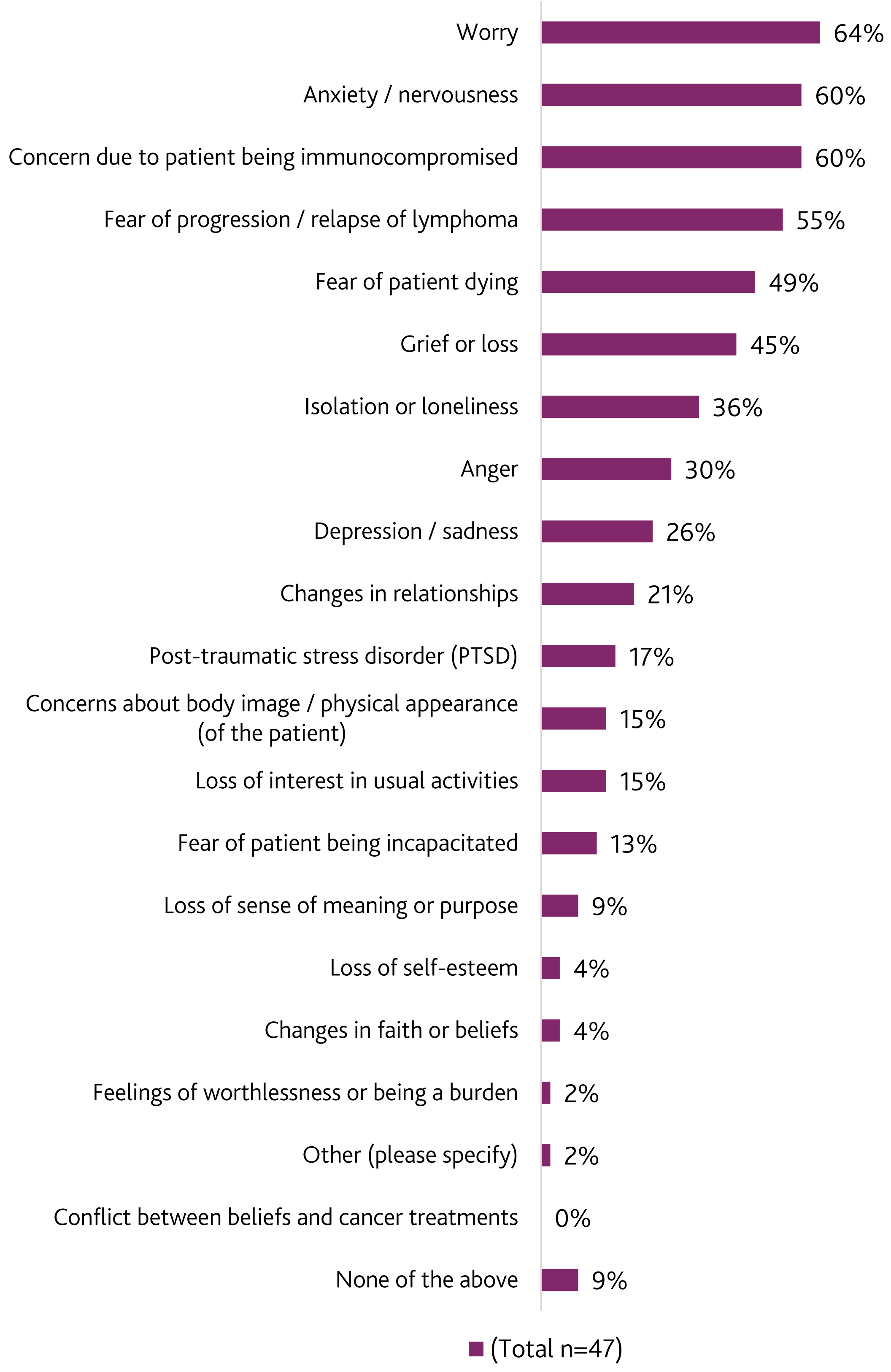
2. Concern about work ability being questioned or difficulty being promoted (12%, n=25)

3. Other (please specify) (9%, n=19)

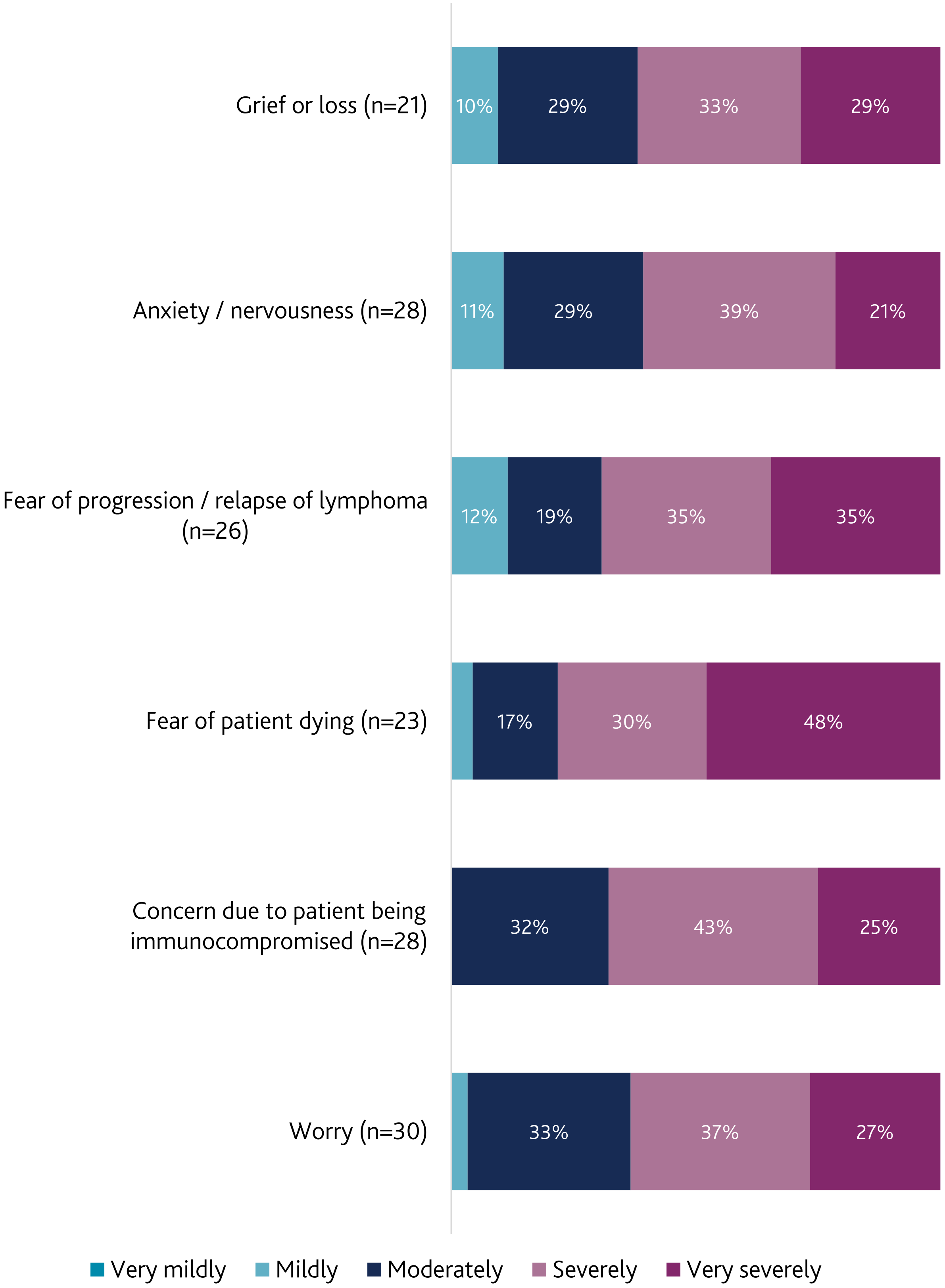
The following proportion of respondents would like to see improvements for awareness in the workplace that people with Lymphoma or CLL…

- May currently have health problems or be at high risk for health problems in the future (38%, n=71)
- May have decreased or different work ability due to their diagnosis and treatment (41%, n=78)
- May have decreased ability to perform daily tasks compared to their co-workers (36%, n=67)
- Can have their emotional behaviours and personality affected by Lymphoma or CLL (34%, n=64)
- May have various limits in socialising or developing relationships with co-workers due to their diagnosis (22%, n=42)

Emotional impact on care partner in last 6 months



Extent of emotional impact on care partner in last 6 months



Care partner wellbeing

47% (n=20) of care partners discussed their worries and concerns with a healthcare professional

Since the patient was diagnosed, 20% (n=9) of care partners have had to stop working (either temporarily or permanently), 11% (n=5) have had to work reduced hours, and 0% (n=0) have had to work additional hours

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 90 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.

LC's current strategy is focused on ensuring impact within two pillars: information and advocacy, which is partially achieved through collecting data from the biennial Global Patient Survey (GPS).

Our vision

A better future for everyone impacted by lymphoma.

Our mission

Enabling global impact by fostering a lymphoma ecosystem that ensures local change and evidence-based action.

For more information on the work Lymphoma Coalition do, 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 ISO20252:2019 (GB08/74322) via SGS and ISO27001:2013 (GB10/80275) via Alcumus ISOQAR. We comply with Data Protection Laws including the General Data Protection Regulation, the Data Protection Act 2018 and the Market Research Society's (MRS) Code of Conduct.

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