2024 Global Patient Survey on Lymphomas & CLL

Global Report

LYMPHOMA
COALITION

Contents

Executive summary

Lymphoma Coalition (LC) is a non-profit organisation comprised of a worldwide network of patient advocacy groups that support those affected by lymphoma, including chronic lymphocytic leukaemia (CLL). LC was formed in 2002, launched its first web-based Global Patient Survey on Lymphomas and CLL (GPS) in 2008, and has conducted a biennial survey ever since. The goal of the GPS is to understand the patient and caregiver experience in lymphomas and CLL, and the impact of treatment and healthcare. The data generated from the GPS helps drive planning and policy development, bridge knowledge gaps, and advocate for equitable care across borders. The data collected serves as the foundation for scientific abstracts, joint research initiatives, policy papers, and international collaborations and presentations.

The GPS underwent extensive review to develop the 2024 questionnaire and included the introduction of new topics to better understand the impact on employment and health literacy through the comprehension of medical terms and treatment options. Health related quality of life and performance status were also assessed for respondents. LC member organisations in countries with 100+ responses to the 2022 LC GPS were invited to add up to five country-specific questions. Two subtype-specific member groups were provided the same opportunity.

Picker was commissioned by LC to deliver the 2024 GPS on lymphomas and CLL. The survey was available in 20 languages and was promoted by LC member organisation networks, healthcare professionals, and scientific and community partners worldwide.

The 2024 Global Patient Survey received 11170 responses from 79 countries. Of these respondents, 87% (n=9693) have been diagnosed with lymphoma or CLL (patients), while 13% (n=1477) are caregivers, friends or family members of someone who has lymphoma or CLL. This report presents the data from all respondents.

Key findings

Patient information at diagnosis

49% (n=4449) of patients who experienced symptoms, saw a doctor three or more times about their symptoms before receiving a diagnosis of lymphoma or CLL.

66% (n=7309) of patients were told the lymphoma subtype they had or that they had CLL at diagnosis.

33% (n=3614) of respondents reported that the patient did not receive a correct first diagnosis.

51% (n=5709) agreed their diagnostic tests and results were completely explained in a way they could understand.

Patient involvement in care and treatment and shared-decision making

59% (n=6641) of respondents felt well or very well informed about the processes and stages of the patient's health care related to the lymphoma or CLL diagnosis.

52% (n=4875) of patients were definitely involved as much as they wanted to be in decisions about their care and treatment.

When thinking about their current or most recent treatment, 61% (n=4690) felt they were given adequate time to think about their treatment options before a decision was made.

70% (n=5240) of patients were <u>not</u> given more than one treatment option before their current or most recent treatment.

11% (n=800) of patients would have chosen a different treatment option in hindsight.

Experience of barriers

41% (n=3030) of patients experienced a barrier that made getting their most recent treatment more difficult.

69% (n=595) of caregivers reported experiencing a barrier that made going through the most recent round of treatment difficult.

21% (n=2164) of patients have felt discriminated against in accessing banking, credit or insurance services because of their lymphoma or CLL diagnosis.

23% (n=2185) of patients agreed that the current measures implemented in their care centre to stop the spread of COVID-19 act as a barrier to optimal care for their lymphoma or CLL.

45% (n=453) of caregivers have had to stop working either temporarily, permanently or reduce their working hours since the patient was diagnosed.

Side effects of treatment and fatigue

94% (n=6838) of patients experienced side effects from their most recent treatment for lymphoma or CLL. The most common side effect experienced was fatigue (66%, n=4794).

46% (n=3150) of patients who experienced fatigue reported their doctor had <u>not</u> provided them with any fatigue related information/ support over the last two years.

Clinical trials

48% (n=4632) of patients did not receive any information about clinical trials from their lymphoma or CLL doctor, while 17% (n=1643) reported they did not receive this information because they needed to start treatment without delay.

77% (n=7388) of patients were aware that participation in a clinical trial provides access to newer drugs with potentially better outcomes compared to standard therapy.

Only 13% (n=1227) of patients have participated in a clinical trial for their lymphoma or CLL either in the past or presently.

59% (n=5626) of patients indicated that they were likely to participate in a cancer clinical trial in the future, if invited.

Patient wellbeing

25% (n=2292) of patients reported that their doctor did not ask questions that were relevant to their quality of life at their last appointment.

Only 38% (n=3504) of patients reported that their doctor greatly understands the impact of lymphoma or CLL on their quality of life.

Since their diagnosis of lymphoma or CLL, 72% (n=6681) of patients reported making changes to their lifestyle, such as dietary changes, less use of alcohol, exercise etc. 94% (n=5078) reported they are maintaining these lifestyle changes now.

40% (n=2895) of patients who experienced an impact to their wellbeing in the last 6 months did not receive any recommendations from their healthcare team. 55% (n=3088) of patients reported that their healthcare team did not follow-up with them about their worries or concerns.

Background

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.

Our vision

Equity in lymphoma outcomes across borders.

Our mission

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

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).

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

Background on the Global Patient Survey

LC launched its first online-based GPS on Lymphomas and CLL in 2008 and has conducted a biennial survey ever since. The survey seeks to understand the patient experience with lymphomas, including CLL, and the impact of treatment and care. The GPS is promoted by LC patient member organisations, scientific partners, healthcare providers and community alliances. Examples of some of LCs partners and alliances include the Hematology Nurses and HealthCare Allied Professionals group (HNHCP), European Hematology Association (EHA), International Lymphoma Epidemiology Consortium (InterLymph), Union for International Cancer Control (UICC), and multidisciplinary healthcare professionals, among many others.

The survey responses have provided rich datasets that have fostered a culture of collaboration and knowledge sharing. Patient experiences from the GPS have served as the foundation of scientific abstracts, publications, reports and the development of various patient resources in addition to highlighting areas for further research. The information collected over the years has been instrumental in advocating for equitable care and evoking change for people affected by lymphoma. The dissemination of data has served to develop successful campaigns and presentations to healthcare professionals and other stakeholders who play a role in the care of patients.

Methodology

Questionnaire development

An extensive review was completed to develop the 2024 GPS questionnaire. The survey was redesigned with consultation between Lymphoma Coalition, patient member groups and Picker. Picker was commissioned by LC to deliver the 2024 GPS on lymphomas and CLL. New topics were introduced to further understand the impact of lymphoma and CLL on employment, health literacy and treatment options. 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 caregivers, 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. For example: Q23: “What statement best describes where you are in the lymphoma or CLL experience?”. Only respondents who answered “In remission” to this question, were directed to Q25: “You have said that you are in remission, how long has it been since the last treatment?”. Consequently, some questions were only asked to 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.

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.

At the end of the survey, respondents were redirected to a follow up survey that asked if they would like to be contacted in the future about other surveys or research related to their health experiences. 5665 respondents indicated they would like to be contacted about future research opportunities. Due to the redirection to a new survey, contact details could not be linked to answers provided within the GPS and responses remained confidential.

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.

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 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, 2811 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 means the percentage had 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.

Dissemination

The LC dissemination and data preservation plan ensures all best practice and ethical guidelines have been met. All critical data and documentation files produced during the data collection process are stored behind a security system, on the LC password protected server.
In addition to the global report, country specific and subtype specific reports are available as separate documents and include[1]:

- Argentina
- Australia
- Belgium
- Bulgaria
- Canada
- China
- Denmark
- France
- Germany
- India
- Ireland
- Israel
- Italy
- Japan
- Netherlands
- Philippines
- Portugal
- Republic of Korea
- Serbia
- Slovakia
- Switzerland
- United Kingdom
- United States of America
- Cutaneous Lymphoma
- Waldenstrom's Macroglobulinemia

Please visit the following for examples of how the data collected from the GPS is used and disseminated:

- LC 2022 GPS survey reports
- Lymphoma report card (2022)
- European report 2022
- Abstracts and scientific posters
- Subtype reports e.g., CLL
- World Lymphoma Awareness Day (WLAD)

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[1] Country and subtype specific reports will be available online from November 2024.

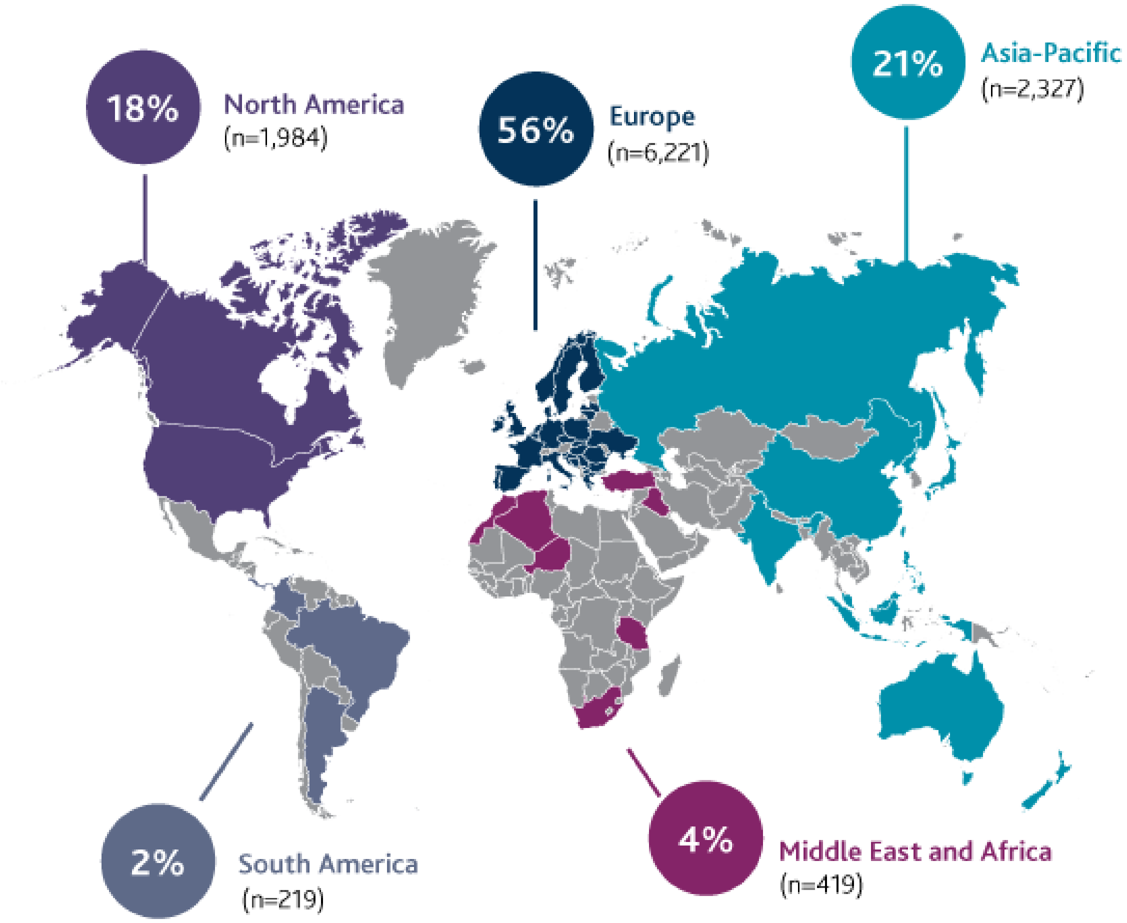
Patient and caregiver characteristics

The 2024 Global Patient Survey received 11170 responses from 79 countries. Of these respondents, 87% (n=9693) have been diagnosed with lymphoma or CLL (patients), while 13% (n=1477) are caregivers, friends or family members of someone who has lymphoma or CLL.

In total, 23 countries had 100+ responses to the 2024 GPS. Countries with the most responses were:

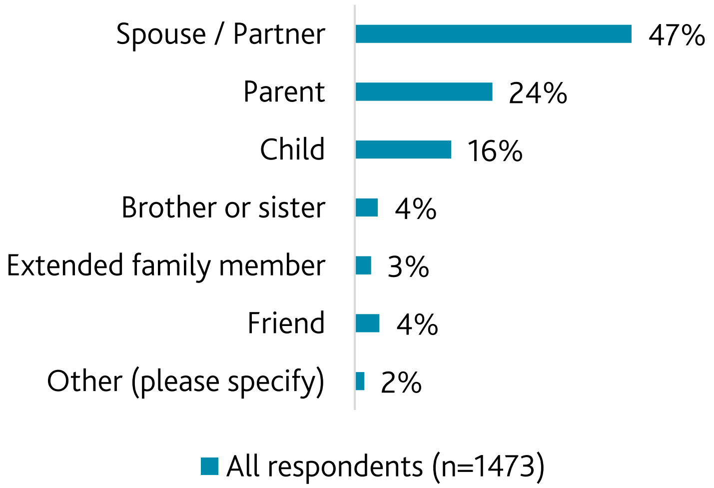
- France (17%, n=1890)
- United Kingdom of Great Britain and Northern Ireland (11%, n=1204)
- United States of America (10%, n=1167)

Global region distribution



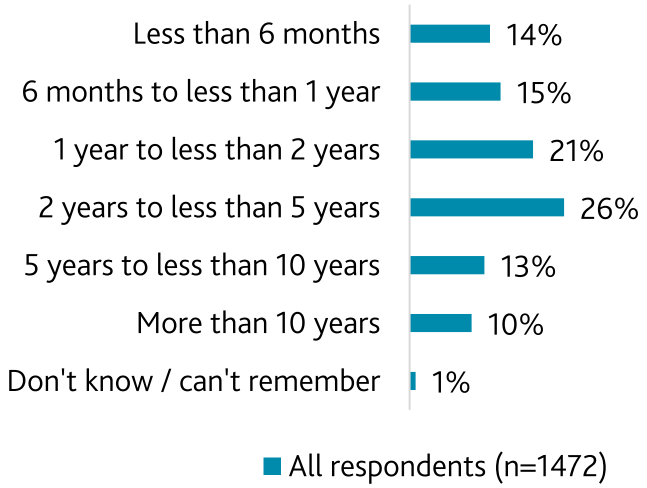
- Among the respondents who identified as caregivers, friends, or family members of someone with lymphoma or CLL, nearly half (47%, n=698) indicated that they provide care and support to their spouse or partner (Figure 1).

Figure 1. Q4 What is your relationship to the person you are providing care and support to?



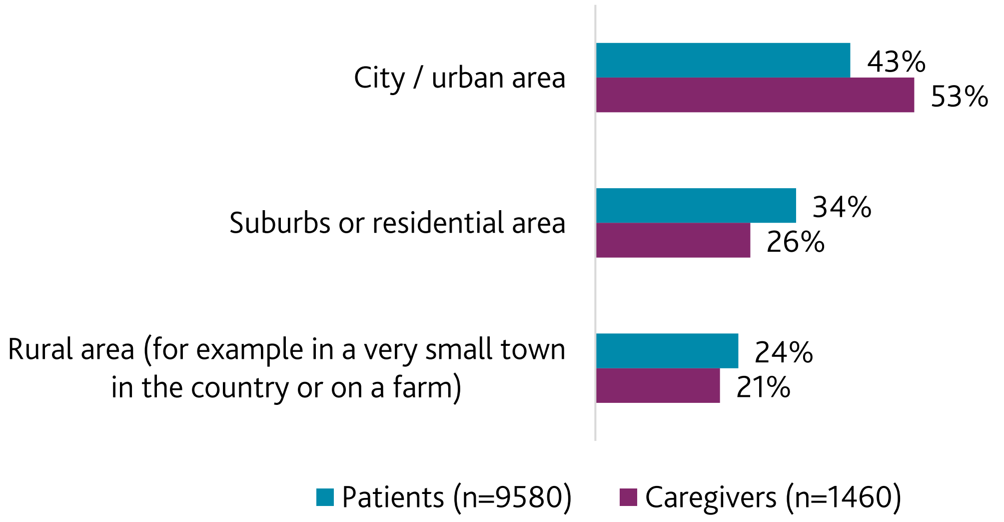
- A quarter (26%, n=384) of caregivers have been providing cancer-related care and support to the person with lymphoma or CLL (patient) for between 2 years to less than 5 years. One fifth (21%, n=307) of caregivers have been providing cancer-related care and support for between 1 year to less than 2 years (Figure 2).

Figure 2. Q5 How long have you been providing cancer-related care and support to the person with lymphoma or CLL?



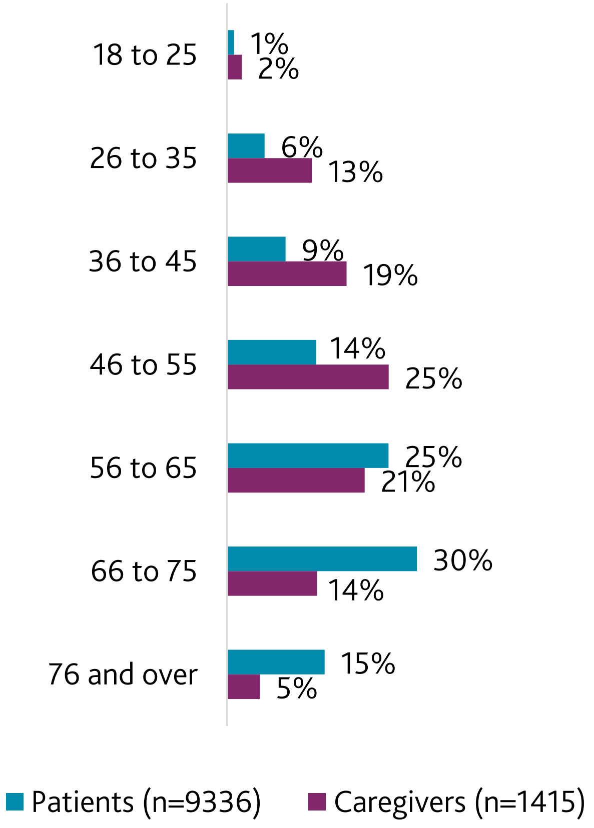
- Describing the area they lived in, 43% (n=4080) of patients reported living in a city / urban area as shown in Figure 3. Slightly more caregivers, just over half (53%, n=778) reported living in a city / urban area.

Figure 3. Q10 Which best describes the area you live in?



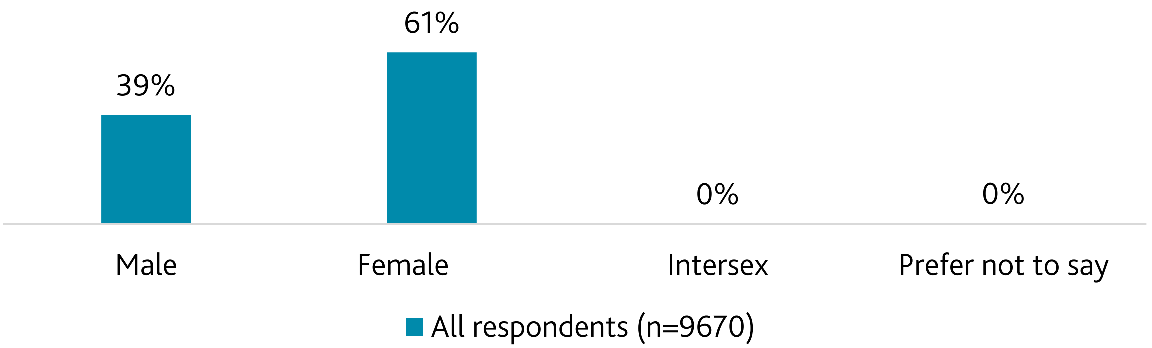
- Respondents were asked to provide their year of birth, which was then grouped into age categories. Patient respondents were most likely to be aged 66 to 75 (30%, n=2766), while caregivers were most likely to be aged 46 to 55 (25%, n=357) (Figure 4).

Figure 4. Q11. What year were you born? Please enter YYYY e.g., 1985 [derived]



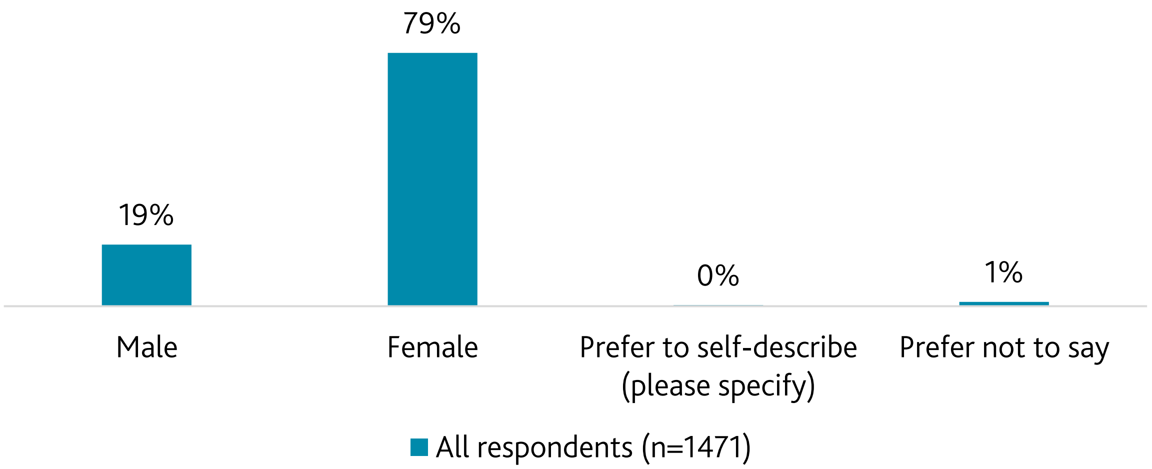
- Of patients, 61% (n=5899) reported being of female biological sex, while 39% (n=3747) reported being of male biological sex (Figure 5).

Figure 5. Q12 What is your biological sex? We ask this question because some lymphomas have a higher incidence in different biological sexes.



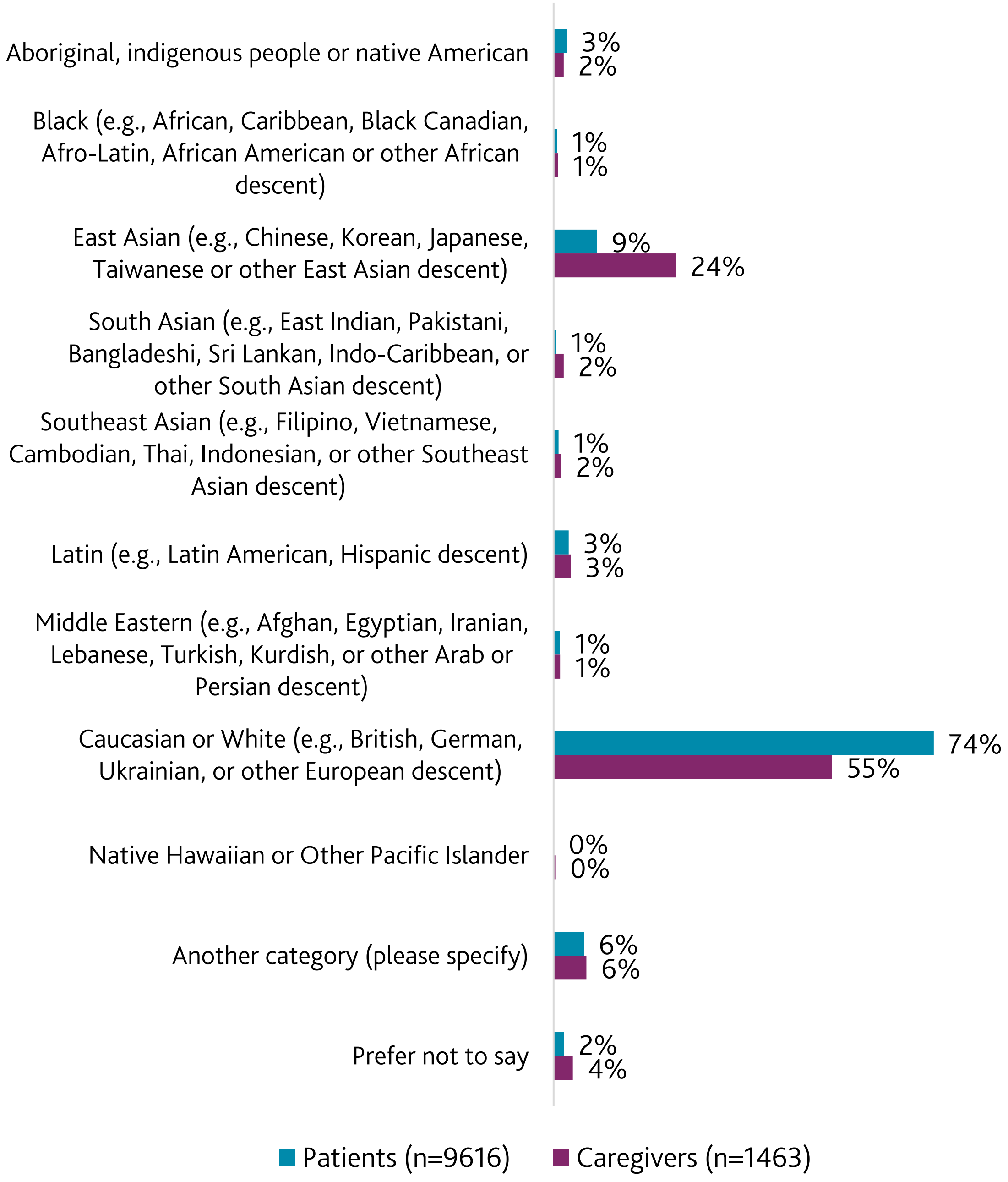
- Of caregiver respondents, 79% (n=1163) identified as female, while 19% (n=283) identified as male (Figure 6).

Figure 6. Q13 What is your gender?



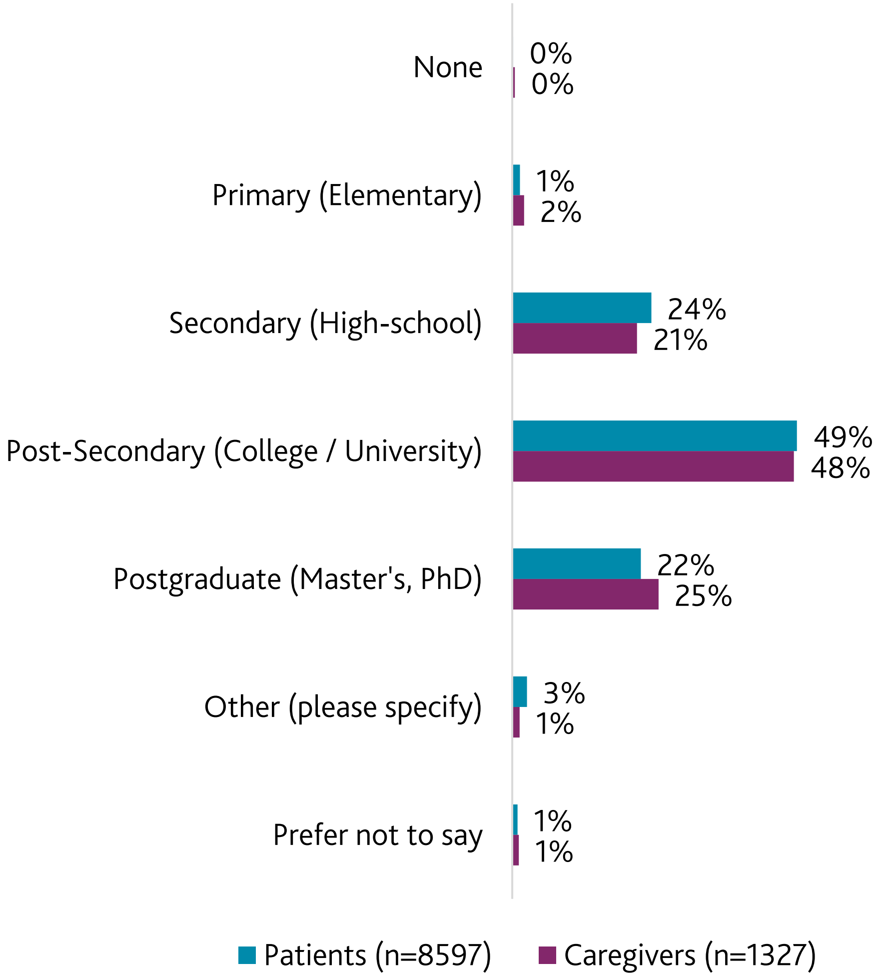
- The majority of respondents self-identified ethnicity were Caucasian or White (e.g., British, German, Ukrainian, or other European descent). Specifically, 74% (n=7163) of patients reported being Caucasian or White, while 55% (n=798) of caregivers identified as Caucasian or White. This data is illustrated in Figure 7.

Figure 7. Q14 How do you identify your ethnicity?



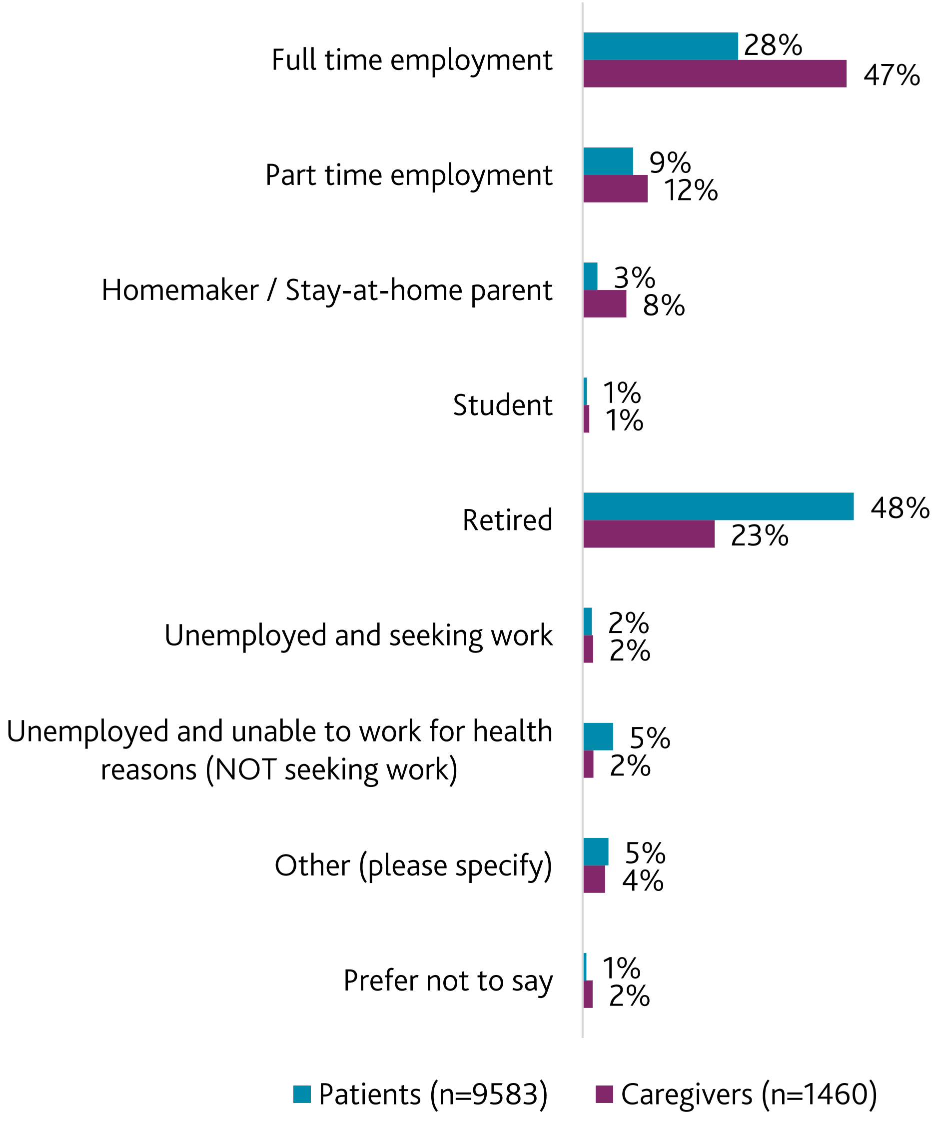
- Nearly half of respondents reported completing post-secondary (College / University) education (49%, n=4210 of patients and 48%, n=643 of caregivers). One quarter of caregivers (25%, n=334) and 22% (n=1903) of patients reported completing postgraduate (Master's, PHD) education. Nearly a quarter (24%, n=2058) of patients and 21% (n=285) of caregivers reported completing secondary (High-school) education, as shown in Figure 8.

Figure 8. Q15 What is your highest educational level completed?



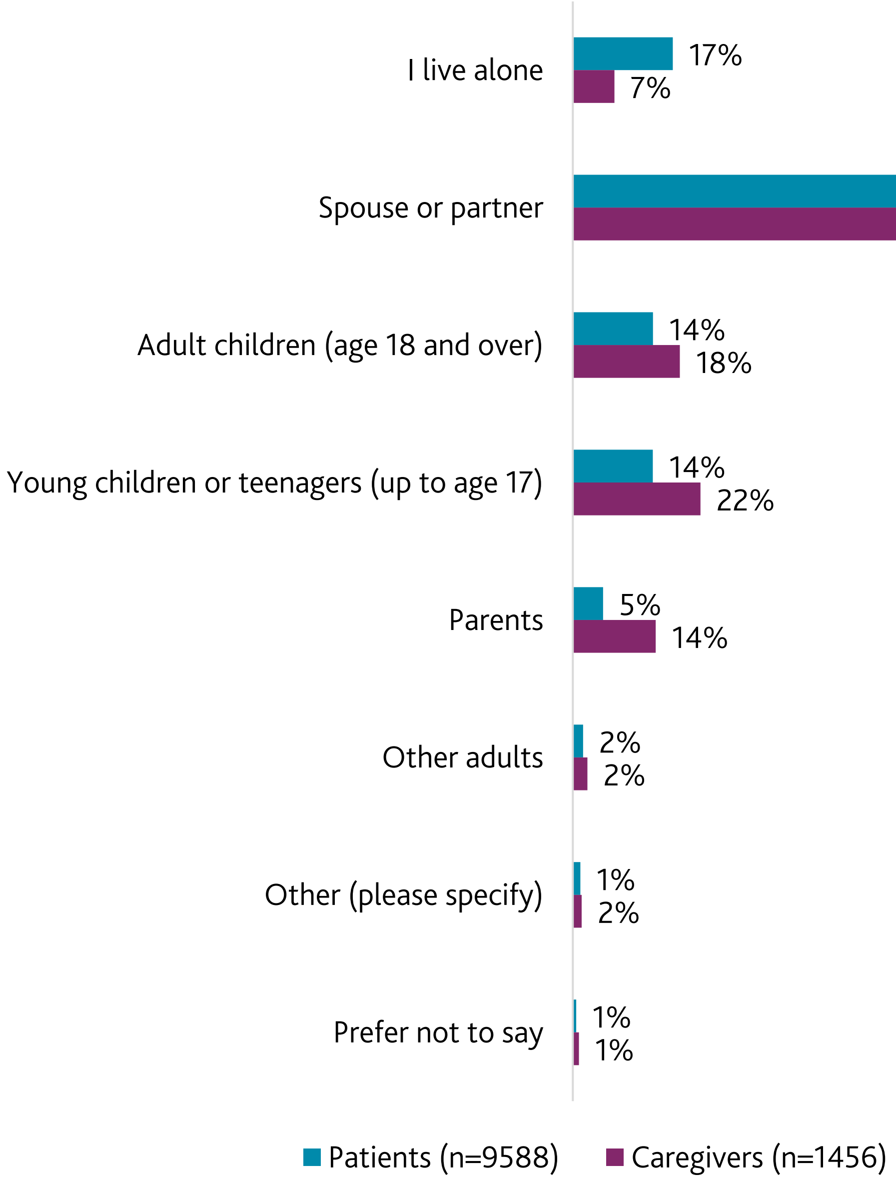
- Forty-eight percent (n=4597) of patients reported being retired, while 28% (n=2638) reported that they are currently in full time employment. In contrast, the largest proportion of caregivers, 47% (n=682) reported being in full time employment and 23% (n=341) reported they are retired. This data is illustrated in Figure 9.

Figure 9. Q16 Which of the following best describes your current employment status?



- The majority of respondents live with a spouse or partner, with 73% (n=6958) of patients and 72% (n=1045) of caregivers reporting this arrangement, as shown in Figure 10.

Figure 10. Q17 Who lives in your household with you? Please select all that apply.



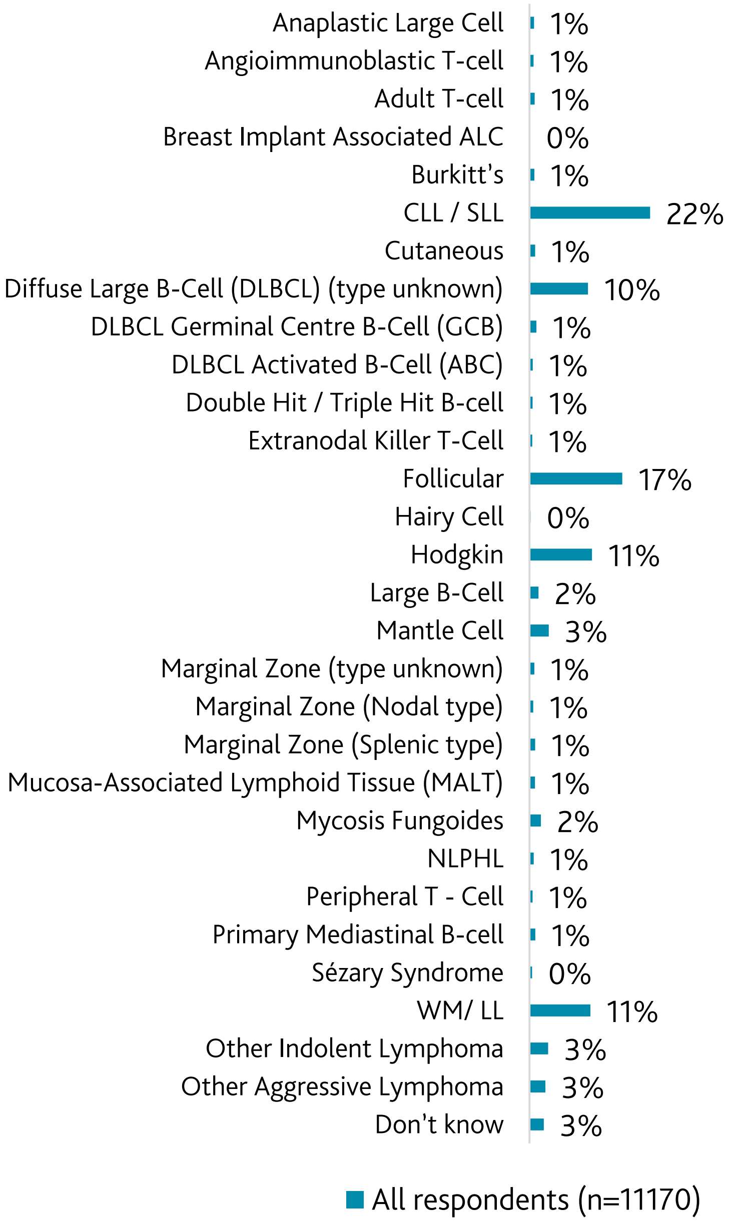
Lymphoma or CLL information

- Patients were most likely to have been diagnosed between 2 years to less than 5 years ago (28%, n=3076). Just under a quarter were diagnosed between 5 years to less than 10 years ago (23%, n=2599) and a fifth (21%, n=2295) reported being diagnosed more than 10 years ago (Figure 11).

Figure 11. Q18 How long ago were you diagnosed with lymphoma or CLL?

- Respondents were most likely to have or care for someone who has Chronic Lymphocytic Leukaemia (CLL) or Small Lymphocytic Lymphoma (SLL) (22%, n=2403). Subtype distribution from respondents is listed in Figure 12.

Figure 12. Q19 What subtype of lymphoma do you have? If you have been diagnosed with more than one type of lymphoma, please answer the survey with the most recent or persistent diagnosis in mind.[2]



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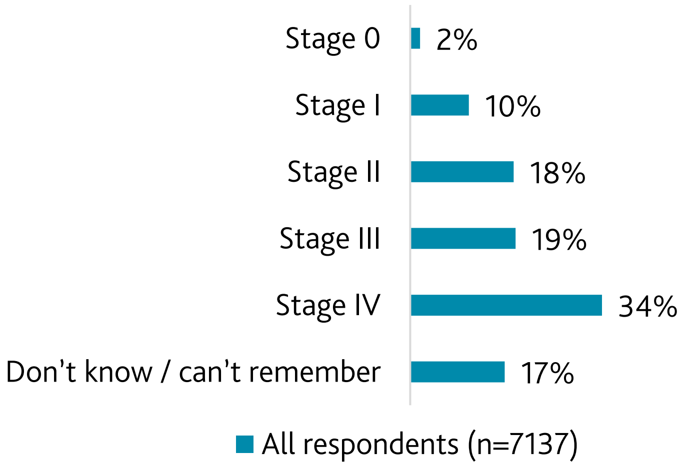
[2] Breast Implant Associated ALC is Breast Implant Associated Anaplastic Large Cell; CLL is Chronic Lymphocytic Leukaemia; SLL is Small Lymphocytic Lymphoma; NLPHL is Nodular Lymphocyte Predominant Hodgkin; WM is Waldenstrom's Macroglobulinemia; LL is Lymphoplasmacytic Lymphoma.

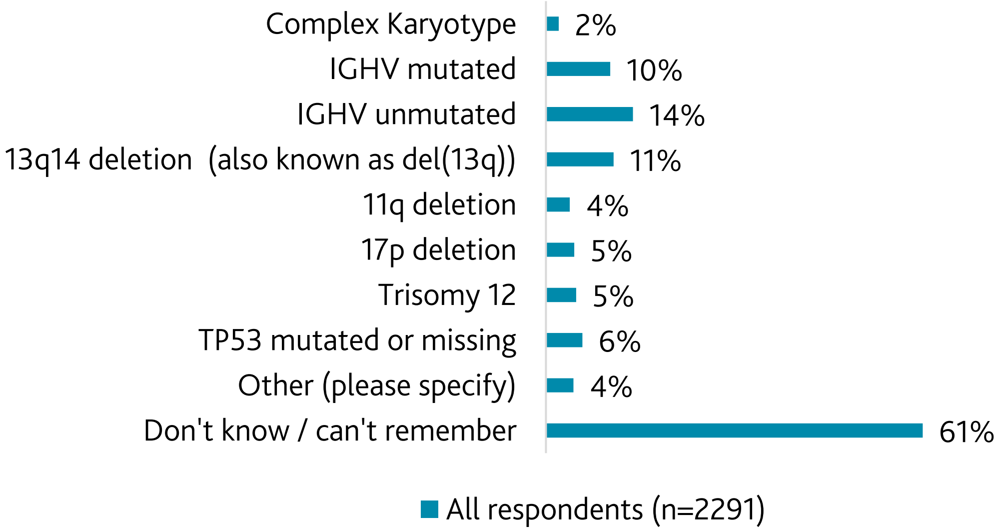
- Respondents reported patients were most likely to be in Stage IV (34%, n=2429) (Figure 13).

Figure 13. Q20 What stage was the lymphoma at diagnosis?



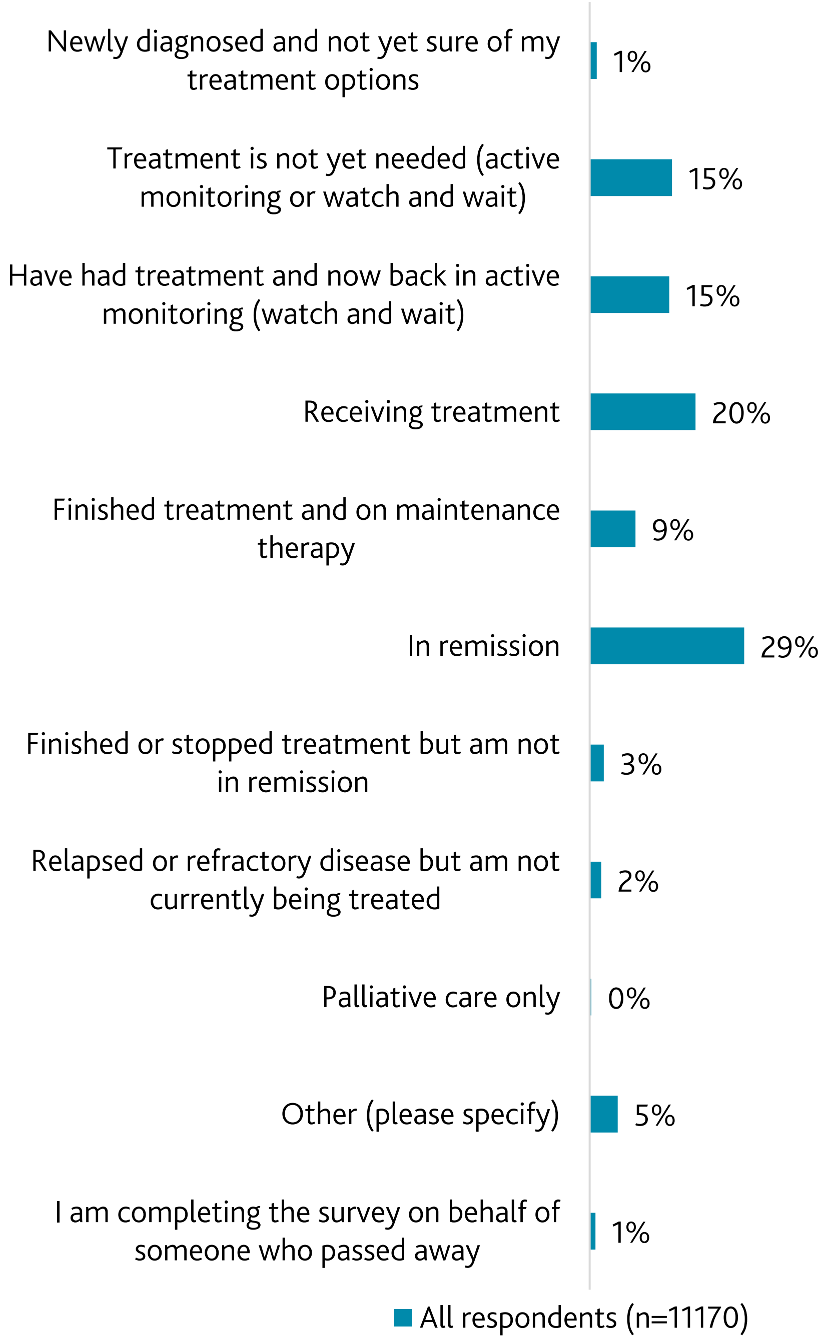
- The majority (61%, n=1408) of patients / caregivers for those with CLL or SLL did not know or could not remember if any genetic and chromosomal abnormalities applied to their CLL or SLL (Figure 14).

Figure 14. Q21 Do any of the following apply to your CLL / small lymphocytic lymphoma (SLL)? Please select all that apply.



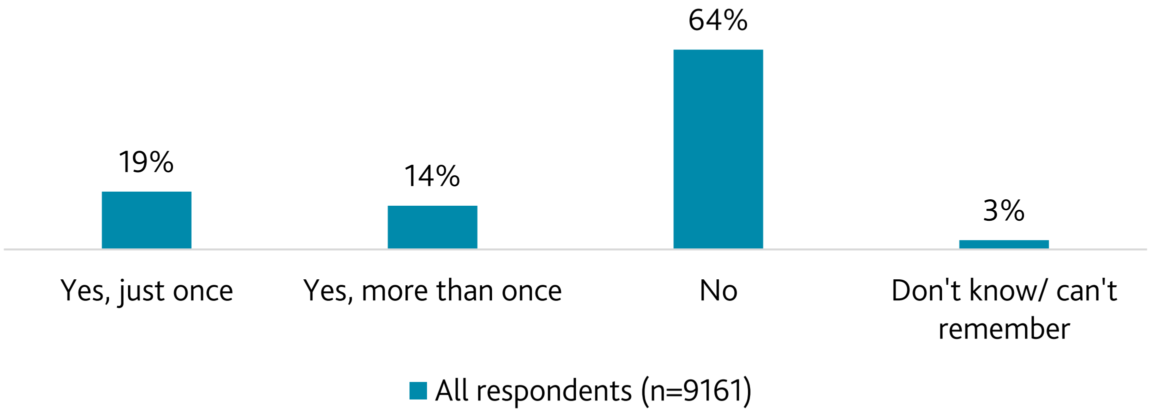
- When asked what best describes where they are in their lymphoma or CLL experience, 29% (n=3218) of respondents reported the patient was in remission and 20% (n=2204) were receiving treatment. A further 15% (n=1659) had received treatment and were back in active monitoring and 15% (n=1715) had not yet needed treatment (Figure 15).

Figure 15. Q23 What statement best describes where you are in the lymphoma or CLL experience?



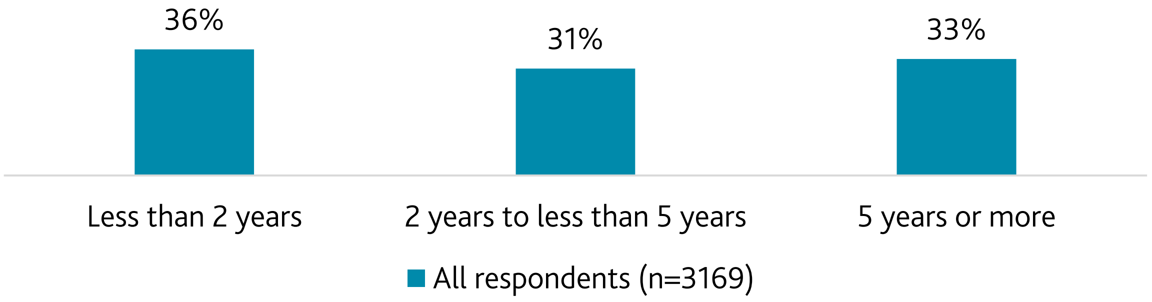
- Nearly two-thirds (64%, n=5892) of patients with lymphoma or CLL have not experienced a relapse or progression. One-fifth of patients (19%, n=1704) reported having relapsed or progressed once, while 14% (n=1291) had relapsed or progressed more than once, and 3% (n=274) didn't know or couldn't remember (Figure 16).

Figure 16. Q24 Has the lymphoma or CLL ever relapsed or progressed (needed another treatment after a period of active monitoring)?



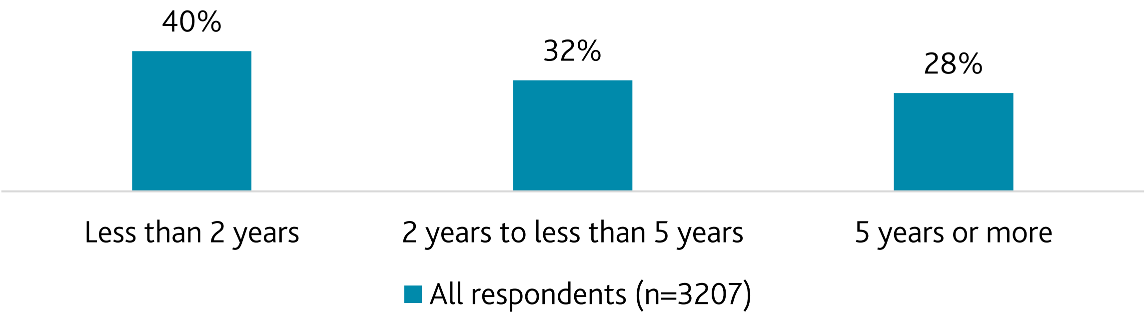
- Of those who indicated they are in remission, 36% (n=1144) of respondents reported that the patient had their last treatment less than 2 years ago, 31% (n=969) between 2 and 5 years ago, and 33% (n=1056) had their last treatment more than 5 years ago (Figure 17).

Figure 17. Q25 You have said that you are in remission, how long has it been since the last treatment?



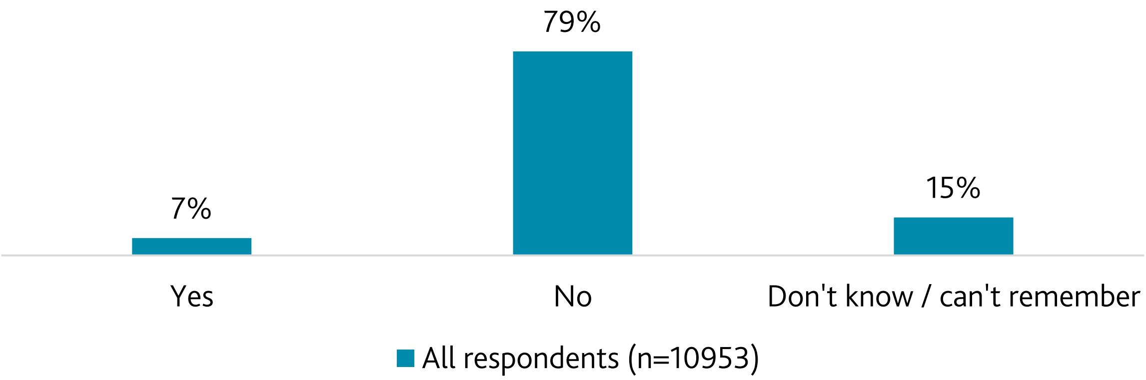
- Of those who indicated they are in active monitoring, 40% (n=1287) of respondents reported that the patient has been in active monitoring for less than 2 years, 32% (n=1019) for 2 years to less than 5 years, and 28% (n=901) for 5 years or more (Figure 18).

Figure 18. Q26 How long have you been in active monitoring (watch and wait)? If you have experienced more than one period of active monitoring then please think about the most recent.



- When asked whether their lymphoma or CLL transformed (e.g., indolent (follicular or CLL) to aggressive (DLBCL), 79% of respondents (n=8617) reported that the lymphoma or CLL had not transformed, while 7% (n=730) reported that it had (Figure 19).

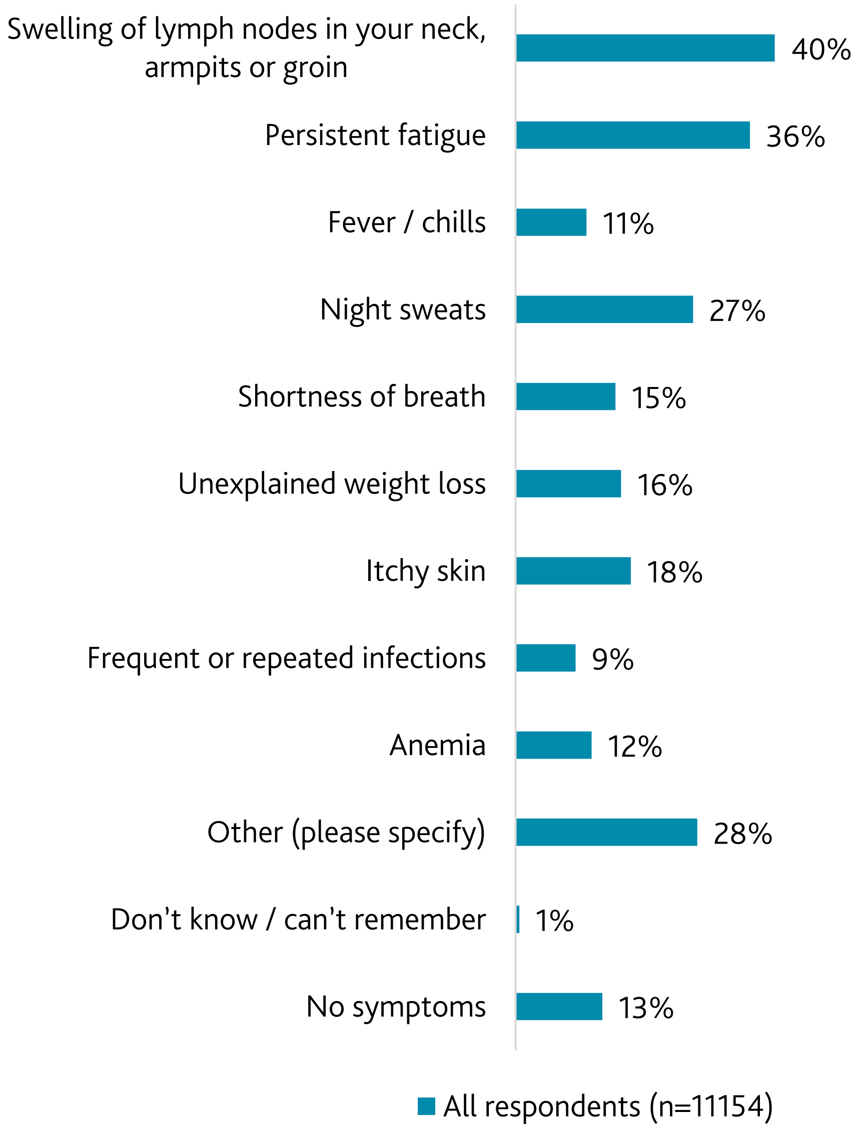
Figure 19. Q27 Has the lymphoma or CLL transformed (e.g., indolent (follicular or CLL) to aggressive (DLBCL))? In CLL, this is called a Richter's Transformation.



Diagnosis

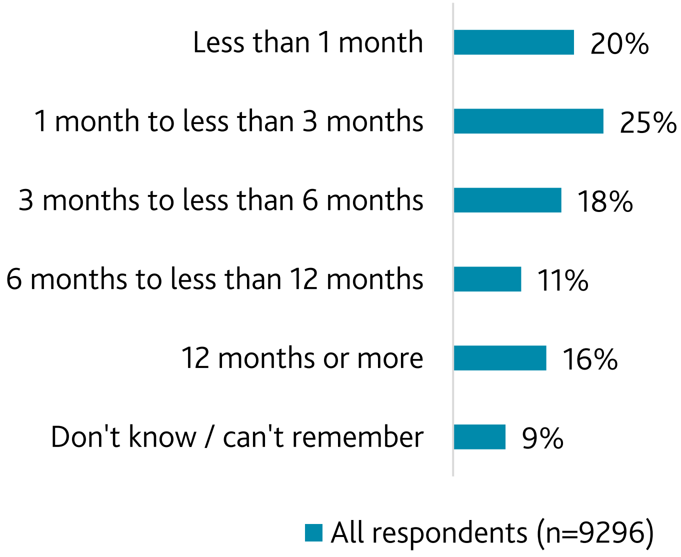
- Before being diagnosed with lymphoma or CLL, 40% (n=4469) reported that the patient experienced swelling of the lymph nodes. Thirty-six percent (n=4043) experienced persistent fatigue, and 27% (n=3061) experienced night sweats. Notably, 13% (n=1496) of respondents reported no symptoms (Figure 20).

Figure 20. Q28 Before you were diagnosed by a doctor as having lymphoma or CLL, what symptoms, if any, did you have that made you seek medical advice? Please select all that apply.



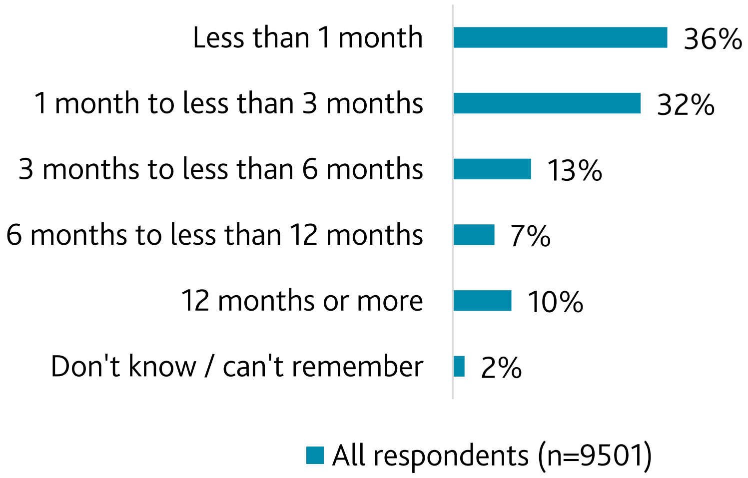
- Of patients who experienced symptoms, 45% (n=4251) reported that they had experienced symptoms for less than 3 months before they sought medical care (Figure 21).

Figure 21. Q29 How long did you experience lymphoma or CLL symptoms before you sought medical care? If you experienced more than one symptom, think about the symptom that you had experienced the longest before seeking medical care.



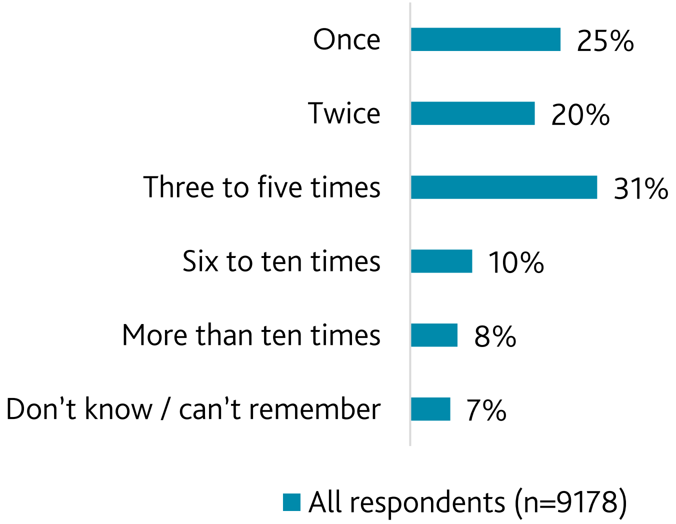
- Where the patient had experienced symptoms, 68% (n=6451) reported they received a diagnosis of lymphoma or CLL in less than 3 months from when they sought medical care for their symptoms (Figure 22).

Figure 22. Q30 After you sought medical care due to your symptoms, how long did it take to get a diagnosis of lymphoma or CLL?



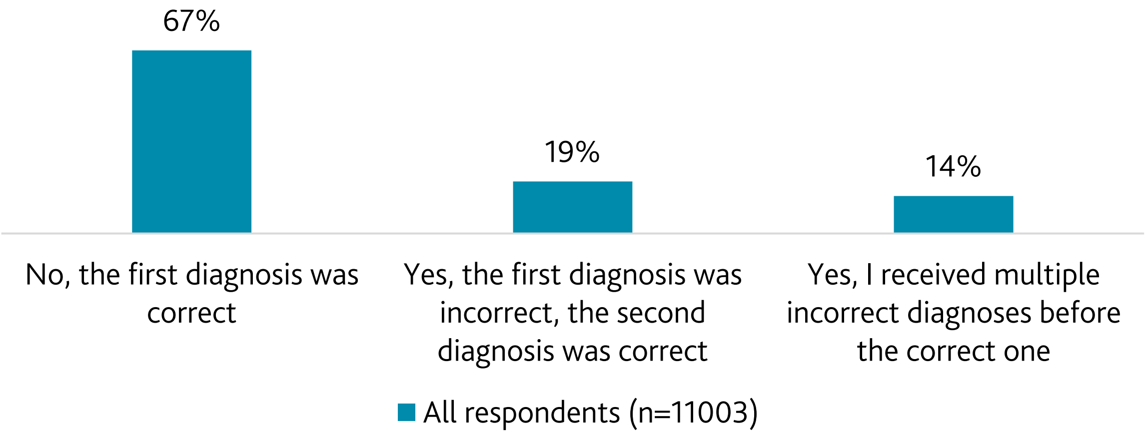
- Before receiving a diagnosis of lymphoma or CLL, 49% (n=4449) of those who experienced symptoms saw a doctor three or more times about their symptoms (Figure 23).

Figure 23. Q31 Before you were diagnosed with lymphoma or CLL, how many times did you see a doctor (same doctor or a different doctor) about your symptoms?



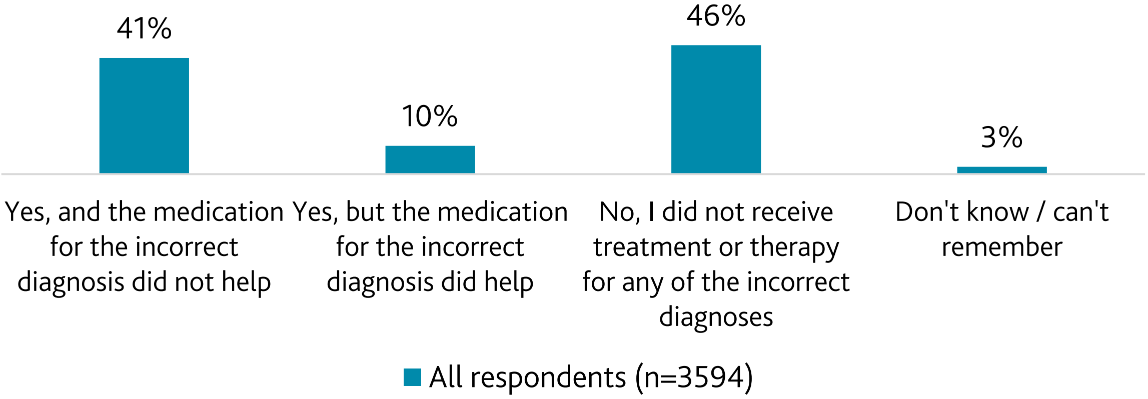
- Before the patients' lymphoma or CLL diagnosis was confirmed, one-third (33%, n=3614) of respondents reported that the patient did <u>not</u> receive a correct first diagnosis (Figure 24).

Figure 24. Q32 Were you given a different diagnosis before your lymphoma or CLL diagnosis was confirmed?



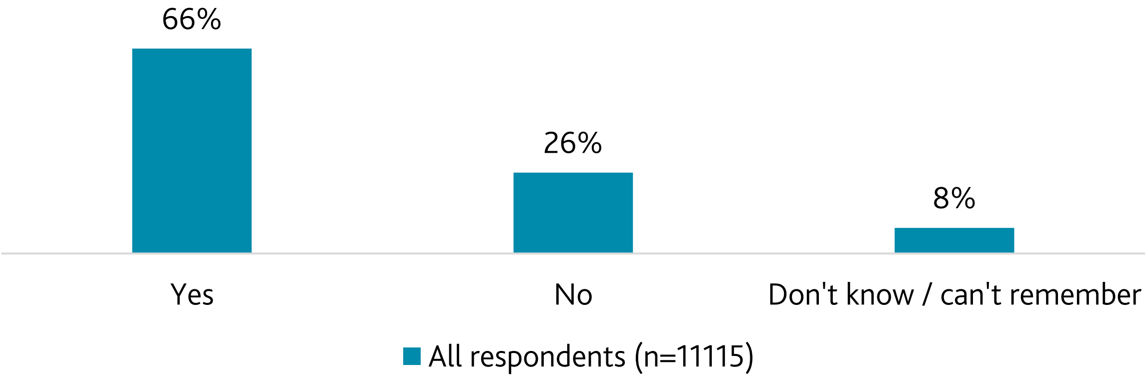
- Where patients did not receive the correct first diagnosis, more than half (51%, n=1850) did receive treatment, for which, 41% (n=1487) reported that the medication did not help. Conversely, 46% (n=1650) reported that no treatment was given for the incorrect diagnosis (Figure 25).

Figure 25. Q34 Did you receive treatment, therapy or medication for (any of) the incorrect diagnosis?



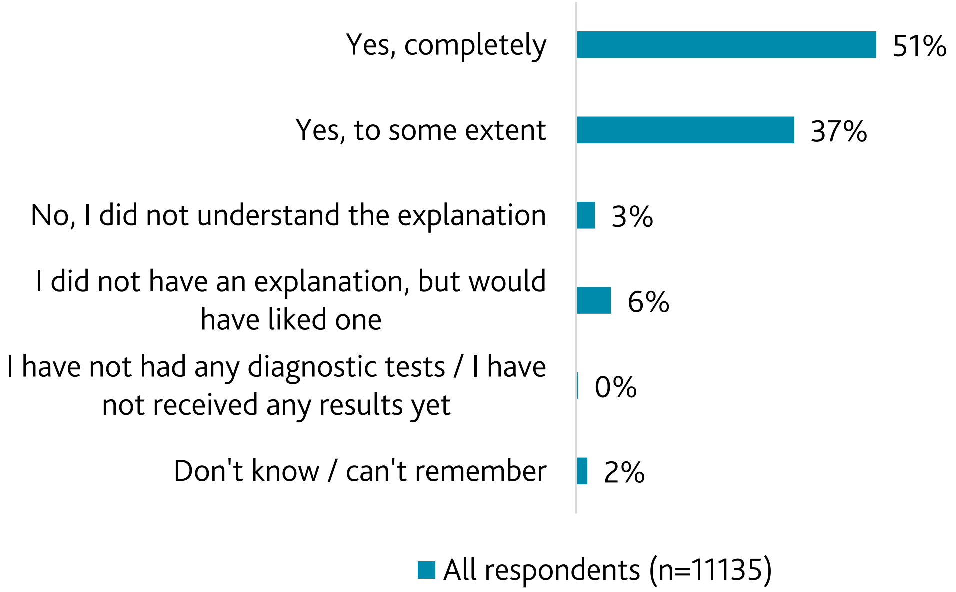
- When first diagnosed, two thirds (66%, n=7309) were told their lymphoma subtype or that they had CLL. Twenty-six percent (n=2889) were not told this information, while 8% (n=917) didn't know or could not remember (Figure 26).

Figure 26. Q35 When first diagnosed, were you told the lymphoma subtype or that you had CLL?



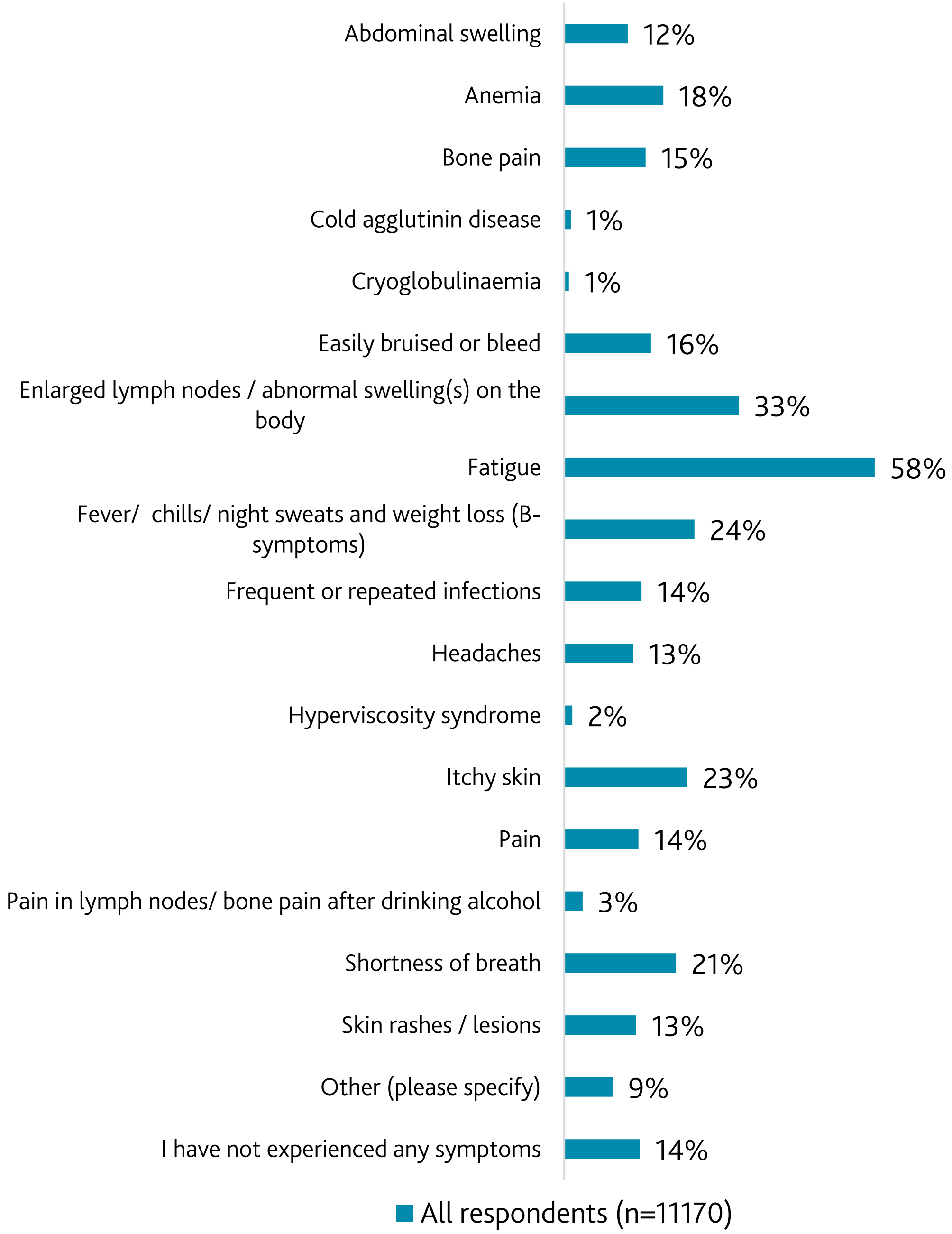
- When asked if the diagnostic tests and results were explained in a way that could be understood, 51% (n=5709) agreed they were completely explained. Thirty-seven percent (n=4149) agreed they were explained to some extent. However, 3% (n=361) reported that they did not understand the explanation, and 6% (n=665) did not receive an explanation but would have liked one (Figure 27).

Figure 27. Q36 Were diagnostic tests and results explained to you in a way you could understand? By diagnostic tests, we mean tests that helped to diagnose lymphoma or CLL, such as blood counts, pathology report, molecular testing results etc.



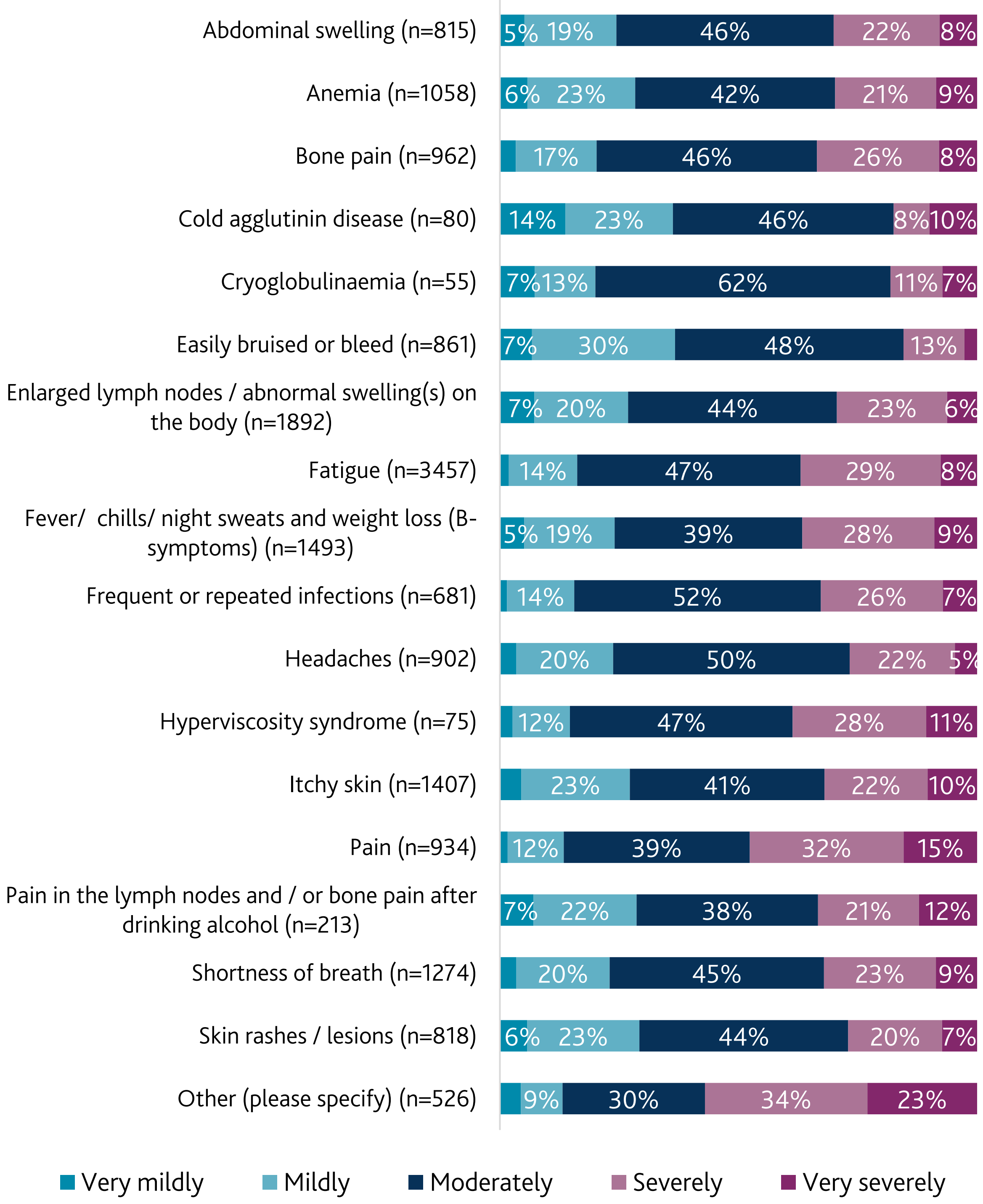
- When asked which symptoms they had experienced since their lymphoma or CLL diagnosis, 58% (n=6457) experienced fatigue, 33% (n=3631) experienced enlarged lymph nodes / abnormal swelling(s) on the body, 24% (n=2707) experienced a fever / chills / night sweats and weight loss (B-symptoms), 23% (n=2560) experienced itchy skin and 21% (n=2326) experienced shortness of breath (Figure 28).

Figure 28. Q37 Which of the following symptoms, if any, have you experienced since your lymphoma or CLL diagnosis? This is only referring to symptoms of your cancer, not side effects of treatment. Please select all that apply.



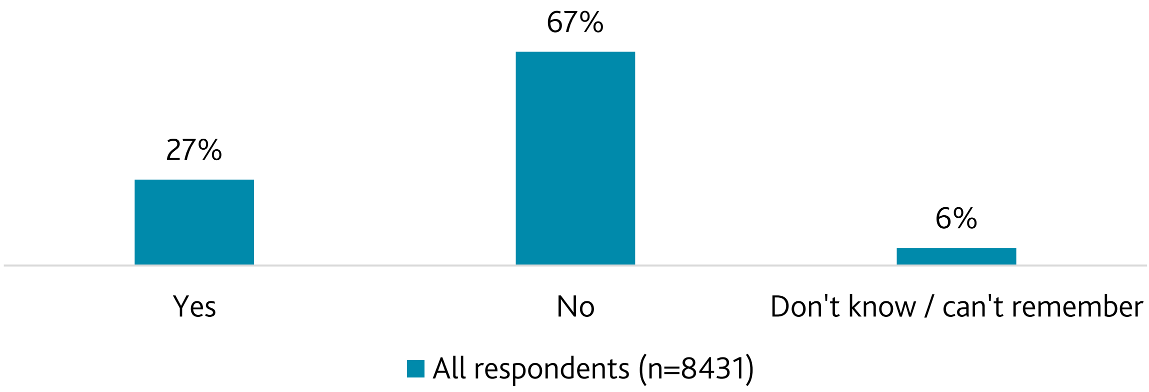
- Respondents were most likely to report experiencing the following symptoms severely or very severely (Figure 29): pain (47%, n=445); hyperviscosity syndrome (39%, n=29); B-symptoms such as fever, chills, night sweats, and weight loss (37%, n=547) and fatigue (37%, n=1279).

Figure 29. Q38 You previously said you have experienced the following symptom(s) since your diagnosis of lymphoma or CLL. How mild or severe have you experienced the following symptoms?



- Respondents who reported they did not experience fever and / or chills and / or night sweats and weight loss (B-symptoms) since their diagnosis, were asked if they experienced fever, heavy sweating or unexplained weight loss at any point in the six months leading up to their diagnosis. Twenty-seven percent (n=2284) did experience these symptoms, while 67% (n=5679) did not experience these symptoms (Figure 30).

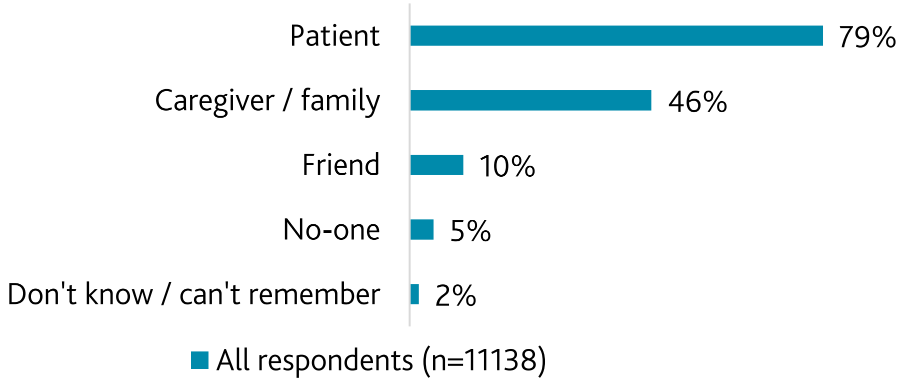
Figure 30. Q39 Did you experience fever, heavy sweating or unexplained weight loss at any point during the six months prior to diagnosis?



Health care information

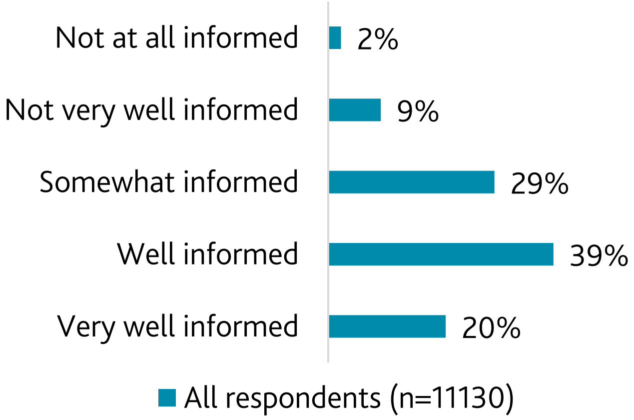
- Following a lymphoma or CLL diagnosis, it was most commonly the patient who sought information about the disease and potential treatments (79%, n=8762). Caregivers or family members also played a significant role in seeking information, with nearly half (46%, n=5123) of respondents reporting that they looked for related information, as shown in Figure 31.

Figure 31. Q47 Following the lymphoma or CLL diagnosis, who, if anyone, looked for information about the disease and potential treatments? Please select all that apply.



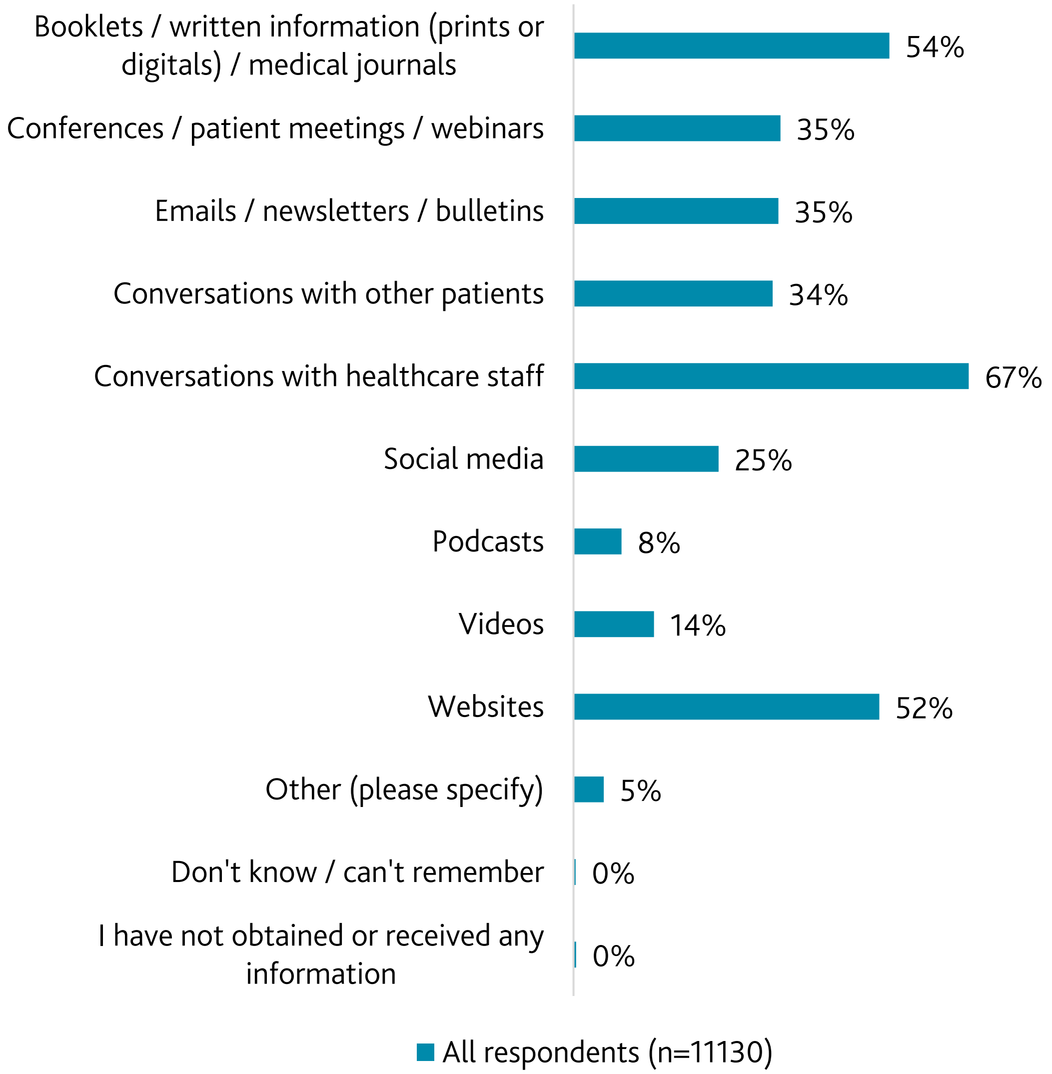
- Fifty-nine percent (n=6641) of respondents indicated they were well informed or very well informed about the processes and stages of the patient's health care related to their lymphoma or CLL diagnosis. Additionally, 29% (n=3223) of respondents reported being somewhat informed, as illustrated in Figure 32.

Figure 32. Q48 How informed do you feel now about the processes and stages of your / the patient's health care as it relates to the lymphoma / CLL diagnosis (e.g., diagnosis, treatment, resources available for support and self-care)? The information can have come from any source



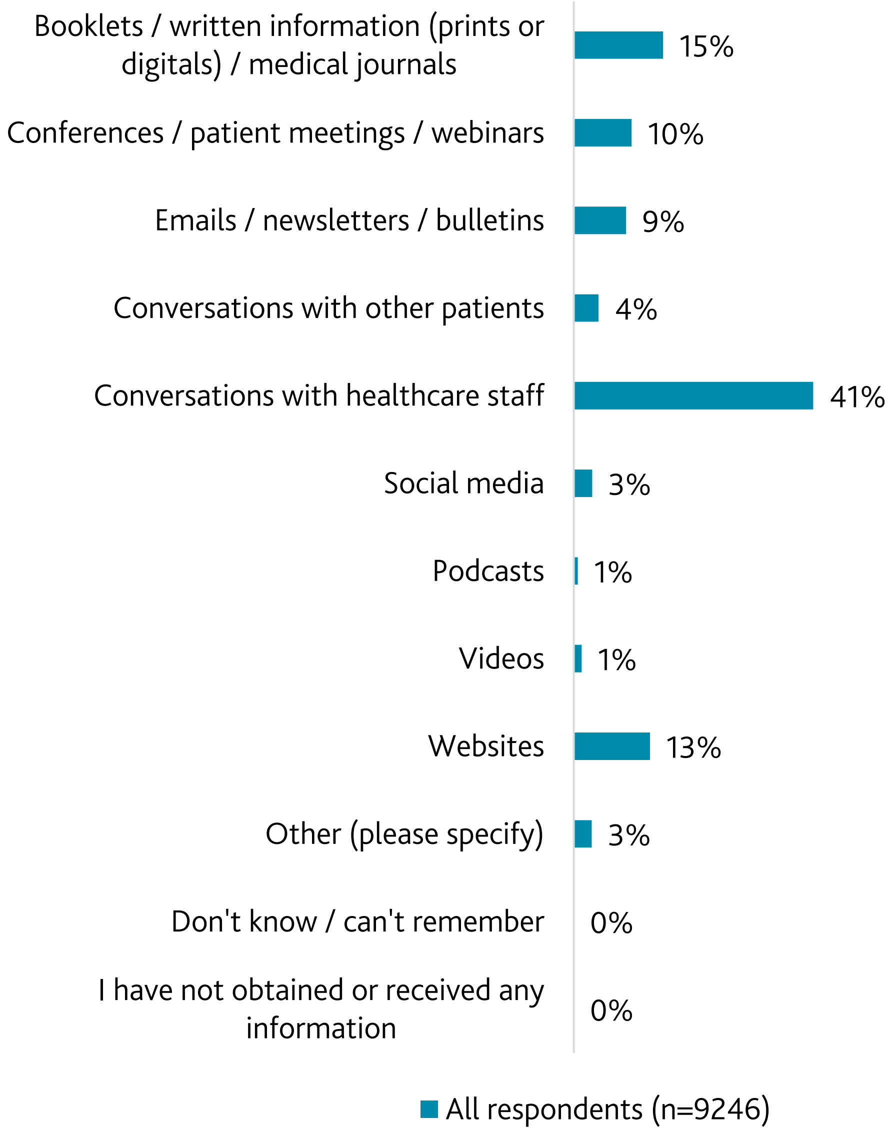
- Conversations with healthcare staff were the preferred method for getting information about lymphoma or CLL, as reported by 67% (n=7488) of respondents. This was followed by booklets, written information (prints or digitals) or medical journals preferred by 54% (n=5985). Websites were reported as the third most used method for obtaining information about lymphoma or CLL (52%, n=5793). This is detailed in Figure 33.

Figure 33. Q49 What are your preferred methods for getting information about lymphoma or CLL? Please select all that apply.



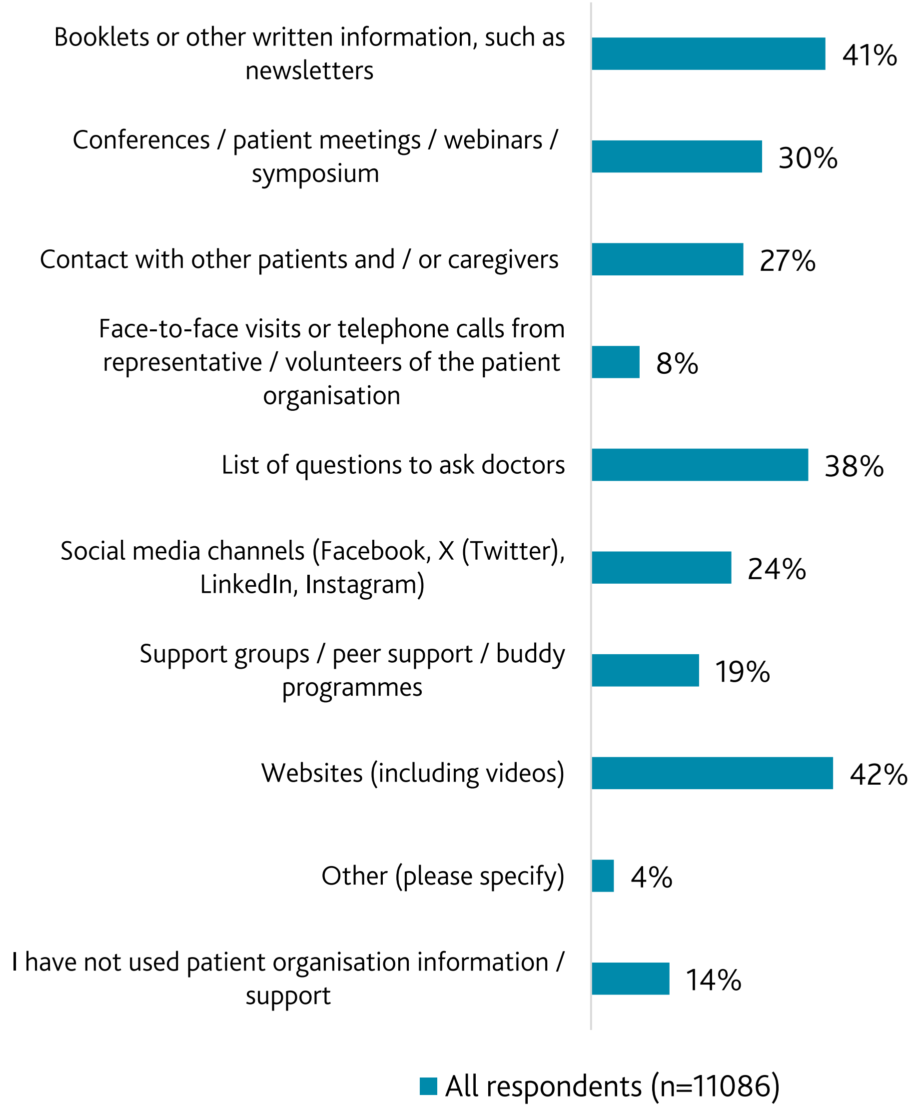
❖ Following the same trend, when respondents were asked to pick one method of getting information, 41% (n=3765) selected conversations with healthcare staff, as shown in Figure 34. This was followed by booklets, written information (prints or digitals) or medical journals, preferred by 15% (n=1405) of respondents, and websites chosen by 13% (n=1198) of respondents.

Figure 34. Q50 If you could only pick one method of getting information, which would it be?



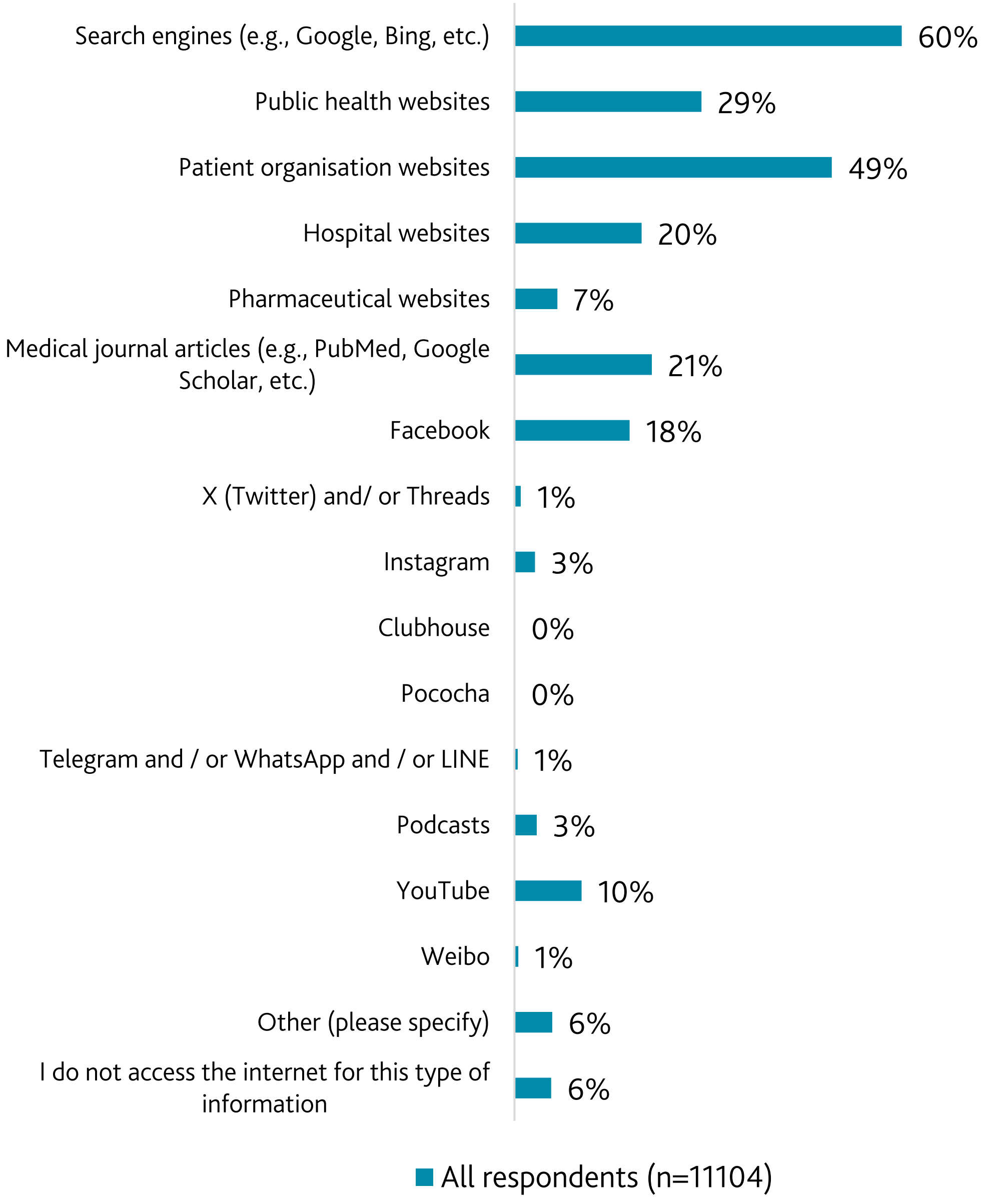
- As shown in Figure 35, during the past 12 months the most frequently utilised patient organisation information and support resources were:
    - Websites (including videos) (42%, n=4666)
    - Booklets or other written information, such as newsletters (41%, n=4519)
    - Lists of questions to ask doctors (38%, n=4188)
    - Conferences, patient meetings, webinars, or symposiums (30%, n=3298)
    - Contact with other patients and/or caregivers (27%, n=2938)
    - Social media channels (Facebook, X (Twitter), LinkedIn, Instagram) (24%, n=2705)
    - Support groups, peer support, or buddy programs (19%, n=2082)

Figure 35. Q51 Thinking about the last 12 months, what, if any, of the following types of patient organisation information or support have you used? Please select all that apply.



- As shown in Figure 36, when asked where on the internet they usually get their lymphoma or CLL information from, respondents were most likely to report:
  - Search engines (e.g., Google, Bing, etc.) (60%, n=6654)
  - Patient organisation websites (49%, n=5452)
  - Public health websites (29%, n=3214)
  - Medical journal articles (e.g., PubMed, Google Scholar, etc.) (21%, n=2360)
  - Hospital website (20%, n=2186)
  - Facebook (18%, n=1979)

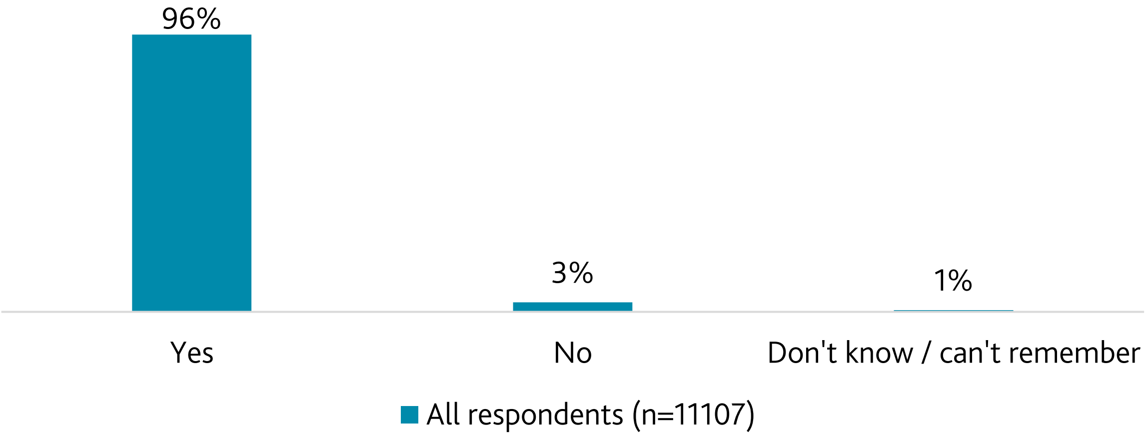
Figure 36. Q52 Where on the internet do you usually get your lymphoma or CLL information from? Please select all that apply.



Care from healthcare professionals

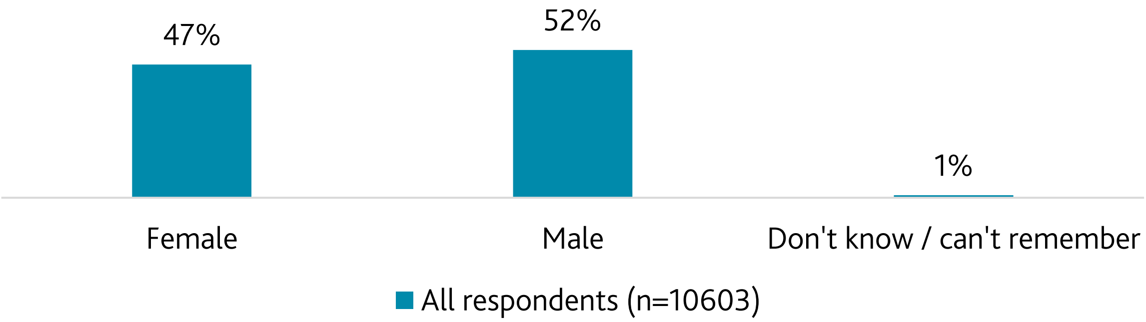
- A significant majority (96%, n=10678) of respondents indicated that they have seen a haematologist and / or an oncologist and /or a dermatologist for their lymphoma or CLL as illustrated in Figure 37.

Figure 37. Q60 Have you ever seen a haematologist and / or an oncologist and /or a dermatologist for your lymphoma or CLL?



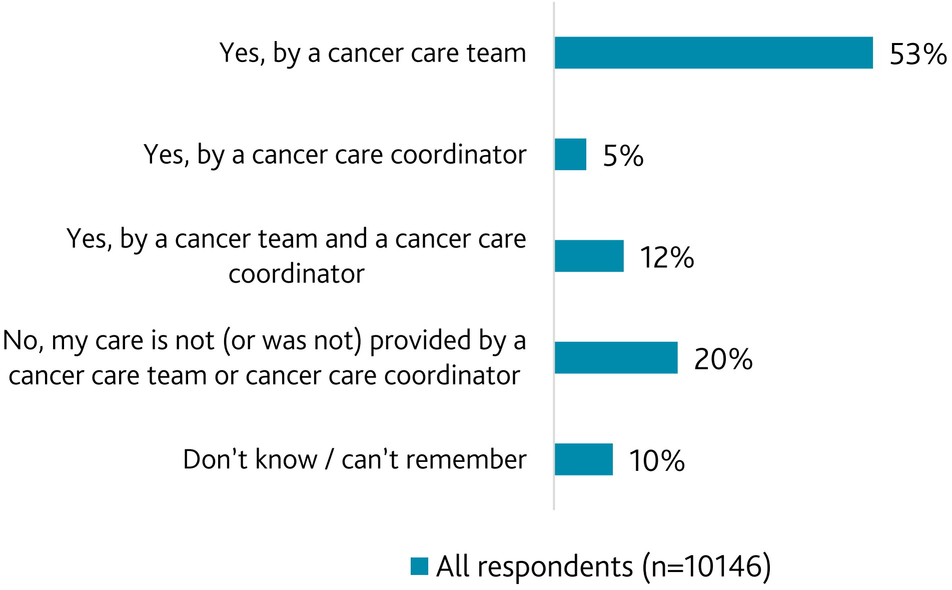
- Just over half (52%, n=5528) of respondents who indicated that they had seen a haematologist and / or an oncologist and / or a dermatologist for their lymphoma or CLL reported that the specialist was male, while 47% (n=4983) reported that the specialist was female (Figure 38).

Figure 38. Q61 What is the gender of the haematologist and / or oncologist and / or dermatologist? If you see more than one specialist, please think about the specialist you see most often for your lymphoma or CLL care.



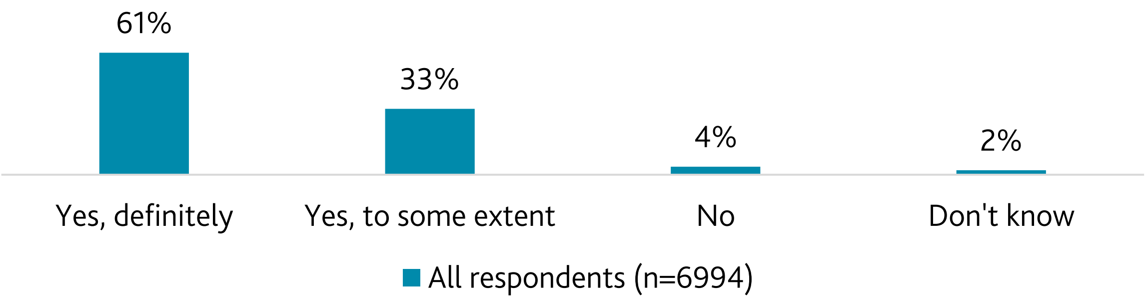
- Just over half (53%, n=5362) of respondents indicated that their lymphoma care was provided by a cancer care team. Conversely, one fifth (20%, n=2079) of respondents indicated that their lymphoma care was not provided by a cancer care team or cancer care coordinator, as shown in Figure 39.

Figure 39. Q62 Is (or was) your lymphoma care provided by a cancer care team (multidisciplinary cancer care team) and / or cancer care coordinator?



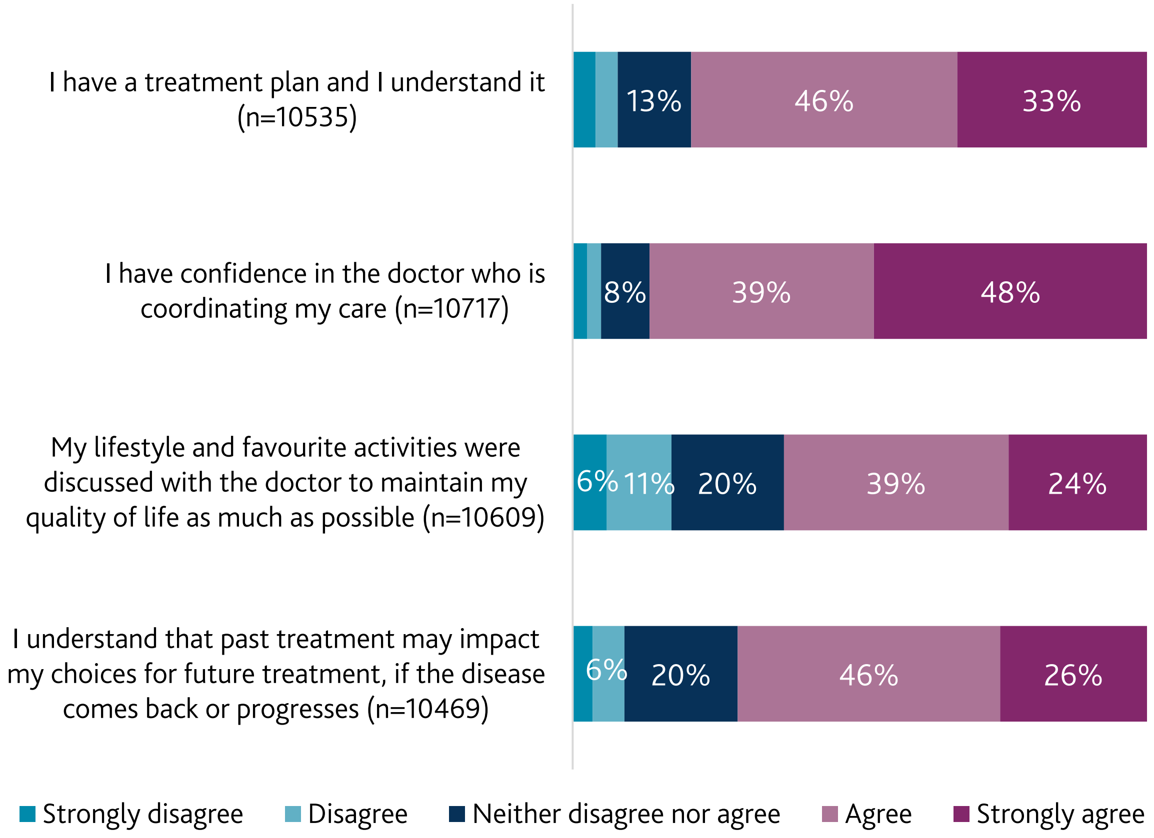
- Of the respondents who indicated their lymphoma care was provided by either a cancer care team, a cancer care coordinator (or both), 61% (n=4259) reported being definitely informed of the decisions and conclusions made by their multidisciplinary team (Figure 40).

Figure 40. Q63 Are you informed of the decisions and conclusions made by your multidisciplinary team?



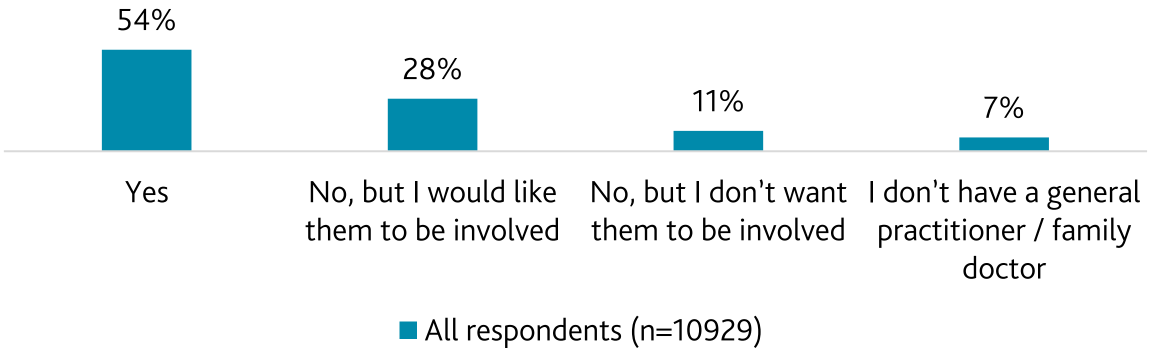
- Figure 41 illustrates that 87% (n=9282) of respondents agreed or strongly agreed that they had confidence in the doctor who was coordinating their care.

Figure 41. Q66 Thinking about your experience with lymphoma or CLL, to what extent do you agree or disagree with the following statements? Please select one option per row.



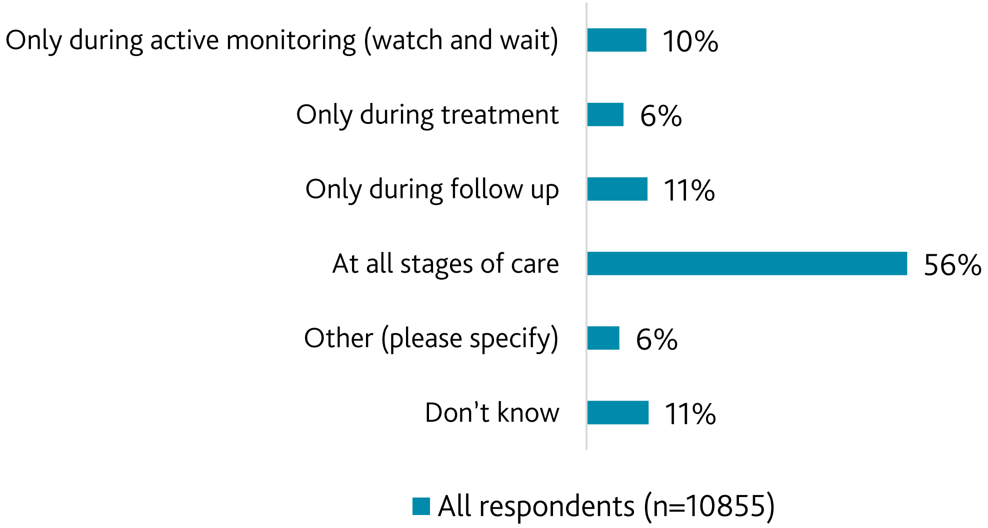
- Fifty-four percent (n=5893) of respondents reported that their general practitioner / family doctor was involved as much as they wanted them to be in their follow-up care for their lymphoma or CLL, as shown in Figure 42.

Figure 42. Q67 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?



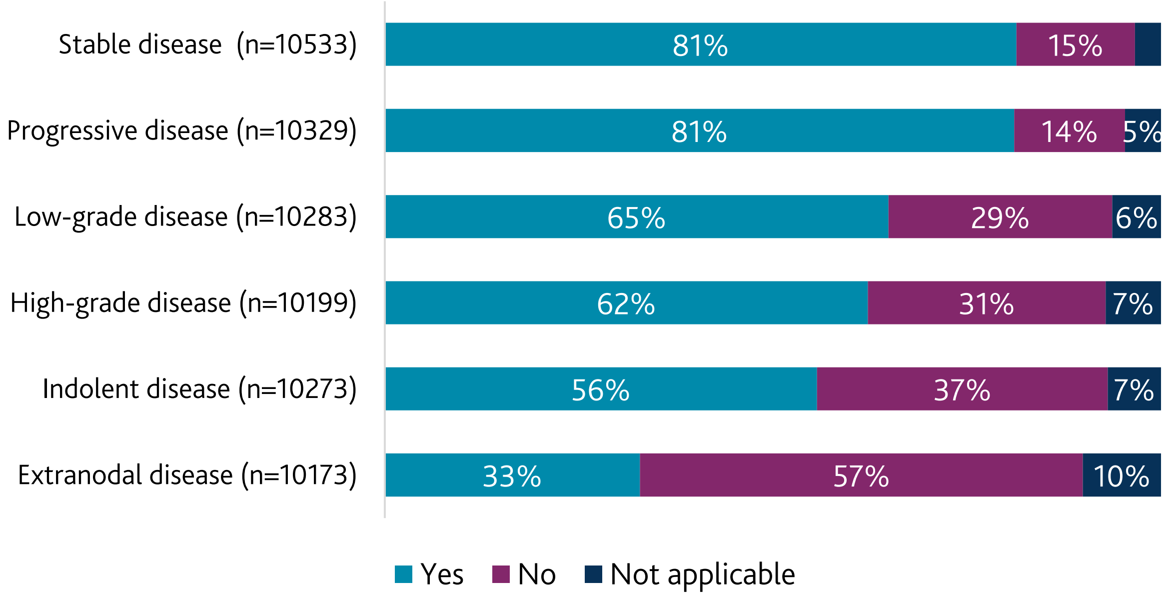
- Fifty-six percent (n=6070) of respondents reported that it would be most helpful to have their general practitioner / family doctor involved at all stages of care in the follow-up and management of their lymphoma or CLL (Figure 43).

Figure 43. Q69 During which stage of care would your general practitioner / family doctor be most helpful in the follow-up and management of your lymphoma or CLL?



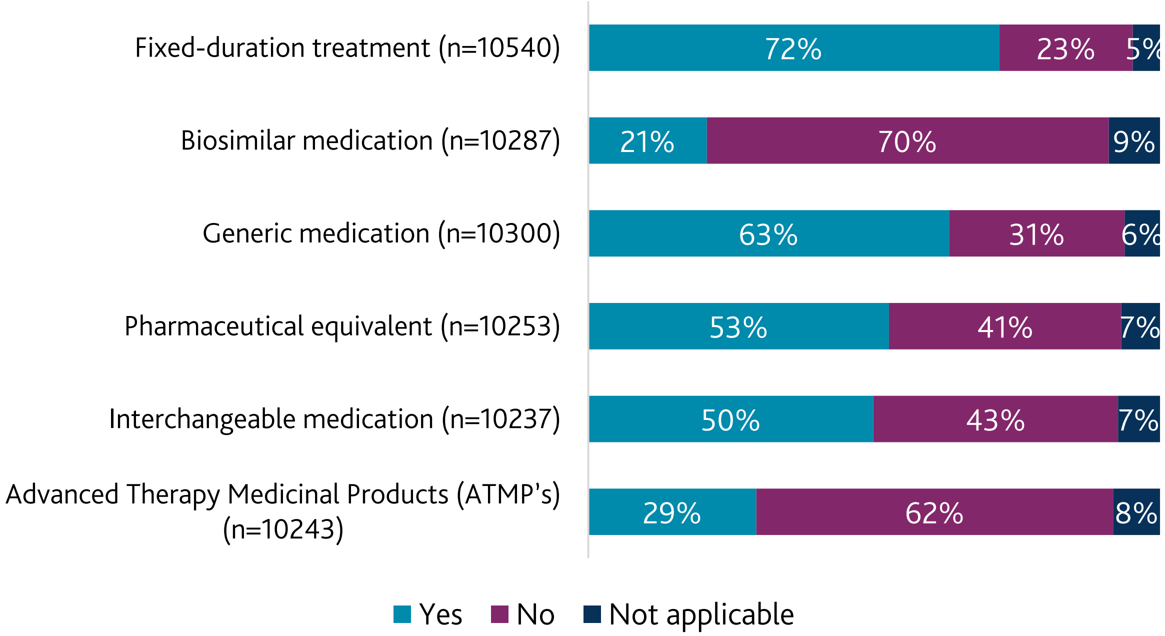
- Figure 44 shows where respondents reported having enough understanding of disease status terms. Eighty-one percent (n=8570) reported having enough understanding of the term stable disease, and 81% (n=8375) reported having enough understanding of the term progressive disease. Conversely, more than half (57%, n=5805) of respondents reported not having enough understanding of extranodal disease.

Figure 44. Q70 Do you have enough understanding of the following terms about disease status?



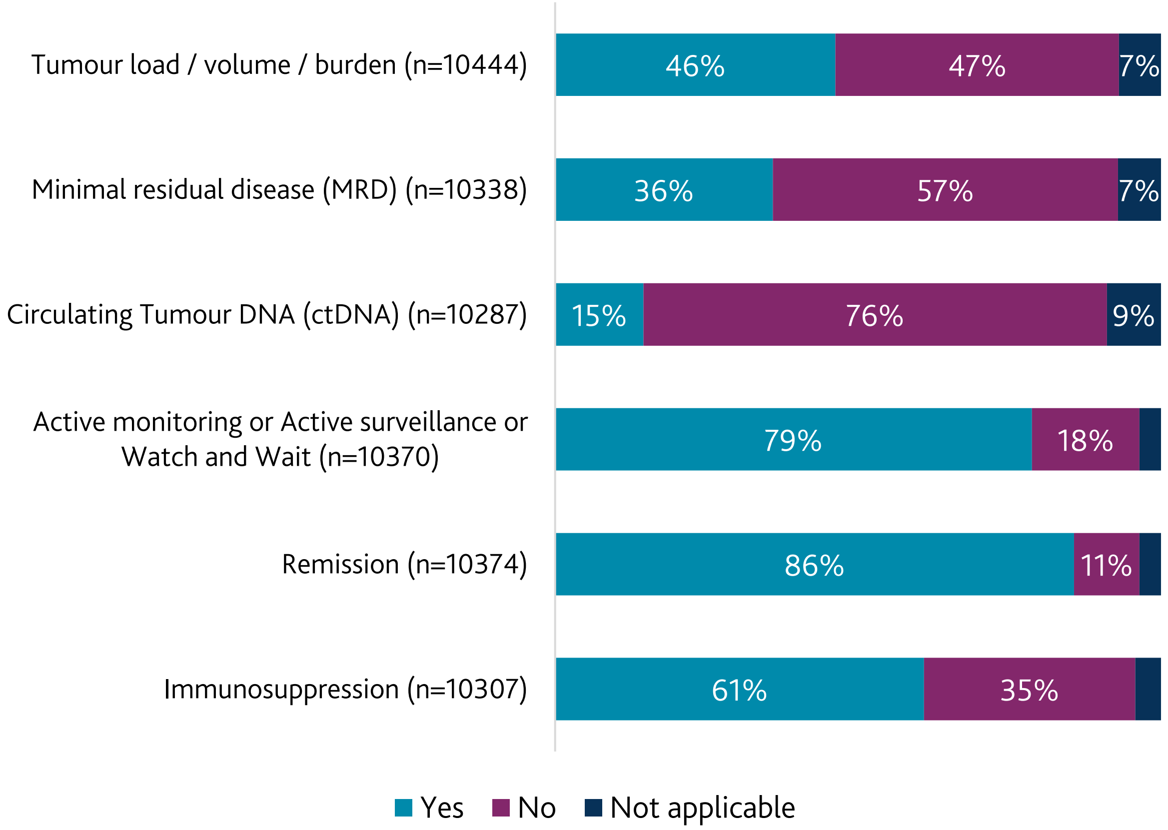
- Figure 45 shows where respondents reported having enough understanding of most treatment options. The highest reported understanding was for fixed-duration treatment, with 72% (n=7581) of respondents indicating they had enough understanding of this term. The treatment option terms with the lowest reported understanding were biosimilar medication, 21% (n=2134) and advanced therapy medicinal products at 29% (n=3009).

Figure 45. Q71 Do you have enough understanding of the following terms about treatment options?



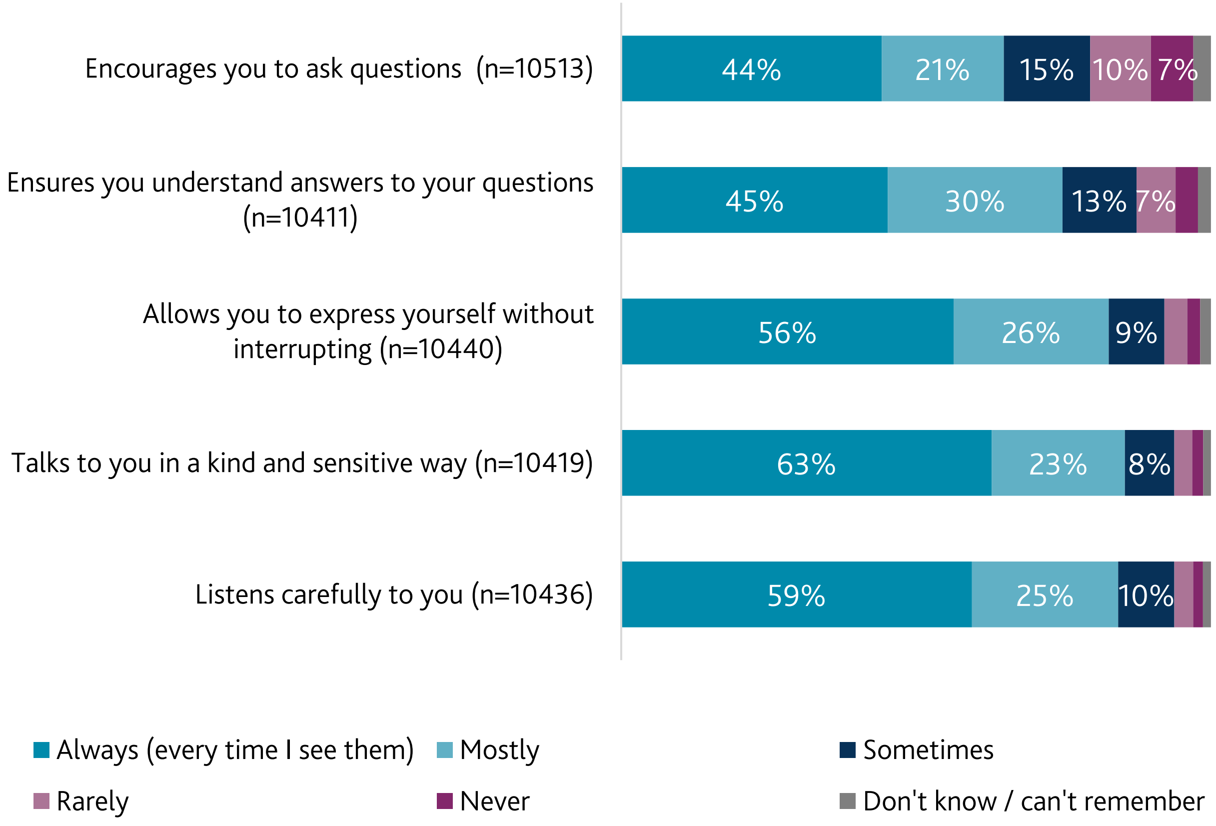
- Figure 46 shows where respondents reported having enough understanding of possible treatment outcomes and phases. The highest reported understanding was for remission, with 86% (n=8883) of respondents indicating they had enough understanding of this term. The lowest reported understanding was for circulating tumour DNA, with only 15% (n=1499) of respondents having enough understanding of this term.

Figure 46. Q72 Do you have enough understanding of the following terms about possible treatment outcomes and phases?



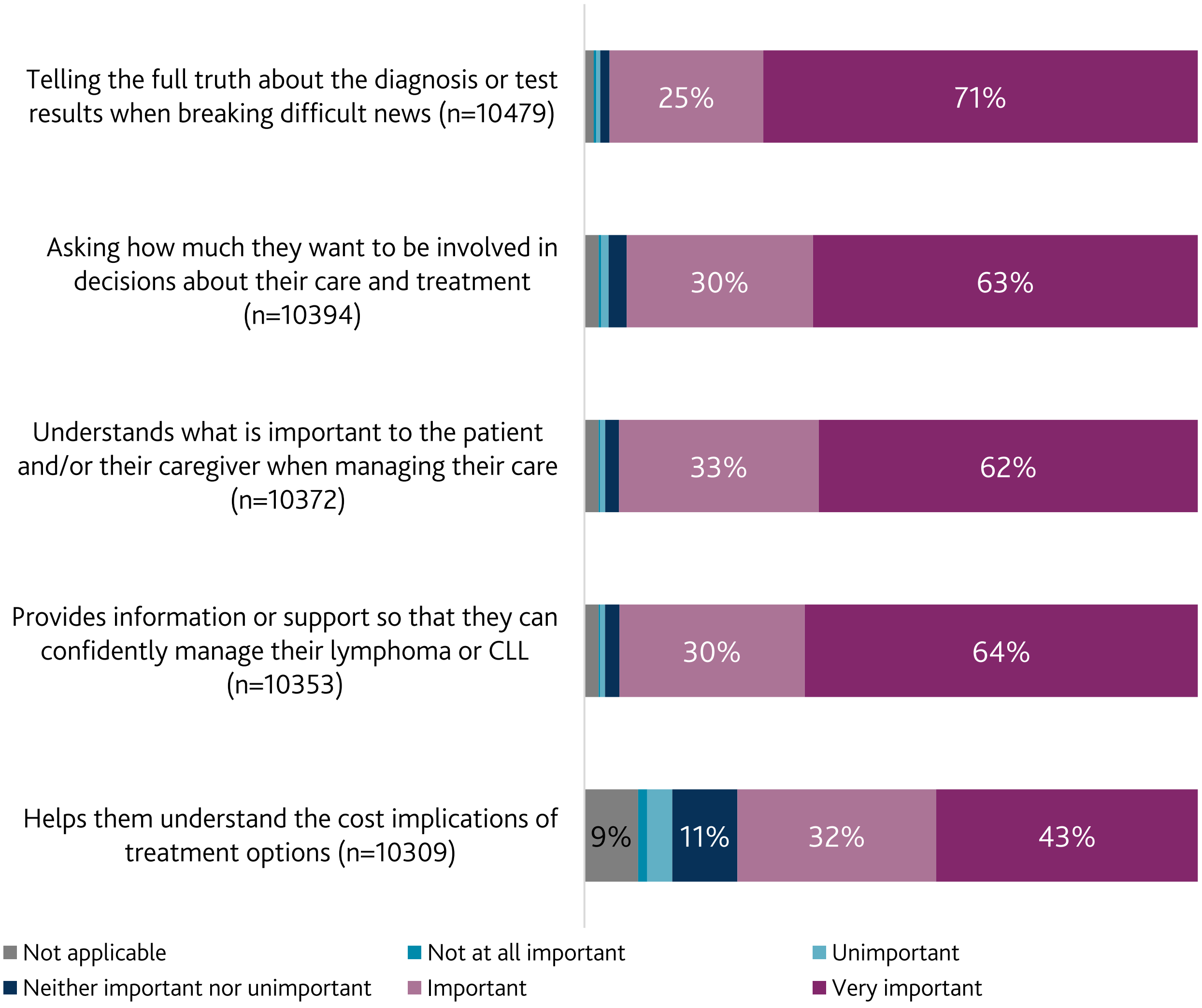
- Patients were asked whether their lymphoma / CLL doctor encourages participation in decision-making about their care. The most highly reported patient centred communication strategy was their lymphoma / CLL doctor always or mostly talking to patients in a kind and sensitive way (86%, n=8900), closely followed by listening carefully (84%, n=8793) and the doctor allowing the patient to express themselves without interrupting (82%, n=8631) (Figure 47).

Figure 47. Q73 Thinking about the last 12 months, does your lymphoma / CLL doctor do any of the following to encourage participation in decision-making about your care?



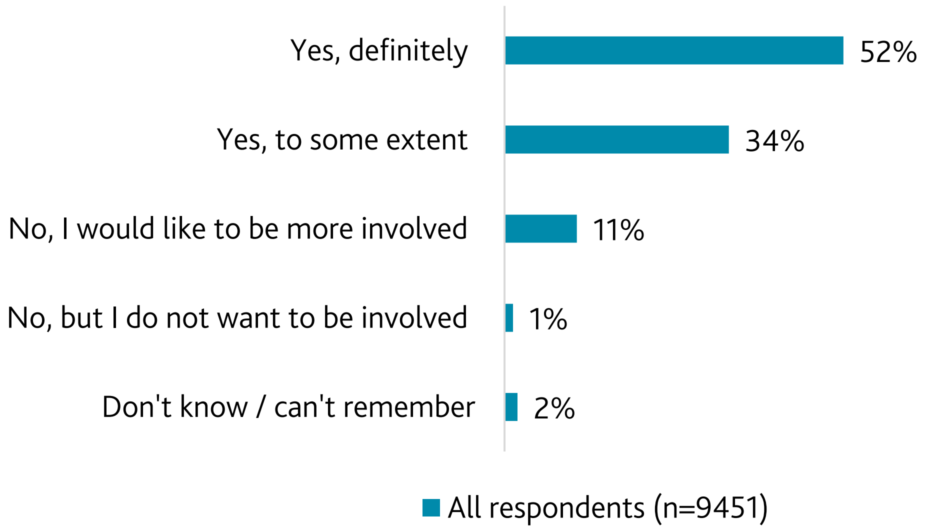
- Figure 48 illustrates the importance respondents placed on specific comprehensive patient-centered care practices. The highest-rated practice was doctors telling the full truth about the diagnosis or test results when breaking difficult news, with 96% (n=10051) rating this as important. This was closely followed by understanding what is important to the patient and / or their caregiver when managing their care (95%, n=9788) and providing information or support so that they can confidently manage their lymphoma or CLL (94%, n=9763). Additionally, asking patients how much they want to be involved in decisions about their care and treatment, was rated as important by 93% (n=9679) of respondents.

Figure 48. Q74 How important or unimportant is it to you to have the lymphoma or CLL doctor do the following?



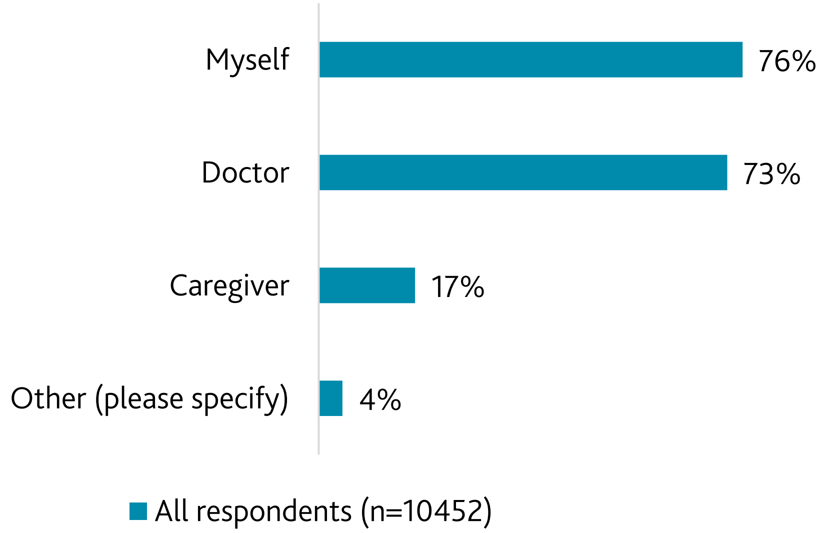
- Fifty-two percent (n=4875) of respondents reported that they were definitely involved as much as they wanted to be in decisions about their care and treatment, as indicated in Figure 49.

Figure 49. Q75 Do you feel you are as involved as much as you want to be in decisions about your care and treatment?



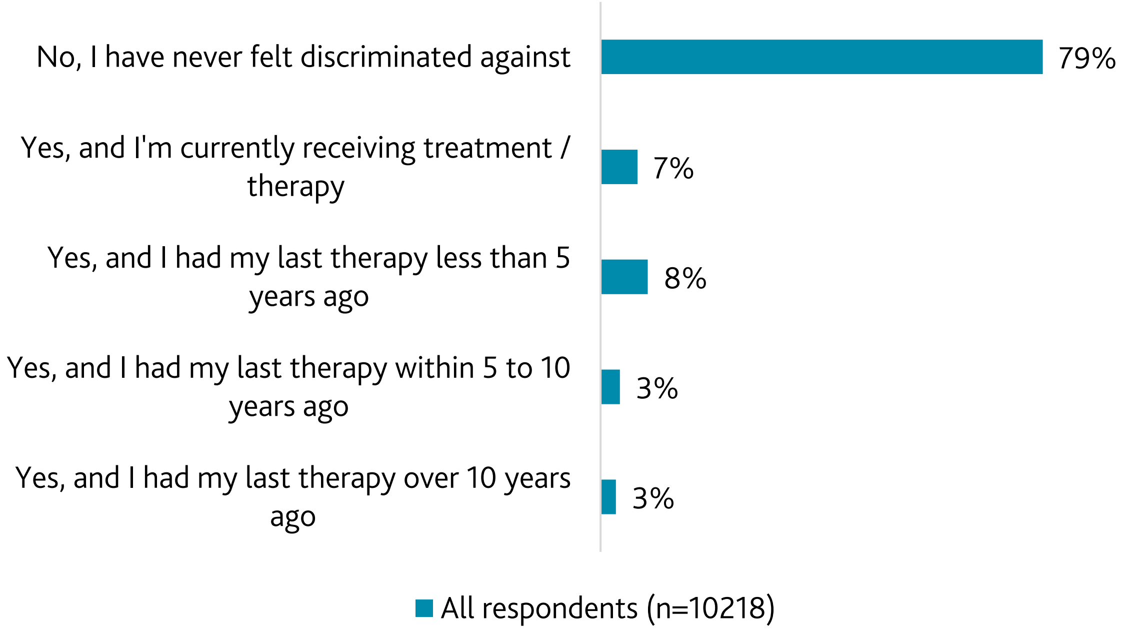
- When asked who they would ultimately like to make healthcare decisions, 76% (n=7936) of respondents chose themself. This was closely followed by doctors (73%, n=7648) (Figure 50).

Figure 50. Q76 Who would you ultimately like to make healthcare decisions? Please select all that apply.



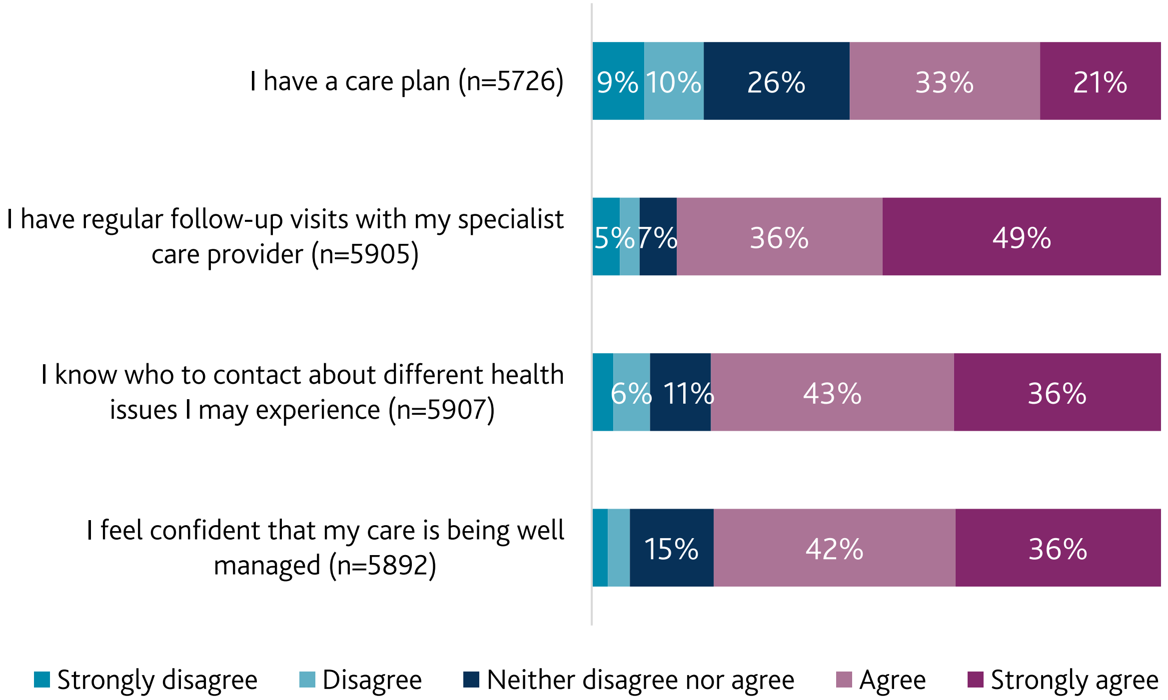
- ❖ Figure 51 shows 79% (n=8054) of respondents indicated that they have never felt discriminated against in accessing banking, credit or insurance services because of their lymphoma or CLL diagnosis.

Figure 51. Q77 Have you ever felt discriminated against in accessing banking, credit or insurance services because of your lymphoma or CLL diagnosis?



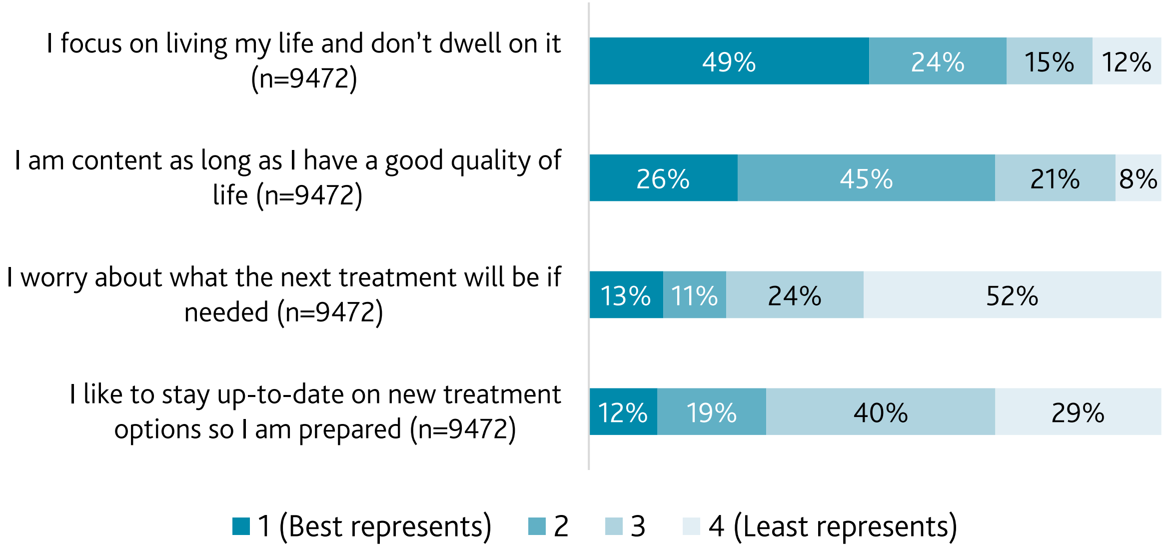
- Figure 52 details the extent to which respondents who are in active monitoring, watch and wait or who are in remission agree with aspects of coordinated and comprehensive care management. Of these respondents, 85% (n=5024) agreed that they have regular follow-up visits with their specialist care provider. This is closely followed by 79% (n=4670) who agreed that they know who to contact about different health issues they may experience, and 78% (n=4630) who agreed that they feel confident that their care is being well managed.

Figure 52. Q78 In thinking about your cancer care right now, to what extent do you agree or disagree with the following statements?



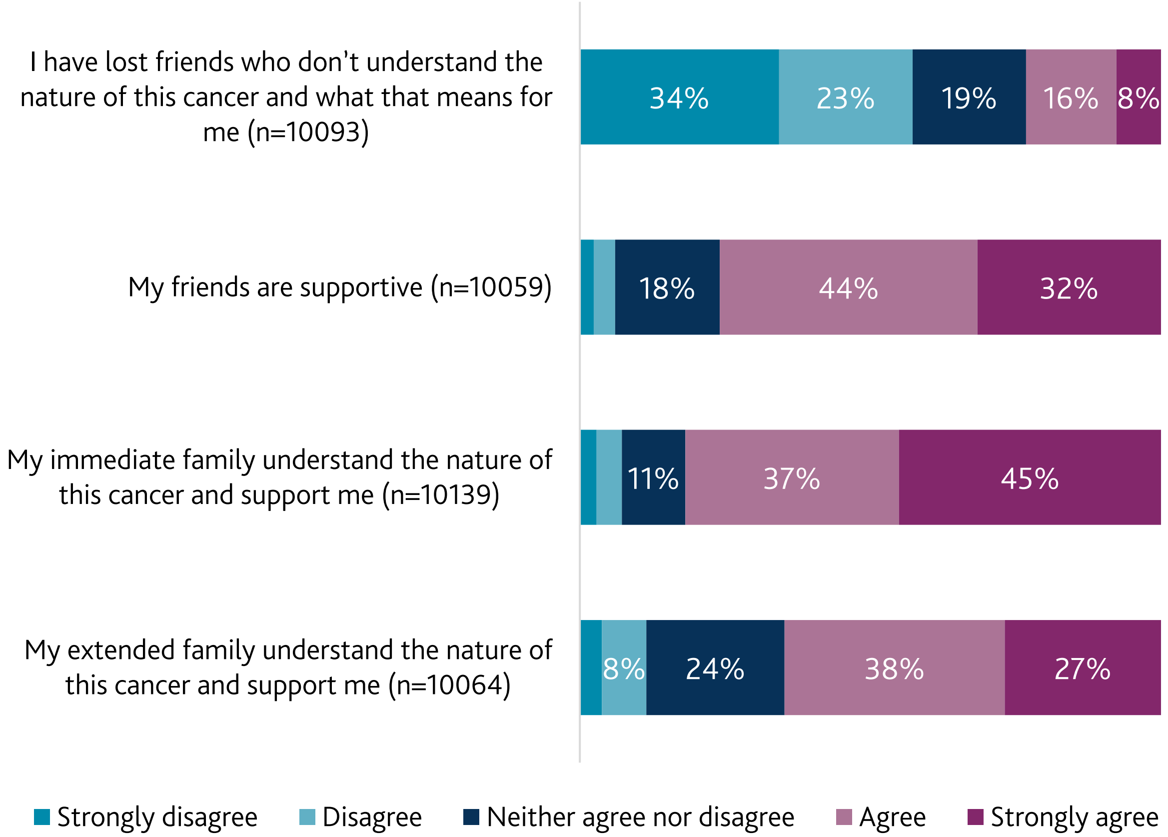
- Nearly half (49%, n=4675) of patients felt that the statement that best represented their current feelings about living with cancer was 'I focus on living my life and don't dwell on it' (Figure 53).

Figure 53. Q79 Please rank the following statements where 1 best represents your current feelings about living with cancer and 4 least represents your current feelings about living with cancer. Please drag and drop each statement into your preferred order.



- When asked about the impact of living with cancer on their relationships, respondents were most likely to agree that their immediate family understands the nature of their cancer and supports them (82%, n=8298). Only 24% (n=2346) agreed that they have lost friends who don't understand the nature of this cancer and what it means to them (Figure 54).

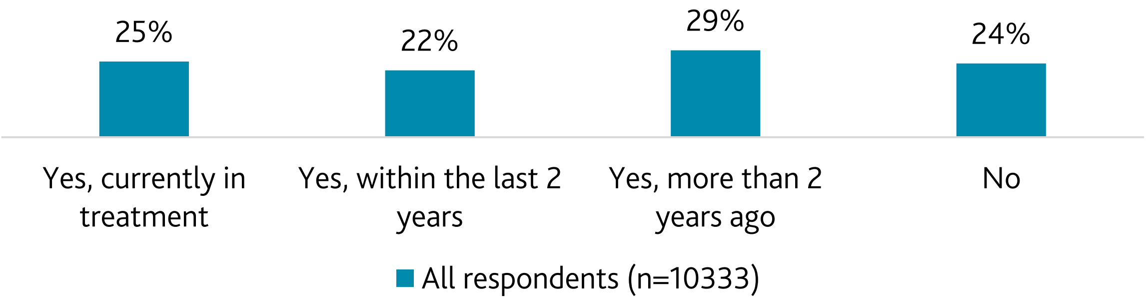
Figure 54. Q80 To what extent do you agree or disagree with the following statements about the impact living with cancer has on your relationships?



Treatment

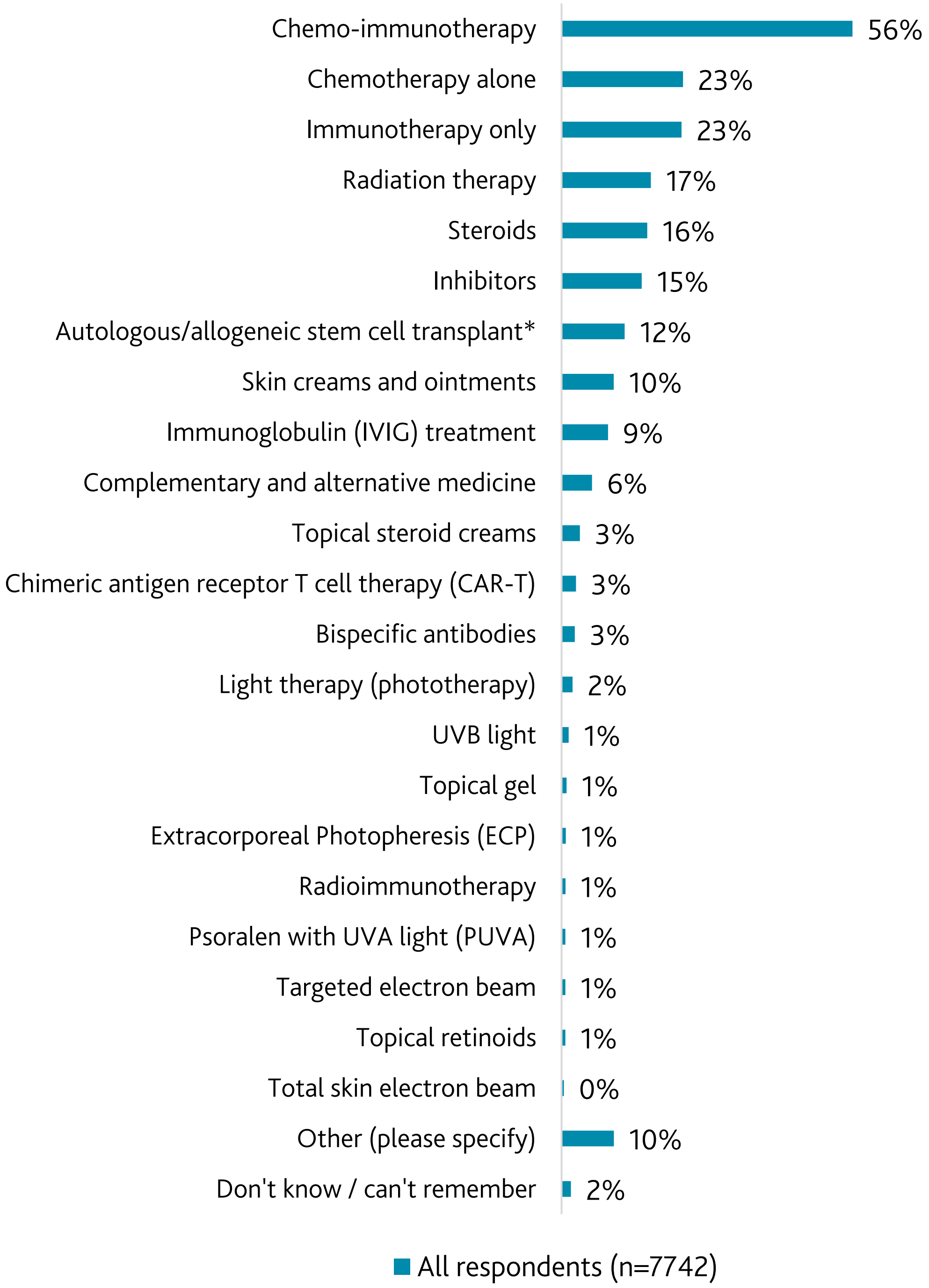
- A quarter of respondents (25%, n=2579) reported that they were currently undergoing medical treatment for their lymphoma or CLL. Twenty-two percent (n=2280) have received treatment within the last 2 years, while 29% (n=2961) had treatment more than 2 years ago. Twenty-four percent (n=2513) have not had any medical treatment for their lymphoma or CLL (Figure 55).

Figure 55. Q81 Have you received or are you receiving any medical treatment (e.g., chemotherapy, radiation) for your lymphoma or CLL?



- Of those who are currently in treatment or who have had treatment in the past, 56% (n=4300) have received chemo–immunotherapy, 23% (n=1795) have received chemotherapy alone, and 23% (n=1774) have received immunotherapy alone (Figure 56).

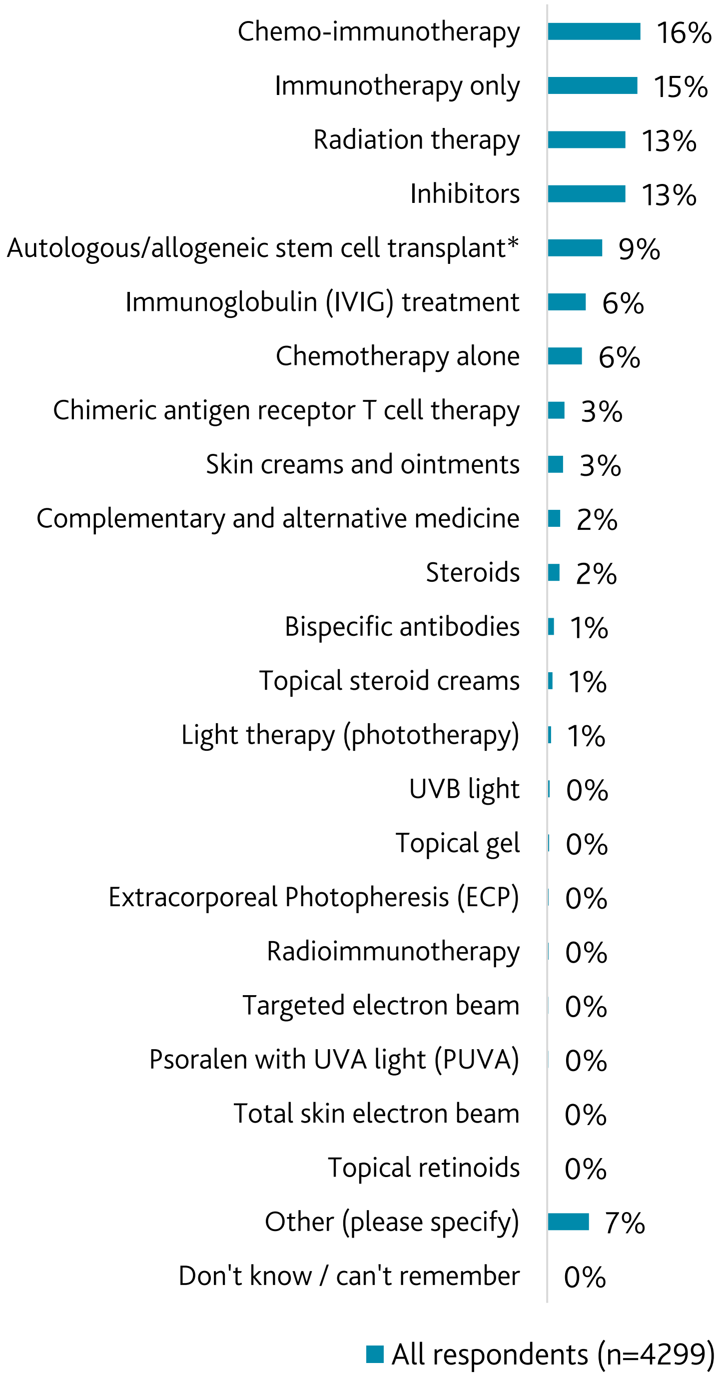
Figure 56. Q82 Which of the following treatments, if any, do you receive currently, or have ever received in the past? Please select all that apply.



*Also known as bone marrow transplant

- Of those who have received more than one treatment, 16% (n=674) reported that chemo-immunotherapy was their most recent treatment, while 15% (n=652) reported immunotherapy only was their most recent treatment (Figure 57).

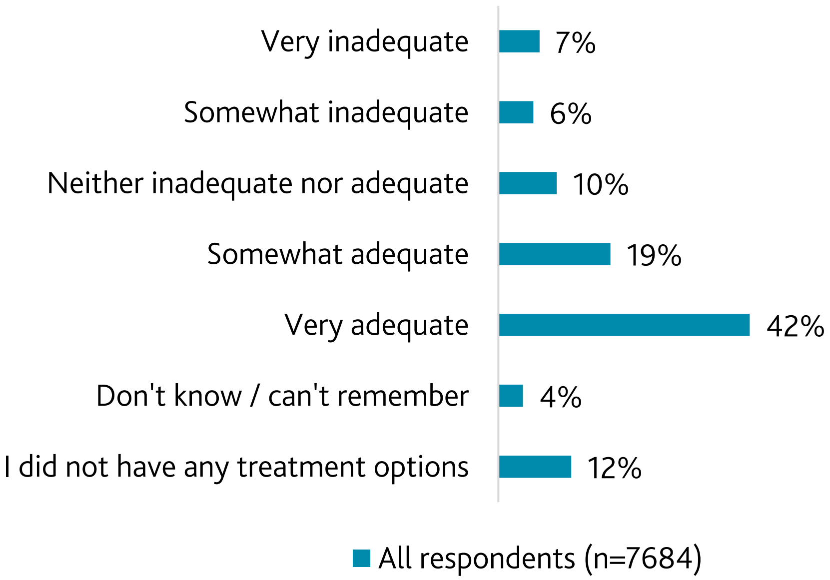
Figure 57. Q83 Of the following treatments you have received, or you receive currently, which is the most recent?



*Also known as bone marrow transplant

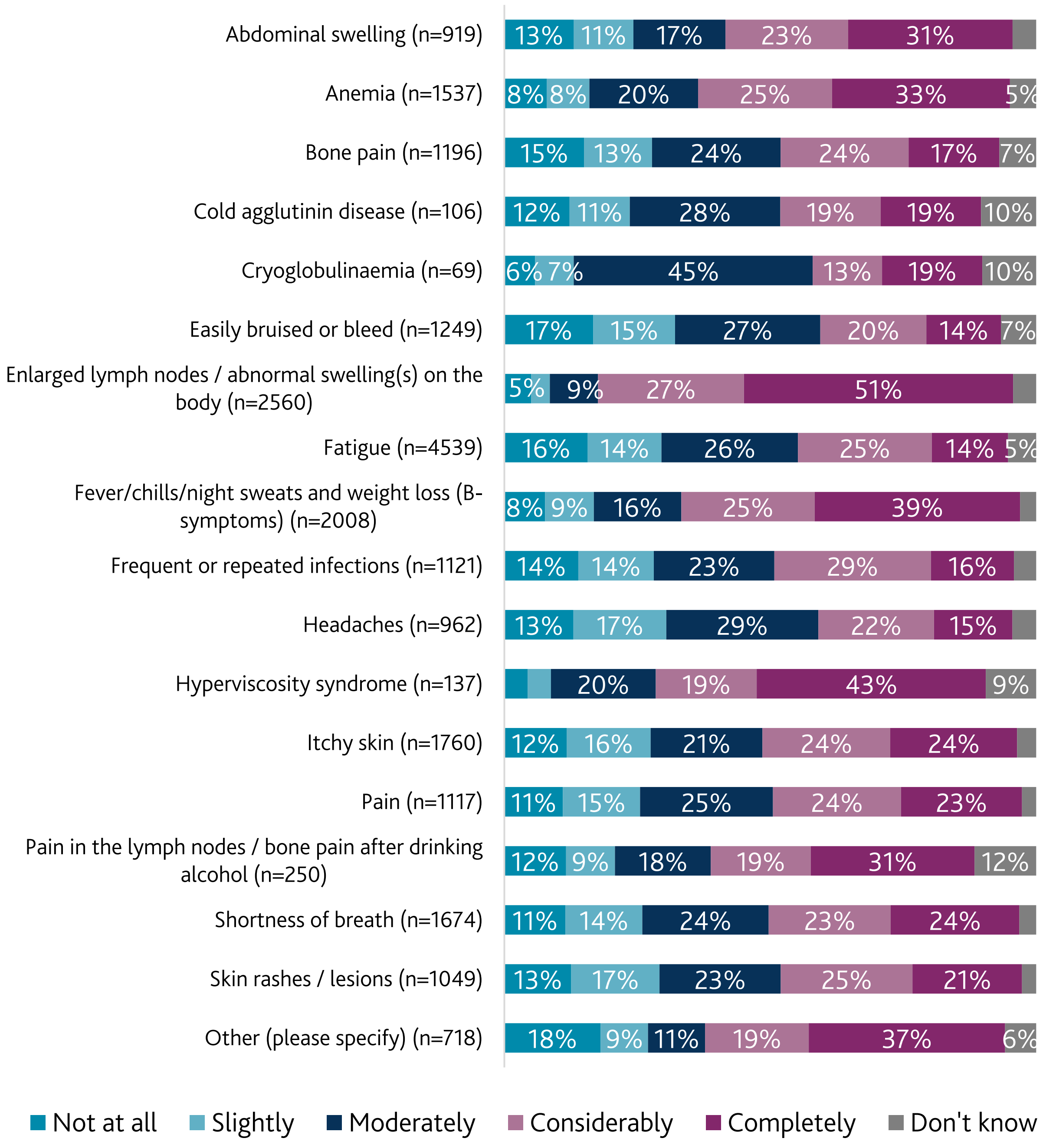
- When thinking about their current or most recent treatment, 61% (n=4690) felt they were given adequate time to think about their treatment options before a decision was made (Figure 58).

Figure 58. Q84 Thinking about your current (or most recent) treatment, how adequate was the amount of time you were given to think about your treatment options before a decision was made?



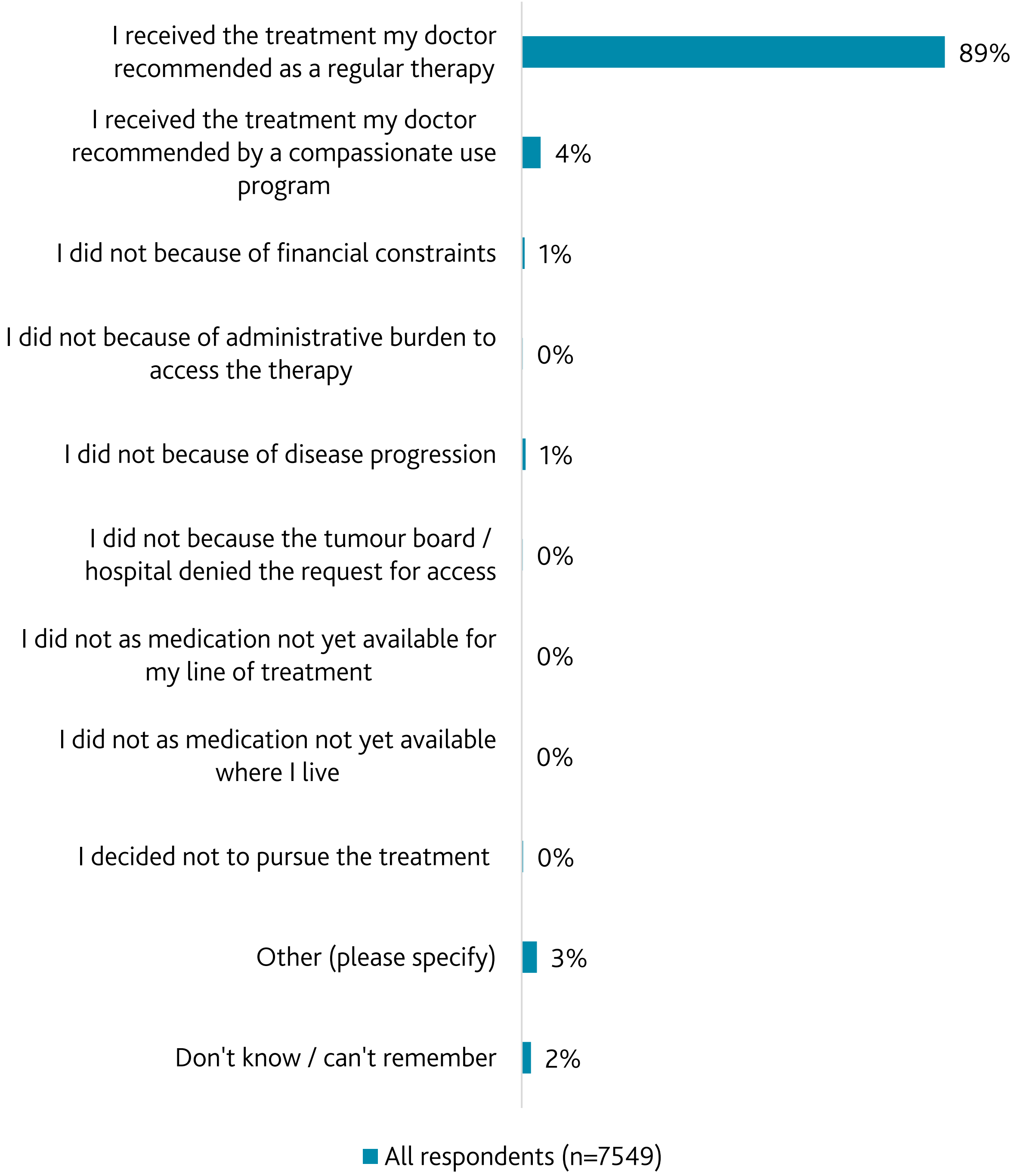
- When asked how helpful treatment has been in managing symptoms, respondents were most likely to report that treatment considerably or completely helped manage the following (Figure 59): enlarged lymph nodes / abnormal swelling(s) on the body (78%, n=1998); B-symptoms such as fever, chills, night sweats, and weight loss (64%, n=1279); and hyperviscosity syndrome (62%, n=85).

Figure 59. Q85 You previously said you experienced the following symptoms which prompted you to seek medical consultation. How helpful, if at all, do you think your treatment has been in managing these? Please do not include any side effects you may be experiencing as a result of your treatment.



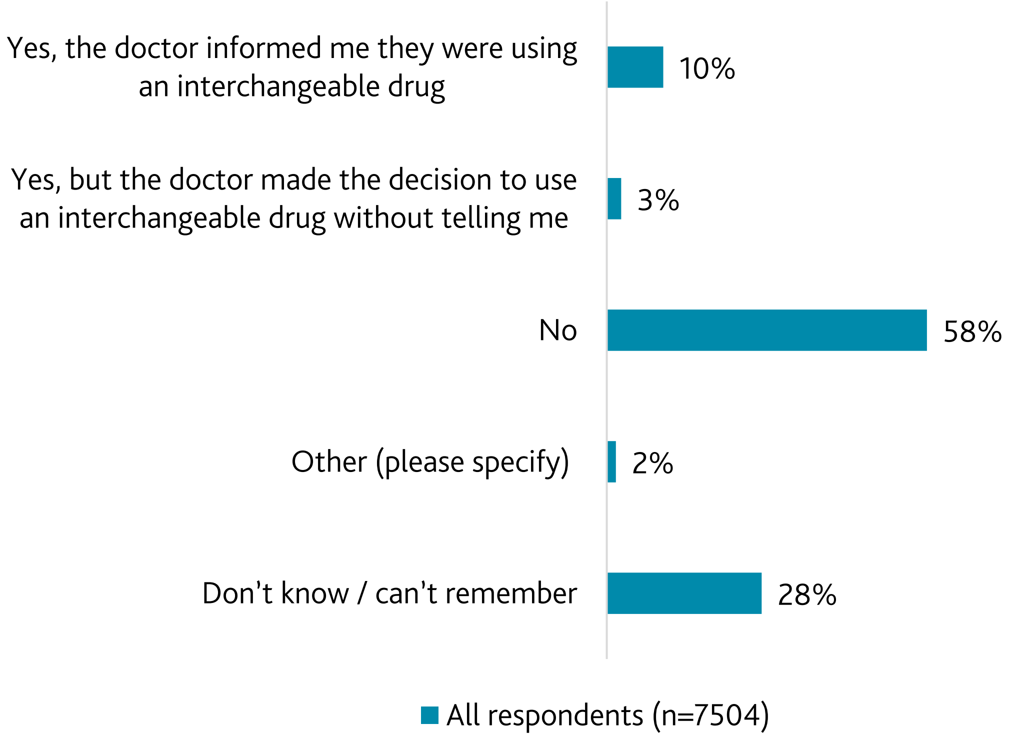
- When thinking about their recent treatment, 89% (n=6681) received the treatment option recommended by their primary lymphoma / CLL doctor as a regular therapy (Figure 60).

Figure 60. Q86 With regard to your most recent treatment, did you receive the first treatment option recommended by your primary lymphoma / CLL doctor? If not, please choose the main reason why you did not.



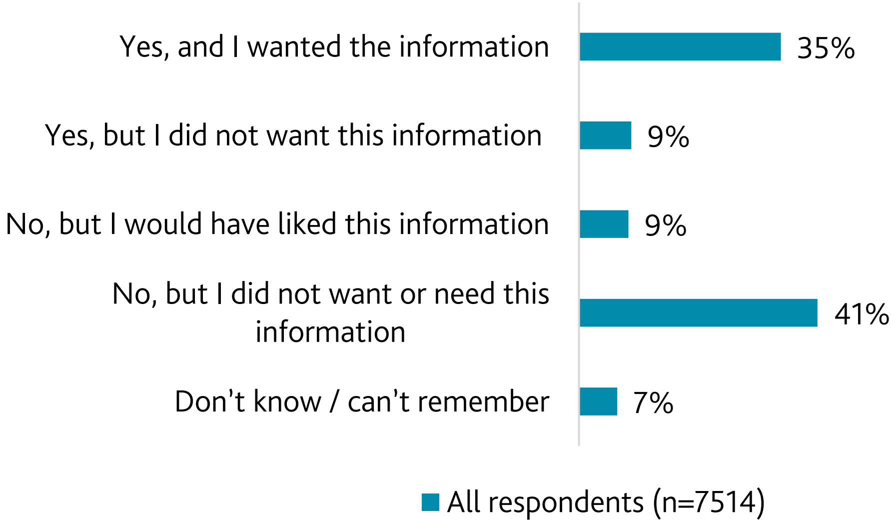
- For 58% (n=4330) of respondents, interchangeable / equivalent drugs were not used during their treatment, however, 13% (n=957) reported that interchangeable / equivalent drugs were used (Figure 61).

Figure 61. Q88 Were interchangeable / equivalent drugs (e.g., generic, biosimilars, pharmaceutical equivalents) used during your treatment?



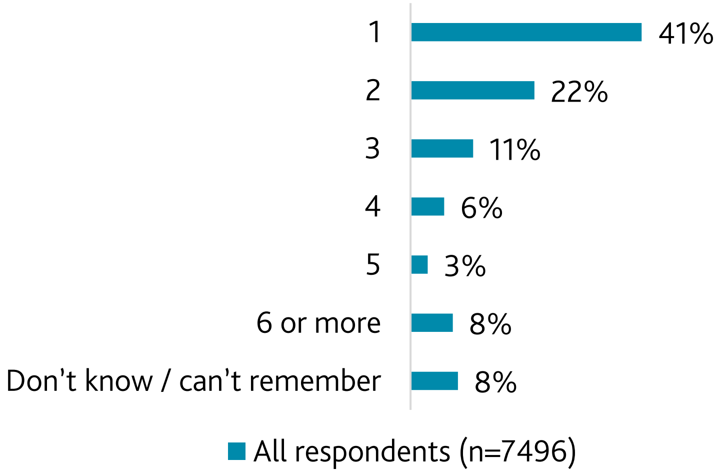
- When asked if any information about treatment side effects on fertility and fertility preservation opportunities was shared by the medical team before treatment, 35% (n=2613) received and wanted the information. Nine percent (n=677) received this information but did not want it, while 9% (n=640) were not given this information but would have liked to receive it (Figure 62).

Figure 62. Q89 Before your treatment started, did the medical team give you any information about treatment side effects on fertility and about fertility preservation opportunities?



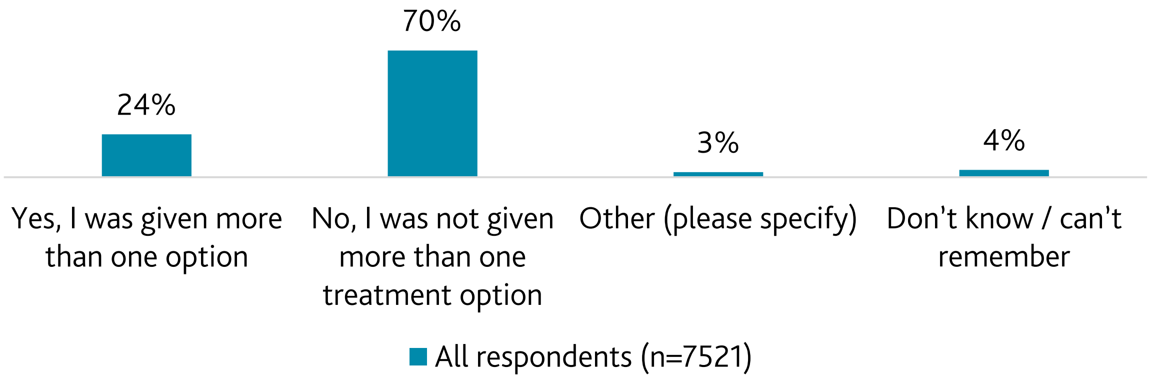
- The most frequent number of treatment regimens received was 1 (41%, n=3104), followed by 2 (22%, n=1665). Twenty-eight percent (n=2090) had received three or more treatment regimens (Figure 63).

Figure 63. Q90 How many different treatment regimens have you received to date for your lymphoma or CLL? A "regimen" is a structured treatment plan that includes one or more drugs or other interventions designed to treat lymphoma or CLL.



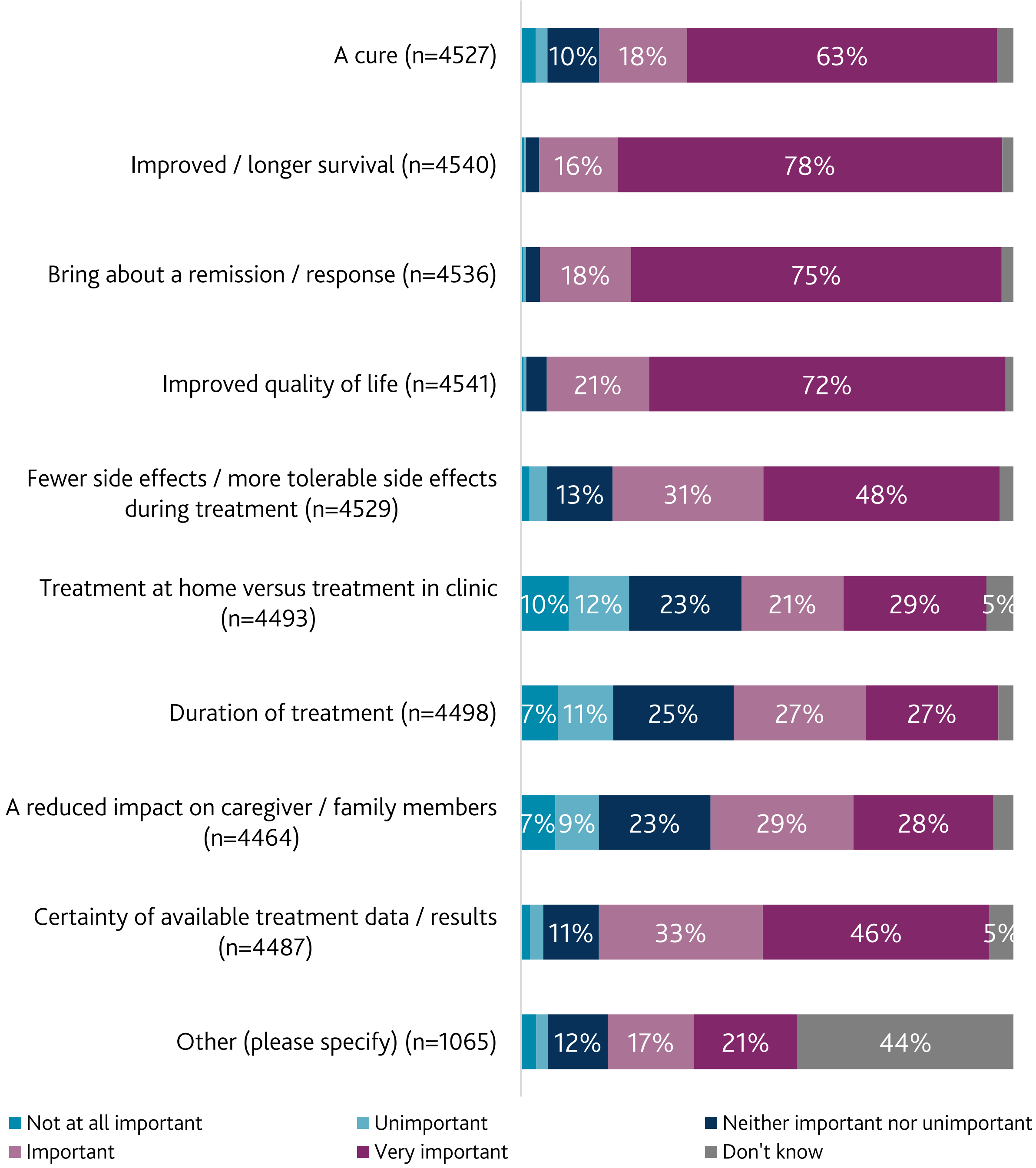
- Seventy percent (n=5240) of respondents were not given more than one treatment option before their most recent treatment, while 24% (n=1771) were given more than one treatment option (Figure 64).

Figure 64. Q91 Before your current or most recent therapy / treatment, were you given more than one treatment option? (for instance, different types of chemotherapy regimens to choose from or a choice between a stem cell transplant and a new targeted therapy)



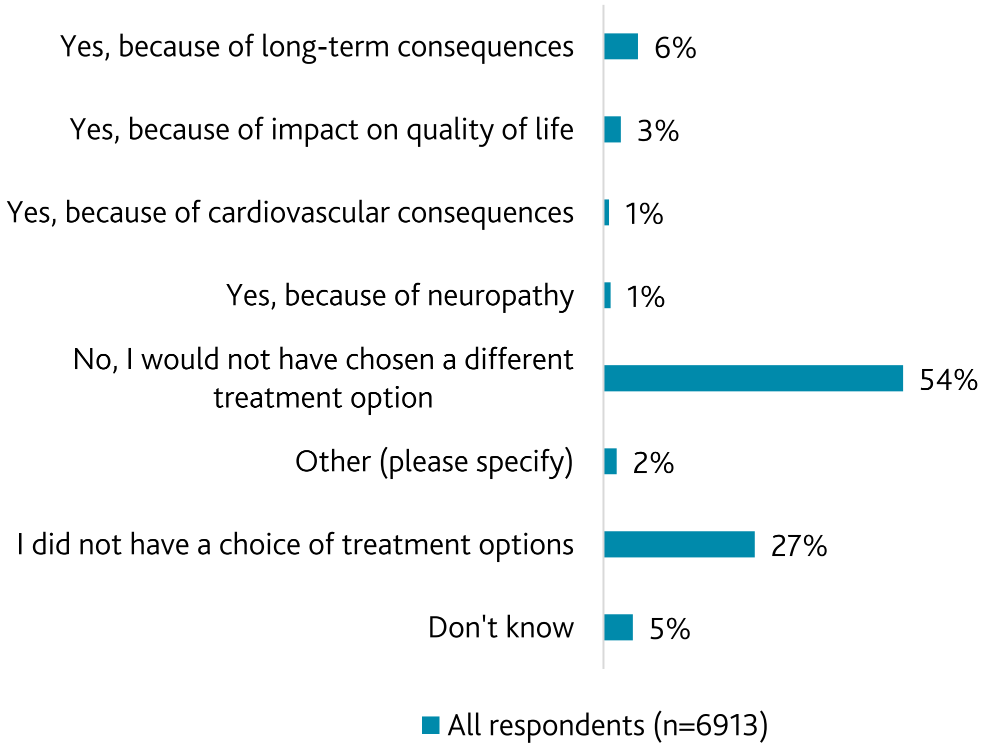
- Of respondents who have had or are currently undergoing treatment, 94% (n=4268) reported that improved or longer survival was important when deciding on their most recent treatment. Similarly, bringing about a remission or response (93%, n=4249) and improved quality of life (93%, n=4229) were identified as being important factors when deciding on the patient's most recent treatment (Figure 65).

Figure 65. Q92 When deciding on your most recent treatment for your lymphoma or CLL, how important were the following?



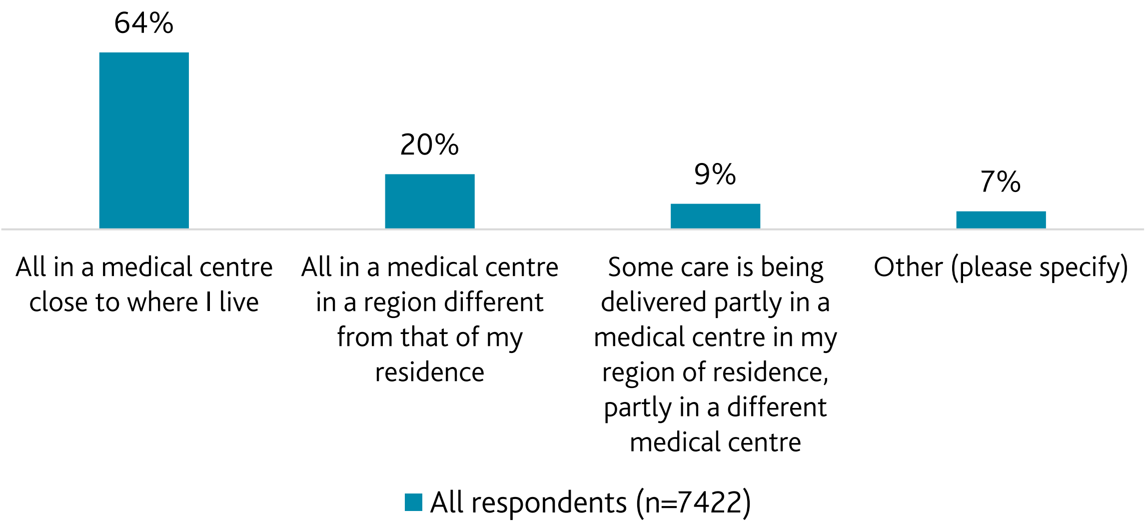
- Figure 66 demonstrates 54% (n=3711) of respondents who have had or are currently undergoing treatment reported that, in hindsight, they would not have chosen a different treatment option. Moreover, 27% (n=1875) reported that they did not have a choice of treatment options.

Figure 66. Q93 In hindsight would you have chosen a different treatment option? (e.g. considering late effects experienced from treatment)



❖ Nearly two-thirds of respondents (64%, n=4763) who have had or are currently undergoing treatment, indicated that their treatment and / or follow-up appointments were all delivered in a medical centre close to where they live. Twenty percent (n=1486) reported that all of their treatment and / or follow-up appointments were delivered in a medical centre in a region different to that of their residence. Nine percent (n=688) reported that some of their care was partly delivered in a medical centre in their region of residence and partly in a medical centre outside of their region (Figure 67).

Figure 67. Q94 Where are your treatment and / or follow-up appointments being delivered?



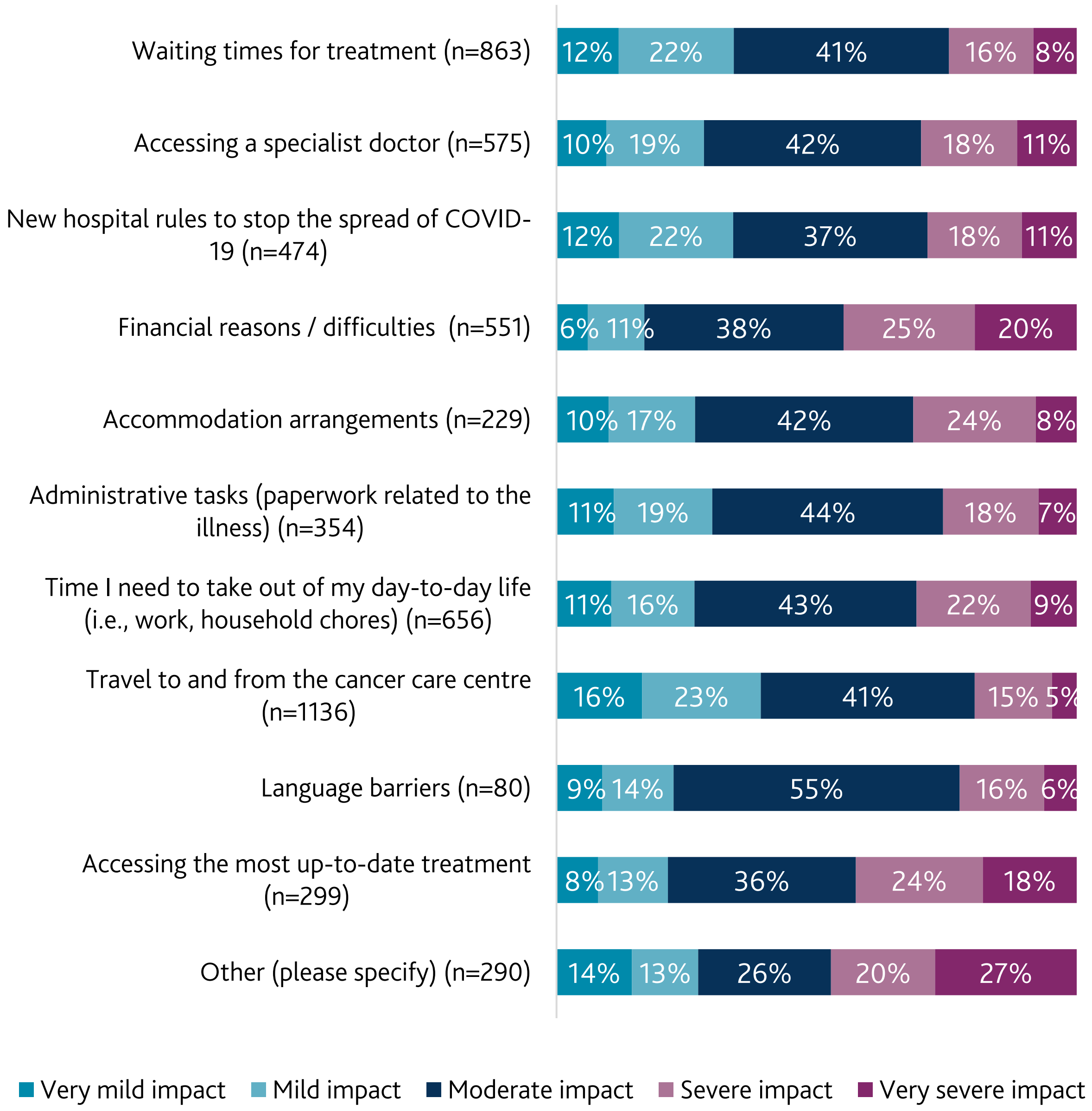
Barriers to treatment

- Of respondents who have received treatment, 59% (n=4339) reported that nothing had made getting treatment difficult. The most commonly reported barrier cited was travel to and from the cancer care centre, cited by 16% (n=1146) of respondents. This was followed by waiting times for treatment, reported by 12% (n=875) of respondents, as depicted in Figure 68.

Figure 68. Q103 What, if anything, has made getting your most recent treatment more difficult? Please select all that apply.

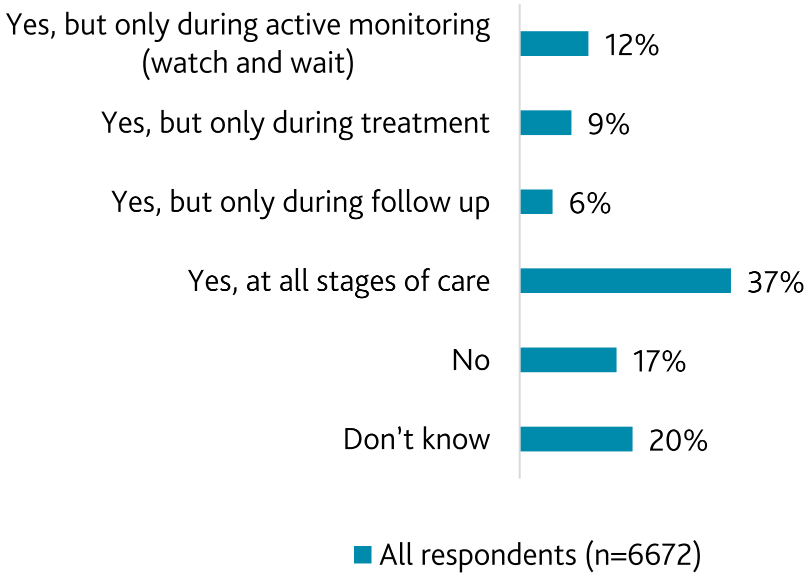
- Respondents who identified barriers to accessing their most recent treatment were most likely to report financial reasons/difficulties (45%, n=247) and accessing the most up-to-date treatment (42%, n=127) as having a very severe or severe impact in getting their most recent treatment (Figure 69).

Figure 69. Q104 To what extent has the barrier impacted you getting your most recent treatment?



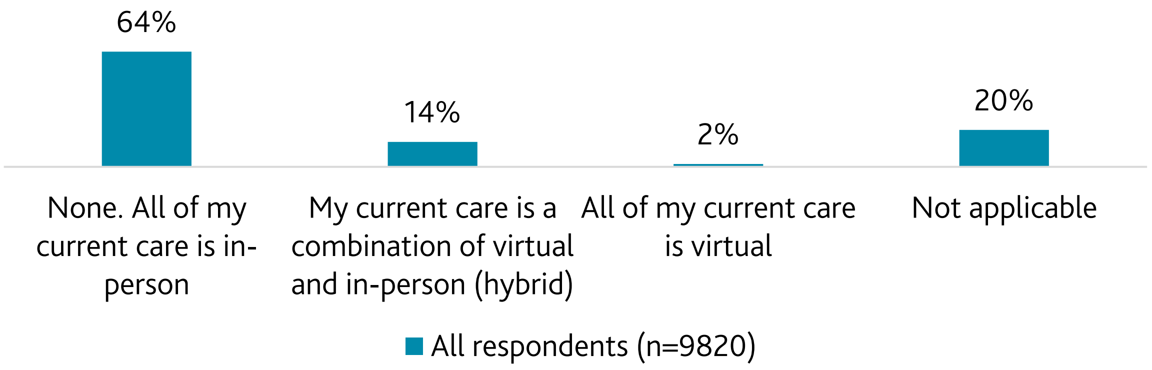
- Respondents who are currently receiving treatment, have received treatment in the last two years, have not yet received treatment but are in active monitoring or watch and wait, or have had treatment and are back in active monitoring or watch and wait, were asked if they were comfortable with the idea of using telemonitoring or information technology (such as apps or wearable devices) to monitor some of their health from a distance. Of these respondents, 37% (n=2454) reported that they would be comfortable with this at all stages of care (Figure 70).

Figure 70. Q105 Are you comfortable with the idea of using telemonitoring or information technology (such as apps or wearable devices) to monitor some of your health from a distance?



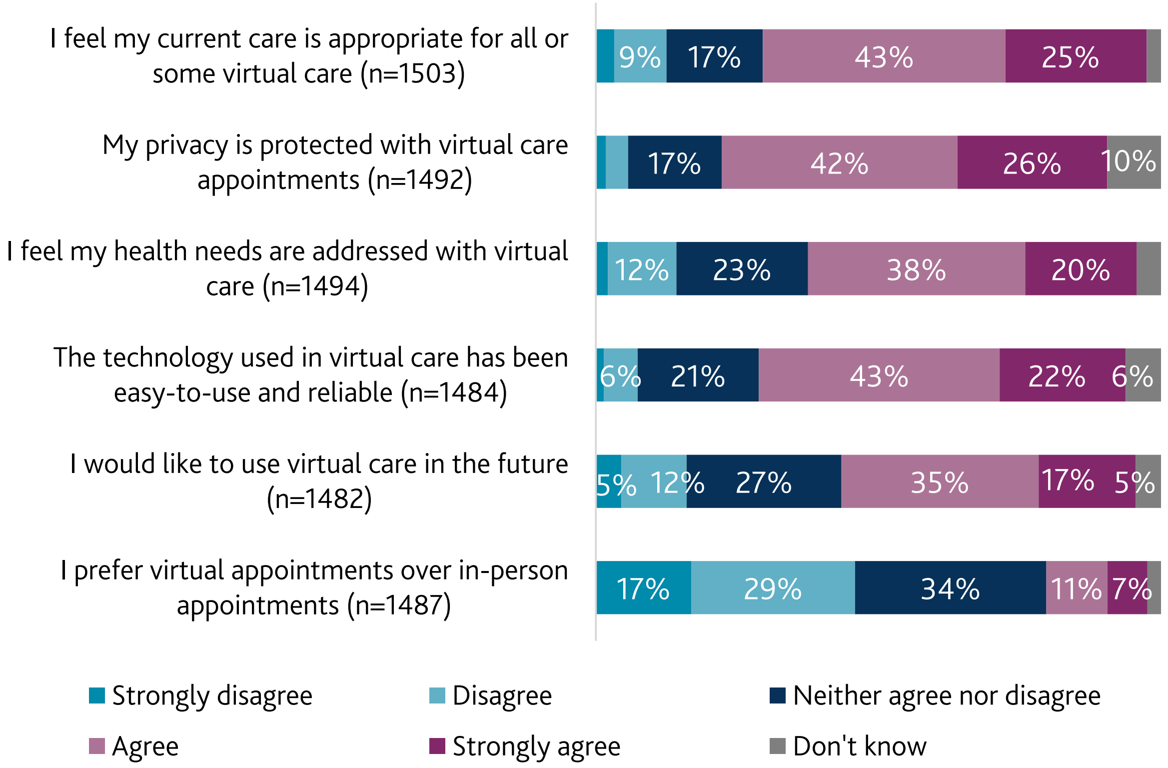
- Figure 71 shows that 64% (n=6288) of respondents reported that none of their current care for lymphoma or CLL is provided using virtual / online care (telemedicine) methods; all their current care is in person.

Figure 71. Q106 What role does virtual / online care (telemedicine) play in your current care for lymphoma or CLL?



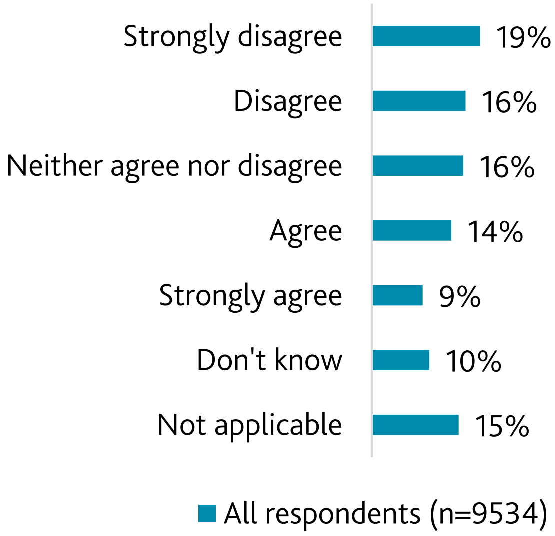
❖ Figure 72 presents data from respondents who indicated that all their care is provided virtually or through a combination of virtual and in-person methods. Of these respondents, 68% (n=1021) agreed that their current care is appropriate for all or some virtual care. Sixty-eight percent (n=1018) agreed that their privacy is protected with virtual care appointments, while 65% (n=963) agreed that the technology used in virtual care has been easy-to-use and reliable.

Figure 72. Q107 Regarding virtual / online care (telemedicine), to what extent do you agree or disagree with the following statements?



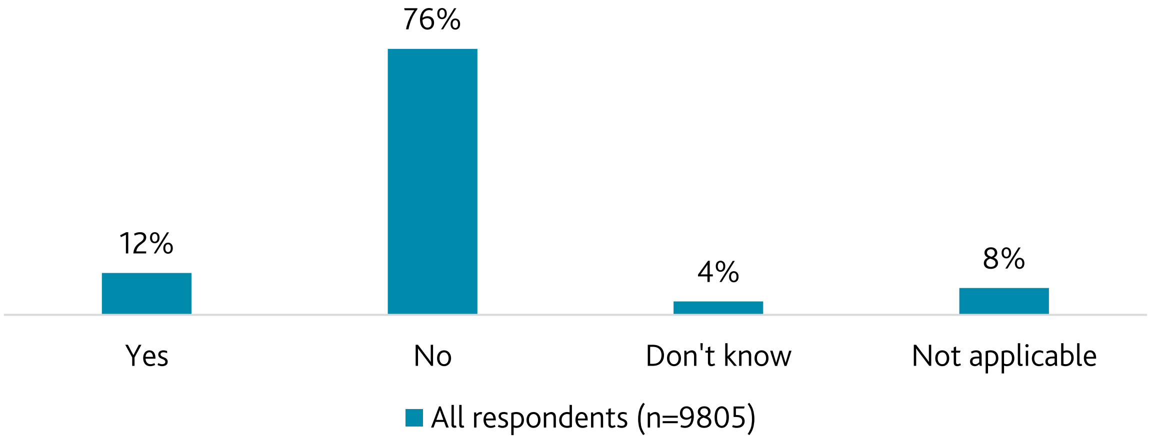
- Figure 73 shows that nearly a quarter (23%, n=2185) of respondents agreed that the current measures implemented in their care centre to stop the spread of COVID-19 act as a barrier to optimal care for their lymphoma or CLL.

Figure 73. Q108 To what extent do you agree or disagree that the current measures in your care centre, implemented to stop the spread of COVID-19, act as a barrier to optimal care for your lymphoma or CLL?



- Three quarters (76%, n=7492) of respondents reported that they did not feel fearful of in-person visits to their healthcare provider for treating their lymphoma or CLL due to the risk of contracting COVID-19 (Figure 74).

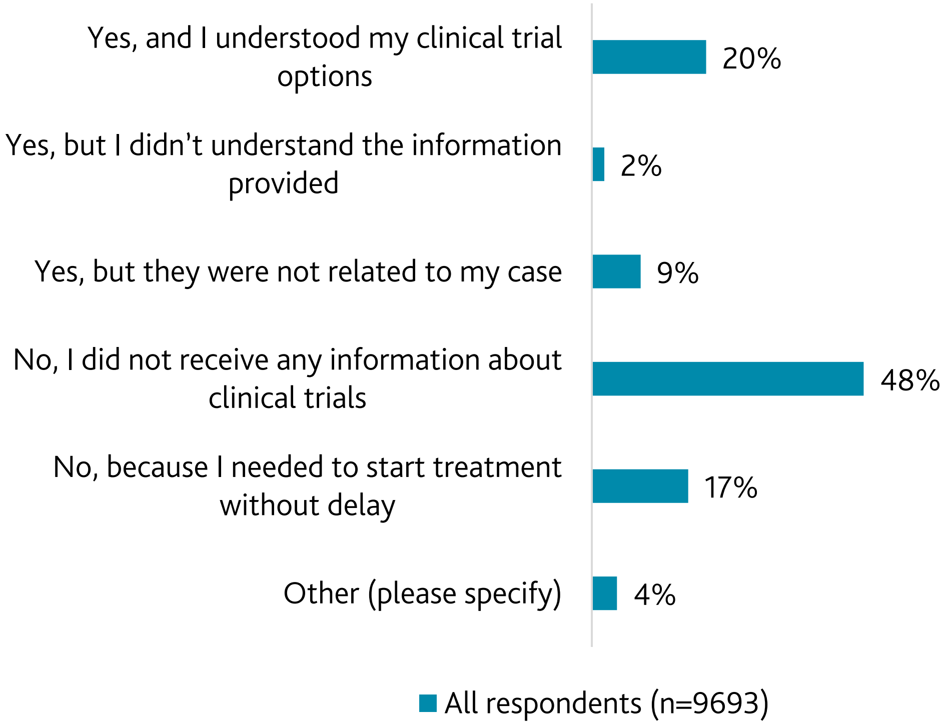
Figure 74. Q109 Do you currently feel fearful of in person visits to your healthcare provider for the purpose of treating your lymphoma or CLL because of the risk of contracting COVID-19?



Clinical trials

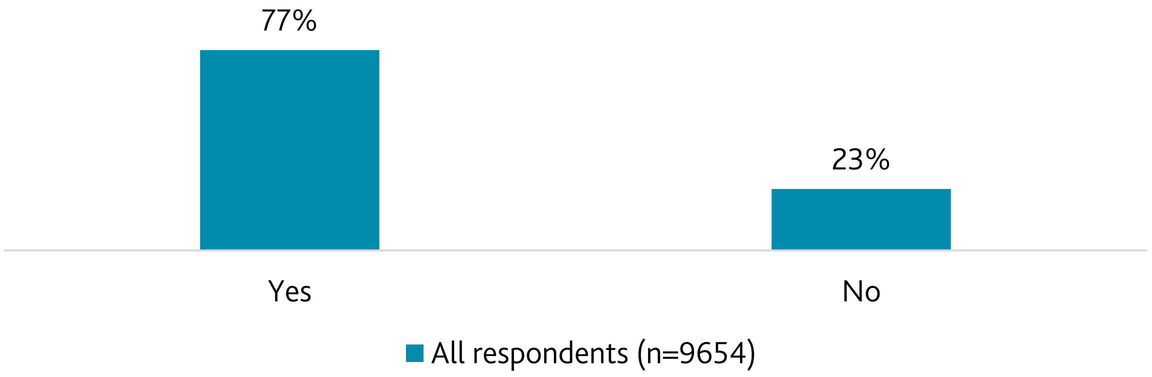
- During meetings with their lymphoma or CLL doctor, nearly half (48%, n=4632) of respondents indicated that they did not receive any information about clinical trials, while a further 17% (n=1643) reported they did not receive this information because they needed to start treatment without delay. In contrast, one fifth (20%, n=1947) of respondents reported they understood their clinical trial options, as shown in Figure 75.

Figure 75. Q115 During your meetings with your lymphoma or CLL doctor, did you receive any information about clinical trials? Please choose the response that best fits your situation.



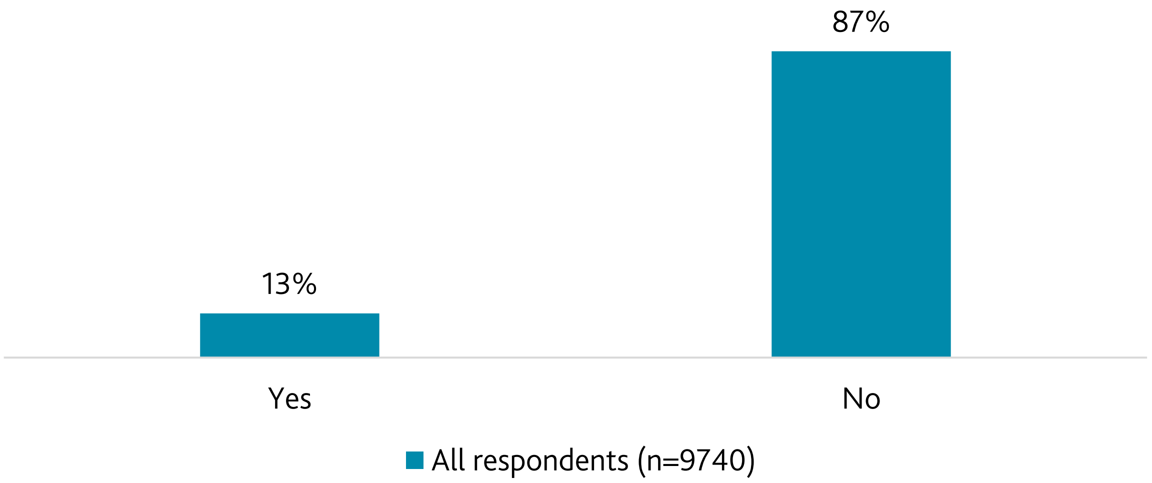
- As depicted in Figure 76, 77% (n=7388) of respondents reported being aware that participation in a clinical trial provides access to newer drugs with potentially better outcomes compared to standard therapy.

Figure 76. Q116 Are you aware that participation in a clinical trial provides access to newer drugs with potentially better outcomes compared to standard therapy?



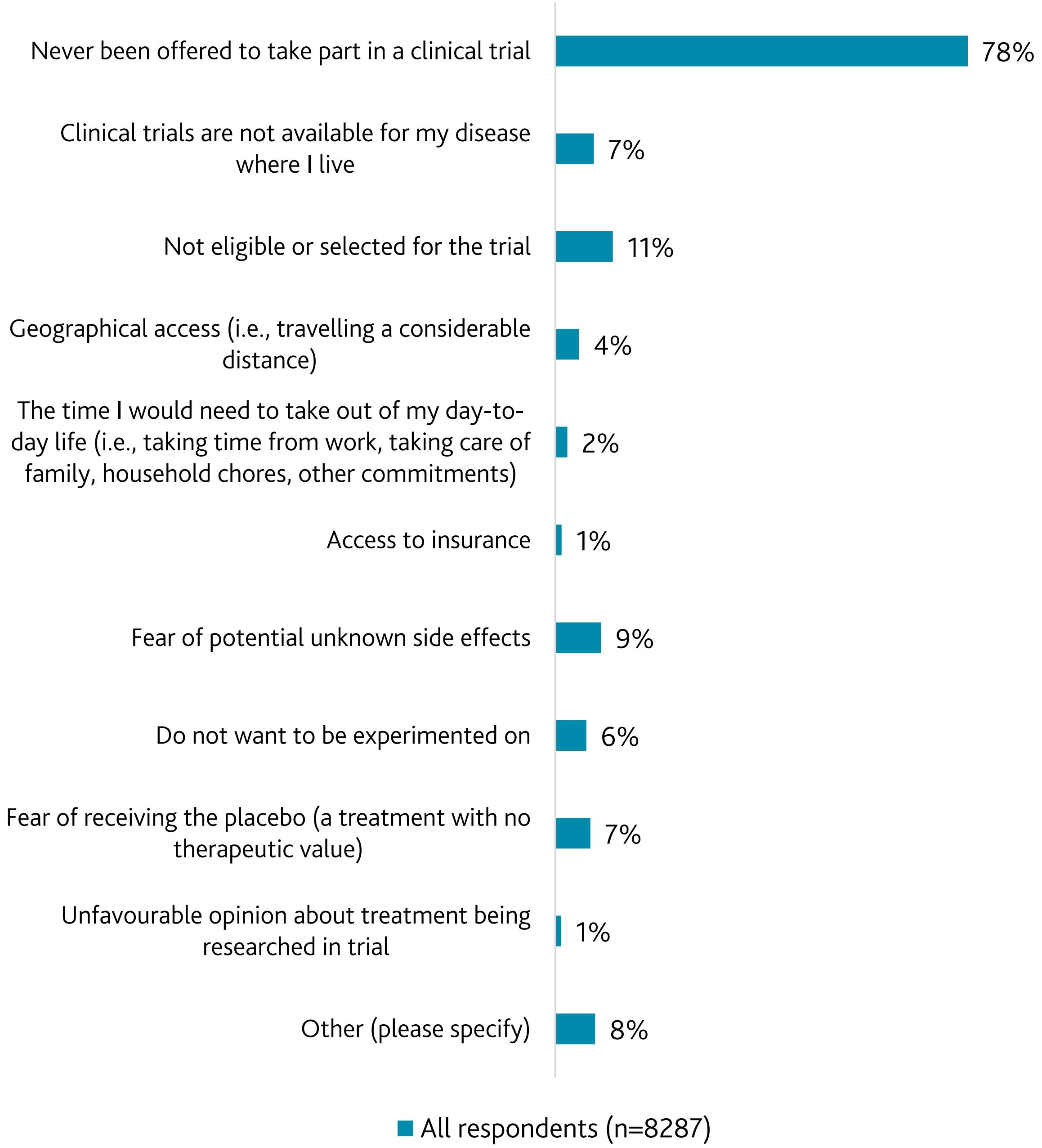
- Only 13% (n=1227) of patients have participated in a clinical trial for their lymphoma or CLL either in the past or presently (Figure 77).

Figure 77. Q117 Have you participated in a clinical trial for your lymphoma or CLL in the past or presently?



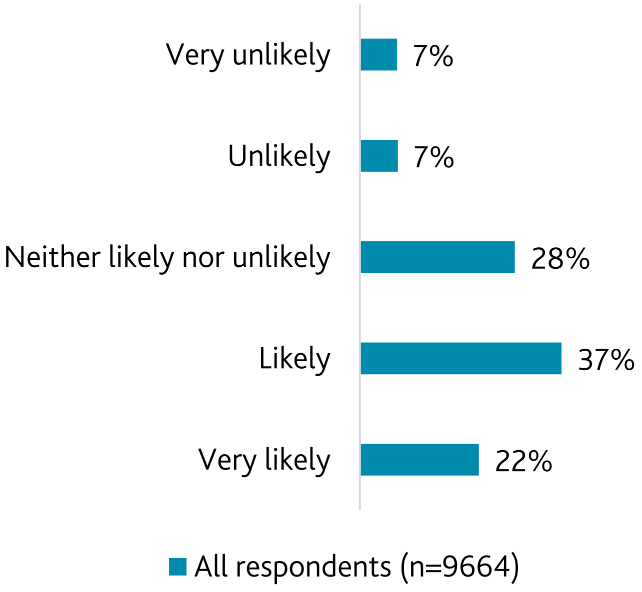
- When asked what has prevented them from participating in a clinical trial for their lymphoma or CLL, 78% (n=6481) reported they have never been offered to take part in a clinical trial. Eleven percent (n=903) indicated that they were not eligible or selected for the trial, while 9% (n=719) reported that the fear of potential unknown side effects was a barrier preventing them from participating in a clinical trial (Figure 78).

Figure 78. Q118 What, if anything, has prevented you from participating in a clinical trial? Please select all that apply.



- Fifty-nine percent (n=5626) of respondents indicated that they were very likely or likely to participate in a cancer clinical trial in the future, if invited (Figure 79).

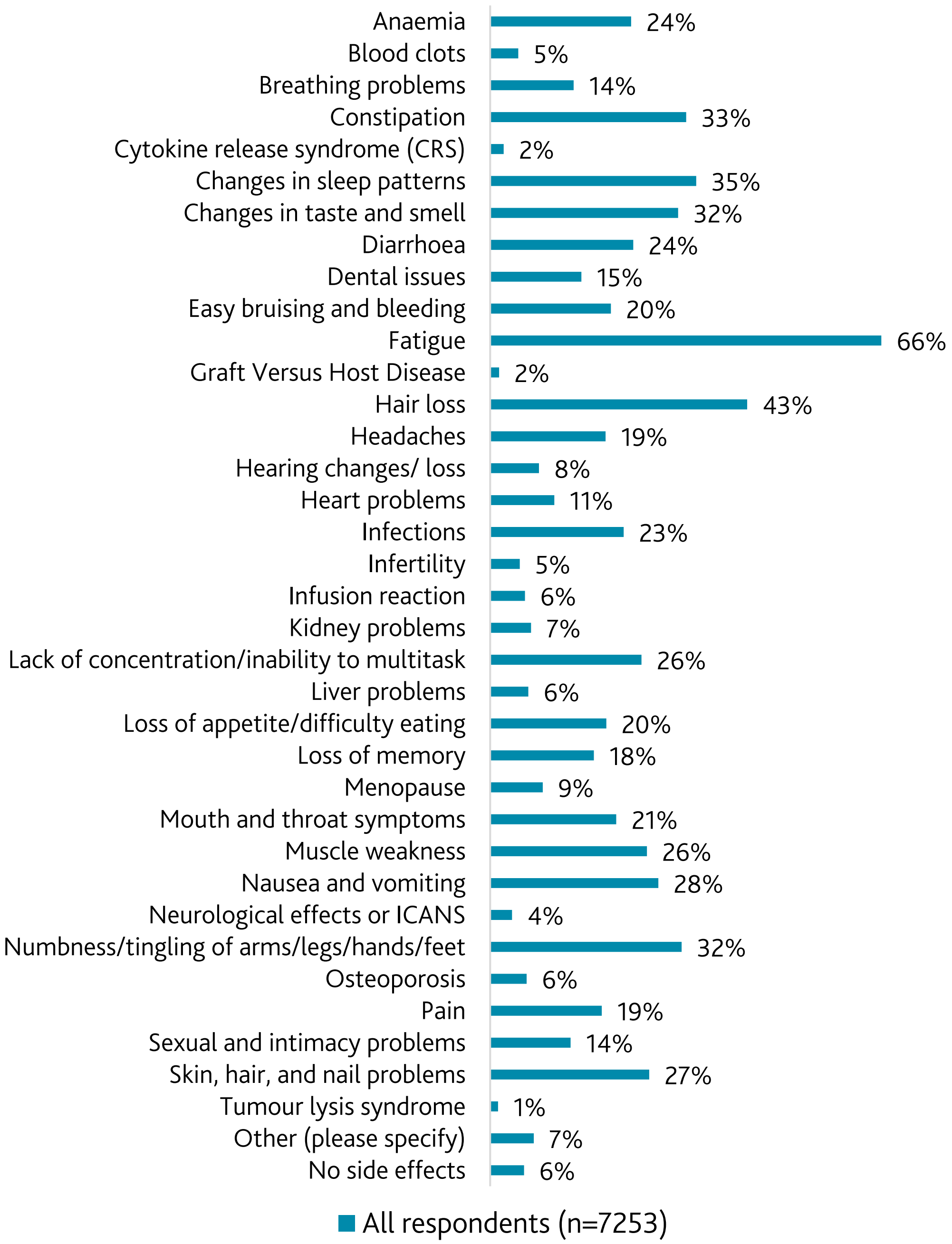
Figure 79. Q119 In the future, if you were invited, how likely is it that you would participate in a cancer clinical trial?



Side effects of treatment and fatigue

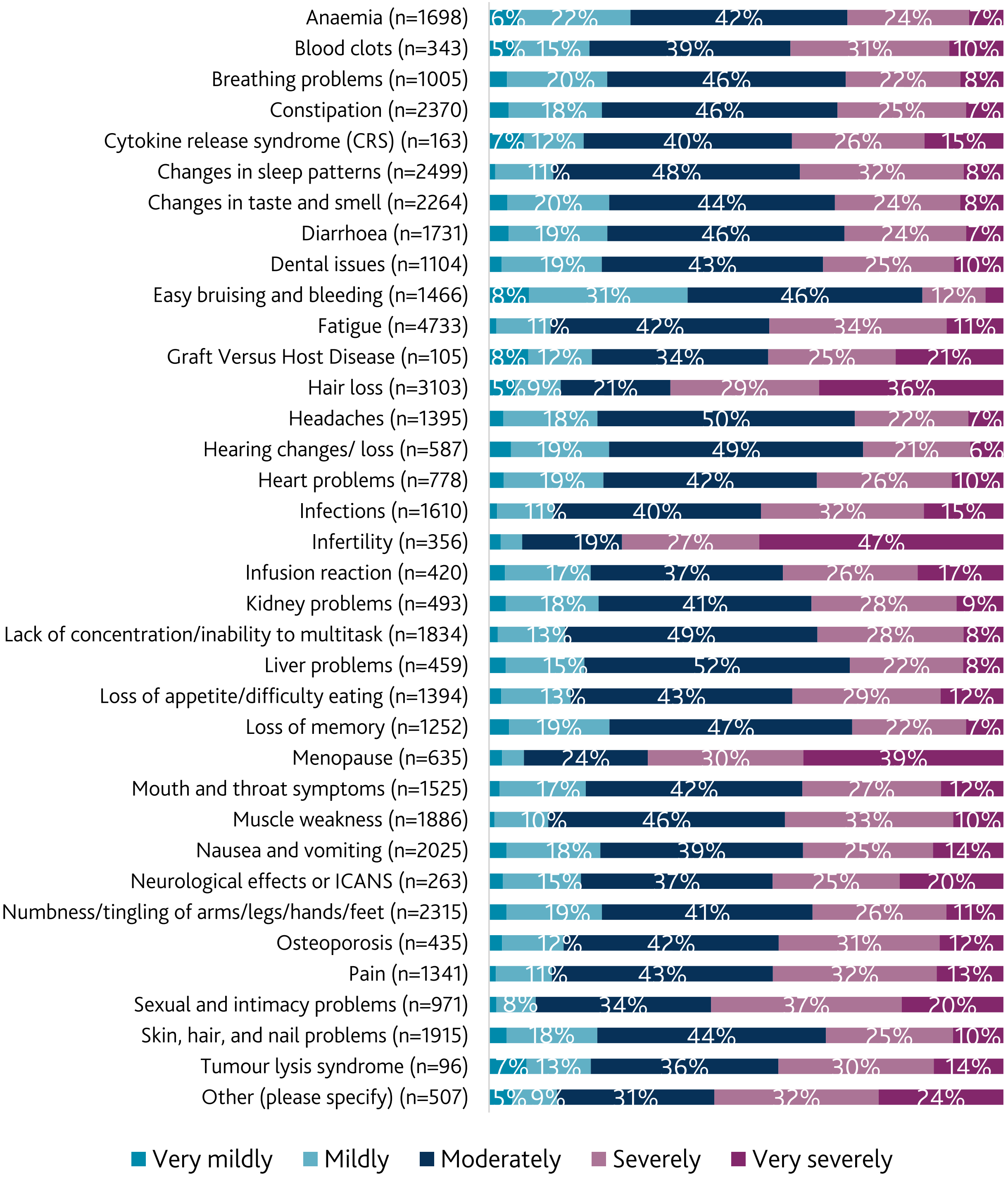
- Ninety-four percent (n=6838) of patients experienced side effects from their most recent treatment for lymphoma or CLL. The most common side effect experienced by patients was fatigue (66%, n=4794) (Figure 80).

Figure 80. Q121 Thinking about your most recent treatment for lymphoma or CLL, which of the following side effects, if any, have you experienced? Please select all that apply.



- Respondents who experienced side-effects from their treatment for lymphoma or CLL were most likely to report the following side-effects as having a severe or very severe impact (Figure 81): infertility (74%, n=264); menopause (69%, n=439) and hair loss (65%, n=2009).

Figure 81. Q122 You previously said you have experienced the following side-effect(s) from your treatment for lymphoma or CLL. To what extent have the side effect(s) affected you?



- Respondents who experienced side effects from their treatment were asked what their doctor or other members of their medical team did to help them cope with the side effects they experienced (Figure 82; Figure 83; Figure 84; Figure 85; Figure 86). At least half of respondents who experienced the following side effects reported that their medical team did not provide any help:
    - Lack of concentration/inability to multitask (64%, n=1087)
    - Loss of memory (64%, n=739)
    - Sexual and intimacy problems (61%, n=536)
    - Hair loss (58%, n=1635)
    - Changes in taste and smell (55%, n=1167)
    - Fatigue (53%, n=2313)
    - Easy bruising and bleeding (53%, n=717)
    - Muscle weakness (52%, n=888)
    - Hearing changes/ loss (51%, n=281)
    - Menopause (50%, n=285)

Figure 82. Q123 What did your doctor or other members of your medical team do to help you cope with each of the following treatment side effect(s) you experienced? Please select all that apply. (Part 1)

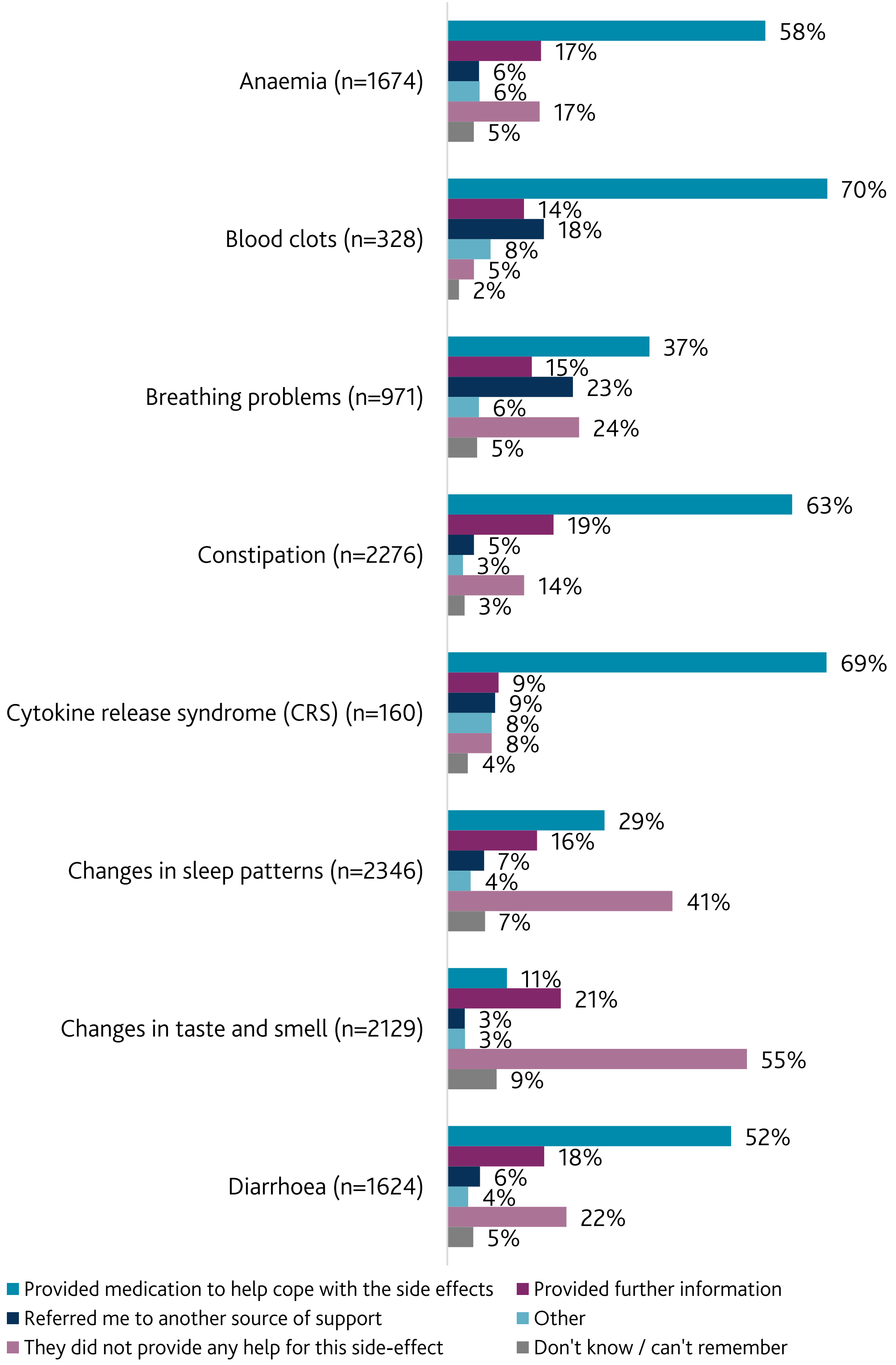


Figure 83. Q123 What did your doctor or other members of your medical team do to help you cope with each of the following treatment side effect(s) you experienced? Please select all that apply. (Part 2)

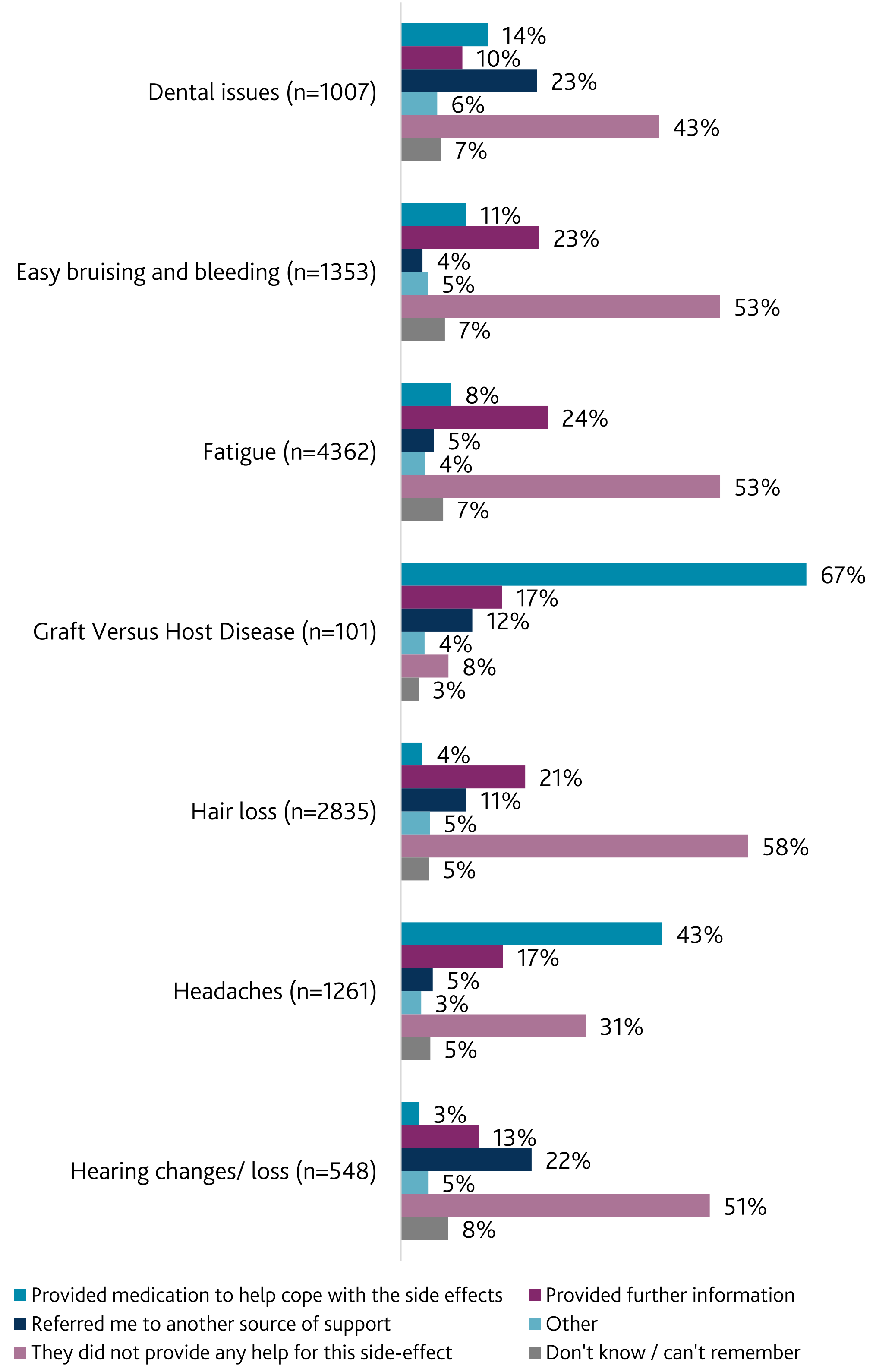


Figure 84. Q123 What did your doctor or other members of your medical team do to help you cope with each of the following treatment side effect(s) you experienced? Please select all that apply. (Part 3)

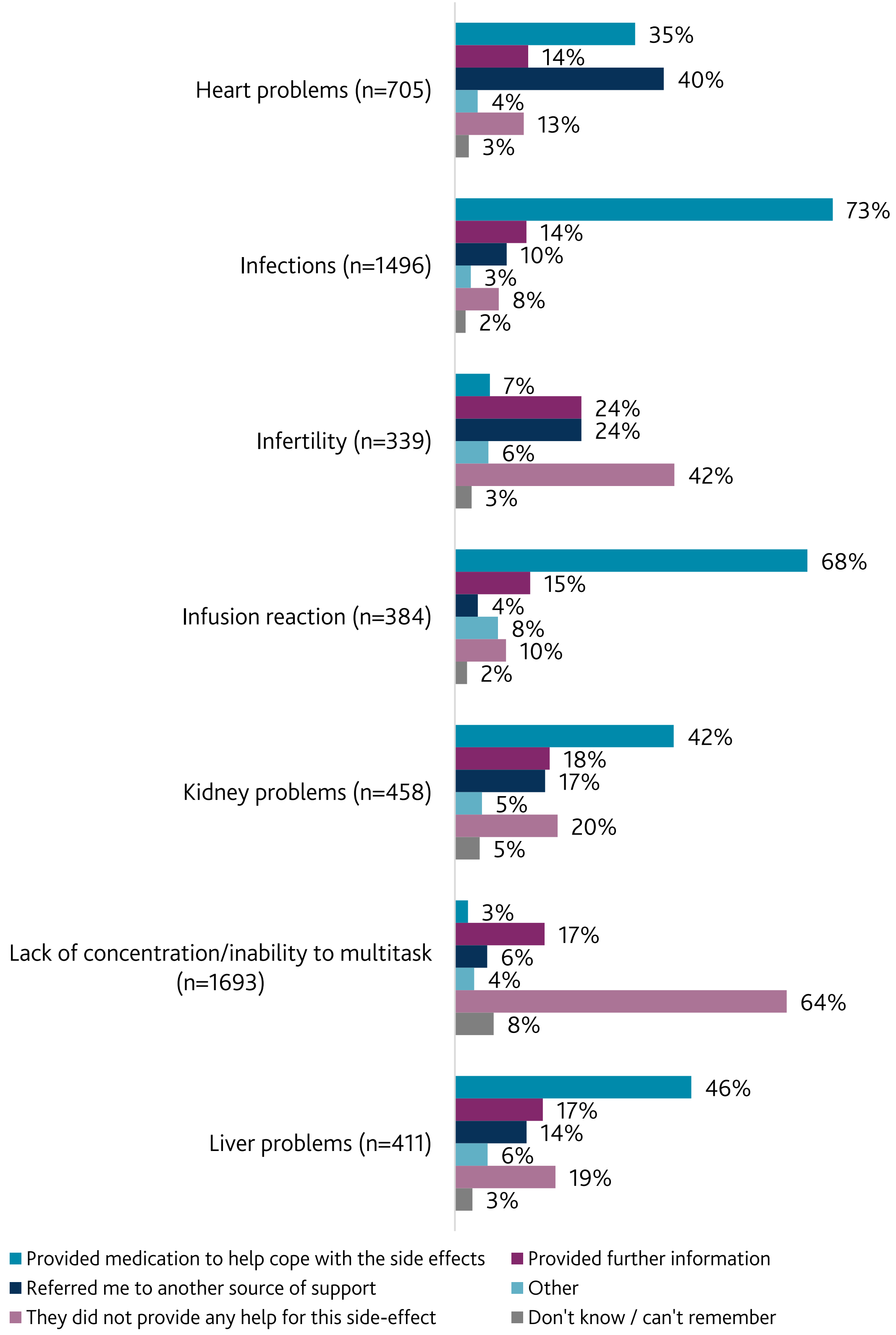


Figure 85. Q123 What did your doctor or other members of your medical team do to help you cope with each of the following treatment side effect(s) you experienced? Please select all that apply. (Part 4)

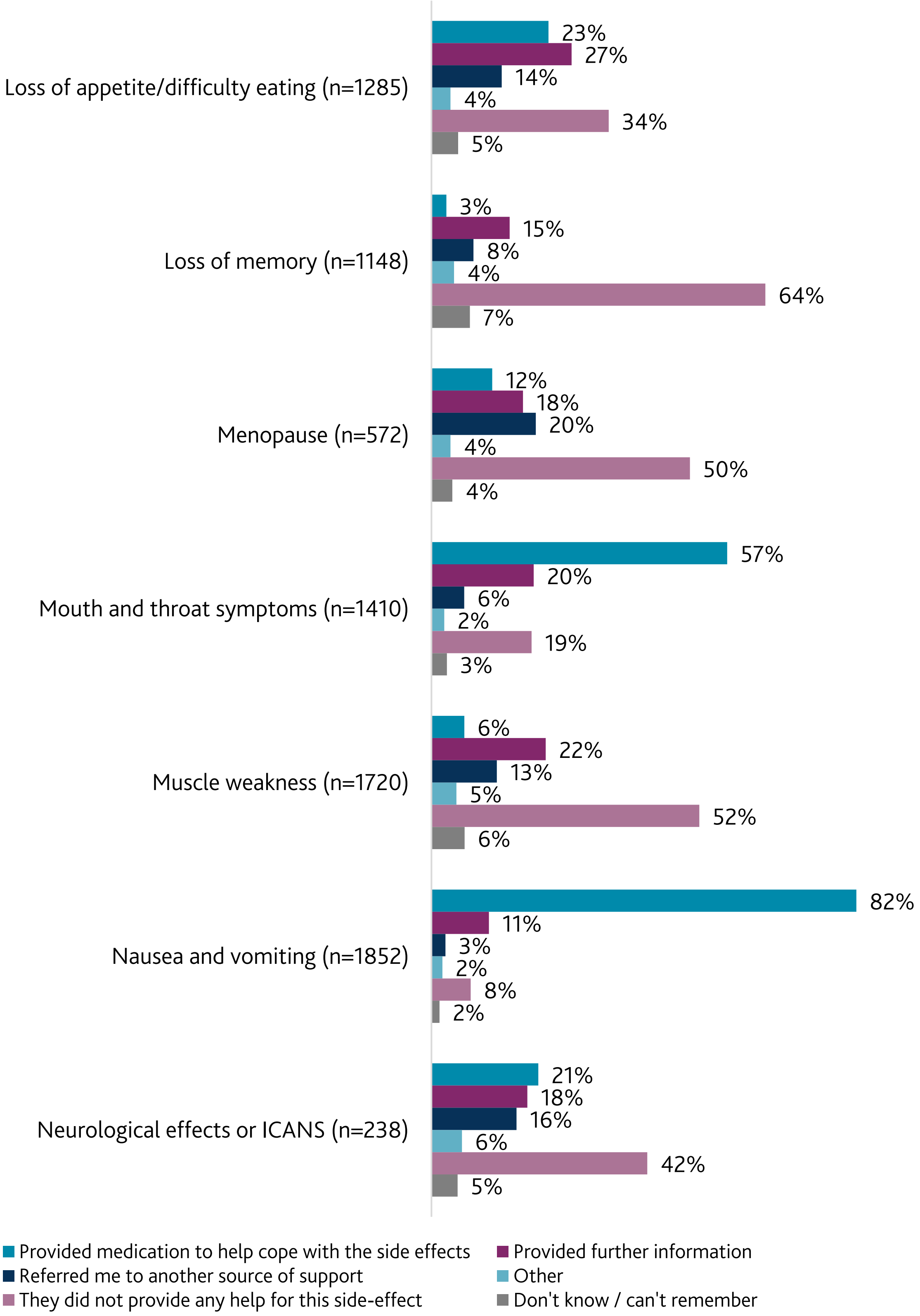
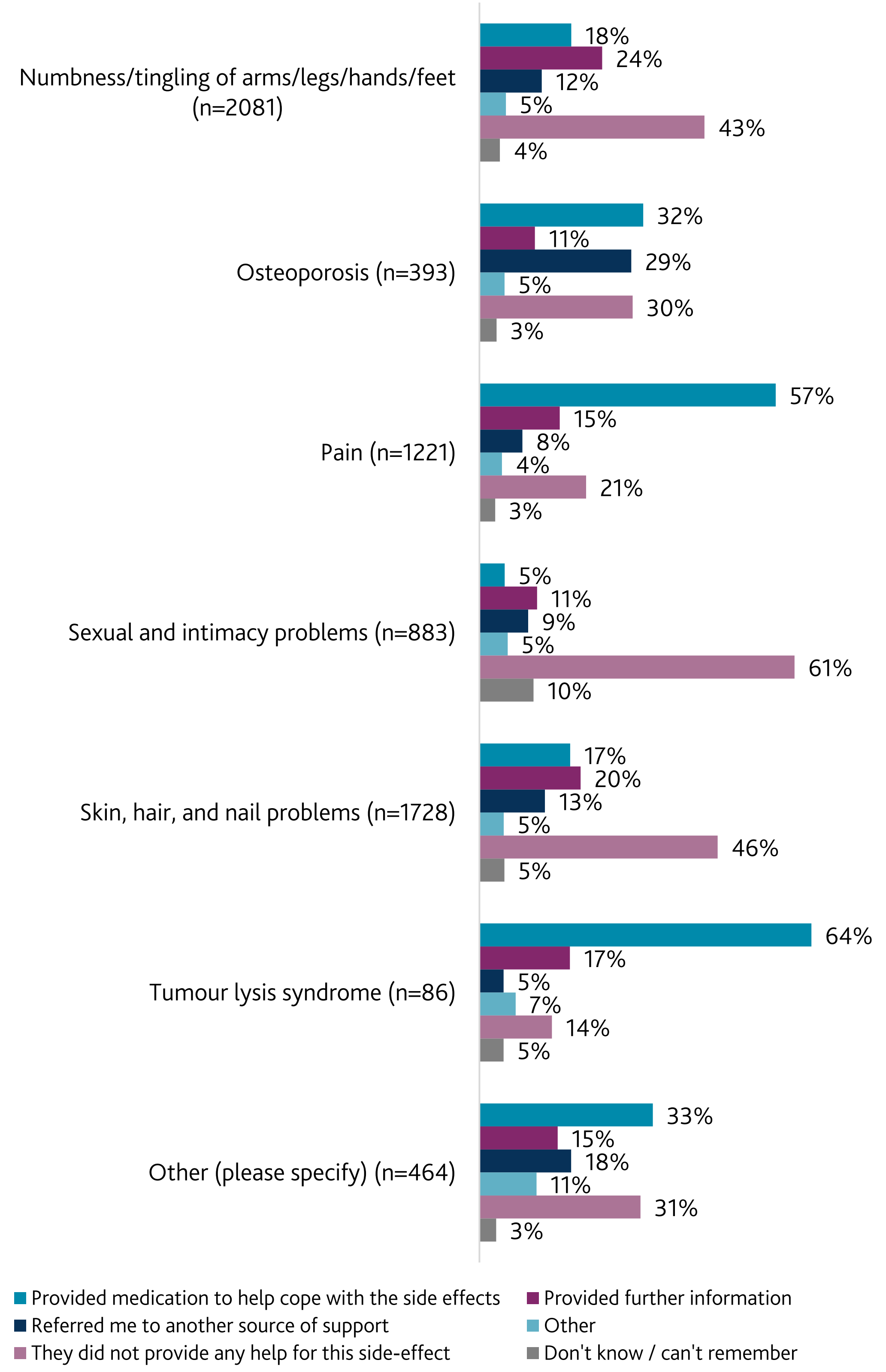
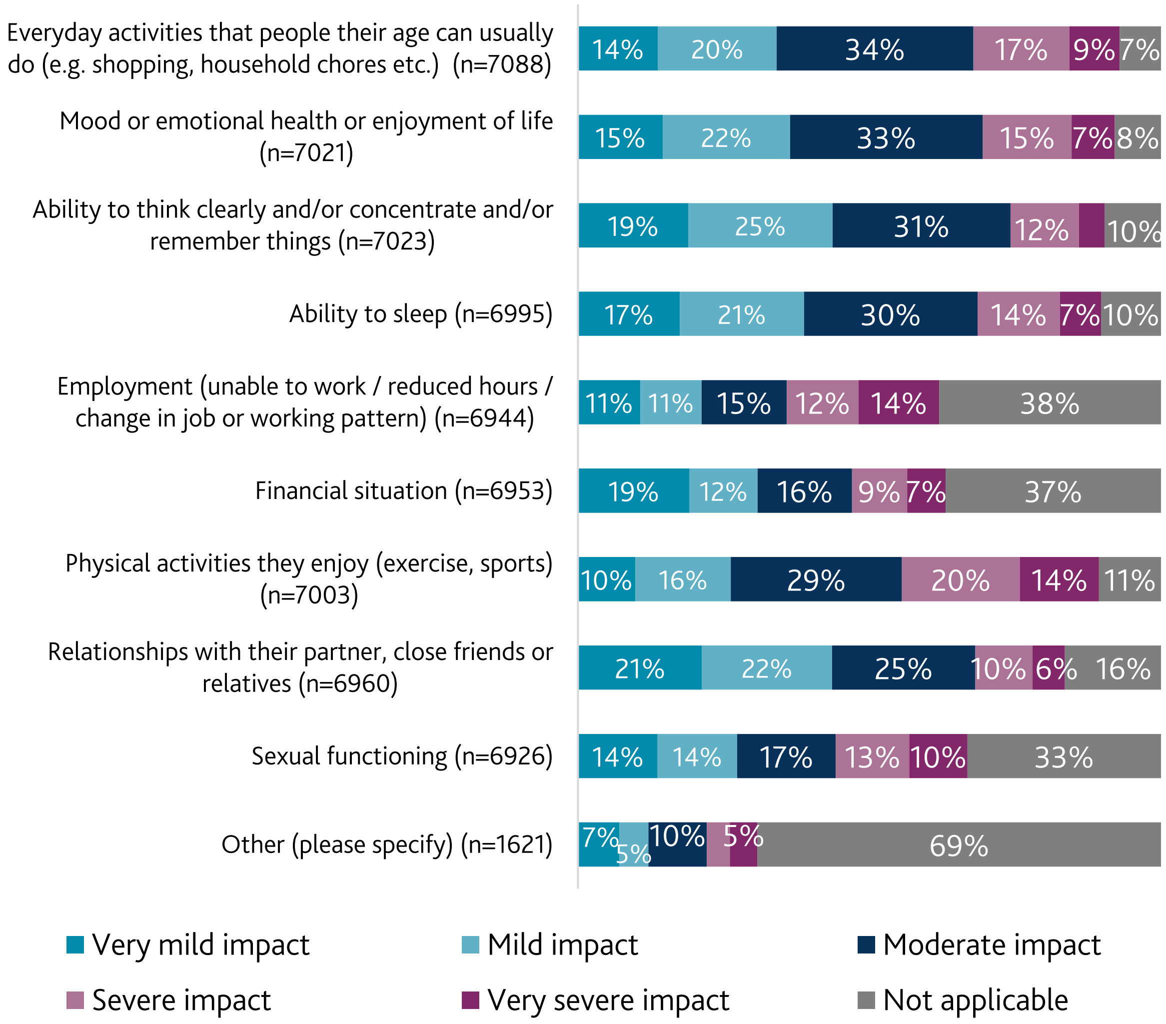


Figure 86. Q123 What did your doctor or other members of your medical team do to help you cope with each of the following treatment side effect(s) you experienced? Please select all that apply. (Part 5)



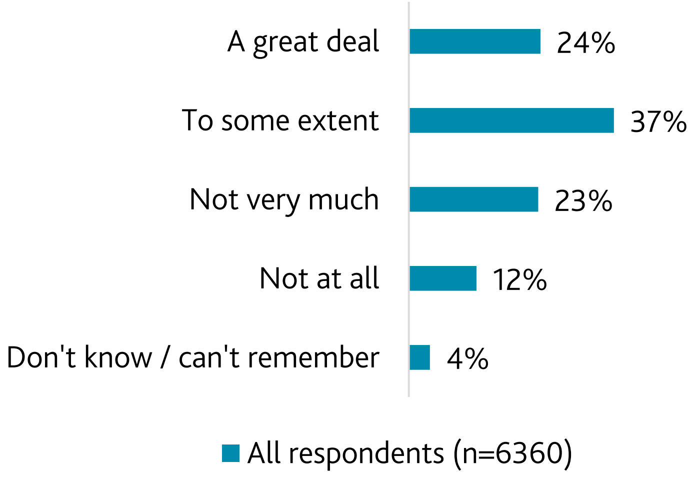
- Respondents who indicated they have experienced fatigue as a result of their lymphoma or CLL or its treatment, were asked to what extent fatigue has impacted aspects of their day-to-day life (Figure 87). Respondents were most likely to report the following aspects of their daily life were severely or very severely impacted as a result of fatigue:
    - Physical activities they enjoy (exercise, sports) (34%, n=2367)
    - Employment (unable to work / reduced hours / change in job or working pattern) (26%, n=1816)
    - Everyday activities that people their age can usually do (e.g. shopping, household chores etc.) (26%, n=1779)
    - Sexual functioning (23%, n=1565)
    - Mood or emotional health or enjoyment of life (22%, n=1588)

Figure 87. Q128 You previously said that you experienced fatigue as a result of lymphoma or CLL or its treatment. Thinking about how your fatigue has affected your day-to-day life in the last week, to what extent has it impacted the following areas?



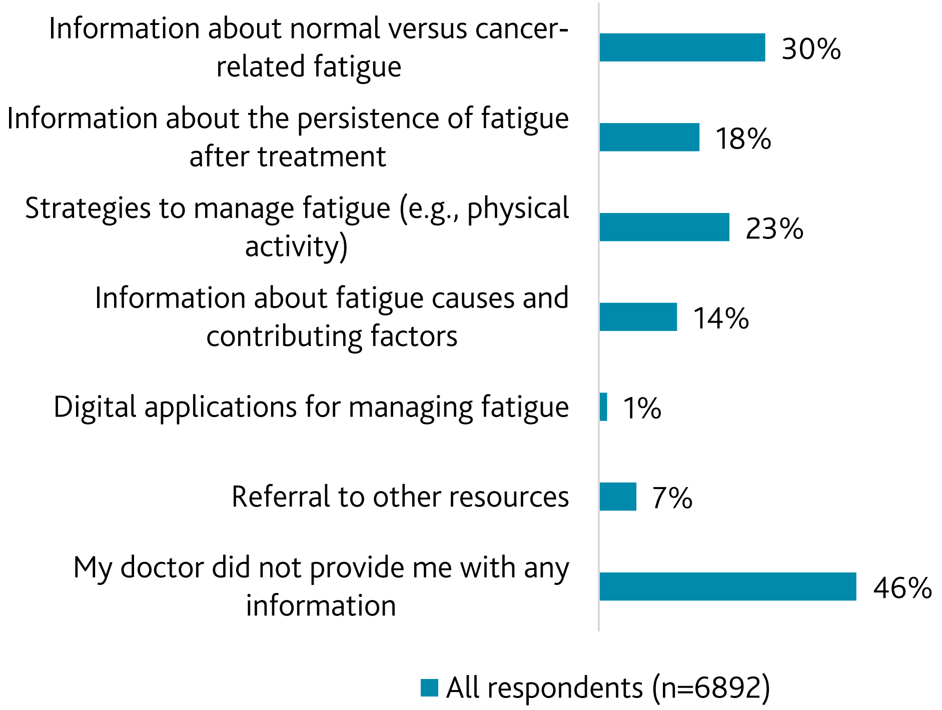
- Twelve percent (n=775) of respondents who reported that they had experienced fatigue said they have not had the opportunity to discuss their fatigue with a doctor over the last 2 years. In contrast, 24% (n=1509) felt that they had a great deal of opportunity to discuss their fatigue with a doctor over the last two years (Figure 88).

Figure 88. Q129 Thinking about the last 2 years, to what extent, if at all, have you had the opportunity to discuss your fatigue with a doctor?



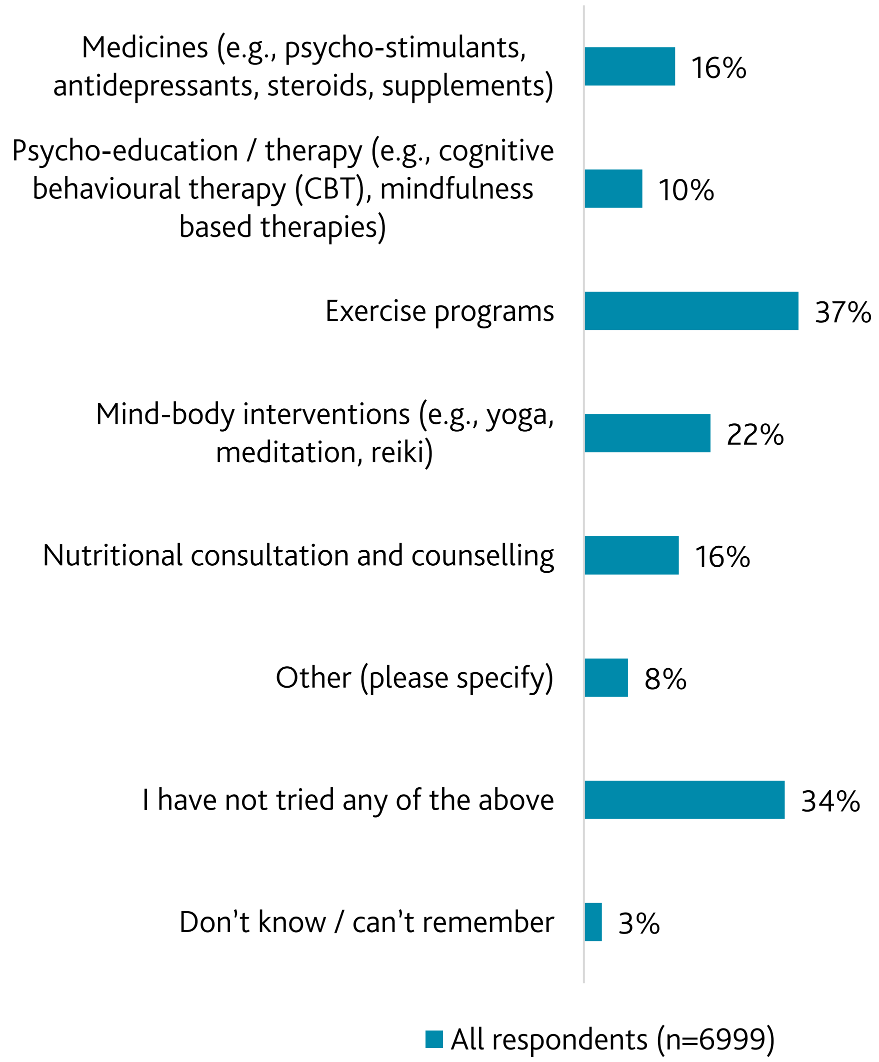
- When asked about the types of fatigue related information or support that had been provided by their doctor over the last two years, 46% (n=3150) said that their doctor had <u>not</u> provided them with any information. In terms of the types of information that had been provided (Figure 89):
    - 30% (n=2036) were provided with information about normal versus cancer-related fatigue
    - 23% (n=1597) had been given strategies to manage their fatigue
    - 18% (n=1231) were given information about the persistence of fatigue after treatment
    - 14% (n=958) received information about fatigue causes and contributing factors

Figure 89. Q130 Thinking about the last 2 years, what following types of information / support on fatigue has your doctor given you? Please select all that apply.



- Patients reported the most helpful method they found to manage their cancer-related fatigue was participating in exercise programs (37%, n=2578). One third (34%, n=2413) of respondents who experienced fatigue reported they have not tried to manage their fatigue with medicines, psycho-education / therapy, exercise programs, mind-body interventions or nutritional consultation and counselling (Figure 90).

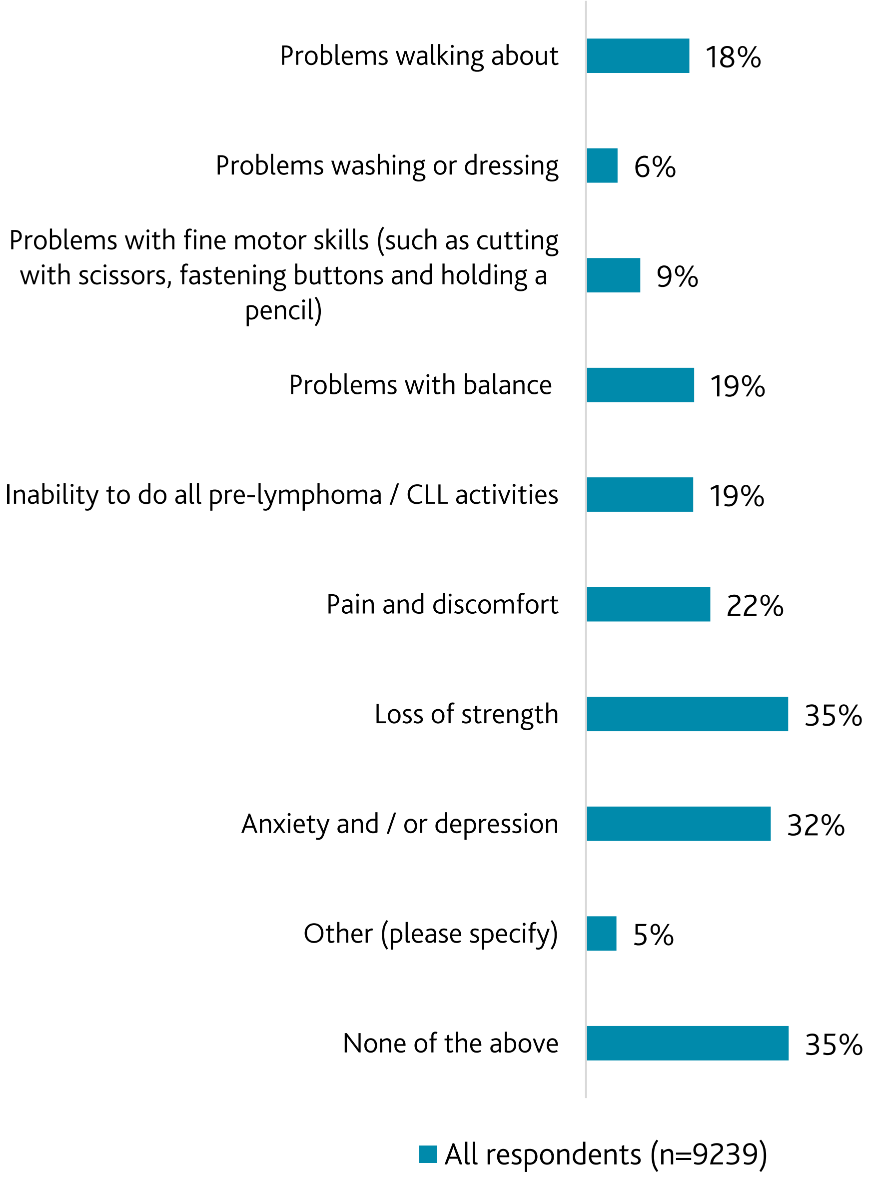
Figure 90. Q131 Which of the following, if any, have you found helpful in managing cancer-related fatigue? Please select all that apply.



Wellbeing

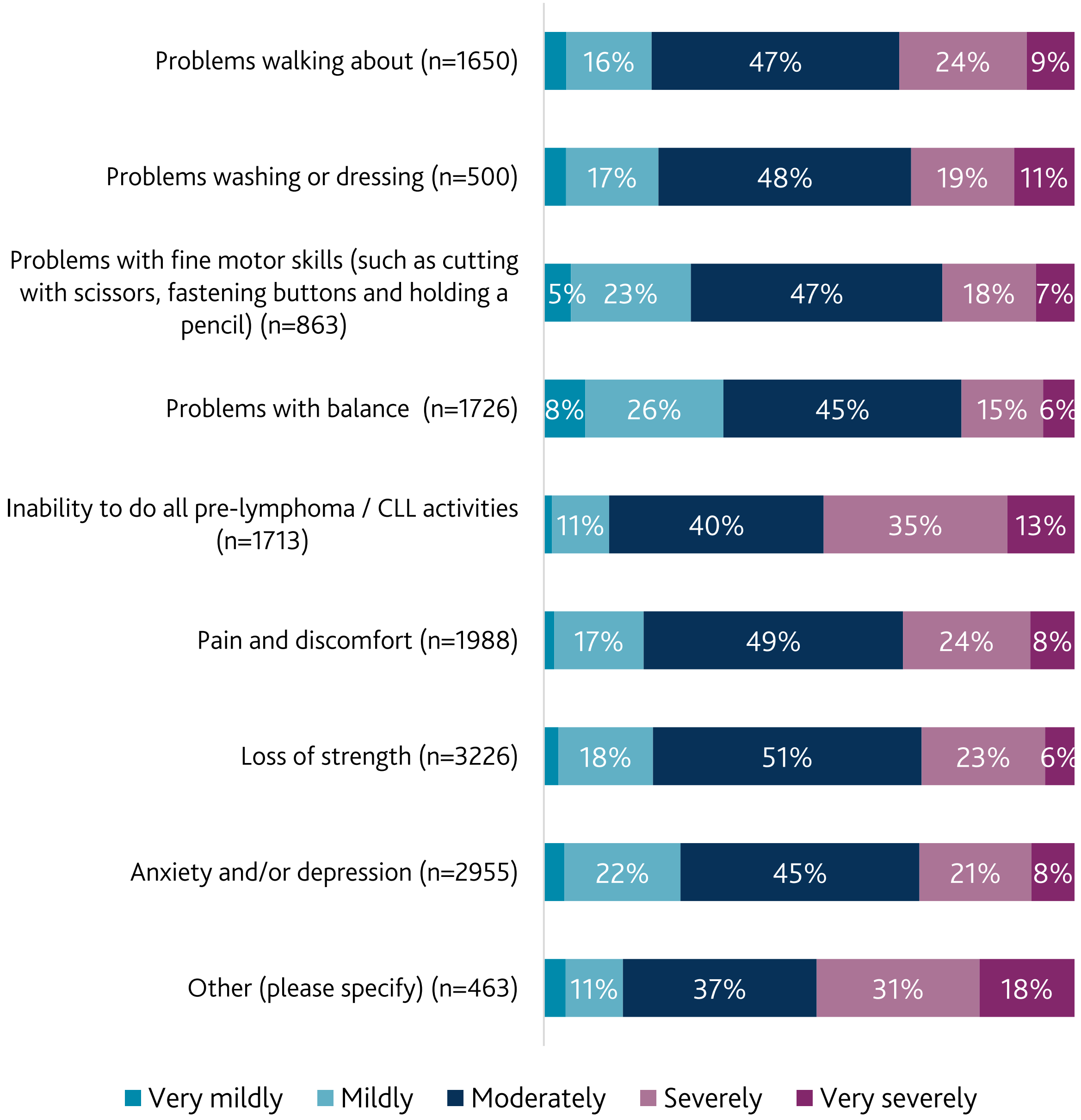
- When asked to think about their experience with lymphoma or CLL over the past month, 35% (n=3258) experienced problems with loss of strength, 32% (n=2976) experienced anxiety and / or depression, and 22% (n=2002) experienced pain and discomfort (Figure 91).

Figure 91. Q132 Thinking about your experience with lymphoma or CLL over the past month, which of the following problems have you experienced? Please select all that apply.



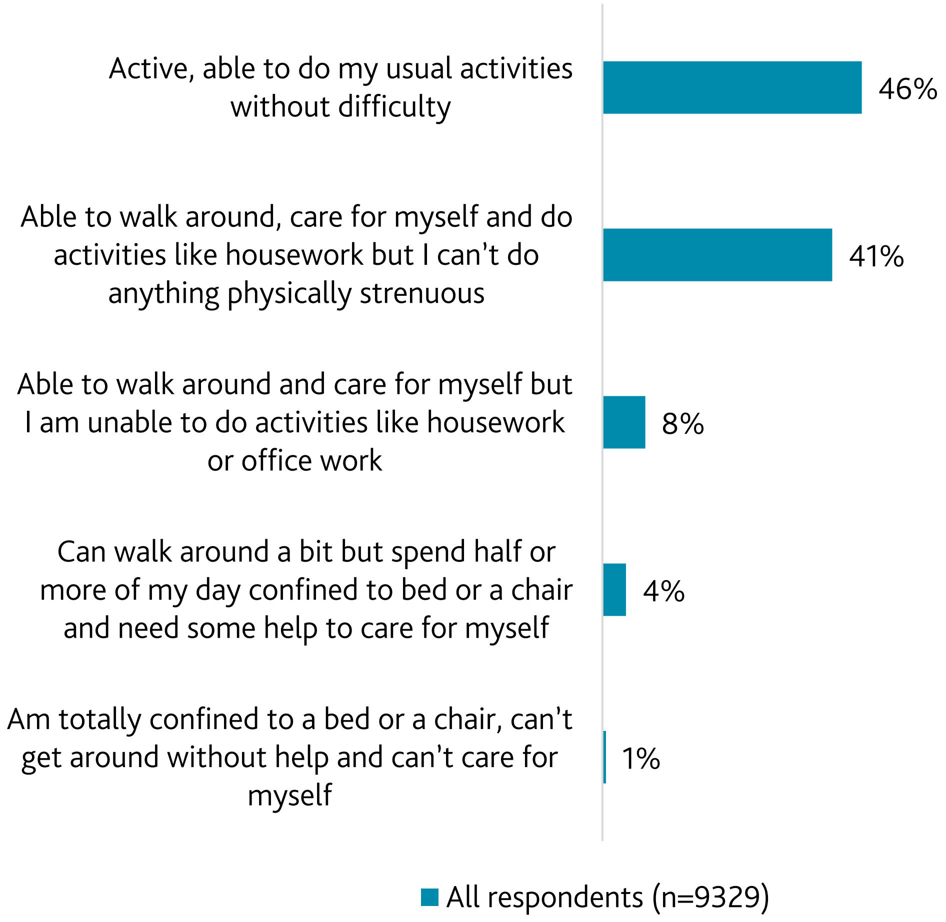
- In the month prior to survey completion, respondents were most likely to report the following aspects of life were severely or very severely impacted (Figure 92):
    - Inability to do all pre-lymphoma / CLL activities (48%, n=810)
    - Problems walking about (33%, n=545)
    - Pain and discomfort (32%, n=643)
    - Problems washing or dressing (30%, n=154)

Figure 92. Q133 You previously said that in the last month you have experienced the following problems. To what extent have they affected you?



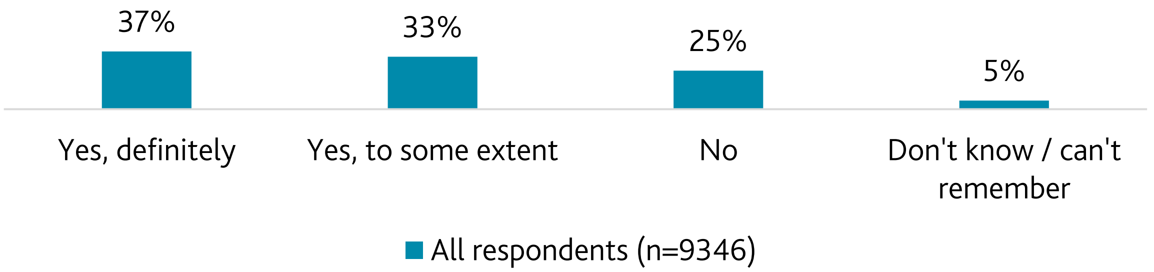
- When asked to choose a statement that best describes their physical ability, 46% (n=4327) said they were able to do their usual activities without difficulty, while 41% (n=3833) said they were able to walk around, care for themselves and do activities like housework but can't do anything physically strenuous (Figure 93).

Figure 93. Q134 Please choose the statement that best applies to your physical ability.



- Thirty-seven percent (n=3430) of respondents reported that at their last appointment, their doctor definitely asked questions that were relevant to their quality of life. Thirty-three percent (n=3113) said their doctor asked relevant questions about their quality of life to some extent, while 25% (n=2292) reported they were not asked these questions (Figure 94).

Figure 94. Q135 At your last appointment, do you feel that your doctor asked questions that were relevant to your quality of life or wellbeing?

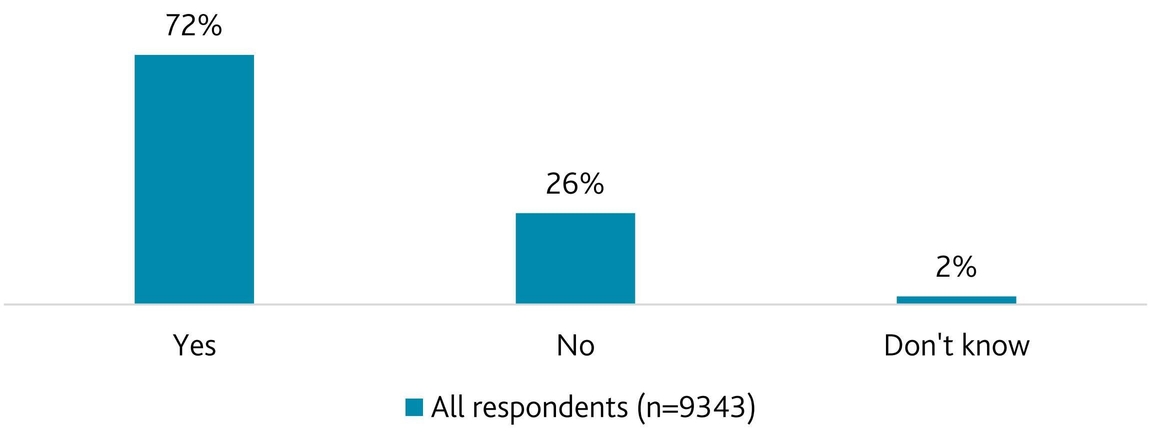


- Thirty-eight percent (n=3504) of respondents reported that their doctor understands the impact of lymphoma or CLL on their quality of life a great deal, while 36% (n=3329) felt their doctor understands to some extent. Eight percent (n=711) said their doctor does not ask questions about their quality of life (Figure 95).

Figure 95. Q136 To what extent, if at all, do you think the doctor understands the impact of your lymphoma or CLL on your quality of life?

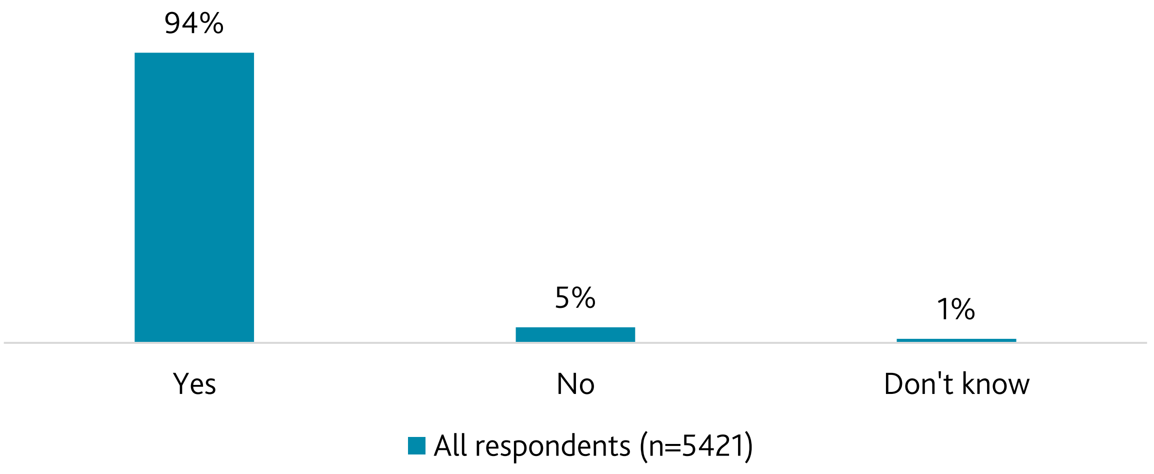
- Since their diagnosis of lymphoma or CLL, 72% (n=6681) of respondents reported making changes to their lifestyle, such as dietary changes, less use of alcohol, exercise etc. (Figure 96).

Figure 96. Q137 Since your diagnosis of lymphoma or CLL, have you made changes to your lifestyle? (e.g. dietary changes, less use of alcohol, less working hours, exercise)



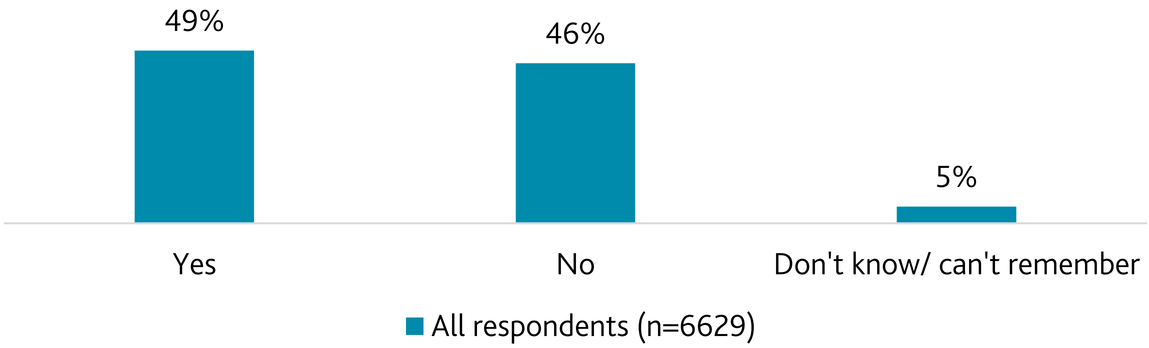
- Of those who had made changes to their lifestyle, 94% (n=5078) reported they are maintaining these lifestyle changes now (Figure 97).

Figure 97. Q138 Are you still maintaining these lifestyle changes now?



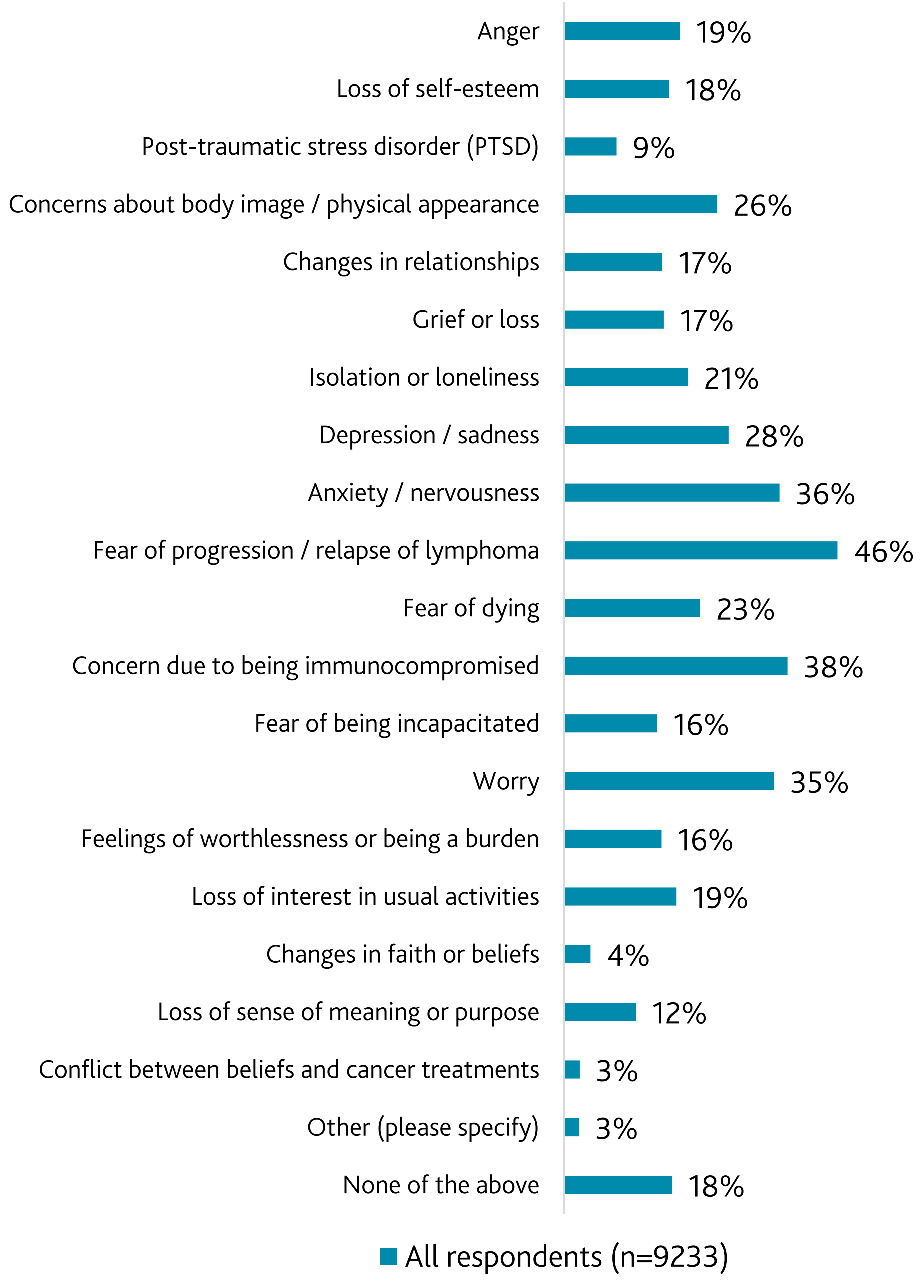
- Half (49%, n=3277) of those who made changes to their lifestyle have discussed these changes with their lymphoma or CLL doctor or another member of their medical team (Figure 98).

Figure 98. Q139 Did you discuss the lifestyle changes you made with your lymphoma or CLL doctor or another member of your medical team?



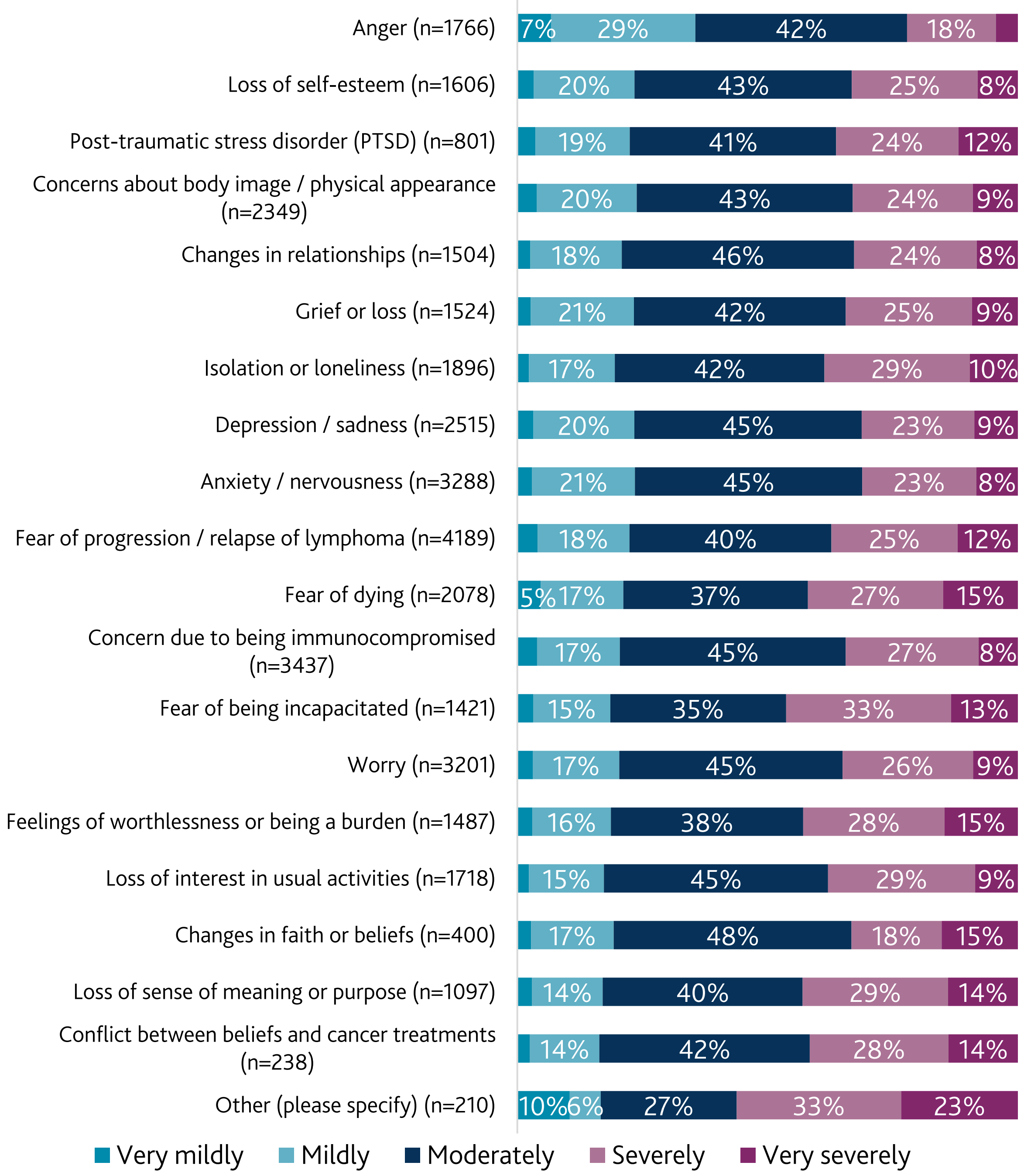
- During the last 6 months, respondents were most likely to report they have experienced the following as a result of their lymphoma or CLL (Figure 99): fear of progression / relapse of lymphoma (46%, n=4237); concern due to being immunocompromised (38%, n=3464); anxiety / nervousness (36%, n=3341); worry (35%, n=3255); depression / sadness (28%, n=2553) and concerns about body image / physical appearance (26%, n=2376).

Figure 99. Q143 During the last 6 months, which of the following have you experienced as a result of your lymphoma or CLL diagnosis? Please select all that apply.



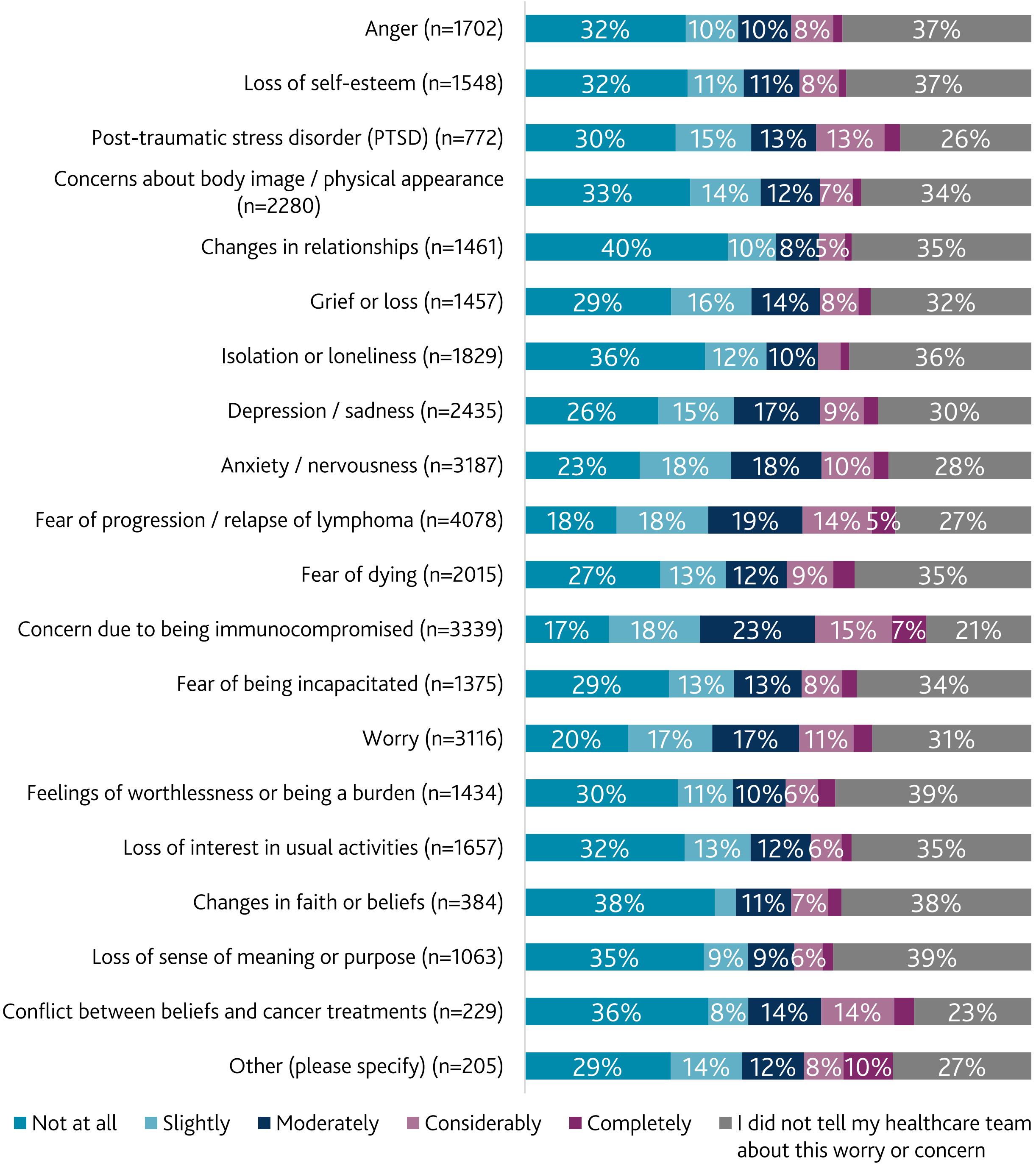
- Respondents who reported experiencing an impact to their wellbeing in the last 6 months were most likely to report the following as having a severe or very severe impact (Figure 100): fear of being incapacitated (46%, n=658); feelings of worthlessness or being a burden (43%, n=638); loss of sense of meaning or purpose (43%, n=472); fear of dying (42%, n=872) and conflict between beliefs and cancer treatments (42%, n=99).

Figure 100. Q144 You previously said that in the last 6 months you have experienced the following problems. To what extent have they affected you?



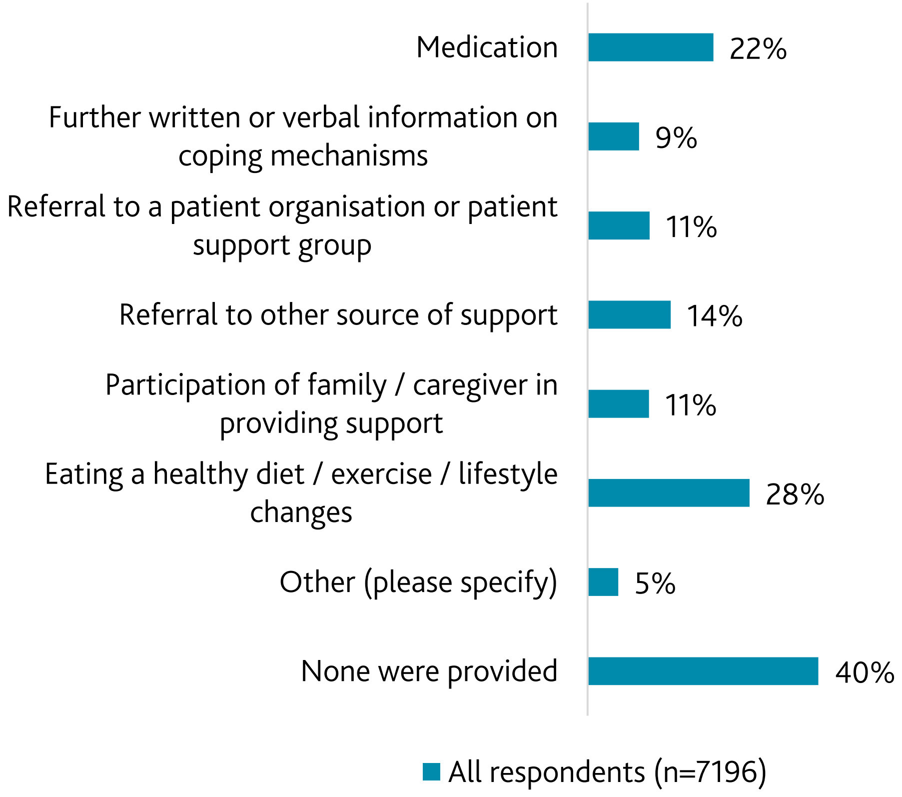
- Respondents who experienced an impact to their wellbeing in the last 6 months were asked to what extent their healthcare team were able to help (Figure 101). Respondents were most likely to report their healthcare team considerably or completely helped them with their: concern due to being immunocompromised (22%, n=733); fear of progression / relapse of lymphoma (19%, n=748) and conflict between beliefs and cancer treatments (18%, n=42).

Figure 101. Q145 For each of the worries or concerns listed below that you have experienced, how much, if at all, was your healthcare team able to help?



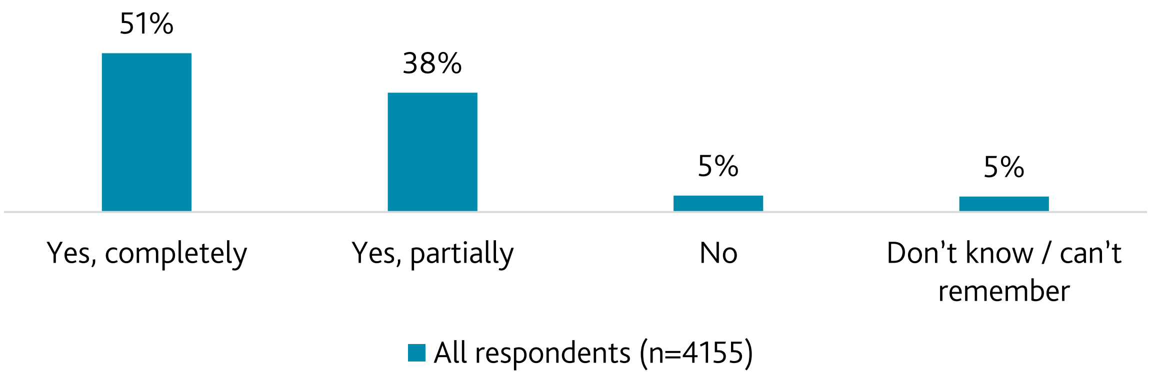
- Respondents who experienced an impact to their wellbeing in the last 6 months were asked if their healthcare team provided any recommendations to help them with their worries or concerns (Figure 102). Forty percent (n=2895) reported they did not receive any recommendations from their healthcare team, while 28% (n=2032) received recommendations to make lifestyle changes, such as eating a healthy diet or exercise, while 22% (n=1579) received medication.

Figure 102. Q146 Still thinking about the last 6 months, which of the following, if any, were recommended by your healthcare team to help with the worries or concerns you experienced? Please select all that apply



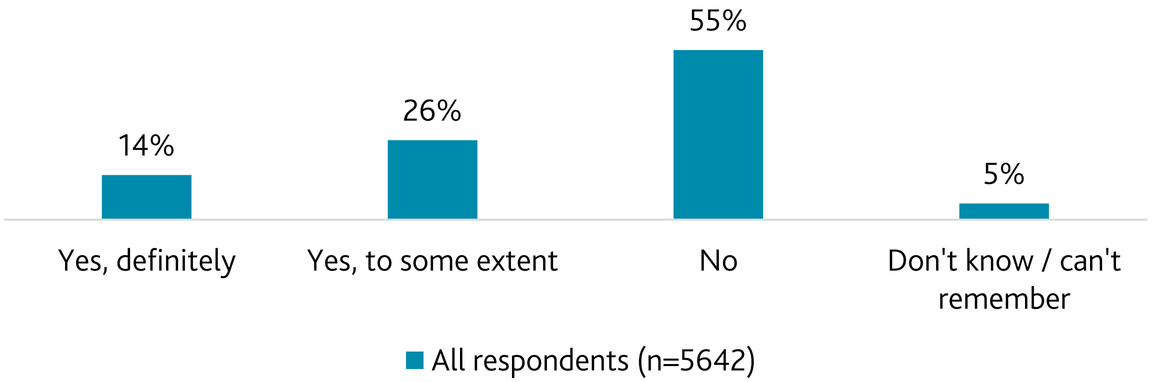
- Where recommendations had been provided by their doctor for their worries or concerns, 51% (n=2130) reported they completely followed through with the recommendations, while 38% (n=1599) partially followed through with the recommendations (Figure 103).

Figure 103. Q147 Did you follow through on the recommendations of your doctor regarding the issues that you were experiencing?



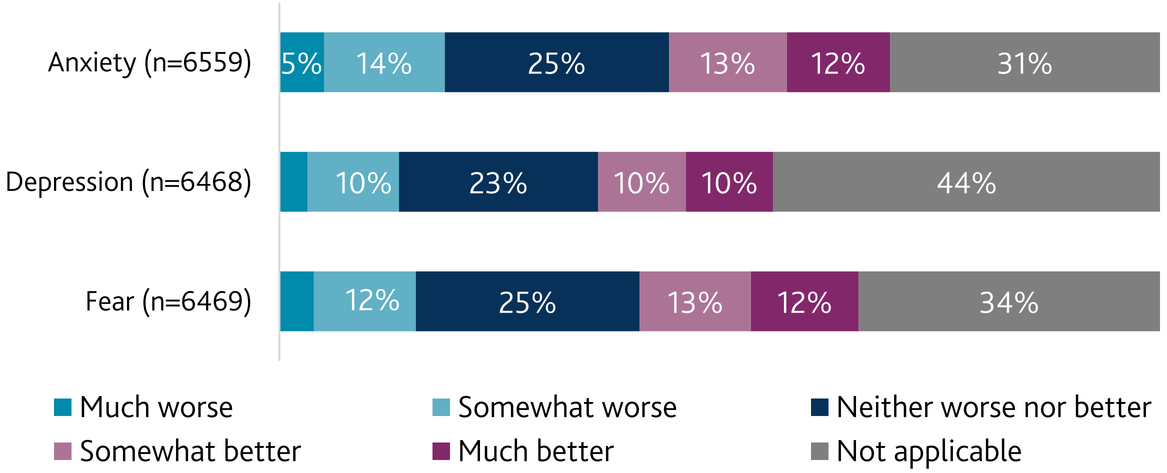
- Fourteen percent (n=812) of respondents reported that a member of their healthcare team had definitely followed up with them about their worries or concerns, 26% (n=1447) said they had followed up to some extent, while 55% (n=3088) of respondents reported that a member of their healthcare team did not follow-up with them about their worries or concerns (Figure 104).

Figure 104. Q148 Did a member of your healthcare team follow-up with you about the worries or concerns you were experiencing?



- Nineteen percent (n=1232) of respondents reported that in the last 2 years, their anxiety had gotten much worse or somewhat worse. This is compared to 16% (n=1002) who said their fear had gotten worse, and 13% (n=878) who said their depression had gotten worse in the last 2 years (Figure 105).

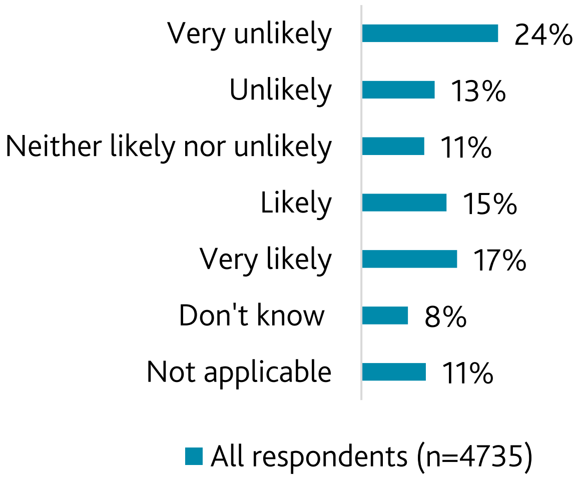
Figure 105. Q149 Thinking back over the last 2 years, please rate how your following emotional states have changed, if at all. If you have not experienced anxiety or depression or fear, please select 'Not applicable.



Employment

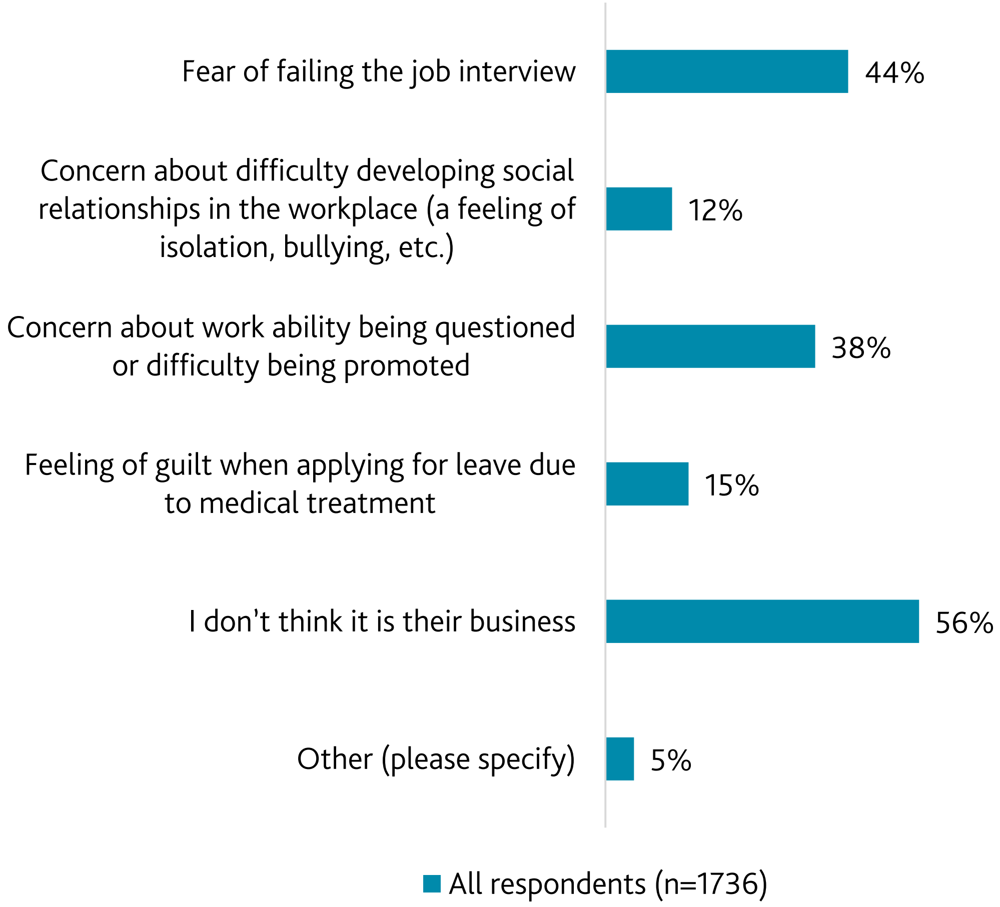
- If invited to an interview for a job, 32% (n=1517) said they are likely to disclose their lymphoma or CLL diagnosis, compared to 37% (n=1760) who said they would be unlikely to disclose this information (Figure 106).

Figure 106. Q154 If you were to interview for a job, how likely or unlikely would you be to disclose your lymphoma / CLL diagnosis?



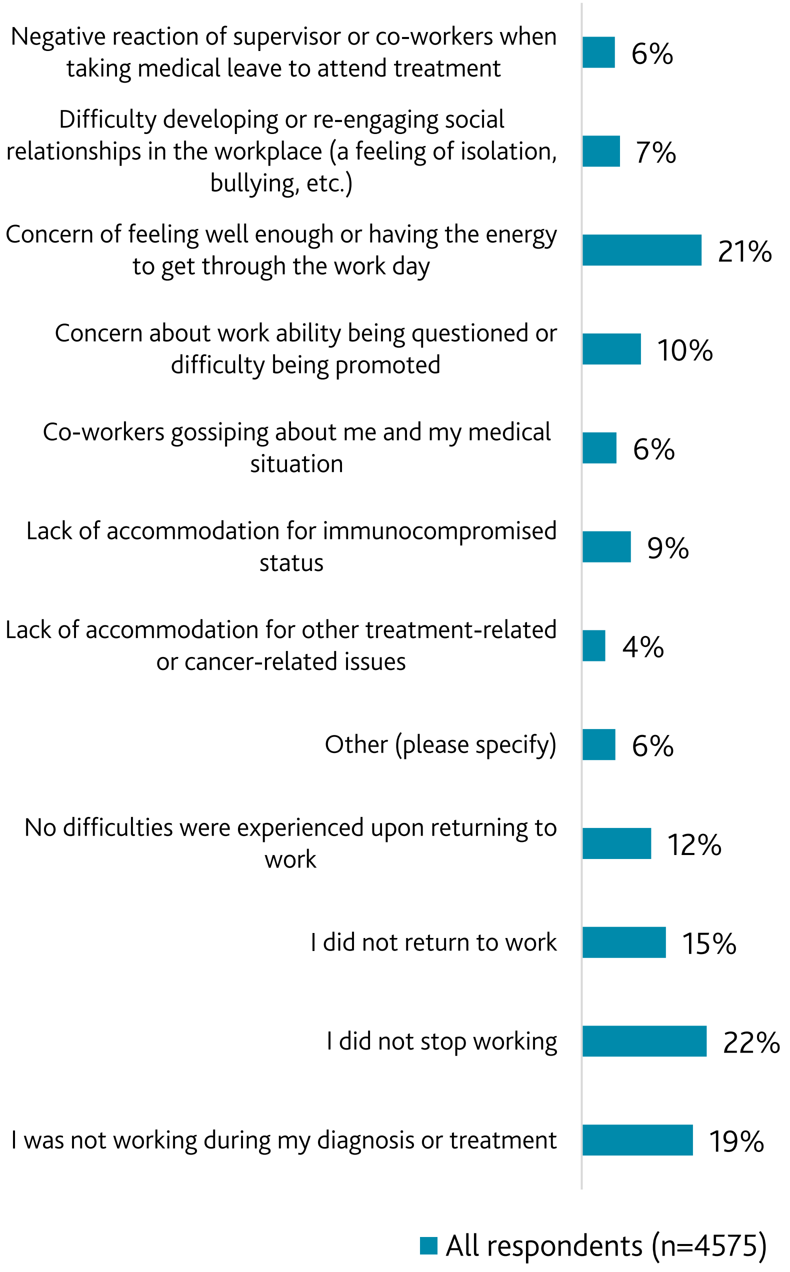
- Of those who would be unlikely to disclose their lymphoma diagnosis at a job interview, 56% (n=978) said this is because they don't think it is the organisations business. Forty-four percent (n=757) would not disclose their diagnosis for fear of failing the job interview, while 38% (n=654) would not disclose because of concerns about their work ability being questioned or difficulties being promoted (Figure 107).

Figure 107. Q155 Why would you be unlikely to disclose your lymphoma diagnosis at a job interview? Please select all that apply.



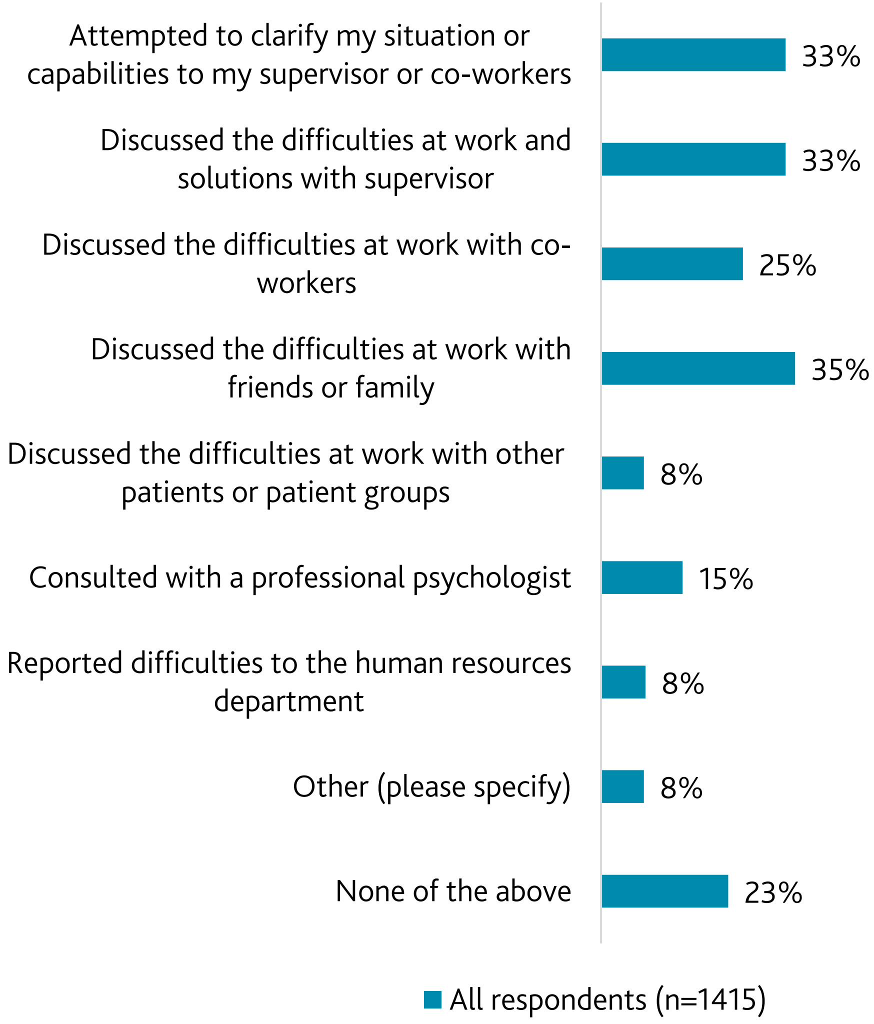
- Upon returning to work, 21% (n=948) of respondents experienced concerns of feeling well enough or having the energy to get through the workday. Twenty-two percent (n=989) of respondents did not stop working during diagnosis or treatment, while 19% (n=880) were not working during diagnosis or treatment. Fifteen percent (n=666) did not return to work following their diagnosis or treatment (Figure 108).

Figure 108. Q156 If you stopped working during diagnosis and treatment, what difficulties, if any, did you experience upon returning to work? Please select all that apply.



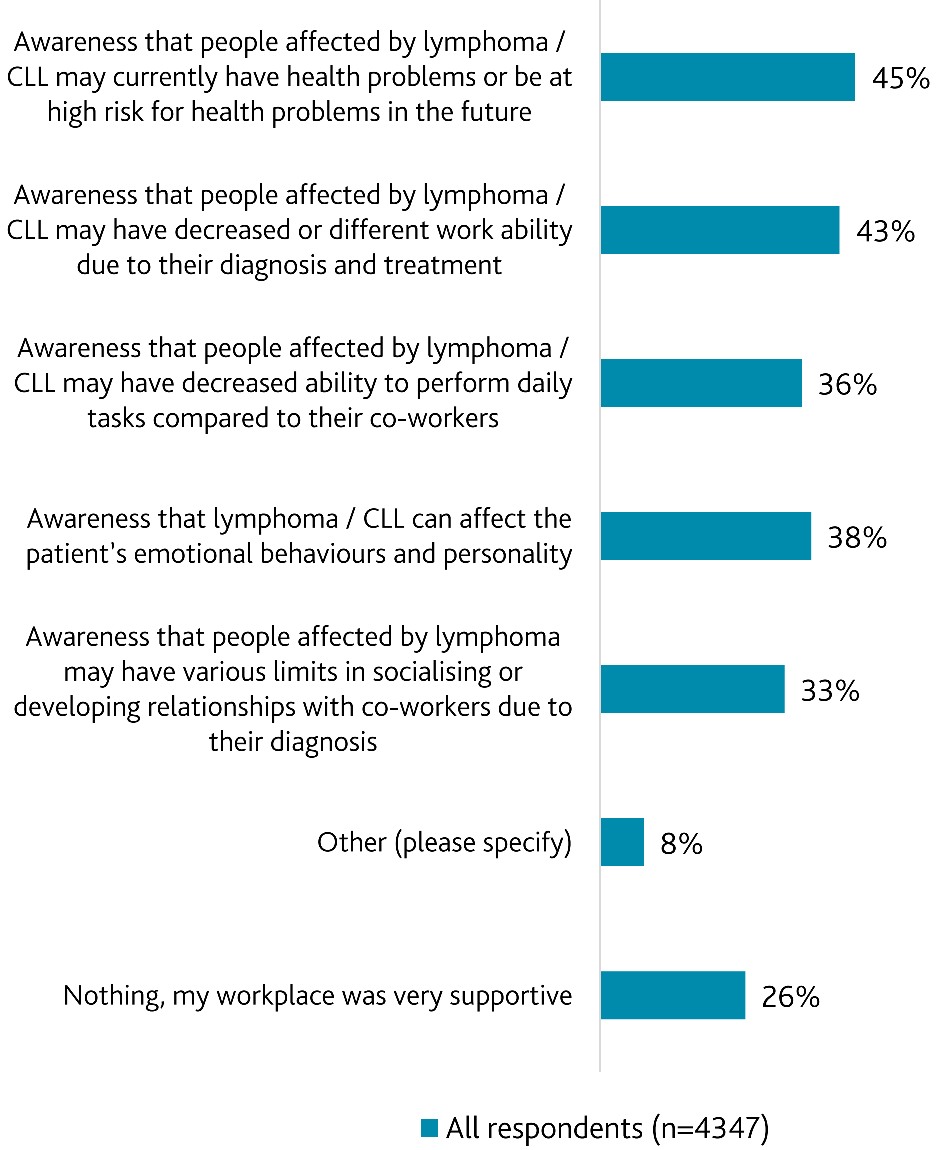
- Of those who experienced difficulties upon returning to work, 35% (n=490) discussed these difficulties with friends and family, 33% (n=466) had attempted to clarify their situation or capabilities with their supervisor or co-workers, and 33% (n=466) said they had discussed the difficulties at work and solutions with their supervisor (Figure 109).

Figure 109. Q157 When you experienced these difficulties at work, how, if at all, did you deal with them? Please select all that apply.



❖ When asked what kinds of improvements are needed in terms of awareness about lymphoma or CLL in the workplace, respondents were most likely to say increased awareness that people affected by lymphoma or CLL may currently have health problems or be at high risk for health problems in the future (45%, n=1977). Increased awareness that people affected by lymphoma or CLL may have decreased or different work ability due to their diagnosis and treatment was identified as a necessary improvement by 43% (n=1856) of respondents. Twenty-six percent (n=1127) felt that their workplace was very supportive, and no improvements were needed (Figure 110).

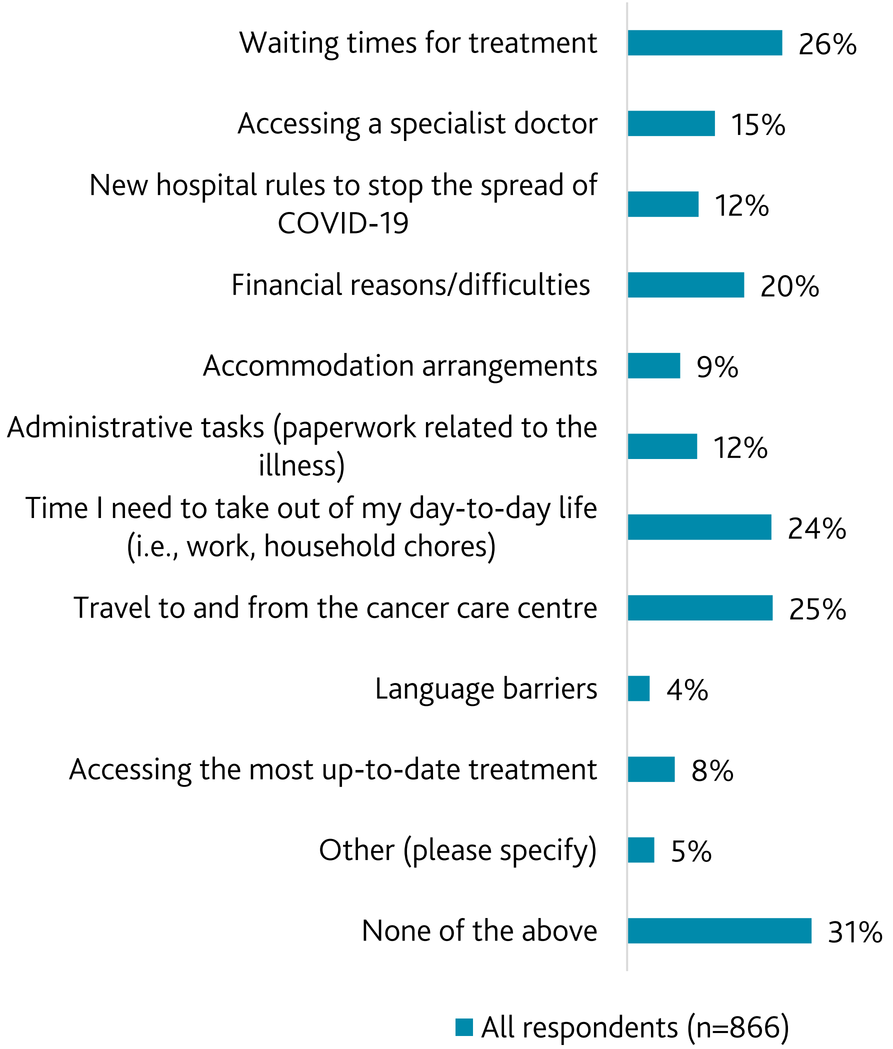
Figure 110. Q158 What kinds of improvements are needed in terms of awareness about lymphoma or CLL in the workplace? Please select all that apply.



Caregivers, friends and family members

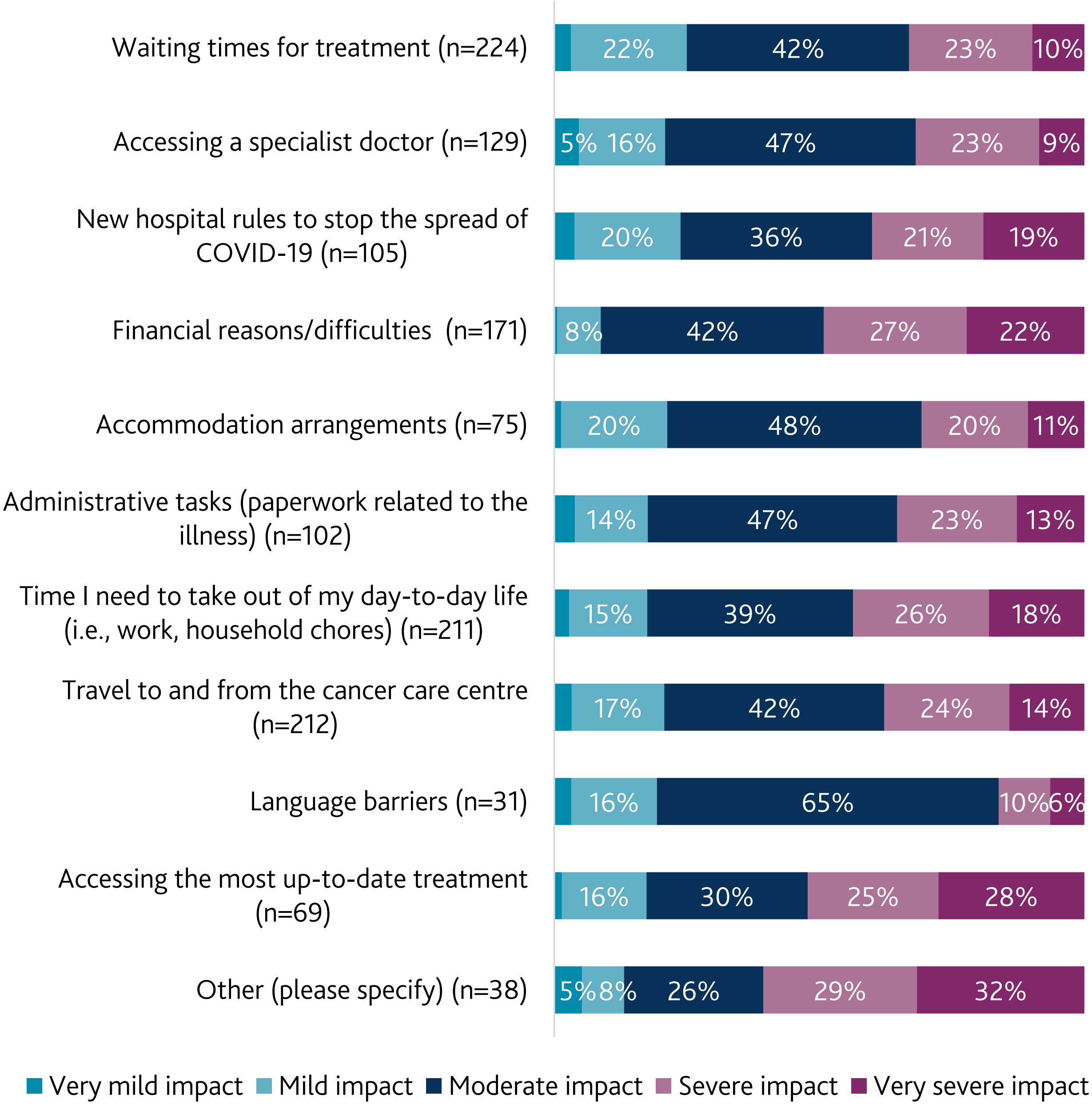
- When caregivers, friends, or family members of someone who has lymphoma or CLL were asked what, if anything, has made going through the most recent round of treatment difficult, 69% (n=595) reported experiencing a barrier. This was most likely to be waiting times for treatment 26% (n=228), travel to and from the cancer care centre (25%, n=214), and time taken out of day-to-day life (24%, n=212). Twenty percent (n=172) experienced financial difficulties, while 15% (n=129) reported challenges in accessing a specialist doctor. Thirty-one percent (n=271) of caregivers, friends and family members reported that nothing had made going through the most recent round of treatment more difficult (Figure 111).

Figure 111. Q159 What, if anything, has made going through the most recent round of treatment difficult? Please select all that apply.



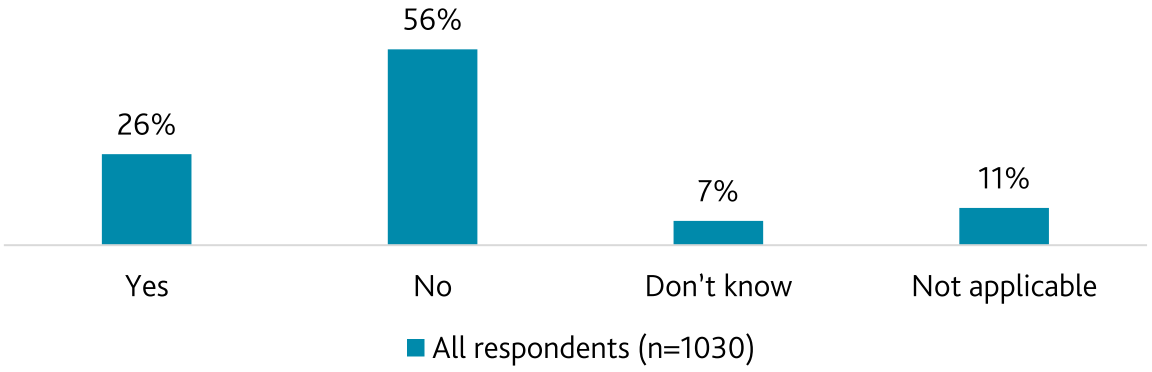
- Caregivers, friends, or family members who reported experiencing difficulties in the most recent round of treatment were most likely to say the following had a severe or very severe impact to their wellbeing (Figure 112):
    - Accessing the most up-to-date treatment (53%, n=36)
    - Financial difficulties (49%, n=84)
    - Time taken out of their day-to-day life (44%, n=92)
    - New hospital rules aimed at stopping the spread of COVID-19 (40%, n=42)

Figure 112. Q160 To what extent has the barrier impacted your wellbeing?



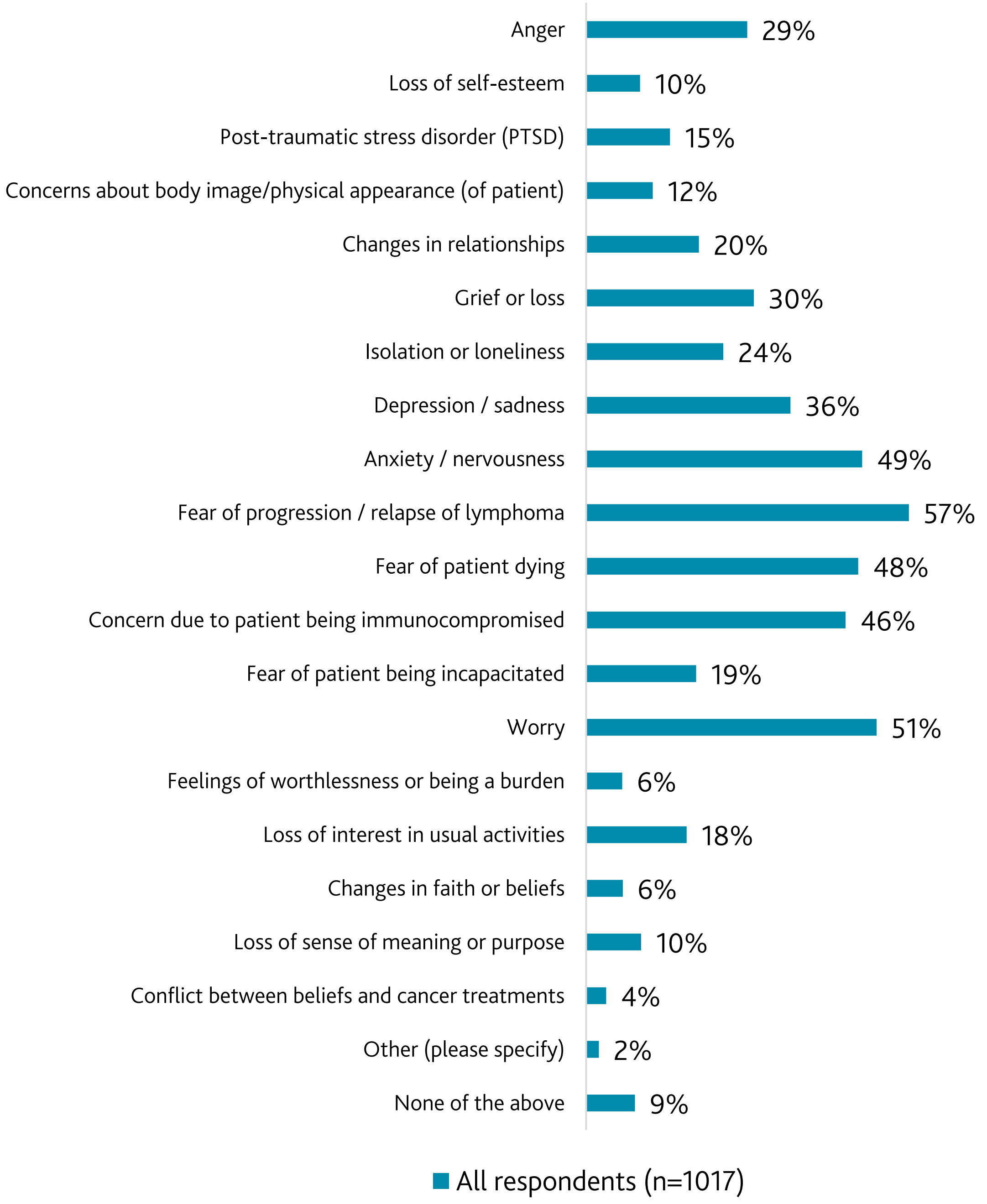
- Fifty-six percent (n=579) of caregivers, friends, or family members do not currently feel fearful of in person visits the patient attends for the purpose of treating their lymphoma or CLL because of the risk of contracting COVID-19. This is compared to 26% (n=269) who reported they do feel fearful (Figure 113).

Figure 113. Q161 Do you currently feel fearful of in person visits the patient attends for the purpose of treating their lymphoma or CLL because of the risk of contracting COVID-19?



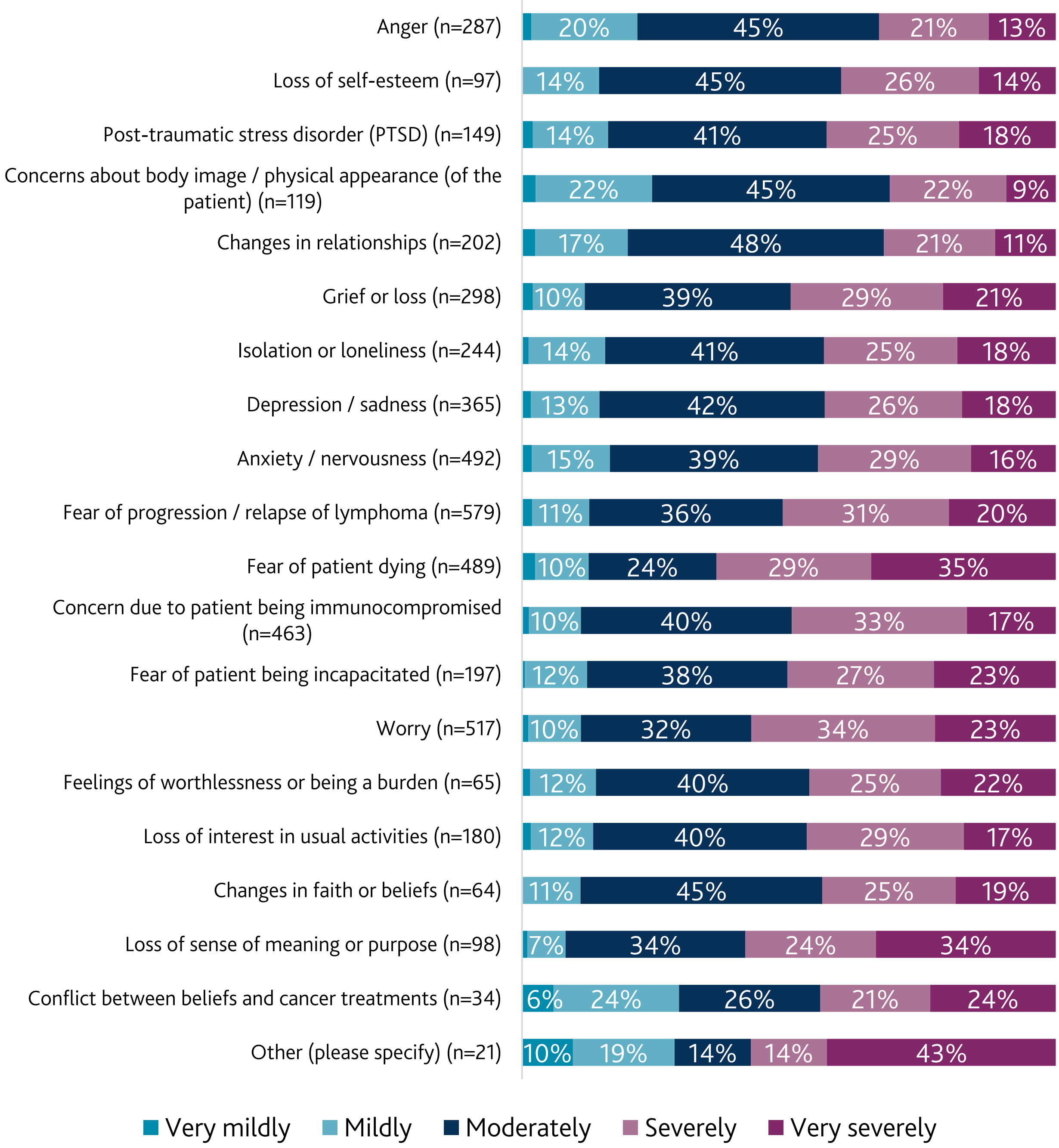
- During the last 6 months, caregivers, friends and family members were most likely to report their wellbeing was impacted by the following (Figure 114): fear of progression / relapse of lymphoma (57%, n=581); worry (51%, n=523); anxiety / nervousness (49%, n=497); fear of patient dying (48%, n=490) and concern due to patient being immunocompromised (46%, n=467).

Figure 114. Q162 During the last 6 months, which of the following have you experienced as a result of being a caregiver, friend or family member of someone who has lymphoma or CLL? Please select all that apply.



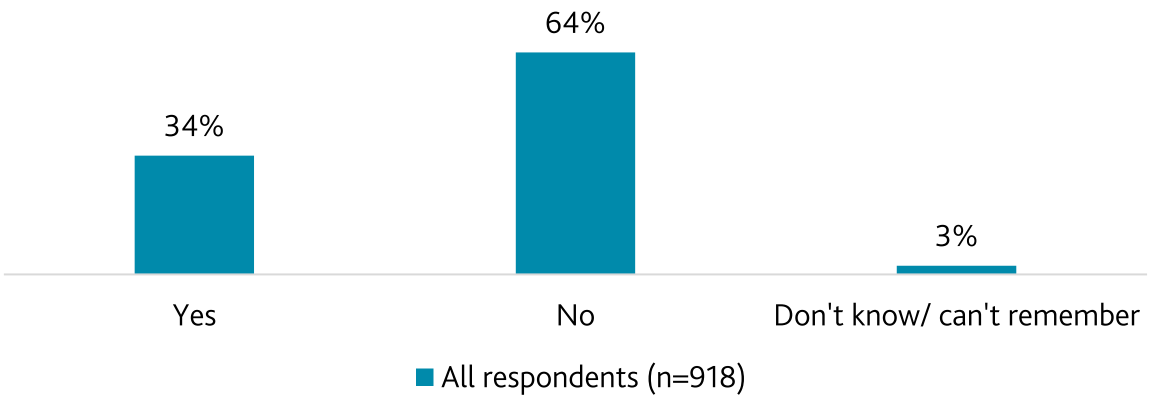
- Caregivers, friends, or family members who experienced an impact to their wellbeing in the last 6 months were most likely to report the following as having a severe or very severe impact (Figure 115): fear of patient dying (64%, n=311); loss of sense of meaning or purpose (58%, n=57); worry (57%, n=295); fear of progression / relapse of lymphoma (51%, n=296); grief or loss (50%, n=148) and fear of patient being incapacitated (50%, n=99).

Figure 115. Q163 You previously said that in the last 6 months you have experienced the following problems. To what extent have they affected you?



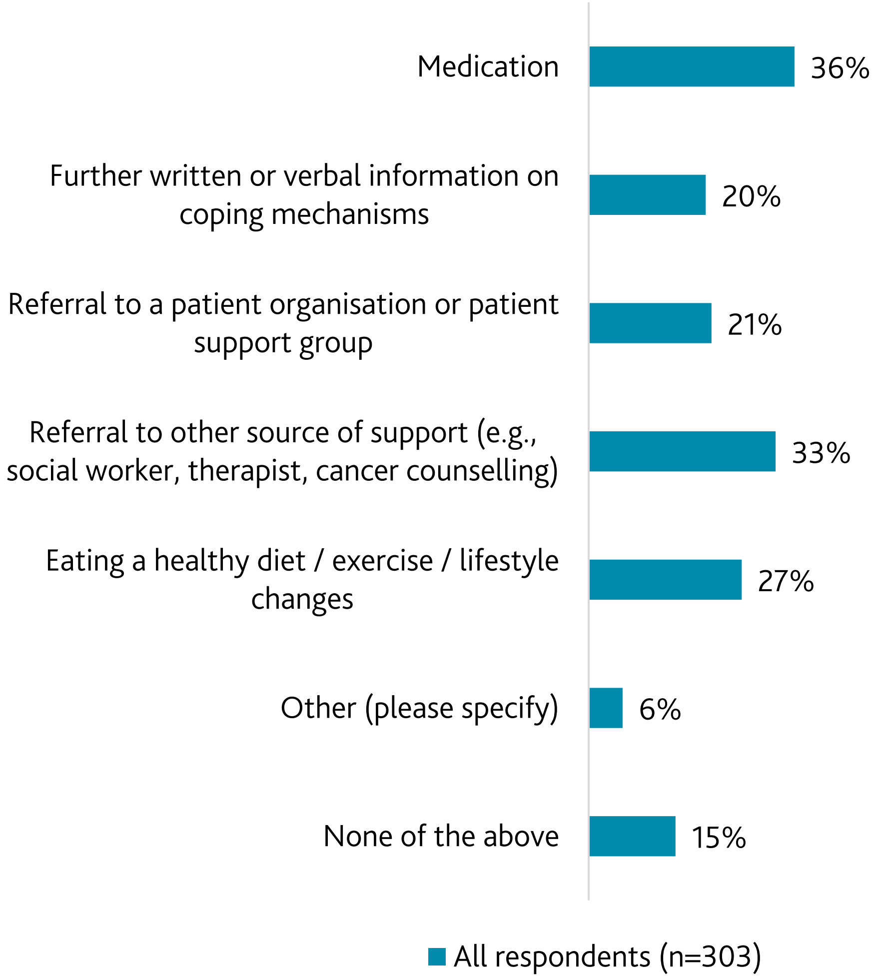
- Of caregivers, friends, or family members who reported having experienced problems during the last six months, almost two-thirds (64%, n=583) had not discussed their worries or concerns with a healthcare professional (Figure 116).

Figure 116. Q164 Have you discussed your worries and concerns with a healthcare professional? (e.g, doctor, nurse)



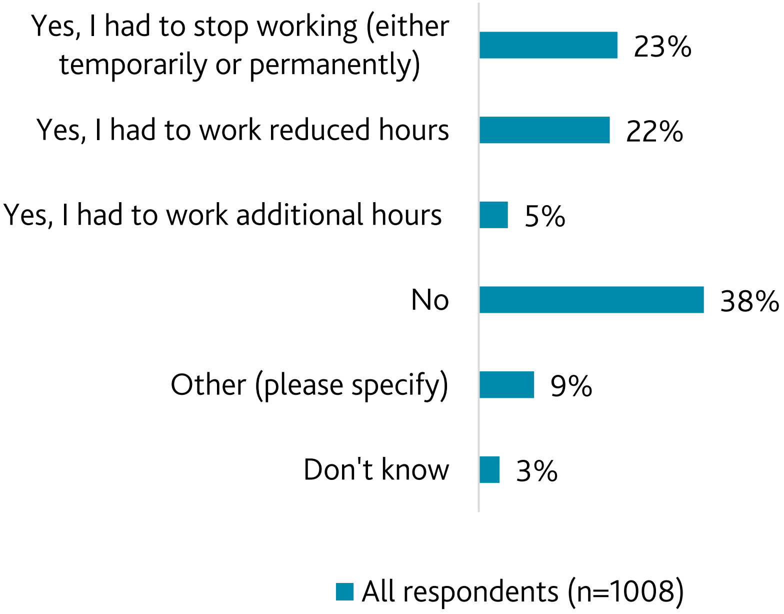
- Thirty-six percent (n=109) of caregivers, friends, or family members who had discussed their worries or concerns with a healthcare professional were prescribed medication, while 33% (n=99) were referred to other sources of support (such as a social worker, therapist or for cancer counselling) (Figure 117).

Figure 117. Q165 Did the healthcare professional you spoke to recommend any of the following to help with the worries or concerns you experienced? Please select all that apply.



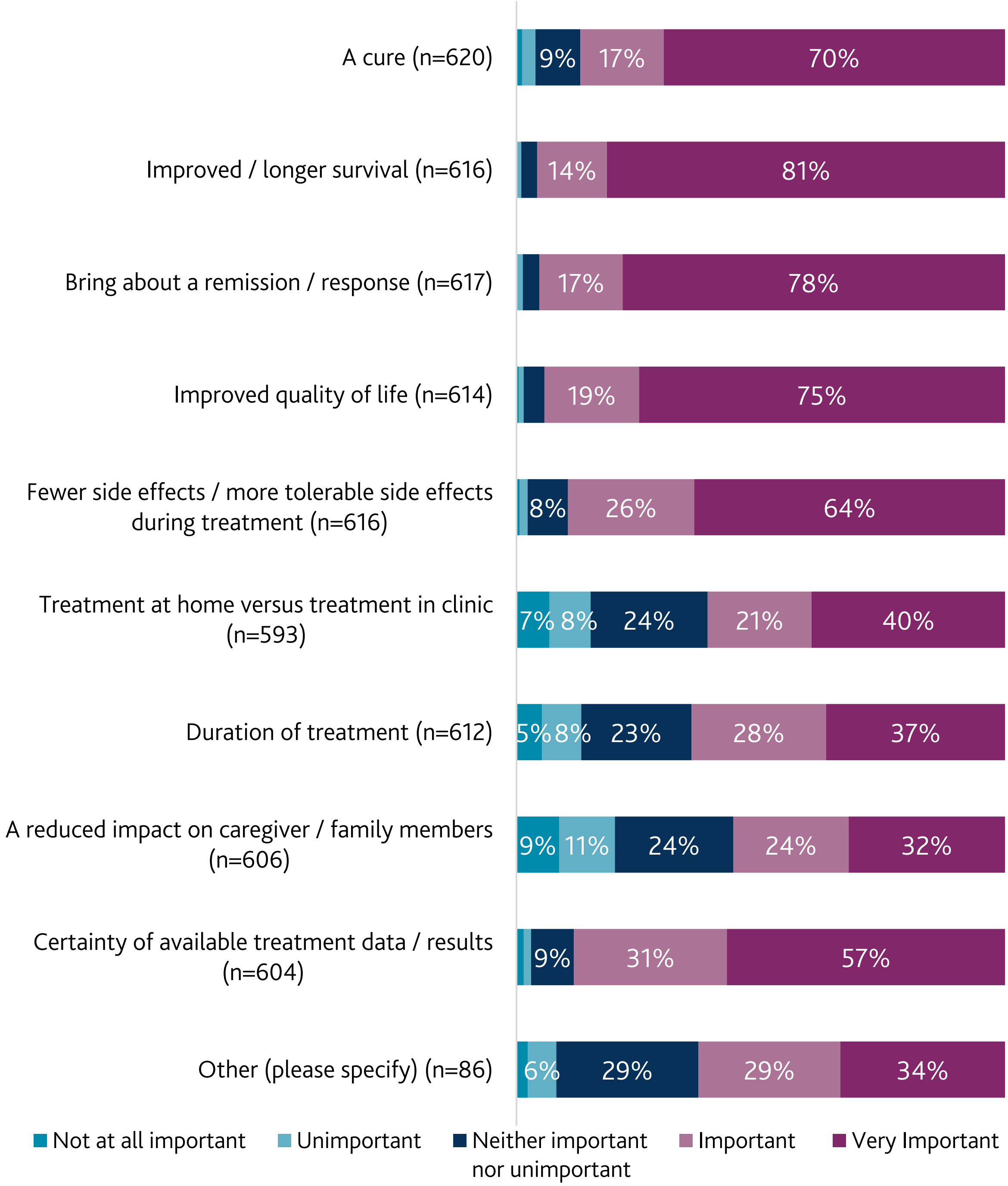
- Almost half (45%, n=453) of caregivers, friends and family members have had to stop working either temporarily, permanently or reduce their working hours since the patient was diagnosed. Thirty-eight percent (n=378) reported their ability to work has not been impacted since the patient was diagnosed (Figure 118).

Figure 118. Q166 Has your ability to work been affected since the patient was diagnosed?



- Caregivers, friends and family members were most likely to report the following treatment aspects as being important or very important when deciding on the patient's most recent treatment for their lymphoma or CLL (Figure 119): Improved / longer survival (95%, n=590); bring about a remission / response (95%, n=588); and improved quality of life (94%, n=579)

Figure 119. Q167 When deciding on the patient's most recent treatment for their lymphoma or CLL, how important were each of the following to you?



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