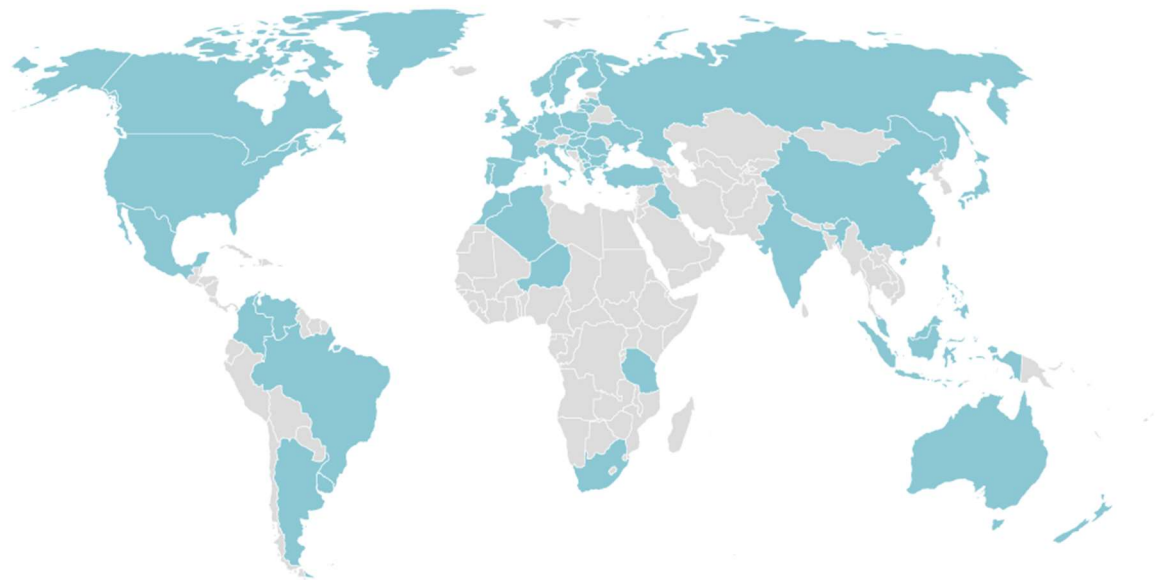




PSYCHOLOGICAL IMPACT OF LYMPHOMA

LEARNINGS FROM THE 2020 & 2022
GLOBAL PATIENT SURVEYS ON LYMPHOMAS & CLL

2023





About 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). The need for a central hub of consistent, reliable, and current information was recognized. It was also clear there was a need for lymphoma patient organisations to share resources, best practices, and policies and procedures. With this in mind, four lymphoma organisations started LC in 2002 and it incorporated as a not-for-profit organisation in 2010. Today, there are more than 90 member organisations from 55 countries.

As the organization grew, an additional workstream was added dedicated to advocating for equitable care globally. LC's current strategy remains focused on ensuring impact within two key pillars: information and advocacy.

Vision

Equity in lymphoma outcomes across borders.

Mission

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

Disclaimer

LC provides the Psychological Impact of Lymphoma report for general information. While LC makes every effort to ensure accuracy, the information contained in the report is taken from various public and private sources. No responsibility can be assumed by LC for the accuracy or timeliness of this information.

The report should not be used for the purpose of self-diagnosis, self-treatment or as an alternative to medical care. If you have any concerns arising out of the information contained in this report, you should consult your own physician or medical advisor.

Acknowledgements

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Introduction

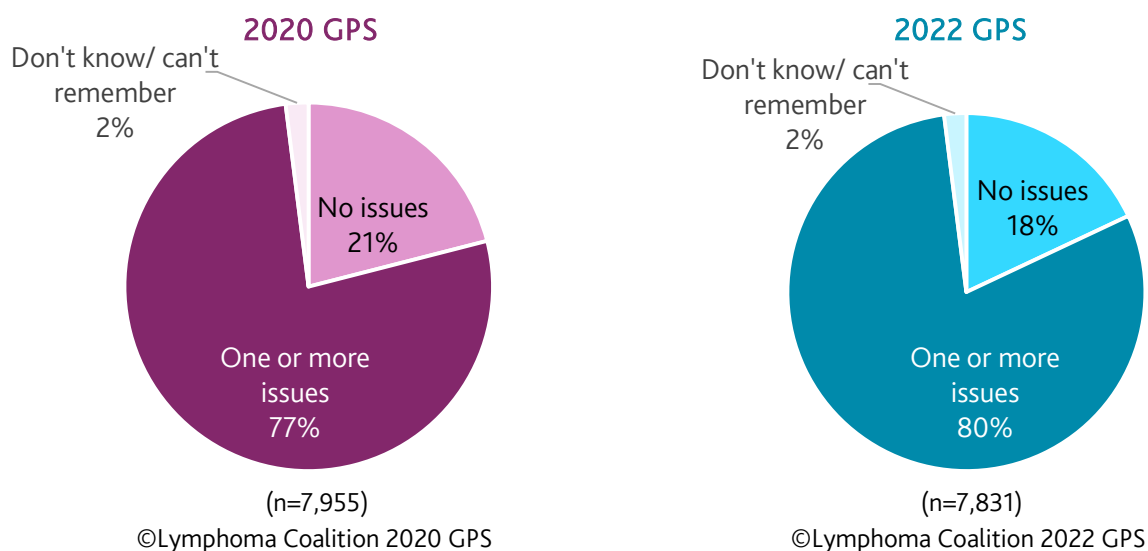
Every two years, Lymphoma Coalition (LC) conducts a Global Patient Survey (GPS) on Lymphomas & CLL (chronic lymphocytic leukaemia) to get an understanding of patient experience and how it is changing over time.

The survey investigates many aspects of the patient experience, including distress.

Distress is defined as a multifactorial unpleasant experience of a psychological (i.e., cognitive, behavioural, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment.¹

In the 2020 and 2022 surveys, over three-quarters of patients reported personally experiencing in the last year one or more of the following due to their lymphoma diagnosis: anxiety, body image concerns, changes in relationships, depression, fear, isolation, loss of self-esteem, and/or post-traumatic stress disorder.

Figure 1. In the last 12 months, have you personally experienced any of the listed issues as a result of your lymphoma diagnosis?



Why is this important?

- Research has confirmed the 12-month prevalence rate for any psychological disorder is significantly higher in patients with cancer compared with the general population.²
- Issues like fear, anxiety and depression have been proven to have negative impacts on quality of life, healthcare service use, adherence to cancer treatment and follow-up recommendations, and in some cases, overall survival.^{3,4,5,6}
- The psychosocial and quality of life needs of patients with lymphoma remain understudied.^{6,7} Research like this would help identify patients most likely to develop issues and require support, as well as help determine the best interventions to help patients cope.
- Patients don't talk about their psychological concerns the same way they do about their medical or physical issues, meaning many are not directed to appropriate support.

- Clinicians may minimise the impact of these issues on patients. Doctors may confuse clinical depression (feeling hopeless, helpless, worthless, or suicidal) or anxiety disorders (phobic avoidance, agitation, constant worry) with normal sadness and preoccupation, mistakenly believing “it is normal to feel sad or anxious because of cancer.”⁹
- Psychological distress is often unrecognized and undertreated.⁸ It is estimated 30–40% of cancer patients experience psychological issues that are not identified by their medical team and are not referred to appropriate therapy.⁹

Regular assessment and treatment of distress has been mandated by a number of regulatory bodies. The International Psycho-Oncology Society (IPOS) Standard on Quality Cancer Care, says psychosocial cancer care should be recognized as a universal human right; quality cancer care must integrate the psychosocial domain into routine care; and that distress should be measured as the sixth vital sign.¹⁰

It is critical clinicians are equipped with information about how to identify who needs additional psychological care, what treatment or support would be best, and when this is necessary. Organisations like the American Society of Clinical Oncology (ASCO)¹¹, the European Society of Medical Oncology (ESMO),⁷ the National Comprehensive Cancer Center (NCCN)¹ and others, have created guidelines to ensure patients with cancer are screened for psychological issues and treated appropriately. There is also a practical guide for clinicians available regarding cancer-related fear.¹³ Despite the availability of various tools and evidence-based guidelines they are not being widely used in clinical practice. As such, many patients require more support to manage the long-term impact of distress on their wellbeing.¹²

This paper gives an overview of learnings from the LC 2020 and 2022 GPS regarding three leading types of distress.

1. Fear

Fear is the most commonly reported psychological issue for patients with lymphoma each time the GPS is conducted. Due to the different ways lymphoma manifests and is treated, respondents are able to describe their fear as fear of relapse (lymphoma coming back) or fear of progression (lymphoma getting worse).

Cancer-related fear is considered a unique and significant mental health issue in its own right.¹³ It can impact an individual's quality of life and is associated with anxiety, depression, and isolation. Cancer-related fear can also inhibit the ability to plan for the future.

2. Anxiety

Anxiety was described to survey participants as intense, excessive, and persistent worry; feeling afraid; feeling restless; sudden feelings of intense anxiety; nightmares; panic attacks. Elevated anxiety is related to lack of adherence to recommended therapies, and higher use, and costs of medical care.¹¹

3. Depression

Depression was described to survey participants as persistent sadness, low mood, loss of interests or pleasure, fatigue, or low energy most of the time for at least two weeks. Depression at diagnosis and throughout the cancer trajectory correlates with lower adherence to treatment and follow-up care, increased inflammation, impaired immunity, and reduced survival.^{1,11,14}

Learnings: 2020 & 2022 GPS on Lymphomas & CLL

Prevalence of Psychosocial Issues

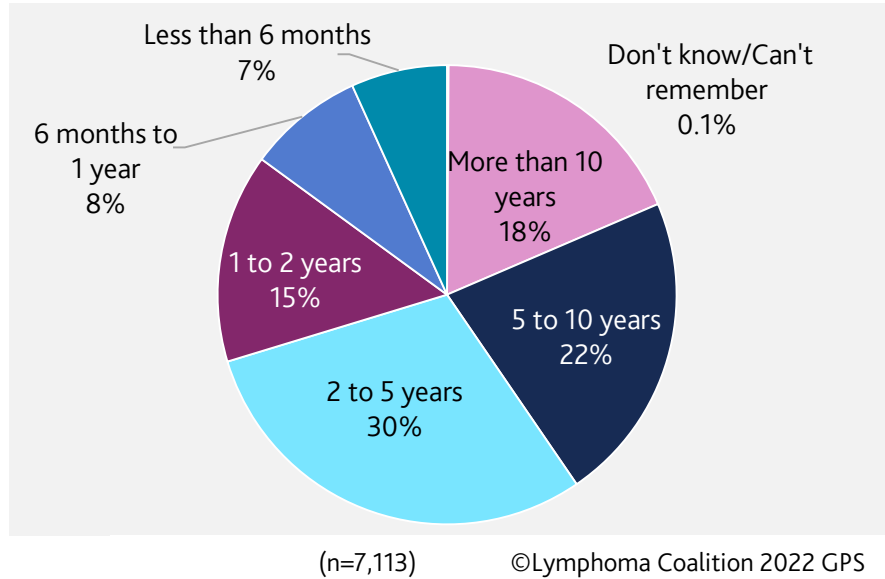
Four out of every five patients with lymphoma, including CLL, who responded to the surveys experienced at least one psychosocial issue in the last year.

Over 7,100 patients responded to the 2022 survey globally, having lived with lymphoma for various timeframes.

Despite the fact some patients received their diagnosis many years ago (figure 2), these patients are still reporting psychosocial issues in the last 12 months.

This shows the significance and persistence of these worries and concerns, that start with diagnosis and last into survivorship.

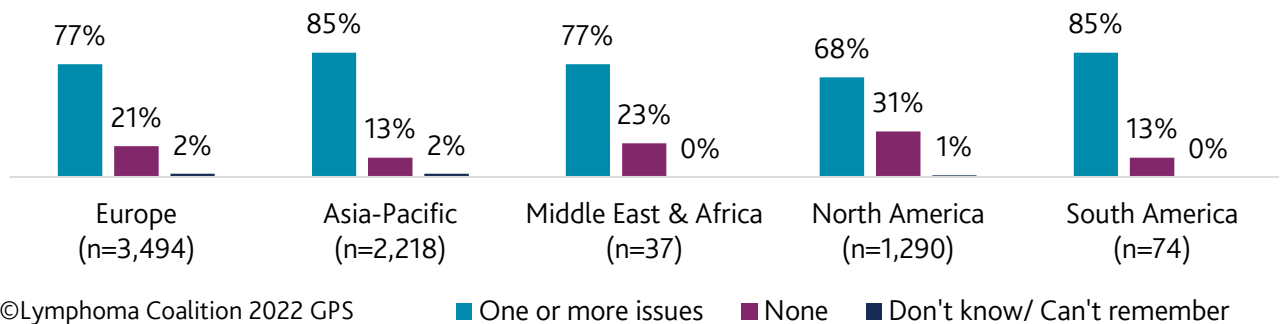
Figure 2. How long ago were you diagnosed with lymphoma or CLL?



Guidelines stress the importance of screening patients for distress regularly throughout their patient experience, but especially when they transition through different phases of care (e.g. active treatment, remission, recurrence).^{1,7}

Survey data also shows this is truly a global issue, with most patients in all regions in the world indicating they are experiencing worries and concerns related to their lymphoma.

Figure 3. In the last 12 months, have you experienced any psychosocial issues as a result of your lymphoma diagnosis? (Results by region)

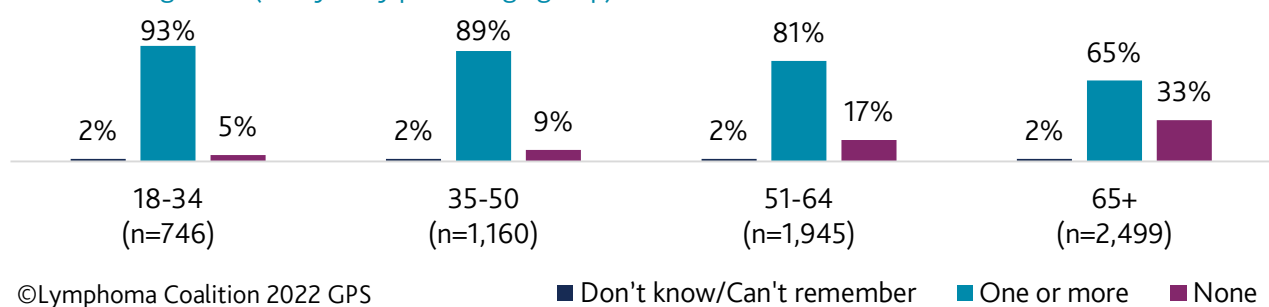


While fewer patients in North America seem to be impacted, this correlates to the lymphoma subtypes that make up 72% of the responses from the region rather than geographic differences. Namely Waldenström's macroglobulinemia (43% of respondents), which had the highest number of patients without any psychosocial

impact at 31%, and cutaneous lymphomas (29% of respondents), which had 19-22% of patients reporting no issues, depending on the type.

Younger patients, aged 18-34 years, report the most issues (93%) (figure 4). Other studies have shown similar results, as well as illustrating those with Hodgkin lymphoma - typically diagnosed in a younger age group - have more psychological disorders compared to other lymphomas.^{12,15,16,17} Incidence of psychosocial concerns decreases with increasing age, with 65% of the 65+ group having worries like these. Despite the lower prevalence, this is still a significant concern for older populations and cannot be ignored. Especially since there has been research showing distressed older adults are less likely to use mental health services compared to younger adults.⁶

Figure 4. In the last 12 months, have you experienced any psychosocial issues as a result of your lymphoma diagnosis? (Analysis by patient age group)



Several other factors have been named as increasing the risk for the onset of psychological conditions, such as inadequate and poor social support, uncontrolled symptoms, female gender, and previous history of psychiatric disorders or trauma.^{1,18} While the LC surveys don't ask questions related to all of these factors, more females than males (83% vs 71%) did indicate experiencing one or more concerns or worries in the last year.

What exactly were the patients' primary psychosocial effects?

Fear remains the main issue for patients each time the survey is conducted, whether it be described as fear of cancer relapse or recurrence (FCR) or fear of progression (FOP).

In the LC GPS 2022, half of patients indicated they had FCR and almost half said they experienced FOP (figure 5).

Patients can experience cancer-related fear along a spectrum ranging from mild to severe. Patients with mild FCR or FOP may have occasional thoughts about cancer and anxiousness that is triggered by external factors like follow-up appointments or scans. It lasts for a few days then goes away.¹³ Patients with moderate to severe cancer-related fear may have more frequent thoughts about cancer with or without triggers, an inability to control these thoughts, and strong associated distress. When severe, this type of fear is considered clinically significant and is unlikely to ease or stop without clinical intervention.¹³

Studies suggest that cancer-related fear is one of the most frequently cited unmet needs among cancer survivors. Survivors consistently report FCR to be among their top concerns, regardless of the level of severity at which

they experience it (low, moderate, high).^{17,19,20} Further, studies conducted over long periods of time, show that FCR is long-lasting for survivors of cancer, and without intervention it may not lessen over time.¹³

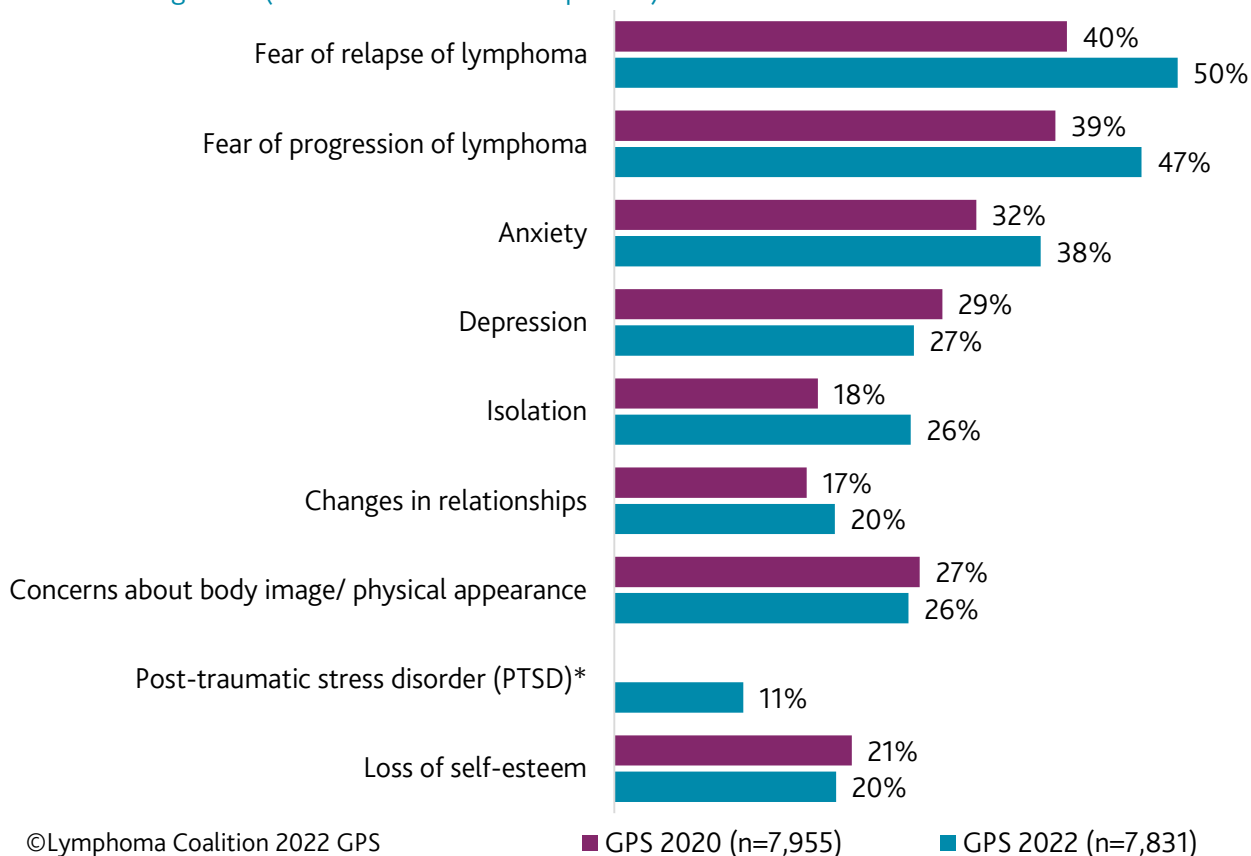
Anxiety was an issue for 38% of patients and depression for 27%.

Like fear, anxiety and depression can range from mild (worry, uncertainty, sadness, loss of hope) to severe syndromes (i.e. anxiety and depressive disorders) that are associated with significant distress, disability, poor quality of life, and increased physical symptoms.⁷

For those in remission, anxiety represents one of the most common and unaddressed concerns, that can persist for 10+ years post treatment.²¹

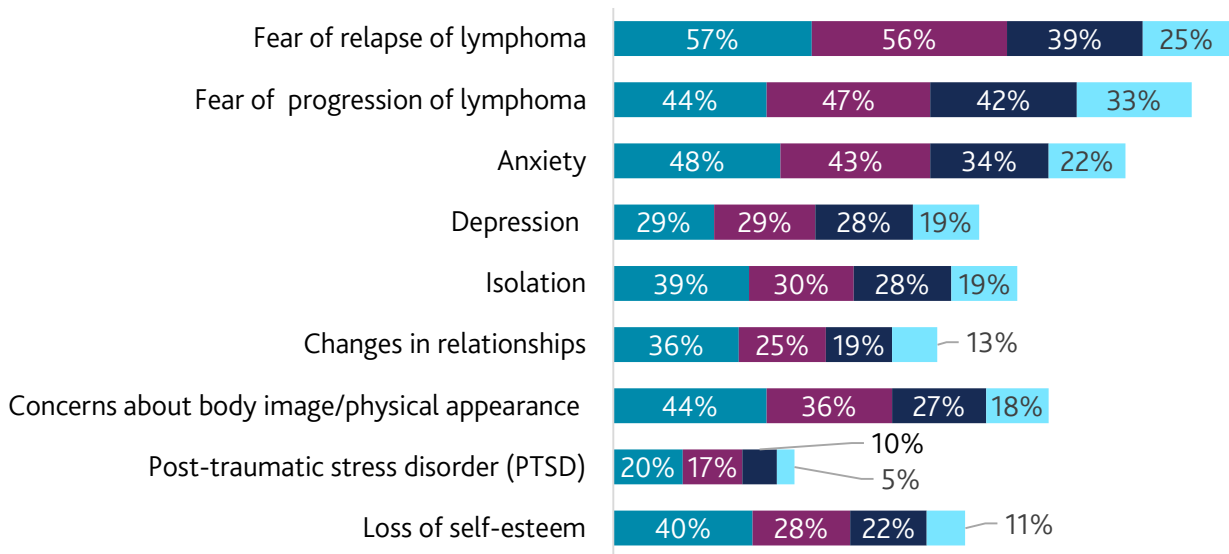
Patients who have depression prior to their cancer diagnoses are at an increased risk for moderate or severe distress.¹

Figure 5. In the last 12 months, have you experienced any psychosocial issues as a result of your lymphoma diagnosis? (2020 and 2022 GPS comparison)



When the same data is looked at by age group, younger patients aged 18-34 years and those age 35-50 years are more likely to experience all of the issues (figure 6). The exceptions are depression and isolation, which are experienced by older patients (over age 51) at similar percentages to the younger age groups.

Figure 6. In the last 12 months, have you experienced any psychosocial issues as a result of your lymphoma diagnosis? (Analysis by patient age group)

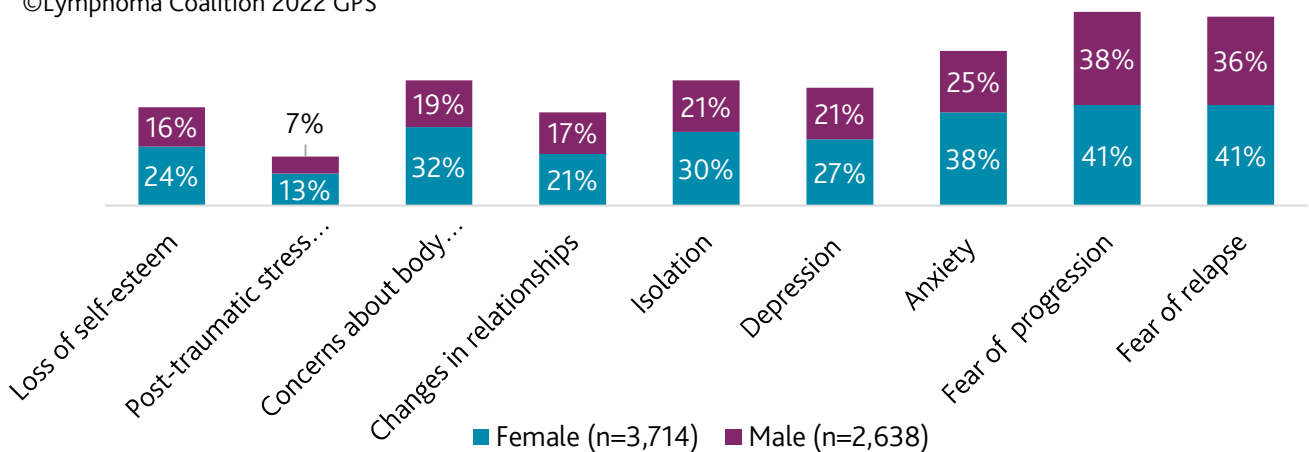


©Lymphoma Coalition 2022 GPS 18-34 (n=746) 35-50 (n=1,160) 51-64 (n=1,945) 65+ (n=2,499)

Females recounted experiencing every issue more than males (figure 7). Fear was still the main worry for both genders. Concerns about body image or physical appearance was significantly higher in females (32%) compared to males (19%), as was anxiety (38% vs 25%).

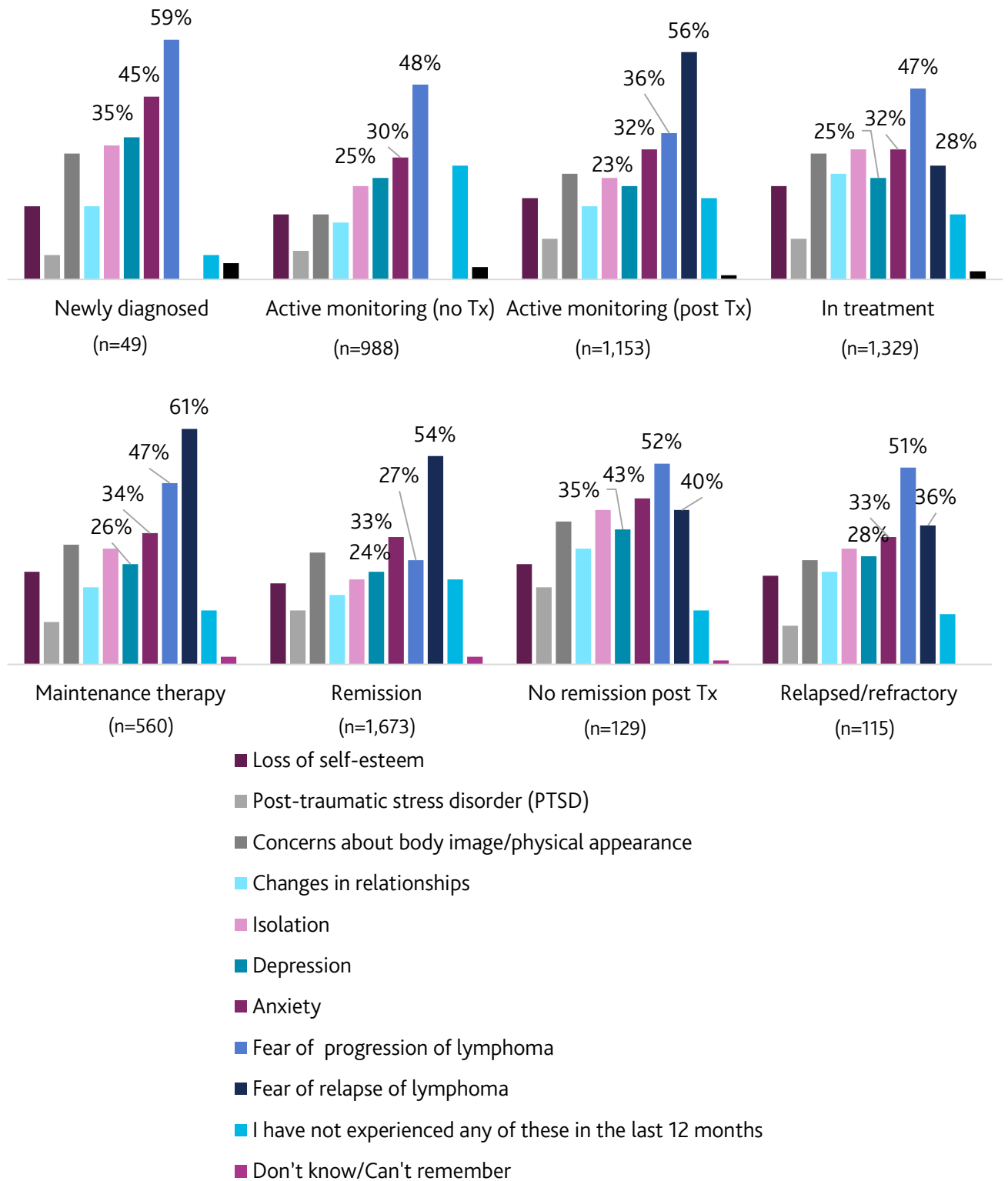
Figure 7. In the last 12 months, have you experienced any psychosocial issues as a result of your lymphoma diagnosis? (Analysis by gender)

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A further analysis was conducted by disease status. Almost all worries and concerns start early in the patient experience. Newly diagnosed patients have the highest percentage of those fearful of lymphoma progression (59%), anxiety (45%) and depression (35%) (figure 8). This indicates a need to ensure adequate education and support for psychological issues are introduced early into clinical care.

Figure 8. In the last 12 months, have you experienced any psychosocial issues as a result of your lymphoma diagnosis? (Analysis by disease status)



©Lymphoma Coalition 2022 GPS

For patients who are experiencing anxiety for the first time in their lives, research has shown the level of anxiety is often related to the intensity of their cancer experience. Higher rates are seen in those with advanced disease, going through difficult treatment, and enduring ongoing side effects.⁶ In lymphoma, those with a history of recurrent lymphoma are thought to be more at risk of anxiety.⁶ The LC 2022 GPS did show anxiety was a problem for almost half (43%) of those who didn't achieve a remission after treatment, a similar percentage to those newly diagnosed. Just over half of patients in the same group also reported fear of progression and 35% said they had depression, both of which are amongst the highest incidences across all treatment phases. In the relapsed/refractory group, fear of progression (51%), was the only concern that was noticeably higher.

Fear of relapse was most likely to happen for those in maintenance therapy (61%) or active monitoring after treatment (56%).

It is also important to highlight the psychological impact experienced by those in active monitoring. Given these patients are not treated until they become symptomatic, they may live with fear of the unknown for an extended time, wondering when the disease will progress, and may suffer from associated anxiety and depression. Furthermore, if active monitoring is not well explained and understood from the outset of diagnosis, it may seem like a risky or passive approach to a serious disease. All of these factors can elicit a great deal of distress for patients. Patients in active monitoring require more support for their distress, as well as ongoing reassurance that their symptoms are being actively monitored and that treatment will begin when necessary.

Different phases of the illness trajectory can trigger emotional distress and the onset of psychological disorders.¹ This analysis confirms it is important to assess psychological distress along the entire patient treatment trajectory and offer timely and adequate support. Guidelines emphasize how important it is to assess psychological distress at each checkup. Unfortunately, this activity is not yet widespread in clinical practice.¹²

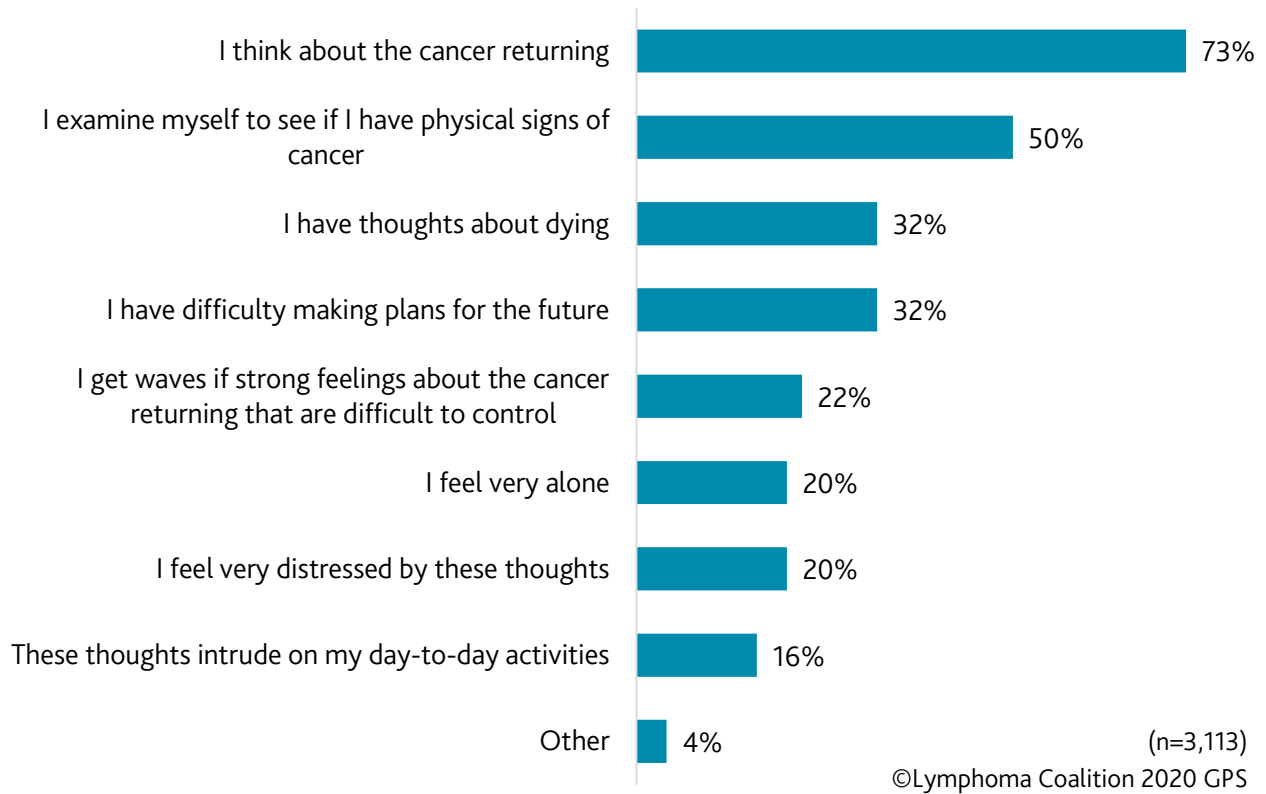
The rate of psychosocial concerns also varied by lymphoma subtypes. Patients with extranodal killer T-cell lymphoma had the highest numbers experiencing anxiety (62%), fear of progression (65%) and fear of relapse (82%). This subtype of lymphoma is rare, with limited long-term treatment success. It is also harder to find credible information on this disease. All of these factors can contribute to higher distress. Patients with breast-implant-associated anaplastic large-cell lymphoma (BIA-ALC) were most likely to report loss of self-esteem (72%), isolation (88%) and changes in relationships (50%). These patients are often coping with physical changes to their bodies as the lymphoma can cause disfigurement, and subsequent treatment often means the removal of their breast implants and surrounding tissues. Patients with Waldenström's macroglobulinemia (31%), CLL (27%) and cutaneous lymphomas (ranging from 19-22% depending on the type) were the groups most likely not to experience any psychosocial issues.

Other surveys have found that 20-52% of patients with cancer show a significant level of distress, but there is variance by type and stage of cancer.^{22,23} There is early research suggesting lymphoma patients can have notably diminished psychological wellbeing, but more research is needed to identify meaningful aspects of distress in patients with lymphoma.⁶

The LC GPS isn't able to ascertain which of the respondents have more clinically significant distress, but the LC 2020 GPS did explore the impact of cancer-related fear on patients' lives.

Three-quarters of patients who experience FCR said they think about the cancer returning, and 50% examine themselves to see if they have physical signs of cancer. More concerning is nearly a third (32%) have difficulty making plans for the future, 20% feel very alone, have difficulty controlling their feelings about the lymphoma returning and are distressed by their thoughts (figure 9).

Figure 9. You have indicated that you have experienced a fear of relapse, which of the following have you experienced?



Impact of the Covid-19 Pandemic

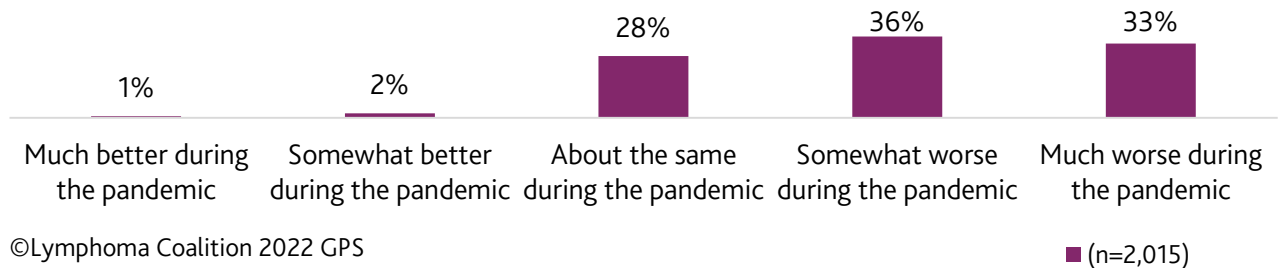
In recent years, the incidence and prevalence of both anxiety and depression disorders in the general population have rapidly increased.⁷ This is due to the global Covid-19 pandemic and the related measures to halt the spread of Covid-19, which created an environment that worsened known causes of poor mental health.^{24,25} The added stressors from Covid-19 measures intensified pre-existing psychological issues as well as leading to the development of new cases.²⁵ The burden from these diseases is becoming an increasingly significant global problem.⁷

Compared to 2020, the LC 2022 GPS shows an increase in almost all of the reported psychosocial effects (figure 5, page 8). The 2022 survey was conducted February-April 2022, when many countries were still in the midst of the pandemic.

Patients who reported having anxiety were asked how the Covid-19 pandemic affected their anxiety level. Almost 70% stated their anxiety level was worse during the pandemic.

Two-thirds of patients with cancer who report symptoms of anxiety have no history of anxiety prior to their cancer diagnosis.²¹ This is something new they have to learn to cope with, alongside adapting to their diagnoses. This was more challenging with the addition of the pandemic.

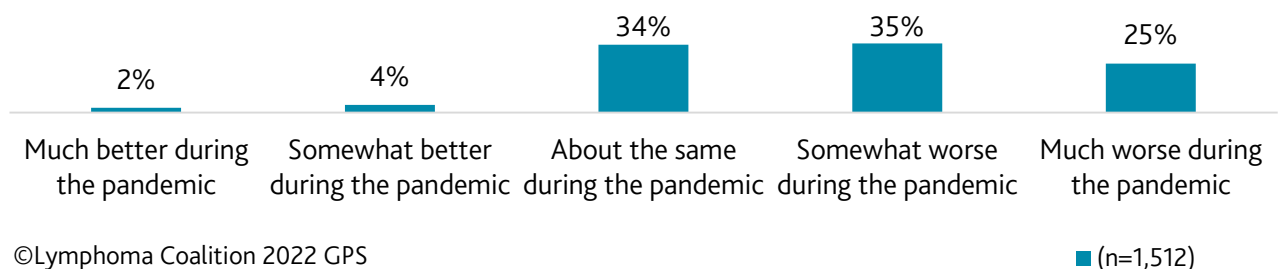
Figure 10. Please describe your level of anxiety during the Covid-19 pandemic, compared to your level of anxiety before the pandemic.



The number of patients indicating worse anxiety was slightly lower for those in maintenance therapy (64%) or those whose lymphoma is in remission (66%). Patients elsewhere in the treatment trajectory, including those newly diagnosed and those in active monitoring, anxiety was worse for 69-75% of patients.

Three out of every five patients with depression stated their level of depression was worse during the pandemic.

Figure 11. Please describe your level of depression during the Covid-19 pandemic, compared to your level of depression before the Covid-19 pandemic.

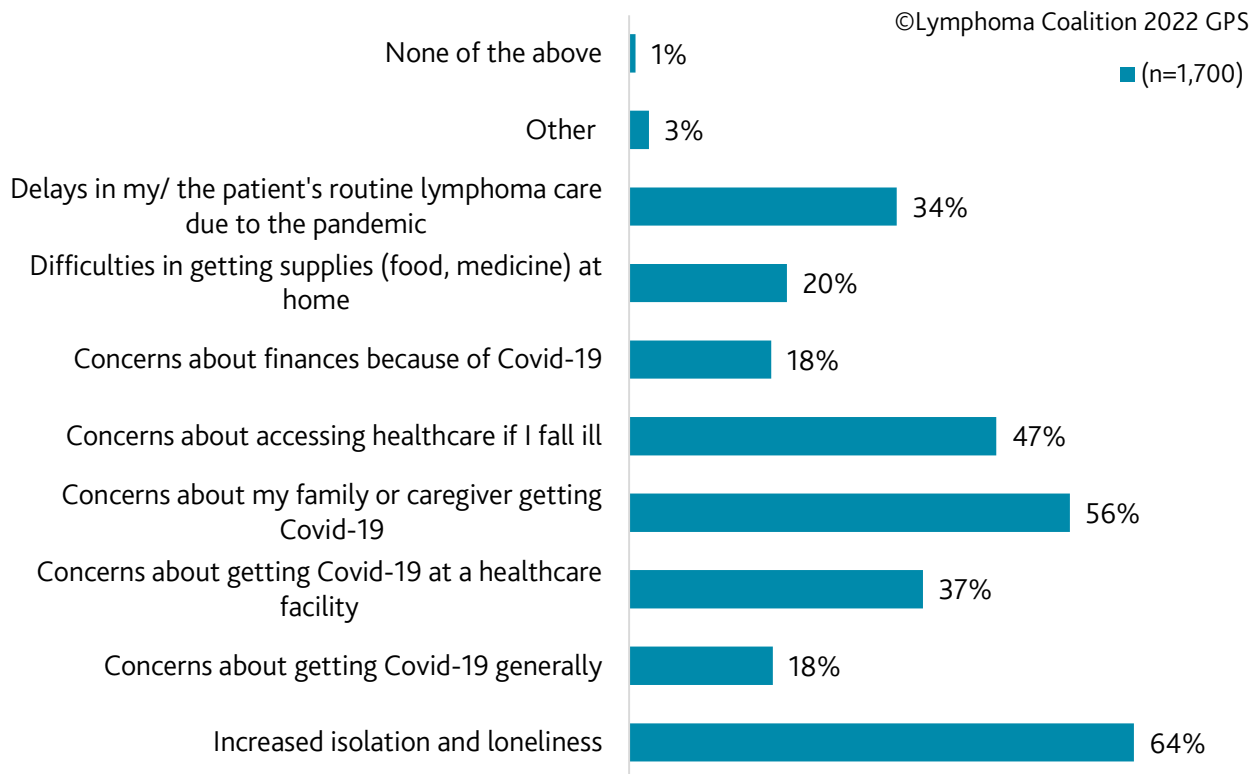


Patients that were either in active monitoring (60%), treatment (65%) or had finished treatment but their disease was not in remission (73%) were more likely to see a worsening of their depression.

Patients reported the top stressors contributing to the increase in their distress:

- Increased isolation and loneliness.
- Concerns about family or caregiver getting ill.
- Concerns about healthcare should they fall ill.

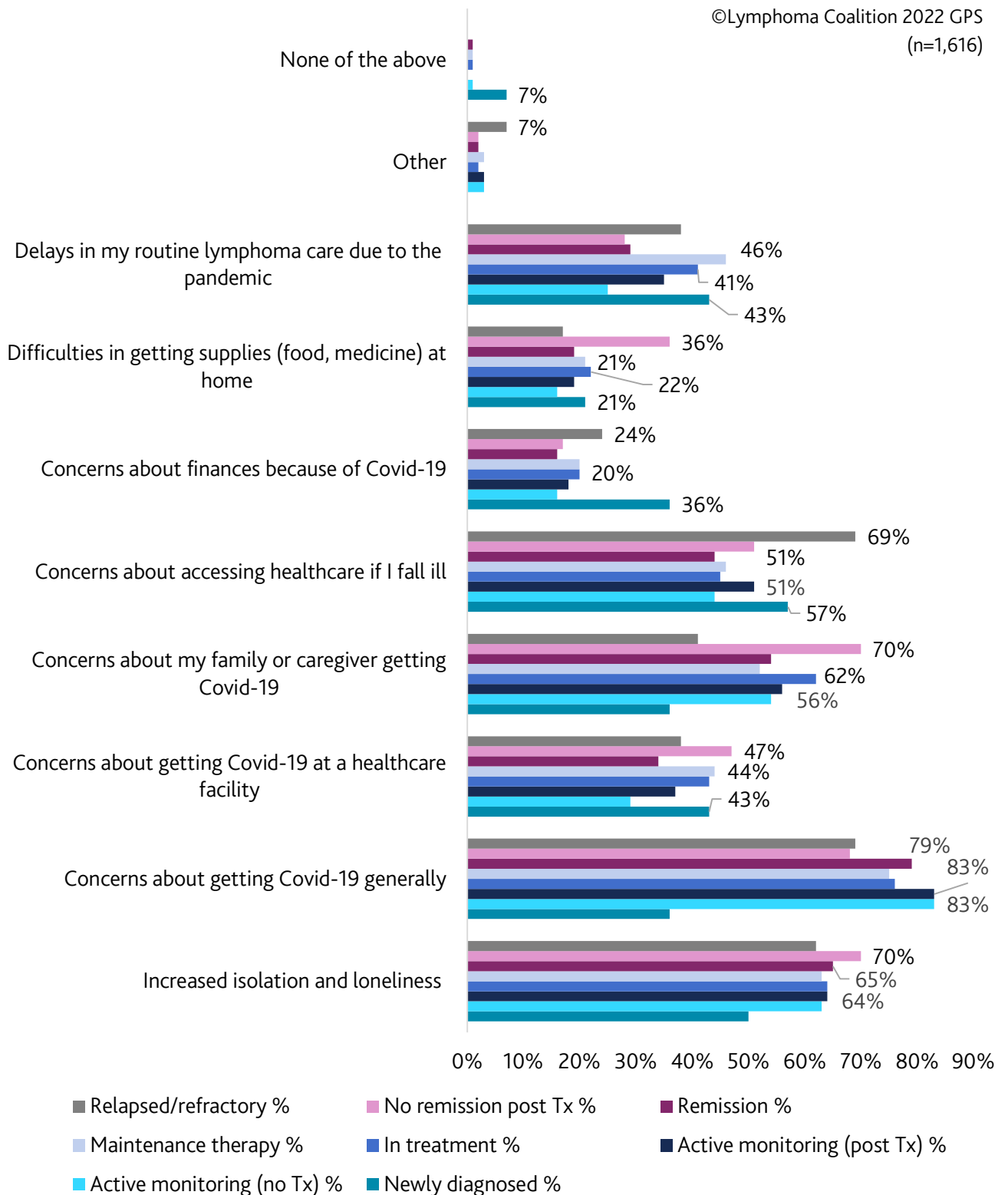
Figure 12. Which of the following were contributing factors for the worsened anxiety and/ or depression?



When reviewing this data by disease status, there were interesting differences (figure 13). Those with relapsed/refractory lymphoma were more likely to be worried about accessing healthcare. Patients whose treatment had not resulted in a remission were more concerned about the people around them being ill, whether that be at home or in a healthcare setting. Newly diagnosed patients and those in maintenance therapy were more worried about disruptions to their care. This makes sense as there were problems for newly diagnosed patients getting into the appropriate care due to Covid precautions at hospitals, healthcare staffing challenges and testing delays. As well, treatment protocols shifted as doctors balanced what was best to treat the lymphoma while reducing patients' potential exposure or susceptibility to Covid-19. This meant many clinics decided to stop maintenance therapy for patients with certain types of lymphoma. Patients who would have been prescribed maintenance treatment pre-pandemic were left wondering if this decision left them at risk of their cancer returning.

It remains to be seen if psychosocial issues return to pre-pandemic levels now the pandemic has been declared over. But right now there are a significant number of patients dealing with increased levels of distress.

Figure 13. Which of the following were contributing factors for the worsened anxiety and/or depression? (Analysis by disease status)



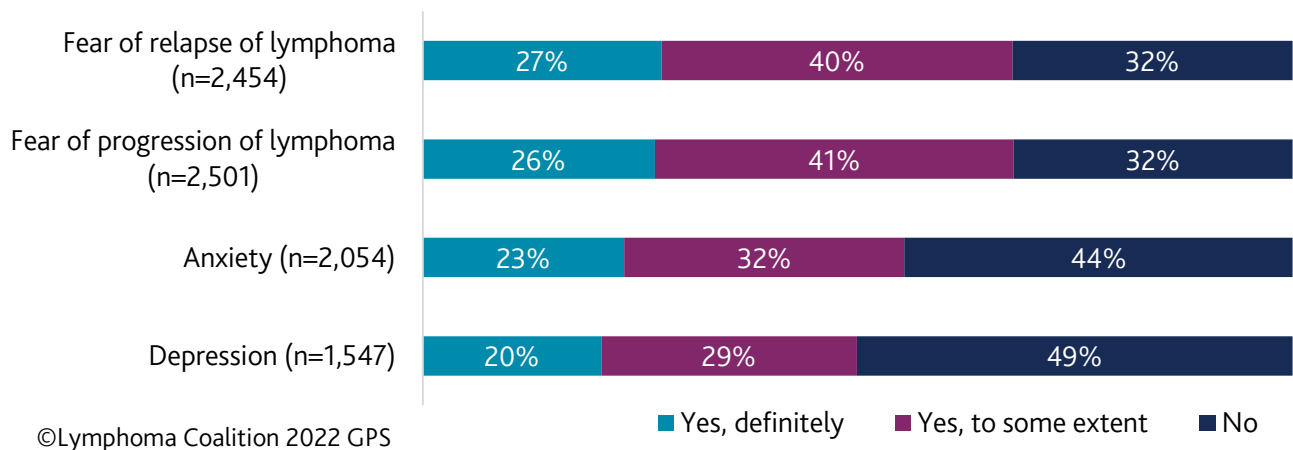
Talking About Psychological Issues

Two-way information exchange between patients and their treating physicians is critical for optimal care. This includes not only communication about medical and physical issues, but also psychosocial effects. Research has shown a correlation between patients who feel they have good communication with their doctor and better patient emotional health.^{26,27}

Currently, distress identification relies on self-reporting by patients, which depends on their willingness to report symptoms.⁶ As well, factors such as clinicians' lack of sympathy, patients feeling uninformed, and the busyness of the clinical environment leads to patients feeling disconnected from their medical team or unable to express their needs.^{28,29} There is research showing many patients don't discuss the psychological effects of cancer with their doctors. As a result, they are not connected to services to help them cope.⁸

Respondents to the LC 2022 GPS followed this pattern, with only 20-27% saying they definitely discussed and 29-40% saying they somewhat discussed their psychological issues with their doctor. More patients reported discussing their fear than their anxiety or depression (figure 14).

Figure 14. For each of the psychological issues that you have experienced, please indicate if you have discussed it with a doctor?



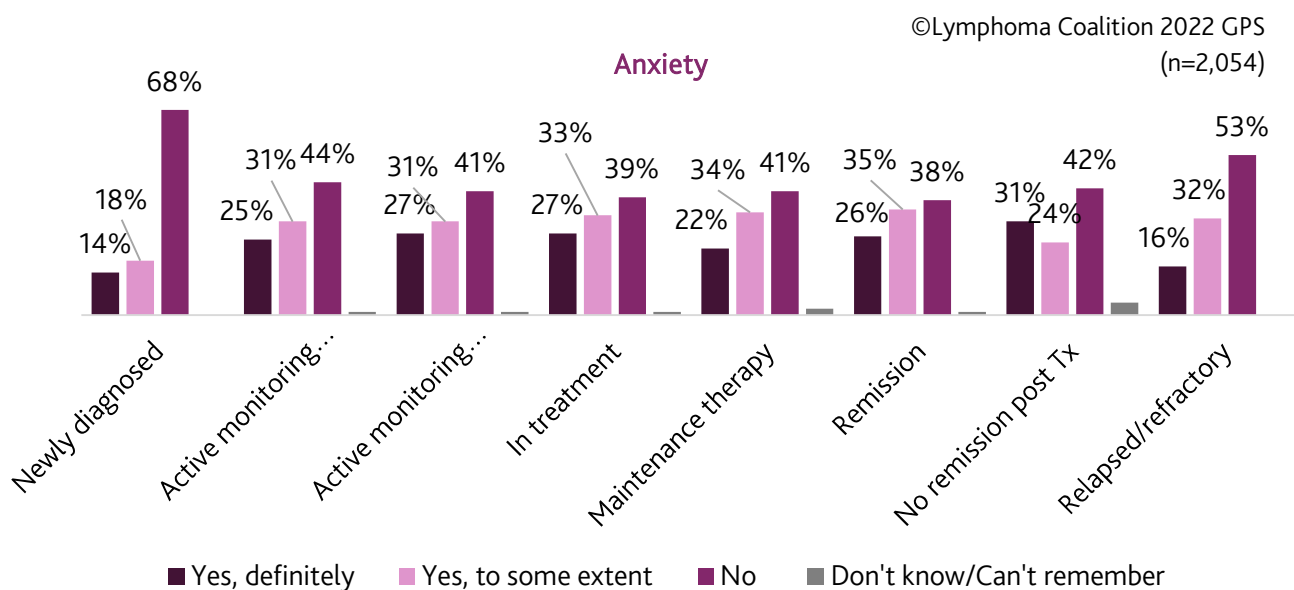
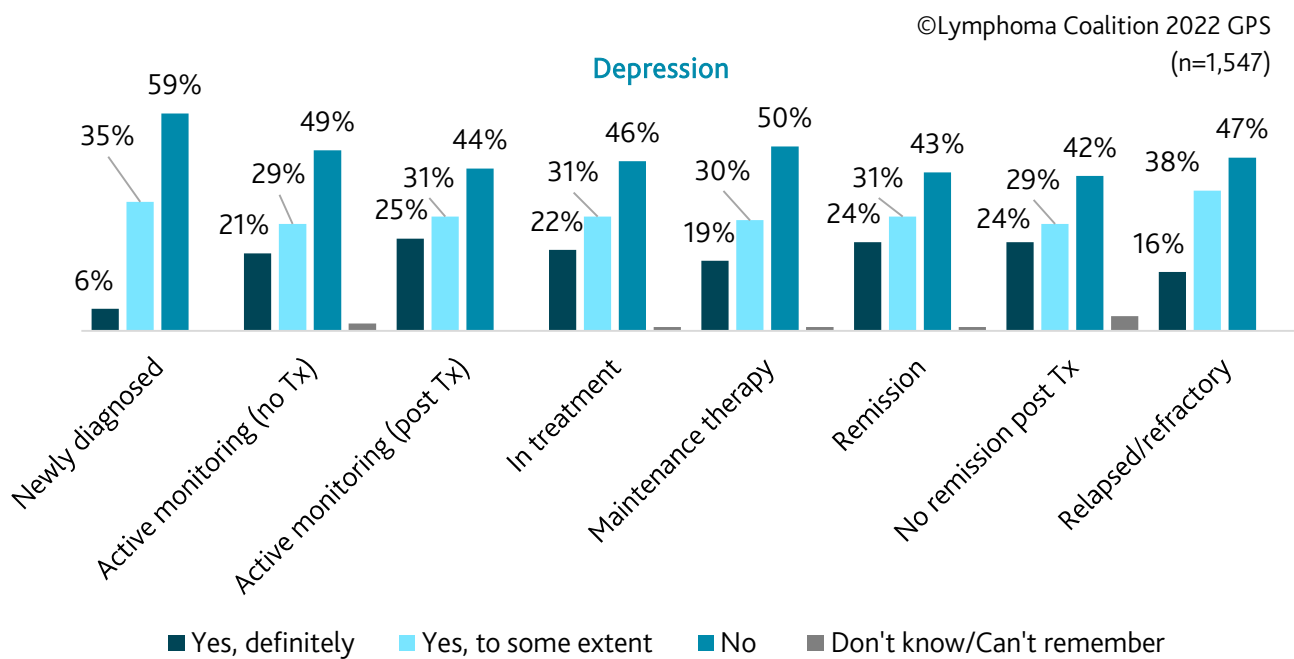
Despite the fact they were more likely to experience anxiety and depression, more patients in the youngest age group (18-34yrs) did not discuss their depression (57%) and anxiety (52%) with their doctors compared to the older age groups.

In some countries and cultures, there is a continuing stigma surrounding mental health that can also impact a patient's willingness to admit they have any such problems. Patients living in Asia-Pacific were less likely to discuss their concerns than patients in other regions of the world. Half of patients in Asia-Pacific said they don't talk to their doctor about their anxiety or depression at all, and 44% don't talk about their fear. Cultural norms may be a factor here, but this still leaves patients without coping mechanisms for issues affecting their wellbeing.

As well, there is a smaller chance newly diagnosed patients will discuss any of their psychological concerns even though they had the highest rates of fear of progression, anxiety, and depression. It is at this point in their journey they are establishing their communication patterns and habits with their medical team that will carry them through their disease trajectory.

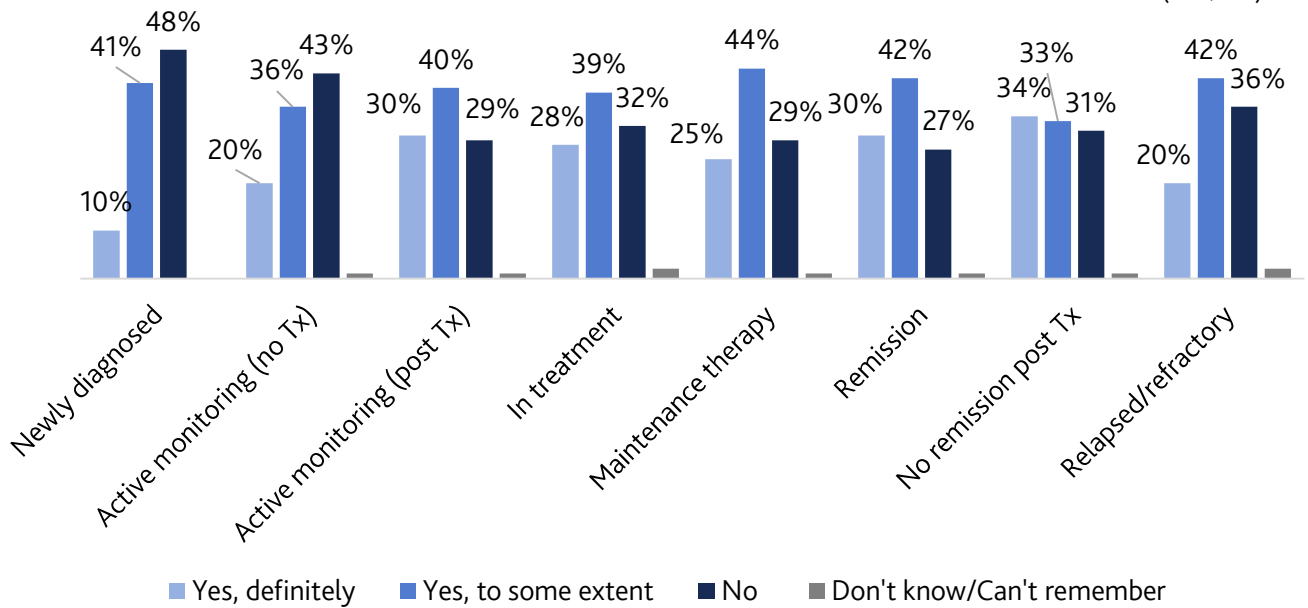
More should be done to encourage all patients open up about their worries to ensure they get adequate support to help them cope.

Figure 15. For each of psychological issues that you have experienced, please indicate if you have discussed it with your doctor? (Analysis by disease status)
**Only asked to those who experienced depression OR anxiety OR fear of progression OR fear of relapse*



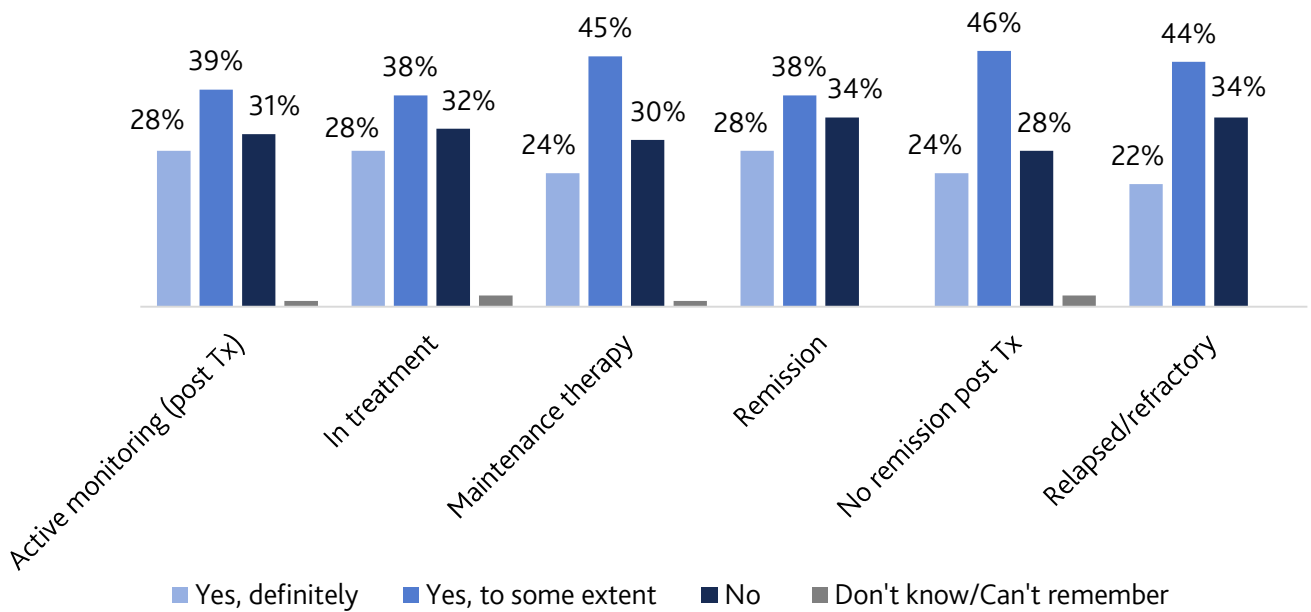
Fear of Lymphoma Progression

©Lymphoma Coalition 2022 GPS (n=2,501)



Fear of Relapse or Recurrence

©Lymphoma Coalition 2022 GPS (n=2,454)



Two common patient barriers to seeking help for distress are a preference for self-help and not believing their distress is severe enough to necessitate intervention.³⁰ Findings from the LC 2020 GPS aligned with this. Patients indicated they didn't discuss their depression or anxiety with their doctor because:

- They thought they could handle it on their own (depression: 49%; anxiety: 50%)
- They did not want to bother their doctor (depression: 27%; anxiety: 29%)

Table 1. For each worry or concern that you have experienced, please indicate what were your reasons for not discussing it with your doctor.

©Lymphoma Coalition 2020 GPS	Depression (n=1,308)	Anxiety (n=1,266)
I thought I could handle it on my own	49%	50%
Didn't think it was a big deal	19%	19%
Didn't want to bother them	27%	29%
Didn't want the dose that is working to be lowered	3%	3%
Didn't want to be taken off a treatment that is working	6%	5%
Other	14%	13%
Don't know/ Can't remember	5%	5%

The LC 2020 GPS also asked who else patients had spoken to regarding their worries or concerns. In most cases, patients reported that they had spoken with their family and friends rather than other healthcare professionals or they had simply not spoken about these issues with anyone. While family and friends may be empathetic, it is unlikely they will have the necessary knowledge to screen and direct patients to the appropriate type of support.

Table 2:. For each worry or concern that you have experienced, please indicate who else you have spoken with to help support you?

©Lymphoma Coalition 2020 GPS	Depression (n=2,282)	Anxiety (n=2,473)	Fear of Relapse (n=3,113)	Fear of Progression (n=3,061)
I did not speak to anyone else	30%	25%	29%	32%
Family and/or friends	54%	57%	59%	55%
Nurse	6%	8%	9%	9%
Social worker	3%	4%	3%	2%
Complementary therapist	12%	14%	9%	7%
Another doctor	13%	14%	11%	13%
Other	3%	4%	3%	3%
Don't know/ Can't remember	2%	2%	2%	2%

Good patient-doctor communication is linked with reduced emotional distress.¹³ Patients who were able to communicate their worries and concerns to their physicians without interruption were as much as 20% more likely to receive interventions such as referral to therapists and exercise as a way of dealing with anxiety and depression.³¹

To encourage communication, it can be helpful for doctors to clearly acknowledge the emotional impact of a cancer diagnosis in their first interaction with a patient, and to respond to emotional cues from the patient and their family throughout their experience.¹³ This has been proven to encourage patients to speak more easily about

their feelings. It also lets a patient know that addressing their worries and concerns is an important and usual part of cancer care.¹³

For instance, some degree of distress is expected with a diagnosis of cancer. The clinician and other members of the cancer care team can explain to patients they can expect symptoms such as:¹

- Fear and worry about the future.
- Concerns about the lymphoma.
- Sadness about losing their health.
- Anger and frustration due to feeling that their life is out of control.
- Problems sleeping.
- Lack of appetite.
- Difficulty concentrating.
- Preoccupation with thoughts of illness, death, treatment, and side effects.
- Concerns about how to continue fulfilling their personal roles (e.g., being a good mother or father).
- Spiritual concerns.

These feelings and symptoms can happen at any point, including long after treatment is completed. Patients should not be made to feel like they need to adopt a 'positive outlook' or 'get back to normal'. Recognizing the normalcy of distress can help to reduce stigma and patient denial of their feelings.¹³

The fact patients struggle to speak about the emotional impact of lymphoma reinforces the need to follow clinical practice guidelines on distress.

Even if patients aren't talking about their psychological issues, their distress should be captured by routine screening in the clinic.

Screening for distress in patients with cancer is important. Early screening for distress leads to timely management of psychological issues, which then improves medical management of the cancer.^{13,32} Distress guidelines provide strategies for screening in the clinic, which is now a standard for accreditation in several countries.⁷ Most guidelines recommend the use of a simple distress tool that has been validated with patients with cancer.⁷ These tools often involve the patient answering a brief list of questions. Screening using these simple tools is only the first step. Patients displaying any symptoms of moderate to severe distress should be referred to a psycho-oncology specialist for a more formal assessment using in-depth diagnostic techniques and then receive a tailored treatment plan.^{7,33} Despite these recommendations and expectations, cases are rarely identified by treating physicians and not many patients with cancer are referred to specialist psychiatry services.⁷

Doctors play a vital role in screening, encouraging patients to talk about their feelings, and motivating patients to accept any recommended treatments.³⁴ Data shows there is much room for improvement in this area.

Management & Support

Timely management of psychological effects leads to better medical management of patients with cancer.³² Supporting patients through first signs of worries or concerns, and then providing tools to help them cope is critical.

Many patients with cancer who need psychological care don't get the help they need because of the under-recognition of patients' psychological needs by their cancer care team, as well as a lack of knowledge of community resources that can augment what is available within the cancer clinic.³⁵

Evidence suggests that the majority of cancer patients express interest in receiving strategies, learning coping mechanisms, and engaging in discussion about cancer-related fear.³⁶ Simple targeted interventions that all members of a patient's cancer team can implement have been shown to reduce cancer-related fear levels in sample populations. Much of this revolves around providing good information and talking to patients about their fear. Despite this, fear is often omitted from survivorship planning and discussions with healthcare professionals.³⁷

There is agreement amongst the clinical practice guidelines about the optimal management of distress.

Doctors should offer:

- | | |
|--|-------------------------------------|
| ✓ Education | ✓ Behavioural activation |
| ✓ Supportive therapy or counselling | ✓ Structured physical activity |
| ✓ Mindfulness-based therapies or relaxation training | ✓ Acceptance and commitment therapy |
| ✓ Cognitive behaviour therapy | ✓ Interpersonal therapy |
| ✓ Problem-solving therapy | |

Guidelines do include drug therapy as an option for depression or anxiety despite their being limited evidence for drug management of these issues in patients with cancer. This option is qualified by the fact it should only be considered for patients where access to the preferred therapies listed above are not available, the patient themselves prefers to be treated with drugs vs other types of therapy, or where other psychological or behavioural therapies have not helped.¹¹

Doctors are advised to use a stepped-care model when providing support for distress. They should choose the most effective and least resource intensive intervention based on the severity of the patient's symptoms.¹¹ Patients should participate in the decision about which therapy might work best for them. The exploration of patient preferences by the treating physician had a positive impact on the perceived fear of relapse and fear of progression through the use of empathy by as much as 20%.³¹ Other factors to consider are availability of services, accessibility, how likely it is the patient will follow through on recommendations, and cost.¹¹

There may be a lack of psychosocial support within cancer clinics, which may make following guidelines difficult. Healthcare providers cannot be expected to provide all the information and support patients need, especially in light of time limitations. However, patients must be directed to the appropriate resources (e.g., patient organisations; other hospital, or community-based resources). The cancer team can assess options available locally, as well as resources available online or through apps, to ensure there are many options for patients to try.

According to guidelines, all patients with cancer at minimum should be offered education regarding depression and anxiety. As well, factors that can reduce fear for patients include how well they understand information about their disease, symptom management, and care co-ordination.³⁸ Any information provided should be culturally appropriate and easily understandable. It can be written in a printed or digital version or be conveyed in a conversation.^{7,11}

Only 13-15% of patients with lymphoma said they received any information about distress (table 3). More patients received information about fear, but this was only slightly higher at 20%, leaving much room for improvement.

Guidelines also recommend patients receive some kind of counselling or behaviour therapy. Most patients responding to the LC 2022 GPS did not get this type of support. Only 31% of those with depression and 25% of those with anxiety were referred to a therapist or for counselling. The situation is even worse for those with fear, with only one on every ten patients being referred to this type of support.

Instead, those affected by depression and anxiety were likely to receive medication, even though guidelines recommend other therapies first due to the lack of evidence of the effectiveness of pharmacological therapies in patients with cancer. Patients in Asia-Pacific were less likely to be prescribed medication for anxiety (36%) compared to Europe and North America (both over 50%).

Patients who spoke to their doctor about their fear were most likely to get an empathetic response from the clinician (55-59%). While this is helpful to encourage an ongoing dialogue with patients, practical support is also needed to help patients cope. For fear of progression, about 30% of patients were advised to exercise or eat a healthy diet or were connected to a patient organisation or patient support group. For fear of relapse, a third of patients were told exercise would help.

Table 3. What type of help were you provided with?

©Lymphoma Coalition 2022 GPS	Depression (n=618)	Anxiety (n=906)	Fear of Progression (n=1,258)	Fear of Relapse (n=1,205)
Medication to help cope with this worry or concern	55%	43%	17%	13%
Further written or verbal information	13%	15%	20%	19%
The empathetic/ understanding approach of my doctor when I told him/ her	50%	53%	55%	59%
Patient organisation or patient support group	19%	24%	31%	24%
Referral to other sources of support (e.g., social worker, therapist, counselling)	31%	25%	12%	12%
Exercise	34%	35%	31%	34%
Participation of family/ caregiver in providing support	23%	31%	30%	24%
The empathetic/ understanding approach of my nurse when I told him/ her	16%	18%	14%	13%
Eating a healthy diet	25%	26%	30%	28%
Other	4%	4%	4%	5%

Research indicates that many patients (40%-50%) decline help for distress, and only a quarter accept referrals to, or use, mental health services (e.g. psycho-oncology)^{30,39,40} This reinforces the importance of good communication and information about the importance of emotional health and how it impacts overall medical health, as well as the need for follow-up to ensure any recommended intervention is being used.

In addition to recommended interventions, the ASCO, NCCN and ESMO guidelines also make a number of recommendations about follow-up.

- ✓ Psychological issues should be followed-up at regular intervals and at key transition points in treatment.^{2,7}
- ✓ Treating physicians should help troubleshoot any logistical or psychological problems that might interfere with patients accepting or following through with recommended treatment for distress.^{7,11}
- ✓ If drug therapy is used, the doctor should regularly assess the patient's symptom relief, any side effects, and how satisfied the patient is with this type of treatment and re-evaluate the treatment plan as needed.
- ✓ If distress symptoms don't improve after 8 weeks of treatment despite good adherence to the recommended therapy, the treatment plan should be re-evaluated.¹¹
- ✓ Clinicians should also liaise with psycho-oncology units or programmes to coordinate care.⁷

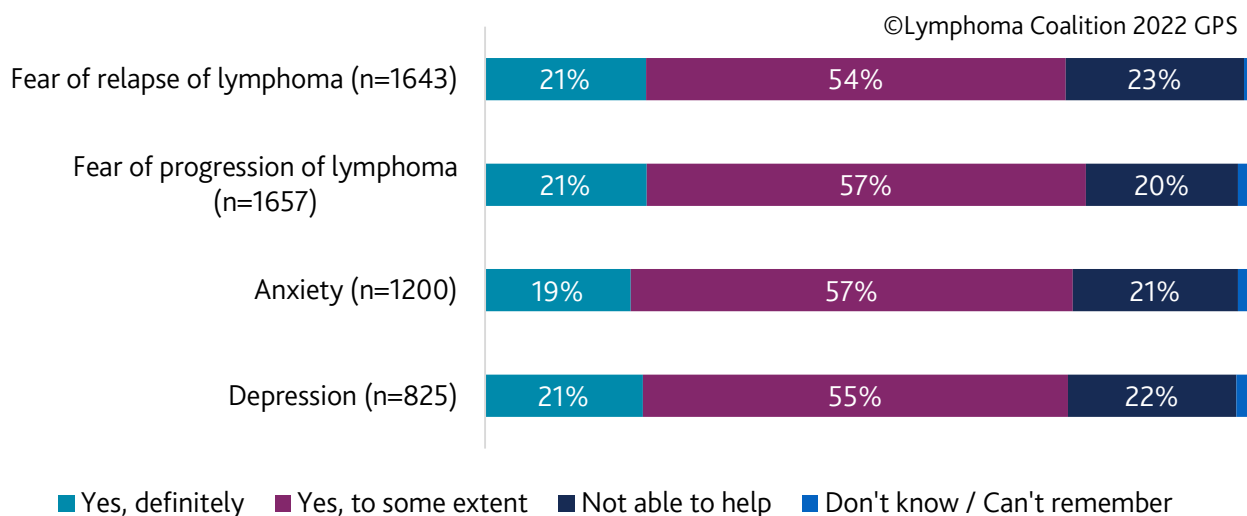
Yet, when asked, 64% of patients said their doctor never followed up on their worries and concerns.

Figure 16. Did your doctor follow up with you about the psychosocial issues you were experiencing?



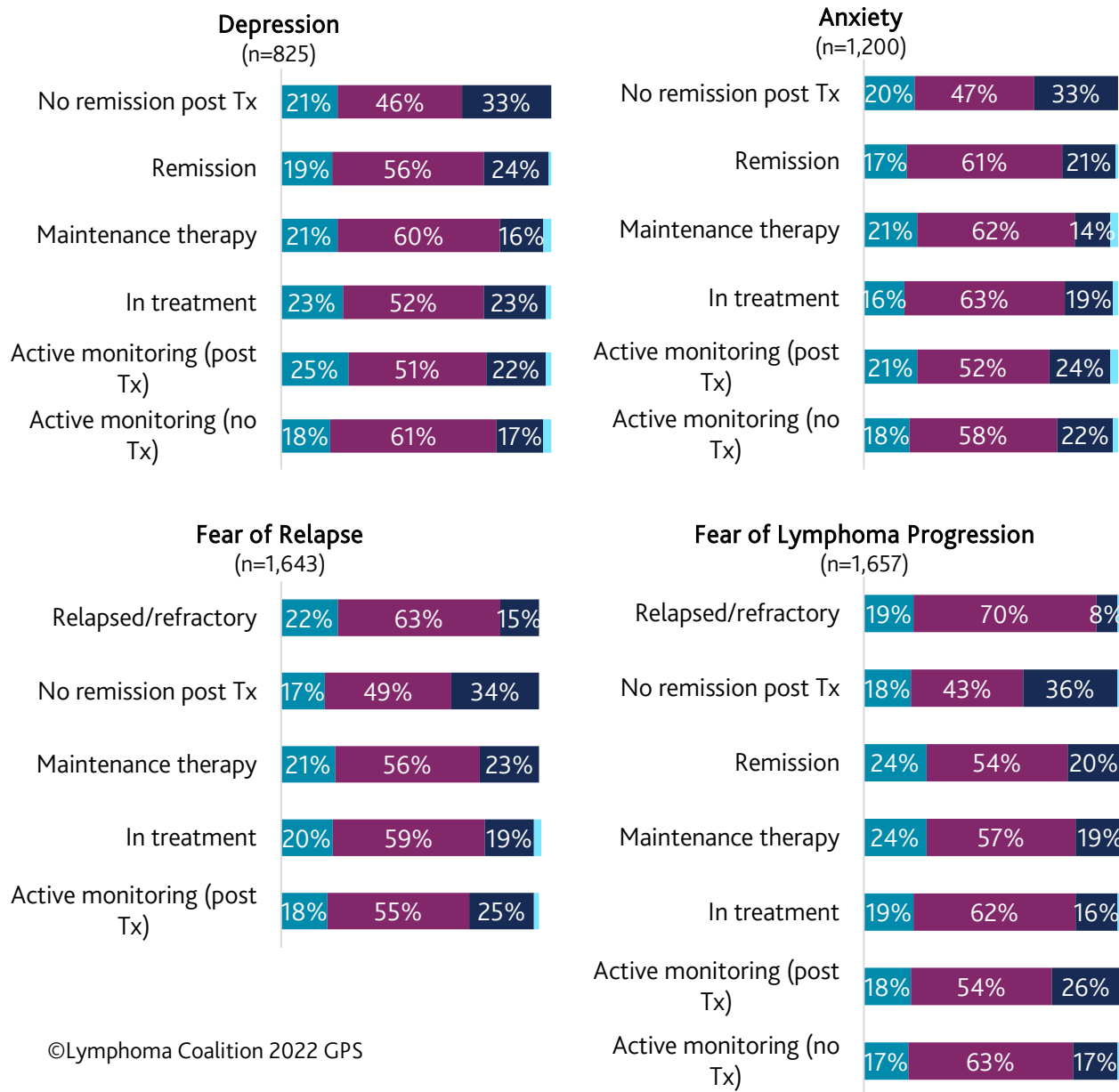
Patients were asked if the interventions provided or recommended by their doctor helped. Just over half of patients said they helped to some extent. About one in every five patients were not helped at all (Figure 17).

Figure 17. For each of the worries or concerns that you discussed with your doctor, please indicate how much, if at all, the doctor was able to help.



Patients who had finished treatment but whose disease was not in remission were more likely to say they were not helped.

Figure 18. For each of the worries or concerns that you discussed with your doctor, please indicate how much, if at all, the doctor was able to help. (Analysis by treatment status)



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■ Yes, definitely
 ■ Yes, to some extent
 ■ Not able to help
 ■ Don't know/can't remember

Follow-up is imperative to add into any care model, especially since most patients are saying the support provided has not fully helped.

Conclusions & Recommendations

There is much evidence pointing to the link between emotional health and disease outcomes. Most patients, regardless of their disease status, experience psychosocial issues related to their lymphoma diagnosis. This is a wide-reaching problem. Therefore, it is important to ensure patients' distress is identified, support provided, and followed up on regularly, from diagnosis through survivorship. Doctors play a critical role in recognising distress and signposting patients to appropriate care.

This review has identified care gaps that should be addressed to ensure patients have the tools and support needed to cope with their worries and concerns.

- **Patient-doctor communication:** Patients need to be encouraged to speak up about their emotional health. Clinicians should not minimise patients' worries and concerns and instead act on what is conveyed to them. Patients' emotional response to their cancer will ebb and flow throughout their experience. It is important that they be encouraged early on to speak about how they are feeling and for treating physicians to ensure a member of the medical team is checking in on this aspect of patient health at every visit.
- **Information provision:** Patients are not being provided with understandable information on the potential impact of their lymphoma diagnosis on their emotional health. At a minimum, all patients with lymphoma should be provided with verbal or written information on the different elements of distress they may experience, the symptoms they may feel, that this is a normal reaction to being diagnosed with cancer, and what kind of supports are available.
- **Application of distress guidelines:** Available guidelines should be followed to ensure patients' distress is recognised, appropriate screening happens, they are directed to relevant support, and any recommended intervention is followed up on to see if it is helping the patient cope.
- **Research into distress in patients with lymphoma:** More research is needed to identify factors of distress in patients affected by lymphoma to support clinicians in identifying them and providing interventions where necessary.⁶ This should include research on the incidence and prevalence of anxiety and depression in patients with lymphoma, and whether patients are experiencing mild, moderate, or severe symptoms, as well as their response to treatment.⁷ While distress is an issue for most patients, particular attention should be paid to patients younger than 50 years and females as these groups do show higher rates of distress.

There are steps that all members of a patient's cancer team - from haematologists and oncologists to nurses and allied health professionals - can take in order to effectively address psychological issues and better support patients.

- ✓ Ensure there is training available on distress guidelines and screening tools.
- ✓ Assess and screen for distress throughout the treatment trajectory as it is normal for there to be fluctuations.
- ✓ Provide all patients with understandable information about fear, anxiety, and depression. Examples are available at <https://lymphomacoalition.org/psychosocial-effects>.
- ✓ Normalize emotional health and encourage patients to discuss it.
- ✓ Warn patients and families that psychological issues may continue for many years into survivorship.
- ✓ Discuss behavioural strategies to help patients cope, both those available in the clinic and those in the community (including patient organisations; <https://lymphomacoalition.org/member-organisation>).
- ✓ Provide adequate information about signs and symptoms of a recurrence to help alleviate patients' distress.
- ✓ Avoid ordering extra tests to reassure an anxious patient (this can indicate to the patient that the physician is also anxious/concerned about the risk).
- ✓ Refer patients to appropriate support (psycho-oncology care, [patient organisations](#), etc.).

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