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INTRODUCTION

In early 2008, Lymphoma Coalition (LC) launched its first Global Patient Survey. Since then, LC has established the tradition of launching a global patient survey every two years. Through this survey, patient experience in lymphomas as well as the impact of treatment and care can be better understood, and LC and its global members can bring the patient voice forward.

The 2018 Global Patient Survey went live in January 2018 and closed in March 2018. It was prepared and made available in 19 languages through at least 65 patient organisations’ social media, the Lymphoma Hub, scientific partners, INTERLYMPH, and a small portion of the healthcare community. The Institute of Applied Biosciences at CERTH, The Centre for Research and Technology Hellas (INAB | CERTH) performed the analysis and wrote the report.

Overall, 6,631 participants took part from all over the world, demonstrating a marked increase from 4,129 participants in 2016.

METHODOLOGY

Survey Development and Launch

Lymphoma Coalition developed the 2018 survey based on the 2016 survey findings and questions, which were modified and expanded as needed. The resulting questions were first reviewed by the LC internal committee, and then sent out to the LC membership for review. The questions were subsequently reviewed by the Institute of Applied Biosciences at CERTH, (INAB | CERTH), which is an external scientific research body. Commentary and feedback from all parties on the English version was analysed, and appropriate revisions and edits were made. The finalised version of the survey contained 29 questions. It was translated into 19 languages by a third-party translation firm. As a final step, translated surveys were sent to LC membership for an opportunity to correct language errors. When the procedure was completed, the survey was launched on a third-party hosting portal. A patient and a caregiver version of the survey were made available. These two surveys were identical in questions and only differed in wording so that a caregiver could answer on behalf of a patient.

Survey Analysis

In order to perform the analysis, the surveys completed by patients and those completed by caregivers were merged. For example, responses to question 1 completed by patients (Q1 P) and responses to question 1 completed by caregivers (Q1 C) were considered together and analysed as a single group of respondents (Q1 P + Q1 C= Q1 total). The same method was followed for all remaining survey questions.

Descriptive statistics were performed for all questions of the survey. In addition, associations between factors and levels of statistical significance were examined through cross-tabulations and chi-square tests. The level of
significance used for interpretation of findings was p=0.05. All statistical analyses were performed with IBM SPSS v21.

Incomplete responses to the survey were eliminated to enable statistical analysis. For a full account of treating the raw data, performing checks, merging caregiver and patient survey responses as well as elimination of incomplete responses, please see Appendix 1 (page number 46).

**Goals for the 2018 Global Patient Survey**

The goal for the 2018 Global Patient Survey was to gather information that will assist LC and its members to begin to understand the patient experience, through examination of the following areas:

I. Patient Information, Guidance and Support  
II. Fear of Relapse  
III. Fatigue  
IV. Living with Side Effects  
V. Barriers and Impediments

More specifically, the 2018 Global Patient Survey would like to investigate:

I. Patient awareness and understanding, sources and level of information and support, support from healthcare professionals (HCPS), and the impact this has on the patient experience; how a patient ‘feels’ when they have the information and support they perceive they need;

II. Trends in patient ‘fear of relapse’ to ensure that patients are getting enough proactive psychosocial support during/after the treatment process;

III. A variety of fatigue-related issues and demographics, and determine how often patients are communicating these issues to their HCPS;

IV. Issues around physical/medical/psychosocial side effects; and

V. Availability and efficacy of services by country and by area (rural/urban), and determine if/how that affects the patient experience (communication, side effects, information-seeking, etc.)

By sharing this information with HCPS, government and the public, LC and its members will be better equipped to educate the lymphoma community and develop advocacy platforms for change, thereby having a positive effect on the lives of lymphoma patients everywhere. This report identifies specific results for the lymphoma population in Japan. With this information, LC and Group Nexus, the lymphoma patient support group in Japan, can be better equipped to serve the needs of their lymphoma community.
OVERVIEW

One hundred and seventy (170) respondents from Japan took part in the 2018 LC survey. Most Japanese respondents were aware of their subtype at the time of the survey. However, many found the different medical treatment options and side effect management difficult to understand. Two thirds of Japanese respondents wanted additional information and searched for information and support mostly immediately after their diagnosis. The primary sources of information for Japanese respondents were doctors and websites. If a respondent felt they had adequate information overall, it positively influenced such feelings as confidence in determining the trustworthiness of information about their health condition and treatment choices. It also positively impacted respondent’s communication with the doctor; for example, feeling like they had the right to take the doctor’s time to discuss their concerns.

Overall, fatigue and hair loss were the most frequently reported physical conditions. The most commonly reported medical issues were numbness and neutropenia both during and after treatment. Concerns about body image/physical appearance changes were the most commonly reported psychosocial issues during treatment, while fear of relapse was very common after treatment. In their totality, medical issues, physical conditions and psychosocial issues experienced were diverse and lasted for various lengths of time after treatment.

As a result of their lymphoma, the majority of Japanese respondents had experienced changes in their lifestyle and about half had experienced changes in their independence. Respondents’ reports of fear of relapse peaked between 2 and 5 years after treatment, but some also reported it at 8+ years after treatment. Fear of relapse was associated with feelings of anxiety, depression and isolation, which were rarely discussed with the doctor. Respondents’ reports of fatigue peaked immediately following treatment as well as 3-5 years following treatment, but some also reported experiencing fatigue for 8+ years. Fatigue affected respondents’ independence, but more so their lifestyle, with general activity suffering the largest impact. Japanese respondents commonly reported that financials constituted a barrier to treatment, followed by wait time to treatment that was longer than necessary. There were barriers found to be associated with respondents’ area of residence. For example, access to treatment centre/prohibitive travel was the most frequently reported barrier for respondents who resided in suburban areas compared to rural or urban areas. Moreover, availability of the appropriate specialty physician locally and wait time to treatment constituted barriers for respondents in rural areas. Respondents’ interest in services included: credible websites, downloadable materials, treatment information, and live education sessions. Support services most frequently reported to be unavailable in Japan were: social workers, spiritual support, and complementary therapist services. When respondents were asked to rate service types that they had already used, they specified that patient organisations/support groups and dietician/nutritionist services were the services that they found to be most helpful.
SURVEY RESULTS

I) Demographics

A total of 170 individuals from Japan answered this year’s Global Patient Survey. Of these, 138 (81%) were patients diagnosed with a lymphoma and 32 (19%) were respondents answering on behalf of a patient. From this point forward, both groups will be considered as one and will be referred to as ‘respondents’.

Respondents’ Demographic Profile

119 (70%) of the respondents said they had never participated in the Global Patient Survey before, while of the 51 (30%) who said they had, some had participated in more than one year so direct correlations could not be made for trending analysis.

48% were males, and 52% were females.

77% of the respondents were 40-69 years old.

More specifically:
- 18-29 (6%)
- 30-39 (7%)
- 40-59 (44%)
- 60-69 (33%)
- 70+ (10%)

Regarding the area of residence:
- 45% lived in an urban area
- 21% lived in a suburban area
- 34% lived in a rural area

Responses varied with regards to the level of school completed/highest degree; however, most of the respondents had received some secondary training. In more detail, respondents had completed/acquired:

- Pre-secondary school: 2%
- Secondary school diploma or equivalent: 16%
- Some college/university, no diploma/degree: 19%
- College/University diploma/degree: 50%
- Trade/technical/vocational training: 5%
- Master’s degree: 7%
• Professional degree: 1%

Diagnosis included the following lymphoma subtypes (Table 1) (Figure 1):

Table 1. Distribution of lymphoma respondents in Japan.

<table>
<thead>
<tr>
<th>Lymphoma Subtype</th>
<th>% of Lymphoma Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Follicular</td>
<td>40</td>
</tr>
<tr>
<td>DLBCL if not told what specific type</td>
<td>23</td>
</tr>
<tr>
<td>DLBCL GCB type</td>
<td>2</td>
</tr>
<tr>
<td>DLBCL ABC type</td>
<td>1</td>
</tr>
<tr>
<td>Extra nodal killer T cell</td>
<td>2</td>
</tr>
<tr>
<td>Hodgkin</td>
<td>6</td>
</tr>
<tr>
<td>MALT/MZ</td>
<td>6</td>
</tr>
<tr>
<td>Mantle cell</td>
<td>5</td>
</tr>
<tr>
<td>Peripheral T-cell</td>
<td>4</td>
</tr>
<tr>
<td>Other aggressive lymphomas</td>
<td>2</td>
</tr>
<tr>
<td>Transformed</td>
<td>2</td>
</tr>
<tr>
<td>Waldenstrom’s Macroglobulinemia</td>
<td>2</td>
</tr>
<tr>
<td>Other indolent lymphomas</td>
<td>1</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
</tr>
<tr>
<td>Burkitt’s</td>
<td>1</td>
</tr>
<tr>
<td>Cutaneous</td>
<td>1</td>
</tr>
<tr>
<td>CLL/SLL</td>
<td>1</td>
</tr>
</tbody>
</table>

Copyright © 2018 Lymphoma Coalition. All rights reserved.
Figure 1. Distribution of lymphoma respondents in Japan.
Abbreviations: CLL, Chronic Lymphocytic Leukaemia; SLL, Small Lymphocytic Lymphoma; DLBCL, Diffuse Large B-cell Lymphoma; GCB, Germinal Centre B-cell; ABC, Activated B-cell

DLBCL lymphoma cases included patients with a DLBCL diagnosis who were not aware of their specific type, and patients belonging to the Germinal Centre (GCB) and Activated B-cell (ABC) DLBCL subtypes. All subtype analysis concerning respondents with a DLBCL diagnosis will refer to those who have not been told their specific subtype as well as those belonging to the Germinal Centre (GCB) or Activated B-cell (ABC) DLBCL subtypes as one group (DLBCL).

Respondents reported their year of diagnosis as:

- 1996-2002: 5%
- 2003-2009: 24%
- 2010-2016: 54%
- 2017: 16%
- I don’t know: 1%
The stage that best described where the respondent was in their experience:

- 5% were newly diagnosed
- 9% had been diagnosed and were in treatment
- 6% had been diagnosed and have been told treatment is not yet needed
- 14% were in remission and have been treatment free for 2 years or less
- 14% were in remission and have been treatment free for 2 to 5 years
- 15% were in remission and have been treatment free for more than 5 years
- 7% had relapsed for the first time and were in treatment
- 8% had relapsed more than 2 times and were in remission
- 6% had relapsed more than 2 times and were in treatment
- 14% had finished treatment and were in maintenance therapy
- 2% had transformed
II) Patient Information, Guidance and Support

LC Objectives:

LC has anecdotal and research-backed insight that the success of the patient may lie in having the right information at the right time. A patient may feel differently depending on how ‘informed’ they feel, and this can translate across many other aspects of their experience (i.e. information/support seeking, communication, side effects). In the LC recent White Paper “The Knowledge Age: ‘Better’ Outcomes for the ‘Informed Patient’?”, confidence was a key patient quality behind patients reporting better overall healthcare experiences. We would like to further explore this idea looking at the results from the survey.

Key Findings:

Most Japanese respondents were aware of their subtype at the time of the survey. However, many found the different medical treatment options and side effect management difficult to understand. Two thirds of Japanese respondents wanted additional information and searched for information and support mostly immediately after their diagnosis. The primary sources of information for Japanese respondents were doctors and websites. Respondents who considered themselves to be adequately informed wanted to overcome the disease and felt in control most days, they also had good conversations with their doctors. Respondents who were somewhat adequately and inadequately informed wanted to overcome the disease but felt in control and had good conversations with their doctors to a lesser extent. Adequately informed respondents were confident they could determine if they needed medical care or could handle a health problem on their own, they were also confident in their ability to determine the trustworthiness of information about their health condition and treatment choices. Somewhat adequately informed respondents felt less confident in the aforementioned areas, and inadequately informed respondents never felt confident in these areas in 41% and 50% of cases respectively. Moreover, compared to respondents with somewhat adequate/inadequate information, respondents with adequate information sought clarification on things they did not understand more frequently, felt more confident voicing their concerns to their doctors, and felt that they had the right to take the doctor’s time to discuss their concerns. Most Japanese respondents raised questions about side effects during discussions with their doctor and felt that it helped. Respondents’ interest in services included credible websites, downloadable materials, treatment information, and live education sessions.

Most of the respondents (85%) were made aware of their lymphoma subtype during their initial diagnosis, whereas 14% were not informed and 1% were not sure.

Next, we asked participants to rate on a scale of 1-5 (5 being the highest) their understanding of (1) their diagnosis, (2) the characteristics of their particular subtype, (3) the different medical options, (4) initial treatment if started right away, (5) the potential side effects of treatment options, (6) side effect management, (7) the process and stages of their care and (8) active surveillance (‘watch and wait’), if applicable (Table 2).
Interestingly, what respondents in Japan had the most difficulty understanding concerned side effect management and different medical treatment options (30% each) (responses 1+2).

**Table 2.** Respondents’ understanding (1 lowest, 5 highest) after their initial visit to the doctor.

<table>
<thead>
<tr>
<th>Issues Around Diagnosis and Care</th>
<th>Respondents’ Level of Understanding</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 (%)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>10</td>
</tr>
<tr>
<td>Characteristics of the particular subtype</td>
<td>14</td>
</tr>
<tr>
<td>Different medical treatment options</td>
<td>16</td>
</tr>
<tr>
<td>Initial treatment if started right away</td>
<td>8</td>
</tr>
<tr>
<td>Potential side effects of treatment options</td>
<td>7</td>
</tr>
<tr>
<td>Side effect management</td>
<td>15</td>
</tr>
<tr>
<td>Process and stages of care</td>
<td>8</td>
</tr>
<tr>
<td>Active surveillance ('watch and wait'), if applicable</td>
<td>5</td>
</tr>
</tbody>
</table>

When asked if they would have liked to receive additional medical or associated support information at their initial diagnosis meeting with the doctor:

- 65% would like to receive additional information
- 15% felt overwhelmed and did not want more information as it was too much to take in at the time
- 14% received enough information and,
- 6% did not want additional information.

Respondents were most active in seeking information immediately upon diagnosis (65%) and 1-3 months after diagnosis (20%). Similarly, they were most active in seeking support immediately upon diagnosis (48%) and 1-3 months after the diagnosis (27%) (Table 3).

**Table 3.** Respondents’ information and support seeking at different time points.

<table>
<thead>
<tr>
<th>Time Points</th>
<th>Information (%) of Respondents</th>
<th>Support (%) of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediately upon diagnosis</td>
<td>65</td>
<td>48</td>
</tr>
<tr>
<td>1-3 months</td>
<td>20</td>
<td>27</td>
</tr>
<tr>
<td>3-6 months</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>6 months-year</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>1 year-onwards</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Never</td>
<td>2</td>
<td>5</td>
</tr>
</tbody>
</table>

For those who never sought additional information or support, they reported reasons as follows:
49% felt they had the support they needed
17% felt like they had the level/type of information they needed
17% did not want support
17% asked someone (friend, spouse, caregiver etc.) to seek information for them

When asked what level of information they felt they had overall, 30% of respondents felt they had received adequate information, 51% somewhat adequate information and 19% inadequate information. Respondents’ associated feelings according to their perceived level of information, adequate, somewhat adequate and inadequate respectively, can be seen in Tables 4, 5, 6 below.

Table 4. Feelings experienced by respondents with an adequate information level.

<table>
<thead>
<tr>
<th>Feelings Experienced with an Adequate Information Level</th>
<th>Most days</th>
<th>Sometimes</th>
<th>Never</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>In control</td>
<td>50</td>
<td>46</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>Out of control</td>
<td>7</td>
<td>46</td>
<td>26</td>
<td>21</td>
</tr>
<tr>
<td>Wanted to get into bed and hide</td>
<td>9</td>
<td>13</td>
<td>57</td>
<td>21</td>
</tr>
<tr>
<td>Wanted to overcome this disease</td>
<td>71</td>
<td>18</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Overall fearful</td>
<td>29</td>
<td>55</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Fearful for the future</td>
<td>31</td>
<td>60</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>At a loss</td>
<td>25</td>
<td>35</td>
<td>31</td>
<td>9</td>
</tr>
<tr>
<td>Confident</td>
<td>26</td>
<td>36</td>
<td>26</td>
<td>12</td>
</tr>
<tr>
<td>Felt mentally strong and capable</td>
<td>21</td>
<td>31</td>
<td>33</td>
<td>15</td>
</tr>
<tr>
<td>Felt physically strong and capable</td>
<td>15</td>
<td>39</td>
<td>30</td>
<td>16</td>
</tr>
<tr>
<td>Had good conversations with my doctor on my care and treatment plan</td>
<td>46</td>
<td>48</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>I was confident could determine if I needed to get medical care or if I could handle a health problem myself</td>
<td>39</td>
<td>41</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices</td>
<td>45</td>
<td>45</td>
<td>6</td>
<td>4</td>
</tr>
</tbody>
</table>

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### Table 5. Feelings experienced by respondents with a somewhat adequate information level.

<table>
<thead>
<tr>
<th>Feelings Experienced with a Somewhat Adequate Information Level</th>
<th>Associated Frequency of Feelings (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Most days</strong></td>
<td><strong>Sometimes</strong></td>
</tr>
<tr>
<td>In control</td>
<td>29</td>
</tr>
<tr>
<td>Out of control</td>
<td>10</td>
</tr>
<tr>
<td>Wanted to get into bed and hide</td>
<td>6</td>
</tr>
<tr>
<td>Wanted to overcome this disease</td>
<td>60</td>
</tr>
<tr>
<td>Overall fearful</td>
<td>34</td>
</tr>
<tr>
<td>Fearful for the future</td>
<td>42</td>
</tr>
<tr>
<td>At a loss</td>
<td>29</td>
</tr>
<tr>
<td>Confident</td>
<td>3</td>
</tr>
<tr>
<td>Felt mentally strong and capable</td>
<td>5</td>
</tr>
<tr>
<td>Felt physically strong and capable</td>
<td>2</td>
</tr>
<tr>
<td>Had good conversations with my doctor on my care and treatment plan</td>
<td>20</td>
</tr>
<tr>
<td>I was confident I could determine if I needed to get medical care or if I could handle a health problem myself</td>
<td>14</td>
</tr>
<tr>
<td>I was confident I could source and determine the trustworthiness of information about my health condition and treatment choices</td>
<td>12</td>
</tr>
</tbody>
</table>

### Table 6. Feelings experienced by respondents with an inadequate information level.

<table>
<thead>
<tr>
<th>Feelings Experienced with an Inadequate Information Level</th>
<th>Associated Frequency of Feelings (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Most days</strong></td>
<td><strong>Sometimes</strong></td>
</tr>
<tr>
<td>In control</td>
<td>7</td>
</tr>
<tr>
<td>Out of control</td>
<td>18</td>
</tr>
<tr>
<td>Wanted to get into bed and hide</td>
<td>24</td>
</tr>
<tr>
<td>Wanted to overcome this disease</td>
<td>47</td>
</tr>
<tr>
<td>Overall fearful</td>
<td>47</td>
</tr>
<tr>
<td>Fearful for the future</td>
<td>48</td>
</tr>
<tr>
<td>At a loss</td>
<td>45</td>
</tr>
<tr>
<td>Confident</td>
<td>3</td>
</tr>
<tr>
<td>Felt mentally strong and capable</td>
<td>4</td>
</tr>
<tr>
<td>Felt physically strong and capable</td>
<td>-</td>
</tr>
<tr>
<td>Had good conversations with my doctor on my care and treatment plan</td>
<td>11</td>
</tr>
<tr>
<td>I was confident I could determine if I needed to get medical care or if I could handle a health problem myself</td>
<td>-</td>
</tr>
</tbody>
</table>

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In analysing what respondents felt ‘most days’ according to their perceived information level, respondents who considered themselves to be adequately informed wanted to overcome the disease (71%), felt in control (50%) and had good conversations with their doctors (46%). Respondents who were somewhat adequately informed wanted to overcome the disease (60%) but felt in control in only 29% of cases and had good conversations with their doctors in only 20% of cases. They were also overall fearful (34%) and fearful about the future (42%). Inadequately informed respondents wanted to overcome the disease (47%) but felt in control in only 7% of cases and had good conversations with their doctors in only 11% of cases. They also felt overall fearful (47%), fearful about the future (48%) and at a loss (45%).

Moreover, adequately informed respondents were confident they could determine if they needed medical care or could handle a health problem on their own (39%), as well as determine the trustworthiness of information about their health condition and treatment choices (45%). Somewhat adequately informed respondents felt less confident in these same two areas (14% and 12%, respectively), and it is noteworthy that inadequately informed respondents never felt confident in these areas (41% and 50%, respectively). Additionally, respondents with inadequate information never felt confident generally (45%).

The perceived level of information seems to play a significant role with regards to the way respondents are feeling. Please see Figures 2a and 2b below, which provide a graphic comparison among adequately, somewhat adequately and inadequately informed respondents’ feelings.
Figure 2a. Feelings experienced by respondents with different perceived information levels ‘most days’.
Figure 2b. Feelings experienced by respondents with different perceived information levels ‘most days’.

During their patient experience, respondents’ primary sources for information were:

- Doctor 81%
- Websites 70%
- Patients organisations 45%
- Online blogs/social media 35%
- Nurse 24%
- Family/friends 19%
- Other 9%

Table 7 describes respondents’ communication with the doctor, and the impact that this communication may have had on the different issues that the respondents faced.
<table>
<thead>
<tr>
<th>Communication with Doctor on Topics Concerning the Patient Experience</th>
<th>Yes (%)</th>
<th>Somewhat (%)</th>
<th>No (%)</th>
<th>N/A (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you communicated any of your physical and/or medical issues to the doctor?</td>
<td>62</td>
<td>29</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Was the doctor able to help?</td>
<td>35</td>
<td>41</td>
<td>21</td>
<td>3</td>
</tr>
<tr>
<td>Have you communicated any of your emotional issues to the doctor?</td>
<td>30</td>
<td>24</td>
<td>40</td>
<td>6</td>
</tr>
<tr>
<td>Was the doctor able to help?</td>
<td>21</td>
<td>29</td>
<td>33</td>
<td>17</td>
</tr>
<tr>
<td>Did you bring forward questions about side effects?</td>
<td>79</td>
<td>14</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Was the doctor able to answer your questions?</td>
<td>61</td>
<td>27</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Was the doctor able to help you cope with your side effects by providing medication or other support?</td>
<td>59</td>
<td>27</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Did you seek clarification on things you did not understand?</td>
<td>36</td>
<td>44</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>Was the doctor able to answer your questions?</td>
<td>49</td>
<td>36</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Did you discuss your fear of relapse with your doctor?</td>
<td>32</td>
<td>26</td>
<td>33</td>
<td>9</td>
</tr>
<tr>
<td>Do you feel that it helped to alleviate the fear?</td>
<td>15</td>
<td>38</td>
<td>29</td>
<td>18</td>
</tr>
<tr>
<td>Did the doctor or nurse refer you to further support you were able to use?</td>
<td>30</td>
<td>24</td>
<td>41</td>
<td>5</td>
</tr>
<tr>
<td>Did you feel confident/comfortable voicing your concerns to your doctor?</td>
<td>31</td>
<td>39</td>
<td>27</td>
<td>3</td>
</tr>
<tr>
<td>If you experienced fatigue issues, did the doctor or nurse refer you to further support or information that you were able to use?</td>
<td>20</td>
<td>29</td>
<td>37</td>
<td>14</td>
</tr>
<tr>
<td>Did you feel you had the right to take the doctor’s time to discuss any of the above during your visits?</td>
<td>36</td>
<td>25</td>
<td>27</td>
<td>12</td>
</tr>
<tr>
<td>Did the doctor encourage discussion with you on any of the above?</td>
<td>40</td>
<td>29</td>
<td>29</td>
<td>2</td>
</tr>
</tbody>
</table>
In their totality respondents who felt, at the time of the survey, that they had adequate information also reported that they had a greater understanding of the following issues after the initial visit to the doctor, as reflected in Table 8.

Table 8. Respondents’ understanding after the initial visit with the doctor based on their perceived level of information.

<table>
<thead>
<tr>
<th>Topics Around Diagnosis and Care</th>
<th>Adequate Information (%)</th>
<th>Somewhat Adequate/Inadequate Information* (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>71</td>
<td>41</td>
</tr>
<tr>
<td>Characteristics of the particular subtype</td>
<td>63</td>
<td>35</td>
</tr>
<tr>
<td>Different medical treatment options</td>
<td>60</td>
<td>28</td>
</tr>
<tr>
<td>Initial treatment if started right away</td>
<td>72</td>
<td>45</td>
</tr>
<tr>
<td>Potential side effects of treatment options</td>
<td>70</td>
<td>45</td>
</tr>
<tr>
<td>Side effect management</td>
<td>54</td>
<td>32</td>
</tr>
<tr>
<td>Process and stages of care</td>
<td>69</td>
<td>40</td>
</tr>
<tr>
<td>Active surveillance ('watch and wait'), if applicable</td>
<td>74</td>
<td>39</td>
</tr>
</tbody>
</table>

* For the purpose of analysis, somewhat and inadequate information levels were grouped as a comparator against adequate information.

Figure 3 points to where respondents were looking for information; those who felt they had received adequate information did not differ significantly from those who felt they had inadequate (somewhat adequate/inadequate) information regarding their primary sources of information.
Interestingly, no associations could be inferred between perceived level of information and area of residence (Table 9).

Table 9. Respondents’ perceived level of information based on the area of residence.

<table>
<thead>
<tr>
<th>Area of Residence</th>
<th>Adequate (%)</th>
<th>Somewhat Adequate (%)</th>
<th>Inadequate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural</td>
<td>28</td>
<td>56</td>
<td>16</td>
</tr>
<tr>
<td>Urban</td>
<td>32</td>
<td>43</td>
<td>25</td>
</tr>
<tr>
<td>Suburban</td>
<td>31</td>
<td>57</td>
<td>12</td>
</tr>
</tbody>
</table>

Figure 3. Primary sources of information by respondents’ perceived level of information.
For the purpose of analysis, somewhat and inadequate information levels were grouped as a comparator against adequate information. Respondents with adequate information sought clarification on things they did not understand more frequently (62%) compared to those with perceived somewhat adequate/inadequate information (26%). Moreover, respondents with adequate information felt more confident voicing their concerns to their doctors (51%) compared to respondents with somewhat adequate/inadequate information (23%).

The impact of the perceived level of information on respondent-reported confidence was higher in respondents who felt they had adequate information. Of these, 26% felt confident most of the days versus 4% of those who felt they had received somewhat adequate/inadequate information.

Almost half (46%) of the respondents with adequate information felt that they had the right to take the doctor’s time to discuss their concerns as opposed to 32% of respondents with somewhat adequate/inadequate information.

When asked what barriers had been experienced in receiving lymphoma treatment, respondents who felt they had received somewhat adequate/inadequate information identified barriers more frequently compared to those who felt they had received an adequate level of information.

Interestingly, experiencing no barriers in receiving lymphoma treatment was the option most reported (36%) by those respondents with an adequate information level. Only 18% of the respondents with a somewhat adequate/inadequate level of information reported experiencing no barriers (Table 10).

Table 10. Barriers in receiving treatment based on the respondents’ perceived level of information.

<table>
<thead>
<tr>
<th>Barriers in Receiving Treatment</th>
<th>Perceived Level of Information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adequate Information (%</td>
</tr>
<tr>
<td></td>
<td>Somewhat Adequate/Inadequate Information* (%)</td>
</tr>
<tr>
<td>Financial</td>
<td>33</td>
</tr>
<tr>
<td>Access to treatment centre/prohibitive travel</td>
<td>12</td>
</tr>
<tr>
<td>Access to the most up to date treatment</td>
<td>-</td>
</tr>
<tr>
<td>Wait time was longer than necessary</td>
<td>24</td>
</tr>
<tr>
<td>Personal support</td>
<td>-</td>
</tr>
<tr>
<td>Specialty physician available locally</td>
<td>3</td>
</tr>
<tr>
<td>Could not give up caregiver role (child, parent, disabled person)</td>
<td>6</td>
</tr>
<tr>
<td>None</td>
<td>36</td>
</tr>
</tbody>
</table>

* For the purpose of analysis, somewhat and inadequate information levels were grouped as a comparator against adequate information.

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When asked about patient services, respondents showed the greatest interest in credible website links (65%) and reported less interest in phone-line support (16%) (Table 11).

Table 11. Respondents’ interest in different services.

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Interest of Total Respondent Population (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credible website links</td>
<td>65</td>
</tr>
<tr>
<td>Downloadable materials</td>
<td>59</td>
</tr>
<tr>
<td>Treatment information</td>
<td>57</td>
</tr>
<tr>
<td>Live education sessions</td>
<td>55</td>
</tr>
<tr>
<td>Information on patient organisation services</td>
<td>53</td>
</tr>
<tr>
<td>Patient organisation support</td>
<td>51</td>
</tr>
<tr>
<td>Hard copy materials</td>
<td>49</td>
</tr>
<tr>
<td>Clinical trial options</td>
<td>49</td>
</tr>
<tr>
<td>Professional physical support</td>
<td>47</td>
</tr>
<tr>
<td>Professional emotional support</td>
<td>39</td>
</tr>
<tr>
<td>Support in navigating the insurance system</td>
<td>39</td>
</tr>
<tr>
<td>Financial support</td>
<td>35</td>
</tr>
<tr>
<td>Complementary nutrition/fitness information</td>
<td>31</td>
</tr>
<tr>
<td>Fatigue support</td>
<td>31</td>
</tr>
<tr>
<td>Online chats</td>
<td>22</td>
</tr>
<tr>
<td>In person support groups</td>
<td>20</td>
</tr>
<tr>
<td>Phone-line support</td>
<td>16</td>
</tr>
</tbody>
</table>

When compared to the total respondent population, those who felt they had adequate information expressed interest in services in a different order. Their major interest focused on professional physical support (86%) followed by professional emotional support (78%) (Table 12).

Table 12. Interest in different services by respondents with perceived adequate information.

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Interest of Adequate Information Respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional physical support</td>
<td>86</td>
</tr>
<tr>
<td>Professional emotional support</td>
<td>78</td>
</tr>
<tr>
<td>Credible website links</td>
<td>65</td>
</tr>
<tr>
<td>Downloadable materials</td>
<td>59</td>
</tr>
<tr>
<td>Treatment information</td>
<td>57</td>
</tr>
<tr>
<td>Live education sessions</td>
<td>55</td>
</tr>
<tr>
<td>Information on patient organisation services</td>
<td>53</td>
</tr>
<tr>
<td>Patient organisation support</td>
<td>51</td>
</tr>
<tr>
<td>Hard copy materials</td>
<td>49</td>
</tr>
</tbody>
</table>
Interest in different patient services was also analysed by subtype. Subtype analysis was restricted only to lymphomas with more than 10 answers in this question to reach significant conclusions, this included only DLBCL and follicular lymphoma.

Respondents with a DLBCL diagnosis were more interested in treatment information (83%), information on patient organisation services (81%) and downloadable materials (79%).

Respondents with a follicular lymphoma diagnosis were more interested in credible website links (94%), treatment information (94%) and downloadable materials (94%) (Table 13).

<table>
<thead>
<tr>
<th>Service Type</th>
<th>DLBCL (%)</th>
<th>Follicular (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional physical support</td>
<td>78</td>
<td>35</td>
</tr>
<tr>
<td>Professional emotional support</td>
<td>66</td>
<td>69</td>
</tr>
<tr>
<td>Information on patient organisation services</td>
<td>81</td>
<td>88</td>
</tr>
<tr>
<td>Credible website links</td>
<td>74</td>
<td>94</td>
</tr>
<tr>
<td>Patient organisation support</td>
<td>69</td>
<td>87</td>
</tr>
<tr>
<td>Phone-line support</td>
<td>35</td>
<td>47</td>
</tr>
<tr>
<td>In person support groups</td>
<td>35</td>
<td>40</td>
</tr>
<tr>
<td>Online chats</td>
<td>34</td>
<td>35</td>
</tr>
<tr>
<td>Live education sessions</td>
<td>67</td>
<td>85</td>
</tr>
<tr>
<td>Hard copy materials</td>
<td>76</td>
<td>80</td>
</tr>
<tr>
<td>Downloadable materials</td>
<td>79</td>
<td>94</td>
</tr>
<tr>
<td>Financial support</td>
<td>52</td>
<td>66</td>
</tr>
<tr>
<td>Clinical trial options</td>
<td>76</td>
<td>84</td>
</tr>
<tr>
<td>Treatment information</td>
<td>83</td>
<td>94</td>
</tr>
<tr>
<td>Complementary nutrition/fitness information</td>
<td>68</td>
<td>61</td>
</tr>
<tr>
<td>Support in navigating the insurance system</td>
<td>69</td>
<td>68</td>
</tr>
<tr>
<td>Fatigue support</td>
<td>71</td>
<td>75</td>
</tr>
</tbody>
</table>
In considering different stages of the patient experience, respondents who reported being in remission and treatment free for 2 years or less were the most confident in voicing their concerns to the doctor (Table 14).

### Table 14. Confidence in voicing concerns to the doctor at different stages of the lymphoma experience.

<table>
<thead>
<tr>
<th>Stages</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (%)</td>
</tr>
<tr>
<td>Newly diagnosed*</td>
<td>33</td>
</tr>
<tr>
<td>Diagnosed and currently in treatment</td>
<td>18</td>
</tr>
<tr>
<td>Diagnosed and have been told that treatment is not yet needed*</td>
<td>-</td>
</tr>
<tr>
<td>In remission and treatment free for 2 years or less</td>
<td>47</td>
</tr>
<tr>
<td>In remission and treatment free for 2 to 5 years</td>
<td>38</td>
</tr>
<tr>
<td>In remission and treatment free for more than 5 years</td>
<td>29</td>
</tr>
<tr>
<td>Have relapsed for the first time and currently in treatment*</td>
<td>20</td>
</tr>
<tr>
<td>Have relapsed more than two times and in remission*</td>
<td>33</td>
</tr>
<tr>
<td>Have relapsed more than two times and currently in treatment*</td>
<td>29</td>
</tr>
<tr>
<td>Have finished treatment and currently in maintenance therapy</td>
<td>13</td>
</tr>
<tr>
<td>Have transformed*</td>
<td>67</td>
</tr>
</tbody>
</table>

*These percentages were not used for comparison due to the small number of individual respondents per category (fewer than 10)*
III) Fear of Relapse

LC Objectives:

The 2016 Global Patient Survey indicated that psychosocial conditions have continued to negatively impact patients, with the fear of relapse having the most profound effect occurring most particularly after treatment (87% of those who reported fear of relapse reported it as occurring after treatment). We will further investigate ‘fear of relapse’ to ensure that patients are getting enough proactive psychosocial support during and after treatment.

Key Findings:

Fear of relapse was experienced by respondents during treatment with levels rising significantly after treatment. Respondents’ reports of fear of relapse peaked around 2-5 years after treatment, and it was reported by some respondents to continue for 8+ years. Fear of relapse was associated with feelings of anxiety, depression and isolation. However, these feelings were rarely discussed with the doctor. Among respondents with fear of relapse, most felt they had somewhat adequate or inadequate information. Both during and after treatment, respondents experiencing fear of relapse commonly report doctors and websites as their primary sources of information followed by nurses. Interestingly, following treatment, respondents indicated using patient organisations more often.

Fear of relapse was a major issue for respondents as it was present during and after treatment, showing a remarkable increase from 36% during treatment to 74% after treatment. Fear of relapse lasted for various lengths of time. (See Table 24) (Figure 4).

Of those who experienced fear of relapse, 32% discussed and somewhat discussed (26%) this fear with their doctor. Only, 15% felt this helped and 38% felt it helped somewhat. However, 29% did not feel it helped alleviate the fear.
Figure 4. How long fear of relapse lasted amongst respondents.

In some cases, fear of relapse was accompanied with feelings of isolation, depression and anxiety either during treatment or after treatment (Tables 15 and 16) (Figures 5 and 6). Beside each feeling, respondents were asked to indicate if they had discussed it with their doctor. Respondents did not discuss their feelings of isolation, depression and anxiety as often as they felt them. Interestingly, even though most feelings were reported less frequently, they were still reported after the end of treatment.

Table 15. Feelings of isolation, depression and anxiety during treatment amongst respondents who experienced fear of relapse, and their discussion with the doctor.

<table>
<thead>
<tr>
<th>Feelings During Treatment</th>
<th>(%)</th>
<th>I Have Discussed It with My Doctor (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isolation</td>
<td>41</td>
<td>3</td>
</tr>
<tr>
<td>Depression</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>Anxiety</td>
<td>50</td>
<td>6</td>
</tr>
<tr>
<td>Fear of relapse</td>
<td>36</td>
<td>13</td>
</tr>
</tbody>
</table>

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Figure 5. Feelings of isolation, depression and anxiety during treatment amongst respondents who experienced fear of relapse, and their discussion with the doctor.

Table 16. Feelings of isolation, depression and anxiety after treatment amongst respondents who experienced fear of relapse, and their discussion with the doctor.

<table>
<thead>
<tr>
<th>Feelings After Treatment</th>
<th>(%)</th>
<th>I Have Discussed It with My Doctor (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isolation</td>
<td>26</td>
<td>4</td>
</tr>
<tr>
<td>Depression</td>
<td>17</td>
<td>4</td>
</tr>
<tr>
<td>Anxiety</td>
<td>33</td>
<td>8</td>
</tr>
<tr>
<td>Fear of relapse</td>
<td>74</td>
<td>13</td>
</tr>
</tbody>
</table>

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Figure 6. Feelings of isolation, depression and anxiety after treatment amongst respondents who experienced fear of relapse, and their discussion with the doctor.

Among those with fear of relapse 9% had adequate information, 69% had somewhat adequate and 22% had inadequate information.

Sources of information for those who experienced fear of relapse during treatment were as follows: doctors 95%, nurses 40%, websites 68%, online blogs 38%, family/friends 22% and patient organisations 35%. Those who experience fear of relapse after treatment used sources as follows: doctors 79%, nurses 28%, websites 75%, online blogs 50%, family/friends 19%, and patient organisations 56%.

Moreover, for those who experienced fear of relapse, we tried to identify possible differences with regards to the information sources they used depending on the level of information they felt they had. When directly examining the use of information sources by adequately informed respondents, it seems that respondents with fear of relapse during treatment rely more on doctors (67%), patient organisations (33%) as well as online research, while after treatment they rely on doctors (83%) and patient organisations (67%) more.
IV) Fatigue

LC Objectives:

The 2016 Global Patient Survey indicated that physical conditions continue to have a negative impact on patients, with fatigue still the pre-eminent condition reported in most countries. Despite its prominence, fatigue remains largely undiscussed across the healthcare community. We would like to further investigate a variety of fatigue-related issues and demographics and determine how often patients are communicating these issues to their healthcare providers.

Key Findings:

Fatigue was the most frequent physical condition experienced by respondents. Respondents’ reports of fatigue peaked immediately following treatment as well as 3-5 years following treatment, but some respondents reported experiencing fatigue for 8+ years. Fatigue affected respondents’ independence but more so their lifestyle, with general activity suffering the largest impact. Interestingly, respondents who reported fatigue showed a higher percentage of fear of relapse after the end of treatment. In terms of psychosocial issues, due to fatigue, respondents mostly reported experiencing concerns about body image/physical appearance changes and difficulties on the job or at school during treatment, and fear of relapse along with difficulties on the job or at school after treatment.

Fatigue was the most frequent physical condition affecting the respondents’ sense of wellbeing since diagnosis. It was reported by 67% of respondents and it lasted for various lengths of time (Table 19) (Figure 7).
Figure 7. How long fatigue lasted amongst respondents.

Those who experienced fatigue reported that as a result of it, they have also experienced changes in several areas of life (Figure 8). Respondents mentioned that life has changed (35%) or moderately changed (63%), or that they sleep well but the fatigue does not go away (52%). Only the minority reported that fatigue is constant however it has not changed their daily activities (16%).
Figure 8. Life changes brought on by fatigue and their discussion with the doctor.

Amongst the respondents who reported fatigue, some also reported that their lifestyle was affected (71%) as was their independence (37%), and only in 26% of these cases did the doctor refer them for support.

Fatigue was associated with other issues as well (Table 17). Interestingly, respondents who reported fatigue showed a higher percentage of fear of relapse after the end of treatment (50%) than during treatment (18%).
Table 17. Psychosocial issues affecting wellbeing during and after treatment amongst respondents with fatigue.

<table>
<thead>
<tr>
<th>Psychosocial Issues Affecting Wellbeing During and After Treatment Amongst Respondents with Fatigue</th>
<th>During (%)</th>
<th>After (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in relationships with loved ones, friends or co-workers/social life</td>
<td>24</td>
<td>23</td>
</tr>
<tr>
<td>Stress related to financial issues</td>
<td>22</td>
<td>16</td>
</tr>
<tr>
<td>Loss of self-esteem</td>
<td>24</td>
<td>19</td>
</tr>
<tr>
<td>Concerns about body image/physical appearance changes</td>
<td>27</td>
<td>14</td>
</tr>
<tr>
<td>Loss/reduction in employment</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>Isolation</td>
<td>19</td>
<td>14</td>
</tr>
<tr>
<td>Depression</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>Anxiety</td>
<td>22</td>
<td>17</td>
</tr>
<tr>
<td>Fear of relapse</td>
<td>18</td>
<td>50</td>
</tr>
<tr>
<td>Difficulty on the job or in school</td>
<td>25</td>
<td>29</td>
</tr>
<tr>
<td>Problems getting health or life insurance coverage</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td>Difficulty working effectively through the healthcare system</td>
<td>8</td>
<td>14</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

V) Living with Side Effects

LC Objectives:

It is important that LC continue its work investigating the issues around physical, medical, and psychosocial side effects. This includes exploring side effect management plans and further examination of longer-term medical issues reported by respondents. There appears to be a need for education and further examination of the relapsed stage (among all other stages) of the patient experience, as there seems to be an increased level of psychosocial issues in this group of patients. A discussion may need to be opened about what is an acceptable side effect, both short- and long-term. There may be an opportunity in this respect for LC to help make a difference at the clinical trials development stage.

Key Findings:

Overall, fatigue and hair loss were the most frequently reported physical conditions by respondents. The most commonly reported medical issues were numbness and neutropenia both during and after treatment. Concerns about body image/physical appearance changes were the most commonly reported psychosocial issues during treatment, while fear of relapse was very common after treatment. Moreover, respondents’ reports of fear of relapse peaked between 2 and 5 years after treatment, but some also reported it at 8+ years after treatment. In their totality, medical issues, physical conditions and psychosocial issues experienced were diverse and lasted for various lengths of time after treatment. As a result of their lymphoma, the majority of Japanese respondents had experienced changes in their lifestyle and about half had experienced changes in their independence.
Respondents communicated medical issues to the doctor more frequently than they did emotional issues. Respondents raised the topic of treatment side effects in conversation with their doctor, and the majority found ways to be supported.

Looking at the entire sample, there is a range of physical conditions affecting the wellbeing of respondents. A significant percentage of patients are facing fatigue (67%) and hair loss (62%) (Table 18). Respondents have reported these physical conditions to last for various lengths of time.

**Table 18.** Physical conditions affecting wellbeing since diagnosis.

<table>
<thead>
<tr>
<th>Physical Conditions</th>
<th>Percentage of Respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>67</td>
</tr>
<tr>
<td>Hair loss</td>
<td>62</td>
</tr>
<tr>
<td>Changes in taste and smell</td>
<td>50</td>
</tr>
<tr>
<td>Muscle weakness</td>
<td>45</td>
</tr>
<tr>
<td>Bowel changes</td>
<td>40</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>40</td>
</tr>
<tr>
<td>Problems fighting infections</td>
<td>40</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>36</td>
</tr>
<tr>
<td>Changes in sleep patterns</td>
<td>34</td>
</tr>
<tr>
<td>Mucositis/mouth ulcers</td>
<td>33</td>
</tr>
<tr>
<td>Skin reactions</td>
<td>30</td>
</tr>
<tr>
<td>Weight loss</td>
<td>30</td>
</tr>
<tr>
<td>Trouble concentrating</td>
<td>25</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>25</td>
</tr>
<tr>
<td>Itching</td>
<td>18</td>
</tr>
<tr>
<td>Problems concentrating</td>
<td>17</td>
</tr>
<tr>
<td>Night sweats</td>
<td>16</td>
</tr>
<tr>
<td>Weight change</td>
<td>15</td>
</tr>
<tr>
<td>Swelling of arms and legs</td>
<td>15</td>
</tr>
<tr>
<td>Change in sexual function</td>
<td>11</td>
</tr>
<tr>
<td>Memory loss</td>
<td>7</td>
</tr>
<tr>
<td>Fluid retention</td>
<td>5</td>
</tr>
<tr>
<td>Loss of fertility</td>
<td>5</td>
</tr>
<tr>
<td>Burning</td>
<td>4</td>
</tr>
<tr>
<td>Cramps</td>
<td>2</td>
</tr>
<tr>
<td>Viral reactivations</td>
<td>3</td>
</tr>
<tr>
<td>Incontinence</td>
<td>1</td>
</tr>
<tr>
<td>I had no changes in my physical condition whatsoever</td>
<td>7</td>
</tr>
</tbody>
</table>
### Table 19. How long did these physical conditions affecting wellbeing last?

<table>
<thead>
<tr>
<th>Physical Conditions</th>
<th>Less than 1y (%)</th>
<th>1y (%)</th>
<th>2y (%)</th>
<th>3-5y (%)</th>
<th>6-8y (%)</th>
<th>8+y (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>38</td>
<td>14</td>
<td>12</td>
<td>22</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Hair loss</td>
<td>67</td>
<td>24</td>
<td>5</td>
<td>3</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Muscle weakness</td>
<td>41</td>
<td>21</td>
<td>15</td>
<td>13</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Trouble concentrating</td>
<td>52</td>
<td>17</td>
<td>13</td>
<td>11</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Changes in sleep patterns</td>
<td>55</td>
<td>12</td>
<td>15</td>
<td>10</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Changes in taste and smell</td>
<td>69</td>
<td>14</td>
<td>5</td>
<td>7</td>
<td>-</td>
<td>5</td>
</tr>
<tr>
<td>Bowel changes</td>
<td>68</td>
<td>9</td>
<td>11</td>
<td>6</td>
<td>-</td>
<td>6</td>
</tr>
<tr>
<td>Aching joints</td>
<td>60</td>
<td>11</td>
<td>15</td>
<td>9</td>
<td>-</td>
<td>5</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>85</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Problems fighting infections</td>
<td>51</td>
<td>13</td>
<td>9</td>
<td>14</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Memory loss</td>
<td>79</td>
<td>5</td>
<td>9</td>
<td>5</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Skin reactions</td>
<td>57</td>
<td>19</td>
<td>10</td>
<td>9</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Mucositis/mouth ulcers</td>
<td>79</td>
<td>7</td>
<td>7</td>
<td>6</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>82</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Change in sexual function</td>
<td>60</td>
<td>3</td>
<td>14</td>
<td>12</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Weight loss</td>
<td>75</td>
<td>6</td>
<td>6</td>
<td>9</td>
<td>-</td>
<td>4</td>
</tr>
<tr>
<td>Fluid retention</td>
<td>94</td>
<td>2</td>
<td>-</td>
<td>4</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Weight change</td>
<td>66</td>
<td>4</td>
<td>11</td>
<td>11</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Loss of fertility</td>
<td>81</td>
<td>-</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Swelling of arms and legs</td>
<td>74</td>
<td>3</td>
<td>9</td>
<td>12</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Itching</td>
<td>70</td>
<td>7</td>
<td>8</td>
<td>8</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Burning</td>
<td>69</td>
<td>8</td>
<td>14</td>
<td>8</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Incontinence</td>
<td>100</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Cramps</td>
<td>92</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>66</td>
<td>11</td>
<td>9</td>
<td>9</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Viral reactivations</td>
<td>88</td>
<td>5</td>
<td>4</td>
<td>-</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Night sweats</td>
<td>84</td>
<td>4</td>
<td>7</td>
<td>5</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Problems concentrating</td>
<td>60</td>
<td>9</td>
<td>15</td>
<td>11</td>
<td>-</td>
<td>5</td>
</tr>
</tbody>
</table>

*Relative frequencies are displayed, and the percentages were calculated per issue (rows), and then compared within different time points (columns) to show the length of time each issue impacts patients reporting this specific concern. Each row totals 100%. Refer to Table 18 to see overall issue prevalence.

Focusing on different lymphoma subtypes, it was evident that different physical conditions were more prominent in different lymphomas (Table 20). Subtype analysis was restricted only to lymphomas with more than 10 answers in this question to reach significant conclusions. For respondents with a DLBCL diagnosis (not told the specific subtype, GCB and ABC subtype) the most frequently reported issue was hair loss (80%) followed...
by fatigue (57%). For respondents with a follicular lymphoma diagnosis, the most frequently reported issue was fatigue (72%) followed by hair loss (54%).

**Table 20. Physical conditions amongst respondents with DLBCL and Follicular Lymphoma.**

<table>
<thead>
<tr>
<th>Physical Conditions</th>
<th>DLBCL (%)</th>
<th>Follicular (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>57</td>
<td>72</td>
</tr>
<tr>
<td>Hair loss</td>
<td>80</td>
<td>54</td>
</tr>
<tr>
<td>Muscle weakness</td>
<td>50</td>
<td>44</td>
</tr>
<tr>
<td>Trouble concentrating</td>
<td>32</td>
<td>24</td>
</tr>
<tr>
<td>Changes in sleep patterns</td>
<td>34</td>
<td>40</td>
</tr>
<tr>
<td>Changes in taste and smell</td>
<td>54</td>
<td>53</td>
</tr>
<tr>
<td>Bowel changes</td>
<td>48</td>
<td>37</td>
</tr>
<tr>
<td>Aching joints</td>
<td>23</td>
<td>18</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>41</td>
<td>37</td>
</tr>
<tr>
<td>Problems fighting infections</td>
<td>45</td>
<td>40</td>
</tr>
<tr>
<td>Memory loss</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>Skin reactions</td>
<td>32</td>
<td>31</td>
</tr>
<tr>
<td>Mucositis/mouth ulcers</td>
<td>39</td>
<td>25</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>39</td>
<td>38</td>
</tr>
<tr>
<td>Change in sexual function</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Weight loss</td>
<td>36</td>
<td>25</td>
</tr>
<tr>
<td>Fluid retention</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Weight change</td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td>Loss of fertility</td>
<td>9</td>
<td>-</td>
</tr>
<tr>
<td>Swelling of arms and legs</td>
<td>23</td>
<td>7</td>
</tr>
<tr>
<td>Itching</td>
<td>14</td>
<td>22</td>
</tr>
<tr>
<td>Burning</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Incontinence</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td>Cramps</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>36</td>
<td>18</td>
</tr>
<tr>
<td>Viral reactivations</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Night sweats</td>
<td>5</td>
<td>21</td>
</tr>
<tr>
<td>Problems concentrating</td>
<td>20</td>
<td>16</td>
</tr>
<tr>
<td>I had no changes in my physical condition whatsoever</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
<td>10</td>
</tr>
</tbody>
</table>

Many of the medical issues that respondents had to cope with during their treatment were less reported after the end of treatment, whereas some others remained on the same levels. The most commonly reported medical issues both during and after treatment were numbness and neutropenia (Table 21).
Table 21. Medical issues amongst respondents during and after treatment.

<table>
<thead>
<tr>
<th>Medical Issues</th>
<th>During (%)</th>
<th>After (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart-related issues</td>
<td>19</td>
<td>16</td>
</tr>
<tr>
<td>Stomach-related issues</td>
<td>31</td>
<td>8</td>
</tr>
<tr>
<td>Issues with other organs</td>
<td>22</td>
<td>18</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>26</td>
<td>3</td>
</tr>
<tr>
<td>Numbness</td>
<td>53</td>
<td>47</td>
</tr>
<tr>
<td>Neutropenia</td>
<td>52</td>
<td>21</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Any other blood condition</td>
<td>27</td>
<td>17</td>
</tr>
<tr>
<td>Secondary cancer</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Diabetes</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Tingling</td>
<td>14</td>
<td>16</td>
</tr>
<tr>
<td>Eyesight issues</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Enlarged lymph nodes</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Pain</td>
<td>21</td>
<td>15</td>
</tr>
<tr>
<td>Headaches</td>
<td>17</td>
<td>11</td>
</tr>
<tr>
<td>Bleeding</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Thrombosis</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>I do not have any other medical issues</td>
<td>12</td>
<td>17</td>
</tr>
</tbody>
</table>

Table 22. How long medical issues lasted after treatment.

<table>
<thead>
<tr>
<th>Medical Issues</th>
<th>Less than 1y (%)</th>
<th>1y (%)</th>
<th>2y (%)</th>
<th>3-5y (%)</th>
<th>6-8y (%)</th>
<th>8+y (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart-related issues</td>
<td>52</td>
<td>23</td>
<td>13</td>
<td>7</td>
<td>-</td>
<td>7</td>
</tr>
<tr>
<td>Stomach-related issues</td>
<td>67</td>
<td>10</td>
<td>3</td>
<td>13</td>
<td>-</td>
<td>7</td>
</tr>
<tr>
<td>Issues with other organs</td>
<td>48</td>
<td>19</td>
<td>7</td>
<td>19</td>
<td>-</td>
<td>7</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>79</td>
<td>4</td>
<td>1</td>
<td>4</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Numbness</td>
<td>37</td>
<td>8</td>
<td>22</td>
<td>12</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>Neutropenia</td>
<td>61</td>
<td>19</td>
<td>12</td>
<td>7</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>46</td>
<td>-</td>
<td>8</td>
<td>8</td>
<td>-</td>
<td>39</td>
</tr>
<tr>
<td>Any other blood condition</td>
<td>35</td>
<td>13</td>
<td>30</td>
<td>13</td>
<td>-</td>
<td>9</td>
</tr>
<tr>
<td>Secondary cancer</td>
<td>75</td>
<td>13</td>
<td>13</td>
<td>0</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Diabetes</td>
<td>64</td>
<td>9</td>
<td>-</td>
<td>27</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Tingling</td>
<td>79</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Enlarged lymph nodes</td>
<td>87</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>13</td>
</tr>
<tr>
<td>Pain</td>
<td>39</td>
<td>9</td>
<td>30</td>
<td>9</td>
<td>-</td>
<td>13</td>
</tr>
<tr>
<td>Headaches</td>
<td>47</td>
<td>11</td>
<td>16</td>
<td>11</td>
<td>-</td>
<td>16</td>
</tr>
</tbody>
</table>
Respondent’s wellbeing was affected not only by physical and medical conditions, but also by psychosocial issues in different degrees and for various lengths of time (Tables 23 and 24).

Specifically, these issues seemed to differ in the respondents’ experience during and after treatment (Table 23). Concerns about body image/physical appearance changes were most commonly reported during treatment (46%), while fear of relapse was very common after treatment (74%). Moreover, respondents’ reports of fear of relapse peaked between 2 and 5 years after treatment, but some also reported it at 8+ years after treatment.

Table 23. Psychosocial issues affecting respondents' wellbeing during and after treatment.

<table>
<thead>
<tr>
<th>Psychosocial Issues Affecting Wellbeing</th>
<th>During (%)</th>
<th>After (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in relationships with loved ones, friends or co-workers/social life</td>
<td>42</td>
<td>33</td>
</tr>
<tr>
<td>Stress related to financial issues</td>
<td>33</td>
<td>26</td>
</tr>
<tr>
<td>Loss of self-esteem</td>
<td>36</td>
<td>26</td>
</tr>
<tr>
<td>Concerns about body image/physical appearance changes</td>
<td>46</td>
<td>22</td>
</tr>
<tr>
<td>Loss/reduction in employment</td>
<td>10</td>
<td>17</td>
</tr>
<tr>
<td>Isolation</td>
<td>35</td>
<td>25</td>
</tr>
<tr>
<td>Depression</td>
<td>14</td>
<td>17</td>
</tr>
<tr>
<td>Anxiety</td>
<td>38</td>
<td>29</td>
</tr>
<tr>
<td>Fear of relapse</td>
<td>36</td>
<td>74</td>
</tr>
<tr>
<td>Difficulty on the job or in school</td>
<td>40</td>
<td>39</td>
</tr>
<tr>
<td>Problems getting health or life insurance coverage</td>
<td>21</td>
<td>19</td>
</tr>
<tr>
<td>Difficulty working effectively through the healthcare system</td>
<td>14</td>
<td>20</td>
</tr>
<tr>
<td>None</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 24. How long psychosocial issues affecting wellbeing lasted.

<table>
<thead>
<tr>
<th>Psychosocial Issues Affecting Wellbeing</th>
<th>Less than 1y (%)</th>
<th>1y (%)</th>
<th>2y (%)</th>
<th>3-5y (%)</th>
<th>6-8y (%)</th>
<th>8+y (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in relationships with loved ones, friends or co-workers/social life</td>
<td>33</td>
<td>15</td>
<td>19</td>
<td>19</td>
<td>-</td>
<td>14</td>
</tr>
<tr>
<td>Stress related to financial issues</td>
<td>24</td>
<td>17</td>
<td>21</td>
<td>24</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Loss of self-esteem</td>
<td>32</td>
<td>17</td>
<td>20</td>
<td>15</td>
<td>-</td>
<td>17</td>
</tr>
</tbody>
</table>

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Concerns about body image/physical appearance changes | 39 | 18 | 25 | 12 | - | 6
Loss/reduction in employment | 44 | 4 | 30 | 9 | 4 | 9
Isolation | 39 | 3 | 21 | 26 | - | 13
Depression | 25 | 14 | 21 | 18 | - | 21
Anxiety | 23 | 9 | 23 | 19 | 5 | 21
Fear of relapse | 18 | 12 | 23 | 24 | 7 | 15
Difficulty on the job or in school | 36 | 16 | 16 | 16 | 6 | 10
Problems getting health or life insurance coverage | 34 | 3 | 25 | 22 | 3 | 13
Difficulty working effectively through the healthcare system | 32 | 4 | 28 | 20 | 4 | 12

*Relative frequencies are displayed, and the percentages were calculated per issue (rows), and then compared within different time points (columns) to show the length of time each issue impacts patients reporting this specific concern. Each row totals 100%. Refer to Table 23 to see overall issue prevalence.

Interestingly, respondents did not communicate the issues that they experience very frequently with their doctor (Table 25).

Table 25. Psychosocial issues affecting respondents’ wellbeing and their communication with the doctor.

<table>
<thead>
<tr>
<th>Psychosocial Issues Affecting Wellbeing</th>
<th>Respondents Who Have Discussed with Their Doctor (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in relationships with loved ones, friends or co-workers/social life</td>
<td>7</td>
</tr>
<tr>
<td>Stress related to financial issues</td>
<td>3</td>
</tr>
<tr>
<td>Loss of self-esteem</td>
<td>2</td>
</tr>
<tr>
<td>Concerns about body image/physical appearance changes</td>
<td>7</td>
</tr>
<tr>
<td>Loss/reduction in employment</td>
<td>4</td>
</tr>
<tr>
<td>Isolation</td>
<td>3</td>
</tr>
<tr>
<td>Depression</td>
<td>4</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5</td>
</tr>
<tr>
<td>Fear of relapse</td>
<td>13</td>
</tr>
<tr>
<td>Problems getting health or life insurance coverage</td>
<td>9</td>
</tr>
<tr>
<td>Difficulty working effectively through the healthcare system</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
</tr>
</tbody>
</table>

As a result of their lymphoma, 82% of the Japanese respondents have experienced changes in their lifestyle and 52% have experienced changes in their independence.
Respondents communicated medical issues to the doctor in 62% of cases and emotional issues in only 30% of cases.

Respondents indicated that the doctor was able to help with the medical issues in 35% of cases, and to somewhat help in 41% of cases. As far as emotional issues are concerned, the doctor was able to help in 21% of cases and to somewhat help in 29% of cases.

Turning to side effects, 79% of respondents communicated questions about side effects to their doctor, and 61% indicated that the doctor was able to answer these questions. In 59% of cases, respondents indicated that the doctor was able to help them cope with the side effects (Table 26).

Table 26. Communication with the doctor about side effects.

<table>
<thead>
<tr>
<th>Communication of Side Effects</th>
<th>Respondents’ Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (%)</td>
</tr>
<tr>
<td>Did you bring forward questions about side effects?</td>
<td>79</td>
</tr>
<tr>
<td>Was the doctor able to answer your questions?</td>
<td>61</td>
</tr>
<tr>
<td>Was the doctor able to help you cope with side effects by providing medication or other support?</td>
<td>59</td>
</tr>
</tbody>
</table>

Of those who after their initial visit to the doctor, understood the potential side effects of treatment options, 76% brought forward questions about side effects to their doctor. 62% received answers from the doctor, and 63% received help coping with side effects through the provision of medication or other support (Table 27).

Table 27. Respondents who communicated with the doctor about treatment side effects and who after their initial visit to the doctor, understood the potential side effects of treatment options.

<table>
<thead>
<tr>
<th>Communication of Side Effects</th>
<th>Respondents’ Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (%)</td>
</tr>
<tr>
<td>Did you bring forward questions about side effects?</td>
<td>76</td>
</tr>
<tr>
<td>Was the doctor able to answer your questions?</td>
<td>62</td>
</tr>
<tr>
<td>Was the doctor able to help you cope with side effects by providing medication or other support?</td>
<td>63</td>
</tr>
</tbody>
</table>
VI) Barriers & Impediments

LC Objectives:

The 2016 Global Patient Survey examined barriers to care by gender and country. It was found that females had been experiencing more barriers to treatment in terms of their caregiver role and personal support, while males had been significantly more affected by medical issues such as access to treatments and specialty physicians. In the 2018 Global Patient Survey, we aim to examine the availability and efficacy of services by country and by area (rural/urban) and determine if and how this might affect the patient experience.

Key Findings:

Japanese respondents commonly reported that financials constituted a barrier to treatment, followed by wait time to treatment that was longer than necessary. There were barriers found to be associated with respondent’s area of residence. For example, access to treatment centre/prohibitive travel was the most frequently reported barrier for respondents who resided in a suburban area compared to rural or urban areas. Moreover, availability of the appropriate specialty physician locally and wait time to treatment constituted barriers for respondents in rural areas. Support services most frequently reported to be unavailable in Japan were social workers, spiritual support, and complementary therapist services. When respondents were asked to rate service types that they had already used, they specified that patient organisations/support groups and dietician/nutritionist were the services that they found to be most helpful. Respondents who had good conversations with their doctors most days reported experiencing fewer barriers to treatment than did those who reported having good conversations only sometimes or never.

Barriers respondents have identified in receiving their lymphoma treatment were:

- Financial (28%)
- Wait time to treatment was longer than necessary (21%)
- Access to treatment centre/prohibitive travel (19%)
- Access to the most up to date treatment (12%)
- Could not give up caregiver role (child, parent, disabled person) while in treatment (7%)
- Specialty physician available locally (4%)
- Language (1%)
- Personal support (1%)
- None (15%)

We asked participants to rate on a scale of 1-5 (5 being the highest) how helpful different services they may have used were, and to indicate if those services are not available in their country. Dietician/nutritionist support was rated to be the most helpful (37%), followed by patient organisations/support groups (30%). The highest rates of missing services in Japan were identified in social worker services (17%) (Table 28).
Table 28. Respondent’s evaluation (1 lowest, 5 highest) of different services in Japan.

<table>
<thead>
<tr>
<th>Types of Services</th>
<th>Evaluation of Services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 (%)</td>
</tr>
<tr>
<td>Social worker</td>
<td>9</td>
</tr>
<tr>
<td>Patient organisation/support group</td>
<td>3</td>
</tr>
<tr>
<td>Dietician/nutritionist</td>
<td>10</td>
</tr>
<tr>
<td>Counsellor/psychologist</td>
<td>9</td>
</tr>
<tr>
<td>Spiritual support</td>
<td>9</td>
</tr>
<tr>
<td>Physical therapy</td>
<td>9</td>
</tr>
<tr>
<td>Pain management</td>
<td>9</td>
</tr>
<tr>
<td>Complementary therapist</td>
<td>9</td>
</tr>
</tbody>
</table>

For those who used the services mentioned above, the information for those services was provided by:

- Patient organisation/support group in 37% of cases;
- A nurse in 20% of cases;
- A doctor in 18% of cases;
- Online research in 17% of cases;
- Another patient in 9% of cases;
- A family member in 8% of cases;
- A friend in 1% of cases and;
- Respondent was not provided with service information 11% of cases.

In comparing the entire sample with only those that selected adequate information level, the efficacy rating of services changed. The highest rates were identified in patient organisation/support group services (37%) (Table 29).
Table 29. Evaluation of different services (1 lowest, 5 highest) in Japan by respondents with perceived adequate information.

<table>
<thead>
<tr>
<th>Types of services</th>
<th>Evaluation of Services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 (%)</td>
</tr>
<tr>
<td>Social worker</td>
<td>6</td>
</tr>
<tr>
<td>Patient organisation/Support group</td>
<td>3</td>
</tr>
<tr>
<td>Dietician/nutritionist</td>
<td>6</td>
</tr>
<tr>
<td>Counsellor/psychologist</td>
<td>6</td>
</tr>
<tr>
<td>Spiritual support</td>
<td>9</td>
</tr>
<tr>
<td>Physical therapy</td>
<td>13</td>
</tr>
<tr>
<td>Pain management</td>
<td>10</td>
</tr>
<tr>
<td>Complementary therapist</td>
<td>10</td>
</tr>
</tbody>
</table>

For respondents living in rural and urban areas, access to treatment centre/prohibitive travel was identified more frequently as a barrier compared to respondents living in suburban areas. In addition, respondents living in rural areas identified the availability of the appropriate specialty physician locally and wait time to treatment more often than respondents living in urban and suburban areas (Table 30).

Table 30. Barriers to treatment based on area of residence.

<table>
<thead>
<tr>
<th>Types of Barriers to Treatment</th>
<th>Area of Residence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rural (%)</td>
</tr>
<tr>
<td>Financial</td>
<td>44</td>
</tr>
<tr>
<td>Access to treatment centre/prohibitive travel</td>
<td>34</td>
</tr>
<tr>
<td>Access to the most up to date treatment</td>
<td>20</td>
</tr>
<tr>
<td>Wait time was longer than necessary</td>
<td>42</td>
</tr>
<tr>
<td>Specialty physician available locally</td>
<td>15</td>
</tr>
<tr>
<td>Could not give up caregiver role (child, parent, disabled person)</td>
<td>12</td>
</tr>
<tr>
<td>None</td>
<td>17</td>
</tr>
</tbody>
</table>

Respondents who never or sometimes had good conversation with their doctors identified wait time longer than necessary as a barrier to treatment more than respondents who had good conversations with their doctors most days. In addition, respondents who reported having good conversations with their doctors most days did not identify barriers to treatment in 40% of cases in contrast to respondents who reported having good conversations with their doctors sometimes (17%) or never (10%) (Table 31).
Table 31. Barriers to treatment based on the quality of respondent communication with the doctor.

<table>
<thead>
<tr>
<th></th>
<th>Good Conversation With Their Doctor</th>
<th>Barriers to Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Financial (%)</td>
<td>Access to treatment centre/prohibitive travel (%)</td>
</tr>
<tr>
<td>Most days</td>
<td>40</td>
<td>8</td>
</tr>
<tr>
<td>Sometimes</td>
<td>48</td>
<td>33</td>
</tr>
<tr>
<td>Never</td>
<td>40</td>
<td>40</td>
</tr>
</tbody>
</table>

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APPENDIX 1

**Step 1.** The excel files were processed so that completed patients’ and caregivers’ responses were merged with the incomplete patients’ and caregivers’ responses. This included removal of the ‘I don’t know’ columns from certain questions from the caregivers’ version of the survey.

**Step 2.** The merged excel file was then exported into an SPSS file. This new SPSS file was then processed i.e. ‘values’ were put in, namely the coding of all variables, using the standard SPSS file you sent us as a guide. Open text variables were removed, as they make no sense in SPSS.

**Step 3.** Random checks were performed, to ascertain that no error had occurred during Steps 1 & 2. For example, 15 individual participants were selected from the SPSS file, subsequently traced in the Excel files using their ID number. The data recorded in the Excel files for each of those participants was compared with their data in the SPSS file. No errors were found.

**Step 4.** According to the key target variables included in the analysis, we defined a separate new variable for each one of them, i.e. 'name of variable_M'. The Total_M variable is defined as the sum of the 'name of variable_M' variables and represents the percentage of all missing responses in the key target variables. We selected to keep participants with values in the Total_M variable with a maximum of 0.70. These participants are therefore those who have completed at least 30% of these target variables. If we considered participants with for example a maximum value of 0.3 we would end up with 4.201 participants (approximately the completed study cases). So, we did consider a threshold that within reason led to the final number of 6,631.