

# A cross-sectional study on the global disparities in information experiences and needs of patients with lymphoma and CLL



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## INTRODUCTION

Patient-centricity remains a cornerstone in the care of patients with lymphoma and CLL, as informed patients are consistently associated with better outcomes and healthcare experiences.

This study uses the Lymphoma Coalition (LC) 2020 Global Patient Survey (GPS) on Lymphomas and CLL to describe the global differences in patients' information experiences at diagnosis, as well as to compare the areas of need for more information.

## METHODS

### Study design

- This study is a sub-analysis of the **LC 2020 GPS**, which is an online global survey of patients with lymphoma and CLL, carried out every two years
- The LC 2020 GPS was hosted on a third-party portal from January- March 2020 in 19 languages

### Respondents

- Globally, **9,179 patients** and **2,699 caregivers** from **90+ countries** participated
- The countries were grouped into **geographic regions**, and regions with greater than 200 patient respondents were included in this analysis.
- The **five regions** analysed are shown in **table 1**

Table 1. Geographic regions, patient count, and countries involved in the analysis

Region* (Count)	Countries
Asia (AS) (n=2326)	China, Hong Kong, India, Indonesia, Japan, Lao, Malaysia, Nepal, North Korea, Philippines, Singapore, Republic of Korea, Tonga, Turkey, Vanuatu
Europe (EU) (n=4343)	Albania, Andorra, Austria, Belgium, Bosnia & Herzegovina, Bulgaria, Croatia, Cyprus, Czechia, Denmark, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Italy, Lithuania, Luxembourg, Republic of North Macedonia, Malta, Monaco, Netherlands, Norway, Poland, Portugal, Rep. of Moldova, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, United Kingdom
Oceania (OC) (n=695)	Australia, New Zealand
North America (NA) (n=1543)	Barbados, Canada, Mexico, United States of America
South America (SA) (n=214)	Argentina, Brazil, Chile, Colombia, Costa Rica, Dominican Republic, Peru, Uruguay, Venezuela

\*Middle East & Africa- not included in analysis due to inadequate responses

### Statistical analysis

- Raw data was entered, merged, and cleaned in IBM SPSS v.27
- Demographics of the five regions were compared and descriptive analyses were conducted for questions about patients' information experiences.

## RESULTS

All the regions differed significantly (p< 0.001) in age, sex, education level, employment, household status, and area of residence. The breakdowns for age, sex, and area of residence are shown in **table 2**.

Table 2. Demographic comparison of the geographic regions

	AS	EU	OC	NA	SA	X <sup>2</sup> (p-value)
	Count (%)*	Count (%)*	Count (%)*	Count (%)*	Count (%)*	
<b>Age Range (years)</b>						
18-29	326 (14)	222 (5)	32 (5)	18 (1)	34 (16)	1610.6 (<0.001)
30-39	569 (25)	470 (11)	44 (6)	51 (3)	46 (22)	
40-59	1083 (47)	1457 (34)	244 (35)	381 (25)	75 (36)	
60-69	279 (12)	1159 (27)	199 (29)	529 (35)	40 (19)	
70+	68 (3)	977 (23)	174 (25)	527 (35)	16 (8)	
<b>Biological Sex</b>						
Male	1167 (50)	1820 (42)	238 (34)	636 (41)	62 (29)	113.4 (<0.001)
Female	1152 (49)	2523 (58)	457 (66)	902 (59)	152 (71)	
<b>Residence</b>						
City/ Urban area	1691 (73)	1998 (46)	171 (25)	563 (37)	187 (87)	1366.7 (<0.001)
Suburbs	239 (10)	879 (20)	347 (50)	669 (43)	6 (3)	
Rural area	396 (17)	1466 (34)	177 (25)	311 (20)	21 (10)	

(%)\*- valid percentages.

Relating to how patients felt about the amount of information they were given upon diagnosis with lymphoma, patients from AS were the most prevalent in reporting they were not given enough information (55%) followed by patients from NA (36%) (**figure 1**).

Additionally, only 30% of patients from AS reported receiving the right amount of information, while 60% or more, of patients from NA, EU, SA and OC reported the same ( 60%, 67%, 71% and 70% respectively) (**figure 1**).

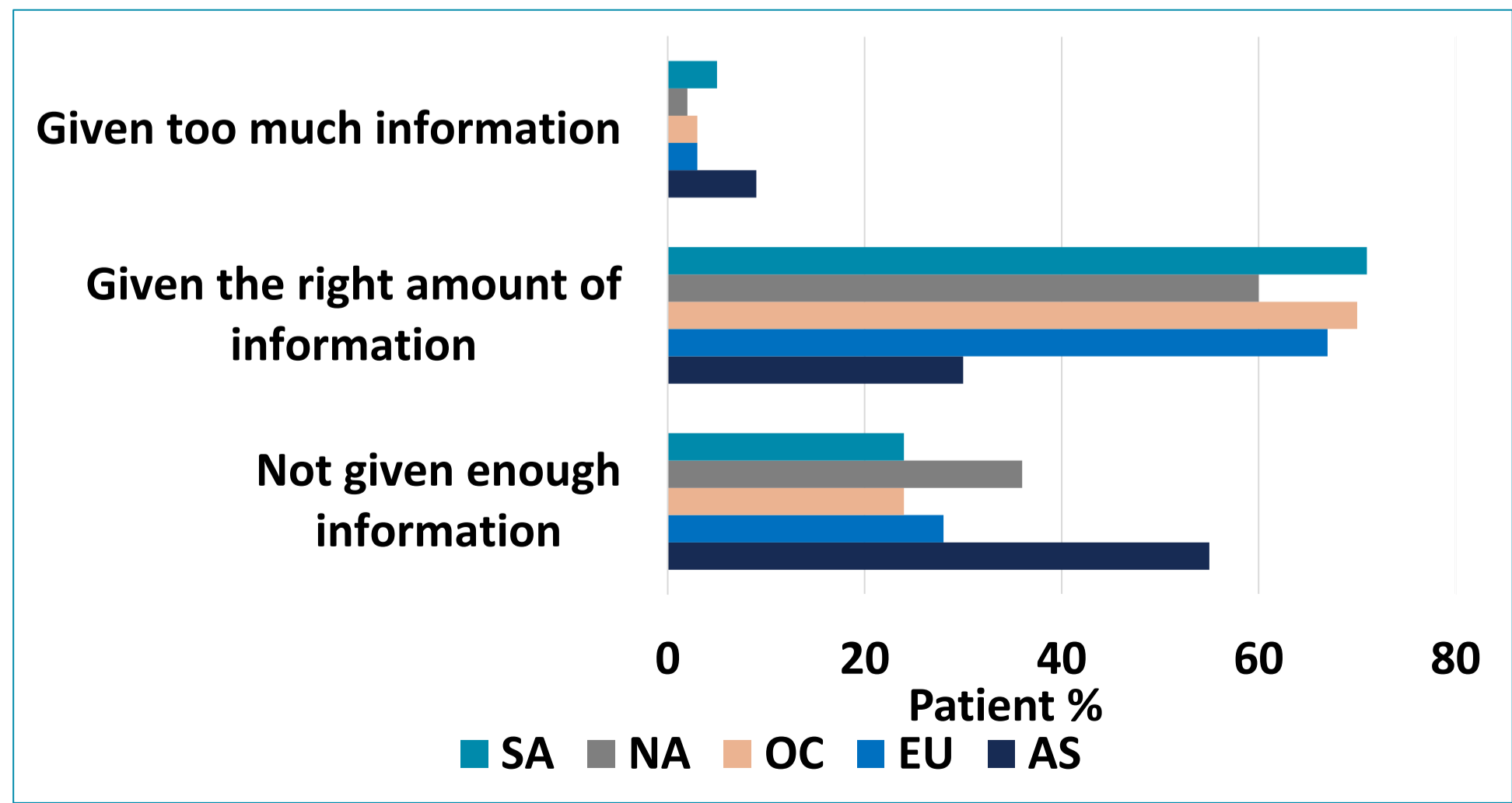


Figure 1. How patients felt about the amount of information they were given at the time of their diagnosis

## RESULTS (cont.)

When asked about the specific areas that patients needed more information about (**table 3**), the most commonly reported areas in all regions were 'treatment options' (AS-76%, OC-44%, EU-50%, NA-61%, SA-40%), 'diagnosis and what it means' (AS-58%, OC-45%, EU-56%, NA-51%, SA-38%), and 'treatment side effects' (AS-61%, OC-44%, EU-45%, NA-38%, SA-41%).

Patients also reported needing more information about 'support for self care', 'psychological support', 'support for their families', and 'fertility' (**table 3**).

Table 3. Information needs of patients with lymphoma and CLL

Which of the following, if any, have you needed more information about? **	AS	EU	OC	NA	SA
	Count (%)*	Count (%)*	Count (%)*	Count (%)*	Count (%)*
Diagnosis and what it means	1315 (58)	2403 (56)	310 (45)	785 (51)	80 (38)
Treatment options	1734 (76)	2161 (50)	304 (44)	929 (61)	85 (40)
Support for self-care	1103 (48)	599 (14)	148 (21)	266 (17)	46 (22)
Psychological support	853 (37)	1110 (26)	183 (26)	353 (23)	41 (19)
Support for my family	588 (26)	493 (12)	105 (15)	136 (9)	32 (15)
Treatment-related side effects	1407 (61)	1920 (45)	305 (44)	575 (38)	87 (41)
Fertility	414 (18)	365 (9)	30 (4)	34 (2)	31 (15)
I have not needed more information	50 (2)	486 (11)	131 (19)	238 (16)	39 (18)

(%)\*- valid percentages | \*\*- patients allowed to select more than one response.

Fewer patients from AS (2%) reported not needing any additional information compared to the other regions (OC-19%, EU-11%, NA-16% and SA-18%) (**table 3**).

## CONCLUSION

Access to timely and credible medical information remains an essential aspect of a successful patient experience, and this study shows that patients with lymphoma have diverse information experiences and needs.

It is therefore important that doctors provide information that addresses each patient's unique information needs. In the future, LC would like to explore how demographic differences may have confounded results.

## CONTACT INFORMATION

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For further details on the LC 2020 GPS, please scan the QR code or visit <https://lymphomacoalition.org/global-patient-survey/>.

