A Cross-Sectional Study Examining Potential Demographic Barriers to Receiving Information on Clinical Trials in Relapsed/Refractory Patients who have Received Stem Cell Transplants (SCT)

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INTRODUCTION

Lymphoma Coalition (LC) supports almost 90 patient organizations across more than 50 countries. LC's overarching goal is to facilitate a community of patient organisations supporting efforts to help patients with lymphoma receive optimal care and support. Stem Cell Transplant (SCT) and clinical trials involving new treatments provide increased opportunities for longer lasting remission in patients with lymphoma with relapsed or refractory settings. Not all patients are given information or the opportunity to access clinical trials. This study investigates the potential socioeconomic barriers to receiving information on clinical trials or the opportunity to participate in them for patients with lymphoma who have previously received SCT.

METHODS

Study design

This study reports on sub-analysis of the LC 2022 Global Patient Survey (GPS), which is an online global survey distributed to patients with lymphoma and CLL, carried out every two years. The electronic survey link was distributed to all participating member organisations across the globe, who then distributed it to patients and caregivers who engage with these organizations. Individuals who chose to, completed the survey on a third-party portal. This study cohort reflected patients with >1 relapse or refractory disease who had previously received SCT.

Respondents

Globally, 8637 respondents, comprising 7,113 patients and 1,524 caregivers from 84 countries, completed the 2022 LC Global Patient Survey (GPS). After exclusion criteria were applied, 137 respondents remained (Figure 1).

Statistical analysis

The data was cleaned and organised, removing partially completed responses to ensure accuracy and completeness. The data sets were grouped into categories using Qualtrics prior to export. Frequency tables and charts were used to represent the data and identify patterns and trends visually. Additionally, appropriate statistical tests were performed to determine the significance of any observed differences between groups. Cross tabulations across age, gender, ethnicity, education, residential area, and those classified as having a partner relative to those reported as single were analysed. Differences found in cross-tabulations were assessed using the likelihood ratio Chi-Square or Fisher's Exact test as appropriate. All analyses were computed with JMP Pro v17, SAS Institute, Cary NC U.S.A.

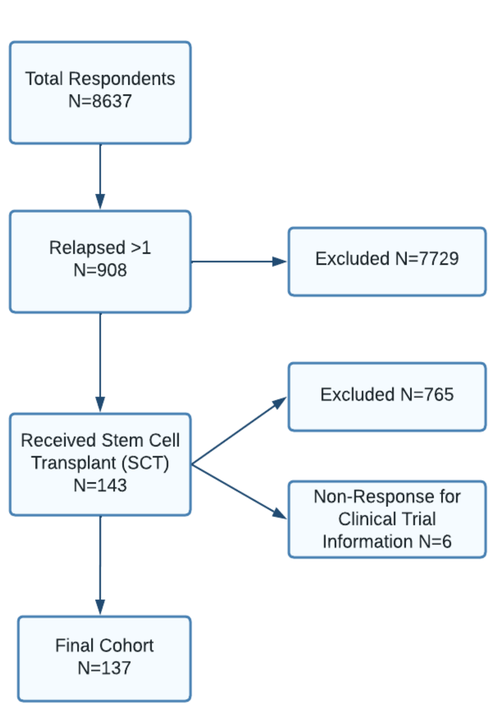

Figure 1. Flow diagram of participant exclusion based upon pre-defined exclusion criteria.

RESULTS

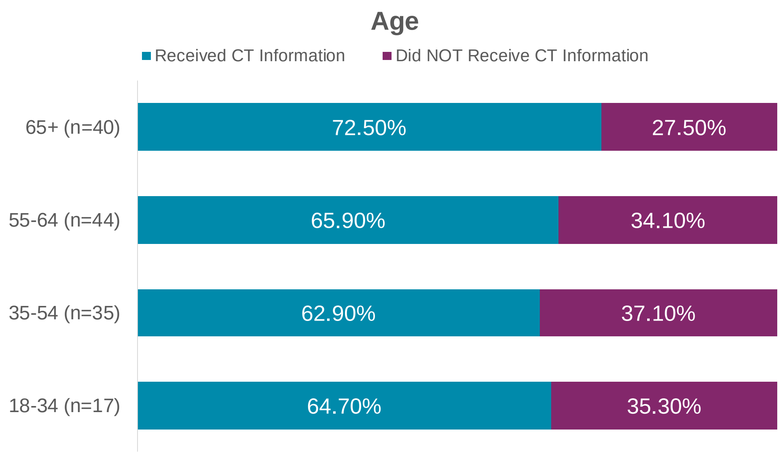

Figure 2. Cross-tabulation of categorised age by the outcome of whether information on clinical trials was provided (p=0.8)

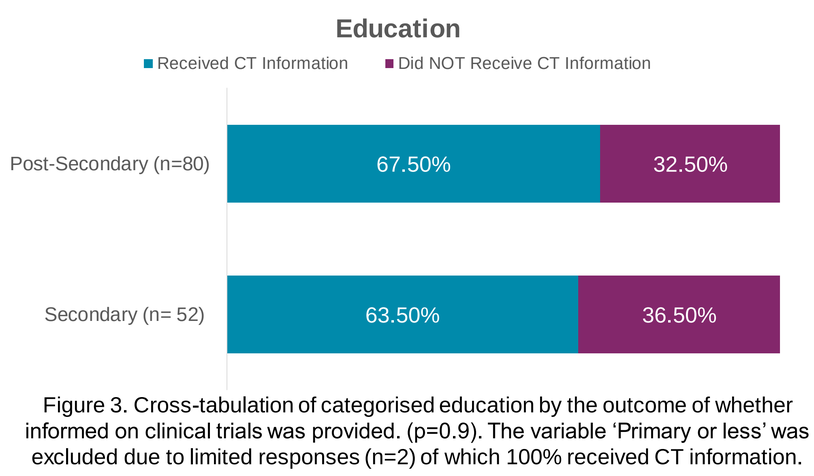

Figure 3. Cross-tabulation of categorised education by the outcome of whether informed on clinical trials was provided. (p=0.9). The variable 'Primary or less' was excluded due to limited responses (n=2) of which 100% received CT information.

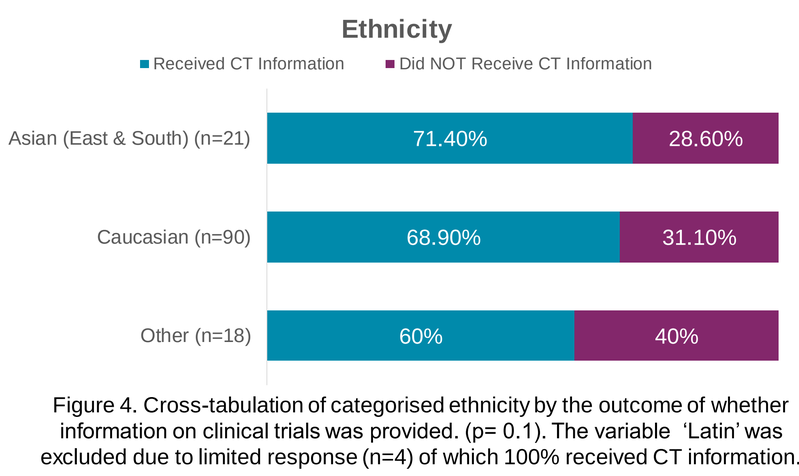

Figure 4. Cross-tabulation of categorised ethnicity by the outcome of whether information on clinical trials was provided. (p= 0.1). The variable 'Latin' was excluded due to limited response (n=4) of which 100% received CT information.

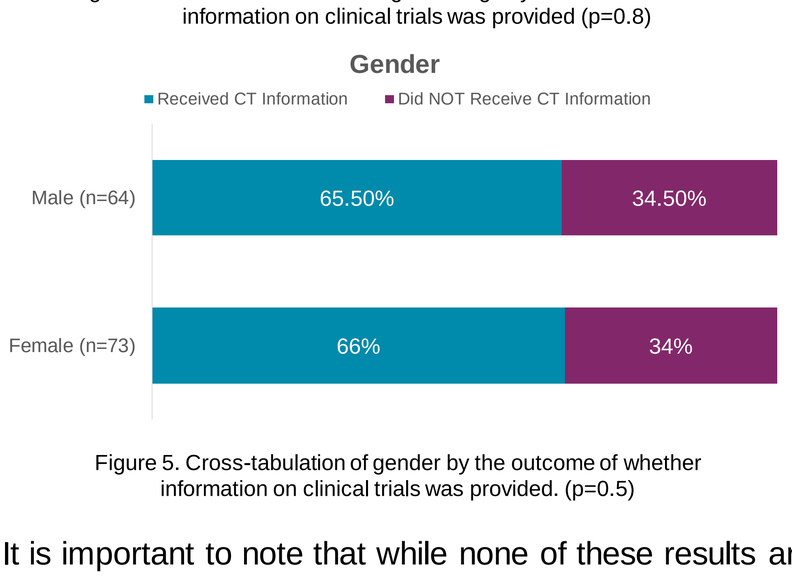

Figure 5. Cross-tabulation of gender by the outcome of whether information on clinical trials was provided. (p=0.5)

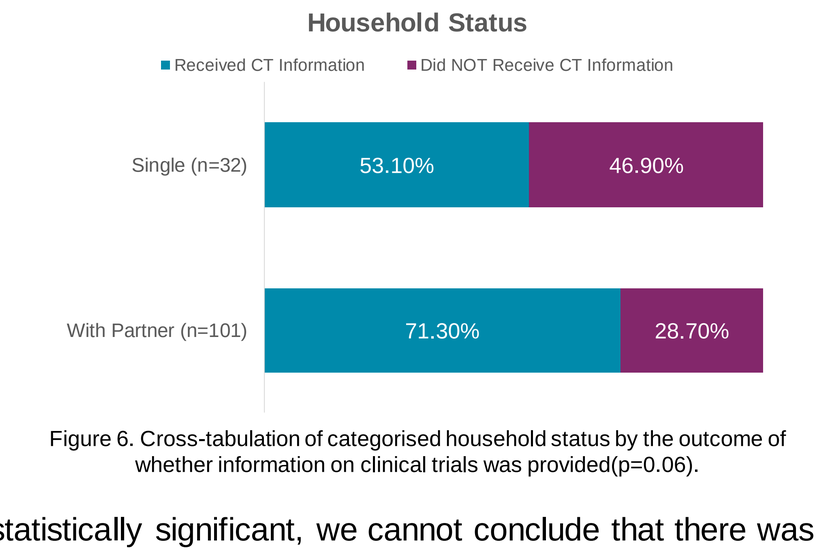

Figure 6. Cross-tabulation of categorised household status by the outcome of whether information on clinical trials was provided(p=0.06).

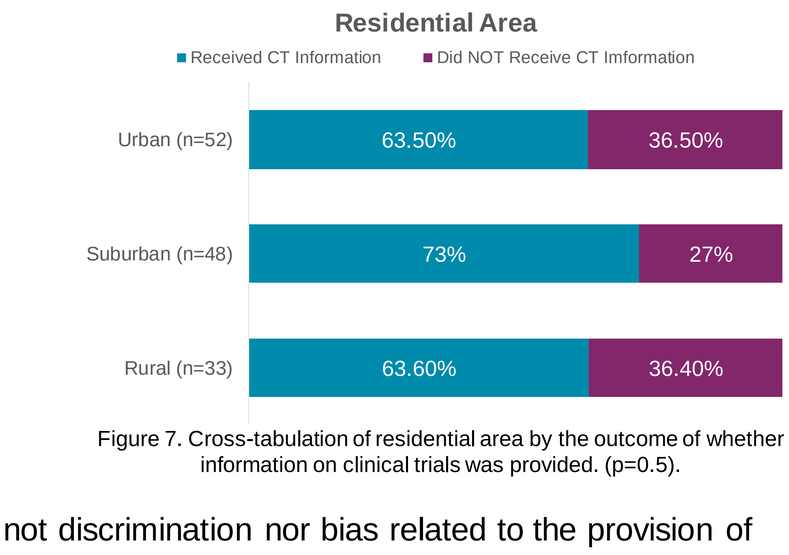

Figure 7. Cross-tabulation of residential area by the outcome of whether information on clinical trials was provided. (p=0.5).

It is important to note that while none of these results are statistically significant, we cannot conclude that there was not discrimination nor bias related to the provision of information on clinical trials. It is at the physician's discretion to discuss clinical trial options with patients or not. Due to the small cohort size this data cannot be generalized to the full population. Amongst the regions with the most significant response rates (APAC, Europe and North America), approximately 65% - 75% of respondents reported being provided information on a clinical trial. Interestingly, patients who had a partner were provided with more information on clinical trials (71%) relative to those who classified themselves as being single (53%); (p=0.06).

CONCLUSION

LC advocates equitable access to care for all patients with lymphoma regardless of where they reside. Thirty percent of respondents with relapsed/refractory disease who have received SCT had never been provided information or presented an opportunity to participate in a clinical trial from their doctor. The data does not reflect a significant cause in the survey using our core demographics apart from a trend in household status. We suspect that those with a partner are, in part, advocating for more information or encouraged by their family members to seek additional options for increased quality of life and life extension. We are encouraged that we were unable to find significant differences amongst most of our core demographics. Interpretation of this data indicates that inequities in access to clinical trials are unlikely to be ascribed to common causes of discrimination based on patients described in this cohort. The implications of this study indicate that further efforts are needed to improve access to clinical trials for all patients, starting with improved communication between patients, caregivers and their doctors. Improved communication will yield a collaborative approach to shared decision-making, empowering patients with relapsed and refractory lymphoma.

DISCLOSURE

The study was sponsored by AbbVie, BMS, Pharmacyclics and Roche. None of the authors benefited personally from the research.

For further details on the LC 2022 GPS please **scan the QR code** or visit https://lymphomacoalition.org/global-patient-survey/.

Please direct any queries to the department of Research & Information at Lymphoma Coalition: skalloger@mac.com