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# Week Two Update: 2024 Global Patient Survey

1 bericht

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16 februari 2024 om 19:38





**The Global Patient Survey** 

on Lymphomas & CLL

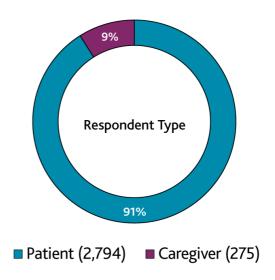
**Week Two Update** 

We are pleased to report that since the survey opened two weeks ago, on 2 February, a total of **3,069** responses to the 2024 Global Patient Survey on Lymphomas & CLL have been submitted! Thank you for your enthusiasm in helping to spread the word about the survey. Let's keep this excitement going it will be essential in driving momentum over these next two months!

Here is the link directly to the survey, so you can easily share: https://bit.ly/LCGPS2024

Below is a breakdown of the 3,069 survey responses by respondent type.





We have been asked why it is that pharmaceutical and marketing companies can pay people to participate in their surveys, but LC does not pay people to complete the GPS, nor do we advise Members to pay individuals to complete the GPS.

This all comes down to how we use the data and who we try to influence with the data. When publishing research and using data from surveys at professional healthcare conferences or with HTA and other government bodies, we need to ensure the data is authentic. Which is why payment for survey completion is not ideal as it can result in some people feeling inclined to complete a survey even if they don't have a connection to the disease, so they can get paid. Since the survey is online, paying for responses can also attract bots. We have worked hard to have our combined data taken seriously and don't want anything to take away from how strong it is. As such, we want to avoid situations like this that can cause anyone to question the validity of the data. A great way to ensure the GPS maintains its credibility is to limit things like cash prizes or other gifts in exchange for a survey being completed.

We appreciate your understanding and all your hard work in promoting the survey, we could not do this without you! If you have any questions at all about this, please contact <a href="mailto:marketing@lymphomacoalition.org">marketing@lymphomacoalition.org</a>.

In the spirit of keeping everyone up to date on all things GPS, we encourage those of you who have not yet joined the Lymphoma Coalition Members group on WhatsApp to add yourself so you can join in the conversation and receive real-time updates.

To join, simply follow this link: https://chat.whatsapp.com/ICGApc9iiFR6koNBpkyFyY

### What's Next?

We want to note that the Lymphoma Coalition website is currently unavailable as the server is down. Unfortunately, this impacts the ability to access and download GPS toolkit materials. We apologise for this inconvenience and realise the timing is not ideal. The team managing our web hosting is working on repairing the issue and hope to have it back online soon.

- Continue using the materials to help share the news about the survey with your communities and encourage them to take the time to complete the survey.
  - Materials in other languages: the two infographics are now available on both the Member and public side of the website, in French and Spanish.
- We have had the five (5) social media tiles translated into the 19 other languages which are now available on the Member side of the website, in the existing toolkits along side all the previously translated materials.

If you have any additional translation requests for the infographics or have questions at all about the materials or need help with your username and password, please contact: marketing@lymphomacoalition. org.

## **Survey Responses: By Member Countries**

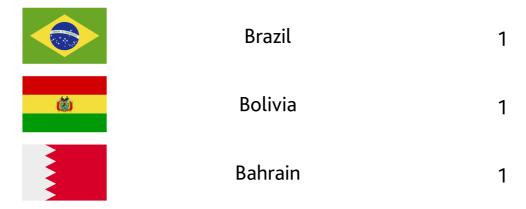
#### Week Two

Please note this breakdown is based on the data pulled on 16 February 2024 at 11:00 AM EDT.

	Country/ Region	Responses
	United Kingdom of Great Britain and Northern Ireland	533
	France	514
	United States of America	452
	Netherlands	282
*	Canada	204
	Italy	121
	Belgium	117
	Bulgaria	101
#	Slovakia	69
	Germany	67
	Argentina	67
	Ireland	66
	Serbia	62
	Portugal	49







Congratulations to the following **8 regions** who have **100+ patient respondents** and will be receiving a country report:

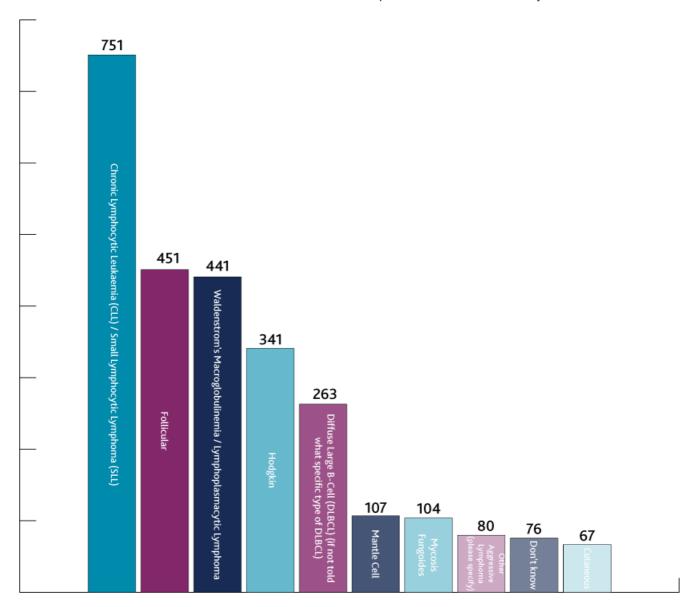
- · United Kingdom of Great Britain and Northern Ireland
- France
- · United States of America
- Netherlands
- Canada
- Italy
- · Belgium
- Bulgaria

The country report will highlight the findings, which can be used for local planning to help ensure activities align with patients' needs, as well as advocacy efforts. In addition, Lymphoma Coalition can support your organisation with data needed for therapy approvals.

Currently, there are **1,645** partially-completed surveys. If respondents use the same browser and have cookies enabled, responses to date will have been saved and they can pick up where they left off and complete the survey.

## **Survey Responses: By Subtypes**

The following 7 subtypes shown in the graph have surpassed 100 respondents and will have a subtype report.



## **Friendly Reminders:**

- 1. Host the information on your website.
- 2. Send an email to your membership, sponsors and other partners encouraging them to take the survey and pass the message along!
- 3. Share with your followers on social media.

As many of you are aware, our goal is to truly understand the current voices and values of adult patients and caregivers and to do this we need to hear from as many people as possible from around the world. This will ensure those impacted by lymphoma and CLL are accurately represented in the work we do moving forward, to improve care across the globe.

We greatly appreciate your continued support in promoting the participation of the 2024 Global Patient Survey. By working together, we will ensure those impacted by lymphoma are given the opportunity to share feedback about their experience and help shape the global lymphoma landscape.

With deepest thanks,

## Lymphoma Coalition Team



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