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## 2303 Experiences and Views of Leukemia Patients: A Global Survey

Oral and Poster Abstracts

Session: 906. Outcomes Research—Myeloid Malignancies: Poster I

Saturday, December 10, 2022, 5:30 PM-7:30 PM

Hall D (Ernest N. Morial Convention Center)

**Zack Pemberton-Whiteley<sup>1\*</sup>**, Samantha Nier<sup>1\*</sup>, Nick York<sup>2\*</sup>, Deborah Baker<sup>3\*</sup>, Michael Rynne<sup>3\*</sup>, Nicole Schroeter<sup>3\*</sup>, Denis Costello<sup>4\*</sup>, Lidija Pecova<sup>5\*</sup>, Esther Natalie Oliva, MD<sup>6</sup>, Tatiana I. Ionova, Prof.<sup>7</sup>, Sam Salek, PhD RPh FFPM MCMS MRPSGB FESCP<sup>8\*</sup> and Jennie Bradley<sup>9\*</sup>

<sup>1</sup>Acute Leukemia Advocates Network, Bern, Switzerland

<sup>2</sup>CLLAN - CLL Advocates Network, Bern, Switzerland

<sup>3</sup>CLL Advocates Network, Bern, Switzerland

<sup>4</sup>CML Advocates Network, Bern, Switzerland

<sup>5</sup>CML Advocates Network, Bern, Switzerland

<sup>6</sup>Division of Hematology, Azienda Ospedaliera (B-M-M), Reggio Calabria, Italy

<sup>7</sup>University Clinic, St. Petersburg State University and Multinational Center for Quality of Life Research, Saint-Petersburg, Russia

<sup>8</sup>University of Hertfordshire, School of Life and Medical Sciences, Hatfield, United Kingdom

<sup>9</sup>IQVIA, Chesterfield, ENG, United Kingdom

A deeper understanding of patients' experiences with leukemia is necessary given the ongoing discussions about patient-centricity and how to return the patient to the center of care.

The Acute Leukemia Advocates Network (ALAN) in collaboration with CLL Advocates Network (CLLAN) and CML Advocates Network (CMLAN) developed a multi-country survey to understand the issues and gather information on the current and emerging treatment landscape, experiences and quality of life (QoL) of adult patients with leukemia.

This survey was designed to focus on the patient perspective. This includes but not limited to: experiences through patient journey, the QoL and impact of leukemia on daily life, and what information and support was provided. Analysis of the data identified areas within the patient journey where opportunities exist to improve patient care and experiences.

### Methods

Developed by a panel of expert leukemia patient advocates, the questionnaire was tested twice and comprises sixteen sections with the aim to collect insight and understanding into the patient's experience, rather than the clinical perspective. The questionnaire consists of 200 questions (some with sub-questions) including HM-PRO, a validated QoL assessment tool in those with hematological malignancies.

Patients completed the sections relevant to their type of leukemia. Data on relevant patient characteristics, such as gender, age, and countries of residence, were collected in the demographic section.

The administration of the questionnaire was web-based, between 18 September 2021 and 07 January 2022 and was made available in 10 languages. It was promoted by ALAN, CLLAN, CMLAN and member organizations via websites, newsletters, emails, and social media channels. Participation was on a voluntary basis therefore may not

reflect the perspectives of all leukemia patients.

## Results

There were 2646 respondents with different types of leukemia: acute myeloid leukemia (n=312), acute lymphoblastic leukemia (n=104), chronic lymphocytic leukemia (n=1202), chronic myeloid leukemia (n=896) and other types of leukemia (n=132).

Of the 2646 patients who responded to the survey, 56% were female (n=1426), 56% were within the age range 55-74 years old (range <16 to >85), and living situation, employment status and education levels varied.

Responses were collected across 76 countries. Respondents were grouped into the designated World Health Organization (WHO) regions; 66% (n = 1749) were from countries assigned to the European region, 14.7% (n=389) from the Americas region, 7.4% (n=195) from the Western-Pacific region, 2.1% (n=56) from Africa region and 1.5% (n=39) from Southeast Asia region.

Overall, at diagnosis, 62% (n=1582) partially / did not understand the information provided by their healthcare professional and about half of patients were offered written information on leukemia, while 51% (n=1337) were not offered or directed to any support to help with concerns and worries. The majority of patients reported they would have liked to be provided with information and/or support. Similar numbers are reported while under treatment.

62% (n=1271) of respondents reported that they were not offered a choice of treatment options and half wanted to be more involved in decisions. Similarly, 60% (n=1225) were not offered the option of a clinical trial, but 43% reported they would have liked to have had it offered.

Of the patients with childbearing potential, 34% (n=860) reported that fertility preservation was not discussed with their healthcare teams.

The majority of respondents (92%, or 2362) said they had to use the internet to find information about their disease, treatments, or any other topic related to leukemia (finances, patients' rights, emotional support, wellbeing, etc.).

## Conclusion

We believe this study is the largest ever conducted among leukemia patients to gather information about their experiences, QoL, and preferences. This study is the only one of a limited number that explores patients' experiences throughout their journey.

Our data show that opportunities to provide patients with information / emotional support are still being missed. Additionally, there is still a need to include patients in decision-making and to place them at the center of care (for example, to discuss treatment options and clinical trials, to preserve fertility, etc.), confirming the need to continue discussions on patient centricity.

**Disclosures:** **Pemberton-Whiteley:** CML Advocates Network: Consultancy; **Acute Leukemia Advocates Network:** Consultancy; **Leukaemia Care:** Current Employment; **Takeda:** Consultancy, Other: Grant funding to the organization; **Sobi:** Consultancy; **Servier:** Consultancy, Other: Grant funding to the organization; **seagan:** Consultancy; **Roche:** Other: Grant funding to the organization; **Pfizer:** Consultancy, Other: Grant funding to the organization; **MDS:** Consultancy; **Novartis:** Consultancy, Other: Grant funding to the organization; **Mallinckrodt:** Other: Grant funding to the organization; **Kyowa Kirin:** Other: Grant funding to the organization; **Kura Oncology:** Other: Grant funding to the organization; **Kite/Gilead:** Consultancy, Other: Grant funding to the organization; **Ostuka:** Consultancy, Other: Grant funding to the organization; **Lily:** Other: Grant funding to the organization; **Janssen:** Other: Grant funding to the organization; **Beigene:** Other: Grant funding to the organization; 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