



## 2934 CML Patients' Views on Psychological Support throughout the Treatment-Free Remission Journey

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Hematology Disease Topics & Pathways:

Adult, Diseases, CML, Study Population, Myeloid Malignancies

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Hall B, Level 2 (Orange County Convention Center)

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## Background

In Chronic Myeloid Leukemia (CML), Treatment-free Remission (TFR) refers to having a stable deep molecular response without the need for ongoing Tyrosine Kinase Inhibitor (TKI) treatment. While first recommendations exist about how to manage stopping and re-starting therapy, based on data from the EURO-SKI study, much is still unknown about the experiences of those considering and undertaking TFR. Through this study, we sought to obtain quantitative evidence of patient experience that has previously only been anecdotal and to identify areas of unmet needs. One strong theme to emerge was patients' differing views on the need for psychological support.



## Method

A global online survey was conducted, recruiting patients through CML patient associations, via online forums, social media and other methods. The questionnaire was designed by an expert panel of eight CML patients to capture the experiences of people along all phases of the TFR journey. The different phases were classified as: Phase I – Considerations around stopping treatment; Phase II – Probation period (experiences during the first 6 months of stopping treatment); Phase IIIA – Restarting treatment (experiences where treatment had to restart due to molecular reoccurrence), and Phase IIIB – Long-term remission (experiences of being in long-term, treatment-free remission). Once the question set was agreed, the questionnaire went through two rounds of testing by eight volunteers. This exercise contributed towards refining the questionnaire into a finished version. The questionnaire was translated into eleven languages: Arabic, Danish, English, Finnish, French, German, Hebrew, Italian, Japanese, Russian and Spanish. Fieldwork lasted 20 weeks.

## Results

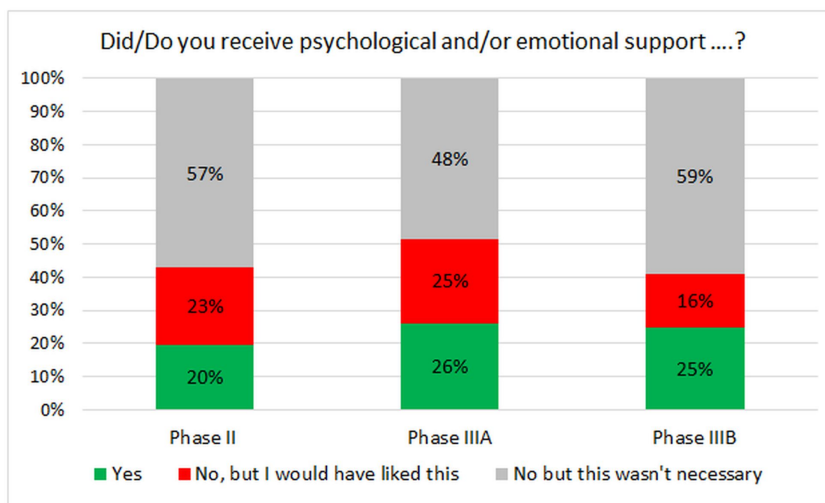
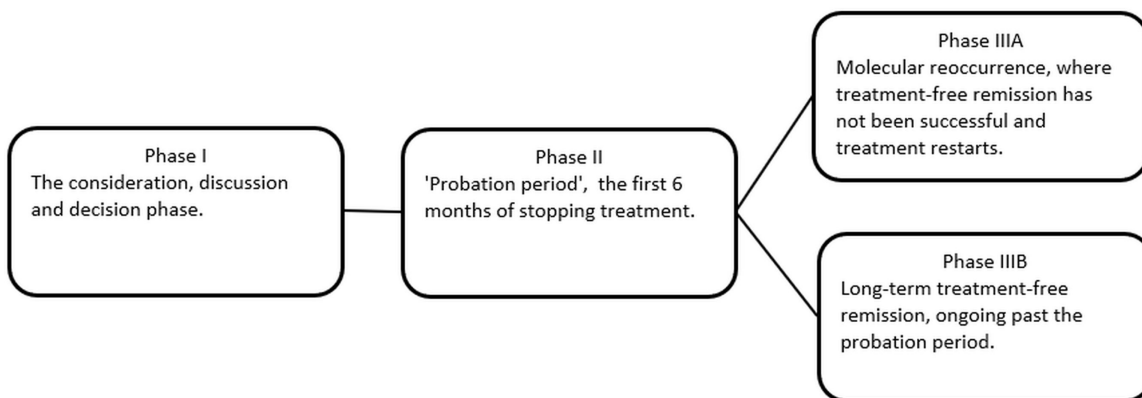
A total of 1016 responses were collected from CML patients across 68 countries. Patients only answered the sections of the questionnaire that were relevant for them. All 1016 had experience of Phase I, 494 (49%) had experience of Phase II, 159 (16%) had experience of Phase IIIA, and 203 (20%) had experience of IIIB. Of the 494 patients who stopped treatment, 32% said disease reoccurred and 41% reported being in long-term remission (this includes <1% who said, after stopping treatment, they had to restart, but they attempted stopping again and are currently in long-term remission). During Phase I, 22% said they would have liked to have received information on psychological effects. During Phase II: 18% of respondents said they discussed how to deal with psychological aspects with their doctor; 31% of respondents said they felt fear or anxiety before and/or after PCR monitoring tests, and overall 56% of respondents said they felt fear or anxiety and some point during the phase. 45% of males said they felt fear and anxiety during this phase, compared to 63% of females. There were differences in reported psychological and/or emotional support received across Phases II, IIIA and IIIB. Phase II had the smallest proportion of patients who said they received support (20%); in Phase IIIA, this was 26% and in Phase IIIB, 25%. Phase IIIA had the largest proportion of patients who wanted support but didn't receive it (25%); in Phase II, it was 23%, and it was lowest in Phase IIIB, 16%. While the highest proportion of patients answered that psychological/emotional support was not necessary; this varies by gender and across the TFR journey. Phase IIIA had the smallest proportion of patients who said they did not need support (48%); in Phase II this was 57%, and in Phase IIIB it was 59%. Across all phases, a larger proportion of male respondents said support was not necessary, compared to female respondents.



## Conclusions

There are opportunities for more communication and support around psychological issues to be given through the provision of information during the decision-making stage, and/or discussions between doctors and patients during the stopping stage. A considerable proportion of patients feel fear or anxiety at some level during stopping treatment, and not all patients who want psychological and/or emotional support receive it. The psychological well-being of patients should be a consideration of healthcare professionals and addressed at all stages of the TFR journey, to ensure patients receive support at the level they want through personalised care.

The four phases of treatment-free remission.





# CML Advocates Network

**Disclosures:** **Sharf:** Incyte: Honoraria, Other: Advocacy Advisory Board, Research Funding; Abbvie: Other: Advocacy grants funding; Roche: Other: Advocacy grants funding; BMS: Other: Advocacy grants funding, Research Funding; Takeda: Other: Advocacy grants funding; Janssen: Other: Advocacy grants funding; Novartis: Honoraria, Other: Advocacy Advisory Board, Research Funding; Pfizer: Honoraria, Other: Advocacy Advisory Board, Research Funding. **Geissler:** Pfizer: Consultancy, Research Funding, Speakers Bureau; Janssen: Consultancy, Speakers Bureau; Novartis: Consultancy, Research Funding, Speakers Bureau; Bristol-Myers Squibb: Consultancy, Research Funding, Speakers Bureau; Biomarin: Consultancy; Takeda: Research Funding; Amgen: Consultancy; Incyte: Research Funding; Roche: Consultancy; Servier: Consultancy; UCB: Consultancy, Speakers Bureau. **Marin:** Leukemia Patient Advocates Foundation: Employment. **Pemberton-Whiteley:** Acute Leukemia Advocates Network (ALAN): Consultancy; CML Advocates Network: Membership on an entity's Board of Directors or advisory committees; Patient Evidence: Equity Ownership; Daiichi Sankyo: Other: Grant funding; Gilead: Other: Grant funding, Speakers Bureau; Incyte: Consultancy, Other: Grant funding; Jazz: Other: Grant funding, Speakers Bureau; Janssen: Consultancy, Other: Grant funding; Kyowa Kirin: Other: Grant funding; Novartis: Consultancy, Other: Grant funding, Speakers Bureau; Pfizer: Consultancy, Other: Grant Funding, Speakers Bureau; Takeda: Other: Grant funding; Shire: Other: Grant Funding; AbbVie: Other: Grant funding; Amgen: Consultancy, Other: Grant funding, Speakers Bureau; Bristol-Myers Squibb: Consultancy, Other: Grant funding, Speakers Bureau; Celgene: Consultancy, Other: Grant funding; Leukaemia Care: Employment. **Bombaci:** CLL Advocate: Consultancy, Membership on an entity's Board of Directors or advisory committees, Other: grant funding ; CML Advocate: Consultancy, Membership on an entity's Board of Directors or advisory committees, Other: Grant funding ; Incyte: Consultancy; Onlus: Consultancy, Membership on an entity's Board of Directors or advisory committees, Other: grant funding; Novartis Pharma AG: Consultancy, Other: Advisory board ; MPN Advocate: Consultancy, Membership on an entity's Board of Directors or advisory committees, Other: grant funding ; Abbvie: Consultancy, Other: grading funding; Bristol-Myers: Consultancy, Other: Grant Funding; Jazz: Consultancy, Other: Grant funding ; janssen: Consultancy, Other: grant funding. **Christensen:** Novartis: Consultancy, Other: Advisory Board; Incyte: Consultancy, Other: Advisory Board. **Gouimi:** AMAL: Membership on an entity's Board of Directors or advisory committees; Novartis Pharma: Consultancy, Other: Advisory Board; Bristol-Myers: Consultancy; Novartis: Consultancy, Other: funding grant; Takeda: Consultancy; Pfizer: Consultancy. **Deekes:** Novartis Pharma: Honoraria. **Bradley:** Quality Health: Employment.