

## Introduction

Due to recent changes in acute leukemia treatment, there is an urgent need for greater understanding of the factors affecting quality of life at different points in the journey of patients.

The Acute Leukemia Advocates Network (ALAN) is running a multi-country survey to gather information on the experiences, quality of life and symptoms of adults (16+) with different types of acute leukemia. The study objectives were to: (1) investigate whether the HM-PRO scores differ according to disease state; (2) determine whether those with worse scores on Q13-Q18 (patient-reported experience) will also report higher HM-PRO scores (a worse quality of life); (3) examine if there are significant differences for the HM-PRO scores between acute leukemia types and gender.

## Methods

This survey comprises 99 items and was designed based on a literature review of quality of life and acute leukemia followed by input from clinical and patient advocacy experts. HM-PRO, an instrument to measure patient-reported outcomes in patients with hematological malignancies, was incorporated into the survey for assessing quality of life and symptoms. This is a composite measure consisting of: Part A (impact/quality of life) and Part B (signs and symptoms). A higher score in each part represents more impaired outcomes.

Question 9 provides a measure for disease state (undergoing treatment, in remission following treatment or relapsed following treatment).

We hypothesised that patients with a worse experience in each of these areas would report a worse overall quality of life:

Experience Category	Question
Physical symptoms and side effects	13
Emotional impact	14
Physical and mental health	15
Information from healthcare professionals	16
Ability to perform meaningful activities	17
Well-being of carers, friends and family	18

These are itemised on an interval scale ranging from 0-10, where 0 represents a bad experience and 10, a good experience.

Questions 19-99 investigated further each of the hypotheses, to identify patient issues and background demographic questions.

The survey was translated into 9 languages and promoted via patient advocacy groups from 1/3/19 to 22/11/19. A cut of the data was taken on 31/5/19, which is used for this analysis.

Spearman correlation analysis was used to determine the direction and strength of relationships between the measures. Two sample Wilcoxon rank-sum tests and Kruskal-Wallis rank test were applied to test for differences between groups.

## Results

There were 371 respondents in the interim data cut:

Leukemia Type	Respondents
Acute myeloid leukemia (AML)	213
Acute lymphoblastic leukemia (ALL)	86
Acute promyelocytic leukemia (APL)	72
Total	371

There was no evidence of any difference in the HM-PRO score for either Part A – quality of life (p=0.9) or Part B – signs and symptoms (p=0.4) between acute leukemia types.

# Identifying differences in the quality of life of patients with acute leukemia: a global survey

Zack Pemberton-Whiteley<sup>1</sup>; Jan Geissler<sup>1</sup>; Sophie Wintrich<sup>1</sup>; Esther Oliva<sup>2</sup>; Sam Salek<sup>2</sup>; Tatyana Ionova<sup>2</sup>; Rosemary Tate<sup>3</sup>; Jennie Bradley<sup>3</sup>

1- Acute Leukemia Advocates Network; 2- HM-PRO; 3 – Quality Health Limited

## Acute leukemia patients are more likely to have a reduced quality of life if they:

- are undergoing treatment
- are female
- report a worse patient experience.

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## Results

Of these 149 were men and 219 female and 3 provided no gender. The median Part A score for males and females was 24.1 and 30.39, respectively (p=0.07). The median for Part B was 17.6 and 23.5 for males and females, respectively (p=0.01) with females reporting greater burden of signs and symptoms.

The analysis suggests that there is a difference in the HM-PRO scores between disease state, with those in remission following treatment having lower HM-PRO scores (better quality of life) than those currently undergoing treatment.

Figure 1: Boxplots showing the distribution of HM-PRO Part A score according to the three disease states: in treatment, in remission following treatment, relapsed after treatment\*

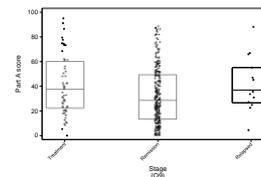
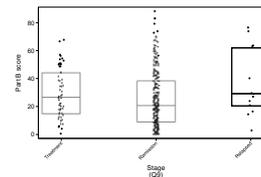


Figure 2: Boxplots showing the distribution of HM-PRO Part B score according to disease state\*



\* A small amount of random noise was added to the points for display purposes.

The results confirmed our hypotheses that those with worse scores for Q13-Q18 have a worse quality of life (higher HM-PRO score). The responses to all of these questions were either weakly or moderately related to scores of both parts of the HM-PRO. The correlations (negative) were all statistically significant, suggesting that low HM-PRO scores are associated with good experiences and vice versa. Some individual questions were also highly correlated ( $r_s \geq 0.7$ ) with one another (e.g. Q14 and Q13, or Q17 and Q18), showing internal stability of the items.

Table 1: Correlations between HM-PRO scores and Q13-Q18 (patient-reported experience)

	Part A score	Part B score	Q13	Q14	Q15	Q16	Q17	Q18
Part A score	1.000							
Part B score	0.632	1.000						
Q13	0.388	0.397	1.000					
Q14	0.481	0.365	0.775	1.000				
Q15	0.230	0.470	0.266	0.603	1.000			
Q16	0.408	0.322	0.427	0.685	0.498	1.000		
Q17	0.682	0.524	0.410	0.440	0.553	0.446	1.000	
Q18	0.578	0.433	0.346	0.403	0.519	0.357	0.711	1.000

## Conclusion

Based on this interim data, the study evidences that acute leukemia patients in remission report a better quality of life than those currently undergoing treatment. However, there is no evidence of any difference in the HM-PRO scores between acute leukemia types which needs to be further explored in controlled studies. In terms of gender differences, the results indicate that female patients experience greater impact on signs and symptoms. Furthermore, patients with worse reported experience (in each category, Q13-18) have a lower overall quality of life, suggesting that improving support in these areas may enhance overall quality of life.

