

Patient and Clinician Experience of Using Goal Attainment Scaling for Hemophilia (GAS-Hēm), an Innovative Patient-Centered Outcome Measure

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Introduction

- The value of the patient perspective in guiding clinical care is increasingly recognized, but there are a limited number of tools available to facilitate and document this important aspect of care
 - Current outcome measures for patients with hemophilia have some inherent limitations, particularly as the number of treatment options increases¹
- The ability to measure clinically meaningful improvements in patient outcomes is of great importance for:¹
 - Patient-centered care
 - Real-world clinical research
 - Demonstrating the value of hemophilia treatment centers (HTCs)
- Goal Attainment Scaling for Hemophilia (GAS-Hēm) is an innovative, patient-centered outcome measure and clinical engagement tool used to establish and measure progress toward patient goals,^{2,3} based on established GAS methodology.⁴⁻⁶ GAS-Hēm:
 - Encourages patients to set measurable, personally meaningful goals
 - Provides a method for documenting goal attainment in a structured manner that allows for quantitative analysis⁷
 - Fosters patient engagement in treatment planning and enhances the conversation between clinician and patient⁸
- A feasibility study was undertaken to evaluate the acceptability, validity, and responsiveness of the GAS-Hēm^{9,10}
 - The results of this study were presented earlier this year at the Hemostasis and Thrombosis Research Society annual meeting⁹ and the International Society on Thrombosis and Haemostasis congress¹⁰
 - Data from this study provided evidence that GAS-Hēm is able to show personally and clinically meaningful change over a short timeframe in adult and pediatric patients with hemophilia

Objective

- To describe the patient and clinician experience of using GAS-Hēm for setting goals and tracking goal attainment

Methods

- A 12-week feasibility study was carried out at four study sites in the United States and Canada, between December 2015 and November 2016
- Participants with severe hemophilia A or B (ages 5–65 years) took part in face-to-face GAS-Hēm-facilitated goal-setting interviews at the study start
- Goal attainment was assessed at 6 and 12 weeks (in person or by telephone) and rated separately by participants and clinicians
- Participants' experience using the GAS-Hēm tool was captured using a 13-item, self-report end-of-study survey (P-ESS) administered at the final study visit
 - Most questions were open ended (n=9)
 - Others were "Yes/No" or based on a five-point Likert scale
- Clinicians' feedback on the GAS-Hēm tool was captured using a 25-item end-of-study survey (C-ESS) and during a post-study debrief meeting

Results

- Participants included pediatric (n=9), adolescent (n=9) and adult (n=24) patients with severe hemophilia (Table 1)
 - All participants set at least one goal, and half set two goals (median=1.5, range=1-2)
- 38/42 participants (90%) completed the P-ESS
 - None had previously used anything similar to GAS-Hēm
 - Most (29/38) reported that GAS-Hēm was useful in managing hemophilia (including 12 participants who rated it very/extremely useful)

Table 1: Participant Demographics

Parameter	Pediatric n=9	Adolescent n=9	Adult n=24	All N=42
Age (y), median (range)	8 (5–12)	15 (13–18)	29 (19–64)	24 (5–64)
Race, n (%)				
White	7 (78)	8 (89)	20 (83)	35 (83)
Asian	1 (11)	0	2 (8)	3 (7)
Black	1 (11)	1 (11)	0	2 (5)
Other	0	0	2 (8)	2 (5)
Total duration on any prophylaxis regimen (y), median (range)	7 (4–9)	14 (11–17)	19 (1–29)	16 (4–29)

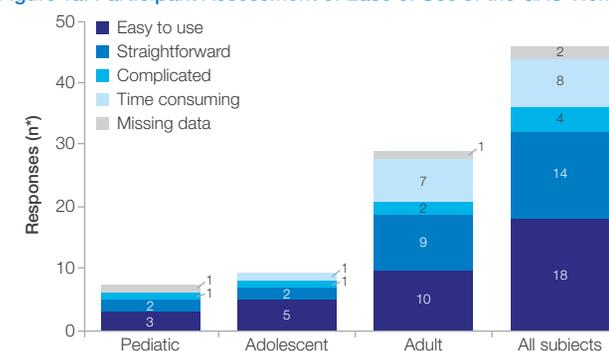
In response to open-ended questions, participants' enthusiasm for personalizing their goals emerged as a clear theme, as well as a desire for increased accountability (Table 2)

Table 2: Selected Participant Responses to Open-Ended Survey Questions

Positive Feedback	Constructive Criticism
<ul style="list-style-type: none"> "I was able to choose my own goals" "Gave me motivation and a goal" "Holds you accountable" "Gave me a small push to actually change" 	<ul style="list-style-type: none"> "Invisible in-between visits" "Call more to push people to do their goals" "There should be additional accountability" "Some goal descriptions were too vague"

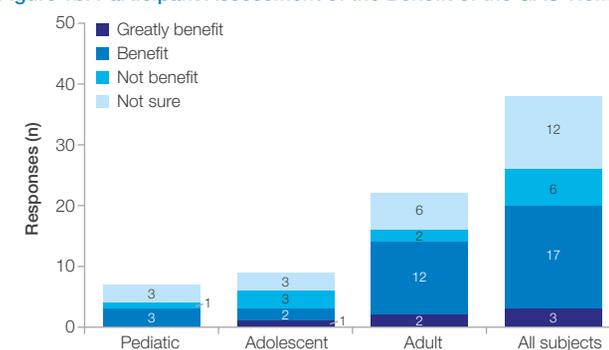
About half of patients found GAS-Hēm easy to use, whereas only one in five found it to be time consuming and one in 10 found it to be complicated (Figure 1a)
Similarly, about half of patients felt that using GAS-Hēm would benefit them, while just one in three was uncertain and one in six felt it would not (Figure 1b)

Figure 1a: Participant Assessment of Ease of Use of the GAS-Hēm



*The total number of responses can be greater than the number of participants, as more than one option could be selected.

Figure 1b: Participant Assessment of the Benefit of the GAS-Hēm



Clinician Assessment of the GAS-Hēm Tool

- Six clinicians completed the C-ESS and eight participated in the debrief; all sites were represented
 - Clinicians from the disciplines of nursing, social work, and medicine were included
- As a tool for care planning, case management, and measuring patient outcomes, all respondents rated GAS-Hēm as "somewhat or very useful"
- In response to open-ended questions and during the debrief session, clinicians reported that a particularly important benefit of using GAS-Hēm was its impact on the quality of their patient interviews and on patient motivation (Table 3)
 - The requirement for training and the challenge of learning to use a new tool were noted as potential barriers to adoption

Table 3: Selected Responses to Survey Questions and During the Debrief Session

Positive Feedback	Constructive Criticism
<ul style="list-style-type: none"> "Incredibly useful" "Facilitated productive interviewing" "Provided personalization and guidance" "A great conversation opener and motivator" 	<ul style="list-style-type: none"> "Requirement for significant staff training" "The learning curve is steep" "Can be time consuming" "Highly dependent on patient motivation/willingness"

Conclusions

- These findings support the merit of the GAS-Hēm tool, suggesting that patients and clinicians would find value in incorporating this approach in routine clinical practice
- A revised tool (rebranded as "GOAL-Hēm") integrating patient and clinician input from the feasibility study is currently in development and will be supported by a comprehensive clinician training program

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Contributorship

SL conducted the GAS-Hēm interviews. ES and JG led the development team for the GAS-Hēm. SF and CC analyzed the data. All authors collaborated on this poster.

Acknowledgments

Professional medical writing support was provided by Bill Kadish, MD, of PAREXEL and funded by Shire.

We are indebted first and foremost to the patients and caregivers who participated in the study.

We are thankful for the involvement of the investigators, clinician interviewers, HTC staff, DGI staff, and Shire Medical Affairs staff for their invaluable contributions to this study and to the development of the GAS-Hēm.