



Integrating PROBE into clinical care to facilitate transformation to a Value-Based Health Care Model in hemophilia.



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INTRODUCTION

The PROBE survey was developed by patients, hemophilia caregivers and methodological experts as a stand-alone cross-sectional instrument with multistep validation and control group data.¹

While not developed for use in clinics, it measures important value-based health outcomes including health status, mobility, independence, acute/chronic pain and overall quality of life.²

Measuring health outcomes that matter to patients in a condition such as hemophilia is a key feature of Value Based Health Care.³

AIM

We report initial results from a feasibility project using PROBE during routine care to enable patients to provide outcome measures to clinical teams and improve quality, value and experience of hemophilia care.

METHOD

With endorsement from the PROBE investigators, three patients from the British Columbia (BC) Adult Bleeding Disorders Provincial Program were identified to guide a BC steering group of clinicians and coordinators and the McMaster PROBE group. The steering group endorsed adding six additional vocational survey items to the 30 question PROBE instrument. An anonymized link was sent to patients with all severities of hemophilia A and B 1-2 weeks pre routine clinic visit and upon completion, patients were given the option to share survey results with the clinical team. All patients were sent an evaluation form post-visit.

RESULTS

102 survey links were sent and 54 patients completed the survey in full (53% completion rate). Six had technical issues sharing the survey and 48 independently completed and shared the survey.

After the clinic visit, 24 patients (44% of those who completed and attended clinic) voluntarily provided a 10 question post-clinic evaluation (see Figure 1).

- 94% indicated PROBE covered all areas that they felt were important to address
- 94% were willing to take it again
- 94% felt the PROBE responses had a very beneficial or beneficial impact

1	The Hemophilia Team provided you with some information to explain the PROBE survey and asked you to complete it. How informed about PROBE did you feel after reviewing this information?
2	Surveys take time to complete. How would you rate the overall impact/burden of completing the PROBE survey on you?
3	Were there any areas not covered by the PROBE survey that you think are important to include? If yes, please specify:
4	When you had your appointment with the team, to what degree did you think they were knowledgeable about your PROBE survey responses?
5	How willing are you to take the PROBE survey again?
6	What benefit do you think your PROBE survey responses had on the team members ability to have meaningful discussion with you during your recent visit?
7	Your PROBE dashboard will allow you to trend your scores over time (eg. Did your activity levels change over time? How much?). How important is this feature to you?
8	Your PROBE dashboard will allow you to compare your scores to other groups you select (eg. Canadian males over the age of 60). How important is this feature to you?
9	PROBE isn't the only survey you are asked by the Hemophilia Team to complete. What statement best describes your opinion on team requests to complete these surveys?
10	How likely would you be to recommend completion of the PROBE survey to other people with Hemophilia?

FIGURE 1. PROBE in Clinic Evaluation Questions

Based on feedback from patients and caregiver, we created a dashboard to track the result of the questionnaire over time, and to compare these results with other participants (Figure 2).

To reduce the respondents' burden, we created a short version of the PROBE questionnaire to be administered after the first completion of the full PROBE.

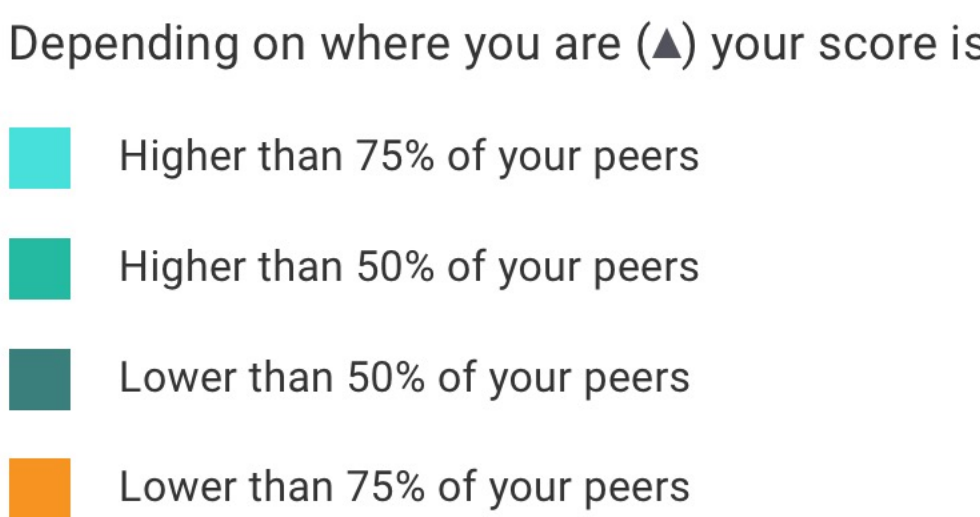
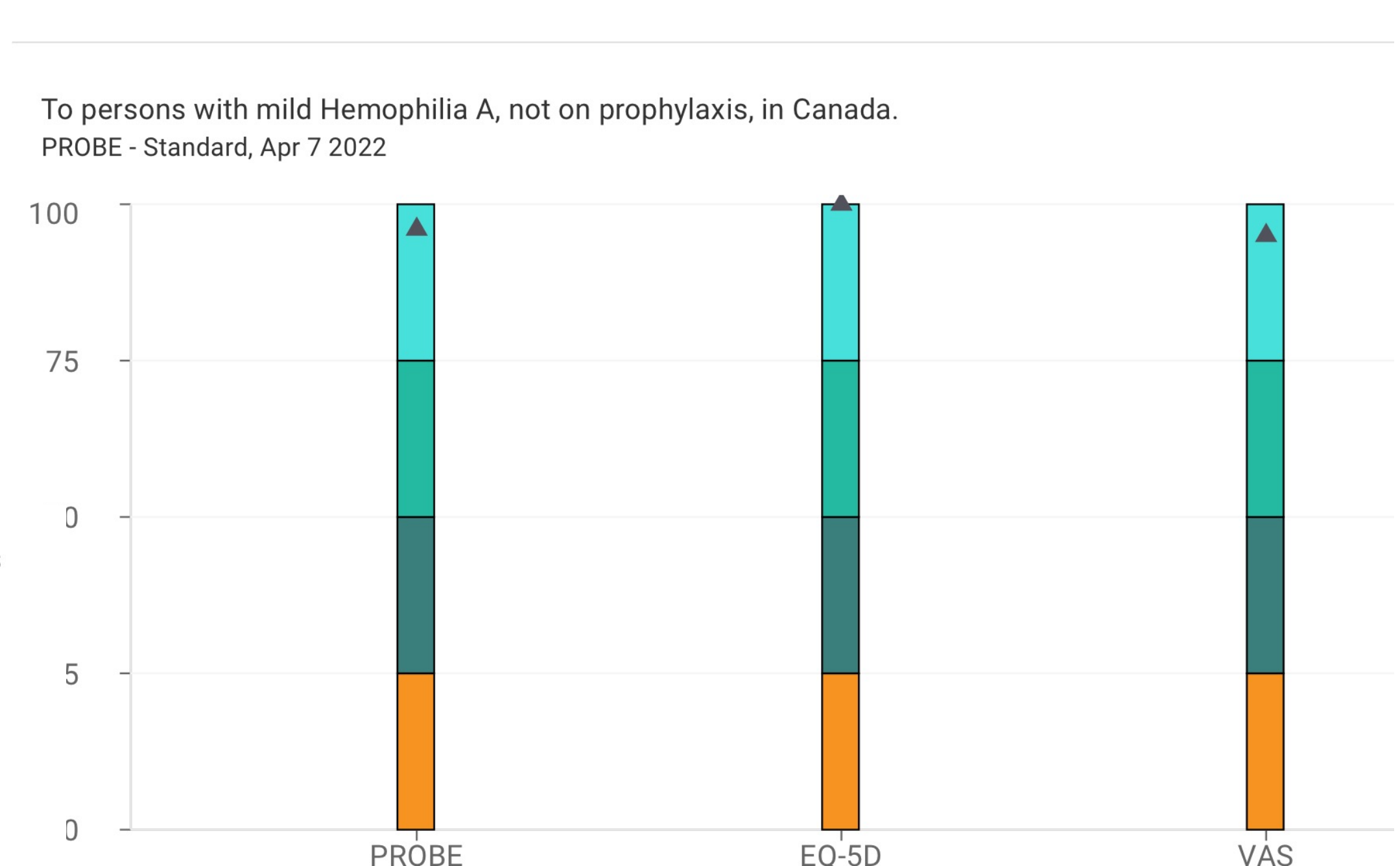


FIGURE 2: a portion of the participants' dashboard on the PROBE website



CONTRIBUTE

Both people with and without hemophilia can contribute to the probe project!

Please, complete the PROBE questionnaire using one of the following links:



CONCLUSIONS

It is feasible to embed PROBE into routine care from a patient and clinician perspective to enhance longitudinal single patient or population-based health outcome measurement.

Next steps include enhancing the interface for clinician viewing, allowing patients to trend their results over time and allowing the option for patients to compare their results to selected peer groups within the National/Global PROBE system.

Currently, this can be done for the quality of life scores. We are working on extending this feature to various domains of the PROBE questionnaire (e.g. pain, use of mobility aids, comorbidities...).

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REFERENCES

1. Skinner MW et al. The Patient Reported Outcomes, Burdens and Experiences (PROBE) project: Development and evaluation of a questionnaire assessing patient reported outcomes in people with haemophilia. Pilot Feasibility Study. 2018; 4:58
2. Patient-relevant health outcomes for hemophilia care: development of an international standard outcomes set. Van balen EC, O'mahony B, Cnossen MH, Dolan G, Blanchette VS, Fischer K, Gue D, O'hara J, Iorio A, Jackson S, Konkle BA, Nugent DJ, Coffin D, Skinner MW, Smit C, Srivastava A, van Eenennaam F, van der Bom MD JD, Gouw SC. Research and practice in thrombosis and haemostasis.2021. <https://doi.org/10.1002/rth2.12488>
3. What is value in health care? Porter, ME. NEJM 2010; 363:2477-2481