

Development and testing of the myPROBE app and integration with the Canadian Bleeding Disorder Registry

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INTRODUCTION

Advances to support accessibility and robust data collection is important in a world of rapidly changing technology.

We aimed at supporting longitudinal data collection on the PROBE questionnaire¹ and integrating the data collection with other databases, using the Canadian Bleeding Disorder Registry (CBDR) as a proof of concept.

METHODS

- Series of semi-structured interviews were conducted to assess the needs and expectations of the following:
 - PROBE Investigator
 - People with Hemophilia
 - Representatives of the Sponsors
- Development of the App for iOS and Android using react-native, with user-centered approach (multiple iterative circles)
- The myPROBE App was evaluated BY:
 - System Usability Scale (SUS)
 - Open feedback framework



Patient Reported Outcomes Burdens and Experiences Study

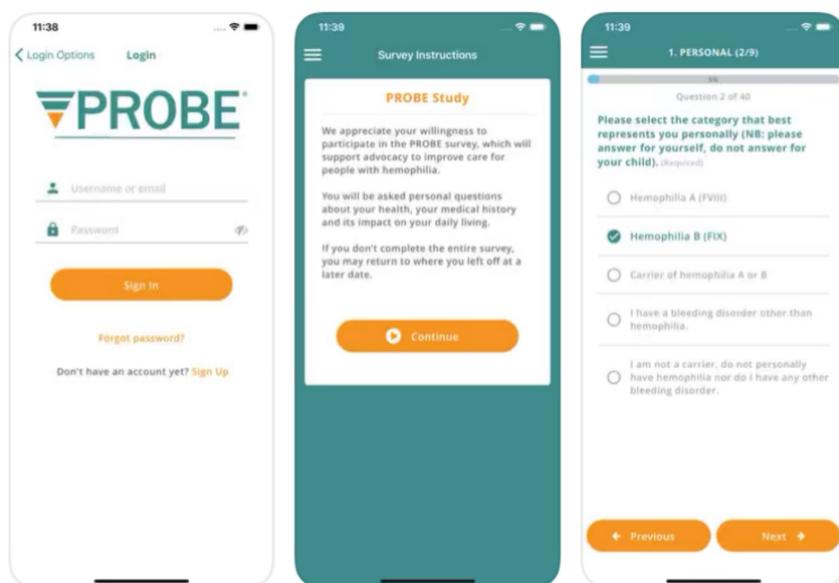
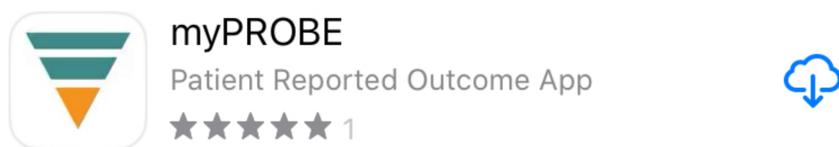
www.probestudy.org ▼ info@probestudy.org

RESULTS

- App released in July 2019
- 17 users (age 23-67 years) evaluated the published version
- Median SUS score (first, third quartile) 85 (68, 88) out of 100
- The newly introduced functionalities:
 - The capability of longitudinal tracking and repeated filling of the survey at different time points
 - Connection with CBDR
 - Removing and adding questions as needed
- Development of the new secure database storage for personal information
- 1148 participants completed PROBE since the app release, 162 of which using CBDR credentials
- The myPROBE app is available in 70+ countries and 75+ languages and continues to grow.

CONCLUSIONS

The online survey was updated successfully, and the myPROBE app was developed. In the first months after the product's release, the responses from testers and users have been largely positive. The median SUS compares well with the top 10 most used and popular apps across all categories (78).

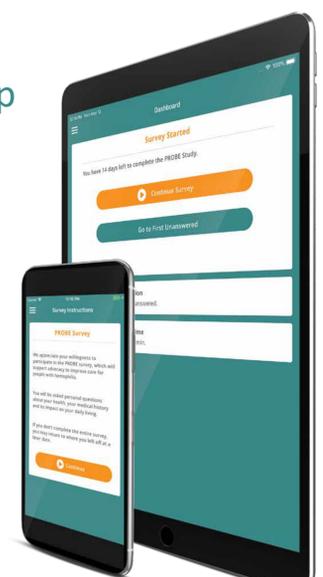


Scan the QR code to download the myPROBE app

Apple



Android



ACKNOWLEDGEMENTS

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REFERENCES

1 Skinner MW, Chai-Adisaksopha C, Curtis R, 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 Stud 2018;4:58.