

3 apps in 1: MyCBDR, myWAPPS and myPROBE

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Page 1, ChatrieChai Adisaksopa 2, 3, Randall Curtis 4, Neil Frick 5, Federico Germini 2, Arun Keepanasseril 2, Alfonso Iorio 6, 7 Michael Nichol 8, Declan Noone 9, 10, Brian O'Mahony 11, 12, Mark W. Skinner 6, 13, Jeff Stonebraker 14

Introduction and Objectives

MyCBDR is the patient/caregiver bleed and infusion reporting app connected to the Canadian Bleeding Disorder Registry (CBDR). myWAPPS (Web Accessible Population Pharmacokinetics Service) is an app that enables patients to see their predicted plasma factor levels in real-time, based on a personalized pharmacokinetic (PK) study. These two apps were connected in July 2019 such that an infusion reported in MyCBDR instantly updates factor levels in that person's myWAPPS app. myPROBE is an app that allows people with hemophilia to complete the PROBE (Patient Reported Outcomes, Burdens, Experiences) survey anonymously. It, too, was linked in July 2019 such that the MyCBDR login can be used to access the survey. MyCBDR users can be followed over time, receive yearly reminders to complete the PROBE survey and receive reports on changes to their PROBE score. The objectives of this connectivity are to make data collection more user-friendly, useful and attractive; provide personal health information feedback; and increase the number of people reporting.

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Results

Seventeen (17) users aged 23 to 67 years evaluated the final version of the PROBE app using the SUS. The median (first, third quartile) SUS score for the app was 85 (68, 88) out of 100. The median SUS compares well with the top 10 most used and popular apps across all categories (78).

As of May 2020, 882 Canadians with hemophilia A and B report bleeds and infusions via MyCBDR. 188 of them used their MyCBDR login credentials to access and complete the PROBE study between July 2019 and May 2020.

161 Canadian patients have undergone a WAPPS study. 317 of them are registered with MyCBDR. Only 44, however, receive their updated real-time factor levels on their MyWAPPS app by reporting infusions directly via MyCBDR.

Conclusions

In the 10 months after the apps were linked, the responses from testers and users have been largely positive. The ease of access has led to a much more representative sample (188/882, 21%) of people registered with MyCBDR (principally, home infusion patients with hemophilia A and B) completing the PROBE survey. This in turn has provided the Canadian patient organization, the Canadian Hemophilia Society, with valuable patient-reported outcome data on pain, education and employment, need for mobility aids and impact of hemophilia on activities of daily living. These data are used in patient organization submissions for health technology assessments of novel therapies.

With time, it is hoped that the numbers reporting outcomes annually via the PROBE survey will continue to increase, revealing individual and collective changes.

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Materials and methods

The Health Information Research Unit team at McMaster University and Design2Code Inc. developed an online survey using Windows.net technologies and a mobile application for iOS and Android using react-native, in collaboration with the PROBE investigators. A user group evaluated the final product using the System Usability Scale (SUS) and an open feedback framework. In addition, the number of Canadian patients who, after undergoing a previous WAPPS PK study, registered through MyWAPPS was measured. The PROBE and CBDR databases were queried to measure inter-connectivity.

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Institutions

1 Canadian Hemophilia Society, Montreal, Canada; 2 Department of Medicine, McMaster University, Hamilton, Canada; 3 Department of Internal Medicine, Chiang Mai University, Chiang Mai, Thailand; 4 Factor VIII Computing, Berkeley, US; 5 National Hemophilia Foundation, NYC, US; 6 Department of Health Research Methods, Evidence, and Impact, Hamilton, Canada; 7 McMaster-Bayer Endowed Research Chair in Clinical Epidemiology of Congenital Bleeding Disorders, Department of Medicine, McMaster University, Hamilton, Canada; 8 University of Southern California, Sol Price School of Public Policy, LA, US; 9 Health Decisions Consultants, Dublin, Ireland; 10 European Haemophilia Consortium, Belgium; 11 Irish Haemophilia Society, Dublin, Ireland; 12 Trinity College Dublin, Dublin, Ireland; 13 Institute for Policy Advancement Ltd., Washington, US; 14 North Carolina State University, Poole College of Management, Raleigh, US

David Page 1; ChatrieChai Adisaksopa 2, 3; Randall Curtis 4; Neil Frick 5; Federico Germini 2; Arun Keepanasseril 2; Alfonso Iorio 6, 7 Michael Nichol 8; Declan Noone 9, 10; Brian O'Mahony 11, 12; Mark W. Skinner 6, 13; Jeff Stonebraker 14

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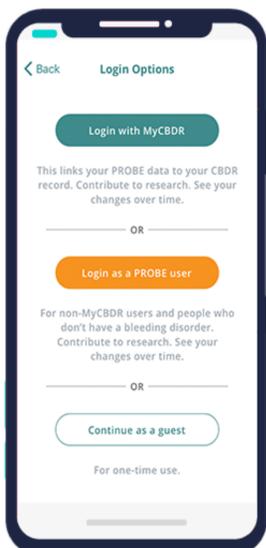


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CONCLUSIONS

In the 10 months after the apps were linked, the responses from testers and users have been largely positive. The ease of access has led to a much more representative sample (188/882, 21%) of people registered with MyCBDR (principally, home infusion patients with hemophilia A and B) completing the PROBE survey. This in turn has provided the Canadian patient organization, the Canadian Hemophilia Society, with valuable patient-reported outcome data on pain, education and employment, need for mobility aids and impact of hemophilia on activities of daily living. These data are used in patient organization submissions for health technology assessments of novel therapies.

With time, it is hoped that the numbers reporting outcomes annually via the PROBE survey will continue to increase, revealing individual and collective changes.

The number of people taking full advantage of the inter-connectivity between myWAPPS and MyCBDR is low, and needs to be better promoted by both the patient association and treatment centres.

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ABSTRACT

Introduction and Objective: MyCBDR is the patient/caregiver bleed and infusion reporting app connected to the Canadian Bleeding Disorder Registry. myWAPPS is an app that enables patients to see their personalized predicted plasma factor levels in real-time. These two apps were connected in July 2019 such that an infusion reported in MyCBDR instantly updates factor levels in myWAPPS. myPROBE is an app that allows people with hemophilia to complete the PROBE survey on patient-reported outcomes on-line and, through anonymous registration, be followed longitudinally. It, too, was linked in July 2019 such that the MyCBDR login can be used and MyCBDR users can be followed over time, receive yearly reminders to complete the PROBE survey and receive reports on changes to their PROBE score. The objective of this connectivity is to make data collection more user-friendly, useful and attractive. **Materials and Methods:** The Health Information Research Unit team at McMaster University and Design2Code Inc. developed an online survey using Windows.net technologies and a mobile application for iOS and Android using react-native, in collaboration with the PROBE investigators. A user group evaluated the final product using the system usability scale (SUS) and an open feedback framework. In addition, the number of Canadian patients who, after undergoing a previous WAPPS pharmacokinetics study, registered through MyWAPPS was measured. **Results:** Seventeen users aged 23 to 67 years evaluated the final version of the PROBE app using the SUS. The median (first, third quartile) SUS score for the app was 85 (68, 88) out of 100. The median SUS compares well with the top 10 most used and popular apps across all categories (78). 165 Canadians with hemophilia used their CBDR credentials to complete the PROBE study. 37 Canadian patients registered for myWAPPS via MyCBDR. **Conclusions:** In the first months after the apps were linked, the responses from testers and users have been largely positive. Over time, the inter-connectivity will lead to increased patient/caregiver engagement with their care and improved data collection.