



Integration of the Mexican Registry of Coagulopathies (RMC) with PROBE

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Acknowledgements

We thank the participating patient organization: Federation of Hemophilia of the Mexican Republic, AC (Mexico)



Disclosures

PROBE is an independent investigator led research project with grant / research support from: Bayer, CSL, Novo Nordisk, Roche, Sanofi, Sobi, Takeda and collaboration of the US National Hemophilia Foundation and McMaster University.





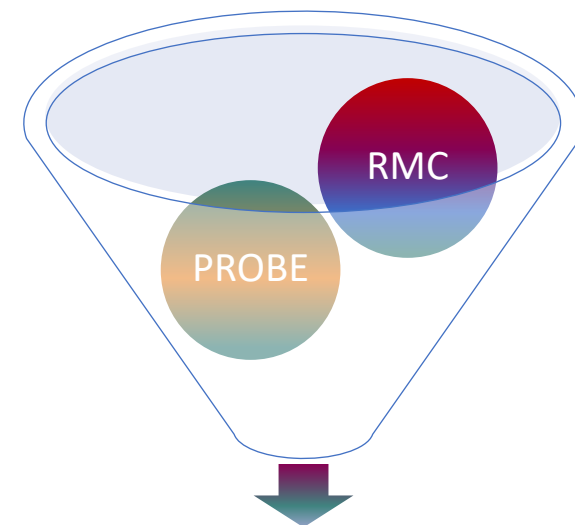
OBJECTIVES

Registro Mexicano de Coagulopatías (RMC) is a national registry app for people living with hemophilia, von Willebrand disease or other bleeding disorder as well as caregiver to report infusions and bleeding connected to the Federation of Hemophilia of the Mexican Republic (FHRM).



PROBE is the global self-reported quality of life survey by patients or individuals without bleeding disorder. PROBE tool available in three different platforms: paper, online website, and phone/tablet application

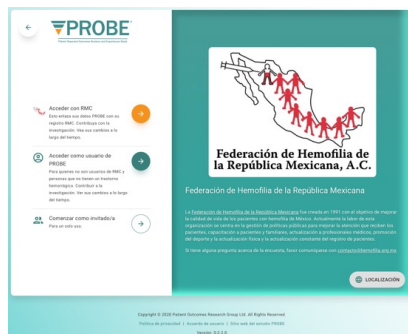
- These two tools were linked in October 2020 such that the RMC login can be used to access the survey.
- RMC users can be followed over time, receive yearly reminders to complete the PROBE survey and receive reports on changes to their PROBE score. The objectives of this connectivity are to make data collection more user-friendly, useful and attractive; provide personal health information feedback; and increase the number of people reporting.



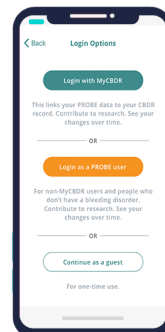
**BETTER DATA =
STRONGER ARGUMENT**



myPROBE Web

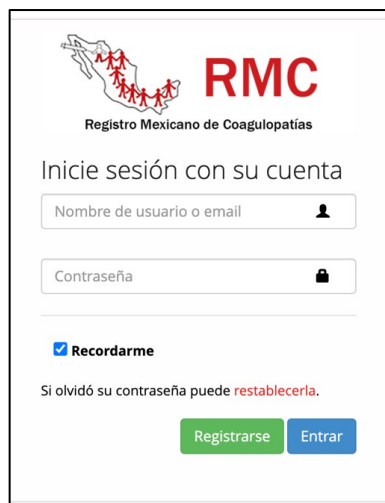
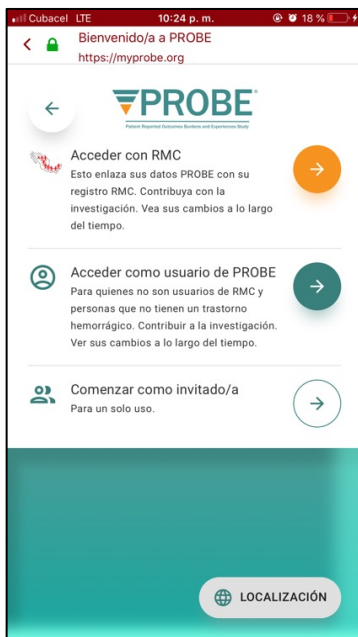


myPROBE App

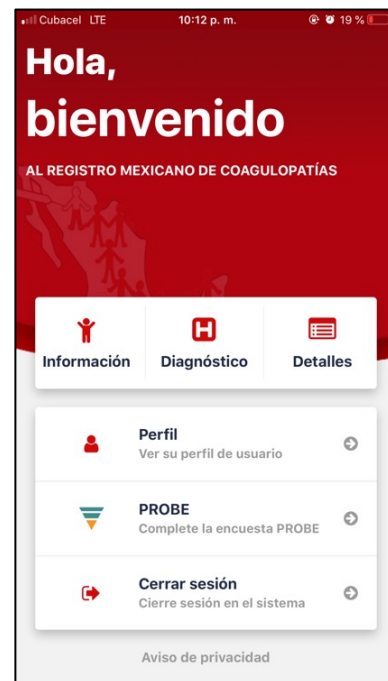


The Health Information Research Unit team at McMaster University and Design2Code Inc. developed an online survey using Windows.net technologies and a mobile application for iOS and Android using react-native, in collaboration with the PROBE investigators and FHMR. The PROBE and RMC databases were queried to measure inter-connectivity.

RESULTS



OR



The new management system of the FHRM allowed RMC project to begin development in September 2018. In January 2019, RMC reached its deployment phase. Shortly after, RMC and PROBE started to develop connection between tools for online platform and a mobile application for iOS and Android. In October 2020, RMC collaboration with PROBE study has been completed.



CONCLUSIONS

- 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 myPROBE and RMC is low and needs to be better promoted by both the patient association and treatment centers.
- It will provide the Mexican patient organization, the Federation of Hemophilia of the Mexican Republic, AC, with valuable patient-reported outcome data on pain, education and employment, need for mobility aids and impact of hemophilia on activities of daily living.

