

Exposing Benefits and Barriers: mHealth Use in Managing Hemophilia

A White Paper Exploring the Utilization of Mobile Apps
within the Hemophilia Community

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**Appendices B and C are not included in this document and are available upon request to the author.*

Executive Summary

BACKGROUND

Mobile phone health apps (mHealth) are changing the landscape of healthcare and are showing promise to improve the lives of individuals with hemophilia. The influx of mobile apps within the bleeding disorders community provides an alternative to manual record keeping and can help patients better manage their bleeding disorder. However, limited data exists regarding consumer usage and the perceived value of these apps.

OBJECTIVE

The purpose of this study is to systematically evaluate current hemophilia mobile apps (hemophilia mHealth), investigate the potential benefits of usage, and identify the barriers to broader adoption and usage.

METHOD

A three-phase process was followed: phase 1 consisted of a review of published research of the use of general (non-hemophilia related) mHealth; phase 2 involved a survey of the bleeding disorders community; phase 3 entailed a systematic evaluation of current hemophilia mobile apps.

RESULTS

World Health Organization's (WHO) adoption of mHealth initiatives is accelerating awareness of the inherent potential in mHealth. However, research has exposed many barriers to broader implementation including cost of an app, concerns over protected health information, and lack of regulatory approval. Barriers to continued and consistent app usage include difficulty in understanding and using healthcare apps due to unnecessary complexity and demanding or burdensome data entry requirements.

The results of this hemophilia mHealth study were generally consistent with previous published research on the usage of mHealth. Despite proven significant benefits that can result from using mHealth, adoption rates are low. There is only a limited understanding of potential benefits, and resources available to both consumers and physicians to help evaluate and select an appropriate app are extremely limited.

Our survey revealed 55% of respondents have never downloaded a hemophilia mobile app to manage their bleeding disorder. Barriers to adoption of hemophilia mHealth included a lack of awareness of currently available hemophilia mobile apps, lack of recommendations from physicians, perceived level of complexity, alternate practices to keeping treatment records (noncompliance or preference for manual record keeping), concerns over the security of protected health information, and a lack of understanding of the potential benefits. Of the 45% of survey respondents who had downloaded a hemophilia mobile app, many have already abandoned use. Only 14.5% of respondents were regular hemophilia mobile app users.

CONCLUSIONS

While many survey respondents had a favorable opinion of hemophilia mHealth, most have not eagerly embraced the use of these apps. Based upon the review of published literature, an analysis of survey results, and conclusions reached from the evaluation of currently available hemophilia mobile apps, recommendations to increase hemophilia mHealth usage that will encourage improved bleeding disorder management are offered within this paper.

Introduction

Seventy-seven percent of American adults own a smartphone and half own some sort of tablet.¹ According to IMS Institute for Healthcare Informatics, “Most smartphone users have more than 20 apps on their phone device at present; in many cases, this is closer to 30 apps.”² While the highest percentage of app usage is associated with social media and gaming apps, 58% of smartphone users gather health-related information through mobile apps related to healthcare.³

The advent of mobile health apps provides a new alternative to managing a bleeding disorder. Individuals can set reminders and track their treatment, record information related to bleeds, generate logs, access additional resources, and even locate a hemophilia treatment center (HTC), while traveling, all from the palm of their hand. Despite the potential benefits mHealth offers, many people have not embraced this new technology. Insufficient information, lack of physician recommendations, and other barriers have positioned hemophilia mHealth on a rather sluggish adoption trajectory.

The purpose of this paper is to provide insight into the current use of hemophilia mHealth, to increase awareness of potential benefits, and to provide recommendations to increase usage with the goal of improving health outcomes for people living with bleeding disorders. Within this document, the inclusion of hemophilia mHealth comparison charts provides a comprehensive overview of these apps. These charts are meant to aid patients and physicians in the selection of an app that satisfies specific consumer needs. (See Appendix A)

COMMON TERMS:

mHealth: Medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices.

*Global Observatory for eHealth (GOe)*⁴

mAdherence: Any use of mHealth tools by patients and health care providers to improve adherence to chronic disease management.

*Journal of Medical Internet Research (JMIR)*⁵

Digital Native: A person born or brought up during the age of digital technology and so familiar with computers and the Internet from an early age.

*Oxford Dictionary*⁶

ADVANTAGES OF mHEALTH

According to the FDA, “The widespread adoption and use of mobile technologies is opening new and innovative ways to improve health and healthcare delivery.”⁷ The FDA has issued guidelines for the development of mHealth to create standardization and to encourage consumer protection; yet, these guidelines are only suggestions. As the number of available mHealth apps increases, the consumer has more choices. However, these apps are often complex and may not adhere to FDA guidelines, resulting in a confusing array of choices with little guidance regarding app recommendations. Researchers are carefully examining the role these apps play in transforming healthcare with the hope of highlighting the ultimate benefits of mHealth and eliminating some of the confusion that has ensued.

In 2013, Quantile IMS conducted an extensive review of mHealth. This was the first study of its kind to investigate a wide range of healthcare apps including functionality and barriers that might limit usage. The study highlighted the promising impact of mHealth used by consumers/patients as part of a wellness, prevention, or treatment regimen. The study concluded there was a need for insurance companies and providers to become more engaged in the mHealth field to help guide consumers in their choice of an appropriate app.

The study identified an mHealth user was more engaged, better focused on their health, and took more responsibility in managing their healthcare. Researchers further suggested, “healthcare apps have the potential to bring efficiencies into healthcare systems by reducing the frequency and cost of direct interventions by healthcare professionals with patients.”⁸

Other studies investigating advantages of using mobile healthcare apps have also supported the use of this technology in preventative care and the treatment of chronic illnesses.⁹ The benefits of transforming mobile apps from “novelty to mainstream” include the following: greater patient engagement; improved adherence to treatment through reminders or alerts; improved record keeping of vital health information; assistance with transition of care; improved communication with physicians; and improved quality of life for patients.¹⁰

HEMOPHILIA: THE NEED FOR ADHERENCE AND THE POTENTIAL OF mHEALTH TO IMPROVE ADHERENCE

Considerable clinical evidence has shown prophylaxis treatment prevents bleeding from an early age, allowing those living with hemophilia to lead a fuller life with minimal restrictions. In fact, prophylaxis has become the evidence-based first-choice treatment recommended for children with severe hemophilia.¹¹ Yet, despite medical recommendations, many patients do not consistently remain adherent to their prophylactic schedule. According to the National Hemophilia Foundation, “Lack of adherence is a common pattern seen in people with chronic medical conditions that don’t always have a visible impact on daily health.”¹² An individual is more likely to adhere to treatment when experiencing pain due to a bleed rather than treating in the absence of pain or bleeding. Additionally, since prophylaxis results in minimal bleeding episodes, patients on this regimen do not fully experience the discomfort associated with internal bleeding and often don’t appreciate the importance of regular and timely treatment.

According to the World Health Organization, as quoted in Hemaware, “Individuals who have chronic illnesses in industrialized nations stick to their treatment plans only half the time. However, for individuals with severe hemophilia, the price of nonadherence can be high.”¹³ Failure to adhere to a prophylactic schedule often results in needing additional medicine to control a bleed, thus leading to higher medical expenses. Additionally, continual internal bleeding can result in joint damage, resulting in even higher medical costs. A report by Managed Market

Network in April 2016 states, “Hemophilia is associated with staggering direct costs from hospitalizations, outpatient visits, and drug treatments, as well as high indirect costs from diminished work productivity and absenteeism from work and school. Additionally, hemophilia incurs tremendous intangible costs, including reduced quality of life, pain and suffering, and the emotional and physical toll on the patient and caregivers.”¹⁴ Therefore, long-term adherence to prophylactic therapy results in optimal treatment outcomes, lowers healthcare expenses, and enhances the quality of life, while failure to adhere results in the opposite.

Lack of adherence isn’t limited to maintaining a prophylaxis regimen, but also extends to appropriate treatment recording keeping. As stated in *Managing Hemophilia: The Role of Mobile Technology*, “Good record keeping is an essential component of home-based hemophilia care. Well-kept treatment diaries can help healthcare professionals to ensure optimal factor use, adherence with treatment regimens and timely infusion practices.”¹⁵ However, many individuals find record keeping to be an inconvenience. People with bleeding disorders lead very active and busy lives, which makes adherence to overall medical management a challenge. Some researchers have found a missed prophylactic treatment is more often due to inconvenience and lack of time rather than simply forgetting about the need to treat.¹⁶ Unfortunately, adequate record keeping is often a low priority for those living with a bleeding disorder; the failure to maintain proper records often results in sub-optimal outcomes.

A NEW ALTERNATIVE: MANAGING HEMOPHILIA HEALTHCARE THROUGH HEMOPHILIA mHEALTH

mHealth has enormous potential to impact chronic disease management around the globe.¹⁷ The World Health Organization’s (WHO) adoption of mHealth initiatives (appointment reminders, treatment compliance, and patient monitoring) are accelerating awareness of the inherent potentials in mHealth. According to WHO, “If implemented strategically and systematically, mHealth can revolutionize health outcomes.”¹⁸

With the emergence of hemophilia mHealth, individuals with hemophilia are provided a new alternative to manual treatment diaries. Individuals can set reminders, track their treatment, record information related to bleeds, generate logs, access additional resources, and even locate an HTC while traveling. Hemophilia mHealth has the potential to lead to mAdherence: any use of mHealth tools by patients and healthcare providers to improve adherence to chronic disease management.¹⁹ However, the potential for mAdherence goes beyond adherence to taking medication and can include better monitoring and understanding of symptoms, improved patient-provider communication and relationships, and better transition of care and education through added resources. Experts predict overall medical care would improve if more people adhered to the use of mHealth.²⁰

BARRIERS TO BROAD ADOPTION OF mHEALTH

Mobile healthcare apps can vary in capabilities and function and, for a community of users to develop, an individual must be able to evaluate existing apps to ensure a match between user needs and app functionality. Without reliable measures of app verification, “Consumers are reliant on numbers of downloads and individual reviews as a guide to usage by the wider public, and hence become involved in a self-reinforcing cycle of most downloads continuing to inspire future downloads.”²¹

Information regarding each app’s utility is often limited and several barriers exist to broad adoption. Barriers to initial app use noted throughout research include cost of the app, concerns over privacy, security of protected health information, and lack of regulatory approval. Barriers related to continued and consistent app usage include difficulty in understanding and using healthcare apps due to unnecessary complexity and demanding or burdensome data

entry requirements. Responses from a national survey, reported in the Journal of Medical Internet Research, revealed a strong interest in simplified apps that allowed users to track data without manual entry.²²

Finally, patients and physicians fail to understand the potential significant health benefits that result from adopting mHealth, and this lack of understanding is one of the central challenges to broader implementation. The selection and consistent usage of a mobile healthcare app is impeded by a shortage of clinical evidence regarding its efficacy in improved health outcomes, by a lack of clarity around regulatory approval, and by minimal recommendations from physicians. According to Quintiles IMS, more “curation and evaluation” of mHealth is needed in order guide physicians and patients to make smart decisions when selecting a particular app.²³

Description of Research Methodology

PHASE 1: mHEALTH INDUSTRY RESEARCH

Research questions were structured to provide a foundation for this inquiry and serve as a basis for methodology.

- What is the role of mHealth in preventative care and the treatment of chronic illnesses?
- What is the impact of nonadherence to the treatment of chronic illnesses?
- What potential role can mHealth serve to improve adherence?
- What information is available regarding the use of hemophilia mHealth?

PHASE 2: mHEALTH SURVEY

Survey Design and Sample

A cross-sectional survey using Survey Monkey was conducted within the bleeding disorders community over a period of 6 weeks in April/May 2017. The survey targeted a representative sample of individuals identified as highly likely to maintain an infusion treatment log. The sample included individuals with severe hemophilia A or B, individuals with an inhibitor, and/or primary caregivers within these categories. The survey was 100% anonymous and voluntary. The survey was hosted by BioMatrix SpRx, the parent company for a family of industry-leading specialty pharmacies providing pharmacy services and digital health technology solutions for a range of chronic health conditions, including bleeding disorders. A total of 90 completed surveys were obtained.

Survey Items

Individuals who had downloaded a hemophilia mobile app answered 28 survey questions, while participants who hadn't downloaded a hemophilia mobile app answered 20 questions. (See Appendix B)

Questions were arranged as follows:

- Type of hemophilia, age range, and other demographic information
- Current treatment plan, adherence to treatment, and record keeping practice
- Type of mobile phone, tablet, and mobile app use
- Opinions regarding technology use, including those related to voice-activated technology, such as Alexa or Google Home
- Mobile app preferences and experience with general healthcare apps
- Awareness, recommendations, use, and opinions regarding hemophilia mobile apps
- Perceived benefit of hemophilia mobile apps
- Reasons for using (or not using) a hemophilia mobile app, including opinions regarding common app features and data entry

The survey also allowed for write-in responses and additional opinions.

PHASE 3: FOCUS GROUP REVIEWS OF EXISTING HEMOPHILIA MOBILE APPS

Identification of Actively Supported Hemophilia Mobile Apps

A search for hemophilia mobile apps was conducted through Google search, Google Play, iTunes, myhealthapp.net, a review of articles within the bleeding disorders community, and discussions with pharmaceutical companies that have developed hemophilia mobile apps.

Difficulty arose in locating hemophilia mobile apps and determining those that are currently supported. For example, one of the apps could only be located by typing its name in the search bar, two apps are no longer supported, and one, although supported, was not available for download.

Seven hemophilia mobile apps were supported by a developer. Six hemophilia mobile apps were functional and available for download, and are reviewed in this study.

Hemophilia mobile apps identified for review (in alphabetical order):

APP NAME	APP DEVELOPER	NOTES
Beat Bleeds	Shire US Inc.	
HemaGo	Novo Nordisk Inc.	Not Available for Download
HemMobile	Pfizer Inc.	
HemoTrax	CSL Behring LLC	
MicroHealth Hemophilia	MicroHealth LLC	
Micro8	MicroHealth LLC, for Bioverativ	
MyFactor	BioRx LLC	

Customized Hemophilia Mobile App Rating Scale (hMARS)

Mobile apps are often evaluated according to a standardized mobile app rating scale (uMARS) that helps to provide consistency when comparing attributes of various healthcare mobile apps. However, some customization of uMARS was required to make the rating scale more relevant to hemophilia mobile apps. The resulting 21 question hemophilia Mobile App Rating Scale (hMARS) was constructed as follows:

- Ten questions were retained from the uMARS without any change
- Five questions were removed to achieve an effective opinion-based rating
- Eleven questions were slightly reworded to denote an evaluation specific to hemophilia mobile apps

Participants rated each app using a scale of 1 to 60 based on 4 categories: functionality, engagement, aesthetics, and information. In addition, a subjective quality score (on a scale of 10) and perceived impact score (on a scale of 30) were also obtained. A final score for each app was calculated on a total scale of 100. (See Appendix C)

Focus Groups

Three focus groups consisting of 4 or 5 participants, for a total of 13 evaluators, met to discuss and evaluate the hemophilia mobile apps identified for this study. Focus groups represented current hemophilia app users, non-hemophilia app users, patients with severe hemophilia A or B, inhibitor patients, and primary caregivers.

Control for Confounding Variables

At the start of each focus group meeting, each evaluator completed a participant assessment to help identify and provide controls for any confounding variables that could interfere with rating validity or otherwise skew results. These variables included the age of the evaluator, the type and version of mobile operating system used during the evaluation rating process, and digital technology experience. Participants downloaded Speedtest.net (by Ookla) to their mobile device to assess data transfer speed through Wi-Fi or cell tower connections. Download and upload speeds were noted for each participant's device and was taken into consideration during the mobile app evaluation rating process to ensure slow connection speeds did not taint results.

A Systematic Review and Quantitative Evaluation

Hemophilia mobile apps were reviewed by all focus group participants using a consistent delineated method. Participants were first provided a set time frame during which they freely explored each app. A qualitative evaluation was conducted using hMARS.

Results

PHASE 2. HEMOPHILIA MOBILE APP SURVEY

Demographic

A total of 90 individuals from 20 different states, responded to the survey:

Not all participants indicated in which state they reside; therefore, additional states may be represented in this survey sample.

- 70.5% of survey participants were patients, while 29.5% were caregivers
- Inhibitor patients represented approximately 10% of the total survey responses
- 52% of participants were between the ages of 34 – 60 years, although there were participants representing ages 18 to over 60.
- 85.6% respondents reported being on prophylaxis, 12.2% treated on-demand and 6.7% were on immune tolerance. Some survey participants responded to being on both prophylaxis and immune tolerance.

Technology and mHealth Usage

Most survey respondents had access to mobile technology and were quite familiar with mobile apps. Ninety-three percent use a smart phone and 65% use a tablet or other portable personal computing device with a touchscreen interface. Only 5% were non-app users. Furthermore, 90% use mobile apps daily, with a majority using between 1 and 5 apps per day with social media, photo/video, and music/games/entertainment being the most frequently used apps. A little over half (56%) had experience with mHealth, but only 14.5% regularly use hemophilia mobile apps. The survey results confirmed research findings that very few consumers are actively engaged in mHealth despite its potential benefits.

Fig. 1 Number of Apps Used Daily

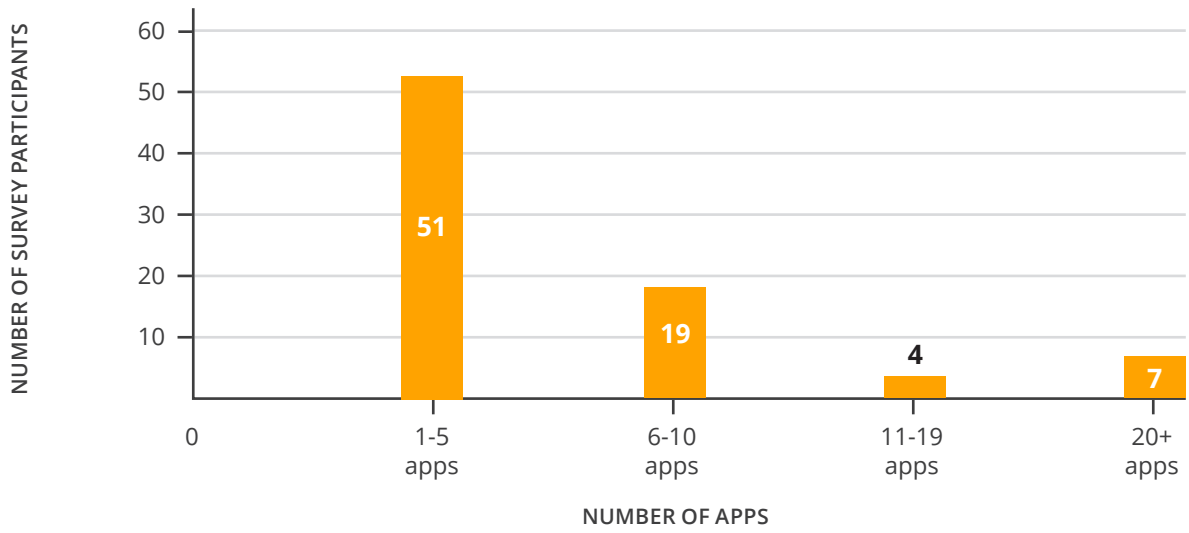
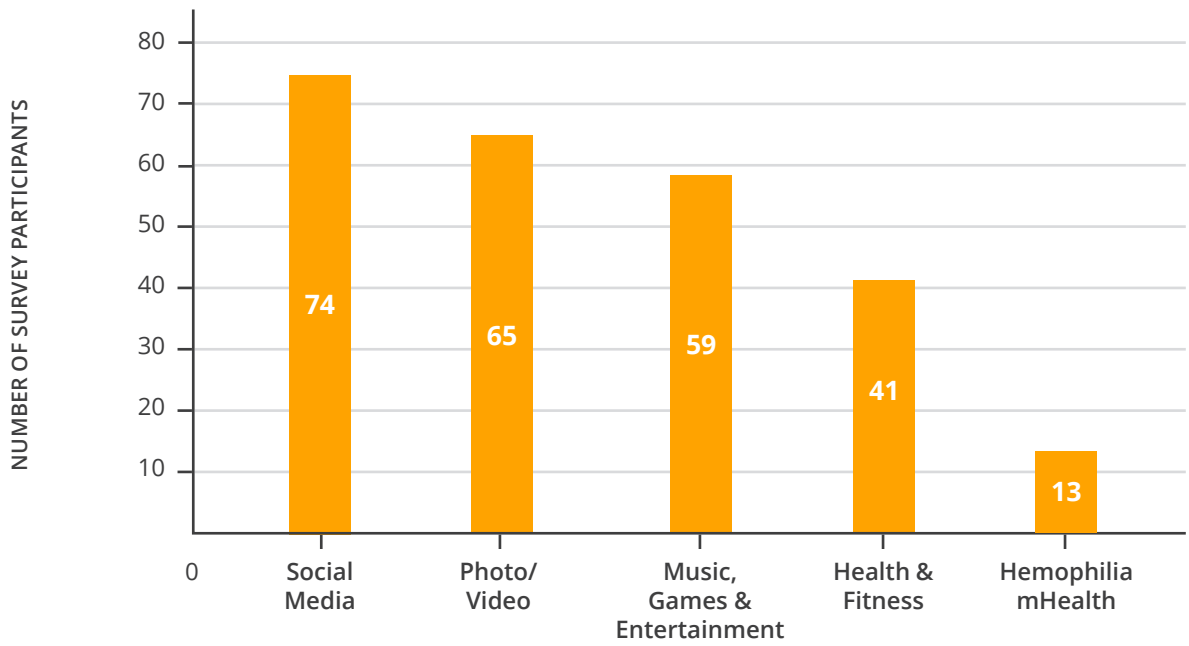


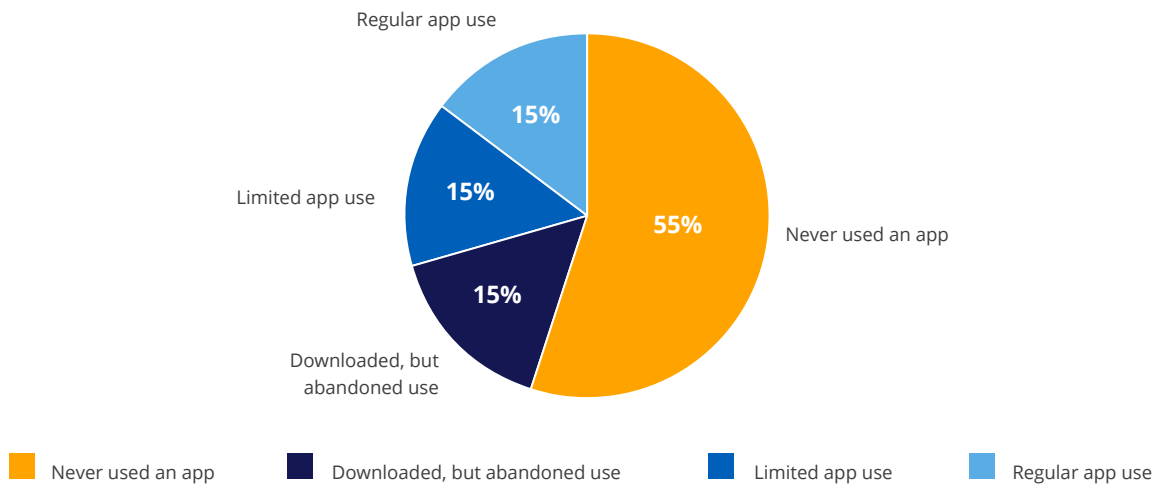
Fig. 2 Types of Apps Used Daily



Familiarity with Hemophilia mHealth

- Majority of survey respondents (68%) were not aware of the scope of hemophilia mobile apps currently available
- While there was a wide spread of opinions regarding the benefits of using hemophilia mHealth, 32% saw no benefit
- 66% indicated use of an app was never recommended by their doctor or HTC
- 45% had downloaded a hemophilia mobile app. From this group:
 - Approximately 1/3 discontinued using the app
 - Approximately 1/3 use the app on a regular basis (a few times a week)
 - Approximately 1/3 are limited users (once a month or only for the alert feature)

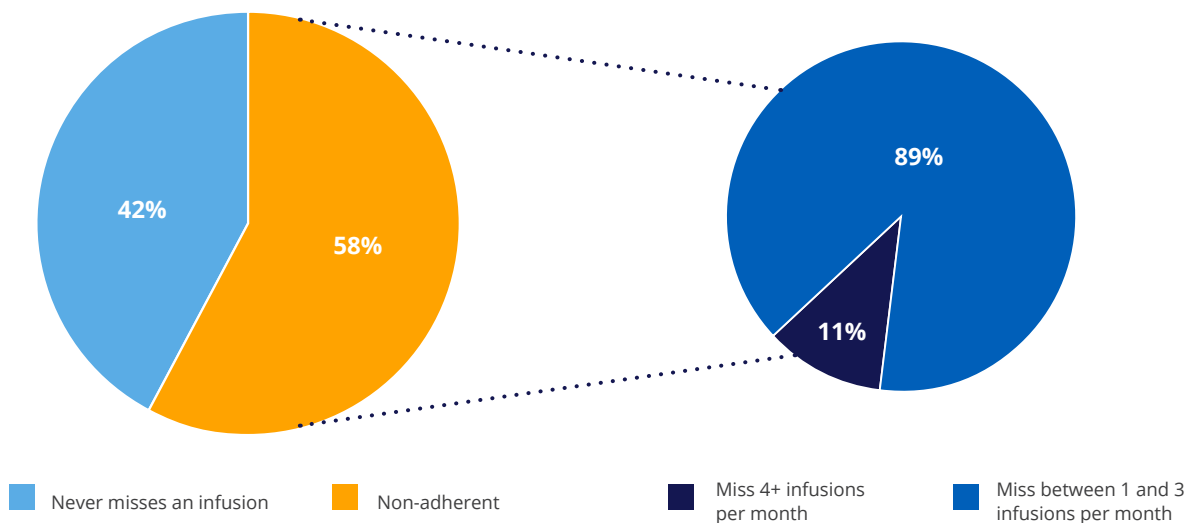
Fig. 3 Hemophilia Mobile App Use



Relationship Between Adherence to Infusion Regimen and Thorough Record Keeping

To better understand the level of adherence to an infusion regimen, respondents were asked to report the number of times scheduled treatments were missed. Fifty-eight percent of individuals reported some degree of nonadherence to treatment, defined as missing a regular scheduled infusion over a period of one month. Within this group, 89% missed between 1 and 3 infusions per month and 11% missed 4 or more infusions per month.

Fig. 4 Adherence To Treatment

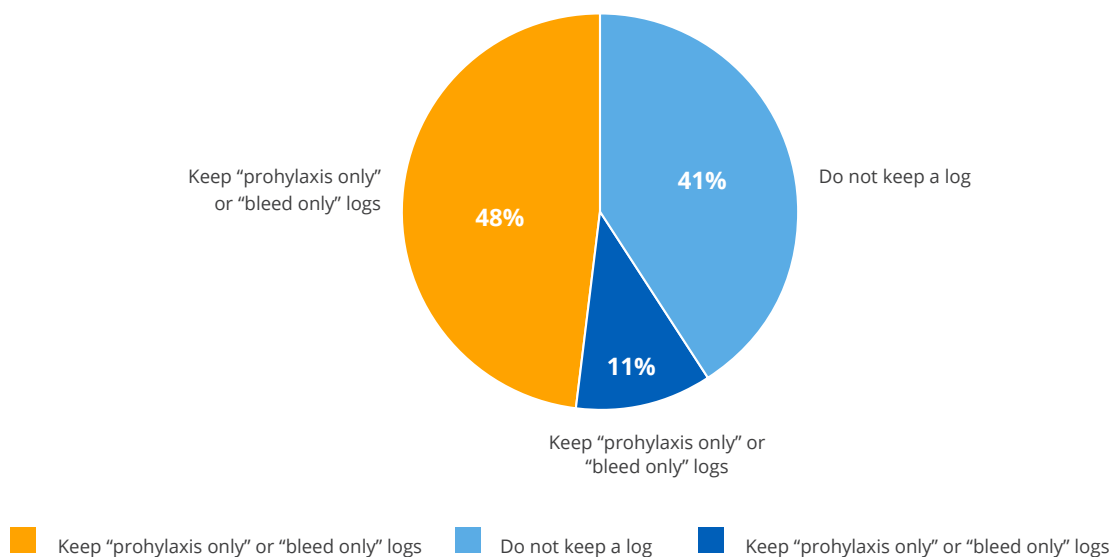


Regarding adherence to record keeping, our survey responses were more positive than expected given research findings indicate “compliance with record keeping is notoriously poor.”²⁴ Survey data within this group revealed:

- 41% do not keep any treatment records
- 11% keep “prophylaxis only” or “bleed only” records
- 48% keep a record of both regular prophylaxis treatment and bleeds

Adherence to record keeping was lowest in the age 18-24 category and highest in the age 60+ category.

Fig. 5 Adherence To Keeping a Log



While we were unable to draw statistically significant conclusions from this study regarding the relationship between adherence to a treatment regimen and good record keeping, it appeared those who kept some sort of a log were less likely to miss scheduled treatments. Additionally, those who use a hemophilia mobile app appeared more likely to remain adherent to treatment. Open-ended responses to survey questions highlighted the value of an “alert feature,” serving as a reminder to infuse and thus supporting adherence to a treatment regimen. One parent commented, “When my first son went to college, he did not use a hemophilia mobile app or keep a log. As a result, he experienced many bleeds (including 2 kidney bleeds) due to missing treatment. When my second son went to college, he used a hemophilia mobile app just for the alert feature (he did not log treatments). However, he remained 100% adherent to his treatment and didn’t experience a single bleed during his first year of college.”

These findings are consistent with previously published research highlighting the potential of hemophilia mHealth to improve adherence to a treatment regimen, which in turn, results in better health outcomes.

Preferences for App Features

Seventy-four percent of survey respondents indicated bar scanning technology to automate the logging of dosage information was the most wished-for feature that would encourage use of a hemophilia mobile app. Other noteworthy desired features include the following: the ability to locate an HTC when traveling (45%), the ability to share information with a personal HTC or doctor (44%), and the ability to use voice command to enter data (42%). Other recommended features included sending alerts for treatment, reordering factor and supplies from a pharmacy, recalling product information, printing graphs from logs, tracking inventory, and customizing and capturing data to accommodate inhibitor patients.

Non-use and Reasons for Discontinued Use

For those who had never downloaded a hemophilia mobile app, the most common reason for not using an app included, “I don’t keep a log,” “I’m not familiar with hemophilia apps,” “They are too complicated or too much of a hassle to use,” and, “I prefer to use paper logs or a spread sheet.” A lack of interest in an app and a lack of trust in the protection of personal data were also noted concerns.

Common reasons for discontinuing the use of a hemophilia mobile app included failure of an app to do the following: to allow for multiple patient profiles, to accommodate a respondent’s current factor product, to meet the needs of patients with inhibitors, to provide an easy-to-use interface, and to work without malfunction.

Considering Other Technologies

Voice-activated Technology—While only 10% of those surveyed reported using voice-activated technology in the home, such as an Alexa or Google-Home device, 55% reported having interest in voice-activated technology. Those who had downloaded a hemophilia mobile app tended to be universally interested in using voice-activated technology, whereas those who had never downloaded an app were equally divided in their interest.

Fitness Tracker—Approximately 1/3 of respondents expressed interest in linking a fitness tracker, such as a Fitbit or Garmin, to a hemophilia mobile app.

Perceived Impact

Perceived impact varied based upon previous experience with hemophilia mHealth. The vast majority of respondents (90%) who had downloaded a hemophilia mobile app (not necessarily current users) believed the use of a hemophilia mobile app would improve their healthcare. Opinions were equally divided among those with no previous experience with hemophilia mHealth.

Despite favorable opinions regarding the perceived benefits of hemophilia mobile apps and current research findings supporting their adoption, many respondents have not eagerly embraced the use of this technology, and some respondents that attempted use have since stopped using the technology.

Phase 2 Conclusions

- Although the sample size was too small to determine a statistically significant relationship, the study is consistent with earlier research findings, which have found that hemophilia mHealth improves adherence to a treatment regimen
- Access to mobile technology (smart phones and tablets) is high
- Respondents generally embraced technology and were quite supportive of technological solutions to improve healthcare. Many respondents were also receptive to solutions beyond hemophilia mHealth, including the use of voice-activated technology
- Respondents were generally aware of the benefits of hemophilia mHealth and its likelihood of improving adherence
- Despite access to technology, willingness to employ the technology towards managing their healthcare, and an understanding of the benefits of using hemophilia mHealth to improve adherence, adoption rates of hemophilia mHealth remain quite low
- Several factors seem to be driving low adoption rates of mHealth: a lack of awareness of hemophilia mHealth options, app complexity, burdensome data entry, concerns with the protection of health information, and inflexible app features (e.g. unable to use with an individual’s factor product, cannot be customized to accommodate inhibitor patients, etc.).

PHASE 3. HEMOPHILIA MOBILE APPLICATION REVIEW

Focus Group Composition

Focus groups met for a full day to discuss and evaluate the hemophilia mobile apps identified for this study. There were 13 focus group participants: 7 patients and 6 caregivers. Three of the focus group participants are current hemophilia mHealth users, while 10 were non-mHealth users, 5 of which previously attempted using a hemophilia mobile app.

Focus Group Highlights

1. Problems Identifying an App that Best Meets Consumer Needs

Focus group participants determined app download statistics and user rating scores were not a reliable indicator of app quality or value. There was a significant skew in download volume for hemophilia mobile apps, with only 4 achieving more than 500 downloads. Challenges to locating certain apps within Google Play or iTunes could have easily hindered this grading. Additionally, every app had a limited user rating response with only one app securing a user rating response of over 100. The reason for a higher ratings response might be explained by the fact the app contained a ratings option within the menu settings.

Negative focus group feedback on the use of download statistics and user ratings to select an app is consistent with the Journal of Medical Internet Research, which found that, "Download statistics and feedback ratings from apps stores are available, but such data lack validity and do not provide detailed information with regard to important information."²⁵

Instead of ratings and download statistics, focus group participants would prefer hemophilia mobile app summary charts that identify app features to help guide consumers in identifying an app that best meets their needs. Other information, such as consistency of app use and feedback regarding barriers to use, would also be helpful to consumers, but is often not available.

2. Opinions on Hemophilia mHealth

Many focus groups expressed little interest in using hemophilia mHealth due to a lack of interest in record keeping and a lack of time. Barriers to adoption within the focus groups echoed findings from the Phase 2 survey. Participants who currently use a hemophilia mobile app to manage their bleeding disorder expressed they preferred to use an app for the convenience of having their medical information accessible, the ability to share information with their physician, and for supporting management of their bleeding disorder.

3. Concerns over Protected Health Information

Protection of health information within the app and the transmission of treatment logs through a non-secure method were expressed as major concerns. However, most focus group participants acknowledged never reading a privacy policy or statement within a hemophilia mobile app. Furthermore, several participants were unsure of whether an app was considered compliant with the Health Insurance Portability and Accountability Act of 1996 ("HIPAA") and were unable to locate a privacy statement within the app.

Focus group participants expressed a preference for an app that enables sharing information through a secure website. Participants also requested apps include a print function, allowing users to print their logs directly from their app without having to email them.

4. Registering and App Permissions

While several apps required users to create a username and password for exploration, focus group participants favored an app that allowed users to investigate the product without the prerequisite of registering. All participants disliked the need to grant permission for an app to access information from their device and expressed concerns over third party access to even basic information such as geolocation. This initial information permission request was often a deterrent to a participant's willingness to use an app.

5. App Complexity versus Simplicity

Initial exploration time varied between hemophilia mobile apps. While features within some apps could be explored in under 10 minutes, others apps took far longer, given additional options and complexity. Apps that had too many menus or features prevented clear navigation, and were perceived as complex and frustrating. Apps with fewer menus and features were considered uncomplicated and straightforward.

Participants who identified themselves as "not tech-savvy" preferred an app perceived as simple, intuitive, and easy to use. Those who considered themselves as "tech-savvy" were less likely to be dissuaded from an app with more advanced features, but still indicated preference for an app that was streamlined, had the ability to keep the user engaged, had a simple process for recording treatments, and required minimal manual data entry.

6. App Layout, Graphics and Visual Appeal

Opinions varied between digital natives and older users who have acquired familiarity with emergent technologies over time. Younger focus group participants preferred a hemophilia mobile app that had a tracking calendar as a main screen to make it less identifiable as a medical app. They disliked company logos or images of individuals with hemophilia on the opening screen as this gave the perception the app was created with a marketing purpose. They also expressed an interest in "hamburger menus" (three vertical lines in the top corner of the app, which serves as the main menu), indicating it is intuitive and doesn't require a user to sift through numerous icons.

Those who have settled into digital technology over time (non-digital natives), had mixed opinions regarding the home screen. Some, like the digital natives, preferred a calendar home screen, while others preferred a home screen with treatment tracking information or logging icons so they could easily record a treatment. Although they identified the calendar as an important feature within an app, they preferred a separate home screen through which a calendar could be accessed rather than having it on the home screen.

Unlike the digital natives, older users weren't bothered by hemophilia images on the home screen. However, these users disliked heavily branded apps that included a company name on the home screen.

Focus group participants also expressed a preference for icons that were proportionate and consistent in style, treatment tracking symbols on calendars, and the ability to view history from a graph.

7. App Data Entry

Most participants were frustrated by an app's inability to submit a bleed or infusion record without providing 100% of the requested data. A participant shared, "A user should be able to determine how much and which information to include. Data input should not be dictated by an app." Another participant recommended a "popup reminder" asking the user if they wanted to complete data entry at a later point in time. All group participants considered the ability to add notes (referred to as a "notes" feature) as an important feature. Current hemophilia app users indicated they use a notes feature to record additional information that otherwise wasn't captured within the app. A current user commented, "I like the notes feature in case I need to include anything significant related to a bleed (related pain/suffering/lesson learned), as well as administration, as in the case of broken transfer device."

8. Feature Preferences

The most valued features included treatment alerts through a mobile device along with the ability to log an infusion by responding to an app alert. Younger participants stated these features would increase the likelihood of adopting hemophilia mHealth to manage their health, while older participants considered it to be a useful feature to encourage younger patients to assume greater responsibility for their care and to improve adherence.

Other noteworthy preferences included:

- Ability to locate a hemophilia treatment center (HTC) along with an address link to Google Maps
- Providing activity-risk information after selecting cause of a bleed
- Promoting RICE (Rest, Ice, Compression, Elevation)
- Tracking ABR (Annual Bleed Rate)

9. hMARS Results

hMARS (hemophilia Mobile App Rating Scale) scores were calculated for 6 hemophilia mobile apps. Scores reflected user engagement, functionality, aesthetics, information, subjective quality, and perceived impact. The hMARS scale ranges from a lowest score of 1 (app has no apparent value) to 100 (app perfectly satisfies user needs).

- 2 Hemophilia mobile apps scored in the 80% range
- 2 Hemophilia mobile apps scored in the 60% range
- 2 Hemophilia mobile apps scored in the 40% range

10. Benefit of Focus Group Meetings Beyond App Evaluation

The process of conducting focus group meetings had greater value than expected. While the intent of these meetings was to aid in the assessment of current hemophilia mobile app usage, the evaluation process served as a beneficial educational opportunity for all group participants. All 10 participants that didn't use a hemophilia mobile app are now using an app to manage their bleeding disorder. Although this was just a small sample size, the implications of this finding confirm education can serve as a powerful tool in increasing hemophilia mHealth adoption.

Conclusion

Research studies have concluded there is great potential for mobile healthcare apps to facilitate improved adherence to chronic disease management. Although the obvious feature of treatment reminders through SMS is "most widely, frequently and successfully used to facilitate adherence to chronic disease management,"²⁶ hemophilia mHealth can potentially improve overall medical adherence by cultivating other motivational factors including the following: improved patient-provider communication and relations, better monitoring and awareness of bleed warning signs, increase in adolescent independence, confidence in managing care, and self-empowerment.

Nonadherence to treatment within the hemophilia community is high and remains a primary concern. Hemophilia mHealth can improve the level of adherence, which can lead to improved health outcomes. The hemophilia community (drug manufacturers, app developers, HTCs, physicians, and consumers) should focus time and resources to develop an action plan to overcome the barriers that have resulted in limited adoption of hemophilia mHealth.

Recommendations to increase hemophilia mHealth:

- App developers should address the key barriers to wider implementation and usage
- mHealth informational resources and databases should be made available to the hemophilia industry to help educate and to highlight the significant benefits that result from using mHealth to manage a bleeding disorder
- The hemophilia industry should increase awareness among consumers by providing educational opportunities to highlight these benefits and should make specific hemophilia mHealth recommendations
- Further assurance that protected health information is secured and HIPAA compliance is met needs to be addressed within the bleeding disorders community
- Educational materials, such as user guides and comparison charts, need to be made available to aid physicians and patients in the selection of an app that satisfies specific consumer needs

Recommendations for future hemophilia app development:

- Create a single hemophilia mobile app with the flexibility to handle multiple products
- Include a detailed privacy statement on the home screen. According to Future Privacy Forum, “even though a privacy policy is not the be all and end all for building consumer trust, there is no excuse for failing to provide one – doing so is the baseline standard.”²⁷
- Safeguard security of shared data. Data should only be shared through a secure website; alternatively, a user should be provided a print option within the app
- Enable users to determine the data they chose to document when recording a bleed. Include a “pop-up” reminder to provide users with the option to include additional information later
- Enable users to investigate the app without the prerequisite of creating an account. Include a brief tutorial at the opening of each app allowing users to freely explore
- Develop an app with the flexibility to provide multiple interfaces, depending upon user needs

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Appendix A. Data Storage, Protection and Sharing of Information

	Password Protection	HIPAA Compliant	Privacy Statement within the app	Option to share data through a secure website	Connect to ATHN database to share information with HTC	Generate & share treatment log via email	Data stored on device (Requires Backup)	Data stored on cloud
MicroHealth <i>MicroHealth LLC</i>		X	X	X		X		X
Micro8 <i>MicroHealth LLC For Bioverativ</i>		X	X	X		X		X
Beat Bleeds <i>Shire US, Inc.</i>		X	X			X	X	
HemMobile <i>Pfizer, Inc.</i>	X	X	X			X	X	
MyFactor <i>BioRx LLC</i>	X	X	X			X		X
HemoTrax <i>CSL Behring LLC</i>		X	X			X	X	
HemaGo <i>Novo Nordisk, Inc.</i>	X	X	X	X	X	X		X

Appendix A. Data Entry Features

	1 step log response from app or text alert	Record infusion site	Body image to record a bleed	Bar scan	Take photo of bleed	Locate an HTC	Link with a wearable device to track activity	AI Artificial Intelligence Voice Capability
MicroHealth <i>MicroHealth LLC</i>	X			X	X			
Micro8 <i>MicroHealth LLC For Bioverativ</i>	X			X Bioverativ product only	X			
Beat Bleeds <i>Shire US, Inc.</i>		X	X		X			
HemMobile <i>Pfizer, Inc.</i>		X	X	X Pfizer product only	X	X	X	
MyFactor <i>BioRx LLC</i>		X	X		X			
HemoTrax <i>CSL Behring LLC</i>		X	X	X CSL Behring product only	X			
HemaGo <i>Novo Nordisk, Inc.</i>			X		X			

Appendix A. App Availability and Basic Features

	iPhone app	Android app	Non-smart phone text logging	Available in Spanish	Syncs to a website	App intended for specific factor product	Functioning treatment reminder that sends alerts to your phone	Doctor appointment reminder	Medication refill reminder	Multiple profiles	Treatment tracking calendar within the app
MicroHealth <i>MicroHealth LLC</i>	X	X	X	X	X	Any Product	X		X Set up schedule from website	X	X
Micro8 <i>MicroHealth LLC For Bioverativ</i>	X	X	X		X	Elocate	X		X Set up schedule from website	X	X
Beat Bleeds <i>Shire US, Inc.</i>	X	X				Any Product	X			X	X
HemMobile <i>Pfizer, Inc.</i>	X	X				Any Product		X	X Monitor units from app	X	
MyFactor <i>BioRx LLC</i>	X	X				Any Product				X	
HemoTrax <i>CSL Behring LLC</i>	X	X				Idelvion and Afstyla				X	
HemaGo <i>Novo Nordisk, Inc.</i>	X	X			X	Any Product	X			X	