

Understanding the mHealth needs for sexual and reproductive health information in the United States

BACKGROUND

Despite legalization in 1973, abortion remains difficult to access for many in the United States. Over 30% of all laws restricting abortion access since 1973 were passed in just six years (2010-16),¹ bringing the total number of restrictions on abortion to 338 by the end of 2016.² These laws can restrict access to abortion in a number of ways, for example, limiting the kinds of clinicians who can provide abortion care, the types of abortion services that clinicians can provide, how long a patient must wait to access the procedure, whether insurance can cover the cost of an abortion, and even what kind of information a medical professional must relay to a patient about abortion, including the mandatory sharing of medically inaccurate information.

While abortion has been subject to unprecedented regulation, other areas of health care not burdened by decades of stigma and restrictions have benefitted from the digital revolution in using smartphone applications (apps) to increase access to health care information. Research shows that apps increase medication adherence,³ increase health knowledge and agency,⁴ and improve health outcomes.⁵

In 2015, seeking to understand how to use technology to increase access to information about abortion, Ibis partnered with colleagues at a safe-abortion hotline in Southeast Asia. An app was developed to serve people who call the hotline seeking information about and support during the medication abortion process. The pilot study demonstrated acceptability and usability among a small group of women; a full, randomized control trial, to evaluate the effectiveness of the app in helping women feel supported during their medication abortion process, was then completed.

This brief describes a project that sought to adapt the formative research methods used in the Southeast Asia study to a US context. Through this research, we aimed to identify populations of people who can get pregnant and better understand their smartphone use patterns, sexual and reproductive health (SRH) information needs, and desire for an app that would help fill SRH information gaps. Because reliable information about abortion is often difficult to identify, the study focused specifically on interest in the use of smartphone technology for abortion information.

METHODS

Ibis conducted a landscape analysis of existing SRH apps on the App Store and Google Play Store. Apps were classified into one of six categories based on the main purpose of the app; classification groups included abortion, birth control, period tracking, SRH education, fertility tracking, and pregnancy. The analysis focused on seven broad domains of interest: design, language, privacy and security features, accessibility, resources, personalization, and initiation/overview (Figure 1). Findings from the landscape analysis helped to inform qualitative research by identifying patterns in the seven domains and existing gaps in SRH information available on the app stores.

Domains	Criteria
<i>Design</i>	Look, feel, color, and navigation
<i>Language</i>	Tone, information, intended user, and inclusivity/exclusivity
<i>Privacy & security</i>	Passwords, terms of services, and data confidentiality
<i>Accessibility</i>	Internet connection, price, advertisements, and account access
<i>Resources</i>	Testimonials, live feedback, and references
<i>Personalization</i>	Setting adjustments and notifications
<i>Initiation/overview</i>	Account registration/requirement and onboarding process

Figure 1. SRH smartphone app domains

Researchers partnered with abortion clinics, reproductive justice organizations, and youth advocate colleagues to conduct three focus group discussions (FGDs) and eight in-depth interviews (IDIs) to discuss findings and inquire about user preferences in an SRH app. Partner organizations were identified based on their geographic location and the communities they served, with the intention of reaching a diverse group of people who could get pregnant. Eligibility criteria for focus groups included being 16-49 years old, speaking English or Spanish, owning a smartphone, and having the ability to become pregnant. To be eligible for interviews, participants had to be 18-49 years old, speak English, own a smartphone, and either identify as LGBTQ, have had an abortion, or have sought information about abortion in the past two years.

FGDs and IDIs were conducted in person and over the phone between April and June 2017. All focus groups were recorded and transcribed in English. The research team at Ibis developed a codebook to identify the explicit user needs (i.e. SRH content areas) and implicit user needs (i.e. desire for a sense of community) to inform design, language, features, and privacy and security. Two researchers coded the transcripts and conducted a content and thematic analysis using Dedoose Version 7.6.17. Key content areas, themes, and patterns were identified through the analysis.

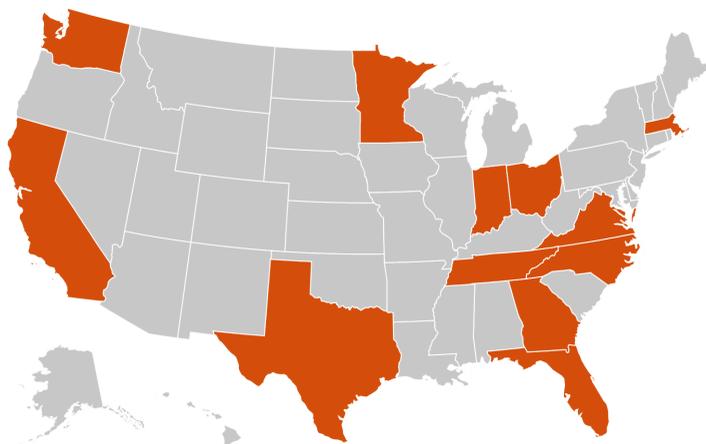


Figure 2. Formative research locations

LANDSCAPE ANALYSIS FINDINGS

The landscape analysis found a total of 11 apps that fit one of the six pre-defined categories of classification. These apps covered a range of SRH topics; four provided information and tracking options for menstrual cycles, ovulation, and fertility, while two apps focused on pregnancy tracking, support, and advice. One app was specifically designed to set birth control reminders through a calendar feature. Two apps offered more comprehensive SRH education; one included topics such as sex, sexuality, and relationships, while the other had additional recommendations for choosing a birth control method, recognizing and dealing with sexually transmitted infections, and understanding menstruation—neither of these apps included information about abortion.

Two of the 11 apps provided some information about abortion;* one provided assistance with finding the nearest abortion clinic in the United States with some information on state-level abortion laws. The other app provided country-

* Since the completion of this landscape analysis, an additional app that provides information on safe use of medication abortion has been released. That app, and any other SRH apps that have come out since the conclusion of our analysis, are not included in this review.

level facts on abortion laws, availability of abortion pills in that country, and information on medication abortion, such as the WHO protocol, and how to access misoprostol and mifepristone.

We tested the 11 apps against the seven domains of interest to better understand some of the most prevalent topics covered by current SRH apps. In some apps, design features such as calendars were limited to tracking only specific elements, particularly those related to the user’s fertility cycle. Other apps had features suggesting an intended user base of cisgender women, indicated by the frequent use of she/her/hers gender pronouns, pink or purple color palettes, and illustrations or icons commonly associated with cisgender women (e.g. flowers). Interaction with these apps also revealed factors such as limited availability of languages besides English, unclear or confusing information on data confidentiality, and the need for an internet connection to use the app’s main features.

QUALITATIVE FINDINGS

A total of 40 people participated in the qualitative research phase of the study, 80% (n=32) in FGDs, and 20% (n=8) in IDIs. When asked about their smartphone operating system, 75% of participants said they owned an iPhone, and 22.5% said they owned an Android device. When asked about privacy around their smartphone use, 92.5% of participants said they did not share their phone with anyone else; however, only 37.5% reported using a password and not sharing it with others.

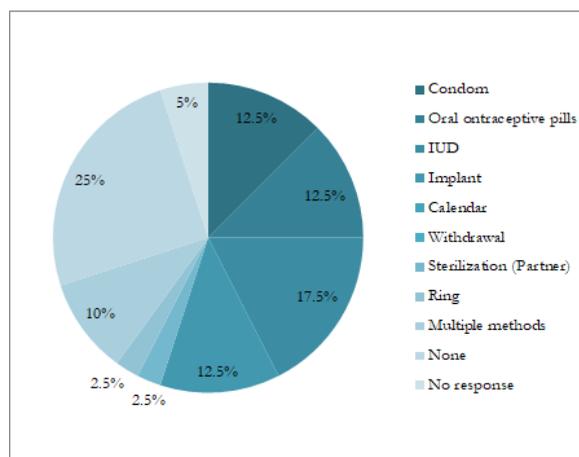


Figure 3. Participant contraceptive use

A comprehensive SRH app

Results from the FGDs and IDIs indicated that participants across the board wanted an app that would provide comprehensive SRH information. Participants reported a

need for information on miscarriage, contraception, sexuality, relationships, sexually transmitted infections, pregnancy options, menstrual tracking, and surgical abortion as well as medication abortion. Within these content areas, participants consistently expressed a desire for easy-to-understand, accurate information that they can interact with and that is relevant to their lives. This includes information about connecting to health care providers and setting reminders for health needs such as doctor's appointments and medication adherence.

Consistent with findings from the landscape analysis, participants noted that there were no apps currently available that contained information about abortion or sufficient information about issues like miscarriage and sexuality all in one place. One woman, when reflecting on her experience with medication abortion, explained that having information about medication abortion already in an app could be better than trying to find accurate information online. When asked about specific information she wanted in an app, she discussed the need of abortion information, such as:

“
...side effects, long-term [and] short-term. What to expect during, where I can go and get them. Where can I go and get a medication abortion? All those things would be helpful if you can just go to an app to find those things, instead of going to Google where you get a broad thing.”
- Medication abortion client, Minnesota

Supportive, inclusive, and customizable

The most prominent design needs that participants articulated were a user interface conveying feelings of support, inclusivity, and the ability to customize the different features of the app. Emotional support or feeling supported logistically by the app was important to participants, because many of them felt that reproductive health decisions are complex and often difficult to talk about with others. Participants wanted affirmation that their SRH decisions were common, acceptable, and that they had the accurate information they needed to make those decisions.

Participants felt current reproductive health apps make assumptions about who the users are and/or why they are using the app. Common incorrect assumptions that

participants described among current apps included algorithms based on regular, 28-day menstrual cycles; cisgender normative programming and design; information geared at monogamous and heterosexual relationships; and information geared at those with a desire to get pregnant. In response to these incorrect assumptions, participants articulated a desire for an app that did not make assumptions about who they were or how they used their health information. They felt that design and content had to reflect the diverse spectrum of users who could get pregnant and be inclusive of sexual practice, race and ethnicity, age, education, and reproductive health experiences.

To balance the need for comprehensive SRH information that addresses the needs of a diverse user group, participants wanted to be able to customize the content that was most relevant to their current reproductive health needs. Participants also wanted to be able to tailor their notifications and tracking options so as not to be overwhelmed with information that was not relevant to their lives.

“
Maybe that's another point, making the home page customizable. If you're marketing as a holistic app, and we're already using it, and it just has all of this information, and we're just learning that, 'Oh, this information I might be able to use one day.' And then that one day comes and you're like, 'I've got it. It's right here. I'm okay. I'm going to be okay.'”
- Focus group discussion participant, California

Privacy and security in design

Privacy and security was one of the most important issues raised by participants. When considering the sensitive health information the app might store on the phone, participants said functions like passwords, automatic data purging, discreet icons, optional tracking, discreet notifications and reminders, and easy exit from the app were important. Participants described concern about random observers, abusive partners, and parents or guardians being able to see private content on the phone.

When describing an app that would have information about abortion, one woman said:

“ I think that will be a safe place to start, because if you want to do it without telling your family or telling someone, it’s a safe place, and you can access information through there. ”

- Focus group discussion participant, California

Participants made it clear that they wanted a space where they knew their personal information would be protected and where they would have unlimited access to reproductive health information.

DISCUSSION

A variety of reproductive health apps exist on the market today, yet they commonly focus on fertility and provide select topical content for their users, such as information about contraceptive methods, period tracking, and pregnancy-related information. These smartphone apps do not address the comprehensive SRH needs of those who could get pregnant. The two apps that provide any information on abortion are completely devoid of information about other SRH issues, and, conversely, abortion is absent from any of the apps that focus on SRH.

Participants in our study expressed a desire to access comprehensive reproductive health information, including about abortion, through a smartphone app. These results should be unsurprising when we consider any number of potential users. For example, a user may be someone who wants to prevent pregnancy and is interested in tracking their menstrual cycle, using contraceptives, monitoring medication adherence, and seeking information about healthy relationship communication and STIs. Another user may be someone who wants resources and information about pregnancy options and abortion in the event of contraceptive failure.

In addition to the content gaps identified in existing reproductive health apps, the voices and perspectives of many communities and people who can get pregnant are absent from current apps—including queer women, transgender people, gender non-conforming people, people with multiple sex partners, and people with irregular periods. Some of these people and communities also tend to be misunderstood or marginalized by the medical system, and apps currently available leave them with inaccurate or irrelevant information for their sexual and reproductive lives.

An important opportunity exists for the development of a truly comprehensive SRH app that can provide tailored information to fit the needs of these different users, and provide reliable, accurate information in an inclusive manner—eliminating many of the assumptions identified through our qualitative research. Additionally, there is an opportunity for an app to reach communities who do not regularly engage with the medical system because their experiences have been excluded or misunderstood. Moving forward, it is essential that the development process of such an app include iterative participation, including review of content and design, from potential users in order to address the gaps in SRH information needs.

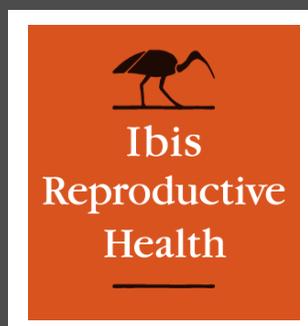
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Thank you to the amazing organizations that made this research possible!



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