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Respecting People's Rights To Control LARC Use:

Research On The Feasibility And Desirability Of A Device For IUD Self-Removal

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Background

For two decades reproductive health experts, service providers, governments, and donors in the United States (U.S.) have made considerable efforts to increase the availability and use of long-acting reversible contraception (LARC). These methods, including implants and intrauterine devices (IUDs), are the most effective reversible methods available to prevent pregnancy but they have a potential drawback for users. To use a LARC method, a user must visit a trained provider for both insertion and removal of the device. When an individual wants to have their IUD removed, they must have access to a provider who can do the removal and usually, if it is prior to the end of approved duration of use, explain their rationale for desiring removal. In some cases, providers may be hesitant to honor IUD removal requests prior to the end of approved duration of use because of their own feelings that it is not in the user's interest.[1] Due to the history of eugenics and forced contraception and sterilization in the U.S., women of color in particular may find it unacceptable not to have control over discontinuation of contraception.[2] Perceived and real barriers to IUD removal which threaten reproductive autonomy may make IUDs a less appealing option for some people.

We know from previous research that only one in five women who were willing to try removing their own IUD was successful in doing so without assistance.[3] With the goal of expanding reproductive autonomy and improving self-removal success rates, Medicines360, a nonprofit pharmaceutical company, is exploring the idea of a device intended to facilitate IUD self-removal. Medicines360 conducted qualitative research with potential users of an IUD self-removal device to understand if and how users or potential users would benefit from a device that grants autonomy over IUD discontinuation and to provide input on preferred design features. This research was supported by Medicines360 and Arnold Ventures.

Methodology

Potential users of an IUD removal device were asked about their experiences with, perceptions of, and interest in IUD self-removal; their perceptions of and interest in an IUD self-removal device; and their perceptions of specific potential design aspects of a self-removal device. This qualitative study involved two types of data collection:

1. **In-depth interviews (IDIs)** to understand experiences with and interest in IUD self-removal and specific potential design aspects of an IUD self-removal device; and

2. **Focus group discussions (FGDs)** to understand community and societal perspectives on IUD self-removal and potential design aspects of an IUD self-removal device.

Participants were recruited via ads on Facebook Audience Network (Facebook & Instagram), and Reddit. Social media recruitment has been used successfully in similar previous projects and has been shown to result in samples that are comparable to samples comprised through other forms of recruitment. General internet access and usage (including through computers and smartphones) is extremely high in the U.S., with almost all adults in the age groups of interest in this study reporting using the internet and more than three-quarters of adults reporting using social media; Black and Hispanic individuals and women are more likely to report using social media than white individuals and men.[4,5] Social media recruitment techniques have also been shown to facilitate recruitment of racially and geographically diverse samples,[6,7] as well as being an effective and acceptable method for recruiting gender and sexual minorities.[7]

Interested participants completed an online eligibility screening and, if eligible, provided their contact information and completed a sample diversity survey to help us in effective purposive sampling. To be eligible for the study, participants had to be assigned female at birth (AFAB); live in the United States, not including Puerto Rico; not be a healthcare provider ; and be able to participate in English. Participants had to be between 18-49 years old, with exceptions for participants living in Nebraska or Alabama (age eligibility 19-49 years old) and participants living in Mississippi (age eligibility 21-49 years old) due to state age of consent policies.

We received 752 eligibility surveys, out of which 303 were complete and eligible. We contacted eligible participants with invitations to sign up for an interview or focus group via a Calendly online scheduling link, on a first-come-first-serve basis. After the first few interviews, we targeted recruitment by race/ethnicity, region, and prior and current IUD use/non-use in order to obtain diversity in the sample and oversample people of color. All participants received a $50 Visa digital debit card incentive upon completion of the interview or focus group. Participants completed an electronic consent form in advance of taking the eligibility and sample diversity surveys, and if selected to participate in an IDI or FGD, completed a second consent form before the interview or focus group. Advarra's Center for IRB Intelligence (CIRBI) approved the study protocol as exempt (CIRBI ID Pro00064519).

Individual Interviews

We conducted 32 interviews; 2 interviewees were determined to be outside of the U.S. and therefore ineligible for the study, so their data was subsequently excluded from analysis for a final analytic sample of 30. Interviews were conducted on Zoom and averaged 52 minutes in length (range: 30-75 minutes).

The semi-structured interview guide included open-ended questions on:

- current and previous contraceptive use;
- experience and comfort with intravaginal products such as tampons;
- IUD removal experience, if applicable;
- general knowledge of and perspectives about self-removal;
- perspectives on self-removal with a device;
- perspectives about telehealth;
- responses to theorized possible device features, such as a camera for direct visualization, size, shape, cost, and access

Card sort activity

We also included a card sort activity in which we asked participants to use an online whiteboard application (Miro) to choose the three most important potential features that a self-removal device might have and the three least important potential features. 'Cards' listed potential features individually, and participants could move the 'cards' to a green box for their three most preferred features and a magenta box for their three least preferred features (see *Appendix A: Card sort activity* for the list of potential features and a screenshot of how the card sort activity appeared to participants).

Focus Group Discussions

We conducted 12 FGDs; each FGD had between 2–6 participants for a total of 48 participants across all FGDs. In line with established FGD protocol, focus groups were organized so that participants would be able to take part in a discussion with others of similar ages, race/ethnicities, and contraceptive histories, with the goal of ensuring that participants would be comfortable discussing subjects such as contraception and IUD self-removal. Focus group discussions were conducted on Zoom with one team member as facilitator and a second team member as note-taker and logistics support. The average length of focus groups was 73 minutes (range: 54–99 minutes).

During the focus groups, while we discussed some similar questions and themes as in the interviews, our goal was to understand higher-level community norms and perceptions around IUD self-removal. Thus, questions also prompted participants to consider how they thought other people they know would react to a self-removal device, not only their own individual experiences. We used a semi-structured guide with open-ended questions on knowledge of and perspectives about IUD self-removal in general, perspectives on self-removal with a device, and perspectives about telehealth and cameras for direct visualization in a device.

Image responses

To understand more about how potential users might feel about different options for the design of a self-removal device, we screen-shared images of existing intravaginal products and devices expected to be similarly sized and/or shaped as the potential self-removal device. We asked participants to respond to the design elements of each product, focusing on design and size elements that would make them more or less interested in a device. Pictures included tampons (including regular and reusable applicator), a transvaginal ultrasound wand, and a vibrator.

Body mapping

After the image responses, we asked focus group participants to do a body mapping exercise to create a visual representation of how they would imagine using a self-removal device. Body mapping is a qualitative projective technique that involves participants drawing maps of the human body in response to a prompt; it can be a useful technique for sensitive reproductive health topics where participants might be hesitant to share their experiences or perceptions.[8]

We asked participants to imagine that they had an IUD and wanted to use a device to self-remove it. We prompted them to imagine how they would position their body to use the device, where they would envision using a self-removal device, and who (e.g., partner, friend, family member) they might want to have with or near them. We asked participants to draw a quick stick figure drawing on a piece of paper or via the Google Jamboard online whiteboard application. An additional prompt then asked participants to think about the potential for the device to have a camera which requires a phone nearby to see a video feed, and to make any edits or additions to their drawing based on the camera and phone requirements. Each participant then shared their drawing with the rest of the group and the group discussed the drawings and their similarities and differences. At the conclusion of the FGD, participants emailed or texted their drawings to us.

Analysis

Interviews and focus group discussions were audio-recorded digitally through Zoom and transcribed verbatim by 3Play Media. Transcripts were uploaded to Dedoose qualitative data analysis software for coding and analysis.

We drew from two main qualitative analytic approaches to inform our analysis process: the Rapid Assessment Process[9] and the Sort and Sift, Think and Shift[10] method. We took detailed notes on the interview guide document while conducting IDIs, and after completion of the interview, we used a standard memo template to summarize key points learned from the participant and how the IDI contributed to our knowledge. We also kept ongoing memos on our thinking about key topics of interest and how our thinking was evolving as we completed interviews. We exported the card sort data in image and spreadsheet formats so that we could sum the most and least preferred features in a Google Sheets analysis matrix. For the focus group discussions, one team member took detailed notes on the discussion guide while the other team member facilitated the discussion. After each FGD, we debriefed, discussing key points learned in the FGD and new questions that arose. These analytic processes that occurred during data collection enabled us to assess data saturation (the point at which we were no longer learning anything new during data collection and additional data collection was not necessary), adjust our purposive sampling and question wording and emphasis as needed, and provided foundation for our codebook.

We used the interview and focus group question guides, notes, memos, FGD debriefs, card sort data, and body mapping drawings to create an iterative analytic codebook. We started with a set of a priori codes based on the questions in the IDI and FGD question guides and Medicines360's primary topics of interest, and subsequently added codes stemming directly from the data (inductive codes). After a first draft of the codebook was created, multiple team members coded the same interview to assess whether coders were applying the codes uniformly (inter-rater reliability). After review and discussion, we clarified code definitions and added and consolidated codes to facilitate coding. After additional coding had been completed, we again reviewed the codes and their application, and several more inductive codes were added. Throughout coding and analysis, we used team meetings to review, discuss, and further analyze the IDI and FGD data.

Findings

Participant characteristics

This project prioritized hearing from people of color, and with oversampling, over two-thirds of participants were people of color (IDIs: 87%, FGDs: 69%, overall: 76%) (see Appendix B for additional detail). Interview participants tended to be younger (mean age: 30.2 years; range: 20-49) than focus group participants (mean age: 34.9 years; range: 19-49). Almost all participants identified as women; one participant identified as non-binary and two participants did not state their gender identity. Just over half (57%) of IDI participants and just under half (46%) of FGD participants had never used an IUD, with the remainder split approximately equally between past and current IUD users. About two-thirds (63%) of IDI participants and 58% of FGD participants had not previously heard of IUD self-removal prior to signing up for the study.

Major themes

We present the majority of findings across both IDIs and FGDs, as most themes identified were extant in both. We note where a theme only surfaced in one data type. Findings from the focus groups' responses to the images, the body mapping activity, and the interview card sort activity are presented separately but integrated into discussion of other themes where applicable.

We identified six major themes:

1. Evolution throughout the conversation
2. Recognition of the benefit of a self-removal device for autonomy
3. Self-removal recommendations and legitimacy
4. Medical misinformation/worst case scenario
5. Discomfort with non-sexual touch
6. Information users need

Evolution throughout the conversation

When first introduced to the concept of self-removal, the majority of participants across both interviews and focus groups were not familiar or comfortable with self-removal.

When we introduced the potential of a device for self-removal, many participants started to become more comfortable with the idea of self-removal. Interest increased again when we described the possibility of a device with a camera that would allow users to directly visualize where the device was moving. Some participants had concerns about finding the IUD strings during self-removal without a device and described how a camera would take the guesswork out of the process and alleviate those concerns.

Throughout the interview or focus group discussion, participants became more receptive to the idea of self-removal in general and with a device. This progression was very common. When compared to self-removal without a device, participants identified benefits of self-removal with a device.

Evolution in thinking in an IDI participant who had never used an IUD and had not previously heard of self-removal

Self-removal

"A little scared in the beginning. Given the fact that you hear so much that it's only like, you should only take it out at a medical office, or with doctors, someone professional who knows how to go in there and take it out. I'm like, I'll be a little skeptic."

Self-removal with a device

"Yeah, sounds good. But I do know that IUDs usually--like you put it in and you take it out like maybe years after. So that's not something that you can do like on a monthly basis, like for me, the ring. Or you can try it, or if that's like one time thing. Like you do it once and you're done, unless you try again a couple of years and put another IUD, then you do it again. So I'll be like, maybe."

Self-removal with a device with a camera for visualization

"But if they have the camera, I think that would definitely be a seller. The camera would be like, OK. A lot of people would consider it, given the camera point, because a lot of, I think, risk and questions would come from the 'I can't see what I'm doing' or 'I don't know what I'm doing.'"

Recognition of the benefit of a self-removal device for autonomy and accessibility

After becoming familiar with the concept of IUD self-removal and the possibility of a self-removal device, most participants subsequently noted the potential advantages of self-removal for autonomy and accessibility:

"I feel like it would give more autonomy, like a sense of more autonomy in terms of medical care if this is a decision that you can basically undo by yourself or remove by yourself, and especially at a time when women's bodily autonomy is not being terribly respected in a lot of the United States. I think that it could be a good option for women who might be worried about side effects or what could happen, to know that they have the option to take it out whenever they want." – Never IUD user

Few participants not already using an IUD had the intention to use one, and the possible availability of a device and knowledge of self-removal did not appear to change those intentions. However, regardless of whether it was their personal intention to use an IUD, participants discussed how a device could be beneficial for autonomy over reproductive healthcare decisions. They discussed how it could increase access to care because a device would not require insurance or in-person doctor's visits.

Providers' self-removal recommendations and legitimacy

Participants were divided in their opinions about providers' recommendation for self-removal or self-removal with a device. Perspectives differed by participants' relationships with medical providers and medical institutions. For some participants, having a provider's recommendation to self-remove legitimized the process and its safety, and boosted their confidence that they could successfully self-remove:

> *"I would feel a little bit more reassured just because the medical professional told me that it's OK, because based on their knowledge and what their experience is with that kind of device or that kind of device, then I think it'd be more OK." – Never IUD User*

Others were skeptical, noting that it provoked questions about why the provider would recommend it and the quality of the provider. Participants who described having had poor experiences with conventional healthcare described how they would distrust a self-removal recommendation from one of the same providers with whom they had had negative experiences:

> *"I wouldn't trust it. I think of--with my experience going to the gynecologist's office or my doctor's office, I always feel like I get rushed out, and I almost feel like they're just kind of like, you can do it yourself. It makes me uncomfortable and makes me feel like they don't want to help me." – Never IUD User*

Medical misinformation/worst case scenario

Some participants across both interviews and focus groups expressed a lack of knowledge of female anatomy, IUDs in general, and IUD insertion and removal. As a result of this medical misinformation, there was some catastrophizing around IUD removal. Many of the questions about user experience and how the device would work were tied to these misconceptions. For example, these participants were very concerned with the IUD getting stuck, "bleeding out," needing to perform surgery on themselves to remove the IUD, or needing to visit the emergency room for assistance. These 'worst case scenarios' made participants skeptical of self-removal.

> *"In my own home if something went wrong--I can trust somebody [to help remove the IUD] but if I start bleeding out, will they freeze? Like what's the worst-case scenario? Are there any stats about how often this worst-case scenario happens when you do it yourself versus in the office?" – Never IUD User*

> *"If it's something like you've got to cut yourself to get it out, I would not be up to it. – Never IUD User*

Discomfort with non-sexual self-touch

Some participants in both IDIs and FGDs described their hesitancy about a self-removal device as related to their experiences with the cultural implications of inserting tampons or other vaginal products. They explained that using tampons or vaginal products was looked down upon in their communities and families and there was an implication of sexual behavior or 'impurity' if someone used tampons:

> *"In my family and in my community, they don't seem to be big fans of inserting things into female parts of the body...I remember my mom was like, I won't buy those [tampons] for*

you...I use pads. You use pads...And so she would tell me like, oh, if you insert them, then you lose your virginity. There was just all kinds of discourse back then and continuing about like, it's just not good to put things in your body. That's a sensitive area of your body. You don't want to insert anything. You want to stay a virgin."

"It was more like, you can't do this because it leads to--you use tampon, you get an IUD, and then you have sex, and then you have a baby, and then you die apparently. So it was just like this progression where it was like it's a gateway thing." – Participants in focus group #2

Others described similarly feeling uncomfortable touching their bodies, but for no particular cultural reason:

"I'll be scared to just do that because I never just--I wouldn't think about it as playing with my vagina. But I would say, ugh, I've got to do that myself? So I don't know. If I had to use a device to do it, I probably, if I see the strings right then and there, I probably would use the device. But if I didn't, I'd probably get a male to do it. I don't know why. I'd probably get my mom to do it or a doctor, all because, I don't know, it's just gonna feel weird to me. It's going to feel like, I'm not going to say playing with myself, but I don't know. It's just not going to feel right to me." – Never IUD User

Some participants who didn't like the idea of using their fingers or touching themselves were more interested in the possibility of using a device for self-removal over self-removal using their fingers. Participants expressed several reasons for this preference. The majority of users thought that using some sort of device would be easier, felt the device would help with locating the strings, and thought a device would be more comfortable.

"I think that it would be a lot easier using the application versus using fingers...It just, it can reach better. I've had tampons that weren't in the applicator. And me trying to put them joints in myself, it just, I couldn't do it." – Past IUD User

Information users need

Participants were vocal in describing the information that they would need in order to consider a self-removal device. While we also list the specific questions and suggestions that participants had separately in Appendices D and E, this theme relates to a deeper need for accessible information, knowing where that information and/or research originated, and feeling satisfied with available information to make an informed choice about use or non-use of a self-removal device. Participants in both IDIs and FGDs spoke about wanting to have detailed, multimedia, multisource information prior to deciding to use a self-removal device, at the time of use, and in case follow-up is needed after use. Participants commonly described wanting information about safety, contraindications, pain and/or side effects, efficacy of self-removal with a device vs. removal at a provider's office, how the device would actually work, and what the user experience would be like. While some participants had one or two preferred modes of learning, other participants described wanting information about the self-removal device available and delivered to them in multiple ways, such as written in a pamphlet, online, videos with animation, videos with real people, illustrations, photographs, and in both printed and online or app-based modes.

Regardless of prior knowledge or use of IUDs, participants almost uniformly wanted extensive safety information about a self-removal device to be widely available, specifically about potential for injury, infection, or future fertility problems. Participants mentioned needing information about the device's testing and approval process and confirmation that it is FDA approved. Some participants described wanting to see evidence-based information and research studies, as well as testimonials from providers and other users.

> *"I want to know how long the product been out, how have anybody else used it, has it been successful? Yeah, I just want to know like, has any other patient tried it, and what did they think? And did it work out for them? That'd be like my big question. And of course, how long it's been out? How much does it cost? All of that. You just need to know." – Past IUD User*

> *"Bring me the data, and I will also—women, what we do is we go online, we go to BabyCenter, there are blog posts on this, this, this, this. We search it on Google, and we see if any woman have any problem with this doctor or this product. Understand that we're going to Google it and we're going to figure it out." – Never IUD User*

Related to the complicated ideas around taking providers' advice and reproductive autonomy, a few participants also expressed skepticism about any evidence and information that could be presented, such as a focus group participant who noted, "But a lot of things have been said to be safe but didn't exactly turn out to be safe. So people are very skeptical these days."

Additional results

Several additional topics arose in interviews and focus groups. These are not conceptual themes like the themes above, but topics of interest stemming from either our specific questions and activities or from participants' questions or responses.

Differences in cost estimations and perceptions of willingness to pay

In IDIs, we gave participants specific cost and payment options to choose from in the card sort activity: costs no more than $30; costs no more than $20; costs no more than the co-pay I would pay for a doctor visit; at least partially covered by my insurance/health savings account; completely free to me. Overall, the cost 'cards' were among the top most preferred features out of all potential features included in the activity. Participants focused on low cost as a key component in a self-removal device.

Conversely, we asked focus group participants an open-ended question about cost and willingness to pay (How much do you think people would be willing to pay for a product like this?). Their estimates were generally higher than any of the options given to IDI participants in the card sort activity and varied widely, from $20 to upwards of $150. Participants discussed how insurance coverage, the perceived quality of the device and its aesthetics, presence of a camera, and whether it could be used more than once could all influence the amount people would be willing to pay for the device.

Card sort activity

Table 1. Card sort activity results summary

Feature category & specific feature options	Most preferred features		Least preferred features		Illustrative quote
	Percent of participants who picked at least 1 in the category (n=29)*	Percent of all most preferred picks (n=87)**	Percent of participants who picked at least 1 in the category (n=29)	Percent of all least preferred picks (n=86)***	
Camera Has a camera You have to use the camera in order for it to work (so you have to see your own cervix and IUD strings) Has a camera that can be used with iOS (iPhone) or Android Can send photos to my healthcare provider if I want to Automatically sends photos to my healthcare provider	**82.76%**	**27.59%**	**13.79%**	**4.65%**	*"[A camera] makes me feel more confident that I'm not going to lose it or I'm not messing things up. It's not a guessing game anymore."* *– Never IUD User*
Cost Costs no more than $30 Costs no more than $20 Costs no more than the co-pay I would pay for a doctor visit At least partially covered by my insurance/health savings account Completely free to me	**75.86%**	**25.29%**	**13.79%**	**4.65%**	*"An OB visit could run $1,000 or more depending on exam and things. And I would think a telehealth visit might be like $80. [The device] could be really cheap for like--and figure something like it'd take, what, 15, 20 minutes."* *– Current IUD user*
Accessibility: no prescription required Available at a pharmacy without a prescription (over the counter) Available online without a prescription	**37.93%**	**12.64%**	**10.34%**	**3.49%**	*"I would definitely want it to be available without a prescription for reasons of if you don't have a good relationship with your doctor, if you think that your doctor is going to try to dissuade you or talk you into coming in and also just for ease of accessibility."* *– Never IUD User*

Feature category & specific feature options	Most preferred features		Least preferred features		Illustrative quote
	Percent of participants who picked at least 1 in the category (n=29)*	Percent of all most preferred picks (n=87)**	Percent of participants who picked at least 1 in the category (n=29)	Percent of all least preferred picks (n=86)***	
Higher effectiveness More effective than self-removal without a product	20.69%	6.90%	0.00%	0.00%	*"That one seems really important to me because if I'm going to use a tool, I want it to work really well."* *– Never IUD user*
Accessibility: prescription required Available at a pharmacy with a prescription from my healthcare provider Available at a clinic	10.34%	3.45%	3.45%	1.16%	*"If I should need it for removing a device, prescription only because people abuse the system. And they'll be using it for something different. So just to make it safe on my side and everybody else's side to make sure that it don't get taken away from us."* *– Never IUD User*
Aesthetics It doesn't look like a medical device It looks like a sex toy I like the design–the color(s), shape, feel, etc. Its design is gender-neutral Its design has traditionally feminine aspects (e.g., it's pink)	13.79%	4.60%	141.38%	47.67%	*"It's a functional device, right? So I wouldn't prioritize if I like the design or something like that because it's a very functional product. Its design has a traditionally feminine aspect, it's pink–it doesn't matter to me, personally. Doesn't matter at all."* *– Never IUD user*
Single use The product can only be used once	0.00%	0.00%	24.14%	8.14%	*"For sustainability. I don't think that would be very smart."* *– Current IUD user*

Feature category & specific feature options	Most preferred features		Least preferred features		Illustrative quote
	Percent of participants who picked at least 1 in the category (n=29)*	Percent of all most preferred picks (n=87)**	Percent of participants who picked at least 1 in the category (n=29)	Percent of all least preferred picks (n=86)***	
Smaller size It is no bigger than a tampon	10.34%	3.45%	17.24%	5.81%	*"I'm not really concerned about the size of it as long as it's still something that's comfortable to use and isn't like too, I guess, what's the word I'm looking for? Intimidating."* *– Never IUD user*
Re-use The product can be used more than once	6.90%	2.30%	13.79%	4.65%	*"To me, that just seems unsanitary. Like, are you going to throw it in the dishwasher?"* *– Current IUD user*
No camera Does not have a camera You do not have to use the camera in order for it to work	3.45%	1.15%	6.90%	2.33%	*"I think it is important that it has a camera. So it not having a camera to me is--I think it should have one...It wouldn't be a deal breaker, but I feel like I would be more of open to using it if it had some type of camera or device to guide me or whoever's removing it."* *– Past IUD user*
Larger size It is no bigger than a sex toy like a vibrator	3.45%	1.15%	3.45%	1.16%	–
Similar effectiveness As effective as self-removal without a product (i.e., using my fingers)	3.45%	1.15%	0.00%	0.00%	–

* 1 participant did not complete the card sort activity. Categories are not mutually exclusive, and totals may be greater than 100% if participants picked more than 1 card in the category for most or least important features (e.g., if a participant chose both 'costs no more than $30' and 'costs no more than a co-pay' for 2 of their 3 most important feature picks).

** Participants picked 3 most important features

*** Participants picked 3 least important features, but 1 participant only picked 2 least important features

Image responses

In the image response section, we showed participants images in the order of smallest product/device to largest (regular plastic applicator tampon, reusable applicator tampon, transvaginal ultrasound wand, vibrator). Overall, participants seemed most comfortable with the size of tampons because of their familiarity and ease of use, though there were some questions about whether a tampon-sized device would be long enough for the purposes of IUD self-removal. Very few participants had familiarity with reusable tampon applicators prior to being shown the images. Most felt that the reusable applicator tampons seemed bulkier than a standard tampon and even "intimidating."

Overall, participants had quite negative responses to the transvaginal ultrasound wand. Participants equated the possibility of an IUD self-removal device being sized/shaped like an ultrasound wand with their previous negative or uncomfortable experiences with transvaginal ultrasounds. While some agreed the length and circumference would be more appropriate for removing an IUD than a tampon-sized device, others felt it was too long. Participants also had concerns that the wand's material would be too hard and inflexible, and pointed out that the shape would be more comfortable if it were curved.

Responses to the vibrator were mixed as well. There tended to be initial reactions about the size being too big, but then after more thought and discussion, participants thought the curved shape and silicone material would make using it more comfortable. They also mentioned that it could be more comfortable to hold in their hand, as opposed to the small, hard plastic of a tampon applicator. Some participants mentioned its more positive connotations as opposed to the ultrasound wand. Reactions to the vibrator also seemed to vary by age and experience with using a vibrator; many participants in the older age ranges said that they had never used a vibrator.

Body mapping

In the body map drawings, focus group participants overall prioritized being physically comfortable, having privacy and good lighting, and having everything they would need at arm's length (see *Appendix E: Selected body mapping drawings* for several illustrative drawings). Participants depicted themselves using a self-removal device in bed for comfort or in the bathroom for cleanliness and privacy. Most participants drew themselves on their backs, often with a towel underneath, with knees up, and emphasized having all the items they imagined they would need nearby (e.g., towels, pillows, lubricant, mirror, and/or phone). Many participants focused on how they could prop up their phones where they could see video hands-free, without having any cables get in the way.

> *"My bed, or maybe like on the couch--something like when you have a pap smear, kind of not really your feet up, but curved like that in that position. I just think it would be easier to get out. And then I put my phone on a little tripod or something like that, where I could get it situated where it needs to be if I had to use it, or whatever. And then I'd put like lube, and water, and wipes, and then at the bottom, I put like cleaning supplies down here, and then a trash can." – Participant in focus group #10*

Participants also drew themselves standing over the toilet or laying, sitting, or standing in the bathtub due to concerns around ease of cleaning up, as well as familiarity with tampon insertion/removal positioning. Regardless of room location, participants noted the importance of good lighting to assist in the removal process. A minority of participants drew another person with them to assist with removal, although a few others mentioned having someone else nearby in case of problems.

> *"I'm standing in the shower and the sun denotes that there's light in the room. So it's bright. And you can see that I have my legs open. One leg is like bent over the side of the tub. And I'm inserting it like I would a tampon in the shower, though, because if there's any--I just--I think, clean. I'm naked. I can wipe--use any water to wipe away anything I need to. And it's private. So that's what--and I think the water would help me--and I don't want to say lube, but it's wet." – Participant in focus group #2*

Discussion

Participants in this multi-method qualitative study had a wide range of personal experiences and attitudes towards IUD self-removal and attitudes about self-removal with a device. While there was a lack of knowledge about IUDs and IUD removal that influenced initial perceptions of self-removal, overall, having a device for self-removal (particularly one with a camera) seemed to make the concept of self-removal more legitimate and acceptable, with less of a DIY feeling than just using fingers or hands.

Participants engaged in perspective-taking, in which they assessed the potential of a self-removal device based not only on their own experiences and attitudes, but from what they know or perceive others to experience. This was most apparent in discussions of the pros and cons of a self-removal device. Even those who were not interested in using IUDs or a self-removal device in the future acknowledged the benefits of autonomy and accessibility through self-removal and/or self-removal with a device, but this recognition of the potential for autonomy and accessibility did not necessarily impact or signal a desire for personal use. Few participants reported that knowledge of the existence of a self-removal device would change their interest in using an IUD, but they quickly identified it as something that may be useful for others. Specifically, participants related low cost and ease of self-removal device availability to the idea of reproductive autonomy, contrasting the potential of a low-cost self-removal device that could be purchased online or over the counter to the high costs, barriers to accessing care, and negative experiences receiving care in the U.S. healthcare system. As in at least one other study,[11] the theory that knowledge of self-removal or of a self-removal device could influence initiation of IUD use may not bear out. However, it is worth noting the difference between knowledge of self-removal and lack of knowledge of self-removal as influences on IUD use. While IUD users with self-removal knowledge may not change behavior, IUD users without knowledge of self-removal may be more likely to consider discontinuation.[11] Further research is needed to disentangle the relationship(s) between knowledge of self-removal, IUD satisfaction, and IUD use.

Participants' top priority for a self-removal device is safety, consistent with participants' concerns in previous studies on IUD self-removal (without a device).[3,12] They need reassurance that the device is safe to use at home, and that it is equally effective as removal at their medical providers' office. Participants want reassurance from a variety of sources: scientific studies and clinical trials, device approval/recommendation from institutions such as the FDA, providers,[13] and other users.[13] For some, recommendations from their own provider would provide a vote of confidence. Additionally, it was especially important for participants to have the experiences, testimonials, and reviews from users themselves. They are seeking this type of user experience on different internet and social media forums[13,14] (TikTok was specifically mentioned multiple times as a source of reproductive health knowledge), or word of mouth. If this type of user experience information doesn't exist, or is overwhelmingly negative, participants unequivocally declared that they would be less likely to use the device. Interestingly, the participants in our study who mentioned learning about IUD self-removal on social media had seen generally negative depictions of self-removal, whereas in other studies, social media or online depictions of self-removal were more positive.[13–15] It would be especially important to draw on the

experiences of users in marginalized communities, with representation in studies, informational materials, and reviews/testimonials. Given the U.S.'s history of medical exploitation and abuse, people of color may be skeptical about the safety and effects of the device, even if people of color may be more likely to be interested in self-removal[3,15] and the device comes with provider or institutional recommendations.

Given the misperceptions and misinformation about IUDs, IUD removal, and reproductive anatomy in general, potential users (including those who already have an IUD and those who do not) may also need an accompanying, more comprehensive educational campaign or tools— not only education about the IUD self-removal device. This should include information about anatomy of the uterus, cervix, and vagina; what an IUD is and where in the body it is placed; how IUD insertion and removal works (at a provider and in self-removal); and the differences between the insertion and removal processes. Increased knowledge and comfort with reproductive anatomy and one's own involvement in reproductive health care would likely be helpful in addressing the barrier to self-removal and self-removal with a device that lack of knowledge and unease with the body seems to present. Subsequently, educational materials and user instructions for using a device will be more effective.

Ultimately, safety, ease of use (effective, comfortable, not painful, no side effects), cost (no more than co-pay for office visit), and accessibility (ideally available at the pharmacy or online without a prescription) are the biggest factors in potential uptake of a self-removal device.

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Appendix A: Card sort activity

Potential self-removal device features listed on the 'cards' in the card sort activity:

- Costs no more than $30
- Costs no more than $20
- Costs no more than the co-pay I would pay for a doctor visit
- At least partially covered by my insurance/health savings account
- Completely free to me
- Has a camera
- Does not have a camera
- You have to use the camera in order for it to work (so you have to see your own cervix and IUD strings)
- You do not have to use the camera in order for it to work
- Has a camera that can be used with iOS (iPhone) or Android
- Can send photos to my healthcare provider if I want to
- Automatically sends photos to my healthcare provider
- Available at a pharmacy without a prescription (over the counter)
- Available at a pharmacy with a prescription from my healthcare provider
- Available online without a prescription
- Available at a clinic
- The product can be used more than once
- The product can only be used once
- It doesn't look like a medical device
- It looks like a sex toy
- I like the design–the color(s), shape, feel, etc.
- Its design is gender-neutral
- Its design has traditionally feminine aspects (e.g., it's pink)
- It is no bigger than a tampon
- It is no bigger than a sex toy like a vibrator
- As effective as self-removal without a product (i.e., using my fingers)
- More effective than self-removal without a product

Card sort activity screen as seen by participants:

Hello!

🎬 **Introduction**
Thanks for taking part in this card-sorting activity.
The goal is to identify the **3 most important** and **3 least important** features that a potential at-home IUD removal product could have.

🖥 **What to do?**
1. **Create groups**. Look at the cards one at a time and place them in in the **3 Most Important Features** box or the **3 Least Important Features** box.
2. You can **move cards in and out of the boxes** as you think about the features. Just leave cards that you don't choose anywhere in the grey areas.
3. Take as much time as you need! When you're satisfied with your sorting, **let your interviewer know.**

🙏 **Thank you!**

👆 **Sort the cards below**

Costs no more than $30

Costs no more than $20

Costs no more than the co-pay I would pay for a doctor visit

At least partially covered by my insurance/health savings account

Has a camera

Does not have a camera

Automatically sends photos to my healthcare provider

You do not have to use the camera in order for it to work

You have to use the camera in order for it to work (so you have to see your own cervix and IUD strings)

Has a camera that can be used with iOS (iPhone) or Android

Available at a pharmacy with a prescription from my healthcare provider

Available at a pharmacy without a prescription (over the counter)

Can send photos to my healthcare provider if I want to

Completely free to me

It is no bigger than a tampon

More effective than self-removal without a product

As effective as self-removal without a product (i.e., using my fingers)

It is no bigger than a sex toy like a vibrator

It looks like a sex toy

Available at a clinic

Its design has traditionally feminine aspects (e.g., it's pink)

Its design is gender-neutral

The product can be used more than once

I like the design–the color(s), shape, feel, etc.

It doesn't look like a medical device

The product can only be used once

Available online without a prescription

3 Most Important Features

3 Least Important Features

22

Appendix B: Participant characteristics

	Total (n=78)		Interviews (n=30)		Focus groups (n=48)	
	n	%	n	%	n	%
Race/ethnicity						
Black	23	29%	6	20%	17	35%
Latina	12	15%	5	17%	7	15%
Asian	11	14%	6	20%	5	10%
White	19	24%	4	13%	15	31%
Another race/ethnicity, multiple	13	17%	9	30%	4	8%
Age						
18-29	28	36%	16	53%	12	25%
30-39	34	44%	10	33%	24	50%
40-49	16	21%	4	13%	12	25%
Region						
Northeast	19	24%	8	27%	11	23%
South	25	32%	9	30%	16	33%
Midwest	15	19%	6	20%	9	19%
West	19	24%	7	23%	12	25%
IUD use						
Current user	20	26%	7	23%	13	27%
Past but not current user	19	24%	6	20%	13	27%
Never user	39	50%	17	57%	22	46%
Heard of IUD self-removal						
Yes	26	33%	10	33%	16	33%
No	47	60%	19	63%	28	58%
I'm not sure	5	6%	1	3%	4	8%
Education						
High school degree/GED	8	10%	5	17%	3	6%
Some college, no degree	20	26%	12	40%	8	17%
Associate's degree	8	10%	3	10%	5	10%
Bachelor's degree	29	37%	8	27%	21	44%
Graduate or professional degree	11	14%	2	7%	9	19%
Unknown	2	3%	0	0%	2	4%

Appendix C: Participants' questions about a potential device

1. What kind of material will the device be made from?

   1a. What kind of lubrication is compatible with the device?

2. Does the device work with only one kind or brand of IUD (newer) or can it work with already inserted (older) IUDs/all brands of IUD?

3. Will the device work with different types of anatomies or issues (e.g., tilted uterus, fibroids, cysts)?

4. Can the device be used more than once? If so, can it be sterilized? Would it degrade over time between IUD removals?

5. How do you dispose of the device safely? Is the IUD and/or the device considered medical waste?

6. Is the device single-use plastic? Is it environmentally responsible?

7. What are the security protocols in place to connect camera with an app and transmit/store data? (Via bluetooth? Cable?)

8. Where would images be stored (e.g., in the cloud, in an app, locally on the user's phone)?

9. Who would own or have future access to any images that might be captured (e.g., an app? a pharma company? the device manufacturer? their provider's office or hospital system?)?

10. Exactly how will the device grab the strings?

11. Does it require any sort of special skills to use?

12. Is there a possibility of trauma to the uterine wall or any complications?

13. Is there any aftercare that needs to happen after removal?

14. How was it tested? Approved? Evidence?

15. How do you know if you've done it correctly and successfully removed the IUD?

16. When should you get help if you've done it incorrectly?

# Appendix D: Participants' suggestions for a device

1. Comes in a 'kit' which includes: sterilization materials, gloves, lubricant, etc.

2. Device should be curved for comfortable insertion

3. Includes hotline number to call for questions and support

4. Includes directions to online discussion board of other's experiences with removal (for support)

5. Camera has target guidance on video screen

6. Makes sound to indicate positioning (like a car back-up or GPS beeping when not in correct location)

7. Tool/quiz/questionnaire to see if it's the right option for an individual to give peace of mind to know if was safe for specific body and issues

8. Offer mini workshop online—watch someone do it in real time

9. Multiple types of instruction materials—written (printed), app-based, illustrations and videos showing real people and animated version

Appendix E: Selected body mapping drawings

Note: Only drawings for which the participant consented to sharing the drawing are included here.
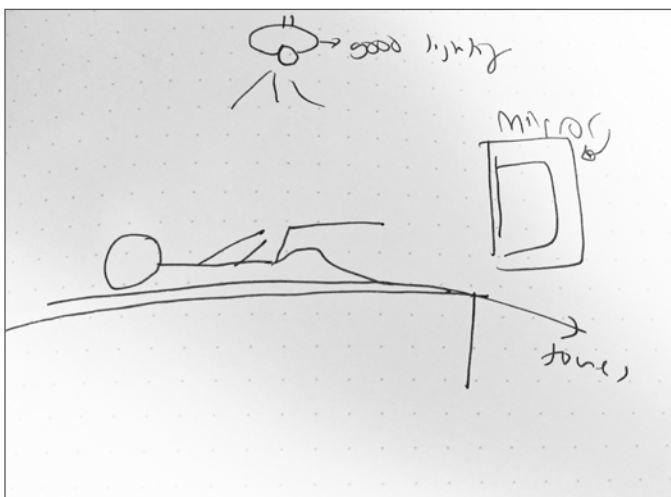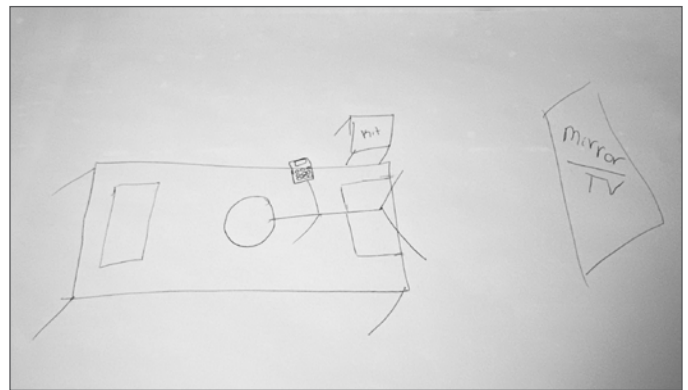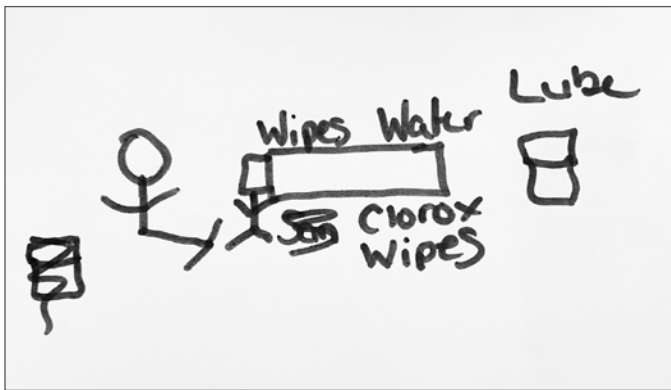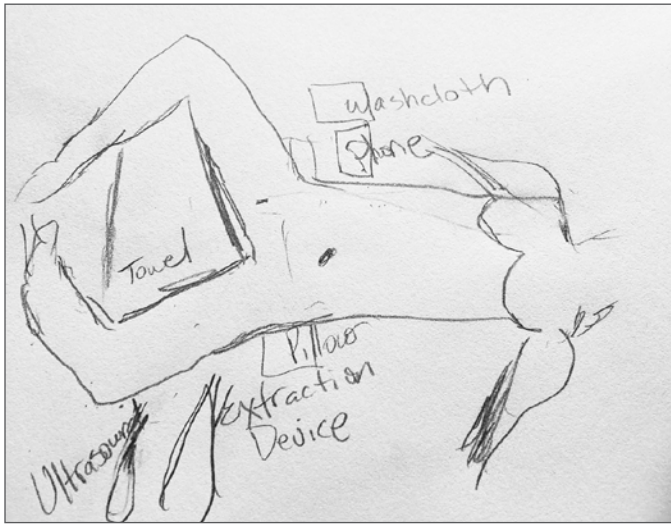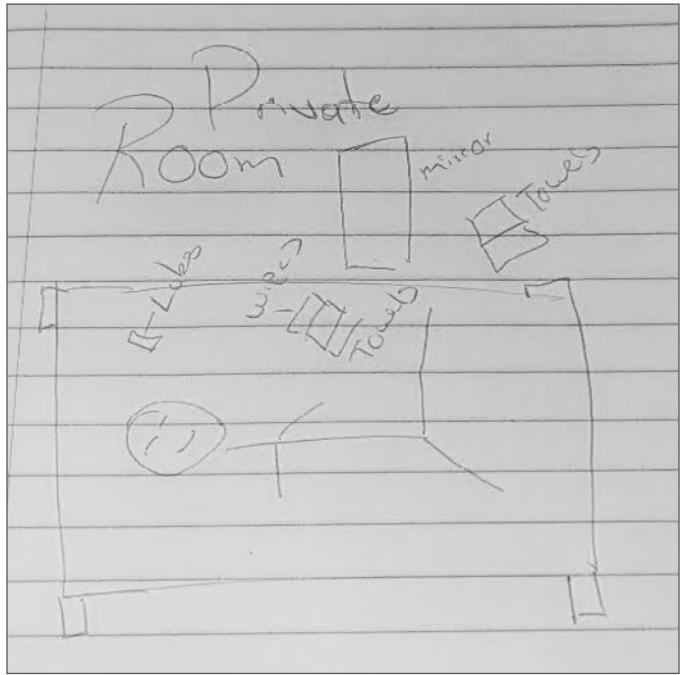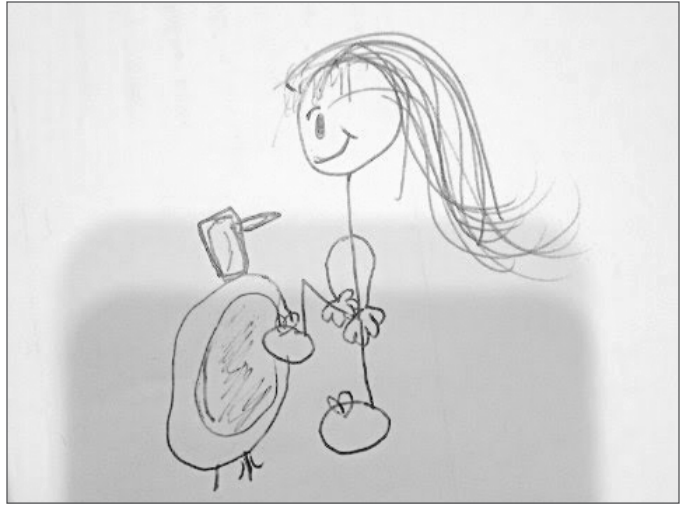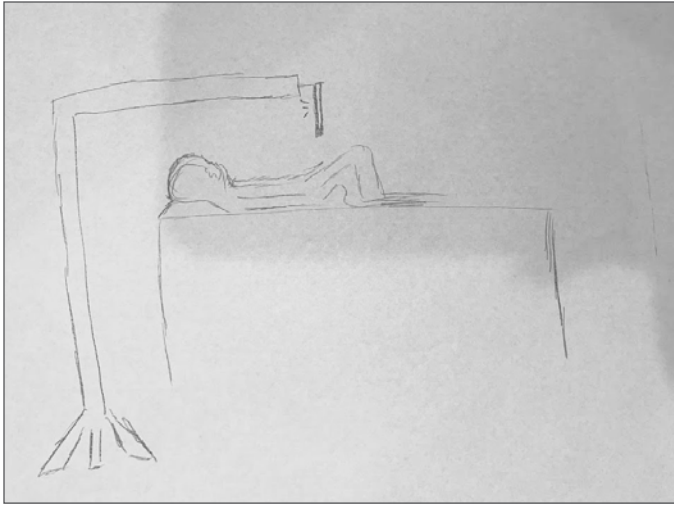
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