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Abstract

Developing a Youth Contraception Navigator Program: A Human-Centered Design Approach

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Purpose: To determine key elements of a contraception navigator program that provides a personalized approach to overcoming patient-specific barriers by a trained navigator in central Indiana.

Methods: A human-centered design approach was used to engage adolescents and community stakeholders in co-design sessions. Sessions incorporated techniques, such as divergent brainwriting and journey maps which led to the exploration of various themes that were ultimately used to inform key elements of the contraception navigator program.

Results: Adolescents aged 15-17 years (N=35) and community stakeholders (N=11) participated in co-design sessions. Analysis verified the process of obtaining contraception for pregnancy prevention can be intimidating for young people. The importance of language, presence of stigma and the knowledge of side effects were all discussed. Essential elements of a contraceptive navigator program included building trust to ultimately co-create a plan that can overcome patient-specific barriers. Having a variety of communication methods available, as well as contraceptive side-effect support, will be essential.

Conclusions: Using human-centered design techniques to engage adolescent and community stakeholders can help inform the development of a contraceptive navigator program. A trusted navigator that can address patient-specific barriers to contraception access both before and after contraception is obtained is a key element identified by stakeholders.

Keywords: Adolescents, Contraception, Adolescent Health Services, Access to Health Care, Human-Centered Design, Patient Engagement, Pregnancy, Barriers

Abbreviations: Adolescent and Young Adults (AYA), Reasoned Action Approach (RAA), Human-Centered Design (HCD), Research Jam (RJ), Actions, Environments, Interactions, Objects, and Users (AEIOU)

Implication and Contributions Statement: Assuring access to contraception is imperative for young people. Using a human-centered design approach, stakeholders identified key elements of a contraception navigator program that can overcome patient-specific barriers to contraception access.

Introduction

The unintended adolescent pregnancy rate has seen a 51% decrease from 1990-2010 in the United States, with the primary driver of this decline being improved hormonal contraceptive use. (1) While this trend is encouraging, adolescents and young adults (AYA) still lack access to youth-friendly care to initiate and continue contraception use, leading to adolescent use of less effective methods of contraception for pregnancy prevention. (2)

Adolescents and young adults face unique and significant external (e.g. economic, logistic) and personal barriers to accessing and using contraception. (3, 4) These external barriers intertwine with personal barriers of knowledge, confidentiality concerns, partner involvement, and normative beliefs. (5, 6) A variety of strategies have been employed to overcome the external barriers identified above; (7-9) however, many of these interventions have been directed at removing barriers to access only after an adolescent is within the clinical system and few address barriers outside the healthcare system. (7-10) Additional barriers include state-specific statutes which do not give minor's explicit consent to contraception, school sexual education that must emphasize abstinence and vast geographic areas that are considered contraceptive access deserts.(11-13)

Interventions and strategies focused on issues encountered by adolescents at all stages of the process to obtain contraception are needed.(14) It is vital to attend to barriers faced prior to engaging with the health care system, within the clinical encounter itself and afterwards in continuing to use their chosen method of contraception. Understanding that individuals have a unique set of barriers to overcome, the use of a trained navigator to address various barriers on a personal basis is a promising and proven approach. (15-18) A navigator is trained to work with patients to overcome barriers and understand the medical system to ultimately achieve better health outcomes. Patient navigator programs' primary focus is the individual rather than the system, and the conceptual foundation of navigation has much in common with the strengths-based perspective in social work practice and promoting self-efficacy. (15, 18)

One approach to designing patient navigator programs with improved uptake and ultimate success is human-centered design. Human-centered design (HCD) is a stakeholder-centered approach for intervention development. (19-21) When the ultimate end-users are not engaged in the development process, resulting interventions may be culturally unsafe, amplify stigma, create mistrust or cynicism, or be ineffective or even harmful in worse-case scenarios.(22) HCD is not new, but its application to healthcare is still in its infancy compared to similar approaches such as community-based participatory research. HCD is centered on end-users as the driver of intervention development, while community-based participatory research is focused on equity and empowerment of the community as part of a research team and usually consists of a longer partnership commitment. (20, 23, 24) Previous work has shown that adolescents are able to conceptualize and articulate their needs for contraceptive services, and youth participatory approaches are increasingly widely used and successful.(25)

We aimed to use a human-centered design approach with the insight of adolescent and non-adolescent stakeholders to identify key elements of a contraception navigator program to help young people in central Indiana to overcome both personal and external barriers to obtaining and using contraception for pregnancy prevention.

Methods:

Study Design and Study Population.

We conducted four HCD sessions: the first one with community stakeholders that helped provide content for the subsequent three sessions with adolescents aged 15-17 years. This age range was chosen to capture insight of legal minors that have consent barriers within our state and to reflect common ages of sexual activity initiation. The non-adolescent stakeholders were of varying professions within the health and medical systems and from the larger community representing adults to whom adolescents may turn for contraceptive help and advice—such as a school nurse, community pediatrician, teacher or minister. We partnered with Research Jam (RJ), the Indiana Clinical Translational Science Institute's Patient Engagement Core which has expertise in applying human-centered design techniques to health services research through a combination of qualitative research and design research methodologies.(26-28). The Indiana University Institutional Review Board approved of this study with a waiver of parental permission for participants less than 18 years of age.

Recruitment

Both community and adolescent stakeholders were recruited through community relationships and organizations that interact with young people, such as schools and standing youth advisory boards. Adolescents ages 15-17 years and non-adolescent stakeholders who lived in central Indiana and spoke/read English were recruited until approximately 12 participants were in each human-centered design session. After the HCD session, a survey was completed. No questions were required and zip code information was asked to evaluate rural/urban designation.(29)

Human-Centered Design Sessions

The Reasoned Action Approach (RAA) integrated theory of social behavior change suggests the single best predictor of whether someone will perform a behavior is the person's intention to perform that behavior. The RAA proposes that perceived norms, self-efficacy, and an individual's attitudes about action can directly impact intentions.(30, 31) Additionally, the RAA suggests that an individual's actual skills/abilities as well as environmental factors influence the degree to which intention predicts or leads to behavior. Using the RAA framework, HCD sessions were used to focus stakeholder activities, uncover motivations and intentions and environmental factors, interpret outputs and translate them into navigator program components that focus on self-efficacy, attitudes, environmental factors and concepts under the adolescent's control (i.e., actual skills/abilities).

Each human-centered design session followed a similar agenda and took place between October 2019 and February 2020. Preliminary work was done to explore known barriers to access and various design activities that would be helpful in eliciting information about program components. Sessions were led by HCD team experts and began with a diverging brainwriting exercise where participants individually wrote down barriers that could exist for adolescents when obtaining contraception on their own. Each barrier was written on a separate post-it notes (each session with a different designated color). Brainwriting, a quiet, written version of brainstorming, allowed for the generation of a large quantity of ideas before worrying about the quality.(32) After this brainwriting period, participants were asked to place the identified barriers into the following pre-determined larger categories: clinic access (not knowing where to go), confidentiality, financial concerns, transportation and knowledge (not knowing which form of birth control to get). There was also an “other” category that was available if the barrier did not fit into any specific category. Participants placed their barriers in categories themselves, but group discussion developed when there were questions about best fit. After barriers had been sorted and reviewed by the group, additional barriers were identified and added.

Participants then worked on a journey map activity in two smaller groups. Journey maps are a visual representation of touchpoints in a particular experience from start to finish.(33) The process of creating a journey map as a group can uncover key moments that, once identified, can lead to discussion, and generate valuable additions to the map, ultimately creating a more holistic map of the overall experience.

A “best guess” journey map was created prior to the design session and presented to each group and included five steps to obtain hormonal contraception: 1) adolescent is sexually active and wants contraception, 2) figures out what kinds are available, 3) goes to doctor, 4) obtains contraception, 5) uses contraception. These steps were tentatively ordered, and participants were asked to call on their expertise to provide additional details and corrections to the maps. Participants drew out specific movements and interactions during the scenario of seeking and obtaining contraception for pregnancy prevention as an adolescent in both rural and urban settings. The participants then added barriers to obtaining contraception to each step. They pulled from the diverged list created during the brainwriting activity and added more as they emerged.

After barriers at each point were discussed, potential solutions to those barriers were proposed and placed on the journey map. At this stage, the adolescents also gave direct feedback on the solutions generated by the non-adolescent stakeholders in the first session.

All the HCD sessions were recorded and transcribed. The sessions ranged from 90-120 minutes in length, and participants were compensated for their time with a $40-60 gift card of their choice.

Analysis and Synthesis:

Four design researchers reviewed transcripts and session artifacts (ex. journey maps with various barriers and solutions overlayed that were created during the sessions) using affinity diagramming, concept mapping and challenge mapping approaches. These analysis approaches were used to uncover patterns in the journey map, barriers and potential solutions for contraception access and were used iteratively with probing and exploring when there was disagreement among design team members.(34, 35) A consensus was eventually met through additional discussion.

First, affinity diagramming organizes ideas into categories based on similarity. This work was done by laying all the individual barriers from each session and then moving them into groupings based on relatedness of the content. Once grouped, a heading that reflected the overall theme was discussed and agreed upon by the HCD team (Appendix A).

Visual modeling through concept mapping was then used to create relationships between those identified themes. Individual members of the team would create a concept map showing how themes were related. These various concept maps were presented to the team and then further organized through discussion for a final version. into the Actions, Environments, Interactions, Objects, and Users (AEIOU) framework, which is helpful in designing user experiences for solution development.(36) The same process of concept mapping described above for barriers was used to explore the relationships between proposed solutions and solution themes. The team collaboratively worked to identify, discuss, negotiate, and confirm relationships between identified concepts for both barriers and solutions.

Once areas of barriers were organized into the AEIOU framework, the team engaged in challenge mapping to diverge on solutions for particular barriers and then selected solutions that were most appropriate based on what was learned. Challenge mapping uses statements such as “how might we…” and “what is stopping us?” to generate ideas for overcoming barriers to augment what participants had proposed. These generated ideas were refined through additional discussion and ultimately helped inform the essential elements of the navigator programmatic content during the synthesis phase.

Results

A total of four human-centered design research sessions were conducted—three sessions consisted of adolescents aged 15-17 years (N=35) and one with community stakeholders (N=11) (Table 1). The adolescents were distributed relatively evenly between the three ages, 60% identified as African American. A majority reported being attracted to boys and a third reported being sexually active. The community stakeholders were predominately female (81.8%), white (90.9%) and non-Hispanic. For both adolescents and community stakeholders, they all reported living or working in an urban zip code.

The original journey map was refined through the co-design sessions and additional touchpoints and steps were added, including determining where to go and researching side-effects (Figure 1).

Selected barriers identified from concept mapping were organized into various AEIOU categories (Figure 2). There were five over-arching themes that emerged through the affinity diagramming and concept mapping process. Additional statements are presented in Table 2.

Process of choosing and obtaining contraception is intimidating

A common sentiment in both adolescent and non-adolescent stakeholder sessions was an acknowledgement that the process of obtaining contraception for pregnancy prevention was intimidating. Various elements were noted, such as how to start the conversation or find the right clinician, with the assumption this conversation was centered within the health-care system.

> *I don't even know how to ask [the doctor about birth control]. They didn't really say anything. If I didn't say what is best for me or whatever, they probably would have just went and given me something else. (adolescent stakeholder)*

Language is everything

Participants described the importance of various words and language on setting the tone for an interaction between patients and the clinical system.

> *My doctor, she didn't call it birth control. She told my parents at first, well, my parents knew it was birth control, but she at first just said it's hormones. We're going to give her some hormones to take. (adolescent stakeholder)*

As young people have emerging skills as health care consumers, checking in about simple things such as terminology is important. For example, the term "provider" was used to encompass various medical professionals but was not clear to all adolescent stakeholders at first.

Stigma and shaming from close connections and the medical community

Stigma and shaming were discussed in all co-design sessions. The adolescents expressed that they felt less stigma from society as a whole, while the non-adolescent stakeholders felt that this stigma was a concern. Perhaps this indicates a change in the wider cultural environment over time.

> *It's a paradigm, but sexuality is so stigmatized. It is so stigmatized…dirty. (non-adolescent stakeholder)*

Shaming became more relevant and prominent at the community level and closer. This included concerns around lack of privacy within small communities as well as based on religion and national origin and attributing character flaws.

> *So if you think about some of our rural communities, they have one or two Docs or if there's a planned Parenthood in the rural community that's just right there. Everybody knows what you're doing at planned parenthood. (non-adolescent stakeholder)*

Adolescent stakeholders noted their main concerns for stigma was from those in their smaller orbit and not the larger community, with parents a main potential source for some adolescents.

> *I feel like most teenagers, they don't worry about what people think as much. They kind of worry about different sections of the people that are closest to them and what they think about them, not other people.*

However, adolescents did note that the stigma from the medical community was part of their smaller orbit and palpable.

> *A lot of doctors say that you shouldn't do it if you're not ready to have babies. So, it kind of seems like they're judging you, if you say you are.*

Concerns about contraception side effects are a barrier

Stakeholders discussed that birth control side effects are a significant consideration for those deciding to use birth control. The specific information discussed by participants was not always medically accurate but was from a source they considered trustworthy.

> *Doing your research is very important about the different birth controls. Is this birth control good if 58 percent of people gain weight? You don't want to gain weight because of the birth control, don't do that part. Or this one, 99 percent of people got depressed after using this, don't use that one. (adolescent stakeholder)*

Side effect information came from friends, the internet, and family members. Perceptions of the trustworthiness and accuracy of each source differed amongst participants.

> *A lot of [internet sources] say a lot of different things though. That's why I don't know. Then, when people tell me about their experience*

> *versus the internet, too, that's why I don't know if it's good or bad. (adolescent stakeholder)*

Youth as healthcare consumers

Adolescents were clear as to their desires for better information and neutrality from their clinical caregivers.

> *I'd change my doctor, because I had a doctor that was biased, and I changed her. It came to a point where it was just nope. I needed something, and I kept on telling her this is really affecting me and I need to get this certain medication, and she was like, "No; you can try this"*

Synthesis: Ideal contraception navigator program components

During the synthesis phase of the work, the essential elements of a contraceptive navigator program and an overview of the program was created through visual mapping. (Figure 3). Essential elements of the navigator program include building trust, providing desired information and support for overcoming assessed barriers, the co-creation of a plan and continued support and feedback.

Building Trust

Building trust between the adolescent and the navigator will be crucial and may be challenging given the potential online or virtual nature of the interactions. For that reason, having multiple methods of connecting (texting, video chat, email, etc) in addition to or instead of a phone call will allow participants to engage with the navigator directly in a way that fits their needs at that moment.

A portion of the trust must come from the credibility of the source of information. Therefore, assuring there is a connection between the navigator to an organization or institution that has been deemed trustworthy within the community will be important. In addition, due to potential stigma from close or community sources, it will be important to offer adolescents anonymity throughout.

Providing Desired Information

Adolescents want information regarding contraception and, most importantly, want that information to be accurate. In addition to training for patient-centered contraception counseling, navigators will need to be able to sensitively assess young people's information needs and tailor their resources for those needs. Assuring the navigator is able and available to answer any follow-up questions participants have will be important. Easily accessible resources for additional contraception information after contact with the program can also serve as reference material for participants and their peers.

Anticipated Barriers

Assessment of patient-specific barriers that the navigator can help address will also be an element of the program. Navigators will need to know information and resources on addressing specific barriers in advance. Potential solutions to barriers such as financial and confidentiality concerns and transportation within various communities will be important to identify in the early phases of programmatic design.

Plan Co-Creation

The navigator will provide reassurance that adolescents are not alone and that they can build a plan together. Working together on various elements also enables questions to be answered quickly and helps assure momentum is not lost. Once the initial plan is created, having the ability to continue to communicate with the navigator will be critical.

In addition to creating a plan together with participants, the trained navigator could provide guidance on how to talk about birth control with various audiences. Key conversations to consider would be those with health care providers, peers, parents and partners. The development of communication guides that can be customized for participants based on their scenario could be used.

Don't Stop There

The ability to provide the option for on-going communication and support with the navigator, including after contraception has been obtained, could be helpful. This support could include help navigating around additional barriers that develop after contraception has been obtained, side-effect support, alterations to the co-created plan, communication with healthcare providers or family and friends, in particular around stigma concerns.

Sharing

Enabling participants to share feedback will be important to allow for iterative improvements of the program. Giving participants the option to share information about the program with their peers could also help build visibility and trust within the community in an intentional and prospective manner.

Discussion

Our study utilized human-centered design approaches to engage both adolescent and non-adolescent stakeholders to improve the process of obtaining contraception for adolescents. Our findings confirmed that adolescents face a lack of support and stigma from parents, providers and their community while also being inundated from information from peers, partners and the internet and have trouble sorting through inaccurate information. Adolescents are concerned about side effects and have limited reliable resources to help them weigh and then adjust for those. While we initially imagined a trained navigator would help adolescents choose and then obtain contraception, our results showed that it will be critical for the navigator to offer continued support all the way through to using the contraception and trouble-shooting barriers to use.

Through this approach important themes were identified and informed essential programmatic elements of a contraception navigator program. Those elements include trust-building between the navigator and adolescent through positioning the navigator program as a trusted source, flexible methods of on-going communication, and assuring the navigator is able and available to answer method-specific questions accurately. It is also critical that the co-created plan to overcome individual barriers to accessing contraception includes continued support from the navigator even after contraception is obtained. In addition, it will be important for the navigator to have awareness of the various settings, people, and factors that can impact the journey to obtaining contraception that works for the individual. To understand this all from a patient perspective will require having a platform and opportunity for laying the groundwork of trust through sharing and continued conversations. This approach to the development of a contraceptive navigator program is novel.

The description by stakeholders that the process to obtain contraception can be intimidating and burdensome is not new.(37, 38) Previous literature has shown that adolescents will choose not to access healthcare due to concerns of confidentiality and even pelvic exams.(39, 40) The concerns over potential stigma and shaming are important to understand and address to ensure equitable care which supports reproductive and sexual justice.(41) These barriers in particular are present well before any clinical care has been accessed. Having a navigator program that can connect with adolescents outside of the clinical system and provide adolescents with skills to help overcome these types of barriers can potentially improve adolescent engagement with healthcare systems. While there has been increased awareness of the importance of patient-centered care, our results show that there is still work to be done. In the setting of general reproductive healthcare, this can be operationalized in assuring patients feel clinical encounters are beneficial to their needs and that stigma is not perpetuated by healthcare providers through the language used. Assuring adolescents obtain healthcare from providers that are skilled and experienced in these conversations can be an important element of the navigator program.

Finally, the co-creation of a plan to overcome barriers with the participant and navigator is essential as no two people have the same set of barriers to overcome.

Furthermore, having a trusted contact and resource that is accessible prior to and after interacting with the health care system is particularly helpful for adolescents and something that a navigator can provide. This interaction may be the entry way for adolescents to engage with the wider range of adolescent health care services beyond just reproductive health care. It is also clear that accurate, youth-focused information and side effect support is desired and needed by participants. We anticipate that this ongoing support from a navigator will have a user-directed end point, but the opportunity to re-engage with the navigator and program will be an option.

Additional programmatic elements will include navigator training on patient-centered contraception counselling, creation of a barrier assessment to be completed by participants and a data base of community-specific resources to overcome barriers. Another important element will be how to reach adolescents that may benefit from this program, which may rely on more virtual formats given the recent pandemic restrictions. A plan for a dedicated outreach strategy for this program using HCD methods is a subsequent step of this program development.

There are some limitations to our study. First, the HCD sessions were conducted with the a priori solution of a contraception navigator. It is possible this is not the only or best solution to overcoming barriers to access; however, utilizing HCD methods to develop this intervention is a benefit other interventions do not incorporate. There is also potential that all relevant issues were not addressed with our approach, such as contraception use for non-pregnancy prevention reasons and also prevention of sexually transmitted infections, and analysis and could be somewhat specific to our regional landscape. However, we believe that most of the themes will resonate in varied settings and if opportunities for feedback are incorporated, iterations can continue to improve and be specifically tailored to different locales. In addition, recruited participants all lived or worked in an urban zip code. However, given the diversity of central Indiana in terms of urban density, we believe that participants were able to reflect on experiences with both rural and urban settings. (42) Finally, parents were not specifically engaged, and their input could provide additional important elements of this intervention.

Nonetheless, our study approach and results are helpful in creating interventions to help adolescents overcome barriers to contraception access that exist prior to, during and even after contraception has been obtained. The intervention of a navigator program can provide specific patient-tailored support that may be more necessary for adolescents navigating health systems for the first time as consumers. Additional work can be done to broaden the definition of contraception uses beyond pregnancy prevention, and to include elements of prevention of sexually transmitted infections. Next steps include using a HCD approach to develop an outreach strategy for the contraception navigator program, to reach adolescents that could benefit from this program.

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Figure 1: Refined Journey Map

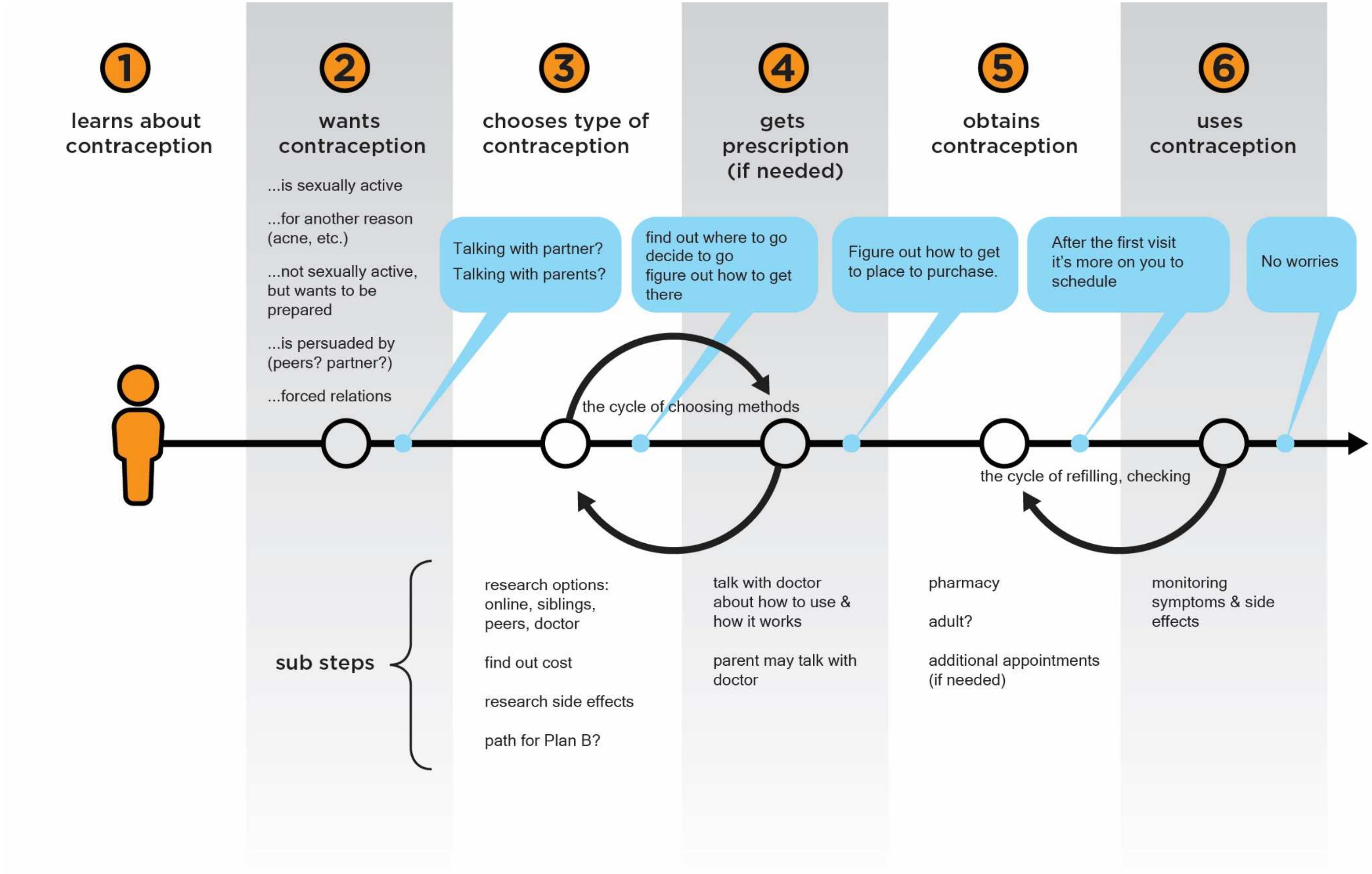

Figure 2: Concept Map of Barriers

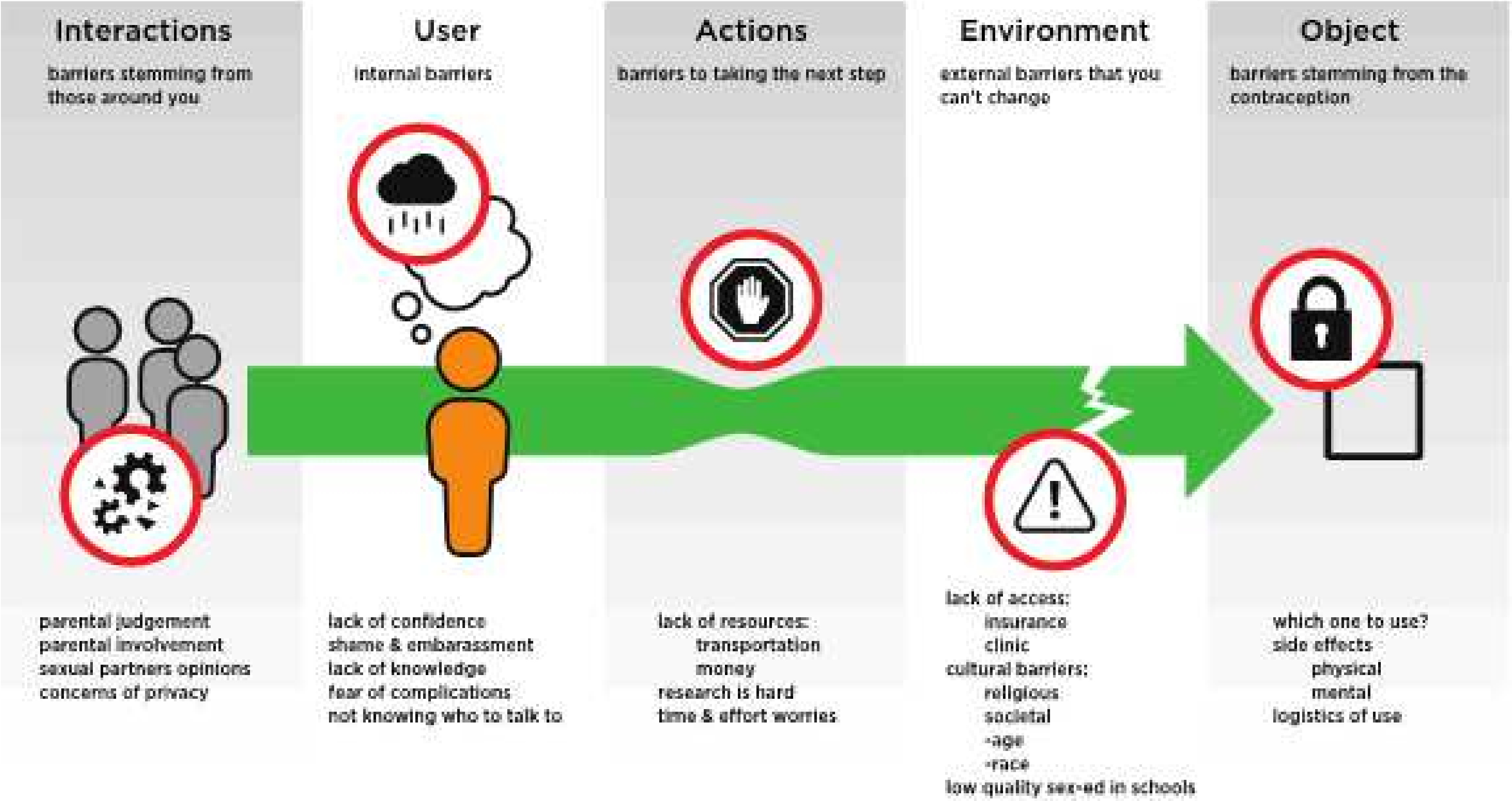

Figure 3: Overview of Programmatic Elements

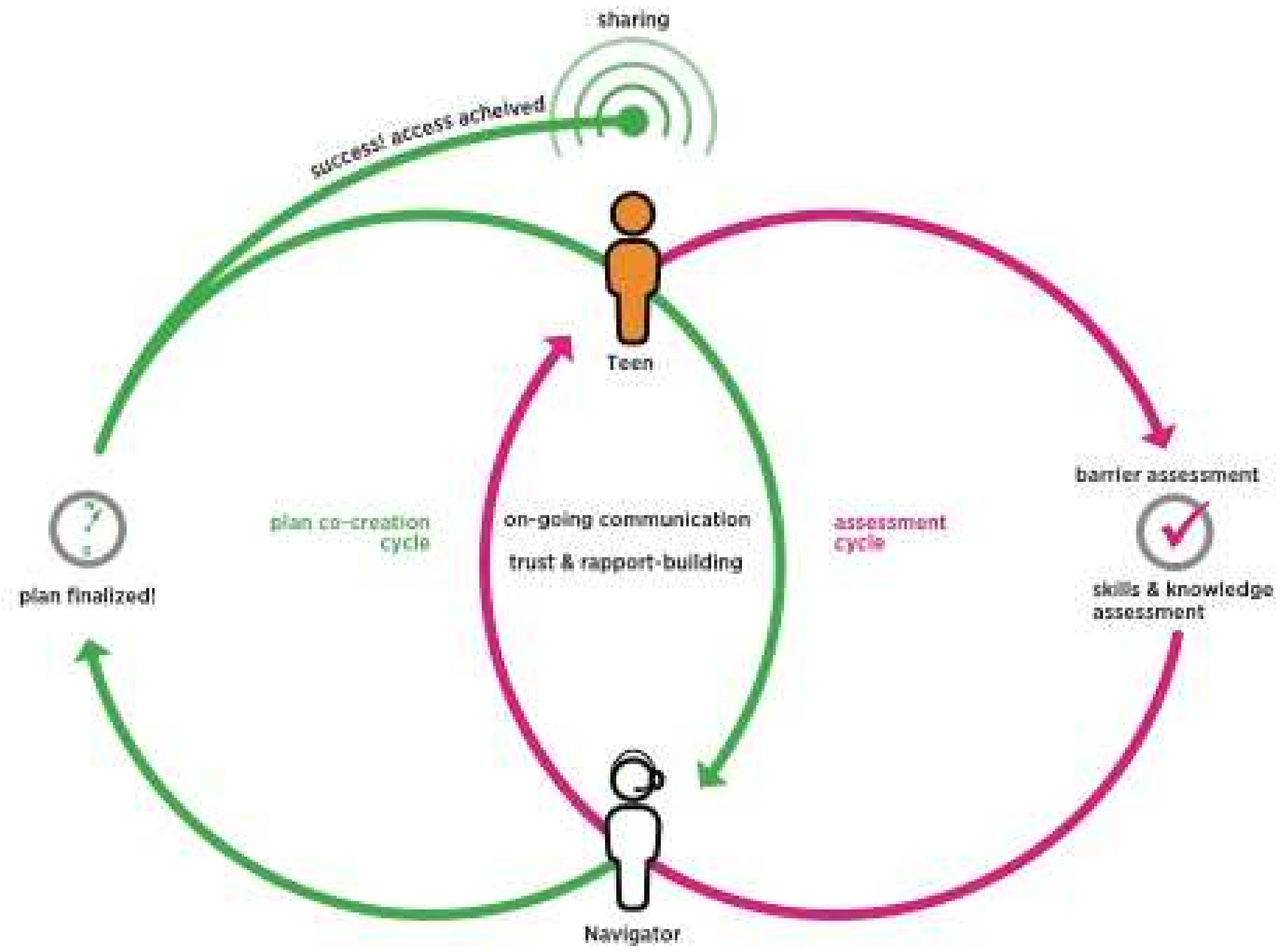

Table 1: Human-Centered Design Session Participants

Adolescent Participants	**Total (%)* N=35**
Age	
15	11 (31.4)
16	9 (25.7)
17	15 (42.9)
Self-Described Gender	
Female	35 (100%)
Race (check all that apply)	
White	8 (22.9)
African American	21 (60.0)
Asian/Pacific Islander	5 (14.3)
Mixed	6 (17.1)
Prefer to self-describe	4 (11.4)
Ethnicity	
Hispanic	5 (14.3)
Non-Hispanic	23 (65.7)
Missing	7 (20.0)
Insurance Coverage	
Parent's insurance	29 (82.9)
Don't Know	5 (14.3)
None	1 (2.9)
Sexual Attraction	
Attracted to Boys	30 (85.7)
Attracted to Girls and Boys	5 (14.3)
Sexually Active	
Yes	11 (31.4)
Prefer not to Answer	3 (8.6)
Used contraception or condoms in the past	14 (40.0)
Urban Home Zip Code	35 (100%)
I know enough about prescription birth control to get it when I (or a partner) needs it	
Strongly Agree	6 (17.1)
Agree	14 (40.0)
Neutral	10 (28.6)
Disagree	3 (8.6)
Strongly Disagree	2 (5.7)
Community Stakeholders	**Total (%)* N=11**
Gender	
Female	9 (81.8)
Male	2 (18.2)

Race	
White	10 (90.9)
African American	1 (9.1)
Ethnicity	
Hispanic	1 (9.1)
Non-Hispanic	10 (90.9)
Urban Employment Zip Code	11 (100%)
*Participants were not required to answer every question	

Table 2: Themes from Affinity Diagraming and Concept Mapping Process-Additional Statements

Process of Choosing and Obtaining Contraception is Intimidating
Maybe it's just my family doctor, but he once said something about how if you need it I could get it for you. But I don't know if every doctor would help. (adolescent stakeholder)
I would say even at my age, it's not always clear if I'm going to talk to someone with a medical degree about this. Can any doctor like prescribe me something? Is it an OBGYN? Is it a nurse? Do I go to a specialty clinic? (non-adolescent stakeholder)
Language is everything
Also big words, very, very big words that do not need to be used. Like 17 syllable words. (adolescent stakeholder)
Stigma and shaming from close connections and the medical community
I think slut shaming should be over there too. I mean it's all through out of there. Whether you are thinking about getting it and you have it and don't want people to know. It's all of it. (non-adolescent stakeholder)
And I know that being from an Indian community and a Muslim community, that's an additional level of stigma…But I just feel it's an added note of where that could come from. I don't know, like an extra level of depth to what that stigma looks like. (adolescent stakeholder)
To be honest, if one of my friends would be like, "Sydney, let's have a conversation; you're doing some things you shouldn't be doing. You're being a ho." Then I'd be like, oh, maybe I should sit down and think about what I'm doing. But if somebody else were to say that to me, I'd be like "okay, you don't know me" (adolescent stakeholder)
I heard one person wanted contraception so they went to the health facility, and one of the doctors there happened to be a very religious person, so they pressured them not to take contraceptives, and then they ended up having to go to another clinic because in that one they felt very judged. (adolescent stakeholder)
Concerns about contraception side effects are a barrier
I heard it lowers your chances of having kids. That's what my sister told me. (adolescent stakeholder)
I think when they are using too is if they experienced side effects from the contraception and they may or may not be likely to continue with it. (non-adolescent stakeholder)
Youth as Healthcare Consumers
Yeah, it is [the providers'] job., they should just know how to talk about contraception. Or somebody's salary needs to go lower. (adolescent stakeholder)