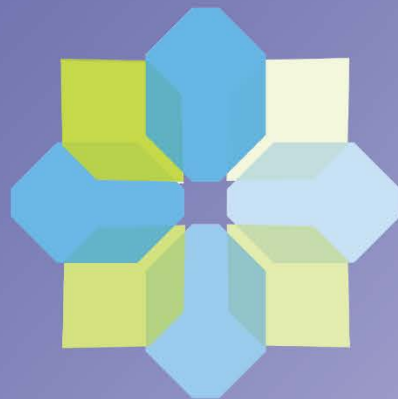




Navigating Contraception: Research Results on Contraceptive Journeys

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2020 NFPRHA
NATIONAL CONFERENCE

Objectives

- Define common themes among contraceptive journeys
- Describe the impact that patients' contraceptive journeys have on clinical care

National
Family Planning
& Reproductive Health Association



NAVIGATING CONTRACEPTION: RESEARCH RESULTS ON CONTRACEPTIVE JOURNEYS

REBECCA SIMMONS, PHD MPH

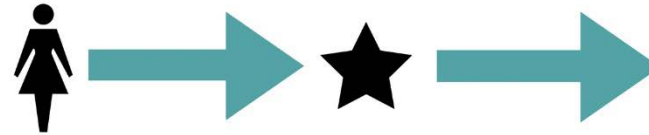
Disclosures: Rebecca Simmons & co-authors have no relevant financial relationships with ACCME-defined commercial interests

First, let's talk about you

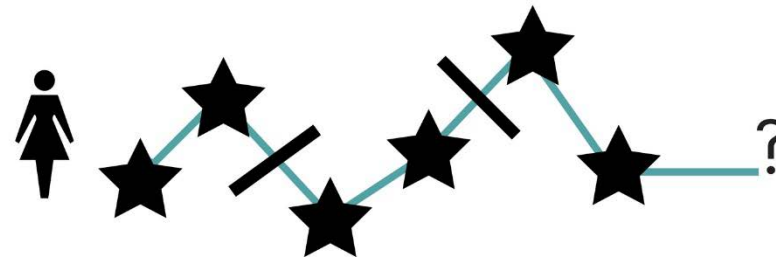


PERCEPTION VS. LIVED REALITY

How we currently think about
method use

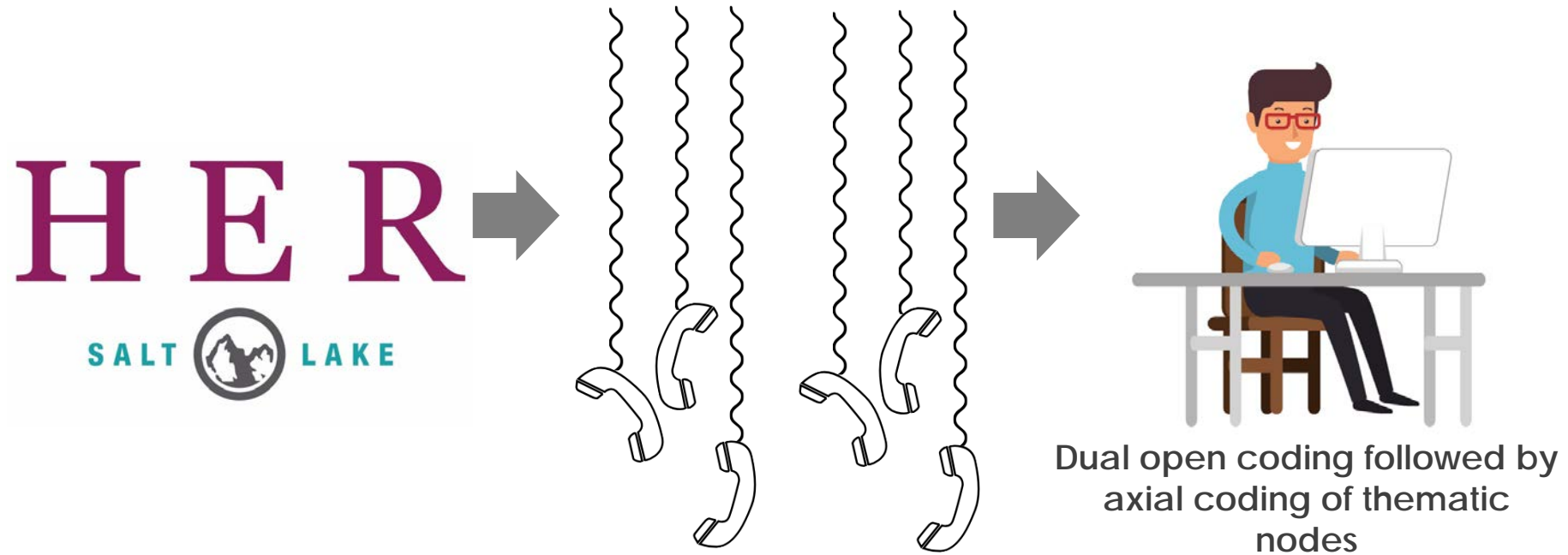


Reality

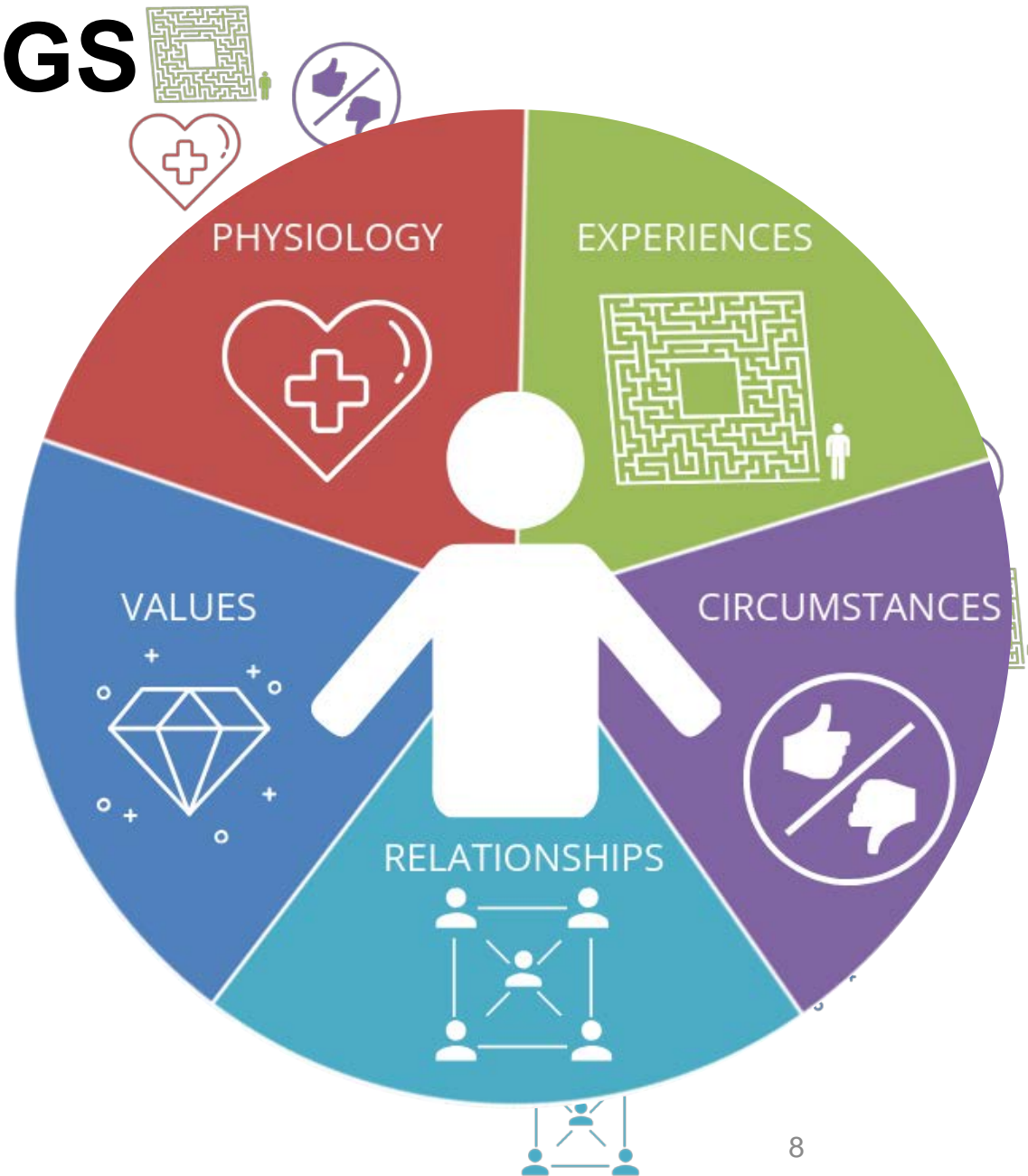


Methodology

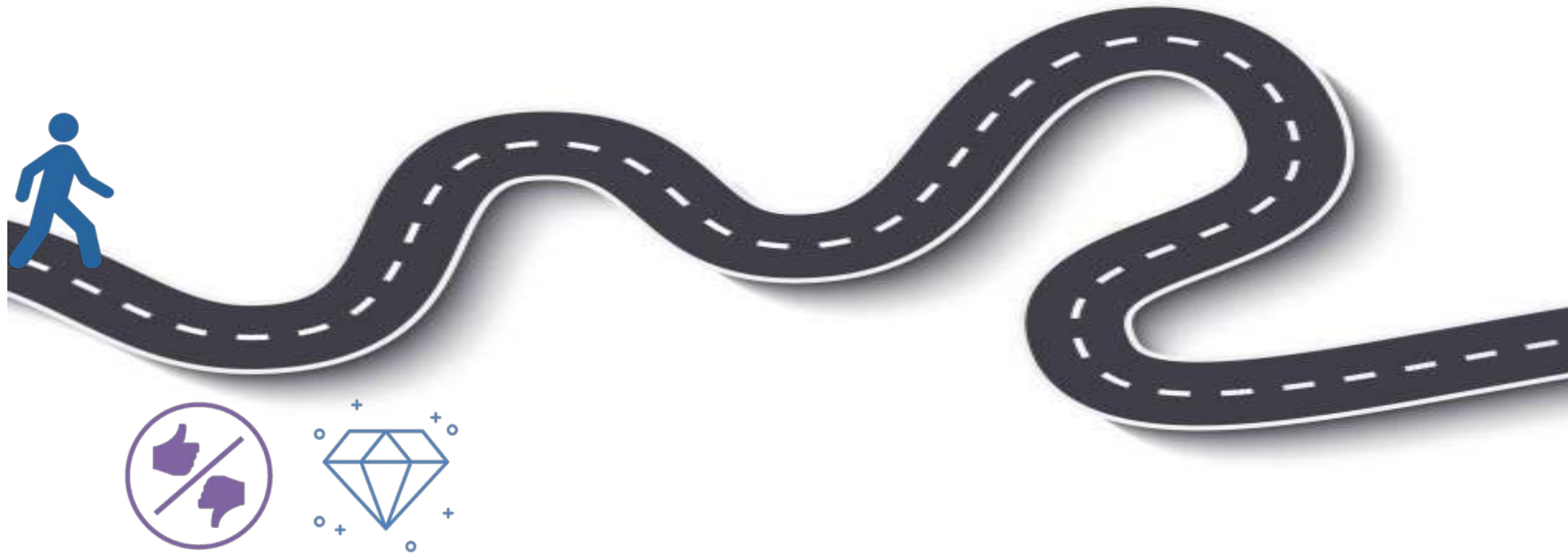
35 in-depth interviews with HER participants



FINDINGS



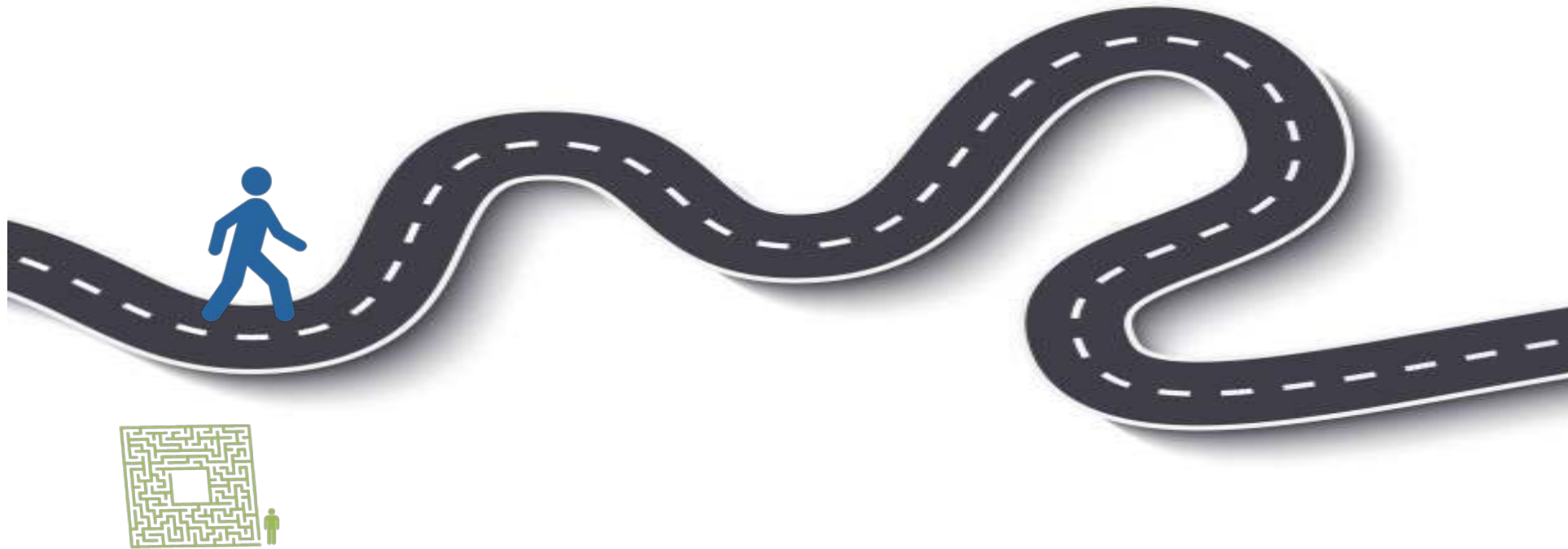
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"I grew up LDS [Mormon]. And so obviously, it was always abstinent-based.

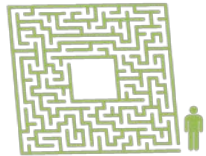
And also grew up in Utah. So, never learned too much about contraception. So, all growing up I really didn't know about too many methods....

NEED



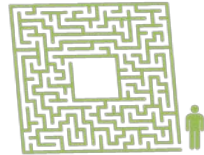
“And then my freshman year of college, which was in 2015, I was actually raped. And at that time, I was so panicked and remember Googling....I was Googling questions like, “How do I know if I’m pregnant?” and what’s going on?...

NEED



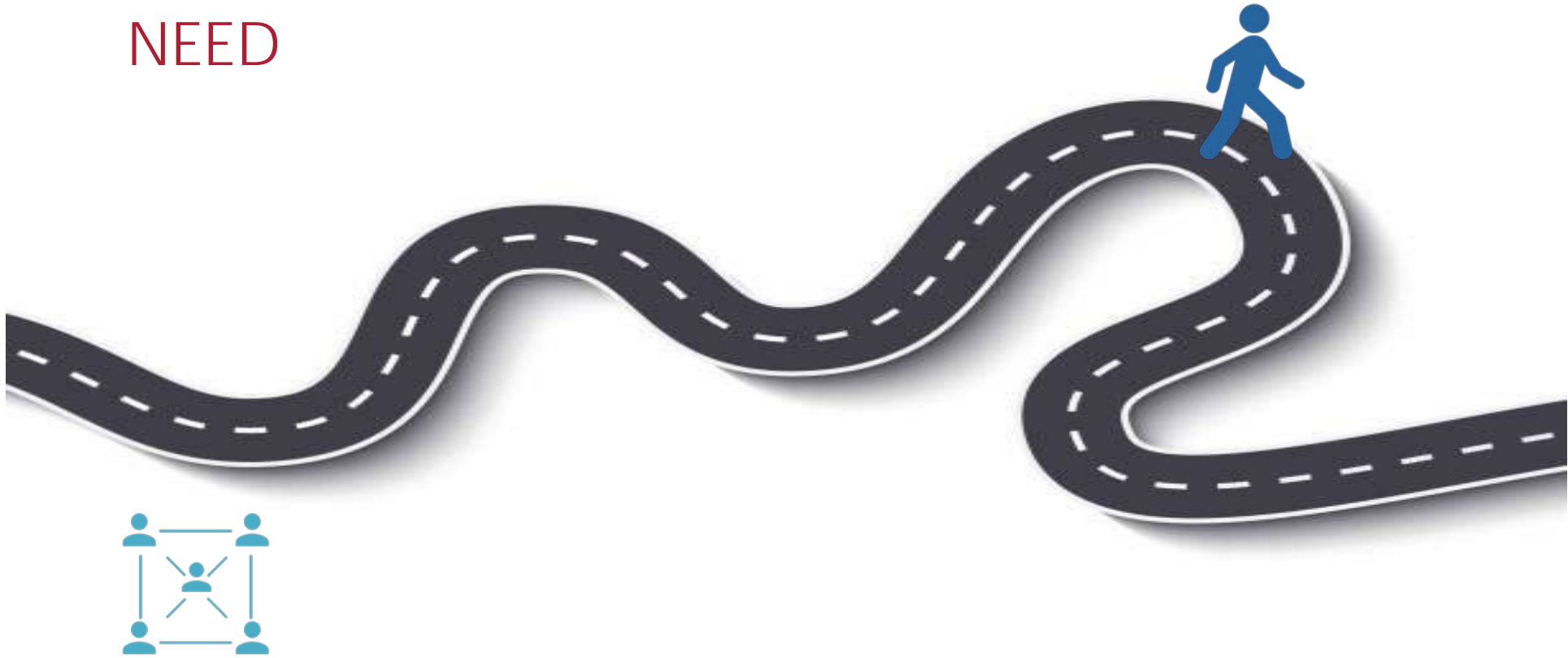
"I really didn't know anything... I really started reading on the Planned Parenthood website and found out a lot about contraception and things like that. And so then, I was like, "Ok, well probably won't ever have sex again for the rest of my life, so it doesn't really matter. But at least I know..."

NEED



“And then as time went on, I obviously started having other relationships....I always wanted to use condoms. So, I always used condoms...”

NEED



“And then one boy asked, “Are you on birth control?” and I said...at the time I lied and said yes because I didn't want him to freak out. And the next day I went and got Plan B because that night we hadn't used protection...

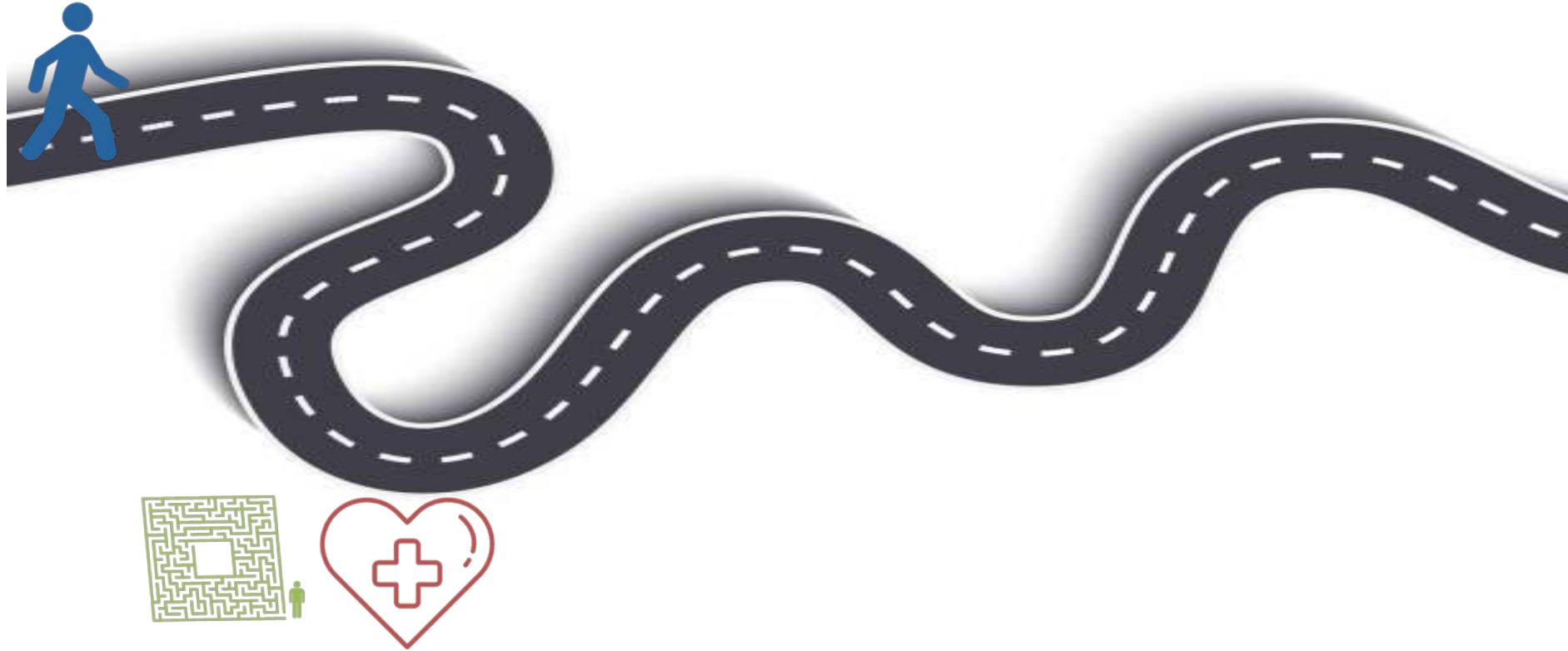
NEED



“And then I was like, ‘All right, this is a bad idea. If I’m going to be sexually active, I should have actual birth control where I don’t have to panic about being pregnant all the time.’”

– Audrey (age 22, white, non-Hispanic)

CESSATION/INITIATION



"I decided that I didn't want to get any more of the injections, but I had to let it wear off. I had two more months, I think, so you couldn't really do anything about that. I just scheduled a time to get a meeting and discuss another option..."

CESSATION/INITIATION



"I think I went back to the same Planned Parenthood and told them I didn't want to get the Depo and told them why and I told them I wanted to go back on the pill because I thought I was sure that I was going to be able to get it a little bit more regularly scheduled. And they just would not take that as an answer really... Yeah, they just thought that I should try something else..."

INITIATION



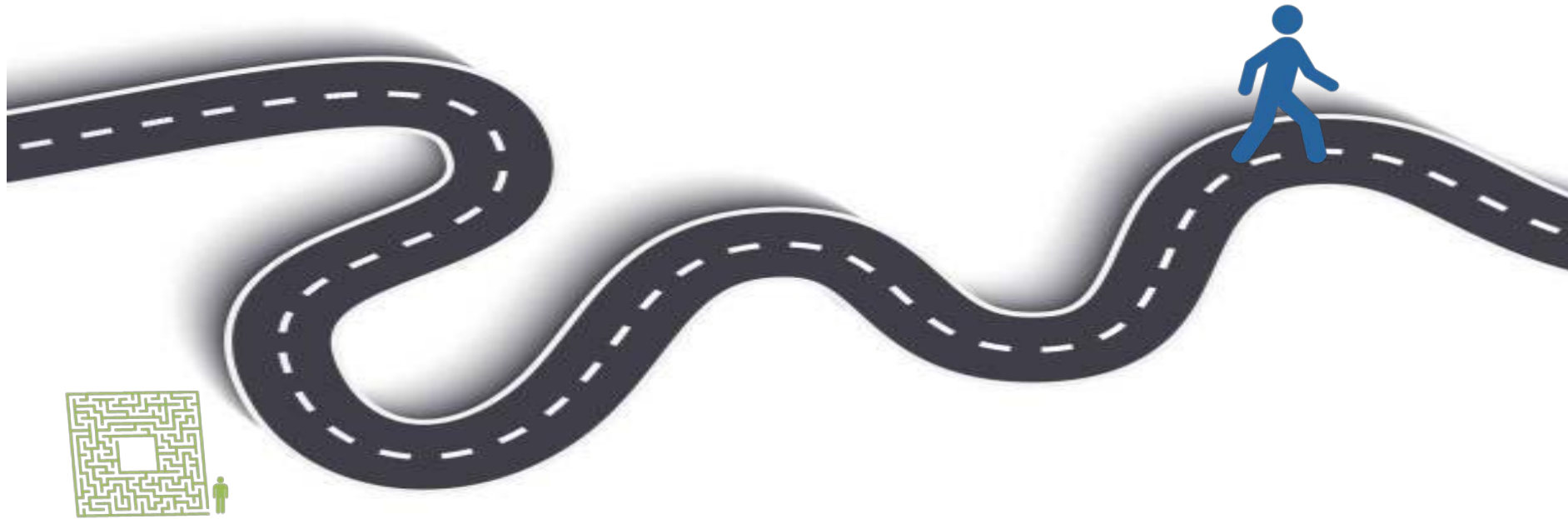
“And in the end I was just getting really frustrated and I just wanted to leave and then I got talked into someone ordering me the ring and I really didn’t like the sound of that much, but I thought I could maybe give it a try. But then I think that must’ve been right before Christmastime last year and I left town and I hadn’t picked it up and I went home and then I just decided I wasn’t going to get it ...

INITIATION



"I just decided that I was going to be off birth control for a while which actually was going really well because I just felt really good and I didn't have the headaches anymore or anything..."

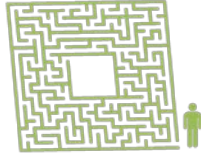
INITIATION



"And I know I could have tried other options, but I was just so happy to not be dealing with it for a while. So then that was last winter and then I went through spring and then I went partially through summer. And I was being careful using protection, but at some point in the summer there was this slip up and...I ended up pregnant."

-Isa (age 24, white, non-Hispanic)

USE



"I felt awful. It was really painful to get in. I think about it and it was like the worst pain I have ever felt. And my struggle with the IUD was that I remember looking up and I was just doing research and seeing, they said you typically have really bad cramps for six months or so...

USE



“And I had really bad cramps for over a year...And it was awful. And it would come randomly too, so for the majority of the time I was always on ibuprofen. But I don't know, just eventually it went away. I was abstinent for a while when I broke up with my boyfriend, but when I started [having sex] again I got some cramps back briefly, but they've gone away since...

USE



"There were a few times when I went to Planned Parenthood and I was worried about it. I almost got it taken out a few times, but they kept telling me it was normal. And so I stuck it out. But when I had the cramps come back at the beginning of this year, I was honestly almost worried enough that I was going to take it out because I was worried about it possibly making me infertile...

USE



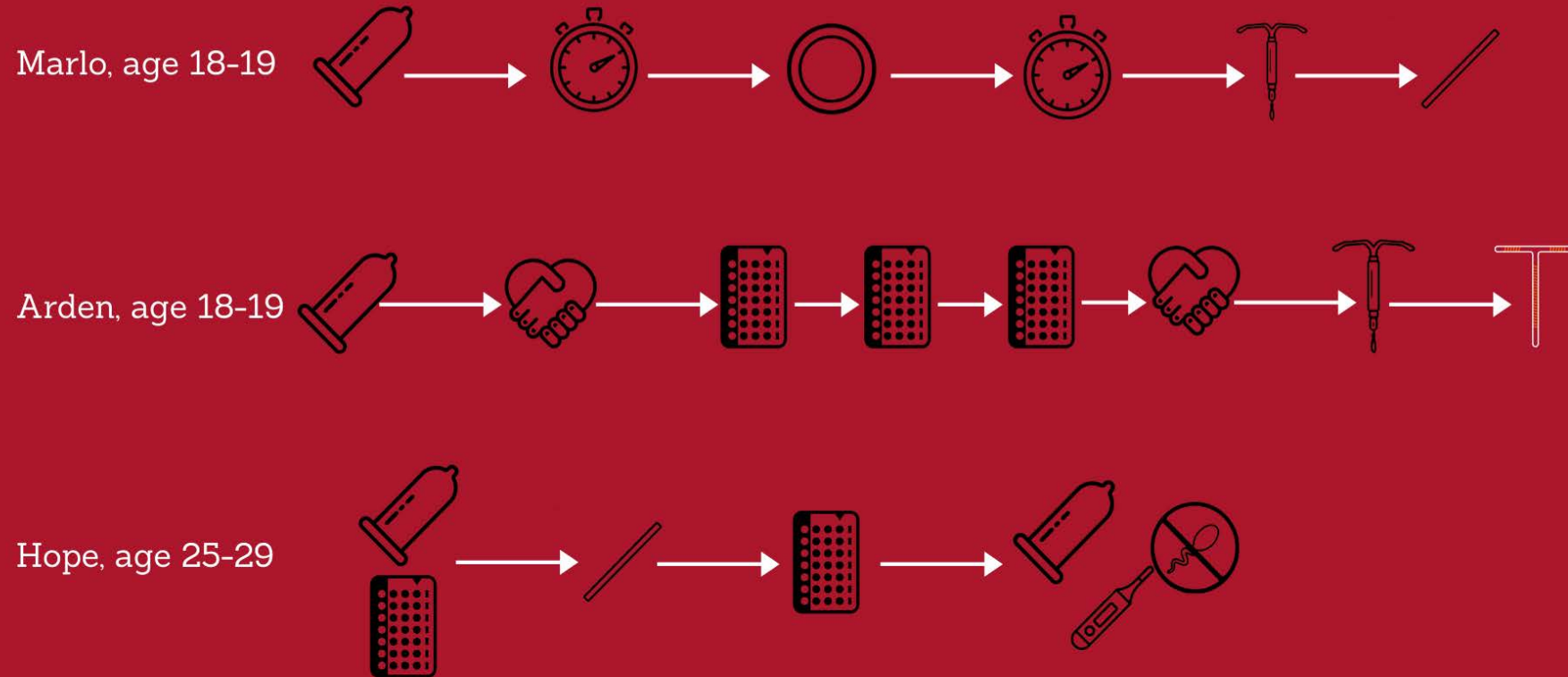
"But I kept it and...Now that I have none of the side effects, it's fantastic. I dread having to replace this thing because it was just so, so painful when I got it in, but I want a long-lasting birth control and I think the second longest lasting is the one that goes in your arm and I really don't want that one."

– Adira (age 25, multiracial)

SOME JOURNEYS LOOK LIKE THIS (SO FAR):



OTHERS LOOK LIKE THIS (SO FAR):

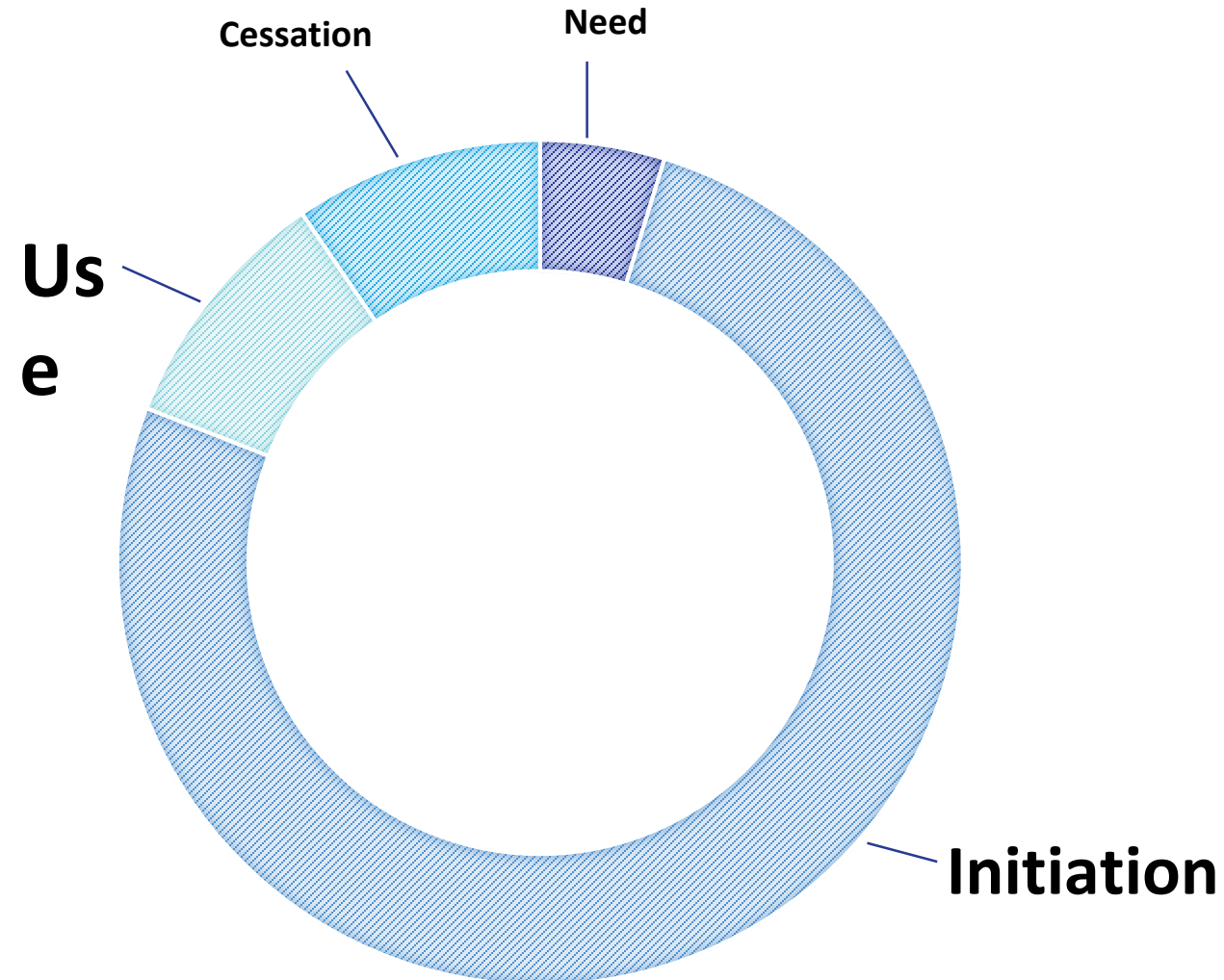


Findings to discuss today

- The story of method use
- How healthcare providers can support contraceptive journeys
- How to incorporate the contraceptive journey into our paradigm and care

The story of method use

Where we most often engage with a client



People really want it to work



Initial Excitement

“It’s going to...it sounds so stupid, but you know, as a young teenage girl, I was excited to start the pill because I had seen and heard some of my friends who are on the pill, who their boobs got bigger, maybe their butt got bigger. You know, I was all about that.”

- Aubrey, age 25-29

“I was wanting an IUD the whole year I wasn’t on anything. I did a lot of research and I was like, ‘this is going to be great.’ And so when I saw the advertisement for the study online, I immediately signed up for it. And I was like, ‘this is going to be so good for me.’ – Callie, age 18-19

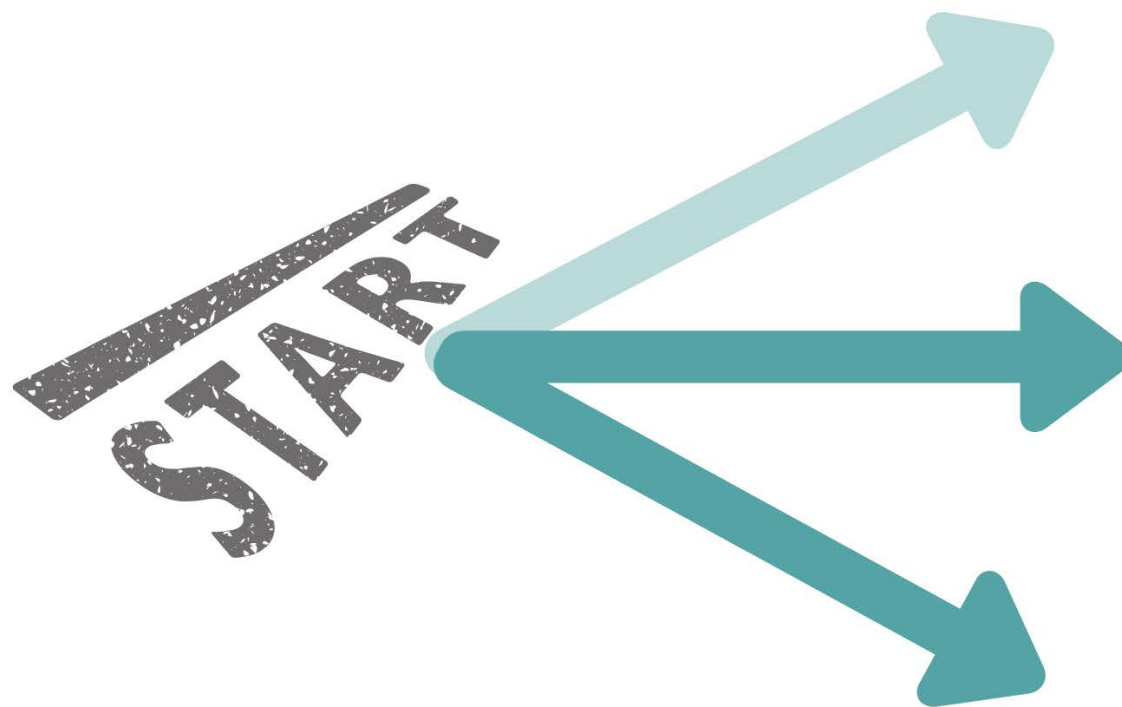
“I tried another pill after that. I’m like, ‘Maybe if I try a different brand it’ll be better this time.’ Like Yasmin. I think that’s one of the brands I tried.”

- Roxanna, age 20-24

“When I first started it, I felt...I was really excited to not be relying on condoms anymore. And eventually, or pretty quickly, stopped using condoms because I wasn’t worried about sexually transmitted diseases or anything like that. So, I did feel really good and really excited.”

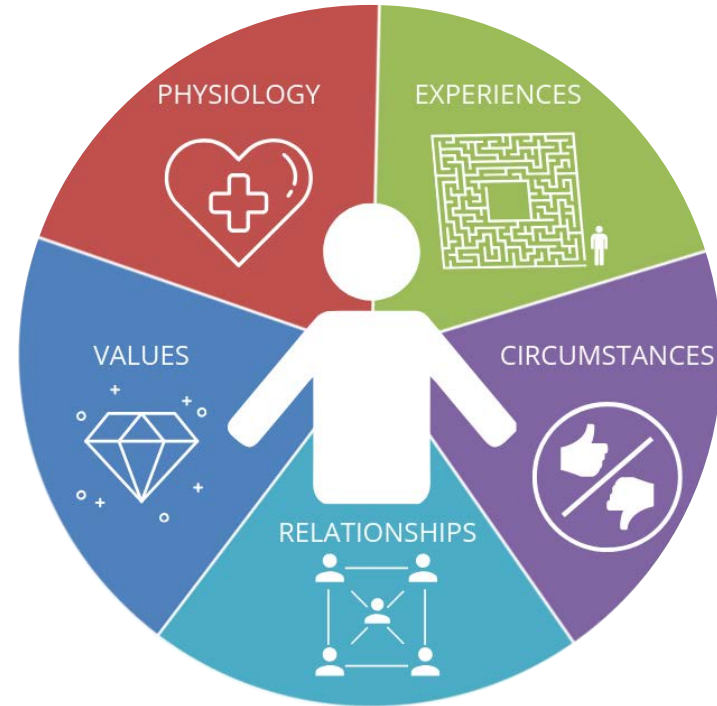
-Esther, age 20-24

Ceiling Effect



Reality

- **Method attributes**
- **Side effects**
- **Life**



Method Attributes

"When you're having sex, it [vaginal ring] sometimes pops out or gets stuck in places. And then I started taking it out for that and then washing it and putting it back in. And I was like, 'Is this ok? Is it still going to work? I don't know.'" – Peri, age 20-24

"I didn't like it though, because the patch is hard to hide. And it left a sticky residue and sometimes it fell off. The sticky residue on my skin is where I remembered it really bothered me. It would stay for two or three weeks after I moved it." - Eliza, 30-34

"I wasn't a huge fan because that one [Depo] you had to get every three months or so. I had a really busy work schedule, so it was difficult to get in. Then, the whole waiting in the office thing was really annoying. Then, the shot itself was just kind of painful for several days afterward. So I got kind of annoyed with it and tired of it pretty quickly." - Frankie, age 20-24

"Well, it was the most painful experience I've ever been in in my life. I was in the patients room or whatever for about five hours because I couldn't move. I had to drive home. I ended up throwing up on the highway and then couldn't get out of bed for at least three days after that."

- Jenna, age 20-24

Questions

- Do we know what attributes of each method are most problematic for users?
- Are there ways to challenge/change some of these attributes so they are more user friendly?
- How should we incorporate conversations about method attributes into counseling discussions?

Side Effects

“I was just noticing a lot of pain during intercourse and I started getting migraines...I’ve always gotten migraines here and there, but I started getting more and I started getting all these intense auras in my vision, either with or without migraines.” - Lily, age 20-24

“My breasts would get very tender. That is one thing, I would have really bad mood changes. I would get very depressed. I would be like, ‘Why am I so sad? I don’t know what’s wrong with me, I feel so down and I’m so sleepy.’” - Parker, age 20-24

“It was big clumps of hair. I would be in the shower and be afraid to even take a shower because I would just feel the hair streaming down my neck and I was scared to brush my hair because it would just come out in clumps.” - Alma, age 20-24

“I gained so much weight. And so it was like, oh my gosh. So, I gained a lot of weight and then I got really depressed and I had my period for three months straight and I was like, ‘Alright, I’m not going to get my second round of shots. It just sucks.’” – Patrice,

Questions

- Why *don't* we develop personalized medicine around side effect likelihood?
- What kind of side effects counseling do clients find helpful? What should side effects counseling include?
- Are we (as health professionals) familiar with the side effects that are possible for each method? (not just the common ones)

Life (relationships, circumstances, experiences, values)

"Following college, I believe I was off it [contraception] for years. I never got back on it again. I was moving a lot and I couldn't find a consistent provider. And I was changing states, living in different states for different jobs." - Hope, age 25-29

"Cost was a big thing, but it was also – I had broken up with that boyfriend and at the time I was like, 'I truly don't feel like spending any money on this because I'm not seeing anybody right now.' I went to pick up my prescription and it was going to be like \$120 for a three-month supply and I just said. 'forget it.'" – Regan, age 20-24

"It [NuvaRing] sounded easier than the pill and it wasn't as scary as getting something inserted into you and leaving it there for three to five years. ...Back then, I thought that was going to work out. But then I ran into challenges of, 'how am I going to keep this refrigerated without my family finding out?'" – Roxanna, age 20-24

"I felt like I had some weird religious guilt during this time, so I think I would go through phases of being like, 'Oh, I don't want to have sex,' and then wanting to have sex and having sex. And so that's maybe why the pill didn't really stick with me then because I would go through phases of being like, 'I don't really need this.'

And that's not really how you take the pill and it works" – Mari, age 20-24

Questions

- What types of interventions have been shown effective in improving people's ability to integrate contraception into their lives?
- What would clients *like* that would support them through the process of integrating a method's use into their lives?

a balancing act



Relief

“I plan on being on it, really, until I don’t need it anymore. I’m in a relationship, but I’m not really serious on the whole kids idea. So really, it’s important for me to stay on it. And this time around the acne has subsided. I had to go to the dermatologist before. Now I don’t. And again, that could be a lot of things – I get that. It could be I changed jobs, so it was maybe less stressful. But so far, without the spotting and being in a new relationship where it’s important....It’s really preventing pregnancy. It’s worked well for me, so I’d say, I’d stay on it until I can’t, or if my body decides to start refusing it, like the others.” - Issa, age 25-29

“It went really well. They were able to find a good balance where it was pretty much everything I was looking for. Something that still helped with my skin and something that was going to be a good balance of libido and crazy girl. I didn’t feel like I was having weird thoughts. I didn’t feel crazy at certain times of the month and it didn’t affect my libido as much as the other ones had.” - Callie, age 25-29

Fatigue

“On the one hand, I don’t really, I don’t want children, so I’m kind of just trying to figure things out. I feel like right now, I’m kind of at a place where I’m sort of unsure about my next steps and whether or not I want to try anything else. I feel like I’ve tried pretty much everything. I haven’t tried the implant, so I’ve thought about that, but I just get a little weary, because it’s [the same] hormones from the minipill.” - Mari, age 20-24

“Well, I’d say it’s affected my life a lot. And maybe, sometimes, it’s not so much, but other times it’s affected it a huge amount and it honestly, just kind of pisses me off at this point, because it’s like, ‘I don’t know, I don’t know.’ I think a lot of people my age think, ‘Oh well, a lot of girls are probably on birth control and on this and that and whatever,’ but I don’t think people always understand the effects it has on you or all the time and energy it takes to get it, and then there’s the issue of paying for it and there’s not always a place to get it for free. Sometimes there is, but it’s just really frustrating mostly. And I’d say it has a big impact on my life.”

- Lily, age 20-24

Questions

- How do we/should we incorporate past history about contraception into counseling?
- How can we better care for people whose contraceptive journeys have been complicated?

Advice from participants to health professionals

Understand their histories

"I think maybe talking about your history of them [contraceptives] is pretty important. I think that was kind of the difference between going to her and then just also going to my provider. I don't think I've ever had an additional provider as me about my previous ones that I've tried in-depth." - Arden, age 18-19

"In my experience, it's always good to talk about how sensitive you've been, the other methods, how your periods are, how long do you think you're going to be using this method..." – Regan, age 20-24

"I want it to be more of a free-flowing conversation, I guess, very informative. I would also like them to ask me lots of questions about my history with contraception. Maybe what methods I used, if I could remember, like specific brands, and you know, the effects of them." - Callie, age 25-29

"Your medical history is important. The problems you had in that regard [with methods]. For example, in my case, my menstrual problems and the cysts in my breasts. The medical provider should know all about this." – Zoe, age 30-34

Don't play favorites

"The provider I talked to in the beginning was very...it was very clear to me which methods he supported and which he didn't. And that was really frustrating for me, because in the end, I ended up trying both ones, but he supported the pill....because he was so set on me starting the pill, he was very anti-IUD for example, for anyone who hadn't had a baby yet. I feel like providers need to have the skill to be a little more neutral in how they present the different options and what they teach you about each option." - Jules, age 20-24

"I'd just say, make sure that you're informing them about each one equally, because the first time I went, they were kind of leaning towards a longer-term one...but I'd say just give a lot of information about each one because some people would benefit from shorter-term ones, I think. I think it depends on the person they're talking to." - Patricia, age 20-24

"I would say that it would be important to make sure women know that no choice is the wrong choice necessarily. You could do whatever fits your lifestyle best." – Wren, age 20-24

Don't sugarcoat it

“Just be upfront and honest. I appreciated the frankness of the person who gave me my IUD. She was just straight up, she's like, “This is going to hurt, so here's what you have to do to get through the experience.” That was important to me. And talking about it not like it's a taboo or something is awesome. It like it when someone's just talking to me about it like it's any other medical thing.” – Katya, age 20-24

“Just be completely open and be honest. Just say, “If you have any questions...this is also the bad side. This is what could happen, these are also the side effects. Just give me both the pros and cons and don't just try to make it look good while not giving me anything that looks bad. I want to know everything about it so I can weigh my choices about what I want to happen.” – Iris, age 18-19

“I think for me, I would just really like to feel that they care. I think as long as they're open-minded and can give honest advice off their experience, that's how I'd like conversations to go.” - Arden, age 18-19

Applying the journey paradigm to SRH work

Clinical care

- Ensuring comprehensive method availability
- Method switching is normal
- Efficacy is important...but so is history
- Campsite Rule



SRH Research



- Redefine “success” around pregnancy prevention
- What measurements align with reality?

Public health

- New method development (particularly nonhormonal and male methods)
- Prioritize opportunities for increased method access



Thank you!



Acknowledgements:

**Our participants
&
Family Planning Division team**

SRH Research

Reproductive Justice

1. Right to have a child
2. Right not to have a child
3. Right to parent a child in safe/health environments
4. Right to bodily autonomy

Exist simultaneously



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graph LR; A[1. Right to have a child] --> C(( )); B[2. Right not to have a child] --> C; D[3. Right to parent a child in safe/health environments] --> C; E[4. Right to bodily autonomy] --> C; C --- F[Exist simultaneously]
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Take Home Messages:

- Contraceptive journey is a thing

Importance of expanded, full method choice - women NEED options in order to figure out what will work best for them at any given moment and in different circumstances

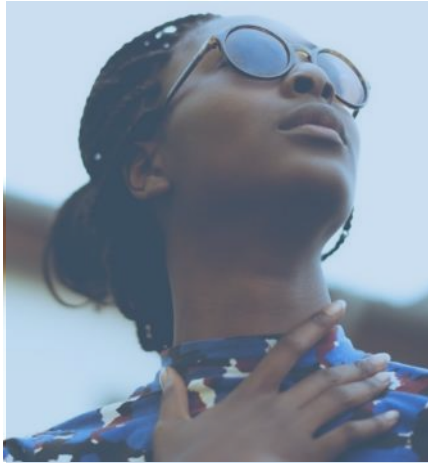
- Contraceptive Campsite rule - leave the person better than when you found them. Because your role in their access, use, and cessation matters.
- The current tortuous route of navigating contraception is an immense, aggregate burden. If we acknowledge that the journey is a thing, we must also acknowledge that the barriers women navigate to getting it are ongoing.

Contraceptive Journey Paradigm

Impacts:

- Clinical care
 - ensure comprehensive method availability
 - method switching is normal!
 - consider utility of efficacy emphasis
 - counseling (**Contraceptive Campsite Rule**)
- In academia/research
 - redefine “success”
 - reassess measurement
- In public health
 - support for new method development
 - improve accessibility at ALL points of the journey (initiation/use/cessation)
 - change the framework of implementation work/initiatives

Q&A



Bottom left photo is from The Gender Spectrum Collection

THANK YOU



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