Moderator: (0:07) Today is September 17, 2025. It is 6:09 p.m., and this is focus group 30-06. So, before we begin, I want to help our minds think creatively and openly, and because we're not sharing our names or personal information, I have one short question just to kick us off. That is, what animal do you most relate to, and why did you pick that animal? I'm going to say, tonight, a duck because I really like to be on the water, but I also like to be on land.

Lily: Butterfly.

Moderator: (0:51) Lily, butterfly. Why did you pick that?

Lily: Because they're beautiful, and they… travel far.

Moderator: (1:05) Okay. Anyone else? Lucy, what about you?

Lucy: Oh, god. I'd go with… a cheetah [**M: Yeah**] because they're very ferocious, but they're actually quite nice (laughs). [others laugh] (01:44 unclear) That's just something I learned recently, so I guess cheetah.

Moderator: (1:29) Great. What about you, Ellie?

Ellie: I think a horse. Just, I guess, running free and wild, and also that sense of majesty, in a way. Yeah.

Moderator: (1:45) Great. Olivia?

Olivia: The only thing that comes to mind is a squirrel (laughter). I just feel like my mind is just always all over the place, and I like squirrels when they're just, like, moving around, like, all the time. Yeah.

Moderator: (2:04) And Emma?

Emma: I'll go with bear. I like the woods, the trees, and I like sleeping. [*chuckles*]

Moderator: (2:17) Perfect, great. Well, thank you for indulging that question. And we are very happy that each of you joined our conversation tonight. So now, for the rest of the discussion, we are going to talk about menstrual cycles. So, people sometimes use different words when talking about their menstrual cycle or the days of the month when they are bleeding. What are some of the words that you use? Feel free to raise your hand. Lucy.

Lucy: I just call it 'my time'. Or sometimes when I'm feeling kinda silly, like 'my moon time'. You know? Just to be, like, a little funny about it. But just, "My time."

Moderator: (2:52) Yeah

Lucy: Yeah.

Moderator: (2:53) Others? Olivia?

Olivia: Yeeah, I just call it 'my period'.

Moderator: (2:57) Period? Yeah.

Emma: Period too.

Moderator: (2:59) Emma? Period?

Ellie: I think sometimes I say 'strawberry week' Llaughs; Others laugh loudly; Some cross-talk about it: 'I

love that' 'That's great' 'I have not heard that one before']).

Moderator: (3:06) .And then, what are just, like, other things you've heard people say? It might not be what you say, but, like, other ways that this is referred to?

Lily: Time of the month.

Ellie: Yeah. [*agreeing*]

Moderator: (3:21) Time of the month? Yeah Another classic.

Lucy: Aunt Flow is visiting. You know? I never use it, but that's just something I've heard. [*others agreeing*]

Moderator: (3:32) What about ways that people keep track of their menstrual cycles to know when they might start bleeding next time? What do you do, or what do you know people to do to keep track?

Lily: With an app.

Moderator: (3:47) So, Lily said app?

Lily: Yeah.

Moderator: (3:49) And Olivia?

Olivia: Yeah, likewise. I use an app.

Moderator: (3:51) An app, yeah.

Olivia: Mm-hmm (affirmative).

Lucy: I just mark it in my calendar. It's not always correct, but I just have, like, again, "Moon time" [*laughs*] in my calendar (*others laugh*). And that's basically how I keep track right now.

Emma: I don't keep track on—written, anything, but there are certain, like, signs I know that come along with, like, ovulating, so then I know I'm going to start at a certain point. And then, like a couple of days after, my boobs start hurting, then I start. So, just like, "Oh, okay, it's coming up," more so than, like, scheduling and tracking things.

Ellie: Yeah, I guess for me, I take oral contraception, so it's pretty much always very punctual. [*laughs*] I know, you know, when, when the placebo pills are coming up And then, yeah, three or four days later, it's there. It's very easy.

Moderator: (4:47) And we'll get into that. Alright, so. Just so we have the same understanding, for the rest of the discussion, when I say "menstrual cycle," I'm talking about the monthly cycle that people who menstruate have. This includes the days when you are bleeding, the time just before you bleed, the time just after, and then other times of the month in between. Alight? So, the full cycle. Does that make sense? [*Participants agreeing*] Great, okay, so now, I would like you to think about your own—how your own menstrual cycle has changed while you're using contraception. Both changes that you have liked, and that you have not liked. First, could you please tell me any ways that contraception has changed how often you have bleeding? How often. Feel free to raise your hand. Lily?

Lily: I have an implant, and so I didn't think I was supposed to have a period, but it comes randomly.

Moderator: (5:56) Okay. Others? Olivia?

Olivia: Yeah, so I've actually, I've, I've been on the pill so that, like, the bleeding was pretty consistent. I had the Nexplanon for a couple of years. I can't remember exactly, like, what the bleeding pattern was like each year, but towards the end of me wearing it, like it was just very inconsistent. I wasn't sure when I was going to get it, and that always brought fear, which is one of the reasons why I got rid of it. And then I got it again last year, and I only had it for one year. And I pretty much was spotting, like, for a week every month, and that kind of was annoying. Yeah, so that's been different from what I'm currently experiencing without the Nexplanon.

Moderator: (7:06) Okay. Other thoughts on how often? We're going to get into all of these types of things. More often? Less often?

Emma: Yeah, I mean, I like feel different—she mentioned it. I experienced different things depending on the type of birth control. So, on the pill, very regular, everything's, like, scheduled. On the IUD, I had no periods whatsoever. And then, now, on Depo, it's regular spotting.

Moderator: (7:40) Okay. And Lucy?

Lucy: Yeah, I—my situation is a little unique because I did a study of an injection, here at OHSU. And it was the first time I ever, like, did birth control. And some days, sometimes there was just nothing would happen for, like, a month. And then, the next—the other—the next month would be like, I'm doing nothing but bleeding. I once bled the entire month. [**Others**: wow] Yeah, it was not fun! And again, this was a test that I did here. And, other—yeah, that was basically the pattern, and it was not fun. I'm trying to think of others–I'm sorry, I'm kind of babbling, but that's basically the flow, or the way how my period happened. It was just, like, bone dry, and then sometimes I just bled all through [**Other**: Oh, god] Yeah, it was not fun.

Moderator: (8:39) Okay. So, some of you have mentioned this already, but I want to also ask about how contraception has changed how regularly you've had bleeding. So, Lily, you, kind of, kicked us off with that. We're talking about how consistently, how regularly, how has that changed?

Lily: I haven't really kept track, honestly. Like I said, there's, like, no consistency, so—[**M: Yeah, so not consistent**.] No. [**M: Yeah**] Not at all. And I don't like not knowing when I'm going to have my period. [**Lily**: Yeah, agree]

Moderator: (9:12) Yea, so that was your experience as well?

Lucy: Not consistent, no. It was—[**M: Not consistent**] It was very unpredictable.

Moderator: (9:21) Okay, great. Thanks. And then, Ellie?

Ellie: Very predictable, very regular (laughs).

Moderator: (9:29) And Olivia? Do you want to—

Olivia: Oh, sorry. [*referring to not recognizing their alias*] Yeah, like consistency? It was consistent, and now without any contraception, I, I feel like I'm more, like—I have a regular cycle. [**M: Okay**] Yeah, Mm-hmm (affirmative), And it's shorter.

Emma: Yeah, I mean, like I said, on what I have now, currently, it's pretty regular with some spotting. On other birth controls, it was not at all, and I, I never knew that it was not going to be at all. Like, I wish that was something I was aware of.

Moderator: (10:25) Thanks, Emma. Alright, so now, I want you to tell me ways that contraception has changed how long you have bleeding? So, when you bleed, how long you have bleeding? [*Pause*] Ellie?

Ellie: Yeah, I think before, it was probably a week full on, and now it's two or three days.

Moderator: (10:48) Yeah. Okay. And Lily? What were you going to say?

Lily: Mine seems to be less, like, less, or like a week or a week and a half. And it's pretty heavy.

Moderator: (10:58) How has that changed? Is that longer?

Lily: It's longer than prior.

Moderator: (11:06) Longer, okay. Lucy, what about you?

Lucy: Well, when I had it, it was, yeah, it was unpredictable. So, like, sometimes it'd be, like, a little bit of spotting for a couple days. And then one time, where I, like, was full-on bleeding all the time. [**M: Yeah**] Yeah, so that happened the one time for one month. Yeah, all, all weird, [*laughs*]. That's the best way to describe it.

Moderator: (11:36) Mmm-hmm (affirmative) What about over here? Emma?

Emma: Yeah, mine is definitely shorter on birth control. Not on birth control, it's, like, six or seven days. And now, more like four.

Moderator: (11:51) Okay, yeah. [Emma: Yeah**] What about you, Olivia?**

Olivia: I feel like—so, for me, it has been changing a lot. So, prior to Nexplanon, I think my period was probably five days. Yeah, I was bleeding for about five days. With Nexplanon, its—last time, it was, like, a week—yeah, it was a week of spotting. And now, being off Nexplanon, my period is like three days, and, like, maybe a day or two of spotting.

Moderator: (12:34) Okay. Alight. So, now, when you have bleeding, how does the contraception change how much bleeding you have? The amount of blood.

Lily: I tend to have a lot more.

Moderator: (12:48) Lily, yes? A lot more?

Lily: Mm-hmm (affirmative).

Moderator: (12:52) Lucy?

Lucy: Depends on month to month, really. It was a little bit of spotting, and then one month, it was just a lot. It was kind of concerning. Since, again, I'm within that test—I only recently I stopped doing it. Now it just seems like it's kind of getting back to normal. But when I did do it, I think it was just either one month, very, very little, and then the next month, a lot. Yes.

Moderator: (13:28) Ellie?

Ellie: I feel like it's dep—Yes, it's like one month, as she said, it's not a lot, and the next month it's more. Overall, maybe I feel like it's less, but there are just some months in between where it's just more than usual.

Moderator: (13:46) What about you, Olivia?

Olivia: Less bleeding.

Moderator: (13:48) Less?

Olivia: Yes, less. Yes.

Moderator: (13:53) Less for you, too?

Emma: Yes, less.

Lucy: I'm thinking I should reiterate, I had an injection. [M: Yeah; Other: Yeah] So, I don't know if that's what did it…. [**Other** (talking over): Well, same here] So, different than, like pills. I just wanted to emphasize that.

Moderator: (14:08) How about what the bleeding looks like? Has contraception changed what the blood looks like? [*Slight pause*] Color, consistency, things like that?

Participant: Erm… [*uncertain*]

Emma: Uh-uh [*indicating no*]

Moderator: (14:17) No changes?

Emma: Yes, it's always looked regular. It goes through its cycle of different colors normally. (Laughter.) That hasn't changed.

Moderator: (14:30) Can you say more about that?

Emma: It'll be more pink when it's coming on, and then more bright red during and throughout. Then, when it's getting browner, I know it's ending. That change, and the consistency or anything, that hasn't changed.

Moderator: (14:53) Thanks, Emma. Lily, were you going to say something?

Lily: Mine seems to be darker and more clottier.

Moderator: (15:03) Would anyone else maybe like to add?

Olivia: As I mentioned, on Nexplanon, I was just spotting, so a day or two pinkish, and after that it was more the dark red/brown sort of color. Nothing bright red.

Moderator: (15:24) Can you all tell me how contraception has changed your menstrual cramps, if at all?

Lucy: I don't think I remember having really terrible cramps. I think I just had regular cramps. Honestly, I had a lot of leg pain when I was on it. It was really weird, but I think I had some other underlying issues, but it exacerbated that. Honestly, cramps never really were affecting me, even before I took the contraception. When I drank coffee, yes, that hurts you, but from what I remember, mostly I had just leg

pain. It was really weird.

Moderator: (16:14) Both before and after, the same kind of pain?

Lucy: Yes, leading up, yes. I had pain mostly in my legs. I'm on my feet all the time because I'm a cashier, so I think certain things got exacerbated, but I felt it when I was sleeping, back pain and leg pain, not necessarily cramps.

Moderator: (16:32) What about others? How has it changed your cramps?

Ellie: I also don't really feel cramps. I have pain most of the time. That does more depend on the month. I feel like it didn't really change much before and after.

Moderator: (16:57) Olivia?

Olivia: I'm trying to think back to more of what the cramping intensity was prior to being on Nexplanon. I feel like it was probably about the same not during on Nexplanon. Again, I'm just going back and forth between not being, being, and then not being. The time before being on Nexplanon and the time during on Nexplanon, I feel like the intensity was probably about the same. I've been off Nexplanon for four months now, maybe. I haven't been cramping.

Moderator: (17:53) Emma, what about you?

Emma: Yes, the cramping and lower back pain are definitely worse on the birth control.

Moderator: (18:06) While you've been sharing your experiences, [notetaker names] have been noting them on cards to help us remember. They're going to place them up on the wall here, and then we'll review and talk about them. [Notetakers put up cards, softly confer with each other] (18:30-18:45 Silence.) When we're talking about how often, we heard more often: "bleeding the whole month," "nothing for a month," less often: "no period," "regular," "spotting a week a month," "inconsistent," and "random." When we talked about how regular, we heard: "no bleeding," "inconsistent," "unpredictable," "don't keep track," "shorter, regular cycle," "very regular," and "regular with some spotting." **When we talked about how much bleeding**: "more blood," "some spotting only," and then next a lot, "Overall less, but some months it's more," and "less bleeding." **When we talked about the menstrual cramps**: "worse without contraception," "no cramping," "back pain," "leg pain," "similar cramping as before," and "same as before." **When we talked about what the blood looks like**: "one to days," "pink on birth control," "more clots," "more red during period," "no changes," "more pink initially," and then "darker now on birth control." **Finally, when we talked about how long**: "a week long of spotting," "shorter on birth control," "bleeding all the time," "sometimes spotting a couple days longer," and "two to three days of bleeding." **I'll give you a moment to take that all in, and what did we miss? What else would you add to any of those categories?** (20:46-21:05 Silence while the respondents read.)

Ellie: Maybe how much it has been unchanged, for example? I'm not sure.

Moderator: (21:14) Anything else? Any other ways contraception has changed your menstrual cycles that we haven't talked about that you want to add up there?

Lucy: Is there a question about mood coming up?

Moderator: (21:33) Yes. Yes, great segue, so now, how have all of these changes made your body

feel? However you interpret that. Lucy, did you want to say something about—

Lucy: I'm also taking antidepressants, so it's very important that I stay on that. So, that does affect my mood even more so when I skip a day and it happens to be my period. I didn't really feel much of a change when I was on the injection in terms of my mood. My mood was pretty even-keeled, actually. I should say almost all of the problems I had were just pain and irregularity.

Moderator: (22:25) Do you have anything else to add about how these changes have made your body feel?

Lucy: I'm just trying to think. Are we talking— Just more purely in terms of mood, or just pain?

Moderator: (22:39) Anything. Whole body. You can take a minute to think about that. Do others have— Lily, yes.

Lily: A lot more bloating.

Moderator: (22:49) Bloating, okay.

Lily: Yes.

Moderator: (22:51) Some nodding there.

Participant: Yes.

Moderator: (22:54) Emma?

Emma: I have bloating. My breast hurt. I get really tired, I'm super fatigued when I'm on my period, whether I'm cramping or not. I have ADHD, so I take stimulants, and those are less effective during my period. Almost everyone that I talk to says that, and no doctors know what. We know that. [*Others chuckle*] We tell everyone's doctor [*laughs; others laugh*] It definitely, the hormone shift changes how well I'm able to regulate my emotions, any sensory issues I have, my motivation, my ability to stay on focus, all of those things are affected, and my medications are—

Moderator: (24:01) Lucy, you're next.

Lucy: I'm just starting to remember. I blocked it out because it was unpleasant. It was a little bit more intense when I was on birth control, my emotions, in terms of I could tell I was about to have my period because my sex drive would go up. I'm not a very sexually active person, so I identify more as asexual. Even then, it's like, I'm feeling more sexually activated, and that's when it leads up. It felt a little more intense when I was on the birth control. That's how I feel, but it's always intense. It's hard to tell if it's even more intense because, in general, it's always going to happen in the lead-up, but I felt a little bit more, like, "Ooh." Beyond that, I did feel a little bit more aggressive when it would— Again, the Lexapro that I was taking really helps even things out. Even then, I'd just get really irritated really easily for maybe two days, and then I'll be fine. I did feel intense emotions when I was taking that.

Moderator: (25:26) Others? How these changes have made your body feel? Olivia?

Olivia: I was going to say, I think that I felt, right around my period, I would feel less motivated, tired, irritated. Then maybe the last four months, I started doing yoga, exercising, so that helped with the mood swings and the energy and all of that. Also, I think when I was feeling the most just negative, it was during the winter, so I don't know if that was causing part of the feeling as well.

Moderator: (26:46) What about you, Ellie?

Ellie: I think, before it starts, I feel pretty agitated. Sometimes I cry for nothing, also. There's really no reason why I would cry, it just happens. Then, once it starts, I actually feel better. I feel more energized. I also lift a lot, and I'm usually the strongest during that week, which is super weird to me, I don't know why. Then afterwards, I crash. Once it's over, I'm so tired, I'm so, yes. I need a week to recover (laughs).

Moderator: (27:31) Now, how have all these changes impacted your day-to-day life?

Lucy: Like I said, it makes it harder for my job because I'm on my feet. Then, during those times, it was super, super painful to stand. I think there were a couple of days where I left early. Like, "My legs can't handle this anymore." Again, I have issues in general, but I felt like that exacerbated them.

Olivia: I think decreased productivity.

Moderator: (28:10) Yes?

Olivia: Yes. Mm-hmm (affirmative). Yes, just not feeling unmotivated and tired, feeling like [*28.18 unclear*]. After, I just, I honestly just want to go home. There's no reason for me to be here. I'm not paying attention, yes.

Moderator: (28:33) Is that specifically at work, the decreased productivity, or would you say that's in other areas of your life?

Olivia: Yes, I think also at home. Yes, I could tell that it's happening, but it's a week or whatever after, I'd see stuff piled up, and I was not feeling it last week, or whatever.

Moderator: (29:00) Lucy?

Lucy: One thing I just remembered, I always have a little bit of trouble sleeping during my period. During the time I had the injection, I had a really bad time sleeping.

Moderator: (29:12) Hard time sleeping?

Lucy: Yes, I took a lot of magnesium, three big pills sometimes when it got really bad, just to make myself go to sleep.

Emma: Yes, the back pain makes it really hard to get to sleep. It makes it hard for me to get comfortable, to fall asleep, and to stay asleep. I'd get nothing done at home, I just don't want to do anything. Just lay on the couch or take a nap or something) At work, yes, I'd want to go home. In fact, the reason I got on birth control when I was—so long ago–was, not because I was sexually active, but because my periods were so bad I was missing a day of school every month, sometimes more than that. That's not that bad anymore. On birth control, it's significantly better, but I know that that's how bad it can get. It can just totally disrupt the day and have nothing able to get done because you can't ignore that lingering pain in your body.

Moderator: (30:27) Any other thoughts on how these changes have affected your day-to-day life? Ellie?

Ellie: I think for me, it's just another day. I don't know. I don't really get too irritated by it. I'm pretty good at pretending everything is fine, and then convince myself that it is. Just go on with my life.

Moderator: (30:53) Once again, Maddy and Lea have been noting what you've said on cards to

help us remember. We will review again and respond to them. For how it makes your body feel, we heard: "fatigue," "less motivation," "heightened emotion," "breast pain," "increased libido," "mood changes," "bloating," "increased irritability," and "medication less effective, specific to ADHD." **Impact on life**: "better for managing birth control symptoms," "impacts wanting to get things done," "feeling less energized." "hard to feel comfortable sleeping," "trouble sleeping when on birth control," "decreased productivity at work and at home," and "decreased motivation and energy," and then "harder on job due to increased pain." **Anything else you want to add to how it makes your body feel or how the changes impact your day-to-day life?** (32:28-32:41 Silence.) **We'll leave these up here and we're going to move onto a different activity. This is to show us about your experiences with menstrual cramping while using contraception, and your experiences with pain. We are going to use these pictures of the body, and we're going to sticker— We're going to put this here at both front and back. We're going to give you stickers and ask you to put them on the poster anywhere on the body, front and back, where you've felt menstrual cramping or menstrual pain while using contraception. These stickers are different colors depending on the type of contraception. First, let's have all the people who are using pills, or have used them in the past, come and get yellow stickers and place as many yellow stickers as you would like on the body, front to back, in the places where you've experienced menstrual cramping or menstrual pain.**

Ellie: Could I please, just, like reach over these several wires? [*referring to where the body maps were places on the wall*]

Moderator: (34:09) Yes.

Lucy: I wasn't sure which side was going to be better [*referring to which side of getting to the body maps on the wall would be an easier approach*]. [*laughing*]

(34:14-34:24 Silence.)

Moderator: (34:24) While the pill users are putting those up, the next one we have is for injectables. These are green stickers. If you're using an injectable, you've used it in the past, you'll grab green stickers and place them anywhere on the body. For implants, we have blue stickers. For implant users, or if you've used them in the past, grab a blue sticker.

[*Participants discuss if a method is an implant or an IUD*]

Moderator: (35:11) No. No, we have a separate one for IUD. (35:16-35:29 Silence.) We have some colorful maps today

Emma: We're putting stickers where we have pain?

Moderator: (35:42) Yes, menstrual pain. Cramping, or pain that you associate with menstruation. Then, if you've used a non-hormonal or copper IUD, we have purple, and a hormonal IUD, red. That's hormonal. Red for hormonal, purple for copper.

Lucy: What is the Mirena?

Moderator: That's hormonal. Red for hormonal, purple for non-hormonal.

Emma: That means nothing [*referring to sticker placed outside of body*]

Moderator: (36:19) Oh, okay, so no–Thank you for doing that.

Emma Should I move it?

Notetaker:: (36:21) No, Emma. That's alright.

Moderator: (36:27) So, no pain when it's just floating in space there.

Emma: Yes. [*laughs*]

Moderator: (36:37) Then, if anyone has used a different hormonal method that we haven't mentioned, like a NuvaRing or something like that, we have orange. Any other hormonal method— Then, finally, we have one last sticker, and it's a gold star. Everyone is going to get just one gold star. I want you to put it on the body on the place where the cramping or pain bothers you the most. (37:12-37:23 Silence.) You can use two if it's like the two sides of the body, but really just one section.

Emma: We should put two.

Moderator: (37:31) Where it bothers you the most.

Lily: It's so full over here.

Moderator: (37:39) Pile them up.

Emma: Can somebody put this sticker on the lower back? That would be easier than me going there.

Lucy: I'm just going to put four because it's the whole leg. Is that okay?

Moderator: (37:50) Okay, yes.

Emma: Yes, right on the tailbone.

Moderator: (37:54) We're going to go through and talk about it section by section. (38:00-38:10 Silence.) Head for your seats. We've got a lot of stickers on these, so we're going to go through these kind of quickly. We'll start with the front of the body. What words would you use to describe this area?

Lily: Head.

Olivia: Head.

Lucy: Brain.

Moderator: (38:26) Someone who put a sticker here, just tell me about your experience with menstrual pain in the head. Yes.

Lucy: I just feel like I get a headache, you blame it on—

Lily: Yes.

Moderator: (38:39) We're talking about headaches here. How about here? What words would we use?

Lucy: The shoulder.

Moderator: (38:45) Shoulders? Yes, Lily, can you tell me a bit about your experience with

menstrual pain or cramping in your shoulders?

Lucy: They're tense.

Moderator: (38:55) What about this area of the body? Breasts? Yes? Was that you, Ellie?

Ellie: Yes.

Moderator: (39:02) Do you want to tell me a little bit about that? Well, first of all, I'm sorry. [*Referring to sorry participant was in pain*] (Laughter.)

Ellie: It's like soreness.

Moderator: (39:11) Soreness in the breasts.

Ellie: Yes.

Moderator: (39:15) This area, we've got all kinds of stickers here. What words would you use to—

Lucy: The stomach.

Moderator: (39:20) Stomach?

Lily: Pelvis, the pelvic region.

Moderator: (39:23) Pelvis.

Lily: Yes.

Moderator: (39:25) Lower torso.

Olivia: I'd say a localized pain at first, from one side. Then yes, overall, it'll be in here.

Lucy: Yes.

Moderator: (39:39) Thanks Olivia. Who else wanted to just talk about your experiences with menstrual pain and cramping in this area? What does it look like?

Lily: Sharp.

Moderator: (39:48) Lily says sharp pain.

Lily: Mm-hmm (affirmative).

Lucy: Sore.

Moderator: (39:52) Lucy feels sore.

Emma: It comes in waves, like the sea.

Moderator: (40:01) We do have one gold star here, so can someone who put a gold star there just tell me what is it about this that bothered you the most?

Lily: It was me. [M: Lily] Burning, I'd say it feels burning.

Moderator: (40:23) This area of the body— Would we differentiate higher or lower, or is this just— All you, Lucy?

Lucy: Well, you know, it's my legs. I think it may be my shins, my lower legs, kind of, like, felt the hurt, but they also just, kind of, went up and down, up and down. Yes, but I should specify, I have sciatica. It would get exacerbated during my time. It just really hurt. When I had the injection, it was all very there.

Moderator: (41:01) These are your gold stars, right?

Lucy: Yes.

Moderator: (41:03) Can you just talk a little bit about why it bothered you the most?

Lucy: It just was painful. I keep going back to my job, but I think my legs would just get inflamed. My body is just not very good with pain, so it would just get exacerbated, the pain, during my time.

Moderator: (41:29) What about, now we're going to go to the back of the body? What words would you use to describe this are here?

Emma: Lower back.

Lily: Lower back.

Olivia: Lower back.

Moderator: (41:38) Does someone want to tell me about their experience with cramping and pain in the lower back?

Emma: It feels like everything inside is pushing. It feels like it's just really— For me, the cramps are cyclical, the back pain is constant.

Lucy: How I'd describe it is very sharp.

Moderator: (42:05) Sharp?

Luck: Yes.

Ellie: Mm-hmm (affirmative). Stabbing.

Moderator: (42:09) Ellie says stabbing pain?

Lucy: I agree with that.

Emma: Especially on the tailbone.

Olivia: Very tight.

Moderator: (42:19) Olivia, thank you, tight in the back. What about our gold stars in this area? Emma? Can you just say a little more about why that pain bothers you the most?

Emma: It's the most distracting. I feel like I can take some ibuprofen to help with cramps, or they come in waves, so it's just not as bad. Sleeping, being comfortable sitting anywhere, sitting and being productive on a computer, it very disruptive.

Moderator: (42:49) Anyone else with a gold star here?

Ellie: I put one down there too.

Moderator: (42:52) Ellie?

Ellie: Yes, I think it's just a sharp, stabbing pain and it's constant which makes it really hard to focus. Sitting during that time is super uncomfortable. I mean I always have trouble sleeping, but that, like sucks. That shooting—but yeah, that's why I put it there.

Moderator: (43:16) What about here?

Lucy: That was me.

Moderator: (43:23) Tell us about what words would you use to describe this area?

Lucy: Excruciating. Very painful. Like Lucy, I also have a case of sciatic inflammation, or whatever. I think it just basically starts with the back, and then after that, that just triggers pain down my leg, which is where I also put a gold star on one side. Because it's so painful. The other— The bloating and the stomach cramps, or abdominal and back pain, that will go away, but that there, it's just all day long, and it might last several days. Yes, it's very painful, and yes, I have a hard time being comfortable sitting down, laying down.

Moderator: (44:26) What word would you describe this part of you? What would you call that?

Lucy: Excruciating.

Moderator: (44:31) No, no, I'm sorry. The part of the body. Hips? Butt?

Lucy: Yes, hip. Thigh, upper thigh, outer thigh here.

Moderator: (44:46) A red star is up in space. This is great because the team talked about how we should have a "No pain" section.

Emma: Yes.

Moderator: (44:53) You read our minds.

Emma: I didn't even know if I was ovulating. It was like I was just a human without a period. Yes, I was breastfeeding part of that, because I wasn't really my own human. [chuckles] I had never not had a period before, since I was a kid. It was very, like—

Moderator: (45:20) –and so, Emma, this is the Mirena IUD?

Emma: Yes.

Moderator: (45:24) Just a human without a period.

Emma: Yes. (Laughter.)

Moderator: (45:29) Anything to add on the body maps, or we'll leave this here? (No audible response.) All good?

Emma: Mm-hmm (affirmative).

Moderator: (45:38) Now, I'm just curious, what do you do to manage your menstrual cramping or pain? What strategies?

Lily: Heat.

Moderator: (45:47) Heat, yes?

Lily: Mm-hmm (affirmative).

Moderator: (45:51) Lily said heat, a lot of others as well.

Emma: Ibuprofen.

Lucy: I've found Pamprin is really good. I always use that one because it's the cheaper option. I really felt like that was actually quite effective most days.

Moderator: (46:12) Yeah, great. Thanks, Lucy. Olivia?

Olivia: Yoga is helping me manage the sciatica discomfort. If I were to skip a week or something like that, it would come back.

Moderator: (46:29) What about— Yes, go ahead Ellie.

Emma: I would also say exercise, or just going for a walk. Just trying to move. Maybe that also distracts in a way, but that also helps.

Moderator: (46:43) Yes, anything that you avoid doing because of cramping or pain? Things that make it worse that you would avoid?

Olivia: I would do stretches and yoga, depending on how I'm feeling, but I'm not going to go do a strenuous activity or anything.

Moderator: (47:19) Go ahead, Lucy.

Lucy: I would just avoid certain foods. It sucks because in general, I'm just a very tired person, so whenever I drink coffee, it would immediately make it worse. I don't know why it is, but it's just like, "Oh (pained)!" I have indigestion problems too, so I have to avoid something with a lot of caffeine in it. Sometimes I have to just grin and bear it because I just need the caffeine, but it can exacerbate it.

Moderator: (47:55) We went over this a little bit over here when we talked about menstrual cramps on the wall, but have any of you had less or reduced menstrual cramping and pain while on contraception? There was a lot of "the same."

Emma: Yes.

Moderator: (48:13) Emma was less.

Emma: I think mine was less when I was on birth control, yes.

Lucy: When it's those months where it was very, very light, practically no blood at all, I didn't feel much of anything. I was pretty numb. Then, again, it made up the next month, but those months, definitely, for sure.

Moderator: (48:37) Yes?

Lucy: Yes.

Moderator: (48:40) Now, for the next few questions, let us look back at all the ways that contraception has changed your menstrual cycle that we have here on the wall. All the places on your body where you've experienced menstrual cramping and pain, and the ways that these changes have impacted you. I'm curious what information did you get from your healthcare

provider or clinic about changes to your menstrual cycle before you started the method of contraception that you're currently using? Sorry, Lily, yes?

Lily: I was told that with the implant, I wouldn't have my period. Then, all of a sudden, I had my period, and it scared me a little bit. I called and made an appointment to find out if that was normal, and apparently it's normal.

Moderator: (49:42) Would you say that information that you got was useful or confusing?

Lily: It was very confusing, yes.

Moderator: (49:49) Yes. What about others? Information that you got about the changes before you started.

Emma: The only thing that really sticks out is just a change in bleeding patterns. That's the only thing that was really talked about.

Moderator: (50:09) Was that information helpful?

Emma: I don't think it made a difference, really. (Laughs.)

Lily: I gained quite a bit of weight.

Emma: I feel like that's what they talk about a lot, is like, "These are the other side effects that could happen from birth control." They don't talk about like, "This is what it will do to your cycle." I feel like they said, "There may be changes to your bleeding pattern." Okay. More? Less? Good? Bad? Then there's this whole long list of other side effects that have nothing to do with your menstrual cycle that they should share.

Moderator: (50:49) Emma, I'm hearing you were told that there would be changes, but they weren't specific?

Emma: Not specific, yes. Yes. More, just like, "You can expect changes to your bleeding patterns." You don't know if it's going to be good or bad.

Moderator: (51:06) Yes, got you. What about those other side effects that you mentioned that you are saying are not related?

Emma: Yes, they say, "You may have increased weight gain or a decrease to your libido," or whatever all the things are. Some people do, some people don't. I always feel like when I get those, it's just, this is you just telling me that, "We did a study of this medication on everyone, and these are all the things that were statistically significant. Here you go." That's what it feels like. It's not the doctor educating me on the thing I am putting in my body.

Moderator: (51:53) What would you have wanted more of?

Emma: It's funny because with literally the questions that you're asking me here, I have gone to medical professionals that I trusted, and they haven't ever asked these questions about my cycle. It's, "When was your last period? Has anything changed?" Check, check, done. It's not, "What is it like for you? What was it like when you were a teenager? Has that changed? I'm a doctor, and I can tell you're 30 and you started when you were 13, or you're 50 and you started— Just taking into consideration, not just the holistic person, but the holistic process of, "I am now giving you a medication that's going to change

your body. That happens all the time. This is what it's going to do. You're here, you can expect to go here or here because that's what we see, statistically, or whatever. I can't guarantee, I can't tell you that you're not going to have a period, and have you walk away confused. A more, for lack of a better word, a teacher experience. I'm not the expert, you are. Speaking to the doctor.

Moderator: (53:17) Thanks for sharing that. What about others, information that you got?

Lucy: Again, mine was a trial run for a certain injection that I took.

Moderator: (53:27) This was a study?

Lucy: This was a study, that was the word I was looking for. It was done here at OHSU. I can give you that information if you want. It was vague. It was just like, "We're going to do this, and then during a specific time after that, we're going to take a sample of my uterine lining," and that's what they did. That was the whole point of it. They were just researching more and more about how things are when you're doing the injection, and this happened every three months. They took the sample and now they're studying it, to see how that affects— For me, it was vague. They just were like, "You're going to go through some changes, and please tell us how it is." I was very specific. I was like, "This happened, and this happened, and this happened," and just gave them all the information every time I saw them.

Moderator: (54:23) In that circumstance, they're trying to learn from you what the changes are.

Lucy: Exactly.

Moderator: (54:28) In other settings, when you're starting something in a clinic? Information that the provider gave you? Ellie, do you recall)?

Ellie: I think I mostly heard about the weight gain, the libido. I feel like also something about my skin or something. Clear, or I honestly don't remember, but it was mostly just not really looking at me as a person, but just a general, "This could happen."

Lily: Like we're mother f-ing guinea pig.

Ellie: Yes. (Laughter.)

Lily: They don't give straightforward answers for an individual person.

Moderator: (55:26) Thinking about all of these changes and all of these things that we're talking about, what do you wish they had told you more about, with regard to these changes to your menstrual cycle? What do you wish you would've known before you started? Anyone want to kick us off?

Lily: Actually, what the result would be, or whatever.

Moderator: (55:49) Yes, so what do you wish you had known?

Lily: Mm-hmm (affirmative), more information, I guess.

Moderator: (55:56) On what the changes would be like?

Lily: Mm-hmm (affirmative).

Moderator: (56:00) Others?

Olivia: I think for me, it's just like back to the last question. The first time that I got the Nexplanon, one of the other things that sticks out is the gynecologist listed a few methods, and she also mentioned the efficacy of each, and how often they need to be changed or whatever… wait, what was the question? (laughs).

Moderator: (56:41) No, no, no, it's fine. Just thinking about what you wish had known, what you wish someone had told you before starting.

Olivia: I never gave it a thought for me. It was just like, "Is this going to work?" Because we're all different, so it's going to affect us differently. We talked about it already, some bled more than others, or whatever. I knew ahead of time that I may or may not have all these symptoms. Again, for me, the only thing I really wanted to know was the efficacy.

Moderator: (57:25) Thanks, Olivia. Anyone else? Things that you wish you would've known?

Participant: I feel like I did.

Moderator: (57:32) What do you think is the most important information that you would want a friend to know about these changes? If you had to pick one thing, what's the most important thing to know before starting a contraception?

Emma: I think that even though the efficacy is really comparable if used correctly for a lot of birth control methods, that even here you can see, they all affect you differently, and everyone's body is different. I wouldn't say any of these things to my friends, except that any of these things could happen, or could not happen. Which just makes it important that you know what you're getting into and that you have a conversation with your doctor.

Moderator: (58:33) Others? Thanks Emma.

Olivia: Just be ready for anything, really. Yes.

(58:40-58:51 Silence.)

Moderator: (58:51) Alright, well, we're going to do one last activity. For this last activity, we're going to talk about two different questions that healthcare providers or researchers might ask you about your menstrual cycle. I'm going to ask each of the questions, and then I'll have you answer, and then we'll discuss. The first question: When you last had a period, would you describe it as light, moderate, or heavy? Please raise your hand if you would say "Light." [*No one*] No one. If you would say "Heavy"? [*Lucy*] Okay, Let's have you—Do you guys mind standing up and moving around a little bit? Not yet, but you [*Lucy*], heavy, let's have you stand over here.

Moderator: Then, the rest of you would say "Moderate"?

Emma: It changes every day,

Moderator: (60:05) We're going to get into that.

Emma: If my doctor asked me that, I would say, "I'm going to give you a complicated answer."

Ellie: Just thinking about the last one we had, right?

Moderator: (60:18) When you last had a period, would you describe it as light, moderate, or heavy? Let's put moderate over here, heavy over here. Emma, you can choose to— Yes, and this is

exactly the point of this exercise. [Emma, Ellie, and Olivia]

Moderator: How did you decide on your answer? Let's start with you, Lucy. You said heavy.

Lucy: It was definitely heavy. Again, I just got off the injection, and it was just— Is this an okay answer? Because I got off the injection.

Moderator: (61:04) Yes, yes.

Lucy: I'm sorry, I know my situation is a little weird.

Moderator: (61:07) That's, no, we just want to hear your experience.

Lucy: I got off the injection, and it was very heavy. It was like my body was catching up with me because I'd been so dry up until that point. A lot of clotting, a lot of clots, and it was just very, very heavy the entire time. That struck me.

Moderator: (61:31) Then, moderate, we have Emma, Ellie, and Olivia. How did you decide on your answer?

Emma: I averaged it.

Ellie: Yes, same.

Moderator: (61:45) Ellie and Emma averaged an answer based on that. What about you, Olivia?

Olivia: Yes, I have heavy periods and I've had a lot of spotting while I was on Nexplanon. Now, it seems more normal. I did want to add, though, the first month after I got off Nexplanon, it was very heavy. Very heavy, very painful, very clotty.

Moderator: (62:20) How long ago was the period that you were thinking about when you answered this question? Could you raise your hand if it was within the last month or two? [Lucy, Emma, Olivia, Ellie] That is everybody, yes. Was there anything about this question that made it difficult to answer?

Emma: Yes.

Moderator: (62:40) Emma, why don't you kick us off?

Emma: Because a period is not one thing. It's days, it's times during the day, yes.

Moderator: (62:52) Others? If it was hard to answer?

Lucy: I was a bit confused because you wanted me to answer the last time I was on the birth control and I had my period. I can tell you it was very light, but my very most recent one, in the last month or two, since I went off? Heavy.

Moderator: (63:13) Other reasons why this might be hard?

Ellie: It's also not clear, because I feel like even the timeframe when you start bleeding, and then the heavier days, and then the aftermath. It's never the same. It never bleeds the same every day, even on your period.

Lily: Is this talking about bleeding or cramping or what? (Laughs.) Or how long it is, or what?

Moderator: (63:46) Yes, yes. When you last had a period. We're going to stay in our groups. We have one more question. Last question, on the heaviest day of your last period, how many pads, tampons, or other materials did you need to use to collect or absorb your bleeding for that day? Please raise your hand if you used one. [No one] Two, three, or four. [Lucy (Heavy), Emma, Olivia (both Moderate)] Lucy and Emma, and Olivia? Five, six, or seven. [Ellie (Moderate)]

Moderator: (64:34) Ellie. Why do you think people in your group had different answers?

Emma: Because not all of the pads and tampons are the same.

Lucy: I have to use super, super, super, and even then, I had to change it three times.

Emma: If all I had was regular, I would use more than that, if I had it.

Ellie: I change it every time I go to the bathroom, so if it's not full, I just—

Moderator: (65:12) We're getting into my next question here, which is what made this question difficult to answer? Different types of products, if you're using the restroom. What else?

Lucy: I don't think any of us have been using the cup, but there's that possibility. [Other: Or like underwear] Period underwear. Yeah, that's true [others agreeing] Yes, I think it should be a little bit more specific. "Other materials," I guess that's a little vague, but I don't know. I think when you say, "pads or tampons," I think that's the first thing people think of [others agreeing] Maybe involve the word "cups." How many times did you empty your cup?

Moderator: (65:58) No, that's a great point because it's not necessarily just answering for you, but how would this be a difficult question for anyone? If you're using other materials— Yes. How many, what? Other reasons?

Emma: I'm way too analytical. I would be like, "Why do you want to know that? What information is this giving you that you need to know about how much blood I'm expelling from my body and not other things?" That's what I would want to know. I can answer this for you, but I'm not sure what it's going to give you.

Moderator: (66:49) We can take our seats again. We are moving on through. Some people have very small amounts of bleeding, and they may not need to use any kind of menstrual pad, tampon, other material. What are words that would you use to describe that kind of bleeding? (No response.) A very little amount of bleeding, so you're maybe not using anything.

Emma: I learned just recently that spotting apparently is only on the toilet paper, so I would've said spotting. I would say, now, very light bleeding. If I'm only wearing a panty liner and not a tampon, then it's very, very light.

Moderator: (67:41) Very light? But some might say spot—

Olivia: I would call it spotting.

Moderator: (67:44) Spotting? Did you say spotting? Yes? Any other words? What does spotting mean to you? Emma gave us one interpretation.

Lucy: Light pink.

Moderator: (68:00) Then, how do you know when you've had this type of bleeding?

Lily: Pretty much only with, like, toilet paper or underwear. [*Others agreeing*]. I don't have any other feelings, sensations, any of that when it's spotting.

Moderator: (68:18) Other experiences with spotting? (No response.) You have been very helpful in telling us information about these two questions, thank you. We're coming to the end here. We've got just the last section. We're going to talk briefly about sex and sexual relationships, and I just want to restate what I said at the beginning, which is to acknowledge that this can be sensitive and uncomfortable for some. Especially in this environment where we don't know each other, so you don't have to share anything you're not comfortable with. You can step out, or we can just skip this altogether. I have two more questions that healthcare providers or researchers may ask people using contraception, and we would like your opinion. Okay? [participants agree] I see heads nodding. Sometimes, healthcare providers or researchers want to know about whether or not you've had sex recently. For some people, this is a sensitive topic, and maybe hard to talk about. How would you like to be asked if you've had sex or not? (no response) Any reactions to that question? So, if you're using contra—

Lily: Just ask it.[*Laughter*]

Moderator: (69:33) Yes, yes. Just ask it?

Ellie: Why not?

Lily: Yes.

Moderator: (69:39) Other thoughts? Emma?

Emma: I always want to know why. I know it's my doctor, but it's also just like, "Why do you need to know that?" If you just tell me why, I'll answer the question. Again, more education.

Moderator: (70:04) Other thoughts on that question? (No response.) No comment?

Olivia: No. I don't really care. (Laughter.) It doesn't offend me or anything like that.

Lucy: Maybe disclose to them, like, "I'm going to ask for some personal information," like you were saying. Because we don't know everybody. Some people are very, very shy about that. Maybe just like, "I'm going to ask some very personal information related to sexual intercourse," or something like that. You just let them know, and they can say, "Oh, I don't want to." Give them that option to talk about.

Moderator: (70:40) Lucy is saying, just a heads-up, a warning, and Emma wants to know why. What is this information used for?

Lucy: Yes.

Moderator: (70:49) The second question healthcare providers or researchers sometimes ask is whether or not you've used a second method of contraception when you last had sex. How do you think it is best to ask that question? Any reactions to that question?

Emma: I think what you just said is straightforward.

Ellie: Or, like, why?

Moderator: (71:14) Yes, why?

Ellie: Just, why.

Emma: That too, yes.

Ellie: I already told you I had intercourse. So, do I need to tell you—

Moderator: (71:25) Ellie is saying, "What's the motivation for that question?"

Ellie: Yes.

Lucy: Maybe just be like, "We want to look into if you've got an STD or—" I don't know. Just go into the details of why… [**Others**: Yeah! (*lots of agreement*)]

Emma: I don't know. This is a silly example. If you then said, "I actually used two condoms," then your doctor can say, "No, no, no, no, don't do that." Because I just can't imagine what that information would lead to besides being, "Yes, I'm being double sure. Aren't you proud of me, Doctor?" I don't know what it would lead to. I guess just more information.

(72:09-72:25 Silence.)

Moderator: (72:25) Before we end, is there anything else that you think we should know about your experiences with your menstrual cycles while taking contraception that we did not talk about yet?

(72:38-72:49 Silence.)

Emma: The things that lead to when we're not on our period to help ourselves cope are not as effective while we're on our period. Not enough studies are done on women and the impact that their period has to everything else.

Moderator: (73:12) I know you got into that before.

Emma: I feel strongly about it.

Moderator: (73:17) Exactly, which is why I want you to just spell it out for us a little bit.

Emma: My experience is directly coming from having ADHD in groups with women who are late diagnosed, and are now going through learning what it's like to live with this and how to treat it, and that most of the research that exists is done on young boys, and not grown women who have full cycles, who have hormone fluctuations, who have all of these things. Then, once you scratch a little bit of that, you learn just how few studies have been done on, insert whatever in the blank, while women are on their period. That's the frustrating thing.

Moderator: What else does—

Emma: I mean, we already know what happens to us when we're on our periods, and we're all just sitting here in the room talking about how horrible it is, and it's like, "Yet, and we still go live our lives." [others laughing] You know, like run some studies on us!

Moderator: Well, thank you for sharing that with us.

Emma: Thank you for what you're doing. (Laughter.)

Moderator: (74:35) Anyone else? Anything else you want to add to our whole conversation today about physical, emotional, how this affects your lives, your bodies?

Ellie: I think I want to add that, I don't know, I feel like some people are just not really aware of what women are going through for months. They're calling you crazy sometimes, just because you're starting to get your period. Maybe just more awareness in a way, and just learning about the menstrual cycle.

Lily: Yes, maybe more education. That would be good.

Moderator: (75:23) Thanks, Ellie. Alright, last call for— Thank you for joining our discussion. We're really grateful for everything that you shared; it's really helpful. Helpful information for our study, and to hopefully, make improvements in this space. We're going to stop the recording. Today is September 17, it is 7:25 p.m., and this is focus group 30-06.

(End of audio.)