**Appendix**

|  |
| --- |
| **A1. Body Image & Scarring**  *I remember looking down at the scar. Because I already had a Cesarean scar from my son’s birth, and that was okay. But this scar, it was huge. It’s from hip to hip, and I was just like, ‘Holy crap, did they cut me? How far did they cut me?’ And it's still a huge scar, and I remember looking down and going, ‘What the hell? What did they do to my boobs? Where’s my nipple? What happened to my stuff?*  (P1, ~40 years, M, dx in 2016, BPM, child ≥ 2) |
| **A2. Feelings of Isolation and Feeling Different**  *The first couple of years, I would be on the bus. I’d look around and you’re just like, these people…You don’t know if they have it or not. But it’s likely that they’re not dealing with that. And you think about how you used to go through life not thinking about having cancer. And every little twinge you feel, you worry, it might be something growing. And so, it’s, especially finding out in your early thirties, it’s a sense of your own mortality that people at that age generally aren’t faced with. I felt like I was now part of a club no one wants to be a part of.  And that many people aren’t. And people would...talk about things. And then I would realize, oh, I’m not going to have that in my life. I will have to have breast surgery. And I will have to have these problems. You definitely feel like you’re kind of walking the path alone.*  (P8, ~40 years, S, dx in 2011, surveillance, child 0) |

|  |
| --- |
| **A3.** **Feelings of Isolation and Feeling Different**  *Especially right after, there were still a lot of moms that I knew from my daughter's age that were having babies, and I definitely felt like I wasn't in that group anymore because having more children was not something I could do. Even though I didn't want to have more, I felt like that, [laughs]—like I kind of left that area of the women that were getting pregnant and having babies far behind.* (P5, ~40 years, M, dx in 2014, BPM and BPSO, child ≥ 2) |
| **A4. Confronting Menopausal Symptoms**  *As far as prophylactic surgery for the ovaries and such, I am just concerned about the change in hormones. How is that going to affect my depression? How is that going to affect my anxiety? How is it going to affect my sex life? If I’m a 30-year-old woman that’s going through menopause, how is that going to seem? That’s going to be kind of crazy. And then I worry about bone density issues and things like that, like keeping myself healthy. I’m already struggling with body image because I’ve gained a lot of weight recently from my depression.*(P11, ~30 years, M, dx in 2014, surveillance, child 1) |
| **A5. Problems with Implants and Autologous or Flap Reconstruction**  *I sleep basically on top of two cantaloupes right now. I haven’t been able to sleep properly in*  *a long time…then my implants have been flipping. My surgeon finally taught me how to flip*  *them back. He’s like, ‘This is just something that’s going to happen.’ And I was like, ‘Well,*  *this stinks.’ One day, I asked my fiancé to do it. And he’s like, ‘Listen, when it’s wound care*  *and I have to take care of you, that’s one thing. But this kind of grosses me out.’ And that*  *made me feel like—yeah, I was ugh…* (P4, ~35years, M, dx in 2014, BPM and BPSO, child 0) |
| **A6**. **Problems with Implants and Autologous or Flap Reconstruction**  *What bothers me the most is seeing the muscle on top, and seeing flexion and not having the*  *same kind of soft tissue as I did before…It’s clear that it’s muscle with something underneath*  *it. It’s big...it doesn’t react the same way to movement...like drying myself off after I*  *shower…Flexes the pectoral muscles, and I look at it, and I’m like, ‘Uh, that’s disgusting.’*  *[laughs] You know, so I don’t like to look in the mirror because of that… during the process*  *of expansion. It was painful. I had some struggles physically whenever we would expand,*  *they’d try to expand too much, and then, I’d have a big reaction. So, we had to slow it*  *down. And then I stopped it and said, ‘I’m where I want to be,’ which was smaller than they*  *thought I should be. ‘Nope, this is where I want to be.’ We went into reconstruction, and I*  *was adamant, I told everyone, the surgeons, the PA, ‘This is as big as I want to be. I do not*  *want to be any bigger than that.’ I came out of reconstruction bigger than that, and I was mad.*  *I was so mad.* (P9, ~40 years, M, dx in 2017, BPM, child 1) |

|  |
| --- |
| **A7. External Influences on Decision Making**  *I remember one woman, she had no hair or anything like that, and she was waiting to*  *go see a plastic surgeon, and I told her my [story] and she told me hers, and I was still in this*  *process of I’m not sure yet, I’m just here to talk to them. She was all like, ‘You know, if I*  *knew I had, if I had a chance to get rid of my boobs when I was your age,’ because she*  *thought I was 20…she was like, ‘I would do it. I would automatically get it done. Because you*  *don’t want this.’ And I remember looking at her, and I’m like, ‘Okay, yeah, I don’t want that.’*    (P1, ~40 years, M, dx in 2016, BPM, child ≥2) |
| **A8. Internal Influences, Perceptions, Lived Experiences, and Attitudes**  *I think the mastectomy brought with it more concerns about body image or whether…people*  *could tell that I had the surgery… I've made this choice prophylactically. I never had the*  *cancer diagnosis. I don't know if I would have and I'm pretty comfortable with making the*  *decision that I'd rather do it prophylactically than have cancer. But there's also a little part of*  *me that wonders if I've moved heaven and earth for potentially nothing...if I never would have*  *gotten cancer*. (P3, ~45 years, M, dx in 2017, BPM, child ≥ 2) |
| **A9. Lack of Communication with Provider and Discordance with Setting**  *My doctor makes me feel like she doesn’t even know that I have this gene. During my annual*  *physicals, it never gets brought up. Could I talk to her about it? Maybe. But I don’t know that*  *I’d want to…that’s definitely my biggest frustration with this.*  (P14, ~25 years, S, dx in 2016, surveillance, child 0) |

|  |
| --- |
| **A10.** **Lack of Communication with Provider and Discordance with Setting**  *As my surgeon pointed out, really most of the materials out there are for women who have a*  *cancer diagnosis...It's also for women who are going through a different path than I am…my*  *surgeon's office gave me some little comfort care pillows and little pouches to hold the*  *drainage bottles in. All of that was wonderful, and, you know, I never turn down, I guess, bags.*  *I also started crying when it was all pink and pink ribbonry because then, I suddenly felt like*  *a cancer patient*. (P3, ~ 45 years, M, dx in 2017, BPM, child ≥ 2) |
| **A11. Sexuality**  *There are accommodations that I feel I have to make to keep him from being distracted*  *by the fact that I am not the same as I was. So, things like making sure I’m covered there, or*  *that I have the prosthetic nipples on. (*P9, ~40 years, M, dx in 2017, BPM, child 1) |
| **A12. Sexuality**  *I think it’s been difficult for me to verbalize, especially, at first, sort of, my fear, in terms of body image and sexuality. And just not either having breasts or having breasts that I can’t feel. I think that has been harder for me much more than talking about having cancer or having to go through chemo or radiation.*  (P10, ~30 years, M, dx in 2015, surveillance, child 0) |

|  |
| --- |
| **A13. Femininity**  *A couple of weeks ago, I was talking with this older gentleman, and he had some*  *health issues…I shared my experience with having this mutation. And I was like, ‘I*  *understand what it’s like to get those tests and worry about it all the time.’ And he said to*  *me, ‘Well, why don’t you just cut your breasts off?’ [laughs] I was just like… ‘Because*  *they’re a part of who I am. And I’m in my thirties.’ I almost wanted to say to him,*  *‘Would you cut your testicles off?’*  P8, ~40 years, S, dx in 2011, surveillance, child 0) |
| **A14. Femininity**  *It’s stitches, it’s scarring, it’s blue, it’s all that stuff. It’ll pass. Once all this is over, it’s going*  *to look fine. They’re going to look like breasts. But right now, I’m at the point where they*  *don’t look like breasts right now, so I’m still not quite woman. I don’t feel like different, but I*  *feel like not quite womanly. It’s just not quite woman, you know?*  (P1, ~40 years, M, dx in 2016, BPM, child ≥ 2) |
| **A15. Being a Parent**  *It was very difficult physically, but also, emotionally not to be able to pick up my kids.  I*  *needed help with cooking, cleaning,* *childcare, and carpooling. Then emotionally, it's hard to*  *go from being a mom taking care of people to being taken care of and not being able to do a*  *lot on your own.*  (P5, ~40 years, M, dx in 2014, BPM and BPSO, child ≥ 2 |
| **A16. Future Childbearing**  *I’m dealing with the process of realizing that I’m not going to meet somebody in time to have*  *a family. And so that part has been hard, because I have a date when or a year when I need to*  *get my ovaries out. And that will be the end of my opportunity to have kids. And*  *so…there’s a part of me that’s kind of well, I spent all of this anxiety and kept my*  *ovaries for all this time, and now I’m not even going to use them.*   (P8, ~40 years, S, dx in 2011, surveillance, child 0) |

|  |
| --- |
| **A17. Breastfeeding**  *I was breastfeeding my son at the time. That was really important to him. I had to wean and*  *tell him, ‘Sorry.’ I didn’t realize for him how important my breasts were to him. And when I*  *had surgery, he was 18 months old and it created massive relationship challenges with he*  *and I, and we still haven’t repaired those. Because I no longer have breasts, he doesn’t trust*  *me the same way he trusts my husband. So, he goes to my husband for comfort. He*  *immediately used to have his hand down my shirt for comfort when he had anxiety…he*  *goes to my husband now because my husband has nipples and I don’t.*  (P9, ~40 years, M, dx in 2015, PM, child 1) |