

# A Patient-Centered Research Roadmap to Advance Equity in Endometriosis Care for Black Women

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I was told at that time this is a  
'White women's disease,' and they didn't know  
how to care for a Black woman."*

**BLACK WOMAN WITH ENDOMETRIOSIS**

*"Imagine adding [the burden of  
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**BLACK WOMAN WITH ENDOMETRIOSIS**

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## EXECUTIVE SUMMARY

We are failing Black women with endometriosis. Their experiences are often overlooked and they face significant inequities in care, marked by extreme pain and insufficient pain management, delays to diagnosis, and restricted access to specialized treatments. Despite the severe impact of this disease, a troubling lack of research has led to limited understanding of endometriosis and its treatment. This deficit leaves healthcare providers ill-equipped to deliver or recommend best-practice care due to inadequate training and education, leading to poor-quality care, denial of treatment coverage, and diminished quality of life for patients—challenges that disproportionately affect Black women.

To address this gap, Massachusetts Health Quality Partners (MHQP) and the Endometriosis Association (EA) collaborated to develop a Roadmap for advancing equity in endometriosis care. Grounded in the experiences of Black women and developed through collaboration with patients, providers, researchers, and health plan representatives, this Roadmap outlines actionable research priorities to drive systemic change and improve quality of care.

During two multi-stakeholder convenings, participants emphasized the need for increased research, support, and organized activism to improve endometriosis care, as illustrated by the quotes below:



**My life's work [as a provider caring for women with endometriosis] has been sort of painful – reversing all of what I've been taught originally in training and figuring out that there [needs to] be a better way... This kind of organization, mobilization, [and] activism in a disciplined way is sorely needed.**

**PROVIDER**



**[Understanding] how little research has been done for endometriosis [as well as for women of color] is what brought me here today and I hope we do more for [the] women that are that are coming behind [us so]that they don't have to suffer in silence.**

**BLACK WOMAN WITH ENDOMETRIOSIS**

Discussions during the convenings also underscored the diagnostic and treatment hurdles faced by all women with endometriosis, while highlighting the disproportionate burden imposed on Black women as they navigate racial and other systemic inequities in the healthcare system. These intersectional dynamics framed the group's identification of challenges and structural barriers that Black women face when seeking endometriosis care, including: dismissal of symptoms, misdiagnosis, and medical gaslighting; lack of knowledge and understanding among providers, particularly the falsity that



endometriosis affects only White women; access and affordability barriers; lack of individualized and multi-disciplinary care plans; limited consideration of alternative care options; lack of shared decision-making; lack of focus on quality of life; and the impact of endometriosis on fertility.

The quotes below highlight some of the challenges Black women with endometriosis experience in their care journey:



**Endometriosis [is] like a bad layer cake. You start with the bottom layer, which is access. If you don't have insurance or your insurance is saying 'no you don't need that test' or 'you don't need that MRI' then how are you actually getting the care that you need?... Then you add in all of the other layers around endometriosis... so much scar tissue everywhere within your body, causing all kinds of chronic pain... It's like a terrible cake that nobody wants to take a bite out of.**”

**BLACK WOMAN WITH ENDOMETRIOSIS**



**I was given a lot of those drugs. Nobody talked to me about side effects. I was not given the opportunity to make a fully informed patient decision because they were the doctors, and I just believed what they told me... Nobody told me I would become suicidal. Nobody told me my hair would fall out. Nobody told me that I would have depth perception issues... Nobody told me any of those things, it was just 'here, take the medicines.' Then, after the medicines [weren't] working it was like 'oh, we don't know what to do with you.'**”

**BLACK WOMAN WITH ENDOMETRIOSIS**



**When I had my follow up with the doctor, I was told at that time this is a 'White women's disease,' and they didn't know how to care for a Black woman.**”

**BLACK WOMAN WITH ENDOMETRIOSIS**



**Pelvic floor PT not being a standard offering after any sort of surgery in that area. Having to basically beg insurance to actually get care there.**”

**BLACK WOMAN WITH ENDOMETRIOSIS**



Participants then discussed topic areas that would benefit from patient-centered research to identify and test specific programs, policies, and treatments to reduce disparities in endometriosis care.

The group proposed six areas for future research:

1. Improving training for medical providers
2. Implementing standardized protocols
3. Implementing multidisciplinary and individualized treatment plans
4. Enhancing quality of life and behavioral health
5. Fostering patient education and self-advocacy
6. Elevating patient narratives

Acknowledging the persistent challenges and deeply entrenched inequities in endometriosis care, this Roadmap provides a foundation for future research and collaboration. Researchers are urged to collaborate with the endometriosis community to develop and test patient-centered comparative effectiveness research (CER) questions that align with stakeholder priorities and center the experiences of Black women with endometriosis. Identifying the most effective treatments for patients through patient-centered CER will lead to improved outcomes, equipping providers with evidence-based approaches and insurers with the information needed to make informed coverage decisions. The MHQP and EA teams are hopeful that this work will drive meaningful improvements in endometriosis care.

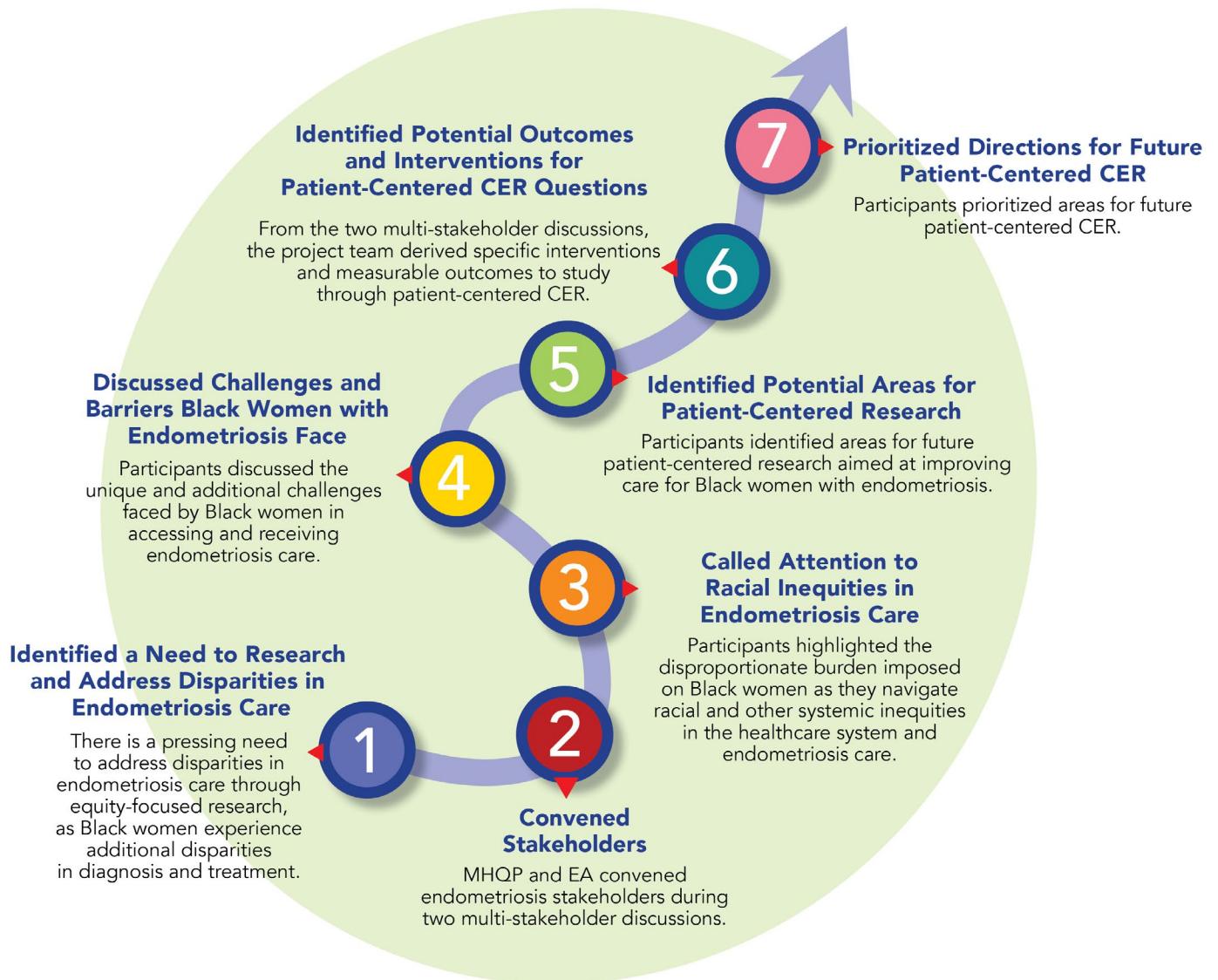


## ABOUT THIS ROADMAP

Massachusetts Health Quality Partners (MHQP) and the Endometriosis Association (EA) collaborated to develop this Roadmap, which offers stakeholder-identified insights to guide research into advancing equity in endometriosis care for Black women.

This document specifically highlights future directions for patient-centered comparative effective research (CER). Figure 1 below displays a summary of the community-driven process used to create this Roadmap.

**Figure 1:** Creating a Patient-Centered Research Roadmap to Advance Equity in Endometriosis Care for Black Women



## ACKNOWLEDGEMENTS

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Additionally, we extend our deepest appreciation to all participants who contributed to this project. Your insights, feedback, and commitment have been crucial in shaping our work. We are especially grateful to the Black women with endometriosis who courageously shared their personal experiences and perspectives, offering invaluable guidance throughout the Roadmap development process.

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## IDENTIFIED A NEED TO RESEARCH AND ADDRESS DISPARITIES IN ENDOMETRIOSIS CARE

### Endometriosis: Understanding the Disease and Its Impact

Endometriosis is a chronic, multi-systemic disease of inflammation (Eskenazi & Warner, 1997; Zondervan et al., 2018, 2020) where tissue similar to the lining of the uterus grows outside the uterus (WHO, 2023). It can cause a range of symptoms, including severe pain and infertility, which can deeply affect an individual's health and quality of life (Nnoaham et al., 2011; Missmer et al., 2021; Zondervan et al., 2018).

On average, it takes 7 to 10 years after the onset of symptoms to get a diagnosis of endometriosis (Bougie et al., 2019). Delays in diagnosing endometriosis can lead to several negative outcomes, including increased clinical and economic burdens, with patients experiencing more symptoms, comorbidities, and significantly higher health-care utilization and costs compared to those diagnosed sooner (Surrey, Soliman, Trenz, Blauer-Peterson, & Sluis, 2020).

### Funding Disparities in Endometriosis Research

Despite the fact that it affects 6.5 million women in the United States alone, endometriosis continues to receive inadequate funding for research and treatment (Ellis, Munro, & Clarke, 2021). In 2023, the funding allocation for endometriosis from the National Institutes of Health (NIH) was \$29 million (NIH, 2023). In comparison, that same year, Crohn's disease, a chronic inflammatory condition like endometriosis that affects approximately 3 million people in the United States (CDC, 2024), received \$92 million in funding (NIH, 2023).

The infographic below (Figure 2) presents a comparative look at the disparities between endometriosis and Crohn's disease fundings, relative to the number of lives affected.

**Figure 2:** Comparing Research Funding for Endometriosis and Crohn's Disease

## ENDOMETRIOSIS VS CROHN'S

<p><b>Endometriosis affects approximately <u>6.5 million</u> women in the US</b></p> <p><b>In 2023, the NIH funding allocation for endometriosis was <u>\$29 million</u></b></p>	<p><b>Crohn's affects approximately <u>3 million</u> people in the US</b></p> <p><b>In 2023, the NIH funding allocation for Crohn's disease was <u>\$92 million</u></b></p>
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### **Inequities in Care and Outcomes**

Inequities in healthcare quality experienced by women, and more specifically Black women, are well known and are frequently related to pain care (Morales & Young, 2021; Samulowitz et al., 2018). Specifically, research has shown that women's pain is frequently dismissed and that Black women in particular are systematically undertreated for pain (Hoffman et al., 2016; Morales & Young, 2021).

These disparities also extend to obstetric and gynecological outcomes. For example, Black women face significantly higher maternal mortality rates (CDC, 2023) and are three times more likely to develop uterine fibroids at a younger age than White women (Catherino, Eltoukhi, & Al-Hendy, 2013), experiencing more severe symptoms (Catherino, Eltoukhi, & Al-Hendy, 2013) and higher rates of complications during treatment (Hakim et al., 2004; Kim et al., 2020). A report by *Five X More* further highlighted disparities in pain care for Black women during maternity, revealing that 43% felt their pain relief options were not clearly explained (Tubb, 2022). Additionally, over half of those who did not receive their preferred pain relief were not informed about the reasons for its unavailability (Tubb, 2022).

In addition to the systemic and interpersonal inequities that Black women face in the healthcare system, research has shown that Black women are disproportionately exposed to environmental and other contaminants, such as pesticides and heavy metals, that are linked to increased rates of breast cancer, Polycystic Ovarian Syndrome (PCOS), uterine fibroid development, and endometriosis (Rumph et al., 2022).

### **Inequities in Endometriosis Care**

The health inequities experienced by Black women are also documented in endometriosis care. Historically, many physicians believed that endometriosis was a disease that affected only White women (Jacoby et al., 2010). As a result, compared with White women, Black women are less likely to be diagnosed with endometriosis (Bougie et al., 2019; Bougie, Healey, & Singh, 2019), and, on average, are diagnosed at ages 2.6 years older than White women (Li et al., 2021). Black women also receive lower-quality endometriosis care compared to their White counterparts, a disparity often rooted in stereotypes about Black patients' pain tolerance and implicit and explicit biases held by providers (Bougie, Nwosu, & Warshafsky, 2022). For example, research indicates that Black women with endometriosis are less likely to undergo minimally invasive surgery compared to White patients (Katon et al., 2023).

### **Addressing Gaps in Endometriosis Care: The Need for Equity-Focused Research and Funding**

The limited funding endometriosis receives in the context of the number of lives it impacts, compounded by the inequitable care that Black women with endometriosis experience, underscore the need for more patient-centered research aimed at improving the quality of endometriosis diagnosis and treatment for Black women.

Project participants highlighted that the lack of research on the effectiveness of interventions and treatments is a major barrier to improving care and securing insurance coverage, especially in endometriosis care, where disparities-focused research is limited. Increased research funding is essential to build a strong evidence base, demonstrate the value of interventions, and improve care and coverage for Black women.

The quotes below from the multi-stakeholder convenings illustrate the need for patient-centered research to address this gap and elevate the voices of Black women in endometriosis research.



**We talk about lack of research dollars, and this isn't an excuse for where we are today, but I think it should be part of the conversation [that] 10 times less research dollars [is spent] for a much more prevalent and equally burdensome [chronic disease].**

**RESEARCHER**



**It is very hard to now understand how little research has been done for endometriosis as well as for women of color... I hope we do more for [the] women that are that are coming behind [us so] that they don't have to suffer in silence.**

**BLACK WOMAN WITH ENDOMETRIOSIS**



**I've been doing more and more disparities research... When I was trying [to] understand endometriosis in Black women you wouldn't even say there's a gap in the literature – there's nothing there! So, [it] is really critical to bring this group together.**

**RESEARCHER**





## CONVENED STAKEHOLDERS

To address the lack of patient-centered research into interventions to reduce disparities in endometriosis care, MHQP and the EA held two virtual multi-stakeholder convenings in April and June of 2024 focused on setting future research directions on this topic. The meetings were facilitated by Dionne Grayson, a Black woman living with endometriosis, an author, and the owner of Building Your Dreams LLC. She was joined by 16 participants – 8 Black women with endometriosis between the ages of 19-50, 4 providers, 2 researchers, and 2 health plan representatives. Participants shared various motivations for participating in this project, including advocacy, their professional roles, and research interests. All participants shared a common commitment to reducing disparities in endometriosis care.



**I’ve had symptoms since around maybe 16-17 years of age, and I was not diagnosed until I was 33... I’m now 48 so [it’s been] about 15-16 years [that] I’ve been living with this disease... [I’ve] create[d] my own education and awareness initiative... to lean more into my own advocacy. I’m here because anytime there is an opportunity for me to lend my voice to... further the care for endometriosis, particularly for Black women and women of color, I’m always all in.**

**BLACK WOMAN WITH ENDOMETRIOSIS**



**I hope that we’re able to use all of our voices here in order to get to a point where we have so much more to offer Black women in pain and Black women specifically with endometriosis.**

**PROVIDER**





### 3 CALLED ATTENTION TO RACIAL INEQUITIES IN ENDOMETRIOSIS CARE

The conversations during the two convenings highlighted the diagnostic challenges, limited treatment options, and low-quality care experienced by women with endometriosis, while emphasizing that Black women bear a disproportionate burden as they navigate the healthcare system, especially for pain management. Stated differently, while Black women with endometriosis face many of the same challenges as White women, the barriers to care they experience are further compounded by racial inequities.

Several Black women with endometriosis shared that they were marginalized and overlooked by medical professionals who held biases and harmful racial stereotypes, such as the myth that endometriosis affects only White women. This discrimination and disrespect added to the burden of their disease.



**I was meeting with a doctor [and] the first question was ‘how many sexual partners do you have?’ not ‘are you sexually active?’ not ‘do you have any partners,’ it was just immediately ‘how many?’ This goes back to those very rooted biases about Black women being sexually promiscuous. At that time, I was practicing abstinence so there were no sexual partners and so that stuck with me.**

**BLACK WOMAN WITH ENDOMETRIOSIS**



**Imagine adding [the burden of having painful menses] to the weight that we already carry as Black women... everyday.**

**BLACK WOMAN WITH ENDOMETRIOSIS**



**When I had my follow up with the doctor, I was told at that time this is a ‘White women’s disease,’ and they didn’t know how to care for a Black woman.**

**BLACK WOMAN WITH ENDOMETRIOSIS**



**For me, it was [because] I come from Cape Verde. [My doctor] made me feel that there was some kind of infection that I [was] carrying from Africa.**

**BLACK WOMAN WITH ENDOMETRIOSIS**



**My primary care doctor referred me to a gastroenterologist and his diagnosis was that I just missed my mom’s home cooking...[the gastroenterologist] was like ‘you’re good, you just missed your mom’s cooking... Go home have some of her fried chicken [and] you’ll be great.’ [He just] totally dismissed my pain.**

**BLACK WOMAN WITH ENDOMETRIOSIS**





## DISCUSSED CHALLENGES AND BARRIERS BLACK WOMEN WITH ENDOMETRIOSIS FACE

During the first convening, Ms. Grayson engaged the group in a multi-stakeholder discussion to hear about endometriosis care journeys, perspectives, and priorities. Participants discussed the challenges and barriers that Black women uniquely and disproportionately face in receiving an endometriosis diagnosis, as well as accessing and receiving endometriosis care. Table 1 below shows descriptions of the challenges and barriers identified during the first convening, alongside quotes from the discussion.

**Table 1:** Challenges and Barriers Identified in Convening #1

RESEARCH THEME	DESCRIPTION	QUOTES
<b>Dismissal of Symptoms, Misdiagnosis, and Medical Gaslighting</b>	<ul style="list-style-type: none"> <li>• Many Black women with endometriosis experienced symptoms from a young age, but these symptoms were often dismissed or normalized by healthcare providers, leading to delayed diagnosis and treatment.</li> <li>• As described above, Black women with endometriosis shared that providers held harmful racial stereotypes, such as the misconception that endometriosis primarily affects White women and assumptions about Black women’s sexual behavior, leading to delays in diagnosis and misdiagnosis.</li> <li>• Several women shared that they often had to advocate for themselves and push for diagnostic procedures to confirm endometriosis.</li> </ul>	<p>“I was talking with this specialist, and I [shared that] I’m in pain all the time... and then she [said] something in the visit [along the lines of] ‘don’t worry menopause is just around the corner’ and so I was like I have to find someone else... I can’t see this person, they’re not taking my pain seriously, they don’t listen to me.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“[Endometriosis] was just what you had to deal with as part of being a woman. I believed it. I was like women have been having periods and birthing babies since the beginning of time, so I guess this is true. It led me a lot to not even talk about my symptoms, to not even bring it up because [I thought] this is just your burden to bear.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“I was young, [and] I believed what I was told, and I didn’t challenge it. If the doctor said, ‘this is what it is, you have IBS,’ then you get treated for that.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“I brought up endometriosis and my doctor didn’t believe that’s what it was. I was the one who convinced [my doctor] to do the surgery. [I said] ‘just do the laparoscopy and we can figure out whether it’s there or not, it won’t hurt anything, but at least I’ll know, and you will know whether it’s there.’” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>

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**Table 1:** Challenges and Barriers Identified in Convening #1 *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
<p><b>Dismissal of Symptoms, Misdiagnosis, and Medical Gaslighting</b> <i>continued</i></p>		<p>"[My OB/GYN] hollered at me [and told me] 'if you would start having sex you wouldn't have these problems'... and I remember going home and crying to my mom, [saying that] I'm being penalized for being a virgin. You know, and I believed him... I thought that the reason that I was experiencing [pain was] because I wasn't having sex and I just felt like it was crazy that I would have to do this, in order to get some kind of relief."</p> <p><b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>"I had never been to a gynecologist before, I'm thirteen years old, I'm not sexually active... It was a very traumatic experience. From that visit, the matter was not rectified, he pretty much just told my mom just keep giving me ibuprofen and I'll be fine."</p> <p><b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>
<p><b>Lack of Knowledge and Understanding Among Providers</b></p>	<ul style="list-style-type: none"> <li>• Several participants shared that there is a knowledge gap among healthcare providers, including pediatricians, regarding the recognition and management of endometriosis.</li> <li>• The lack of comprehensive and accurate training leads to misdiagnosis, treatment options that do not address patient needs, inadequate management of pain, and prolonged suffering.</li> <li>• This knowledge gap, compounded by racial biases, results in providers overlooking or downplaying Black women's pain.</li> <li>• One participant expressed that the term "endometriosis specialist" is misleading, which highlights the critical need for increased research funding to enhance providers' understanding of and treatment approaches for endometriosis, given that the root causes of the disease remain unknown and current treatment options are limited.</li> </ul>	<p>"No one ever talked to me about endometriosis being a whole-body disease. The fact is that endometriosis is a disease that by its very definition occurs outside of the uterus, but so much talk from providers surrounds the uterus and reproductive system."</p> <p><b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>"Unfortunately, my traditional training, [was] based upon a 1927 theory of endometriosis... [which] was A) not to 'hear' it [when patients describe their symptoms]; B) not to 'see' it [at the time of laparoscopy]; and C) never [be] given the skills to be able to take it all out. I'll take on the guilt of my GYN colleagues and plead a little bit of the training isn't there." <b>PROVIDER</b></p> <p>"People refer to this to me as an 'endometriosis specialist.' I find providers that use that term very misleading... How can you be an expert or a specialist in something we don't have an idea about [what] causes it? It's a chronic condition, we can't tell you what causes it, and yet we wear the hats of experts very casually and easily." <b>PROVIDER</b></p>

**Table 1:** Challenges and Barriers Identified in Convening #1 *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
<p><b>Access and Affordability Barriers</b></p>	<ul style="list-style-type: none"> <li>• Black women with endometriosis disproportionately face barriers to access and affordability in endometriosis care.</li> <li>• Participants noted the difficulties in obtaining necessary tests and treatments due to insurance limitations and high out-of-pocket costs.</li> <li>• Without research supporting the benefits of interventions, treatment options often go uncovered by insurance.</li> </ul>	<p>“Endometriosis [is] like a bad layer cake. You start with the bottom layer, which is access. If you don’t have insurance or your insurance is saying ‘no you don’t need that test’ or ‘you don’t need that MRI,’ then how are you actually getting the care that you need?... Then you add in all of the other layers around endometriosis... so much scar tissue everywhere within your body, causing all kinds of chronic pain... It’s like a terrible cake that nobody wants to take a bite out of.”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“That’s one of the biggest barriers I think for insurance coverage is that the response will be: there is not sufficient medical evidence to support that X, Y, and Z treatment would be beneficial, so... the research needs to be there.” <b>HEALTH PLAN REPRESENTATIVE</b></p> <p>“Being able to afford care is also another issue. You have specialists that don’t take insurance, so here you have \$10,000 worth of a bill coming your way out of pocket for basic human care.”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“Pelvic floor PT not being a standard offering after any sort of surgery in that area. Having to basically beg insurance to actually get care there.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“Chiropractic care helped with minimizing pain. I was in care for two years, but I had to stop because my insurance only covered so much, and I had to pay the difference. I could no longer afford it.”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“A lot of the aftercare to improve the quality of life, the mental health therapy if you need to see a psychiatrist, psychologist, medications, whatever, a lot of that stuff is not covered.”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“For me [hysterectomy] was looked at as an elective procedure and I was initially denied even though I had this whole disease that was literally eating a hole in my uterus.”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>

**Table 1:** Challenges and Barriers Identified in Convening #1 *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
<p><b>Lack of Individualized and Multi-Disciplinary Care Plans</b></p>	<ul style="list-style-type: none"> <li>• Black women with endometriosis recounted being offered limited treatment options, often centered around hormonal birth control or hysterectomy. This narrow focus overlooks other potential approaches to managing pain, contributing to prolonged suffering and dissatisfaction with their care.</li> <li>• The conversation revealed that Black women are often not provided with comprehensive and personalized care plans for managing endometriosis.</li> </ul>	<p>“Particularly with Black women, a lot of times [hysterectomy] is [automatically] the go to. When, through research, we know that hysterectomy, while it is a viable treatment option for a lot of people, it doesn’t cure endometriosis because endometriosis is a disease that occurs outside of the uterus.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“The providers who were most holistic in my care were my acupuncturist and herbalist and [they] provided the most education and pivoting even though I’ve been seeing [an endometriosis] specialist for a decade. So, I also just wanted to bring in that lens of the sort of multiple levels of providers that have supported me through this journey.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“If one birth control wasn’t working [providers were just like] ‘OK let’s jump to this new one,’ and I feel like there wasn’t an appreciation of the impact [on my body] on adjusting to a new birth control and all the side effects, and you know seeing if that works and if it doesn’t work.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>
<p><b>Limited Consideration of Alternative Care Options</b></p>	<ul style="list-style-type: none"> <li>• Several participants highlighted the benefits of alternative pain management strategies like acupuncture and pelvic floor therapy. However, the discussion uncovered that Black women often have to advocate for providers to consider alternative care options.</li> <li>• It is important to note that surgical treatments play an important role for many women, but these are often miserable experiences and not curative. This underscores the importance of surgery aftercare, such as pelvic floor physical therapy, as emphasized in the discussions.</li> </ul>	<p>“No one ever said ‘hey, what about pelvic floor PT?’... I had to fight for it and ask for it before I could finally recently get some pelvic floor PT to try to help with some of the pain and discomfort that I experienced in daily life. [If] you have pelvic surgery, [pelvic floor PT] should be the obvious [next] step and for a lot of doctors [it] isn’t.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“It was my acupuncturist who [mentioned] sciatic endometriosis [to] me, because I had talked about sciatica as my main pain presentation, and no one had ever like suggested it might be because there’s actually [endometrial] tissue in the muscle.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“I’ve spent the last 12 years since my diagnosis doing everything to try to get out of pain... I explored several non-traditional methods. I tried low dose immunotherapy, which had its moments of helping to kind of compress the pain for me down to several days a week versus most of the month, but even that stopped working after a while... I even got my medical marijuana card in New Jersey. I’ve never used any drugs, I was 49 years old, but it just got to the point where something had to give.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>



**Table 1:** Challenges and Barriers Identified in Convening #1 *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
<p><b>Lack of Shared Decision-Making</b></p>	<ul style="list-style-type: none"> <li>Black women with endometriosis shared that they were often given treatment options without any discussion about the possible side effects and therefore were not given the opportunity to make fully informed decisions.</li> </ul>	<p>“I was given a lot of those drugs. Nobody talked to me about side effects. I was not given the opportunity to make a fully informed patient decision because they were the doctors and I just believed what they told me... Nobody told me I would become suicidal. Nobody told me my hair would fall out. Nobody told me that I would have depth perception issues... Nobody told me any of those things, it was just ‘here, take the medicines.’ Then, after the medicines [weren’t] working it was like ‘oh, we don’t know what to do with you.”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“[My doctor] swore that once I got on birth control it would stabilize my cycle [and] I would not be in much pain... and that was the only option that he offered.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“There’s basically no discussion with providers about some of the side effects or long-term consequences [of treatment options].”  <b>RESEARCHER</b></p>
<p><b>Lack of Focus on Quality of Life</b></p>	<ul style="list-style-type: none"> <li>The emotional toll of living with chronic pain and enduring years of mistreatment, misdiagnosis, and inadequate treatment was evident in the narratives shared. The chronic pain and other symptoms associated with endometriosis significantly affect the ability to work, engage in daily activities, and spend time with family members.</li> <li>Participants shared that Black women diagnosed with endometriosis frequently encounter obstacles to accessing the necessary resources and support, including stigma around mental health care and the lack of specialized mental health providers who understand their specific medical context, which can result in mental health challenges.</li> </ul>	<p>“The other thing too that I don’t think [is] named [is the] impact of the fatigue of endometriosis, that sometimes the fatigue is even more damaging than the actual pain... Not being able to predict what is my day going to look like. So, there’s also this constant fear of how bad is the pain going to be today. What can I get done?”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“I want to speak to barriers that patients face to accessing mental health care. Some patients, especially Black women, still have stigma surrounding mental health care and not knowing how to navigate that space.”<b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“This has totally impacted [my] quality of life, which I think that my providers hadn’t really appreciated the impact of. [For example,] I have a new child [and] I can’t spend time with them.”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“I just want to underscore [that] quality of life is so critical because now when I go out with [my son], he’s always surprised – he’s always like ‘oh, you’re coming too mommy,’ because most of his life, I’ve just been in bed.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>

**Table 1:** Challenges and Barriers Identified in Convening #1 *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
<p><b>Lack of Focus on Quality of Life</b> <i>continued</i></p>	<ul style="list-style-type: none"> <li>• Black women with endometriosis expressed frustration, despair, and discontent regarding their treatment within the healthcare system, particularly as they navigated it while grappling with chronic pain.</li> </ul>	<p>“[OB/GYNs] don’t even ask for the quality of life.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“I know I went through severe depression, became suicidal throughout the course of my initial diagnosis and treatment.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>
<p><b>Impact of Endometriosis on Fertility</b></p>	<ul style="list-style-type: none"> <li>• Participants underscored the profound impact of endometriosis on fertility and the challenges individuals face in conceiving and maintaining pregnancies amidst the disease’s symptoms.</li> <li>• The quotes from Black women with endometriosis revealed a pattern of delayed diagnosis and limited treatment options, leading to fertility challenges.</li> </ul>	<p>“At this point in my life I have some regrets. I do think if I had been diagnosed earlier, I probably could have preserved my fertility or at least made some other plans.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“I believe that is one of the reasons that I am dealing with fertility issues to this day. I got on birth control at the age of 17 [and] I didn’t get off [it] until I was 32.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“It was not my choice, but it really came down to a life-or-death situation for me. My doctor was like ‘even if you did manage to get pregnant, as the baby grew this hole in your uterus will grow and that could be detrimental to both of you.’ In 2018, I finally made the decision to have the hysterectomy.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>



## IDENTIFIED POTENTIAL AREAS FOR PATIENT-CENTERED RESEARCH

During the second convening, Ms. Grayson led the group in a multi-stakeholder discussion aimed at identifying patient-centered research areas to improve endometriosis care for Black women. Continued collaboration with the endometriosis community is essential to create and test targeted interventions — including programs, policies, and treatments — designed to reduce disparities in care.

### Participants identified the following areas for future research:

- Improving training for medical providers
- Implementing standardized protocols
- Implementing multidisciplinary and individualized treatment plans
- Enhancing quality of life and behavioral health
- Fostering patient education and self-advocacy
- Elevating patient narratives

Table 2, on the following page, includes a description and illustrative quotes for each research area.



**Table 2:** Research Areas

RESEARCH THEME	DESCRIPTION	QUOTES
<p><b>Improving Training for Medical Providers</b></p>	<ul style="list-style-type: none"> <li>• There is a need for improved provider education and training to facilitate earlier diagnosis and appropriate referrals, particularly for Black women who are often diagnosed with endometriosis later than White women. Education should be integrated not only into medical school curricula, but also during residencies and ongoing professional development.</li> <li>• However, the limited research on endometriosis has led to significant knowledge gaps and outdated information among providers, highlighting the need for further research to support effective training programs.</li> </ul>	<p>“There is a whole lot we can do with educating non-gynecology providers. So that it’s not an automatic – copy the same notes from last year to this year, to the following year, to the following year – and then we look back like, ‘oh, this patient didn’t even get an ultrasound.”  <b>PROVIDER</b></p> <p>“You really need exposure [to a certain] level of knowledge in order to even begin to even recognize symptoms to know when to refer.”  <b>HEALTH PLAN REPRESENTATIVE</b></p> <p>“Training should not only occur in medical school, but also during residencies and through continuous professional development.”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“Medical school has 30 seconds of the reproductive cycle as a lecture. It’s a rarity even then [that] endometriosis is spoken of... We’re not even at the first step there. So, reaching down into the youth to get an awareness of a disease that affects [so many] women.” <b>PROVIDER</b></p>
<p><b>Implementing Standardized Protocols</b></p>	<ul style="list-style-type: none"> <li>• Standardized protocols, checklists, and systemic changes like electronic health record flags and routine screenings for endometriosis can enhance early detection and referral by non-gynecology providers.</li> <li>• Implementing these protocols can help reduce disparities by ensuring consistent and objective evaluation and treatment plans.</li> <li>• However, OB/GYN referrals should not be viewed as the sole solution to diagnosing endometriosis. Gynecologists themselves are sometimes more likely to misdiagnose the disease compared to other practitioners (Bontempo &amp; Mikesell, 2020). Simply referring Black women with endometriosis to an OB/GYN</li> </ul>	<p>“It would also be great to have a standardized question about menstrual cycles for primary care doctors.” <b>RESEARCHER</b></p> <p>“It’s almost as if we could create an endometriosis packet. These are common conditions that occur with the diagnosis of endometriosis. These are resources that need to be available and almost give it a checklist where a nurse or patient care assistant could sit down with a patient for a longer period of time.” <b>HEALTH PLAN REPRESENTATIVE</b></p> <p>“There are patterns to how patients present with this disease... If a short questionnaire is filled [out, it] should trigger an ultrasound automatically. And that should trigger a referral to a gynecologist automatically... Something protocolized... Just a few questions that trigger something and that will take away a lot of the disparities that we’re talking about.” <b>PROVIDER</b></p>

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**Table 2:** Research Areas *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
<p><b>Implementing Standardized Protocols</b> <i>continued</i></p>	<p>without addressing the systemic barriers they face in accessing care can exacerbate disparities in diagnosis and treatment, underscoring the need for a more equitable and comprehensive approach.</p>	
<p><b>Implementing Multidisciplinary and Individualized Treatment Plans</b></p>	<ul style="list-style-type: none"> <li>• Endometriosis affects multiple body systems and requires a multidisciplinary team-based approach. This includes having specialists such as gynecologists, pelvic floor physical therapists, endocrinologists, nutritionists, pain management experts, chronic illness-focused mental health practitioners, urologists, and gastroenterologists working together to ensure that all aspects of the patient’s health are addressed without the patient needing to navigate the system alone.</li> <li>• Treatment plans should be tailored to each patient’s unique needs and experiences. What works for one patient may not work for another, so individualized plans are essential.</li> </ul>	<p>“In my [endometriosis] care, I have never received the kind of care that I received until I had [a] cancer diagnosis. [Providers from multiple disciplines] talked to each other.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“I think that one thing that’s come out of this conversation is that endometriosis needs to be a team sport versus just ‘I’m gonna go see my gynecologist and then he’s gonna send me to a specialist and then I’m gonna just have to figure it out’.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“Endometriosis affects multiple body systems and often requires a multidisciplinary team-based approach.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“I also want to add that when it comes to the health plans [and] doctors, [they need to] understand that there needs to be individualized [care] plans, because what works for one patient may not work for me.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>

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**Table 2:** Research Areas *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
<p><b>Enhancing Quality of Life and Mental Health</b></p>	<ul style="list-style-type: none"> <li>• Several Black women with endometriosis stressed the need to consider the mental health toll of endometriosis, including the anxiety and depression caused by chronic pain and inadequate care. They highlighted the importance of addressing these aspects to improve patients’ overall quality of life.</li> <li>• It is important to call out the dangers of suggesting referrals to mental health for Black women experiencing chronic pain. Often, providers treat the pain as solely a mental health issue and dismiss Black women’s pain symptoms. Research shows that addressing underlying endometriosis-related pain can reverse its negative impact on mental health (Jia et al., 2012). Therefore, the focus should shift towards referrals to mental health professionals who specialize in chronic illness psychology, ensuring that these therapists are equipped to understand and treat the complexities of chronic pain.</li> </ul>	<p>“And one of the things that’s been really powerful in one of the models in the particular department that I’m in is that they have a mental health provider that’s based in the OB/GYN department, specifically based in the pain department. That has really resonated for me because it’s someone who has a lens and understands the disease as opposed to just a general mental health practitioner who may not have the same context and it’s been really powerful in the sense that one of the things for me that was unexpected was a lot of grief came up after surgeries and I felt that even though I was starting a new relationship, the person already had that context, which made the therapy even more powerful.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>

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**Table 2:** Research Areas *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
<p><b>Fostering Patient Education and Self-Advocacy</b></p>	<ul style="list-style-type: none"> <li>• Educating patients to advocate for themselves within the healthcare system is crucial, as many participants shared that they often felt like they were managing their care and treatments alone.</li> <li>• Participants also shared that support groups and community resources are invaluable in offering both information and emotional support.</li> <li>• Fostering a medical culture that values patient input and encourages self-research can significantly improve patient outcomes.</li> </ul>	<p>“Advocating for myself was a learned behavior. I had to learn from talking to other people that ‘no, you need to do your own research’ or ‘no, you need to ask this question’ or ‘no, show them this’.”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“Communicating with... women that have been in my support groups. I definitely think that that [has been] incredibly helpful.”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“It’s amazing when a patient can come in – just because we know our bodies more than anyone does – and then just having those conversations so that we can come to some kind of resolve and do things that are actually beneficial for the patient.”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“...Teaching patients how [to] create self-advocacy situations and then we [need] to defuse the large egos that white coats will have, regarding that they know best, when actually their patients do know best.”  <b>PROVIDER</b></p> <p>“Whatever [the doctors] said [I believed]. It wasn’t until years later that I said, it’s okay for me to ask questions and do my own research and to come back and say, ‘what do you think about this?’”  <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p> <p>“I started having issues with my right side and once again... I was the one who prompted surgery because [my doctor] wanted to just put me on medication. I don’t want to be put on medication if you can’t tell me why I’m on this medication – we need to get to the bottom of the problem.” <b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>

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**Table 2:** Research Areas *continued*

RESEARCH THEME	DESCRIPTION	QUOTES
<p><b>Elevating Patient Narratives</b></p>	<ul style="list-style-type: none"> <li>• Participants emphasized the power of patient narratives in educating both medical professionals and the wider public. Sharing personal experiences can help raise awareness and improve understanding of endometriosis among healthcare providers and patients.</li> <li>• Highlighting Black women’s experiences specifically is crucial for improving endometriosis diagnosis and treatment, as their stories can foster a deeper understanding of the unique challenges and inequities they face when navigating the healthcare system for pain care.</li> </ul>	<p>“I believe in the power of telling your story... Telling the story in a way that is so powerful... You tell your story of how it has been navigating endometriosis [and] you’re sharing [it] with the public. [Sharing] narratives not just with medical providers but with the whole world.”</p> <p><b>BLACK WOMAN WITH ENDOMETRIOSIS</b></p>





## 6 IDENTIFIED POTENTIAL OUTCOMES AND INTERVENTIONS FOR PATIENT-CENTERED CER

Based on the discussions held during the two multi-stakeholder convenings, the project team identified patient-centered outcomes, as well as potential interventions that could be tested for effects on the outcomes that matter most to the endometriosis community. The overarching aim of this project is for researchers and endometriosis community members to leverage the findings from this Roadmap to drive patient-centered CER, with the ultimate goal of identifying best-practice care approaches for reducing disparities in endometriosis care. This involves developing patient-centered CER questions, which compare patient-centered outcomes of two or more approaches to healthcare.

### What are outcomes that matter most to Black women with endometriosis and other endometriosis stakeholders?

Based on the challenges and opportunities described by participants, several measurable patient-centered outcomes of interest were derived from the conversation (see Table 3 below). Note that outcomes should be stratified by race to measure and monitor disparities in care.

**Table 3:** Patient-Centered Outcomes

OUTCOME TYPE	OUTCOMES
<b>Patient-reported</b>	<ul style="list-style-type: none"> <li>• Average time from symptom onset to a confirmed diagnosis</li> <li>• Patient satisfaction with their care/symptom management, particularly focusing on pain management, surgical outcomes, and long-term health following treatment for endometriosis</li> <li>• Patient quality of life through personalized indicators, such as daily functioning, ability to work full-time, fatigue levels, and mental health</li> <li>• Patient satisfaction/experience, including patient-provider communication (e.g., listening carefully to the patient and treating the patient with respect and empathy)</li> <li>• Frequency and outcomes of pelvic floor therapy as part of post-surgical care for patients with endometriosis</li> </ul>
<b>Clinical</b>	<ul style="list-style-type: none"> <li>• Percentage of younger patients being screened for and diagnosed with endometriosis</li> <li>• Adoption and utilization of standardized diagnostic protocols (e.g., questionnaires triggering automatic ultrasounds) in primary care and emergency settings</li> <li>• Rate and timeliness of referrals from general practitioners to endometriosis specialists, including minimally invasive surgeons and reproductive endocrinologists</li> <li>• Frequency and coordination of other specialists engaging with primary care providers and OB/GYNs to support endometriosis care</li> <li>• Referrals to chronic illness-focused mental health services</li> </ul>
<b>Provider Training/Education</b>	<ul style="list-style-type: none"> <li>• Knowledge about endometriosis among general practitioners and other healthcare professionals</li> <li>• Changes in medical school curricula to include comprehensive education on endometriosis</li> <li>• Number of Continuing Medical Education (CME) programs available and attended that focus on endometriosis</li> <li>• Number of providers obtaining specialized training or certification in endometriosis care</li> </ul>

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**Table 3:** Patient-Centered Outcomes *continued*

OUTCOME TYPE	OUTCOMES
<b>Access to and Financial Aspects of Care</b>	<ul style="list-style-type: none"> <li>• Wait times for appointments and surgeries</li> <li>• Percentage of patients receiving necessary tests and treatments without insurance denials based on insufficient evidence</li> <li>• Percentage of patients receiving full reimbursement for recommended endometriosis treatments</li> <li>• Out-of-pocket expenses for endometriosis care</li> </ul>

**What interventions could be tested for effects on patient-centered outcomes?**

Examples of potential interventions that could be tested for effects on one or more of the outcomes listed in Table 3 are outlined in Table 4 below.

**Table 4:** Potential Interventions

RESEARCH THEME	POTENTIAL INTERVENTIONS
<b>Improving Training for Medical Providers</b>	<ul style="list-style-type: none"> <li>• Develop and integrate a comprehensive module on endometriosis into medical, nursing, and allied health professional schools and residency training programs</li> <li>• Develop continuing medical education (CME) courses on endometriosis for primary care physicians, emergency room doctors, and other non-gynecology healthcare providers</li> <li>• Incorporate patient stories and advocacy into medical education and training programs</li> <li>• Include a specific medical school elective or course focusing on endometriosis, its pathophysiology, diagnosis, and management</li> <li>• Implement cultural humility training for providers</li> <li>• Implement implicit bias training for providers</li> </ul>
<b>Implementing Standardized Protocols</b>	<ul style="list-style-type: none"> <li>• Implement protocols (e.g., protocols, checklists, or routine screenings) in primary care settings that include specific questions about menstrual symptoms and establish a standard pathway for referrals to gynecologists based on responses to these questions</li> <li>• Utilize EHRs to automatically flag potential endometriosis symptoms based on patient records</li> <li>• Create artificial intelligence tools to assist in the early detection of endometriosis based on patient data and symptoms</li> </ul>

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**Table 4:** Potential Interventions *continued*

RESEARCH THEME	POTENTIAL INTERVENTIONS
<b>Implementing Multidisciplinary and Individualized Treatment Plans</b>	<ul style="list-style-type: none"> <li>• Establish communication across specialties including but not limited to gynecologists, pelvic floor physical therapists, endocrinologists, nutritionists, pain management specialists, urologists, and gastroenterologists for comprehensive endometriosis care</li> <li>• Create structured surgery aftercare programs involving pelvic floor physical therapy, pain management, and chronic illness-focused mental health support</li> <li>• Create personalized care plans (shared plan of care between provider(s) and patient) to ensure treatments are tailored to patients' individual needs</li> </ul>
<b>Enhancing Quality of Life and Mental Health</b>	<ul style="list-style-type: none"> <li>• Include chronic illness-focused mental health professionals in endometriosis care teams</li> <li>• Develop interventions aimed at reducing barriers to mental health care for endometriosis patients, particularly focusing on stigma and geographic accessibility</li> <li>• Have a chronic illness-focused mental health practitioner who is familiar with endometriosis within the OB/GYN or pain management departments</li> </ul>
<b>Fostering Patient Education, Empowerment, and Advocacy</b>	<ul style="list-style-type: none"> <li>• Establish forums and support groups where patients and providers can share experiences and knowledge about endometriosis</li> <li>• Create educational materials and patient-led programs to teach individuals with endometriosis how to advocate for themselves in healthcare settings, including how to present their symptoms and concerns effectively to providers</li> <li>• Facilitate workshops and seminars led by both patients and experts to foster a better understanding of the disease</li> </ul>
<b>Elevating Patient Narratives</b>	<ul style="list-style-type: none"> <li>• Share patient experiences of care (e.g., through quantitative surveys and qualitative data collection) with providers, policymakers, health plans, research institutions, and potential funders</li> <li>• Launch public health campaigns to raise awareness about endometriosis and promote early diagnosis and treatment</li> </ul>

### **How might researchers utilize these findings to develop patient-centered CER questions?**

Researchers should partner with Black women with endometriosis and other members of the endometriosis community to develop and test patient-centered CER questions informed by this project's findings. By involving those directly impacted by endometriosis—including patients, caregivers, advocacy groups, and healthcare professionals specializing in endometriosis care—researchers can ensure that research studies are relevant, meaningful, and aligned with the community's most pressing concerns and priorities. Additionally, collaborating with organizations like MHQP, which has extensive experience in patient experience and health equity research, can further strengthen the research's focus on understanding and improving the care experiences of Black women with endometriosis. This collaborative approach enhances the research's relevance and applicability, leading to more impactful and patient-centered outcomes.

### **Based on this work, some examples of patient-centered CER questions could be:**

- What are the differences, if any, in rates of endometriosis diagnosis by race between populations receiving standardized screening of endometriosis symptoms and those not receiving standardized screening?
- What are the differences, if any, in pain management outcomes for Black women with endometriosis between those participating in a pelvic floor physical therapy aftercare program and those receiving standard care (the usual care provided to patients based on current medical practices, guidelines, or protocols)?



## **PRIORITIZED DIRECTIONS FOR FUTURE PATIENT-CENTERED CER**

Following the second convening, the project team sent out a survey to gather participants' perspectives regarding priorities for future research.

### **Participants identified the following as key areas moving forward:**

- Fostering patient education, empowerment, and advocacy
- Improving provider training
- implementing standardized protocols



## CLOSING REMARKS

Through the results of this project, the MHQP and EA teams recognize that significant efforts are still needed to make meaningful strides in reducing disparities in endometriosis care. We are optimistic that this Roadmap will be utilized by researchers in the endometriosis space to begin to facilitate the identification, implementation, and coverage of the best ways to improve endometriosis care for Black women.

If you have any questions about the research Roadmap, please contact Natalya Martins (nmartins@mhqp.org), Mary Lou Ballweg (marylou@endometriosisassn.org), Genika Reed (genikareed@sbcglobal.net), or Kim-Cook Boyd (kcookboyd@yahoo.com).



**I'm hopeful that the findings from this project will lead to solutions for my daughters and future grandchildren who may encounter such a disease.**

**BLACK WOMAN WITH ENDOMETRIOSIS**



**As researchers, we need to be pushing [for] more money for endometriosis [research], specifically and in populations that have been understudied. To me, that's one of the places we have to start because without the research it's really hard to convince people to make change.**

**RESEARCHER**



**It's a matter of not just educating providers, educating patients to be self-advocates, but also educating health plans as far as what would be – what we would hope to be standard of care for treatment for endometriosis.**

**HEALTH PLAN REPRESENTATIVE**



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