Developing a trauma-informed social media campaign to disseminate endometriosis specific qualitative arts-based research findings: A tutorial

Kerry Marshall, Hargun Dhillon, A. Fuchsia Howard, Heather Noga, Grace J Yang, William Zhu, Jessica Sutherland, Sarah Lett, Anna Leonova, Paul Yong, Natasha L Orr

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Abstract

Trauma-informed approaches promote the creation of systems that prioritize safety and empowerment to improve patient well-being. These approaches are especially important in sexual and reproductive healthcare, where patients are often asked to disclose sensitive and personal information. This disclosure is particularly relevant in the context of endometriosis, a condition that affects 10% of reproductive-aged women and causes debilitating pelvic pain. Our team led a trauma-informed social media campaign to raise awareness and improve understanding of endometriosis by sharing research findings from a photovoice study focusing on Asian women's experiences of endometriosis during the COVID-19 pandemic in Canada (EndoPhoto Study). In this manuscript, we describe how we adapted and applied trauma-informed approaches to the development and implementation of the social media campaign by following five principles: support and collaboration; trustworthiness and transparency; safety; empowerment and voice; and cultural and gender sensitivity. We co-designed this campaign with patient partners with lived experience of endometriosis to facilitate collaboration and mutuality. Additionally, we shared details about the funders of this study to increase trust and transparency, moderated comments and de-identified images to promote participant safety, chose safer platforms to enhance empowerment and voice, and avoided stereotypes and shared authentic experiences of Asian people with endometriosis to support cultural and gender sensitivity. The campaign launched on Instagram and Pinterest in March 2025 to coincide with Endometriosis Awareness Month. The social media campaign received 8,540,528 total impressions over the course of the month and had a 6.23% and 1.4% engagement rates on Instagram and Pinterest, respectively.

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Original Manuscript

Title: Developing a trauma-informed social media campaign to disseminate endometriosis specific qualitative arts-based research findings: A tutorial

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Keywords: trauma-informed approach; social media; knowledge translation; endometriosis; information dissemination; content creation

Abstract: Trauma-informed approaches promote the creation of systems that prioritize safety and empowerment to improve patient well-being. These approaches are especially important in sexual and reproductive healthcare, where patients are often asked to disclose sensitive and personal information. This disclosure is particularly relevant in the context of endometriosis, a condition that affects 10% of reproductive-aged women and causes debilitating pelvic pain. Our team led a trauma-informed social media campaign to raise awareness and improve understanding of endometriosis by sharing research findings from a photovoice study focusing on Asian women's experiences of endometriosis during the COVID-19 pandemic in Canada (*EndoPhoto Study*). In this manuscript, we describe how we adapted and applied trauma-informed approaches to the development and implementation of the social media campaign by following five principles: support and collaboration; trustworthiness and transparency; safety; empowerment and voice; and cultural and gender sensitivity. We co-designed this campaign with patient partners with lived experience of endometriosis to facilitate collaboration and mutuality. Additionally, we shared details about the funders of this study to increase trust and transparency, moderated comments and de-identified images to promote participant safety, chose safer platforms to enhance empowerment and voice, and avoided stereotypes and shared authentic experiences of Asian people with endometriosis to support cultural and gender sensitivity. The campaign launched on Instagram and Pinterest in March 2025 to coincide with Endometriosis Awareness Month. The social media campaign received 8,540,528 total

impressions over the course of the month and had a 6.23% and 1.4% engagement rates on Instagram and Pinterest, respectively.

Background/Rationale

Endometriosis is a chronic inflammatory condition characterized by the presence of endometrial-like tissue outside the uterus [1]. Symptoms may vary, though often include severe pelvic pain, painful periods, painful sexual intercourse, and infertility [2]. Despite affecting approximately 10% of reproductive-aged women and girls, and an unmeasured number of gender diverse people, endometriosis remains significantly underdiagnosed and misunderstood [1, 3]. Although diagnostic delays average five years in Canada, some individuals have reported a formal diagnosis taking up to 20 years [3, 4]. The invisibility of symptoms, stigma surrounding sexual and menstrual health, and dismissal of women's pain all contribute to misinformation and present barriers to timely diagnosis and treatment and ultimately affect the mental and physical health of those with endometriosis [3, 5, 6]. Furthermore, racialized populations may experience additional barriers to endometriosis diagnosis and care [7]. For instance, one study found that East and/or Southeast Asian people were eight times more likely than their White counterparts to experience severe disease before being referred to more specialized care [8].

Globally, the COVID-19 pandemic further exacerbated the gaps in endometriosis care as it upended the healthcare system, causing resource redirection towards patients with COVID-19, and interrupting the continuity of care for patients with chronic conditions like endometriosis [9, 10]. In Canada, appointments and surgeries for people with endometriosis were postponed or cancelled as hospitals became overwhelmed and healthcare providers transitioned to virtual environments [11]. Concurrently, mandatory self-isolation measures dramatically altered people's levels of social support, contributing to worsening psychological symptoms such as depression and anxiety [12]. Additionally, the COVID-19 pandemic was marked by a global rise in anti-Asian sentiment, with people of Asian descent reporting increasing episodes of violence and feelings of vulnerability to discrimination [13].

Given these compounding factors, our team conducted a study—the *EndoPhoto Study*—with

22 South, East, and/or Southeast Asian cisgender women with endometriosis in Canada to better understand the experiences of people in these communities during the COVID-19 pandemic. This study employed photovoice, an arts-based methodology that provides opportunities to use photographs to share experiences and emotions related to stigmatized or hidden conditions [14]. Results from the *EndoPhoto Study* are published elsewhere [see forthcoming 15, 16, 17] and highlight several key themes. These themes include the ways in which the pandemic exacerbated feelings of isolation and created additional challenges in accessing healthcare for those living with endometriosis. Participants also built resilience during the pandemic by accepting social support from peers, advocating for themselves in healthcare interactions, and taking empowering actions to self-manage their conditions. The *EndoPhoto Study* was approved by the UBC C&W Research Ethics Board (H22-02390).

Findings from the *Endophoto Study* and our previous research highlighted the importance of sharing evidence that validates the experiences of people affected by endometriosis, helps people feel they are not alone, fosters hope, and recognizes the strengths of those affected. As guided by our Patient Research Advisory Board (PRAB; a group of people with lived experience of endometriosis), we chose to disseminate the study findings to a public audience through a social media campaign. The goal of the campaign was to amplify the stories shared by Asian women regarding their experiences during the COVID-19 pandemic, while focusing on disrupting silence related to medical dismissal, social isolation, and cultural stigma of pelvic pain and endometriosis. We recognized the relevance of using a trauma-informed approach to develop and implement the campaign, however, we found limited literature offering guidance on applying a trauma-informed lens in the context of a social media campaign.

The primary aim of this manuscript is to describe our development of a social media campaign that was informed by the core principles of a trauma-informed approach, designed to share the findings of a qualitative, arts-based endometriosis study. Our secondary aim is to share the engagement results of the social media campaign. The target audience for this manuscript includes individuals and teams interested in trauma-informed social media content creation, particularly those disseminating health-adjacent research findings.

Our Team

We are a multigenerational team with diverse genders, sexualities, ethnicities, and experiences, and are committed to improving the understanding and awareness of endometriosis through cutting-edge interdisciplinary research and knowledge translation. We recognize the importance of disseminating intentionally curated, evidence-based, and nuanced research findings to the endometriosis community and the public. Our team includes researchers, clinicians, healthcare trainees, and patient partners who are part of our PRAB. We are affiliated with the Endometriosis and Pelvic Pain Laboratory at the University of British Columbia, Canada.

What Are Trauma-Informed Approaches?

The formal conceptualization of trauma-informed care was first introduced by Harris and Fallot [18], in the context of mental health and substance use treatment systems, however, these principles have roots in long-standing community-based practices, including those within Indigenous traditions [19]. Since its inception, trauma-informed care has been adapted to various other disciplines, with the Substance Abuse and Mental Health Services Administration’s (SAMHSA) framework often cited [20]. Trauma-informed approaches acknowledge that trauma is widespread, with some reports suggesting that up to 70% of the global population will experience some form of traumatic event in their lifetime [21], and support actively creating systems that promote physical and psychological safety [20].

SAMHSA defines trauma broadly, encompassing experiences at individual and structural levels that stemming from experiences that can be considered emotionally harmful [20]. SAMHSA’s trauma-informed approach rests on four key assumptions: (1) realizing that trauma is widespread and can deeply affect individuals, communities, and societies; (2) recognizing the signs of trauma; (3)

responding to trauma by integrating trauma-informed approaches; and (4) resisting re-traumatization [20]. These assumptions are operationalized through six guiding principles: safety; trustworthiness and transparency; peer support; collaboration; empowerment, voice, and choice; and cultural, historical, and gender issues [20].

In healthcare settings, trauma-informed approaches in the provision of care have been shown to improve negative mental health symptoms and increase patient satisfaction, especially among populations with histories of trauma or medical dismissal [22]. Trauma-informed approaches are particularly relevant in sexual and reproductive health, where patients are frequently asked to disclose sensitive information and are more likely to have experienced prior healthcare-related trauma [23]. People with endometriosis have described feelings of shame and emotional distress related to their healthcare encounters where their symptoms have been diminished, normalized, or dismissed [24]. Interactions with healthcare systems, and providers—as well as with broader public discourses that minimize people’s experiences of endometriosis—have been further characterized as harmful, disempowering, and socially isolating. These experiences highlight the importance of utilizing a trauma-informed approach that prioritizes safety, empowerment, and collaboration [24].

Social Media, Knowledge Dissemination, and Trauma-Informed Approaches

‘Social media’ is broadly defined as digital spaces “built around the convergence of content sharing, public communication, and interpersonal connection” [25:1]. Social media has increasingly become a pervasive aspect of everyday life and a powerful knowledge dissemination tool where various social media platforms, such as Facebook and TikTok, have been used by the healthcare community for patient education, peer support, and advocacy [26-28]. Social media platforms are easy to access and participatory, thus they allow individuals and organizations to disseminate information and rapidly engage large, globally-connected audiences [29]. Content shared on social media platforms can provide unique opportunities to build community, share experiences, and influence public health discourse [27]. Specific to endometriosis, social media has been used to increase advocacy, activism, and awareness of the condition [30]. Conversely, the nature of instant access to information and a lack of fact-verifying measures can also lead to the unchecked and rapid spread of mis- and disinformation to the public. Moreover, algorithms may incidentally lead to re-traumatization and feelings of stigmatization [31-33]. Furthermore, considering people often consume social media content in isolation, there is little way for content creators to recognize potential (re)traumatization of viewers, highlighting the importance of creating and sharing content in an intentional way to prevent content-based (re)traumatization from the outset.

As knowledge dissemination of health-adjacent information increasingly moves onto social media platforms, trauma-informed approaches appear particularly relevant and potentially useful when working in these virtual environments. While there is limited guidance for applying trauma-informed approaches in digital spaces [34], literature is emerging. We drew upon three frameworks that highlighted the potential of these approaches to reduce harm when sharing health-adjacent information digitally. First, Josephs et al. [35] emphasized three key pillars for digital trauma-informed design specific to sexual and reproductive health: privacy and confidentiality, intuitive and representative designs, and inclusive language. Second, *Trauma-informed computing*, introduced by Chen et al. [36], is a framework guiding the adaptation of trauma-informed principles to digital design. This framework recognizes that digital tools can cause or exacerbate trauma and seeks to enable safer technological experiences [36]. Key adaptations of trauma-informed principles for online settings include safety, trustworthiness, peer support and collaboration, empowerment and choice, and cultural sensitivity. Lastly, Scott et al. [32] built upon the framework from Chen et al. [36], adding specific aspects and examples to consider when applying trauma-informed approaches to social media engagement. The framework from Scott et al. [32] outlined six guiding principles: (1) safety (e.g., safe data collection and storage, relaxing colors); (2) trustworthiness and transparency (e.g., transparent about what user data is collected and why); (3) peer support (e.g., protection for those sharing their unique stories); (4) collaboration and mutuality (e.g., co-design with people with lived experience); (5) empowerment, voice, and choice (e.g., no real names); (6) cultural and historical gender issues (e.g., acknowledge algorithmic biases).

Developing our Trauma-Informed Social Media Campaign

Theoretical Approaches

Throughout the development of the campaign's design, content creation, data interpretation, and dissemination strategies, we were primarily guided by principles of intersectional feminism and integrated knowledge translation (IKT). An intersectional feminist perspective informed our understanding of how overlapping identities such as race, gender, and country of origin shape individuals' healthcare experiences. IKT is a collaborative process that emphasizes partnership between researchers and knowledge users throughout all stages of research [37]. IKT informed how we identified priorities, designed methods, interpreted data, and shared results [37]. Unlike traditional models that position researchers as the primary producers of knowledge, IKT recognizes the expertise of both researchers and community partners, aiming to minimize power differentials and promote equitable, contextually relevant knowledge creation [38].

With these guiding frameworks, the content that was shared during the social media campaign was initially designed by H.D (quote posts), G.Y (image posts), and W.Z (videos/reels), who drew upon findings from the *EndoPhoto Study* under the guidance of the content lead (H.N). Before final approval, content, including images and associated captions, was reviewed and discussed with the broader research team during bi-weekly team meetings and bi-monthly PRAB meetings.

Campaign Goals

Our main goal for the social media campaign was to share key research findings from the *EndoPhoto Study,* increase awareness of Asian women's experiences living with endometriosis, and direct viewers to our newly developed interactive EndoPhoto website [39]. The website showcases images submitted by *EndoPhoto Study* participants alongside general endometriosis and pelvic pain health information and resources co-created by researchers, clinicians, and patient partners. Our adaptation of the frameworks for a trauma-informed approach informed the formation of partnerships, development of content, and moderation of digital spaces throughout the campaign. In conducting the campaign, we aimed to foster a sense of validation, emotional safety, and support, for both previous research participants and audiences, and minimize their risk of re-traumatization. The campaign's central message, *your pain is real, you are believed, and you are not alone*, matched the overall messaging of content produced by our team and shared on the website. Additionally, this message was consistently emphasized across all digital platforms.

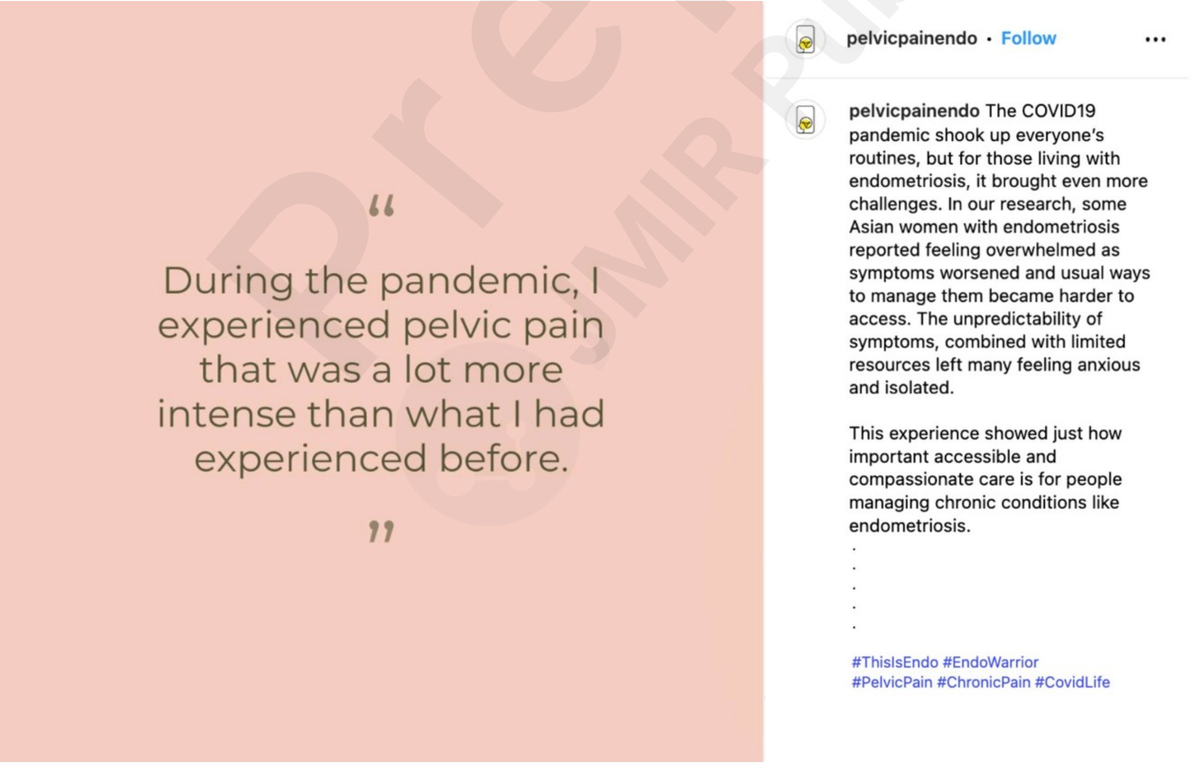
Campaign Launch

We launched the campaign in March 2025 to coincide with Endometriosis Awareness Month. The Endometriosis and Pelvic Pain Laboratory had a previously established Instagram profile (@pelvicpainendo) with approximately 1000 followers before the campaign, and a Pinterest account (@pelvicpainendo), which was created for this and future campaigns. These platforms aligned with the campaign's visual and trauma-informed goals, offering features such as content warnings and comment moderation. Content shared was similar for both platforms but adapted in format to best utilize each platform's features. For example, Instagram's reels, stories, and carousels supported a balance of educational content and personal narratives, while Pinterest enabled thematic curation through boards and infographics. Pinterest also has a different set of users and is more aligned with artistic communities. Please note, we chose to share the images of content only from Instagram in this manuscript due to easy viewability of the entire post from Instagram versus Pinterest. In total, the campaign featured 41 posts between March 1st and March 31st across Instagram and Pinterest. All the posts incorporated the widely recognised community hashtag #ThisIsEndo, supplemented by topic-relevant hashtags. The team deliberately declined to create a new hashtag for the campaign, given the objective of using social media as a mechanism to reach a wide audience of users rather than share isolated content with limited reach.

Considering Pinterest policies restrict the use of paid advertisements for new accounts, a soft launch on the platform began on February 19th, 2025. Because of this, we published several posts prior to the full campaign, which allowed us to generate early interest, establish baseline engagement, and be considered an established account.

Early Challenges

Early in the campaign (March 3, 2025), our Instagram account was flagged by the Meta algorithm into a category called ‘Health and Wellness.’ This category was designed by Meta to reduce ‘negative’ advertising and monetization of organizations that were using advertising to sell products and services. Although we were not advertising products, our placement in this category limited what content could be promoted. Posts that included any features flagged as ‘negative’ by the algorithm were prohibited from being advertised. Considering that endometriosis experiences often involve challenges, our pre-planned content required significant changes in order to meet the algorithm’s criteria. Figure 1 shows the original post that was flagged.



“During the pandemic, I experienced pelvic pain that was a lot more intense than what I had experienced before.”

pelvicpainendo The COVID19 pandemic shook up everyone’s routines, but for those living with endometriosis, it brought even more challenges. In our research, some Asian women with endometriosis reported feeling overwhelmed as symptoms worsened and usual ways to manage them became harder to access. The unpredictability of symptoms, combined with limited resources left many feeling anxious and isolated.

This experience showed just how important accessible and compassionate care is for people managing chronic conditions like endometriosis.

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#ThisIsEndo #EndoWarrior #PelvicPain #ChronicPain #CovidLife

Figure 1. Original post on Instagram that was flagged by the algorithm as being ‘negative’.

Incorporating Trauma-Informed Principles

Based on the previously mentioned frameworks, we adapted our campaign to focus on the following principles of a trauma-informed approach: (1) support and collaboration; (2) trustworthiness and transparency; (3) safety; (4) empowerment and voice; and (5) cultural and gender sensitivity. In the following section, we discuss how we enacted these aspects. Please note, although these aspects are presented as being separate ideas, many have overlapping and related actions. Table 1 summarizes the approaches we took when developing this campaign.

Table 1. Our Approach to trauma-informed principles

Trauma informed guiding principle	**Our approach**	**Considerations**
Collaboration and mutuality	• Co-designed with PRAB members and diverse interdisciplinary team of experts • Incorporated feedback throughout process • Shared content from lived experiences • Engaged with known influencers to promote content	• More time may be needed to include all team members' feedback and ideas, and thus longer timeline to project completion
Trustworthiness and transparency	• Shared our research team positionality statement • Created transparency around funding and what this meant • Informed participants of purpose/content when consenting to original study • Obtained explicit and ongoing consent related to use of data	• Viewers may have personal negative feelings about funders • Additional human resources needed to gather confirmatory consent from participants • Opt-out versus opt-in could incidentally include photos that participants did not want to share, but did not see the email
Safety	• Used gentle colors in content creation • Moderated comments • Included content warnings • Grouped images and shared select images • Engaged with specific platforms (Instagram and Pinterest) • De-identified images	• Participants may provide images that violate design principles and gentle colors • Additional human resources required for moderating comments • Not including all experiences captured as many images were not selected • Not as wide reach due to including only select friendly platforms • Temporary stories reduce reach • De-identifying images or using the photos without the original captions may alter the intended goal and impact of the image, limiting participant creativity
Empowerment & voice	• Used friendly, non-stigmatizing, and everyday language when captioning photos • Leveraged platforms to amplify voices	• Potential for less reach when only using select platforms and also reach to certain groups (e.g., older people who more often use Facebook) might be reduced; demographics can vary across platforms • Participant caption not always included with photograph, which could change intended meaning

		- Focus on 'positive' aspects due to algorithm could represent a one-sided or skewed representation of experiences - Sharing content that is 'trauma-informed' may incidentally portray the information and experiences as being neutral or positive
Cultural and Gender Sensitivity	- Ensured sharing only 'positive' language and experiences due to the Meta algorithm - Avoided stereotypes and stigmatization - Avoided hyper-gendered content	- Excluding images that depicted too much pain or had identifying information may reduce the transparency of people's experiences - Some people might feel the non-hyper-gendered colors and content do not relate to them as much

1. Support and Collaboration

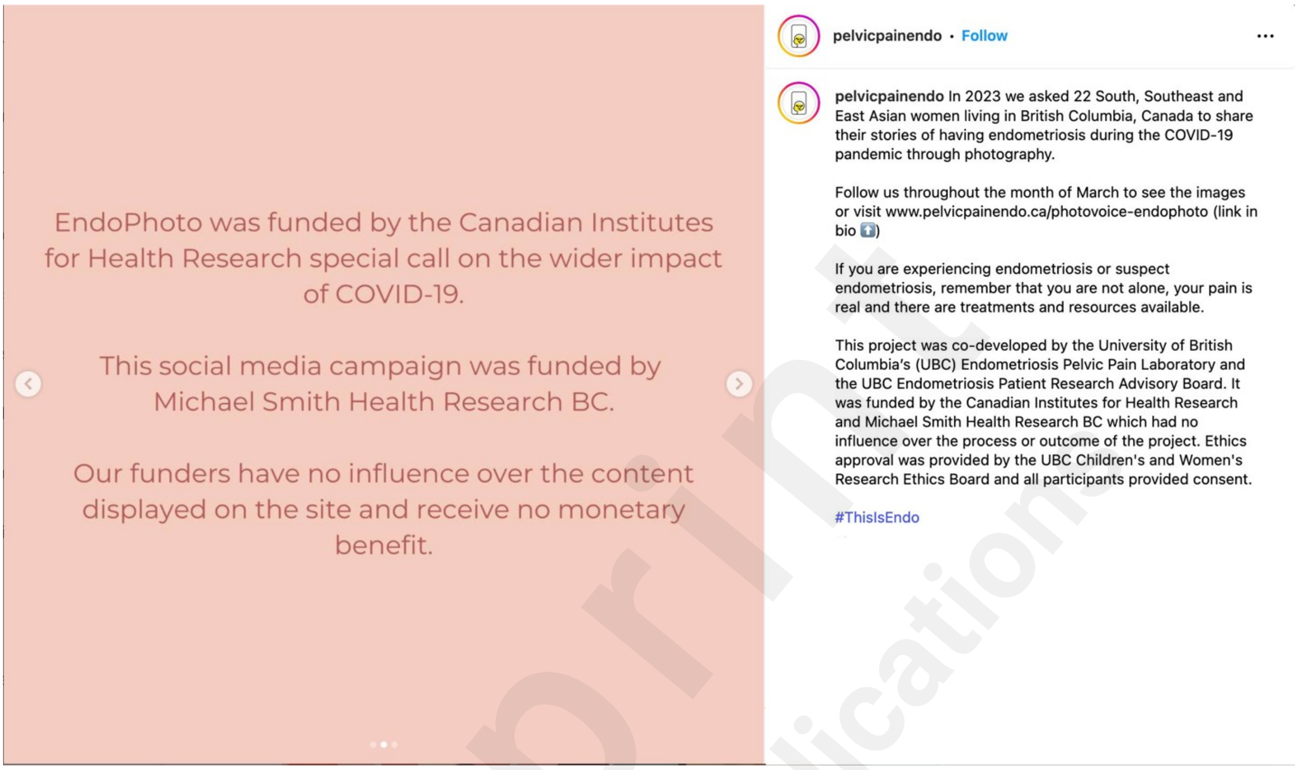
We defined support and collaboration as intentional actions taken to meaningfully engage with those with lived experience and others in the community doing similar work. As such, PRAB members defined campaign goals, reviewed and co-developed content, and ensured that materials were safe, empowering, and contextually relevant. The PRAB involvement created an opportunity for safety by foregrounding lived experience and ensuring that social media content reflected their values and perspectives. The campaign was also managed by an external communications agency, where the partner and social media specialist (S.L) was someone with lived experience of endometriosis who simultaneously acted as a member of the PRAB.

We also took a collaborative approach to promoting the campaign, leveraging our known and existing networks. This involved approaching familiar social media accounts, including science communicators, non-profit organisations, news outlets, and independent influencers, and asking them to share and promote our content. The campaign also partnered with advocacy organizations, including The Endometriosis Network Canada, to broaden outreach and ensure alignment with existing efforts in the endometriosis advocacy landscape.

2. Trustworthiness and Transparency

We considered trustworthiness and transparency aspects that involved disclosing who is behind the campaign, our goals, funders and where the content came from, as well as being transparent with the participants of the *EndoPhoto Study* about how we were using their data. (Figure

2)



EndoPhoto was funded by the Canadian Institutes for Health Research special call on the wider impact of COVID-19.

This social media campaign was funded by Michael Smith Health Research BC.

Our funders have no influence over the content displayed on the site and receive no monetary benefit.

pelvicpainendo In 2023 we asked 22 South, Southeast and East Asian women living in British Columbia, Canada to share their stories of having endometriosis during the COVID-19 pandemic through photography.

Follow us throughout the month of March to see the images or visit www.pelvicpainendo.ca/photovoice-endophoto (link in bio ⬆️)

If you are experiencing endometriosis or suspect endometriosis, remember that you are not alone, your pain is real and there are treatments and resources available.

This project was co-developed by the University of British Columbia's (UBC) Endometriosis Pelvic Pain Laboratory and the UBC Endometriosis Patient Research Advisory Board. It was funded by the Canadian Institutes for Health Research and Michael Smith Health Research BC which had no influence over the process or outcome of the project. Ethics approval was provided by the UBC Children's and Women's Research Ethics Board and all participants provided consent.

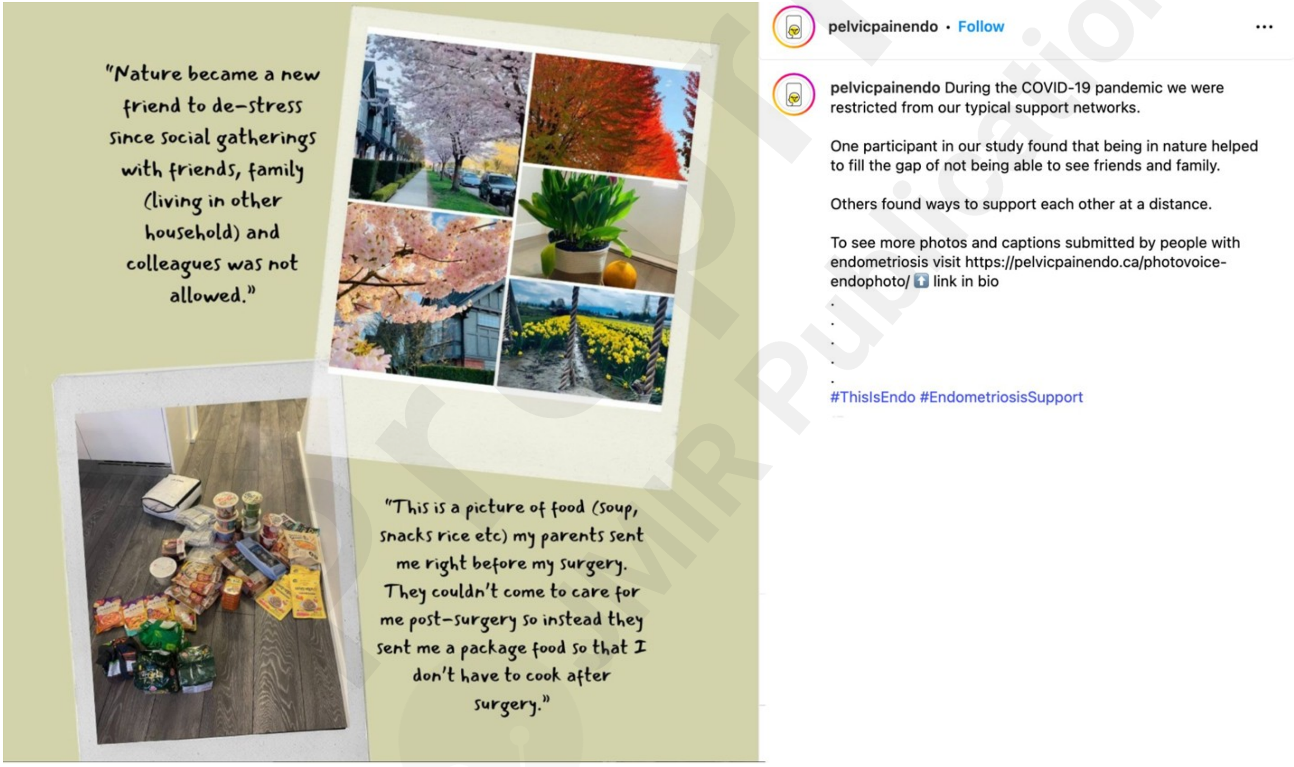
#ThisIsEndo

Figure 2. Instagram post explaining our research funders.

All participants in the *EndoPhoto Study* provided explicit informed consent to have their photographs used in a social media campaign. We also provided participants with a lay summary of the results via email that included an ‘action required’ message, showing participants the website [39] where photographs had been included in a virtual gallery, and gave participants the ability to withdraw their photographs and quotes at any point. We also strongly encouraged *EndoPhoto Study* participants to review their photos to ensure they were comfortable with these being shared. No participants opted out of their photos being shared.

3. Safety

When considering safety, we centered the principles of privacy and confidentiality from Josephs et al. [35], and prioritized safety and preventing re-traumatization of participants of the *EndoPhoto Study* whose images we shared. First, to maintain the emotional safety of those who participated in the research and shared their photos, we intentionally curated visual content in a way that still honored participants' lived experiences. We did this by choosing images that were not intimately personal, or overtly medical in nature, or depicted individual people in moments of visible distress. Instead, the campaign showcased strength-based visuals such as nature scenes, symbolic objects, and comforting moments, like participants' pets offering support (see Figures 3 and 4). When possible, images were paired with participant-authored captions that emphasized resilience, healing, and other personally meaningful themes to balance narrative authenticity with emotional safety. We also intentionally blurred faces to protect identities, or selected images that further supported anonymity, such as the use of a surgical mask (as seen in Figures 4 and 5).



pelvicpainendo During the COVID-19 pandemic we were restricted from our typical support networks.

One participant in our study found that being in nature helped to fill the gap of not being able to see friends and family.

Others found ways to support each other at a distance.

To see more photos and captions submitted by people with endometriosis visit https://pelvicpainendo.ca/photovoice-endophoto/ ⬆️ link in bio
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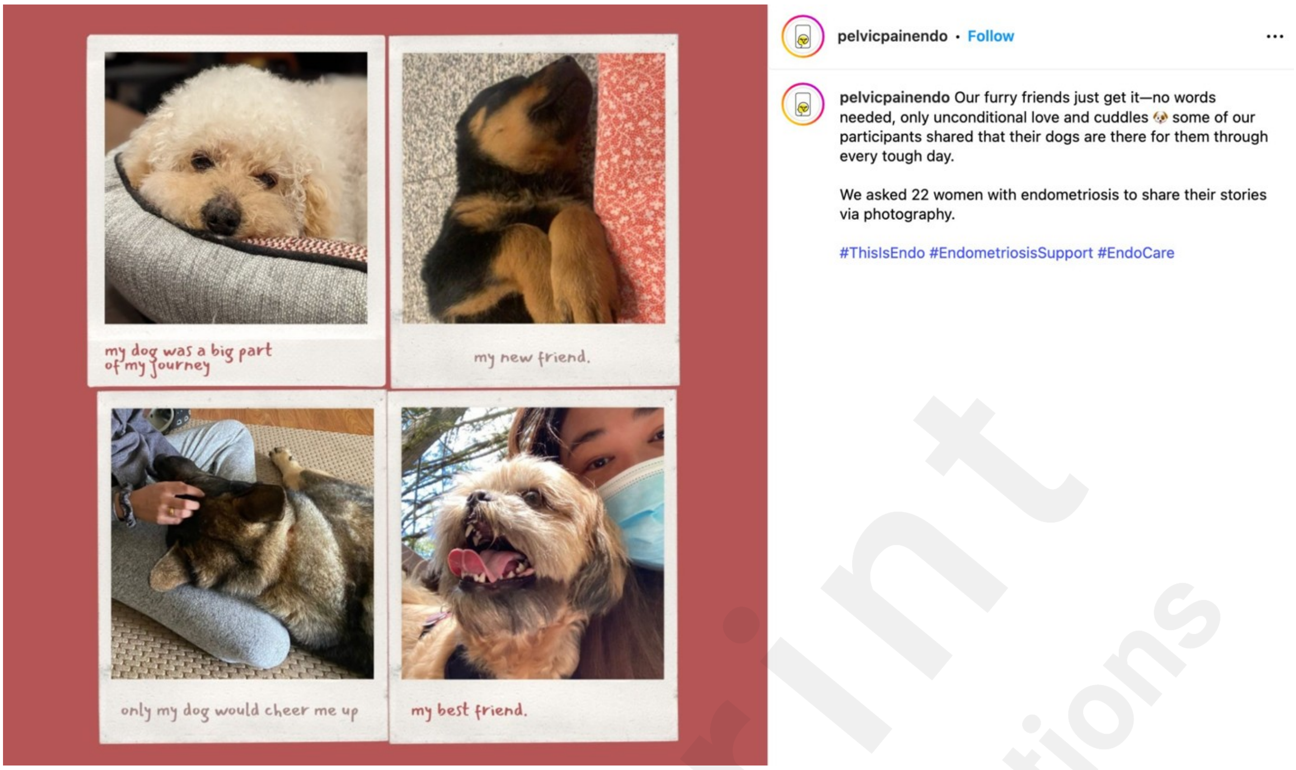
#ThisIsEndo #EndometriosisSupport

Figure 3. Collage of nature and social support.



pelvicpainendo Our furry friends just get it—no words needed, only unconditional love and cuddles 🐶 some of our participants shared that their dogs are there for them through every tough day.

We asked 22 women with endometriosis to share their stories via photography.

#ThisIsEndo #EndometriosisSupport #EndoCare

Figure 4. Pets providing comfort.

Second, careful consideration was given to how participant photographs were shared. We opted to present images as collages or grouped images rather than posting them individually (example includes Figure 6). This approach was chosen to minimize the risk of certain photos receiving disproportionately more ‘likes’ or ‘shares’ than others, which could cause distress among some participants who noticed their photos were less ‘liked’.

During the pandemic:
Constant visits to the Emergency.
Unable to manage the pain at home.

No one to take
care of my hair
after surgery

Prescribed
morphine for
the pain

Admitted to ER due to
severe pain related to
endometriosis.

I took this photo to prove
to my employer why I had
to miss work that day.

After surgery:
Painful but happy, hoping
to have some relief.

pelvicpainendo We asked 22 Asian women with endometriosis to share their stories via photography.

Pain, ER visits, surgeries—you are not alone. Here are some snippets and photos different participants submitted about their journey.
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.
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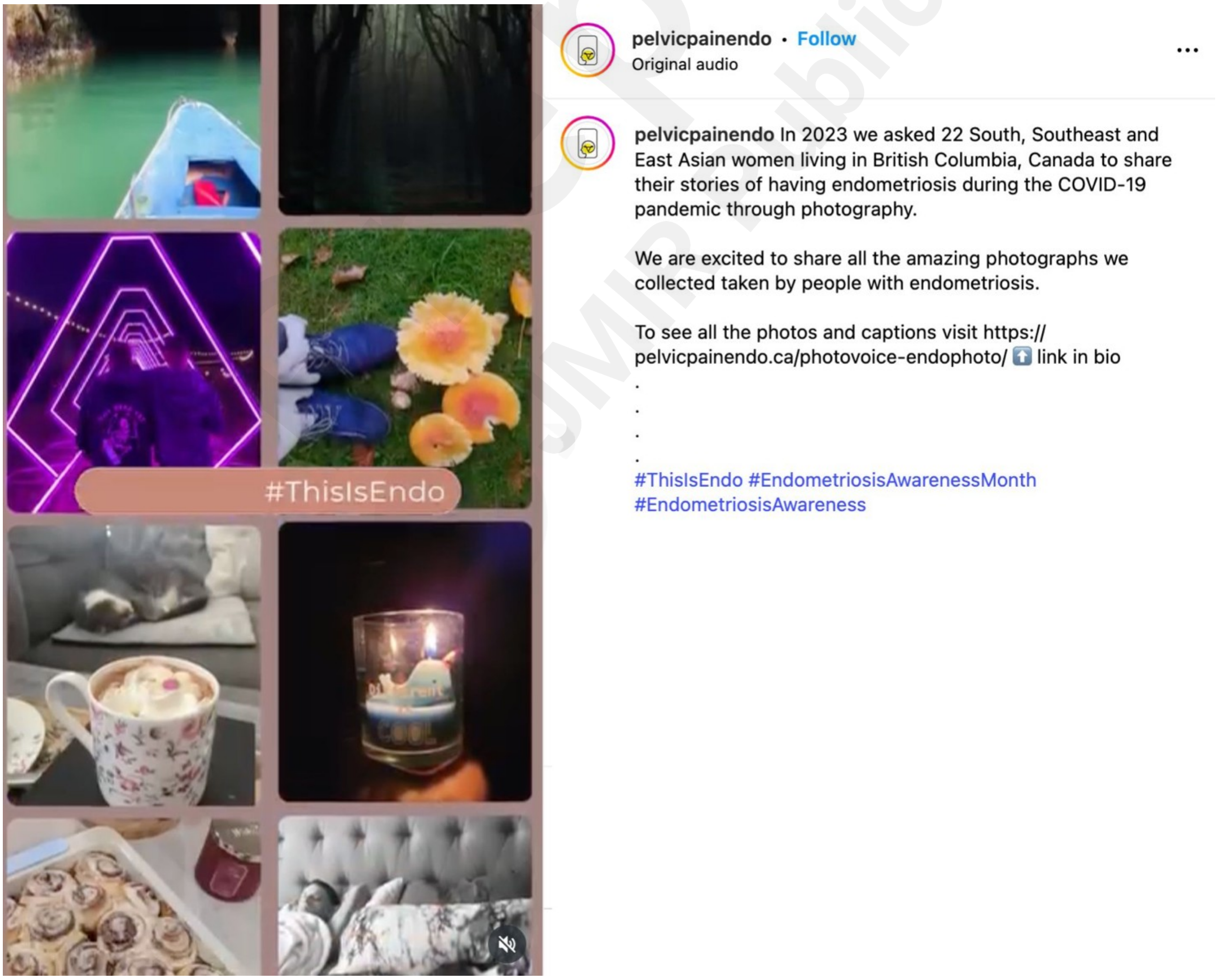
#ThisIsEndo #AsiansWithEndo #EndoAwareness #EndoAsian

Figure 5. Examples of identity protection on Instagram.



pelvicpainendo In 2023 we asked 22 South, Southeast and East Asian women living in British Columbia, Canada to share their stories of having endometriosis during the COVID-19 pandemic through photography.

We are excited to share all the amazing photographs we collected taken by people with endometriosis.

To see all the photos and captions visit https://pelvicpainendo.ca/photovoice-endophoto/ ⬆️ link in bio
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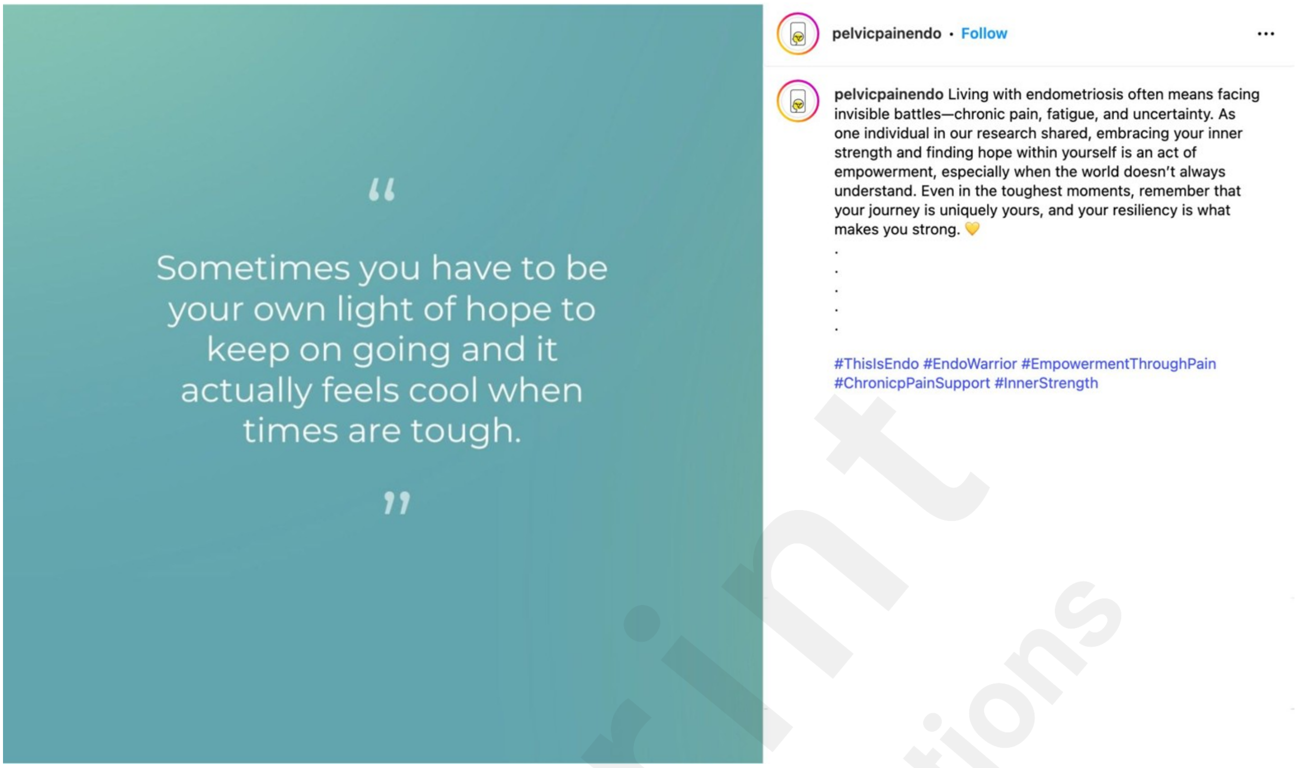
#ThisIsEndo #EndometriosisAwarenessMonth #EndometriosisAwareness

Figure 6. Shared collage of participant photos from an Instagram reel.

Third, based on recommendations from our social media specialist and patient partners, Instagram and Pinterest were specifically chosen as platforms for this campaign, given they are well-suited to image-based storytelling and, anecdotally, were considered less volatile during the dates of the campaign, with lower rates of reproductive-health-online-harassment compared with other well-known platforms. Fourth, elements of safety were further considered through active moderation of comments to identify and remove hate speech, trolling, and unsolicited medical advice; however, we did not find these were an issue in this campaign.

4. Empowerment and Voice

We considered empowerment and voice to focus on ensuring we were truthfully representing participant experiences of the *EndoPhoto Study*, opting to share content that was more strengths-based and showcased resilience and empowerment, while also sharing the reality of experiencing endometriosis (Figure 7 and 8). In order to accomplish this, we used non-stigmatizing, everyday language, and often incorporated participants’ own words in explaining the context of the photos (Figure 9).



“

Sometimes you have to be your own light of hope to keep on going and it actually feels cool when times are tough.

”

pelvicpainendo Living with endometriosis often means facing invisible battles—chronic pain, fatigue, and uncertainty. As one individual in our research shared, embracing your inner strength and finding hope within yourself is an act of empowerment, especially when the world doesn't always understand. Even in the toughest moments, remember that your journey is uniquely yours, and your resiliency is what makes you strong. 💛

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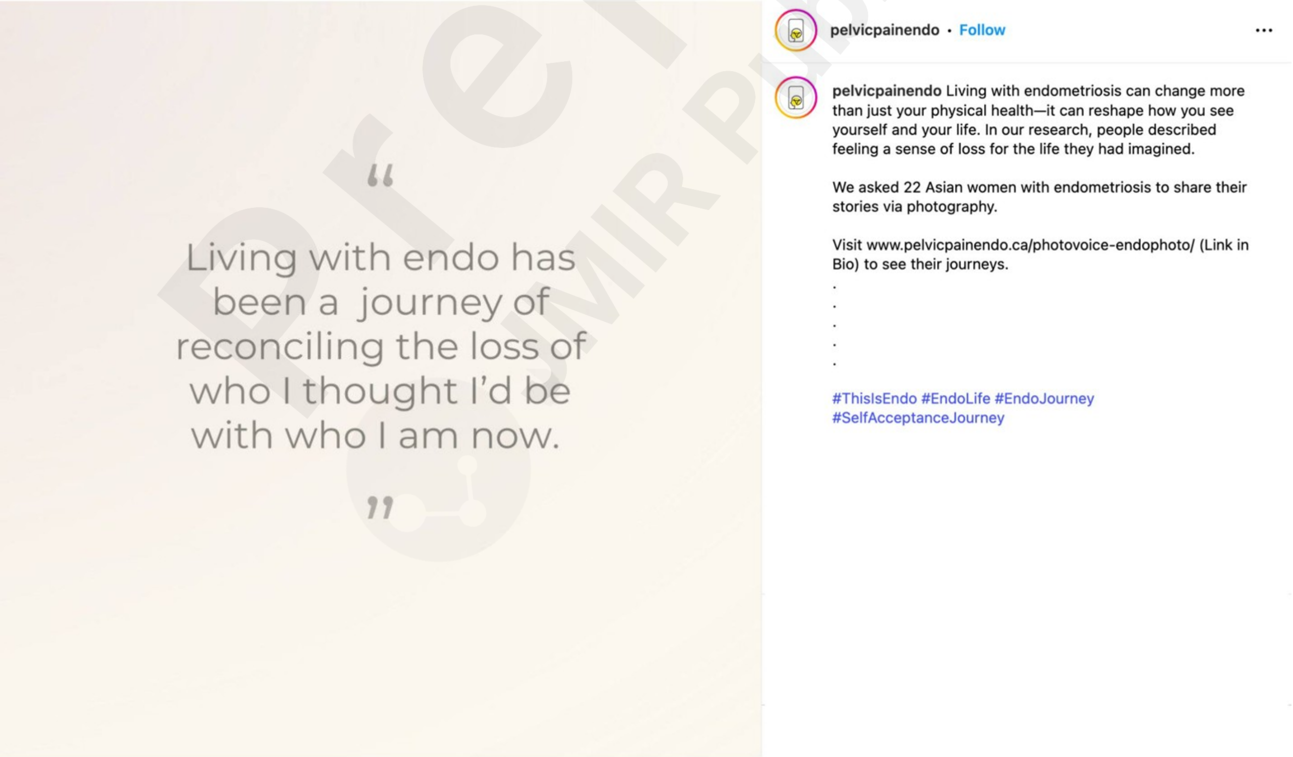
#ThisIsEndo #EndoWarrior #EmpowermentThroughPain #ChronicpPainSupport #InnerStrength

Figure 7. Quote-based content on strength while living with endometriosis.



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Living with endo has been a journey of reconciling the loss of who I thought I'd be with who I am now.

”

pelvicpainendo Living with endometriosis can change more than just your physical health—it can reshape how you see yourself and your life. In our research, people described feeling a sense of loss for the life they had imagined.

We asked 22 Asian women with endometriosis to share their stories via photography.

Visit www.pelvicpainendo.ca/photovoice-endophoto/ (Link in Bio) to see their journeys.

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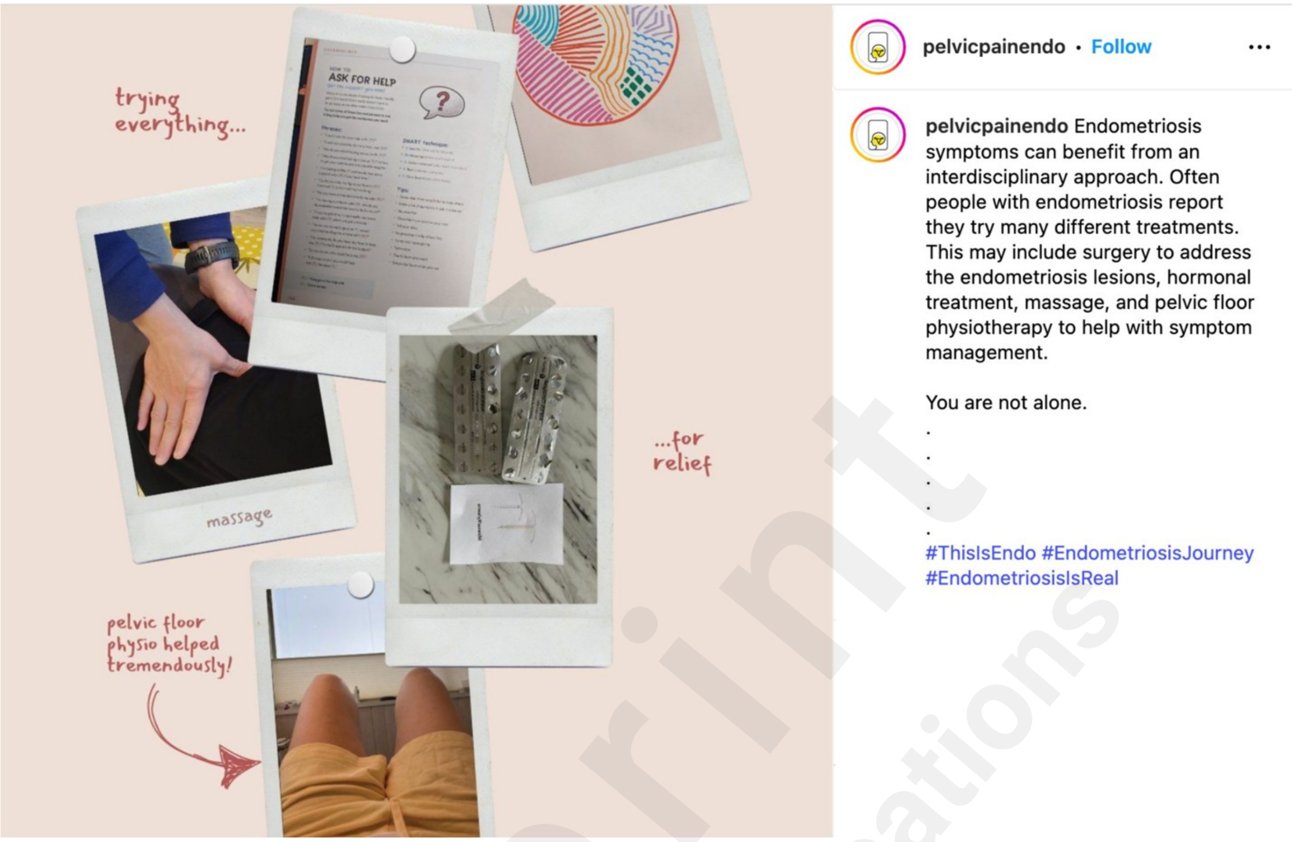
#ThisIsEndo #EndoLife #EndoJourney #SelfAcceptanceJourney

Figure 8. Quote based content on living with endometriosis.



pelvicpainendo

pelvicpainendo Endometriosis symptoms can benefit from an interdisciplinary approach. Often people with endometriosis report they try many different treatments. This may include surgery to address the endometriosis lesions, hormonal treatment, massage, and pelvic floor physiotherapy to help with symptom management.

You are not alone.
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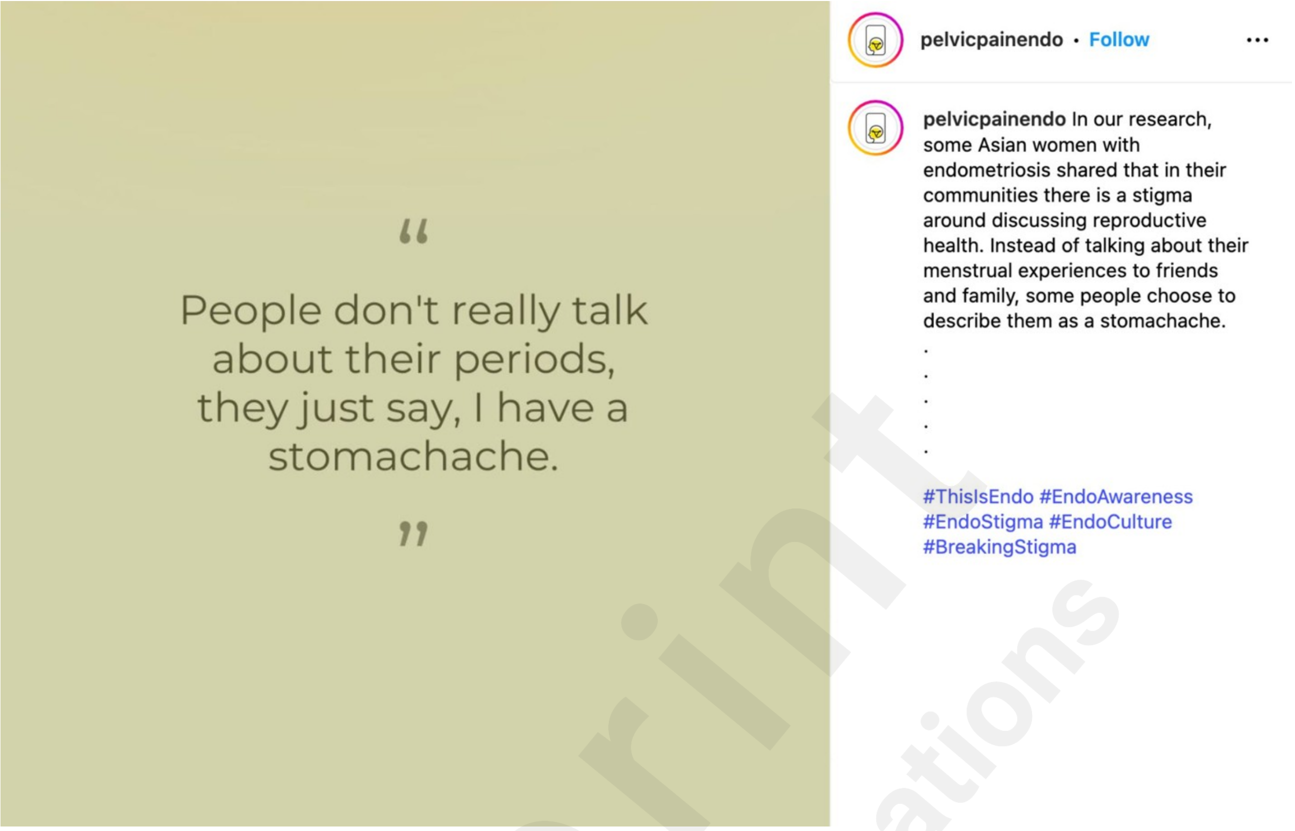
#ThisIsEndo #EndometriosisJourney #EndometriosisIsReal

Figure 9. Everyday language in caption.

By integrating visual narratives with participant-authored captions, the campaign created opportunities for individuals to reclaim agency in narrating their healthcare experiences, particularly where medical and workplace systems had previously been invalidating. For example, one post focused on how cultural taboos surrounding menstruation can lead to a lack of communication and discussion of pain. This caption drew attention to the compounding effects of stress, isolation, and reduced access to care (Figure 10). Together, we intended these posts to help humanize the lived realities of people with endometriosis, while fostering empathy, reducing stigma, and encouraging public dialogue.



"People don't really talk about their periods, they just say, I have a stomachache."

pelvicpainendo • Follow

pelvicpainendo In our research, some Asian women with endometriosis shared that in their communities there is a stigma around discussing reproductive health. Instead of talking about their menstrual experiences to friends and family, some people choose to describe them as a stomachache.
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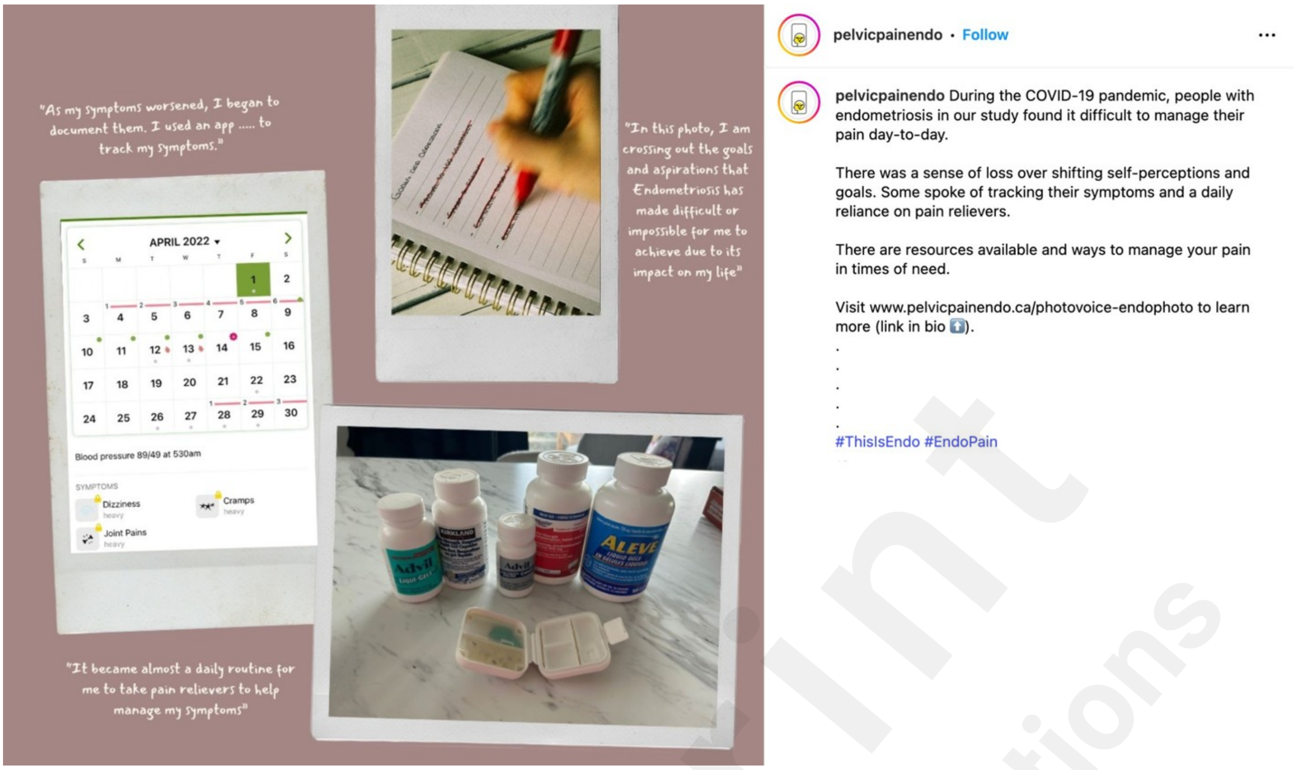
#ThisIsEndo #EndoAwareness #EndoStigma #EndoCulture #BreakingStigma

Figure 10. Content highlighting cultural taboos around menstruation.

5. Cultural and Gender Sensitivity

Striving for cultural and gender sensitivity, we carefully curated content to avoid sensationalism, incidental stigmatization, stereotypes, clinical or diagnostic language, and potentially distressing imagery. The campaign content aimed to disrupt the silence surrounding pelvic pain and endometriosis, particularly the effects of medical dismissal, social isolation, and cultural stigma. Considering the gendered nature of endometriosis—and although all the participants whose photographs we shared identified as cisgender women—we intentionally avoided making the content hyper-feminized or gendered towards women exclusively. We also aimed to avoid perpetuating stereotypes and hyper-feminized content by choosing a colour palette that was both intentionally calming, while not overly gendered (Figure 11).



pelvicpainendo During the COVID-19 pandemic, people with endometriosis in our study found it difficult to manage their pain day-to-day.

There was a sense of loss over shifting self-perceptions and goals. Some spoke of tracking their symptoms and a daily reliance on pain relievers.

There are resources available and ways to manage your pain in times of need.

Visit www.pelvicpainendo.ca/photovoice-endophoto to learn more (link in bio ⬆️).

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#ThisIsEndo #EndoPain

Figure 11. Avoidance of hyper-gendered or stigmatizing language or colours

Increasing Reach Through Advertisements

To increase the reach of the social media campaign, that is, the number of people who have seen online content at least once, we paid for advertisements on both platforms with a total budget of $3,000 CAD. For our paid advertisements, a detailed audience profile was developed to guide content creation and ad targeting. The intended audience included individuals who either had a confirmed or suspected endometriosis diagnosis, were assigned female at birth, of reproductive age (inclusive of all gender identities, sexual orientations, and relationship statuses), with moderate levels of health literacy, and understood English. High-frequency search terms related to pelvic pain and endometriosis were identified to optimize advertisement discoverability (for example, pain, symptoms, selfcare, journey, resilience, reflection).

Measuring Campaign Engagement

We used platform-integrated analytics (Instagram Insights and Pinterest Analytics) to monitor primary performance indicators. For consolidated definitions of terms used to measure engagement see Table 2. Metrics included reach, engagement (likes, shares, comments, profile visits, and link clicks), and website page visits. We reviewed these metrics throughout the campaign to enable real-time optimization of posting frequency and timing, as well as advertising spend based on platform recommendations and observed audience behaviour. Over the 31-day campaign, the website attracted 6,326 unique users. Instagram generated both the greatest volume of sessions and the longest dwell time. Pinterest's shorter dwell times likely reflected the account’s infancy (new profile, first campaign, algorithmic learning period). The high number of impressions was largely attributed to three posts that ‘went viral’ during the campaign, meaning they received over 1 million views each (Figure 12, 13, and 14). These posts reflected messages of support, resiliency, and healing. Ads drew in the largest number of platform users to the page, accounting for most of the sessions and engagement, with arguably the least human resources (for engagement measures, see Table 3).

pelvicpainendo In 2023 we asked 22 South, Southeast and East Asian women living in British Columbia, Canada to share their stories of having endometriosis during the COVID-19 pandemic through photography.

Though it looked a little different during the pandemic, connection was found to be an essential component of the lives of people with endometriosis.

Many described both the benefits and challenges of navigating the social world with endometriosis.

To see all the photos and captions submitted by people with endometriosis visit https://pelvicpainendo.ca/photovoice-endophoto/ ⬆️ link in bio
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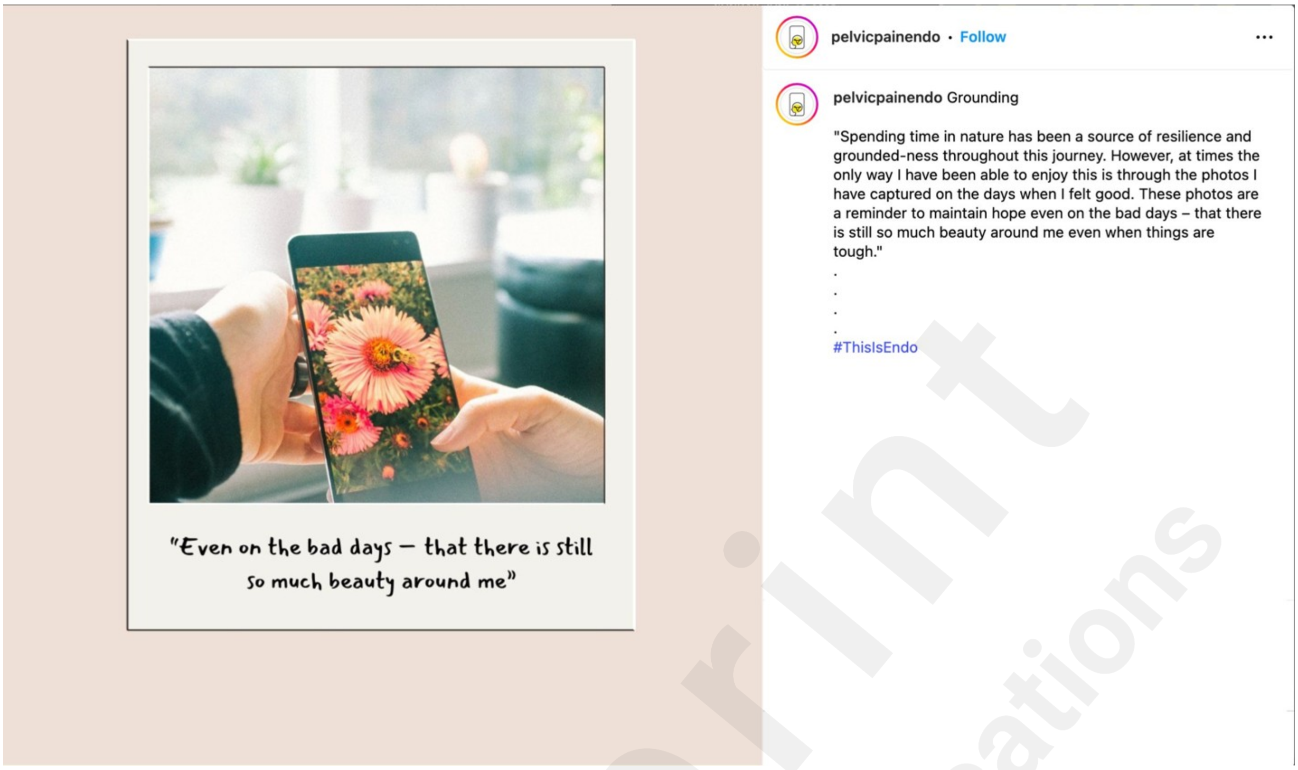
#ThisIsEndo #EndometriosisSupport #EndoStrong

Figure 12. Still image from a reel that ‘went viral’ during the campaign.



pelvicpainendo Grounding

"Spending time in nature has been a source of resilience and grounded-ness throughout this journey. However, at times the only way I have been able to enjoy this is through the photos I have captured on the days when I felt good. These photos are a reminder to maintain hope even on the bad days – that there is still so much beauty around me even when things are tough."

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#ThisIsEndo

Figure 13. Post that ‘went viral’ during the campaign.

pelvicpainendo • Follow
Original audio

pelvicpainendo Despite the challenges faced by people with endometriosis in our study, many described a strong sense of resiliency, noting that there was hope for the future.

Visit www.pelvicpainendo.ca/photovoice-endophoto (link in bio)
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#ThisIsEndo #Resilient #Hope

Figure 14. Still image taken from the second reel that ‘went viral’ during the campaign.

Table 2. Consolidated Definitions of Terms used to Describe Campaign Engagement

Term	**Definition**
Reach	Reach is defined as the number of unique users who have seen online content at least once
Engagement	Likes, shares, comments, profile visits, and link clicks
Impressions	The total number of times the content was presented to potential users on screen
Volume of sessions	Number of visits to the website
Dwell Time	How long people view the content for
Click through rates	Percentage of people who click on a link to the website within your content

Table 3. Engagement Results from Instagram and Pinterest

Platform	**Metric**	**Value**
Overall	Total Social Impressions	8,540,528

Instagram	Engagement*	6.23%
	Ad Impressions	7,941,457
	Ads Reach	3,550,309
Pinterest	Total Impressions	581,081
	Total Engagement	5,528

*Please note, on Instagram for 'engagement' anything above 6% is considered high engagement and on Pinterest anything between 1% - 2% is considered average engagement [40, 41].

Discussion and Lessons Learned

This manuscript describes the development of a trauma-informed social media campaign designed to disseminate findings from the *EndoPhoto Study*, which explored the experiences of South, East, and Southeast Asian women living with endometriosis in Canada during the COVID-19 pandemic. We intend for this work to serve as a guide for others seeking to share their research findings through social media, with broader applicability for those interested in trauma-informed content creation. By integrating trauma-informed principles, the campaign not only centered the voices of underrepresented communities but also demonstrated the potential for digital platforms to promote trauma-informed knowledge dissemination.

Upon reviewing our engagement metrics, we found that quote-based content (opposed to image-based content) produced the highest click-through rates on both platforms; announcement posts (e.g., study overview) generated the greatest engagement; and Instagram ads, particularly quote graphics, outperformed other creative formats. Although it is challenging to measure how the content truly impacted viewers, some of these indicators may provide insight into the meaning viewers garnered from the content. For example, the option to 'save' content on Pinterest may suggest that some of the posts resonated enough for viewers to want to share or review the content at a later date, perhaps indicating a feeling of added value.

While trauma-informed principles are increasingly recognized in clinical and community settings, their application to digital media, particularly social media, remains largely underexplored.

This tutorial highlights how principles such as collaboration, safety, trustworthiness, voice, and cultural and gender sensitivity can be applied in online spaces to mitigate harm and increase engagement. Additionally, this project helps to address the critical gap in the representation of racialized individuals, particularly Asian women, in endometriosis advocacy and online discourse.

One unanticipated lesson learned was the suppression of women’s sexual and reproductive health information on Meta platforms. A recent report published by Center for Intimacy Justice [42] highlighted that a bias exists on major Meta platforms, where organizations experienced their content and advertisements related to women’s sexual and reproductive health, including fertility and pelvic health, being censored and over-moderated. Social media algorithms, driven by artificial intelligence, limited content visibility when posts included ‘sensitive’ health-related terms or were deemed to violate vague platform policies such as Meta’s ‘Personal Health and Appearance’ guidelines. This report aligned with our experience, as our content was flagged as not aligning with community standards due to its ‘negative’ nature and association with healthcare. This flag necessitated a shift toward resilience-focused and positively framed messaging only, which may have constrained the full scope of participant narratives.

Strengths of the Campaign

One of the campaign's primary strengths was its collaborative, interdisciplinary approach. The involvement of patient partners through the PRAB ensured content authenticity and emotional safety. As well, working with a social media specialist was invaluable in navigating the landscape of digital media. The campaign also benefited from sufficient funding, allowing strategic investment in high-performing ad formats and continuous optimization based on analytics. Considering the expertise of the team, content development led by those with lived, clinical, and research experience added legitimacy, credibility, and multiple perspectives that countered misinformation in digital health spaces. Importantly, the campaign filled a representational void by centering the narratives of South, East, and Southeast Asian individuals with endometriosis, a demographic historically underrepresented in both research and advocacy.

Limitations of the Campaign

Considering platform selection was intentional, using only Instagram and Pinterest (chosen for their visual nature and perceived safety) may have excluded audiences who primarily engage with platforms like TikTok, X (formerly Twitter), or Facebook. Additionally, the metrics used to gauge success, such as views, impressions, and likes, offer limited insight into true impact. While some posts featuring animals gained viral traction, it is unclear whether the viral nature was due to their relevance to endometriosis or due to the important role that animals can play in people's lives, prompting questions about whether high engagement with content truly reflected increased awareness or understanding of endometriosis, specifically.

Key Takeaways

- Trauma-informed principles can be adapted for digital health communication and effectively applied in social media campaigns.
- Posts that featured quotes, support networks (including pets), and announcements consistently maximized engagement, suggesting these formats may be prioritized to ensure engagement.
- Early budget reallocation toward viral creative assets improved cost-efficiency.
- Paid advertisements created opportunities for ensuring wider reach and may be helpful in providing opportunities for content to be viewed by a larger audience.
- Inclusive online storytelling that prioritizes participant voice and emotional safety resonates with audiences and supports effective knowledge translation.
- Algorithmic biases targeted toward women's sexual and reproductive health may necessitate creativity to avoid being flagged or framing messaging in 'positive' ways. This can ensure wider reach but highlights gender bias within social media platforms.

Acknowledgments: We would like to thank the participants of the *EndoPhoto Study* who shared their stories and experiences with us. Also, we are grateful to have worked with Mass Velocity Media to develop this social media campaign.

Funding: This work was funded by a 2024 Michael Smith Health Research BC Reach Award [RA-2024-04266]

Authors contributions (CRediT):

KM: Funding acquisition, Methodology, Visualization, Supervising, Writing-Original draft, Writing-Review and editing.
HD: Methodology, Visualization, Writing-Original draft, Writing-Review and editing.
AFH: Conceptualization, Funding acquisition, Methodology, Supervision, Writing-Review and editing.
HN: Conceptualization, Data curation, Methodology, Investigation, Resources, Funding acquisition, Project administration, Supervision, Visualization, Writing-Review and editing.
GY: Methodology, Visualization, Writing-Original draft, Writing-Review and editing.
WZ: Methodology, Visualization, Writing-Original draft, Writing-Review and editing.
JS: Funding acquisition, Methodology, Writing-Review and editing.
SL: Formal analysis, Investigation, Methodology, Writing-Review and editing.
AL: Funding acquisition, Methodology, Visualization, Writing-Review and editing.
PJY: Funding acquisition, Methodology, Writing-Review and editing.
NLO: Conceptualization, Methodology, Visualization, Writing-Original draft, Writing-Review and editing, Project administration, Supervision, Funding acquisition.

Conflicts of interest: No major conflicts of interest; however, SL acted as a patient partner and a paid consultant from Mass Velocity Media who contributed to the development and strategies of the social media campaign.

Data availability: Data sharing is not applicable to this article as no data sets were generated or analyzed during this study.

Abbreviations:

IKT: Integrated Knowledge Translation

PRAB: Patient Research Advisory Board

SAMHSA: Substance Abuse and Mental Health Services Administration’s framework

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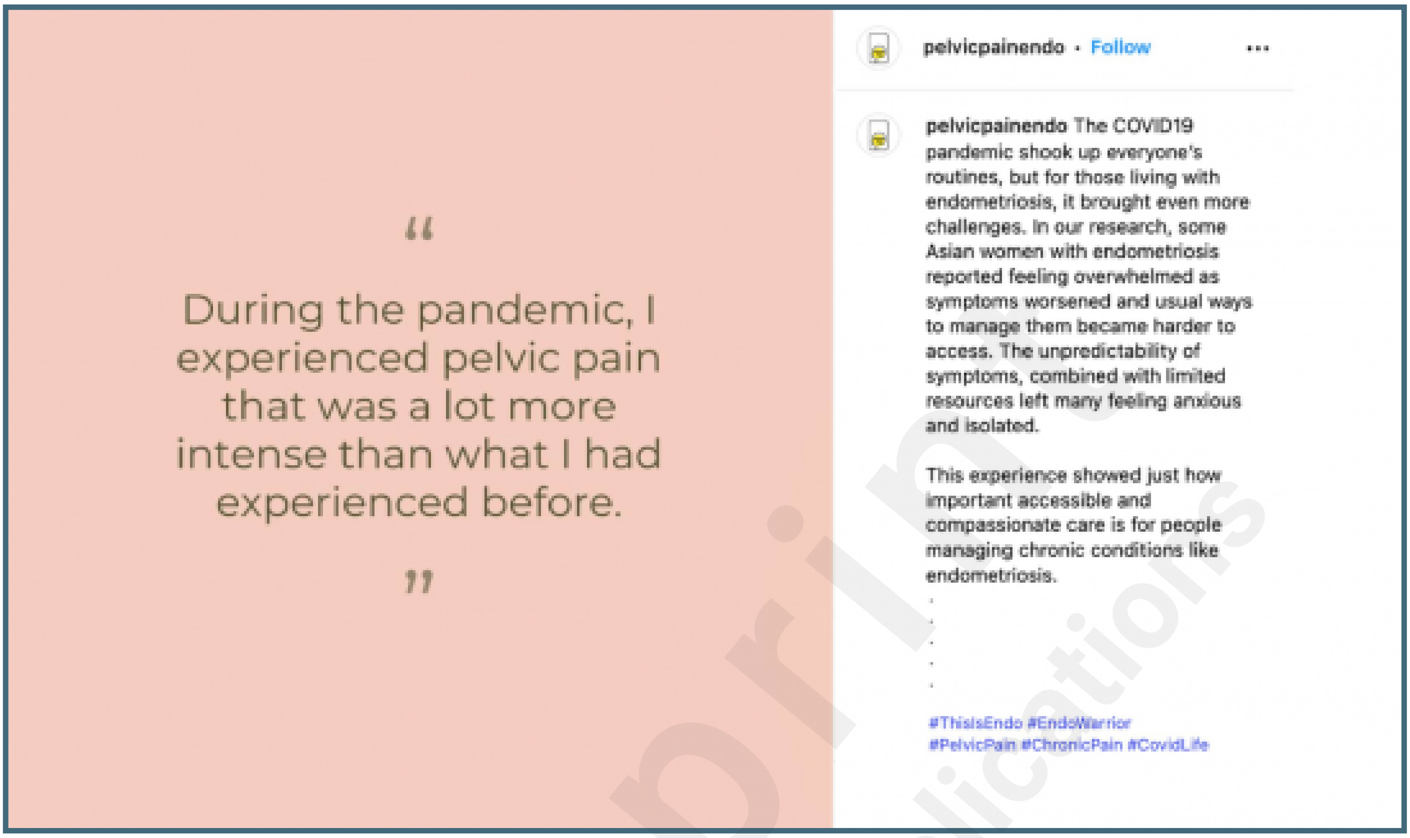
Supplementary Files

Figures

Original post on Instagram that was flagged by the algorithm as being ‘negative’.



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During the pandemic, I experienced pelvic pain that was a lot more intense than what I had experienced before.

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pelvicpainendo The COVID19 pandemic shook up everyone's routines, but for those living with endometriosis, it brought even more challenges. In our research, some Asian women with endometriosis reported feeling overwhelmed as symptoms worsened and usual ways to manage them became harder to access. The unpredictability of symptoms, combined with limited resources left many feeling anxious and isolated.

This experience showed just how important accessible and compassionate care is for people managing chronic conditions like endometriosis.

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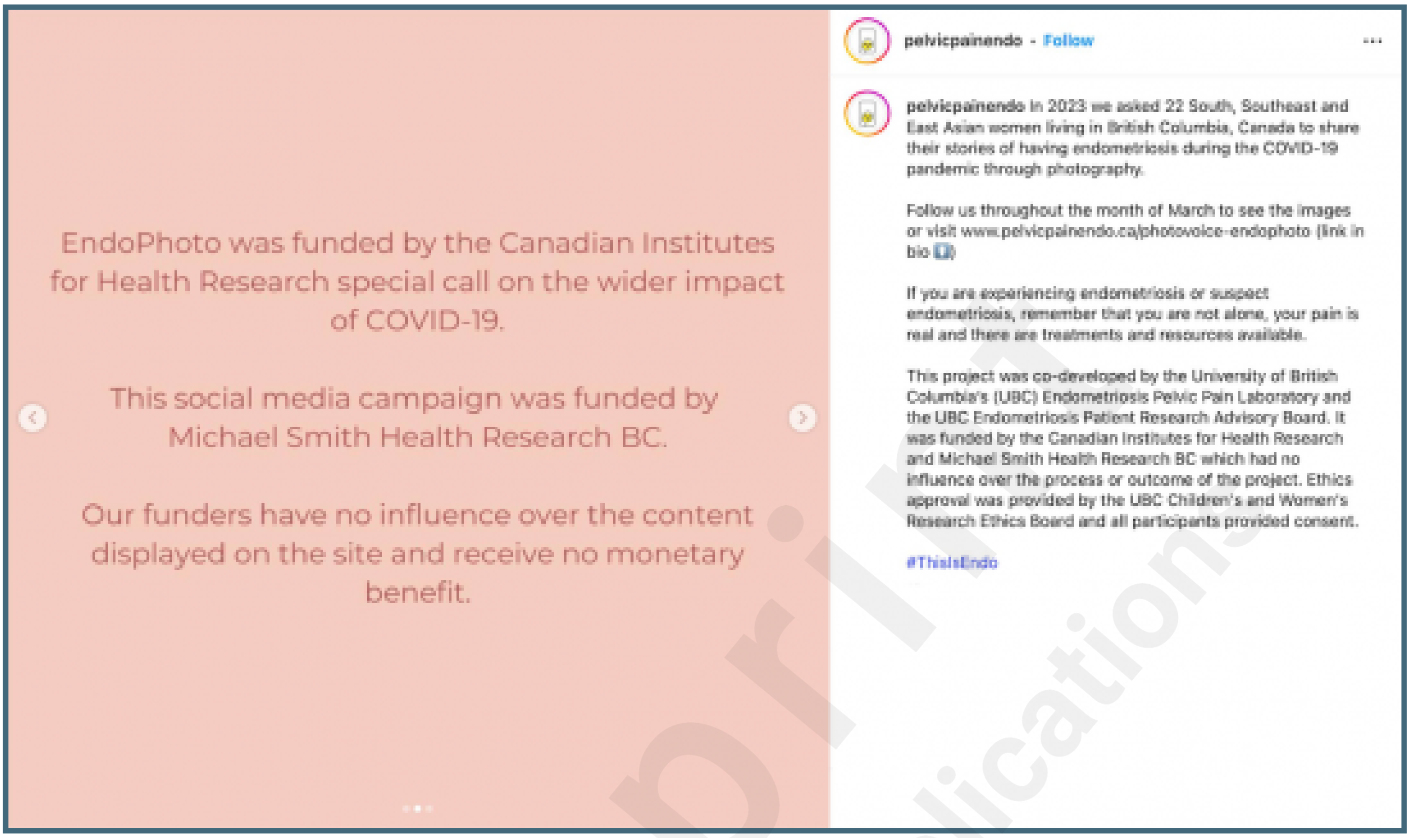
#ThisIsEndo #EndoWarrior #PelvicPain #ChronicPain #CovidLife

Instagram post explaining our research funders.



EndoPhoto was funded by the Canadian Institutes for Health Research special call on the wider impact of COVID-19.

This social media campaign was funded by Michael Smith Health Research BC.

Our funders have no influence over the content displayed on the site and receive no monetary benefit.

pelvicpainendo In 2023 we asked 22 South, Southeast and East Asian women living in British Columbia, Canada to share their stories of having endometriosis during the COVID-19 pandemic through photography.

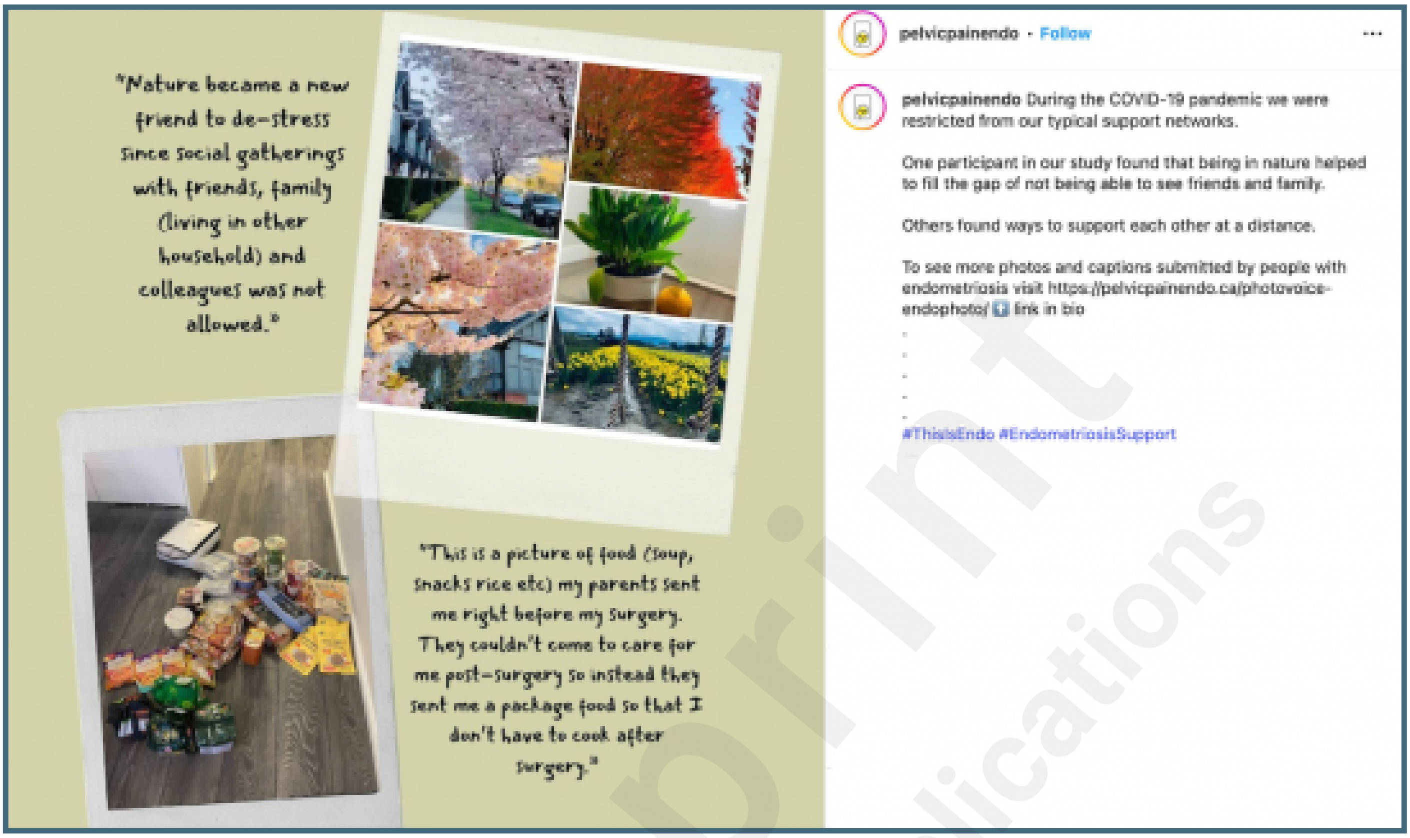
Follow us throughout the month of March to see the images or visit www.pelvicpainendo.ca/photovoice-endophoto (link in bio ⬇)

If you are experiencing endometriosis or suspect endometriosis, remember that you are not alone, your pain is real and there are treatments and resources available.

This project was co-developed by the University of British Columbia's (UBC) Endometriosis Pelvic Pain Laboratory and the UBC Endometriosis Patient Research Advisory Board. It was funded by the Canadian Institutes for Health Research and Michael Smith Health Research BC which had no influence over the process or outcome of the project. Ethics approval was provided by the UBC Children's and Women's Research Ethics Board and all participants provided consent.

#ThisIsEndo

Collage of nature and social support.



"Nature became a new friend to de-stress since social gatherings with friends, family (living in other household) and colleagues was not allowed."

"This is a picture of food (soup, snacks rice etc) my parents sent me right before my surgery. They couldn't come to care for me post-surgery so instead they sent me a package food so that I don't have to cook after surgery."

pelvicpainendo During the COVID-19 pandemic we were restricted from our typical support networks.

One participant in our study found that being in nature helped to fill the gap of not being able to see friends and family.

Others found ways to support each other at a distance.

To see more photos and captions submitted by people with endometriosis visit https://pelvicpainendo.ca/photovoice-endophoto/ ⬆️ link in bio

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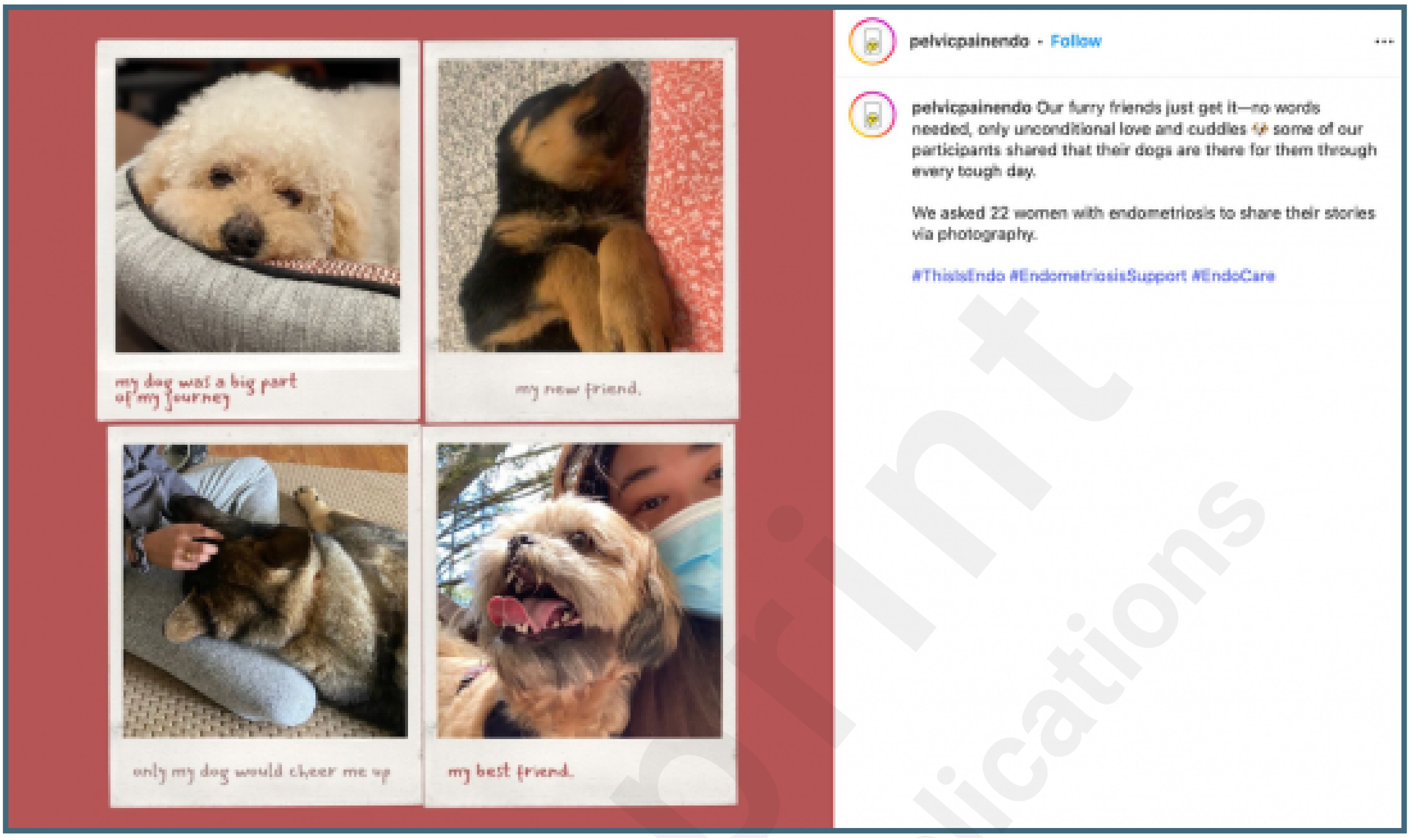
#ThisisEndo #EndometriosisSupport

Pets providing comfort.



pelvicpainendo Our furry friends just get it—no words needed, only unconditional love and cuddles 🐶 some of our participants shared that their dogs are there for them through every tough day.

We asked 22 women with endometriosis to share their stories via photography.

#ThisIsEndo #EndometriosisSupport #EndoCare

Examples of identity protection on Instagram.

pelvicpainendo We asked 22 Asian women with endometriosis to share their stories via photography.

Pain, ER visits, surgeries—you are not alone. Here are some snippets and photos different participants submitted about their journey.

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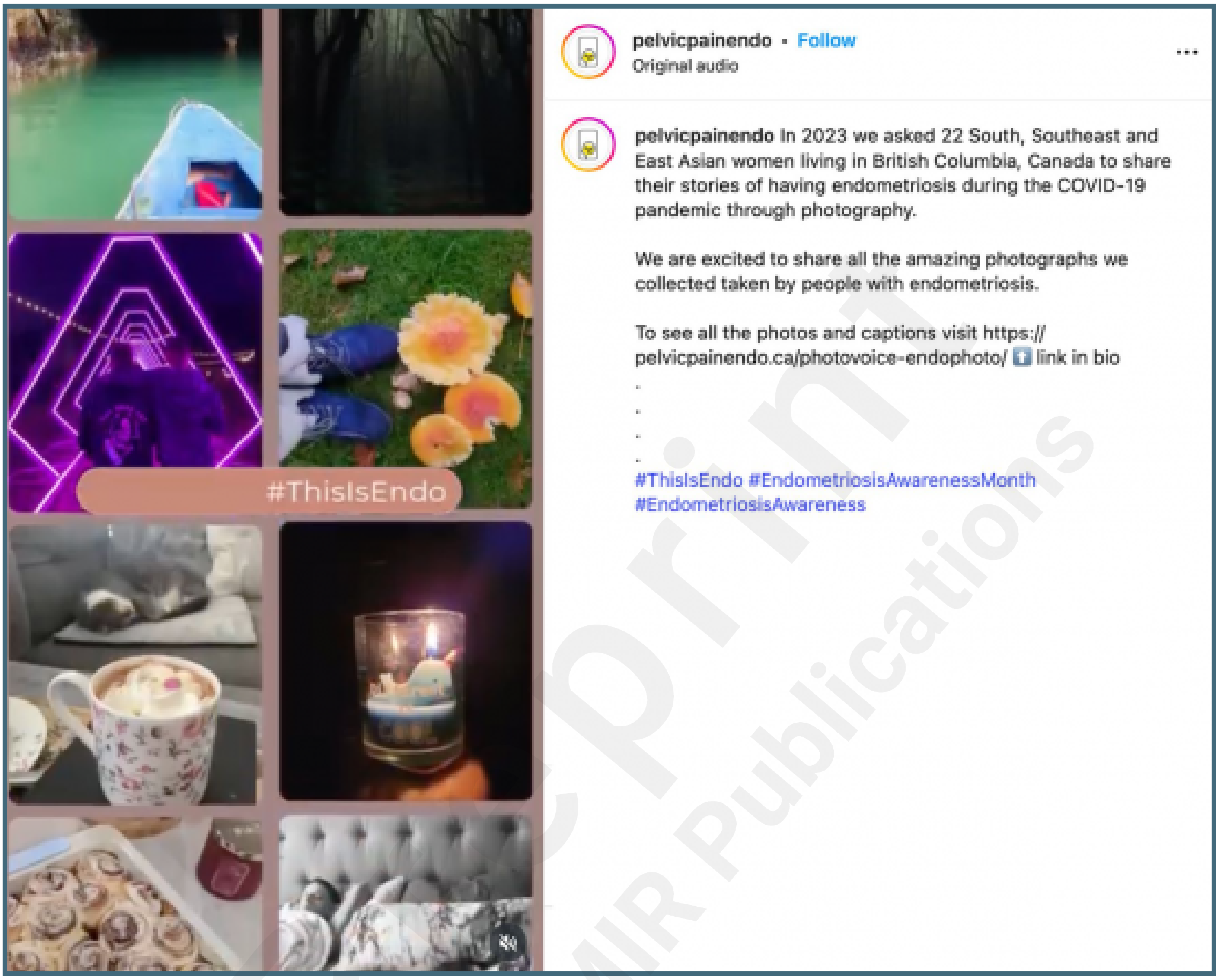
#ThisIsEndo #AsiansWithEndo #EndoAwareness #EndoAsian

Shared collage of participant photos from an Instagram reel.



pelvicpainendo In 2023 we asked 22 South, Southeast and East Asian women living in British Columbia, Canada to share their stories of having endometriosis during the COVID-19 pandemic through photography.

We are excited to share all the amazing photographs we collected taken by people with endometriosis.

To see all the photos and captions visit https://pelvicpainendo.ca/photovoice-endophoto/ ⬆️ link in bio

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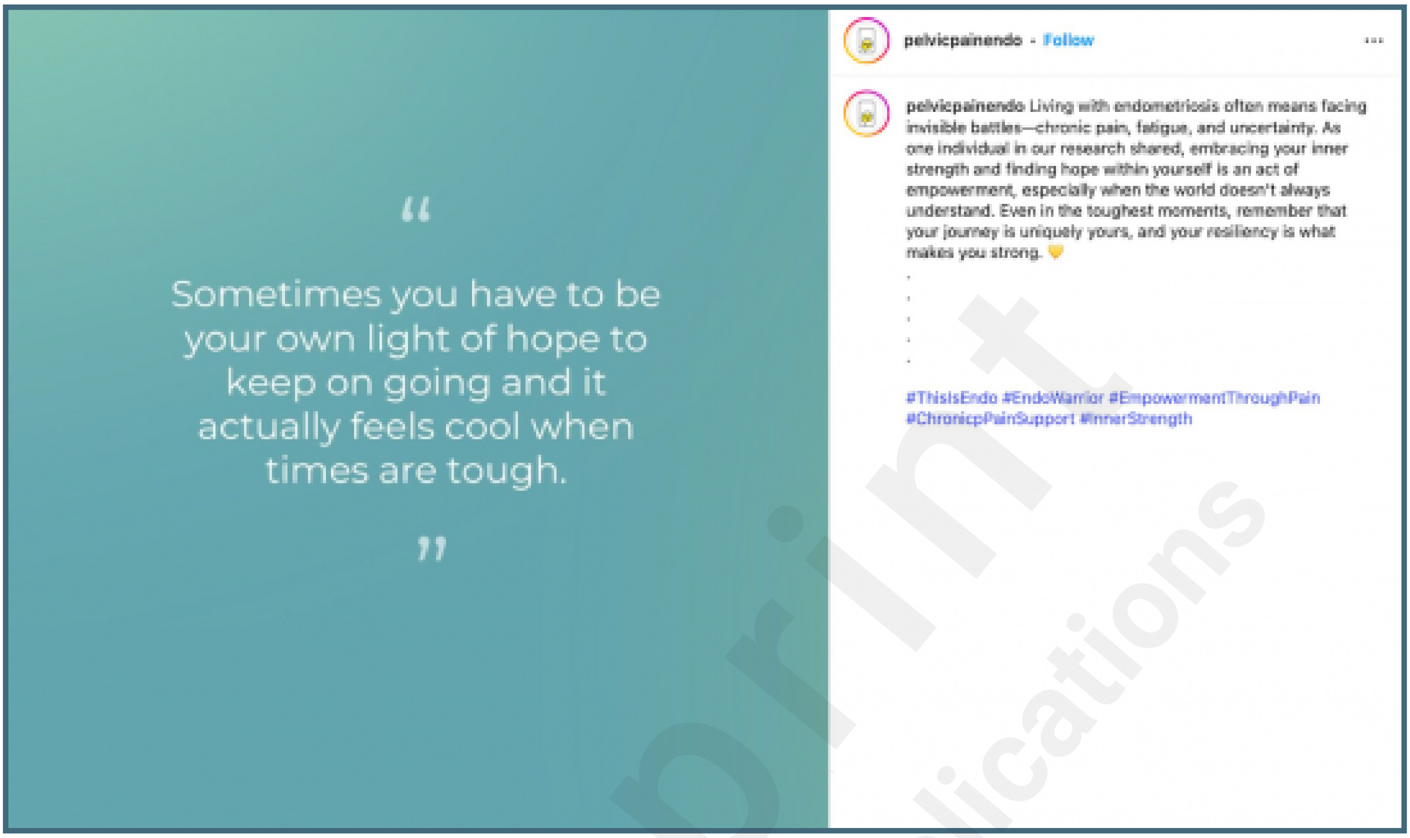
#ThisIsEndo #EndometriosisAwarenessMonth #EndometriosisAwareness

Quote-based content on strength while living with endometriosis.



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Sometimes you have to be your own light of hope to keep on going and it actually feels cool when times are tough.

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pelvicpainendo Living with endometriosis often means facing invisible battles—chronic pain, fatigue, and uncertainty. As one individual in our research shared, embracing your inner strength and finding hope within yourself is an act of empowerment, especially when the world doesn't always understand. Even in the toughest moments, remember that your journey is uniquely yours, and your resiliency is what makes you strong. 💛

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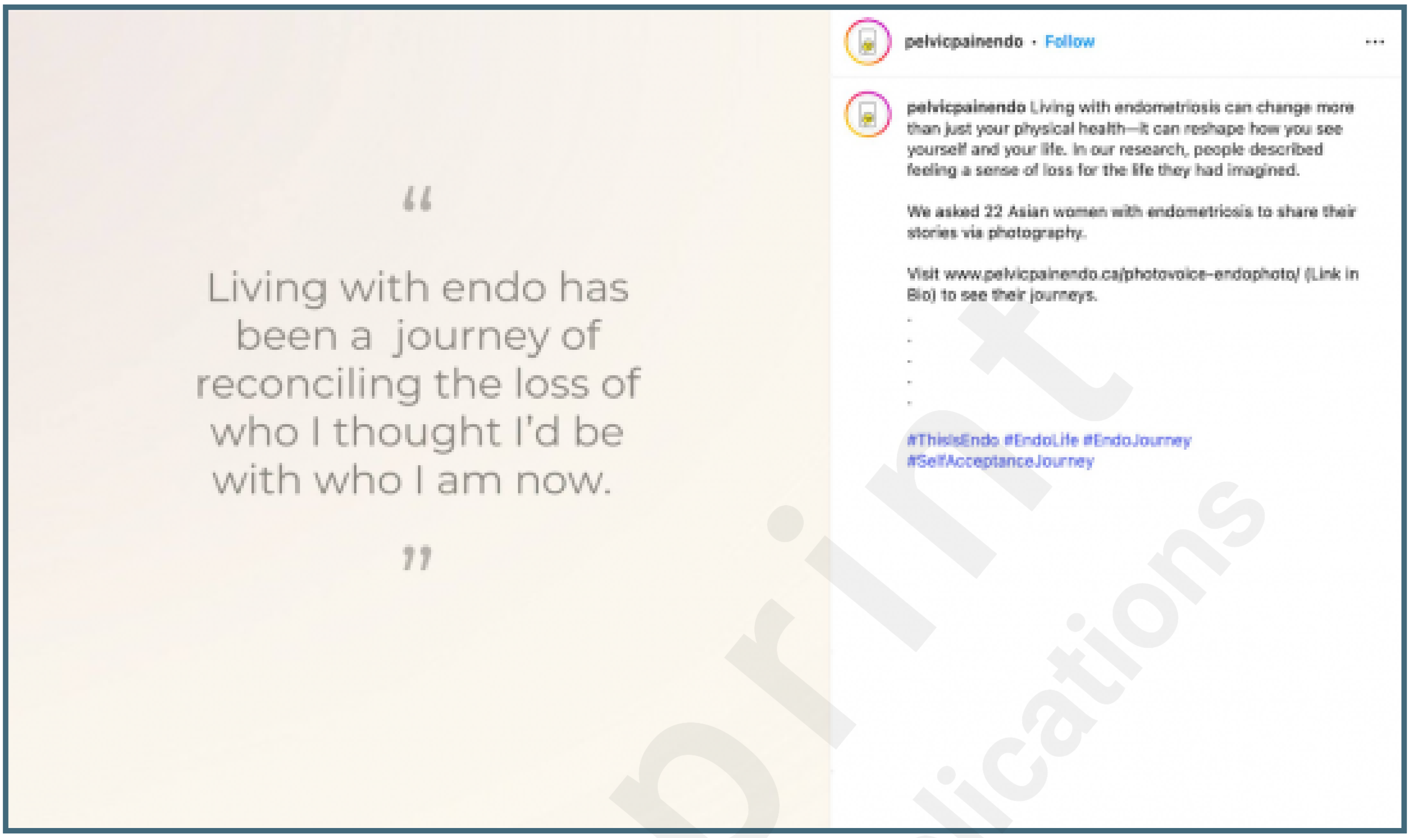
#ThisIsEndo #EndoWarrior #EmpowermentThroughPain
#ChronicpPainSupport #InnerStrength

Quote based content on living with endometriosis.



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Living with endo has been a journey of reconciling the loss of who I thought I'd be with who I am now.

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pelvicpainendo Living with endometriosis can change more than just your physical health—it can reshape how you see yourself and your life. In our research, people described feeling a sense of loss for the life they had imagined.

We asked 22 Asian women with endometriosis to share their stories via photography.

Visit www.pelvicpainendo.ca/photovoice-endophoto/ (Link in Bio) to see their journeys.
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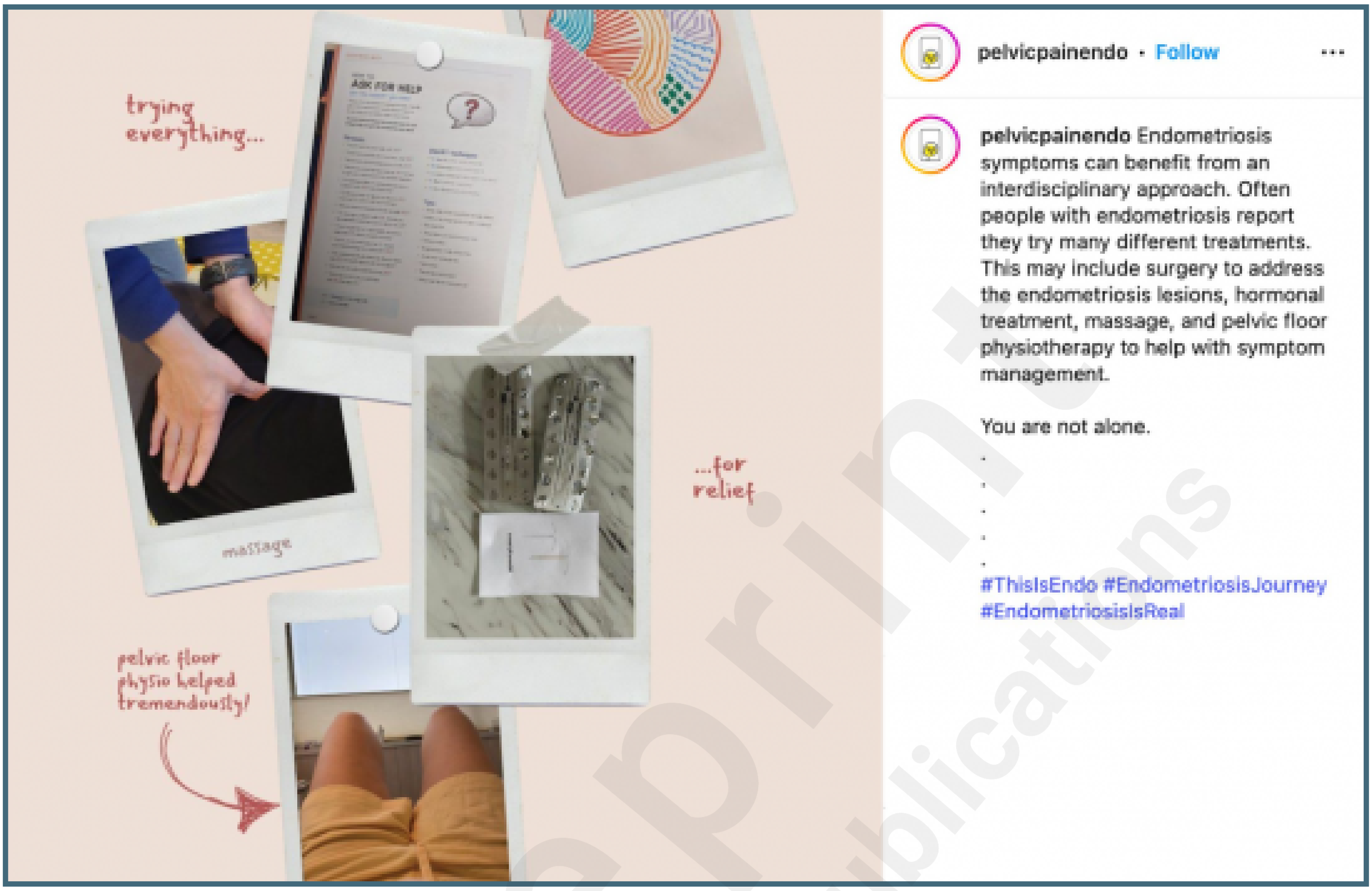
#ThisisEndo #EndoLife #EndoJourney
#SelfAcceptanceJourney

Everyday language use in caption.



pelvicpainendo Endometriosis symptoms can benefit from an interdisciplinary approach. Often people with endometriosis report they try many different treatments. This may include surgery to address the endometriosis lesions, hormonal treatment, massage, and pelvic floor physiotherapy to help with symptom management.

You are not alone.

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#ThisIsEndo #EndometriosisJourney #EndometriosisIsReal

Content highlighting cultural taboos around menstruation.

“People don't really talk about their periods, they just say, I have a stomachache.”

pelvicpainendo In our research, some Asian women with endometriosis shared that in their communities there is a stigma around discussing reproductive health. Instead of talking about their menstrual experiences to friends and family, some people choose to describe them as a stomachache.

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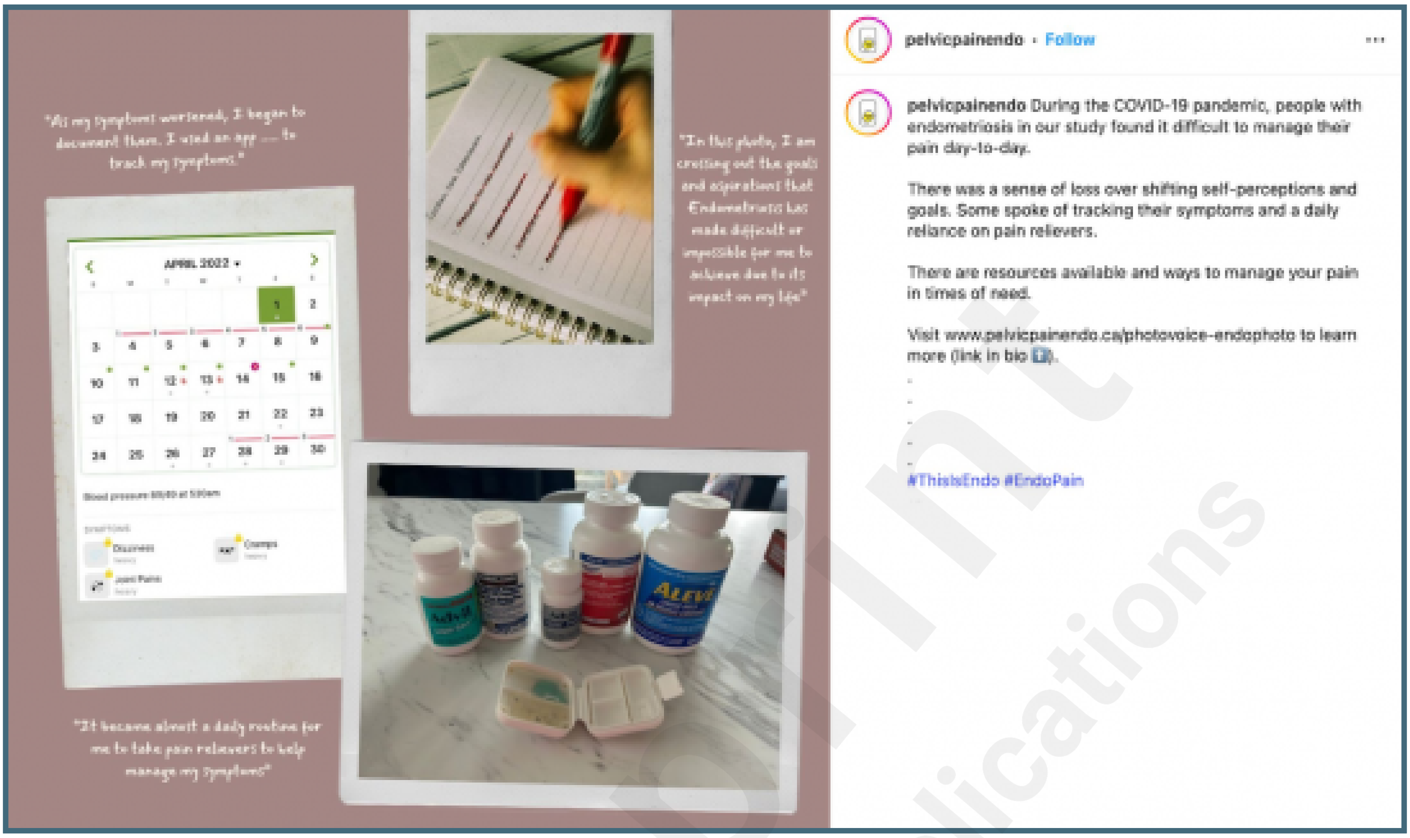
#ThisIsEndo #EndoAwareness #EndoStigma #EndoCulture #BreakingStigma

Avoidance of hyper-gendered or stigmatizing language or colours.



"As my symptoms worsened, I began to document them. I used an app — to track my symptoms."

"In this photo, I am crossing out the goals and aspirations that Endometriosis has made difficult or impossible for me to achieve due to its impact on my life"

"It became almost a daily routine for me to take pain relievers to help manage my symptoms"

pelvicpainendo During the COVID-19 pandemic, people with endometriosis in our study found it difficult to manage their pain day-to-day.

There was a sense of loss over shifting self-perceptions and goals. Some spoke of tracking their symptoms and a daily reliance on pain relievers.

There are resources available and ways to manage your pain in times of need.

Visit www.pelvicpainendo.ca/photovoice-endophoto to learn more (link in bio ⬆️).

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#ThisIsEndo #EndoPain

Still image from a reel that ‘went viral’ during the campaign.

pelvicpainendo In 2023 we asked 22 South, Southeast and East Asian women living in British Columbia, Canada to share their stories of having endometriosis during the COVID-19 pandemic through photography.

Though it looked a little different during the pandemic, connection was found to be an essential component of the lives of people with endometriosis.

Many described both the benefits and challenges of navigating the social world with endometriosis.

To see all the photos and captions submitted by people with endometriosis visit https://pelvicpainendo.ca/photovoice-endophoto/ ⬇️ link in bio

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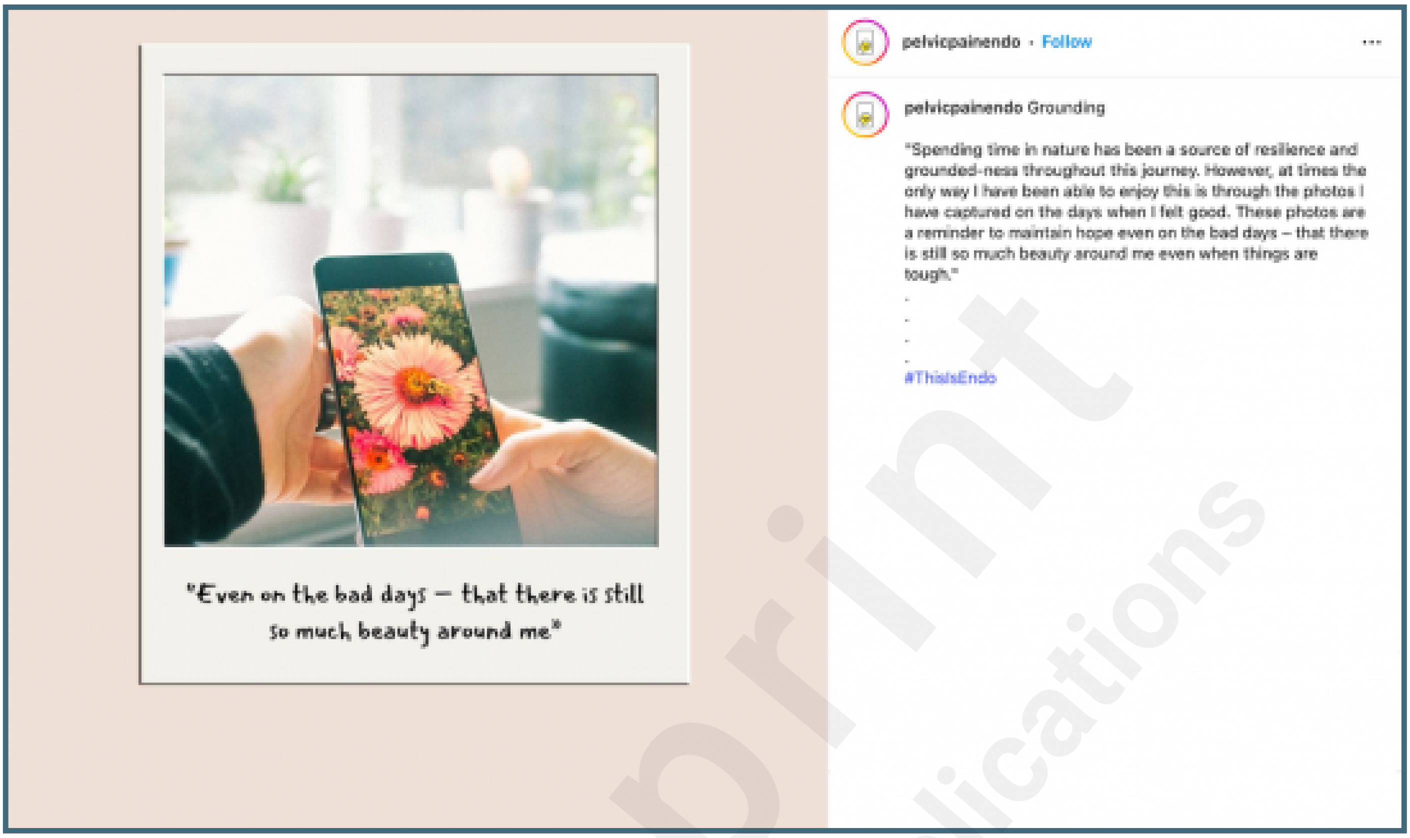
#ThisIsEndo #EndometriosisSupport #EndoStrong

Post that ‘went viral’ during the campaign.



pelvicpainendo Grounding

"Spending time in nature has been a source of resilience and grounded-ness throughout this journey. However, at times the only way I have been able to enjoy this is through the photos I have captured on the days when I felt good. These photos are a reminder to maintain hope even on the bad days – that there is still so much beauty around me even when things are tough."

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#ThisIsEndo

Still image taken from the second reel that 'went viral' during the campaign.

pelvicpainendo Despite the challenges faced by people with endometriosis in our study, many described a strong sense of resiliency, noting that there was hope for the future.

Visit www.pelvicpainendo.ca/photovoice-endophoto (link in bio)

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#ThisIsEndo #Resilient #Hope