

Understanding the Needs of Endometriosis Patients Through Social Media Data

Prepared by the Cerner Enviza Digital Insights Team



Approach

Cerner Enviza looked at the topic of endometriosis across social and digital media before homing in on patient experiences - their organic interactions with one another and Healthcare practitioners (HCPs) & organizations – for an enhanced understanding of patient experience.

At Cerner Enviza, we commit to handling data with care and ensure all publicly available social media data is assessed within the context of the broader healthcare industry. To identify patients, the digital team focused on the terminology and personal descriptions patients used to describe their experiences, along with specialised communities dedicated to patients.

The Cerner Enviza digital insights team is adept at filtering out online noise, so that high quality relevant data is prioritised and assessed. The digital team has expertise using tools such as Brandwatch, Buzzsumo and Quid, and open search intelligence techniques to collect public social and digital media data.

- **Scope:** Global English
- **Timeframe:** Automated search: September 1st 2021, February 28th 2022 | Manual Search: Lookback period - up to two years
- **Data analyzed:** Over 11K data points across social & digital media
- **Social Media Platforms included:** Twitter, Instagram, Reddit, Forums, Facebook & TikTok

Social media plays a role in helping endometriosis patients receive a diagnosis and in informing their decisions about treatment



Patients with endometriosis go through a long and difficult journey until they receive a diagnosis.

With the average length of time for a diagnosis set at eight years ⁽¹⁾, personal struggles with diagnosis combined with inadequate treatment options drive patients to go online where they have access to established private and public communities dedicated to endometriosis.

Patients with endometriosis - a long-term condition where tissue similar to the lining of the womb grows in other places including ovaries and fallopian tubes – can experience pelvic or back pain, severe period pain, painful sex and excess bleeding among symptoms and fertility issues.

The combination of a high number of posts from patients online along with increased media attention in recent years has helped raise more awareness around the condition and social media spaces have transitioned into vital outlets for patients to openly discuss their experiences.

Key Findings

Guidance for HCPs around the struggles faced by endometriosis patients – both physically and emotionally – could be key for improving patient experience with the healthcare sector

Finding

Patients show a strong desire to have a more trusting and supportive relationship with their HCPs, however, repeated attempts to receive a diagnosis has fostered a sense of distrust towards HCPs among the patient community

Highly engaged social media posts from patients detailed negative experiences that patients encountered during their attempts receive a diagnosis. Not feeling understood and not feeling supported, along with complaints about the practical side of diagnosis including delays with the diagnosis process, were prevalent patient complaints.

Social Media Insight

Key voices in the HCP community have been successful in establishing trust and rapport with endometriosis patients by acknowledging the full extent of patients' struggles – often in creative formats including as TikTok reels.

A deeper understanding of how HCPs are successfully using social media to build relationships with endometriosis patients would offer key insights to help further guide and inform HCPs in their interactions with endometriosis patients.

Key Findings

Endometriosis patient-communities play a key role when it comes to making decisions about treatment.

Patients will often use endometriosis-patient communities for vetting treatment options

Encountering difficulties during the diagnosis process and feeling like symptoms aren't being correctly understood, drive patients to take control over their treatment experience. As online endometriosis communities offer a wealth of knowledge and first-hand experiences, patients are likely to engage with posts relating to treatment specifically and to start discussion threads and ask questions about the pros and cons of various treatment options; particularly when it comes to surgeries.

Social Media Insight

Companies offering symptomatic treatment options including Ovira which markets a TENS device to help symptoms of period pain, have been trying to positively impact patients' treatment experience by creating online communities such as Facebook, for women to connect, openly discuss their experiences of pain along with difficulties and tips relating to diagnosis.

Key Findings

Advocates for women's rights and social justice are amplifying awareness around endometriosis and women's health issues more broadly.

Endometriosis is often discussed online within the contexts of equality and social justice

The fact that the condition has low awareness despite affecting 1 in 10 women and the impact the condition can have on fertility, raises broader concern around lack of investment and treatment for certain demographics and a woman's right to make personal decisions with regard to their fertility. Advocates for endometriosis can often draw links between movements for equality and social issues in discussions of the disease.

Social Media Insight

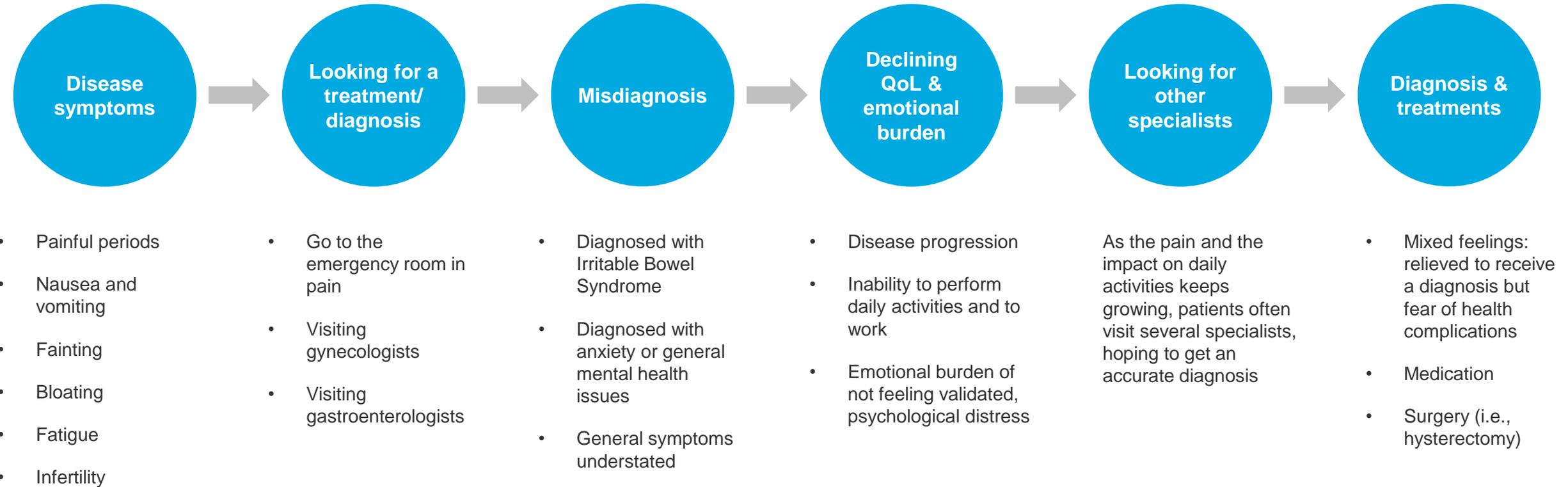
One Endometriosis patient, a well-known UK influencer, claimed they were called out for making "endometriosis trendy" for speaking out about the condition without providing full context of the emotional, physical and social weight surrounding it. Understanding the broader social cultural context around endometriosis is crucial for understanding patient experience and the broader events and conversations which may impact their understanding of the condition.

Social & Digital Media Analysis



The diagnosis journey is challenging for women who must manage symptoms of pain, while facing a long, complicated journey to diagnosis.

The patient journey based on prevalent themes from online patient communities.



“I can honestly say I have learnt far more from social media pages and groups about endo than I have from a doctor!” (2)

Patient Verbatim, Instagram

What drives patients to post online?

To share their diagnosis experiences

To raise awareness towards endometriosis

To expressing the emotional burden of living with endometriosis

To discuss endometriosis and fertility/pregnancy

To discuss and find information about treatments

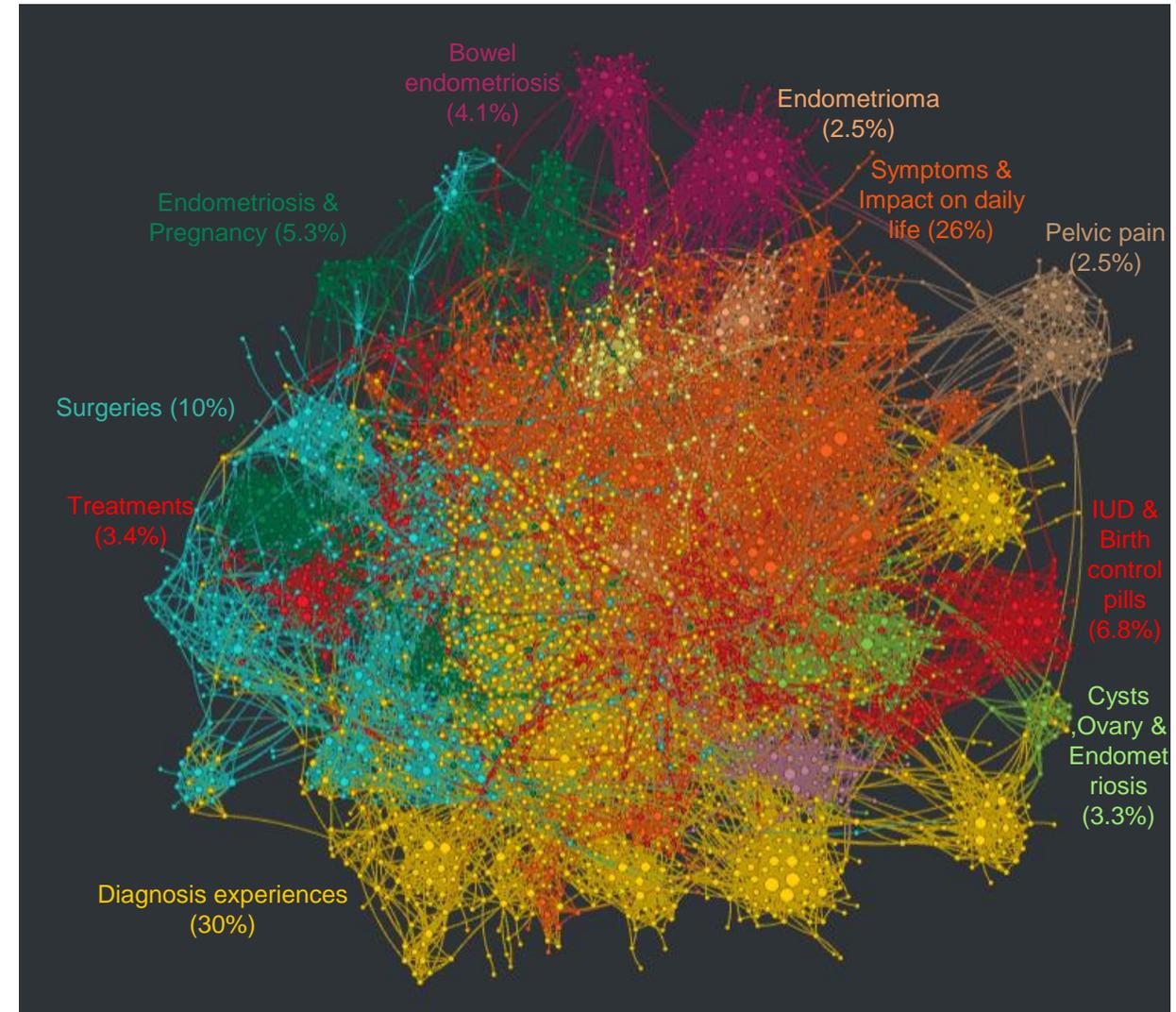
To engage with other communities, including advocates, organizations, & HCPs

Reddit conversations are primarily focused on experiences of diagnosis – the most prevalent pain-point for patients

3,470 posts from the r/endometriosis community were analysed using Quid, a natural language processing tool, for an understanding of key topics of importance to patients.

Key findings from the topical analysis conclude:

- Conversations are highly dominated by **diagnosis experiences conversations (30%)**, immediately followed by topics around **symptoms and impact on daily life (26%)**
- **Surgery procedures (10%)** are also a common theme that overlaps with diagnosis-experiences to some extent, as laparoscopy is a surgical procedure that may be used for diagnosis purposes ⁽³⁾
- Specifics around endometriosis are also highly discussed by patients. Prevalent topics also include:
 - Pregnancy
 - Birth control and IUD as prescription solution to manage pain
 - Pelvic floor pain as a symptom of endometriosis. Patients share details over pelvic floor rehabilitation, as to ease their symptoms
 - Specific areas impacted by endometriosis, including references to cysts, bowels, ovaries



Posts about negative experiences with HCPs have attracted the highest engagement cross-platform

Patients use various formats including discussion threads, videos and memes to help amplify awareness around their condition

Dismissing experiences



(4)

Diagnosis delays

When they ask you when you had the first endo symptom



(5)

Sharing their stories, aiming to raise awareness

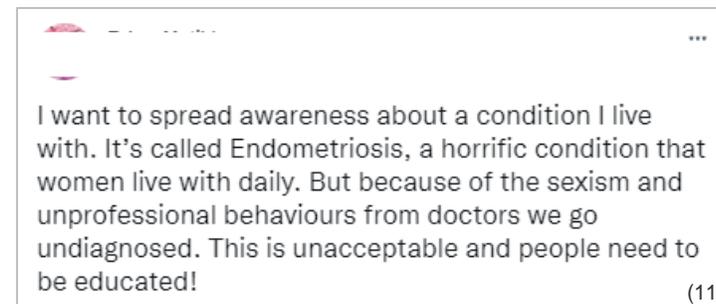
*"Have you ever been to the ER in excruciating pelvic pain to the point of screaming and crying only to have the doctor tell you to please be quiet because you are scaring people in the ER? Perhaps you've been given anxiety medication to "calm you down" and then sent home with an **anxiety diagnosis**. Maybe you actually were able to get an ultrasound to see where the pain is coming from. Perhaps the ultrasound tech gasped and said "wow, you are covered in cysts!" You return to your bed thinking "**finally they will treat me and not gaslight me!**" Only to be told me the doctor "we couldn't find anything to explain your pain, we are going to discharge you now." All of these things have happened to me in many different states in the US. It is not an isolated problem and women (especially BIPOC women) are often gaslit and treated for "hysteria" when we are in very real pain."*

(6)

Patients drew upon their experiences to help other patients and to amplify awareness about the condition

Key themes:

- Escalate messages towards a medical system that, in their experience, does not listen to their needs
- Demonstrating their symptoms to highlight how these impact their routine ⁽⁷⁾
- Validating other patients' level of pain ⁽⁸⁾
- Being vocal about the fact that painful periods are not normal, and solutions should be provided
- Sharing and creating informative content, as well as building communities to support patients when it comes to diagnosis ⁽⁹⁾
- Being their own advocate, sharing the most common treatments and procedures to manage their condition ⁽¹⁰⁾
- Finding the right HCPs and having educated discussions with their HCPs about their options for treatment



Highly engaged digital media articles highlight the diagnosis and treatment burden on patients

Celebrities and patients' stories were at the core of digital media articles and generated significant engagement on social media.

- The story of a media worker, who has been open about the struggles of getting a proper diagnosis and being heard by HCPs, attracted the highest engagement (24.7K) online. The patient's criticism is directed towards the general healthcare system generally:

“It shouldn’t have taken me 13 years to find that support, and it shouldn’t be on the sick to educate themselves.” ⁽¹³⁾

- Articles which highlight the mental health struggles of patients are particularly resonant with the patient community.
- Beyond patient-centric stories, an article ⁽¹⁴⁾ that analyses the most common surgery procedures and their associated risks, attracted 15.7K engagements.

Endometriosis affects 1 out of 10 women like me. Yet it often takes a decade to get diagnosed.

For those suffering and told it's "just a bad period," it's not. Please find a new doctor. Please know you are not alone. Please know it's not in your head.

(15)

Celebrity story: 25.6K engagements

‘I was told to live with it’: women tell of doctors dismissing their pain

(16)

Patient story: 15.1K engagements

A common treatment for endometriosis could actually be making things worse

Repeat surgeries for endometriosis could be exacerbating pain symptoms, experts say

(17)

Treatment-focused article: 16.4K engagements

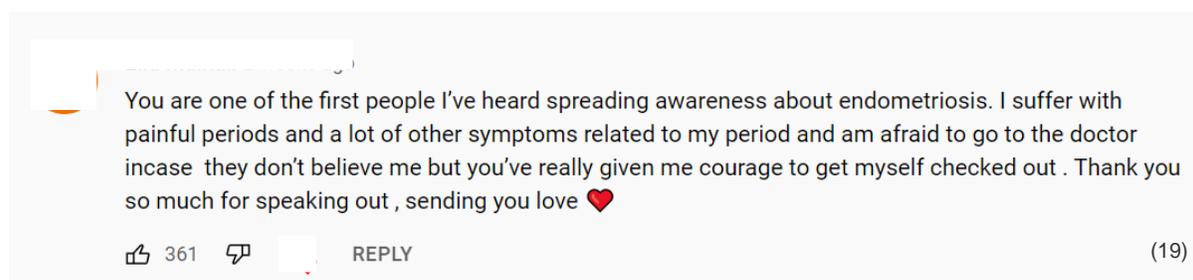
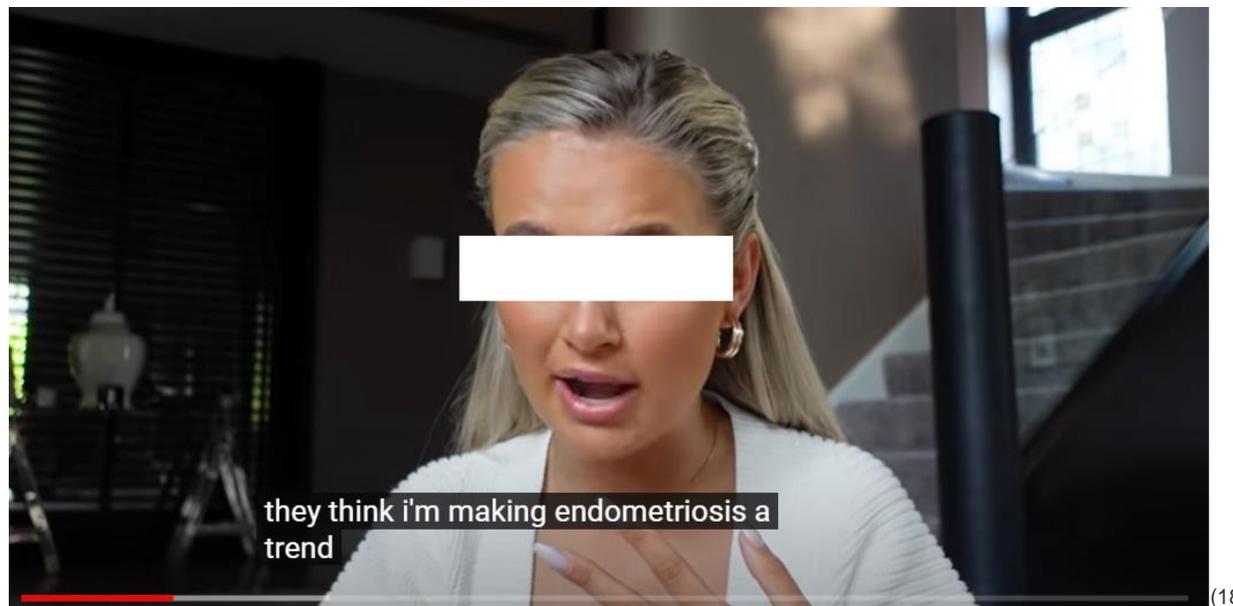
Celebrities play a crucial role in increasing understanding around the impact of the condition on day-to day life, but are also open to criticism

An endometriosis patient who is also well-known British influencer was accused of making "endometriosis a trend" when briefly referencing her experience of the condition on YouTube and on Instagram.

The patient claimed she felt she had to be cautious when discussing her experience as she had received private messages which accused her of using the condition to bolster her popularity.

The patient subsequently released a YouTube video opening up fully about her endometriosis experience, including showing her laparoscopy scars and detailing the impact the condition has had on her day-to-day life and her relationship with her partner, attracting strong positivity.

The example shows how passing references to the condition can carry significant social and emotional weight online.



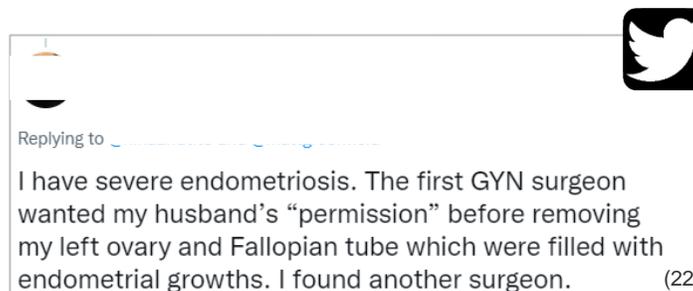
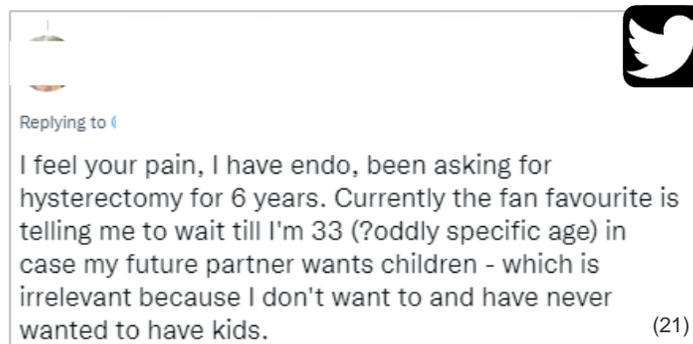
Posts about the impact of endometriosis on fertility reflected pregnancy struggles and successes, and led to broader debate around women's rights

Instagram: The hashtag #endometriosispregnancy (1499 posts) was used by patients to share messages of happiness, success, and hope.



*“There is hope in the darkest corners of this illness we call Endometriosis 🌱
 This was taken 31st December 2019 on a hospital bed.
 The second one today as I am nearly 6months pregnant.
 If you told me this time last year I could be pregnant. I would have just laughed at you and called you crazy. We got told my tubes collapsed, and my right ovary had a large ovary cyst with bleeding each other month.
 I cried nearly every week, from the pain. From not being able to control my own body. I was over the cycle of hospital beds and explaining my illness to strangers.
 Here is me writing to you, have hope ❤️” (20)*

Twitter: Treatment for endometriosis sparked broader discussion about women's rights attracting interest from equality activists due to the overlap between women's health and highly visible societal and political issues



Forums & Reddit: searching for information by freely expressing fears and concerns, as well as sharing positive stories



Patients sought reassurance from other patients when faced with choosing between treatments – which varied from over-the-counter painkillers to hysterectomies

A large variance in the treatments used for endometriosis often left patients overwhelmed and further driven to do their own research to choose the best option for them based on their symptoms and plans for the future.

Commonly discussed treatments varied from symptomatic treatments which included medication & over the counter painkillers – to hormone treatments including birth control – to surgeries which included laparoscopies, excision surgeries and hysterectomies.

Patients were most in need of informative content around surgeries, in particular, and posts about surgeries for endometriosis yielded a high amount of comments and questions the patient community ⁽²⁶⁾. However, patients are also seeking for reassurances,

↑ Posted by i

4 **I need advice please**

↓

I'm 25 and just had my first laparoscopic surgery two weeks ago and also a loop procedure. My gyno diagnosed me as having a variant of endo and told me I have two options for treatment. I can either be put into menopause via a shot every 3 months, or I can have a peritoneal resection that he said may or may not help me and may or may not result in my losing any fertility I have. I'm so tired of hurting, but I'm not sure what to do. Has anybody else been told that these are their only options? Do I have any other options?

(27)

onths ago • 10 Replies

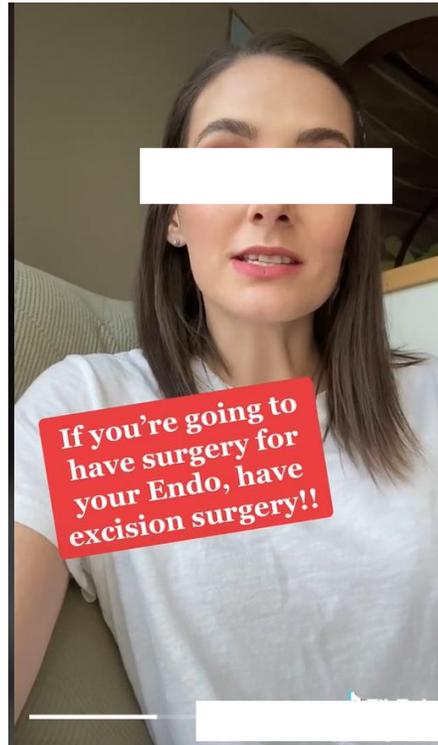
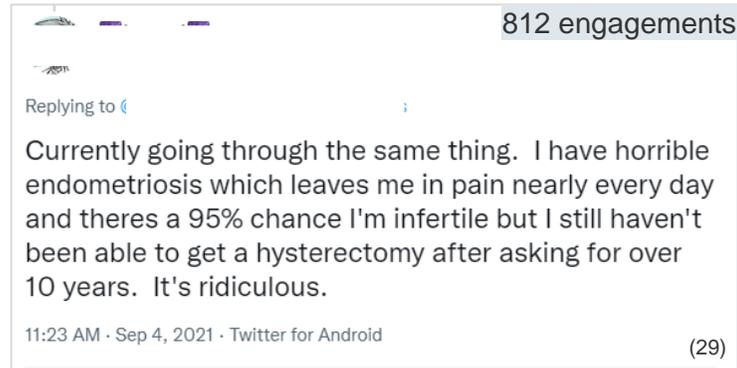
Hi everyone,

I've had an appointment today with the gynaecology specialist nurse after I described my symptoms she said she's more that sure that it's endometriosis she give me a few options but I'm so scared she said an MRI scan but she was worried about the radiation as I'm 18 she is sending me for an ultrasound to check for cysts on Friday she told me about surgery but said it can cause scarring and adhesions and then she said would I like the coil I panicked and agreed but I really don't want it I would prefer the surgery to get rid of it rather than putting the coil in to just ease the Heavy bleeding because what about the complications in the future I'm only 18 I haven't even had inter course so what if there's infertility issues in 5 - 10 years ? she also said it could be painful to put in I really don't know what to do please could you help ? I'm already on the pill to stop the bleeding and on mefanatic acid to stop the pain. Shout I push for surgery I know that it could grow back but I'd rather have it gone I'm just really scared there's so much information to take in and it's all confusing to me x

(28)

Patients often have a specific idea of what treatment they require based on their extensive self-research

Patients often pushed for specific treatments based off their own research and perceptions gleaned from other peoples' experiences.



“I was no longer willing to accept the situation and just power through it. I was going to take control and take my life back. I was on a mission to learn everything I could about treating the illness that afflicted me. That's when I found out that so many sufferers of this disease did the same: They got their information about their illness on social media and by self-education.” ⁽³²⁾

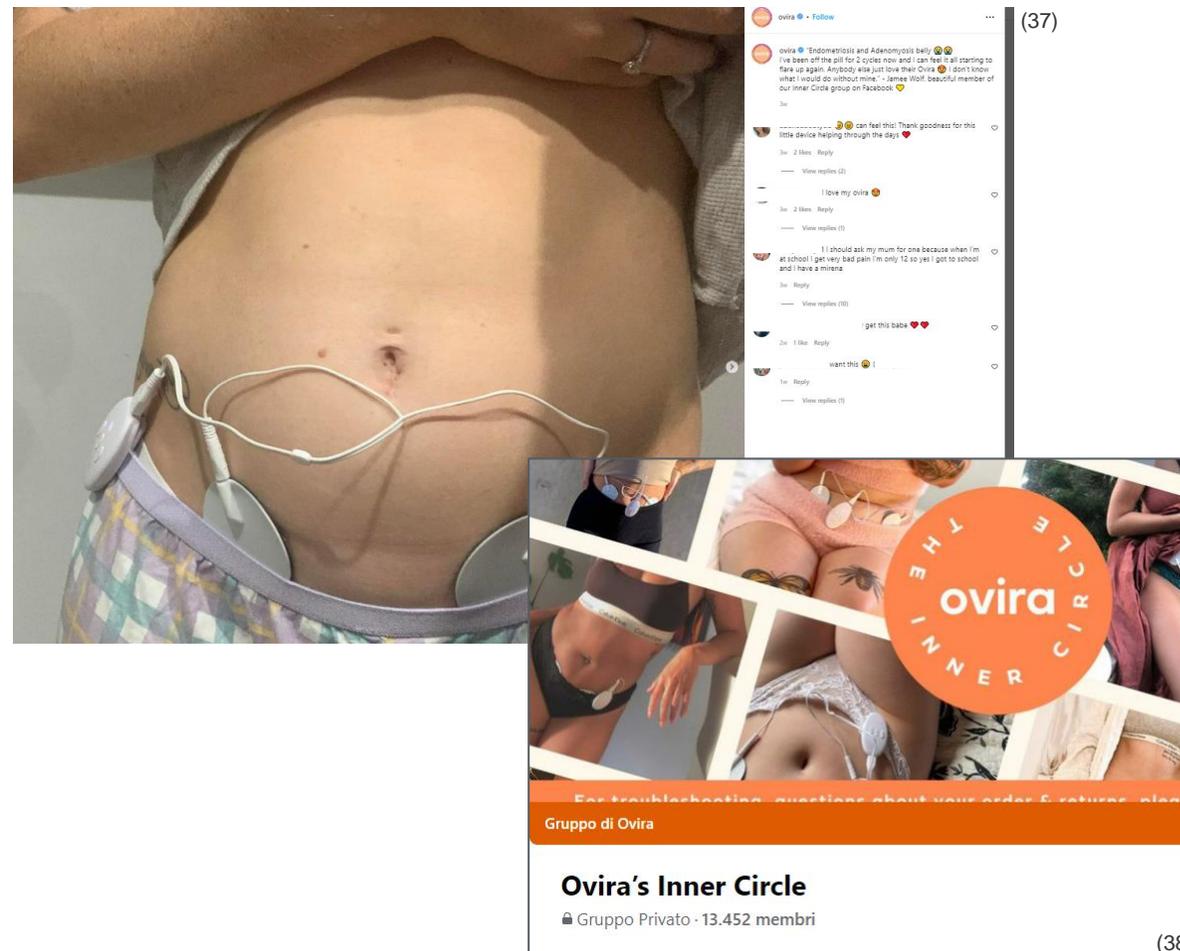
Patient Verbatim, NBC News

Start-ups focused on easing menstrual pain have found a way to connect with endometriosis patients

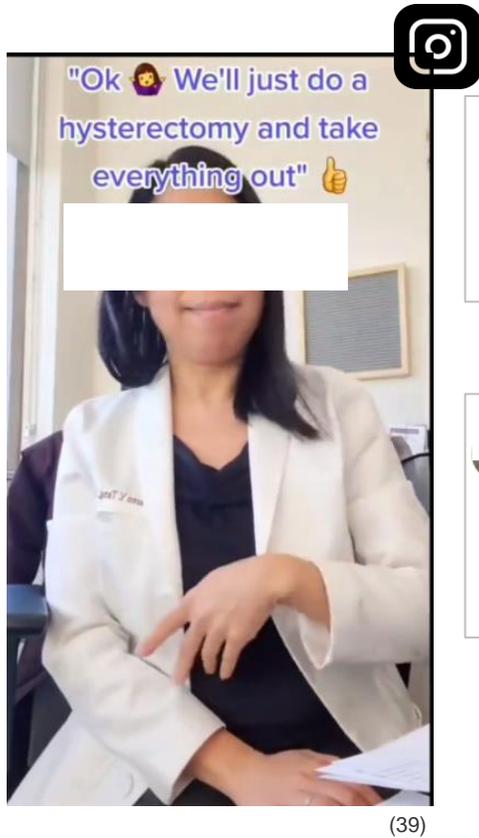
Start-ups who have developed devices based on Transcutaneous Electrical Nerve Stimulation (TENS) technology to help patients find relief from pain include Monthli (33), and FDA approved Livia (34) and Ovira (35).

Ovira, founded by a woman who struggled with endometriosis, released a device to manage endometriosis and PCOS pain named “Noha,” that uses *“pulse therapy to interrupt the pain signals that are being sent to the brain”* (36).

What differentiates this treatment over others is Ovira's emphasis on community. Ovira understands the need for patients' voices to be heard and understood and encourages customers to join dedicated online communities, including a private Instagram page and a Facebook group so that patients can share their experiences in a safe space and connect with others to find information and advice.



Across social media, HCPs have had success engaging with patients by addressing and validating the struggles they experience



(39)

Patients' comments

It's taken 30 years for a doctor to even suggest that I have endometriosis---and even still, none of my doctors have actually done any testing to confirm it. My first gyno who was very conservative suggested I just needed "to have a few kids" to help my pain. I was 17. (40)

🙏🙏🙏 thank you so much for sharing your knowledge and empowering women to be their own advocates. This happens way too often for women that have endometriosis. It took me 8 years to be properly diagnosed and unfortunately another 8 to find a qualified excision specialist. ❤️❤️❤️ (41)



(42)

Patients' comments

wait a min....so they aren't supposed to cause vomiting either? I thought crying/eat/sleep was normal...and what about palm size blood clots though?
2020-1-31 Reply
D • Creator
No and no not normal
2020-1-31 Reply (43)

LOUDER FOR THE KIDS IN THE BACK BEING TOLD TO "Get over it, it's just a period". It took FIFTEEN YEARS for someone to listen to me.
2020-2-11 Reply (44)

Just had surgery yesterday to find endometriosis bc I passed out from the pain. They found stage 2. Glad there's docs on this app!
2020-2-26 Reply
• Creator
Hope you are recovering well!!!
2020-2-26 Reply (45)

Possible follow-up areas for online research

Area	Follow-up areas
Treatment	<ul style="list-style-type: none">• An analysis focused to see how start-ups using innovative technologies to address symptoms including menstrual pain are connecting with endometriosis patients
Patient Influencers	<ul style="list-style-type: none">• An in-depth analysis of patient influencers – the type of content the post, the issues they raise and how they connect with the broader endometriosis community
HCPs	<ul style="list-style-type: none">• An analysis of key HCP influencers in endometriosis conversation• An analysis of the language they use when discussing the condition and how they connect with patients
Advocates/ Advocacy Groups	<ul style="list-style-type: none">• To what extent do advocacy groups influence patients?• What pain points are most highlighted by advocacy groups?• Do advocacy groups collaborate on any particular issue, or do they work in isolation?

For information about this study please contact our Search & Social Intelligence team



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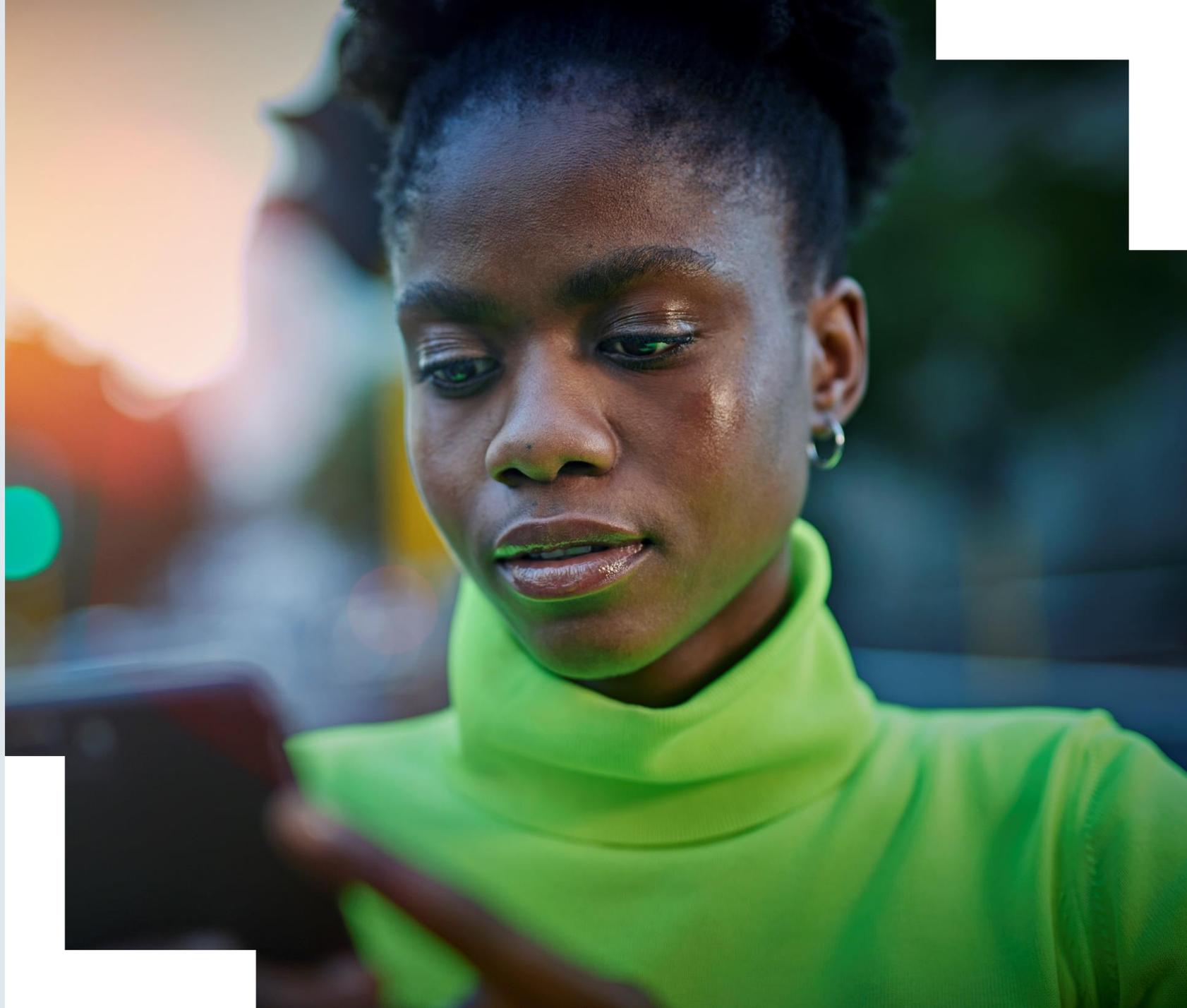
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Appendix



How can social and digital media be used for an enhanced understanding of patient needs?

Cerner Enviza utilises data from across social and digital media, to provide insights at speed for clients who need an understanding of what is driving interest around a priority healthcare area online—with a focus on the behaviours and interests of key audience groups.

Patients often turn to social media to connect with patients and HCPs, to document their experiences, to share information, and to look for support. Understanding why patients post and what they post about, can provide vital insights around the topics that matter to them most, as well as providing strong indications of unmet needs.

Cerner Enviza only analyses publicly available data and anonymises examples, when drawn upon, for a better understanding of patient experience.

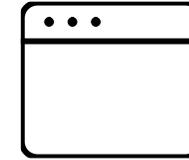
Our legacy healthcare expertise combined with our experience using social listening tools, natural language processing, and data analysis techniques, ensures insights are viewed



Insights from discussions

What topics are patients discussing?

What are patients' key needs and challenges?



Insights from content

What content is generating engagement online?

What type of content and information are people asking for and/or sharing?

Methodology

Over 11K data points from audiences discussing endometriosis on a global English level were analysed for the purpose of this report.

Cerner Enviza uses tools such as Brandwatch, Buzzsumo and Quid, and open search intelligence techniques to collect public social and digital media data. Social media analysis included the following platforms: Instagram, Reddit, Forums, Twitter and TikTok. A **mention** is when a brand or specific term is referenced, or "mentioned" online. **Engagement** is the sum of shares, reactions and comments on a post.

Approach

Cerner Enviza develops custom boolean queries and inputs these via Brandwatch, a social media listening tool, which collects millions of public posts across social media and forums and blogs daily. Queries are tested and assessed to ensure clean and relevant datasets. Results are supplemented with digital media data from Buzzsumo, a tool which collects digital media content and ranks these by cross platform engagement. Quid, a text-based data analysis and visualisation tool, which uses machine learning and natural language processing to identify patterns within a text-based datasets assists is used for identifying topic groupings and signalling similarities and patterns in language.

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All research is conducted in accordance with the requirements of our Quality System, which confirms to ISO 20252:2019 the International Standard for Market Research, Certification Number : 1019

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