END OF PROJECT REPORT

executed by

WOMEN WITH WINGS

an initiative of
PAIR Academy

SUPPORTED BY

BACKGROUND

Endometriosis is a chronic gynecological condition characterized by the presence of endometrial-like tissue outside the uterus, often leading to pain and infertility. Affecting approximately 10% of women of reproductive age globally, its impact in India is significant yet often underreported.

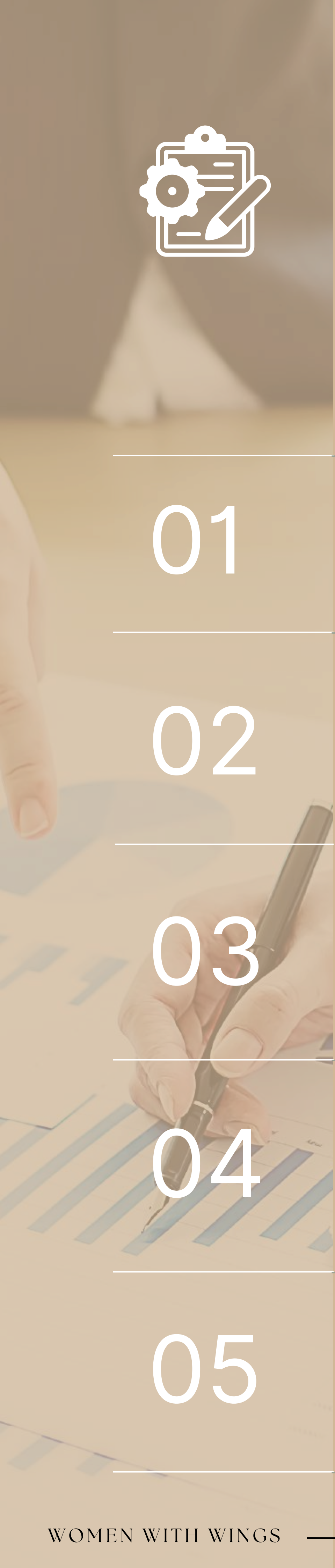
In the country, cultural stigmas surrounding menstruation and reproductive health contribute to delayed diagnosis and treatment, amplifying the physical and emotional toll on patients. The lack of awareness and limited access to specialized healthcare further complicate the management of endometriosis. Women often endure symptoms for years before receiving a correct diagnosis, with an average delay of 6-8 years.

The economic burden of endometriosis in India is also substantial, affecting women's productivity and quality of life. Financial constraints often limit treatment options, and there is a critical need for affordable and accessible care.

Through this project, the **"Women with Wings"** initiative has succeeded in raising awareness and providing educational resources for women affected by endometriosis in India. Our primary objective was to address the significant gap in knowledge and understanding while getting an insight into the patient journeys of those suffering from the illness in the country. To this end, we developed and disseminated educational materials that empower patients with the information needed for early diagnosis and effective management of this chronic condition, as well as educate physicians on the hurdles faced by millions of women struggling with endometriosis.

This report summarizes our efforts and achievements over the course of the project.

PROJECT DELIVERABLES



01

Focus Group Discussions

Total: 8

02

Patient Videos

Total: 4

03

Endoruns

Total: 4

04

Guidebook

Total: 1

05

Narrative Review

Total: 1

FOCUS GROUP DISCUSSIONS

The Focus group discussions (FGDs), also known as **“EndoTalks”**, were conducted with 80 participants from different parts of India. The participants were selected through screening of existing patient support groups and outreach on social media platforms. After obtaining informed consent for audio/video recording and documentation, they were invited via email to share their experiences with endometriosis. All participants were 18 years or older, could speak and understand either Hindi or English, and had been diagnosed with endometriosis by a healthcare professional.

The FGDs were held in closed-room settings to encourage open dialogue. Moderated with open-ended questions, these discussions aimed to uncover participants' experiences, challenges in diagnosis, disease management strategies, treatment experiences, and issues with healthcare services. Participants shared their struggles with managing severe symptoms, such as heavy menstrual bleeding and chronic pain, and highlighted the varied effectiveness of different treatments, including hormonal therapies and surgical interventions. Many expressed frustration with the lack of clear, long-term treatment plans and the frequent need to consult multiple doctors to find effective care. They emphasized on a substantial unmet need for timely diagnosis, highlighting the importance of improving awareness, diagnostic accuracy, and holistic care approaches for endometriosis in India.

Insights and data gathered from these discussions were instrumental in creating a comprehensive patient guidebook, which provides practical advice and resources for managing endometriosis. The patient narratives also formed the basis for a detailed narrative review, highlighting common themes and challenges faced by endometriosis patients in India.


Organised By

WOMEN WITH WINGS

PAIR Patient Academy for Innovation & Research

"Empowering Voices, Shaping Solutions"

Endo Talk

Join us for PAN-INDIA Online “FOCUS GROUP DISCUSSIONS” with ENDO WARRIORS

Sun Nov 19th, 2023
1:00PM - 2:00PM

REGISTER NOW!


Organised By

PAIR Patient Academy for Innovation & Research

WOMEN WITH WINGS

Venue Partner

Apollo HOSPITALS

Scan to connect and discov more

"Empowering Voices, Shaping Solutions"

Endo Talk

“EndoTalk - Empowering Voices, Shaping Solutions,” a series of thought-provoking and insightful focus group discussions designed to gather perspectives and experiences from individuals living with endometriosis.

04 NOV 2023, SATURDAY, 3 PM - 5 PM

3RD FLOOR CONFERENCE HALL,
APOLLO HOSPITAL, JUBILEE HILLS, HYDERABAD

womenwithwings.pairacademy.org

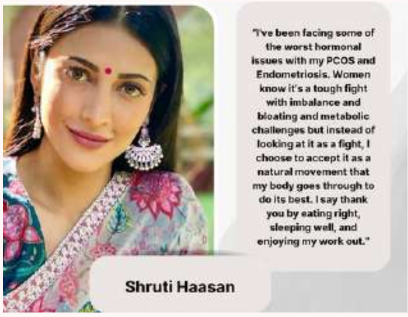
PATIENT- LIVED EXPERIENCES

As part of our project, we recorded and documented the "lived experiences" of Endo Warriors, focusing on three critical topics:

- Diagnosis
- Heavy Menstrual Bleeding
- Long-term Treatment.

One such story was recorded in a detailed document, highlighting the journey of a patient diagnosed in 2022 by chance during a laparoscopy for a femoral hernia. This patient faced significant challenges, including severe menstrual pain starting from adolescence, frequent flare-ups post-surgery, and a misdiagnosis and lack of appropriate treatment that severely impacted her physical and mental health.

The patient's narrative revealed that her biggest challenge was learning to function despite constant pain and fatigue, coupled with the emotional toll of not being believed by others. Treatment options provided were initially limited and not fully explained, leading her to refuse certain medications and seek out specialized surgery abroad, which remains financially challenging. Despite not yet undergoing surgery for endometriosis, she continues to explore pain management strategies and undergoes therapy to cope with mental health struggles.



"I've been facing some of the worst hormonal issues with my PCOS and Endometriosis. Women know it's a tough fight with imbalance and bloating and metabolic challenges but instead of looking at it as a fight, I choose to accept it as a natural movement that my body goes through to do its best. I say thank you by eating right, sleeping well, and enjoying my work out."

Shruti Haasan

Her message to all the Endo Warriors : "Don't give up; we need to fight for ourselves and change this for future generations. Only we can do that".

This patient story, along with others recorded, provided invaluable insights into the patient journey, helping to create a comprehensive patient guidebook and contribute data for a detailed narrative review.

ENDORUN

Through this project, the Women with Wings initiative celebrated Endometriosis Awareness Month by organizing EndoRun events in four cities across India, namely Gurgaon, Lucknow, Hyderabad, and Mumbai. Additionally, a social media campaign called "Miles for Endo Awareness" was launched to raise awareness about endometriosis in society. Each event attracted students, healthcare providers, endo warriors, and community members, fostering a collective effort to highlight the challenges of endometriosis.

As part of the event, A QR code for self-examination was also introduced, allowing participants to assess their symptoms by answering a collection of questions that helped find out whether they had any symptoms of endometriosis, thus aiding in timely possibilities of intervention.

Lastly, menstrual hygiene product kits were distributed to winners of the “lucky draw”. The Coffee Table Book featuring narratives of endo warriors showcasing their strength and resilience was also relaunched.

THE IMPACT

Overall, the EndoRun events successfully increased awareness of endometriosis, enhanced education about the disease, and strengthened community support for endo warriors. The initiatives fostered a collaborative approach to tackling endometriosis, emphasizing the need for early diagnosis, comprehensive care, and societal change to improve the lives of those affected by endometriosis.

PATIENT GUIDEBOOK

A comprehensive patient guidebook covering a wide range of topics essential for understanding, diagnosing, and managing endometriosis was developed as part of the project. The guide gives an overview of the disease, and details on the diagnostic process and treatment options Additionally, it addresses important aspects of menstrual health, explores the impact of endometriosis on fertility and also includes practical advice for the patients.

NARRATIVE REVIEW

During the course of the project, a scientific paper on Endometriosis was drafted to highlight the historical context of endometriosis, its impact on patients, and the prevalent issues of underdiagnosis and misdiagnosis in India.

Details of the Semi-Structured Qualitative Study (Focus Group Discussions and AI Analysis) were used as evidence to support the findings of the review. The paper is under process for publication.