STANFORD
MUSSALLEM CENTER FOR
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# USER RESEARCH WHEN DEALING WITH STIGMATIZED TOPICS

*"Through multiple conversations with patients and physicians who work directly with the problem [of fecal incontinence], we were able to compose a guide of best practices and language to use that helped us get the most from patient interviews and understand the unmet need in this area."*
—Miles Rosen, Co-founder of Pelvalon

## Background

People with fecal incontinence experience the loss of standard bowel control, creating the accidental leakage of stool and gas through the anus. It is caused by damage to the anal sphincter from a variety of different factors, ranging from lack of physical activity and constipation to rectal prolapse and pelvic floor weakness. Women are especially at risk of developing this condition, with approximately one in 10 affected by the issue globally.[1] When women develop the condition, the associated unpredictability and embarrassment can lead to social isolation. When Stanford Biodesign trainee Miles Rosen discovered the magnitude of the unmet need surrounding fecal incontinence, he and his co-founder, Steve Herbowy, were eager to make a difference. Ultimately, the team went on to develop an inflatable system, inserted into the vaginal canal, that can be used to block the passage of stool from the rectum between bowel movements, thereby ensuring autonomy over their timing.

## Talking to Patients about Fecal Incontinence

Clinical literature on fecal incontinence provided Rosen and Herbowy with deep scientific knowledge about the problem but offered little perspective on people's experiences in living with the condition. Accordingly, the co-founders invested significant time and energy in conducting first-hand user research. Rosen recalled speaking to over 100 patients over several months.

The team anticipated that patients would feel uncomfortable discussing the problem, given that the literature indicated the level of shame and stigma associated with fecal incontinence is higher than that of depression or cancer.[2] They also had some concerns that women might be less receptive to their inquiries, given that they were two men working in the area of women's health. However, as a result of careful preparation and planning for their interviews, they were they were encouraged that women of all ages opened up relatively easily. When asked about the key to their success, he emphasized the importance of establishing rapport and using effective language.

Rosen viewed building rapport as an essential first step in any interaction. "We were clear from the beginning of each interview that we were interested in understanding the problem and developing an effective solution. This helped us convince the patients that we were committed to the issue and that they could trust us." By expressly acknowledging the sensitive nature of the subject, demonstrating genuine empathy for each interviewee, and ensuring them that their responses would be kept confidential and not attributed to individuals by name, the team was able to create a "safe space" in which people felt comfortable speaking candidly. They were also careful not to make the interview feel like a doctor's appointment, with the person asked to describe their symptoms, reactions, or episodes in the most factual

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manner possible. Instead, they treated each interview as a genuine conversation, encouraging people to share stories about their experiences and discuss the ways they had learned to cope with the condition.

In terms of language, Rosen remembered that they purposefully wanted each discussion to feel validating to each individual rather than making them feel like there was something abnormal or "wrong" with them as a person. This meant choosing language that would help normalize the condition rather than further stigmatizing it. For example, instead of asking about "incontinence" or "bowel leakage," they learned to refer to incidents as "bowel control issues." They also avoided unnecessary medical jargon in favor of commonly used words and concepts. For instance, when they began seeking feedback on their solution concept, they likened it to a tampon instead of describing it as an "inflatable balloon system inserted into the vaginal canal." Making the interviews as visual as possible was another way to avoid using anatomical and clinical language that could make people feel uncomfortable. They were intentional about using illustrations and animations to ensure that patients understood their solution clearly and could give feedback appropriately. Based on their learnings, Rosen and Herbowy created an interview guidebook that outlined preferred language, effective phrasing, and fruitful approaches. They regularly edited the guidebook as they accumulated knowledge about how to interact with interviewees in a productive and affirming manner. This guidebook ultimately served as the basis for their product's preliminary branding and marketing when it was time to launch their device, helping to ensure that individuals saw their needs reflected in the product.

As a result of the team's efforts, the interviews ultimately revealed important experiential details that helped inform the project's direction. For example, they were able to discern that it was not necessarily the quantity of accidents that mattered most to patients, but rather when accidents happened. For instance, he recalled speaking with a young woman in Silicon Valley who had just started a new job but had to schedule her whole day around this problem. She had to wait to take the train to the city after 10:00 am, when her bowel movement of the day was complete, in case it happened at a moment when she could not use the restroom. "She wanted to regain control of her life," he explained. "These conversations gave me so much insight beyond what was in the literature. They revealed the nuanced details of people's lives that are difficult to understand when only doing desktop research." He continued, "In addition to the insights we gained, these discussions helped me internalize the need, which was incredibly motivating. When you are working on PowerPoints and in the engineering lab, you can forget the impact of your work, but these conversations stay with you at an emotional level. They galvanize you to find a way to make the venture work so that you can help these patients."

## Key Take-Aways

- Understand that when working with stigmatized topics, it is essential to conduct extensive user research to capture insights that are not readily available in traditional literature.
- Find individuals who are highly motivated to solve the unmet need when initiating these types of interviews.
- Invest time in building rapport at the outset of each interview to create a safe space for people and encourage them to speak candidly.
- Use language and phrasing that is affirming and relatable, ensuring clear communication and a shared understanding.
- Leverage the insights from these interviews to guide the design and development of a product that will genuinely address the unmet need.

1 "Fecal Incontinence," Baylor Medicine Obstetrics and Gynecology, 2023, https://www.bcm.edu/healthcare/specialties/obstetrics-and-gynecology/urogynecology-and-reconstructive-pelvic-surgery/fecal-incontinence (May 19, 2025).
2 Rantell, A. "Tackling the Stigma of Incontinence," CRC Press eBooks, 2023, pp. 10–16, https://doi.org/10.1201/9781003144236-3 (May 19, 2025).