

How SHG delivered actionable insights to shape patient care strategies for Fabry disease



Background

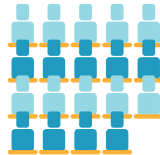
SHG conducted a mixed-methodology project with Fabry disease patients to explore their disease journey, daily challenges, perceptions of Enzyme Replacement Therapy (ERT), infusion experiences, feelings between infusions, changes over time and unmet support needs.

Specifications

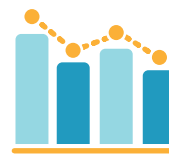
Methodology

In-home interviews (90 minutes, conducted 1-2 days post-infusion), three online surveys tracking patient experiences and follow-up calls (45 minutes, days before the next infusion)

Quota:
19 Fabry patients



Incidence rate:
40%



Location:
UK



Approach

This patient-centered approach provided in-depth insights into the physical, emotional and social aspects of living with Fabry disease. Recruiting was challenging, due to the rarity of the condition, but SHG creatively partnered with patient association groups and used referrals to meet the quota. Coordination around infusion schedules required flexibility and proactive communication, which SHG managed seamlessly, building rapport to keep patients engaged.



Results

- **We exceeded expectations** by recruiting an additional respondent of interest to the client.
- **We strengthened client rapport** through weekly calls, regular updates and transparency, fostering cooperation throughout the project.
- **We developed strong relationships** with the PAC and respondents, culminating in a successful study where two Fabry patients participated in a face-to-face group interview.



Partnering with SHG on this patient ethnography piece allowed us to create a methodology that suited our patients (something we don't always do in market research) and helped us get deeper insights. SHG was a pivotal partner in not just organising the fieldwork but collecting meaningful data for us. Our client loved the outputs and we're already planning further research as a result.

This study highlighted the benefits of a flexible, patient-centered approach for understanding the Fabry disease experience. SHG's collaboration and adaptability helped deliver actionable insights that are shaping patient care strategies. The study's findings received positive feedback from patients and the client, with participants expressing a better understanding of their condition and the client finding the insights highly valuable for future planning. The research study will be published.

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