

# Exploring Physicians' Perspectives on Barriers to Engaging Patients with Rare Diseases and/or Their Caregivers in Shared Decision-Making in the United States (US): Findings from a Cross-Sectional Survey

**Authors:** Amina Omri<sup>1</sup>, Stacey Purinton<sup>2</sup>, Tim Irfan<sup>3</sup>, Perrine Le Calvé<sup>1</sup>, Bastien Vincent<sup>1</sup>, Tarek Mnif<sup>1</sup>, Vicky Nogueira Pileggi<sup>4</sup>, Franco Esposito<sup>5</sup>, Tanya Collin-Histed<sup>6</sup>, Suzanne Reed<sup>1</sup>

**Affiliations:** 1. Oracle Life Sciences, Paris, France; 2. Oracle Life Sciences, Kansas City, MO, USA; 3. Oracle Life Sciences, Munich, Germany; 4. Oracle Life Sciences, São Paulo, Brazil; 5. All Global, London, United Kingdom; 6. International Gaucher Alliance, London, United Kingdom

## Background

- Shared decision making (SDM) is a collaborative process in which clinicians and patients work together to select treatments based on clinical evidence and the patient's informed preferences and values<sup>1,2</sup>.
- SDM is a two-way process requiring patients to effectively communicate their values, experiences, and concerns, while clinicians share medical and risk information to reach the best individual decision<sup>2,3</sup>.
- In rare diseases (RD), evidence may be limited and care pathways are complex. SDM can improve patient-reported outcomes and strengthen the clinician-patient relationship, making patient and caregiver engagement a cornerstone of quality care<sup>4,5</sup>.

## Objective

To understand primary care physicians' and specialists' perceptions of the main barriers to shared decision-making in rare disease.

## Methods

- In this cross-sectional survey, PCPs and specialists from the US were recruited through physicians' panels. Data collection occurred between October and November 2025.
- Data analyses were of a descriptive nature, for the overall sample and stratified by PCPs, and specialists. Differences between the two groups were measured with Pearson's Chi-squared test or Fisher's exact test.

**References:**

- Faiman B, Tariman JD. Shared Decision Making: Improving Patient Outcomes by Understanding the Benefits of and Barriers to Effective Communication. *Clin J Oncol Nurs*. 2019;23(5):540-542. doi:10.1188/19.CJON.540-542
- Muscat DM, Shepherd HL, Nutbeam D, Trevena L, McCaffery KJ. Health Literacy and Shared Decision-making: Exploring the Relationship to Enable Meaningful Patient Engagement in Healthcare. *J Gen Intern Med*. 2021;36(2):521-524. doi:10.1007/s11606-020-05912-0
- Rosca A, Karzig-Roduner I, Kasper J, Rogger N, Drenwaniak D, Kroner T. Shared decision making and advance care planning: a systematic literature review and novel decision-making model. *BMC Med Ethics*. 2023;24(1):64. doi:10.1186/s12910-023-00944-7
- Babac A, von Friedrichs V, Litzkendorf S, Zeidler J, Damm K, Graf von der Schulenburg JM. Integrating patient perspectives in medical decision-making: a qualitative interview study examining potentials within the rare disease information exchange process in practice. *BMC Med Inform Decis Mak*. 2019; 19:188. doi:10.1186/s12911-019-0911-z
- Forsythe LP, Szydłowski V, Murad MH, Ip S, Wang Z, Elraiyah TA, Florence R, Hickam DH. A Systematic Review of Approaches for Engaging Patients for Research on Rare Diseases. *J Gen Intern Med*. 2014;29(Suppl 3): 788-800. doi: 10.1007/s11606-014-2895-9

## Results

Participants included:

**206** PCPs      **411** Specialists

**Table 1** Distribution of medical specialties among participating physicians

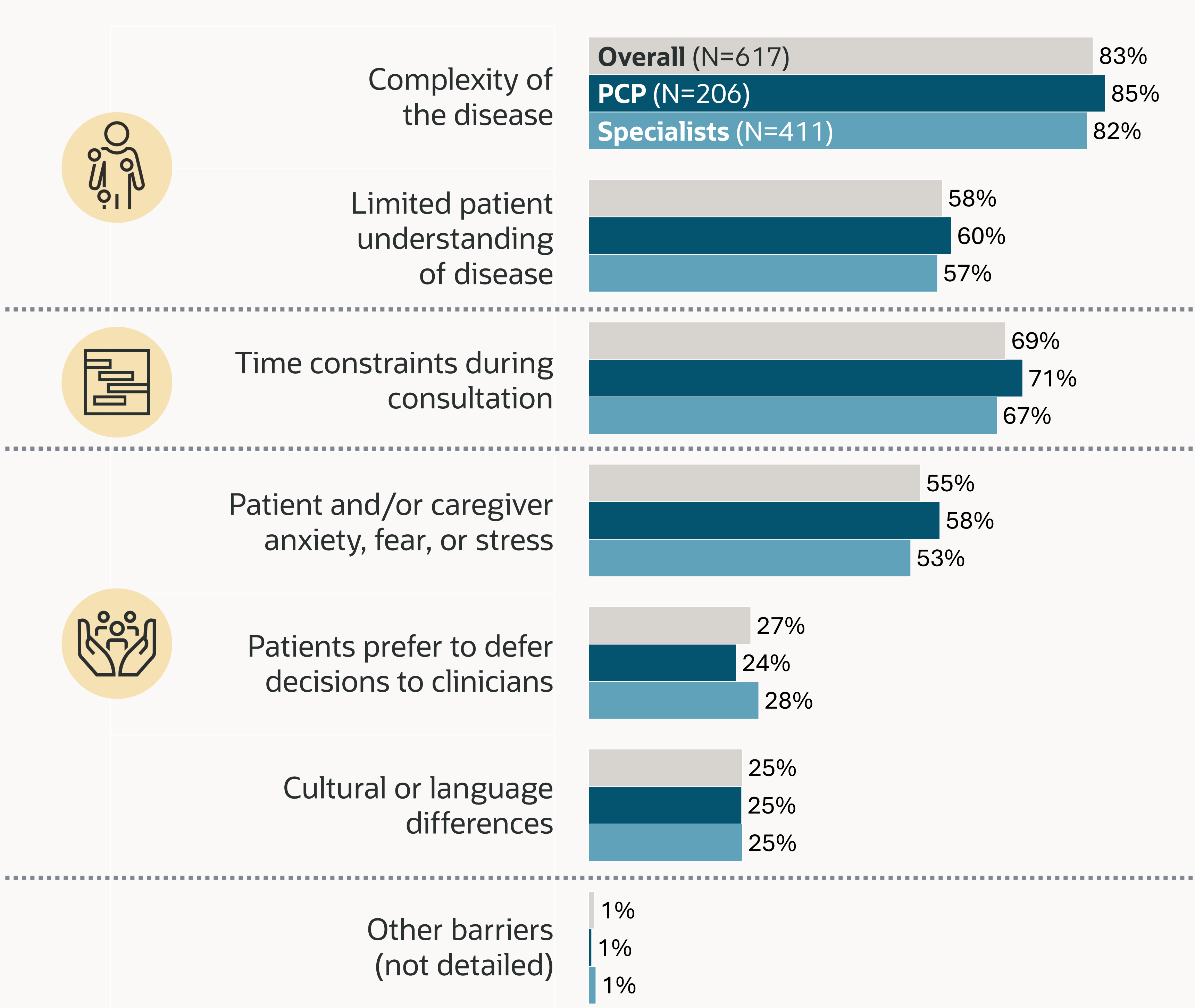
Medical specialty	N=617, n (%)
Family Medicine / General Practice	124 (20.1%)
Internal Medicine	82 (13.3%)
Pediatrics	44 (7.1%)
Cardiology	44 (7.1%)
Gastroenterology	39 (6.3%)
Ophthalmology	36 (5.8%)
Obstetrics & Gynecology	31 (5.0%)
Nephrology	30 (4.9%)
Neurology	30 (4.9%)
Rheumatology	30 (4.9%)
Pulmonology	29 (4.7%)
Dermatology	27 (4.4%)
Infectious Disease	21 (3.4%)
Urology	19 (3.1%)
Endocrinology/Diabetes	18 (2.9%)
Hemato-oncology	13 (2.1%)

When asked about barriers to engaging patients with rare disease and/or their caregivers in decision making, respondents could select items from three main categories:

- Patient-related barriers**
- Disease understanding barriers**
- Organizational barriers**

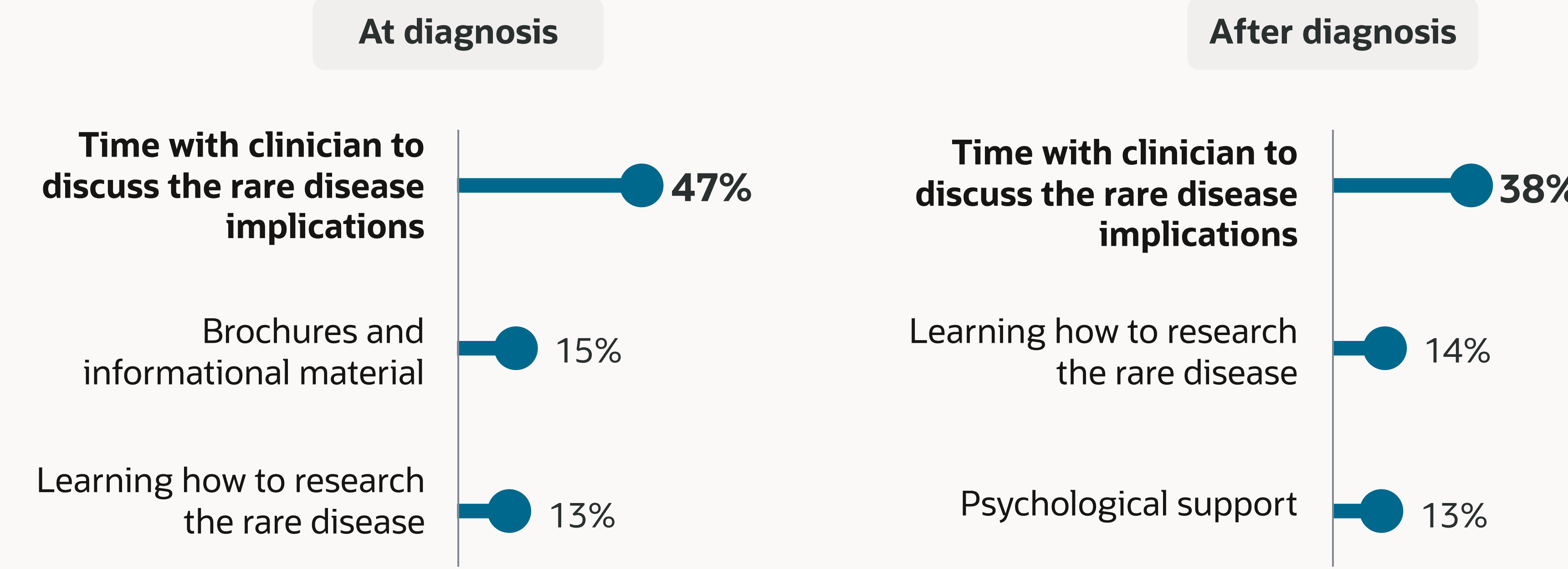
**Physicians most frequently cited the complexity of the disease** (83% overall, 85% PCPs, 82% specialists), followed by time constraints during consultation (69% overall, 71% PCPs, 67% specialists), and limited patient understanding of disease (58% overall, 60% PCPs, 57% specialists) as perceived barriers (**Figure 1**).

**Figure 1** Physician-perceived barriers to shared decision making with patients with rare disease and/or their caregivers



**Time constraints being a barrier to engagement was further reinforced** when physicians were asked about the top additional support needed by patients and/or caregivers. **Physicians ranked "time with clinician" as the number one priority** most frequently, both at and after diagnosis (**Figure 2**).

**Figure 2** Patient support needs most frequently ranked as top priority by physicians



## Conclusion



- RD complexity and limited patient understanding were the most frequently reported barriers to engagement, highlighting the need for targeted patient education to support informed decision-making in RD.
- Time constraints were equally prominent, further reinforced by physicians identifying additional allocated time with clinician as the top support priority for patients.
- SDM represents a collaborative model of care that treats patients as partners rather than passive recipients, yet its implementation in RD remains challenged by several barriers. Addressing these barriers through broadened awareness of RD patient advocacy groups and dedicated consultation time is essential to enhance the implementation of SDM in RD.

