

PATIENT AND CAREGIVER PERSPECTIVES AND EXPECTATIONS OF PLAIN LANGUAGE SUMMARIES (PLS)

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BACKGROUND

- Patient involvement in drug development and healthcare decision-making is increasing, with patients playing a more active role beyond participation as trial subjects. As this involvement grows, **there is a greater need to communicate clinical and real-world research results to patients and caregivers** in ways that are clear, meaningful, and easy to understand.
- Health authorities increasingly support patient engagement and the use of patient-friendly research communication. **Plain Language Summaries (PLS) are one way to share study results with patients**; however, they remain uncommon, vary widely in quality, and rarely incorporate patient input.
- **This study aimed to identify patient and caregiver preferences for presenting research outcomes** to better understand effective ways for communicating medical research findings to patients and their caregivers.

METHODS

- Patients and caregivers aged 18+ living in the US and UK were recruited via social media to complete a 20-minute online survey.
- Recruitment aimed for a diverse and representative sample across age, gender, education, income, race, ethnicity, and medical conditions.
- Individuals with education or professional experience in medical science or clinical research were excluded.
- The survey included 32 items (open- and closed-ended questions) and assessed awareness and prior experience with PLS, preferences for PLS content, format, length, and access, interest in using PLS, and views on PLS authorship.

RESULTS

Box 1: Demographic characteristics

A total of 51 participants (41 patients, 10 caregivers) from the UK (n=21) and US (n=30) completed the survey in early 2025. The sample was diverse in age, gender, race/ethnicity, education, income, and medical conditions.

Figure 1: Race US (n=30)

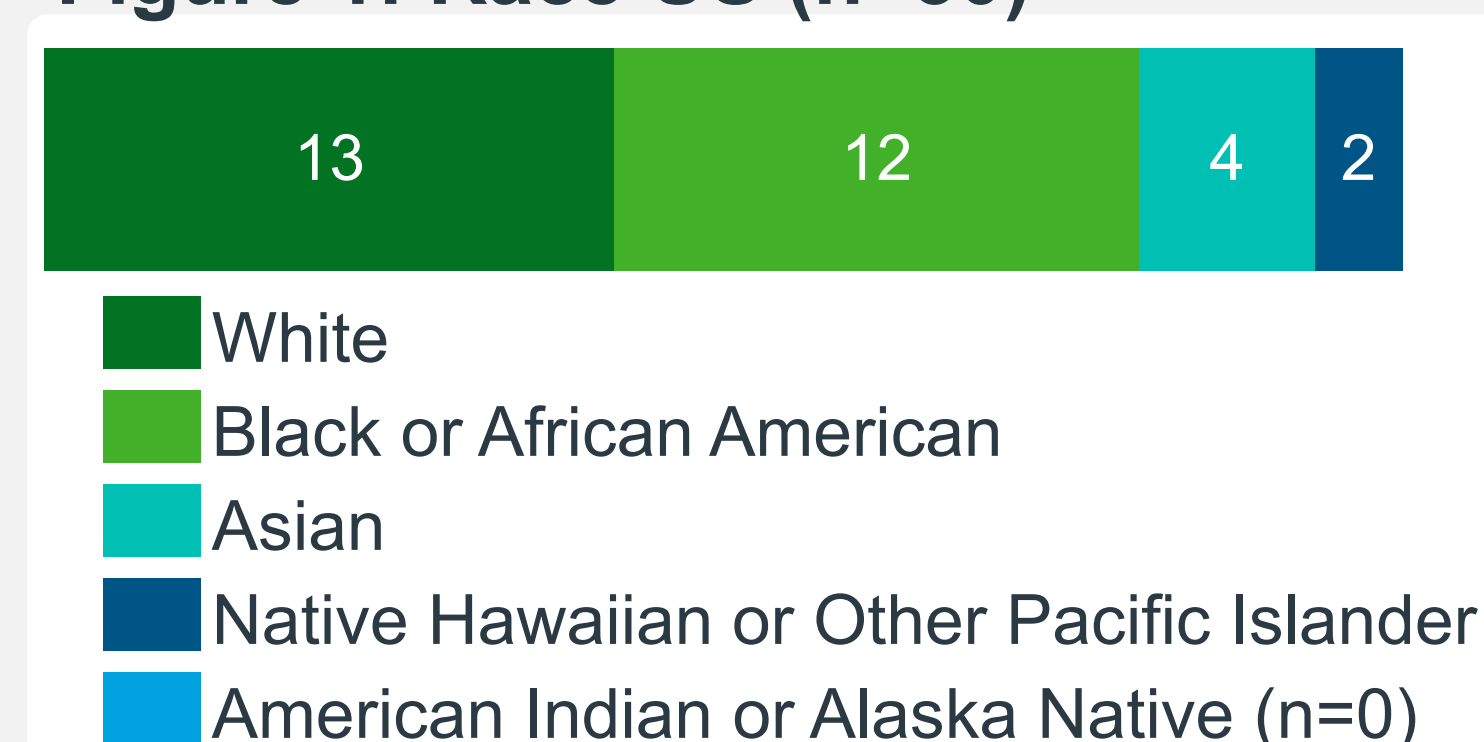


Figure 2: Race UK (n=21)

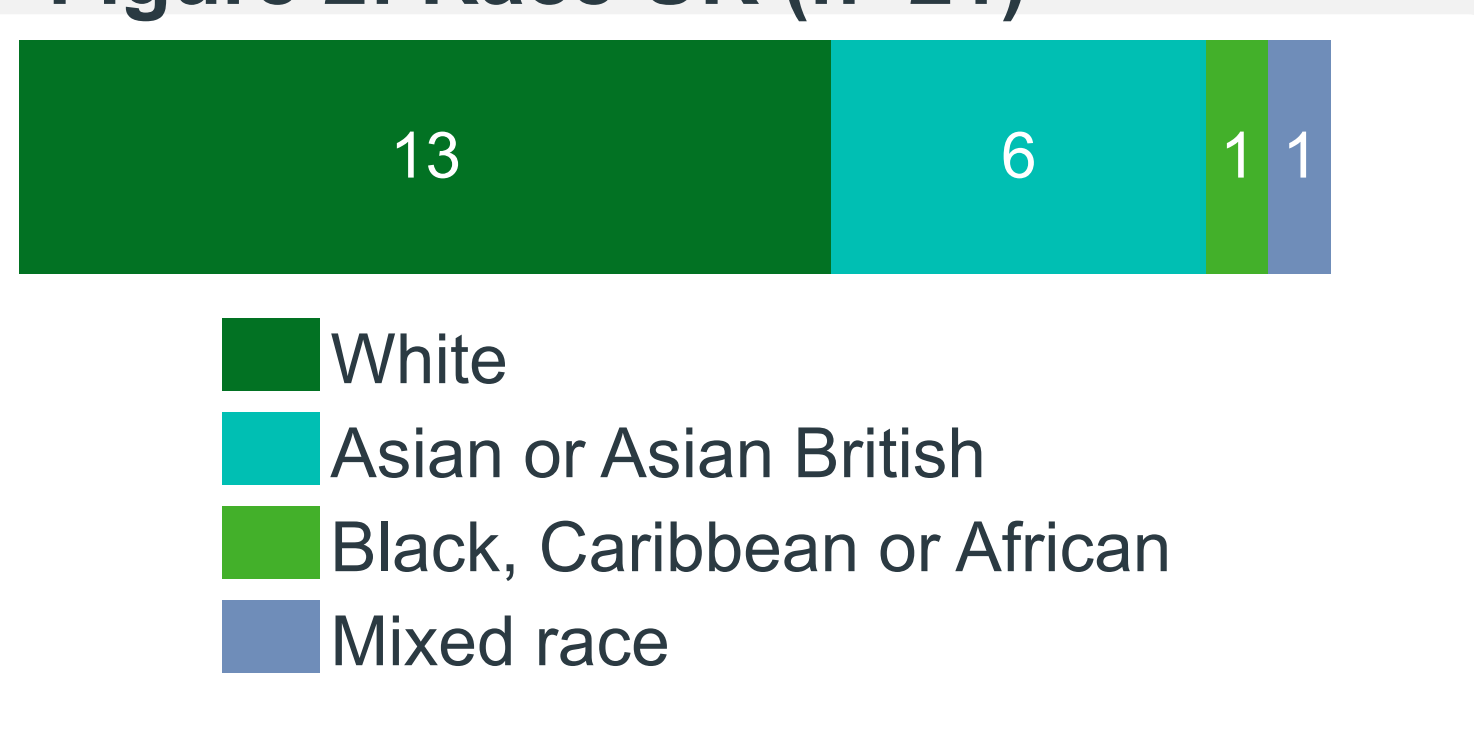


Figure 3: Education level (n=51)

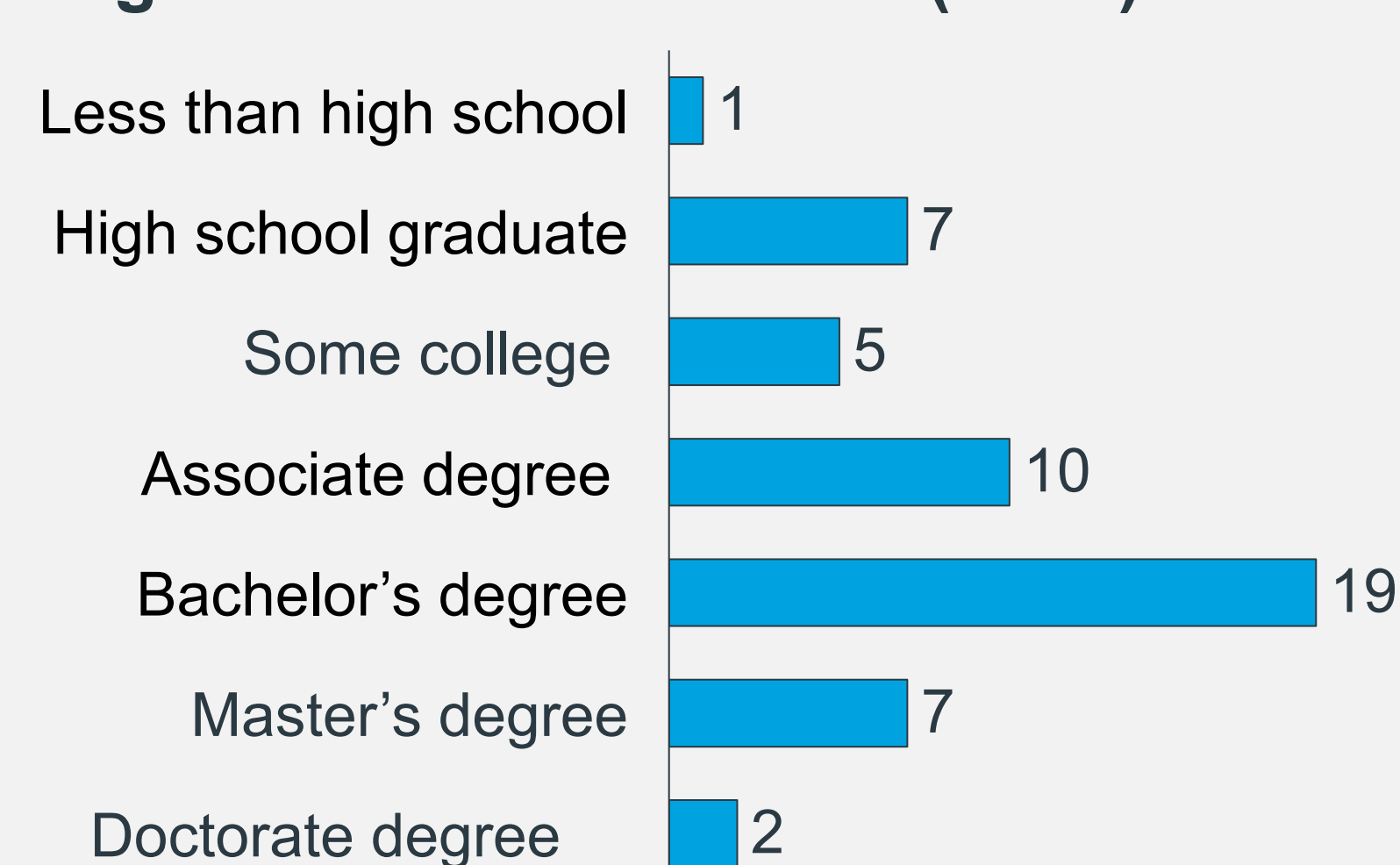


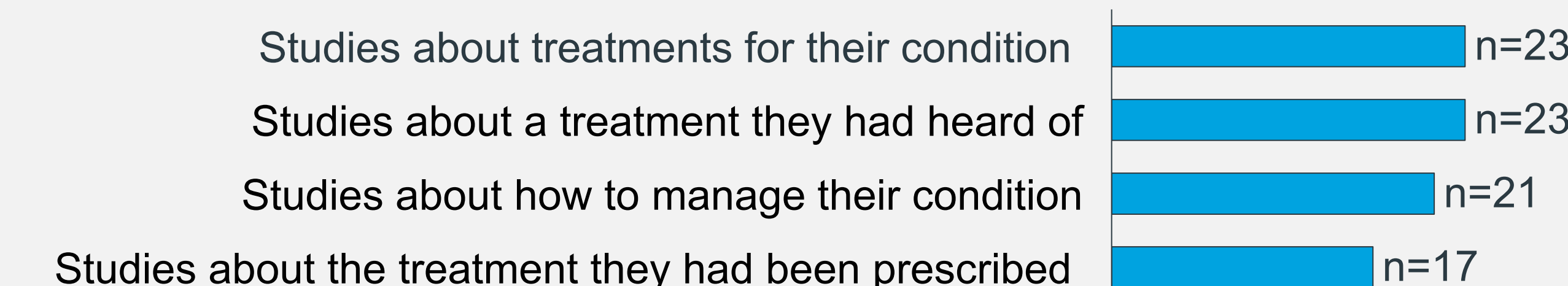
Table 1: Conditions (n=51)

| Condition | Total n=51 |
|--|------------|
| Rare disease | 5 |
| Acute disease | 4 |
| Cardiovascular or other chronic diseases | 16 |
| Cancer | 17 |
| Mental health and neurological disorders | 8 |
| Other | 1 |

Box 2: Awareness and interest in PLS

- Most participants **knew that medical research results** are published in journals (n=37; 73%) and that PLS are written for the public (n=33; 65%).
- A majority were **interested in reading PLS** (n=44; 86%) and had already searched online for study results (n=36; 71%).
- No differences were observed by country (US vs UK) or by role (patients vs caregivers).

Figure 4: Topics searched by participants who looked online for medical study results related to their condition or treatment (N=36)



Box 3: Previous experience with PLS

- Of those who searched online (n=36), **half found information 'easy to locate' (n=18; 50%), while 19% (n=7) found it 'difficult'**. Google or other search engines were most frequently used to find results of medical research.
- Information from **patient association or medical charity websites** was consistently well understood.
- **Participants reported difficulty understanding information on pharmaceutical company websites** (n=2/3; 67%); and PLS in medical or scientific publications (N=4/10; 40%). Moderate difficulty was reported for search engines and healthcare websites.

Figure 5: Sources used by participants to find results of medical research (N=36)

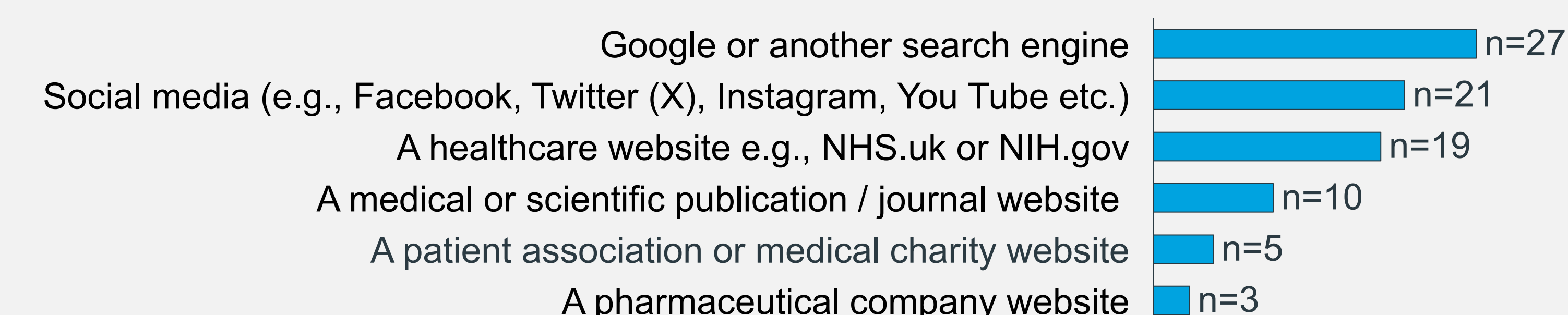
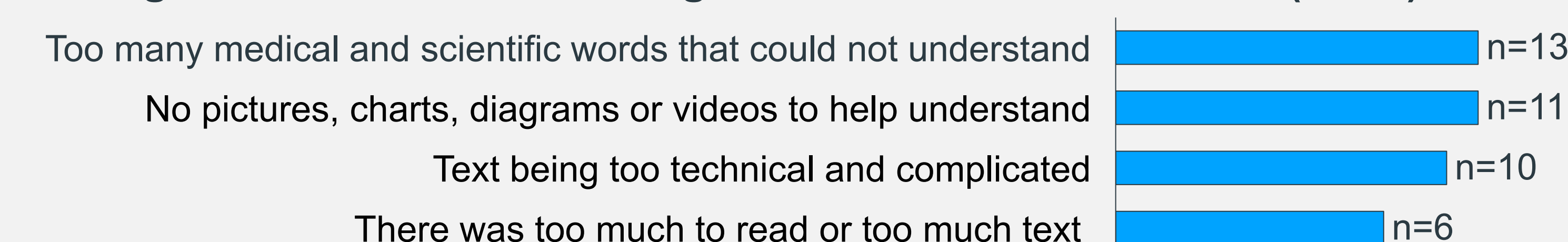


Figure 6: Reasons for finding PLS difficult to understand (N=20)



- Participants (n=26) found the information useful (slightly useful, n=6; moderately useful, n=18, and very useful, n=12).
- Eleven participants **reported missing information and indicated they would have liked more detail on disease management, prevention, causes, treatment options, and more personalized or age-specific content.**
- Over half of the participants (55%) had used **AI to find healthcare information** and described the experience as excellent or good.

Box 4: Desired PLS content and format

- Participants (n=51) desired content included **trial results, quality of life impacts, treatment benefits vs. risks, and trial population characteristics.**
- Preferred formats were **written text** (n=40/51; 78%), **pictures/graphs** (n=37/51; 73%), and **short videos** (n=24/51, 47%).
- Participants (n=41; 80%) expected a **doctor or scientist to lead summary development.**
- If written, participants (n=39/51; 78%) prefer the PLS to be **~1 page long** and needing 6-20 mins to read; if video, duration should be 1 min or longer.
- Most participants would use the PLS to understand more about their **condition** (n=45/51; 88%).

Figure 7: PLS format preferences (N=51)

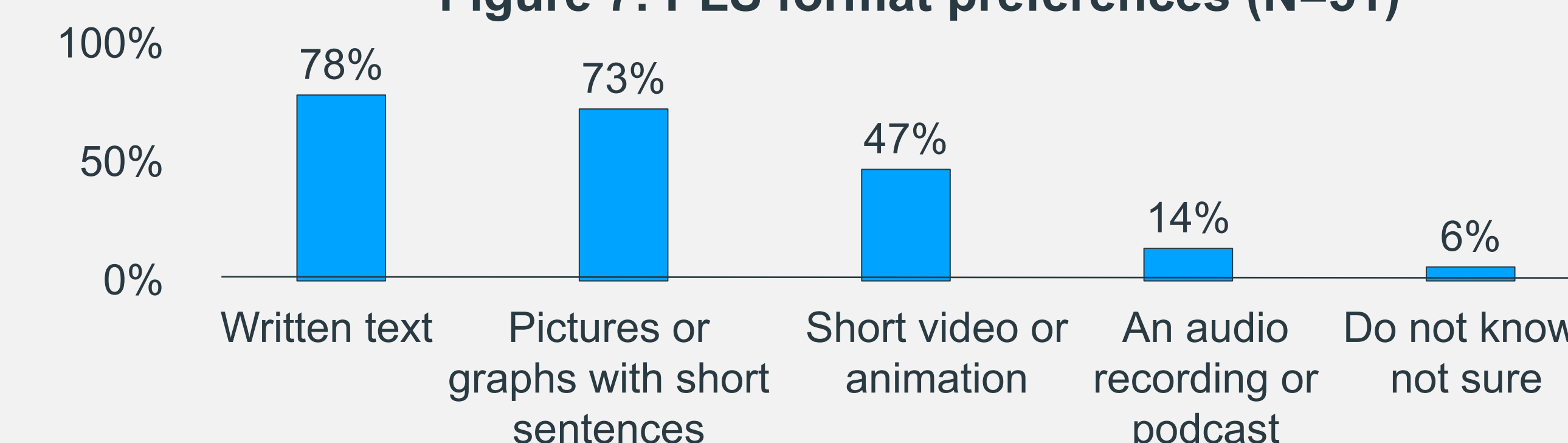
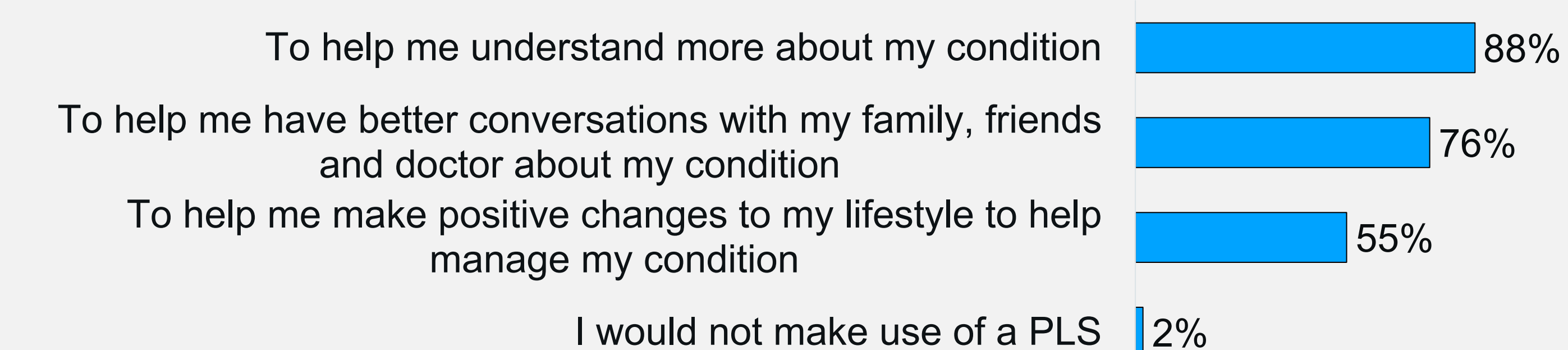


Figure 8: Reasons for using a PLS (N=51)



CONCLUSIONS

Patients and caregivers actively seek information about treatments for their condition, disease management and potential impacts on daily life. They prefer content presented as written text with pictures or graphs. Although the study sample was diverse, with some skew toward higher education, many participants still reported difficulty understanding PLS, indicating that current materials remain too complex and technical. These findings demonstrate high demand for PLS and highlight the importance of integrating patient and caregiver perspectives throughout the development of PLS, to ensure that content is accessible, relevant, and aligned with their information needs. Doing so can improve understanding, build trust, and more effectively support informed decision-making.