Patient Awareness of and Perspectives on Plain Language Summaries

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Background

- Plain language summaries (PLS) explain medical research and complex medical topics in a clear and understandable way to engage a broad readership, including nonspecialist healthcare professionals, patients, and the general population
- PLS can help patients to better understand medical topics and facilitate shared decision-making between patients and providers, thus enabling patients to become better advocates for their own health
- Numerous journals are now publishing PLS, and patients are more frequently being involved in medical publications like PLS
- Data are limited pertaining to patient awareness of PLS, how patients access PLS, and how they use information gained from PLS

Objective

- To understand awareness and use of PLS in adults with urologic conditions

Methods

- We conducted an internet-based survey distributed through the National Association for Continence (NAFC)
  - A link to a new survey opportunity was posted to NAFC (web pop-up) and in a digital newsletter
- The survey included questions on PLS awareness, interest in reading and authoring PLS, and topics for inclusion in PLS
- Responses from those who identified as patients with a urologic condition and who responded to a question on PLS awareness were analyzed descriptively

Results

Survey Responses

233 responses   **165** patients

Responses were received December 20, 2022– January 3, 2023
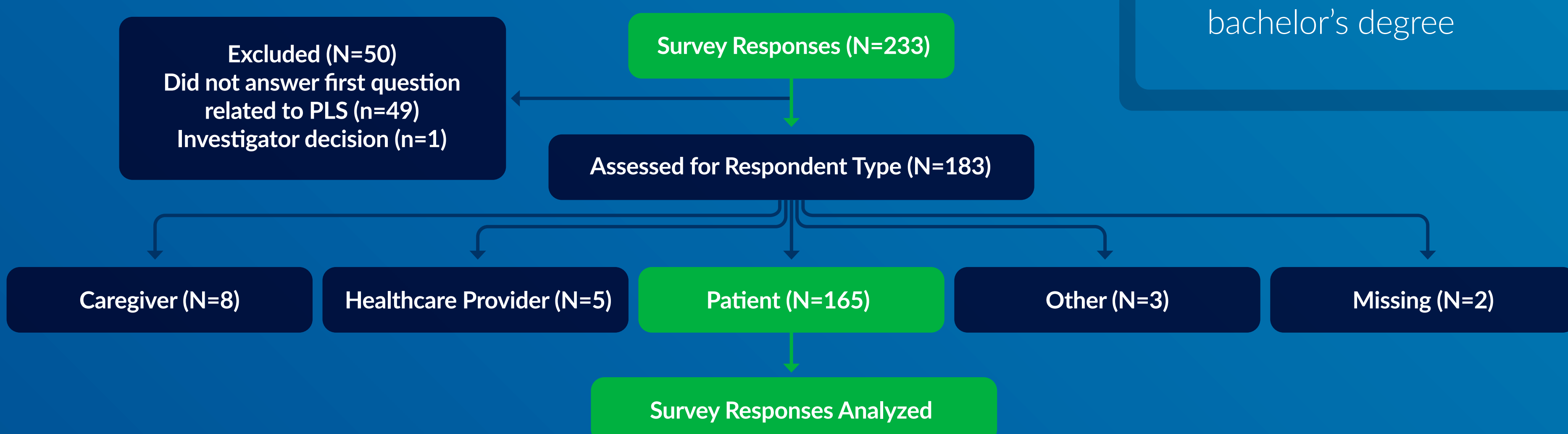
Respondent Characteristics

- Most respondents (62.4%) were ≥60 years of age
- Respondents tended to be white (83.0%) and educated, with 63.6% having at least a bachelor's degree

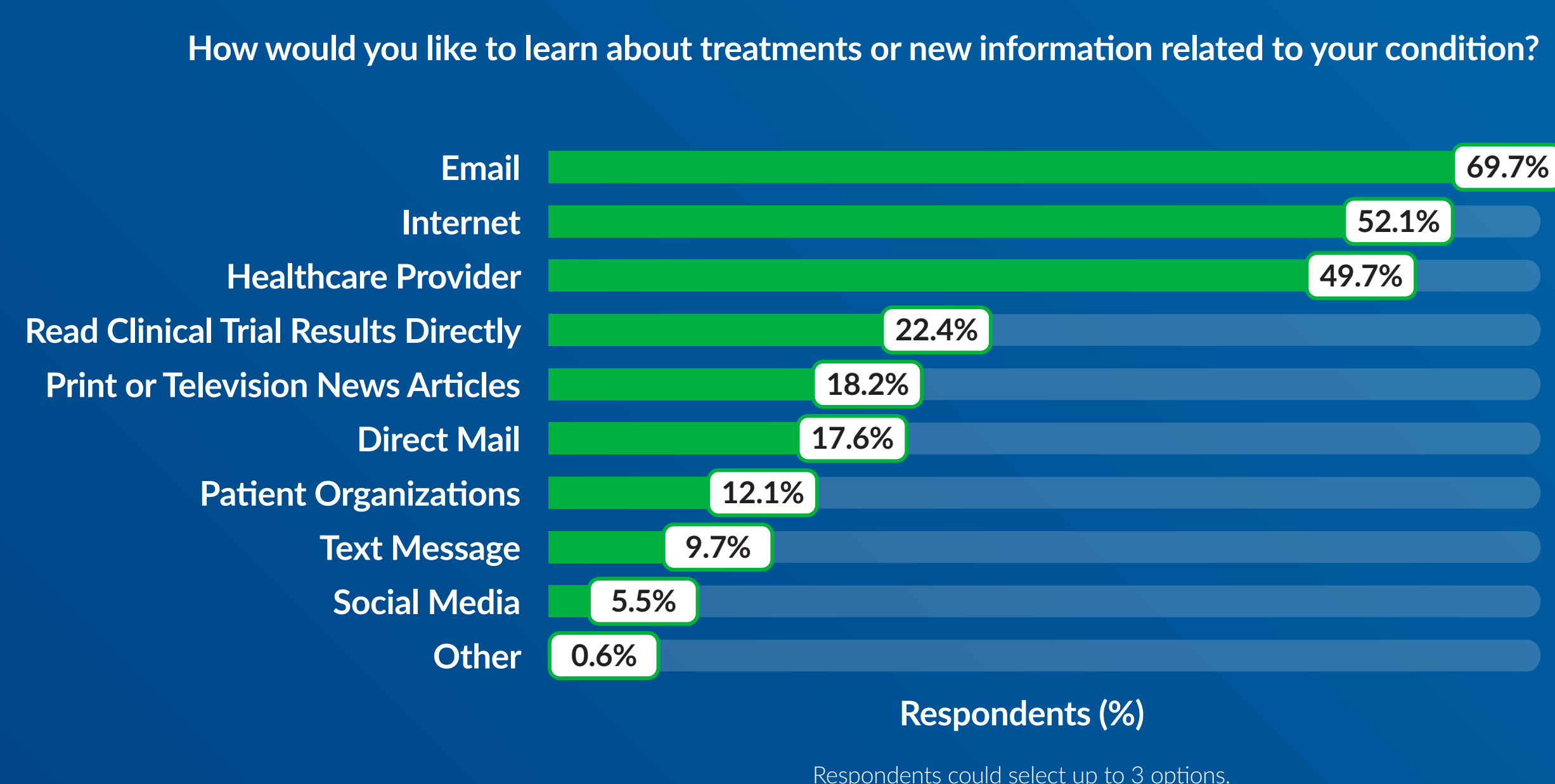| Patient Demographics, n (%)	Respondents N=165
Age range, y	
18–29	3 (1.8)
30–39	7 (4.2)
40–49	14 (8.5)
50–59	21 (12.7)
60–69	43 (26.1)
70–79	38 (23.0)
≥80	22 (13.3)
Prefer not to say/missing	17 (10.3)
Gender	
Female	57 (34.5)
Male	92 (55.8)
Non-binary	1 (0.6)
Prefer not to say/missing	15 (9.1)
Race/Ethnicity	
White	137 (83.0)
Black/African American	3 (1.8)
Asian/Asian American	2 (1.2)
Multiracial	2 (1.2)
Native American/Alaska Native	1 (0.6)
Prefer not to say/missing	20 (12.1)
Highest Level of Education	
Some high school	1 (0.6)
High school	28 (17.0)
Bachelor's degree	54 (32.7)
Master's degree	35 (21.2)
Doctoral degree	16 (9.7)
Other	17 (10.3)
Prefer not to say/missing	14 (8.5)

Familiarity With Plain Language Summaries

- Only 29.7% of patients had previously heard of PLS; of those, 40.8% had read a PLS
- Of those who had read a PLS, 65.0% indicated it was easy to understand
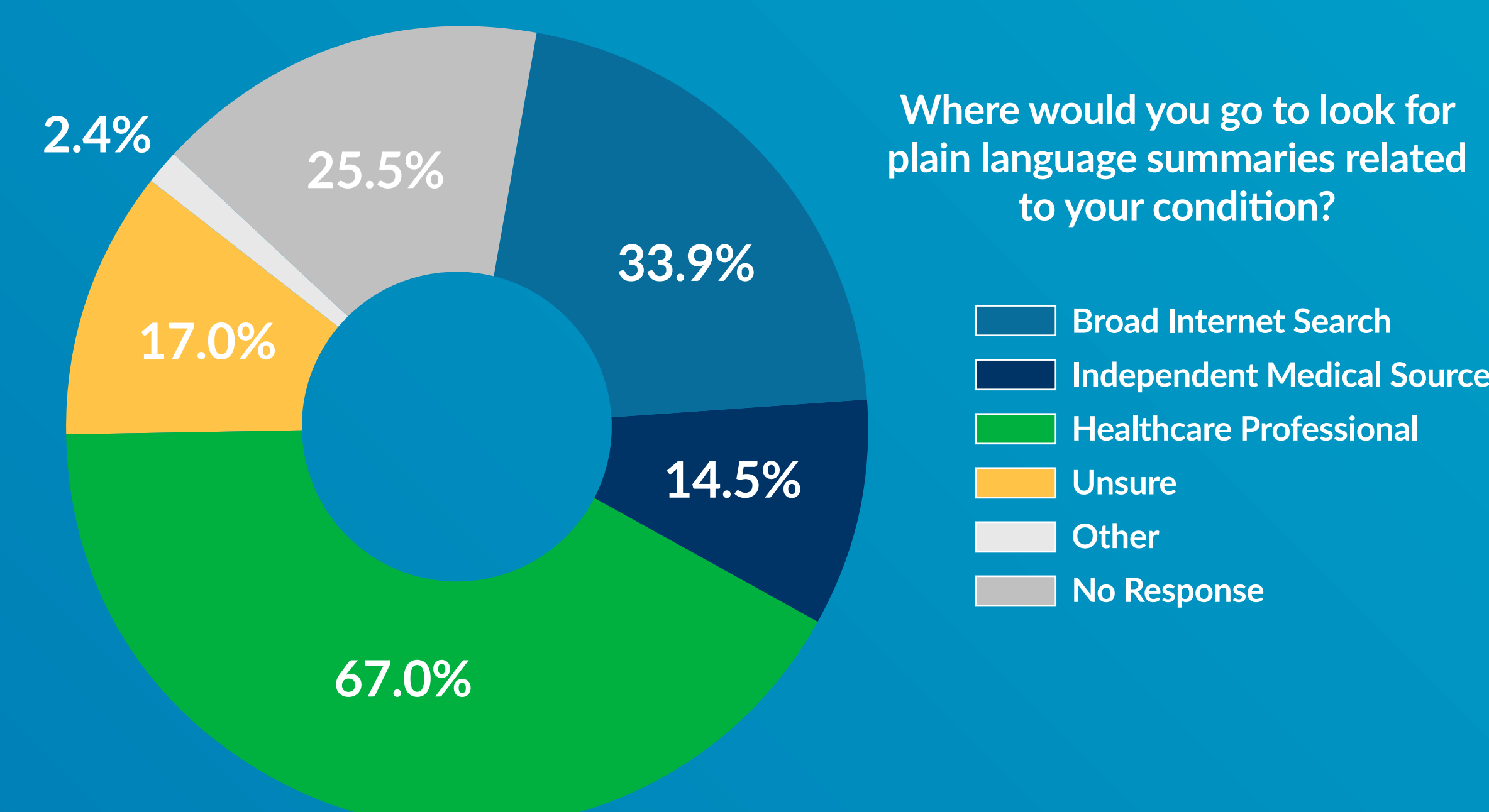
- Patients ranked information about their condition and treatment efficacy as the most important topics for PLS

Patient-Ranked Importance of Topics to Cover in PLS

Respondents ranked topics from 1–6, with 1 indicating the most important topic.

- Most patients (85.5%) indicated they would be interested in reading a PLS
- 31.5% indicated interest in being a patient author

Staying Current With Updates

- 70.9% reported that they stay current with scientific/medical updates

How would you like to learn about treatments or new information related to your condition?

	Respondents (%)
Email	69.7%
Internet	52.1%
Healthcare Provider	49.7%
Read Clinical Trial Results Directly	22.4%
Print or Television News Articles	18.2%
Direct Mail	17.6%
Patient Organizations	12.1%
Text Message	9.7%
Social Media	5.5%
Other	0.6%

Respondents could select up to 3 options.

Familiarity With Clinical Trials

Did you know results from clinical trials are published or posted?

YES 51.5%   MISSING 17.0%   NO 31.5%

If you have read the results from a clinical trial on ClinicalTrials.gov or in a medical journal, did you find the study and results easy to understand?

YES 42.4%   NOT APPLICABLE 24.7%   NO 32.9%
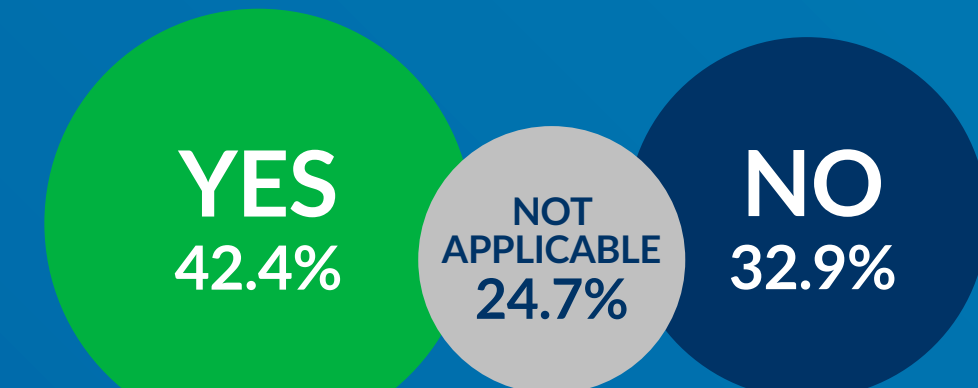
Have you ever visited ClinicalTrials.gov to view clinical trial results? — YES 34.1% / NO 65.9%
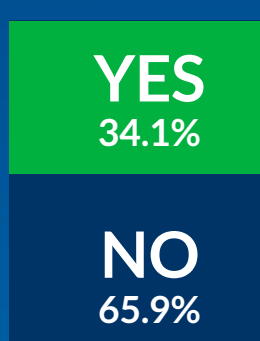
Have you ever read clinical trial results in a medical journal? — YES 61.2% / NO 38.8%

Have you ever read clinical trial results in another way? — YES 64.7% / NO 34.1% — MISSING 1.2%

Limitations

- Survey respondents may not be representative of the overall population
  - Most respondents were 60 years old or above, typical for a population of people with urologic conditions
  - Respondents with higher education may be overrepresented compared with the overall population, and their responses may not be reflective of how the general population keeps up with scientific or medical advances

Conclusions

- In this online survey of patients with urologic conditions, a small percentage of patients with a urologic condition (~one-third) reported having awareness of PLS
- Patients are interested in engaging with PLS and found them understandable
  - Most patients indicated that PLS providing an overview of a specific disease or condition or related to treatments would be the most important to them
  - A small, but not negligible, percentage of respondents indicated they would be interested in authoring a PLS
- Medical communications professionals should fill the unmet need for plain-language medical information by increasing awareness and visibility of PLS and by implementing PLS publications in publication planning and strategies

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