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Are plain language summaries (PLS) reaching patients? Perspectives from a UK type 2 diabetes study.

Conclusions

- Our user-centred research suggests that the awareness of PLS (as either a type of information or the terminology "PLS") is low among UK patients with type 2 diabetes (T2D) although many patients deemed this type of information to be useful.
- Patient experience of PLS appeared to be positive overall; patients thought PLS were relatively easy to find and easy to understand.
- Implementing strategies to optimise patient awareness, accessibility, and discoverability of PLS, such as consistent nomenclature for search engine optimisation and trusted dissemination channels, is key to improving PLS utility and meeting patient needs.

Introduction

- We know that patients readily search for information via the internet,[1] and with increasing patient inclusion in the drug development process,[2,3] the accessibility of trusted health-related information by patients is key to improved understanding and health outcomes.

- PLS are one kind of resource that is increasingly available online that can help patients easily understand clinical research.[1,4]

- Recent research and subsequent guidance have provided recommendations in making PLS user-friendly and comprehensible.[5-8] Nevertheless, there appears to be low awareness of PLS among patients[9] and little user-centred research in this area.

Research design and methods

- Patients who had been diagnosed with T2D by a healthcare professional (HCP) and who had actively sought information online about their condition were recruited from a national UK database.

- Patients with a chronic, common disease were chosen for ease of sampling:
  - Anticipated broad patient population
  - Range of experience accessing online information
  - Active field of research with multiple treatments

- Patients completed a 15-minute online mixed-method survey during August and September 2023 and received an honorarium at fair market value principles for their time.

- Data are presented descriptively; comparisons were made across categories using complement testing (to examine whether two sets of data are significantly different by assessing the elements that are unique to each set).

- Data interrogation was conducted to determine the most meaningful way to categorise the data. Subsequently, data were categorised by time since diagnosis (within the last year, 1–5 years ago, and 6+ years ago) and by those who had recalled reading/using a PLS vs. those who had not. During analysis, we also made comparisons across several other data cuts to explore the data for meaningful insights.

> The objective of this study was to understand how patients search for information relating to their condition, including PLS, in order to improve awareness. As a community, we need to know where patients are looking for information and what search terms patients are using to find that information.

Results

Overall, 200 patients completed the online survey. Patient demographics are shown in **Table 1**.

Education level	N=200	Ethnic group		Patient type		Language preference	
Secondary school up to 16 years	23%	White	92%	Patient	86%	English	100%
Higher/secondary/further education	21%	Asian/Asian British	5%	Patient advocate	1%	Other	0%
College or university	37%	Black/African/Caribbean/Black British	3%	Patient with scientific background	13%		
Postgraduate degree	20%	Mixed/Multiple ethnic groups	1%	Patient advocate with scientific background	1%		
		Other ethnic group	1%				

General information searching behaviours

Figure 1a. Most commonly searched-for topics by patients online

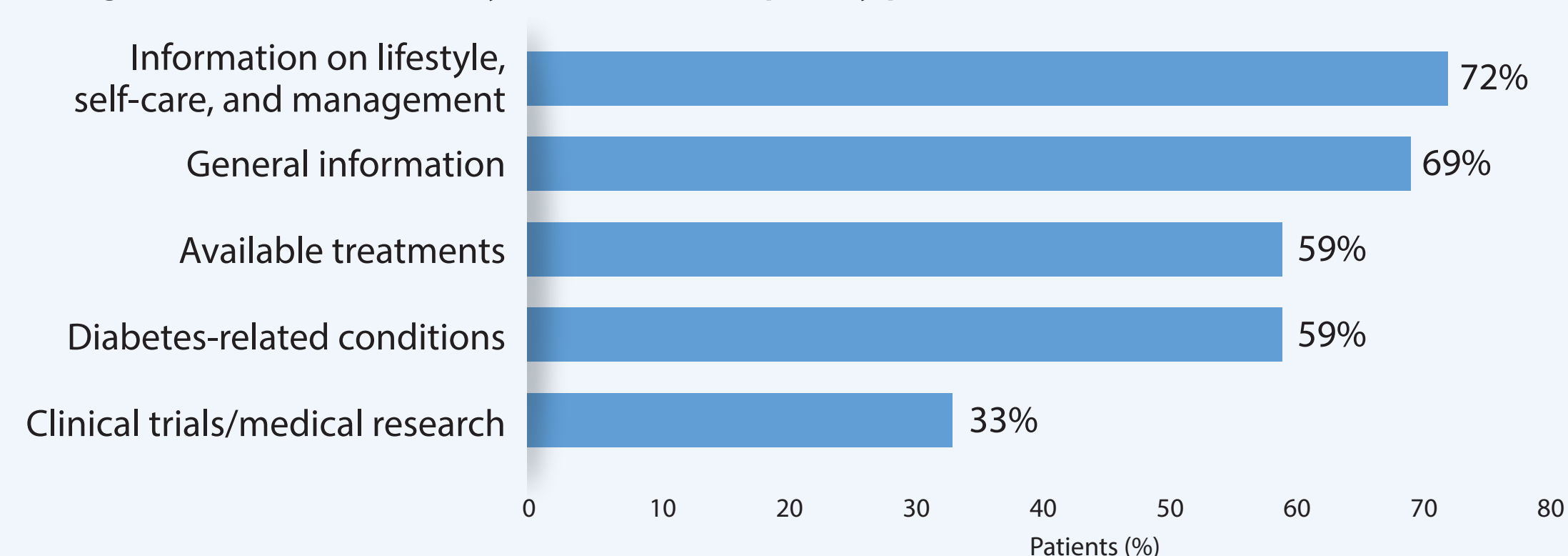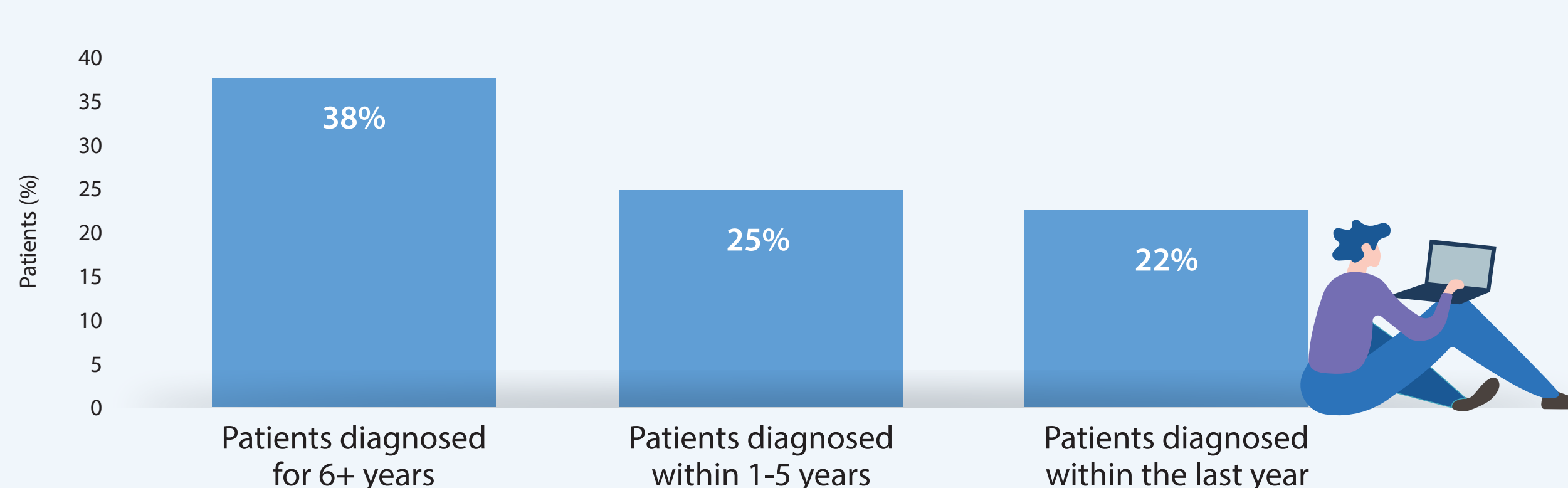| Topic	Patients (%)
Information on lifestyle, self-care, and management	72%
General information	69%
Available treatments	59%
Diabetes-related conditions	59%
Clinical trials/medical research	33%

Figure 1b. Information relating to clinical trials/medical research was searched for by a higher percentage of patients whose time since diagnosis was longest (6+ years) compared with those with a more recent diagnosis

- Patients diagnosed for 6+ years: 38%
- Patients diagnosed within 1-5 years: 25%
- Patients diagnosed within the last year: 22%

- 60% of patients ranked accessing information from an HCP as their most used channel, followed by 49% online (search engine/website).

- When looking for information online, 80% used diabetes-specific websites, 78% used search engines, and 12% used medical journals.

PLS awareness is low

- Having been provided with a description of a PLS within the survey, fewer than 4 in 10 patients (38%) were aware of and had read a PLS.
  - Of those who did not recall previously reading or using a PLS (n=124), only 11% had come across or had heard about them.

- No patients used "PLS" or "plain language summary" as a term when prompted to type what to search if they wanted this information, although "summary" was used in 5.5% of the respondents' answers.

Of those who were aware of and had read a PLS (n=76):

- **58%** accessed them via a search engine
- **47%** accessed them via an NHS website
- **22%** had had them recommended via an HCP

> 75% of these patients said PLS were easy/very easy to find, 80% stated they were easy/very easy to understand, and 82% stated they were fairly/very useful.

**Of those who had not used or heard of a PLS (n=124):**

- **63%** stated that a PLS would be fairly/very useful
- **75%** expected to find a PLS via an NHS website
- **63%** expected to find a PLS via a search engine
- **44%** expected to be recommended a PLS via an HCP

> When asked why they had not used or accessed this type of information online, 51% stated there was nothing that would prevent them from doing so.

- Those who had been diagnosed longest (6+ years, n=117) were significantly more likely to prefer a scientific platform/journal website (9%) as the best way of accessing a PLS vs. 2% of those diagnosed within the past 1–5 years (n=65).
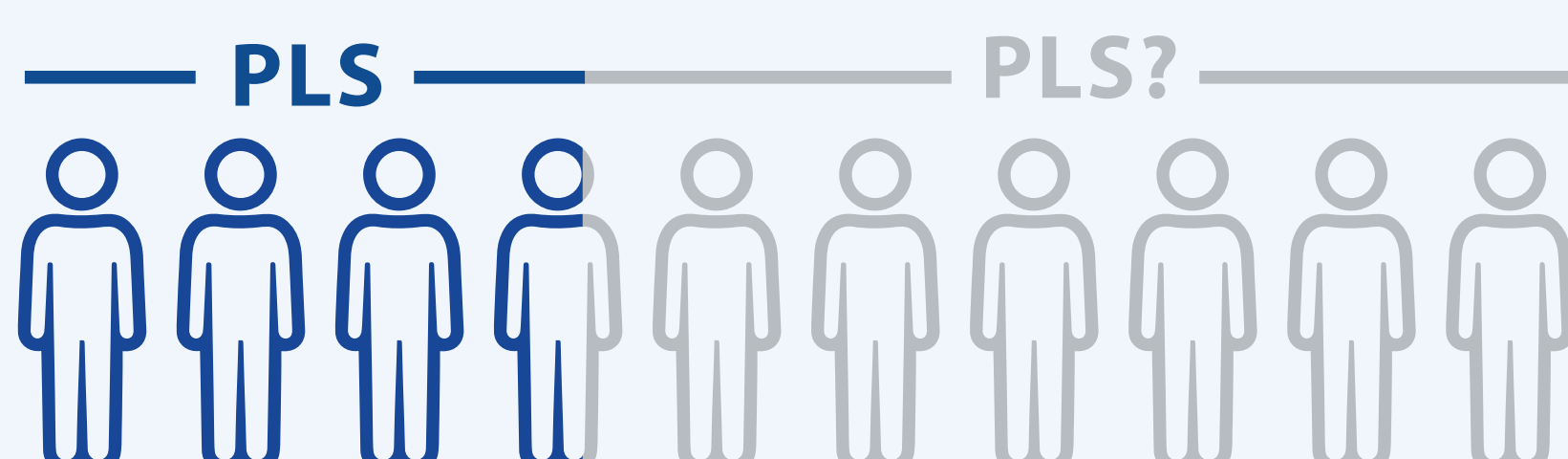
Plain language summaries are useful

- A high percentage of patients (89%) felt that PLS were or would be useful in improving their understanding of diabetes, in having conversations with HCPs (86%) and in the management of their condition (85%).

Trusted information sources include the NHS and HCPs

- Overall, for both those who had and those who had not previously read a PLS:

- **99%** NHS websites*
- **96%** HCP recommendations
- **67%** Scientific online platforms/journal websites
- **52%** Pharmaceutical company-sponsored websites

*Those stating "some" or "high" trust

Figure 2. Scientific online platforms/journal websites and pharmaceutical company-sponsored websites were trusted by a higher percentage of patients who had previously read or used a PLS vs. those who had not

	Had previously read or used a PLS (n=76)	Had not previously read or used a PLS (n=124)
Scientific online platforms/journal websites	76%	61%
Pharmaceutical company-sponsored websites	62%	45%
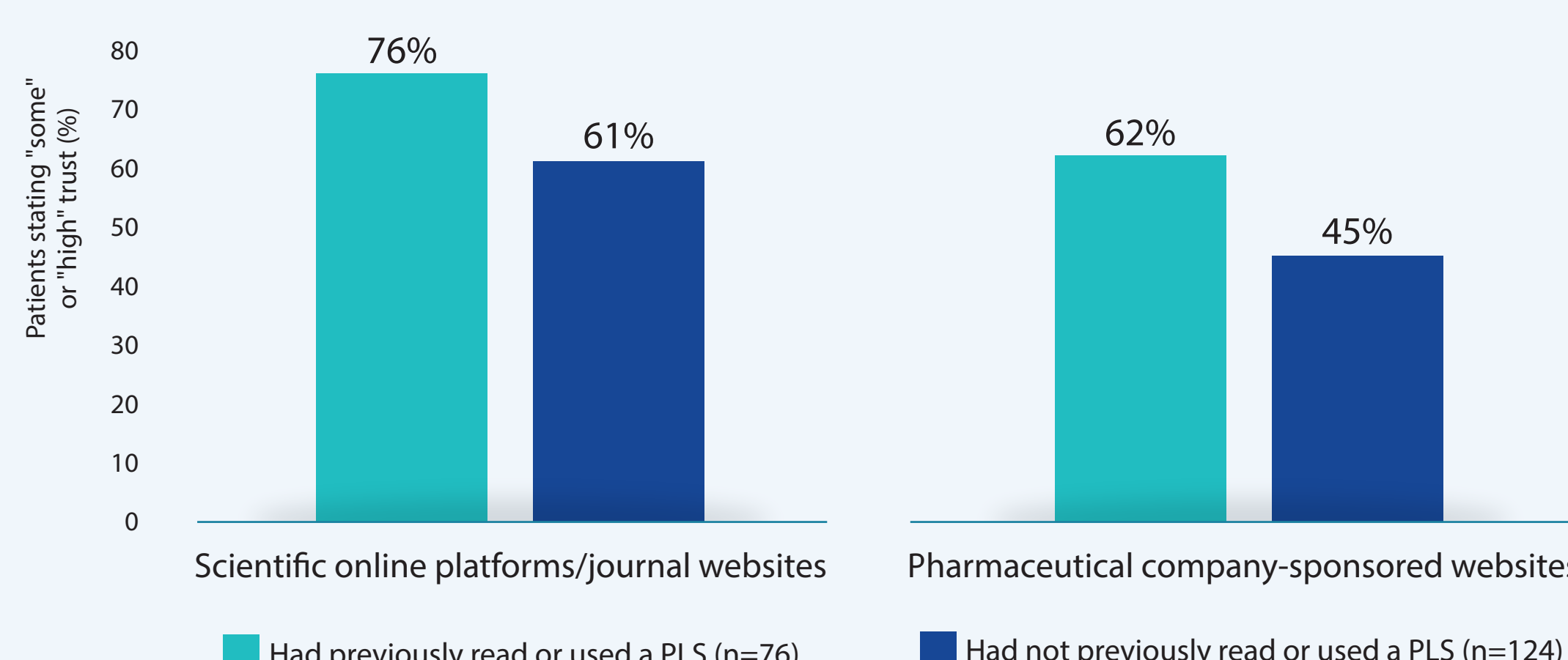
Please access the QR code for a short poster presentation and further details about the study

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