

Cracking the code: how discoverable are plain language summaries?



Taylor & Francis



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Objective

Our aim was to understand how plain language summaries (PLS, including plain language summaries of publications) of published medical research are discovered by different stakeholders and whether there is an unmet need for a centralized database aggregating PLS.

Research design & methods

We developed and shared a multiple-choice online survey via social media (LinkedIn and X) and the ISMPP Connect Forum between November 2023 and January 2024.

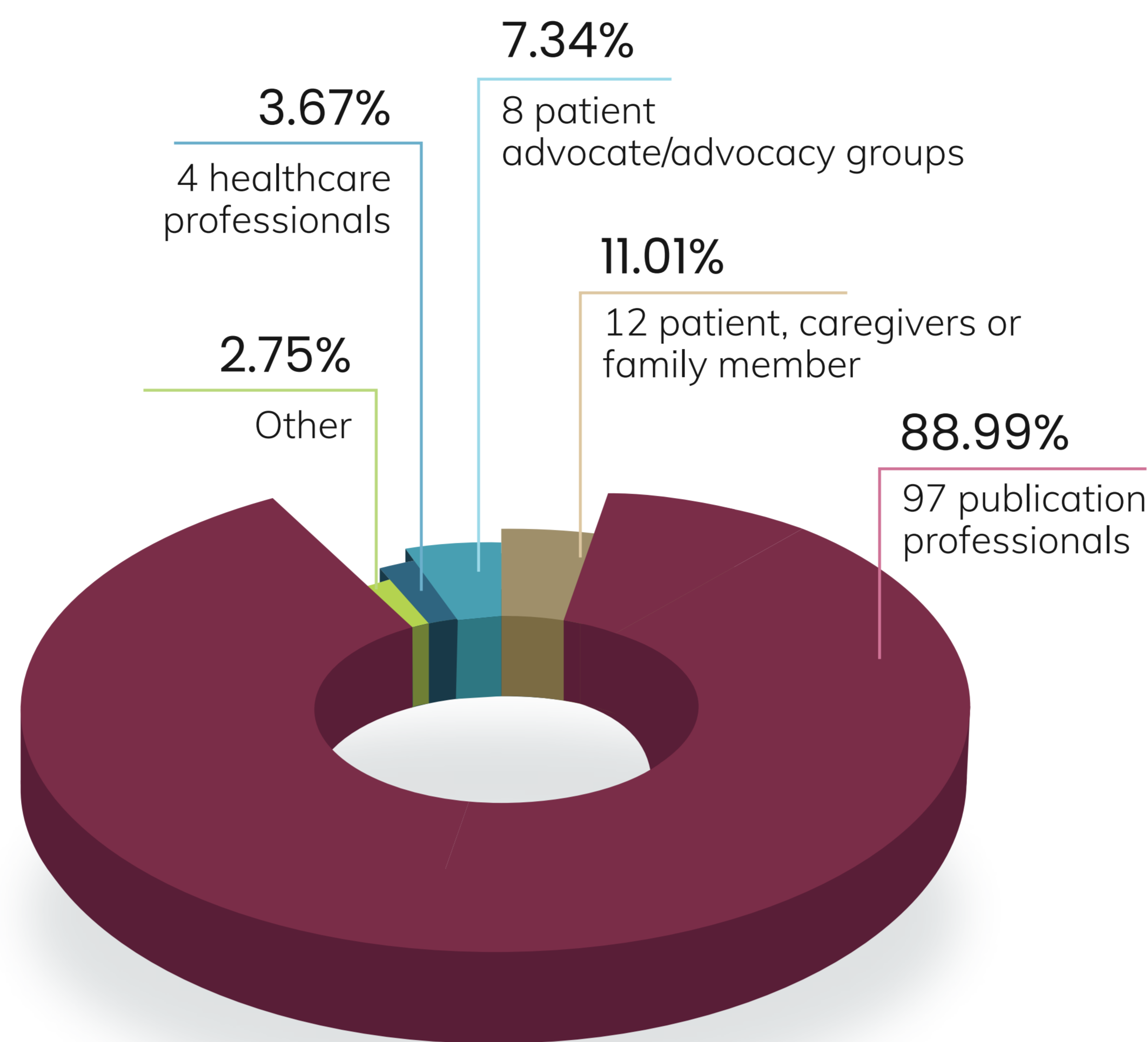
Results

- The survey had 109 respondents that chose one or more affiliations: 97 publication professionals (88.99%); 12 patient, caregiver or family member (11.01%); 8 patient advocate/advocacy groups (7.34%); 4 healthcare professionals (3.67%); and 3 other (2.75%) (Figure 1).
- When asked to rank why PLS are important in the reporting of medical information, respondents chose 'improving awareness of therapies', 'helping a broader audience understand clinical trials', 'preventing disinformation', and 'improving disease awareness' (Figure 2).
- The routes through which respondents discovered PLS were publisher websites (66.36%), Google (60.75%), PubMed (52.34%), patient advisory groups (3.36%), social media (16.82%), word of mouth (16.82%), and healthcare professionals (9.35%) (Figure 3).
- Respondents reported that most of the time (54.63%) they were unable to discover PLS, followed by some of the time (42.59%), every time (1.85%), or not at all (0.93%) (Figure 4).
- The majority indicated they would find a database to discover PLS extremely useful (76.15%) (Figure 5).

Conclusions

These results reinforce the value of PLS of published medical research and highlight limitations in the discoverability of such content. This suggests a need for an independent, dedicated website or database aggregating PLS. Further work is being conducted by this cross-publisher initiative to understand the needs and requirements for this database.

Figure 1. What are the affiliations of the 109 survey respondents?



*More than one affiliation could be selected.

Figure 2. Why PLS are important in the reporting of medical information. (ranked by most important to least important)

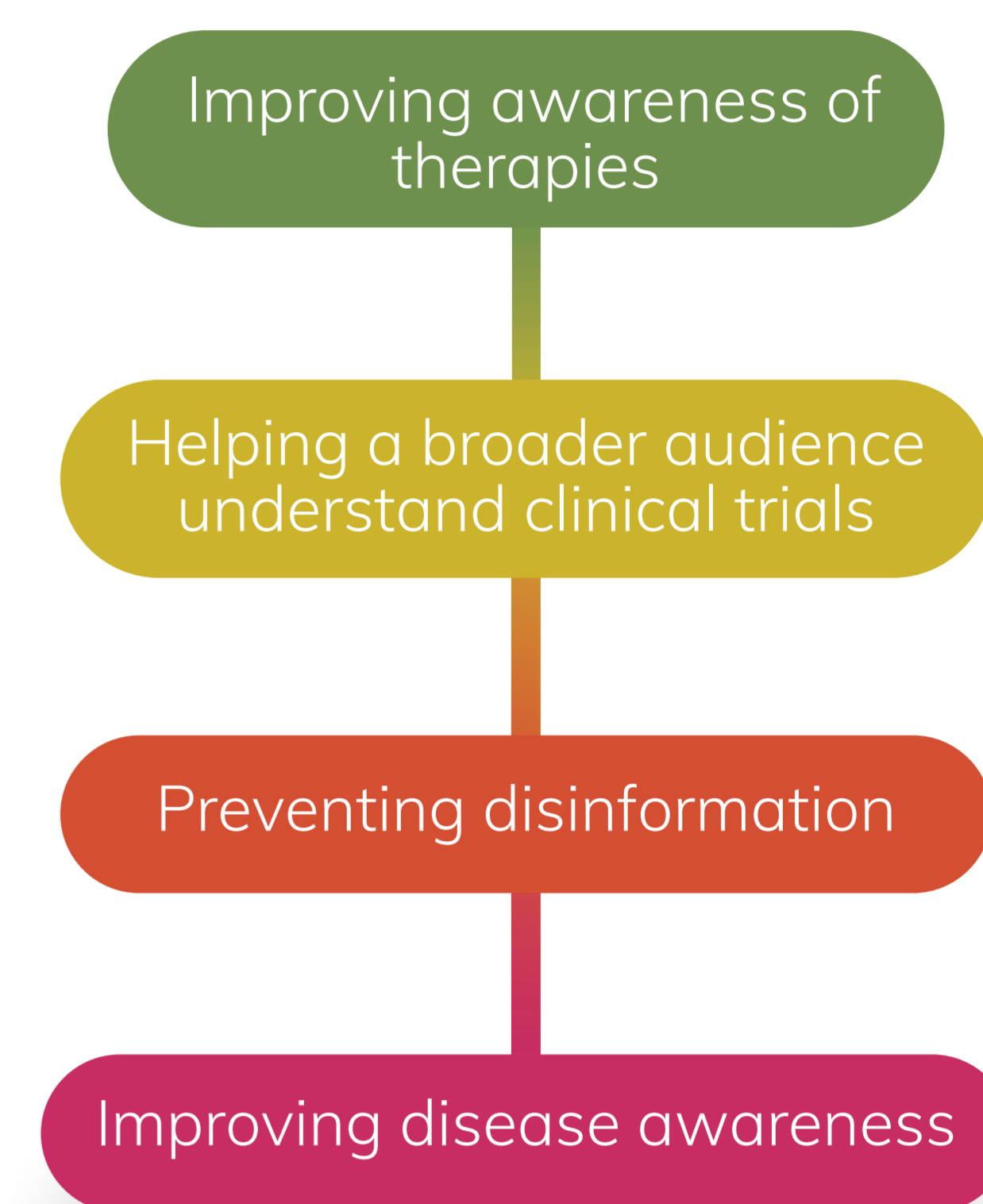


Figure 3. How do you find PLS content?

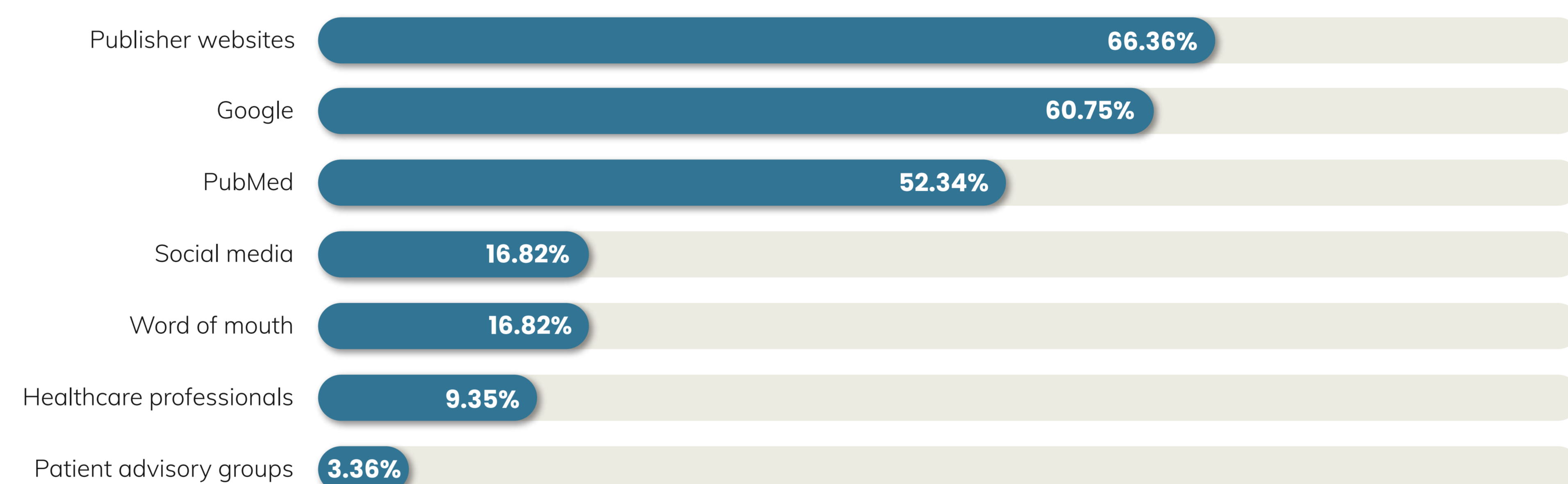


Figure 4. How often can PLS be discovered?

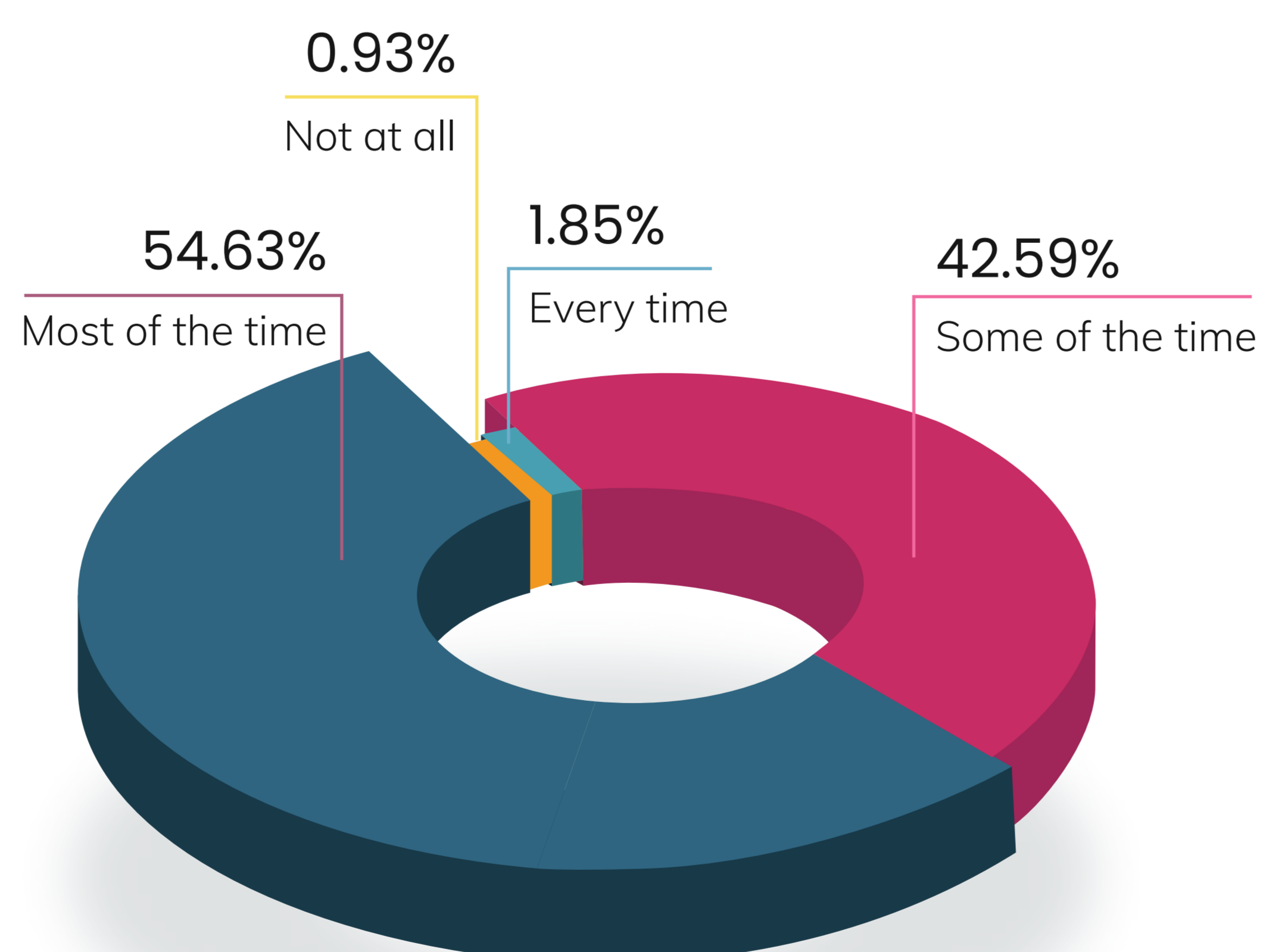
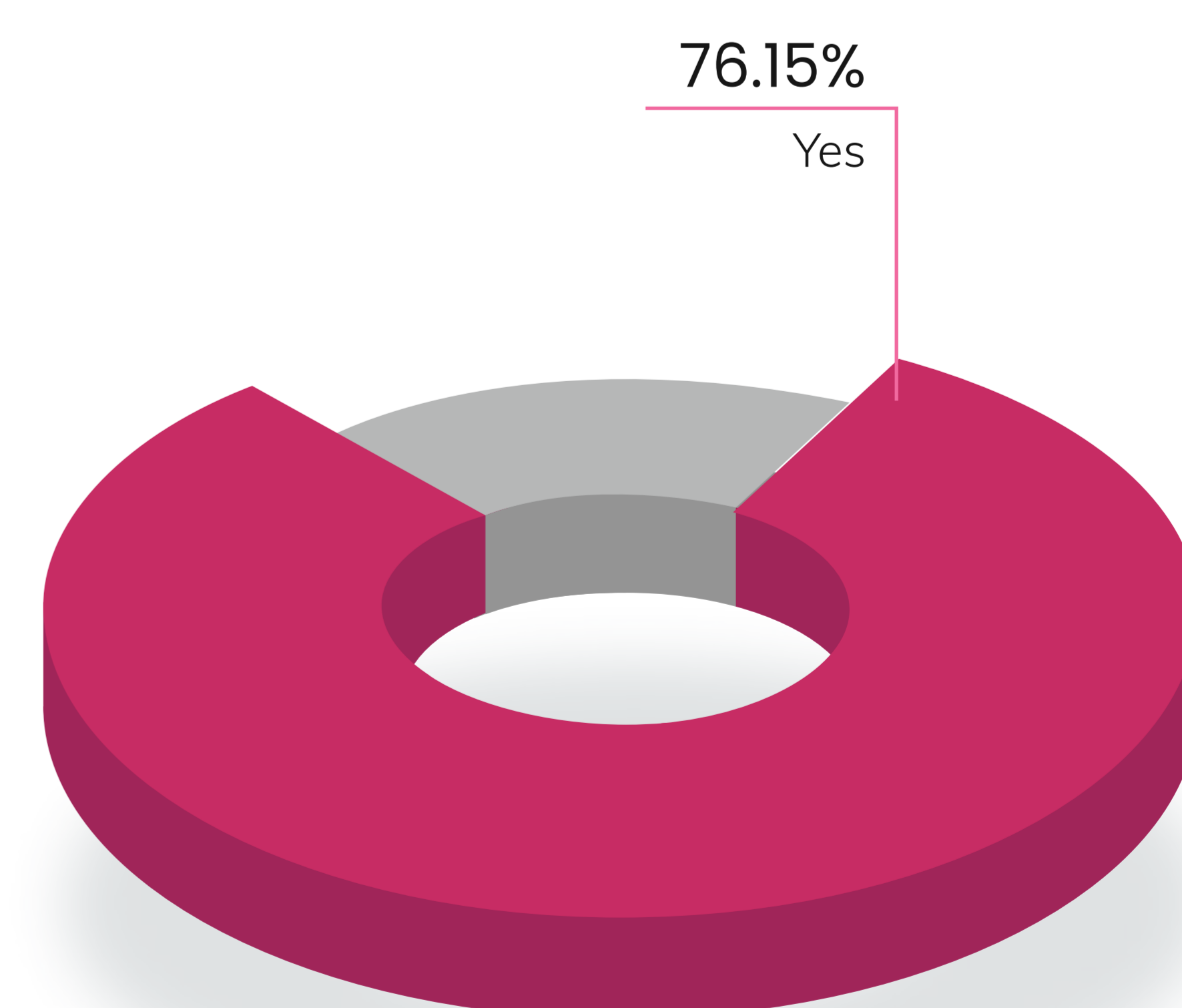


Figure 5. Would a central website or database to discover all PLS be useful?



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