

Case Study

Patient Input in Clinical Trial Recruitment

How Smart Patients Advisers Helped Inform
Citeline Connect Content

November 2024



Overview

Clinical trial patient recruitment remains a thorny problem for many sponsors. One reason traditionally cited is patients' lack of willingness to participate. Not all statistics bear this out, however. For example, 91% of respondents in the 2023 Perceptions & Insights study from the Center for Information and Study on Clinical Research Participation (CISCRP) said they were at least somewhat willing to participate in a clinical trial.¹

Clearly, there is a disconnect between patients who want to participate in clinical trials and the sponsors who run these trials. One way to bridge this divide is to connect with patients where they are looking for study information — and increasingly that is online. According to CISCRP's 2023 study, aside from speaking with their doctor, more than one-third of respondents said their first step in identifying a clinical study that is right for them would be to conduct an online search.¹

To continue narrowing the gap between patient candidates and clinical trial sponsors, Citeline engaged Smart Patients' Virtual Patient Advisory Board (vPAB) panel to gain patient insights on its Citeline Connect patient engagement and recruitment solution. The vPAB consultations involved sample versions of Citeline Connect's IRB-approved outreach materials and three of its Clinical Trial Portfolio Websites.



Part 1: Citeline Connect Patient Engagement

Research methods included focus groups and surveys involving patients diagnosed with chronic illnesses. The advisers on the vPAB were asked about their experiences with sample versions of Citeline Connect’s clinical trial outreach, including their preferences in imagery and wording.

By gathering this feedback, Citeline sought to understand patients’ preferences and expectations regarding clinical trial communication in order to enhance the design and functionality of Citeline Connect’s IRB-approved outreach materials.

Insights



Images

- Patient advisers discussed whether images of real individuals, models, or actors were a crucial factor in establishing **authenticity** and **trust**.
- They examined images for **relatability** and **specificity**, as well as **balance** in terms of emotions referenced in conveying information.
- They suggested which graphics were more **eye-catching**, especially in waiting rooms and doctors’ offices.



Tone

- Patient advisers gave feedback as to what tone helped **empower** patients.
- They discussed whether a call to action was recommended to **encourage** patients to **explore** clinical trial opportunities further.



Language

- Patient advisers discussed what made up a **clear** and **concise** explanation of the study’s purpose and goals, along with information about why individuals should consider participating.
- They advised as to what constitutes **accessible** language and how many requirements to include in recruitment materials.

“... If I had condition X and were browsing online for information about it and came across a link that used the word ‘study’ or ‘trial’ or the name of my condition, I would want to click on it... I would be further intrigued by the wording to ‘see if I qualify’ because that would pique my interest. I have joined studies and trials or at least looked for further information by such means, especially if I read that said study was coming from a known teaching and research hospital.”

— SMART PATIENTS ADVISER



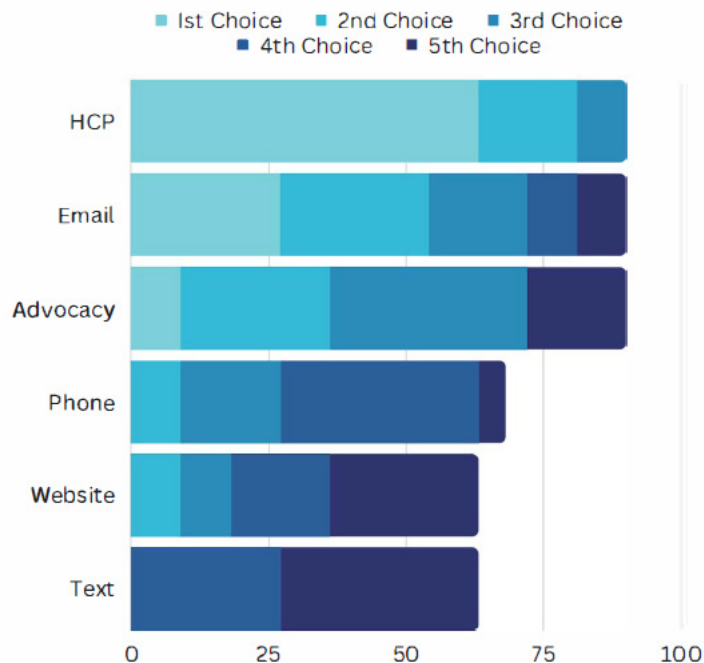
Identifying study sponsor

- The vast majority (90%) of advisers expressed a desire to know the name of the study sponsor, citing it as a critical factor in their decision to participate. This transparency was instrumental in building **trust** and **credibility** with potential participants.



Preferred contact methods

- The advisory group ranked preferred methods of being contacted about trials, with healthcare professionals (HCPs) being the first choice among the majority of patient advisers.



Source: Smart Patients

Part 1 Conclusion

The insights gathered from patients through the Smart Patients vPAB were instrumental in shaping Citeline Connect's IRB-approved outreach materials. By prioritizing patient perspectives, Citeline ensures that recruitment content is not only patient-friendly but also deeply resonates with potential participants. This patient-led approach reflects Citeline's commitment to making clinical trials more accessible and impactful, ultimately strengthening recruitment by addressing real patient needs and preferences.

Part 2: Clinical Trial Portfolio Websites Patient Engagement and Search Experience

Citeline sought to elevate patient engagement and optimize the usability of its Trial Portfolio Websites by engaging a Smart Patients vPAB to conduct a comprehensive evaluation of several websites and their search functions. The overarching goal of gathering this feedback was to confirm the functionality and attractiveness of the websites to patients and use this information to inform future sites.

In their evaluation, the vPAB advisers closely examined representative Trial Portfolio Websites of three sponsors. They also conducted specific searches on the sites, highlighting their experiences and providing feedback to help refine the clinical trial search process.

Insights



Sponsor A's Website

- The patient advisers singled out its **user friendliness** and inviting welcome page.
- They recommended **refining the trial search engine**.

“Sponsor A is very easy to search, read summaries, and review inclusion/exclusion criteria... AND ... it has empowering language on the first page (‘Thanks to the ongoing dedication of the people who participate in our clinical trials’ and ‘educate and support patients’).”

— SMART PATIENTS ADVISER



Sponsor B's Website

- The patient advisers cited the site's **visual appeal** and simple, **concise language**.
- They suggested **filtering out** irrelevant search results and **thanking** potential participants on the page.

“I agree with ... my best choice being Sponsor B, and I especially liked the little red text ‘about...’ video links that explained in easy to understand language the various aspects of clinical trials.”

— SMART PATIENTS ADVISER



Sponsor C's Website

- The patient advisers praised the site's **clarity**.
- They recommended incorporating more **images** and presenting key information more **succinctly**.

“The Sponsor C website seems thinner, clearer, and easier to navigate and read than the Sponsor A and Sponsor B. ... Their use of photos, actual pictures was very good, as was their various explanations because they were simpler, straightforward, and easier to understand. On that note, in the transparency section they specifically stated that their emphasis is on ‘plain language.’ Excellent!”

— SMART PATIENTS ADVISER



General website feedback

- In general, the patient advisers said all three sites were **patient friendly** and **informative**.
- Some of their recommendations were as follows:
 - Provide information on the **use of placebos** in clinical trials, particularly the assurance that patients with active life-threatening conditions wouldn't receive placebos without standard care
 - Include a brief explanation of clinical trials and their purpose on the landing page, with an option to **learn more**
 - Categorize studies as “**actively recruiting**,” “in progress/full,” and “concluded” for improved relevance
 - Include a mechanism for trial participants to follow up on **completed studies**
 - Add “**About Us**” section to help users understand the entities behind the websites



Search-specific Challenges and Pain Points

- **Lack of time** for extensive trial searches
- Reliance on **oncologists' recommendations**, which may not always lead to qualification
- Reliance on **notifications** from disease foundations and online communities to discover new trials
- **Qualification issues** for trials recommended by specialists
- Difficulty finding **contact information** for trials
- Inaccurate results and irrelevant information from **search engines**



Search-specific Recommendations for Sponsor Websites

- Implement **notification systems** for new trials matching user criteria
- Simplify and display relevant **filters** more prominently
- Ensure that website language is **clear and relevant**
- Encourage **standardized data** from trial designers
- Make trial descriptions **patient friendly** by using clear language that is easy to understand

Part 2 Conclusion

The vPAB's feedback offered valuable insights into the patient perspective, affirming the patient-friendliness and informativeness of the Trial Portfolio Websites while also pointing out opportunities for enrichment in both the websites and the clinical trial search platforms.

These findings underscore Citeline's dedication to advancing patient engagement and enhancing clinical trial recruitment through product refinement. By implementing these patient-driven recommendations, Citeline is not only improving the accessibility and efficiency of its tools but also empowering patients and caregivers to take an active role in their clinical trial journey, ultimately fostering a more inclusive and impactful recruitment process.

In Summary

The Smart Patients advisory boards closely studied several aspects of Citeline Connect patient engagement and recruitment content and provided their observations as to what was working, as well as a few recommendations for making the content even better.

One finding that stood out was the advisers' desire for a balance between clear, concise language and access to more detailed information. While they themselves were often not new to clinical trials, they liked the sites to include at least a brief description of the clinical trial process (including enrollment) for those who had little experience with trials. They also appreciated it when the sites and recruitment materials included enough specifics about the trial for them to make an informed decision.

Another notable takeaway from these sessions was that the advisers were reluctant to hand over their personal information for anything less than a list of potential trials matched to their specific needs. Asking for demographic information before actually matching the patient to trials eroded trust, and some advisers said they would be likely to leave the site if that were to happen.

By leveraging patient insights from Smart Patients' quality-driven online community, Citeline has been able to take the information provided by these advisers and use it to shape the continued development of Citeline Connect and Trial Portfolio Websites content in ways that will best engage and enroll patients in clinical trials. Through these efforts, Citeline reinforces its position as a leader in patient-focused engagement and recruitment solutions.

Resources

1. Center for Information and Study on Clinical Research Participation (CISCRP), 2023 Perceptions & Insights Study. Available from <https://www.ciscrp.org/services/research-services/perceptions-and-insights-study/> (Accessed Aug. 26, 2024)

About Smart Patients

Smart Patients hosts over 100 communities for patients and families affected by various illnesses, including oncology, autoimmune, and neurodegenerative diseases. These communities offer a platform for patients and caregivers to learn about scientific developments, share questions and concerns, and apply insights to their own care.

This trusted community platform facilitates rapid-cycle patient insights that inform healthcare. Engaging patients across all stages of the product lifecycle, Smart Patients focuses on agile evidence generation in serious disease areas, ensuring patient perspectives not only contribute to but actively shape the healthcare landscape.

For more information, visit [Smart Patients](#) and follow on [LinkedIn](#).

About Citeline

Citeline, a Norstella company, powers a full suite of complementary business intelligence offerings to meet the evolving needs of life science professionals to accelerate the connection of treatments to patients and patients to treatments. These patient-focused solutions and services deliver and analyze data used to drive clinical, commercial, and regulatory related decisions and create real-world opportunities for growth.

Citeline's global teams of analysts, journalists and consultants keep their fingers on the pulse of the pharmaceutical, biomedical, and medtech industries, covering them all with expert insights: key diseases, clinical trials, drug R&D and approvals, market forecasts, and more. For more information on one of the world's most trusted health science partners, visit [Citeline](#) and follow on [LinkedIn](#) and [X](#).