

Within3



Closes in 21 Days



Treatment Side Effects



Patient 16 2:38 PM



Patient 8 12:20 PM

Private Comments & Discussions

The complete guide to **Patient Centricity** for Medical Affairs



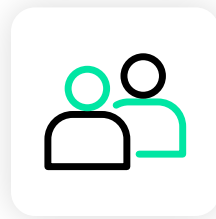
Table of Contents

Introduction	4
Patient-centric engagement: The time is now	8
The insights management ecosystem: Where do patients fit?	10
Best practices: Patient-centric insights management and virtual engagement	12
Health check: How do you know you're getting patient centricity right?	16
In the real world: How your peers are building patient-centric organizations	18
• Medical affairs	20
• Clinical	22
• Commercial	24
Take action: Practical tips to use now	26
Conclusion	28

Introduction

Pharmaceutical and medical device companies work hard to understand patient needs. And while most life science companies maintain a commitment to improving patients' lives, this commitment can stop short of engaging patients meaningfully throughout the product development process. These organizations are bypassing a valuable source of information – one that can provide an important strategic advantage and help bring life-changing treatments to market.

Traditional barriers to better patient engagement center around compliance, patient privacy, and logistics:



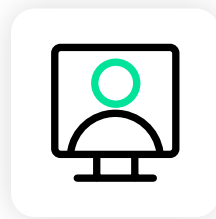
Pharma and medical device companies may be reluctant to engage patients in order to avoid risk



Patients may find it difficult to share sensitive medical information in face-to-face meetings

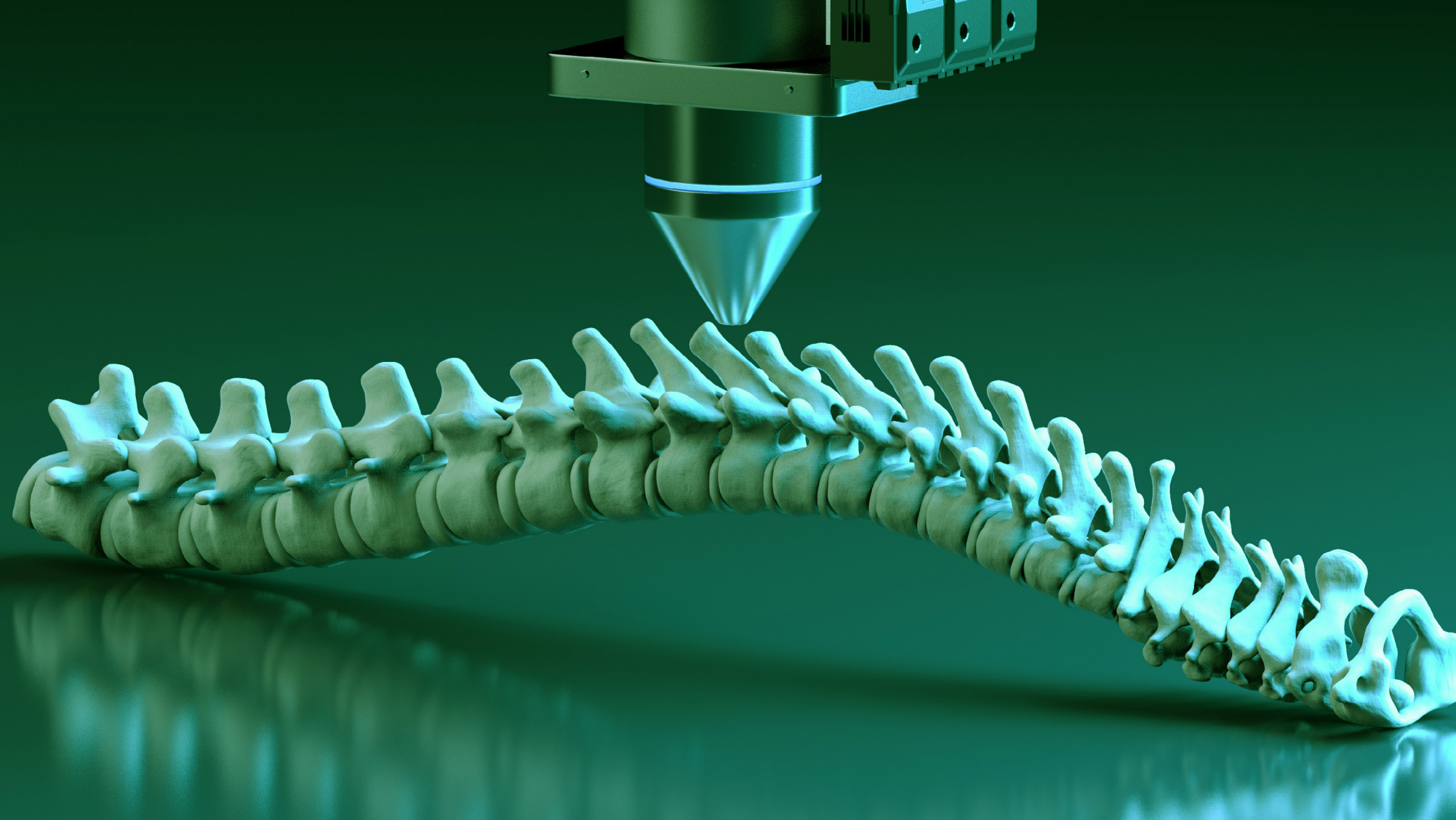


Patients dealing with conditions that cause them to feel unwell or make it difficult to travel may decline to participate in engagements that are inconvenient



Video meetings may be unmanageable for both experts and patients due to work or family commitments



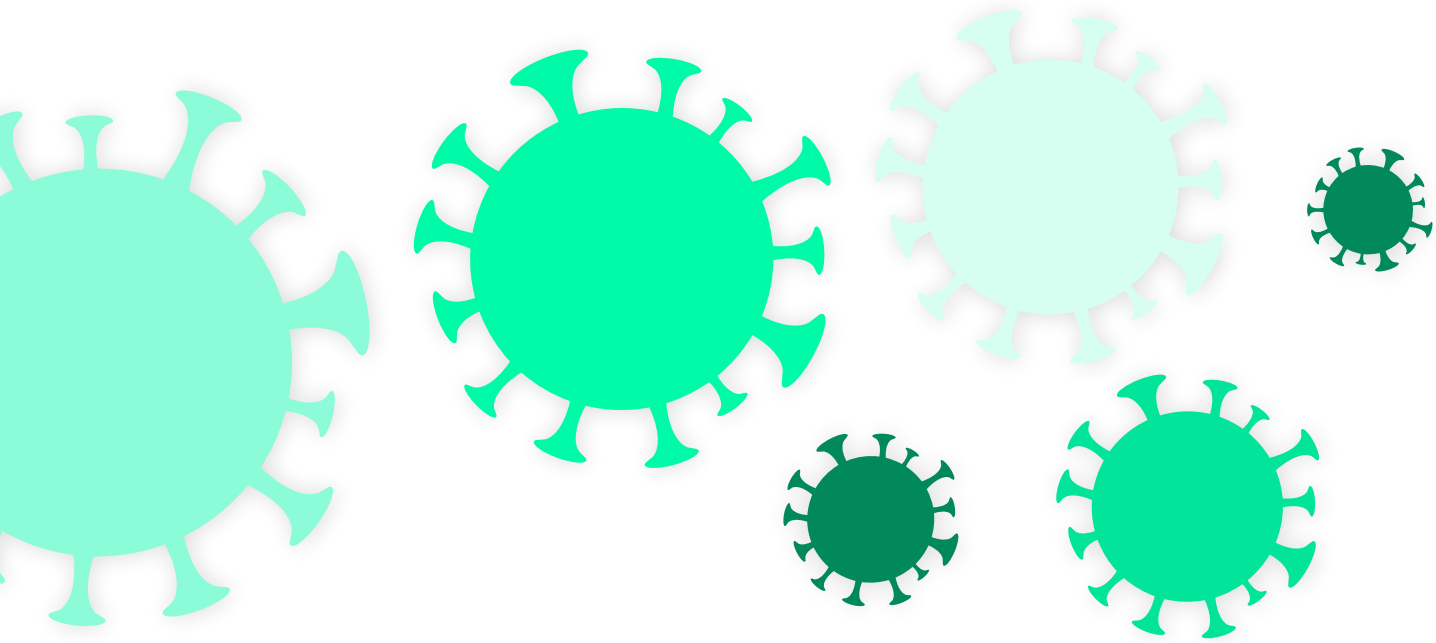


Fortunately, life science teams seem to have found the answer in [asynchronous virtual engagement](#), which takes place over a period of days or weeks and allows participants to log in and answer questions on their own schedule, whenever they feel most able to focus. These capabilities became even more important during the COVID-19 pandemic, when clinical trials, patient advisory boards, and other patient-facing activities needed to continue amid lockdowns and travel restrictions.

Now, pharmaceutical and medical device teams are prioritizing virtual engagement as part of a more holistic [insights management strategy](#) – an approach that treats insight-gathering as a single strategic process rather than a disconnected series of siloed activities.

In this e-book, we'll discuss why life science organizations should act now to improve patient engagement, how organizations can include patients as part of their insights management strategy, and some best practices for patient-centric online engagement.

The time is now



Prior to the COVID-19 pandemic, patient uptake of digital health tools was in decline. Of patients surveyed in one [report](#), those who said they used digital tools to manage their health fell from 43% in 2018 to 35% in 2020. But the pandemic forced a shift in this behavior, and patients are more accustomed than ever to discussing and managing health issues in a virtual environment.

This is also a moment of unprecedented positive sentiment for life science companies. Prior to the pandemic, just [47% of patients](#) said they felt pharmaceutical companies understood their emotional, financial, and other needs related to their condition, and only a third reported interacting with a pharmaceutical company on a regular basis. But thanks to an accelerated vaccine development effort, patients now have a better opinion of pharmaceutical and medical device companies. [New research](#) shows that patient trust in the healthcare ecosystem has increased overall, with a boost of 45% for pharmaceutical companies and 44% for medical device companies.

As more digital natives enter both the patient population and the ranks of pharmaceutical companies, engaging patients virtually will become more and more commonplace. Therefore, it's imperative that life science teams equip themselves with a means to engage patients in a virtual setting that's easy to access and available when they are.

These market trends and demographic shifts provide life science organizations with an opportunity to establish or re-establish productive relationships with patients – experts who can share first-hand experience with conditions, treatments, and trials. Incorporating patient input throughout product development, from preclinical stages through launch and beyond, can broaden teams' perspectives and help close insight gaps that are costly in terms of both time and money.



Ali Chiu, MD

TREATMENT COMPARISON

Treatments have evolved over time to be safer and more effective. Data has shown our treatment to be several times more effective than previous treatments in all age categories, treating patients more effectively in much less time. This effect is proven in initial clinical trials and an ongoing study. In addition, the safety profile of the treatment is unmatched. Pre-existing treatments on the market had a wide variety of side effects that ranged from mild to severe. Our treatment, however, has the fewest side effects of any treatment on the market, and these are often extremely mild.

Ali Chiu, MD
4/2/2020 12:30 PM
Inserted: More effective

Last Edit: 12:31PM

RESPONSE BY WEEK

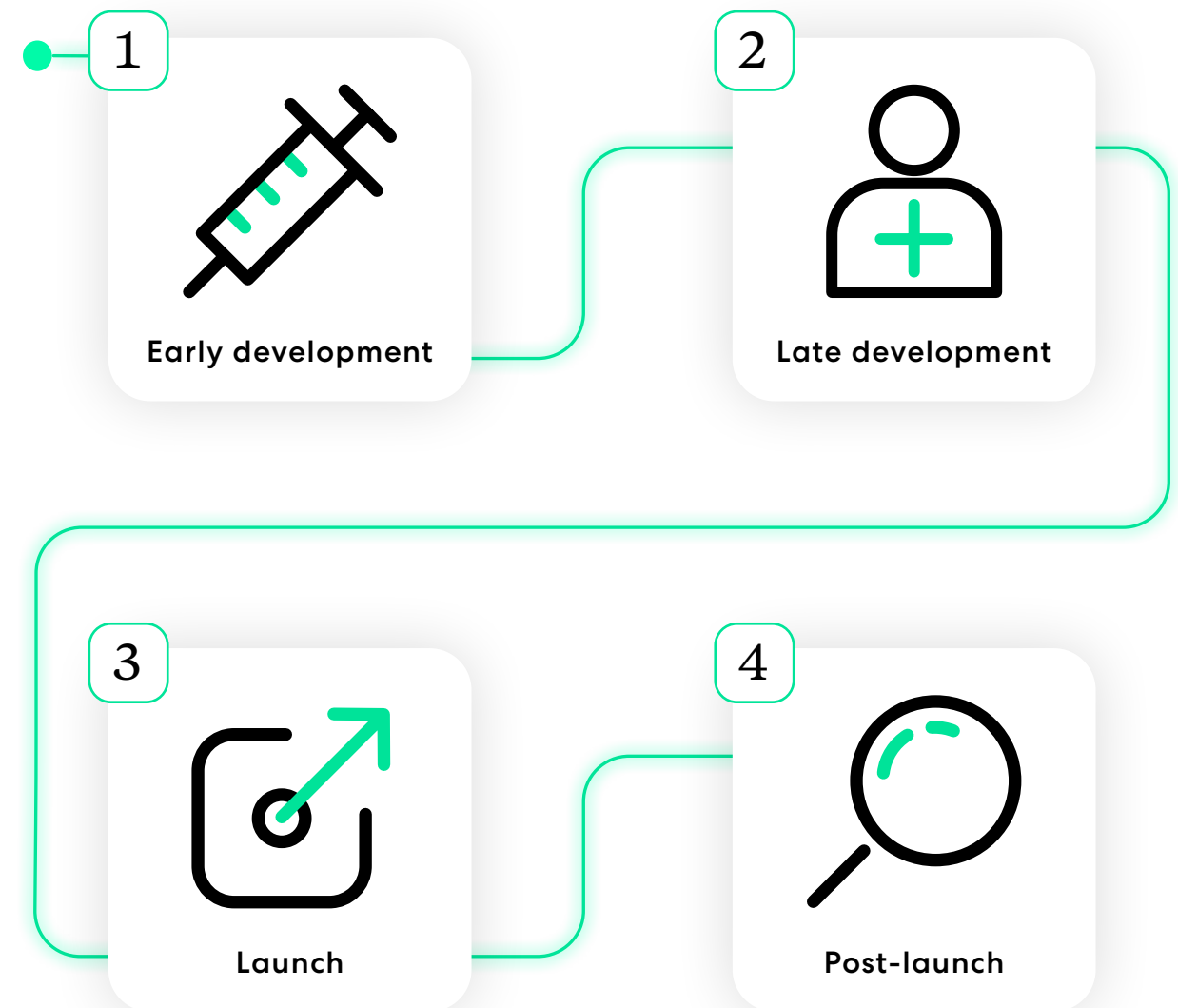
50 | Complete response

Where do patients fit?

Patients have a wealth of information that can impact the trajectory of a product during development and post-launch. Examples of how patients can participate in the product development process include:

- ✓ Input on proposed trial protocols
- ✓ Sharing personal experiences of different conditions, across all types of demographics, from time of diagnosis through treatment or living with a chronic disease
- ✓ Feedback on proposed patient-facing educational materials, including brochures, advertisements, videos, and websites
- ✓ Sharing impressions of administration or dosing regimens
- ✓ Participating in market research

In other words, patients are a key part of the scientific narrative that develops over a product's lifecycle. While physicians can share what their patients tell them, patients can directly share their lived experiences. This provides an outlet for patients and supplies life science companies with valuable insights that help shape product development. These insights – paired with that of physicians and other healthcare professionals – create a more complete picture of specific disease communities.



BEST PRACTICES:

Patient-centric insights management and virtual engagement

Based on hundreds of patient sessions conducted by the world's top drug and device companies, here are five best practices for asynchronous virtual patient engagement. These practical tips will help clinical, medical affairs, and commercial teams create meaningful opportunities for patients that yield deeper, more actionable insights. Following are some areas of focus.



Sofia Ruiz, PharmD



Patient 1



Patient 2

Choosing the right participants

Teams need to be certain they are engaging with the right patients for participation – those who meet specific criteria and are able to participate within the time frame for the virtual meeting. Communicate clearly to patients about what to expect during the online session, including what your team is hoping to achieve. Recognize that there might be varying levels of digital savvy among patients, and offer how-to or welcome documentation accordingly.

Teams will also need to give some thought to moderation – who will moderate the session, and are they familiar with patient engagement practices? Some general guidelines for moderating a patient session include:

- 1 Be neutral, without reacting to comments in a positive or negative way. Instead, use language that encourages more feedback: “Can you say more about that?”
- 2 Provide encouragement to keep the conversation going. Try “Thanks for sharing your experience,” or “This is valuable information, I appreciate it.”
- 3 Remain a moderator and not a participant. Resist the temptation to add your own experiences.
- 4 Be an empathetic listener and an active moderator, so patients will know their feedback is valued. A good way to demonstrate that you are following the conversation is to refer back to or ask about previous comments.



Private Comments & Discussions

Blind and double-blind sessions

Protecting the identity of patients during a session can be necessary to ensure compliance. Pharmaceutical teams can offer anonymity by creating a naming convention, such as initials or generic names like “Patient 3” or “John S.” Moderator identities can also be hidden – preferably using a different naming convention to avoid confusion.

Names and logos of pharmaceutical companies can also be hidden by using an unbranded online space when desired. If there is a webcast component to the session, we recommend using a webinar option that does not enable members to see one another.

Question

1

What reactions did you have?

Questions and content

Asking the right questions will help pharmaceutical teams get the insight they need to achieve their objectives. Varying the types of questions asked will also help keep the participants' interest during a session, particularly if there are a high number of questions. In our experience, teams get the best results when they stick to the following guidelines:

- ✓ Use a variety of question types – multiple choice, ranking, true or false – to break up the content and keep patients engaged.
- ✓ Include open-ended questions to allow patients to share their personal experiences.
- ✓ Mix private and non-private questions to provide a group discussion opportunity. Use private questions for sensitive information, and public questions when looking for unbiased patient commentary.

Be mindful that discussing personal details about a challenging medical condition can be difficult for some patients. If necessary, teams can also include language that provides patients with additional resources or help, such as crisis hotlines or other ways to connect with experts for assistance.



Name:
DOB:



Name:
DOB:

Maintaining confidentiality

Pharmaceutical teams can take advantage of several opportunities to remind participants of the need for confidentiality. Orientation training or any contact prior to the meeting is a good time to do this. For the most part, simply reminding participants not to include any identifying information, names, or other personally identifiable information should suffice.



HEALTH CHECK:

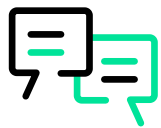
How do you know you're getting patient centricity right?

As discussed earlier, there can be a discrepancy between believing in the concept of patient centricity and actually achieving it. While it's true that life science companies are focused on developing products that improve and even save lives, patients should play an active role in the process of bringing those products to market.

To understand where your team stands when it comes to maintaining a patient-focused strategy, ask yourself the following questions:



Do patients have a voice throughout the product development process (research and development, study protocol design, patient materials feedback, post-launch activities)?



When your team engages patients, what does that look like? Is participation higher or lower than you would expect? Are patients given choice or flexibility in when and where they participate?



Do you understand the reasons patients decline to participate or stop participating in your engagement efforts?

If it's difficult to answer these questions, you have an opportunity to improve your patient focus. Let's examine how your peers in patient advocacy, clinical, and commercial teams are using virtual engagement to build more patient-centric insight-gathering strategies.



IN THE REAL WORLD:

How your peers are building patient-centric organizations

Pharmaceutical and medical device teams are already using virtual engagement to incorporate patient input into every stage of product development. To help illustrate how patients can offer insight that significantly impacts how drugs and therapies are developed, read these real-world examples drawn from thousands of successful Within3 sessions.

CUSTOMER SUCCESS STORY:

Global patient advisory board – rare disease



A medical affairs team wanted to gather patient perspectives about living with a chronic, but treatable, rare disease. The team had three primary objectives:

- 1 Understand patient perspectives on a gene therapy clinical trial
- 2 Obtain feedback on patient materials
- 3 Gather input on patient education needs

The medical affairs team decided to reach out to 11 patient advisors via the Within3 Connect virtual engagement platform, which would not require the patients to travel or all be available to attend a webcast at the same time. This was especially important given that patients were located in the United States, Europe, and Canada. Patients answered a variety of questions, including open-ended and multiple choice. Participants also used Within3's document annotation features to provide input on patient-facing materials. During the sessions, moderators used the platform's built-in tools to remind or encourage patients to respond to questions or contribute to the conversation.

The medical affairs team achieved its objectives for the rare disease patient advisory board. With the virtual engagement approach, the medical affairs team was able to:



Receive 100 pages of robust patient feedback on the observational study



Obtain detailed responses pertaining to brochures and other patient materials



Gather valuable insight to update patient-facing educational content

CUSTOMER SUCCESS STORY:

Engaging patients and investigators to optimize study design

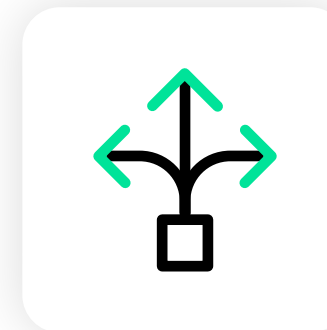


A leading pharmaceutical company engaged patients and investigators online to optimize a phase II clinical trial protocol. The clinical development team had three primary objectives:

- 1 Review and discuss protocol design
- 2 Assess logistical considerations for the conduct of the trial
- 3 Confirm the primary and secondary endpoints of the trial

The clinical development team used Within3 Connect to make it easy for patients and investigators to provide feedback on the proposed study design from any device, including a smartphone or tablet, whenever it was convenient for them.

First, a blinded patient session was conducted to gather feedback about key aspects of the clinical trial. Following the patient session, the team convened 10 investigators for two 7-day sessions. Using patient feedback, the clinical development team optimized the study design by:



Understanding logistical considerations for patients

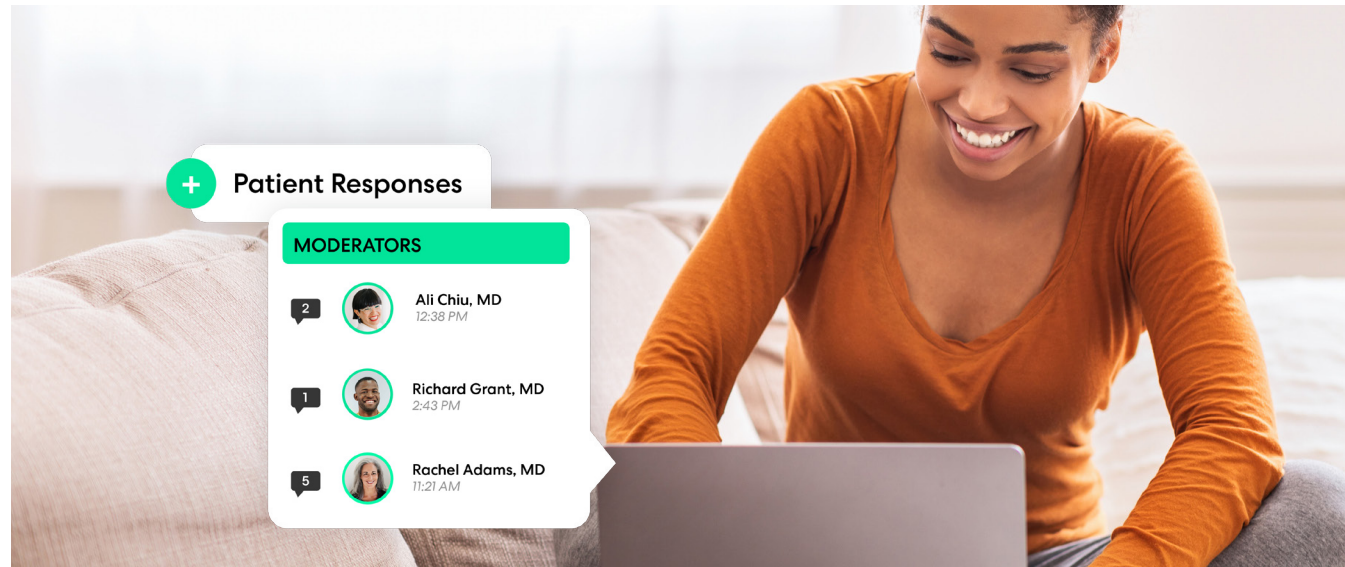


Assessing patient recruitment considerations with investigators before finalizing the trial protocol



Validating primary and secondary endpoints with investigators

Commercial advisory board, the patient journey



A commercial team within a leading pharmaceutical company wanted to better understand the emotional implications of being diagnosed with and starting treatment for a severe chronic condition. Initially, the team planned to conduct one-on-one interviews with 40 patient ambassadors, some of whom were already taking part in a related clinical trial. As details of the program were developed, the commercial team identified the following concerns:

- 1 Patient reluctance to disclose sensitive personal information to an unknown interviewer
- 2 Hard costs and scheduling challenges related to having an interviewer contact 40 patients for time-consuming discussions
- 3 Lack of ability to quickly follow up with patients based on their responses, possibly degrading the overall results

The commercial team decided to use an innovative approach to accomplish their goals for the patient interviews. Instead of traditional in-person interviews, the team used Within3 Connect to interview patients in an asynchronous virtual forum, allowing the team to preserve the patients' privacy and eliminate logistical hurdles.

The patient advisors were divided into two groups – one for patients participating in the related clinical trial and one for those who were not in the trial. This allowed the commercial team to vary the questions somewhat based on each patient's situation. Each patient engaged in a virtual dialogue with a moderator. The team used private questions so that each patient's responses were only viewable by their interviewer, preserving the secure nature of a one-on-one conversation.

Through more than 600 patient responses, the commercial team gained deeper insight into the patient journey using the virtual forum as compared to previous interviews conducted by phone or web meeting. Patients were able to be candid about their feelings, challenges, and successes related to diagnosis and treatment. Post-session patient feedback included:

“The most valuable part for me was the **ability to take my time** answering each question in the comfort of my own home. I was able to relax and not feel pressured to hurry up and answer.”

“The questions were **very well organized** and pertinent to the process.”

“The open-ended style of questions allowed me to **give a true representation of what my experience was**. Hopefully that knowledge can be used to assist others...to gain a better understanding.”

TAKE ACTION:

Practical tips to use now

Now that you understand the value of patient engagement and how other successful organizations are changing their approach to patient engagement, you're ready to design patient interactions that drive your business strategy. Use these tips right away to increase patient centricity in your insight-gathering strategy.

Preparing for a patient engagement

- ✓ Confirm that all patients meet necessary requirements and are available to participate
- ✓ Communicate clearly about what patients should expect during the session
- ✓ Spell out the goals for the session, and what your team hopes to learn



Bonus Tip: Ensure your moderator is familiar with patient engagement practices and can interact in a neutral, encouraging manner.

Creating a successful patient discussion

- ✓ Vary question types – multiple-choice, polls, open-ended – to provide variety and maintain interest
- ✓ Use private questions when requesting sensitive or personal medical information
- ✓ Provide an opportunity for patients to interact, share common experiences, or learn from one another



Bonus Tip: Discussing personal details about a challenging medical condition can be difficult for some patients. If applicable, consider providing patients with additional resources or help, such as crisis hotlines or other ways to connect with experts for assistance.

Reducing risk to your organization

- ✓ Blind or double-blind the discussion to ensure privacy and avoid bias or influence
- ✓ Remind patients not to disclose any names or other personally identifiable information
- ✓ Provide any other required disclosures or terms



Bonus Tip: Orientation training or other communication prior to the meeting is a good time to remind participants of the need for confidentiality.

Conclusion

Thoughtful patient engagement reinforces a life science company's commitment to patient centricity. By eliminating barriers to communications and including patients as experts in their own right, pharma and medical device teams can accelerate and add value to the product development process.



ABOUT WITHIN3

Within3 invented a better way for life science companies to get deeper insights and make faster decisions across the product development lifecycle. With the power to identify the right experts, effectively engage them, and quickly obtain actionable information, life science teams can close the insight gap and drive projects forward with confidence. Our insights management platform gives stakeholders the freedom to collaborate anytime, anywhere, on any device, plus practical tools to foster meaningful discussions, co-create and edit documentation, and rely on the power of AI to achieve faster and more accurate decision-making. With a dedicated client success team on every implementation, most Within3 projects achieve 100% stakeholder participation. To learn more and request a needs assessment and demo, visit www.within3.com.