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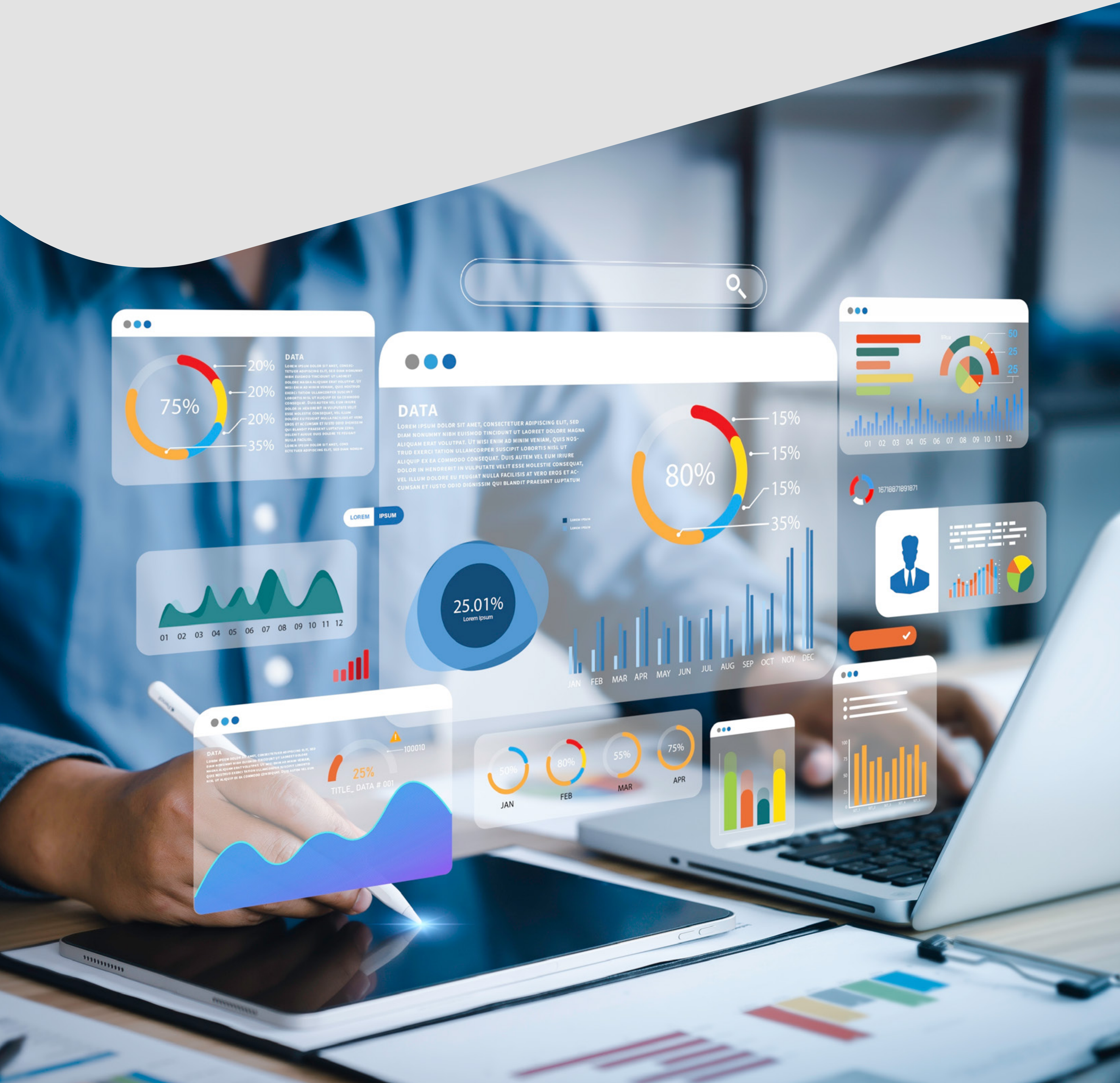
The Patient Review of Pharma's Engagement Strategy



EXECUTIVE SUMMARY

Patient engageme'nt is now an essential function in the pharma industry. Leading companies all publicly proclaim their commitment to patients and invest in projects intended to forge ties to the communities that rely on their products. Yet, patient engagement remains a work in progress and companies need to continue to refine their strategies and show their long-term commitment to win over sceptics.

A survey of 92 patients, caregivers, patient advocacy organisations, and other stakeholders revealed both drivers of scepticism about pharma companies and ways that the industry can improve its standing in the communities. Patients and their advocacy organisations made up two-thirds of the respondents. Most (77%) of the respondents frequently or very frequently engage with drugmakers, making the survey a snapshot of how pharma companies are seen by the patients who know them best.

"I have spent 40 years trying to convince pharma to engage with patients. While regulations can create barriers, little innovation has been seen," Graham Wilson, chairman at Ecoutai, said. "New technologies now allow this, in a more effective way than ever before, going beyond big data collection to real patient involvement and new idea generation pre-launch and post-launch."

COMPANIES NEED TO BUILD TRUST

"There's a trust issue," one respondent said, summing up in four words a problem that is echoed across the survey results. Some patients and their advocates are sceptical of pharma companies' motivations and their willingness to commit for the long-term, with one respondent saying drugmakers withdraw if they do not see returns in a short time.

PATIENTS WANT TO PARTICIPATE

Pharma companies that want to form true collaborations with patients will find willing participants. The survey shows patients want to co-create with drugmakers, which, in the words of one respondent, would benefit from "more listening at the outset as opposed to feedback at the end." Co-creation could help companies to deliver materials such as information sheets that better meet the needs of patients.

THERE IS A ROADMAP TO SUCCESS

Patients and their advocates know what they want from pharma companies and have seen examples of engagement done well. By listening to patients and studying what has worked in the past, companies can engage with communities in ways that benefit all parties.

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>
> **Graham Wilson**
> Chairman at Ecoutai

HOW PATIENTS PERCEIVE PHARMA

WHAT PHARMA IS DOING TODAY

More than half of respondents said pharma companies are meeting the needs of patients, caregivers, or advocates at least moderately well. However, only 5% of people said the pharma industry is doing very or extremely well. Dissatisfaction is more common, with 14% of people answering "not well at all" and a further 32% saying companies are only doing slightly well. Yet, patients are sympathetic to the challenges the industry faces.

"It is difficult and there is fault on both sides. Effective patient engagement is difficult, time consuming, and costly, just like most things worth doing, although less costly than not doing it—but that opportunity cost is often unexplored and unknown," Russell Wheeler, Patient Advocate, LHON Society, said.

Respondents are divided on the visibility of pharma companies in their patient communities. Almost half of people said companies are somewhat or very visible. Yet, 37% of respondents said companies are not very visible or completely invisible.

The split responses potentially reflect varying visibility in different therapeutic areas. Maria De Leon, MD, said pharma companies are visible in the Parkinson's disease community "but not so much for my other conditions like diabetes and lupus, especially within the Hispanic countries where these diseases are rampant." Companies may be invisible to patients even when they are active in a disease area.

"They collaborate with the healthcare system and patient associations, but their direct involvement in the daily experience of patients is limited," Fundación VISIBLE's Patricia Ripoll Ros said. "The visibility of their programs and support campaigns, for example, is not always evident to most of the population." Another respondent said patients may be unaware of smaller companies active in a disease area.

Visibility is only part of the challenge, though. Companies also need to be authentic. Heather Guidone, Program Director, Center for Endometriosis Care and Board-certified Patient Advocate, said companies are "visible but incredibly performative at best and disingenuous at worst."

A question about how transparent companies are when engaging with communities revealed similar concerns. One respondent said the people they engage with "are well meaning" but "likely have many competing priorities that get in the way of serving patients." Ros added that companies are "'neutral' in terms of transparency about their intentions" but their commercial motivations are "unclear".

Wheeler added that "some try hard to be transparent but many are not even fully sure of their intentions themselves." Family Reach CEO Carla Tardif said their organisation's work with many pharma companies has revealed varying levels of transparency.

"Some are up front about their patient facing goals, others are not," Tardif said. "I truly believe there is a huge awareness gap for pharma when it comes to the patient reality. It would be great if we could flip the script and have pharma ask advocates what the patient really needs in order to stay adherent to treatment and what support they truly need to access it."

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> **Patricia Ripoll Ros**
> Fundación VISIBLE'

WHAT IS WORKING

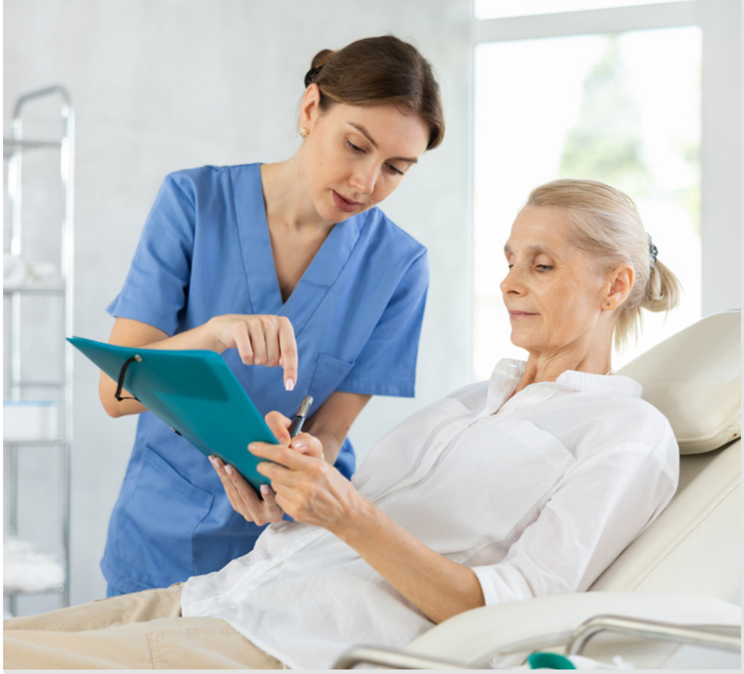
While the survey showed dissatisfaction with aspects of engagement, it also provided evidence that the industry is getting better at working with patients.

Respondents praised a targeted Parexel campaign on Instagram, Boehringer Ingelheim's Global Advisory Board for diversity, equity, and inclusion, Servier's patient involvement programme for its R&D institute, Ecoutai's digital human conversational technology, and Immunogen's Elahere support program. De Leon named Bayer's Parkinson's lived experience standing expert panel as a recent highlight.

"This has been the most comprehensive educational patient advisory board I have ever been part of that [is] aimed at getting to the root of not only clinical presentation but gaps in treatment and need for novel advance therapies and how to diffuse information across communities to increase participation in trials," De Leon said.

However, some praise came with caveats. Wheeler has seen "some good work here but mostly too little too late." Connie Lee Montgomery, Global Patient Advocate, was among the respondents to call for pharma to do more.

"Pharma introduces their products and services to patients, advocates, organisations, and healthcare systems but it is time that pharma partners with each entity to co-create beneficial, sustainable, accessible, and affordable products and services," Montgomery said.



CLINICAL TRIAL STRENGTHS AND WEAKNESS

Mohsena Olath, operations manager, Haemophilia Association of Mauritius, was among the people to highlight the positive changes companies have made in relation to clinical trials.

"Many pharma companies have made efforts to be more open and upfront about their intentions. They are more proactive in disclosing information about clinical trials, drug pricing, and potential conflicts of interest," Olath said.

Other respondents named clinical trial activities among the best programmes and engagements they have seen from companies in the past 12 months. Lorna Pender, Global Patient Engagement Lead at Clingen, highlighted a Galapagos project in the UK.

Galapagos partnered with Prof Julia Frost at the University of Exeter on a project funded by the UK Medical Research Council. Prof Frost conducted a citizens' jury with patients and caregivers "to learn about important issues, discuss them, and then make recommendations for change," Pender said. "The jurors deliberated on what patients in clinical trials need to know, how information should be shared, and how trials can be made more accessible to patients."

Another respondent listed "returning individual results to study participants" as the mechanism that has provided the most impact for them or their organisation. However, feedback from Ginger Davis, President, Sickle Cell/Thalassemia Patients Networks, Inc., shows there is still work to do on clinical trials.

"I would like to see pharma companies actually do Phase 4 of their trial, and go beyond patient families into the broader community to educate people, particularly Black, Indigenous, and people of colour, about the importance of participating in Phase 1 of clinical trials," Davis said.

Medonations' Marina El Khawand made a related point in a call for greater transparency and inclusivity, making the case that pharmaceutical companies must ensure patient advocates are involved early and throughout the drug development process.

"This includes transparent communication about trial designs, results, and potential risks and benefits. Inclusion of diverse patient perspectives can lead to more patient-centred outcomes and increased trust," El Khawand said.

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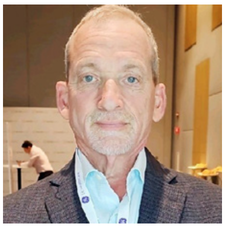

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Founder
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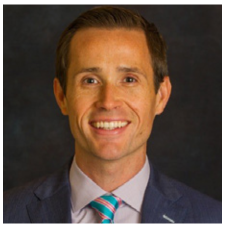

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HOW PHARMA CAN IMPROVE

The survey gathered feedback on the specific actions pharma companies can take to help patients and advocates. Pender said "companies must seek to gain a representative patient voice from independent patient experts, to patient organisations, and advocacy groups as well as individual members of the patient community who do not regularly engage with pharma" because "representation matters."

The feedback is aligned with Ros' call for companies to involve "patients more in all phases of the chain, from drug development to treatment follow-up." Ros and some other respondents said companies should provide more support for co-creation with patient communities. Co-creation could help address calls for improved patient information sheets, informed consent forms, and lay summaries of study data.

Montgomery believes pharma companies need to look at their own organisations, taking deep dives into their cultures and practices to assess if health equity is considered at every level of business. Companies that are yet to embed health equity at all levels should consult and partner with organisations such as the Camden Coalition and its National Center for Complex Health and Social Needs initiative, she said.

Other respondents want pharma companies to do more to help other organisations that interact with patients. One respondent said the industry should help complex delivery centres with care coordination. The respondent wants pharma to help address problems they summarised as "so many people involved, little coordination, information all over the place." Tardif said support for nonprofits that provide basic needs resources such as food and housing to people is "dramatically overlooked" by pharma companies.

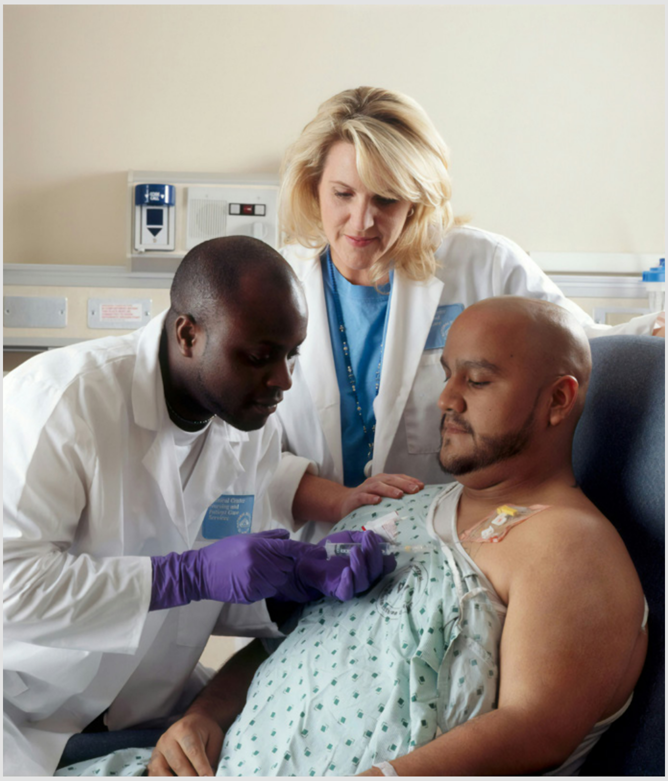
"Until a patient (and their family) have their basic needs met, cancer care is going to take a backseat. Basic needs cannot be ignored. When addressed, the trust factor increases, ability to access care and stay adherent increases. Of course patients want to do both, they are just literally not able to if their basic needs are in jeopardy and their family is at risk," Tardif said.

The survey also asked respondents for the top three changes they would like to see in how pharma companies engage with patient advocates. The responses overlap with the feedback on other questions. Pender's response touched on points made by multiple other respondents.

"Invite patients to speak to different functions in your organisation to educate on living with the medical condition, co-create your strategies together with the patient community, actively listen to the patient community, and build these insights into your strategy and embed engagement with patients into your sustainability strategy," Pender said.

As well as adding to the calls for co-creation, Lindsay Logan Allen, Director at the Institute for Healthcare Improvement, echoed Tardif's point about the financial consequences of chronic illness. Allen warned people "fall through the cracks this way when we don't enter in the invisible costs of having a chronic illness" and outlined ways pharma companies can help.

"Pharma companies must expand their understanding and scope of what financial burden chronic illness can have on patients and work better to understand the financial barriers and advocate for access justice that acknowledges the identities and full scope of responsibilities patients hold," Allen said.



CONCLUSION

The survey suggests that, while pharma companies have made some progress, many patients, patient advocacy organisations, and caregivers remain unhappy with aspects of industry engagement. Pharma companies are yet to win the trust of people who, stung by negative experiences, are sceptical that the industry is committed to long-term, mutually beneficial partnerships with their communities.

There is a path forward, though. The survey shows patients and their advocates want to work with the industry, including through co-creation projects that could build trust and deliver materials that meet the needs of communities. Exactly what works will vary between different companies and communities, but Wheeler provided a catch-all message for how the industry can improve: "Take it seriously and LISTEN!"

By heeding that advice, pharma companies can overcome scepticism and tap into the knowledge and expertise of people who have a unique, first-hand perspective on living with the diseases they treat.