

The value of diverse patient representation and engagement in cancer treatment

ENVISION PHARMA GROUP

Driven by evidence, enabled by technology

Introduction

To improve outcomes for cancer patients and take advantage of the groundbreaking scientific and technological progress made in oncology prevention, diagnosis, therapy, and care over recent years, it is of crucial importance to ensure all patients with cancer have a role and an ongoing dialogue with the healthcare team.

However, over the last two years the COVID-19 pandemic has interrupted that dialogue in many places. "A lot of people living with cancer, especially patients in underserved populations, are worse off now than they were at the start of the pandemic," states Rebecca Goldstein, scientific solutions division lead at Envision Pharma Group.

This whitepaper explores the value of diverse patient representation and patient centricity, as well as engaged patients in cancer prevention, early detection, and therapy outcomes.



Pandemic impact on patients with cancer

The coronavirus pandemic both highlighted and exacerbated existing health disparities in the quality of and access to care.

Certain populations who historically have been challenged to advocate for their own health, such as those from ethnic minorities or low socio-economic backgrounds, struggled even more during the pandemic due to reasons beyond their control. For example, if they held a frontline job where staying safe by working from home wasn't possible and a reduction or total loss of income wasn't an option.



"The pandemic deepened those differences in access to healthcare," observes Mark Lakeram, head of behavioural science for Envision Pharma Group. "The healthcare industry and decision-makers around the world need to address and close those gaps."

In cancer, long-term uninterrupted access to quality healthcare can mean the difference between life and death: people at risk need to be screened; patients with active disease must receive timely treatment and monitoring; individuals in remission need appropriate follow-up to catch recurrences quickly. However, during the peaks of COVID-19 in 2020 and 2021, these steps were delayed or disrupted as individuals and healthcare resources turned their focus to fighting the pandemic. So, for many patients with cancer, the primary focus became staying safe in a crisis, and living with cancer dropped to a close second place.

The unprecedented large-scale pivot to telehealth was a welcome relief for them in some respects (eg, easier to visit the cancer care team without the need for travel) but fell short in others (eg, virtual examinations can be less thorough and lack the personal connection patients need for emotional support). Patients with inadequate access to or comfort with telehealth technology experienced more shortfalls than relief: yet another disparity in care to address.

Today, facilities are back up and in-person visits have returned, yet in many places there is still a sense of resource limitation due to supply chain delays and staffing shortages. "It's one more set of barriers to advocating for yourself or your loved one who has cancer. Appointments are taking longer to schedule. People are not getting their screenings, or if they do and get a bad signal it's more difficult to actually see a care provider to understand what that signal means and the next steps they need to take. Follow-ups are not happening as quickly or as regularly as they should," says Goldstein.

The net result is that since 2020, many patients have been diagnosed with cancer in a more advanced stage than they would have been previously, making a cure more elusive. Patients with active cancer might not have received their full complement of treatment, timing may have been delayed giving the cancer more time to grow, or side effects may have escalated to something more serious. More recurrences have been going unnoticed because timely follow-ups did not happen.

"All in all, the cancer community has not yet recovered from the COVID-19 pandemic, with both a substantial emotional and logistical toll still being placed on patients and caregivers," Goldstein concludes.



Behavioural science can achieve lasting change

Caregivers need a robust understanding of a person's internal drivers (emotional state and rational thought process) plus their external environment in order to apply better disease prevention, diagnosis, and management.



Using behavioural science, which includes multiple fields like sociology, social and cultural anthropology, psychology, and economics, we can start to scratch the surface in understanding human behaviour. Intrinsic to most behavioural change models is that behaviours are driven by emotional, rational, and environmental cues. People can only change if all three types are engaged.

"At Envision Pharma Group, we call this approach Feel-Think-Do," explains Lakeram. "We created a suite of tools to gather insights around crucial elements and use them to inform behaviour change strategies."

In this model, Feel refers to the amygdala part of the brain that drives our automatic, impulsive, emotional response. In contrast, Think comes from the prefrontal cortex and determines our deliberate, reflective, analytical actions. It's what the Envision team tags as a person's internal environment – their deep beliefs, motivations, or long-standing habits.

Finally, the Do relates to external factors influencing behaviour. In a cancer setting, these include a person's financial means but also education, language barriers, technology literacy, and other skills. Are they able to make the right appointment to seek medical help when they are not feeling well? How far do they need to travel to get to a specialist? Do they have health insurance coverage? Are basic needs covered like food or rent, so that they can invest in their health? Environmental aspects like social integration, support available through family or community, or peer influence can play a decisive role too.

Removing health barriers for underserved populations

"Health disparities can result from socio-economic factors, such as a person's financial stability, where they live, or access to resources like technology and transportation; or biases stemming from an individual's racial or ethnic background, age, gender, sexual orientation, or cultural community. Any of these can significantly compromise a person's quality of healthcare. Without taking into consideration all factors – many of which lie outside the traditional pharma role – we are not going to see the desired health outcomes," adds Lakeram.



A holistic view of patient backgrounds can highlight missing data and enable scientists to deliver oncology innovation that benefits every patient at a speed and cost society desires. "We need to look at the data we don't have today, and include diverse backgrounds so that a broad range of patients can relate. This will allow for more meaningful interpretation and lead to stronger patient engagement and results."

One important approach to removing barriers and making it easier for underserved populations to engage in their health is through adequate communication. An environmental behaviour cue Lakeram's team looks at are people's societal norms. "When we provide information in a way so that people can recognise other people like themselves, even if it's as simple as using adequate pictures and ethnic profiles that the target audience can relate to, we're able to stimulate considerable action in people of that background."

When seeking to enrol certain backgrounds into a clinical programme to generate real-world outcomes, another path to lowering barriers may be to choose trial sites based in or near these communities, as well as build trust through dedicated community outreach providing education about the benefits and availability of clinical trials.

Finding out what patients want

To find out about the true internal and external factors determining patient behaviours – and how to influence them positively – patient centricity is key. Unless we put ourselves in the shoes of the patient, we won't know what is going to make a meaningful difference to them.

"We're currently seeing a lot of investment into scientific advancements in oncology," comments Goldstein. "If these investments go into areas of assumed patient benefits, we may not be investing in the right place. It's critical that we put our finite resources towards all patient needs, not just those we assume are important."



Take overall survival, the traditional gold standard endpoint of oncology trials. Of course, it will always be important to see patients with cancer live longer because of an intervention. However, when patients are asked what is important to them, living longer is only one component. A lot of people are, in fact, more interested in living better through improved quality of their daily function during and after treatment. This includes taking into account one's mental and emotional health: post-cancer trauma is very real, even in patients whose cancer or physical symptoms are gone.

However, "A company saying they are 'patient-centric' is not enough," adds Lakeram. "Companies need to place health equity at the centre of their vision, strategy, and interactions with policymakers. A strong culture of diversity, equity, and inclusion needs to run through the fabric of an organisation. The industry should strive to partner with local administration and health authorities to strengthen equitable access, increase the diversity of healthcare workers and educational materials, and to dispel biases on all levels. Companies and policymakers are judged by their actions – not statements."

Engaging patients – but how?

When you ask a patient with cancer how they wish to be involved in product development, you will get a variety of responses with one recurring theme: they are being involved too late in the process. Companies tend to hold patient advisory boards or focus groups for validation purposes close to the end, when it is too late to make much impact on the design of a clinical trial, access programme, or patient engagement platform. In practice, patients can make a more valuable impact when they are brought in at concept-phase and then continuously consulted across the research and development process. It is also what they prefer: a timely, respectful, eye-level partnership versus being added on just as the cycle closes.

It can be all too easy for industry professionals to hesitate to bring in patients as fundamental contributors rather than validators, because we assume patients won't be sophisticated enough to understand the science or technology they are looking at. "But that's not true," comments Goldstein. "If the right patient advocates get invited and the right questions are being asked in a way that speaks to them, patients can inform and improve everything from trial design to enrolment strategies, market access programmes and direct-to-consumer advertising, to how the company goes about the actual launch."



Helping patients ask the right questions about oncology innovation

Recent years have brought an explosion in novel approaches to cancer screening, therapy, surgery, and care. Fundamentally, our understanding of the diverse biology of many cancers has improved massively, so that now there are more cases in which oncologists can precisely match individualised therapies to individual patients. Concurrently over the past decade, better drug screening and design technology have opened the door for more smaller biotech companies to contribute their own innovations to cancer care. The result is a staggering number of cancer therapies in development and on the market – and a landscape that is in a state of constant evolution to the point where even trained oncology professionals have a hard time keeping up.



A patient just diagnosed with cancer, already reeling from a life-changing revelation, quickly runs into heaps of unfiltered information about various therapy classes and medicines, with little to no guidance as to which of these advances may have the most impact on their care. The simplest way to improve this aspect of someone's cancer journey is to ensure every effort is made to cut through the 'clutter' so patients and caregivers can feel informed enough to raise questions to a trustworthy expert, primarily the oncology care team.

For example, a tech-savvy patient or caregiver might quickly learn that biomarker testing can reveal a more bespoke way to treat their cancer; for instance, using an oncogenic targeting agent. Similarly, it is not hard for any patient with an information source to run into stories about the promise of immunotherapy. Patients and their loved ones can benefit from these advances even without a complete understanding of every scientific detail.

"Essentially, patients need to know enough to ask about it when they meet with their oncology care team," suggests Goldstein. "They need to be empowered to ask questions like: 'Are any tests available to help inform my treatment?' or: 'I read about this new approach in immunotherapy – is that an option for me?' Asking the right questions helps your oncology team to help you understand your options and even identify access programmes. When these conversations happen more regularly among all types of patients, then cancer outcomes will materially change."



Single-target biologics or small molecules have been very effective – until they stop working due to acquired resistance. The drug blocks a path the cancer uses to survive, but the cancer finds a parallel path around the drug's target and continues to grow. Newer multimodal biologics that target two or more aspects of the pathways at once can eliminate more of the cancer's possible escape routes, extending the benefits for longer and for more patients. Additionally, design improvements have raised the impact of next-generation antibody-drug conjugates (ADC), agents which use the oncogene to deliver chemotherapy instead of relying on cell-killing pathways. Better clinical efficacy over first-generation ADC has meant that more patients can benefit from expression of an oncogene without having to experience system-wide exposure to chemotherapy.

A new conversation about innovation and advocacy

Empowering patients with the knowledge to ask questions can also unlock what is a major, untapped resource for innovative care: clinical trials. It has been repeatedly estimated that less than 3% of adult patients with cancer enrol in cancer trials, even though around 70% of people in the United States alone could be eligible to participate. More importantly, most of our current clinical trials fail to adequately represent most racial and ethnic minorities, low-income individuals, and people who live in rural areas, even though we already know that baseline outcomes are different in these groups.

One problem seems to be the way trials are perceived by the public, an issue that can be corrected by how clinical trials are explained to patients and their families. "In many settings, a clinical trial is a standard-of-care option for therapy and may even be included in cancer treatment guidelines, but patients may misunderstand the ways we describe them," says Goldstein.

"From a behavioural point-of-view, just using language like trial, would mean most people balk at the idea," Lakeram adds. "Who wants to be part of an 'experiment'? They want the best."

Misconceptions about clinical trials can be corrected effectively with education delivered in a caring, sensitive way by a trusted, credible source. The rarity with which this happens in practice speaks to another fundamental challenge Goldstein sees: inability among healthcare providers and life-science companies to speak plain, accessible language.

"For one thing, most healthcare professionals don't receive enough formal training in how to effectively speak to their patients. They know so much that they're often unable to express succinctly what the patient needs to know or convey it in a thoughtful, respectful, sensitive way," says Goldstein. "Also, healthcare professionals are incredibly, incredibly busy."

Newly diagnosed patients with cancer probably do not receive enough upfront education from their healthcare team. The person sharing the diagnosis will probably give them just enough but then quickly run out of time. The patient will often leave stunned, uncertain, and hungry for more information – yet not quite sure where to turn.

As the next step, hopefully, they are being put in touch with a nurse navigator from the healthcare team who can spend more time with them. However, sadly, that doesn't happen for many patients. Patients and families that look online to supplement their knowledge will then be inundated with a flood of information – some relevant, some completely incredible, and some not written in a voice that is accessible to an individual without medical training. Even intelligent, empowered patients can quickly be overwhelmed and discouraged, unsure of how to proceed.

To address the situation, we need a better fundamental understanding of how patients with diverse backgrounds and attributes prefer to receive information. We all understand the need to educate patients with cancer, but right now, every clinic or healthcare professional, company, and patient organisation is speaking to patients in their own unique way.

Most have started using a multichannel approach, but only certain patients will effectively process information through, for instance, a standard TV spot, a brochure and a website; others will not. "Right now, there is a divide between the haves and have-nots of information. And that divide continues to grow," Goldstein says.

To reach patients broadly and get them engaged in meaningful actions, a unified, truly multichannel approach is required. This means looking 'community by community' at how those patients consume information and what constitutes a trustworthy source they will listen to. While some people will listen up when a renowned expert in cancer is speaking, others may regard that same expert with mistrust and shut down immediately.

A truly effective multichannel approach considers the biases prevalent in individual communities and implements strategies to dispel them. While pockets of progress have been made in this area, reaching deep into diverse patient communities needs a collective effort.



The future of cancer therapy and patient access

Pharmaceutical companies have been working on strengthening patient focus for some time. Substantial advances in patient centricity have only become possible relatively recently thanks to advances that are evolving cancer from a 'death sentence' to a chronic disease, reminiscent of HIV, even in late-stage metastatic settings. It is more feasible to understand the patient perspective if there are more survivors who are able to share their experiences, needs, and expectations. It is also more realistic to have higher expectations of what it is like to live with cancer: now more than ever, more people can hope not just to live longer, but to lead a normal, fulfilled life.



Further contributing to this shift in patient centricity are advances in technology, which connect people with cancer and give them a more unified, impactful voice. Even with rare tumours, patients and advocacy groups can uniquely exchange experiences, mobilise online, and have a collective voice that gives them more influence.

Now and in the coming years, the voice of patients and families impacted by cancer will be a critical influence on the next wave of cancer care innovation, as newer advancements that have become standard of care in late-stage metastatic settings, where the goal is living longer, are starting to move into earlier, pre-metastatic stages of cancer and even pre-malignant phases, where the goal is to be cancer-free. This wave of new opportunities presents a need to reassess how we prioritise therapeutic goals and assign value to interventions. As traditional metrics like overall survival may not be accurately measurable, payors and regulators are becoming more accepting of endpoints like interception of pre-malignant symptoms, event-free survival, or relapse-free survival in many tumour types.



Lakeram concludes, "To ensure we don't miss a trick and are able to fully capitalise on this shift, we must engage patients and caregivers with new questions about their needs, perspectives, and experiences. Taking into account their personal internal environment and the external environment, we can ensure that therapeutic goals and health-system priorities are in line with what patients actually want."

"For any cancer, in any setting, we need to understand what patients view as important rather than assuming so that our priorities match theirs," concludes Goldstein. "The absolute best chance for a cure is to avoid getting sick in the first place — so given a choice, anybody would prefer effective cancer prevention. If it is too late for that, any patient will want access to treatments that hold some hope for a cure. Slowly, that's what our overall goal in cancer is becoming — no more evidence of cancer — and I think it's realistic to expect more and more curable cases of cancer. In the path to curing more patients with cancer, though, innovation in medicine only goes so far without innovation in equitable information and access to care that keeps pace. Curing cancer is an important enough goal to warrant investing the time and resources to ensure that the best care and the appropriate information is available to all people equally."

About the interviewees



Rebecca Goldstein currently serves as a scientific solutions division lead at Envision Pharma Group. A PhD-trained cell biologist and immunologist, Rebecca has held many roles over the years, supporting oncology and immuno-oncology development teams as a researcher and in strategic scientific communications. She lives in central New Jersey in a full house with her husband, three children, extended family, and two Siberian huskies.



Mark Lakeram is the head of behavioural science for Envision Pharma Group. Mark leads the behavioural science team that ensures the company incorporates the multiple fields behavioural science encompasses in the best way it can for its clients to ultimately change the lives of patients for the better. Previous and current clients include governments, pharma, and biotech companies. He is a published author, living in London, UK.

About Envision Pharma Group

Founded in 2001, Envision Pharma Group is a global, innovative technology and scientific communications company serving pharmaceutical, biotechnology, and medical device companies.

Envision is a leading provider of evidence-based communication services and industry-leading technology solutions (iEnvision) that have applicability across many areas of medical affairs and related functional responsibility.

Envision provides services and technology solutions to more than 90 companies, including all of the top 20 pharmaceutical companies.

Envision has 20 offices: six in the United Kingdom – Bishop's Stortford, Glasgow, Horsham, London, Wilmslow, and Alderley Edge; one in Serbia – Subotica; one in Hungary – Szeged; one in Coimbra, Portugal, nine in the United States – Fairfield and Glastonbury, CT, Philadelphia and Wyomissing, PA, Warren, NJ, Boston and Melrose, MA, Powell, OH, Pasadena, CA; and two in the Asia-Pacific region – Tokyo and Sydney.

The company employs 1100+ team members, including over 250 highly qualified and experienced in-house medical writers, and 200 technology solutions team members who provide software development and customer support. To find out more, visit www.envisionpharmagroup.com.



ENVISION PHARMA GROUP

Driven by evidence, enabled by technology