OPEN HEALTH

Making HEOR More Accessible to Patients

Unlock partnerships that deliver outcomes

Foreward

The Health Economics & Outcomes Research (HEOR) landscape has long been evolving, but we now find ourselves in the midst of a revolution. In tandem with a shift in healthcare towards greater personalization, there are three key technological drivers of rapid change in both healthcare delivery and HEOR: big data, cloud-based computing, and artificial intelligence (AI).

It is interesting to observe the foundational role that patient centricity must play if we are to maximize the potential of these technological drivers to improve individual, systemic, and societal outcomes. Indeed, if we fail to emphasize patient centricity, healthcare delivery risks being driven by a set of automated, algorithm-based processes, loudly crunching through reams of health data, such that the patient's voice in treatment decisions gets completely drowned out amidst the statistical noise.

Patients, caregivers, and those that advocate for them are therefore taking greater ownership of their health outcomes and data. Activating these communities as partners in HEOR will create virtuous circles for improving and accelerating the HEOR process and, ultimately, creating better health outcomes. Patients' early and sustained involvement in the research process will generate better data sources and enable more effective communications. This, in turn, will drive faster and better decision-making and eventually lead to broader access. This is an underappreciated aspect of what is sometimes called "the learning healthcare system."

To enable a truly patient-centric approach to HEOR, we need to both involve patients in the research process and improve the way we communicate the results. We need to be mindful of how we partner with patients, acting with transparency, humility, inclusiveness, and a willingness to listen carefully and take action thoughtfully. To guide the industry in achieving this aim, we have outlined a spectrum of patient participation. This can help stakeholders assess the appropriate level of patient engagement for individual projects and strategize how this can potentially evolve over time.

We need to change the language we use to make it more understandable to those outside the HEOR world, including members of the general public with various backgrounds. We must also focus on the things that are most meaningful to patients. The research process and our communications should be centered on these things to effectively demonstrate their value and accelerate change. In addition, we need to engage in ways that are compliant with company standards and local regulations and that cultivate the trust of the patient communities that we strive to serve.

Given the critical importance of patient centricity within the current revolution in HEOR, we are pleased to share our thinking on the topic in this white paper. This is a collaborative project drawing on expertise from across our numerous functions focused on HEOR, communications and, of course, patient writing and health psychology. The power of this collaboration gives us a unique skill set that we leverage to deliver patient centricity within research processes. We look forward to further dialogue with you on this critical enabler of HEOR's future.

DAVID THOMPSON PHD
CEO OPEN HEALTH EVIDENCE & ACCESS

Introduction

As the number of available healthcare treatments and therapeutic options has expanded over the past few decades, there has been a growing need to synthesize evidence across multiple sources to determine which interventions are most likely to lead to favorable outcomes over the long term. Health Economics & Outcomes Research (HEOR) addresses these issues, investigating unmet patient needs and treatment gaps and evaluating the efficacy and cost-effectiveness of treatments in the real world. As its name implies, HEOR encompasses both health economics, which focuses on measuring and evaluating the results of healthcare interventions, and outcomes research, which examines the effects of healthcare interventions on patients. HEOR brings these two domains together, with the goal of supplying data and insights to improve healthcare decision-making.

By design, since its intent is ultimately to create better patient outcomes, HEOR needs to be patient centric. By this, we mean that the patient's lived experience, perspective and needs should be front-of-mind throughout the research process, patients should be more deeply involved within it, and the results should be shared with patient communities in ways that are meaningful and clear. When patients are not involved in research projects, they are less likely to be invested in their outcomes, and researchers are less likely to consider the outcome measures that matter most to patients. If patients' needs aren't considered, therapeutics may have intolerable side-effect profiles or methods of administration that detract from their effectiveness in real-world settings, no matter how promising clinical trial results may have been. And when HEOR's results aren't communicated with patients in ways that are immediately understandable, patients are unlikely to understand their value or relevance. We also need to recognize that involving patients has the power to improve study and research outcomes by accelerating recruitment and improving decision-making, among other factors.

Today, healthcare in general is moving towards greater patient centricity. This means that more patients are being empowered to take ownership of their own health data. It also means that regulators are attending more closely to patient-reported outcomes (PROs). It is increasingly important to adopt a more patient centric approach within HEOR as well.

There are several reasons for this. First and foremost, patients' perspectives are changing. In this sense, the COVID-19 pandemic has served as a watershed moment within the transition to digitally enabled, patient-centric care. With the media spotlight on vaccine development, the public became much more attuned to the importance of health data, spurring greater lay interest in scientific research.

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>
> **SOPHIE TSAI, MD**
> PHYSICIAN AND A SENIOR SCIENTIST, OPEN HEALTH

"Historically, the healthcare sector has been somewhat resistant to change and slow to accommodate new technologies," says Sophie Tsai, MD, a trained physician and a senior scientist focusing on patient-centered outcomes and patient engagement at OPEN Health. "COVID-19 changed the dynamic and accelerated the technology transformation. This has helped to better support the patients by allowing treatments and clinical trials to be more personalized, mobile, and convenient to the patient. It also seems that the medical community as a whole has become more willing to invest in these technologies because they've seen the advantages of utilizing them and — having been forced to adopt them by the pandemic — are now more comfortable with them."

Along with the rapid digitization of healthcare, the past few years have seen an increase in awareness of the importance of patient centricity among both pharmaceutical companies and regulatory agencies. The pharmaceutical industry is increasingly recognizing the value of engaging patients during the discovery and development of new therapeutics, especially as treatments become more personalized. With less profit to be found in the commercialization of blockbuster drugs, life sciences companies need to create new operating models to develop the digitally enabled, highly individualized therapies that will comprise the next generation of care.

To do so successfully, the pharmaceutical sector will need to earn patients' trust, something that it has not always had — or actively prioritized — in the past.

"In the past, a stigma surrounded pharma among the general public," says Priya Patel, MSc, principal real-world evidence consultant at OPEN Health. "Naturally, there will always be patients who do not fully appreciate the purpose and intentions of the pharmaceutical industry in developing new treatments and ensuring they're accessible to the patients who need them. There may also be patients who are influenced by negative media stories and believe that the industry does not have patients' best interests at heart.

This can create reluctance to participate in research on behalf of pharmaceutical companies. This is where education is key. We need to show patients the importance of doing the research and how it will benefit them. Similarly, in the digital age, patients are becoming a lot more aware of issues surrounding data privacy and consequently are more protective of their information, so they are less quick to sign off on the use of their personal data. Dealing with this, again, comes back to education. Our patient resources and consent forms must be very clear on how we intend to use data. We must reassure the patient that they are in control of their data, and that, if they want to withdraw at any time, they can."

At the same time, regulatory pathways are changing. Agencies including the US Food and Drug Administration (FDA) and the European Medicines Agency (EMA) have signaled a greater willingness to access real-world data (RWD) and real-world evidence (RWE) in decision-making processes. Regulators are also pressing stakeholders to include PROs in both clinical trials and post-marketing studies, and they are encouraging the adoption of more patient-centric measures within health technology assessments (HTAs).

This creates a need for change within healthcare and the life sciences. Stakeholders must promote health literacy and education among patient populations and the general public while working to ensure that they are communicating in language that is suited for its audiences. They must develop new models for ensuring that patient voices are heard throughout the research process, going beyond merely surveying prospective participants at a project's start to encompass co-creation (including patients among a study's named authors).

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>
> **LARA GROVES, PHD**
> PRINCIPAL REAL-WORLD EVIDENCE CONSULTANT, OPEN HEALTH

They must actively strive to empower patients to be full participants in research and health communications to ensure that their needs are kept front and center at all times.

"The COVID-19 pandemic really highlighted the importance of communicating medical information from a position of compassion and understanding," says Lara Groves, PhD, a principal real-world evidence consultant at OPEN Health. "It also taught us how critical it is to have access to information that's both accurate and up-to-date. Research needs to learn these lessons. It must be equitable, inclusive, and accessible for all patients."

Making HEOR accessible to patients is a broad-ranging topic spanning multiple disciplines and capabilities. Accordingly, we interviewed numerous people from across our organization, inviting them to share their knowledge, experiences, and thoughts for the future. They are experts in patient engagement and writing, health psychology, data dissemination, health literacy, communications and, of course, HEOR methodologies and processes.

To serve as a framework for our thinking and guidance, we developed the concept of the four domains of patient participation in the HEOR process.

These domains correspond to four areas where collaboration with patient communities will drive better outcomes, both for the research and ultimately for the patients we strive to serve. These stages span the entirety of the project lifecycle, from its conception to the communication of results. Alongside the spectrum of patient participation, we hope these domains will help our industry colleagues achieve deeper and more lasting partnerships with the patient community.

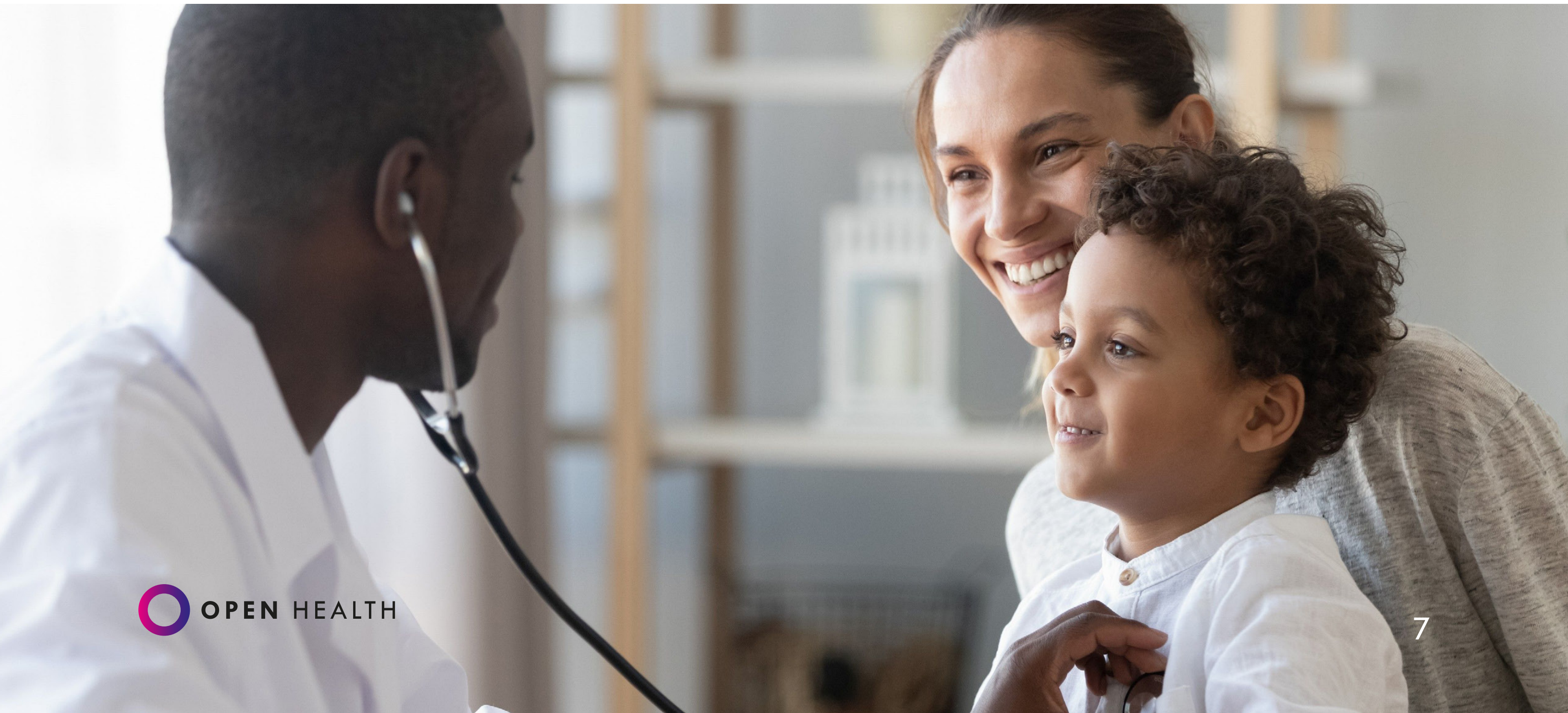
In so doing, they will create virtuous circles where engagement will speed up research processes and improve communications, which, in turn, will accelerate access, advance patient outcomes, and increase trust in the pharmaceutical industry.

The OPEN Health Spectrum of Patient Engagement with the Pharmaceutical Industry

Much progress has been made in enabling effective collaboration between patient communities and the pharmaceutical industry. There are some fantastic ongoing partnerships where trust, transparency, and appropriate win-win relationships have been forged over many years. However, we must face the reality that we have further to travel to achieve a wholesale recognition of the true value of collaboration and equitable partnerships, and to achieve trust among all members of both parties. There remains significant mistrust of the pharmaceutical industry within some patient communities. There's also uncertainty among researchers about how to ensure equitable relationships while maintaining a partnership of independent voices grounded in compliance.

It is clear that to create the level of trust that will be needed for a true partnership between industry and the patient community, there is still much work to be done. And this will demand thoughtful communication. Individual projects will have unique participation requirements, and the process will evolve as collaboration becomes more frequent and trust increases.

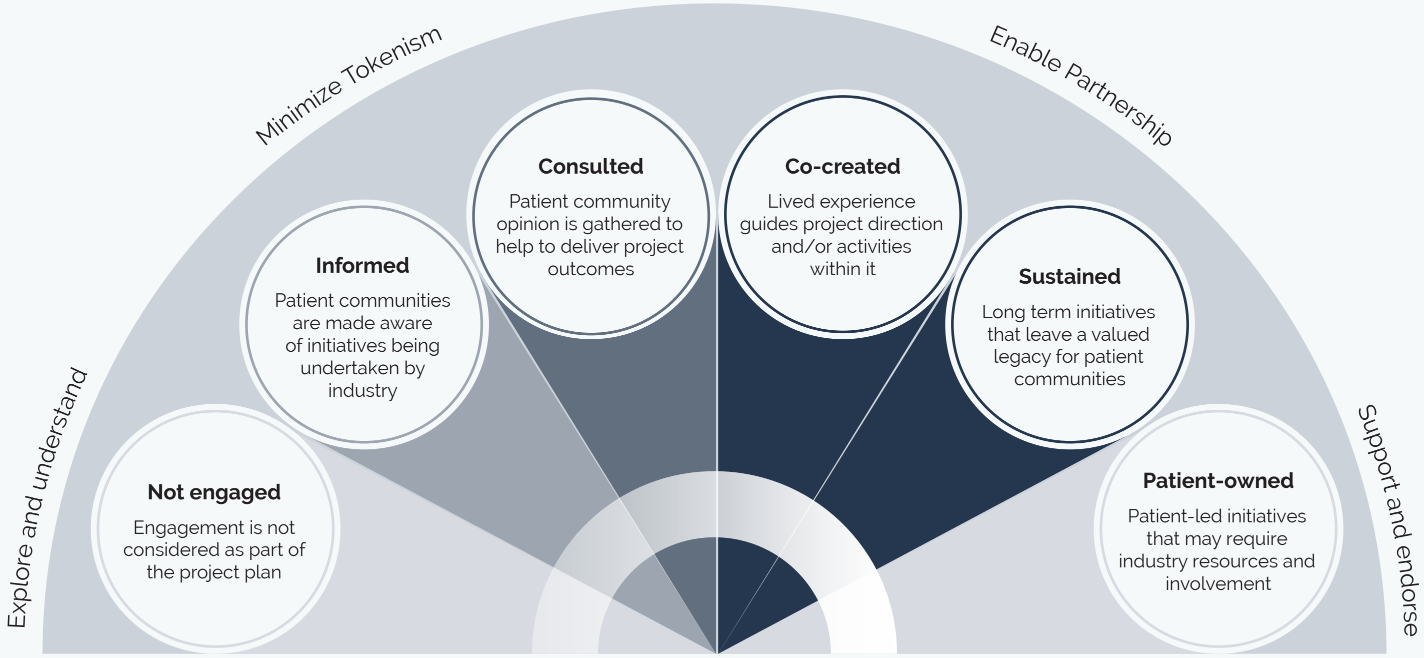
With this in mind, we have created the below infographic to guide stakeholders in increasing patient participation in their projects. The infographic presents the various levels of patient participation that collaborative projects may offer. It identifies that sweet spot where co-creation and sustained partnership can bring the greatest value to patient communities, the pharmaceutical industry, and the HEOR process. We do recognize that participation does not have to fall into that sweet spot to have value. Patient involvement can and should evolve as projects develop and trust grows.



The objectives of the Spectrum of Patient Engagement are to:

1. Guide the industry in establishing relevant levels of participation with patient communities to help move away from token engagements and instead move towards true partnership
2. Seek stronger partnerships as treatment innovations generate a greater need for collaboration
3. Understand that individual projects will require different levels of collaboration
4. Recognize that building trust and the industry's reputation will open up possibilities for deeper and more sustained engagement
5. Support the industry and patient communities to better engage so that they will collaborate more effectively to achieve better outcomes

THE SPECTRUM OF PATIENT PARTICIPATION



Not engaged
Engagement is not considered as part of the project plan

Informed
Patient communities are made aware of initiatives being undertaken by industry

Consulted
Patient community opinion is gathered to help to deliver project outcomes

Co-created
Lived experience guides project direction and/or activities within it

Sustained
Long term initiatives that leave a valued legacy for patient communities

Patient-owned
Patient-led initiatives that may require industry resources and involvement

Level of participation can evolve through growth of trust and project needs. Projects may not require the upper levels of participation to succeed.

The Four Domains of Patient Participation in the HEOR process

In order to make HEOR more accessible to patients, we will need to engage patient communities earlier, deepen those engagements, and sustain them. Greater accessibility will create a virtuous cycle in which engagement will make the HEOR process more efficient, leading to faster and more informed decision-making regarding access to new interventions. This, in turn, has the potential to accelerate outcomes.

Such engagement will require effort from both sides. To build trust and partnership between stakeholders who come from different worlds, we will need to stay true to our shared ambition to improve outcomes for people living with disease.

Patients who trust pharmaceutical companies are more likely to participate in pharmaceutical research, of course, but the benefits of this participation ultimately accrue to the patients themselves. Those who suffer the burden of disease will not only have access to the more effective therapies that pharmaceutical research yields, but will also gain access to treatments that were designed with their physical and emotional needs, preferences and quality of life in mind. HEOR is a multidisciplinary and multifaceted field. To help stakeholders understand how and where to involve patient communities, we've identified the following four domains of patient participation in the HEOR process. These domains extend across every stage of the project lifecycle, because patient involvement is just as important at a project's inception as it is when conveying the results – and explaining why they matter.

THE FOUR DOMAINS OF PATIENT PARTICIPATION IN HEOR

INTENT: to improve outcomes

①

All research and communications are driven by a mission to improve patient outcomes. Enabled by co-creating projects that comprehend the needs of patient communities and translate this into programs that deliver impact and change.

INVOLVEMENT: at every step

②

Throughout the research process the patient community is appropriately engaged to inform all elements spanning concept, design, involvement, and communications. A fully representative cohort of a patient population is engaged throughout.

INSPIRED: by moments that matter most

③

The research process fully considers the practical and real-life challenges of living with disease. This will ensure timely evidence generation truly reflects the unmet patient needs and the prospective value that new interventions can provide.

INFORMED: through thoughtful communications

④

The research process must be presented in a way that provides information that is fully understandable by stakeholder groups. Multiple channels should be considered and it should be developed to enable shared decision making.

The Domains of Patient Participation in Depth

THE INTENT OF HEOR IS TO IMPROVE OUTCOMES

At its core, HEOR is a purpose- and mission-driven activity. All research and communications should always be conducted with a single aim in mind: to improve patient outcomes. Ultimately, this means that research projects should be created on the basis of a full and complete understanding of the needs of patient communities. The goal should be to translate this understanding into results that will have an impact on the problems that matter most to patients.

By better understanding patients' lived experience, stakeholders are empowered to be empathic. They are also better able to design research protocols that take participants' needs and preferences seriously. This enables them to demonstrate outcomes that are better aligned with patients' goals for improving their quality of life.

Sophie Tsai, MD, has noticed that adopting a patient-centric approach in healthcare research not only supports empathy but also enhances the quality of the data that is collected.

"For me, patient centricity comes down to 'caring'," she says. "Caring goes both ways. It is a partnership between patients who 'care' about their own health and other stakeholders in the healthcare system who 'care' about the patients. Patients who 'care' are empowered self-advocates, have a certain degree of health literacy, and/or are actively seeking information and asking questions."

> When we see our research, we need to see the patient: their face, their journey, the world they inhabit. We should immerse ourselves in the patient perspective.
>
> **JASMINE MALONE, BSC**
> HEAD OF PATIENT CONTENT, OPEN HEALTH

"Once the patients have a voice, they will need a stage and an amplifier — that could be regulators, researchers, clinicians, or other stakeholders who recognize the value of patient voice and then actively seek out opportunities to engage the patients. To me as a researcher, engaging patients and patient communities in our studies makes total sense. Not only does it make my work so much more enjoyable, but it can also help generate meaningful research questions and lead to higher recruitment rates. Additionally, engaged research participants, such as patients or caregivers who 'care' and invest in the process, will typically elevate the quality of the data generated."

Larry Radican, PhD, head of HEOR at OPEN Health Communications, concurs. "HEOR has two primary functions," he says. "Conducting research to help understand unmet needs and treatment gaps and identifying the value of treatments. Everything that we do — collecting data, communicating, developing the message — has to be for the patient. We have to keep the patient at the very front of our minds. When we see our research, we need to see the patient: their face, their journey, the world they inhabit. We should immerse ourselves in the patient perspective."

As a former academic editor and journalist who now serves as head of patient content at OPEN Health, Jasmine Malone, BSc, is accustomed to putting herself in others' shoes. "For healthcare practitioners (HCPs) and agency stakeholders, patient centricity means remembering that one day you might also be a patient, so you want to ensure that any communications targeted towards or involving the patient in any way are put together in a way that you wouldn't mind participating in or receiving yourself," she says. "You would want that communication to be done in a thoughtful way, which is understanding of both your circumstances and your emotions during that time — as well as your specific informational needs."

PATIENT INVOLVEMENT NEEDS TO HAPPEN AT EVERY STEP

The patient community should be appropriately engaged throughout the research process so that their contributions and perspective can inform every stage of a project, from conception and design to data collection and communications. To be effective, this engagement must be inclusive; that is, a fully representative cohort of the patient population must participate. This can be challenging, since certain groups (namely, those with higher levels of health literacy at the start) tend to be easier to recruit and engage.

In both the US and Europe, it is becoming more common for pharmaceutical companies to consult patients and/or patient advocacy groups (PAGs) early on in the study design process, with the goal of creating protocols that will be more comfortable and tolerable and striving for outcomes that better align with patient needs.

Radican says, "Right from the first discussions about a research study, we should be thinking, 'Let's get patients involved – let's find patients who have this disease or condition and bring them in from the very beginning.' We want them as partners at the research table; we want and absolutely need their insights, their perspectives, and their learnings. Patients should be included from the study conceptualization to the dissemination of research results, and every step in between."

"Patient-centered outcomes and patient-reported outcomes are increasingly accepted as standard practice within the pharmaceutical field," says Karen Bailey, PhD, a London-based scientist who leads qualitative research at OPEN Health Evidence & Access, UK. "Less widely understood, but definitely growing, is patient engagement at the study design stage under the banner of patient-public involvement (PPI). We recently reviewed some of OH's HEOR projects to identify examples of research that involved patients or PAGs in this way. Patients or patient representatives were invited to advise on the design of the study, particularly whether the proposed patient-reported outcome measures were appropriate and captured all the symptoms and impacts. They were also asked to look at the study material itself, providing feedback on issues like the appropriateness and time burden of interview questions."

Bailey explains that patient engagement in a study's early stages can go beyond advising on study design. "Another key aspect of patient engagement is asking patient participants to support recruitment efforts," she says. "I believe that this can be entirely valid as long as it is in the context of a wider relationship, where patients can take part in discussions and be involved in the study's design — though we should try to avoid using PAGs as nothing more than recruitment vendors. We find that if patient groups are involved in the process from the early stages, they are more likely to provide additional support on the recruitment side."

Jasmine Malone, BSc, emphasizes that many patients have valid reasons for hesitating to participate, and an important aspect of inclusiveness is breaking down these barriers in ways that display sensitivity and understanding.

"Patients can be resistant to participating in research for a number of reasons, ranging from practical concerns to ethical concerns or their own personal views," she says. "Commonly, practical reasons far outweigh ideological ones. These are situations where patients are already physically or emotionally burdened by the treatment or their experience of the disease itself, and they do not necessarily want to relive that for the purposes of evidence-gathering. It can be hard to share — you have to be at the right part in your journey to want to talk about how a disease has affected you or your child or your loved ones — and it is often very much about finding the right patient at the right time in their journey, when they feel ready to share their experience and become an advocate for their condition and the associated unmet needs."

Tailoring communications about a project to the health literacy level of prospective participants can increase their willingness to take part, Malone explains. "If a patient's comprehension of their condition is low — meaning the level of information they are getting is not well-suited to their level of health literacy — they may be less confident about participating, especially in a group setting that may include patients or HCPs that they think of as more advanced or better informed," she says. "We tailor our patient participation programs to all levels of health literacy and frame the conversations to be as inclusive and open as possible. There is no wrong statement. There is no wrong answer. We just want to hear in your own words what your answers to specific questions are — and if you don't know the answer, that's fine as well."

Oliver Childs, BSc, global scientific director at OPEN Health Communications, agrees that the right communications strategies – and the right recruitment strategies – are essential for inclusiveness. "Patient participation is not necessarily linked to patients' willingness to be involved so much as their opportunity to be involved," he explains. "The patients who work with pharma and engage with patient associations are, by definition, going to be those with slightly more health-literate backgrounds; often, they have actively identified that there is a pharma company out there that they could engage with, to offer help and potentially influence their work. These 'professional patients' add huge value with their personal perspectives, but less health literate patients tend to be under-represented."

"People with the lowest health literacy tend to be the most disadvantaged," he continues. "These are the people who are less likely to be digitally literate. They're less likely to have access to one or more devices at home that they can use to get information about disease. Their experience will be very different than that of the patients who are easier to access. The seeming ubiquity of digital masks the fact that many of the most vulnerable and least healthy are those who are also digitally isolated. This digital divide must be addressed. Otherwise, we're in danger of cementing inequalities through digital health rather than shrinking them. True inclusiveness goes beyond simply building usable 'things' — it's just as much about work to widen digital participation."

> Who are we to sit and design a study about a disease and not include a single patient with the disease in that design? How can we know that our studies will include all aspects of the disease and the intervention that are relevant and important to patients?
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> **LARRY RADICAN, PHD**
> VICE PRESIDENT, HEOR, OPEN HEALTH

BE INSPIRED BY THE MOMENTS THAT MATTER MOST

Stakeholders in the research process need to understand and fully consider the practical, real-life challenges of living with disease. This will ensure that successful evidence generation truly reflects unmet patient needs. It will also make it possible to develop new interventions that can offer greater value to patients, healthcare systems, and society.

Without this necessary perspective, research teams tend to leverage off-the-shelf outcome measures, which can miss the things that are most meaningful to patients. Research teams might focus their attention on an aspect of disease that is not the highest priority for the patient. Healthcare companies may focus on aspects of treatment and management that are not the most pressing issues for those who are living with the condition.

"We need to re-define and re-focus our research and data collection on endpoints that are truly relevant for the patient.," says Rosemary Jose Haaksman, PhD, a Netherlands-based pharmacologist who serves as a senior director for strategic market access at OPEN Health. "Health technology committees might define the value of innovative treatment based on clinical markers, for instance, of inflammation or mobility. For the patient, however, it is probably improvement in the ability to perform simpler everyday tasks that matters the most. These kinds of mismatches are, sadly, quite common, and it is therefore crucial to our value demonstration that we seamlessly incorporate the patient voice."

One way we can achieve this is by involving patients in PPI activities, as described above. We can also supplement structured quantitative questionnaires with more qualitative, open-ended interviews.

Sonya Snedecor, PhD, an Executive Director of HEOR who leads the Interactive Analytics and Communications group at OPEN Health, agrees. She explains how incorporating patients' perspectives can improve the quality and outcomes of HTAs.

"The mandate of HTA is to maximize the health of the entire population by determining how to efficiently distribute limited resources across all healthcare interventions," she says. "The challenge that healthcare companies and governments face with HTAs is that the decisions that maximize the health of the population and optimize the use of resources are not necessarily the decisions that will make any one person happy. Everyone has different priorities, and for decision makers to take the right action, they need to have the right knowledge, the insight to interpret that knowledge, and the necessary context to understand its relevance."

An additional way to capture the moments that matter most to patients is to involve patients not just in study designs, but in capturing outcomes, including being able to submit and track their own data and by incorporating patient-centric measures among real-world evidence (RWE). Priya Patel sees momentum in this area.

"There's a lot more research now that involves patient input," she says. "Patients are being encouraged to contribute their own data and are empowered to take ownership of their own health — whether this is through study questionnaires or via advanced mobile applications that enable them to monitor and track their own data. Many patients are experts in their own conditions, being the ones that are experiencing their impact on quality of life firsthand. It is still relatively unique within the industry for an RWE agency to have a team that focuses explicitly on patient-centered outcomes, as OPEN Health does, but having this brings significant benefits, including a much more in-depth understanding of patient experience. It's important to note that it is this qualitative research that is providing these additional insights."

"Even as treatment strategies become more tailored and personalized, the medical community may not always immediately recognize the importance of considering the patients' perspective. I recently worked on a patient preference study where our client developed a treatment that is comparable to the standard of care in terms of efficacy and side effects. The only difference was in the mode of administration -- our client's therapy was oral versus the standard of care which includes IV infusions and SC injections."

"The patients we interviewed described the burden of IV/SC therapies and spoke about their strong desire to receive their treatments orally. Oral therapies would decrease the number of required visits to the doctor's office, which can be especially meaningful to older and frailer patients. Most patients appreciated the convenience an oral drug could bring and spoke about how it would give them part of their lives back. One patient heard about the oral treatment and immediately went to the doctor's office to advocate and request the oral drug. However, the doctor didn't see a need for it at the time because the efficacy and adverse event profiles were largely the same."

— Sophie Tsai, MD, Sr. Scientist, Patient-Centered Outcomes & Patient Engagement, OPEN Health

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> **SOPHIE TSAI, MD**
> SR. SCIENTIST, PATIENT-CENTERED OUTCOMES & PATIENT ENGAGEMENT, OPEN HEALTH

KEEP PATIENTS INFORMED THROUGH THOUGHTFUL COMMUNICATIONS

One of the longstanding challenges in HEOR has been that communications were traditionally not tailored to be engaging for, and easily comprehended by, diverse audiences, including patients. Information about the research process and its outcomes must be presented in a way that is both accurate and fully understandable for all stakeholder groups. All communication mediums that support this should be used — including digital or social media, where appropriate — and the process should be designed to enable shared decision-making.

Oliver Childs, BSc, elaborates on the need to communicate in non-specialist terms: "There are parallels between legalese and health jargon," he says. "When you go over legal documents and contracts, you find that they are very much geared towards people with a solid grounding in law. The medical field is similarly inward-looking in the language we use — it tends to be much more medicine-centric than patient- or end user-centric. We're not putting ourselves in the shoes of the person looking at the website, brochure, or app. This is categorically not about dumbing down information – it's about 'opening it up' to be more accessible. Simpler does not mean simplistic."

Jasmine Malone, BSc, explains that ultimate goal of HEOR communications is to facilitate accurate information exchange. "The challenge of sharing scientific information with patient communities is an exercise in health literacy communication," she says. "The starting point is to understand right from the beginning that there is no longer just an academic audience to consider at the end of any research or scientific data project. In an information age, where the internet offers a library of content that is far more accessible than anything was in the past, more and more people are turning directly to scientific papers for their data."

"Audiences know that they need to go straight to the horse's mouth and look at what the scientists have written about their condition, whether that is potential treatments, survival rates, treatment adherence rates, or side effect monitoring. But when they look at those academic papers, they are in danger, because those papers are written for a level of health literacy that is so much higher than the average person's, educated or otherwise. This drastically increases the chance that lay readers could draw misinformation from papers that they do not wholly understand, or that their comprehension of what they read might not reflect the entirety of the picture that the research presents. It is crucial for those papers to be made available at multiple levels of health literacy."

"HEOR has to be understood by the patient," says Larry Radican, PhD. "We have a lot of specialized terminology within the field that's not accessible to wider audiences. But HEOR is about practical things, like quality of life, work function, social function, family function, treatment satisfaction, preferences. These are very down-to-earth terms. Why don't we use them more, instead of relying on jargon?"

Radican sees three main places within HEOR communications where the language could be made more accessible. "First is the inclusion of patient lay summaries (PLSs) with published articles," he says. "We are seeing more and more journals accepting and even requiring PLSs, which is very encouraging, because it provides an opportunity for the research team to distill their jargon down to something that is accessible and usable by everyone reading the paper."

"Next is the use of graphical abstracts to get a message across quickly," he continues. "A graphical abstract is a box on the page containing extremely brief descriptions — usually just a few words — of the study objectives, methods, and results, combined with graphical representations of the research; this may include infographics of patients, technology, and equipment that was used in the study, outcomes, or events of interest. When we combine a PLS with a graphical abstract, we can deliver the most critical information about the study very concisely and quickly."

Finally, Open Access publishing can also help, particularly if care is taken to ensure that language and presentation of findings are no longer barriers to understanding. In the Open Access model, published academic research is made permanently and freely available online. This includes peer-reviewed scientific research published in academic journals. All of these results can be built upon by other experts working in the same or adjacent areas, or read and shared by members of the general public.

THERE ARE FOUR KEY AREAS OF DATA COMMUNICATION THAT WE FEEL COULD BE IMPROVED:

1. Data-heavy research can be very difficult to navigate. Rather than saturating a paper with tables, what we can do is **create an accessible dashboard tool** that enables the user to interact with large amounts of data and even perform some basic analytics.

2. PowerPoint presentations are a common means of communicating research, but they can be quite linear and repetitive. We have ways to add more dynamism and creativity. We can combine data streamlining with the presentation, for example by **integrating a slide deck and an impact model into the same tool.** The user can then interact with the different aspects of the tool to best showcase the data for different audiences.

3. A lot of journal articles have appendices filled with tables of data. We can **create an HTML file that includes all those extra pieces of data to act as a supplementary appendix** to the article. Instead of having to make a whole second PowerPoint to explain the publication, clients can just use that one file, which lives on the journal's website, as a detail aid. This has been very useful for data-heavy articles.

4. When you perform a comparative effectiveness analysis, every country needs its own analysis because every country has a different list of chemicals or drugs that are approved and not approved. This has meant that the analysis will have to be redone for every submission. We can **create an online tool that automatically performs those adaptations.** We input all the data once, and then the user can perform any investigations or analyses they like with their own parameters.

— Sonya Snedecor, PhD, Executive Director, HEOR and Strategic Lead, Interactive Analytics and Communications, OPEN Health

Conclusion

In the coming years, making HEOR processes more accessible to patients will be increasingly important and it will be critical to take a multidisciplinary approach to achieving this. Incorporating patient perspectives into study designs will not only accelerate the full HEOR process, but it will lead to the generation of outcomes that are more meaningful to those living with disease. By targeting the moments that matter most to patients and caregivers, we will make new innovations more valuable to them and society as a whole. Aligning this evolution with the increasingly patient-centered focus within regulatory and HTA processes can only lead to more effective and accelerated decision-making. Co-creating and validating projects with patients will substantively change the patient's status from object of inquiry to subject who understands how scientific research can increase their quality of life. Improving the way results are shared will ultimately render the entire process more open and accessible, furthering both its reach and its potential value to all. In turn, ensuring data is not just accessible but is understandable will further empower patients to become owners of their own health outcomes and improve shared decision-making with those supporting their care.

No one knows more about the patient's experience than the patient does. It is time for stakeholders across the drug development and approval process to engage patients more deeply in every aspect of that process. Making HEOR more accessible is only the start. We are excited to be at the forefront of a new paradigm where HEOR is a two-way dialogue of empathy, partnership, understanding, and ultimately trust.