**Patient Inclusion Series** 

## From Transactional to Transformational Bringing Patient Centricity to the Next Level



© Cactus Life Sciences Inc. All rights reserved. All registered trademarks are property of their respective owners.



## **CONTRIBUTORS**

This whitepaper would not have been possible without our industry experts who provided their insights and feedback at various stages of content development. We would like to thank them for sharing their time and experience with us.

Join Cactus Life Sciences and industry experts who have contributed to this whitepaper at the Medical Affairs Professional Society's (MAPS) 2022 Global Annual Meeting, where we will be delivering a workshop on innovating patient partnerships.

The MAPS annual meeting is about providing participants with the best actionable insights, practical strategies, and tools to lead the industry. This year, Cactus Life Sciences will be joining leading industry experts to present a workshop at the MAPS annual meeting, where you can learn new perspectives on patient inclusion and how we can make a difference for the patients we serve.

## THE WORKSHOP

### From Patient-Centric to Patient Inclusive: Guiding this Important Transformation

SAVE THE DATETIME 8:30-10:30 AM CSTTuesday, March 22, 2022LOCATION New Orleans, LAROOM Celestin Ballroom BC

#### **LEARNING OBJECTIVES**

Upon completion, participants should be able to:

- Understand the cause and effect of not including patients early and often in clinical protocols
- Appreciate how to apply real world learnings from patient experience/pain points into a solution to improve care
- Grasp the importance of building cross-functional communication materials to meet patients and caregivers in a unified way can reduce communication issues and improve outcomes
- Empathize through a real-life caregiver to understand why these insights are so valuable for patients

#### LEARN FROM THE EXPERT SPEAKERS



#### Leigh M. Boehmer, PharmD, BCOP

Dr. Leigh Boehmer is the Chief Medical Officer for the Association of Community Cancer Centers (ACCC). In this role, he is responsible for

assessing educational needs and designing interventions for multidisciplinary cancer care teams serving patients in community oncology programs and practices. He also serves as a liaison with external stakeholders, including patient advocacy organizations, policy experts, and governmental agencies, to advance the objectives of ACCC membership and projects. An alumnus of the University of Iowa College of Pharmacy, Dr. Boehmer completed his oncology residency training at The Johns Hopkins Hospital. He has worked in both in- and out-patient medical oncology settings, spanning large academic to rural community oncology environments. Current areas of concentration include building capacity for community oncology research, mitigating cancer care disparities, and using a quality improvement framework to empower community oncology practice transformation.



#### Maarten Beekman, MD

Maarten Beekman is a Dutch physician by background and an experienced International Pharmaceutical Executive with a strong track record in global clinical development and local, regional, and global medical affairs.

After over 33 years in Corporate Pharma, of which the past 11 years were at AstraZeneca, he has now moved to the next chapter in his life to help medical leaders and companies to increase the impact of the medical affairs function for the benefit of the patients they serve. He is an author on recent publications on the role and the future of medical affairs and on several publications as a result of his work in medical affairs.



#### Lily Chu, MD, MSHS

Lily Chu, MD, MSHS, has a background in internal medicine, geriatric medicine, and public health. In 2006, she came down with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), a chronic

medical condition that is poorly understood and often neglected by healthcare professionals and organizations. For the past 4 decades, patients and their families have felt their concerns were unheard, dismissed, and even ridiculed. Thus, Dr. Chu inadvertently became a connector among medical, scientific, and patient/caregiver groups. She is currently Vice President of the International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFSME, www.iacfsme.org) and has also advised the Stanford University ME/CFS Initiative and the US government on numerous ME/CFS-related projects. Dr. Chu hopes to bring all 3 of her perspectives to this workshop.



#### Jessica (Byam) Klein

Jessica is a rare disease champion with a passion for bringing better health and brighter futures to people living with rare diseases. She was a loving mom and caregiver to Isaac Klein who lost his fight with a rare form of

muscular dystrophy in 2008. Though small in body, Isaac possessed a huge soul, which allowed him to be brave, sweet, and funny beyond his years.

Sign up and let's make a real difference for patients together.



#### Elvira D'souza

#### President, Cactus Life Sciences

Leading a global team that works with pharma, biotech, and device companies, Elvira plays a key role in helping these organizations communicate their research to various stakeholders. She has a sound understanding of global outsourcing of medical and patient-centric communications services and works extensively with key decision makers within medical affairs teams globally to provide

customized solutions that meet their needs. She is extensively involved with medical writing communities, especially in the Asia-Pacific region. She is a member of the Medical Communications Focus Area Working Group at Medical Affairs Professionals Society (MAPS). She also has an ELS certification from the Board of Editors in the Life Sciences and is an active member of the International Society for Medical Publishing Professionals (ISMPP).

## TABLE OF CONTENTS

2	The Workshop
	Building a Patient Inclusive Communication Continuum
5	The Meaning of Patient Centricity
	Introduction
	Obstacles to Patient-Centric Initiatives
7	From Patient-Centric to Patient Inclusive
	Why the Success of Patient Centricity Hinges on Health Literacy
	The Power of Patient Advocates
	The "Patient Expert": A Concept in Development
	Patient-Centricity Opportunity Spaces
	Building a Patient-Centric Approach
14	The Role of Medical Affairs Matters
	The Role of Medical Affairs: What Happens Next?
	How to Involve Medical Affairs in Patient Collaborations When Creating
	Scientific Communications
17	Integration and Involvement
	More Efficient Patient Communication Programs
	Train Patients to Support the Peer Review Process
	Expand Patient Authorship
22	Creating the Right Approach
	Develop Digital Tools, Communities, and Easily Digestible Content
	Localize Content
24	Being Trustworthy
	Build Brand Awareness to Gain Brand Affinity
25	Summary
26	References

# THE MEANING OF PATIENT CENTRICITY

## **INTRODUCTION**

Clinical trials have always been designed to achieve approval of a new medicine, with the main focus being on efficacy, safety, and dosing. The traditional idea of "patient centricity" could be more accurately defined as "patient-end benefit," with endpoints that encompass things like overall survival, performance of Activities of Daily Living, or Quality of Life Years. These endpoints, while valuable, do not always accurately reflect real-world patient experiences or address what is most important to a patient. Moreover, today's patients have access to more scientific information, are better informed about their conditions, and are more vocal about their desire for inclusion in all aspects of the life cycle of a medicine. Many of these patients are demanding more than a product-focused effort from pharmaceutical companies. They want a voice in the drug development process and beyond, with clinical endpoints that take into account their holistic viewpoint of care delivery. In short, they are done with the transactional and are moving toward transformational engagement, and pharma has a unique opportunity to help define what success in the context of this engagement looks like.

## **OBSTACLES TO PATIENT-CENTRIC INITIATIVES**

Many pharma companies have made strides in incorporating patient centricity into their clinical research models, messaging initiatives, educational efforts, and other activities. These efforts include developing better tools and processes to prioritize patient needs<sup>1</sup>; involving patients in drug or device-specific understanding; and collaborating via patient registries, clinical trial input, and ongoing relationships with patient advocates and organizations. However, there is a long way to go.

There are still concerns in the industry about patients' ability to understand medical concepts in drug development discussions, alongside concerns about patient objectivity and the feeling that companies cannot justify their time and financial investment in such collaborations.<sup>1</sup> Therefore, as Dr. Maarten Beekman, Managing Director, Medical Impact+ and former International Medical Director, AstraZeneca, puts it, the industry still "often talks for the patient or thinks for the patient, but doesn't ask the patient directly, 'What do you need?'"

# FROM PATIENT-CENTRIC TO PATIENT INCLUSIVE

## WHY THE SUCCESS OF PATIENT CENTRICITY HINGES ON HEALTH LITERACY

Some of the industry's concerns are well founded. Health literacy—the ability of a layperson to understand and act on information provided about their health—is more than a comprehension issue. Low health literacy also negatively impacts health outcomes.<sup>2</sup>

The average literacy level in the United States is no higher than the 8th grade level. Moreover, it's important to note that health literacy does not refer to a person's overall educational level, but to their ability to grasp health-related information.

For example, someone may be highly educated in a certain field such as accounting or law, and still struggle to understand materials about a disease. It has been reported that 47% of Europeans<sup>3</sup> and approximately 36% of Americans<sup>4</sup> have poor health literacy. This means that although patients want to be more informed, they often lack the context to critically interpret medical information. This issue is exacerbated by the proliferation of content on social media, and from inaccurate or misinformed sources like broadcast media, friends, and family. Worse, the more a patient consumes content from these sources, the more likely it is that the same information will appear on their social media feed, creating a continuous feedback loop of misinformation.

Pharma companies, clinical researchers, and healthcare professionals (HCPs) find themselves caught between a rock and a hard place when trying to dislodge misinformed perspectives that are at best not helpful, and at worst, a real health risk.



Many admit that the so-called "empowered patient" poses a challenge, particularly if they regularly consume misinformation.<sup>5</sup>

Accurate, non-promotional, plain-language content for patients can help HCPs overcome some of these obstacles. Moreover, including patients in developing not only patient-facing disease- and product-related materials, but also the communication strategy when creating educational materials and tools, can increase trust and credibility. Providing patient-friendly collaboration opportunities, understanding their stories, and delivering high-quality educational content that makes it simpler for patients to understand medical information are all key to overcoming health literacy challenges.

### THE POWER OF PATIENT ADVOCATES

Patient advocates were the trailblazers in the clinical-to-commercial connection. The concept of patient advocacy began in the 1950s with cancer research, but the best-known example is the patient advocacy of the 1980s during the HIV epidemic.<sup>6</sup> This

I have worked in the asthma-COPD space for the last 5 years. An important question I always ask myself is, 'Who is the asthma or COPD patient?' Many patients from the lower social classes don't have the opportunity to express themselves. Hence, it is important for medical affairs to identify these patients as well, and understand their needs."

Dr. Maarten Beekman Managing Director, Medical Impact+ and former International Medical Director, AstraZeneca effort continued to grow and expand in 1991 when the FDA formed its <u>Patient</u> <u>Representative</u> <u>Program.<sup>7</sup></u>

Today, this program partners with many different patient organizations and encompasses up to 500 diseases. conditions. and device experiences.<sup>7</sup> And while the range of therapeutic areas that have strong patient advocacy initiatives is expanding, it is important to note that many larger populations with more common diseases (hypertension, diabetes, etc.) lack adequate patient advocacy representation. especially in lessdeveloped countries.



Patients can wander the system for a long time before they get an accurate diagnosis. They're scared and confused. Our job is to help them navigate the system, get informed, make decisions about the best path for them, and advocate for themselves."

Jessica (Byam) Klein Rare Disease Advocate and caregiver

Patient advocacy and other partnerships with patients rely on a variety of criteria that circle back to patients' health literacy, including<sup>7</sup>

01 Being an active participant in a patient advocacy organization and having direct personal experience with the disease or condition

02 Being knowledgeable about treatment options and research

03 Being able to grasp scientific principles, understand issues, and make informed decisions based on complex data

04 Being able to clearly communicate their understanding and decision-making around health issues

## THE "PATIENT EXPERT": A CONCEPT IN DEVELOPMENT

The patient expert concept is based on the premise that designing and implementing educational and self-care programs will help patients actively manage their conditions better. Extrapolating this into clinical research and beyond, it presumes that the better informed a patient is about a particular condition or therapeutic option, the more they can contribute. The purpose is to empower these patients to participate in the research process by inviting them to directly collaborate with pharma, regulatory agencies, or

We need to tell patients that their safety is paramount to us in clinical trials. An average person does not understand the meaning of a placebo or a double-blind trial. I once had someone approach me asking to be put on "placebo" because they saw the side effects of the drug. It just shows you that we are not doing a very good job currently."

Jessica (Byam) Klein Rare Disease Advocate and caregiver

#### patient advocacy groups.

This serves to overcome the perception that knowledge based on lived experience is less valuable than scientific data.<sup>8</sup> So while a patient may not be a member of the medical profession, someone with direct experience of a disease can provide insight on the real-world impact of the condition, diagnosis journey, self-help programs developed by pharma, and available treatments (if any). Bolstering this experience with education and training provides an additional level of credibility and understanding that may prove invaluable to the scientific community.

Still, the need for patient participation faces significant barriers such as clinical trial access, demographic and socioeconomic challenges, inappropriate or excessive procedures, broad exclusion

criteria, lack of patient-centric trial designs, and patient and physician attitudes. While not every barrier may be readily overcome, providing a more collaborative and transparent process—including an investment in patient education—will allow pharma companies to normalize research and gain valuable insight into what patients really need. Additionally, this transparency and inclusion will bolster trust among patients, caregivers, and families. After all, without patient participation in research, there is no progress and no knowledge gained that may help benefit patients in the future.<sup>8</sup>

## To date, the pharmaceutical industry has made progress on addressing some of these concerns, with inroads being made in

- Involving patients in formulating drug- or device-specific communications to improve understanding
- Focusing on data creation around clinical study benefits/results
- Designing clinical study protocols with patient input
- Furthering patient authorship/co-creation opportunities
- Collecting additional, real-world, life-impact data via patient registries
- Creating plain-language summaries of clinical trial findings

#### Areas for improvement include

- Engaging patients earlier to determine the best ways to guide disease area understanding (current treatments, unmet needs, subpopulations, preferences, etc.)
- Increasing the diversity of clinical trial participants and the workforce that supports these trials
- Getting patient input on study protocols, potential barriers to enrollment, and study endpoints
- Collaborating on communication strategies when creating counseling materials, lay summaries, disease awareness materials, clinical study outputs, etc.

## **PATIENT-CENTRICITY OPPORTUNITY SPACES**

Much of the focus of patient centricity has been on clinical trial recruitment and participation and on delivering easily understood patient education materials post-approval. This leaves a gap between the end of a clinical trial and commercialization, where patients feel left out of the process. Patients who have participated in clinical trials want to know what happened, including the following:

- Access to their data after clinical study participation
- The understanding of how their personal data are used, and reassurance that privacy protocols are in place
- An explanation of placebo group and active group, including follow-ups on whether patients on placebo will now get active medication, or if patients in the active drug study group will continue to receive the medication after the trial ends
- Plain-language clinical study results
- The ability to access the medication at a reasonable cost once it is available commercially
- Authentic, objective, understandable, and trustworthy information around diseases

## **BUILDING A PATIENT-CENTRIC APPROACH**

Incorporating a patient pillar into the scientific process is critical for seamless communication of data on a new medicine and meaningful dissemination of information to all relevant audiences. Medical affairs plays a crucial role in developing this pillar, in concert with patients, as they have the communication expertise necessary to ensure that the strategy for patient inclusion covers the entire spectrum of the

#### patient journey.

Medical affairs' involvement can also preclude the siloed approach that leads to disjointed patient communication across clinical trial phases, disease education, and post-approval messaging.

#### Building a patient-centric pillar comprises 3 steps:



#### Human-centred Design

This helps determine why a particular approach is being adopted and can help formulate actionable drivers to change patient behavior and thus improve results. For example, developing a patient lexicon can help patients understand terms like "dosing" and why a medicine is administered a certain way, preventing adverse events that occur frequently when patients do not follow medication directions. Such issues occur due to varying literacy levels among patients, and physicians failing to deliver easily understandable instructions.<sup>9</sup> For instance, patients may not know that crushing tablets to overcome swallowing issues can inadvertently change the stability, toxicity profile, or bioavailability of a medicine.<sup>2</sup>



#### **Alignment Sessions**

These sessions should be ongoing consults in which all participants collaborate to address issues before, during, and after a clinical trial.



#### Prototyping

Develop messaging for before, during, and after a clinical trial as a minimum viable product (the essential communication to get your message across). Fine-tune and adapt during the process and adjust as needed before a final output is agreed upon.

# THE ROLE OF MEDICAL AFFAIRS MATTERS

## THE ROLE OF MEDICAL AFFAIRS: WHAT HAPPENS NEXT?

Medical affairs plays a vital role in strengthening the collaboration between patients and the healthcare industry, especially after a clinical trial is over and during the market authorization process. Many materials created by medical affairs and agencies focus on educating HCPs about the disease state, about what is happening in the therapeutic area, or about a particular medicine. What these materials do not do adequately

> is inform the patient or act as a bridge to foster mutual understanding between patients and providers.

We have an opportunity to assist patients in being more active participants in their care journey through creation of patient-informed summaries of trial results, designed to be used by providers when discussing care planning with their patients."

Leigh Boehmer Chief Medical Officer, Association of Community Cancer Centers Medical affairs has an unparalleled opportunity to collaborate with HCPs and patients/caregivers to co-create patient-centric materials. These bidirectional communication tools can help to contextualize trial data in easy-to-understand ways and put the emphasis on patient understanding of why a particular trial or treatment may be a good choice for them.

This includes covering everything patients are dealing with. Pharma doesn't usually talk about the daily life of a person with a disease. Medical affairs can play an important role here, as evidenced by the <u>"Cancer101.org"</u> initiative. Multiple pharma companies joined together to create this site to provide access to unbiased information that patients truly

need. The website covers many aspects related to cancer treatment, from technical terms through lifestyle impacts to clinical trials. It includes resources on navigating cancer, questions to ask the healthcare team, clinical trials, cost management, intimacy and fertility, care partner support, and a lexicon of terms. The intimacy and fertility section, for example, provides a variety of resources on fertility issues in girls, boys, women, and men, as well as fertility preservation information. The lexicon includes useful cancer terms, technical definitions of cancer drugs, definitions of genetic terminology, and an invitation to reach out with additional confusing terms that patients encounter. Another similar nonprofit that has leveraged multiple corporate supporters is Lazarex Cancer Foundation. But in other disease areas with more "common diseases," we are far from there.

## HOW TO INVOLVE MEDICAL AFFAIRS IN PATIENT COLLABORATIONS WHEN CREATING SCIENTIFIC COMMUNICATIONS

Medical affairs departments are often led by individuals with advanced medical or science degrees.<sup>2</sup> Therefore, their traditional role was to generate scientifically accurate content, and their main focus has been on disease state or on-label messaging that is specific to HCPs. However, as medical affairs departments are evolving, they need to be able to pivot to communicate in plain language that may not be on label, but that patients can understand. This increasing need can be a challenge under the current regulatory system within the US. Bringing everyone together to hear patients' concerns early and often can help to overcome this potential barrier.

As the team in charge of stakeholder relationships, medical affairs needs to play an active role in bringing patient centricity themes to the R&D and commercial arms. This is not an easy task. Medical affairs is set to navigate more information data types and cater to more varied audiences than ever before. Moreover, about 60% of the professionals in medical affairs believe that they're not yet set up for success with the functions they'll need to own in the coming years<sup>10</sup>, including



- Clarifying the value of a medicine to payers and HCPs, to ensure patients will receive the best medical treatment
- Educating a range of healthcare stakeholders on what patients are talking about among themselves—in other words, top-of-mind topics that patients may not be comfortable discussing with an HCP, but bring up in their own communities
- Providing unbiased medical information to gain credible external recognition of developed treatments
- Access to a multifaceted talent pool to successfully navigate the new landscape

Many pharmaceutical companies have realized the growing importance of medical affairs in this patient-centric effort, and have instituted widespread initiatives to help them prepare for the future.

# INTEGRATION AND INVOLVEMENT

## MORE EFFICIENT PATIENT COMMUNICATION PROGRAMS

Gaining access to patients and developing an ongoing collaborative relationship with them are key to the success of today's clinical trial and drug commercialization process. For instance, AstraZeneca created a <u>Patient Research Framework</u> to include patient insights early on in protocol development and to engage patients throughout studies.

This framework enables the company to collect data, learn about what matters to patients and what's reasonable to ask of them, and then design protocols accordingly.<sup>11</sup> It also allows the company to develop a relationship with their patients, keep them informed, and answer their

questions. Similarly, the biotechnology company Genentech has 140 members in its <u>Patient Co-creation Council</u>, which co-creates patient education materials. The Council also co-develops products and services with the people who need them the most.<sup>12</sup>



In 2011, a trial by the British government failed to meet its goals, because it didn't incorporate patient or caregiver input early, appropriately, or enough. It sparked a patient rebellion that led to international press coverage, a court case, and eventual withdrawal of the treatment."

Lily Chu, MD, VP, International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis

## TRAIN PATIENTS TO SUPPORT THE PEER REVIEW PROCESS

Training patients and caregivers to participate in the peer review process of journal articles before they're published can eventually increase pharma's credibility and research quality. Training also provides long-term dividends as a better-educated and health-literate patient can more robustly contribute to ongoing patient-centric initiatives. During the pre-publication phase, patients can provide a unique perspective on how findings are conveyed, and this can lead to a more balanced representation of the data.

They can also bring new perspectives regarding challenges faced in access and adherence to the treatment(s) covered in the study and suggest follow-up study ideas based on their real-world needs,<sup>13</sup> which can improve drug development. For example, the <u>American Heart Association</u> (AHA) has been including lay stakeholders in their scientific evaluations since 2014.<sup>14</sup>

#### AHA: 5 key steps to program implementation<sup>14</sup>



Defining program expectations and metrics



Soliciting support from staff and science volunteers



## Selecting the right volunteers via channels such as

- recommendations from executive staff leaders at affiliate offices
- ambassador programs involving disease-specific volunteers
- other organizations and social media sites



#### Effectively training and developing volunteers, including

- pretraining assessment
- training modules on peer reviewing research grant applications, research writing, and serving on research and scientific committees
- individual training for those serving on working groups and committees



#### Maintaining volunteer engagement by helping them to

- gain an understanding of, and respect for, the research process
- increase their knowledge and engagement with others
- be a part of future advancements
- be aware that real-world contributions influence the direction of research
- be a part of a global community focused on solutions

The AHA model for involving lay reviewers can be extrapolated into many different areas within the pharma arena, from clinical researchers, to medical affairs personnel, to journal publishers. Each discipline can use the AHA framework to create their own best-practice approach to find,

train, and retain a group of highly knowledgeable, motivated, and engaged patients to strengthen their patient communication strategy.

Of course, before a medical affairs team develops training materials for

Medical affairs needs to work toward a future where medical education is not just developed for the patient, caregiver, or HCP, but is informed by all stakeholders to improve comprehension and communication among them."

Leigh Boehmer,

Chief Medical Officer, Association of Community Cancer Centers

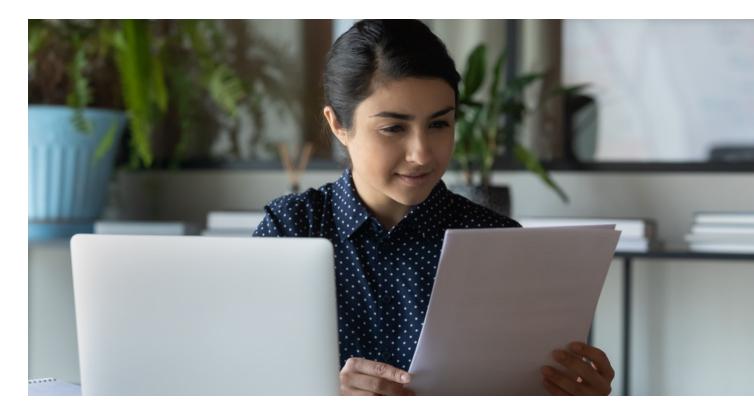
patient peer review, it is important to talk and listen to patients themselves and find out what they need. Motivations for becoming patient peer reviewers vary, including a desire to influence literature quality, wanting the patient voice to be included, trying to ensure that literature supports patients' needs, getting acknowledged on journals' websites, and gaining access to journals. In many cases, peer reviewers are invited to review based on their expertise, which means it's more likely that a patient could be a peer reviewer if they have a science/medical background and/or have prior experience contributing to articles in peer-reviewed journals. This is why patients who want to be peer reviewers wish for a more user-friendly and time-generous process, better training, samples of previous peer reviewes and feedback on their own, plus a greater sense of community and collaboration among reviewers.<sup>10</sup>

## **EXPAND PATIENT AUTHORSHIP**

The benefits of patient authorship in publications are gradually becoming evident to the industry. In fact, several publishers are even introducing journals with patients as the target audience, for example, <u>The Patient and</u> <u>The Journal of Patient Experience</u>. Patient authorship increases real-world healthcare relevance, improves the patient's relationship with healthcare stakeholders and sponsors, and creates new business opportunities. Moreover, excluding patient authorship collaborations could cost companies their reputation, as patient groups will potentially publicly criticize them, and patients might avoid joining their clinical trials.<sup>15</sup>

While patient authorship is still not the standard, more companies want to know how to make it happen.<sup>16</sup> That said, it's not always easy. Patients might lack the confidence, knowledge, or experience to serve as authors. They might not understand the science well enough, know how to communicate digitally, or even have enough time to dedicate to these projects.<sup>17</sup>

Early collaboration with patients will help medical affairs teams identify and properly train the right patients for potential research author or contributor roles.<sup>16</sup> Additionally, processes for equitable patient partner inclusion need to be established across the industry to support journal editors-in-chief in incorporating patient perspectives.<sup>18</sup>



# CREATING THE RIGHT APPROACH

## DEVELOP DIGITAL TOOLS, COMMUNITIES, AND EASILY DIGESTIBLE CONTENT

Creating a patient network forum, alongside a website and a newsletter, simplifies collaboration between patients and researchers despite busy schedules. Patients are able to input data, have influence over how the data are used, and participate in various activities.<sup>19</sup> Online communities can also impact how patients participate in healthcare. Seven out of 10 members of patient communities correctly use their medicine, and 8 out of 10 feel more prepared when it's time for medical consultations.<sup>20</sup>

A good example of this is from the biopharmaceutical company Bristol Myers Squibb (BMS). Their <u>Universal Patient</u> <u>Language (UPL) website</u> provides tools, case studies, and best practices for internal patient communication teams. It was co-developed with a range of stakeholders, including patients, advocates, caregivers, HCPs, and experts in visual communication. It guides teams on empathy, content visualization, level of detail, avoiding jargon, and more.<sup>21</sup>

Other companies take a different approach, turning to patient influencers for disease state education and treatment option discussions, insights from their social media audiences, or insights to pharma themselves. In such instances, medical affairs collaborates with the influencers to create social media content for disease-related education. Some influencers are paid and some aren't, but when the collaboration is done ethically and efficiently, compensation is well worth it. This type of communication, if permitted by governing regulatory bodies, is significantly cheaper than the traditional forms-for example, TV commercials—and it yields a high return on investment. As an example, almost 9 in 10 Americans who hear about a medicine from influencers ask their HCPs about it. which then leads to them receiving a prescription for the medicine in many cases.<sup>22</sup> Most importantly, this collaboration with patients and influencers helps pharma companies develop respectful and authentic content. "For example, patients with chronic fatigue syndrome are usually visually portrayed as individuals who have a bad day at work and are tired or have a headache but that's not how most patients feel. Many are too sick to work, and some are bedbound. So, people are insulted by these images, which leads to broken trust," says Lily Chu, VP, International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis.

## LOCALIZE CONTENT

Since pharma companies often serve patients in multiple countries, cultural sensitivity must be at the heart of content creation. Laura Perry, VP Global Marketing for Cactus Life Sciences, mentions, "One of the biggest insights from the 2021 Reuters Pharma & Patient USA Conference was that translating from English to other languages is no longer the preferred process. Each culture may have different nuances to focus on, particularly looking at discussing unmet needs in disease state education. She emphasizes that it is necessary that native teams do a cultural translation, not just a language translation, and that they may even choose to write content from scratch for specific markets.

# BEING TRUSTWORTHY

## **BUILD BRAND AWARENESS TO GAIN BRAND AFFINITY**

Whether patients know a company's name makes a difference. Patients who know which pharma company manufactures the medicine they use see the pharma industry as a whole as more patient-centric. However, less than 30% of patients can identify any pharma company by name.<sup>23</sup> All the strategies detailed above can help pharma companies gain brand awareness, and gradually, brand affinity and loyalty. When patients believe a company is focused on their needs, they are more likely to trust its products and request them from their HCPs.

### **SUMMARY**

As we move further into this new decade, the pharma industry's focus is shifting from the transactional to the transformational by partnering with patients for clinical trial development and beyond. Medical affairs is a vital additional partner in the equation, bridging the gap between pharma and patients.

For starters, patients and pharma representatives have different motivations for driving science forward, but many of them share insecurities about patients' ability to become true partners. This challenge is exacerbated by low health literacy and the proliferation of misinformation due to an explosion of broadcast and social media content. Close collaboration between medical affairs, patient advocacy groups, patient experts, and influencers can help overcome health literacy issues and drive the distribution of medically accurate and easily understandable information. It is essential to institute, implement, and expand patient-centric collaboration across the life cycle of a medicine in order to build trust and relevance moving forward. Evaluating the need for and creating/ curating patient training programs in health literacy, effective communication, and complex scientific concepts are essential factors for building a patient pillar for a scientific platform.

Thus, medical affairs departments are needed for much more than their traditional role of serving HCP audiences. This is especially true as the demand for accurate and understandable medical content increases along with the need to balance patient collaboration with regulatory compliance.

## ACKNOWLEDGEMENTS

The Cactus Life Sciences team would like to thank the following authors and contributors who supported the development of this whitepaper: Ayelet Weisz, Donna Ambriano, Laura Perry, Kwisha Shah, Prerna Motwani, Clarinda Cerejo, Lauren Bernard, and Shivani Sharma. We also thank our industry experts who provided their insights and feedback at various stages of content development: Maarten Beekman, Leigh M. Boehmer, Lily Chu, Jessica (Byam) Klein, and Elvira D'Souza.

## REFERENCES

- Lowe MM, Blaser DA, Cone L, et al. Increasing Patient Involvement in Drug Development. Value in Health. 2016; 19(6): 869-878. https://doi.org/10.1016/j.jval.2016.04.009.
- McGrail, S. Impact of Medical Affairs on the Pharmaceutical Industry. PharmaNewsIntelligence. 2021; https:// pharmanewsintel.com/news/impact-of-medical-affairs-onthe-pharmaceutical-industry. Accessed January 25, 2022.
- Srensen K, Pelikan JM, Rothlin F, et al. On behalf of the HLS-EU Consortium. Health Literacy in Europe: Comparative Results of the European Health Literacy Survey (HLS-EU). European Journal of Public Health. 2015; 25(6):1053–1058.
- Mahadevan, R. Health Literacy Fact Sheets. Center for Health Care Strategies. 2013; https://www.chcs.org/ resource/health-literacy-fact-sheets/. Accessed April 30, 2021.
- Cactus Life Sciences. Stakeholder Perspectives on Digital Scientific Content: What HCPs, Patients, Payers, and MSLs Really Want from Medical Affairs. 2021; https://lifesciences. cactusglobal.com/thought-leadership/stakeholderperspectives-on-digital-scientific-content/. Accessed January 25, 2022.
- Gonzalez AR. Patient Advocacy History, Evolution and Impact on Health. Juniper Online Journal of Public Health. 2018; 3(3): 1-3.
- 7. Miller, S. US Food and Drug Association: FDA's Patient Representative Program. 2018: 1-16.
- Sacristan JA, Agaron A, Avendano-Sola C, et al. Patient Involvement in Clinical Research: Why, When, and How. Patient Preference and Adherence. 2016; 10: 631-640.
- Lin K. Tips from Other Journals. Patients Commonly Misunderstand Medication Instructions. American Family Physician. 2007; 75(12): 1851-1854.
- Schroter S, Price A, Flemyng E, et al. Perspectives on Involvement in the Peer-review Process: Surveys of Patient and Public Reviewers at Two Journals. BMJ Open. 2018; 8: 1-8. https://doi.org/10.1136/bmjopen-2018-023357.
- Gardner J, Hagger L, Chin A, et al. Patient Involvement: Current Practices in Medical Research; Driving Change in Medical Publications. International Society for Medical Publication Professionals. 2019; https://ismpp-newsletter. com/2019/03/13/patient-involvement-currentpractices-in-medical-research-driving-change-in-medicalpublications/. Accessed January 25, 2022.
- Genentech. Create with Us. 2022; https://www.gene.com/ patients/create-with-us. Accessed December 8, 2021.
- Vander Ley K, Ivlev I. Supporting Patients in Peer Review Can Improve the Relevance of Research. BMJ. 2021; https://blogs.bmj.com/bmj/2021/01/15/supportingpatientsinpeerreview/. Accessed January 25, 2022.

- Roach WH, Bischoff JM, Dennis B, et al. Lay Stakeholders in Science and Research Initiative: A Science Advisory from the American Heart Association. Circulation. 2021; 144: e96-e106.
- Patient Authorship: Key Questions Answered (Part A). The Publication Plan. 2020; https://thepublicationplan. com/2020/06/12/patient-authorship-key-questionsanswered-part-a/. Accessed November 17, 2021.
- 16. Patient Involvement in Medical Publishing: Insights from a Publication Professional. The Publication Plan. 2020; https://thepublicationplan.com/2020/01/17/patientinvolvement-in-medical-publishing-insights-from-apublication-professional/. Accessed November 17, 2021.
- Woolley K, Yamamoto B, Stephens R, et al. Patient Authorship: Three Key Questions (& Answers!) for Medical Communications Professionals [Part B]. International Society for Medical Publication Professionals. 2020; https:// ismpp-newsletter.com/2020/05/26/patient-authorshipthree-key-questions-answers-for-medical-communicationprofessionals-part-b/. Accessed December 8, 2021.
- Cobey, KD, Monfaredi, Z, Poole, E, et al. Editors-in-chief Perceptions of Patients as (Co) Authors on Publications and the Acceptability of ICMJE Authorship Criteria: A Crosssectional Survey. Research Involvement and Engagement. 2021; 7: 39. https://doi.org/10.1186/s40900-021-00290-1. Accessed November 17, 2021.
- Hamakawa, N, Kogetsu, A, Isono, M, et al. The Practice of Active Patient Involvement in Rare Disease Research Using ICT: Experiences and Lessons from the RUDY JAPAN Project. Research Involvement and Engagement. 2021; 7: 9. https://doi.org/10.1186/s40900-021-00253-6. Accessed November 17, 2021
- Pregueiro, A. Top Customer Engagement Trends in Pharma. IQVIA. 2021; https://www.iqvia.com/locations/unitedstates/blogs/2021/05/top-customer-engagement-trendsin-pharma. Accessed November 17, 2021.
- 21. About the Universal Patient Language. The Universal Patient Language. Unspecified Year; https://www.upl.org/ about. Accessed December 8, 2021.
- Sheridan, K. As Social Media 'Influencers,' Patients are Getting a Voice. And Pharma is Ready to Pay Up. STAT. 2018; https://www.statnews.com/2018/11/13/patientinfluencers-get-a-voice-and-pharma-is-ready-to-pay-up/. Accessed December 8, 2021.
- 23. Lubkeman M, Lee M, Barrios G. What Do Patients Want, and Is Pharma Delivering? Boston Consulting Group. 2020; https://www.bcg.com/publications/2020/what-patientswant-is-pharma-delivering. Accessed November 17, 2021.

## **ABOUT CACTUS LIFE SCIENCES**

At Cactus Life Sciences, we deliver scientific content better, faster, and with greater value than ever before.

Using scientific acumen, cutting-edge creative and digital solutions, advanced technology, and transformational delivery models, we redefine efficiency across the healthcare continuum by delivering personalized and impactful content that provides lasting quality and value.

#### **CONTACT US**

214 Carnegie Center, Suite 102 Princeton, New Jersey 08540 USA

267.332.0051

inquiry.lifesciences@cactusglobal.com

lifesciences.cactusglobal.com



© Cactus Life Sciences Inc. All rights reserved. All registered trademarks are property of their respective owners.