Marc Boutin â?? CEO, National Health Council, USA

> [Over the last 25 years] we have witnessed a cultural phenomenon around expectations for customization in nearly all elements of our lives. This concept is finally beginning to enter the healthcare space

27.04.2020

Tags:

USA, NHC, Patients, Patient Association, Association

Marc Boutin, JD, CEO of the National Health Council (NHC), introduces the organization and its mission to provide a united voice for the 160 million people in the US living with chronic diseases and disabilities and their family caregivers. He addresses the challenge faced by patients living with chronic diseases and disabilities. Boutin goes on to describe the transformation in healthcare in which patients are becoming more engaged and increasing the visibility of their own desired health outcomes. Lastly, he describes how the current COVID-19 health crisis has highlighted the need for improvement in US public health infrastructure.*

This year, the NHC celebrates 100 years of existence. Can you please introduce the organization and its structure?

The NHC was created 100 years ago by patient organizations for patient organizations. Our members include representatives from a broad array of patient groups such as the American Cancer Society and American Heart Association on one end of a spectrum and smaller patient associations representing rare diseases on the other end. The NHC focuses on systemic issues that are important to all people living with chronic conditions such as access to care and driving patient-centered innovation. In order to truly have an impact on these issues, we need to understand the different perspectives of all stakeholders. Therefore, we have representatives across the entire health spectrum in membership, including the biopharmaceutical, generic drug, device, diagnostic, payer, researcher, and caregiver communities.

How difficult is it to address common issues among such a broad community of members?

While this task might not be easy, when it works well, it is incredibly impactful. Over the course of the last 10 years, the NHC drafted more than 30 provisions included in the Affordable Care Act and authored sections incorporated in the 21st Century Cures Act. By having an organizational governance structure that is controlled by the patient community and a transparent decision-making process that is informed by all stakeholders, we generate patient-centered impact even when some stakeholders occasionally disagree with a specific position on a certain issue.

How do you ensure that companies are not inappropriately influencing patient groups participating in NHC panels?

The NHC requires patient organizations in membership to meet 38 Standards of Excellence â?? the most strident standards in the nonprofit community globally. There are approximately 10 standards that address transparency, public trust, and corporate relations, which patient groups must adhere to. This is an important factor in mitigating inappropriate influence from the industry. Recently we brought together a group of ethicists to review our standards and their conclusion was that the NHC was excelling in addressing this important issue.

While we agree, any form of undue influence must be mitigated, it is important to note that anyone who supports any nonprofit generally does so because their perspective is aligned with that organization. For example, any individual or company who donates to a cancer-related patient group usually has a personal connection with issues related to cancer.

Similarly, both patient groups and industry share a common interest in driving high-quality innovation and ensuring meaningful access to care. While all members may not always align on all topics, like drug pricing for example, we must be able to openly disagree in the same way that we cooperate on mutual issues of interest without inappropriate influence.

In the 1980s, there were examples of industry creating organizations that looked like patient groups and while this is not nearly as prevalent today, it still occasionally happens. This is a major issue as it undermines the credibility of legitimate patient organizations and ultimately their ability to serve patients. It is critical that we distinguish between genuine patient organizations and what are called â??astroturfâ?• groups.

In several past interviews, you have mentioned that â??the pharma industry is going through a transition, and I am not convinced the sector itself realizes the transition it is in.â?• What do you mean by that?

One of the reasons I became a patient advocate was to help elevate the voice of patients after chronic diseases affected so many people in my life. Over the course of the last 25 years, patient advocates have done a lot to shift the environment, and in just the last decade we have seen dramatic changes in how industry engages patients in R&D for drugs and devices and in clinical trial protocol development.

During this same period, we have witnessed a cultural phenomenon around expectations for customization in nearly all elements of our lives. This concept is finally beginning to enter the healthcare space. Value assessors, payers, and providers are all beginning to explore their roles in the delivery of healthcare, not just on a population model, but rather through customization that meets the needs of subpopulations and individual people. For the most part, industry has focused on inconsistent, nonsystematic measures that address the needs of a single stakeholder rather than considering the holistic impacts of this culture shift on all their customers â?? payers, providers and patients. The industry has not yet fully realized the transition that is happening around it.

To be clear, when I speak of customization, I am not only referring to personalized medicine but rather personalized health. Overall wellness lies at the intersection of all the determinants of health (i.e., biological, social, economic, and environmental) and the desired outcomes of individuals. What has been missed historically in the health debate is the importance of those outcomes. While survival is important, so are how we feel and function. How we balance the three is highly personal. When healthcare is aligned with that balance, we improve aspects like adherence and overall health outcomes â?? often at reduced costs. As the healthcare ecosystem increasingly recognizes the benefits of personalizing health (not just medicine), models of value assessment, outcomes-based contracting and insurance design will evolve and in turn realign how care is delivered, directly impacting drug pricing, reimbursement and development incentives.

In your view, who will be the primary drivers of this transformation?

Obviously, patients will have to drive this transformation. The complexity of the US health ecosystem is part of why the patient community pushed for the creation the Patient-Focused Drug Development initiative. This prompted a cultural shift and got stakeholders thinking about what it means to customize health and understand outcomes that matter to patients. Now we are supporting multi-stakeholder development of core outcome sets to identify the most important outcomes that should be included in the development of all new medicines, especially those important to patients. Core outcome sets have the potential to create efficiency in medical-product research and development, improve our comparative effectiveness data, and support a more nuanced value-based pricing system. There are a lot of moving parts when it comes to identifying who the right players are to make this change, but it started with shifting the culture to engage patients.

The utilization of patient data has arisen as a hot topic among the global healthcare community. What is your view on the opportunities that exist when it comes to leveraging healthcare data?

We completely support the concept of being data-driven. The NHC is involved in a number of initiatives to harness data, which can lead to better understanding populations and individuals to match them with the right solutions that fulfil their desired outcomes. The challenge we face is that many stakeholders, particularly in the AI space, see data as a substitute for patient engagement. The NHC and our patient organization members need to be in the conversation on how data will be gathered, stored, and curated. While AI can tell you if a child places their wearable of the family dog, it canâ??t tell you why. Patients and their families can. We can help you interpret data and ask better questions. This is an opportunity to engage patients and their family caregivers rather than seeing data as a replacement for those insights.

The reality is, data is collected in so many different ways that it is not homogenous. One of our biggest challenges is how to validate and understand all the data that we have. Data today gives us very good insights but is not yet at the level of quality where it can be used to make many regulatory decisions. It is a promising tool, but a product could not and should not be newly approved on the basis of real-world data only.

What is the Councilâ??s view of the current status of access and affordability in the US?

This is a huge issue for the NHC. Our main focus is to drive meaningful and affordable access to high-value care, and we still have a long way to go. The influence we had in the Affordable Care Act (ACA) has granted access to tens of millions of people in the United States. The unfortunate reality is that it created unintended consequences of new barriers to access and cost-shifting to people with chronic conditions. The out-of-pocket costs that Americans are paying have become so large that they are often not able to see their doctor, get medications, undergo procedures, etc. In the US, if a patient is working above the poverty line and not eligible for subsidies, the deductible and out-of-pocket costs could add up to about 20 percent of their annual income. There is a huge inequity in a country where the life expectancy of the 48 percent of the population in the lower socio-economic status has been decreasing so rapidly that it brings down the entire average of the US.

We are living in incredible times â?? where public health in every nation, as well as individual approaches to public health, is being tested by the COVID-19 crisis. What are Americans reflecting on vis Ã vis their own public health system?

The US public health infrastructure has been ignored for a long time, and as a result, does not have the capacity to respond to this crisis. I believe there will be a strong push to improve it, but I worry about the displacement of resources. There was an enormous needed financial relief package passed following a significant overhaul of tax structures. You have to wonder where the money will come from â?? and its potential impact on existing health programs or research infrastructure. There is a renewed push to ensure that patients have meaningful access to care, but the challenge will be how do we fund these activities.

Are there any final comments you wish to conclude with?

People with chronic conditions are most at risk and have been heavily impacted by COVID-19. These patients are having extreme difficulty gaining access to their usual care as many services are being disrupted due to the health system quickly becoming overwhelmed. We are concerned about potential discrimination caused by the shortage of resources. We donâ??t want to see a situation where a young healthy person is prioritized over someone with a chronic health condition or disability. This is against the law and thankfully the Federal government recently issued guidance to make it clear that this type of action is inappropriate.

* This interview was first published in April 2020. In August 2020, Marc Boutin was appointed Global Head of Patient Engagement & Advocacy at Novartis.

See more interviews