



NATIONAL HEALTH COUNCIL

## The 2023 National Health Council International Patient Forum

### Summary and Recommendations

#### Background and Introduction

On May 31, 2023, the National Health Council (NHC) held a virtual patient forum to bring together health care experts and stakeholders to discuss policies and other health care interventions that allow better service provision, unity, and cohesion within in the health care sector. Created by and for patient organizations more than 100 years ago, the NHC brings diverse organizations together to forge consensus and drive patient-centered health policy. Made up of more than 150 national health-related organizations and businesses, the NHC's core membership includes the nation's leading patient organizations. Other members include health-related associations and nonprofit organizations including the provider, research, and family caregiver communities; and businesses representing biopharmaceutical, device, diagnostic, generic drug, and payer organizations.

NHC members are working both nationally and globally to create a lasting international impact, ensure that patients and caregivers in other countries can access health care, and provide other resources for international communities to support their desired public health outcomes. This virtual forum was hosted by the NHC to highlight critical issues affecting public health such as patient engagement, innovation, and health care policies. This forum also brought together various patient groups and other NHC member organizations with a global presence to identify new policies and practices in the international space. This paper evaluates and summarizes some of the most notable themes from the [Inaugural International Patient Forum](#).

#### Overview of the International Patient Forum

Panelists in the forum were critical in providing insights into how various chronic diseases, disabilities, and illnesses are managed and governed in the U.S., as well as some of the policies aimed at providing health care services to the international community. In this two-hour forum, 45 member organizations were represented in the audience. Speakers and panelists for the forum included:

- Donna Cryer, President & CEO, Global Liver Institute;
- Cyndi Zagieboylo, President & CEO, National MS Society;
- Julia Jenkins, Executive Director, Everylife Foundation;
- Pat Furlong, Founding President & CEO, Parent Project Muscular Dystrophy (PPMD);
- Celina Gorre, CEO, WomenHeart Foundation; and
- Lisa Butler, Executive Director, GBS – CIDP Foundation.



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### **Major Themes**

The major themes that came out of this meeting include access to health care, patient engagement, advocacy and innovation, and talent and recruitment.

### **Accessibility to Health Care**

One of the primary goals of the NHC is to develop health policies that will not only benefit the people in the U.S. but have a lasting global impact. Access to health care services is a critical issue discussed during this forum. One panelist elaborated on some of the problems surrounding the accessibility of health care, especially in developing countries that lack adequate resources. Critical to addressing this disparity is a deep understanding of what access means in developing countries. Information and high-quality evidence are essential to developing policies that will not only create awareness but will also make health care more adaptable to those who need access to it most. Using examples from their work, the panelist noted that their organization fought tenaciously for equal access to resources and treatments for liver health, especially for historically underrepresented and underprivileged groups. They further emphasized that addressing access gaps is crucial for enhancing overall health outcomes, drawing on their personal experience as a liver transplant recipient and extended career in health care advocacy. The panelist also underlined the need for patient advocacy in advancing accessible and affordable policies.

### **Patient Engagement**

Another notable theme discussed in the forum was the importance of meaningful patient engagement and equitable patient participation in research. Building awareness of chronic illnesses and their impact on communities allows leaders to avail resources necessary for treatments to be easily accessible, resulting in health care service providers to better engage with patients both locally and internationally. Engaging the patient and caregiver population in research and providing first-hand evidence of their desired outcomes and experiences is essential. Patient engagement can assist in educating the public, especially when managing communicable diseases and minimizing social stigma. Patients were interested in learning best practices. The panelist also spoke regarding the challenges of cultural communication, as definitions and terms in one country may mean something different in another.

When discussing the medical process, another panelist highlighted the significance of patient participation and engagement. Patients and their families should be actively engaged in choices regarding their treatment. Additionally, the panelist noted how necessary it is for health care professionals (HCPs) to pay attention to patients' viewpoints, concluding that bi-directional communication and power sharing can result in better patient-centric treatment.

Another panelist spoke about their organization's ongoing initiative to meaningfully include individuals with chronic diseases and their families in advocacy and research.



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The panelist emphasized the value of having the patient decide how to conduct research and develop new medicines, stressing that patients and their families are the best spokespeople for their own medical needs.

### **Advocacy and Innovation**

Each panelist offered a unique perspective on how innovation affects health care transformation and progress. As a consensus, the ability to provide health care services to the international community effectively calls for elaborate advocacy protocols and — most importantly — innovation in medicine. Many of the panelists argued that global governments should advocate for policies that allow rigorous research and awareness interventions, especially in managing chronic illnesses like multiple sclerosis. Such advocacy can also be essential in obtaining funding and resources for large-scale health care projects, such as the construction of new hospitals and the acquisition of drugs and treatments. Fundraising can also ensure that health care services are more accessible through subsidy programs that promote long-lasting, positive impacts. Such advocacy allows government and international health care organizations to be more innovative, which in turn can identify more effective treatments.

Communication is another critical component of advocacy work. One panelist noted the vitality of exchanging information and the accessibility of shareable resources (i.e., webinars, briefs). Moreover, incorporating consistent messaging adds levels of engagement and advocacy that can be beneficial to the consumer. Panelists offered insightful commentary on the significance of lobbying in the health care sector, along with their own experiences and viewpoints on this topic.

Panelists stressed the value of advocacy work as it pertains to enacting change and raising awareness of rare diseases. One panelist highlighted the importance of activism in educating policymakers and the public about the challenges patients and their families face. Another panelist emphasized the significance of patient-driven advocacy as a driver of advancement. In a panelist's work in governance, policy, consulting, and nonprofit management, they found that patient advocacy significantly impacted charitable endeavors, clinical trial enrollment, and health care regulations.

The role of technology in health care was another topic. Technological advances play a crucial role in health care advances, like telemedicine and wearable technology. It has also afforded new opportunities for individuals to participate in their own treatment and created new ways for individuals to actively monitor their health. A panelist emphasized that in addition to developing novel therapies, recent innovations have enhanced the patient's experience and increased access to health care information.

### **Talent Recruitment**

Health care requires practitioners to be knowledgeable, innovative, and proactive to advance medicine at a rate that can keep up with ever-changing trends. The right



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recruitment initiatives are essential to advancing a diverse workforce that can better serve the needs of patients. One panelist argued that managing chronic illnesses, such as Muscular Dystrophy (MS), requires talented personnel who are skilled in the treatment or management of the illness and can also provide personalized, transformative care to patients for overall treatment satisfaction. One organization, for example, rewards researchers and health care service providers for contributing towards research and innovation programs that yield desired treatment outcomes, which is a good practice for identifying and appreciating talented personnel. Other panelists emphasized the need for practical advice and research to promote improvements in health care.

When responding to a question from an audience member regarding staffing structures and resources, one panelist noted that one of the largest challenges in recruitment is understanding and learning the various rules and regulations for hiring in different countries and then budgeting for unexpected expenses. Larger social welfare systems, for example, can add increased costs to hiring. Furthermore, determining whether to keep staffing U.S. based or hire internationally was among other popular branches of discussion, as well as the processes and challenges of incorporating local human resources organizations and/or advisors.

One panelist offered their expertise in hiring top talent for corporate social responsibility and international health initiatives. On this topic, the panelist shared that leaders should look for people who, in addition to having the prerequisite skill sets needed to do the job, are passionate about improving health care. The panelist underlined that hiring people with various skill sets — including those in technology, communication, and advocacy — goes beyond finding people with clinical knowledge.

### **Recommendations**

Panelists advocated for:

- Research and innovation on a global scale;
- Increased resources for desired outcomes that are meaningful to the international community;
- Deeper and more frequent discussions with global leaders and stakeholders in the health care sector — both locally and internationally; and
- Policies that will make health care more accessible, affordable, and effective.

### **The NHC and the International Patient Forum’s guest speakers recommend a collaborative effort in managing health care outcomes in the U.S. and globally.**

The presenters emphasized the need for practical advice and new research to promote improvements in health care.



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### **Conclusion**

During the International Patient Forum, a diverse group of organizations shared their in-depth perspectives and experiences on global patient involvement of patient organizations. The panelists outlined the crucial role that patient advocacy, innovation, equitable access, talent recruiting, and collaborative initiatives play in determining the future of global health care. Together these themes demonstrate the necessity of teamwork, equity, patient-centered techniques, and evidence-based design to solve the international patient communities' health care needs and eventually enhance patients' well-being worldwide.