

## HEALTH POLICY SHAPING SESSION HIGHLIGHTS

More than ever, patients have the power to shape the future of health. At the APPIS 2023 Summit, we invited speakers from diverse backgrounds and experiences to share insights about how to leverage real-world evidence (RWE) and build powerful stories to strengthen patient voices and drive health policy action.

### OUR SPEAKERS



**AJAY TIKU**

Regional Medical Head, Novartis Asia Pacific, Middle East and Africa



**DR. GIA SISON**

Head, Wellness Center at Makati Medical Center; Host, G Talk, CNN Philippines



**JULIE CINI**

Founder and CEO, Spinal Muscular Atrophy Australia Inc.



**PIETER DE RICHTER**

Head of APAC/MENA Syndicated Real world Evidence, Ipsos Healthcare



**RUTH KUGURU**

Executive Director, Communications & Engagement, Novartis Asia Pacific, Middle East and Africa



**DR. SAWSAN A. S. AL MADHI**

Founder & CEO, AlignnEfficient Health Consultancies; Former Director-General, Friends of Cancer Patients Charity UAE



**WARREN FERNANDEZ**

CEO, Asia Pacific, Edelman



**ZACK PEMBERTON-WHITELEY**

CEO, Leukaemia Care and Founding Chair, Acute Leukemia Advocates Network

### KEY REFLECTIONS



#### Collaborate on collecting real world evidence (RWE)

Pieter De Richter from Ipsos Healthcare explained the different types of real-world evidence (RWE), data collection methodologies and how collecting patient data can spur action for health policy. He highlighted how RWE can reveal real-world obstacles and inequities that clinical trials can't and encouraged patient organizations to team up with partners to collect RWE and amplify patient voices.



#### Bring in patient advocacy groups from the start

Julie Cini from Spinal Muscular Atrophy Australia emphasized the importance of communicating with patients from the beginning to better understand their unmet needs. By understanding their day-to-day challenges, we can better utilize RWE to advocate for patients.



#### Create compelling, visual stories to resonate with media

Former journalist, Warren Fernandez from Edelman highlighted the power of storytelling in educating the public and promoting actionable change. He emphasized that compelling stories are essential when engaging with the media, but it is equally important to build relationships with journalists and help them to understand the story by providing facts, figures, and visuals.



#### Harness the power of authentic storytelling for advocacy

Breast Cancer survivor and practicing Occupational Medicine doctor Gia Sison shared her personal journey as a breast cancer survivor and reiterated that for her, authenticity was key to sharing her own story with the world. She highlighted that "authentic patient stories can really connect, educate and inspire."

## DIGGING INTO THE DATA

On the first day of the Health Policy Shaping session, Julie Cini introduced how patient organizations can use Real World Evidence (RWE) to gain disease awareness traction and shape health policy, emphasizing the importance of collaboration among multiple stakeholders.



**Pieter De Richter**

Head of APAC/MENA Syndicated Real World Evidence,  
Ipsos Healthcare

Real World Evidence can help identify unmet needs, showcase inequities in ways that clinical trials cannot. Identifying partners that patient organizations can collaborate with **to collect RWE will be the key to accelerate access for patients.**

## THE A-TO-Z OF RWE

You may have heard of RWE, but what does it really entail and why does it matter when it comes to health policy shaping? Pieter De Richter, began the session by sharing his definition of RWE and his thoughts on how collecting patient data can further amplify the patient voice and spur action for health policy.

He then went on to explain the relationship between RWE and real-world data (RWD). RWD and RWE exist on a scale of complexity, from connected health wearables to complex data such as electronic health records. However, it doesn't have to be used at this level of complexity. Simple initiatives like patient surveys can go a long way to help shine a light on specific challenges and serve as evidence for health policy makers – and this evidence is critical to advocacy for access to new treatments. The continuous use of the same surveys to see how the patient experience has changed, can provide insights on what unmet needs persist and as well as shed light on other disease challenges.

Because RWE is derived outside the confines of clinical trials, **RWE can spotlight real-world barriers, inequities, and their impact on outcomes** in ways that clinical trials cannot. Patient organizations who find the process of collecting RWE to be opaque and daunting can overcome these challenges by **finding the right partners to work with who are equally as passionate about accelerating access for patients.**

## STORIES OF SUCCESSFUL HEALTH POLICY SHAPING

To bring RWE to life, our panelists, Julie Cini, Pieter De Richter, Advocacy Adviser of AlignnEfficient Health Consultancies Dr. Sawsan Al Madhi, and Zack Pemberton-Whiteley from Acute Leukemia Advocates Network, shared their own experiences and stories on **how using real-world evidence helped elevate their patient organizations** and outlined some hints and tips on how other organizations can learn from their experiences.

For example, Zack recommended that patient organizations **expand their network** and speak to organizations in other countries. Cross collaboration and sharing can help groups learn from each other's best practices when it comes to collecting RWE.

Julie discussed the importance of understanding our patient community to help policy makers in their decision making. **Continuing conversations with patients about their experiences** is crucial in making sure that we are constantly evolving our thinking to meet critical patient needs. She also suggested to connect and collaborate with all the **key regulators** in their market. While it is key to understand the information regulators require, it's also important to identify the information patient organizations want to tell them. Dr. Sawsan advised using academia as a point of reference to identify what is missing so that **patient organizations can fill in the gap to make an impact.**





### Dr. Sawsan A. S. Al Madhi

Advocacy Adviser, AlignnEfficient Health Consultancies; Former Director-General, Friends of Cancer Patients Charity UAE

Look at the current data that the government or academia has generated, and see what is the missing gap that we can fill.



### Zack Pemberton-Whiteley

CEO, Leukaemia Care and Founding Chair, Acute Leukemia Advocates Network

If you are struggling, speak to other organizations - see how you can work together, see if you can learn from what they're doing.



### Julie Cini

Founder and CEO, Spinal Muscular Atrophy Australia Inc.

Collaboration should be about helping the next patient organization get to the finish line faster than the previous.

## HITTING THE HEADLINES

In a world where we consume media within seconds, it would be beneficial to patient organizations to learn how to capture the audience's attention - but how can they get through to the media to publicize their stories?

Former journalist Warren Fernandez from Edelman shared his advice on how patient organizations can cut through the noise by building a story that hits the headlines. **Stories should be compelling, personal and engaging**, and with the range of publications out there, Warren encourages storytellers to understand what each platform is looking for and adapt to the different mediums and styles with the **3 V's** in mind - **Video, Voice and Visuals** - as well as the **TRUST** elements that make a story newsworthy: **Topical, Relevant, Unusual, Story and Tension**.

Warren advises that when it comes to the media, it's important to start establishing relationships early and provide journalists with the firsthand facts, the figures, the picture, the story and the visuals that will help to tell a compelling story to be published.



### Warren Fernandez

CEO, Asia Pacific, Edelman

Journalists need help from patient organizations, to interpret and tell story in an accurate, reliable and compelling fashion.



## FROM PERSONAL TO POWERFUL

From a patient's perspective, Dr. Gia Sison, a 10-year breast cancer survivor and doctor, shared her personal journey from advocate to storyteller, her struggle with mental health and why she felt the need to share her story publicly to make a difference.

Her story resonated deeply and widely throughout the Philippines, and Dr. Sison noted that in order for your story to really stand out, you must know who your audience is, what message you want to convey, and why you want to share it. She also stressed the importance of creating and sharing real successes and case studies to build a strong community online and drive action.



### Dr. Gia Sison

Head, Wellness Center at Makati Medical Center; Host, G Talks, CNN Philippines

**Hope is something we should always anchor ourselves in.**

**Authenticity is very important. As long as you live your truth, leverage on your passion to help others and the rest will follow.**



We invite you to share our APPIS 2023 highlights with your network, to help prioritize action to accelerate patient access.



Access all the APPIS Summit 2023 recorded sessions at: [www.appisinitiative.com/appis-summit-2023](http://www.appisinitiative.com/appis-summit-2023)



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