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Patient Voice to Data: How Novartis Is Listening Up, Harnessing RWE in APMA

by Anju Ghangurde

Physician-turned-pharma executive Iris Zemzoum leads Novartis in the Asia Pacific, Middle East and Africa (APMA) region. She tells *Scrip* how the Swiss group is empowering patients to help shape the future of healthcare and also partnering across the diverse region to leverage real-world evidence.

Not all pharma executives can perhaps relate to the patient journey as closely as Iris Zemzoum, *Novartis*'s president for the Asia Pacific, Middle East and Africa (APMA) region. The gynecological oncology physician-turned-pharma executive has likely seen patients in their most vulnerable state and "understands their challenges first-hand."

It's those kinds of sharp yet delicate insights that Zemzoum hopes to build on as companies like Novartis seek to improve health literacy, empowering patients to "speak up for themselves" and also amplify patient voices giving them a "seat at the table" in health policy-shaping.

"From the beginning my driver and North Star has been the patient," declared Zemzoum in an interview with *Scrip* outlining the strides made by Novartis's fledgling initiative, Alliance and Partnerships for Patient Innovation and Solutions (APPIS), which she spearheads.

The APPIS platform essentially brings together different voices across the healthcare community, helping to drive patient action and impact in the diverse APMA region and beyond (many countries outside of APMA are already participating in the platform). Since its inception

in 2021, it has convened more than 2,000 people across the spectrum of healthcare in over 60 countries.

Discussions are also underway with other regions around how the platform can be replicated in other markets, the executive indicated.

Leap of Faith

Zemzoum, who made a career switch to the biopharma sector in 2003 from being a consulting physician at the department of obstetrics and gynecology, University Hospital TUM Munich, clearly knows a thing or two about the complex patient journey.

She described her own crossing to industry as “more of an evolution,” though.

The executive perhaps had a bird’s-eye view of things very early on at the university hospital as a young co-investigator in breast and ovarian cancer therapy trials. Meeting one of her “role models in research and patient engagement,” Dr Nadia Harbeck at ASCO 2023 recently, Zemzoum acknowledged, in an online post, that she was lucky to have been picked by Harbeck to work with her in the breast cancer research unit at TUM Munich University.

Harbeck, who serves on the ESMO executive board, is director of the Breast Center and holds the chair for Conservative Oncology at the department of obstetrics and gynecology, LMU University Hospital, Munich, Germany, among a string of other key positions; she is one of the most frequently cited clinical researchers worldwide.

The trials experience clearly exposed the young Zemzoum to research and the industry, attending congresses along the way and also seeing some of the research work that the department did in collaboration with pharma get published.

“I think that’s what intrigued me or raised my interest in the industry,” Zemzoum said but admits that when she left the university hospital, she wasn't “100% sure” it was the right decision.

How Novartis Is Tailoring Its Strategy In Asia Pacific, Middle East and Africa

By [Anju Ghangurde](#)

Dec. 22, 2021 Iris Zemzoum, Novartis Pharma's president for Asia Pacific, Middle East and Africa, outlines how the company is shaping its strategy in the region, which comes with “extremes” in market profiles, via a distinct archetype that factors in commonalities between national healthcare systems. The company is also progressing interesting initiatives in digital therapeutics.

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“But if you don't try, if you don't explore, you will never know. So, I took the leap of faith. It was one of the best decisions of my life because I had it all - the science, global perspective and I still had what was always my North Star (the patient) and the possibility to shape the healthcare environment to focus on what is needed to better health for patients”.

APPIS-Related Traction

Shaping the healthcare environment with the patient at the fulcrum is among the areas where the Novartis executive appears to be putting pedal to the metal and there are signs of early momentum in the some of the 30-odd markets that fall under APMA.

Zemzoum outlined how an APPIS-related effort in Taiwan led to the co-creation of a journal article on the importance of incorporating the voice of patients in health technology assessment (HTA). Authored by Prof. Fei-Yuan Hsiao from Taiwan's Pharmaceutical Benefit and Reimbursement Scheme (PBRs) committee (the local HTA body) together with cancer patient organizations, it was published this year in the Journal of the Formosan Medical Association.

In another instance, the Swiss multinational backed the breast cancer advocacy group ICanServe Foundation's "The Circle of Life" project in the Philippines. The project builds the data and digital infrastructure of the Ating Dibdibin, the community-based early breast cancer detection program. (Also see "[Novartis' Bouchard on Delivering Personalized Cancer Medicine in Asia Pacific, Middle East, Africa](#)" - Scrip, March 23, 2022.)

Digitalizing the program will facilitate efficient monitoring of patients for early detection and timely consult at the primary care level, implying fewer late diagnosis that require specialist care and more advanced diagnostics and treatments. The innovative system is expected to serve as a backbone of implementation of Philippines' National Integrated Cancer Control Act and localization in local government units.

Several big pharma peers are similarly investing and working independently or alongside partner organizations to improve and amplify programs to educate and empower patients. For instance, [Pfizer Inc.](#)'s "Find Your MBC Voice" was created by the US multinational with the help of patient advocates to help people with metastatic breast cancer understand their diagnosis and consider treatment options.

Listening to Patients

Zemzoum underscored that it's really important to listen to patients, because “they give you the right clues of what their needs are, and how they can navigate every single step of their journey in the healthcare system, which is really complex, to ultimately have a great outcome.”

But industry also needs to recognize that these complex healthcare system issues can't be solved on its own and requires collaboration with all stakeholders, whether it's the healthcare

professional, payer or government, she added.

“We need to sit together and understand how it is feasible to best treat [patients] and get the best outcome for that specific patient in a specific disease area and then work together to shape policies or healthcare solutions for that patient.”

Referring to some “frightening” statistics, Zemzoum pointed out that while the APMA region is home to over half of the world’s population, this segment of the population also has some of the lowest levels of healthcare – “the inequity, even amongst our region, is shocking.”

She highlighted breast cancer as an example where according to the World Health Organization, survival rate in India is 66% versus around 40% in South Africa, compared with 90% of survival in high income countries.

“Just looking at the statistics we know what we have to dowe can’t stay still and just watch that inequity. But to break down these barriers, we need to act. We need to act really fast, and we need to act together,” Zemzoum stressed.

Growing Importance of Real World Evidence

While pharma has long touted patient centricity as being at the core, the increasing influence of the patient voice in the evolving healthcare landscape also makes the association symbiotic. Improved patient experiences, health outcomes and also business results are among the key benefits that can accrue.

Real-world evidence (RWE) that factors the real-world experiences of patients in understanding the effectiveness of treatments can be pivotal across the product life cycle – various stakeholders and agencies are also increasingly calling for more patient-centric drug development and evidence-generation recognizing the significance of these patient inputs.

The EU, for instance, has made significant strides in the area. The Data Analysis and Real World Interrogation Network (DARWIN EU), an EU-wide platform that’s been operational for a year, delivers real-world evidence from across Europe on

EMA Makes Progress on Real-World Evidence ‘Use Cases’ with HTA Bodies & Payers

By **Vibha Sharma**

April 24, 2023

The European Medicines Agency is looking at how it can generate real-world evidence on multiple myeloma and non-small cell lung cancer using its new DARWIN EU platform so that the outcomes can also be of use for health technology assessment bodies and payers.

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diseases, populations and the uses and performance of medicines. The European Medicines Agency was recently reported to be evaluating new use cases for cancer via the platform. (see side bar) (Also see "[Canada Publishes Real World Evidence Guidance For HTA And Regulatory Decision Making](#)" - Pink Sheet, May 23, 2023.)

Industry experts have in the past noted that similar to real-world evidence, patient experience data is important in almost all stages of the product lifecycle—not just in the post-marketing aspect. “For example, understanding the treatment pathways and patient experiences on first-line therapies can help shape what comparators and outcomes should be captured in future randomized controlled trials to differentiate the drug in the market,” a senior executive from Aetion, a healthcare technology company that provides decision-grade real-world evidence solutions to biopharma companies, payers, and regulatory agencies was earlier reported as saying.

Novartis’ Zemzoum underpinned the value of real world evidence, now seen as “very critical” to support healthcare policy changes and decisions taken by major stakeholders in the healthcare system.

“We've been investing quite a lot in partnerships with different stakeholders to explore and provide enough support on the data analysis of real-world evidence,” she explained.

She outlined how Novartis was trialing a new model of treating cardiovascular disease (CVD) patients in Australia - the ASCERTAIN implementation science study that is expected to review around 600 patients across 20 sites in the country.

The study has been designed by and will be overseen by experts from the Monash University’s Victorian Heart Institute and enabled by technology provided by e-health company Telstra Health.

“That is a great collaboration which will inform us in terms of real-world evidence, how we can better manage the patient,” Zemzoum said.

The new hyper-care model of care pilot is expected to help improve patient management via

Global Medical Sciences Group Looks at Benefits, Challenges and Risks of Using RWD

By [Vibha Sharma](#)

June 12, 2023

The nonprofit Council for International Organizations of Medical Sciences (CIOMS) has issued draft recommendations on using real-world evidence for the approval, use and reimbursement of medicinal products.

[Read the full article here](#)

participating clinics with the support of digital tools (such as educational text messages, questionnaires) and nurse practitioners. Empowering GP clinics with all the tools could improve the outlook for heart patients in Australia.

“Australia has a CVD emergency - every 12 minutes there is a patient dying from a cardiovascular event. So, it's really something that Australia needs to focus on,” the Novartis executive added.

If successful, the new model can be scaled nationally, helping to address the treatment gap experienced by Australians with CVD, in particular those in rural and remote settings.

Management of ASCVD in the UAE

Along similar lines, Novartis had earlier entered into a memorandum of understanding with the Department of Health Abu Dhabi to support its digital health strategy and establish a population health management model to address atherosclerotic cardiovascular disease (ASCVD). The effort is expected to significantly reduce the burden of heart disease in the United Arab Emirates by advancing prevention, early intervention, and care management.

“Through analysis of local RWE data, we are actually able not only to highlight the current burden of disease and the unmet needs in the system, but also to forecast the future burden using different disease impact simulators,” Zemzoum explained.

Moreover, such efforts can also demonstrate the savings for the healthcare system from tackling such a high burden disease up front.

“So, these insights will ultimately help healthcare systems, in this case, the Department of Health Abu Dhabi to inform their healthcare policies and evaluate and implement solutions and even establish new standards in the management of ASCVD,” Zemzoum added.

BioAsia 2023: Leaders from Novartis, Apple Talk Innovation, Tech, Data Privacy

By [Anju Ghangurde](#)

Feb. 28, 2023

BioAsia 2023 was a melting pot of ideas with Novartis's CEO and a senior executive from Apple, among others, discussing a range of topics including the potential of novel therapies and platforms such as siRNA and radioligand and also where things were headed as the union of technology and biotech drives new insights into biology and promises to help reimagine healthcare.

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The executive, though, did not want to get drawn into specific product-related uptake in these markets, given certain confidentiality aspects and other nuances.