



HEALTH LITERACY SESSION SESSION HIGHLIGHTS

At the core of APPIS is the drive to accelerate access for patients in Asia Pacific, Middle East and Africa. Health Literacy is a crucial part of that drive. During our 2023 Summit, we explored the overarching theme of **empowering meaningful conversations between patients and healthcare professionals** with our diverse line up of speakers who shared their expertise and experience.

OUR SPEAKERS



EL AMIRA NERMINE ZAKARIA
Founding Member of Psoriasis Patient Organization Egypt



DR. HANI SABBOUR
Asst. Prof. Cardiology,
Brown University Medical School;
Consultant Cardiology &
Pulmonary Hypertension, Abu Dhabi



DR. MAHIRA EL SAYED
Professor of Dermatology and
Venereology, Ain Sham University &
Board Member of the International
Psoriasis Council



ROD PADUA
President, Touched By Max Inc. Philippines;
Chair, Chronic Myeloid Leukemia
Advocates Network



STANLEY LI
Founder and Chairman, DXY.cn



VIJI VENKATESH
Region Head, India & South Asia,
The Max Foundation

KEY REFLECTIONS



Access to trusted and easy to understand information is the foundation for improving health literacy

The #CareUnblocked session uncovered the importance of giving patients access to multiple, trusted and easy to understand sources to better inform treatment decisions. With health misinformation online becoming more prevalent, there is an urgent need for governments to take responsibility for fact-checking information and for healthcare practitioners and patient organizations to disseminate credible and reliable information.



Closing the literacy gap through on/offline platforms is a two-way effort between doctors and patients

Tackling health literacy from the perspective of virtual health, Stanley Li, Founder and Chairman of DXY.cn, shared how training doctors to provide online consulting services is key for patients to gain trust. From his experience running the major platform in China, he emphasized the two-way process: both doctors and patients have a role to play in closing the health literacy gap.



Patient groups have an important role to play in encouraging patients to adhere to appropriate care

Viji Venkatesh from The Max Foundation shared a case study on their organization's health literacy program for Chronic Myeloid Leukemia (CML) patients in India showed that patient organizations play a big role as a safe platform to address the concerns of patients and promote adherence to treatment.

MIND THE GAP

Reflecting on the progress made since APPIS 2022, Rod Padua from Touched by Max Inc. Philippines discussed the key barriers facing patient communities, such as access to credible, digestible information. Rod highlighted some of the resources that have been created as a result of the 2022 Summit including the [‘Engage in Health Literacy Interventions for Better Patient Experience Guidance Report’](#) and the [‘APPIS 2022: Health Literacy Handout and Template’](#) which have already helped many APPIS community members to make progress in these areas.

#CAREUNBLOCKED

The #CareUnblocked session centered around **how misinformation has become a major challenge when it comes to patient care**. In an age where patient empowerment around treatment considerations is not only encouraged but critical, ensuring **access to trusted information** has never been more important. The foundation of health literacy is the availability of accurate, credible and easy to understand health information.

The session started with scenarios exploring how patient-doctor interactions can be impacted by information from alternative sources, whether from family and friends, social media or online sources, that influence patient decision making around treatment. With the consensus that this was a common scenario, Dr. Hani Sabbour, Asst. Prof. Cardiology, Brown University Medical School and Consultant Cardiology & Pulmonary Hypertension, Abu Dhabi; Dr. Mahira El Sayed, Professor of Dermatology and Venereology, Ain Sham University & Board Member of the International Psoriasis Council and El Amira Nermine Zakaria, Founding Member of Psoriasis Patient Organization Egypt, dissected how both patients and doctors can work together to navigate important discussions around alternative treatments, starting or stopping treatments and non-compliance of physician prescribed medication. Psoriasis patient leader Nermine explained that in many cultures, diseases can be taboo leaving the patient susceptible to seeking advice about treatment from sources other than their doctor.

For this reason, Nermine suggested **there is a critical need for healthcare practitioners to actively listen to patients with empathy**, so that patients feel comfortable seeking the help that they need and are able to easily discuss subjects that might be difficult to broach. Dr. Sabbour echoed the sentiment that “when patients talk, they are the ones giving you the diagnosis, we have to listen”.

Aside from building rapport between patient and doctor, Dr. Sabbour stressed the need to **disseminate reliable and credible information where the patients are looking** – online. It is not enough to place validated information online such as making peer-reviewed journals openly available, we must actively promote it rather than assuming patients will passively consume it.

To enable this to happen, there is a need for **more collaboration opportunities and partnerships between patient organizations** and professional healthcare organizations as well as policy and decision-makers. It is important for HCPs and organizations to take an active role in ensuring that quality, digestible health information is accessible, accurate and credible.



El Amira Nermine Zakaria

Founding Member of
Psoriasis Patient Organization Egypt

In Egypt, psoriasis is a taboo. Patients don't want others to know they have a disease, they are looking for answers away from doctors. That's why we need to break the taboo – information needs to be passed to people.



Dr. Mahira El Sayed

Professor of Dermatology and
Venereology, Ain Sham University &
Board Member of the International
Psoriasis Council

First of all, we, as healthcare practitioners have to listen more. Second of all we have to learn *from* the patient.



Dr. Hani M. Sabbour

Asst. Prof. Cardiology, Brown
University Medical School; Consultant
Cardiology & Pulmonary Hypertension,
Abu Dhabi

We, as healthcare practitioners, have to anticipate what the patient is going to look up on the internet and be sure we are developing quality information that is available in places patients are searching for it.

LESSONS LEARNED FROM CHINA

Stanley Li shared his experience leading China's most prominent virtual health and telemedicine platform, DXY.cn, and emphasized the importance of the joint effort between both the doctor and patient in order to make the most of each engagement.

In the patient journey, when the patient seeks information online, the key is to encourage the patients and their loved ones to seek the correct information early. The typical patient experience can be divided into two main categories: 'Upstream' focusing on lifestyle decisions, when preventative measures can be taken and 'Downstream' when an illness or condition requires intervention and management.

According to Stanley's research of doctors' service levels on the virtual platform, it shows that we should not take for granted that doctors will be able to deliver quality and safe services online just as they would offline. **Doctors need good quality and specific training to deliver online healthcare advice and services to the patient.**

Stanley also encouraged healthcare providers to think 'as' a patient, not 'for' their patient. Patients need much more than just medicine; doctors must recognize the needs of the patient as a person first, and address the needs of the whole person, not just their condition or illness. He pointed out that healthcare providers **must constantly be thinking about the patient's experience in the same way technology companies think about the User Experience (UX)**, constantly seeking to improve our UX.



Stanley Li

Founder and Chairman of DXY.cn

It is crucial that we think *as* patients, rather than *for* patients when we're building platforms to aid meaningful conversations between healthcare practitioners and patients.

MEASURING THE IMPACT OF HEALTH LITERACY

Viji Venkatesh spoke about the role patient groups and other parties beyond healthcare professionals can play in **ensuring patients adhere to appropriate treatment and care.**

Sharing her personal experience of how The Max Foundation has been supporting Chronic Myeloid Leukemia patients, Viji emphasized that **the patient support group is a safe platform to address the concerns of patients, promote good adherence behavior and perhaps most importantly to provide access to disease information.** She underlined the importance of improving health literacy as part of the drive to improve patient outcomes.


Viji also provided a roadmap for processes related to the establishment and smooth running of a patient organization. She reiterated the importance of the relationship between patients and caregivers, specifically citing the impact of a family member's participation in a patient advocacy group.




Viji Venkatesh


Region Head, India & South Asia, The Max Foundation

The job of the patient organization is never done. There will always be more to do. We must ensure that we are constantly aligning with patient needs, which continue to change.

 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

 **Download** the Digital Health & Communications guidance report: www.appisinitiative.com/resource-centre

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