

# **REPORT**

# 1<sup>st</sup> African Patients Congress

**Co-creating Better Healthcare Systems** 

20-21 July 2021

Virtual

#### Introduction

The 1st Virtual African Patients Congress: 'Co-creating Better Healthcare Systems' (APC 2021) held on 20 -21 July 2021, was a patient led regional convening bringing together IAPO's African membership with a variety of high-level healthcare stakeholders to share their vision and experience on how we can build back better African health systems after the pandemic.

Through a range of interactive capacity building and knowledge-sharing sessions, delegates developed the tools to ensure that the patient movement across the region is made up of strong patient advocates. The goal was to prepare ourselves, as patient advocates, to take on the challenges and opportunities that have arisen as a result of the COVID-19 pandemic, as well as from increasing regulatory harmonisation across Africa with the set-up of the African Medicines Agency.

APC 2021 aimed to create an enabling environment for African expert patients and innovators to share their vision and experience as to how we can build back better health systems after the pandemic. This patient co-created health innovation will be critical in saving lives, extending services, improving effectiveness and efficiencies across the entire African healthcare ecosystem after the pandemic.

# **Acknowledgments**

We would like to express our special thanks to our members, collaborating partners and supporters who made the 1st African Patients Congress a great success despite the difficult circumstances that they were all facing. They stepped forward to help in planning the event by joining our APC 2021 Organising Committee and later as moderators and speakers during the congress.

We thank our Industry Partners without whose partnership and resources we could not have delivered this quality virtual congress.

Lastly, we would like to thank the speakers and delegates for their participation and for sharing their invaluable insights and suggestions, bringing us a step closer to actualizing patient-centred healthcare in the region.

# Background - Revisiting the disrupted UHC 2030 programme in Africa

The APC 2021 revisited the Universal Health Coverage 2030 (UHC 2030) goal. Africa will need all the ingenuity it can harness to get back on track to achieve UHC 2030. The pandemic derailed most of the progress already made. Innovative strategies such as mobile and digital health are critical to ensure attainment of the UHC 2030 in Africa. Digital and connectivity solutions will improve health governance, informatics, financing, service delivery, health workforce, regulation of innovative medicines and health technologies.

Mobile and digital health promises to improve access to health care services especially for those in hard-to-reach rural areas and improve patient safety and quality of healthcare services and medication. They will enhance health work force's, communities' and patients' access to medical knowledge and health information.

Where finance is critical, especially in post pandemic economic downturn, mobile and digital healthcare promise cost savings, and efficiencies in health services delivery. This is critical when budgets are either frozen or cut. The knock-on effect is that these advancements can lead on to the improvements in the social, economic, and environmental determinants of health.

When taken together, patient co-created solutions will contribute to the attainment of universal health coverage. These innovations will start repairing the long-standing fault lines and fragilities in African health systems and address the societal inequalities (structural social and economic inequalities). Innovation can decrease systemic discrimination against women, girls, and vulnerable groups. In achieving vaccine equity, many countries have unleashed innovative co-production joint ventures with global pharmaceutical companies.

Before the pandemic, the power of mobile telephony was already shaping up a new African enterprise culture, from banking to agriculture to healthcare. These innovations have proven themselves as a health system integrator and are revolutionizing the management of large-scale health schemes and supporting the drive for universal health coverage in Africa.

# Aims and Objectives

- Gather Africa's health innovators: To bring together expert patients, regulators, policy
  makers and other stakeholders across Africa to reflect upon how we can build back better
  and co-create innovative solutions for our health systems and work towards UHC 2030 and
  health for all.
- Reflect on to restore disrupted healthcare services: Fragile health systems have been
  overwhelmed by COVID-19 and many healthcare services have been disrupted. APC 2021 was
  a forum to share patient experience and recommend strategies to restore the essential
  health care services, especially those in non-communicable disease, by applying innovative
  patient co-created solutions.
- Intensify advocacy on the ratification of the African Medicines Agency Treaty: Since 2017, IAPO's call for the African Union Member States to ratify the African Medicines Agency Treaty had remained unanswered. We want to ensure that the treaty is ratified, and the future AMA becomes more patient centric by incorporating patient engagement and co-creation in its regulatory framework through law, policy, practice, and standards. We invited the African Union (AU), African Medicines Agency (AMA) and African Centre for Disease Control (ACDC) to join our APC2021.
- Call for Equity on COVID 19 Vaccination (CEPI COVAX and ACT Accelerate). No one is safe
  unless everyone is safe. It is important Africa gets all the COVID-19 Vaccines it needs. The APC
  2021 pushed this message forward.

- Advance current COVID-19 treatment and services. What if the mutations and variants
  overwhelm us? Can we at least prevent the hospitalisation and the high mortality rates
  through other medicines? APC 2021 reflected on WHO Solidarity Trials and repurposed drugs
  initiatives, what it is and how patients can engage with it.
- Advocate for the Pandemic Preparedness Treaty. Kenya, Rwanda, Senegal, and South Africa
  are promoters of a new Pandemic Preparedness Treaty. They have joined 21 other countries
  around the world and called this new treaty. The APC 2021 reflected on the pressing need for
  patient engagement and co-creation in this new African pandemic preparedness framework.

## Programme

APC 2021 took place over two days, 20 -21 July 2021. It was a virtual congress, timed to UTC or Accra Ghana Time 9.00am to 4.00pm each day, where we had 10 sessions in total. Each session was 1 hour long and had a moderator and three speakers to a panel. Each panellist had 10 minutes to speak. We reserved 30 minutes for panel discussion. See the <a href="Programme">Programme</a>. All Congress' sessions were recorded and can be accessed online: <a href="African Patients Congress">African Patients Congress 2021</a>.

#### Day 1 - 20th July 2021

Session	Time (GMT)	Session Title
1	09:00	Welcome and opening remarks
		Bisi Bright, Board Member, IAPO
		Ellos Ellard Lodzeni, Board Treasurer, IAPO
		Kawaldip Sehmi, CEO, IAPO
		Dr. Ratna Devi, Chair, IAPO
		Keynote Speech: Can Africa be the first to eliminate and even eradicate ALL infectious diseases this time by 2030?
		<b>Dr Hala Zayed,</b> Minister of Health and Population - Egypt
		Dr Ahmed Ogwell, Deputy Director, Africa CDC
2	09:55	Is it the dawn of a new African healthcare ecosystem: enabling patient engagement and co-creation in UHC 2030
		Danjuma Adda, President-Elect, World Hepatitis Alliance (Moderator)
		Fatima Seedat, Development Manager, The South African Depression and Anxiety Group - SADAG
		Prof Adenike Grange, former Health Minister in Nigeria
	10:55	Break
3	11:05	African patient engagement in the Global Patient Safety Plan 2021-2030
		Ellos Ellard Lodzeni, Board Treasurer, IAPO (Moderator)
		Gertrude Avortri, Patient Safety Focal Point, World Health Organization Africa
		Dr Neda Milevska-Kostova, Vice-Chair, IAPO
		Dr Titus Beyuo, Obstetrician Gynaecologist and Co-founder, Comprehensive Care Group, Ghana
	12:05	Lunch Break
4	13:00	African healthcare innovation: Is there room for patient engagement and co-creation in healthcare innovation?
		Bisi Bright, Board Member, IAPO (Moderator)
		Emily Sheldon, CEO, Africa Health Innovation Center
		Emile Tata Kongnso, CEO, Center for the Promotion and Protection of Patient's Rights in Cameroon
		Padmaja Kamath, Director Regulatory and Scientific Affairs, Global Self-Care Federation
	14:00	D Break
5	14:10	African patient engagement in clinical research and development of medicines, vaccines, and health devices
		Kawaldip Sehmi, CEO, IAPO (Moderator)
		Dr Adeline Edgal, Chief Scientific Officer for SSA, Novartis
		Dr Nilufar Ahmed, Bristol University - Co-production of Clinical Research
		Dr Miriam Mutebi, Assistant Professor in the Department of Surgery, Aga Khan University Hospital in Nairobi
	15:10	Closing Keynote: Africa's healthcare: Caring for all
		Kawaldip Sehmi, CEO, IAPO
		Menassie M. Taddese, President for Emerging Markets, Viatris
	15:25	Day 1 Wrap Up

Kawaldip Sehmi, CEO, IAPO

#### Day 2 - 21st July 2021

Session	Time (GMT)	Session Title
6	09:00	Can African health systems advance using personlised healthcare?
		Kawaldip Sehmi, CEO, IAPO (Moderator)
		Marlene Thomas, Global Patients Affairs, Roche
7	09:30	Antimicrobial resistance and Africa. The next pandemic: Are we prepared?
		Danjuma Adda, President-Elect, World Hepatitis Alliance (Moderator)
		Bisi Bright, Board Member, IAPO
		Dr Chrispin Kambili, Medical Affairs Lead Global Public Health group, Johnson & Johnson
		Dr Nicholas Adomakoh, Global Medical Affairs Lead for Anti-infectives, Novartis / Sandoz
		Dr Greg Frank, PhD, Global Public Policy Director, MSD
		Dr Walter Fuller, AMR Stewardship and Awareness Lead, WHO Afro
		Dr Michael Anderson, London School of Economics and Political Science
		Dr Mirfin Mpundu, Director, ReACT Africa
	11:00	Break
8	11:10	Health equity in Africa: Neglected Tropical Diseases, entrenched infectious diseases and UN Resolution on Rare Diseases
		Johnpaul Omollo, Health Research and Development - Program Officer, PATH (moderator)
		Kelly du Plessis, CEO, Rare Disease South Africa
		Samuel Agyei-Wiafe, Executive Director, Rare Disease Initiative Ghana
		Dr Elizabeth Juma, World Health Organization Africa
		<b>Dr Roger Sombie</b> , Professor of Hepato-gastroenterology, Yalgado Ouédraogo University Hospital & Joseph Ki-Zerbo University, Ouagadougou, Burkina Faso

#### 9 12:10 Have the big four NCD (CVD, Cancer, Diabetes, COPD) vertical programmes overshadowed other NCDs in Africa?

Flavia Kyomukama, Executive Director, Action Group for Health, Human Rights and HIV/AIDS in Uganda (Moderator)

**Manan Shah,** Vice President, Global Public Affairs, LEO Pharma & Assistant Professor of Public Health, School of Pharmacy & Health Sciences, Fairleigh Dickinson University

Christopher Agbega, Advocacy Officer, Sharecare Ghana

Lefate Makunyane, The South African Depression and Anxiety Group - SADAG

Dr Chandrashekhar Potkar, Chief Medical Officer, Emerging Markets, Viatris

13:20 Lunch Break

#### 10 14:00 Can African UHC 2030 benefit from health technology assessment?

Kawaldip Sehmi, CEO, IAPO (Moderator)

Dr Dalia Dawoud, Scientific Adviser, National Institute

for Health and Care Excellence

Mohamed Gad MD, MA, health economist at the Department of Global Health & Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine 15:00 African Medicines Agency Treaty regulatory convergence & reliance

John Mwangi, Co-Chair – Africa Regulatory Network, IFPMA (Co-moderator)

Kawaldip Sehmi, CEO, IAPO (Co-moderator)

Mimi Darko, CEO, FDA Ghana

Dr Margaret Agama-Anyetei, Head of the Health, Nutrition and Population Division Africa Union

Johnpaul Omollo, Health Research and Development - Program Officer, PATH

16:00 Call To Action and Wrap Up: End of Congress

Bisi Bright, Board Member, IAPO

Ellos Ellard Lodzeni, Board Treasurer, IAPO

Kawaldip Sehmi, CEO, IAPO

# **Patient Organizations Participation**

It is key for IAPO to increase the participation of patient organizations in the events we hold and at APC 2021 it was not different. For this purpose, we established a Call for Applications to ensure more patients played an active role at the Congress, but also offer the opportunity for them to present their work towards building back better African health systems after the pandemic.

The Call aimed at IAPO Members in Africa who were willing to contribute to APC 2021 as a speaker or moderator. The following African members represented the patient voice in the event:

- Christopher Agbega (Advocacy Officer, Sharecare Ghana) spoke at the session "Have the big four NCD (CVD, Cancer, Diabetes, COPD) vertical programmes overshadowed other NCDs in Africa?".
- Danjuma Adda (Executive Director, CFID Taraba and Chagro-Care Trust & President-Elect,
  World Hepatitis Alliance) spoke at the session "Is it the dawn of a new African healthcare
  ecosystem: enabling patient engagement and co-creation in UHC 2030" and moderated the
  session "Antimicrobial resistance and Africa. The next pandemic: Are we prepared?".
- Fatima Seedat (Rural Development Manager, The South African Depression and Anxiety
  Group) spoke at the session "Is it the dawn of a new African healthcare ecosystem: enabling
  patient engagement and co-creation in UHC 2030".

- Lefate Makunyane (The South African Depression and Anxiety Group) spoke at the session
   "Have the big four NCD (CVD, Cancer, Diabetes, COPD) vertical programmes overshadowed
   other NCDs in Africa?".
- Flavia Kyomukama (Action Group for Health, Human Rights and HIV/AIDS in Uganda)
   moderated the session "Have the big four NCD (CVD, Cancer, Diabetes, COPD) vertical
   programmes overshadowed other NCDs in Africa?".
- Samuel Agyei-Wiafe (Executive Director, Rare Disease Initiative Ghana) spoke at the session
   "Health equity in Africa: Neglected Tropical Diseases, entrenched infectious diseases and UN
   Resolution on Rare Diseases".
- Bisi Bright (IAPO Board & LiveWell Initiative LWI) participated in the event "Opening
  Ceremony", moderated the session "African healthcare innovation: Is there room for patient
  engagement and co-creation in healthcare innovation?", and spoke at the session
  "Antimicrobial resistance and Africa. The next pandemic: Are we prepared?".
- Ellos Ellard Lodzeni (IAPO Board Treasurer & Patron and Founder Trustee, Patient and Community Welfare Foundation) participated in the event "Opening Ceremony" and moderated the session "African patient engagement in the Global Patient Safety Plan 2021-2030".

# Delegates' Attendance

Being a virtual event allowed us to reach out to delegates who wouldn't otherwise be able to travel to attend a face-to-face event, whether due to health issues or financial restrictions. APC 2021 brought together 2229 delegates in total representing 84 countries from regions of the world. 342 delegates were representatives of patient organizations, and 68 were IAPO member organizations. We also had 567 delegates representing Non-Governmental Organizations, 582 representing

Governments, and 278 from Academia. Almost 120 delegates came from the Pharmaceutical Industry.

# **Event Delivery**

## **Resources and Inputs**

The Congress was delivered via an interactive event platform managed by Pin Crowd Events. This all-in-one platform provided the delegates with a unique and interactive experience to simulate a face-to-face event. The platform offered the following features:

- Lobby Area
- Auditorium
- Networking via chat
- Downloadable resources

# **Advisory Committee Members**

- Bisi Bright, Board Member, International Alliance of Patients' Organizations (IAPO) & 1st Vice
   Chairman and CEO, LiveWell Initiative LWI (IAPO Member)
- Ellos Ellard Lodzeni, Board Treasurer, International Alliance of Patients' Organizations (IAPO)
   & Patron and Founder Trustee, Patient and Community Welfare Foundation of Malawi (IAPO Member)
- Danjuma Adda, Executive Director/Founder, CFID/CCT Taraba & President-elect, World Hepatitis Alliance (WHA) (IAPO Member)
- Dalilah Kalla, Secretary, Lupus Alert (IAPO Member)
- Nana Yaa Agyeman, Director, Sharecare Ghana (IAPO Member)

 Prof. Amany El-Sharif, Dean Faculty of Pharmacy, Al-Azhar University, Director of AAU North Africa Regional Office (NARO)

#### **Committee Secretariat**

- Kawaldip Sehmi, Chief Executive Officer, International Alliance of Patients' Organizations
   (IAPO)
- Dani Mothci, Member Engagement Manager, International Alliance of Patients' Organizations
   (IAPO)
- Rachel Githinji, Communications Lead, International Alliance of Patients' Organizations
   (IAPO)

# Congress Call to Action - African Medicines Agency Treaty Ratification

By June 2021 only 9 African Member States had ratified the African Medicines Agency (AMA) Treaty and deposited the ratified treaty instrument with the African Union. For the AMA Treaty to come into force, it was important that 15 Member States ratify and deposit the Treaty.

While this was a considerable improvement from IAPO's African meeting in Entebbe Uganda in 2017, when we had no signatures on the Treaty, IAPO revisited its <u>2017 Entebbe Statement</u> and once again called for the African Union Member States to ratify the Treaty and create an enabling framework for patient engagement and co-creation in the African Medicines Agency.

The Treaty for the Establishment of the African Medicines Agency entered into force on 5<sup>th</sup> November 2021, thirty (30) days after the deposit of the 15th instrument of ratification, on the 5th of October 2021, by the Republic of Cameroon at the African Union Commission (Article 38, AMA Treaty).

IAPO's African patients' organisations now want to shape the regulatory environment that benefits all. IAPO formed the African Medicines Agency Treaty Alliance (AMATA) and is advocating the

establishment of structures like the Patient and Consumer Working Party (European Medicines Agency) and the Patient Engagement Partnerships and Consortium (FDA) to ensure patient co-creation and co-production of a patient centred Pan-African medicines regulation regime through the African Medicines Agency.