



African Patients Congress 2021 (DRAFT)
20 - 21 July 2021
Co-creating Better Healthcare Systems

DAY 1

Session	Time	Session Title
1	9.00	<p>Welcome and opening keynote:</p> <p>Can Africa be the first to eliminate and even eradicate ALL infectious diseases this time by 2030? WHO Immunization Agenda 2030 recommends that immunisation programmes should be made a priority in African universal health coverage 2030</p> <p>Objective: To raise awareness and mobilise support for WHO Immunization Agenda 2030. To advocate for the creation of an enabling health ecosystem for patient engagement and co-creation in the African immunisation programmes in the elimination and eradication of infectious disease in Africa.</p> <p>The WHO's public health fight against an infectious disease starts with efforts to first control it, it then intensifies to eliminate it from regions, and lastly a global effort is made to eradicate it total so that we achieve zero prevalence in all regions and countries, having removed the pathogen totally from our environment as was the case with smallpox eradication.</p> <p>Africa was the last continent to eliminate the smallpox virus in 1977. This helped the world eradicate smallpox for ever. No one was safe from smallpox, until everyone was safe. It had taken Africa an additional 25 years to eliminate smallpox. The USA and Europe had already eliminated it in 1953.</p> <p>Africa is a continent that currently has a novel virus, COVID-19, spreading alongside ancient pathogens that it has failed to</p>



		<p>eliminate for over 60 years. The current African generations cannot afford the economic, social, and cultural cost of delays in eliminating diseases. Africa cannot remain a reservoir of entrenched ancient pathogens and novel viruses. Africa cannot afford to come in last.</p> <p>This keynote session will look at how African patients and whole of society can engage with the WHO Immunisation Agenda 2030 (WHO IA 2030), that received unanimous support from WHO Africa's Member States at the at the 74th World Health Assembly, is a strategic framework setting immunisation strategies within universal health coverage settings for 2021–2030. The framework not only addresses immunisation for COVID-19, but it also extends to all other infectious diseases for which we currently have vaccines available. The framework also recommends that we research and develop new vaccines against pathogens for which we currently have no vaccines.</p>
	9.45	Break
2	9.55	<p><i>Is it the dawn of a new African healthcare ecosystem: enabling patient engagement and co-creation in UHC 2030.</i></p> <p>Objective: To raise awareness and advocate the creation of an enabling ecosystem for patient engagement in African UHC 2030 and encourage patient led innovation and co-creation</p> <p>This session will explore the need to create an enabling ecosystem for patient engagement in African UHC 2030 and encourage innovation and co-creation. It will advocate high-level political commitment and a supportive framework (law, policy, practice, standards) to institutionalise patient engagement in African universal health coverage programmes. The session promotes the idea of national capacity building and the creation of a network of African expert patients (The uber advocates). Patient engagement should be institutionalised throughout the healthcare spectrum from primary health care services and health promotion to prevention, treatment, rehabilitation, and palliative care across the whole life course settings.</p>



		<p>UN Member States' adoption of the high-level political declaration on universal health coverage requires Member States set-up sustainable integrated people centred UHC by 2030. This mandates patient engagement and co-creation in UHC 2030. African expert patients (uber advocates) can bring great patient insight and perspective into their healthcare service design and delivery. These patient advocates can also support UHC investment related decision-making by joining health technology assessment and regulatory affairs bodies.</p> <p>Africa will need all the homegrown healthcare innovation it can muster to get back on track to achieve UHC 2030. Patient co-creation and innovation is playing a big role now in the recovery of health systems all over the world. Africa will need patient engagement and co-creation to improve the reach, effectiveness, efficiency, and impact of their health systems within UHC 2030.</p>
	10.55	Break
3	11.05	<p>African patient engagement in the Global Patient Safety Plan 2021-2030</p> <p>Objective: To raise awareness on WHO Global Patient Safety Plan 2021-2030 and advocate for patients lead on this plan and ensure that through their engagement and co-creation we can eliminate all avoidable harm in African UHC 2030.</p> <p>The WHO Africa at the 74th World Health Assembly in May 2021 adopted the flagship WHO Global Patient Safety Action Plan 2021-30. WHO Africa Region and its African Member States must deliver this plan over the next 10 years. Patient engagement and co-creation is critical in the delivery of WHO GPS Action Plan 2021-30. How can African expert patients engage with and co-create safe healthcare in Africa? This session will have African institutes and IAPO Patients 4 Patient Safety Observatory lead on discussing a road map as to how African patient organisations can engage with and co-create an effective patient safety framework with appropriate law, policy, practice, and standards to eliminate all avoidable harm in African UHC 2030.</p> <p>The session will also be used to discuss IAPO and African patient engagement in World Patient Safety Day 17 Sept 2021.</p>



		<p>The theme is Safe maternal and new-born care. The WHO Global Action Plan 2021-2030 has given us key maternal and new-born harm and safety areas to address. Unsafe surgery (caesareans), safe blood transfusions and oxytocin (post - partum haemorrhaging), hospital acquired infections and parent-to-child transmission (PTCT), diagnostic errors (includes genetic tests and sickle cell), injection safety (epidurals, vaccinations etc), and preeclampsia. How will we lead on this on 17 September 2021.</p>
	12.05	Lunch break
4	13.00	<p>African healthcare innovation: Is there room for patient engagement and co-creation in healthcare innovation?</p> <p>Objective: To show-case how patient co-created innovation is now transforming healthcare worldwide and making healthcare more patient centred by personalising it. African patient engagement and co-creation in healthcare innovation as a central pillar of UHC 2030</p> <p>This session will look at.</p> <ul style="list-style-type: none"> • Digital Health, health informatics and AI enabled health devices and their role in African healthcare. • Personalised Healthcare and the New PHC Toolkit • Innovation in Self-Care and Community Pharmacy in Primary Healthcare. Nigeria IMI Med Safety App Adapted <p>Can African healthcare systems leapfrog into the future using Digital Healthcare and other African patient co-created healthcare innovation? Can Personalised Healthcare take root in Africa and improve health system effectiveness and efficiency. How can innovative community pharmacy development and apps like IMI Med Safety App Adapted improve patient education and pharmacovigilance/ patient safety?</p> <p>Lock downs forced changes to many healthcare service delivery models in Africa. Self-care, telehealth, community pharmacists, and community organisation participation in healthcare service delivery played a big role in shoring up</p>



		<p>Africa's healthcare. Innovative approaches such as investment in digital health, artificial intelligence (AI) and machine learning are now needed to ensure universal health coverage in Africa.</p> <p>African owned and patient co-created digital healthcare innovation will impact supply and demand side of African healthcare. This will improve access to healthcare in hard-to-reach areas, improve healthcare safety and quality, improve knowledge and access of health workers and communities to health information; cost savings and efficiencies in health services delivery; and improvements in access to the social, economic, and environmental determinants of health.</p>
	14.00	Break
5	14.10	<p>African patient engagement in clinical research and development of medicines, vaccines, and health devices</p> <p>Objective: To raise awareness and motivate African patient engagement in clinical research and development of medicines, vaccines, and health devices, and explore the role of African Medicines Agency in regulating this area, and EUPATI educating and supporting patients to engage in it.</p> <p>This session will explore the need for African patients' engagement in clinical research and development of medicines, vaccines, and health devices. Patients need not only be the subjects and passive participants in research. Patient engagement must open up and extend to engagement in the conduct of the research and as advisors to the research team, and even become research partners, reviewers, co-authors, and disseminators. This role can also extend later into submitting evidence for the national regulators and health technology assessment bodies.</p> <p>With establishment of the African Medicines Agency, will Africa need a body like the European Patients' Academy on Therapeutic Innovation (EUPATI). This multi-stakeholder public-private partnership body bridges the knowledge and skills gap within European patients' organisations and the European Medicines Agency (EMA). The African Union Patients Academy (AU-PATI) can bridge that gap between AMA and the patients' organisations.</p>



		<p>Pharmacogenomics has raised the need for diverse genotype and phenotype inclusion in medicines development. Many national regulators are now requiring medicines developers to show how local patients were involved and represented in the clinical trials.</p> <p>The African Medicines Agency, that will eventually regulate pan-African clinical trial registration, and the African manufacturers and universities that conduct clinical trials will need a new engagement framework like that provided by the European Medicines Agency to enhance innovation and societal engagement (patient engagement).</p>
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Day 2

6	9:00	<p>Patients Shouting Café- How to influence change through open, transparent, and collaborative public/patient dialogue.</p> <p>Objective: Introducing a new way to advocate in a community of practice setting and ensuring an open dialogue on addressing patient harm and change</p> <p>This session will look at a new way to advocate in an open and consultative way. Africa needs to use the current digital and social media innovation to improve dialogue in the health systems. Healthcare is a whole-of- society, -government and -health professional partnership.</p> <p>Our partner alliance, the Korean Alliance of Patients Organisations (KAPO) has developed a unique town-hall type of open forum at which expert patients, their healthcare teams, legislators, and others participate to address issues of patient harm and other difficulties of access, quality and acceptability. The session will cover:</p> <ul style="list-style-type: none"> • Introduction to the method • Why it is successful in Korea. • Method and activities • How can it work for Africa?
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7	10.00	<p>Antimicrobial resistance and Africa. The next pandemic: Are we prepared?</p> <p>Objective: Raise awareness on AMR and explore patient engagement and co-creation Global Action Plan on Antimicrobial Resistance (AMR).</p> <p>WHO Africa Region has adopted the World Health Assembly resolution on the Global Action Plan on Antimicrobial Resistance (AMR). AMR is seen as the next pandemic in Africa. IAPO has established an AMR Patients Alliance under the IAPO P4PS Observatory to address AMR. We need a whole of government and whole of society action to prevent AMR becoming a pandemic.</p> <p>Eliminating AMR means the whole of the patient movement in Africa participating in this prevention activity. This session will look at what African patients can do in supporting the WHO Five Strategies in the Global action Plan on AMR:</p> <ul style="list-style-type: none"> • Improve awareness and understanding of antimicrobial resistance through effective communication, education, and training. • Strengthen knowledge through surveillance and research. • Reduce the incidence of infection through effective sanitation, hygiene, and infection prevention. • Optimize the use of antimicrobial agents by strengthening stewardship and eliminating irrational use. • Develop the economic case for sustainable investment in new medicines, diagnostic tools, vaccines, and other interventions.
	11.00	Break
8	11.10	Health equity in Africa: Neglected Tropical Diseases, entrenched infectious diseases and UN Resolution on Rare Diseases



		<p><u>Objective:</u> Raise awareness on and look at patient engagement and co-creation in eliminating Neglected Tropical Diseases, entrenched infectious diseases.</p> <p>This Session will look at the needs of Africa’s neglected and forgotten patient groups. The session will also look at meeting the needs of African patients with Rare Diseases in a UN resolution. The 74th World Health Assembly declared that January 30 will be the World Neglected Tropical Diseases (NTD) Day to raise the profile of these patients and their needs. Malaria, TB, and HIV/Aids are entrenched infectious diseases that Africa has failed to eliminate. When the University of Oxford announced that they have a successful Malaria vaccine in April 2021, many observed that compared with the COVID-19 vaccine development and approval, it had taken 60 years to get a vaccine for malaria within the Global Malaria Eradication Program that had started in 1955.</p> <p>Patients with rare diseases do not enjoy the same level of access to quality health information and services that other patients enjoy. The Rare Diseases International is proposing a United Nations Resolution on Persons Living with a Rare Disease and their Families that effectively recognises the complex needs of persons living with a rare disease and promotes the human rights and full participation in society of all people living with a rare disease. How will Africa support this?</p> <p>This session also looks at the new biotechnology and genomic medicine clusters of excellence and regulatory collaboration that have become a game changer in addressing many rare and orphan diseases using cell and gene therapies, and other health technologies improving diagnostics and tests, medical devices, repurposed medicines and biotherapeutics.</p>
	12.10	Break
9	12.20	<p>Have the big four NCD (CVD, Cancer, Diabetes, COPD) vertical programmes overshadowed other NCDs in Africa?</p> <p><u>Objective:</u> Raise awareness and open a dialogue on build back better of mental health and other neglected health</p>

		<p>services like skin and dermatology amidst overwhelming needs of the main NCD healthcare demand of CVD, Cancer, Diabetes and COPD healthcare</p> <p>This session will look at two specific NCDs as a contrast to the big four CVD, Cancer, Diabetes and COPD. It will look at the impact that the pandemic had upon access to these services and explore the solution to build back better:</p> <ul style="list-style-type: none"> • Mental health services • Dermatology and skin care services <p>We all know how severe the impact of non-communicable diseases was on Africa before the pandemic. During the pandemic, this became a severe crisis for NCD patients. First, COVID-19 disproportionately impacted NCD patients as shown by the high mortality and morbidity within NCD patients. Many NCD patients had to voluntarily shield themselves. Then in a double whammy, the unplanned lockdowns not only prevented the NCD patients having adequate access to medical support and social welfare during their shielding, but they also disrupted patients' access to timely safe and quality ongoing treatment and care. Disruption of NCD healthcare services has increased the mortality and morbidity. The vaccination programmes have also been a let-down as many high-risk patients have not accessed them.</p> <p>COVID-19 will result in further mental health problems as job losses rise and healthcare service fail put NCD patients under severe pressure. Services like dermatology and skin care are now affected by the long-COVID and other demands in healthcare systems.</p>
	13.20	Lunch break
10	14.00	<p>Can African UHC 2030 benefit from health technology assessment?</p> <p>Objective: Raise awareness on what HTA is and how patients can engage in the process as Africa invests in health technology to meet UHC 2030 targets.</p>



		<p>WHO says <i>Health technology assessment (HTA) refers to the systematic evaluation of properties, effects, and/or impacts of health technology. It is a multidisciplinary process to evaluate the social, economic, organizational, and ethical issues of a health intervention or health technology.</i></p> <p>This session will look at how African countries can invest in their universal health coverage 2030 in an efficient and effective manner so that they can provide innovative healthcare services, devices and medicine and ensure that accessing this healthcare is not financially ruinous. The session will also look at how African patients can engage with HTA and be co-creators.</p> <p>Health is a political choice. UHC 2030 investment choices are being made within a complex post-covid competing ecosystem. How will innovative evidence-based medicines, services, health devices and other health technologies be procured to ensure that WHO African Member States can extend their UHC 2030 to cover most of their population, giving them more appropriate and effective healthcare services and medicines, and reducing their out-of-pocket contributions? How do you then decide what is reimbursed?</p> <p>Many LMIC are now looking at Health Technology Assessment approaches to help them support decision-making. HTA should help decision-makers balance clinical efficacy, patient preferred outcomes, societal values, and economic realities of the country with the cost-effectiveness of the new health technologies. In Europe and elsewhere, civil society and patient engagement in HTA bodies like NICE England is now institutionalise. Can Africa enjoy this level of patient engagement in HTA?</p>
11	15.00	<p>African Medicines Agency Treaty regulatory convergence & reliance</p> <p>Objectives: Raise awareness and seek support for the ratification of African Medicines Agency (AMA) Treaty and advocate for regulatory convergence and regulatory reliance in Africa.</p> <p>African patients were left concerned by the global and African vaccines' regulation processes. Many vaccination</p>



	<p>programmes were suspended midway during their immunisation programmes. This created an infodemic and vaccine hesitation. There was no overarching regulatory oversight in Africa.</p> <p>IAPO had called for the ratification of the African Medicines Agency (AMA) Treaty in 2017 at our Entebbe Meeting to ensure we had a pan-African oversight and convergence of medicines, vaccines, and health devices regulation. AMA will ensure African patients get timely access to safe, quality, acceptable innovative medicines, and health devices from Cape to Cairo. IAPO's members had envisaged a COVID-19 like pan-African scenario with Ebola and we did not want to compromise vaccine and medicines safety and quality, and equity. The AMA treaty has not been ratified.</p> <p>IAPO is now forming the AMA Treaty Alliance (AMATA) to ensure the AMA treaty is ratified quickly and the AMA is established and operational quickly. IAPO is also looking creating an enabling environment with AMA for African patients' engagement like the European Medicines Agency has done with its Patients and Consumers Working Party.</p> <p>WHO says Regulatory Convergence: "represents a voluntary process whereby regulatory requirements across economies become more uniform, or "aligned," over time, as a result of the gradual adoption of internationally recognized technical guidance documents, standards, and scientific principles (harmonization), and common or similar practices and procedures."</p> <p>Regulatory Reliance is when one National Medicines Regulatory Authority in one jurisdiction may consider and give significant weight to and partially/wholly rely on evaluations performed by another NMRA or trusted institution in reaching its own decision. The relying authority remains responsible and accountable for decisions taken even when it relies on the decisions and information of others.". The regulatory work done is shared by the trusted authority (e.g. through assessment or inspection reports), while the receiving authority uses this work according to its own scientific knowledge and regulatory procedures and retains its own regulatory responsibilities.</p> <p>This session explores African patient engagement in:</p>
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		<ul style="list-style-type: none">• African Medicines Agency and the African Medicines Agency Treaty Alliance (AMATA)• What is regulatory convergence and reliance and how it benefits African patients and what role we can play in it?• How can patients engage with AMA and RR/RC and co-create and build back better a Pan African Institution and regulatory ecosystem?
	16.00	Call to Action and Wrap Up End of Congress