The 1\textsuperscript{st} Africa Regional Virtual Meeting Report.

25-August-2022, 8:00AM – 4:00PM EAT;

The Africa patient empowerment and engagement event by the World Patient Alliance and its partner patient organizations in Africa and around the globe;

Theme: Raising patient voices as a path way to quality and safe care in Africa;
Acknowledgement

The report has been developed by the World Patient Alliance (WPA) office and Africa Regional Meeting Committee while coordinating with the Africa Regional Meeting Coordinator (Ziwa Hillington) and with leadership from the WPA board members (Regina N. Kamoga and Hussain Jafri). And also with substantial input from the meeting presenters.

It is so much gratitude for the contribution of the Africa Regional Meeting Planning Committee that included Regina N. Kamoga, Hussain Jafri, Haris Khalid and Rehan Mujeeb from the WPA office, then the patient organizations and other event affiliations which included;

- Ziwa Hillington: Community Health and Information Network
- Donny Ndazima: Integrated Community Approach to Development
- George Kiwanuka: Story Mic Uganda
- Rebecca Chilenga: Women in Communities Zimbabwe
- Roselyn Odero and Christine Mutena: Rare Disorders Kenya
- Irene Mpangile, Albany Ngoitanile, Hawa Bandera: Tanzania Breast Cancer Foundation
- Cecilia Nantume: Patient Safety advocate and expert
- Kwame Appiah: Advocacy for medical malpractice victims
- Alphonce Mbarushimana: Rwanda NCD Alliance
- Danjuma k. Adda: Centre for Initiative and Development (CFID)
- Dr. Golum Godfrey: Lugei Foundation Uganda
- Mercy Kukundakwe: Infectious Diseases Institute
- Dr. Joshua Atepo: Ministry of Health Uganda

It is sincere thanks to the WPA board members who endorsed the hosting and also contributed to the design of the event. We recognize Regina N. Kamoga, the meeting chairperson with her leadership team including; Hussain Jafri and Andrew Spiegel.
It is also sincere gratitude for our event speakers who shared resources and insights to promote patient engagement and empowerment, as interventions to promote Universal Health Coverage, and these included;

- Andrew Spiegel: World Patient Alliance
- Hussain Jafri: World Patient Alliance
- Regina N. Kamoga: World Patient Alliance
- George Kiwanuka and David Kanja: Story Mic Uganda
- Dr. Ernest Konadu Asiedu: Ministry of Health Ghana
- Dr. Avotri Gertrude: World Health Organisation-AFRO
- Roelinde Bakker: Pharma Access
- Dr. Janet Byaruhanga: African Union Development Agency – NEPAD
- Catherina Scheepers: Max Foundation
- Alex Adusei: Women’s Hope Foundation
- Tsitsi Monera-Penduka: University of Zimbabwe
- Christine Mutena: Rare Disorders Kenya
- Ziwa Hillington: Community Health and Information Network
- Irene Impangile: Tanzania Breast Cancer Foundation
- Fatima Seedat: The South African Depression and Anxiety Group (SADAG)
Introduction

The World Patients Alliance (WPA) is a non-profit umbrella organization of patients and patients’ organizations from around the globe. The WPA provides the platform to empower and raise the patients’ voice for the provision and access to safe, quality and affordable healthcare. WPA works to ensure patients have an active role to play in all the stages of healthcare that include planning, provision, monitoring, research and evaluation of health services. The WPA vision is that all patients have access to safe, high quality and affordable healthcare everywhere in the world. The Organization’s mission is to be the global voice of patients and work toward patient empowerment & engagement, improved access to safe innovative treatment and patient centered healthcare throughout the world.

Members of the World Patient Alliance, are patient organizations, serving the under served patients in the most isolated communities of Africa and the globe, through policy advocacy and also empowering of patients to navigate the health systems of their respective countries to access quality health care, with a specific outcome of living a high quality of life. From time to time the WPA and its members design, develop and implement interventions that are geared towards supporting member organizations to address health care challenges in their respective communities. One significant approach to the designing and delivering interventions is for both the members and WPA to organize knowledge sharing events for the patients, and one of the significant knowledge sharing event was the 1st African Patients Virtual Regional Meeting.

The 1st African Patients Virtual Regional Meeting, the first of its kind, was an initiative of the World Patient Alliance (WPA) in collaboration with its strong network of patient organizations in Africa. The initiative was part and parcel of the WPA’s long time quality and safe care advocacy around the globe, as well as the engagement and empowerment of patient organizations around the globe.

The meeting was held on the August, 25, 2022, from 8:00am until 4:00pm EAT. And attracted over 100 participants who were patients, patient's organizations, as well as other private and public sector players from Africa and around the globe, who shared learning experiences on promoting patient engagement and empowerment to achieve quality and safe care in Africa with a specific focus on Universal Health Coverage.

Ultimately the meeting promoted the alignment of patient engagement and empowerment goals amongst the different stakeholders and the strengthening of a patient organizations’ community who past the event will advocate for quality and safe care, and this approach very much concretized the event theme; Raising patient voices as a pathway to quality and safe care in Africa.

The World Patient Alliance understands that creating and empowering patient-based support systems to create interventions that promote Universal Health Coverage is critical in addressing barriers to quality and safe health care in Africa. That is why during the event, participants presented and discussed the underlying issues of why Over 615 million people in Africa can’t access essential services and then the services available are of every low quality and there is low sense of ownership and trust in the health care systems. The participants also presented on current interventions that are addressing barriers to quality health care.

The barriers to achieving Universal Health Coverage and recent interventions to address the barriers, were articulated into two sessions;

- One which presented an opportunity to the global and high-level health stakeholders to present on the Universal Health Coverage framework of actions to promote quality and safe care in Africa;
- And the other, during which patient organizations and health experts shared case studies on patient engagement in promoting access to quality and safe care.

Based on the knowledge sharing and learnings during the event, WPA, its members and partners consolidated and created a road map to bring patient organizations, patient communities as well as private and public sector partners, to start contributing to the Universal Health Coverage framework of actions to achieve quality and safe care for the “African patient, family and community”
Meeting Highlights

- **About 9 hours** of online engagement;
- Convened and empowered **over 100 patients**, patients' organization, key global development stakeholders, policy teams, industry representatives;
- **14 key presentations** from patient organizations as well as global private and public sector health agencies promoting UHC;
- **Two event sessions**; One focused on global interventions and policies promoting UHC, and the other focused on case studies on patient safety across Africa;
- Shared resources on the **application and results** of the Universal Health Coverage framework of actions to achieve quality and safe care.
The Intro – session summary

**Intro-session:** Arrival, Login, event overview

**Session objective:** Welcome participants and provide an overview of the event

**Session period:** 8:30am to 10:15am EAT.

**Topic 1:** Opening Remarks by Andrew Spiegel, World Patient Alliance Chair;

**Topic 2:** Introduction to the World Patient Alliance by Hussain Jafri, World Patient Alliance, Executive Director;

**Topic 3:** Introduction to the World Patient Alliance Africa Regional Meeting by Regina N M Kamoga, World Patient Alliance, Founding Board Member;

**Topic 4:** Patient story by Story Mic Uganda.
Andrew acknowledged Regina’s leadership for the meeting, and also recognized Dr. Hussain and the WPA office, the organizing committee, as well as the WPA partners such as the African Union, World Health Organization, Ministry of Health, the patients’ organizations for contributing to the event. He highlighted that it was critical for World Patient Alliance to hold the meeting first in Africa, because of the challenges to accessing quality health care. He further emphasized the commitment to ensure that access to quality care isn’t determined by where you live, hence the high priority for the meeting to advance access to quality care in Africa. Andrew hoped that future would provide an opportunity to organize an in-person meeting.

"It has always been my feeling that where you live should not determine whether or not you live or die from a disease” Andrew indicates the need for safe care in Africa.
Introduction to the World Patient Alliance (WPA).

Dr. Hussain thanked and congratulated Regina the meeting chairperson and the event organization committee as well as the WPA office for the dedication and expertise invested for more than two months and almost on a daily basis to bring the event into existence. The presenter indicated the great opportunity to form a strong patient network and platform, as well as forecasted that the event would allow for sharing short- and long-term recommendations for strengthening the patient network and also working together on patient issues and these would be significant to WPA's role of promoting patient advocacy around the world.

The WPA is a world leader in patient advocacy and empowerment, and by August 2022, the organization had the largest network of about 370 patient organizations across 114 countries representing different disease areas, and such a result was possible in a very short time since the organization's launch in 2019. The WPA exists with a global leadership of world patient advocates who are professionals from both the development and health care disciplines (https://www.worldpatientsalliance.org/our-founders/). Supplementary to the expert leadership is a set of 9 patient-based principles that are referred to while developing patient care solutions at WPA (https://www.worldpatientsalliance.org/about/#our_principles), at the forefront the principles highlight WPA's role of advocating for innovative and affordable quality health care solutions, and also promote the capacity building of patient groups around the world while leveraging collaboration with key global development partnerships (https://www.worldpatientsalliance.org/our-partners/). It is significant to note that WPA's membership and interventions are all free for the membership organizations and patients around the world, such as a series of educative events and trainings that have been implemented since the launch of WPA and some of these are highlighted in the 2021 annual report (https://www.worldpatientsalliance.org/wp-content/uploads/WPA_AnnualReport-2021-Final.pdf).

The presenter also highlighted some of the best-case studies of interventions completed and planned in 2022, such as the grant financing of about 800 global initiatives by patient organizations to promote medication safety regarding the World Patient Safety Day on the 17th September 2022 (https://www.worldpatientsalliance.org/world-patients-safety-day-wpsd-2022/). Then the 1st World Patients Conference in Rome on the 15th-16th October 2022, to focus on health policy, patients Rights and Patient Engagement (https://www.worldpatientsalliance.org/all-events/conference/).
**Introduction to the World Patient Alliance Africa Regional Meeting.**

Regina expressed the sincere gratitude to the meeting organization committee, for without them the event wouldn’t have been possible. She also appreciated the World Patient Alliance board, office and partners for being part of the great milestone. Regina explained that the 1st African Patients Virtual Regional Meeting was one of the pathways to achieving Universal Health Coverage (UHC) framework of actions which include; Financing for effective health intervention, Services that are patient centered, Equitable health care which includes the poor and the marginalized, Preparedness of the health security systems, and the streamlined governance on political and institutional foundation for the UHC agenda (https://openknowledge.worldbank.org/bitstream/handle/10986/26072/108008-v1-REVISED-PUBLIC-Main-report-TICAD-UHC-Framework-FINAL.pdf?sequence=1&isAllowed=y). The presenter elaborated that to achieve UHC, patients need to be engaged and empowered and quality and safe care be achieved, which was the main reason why WPA while working with its patient organizations and partners were convening to “Raise Patient voices as a path-way to quality and safe care in Africa.”

The presenter highlighted the objectives of the event which were; Providing patients, the platform and opportunity and raise patients voices regionally as well as globally; Promoting interventions under Universal Health Coverage framework of actions and creating a pathway for a sustainable platform for patient's organization and partners to collaborate and foster patient safety interventions. Further more she emphasized the event would lead to short term outcomes such as convening patients, patients organization, key global development stakeholders, policy teams, industry representatives and sharing resources on the application and results of the Universal Health Coverage framework of actions to achieve quality and safe care while the long-term outcomes would be to create the WPA African Regional Membership Steering Committee to build capacities of patients organization to promote safe care; create an online information sharing and knowledge management portal for tracking the progress of Universal Health Coverage interventions and also map and form a network of the African continent patient advocacy working groups to advance patient quality and safe care.

Regina over emphasized the power of working together to engage and empower the patient to achieve quality health care. Where working together should include all key stakeholders including the patient as well as the private and public partners.
Patient story by Story Mic Uganda.

David Kangye who is a Ugandan blogger and writer based in Uganda Entebbe and George Kiwanuka who is a legal expert also based in Kampala and also runs runs Story Mic Kampala, a live monthly themed amateur storytelling event, discussed a story on patient care. The story was about David’s patient care experience when he got a motorcycle accident.

On 25th/6/2020, David lost his father and as his family and him organized for the vigil, he went to fetch fuel that would run the generator through the night. Unfortunately, during the sad moment of his life as he was mourning his father, David also got a motorcycle accident at 1 am EAT, he was then rushed by an ambulance to a local health center called St. Stephen’s hospital. David indicates that it was very challenging as the hospital didn’t have an x-ray and the health care providers weren’t immediately available as the night shift doctors were leaving the hospital and the early morning shift doctors hadn’t arrived. In fact, David was moved to 5 hospitals before he would access an x-ray at Nsambya hospital. That moment was one of David’s most depressing moments of his life, as he had lost his father then at the same time he was struggling for his life after getting an accident. What David explains as a relief and support during such a trying moment was meeting an empathetic doctor at Nsambya hospital called Joyce. David narrates and praises the psychotherapy that offered him mental health stability. David explains that Joyce went beyond providing physical health support by providing mental health support. Joyce kept around David through out a full time, and only moved away a day later. The moral of the story as explained by David is that everyone is a potential patient, and you never know when you might need patient care.
The Session One Summary

Session one: Universal Health Coverage framework of actions to promote quality and safe care

Session objective: Describing global interventions and policies for promoting Universal Health Coverage and health care quality and safety through patient engagement and empowerment in Africa.

Session period: 10:15 am to 12:40 pm EAT.

Topic 1: Reaching national patient quality and safe care goals through developing improved national preparedness plans which include organizational structure of the governments by Dr. Ernest Konadu Asiedu, Ministry of Health Ghana;

Topic 2: World patient’s safety action plan by Dr. Avotri Gertrude, World Health Organisation-AFRO;

Topic 3: Access to quality and affordable health care for vulnerable populations through low-cost insurance platforms tailored to patient needs, by Roelinde Bakker, Pharma Access;

Topic 4: AUDA-NEPADs efforts to address last mile delivery of health services, by Dr. Janet Byaruhanga, African Union Development Agency – NEPAD;

Topic 5: Supporting medicines supply chain and building global networks of health care givers to establish people-centered health services to improve the quality of services and patient safety, by Catherina Scheepers, Max Foundation.
Reaching national patient quality and safe care goals through developing improved national preparedness plans which include organizational structure of the governments.

Dr. Earnest, explained Ghana’s streamlined and developed health care system that prioritizes patient safety and quality health care as well as community engagement and empowerment. The Ghana health system identifies with significant interventions and features that are impacting the patient, such as;

- Ghana’s health system with 23 consolidated agencies;
- The National Health Care Quality strategy;
- The model health center which is a developed district hospital, which is referenced by both private and public health care facilities;
- The community score card ([https://www.youtube.com/watch?v=hih8d4GlwDU](https://www.youtube.com/watch?v=hih8d4GlwDU)) used to identify gaps and leads to wards developing quality health care solutions with the community for the community;
- The mandatory National Insurance Scheme which is a Universal Health Coverage strategy;
- The Agenda 111 ([https://agenda111gh.com/](https://agenda111gh.com/)) which ensures expansion of standard health care facilities in all 88 districts of Ghana;
- The developed structure for promoting and regulating the traditional medicines sector
When Dr. Earnest was asked about the progress of Ghana, in regards to the Abuja declaration (https://apps.who.int/iris/bitstream/handle/10665/341162/WHO-HSS-HSF-2010.01-eng.pdf?sequence=1), where the African Union member states pledged to allocate at least 15% of their annual budget to improve the health sector, he indicated that Ghana is progressing between 9% to 12%, as evidenced by the data existing, however he emphasized that there is also undocumented progress, such as the contribution of the community and other development partners.

Another critical insight was how Ghana has integrated traditional medicines as part of the health remedies. Dr. Earnest explained the consolidated criteria and system in place to regulate and manage the traditional medicines sector, such as:

- Traditional Medicines Council responsible for regulation.
- The Food and Drug Authority, which tests and checks the quality of the medicines.
- The Plant Medicine Research Center, which does research on traditional medicines.
- The Association of Traditional Service Providers.

It is important to highlight Dr. Earnest’s recommendations for systems development and improvement to achieve patient safety and quality care, which included:

- Developing a strong leadership and coordination among line ministries and agencies.
- Identifying gaps in-habiting improved patient care and outcome using improved data systems for real time data and management.
- Collaborations with patients to ensure evidence based and practical solutions for patient problems clearly identified.

"We know that patients would definitely look for other sources of health care apart from the orthodox ones" Dr. Earnest explains one of the reasons, for integration of the traditional medicines in the health care system.
Global Patient Safety Action Plan (GPA).

Dr. Gertrude articulated the Global Patient Action Plan (https://www.who.int/teams/integrated-health-services/patient-safety/policy/global-patient-safety-action-plan) with a special focus on Strategic Objective # 4. The Global Patient Safety Action Plan which was adopted in May 2021, declared patient safety as a global health priority. The presenter elaborated the structure of developing the action plan, the recent outcomes and future prospects were explained, below is an outline of the key considerations from the presentation:

▪ The 72nd World Health Assembly (WHA) May 2019, recognized patient safety as a global health priority;
▪ Then the annual World Patient Safety Day was established and now celebrated every year on the 17, September;
▪ The 7 strategic objectives are guide the implementation of the plan;
▪ Strategic objective # 6, is still far fetched, as access and availability of data is a big challenge, however WHO is working closely with member states and partners to address this challenge;
▪ The regional webinar was organized for 47 member states and patients’ representatives, during which awareness was created and the GPA was disseminated;

The Strategic Objective # 4, was key during the presentation and the presenter explained the several interventions progressing in regard to the objective, and some of these included;

▪ The Patient for Patient Safety Network, which advocates for patient safety, and includes members of the community who have been harmed during access to health care;
▪ The development of the Africa Regional plan, to contextualize issues in Africa that were not addressed in the GPA;
▪ The development of the significant strategy to operationalize the GPA, with a special focus on issues affecting Africa.

Dr. Gertrude emphasized the need for all participants to make input to the ongoing works, and also pointed out that patient safety should be made a state of mind.
The Session One Presentations

Access to quality and affordable health care for vulnerable populations through low-cost insurance platforms tailored to patient needs.

Roelinde demonstrated how Pharma Access with its partners made possible the access to quality health care to about 2.3 m patients in 2021, in the different countries of operations. Notably 60% of the patients were women and children part of low-income groups. To achieve such a result, Pharma Access presented a model through which inclusive health markets are made to work, by leveraging digital technology and the stimulation of public-private partnerships. Through its approach, Pharma Access presents a unique opportunity to address access to quality health care for the vulnerable communities. This approach proposes the following features:

- In 2009, “Safe Care” was developed and accredited by ISQA, and this allowed for setting new inclusive standards covering the full range of medical and non-medical aspects of care;
- The “Safe Care” is implemented in collaboration with the key eco-system players at levels including the clinic, policy and network;
- The eco-system players are beneficiaries of an integrated assessment and improvement approach which is an integral part of the “Safe Care” program;
- A significant feature of the Safe Care program is for example when health facilities improve quality care provision by utilizing improvement insights from Pharma Access’s offline and online service provision tools. Once the health facilities benefit from the insights, they are also in position to assess the improvement through a step wise approach that measures improvement through a number sequence (1 indicating low quality and 5 indicating high quality);
- In 2021, a total number of 2026 facilities in Nigeria, Kenya, Ghana and Tanzania, benefitted from the integrated assessment and improvement program. And 79% health faculties improved their quality care;
- What makes Pharma Access’s quality care approach efficient is the online quality platform; the tool which is used in all in levels and activities of quality care assessment and improvement, this tool doesn’t only support health care providers, but is also used by policy makers and government bodies to assess the impact of interventions but also receive insights on strategies for improving health care.

Two case studies were presented; one where Pharma Access has supported Ghana’s national health insurance scheme, with a specific focus on digitization and data, and the other where the health care system in Zanzibar has been transformed from free to sustainable, the project in Zanzibar presented key successes such as, strengthening the capacity of the Council Health Management Teams (CHMT), the digitized system which is a routine for the Ministry of Health staff, and a significant quality care improvement where 102 health facilities moved from quality care level 1, stepping up to levels 2 & 3. Roelinde, emphasized that quality care approaches and systems should bring transparency to the patients, as this will empower them to know where to look for the quality health care, she highlighted how this is possible through digitization, health insurance and continuous assessment and improvement of the health care systems. And on this she hinted on Pharma Access’s scaling plan to new countries. In her conclusion, she highlighted that one significant way forward is for governments is for governments to work on national quality management frameworks.
Dr. Janet Byaruhanga, Head health unit, African Union development Agency-NEPAD

“AUPH needs to be acceptability, accessibility, participation of the community in deciding what their health is going to look like and the other key area is that the health care should be affordable and creates self reliance”

Dr. Janet articulates Primary Health Care.

AUDA-NEPADs efforts to address last mile delivery of health services.

Dr. Janet elaborated the pilot project BIJIMIN, which is AUDA-NEPADs intervention to support member states’ efforts to strengthen resilience of health systems through improvements in community health workforce capability. This project is targeting 5 countries including; Chad, Burundi, Lesotho, Central Africa Republic, and South Sudan started 2022 until 2024. The project directly improves Primary Health Care in the respective countries.

The BIJIMIN primary health care guiding principles are the; 8As (Appropriateness, adequacy, accountability, availability, accessibility, acceptability, affordability & assessability) and the 3Cs (Completeness, continuity & comprehensiveness) while the 3 pillars of implementation, include; 1) Training and Upskilling of Community Health Care Workers, 2) Education and Awareness raising, 3) Strengthening PHC infrastructure; fundamentally the pillars benefit the key stakeholders in the Primary Health Care value chain, who are; firstly the Community Health Worker, secondly the marginalized communities, and thirdly the policy and other private sector partners.

Ultimately AUDA-NEPAD, is building a sustainable eco-system to sustain and improve Primary Health Care, by leveraging the financing, technical expertise, digitization, and a global network to deliver the most significant outcomes for the patients and the community, the community health workers, and the entire health systems in the respective countries. Dr. Janet, further highlighted that the project is to deliver which included:

- Proportion of additional community healthcare workers to baseline
- Number of beneficiaries of education campaigns/workshops conducted that pass the KAP assessment
- Number of brownfield community health infrastructure projects initiated
The Session One Presentations

Catherine Scheepers
Region Head for The Africa and Middle East Region, Max Foundation

“Patient safety, first of all, it starts with ensuring patients have correct diagnosis, if we don’t have the correct diagnosis, and we are prescribing, we know the outcome, of that is either over treatment or toxicity” Catherine, explains the use of building a system that takes of care of the right diagnosis and monitoring of patient results.

Supporting medicines supply chain and building global networks of health care givers to establish people-centered health services to improve the quality of services and patient safety.

Catherine explained the approaches to patient safety and medicines provision to Nearly 8,000 patients in 29 countries in Africa. Max Foundation provides free oncology and rare disease medicines to the grassroots community in developing countries, through an effective eco-system that comprises of; an independent shipping and logistics company, the network of expert health care providers who are Physicians, the net work of in-country Max Foundation staff members and patients’ organizations, as well as the PAT digital monitoring and reporting system. Diagnosis and monitoring are fundamental building blocks to providing the medicines, to which Catherine explained that with out the proper diagnosis and patient monitoring, patient safety can’t be achieved. The comprehensive health care and medicines distribution system implemented by Max Foundation, implies that the physicians will carryout efficient diagnosis to understand the patient needs, then they will go ahead to prescribe the right treatment, and then enroll the patient to access programs, also very significant is that the physician will dispense at the point of the patient. Added to the physicians’ efforts, are the in country patient groups, who uniquely support to break cultural barriers to using the medicines, they are fundamental at creating awareness on usage. PAT which is Max Foundation’s in house technology for monitoring, is a unique element that advances reporting on patient needs and effects of the medicines, for example adverse events are reported with in 24 hours upon occurrence. Despite the enormous success made, Catherine mentioned that there still are big barriers to getting medicines where they are most needed, such as getting past the country customs, acquiring waivers, among others.

The presenter emphasized the impact of working together by streamlining solutions, so that resources are not duplicated. She suggested that organizations should specialize on their core focus. She also gave insights on the challenge of sustainably distributing the medicines, however the despite the challenges on building the sustainable distribution, Max Foundation is already work on interventions and suggesting for local government ministries to transform the free medicine intervention into a locally owned program. While concluding her presentation, she recognized the significant impact achieved by Max Foundation where a patient with Chronic myeloid leukemia (CML) in a developing country now has the same life expectancy as a patient that resides in a developing country. And finally, she endorsed that based on Max Foundation’s work and impact, as well as other partners’ works that it is true that Access to Treatment is equal to Access to life.
The Session Two Summary

Session two: Patient engagement in promoting access to quality and care; insights from patients organizations and experts in Africa.

Session objective: Sharing experiences of Patient organizations in engaging and involving communities and patients in improving quality and safety of care.

Session period: 12:40 am to 2: 25pm EAT.

Patient safety engagement interventions to reach quality and safe care

Topic 1: Promoting patients and family engagements in global patient safety action plan in Africa by Alex Adusei, Executive Director, Women’s Hope Foundation;

Topic 2: Promoting medication safety in patients transitioned to new regimen by Tsitsi Monera-Penduka, PhD, AAHIVP HIV Pharmacy Specialist, and Senior Lecturer at the University of Zimbabwe;

Patient organizations’ case studies on patient engagement to promote access to quality and safe care for the patients

Topic 1: Case study Rare Disorders Kenya by Christine Mutena, Co-founder;

Topic 2: Case study Community Health and Information Network, by Ziwa Hillington, Strategy and programs development;

Topic 3: Case study Tanzania Breast Cancer Foundation, by Irene Impangile, Program Manager;

Topic 4: Case study The South African Depression and Anxiety Group (SADAG), by Fatima Seedat, Development Manager.
The Session Two Presentations

Promoting patients and family engagements in Global Patient Safety Action Plan (GPSAP) 2021-2030 in Africa.

Alex described the patient safety challenge with solid examples, such as the patient safety harm information from the World Health Organization, which reveals that 1 in 4 patients is harmed in low- and middle-income countries while they access health care, and overall, 60% of deaths in low- and middle-income countries are due to unsafe and poor-quality care. He went on to give examples how patient organizations while creating collaborations with other stakeholders can localize the Global Patient Safety Action Plan 2021 - 2030 to address unsafe care. Alex pointed out the “Strategic Objective 4” (SO4) which is part of the GPSAP, as a core component for the patients’ organizations to focus on, when promoting patient safety. The SO4 elaborates key approaches on how patients and families can be uniquely engaged, and these include: **Strategy 4.1**: Engage patients, families, and civil society organizations in co-development of policies, plans, strategies, programs, and guidelines to make health care safer; **Strategy 4.2**: Learn from the experience of patients and families exposed to unsafe care to improve understanding of the nature of harm and foster the development of more effective solutions; **Strategy 4.3**: Build the capacity of patient advocates and champions in patient safety; **Strategy 4.4**: Establish the principle and practice of openness and transparency through health care, including through patient safety incident disclosure to patients and families; **Strategy 4.5**: Provide information and education to patients and families for their involvement in self-care and empower them for shared-decision making. In Ghana, Women’s Hope Foundation and its partners are already implementing patient safety solutions while referring to the SO4 and its detailed components. And has such the presenter explained the key interventions, which some examples are outlined below:

- Streamlining patient safety as a national priority;
- Implement national awareness by engaging during the World Patient Safety Day (WPSD);
- Development and dissemination of the Patient Safety Rights Charter;
- Raising awareness on patient safety reporting systems;
- Build and empower networks of patient safety advocates, among others.

As a way forward Alex, emphasized the GPSAP, should be promoted with work that target the root cause of the problems of unsafe care. Additionally, the government and international organizations should develop funding mechanisms for interventions that promote the GPSAP.
Promoting medication safety in patients transitioning to a new regimen

Dr. Monera presented an initiative in Zimbabwe that promoted medication safety in people living with HIV transitioning to dolutegravir (DTG) (https://www.who.int/news/item/22-07-2019-who-recommends-dolutegravir-as-preferred-hiv-treatment-option-in-all-populations). The presenter explained how the initiative enabled access to treatment for people living with HIV while prioritizing medication safety. She elaborated on why medication safety is critical, for example when patients enroll on new drugs, there is a high risk of drug-related problems that compromise patient safety which in the end interfere with treatment goals. These problems can include: overdosage, adverse reactions and drug interactions. She highlighted that in response to the drug and medication safety problems, the World Health Organization launched a global patient safety challenge with 3 priority areas including; medication safety in transitions of care, polypharmacy, and other high-risk situations: these should be highly prioritized while implementing drug interventions to address promote patient safety.

Dr. Monera explained that drug-related problems in HIV care can interfere with the UNAIDS targets for HIV management, where 95% of patients with HIV should know their status, of those who know their status, 95% should be on treatment and of those on treatment, 95% should be virally suppressed. She also gave insights on how poor adherence can lead to sub-optimal blood levels and finally lead to drug resistance which limits drug options for antiretroviral therapy. Dr. Monera explained how transitioning patients to DTG can present a high risk for drug-related problems. Firstly; there is a change of practice, and healthcare providers have limited experience with using DTG. Secondly, healthcare centers are usually short-staffed which results in work pressure. Lastly, polypharmacy is also common since patients are on a combination of ART treatment and other lifelong treatment.

The initiative developed a Medication Use Review (MUR) tool to identify and address drug-related problems during each patient visit at Parirenyatwa hospital in Zimbabwe. The initiative ensured the right individuals transitioned to DTG, for the right reasons, and took the right doses at the right time. All the health outcomes were documented, and patients had the right to refuse the transition. The specific outputs and outcomes were; enrollment of final year pharmacy students from the University of Zimbabwe to work with the pharmacy manager; the development of the patient workup tool to document the clinical characteristics of patients transitioned to DTG. 129 people living with HIV were reviewed 76 drug-related problems were identified. 93% of the problems were resolved on the same visit, and 26 case safety reports on ADRs were submitted to the national pharmacovigilance centre.

Dr. Monera, advised patients to speak about their medication experience, and this in return will enable healthcare providers to assess the adverse reactions and health benefits of the medicines.
Patient engagement and empowerment, Rare Disorders Kenya casestudy.
Rare Disorders Kenya (RDK) is a patient-led organization of patients, parents and caregivers of People Living With Rare Disorders (PLWRD) in Kenya. RDK aims to engage various stakeholders to address the unique needs of PLWRDs. RDK has so far recorded (+70) with common examples including:
Multiple sclerosis (MS), Muscular dystrophy (MD), Narcolepsy.

Christine explained that the RDs is any disease that affects a small percentage of a given population. They are often serious, chronic and progressive in nature. The RDs are mostly lifelong hence the need to be managed continuously by a multidisciplinary team of Health Care Professionals (HCPs). The RDs are recognized in the Universal Health Coverage health agenda, and over 7000 RDs exist and affecting 300million people worldwide. She expounded that 72% of the RDs are genetic and 70% of these affect children, and only 5% of the RDs have treatment.

Rare Disorders Kenya (RDK) advances the patient engagement and empowerment objectives including; education and awareness on RDs in Kenya; improves lives of the PLWRD by creating and empowering support networks; promotes research on RDs in Kenya; promotes collaboration with the national government and other stakeholders to drive best outcomes for PLWRD. RDK has also developed a solid road map for patient engagement and empowerment, which integrates several features, such Member Acceptance, Advocacy, Patient Skills and Patient Centric Care, these features entail providing a holistic care for patients, while engaging the different stakeholder like the Health Care Professionals, government and other stakeholders. These features also entail for patients to be empowered and become their own voices.

Christine’s advocacy on RDs highlighted that Patient Empowerment and Engagement should be a deliberate process that involves trust between all stakeholders, and it can’t be imposed but facilitated. Also, Patient Advocacy Groups should be treated as key partners when it comes to patient quality and safe care.
The Session Two Presentations

Patient engagement and empowerment, Community Health and Information Network, case study.

Community Health and Information Network (CHAIN), is a non-for-profit, civil society organization founded in 2004, in Uganda. CHAIN is comprised of an integrated network of community-based care givers, including; patient organizations, Health Care Professionals (HCPs) and Community Health Workers (CHWs), who are addressing barriers of quality health care amongst the most isolated and vulnerable communities in Uganda. CHAIN is the secretariat of the Uganda Alliance of Patients Organizations; an alliance is compromised of patient’s organizations addressing different disease areas.

Ziwa explained that CHAIN is a community champion, and the organization is creating an expert and resilient African patient, by leveraging its community and high-level partnerships. CHAIN has identified the building blocks that lead to quality health care for the patient, family and community which include; an infrastructure of key resources such as the patient organizations, the Community Health Work, the data hub, the continuous health education school, the medical experts and community health center. The outcome of the infrastructure is the quality health goods and services, such as evidence-based data on patient needs that informs policy advocacy and health services and also the promotion of health literacy in communities. Then finally part of the building blocks is the beneficiary eco-system, which firstly includes the patient, family and community who benefit from the quality health care enabled and advocacy for their needs, the Community Health Workers and medical experts who benefit from continuous health literacy and patient safety training which allows them improve service delivery, then the public and supply chain partners who benefit from evidence based data about the patient needs so that they can develop intervention while focused on the actual patient needs.

The presenter explained some of the interventions that CHAIN is implementing such as the collaboration with the National Drug Authority to sensitize the community to report the Adverse Reactions (ADRs) resulting from the medicines they are taking through phone messaging direct to NDA. Another example is how CHAIN is promoting health and patient safety in schools through the “Start Early Initiative” through which school children are empowered to be young health ambassadors through a series of training and research on topics like medication safety, hand hygiene, among other. The school initiative has empowered about 20,000 school children, 50 schools have been reached in 3 districts in Uganda, 50 health literacy clubs have been formed and about 1000 households have been sensitized by the school children and have constructed Tippy taps and improved hand washing, which has reduced infections.

CHAIN’s work over the 20 years, is exemplary of how the patient, family, and community can be engaged and empowered, while leveraging community owned resources such the Community Health Workers and patients’ organizations as well as partnerships with key public and private stakeholders.

Ziwa Hillington
Strategy and Programs Development, Community Health & Information Network.

“It’s common that people can buy from or listen to people they relate to” Ziwa emphasizes that Community Health Workers and Patients Organizations should be integrated while developing and delivering quality health care, because the community listens to them most.
The Session Two Presentations

Patient engagement and empowerment, Tanzania Breast Cancer Foundation case study.

Tanzania Breast cancer Foundation (TBCF) was formed in 2008 where the initiative to form the NGO arose from a group of survivors' personal experiences as patients and the realization that they could contribute to cancer care in Tanzania. These survivors' efforts went towards making fellow affected women have less traumatic experiences and to foster hope for a cure if they report early for treatment. Ultimately TBCF works to shift state of diagnosis of breast cancer from late stage (3 and 4) to (0 and 2) where the disease is most curable and treatment costs are lowest, by providing emotional and financial support, as well as partnerships with relevant authorities and similar organizations like TBCF to enhance community outreach.

Irene explained that late diagnosis is the root cause of cancer in Tanzania, and it is characterized by different problems which are structural, systemic as well as socio-cultural and socio-economical. For example, there are limited health facilities especially in rural Tanzania for cancer detection, the populations lack education on the disease, there exists stigma around the disease such the myth spread that if someone gets cancer, they won’t give birth. The presenter showcased TBCF’s community engagement model which addresses late diagnosis, the organization empowers groups of cancer survivors who together with the organization mobilize and sensitize their communities about early diagnosis, this approach leads to acceptability and participation in clinical trials as well as care and support interventions.

The presenter highlighted TBCF’s work and it’s related impact since 2019, during which the organization impacted 4,025 people through home and hospital visits, some examples of hospitals included; Ocean Road Cancer Institute and Muhimbili hospital; 3,955 people received counselling on side effects of treatment, the type of exercise and diet required after surgery; 19,140 people sensitized during awareness seminars conducted in schools, religious centers, market places, etc.; 14,817 people sensitized during awareness events such as charity walks, Gala dinner, etc.; 330 people who received Mastectomy Bras & Prothesis and these improved women’s self image and femininity which led to self confidence and joy; 44 million Tanzania Shillings invested to support newly diagnosed patients who can’t afford treatment, and as such 52 women were supported since 2015. Irene mentioned one of the recent intervention at the organization was the partnership with Tanzania Cancer Comprehensive Care (TCCP), The District Medical Officer’s office and other stakeholders to provide services to the underprivileged societies during an awareness and screening campaign in Morogoro as well as the plan to commemorate the Breast Cancer month in Kilwa, South to plant 1,000 trees to symbolize hope and also remember women that lost the battle with breast cancer. It is critical to note in Irene’s presentation that though the TBCF focused on cervical and breast cancers, there is a significant need to include prostate cancer, for men inclusion, furthermore it is critical that survivorship is made a priority and as such the beneficiaries should be taken care of prior, during and post the cancer challenges.
The Session Two Presentations

Patient engagement and empowerment, The South African Depression and Anxiety Group (SADAG) case study.

SADAG is a Non-Profit Organization, a Registered Section 21 Company, with an 18a tax exemption. It has on its board a powerful team of Patients, Psychiatrists, Psychologists, and General Practitioners. SADAG was established twenty years ago to serve as a support network for the thousands of South Africans who live with mental health problems. 1 in 3 South African’s will or do suffer from a mental illness. Only 25% of people with a mental illness access/will access treatment or help which Leaves 75% of people living with a mental health issue not accessing help or treatment. The impact of SADAG’s solution is immense for example; the organisation has set up 30 toll free helplines, and post Covid-19, 3,500 calls were received per day, the innovative speaking book on mental health issues developed for illiterate and semi-illiterates for which each book reached 120 people.

Fatima elaborated SADAG’s innovative initiative of the counselling container which is a pilot project in South Africa which has become a prominent and effective approach to engage and empower patients affected by mental health. The initiative converted shipping containers into mental health convergence spaces located in populated centres where other NGOs have offices; Sought and recruited community members who were not necessarily mental health experts but received training on topics such as basic counselling, presentation skills, during a daily 3 weeks training program; carried out advertisement on the mental health services to the community. An example of the outcome is 77% of the patients indicated high/extremely high distress levels in the first training session while in the next session only 25% of the patients were displaying high distress levels as a result of the training and support received. To date the container community service model continuously deploys it’s key services including; Free Face to Face Counselling; Stakeholder Engagement which involves creating cohesion with stakeholders and introduce them to mental health training; Support Groups, at different levels like the family level to address gender based violence, address stigma issues affecting men; Community Awareness, where the SADAG team visits and creates awareness at Clinics, police, churches, etc.; School Talks where SADAG, promotes a signature talk branded “Suicide Shouldn’t be a secret Talk”.

SADAG’s solution delivered at the containers are backed by evidence and data generated through research on community mental issues. Fatima presented an example of a mental health profile generated through research. The research targeted the locations of Diepsloot and Ivory Park, interviewing 1,176 township residents of which 48% were aged 18 -35 years, 27% were aged 36-45 years and 25 % were greater than 46 years. The results indicated top five mental challenges including; Crime, Unemployment, Substance Abuse, Lack of adequate housing and COVID-19. On the access to mental health services, 12% reported lack of mental health services and 80% reported they didn’t see a mental health professional. The several sources of how the respondents learnt about mental health were as follows (80% Clinics, 70% Press and Media, 62% Social Media and 32% Family and Friends). The respondents also made suggestions to improving mental health in the community where 40% indicated increased education and awareness while 27% indicated the need to increase mental health services.
The Session Three Summary

**Session three:** Event Wrap and collection of insights.

**Session objective:** Acknowledging participants and laying strategies for advancing quality and safety of care in Africa

**Session period:** 2:25pm to 4:00pm.

**Topic 1:** Call to action: Laying strategies for advancing quality and safety of care in Africa

**Topic 2:** Wrap up and acknowledgments
### The Summary Key Insights (Q&A, Call to Action, Etc.)

<table>
<thead>
<tr>
<th>Session</th>
<th>Key Insights (Q&amp;A, Call to Action, etc.)</th>
</tr>
</thead>
</table>
| Session One | ▪ Dr. Ernest Konadu Asiedu part of the National Quality Management Unit PPMED, Ministry of Health Ghana, gave insights on the possibilities of under declaring Ghana’s progress on the health spending target of 15% in regard to the Abuja Declaration. He claimed that there can be undeclared monitory contribution of the community, on which he commented that Ghana was launching a research and publication focused on monetizing the community contribution to health interventions.  
▪ Prisca Githuka, part of Pink Hearts Cancer Support Foundation Kenya, acknowledged the great event and teams that put it together, she requested for insights on educating the cancer patient to be empowered with knowledge with regard to their treatment plan, as she noted that patients in most cases, the decisions on medication are independently guided by the doctors and patients might not necessarily understand whether the suggested treatment can be wrong. Dr. Avotri Gertrude part of the World Health Organisation-AFRO gave her perspective on the inquiry by first highlighting that sometimes-patient challenges don’t have the same advocacy solutions. Her insight was a case of an antenatal project she was engaged, to which she noted that beneficiaries were addressed in English, but not all of them were familiar with the language and therefore the education intention wasn’t achieved, therefore she advised one solution to providing patient solutions can be organizing one on one sessions and patients be spoken trained in a language the understand. The answerer further recommended employing a structured approach to providing patient education while utilizing the WHO guide documents.  
▪ Tsitsi Monera-Penduka, part of the University of Zimbabwe, inquired on how the patient safety culture can be promoted amongst Health Care Professionals. Dr. Monero who is part of regulating pharmacy in Zimbabwe seeks to develop and promote a framework of disclosing medication and treatment errors. During the meeting she sought to learn on interventions advanced by the World Health Organization in respect to the matter. Dr. Avotri Gertrude part of the World Health Organisation-AFRO , commented that this has been a big challenge overtime because of the issue of blame and fear of implications, she gave an example of a project in Ghana where even anonymous reporting was rejected. However, though far fetched, Dr. Gertrude emphasized that there are already pockets of countries where error reporting is being streamlined by integrating appropriate legal approach and other strategies. |
## The Summary Key Insights (Q&A, Call to Action, Etc.)

<table>
<thead>
<tr>
<th>Session</th>
<th>Key Insights (Q&amp;A, Call to Action, etc.)</th>
</tr>
</thead>
</table>
| **Session One** | - Dr. Nimeeta Ghakar part of SWASTI organization, explained her experience on the challenge of promoting quality of care when navigating the health care system, which compromised of competing perspectives and diverse levels of accountability. She asked how Pharma Access managed to set standards for quality of care in the competing and diverse systems. Roelinde Bakker part of Pharma Access answered by emphasized the need to reference and adopt World Health Organization international standards when developing the standards of the quality of care. She also indicated that a step by step approach should be taken when developing and implementing standards of quality, such as the involvement of patients, building partnerships at the synergy and networking levels, and in Roelinde's experience it can take about (5 to 10 years) to institutionalize standards of quality care.  
- When Roelinde was asked about Pharma Access’s approach to improve the health eco-system in the different African countries, she highlighted that it is about team work and coalition at national level, on this she gave an example of Kenya where Pharma Access provided technical assistance during the development of the Kenya Quality Management Framework. During the development of the framework, international standards from WHO were referred and insights from institutional stakeholders were also regarded. |
### Session Two

Irene Impangile, part of Tanzania Breast Cancer Foundation (TBCF), when asked about how her organization addressed the challenges of community fear on the HPV vaccine ([https://en.wikipedia.org/wiki/HPV_vaccine](https://en.wikipedia.org/wiki/HPV_vaccine)), she explained that one of the mistakes was the government administering the vaccine without educating the public about it, and to address the community stigma and limited adaptability to the vaccine, TBCF sensitized the community, engaged community leaders like the religious leaders to create awareness on the vaccine and also carried awareness sessions in secondary schools.
<table>
<thead>
<tr>
<th>Session</th>
<th>Key Insights (Q&amp;A, Call to Action, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session Three</td>
<td><strong>Call to action: Laying strategies for advancing quality and safety of care in Africa</strong></td>
</tr>
<tr>
<td></td>
<td>This section highlights some of examples of key take away suggested by the participants at the peak of</td>
</tr>
<tr>
<td></td>
<td>the event, the insights are inclusive of the very many learnings and call to action that were part</td>
</tr>
<tr>
<td></td>
<td>of session one and two;</td>
</tr>
<tr>
<td></td>
<td>-  Fatima Seedat part of The South African Depression and Anxiety Group (SADAG), pointed out that</td>
</tr>
<tr>
<td></td>
<td>patient education and providing quality health care services in areas without such services is key</td>
</tr>
<tr>
<td></td>
<td>to achieving quality health care. She gave an example of how they used community education to create</td>
</tr>
<tr>
<td></td>
<td>awareness on mental health and eliminated mis diagnosis through patient education, she explained</td>
</tr>
<tr>
<td></td>
<td>that the more they educated the community the more the members became aware of the signs and</td>
</tr>
<tr>
<td></td>
<td>symptoms of mental health challenges.</td>
</tr>
<tr>
<td></td>
<td>-  Alex Adusei part of Women’s Hope Foundation, Identified the huge collaboration gap between</td>
</tr>
<tr>
<td></td>
<td>government, the patient, private and public sector players. He advised that while governments</td>
</tr>
<tr>
<td></td>
<td>develop health solutions they should integrate input from all stakeholders such as; traditional</td>
</tr>
<tr>
<td></td>
<td>medicines providers, traditional leaders, religious leaders, among others.</td>
</tr>
<tr>
<td></td>
<td>-  Emmanuel Ayire part of World Child Cancer in Ghana, resounded and emphasized Ghana’s Community</td>
</tr>
<tr>
<td></td>
<td>Score, his emphasis was on how the community gives in put to development of interventions using this</td>
</tr>
<tr>
<td></td>
<td>tool. Then also how the tool is digitized and used for planning as well as monitoring and evaluation</td>
</tr>
<tr>
<td></td>
<td>of health interventions such health insurance, safe care, availability of logistics among others.</td>
</tr>
<tr>
<td></td>
<td>-  Rebecca Kirenga part of Women in Communities Zimbabwe, was keen on the exploring solutions for</td>
</tr>
<tr>
<td></td>
<td>mental health issues on which she pointed out that they are usually disregarded and not receiving</td>
</tr>
<tr>
<td></td>
<td>the enough and appropriate treatment. For example she had curiosities whether drug addiction patients</td>
</tr>
<tr>
<td></td>
<td>are receiving the appropriate service treatment. Rebecca is not convinced that addiction patients</td>
</tr>
<tr>
<td></td>
<td>should be in Psychiatric wards, she suggests that they should rather be rehabilitated. She advised</td>
</tr>
<tr>
<td></td>
<td>that stakeholders should prioritize issues on mental health, hold a workshop on mental health to</td>
</tr>
<tr>
<td></td>
<td>specifically discuss the issues of mental health and also propose interventions.</td>
</tr>
<tr>
<td></td>
<td>-  Haris Khalid part of the World Patient Alliance(WPA) office, advised participants who were not</td>
</tr>
<tr>
<td></td>
<td>already members of WPA, to visit the WPA web page, Identify the “Join Us” section, fill up the</td>
</tr>
<tr>
<td></td>
<td>membership application and await feed back of approval (<a href="https://www.worldpatientsalliance.org/join-us/).">https://www.worldpatientsalliance.org/join-us/).</a></td>
</tr>
</tbody>
</table>
Regina thanked the participants, the event planning team and presenters for the successful meeting. She did a brief on all presentations and also highlighted key actions which are fundamental to patient safe care, including:

- Collection and management of data on patient issues and safe care interventions to help in development of evidence based safe care solutions;
- Fostering collaborations between the patient, government, as well as public and private sectors to continuously discuss patient problems and potential solutions. For example, to lobby for governments to increase health financing.

Regina emphasized that the meeting wasn’t just a one-time activity and ensured that all participants have a role to continue implementing potential solutions towards patient safe care. And as such we don’t have a scenario of “No Action, Talk Only”, a phrase she referred to while explaining the challenges of not acting but only talking.
Resources & References

- **Event website**: [https://www.worldpatientsalliance.org/africa-regional-meeting/](https://www.worldpatientsalliance.org/africa-regional-meeting/)
- **The Health Agenda for the event**: The state of universal health coverage in Africa: Executive summary report on the Africa Health Agenda Internal conference commission (2021).