

The patient's voice in global health care decision making

**Setting Priorities Fairly: Sustainable policies for
effective resource allocation in Africa**

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Introduction

- Uganda faces a **double burden** of communicable and non-communicable disease, coupled with a number of healthcare challenges including;
- **Low government prioritization and spending** on health: The proportion of the national budget allocated to the health sector in 2016/17 budget was 7% below the Abuja Declaration commitment.
- Inadequate human resources for health
- Weak medicine regulatory and pharmacovigilance systems

Patient

Patient : refers to Patient, family and carer

Mostly Vulnerable

- This vulnerability is evidenced in;
 - double burden of communicable and non communicable diseases
 - lower life expectancy
 - reduced access to care –patients die because medicines are too expensive or not available
 - diminished quality of life
 - Illiteracy and low health literacy
 - Poverty



Why Patient Engagement

- The critical role of patients cannot be overemphasized
- Patients bring unique and important perspectives on their own care, on the experience in health care organizations, and on the coordination and cooperation among various elements of their care. Unfortunately, patients, their families and other caregivers, and the public all too often are not meaningfully engaged in care or as partners in its improvement.



Patient interest/needs

- Patients need a healthcare system that is Patient centred ; designed and delivered to meet the needs of the patient including preferences and values
- **MEANINGFUL** involvement
- Patient empowerment
- Good patient /doctor relationship
- Effective communication-Listened to
- To be active participants not perceive receivers of care

Patients needs/interests cont'd

- To participate in key decision making process and ensure that the patient voice is included such as ;
- The African Medicines Regulatory Harmonization (AMRH) Initiative that was established in 2009 to “accelerate and ensure” regulatory harmonisation in the African continent Initiative and to remove barriers that hinder patient access to healthcare products in Africa, including the establishment of the African Medicines Agency (AMA)

Roles of patients/organisations

- Advocacy-to ensure health processes and decision making is patient centered and addresses their needs and preferences.
- Participation in development of health guidelines e.g. CHAIN has participated in the development of WHO surgical site guidelines, Developing of the patient centered healthcare intervention in hospitals in Uganda and patient safety ongoing processes .
- Sits on TWG on monitoring and evaluation, Sicklecell Association sits on NCD committee ,National Organisation of people with HB sits on HB technical working group and has influenced budget allocation of \$ 3m a year for HB prevention ,treatment and care .

Roles cont'd....

- Patients' organizations can provide a platform for patients' stories and interviews on health conditions and health technologies for example in Uganda the - Uganda Alliance of Patients Organization platform, provides the patients an opportunity to speak about the successes, health needs and challenges to health care access



THE UGANDA ALLIANCE OF PATIENTS' ORGANIZATIONS (UAPQ)
PATIENT SOLIDARITY DAY 2017

THEME: "GLOBALLY EMPOWERED PATIENTS: POWER THROUGH KNOWLEDGE"

VENUE: ST. JAMES C.O.U HEALTH CENTRE, MASIRIBA - KIBOGA DISTRICT
DATE: WEDNESDAY 6TH DECEMBER 2017 TIME: 9:00AM - 4:30 PM

The following services will be provided free of charge:

- Cancer, Sickle Cell and Hepatitis B Screening
- HIV Counseling and Testing on Site Medical Consultation and Treatment
- Provision of Information on Diabetes, Sickle Cell, Epilepsy, Lung Disease, Family Planning, Substance Abuse, Mental Health And Fertility Issues Exhibitions.

Logos: Patient Solidarity, World Health Organization, Ciplaqo, JMS, iMedical, and various other partner organizations.



Roles cont'd...

- Increase patients health literacy
- Build the capacity of patient organizations to advocate to decision-makers at both the local and national levels
- Empower patients with knowledge of their health-related rights and responsibilities
- Advocate for increase in health financing and Human resources for Health
- Advocate for access to quality and safe medicines

Campaign :Drug stock-out kills! Stop it

- In late 2015, Uganda faced a health crisis when a stock out of HIV/AIDS and tuberculosis (TB) drugs threatened health facilities across the country
- PATH's partners under the Advocacy for Better Health (ABH) project, in response, developed a campaign: "Drug stock-out kills! Stop it." The campaign urged government to address the crisis, and the coalition prioritized three actions: gathering the best evidence available; communicating one "voice;" and engaging in solution-oriented outreach with key decision-makers.
- Within a month, the Ugandan government had committed to securing a US\$200 million loan, partly to be used to re-stock the country's HIV/AIDS and TB drugs. The government also successfully negotiated with the Global Fund, which agreed to frontload its future budget to the country's HIV/AIDS and TB programs to purchase lifesaving drugs.
- Officials at the Ministry of Health and the National Medical Stores also revealed pipeline plans to spend US\$5 million to build additional drugstores to accommodate more antiretroviral drugs and other drug supplies. They agreed to hold quarterly dialogues with civil society advocates and provide direct access to the President of Uganda if future stock-outs persist. The dialogues continue today and have proven to be a very useful platform for addressing some of the country's supply chain gaps.

Roles of Private Sector and Government

- Private sector-Financing, technical support, capacity building
- Govt-policy ,ensure universal health coverage, Patient centered health policies, regulation and standards
- Challenges
- Interests/priorities,conflict of interests –how is this managed

Examples

- Currently the Ugandan government through the Ministry of Health is advancing patient safety by promoting platforms where private sector , civil society organizations dialogue on improving health policies, for example a patient safety workshop was organized where issues such regulation of private practitioners was highlighted
- Private sector, can influence the quality of services and medicines provided to patients by fostering relationships with civil society organizations and the government, for example Medical Access a non for profit organization that supplies quality medicines to the Ugandan community was first launched as pilot project between a development agency, the Ugandan government and pharmaceutical companies.
- Pharmaceutical companies financing health interventions that promote health literacy and patient safety and collection of information on patient feedback on the different medicines to inform health policies is critical

HTA

- Patients have an interest in HTA because it can be an important tool in leveraging scientific and engineering advancements for better patient outcomes if appropriately executed
- However it should be designed with patient centered focus.
- Should be administered in an efficient manner that promotes patient access to high quality healthcare
- Evidence based
- transparent and in consultation with broad range of stakeholders. Including patients and roles clearly defined,
- High impact and relevant to country health priorities

HTA capacity Building

- There is still very low awareness of HTA among patients /organisations
- There is need for HTA capacity building to allow patients participate in HTA programs effectively.

Lessons learnt and experiences (HTA and policy)

- regulation critical
- patients need to be at the center of all decisions impacting their health
- Low HTA capacity

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