Opportunities and Challenges for Patient Involvement in Development and Safe Use of Medicines in Resource Limited Settings

29th August 2019 at the National Drug Authority Head Office

Lumumba Avenue, Kampala - Uganda.

The Workshop organized by Community Health And Information Network, Uganda Alliance of Patients Organizations and National Drug Authority in partnership with Council for International Organizations of Medical Sciences (CIOMS)

Acknowledgment:

It was a remarkable opportunity to dialogue on advancing patient involvement in the development and safe use of medicines in Resource Limited Settings (RLS). Special thanks to the Council for International Organizations of Medical Sciences (CIOMS), National Drug Authority (NDA), Community Health and Information Network (CHAIN), Uganda Alliance of Patients Organisations (UAPO), Members of the organizing committee and all participants for their contribution and support to the workshop.

Acronyms:

CABS – Community Advisory Boards

CHAIN - Community Health and Information Network

CIOMS - Council for International Organizations of Medical Sciences

ESAU - Epilepsy Support Association Uganda

IDI - Infectious Disease Institute

NDA - National Drug Authority

SMS – Short Message Service

SOPs - Standard Operating Procedures

TMCG - The Medical Concierge Group

UAPO - Uganda Alliance for Patients Organizations

PEPFAR - Presidential Emergency Programme for Aids Relief

PSU - Pharmaceutical Society of Uganda

RLS - Resource Limited Settings

WHA - World Health Assembly

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1. Introduction

Background:

While the patient is recognized as a key stakeholder in CIOMS guidelines, their role in existing and previous guidelines has been defined primarily by other stakeholders such as regulatory authorities and pharmaceutical companies rather than by direct involvement of patient advocates and patient organisations. CIOMS recognizes that there are some areas where re-evaluation and additional input from key stakeholders such as patients is now warranted, and as such, a working group on patient involvement in the development and safe use of medicines was formed to offer relevant initiatives in different settings. The process of developing these guidelines is ongoing and includes chapters on Landscape of patient engagement, patients involved in regulatory initiatives, the role of patients in developing regulated information for patients about medicines, Patient involvement in the design, implementation and evaluation of additional risk minimization measures, Patient involvement in the generation of safety data, Patient involvement in developing crisis/time-bound communications, Guiding principles for engagement and Patient Involvement in Advancing Treatments for their Disease. However, during the working group meetings it was noted that there was a need to include a chapter on the challenges and opportunities for patient involvement in RLS to ensure that all perspectives from different settings are included. One of the ways to generate content for the chapter was through workshops, hence the Uganda workshop.

Workshop Objectives

On 29th August 2019, CHAIN Uganda, UAPO and the NDA in partnership with the Council for International Organizations of Medical Sciences (CIOMS) organized a one-day workshop which was held at the NDA head offices in Kampala, Uganda. The objective of the workshop was to bring together key stakeholders to dialogue on challenges and opportunities for patient involvement in the development and safe use of medicines in RLS.

The workshop brought together 60 participants from the Ministry of Health, health professional associations, supply chain and human rights organisations, health care service providers, pharmacists, radiologists, nurses, surgeons, physicians, pediatricians, lawyers, public health specialists, social workers, community representatives on ethics committees and a bioethics working group, clinical research ethics committees, Community Advisory Boards, National council for older persons, an Inter religious council, lawyers, journalists, patient

advocates and patient organisations focusing on cancer, epilepsy, sickle cell disease, HIV/AIDs, Hepatitis B and mental health.

Key outcomes and approach for the workshop:

Through presentations, participatory dialogue and group work, the participants generated content for the chapter on patient involvement in the development and safe use of medicines in RLS. The topics of discussion included how patients can be meaningfully involved, advancement of patients' voice to policy, best practice principles for patient involvement in designing patient package inserts & patient information leaflets, pilot testing materials, and evaluation of the effectiveness once the product is on the market. Participants also shared knowledge, experiences, challenges and opportunities for patient involvement in RLS.

Prior to the workshop, pre-meetings were held with the organizing committee members and facilitators to ensure the workshop achieved its desired objective. To further enrich the information generated during the workshop, post meetings were held with the organizing committee and other key stakeholders who made further contributions to the report.

2.0. Opening session

Remarks from National Drug Authority

The National Drug Authority was delighted to host the workshop and commended CIOMS for the innovative approach that will eventually contribute to increased access to more cost effective medicines and healthcare products in resource limited settings like Uganda. The need for partnerships with patient organisations such as one between the NDA and CHAIN was hailed as being fundamental in raising awareness about medicine safety issues among patients. Such partnerships as highlighted above help solve complex challenges that can hardly ever be solved by any single party involved because they allow pooling of expertise, knowledge, experiences and resources, explained Ms. Helen Byomire Ndagije, Director Product Safety, NDA.

'*In the last few decades, the development costs per drug have been increasing. Research has shown that many drug molecules are dropped in the later development stages than would have been desired yet there is increasing pressure on the manufacturers to lower the drug prices in order to facilitate access. The patient therefore being involvement earlier in the* discussions of drug development is of critical importance', she narrated.

Mr. Brian Sekayombya, the Principal Regulatory Officer for medicines also informed participants that the NDA was established as a result of an Act of Parliament to ensure the availability, at all times, of essential, efficacious and cost-effective drugs to the entire population of Uganda as a means of providing satisfactory healthcare and safeguarding the appropriate use of drugs.

He further highlighted the role of National Drug Authority in drug development which is to regulate drug-related clinical trials in Uganda; where a lot of information is collected from patients during clinical practice and clinical trials that contribute to drug development. He explained that the NDA values patients input and their engagement in monitoring drug safety is critical.

The phases of drug development were explained to the participants to enable them identify areas for patient involvement.

2. The workshop in progress

2.1. Remarks and Presentations

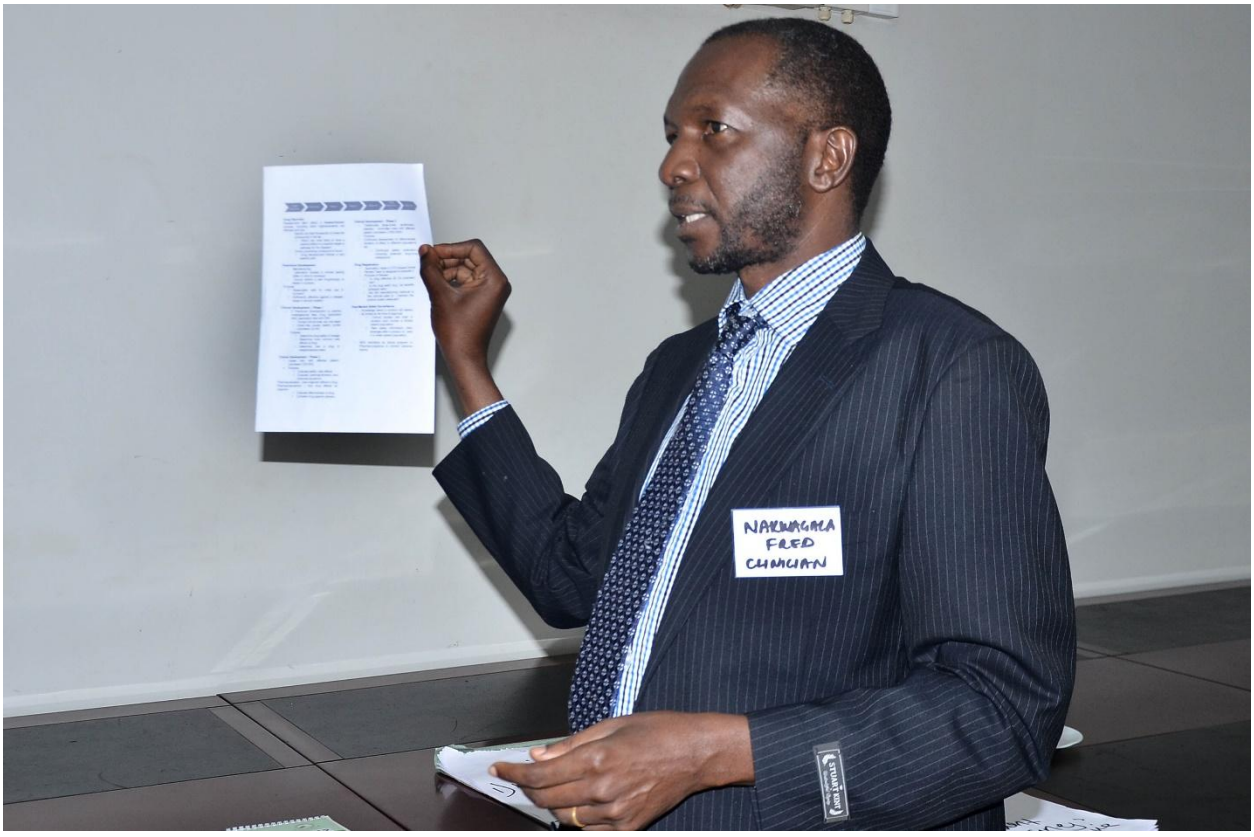
Remarks from Community Health and Information Network (CHAIN) by Ms. Regina Mariam Namata Kamoga, Executive Director.

CHAIN Uganda is a grassroots organization promoting health and social development, advocating for patient centered healthcare and patient safety. Regina informed participants about her role in promoting patient safety as well as her involvement with CIOMS as a working group member of the guideline on patient involvement in drug development and safe use of medicines. She noted that patients are increasingly being looked at as important stakeholders and the CIOMS guideline was a testimony. She elaborated CIOMS strategy of advancing public health through guidance on health research including ethics, medical product development and safety. She noted that the guidance on patient involvement is intended to provide a comprehensive overview of patient knowledge and existing initiatives and will also address a wide range of opportunities, challenges and practice gaps. She urged participants to use this opportunity to make a contribution to this process to ensure that the guideline is truly global.

Regina highlighted existing and future opportunities in which patients are voicing their needs, which included patients sitting on decision making platforms such as technical working groups at the Ministry of Health, Uganda Cancer Institute board, research institutions, Community Advisory boards among others. She encouraged patients to fully optimize these opportunities to advance the patient voice.

She informed participants about the *72nd World Health Assembly resolution* which recognized Patient Safety as a global health priority, and also adopted a resolution on Patient Safety which endorsed the establishment of World Patient Safety Day to be observed annually on 17th September. She requested the participants to join and support activities planned for the day by the Ministry of Health and also ensure that they raise awareness within their spheres of influence.

Dr. Fredrick Nakwagala, a senior consultant physician and chairperson Bio-ethics working group, Mulago hospital.



Dr. Frederick Nakwagala making his presentation

Dr. Nakwagala pointed out the uniqueness of the workshop, being the first of its kind in Uganda addressing challenges and opportunities for patient involvement. In his presentation, he explained that in the past years, during clinical care, doctors took full responsibility of making decisions for the patient. He commended recent efforts where increasingly patients are engaged in decision making processes. He emphasized the need to contextualize scientific

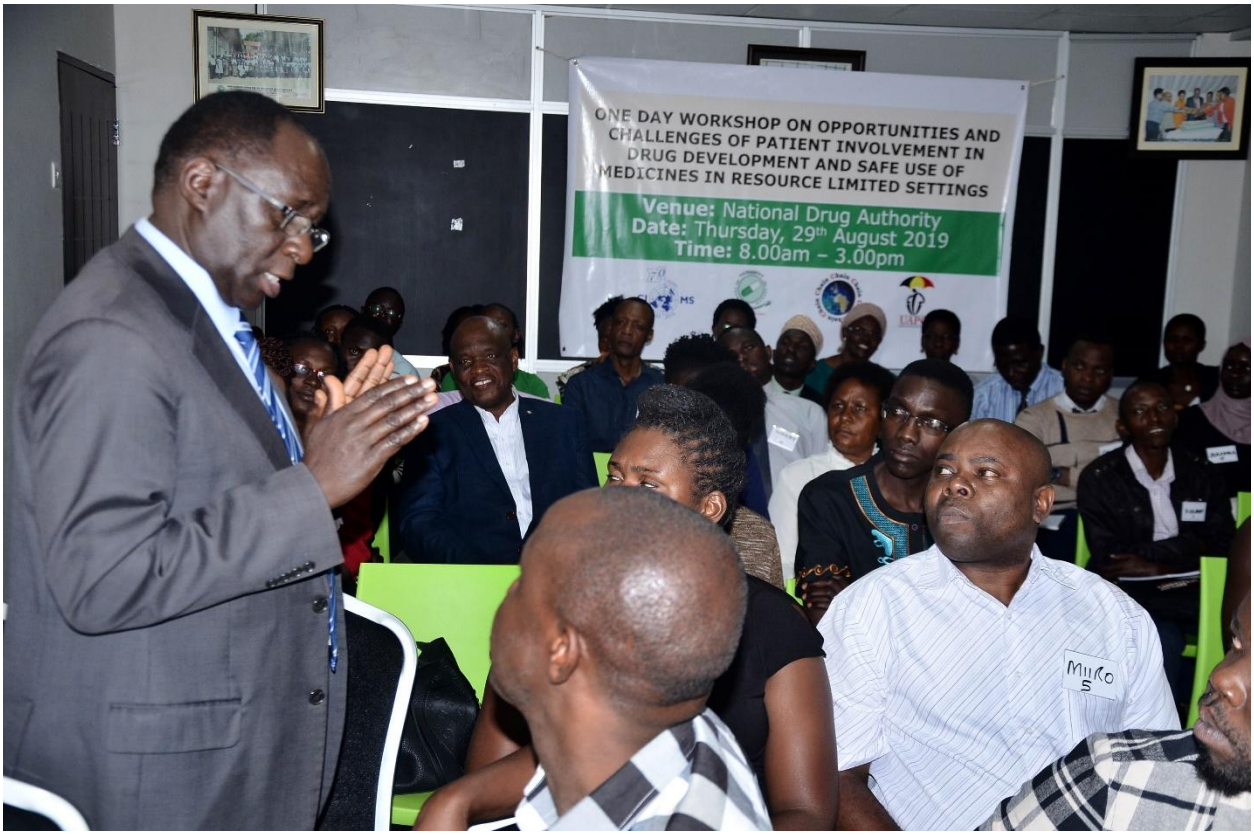
research, for example even when scientists are innovators the potential benefits of a research activity/activities should outweigh the risks involved.

On the issue of Vulnerability, he noted with concern that scientists in RLS are very vulnerable due to prevailing high poverty levels. The temptation to engage or actually engage in unethical practices is high. He further explained that part of the vulnerability is as a result of the existing research 'illiteracy'. Many members of the public are unaware of the rules and regulations in place that relate to research ethics.

He also talked about therapeutic misconception and cited cases of where patients are not informed of the specifics of the research. He urged researchers to ensure that patients receive clear information while signing consent forms that the study is an "EXPERIEMENT", to avoid any misconceptions.

Dr. Nakwagala found it critical to advance the current clinical research process by understanding local communities for example how they talk, what they believe in, their fears and expectations. He concluded by saying that 'The current research processes are inadequate and there is still low level of community involvement but it is evolving'.

Reactions to the presentations:



Prof. Michael Kawooya making comments at the workshop

- There were several remarks and questions after the presentations; participants applauded NDA, CHAIN, UAPO and CIOMS for organizing such an important meeting. They were happy that CIOMS was reaching out to RLS to provide them with an opportunity to raise their issues and contribute to the guideline, African voices are glaring lacking on global platforms for drug development and safety. In most cases guidelines are developed in high-income countries and do not address their unique needs. Many patients were not aware of the drug development process and were glad to acquire knowledge in that area.

Regarding patient involvement, some participants agreed that indeed efforts were being made to bring patients to the center, while others felt that much as patient involvement was widely acknowledged as being critical, in reality meaningful involvement was still minimal. Patient involvement was more significant in the clinical trial phase particularly in HIV. However, they felt that the involvement at this phase is not yet meaningful to address the needs of the patients.

“There are different variations that exist with human beings for example race and genetic variations which can result into variations in drug responses. Because of these variations it is important that with every drug developed there must be strong involvement of the end user (patient),” - Sam Opio, Secretary General, Pharmaceutical Society of Uganda (PSU).

They also noted that despite clear guidelines on informed consent, the practical reality was that patients sometimes do not fully understand the risks and benefits of participating in a clinical trial. Scientists take advantage of their illiteracy and vulnerability. They cited examples of patients enrolling in more than one trial for anticipated incentives.

The issue of transparency, data sharing in clinical trials was of great concern as well as post trial treatment. Both the scientists and patients at the workshop agreed about the need to address those issues. Many participants had never accessed information on clinical trials even for those who participated. They called for deliberate efforts to ensure that information is availed to all stakeholders using appropriate channels. It was pointed out that sponsors also needed to find out what was happening on ground and understand the practical realities rather than just funding the research.

On the issue of drug monitoring, patients felt that the NDA has not fully taken advantage of patient input and feedback regarding the safe use of medicines and as such there are a lot of unreported adverse drug events at community level.

Patients also decried the uncontrolled advertisement of herbal medicines by herbalists on radios, televisions and new papers, which has led to many people using these invalidated herbal concoctions. They also noted with concern the practice of buying prescription medicines from pharmacies without a prescription, hawkers selling medicines in buses and markets. A situation that is made worse by the prevalent self-medication practice putting the lives of the patients at a risk. The NDA was requested to urgently address these issues.

2.2. Group Discussions

Participants were organized into four groups to discuss the questions below;

- How are patients involved in the development of drugs and safe use of medicine?
- What are the roles of key stakeholders?
- What are the priority areas in which patients can be involved in the development of drugs and safe use of medicine?
- What are some of the critical challenges that are faced in having patients fully involved in the drug development process and the safe use of medicines?
- What opportunities exist to have meaningful involvement of patients?

Feedback from Group work

Group 1: How are patients involved in the development of drugs and safe use of medicine?

The group noted that it is important that patients are involved in most of the phases of drug development. They pointed out that patients are mainly involved at the clinical trial stage and post market safety surveillance. Success has been registered in the HIV and Aids response and

the need to learn from those experiences was emphasized. Uganda was among the first countries to be open about the disease with the president leading the campaign in 1986. The Ministry of Health efforts were focused on public education, electronic and print media, Information Education Communication materials, Music, Dance & Drama among others. It was also the first country through the Joint Clinical Research Centre (JCRC) to access free treatment from PEPFAR.

The formation of patient groups/expert clients took center stage. The Community Drug Distribution Point (CDDP) by The AIDS Support Organisations (TASO), the first HIV organization in Uganda is a classic example of patient involvement in medication safety. Patients are involved right from prepacking of medicines to monitoring its use.

Examples

Greater Involvement of people living with HIV/AIDS (GIPA)

The Greater Involvement of People Living with HIV Program is a rights-based approach formalized at the 1994 Paris AIDS summit. At IDI in Uganda, it's a program which calls for the active and meaningful participation of people living with HIV in order to acknowledge their universal rights to self-determination and participation in decisions that affect their lives.

Additionally, the Friends council under the (GIPA) programme at IDI is a patient led volunteer council engaged in supporting day to day patient related activities in the clinic like representing and maintaining communication mechanisms for information from clinic administration to patients and generating feedback and ideas from patients and conducting health talks on various topics such as medication safety, patients' rights and responsibilities in research.

There are some efforts by the NDA and other health care providers, Patient organisations to involve patients in post marketing and surveillance however, due to weak pharmacovigilance systems, human and financial resource constraints a lot of gaps still exist.

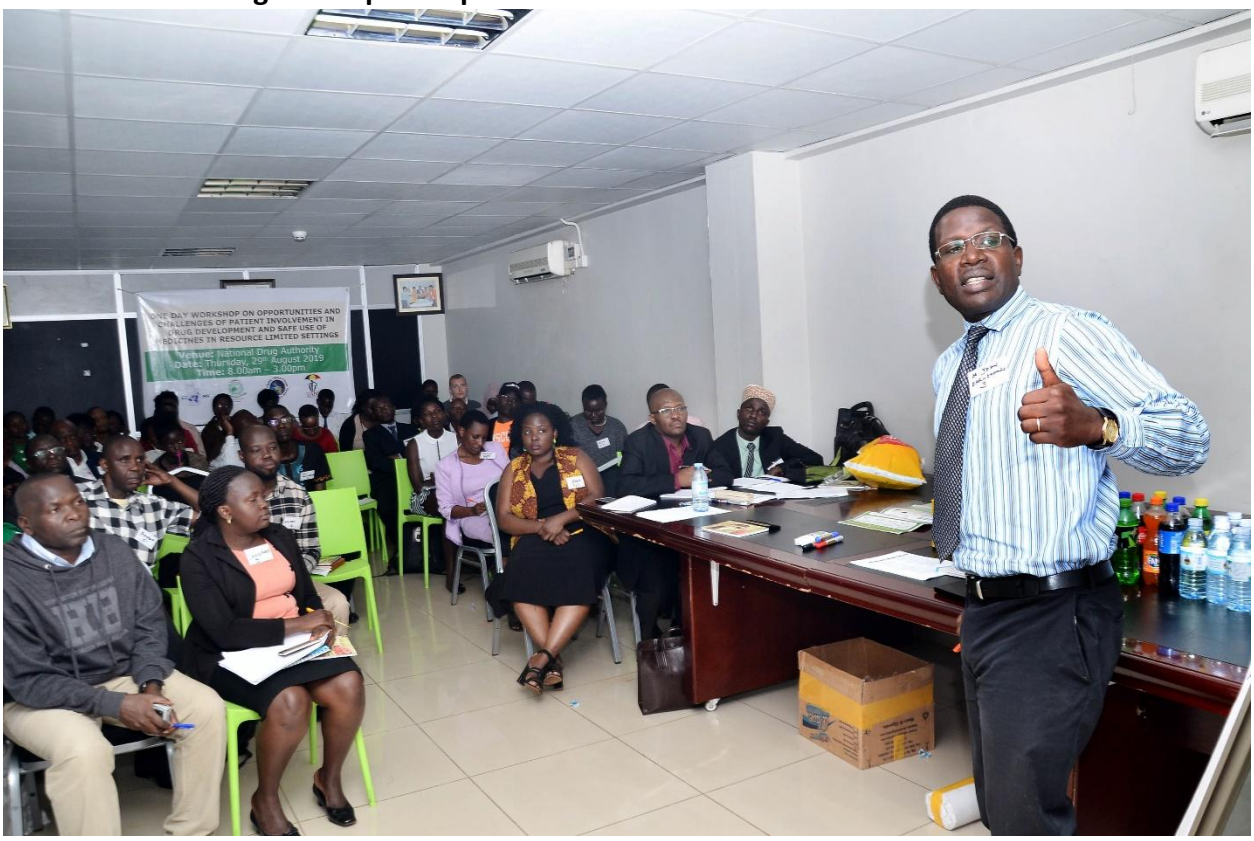
Group 2: What are the priority areas in which patients can be involved in the development of drugs and safe use of medicine?

- It was unanimously agreed that patients should be involved in the whole process of drug development and safe use of medicines. However, priority areas were also identified and these included:
  - Developing patient information and communication strategies
  - Protocol development
  - Developing ethical standards in research
  - Informed consent process

- Treatment decisions
- Develop approaches that allow the community to participate at all levels of drug development is critical
- Ethical standards should be followed at all levels
- Toll free lines should be set up for the public to easily access and also be effectively attended to
- Involvement in Policy and decision making processes to ensure their needs are catered for.
- Patient empowerment and education on safe us of medicines.

3. Challenges

Group 3: What are some of the critical challenges that are faced while having patients fully involved in the drug development process and safe use of medicines?



- Lack of a strong patient voice; there are very few patient /consumer organisations with adequate knowledge and skills to engage effectively and also empower the communities they work in.

- There are insufficient platforms for patient engagement in drug development and safe use of medicines. Many are unware about drug development processes. Awareness and education on drugs usage in communities for example communities can be educated on drug challenges and benefits while relating to the drug development process.
- The patient contributions to the health system is limited knowledge on the health rights and information
- Paternalism in RLS limits patients' effective participation in drug development processes and safe use of medicines. Examples were cited where patients concern, needs and preferences have been subdued. On the other hand the patients themselves consider themselves 'unfit', to engage with the healthcare professional who they consider a 'small god'. Many times they do not ask questions about their medication or even report side effects.

Unethical clinical trials

- Due to patients' vulnerability in resource limited settings, many become victims to unethical clinical trials.

- Unfair collaborations: scientist/researchers in RLS are used as a means to accomplish collaborators or sponsor's aims and data collected may not be easily accessed by the local partners once research is completed.
- Non adherence to informed consent process; Patients enrolled into clinical trials without consent, due to their vulnerability.

Paternalism: Patient's views are not listened to during clinical trials, patients confessed to being mishandled during clinical trials and looked at as mere subjects with just a body and no mind. This is also common during patient and health worker interactions.

Misconceptions

Due to poor media reporting, social cultural influences, low health literacy and illiteracy many people in Uganda have negative perceptions about drugs which impact their involvement in any related initiatives. For example, communities in Uganda are hesitant to take their children for HPV vaccination with an assumption that these drugs are aimed at harming them.

Resource constraints

- Patients pay for healthcare out of pocket and due to high poverty levels they cannot afford seeking healthcare from a qualified health worker. Hence resort to self-medication which includes buying half doses.
- Inadequate financial and human resource capacity to monitor drug safety

Low health literacy

- There are low health literacy levels among patients which has led to unsafe practices like self-medication and unsafe use of medicines. They are also unable to understand, process and act on information provided to enable them make informed decisions. The use of medical jargon by health workers is discouraged.
- Poor reading culture for the literate also exposes them to unsafe use of medicines.

"Patients are at the tail of supply chain, and as such they need information from the health care provider. Most patients in resource-limited settings are illiterate which means that the information given to them needs to be simplified in layman language to address the patients' needs. Unfortunately, due to heavy workload, health workers are too busy to update on the information they have or even end up giving the patient wrong medication or dose". Ms. Victoria Nambasa, Manager Pharmacovigilance

Unregulated counterfeit and herbal medicines

- There are weak regulatory systems leading to pilferage and increase in substandard and fake medicines.
- Unqualified service providers are protected by the community, in the name of societal values, which leads to unsafe use of medicines
- The patients are concurrently using herbal and manufactured medicine, without prescription, which poses health risks
- There is barely no regulation on herbal medicines and yet illegal players extensively market the medicines and sell them cheaply. The communities find them favorable to buy however these have adverse health effects on their health.

Health system challenges

- Paternalistic relationship between the patients and health care providers limits patients' participation in receiving care. Patients on the other hand resort to traditional practitioners who treat them with respect and care.
- Research vulnerability for local researchers which limits influence

- There are high stock outs resulting from alleged mismanagement of medicines and as a result, patients seek alternative care which compromises their safety.
- The education system for health workers is more theoretical than practical and as such some health workers lack the practical skills and experience to offer quality care.
  There are also many mushrooming unmonitored medical training institutions offering poor training to medical students.
- The mechanisms for patient involvement in health facilities are not functional.
- Risk management in RLS has impacted financial and human resource constraints making it difficult to operationalize policies.
- Unfavorable Doctor-patient ratio at 1: 10,000 as opposed to 1:1000 recommended by WHO.

Self-Medication

- It is not easy to report adverse events since patients are not assessed by a qualified health worker.

4. Opportunities

Group 4: What opportunities exist to have the meaningful involvement of patients?

- Embrace the use of IT since it is the global trend now to enable patient's access their information. There is need to create online platforms through which various stakeholders can interact on issues of safe use of medicines and patient involvement.
- Utilise and make use of existing frameworks, guidelines in various ministries and statutory bodies for patient feedback, for example the whistle blowers ACT, chapter 12 of the Uganda National Council of Science and technology guidelines which provide for community engagement in research and existing hotlines for reporting drug side effects. These need to be popularized to enable patients to make use of them. Uganda is well known for developing good policies and the only challenge is implementation.
- Mutual collaboration for research between local and international institutions.
- The existence of strong social support systems is a strong opportunity for patient involvement.
- The existing patient organisations need to strengthen their collaboration to have a stronger patient's voice. These patient organisations already participate on different technical working groups and engage patients and policy makers, therefore they can form a good platform for patient involvement.

- There is need to make use of the existing Community Advisory Boards to strengthen community engagement in research.

5. Recommendations

Government

- Government to implement policies that protect patients from unethical practices.
- There is need to empower community health workers with information on safe medicines so that they can reach out to their communities. This should be a government program where health workers from higher facilities and regulators conduct regular visits to discuss drug safety in communities.
- Government should have stringent laws to regulate advertising of medicines including the herbals.
- Government and other key stakeholders should support patient/consumer to strengthen their voice and effectively engage.
- Create more opportunities for patient involvement in decision making processes.
- The legal framework in RLS is needed to access medicines in a timely manner but must also protect the patients from harm in the process of improving science for the societal benefit.
- The Patients' and Medicines Charters should be considered key documents in the process of involving patients and availing them with information on safe use of medicines.
- Sensitization on drug development and safe use of medicines in schools.

Patient engagements and empowerment

- Organize regional workshops to collect the patient's experiences in development and safe use of medicines.
- Empower and build capacity for patients in health literacy. Patients are not empowered to report or give feedback to the health care providers.
- Strengthen and make CABS more functional to fully represent patient views. They should also be evaluated and monitored to maintain their relevance and ensure they truly represent patient views.

Regulators

- Regulatory authorities like the NDA to invest in creating awareness by developing patient friendly toolkits, media activities with the aim of educating/sensitizing members of the public/patients on drug development and the safe use of medicine.
- Empower patients in pharmacovigilance to actively participate in monitoring of drugs
- User-friendly feedback platforms such as “sms” to disseminate the right information on the safe use of drugs to the community and for the community to report adverse events.
- Strengthen laws on use of herbal medicines because most of the herbals are mixed with conventional medicines. The herbal medicines for HIV are mixed with ARVs. Such concoctions harm patients by causing drug resistance to ARVs and antibiotics.
- Patients also need to be empowered to be able to be involved in pharmacovigilance.
- Research regulatory bodies must ensure that researchers indicate all risks involved in the study in their protocols and follow up to ensure that patients receive clear communication about the potential risks. A definite step has to be taken by the regulators to ensure that the issues of consent are clearly understood by the patients.
- NDA should establish a peer review advisory committee with patient representatives as members.
- Ensure protocol community engagement plans are adhered to.
- There is need to build the capacity of research institutions in terms of infrastructure and mandate.
- Use of big data: The search for regulatory pathways to shorter timelines in the introduction of new drugs has recently led to the use of “big data” to leverage existing information into knowledge for drug discovery and development. Emerging trends in the use of big data include pharmaceutical and other healthcare companies applying its analysis to aggregate information from previous clinical trials to identify potential problems or adverse events. Big data may also allow real time analysis of clinical data to incorporate insight from the behavior of similar drugs under development, something of potential interest not only to pharmaceutical companies but also to regulatory authorities.

Multi-stakeholder engagement

- There is need to involve social scientists and community health workers in medication safety. They are the first point of contact in the community and interact with the patient on a regular basis. They can therefore contribute to improved reporting of side effects.
- There is a need for stakeholders in different fields to be oriented on issues of patient safety and involvement.
- There is a need to conduct audit peer reviews where different stakeholders are engaged to discuss patient involvement and the safe use of medicines. Patient Organizations

need to come out strongly about the activities of research bodies as checks and balances.

- There is need for patient care organizations to partner with facilities to help them improve clinical care and research practices. Patient representatives need to get directly involved in surveillance and supervision.
- Build capacity of African scientist to engage in the drug development processes

CIOMS

- CIOMS should encourage the development of a strategy for patient involvement which countries can adopt and tailor to their specific contexts. The strategy can have clear goals and the relevant stakeholders to be involved. Such strategies and platforms should be user friendly by the clients. For example, an online platform where patients can give feedback on their experiences during drug development and safe use of medicine.

6. Conclusion

The 60 participants shared knowledge on the challenges and opportunities for patient involvement in the development and safe use of medicines in RLS and made recommendations. This opportunity opened a platform of stakeholders with a high potential to contribute to the development of the chapter on the challenges and opportunities for patient involvement in the development and safe use of medicines in RLS. Further, the workshop created a network of stakeholders who will advocate for both local and policy level patient engagements.

7. Appendices

Appendix 1: Organizing Committee and Resource persons

Name	**Organization and Role**
Ms. Helen Byomire Ndagire	Director of product safety – NDA
Mr. Brian Sekayombya	Principal regulatory officer for medicines – NDA
Vicky Nambasa	Pharmacovigilance Manager -NDA
Ian Mugisa	NDA
David Walusimbi	NDA
Ms. Regina Mariam Namata Kamoga	CHAIN
Jean Wabulyu	UAPO
Dr. Fredrick Nakwagala	Senior Consultant Physician and chairperson Bio ethics working group, Mulago Hospital
Dr. John Barugahare	Department of Philosophy

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Robert Ssekubugu	Head of Department Epidemiology – RHSP, Member Research and Ethics Committee, Uganda Virus Research Institute
Milly Katana	Director Senior Support Services Public Health Specialist
Gladys Nalukenge	Programme Manager- CHAIN
Dr. Kanyesigye Edward	Dean, School of Medicine, Uganda Christian University
Godfrey Mafabi Ceaser	Center Manager, TASO
Betty Nabirye	Manager Psycho-social And Community Systems Strengthening-TASO
Mr. Andrew Mijumbi	Ojok Andrew Mijumbi / ethics administrator at TASO mijumbia@tasouganda.org
Sam Opio	Secretary General Pharmaceautical Society of Uganda and Chief Pharmacist CIPLA

Appendix 2: Attendance List

No.	Names	Organization	Designation, Email & Contact
1.	Dr. Paul Patrick Mirondo	The Medical Concierge	Paul.mirondo@tcmg.co.ug 0706173187
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5.	Najjingo Solome	Uganda Catholic Medical Bureau	snajjingo@ucmb.co.ug 0784980311

6.	Gerald Ssebulime	Medical Access Uganda Limited (MAUL)	Gerald.sebulime@medicalaccess.co.ug 07526274494
	Sheba Ninsiima		Support services coordinator Sheba.nakimera@medicalaccess.co.ug 0759207232
8.	Julius Lebo S	POMU	Julius.julepa@gmail.com 0784095426
9.	Dr. Nakwagala Fredrick	Mulago Hospital	Clinical Head of the Directorate of Medicine at Mulago Hospital Faculty in the Department of Medicine of the College of Health Sciences at Makerere University. Teaches undergraduates and post graduates including supervision of research for post graduate theses. Clinical Head of the Directorate of Medicine. Supervisor of all clinical units and reports to the Executive Director of Mulago Hospital. nakwagala@yahoo.com 0772325869 0704325869
10.	Ajalo Ruth	Center for Health, Human Rights and Development (CEHURD)	Legal officer ajalo@cehurd.org 0775166862
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12	Dr. Michael Kawooya	Ernest Cook Ultrasound Research & Education Institute (ECUREI)	Physician, academic researcher and academic administrator. Director at ECUREI. Professor of Radiology at Makerere University College of Health Sciences. kawooyagm@yahoo.co.uk 0772505189
13	Julius Steen	CHAIN Volunteer	Juliussteen1995@gmail.com
14	Muyinda	EDCO	Pharmacist

	Nathan		nathanmuyinda@yahoo.com 0701080340
15	Hellen Ndagijje	National Drug Authority (NDA)	Pharmaco-epidemiologist Director Pharmacovigilance at NDA hndagije@gmail.com 0772469094
16.	Regina Kamoga	Community Health And Information Network (CHAIN)	Executive Director regina@chainproject.co.ug 0787499087
17.	Dr. Katagira Wincey	Makerere Lung Institute(MLI)	Internal Medicine Physician Research Fellow at the MLI wincegira@gmail.com 0782869980
18	Ivan Segawa		Pharmacist Skilled in Clinical Trial Research
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23	Ruth Nankanja Mukiibi	Sicklecell Association of Uganda (SAU)	Advocates for people living with sicklecell Executive Director SAU hello@sicklecelluganda.org 0702637144
24	Gladys Nalukenge	Community Health And Information Network (CHAIN)	Program Manager – CHAIN gladys.nalukenge@gmail.com 0782304880
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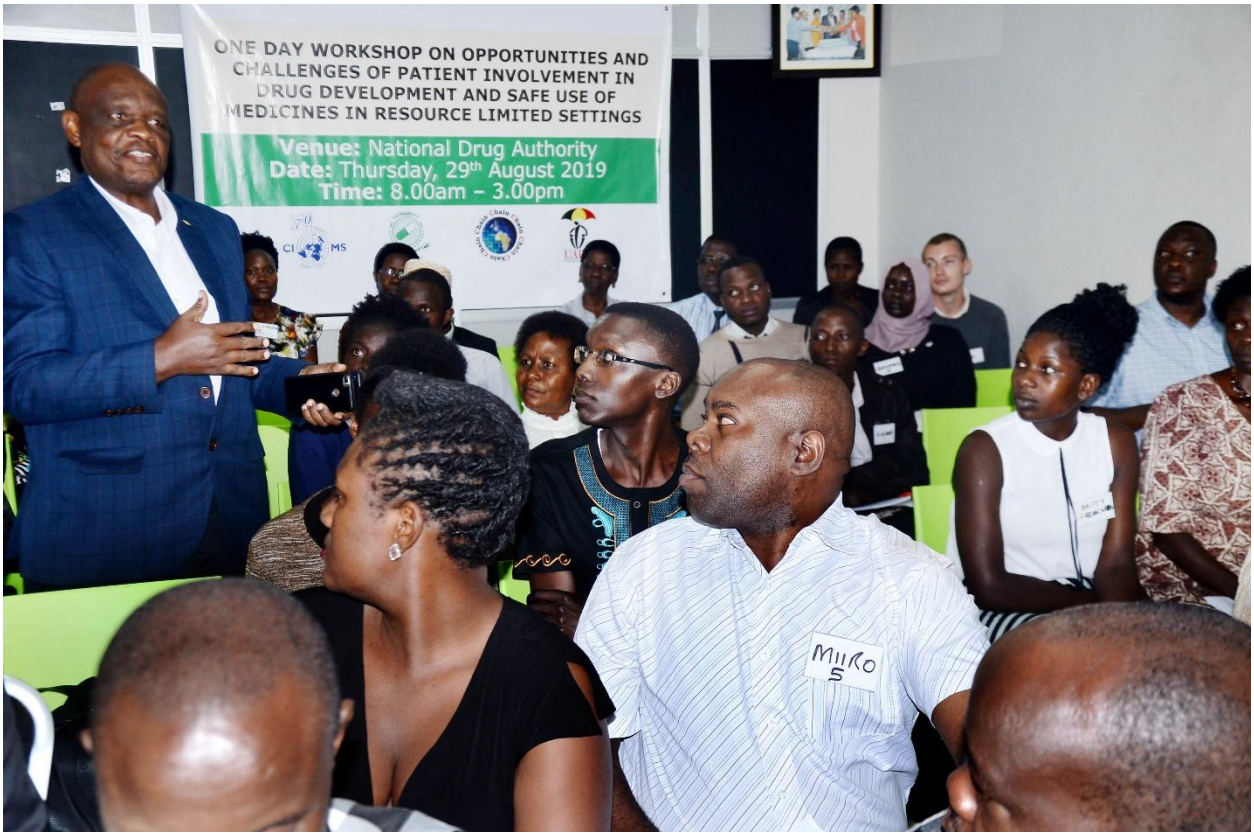
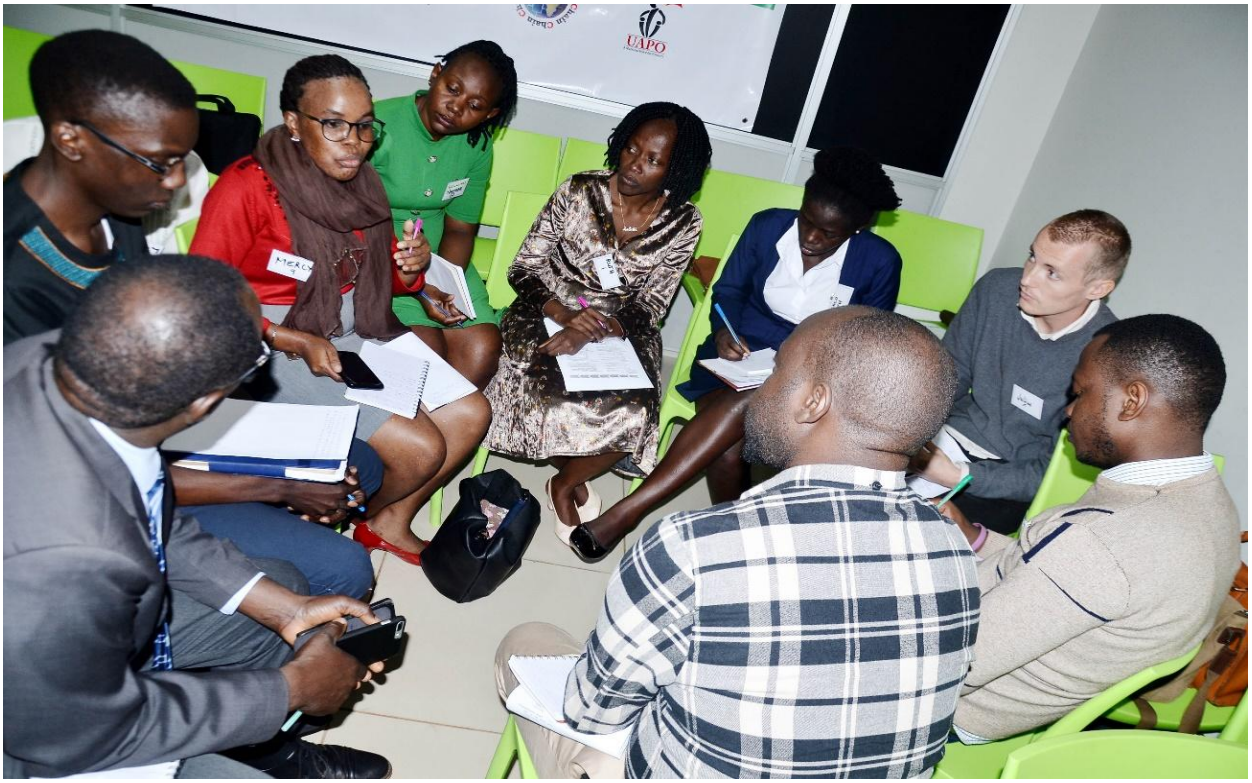
57	Dr Eva Laker	Infectious Diseases Institute (IDI)	Pharmacist elaker@idi.co.ug
58	Ssebunya Wycliff	Radio One	Journalist 0782579917
59	Dr Edward Kanyesigye	Uganda Christian University School of Medicine (UCU)	Dan school of medicine UCU ekanyesigye@ucu.ac.ug 0772770839
60	Ndhale Moses	KFM Radio	0772882126

Appendix 3: Pictorial




Venue: Nationa
Date: Thursday,
Time: 8.00a
70 YEARS
CIOMS
1949 - 2019


UAPO


ONE DAY WORKSHOP ON OPPORTUNITIES AND CHALLENGES OF PATIENT INVOLVEMENT IN DRUG DEVELOPMENT AND SAFE USE OF MEDICINES IN RESOURCE LIMITED SETTINGS
Venue: National Drug Authority
Date: Thursday, 29th August 2019
Time: 8.00am – 3.00pm