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MEETING REPORT

Acknowledgements

World Health Organization

THE REPUBLIC OF UGANDA
MINISTRY OF HEALTH

This report summarizes the proceedings, presentations and discussions related to, or those that took place during the Patients for Patient Safety (PFPS) Uganda workshop. The workshop was jointly hosted by the Community Health and Information Network (CHAIN), Uganda Ministry of Health, World Health Organization (WHO) Uganda Office, and WHO Service Delivery and Safety (SDS) department.

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Abbreviations

ADR	Adverse Drug Reaction
APPS	African Partnerships for Patient Safety
CHAIN	Community Health and Information Network
HBV	Hepatitis B
HIV	Human Immunodeficiency Virus
IAEA	International Atomic Energy Agency
IDI	Infectious diseases institute
IPC	Infection prevention control
MakSPH	Makerere University School of Public Health
MAUL	Medical Access Uganda Limited
MoH	Ministry of Health
NDA	National Drug Authority
PCIHS	People-Centred and Integrated Health Services
PFE	Patient and Family Engagement
PFPS	Patients for Patient Safety
PSQ	Patient Safety and Quality Improvement
PASIMPIA	Patient Safety Improvement in Africa
SDS	Service Delivery and Safety
WHO	World Health Organization
UAPO	Uganda Alliance of Patients Organizations
UHC	Universal Health Coverage

Day 1: 3 November 2015

1.0 Introduction

WHO PFPS

The PFPS team provided technical support for the first Ugandan Patients for Patient Safety (PFPS) workshop on 3 – 5 November. Hosted by the Community Health and Information Network (CHAIN), the workshop focused on awareness raising and capacity strengthening for patient and people engagement and empowerment for patient safety and people-centred quality Universal Health Coverage (UHC). The three-day event brought together approximately 60 participants including WHO Country office, Uganda Ministry of Health, health professionals (including hospital managers, radiologists, surgeons, nurses), patients and family members. Most participants were from Uganda, with the exception of key speakers from Geneva. The programme and the list of participants are included in Appendices 1, 2 and 3.

Regina Kamoga

The workshop was opened by Regina Kamoga, representing the Community Health and Information Network, and the WHO global network of Patients for Patient Safety advocates respectively. Regina welcomed the participants and articulated the purpose and process of the workshop and the vision for the goal and expected outputs.

1.1 Rational, purpose and objectives of the workshop

Patient and family engagement is now at the top of agenda of many health-care systems. However, those who are involved in health-care systems and delivery, such as chief executives, managers and frontline staff delivering health services, have little example on how to implement this concept in practical terms. Integrating patients, families, health professionals and policy-makers in a shared discussion will be helpful in promoting a better understanding and the practice of meaningful involvement with patients and families in health care.

The purpose of the PFPS workshop is to strengthen individuals to become PFPS advocates, in efforts to build regional and national networks of patient advocates across the world.

The Uganda PFPS workshop aims included:

- Raising awareness about patient safety and the importance of patient and community involvement in health-care services and improvement initiatives;
- Training and orienting individuals in advocacy skills for patient safety and to promote positive engagement and partnerships between patients, health-care professionals, policymakers and health-care leaders;
- Capacity strengthening participants to have more knowledge on local health-care systems, patient or consumer networks and/or local resources relevant to health-care quality and patient safety initiatives.

PFPS workshop objectives were:

- Providing a forum for discussion and a means to turn feelings of frustration and anger to positive action;
- Introducing individuals to the concept of collective action and collaboration to achieve health-care improvements;
- Facilitating a sharing of ideas, experiences and network locally, nationally and globally.

1.2 Official opening

Henry Mwebesa

Mr Mwebesa, on behalf of the Ugandan Ministry of Health, extended a warm welcome to all the participants. He reported on Uganda's progress in the area of patient safety, and explained how re-orienting health systems for improved quality and safety is a key aim of Uganda's five-year strategy towards sustainability in the health system. He identified key objectives of this strategy which included:

- Increased access to direct care through improved infrastructure;
- Increased availability of essential medicines;
- Reduced patient to health professional ratios:
- Improved professional training;
- Increased meaningful engagement of patients and families in health systems and services.

Mr Mwebesa stated the Ministry of Health's commitment to bringing the voices of patients, families and communities into health systems and services, recognizing these stakeholders are the only constants in the increasingly complex health-care system. He stated that, to improve health-care quality, the system should provide mechanisms to enable patients and family members to express their feedback, perspectives and experiences. Mr Mwebesa explained how patients and families are repository of critical information, which they can share when engaged and empowered. The Ugandan strategy for increased quality and safety will aim for close collaboration with patient organizations, to address gaps in current systems, and to ensure their voices are heard.

Mr Mwebesa explained the importance of patients and families in the self-management of their care. This leading role was expressed as essential in reducing the burden on already under-resourced national health systems. The importance of informed and health literate patients, in an open and transparent dialogue with their health professionals was seen as key.

The speech also emphasized the role of patients and families in health policy. By sharing their personal experiences, health-professionals and policy-makers can orient policy to be more patient-centred with higher quality aimed at their personal needs. Thus, it was emphasized how patient engagement should be embedded in health-care policy design, and implementation.

The minister congratulated the stakeholders involved in organising the meeting, including WHO PFPS team, WHO country office, CHAIN, and the Uganda Alliance of Patient Organizations (UAPO).

1.3 Setting the context

1.3.1 Key note address: Vision for patient and family engagement in health care in Uganda

Professor Freddie Ssengooba

Professor Freddie Ssengooba gave a keynote address to the participants, providing impetus of a common vision for patient and family engagement in efforts towards improving safety, quality and equity in access to Ugandan health care. Issues discussed included patient safety and quality as a health systems outcome, the role of patients and people in progress towards quality universal health coverage in Uganda, and the importance of integrated health-care services to forge for change. Service delivery and safety (SDS) was addressed as a core building block towards improved health systems performance, alongside health governance, health financing, the health workforce, health literacy, medical products, community health and health infrastructure.

Professor Ssengooba outlined integral factors that will contribute to improved health outcomes in the Ugandan health systems services and processes. These included patient and provider communication, sufficient supplies and an enabling environment, which facilitates governance with leadership, safe protocols, accountable and transparent financing, patient-centered values and information distribution. The professor also highlighted factors at the national policy level of health care that impact health systems performance, equity, access, quality, efficiency and sustainability. These included stewardship, financing, human resources management, pharmaceutical management, and provision of information systems.

The address emphasized the need for an approach that will assess and evaluate health systems effectiveness comprehensively, with a standardized set of indicators. Consistent evaluations will help to prioritize service and systems strengthening interventions, by assessing strengths and weaknesses of key areas. Tools aimed at health systems strengthening should ensure integration and collaboration between and across health services and recommendations with a consistent set of indicators.

Key challenges that need to be addressed to overcome heavy burdens on the already under-resourced health systems and services include:

- High fertility rates (figure 1). The high rate of population growth in Uganda is not matched with the growth in the economy and service provision;
- Inequalities in access to services (figure 2), high diversity in health needs, an endemic double burden of disease and high patient to workforce ratios in fragmented services increasing pressures and demands on services to perform better;
- Government priorities being focused on infrastructure, energy, science and technology and agriculture resulting in cuts to the health sector, causing services to rely on fluctuating and segregated external aid and support;
- Negative media reports of frontline health professionals despite their powerlessness to cause change without upstream support systems.

Figure 1: Population pyramid and fertility graph representing Uganda's young population

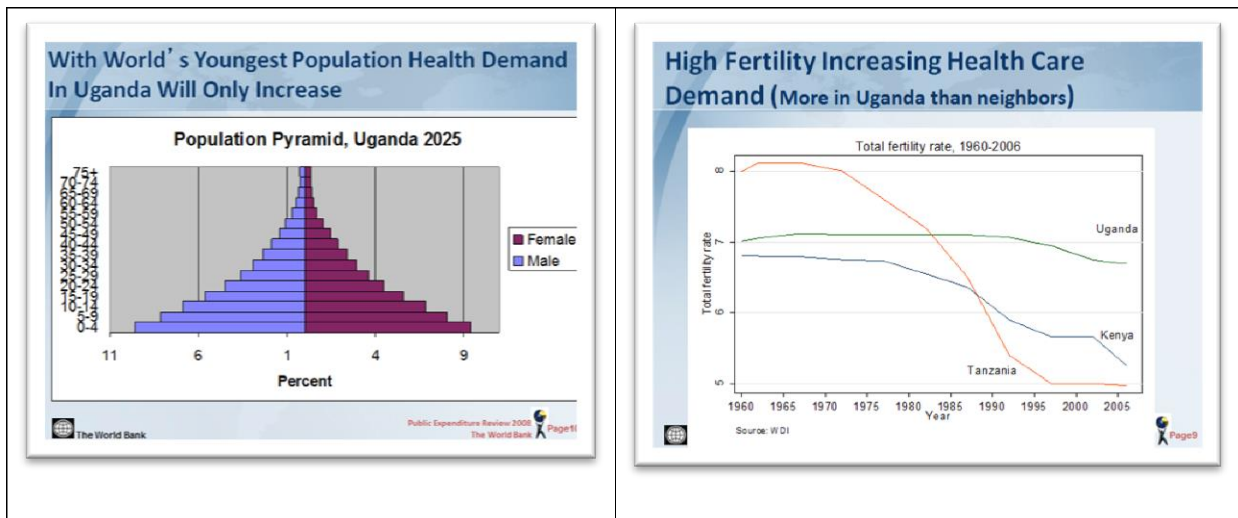


Figure 2: Dual systems and inequalities in quality of health care across Uganda

Professor Ssengooba outlined the importance of Universal health coverage (UHC) in providing all people with access to the necessary health services with quality, without imposing substantial financial hardship. He highlighted four dimensions of UHC and five lessons from successful nations on UHC (table 1 and 2):

Table 1: Four dimensions to UHC and their implications

	Dimension of UHC	Implications
1.	Decrease financial hardship for care;	• Government financing • Private/social health insurance • Reduce direct user-charges
2.	Increase the services of good quality provided	• Service package and standards • Priority prevention interventions • Epidemic response and preparedness
3.	Expand the population groups benefiting from the services	• Cover all population groups • Start with most in need

4.	Build resilient systems to sustain coverage	• Health workforce • Medicines and effective regulation • Invest in affordable provision systems • Sustain demand for vital programmes

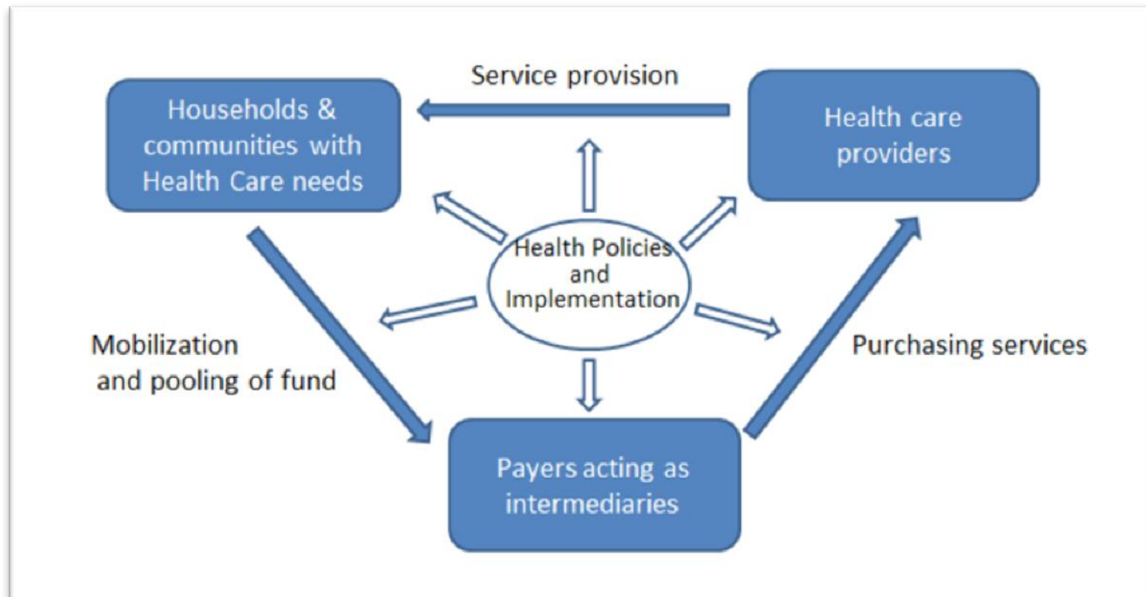
Table 2: Lessons from successful nations on UHC

	Core action	Lessons learnt
1.	Population and service demand management	• Effective and sustainable contraception programmes
2.	Laying a strong foundation - health systems development	• Think system-wide not project-focused • Think rights, obligations and interdependence
3.	Political economy of health and welfare;	• Financing of entitlements and social health insurance • Build coalitions to advocate for better health
4.	Disease prevention innovation	• Improve sanitation, nutrition, lifestyles • Prevent malaria, HIV and epidemics
5.	Governance strengthening	• Distributed governance across sectors o Facility and community levels o Private and civil sector partnerships o Development partnership

Core aims of quality UHC need to be integrated into health policy for service functions to strengthen (figure 3). For instance, improving equity in access and service use, improving health care quality and providing financial protection, through strengthening health systems. Mechanisms for strengthening systems included investing in services through pooling funds and human resources, reducing fragmentation in health services through a coordinated multi-sectorial approach and building the role of the patient, family and community into health policy.

The professor closed his address through outlining the 'SPEED' initiative in Uganda. This initiative is aimed at progressing towards quality UHC and resilient health systems, with a vision to have state and non-state agencies that understand what UHC entails and what roles they individually and collaboratively have to play in its realization. Furthermore, to capacity strengthen the Makerere University School of Public Health towards training for policy analysis, advice and influence for UHC and resilient health systems in Uganda. Engagement and empowerment of key health stakeholders including policy-makers is a core objective of the initiative, in order to assess and evaluate contextually relevant and bottom-up evidence for improved health policy. The roles of patients and families are vital to support policymakers to monitor the implementation of these programmes and to enhance the expertise, knowledge and resources for policy analysis, advice and influence at MakSPH and partner institutions.

Figure 3: Health policies and functions to strengthen in Uganda



For more information on the SPEED initiative please visit: www.speed.musph.ac.ug/

To see the presentation slides, please visit,
https://www.dropbox.com/s/fwubxlt7ugj7xms/MoH%20presentation%20on%20Patient%20Safety.ppt?dl=0

1.3.2 The health system in Uganda: How it supports patient safety and quality improvement

Dr Martin Ssenendyona

Dr Ssenendyona, a lead in the quality assurance department of the Ministry of Health, gave an overview of current and developing Ugandan health policy that promotes a safer and better quality health service. He identified policy interventions to improve patient and public engagement through education, capacity development, and monitoring and feedback mechanisms. He emphasized competing priorities and resource allocation as key challenges to achieving these goals at the policy level.

The Ugandan Ministry of Health mandates quality assurance and supports supervision of progress re-orienting services to being safe and higher quality. The mandates currently include:

1. Infection control guidelines disseminated in all facilities;
2. Capacity development for health professionals at all levels;
3. Health sector quality improvement committees and safety policy that targets regional and district facilities;
4. Patient responsiveness – disseminated feedback mechanisms in the local language;
5. Patient charter 2012 disseminated to all health facilities and accessible on the Ministry of Health website in three languages.
6. National injection safety programme;
7. National preparedness and response.

Dr Ssenendyona highlighted some examples of planned interventions for the future, including:

1. Health service development policy including patient safety policy and guidelines - This will be designed with the involvement of international organizations such as WHO. It will prioritize capacity development.
2. Patient responsiveness - Awareness and engagement of patients and families in health systems and services will be increased and monitored.
3. Existing guideline usage to be improved with monitored and assessed implementation. This will include clinical services, pharmacies and usage of essential drugs.

1.4 The Global Context: WHO Patients for Patient Safety Global Network

Nittita Prasopa-Plazier

Nittita Prasopa-Plaizier, technical lead of the Patients for Patient Safety (PFPS) programme at WHO headquarters, Geneva, provided an overview on engagement and empowerment for safe, quality and people-centred universal health coverage. This was a good opportunity to raise awareness of and share international experiences about integrating patient and health professional engagement and empowerment into the national patient safety health-care quality policy agenda. In Uganda, patient and people engagement remains low in many areas, and patients and policy-makers sharing and learning in partnership was a step forward.

The presentation described the Patients for Patient Safety (PFPS) programme. Patient engagement was considered the hot topic in global health. People wanted to have this as a component in their health-care systems and processes. The issue was how to ensure that it is meaningful and not just ticking boxes.

Key points from the presentation:

- WHO PFPS programme: It was created in 2005 as a core pillar of the then World Alliance for Patient Safety. It began with a workshop in London in 2005 where 22 individuals from 20 countries gathered to share experiences and exchange ideas. Their collective passion led to the drafting of the 'London Declaration', the vision of safe health care that incorporates patients' and families' perspectives through positive engagement and empowerment. Ever since, participation in a PFPS workshop and a commitment to uphold the London Declaration have become the centrepiece of and a core principle for becoming a PFPS advocate (referred to as a 'PFPS champion'). To date, the PFPS global network has nearly 400 champions across 54 countries worldwide;

- Ten years since the PFPS programme's inception, the programme has broadened and its mission has widened to include engagement for people-centredness and universal access and quality care. Engaging and empowering people is one of the five strategies of the WHO framework for People-Centred and Integrated Health Services (PCIHS) and a key element of quality UHC. Engagement is not only crucial for patients in institutional care, but also for members of the communities who wish to participate in health care initiatives and programmes from promotion to palliation. The programme no longer engages solely with patients, but with health professionals, academics, civil societies and policy-makers, recognizing the importance of engagement will all key stakeholders for patients and families to be meaningfully heard and respected;

- The WHO strategy on people-centred and integrated health services aims to:

- Empower and engage people;
- Place importance on primary and preventative health care, and promote a healthy lifestyle;
- Co-ordinate all health services;
- Put in place governance and accountability for services and health professionals;

- The patient is the 'final frontier'. Patients and family members are required to seek medical help and to undergo necessary treatments, and their feedback can improve clinical and cost effectiveness of services. A patient being provided concise and accurate information should be a minimum expectation of care, not an optional 'luxury';

- Health professionals and policy makers need to be engaged, in order to feel appreciated and encouraged. The role of positive feedback on health services was expressed as key;

- Responsibility and accountability should be included in health-care delivery structure;

- Meaningful engagement – patient and family tokenism is a challenge. Patients may be included in many initiatives, but the roles and levels of engagement vary. Monitoring and evaluation of patient and family engagement needs progressing, to ensure the voice of patients is fed back to the workforce at all levels;

- Change requires leaders with vision and commitment.

1.5 WHO Patients for Patient Safety programme - a 10 year journey

Felicity Pocklington

Felicity Pocklington provided an overview of the WHO Patients for Patient Safety (PFPS) programme and a summary of the patient interviews conducted as part of this programme. The interviews captured activities, opportunities and challenges of PFPS champions and sought to understand what they perceived as meaningful engagement.

Main points from the presentation:

- PFPS interviews: WHO PFPS conducted semi-structured interviews with 60 PFPS champions to explore their perceptions and experiences of engagement and empowerment. The concepts and practices of engagement vary according to local contexts. Differences in cultural concepts between some countries made the term 'partnership' problematic. It is unclear to some patients what is meant by accountability. Providers have similar reservations, indicating close relationship created through partnership may make it difficult to provide objective advice or services for fear of offending patients. Cultural contexts need to be taken into account when engaging people in health care;

- Meaningful engagement: The interviews explored the perception of meaningful engagement. They indicated that tokenism engagement still exists. Patients may be included in many initiatives, but the roles and levels of engagement varied. For them, meaningful engagement means they participate fully; that they can have opinions, be listened to and responded to, etc;

- Engagement experience: PFPS champions have engaged or have been engaged in different levels of health systems - in individual care (own care or family), in policy, in organizational governance (services and processes), in community empowerment and education

(grassroots level), in research and in peer support. One of the most common forms of engagement was presentations/speaking at conferences or meetings. They perceived themselves as quite knowledgeable and could be a resource to help connect with patients and with the community as a catalyst for change;

- Many PFPS champions worked as volunteers in their local hospitals. They provided insights into how the hospital handles complaints, reviewed internal processes and contributed to accreditation while also providing feedback and advice to health-care providers and patients. They emphasized the important point that not all patients can become a champion (due to knowledge gaps, availability, capacity, resources) and that not all wanted to be involved at the same level of intensity.

Opportunities:

- Engaging 'local heroes': Create sustainability through engaging and empowering local leaders and organizations. WHO can offer technical assistance, but success depends on the capacity and ability of local people taking the lead and owning the initiative;

- Capacity-development: One of the WHO approaches to capacity-building is through awareness-raising and capacity-building workshops for patients, health-care providers and policy-makers. For example, a workshop in Shanghai, China, was conducted to gain the perspectives of health-care providers in order to develop ways to support their efforts to engage with patients and families.

Challenges:

- Open disclosure: lack of a process/mechanism for meaningful and respectful communication following an adverse event;

- Use of medical jargon and complex terms;

- Misinformation and stigma of disease/illness impacting on advocacy activities;

- Lack of engagement with patients who may have a lower educational status;

- Feedback mechanism/reporting system: lack of mechanisms for feedback, complaints or reports, which not only limits patient engagement, but also prevents patients from having a voice. With no avenue to express opinions or raise concerns, the only way for patients to be heard was to take legal action;

- Acknowledging harm: patients sought appropriate acknowledgements when harm happened. They were not looking for revenge, but to be assured that learning had taken place and that actions would be taken to mitigate the problem or prevent future occurrences;

- System issues: they acknowledged that it was not about the fault of individuals, but weaknesses in the system. However, they emphasized that a system is managed by people, and therefore it can be changed by people.

2.0 Patient Safety – Key topics in the Ugandan context

The workshop facilitated multiple presentations and discussions from high-level speakers, both from Uganda and the international patient safety field. These presentations were designed to provide a baseline knowledge of pertinent issues in patient safety and quality-improvement in health care to the audience. The presentations initiated in-depth discussions and questions from the audience, which can be read at appendices 4, 5 and 6.

2.1 Engaging and empowering for safer and higher quality direct care

2.1.1 Injection Safety

Dr Augustine Lubanga

Dr Lubanga presented an overview of infection safety, and the importance of engaged and empowered patients and families to reduce preventable harm.

Unsafe injections are those given with unsterile or improper needle stick injury. Common diseases transmitted may include:

- Hepatitis B – 3–10% (up to 30%);
- Hepatitis C – 0.8–3%;
- HIV – 0.3% (mucous membrane exposure risk is 0.1%).

A safe injection, otherwise known as phlebotomy (drawing blood), lancet procedure or intravenous device insertion is one that does not harm the recipient, does not expose the health professional to any avoidable risk and does not result in any waste that is dangerous for other people. This presentation outlined conditions that increase risks of unsafe injections and blood collection (table 3).

Table 3: Preventable causes of injection safety adverse event

Health professional	Community health workers or village health teams	Patient
Low phlebotomy technique	Reuse of needles or syringes	Unnecessary injections
Unnecessary injections	Unsafe disposal of sharps waste	Low hand hygiene and cross-contamination
Two-handed recapping of needles	Increased waste from unnecessary injections	Socio-cultural barriers to asking questions
Manipulation of used sharps	Lack of protective clothing for waste handlers	Non-sterile or reprocessed syringes and needles
Lack of sharps box within arm's reach		Reuse of injection equipment
Poor positioning of the patient		Medication vials
Non-segregated sharps waste		
Two-handed transfer of blood		
Unsafe transport of blood		
Poor hand hygiene		
Not listening to the patient's needs		

The presentation outlined how these preventable risks can be improved through patient, family and health professional health literacy and meaningful patient to doctor engagement and communication. Having adequate resources to provide single-use devices and vaccinating health workers was also explained as core to reducing patient harm. The presentation provided capacity strengthening resources for the audience including practical guidance and recommendations on the use of injection devices and waste management.

For more information and examples of practical tools to improve injection safety please see slides at:

https://www.dropbox.com/s/gj28z2du0xi3wuh/Injection%20safety.pptx?dl=0

2.1.2 Infection control and hospital acquired infections

Dr Jackson Amone

Dr Jackson Amone, Assistant Commissioner for Integrated Curative Services in the Ugandan Ministry of Health, presented on the importance of adopting a patient-centred approach to infection prevention and control. He identified key roles and responsibilities of patients and families, the community, health professionals and policy-makers in improving infection prevention and control (IPC) (figure 4).

Dr Amone explained how the community has a responsibility for infection surveillance, monitoring and assessment, along with health professional adherence to hygiene policy and protocol at all levels. He gave a first-hand account of his experience in Sierra Leone to the participants, where he co-ordinated strategies to control and prevent the spread of Ebola. Learning off the Ebola response, the presentation highlighted how community health systems can use social mobilization, psychosocial support and the media to improve patient and people safety. Many infections and diseases create socio-cultural and mental issues such as stigmatization, anxiety, feelings of punishment, inability to receive services and isolation. Diverse patient and family needs and perspectives need to be incorporated into infection control response, with dignity and privacy for achieving high quality, patient-centred care.

The presentation emphasized why patients, families and communities should participate not only as a recipient of care, but also in the design, development and dissemination of IPC information, tools, resources, policy development and implementation. Risk assessment systems, processes and policies should include the perspectives and experiences of patients and people, to ensure they are relevant and useful for patients and people.

In essence, for IPC strategies to improve, Dr Amone emphasized the importance of strengthening meaningful collaboration and integration between the roles and responsibilities of all health stakeholders. Patients and people were emphasized as core stakeholders for improved safety and hygiene.

Figure 4: Core stakeholders to integrate and work collaboratively for improved IPC

2.1.3 Radiation Safety

2.1.3.1 Radiation protection among children and chronically ill patients

Professor Michael Kawooya

Professor Kawooya, director of the Ernest Cook Ultrasound Research and Education Institute at Mengo Hospital, and the chairman of AGROSAFE, presented an overview of radiation protection among children and chronically ill patients. He outlined key issues including radiation safety in imaging and the appropriateness of imaging; how to prioritize the most in need patients.

All imaging confers some degree of human and financial cost, even when carried out appropriately and when it is clinically justified. Adverse effects of care may be deterministic (dose dependent), or stochastic (caused from mutations in DNA). The professor explained that in Uganda, the ratio between patients to radiologists is 1:900,000. Due to these challenges and risks, it is important all imaging is safe, effective and justified.

The presentation gave an overview on the importance of engaging and empowering patients and families in health-care imaging. Meaningful communication between health professionals and patients and families must collaboratively discuss the risk considerations and the potential health benefit for individual cases. This can improve their health literacy, reduce service utilization and cost through less wasted resources, and reduce adverse events. For instance, a patient may be reluctant to communicate initially because they are not knowledgeable about the risk, benefits, impacts of technologies, or they may be too afraid to venture into the communication. It is important patients and people are engaged in every stage of care from the very beginning, so they can be educated and be part of an informed decision in their own care. This is to ensure that any procedures are fully justified, and they are a result of a shared-decision.

Table 6 provides a summary of the Ugandan barriers to appropriate imaging. It also provides suggested safety procedure solutions.

Table 6: Causes of inappropriate imaging in Uganda and possible safety solutions

Inappropriate use of imaging may occur due to:	Potential safety procedures to reduce risks of care:
• Low patient awareness of the risks of imaging;	• Using caution signs and red lights on doors of imaging facilities to protect health-care workers, patients and people;
• Lack of health professionals following clinical guidelines and training – Resorting to imaging too early;	• Confirming people who will be exposed are not pregnant;
• High litigation pressure on health-care workers;	• Monitoring the time a patient is exposed, their distance from source, and shielding;
• High rates of unjustified imaging - Private facilities make money from referring patients or providing imaging themselves;	• Providing protective clothes for carers;
• Insufficient communication between referring doctors and trained radiologists.	• Facilitating a positive dialog between health-care workers, patients and people.

2.1.3.2 Role of Patient safety initiatives in paediatric radiation safety awareness: championing for radiation safety

Nittita Prasopa-Plaizier

Ms Prasopa-Plaizier opened her presentation by highlighting dangers related to imaging including:

- Lack of access for those who would benefit from imaging;
- Delayed diagnosis for those without access;
- Inappropriate interpretation of imaging;
- Unnecessary tests and radiation exposure;
- Errors in administering tests and treatment;

- Unacceptable effects of treatment.

She stated that for safe imaging, the two key principles are justification (of the imaging method, dose, and level of exposure) and optimization (using the lowest effective dose, ensuring safety measures and adequate protection). Suggestions roles of patients and families in these two principles to increase the safety of care, such as:

- Being informed;
- Collaborating with health professionals;
- Being involved at policy level;
- Advocating for increased training, secondments and conferences for health-care workers involved in imaging and imaging referrals;
- Asking questions;
- Giving feedback about the services they receive.

The presentation also suggested that health professionals have a role to communicate effectively with patients, to ensure they are fully informed of the treatment information including risks. Patient education and health literacy would facilitate a meaningful interaction. Therefore, deficits in accessible information should be addressed, and consultation processes should be implemented.

2.1.3.3 Radiation safety, past, present and future

Dr Kimberly Applegate

Dr Applegate, International Atomic Energy Agency (IAEA) delegate from the United States, presented on paediatric imaging safety and the imaging safety timeline. Key points from her presentation are summarised below:

- We need to be passionate about systems of care, not just the individual;
- Transparency of treatment is crucial for patients;
- Campaigns for safe imaging are not just about protection, but about doing the right thing for patients, and sharing information;
- CT scans save lives, but radiation matters. Children are particularly susceptible to radiation, and exposure lasts a lifetime; children therefore have more time in which to develop problems. One scan in a specific, limited area is often enough to make a diagnosis;
- There is large importance of training for radiologists so they know to look for specific conditions for which imaging is used in children;
- 75% of ionising radiation in children is from CT scans. There are concerns over adequate training. Facilities must be accredited, and several staff members are required to operate each machine.

2.1.3.4 Dose optimization in paediatric cardiac x-ray imaging

Ms Hadijjah Ndagire

Ms Ndagire, a medical physicist discussed dose optimization in paediatric cardiac x-ray imaging. Paediatric cardiac x-ray may be diagnostic or interventional. There are various doses and

diagnostic procedures may be longer. Doses are optimized by dividing patients into weight groups. The radiation is quantified using factures such as procedure time and volume of contrast medium. The machine programme is determined by the child's age and weight. Referring doctors often just want to see the images. Physicists have a role in dose optimization required for imaging specific problems.

2.1.3.5 Care of paediatric patients and their carers

Dr Tsongo Sosthene

Dr Sosthene explained the benefits of ultrasound as an imaging method for paediatric patients, as there is no ionising radiation reducing treatment risks. Despite this clinical risk, imaging can be psychologically distressful for many patients and families. Dr Sosthene discussed the need to calm fears and make scanning stress-free. The best imaging results are achieved with a co-operative patient, and this requires good communication. He brought attention to a useful anagram to help keep imaging stress free for the young generation:

Preparation: Be ready before child enters room
Environment: Bright colours, pictures, allow parents to be close
Darkness: Adjust before child enters
Information: Gain confidence of child and parents
Anxiety: Be relaxed and friendly
Toys: Distract and entertain
Rewards: Congratulate child for being good
Initiative: To get required images, but stop if child stressed
Control: Make child feel involved
Speed: Small window of opportunity

2.2 Engaging and empowering for safer and higher quality health systems and processes

2.2.1 Self-reflecting on our safety culture: Increasing transparency and accountability

James Mwesigwa

Mr Mwesigwa, Advocacy and Communication Advisor for Patient Safety Improvement in Africa (PASIMPIA) presented on self-reflecting for Uganda's safety culture. He stated that a root cause of patient safety challenges in individual care across the globe comes from a lack of communication and active engagement between patients, health professionals and policy-makers for shared decision-making. This presentation explained difficulties in improving patient safety and health-care quality in cultures promoting a 'no-blame' culture. A 'no-blame' culture is one that may cause a lack of open-disclosure and honesty around adverse events, and in some cases medical unaccountability and cover up. This prevents learning from past mistakes in unsafe care and patient engagement and cooperation.

Mr Mwesigwa highlighted the lack of data concerning the prevalence of adverse events in sub-Saharan Africa, with a specific focus on Uganda. He explained the need for a safety culture, which provides a transparent and accountable environment enabling professionals to safely

accept responsibility for the safety of themselves, their co-workers, patients and the community. As Sir Liam Donaldson stated at the World Health Assembly in 2012:

"To err is human;
...To cover up is unforgivable;
...To fail to learn is inexcusable".

A safety culture that learns from adverse events would increase sustainability of the solutions, meaning the same mistakes are less likely to occur again. A proactive system would actively seek to identify risks and potential challenges, and implement solutions before mistakes happen, whereas a reactive system only responds when a mistake has been made. This presentation explained the importance of establishing the former system. Mr Mwesigwa finished his presentation by outlining key features of a safety culture in health care (WHO 2005):

- To prioritise safety above financial and operational goals;
- To encourage and reward the identification, communication and resolution of safety issues;
- To provides for organizational learning from accidents;
- To provides appropriate resources, structure and accountability to maintain effective safety systems;
- To enable transparent and accountable health professionals in a safe environment, to accept responsibility for the safety of themselves, their co-workers, patients and family members.

To see the presentation slides, please visit,
https://www.dropbox.com/s/t1in6rh2vdg6kt0/Patient%20For%20Patient%20Safety%20Presentation%201.ppt?dl=0

2.2.2 Role of medical ethics in improving patient safety and quality

Dr Frederick Nelson Nakwagala

Dr Nakwagala, a consultant physician at Mulago hospital, and chairperson of the Mulago hospital bio ethics working group, gave a presentation on the role of medical ethics in improving patient safety and quality. He explained how medical ethics are built on moral rules, and give a pattern and order for patient safety. Moral foundations are built on respect and dignity for human beings. This necessitates viewing patients as human beings, and not as cases, or symptoms. Patients should leave health services feeling they have been treated like a person. Both individuals and communities have the right to make choices about health care. He described how frameworks need to be in place to facilitate dealing with moral dilemmas. Moral 'rules' become broken, if patients are subjected to unsafe treatments. Doctors should feel pride in belonging to a profession which is considered noble. Belonging to this profession should confer a form of character integrity. This translates altruistic behaviour, and not seeking to mislead patients.

Dr Nakwagala explained the importance of creating formal professional standards that evolve from these concepts to become frameworks. Through these frameworks, professional behaviour can be monitored and assessed based on the patient's needs and values. These standards should aim to 'immunise' patients against abuses. Health professionals who do wrong should be

corrected through this ethical framework, ensuring accountability. Junior staff should be trained on the framework at an early stage.

To see the presentation slides please visit,
https://www.dropbox.com/s/habvw6uls9t122l/MEDICAL%20ETHICS%20IN%20PATIENT%20SAFETY.ppt?dl=0

2.2.3 The role of supply chain organisations

Ashraf Kasujja

Mr Kasuijja gave an overview of Medical Access Uganda Limited's (MAUL's) commitment to improved quality assurance of products, processes and patient safety. The presentation went into detail on the process of MAUL product quality assessment and safety steps. The importance of patient and family roles in feedback mechanisms was highlighted, to measure and assess the quality of MAULs products, and to ensure they meet the statutory and regulatory standards. The importance of comprehensive complaint handling systems, capable of identifying, investigating and reporting on product complaints, defects and quality issues was emphasized.

To see the presentation slides, please visit,
https://www.dropbox.com/s/s17vozahd9zl7y1/PQAM.ppt?dl=0

2.2.4 Adverse event reporting as a basis for quality improvement in hospitals

Dr Ronald Kiguba

Dr Kiguba, on behalf of Makerere University and Uganda's National Drug Authority (NDA) explained the importance of patient reporting for national pharmacovigilance. Pharmacovigilance is the detection, assessment, understanding and prevention of adverse drug reactions (ADRs). In Uganda there are 14 regional centres for ADR reporting, but no formal system for reporting medication errors. The NDA is currently facing large challenges to the detection and recognition of ADRs with only a small amount being detected, and of these cases, only 6 – 13 % are reported. Furthermore, when reported, there is often inadequate detail on the report forms to successfully identify the cause of the ADR.

Dr Kibuga stated that patient reporting on side effects to treatment is the predominant means by which health professionals may detect an ADR. Therefore, it is vital for patients to feel empowered to report side effects in order to strengthen pharmacovigilance mechanisms. The presentation explained that health professionals would approve the establishment of a national medication error reporting system in Uganda, and two-thirds would value patient involvement in adverse event reporting.

To see the presentation slides, please visit,
https://www.dropbox.com/s/nf9191la43ek32u/Patient_Safety_Wkshp_Kiguba_Ronald_04Nov2015.ppt?dl=0

2.3 Engaging and empowering for safer and higher quality health policy

2.3.1 Patient safety momentum in Uganda: the power of partnerships in catalysing change

Dr Tonny Tumwesigye

Dr Tumwesigye, executive director of Uganda Protestant Medical Bureau, described a pilot project for an African Partnership for Patient Safety (APPS).

WHO APPS programme was initiated as response to the ministerial commitment and mandate for patient safety action from all 47 Ministries of Health in the WHO African Region in 2008. At a similar time, the Department of Health in the United Kingdom (UK) published it's five year strategy "Health is Global", highlighting access to medicines, technologies and innovations for patient safety.

The WHO APPS programme was born out of the recognition on the effective use of institutional health partnerships to strengthen health service delivery. The APPS approach to patient safety improvement involves establishing a formal hospital-to-hospital partnership between European and African hospitals, led by senior clinicians on each arm, and with support and endorsement from national ministries of health and other relevant institutions, and from WHO country and regional offices. Partnerships are actively encouraged because of the benefits they can confer on more developed health systems.

Dr Tumwesigye explained the working partnership between a hospital in Uganda, and a UK hospital run by the National Health Service (NHS). Key individuals from the UK institute visited the hospital in Uganda, and alongside the hospital management and board of directors, formed a patient safety team.

Key areas for improvement were outlined, and within these, specific components for change were identified (see below). After initial visits, the partnership was maintained through email contact and teleconference. Hospital internal guidelines were produced, where no national guidance was available. The local community was engaged in various activities, such as hand hygiene awareness. Local solutions were brought in, to ensure sustainability. For example, alcohol hand gel was produced from locally grown bananas. The community therefore had a vested interest in the new procedures. Educational awareness sessions were conducted for all staff, including porters and cleaners, to involve the entire hospital. Re-alignment of services was required to fully integrate patient safety, however new service components were scaled up through the existing framework.

Six step process for change model:

1. Partnership development;
2. Needs assessment;
3. Gap analysis;
4. Action plan;
5. Implementation;
6. Evaluation.

Examples of areas for change forged out of the APPS pilot:

- Health centre acquired infection – Currently there are insufficient guidelines in place and no method to assess compliance to guidelines, no hand hygiene, limited training, laundry, waste disposal;
- Medication safety – Currently there is little use of the adverse event reporting system;
- Surgical care – Currently a high workload and limited use of WHO safe surgical checklist.

To see the presentation slides, please visit, https://www.dropbox.com/s/9zra95m06xqh1a0/Patient%20Safety%20Momentum%20in%20Uganda-The%20power%20of%20partnerships%20in%20catalyzing%20change.ppt?dl=0

3. Ongoing engagement to improve patient safety

All participants

Participants had the chance to share stories of adverse events and successful patient, family and community engagement in efforts to find solutions to lapses in quality and safety of health-care in Uganda. Storytelling is an integral element of the workshop, emphasizing the importance and value of patient stories in being catalysts for change. The purpose of this element of the workshop is to unite the group, with compassion and a shared collective vision for safer and higher-quality care. Below is a brief overview of some participant's stories that discussed how people can turn a negative experience into positive advocacy for change.

One participant described how they tested positive for the hepatitis B (HBV). They received a lack of information on HBV treatment when the diagnosis was made. They were told they should take antiretroviral, but the patient did not understand why, as they thought antiretroviral were for HIV not HBV. It was not explained that some antiretroviral treatment can be used to suppress HBV. On seeking an opinion from another health professional, they were told that they did not yet need treatment. This participant started an organization to increase awareness of HBV infection and the common safe treatments, as they found little information available from the health providers which diagnose the condition.

Another participant described the experience of a friend with HIV who had been arrested, and was denied access to their antiretroviral treatment while in prison. This had caused the person anxiety and the actions may have been harmful to their health. The participant explained how patient and people perspectives and experience can be useful for the Ministry of Health and the police force when making policy for patients with chronic conditions.

After this session, the Ministry of Health commented that "the stories have given insight into issues affecting patients and families". He was very enthusiastic about how patients and families can contribute to health system improvements, stating "the stories have highlighted failings and issues surrounding human resources and medical supplies. Channels of communication need to be opened, as well as tools for monitoring change". He added that he will aim to engage with both CHAIN and WHO country office and the community in steps moving forward.

4. Vision, priorities, challenges and lessons learnt

Participants formed a 'round circle', and were asked to:

- List their hopes and visions for the future;
- Define priorities;
- Identify key steps in taking their role in patient safety forward.

These visions are still being finalized.

4. Closing session

Ms Regina Kamoga thanked all of the participants; health professionals, Ministry of Health, WHO representatives, patients and family members for welcoming, respecting and learning from each other in the workshop. She called on the Ministry of Health to invite patients and people to engage in health care in a meaningful way, as colleagues, and to create opportunities for patient collaborations. She called on all participants to share their experiences with their peers, fellow medical students, communities, colleagues, and families, to further spread the word on the importance of patient and family engagement in health care.

The Ministry of Health stated their commitment to engaging patients, families and the community at two levels. Firstly patients at health facilities to be educated and informed, and to able to take a role in their own treatment decisions, if they are able. Secondly, patients and community members to be included in technical groups who are creating health-care policy, where their input should be considered in a meaningful way.

All participants were awarded a certificate signed by the Ministry of Health and WHO country office, for giving up their time for this excellent workshop. All participants were invited to join the PFPS network of global advocates, after taking a few days to consider how much they will be able to commit.

In closing, Ms Kamoga declared that the meeting objectives had been met and that the ideas and recommendations of all the participants will be key in taking the PFPS Uganda network forward.

Appendices

Appendix 1: Workshop programme

PATIENT SAFETY WORKSHOP
Tuesday 3th to Thursday
5th, November 2015
Mulago Hospital Guest House (Near Galloway)

Day 1: Tuesday 3rd November- 2015			
TIME	TOPIC	PRESENTER	CHAIR
8:00-8.30 am	Registration of workshop participants	CHAIN	
8.30-9.30am	Welcome and opening remarks (Objectives and expected outcomes of the workshop, introduction from all participants, their name, town, affiliation	Regina, organising committee, all participants	Dr. Henry Mwebesa Ag. DHS(P&D)
9:30-9:45am	Patient For Patient Safety programme(PFPS) Global Network	Ms Nittita Prasopa Plaizier- Program manager and Technical Lead Patients for Patient Safety, WHO Geneva.	
9:45-10.00am	Key note Address- Patient Safety and Quality in the context of Universal Health Coverage	Prof. Freddie Ssengooba- Makerere University School of Public Health	
10:00-10:15am	Remarks : WHO Patient Safety programme	Dr. Wondimagegnehu Alemu- WHO Country Representative WHO Kampala	
10.15-10.40am	Official opening -Guest of honor	Hon. Minister of Health	
11.00-11.30am.	Tea Break		
11.30-11.50 am	Injection safety- Ensuring safety of injections in reducing the burden of HIV and HBV in the community	Mr. Henry Magara- Country Director Uganda Cares	Dr. Jacinto Amandua CHS(CS)
11.50-12.20pm	Infection control and Hospital Acquired infections-Lessons	Dr. Jackson Amone- Assistant Commissioner	

	learnt from the Ebola outbreak	clinical services, Ministry of Health	
12.20- 1.00pm	Q & A	UNASO	
1.00-2.00pm	Lunch		
2.00-2.15pm	Radiation protection among children and chronically ill patients	Prof. Michael Kawooya - Director ,Ernest Cook Ultrasound Research &Education Institute((ECUREI), Mengo hospital Chairman AFROSAFE	Dr. Rosemary Byanyima- Mulago Hospital
2.15-3.00pm	Key stakeholders panel(Interactive Q & A) Ministry of Health, Uganda National Medical Stores, Medical Access, Joint medical Access(JMS) Hospital directors, Uganda Private Medical Practitioners Association(UPMPA)	Representatives from : MoH, NMS, MAUL, JMS, Hospital directors, private sector in health, Uganda Blood Transfusion Services	
3.00-3.45pm	Best practices in Patient safety in Uganda	-Dr. Benard Odu – Director Arua Referral Hospital , -Dr. Olaro Charles – Director Fort portal referral Hospital	
3.45-4.00pm	PFPS Journey – 10 years on	Ms Felicity Pocklington- Consultant of the Patients for Patient Safety programme, WHO Geneva	
4.0- 4.45pm	Sharing experiences: Why are we here?	Robinah Kaitiritimba - Executive Director, UNHCO and Patient Safety Champion) And all participants with stories to share	
4.45-5.00pm	Video clip show		
5:00pm	End of day 1		
Day 2: Wednesday 4th November -2015			
9.00- 9.15am	Review of Day 1	All	
9.15-9.25am	Safety culture in healthcare	James Mwesigwa Lwanga- Advisor and Advocacy and Communication UPMB	Dr. Jackson Amone –ACHS(CS)
9:25-9.45am	Health systems in Uganda and How it promotes/support Patient Safety & Quality Culture?	Dr. Martin Ssendyona – Quality Assurance Depart -MoH	

9:45- 10.00am	Engaging patients and families in health services and systems: The Ugandan context	Dr. Michael Etukoit- Executive Director, The Aids Support Organisation (TASO)	
10.00- 10.15am	Role of Medical Ethics in Improving Patient Safety & Quality	Dr. Frederick Nelson Nakwagala- Consultant Physician, Mulago Hospital and chairperson of the Bio ethics working group	
10.15- 10.45am	Tea Break		
10.45- 11.15am	Adverse event reporting as a basis for quality improvement in hospitals	National Drug Authority (NDA)	Dr. Tonny Tumwesigye-UPMB
11.15-11.45 am	Concept of patient and community involvement in Improving quality of healthcare	Ms Nittita Prasopa Plaizier-Program manager and Technical Lead Patients for Patient Safety, WHO Geneva -Regina Kamoga, Executive Director CHAIN and Patient Safety Champion.	
11.45- 12.45pm	Part 1 - PFPS Uganda network – What do we want?	Joshua Wamboga - Executive Director Uganda National Aids Service Organisation(UNASO)	
12.45 – 1.45pm	Lunch Break		
1.45 - -3.45 pm	Part 2 - How can we get there?	Robinah Kaitiritimba- Executive Director- UNHCO and Patient Safety Champion (presentation) All (discussion)	Prof. Michael Kawooya
3.45- 4.15pm	Way forward	Joshua Wamboga - Executive Director UNASO Ms. Nittita Prasopa Plaizier - Program manager and Technical Lead Patients for Patient Safety, WHO Geneva	
4.15- 5.00 pm	Presentation of Patient for Patient certificates to Champions		

Day 3: Thursday 5th November 2015

Patient safety workshop participants will join the Uganda Society for Advancement of Radiology and Imaging(USOFARI) preconference

Theme: Radiation safety during pediatric imaging
Venue: Makerere University College of Health Sciences Mulago National Referral Hospital

Time	Topic	Presenter	Chair person
8.00-9.00 am	Registration	Ms. Harriet Wamala	
9.00-9.10 am	Welcome remarks	Prof Michael Kawooya - Director ,Ernest Cook Ultrasound Research &Education Institute((ECUREI), Mengo hospital and Chairman AFROSAFE	To be determined and shared
SESSION 1: Safety awareness in pediatric imaging			
9.10-9.50am	Role of patient safety initiatives in pediatric radiation safety awareness :- Championing for radiation safety	Dr Kimberly Applegate (IAEA delegate) Dr Nittita Prasopa-Plaizier(WHO delegate)	
9.50-10.10 am	DISCUSSION		
10.10-10.40 am	TEA BREAK		
SESSION 2: Safety awareness in pediatric imaging			
10.40-11.10am	Incident and accident reporting in pediatric imaging from the patient and provider perspective	Interactive session (Q & A) Regina N.M. Kamoga (CHAIN)	
11.10-11.40am	DISCUSSION	Dr. Kisembo Harriet- President Uganda Society for Advancement of Radiology and Imaging(USOFARI) preconference (USOFARI)	
SESSION 3: Optimization for pediatric imaging			
11.40-11.55pm	Health Technology assessment (HTA) in promoting pediatric radiation safety	Dr Kimberly Applegate (IAEA delegate)	
11.55-12.25pm	DISCUSSION	Dr Kisembo Harriet- President USOFARI	
12.25-12.45pm	Closing Remarks	Prof Michael Kawooya - Director ,Ernest Cook Ultrasound Research &Education Institute((ECUREI), Mengo hospital and Chairman AFROSAFE	
12.45-2.30pm	Lunch and Departure		

Appendix 2: List of workshop audience participants

Participants				
No.	**NAME**	**COUNTRY**	**DISTRICT**	**PROFESSION**
1	Rwankore Molly Kate	Uganda	Kampala	Public Health specialist
2	Frances Mbabazi	Uganda	Kampala	Medical officer –police force
3	Shila Natenda	Uganda	Wakiso	Health Counselor
4	Simon senteza	Uganda	Kampala	Social Worker
5	Donny Ndazima	Uganda	Wakiso	Public Health
6	Richard Serunkuuma	Uganda	Wakiso	Health advocate/counsellor/trainer
7	Kay Seden	Uganda	Kampala	Pharmacist
8	Hawa Sempa	Uganda	Kampala	Village Health Team (VHT)
9	Issa Sunday	Uganda	Hoima	Social Worker
10	Annet Onzia Aketoko	Uganda	Kampala	Medical Officer
11	Benjamin Wamala	Uganda	Wakiso	Counsellor / VHT
12	James Lule	Uganda	Kampala	Counsellor
13	Resty Nalwanga	Uganda	Kampala	Counsellor /Advocate
14	Joerier Nabitwere Walusimbi	Uganda	Kampala	Cancer survivor /advocate
15	Florence Nakaayi	Uganda	Mpigi	Journalist/social worker
16	Sula Mufumba	Uganda	Kampala	Laboratory technician
17	Kenneth Kabagambe	Uganda	Kampala	HB activist
19	Alex Ngobi Pande	Uganda	Kampala	Teacher
20	Nathan Muyinda	Uganda	Kampala	Pharmacy technician
21	Ruth Nankanja Sempa	Uganda	Kampala	Teacher
22	Enoch Magala	Uganda	Wakiso	Programs Director of a CBO
23	Peter Ssonko	Uganda	Kampala	Nutritionist/dietician
24	Proscovia Namakula	Uganda	Wakiso	Teacher
25	Christopher Draiko Vunni	Uganda	Moyo	Public health, nursing
26	Birungi Irene Josephine	Uganda	Wakiso	Social worker
27	Wabulyu Janepher Ogwal	Uganda	Kampala	Social worker
28	Nalukenge Gladys	Uganda	Kampala	Social worker
29	Amanya John	Uganda	Wakiso	Mental Health Worker/PCO
30	Flavia Kyomukama	Uganda	Kampala	HIV activist /Teacher
31	Juliat Namuwaya	Uganda	Kampala	Journalist
32	Hope Waseni	Uganda	Kampala	Sex Worker
33	Betty Babirye Kwagala	Uganda	Kampala	Counsellor
34	Elizabeth Tindyebwa	Uganda	Kampala	Social Worker
35	Mwanje Godfrey	Uganda	Kampala	Graphic designer/Business man
36	Doreen Kayegi	Uganda	Entebbe	Accountant

Appendix 3: List of workshop key stakeholders and speakers

No.	NAME	PROFESSION	CONTACT
1	Hon. Minister of Health	Hon. Minister of Health	Ministry of Health
2	Dr. Wondimagegnehu Alemu	WHO Country Representative WHO Kampala	WHO
3	Ms Nittita Prasopa Plaizier	Program manager and Technical Lead Patients for Patient Safety, WHO Geneva	WHO, Geneva
4	Ms Felicity Pocklington	Consultant of the Patients for Patient Safety programme, WHO Geneva	WHO , Geneva
5	Dr. Henry Mwebesa	Ag. DHS(P&D)	Ministry of Health
6	Dr. Jacinto Amandua	CHS(CS)	
7	Dr. Jackson Amone	Assistant Commissioner clinical services, MoH	Makerere School of Public Health
8	Prof. Freddie Ssengooba	Makerere University School of Public Health	
9	Prof. Michael Kawooya	Director - Ernest Cook Ultrasound Research &Education Institute((ECUREI), Mengo hospital & Chairman AFROSAFE	Mengo hospital
10	Dr. Rosemary Byanyima	Mulago Hospital	Mulago hospital
11	Dr Augustine Lubanga	Uganda Cares	Uganda Cares
12	Moses Kirigwajo	UNHCO	UNHCO
13	Regina Kamoga	Executive Director, CHAIN and Patient Safety Champion	CHAIN
14	Dr. Olaro Charles	Fortportal referral hospital	Fortportal
15	Dr. Odu Benard	Arua referral hospital	Arua
16	Dr. Tonny Tumwesigye	Uganda Protestant Medical Bureau (UPMB)	UPMB
17	James Mwesigwa Lwanga	Advisor and Advocacy and Communication UPMB	UPMB
18	Dr. Martin Ssendyona	Quality Assurance Depart -MoH	MoH
19	Dr. Michael Etukoit	Executive Director, The Aids Support Organisation (TASO)	TASO
20	Dr. Frederick Nelson Nakwagala	Consultant Physician, Mulago Hospital and chairperson of the Bio ethics working group	Mulago Hospital
21	Kiguba Ronald	National Drug Authority (NDA)	NDA
22	Joshua Wamboga	Executive Director Uganda National Aids Service Organisation(UNASO)	UNASO
23	Lubega Ssubi	Medical Access	Medical Access
24	Dr. Mukuzi Muhereza	Uganda Private Medical Practitioners Association	UPMPA
25	Joint medical Stores		JMS

Appendix 4: Key discussions, questions and answers following day 1 morning session

Issue raised/question	Solution/answer
Doctors fear litigation if they report adverse events. What can the ministry do to promote a safety culture?	- Emphasize that disclosure of mistakes or errors is done to learn, not to apply punishment. A national patient safety reporting guidance document will go to parliament soon, which will outline responsibilities. - It is inevitable that litigation cases against health workers will increase, as patients become more health literate and aware of their rights. The medical council will have procedures in place, which may include a professional insurance system.
Patients have a right to know what medicines they are taking, but are often not aware. What can be done?	- Patients do have this right, but are often not aware. The ministry is aware that patients are not routinely counselled, which may be due to lack of time and resources
In some cases where patients have chronic serious illness like HIV or cancer, pastors may extort money from patients for prayer, also preventing patients from seeking appropriate healthcare. What can the ministry do?	- These are very complicated issues and would be difficult to regulate. May not fall under the remit of the MoH.
Private health centers may extort money for simple tests, which may not be necessary for treatment of the patient. What can be done?	- This is an issue for the regulatory authorities.
What is the role of the community in Ebola control?	- The community must feel that they 'own' the epidemic, and have responsibilities. They must be educated to recognise the signs and symptoms, and the importance of isolation. Engagement and education is essential to the success of control strategies.
Is there a risk of sexual transmission of Ebola after the patient has recovered from the acute infection?	- There is evidence that Ebola virus is present in semen for up to six months after acute infection. However, there is currently no evidence that the infection can be sexually transmitted.
How can healthcare workers/users be involved in strategies to improve patient safety?	- There may be a knowledge gap among healthcare workers around medical errors. Training is important in this area, including how to assess and report, as NDA pharma-covigilance forms are often incomplete, or not returned. There is a need for statistics, detailing the burden of errors on patients, health facilities and systems. National patient safety policy will play an important role in healthcare worker awareness of the issues, and good practice. - Healthcare users and the wider community should be empowered, which is achieved via education and understanding. The public should understand their rights, and how to ask for and expect quality services.

Appendix 5: Day 1 afternoon session: Stakeholders panel discussion

Chair: Dr. Rosemary Byanyima. *Representatives from Ministry of health, Medical Access, MAUL, JMS, TASO, Private sector, Public hospital directors*

<table>
<tr><th colspan="2">Question one: How can engagement of patients and families ensure safe health-care delivery?</th></tr>
<tr><td colspan="2">Key responses:</td></tr>
<tr><td rowspan="3">Panel members:</td><td>Improved communication between patients and health professionals - There needs to be a culture of engaging patients.
For instance - health professionals in all sectors are employed by their patients, yet the patient often is not given time to express themselves, as the health professional may focus on the disease, rather than the person. The health professional and patient have a role to discuss the full history of the patient, and the family has a key role in achieving this. It is the responsibility of the health professional to listen for meaningful communication. Channels of communication need to be open to determine each stakeholder's expectation of care.</td></tr>
<tr><td>Improved health literacy of patients and people – Patients and people should be informed and sensitized to their roles, responsibilities, rights and obligations.
For instance - engagement is most easily achieved with patients who are educated, and have chronic conditions. Often doctors do not consider the patient's environment, to determine what the community expects.</td></tr>
<tr><td>Improved transparency, accountability and adverse event reporting - To fully report a suspected adverse drug reaction to the National Drug Authority (NDA), the patient's experience needs to be fully heard, in order to report accurately.</td></tr>
<tr><td colspan="2">Issues raised:</td></tr>
<tr><td rowspan="2"></td><td>In private community pharmacies it may be difficult to monitor adverse drug events, as patients often do not know what they have taken. Sometimes drugs are prescribed, but with no diagnosis. It is hard to contact the prescribing doctor to confirm, and therefore pharmacists often don't have enough information to make safety checks.
- Educating patients to know to ask doctors what they have been prescribed, the dosage and recurrence of taking the drugs is important.</td></tr>
<tr><td>Unregistered practitioners can be a challenge, especially in the rural areas. It is important for patients and people to know the risks of such facilities.</td></tr>
<tr><th colspan="2">Question two: Policy decisions about devices, equipment and drugs should take into account cost-effectiveness. How can systems considerations for patient safety be incorporated?</th></tr>
<tr><td colspan="2">Key responses:</td></tr>
<tr><td>Panel members:</td><td></td></tr>
<tr><td rowspan="4"></td><td>Standardized equipment across health facilities by the Ministry of Health - Guidelines are needed for new technologies, which take into account the needs of different patient groups, and are relevant to diverse health settings.</td></tr>
<tr><td>Responsive private sector to the market - To immediately introduce what is perceived by patients to be effective.</td></tr>
<tr><td>Patient consultations on the possible side effects of drugs, and poor efficacy of new technologies and/or treatments - Cost-effectiveness analysis is important, but everybody should be aware that they may one day become patients, and could benefit from this information.</td></tr>
<tr><td>Meaningfully involving patients and people in the guideline approval process - Service providers should accommodate the interests and opinions of patients when they are applying guidelines. The guideline approval process should involve stakeholders, including patient representatives, as part of the technical working group.</td></tr>
</table>

Issues raised:	
	The Ugandan Infectious Diseases Institute (IDI) initiated a scheme to involve patients in their care. This includes the promotion of adherence, education and involvement in decisions at a higher level than just their own care.
	Lay people are uneducated on health equipment, for example, CT scans, preventing their involvement in treatment decisions. Patients need to be educated about newer technology and advancements, and empowered to be more communicative.
	Concerns that private facilities are using new equipment without regulation.
	Patients stop taking drugs if they experience adverse events, as they have no reassurance that they may occur, and the risks/benefits of the treatment. Patients do not always understand written information due to language barriers or inability to read.
	Treatment is too expensive.
	Mass media communication is an underused tool, which should be used to empower communities with information on their rights, roles and responsibilities.
	Patients often bypass primary health care, as they want to see a specialist immediately. This causes inappropriate care without consultation.
	Patient abandonment may occur due to omission or work overload. Wilful neglect is a separate, serious issue.

Appendix 6: Key issues, questions and answers from day 2 morning session

Issue raised/question	Solution/answer
What has been achieved by the Ministry of Health in terms of support to health-care centres at all levels?	- The Ministry of Health strategy is being improved to be more comprehensive. This includes inspection and supervision, and quarterly area support. Most issues on the ground are addressed by local teams (approximately 80%), while a smaller proportion of issues are dealt with at policy level. - Strategies for strengthening governance and accountability are important. The WHO can work alongside the Ministry of Health, including strengthening advocacy for change, and also facilitating how to implement change at the hospital level.
To what extent do bodies such as the Medical Council defend health-care workers against litigation?	- In Uganda, health professionals who have an accusation against them are considered innocent until proven guilty. Such cases should determine whether professionals deviated from accepted standards.
Is patient safety training available for medical students?	- There is a WHO patient safety curriculum available. In some countries, patients or patient advocates have given lectures to medical students on patient safety.
Did the UK hospital learn anything about patient safety in the partnership process with Uganda?	- Innovation. The importance of a clear vision and strategy. A lot can be done with little resources by involving family members and the community in health-care improvement.

Appendix 7: Sample photos from the workshop.

Full gallery can be found at: https://flic.kr/s/aHskoKmWva

Why engage?