PATIENT SAFETY ADVOCATES MEETING REPORT

AT CHAIN OFFICES IN KIWENDA, WAKISO DISTRICT

Community Health And Information Network (CHAIN) promotes patient safety at the community, national and international level

Patient Safety Advocates meeting participants

7TH SEPTEMBER 2018

CHAIN Contacts: www.chainproject.africa
info@chainproject.africa
Contact persons: Regina Kamoga- regina@chainproject.africa
Gladys Nalukenge- Gladys@chianproject.africa

ACKNOWLEDGEMENT

Improving the community health is a core mandate of CHAIN, but this is possible because the community has welcomed us, we therefore acknowledge the support provided by the communities we serve. We also recognize our national and international partners who make this possible, specific to this event we thank the participants, Ministry of Health Uganda, Human Rights and Peace Centre as well as Nottingham Law School, Nottingham Trent University.

Organizing and supporting partners:

GLOSSARY

ADRs – Adverse Drug Reactions
ARVs – Anti-RetroVirals
CHAIN – Community Health and Information Network
EAT – East African Standard Time
GIPA- Greater Involvement of People Living with Aids
IDI – Infectious Disease Institute
LC 1 – Local Council one
NDA – National Drug Authority
NTU – Nottingham Trent University
UK – United Kingdom
VHTs – Village Health Teams
WHO- PFPS- World Health Organisation Patient For Patient Safety
WHO – World Health Organisation

EXECUTIVE SUMMARY

Patient safety has been defined as 'the absence of preventable harm to a patient during the process of health care and reduction of risk of unnecessary harm associated with health care to an acceptable minimum' (World Health Organization, 2017). The consequences of failures in patient safety are diverse and far-reaching: pain, suffering and even death for patients; the loss of loved relatives, or extra caring responsibilities, for families; the temporary or permanent loss of active members of the community; additional strains placed on already limited healthcare resources.

There is an increasing acceptance in countries across the world that medical errors can occur across the whole spectrum of health services and treatments and can be attributed to both human and system factors. Developed countries are not immune to the effects of patient safety incidents: it is estimated that, in the UK, a preventable adverse incident occurs every 35 seconds. However, two-thirds of all adverse events across the globe occur in low- and middle-income countries.

It is important to note, that because patient safety is a complex, multi-dimensional challenge the solutions to providing safer, high quality care cannot be found through the isolated efforts of interested stakeholders. Rather, there must be ongoing, concerted actions by all those with responsibilities, experience and expertise in healthcare. These stakeholders are diverse and are drawn from all levels of national and international organisations, including: relevant ministries, policy-makers, regulators, healthcare providers, healthcare professionals, researchers, educators, lawyers, civil society, community health workers patients and family. Such groups, working together, can develop regulatory frameworks, leadership, and organisational management alongside the on-the-ground capacity to successfully implement and maintain safety strategies, procedures and practices.

The patient safety advocates meeting was organized on the 7th of September 2018, and hosted at the CHAIN offices in Kiwenda. The event began at 8:30 am and ended at 5:00 pm EAT and was attended by 48 participants including the patient safety advocates, academia and patient leaders/organizations. The event allowed for the direct interaction with the patient, through the community patient safety advocates, who are community members but have been empowered and trained in 2015 to promote patient safety.

The event presented manifold benefits including;

- patient safety advocates shared knowledge and experiences on patient safety
- The national and international health experts trained on patient safety issues at the national and international level
- Analysis of the achievements of the patient safety advocates since 2015 and agreement on the way forward to increase impact of patient safety interventions.

Presentations were delivered on a range of safety issues, including: The importance of driving quality into healthcare provision; consent to treatment in patient safety; case study on advocates for Patient Safety in a large HIV outpatient facility; what is Dementia and dementia care; Injection safety; Medication safety; Safe and genuine drugs. The participants also discussed Involving Patients, family and Community in patient safety as well as the Patients Safety advocates sharing their experiences on patient safety incidents.

INTRODUCTION

CHAIN has promoted Patient Safety at the community level since 2011. This has involved engaging and empowering Community Owned Resources (CORs) including Village Health Teams (VHTs), local leaders (religious, cultural and political leaders) through capacity building trainings on patient safety and advocacy. The Patient safety advocates meeting was an empowerment event whose aim was to update the Patient Safety advocates about new tools, the national and international issues about patient safety. The whole day event presented an opportunity of patient safety education delivered by health experts, with a session for question and answer as well as discussion. The advocates shared experiences on patient safety incidents and agreed on actions to continue patient safety advocacy in the community.

Table 2: Summary table for the event activities (presentations and participatory session)

MINUTES	ACTIVITY	RESPONSIBLE PERSON
30	Introductions, & Objectives of the meeting	Regina- Executive Director- CHAIN
10	Welcome remarks	LC 1 Chairperson
20	Patient Safety and Universal Health Quality: The importance of driving quality into healthcare provision	John Tingle Associate professor Nottingham Law School ,Nottingham Trent University, UK

20	What do we mean by informed consent to treatment in patient safety? When is consent not consent?	Dr. Clayton O'Neill Lecturer Nottingham Trent University, UK
20	Advocates for Patient Safety in a large HIV outpatient facility: Feasibility and impact of a pilot training program in Uganda	Mercy Kakundakwe- IDI
20	What is Dementia and dementia care	Amanda Cattini, Nottingham Trent university
15	Injection safety	Sulah Mufumba- Laboratory technician- Koamamboga HC111
	Medication safety	Nathan Muyinda- EDCO
15	Safe and genuine drugs: what the WHO is doing about the problem of defective and fake drugs and what more can be done.	Morgan Shimwell Lecturer Nottingham Trent University
60	**Discussion**	**ALL**
20	Involving Patients, family and Community in patient safety	Regina Kamoga- CHAIN
60	**Sharing experiences on patient safety incidents**	**ALL**
20	**Way forward**	**John Tingle and Regina**

WELCOME REMARKS

Regina M.N.Kamoga – Community Health And Information Network(CHAIN)

Mrs. Regina Kamoga welcomed all participants and guests, thanked them for taking time off their busy schedules to participate in the event. She requested participants to introduce themselves, their organizations and the work they do. She noted that many of the participants were members of the Patient Safety Network, established in 2015 after the National Patient For Patient Safety workshop. She informed them that CHAIN continues to lead the mobilizing of advocates to ensure that a critical mass is created to promote patient safety. She further informed them that CHAIN has integrated patient safety in its work and appealed to everyone to do the same. She explained the purpose of the meeting and urged them to share their experiences, challenges and opportunities in promoting patient safety.

PRESENTATIONS

John Tingle – NTU: Patient Safety and Universal Health Coverage

Professor John Tingle began by acknowledging the fantastic work being done by CHAIN in promoting patient safety and thanked Regina for inviting him and his colleagues to come to Uganda.

He highlighted the need for countries to offer safe and quality healthcare for their citizens. 'To compromise on the quality of care is to undermine the principles of universal health coverage', he said. Prof. Tingle reflected on the recent World Health Organization (WHO) report on *The State of Health in the WHO African Region* which recognized that Uganda is currently out-performing its socio-economic classification as a low-income country. Key health indicators such as mortality, morbidity and life expectancy rates are better than the regional average. The commitment and hard work by community health worker and organizations like the IDI and CHAIN (amongst a range of others) contribute to those achievements and should be celebrated.

He informed the participants that patient safety is vitally important at all levels of healthcare and is being increasingly recognized as a global health challenge. However, it was important to note that there are very different contexts in each country, but there are common challenges facing all health systems.

He urged advocates, policy-makers, healthcare workers, lawyers, academics, volunteers and other healthcare stakeholders to work together and develop strategies and solutions to these common problems.

He continued to share with examples where necessary that;

- One of the fundamental challenges for patient safety in any healthcare system is failures in communication. This may be communication over patient discharge for hospital, the medications required, and follow-up treatments required or even treating the correct patients. Errors can occur very easily, but have very serious consequences.

In England, the National Health Service still suffers from these types of failures and others. Resources are already limited, but have to be spent correcting harms which patients have suffered whilst receiving care and even defending itself in courts of law when negligence claims are made.

He however, noted that patients are generally uninterested in making legal claims against healthcare providers. Rather, they want their injuries to be acknowledged; they want an apology for the poor-quality care and treatment that they have received. But, handling patient concerns and complaints is very complex and, in countries like the UK, is largely becoming standardized and bureaucratic. This does not appear to provide an adequate remedy for injured patients. Therefore, litigation is becoming the only viable mechanism to have harms officially recognized. However,

this is having a significant impact on the money available to be spent on improving healthcare services and very rarely results in deep, long-lasting changes to the system to prevent such harms occurring again to others.

The relationship between doctors and patients is changing. Traditionally, there has been a culture of 'doctor knows best'. Doctors made decisions for patients with very little discussion about how the patient would like to be treated. The risks of treatment are only communicated if the doctor feels that they are significant enough to warrant sharing. However, patients are becoming more empowered. The law is moving to provide patients with rights – the Ugandan Patient Charter, the Bill of Rights in the Ugandan Constitution; in the UK, the Human Rights Act – and respecting that patients need to be involved in the decision-making process to ensure that they understand what is being proposed, how this may benefit them but also what risks they will be exposed to. Whilst this sounds like a very positive move, there is a concern that this does not flow down into the daily reality of most patients. It is an important role for patient safety advocates and educators to ensure that patients understand their rights, to allow them to feel empowered when they enter the healthcare system.

This work can start in the community, but it must also take place at all levels of healthcare, both within countries but also between countries. The top and bottom-levels of healthcare must be brought together to share knowledge, experiences, needs, interests, demands, problems and solutions. Through this interaction, the practices can be aligned with the policies to ensure that they work together to provide good quality care for all.

Dr Clayton Ó Néill – NTU: What do we mean by informed consent?

He started off by reminding the patients about their universal right to health, as articulated in a number of international and national laws and human rights documents. However, the concern is that these rights do not necessarily translate into our everyday lives. Patients may be legally empowered, but are not practically empowered when they visit healthcare professionals. An important concept in ensuring that patients feel that they are involved in the care which they receive is that of informed consent.

He informed the participants that in many countries, including Uganda and the UK, there has been a long-held belief that doctors are authority figures who should not be questioned, not to mention challenged by a patient. There is an inherent knowledge imbalance between doctors and patients. This may go against a sense of having a right to ask questions about the rightness of particular treatments. However, this culture needs to be changed.

He further noted that the law has, until recently in the UK, endorsed the 'doctor knows best' approach to healthcare. For a successful claim to be brought against a doctor who has caused harm to a patient, or failed to provide information about the

risks of treatment, it had to be proved that the doctor has acted so unreasonably that no other doctor would agree with his actions. This made bringing legal claims against doctors very difficult for patients. However, in 2015 in the UK, this legal approach was changed by the Supreme Court. Now, the position in law is that patients should be told information about benefits, risks and alternative treatments whenever those risks are so significant, such that a reasonable patient would want to know them. This means that doctors need to engage in discussions with patients to know what kinds of concerns they have, as a means of understanding which treatments would be appropriate to offer. In this way, patients gain a more active role in their relationship with health professionals, and are protected in this by the law.

Whilst this is a very positive move in the law, there are still significant challenges facing patients in enjoying these rights. Poor health literacy is a serious barrier to patients being able to have discussions with doctors and to be able to understand the information given to them about risks and alternatives. Where patients cannot read information, then they will struggle to be able to understand that information; if they cannot understand, then it becomes very difficult to feel like they have a meaningful role in deciding whether or not to have a treatment. The right to have information and be included in deciding how to be treated becomes a very empty notion he said.

Much work is needed to ensure that patients are better informed about their health, about treatments and about their rights before they even go into the doctor's office. Education and awareness-raising must be prioritized and supported in the community. Health professionals themselves can have an important role in this process. This has the benefit of breaking down the cultural barriers between doctors and patients. But it also increases the access of patients to the rights to which they are legally entitled.

Question and Answer

Question: Does the law give account to 'adequate' and 'accurate' levels of information?

Answer: We should assess and evaluate the level of information with regard to the information required to vindicate the patient's autonomy. This would mean that 'adequate' information is that information which would enable a patient to be able to decide, being aware of the risks and alternative treatments. The accuracy of information would have to be determined by available medical evidence – if there are problem with inaccurate information being disclosed to patients then may result in a successful claim of negligence.

Of course, the level of information will depend on the abilities and capacities of the patient. So, an adult would be treated differently to a child, whose understanding may be far more limited. This becomes more problematic with adolescents, whose ability to understand may be near that of an adult, but who are still under the care of parents. In England, the courts have taken the approach that a young adult has sufficient intelligence and maturity to understand the nature of the proposed

treatment, then it is their decision to take without the approval of their parents. Where the young adult does not have sufficient intelligence, it is for the doctor to determine what course of action would be in the patient's best interests. Whilst the doctor should direct themselves to what would be best for their patient, including respecting their wishes, there is, ultimately, room for the doctor to take a paternalistic approach.

Mercy Kakundakwe -IDI: Advocates for Patient Safety: A pilot study in a large HIV clinic

Similar to the event (Patient safety Symposium) on the 6th September 2018 , organised by CHAIN and other partners at IDI , Mercy explained the pilot case study in a large HIV clinic. She explained the overall lessons from the project to the patient safety advocates which included:

- Training on Patient Safety and rights is very important for clinic staff and patients.
- There is a need for further definition of the role of advocates.
- The active reporting of safety incidents in a transparent way allows for better planning and ongoing improvement of services.
- Advocates played key roles in recognizing and reporting issues, leading to resolution and quality improvement.
- Many of the incidents reported resulted from discussions with patients, emphasizing the importance of patient involvement on patient safety.

This all suggested that this type of training programme is both feasible and useful in detecting, resolving and reporting safety issues, but also for developing links between healthcare workers and patients. Embedded advocates in the patient safety framework can lead to improvements in the safety and quality of the healthcare system, and also the patient experience of the healthcare process. Since the pilot, 78 more trainees have begun training. More applicable to the patient safety advocates, she explained that the Infectious Disease Institute (IDI) can partner with other healthcare provider institutions. The training of advocates through the IDI can be rolled out to these providers as the programme develops. In the future, there are plans to extend the training programme to other healthcare actors, such as VHTs. At the moment, the VHTs have very different roles to the advocates – they act as auxiliary clinicians. But, there is scope to increase their advocacy roles.

Amanda Cattini – NTU: What is Dementia and Dementia Care

She explained what dementia is; a persistent disorder of the mental process caused by a disease on the brain or injury marked by memory disorders, personality changes and impaired reasoning. It is an 'umbrella term' for a range of diseases and injuries, such as Alzheimer's disease and Louis-Vardi's Diseases. At the moment, there is no cure for dementia. Rather, the symptoms must be managed.

In the UK, currently 1 in 14 people over the age of 65 will develop dementia. However, it is likely that in the future 1 in 3 people will suffer from dementia in their lifetime. However, the number of researchers working to understand, treat and support dementia and those who suffer from dementia is currently limited.

In the UK, for every 1 dementia researcher, there are 4 cancer researchers. London is working to be the first Dementia Capital City of the World, advocating, supporting and promoting dementia care. Support groups, 'dementia cafes', social organisations, clinics, training programmes and awareness campaigns have all been developed to ensure that there is holistic care for those living with dementia. However, there needs to be close cooperation between these different organisations, the research groups and healthcare providers to ensure that there is linked-up, coordinated work. One of the great challenges for effective dementia treatment is that sufferers 'fall through the gaps' – they may be admitted to hospital for their symptoms but not discharged into the care of community nurses and dementia support workers.

Currently a prevention campaign is underway. Whilst there is little research into the 'causes' of dementia diseases, it is generally understood that healthy living during earlier life (taking regular exercise, eating a balanced diet, keeping mental stimulated) can help to reduce the risk.

Sulah Mufumba – National Health Laboratory Services: Injection Safety

He started off by explaining the two aspects of injection safety: '*biosafety*' which protects the patient from harm caused by the application of the injection to their bodies and *biosecurity*' protecting the healthcare worker from the health conditions of the patient that they are treating.

He emphasized the importance of having Personal Protective Equipment (PPE) as its key to both biosafety and biosecurity – a basic example being the use of different gloves for each patient.

He highlighted the different question to consider before considering giving the injection and these include; why an injection is being used:

- Has it been prescribed by a doctor? Are there any other options that can be used?

- Other issues to consider included ensuring the injection is properly sealed. Before opening, the expiry date of the injection must be checked and has not expired. This should be done by the health worker, but patients should also be able to check.
- How is the injection being delivered – intra muscular (IM) or intra venous (IV)? For whichever route, the site must be chosen carefully and accurately to avoid pain for the patient and making the injection ineffective.
- How to dispose of the used injection? One injection for one patient and then dispose: the injection is then disposed of in the sharps box. But sharps boxes should only be filled ¾.
- There are problems though with availability of supplies.

He informed the participants that the correct procedures for injection safety are prescribed by AMLTA – ISO1169. It is mandatory to follow these standards.

Question and Answer

Question: Do patients have time and the opportunity to check the expiry date on all injections that they have? Will the health worker allow them to?

Answer: There must be a close relationship between healthcare workers and patients, built on a good rapport, with confidence and trust in each other's' abilities and intentions. However, there is always the challenge facing healthcare workers that they have limited time and large caseloads. This should not compromise the standard procedures. However, patients should feel comfortable to challenge them where they see standards not being followed. However, this will only happen if patients are empowered. Hence the urgent need to engage and empower patients.

He also shared how patients demand for injections due to ignorance, they believe if they do not receive an injection they will not get better.

Morgan Shimwell – NTU: Fake drugs – what is the WHO doing about them and what more needs to be done

The WHO appears to be working under the assumption that patients lack knowledge and rely on health professionals to educate them about their health conditions. The supply and consumption of falsified medicines is largely happening beyond the scope of the global medication safety programme, as it is currently outlined. Whilst accepting the need to try to limit the scope of an already complex programme, falsified medicines can and will have huge implications for medication safety. The assumption that patients can access health professionals, and trust them to provide them with, and educate them about, safe and good quality medicines could be proved deeply flawed if the medication safety framework fails to appreciate the dangers of falsified medicines. Further, falsified medicines have their own medication process, which is not visible, is poorly understood and is resilient to regulatory intervention. Excluding this from the strategic framework will only exacerbate these problems.

Participant comments and questions

Comment: A concern about regulators ensuring the high quality of drugs and enforcing against falsifiers/counterfeiters is the issue of corruption at the agency.

Question and comment: Who bears the loss when falsified/counterfeits are discovered? Patients have paid for them, pharmacists have ordered what they thought was a legitimate batch, but once these drugs are destroyed that money is lost. There needs to be mechanisms for recovery of losses from the counterfeiters (but this is incredibly difficult as the suppliers are hard to track down and are often outside of the jurisdiction) or compensation – but from who?

<u>Nathan Muyinda - General Manager and Managing Director of EDCO: Safe Use of Medicines</u>

Nathan works for a chain of pharmacies called ECOPHARM) and is an expert in medication safety. He explained that Uganda has a population of 34 million. He noted that these people seek healthcare in different ways and how they seek care is influenced

by many factors including availability, accessibility, affordability and acceptability.

Factors that have led many Ugandans to resort to other options which include traditional / herbal medicines which may not be validated. The prescribers in Uganda may be found in hospitals, but there are also 'prescribers'' in the community ('key opinion leaders'). These unofficial guides recommend to patients which medicines to use. This can compromise the quality of the information being received by patients. The lack of understanding about who is qualified and authorized to prescribe and deliver information can seriously impact safe use of medicines.

Drivers of poor medication safety:

- 'key opinion leaders' – these people thrive on the distrust that patients have for doctors
- Incompetent medical professionals – making incorrect diagnosis or prescribing inappropriate medicines. This may be because these people lack up-to-date information and Continuous Medical Education (CMEs). Or it may be due to lack of diagnostic equipment they fail to properly investigate and diagnose the patient's condition. The issue of Alternative 'quack' healthcare professionals is wide spread and needs to be curbed.
- Incompetent regulatory agencies – either not performing their duties adequately, or not doing so with the passion required to be diligent in their duties.
- Patients – demanding inappropriate medications, not following the instructions for safe usage.
- Self-medication is also prevalent

What can be done to reduce harms from medicines?

- Retraining medical professionals – updating their knowledge and sharing experience of safe usage and unsafe behaviors/side-effects/ADRs
- Have medication champions who raise awareness and advocate for safe use of medicine.
- Pharmacists must engage/discuss with patients to assess their understanding about use of medicines. This could include asking them questions about what time they can take the medicine – when do they work (work schedule), when do they go to bed. The pharmacist can then tailor their advice to that patient to ensure that they use their medication safely.
- Pharmacists can check patients' medication lists to ensure that the medicines will not contraindicate each other or cause severe side effects. This may also include checking whether the patient really needs the medicine – DE prescribing may need to be explored.
- Patients need to take some responsibility for trying to manage their own medication lists. At the least, this can mean asking those who are experts

(pharmacists, doctors) for medication instructions and to discuss side-effects/ADRs/contraindications. Building relationships with these experts will make these conversations easier.

DISCUSSIONS

- The development of policies by different agencies is underway, but implementation is a challenge. There is need for government support and commitment at all levels.
- The NDA enforcement teams are increasing efforts to crack down on unregistered drugs and drug shops. However they need to strengthen their enforcement and regulatory systems as well as support of relevant agencies such as police.
- Why many people in Uganda opt for traditional medicine/practitioners?
  The following were highlighted; Cost – it's much cheaper than the modern medicines and there is no consultation fees required to see a traditional practitioner as opposed to seeing a doctor, one can pay through a barter system.
- Poor attitude of healthcare workers drive away patients, the traditional practitioners are very good at handling their customers, they have mastered the art.
- Long waiting hours to see health professionals
- Public scandals and unethical practices in healthcare lead to loss of trust in healthcare system.
- There is confusion about the difference between branded products and generic products. Practically, this becomes a problem when a patient goes to a pharmacist and is faced with many different versions of the same drug. How are patients to know which drug to take?
- Whilst in principle generics should have the same biological effect, and be of the same quality, as the branded products. However, in practice there can be variation in the effectiveness of generic products, and even variation in the dosage of active ingredients. This should be identified by regulators initially through licensing but through monitoring and inspections whilst the drug is on the market. However, it is apparent that inspections may not be as regular as required and testing of the products only taking place when problems have been reported.

- Whilst generic medicines can provide essential, affordable medicines, they are also fertile ground for falsified/counterfeits to enter the market, given the lack of patient understanding about generics, lack of familiarity with these 'brands' of generics and overseas manufacture.

Regina Kamoga – CHAIN: Engaging Patients, Family and Community in Patient Safety

Ms Kamoga shared her personal experience with patient safety and joining the WHO Patients for Patient Safety programme in 2011.

She talked about person-centered care and how it places the values and needs of the patients and families at its centre. It also gives power to patients to be involved in the medical process. Importantly, patients are able to raise questions and may be better placed to notice when harmful actions are about to take, or have taken, place than the busy health professional.

She also talked about community engagement and how it is about true partnerships, with collaborative relationships between patients, families and healthcare professionals. This requires relationships of mutual trust and respect facilitated by open, honest communication.

- Patients can be experts in their own right, with a wealth of experience of their health conditions and treatments. This knowledge and experience should be harnessed by health professionals for more effective treatments.
- Patient and family engagement can have benefits for patients, healthcare professional and healthcare providers, including more effective and efficient management of health conditions (especially chronic illnesses), safer healthcare environments, a reduction in the diversion of patients to traditional healers, better trust and confidence in the healthcare process and reductions in complaints and litigation.

She informed the participants about CHAIN's work and how it has engaged and empowered patients and communities on different patient safety issues including: medication safety, hand hygiene, injection safety, participation in clinical trials, maternal and child health issues. Its approach is collaborative: with patients, healthcare professionals, healthcare providers, regulators, WHO.

- CHAIN utilizes a diverse range of activities to raise awareness – SMS text information dissemination, dramas, music, community outreaches, school debates.
- Patient Safety is being recognized in Uganda and has been prioritized in the National Development Plan 2015/16 – 2019/20 and there is now a global patient safety agenda. However, developing countries need to engage and be engaged in these high-level policy meetings to ensure that policies under development reflect the health needs of these countries.
- CHAIN has worked with Medical Face International to organize National health research and debates in primary schools –working with school children to improve health literacy. Teaching these children safe practices and behaviors from an early age enables adoption of principles, values and practices of safe care into their daily lives thus inculcating a patient safety culture at an early

age. Through debates, instead of telling children how to think and do things, the programme asks questions and encourages the children to research the answers. This empowers children to seek answers, to think critically, to inquire about how to improve. Their learning trickles down to the family and the community. The children; families have provided testimonials about how much their own health behaviors have changed as a result of their children's learning. However, the programme needs to be rolled out to more districts and requires funding.

SHARING EXPERIENCES ON PATIENT SAFETY

Patient safety advocates have been working since the first National PFPS workshop in 2015. Since then they have been working within their respective organisations and communities to advocate and promote patient safety.

Experience 1: Elizabeth Tindyebwa – IDI: Greater Involvement of People with Aids (GIPA)

Elizabeth participated in the PFPS workshop in 2015 and when she went back to IDI, she shared with her supervisors about patient safety. They readily appreciated and embarked on the process of integrating patient safety into their work. Mrs. Regina Kamoga was invited to support the process. A pilot project was conducted (see Mercy's presentation above).

The advocates ('Friends Counsel') are based in clinics to bridge the gap between healthcare workers and patients, to provide advice and information on a range of safety issues and to raise awareness of patient rights. The advocates work to create harmonious relationships. They feel empowered and are making a real difference at the clinics.

The IDI is developing an incident reporting policy, which helps to identify the types of errors occurring and to respond to common problems.

Experience 2: Magola Samuel, VHT Coordinator, Kampala
Patient safety is a complex issue. Small steps have to be taken to start the process of bringing about change. In practice, one of the first steps is to teach communication skills to healthcare workers and students at medical school as a means of improving doctor patient relationship and patient outcomes.
'If the relationship is not good, the patient will not tell the doctor how he truly feels and this may lead to misdiagnosis!' Magola says.

He further added that health workers look at patients as mere objects or even worse as a source of income. They should look at them as people with feelings and needs, who need to be cared for. Magola's work is mainly focused on improving patient doctor relationship because he thinks that's where the real problem is. He also raises

awareness in the community on patient rights and responsibilities. His major challenge though is working with health workers. They have not yet appreciated the value patients/patient advocates they bring to the healthcare process. He has hope though that with continuous awareness, things will get better.

Experience 3: Sheila Natenda – Golden Centre for Women's Rights

Ever since participating in the PFPS workshop, she became more aware and passionate about patient safety. She integrated patient safety in her HIV/AIDS work. She uses every opportunity to promote patient safety. The Golden Centre works with women with HIV or at risk of infection, including women involved in the sex trade. They offer trainings on ARV treatment, transmission of mother to child transmission, medication protocols, the side-effects of treatment, and the effects of non-adherence to treatment, hygiene and safe sexual practices. In 2018, so far, 14 people have been educated in HIV treatment while 16 others have been educated about the Patient Charter 2009 to increase awareness of patient rights and healthcare providers' responsibilities. They also empower their beneficiaries with income generating activities.

Patient Safety Advocates share experiences on Patient Safety in the communities

Experience 4: Mastulah Nakisozi - Kawempe Home Based Care

After attending the patient safety workshop, she incorporated patient safety issues particularly safe use of medicines in their work.

She shared how patients were not attending clinics because of negative experiences encountered and resorted to buying medication from unsafe sources because they were cheaper and had good customer care. Mastulah and her team educate the patients and community about the dangers of buying medicines from unauthorized sources. They are given tips on how to take, store their medicines and report side effects. They have been vigilant in identifying and reporting people who deal in drugs illegally in the community. This has led to closure of some of these clinics and drug stores.

Experience 5 Resty Nalwoga
Shared a testimony of misdiagnosis. Resty was misdiagnosed and given wrong treatment for malaria. This resulted in severe illness which almost killed her. The problem was later identified and she was given proper malaria treatment. Resty is one of the many people who suffer preventable harm of near miss incidents. Upon becoming a patient safety advocate, Resty returned to her community to share her training on patient safety, a topic she said was new to the people as it was for her before she attended the workshop.
There were many issues especially misuse of medicines and non-adherence. Many patients do not want to be on medication, especially for a long time, while others use herbal medications which they also mix with modern medicines. She took it upon herself to educate people in her community on proper use of medicine.

Experience 6: Harriet Nakayiza :
Harriet says she gained a lot of information on patient safety, she learnt that many people not only in Uganda where have been affected by unsafe care. It was shocking to hear many stories of how people were harmed and some losing their lives, even health workers.
When she went back to her organization after the workshop, she was determined to make a change in her community. Her organization works with sex workers on issues of health rights, Water Sanitation and Hygiene to reduce the spread of infections. They have also engaged with community lodge owners to ensure that they are have constant running water because many of these lodges in the community do not have water for their clients.

Concluding remarks and Way forward

John Tingle and Regina Kamoga

- *"There are significant challenges facing patients, healthcare workers, advocates, and health-promoting organization. However, there is fantastic work being done by the advocates and other organisations. Real change is being done and will continue to be done. The health of Ugandans is being improved by this work. This must be celebrated"*, Prof. Tingle noted.

- John applauded CHAIN's work on patient safety, which he learnt about when he was searching on line for organisations involved in patient safety in Africa. He contacted Regina and that's how this partnership was formed. The university will continue to work with CHAIN and the ministry to advance patient safety.

- Regina applauded the patient safety advocates for their work on patient safety."Patient safety is still a grey area which has not been appreciated by many people. It is therefore important for each one of us here to make a contribution at their level".
- Advocacy right from community to international level is needed.

Lessons Learnt and Way Forward

- Limited awareness on Patient safety among key stakeholders
- Ministry of health, WHO, regulatory authorities such as National Drug Authority(NDA) academia, research institutions, supply chain organisations need to work together in a coordinated effort to design and implement appropriate interventions to address safe and quality care
- Research on patient safety is urgently needed for evidence based interventions
- Patient safety should be incorporated in service delivery systems and medical curriculum
- Funding is needed to support patient safety initiatives
- Establishment of patient safety advocates networks throughout the country
- Regular meetings for patient advocates to share their experiences and develop a strong network that will drive systemic change.
- Collect and share patient stories of harm and positive experiences
- Uganda Patient charter should be disseminated widely , there is very low awareness on patient rights and responsibilities

PICTORIAL

Patient safety advocates during the meeting

CERTIFICATES FOR THE EDUCATED PARTICIPANTS

The participants were awarded certificates, signed by Regina on behalf of CHAIN and John Tingle on behalf of Nottingham Law School, recognizing the contribution towards patient safety and knowledge acquired during the event.

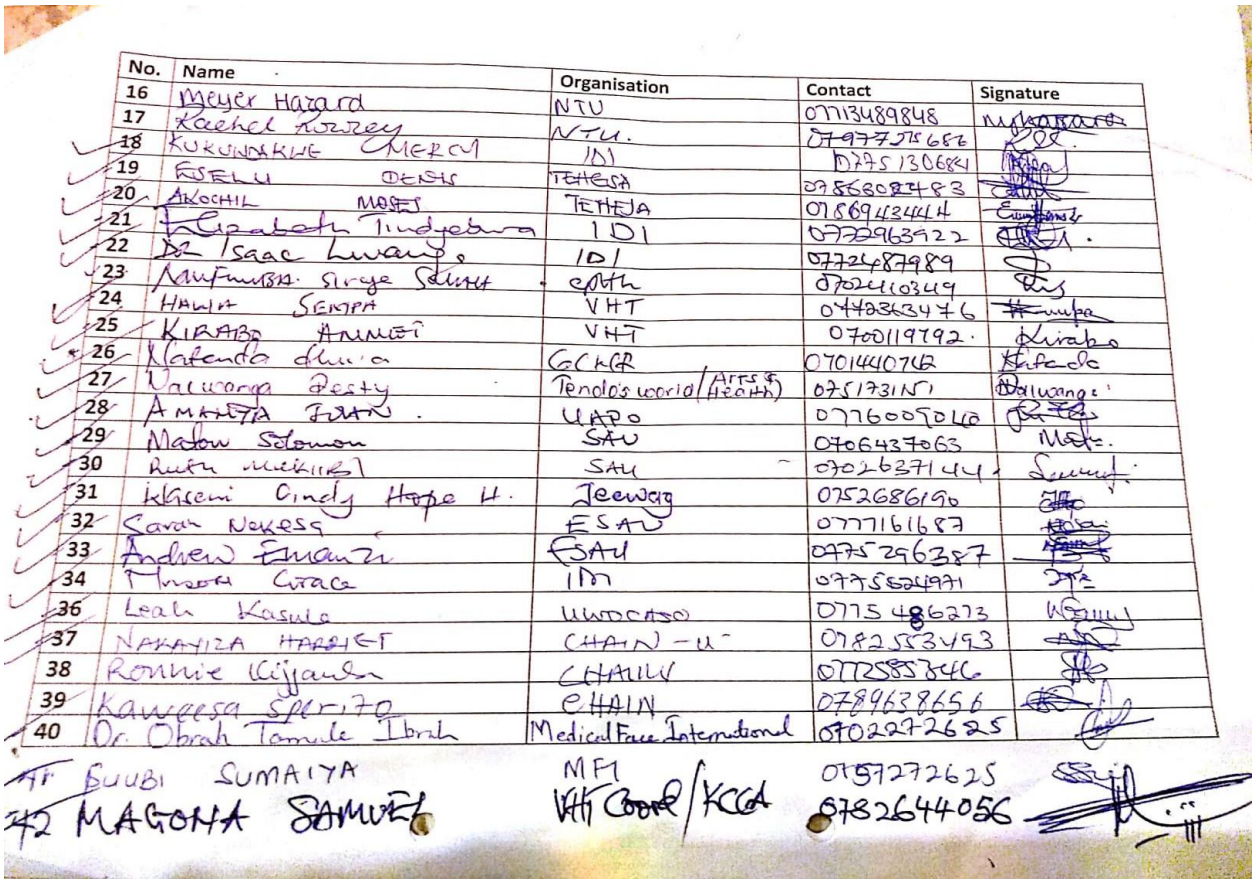
ANNEX

PARTICIPANTS' LISTS

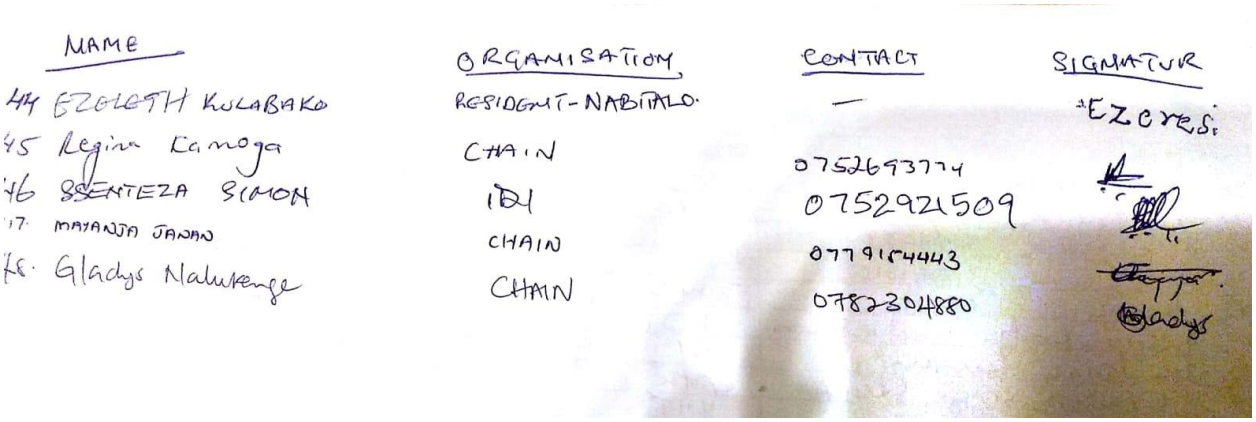
PATIENT SAFETY MEETING AT CHAIN KIWENDA: 7TH SEPTEMBER 2018

REGISTRATION FORM

No.	Name	Organisation	Contact	Signature
1	Rose Wakikona	CEHRD	0774033436	
2	Kashaija Annet	KHBCA	0704620570	
3	NALUBOZI MASTULAH	KHBCA	0753524741	Mastulah
4	MUWANIKA DANIEL		0758080903	
5	MUYINDA NATHAN.	Edco International	0701560340	
6	Njazima Aonny Silus	ICAD	0775562020	
7	John Tingle	NTU	01159777036	
8	MUYIRA GODFREY	CHAIN	0772428493	
9	Jacqueline Evers	CHAIN	0786286319	
10	Tina Wallner	CHAIN	07862132345	
11	JAMES LULE	KADDU	0776380676	
12	Josephine Nabulyu Otunol	UAPO	0772936892	
13	MORGAN SHIMWELL	NOTTINGHAM TRENT UNI	07549663529	
14	Clayton O'Neill	Nottingham Trent Uni	00447722347781	
15	Amanda Cattini	"	07534389111	



No.	Name	Organisation	Contact	Signature
16	Meyer Hazard	NTU	07713489848	
17	Rachel Kerrey	NTU.	07977756[illegible]	
18	KUKUNDAKINE MERCY	IDI	0775130684	
19	ESTELLA DENIS	TEHESA	0758082483	
20	AKOCHIL MOSES	TEHEJA	0756943444	
21	Elizabeth Tindyebwa	IDI	0772963922	
22	Dr Isaac Luwaga	IDI	0772487989	
23	Nanfuuka Sirya Sarah	CMTH	0702410349	
24	HAWA SEMPA	VHT	0742363476	
25	KIRABO ANNET	VHT	0700119792	
26	Nalenda Olivia	GCKGR	0701440762	
27	Nalwanga Resty	Tendos world (AIDS & HEALTH)	0751731151	
28	AMANYA JOAN	UAPO	0776005040	
29	Matovu Solomon	SAU	0706437063	
30	Ruth Nakiibi	SAU	0702637144	
31	Kisseni Cindy Hope H.	Jeeway	0752686190	
32	Sarah Nekesa	ESAU	0777161687	
33	Andrew Ewanzu	ESAU	0775296387	
34	Timoth Ciraca	IDI	0775524971	
36	Leah Kasule	UWOCASO	0775486273	
37	NAKAYIZA HARRIET	CHAIN-U	0782553493	
38	Ronnie Kijjambu	CHAIN	0772553546	
39	Kaweesa Spencer	CHAIN	0789638656	
40	Dr. Obrah Tomule Ibrah	Medical Face International	0702272625	
41	BUUBI SUMAIYA	MFI	0757272625	
42	MAGONA SAMUEL	VHT Coord/KCCA	0782644056	



NAME	ORGANISATION	CONTACT	SIGNATURE
44 EZEKIEL KULABAKO	RESIDENT-NABITALO.	—	
45 Regina Lamoga	CHAIN	0752693774	
46 SSENTEZA SIMON	IDI	0752921509	
47 MAYANJA JAMAN	CHAIN	0779154443	
48 Gladys Nalukenge	CHAIN	0782304880	

Thank You!

Keep in touch with us:-

Website: www.chainproject.africa
Email: info@chainproject.africa
regina@chainproject.africa

namata.kamoga@gmail.com