



International Alliance of
Patients' Organizations
A global voice for patients

Working Together to Strengthen Healthcare Systems in Africa

Kampala, Uganda  November 2008



regional
meeting
report
FOR AFRICA



Organized by the International Alliance of Patients' Organizations (IAPO)

With our thanks

The IAPO Governing Board and Staff Team would like to thank everyone who gave their valuable time in planning, hosting, facilitating and participating in this fantastic series of events in Kampala, Uganda. In particular, we would like to thank Regina Namata Kamoga, Community Health and Information Network (CHAIN), Rita Sembuya, Joyce Fertility Support Centre (JFSC), and Robinah Kaitiritimba, Uganda National Health Consumers' Organisation (UNHCO), for their amazing energy and commitment to hosting these events. We would also like to thank and acknowledge those that sponsored the event: GE Healthcare; the Medtronic Foundation; and the Pharmaceutical Research and Manufacturers of America (PhRMA). We would like to thank Design IT Ltd for the meeting photography as included in this report. Finally, we would like to thank all the participants for their enthusiasm and engagement in the workshop which ensured that we had a very productive day and have a strong foundation on which to build future collaborations.

Meeting materials

The meeting programme including the agenda, speakers' PowerPoint presentations, the participants list and other resources are available on the IAPO website at: www.patientsorganizations.org/africa

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Introduction



On Monday 3 November 2008, IAPO hosted three events in Kampala, Uganda. The aims of these events were to help develop the productive networks between patients' organizations working in Africa; to move towards stronger multi-stakeholder working in African healthcare systems; and to strengthen the contribution of the African patient voice in international healthcare policy.

During a day-long workshop, representatives from 25 patient groups had the opportunity to work together towards advocating for patient-centred healthcare. The participants came from seven countries: Ghana, Kenya, Nigeria, South Africa, Tanzania, Uganda and Zimbabwe. The groups represented patients with a range of health conditions including diabetes, HIV/AIDS, mental health, autoimmune diseases, haemophilia, cancer and epilepsy. The groups were then able to employ these collaborative approaches to advocacy during a multi-stakeholder panel discussion later that day, where they joined representatives from the Uganda Medical Association (UMA) and Makerere University (Kampala, Uganda) amongst others. Participants continued their discussions during an evening reception, which was attended by high-level stakeholders including representatives from the Ugandan Ministry of Health.

A key outcome of the day was that the patient groups made a strong call for African governments and all stakeholders in healthcare to:

- **Work together to provide patient-centred healthcare for all patients in Africa**
- **Involve patients and patient representatives as equal partners in healthcare decision-making to strengthen healthcare systems in Africa**

We look forward to working with our new colleagues and friends in Africa towards stronger healthcare systems which address patients' needs in Africa and worldwide!

Joanna Groves
Chief Executive Officer, IAPO

The Importance of the Patient Voice in Africa



I would firstly like to express my appreciation to all of the IAPO members who made the workshop such a great success. It was such an important opportunity for Uganda to share its successes and challenges in regard to patient-centred healthcare. We do believe that the journey to patient-centred healthcare in Uganda, and Africa, is long, but at the same time we are motivated to take this path no matter the challenges.

Some of the greatest barriers to improving African healthcare include the inadequate level of financial resources received by the health sector; a lack of human resources such as doctors; stigma and discrimination which inhibits diagnosis and treatment; inadequate information on health and healthcare; and inadequate access to medical facilities and treatment. These problems are compounded by widespread poverty and a lack of collaboration between and within sectors.

Though these challenges are great, I strongly believe, as do many of my fellow patient advocates in Africa, that we can improve the situation through the practice of patient-centred healthcare. Patient-centred healthcare is the most effective way to align healthcare systems with patients' needs. This workshop has significantly helped us, as patient advocates, in this work as we are able to take home new knowledge, ideas and actions along with renewed enthusiasm to enable us to further promote patient-centred healthcare.

This visit to Africa has increased IAPO's understanding of the very different realities in different regions, yet we also continue to find that we have a shared purpose that unites patient groups across borders. IAPO is strongly committed to supporting this newly created network of patient groups in Africa, so that they speak as one and so they make a valuable contribution to strengthen the international patient voice.

At IAPO we believe that 'Together we can...', and here in Uganda we have a Kiganda proverb, 'AGALI AWAMU, GE GALUMA ENNYAMA', which means 'the teeth that are together are the ones that are able to bite the meat'. Both express the fact that we cannot work in isolation and we cannot achieve patient-centred healthcare without the collaboration of others, so as patient advocates and supporters of patient-centred healthcare in Africa we are positive that we can succeed by working closely together.

Regina Namata Kamoga
IAPO Board Member and Country Manager (Uganda),
Community Health and Information Network (CHAIN)



Healthcare in Africa: Towards Patient-Centred Healthcare

“Noncommunicable diseases (NCDs) are increasing in epidemic proportions in developing countries. In Africa, they represent a significant burden to the public health services of Member States that still have to contend with the unfinished agenda of communicable diseases.”¹

In order to address the chronic pressure that both communicable and noncommunicable diseases place on healthcare systems in Africa, it is necessary for patients to be involved in strengthening the system, and critical that they are encouraged to play a role in ensuring better healthcare for Africa. During the workshop, the participants shared their experiences of the challenges to accessing patient-centred healthcare in Africa, and the strategies they are using, or could use, to overcome them.



Stephen McMahon, IAPO Board Member, facilitating group discussion on Patient Information

Working in groups, participants had the opportunity to discuss these issues

as they relate to four of the key themes of patient-centred healthcare: **Access to Healthcare; Patient Information; Patient Involvement in Healthcare; and Patient Safety**. This was a stimulating session in which participants considered how issues that affect their work are also present in other disease areas, and other countries within the region.

The outcomes from this session provided an overview of some of the challenges currently facing African healthcare systems, identifying key barriers for patients in accessing safe, appropriate healthcare, and helping to engage with and strengthen health systems in Africa. With this shared understanding we can start working together to address these issues.

This report provides a summary of these challenges and, most importantly, the hope and actions that participants will take to drive forward patient-centred healthcare and patient involvement throughout Africa.

Access to Healthcare



Resources

“Sub-Saharan Africa... While it has 25% of the global burden of disease, has only 3% of the world’s health workers. Thirty-six countries in Africa are confronting critical shortages, meaning they have fewer than 2.3 doctors, nurses and midwives per 1000 people.”²

Participants told of many experiences that highlighted the chronic lack of resources, facilities and health workers in Africa; shortages that are preventing many patients from accessing the healthcare that they need. Poorly funded and resourced medical centres, expensive drugs and a lack of medical expertise in many areas make access to treatment often difficult or impossible. Many diseases, for example, breast cancer go largely untreated because of a lack of medicines and healthcare facilities. Participants said that in Uganda there is only one cancer clinic in the whole country, with only one radiation machine, and mammography is not available at all. IAPO staff and Board Members visiting Mulago Hospital, the main hospital in Kampala, found that even basic equipment, such as stethoscopes and blood pressure pumps, were in short supply.

There are some successes, with the governments of Nigeria and Kenya now manufacturing anti-retroviral drugs for the treatment of HIV and AIDS, available at no cost to the patient. Participants were committed to addressing these fundamental issues and highlighted some of the positive roles that patient groups can play, both in advocating for essential treatments and resources and, in some cases, in finding new ways to ensure patients receive medicines such as the patient group procuring and providing medicines.

Social Stigma

The stigma associated with a number of diseases and medical conditions in Africa was reported by many participants as a major barrier to patients accessing the diagnosis, advice and treatment that they need. An example of social and government responses to Sickle Cell in Uganda was given. The disease is highly stigmatised and often people do not admit that they or their children have the disease. Participants explained that many misconceptions exist, for example, people often do not realise that you can survive to adulthood or live a relatively normal life if you have Sickle Cell. These problems, combined with a lack of resources or public awareness campaigns by the government, lead to many patients dying before they can access treatment. Other diseases where participants highlighted that stigma creates a barrier to access to healthcare in Africa included HIV and AIDS, arthritis, epilepsy, mental health, and cancer.

Patient advocates highlighted the positive approach they are taking to address this situation. For example, the Sickle Cell Association of Uganda provides counselling, information and support to those diagnosed with Sickle Cell. These simple services are starting to show success in overcoming the problem of stigma around Sickle Cell in Uganda.

² WHO Website, Do most countries have enough health workers?: www.who.int/features/qa/37/en/index.html [Accessed: 04/12/2008]

Distance from Healthcare Settings

“Only 49% of households... have access to healthcare facilities in Uganda. Access... has been limited by poor infrastructure, especially in the rural areas where the majority of the population live.”³

Participants raised the issue of distance from healthcare settings as a major barrier to accessing care for patients in Africa. Even when diagnostic or treatment facilities exist they are often centred in the major cities. Many people live in rural areas where the infrastructure is often very poor. This can prevent them from accessing the treatment that they need.

Patient groups are playing a vital role in ensuring that those in remote areas can access the health services they need. For example, Community Health and Information Network (CHAIN) are dealing with this problem by undertaking income-generating activities to address the poverty that prevents people accessing transport so that they can travel to clinics and medical centres from rural settings.





Communities – Misinformation and Mythology

Misinformation and mythology concerning certain conditions and diseases continue to have dire consequences for health and social well-being in Africa. Participants reported several myths that they had encountered through their work. For example, rumours have spread that sleeping with a virgin can cure HIV and AIDS. Rumours are sometimes perpetuated by community leaders and others in authority; those that are often trusted as reliable and respected sources of information. Public health information is also misinterpreted. There was a drive in Uganda to encourage male circumcision, as it is known to reduce the risk of being infected by HIV. However, this message developed into a rumour that led people to believe they could not be infected by HIV if they were circumcised.

Many of the groups are working on providing accurate information to patients. They stressed the important role of community organizations as providers of health information, as they are ideally placed to make contact with those most in need, and were often able to communicate more effectively with local people. Former patients also have an important role to play as the information they pass on is trusted. Through their experiences, they are able to prove rumours to be false and can act as positive role models for others in the community.

Information and Literacy

“In some of the poorest countries, such as Niger and Burkina Faso, only 10% of women can read and write. A mother’s level of education correlates closely with a child’s risk of dying before age 2.”⁴

Low levels of literacy and health literacy are a major barrier to informing patients about health issues in Africa. Often information presented in a written form, such as leaflets, will be thrown away either without being read, because the person has a low literacy level, or after one reading but before messages have had a chance to be understood and remembered.



Patient groups are engaging in innovative and successful work to address these issues, such as using drama and songs to convey health messages to people. Another example given was the series of award-winning speaking books⁵ developed by the South African Depression and Anxiety Group (SADAG), being demonstrated here by Elizabeth Matare, Chief Executive Officer.

⁴ IS Kickbusch (2001), Health literacy: addressing the health and education divide. Oxford Journals, 16 (3), 289–297.

⁵ Speaking Books: Books of Hope Website: www.booksofhope.com



Patient Involvement

Health Professional-Patient Relationships

A major problem highlighted was the relationship between patients and health professionals in Africa and particularly the communications between them. This problem can be caused by either party. Some patients may not give accurate information about their symptoms, which can lead to misdiagnosis. They may also be reluctant to ask doctors questions about their condition or the treatment options. Participants also drew attention to a common problem of doctors giving limited information about treatments to patients because of time pressure on them. There were also a number of examples discussed where patients were not given information about, or involved in decisions about, their treatment, which may have ramifications not only for their prognosis but also the way that they live their lives. Doctors carry a high social status in Africa and it can be hard for there to be an open relationship between patients and their doctors.



Participants agreed that informed patients can help to address the communications gap by having the confidence to ask doctors appropriate questions, and engage actively in treatment decisions. This is an area where through training and educating, patient groups are helping patients to take a positive role in their own healthcare. The National Care Centre (Uganda) provided an example in the area of mental health where there are a number of problems. The first is that medicines are not available for people with mental health conditions and so they act erratically and are then picked up by the police for unsocial behaviour. Often the police do not recognise that the person is mentally ill and so do not call anyone to get support for the person. The National Care Centre therefore involves police and health workers in workshops to raise awareness and help them to understand the situation and what they can do about it. A positive step that patient groups can take is to provide information to health professionals and community leaders, through meetings and workshops, so that they have the capacity to understand the healthcare issues and how to communicate with patients.

Patients Helping Themselves

Participants spoke of the importance of the role that patients themselves have, both in taking responsibility for their own health and gaining support and motivation through peer support mechanisms. Groups working with people with different conditions, such as HIV, epilepsy and infertility, described the powerful connection that patients often have with those that have also experienced their particular condition. The Zimbabwe Haemophilia Association described how they encourage their members to give some time to be involved in their work, including speaking to other patients. The connection between patients can be harnessed to provide support to others, and to create changes in lifestyle choices such as nutrition and exercise, and promoting the taking of medicines correctly.

Patients on Health Committees

“Dialogue between healthcare providers and patients has begun, and consumers increasingly know and demand their health rights. The notion that the healthcare provider is KING is slowly disappearing.”⁶

One of the main methods of involvement that participants considered important was participation on committees with health professionals, policy-makers and others. They believe that there is a very great need for this type of patient engagement. One participant shared his organization’s experience of joining a committee where it was apparent that they were only included as a token patient representative, and that the input they gave was never reflected in the policies that came from the committee. After speaking to the committee’s convenors the situation has now changed and they are able to have meaningful input, which influences the policy outcomes from the committee. Another participant highlighted the importance of patients speaking with one voice, to ensure real improvements for all patients, not small improvements for one disease group or another. She also advocated for the importance of patient groups engaging with central government on health policy, as well as budget allocation and other areas that affect patients.



[One] participant highlighted the importance of patients speaking with one voice, to ensure real improvements for all patients //

⁶ Participant/Presenter Robinah Kaitiritimba, National Coordinator, Uganda National Health Consumers Organization (UNHCO).



Patient Safety

Drug Safety

Many different issues relating to drug safety were raised by participants: ineffective treatment choices; the wrong dosage given; problems with administering of drugs; inadequate guidance on the issue of counterfeit medicines; problems managing unexpected side effects; and poor patient compliance, particularly amongst those taking anti-retroviral medicines for whom timing and nutritional needs are complex. Lack of staff capacity and inadequate training were cited as causes. It was felt that better training was needed for pharmacists, in particular, as well as other healthcare workers. Many also cited the lack of suitable patient information, and the lack of engagement with families and carers of patients regarding the drugs they were given, possible side effects, and compliance.

Participants outlined a number of positive ways to improve the situation including advocating for better training of healthcare professionals, involving patients and their families in care, and improving patient information so that patients know how to take their medicines correctly and recognise any adverse effects of their treatments.

Injection Safety

“Up to a quarter of all injections in East and Southern Africa are given with reused needles in the absence of sterilization per year.”⁷

Participants raised a number of issues relating to injection safety. In particular the use of unclean needles leading to infection with HIV, Hepatitis B and C, and other blood-borne diseases. The incorrect administering of intravenous drugs had led to infection and even amputation. It was felt that healthcare workers did not have enough knowledge about injection safety and that better training and guidelines were needed. Participants discussed that they have a role to play in advocating for stronger government policy and guidelines on injection safety and for necessary training of healthcare professionals to follow the guidelines.

Hygiene

The crucial issue of hygiene in healthcare settings was raised. Many healthcare settings lack fundamental facilities, such as running water, which makes it difficult to maintain a basic level of cleanliness. On a visit to Mulago Hospital, Kampala, IAPO staff and Board Members saw this for themselves. One staff member wrote of the visit: *“Conditions were unsanitary, and there was no sign of hygiene notices or posters for patients or staff. A man had died in the corridor outside the labour ward and had been covered with a sheet and a screen, but it took some time for the body to be removed, and the area did not appear to have been cleaned afterwards.”* Participants recognised the challenges in the hospitals and that a comprehensive approach would be needed to improve the situation, focusing on changing simple practices to improve the hygiene in hospitals.

Working Together Across Boundaries



Having discussed the issues that are affecting patients in Africa, participants spent the afternoon session working together in small groups forming joint advocacy approaches to common issues. IAPO believes that we cannot achieve patient-centred healthcare by working on our own, and that patients are able to effect more change when they work in partnerships across all areas of healthcare development and delivery. Partnerships with patients' organizations, policy-makers, hospitals, professional bodies, industry and others are central to IAPO's work and considered to be of great value.



Tendayi Westerhof, Public Personalities Against Aids Trust – Zimbabwe, presenting her group's advocacy plan to the room

The groups considered how they could work with stakeholders who they are not currently actively engaging with, including those in different disease areas or even in different countries who may have similar concerns. Within a limited amount of time the groups came up with some compelling plans, which can act as a basis for advocacy campaigns in the participants' home countries or disease areas.

"I learnt that it is not only for cancer patients, or in African countries, that the lack of patient-centred healthcare is a problem, but across all diseases and globally. I learnt that we can work as a team regardless of disease or race and achieve positive results for the people that we serve. I also learnt that in advocacy it is important to involve all stakeholders, including enemies, to be able to achieve results."

Gertrude Nakigudde, Public Relations & Advocacy Officer, Uganda Women's Cancer Support Organization (UWOCASO)



Multi-Stakeholder Panel Discussion



The panel (from left to right): Dr Ute Jenifer Kavuma, General Secretary, Uganda Medical Association; Dr Maxwell Abok Amullah, Deputy Director, Operations, Regional Centre for Quality of Healthcare; Obatunde Oladapo, Chair, Positive Life Association of Nigeria; Dr Eugene Rurangwa, Executive Strategy, Great Lakes Initiative on HIV/AIDS (GLIA); Myrl Weinberg, Chair, IAPO

In the afternoon seminar, patient groups joined a panel discussion with a wide range of stakeholders from across the healthcare system in Uganda. The question posed for discussion was: *'How can working with patients strengthen healthcare in Africa?'* Brief opening remarks provided by panelists led to an open discussion with stimulating and in-depth debate.



A number of important points were raised through this forum. Many of the patient representatives stressed their willingness and ability to play a key role in supporting and educating patients, and requested that broader recognition is required from all the stakeholders, including the Ministries of Health, so that their role is both supported and meaningful.

The panelists acknowledged the key contribution of patient groups to healthcare systems, and the challenges of ensuring broader recognition among those involved in healthcare delivery. Several panelists urged the patient

groups to work together to strengthen their messages and to advocate broader cross-cutting objectives, stating that these would be easier to respond to and would be more likely to achieve long-lasting results.

Moving Forward



Next Steps for IAPO

This meeting was IAPO's first regional event and has been a great opportunity for all involved. Over the coming years IAPO will develop this work; building the capacity of patients' organizations and patient networks at the regional level, in turn strengthening the global voice on patient-centred healthcare.

Since IAPO is currently consulting with our membership and external experts for our next strategic plan, this is a good time for the knowledge gained from this event to inform actions proposed for our next strategic plan. Due to start in 2009, this plan will build on the strengths of our work to date. IAPO is committed to working with and supporting patient groups all over the world and to learning from those based in Africa. In the future, we hope to build on our successes in Africa.

Next Steps for Patient Group Participants

*"According to today's workshop I plan to strengthen partnerships because two heads are better than one, therefore if we meet in a coalition we are able to come up with solutions to our problems."*⁸

The patients' organizations that attended these events have indicated that they will be taking forward their new learning and networks in a wide range of ways. Of the 19 organizations that completed evaluation forms:

- Seven organizations plan to use the principles of patient-centred healthcare to guide their work in a more significant way
- Seven organizations plan to run workshops with their colleagues and others to share what they have learnt
- Six organizations are planning to establish new local (3), national (1) or pan-African (2) networks of patient organizations
- All 19 organizations plan to work more collaboratively and with new partners, whether in other disease areas or from central government

*"I plan to mount a systematic patient/citizen advocacy campaign on the participation and involvement of patients in the processes towards developing National Health Policies."*⁹

Whatever approach is planned the goal is the same: 'To get patients' voices heard in African healthcare systems.'

⁸ Susan Mukanza, Asst. Administrative Officer/Members' Department, Joyce Fertility Support Centre, Uganda.

⁹ Elizabeth Matare, Chief Executive Officer, South African Depression and Anxiety Group (SADAG).



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