

# 2012

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## **REPORT OF THE CIVIL SOCIETY MEETING WITH THE UN SPECIAL RAPPORTEUR ON THE RIGHT TO HEALTH**

The meeting was organised by CEHURD with funding support from the UNDP on Tuesday, 14 August, 2012, at the Hotel Africana, Kampala. The objective of this meeting was to give the Rapporteur on Health the opportunity to hear, firsthand, the different perspectives on key issues challenging access to essential medicines, particularly as they affect constituents of the different stakeholders.

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### LIST OF ABBREVIATIONS

|       |  |
|-------|--|
| ICWEA | International Community of Women Living with HIV/AIDS in East Africa |
| CHAU  | Community Health Alliance Uganda                                     |
| RHU   | Reproductive Health Uganda   |
| T.B   | Tuberculosis   |
| EAC   | East African Community   |
| MHCP  | Minimum Health Care Package  |
| HC    | Health Center  |
| MOH   | Ministry of Health   |
| EMONC | Emergency Obstetric Care   |
| NMS   | National Medical Stores  |
| NDA   | National Drug Authority  |

# 1. INTRODUCTION

## 1.1 Background

In his capacity as UN Special Rapporteur on the Right to Health, Mr Anand Grover, was directed by the UN Human Rights Council to present a special report on access to medicines by March of 2013. In that regard, he visited Uganda between 12 and 15 August 2012. Meetings with Government bodies, pharmaceutical manufacturers, civil society, communities, and other stakeholders were set up for him.

CEHURD, supported by UNDP, convened the meeting between the Rapporteur and the civil society. The meeting was attended by 89 civil society representatives, including members of the media. The meeting took place on 14 August 2012 at Hotel Africana in Kampala.

The objective of the meeting was to give the Rapporteur the opportunity to hear, firsthand, the different perspectives on key issues of access to essential medicines, particularly as they affect constituents of the different stakeholders.

The two-hour meeting was chaired and moderated by Mr Kabumba Busingye. There were presentations from five panellists: Denis Kibira from HEPS-Uganda; Leonard Okello from CHAU; Hasifa Naluyiga from RHU; Tinah Ntulo from Basic Needs Uganda; and Moses Mulumba from CEHURD, as well as from the Rapporteur. The presentations were followed by a general discussion and closure.

## 1.2 Opening remarks and welcoming of Special Rapporteur

*Mr Moses Mulumba, Executive Director, CEHURD*

In his remarks, Mr Mulumba introduced Mr Grover and welcomed him to Uganda. He noted that Mr Grover, in his previous role as an activist, has already done a lot of work on medicines and intellectual property (IP) and that he understands the civil society well because he was previously part of it.

Mr Mulumba said civil society members attending the meeting were to share how access to medicines in terms of availability, affordability and quality affects the respective constituents they represent. He cited the recent stopping of medicines from one manufacturer (India's Flammingo) over quality concerns, which has generated further debate and undue confusion between substandard and generic medicines.



Moses (CEHURD left) welcomes Participants to Listen to Anand (UN Special Rapporteur on Health, right)

He said the Special Rapporteur's focus on access to medicines was an opportunity to engage government to protect, promote and fulfil the right to access medicines. He added that the civil society in Uganda has used the human rights approach but the right to access medicines, like the right to health, continues to be downplayed by classifying it as a socioeconomic right which is to be realised progressively. He cited the case of the Constitutional Petition on Maternal Health that raised an important issue of access to medicines, but was misinterpreted and judged to have political implications on the separation of powers between the Judiciary and the Executive arms of government.

Mr Mulumba outlined the following as the issues in access to essential medicines that need the Rapporteur's special attention in Uganda:

- Corruption and misuse of resources meant for initiatives to increase access to essential medicines, such as the Global Fund to fight AIDS, TB and Malaria (GFATM), and the Global Alliance for Vaccine Initiative (GAVI)
- Slow progress on realising access to medicines as a human right, which does not even feature in the Human Rights Tribunal at Uganda Human Rights Commission (UHRC)
- Limited transparency and stakeholder participation in procurement
- Medicine pilferage in government health facilities
- Substandard and low quality medicines on medicines
- Stock-outs of medicines in public health facilities, particularly for terminal conditions as HIV and others
- Intellectual property (IP) laws and draft laws that threaten access to medicines
- Special challenges in access to medicines by vulnerable groups, such as people with mental disorders, persons with disabilities, HIV-positive children, and others
- Limited access to reproductive health commodities, which is leading to unwanted pregnancies, maternal deaths and unsafe abortions
- Underfunding of the health sector and plans for a national health insurance scheme
- The implications of the regional integration process for access to medicines and the lack of clarity on emerging and potential regulatory mechanisms.

Mr Mulumba acknowledged some of the successes of the partnership between the civil society in Uganda and Mr Grover's predecessor Paul Hunt that led to the establishment of a human rights unit at the Ministry of Health and another on the right to health at UHRC. MOH encouraged to establish HR and also at HRC.

He told Mr Grover that the civil society was looking forward to continue that partnership on the above issues, and introduced the panellists.

## **2. PANEL PRESENTATIONS**

### ***2.1 Medicines systems/ communicable and non-communicable diseases***

*Mr. Denis Kibira, HEPS-Uganda*

Mr Kibira started his presentation by giving the background to the development of the current medicines sector, which he said began with the National Drug Policy and Act, leading to the birth of the National Drug Authority (NDA) and National Medical Stores (NMS) in the early

1990s. He said the sector had since formalised, growing from a budget UGX 10 billion to slightly over 200 billion currently.

He related the history of access to medicines over the period, reporting that availability of medicines was as low as 30% in the early 2000s. It has since improved to roughly 50%, meaning that a client has a 50% chance of getting medicines at a public health facility.

He noted that while there has been an improvement in availability of medicines in general, availability of medicines for non-communicable diseases (such as hypertension, cancers, and others) as well as for paediatric, remains far below 50%.

He said that at the current spend of US\$2 per capita, the medicines budget is too little to meet the needs of the public. He lamented that in the private sector, where people turn to when medicines are out of stock in public facilities, medicines are sold expensively, at least five times the international reference prices. He reported that the civil society was in the process of discussing with stakeholders ways to control pricing of medicines in the private sector.

Mr Kibira further reported a high prevalence of irrational use of medicines, which is causing resistance and creating new challenges for access. He cited the case of malaria that became resistant to quinine and fansidar which were cheaper and forced the country to shift to artemicin-based treatments that far more costly.

He appreciated efforts at the national level to streamline medicine distribution, but added that constraints at the facility level, in terms of human resource inadequacies and disharmony between need and supply, continue to dog effective access.

Mr Kibira also pointed out that quality was increasingly becoming a big challenge to Uganda, with some professionals continuing to ignore the national prescription guidelines and confusing generic medicines for standard medicines. He recommended that NDA should be supported to assure the quality of all medicines on the Ugandan market.

He emphasized the need to invest in health promotion, arguing that 80% of diseases in Uganda are preventable and prevention interventions would reduce the demand for medicines significantly.

## **2.2 Challenges of access to medicines by persons living with TB and HIV**

*Mr. Leonard Okello, CHAU*

Mr Okello began by noting that the right to health is not explicitly stated in the Constitution of Uganda and joked that the Rapporteur's job was "close to unconstitutional in this country".

He expressed concern at the long referral mechanisms in Uganda's health system, which has a village health team (VHT), health centre levels II-IV, district hospital, regional referral hospital and national referral hospital. He said a structure of this length would mean many people dying along the way as they are referred from one level of care to the next. Some shorter systems normally have three levels of referral: community, district and national.

The presenter also took issue with health unit management committees (HUMCs), which he said have become a challenge to access to medicines. He said members of HUMCs are "the

elites of the health unit” who have prior knowledge about upcoming medicine deliveries and accordingly mobilise relatives to turn up as soon as medicines come to pretend that they are sick and receive medicines on their behalf to sell through private clinics.

Mr Okello also highlighted the staffing crisis in public health facilities, which has meant that HIV clients can only be attended to on one or two days a week and increased lost-to-follow-up rates, especially for paediatric clients. He said staffing shortages had made it impossible to integrate HIV care services into general services and meant that the biggest cost of HIV management still falls on the client and their family. He cited a case of a second level health centre (HC II) which is only two staff, a nurse and a watchman. He reported that the nurse, overwhelmed by the amount of work, decided to “train” the watchman, a form six drop out without any medical background, to become the medicine dispenser.

Mr Okello appealed for scale-up of HIV treatment, particularly because it has been found to have prevention benefits. This will help reduce the number of new infections, the number of new people that need antiretroviral therapy (ART) and tame the growth of demand for ARVs.



Tinah (Basic Needs- Uganda), Hasifa (RHU), Leonard Okello (CHAU), Speak of the challenges on access to medicines in Uganda

### **2.3 Challenges of access to maternal and reproductive health commodities in health facilities in Uganda**

*Ms. Hasifa Naluyiga, Advocacy Coordinator, Reproductive Health Uganda*

Ms Naluyiga’s presentation centred on challenges of access to commodities for emergency obstetric and newborn care (EmONC) and family planning. She said the biggest challenge was the inadequate funding for maternal and reproductive commodities, which has stagnated around UGX 1.5 billion per year since 2005, far lower than the estimated need of UGX of 24 billion, yet actual expenditure goes as low as UGX 0.5 billion.

She noted however, that advocacy effort are beginning to bear fruit, as the current budget has allocated UGX 7.5 billion, and in July, government pledged to raise the allocation to US\$ 5 million (about UGX 12.5 billion). She said the civil society, in partnership with the UN Special Rapporteur, should put pressure on government to fulfil this promise.

She also outlined other challenges in accessing EmONC and family planning commodities. She said the choice of family planning methods is limited by the range that NMS supplies and by lack of skills among some health workers to administer implants and other long-term methods. She also pointed out that quality has become an issue because of high failure rates of contraceptives.

## **2.4 Challenges of access to medicines by persons with disabilities, sexual minorities and other vulnerable groups: a mental health perspective**

*Ms. Tinah Ntulo, Basic Needs Uganda*

Ms Ntulo told the audience that the current challenges of access to essential medicines as so enumerated by other presenters and other stress factors were all contributing to a rising burden of mental health problems in Uganda. She said the rate of mental-related disorders may be as high as 80% in the population, which is facing new challenges, such as the nodding disease syndrome.

He said the progress that had been made by training and deploying mental health nurses has been reversed by the new “push system” for a pre-determined kit of medicines for HC IIs and HC IIIs. She said this push system has rendered the mental nurses idle as they do not participate in planning and quantifying medicine needs.

She said the kit for HC IIs and HC IIIs for instance, has only one tin of Clopromazine, which treats psychotic disorders, and one tin of Phenytoin, an antiepileptic in children. Each of these tins contains 1000 tablets, enough to treat only three patients for a month, and yet a typical HC III has 30-40 children suffering from epilepsy. She said that there was a high failure rate of treatment for epileptic and psychotic disorders because of treatment interruptions due to inability to access medicines on a continuous basis.

She said the prevalence of epilepsy is on the rise because people are unable to access timely treatment for malaria and other fevers, which is creating a rising number of disability cases.

She said the poor management of mental disorders is contributing to household poverty and abuse of children’s rights, because parents spend time attending to sick children while others tether or lock them up to go to work. She said it is common to find several children with epilepsy in poor families, and appealed to the UN Special Rapportuer to intervene their plight.

## **2.5 Intellectual property legal and policy environment on access to medicines**

*Mr Moses Mulumba, CEHURD*

Mr Mulumba said the absence of a constitutional provision on the right to health has made it difficult to hold government accountable, unlike in Kenya, where an amendment to the Constitution has been made for a specific provision. In Uganda, the right remains in the objectives of the Constitution, and there is need to engage the judiciary to enable judges understand the right to health.

He said the Constitutional Petition on Maternal Health was having a severe backlash as maternal health is no longer “a right but an offence”. He cited the case of a doctor in Jinja Hospital who was recently arrested for the death of an expectant mother. He reported that even the civil society was finding it difficult to advocate as it has to rely on alternative arguments and how the right to health is linked to the right to life.

He said the Public Health Act was enacted in 1960 and is colonial in nature, which encourages violation of the rights of TB patients who are being silently arrested and forced to take medicines as been happening in Kenya. He also mentioned the challenges that people

with mental disabilities are facing in accessing justice under Uganda's judicial system as well as some people that have been stealthily imprisoned extra-judicially on grounds of their health conditions.

Mr Mulumba also highlighted gaps in medicine regulation and said NDA does not have sufficient capacity to assure the quality of medicines on the Ugandan market.

He noted that the right to health has been recognised in the National Development Plan (NDP) and the National Health Policy. However, the practice remains different. He pointed out that from the human rights perspective, the Minimum Health Care Package (MHCP) constitutes the minimum that government must provide immediately, not a long-term goal.



Leonard Okello (CHAU), Denis Kibira (HEPS -Uganda), & Kabumba Busingye (DLA, MUK)

Mr Mulumba concluded by stating that IP is not just a trade issue but a health issue as well. The different IP-related draft legislations are a major concern, and they need to be monitored at both national and regional levels, particularly because laws enacted by the East African Community (EAC) override national laws.

### **3. REMARKS FROM THE UN SPECIAL RAPPORTEUR ON THE RIGHT TO HEALTH**

*Mr Anand Grover*

Mr Grover clarified that his assignment by the UN Human Rights Council is to prepare a report on existing challenges with regard to access to medicines in the context of the right to health, ways to overcome them and good practices. He said the assignment does not involve reporting on Uganda, but to identify good practices that can be applied in other countries to enhance access to essential medicines. He said Uganda is one of the few countries that he is visiting and that it is unique because of the existence of the local medicine manufacturing by the Quality Chemicals-Cipla venture.

The Rapporteur told the Uganda civil society health is a political issue and multinational corporations work to stifle local production in developing countries. He said the case of Quality Chemicals/Cipla is unique and it is important that it thrives because it is a long-term solution to import dependence, which is not sustainable.

Mr Grover underlined the importance of the civil society in trying to improve access to medicines. He lauded the partnership with his predecessor that the panel presentations

showed had made important achievements in this regard. He reported that he had put it to government and NMS in meetings that communities of users and civil society should be key partners in efforts to eliminate medicine stock-outs, as they can support planning, monitoring and accountability.

He said the MHCP is a good step but insufficient. He said procurement needs to be more open and that he had raised stakeholder concerns about the price of ARVs with NMS and appealed for a system to price locally produced generic ARVs. He said the prices of multinationals are not market determined and are not competitive.

The Rapporteur requested the civil society to fight for information, saying the right to information is one of the most important rights for civil society to do their work in monitoring medicine procurement and promoting accountability.



The panellists listen to Mr. Grover Anand the UN Special Rapporteur on Health

He rated distribution to be the second biggest problem, citing Mr Kibira's panel presentation that highlighted serious challenges at the service points. He said if a district health officer (DHO) orders medicines on behalf of facilities they could end up in the private sector. He reported that NMS told him that the distribution system has improved in several aspects, and added that by the end of his visit he would have found out if the new system is good to share with other countries.

He mentioned that the training of judges on the right to health as suggested by Mr Mulumba in an earlier presentation was important. He in the early 2000s, judges in India lived in denial of existence of homosexuality until it emerged that the Chief Justice was gay, and ever since the mentality changed. He said a single event in Uganda could change things for the better and encouraged advocates not to give up. He said India also did not recognise the right to health in its Constitution at first, but judgements were made for the right to life to include the right to health.

#### 4. GENERAL DISCUSSION

The following questions and issues were raised during reactions from the audience, and the responses were provided by Mr Grover.

**The right to health sexual minorities:** The proposed anti-homosexuality bill which is likely to make it more difficult for sexual minorities to access medicines. Therefore, even if medicine availability improves, this group may not access essential medicines and yet it is their right. The Rapporteur was requested to condemn the bill.

**Mr Grover:** I was the first to complaint to the government of Uganda about the bill and since then it has stepped back.

**Expanded treatment can support local production of ARVs:** There is need to expand treatment of HIV and TB, and to eliminate mother-to-child transmission. ARVs from Quality Chemicals are expensive because it is producing at one third of their capacity. Government is purchasing drugs worth UGX 100 billion, so it is necessary to increase this to UGX 300 billion, then economies of scale will lower prices. It is also understood that Rwanda and Kenya have approved Quality Chemicals' ARVs. The participant wanted to know what government was doing to follow-up on this.



*Mr. Anand, Mr. Dennis Odwe (AGHA-Uganda) and Panelists listen to comments from CSO Participants*

Despite human rights/right to health units at Ministry of Health and UHRC, people living with HIV (PLHIV) are not accessing medicines. There is need to go back to the pull system because the push system is not eliminating medicine expiries.

**Mr Grover:** There is a major problem with HIV treatment access, however, considering what the situation was in the early 2000s, there is some progress. It is important to continue the pace.

**Multinationals taking charge of health insurance:** Multinationals are promoting health insurance and as discussion of the national health insurance scheme, are they not likely to control the entire sector and how will this affect local production of medicines?

**Mr Grover:** I don't see that happening.

**Remuneration of health professionals:** Everyone one is talking about medicine availability and no one is talking about motivating health workers. There is currently a ban on the formation of labour unions by Ministry of Labour, presumably because people are riding on labour unions to go to parliament.

**The right to health and access are political:** What is the role of MPs in advocating for allowances? MPs should advocate for access to medicines. What is the role of UN Human Rights Committee to hold the Uganda government accountable?

**Mr Grover:** The UN system has a big role in promoting human rights and accountability. You can report violation of human rights and they will be handled; you can report to me violations of the right to health.



Participants ask questions; make requests and submissions from the day's discussions.

**Contradiction between legislators and NMS:** MPs on the committee on social services have disagreed with NMS claims that there are no more stock-outs of medicines. So who is telling the truth?

**Mr Grover:** Procurement is supposed to be transparent, but it is not and I have told NMS; people need to know the good things you are doing.

**Medicine quality:** Consumers are losing confidence in medicines they are taking. Will the Rapporteur interface with NDA to have recommendations on this?

Syrups are of low quality and they are affecting children's teeth, and Panadol that is not sealed is not effective.

**Multinationals undermining local production of medicines:** Are there international standards for accountability?



Community participants ask, Anawad responds, Moses & Lilliane (ICWEA) give the closing remarks.

**Mr Grover:** One of the suggestions is for WHO to give prequalification.

**The female condom is not accessible:** Women living with HIV need the female condom to control sexually transmitted infections (STIs) and pregnancies, but women at the grass roots cannot access them. the only supplies come from UNFPA; government is not interested.

**Mr Grover:** Female condoms a good thing because men don't know their own male condoms. Sex workers are very good at convincing men to wear condoms. It is therefore possible to empower women with negotiation skills. Gay men too should use condoms with their partners.

## **5. CLOSURE**

### **5.1 Remarks from Mr Mulumba**

Mr Mulumba said it had been a great opportunity the civil society to exchange views and hear from the Rapporteur. He thanked the Rapporteur, the members of the Maternal Health Coalition and the Coalition on Essential Medicines. he also thanked the staff of CEHURD for mobilising for the meeting. He also thanked WHO and UNDP, who he said were great partners.

### **5.2 Closing remarks by Ms. Lillian Mworeko, ICWEA**

Ms Mworeko said the civil society was privileged to have audience with the Rapporteur. He thanked him for accepting to dialogue with the civil society. She said she hoped it was the beginning of long-term dialogue.

Ms Mworeko said in Uganda and Africa, everything is a political issue. There is need to ensure that civil society is better equipped and facilitated to advocate for the right to health. She appealed to the Rapporteur to help the civil society to strengthen its voice, saying not many partners are keen on funding advocacy yet it is important. She also requested him to weigh in against the HIV Prevention and Control Bill, which she said threatens to take the country back.

**END.**