

ECUMENICAL PHARMACEUTICAL NETWORK

Increasing the capacity of church leaders and church-related health services to respond to the massive challenge of HIV/AIDS treatment

Kenya Starting Points Summary

Consultants for EPN: Heather Budge-Reid heatherbr@kclinfo.com
Dr Nathan Nshakira (FARST Africa) farstafrika@cms-africa.org

"Of 10 average people with a need for ARVs, at least half will fear the stigma so won't take them, one or two will be afraid of the side-effects, and none can afford them."

—Focus group participant's conclusion.

"Limited knowledge and negative attitudes towards ARVs on the part of health workers and patients were the main limiting factors to ART uptake... Community education is also essential to ensure adherence, dispel unrealistic expectations, and avoid increasing risk behaviour."¹

An electronic copy of the full report is available from e pn@wananchi.com

This report presents the summary of the findings and the recommendations resulting from a Kenyan-based study, carried out in May/June 2004. These activities were part of the Ecumenical Pharmaceutical Network's programme "Increasing access to ARVs". Work included a desk review, 12 focus groups, 21 priority interviews, and 23 open-ended interviews. Locations included: Nairobi (inner and outer rural areas), Kitui, and Maua.

Abbreviations and acronyms

ART	Antiretroviral therapy
ARV	Antiretroviral drug
CD4	CD4 count test, used to monitor the progression of HIV towards AIDS
CHS	Church-based health service
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV/AIDS	Human immunodeficiency virus/Acquired immune deficiency syndrome
PEPFAR	[United States'] President's Emergency Plan for HIV/AIDS Relief
PLWHA	People living with HIV and AIDS
PMTCT	Prevention of mother-to-child transmission [of HIV]
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
USAID	United States Agency for International Development
VCT	Voluntary counselling and testing [for HIV]
WHO	World Health Organization

¹ Attawell K, Mundy J (2003) Provision of ART in resource-limited settings: a review of experiences up to August 2003. DFID/Health Systems Resource Centre.

1 SUMMARY DESK REVIEW RESULTS

While there is a widespread response to antiretroviral drugs (ARVs) and prevention of mother-to-child transmission (PMTCT) treatment across Kenya, there is still room for improvement in the integration of ARV messages and services, in particular in the response of churches and church health services (CHSs). There is much to praise, but equally much to worry about—some churches reject ARVs and few leaders understand their role in treatment literacy. Kenya can be both a focus for an improved response by churches and CHSs and a source of experience of successful activities.

Both diversity and pluralism are welcome components of any society. However, in Kenya this also means that parts of the media are free to spread rumour and misunderstanding and some churches are free to take extreme and unhelpful positions. Addressing these differences, while maintaining a commitment to diversity and pluralism, is a major challenge.

It is generally thought that there is spare capacity in the area of voluntary counselling and testing (VCT) because too few people take the test. This often means that people do not then go on to access ARVs and, even if they do, it is often too late to make a difference. The advent of access to ARVs changes the ramifications of VCT, but awareness of this change needs to be increased among counsellors, community leaders, and individuals. There is therefore a need for much more encouragement towards VCT.

1.1 Prevalence

- 1.8 million Kenyans are estimated to be HIV-positive and 280,000 require antiretroviral therapy [18:13] (2004)
- 50-60% of hospital-bed occupancy in public and mission facilities is HIV-related (2004)
- National HIV prevalence at ANC sites has dropped in the last 4 years from 13% to 9.4% (2003)
- Projected impact of HIV/AIDS Cumulative deaths due to HIV/AIDS—2.6 million by 2005 (2003)
- Deaths among teachers increased from 450 in 1995 to 1,500 in 1999; largely attributable to HIV/AIDS (2002)
- Children orphaned by HIV/AIDS will top 1.5 million by 2005 (2003)
- Projected reduction in GDP over the next 10 years (from 2003)—14.5%
- Number of infants and children living with HIV/AIDS—100,000 (2003)

1.2 ARV costs

UN experts estimate that 9% of Kenya's 30 million people are infected with the virus. The government says 50–60% of bed space in hospitals is taken up by people with AIDS-related diseases.

Although the prices of ARVs have dropped substantially over the years, from about KShs. 15,000 (US\$ 185) four years ago to KShs. 3,000 (US\$ 38) per month (at the time of study), they still remain beyond the reach of many Kenyans. More than half of Kenya's population live on less than US\$ 1 per day and struggle to afford food, medicine, or decent housing. While continuing price drops are welcomed as they increase the numbers of people who can afford them, ARVs remain out of reach for the poorest.

1.3 Sites where ARVs are provided for the treatment of AIDS

By the end of 2003, an estimated 13,000 people in Kenya were on ART; only 3.5% of the total number of people estimated to need ART.

ARVs in Kenyan church health programmes

Central Province	Patients Started		Current Patients	
Kijabe Hospital	150–170	(Feb 04)	105	(Feb 04)
Kikuyu Hospital	86	(Feb 04)	67	(Feb 04)
Nazareth Hospital	300	(Feb 04)	140	(Feb 04)
Mwea Hospital	30	(Feb 04)	24	(Feb 04)
Gaichanjiru Hospital	10	(Aug 03)		
North Kinangop Hospital	40	(Aug 03)		
Mathare Hospital (Nyeri)			17	(Feb 04)
Naro Moru Health Centre	32	(Feb 04)	17	(Feb 04)
Mugunda Clinic			30	(Feb 04)
Tumutumu Hospital	100	(Feb 04)		

St. Mulumba Hosp (Thika)	42	(Feb 04)		
Mary, Help of the Sick (Thika)			6	(Feb 04)
Eastern Province				
Mutomo Hospital	18	(Feb 04)	9	(Feb 04)
Bishop Kioko Hosp (Machakos)	35–40	(Feb 04)		
Cottolengo Hospital (Meru Cent)			20	(Feb 04)
Nkubu Hospital	52	(Feb 04)	37	(Feb 04)
Maua Hospital	80	(Feb 04)	60	(Feb 04)
Chogoria Hospital	289	(Feb 04)	158	(Feb 04)
Nairobi				
Coptic Hospital			1400	(Feb 04)
St Mary's Hospital, Langata				
Mater Hospital			250	(Aug 03)
Milimani SDA Clinic	10	(Feb 04)	8	(Feb 04)
Nyumbani Children's Home			70	(Feb 04)
Nyanza Province				
St Monica's Hospital, Kisumu	69	(Feb 04)	36	(Feb 04)
St Camillus Hospital, Karungu	6	(Aug 03)		
St Joseph Hospital, Migori	36	(Feb 04)	28	(Feb 04)
St Joseph Hospital, Nyabondo	8	(Aug 03)		
SDA Hospital, Kendu Bay	25	(Aug 03)		
Rift Valley Province				
Tenwek Hospital	20	(Feb 04)		
Litein Hospital	67	(Feb 04)	42	(Feb 04)
Nanyuki Cottage Hosp.	28	(Feb 04)	10	(Feb 04)
St. Joseph Hosp, Kilgoris	11	(Aug 03)		
Kitale AIDS Programme	9	(Nov 03)	8	(Feb 04)
Western Province				
Lugulu	90	(Feb 04)	66	(Feb 04)
St. Mary, Mumias	54	(Feb 04)	19	(Feb 04)
St. Elizabeth, Mukumu	181	(Feb 04)	69	(Feb 04)

NOTE: It is hoped that the feedback meeting will add to this list.

1.4 Mission for Essential Drugs and Supplies

MEDS started stocking ARVs in July 2001, and generic ARVs in June 2002 (even while special authorization from Ministry of Health for formal registration of generic ARVs was still being processed). MEDS supports ART in over 40 mission hospitals. MEDS has distributed Nevirapine donations on behalf of the Ministry of Health since July 2002. Only six mission health facilities have ordered this product; consumption is well below anticipated levels.

There has been a progressive fall in prices; from a high of KShs. 60,000 per month for triple therapy before July 2001, to KShs. 6,000 per month as of June 2001; this enabled MEDS to consider stocking ARVs. The price fell further to KShs. 3,000 per month in June 2002, with availability of generic ARVs in MEDS; this led to an immediate three-fold increase in ARV purchases from MEDS.

2 KENYAN CHURCH LEADERS RESULTS

In Kenya, five priority interviews, 10 open-ended interviews, and 2 focus groups took place. Church leaders are defined as any person with a regular role in the administration or implementation of church activities—from Archbishops and Bishops, to Pastors and Reverends, and lay workers and church-related NGO staff. An analysis of the interviews brought out the following results.

1. All those interviewed were able to give a brief and accurate definition of ARVs as life prolonging drugs for people with AIDS but could not go further and discuss treatment issues, answer questions, etc.
2. Initial comments always indicated that there were no theological issues around ARVs. However, further questioning quickly reached a point where belief structures defined answers and, indeed, caused confusion. Clearly there had been no guidance from within the church on ARV issues and certainly no training. Confusions included, for example:
 - ARVs are for Islamic people as Christ heals all Christians.

- ARVs are for those who can afford them.
 - We don't want to get involved with talking about ARVs because it confuses the Christian issues of abstinence.
 - ARVs are from God to heal sinners.
3. None were able to state the benefits to hospitals of patients receiving ARVs—where an answer was given it involved the reputation of the hospital.
 4. Church attitudes to HIV and ARVs range from “silent” to “supportive, but with too few resources”. However, it was clear that many in the church, while seeing their role in HIV prevention, could not see their role in ARV promotion nor in how their work against stigma fitted with ARV issues.
 5. All of those interviewed said that there had been very little work done on ARVs with the church, no training, no available information, and no guidance about how to talk and pray about ARVs. There was confusion about taking ARVs while on TB or cancer medication, their price, the need for nutrition, whether they can be stopped, if they are available for children, etc.
 6. None of those interviewed were able to give details of HIV prevalence or numbers of people receiving ART nationwide nor locally.
 7. All those interviewed stated that they would not prevent anyone from gaining access to ARVs, and all felt that everyone needs to be aware of all the treatment issues around ARVs—particularly once they had been pointed out to them.
 8. There are problems with existing materials on HIV being out-of-date, and there are no materials on ARVs for congregations, etc.
 9. There were some very inspiring and supportive approaches voiced. Church leaders spoke with openness and interest and in most cases determination to learn more. There are clearly strong voices that can lead changes in attitudes. Because very few churches have policy on HIV, and none on ARVs, responses tend to be more about the current person in position, rather than the actual theological leadership of a particular church. Those with most influence over the churches approach often have little or no influence over the parallel CHS systems and there is no coordination between them.
 10. All leaders interviewed were in favour of openness about HIV and ARVs and disagreed with silence or ignoring the issues. None were able to identify the source of other approaches, except to say that people in personal denial don't want to deal with the issue, and responses from parishioners were also personal. All agreed that their churches did not give enough support to leading and advising their parishioners on this issue: “people just don't want to talk about it—it is so strongly linked to sin”. None felt they were able to do anything about other church leaders who take a stigma-based approach.
 11. PMTCT knowledge was very minimal and those interviewed did not see their role in promoting the use of it nor had they thought about why women might not be able to. After discussion, it was recognised that the problems of non-attended childbirth could be a major message for churches and a link can be found with the safer motherhood campaign.
 12. There was a very wide variety of ‘facts’ quoted:
 - Different understanding of treatment levels: CD4 count ranging from 200 to 500.
 - Estimates of very high of numbers infected but also estimates of very high of numbers not receiving treatment.
 - Wide range of prices quoted for ARVs.
 - Wide variety of places named as providers of information.

2.1 Focus group results

1. In rural areas, the distance to a clinic and the cost in money and time to reach a clinic were seen as major obstacles to VCT and ARVs. Across all areas, it seemed that a combination of the following forces explained the main obstacles to VCT and ARVs:
 - Stigma.
 - Lack of information.
 - Fear of VCT result or ARV side effects.
 - Poverty.
 - Denial.

There was no particular trend in the prioritisation of these issues. However, the same issues were raised in each focus group. It was generally agreed that people fear the stigma of the VCT so don't take it, and certainly not until they either want to get married or are really ill.

2. All the churches used messages around immoral behaviour to try and stop the spread of HIV. Some church leaders did not seem to be able address the issue of HIV infection not relating to an individual's immorality, the issue of forgiveness, nor encouragement to have a VCT and the ARVs. Seminaries producing tomorrow's church leaders are under-resourced on the issue of ARVs and are not covering ethical debates or clinical information on ARVs.
3. People have a range of opinions and hold many myths—the most commonly expressed were:
 - HIV is preventing them from being young people. "It is the older people's way of preventing us from learning what they know already".
 - It is a trick by Americans to discourage African development.
 - Young people are growing with hormones at work and need to be active.
 - We do not like using condoms—they are messy. It is another American idea to improve their economy at our cost. They manufacture them and sell them to us and encourage us to use them.
 - Prayers can help, but only a few.
 - Refrain from masturbation and you will live longer.
 - Drink your own urine to be cured.
 - Never tell anyone you have HIV or are on ARVs.
 - To answer questions you would only go to a doctor, but you fear this as the doctor could tell someone that you have it.
 - Fear exists because people think that they wouldn't take them (ARVs) if they were pregnant, as they affect the unborn baby.
 - They have bad side effects.
 - They can make you impotent.
4. Discussions are dominated by fear or a discussion of side effects. On the issue of side effects, the discussion revolves around "why do people still die even when they are on ARVs?" and "ARVs kill don't they?"
5. Although not universal, the majority felt that the church contributes to stigma more than it reduces it. Stigma is worst in the family—they won't sit next to you; then there is gossip among people at church—church could do more to talk about these things, as it often talks about how families and individuals should behave.
6. While all groups had heard of ARVs, they were not aware of, or showed confusion about, nutrition, the length of time taking ARVs, side effects, passing it on, etc. Clearly, knowing ARVs exist is not enough to address behaviour, myths, and misunderstandings.
7. All those who were on ARVs stated that access to food is the main problem, so they feel sick when they take their ARVs and so they want to stop the treatment or cannot take them every day.
8. The poorest women might sell them to feed their children—the children are the priority.
9. The American/white agenda is often raised as an issue. People believe that the Americans are planning to kill them through providing the ARVs, which are laced with the virus itself.
10. Some believe that the ARVs, instead of making them feel better, increase pain in the body and make a person more sick. In addition, they believe that traditional herbal medicines are better than ARVs as they also have a nutritional value.
11. Women talk a lot of the problem of men—who throw them out if they have HIV without getting their own test; who won't let them go for VCT; who won't let them take PMTCT because if they had to then the husband would throw them out. With ARVs, the gender problem is not related to the power to say no to unprotected sex, but a much broader range of issues, which the church could deal with.

3 KENYAN CHURCH HEALTH SERVICES RESULTS

During the period of study, it appeared that Kenyan authorities were not clear about who exactly is providing ARVs and in what quantities. While this report does contain a list of some CHS provision, it is likely to be out-of-date and does not indicate how many CHS are *not* providing ARVs or PMTCT. Clearly, the full extent of CHS involvement would be an important first question. In Kenya, six priority interviews and six open-ended interviews were undertaken with CHS staff.

1. There is a clear and workable system for the acquisition and distribution of ARVs through MEDS (Mission for Essential Drugs and Supplies). However, it is clear that this system is not being used by everyone. A very wide range of prices are quoted and it would probably be beneficial to review pricing and sources to enable CHSs to access ARV at least cost.
2. It seems that there are some CHS hospitals and health centres that would benefit from learning from the experience and leadership of the more successful ones, particularly in the area of ARV provision, successful ART, reaching the poorest, subsidies, and financial systems. Despite the difficulties, there are some examples of innovative, replicable, and successful approaches in CHSs. However, there is little, if any, evidence of mechanisms or efforts to share experiences on a regular and frequent basis between CHSs or with churches around the issue of ARVs. Among the remarkable and successful approaches that lend themselves to replication are the Coptic church in Nairobi which has a specific system for reaching the poorest; the Catholic Diocese Hospital in Kitui, with their food and nutrition activities; and the Methodist Hospital in Maua for their fundraising for ARV activities. However, it is interesting to note that each of these examples could learn from the others as well.
3. The arrival of ARVs is likely to increase the demand for VCT services and could, in some areas, 'leapfrog' the availability of VCT and CD4 facilities. This is going to require dynamic and cooperative management responses, as CHSs search for funds or shared opportunities for expanding VCT and CD4 testing. There are opportunities for sharing facilities that are currently not being taken up.
4. There is very little, if any, resistance to the principle of ARVs or PMTCT, particularly with recent reductions in cost. However, test costs will remain at previous levels and CD4 count facilities are few. Particularly, there is a lack of PMTCT delivery, even in CHSs with antenatal clinics.
5. CHS board members may well benefit from clarity in the areas of costs and benefits to hospitals, sustainable commitments, and requirements.
6. It was apparent that CHSs are run very independently from their churches, which appeared to be a significant problem for all concerned. Very little evidence was found of church-to-hospital collaboration around HIV/AIDS or ARVs. Some individual churches had HIV/AIDS groups, so did some hospitals. In some cases, there were church groups and hospital groups from the same denomination, but with no cooperation or referral system.

Other information mismatches were found around start dates for ARV service delivery in CHSs, and accessibility to potential patients with pre-knowledge of their status and group support. It was also clear that HIV/AIDS support groups in areas surrounding CHSs were not accessing medical information (such as how long to take ARVs for, the need for testing, nutrition, etc.) So it was possible for a hospital to be aware of ARVs and their attendant issues, while local church groups were not. It is also challenging to note that churches themselves do not seem to avail themselves of, for example, speakers from the local CHSs.

7. The link between PMTCT and ARV treatment seems to be weak. Where PMTCT was given, there does not appear to be a strong system of referral to ART clinics—although this may reflect the relatively recent accessibility of ARVs.
8. All CHSs reviewed were very committed to patient treatment literacy and were interested and surprised to discuss the need for wider community understanding. Issues of access to food and nutrition, stigma, and patients coming 'too late', were all seen as important, and it was recognized that the wider community needed to know about them in order that the CHS work is maximized. Linking with churches to facilitate this was seen, in the main, as a new and possible concept. Working across denominations seemed a more testing approach.
9. There was considerable concern about adherence, and access to food and nutrition support—a provision that hospitals are not normally involved with and yet which is important to the success of the clinical treatments. Advice is needed on how CHSs might address issues of food and nutrition and ARVs
10. Internet access among CHSs is difficult or not available and information for staff is in short supply. CHS staff did not discuss ARVs with people who are not taking them.
11. Apart from one CHS, the benefits to the hospital of successful ARV treatment were not identified or included in an informal analysis around ARV provision. Issues such as reduced demand for opportunistic infection treatment versus cost of ARVs had not been thought through or analysed.

12. While all CHSs stated that reaching the poorest was their goal, there was little evidence of monitoring of this target nor of specific approaches to maximise its achievement. Access to wider pool of ideas in hospital funding, etc., would be beneficial.

4 SUMMARY RECOMMENDATIONS

4.1 Initial recommendations for Kenyan church-based interventions

1. Church leaders and church-based PLWHA groups be provided with full information on ARVs and on spreading the message to the wider community—with particular reference to overcoming myths and misunderstandings around ARVs in Kenya, and issues such as continuing infectiousness, nutrition, adherence, and seeking medical advice. The impact of stigma on ARVs should be examined.
2. Existing HIV and AIDS materials for church leaders and teaching curricula for future church leaders should be updated to include ARVs.
3. Advice on how to encourage people to have VCT tests and CD4 tests (as the first steps towards taking ARVs) should be provided.
4. Advice on the wider picture, in the context of ARVs, of AIDS in the community, HIV, and food and nutrition requirements should be provided, so that advocacy programmes at all levels can take place.
5. Institutional, cooperative, financial, and information links between churches and CHSs on the issue of ARVs should be supported.
6. Links between churches of different denominations and the sharing of their experience and resources should be supported.

4.2 Initial recommendations for Kenyan CHSs

1. **Increase lesson learning and exchange.** Draw out experiences and share them within Kenyan CHSs and with other CHSs in other countries. This might include case study publication and exchange visits, with a focus on PMTCT, VCT, CD4, ARVs, and ART.
2. **Increase CHS capacity to manage ARV delivery.** Particularly information is needed on potential solutions to the problem of reaching the poorest in a sustainable manner.
3. **Increase linkages and cooperation between CHSs, churches, and HIV/AIDS support groups.** Attempt to link CHSs and churches around ARV issues, including the joint organization of HIV/AIDS support groups, availability of speakers, regular updates.
4. **Increase CHS capacity to deal with food and nutrition issues.** Provide training support for pharmaceutical staff in the systems and requirements of food and nutrition support for people with HIV and receiving ARVs, and ways to access supplies, monitor distribution, and reduce dependency over time.

*“Stigma is the issue, poverty is the problem”
–Participant on why people don’t go for VCT or take ARVs.*