FREE by 5

Economists', public health experts' and policy makers' declaration on free treatment for HIV / AIDS

We, economists, public health experts and policy makers involved in the fight against AIDS are committed to scaling up access to healthcare, including ARVs, for HIV positive people with the objective of universal access. We consider it a rational economic decision and an absolute priority.

We believe that a prerequisite for ensuring that treatment programs are scaled up, equitable and efficient, and provide quality care, is to implement *universally free* access to a minimum medical package, including ARVs, through the public healthcare system.

We believe that the treatment package should include HIV tests, prophylaxis and treatment of opportunistic infections, all laboratory and associated examinations, consultation and hospitalisation fees, and ARVs.

We argue that WHO, UNAIDS, the governments of resource-poor countries and international donors, among them the Global Fund, the World Bank, PEPFAR and bilateral cooperation agencies, must adopt and actively promote the principle of universal *free* access to treatment (including ARVs) and contribute to its implementation.

We urge that additional resources be mobilized through long-term commitments. These should come mainly from donor funding, with the contribution of other stakeholders. Governments in resource-poor settings should engage in an appropriate allocation of domestic resources to show commitment to achieving this goal.

We are committed to promoting the principle of free treatment, and to contributing to its implementation. Otherwise, the idea of universal access will remain a dream.

Introduction

There is consensus on the necessity for providing healthcare in general, and ARV programs in particular, for HIV positive people in resource-poor settings.

In June 2001, the United Nations General Assembly Special Session on HIV / AIDS unanimously adopted a Declaration of Commitment recognizing that: "effective prevention, care and treatment will require behavioural changes and increased availability of and non-discriminatory access to (…) drugs, including anti-retroviral therapy, diagnostics and related technologies"[1].

In 2004, the Copenhagen consensus of economists identified the fight against AIDS as the top priority in advancing global welfare on the grounds that: "the scale and urgency of the problem - especially in Africa, where AIDS threatens the collapse of entire societies – are extreme"[2]. The consensus accords the highest priority to preventing the spread of HIV / AIDS. We note that if 'the collapse of societies' is to be averted treatment is essential as so many people are already infected.

Treatment is justified on economic grounds and for human rights reasons. If we fail to provide it societies face catastrophe.

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The goal set by WHO is to have 3 million people on treatment by the end of 2005. There are, of course, major concerns around the scaling up of access to treatment. What it will cost, who will do it and how are will be done is still being debated, and we have much to learn. How can these programs improve the uptake? How can they reach the most vulnerable and poor populations[3,4]? How can they achieve a high level of adherence to ARV treatments in order to avoid resistance?

We are faced with many uncertainties but we also have some evidence. This declaration sets out a principle we all should subscribe to and apply: **the principle of a comprehensive minimum package of treatment provided *free* to all the people living with HIV/AIDS.**

Are there international guidelines as far as free or affordable treatments are concerned?

The WHO strategy "Treating three million by 2005, making it happen", published in 2003, recommended making ARV therapies "affordable". The document implied that poor people should be given the treatment free[5]. But what affordability means and who the poor people are is not defined.

The 2003 revision of WHO treatment guidelines[6] argues that we should: "provide medications free of charge for those who can least afford treatment through subsidized or other financing strategies", without defining who these patients are.

In November 2003, the participants in the Lusaka meeting -whose aim was to draw technical and operational recommendations for scaling up - did not reach a consensus on free ARVs. The report indicates: "most participants considered that ARV therapy should be provided free of charge to the person receiving the therapy with a minority cautioning against stating this as a principle"[7].

In January 2004, a WHO consultation concluded that "Strategies should be developed to provide ART free at the point of delivery to those who cannot afford it (…). However, if cost recovery schemes prove inefficient or obstructive to access, free delivery to all should be considered"[8].

The important issues of what affordability means, who should be given free access to treatment programs in resource-poor settings and under what conditions have not been dealt with adequately at international levels.

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1. United Nations General Assembly Special Session on HIV/AIDS, "Declaration of commitment on HIV / Aids", A/RES/S-26/2, 27th June 2001, article 23 p.4
2. http://www.copenhagenconsensus.com/Files/Filer/CC/Press/UK/copenhagen_consensus_result_FINAL.pdf
3. Holmes, Wendy, "3 by 5, but at what cost" in The Lancet, vol 363 March 27 2004, pp 1072 – 1073.
4. Mukherjee, Joia, "Basing treatment on rights rather than ability to pay", in The Lancet, vol 363 March 27 2004, pp 1071 – 1072.
5. "Uptake of ARV therapy has been lower than anticipated in some high prevalence settings, suggesting that in addition to making ARV therapies services available, physically acce sible and *affordable*, demand must also be stimulated" and "The aim will be to create sustainable financing mechanisms that will exempt the people from co-payment" in "Treating three million by 2005, making it happen", WHO strategy, WHO, Geneva, 2003, page 17.
6. "Scaling up ARV therapy in resource-limited settings : treatment guidelines for a public health approach", WHO, Geneva, 2003, page 34.
7. "Emergency scale up of antiretroviral therapy in resource limited settings: technical and operational recommendations to achieve three by five", report of the WHO / UNAIDS meeting held in Lusaka, Zambia, 18-21 November 2003" p.8
8. "Consultation on ethics and equitable access to treatment and care for HIV/AIDS", Summary of issues and discussions, WHO/UNAIDS, Geneva, 26-27th January 2004, p.3.

The current situation: many patients are being asked to pay for their treatment

The first programs that were set up, such as those in Uganda, asked the patients to pay for the total cost of treatment[9]. Today there are a range of programs and conditions for access to treatment. Brazil, Uganda and Venezuela are providing free ARV therapy, which proves this is feasible. In 2004, Thailand announced that ARV treatment would be provided for free. Other countries including South Africa are starting to implement ARV programs where all medical needs should be covered.

But in the vast majority of resource-poor countries, access to treatment is not free.

In Senegal, ARVs, CD4 counts and viral load tests are free, but other laboratory exams[10] required to initiate therapy have to be paid for and are a major obstacle to access to ARVs. Laboratory exams and drugs for opportunistic infections are not free either. People who would qualify for free drugs cannot afford the tests to obtain them and may die of opportunistic infections despite the fact they have free access to ARVs.

In other countries ART is heavily subsidized, but a monthly contribution is sought from patients: in Burkina Faso patients are expected to contribute 8,000 FCFA per month (12 euros); in Cameroon the current cost for the patient is between 15,000 and 28,000 FCFA (between 23 and 43 euros)[11]; and Niger, in its proposal presented to the Global Fund, will have a range of contributions from 8,000 FCFA (12 euros) to 75,000 FCFA (114 euros) according to the patient's income.

The cost of drugs for opportunistic infections, laboratory exams, consultations and hospitalisation fees must be added to these contributions.

A study in Senegal assessed the cost to patients and found that those on ARV treatment had to pay an average of 5,200 FCFA per month (7,9 euros)[12], i.e. 95 euros per year for their medical expenses additional to the cost of ARVs. The French National Agency for AIDS Research (ANRS) estimated that, other than ARVs and CD4 counts, 150 euros per patient per year is needed to cover all medical expenses[13].

These examples give an idea, however imprecise, of the burden of medical expenses on the patients' and their families' finances.

Why do we need free treatment?

There is evidence that user fees in healthcare pose a wide variety of problems, which will worsen in the case of HIV. Therefore, there are many reasons for the provision of free HIV/AIDS treatment: among them are public health and ethical arguments.

Uptake

In order to reach a large number of people, most of them living below the poverty line, and to achieve the 3 x 5 goal, treatment will have to be free. It is unrealistic to believe that treatment programs can be scaled up otherwise. Free treatment is a prerequisite for the achievement of universal access.

Equity

Research shows that even when the contribution sought from the patient for ARVs is small, some are excluded because they cannot afford it[14]. Therefore, providing free treatment will help poor people to have access.

We are fully aware that giving free access to HIV treatments will not be sufficient to achieve equity in these programs, and far more needs to be done. In particular, the needs of the most vulnerable groups must be addressed. But providing treatment free of charge is a necessary condition for the achievement of equity.

Efficiency

Research in Senegal shows the main reason patients were not adherent was that financial problems led to treatment interruptions[15]. In Kenya, patients have discontinued ARV treatment due to lack of money[16]. Adherence must be high in order to avoid resistance and ensure long-term benefit for the patient. Providing treatment for free will contribute to adherence.

Moreover, free treatment is the best way to reduce demand for antiretroviral drugs on the informal market, misuse and consequent viral resistance and to minimize the number of people lost to follow up. Finally, paying for care causes delays in health seeking when, ideally, HIV patients should come at the early stage of illness to optimize the outcome of treatment. Providing treatment for free will contribute to adherence and efficiency at the individual and population level.

Quality

Payment of treatment can have other side effects: diagnostic tests are skipped because patients cannot afford them; patients in hospital suffer delays in treatment until they can pay for extra investigations or care. Free treatment will improve quality of care and reduce the delay in effective care.

We believe that a prerequisite for ensuring that treatment programs are scaled up, equitable and efficient and provide quality care, is to implement free access to treatment.

9. Katabira, Elly. (1997). "Les traitements antirétroviraux en Ouganda." In World Health Organization, *Les incidences des traitements antirétroviraux: Consultation informelle*, edited by Eric van Praag, Susan Fernyak, and Alison Martin Katz, 119–124. Genève: WHO.
10. Exams to assess anaemia, and liver and kidney function.
11. Communication by Laura Ciaffi, MSF, on the e-med mailing list on June 21st 2004.
12. This includes direct medical costs (costs of medical visits, biological and radiological examinations, hospitalization, and medicines for opportunistic infections) and travel expenses in Canestri, Ana. (2002).
13. including cotrimoxazole, TB prophylaxis, hospitalizations, diagnosis and treatment of opportunistic infections provided the treatment is part of WHO essential drugs list – See Charte d'éthique de la recherche dans les pays en développement, ANRS, may 2002, http://www.anrs.fr/index.php/article/articleview/695/1/127
14. Desclaux Alice, "Equity in access to AIDS treatment in Africa : pitfalls among achievements", in *Unhealthy Health initiatives: a critical anthropological examination.* Castro A, Singer M. (eds), Altamira Press, Sept 04.
15. Lanièce, Isabelle et al. "Adherence to HAART and Its Principal Determinants in a Cohort of Senegalese Adults." *AIDS* 17, supp. 3: S103–S108.
16. "Aids Patient quitting treatment", African Woman and Child Feature Services (Nairobi), All africa.com, posted September 30, 2004.

Do we need free treatment for all?

Some countries seek a contribution from the patient, except the poorest or special populations who are given free access to treatment. WHO argues for free treatment for the poorest only[17]. But this will not achieve equity nor is it a rational utilization of scarce human resources in many settings.

The poor are the majority

In resource-poor settings the poorest are not a minority! In Senegal, 60% of the population lives below the poverty line; in Botswana, it is 50,1% of the population, in China 47,3%, in India 79,9%, in Ivory Coast 49,4%, in Nigeria 90,8%, and in Uganda 96,4%[18]. If the vast majority of the population is eligible to free treatment, what is the rationale for exemptions that will be costly to put in place and administer?

Asking people to pay will increase vulnerability

Research by economists shows AIDS is impoverishing[19]. AIDS increases inequality and affected households could be pushed into deep poverty. In Kenya, death of a male household head is associated with a 68% reduction in the net value of the household's crop production. In South Africa's Free State Province, per capita expenditures on food were 23% and 32% less among urban and rural affected households than among unaffected urban and rural households.

Death and sickness cost money and increase poverty. People are usually diagnosed HIV positive after a long period of treatment-seeking when they have mobilized all their (and extended family) resources and when it is difficult to mobilize additional money. In affected households, money devoted to healthcare of HIV positive people is diverted from other uses such as care of other members of the family, education of the children and investment[20]. Even in cases of diseases that require simple and inexpensive treatment regimens, it has been shown that increases in out-of-pocket health costs have driven some families into poverty and increased the hardship of those who are already poor.

Asking patients to pay for their treatment will increase economic vulnerability of affected households and strengthen the devastating impact of AIDS.

Exemptions cannot achieve equity

Exemptions for the poor are difficult to administer and may lead to arbitrary decisions about who will be given access to free treatment and who will not. Even the definition of poverty may be arbitrary, and once a level is set then assessing people's incomes –especially where the informal sector dominates- is fraught with difficulty. Recent studies have shown that systems including exemptions or waivers do not enable the achievement of equity because they are seldom offered to patients who need them and have the right to obtain them[21]. Finally, it may also open the way to corruption. These observations challenge the capacity of "positive discrimination" based on income criteria to ensure equity in access to treatment.

An alternative route is to identify specific groups for treatment – such as people belonging to declared PLWHA groups or women undergoing PMTCT. Such decisions, which are not based on the evaluation of the ability to pay, are arbitrary and do not address the needs of the poorest and most vulnerable groups.

Exemptions or waivers systems are not cost-effective

Finally, the process of defining who gets free treatment and who will not is a resource-consuming process. It takes time, money and personnel, and the amount of money collected is usually not worth it. Scarce human resources can be used for other purposes (providing support for adherence, looking for people lost to follow up and so on). Moreover, the patient may die or be lost during the process. Contrary to the idea that free treatment "would be difficult to implement in many health systems"[22], we believe that it will be easier and more cost-effective to provide treatment to all patients for free.

For all these reasons we believe that treatment should be provided free of charge to *all* people living with HIV and AIDS, regardless of their socio-economic status.

17. "Scaling up ARV therapy in resource-limited settings : treatment guidelines for a public health approach, 2003 revision", WHO 2003, page 34.
18. The World Development Indicators, the World Bank, 2003. Poverty line defined as $2 a day.
19. Basia Zaba, Alan Whiteside and J. Ties Boerma, Demographic and socioeconomic impact of AIDS: taking stock of the empirical evidence, AIDS 2004, 18 (suppl 0):1–7.
20. Desclaux Alice, "Equity in access to AIDS treatment in Africa: pitfalls among achievements", in *Unhealthy Health initiatives: a critical anthropological examination*. Castro A, Singer M. (eds), Altamira Press, Sept 04.
21. Desclaux Alice, "Equity in access to AIDS treatment in Africa: pitfalls among achievements", in *Unhealthy Health initiatives: a critical anthropological examination*. Castro A, Singer M. (eds), Altamira Press, Sept 04.
22. Emergency scale up of antiretroviral therapy in resource-limited setting : technical and operational recommendations to achieve three by five, report of the WHO / UNAIDS meeting held in Lusaka, Zambia, 18-November 2003, p.8.

What are the main arguments against free treatment and why are they not valid?

"People must pay to give value to the treatment and thus be adherent"

Studies conducted in Senegal show exactly the opposite: the more patients have to pay, the less they are adherent, because frequent treatment interruptions occur due to financial problems. This led the President of Senegal to make ARVs universally free in December 2003.

"There should be no AIDS exceptionalism"

One of the major arguments opposed to free treatment in the field of HIV is based on the principle that what cannot be done for all must not be done at all. There are three arguments against this.

1. In fact, there is an AIDS exceptionalism as UN Secretary-General Kofi Annan stated: "HIV/AIDS is the worst epidemic humanity has ever faced. It has spread further, faster and with more catastrophic long-term effects than any other disease. Its impact has become a devastating obstacle to development"[23]. This exceptionalism of the epidemic justifies exceptionalism in the responses. WHO Director General Lee Jong-Wook affirms: "lack of access to antiretroviral treatment is a global health emergency… To deliver antiretroviral treatment to the millions who need it, we must change the way we think and change the way we act."

2. Other diseases are treated free in various countries (TB, leprosy for example) when there is a public health reason to do so.

3. Dealing with equity, we should not consider that "the lowest common denominator" must be the rule. Because we cannot provide immediate free treatment for all diseases, this does not mean we should not provide free treatment for as many diseases as possible.

"Patients' contribution is necessary to ensure sustainability of HIV/AIDS treatment programs"

Some argue that patients' contribution is important to ensure the sustainability of treatment programs. However, it is unlikely that in resource-poor settings this will make a significant contribution to the total cost. The Senegalese experience shows that only 10% of the cost of the drugs were paid by the patients, and this does not take into account other costs such as medical staff, training, social services etc. The only way to achieve sustainability is to obtain long-term commitments from donors and an appropriate allocation of domestic resources.

"The health system will be overwhelmed by people coming from other countries"

It has been recorded in French Guyana in South America that people move across borders in search of treatment. There are indications of it happening in Botswana. That is why the issue of equity must be dealt with at the international and regional level: comparable regional treatment initiatives may be essential to avoid this.

"Financial contributions avoid excessive consumption of healthcare"

This argument is based on the experience of the rich world – where healthcare demands are unlimited. There is little evidence of 'excessive consumption' in the resource-poor world. But do we *want* to limit the consumption of AIDS treatment? Precisely not: the challenge is to manage to improve the uptake of ARVs.
For example, in Zambia, only 4000 patients were on treatment at the end of 2003 when the program planned to have 10 000 people. One of the reasons may be the cost of laboratory examinations required prior to initiation of therapy ($70 for viral load and CD4 prescribed by the physicians) and the cost of ARVs ($10 per month)[24]. In Kenya also, the money required to meet costs of laboratory tests is deterring people from joining the program[25].

Therefore arguments against free treatment do not hold.

What is to be made free?

If treatment is to be free then more than drugs are needed. The question of what is to be made free is a big issue, and needs further research, reflection, and international guidelines. At this stage, we propose a minimum package that should be made available free through the public healthcare system.

This should include:

- HIV tests
- Consultations with medical staff
- Laboratory examinations (according to WHO medical guidelines or to national medical guidelines if they are more extensive)
- Hospitalisation
- Treatment of common opportunistic infections
- Prophylactic treatment
- ARVs

We recognize that choices will still have to be made. For example in most countries, at this stage, only one or two combinations of therapy may be available; few laboratory exams may be used, etc. But that should be monitored because prices change and technologies improve[26].

23. UN Secretary-General Kofi Annan, press release of the 15th of January 2004.
24. "Access to Treatment and ARV Uptake in Zambia", Namposya Nampanya-Serpell, Plusnews, May the 11th 2004.
25. "Aids Patient quitting treatment", African Woman and Child Feature Services (Nairobi), All africa.com, posted September 30, 2004.
26. The famous economist John Kenneth Galbraith is quoted as saying 'When the facts change I change my mind. What do you do?"

Who will pay for it?

The total cost of providing treatment through the 3 by 5 initiative alone ranges from $5.4 to $6.4 billion for the two years 2004 and 2005[27]. UNAIDS estimates that the amount of money needed for treatment and care in 2005 is $3.8 billion, and this will increase to $6.7 billion in 2007[28]. The amounts at stake will not change if free treatment is implemented.

Patients' contributions are marginal in the overall cost of programs because their ability to pay is very limited in a context of generalized poverty. Therefore the implementation of free treatment will not dramatically change the level of contributions asked of other stakeholders (donors, governments, etc).

Financing the response to HIV/AIDS is an enormous challenge, but it will not be heightened by the provision of free treatment.

We note with great concern that the funding gap involved in providing a comprehensive package of care through the 3 by 5 initiative was over $2.5 billion for 2004-2005[29] as of December 2003, and will increase in the years to come. Therefore we urge international donors, and other stakeholders to fund the minimum package through long-term commitments.

We further expect resource-poor countries to make the appropriate contribution. In April 2001, African leaders meeting in Abuja committed themselves to allocating 15% of their public expenditure to health. The First Conference of Health Ministers of the African Union in Tripoli, April 2003, approved the NEPAD Health Strategy, which reconfirms the Abuja targets and aims to scale-up communicable disease control programs. African leaders have endorsed these policy statements and must ensure they are implemented.

All stakeholders have the responsibility to work in partnership to ensure the provision of free treatment.

Conclusion

To meet the scale up, equity, efficiency and quality objectives in treatment programs, we should move beyond concepts and values resulting from decades of public health emphasis on user fees. Of course, there is much work to be done and a research agenda needs to be developed. But we must start with a common agreement on what is non-negotiable.

We, economists, public health experts and policy makers involved in the fight against AIDS believe that a prerequisite for ensuring that treatment programs are scaled up, equitable and efficient and provide quality care is to implement universally free access to a minimum medical package, including ARVs, through the public healthcare system.

We believe that the treatment package should include HIV tests, prophylaxis and treatment of opportunistic infections, all laboratory and associated examinations, consultation and hospitalization fees, and ARVs.

We argue that WHO, UNAIDS, the governments of resource-poor countries and international donors, among them the Global Fund, the World Bank, PEPFAR and bilateral cooperation agencies must adopt and actively promote the principle of universal free access to treatment (including ARVs) and contribute to its implementation.

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We are committed to promoting the principle of free treatment, and to contributing to its implementation. Otherwise, the idea of universal access will remain a dream.

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If you require further information or wish to sign the declaration please send an email to Sabrina Lee (freeby5@hotmail.com) stating your name, position, organization and contact details, and whether you sign on behalf of your organization or as an individual.

This declaration is available on the HEARD web site: www.heard.org.za
Signatories will be updated regularly on this website.
This declaration will soon be available in French.

The deadline for signatures is 20th November 2004

27. WHO/UNAIDS Estimated funding gap to reach the target of 3 million with access to antiretroviral drugs by 2005 ("3 by 5") Bulletin Number 1: Estimates as of 31 December 2003.
28. UNAIDS, Financing the expanded response to AIDS, July 2004, p.11.
29. WHO/UNAIDS Estimated funding gap to reach the target of 3 million with access to antiretroviral drugs by 2005 ("3 by 5") Bulletin Number 1: Estimates as of 31 December 2003.

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