

Consultation on ethics and equitable access to treatment and care for HIV/AIDS



Summary of issues and discussion
26-27 January 2004
Geneva

World Health Organization and
Joint United Nations Programme on HIV/AIDS



Joint United Nations Programme on HIV/AIDS
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Acknowledgements

This publication provides an account of the points discussed at a global consultation on Ethics and Equitable Access to Treatment and Care for HIV/AIDS held in Geneva on 26-27 January 2004. The meeting was convened by UNAIDS and WHO's ETH, HDP and HIV departments. This report presents the views of the consultants, not necessarily those of the sponsoring organizations. It has, however, been indispensable in the process of preparing guidance material on this topic for WHO Member States, and we are very grateful to all the consultants, particularly to Professors Ruth Macklin and Norman Daniels who wrote background papers.

A special debt of gratitude is owed to the meeting's rapporteur, Susan Timberlake, who prepared the report with great expertise and alacrity. Her draft was submitted to the participants, and we are grateful for their comments and sugges-

tions. Thanks also go to the WHO and UNAIDS staff who reviewed the report and provided invaluable feedback, and especially to Julian Fleet, Amine Kébé, Claudia Garcia-Moreno, Ian Grubb, Craig McClure, Thierry Mertens, Carla Makhoul Obermeyer, Andreas Reis, Jason Sigurdson, Alaka Singh, Yves Souteyrand, and Eugenio Villar for detailed editorial suggestions. The accuracy and completeness of the report benefited greatly from all of this input, and the fault for any remaining omissions lies with the Secretariat.

Finally, we thank Carole Emery, Corrine Harvey, Anne Newson, Annette Schulz-Baldes and Verina Wild, for their efficient help in organizing the consultation, and Angela Firley for seeing this report into print.

A.M. Capron, Director, ETH/SDE

WHO Library Cataloguing-in-Publication Data

Consultation on Ethics and Equitable Access to Treatment and Care for HIV/AIDS (2004 : Geneva, Switzerland)
Consultation on Ethics and Equitable Access to Treatment and Care for HIV/AIDS , 26-27 January 2004, Geneva : summary of issues and discussion / World Health Organization and Joint United Nations Programme on HIV/AIDS.

1.Acquired immunodeficiency syndrome – drug therapy
2.Anti-retroviral agents – supply and distribution 3.Ethics, Clinical 4.Patient rights 5.Social justice 6.Health services accessibility – ethics I.World Health Organization e. II.UNAIDS. III.Title.

ISBN 92 4 159233 8

(NLM classification: WC 503.7)

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Printed in Switzerland

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Executive summary

The “Treat 3 Million by 2005 Initiative” – the “3 by 5 initiative”, launched by the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) – provides additional hope that millions of people with HIV/AIDS will have access to life-saving treatment in the coming years. However, even if antiretroviral therapy (ART) is delivered to three million people in developing countries by 2005, this accounts for only half the number of people in need of life-saving HIV/AIDS treatment and care. Furthermore, the “3 by 5 target” represents only an urgent first step in an effort that will have to be sustained for the lifetime of those receiving the treatment and for the duration of the epidemic – at least a matter of decades. In response to the serious ethical and operational challenges presented by this situation, WHO and UNAIDS convened an international consultation on Ethics and Equitable Access to Treatment and Care for HIV/AIDS to clarify the ethical principles and concerns that should be addressed in the progressive scaling up of ART programmes. The following is a summary of the conclusions reached during the meeting.

The 3 by 5 initiative specifically – and expansion of access to ART in general – is about people living with and affected by HIV/AIDS. They comprise the essential resource for input, involvement and cooperation if the 3 by 5 target is to be reached. In order to generate demand and ensure adherence, every effort must be made to overcome stigma and discrimination and to support the mobilization of communities and people living with HIV/AIDS. A holistic approach to the scaling up of ART, locating it firmly in a comprehensive response to the epidemic and in the primary health care context, will go a long way towards achieving the broad goals of HIV prevention and care, alleviating the impact of the epidemic, and benefiting health systems in general.

Human rights, laws and ethical principles provide guidance on expanding access to ART in a just and equitable manner. The human rights to life, health, equality and nondiscrimination oblige states to provide HIV-related treatment and care without discrimination to all those who need it. Guided by ethical principles and human rights, the ultimate goal is universal access to HIV/AIDS treatment and care. Towards this end, governments and donors should develop practical and sustainable strategies and plans that include timetables and benchmarks as part of their commitment to the progressive realization of the right to health, including the right to ART and other aspects of care for people with HIV/AIDS.

The principles of utility, efficiency, fairness and sustainability are the critical ethical principles that should guide efforts to select those who will have priority for receiving ART and to determine where and how ART will be provided. Broadly, these principles seek to:

- ▶ maximize all benefits (including, but not limited to, health benefits) that stem from the use of limited resources;
- ▶ distribute these benefits in a way that is fair, and
- ▶ where appropriate, compensate those who have been harmed or who have taken particular risks related to HIV/AIDS, such as participants in research.

Depending on the weight given to these principles, various groups could be chosen to benefit from the early provision of ART. In no particular order of priority, these include those close to death from AIDS, health care workers, parents, pregnant women, the poor, sex workers, injecting drug users, men who have sex with men, people who have participated in HIV-related research and people who were infected because of negligent blood transfusion.

Because reasonable people may disagree on which groups should be given priority based on ethical considerations, fair processes are needed for discussions and decisions about who should get ART, when, how and where. Public, transparent, inclusive and revisable processes will help to ensure that the decisions regarding who receives ART are equitable, and are acceptable to those affected by them. Such processes should be conducted at various levels within a country and should involve all stakeholders, including people living with HIV/AIDS and other marginalized groups. Implementation of a fair process will help to educate people about ART, generate demand for HIV prevention and care services, mobilize people around health as a right, and increase transparency and public accountability. It is recommended that fair process be implemented as soon as possible, wherever possible, and that initial steps should involve planning, training, workshops, development of indicators and research regarding fair process.

Immediate steps can be taken to provide ART to those with advanced AIDS-related disease who report for treatment where the infrastructure is already in place to support ART using simplified treatment guidelines. Governments should make efforts to build infrastructure where there is none and, simultaneously, to reach out to marginalized groups in other ways, such as through public information and education campaigns and social marketing of testing, counselling, treatment and care.

The goal of universal access means that cost and/or economic status must not be a barrier to access to treatment and care, and particular efforts should be made to enable the poor to gain access to treatment. Strategies should be developed to provide ART free at the point of delivery to those who cannot afford it. In systems where health care is partially or totally financed on a private basis, cost recovery for ART could involve a mixture of public and private schemes to cater for different income groups – free to those who cannot pay and have no health insurance, payment by insurance schemes for those in the formal workforce, and payment out of pocket by those wealthy enough to do so. However, if cost recovery schemes prove inefficient or obstructive to access, free delivery to all should be considered. In addition to poverty, there are other barriers to equity that must be addressed. These include stigma and discrimination; harmful gender norms; lack of governance, transparency and accountability; corruption; and ethnic, educational and/or geographical isolation. Women represent a large group who may be denied access for reasons other than lack of wealth, such as discrimination.

In addition to the provision of the drugs themselves, the integration of ART into health services provides a critical opportunity to improve national health overall and to strengthen primary health care systems. To seize this opportunity, the necessary steps must be taken to integrate ART delivery into local primary care networks; avoid vertical programmes; improve systems for the procurement of essential drugs and their distribution and monitoring; set up sustainable government financial systems; address the human resource crisis in health care through adequate salaries, incentives, and training; and involve and support communities, social services and associations of people living with HIV/AIDS. It will be necessary to develop indicators and systems by which to monitor and evaluate the efficiency and fairness of ART delivery, the extent to which a fair process has been achieved, and the overall effects of ART on national health systems and the delivery of health care.

The challenges involved in the equitable provision of HIV/AIDS treatment and care are undeniably huge. However, with sufficient commitment to appropriate ethical principles, to a comprehensive and primary health care approach, and sustained national and international solidarity, expanding access to ART holds the promise of saving the lives of millions of people living with HIV/AIDS, on an equitable basis, while supporting health systems for all.

Introduction

1. Inequities in health care have meant that many people worldwide have suffered disease and death from preventable or treatable conditions because they could not access the necessary treatment and care. Since the introduction of ART in 1996, the HIV/AIDS epidemic has cast a glaring light on these inequities, as millions of people have died, and continue to die, because they could not afford this treatment. Of around 40 million people now living with HIV/AIDS, it is estimated that six million are urgently in need of ART to avoid death within about 2 years. However, although the prices of antiretrovirals have dropped dramatically in least developed countries, and there is unprecedented political commitment and financing for treatment, fewer than 7% of those in developing countries who need antiretrovirals are receiving them.

2. On 22 September 2003, LEE Jong-Wook (Director-General of the World Health Organization) and Peter Piot (Executive Director of the Joint United Nations Programme on HIV/AIDS) declared this dire lack of access to life-saving treatment and care a global health emergency. In response, WHO and UNAIDS launched the Treat 3 million by 2005 initiative — the 3 by 5 Initiative.¹ The target of this mobilizing effort is to ensure the provision of ART to three million people living with HIV/AIDS in poor countries by the end of 2005. In addition to being a public health imperative, the need to provide ART is founded on the obligations of states to ensure the human rights to life, health, equality and nondiscrimination. The 3 by 5 target is considered to be the first step in an urgent effort to achieve universal access to ART for all those who need it. The core principles governing the implementation of the 3 by 5 initiative include urgency, equity and sustainability.

3. The provision of ART to three million people by 2005 is a daunting, but achievable, challenge. However, this target accounts for only half of those presently in need of ART. The fact that the need for ART exceeds the current ability to deliver it means that some will receive treatment and others will die. Such a situation poses grave ethical issues for the governments, international agencies, nongovernmental organizations, institutions and health care workers working to scale up access to ART. The most compelling of these ethical dilemmas involve choices that will affect the life and death of millions of people. However, other serious ethical concerns surround the potential diversion of resources from other health and social needs, as well as the possible effects of vertically-implemented ART programmes on fragile health systems, communities and families.

4. In an effort to help ensure the ethical distribution of treatment and care for those with HIV/AIDS, WHO and UNAIDS convened an international consultation on Ethics and Equitable Access to Treatment and Care for HIV/AIDS. The consultation was organized by the WHO Department of Ethics, Trade, Human Rights and Health Law, in collaboration with the Department of MDGs, Health and Development and the Department of HIV/AIDS along with the UNAIDS Secretariat. The objectives of the meeting were as follows:

- ▶ To elucidate issues of ethics and equity that might arise in the course of implementation and scaling up of ART programmes.
- ▶ To lay the groundwork for the formulation of guidance to help governments and other partners to implement ART programmes in an ethical and equitable manner.
- ▶ To consider indicators by which equity in implementation and distribution can be monitored.

5. The participants at the consultation included treatment providers, physicians and other health care workers; ethicists, lawyers and human rights advocates; and representatives of governments, international agencies, nongovernmental organizations, academia, and groups of people living with HIV/AIDS (see Annex 1 for list of participants). The participants reviewed three background papers at the meeting:

- ▶ *Ethics and equity in access to HIV treatment: “3 by 5” initiative*, by Dr Ruth Macklin.
- ▶ *How to achieve fair distribution of ARTs in “3 by 5”: fair process and legitimacy in patient selection*, by Dr Norman Daniels.
- ▶ *“3 by 5”, priority in treatment and the poor*. POV/HDP/SDE/WHO.

6. A summary of the major issues raised and of the discussion about them that took place at the meeting is provided in this document. The insights gained from this meeting have been used by WHO and UNAIDS to develop guidance intended to assist in ensuring the equitable distribution of ART, and standards and procedures by which to monitor and evaluate equitable implementation of ART programmes.

¹ For a detailed description of the 3 by 5 initiative, see: WHO/UNAIDS. *Treating 3 million by 2005, making it happen, the WHO strategy*. Geneva, World Health Organization/Joint United Nations Programme on HIV/AIDS, 2003.

Nature of ethical guidance

7. Throughout the meeting, participants discussed the nature of the ethical guidance that would be useful to countries and other bodies that are scaling up ART programmes. Dr Thierry Mertens (WHO) in his presentation entitled *What guidance to offer on achieving fair access to ART* emphasized that the debate concerning equity in the provision of ART must be considered within the changing context and time frame of the 3 by 5 initiative. This context is characterized by uncertainty in the estimates and forecasts of:

- ▶ the number of people living with HIV/AIDS, taking into account the estimate that some 80% of these people do not know their HIV status; and
- ▶ the number of people who will need ART over the next few years (possibly from 6 to 12 million people).

Producing estimates is complicated by the fact that even when people do know that they are HIV positive, they might not come forward for reasons of stigma and discrimination. Indeed, one of the greatest initial challenges is to create demand for treatment (see also paragraphs 70 and 71.).

8. Equity must be considered in terms of various dimensions, such as socioeconomic status, geographical location, age, gender, severity and duration of infection, and vulnerability. In the light of other rampant diseases and widespread undernourishment, governments have voiced concern about favouring HIV/AIDS patients, in particular with regard to providing ARTs free at the point of service while other HIV/AIDS-related care and treatment for other diseases, has to be paid out of pocket. Dr Mertens stressed that scaling up ART should serve to strengthen health systems through improvements in drug procure-

- ▶ How can ART be justified when primary health care is not being provided?
- ▶ How can ART be provided free of charge when the same patients must pay out of pocket for malaria care?
- ▶ How can the authorities ensure that a health centre has a balanced budget to deal with patients who are not infected by HIV as well as those who are?
- ▶ How will funding be sustained?
- ▶ Should governments start programmes where there is minimal capacity or where there might be greatest impact?
- ▶ How can the appropriate balance between HIV prevention and care be achieved?
- ▶ What should be the policy of governments towards private HIV/AIDS clinics?

The politics of equity form the backdrop in considering all of these questions; it is “ethics in action”.

10. Dr Jancloes urged that the meeting should not result in a generic document on ethics and equity that would not be useful to those in country. Rather, the participants at the meeting should assist WHO and others in offering ongoing, practical advice on the kinds of questions faced by implementers. Towards this end, countries need:

- ▶ context-specific advice for health care implementers, as well as for those working with various branches of government, donors, the press, the private sector, etc.;
- ▶ access to best ethical practice, especially that of neighbouring countries; and

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