

MOBILISING NGOS  
CBOs AND PLHA GROUPS  
FOR IMPROVING ACCESS TO  
HIV/AIDS-RELATED TREATMENT

A HANDBOOK OF INFORMATION,  
TOOLS AND OTHER RESOURCES

Pre-publication Copy, June 2002



## **Preface**

The International HIV/AIDS Alliance, the World Health Organization (WHO) and UNAIDS Secretariat welcome readers to this handbook.

Designed to be a useful resource for the different groups involved in treatment for HIV-related conditions, the handbook is also an implicit *tribute* to these groups. It is a concrete acknowledgement that, without their work, the global response to AIDS would be much smaller – and much less effective – than it is today.

Groups of persons living with HIV/AIDS, nongovernmental organizations (NGOs) and community based organizations (CBOs) have been at the forefront of prevention and care since the world first became aware of the epidemic two decades ago. Instead of passively leaving these tasks to the medical profession or public health authorities, they have become partners in providing HIV-related commodities and services – and in some places, they have been the *only* providers. They have also courageously built roles for themselves as advocates and teachers, changing the way the world thinks about HIV/AIDS and responds to the people who live with it. In doing so, they have built hope, spread important skills and ensured better delivery of HIV/AIDS-related services and commodities.

Recognizing that these groups remain a key resource in the global response, this handbook aims to widen their participation even further by providing them with a useful collection of information and tools. However, the word "providing" implies one-way giving, when in fact the creation of this handbook has been a two-way process: while the Alliance, WHO and UNAIDS Secretariat may be providing the finished product, the essential "raw material" was provided by dozens of individuals and groups in Africa and Asia. Their generous and enthusiastic participation during the design and field testing stages gave the handbook the benefit of their experience and expertise, and kept it focussed on the *practical* needs and challenges of providing treatment to people living with HIV/AIDS.

This process echoes the creation of another book a decade ago, the *AIDS Home Care Handbook*, which was published by WHO after extensive consultation with NGOs working in HIV/AIDS care in developing countries. That pioneering book has been used all over the world, freely adapted to fit widely different conditions in a variety of places.

This new handbook proceeds in the same spirit of partnership. The Alliance has contributed its strong field experience and expertise in collaboration with local NGOs and CBOs. WHO has overseen the technical content, in particular on drug management issues. UNAIDS Secretariat, as a global advocate for mobilizing NGOs' and CBOs' entry in the field of care, initiated the handbook's development, brought in the Alliance and many other NGOs and CBOs, and provided funding.

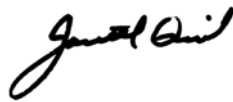
It is hoped that this new handbook will prove as useful as the earlier book – which it does not replace, but complements. We hope that it will encourage

groups already involved in HIV/AIDS care to extend the services they are already providing, and that it will encourage other groups (perhaps doing some other HIV-related activity such as prevention and support, or in other fields of health such as family planning and reproductive health) to get involved.

If the global response to HIV/AIDS can be thought of as a chain, then treatment is one of its essential links. We hope that this handbook will help groups around the world to find their own ways of reinforcing that link – and in doing so, strengthen the entire chain.



*Mr Jeffrey O'Malley*  
Executive Director  
The International HIV/AIDS  
Alliance  
Brighton, United Kingdom



*Dr Jonathan Quick*  
Director  
Essential Drugs and  
Medicines Policy (EDM)  
World Health Organization



*Ms Marika Fahlen*  
Director  
Social Mobilization and Information  
Joint United Nations Programme  
on HIV/AIDS

## **Glossary of terms**

AIDS: Acquired immune deficiency syndrome

ARV: antiretroviral therapy

CBO: Community based organisation

DOT: Directly observed treatment – short course, for example TB medication

EDM: Essential Drugs and Medicines Policy

EML: Essential Medicines List

HAART: Highly active antiretroviral therapy

HIV: Human immuno-deficiency virus

INN: International non-proprietary name

MTCT: mother to child transmission

NGO: Non-governmental organisation

PCP: Pneumocystis carinii pneumonia

PLHA: People living with HIV/AIDS

STI: Sexually transmitted infection

TB: Tuberculosis

UNAIDS: Joint United Nations Programme on HIV/AIDS

VCT: Voluntary counselling and testing

WHO: World Health Organisation

## **Acknowledgement**

We wish to thank all those who have so generously given their time, energy and guidance during the development of this handbook [please see below]. A special thanks to the Alliance partners and the many people with HIV/AIDS who shared their experience and supported the development of this resource. We couldn't have done it without you!

**Authors: Carolyn Green, Dr. Mandeep Dhaliwal, Sarah Lee, Dr. Vinh Kim Nguyen, Hillary Curtis, and Georgina Stock**

### **Technical Officers Responsible:**

**International HIV/AIDS Alliance – Dr. Mandeep Dhaliwal  
UNAIDS Secretariat– Dr. Françoise Renaud-Théry  
WHO – EDM – Marthe Everard, Paula Munderi**

## Organisations that contributed to the development of the handbook

India	Cambodia
<ul style="list-style-type: none"> <li>❑ AIDS Awareness Group (AAG)- New Delhi</li> <li>❑ Chelsea, New Delhi</li> <li>❑ Committed Communities Development Trust (CCDT), Project CHILD, Mumbai</li> <li>❑ Delhi State AIDS Control Society- New Delhi</li> <li>❑ India HIV/AIDS Alliance, New Delhi</li> <li>❑ India Network of Positive People (MNP+), Chennai</li> <li>❑ Lawyers Collective - HIV/AIDS Unit, Mumbai</li> <li>❑ Maharashtra Network of Postive People (INP+), Mumbai</li> <li>❑ Mamta Health Institute for Mother and Child, New Delhi</li> <li>❑ Michael's Care Home, New Delhi</li> <li>❑ Model HIV Counselling Centre, Safdarjung Hospital, New Delhi</li> <li>❑ NAZ Foundation (India) Trust, New Delhi</li> <li>❑ NGO HIV/AIDS Forum, New Delhi</li> <li>❑ RMC Hospital, New Delhi</li> <li>❑ Salaam Baalak Trust (SBT), New Delhi</li> <li>❑ Salvation Army, Mumbai</li> <li>❑ Shadows - Solomon Hospital, Chirala</li> <li>❑ Society for Development Research and Training (SFDRT), Pondicherry</li> <li>❑ Society for Service to Urban Poverty (SHARAN), New Delhi</li> <li>❑ St Joseph's Hospital, Pondicherry</li> <li>❑ United Nations Development Programme (UNDP), New Delhi</li> <li>❑ World Bank, New Delhi</li> <li>❑ World Health Organisation (WHO), New Delhi</li> <li>❑ Y.R. Gaitonde (YRG) Care, Chennai</li> </ul>	<ul style="list-style-type: none"> <li>❑ Association of Farmers Development (AFD), Takeo Province</li> <li>❑ Battambang Womens AIDS Project (BWAP), Battambang</li> <li>❑ Cambodian Children Against Starvation and Violence Agency (CCASVA), Phnom Penh</li> <li>❑ Cambodian HIV/AIDS Education and Care (CHEC), Phnom Penh</li> <li>❑ CARE – Cambodia, Phnom Penh</li> <li>❑ Center National for Tuberculosis (CENAT)</li> <li>❑ Hope – Cambodia, Phnom Penh</li> <li>❑ Human Rights Protection &amp; Rural Development Association (HURIPRUDA), Phnom Penh</li> <li>❑ Indradevi Association (IDA), Phnom Penh</li> <li>❑ Kasekor Thmey (KT), Kampong Cham Province</li> <li>❑ Key of Social Health Educational Road (KOSHER), Phnom Penh</li> <li>❑ Khmer Buddhist Association (KBA), Banteay Mean Chey Province</li> <li>❑ Khmer HIV/AIDS NGO Alliance (KHANA), Phnom Penh</li> <li>❑ Khmer Rural Development Association (KRDA), Battambang</li> <li>❑ Medecin du Mond, Phnom Penh</li> <li>❑ National Centre for HIV/AIDS, Dermatology and STD (NCHADS), Phnom Penh</li> <li>❑ National Centre for TB and Leprosy Control, Phnom Penh</li> <li>❑ Social, Environment, Agricultural Development Organisation (SEADO), Beanteay Meanchey</li> <li>❑ Vithei Chiwit (PLHA group), Phnom Penh</li> <li>❑ World Vision – Cambodia, Phnom Penh</li> </ul>
Zambia	Philippines
<ul style="list-style-type: none"> <li>❑ Archdiocese of Lusaka Home Based Care Programme, Lusaka</li> <li>❑ Catholic Agency for Overseas</li> </ul>	<ul style="list-style-type: none"> <li>❑ Action for Health Initiatives, Inc. (ACHIEVE), Metro Manila</li> <li>❑ Hope Foundation, Manila</li> </ul>

<ul style="list-style-type: none"> <li>Development (CAFOD), Lusaka</li> <li><input type="checkbox"/> Central Board of Health (CBoH), Lusaka</li> <li><input type="checkbox"/> Chikankata Health Services, Mazabuka</li> <li><input type="checkbox"/> Churches Health Association of Zambia (CHAZ), Lusaka</li> <li><input type="checkbox"/> Copperbelt Health Education Project (CHEP), Kitwe</li> <li><input type="checkbox"/> Development Aid from People to People (DAPP) – Hope Humana, Ndola</li> <li><input type="checkbox"/> Family Health Trust (FHT), Lusaka</li> <li><input type="checkbox"/> Joint United Nations Programme on HIV/AIDS (UNAIDS), Lusaka</li> <li><input type="checkbox"/> Kara Counselling and Training Trust (KCTT), Lusaka</li> <li><input type="checkbox"/> Kasaba Home Based Care, Kasaba</li> <li><input type="checkbox"/> Mansa Community Home Based Care, Sisters of Mercy, Mansa</li> <li><input type="checkbox"/> Mbala Catholic Diocese, Mbala</li> <li><input type="checkbox"/> Mongu Catholic Diocese, Mongu</li> <li><input type="checkbox"/> Ndola Catholic Diocese, Ndola</li> <li><input type="checkbox"/> Network of Zambian People with HIV (NZP+), Lusaka</li> <li><input type="checkbox"/> Our Lady’s Hospital, Chilonga</li> <li><input type="checkbox"/> St Francis Community Home Based Care, Livingstone</li> <li><input type="checkbox"/> St Francis Hospital, Katete</li> <li><input type="checkbox"/> St Theresa’s Hospital, Ibenga</li> <li><input type="checkbox"/> Thandizani, Lundazi</li> <li><input type="checkbox"/> World Health Organisation (WHO), Lusaka</li> <li><input type="checkbox"/> Zambia Catholic Secretariat (ZCS), Lusaka</li> <li><input type="checkbox"/> Zambia Integrated Health Programme (ZIHP), Lusaka</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Kabalikat Ng Pamilyang Pilipino, Quezon City</li> <li><input type="checkbox"/> Pamana Development Co-operative Federation Inc., Cavite</li> <li><input type="checkbox"/> Philippines HIV/AIDS NGO Support Programme (PHANSuP), Manila</li> <li><input type="checkbox"/> Philippines National AIDS Council, Manila</li> <li><input type="checkbox"/> Pinoy Plus Association, Manila</li> <li><input type="checkbox"/> Positive Action Foundation (PAFPI), Manila</li> <li><input type="checkbox"/> Remedios AIDS Foundation, Manila</li> </ul>
<b>Côte d’Ivoire</b>	<b>Burkina Faso</b>
<ul style="list-style-type: none"> <li><input type="checkbox"/> CeDReS, Abidjan</li> <li><input type="checkbox"/> Centre d’Assistance Socia-Médicale, Abidjan</li> <li><input type="checkbox"/> Centre Intégré de Recherches Biocliniques d’Abidjan, Abidjan</li> <li><input type="checkbox"/> Centre Plus Yopougou, Abidjan</li> <li><input type="checkbox"/> Projet COTRAME/IRD</li> <li><input type="checkbox"/> Projet RÉTRO-CI, Abidjan</li> <li><input type="checkbox"/> Joint United Nations Programme on HIV/AIDS (UNAIDS), Abidjan</li> <li><input type="checkbox"/> United Nations Development Programme, (UNDP), Abidjan</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Centre Oasis - Association African Solidarité, Ouagadougou</li> </ul>

International HIV/AIDS Alliance, [www.aidsalliance.org](http://www.aidsalliance.org) or [www.aidsmap.com](http://www.aidsmap.com)  
*-a website about the International HIV/AIDS Alliance with many practical publications and helpful links to other useful websites.*

World Health Organisation, [www.who.int](http://www.who.int)  
*-a website about the World Health Organisation with many useful publications.*

Joint United Nations Programme on HIV/AIDS, [www.unaids.org](http://www.unaids.org)  
*-a website about the Joint United Nations Programme on HIV/AIDS with many useful publications.*

The views expressed in this document are solely the responsibility of the authors and do not necessarily represent the views of WHO and UNAIDS. The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by WHO or the UNAIDS Secretariat in preference to others of a similar nature that are not mentioned. Errors or omissions excepted, the names of proprietary products are distinguished by initial capital letters

# **Contents**

# **Page**

## **Read this first!**

**1**

1. What is this handbook? 2
2. Why was this handbook developed? 2
3. How was this handbook developed? 3
4. Who is this handbook for? 3
5. How can this handbook be used? 3  
Additional Materials:  
-Example of workshop schedule
6. What is in the chapters of the handbook? 5
7. What materials are needed to use this handbook? 6
8. Who has developed this handbook? 6
9. Want to know more? 7

## **Chapter 1: First questions to ask**

**9**

- 1.1. Care, support and treatment 10
  - A. Care and support
  - B. Treatment
- 1.2. Linking treatment and prevention 17
- 1.3. Access to treatment 20
  - A. Availability of treatment
  - B. Accessibility of treatmentAdditional Materials:  
-Information Sheet: Barriers to access to treatment  
-Information Sheet: Factors affecting access to treatment
- 1.4. Want to know more? 33

## **Chapter 2: Foundations of treatment**

**35**

- 2.1. The basic elements of treatment work 36

A. Helping relationships for treatment work	
B. Knowledge, skills and attitudes for treatment work	
C. An ethical approach to treatment work	
D. Information for treatment work	
2.2. How different treatments vary	49
2.3. Working with others to improve access to treatment	52
A. Partnerships to improve access to treatment	
B. Advocacy to improve access to treatment	
<u>Additional materials:</u>	
Treatment information sheet	
Treatment assessment sheet	
2.4. Want to know more?	60
<b><u>Chapter 3: Putting treatment into practice</u></b>	<b>62</b>
3.1. Resources for HIV related treatment work	63
3.2. Drugs for HIV-related treatment	69
A. Managing HIV-related drugs	
B. The essential drugs concept	
C. Guidelines for treatment	
A. Choosing the right drugs	
B. Drug names	
C. Using drugs effectively	
D. Fact Sheet – Antiretroviral drugs	
3.3. Sourcing and looking after good quality drugs	89
A. Drug Quality	
B. Sources of drugs	
C. Storing drugs	
D. Keeping records and ordering drugs	
3.4. Providing drugs for people with HIV	104
A. Paying for HIV-related treatment	
B. Drug information	
C. Dispensing drugs	
D. Managing transport for HIV-related treatment	
3.5. Training and management for HIV-related treatment work	112
3.6. Want to know more?	114

**Chapter 4 Assessing needs and resources, and deciding what to do** **116**

- 4.1. The assessment process 117
- 4.2. Assessment frameworks 119
- E. Assessing needs and resources - people with HIV and the community
  - F. Assessing needs and resources – the local environment
  - G. Assessing needs and resources - your NGO/ CBO/PLHA group
- 4.3. Deciding what to do 131
- A. Analysing your findings
  - B. Reaching a decision
- Additional materials:
- Information Sheet: Thinking creatively about what you can do – treatment in context
  - C. Communicating your decision
- 4.4. Want to know more? 138

**Chapter 5: Learning from and improving HIV/AIDS-related treatment work** **139**

- 5.1. Monitoring and evaluating HIV/AIDS-related treatment work 140
- A. Keeping records of your work
  - B. Monitoring your work
  - C. Evaluating your work
- 5.2. Changing and improving HIV/AIDS-related treatment work 145
- A. Making the most of new resources and linkages
  - B. Coping with changes
  - C. Sharing your experiences with others
  - D. Scaling-up, scaling-down or staying the same
- 5.3. Want to know more? 151