

Report of the DHHS Working Group on Dissemination of HIV Treatment Information

The Department of Health and Human Services (DHHS) Working Group on Dissemination of HIV Treatment Information consists of representatives from the DHHS agencies and institutes listed below. The names of the individuals who participated in the development of this report are listed at the end. The Forum for Collaborative HIV Research at the Center for Health Services Research and Policy of the George Washington University School of Public Health and Health Services facilitated the project.

Participating Agencies

Centers for Disease Control and Prevention
National Institute for Allergy and Infectious Diseases
National Institute for Child Health and Human Development
National Library of Medicine
Health Care Financing Administration
Health Resources Services Administration
NIH Office of AIDS Research
Office of HIV/AIDS Policy

Project Goals

The goal of the Working Group is to:

- (1) define the role of DHHS in HIV treatment information dissemination to health care providers and patients;
- (2) identify feasible tasks that can be carried out by DHHS to fulfill this role;
- (3) identify the appropriate roles for specific agencies within HHS to carry out these tasks;
- (4) identify methods to coordinate treatment information dissemination efforts among HHS agencies;
- (5) analyze current research to identify those information dissemination models that lead to implementation and adoption of guidelines;
- (6) identify methods to evaluate whether clinical practices have changed and which dissemination efforts are the most effective.

Executive Summary

Advances in medical knowledge and drug development have led to significantly reduced HIV-related morbidity and mortality in recent years. However, inadequate and inappropriate use of HIV antiretroviral treatment increases the development of organism resistance to the drugs, which diminishes the effectiveness of therapy for patients and increases the likelihood of transmission of multi-drug resistant HIV. There is a public

health need to intensify efforts to ensure optimal use of both initial and salvage antiviral regimens, prophylaxis against AIDS-related opportunistic infections and perinatal transmission of HIV. However, the standard of care for many patients remains inadequate. Ensuring that providers and patients have the most current information about HIV treatment is essential to the overall success of HIV treatment strategies.

To this end, the Department of Health and Human Services (DHHS) has created four guidelines for the treatment of HIV disease and prevention of peri-natal transmission of HIV. The value of those guidelines depends upon the ability to translate and disseminate them to the appropriate audiences for implementation. The DHHS Working Group on the Dissemination of HIV Treatment Information was formed to determine how DHHS can best provide HIV treatment information to providers and patients. The Working Group focused on three target audiences: health care providers/payors, social service providers, and patients. The Working Group examined the many ways that DHHS currently disseminates such information and then developed recommendations to further those efforts. The central findings of the Working Group include:

- As the largest funder of HIV care and research, DHHS has a distinct responsibility in efforts to disseminate HIV treatment information. It has credibility with providers and has many infrastructures in place to disseminate treatment information.
- The DHHS Office of HIV/AIDS Policy should exercise the authority and be given the resources - including funding and staff – needed to coordinate DHHS HIV treatment information activities. Coordinating activities should include regular meetings of the leadership and working level staff from DHHS programs and agencies to develop and implement information dissemination strategies.
- To have the greatest impact, HIV treatment information dissemination efforts should be incorporated into all relevant DHHS programs. The roles for each agency are articulated in the Report.
- DHHS, through NIH, should continue to provide on-going support and coordination of panels of experts to develop and continually update treatment guidelines.
- DHHS should have one centralized location for the repository of new treatment information and for the development, storage and distribution of informational and educational materials. All DHHS agencies should support and utilize that location for their respective programs. This operation would take advantage of all available mechanisms, including electronic technologies, to organize, store and disseminate information. Currently, the AIDS Treatment Information Service (ATIS), managed by the National Library of Medicine, performs some of these functions. An enhanced ATIS, run by NLM, could develop and supply all DHHS programs with treatment information and education materials. The estimated cost of the enhanced ATIS is \$3 – 5 million.
- HIV treatment information dissemination systems must be able to provide regularly updated information.
- Treatment information needs to be translated into formats that meet the needs of the target audiences.
- OHAP should convene a working group to provide guidance in efforts to disseminate treatment information.

- Evaluation of information dissemination efforts must be seen as an essential part of those efforts.

Introduction

DHHS has published four guidelines for the treatment of HIV disease.¹ This plan will outline the role that DHHS can play to disseminate the information contained within those guidelines to health care providers and patients in order to ensure that standards of care are properly implemented. The plan will recommend tasks to fulfill that role and define the appropriate responsibility that agencies within HHS can take in fulfilling those tasks. This report will also recommend methods to coordinate dissemination activities among HHS agencies and methods to evaluate those efforts.

Background

Methodology

The Working Group was convened by Anthony Fauci, M.D., the Director of the National Institute of Allergy and Infectious Diseases, and Eric Goosby, M.D., the Director of the DHHS Office of HIV/AIDS Policy. Together, they serve as the government convenors of the PHS Panel on Antiretroviral Use in Adults and Adolescents. The Working Group was coordinated by the Forum for Collaborative HIV Research at the request of the NIH Office of AIDS Research. The Forum planned and facilitated the Group meetings, prepared background materials, wrote minutes, and drafted the Report. All members of the Working Group met once in March, 1999, where the goals and structure of the project were discussed and agreed to. Each agency designated a representative to the Group for attendance at subsequent meetings. The Group met on a monthly basis. Portions of the Report were drafted after each meeting. The Group first identified the need for treatment information dissemination to the chosen target audiences. Then, each representative described their agency's current methods of treatment information dissemination for their respective agencies and discussed possible ways to expand that role. These ideas were incorporated into the Report. All Group members re-convened to discuss and approve the Report.

¹ There are four HIV-related treatment guidelines: *Report to the NIH Panel to Define Principles of Therapy of HIV Infection and Guidelines for the use of Antiretroviral Agents in HIV-Infected Adults and Adolescents*, MMWR, April 24, 1998, Vol. 47, No. RR-5; *Recommendations for the Use of Antiretroviral Drugs in Pregnant Women Infected with HIV-1 for Maternal Health and for Reducing Perinatal HIV-1 Transmission in the U.S.*, MMWR, Jan.30, 1998, Vol. 47, Po.RR-2, *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection*, MMWR, April 17, 1998, Vol.47, No.RR-4; *1997 USPHS/IDSA Guidelines for the Prevention of Opportunistic Infections in Persons Infected with HIV*, MMWR, August 20, 1999, Vol.48, No.RR-10

Need for Dissemination of HIV Treatment Information

The dissemination of quality medical information to providers and patients is essential to ensure good care for all medical conditions. The need for on-going, high-quality HIV treatment information dissemination is particularly pressing for many reasons, including:

- Inadequate and inappropriate antiretroviral treatment increases the development of organism resistance to the drugs, which diminishes the effectiveness of therapy for patients and increases the likelihood of transmission of multi-drug resistant HIV. Growing numbers of patients who are resistant to HIV antiretroviral therapies will lessen the impact and value of this successful treatment regimen over time. Therefore, there is a public health need to intensify efforts to ensure optimal use of both initial and salvage regimens.
- Data show that even among insured patients, the percentage of patients who receive the recommended standard of care is inadequate. Despite Medicaid coverage of the latest HIV treatments and diagnostic tests, beneficiaries are not always receiving the best care². Better education for physicians and patients can help to rectify this.
- Better implementation of the standard of care can substantially reduce morbidity and mortality³.
- Providers need regularly updated dissemination of HIV treatment information to ensure the prescription of appropriate treatment regimens.
- Patients need regularly updated dissemination of HIV treatment information to be able to make informed decisions about starting and switching therapies, and to assist in efforts to adhere to complex treatment regimens.

Identifying Target Audiences:

Health Care Providers

Three tiers of health care providers were identified:

- The first-tier providers are clinicians who primarily treat HIV patients and write most of the prescriptions. These providers are usually well informed, read the literature, and attend scientific meetings. These providers will need guideline updates with little or no tailoring.
- The second-tier of providers treat a fair number of HIV patients, but are not in a setting that allows them to keep as up-to-date as the first-tier providers. These providers are treating growing numbers of HIV patients and have less time to regularly access information.
- The third-tier of providers treat few HIV patients and the desire to be informed of the latest treatment information competes with many other medical education needs.

² Shapiro MF, Morton SC, McCaffrey DF, Senterfitt JW, Fleishman JA, Perlman JF, Athey LA, Keesey JW, Goldman DP, Berry SH, Bozzette SA. **Variations in the care of HIV-infected adults in the United States: results from the HIV Cost and Services Utilization Study.** *JAMA.* 1999; 281(24):2305-2315.

³ Turjanica MA. **Tracking of hospital-based inpatient HIV/AIDS population demonstrates changing trends in patient care** *Int Conf AIDS.* 1998;12 (abstract no. 43431).

- Major efforts should focus on second- and third-tier providers, who will need to be targeted with special approaches. With third-tier providers, for example, information about potential referrals to providers with greater HIV expertise may be appropriate. Though, it should be noted that such referrals are not always possible given the limitations of physician choice in many health care plans, as well as geographical limitations that place many patients far away from HIV medical expertise. Therefore, other strategies, such as the ‘warmline’ and others should be explored.

Identifying how to reach providers is an important aspect of successful information dissemination. In addition to the identification of individual providers, it is necessary to identify clinics, hospitals, and other places where individuals receive health care. Several DHHS agencies and programs have the ability to identify and reach providers.

Payors

The payor-providers are another important target audience. They include medical directors of managed care organizations (MCOs), health maintenance organizations (HMOs), and State Medicaid Directors. Information dissemination to this audience can impact the formularies and prescribed care plans for whole systems of health care delivery. Of particular importance will be Directors of Medicaid programs, who can incorporate the disseminated information into the specifications for managed care contracts.

Patients

Patients are another important target audience. The adult HIV treatment guidelines state the need for patients to make informed decisions about when to start therapy and to be involved in determining which regimen may be best for them. Patients need to take an active role in determining if they will be able to adhere to treatment regimens and need to be able to recognize the development of treatment side effects. Therefore, treatment information and education targeting patients is an important tool to supplement and support communication with the physician.

Points of special interest or concern regarding this audience include:

- There are fewer mechanisms in place to reach patients than there are for providers.
- Patients are a more diverse group than providers.
- Existing models of information dissemination from community-based organizations need to be investigated and evaluated.
- DHHS could target populations where the disease is accelerating and those who are not reached by existing organizations.
- HIV counseling and testing centers offer an important and under-utilized opportunity to provide patients with treatment information.
- Information targeting patients needs to be understandable and culturally appropriate.

- Social service providers - including case managers, peer educators, and drug treatment counselors - offer an opportunity to provide patients with additional education and support in making and following through on treatment decisions.

Current Knowledge about HIV Guideline Dissemination and Implementation

Background information regarding the use and implementation of HIV treatment practices is provided as an addendum to this report.

General Findings

- **DHHS has a distinct responsibility in efforts to disseminate HIV treatment information.**

Many constituencies play an important role in the dissemination and implementation of guidelines for HIV treatment, including state health departments, health care delivery institutions, community-based organizations, professional associations, academic centers, and pharmaceutical companies. However, there are several reasons why DHHS has a particular responsibility to make certain that HIV treatment information is well disseminated and utilized properly, including:

- The development of the various HIV treatment guidelines has occurred by DHHS-sponsored panels;
 - DHHS is the largest funder of HIV-related health care, including Medicaid, Medicare, and Ryan White title programs;
 - DHHS has credibility among health care providers in a variety of settings. DHHS-sponsored information dissemination will ensure better adoption of optimal care for HIV-infected persons.
 - There are current mechanisms in place within DHHS for information dissemination.
 - DHHS plays a unique role in funding research for pharmaceutical development and approval. In addition they provide funds for AIDS Drug Assistance Programs and co-payor for pharmaceuticals under Medicaid. Therefore, accurate information about current therapies for HIV is essential in providing appropriate prescriptions, adherence to protocols when taking the therapies and the ultimate success in combating HIV disease.
- **The DHHS Office of HIV/AIDS Policy should exercise the authority and be given the resources, including funding and staff, to coordinate DHHS HIV treatment information activities.**

While many agencies and programs within DHHS can and should have a part in information dissemination, there is a need for one office within DHHS to serve as the coordinator to oversee the efforts, allocate responsibility, and organize communication among different programs. The DHHS Office of HIV/AIDS Policy is the most logical center for such coordination. The AIDS Coordinating Committee, representing leadership from each of the relevant DHHS should serve as the initial coordinating body with responsibility for the development of working relationships among the DHHS agencies

and their interactions with national community-based and professional organizations. This Committee needs to meet regularly. Additionally, OHAP should provide coordination of working level staff among DHHS agencies to implement proposed activities. Appropriate staffing and resources at OHAP to adequately coordinate these activities is essential and strongly recommended.

- **The primary function for NIH in disseminating HIV treatment information should be the on-going support and coordination of panels to develop and update treatment guidelines.**

Information about how to most effectively treat HIV disease results from advances in clinical research. Panels to develop and update guidelines provide expertise to help transfer results from research into care. These guideline panels need resources and support in order to adequately and quickly update guidelines as new information emerges. Because it has primary responsibility for clinical research, the NIH is best-suited to coordinate these panels. OHAP and other DHHS agencies should participate on these panels in order to enhance collaboration in guideline development and dissemination.

- **DHHS should have one centralized location for the repository of new treatment information and for the development of education materials. All DHHS agencies can utilize that location for their respective programs.**

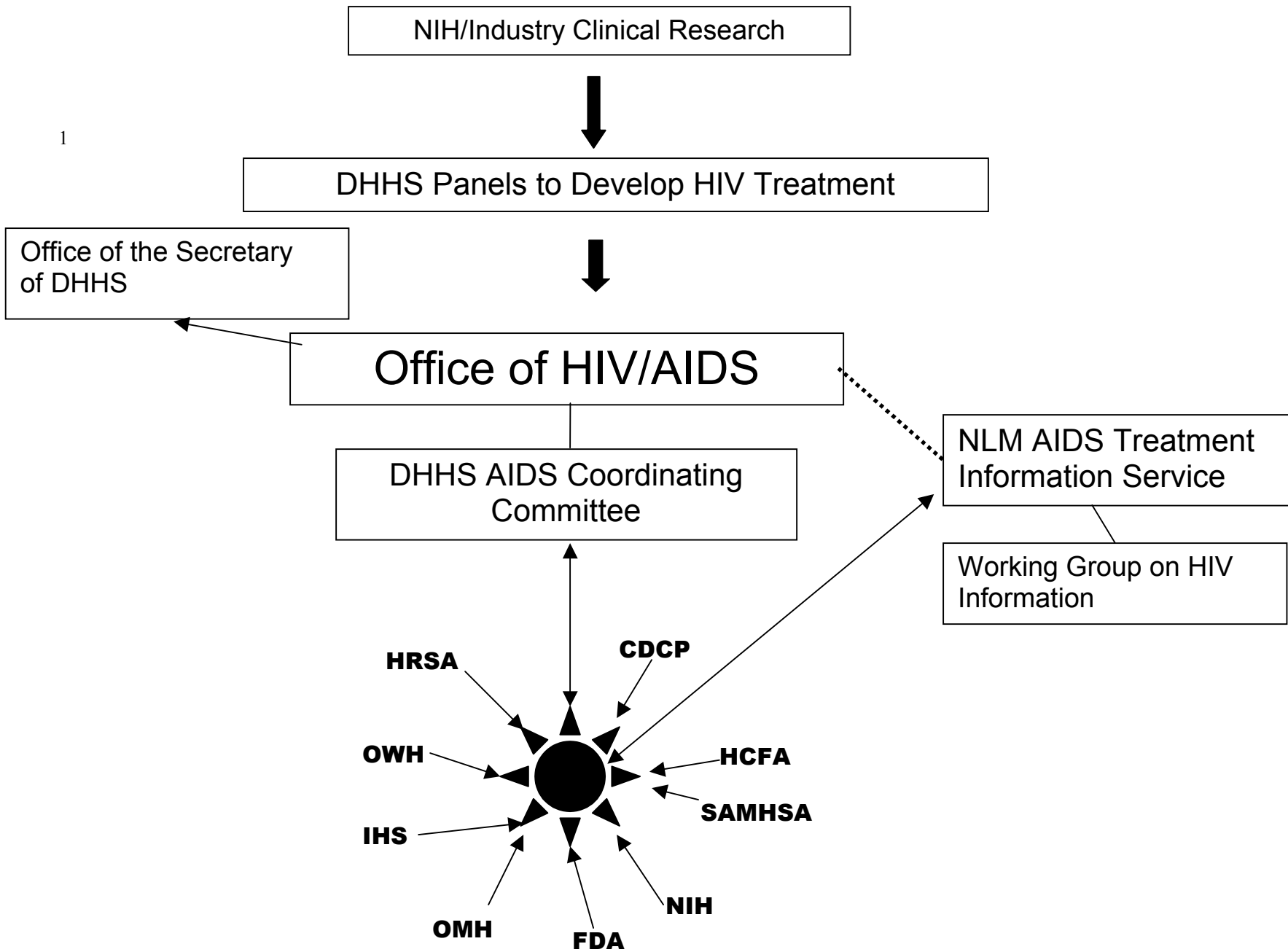
DHHS should create one central location that would receive new treatment information from the guideline panels, develop and run a website, produce printed materials for dissemination, and develop other appropriate mechanisms for collecting, storing and disseminating information. All DHHS agencies can then use one central service, rather than spend time and resources creating their own materials. OHAP and its advisory committees should provide guidance and oversight to this resource and to the DHHS agencies in their use of this entity. All agencies that use this service should support it. The cost associated with this service would include: staffing, printing, warehouse storage and dissemination, postage for single copy, as well as bulk distribution of hard copies, materials development, marketing, and web site development and maintenance.

Currently, one Federal contractor, the National Library of Medicine (NLM), operates the HIV/AIDS Treatment Information Service (ATIS), which performs at least some of these functions (see below). NLM is the appropriate contractor for these functions and ATIS should continue acting as the dissemination point for all federal treatment guidelines if it is sufficiently funded by all DHHS agencies to do so. The cost of this enhanced ATIS is estimated to be between \$3 – 5 million.

- **HIV treatment information dissemination systems must be able to provide regularly updated information.**

On-going developments in clinical research place the standard of care in a constant state of revision, requiring mechanisms for information dissemination that can provide users

with continually updated information. The various DHHS-sponsored panels that develop treatment guidelines need to be able to quickly update guidelines to incorporate new information. Distribution of updates to the guidelines requires a cohesive and agency-wide dissemination plan to ensure that the most current version of all the treatment guidelines are widely distributed. Such a plan should be coordinated by OHAP and implemented within all relevant DHHS agencies. An algorithm for how information could be disseminated within DHHS is provided here.



1

The Panel on Clinical Practices for Treatment of HIV Infection regularly meets and updates its treatment guidelines for the use of antiretrovirals in adults regularly. The guidelines were initially published through CDC's *MMWR*. However, as new data becomes available, the guidelines are updated periodically and are released through the ATIS web site. These updates are known as "living documents" (Internet address: <http://www.hivatis.org/trtgdlns.html>). Supplemental information on such topics as adherence, class adverse events, and hydroxyurea is provided as links from the guidelines documents. The adult treatment guidelines were issued in *MMWR* in April 1998 and as a supplement to the *Annals of Internal Medicine* in June 1998. However, these published versions are now out of date. Another update in *MMWR* and other publications to target a broader audience was suggested for the end of the year by the panel.

Notices in agency publications and linkages from other DHHS websites should regularly notify users about the availability of guideline updates. ATIS has established a listserv to specifically notify subscribers when updates to the guidelines become available. Using listserv email notification is a quick and cost effective mechanism to announce updates to the "living documents".

Additionally, ATIS has in place a toll-free 800 number that callers without internet access or who prefer other means of communication can use to request single copies of all the guideline documents for free. ATIS staff are trained to assist callers with questions about the guidelines. When health care providers call ATIS asking questions about a specific patient, that provider is given the option of being immediately transferred to HRSA's HIV National Consulting Service (Warmline) or given the number to call at a later time. It is not within the scope of the ATIS service to answer specific case management questions from a provider about an individual patient. ATIS also exhibits at many local and national conferences each year where copies of the most current guidelines are always available.

- **Treatment information needs to be translated into formats that meet the needs of the target audiences.**

One reason for difficulty in implementation of the guidelines is their length and level of complexity for practicing physicians, providers and patients. In addition to distribution issues, there is the need to simplify the various guidelines to provide easy-to-read and use documents with specific regimens for providers and patients in different categories. Translation and adaptation of the information contained within the guidelines for different target audiences is an important part of the dissemination effort.

The challenge of translating the information into alternate formats is made more difficult because it is equally important that the information provided be comprehensive and up-to-date as the guidelines change. The Panel on Clinical Practices for Treatment of HIV Disease will attempt to develop two algorithms stating how to treat treatment-naive individuals and how to treat patients with salvage regimens. These algorithms would accompany the complete treatment guideline. OHAP should encourage linkages with the

various panels that develop the treatment guidelines and should be represented on those panels, as well.

- **OHAP should convene a work group of experts to provide advice in efforts to disseminate treatment information.**

To assist the expert panels that develop the treatment guidelines, OHAP should convene a working group to provide guidance on the dissemination and translation/adaptation of the guidelines, as well as on the development of supplementary educational materials. The working group should include expertise in information systems management, information services, development of reading and audio-visual materials, social marketing experts, and medical and consumer education. The group should meet on a regular basis to review dissemination efforts and provide recommendations for further efforts, including methods of evaluation to determine if the dissemination efforts are successful.

- **Evaluation of information dissemination efforts must be seen as an essential part of those efforts.**

Each DHHS program that disseminates HIV treatment information needs to evaluate their efforts. OHAP should also evaluate its efforts to coordinate activities among DHHS programs. NIH and AHCPR should engage in and fund research into dissemination practices and patterns.

Responsibilities and Tasks for Participating DHHS Agencies:

This section of the report outlines the overall responsibility that each agency participating in the Working Group plays in HIV treatment dissemination. Their central responsibilities and description of activities are listed below.

All DHHS agencies should contribute to and support the maintenance of a central repository for treatment guidelines and related supporting information, a resource for the development of materials to support this effort, and for the agency's dissemination efforts. All DHHS agencies can take primary responsibility for disseminating HIV treatment information through their respective programs. The focus of their efforts will depend upon the nature of the program. Each agency will use the central location for materials production and will link their various websites to this central location. Each agency should be responsible for evaluation of their dissemination efforts.

Office of HIV/AIDS Policy (OHAP)

Central Responsibilities

- Coordinate activities among DHHS agencies and programs.
- Provide guidance for the implementation and use of the central repository of treatment information.

- Staff Advisory Committee in information dissemination.

Description of Activities

The Office of HIV/AIDS Policy is the lead within the Department of Health and Human Services for the development and updating of the Guidelines for Use of Antiretroviral Guidelines in HIV Infected Adults and Adolescents. The guidelines are frequently updated and communication about the availability of the latest version is critical at a time when the state-of-the-art treatment is changing so rapidly. The availability of current guidelines is noted in the numerous speeches given by the Secretary, Surgeon General and Director, as well as other leads within the Office of Public Health and Science (OPHS), and communication with the various Operating Divisions (OPDIVs) with HIV/AIDS responsibilities.

In order to better serve the public, OHAP proposes to lead the Departmental effort for systemic dissemination of the availability of the latest version of the guidelines, communication with the various OPDIVs about opportunities for dissemination, and coordinative functions for a central repository for the guidelines and translation of the guidelines for various target audiences. For FY 2001, OHAP has requested additional funds a designated full time equivalent (FTE) to support the coordination of treatment guidelines dissemination among the various OPDIVs and to enhance coordinated efforts across agencies. It is anticipated that OHAP would support an ongoing work group comprised of representatives from the various agencies to enhance these efforts. The charge of the work group would be to implement the plan among the various DHHS agencies.

The Office of Women's Health (OWH) information service has a component of its information service and link to the guidelines on the ACTIS website. OWH has a number of grantees in women's health, including provider groups, that could be mailed information regarding the treatment guidelines in FY 2000.

The Office of Minority Health (OMH) has a Minority Resource Center, and information can be easily distributed through their newsletter about the availability of the latest guidelines. In addition, OMH has a variety of grantees, including minority health care provider organizations such as the National Medical Association and National Nurses Association which can be resources for dissemination to their constituency provider group.

HRSA

Central Responsibilities

- Disseminate up-to-date HIV information to all HRSA grantees and the public on a regular basis.
- Disseminate information and train providers on the Guidelines through the AIDS Education and Training Centers (AETC), the AETC Resource Center, the Targeted

Provider Education Demonstration Project, the Area Health Education Centers, and the national clearinghouses funded by HRSA for mass mailings to grantees

- Develop systems for on going HIV treatment information dissemination through all HRSA bureaus.
- Evaluate implementation of guidelines within HRSA-funded primary care programs.
- Operate Warmline, in collaboration with the CDC, for providers seeking expert guidance in treating HIV.

Description of Activities

HRSA administers funding for the Ryan White CARE Act, the PHS Section 330 Community and Migrant Health Centers program, health professions education programs, the National Health Service Corps, the Maternal and Child Health block grants, the Healthy Start Initiative, and the Emergency Medical Services for Children Program. As such, HRSA has multiple opportunities to reach health care providers, service providers, States, departments of health, and patients with HIV treatment information.

HRSA, through its network of grantees, (States, eligible metropolitan areas, community health centers, migrant health center, homeless health centers, departments of health, AIDS service organizations, and academic health centers) can provide for wide dissemination of HIV treatment guidelines. It does this through grantee mailings, national meetings, web-based technologies, resource centers, newsletters and a number of clearinghouse contracts. Additionally, the agency, through the individual program guidances, has the ability to incorporate PHS-developed guidelines into program expectations, thus ensuring more rapid and uniform implementation across a variety of grantees. The technical assistance provided by HRSA allows for addressing improvements in achieving goals through training and targeted assistance on a wide range of programmatic challenges.

Current HRSA efforts include:

- The AETC program is the major congressionally authorized and funded program to provide professional education in AIDS. The 14 AETC grantees continue to identify HIV providers in their regions that require training. Names of providers are obtained from professional organization mailing lists, Title I and II planning activities, and training sign-up lists. AETCs play a critical role in translating the guidelines for providers/ making a user friendly format based on their extensive experience with training for various levels of health care providers (Tier 1 - 3)
- HIV care curricula have been developed for all 50 states, the District of Columbia, Puerto Rico, and the US Virgin Islands by the AETC, including dissemination of treatment guidelines. Providers are trained on these guidelines and updated regularly. Trainings may occur at conferences, provider sites, academic health centers or local performance sites.
- Nationally televised interactive satellite broadcasts on the guidelines and related topics occur 2 to 3 times per year, in collaboration with other federal agencies.

- Nationally available audio broadcasts addressing specific issues including the Guidelines 3 to 4 times per year
- Technical Assistance Cooperative Agreements address:
 - consumer education,
 - treatment education for mid-level providers,
 - dissemination through the National HIV Pediatric Resource Center,
 - provides on-site and individualized updates and education to a variety of Ryan White CARE Act grantees
 - creation of Purchasing Specifications on HIV for Managed Care contracting which is based entirely on the Guidelines. This is done in collaboration with CDC.
 - Linkages with the community and migrant health center national organization
- Support to several HIV/AIDS constituency organizations to disseminate guidelines widely, at annual and regional meetings, targeting those affected with HIV and those who care for them,
- The Maternal/Child Health Bureau disseminated the PHS Recommendations on Prevention of Perinatal Transmission to its grantees when Title IV was under its auspices.
- The Bureau of Primary Health Care disseminated HIV guidelines to Title III grantees when they were under its auspices.

The Bureaus of HRSA are mission driven and perform the following:

HIV/AIDS Bureau conducts programs to improve the quality and availability of care for low-income, uninsured and underinsured individuals and families affected by HIV/AIDS authorized under the Ryan White CARE Act. The Bureau targets clinical providers, States, EMA's, academic health centers, community-based organizations, departments of health and AIDS service organizations. The Bureau disseminates HIV information through HRSA Care Action Newsletters, mailings to grantees, Web page hotlinks, Listservs, the National HIV Pediatric Resource Center, the National Primary Care Clearinghouse, the AETC Program (which focuses on physicians, nurses, advanced practice nurses, dental providers, and physician assistants), the AETC Resource Center and the Targeted Provider Training Demonstration Project (which focuses on social service providers not covered by the AETC legislation). The above described Warmline is a resource for second and third tier providers who use the consultation of HIV/AIDS experts to assist with the clinical challenges of caring for HIV positive patients. The AIDS Education and Training Centers (AETC) currently have the primary responsibility for developing AIDS treatment education for health care providers. Additional funding has been provided to create a resource center and an evaluation center. Community-based organizations can receive funding for patient-focused treatment education programs under Ryan White Title I programs. State health departments can receive funding for both patient and provider information dissemination programs under Title II. Primary health care for HIV is provided under Title III and can also include treatment education for providers and patients. Pediatric needs are funded under Title IV and can include funding for provider and patient treatment education.

Bureau of Health Professions (BHPr) promotes a health care workforce with a mix of the competencies and skills needed to deliver cost-effective quality care. This is done via support of the educational programs' ability to meet the needs of vulnerable populations. Targets are academic health centers, and providers-in-training. Dissemination efforts include the use of the Area Health Education Centers (AHEC) network of 40 centers' affiliation with more than 100 medical schools. Bureau of Health Professions, administers the following grant programs:

- Residency Training in Primary Care
- Faculty Development in Primary Care
- Academic Units of Primary Care
- Pre-doctoral Training in Primary Care
- Pediatric Primary Care Residency
- Physician Assistant Training

Bureau of Primary Health Care (BPHC), whose mission is to increase access to comprehensive primary and preventive health care and to improve the health status of underserved and vulnerable populations, does this through a network of 700 centers at more than 3000 sites. The National Health Service Corps program has more than 2,400 health care professionals in service throughout the nation. These grantees provide comprehensive primary care services to underserved populations and have an opportunity to impact providers and patients directly. Dissemination to them includes: web page hotlinks, the National Primary Care Resource Center, Program Information Notices, direct mailing to grantees, Clinician's National Forum and other clinical networks web pages and national meetings.

Maternal Child Health Bureau (MCHB) programs aim to achieve one goal: to promote comprehensive, coordinated, family-centered, and culturally sensitive systems of health care that serve the diverse needs of all families within their own communities. The MCHB administers the Maternal and Child Health block grants, the Health Start Initiative, the Emergency Medical Services for Children Program. The program targets States and community-based organizations. Health (NCEMCH).

The Agency could address further dissemination efforts in the following ways if efforts are not duplicative, do not interfere with ongoing and proven efforts, and if additional support was forthcoming:

HIV/AIDS Bureau

If additional funds became available HAB would be interested in:

- identifying ways to inform providers and consumers of the multitude of resources that are already available
- identifying marketing techniques that are successful in reaching these providers to have them access readily available resources
- have the AETCs formalize and "translate" different training strategies to the 3 Tiers of providers and others
- have the AETC Resource Center provide broader functions to a wider audience

- have the AETC Evaluation Center look at dissemination efforts and the impact on provision of quality care
- have the AETC programs understand how to get medical providers to actually understand the guidelines, their relevance and how to use them to improve outcomes of care
- conduct a needs assessment and train to the various needs of the 3 tiers of providers

The AETC Resource center, primarily created to serve the AETC network, could serve a broader range of constituents as it collects, coordinates and disseminates guidelines and other information. It recently received supplemental funding to focus on case managers, social workers, outreach workers, and others not previously within the AETC mandate. Additional funding could provide these services and reduce duplication to others as well.

Bureau of Health Professions

The BHP proposes to:

- Post information on the Bureau's grant WEB page.
- Sponsor an HIV Treatment Information Dissemination special issue of a medical journal.
- Set up a listserv with all PCMEB project directors to receive information.
- The guideline access information above could be provided to the 40 AHEC programs and 170 affiliated AHEC centers. We can provide e-mail lists.
- A hard copy of the guidelines could be mailed out to the AHEC programs and AHEC centers. We can provide the address lists.
- The guidelines could be made available for distribution at national meetings. A representative from the AETC program could do a presentation, or see that hard copies and posters are available.
- The HIV Treatment Guidelines could be included as part of continuing education programs arranged/conducted by individual AETC programs and AHEC centers
- An article could be developed by the AETC for publication in the AHEC Bulletin; its focus could be on the dissemination of HIV Treatment Guidelines and the variety of collaborative dissemination efforts.
- Video broadcasts: collaboration and marketing of video broadcasts on this topic. We could announce the broadcasts via e-mail/listserv, and could focus on certain states/areas.
- Some provider groups/disciplines may not have received as much info as others relative to HIV Treatment Guidelines; targeted efforts could be planned; we may need more resources to expand activities.

BPHC and MCHB could collaborate with other Bureaus to provide Web based links to appropriate web sites and undertake mailings to all grantees once the Guidelines have been released.

As a provider of primary care and the coordinator of funding under the Ryan White CARE Act, HRSA has multiple opportunities to reach health care providers, service providers and patients with HIV treatment information. The AIDS Education and Training Centers (AETC) currently have the primary responsibility for developing AIDS

treatment education for health care providers. ATIS and AETCs should work closely to make sure all of the 15 programs are notified when updates to the guidelines are released. Community-based organizations can receive funding for patient-focused treatment education programs under Ryan White Title I programs. State health departments can receive funding for both patient and provider information dissemination programs under Title II. Primary health care for HIV is provided under Title III and can also include treatment education for providers and patients. Pediatric needs are funded under Title IV and can include funding for provider and patient treatment education.

CDC

Central Responsibilities

- Lead or assist in coordination of panels to develop HIV treatment and prevention guidelines;
- Disseminate information to public health audiences and HIV care providers through CDC publications.(MMWR);
- Operate AIDS Hotline and National Prevention Information Network (NPIN);
- Develop and disseminate treatment information and educational materials for different provider and patient audiences;
- Through surveillance mechanisms and special studies, evaluate provider adherence to treatment and prevention guidelines.

Description of activities

CDC's main role in dissemination of HIV treatment guidelines consists of participation in (and frequently leading the effort in) the development of guidelines, and publishing them in MMWR (all major DHHS HIV treatment guidelines documents were published first in MMWR). Guidelines documents are frequently republished in major medical journals (e.g., the adult antiretroviral guidelines in the Annals of Internal Medicine; the 1997 opportunistic infections guidelines in Clinical Infectious Diseases, the Annals of Internal Medicine, Pediatrics, and American Family Physician). Documents are also available on CDC web sites, or, in the case of updates, inquirers are hyperlinked to the ATIS web site. Updates are also publicized by ••Notice to Readers announcements in the weekly MMWR. CDC also maintains the AIDS hotline and the National Prevention Information Network (NPIN), both of which refer callers to these documents and indicate where they can be obtained. CDC's Technical Information and Communications Branch (TICB) produces a CD with HIV-related MMWR articles, including treatment guidelines, for distribution to persons who request it.

CDC's HIV Epidemiology Branch funds several organizations (e.g., American Academy of Pediatrics, American College of Obstetricians, Association of Maternal and Child Health Providers) to develop and disseminate appropriate educational materials concerning guidelines for prevention of perinatal transmission of HIV and for treatment of pediatric HIV.

Regarding patient information, CDC's TICB maintains expertise in preparing educational materials for different audiences and has prepared a series of pamphlets to educate patients concerning HIV care in general and prevention of opportunistic infections. These pamphlets are available on CDC's Division of HIV/AIDS Prevention web site. Bulk copies of these materials can be made available for distribution to community-based organizations and health care clinics. The TICB also maintains displays at major medical and public health meetings and exhibits guidelines documents and patient educational materials at its display booth at these meetings.

CDC conducts surveillance of HIV-associated conditions, as well as prescription of antiretroviral drugs and OI prophylaxis through large databases, such as the Adult and Adolescent Spectrum of Disease (ASD) Project, which conducts prospective, medical record review-based surveillance in collaboration with local and state health departments in 11 U.S. cities, and the HIV Outpatient Study (HOPS), which conducts more focused surveillance in HIV-infected patients receiving a relatively high standard of care in selected facilities in 7 U.S. cities. Information on prevalence of use of zidovudine-containing regimens by HIV-infected pregnant women to prevent perinatal transmission of HIV is collected through HIV/AIDS surveillance activities, as well as through ASD. Use of antiretroviral therapies by HIV-infected children is assessed through CDC's Pediatric Spectrum of Disease Project (PSD), which is conducted in 6 U.S. sites. These systems provide an opportunity to evaluate dissemination and use of treatment and prevention information throughout the country. CDC also maintains a research program related to prevention of opportunistic infections and has funded several projects pertaining to guidelines dissemination and physician behavior, including 1) a study of medical records in 11 Ryan White Title III facilities in 4 states in 1996-1997, which assessed provider adherence to recommendations concerning antiretroviral therapy and opportunistic infections prophylaxis, 2) a mail survey of over 600 physicians in 1998, with similar objectives, and 3) a study in Seattle, WA to assess physician adherence to guidelines and interventions to improve adherence.

Potential future activities:

- TICB has the expertise to prepare educational materials that might be appropriate for "second and third tier" health care providers, who might not have the time to read the complete guidelines documents. Therefore, once the needs of such audiences have been determined, CDC could prepare, or assist in preparing materials appropriate for these audiences; assistance with printing costs would be required.
- CDC's Community Assistance, Planning, and National Partnerships (CAPNP) Branch funds approximately 180 community-based organizations (CBOs) in the United States; another 200- 400 are funded by state health departments that receive CDC funding. Additionally, CDC funds national minority programs to assist these CBOs. Although most of these organizations target persons at high risk for HIV, some target HIV-infected persons; more effort could be made to disseminate HIV treatment information to these HIV-infected clients. Dissemination of information, appropriate training to ensure that those distributing it are well-informed concerning its content, and appropriate evaluation of these efforts would require additional

resources, i.e., one person to coordinate training activities, and about \$1.3 to conduct training exercises throughout the country and to evaluate these efforts (much of this would be done by contractor).

- Similarly, CDC's Prevention Services Research Branch (PSRB) works with 9,000 • 10,000 HIV counseling and testing sites in various settings throughout the country. More efforts could be made to disseminate information both to counselors and to clients found to be HIV-infected; such material could be supplemented by information concerning whom to consult at the local level. Although responsibility for knowledge of the content of informational materials rests with the grantees, mailing costs, e.g. \$10,000 per mailing, would be associated with sending guidelines to the large number of sites involved.
- In collaboration with other PHS agencies, and pending funding, CDC is currently planning a nationwide effort (termed Project Impact), to encourage persons at risk to learn their HIV status and to access medical care. Such efforts, presumably, would include efforts to provide appropriate information regarding HIV treatments to persons found to be infected with HIV.
- Through contracts currently in place with the managed care industry, CDC could communicate the availability of HIV treatment guidelines and provide treatment information and educational materials to over 1,000 health plans in the United States.

Current plan for dissemination of revised antiretroviral treatment guidelines for adults and adolescents, summer 2000 (that is, with existing resources):

- CDC can publish the revised guidelines in MMWR, provided that we start planning for this now
- Guidelines can be made available on CDC's Division of HIV/AIDS Prevention web site, which can also link to the ATIS web site. Callers to the AIDS Hotline and to NPIN can also be referred to the guidelines at these sites.
- CDC's CAPNP Branch can send a notice regarding the guidelines to its grantees, including CBOs that are directly funded, state and local health departments that support additional CMOs, and national minority programs that assist these CBOs. As indicated above, additional resources would be required to conduct training to ensure that persons distributing such information are knowledgeable on this subject and to perform an evaluation of these efforts.
- CDC's PSRB can send materials to counseling and testing sites, although, as above, this would entail additional mailing costs.
- CDC can announce the availability of the guidelines in the Office of Managed Care's monthly report to medical directors of the 1000 member plans of the American Association of Health Plans (AAHP) and 400 other health care plans.

NIH Office of AIDS Research (OAR)

Central Responsibilities

- Coordinate panels for guidelines development.

- Represent NIH within AIDS Coordinating Committee at OHAP
- Disseminate information to communities affected by AIDS about the value of and need to participate in clinical research and the activities of the NIH.

Description of activities

The OAR supports information dissemination efforts of the NIH institutes, and has recently provided significant additional funding for ATIS/ACTIS. OAR supports an Information Dissemination Coordinating Committee, which provides an opportunity to coordinate its efforts with the institutes and to determine additional ways to improve and increase the distribution of the guidelines. The OAR website provides a linkage to the ATIS/ACTIS sites.

Regional Technology Transfer Program - To quickly disseminate research results to physicians, nurses, dentists, and other health care professionals providing care to infected individuals, and particularly to minorities and communities with limited access to resources, OAR established the Regional Technology Transfer Program in 1990. Seventeen workshops for HIV-infected individuals and health care providers have been sponsored by OAR in collaboration with regional organizations, including those in Puerto Rico and with organizations serving Native Americans. Upcoming workshops will focus on minority communities in the Virgin Islands, on Asian Pacific Islander communities in the U.S., and on issues for individuals providing health care to prison populations. The guidelines will be distributed at these workshops. OAR has initiated a video streaming program to provide conference information over the Internet to individuals unable to attend meetings.

OAR sponsors the NIH HIV/AIDS Programs Exhibit, which is shipped to appropriate conferences, workshops and other locations. Materials describe the NIH AIDS research programs and include copies of the Treatment Guidelines. During 1999 the exhibit will be shipped to 17 locations across the US and internationally.

Community Regional Training and Research Forum Program - OAR initiated this program in 1998 to bring state-of-the-art research, treatment, technical assistance, and prevention information to community health care providers, such as counselors, case workers and health care providers as well as patients and their families. The program is now combined with a project of the National Minority AIDS Council (NMAC) that also provides technical assistance and care information. Forums have been held in more than 15 cities, in collaboration with local community organizations, and a dozen more are planned over the next year, focusing on minority communities. The guidelines will be provided at those meetings.

OAR and many of the Institutes have initiated collaborative programs with other agencies and organizations. For example, OAR and NMAC are collaborating on a project to provide Internet access to minority communities. This project will provide computers and Internet access to more than 100 community sites as well as training workshops for the use of computers. This will include information about accessing the treatment

guidelines. OAR and NMAC are supporting webcasts of various meetings, including the U.S. Conference on AIDS.

A video entitled HIV/AIDS in African American Communities was developed in collaboration with NMAC, and more than 8,000 copies have already been distributed. Additional videos for the Hispanic community and for aging populations are now planned. OAR provides support to the U.S. Conference on AIDS, the largest national meeting focusing on AIDS in minority communities.

To provide Internet access to HIV/AIDS resources and information to physicians, educators, medical students, and students in educational programs, OAR developed a computer kiosk program. In collaboration with HRSA, these kiosks will be provided to Historically Black Colleges and Universities through the AETC program. A kiosk in Spanish/English was placed at the University of Puerto Rico. Access will thus be provided to ATIS and the treatment guidelines.

A collaborative effort with HRSA and NMAC will provide the public with access to expert presentations and opportunities to ask questions via the Internet. Twelve Meet the Expert Sessions are planned, and will be available through the NMAC and OAR web sites. The first of these sessions featured Dr. Goosby speaking about the treatment guidelines.

NIH recognizes the importance of disseminating research and treatment information, patient management guidelines, and research results that impact on the care of HIV-infected individuals in diverse international settings. The existing computerized databases from NLM as well as from ATIS and ACTIS are available worldwide. However, a number of special issues remain, including the lack of computer capabilities and access to journals in many countries, language barriers between the United States and other countries (as well as dialect and cultural barriers within countries), and the lack of resources to provide a standard of care comparable to that available in the United States. To address this issue, future NIH-supported international research and training efforts will include mechanisms to facilitate access of foreign collaborators to current published literature and specific plans for in-country dissemination of research results through exchange of newsletters among grantees, in-country meetings for scientists and trainees, and advanced electronic technology for dissemination of new information as well as less formal exchange and dialogue among sites.

OAR convenes and/or cosponsors forums for U.S. and international agencies to present and discuss emerging HIV/AIDS trends and correlates, develop research agendas, and discuss implications of research results. This information is then distributed to prevention, treatment, and public health agency representatives, researchers, and policymakers.

National Institute of Allergy and Infectious Disease (NIAID)

Central Responsibilities

- Conduct clinical research regarding safety and efficacy of HIV treatment.
- Participate in panels to develop guidelines for HIV treatment.
- Rapidly disseminate emerging information from clinical studies for incorporation into treatment guidelines.
- Issue clinical alerts from clinical studies.

Description of activities

NIAID operates the world's largest HIV research program. The primary function that NIAID can perform in treatment information dissemination is to systematically provide the results of research to the central repository of treatment information.

In addition, NIAID OCPL issues news releases to announce updates to the DHHS HIV/AIDS treatment guidelines or other important treatment-related news and events (see the 5/5/99 release "Newly Updated HIV Treatment Guidelines for Adults and Adolescents Available on the World Wide Web," on the NIAID Web site www.niaid.nih.gov). Releases are sent to the news media, including media outlets serving health care providers and communities disproportionately affected by HIV/AIDS.

Links to the HIV/AIDS Treatment Information Service Web site are listed at several locations on the NIAID Web site. In addition, the HIV/AIDS therapeutics program in NIAID's Division of AIDS is developing a Web page that will provide a comprehensive overview of therapeutics research and development. This resource, which will be available this fall, will regularly update the general public and scientific community about important HIV/AIDS therapeutics issues and as such will be an important channel for disseminating HIV treatment information.

NIAID OCPL maintains a listing of lay and professional constituent organizations. This resource helps ensure widespread distribution of information to key NIAID constituencies. Updates about HIV/AIDS treatment guidelines and related news are communicated to constituent organizations whose members would likely have direct access to target audiences.

National Institute of Child Health and Human Development (NICHD)

Central Responsibilities

- Conduct clinical research regarding safety and efficacy of HIV treatment.
- Participate in panels to develop guidelines for HIV treatment and prevention.
- Rapidly disseminate emerging information from clinical studies for incorporation into treatment guidelines.
- Issue clinical alerts from clinical studies.

Description of activities

NICHHD administers a multidisciplinary program of research, research training, and public information on reproductive biology and population issues, on prenatal development as well as maternal, child, and family health, and on medical rehabilitation. Within NICHHD, the Pediatric, Adolescent and Maternal Aids Branch focuses its attention on supporting and conducting research into the epidemiology, natural history, pathogenesis, transmission and treatment of HIV infection and disease in infants, children, adolescents, pregnant women, mothers, women of childbearing age, and the family unit as a whole.

In carrying out its information dissemination activities, the NICHHD Public Information and Communications Branch, like many other NIH Information Offices, has developed experience in a series of techniques and functions that could be useful in the dissemination of HIV treatment information. This experience includes:

- Media relations and media events, including press conferences, media tours, regional editorial briefings, and other tactics that push an issue higher on the media agenda.
- Promotion of products (e.g., guidelines) to different audiences and fulfillment of requests through the NICCHD Clearinghouse support contract.
- Qualitative research to gauge comprehension, usefulness, readability, etc. of professional products (e.g., treatment guidelines or guideline-driven products) as well as consumer products (e.g., culturally appropriate media based on information in the treatment guidelines).
- Product development based on the results of the type of research noted above.
- Interactive videoconferencing between, for example, DHHS/NIH and academic health centers to describe and discuss new aspects of treatment guidelines.

These activities describe the capabilities of the NICCHD Public Information and Communications Branch. It would not be practical (or possible) for NICCHD to carry out these activities simultaneously and many of these activities would require financial support beyond the current resources of the NICCHD Public Information and Communications Branch. However, in an integrated and on-going guideline dissemination activity, NICHHD has the capability (if not all the resources) to support the above activities.

National Library of Medicine (NLM)

Central Responsibilities

- Collect, organize, preserve, and disseminate medical information, and conduct outreach to all constituency groups to ensure knowledge of an access to this information.
- Develop and maintain databases of medical resources for health professionals and the public.

- Support the National Network of Libraries of Medicine, a network of libraries throughout the United States providing timely, convenient access to biomedical and health care information resources.
- Enhance access to computer-based information services for health care providers and community organizations.

Description of activities

The National Library of Medicine collects materials in all areas of biomedicine and health care, as well as works on biomedical aspects of technology, the humanities, and the physical, life, and social sciences. It organizes this material and makes it available. The Library's computer-based systems allows rapid access to NLM's vast store of biomedical information. MEDLINE enables anyone to query the NLM computer's store of journal article references on specific topics. It currently contains over nine million references going back to the mid-1960's. Other databases provide information on cataloging and serials, toxicological and environmental health data, AIDS, and other specialized areas. Through the World Wide Web at <http://www.nlm.nih.gov> some 350,000 MEDLINE searches a day are being done by health professionals, scientists, librarians, and the public. A relatively new Web service, called MEDLINEplus, links users to many sources of consumer health information.

NLM is a national resource for all U.S. health science libraries through the National Network of Libraries of Medicine (NN/LM). The purpose of the NN/LM is to provide health science practitioners, investigators, educators, and administrators in the United States with timely, convenient access to biomedical and health care information resources. The network consists of eight Regional Medical Libraries (major institutions under contract with the National Library of Medicine), more than 140 Resource Libraries (primarily at medical schools), and some 4,500 Primary Access Libraries (primarily at hospitals). NLM uses this network as a major vehicle for information dissemination activities. In addition to training and outreach activities directed towards health professionals, NLM has started an extensive program of providing information for consumers.

The National Library of Medicine has a broad mandate not only to collect and organize the literature of the health sciences and to provide information services, but also to develop an outreach program aimed at transfer of the latest scientific findings to all health professionals. Health professionals serving minority populations have a special set of problems in accessing information and NLM has geared a variety of outreach initiatives to these communities in the belief that direct access to NLM's databases can help compensate for the absence of other health resources.

Programs targeting specific groups include the Partners in Information Access for Public Health Professionals, which is intended to provide public health professionals timely, convenient access to information resources to aid them in improving the health of the American public. NLM has several minority outreach programs aimed at strengthening

the capacity of historically black colleges and universities to train medical and other health professionals in the use of information technology and in access to technology.

An expanded Health Services Research Information Program is coordinated by NLM's National Information Center on Health Services Research and Health Care Technology (NICHSR). NICHSR works to improve the organization and dissemination of the results of health services research, including practice guidelines and technology assessments. One product of this program is HSTAT, a resource provides access to the full-text of documents useful in health care decision making including: clinical practice guidelines, quick-reference guides for clinicians, consumer brochures, and evidence reports sponsored by the Agency for Health Care Policy and Research (AHCPR); AHCPR technology assessment reports; National Institutes of Health (NIH) consensus development conference and technology assessment reports; NIH Warren G. Magnuson Clinical Center research protocols; HIV/AIDS Treatment Information Service (ATIS) resource documents;

NLM provides project management for HIV/AIDS Treatment Information Service (ATIS) and uses that as its main vehicle for dissemination of treatment guidelines as well as other types of treatment information. This enables the library to provide a continuum of information services which include the AIDS Clinical Trials Information Service, and access to research and clinical literature through MEDLINE.

The annual AIDS Community Outreach program provides funding to community-based organizations and libraries to enhance access to HIV/AIDS-related information by becoming connected to the Internet, purchasing computer equipment, obtaining training, or developing information resources specifically for their communities.

Health Care Financing Administration (HCFA)

Central Responsibilities

- Develop new coverage and payment policies for services recommended in Treatment Guidelines.
- Assure that coverage and payment policy follows rapidly the publication of new scientific advances.
- Utilize existing HCFA channels to communicate information regarding the guidelines, coverage and payment to: beneficiaries, contractors, providers, managed care organizations, and State Medicaid Agencies.
- Use appropriate opportunities in our regulations to encourage implementation of DHHS-endorsed treatment guidelines.

Past and Current Activities:

Coverage and payment:

Medicaid

- HCFA provides States with guidance on the general requirements for mandatory and optional coverage of Medicaid services in the State Medicaid Manual.
- States are required to cover specific medical services such as laboratory tests and physicians services, and may cover additional optional services such as prescription drugs, and dental services.
- States may only cover services that are medical or remedial in nature, and may not provide services that are not medically necessary. However, it is the State, not the Federal government, which has responsibility for defining medical necessity.
- Practice guidelines that are or can be used in clinical settings are often used by States to make medical necessity determinations.
- States may require prior authorization and establish limits for certain services. However, each service must be sufficient in amount, duration, and scope to achieve its purpose.
- States may set their own reimbursement levels for covered services, but must describe their methodology for establishing their rates in the Medicaid State plan. Medicaid payments may not exceed the payment that would be made for the service under the Medicare program.

Medicare

Coverage and payment decisions are made in one of two general ways:

- At the national level: the HCFA Office of Clinical Standards and Quality (OCSQ) receives notification from any of a variety of sources regarding a new test/procedure. OCSQ evaluates the new test/procedure to determine if Medicare should cover it. If a decision is made to cover the new test/procedure, OCSQ then works with the Center for Health Plans and Providers to set a payment rate and to communicate this coverage and payment decision to Medicare's payment intermediaries. These intermediaries then publish the coverage and payment decisions in their Bulletins to physicians and other providers.
- At the local level, an individual claim is submitted to our payment intermediaries for payment for a new test/procedure. The intermediary reviews this, develops Local Medical Review Policy for coverage and payment, and may proceed to pay for this test/procedure in the absence of national policy. Should national policy be developed, as described above, it replaces local payment rules.

Communication of Treatment Guideline Information

HCFA, as the agency administering the Medicare Program, and overseeing the Medicaid and State Children's Health Insurance Program (SCHIP), has a unique opportunity to disseminate treatment guideline information to health care providers.

- HCFA has and will continue to provide Medicaid State agencies with copies of newly released HIV treatment guidelines.
- HCFA encourages State agencies to distribute the guidelines or methods to access them to managed care organizations and other providers with which it has contracts to provide Medicaid and SCHIP services.
- HCFA also uses State Medicaid Director letters to urge States to encourage access to the level of care prescribed in the HIV Treatment Guidelines by establishing reimbursement policies that make treatments truly accessible.
- To enhance access to current guidelines, HCFA provides financial support to the AIDS Treatment Information Service to maintain current versions of HIV treatment guidelines endorsed by DHHS, and make them accessible on their website.
- Regarding Medicaid, HCFA's primary initiative toward educating Medicaid beneficiaries and potential beneficiaries about treatment and prevention guidelines is HCFA's *Maternal HIV Consumer Information Project (CIP)*.
- The *Maternal HIV CIP* aims to inform women of child-bearing age and their providers of the principles of the Perinatal Transmission Prevention Guidelines; and of Medicaid payment for HIV counseling and testing, for the regimens to treat HIV disease, and regimens to prevent perinatal transmission. HCFA provides print materials free of charge in 14 languages, and a video in English and Spanish to States choosing to implement the HCFA program.
- The HCFA *Maternal HIV CIP* website at www.hcfa.gov/hiv/default.htm provides the information described above, and contains a component focused to physicians with links to current versions of prevention and treatment guidelines.
- Social service organizations are not a primary target population for HCFA's efforts. The Agency does, however, disseminate information about Medicaid coverage of services directed to persons living with HIV disease at conferences that draw representatives from social service organizations; e.g., The United States Conference on AIDS. HCFA provides financial support for the US Conference on AIDS through its Minority Outreach Initiative.

Regulation

HCFA, through its rulemaking authority, has the opportunity to provide direction to contractors, for example, Medicaid and Medicare managed care organizations. Regulations proposed to implement the managed care provisions of the Balanced Budget Act were published in the *Federal Register* on September 29, 1998. In these, we broadly outlined a requirement for managed care organizations to evaluate and implement clinical practice guidelines. In anticipation of further BBA regulations in the final rule, expected out later this winter, we are internally discussing what we might add regarding disease-specific and/or federally-promulgated guidelines.

Proposed New/Improved Activities

- HCFA believes that the primary role it can play in guidelines dissemination is facilitating the coverage and payment policy development process to assure that

providers can bill and be paid for services recommended in treatment guidelines in the most timely manner.

- To expedite this process, HCFA's representative to the Clinical Practices for Treatment of HIV Disease will notify HCFA's Medicare and Medicaid coverage policy staff of changes proposed to the guidelines by the Antiretroviral Working Group when they are submitted for a vote to the full panel.
- In addition, HCFA's Representative and Physician advisor to the Clinical Practices for Treatment of HIV Disease will meet with the Director of the Coverage Group in the Office of Clinical Standards and Quality. We plan to discuss any general strategies that may seem appropriate to expedite the process of determining a coverage decision.
- For guidelines other than the Adult and Adolescent Guidelines, the Office of AIDS Research has agreed to inform the DHHS HIV Coordinating Committee when new guidelines have been accepted. HCFA's representative to the Committee will immediately alert Medicaid and Medicare coverage policy staff of the changes.
- This early warning system will permit Medicare coverage staff to determine if changes proposed reflect services covered by Medicare; e.g. laboratory tests, and begin the process of developing coverage and payment policy including requesting the CPT Editorial Board to assign a CPT code.
- Regarding the *Maternal HIV Consumer Information Project*, HCFA has a National Performance Review goal to have projects in all States by the end of the year 2000. (Currently, 24 States are operating projects using HCFA materials, and 14 additional States are operating projects using materials from other sources.)
- With the population of HIV-positive Medicare beneficiaries increasing due to the longer life span of persons with HIV disease, HCFA will increase its efforts to assure that Medicare providers are aware of HIV treatment guidelines and how to access current versions of the guidelines.
- HCFA is developing its outreach to the physician community. In this outreach, we will endeavor to add to our presentations, language stressing the importance of HIV treatment guidelines and how to access current versions of the guidelines. This library of speech text is being developed primarily for use by HCFA physicians when addressing groups of their colleagues, but also might be included in speeches by leadership, as appropriate.
- In addition, the HCFA Center for Health Plans and Providers is developing a variety of new channels of communication to the physician community. HCFA's Representative and Physician advisor to the Clinical Practices for Treatment of HIV Disease will suggest HIV and/or the treatment guidelines as topics for outreach and education of the physician community.

Example of how science is converted to coverage and payment policy and regulation, and then communicated: the theoretical example of the national guidelines panel recommending the use of genotypic and phenotypic testing in the management of persons with HIV.

- At the national level: the Guidelines Panel or DHHS HIV Coordinating Committee Representative notifies the HCFA Representative to the Clinical Practices for

Treatment of HIV Disease of new recommendations. The representative in turn notifies OCSQ Medicare Coverage Group of proposed change to cover genotypic and phenotypic testing. OCSQ in turn verifies the approval requirement and status of the new test/procedure with the Food and Drug Administration. They then evaluate genotypic and phenotypic testing for a coverage decision. If a decision is made to cover the new tests, OCSQ works with the Center for Health Plans and Providers to set a payment rate and to communicate this coverage and payment decision to our payment intermediaries. These intermediaries then publish this in their Bulletins to physicians/providers.

- At the local level, likely while the above is going on nationally, an individual claim is submitted to our payment intermediaries for payment for these new tests. The intermediary reviews this, develops Local Medical Review Policy for coverage and payment, and may proceed to pay for these tests in the absence of national policy. Should national policy be developed, as described above, it replaces local payment rules.
- The Center for Medicaid and State Operations develops and releases an All State Medicaid Directors Letter transmitting the new guidelines to all States, highlights the changes, provides a website where the guidelines can be accessed, and requests Medicaid agencies to inform all providers how to access the new guidelines.
- The All State Medicaid Directors letter informs the State which drugs, tests, and/or procedures they must cover and encourages the State to set a reimbursement rate that is adequate to assure access.
- HCFA will place a news item on our webpage that highlights the release of new guidelines with a hyperlink to the ATIS website containing the guidelines.
- HCFA will provide copies of the new guidelines to their Peer Review Organizations and encourage them to make the guidelines accessible in appropriate format to Medicare providers.

Current Knowledge about HIV Guideline Dissemination and Implementation

HCSUS: Variations in the Care of HIV-Infected Adults in the United States

Minorities, the poor and people who contracted HIV/AIDS through drug use are less likely to get needed care according to the HIV Cost and Services Utilization Study (HCSUS) (1). HCSUS researchers identified about 231,400 American adults with HIV who were receiving at least some medical care outside the military or prison, in all states except Alaska and Hawaii. From this group, a random sample of more than 2,000 patients was chosen for three interviews from January 1996 through January 1998. Researchers measured six components of care, three relating to use of medication and three related to use of doctors and hospitals.

Inadequate HIV care was commonly reported at the time of interviews conducted from early 1996 to early 1997, but overall, care improved from 1996 to 1998. At first, just 29% of all patients were receiving care that met all six standards; by 1998 this increased to 47%. But the care differed widely among groups. In 1998, for instance, 88% of whites were receiving protease inhibitors (PIs) compared with 80% of African-Americans. Similarly, 87% of men infected through sex with other men were taking these drugs in 1998, compared with 81% of those infected through drug use. Inferior patterns of care were seen African-Americans and Hispanics compared with whites, the uninsured and Medicaid-insured compared with the privately insured, women compared with men, and other risk and/or exposure groups compared with men who had sex with men. Access to care improved from 1996 to 1998 but remained suboptimal. Subjects receiving highly active antiretroviral therapy (HAART), compared to non-HAART users, more often reported provider advice was very important in deciding antiretroviral regimen, and were more likely to strongly agree that antiretrovirals prolong and improve quality of life. Efforts are needed to ensure that highly effective treatment for HIV is used by traditionally underserved groups.

Impact on provider practice

Tracking of hospital-based inpatient HIV/AIDS population demonstrates changing trends in patient care. Factors, such as advancements in antiretroviral therapies, have caused shifts in the demographic trends of this data. An analysis of a metropolitan hospital over the last 10 years showed a steady rise in the number of HIV/AIDS patient hospital admissions with a leveling off during the last 3 years (2). There has been a decline in the average length of stay, a decline in hospital days, a decrease in the average cost per admission. Average patient age remains in the upper 30s, with a doubling of the percentage of female patients. Pharmacy costs comprise approximately one-third of the overall hospital costs. The delivery of care for HIV/AIDS patients is shifting from the acute care hospital to the outpatient setting. Therefore, hospitals will need to direct resources to these areas. Nursing care needs to re-focus on assisting patients with adherence to complex medication regimens rather than acute treatment of opportunistic infections (OIs).

The competency of Ryan White-funded providers compared to non-RyanWhite-funded providers was analyzed by studying the quality of medical care provided within the Newark, New Jersey eligible metropolitan area (EMA) (3). The non-Ryan White-funded medical providers was compiled by accessing physician directories from the county medical societies within the EMA. A 12-question survey was designed to solicit information regarding both the physicians' experience with and the level of competency with treating patients with HIV/AIDS. Ryan White-funded physicians demonstrated through the survey responses to have both extensive experience with and significant competency with treating HIV/AIDS patients. All of these physicians were familiar with and followed the HHS Guidelines. A multidisciplinary team approach to care and treatment is engaged in by these physicians' institutions, with case management and patient education being significant components, to meet all of the medical and psychosocial needs of their patients. This group tracks their patient adherence to treatment versus failure rates.

In contrast, of the non-Ryan White-funded physicians responding to the survey, 77% referred HIV/AIDS patients to experienced providers, and 23% reported treating HIV/AIDS patients without referral to other primary care providers. Of the 235 physicians not referring patients, 148 were still prescribing monotherapy as a treatment regimen, 66 (28%) physicians used viral load to establish a baseline, and only 12 (0.5%) physicians used viral load testing to follow treatment. CD4 tests were used by 64 (27%) physicians at regular intervals. The majority of these physicians tended to be in a solo practice (52%) and did not engage in a team approach to care and treatment. These same physicians also reported the inability to address the psychosocial needs of their patients. Adherence rates versus failure rates were not tracked by this population.

The Ryan White-funded physicians within the EMA are the experts in treating patients with HIV/AIDS. According to the survey results, the recipients of Ryan White-funded services are receiving up-to-date, quality medical care. Conversely, the surveys indicate that a substantial number of the non-Ryan White-funded providers within the EMA are not providing the minimum standard of HIV care and treatment. Consequently, the quality of non-Ryan White medical care and treatment is substandard as compared to Ryan White medical care and treatment. All physicians responded unanimously in favor of developing a local algorithm (based on national guidelines) for treating HIV/AIDS patients and distributing it to practitioners throughout the EMA. As a result, the Ryan White Planning Council, collaborating with other entities, must reach outside of the Ryan White arena to raise the standards of all HIV/AIDS medical care and treatment services within the region.

From October to December 1997, physicians in the U.S. were asked through a questionnaire to report the drug(s) they usually prescribed for treatment of HIV infection and prevention of OIs (4). Experience was evaluated along years providing HIV care, number of current HIV patients, and medical specialty training. Of the 655 respondents, most were infectious disease specialists (46%), internists (27%), or family practitioners (15%). Experienced physicians were significantly more likely to recommend the

following per the Guidelines: use of viral load to begin antiretroviral therapy (ART) and to change ART; prophylaxis for *Pneumocystis carinii* pneumonia (PCP), *Mycobacterium avium* complex (MAC), *M. tuberculosis*, and toxoplasmic encephalitis; immunization with pneumococcal vaccine; screening and immunization for hepatitis B; and Pap smears for HIV-positive women. For scenarios that tested use of ART, experienced providers were significantly more likely to follow the Guidelines in all cases. Similar differences by medical specialty in guideline compliance were seen for prevention of OIs and use of ART.

The development of complex HIV treatment regimens has intensified debate about whether care should be restricted to experts in HIV care. A questionnaire was distributed to family physicians attending the 1996 Scientific Assembly of the American Academy of Family Physicians who completed an HIV continuing education workshop (5). The questionnaires were completed by 202 family physicians from 48 states. More than 60% had received training or had practiced in states with a high rate of HIV, and 70% had cared for at least 1 HIV-infected patient in the previous 6 months. Ninety-five percent did not expect to reduce their provision of care and believed that family physicians should become more active in the care of HIV-infected patients. Medical journals were the most requested format for ongoing education in this area, with combination antiviral therapy and new staging laboratory tests the most requested topics. The recent changes in HIV care regimens did not appear to have a major impact on family physicians' desire to continue to provide care for HIV-infected patients. Professional societies responsible for certification and continuing education should conduct additional surveys to validate these results among larger samples nationwide.

A case-based survey administered by facsimile was developed to measure self-reported practice patterns related to the NIH Principles of HIV Therapy guidelines (after release of the draft guidelines), to assess practitioner knowledge of guidelines, perceived barriers to optimal management, and confidence in treatment (6). The survey provided important insights into practitioner thinking about HIV therapies. Respondents were nearly equal split between infectious disease specialists and primary care physicians. Results indicated little variation between draft guidelines and self-reported applications of ART regimens in the management of HIV patients. Variations between providers appear when dealing with more complex cases and are associated with the size of the HIV caseload. Barriers to optimal management include lack of patient adherence, complexity of treatment regimens, and medication side effects. Respondents were most confident in discussing the importance of patient options and least confident in detecting patients who are at risk for noncompliance. This information should be used to better target physician education for HIV/AIDS.

The National HIV/AIDS Treatment Survey, a telephone survey of 476 physicians who care for HIV-positive patients, found that 25% do not adhere to the HHS Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents issued in November 1997 (7). Dr. John G. Bartlett and Dr. Paul Volberding released the survey findings in June 1998. The survey found that women and nonwhites tend to begin ART later in the course of the disease, with 36% of women, 42% of African-Americans, and

43% of patients of Hispanic origin starting treatment only when they become symptomatic. These groups were also more likely to be treated by physicians with less experience in treating HIV. Women and minorities were also more likely to receive either a single drug, like zidovudine (ZDV), or a two-drug therapy. Physicians with the most HIV experience were the most consistent in adhering to the Guidelines. The disparity in the treatment of HIV-especially for particular population-signals an urgent need to educate physicians and patients more aggressively on the guidelines. Some believe a professional society would help standardize care.

Dissemination and adoption of the Guidelines in clinical practice was assessed by the HIV-PRACTICE Cooperative in a random sample chart review of 600 HIV patients in 6 HIV clinics across the U.S. to facilitate assessment of care in their settings (8). The last observed ART regimens during January-June 1997 and July-December 1997 were compared after classification according to the Guidelines recommendations. Those on regimens that weren't recommended (monotherapy or dual nucleoside reverse transcriptase inhibitors) declined during 1997 in this sample, suggesting adoption of the DHHS guidelines. However, over a quarter of patients were on regimens not specified in the DHHS guidelines by the end of 1997.

Adherence to OI guidelines

Adherence by health care providers to OI guidelines in HIV-infected adults in federally funded health care facilities in the United States was determined by a descriptive medical record review study (9). Records of HIV-infected adults (age 13 years and older) in 11 Ryan White Title III facilities in Maryland, New York, Georgia, and Illinois were reviewed for information on eight standard-of-care recommendations for care of HIV-infected adults during November 1996-August 1997. Measurement of HIV plasma RNA and prescription of ART was recorded for 86% and 85% of patients, respectively. Prophylaxis against PCP and MAC had been prescribed for 86% and 69% of eligible patients; and tuberculin skin testing (TST), pneumococcal vaccination (PVAC), toxoplasma antibody testing, and Pap smear testing had been performed for 80%, 70%, 85%, and 88%, respectively. Adherence to recommendations was similar when analyzed by patient age and racial/ethnic group, gender, urban versus rural, and hospital versus clinic setting. Among injecting drug users (IDUs), prescription of MAC prophylaxis (63% versus 70%), TST (71% versus 82%), and PVAC (67% versus 71%) seemed less common than in other HIV risk groups. These data indicate a high level of adherence by health care providers to some, but not all, guidelines for preventing OIs in this sample of federally funded facilities, suggesting that adherence to some guidelines (e.g., MAC prophylaxis, TST, and PVAC) in these facilities could be improved, especially among IDUs.

MAC infection occurs in HIV-infected children and adults with advanced immunosuppression. The OI guidelines incorporate age-specific CD4 counts at which MAC prophylaxis should be used. A questionnaire was sent to 65 centers that specialize in the care of HIV-infected children to determine the extent to which the Guidelines are being followed (10). A strikingly low rate of adherence to age-specific criteria for MAC

prophylaxis was found for the age groups < 1 year and 1 to 2 years (34 and 39%, respectively), in contrast to good adherence for the age groups 2 to 6 years (80%) and >6 years (93%). Reasons for lack of adherence to the guidelines included a perception of low risk of MAC in the youngest age groups and difficulty administering additional medications to these patients. The survey also documented substantial variability in MAC prophylactic and treatment regimens and in susceptibility testing of MAC isolates.

Observational data from a clinical practice database of 1,090 HIV-positive patients with baseline CD4 cell counts between 50 and 500 mm³ who were followed for 1 year were used to test the hypothesis that adherence to treatment guidelines measured at baseline has a measurable and significant impact on patient outcomes using combination ART and OI prophylaxis (11). A number of measures of survival, progression to AIDS, clinical events, change in surrogate markers, hospital days, and total costs of care were determined using traditional analytic methods. After controlling for patient characteristics at baseline, none of these analyses showed statistically significant differences for any of these outcome measures across groups defined by guideline adherence at baseline. Preliminary analyses indicate that other methods of measuring adherence and time-dependent analytical methods that account for the degree of guideline adherence and the duration of guideline adherence could be useful to measure these differences. Although clinical trials have clearly demonstrated the benefit of combination ART and OI prophylaxis, a simplistic approach to the analysis of these observational data in which patients either adhere to guidelines or not is not adequate to identify significant differences in patient outcomes across groups. Policy makers and providers need to consider this when evaluating patient care on the basis of guideline adherence.

Adoption of pediatric guidelines

A multi-site survey was conducted at Pediatric AIDS Clinical Trials Group (PACTG) sites (12). The survey was designed to collect information on PI use in HIV-infected children under the age of 2 years and over the age of 2 years, and also on the number of babies born to HIV-infected mothers in the last 12 months whose mothers were treated at PACTG sites. Data was collected over a 1-month time period from September 1997-October 1997. Of the 487 HIV-positive babies under the age of 2 years, 286 (58.73%) were naive to PIs. Of the 3,891 HIV-infected children over the age of 2 years, 2,300 (59.11%) were naive to PIs. In the under 2 years of age category, (1.64%) were treated with saquinavir, (18.48%) with zidovudine, (21.56%) with zalcitabine, and (0.62%) with didanosine. For children over the age of 2 years, (3.44%) were treated with saquinavir, (17.71%) with zidovudine, (17.71%) with zalcitabine, and (5.11%) with didanosine. There were 1,518 babies born to HIV-infected mothers in the past 12 months at PACTG sites. Of these, 1,425 (93.87%) of the mothers had not been treated with PIs. Of the mothers who had been treated with PIs, (1.05%) were treated with saquinavir, (0.92%) with zidovudine, (1.91%) with zalcitabine, and (2.83%) with didanosine. There were 2,586 HIV-infected children at PACTG sites who were naive to PIs. The results suggest that drugs that are available in pediatric formulations (zalcitabine, zidovudine) are more likely to be used in pediatric populations. The results also indicate that very few women are receiving

PI treatment while they are pregnant.

For women with HIV, ZDV taken during pregnancy, birth, and by the baby after birth reduces the risk of perinatal HIV transmission from about 24% to 8% (**13**). All 50 states, the District of Columbia, and U.S. territories were surveyed to collect laws, regulations, policies, and programs intended to implement HHS guidelines through education, counseling, testing, and treatment of pregnant women and monitoring and treatment of newborns exposed to HIV. As of February 1998, the majority of States had policies or guidelines to prevent perinatal HIV transmission. Eighty-seven percent had policies on counseling and/or testing of pregnant women, 77% on treatment of pregnant women, and 44% on testing, monitoring or treatment of newborns. Only 36% states had adopted laws or regulations on HIV counseling and testing of pregnant women: 28% require HIV testing be voluntary; 2% routinely test women but permit them to "opt out"; and none mandate testing. Fewer states (22%) had laws or regulations regarding testing, monitoring or treatment of exposed newborns. Thirteen percent expressly permit testing of newborns without parental consent. Most laws regarding disclosure of test results mirrored State HIV confidentiality provisions. Fifty-five percent of States criminalized intentional HIV transmission. Thirteen percent of States have proposed or pending legislation in one of the areas surveyed. Virtually all States had programs to disseminate educational information to health care providers, pregnant women, and the public. States report ongoing assessments of practices of providers serving pregnant women (58%), and newborns (31%), as well as the impact of the Guidelines on rates of perinatal HIV transmission (33%). State assessment projects planned for practices related to pregnant women or newborns (26%) and perinatal transmission (28%). States have moved rapidly to implement HHS guidelines. The majority of States have policies, fewer have formal legislation. Most efforts rely on education, counseling and testing (with consent) of pregnant women. Treatment of pregnant women is mostly covered by policies. Fewer states have laws or policies regarding newborns. State efforts include little mandatory or coercive actions. Policy-makers should consider ongoing evaluation data before changing existing State efforts.

To directly assess the implementation of guidelines to reduce perinatal transmission of HIV, as well as those for HIV counseling and voluntary testing of pregnant women, and to identify barriers to the continued reduction of perinatal transmission, four states that conduct surveillance for HIV/AIDS (Louisiana, Michigan, New Jersey, and South Carolina) enhanced routine surveillance activities to conduct a population-based evaluation (**14**). Preliminary results of the evaluation identified increases from 1993 to 1996 in the proportion of pregnant HIV-infected women in whom HIV infection was diagnosed before the birth of their child, increases in the proportion of women offered ZDV, and lack of prenatal care as a critical obstacle to fully implementing the guidelines.

A retrospective analysis of 1,145 children born to HIV-infected women in 1995 and enrolled in the Pediatric Spectrum of HIV Disease Project was conducted to study the implementation of recommendations for the medical care of HIV-exposed infants in the first year of life (**15**). Most children (83%) received antenatal, perinatal, or neonatal administration of ZDV, but only 53% received all three components. In addition, only

46% of the children received PCP prophylaxis as recommended for HIV-exposed children at age 4-6 weeks. Barriers to implementation include the lack of prenatal care or refusal of ZDV by HIV-infected women and the practice of not starting uninfected children on PCP prophylaxis.

The Bureau of Primary Health Care studied how well its funded providers adhered to current protocols to reduce perinatal transmission of HIV through administration of the ACTG 076 regimen, whether all pregnant women were offered HIV counseling and testing, and the providers' comfort level with treating HIV/AIDS patients (16). A mailed survey of 2,000 health care workers from 77 community health centers (CHCs) revealed that a substantial number of health care providers (16%) lack confidence in the ACTG 076 research findings. Only 53% of respondents routinely offer HIV screening to pregnant women, and 50% of respondents offer HIV screening to women of reproductive age. Almost one in five CHC health care providers are uncomfortable with treating AIDS patients. Almost half of respondents felt that HIV-infected individuals should receive care only from HIV specialists, and many providers (18%) referred all HIV-infected patients for care. Surprisingly, many providers in these federally funded CHCs were unaware of or skeptical of the ACTG 076 findings and perinatal guidelines. This stresses the need for additional education of health care providers to ensure that treatment protocols are followed.

Patient care and needs

Racial inequalities exist in the receipt of HIV/AIDS-related treatment (1) and enrollment in clinical trials for persons living with HIV. In one study, 501 persons living with HIV attending one of six public clinics that treat persons with HIV and residing in non-urban communities were recruited during routine clinic visits (17). Information was elicited on demographics, the treatment, medication, and social services received by persons living with HIV. There were no significant differences in insurance status or age between African-Americans and whites. However, significant differences were reported in gender, income, and education. After controlling for these potential confounding factors, African-Americans were 70% more likely to have never been prescribed ZDV, were 80% more likely to have not been enrolled in an AIDS clinical trials for new therapeutic treatments, and were 70% more likely to have not been treated with PIs. This study suggests that African-Americans are less likely to receive HIV-related medical treatment or to be involved in experimental drug trials compared to whites. These differences may partially explain the poor survival of African-Americans living with HIV/AIDS relative to whites. This disparity suggests a need for interventions tailored to African-Americans living with HIV/AIDS to ensure uniform receipt of HIV/AIDS-related drug therapy.

The first in-depth study of HIV-positive patients treated at government-funded clinics in the San Fernando and Antelope valleys in California reveals that most are getting quality medical care, but a majority lack stable housing, much-needed mental health services, and transportation to medical appointments (18). According to the findings, the vast majority were indigent patients with no medical insurance. The Panorama City HIV

clinic, operated by Northeast Valley Health Corporation in Los Angeles, was the lead agency in the 9-month survey.

According to Dr. Mark Henrickson, director of Northeast Valley Health Corp., only one-sixth of the HIV-infected people in the valley area are receiving medical care. The study organized the data by ethnicity, age, sexual orientation and education levels. The findings show that 42.3% of Valley HIV patients are white, 30.2% Hispanic, and 20% African American. About 43% are gay; 45% have not graduated from high school. Nearly 44% of the patients are 36 to 45, and nearly 82% speak English as their primary language. More than half of the patients surveyed have been in jail or have a history of substance abuse, and the median annual income is \$7,800. This is a group that providers think of as hard to serve, yet most are regularly visiting their doctors, and a majority are on new drug therapies. To better serve this population, Northeast Valley Health Corp. received federal funding from the Ryan White Care Act for "HIV Cybermall," a computer-based program that will include information on how and where to get all types of HIV-related services in the Valley area and will link to other county and national information sources. Computers will be available at the clinics to give patients and staff access to the information.

Individuals living with HIV or AIDS use a variety of information sources to manage uncertainty about their illness and treatments and to participate in health care decision making. Participants in a prospective study of persons living with HIV or AIDS were asked to list sources they might use for treatment information and to rate each based on the likelihood of use (19). The most frequently reported source of information was the media. Health care workers were the second most frequently reported source of information and had the highest likelihood of use, of which AIDS specialist physicians had the highest likelihood of use within this category. A surprising finding was that pharmacists scored relatively low in likelihood of use. Activists were more likely than nonactivists to list pharmaceutical companies and less likely than nonactivists to list media sources. Education efforts are needed to familiarize persons living with HIV or AIDS about underutilized sources, such as pharmacists, for treatment information. Activists and those with a self-advocacy orientation named more sources of information than others, suggesting that activism might lead to greater familiarity with, and utilization of, a broader range of sources.

HAART with a PI is recommended for many patients receiving care for HIV disease. In 1997, patients with HIV/AIDS from three teaching hospitals and two community health centers were interviewed regarding details of their clinical care, including ART other medications, provider relationships, satisfaction with care, comorbidity, substance abuse, and demographic factors (20). In clinical practice access to PIs appeared to vary significantly by patient race/ethnicity (African Americans 54.5%; Hispanics 41.7%; compared to whites 70.4%); gender (males 68.6% versus females 46.1%); HIV risk group (men who have sex with men 79.4%, IDUs 53.1%, heterosexual contact 50.6%); and educational attainment (70.3% for those with any college education versus 54.9% for all others). Those who were not receiving treatment with PI-containing regimens were less likely to be satisfied with their care and less likely to have heard of PIs. It is not clear

whether these differences are due to differing levels of HIV/AIDS treatment information, patient preferences, provider prescribing practices, or clinical severity differences. Viral load data analysis will assist with the latter.

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