



Forum for Collaborative HIV Research

**Dissemination and Evaluation
of Clinical Practice Guidelines
for
HIV Disease**

June, 1998

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The Forum for Collaborative HIV Research, (FCHR) situated within the Center for Health Policy Research (CHPR) at The George Washington University Medical Center, is an independent public-private partnership composed of representatives from multiple interests in the HIV clinical research arena. The FCHR primarily facilitates ongoing discussion and collaboration between appropriate stakeholders on the development and implementation of new clinical studies in HIV and on the transfer of the results of research into clinical practice. The main purpose of the FCHR is to enhance collaboration between interested groups in order to address the critical unanswered questions regarding the optimal medical management of HIV disease. By encouraging coordination among public and private HIV/AIDS clinical research efforts, the FCHR hopes to integrate these efforts into HIV/AIDS medical care settings. Therefore, studies performed by these various research entities, separately or in cooperation, can begin faster; duplication of efforts can be reduced; patient enrollment and retention can be further facilitated; and costs of getting answers to the critical questions can be shared. At present, the FCHR is staffed by three persons and consists of over one hundred members, representing all facets of the field. These include pharmaceutical companies; public and private third-party payors; health care delivery system groups; government agencies; clinical research centers; and patient advocacy groups.

For further information about the Forum for Collaborative HIV Research and its projects, please call William Gist at 202-530-2334 or visit our Web site at: www.gwumc.edu/chpr and click on HIV Research.

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Report from the Executive Director and Executive Summary

On May 11 and 12, 1998, the Forum for Collaborative HIV Research (FCHR), with the support of the Henry J. Kaiser Family Foundation, held a workshop to discuss the dissemination and evaluation of clinical practice guidelines for treatment of HIV disease. The workshop brought together experts in information dissemination, clinical researchers, representatives from federal and state government agencies, health care providers, patient advocates, and representatives from the pharmaceutical industry. The workshop was developed by a Planning Committee representing each of these constituencies (*see p. 93 for a list of Planning Committee members*). Workshop participants were provided with information about: (1) the different HIV clinical practice guidelines,¹ (2) the needs for dissemination amongst various target audiences, (3) guideline dissemination and evaluation practices in other diseases, and (4) current HIV treatment information dissemination efforts. The outcome of the workshop is the strategic plan for the development of HIV guideline dissemination efforts contained in this report.

Despite the diversity of both participants and perspectives represented at the workshop, some important common themes emerged. These included:

Coordinated efforts to educate health care providers and patients about HIV treatment is essential to the overall success of the treatment strategies in HIV disease and for the protection of the public health. Simple messages are needed about the unforgiving nature of therapy when it is not used correctly by physicians and patients and about the public health ramifications of drug resistance. While there are many useful current dissemination efforts, this is not enough to meet the need.

While dissemination efforts must be implemented on a local level and will require public and private sector collaboration, leadership for the overall effort should be coordinated at the highest levels of the U.S. Department of Health and Human Services (DHHS).

Treatment information dissemination efforts must be on-going and able to respond to rapidly changing information based on new clinical research developments. Dissemination efforts must

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, June 27, 1998, Vol.46, No. RR-12

recognize the diverse needs of different kinds of service providers and patients.

Any and all efforts to dissemination HIV treatment information must include an evaluation component. Without evaluation, implementation will be significantly less successful.

The strategic plan contained in this report is the product of work group discussions that took place during the workshop and is meant to: (1) outline the need for and components of a coordinated effort of HIV treatment information dissemination to health care providers, patients and social service providers; (2) suggest strategies for the development of such an effort; (3) offer recommendations as to the roles that government, industry, community and professional associations can play; and (4) suggest methods of evaluation of the dissemination efforts.

The work groups suggested strategies for dissemination and implementation efforts on both a national and local level. One important overall recommendation is the need for the DHHS to provide leadership in the national coordination of dissemination efforts. The first step should be to acknowledge that such dissemination efforts are crucial to the success of the HIV treatment strategy and are a high priority for the DHHS. The federal government has spent billions of dollars to develop these promising new treatment strategies. Transferring the results of research into clinical care is as important a component in addressing HIV disease as the research itself. DHHS has already committed vast amounts of money toward HIV care and services through Medicaid, Medicare, Ryan White funds, AIDS Drug Assistance Programs (ADAP), and many other programs. All these programs will be severely compromised if proper attention is not paid to the dissemination and implementation of these clinical practice guidelines.

Dissemination of information needs to start from a national level with: (1) the development of systems to provide of up-to-date information, and (2) the funding of infrastructures that can transfer information to the various constituencies and incorporate it into practice. Equally important will be the collaboration between the public, private, and non-profit sectors to exchange information and expertise, pool resources, and limit redundancy. Some of the salient recommendations in the strategic plan include:

Associations representing health plans and health care providers/payors should convene state-wide meetings to discuss the use of the HIV clinical practice guidelines.

Standards of care articulated in HIV guidelines should be incorporated into specifications for HIV Medicaid managed care contracts.

Using the Agency for Health Care Policy and Research (AHCPR) model,² offer providers both complete versions of the clinical practice guidelines with source information, and synthesized versions of guidelines along with simple algorithms and charts. Different care providers will want different levels of information.

The overall message to the low-level health care providers should be to refer patients to experts if the provider does not feel ready or able to properly administer care. Referral information should be provided. If the provider is not able to refer a patient, then he/she must take responsibility to learn about appropriate HIV care.

A letter from the Surgeon General could be sent to health care providers to “launch” dissemination efforts. Such a letter would highlight the importance of proper care for HIV disease and provide fundamental principles of care, as well as information on how to learn more. The letter could be accompanied with a bulletin from state health departments giving state-based resources for information and referral.

Incorporate the use of computers into patient care. Use automatic reminders and warnings for drug interactions, scheduling diagnostics, and suggesting treatment combinations. Studies have shown this approach to be extremely effective.

Develop patient education materials, workshops, and trainings that are culturally sensitive and target people with diverse levels of education and literacy. Models for these workshops, trainings, and forums already exist at some AIDS service organizations and, where appropriate, should be duplicated. Videos, pictorial education, and pocket cards may be particularly useful for low-literacy populations.

Similarly, develop and implement materials and trainings for social service providers.

Develop a centralized data base for the collection of HIV treatment education materials that will allow easy access to institutions and organizations and prevent duplication of effort.

It is the hope of the FCHR that this document will be used as a blueprint for the development and coordination of specific dissemination efforts on national and local levels. In the coming weeks and months, the FCHR will hold meetings with the project Planning Committee and each of the constituencies represented at the workshop to discuss implementation of the recommendations made in this report. I want to thank all the participants, and the Planning Committee members in particular, for their time, wisdom, and good humor.

² The Agency for Health Care Policy and Research (AHCPR) has created a framework for the dissemination and implementation of clinical practice guidelines. For further information, see the *Overview of Research on Clinical Practice Guideline Dissemination, Implementation and Evaluation*, included in this report. See also: *Using Clinical Practice Guidelines to Evaluate Quality of Care*, AHCPR Pub. No. 95-0045, March 1995.

Strategic Plan for the Dissemination, Implementation and Evaluation of Clinical Practice Guidelines for Treatment of HIV Disease

Introduction

On May 11 and 12, 1998, the Forum for Collaborative HIV Research held a workshop to discuss the dissemination and evaluation of clinical practice guidelines for treatment of HIV disease. The workshop brought together experts in information dissemination, clinical researchers, representatives from federal and state government agencies, health care providers, patient advocates, and representatives from the pharmaceutical industry. Workshop participants were provided with: (1) information about the different HIV clinical practice guidelines,³ (2) the informational needs of various target audiences, (3) background information about medical guideline dissemination and evaluation, and (4) information about current HIV treatment information dissemination efforts. The participants were then divided into workgroups and asked to respond to a series of questions.

This document is the product of those workgroup discussions. It is not a step-by-step outline on how to disseminate HIV treatment information. Rather, it is meant to: (1) outline the need for a coordinated effort of HIV treatment information dissemination to health care providers, patients and social service providers; (2) suggest strategies for such an effort; (3) offer recommendations as to the roles that government, industry, community, and professional associations can play in these efforts; and (4) suggest methods of evaluation of the dissemination efforts. It is the hope of the FCHR that this document will be used as a blueprint for the development and coordination of specific dissemination efforts on national and local levels.

The workgroups were divided according to target audience including: (1) health care workers, (2) patients, (3) social service providers, and (4) health care providers/payors. The workgroups were composed to include representatives from each of the various constituencies present at the

³ 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, June 27, 1998, Vol.46, No. RR-12

conference. Questions that the workgroups were asked to consider are as follows:

What is your target audience and what are their needs for HIV treatment information dissemination, including the special concerns for subpopulations within your audience, and the formats of information transfer that may best serve your audience(s)?

What strategies for information dissemination and implementation are recommended for your target audience?

What are the possible roles of the federal/state government, the community, professional organizations, health care providers, and the pharmaceutical industry in dissemination efforts for your target audience?

What methods are recommended for evaluation of strategies, including possible performance measures that can be built into dissemination programs?

Common Themes and Issues

Despite the diversity of both participants and perspectives represented at the workshop, some important common themes emerged. These include:

The need for coordinated efforts to educate health care providers and patients about HIV treatment is essential to the overall success of the treatment strategies in HIV disease and for the protection of the public health. Simple messages are needed about the unforgiving nature of therapy when it is not used correctly by physicians and patients and about the public health ramifications of drug resistance.

While dissemination efforts must be implemented on a local level and will require public and private sector collaboration, leadership for the overall effort should be coordinated at the highest levels of the DHHS.

Treatment information dissemination efforts must be on-going and responsive to rapidly changing information based on new clinical research developments. Dissemination efforts must recognize the diverse needs of different kinds of service providers and patients.

Any and all efforts to dissemination HIV treatment information must include an evaluation component. Without evaluation, implementation will be significantly less successful.

Identification and Needs of Target Audiences

Health Care Workers

These workers have the primary responsibility for providing medical care to people with HIV/AIDS and, therefore, have the greatest need for up-to-date treatment information. Studies have shown that patients who see physicians with extensive experience providing HIV care live longer and better lives.⁴ For many physicians who lack experience treating HIV disease, referral to an expert may be an appropriate action. However, referral is not always available because of restrictions in the patient's health care delivery system, lack of expertise in a geographical area, or because of the patient's inability to travel. This is a particularly difficult problem in rural areas. Even where referral is available, the local provider needs information about HIV treatment to provide necessary appropriate care, and must be aware of such issues as drug interactions, how to manage side effects, and urgent care problems. The workgroup felt it was critical to reduce the stigma of providing HIV care, particularly in small towns, and to encourage more physicians to care for patients with HIV.

The group defined health care workers broadly as all people who come into contact with patients in the medical setting, including doctors, physician assistants, nurses, nurse practitioners, midwives, pharmacists, case managers, HIV counselors, medical office administrative personnel, mental health workers, and drug abuse treatment personnel. Physicians were stratified into three levels. The top tier are those physicians who treat large numbers of people with HIV infection. These physicians are most likely to attend HIV meetings and conferences, read journals, and access Web sites. They are best able to stay current with and implement new developments in treatment strategies. The middle tier are physicians who treat some patients with HIV. These providers have less access to on-going, updated information and less time to seek it out. The workgroup felt that this was the most important group to reach in planning new treatment information dissemination efforts. The lowest tier are physicians who see few, if any, HIV patients. It was felt that other than providing them with very basic information, it would not be valuable to target this group of providers for detailed HIV education.

⁴ Heath K, et al Physician Concurrence with Primary Care Guidelines for Persons with HIV Disease. *Intl J STD AIDS* 1997;8 (10): p.. 609-613

However, low-volume providers should be supported and told that they are not incompetent and are being supported in their care effort.

The workgroup outlined the needs and messages that should be targeted to health care workers.

Informational needs for all providers include the following:

- Counseling/testing and risk assessment along with prevention messages
- Stages of HIV disease
- Signs and symptoms of illness
- Prophylaxis for HIV-related opportunistic infections
- Components of an initial work-up
- Resources/linkages for more information and for referral
- Information on side effects, drug interactions, and treatment adherence

Additional informational needs for medium- and high-volume providers:

- Use of antiretroviral therapy
- Opportunistic infection treatment
- Drug resistance
- Linkages for drug availability: compassionate care, expanded access programs, financial assistance programs, and AIDS Drug Assistance Programs (ADAP)
- Linkages for prevention and support resources
- Off-label use of drugs
- Clinical trial availability

People Living with HIV/AIDS

Like on-going treatment for many other chronic illnesses, such as diabetes or hypertension, HIV treatment is lifelong and requires the patient to alter his or her lifestyle to adhere to a complicated treatment regimen. The need to involve patients in the process of treatment decision-making, education, and support is essential to the success of the treatment strategy. The ease with which multiple drug resistance can develop through poor patient adherence to antiretroviral treatment only intensifies the importance of teaching patients what their treatments are for and how to take them properly, as well as the importance of on-going support for patient adherence. Any treatment information dissemination plan must include strategies for education of people living with HIV/AIDS.

The key component to engaging patients in following through on treatment regimens is trust. The guideline for the use of antiretroviral agents in adults and adolescents states that physician and patient must consider multiple risks and benefits in deciding when to initiate therapy. The many factors which must be considered are complex and require that the patient take an active role in

contemplation and decision-making. The guideline states:

Intensive patient education regarding the critical need for adherence should be provided, specific goals of therapy should be established and mutually agreed upon, and a long-term treatment plan should be developed with the patient.⁵

People with HIV/AIDS come from many different communities and, therefore, have different needs in how they receive and are able to utilize treatment information. Factors that will affect a person's ability to obtain and use treatment information include:

- Stage of illness
- Education level
- Access to and method of health care delivery
- Age
- Culture/belief systems
- Geography (e.g., rural vs. urban)
- Motivation
- Economic status
- Other responsibilities and crises
- Mental health

A variety of formats targeting patients was recommended. Printed materials should be developed at different reading levels using pictures, charts, and tables. Materials should be culturally appropriate and available in multiple languages. Printed materials may best serve to supplement person-to-person interaction offered through workshops, forums, and peer counseling programs. Patients need to be given the opportunity to ask questions, discuss pending treatment decisions, and talk over their fears about treatment and disease. Computer-based services can be useful for some patients who know how to use and have access to them. However, it should be recognized that many patients do not have access to these resources and, therefore, over-reliance on them may not be valuable. Information about how patients comprehend, retain, and implement treatment information is essential and evaluation of patient treatment education programs is needed. For children, family members need information to make informed treatment decisions.

Social Service Providers

Social service providers have important ongoing interactions with people with HIV/AIDS and, therefore, have many opportunities to provide treatment education and support to patients on HIV therapy. Social service workers also need treatment information to perform their responsibilities as advocates for their clients. These workers play an essential role in assisting in efforts to obtain quality medical care, support efforts to adhere to treatment, provide the ancillary services that are

⁵ Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents, MMWR, April

required if treatment is to be effective, support primary prevention behaviors, and intervene if patients are given substandard medical care. They need to have a basic understanding of the standard of care to fulfill these functions.

Service providers were identified both within institutions where medical care is provided and within communities. Places where medical services are provided include: drug treatment centers, mental health treatment centers, hospitals, clinics, public health centers, in-home health care, family planning clinics, emergency medical services, and alternative medicine programs. Community-based services include: AIDS service organizations (ASOs), community-based organizations (CBOs), daycare facilities, adult day treatment programs, schools, shelters, human resource department, and community institutions such as churches, hair salons, etc. Social services also include: foster care programs, correctional systems, welfare offices, police departments, and unemployment agencies. The group discussed the kinds of providers who need treatment information and generated a hierarchy of these providers extending from those who have least contact to those who have most contact with HIV patients. People who should be targeted include: (1) support providers, e.g., case managers, support group coordinators, crisis intervention workers, and “buddies”; (2) educators, e.g., health educators, peer counselors, Web site managers; (3) caregivers and advocates, e.g., mental health workers, drug treatment counselors, welfare case workers, food service workers and nutritionists, juvenile justice workers, and HIV testing counselors; and (4) support networks, e.g., family, friends, clergy.

Overall information dissemination needs for all providers were identified and general principles for dissemination were listed. The overall needs include:

Many community-based providers need knowledge of the principles of treatment, not necessarily specific details from clinical practice guidelines. Providers also need basic information about the disease and its natural history.

Information from clinical practice guidelines need to be provided in simple formats both for patients and for social service providers. Information must be handy and efforts must be made to reach providers instead of waiting for them to seek out this information.

Different levels and types of information are needed for various providers depending upon their roles and their location, and should take into account the cultural differences, literacy levels, and beliefs of the populations they serve.

Information should not just be limited to facts about HIV treatment, but should also include messages such as the importance of getting tested early, preventing HIV transmission, and recognizing that treatments are difficult and patients need help.

Goals of getting information to each type of provider include the following:

The one-time social service care supporter needs to be sensitive and knowledgeable about HIV and needs lay knowledge of the urgent medical issues.

Providers in a non-HIV-specific, non-medical context, who offer ongoing social support, need to know about adherence and that treatment is difficult and complex. These providers must recognize how the social service system affects the provision of HIV care and the complexity of treatment on the lives of their clients, and they need to put HIV on their list of life issues.

Providers in a medical setting need specific treatment information in a simplified format. They need in-depth knowledge of adherence, side effects, drug interactions, long-term aspects of the effect, and process of care. They need to know about referrals, support groups, advocacy, symptoms, and treatment decision-making.

Families and support people must be aware of how treatment information affects social service provision through adherence, patient support, maintenance of systems, and maintenance of access to care.

General principles to be disseminated to providers include:

- Confidentiality/privacy should be protected and respected.
- Patients and others about HIV disease and treatment should be educated.
- Appropriate HIV testing in a social and political context should be promoted.
- Early and sustained care should be engaged and promoted.
- Treatments are available that prolong and save lives and need to be continuous.
- Treatment is not a cure and effective treatment requires support.
- Decisions about starting treatment are complex and have to be individualized.
- Blood tests are available to help determine when to start treatment.
- Adherence is important, difficult, and requires support.
- Many drugs cause significant side effects.
- Non-adherence is not a crime.
- No one should have preconceptions about who will be non-adherent.
- Crisis/change will affect adherence.
- Lifestyle, especially substance abuse, will affect adherence.
- You can advocate for the patient within the medical care system.
- Information dissemination and education are ongoing processes.

Health Care Providers/Payers

Health care providers are defined as health care managers, payors, and plans both public and private. Medicaid programs are the payor/provider for half of the HIV/AIDS population, including 9 out of 10 children with HIV/AIDS. Medicaid-funded managed care programs are becoming the predominant system of care delivery. Other providers include Medicare, ERISA plans, the Department of Veterans' Affairs, correctional systems, large medical group practices, employers,

and insurers.

In addition to basic information about the epidemic, providers/payors need to understand the implications that changing standards of HIV care have on the development of high-quality, cost-effective systems of care and strategic planning. The executives or leaders of these bodies need an analysis of what HIV treatment guidelines mean for their organizations and budgets. They need purchasing specifications that define administrative needs and structural issues, service and benefit requirements, requisite support services, and guidance about the benefits of implementing guidelines. Clear messages about the complexity of delivering HIV care and the urgency of ensuring that treatment guidelines are followed under guidance of specialist caregivers must be provided. Contracts developed between state Medicaid programs and managed care organizations are perhaps the most important tool for dissemination, implementation and evaluation of HIV clinical practice guidelines.

Strategies for Dissemination and Implementation

The work groups suggested strategies for dissemination and implementation efforts on both national and local levels. One important overall recommendation is the need for the U.S. Department of Health and Human Services (DHHS) to provide leadership in the national coordination of dissemination efforts. The first step in this coordinated effort is the acknowledgement that such dissemination efforts are crucial to the success of the HIV treatment strategy and are a high priority for the DHHS. The federal government has spent billions of dollars to develop these promising new treatment strategies. Transferring the results of research into clinical care is as important a component in addressing HIV disease as the research itself. DHHS has already committed vast amounts of money toward HIV care and services through Medicaid, Medicare, Ryan White funds, ADAP, and many other programs. All these programs will be severely comprised if proper attention is not paid to the dissemination and implementation of these clinical practice guidelines.

Dissemination of information needs to start from a national level with: (1) the development of systems to provide of up-to-date information, and (2) the funding of infrastructures that can transfer information to the various constituencies and implement it into practice. Equally important will be the collaboration between the public, private, and non-profit sectors to exchange information and expertise, pool resources, and limit redundancy. On a State and local level, dissemination efforts

should be developed to meet the specific needs of diverse audiences. The literature shows that the use of local opinion leaders to carry messages back to their respective communities is an important route of effective dissemination. The use of claims information, particularly by Medicaid programs, may provide an important way of learning more about who is providing care and the current standard of care. State-run programs and health care providers can use this information to target dissemination efforts to particular practitioners. However, current claims information is not readily available.

The workgroup participants offered strategies regarding the infrastructures in which information could be provided, the kinds of programs and policies that can be developed to reach the targeted audiences, and the context in which information needs to be delivered to the various audiences.

Provider/Payers

Associations representing health plans and health care providers/payers should convene state-wide meetings to discuss the use of the HIV clinical practice guidelines.

States should mail copies of the HIV guidelines to health maintenance organizations (HMOs), medical societies, public health entities, hospitals, physicians, and others.

Corporate medical directors of large health plans can communicate with counterparts in other organizations, through meetings of medical directors, professional associations, newsletters, and other activities. They should communicate internally with the pharmacy benefits managers, utilization review agents, pharmacy and therapeutics review committees, and through other means.

Standards of care articulated in HIV guidelines should be incorporated into specifications for HIV Medicaid managed care contracts.

Health Care Workers

Using the AHCPR model,⁶ offer providers both complete versions of the clinical practice guidelines with source information, and synthesized versions of guidelines, along with simple algorithms and charts. Different care providers will want different levels of information.

⁶ The Agency for Health Care Policy and Research (AHCPR) has created a framework for the dissemination and implementation of clinical practice guidelines. For further information, see the *Overview of Research on Clinical Practice Guideline Dissemination, Implementation and Evaluation* included in this report. See also: *Using Clinical Practice Guidelines to Evaluate Quality of Care*, AHCPR Pub. No. 95-0045, March 1995.

In addition to specific information from the clinical practice guidelines, provide referral information about available training resources: conferences, courses, print alerts, Web sites, and other sources.

Physicians and other health care providers can also be reached through teleconferences, Continuing Medical Education (CME) courses, and dinner meetings. Local opinion leaders and nationally-recognized experts are both important means of information transfer. The literature shows that physicians are more likely to accept new medical information when it is provided to them from a respected and known source.

The overall message to the low-level health care providers should be to refer patients to experts if the provider does not feel ready or able to properly administer care. Referral information should be provided. If the provider is not able to refer a patient, then he/she must take responsibility to learn about appropriate HIV care.

A letter from the Surgeon General could be sent to health care providers to “launch” dissemination efforts. Such a letter would highlight the importance of proper care for HIV disease, as well as provide fundamental principles of care and information on how to learn more. The letter could be accompanied with a bulletin from state health departments giving state-based resources for information and referral.

Increase the capacity for physician “warmlines” and hotlines to provide on-the-spot treatment information.

Providers respond well to case-based learning. This is an important model for developing curricula for physicians and other health care workers.

Incorporate the use of computers into patient care. Use automatic reminders and warnings for drug interactions, scheduling diagnostics, and suggesting treatment combinations. Studies have shown this approach to be extremely effective.

Patients/Social Service Providers

Develop patient education materials, workshops, and trainings that are culturally sensitive and target people with diverse levels of education and literacy. Models for these workshops, trainings and forums already exist at some AIDS service organizations and, where appropriate, should be duplicated. Videos, pictorial education, and pocket cards may be particularly useful for low-literacy populations.

Similarly, materials and trainings for social service providers should be developed and implemented. Again, curricula for these trainings already exist and should be used as models for expansion of these services. Use national and regional conferences, e.g. United States Conference on AIDS, to train trainers for education of patients and social service providers.

Train peer advocates to teach other patients about HIV disease and treatment. As with primary prevention, the role of peers can be immensely effective in establishing trust and providing support and education. Peer education programs, however, need good training and supervision components to be effective.

Expand the use of the AIDS Education and Training Centers (AETCs) to develop education and training services for patients and social service providers.

Develop a centralized data base for the collection of HIV treatment education materials that will allow easy access to institutions and organizations and prevent duplication of effort. This is a recommendation that was made repeatedly.

Concepts of HIV disease and treatment must be taught before specific detailed treatment information can be understood and utilized.

The internet and the World Wide Web can provide the most current versions of clinical practice guidelines. Changes should be updated regularly and highlighted. Service providers will need broader access to and training for computer services.

Roles and Responsibilities

Each work group determined that dissemination efforts require both a national and local focus. There is not one entity that can be responsible for the entire effort. Instead, each relevant entity has an important role to play in the coordination of dissemination, implementation, and evaluation.

Government

As previously stated, each workgroup stressed that a primary role of DHHS is to provide leadership and coordination of dissemination efforts. The participants felt that the impetus and direction for this effort needs to come from the Secretary with support from the White House.

A new federal entity to take responsibility for HIV information dissemination was not recommended. Instead, it was felt that one group, the DHHS Office of HIV/AIDS Policy (OHAP), could be responsible for coordinating efforts within and between all relevant HHS agencies and programs. In order for OHAP to adequately coordinate these efforts, it will need the funding, staffing and authority necessary to catalyze the various agencies' response. Each DHHS agency will have an important part to play, including the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), the Health Resources Services Administration (HRSA), the Health Care Financing Administration (HCFA), the Substance Abuse and Mental Health Services Administration (SAMHSA), AHCPR, the Indian Health Service, and the Food and Drug Administration (FDA). The first step is to acknowledge the need for and importance of the dissemination effort; then, the roles and responsibilities for each DHHS program involved can be defined. From there, OHAP can work to integrate the activities of the various agencies. This effort will require funding and the DHHS should determine how much it will cost and how the funding should be obtained. Additionally, the effort will also need coordination with the National AIDS Policy Office to ensure collaboration with the Departments of Veteran's Affairs, Justice, Housing, Defense, and Education.

One important way that both the federal and state governments can demonstrate leadership is as a purchaser of health care for its employees and as the purchaser of HIV care through public programs, such as Medicaid, the VA, and Medicare. The standards of care articulated in the HIV clinical practice guidelines can be incorporated into contracts for managed care and should include evaluation components to determine contract compliance. State Medicaid Directors can use HIV treatment guidelines to determine appropriate levels of payment and/or set capitation rates.

The federal government, through the NIH and CDC, should continue to provide up-to-date information, revising the guidelines as necessary and developing routes of access to that information. The government can also develop and maintain a clearinghouse for treatment education materials. Participants did not suggest that the federal government itself develop such materials, but, rather, fund external programs to do so. The government can then provide mechanisms of access to those materials through different channels, e.g., the CDC Web site, the National Library of Medicine (NLM). There was broad agreement that a clearinghouse for educational materials would go far to provide information to patients and service providers and would reduce duplication of effort. Both federal and state governments can fund trainings for social service providers and peer educators. The government will also have an important role in the

evaluation of dissemination strategies through NIH, HCFA, SAMHSA and AHCPR. An important FDA function is to ensure that commercial efforts to promote treatment are appropriate and, when possible, not in conflict with the guidelines.

State governments can transfer information received from federal channels on to local governments and providers through symposia, toll-free numbers, and training. States can help identify local opinion leaders to present information, identify expert centers, and create referral networks. States can conduct quality assurance assessments and, using claims information, track those care givers who are providing sub-standard care and target them for education. States can fund community-based education efforts and support evaluation research.

AIDS Service Organizations

The unique infrastructure of AIDS service and education organizations across the nation provides a crucial opportunity to provide education and support to patients around treatment issues. ASOs and CBOs have a responsibility to train their staff and volunteers about relevant HIV treatment issues, to provide quality services to clients. Many of the services and programs offered at CBOs were created for patients in late-stages of illness. These programs need to be re-evaluated to bring people into services earlier in the course of the illness and to determine the needs of clients who may live longer and better with HIV, but have different and on-going needs for services, such as adherence and primary prevention support and advocacy for continuous access to care. The ways in which new developments in the treatment of HIV disease affect the provision of social services need to be constantly examined and services need to be altered appropriately as treatment changes.

ASOs are often best suited to translate and provide information for patients and assist in treatment adherence efforts. These groups can also assist in patient care by providing transportation, meals, and psycho-social support. The larger organizations should provide leadership by sharing materials and giving technical assistance. Workshops, support groups, peer counseling programs, and forums are useful ways of providing information to clients and family members. These organizations can also play an important role in educating government, academia, and the pharmaceutical industry about the needs of people with HIV/AIDS and the kinds of treatment education they require.

Health Care Provider/Payers

The ultimate responsibility for the implementation of the clinical practice guidelines falls onto health care delivery systems. While the dissemination efforts may begin at a national level, comprehensive

implementation requires that each health care delivery site – from large health maintenance organizations, to hospitals and clinics, to the physician’s private practice – find methods to incorporate and update the standard of care. Research shows that to be successful, systems for guideline implementation must be developed within health care institutions, as opposed to being developed externally. The use of local opinion leaders is shown to be particularly important in getting practitioners to accept and incorporate new information. Providing copies of materials is not enough, as the implementation of new standards of care requires behavior change on the part of health care providers. Structures to assist in that change, which include information provision, reminder mechanisms, the use of performance measures, report cards, and quality assurance evaluations, are all important and useful.

Providers should recognize the important role that social service providers can play in providing support for treatment adherence and addressing psycho-social issues. These services not only enhance treatment, but, in fact, may be the key to its overall success. Therefore, payors and providers should consider partnering with these agencies and incorporating these services into coverage.

Professional organizations which represent providers and medical professionals can develop education programs and promote the use of HIV treatment guidelines. These associations can encourage practitioners to learn about and treat HIV disease, fight against HIV-related stigma and discrimination, and utilize their networks to disseminate updated information.

The Pharmaceutical Industry

Perhaps more than any other entity, industry has spent considerable time and resources to educate providers and consumers about their products, and, in doing so, has developed considerable expertise in marketing information to specific target audiences. Much can be learned from industry’s experience. Industry also has excellent knowledge of those providers offering HIV care and should make information about their networks available for dissemination strategies. Industry should continue to provide funding for educational programs for providers and patients. Industry has done much over the past few years to learn from patient advocates and community organizations. This collaboration should continue. It was suggested that an unrestricted pooled fund for educational efforts be coordinated by the Pharmaceutical Researchers and Manufacturers Association. The pharmaceutical industry also has considerable expertise in evaluating dissemination efforts. This expertise should be mined in developing evaluation of guideline

dissemination strategies.

One critique of industry raised by workshop participants is the issue of promotion of a particular product which may be in conflict with the guideline. It was suggested that industry develop materials that promote the overall approach to therapy, rather than those which are product specific.

Evaluation

The evaluation of efforts to disseminate and implement clinical practice guidelines is an essential component of the dissemination process. Evaluation will determine if the information to be disseminated has been received by the target audience, whether the information has been incorporated into care, and, ultimately, if the information has had a beneficial effect on patients' health and the use of health care resources. Further, research shows that implementation strategies must include built-in evaluation components to be successful, because practitioners are much more likely to incorporate new practices if their behaviors are measured.⁷ Evaluation strategies need to be considered as dissemination and implementation strategies are being designed. Communication needs to be accompanied by messages and mechanisms for accountability and monitoring. Performance standards, contract specifications, and purchasing guidelines that clearly incorporate these specifics are necessary. These specifications need to be clear and easily measurable and focused. One of the challenges of developing evaluations is the fact that the guidelines change rapidly.

⁷ Harr DS, Balas EA, Mitchell J. Developing quality indicators as educational tools to measure the implementation of clinical practice guidelines, *Am J Med Qual* 1996; 11(4): pp.179-185.

The use of report cards at each level to monitor physician performance was recommended, as was the use of chart reviews. Frequency of viral load and t-cell testing and reviews of prescription data were recommended as useful performance measures. Research into how patients comprehend, retain, and incorporate medical information is also needed. Partnerships between academic institutions and community-based organizations may provide the best opportunity for this research.

Summaries of Conference Presentations

Welcome and Introductory Remarks

David Barr, Director, Forum for Collaborative HIV Research (FCHR), on behalf of the FCHR and the Henry J. Kaiser Family Foundation, welcomed participants to the conference. He discussed the purpose and goals of the workshop, outlined the agenda, and described the participants, who included representatives from federal government agencies, health departments, Medicaid programs, community-based organizations (CBOs), national organizations that represent communities, health care practitioners, HIV researchers, communications experts, and representatives from health care plans, private sector health care management, and the pharmaceutical industry.

Sophia W. Chang, MD, MPH, Director of HIV/AIDS Programs, Henry J. Kaiser Family Foundation, noted that the process of development of HIV guidelines is a dynamic one; the April 17, 1998 issue of *Morbidity and Mortality Weekly (MMWR)* is the most recent of several updated guidelines. The recent guidelines for the use of antiretroviral drugs were developed with the best clinical science in mind. Now one must consider the dissemination and implementation of the guidelines, financing of treatments, and other policy questions. The key question is how to best transfer the information in the guidelines into practice. HIV has had a tremendous impact on clinical care and systems of care, and this is another example of asking how we mobilize those same forces that have been used historically throughout the course of the HIV epidemic to help this paradigm shift happen.

The urgency of disseminating the HIV treatment guidelines is profound because improper antiretroviral treatment has tremendous public health implications, especially via the development of resistant strains. We will probably be very effective in keeping HIV experts and high-volume providers up to date. The next tier of providers doesn't have as high a volume of patients but still provides a significant percentage of HIV care in this country, and there is the base of the pyramid with providers who will see 1-5 HIV patients. A key question is how to get across the message of HIV care to these providers and to assure that they do no harm. The answer to this problem is not as simple as referral to HIV because this isn't logistically possible for many individuals in this country. There is a confluence of dynamics or interests that may help us assure that we do no harm, and Dr. Chang asked the participants to consider this as part of their charge.

Eric Goosby, MD, Director of the HHS Office of HIV/AIDS Policy and Lynne Mofensen, MD, Associate Branch Chief for Clinical Research at the National Institute of Child Health and Human Development, then provided the participants with overviews of the three guidelines for the use of HIV antiretroviral therapy. Those presentations are not summarized here and readers are referred to the guidelines for detailed information.⁸

The Need for Dissemination of the HIV Clinical Practice Guidelines

Dr. Charles van der Horst, Associate Professor of Medicine, Department of Medicine, University of North Carolina, Chapel Hill, provided an overview of the importance and difficulty of dissemination of the HIV clinical practice guidelines. He is the principal investigator of the largest AIDS Clinical Trial Unit (ACTU), has treated patients since 1981, and currently has 160 patients. While Dr. Van der Horst's comments highlighted how the guidelines are an important tool in teaching physicians and patients about proper treatment, he also discussed in detail the difficulties of implementing the guidelines into practice, flaws in the development of the guidelines, and the omission of important information about adherence and other factors. He provided suggestions for improving the guidelines and for more useful implementation.

One central point was the difficulty of applying the guidelines to such a diverse patient population. He stated that despite the findings in clinical studies, in his practice, he has found that after a year of providing HAART, barely 50 percent of patients are achieving undetectable viral loads (at 400 copies/ml). For many patients, HIV is but one of many problems. The guidelines do not take multiple diagnoses into account, do not discuss the effect of mental health problems on the proper use of anti-viral therapy, or acknowledge the problems of drug resistance due to suboptimal treatment promoted in former guidelines. Dr. Van der Horst challenged the participants to use the

⁸There 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, June 27, 1998, Vol.46, No. RR-12

guidelines as best as possible but also to remember that there is still much we do not know about HIV disease and treatment.

Dr. Van der Horst addressed problems in the context in which the guidelines are to be applied. For example, he stated that the The AIDS Drug Assistance Program (ADAP) in North Carolina has accepted no new patients in the last six months. Therefore, programs to provide access to treatment are not in synch with the guidelines. He questioned how complicated antiretroviral treatment can be appropriately provided when there are still doctors who aren't prescribing a \$30 per year trimethoprim/sulfa treatment for *Pneumocystis carinii* pneumonia (PCP) prophylaxis. Below are highlights from his presentation.

Reasons why the guidelines are important:

The number of drugs is enormous.

There are complicated drug interactions.

Improper treatment can cause the development of drug-resistant viral strains that can render treatments ineffective for patients and be transmitted to others.

Disease staging is difficult for the average physician.

There is conflicting data that is hard to translate.

Drug toxicity is quite high.

The guidelines can help with starting therapy, switching therapy, strategies to improve adherence, strategies to manage toxicity, manage drug interactions, control costs, and prevent transmission.

Criticisms of the guidelines include:

They do not contain information on some newer drugs, including those available through expanded access programs.

The guidelines do not discuss metabolic complications of HIV therapy, such as lipodystrophy, diabetes mellitus, hypertriglyceridemia, and hypercholesterolemia.

The guidelines were issued almost a year after the therapies were available, heavily prescribed and advertised. Many patients were improperly treated before the guidelines were released and are now resistant to drugs.

Our need for guidelines exceeds our ability to create them. Doctors don't change their practices that fast.

The guidelines were based on small, short studies in highly selective, highly motivated patients and do not necessarily reflect the impact of treatment in a "real world" context. Also, the panelists were not necessarily those practitioners caring for a large population of patients.

The guidelines are vague and at the same time, overly complicated. Physicians don't want to know about clinical studies. They want to know what drug to give at what dose, and if there are complications to what drugs should the patient be switched.

They say providers should treat people with new infections, but they don't say for how long.

The guidelines recommend stopping therapy for people who never achieve undetectable viral load, yet there are those whose CD4+ counts rapidly increased on this therapy. The diversity of medical arguments and opinions with regards to this issue is vast.

The guidelines advocate working with the patient on adherence but provide no practical information for the provider on how to do this.

There is no patient education material attached to the guidelines.

The guidelines don't address speaking to patients about prevention of transmission.

The guidelines do not address how to deal with lack of social support, addiction, psychiatric illness, medication toxicity issues, and confidentiality issues. These are essential issues in order for the treatment strategy to be successful.

The guidelines do not address the many complications which must be considered in determining whether a patient should be on treatment. For example, would it be wise to put a retarded schizophrenic patient on triple drug therapy? The implications in the guidelines are that it would be unethical not to put this person on triple therapy. A person with biliary cirrhosis is undetectable on ZDV + 3TC. It would not be wise to put this patient on a PI, yet the guidelines imply this is unethical. The guidelines are held up as legal documents, the equivalent of an expert witness. They imply that a physician is undertaking malpractice if he/she doesn't prescribe triple therapy.

Dr. Van der Horst raised questions about the quality and quantity of data used to develop guideline recommendations. Specifically he questioned the statement that patients who have failed nelfinavir can successful use indinavir or ritonavir, and the equivalence of saquinivir with other protease inhibitors. He also questioned why delaviradine at 12 pills a day was found to be equivalent to nevirapine at 2 pills a day.

Addressing the problems of patient adherence to treatment was discussed in detail. First, it was recommended that the guidelines provide suggested strategies for assisting in adherence efforts. These include: (1) the provision of patient education materials that are simple to read and understand; (2) the distribution of pill boxes, timers, and reminder cards; (3) the use of mock regimens before starting therapy to help the patient determine if he or she is able to adhere to the regimen; (4) calls to patients to monitor and encourage adherence; (5) show patients progress in their viral load and t-cell counts to provide motivation to adhere to treatment; (6) work with case managers and support groups to support adherence efforts; and (7) devise simpler regimens. New

data showed that ddI monotherapy was as good as ZDV + 3TC in patients with low viral loads, and undetectable viral load was achieved for 48 weeks.

Finally, several suggestions for dissemination were offered, including the preparation of patient education materials, simplified versions of the guidelines for physicians, and the use of videotapes for patient education. Participants were cautioned against over-reliance on the internet and other computer-based formats of information distribution, as many patients do not have access to these tools and many physicians do not use them. The value of effective advertising was stressed, as long as the advertising promotes the overall guidelines, as opposed to any one particular product. Finally, Dr. Van der Horst described a successful effort to disseminate HIV guidelines in North Carolina. When the ACTG 076 study results were completed, NIH immediately issued a press release. The Department of Health immediately ordered all prenatal caregivers, both private and public, to start offering HIV testing to pregnant women. They encouraged all women to get tested, and the Committee decided to make treatment available to all pregnant women in North Carolina. This resulted in less than 5 percent perinatal transmission in the state. Guidelines can work!

Community Patterns of Care for HIV Disease

Dr. Carol Brosgart, Medical Director, East Bay AIDS Center, discussed preliminary data from CDC-funded COMPACT 4 survey, “Community Patterns of Care for HIV Disease,” conducted by the Community Consortium of HIV Providers, a group of 250 physicians in the San Francisco Bay area who provide community-based clinical research. The Consortium was concerned that in the absence of treatment guidelines, there was no standard community practice of care, and decided to look at community patterns of care for HIV disease by conducting a survey. What this survey showed was that the experience of the provider made a difference in the kind of care that physicians reported they were recommending to their patients.

The survey tool was a self-administered questionnaire. Questions were asked about the screening and prophylaxis for opportunistic infections (OIs), antiretroviral therapy, the use of viral load testing, when to begin therapy, what regimens were used, and when to change therapy. The anti-retroviral issues were included in nine different scenarios that tested all of the elements of the guidelines. The Consortium also tried to determine how providers get their HIV-related treatment information.

To prevent bias, providers outside of those in clinical trials groups were included. Unfortunately, there is no national registry or organization of physicians providing HIV care. In the interest of time, the group approached Glaxo-Wellcome, which from marketing data has a list of close to 30,000 physicians who prescribed either ZDV or 3TC in 1995, 1996, and 1997. This list was also segregated by volume of care. They chose a sample of 2,053 physicians from this list and created a sampling frame of 1,000 physicians who provided a high volume of care and 1,000 who had relatively few HIV patients and obtained a 50.3 percent response rate. The focus of the survey was on the impact of the new federal Antiretroviral Guidelines and the OI Guidelines. It was conducted between October 1997 and January 1998.

Preliminary data showed that by medical specialty, 51 percent were infectious disease specialists, 28 percent were internists, 15 percent were family practitioners, and much smaller percentages were pediatricians, hematologists, oncologists, or OB-GYNs. Forty-eight percent provided care in a private practice, 15 percent in public universities, 10 percent in nonprofit community hospitals, 9 percent in private university hospitals, and 9 percent in nonprofit community clinics. The rest practiced in the VA hospitals, public health clinics, and health maintenance organizations (HMOs). A variety of settings was surveyed with the exception of the criminal justice system.

By volume of care 27 percent cared for over 100 patients; 17 percent cared for 51-100 patients; 22 percent cared for 21-50 patients; 21 percent cared for 6-20 patients; and 13 percent cared for 1-5 patients. By years of experience with HIV patients only 2 percent had less than 1 year of experience, and 44 percent had greater than 10 years of experience. Examining the percentage of patients that have HIV in the provider's practice, for 22 percent of the physicians, greater than 75 percent of their patients were HIV patients. This is in contrast with 34 percent of physicians whose HIV patients represent less than 10 percent of their practice. The following are preliminary findings:

In the univariate analysis, volume of HIV patients and medical specialty training were significantly associated with whether the physicians' self-reported prescribing practices were consistent with the current Federal guidelines.

In the bivariate analysis, when volume of HIV patients was controlled for medical specialty training or vice versa, both the volume of HIV patients and medical specialty training were significant independent predictors for whether physicians' self-reported prescribing practices were consistent with the current Federal guidelines. Intuitively, infectious disease-trained physicians were very consistent with implementing OI prophylaxis guidelines.

What resources do physicians use to learn about HIV-related therapies?

Seventy-five percent use medical journals, 60 percent use consultations with other physicians, over 50 percent attend conferences, and over 50 percent use AIDS journals. *MMWR* was used by only 40 percent; AIDSLINE, MEDLINE, drug company bulletins, FDA and NIH bulletins were used by fewer physicians. Survey recipients could indicate more than one resource.

What guidelines do physicians read out of those published 1993-1997?

Five percent reported having read none of these guidelines!

The 1997 antiretroviral guidelines were read by less than 50 percent and the OI Guidelines were read by slightly over 50 percent of physicians.

Since triple therapy has been available, higher volume providers have read at least some of the guidelines publications, whereas many of the low-volume providers reported reading none of the publications.

Infectious disease physicians were more likely to have current and past guidelines.

Analysis of resources for learning about HIV-related therapies:

It is more likely that a high-volume provider (greater than 100 patients) will read an AIDS advocacy newsletter.

This trend holds for use of AIDS journals, AIDSLINE, conferences, *MMWR*, NIH bulletins, and Web sites.

High-volume providers were more likely to have read the guidelines than low-volume providers.

There were differences by specialty in who had accessed resources, but these weren't as great as the differences by volume of care.

Infectious disease physicians and hematologists/oncologists were significantly more likely to have read the guidelines than the other physicians.

Scores on the clinical scenario tests where treatment was to reflect the guidelines varied. No one scored 100 percent on the tests; this is most likely because the guidelines don't quite reflect clinical practice. The median composite scores were around 67 percent. When one looked at median composite scores by patient volume or by medical specialty, there was a trend showing significant differences for physician correctness with federal guidelines and self-reported adherence to federal guidelines.

In summary, when a number of analyses are conducted, there are significant differences and predictors as to who is going to be able to report what are the elements of the guidelines. There are also significant differences in how individuals receive their treatment information. One might

conclude that only physicians caring for more than 100 HIV-infected patients should be allowed to care for HIV patients and only if they are infectious disease-trained. However, this is not reality because there is an epidemic that is not static and the demographics are changing. Those responsible for dissemination and implementation of the guidelines must critically analyze how they are going to disseminate them, whether this means of dissemination is the preferred means for the way physicians obtain their information, and whether those physicians receiving the guidelines implement them in practice. Further studies could determine the exact journals that physicians are reading to focus dissemination efforts and whether low-volume providers consulted high-volume providers. This study will add to the current dialogue regarding the organization of health care delivery for patients with HIV disease and the credentialing of HIV providers.

Patient Comprehension and Retention of Medical Information

Dr. Seth Kalishman, Associate Professor of Medicine, Center for AIDS Intervention Research, University of Wisconsin, described patient factors in retaining medical information and their implication for successful use of HIV therapies. He presented recently collected data from an AIDS Survival Project in Atlanta sponsored by the National Institute of Mental Health (NIMH). As background information he noted that information received by patients at the time of notification of HIV test results is rarely retained, citing data showing that only 91 percent of patients immediately after medication instruction were able to correctly recall the medications and regimens.

A variety of factors are associated with information retention:

Motivation is a factor and one would expect this to be high in HIV patients.

Neurocognitive deficits because of HIV infection, long-term substance abuse, and other lifestyle factors play a role.

Psychiatric illnesses are known to be high in this population. Psychiatric populations don't adhere to their psychiatric medication, so it is not surprising that they don't adhere to HIV regimens.

Active substance abuse is also a key factor.

A critical patient characteristic that is important in information retention is literacy.

Patient literacy and its relation to adherence were studied. Literacy was of interest because it is well studied and encompasses a number of factors including social class and education level and is a good measure for how well people can understand and retain information. Studies of diabetes patients showed that 47 percent of these people had inadequate functional health literacy. Patients with lower health literacy report a variety of poor health outcomes including adherence to medications.

The AIDS Survival Project undertook a study of functional health literacy and its relationship to HIV treatment adherence in a population in a community center in Atlanta. Participants were recruited through community outreach and not through clinics. The population was 70 percent men, 65 percent African American; 50 percent had a history of incarceration, 28 percent had a history of injection drug use, and a variety of sexual orientations were reported. Seventy-eight percent were diagnosed with AIDS, 36 percent reported an undetectable viral load (but blood studies were not done to confirm this), and 23 percent reported not currently taking antiretroviral therapies.

The Test of Functional Health Literacy in Adults (TOFHLA) was used as the instrument in this study. This measure was adapted for the purpose of the HIV study using passages with fill-ins for medical instructions and an HIV-specific passage was developed. There was a TOFHLA numeracy scale given to the participants as an external validator of the reading measure. In these examples people must perform mental calculations to obtain the correct answer to the problem. This test was administered in an interview where medication instructions were given in written form and questions were asked orally. To define literacy the TOFHLA passages were used, and 26 percent of the sample received a score under 93 percent. Six percent couldn't even perform by random guessing (0-50 percent correct); 4 percent scored 51-75 percent, 16 percent scored 76-92 percent, and 74 percent received scores of 93-100 percent. The project considered 80 percent correct as the cutoff for literacy.

Those with low literacy scores were less educated, scored lower on the numeracy TOFHLA, and scored lower on the HIV reading passage. There was internal consistency and so people deemed lower in literacy probably were so.

Treatment adherence was calculated using 2-day recall of medications taken. Participants' medication schedules were reviewed with the patients and checked against a chart stating what the regimen should be. The test administrators tried to reconcile discrepancies since physicians do deviate from the guidelines. A calendar of events for the past week was used to aid in the 2-day recall. Adherence was calculated as the number of pills taken divided by the total pills prescribed. A 2-hour window in scheduling was allowed (plus or minus 1 hour) and low versus high-literacy participants were compared. There was a significant difference in adherence between the lower literacy participants and the higher literacy ones. It is important to note that even the higher literacy patients weren't completely adherent. For the lower literacy patients, 1 in 5 was off schedule for one of the three antiretroviral drugs in the past 2 days. Not all people were on three drugs, but the vast majority were.

Literacy and Treatment Adherence

Medications taken off schedule	Low-literacy participants	High-literacy participants
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None	58%	77%
1 drug	9%	9%
2 drugs	12%	3%
3 drugs	21%	11%

Viewing adherence in terms of the number of pills taken, the high-literacy participants were 94 percent adherent and the low-literacy participants were 88 percent adherent. Of the high-literacy participants, combining the number of times that one was off schedule with the number of times that one missed medications, the mean was 90 percent adherence. For the low-literacy participants, this value was 84 percent adherence. Of the low-literacy participants 7 percent didn't know their CD4+ count and 35 percent didn't know their viral load. This is compared to 1 percent and 13 percent, respectively, for the high-literacy participants.

The logistic regression data analysis for adherence was described. Literacy was a significant predictor for nonadherence. In the multivariate model, predictors of nonadherence included race, patient distress, attitudes towards the physician (trust), and literacy. Literacy was a better index of adherence than education.

Reasons for missing medications in the past month were similar to the general population but in terms of the differences between lower and higher literacy, reasons included having too many pills to take, lack of confidence in the medication's efficacy, depression, and the desire to "cleanse the body." The lower literacy participants don't admit to not being able to follow instructions; being illiterate is a shameful thing and one isn't likely to admit not being able to read.

There are many other factors that influence adherence. For example, some people were adherent during the week when social services provide food and weren't adherent on the weekends when they must find food on their own. Some illiterate people were 90 percent adherent; people can learn if they are taught! Some people were confused about the medication instructions and were very compliant with what they believed to be the instructions versus what the instructions were.

Conclusions from this data and the literature include:

Several factors will affect information retention. Many of these factors are prevalent in HIV/AIDS populations.

Health literacy very likely interferes with adherence to complex regimens. This calls for literacy-based intervention and careful attention to literacy for materials that are disseminated to patients.

Efforts to disseminate treatment guidelines to people with HIV must attend to the literacy issues.

On the basis of prevention studies with this same population, information presented by video may offer a viable medium of dissemination of treatment guidelines. Videotapes are no more expensive than glossy brochures; a 10-minute videotape has been demonstrated to be an effective HIV prevention educator in a variety of nonliterate populations. Videotapes are inexpensive to produce and to distribute. Comprehension of the language still must be addressed in the use of videotapes. The cultural and contextual settings of the patient versus that of his or her provider were not taken into account in this study but are most likely a factor because the correlation between adherence and how patients felt about their physicians was quite high.

Regionalized and contextualized brochures or videotapes are needed. For example, flashy videos turn off some people (adults) and one loses credibility with them. Flashy videos are needed for children to keep their attention. Efforts to regionalize the information must be made. (For example, don't just use the same text but change the actors.) Local patients and providers are much better to use. Race is not so much an issue as social class and local culture.

Target Audiences: Identification and Needs Assessment

Health Care Providers

Dr. Linda Frank, Director, Pennsylvania AIDS Education Training Center, Graduate School of Public Health, University of Pittsburgh, discussed the needs of health care providers for HIV treatment education and technical assistance/consultation. Education and training is needed to address many issues, including the complicated and constantly evolving treatment regimens, need for frequent clinical updates, behavioral interventions and skills, complex psychosocial issues associated with clinical management. Methods of assessment and facilitation of client adherence should be included in health care provider training. All of these educational priorities for health care providers assist in assuring access to the current standard of care for all.

Health care providers require clinically focused and ongoing educational programs, technical assistance, and consultation. One such program is the national AIDS Education and Training Center (AETC) Program, which is part of the Ryan White Care Act. Unfortunately, the AETC program makes up less than 1 percent of the budget for Ryan White programs. For the AETCs to maintain and expand their role in the dissemination of new treatment information, additional resources will be required. The role of the national AETC programs is to facilitate and/or provide education, training, and consultation in assessing, developing, and evaluating clinical standards of care and

clinical support services, and to facilitate the development of strategies to conduct clinically focused outcome evaluation. The AETCs are able to offer education and training that will improve HIV services delivery in urban, rural, and suburban areas.

Health care providers targeted by the AETC include Ryan White-funded programs, community and migrant health centers, health care for the homeless, medically underserved areas (both urban and rural), institutional settings (including jails/prisons), drug treatment programs, and providers of the poor and minorities. It is especially important that the AETCs target education to health care providers within managed care systems, particularly those who have little experience with HIV care.

Dr. Frank defined clinical education as “education approaches that include problem-based didactic and skill building education interventions for clinical care providers.” These approaches aim to increase access and quality of clinical treatment and care framed by the established and evolving clinical guidelines and standards of care. Educational content should include discussion of specific drugs and combinations, drug interactions, monitoring methods, readiness assessment of patients, initiation of therapy, changing therapy, adherence approaches, psychosocial impact, managed care issues, and clinical outcome evaluation. Formats for education should include case-based learning, small group activities, regional cluster training programs to address local issues, self-instruction modules, print alerts, and distance learning.

Dr. Frank defined technical assistance as “a process by which a technical assistance consultant (expert, specialist, peer) provides resources, consultation, and/or guidance in developing, monitoring, evaluating, or improving service delivery, performance, efficiency, or cost effectiveness of a program or provider.” This technical assistance/consultation should discuss clinical performance indicators, clinical pathways, quality assurance, managed care integration into primary medical care, behavioral change interventions to increase compliance or risk reduction, case-based clinical consultation, team development, and clinical program evaluation. The formats for this technical assistance should include such approaches as clinical on-site training, clinical small group focused training, clinical discipline-specific training, clinical miniresidencies and preceptorships, distance learning, and phone/fax consultation.

Types of clinical technical assistance and consultation include client-centered case consultation, which focuses on the clinical management of an individual client/patient. Many formats can be used to do this. There are also consulted-centered case consultations where the individual provider is

coached regarding improving the clinical management of patients or provided with an update on current treatments. Program-centered administrative consultation focuses on specific organizational issues or administrative problems within a clinical unit, which may be a barrier to accessing quality HIV care. Consultee-centered administrative consultation is aimed at providing assistance to the clinical leadership of a clinical program related to the functioning of the director or other members of leadership.

Evaluation of health provider training and consultation activities includes several factors. Any change in a providers clinical practice may be related to a specific educational program or from seeking case-based consultation from more experienced providers as the need arises. It is critical that those providing HIV care have access to HIV experts. The national AETC program provides a vehicle for providers to obtain such assistance and guidance. All clinical programs should be involved in evaluating care delivery. Evaluation includes a “systemic collection of information about activities, characteristics, and/or outcomes of programs/systems to make judgements about the program or system; to improve programs/systems effectiveness; and to assist in making decisions about future programming or approaches.”

The two types of evaluation are process evaluation and outcome evaluation. It is critically important that HIV health care providers are provided with opportunities to participate in evaluation activities to monitor and explore a means of improving clinical care. In terms of educating health care providers, evaluation provides a means of ascertaining how well programs or systems are moving toward achieving their objectives, identification of problems or barriers, and identification of successes and accomplishments. Outcome evaluation includes assessment focused on collecting information or providing summary statements about whether a program/system achieved its objectives and assessment of the impact of the program on the intended beneficiaries. We must determine whether the guidelines are being disseminated to those who need them and whether or not they are making a difference in terms of the quality of care that people are receiving in the primary care setting.

Patients

Mr. Billy Pick, Minority Initiatives Counselor, San Francisco Department of Public Health, discussed the HIV information dissemination needs of patients. The diversity of the communities affected by HIV makes it difficult to generalize about what patients need from the guidelines. He was reluctant to draw on his personal experience, because he felt it is not typical of most patients as

he is highly motivated to learn and has access to much information. He cautioned the participants to keep in mind that some patients do not want to know things, and no matter how much education you give them they will not learn anything. Information must be put into the context of what patients need holistically. Where does HIV treatment guideline information fall in terms of socio-economic issues and social justice? For people with HIV this is really important on a daily basis, although this might not be for the population in general. A small cadre of patients has access to treatment information through the AIDS newsletters and other treatment information sources. What the group must focus on is patients who don't want to know all about the treatment guidelines or who can't because their lives are a little bit different.

The group should focus on the complexity of the information that is distributed to clients. He advised targeting information to different groups. If one is discussing the antiretroviral guidelines with a woman and she becomes pregnant, then there are many more issues to discuss. Consider if the information is going to overwhelm clients. He said that when patients become overwhelmed with information they become frustrated and you will lose them to care because they will be embarrassed that they can't learn the information, their self esteem will plummet, and their level of participation will decrease. The group must not only consider what these patients should learn, but must also be aware that once the information is learned by patients it can become set in stone. He stated that the best way education happens is from other patients; the problem with this is that often peers disseminate out-of-date material. There is a danger in how we educate patients because of this.

He said that we need to do an assessment on various groups and what they want from their physicians. Many patients expect the doctors to know the treatments, and their sense of empowerment lies in the fact that they showed up for their appointment. Information should also be available to patients who do want to know the guidelines, but many of these patients will obtain the information anyway through other sources. He suggested prioritizing what to teach people. Although attempts have been made to simplify the guidelines, they are still too complicated for many people. Provide simple adherence strategies.

He was concerned about the undereducated patients and those who don't have as many resources as patients have had in the past. These are the patients that will be problematic for the group and the ones who should be addressed.

Social Service Providers

Moises Agosto, Director of Treatment Advocacy at the National Minority AIDS Council was unable to attend. David Barr, FCHR, spoke about service providers from the perspective of when he ran treatment education programs at the Gay Mens' Health Crisis (GMHC). He described the intake process for new clients at GMHC before the development of the treatment education program. New clients were interviewed and a lengthy form was completed in a process that took approximately 2.5 hours. Those providing the intake interviews were social workers, and psycho-social issues were the major focus of the intake form. Buried within this process were questions about t-cell count and medications. The intake staff had much training, but never had received training about HIV beyond how it is transmitted. No one had ever trained the counselors about PCP prophylaxis, so when a new client would state he/she had 150 t-cells and did not list PCP prophylaxis as a prescribed medication, nothing was done. An important opportunity to advocate for a client and prevent a medical crisis was wasted. To correct this, a training on treatment issues was developed and made mandatory for all staff.

There is an opportunity in HIV disease that one doesn't have with asthma, diabetes, or cancer, because there is a community-based infrastructure that provides us with the opportunity to contribute support and education to patients in a way unlike ever before. Lessons have been learned, particularly coming out of prevention education, in how one provides support, care, and education to people. Much work on behavior change may carry over into adherence and treatment education. Every single person that has an interaction with the person with HIV has the opportunity to ask the patient about medication-taking behaviors. Think of the case manager, the drug counselor, the resident coordinator, the peer educator, the support group facilitator, and the receptionist as a team. These people have the opportunity to look for red flags and to provide support and treatment information. Maybe the trust level is higher with these people than it is with the physician. Maybe this person has more time to spend with the client than the physician does. Perhaps this person resembles the client and talks more like the client. The opportunities here are enormous, provided that funding is available along with good training and supervision for staff and volunteers.

Health Care Providers/Payors

Dr. John Ludden, Senior Vice-President, Harvard Pilgrim Health Care, discussed implementing HIV guidelines in the managed care setting. In his experience an emphasis on measurement has superseded giving physicians specific instructions on how to provide care. Without measurement of

the use of a guideline, physicians are much less likely to implement them. Performance measurements should be considered an essential part of any guideline implementation plan.

It is important to start with a target, remembering that guidelines serve goals and not the other way around. Targets are explicit goals such as performance, outcomes, clinical utilization, and cost. Targets need to be measurable. If achievements are measured over time, one can determine if conditions improved, but not easily compare conditions from one practice or individual to another. If measures are to be comparable across the country then a large process must be developed like the Health Plan Employee Data and Information Set (HEDIS). One must decide the importance of being able to compare targets, because specifying the measurement parameters is complicated. Simplicity and cost of measurement are important considerations. Time is a valuable commodity for physicians and they are often reluctant to take on additional tasks. However, physicians will seek to meet targets if given an incentive. Monetary incentives work well. Physicians are also quite responsive to visible measured performance (e.g., posting on a wall who is using monotherapy and how many cases this is being used for).

Dr. Ludden provided asthma examples to show how setting targets can affect performance. A difference between asthma and HIV is that in asthma the best practices are known, and there are simple outcomes that can be measured such as how much school is missed for children or how much time someone spends in the hospital. Once a target was set and measured, the number of days spent in the hospital by patients went down. Underneath that targeted change in asthma performance was a series of best practices that were also measured (e.g., what percentage of people use steroid inhalers, etc).

There are many interests competing with HIV for time and resources within the managed care organizations. Managed care organizations are most likely to examine diseases or health conditions that are high volume, high utilization, or high cost as priorities. Currently, HIV disease is not high or present on that list of priorities. In terms of receiving the coordinated attention aimed toward a national target, it will be very difficult. Goals for quality improvement include:

- Set a target, then prepare a simple guideline.

- Improve clinical practice results.

- Make improvements through measured performance. Incentives or competition to achieve compliance with a known treatment or practice will lead to improvements in a region or setting.

- Recognize that this systematic practice is what HMOs and clinical managed care plans do best.

Current HIV Treatment Information Dissemination Efforts

Federal Government

Deborah Katz, R.N., Director, Office of Program Operations and Scientific Information, National Institute of Allergies and Infectious Disease (NIAID), described the role of the federal government in HIV/AIDS treatment information. The positive aspects of the federal government's involvement in guidelines dissemination are its influence on third-party payors and policy makers. Government is also able to undertake high volume/high expense activities such as operating hotlines and clearinghouses. The negative aspects of federal government involvement are that not all people trust the government. Anything that happens in the government has a need for review and approval, and this takes a long time. Political oversight is necessary, and this affects what words are used and practices that are mentioned in the guidelines.

An overview of agency involvement in HIV/AIDS information dissemination was provided. These agencies include the CDC, HRSA, SAMHSA, HCFA, NIH, AHCPR, and the FDA. The key problem is that no single agency has the responsibility for AIDS education information dissemination. The current system requires close cooperation/collaboration. There are problems with overlap and duplication, and there are big gaps. In particular, very little is done targeting patients for treatment education.

The agencies involved in guidelines dissemination are CDC, NIH, and HRSA, whose involvement is major; and SAMHSA, HCFA, and the Indian Health Service, with less involvement. AHCPR is no longer actively involved in the process for HIV/AIDS guidelines. Currently, in guidelines dissemination there are individual agency efforts and coordinated efforts. Individual efforts are being made by SAMHSA, by HCFA with their mailing to Medicaid participants, by CDC through the MMWR, by HRSA with their physician warmline and the AETCs, and by the NIH with the development of the guidelines and outreach to the research community.

A combined federal effort is the HIV/AIDS Treatment Information Service (ATIS). This service provides federally approved treatment guidelines for HIV/AIDS on the internet. The most recent version is always available at <http://www.hivatis.org>. The government wanted this service separate from the toll-free number (1-800-TRIALSA) where people call to obtain information about clinical trials to begin to distinguish between clinical trials and care in the minds of the public. There is also

a toll-free number that is staffed by bilingual information specialists who provide information on the guidelines. Calls to this service and hits on the Web site keep increasing.

A DHHS satellite broadcast series on HIV/AIDS-related topics was a collaborative effort that was made under the guidance of HRSA with many other agencies getting involved. The first broadcast was on the adult treatment guidelines. This broadcast went to close to 400 sites with an audience of 32,000 and another 10,000 in delayed broadcasts. There were also many requests for videos of the broadcast. This isn't a lot of outreach, but it is outreach by a group of federal agencies that wanted to make an effort to disseminate the guidelines. The broadcast began with a didactic presentation about the NIH principles of therapy, an overview of the guidelines, and DHHS policy. This was followed by a presentation and discussion of several case studies. This segment resulted in an overwhelming response from people calling in to ask advice on particular cases. The next broadcast will be July 22, 1998 on the pediatric guidelines.

State Government

Dr. Bruce Agins, Medical Director, New York State AIDS Institute, provided an overview of current HIV treatment information dissemination efforts by state governments, of which there are many. The challenge at the state level is to promote and translate the guidelines for people to implement them. There are four major activities that occur at the state level: development, dissemination, implementation, and monitoring. Whether or not the state develops the guidelines, they do need to promote them.

Promotion of the guidelines can occur through many means, including:

- Obtaining buy-in at the local level.

- Engaging professional societies.

- Building on the rapport that already exists at the state level with the medical community.

- Coordinating with the local health units whether it is county or city health departments.

- Co-authoring on local versions of guidelines with local medical groups such as in California and New Jersey.

The states play a key role in dissemination through:

- Coordination of activities.

- Distribution of the guidelines rapidly through their existing systems.

Development of a strategic plan for dissemination and implementation.

Use of connections with local health units.

The Institute of Medicine and its report on guidelines in 1992 defined implementation as “programs and activities that take guidelines out of the abstract phase of development into the actual world of health care decision-making and action.” This is also the challenge that is faced in HIV guidelines implementation. There are a number of vehicles for disseminating and implementing the guidelines. There are educational programs, consultation services, use of local advisory panels and local opinion leaders as champions, formal distribution programs, convening providers to review and approve the guidelines, and monitoring and analysis of implementation. Quality-of-care monitoring is a key role for the state. The state can also issue reminders to providers, support patient-mediated interventions at community-based organizations, and conduct surveys.

Factors influencing the activities in a state include first and foremost HIV prevalence. Other factors include the budget dedicated to HIV activities, the governmental structure itself (e.g., is there a separate AIDS unit devoted to education and guidelines development, or is it integrated with other activities that might dilute HIV-specific activities?); the size of the ADAP program and whether there is a need for interventions related to that program that drive the clinical guidelines process, the history of the state’s role in regulation, and whether there are links to academic medical centers that might lessen or improve the direct involvement at the state level. For example, California relies heavily on activities at UCSF for some of its work. Efforts include local consensus panels such as those related to ADAP advisory committees in Missouri and Washington, and formal guidelines panels such as in New Jersey, New York, and Washington.

Dissemination occurs in many ways. Virtually every state includes information about the guidelines in their newsletters, which are distributed to every practicing physician in the state. There has been much said about needing to condense the guidelines to make them more useful at the state level. There is some sharing of information between Florida and Michigan. Other efforts include direct dissemination of condensed versions to consumers, publications in book format in New Jersey and Texas, issuing regular updates, and specific distribution through local health departments.

States have used some local opinion leaders to champion the guidelines. The most common means was through collaboration with medical societies (Massachusetts, Michigan, New Jersey, and Texas). Other means include using formal governmental advisory bodies, coordination with other

State agencies such as social services, and collaboration with academic medical centers. Continuing education can be used to discuss the guidelines. Most states have a “roadshow” where they speak about emerging infectious diseases or new health care concerns. This may also be done through annual symposia.

There are some creative efforts with regard to consultations. Washington funds (through the University of Washington) a system whereby someone carrying a beeper 24-hours a day can be called by someone needing a consultation. California funds a warmline. Efforts at the local level should be publicized and adopted by other states. Teleconferences with case presentations to local experts are widely received. During the national teleconference on the adult guidelines Florida provided a call-in to present cases to experts. New York has begun to pilot videoconferences, but it is too soon to see how effective those efforts will be.

There is much discussion in the AETC environment in terms of how they need to change and be related to the current guidelines. Massachusetts is funding the local AETC and targeting their activities directly to community health centers and office practitioners to inform people about the guidelines. California is undertaking similar activities and focusing on rural areas. Washington funded their AETC to develop and to distribute a videotape on the guidelines. There may be a role for linking up with ADAP activities as well.

States are monitoring guidelines implementation through different means. Some are reviewing prescribing patterns through Medicaid or ADAP databases and using that information to target their activities (New Mexico, New Jersey, Michigan, and Massachusetts). Quality of care monitoring can consist of medical records review as in New York, Florida and other states, direct observation of clinicians as in Texas, self-assessment tools as in Florida, and distribution of a free software program of indicators in New York that perhaps could be adapted nationwide through the Ryan White Title III Program as part of an ongoing quality improvement program. Other states are promoting centers of excellence (such as New Mexico).

In summary, there are several important activities needed at the level for successful promotion of the guidelines:

- Obtain buy-in at the local level.
- Conduct rapid dissemination using the existing infrastructure.
- Target providers through ADAP.

Tailor the guidelines for community practice variations.

Set up consultation mechanisms by telephone, warmlines, or beeper services.

Develop contractual requirements if appropriate.

Monitor guidelines implementation.

Coordinate with other agencies. Medicaid is an important agency for overseeing clinical care.

Future roles for the states include monitoring quality, especially through efforts linked to managed care; support for patient-mediated intervention; intercoordination, better coordination with the federal government, connections through the AETC, and computerized systems with built-in reminders.

Unresolved issues to consider include the role of regulation and to what extent the state should be involved in oversight of guideline implementation, the level of consultation, the degree of guideline modification that is appropriate, the extent of distribution, and the degree of collaboration that should occur with other agencies. There should be more efforts to cooperate with other disciplines, particularly the nursing profession where much communication about care occurs. Too often our focus is on the prescribing patterns of physicians. Health profession schools should also be targeted to ensure that new professionals are trained about the guidelines.

Community Organizations

Pablo Colon, DPM, Director, Department of Treatment Education and Advocacy, Gay Mens' Health Crisis, provided an overview of dissemination efforts by community organizations. The needs for treatment education are: 1) increasing self-empowerment, so that patients can participate in the treatment process; 2) informing people about the latest treatments; and 3) addressing the need to transform complicated medical terminology into simple and understandable consumer language. Community-based organizations are an important source for treatment information and support because patients often have an on-going relationship with the agency, staff may have more time to spend with clients, and there may be a greater sense of trust with the service provider/educator than with people encountered within the medical care setting.

Community-based organizations produce numerous types of materials and programs targeting patients, staff, and caregivers. The programs are geared to diverse populations with varying cultural, educational, and economic backgrounds and needs. Materials and events are often

developed for people at different stages of knowledge about treatment issues. Translation into different languages is often provided. Materials and programs include:

Treatment newsletters - usually provide detailed, state-of-the-art information about new developments in treatment and research, e.g. GMHC Treatment Issues, AIDS Treatment News, Project Inform's PI Perspective.

Fact sheets - usually short, easy-to-read pieces which focus on a specific opportunistic infection, type of treatment, or symptom. Several organizations develop fact sheets, including: GMHC, AIDS Treatment Data Network, and Project Inform.

Brochures - short pieces that describe an approach to treatment and/or describe available services.

Workshops - small group events that provide information about HIV disease and treatment. These can be geared to entry level or more advanced participants and are run by organization staff or volunteers.

Forums - large events that offer up-to-date information about treatment approaches, usually with the participation of experts from the field. GMHC holds monthly forums in the same place every month and has established a good regular audience. Project Inform holds its "town meetings" in cities around the country.

Trainings - provide staff and volunteers with treatment information to assist them in the provision of quality services to clients.

Peer counseling programs - provide individual counseling regarding treatment and HIV disease.

Libraries - provide books, journals, and computer services to clients.

Telephone services such as hotlines and warmlines.

Computer-based services such as Web sites.

Peer-based programs are an important model for several reasons. First, clients may feel more comfortable speaking with a peer about their HIV disease and their anxieties about making and following through on treatment decisions. Second, peer-based programs provide an opportunity to engage clients more actively in programs, so that the people you provide services to become the people who provide the services. This encourages client involvement and interaction and is the key to self-empowerment. However, peer-based programs require intensive training and supervision. It is important to distinguish between providing information and support from providing medical advice, which is beyond the purview of the counselor.

Community-service providers need opportunities to learn and exchange ideas. National conferences, such as the National AIDS Treatment Advocates Forum and the U.S. Conference on

AIDS are both excellent sources of information, communication, and networking. Following the release of the DHHS guidelines on antiretroviral use, GMHC held two conferences targeting case managers, health educators, peer educators, and people living with HIV. The information was presented by leading community-based treatment advocates involved in the development of the guidelines. Similar seminars have been conducted by other organizations. Computer services also offer an important opportunity for the exchange of information and materials. An effort to place treatment newsletters and fact sheets in one central site, which would allow access to them by community organizations all over the world was discussed. This would greatly increase access to information and reduce redundancy.

Community-based treatment educators also serve as advocates for proper treatment for their clients. They can often intervene with medical providers when clients are receiving substandard care or where communication between the client and the medical provider is faulty. This is a difficult task for community providers, as it may sometimes include suggesting that the client find a new doctor, and may involve speaking with the physician to question the standard of care. Health educators can work with clients to help them develop better relationships with their medical care providers by providing information, assisting in the preparation for the office visit, and explaining treatment options.

Community treatment advocates and educators have been at the forefront of dissemination of HIV/AIDS treatment information and have developed many innovative methods of providing information to both patients and providers. Their expertise in this area is great and should be utilized. The many different types and versions of educational materials that have been developed target patients with varying levels of literacy, knowledge, and cultural backgrounds. There is already an infrastructure for information dissemination to patients. To fulfill its promise, it needs adequate funding.

Professional Associations

John Henning, PhD, Director, Department of STD & HIV, American Medical Association (AMA), provided a perspective on dissemination of guidelines by professional associations. Medical organizations are in the business of communicating medical advances to their members. Most have highly developed information dissemination systems including journals, newsletters, Web sites and periodic direct mailings. If distribution of guidelines would ensure prompt and proper

implementation, then medical organizations must be encouraged to publish the DHHS antiretroviral treatment guidelines, or a notice of guideline availability.

However, HIV antiretroviral guidelines force us to face the modern information challenge for medicine. These guidelines are constantly changing. Physicians who prescribe antiretrovirals on the basis of year-old printed guidelines distributed by their professional organization would not be ensuring patients the full benefit of medical advances – and might do them harm. Therefore, traditional distribution of HIV guidelines by professional groups is only part of the appropriate method of ensuring state-of-the-art clinical practice. Medical associations need to fulfill their responsibility to their profession by promoting the present guidelines and also linking HIV providers to the continuing guidelines development process to ensure that medical practice remains current.

It appears that most major medical journals have ignored the DHHS antiretroviral guidelines that have been available on Web sites for approximately 6 months but were not published until 3 weeks ago. A review of the 1997 and 1998 volumes of 10 major United States medical journals and two major medical association Web sites found almost no mention of the DHHS antiretroviral guidelines. *Journal of the American Medical Association* carried an article on the DHHS guidelines in 1997 and again in 1998. It also printed full text of the International AIDS Society:USA (IAS:USA) guidelines in 1997 with an update in 1998. *American Family Physician* noted the IAS:USA antiretroviral guidelines but not DHHS guidelines; in 1997 there was an article on understanding the IAS:USA guidelines and in 1998 there was an editorial on who should deliver the treatment recommended in these guidelines. *New England Journal of Medicine* referenced the IAS:USA guidelines twice in 1998 in articles that did not focus on recommendations from these guidelines. *Journal of Infectious Diseases* in 1998 noted NIH principles but did not also note DHHS practice guidelines. The Web site of the American Academy of Family Physicians references its journal article on the IAS:USA guidelines, and the AMA Web site carries articles, full text and links to sites for full text of DHHS and IAS:USA guidelines. Greater guidelines awareness is seen overseas with an excellent commentary by the *British Medical Journal* on DHHS guidelines, NIH principles, and British HIV Association Guidelines. Clearly the potential for promoting guidelines through medical journals is there but there has not been much interest yet. Perhaps guidelines do not make for compelling journal articles.

Professional associations must determine a strategy for dissemination and linkage of providers to the ongoing guidelines process. Physicians can be categorized in relation to their HIV prescribing as:

core, involved, or uninvolved. Core physicians are characterized by a large HIV practice or involvement in key clinical antiretroviral trials. These prescribing physicians are most likely to seek out the latest advances in HIV treatment on their own. Therefore, core physicians are not the most appropriate audience for dissemination outreach. Core physicians only require that information on clinical advances generally be accessible to them through Web sites, journals, conferences or collegial telephone calls.

Involved physicians are those with few or a moderate number of HIV cases and a small amount of time to devote specifically to keep current with HIV treatment advances. Involved physicians are prescribing for HIV-infected patients with limited information and therefore should be primary targets for receipt of DHHS guidelines and linkage to the ongoing treatment development process embodied in the guidelines process. These physicians need information in a more concise fashion than is provided by current guidelines. They may also need training and organized, continued contact with core physicians.

Uninvolved physicians are ones who are not treating patients for HIV disease. Their HIV-infected patients receive HIV treatment through a different physician with or without the knowledge of uninvolved physicians — or HIV infection goes unnoticed and untreated. Wide dissemination of DHHS guidelines to these physicians may do harm. The fault is not with the guidelines. The guidelines recommend that physicians who do not have skills and commitment to stay current with treatment become competent or refer patients for HIV specific treatment or provide such treatment in consultation with a knowledgeable expert. This caution can easily be lost in the larger message that treatment is important and successful. The message disseminated to the uninvolved physician is better focused on basic information. Uninvolved physicians still need to identify HIV infection in their patient population, promote risk reduction in their patients, know the importance of appropriate referrals, and have information on drug interactions and side effects if the medical care of infected patients remains with them while a specialist directs HIV treatment. Professional associations can and should support this effort.

But DHHS guidelines raise unresolved questions for the medical community. While there is no wavering from the ethical obligation to treat HIV-infected patients, who competently treats HIV disease? If HIV treatment becomes the province of specialists, will HIV-infected patients be shunned? And how will special competency in HIV treatment be determined? Will all physicians be offered a clear path to HIV treatment competency if that is their calling? The April 24, 1998

publication of the DHHS guidelines is an essential first step in what is a much longer and larger process in the evolution of medicine.

Professional associations must do their share to ensure that the time between each guidelines improvement and actual benefits for patients is mercifully short.

Pharmaceutical Industry

Dr. Martin Mattingly, Director of Marketing, Agouron Pharmaceuticals, gave a pharmaceutical industry perspective on treatment information dissemination. He noted that there are a variety of targets audiences for dissemination and there is no one answer to this problem. A variety of methods are needed. He stated that Agouron's intent is to pilot dissemination efforts and adopt those methods that work. The pharmaceutical industry has two choices for dissemination: supporting independent efforts such as education programs, or conducting their own programs. Pharmaceutical industry programs are highly regulated and require prior approval from the FDA. Generally, if an effort already exists they prefer to form partnerships with that sponsor. A key component of the pharmaceutical industry is its field organization of people from a variety of backgrounds who are continually in contact with doctors, nurses, and pharmacists. This is a vehicle that is unique to the pharmaceutical industry.

Examples for targeting physicians include sponsoring a symposium on the guidelines at the 1997 ICAAC meeting and direct distribution of guidelines by field representatives. Direct mail with phone follow up for the lower-tier physicians is planned. The anticipated success rate for this is low but is cost-effective. Audioconferences often are effective.

Other target audiences include accounts such as corrections systems, managed care plans, and the Veterans Administration. An audioconference featuring the corrections guidelines has received tremendous interest. This is accredited for nurses, physicians, and pharmacists for continuing education. Teleconferences have been directed toward medical directors in managed care organizations and pharmacy directors. A new initiative was to challenge a pharmacy benefits manager to conduct his own drug utilization review within his system. The results were dismal, with 20-30 percent of patients receiving monotherapy. Although Agouron could not directly do anything about that, they could challenge the pharmacy benefits manager to target these physicians and support these initiatives. Caseworkers have been targeted through a quarterly digest and through

symposia. Agouron also sponsored a program at a mid-year clinical pharmacy meeting on the topic of the guidelines.

The pharmaceutical industry has tried to provide useful tools for disseminating the key principles in the guidelines. Such tools include a guide for antiretroviral drugs that is not nelfinavir-specific, sheets of stickers for doses of drugs that can be used on pillboxes for tailoring of the regimen by the physician, and posters and magnets, stating: “Every dose, every day.” A Web-based program is being finalized that will electronically enable providers to tailor a regimen and print the information for patients; it also has the ability to catch common errors. A significant number of patients still use brochures in doctors’ offices so they provide these as well and encourage adherence. They have just launched a campaign aimed at pediatric HIV patients, called the “Victor the Lion” series, to help children understand the disease and the medications. The terms HIV or AIDS are not on the outside covers of the information so that the child is not marked.

Patient surveys were conducted and patient expos were sponsored. From these came suggestions for how to distribute treatment information to underserved populations that included making videos by peers, and the importance of patient empowerment and peer educators. A conference participant noted that socioeconomic status is a more important determinant than race or gender in whether or not a patient is receiving appropriate care, and must be considered as well.

Evaluation of Clinical Practice Guideline Dissemination

Overview and Examples of Guideline Dissemination Evaluation

Steven Asch, MD, MPH, Resident Consultant, RAND Corporation, presented on the challenges of developing performance measures for HIV care. It is clear that evaluation is crucial to any guideline dissemination effort. Performance measures are gauges that give feedback on the dissemination effort. There is a science to constructing such measures just as there is clinical science behind the Guidelines themselves. The challenges to developing HIV-related measures to distinguish between health plans, physicians, or other accountable entities are organized by quality, access, and satisfaction.

HIV presents some very difficult challenges in measure development regardless of which of the content areas one speaks. First and foremost, patients and providers are concerned about the

confidentiality of their relationship. Providers may consequently omit HIV status from the medical record or be reluctant to provide records to those who are trying to measure quality of care. Patients will sometimes agree to sign waivers allowing their records to be reviewed for quality assurance purposes by their health plans. There is a large regional variation in the prevalence of HIV, and some plans or providers won't have enough patients to bother calculating measures. As a consequence of the confidentiality concerns and perceived differences in provider expertise many patients will seek care outside of their plan, making the calculation of these performance indicators problematic. For some types of HIV care, especially centering around prevention and education, there are many providers who feel they should not be held accountable for public health functions. HIV patients are much more likely to use alternative care either in or outside of a plan, and this also poses a problem for indicator development.

Health outcomes measures were described and include mortality, quality of life (QOL), OI incidence, and surrogate clinical markers. Reliance on outcomes measures is difficult because there are so many factors besides good care that effect outcome and that are beyond the provider or accountable entity's control. Risk adjustment is more problematic for HIV than other diseases due to the heterogeneity of the disease scenario. There are many strategies such as adjusting for CD4 count, viral load, risk factors, etc. but these all have associated problems. There is also a feasibility problem with outcomes measures. Mortality, even for HIV, can be too rare. QOL requires sequential interviewing and is very costly.

Process measures are about whether the patient gets the right care at the right time regardless of outcome. (For example, whether a patient with a CD4+ count below a certain threshold receives OI prophylaxis.) The guidelines strive to define good process by rigorously linking these processes with good outcomes using studies in the literature. Much information is easily abstracted from administrative/chart data. Risk adjustment is not as much of a problem. The problem with process measures is that there is a wide variation in the accepted process of care in HIV disease. The standard of care is also rapidly changing, making measurement difficult.

The consequences of the wide variation in standards mean that good quality of care may not lie in whether someone received recommended care but whether options for care were discussed. This is hard to measure through chart review. Patient preference is paramount and is also hard to measure. There is more geographic variation in HIV than in many diseases. Investigational trials may equal good care more than in other diseases. Should all patients enrolled in clinical trials be receiving at

least the standard of care, or should they be excluded from measurements, thereby excluding a larger proportion of patients than in other conditions? Consensus methods may be less reliable in HIV than in other diseases.

Major content areas for good process measures were outlined and include:

Chronic outpatient indicators are better than acute inpatient conditions because this is where the disease lies.

OI prophylaxis is a good performance measure because the rules are clear and do not change as much as the antiretroviral guidelines.

Antiretroviral treatment prescriptions should be assessed.

Counseling and testing are important but are very poorly documented activities.

Although experts vary on how often to conduct these tests, staging and monitoring of CD4+ counts and viral load are crucial to many other process measures and should be evaluated.

Structural measures include how provider groups are organized to care for HIV patients. These are difficult to utilize in HIV. For example, the number of AIDS specialists available to a patient in a plan or a region poses a problem since it is hard to define what an AIDS specialist is. The definition of structural elements in HIV can be uncertain. Structural measures are very remote from clinical outcomes, unlike process measures, which can be linked in the literature to good health outcomes. Access measures include such things as how long must one wait for an appointment. These measures suffer from feasibility problems because by definition they require patient interviews and these are costly. It is possible in the future that electronic appointment or call records can counter this feasibility problem, but for now these access measures will have to depend on patient surveys, and there must be a compelling reason to do this. One reason would be that HIV patients have differential access in certain settings.

Satisfaction measures, although straying from guidelines evaluation, are usually included in performance measures. There is some evidence that HIV patients are less satisfied than patients with other conditions. Some evidence exists to indicate that managed care HIV patients are less satisfied than fee-for-service patients. There is very little evidence that there is variation among different managed care plans in HIV patient satisfaction. This is important, because if there is no variation, then this is a terrible measure. The trend is to combine satisfaction measures with process quality measures for HIV (for example, whether the doctor adequately explained treatment options).

The RAND HIV projects and performance measurements include the Community Health Management Information System (CHMIS), an electronic database, and QA Tool. QA Tool has been funded sequentially by HCFA, AHCPR, and the Robert Wood Johnson Foundation and is striving to develop a global measure of quality of care based on process indicators and performance measures. The system covers 49 conditions and 1,500 indicators. HIV is one of those conditions. The process started with a structured review of the literature using the modified Delphi process and a detailed operationalization process for measuring performance indicators. This tool is currently being tested in health plans and in a national sample. Examples of indicators in QA Tool include offering testing for HIV in the past year for those seeking treatment for STDs, men who have sex with men, current injection drug users, and those with HIV sex partners. This is designed for chart abstraction rather than electronic administrative data abstraction. Those indicators excluded from the tool highlight some of the feasibility/completeness tradeoffs in designing performance indicators. The indicator excludes recipients of blood transfusions in the 1980s because the expert panel thought that there would be very few people left in that category that wouldn't have been tested. The expert panel that helped to develop the QA Tool determined (before the release of the DHHS guidelines) that patients should receive adequate antiretroviral treatment within 1 month of the following unless enrolled in a clinical trial: CD4+ count greater than 500 and viral load greater than 30,000 copies, CD4 count 350-499 and viral load greater than 10,000 copies, CD4 count less than 350, AIDS-defining conditions, or thrush. The panel had troubling defining what adequate antiretroviral therapy was and decided that this would have to be re-evaluated yearly. This is defined in QA Tool as anything better than AZT monotherapy. This indicator also illustrates the clinical trial dilemma because the field is so rapidly changing the panel believed that patients enrolled in a clinical trial testing antiretrovirals should be considered as having been offered the standard of care.

Another project with which RAND is involved along with AHCPR and other institutions is HCSUS. This is a major research effort to collect information on the quality of care of a nationally representative sample of adults in care including 3,000 patients and 150 providers. The data sources are patient and provider surveys, pharmacy data, and chart reviews. The domains include cost utilization, QOL, quality of care, access, satisfaction, and knowledge. There are number of HIV performance measures in HCSUS that could be used to evaluate the guidelines. HCSUS has developed an HIV-specific QOL instrument that could be used as an outcomes measure to test whether the guidelines made a difference. There are a broad variety of process and care measures that could prove useful in the area of provider response to symptoms, use of antiretrovirals, OI

prophylaxis, and diagnostic tests. There is a structural measure related to how the providers are organized. Access measures including symptom response measures and waiting times are included. Satisfaction data are also included.

In summary, there is a wide range of possible HIV performance measures available. Dr. Asch stated his preference for process measures, but a balanced approach between process and outcome measures is probably the best. There are many challenges to developing performance measures; the two most important ones are confidentiality and changing standards of care. A database approach blending chart review and administrative data is desirable. Preliminary survey-based data indicate that the gaps are quite widespread.

Objectives of Guidelines Evaluation

Leonna Markson, ScD., Director, Outcomes Research and Management, Merck and Company, described evaluation of clinical practice guideline dissemination. The objectives of such an evaluation include: 1) assessment of guideline acceptance; 2) assessment of whether current practice patterns are in accordance with the guideline; 3) development of benchmarks or performance measures that can be developed as standards of care from the guideline; 4) testing provider knowledge; and 5) assessing patient awareness.

Assessing acceptance of the HIV guidelines will include those providers who are aware of them. One should not overlook the fact that the guideline panel members themselves can serve as a useful resource. These members should be advocates for the guidelines and questions they have may be disseminated to the field. Information about providers should include:

- Who are the guidelines supporters and skeptics?
- Where have they obtained their information?
- How did they receive the guidelines?
- In what types of settings do they practice?
- What types of patients do they serve?
- How do they view the composition of the guidelines panel?
- How do they view the evidence review process?

To decide where those issues reside, among those who may lean more toward skepticism, what are their specific areas of concern?

Methods to assess guideline acceptance include surveys of providers rating the value and usefulness of the guidelines, a need to develop case examples of where the guidelines work and do not work, and how the guidelines can be improved. Focus group discussions among supporters and panelists might be required to determine this. One of the values of research on acceptance of the guidelines is to gain insight into the rationale for provider buy-in or lack of buy-in on the guidelines. Another value is the identification of certain sections of the guidelines that need more improvement than others and these can be the focus of future dissemination efforts. Limitations of these methods include the focus on people who are most knowledgeable about the guidelines and not learning why the guidelines are not being disseminated.

Assessing current patterns of care for continuous quality improvement include determinations of whether practice is consistent with the guidelines and evaluation of processes through chart review as well as administrative data. The value of this assessment is through feedback of the information to the providers so that they can decide whether to initiate continuous quality of improvement processes. Merck is engaged in a small pilot study called the HIV practice cooperative. The purpose of the program is to review antiretroviral care to improve clinical effectiveness. One must determine disease status prior to the initiation of antiretroviral treatment, and view clinical markers, their frequency after initiation of treatment, and measures of what happens when changes in therapy occur. The clinical value of this kind of approach is that meaningful data can be obtained for direct-care providers, the types of patients not receiving guidelines care can be identified, and the potential to target outreach to patients or providers is created. A limitation is that the rationale for the observed patterns will be difficult to assess without qualitative data.

In contrast, benchmark or performance indicators can be developed as measures of standards of care. These efforts have been mentioned by managed care organizations and HCFA through HEDIS measures. We must evaluate whether there are components of these measures for HIV treatment that are ready to be included in performance-based measures and NCQA accreditation processes. The value of benchmarking is standardization in a public format across different settings. The limitations are that it will be difficult to distinguish practice patterns that reflect provider behavior versus patient choice, and the focus shifts from continuous quality improvement to justification of current practice patterns and severity adjustment issues.

Another approach to evaluating guidelines dissemination is to test provider knowledge. There may be the option of developing test questions to be used before and after CME programs. The baseline information could be used to determine how much the guidelines have been disseminated across the country. Testing after programs could be used to determine whether the education focused on what the provider needs to know and whether the guidelines need clarification. The value of testing provider knowledge is that it combines evaluation of dissemination efforts with efforts to improve knowledge. One might also be able to learn more about the length of time it takes for new knowledge to be disseminated to providers. This is useful to know since HIV treatment information will be updated regularly. The limitation of this evaluation is that providers are uncomfortable with being tested about their knowledge and it may difficult to understand bias among responders. Knowledge and practice patterns may vary and will not be determined by this approach. An evaluation of patient awareness of the guidelines is also important. Survey patients to measure their awareness of the guidelines and whether the guidelines were discussed with them and by whom. Determine whether the patients value the guidelines and the characteristics of patients who value them versus other sources of information. The value is that the patients can help to implement the improvement in quality of care. This approach can aid in the determination of what formats are needed for different types of patients. A limitation is that survey-based research is difficult with patients because of confidentiality issues and may be restricted to focus groups unless they are in large efforts like HCSUS. The ability to generalize this information across different populations can be very difficult.

An Overview of Research on Clinical Practice Guideline Dissemination, Implementation and Evaluation

Introduction

The development of new and more effective treatment strategies for HIV disease, including combination drug therapy and viral load testing, have created the possibility of turning HIV into a chronic but manageable illness. Recent clinical studies have demonstrated that when used properly, combination antiretroviral therapy is tolerable in most patients and can significantly reduce viral replication, thus halting immune system dysfunction, reducing AIDS-related opportunistic infections, and lowering the incidence of death. Combination drug therapy, however, is difficult to adhere to and must be taken for a lifetime. Furthermore, it is difficult to determine the optimal time to begin therapy, the most effective combination to use, and the appropriate treatments for patients for whom therapy is failing. Information about how to best utilize these therapies changes rapidly. Therefore, the development of long-term strategies for successful treatment challenges even the most experienced physicians and patients. The repercussions are severe; if not used properly, the virus can develop resistance to the drugs. Resistance to one drug often leads to resistance to an entire class of drugs. Therefore, improper use of the antiretroviral medication will significantly reduce the benefit to patients and could result in the development and transmission of drug-resistant strains of HIV, which would mitigate much of the progress in treating HIV disease made to date.

Recently released clinical practice guidelines provide physicians and patients with the most current antiretroviral therapy information, as well as provide a decision-making framework in the use of these drugs. The guidelines, developed by a panel of experts convened by the DHHS and the Henry J. Kaiser Family Foundation, provide information on how to monitor HIV viral levels and immune system function; methods to assess when to initiate therapy; how to choose a combination of drugs that will best suit a patient's needs; how to use the drugs during pregnancy; and how to monitor side effects. The guidelines also provide suggestions for switching therapies for patients who are not responding to treatment. The guidelines are expected to encourage the systematic implementation of the most recent clinical findings and to standardize the care and management of HIV patients.

It is essential that the information contained in these guidelines be disseminated to health care providers, patients, and caregivers to ensure the optimal use of these promising, but complicated

therapeutic regimens. Further, it is imperative that physicians and patients fully understand the consequences of improper or suboptimal care. Studies show that patients who see physicians experienced in HIV care live longer and better lives.¹ While some physicians are able to keep up with the ever-changing status of HIV treatment information, most physicians cannot. The new guidelines can provide this important information to physicians, which may improve the quality of care. However, without effective dissemination and implementation of the guidelines, the significant variations in treatment practices will persist, resulting in adverse patient outcomes. Considerable information is available on the clinical practice guideline process, providing the HIV/AIDS medical and service communities the opportunity to learn from past experience and continue research into the development, dissemination, and implementation of practice guidelines.

A Review of the Literature

Clinical practice guidelines are not new to health care delivery. By one account, more than 1,600 separate sets of clinical practice guidelines exist, which have been developed by more than 60 professional provider organizations, federal and government agencies, and third-party payer groups.^{2,3} Guidelines, promulgated to reduce inappropriate care and improve health care outcomes, play an increasing role in how health care is delivered and coordinated.⁴⁻⁶ Because of widespread variation in the management of specific health conditions and rising health care costs (e.g., HIV/AIDS), the aim of clinical practice guidelines is to produce the best consistent medical practice(s), based on scientific evidence, consensus expert opinion, and provider and patient feedback.^{4,5,7} Particularly advantageous to the guideline development process is the multi-disciplinary approach that it fosters. The guideline process requires the input of researchers, physicians, consumers, and other types of health care providers.⁵ Thus, the advantages of clinical practice guidelines are that they offer a useful synthesis of the current scientific evidence and provide the busy clinician with current information, supported by the opinions of responsible and respected colleagues and peers in the field.⁷

Clinical practice guidelines have received extensive attention in the literature. Research into the various facets of the guideline process have either focused on the process of guideline development or on the attributes of an ideal set of guidelines.⁸ Recent writings have emphasized the need for more explicit delineation of the methodologies used to develop guidelines and call for research comparing the effectiveness of different guideline development processes.⁹ But the true success of the present-day clinical practice guideline movement may lie in the methods, enthusiasm, and resources devoted to guideline dissemination, implementation, and evaluation.¹⁰ Guidelines are

considered effective when they improve physician awareness, attitudes, behaviors, and ultimately patient outcomes.⁴

To be successful, guidelines must also provide practical avenues for application,^{6,11} as patient populations and infrastructures for delivery of care differ and may not always fit the criteria defined in the guidelines.⁸ Moreover, guidelines should be modified to meet local needs.¹² The current of knowledge of the guideline process is reflected in the following points:

Dissemination of practice guidelines has been shown to be somewhat effective at raising physician awareness, but is far less effective at changing physician behavior. A change in behavior is more likely to take place if: 1) guidelines are developed by an institution with which the physician has a direct relationship; 2) guidelines are disseminated through an educational intervention; and 3) guidelines are implemented through administrative systems that provide the clinician with automatic reminders at the time of patient consultation.

Various models of physician behavior change suggest that physicians may be more influenced by such factors as personal characteristics (including: attitudes, habits, skills, values, competence, experiences) as well as by peer attitudes and values, social norms, resources, and patient feedback. These traits may serve to either enhance or impede guideline adoption depending on the combination of characteristics that exists.

Guideline adoption is not always feasible for those clinicians who face institutional barriers such as social, structural, logistical, and organizational factors. In addition, variations in the size, type, or location of the health care organization may also have an impact on awareness and adoption of guidelines.

Physicians use a variety of sources to obtain new clinical information, including: medical journals and newsletters, colleagues, continuing medical education classes (CME), professional conferences, and direct mailings.

- Physicians have been found to prefer guidelines that are authoritative, yet brief and easy to read, as well as those that utilize algorithms to help them assimilate guideline information more easily. Similarly, guidelines have the greatest impact when key issues are repeated, reinforced, and supported graphically. The marketing techniques used by the pharmaceutical industry appear to be effective when translated into the non-commercial realm.
- Guidelines are more effectively implemented when an evaluation measuring performance is built into the implementation process.
- The evaluation of clinical practice guidelines should address specific objectives, including:
 - 1) examination of the process of guideline development, dissemination, and implementation;
 - 2) measurement of the extent of implementation of the guideline; and
 - 3) assessment of a guideline's effect on patient outcomes and health care utilization.^{8,13}

One of the goals of practice guidelines is to educate patients, who are increasingly encouraged to become active participants and decision-makers in their medical care.¹⁴ This is particularly important in HIV care, where patient participation in decision-making is cited as an important aspect of successful care in the clinical practice guidelines. Consequently, understanding the characteristics that affect patient behavior will consequently help in designing appropriate strategies and interventions that will enhance how guideline information is presented, passed on, and understood by patients. Factors that influence successful guideline dissemination to patients include: 1) the complexity of the information; 2) the format in which this information is provided; 3) patient characteristics, such as attitudes and beliefs about health care, motivation, education level, cultural background, relationship with the health care practitioner; and 4) access to health care information.

Clinical Practice Guidelines: The Process

The utilization process of a clinical practice guideline has four stages: development, dissemination, implementation, and evaluation. The developmental stage of the HIV clinical practice guidelines began, as with most guidelines processes, with the recognition of gaps in the ability to successfully treat HIV disease and the development of new tools and methods that could fill those gaps and improve care.

There are various methods used in the development of a set of guidelines and each method contains common attributes that are essential to their final product. These attributes include:¹³

Validity: guidelines are only valid if they lead to improved patient outcomes; as part of this assessment, evaluation should consider substance and quality of the evidence cited, the means to evaluate the evidence, and the relationship between the evidence and the recommendations.

Reliability/reproducibility: these are essential when guidelines are tailored at the local level. If local experts can produce similar results under similar clinical circumstances, which can be interpreted and applied consistently by the local providers, then the guidelines are effective.

Clinical applicability: guidelines should be applied to the appropriate target populations.

Clinical flexibility: guidelines must identify the specifically known or generally expected exceptions to what is recommended.

Clarity: guidelines should have unambiguous language, define terms clearly, and use a logical and easy-to-follow mode of presentation.

Multidisciplinary approach: the developmental process must include participation by all relevant stakeholders and representatives of affected provider and patient groups.

Scheduled review: guidelines must include time periods for review to determine whether revisions are warranted given new clinical evidence or professional consensus.

Documentation: everything that takes place throughout the guideline process must be documented, including the procedures followed, participants involved, evidence used, assumptions made, rationale accepted, and the analytical methods used.

These elements guide the development process and require a consolidation of research evidence, expert opinion, clinical experience, and patient feedback. In particular, the multidisciplinary approach helps to ensure that a high degree of collaboration and participation occurs among the various stakeholders concerned with quality care and cost effectiveness.^{13,15} Practice guidelines are often developed by a variety of professional entities. For example, professional societies (e.g. American Medical Association), government agencies (e.g., the AHCPR, CDC, and managed care organizations) may each develop a particular set of clinical practice guidelines, and their position in the medical and health field may influence the successful utilization of a practice guideline by physicians and patients. However produced, the effectiveness of guidelines relies on how successful they are disseminated, implemented, and evaluated. The goals of dissemination and implementation are to change norms, beliefs, assumptions, values, and clinical practices.¹⁶ The goal of evaluation is to assess both the effectiveness of implementation strategies and the effectiveness of a guideline on patient outcomes and care utilization. Guidelines are considered effective when they improve:

Knowledge: the awareness by the target audience of the guidelines.

Attitudes: the acceptance of the new standard of care by the target audience.

Behavior: assimilation and adoption of the new standard of care into practice and care.

Outcomes: improving patient health, controlling costs.⁴

Thus, in order for these changes to take place, the distinct stages of the guideline process must be addressed appropriately.

Dissemination

This is the process by which knowledge and information are made accessible or available to a target audience. It is best viewed as an active and intentional process, and its success can be measured by the degree to which information is made available to the target audience and the degree to which the target audience acknowledges the information.¹⁷ The latter task, however, is often more difficult to achieve than the former. For example, it is not enough to simply mail practice guidelines to every relevant person in a specified group; the information must also be actively recognized — if the piece

of mail is discarded without being opened or read, then dissemination has failed.¹⁷ Thus, effective dissemination goes beyond the traditional concept of diffusion of information and encompasses the process through which target groups become aware of, assimilate, accept, and adopt the disseminated information.⁵

As noted previously, practice guidelines are developed by a variety of professional groups. Their role in the medical/health field can affect how practice guidelines are disseminated and implemented. The common goal of any set of guidelines is to standardize some aspects of the process of care based on average value judgments of expert groups, but these judgments do not always fit with the large spectrum of individual decisions both of the clinicians and patients.¹⁵ For example, nationally based practice guidelines such as those originating from professional societies, develop statements written for a large audience. Such guidelines, however, may not take into account the many geographical variations that exist among medical practices and thus, may be less frequently applied by physicians.¹⁵ In contrast, institution-based guidelines, such as those developed by hospitals or managed care organizations, are tailored more to the clinical practices of its own specific population of physicians and to the scope of their patients.¹⁵ The local context is taken into consideration, which provides a more familiar environment in which to incorporate the guidelines. But it has also been shown that guidelines stemming from a managed care organization are less likely to be well-received by physicians and patients because of their perceived over-arching interest in controlling health care costs by limiting treatment.^{2,18} This negative perception can be avoided if it can be shown that the guidelines are a good reflection of national standards.

While the roles of the various disseminating groups may differ, each group works within a common framework similar to the one employed by the AHCPR. Established in 1989 by Congress, AHCPR was created to enhance the quality and effectiveness of health care services and access to such services. AHCPR carries out its mission through broad-based health services research; assessment of health care technologies; facilitation of development of clinical practice guidelines; performance measures and standards of quality; and dissemination of research findings and clinical guidelines.³ AHCPR's dissemination framework defines the audiences to be reached and describes the various audience-specific guidelines products that can be created to disseminate the guidelines' information.⁵ Dissemination is targeted to six major groups: ⁵

Patients and the groups that represent and/or educate them

Health care practitioners: medical, specialty, and other allied health professional associations or groups, and public health education networks

Policy makers: federal, and local legislators

The health care industry: provider organizations (e.g. hospitals, clinics); group practices (e.g. HMO's, PPO's); third-party payers (e.g. insurers); pharmaceutical manufacturers; federal health care systems (e.g. PHS, DOD, Veterans Affairs); quality assurance and utilization review groups and organizations

Researchers: biomedical, clinical, nursing, and medical researchers; health services researchers and institutions

The press: printed and/or electronic media groups

These six different groups, in turn, help to disseminate guideline information further within their organizations and to the constituencies in which they are part of or serve. The literature also discusses themes surrounding dissemination to physicians, including:

The credibility of the product is crucial to its adoption: a precondition for physician acceptance of practice guidelines in general is the confidence physicians have in the usefulness of particular guidelines. Acceptance depends on whether physicians feel they can trust the process by which the guidelines were developed and the quality of the information used in establishing the guidelines' content.

Use of opinion leaders: using respected individuals in the field (either at the national or local levels) to endorse the practice guidelines through group and/or individual consultation (e.g., seminars, conferences, or peer discussion).

Clarity: most physicians prefer concise, easy to read guidelines that use few ambiguous terms.

Physicians rely on different sources for information so no one mode of dissemination can be considered optimal. Therefore, a combination of dissemination strategies should be used.

- Dissemination alone does not guarantee the use of information: changes in physician behavior are more likely to take place if guidelines are developed by an institution with which the physician has a direct relationship, if they are disseminated through an educational intervention, and if they are implemented through administrative systems that provide physicians with automatic reminders at the time of patient consultation.
- Time is a physician's most important resource: the impact of any dissemination strategy will depend on how long it takes to pass on the information.^{3,8,16}

Information can be transferred in a variety of ways. Traditional dissemination strategies include: direct mail; publication in scientific and general health journals and the general media, continuing medical education classes/programs (CME), professional conferences or newsletters, and electronic databases (e.g., NLM).¹⁶ Studies of these strategies, however, show mixed results.¹² For example,

CME programs, when used by themselves, do not seem to be effective in changing a clinician's behavior, though they might increase awareness of the issues.^{19,20} Browner et al. studied the effects of CME on compliance with the recommendations of the National Cholesterol Education Program Expert Panel (NCEPEP) on high serum cholesterol levels in adults. Primary care physicians in 174 practices either underwent standard or intensive CME. After 18 months, 13,099 medical records from 140 practices were audited. The data showed that there was no significant difference between the two physician groups in compliance with the guidelines or in screening for high serum cholesterol.²¹ Likewise, mass mailings of guidelines or their publication in professional journals without accompanied efforts to encourage feedback or discussion have generally failed or were less effective in changing physician behavior.²² For instance, in a 1989 British study, Fowler et al. mailed guidelines on smoking cessation counseling to all general practitioners in the British Medical Association. Of the 3,420 respondents, 51 percent reported having received the mailing, 28 percent reported having read it, and only 9 percent were able to name one of the three practices promoted by the guidelines.²³ Thus, there is an obvious need for more aggressive strategies or for combining existing strategies.

More recent strategies include interactive computer-based medical/health systems (i.e., medical informatics systems) and the use of the internet. Medical informatics is a rapidly growing field that continues to find innovative ways to record and organize patient data, to interact with existing medical and/or health informational systems, and to disseminate and incorporate new medical information as it becomes available. With the increasing use of electronic medical records, computer-based decision support systems, the Internet, and other types of medical information-interactive programs²⁴, medical informatics can be used to disseminate and integrate clinical practice guidelines into the process of health care delivery. The Internet, for example, can serve as a means for professional groups, government agencies, community/patient organizations, and research institutions to inform their constituencies of new practice guidelines by posting them on their Web sites. In addition, these various groups can offer their advice, opinions, and explanations of the guidelines. The AHCPR and the American Medical Association (AMA), for example, have many published medical practice guidelines available on their websites and can be accessed readily. The advantages of using the Internet as a means for dissemination are that guideline information can be transmitted more quickly than traditional means (e.g., mass mailings or publication in journals); the information can be accessed repeatedly; and disseminating groups can suggest or link their viewers to other sources for guideline information.

Guidelines also need to be packaged in different ways for different audiences. For example, academic clinicians or researchers may find it adequate to read about published practice guidelines in respected medical journals, while some physicians might find it more useful to carry reminder cards or use stickers in patient records.²⁵ When disseminating a new set of guidelines, the AHCPR packages information in different formats for particular target audiences.¹³ Practitioners receive both a detailed version of the practice guidelines, which includes specific statements and recommendations, algorithms, evidence tables, references, and an abbreviated version for day-to-day use. Patients receive a version of the guidelines that has easy-to-understand terms and statements, which describe symptoms, treatment options, benefits, and risks. This version also suggests questions patients can ask their physicians. A third version contains all background and supporting materials for the practice guidelines, including a summary of the scientific evidence, literature review, methodology, and bibliography; it is available to any researcher, clinician, educator, or others.

Implementation

The success of clinical practice guidelines depends not only on their proper development and dissemination, but also on their widespread application in routine medical practice.²² Previous research has shown that about only 60 percent of physicians are aware of national guidelines one year after their release.^{26,27} A 1990 prevention study assessed screening rates for various types of cancer, including prostate, breast, and colorectal cancers. Researchers compared the performance rates of 52 physicians with guideline recommendations made from the American Cancer Society, the NCI, and the U.S. Preventive Services Task Force. Data pulled from medical record reviews of 525 patients showed that actual physician performance rates were much lower than self-reported rates. Actual performance rates varied between 0.3 percent (sigmoidoscopy) and 39 percent (breast examinations).²⁸ This evidence demonstrates that dissemination does not guarantee acceptance, and acceptance does not guarantee use.⁵ Therefore, for guidelines to be effective in standardizing the care for specific medical problems, guideline dissemination efforts should go beyond the basic diffusion of information and help clinicians assimilate and adopt the information into their clinical practices.

The process of guideline implementation includes incorporating the guidelines into the local context; transforming the guidelines into a workable operating system; setting up a system for monitoring and evaluating the designed process; and giving feedback on the experience to the guideline

developers.³ The implementation process is also affected by certain attributes of the guidelines themselves. Consideration should be given to the degree to which the guidelines are perceived as being too complex or difficult to understand and use by the adopting group; the compatibility of the guidelines with an organization's prevailing structure (this includes the degree to which the organization formalizes decision-making processes, as well as its existing levels of communication, coordination, and availability of resources — all these elements can influence how a particular guideline moves through the steps of the implementation process); and the relative advantage or the degree to which guidelines are perceived as being better or worse than the ideas that preceded them.²⁹

Most current development processes do not treat the implementation of guidelines as an integral part of the development procedure.⁶ Incomplete or flawed implementation eventually undermines the value of guideline development and prevents attainment of its goals.²² It is particularly important to address issues of guideline implementation in light of pervasive evidence that the mere development and dissemination of guidelines rarely leads directly to changes in medical practice.²² A 1989 study by Lomas et al. examined the effect of nationally-endorsed guidelines recommending decreases in the use of cesarean sections. The study investigated physician characteristics such as awareness, attitude, knowledge of new guidelines, and physician self-reports on guideline effects on clinical practice. The study concluded that physicians' self-reports indicated a change in practice behaviors, but that data from *actual practice* showed that two years after dissemination of practice guidelines on cesarean sections, physicians' behavior had changed very little; most obstetricians were not, in fact, moving rapidly toward implementation of the recommendations stated in the practice guidelines.³⁰

Every set of guidelines will have specific implementation barriers. Some of these barriers are related to the characteristics of the guidelines themselves and the way in which they are disseminated. Other barriers are related to personal characteristics of physicians and patients^{31,32} including attitudes and beliefs toward practice guidelines, professional background and experience.⁹ A study conducted by James et al.³³ surveyed a group of family physicians' attitudes about the use of clinical practice guidelines. Of the 419 who responded to the survey, 43 percent agreed that practice guidelines challenged physician autonomy, 29 percent viewed guidelines as oversimplified or "cookbook medicine," 30percent found guidelines to be too rigid to apply to individual patients, and 60percent believed that guidelines would likely be used to reimburse physicians. This evidence demonstrates that a careful analysis of personal characteristics should be considered when designing

implementation strategies.⁶ If guidelines are to be fully effective, it is important at the outset to identify the barriers to implementation and initiate constructive strategies for guideline integration.

Implementation strategies should have an impact at four levels: 1) increasing knowledge and awareness of the guidelines; 2) changing attitudes, such that clinicians and patients agree with and accept the recommendations as a better standard of care; 3) changing behavior, such that clinicians change their clinical practice to conform with the guidelines; and 4) changing outcomes, by improving patient health and quality of care.⁴

Changing clinicians' attitudes and practice behavior, in particular, has proven to be one of the most challenging tasks in the incorporation of guidelines into care. Their reluctance to adopt guideline practices has been a consistent finding in the literature⁸ and has been attributed to:

Physicians' fear of loss of autonomy and patient choice

Their distrust in the disseminating body as a credible source

Lack of professional support (e.g. no CME)³⁰

Incomplete information concerning the need for guidelines, or as an unnecessary and/or inappropriate substitute for clinical judgment.²²

Similar to the study conducted by James et al., Tunis and colleagues surveyed 2,513 American College of Physicians (ACP) internists on general attitudes about clinical practice guidelines and about the impact that guidelines have on practice. Of the 1,513 who responded, one-fourth agreed that guidelines are "oversimplified," "too rigid to apply to individual patients," and a "challenge to physician autonomy." In addition, asked about how guidelines affect their practice, 60 percent said that guidelines have had some influence on their decision-making; 16 percent said that guidelines have had a major effect (less than the percentage for colleagues, CME, or textbooks); and 18 percent of internists said that their practice had changed during the past year as the result of a guideline.¹⁸ In addition, differences in medical consultation, clinical experience, and information exchange among patients and peers or colleagues may affect the way in which guideline information is incorporated into care.³⁴ Such factors and how they impact the implementation of guidelines need to be considered when designing appropriate implementation strategies.

When one considers the complex influence of attitudes, norms, beliefs, experience, and practice on physician behavior, the need for specific and innovative implementation strategies becomes evident.

Lessons from other disciplines show us that we can learn from work done in the social sciences and sales and marketing fields about factors that influence human behavioral changes.⁹ Pharmaceutical marketing research, for example, shows us that “academic detailing” has been successful in changing physician behavior. Academic detailing entails an understanding of the social influence perspective, which state that the behavior of one person has the effect or intention of changing how another person behaves, feels, or thinks about something. This approach focuses on physician behavioral change through “peer counseling”; the use of opinion leaders to provide one-on-one consultation with peers. It incorporates the use of a combination of educational visits and information transfer within the context of a well-planned marketing strategy. Important techniques include:

- Investigating baseline knowledge and motivation for current clinical behavior
- Defining clear educational and behavioral objectives
- Establishing credibility
- Providing authoritative and unbiased sources of information, presenting both sides of the issues that exist with the new information
- Stimulating doctor participation in the education process
- Using concise and graphic educational materials that highlight and repeat essential messages
- Providing positive reinforcement of improved practices in follow-up visits

This strategy is successful when the educators are known and respected by the target group. It also provides a greater likelihood of behavioral change than information transfer alone and is likely to have its greatest impact early in the implementation process. The effectiveness of this strategy is well documented in a large body of marketing research and experience^{35,36} and has been evaluated in several empirical trials, which have found significant improvements in prescribing practices following the use of academic detailing strategies.²² A 3-year study conducted by Avorn and Soumerai et al. investigated the effects of face-to-face education of practicing physicians on their drug prescription behavior. Based on previous findings that less than optimal prescription decisions by physicians was common, the authors implemented academic-based detailing methods to help reduce the excessive use of three particular drugs. Participating physicians were divided into three groups: a control group with no intervention; a printed-materials-only group that received drug prescription information; and the third, a face-to-face group which received the exact same printed materials as the second group from trained pharmaceutical educators (six were clinical pharmacists with a Pharm.D. degree, one was a pharmacologist). Results from their study showed that physicians who were offered personal educational visits by the educators along with a series of

mailed “unadvertisements” reduced their prescribing of the target drugs by 14 percent as compared with the control group. Moreover, the positive effect persisted for at least 9 months after the start of the intervention, and no significant increase in the use of the substitute drugs was found. In contrast, those physicians who received only mailings did not show any significant changes in their behavior. The authors concluded that academically based detailing may represent a useful way to improve the quality of drug-therapy decisions and reduce unnecessary expenditures.³⁵

Additionally, guidelines will be effective only if they reach into the local communities. Local opinion leaders have been found to play a key role in shaping local consensus regarding new technologies and thereby encouraging or blocking new behavior. This reinforces the view that while doctors are members of a national or international medical culture, they function largely through their participation in smaller local subgroups.³⁷

A second strategy involves integrating guideline usage into the ongoing activities of clinical practice and into the ongoing process improvement activities of the institution. Here, strategies should not only focus on the physician/clinician, but also on the organization as the unit of analysis and intervention. Effective guideline implementation requires that guideline adoption be integrated with broader efforts to measure and improve organizational performance.³ Barriers to guideline implementation may be related to the capabilities of the delivery system and the overall practice environment.³⁸ These barriers can arise from multiple factors including: inadequate communication of the guideline, inadequate support systems to enable clinicians to recall guideline details at the appropriate time, inadequate support systems to enable the clinician to carry out the recommendations, and disagreement with the recommendations.³⁹ Some approaches to address these potential barriers include: administrative support systems, such as one that notifies physicians of new information and automatically provides clinicians with follow-up letters to send to their patients; computerized training programs to instruct physicians on the use of such systems; and administrative changes that encourage clinicians to follow guideline recommendations, such as providing revised clinical materials (e.g., laboratory test order forms or an updated drug list) that reflect the new guideline information.³⁹

Factoring the patient into the practice setting is also important. Patient-based assessments must be built into the guidelines supporting the information it contains. Patient-centered approaches, including educating patients about the effectiveness of interventions, the probabilities of different outcomes of treatment and their potential impact on quality of life, can help change the behavior of

physicians and influence the treatment they choose.¹² Furthermore, training medical students on how to use guidelines can help to influence future clinical behavior. Students will need to develop critical appraisal skills and learn how to integrate personal experience with changing information. Medical training and apprenticeship programs (including residency and fellowship training) can also provide a unique and valuable opportunity to influence health providers' behavior. This training period entails an intensive transfer of assumptions, beliefs, values, and norms from the senior clinician to the trainee and is intended to impart critical skills in independent thinking and analysis. However, trainees can pick up subtle cues and learn ingrained habits from their mentors, who may impart their fundamental beliefs and assumptions underlying their practices.²²

As with dissemination, computer technology is also facilitating more efficient implementation of guidelines. Interactive computer systems have made it easier to supply, store, and transmit advanced knowledge to individual doctors and providers.¹⁵ The growth of computerized storage and retrieval systems, rapid advances in technology (e.g., CD-ROM, laser disks), and the development of computerized decision-making or decision-support systems present major opportunities for dissemination and implementation strategies for present and future sets of practice guidelines.^{5,24} They can assist in the implementation of guidelines by packaging practice guidelines in various forms. These include text documents, clinical algorithms, and tailored interactive forms.¹⁶ Lobach and Hammond (1997), demonstrated how a computerized clinical practice guideline (the "Computer-Assisted Management Protocol") can be integrated into a decision-support system to assist clinicians in managing diabetic patients. In a 6-month controlled trial at a primary care clinic, 58 primary care physicians were randomized to receive either a special encounter form with the computer-generated guideline recommendations or a standard encounter form. The effect of computer-generated advice on clinician behavior was measured as rate of compliance with guideline recommendations. Of the 58 physicians, 30 were analyzed and results showed that the availability of patient management recommendations generated by the decision-support system were followed by a two-fold increase in clinician compliance with the guidelines for diabetes mellitus.²⁴

Safran and colleagues⁴⁰⁻⁴² studied the effects of the introduction of a computer-based patient record on the dissemination and implementation of locally-developed clinical practice guidelines for the care of patients with HIV. These practice guidelines were similar to those developed by the NIH's national consensus panel at the time of introduction. Safran et al. developed an interactive knowledge-based electronic patient record that integrated rule-based decision support and full-text information retrieval with an online patient record. The computer workstation allowed a physician

to use online information resources and fully electronic patient records during all patient encounters. The resulting database was continually updated with outcome data on patients with HIV. The system also contained statistical methods to measure the effects of electronic alerts (computer messages that informed the clinician about an important clinical event concerning the patient, such as low CD4 count) and reminders (computer messages that appeared only when the clinician looked at the patient's record online, usually to remind the clinician of scheduled laboratory tests or vaccinations). The system also allowed clinicians to 1) retrieve the results of diagnostic studies; 2) search the medical literature; 3) obtain advice and consultation; 4) keep problem lists, medication lists, screening and flow sheets, and progress notes online; and 5) order appropriate diagnostic tests or procedures online. There was no transcription from paper forms, and data entry was shared among clinicians and other staff members.

Data from Safran et al. showed that the presentation of alerts and reminders as part of the computer-based patient record resulted in significantly faster and more complete adoption of practice guidelines by the group of physicians treating patients with HIV. Significant differences were seen in response times to clinical events, scheduled activities, and the initiation of appropriate therapies, resulting in fewer hospital admissions. For example, response times to 303 alerts in the intervention group and 388 alerts in the control group were 11 and 52 days, respectively. The median response time to 432 reminders in the intervention group was 114 days compared to 500 days for 360 reminders in the control group. Additionally, various online resources (e.g. *AIDS Clinical Care*, *Drug Information*, *HIV ProtoCall*, *American Foundation Directory*) were frequently used when examining the patient's electronic record prior to the patient's appointment that same day or at other viewing times. Researchers from this study concluded that an interactive system that included both a patient database and a knowledge database provided a viable means to integrate different types of information (e.g., guideline recommendations, references, abstracts from medical literature, community resource information, drug information, and research protocols) about the care of HIV-infected patients at the point of individual care.

Safran's study provides an excellent example of the potential for computer-based systems to assist in the dissemination and implementation of clinical practice guidelines. For these potentials to be realized, however, the use of computerized systems will have to contend with the likely behavioral and learning obstacles that may exist among clinicians and decision-makers with the use of computer technology.⁵

Dissemination to Patients

Clinical practice guidelines are developed for patients and physicians. The understanding and cooperation of patients in health care is of increasing importance. With the HIV practice guidelines, the need to reach patients as a target audience is essential for appropriate decision-making about when to begin treatment, which combinations to use, and to assist in efforts to adhere to treatment. Developers of guideline dissemination and implementation strategies need to take into consideration how guideline information is presented to patients, how complex the information is, and the format or context in which this information is passed on. Just as physicians differ in how they become aware of, assimilate, and adopt new medical information, patients also differ in the ways they seek, receive, and process the same information. It is essential, therefore, to look into patient factors such as attitudes, beliefs, motivations, level of knowledge and comprehension, cultural background, access to health information, and use of available informational resources to better understand how these factors influence guideline implementation in the patient population. Understanding how these characteristics affect patient behavior will consequently help in designing appropriate strategies and interventions, which can help sustain desired behavioral changes.

Clinicians usually present treatment information to patients at the point of consultation. Several studies have demonstrated that events which occur within the patient-physician interaction can affect how patients make decisions about their care.⁴³ Factors of this interaction include the provider's: language, extent of information exchange, sensitivity, continuity of care, genuine interest, respect, and consultation style. For example, treatment information presented by a physician who uses forceful or condescending language in a 10-minute visit may intimidate the patient and prevent him or her from asking questions and following the treatment regimen. In addition, the physician should remember to repeat important messages and use concise, specific, and organized statements with less technical words; patient recall averages about 50 percent and is often difficult when extensive and complex information is given within the first 5 minutes of consultation.⁴⁴ The physician must also take into account a patient's level of knowledge or comprehension to help educate the patient of his or her treatment options. Cultural barriers, such as language differences, beliefs, or attitudes, may prevent the patient from understanding or accepting what is being said to

them. It is, therefore, critical for the physician to establish trust at the onset of the consultation and express personal interest, sensitivity, and respect for the patient.^{45,46}

Patient access to practice guidelines and other health information and how they utilize this knowledge can also affect the way in which guideline information is incorporated into individual care.¹² The broad availability of resources for health information (e.g. online health resources, treatment education programs, national clearinghouses) gives patients extensive access to guideline information. Providing patients with more information about treatment options and the probabilities of different outcomes associated with these options, as well as their potential impact on their quality of life, may influence the treatment course patients choose, thus influencing the manner in which their physicians will care for them.¹² A study by Manfredi looked at cancer patients' information-seeking behavior, how their behavior affected their interaction with their doctors and their health care decisions. The researchers found that approximately 50 percent of study participants sought treatment-related information from the NIH's Cancer Information Service (CIS), and of this group, approximately 42 percent discussed the CIS information with their physicians. In addition, the researchers found that the most common patient information needs were for exploring all treatment options and being knowledgeable when discussing treatment plans with their physicians.¹⁴ This study highlights the increased role of patients in the management of their care, as well as the impact the availability of health information can have on their interaction with their physicians.

In response to increased patient participation in the decision-making process and interest for current information, the medical and health communities have developed various types of materials to make the information more understandable. This information is usually provided in formats that are easy to follow. For example, AHCPR provides practice guidelines in a "consumer version," one in which information is written in non-technical language (in both Spanish and English) and provides patients with the appropriate information to discuss with their physicians.⁵ In addition, several community and patient advocacy groups have translated complicated medical information and created various educational materials that are easy to understand and that have also been tailored to meet the needs of patients with varying cultural and/or educational backgrounds. Hence, patients can learn what treatment options are available to them, as well as the benefits, side effects, and responsibilities associated with such options.

To date, there is not any one ideal strategy or intervention that exists for complete implementation of clinical practice guidelines. It is likely that a combination of methods is necessary due to the

diversity of practice environments and behaviors.⁶ Implementation strategies need to be treated as an integral part of the development process if practice guidelines are to achieve their fullest potential in changing clinical practice.

Questions still persist on whether practice guidelines reduce inappropriateness in clinical practice, and on whether their impact on patient care results in better patient outcomes.^{3,4} In addition, many practitioners remain skeptical as to whether guidelines can achieve any clinically significant change in physician behavior.⁶ The idea of “cookbook medicine” remains a concern among physicians who believe that clinical practice guidelines may actually decrease their clinical autonomy, thus decreasing individualization of care^{4,7} and may establish medical practice too firmly and inhibit research and innovation.⁷ But while some variations in medical practice are expected, significant and/or unexplained differences in practice raise the concern that some patients are not treated effectively or appropriately and that the health dollars of patients, employers, and third-party payers are wasted.³ Moreover, patients should have the security of knowing that whatever doctor they consult, he or she will provide them with a certain minimum standard of cost-effective care.⁴⁷ Thus, the goal for any physician will be to balance clinical freedom and responsibility. Guidelines can assist them in this effort, where the idea is to manage clinical practices, not physicians.²⁹

Evaluation

The fourth stage of the clinical practice guideline process is evaluation. Without an evaluation component, it is impossible to know if the guideline is being utilized and what effects it is having on patients and on health care delivery. There are three areas of evaluation: 1) dissemination evaluation (did the information reach the targeted audiences?); 2) implementation evaluation (did the target populations change their prior practices and utilize the information from the guidelines?); and 3) outcomes evaluation (did integration of the guideline recommendations have a positive effect on patient outcomes and health care utilization?).

Despite the proliferation of practice guidelines and the enthusiasm which they are promoted, guidelines are rarely systematically evaluated.⁴⁸ Guidelines should be treated like any other form of health technology in need of assessment. Scientific trials of practice guidelines should be encouraged to include an audit of both process outcomes and patient outcomes.^{7,48} Although there is universal agreement that improved health outcomes are the ultimate measure of guideline success, the other areas of evaluation (i.e. dissemination and implementation) are equally important in

determining the success of intermediate or process outcomes. These include: increased awareness of guidelines by the target audiences; changes in physician behavior, and/or a reduction in practice variations.⁴ Multiple evaluations looking at each stage of the guideline process will determine the overall effectiveness of the guidelines.

The value of dissemination evaluation is illustrated by Gorton et al., who examined the effect of three methods used to disseminate nationally-developed asthma guidelines on physicians' behavior and attitudes toward different educational strategies in Area Health Education Centers (AHECs) in Arkansas. Mailed questionnaires were used to collect information before and after the 4-month intervention on the adoption of guideline recommendations. The interventions included a general mailing of the asthma guidelines to all 60 participating physicians and separate combinations of interventions at three different sites: Site A featured a short summary of the guidelines, "detailing" phone calls from peer physicians, and a CME conference; Site B utilized computer strategies and a multimedia approach with facsimile messages, posters, and audiovisual materials; Site C used only a CME conference. A fourth site served as a comparison. In addition, data was collected from outpatient chart reviews and physician interviews. Of the 60 physicians, about 79 percent read the written material that was mailed, sent by facsimile, or presented as posters or participated in telephone conversations. At Site B, 72 percent attended the computer workshop; less than 50 percent of the physicians at Sites A and C attended the CME conference; and only 27 percent of physicians at Site C and 38 percent of those at Site A used the audiovisual materials. Moreover, the researchers found that while each site improved in the use of asthma medication use and peak flow monitoring, none of the sites improved in all areas of asthma care. This study demonstrates the usefulness of evaluating dissemination and implementation strategies; results from this study provided valuable information on intermediate outcomes, such as physician awareness of the practice guidelines and the effects of intervention strategies on guideline implementation.¹⁹

A review of 102 trials of interventions to improve medical practice in Canada found that dissemination-only strategies, such as conferences or mailing of unsolicited materials, produced little or no change in medical practice. Whereas more complex interventions, such as the use of outreach visits or local opinion leaders, sometimes produced moderate reductions in inappropriate measures.⁴⁹ This study illustrates the need for implementation strategies beyond information dissemination and shows that even where such strategies are utilized, the effect on care is limited.

Evaluating the effectiveness of practice guidelines on health care utilization and patient outcomes is also essential. Unfortunately, rigorous investigations of guideline effects on patient outcomes are still lacking.^{6,7,48,50} Worrall et al. reviewed evaluations of clinical practice guidelines to assess whether guidelines improve patient outcomes in primary care. From their search, the researchers identified 91 evaluations of clinical practice guidelines. Of these, 56 were studies of preventive or investigative guidelines and were eliminated from the analysis. Of the remaining 35 studies, only 13 reported data on patient outcomes, of which only 5 showed statistically significant improvements. However, the studies did provide useful data on process outcomes. For example, in their search, Worrall and colleagues found that guidelines resulted in more complete recording of antenatal care, in more appropriate referral of infertile couples to specialist care; and that the rate of inappropriate radiological referrals was reduced. Worrall states that such results are promising if it is assumed that improvements in the process of care will eventually result in improved patient outcomes, something that can only be confirmed through further research.⁵⁰ In addition, a meta-analysis by Grimshaw et al, of 59 published evaluations of clinical practice guidelines, found that only 11 of the studies examined the impact of guideline use on patient outcomes.⁵¹ *

The use of performance measures has become an essential component of guideline evaluation. Performance measures are defined by AHCPR as “methods or instruments to estimate or monitor the extent to which the actions of health care practitioner or provider conform to the clinical practice guideline.”⁵² For example, if a guideline recommends that pain should be assessed and documented routinely at regular intervals postoperatively, as determined by the operation and the severity of pain (e.g., 2 hours while awake for 24 hours after surgery), then a performance measure would be calculating the number of patients whose pain was assessed and documented every 2 hours while awake out of the total number of surgical cases.⁵²

Most important, the incorporation of a performance measure in and of itself has been shown to effect guideline implementation. Harr et al. studied the development of quality indicators as educational tools to measure the implementation of clinical practice guidelines. Using AHCPR guidelines for treatment of depression, Harr and colleagues surveyed a sample of primary care physicians, medical directors and benefits managers to: 1) evaluate expectations and preferences in measuring quality-based clinical practice guidelines, and 2) to evaluate eight quality indicators using the guidelines on treatment of depression. The majority of participants reported that they want no

* The Forum for Collaborative HIV Research will conduct a process to develop a research agenda in HIV-

more than nine quality indicators in a given situation, that quality indicators should be able measure both the process and outcome of care, and that they must provide effective measurement tools that can monitor compliance with established and widely accepted clinical guidelines. Indicators that were measured included: risk factors for progressing disease (in this case suicide), medication prescription, and follow-up treatment. The participants agreed that that quality indicators were valuable educational tools that can be used to improve the quality of health care.⁵³

Ullman et al. compare the effect of an externally driven “report card” methodology with the use of a provider-initiated performance measurement that monitors both processes and outcomes of care coupled with the use of clinical practice guidelines. While they found significant limitations in the use of report cards, the complementary approach of combining “instrument panels” (i.e. performance measures) and clinical guidelines within an overall continuous quality improvement framework appears to have resulted in improved clinical outcomes and reduced costs.⁵⁴ Thus, performance measurements can be built into the guidelines to facilitate the collection and analysis of the relevant data, which can ultimately help evaluators track the adoption of the guidelines into clinical practice, and thus, make appropriate suggestions for improvement.³⁹

Moreover, interactive computer systems used to facilitate the integration of practice guidelines also allow the facilitation of evaluation, audit, and feedback.⁶ Existing software packages make it easier for data (e.g. performance measurements) to be entered and retrieved, and also help to ensure the accuracy of the data. Thus, evaluation of guidelines can take place more rapidly and efficiently. As described earlier, Safran and colleagues and Lobach and Hammond demonstrated that through the use of an interactive computer-based patient record system, dissemination and implementation of practice guidelines could be achieved successfully. In addition, computerization makes evaluation of these methods more efficient. Other examples of guideline evaluation activities include:¹³

- Conducting peer and pilot reviews of drafts of the guidelines
- Analyzing cost of using the recommended health care interventions and procedures
- Monitoring receipt and awareness of guidelines
- Examining the effectiveness of different modes of dissemination
- Conducting targeted evaluation of specific guidelines in a variety of practice settings
- Assessing the long-term effects of guidelines through analysis of longitudinal data sets
- Supporting investigator-initiated research on guideline evaluation

related patient outcomes research in the Fall, 1998.

It is important to realize that the incorporation of clinical practice guidelines into care is an ongoing process. This is particularly true of the HIV clinical practice guidelines, which are very much a work in progress that change rapidly. In developing strategies for dissemination, implementation and evaluation, a combination of approaches will most likely be best to take into account the differing needs of various target audiences. Overall, the literature is clear that without clear-cut, well-defined strategies for dissemination and implementation, clinical practice guidelines, and the advances in clinical research that they represent, can not be effectively integrated into health care delivery. The ramifications of failing to properly implement the HIV clinical practice guidelines for the use on antiretroviral drugs are many and frightening. The successful transfer of these remarkable developments in HIV clinical research and drug development is as important as the discovery of the drugs themselves.

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FCHR Project on the Dissemination and Evaluation of the HIV Clinical Practice Guidelines

**Holiday Inn Downtown
1155 14th Street NW
Washington, DC**

May 11 - 12, 1998

Meeting Agenda

Monday, May 11th

9:00 - 9:30: Continental breakfast

9:30 - 10:00: Welcome and Introductions -

David Barr, J.D. - Director
Forum for Collaborative HIV Research

Sophia W. Chang, M.D., M.P.H. - Director of HIV/AIDS Programs
Henry J. Kaiser Family Foundation

**10:00 - 10:45: Overview of the Guidelines for the Use of Antiretroviral Agents in HIV-
Infected**

Adults and Adolescents, Pediatrics and during Pregnancy -

Eric P. Goosby, M.D. - Director,
HHS Office of HIV/AIDS Policy

Lynne Mofenson, M.D. - Associate Branch Chief for Clinical Research
National Institute of Child Health and Human Development

10:45 - 11:15: The Need for Dissemination of the HIV Clinical Practice Guidelines -

Charles van der Horst, M.D. - Associate Professor of Medicine
Department of Medicine - University of North Carolina, Chapel Hill

11:15 - 11:30: Break

11:30 - 12:00: Community Patterns of Care for HIV Disease

Carol Brosgart, M.D. - Medical Director
East Bay AIDS Center

12:00 - 12:30 : Patient Comprehension and Retention of Medical Information -

Seth Kalishman, Ph.D. - Associate Professor of Medicine
Center for AIDS Intervention Research - University of Wisconsin

12:30 - 1:30: Lunch

1:30 - 2:15: Target Audiences: Identification and Needs Assessment

Health care providers: Linda Frank, R.N., Ph.D. - Director
Pennsylvania AIDS Education Training Center
Graduate School of Public Health - Univ. of Pittsburgh

Patients: Billy Pick - Minority Initiatives Counselor
San Francisco Department of Public Health

Service Providers: Moises Agosto - Director of Treatment Advocacy
National Minority AIDS Council

Health care plans: John Ludden, M.D. - Senior Vice-President
Harvard Pilgrim Health Care

2:15 - 3:15: Current HIV Treatment Information Dissemination Efforts

Federal Government: Deborah Katz, R.N. - Director
Office of Program Operations & Scientific
Information National Institute of Allergies and
Infectious Disease

Government: Bruce Agins, M.D., M.P.H. - Medical Director
New York AIDS Institute

Community Organizations: Pablo Colon - Director,
Dept. of Treatment Education & Advocacy
Gay Mens' Health Crisis

Professional Associations: John Henning, Ph.D. - Director, Dept. of STD/HIV
American Medical Association

Pharmaceutical Industry: Martin Mattingly, Pharm.D.
Director of Marketing
Agouron Pharmaceuticals

3:15 - 3:30: Break

3:30 - 4:15: Evaluation of Clinical Practice Guideline Dissemination

Steven Asch, M.D., M.P.H. - Resident Consultant
RAND Corporation

Leonna Markson, ScD. - Director - Outcomes Research & Management
Merck and Co.

4:15 - 5:30: Current Research Findings

Meeting participants will present findings from current research

5:30 - 6:30: Reception

Tuesday, May 12th

8:30 - 9:00: Continental breakfast

9:00 - 9:45: Challenges to Successful Dissemination

Tim Westmoreland
Federal Legislation Clinic, Georgetown Law School

Richard Jeffreys - Access Project Director
AIDS Treatment Data Network

9:45 - 10:00: Charge to Workgroups

David Barr - Forum for Collaborative HIV Research

10:00 - 10:15: Break

10:15 - 2:00: Workgroup Sessions (a working lunch will be available at 12:30)

2:00 - 3:00: Reports from Working Group/Close

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