

# **Report of a Conference Co-sponsored by the National Library of Medicine and the NIH Office of AIDS Research**

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## REFERENCES

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- (2) Bridging the Gap: A Workshop on HIV Treatment Information Dissemination, February 25-26, 1993, Washington, DC.
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## PREFACE

In an effort to survey its customers, the National Institutes of Health had decided to sponsor a conference of users of its various HIV/AIDS information services. Subsequently, President Clinton called on all Federal agencies to conduct this type of review. The conference took place at the National Library of Medicine on June 28-30, 1993. In attendance were some 200 health care providers, scientists, information specialists, journalists, and members of the HIV/AIDS community.

The purpose of the conference was to review the various HIV/AIDS information resources and services that the National Institutes of Health has instituted since the beginning of the AIDS pandemic. We began by briefly reviewing the many intense efforts to organize and disseminate AIDS information. The goals were to assess our current efforts and to identify additional needs. Based on the presentations, discussions, and resulting recommendations, the conference was a great success.

Information, whether on paper or in electronic form, is crucial in the fight against AIDS. If scientists are to uncover the secrets of the AIDS virus and to develop ways to defend against and fight it, if health care providers and patients are to work together to apply what is known, if the public is to know how to protect itself against HIV/AIDS, then we must ensure that our mechanisms for disseminating information are efficient and, most of all, effective.

This report is intended for wide circulation in the hope that it will both alert the HIV/AIDS community to the services that are presently available and, based on the recommendations contained, serve as a guide to the NIH in improving those services. We at NIH look forward to working with the HIV/AIDS community in ensuring broad dissemination of vital information.

The report is the product of much work and discussion by the invited participants. To them, and to the staff who organized the conference, go the thanks of all who are involved in fighting this disease.

Donald A. B. Lindberg, M.D. Director, National Library of Medicine

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## **EXECUTIVE SUMMARY**

The National Library of Medicine (NLM) and the Office of AIDS Research (OAR) of the National Institutes of Health (NIH) cosponsored an invitational conference on June 28-30, 1993, to examine the role of NIH in providing HIV/AIDS information. The conference brought together representatives from many of the constituencies involved in the AIDS epidemic to discuss their information needs and expectations from NIH and to elicit from them specific observations and recommendations for improvements. The conference was structured around five groups of information users; the following briefly summarizes the major points of their discussions.

CLINICAL RESEARCHERS are faced with the need both to disseminate the results of their research quickly and to, themselves, obtain the information required to carry out their research. In addition to the need to release research findings immediately, it is also important that these data be interpreted for those who will use them. A variety of dissemination mechanisms were discussed. RECOMMENDATIONS 1.1 and 1.2 concern the timely and effective release of information from clinical trials.

Some clinical researchers are part of networks that conduct research in a coordinated way. Members of these networks or groups regularly exchange information informally and formally at group meetings. However, those who are not members of these groups, or who do not attend their meetings, are denied valuable, and sometimes essential, information. RECOMMENDATION 1.3 calls on NIH to disseminate widely final statements and other information from such meetings.

Clinical researchers and others have access to descriptions of HIV/AIDS-related clinical trials being conducted in the United States through such resources as the AIDSTRIALS database on the NLM MEDLARS computer system and via the AIDS Clinical Trials Information Service (1-800-TRIALS-A). However, there is additional information that would benefit this group. RECOMMENDATIONS 1.4 and 1.5 are to expand the scope of

information in AIDSTRIALS, including the addition of information about non-U.S. clinical trials.

Clinical researchers, like most other groups using information resources, obtain their information in many ways. Therefore, it is important that many different avenues be used to provide it. Clinical researchers could benefit greatly by taking advantage of advanced technologies for communication, collaboration, and research. RECOMMENDATIONS 1.6, 1.7, 1.8, and 1.9 deal with alternative methods of information dissemination and how NIH can encourage and support the use of electronic information resources.

MEDICAL, DENTAL, AND NURSING PROVIDERS have information needs significantly different from those of clinical researchers. In analyzing their needs, it is apparent that physicians, dentists, and nurses each have developed their own preferred routes for obtaining information. All rely to some extent on colleagues, and RECOMMENDATIONS 2.1 and 2.2 encourage NIH to foster existing practitioner-to-practitioner pathways and to support conferences and workshops that encourage this information exchange.

Busy practices limit the time health care practitioners can devote to keeping up with new research reported in the literature, analyzing the results, and determining how this affects the treatment plans for their patients. Some practitioners may not have the expertise to do this type of synthesis for HIV/AIDS. Thus, it is important that analyzed, synthesized, and integrated information be available to support optimal patient care. RECOMMENDATION 2.3 calls on NIH to apply electronic technology to creating and distributing summative HIV/AIDS information.

One reason electronic information resources are underutilized by health care providers is the level of expertise required for accessing them. RECOMMENDATION 2.4 is that NIH develop user-friendly electronic information systems and provide training and affordable access.

Often training, educational, and outreach programs are established by a single agency to serve one need. In many cases these programs can be expanded to serve multiple purposes. RECOMMENDATIONS 2.5 and 2.6 call on NIH to work with other organizations to do this, tailoring training programs to specific care settings for physicians, dentists, nurses, and other health care workers.

Health care providers in isolated settings, such as those in rural areas and on Native American reservations, find it especially difficult to obtain up-to-date HIV/AIDS information. They lack ready access to colleagues and institutions that could provide them with information. Identifying and serving such health care providers is the subject of RECOMMENDATION 2.7.

Health care providers need information about the results of clinical trials both quickly and with sufficient detail to evaluate the information. A press release suitable for use by the popular press and the general public does not give physicians and other health care

providers the details they need to determine what modifications are needed in the care regimens of their patients. RECOMMENDATION 2.8 concerns the release of information about clinical trials sufficient to allow health care providers to evaluate its applicability to their patients.

Traditionally, the peer-review function for medical information is fulfilled through publication in medical journals. This process can sometimes take more than a year, and may be much too slow for such a rapidly moving field as HIV/AIDS. Press releases and other types of releases without peer review may not benefit either the health care provider or the patient. RECOMMENDATION 2.9 calls on NIH to convene expert panels for rapid peer review and release of clinical trial results, when such expedited handling is warranted.

"Clinical Alerts" are used by NIH to disseminate the results of clinical trials in urgent cases before formal release or publication of findings. This mechanism allows broad dissemination of clinical trials results in cases where the information can have a profound effect on health care. However, it is clear that Clinical Alerts are not reaching all who can benefit from them. RECOMMENDATIONS 2.10, 2.11, and 2.12 call on NIH to use Clinical Alerts for urgently needed HIV/AIDS information, and to ensure that they reach all health professionals.

Health care workers need guidelines to follow in caring for their patients. A concise, comprehensive manual would ensure that providers have basic patient care information no matter what the setting. Since the treatment of AIDS patients is such a rapidly changing field, guidelines must be kept up-to-date. RECOMMENDATION 2.13 calls for NIH to collaborate with CDC, the Agency for Health Care Policy and Research, and HRSA in the development and promotion of HIV/AIDS patient management guidelines for the various segments of the health care provider community.

ALLIED HEALTH CARE PROVIDERS, social workers, therapists, nutritionists, case managers, etc., often the provider with whom the patient has the most frequent and regular contact, work in varied settings, not necessarily in institutional environments where resources are readily available. RECOMMENDATION 3.1 deals with reaching out to unaffiliated allied health professionals to provide them access to information resources.

Because allied health care providers work in such diverse settings and with many different communities, their information needs are complex and varied. In addition to standard medical and nursing information, they must deal with other problems and questions from their clients, particularly cultural and behavioral issues. RECOMMENDATIONS 3.2, 3.3, and 3.4 concentrate on the importance of information emanating from NIH's support of psychosocial, substance abuse, and nontraditional therapies research.

Particular burden is placed on the allied health care provider because of the disparate nature of the information required by this group and the technical nature of that information. There is no single outstanding source of information for allied health care

workers working with the HIV/AIDS community. For these reasons, RECOMMENDATIONS 3.5, 3.6, and 3.7 call on NIH to explore new models of information access, to provide jargon-free summaries of current information, and to provide training in using electronic information resources for allied health care providers.

Allied health care providers use professional organizations and a number of other techniques to network and share information. RECOMMENDATIONS 3.8, 3.9, 3.10, and 3.11 deal with how NIH should develop partnerships with both professional and community-based organizations to disseminate information, use existing networks of religious and ethnic organizations, and support the development of access tools for the contents of informal information sources such as newsletters.

THE MEDIA is the main vehicle NIH uses to reach the public. This group has very specific information needs. RECOMMENDATION 4.1 confirms this and calls on NIH to work closely with the media at all levels to disseminate information about HIV/AIDS.

Despite the fact that the public generally receives much of its information about HIV/AIDS from the media, journalists generally do not perceive their primary function to be education. Because of the occasional lack of balance and context in stories, the public may be misled by what they read or hear. RECOMMENDATIONS 4.2, 4.3, and 4.4 call on NIH to be aggressive in rebutting misinformation, to encourage sidebar stories with background and context, and to encourage the publication of telephone numbers so readers can request further information.

Access to sources of information is important to journalists preparing their reports. NIH scientists are not always readily available to talk with the media nor are they always adept at presenting their points of view. RECOMMENDATIONS 4.5 and 4.6 are for NIH to provide training in media relations to scientists and to clarify its own policies about journalists' access to NIH scientists.

When scientists do talk with the media, the information they are trying to impart is frequently highly technical and complex. Journalists may not always be able to interpret this information accurately. To help remedy this, RECOMMENDATIONS 4.7 and 4.8 call on NIH to seek out and help writers who serve minorities and the alternative media, to have a toll-free number for journalists at all levels, and to expand the NIH radio news service.

NIH cannot continue to rely on the traditional print and electronic media as its only way of reaching the public with information. There are many other means that are available, and RECOMMENDATIONS 4.9 and 4.10 describe several other channels that NIH should explore, including library-based mechanisms.

PATIENTS AND THE AFFECTED COMMUNITY (families, friends, and advocates of those with HIV) need information to manage their care and make informed decisions. Many feel isolated from information resources. RECOMMENDATION 5.1 calls on NIH

to make information accessible where affected individuals spend time, for example, social services offices and relevant medical clinics.

In addition to information for their own decision making, patients want to feel secure that their health care providers have the latest and best information and therefore can provide the highest quality care. RECOMMENDATIONS 5.2 and 5.3 deal with getting HIV/AIDS information to health care providers and with supporting health educators who work with patients and their families.

Community-based organizations have been providing services to their communities since the early stages of this epidemic. There is a continuing need to do this and even to expand these services as new individuals and communities become involved. This is true not only for direct health and social services, but for information services also.

RECOMMENDATION 5.4 calls on NIH to help community organizations provide HIV/AIDS prevention and treatment information to patients and their families.

HIV-infected people and their advocates want information about research results and treatment options as soon as possible, but only if it is assured to be accurate. The traditional publication process for peer-reviewed data causes some concern that those who want newly developed data quickly cannot obtain it. The results of clinical trials are important to those participating in them and important to their communities as well. RECOMMENDATIONS 5.5, 5.6, and 5.7 deal with NIH disseminating both to participants and to patients at large information resulting from HIV/AIDS clinical trials and about alternative therapies.

It is particularly evident that the psychosocial aspects of HIV infection have a profound impact on persons with HIV. However, information about psychological and behavioral issues is scarce. RECOMMENDATION 5.8 calls on NIH to include more information dealing with the mental health aspects of HIV/AIDS.

There are a number of effective means for reaching different racial, cultural, ethnic, and sexual communities affected by HIV/AIDS. Community leaders and organizations can assume this role because of the high level of credibility they have within their communities. The community groups can channel information between the government and their members and can develop different means of doing this.

RECOMMENDATION 5.9 deals with how NIH can assist community groups in getting information to their constituencies.

Many community groups rely on newsletters as a main means of communicating. Some of these newsletters are valuable resources even outside their local community.

RECOMMENDATIONS 5.10 and 5.11 call on NIH to assist these newsletters and to develop an online and printed index that will make their articles more widely available.

Despite the tremendous potential of electronic information resources, many members of the affected community do not have access to them. RECOMMENDATIONS 5.12, 5.13, and 5.14 call on NIH to facilitate access by the affected community to electronic

information sources and to make NIH's electronic HIV/AIDS offerings available to this community at no cost.

One of the major barriers to the use of HIV/AIDS information by patients and the affected community is language and literacy. Furthermore, the technical terminology used to describe complex clinical research, treatment options, etc., can be difficult to understand. RECOMMENDATION 5.15 deals with how NIH can make information more readily available to such audiences.

Those who seek HIV-related information may prefer to find it on their own, without attracting attention to their HIV status. Public libraries, available in most communities, are a neutral resource, usually accessible to all. RECOMMENDATION 5.16 calls on NIH to provide brochures and other useful information to public libraries.

Many in the community are unaware of the breadth and variety of AIDS information resources available from NIH. The Guide to NIH HIV/AIDS Information Services, distributed at the conference, is a good survey of those resources. The community could benefit from this type of knowledge about NIH's services. RECOMMENDATION 5.17 calls for its wide dissemination.

There is much confusion outside the Public Health Service about the perceived lack of coordination and the duplication of efforts by the government. RECOMMENDATION 5.18 calls for NIH to work with other Federal agencies to coordinate HIV/AIDS information services.

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## **INTRODUCTION**

The AIDS pandemic is inextricably linked to everyone's ability to obtain needed information that can "make a difference." The National Library of Medicine (NLM) and the Office of AIDS Research (OAR) of the National Institutes of Health (NIH) cosponsored an invitational conference on June 28-30, 1993, to examine the role that NIH is playing in providing such information. The meeting involved broad-ranging discussions among members of the various constituent groups who need and generate HIV/AIDS information. A guide to currently available NIH HIV/AIDS information services was prepared as background material for conference participants. [See Appendix A.] In addition, exhibits displaying many of these print and electronic resources were organized for viewing and hands-on demonstration in the NLM lobby. [See Appendix B for the list of exhibitors.]

**SETTING THE STAGE.** On the afternoon of the first day, the conference was formally opened by NLM Director Donald A.B. Lindberg, M.D. OAR Director, Anthony Fauci, M.D., provided conference participants with an overview of the current status of AIDS

research and events at the recently concluded international AIDS congress in Berlin. June Osborn, M.D., Dean, University of Michigan School of Public Health, and Chair, National Commission on AIDS, gave the keynote address, which included remarks on the just-released report of the National Commission on AIDS.(1) Debra Fraser-Howze, Executive Director, Black Leadership Commission on AIDS, concluded the opening session with a brief report of a workshop convened early in 1993 that addressed the challenge of disseminating HIV/AIDS treatment information to persons in underserved communities.(2) [See Appendix C for the complete conference agenda.]

**CONFERENCE OBJECTIVES.** As identified by the Planning Committee [see Appendix D for a listing of members], the major objectives of the NIH HIV/AIDS Information Services Conference were:

- To assess the adequacy of NIH's HIV/AIDS-related information products and services in relation to the multiple and varied audiences for which they are intended. That is, do these resources provide users with the information they need, when they need it, and in a form they can readily use?
- To inform the conference participants, and by extension the community at large, of the full range of HIV/AIDS information services that are currently provided by NIH, and to do so in the context of HIV/AIDS information services provided by other U.S. Public Health Service (PHS) agencies and nongovernmental organizations.
- To involve all user communities, in particular HIV-infected individuals and their advocates, in helping to shape current and future NIH information services.

**THE PANELS.** Following an overview of current NIH and PHS information activities, the core of the conference on the second day consisted of panel discussions, held in plenary, of the issues pertaining to the need for and use of HIV/AIDS information by each of five target user communities or audiences:

- Clinical Researchers
- Medical, Dental, and Nursing Providers
- Allied Health Care Providers
- Media and the General Public
- Patients and the Affected Community

In addition to several representatives from the target community that defined the focus of each panel, membership of each panel also included at least one information provider and one representative of the affected community. This conference marked the first time that these diverse groups have been brought together to consider the role that information services can play in their professional and personal lives. [See Appendix E for a listing of panel members and co-chairs.]

To initiate and stimulate discussion, each panel used a case study that described both successful and unsuccessful experiences in obtaining HIV/AIDS-related information. [See Appendix F for synopses of the case studies presented to the five panels.] Each case study presentation was followed by a panel discussion of the specific issues raised by the case, and the broader issues important to the user community under discussion. The panels considered issues of content, access, and dissemination mechanisms pertinent to each category of user. Participation by the audience in the discussions also provided significant input to the conference findings and conclusions.

OUTCOMES. The panel discussions were then followed on the third day by a meeting of panel co-chairs and the conference Planning Committee. At this meeting, the observations, findings, and conclusions that were put forth during the previous day's discussions were systematically identified and evaluated. A draft conference report was subsequently reviewed by panel members and co-chairs. Its recommendations are intended to reflect the views of the HIV/AIDS community of users as represented at this conference. Within the constraints of NIH's mission and resources, it is expected that implementation of these recommendations will result in the provision of new and enhanced HIV/AIDS information services by the various components of NIH. The recommendations are also intended to foster new opportunities for collaboration within NIH, and with other agencies of the PHS and nongovernmental organizations.

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## **FINDINGS AND RECOMMENDATIONS**

### **PANEL 1: CLINICAL RESEARCHERS**

#### **THE CHALLENGE**

The panel was composed of clinical researchers, members of the affected community, an information provider, and a representative of academic communication research. The initial problem addressed was that many factors, including a dramatically increased level of patient interest in the research process and the general public's high level of concern about the epidemic, have created an enormous and unprecedented "appetite" for current information on AIDS research. The scientific community engaged in biomedical research on HIV/AIDS, accustomed to disseminating research findings through traditional channels of peer-reviewed publications and scientific meetings, is still learning to cope with the new demands placed upon it in this regard. It must also cope with its own difficulties in obtaining the information it needs to carry out research.

## FROM RESEARCH TO PRACTICE

The Concorde Study, a European clinical trial on the role of AZT in the therapy of early HIV disease, was selected as the case study for initiating a discussion that raised the issue of the conflict between the desire for rapid release of medical research information and the quality and authoritativeness of this information. Patients with life-threatening illnesses have a desire and a right to know the outcomes of clinical studies as soon as possible. However, the communication of that information from the scientific community to the popular press has not been entirely successful. Because progress in biomedical research is largely incremental and new research may, in fact, conflict with previous work, it may be difficult to convey that concept to the public.

The panel discussions centered on the responsibility of the clinical researchers to convey the information in the context of prior research, and where possible, in the context of clinical care. It is often the expectation of patients and the public that the results of a research study will have an immediate impact upon medical care. However, clinical researchers are frequently reluctant to make recommendations for changes in therapy based upon a single study. The data must be thoroughly analyzed and subjected to some type of peer review process.

The results of clinical research affect other research and will ultimately be translated into altered practice-changes in care of patients, changes in public behavior, changes in case management. Often it appears to be very difficult to take the research results, translate them effectively into useful information, and disseminate them to the various communities.

### RECOMMENDATION 1.1

NIH should release the results of clinical trials in a timely and effective manner. Such results should be placed in the context of prior research and current clinical care.

In addition to being scientifically and medically accurate, the information disseminated must be free of the jargon that may be intelligible to only a limited audience. Since the information will be used by diverse groups-infected individuals, their families, and supporters-more interaction with these groups in developing the type of information they need and can use would be useful. A better understanding of why and how studies are done may also improve the conduct of clinical trials by assisting recruitment and minimizing premature dropout.

### RECOMMENDATION 1.2

NIH, as the sponsor of many clinical trials, should take more responsibility for making information released about clinical trials understandable to the patient communities, their families, and supporters and develop mechanisms to encourage feedback concerning its usefulness.

## STAYING CURRENT

While the case study focused on some of the issues faced by clinical researchers in disseminating the results of their work, there are also issues confronting this group in trying to obtain the information they need to do this work. Clinical researchers working in HIV/AIDS are generally, but not always, associated with academic health sciences centers or large medical centers. The current expansion of clinical research into community-based research means that larger numbers of those conducting the research may not have such an institutional affiliation. Many of these clinical researchers are part of one of the large networks of academic and other types of organizations set up by NIH to conduct clinical research such as the AIDS Clinical Trials Group (ACTG); the Community Programs for Clinical Research on AIDS (CPCRA); the Division of AIDS Treatment Research Initiative (DATRI); National Institute of Child Health and Human Development (NICHD)-supported clinical trials; and the General Clinical Research Centers supported by the National Center for Research Resources (NCRR). Information about clinical trials, including trial design and results, may reach some clinical researchers through one of these formal or informal communications channels. Other clinical researchers participate in research studies under the auspices of the Department of Veterans Affairs (VA) or one of the military services.

Each of these groups may have regular meetings at which current and projected studies are discussed and protocols developed and reviewed. Only individuals who attend these meetings have timely access to those deliberations and decisions. Others in the clinical research community could benefit from knowledge of the deliberations of these and similar meetings. In addition, it is often difficult to obtain timely information from other national and international AIDS-related meetings. In a fast-paced situation such as exists with HIV/AIDS, clinical researchers would feel more confident if they had facile, reliable access to this type of information. This group expressed a desire to have the information about the presentations, deliberations, and decisions from these various meetings provided to them using multiple communication mechanisms.

### RECOMMENDATION 1.3

NIH should widely disseminate information, such as a final statement, from meetings such as those of the ACTG and CPCRA. Multiple formats should be used for dissemination, including press releases and telefacsimile as well as formats suitable to convey the detailed scientific information needed by researchers.

This group of researchers found that they need information about other clinical trials being conducted, not only in the U.S., but throughout the world. The AIDSTRIALS database does contain information about all the NIH-sponsored clinical trials and privately sponsored trials that have reached the efficacy stage. However, information about some additional clinical studies being done within the United States is not available through that mechanism (e.g., epidemiologic and natural history studies). There are also numerous studies being conducted outside the United States that are not reflected in that database. In general, researchers require information about the design of the trials, the

projected time lines for a study, including when the results are expected to be available, as well as the results of the trials upon completion. This type of information is essential to reduce duplication of studies, improve study design, and to allow researchers to direct their research more effectively. While this type of information is available in AIDSTRIALS for NIH-sponsored clinical trials, it is not available for those trials with other sponsors.

#### RECOMMENDATION 1.4

The AIDSTRIALS database should contain information on NIH and non-NIH-sponsored U.S. clinical trials, including:

- The time line for the trial
- When the results are expected
- Results or references to where results are published
- A statement of the project goal/research question

#### RECOMMENDATION 1.5

NIH should provide access to information about non-U.S. clinical trials so clinical researchers do not unknowingly duplicate research going on elsewhere.

Even this group, generally thought of as sophisticated and with the greatest access to resources, has difficulty in obtaining and sharing its information. Many clinical researchers do not have access to modern, state-of-the-art information resources, including the equipment necessary to use electronic databases and to access these resources over electronic networks, such as the Internet. Current grants and contracts do not usually include support for accessing information resources; therefore, this group may not make optimum use of these resources. Researchers who are affiliated with a larger institution may have access to library and other information services, but these may be inconvenient to access. Unaffiliated researchers find cost a significant barrier to obtaining services, both traditional library services as well as access to electronic networks. There was a strong indication from the participants that many methods for disseminating the information must be used to reach this group adequately. Although electronic information dissemination is considered to be the '-state of the art,' or the '-wave of the future,' too few people have knowledge of these capabilities or training in their use. Therefore, current practice for disseminating clinical research information cannot rely solely upon electronic mechanisms. Further, although researchers recognize that in the future they may be using high performance computing and communication as tools for research and communication, they currently have limited or no expertise or knowledge of this area.

#### RECOMMENDATION 1.6

NIH should explore alternative information dissemination models, such as U.S. Department of Agriculture (USDA) extension services or the approaches used by pharmaceutical companies in marketing their products to physicians (detailing).

#### RECOMMENDATION 1.7

NIH should provide technical and financial assistance to enable those who need this information to access it via the latest electronic information resources, such as the Internet. NIH should expand use of the emerging National Research and Education Network (NREN) for national and international collaboration and data communications.

#### RECOMMENDATION 1.8

NIH should modify its HIV/AIDS-related grants/contracts procedures to: (1) provide funding in research grants and contracts, when appropriate, for a computer and access to NIH-supported databases and other information resources; and (2) clarify the instructions provided to potential grantees to indicate that information access relevant to their research project may be supported.

#### RECOMMENDATION 1.9

NIH should provide clinical researchers with training opportunities in the use of high performance computing systems to facilitate the conduct of HIV/AIDS-related research and collaboration among investigators.

### **PANEL 2: MEDICAL, DENTAL, AND NURSING PROVIDERS**

#### The Challenge

This panel included representatives from the medical, dental, and nursing professions; it also included members of the media and the affected community groups. The initial focus was on the need for the rapid dissemination of clinical research results to health care providers so that they are adequately prepared to provide the best care for their patients and to deal with questions from patients and their families. The example case study used dealt with the dissemination of the results of a drug trial comparing ddI and ddC in patients who could not continue AZT therapy. These health care providers addressed the issues of the type of information required to care for their patients as well as the format that information should take. The diversity of the health care provider community, not only in type of provider, but also in setting of practice, has a significant impact on the type of information needed, the format, and the routes used to disseminate it.

#### The Provider Community

Each segment of this community uses various preferred routes to obtain their information. Traditionally, physicians rely heavily on interactions with colleagues. Dentists also obtain much of the medical information they need through colleague-to-

colleague interactions and at conferences and workshops. However, nurses do not rely as heavily on interactions with their colleagues for acquiring information. Their principal sources include continuing education, specialty journals, and nurse educators. Nurses, however, often lack access to needed HIV/AIDS information sources.

Approaches that take advantage of these already existing routes should be supported. For example, the HIV Telephone Consultation Service ("warmline"), a national service operated in the San Francisco area by the Health Resources and Services Administration (HRSA) AIDS Education and Training Center and supported in part by NIH, was cited as a successful example of linking all of these types of health care professionals with their peers. Through this service, a health care professional can obtain information about an HIV/AIDS-related problem by talking on the telephone with another provider whose knowledge is supplemented by access to such resources as AIDSLINE. This type of personalized, one-on-one service could assist all types of health care providers, particularly those in rural or underserved areas who often lack easy access to colleagues knowledgeable in HIV/AIDS. Similar programs may be required to meet the needs of specific communities.

#### RECOMMENDATION 2.1

NIH should continue to support services that take advantage of the preferred pathways by which practitioners receive information such as practitioner-to-practitioner interactions, e.g., HRSA HIV Telephone Consultation Service. The availability of these services should be widely publicized and access broadened to include minority and other health professionals practicing in rural, inner-city, and other underserved settings.

#### RECOMMENDATION 2.2

NIH should continue support of community, regional, national, and international conferences and workshops to facilitate colleague-to-colleague exchange of HIV/AIDS-related information.

Many medical, dental, and nursing care providers also express a preference for integrated summaries of up-to-date information. They have neither the time nor expertise to continually research the literature, analyze it, and synthesize it into useful formats. The AIDS Knowledge Base, developed and maintained at San Francisco General Hospital, is an example of this type of resource tailored for health care providers. However, producing and maintaining such knowledge bases is expensive and requires substantial investments of time by experts for collecting large quantities of information and distilling extracts significant for practitioners. Electronic technologies can be used to facilitate the creation of these resources and in their dissemination.

#### RECOMMENDATION 2.3

NIH should support the continued development of HIV/AIDS manuals that summarize known information about treatment and are thus useful in the direct provision of patient

care. Electronic technologies should be used to facilitate the creation, maintenance, and access to such resources.

Generally, for physicians and dentists, the use of electronic information sources depends less on costs or availability of equipment than on (1) the knowledge of how to use such resources, and (2) time constraints. For most of these professionals, regularly searching online databases such as AIDSTRIALS or AIDSLINE may not always be a realistic option. In teaching hospitals and similar large institutions, librarians often are available to provide the needed information. In smaller clinics and community-based organizations, library services are rarely available. Electronic information systems, to be more widely applied, need to be extremely easy to use and should be designed specifically to fit into the practice setting.

#### RECOMMENDATION 2.4

NIH should continue to develop and improve user-friendly electronic information systems and services in HIV/AIDS for physicians, dentists, and nurses and, provide readily available training and affordable access to them.

Dentists and nurses are playing large roles in providing care in this epidemic and, therefore, have a critical need for HIV/AIDS information. A dentist is sometimes the first health care practitioner to identify HIV/AIDS symptoms in a patient. As mentioned, nurses often do not have access to the types of information resources used by physicians and dentists. In hospitals, physicians can be a source of information. However, increasingly, nurses work in more isolated settings such as in small clinics, schools, or in home care situations, where acquiring needed information becomes particularly difficult. The 17 AIDS Education and Training Centers (ETC's) supported by HRSA provide education and training for health personnel to assist them in providing diagnoses, primary care, and counseling as well as information about prevention.

#### RECOMMENDATION 2.5

NIH should work collaboratively with other Federal agencies and professional societies to use existing programs and to develop new programs to provide HIV/AIDS information to physicians, dentists, nurses, and other health care workers.

#### RECOMMENDATION 2.6

HIV/AIDS information should be tailored to be maximally useful in specific care settings. Outreach programs should be developed to promote the availability and use of these services.

Health care providers in isolated settings, such as those in rural areas and on Native American reservations, find it especially difficult to obtain up-to-date HIV/AIDS information. They lack ready access to colleagues and institutions that could provide them with such information.

## RECOMMENDATION 2.7

NIH, working with other concerned agencies such as CDC, HRSA, and the Indian Health Service, should initiate efforts to identify underserved users such as rural health care providers and nurses working outside of institutional settings, and make HIV/AIDS information regarding treatment and prevention more widely available to them.

### Rapid Dissemination of Clinical Trials Results

Information developed during HIV/AIDS clinical trials is of primary importance for health care providers. Such information needs to be released as quickly and as completely as possible after the completion or termination of a trial. Several times in the past, NIH has initially disseminated information about the results of an AIDS-related clinical trial as a press release to the general media. Some time after the press release, and after publication in the news media, information was mailed to physicians known to be treating HIV-positive patients. Physicians cannot treat or advise their patients on the basis of a press release alone. An NIH press release about the results of a clinical trial is most useful to the medical community when quickly followed by explanatory information to health care providers linking these results to clinical practice.

## RECOMMENDATION 2.8

NIH should place a high priority on the prompt release and dissemination of HIV/AIDS-related clinical trial results information to physicians and other health care providers. Such releases should be consistently followed by explanatory information linking these results to clinical practice and providing sufficient data for the practitioner to evaluate their applicability to patient care.

Traditionally, the peer review function for medical information is fulfilled through publication in medical journals. This process can sometimes take more than a year, and may be much too slow for such a rapidly moving field as HIV/AIDS. Press releases and other types of releases without adequate evaluation (peer review) may not benefit either health care providers or patients.

## RECOMMENDATION 2.9

NIH should, when warranted, convene special panels of experts to apply rapid peer review to HIV/AIDS clinical trial results information about to be released to the health care provider community and the public.

The Clinical Alert is a mechanism recently adopted by NIH in an agreement with the editors of several leading biomedical journals.<sup>(3)</sup> NIH makes use of this mechanism in urgent cases in which timely and broad dissemination of results of clinical trials could prevent morbidity and mortality, pending formal release of the findings through conventional journal publication. With this agreement, the Clinical Alert does not become a barrier to subsequent publication of the full research paper. The decision to

issue a Clinical Alert is made by an NIH institute director, following consultation with study investigators and review by the data safety monitoring board. Both traditional and electronic communications channels are used to disseminate the Clinical Alert--in summary and full-text form--to health professionals, the media, and the public. These channels currently include press releases and press conferences, online distribution to all users of NLM's MEDLARS online services, telefacsimiles to all medical school libraries, and mailings to some 4,000 other health science libraries throughout the country.

#### RECOMMENDATION 2.10

NIH should use the Clinical Alert mechanism for important HIV/AIDS information as it does for other urgently needed information.

#### RECOMMENDATION 2.11

NIH should develop additional communications channels to ensure that Clinical Alerts pertaining to urgently needed HIV/AIDS information reach all potential users in all settings (e.g., other clinical researchers, practitioners, and community-based organizations).

#### RECOMMENDATION 2.12

NIH should review whether the communications channels effective for Clinical Alerts should be used with all NIH-sponsored AIDS-related clinical trials information.

#### Guidelines for Patient Management

It is clearly important to health care providers that clinical trial results be linked quickly to their effects on clinical practice. The Agency for Health Care Policy and Research (AHCPR) is charged with developing clinical practice guidelines or "standards of care" for a wide variety of subjects, including AIDS. However, in a rapidly changing field such as HIV/AIDS, treatment standards can become quickly outdated. New information is being developed daily and there is great pressure to try to integrate every new finding into the practice setting. Therefore, the speedy development of new HIV/AIDS patient management guidelines, and the rapid updating of existing guidelines is a major--now only partially filled--need of practitioners in this area. Notwithstanding the mission of AHCPR to develop clinical practice guidelines, a consensus of expert opinion such as that made available to physicians and surgeons (and patients) through the National Cancer Institute's Physician Data Query (PDQ) system could provide practitioners with assistance in decision making while developing a plan of action for each patient. Comprehensive yet concise patient management guidelines would enable health care workers in all settings to have the basic information needed to care for their patients. Guidelines need to be written specifically for the different segments of the health care provider community--physicians, dentists, and nurses.

#### RECOMMENDATION 2.13

In collaboration with other concerned agencies and the relevant professional associations, NIH should provide leadership and resources to promote the expeditious development and maintenance of easily understood HIV/AIDS patient management guidelines. Such guidelines should be disseminated in different formats appropriate to the various segments of the health care provider community. These formats could range from full-text online databases to hard-copy publications and guideline compilations.

### **PANEL 3: ALLIED HEALTH CARE PROVIDERS**

#### The Challenge

The allied health care provider panel included representatives from the social work and mental health communities, an information provider, a nutritionist, a physician, and a member of the affected community. The major problems discussed included the need of professionals working in straitened circumstances to access a wide range of resources. Members of the allied health community often have the most extensive contact with the patients and their families and are called upon to provide an array of information within a limited time frame and with few resources. This group is also multidisciplinary and its needs are not as tightly defined as those of some of the other communities. In the past, NIH has not focused strongly on meeting the needs of this group.

#### Serving the Full Range of Health Needs

Initiating the discussion with a composite case study tracing one social worker's attempts to find information that would help her develop a comprehensive treatment plan for her client, the panel focused on the importance of the multidisciplinary approach to patient care involving an entire team. This included the participation of social workers and case managers, with social workers frequently serving as the links between patients and physicians and as important sources of information for their clients and the communities in which they work. The face-to-face time that they spend with clients makes it possible for real patient education and meaningful information transfer to take place.

In addition to allied health professionals, who are traditionally viewed as part of the health care team, the epidemic has brought to the fore other professionals, paraprofessionals, and volunteers who work closely with persons living with HIV/AIDS and people at high risk for contracting HIV. These include the clergy, school health technicians and counselors, teachers, physical and occupational therapists, homeless shelter workers, herbalists, and folk healers, among others. The number of ways that these individuals interact with clients and community members and the settings in which these interactions take place vary widely. Similarly, the span of services provided by this group is very broad, encompassing financial issues, transportation, access to treatment and child care, drug abuse, bereavement, rehabilitation, etc. Because of their important role, these people need easily accessible paths to up-to-date, relevant information.

The settings in which allied health care providers work are as varied as the professions and services they represent. Locations include community clinics, private practices,

social service agencies, houses of worship, and private homes. Even the most basic library services may not be available to these workers. Some providers work in overburdened State and local health agencies struggling with extremely heavy case loads. Their access to both traditional and state-of-the-art information resources may be extremely limited and they have little time, experience, or training in using them, particularly in the case of electronic resources.

#### RECOMMENDATION 3.1

NIH should initiate outreach programs to connect unaffiliated allied health care providers with medical libraries and other NIH-supported resources that could provide access to the required HIV/AIDS information.

#### Diversity of Information Resources

There are gaps in the information available to allied health care providers and their clients. They have difficulty obtaining information that focuses on the use of therapies, such as Kemron, that are important to minority communities; the pros and cons of using various alternative therapies; and the interactions between substance abuse and HIV disease, such as the effect of long-term methadone use on antiretroviral drug efficacy.

#### RECOMMENDATION 3.2

NIH should expand its information services to make available information about the evaluations of alternative and nontraditional therapies for HIV/AIDS.

#### RECOMMENDATION 3.3

NIH should use the resources of the National Institute on Drug Abuse and the National Institute on Alcoholism and Alcohol Abuse to increase the availability of substance abuse research information relevant to HIV/AIDS.

More information about HIV-related mental health issues is needed as well, because of the key role that mental health plays in maintaining a good quality of life among persons living with HIV/AIDS. Other areas that are poorly covered by the existing information resources include the role of spirituality and information about rehabilitation. There is a strong feeling among allied health care providers and their clients that patients should make their own decisions about quality of life issues. However, to do this effectively these patients need information. Because of the close relationships that both traditional and nontraditional allied health care providers develop with their clients, they are in a good position to help make this type of information available to these clients. Allied health care providers also require access to information about prevention. They are in an excellent position to communicate this information to their clients and to implement prevention programs.

#### RECOMMENDATION 3.4

NIH should use all of its resources, particularly those of the most recently added institutes--the National Institute of Mental Health, the National Institute on Drug Abuse, and the National Institute on Alcoholism and Alcohol Abuse--to expand the scope of its information resources and dissemination activities to include information about HIV/AIDS-related psychosocial research. This should include mental health issues as well as behavioral research as it relates to prevention.

Allied health care providers face a number of barriers in accessing many established sources of information. Because of the breadth of information required by this group, a large burden is placed on the busy allied health care provider to determine what is available and to learn the different ways to access or acquire the information. Further, the information is generally highly technical, using the terminology of the many fields represented. This may diminish the ability of the allied health care worker to locate the needed information quickly and in a usable format.

#### RECOMMENDATION 3.5

NIH should work with other involved agencies to organize information resources to make it easier for allied health care providers to access information. NIH should explore the application of 'one-stop-shopping' models such as the National Cancer Institute's Physician Data Query (PDQ) system to HIV/AIDS.

#### RECOMMENDATION 3.6

NIH should translate complex concepts and terminology into concise, jargon-free summaries that are easily understood by allied health care providers and the communities they serve.

#### RECOMMENDATION 3.7

NIH should provide training opportunities and technical support to help allied health care providers gain access to and become proficient in the use of electronic information systems.

#### Developing Linkages

Allied health care providers frequently communicate with each other informally and through professional conferences. Newsletters are also an important source of information for this group, providing practical, concise discussion of important issues. Many allied health care providers keep in close contact with the professional organizations that represent them, and regularly receive a great deal of information through vehicles designed by these groups for this purpose. Others are unaffiliated with professional organizations but can be reached with information through community-based organizations (CBO's) or AIDS service organizations (ASO's) in which they work. Churches and various ethnic organizations also function as nontraditional, but important,

allied health care providers in this epidemic. All of these existing networks have potential as dissemination routes for up-to-date HIV-related information.

#### RECOMMENDATION 3.8

NIH should develop partnerships with professional organizations representing allied health care providers to distribute information through organizational journals, newsletters, conferences, and continuing education programs.

#### RECOMMENDATION 3.9

NIH should develop partnerships with CBO's and ASO's to distribute information to their affiliated allied health care providers using the CBO/ASO newsletters, electronic bulletin boards, and other suitable activities.

#### RECOMMENDATION 3.10

NIH should use existing networks of religious and ethnic organizations as communication pathways to link these nontraditional allied health care providers to the HIV/AIDS information they need.

#### RECOMMENDATION 3.11

To make the HIV/AIDS information disseminated by community-based organizations more accessible, NIH should support the development of a finding tool, such as an electronic index, to the contents of resources such as newsletters that are important sources of information for allied health care providers.

### **PANEL 4: MEDIA AND THE GENERAL PUBLIC**

#### The Challenge

This panel, chaired by nationally recognized members of the print and broadcast media, was composed of representatives from major national print media, the gay press, minority media, and AIDS-specific media. Community members and AIDS information specialists were also represented. The discussion concerned the respective roles of scientists (the generators of new information), journalists, and other members of the media (who report and interpret new information for the public) and, to a lesser extent, Federal public information officials (who sometimes serve as points of information access for journalists). The responsibilities of these groups to inform and educate the public often conflict. The scientific community may not be adept at dealing with the media who, in turn, may not be sufficiently knowledgeable about science.

#### The Media

The term "media" in the context of this conference is loosely defined as any person or organization that serves as a conduit of HIV/AIDS information to the public. Included are reporters for national, local, community, and specialized newspapers and newsletters; writers for national news magazines; radio and television reporters and anchors; and producers of media such as electronic bulletin boards. Producers of low-budget, alternative publications and bulletin boards may work relatively independently, making their own decisions about what to write in a story. Large national newspapers and magazines, however, exercise great editorial control over what is published; stories receive strict scrutiny from editors who determine the newsworthiness of the story relative to what else is happening that day. Many small and community newspapers have no reporters devoted to AIDS or even health issues, and rely on the larger papers or newswire services as their sources of stories.

#### RECOMMENDATION 4.1

NIH should make a determined effort to work with journalists and the media at all levels as they are a most important mechanism for reaching the public with important information about HIV/AIDS.

##### Educate or Inform?

Brief discussions of two recent high-profile cases involving scientists and the media served as a starting point for the panel's discussions. The first case used was the widely aired but highly controversial claim by molecular biologist Peter Duesberg that HIV is not the causative agent of AIDS. The second case described the "mystery virus" story that broke just prior to the VIII International Conference on AIDS in Amsterdam in 1992.

To what extent were reporters not serving the common good in giving prominence and credence to theories that had little or no basis in scientific fact? Since, as several conference attendees commented, one of the primary functions of our free press is "to educate the public," wasn't there an obligation on the part of reporters to research their stories more completely and thus give a more balanced view?

In fact, most journalists do not see their role primarily as one of educating. Rather, they see themselves as simply reporting "news"; whether for education, information, or entertainment, would depend on the nature of the item being reported, the newspaper (or other medium) in which it is being published, and the expectation of the audience. That being the case, it is crucial that institutions like NIH be aggressive and proactive in providing the media with reliable information and background on which to base news stories. This would provide the balance and context that too often are missing from current stories about AIDS.

#### RECOMMENDATION 4.2

NIH should aggressively rebut national media articles that contain misinformation or misleading information.

#### RECOMMENDATION 4.3

NIH should encourage journalists to publish sidebar stories to provide background and context for their main AIDS stories, particularly when reporting something new or controversial. When possible, NIH should provide the necessary information.

#### RECOMMENDATION 4.4

NIH should always include in press releases a telephone number (e.g., an AIDS hotline) for readers to call for further information on the topic. NIH should strongly encourage the media to include the number in the story.

#### Issues of Access

A part of NIH's responsibility is to ensure that journalists have access to knowledgeable and articulate scientists who can discuss the newest claims and reports (regardless of where they originate) with authority. In general, journalists enjoy different degrees of access to scientists depending on their affiliation. Local television reporters are sometimes viewed with fear and suspicion by scientists, while public radio reporters are perceived more favorably, and thus have more doors open to them. Related to the need for access to scientists is the need for scientists to know how to talk to the media. Journalists sometimes consider scientists to be naive; scientists need to recognize that reporters may not always report their views in a sympathetic way.

#### RECOMMENDATION 4.5

NIH should provide training for its scientists in media relations.

Some reporters feel that direct access to scientists is impeded when, for example, an NIH institute requires that a Public Information Officer serve as a reporter's conduit to an NIH scientist. There is currently no NIH-wide practice in this regard. [ed: Since the conference, a Task Force set up by the NIH Office of Communications is currently looking at existing policies in the various institutes to see if any changes are needed in how the media gain access to NIH scientists.]

#### RECOMMENDATION 4.6

NIH should review and clarify its policies concerning whether journalists may have direct access to scientists. This would include clarifying NIH-wide policies as well as the policies of the individual NIH components.

#### Reaching Minority Populations

The fascination of the public with both stories described in the case study can be traced to the fact that it is very difficult to educate people about complex issues like HIV/AIDS. "Strange sound bites" carry orders of magnitude more impact than rational information

because they feed into people's fears, fantasies, and insecurities. However, it must be recognized that often such stories may have a tremendous negative impact on prevention efforts because people will point to them to justify their behavior and claim that difficult behavior changes are useless. These stories fuel denial and seem to release people from their responsibility. This is particularly critical in communities of color where there is widespread distrust of the establishment. Community-based AIDS service organizations, hotlines, and others are then left to deal with people's fears, which are fed by these stories.

Contrary to popular opinion, the gay media, which may cover HIV/AIDS issues in more depth, does not reach the entire gay population. Many participants agreed that mainstream media should also cover HIV/AIDS issues in detail. Both the alternative and the national media should constantly be aware that what they write and broadcast is frequently picked up and reproduced by local media.

#### RECOMMENDATION 4.7

NIH should provide technical assistance through workshops or other training vehicles to writers and editors. NIH should proactively seek out media that serve minorities and small or rural communities and the alternative media to provide this assistance.

#### RECOMMENDATION 4.8

NIH should have a single 800 telephone number for journalists working at all levels, including those serving gay and minority communities. NIH's radio news service should be expanded to include more AIDS information.

#### Other Approaches to Disseminating HIV Information

The panel discussed other approaches to getting accurate, timely information to the public without relying on the traditional print and broadcast media to decide what is newsworthy and to interpret scientific findings. The U.S. public library system is especially well placed to provide this type of service. Libraries can serve as a conduit of government-produced information to the public. This could be particularly useful in small communities.

New technologies can also provide opportunities to communicate directly with the public. Cable television, satellite communications, computerized bulletin boards, information kiosks in pharmacies, and many other mechanisms can play a part in the overall effort to educate the U.S. public about HIV/AIDS.

#### RECOMMENDATION 4.9

NIH should explore the use of different technologies and media that can directly reach infected individuals; for example, videos in waiting rooms, public access cable television,

or minority media such as Black Entertainment Television. The use of the Internet for this purpose should also be explored.

#### RECOMMENDATION 4.10

NIH should work with library associations to develop an efficient mechanism to proactively communicate HIV/AIDS information to libraries and other community information delivery programs.

### **PANEL 5: PATIENTS AND THE AFFECTED COMMUNITY**

#### The Challenge

This panel consisted of representatives from national and community-based AIDS service organizations, including several persons living with HIV, as well as an information provider. The discussion centered on the need for information because of the desire by this community to take charge of their own care and make informed decisions. The difficulty of using existing information resources because of the many barriers is a significant issue. These barriers include high cost, lack of technological capability, social problems, the technical nature of the available information, and the apparent conflicts in the available information. HIV is only one of many problems facing the affected community. Many of its members are poor. Sometimes problems such as hunger and homelessness must be dealt with before HIV can be addressed. Many feel isolated from information and other resources; this is true even for those living in metropolitan areas. Special burdens are faced by women and ethnic, racial, and cultural minorities.

#### An Expanding Community

Since the start of this epidemic over a decade ago, the population infected with HIV has continued to increase in size and diversity. While the initial communities affected were hemophiliacs and male homosexuals, in more recent years the face of the disease has changed. HIV and AIDS is taking an increasingly heavy toll on communities of color, women, injection drug users, and the incarcerated population. The incidence in adolescents is also escalating. The information needs of these different groups is wide and varied. Meeting these needs is extremely complex, and different strategies may be needed for each target group.

The initial case study discussion focused on the specific needs of HIV-positive women and the additional burdens placed upon them because of the position of women in society. Because the communities affected by the epidemic are changing so rapidly, cultural sensitivity is crucial as the epidemic expands. Many of these communities are rural or isolated in other ways. Successful techniques for disseminating information to diverse communities are being used here and abroad, and NIH may benefit by considering those methods. Individuals in different communities often get their information from "nontraditional" sources. It is also important to recognize that information is needed not only by the infected individuals, but also by family and friends.

In some of these communities those who need HIV/AIDS information may not seek it out in traditional settings such as departments of public health or clinics. This is particularly true of information relating to prevention.

#### RECOMMENDATION 5.1

NIH should support efforts to make information accessible where affected individuals are already spending time, e.g., relevant medical clinics, social services or welfare offices. For example, simple information about clinical trials should be available at testing and counseling sites.

Like patients everywhere, many in the affected community rely on their health care providers for treatment information. However, some medical and allied health service professionals are not familiar with HIV-related complications or do not spend sufficient time explaining HIV issues to patients. Also, it is often difficult for busy health care workers to keep up with the latest information about AIDS. Furthermore, many health care providers, especially physicians, are not knowledgeable about or sensitive to special needs and burdens of many in the affected community. Getting more HIV/AIDS information to health care providers will help them deliver higher quality care and result in more information to patients. Health educators and other types of allied health care providers may be able to help get information from the medical care providers to the patients.

#### RECOMMENDATION 5.2

NIH should facilitate access to HIV/AIDS information for health care providers, especially those in high-incidence communities or treating high numbers of HIV/AIDS patients, so that all those treating patients with this disease are knowledgeable about it.

#### RECOMMENDATION 5.3

NIH should develop programs of technical assistance and other types of support for health educators to use in working with patients and their families.

#### Expanding Information Needs

Those with HIV disease and AIDS, their families, and the community organizations supporting them have indicated the need for a wide range of information to combat the disease. The level of sophistication of these information users is highly variable, as are their preferred sources of information, their methods of accessing them, and the types of information desired.

As the epidemic has progressed, some large community-based organizations (CBO's) have not yet made the same commitment to providing information and services relevant to asymptomatic or early HIV/AIDS infection compared to information and services regarding HIV prevention and care for persons with AIDS. In addition, these large

CBO's, set up in the early stages of the epidemic, may not be reaching communities which are now seeing the large increases in infection. Especially in the communities more recently affected by AIDS, many individuals are unfamiliar with the basic information, e.g., the difference between HIV and AIDS, basic prevention strategies, recommended prophylaxis, and treatment. There is a continuing need for this information as new individuals and communities become involved.

#### RECOMMENDATION 5.4

NIH should provide support and technical assistance to CBO's to develop and make available to patients and their families information and services relating to HIV/AIDS prevention, treatment, and disease progression.

HIV-infected people and their advocates want accurate information about research results and treatment options as soon as possible. The traditional, relatively slow, publication process for peer-reviewed data causes some concern that those who want to know about newly developed data quickly cannot obtain it. (See discussion of Clinical Alerts by Panel 2 on page 10.)

#### RECOMMENDATION 5.5

Whatever mechanisms NIH implements to improve the delivery of clinical trial results to health care providers should include delivery of this information to patients and the affected community. This information should be delivered in appropriate formats and languages to be useful to this community.

Clinical trials are complex and participation in them usually requires a large commitment of time and effort for many HIV-positive persons. For those who do participate, there needs to be a sense of trust between patients and trial physicians. Participants require feedback about their trial. Many in the community seek any information available about the results of clinical research, but most prefer that information to be authoritative. Some are also especially interested in any report about alternative therapies.

#### RECOMMENDATION 5.6

NIH should take the initiative in communicating the results of clinical trials to trial participants.

#### RECOMMENDATION 5.7

NIH should collect and disseminate information about alternative therapies, especially research and practical clinical information.

It is particularly evident that the psychosocial aspects of HIV infection have a profound impact on persons with HIV. However, information about psychological and behavioral issues is scarce.

## RECOMMENDATION 5.8

NIH should include more mental health subject matter in its HIV/AIDS information resources.

### Reaching Out

There are many effective means available to reach patients and the affected community with information they want in an appropriate format. Information 'gateways' (e.g., P.E.T.T., the Public Education Technology Transfer project and other networks of community-based organizations) currently exist that could assist NIH in reaching patients and the affected community. These organizations may be better able than NIH to reach some populations at the community level, e.g., the poor, prisoners, and ethnic and cultural minorities. Using these various avenues would enable NIH to take advantage of the credibility these groups have within their own communities, and would help to overcome the distrust that certain communities have for the government.

## RECOMMENDATION 5.9

NIH should assist community groups in getting information to their constituencies. Support should include outreach and technical assistance, especially in resource development and the capacity to use information technology. NIH should develop and evaluate models of information dissemination techniques, solicit feedback ('inreach'), and build trust.

Community groups, patients, and other members of the affected community are using many techniques to communicate and share information with their target populations. These include both traditional and electronic approaches. Many community groups use printed newsletters to reach their audiences. The quality of these publications covers the spectrum from highly researched, technical, and often complicated, to the basic. Although the information in newsletters may be conflicting, leading to confusion on the part of the reader, these newsletters augment the information available to the community. In some cases, they may be the only source of treatment information readily available. Many members of this community find newsletters a good vehicle for obtaining their information, yet, because of the cost, cannot always access them. Health care providers also find newsletters to be useful tools to disseminate important information. Few of these newsletters receive financial or technical support from outside their organizations even though they are educating thousands of people.

## RECOMMENDATION 5.10

NIH should assist producers of newsletters by providing information, technical assistance, and other resources. NIH should also build on this relationship and use newsletters as one of the vehicles for disseminating HIV/AIDS information to the community.

#### RECOMMENDATION 5.11

NIH should support the development of an online and printed index to the articles in these newsletters to make specific information more readily accessible to members of the community.

Electronic bulletin boards and networks are also valuable sources of information with tremendous potential. For example, the Sci.med.aids Internet news group has an extremely wide distribution. However, this type of news group is only available to those with connections to the Internet, and few community organizations or individuals in the affected community have access to the Internet. Electronic bulletin boards, often run on limited budgets by volunteers and by community groups, are accessible to anyone with a computer and modem. Bulletin boards have wide accessibility, but although computerized services are useful to some people, this is far from universally true. Cost, both for access and the technology, and the lack of required skills are barriers to using the full range of this technology. For example, many in the affected community are interested in access to abstracts from the International AIDS Conferences but cannot afford the charges to use the AIDSLINE database where these abstracts are available.

#### RECOMMENDATION 5.12

NIH should expand its AIDS information services available on the Internet and also provide support for other groups working to do this.

#### RECOMMENDATION 5.13

To facilitate access to electronic resources, NIH should provide support, such as equipment, training, and technical assistance, to organizations representing the affected community.

#### RECOMMENDATION 5.14

NIH should provide online access to the information in AIDSLINE, AIDSTRIALS, and AIDSDRUGS at no cost to the community.

One of the major barriers to the use of HIV/AIDS information by patients and the affected community is language and literacy. Furthermore the technical terminology used to describe complex clinical research, treatment options, etc. can be difficult to understand.

#### RECOMMENDATION 5.15

Information should be consistently presented in nontechnical terms. Appropriate formats and languages should be used to reach specific audiences; for example, if people cannot read, games and videos may be appropriate. NIH should help produce these materials and

assist the community in developing them. Other media and dissemination vehicles should also be explored for those with low-literacy skills.

One of the problems faced by those who are HIV-positive is the social stigma that may be attached to them in their communities. When this occurs, individuals are often reluctant to seek out information and assistance from community-based or other organizations. Libraries then become an important vehicle for AIDS information dissemination. The effectiveness of libraries has been shown in both urban and rural areas. However, public libraries are often underfunded and lack knowledge of and access to the available information resources. Individuals looking for HIV information want to be able to find it easily on their own, without attracting attention that might reveal their HIV status. Many libraries need additional resources, funding, and technical expertise to make this type of service available to their constituencies.

#### RECOMMENDATION 5.16

NIH should target public libraries and provide brochures, reports, and electronic resources to them.

Many in the community are unaware of the breadth and variety of AIDS information resources available from NIH. The Guide to NIH HIV/AIDS Information Services, distributed at the Conference, is a good survey of those resources. The community could benefit from this type of knowledge about NIH's services.

#### RECOMMENDATION 5.17

NIH should expand, update, maintain, and widely disseminate the Guide to NIH HIV/AIDS Information Services.

Participants felt that the government's response to the need for AIDS information is not coordinated and that there is too much duplication. For example, there is considerable overlap in the populations targeted by NIH, the Centers for Disease Control and Prevention (CDC), and HRSA. Each agency has its own set of services and resources. People would prefer a central source for information. There is also a lack of coordination among the institutes at NIH. Several in the group requested that the government coordinate its databases and provide a single, central source for information.

#### RECOMMENDATION 5.18

NIH should work with HRSA, CDC, and other agencies to coordinate HIV/AIDS information services. For example, outreach programs to specific populations could be combined, and electronic resources should be coordinated to reduce duplication.

\* \* \* \* \*

## APPENDICES

## **APPENDIX A: GUIDE TO NIH HIV/AIDS INFORMATION SERVICES**

The National Institutes of Health (NIH) supports research to provide insight into the nature of HIV infection, the genetic and biological properties of the virus, immunopathogenesis, the natural history of HIV, consequences of HIV infection on the body, risk factors, and various modes of transmission. NIH supports a major effort to develop vaccines and to develop and test new agents for the treatment of AIDS and HIV infection, including opportunistic infections and HIV-associated malignancies.

NIH sponsors many information services to assist professionals, patients, and the public in the quest for knowledge about HIV/AIDS. This brochure describes many of those services, some of which are components of other HIV/AIDS-related projects, as well as selected information services sponsored by other agencies of the Public Health Service.

The symbols below identify the categories of HIV/AIDS information services of each institute, office, or center.

R=	Research	CT=	Clinical Trials
T=	Treatment	PE=	Patient Education
P=	Prevention	PT=	Professional Training
GI=	General Information		

The symbols below are used to identify the type or format of each HIV/AIDS information service provided.

Tel=	Telephone Service	Pub=	Publication
Db=	Online Database or Electronic Bulletin Board	Ex=	Exhibit, Educational Campaign, or Training appendiProgram/Materials

### **OFFICE OF AIDS RESEARCH (OAR) R, CT, T, GI**

Pub

AIDS Program Advisory Committee: OAR distributes bound proceedings of the AIDS Program Advisory Committee (APAC) meetings to health professionals, media, constituency groups, and the public upon request.

Pub

AIDS Research Accomplishments: OAR publishes an annual report highlighting NIH HIV-related research advances of the previous year, written in relatively nontechnical language. For more information about resources and services provided by OAR, contact NIH, Office of AIDS Research, Building 31, Room 5C-06, Bethesda, MD 20892; (301) 496-0358.

## NATIONAL LIBRARY OF MEDICINE (NLM) R, CT, T, P, GI

Db

**AIDSLINE:** This database contains over 90,000 bibliographic references to published literature about HIV/AIDS and related issues including prevention and treatment. The database includes citations to journal articles, books, and audiovisual materials. AIDSLINE also contains the abstracts of the International Conferences on AIDS.

Db

**AIDSTRIALS:** This database contains information about HIV-related clinical trials, both open (currently accruing patients) and closed. Information about NIH-sponsored clinical trials is provided by the National Institute of Allergy and Infectious Diseases (NIAID); information about privately sponsored efficacy trials is provided by the Food and Drug Administration (FDA).

Db

**AIDSDRUGS:** This database contains information about the agents being tested in trials included in AIDSTRIALS.

Db

**DIRLINE:** This database is an online directory of information resources covering all areas of biomedicine. Included are over 2,000 HIV/AIDS-specific resources such as organizations, self-help groups, and information systems. NLM's online databases are available to health professionals, libraries, and others. Users can access these databases using Grateful Med, a user-friendly software package available from the National Technical Information Service at 1-(800) 423-9255. For more information about NLM's databases, including AIDSLINE, and about obtaining access to them, call 1-(800) 638-8480. For more information specifically on the AIDSTRIALS and AIDSDRUGS databases, call (301) 496-3147. Information from these two databases is also available through the toll-free AIDS Clinical Trials Information Service, cosponsored by NLM, at 1-(800) TRIALS-A (see page 4).

Pub

**Clinical Alerts:** Clinical Alerts are used by NIH in urgent cases in which timely and broad dissemination of results of clinical trials could prevent morbidity and mortality. These clinical trials results are released pending the formal release of the findings through conventional journal publication. Once the decision to issue a Clinical Alert is made by the director of the relevant NIH institute, both traditional and electronic communication channels are used to disseminate the Clinical Alert to health professionals, the media, and the public. These channels currently include press releases and press conferences, online through NLM's MEDLARS computer system, telefacsimile, and mailings.

Pub

**AIDS Bibliography:** NLM publishes the monthly AIDS Bibliography, which includes all citations from the AIDSLINE database. The AIDS Bibliography is available by yearly subscription from the Superintendent of Documents at (202) 783-3238. For more information on the AIDS Bibliography (and general

reference questions on AIDS resources), call (301) 496-6095 or 1-(800) 272-4787.

The monthly AIDS Bibliography, open trials from the AIDSTRIALS database, the entire AIDSDRUGS database, and AIDS-related Clinical Alerts are available via FTP from the NLM Publications Server. (FTP to [nlmpubs.nlm.nih.gov](ftp://nlmpubs.nlm.nih.gov) and login: `as nlmpubs.`)

## **NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAID) R, CT, T, PE**

Tel, Pub

AIDS Clinical Trials Information Service (ACTIS): ACTIS, a toll-free telephone service, is a Public Health Service collaborative project provided by NIAID, NLM, the Food and Drug Administration, and the Centers for Disease Control and Prevention. It provides free, up-to-date information on clinical trials that evaluate experimental drugs and other therapies for adults and children with HIV infection and AIDS. Bilingual reference specialists are available to speak with Spanish-speaking callers. To speak with an ACTIS Reference Specialist, call 1-(800) TRIALS-A (874-2572); TDD: 1-(800) 243-7012.

Tel

NIH clinical trials information phone line: NIAID's Division of Intramural Research/Clinical Center operates a free telephone service for individuals seeking information about participating in clinical trials at NIH. Call 1-(800) AIDS-NIH.

Pub

NIAID research and treatment updates: NIAID's Office of Communications distributes pamphlets, factsheets, press releases, a newsletter, and other print and audiovisual materials about HIV/AIDS clinical trials. NIAID disseminates research results relevant to clinical practice through press releases, Notes to Physicians, and Clinical Alerts.

Pub

NIAID reports: NIAID's Office of Communications disseminates materials resulting from NIAID-sponsored meetings. The Office of Communications also produces materials describing NIAID's current research initiatives, such as information about HIV vaccine development, preclinical drug development, pathogenesis research, and epidemiologic studies.

Pub

NIAID pamphlets and factsheets: NIAID's Office of Communications has developed a number of materials addressing HIV-related clinical trials and treatment issues for clinicians to use with their HIV-infected patients. For more information, or to receive a free list of available materials, write to the National Institute of Allergy and Infectious Diseases, Office of Communications, Building 31, Room 7A-50, 9000 Rockville Pike, Bethesda, MD 20892. Many of these materials are also available by calling the AIDS Clinical Trials Information Service at 1-(800) TRIALS-A (see page 4).

## **NATIONAL INSTITUTE ON AGING (NIA) GI**

Pub

AIDS and the Older Adult: NIA produces this document, one in a series of "Age Pages," that provides general information to the public on AIDS in the older population and lists resources to contact for more information. For a copy, call 1-(800) 222-2225, or write the National Institute on Aging, Building 31, Room 5C-27, Bethesda, MD 20892.

**NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM (NIAAA)  
T, P**

Pub

Alcohol and AIDS: This issue of NIAAA's quarterly bulletin "Alcohol Alerts" provides information to health professionals about the relationship between alcohol consumption and HIV infection and AIDS. It focuses on the relationship of alcohol consumption to unsafe sexual behavior and on the treatment implications of alcohol's effect on the immune system. Copies are available free from the National Institute on Alcohol Abuse and Alcoholism, 5600 Fishers Lane, Room 16C-14, Rockville, MD 20857; (301) 443-3860.

Pub

Alcohol, Health & Research World: Two issues of this peer-reviewed journal featured information about the relationship between alcohol consumption and HIV infection and AIDS: "Alcohol, Infectious Diseases, and Immunity" (\$19.50, PB93160604) and "Prevention of Alcohol Related Problems" (\$19.50, PB94113503). These issues are available for a fee from the National Technical Information Service (NTIS). Call NTIS at (703) 487-4650 for more information.

**NATIONAL CANCER INSTITUTE (NCI) R, CT, T, PE**

Tel

Cancer Information Service: NCI provides a toll-free telephone service for access to information specialists who can provide information about therapies for AIDS-related malignancies and answer questions from physicians, other health care providers, service providers, and the public. Call 1-(800) 4-CANCER (422-6237).

Db

Physician Data Query (PDQ): In cooperation with the National Library of Medicine (NLM), NCI provides an online system for professionals and nonprofessionals containing state-of-the-art treatment information about AIDS-related malignancies and other cancers. A bibliographic database, CANCERLIT, is also available. For more information, call 1-(800) 4-CANCER (422-6237) or NLM (see page 2) at 1-(800) 638-8480. CancerFAX: Health professionals with access to a computer with a fax modem can receive summaries directly from the PDQ database (see above). Summaries are available in both English and Spanish. The fax number is (301) 402-5874.

**NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT  
(NICHD) R, T, P**

Pub

Final Report: Secretary's Work Group on Pediatric HIV Infection and Disease: NICHD produced this report containing the findings and recommendations of a workgroup convened to delineate the problems faced in confronting pediatric HIV infection and to suggest strategies for their solution. Other publications are being developed with information on maternal and pediatric AIDS.

Pub

The New Face of AIDS. A Maternal and Pediatric Epidemic: NICHD wrote and produced this brochure, which includes general information on maternal and pediatric AIDS. Among the areas discussed are routes of transmission, symptoms, prevention, and treatment.

Pub

AIDS Research at the National Institute of Child Health and Human Development: This document lists all current HIV/AIDS-related research projects supported by NICHD. It includes project descriptions, principal investigators, and Institute funding information. To obtain a copy of any of these NICHD documents, write to the National Institute of Child Health and Human Development, Office of Research Reporting, Building 31, Room 2A-32, Bethesda, MD 20892.

**NATIONAL INSTITUTE FOR DENTAL RESEARCH (NIDR) R, PT, P**

Pub

A Guide for Epidemiologic Studies of Oral Manifestations of HIV Infections: NIDR, in collaboration with the World Health Organization, has produced this document, which provides practical information for the design, implementation, and reporting of epidemiological studies.

Ex

Training manuals: Two training manuals will be available in the near future: Building the Capacity for an Oral Health Response to the Global HIV Epidemic-Principles for Developing a Country-Specific Approach, for all national dental coordinators of HIV/AIDS activities, and Mobilizing Oral Health Personnel to Respond to the Development of Country-Specific Plans, for local, regional, and national oral health personnel. The manuals explain steps for preventing HIV transmission in the dental setting. For more information, write to the National Institute for Dental Research, Building 31, Room 2C-35, Bethesda, MD 20892.

**NATIONAL INSTITUTE ON DRUG ABUSE (NIDA) T, PE, P, GI**

Tel

NIDA/CSAT Drug Abuse Treatment Information and Referral Hotline: NIDA's Office of Science Policy Education and Legislation, jointly with the Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Substance Abuse Treatment, sponsors a hotline to provide information to the public about the relationship between drug abuse and AIDS, including the risks

associated with injection drug use, impaired judgment, and unprotected sex. To contact the hotline, call 1-(800) 662-HELP, or 1-(800) 66-AYUDA (Spanish).

Ex

**National Media Campaign on Drug Abuse and AIDS:** NIDA conducts a campaign to make the general public aware that alcohol or other drug abuse could lead to exposure to HIV. Focusing on teenagers, young adults, and women, the campaign includes television and radio public service announcements, advertisements in newspapers and consumer magazines, posters, and pamphlets. Innovative communication channels such as movies are also used. For more information about NIDA's resources and services, write to the National Institute on Drug Abuse, 5600 Fishers Lane, Room 10A-39, Rockville, MD 20857.

### **NATIONAL EYE INSTITUTE (NEI) CT, T**

Pub

**Studies of the Ocular Complications of AIDS:** NEI disseminated the results of the Foscarnet-Ganciclovir Retinitis Trial by distributing a Clinical Alert, press release, and media kit. Results of other trials will be disseminated as appropriate. General information is available on the ocular complications of AIDS and on clinical trials completed and underway. For more information, contact the National Eye Institute, Scientific Reporting Section, Building 31, Room 6A-32, Bethesda, MD 20892; (301) 496-5248.

### **NATIONAL INSTITUTE OF GENERAL MEDICAL SCIENCES (NIGMS) R**

Pub

**AIDS Targeted Drug-Design Project:** Every June, NIGMS sponsors a national meeting of groups active in targeted drug design against AIDS. Abstracts are widely disseminated to interested parties. For more information, contact the National Institute of General Medical Sciences, Westwood Building, Room 922, Bethesda, MD 20892; (301) 594-7735.

### **NATIONAL HEART, LUNG, AND BLOOD INSTITUTE (NHLBI) R, PE, P, GI, PT**

Ex

**NBREP Public Education:** NHLBI's Office of Prevention, Education, and Control sponsors the National Blood Resource Education Program (NBREP), which educates the public about the blood collection and donor screening process to ensure the safety of the Nation's blood supply, including the prevention of transfusion-related HIV transmission, and to encourage donations by autologous and other eligible donors. NBREP conducts mass media campaigns, including radio and magazine public service announcements, and distributes patient education materials.

Ex, Pub

NBREP Professional Education: NBREP educates physicians to be knowledgeable about the appropriate use of blood and blood products to ensure the safety of the Nation's blood supply. The program distributes the following professional education reports: Indications for the Use of RBC's, Platelets, and FFP; Indications for the Use of Autologous Blood; and Transfusion Therapy Guidelines for Nurses. NHLBI also issues a yearly report on its AIDS-related research and other achievements. For more information about NHLBI HIV/AIDS-related services, write to the National Heart, Lung, and Blood Institute, Building 31, Room 4A-05, Bethesda, MD 20892; (301) 496-0554.

## **NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH) R, P**

Pub

AIDS Research: An NIMH Blueprint for the Second Decade: This report provides a brief overview of NIMH's role in AIDS research, including major initiatives in the areas of behavior change and prevention, neurobehavior, and neuroscience. Each section includes a discussion of issues, research opportunities, and questions. To obtain a copy of the report, write to the National Institute of Mental Health, Information Resources and Inquiries Branch, Room 7C-02, 5600 Fishers Lane, Rockville, MD 20857.

## **NATIONAL CENTER FOR RESEARCH RESOURCES (NCRR) R, GI**

Pub

Annual RCMI International AIDS Symposium: NCRR provides this forum for Research Centers and Minority Institutions (RCMI) to stimulate discussion and ideas that will lead to collaborative research on AIDS. Proceedings are produced after each symposium in the series.

Pub

NCRR Office of Science and Health Reports: NCRR's Office of Science and Health Reports produces several publications describing recent NCRR accomplishments, resources, and services, including: Program Highlights, an annual report; Research Resources Reporter, a bimonthly periodical; and directories. AIDS research is one of many biomedical research topics covered in these documents.

Ex

AIDS Animal Model Program: NCRR's Office of Science and Health Reports provides information for the public about the AIDS Animal Model Program and alerts qualified researchers to AIDS animal models. NCRR also supplies table-top exhibits used to promote the spf-rhesus and chimpanzee AIDS animal model programs.

Ex

National Traveling AIDS Exhibit and Education Program: NCRR coordinates a hands-on exhibit and associated educational materials to improve public understanding of the fundamentals of microbiology underlying the AIDS epidemic. The target audiences are students in grades 6-12 and their families and

teachers. Additional small modules on Understanding AIDS and a CD-ROM version are being prepared for use by schools, public libraries, and other institutions. For more information about resources and services provided by NCRR, contact the National Center for Research Resources, Office of Science and Health Reports, Westwood Building, Room 10A-15, 5333 Westbard Avenue, Bethesda, MD 20892.

### **FOGARTY INTERNATIONAL CENTER, R, T, CT, P, PT**

Ex

AIDS International Training and Research Program: The Fogarty International Center sponsors training for foreign scientists to increase their capacity to deal with the AIDS epidemic through epidemiological research, clinical trials, and other prevention projects, and to stimulate cooperation and sharing of research knowledge. For more information, write to the Fogarty International Center, National Institutes of Health, Building 31, Room B2-C32, Bethesda, MD 20892.

### **SELECTED PUBLIC HEALTH SERVICE HIV/AIDS INFORMATION ACTIVITIES:**

#### **OFFICE OF NATIONAL AIDS POLICY (ONAP), EXECUTIVE OFFICE OF THE PRESIDENT, R, T, P, GI**

ONAP serves as the staff office responsible for coordinating and integrating all Federal AIDS-related activities, including the development of policy and the setting of priorities.

Db

OASH BBS: The OASH BBS is the free and publicly accessible electronic bulletin board of the White House ONAP and the U.S. Public Health Service (PHS), Office of the Assistant Secretary for Health (OASH). The White House section of the BBS allows for public input on HIV/AIDS-related issues under consideration. The OASH section distributes many files of AIDS-related information from PHS, including NLM's AIDS Bibliography, news releases from NIAID, Federal Register announcements, CDC's AIDS Daily Summary, and AIDS-related press releases and reports. For more information, contact ONAP, Hubert Humphrey Building, Room 738-G, 200 Independence Avenue, SW, Washington, DC 20201; (202) 690-6248. To connect online to OASH BBS, dial (202) 690-5423 using a computer and a modem.

#### **AGENCY FOR HEALTH CARE POLICY AND RESEARCH (AHCPR) R, T**

AHCPR supports activities designed to enhance the quality, appropriateness, and effectiveness of health care services and to improve access to that care through various

programs, including its AIDS Medical Care Effectiveness Program. The program emphasizes three activities: clinical guidelines development and dissemination, data development, and outcomes research.

Pub

AHCPR reports: AHCPR has produced several reports related to HIV/AIDS, including Pediatric AIDS-Related Discharges in a Sample of U.S. Hospitals: Demographics, Diagnoses, and Resource Use and Forecasts of the Costs of Medical Care for Persons With HIV: 1992-1995. AHCPR is responsible for the development of guidelines for the treatment of HIV-infected individuals. For more information write to the Agency for Health Care Policy and Research, Executive Office Center, Suite 501, 2101 East Jefferson Street, Rockville, MD 20852.

**CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) R, PE, PT, GI, P,**

CDC assesses the status and characteristics of the AIDS epidemic and the prevalence of HIV infection, and supports, via financial and technical assistance, the design, implementation, and evaluation of HIV prevention and education activities. The CDC is a co-sponsor of the AIDS Clinical Trials Information Service (see page 4).

Tel, Db, Pub

CDC National AIDS Clearinghouse: The CDC National AIDS Clearinghouse is a comprehensive HIV/AIDS information service targeted to health professionals, managers of HIV/AIDS programs, educators, and information providers. The Clearinghouse helps professionals access HIV/AIDS-related information through its online databases; obtain key HIV materials, such as the HIV/AIDS Surveillance Report, and articles from the Morbidity and Mortality Weekly Report; and share the latest HIV information through CDC NAC ONLINE, an electronic bulletin board service for AIDS-related organizations. The Clearinghouse's services are available Monday through Friday, 9 a.m. to 7 p.m. eastern time, by calling 1-(800) 458-5231; or 1-(800) 243-7012 (TDD).

Tel, Pub

CDC National AIDS Hotline: The CDC National AIDS Hotline is a toll-free HIV/AIDS-related information service that provides confidential information, referrals, and educational materials to the public. The Hotline operates 24 hours a day, 7 days a week. Call 1-(800) 342-AIDS; 1-(800) 344-SIDA (Spanish); or 1-(800) 243-7889 (TDD).

Tel

CDC automated telephone services: For current statistics on HIV infection and AIDS, call the CDC HIV/AIDS Statistics Information Line at (404) 332-4570. CDC's Voice Information System also provides up-to-date information on a

variety of health-related topics, including HIV/AIDS; call (404) 332-4555. To receive free facsimile documents on a variety of HIV/AIDS-related topics, call the CDC Fax Information Service at (404) 332-4565.

### **FOOD AND DRUG ADMINISTRATION (FDA) CT, T, GI**

FDA is responsible for assuring the safety and effectiveness of drugs, biologics, vaccines, and medical devices used in the diagnosis, treatment, and prevention of HIV infection, AIDS, and AIDS-associated opportunistic infections. FDA also works with the blood banking industry to help ensure the safety of the Nation's blood supply. The agency is a cosponsor of the AIDS Clinical Trials Information Service (see page 4). For more information, contact the FDA Office of AIDS Coordination (HF-12), 5600 Fishers Lane, Room 12A-40, Rockville, MD 20857; (301) 443-0104.

Db

FDA Electronic Bulletin Board: FDA operates a publicly accessible electronic bulletin board. Included are press releases related to AIDS, such as those announcing new drug approvals. For more information, contact the FDA Press Office, 5600 Fishers Lane, Rockville, MD 20857. To connect online to FDA BBS, dial 1-(800) 222-0185 using a computer and a modem. The bulletin board is also accessible through the Internet: [fdabbs.fda.gov](http://fdabbs.fda.gov).

### **HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA) CT, T, PE, PT**

HRSA administers education and training programs for health care providers and community service workers who care for AIDS patients. HRSA also administers programs to demonstrate how communities can organize their health care resources to develop an integrated, comprehensive system of care for those with AIDS and HIV infection.

Tel

National HIV Telephone Consulting Service: HRSA funds the toll-free National HIV Telephone Consulting Service to provide information on drugs, clinical trials, and the latest treatment methods to physicians and other health care professionals who have questions about providing care to people with HIV infection or AIDS. All staff members are health professionals with extensive experience in outpatient and inpatient primary care of people with HIV-related diseases. The service, accessible from 10:30 a.m. to 8 p.m. eastern time, can be reached by calling 1-(800) 933-3413.

Tel

HIV Clinical Conference Call Series: In collaboration with the National Institute of Allergy and Infectious Diseases (NIAID), HRSA offers interactive, toll-free

audio teleconferences during which primary health care providers from many disciplines have the opportunity to discuss timely clinical issues with internationally renowned clinical experts. For more information, contact Abe Macher, M.D., Health Services and Resources Administration, 5600 Fishers Lane, Rockville, MD 20852; (301) 443-6364.

Ex

**AIDS Education and Training Centers:** HRSA supports a network of 17 regional centers that serve as resources for educating health professionals in prevention, diagnosis, and care of HIV-infected patients. The centers train primary care providers to incorporate HIV prevention strategies into their clinical priorities, along with diagnosis, counseling, and care of HIV-infected persons and their families. For more information, contact the AIDS ETC Program, Health Resources and Services Administration, 5600 Fishers Lane, Room 4C-03, Rockville, MD 20857; (301) 443-6364.

Ex

**National Pediatric HIV Resource Center:** The Bureau of Maternal and Child Health, HRSA, supports the National Pediatric HIV Resource Center, which offers a range of services to professionals caring for children, youth, and families affected by HIV infection. The Resource Center provides consultation, technical assistance, policy analysis, and clinical training. The center is accessible from 9 a.m. to 5 p.m. eastern time and can be reached by calling 1-(800) 362-0071, fax: (201) 485-2752, or by writing to the National Pediatric HIV Resource Center, 15 South Ninth Street, Newark, NJ 07107.

Pub

**Clinical Issues Subcommittee:** The Clinical Issues Subcommittee of the HRSA AIDS Advisory Committee was set up to facilitate timely dissemination of information about new developments in clinical research, drug development, and policies on HIV disease into language relevant for practicing caregivers, principally those supported by HRSA's HIV/AIDS-related programs. NIAID and the NIH Office of AIDS Research have participated in all its activities. For information, contact Pearl Katz, Ph.D., AIDS Program Office, Health Resources and Services Administration, 5600 Fishers Lane, Rockville, MD 20857; (301) 443-4588.

## **SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA) R, P, GI, PE**

Drug abuse treatment is a primary HIV prevention strategy. SAMHSA administers the Alcohol, Drug Abuse, and Mental Health Services Block Grant and other grant programs providing States and localities with support for substance abuse and mental illness treatment and prevention programs.

Tel, Pub

National Clearinghouse for Alcohol and Drug Information: SAMHSA's Center for Substance Abuse Prevention sponsors the National Clearinghouse for Alcohol and Drug Information (NCADI), which provides current print and audiovisual materials about alcohol and other drugs, including materials explaining the risk of HIV transmission from sharing needles during injection drug use and from unsafe behaviors practiced due to the effects of substance abuse. NCADI's resources include scientific findings; databases on prevention programs and materials, field experts, Federal grants, and market research; and information about organizations and groups concerned with alcohol and other drug problems. For more information, call NCADI at 1-(800) 729-6686, or 1-(800) 487-4889 (TDD).

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## **APPENDIX B: LIST OF EXHIBITORS**

AIDS Clinical Trials Information Service (ACTIS)

P.O. Box 6421

Rockville, MD 20849-6003

AIDS Education and General Information System (AEGIS)

P.O. Box 184

San Juan Capistrano, CA 92693

American Foundation for AIDS Research (AmFAR)

Treatment Information Services

733 Third Avenue, 12th Floor

New York, NY 10017-3204

Centers for Disease Control and Prevention

CDC National AIDS Clearinghouse

P.O. Box 6003

Rockville, MD 20849-6003

Computerized AIDS Information Network (CAIN)

1625 North Hudson Avenue, Suite 105

Los Angeles, CA 90028

Friends of the National Library of Medicine

1555 Connecticut Avenue, NW, Suite 200  
Washington, DC 20036

Health Resources and Services Administration  
Office of Communications  
Bureau of Health Resources Development  
Parklawn Building, Room 9A-33  
5600 Fishers Lane  
Rockville, MD 20857

Home Nutrition Services  
HIV-NET BBS  
6500 Fannin, Suite 1001  
Houston, TX 77030

National Association of People With AIDS  
1413 K Street, NW, 10th Floor  
Washington, DC 20005

National Institute of Allergy and Infectious Diseases  
National Institutes of Health  
Office of Communications  
Building 31, Room 7A50  
9000 Rockville Pike  
Bethesda, MD 20892

National Institute on Drug Abuse  
National Institutes of Health  
Parklawn Building, Room 10A39  
5600 Fishers Lane  
Rockville, MD 20857

National Library of Medicine  
National Institutes of Health  
8600 Rockville Pike  
Bethesda, MD 20894

Office of the Assistant Secretary for Health  
National AIDS Program Office  
Hubert H. Humphrey Building, Room 738G  
200 Independence Avenue, SW  
Washington, DC 20201

Veterans Health Services and Research Administration  
Educational Programs Division  
Office of Academic Affairs, Room 145C

Department of Veterans Affairs  
810 Vermont Avenue, NW  
Washington, DC 20420

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**APPENDIX C: CONFERENCE AGENDA**

NIH HIV/AIDS Information Services Conference

June 28-30, 1993

National Library of Medicine

Lister Hill Center Auditorium

Bethesda, MD

**MONDAY, JUNE 28**

2:00 p.m.

Opening Remarks--Elliot R. Siegel, Ph.D., Chair, Planning Committee

Welcome--Donald A. B. Lindberg, M.D., Director, National Library of Medicine

Opening Address--Anthony S. Fauci, M.D., Director, National Institute Of Allergy and Infectious Diseases

3:00 p.m.

Break

3:15 p.m.

Keynote Address--June Osborn, M.D., Chair, National Commission on AIDS

Report on NIAID/HRSA Information Dissemination Workshop--Debra Fraser-Howze, Executive Director, Black Leadership Commission on AIDS

5:00 p.m.

Reception--Friends of the National Library of Medicine

\*Exhibits on HIV/AIDS Information Resources will be available during sessions and reception.

## **TUESDAY, JUNE 29**

8:30 a.m.

Opening Remarks and Charge to Panels--Elliot R. Siegel, Ph.D.,

National Library of Medicine

Case studies of experiences in obtaining and using NIH HIV/AIDS information services by various user communities, each followed by a panel discussion on effectiveness and needs for change. Panels will consider:

- Content: Subject coverage of NIH HIV/AIDS information products and services, including adequacy of coverage, gaps, issues of quality and review.
- Information Dissemination: Use and appropriateness of technologies for the creation and dissemination of HIV/AIDS information.
- Access to Information: Reaching the intended audience, barriers to use of NIH HIV/AIDS information products and services.

8:40 a.m.

Overview of NIH HIV/AIDS Information Services--

Jack Whitescarver, Ph.D., Linda Reck, Office of AIDS Research, NIH

9:00 a.m.

Panel 1:

HIV/AIDS Information for Clinical Researchers

Co-Chairs: Charles Carpenter, M.D., Brown University; Lynn Besch, M.D., Tulane University

10:00 a.m.

Break

10:15 a.m.

Panel 2:

HIV/AIDS Information for Medical, Dental, and Nursing Providers

Co-Chairs: P. T. Cohen, M.D., San Francisco General Hospital; Neil Schram, M.D., American Association of Physicians for Human Rights

11:15 a.m.

Panel 3:

HIV/AIDS Information for Allied Health Services Providers

Co-Chairs: Caitlin Ryan, M.S.W., Chief, Office of AIDS Administration, Washington, DC, Department of Health and Human Services; Cornell Scott, Hill Health Center, New Haven, CT

12:15 p.m.

Lunch

1:45 p.m.

Panel 4:

HIV/AIDS Information for the Media and the General Public

Co-Chairs: Joanne Silberner, National Public Radio; Philip Hiltz, New York Times

2:45 p.m.

Break

3:00 p.m.

Panel 5:

HIV/AIDS Information for Patients and the Affected Community

Co-Chairs: Reggie Williams, National Task Force on AIDS Prevention, San Francisco, CA; Michelle Wilson, The Positive Woman, Inc., Washington, DC

4:00 p.m.

General Discussion

4:45 p.m.

Concluding Remarks--Donald A. B. Lindberg, M.D., Director,

National Library of Medicine

5:00 p.m.

Adjourn

**WEDNESDAY, JUNE 30**

9:00 a.m. - 3:30 p.m.

Panel Co-Chairs, Case Study Presenters, NIH Staff draft report and recommendations

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## **APPENDIX E:**

### **PANEL MEMBERS AND CO-CHAIRS**

#### **Panel 1: HIV/AIDS Information for Clinical Researchers**

C. Lynn Besch, M.D., Louisiana Community AIDS Research Program, Tulane University, New Orleans, LA (CPCRA), co-chair

Charles Carpenter, M.D., Brown University School of Medicine, Providence, RI (also chairman of NIH AIDS Program Advisory Committee), co-chair

John Carey, M.D., University Hospitals of Cleveland

Judith Blackfield Cohen, Ph.D., Association for Women's AIDS Research and Education, San Francisco, CA

James Dearing, Ph.D., Department of Communication, Michigan State University

John D. Hamilton, M.D., Department of Veterans Affairs, Medical Center, Durham, NC

Donna L. Keegan, Central Advisory Board, Massachusetts Department of Public Health, AIDS Bureau

#### **Panel 2: HIV/AIDS Information for Medical, Dental, and Nursing Providers**

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Neil Schram, M.D., AIDS Task Force, American Association of Physicians for Human Rights, Los Angeles, CA, co-chair

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Henry Wray, D.D.S., Whitman-Walker Clinic, Washington, DC

**Panel 3: HIV/AIDS Information for Allied Health Services Providers**

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Cornell Scott, Director, New Haven Community Health Center, New Haven, CT, co-chair

William Bailey, Ph.D., American Psychological Association, Washington, DC

Suzanne Gagnon, M.D., University of Kansas Medical School at Wichita

Lark Lands, Ph.D., Carl Vogel Center, Washington, DC

Vickie Strange, HANDI Advisory Committee, Elfund, NC

Russ Toth, Computerized AIDS Information Network (CAIN), Los Angeles, CA

**Panel 4: HIV/AIDS Information for the Media and the General Public**

Philip Hilts, New York Times, co-chair

Joanne Silberner, National Public Radio, co-chair

Jon Cohen, Science

Mindy Thompson Fullilove, M.D., Associate Professor, Clinical Psychiatry and Public Health, Columbia University

Mary Hagar, Newsweek

Jean Hofacket, AIDS Library of Philadelphia, PA

Lisa Keen, Washington Blade

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**Panel 5: HIV/AIDS Information for Patients and the Affected Community**

Reggie Williams, Executive Director, National Task Force on AIDS Prevention, San Francisco, CA, co-chair

Michelle Wilson, The Positive Woman, Inc., Washington, DC, co-chair

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**APPENDIX F:**

**CASE STUDY SYNOPSES**

**Panel 1: HIV/AIDS Information for Clinical Researchers**

Research and the Popular Press: Improving Coverage

In a letter appearing in the journal Lancet, the Medical Research Council (Britain) and INSERM (France) jointly release a summary of preliminary results of the Concorde trial.(4) This study focuses on the role of AZT in the early treatment of HIV disease. Should the physician prescribe it immediately or wait until the onset of symptoms? The trials were opened in October 1988 and closed to accrual in October 1991.

The Lancet letter describes results of an "intent to treat" analysis including data through December 1992, a mean followup of 3 years. "The authors state that the immediate use of this medication did not result in any significant benefit as compared to deferred therapy in terms of survival or disease progression." When comparing their findings to reports that describe events during a shorter followup period, the authors state that "The findings from Concorde at a comparable short followup time were not inconsistent with [the delay in progression to AIDS or ARC, but]. . . such a delay was not seen over the longer followup period."

The translation of this study by the popular press ranges from thoughtful to misleading. Coverage seems to center on the conflict between this study's results with earlier results, rather than presenting them in a larger picture of data from other studies.

The desire of the investigators to make preliminary information available is laudable. However, the process for its release provides insufficient data for other researchers, primary care providers, or patients to make fully informed assessments of the implications of the study.

Considering these problems, certain questions are raised: How can the scientific community better serve itself and the world in quickly and comprehensively presenting the results of incremental research advances? How can the popular press improve coverage of important medical news so that it is presented in a proper and complete perspective?

## **Panel 2: HIV/AIDS Information for Medical, Dental, and Nursing Providers**

Needed: Timely and Coordinated Release of Research Results

An open comparison study of ddI and ddC with the progression of HIV/AIDS (including death) and tolerance of the study drugs was conducted by Community Programs for Clinical Research on AIDS (CPRCA). Research by this group involves community physicians and their patients in studies that evaluate the effectiveness of a broad spectrum of therapies and treatment regimens. Through this diversity, CPRCA extends the opportunity for participation in clinical research to persons underrepresented in traditional HIV studies.

The study opens in December 1990 and by September 1991 the last patient enrolls. For the next year all patients are followed. On January 20, 1993, results are sent to the CPRCA principal investigators and to the NIH AIDS Research Advisory Committee. The Committee recommends that a "Note to Physicians" be sent out by NIAID detailing what has been learned.

In the meantime, AIDS activists learn that the results of the study are known and insist that, for ethical reasons, the public should be made aware of these results as soon as possible. Thus, a press release is sent to the popular media on January 22. The "Note to

Physicians," with details of the study results, is held up pending review by the many individuals involved in the study's implementation.

Ten days later, on February 1, 1993, CPRCA releases the Note to a wide list of more than 4,000, including 2,500 physicians who care for HIV-infected patients, other health care providers, a press list of 141 writers and reporters, and others who have requested information.

The result of the delay between issuing the press release and distributing the "Note to Physicians" is that for 10 days clinical providers have only the information in a newspaper story to rely on in advising their patients. Also, some physicians will never receive the Note. Optimum patient care under such circumstances is impossible.

### **Panel 3: HIV/AIDS Information for Allied Health Professionals**

#### Allied Health Professionals: Lack Access

Margaret enters the office of her supervisor and after a few perfunctory words the supervisor says, "Sit down, because I have a tough case for you."

Margaret, a social worker in a multicultural, low-income area of Chicago, learns that her new client, an African-American woman, aged 31 with three children, married to an injecting drug user, has been diagnosed with AIDS. She has failed to show up for her last two appointments, continues to have unprotected sexual intercourse, and has not taken her medications regularly. Although Margaret has only limited experience with the HIV population, this client is referred to her for case management.

Learning that the client's condition and attitude is all too typical, Margaret decides to design an effective program for HIV-infected African-American women. Initially, she speaks to another case worker in her office who provides her with case summaries that deal with intervention strategies in general. Then she turns to the National Association of Social Workers, which sends her a packet of information including a literature search from its database, Social Work Abstracts.

Another source, the CDC National AIDS Clearinghouse, sends a search from its Educational Materials Database, which includes descriptions and sources of materials relating to HIV disease pertaining to IV drug users and their partners. The Clearinghouse also suggests that Margaret check with her local hospital and university library to see if they will provide literature searches from NLM's AIDSLINE and POPLINE, as well as from Sociological Abstracts and PsycINFO (the psychological abstracts database).

These tools enable Margaret to find several journal articles and texts in the library that provide a thorough review of all these issues as well as actual case studies. She develops a comprehensive treatment plan and program taking into account this client's history and ethnic background.

## **Panel 4: HIV/AIDS Information for the Media and the General Public**

### Ensuring Accurate Information for the Public: A Continuing Problem

The difficulties faced by public health agencies in ensuring the dissemination of accurate AIDS information to the media and the public are illustrated by two recent controversies. The first involves Peter Duesberg, a professor at the University of California at Berkeley, who, in March 1987, startles his colleagues and the public with an announcement that he does not believe the dominant view among the world's scientists that HIV causes AIDS. His continual attacks on what he terms the "AIDS establishment" draw sharp rebuttals from eminent researchers in the United States. Dr. Duesberg contends that correlation is not causation; there must be another unknown agent more virulent than HIV that is causing AIDS. Dr. Duesberg is often quoted by journalists concerning alternative theories of the cause of AIDS.

The second controversy is set at the VIII International Conference on AIDS in Amsterdam in 1992. In the corridors, at cocktail parties, and during council meetings, attendees discuss the article in a weekly news magazine that a few aberrant cases of people with AIDS who did not test HIV-positive indicate that there could be a new transmissible virus. Its sudden and prominent appearance, and the realization by science writers that they had been "scooped" on a major story by a mass market magazine, cause journalists to focus on this "mystery virus" to the virtual exclusion of the 1,100 papers and their authors scheduled for the conference.

Conference organizers respond to the media rush by convening a special scientific session and a press conference to address the issue. The scheduling of the special session lends further credibility to the mystery virus story. Unintentionally, government representatives reveal that information has been withheld about the existence of certain patients. Highly regarded researchers in the audience lend credibility to the rumor of a new virus by admitting that they were observing similar patients.

Weeks after the conference and hundreds of news stories about the possibility of a new sexually transmitted virus, CDC and NIH determine that there is no evidence of an unknown virus. The cases remain mysterious but do not indicate transmission or contagion. The focus on this mystery virus seems to create a problem that, in reality, does not exist.

## **Panel 5: HIV/AIDS Information for Patients and the Affected Community**

### HIV/AIDS Patients: Information Difficult to Find

Lucille became HIV-infected as a result of unprotected sex. She works full-time and has a 20-year-old daughter and a young grandson who live with her. She also supports her severely disabled husband, who has AIDS.

As a group member of a health maintenance organization, she visits her primary care physician for regular checkups every 4 months. He spends 10 to 15 minutes with her, going over current health concerns and recent blood test results.

During her third visit Lucille asks about the possibility (or desirability) of becoming involved in a clinical trial. The doctor promises that if she did the research and found out about the various trials, he would provide an opinion on whether or not she should become involved.

To find clinical trials as well as current and potential treatments, including nontraditional treatment, Lucille goes to her local library. Then she contacts State and Federal Government health agencies for information by mail. Finally, she seeks data from leading HIV/AIDS organizations. That leads to a list of newsletters and bulletins published by health agencies and grassroots/activist groups.

The array of information grows. Some is highly technical, some elementary, some conflicting (i.e., Newsletter A touts the benefits of a certain course of treatment while Newsletter B states that it is useless or downright harmful). Little, if any, is geared toward the specific needs of women.

While Lucille is intelligent and resourceful, it quickly becomes apparent that more is required. Much of the information available is via online computer systems. Lucille has no funds to pay for the information, no access to a computer, and no training in how to retrieve online data.

The stress of "trying to keep it all together" is getting tough. She finds little or no substantive information available about the long-term psychological reactions to living with HIV. This material would be useful for Lucille as well as for her daughter and husband, who are also under a great deal of stress.

Her quest for information on AIDS clinical trials is rewarded with information on the Community Programs for Clinical Research on AIDS, which is composed of 17 research units, consisting of consortiums of primary care physicians and nurses located in 13 U.S. cities. Since these units represent geographic, racial, and risk group diversity, they extend greater opportunity for participation in clinical research to persons, such as Lucille, who are underrepresented in traditional HIV studies.

Lucille's case, too, is anecdotal and deliberately cast as atypical to make a poignant point to the conference panel: If locating basic information is difficult for Lucille, how much tougher might it be for someone less resourceful—someone who doesn't speak English well . . . or read well?

Could there be one-stop shopping for information, through primary health providers, which would ease the burden for women who have to work and care for families even while they are concerned about their own health? How can information be disseminated

to people who do not seek regular medical care or who are hospitalized or are in long-term care facilities, or incarcerated?

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## **GLOSSARY**

## **ACTG**

AIDS Clinical Trials Group is composed of a number of U.S. medical centers that evaluate treatment for HIV and HIV-associated infections. ACTG studies are sponsored by the National Institute of Allergy and Infectious Diseases (see)

**Affected Community**

HIV-positive people, persons living with AIDS, and other individuals, including their families, friends, and advocates, directly impacted by HIV and its physical, psychological, and sociological ramifications

**Agency for Health Care Policy and Research (AHCPR)**

An agency of the Public Health Service that supports activities to enhance health care services and improve access to them

**AHCPR**

Agency for Health Care Policy and Research (see)

**AIDS**

Acquired Immunodeficiency Syndrome, an immune system disease caused by the human immunodeficiency virus in which resistance of the body to certain infections and cancers is lowered

**AIDSDRUGS**

National Library of Medicine (see) online database with references to drugs undergoing testing against AIDS, ARC, and related opportunistic infections

**AIDSLINE**

National Library of Medicine (see) online database with citations and abstracts covering the published scientific/medical literature on AIDS and related topics

**AIDSTRIALS**

National Library of Medicine (see) online database of clinical trials of agents under evaluation against HIV infection, AIDS, and related opportunistic infections

**AIDS Knowledge Base**

Full-text electronic database--available in printed as well as in electronic form--on AIDS, produced and maintained by physicians and other health care professionals. Edited by P.T. Cohen, Merle Sande, and Paul Volberding

**AIDS Research Advisory Committee**

Advisory board that advises and makes recommendations to the Director, NIAID (see) on all aspects of research on HIV and AIDS, including treatment research, vaccine development, pathogenesis, and epidemiology

**AIDS Service Organization (ASO)**

Health associations, support agencies, and other services active in the prevention or treatment of AIDS

**Allied Health Care Providers**

Professionals who provide health-related, usually nonmedical services and who are generally not considered 'health care providers.' Examples include social service workers, nutritionists, and case managers

**Alternative Media**

Nontraditional mechanisms (e.g., local cable TV) for disseminating news and information to the public, usually to special target populations such as racial or ethnic minorities, or groups such as gays, lesbians, and bisexuals

**Alternative Therapy**

In Western countries, alternative therapy refers to any type of medicine that supplements biomedicine or allopathic medicine. In other parts of the world, where traditional medicine predominates, the term may refer to biomedicine itself

**Antiretroviral Agents**

Substances used against retroviruses such as HIV

**ARC**

AIDS-Related Complex. One or a set of symptoms, occurring in a person with HIV, which is not classified as an AIDS-defining condition

**ASO**

AIDS Service Organization (see)

**AZT**

Azidothymidine (also called zidovudine, Retrovir) -- one of the first drugs used against HIV infection. AZT is a nucleoside (genetic building block) analog that suppresses replication of HIV

**BBS**

Bulletin Board System (see Electronic Bulletin Board System)

**CBO**

Community-Based Organization (see)

**CDC**

Centers for Disease Control and Prevention (see)

**CDC National AIDS Clearinghouse**

The CDC's (see) comprehensive reference, referral, and publication distribution service for HIV and AIDS information. The Clearinghouse works in partnership with national, regional, State, and local organizations that develop and deliver HIV prevention programs and services

**Centers for Disease Control and Prevention (CDC)**

Centers for Disease Control and Prevention, a Public Health Service agency responsible for assessing status and characteristics of AIDS epidemic and prevalence of HIV infection. CDC supports design, implementation, and evaluation of prevention activities, and maintains various HIV/AIDS information services

**Clinical Alert**

A mechanism, recently adopted by NIH in conjunction with the editors of several biomedical journals, for urgent cases in which timely and broad dissemination of results of clinical trials could prevent morbidity and mortality. The Clinical Alert does not become a barrier to subsequent publication of the full research paper. Clinical alerts are widely distributed electronically by NLM and through standard mailings

**Clinical Practice Guidelines**

Standards for physicians to adhere to in prescribing care for a given condition or illness

**Clinical Trials**

Controlled trials set up to evaluate the toxicity and effectiveness of drugs or biological agents (e.g., vaccines) in humans

**Community-Based Organization (CBO)**

A locally based service organization that provides social services at the community level

**Community Programs for Clinical Research on AIDS (CPCRA)**

National Institute for Allergy and Infectious Diseases (see) initiative to broaden the base of clinical investigations by involving community physicians in AIDS research and trials

**Concorde Study**

Joint French/British clinical trial of AZT (see) in asymptomatic, HIV-positive individuals

**CPCRA**

Community Program for Clinical Research on AIDS (see)

**Cultural Sensitivity**

An expressed awareness and understanding of psychosocial differences among communities of different ethnic or racial background, sexual orientation, socioeconomic status, or geographic location

**Database**

An organized compilation of information, usually maintained in a computer system

**DATRI**

Division of AIDS Treatment Research Initiative, established by NIAID (see), is a national network to test new therapies for HIV-infected persons. Its hallmark is the ability to rapidly conduct clinical trials and related research that evaluates new therapies and novel treatment approaches for those with HIV disease

**ddC**

Dideoxycytidine (zalcitabine, Hivid) -- a drug (nucleoside analog) that inhibits the replication of HIV

**ddI**

Dideoxyinosine (didanosine, Videx) -- a drug (nucleoside analog) that inhibits the replication of HIV

**Detailing**

Use of pharmaceutical company representatives ('detail men') to bring information about a company's drug products to doctors' offices

**Educational Materials Database**

Maintained by CDC's National AIDS Clearing-house (see), the database is a collection of information about hard-to-find educational materials tailored to a variety of audiences and focusing on different aspects of HIV infection and AIDS

**Efficacy Stage**

The stage of a clinical trial (see) that tests the effectiveness (rather than the toxicity) in humans of the drug or substance under study

**Electronic Bulletin Board System (BBS)**

Computerized information services that are accessed by computers with modems (computer communication devices) linked to telephones. In the HIV/AIDS area, BBS's have become essential means for obtaining current information as well as providing interactive forums for networking among professionals and members of the affected community

**Electronic Index**

Index to an information compilation; the index is built, maintained, and searchable in a computerized system

**Electronic Information Systems**

Computerized information systems, including databases, online retrieval services, electronic bulletin boards, facsimile services, etc.

**End-Stage Disease**

Stage of advanced illness at which there is reasonable certainty that the patient will not recover

**Epidemic**

A disease affecting at the same time a large number of persons in a locality, and spreading from person to person; the disease is not permanently prevalent in that locality

**Epidemiology**

The branch of medical science that deals with the incidence, distribution, and control of a disease in a population

**ETC's**

AIDS Education & Training Centers supported by HRSA (see)

**FDA**

Food and Drug Administration (see)

**Folk Healer**

One who practices healing using treatments based on folk medicine (see)

**Folk Medicine**

The mode of treatment based on traditional beliefs that is common to a group of people. It need not involve a specific medical system, but relates rather to traditional use within a group or tribe of people

**Food and Drug Administration (FDA)**

The PHS agency responsible for ensuring the safety and effectiveness of drugs, biologics, vaccines, and medical devices used in the diagnosis, treatment, and prevention of HIV infection, AIDS, and AIDS-related opportunistic infections. The FDA also works with the blood banking industry to safeguard the Nation's blood supply

**Full Text Databases**

Databases (usually computerized) containing the entire text of a document, not merely abstracts or citations. Searching full-text databases usually implies the ability to search for words occurring anywhere in the text of the document

**Gatekeeper**

Person or organization that facilitates access to an information source, system, or service

**Health Resources & Services Administration (HRSA)**

A PHS agency that administers education and training programs for health care providers and community service workers who care for AIDS patients. HRSA also administers programs to demonstrate how communities can organize their health care resources to develop an integrated, comprehensive system of care for those with AIDS and HIV infection

**Hemophiliac**

Person suffering from hemophilia, a condition of males characterized by a tendency to bleed immoderately, as from an insignificant wound; caused by improper coagulation of the blood

**Herbalist**

Specialist in medicinal plant products to treat various ailments. Herbalists tend to compound and prescribe much as patent drug pharmacists did

**High Performance Computing Systems**

State-of-the-art computing systems under development as part of the High Performance Computing Act of 1991, which funded research and development of high-capacity computers and high-speed networks

**HIV**

Human immunodeficiency virus, retrovirus (see) considered to be the causative agent of AIDS

**HMO**

Health maintenance organization

**Hotline**

Telephone-based information service -- normally for urgent inquiries -- staffed by persons knowledgeable in a special subject area such as HIV infection. Responses to inquiries are provided immediately

**HRSA**

Health Resources and Services Administration (see)

**Indian Health Service (IHS)**

PHS agency providing a comprehensive health service delivery system for American Indians and Alaskan Natives

**Information Kiosk**

Usually a collection of pamphlets and brochures displayed on a rack in a physician's office, clinic, pharmacy, shopping center, or other public place

**Inreach**

Effort to obtain knowledge about the results or effects of an activity or service (also referred to as obtaining feedback)

**INSERM**

France's Institute of Health and Medical Research

**Intent to treat**

Analysis of clinical trial results that includes all data from all patients in the groups to which they were randomized even if they never received the treatment

**Internet**

The worldwide electronic network of networks that connects computer systems at universities, research centers, other institutions, and commercial organizations. The Internet provides file transfer, remote login, electronic mail, news, and other services

**Jargon-Free**

Expressed in nontechnical language

**Kemron**

Low-dose, natural human alpha interferon, reported to improve HIV-related symptoms. Alpha interferon is one of three interferons, natural human proteins produced by the body in response to viral infections

**MEDLARS**

Medical Literature Analysis and Retrieval System--the cluster of online information services provided by the National Library of Medicine (see)

**Methadone**

Synthetic narcotic drug used in the treatment of addiction to heroin and other opium-derived narcotics

**National AIDS Clearinghouse**

CDC National AIDS Clearinghouse (see)

**National Cancer Institute (NCI)**

An NIH institute with the overall mission of conducting and supporting research, training, and health information dissemination with respect to the causes, diagnosis, and treatment of cancer. NCI performs these functions for cancers related to HIV infection

**National Center for Research Resources (NCRR)**

An NIH organization that conceives and develops a wide variety of research resources and ensures their availability, thereby strengthening and enhancing biomedical research supported or performed by NIH. NCRR supports a variety of HIV-related studies

**National Commission on AIDS**

Commission formed under Public Law 100-607 for the purpose of promoting the development of a national consensus on policy concerning AIDS and for studying and making recommendations for a consistent national policy concerning the HIV epidemic

**National Institute of Allergy and Infectious Diseases (NIAID)**

An NIH institute that conducts and supports research to study the causes of allergic, immunologic, and infectious diseases, and to develop better means of preventing, diagnosing, and treating illnesses. NIAID is responsible for the federally funded national AIDS research program

**National Institute of Child Health and Human Development (NICHD)**

An NIH institute that conducts and supports research on the reproductive, developmental, and behavioral processes that determine the health of children, adults, families, and populations. Thus, NICHD supports clinical research related to the transmission of HIV from infected mothers to offspring, the progression of disease in HIV-infected infants and children, and the testing of potential therapies and preventatives for this population

**National Institutes of Health (NIH)**

A multi-institute agency of the Public Health Service, NIH is the Federal focal point for health research. It conducts research in its own laboratories and supports research in universities, medical schools, hospitals, and research institutions throughout this country and abroad

**National Institute of Mental Health (NIMH)**

An NIH institute. NIMH conducts and supports research on the neuroscientific, behavioral, and psychosocial aspects of HIV infection

**National Institute on Alcoholism and Alcohol Abuse (NIAAA)**

An NIH institute. NIAAA conducts and supports HIV-related alcohol research in basic science, epidemiology, and prevention. Studies have shown that alcohol consumption can cause alterations of the immune system that compromise host defenses against HIV infection

**National Institute on Drug Abuse (NIDA)**

An NIH institute. NIDA conducts and supports a wide range of AIDS research. HIV infection is directly related to injection drug use through blood contamination of shared equipment (e.g., needles)

**National Library of Medicine (NLM)**

An NIH institute. NLM is one of three U.S. national libraries. It is the world's largest research library in a single scientific and professional field (i.e., medicine). The library provides electronic and printed information services relating to HIV/AIDS (e.g., AIDSLINE, AIDSTRIALS, AIDSDRUGS, and the AIDS Bibliography)

**National Research and Education Network (NREN)**

National Research and Education Network, a U.S. effort to combine electronic networks, connecting research centers and educational institutions into a single, high-speed network. NREN is part of the Nation's High Performance Computing Systems (see)

**Natural History Studies**

Epidemiologic surveys of the progression of an illness

**NCI**

National Cancer Institute (see)

**Network**

Computerized resources in different geographic areas linked by electronic communication systems (e.g., telephone, cable). In another usage, the term network (or networking) also refers to people meeting or linking up with other people, usually in professional settings such as conferences

**NIAID**

National Institute of Allergy and Infectious Diseases (see)

**NIH**

National Institutes of Health (see)

**NIH Office of Communications**

The unit in the NIH Director's office that is responsible for overall direction, planning, and coordination of NIH information activities

**NLM**

National Library of Medicine (see)

**Note to Physicians**

An NIH document, sent to physicians, which reports on the results or findings of a clinical trial or trials and explains the implication these findings have on recommended clinical practices

**NREN**

National Research and Education Network (see)

**Nurse Practitioner**

A Registered Nurse with an advanced degree who evaluates, diagnoses, and treats patients under the auspices of a licensed physician

**OAR**

Office of AIDS Research (see)

**Office of AIDS Research (OAR)**

Organization in the NIH Director's office that coordinates the scientific, budgetary, legislative, and policy elements of the NIH AIDS research program

**One-stop-shopping Model' for Information Service**

The arrangement whereby a single source or information provider supplies all the information resources necessary for a given subject area (such as HIV/AIDS)

**Outreach**

Policies or activities that involve deliberate reaching out to particular communities with information or services

**Pandemic**

A disease prevalent throughout an entire country, continent, or the whole world

**PDQ**

Physician Data Query System -- a National Cancer Institute-maintained electronic information and referral system, available through (among others) the National Library of Medicine. PDQ provides data on cancer, prognosis, treatment, investigational therapies, experimental drugs, and physicians and health care centers involved in cancer care. PDQ

can be thought of as an example of the 'one-stop-shopping model' (see) for information services

**Peer review**

The process by which new scientific or medical findings announced by one researcher are reviewed by other scientists or physicians before these findings are published

**PETT**

Public Education Technology Transfer (see)

**PHS**

Public Health Service (see)

**POPLINE**

Online database on NLM system with citations and abstracts to worldwide literature on family planning and population. Includes such areas as research in human fertility, contraceptive methods, maternal and child health care, and AIDS in developing countries. Produced by Johns Hopkins Population Information Program

**Prophylaxis**

Treatment that helps to prevent a disease or condition before it occurs or recurs

**PsycINFO**

Online bibliographic database covering the worldwide literature in psychology and the behavioral sciences. Available through several online service providers, including BRS and DIALOG

**Public Education Technology Transfer Project (PETT)**

Project to improve access to information about clinical trials and HIV/AIDS among people who are at risk for, or are involved in, the lives of people with HIV/AIDS

**Public Health Service**

A multiagency (e.g., CDC, HRSA, NIH) organizational component of the U.S. Department of Health and Human Services

**Public Information Officer**

A spokesperson representing an organization such as a government agency whose function it is to represent that organization to the media

**Retrovirus**

A type of virus that invades cells where it converts its genetic information, RNA (ribonucleic acid), into viral DNA (deoxyribonucleic acid). This virus' unusual mode of replication introduces a high rate of genetic mutation that contributes to its ability to evade defense by the body's immune system and-- eventually-- the action of drugs

**Sci.med.aids**

A news group on the Internet (see) specializing in AIDS-related information

**Sidebar**

Journalistic term for additional explanatory information about a concept or an article, usually printed in a box on the side of the article

**Sociological Abstracts**

Online bibliographic database with citations and abstracts to over 1,500 journals in the field of sociology and related disciplines in the social and behavioral sciences. Available through several online service providers including BRS and DIALOG

**Sound Bite**

A short phrase, sentence, or collection of sentences (sometimes taken out of context) quoted on the radio or on television

**Standards of Care**

Treatment regimen or medical management based on state-of-the-art patient care

**STD**

Sexually transmitted disease

**Underserved Areas**

Populations or geographic areas that are not provided with adequate services

**USDA Extension Service**

United States Department of Agriculture Cooperative Extension System, a national educational network which is a partnership of the USDA, State land grant universities, and county governments. Its mission is to help people improve their lives through an educational process that uses scientific knowledge focused on issues and needs

**VA**

Department of Veterans Affairs (formerly Veterans Administration). The Department conducts AIDS prevention programs and provides medical care to veterans with AIDS

**Warmline**

A telephone reference service for nonurgent inquiries (as contrasted with hotline).

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