

**JOINT COLLECTION DEVELOPMENT POLICY
STATEMENT
OF**

THE NATIONAL LIBRARY OF MEDICINE
and
THE LIBRARY OF CONGRESS

**ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS)
and the
HUMAN IMMUNODEFICIENCY VIRUS (HIV)**

INTRODUCTION

As a disease, the acquired immunodeficiency syndrome (AIDS) is an epidemic; as a social and political phenomenon, it has profoundly influenced many aspects of contemporary life. Since its recognition in 1981, the AIDS epidemic "has been paralleled closely by a rapidly expanding literature concerned with many aspects of the disease."¹ "The dramatic growth in production of AIDS information...has occurred across all sectors and in all formats: monographs, serials, audiovisuals, databases, and journal[s]."²

The resulting profusion of published material is unique in the biomedical literature because of an unprecedented, simultaneous demand for information on the topic from the lay public and health professionals, an unusual situation because the migration of biomedical concepts from the primary scientific literature to the popular press generally takes several years.

The National Library of Medicine (NLM) and the Library of Congress (LC) assume a significant role in collecting library materials sufficient to meet information needs on topics relating to AIDS and the human immunodeficiency virus (HIV). In the case of this extremely diverse and multifaceted literature, the general mission and collecting responsibility of these two national libraries cannot be mutually exclusive.

As the nation's library of record in biomedicine, NLM assumes primary collecting responsibility for the clinical and research aspects of the AIDS/HIV literature. NLM also assumes a primary role in collecting and preserving the public health literature. The collecting role of LC is primarily centered on the cultural, psychological, economic, ethical, social, educational and legal aspects of the AIDS/HIV phenomena. LC selects materials to provide a fully representative but non-specialized documentation of the AIDS/HIV phenomenon as it unfolds, with a

strong emphasis on legislation and the legal literature related to AIDS/HIV as well as complete statistical data to chronicle the incidence and socio-economic profile of the AIDS/HIV epidemic.

PURPOSE

As the collecting emphasis of the two national collections differs with respect to the AIDS/HIV literature, a clarification of responsibility for the various components of the literature by subtopic is appropriate to ensure the efficient, cohesive and comprehensive acquisition of materials while avoiding unnecessary and expensive duplication of effort and materials. NLM and LC officials have reviewed their collection development policies with the ultimate goal of facilitating access to AIDS/HIV information for all users. This statement is designed to outline the collecting responsibilities of the two libraries and to clarify the respective roles of LC and NLM in an area of intense interest to health professionals, government officials and the general public.

DEFINITION

Scope definitions for acquired immunodeficiency syndrome and the human immunodeficiency virus in the context of the biomedical literature are provided by MESH®, NLM's authoritative controlled indexing and cataloging vocabulary: AIDS is defined as "an acquired defect of cellular immunity associated with infection by the human immunodeficiency virus (HIV) and increased susceptibility to opportunistic infections and malignant neoplasms. Clinical manifestations also include emaciation (wasting) and dementia."³ In 1985, the Centers for Disease Control published a detailed and lengthy case definition⁴ of AIDS, principally to be used as the guide for reporting the incidence of various manifestations of human T-cell lymphoma virus (HTLV-III, now known as the human immunodeficiency virus, HIV). The definition was revised in 1987⁵ and continues to be used principally for epidemiological purposes. For the purposes of this document, the social, cultural and legal aspects of the disease are also considered as integral parts of an AIDS/HIV definition.

HIV is acknowledged to be the agent responsible for the acute infectious manifestations, neurologic disorders, and immunologic abnormalities linked to the acquired immunodeficiency syndrome.

HIV infections include the spectrum of human immunodeficiency virus infections that range from asymptomatic seropositivity, through AIDS-related complex (ARC), to acquired immunodeficiency syndrome (AIDS).

The literature of AIDS/HIV is substantial in itself and also has important linkages to and relationships with the literatures of many disciplines, among them

epidemiology, ethics, health care delivery, immunology, law, oncology, physiology, pulmonary medicine, psychiatry, public health, religion, sociology and virology.

GENERAL PRINCIPLES GOVERNING COLLECTING OF AIDS/HIV MATERIALS

National Library of Medicine

NLM attempts to assemble a comprehensive collection of the scholarly biomedical literature of AIDS/HIV.

NLM's particular interest in AIDS/HIV literature includes materials dealing with the clinical, research and public health aspects of the disease. These materials are collected comprehensively.

Other substantive AIDS/HIV related literature, including media and print materials which chronicle associated health related developments or trends, are typically produced as narratives or commentaries rather than in traditional scientific style. These materials are collected broadly as well.

Public health issues and crises such as the AIDS/HIV epidemic often engender a large body of literature, not completely biomedical in content or specifically addressed to the health professional. NLM collects selectively such materials emphasizing those which characterize diverse viewpoints, chronicle the public health response of health professionals and policymakers, or document information about AIDS/HIV disseminated to patients and society at large. NLM's collecting focus is on works endorsed by health care associations, important patient advocacy groups, and other influential organizations. Materials limited to civil rights, political issues, religion, criminal behavior and related non-medical concerns are generally excluded from the NLM collection.

Library of Congress

LC will endeavor to acquire materials in all media which contribute to a knowledge of the cultural, ethical, psychological, legal, religious, social, economic, historical, and political aspects of AIDS/HIV, but generally will not acquire works relating to the actual practice of medicine and AIDS/HIV issues addressed primarily to professional practitioners or to the biomedical research community. LC will also collect materials on AIDS/HIV as they relate to research in the biological sciences as a whole, to be covered with the same level of inclusiveness as works in these fields are broadly covered to support general research. LC will collect medical materials to the level prescribed for medical literature established by LC acquisitions policy.

More particularly, LC will attempt to collect comprehensively in the field of legislation and other governmental documentation related to AIDS/HIV, in the United States at both national and sub-national levels, and for foreign legislation, in accordance with established acquisitions policies.

LC will endeavor also to collect a broadly representative sampling of all types of materials and formats that document the impact of AIDS/HIV on the public imagination, as reflected in literary, dramatic and artistic production as well as historical and sociological studies. General canons of selection for materials in these fields shall apply. LC, however, gives special attention to the collecting of graphic and moving image materials.

THE VISUAL RECORD OF AIDS/HIV

NATIONAL LIBRARY OF MEDICINE

Audiovisuals

NLM collects audiovisual materials less broadly than print formats. Materials are considered for selection if the information is considerably enhanced by audiovisual presentation. NLM's collecting interest in AIDS/HIV related audiovisuals is on those produced for use by health professionals or those that are of potential interest to historians of the health sciences. Especially important to the NLM collection are works which document innovations, procedures, attitudes, issues or policies concerning or affecting health care and biomedical science as well as those which document significant events or the life and work of individuals important in AIDS/HIV research and treatment. Audiovisuals of historical interest may include those on AIDS/HIV related topics produced for a broad audience.

Generally only audiovisuals in standard U.S. formats are collected, though other formats may be selected if necessary for the historical collection. Audiovisuals in foreign languages, including those produced in the U.S., and audiovisuals produced outside the U.S., even in English, are collected only when they contain unique information and are of special historical importance.

Prints and Photographs

NLM selects for its Prints and Photographs Collection the following types of materials related to AIDS/HIV: [1] portraits of physicians and health professionals who figure prominently in the chronicle of the AIDS/HIV crisis; [2] photographs illustrating the care of AIDS and other HIV patients in hospitals, hospices, and other health care settings; and [3] fine prints characterized by a strong medically related AIDS/HIV theme. These categories are augmented with a comprehensive

collection of visual material which appears in the clinical and research literature, e.g., photographs of viruses, disease manifestations, health care facilities, etc.

Posters

NLM seeks to identify and acquire public health outreach posters which deal specifically with AIDS/HIV as a public health issue. Themes of interest include AIDS/HIV prevention, safe sex and announcements of related conferences and meetings. Collecting emphasis is on posters issued by professional health associations and medical or public health organizations. Foreign language posters and items from all over the world are collected in an attempt to document as completely as possible the present global, massive health education effort aimed at controlling the epidemic.

LIBRARY OF CONGRESS

Audiovisuals

LC maintains an audiovisual collection which deals broadly with the sociological and political aspects of AIDS/HIV. It is assembled with a view to its potential as a record of how the media, especially television, have dealt with AIDS/HIV. This coverage has an extremely wide range, from educational films and broadcast documentaries to television dramas. Additionally, LC endeavors to maintain major network news coverage about AIDS/HIV on an ongoing basis.

LC does not, however, collect audiovisual materials of a strictly medical diagnostic or therapeutic nature. This material, usually received through Copyright deposit, is offered to the NLM in accordance with standing procedures for the transfer of materials not selected for the LC collections.

LC also endeavors to acquire for the recorded sound collection a representative coverage of audio material on AIDS/HIV, obtained primarily from the National Public Radio programs that are deposited at LC. LC aims to collect audio materials at the higher end of the instructional level, with a substantial portion being obtained through Copyright deposit. The Motion Picture, Broadcasting and Recorded Sound Division serves as the custodial unit for the above-mentioned materials in LC.

Photography and the Graphic Arts

Visual materials related directly to medical practice and public health are normally offered to NLM in accordance with standing procedures. Documenting the impact of disease on society and societal reaction to disease, however, falls within the scope of the established LC collection policies. The Prints and Photographs

Division of LC endeavors to acquire a wide selection of photographic materials depicting events of national political, historical, or cultural impact on American life and history in support of its research collections in other formats.

Artistic response to AIDS/HIV in the late twentieth century, which has hastened the erosion of boundaries between documentary tradition and fine arts practice, is extremely varied in its imagery and format. From depictions of specific physical effects of the infection to broad metaphorical images of the epidemic, the variety in artistic response to the disease has expanded as rapidly as print information. To provide visual documentation of the AIDS/HIV crisis, LC collects a broad sample of artistic representations, selecting materials to express the range of societal issues (e.g., economic, political, cultural, gender-related, etc.) emerging with the spread of the disease. Materials are acquired selectively, yet broadly enough to support future research on the political and social aspects of AIDS/HIV and the visual vocabulary developed in response to the disease.

Photographic acquisitions include the work of representative contemporary photographers, whose subject matter ranges from documentation of living conditions of people with AIDS/HIV through the emotional impact of the disease to symbolic representations of the virus and its effects. Posters are collected with an emphasis on original, activist, socio-political images and themes by important graphic artists and related studios and may include a sampling of public health outreach posters issued by health professional associations and medical and public health institutions (in contrast to the comprehensive approach to collecting public health posters related to AIDS/HIV at NLM). Fine prints, cartoon drawings, and other graphic materials representative of the creative response to the epidemic also are selected for LC's collections on AIDS/HIV to support existing research level collections in other formats.

The Prints and Photographs Division serves as the LC custodial unit for the above-mentioned materials.

COLLECTING LEVELS AT NLM AND LC

National Library of Medicine

NLM's concept of comprehensive collecting is compatible with the Comprehensive level as defined by the Research Libraries Group (RLG).

Comprehensive Level: A collection in which a library endeavors, so far as reasonably possible, to include all significant works of recorded knowledge (publications, manuscripts, other forms) in all applicable languages, for a necessarily defined and limited field. This level of collecting intensity is one

that maintains a "special collection"; the aim, if not the achievement, is exhaustiveness. Older material is retained for historical research.

The scope of the NLM collection, encompassing as it does all of biomedicine, is significantly broader than is generally understood for the "special collection" referred to in the RLG definition.

NLM recognizes that while it is possible to assemble a collection which addresses all topics in biomedicine, it is impossible even for a national library to gather a complete, worldwide collection of all biomedical materials in all formats.

Library of Congress

LC employs collecting level definitions developed by the Research Libraries Group (RLG) and later adopted by the Association for Research Libraries has been used. The RLG definitions for collecting levels used by LC are as follows:

Comprehensive Level: A collection in which a library endeavors, so far as is reasonably possible, to include all significant works of recorded knowledge (publications, manuscripts, and other forms), in all applicable languages, for a necessarily defined and limited field. This level of collecting intensity is one that maintains a "special collection"; the aim, if not the achievement, is exhaustiveness. Older material is retained for historical research.

Research Level: A collection that includes the major published source materials required for dissertations and independent research, including materials containing research reporting, new findings, scientific experimental results and other information useful to researchers. It is intended to include all important reference works and a wide selection of specialized monographs, as well as a very extensive collection of journals and major indexing and abstracting services in the field. Older material is retained for historical research. A sampling of special format materials (such as graphic and moving images) are collected that complement print materials.

Instructional Support Level: A collection that is adequate to support undergraduate and MOST graduate instruction, or sustained independent study; that is, adequate to maintain knowledge of a subject required for limited or generalized purposes, of less than research intensity. It includes a wide range of basic monographs, complete collections of the works of more important writers, selections from the works of secondary writers, a selection of representative journals and the reference tools and fundamental bibliographical apparatus pertaining to the subject.

Basic Information Level: A collection of up-to-date general materials that serves to introduce and define a subject and to indicate the varieties of information elsewhere. It may include dictionaries, encyclopedias, selected textbooks, surveys, histories, directories, bibliographies, handbooks and a few major periodicals, in the minimum number that will serve the purpose. A basic information collection is not sufficiently intensive to support any courses or independent study in the area involved.

Out of Scope: The library does not collect in this area.

This summary of collection development policies for AIDS/HIV literature serves as a statement of national collection level responsibilities and as a user resource guide. The complete collection development policies of the Libraries should be consulted for additional information.

AIDS/HIV COLLECTING LEVELS

The literature of AIDS/HIV can be divided into four broad categories:

1. AIDS/HIV in Society;
2. Epidemiology of AIDS and HIV;
3. Patient Care Information and Education;
4. Research, Management and Treatment.

Collecting levels are stated as COMP. (Comprehensive), RESEARCH, INSTRUCT. (Instructional Support) BASIC (Basic Information) and O/S (Out of Scope).

AIDS/HIV in Society*

TOPIC	NLM	LC
Arts and humanities	O/S	RESEARCH
Economic issues		
Medical insurance	COMP.	RESEARCH
Health care cost	COMP.	RESEARCH
Employment	O/S	RESEARCH
Legal issues		
Civil rights	O/S	RESEARCH
Criminal law	O/S	RESEARCH
Health legislation	COMP.**	COMP.
Political issues		
Health policy	COMP	RESEARCH
Social policy	O/S	COMP.
Religious issues		
Dogma, church policy and philosophy	O/S	RESEARCH
Effect of religious belief on health and health seeking behavior	COMP.	RESEARCH

**Note: NLM generally does not collect materials in the Social Sciences or the Humanities unless these materials have direct relevance to biomedicine.*

***Note: NLM's focus is on U.S. legislation at the federal level.*

AIDS COLLECTING LEVELS

Epidemiology of AIDS and HIV

TOPIC	NLM	LC
Epidemiology in discrete populations (i.e., broad categories defined by age, sex, ethnicity or geography)	COMP.	BASIC
Epidemiology of high risk groups (Including health care givers, family and sexual partners of HIV positive individuals, intravenous drug users, transfused patients, etc.)	COMP.	RESEARCH
Statistical works (Including morbidity, mortality, frequency and distribution of AIDS/HIV)	COMP.	COMP.

Preventive Medicine, Health Education and Patient Care Information*

TOPIC	NLM	LC
Preventive medicine, public health strategies	COMP.	RESEARCH
Health education materials	*	INSTRUCT.
Patient Instruction	*	INSTRUCT.

*Note:

NLM's primary collecting interest lies in the professional and scholarly biomedical literature, but examples of biomedical works which typify or characterize health information available to the lay public including students may also be collected.

Research, Management and Treatment

TOPIC	NLM	LC
Diagnosis, management and treatment	COMP.	O/S
Ethics in health care	COMP.	INSTRUCT.

AIDS COLLECTING LEVELS

TOPIC	NLM	LC
Research investigations and observations	COMP.	INSTRUCT.
Intervention and treatment modalities (e.g., pharmaceutical and vaccine development, immunoreceptor research, genetic intervention techniques, probe development, etc.)	COMP.	O/S
Medical therapies (Including alternative therapies)	COMP.	INSTRUCT.
Health services and health care delivery systems focused on the AIDS/HIV patient (e.g., services of health care providers - nurses, physicians, care partners, etc. in various settings - home care, hospices, clinics, hospitals, extended care facilities, etc.)	COMP.	INSTRUCT.
Physiological aspects (Including etiology, pathogenesis and presentation of HIV infections and AIDS; functional disorders, opportunistic infections etc.)	COMP.	INSTRUCT.
Psychological issues (Including psychopathologies, bereavement, death & dying, family dynamics and the AIDS/HIV patient)	COMP.	RESEARCH
Research models and methodology (Including animal and <i>in vitro</i> studies, case studies, clinical trials)	COMP.	INSTRUCT.
Virology (Including the study of retroviruses, immunodeficiency viruses, immunoreceptors, vaccine research and development)	COMP.	INSTRUCT.

