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Agency for Health Care Policy and Research

Current HIV-Related Projects

This document summarizes current projects that are supported by the Agency for Health Care Policy and Research and that have a primary focus on HIV-related issues. Projects have been placed in three major areas:

- Health Services Research
- Prevention Research
- Services: Information Dissemination

Note that many of the projects are grants awarded in response to investigator-initiated proposals. The focus of unsolicited proposals, as well as the results of the scientific and technical review of each proposal, are difficult to predict. Therefore, we anticipate that new projects will be funded in FY 96, but the specific nature of these projects is not known at present. FY96 projects will most likely deal with policy-relevant issues in cost, quality, and access to HIV-related health services, as projected in the AHCPR sections of the DHHS HIV Research Plan.

AREA: Health Services Research

1. **HIV Costs and Service Utilization Study (HCSUS)**

A. Objectives: (1) To provide national estimates of the cost and use of HIV-related medical and non-medical services.

(2) To provide comprehensive information on unmet needs for service and barriers to accessing services.

(3) To examine effects of different systems of organizing and delivering care on outcomes such as cost, utilization, survival, patient satisfaction, and quality of life.

(4) To examine effects of patient characteristics (including gender, race/ethnicity, substance abuse, mental health, socioeconomic status, insurance coverage) on outcomes such as service utilization, unmet service needs, and costs.

(5) To provide data on service utilization and costs for a representative sample of rural residents with HIV infection.

(6) To examine patterns of transition between different types of provider (e.g., private physician to public clinic) and the relationship of such transitions to changes in clinical status, employment, and insurance coverage.

B. Description: This study will be the first to obtain a true national random sample of people with HIV infection receiving treatment. Approximately 3200 adult patients in urban areas, 500 adult patients living in rural areas, and 400 children (age less than 13) will be enrolled. Patients will be interviewed four times over an 18-month period; data will also be abstracted from medical and billing records.

C. FY95 Resources: $4,000,000.

D. FY96 resources: $4,000,000.

E. Populations Covered: HIV-infected individuals receiving treatment.

F. Constituency Involvement: Community Advisory Board, comprising members of infected and affected groups, has been established.

G. Unmet Needs: Insufficient resources for a national probability sample of pediatric HIV-infected patients. Insufficient resources for a sample of HIV-infected adolescents.

H. Collaborative Relationships: HRSA and NIMH have contributed funds to expand the scope of the core HCSUS project. In addition, proposals for further elaborations are under review at NIDR, NIAAA, and NIDA.

95	96
4,000,000	4,000,000

2. **Women's Interagency HIV Study**
A. Objectives: To examine health care utilization among participants in the NIH-sponsored Women's Interagency HIV Study (WIHS).
B. Description: This project supplements the WIHS by adding a health services research component. Utilization data on women with HIV infection will be collected, in addition to the detailed clinical data obtained in the core study.
C. FY95 Resources: $55,000.
D. FY96 Resources: $75,000.
E. Populations Covered: Women with HIV infection participating in the WIHS.
F. Constituency Involvement: NA (A research grant).
G. Unmet Needs: NA. more $, more info. gathered?

3. **Multicenter AIDS Cohort Study**
A. Objectives: (1) To examine factors affecting health care utilization among participants in the NIH-sponsored Multicenter AIDS Cohort Study (MACS).
(2) To assess quality of life among participants in the MACS and to relate utilization to quality of life measures.
B. Description: This project supplements the MACS by adding a health services research component. Utilization data on men with HIV infection will be collected, in addition to the detailed clinical data obtained in the core study.
C. FY95 Resources: $75,000.
D. FY96 Resources: $0. → why?
E. Populations Covered: Homosexual/bisexual men participating in the MACS in four urban areas.
F. Constituency Involvement: NA (A research grant).
G. Unmet Needs: NA. more $ / more info. Gathered?

4. **HIV Epidemiological Research Study**
A. Objectives: To examine health care utilization among participants in the CDC-sponsored HIV Epidemiological Research Study (HERS).
B. Description: This project supplements the HERS by adding a health services research component. Utilization data on women with HIV infection will be collected, in addition to the detailed clinical data obtained in the core study.
C. FY95 Resources: $50,000.
D. FY96 Resources: $50,000.
E. Populations Covered: Women with HIV infection participating in the HERS.
F. Constituency Involvement: NA (A research grant).
G. Unmet Needs: NA. more $, more info. gathered.

95 (95-94) 96
180,000 ∅ 125,000

5. **Health Care Costs and Utilization in AIDS Home Care**
A. Objectives: (1) To provide longitudinal data on utilization of inpatient, outpatient, home care, pharmaceutical, and other services, and to estimate their associated costs.
(2) To examine the impact of a Medicaid Home and Community-Based waiver on service utilization, costs, functional status, and survival.
(3) To examine any substitutions of formal for informal home care.
B. Description: Interviews conducted with participants in New Jersey Medicaid Waiver program. Data abstracted from Medicaid claims.
C. FY95 Resources: $394,557.
D. FY96 Resources: $0
E. Population Covered: Medicaid recipients with AIDS in New Jersey.
F. Constituency Involvement: NA (A research grant).
G. Unmet Needs: NA.

6. **Ambulatory Care for HIV/AIDS: Models and Outcomes:**
A. Objectives: (1) To examine types of ambulatory care providers used to treat HIV infection.
(2) To examine patterns of transitions between ambulatory provider types.
(3) To examine service utilization and costs for pediatric HIV patients.
B. Description: Analysis of Medicaid claims and eligibility data from New York State Medicaid.
C. FY95 Resources: $392,103 (from FY94 funds).
D. FY96 Resources: $0.
E. Populations Covered: New York State Medicaid recipients.
F. Constituency Involvement: NA (A research grant).
G. Unmet Needs: NA.

7. **Outcomes of Pharmaceutical Therapy in HIV Disease.**
A. Objectives: (1) To assess the impact of antiretroviral, antimicrobial, and prophylactic treatment on the natural history of HIV infection.
(2) To assess the effect of pharmaceutical therapies on service utilization, costs, and clinical outcomes.
B. Description: Develop clinical database linked to Medicaid claims data.
C. FY95 Resources: $527,287.
D. FY96 Resources: $420,000.
E. Populations Covered: HIV-infected population in Maryland.
F. Constituency Involvement: NA (A research grant).
G. Unmet Needs: NA.

more $, more data

now developed

95 (95-94) 96

1,313,947 921,844 420,000

8. **Quality and Costs of Care for HIV Infected Medicaid Patients.**
   A. Objectives: (1) To study issues of costs and quality of care, with a focus on women and children.
   (2) To examine trends and variation in adherence to scientifically-based clinical guidelines.
   (3) To study predictors of variation in treatment, by patient, physician, and practice setting characteristics.
   B. Description: Analyses of Medicaid claims and eligibility data, supplemented with AIDS Registry data.
   C. FY95 Resources: $110,704 (from 1994 funds).
   D. FY96 Resources: $0. ?
   E. Populations Covered: New Jersey Medicaid recipients.
   F. Constituency Involvement: NA (A research grant).
   G. Unmet Needs: NA.

9. **Developing Econometric Models to Estimate AIDS Costs.**
   A. Objectives: (1) Develop an econometric framework for the simultaneous study of health care usage and survival.
   (2) Develop synthetic estimates of per-person lifetime costs of HIV disease for various groups of HIV-infected individuals.
   B. Description: Formulation of statistical models and associated computer software.
   C. FY95 Resources: $188,136.
   D. FY96 Resources: $80,000. – why so much less?
   E. Populations Covered: Participants in the AIDS Costs and Service Utilization Survey, with potential extensions to all persons with HIV disease.
   F. Constituency Involvement: NA (A research grant).
   G. Unmet Needs: NA.

10. **Determinants of Physicians' AIDS-Related Practice Behavior**
   A. Objectives: To identify personal and institutional factors that shape physicians' willingness to care for HIV-infected patients.
   B. Description: Conduct the third in a series of interviews with physicians, who are currently in their sixth post-graduate year.
   C. FY95 Resources: $216,054 (from 1994 funds).
   D. FY96 Resources: $0. Why?
   E. Populations Covered: Physicians who graduated from six New York State medical schools in 1989.
   F. Constituency Involvement: NA (A research grant).
   G. Unmet Needs: NA.

95 514,894

94-94 188,136

96 80,000

11. **Outcomes of Hospital Dedicated AIDS Units**
A. Objectives: To compare outcomes of inpatient care for AIDS provided by dedicated AIDS units versus scattered-bed approaches.
B. Description: Comparative multi-site observational study of 23 hospitals.
C. FY95 Resources: $137,538 (from 1994 funds).
D. FY96 Resources: $0.
E. Populations Covered: 1500 patients receiving services in study hospitals.
F. Constituency Involvement: NA (A research grant).
G. Unmet Needs: NA.

12. **Hospital Cost and Utilization Project**
A. Objectives: Obtain and analyze data on inpatient hospital utilization by people with HIV infection.
B. Description: Assemble database of hospital discharge data from all hospitals in 12 States.
C. FY95 Resources: $500,000.
D. FY96 Resources: $500,000.
E. Populations Covered: Patients with AIDS receiving inpatient care in hospitals in 12 states.
F. Constituency Involvement: NA (A research grant).
G. Unmet Needs: NA.

AREA: Prevention

1. **Demonstrating Computer Support Impact on AIDS Patients**
A. Objectives: To examine the effects of an in-home computer information and support system on health care costs and quality of life.
B. Description: Half of three hundred patients with advanced HIV infection are provided with in-home computer system; the other half receive no intervention. Effects of this system are assessed with respect use of prophylactic treatments, early detection of infections, and quality of life.
C. FY95 Resources: $430,440.
D. FY96 Resources: $390,000.
E. Populations Covered: Study volunteers.
F. Constituency Involvement: NA (A research grant).
G. Unmet Needs: NA.

2. **Cost-Effectiveness of Preventing AIDS Complications.**
A. Objectives: Evaluate the cost-effectiveness of alternative strategies for preventing HIV-related opportunistic infections.
B. Description: Embed clinical and cost data from randomized trials and observational cohorts into a comprehensive decision-analytic, cost-effectiveness model.
C. FY95 Resources: $198,541.
D. FY96 Resources: $225,000.
E. Populations Covered: AIDS Patients.
F. Constituency Involvement: NA (A research grant).
G. Unmet Needs: NA.

- HIV trials?

(95) (95-94) 96
1,266,519 1,128,981 1,115,000

AREA: Information Dissemination

1. **AIDS Treatment Information Service**
   A. Objective: To provide Federally approved and accurate information concerning current and appropriate treatments for HIV-related conditions.
   B. Description: Reference specialists will use NLM's database of AHCPR guidelines, and NIH, CDC and other Federal agency guidelines and consensus statements to respond to specific requests and to provide appropriate treatment information to callers.
   C. FY95 Resources: $41,300.
   D. FY96 Resources: $53,326. - that's all
   E. Populations Covered: Primary care practitioners, case managers, allied health professionals, and HIV-positive individuals.
   F. Constituency Involvement: This PHS interagency project incorporates HIV-positive individuals and advocacy groups.
   G. Unmet needs: NA.

2. **Dissemination of AHCPR's HIV-Related Clinical Guidelines.**
   A. Objective: To provide accurate information to service providers and consumers concerning management of early HIV infection.
   B. Description: A panel of experts reviewed relevant literature and summarized findings into specific clinical practice guidelines, which stress the importance of preventing HIV-related opportunistic infections and the link between prevention and early diagnosis. 1.5 million copies of guidelines have been distributed.
   C. FY95 Resources: $30,000 (to AIDS clearinghouse).
   D. FY96 Resources: $30,000 (to AIDS clearinghouse; proposed).
   E. Populations Covered: Clinical practitioners and individuals with HIV infection.
   F. Constituency Involvement: NA. Physicians, nurses, etc. to
   G. Unmet Needs: NA.

3. **Effective Strategies of AIDS Programs in San Francisco**
   A. Objectives: To assess effective and ineffective dissemination strategies employed by community-based HIV education programs.
   B. Description: Examine organizational strategies used by several community-based HIV education agencies.
   C. FY95 Resources: $198,883 (from 994 funds).
   D. FY96 Resources: $0.
   E. Population Covered: Community-based HIV education agencies in San Francisco
   F. Constituency Involvement: NA (A research grant).
   G. Unmet Needs: NA.

7

95 — 270,183

95-94 — 71,300

96 — 83,326

4. **Development of Consumer Guide on Use of Zidovudine for the Prevention of Perinatal HIV Infection (076 Guide).**

A. Objective: This guide will inform HIV-infected pregnant women about the use of zidovudine (AZT) for the prevention of perinatal HIV infection.

B. Description: The guide will describe the recommendations of the PHS Task Force on the Use of Zidovudine to Reduce Perinatal Transmission of HIV, based on results of AIDS Clinical Trials Group 076. The information will be provided in a format and at a reading level that consumers can comprehend.

C. FY95 Resources: $75,000.

D. FY96 Resources: $0.

E. Populations Covered: Pregnant women with HIV infection and women of child-bearing age with HIV infection.

F. Constituency Involvement: HIV infected individuals and advocacy groups are involved in the development and review of the guide. The guide is cosponsored by multiple Federal and non-Federal agencies.

G. Unmet Needs: NA.

What about other grps-clinicians?

FY95 $7,620,543

minus .9% 6,565,261

FY96 $5,823,326

95 96

75,000 0

GCBB/E

Summary of On-going or Planned Programs

1. AHCPR's HIV-Related Research Program

The continued growth of the human immunodeficiency virus (HIV) epidemic has created an urgent need to better understand the public policy implications of the provision of care to persons with HIV and acquired immune deficiency syndrome (AIDS). In conducting its HIV-related activities, the Agency for Health Care Policy and Research (AHCPR) strives to provide a scientific knowledge base describing the changing, interrelated array of epidemiologic, financial and biotechnical issues affecting health care delivery for persons with HIV infection. An enhanced knowledge base is required for addressing issues such as the:

- epidemic's expansion into new populations (e.g., women, children, adolescents, and minorities);
- availability of new treatment modalities;
- recognition of HIV-related illness as a chronic disease;
- interaction of HIV infection with substance abuse and the resurgence of tuberculosis; and
- effectiveness and availability of health and supportive services within the context of current and reformed health care delivery systems.

Acquiring a strong knowledge base is the principal mechanism by which AHCPR seeks to accomplish its mission to improve the effectiveness and cost effectiveness, quality, and appropriateness of health care, and improve access to health care services. The AHCPR carries out its responsibilities by supporting and conducting health services research, conducting assessments of health care technologies, and facilitating the development of clinical practice guidelines through which AHCPR seeks to translate advances in knowledge into practice.

HIV-related activities focus on three interrelated areas:

- data gathering and analytic activities directed at investigation of barriers to care, health resource utilization, functional status, and financing of care for individuals with HIV/AIDS;
- support of investigator-initiated research to improve clinical practice and patient care delivery for HIV/AIDS; and
- development, updating, and disseminating clinical practice guidelines on HIV/AIDS reflecting the emerging scientific base and the best professional judgment about optimal clinical practice and health care delivery arrangements.

HIV-related activities are managed principally by the following AHCPR Centers and Offices:

Center for General Health Service Extramural Research. Supports investigator initiated research, and gathers and analyses data on services provided to persons with HIV infection, and offers technical assistance on a spectrum of health services research efforts.

Center of General Health Services Intramural Research. Conducts policy research on medical care use and expenditures, health insurance, issues in long term care, and the cost and effectiveness of hospitals and other providers.

Center for Medical Effectiveness Research. Plans and manages a program of research (including investigator initiated research) to enhance the quality, appropriateness and effectiveness of health care services with a focus on patient outcomes research.

Office of the Forum for Quality and Effectiveness in Health Care. Facilitates development of treatment- or condition-specific guidelines and medical care review criteria for clinical practice.

Center for Research Dissemination and Liaison. Engages with private, public, national, State and local agencies, institutions and organizations to disseminate results related to health services research.

With additional staff support provided and directed by the Office of the Administrator, the AHCPR seeks to identify issues of common interest and coordinate research efforts by expanded collaboration with Federal agencies and non-Federal organizations.

2. Scientific Objectives and Strategies

2A. Data Gathering and Analytic Activities

The AHCPR conducts two major efforts directed at gathering and analyzing services provided to persons with HIV infection. These efforts are (1) *ACSUS*--The "AIDS Cost and Services Utilization Survey," and its successor, *HCSUS*--The "HIV Cost and Services Utilization Study," and (2) *HCUP*--"The Hospital Cost and Utilization Project."

ACSUS has been underway since 1989. Data collection was completed in the Fall, 1993, and analyses are ongoing. The survey design included a sample of 2090 HIV-infected patients (including over 100 children) followed prospectively for 18 months. The sample was obtained from 26 sites in 10 communities, and was diverse in terms of racial/ethnic

composition, gender, and exposure group. Data were collected on utilization of inpatient and ambulatory medical care, long-term and nursing home care, dental care, home health care, prescription medications, and psychosocial support services. ACSUS also collected information on perceived barriers to care, out-of-pocket expenditures, employment, insurance coverage, and charge data from bills of providers of medical care. In addition to analyses by AHCPR, the data from ACSUS are being made available on public use tapes which may be obtained from the National Technical Information Service.

The ACSUS data are among the most comprehensive data available in the U.S. for deriving estimates of the cost of medical care for persons with HIV infection from the time of infection until death. The upper bound of the lifetime cost of HIV-related medical care was approximately $119,000. The cost of care from the time of HIV infection until the development of AIDS was estimated to be $50,000. The cost of treating a person with AIDS, which had risen rapidly in the past, has fallen as a result of a reduction in the use of inpatient hospital services. (Hellinger, *J. Amer. Med. Assoc.*, 1993).

The ACSUS data also were used to find that women and adolescent females infected with HIV receive fewer medical services than similarly diagnosed men. This finding remains after adjusting for income, race, insurance and geographic differences, and may reflect the fact that women have more family-related responsibilities. Discrimination, however, could be a factor. (Hellinger, *Health Services Research*, 1993).

To follow-on to ACSUS, in August 1993, AHCPR issued an announcement soliciting grant applications for HCSUS. In addition to cost and utilization data, HCSUS will:

- collect primary data about access and barriers to care in different geographic locations and health care delivery settings; and
- provide current information about relevant demographic and socioeconomic variables (e.g., race, gender, insurance status, income, education, exposure category) from a broad representation of HIV infected persons over an extended period of time.

The HCSUS will be funded for four years beginning in FY 1994, for approximately $15 million over the life of the project.

The second major data collection and analysis effort, *HCUP--"The Hospital Cost and Utilization Project,"* has been based on a national sample of approximately 500 hospitals and has addressed the use of inpatient services by individuals and subpopulations (such as whites vs. Blacks, women vs. men, and other subgroups with specific medical conditions) with AIDS and HIV-related diseases. Issues examined include the costs and financing of AIDS discharges in New York State; the distribution of AIDS patients across hospitals and geographic

regions; mortality rates for hospitalized AIDS patients; and the cost of care for children with AIDS.

The HCUP currently is expanding to cover the period 1988-94, and, by the end of FY 1994, will include all inpatient discharges from all hospitals in 12 States. HIV incidence was a criterion in selecting the States targeted for this database expansion. The inclusion of data from all hospitals in California, Florida, Illinois, Massachusetts, New York, New Jersey and Pennsylvania, will extend markedly AHCPR's ability to study the care received by persons with AIDS and HIV-related illnesses in hospitals. Issues to be examined include variations in treatment for pediatric, as well as adult cases; the geographic distribution of AIDS care in high vs. low incidence areas; variations in severity of illness across diverse HIV populations; and geographic variations in the costs and outcomes of AIDS hospitalizations. The HCUP also will include all discharges from a nationwide sample of 1000 hospitals. It is expected that these data will be used to generate national estimates of the cost of HIV-related inpatient care.

2B. Investigator Initiated Research

Since 1989, AHCPR's extramural grant program has supported approximately 65 investigator initiated research projects concerned with HIV issues, with about 25 being active currently. These projects are supported by large (RO1) and small (R03) grants, including dissertation, postdoctoral fellowship, and conference grants. Examples of currently funded research topics include:

- provision of medical care in hospital settings;
- costs of providing care;
- providers' attitudes toward people with HIV;
- developing quality-of-life measures; and
- assessing pharmacological outcomes.

Selected recent findings from AHCPR-sponsored research, by topic area, are provided at the end of this Section.

To encourage the study of priority research issues, the AHCPR published, in September 1993, a new grant announcement entitled, "Health Care Services for Persons with Human Immunodeficiency Virus (HIV) Infection," developed in coordination with and co-sponsored by the National Institute on Alcohol Abuse and Alcoholism, the National Institute on Drug Abuse, and the National Institute of Mental Health. The announcement was preceded, in November 1992, by an agenda-setting conference co-sponsored by AHCPR, the Health Resources and Services Administration, and the National Community AIDS Partnership.

2C. Development and Dissemination of HIV-Related Clinical Guidelines and Translation of Research Findings

On January 20, AHCPR published a clinical practice guideline on the "Evaluation and Management of Early HIV Infection," which focuses attention on the need for primary care providers to coordinate and manage early HIV infection. The guideline stresses the importance of prevention of HIV-related opportunistic infections and the link between prevention and early diagnosis and care. In addition to the clinical practice guideline, a quick reference guide for clinicians, and consumer guides for adults/adolescents and for parents of children with HIV infection (in English and Spanish) are available. By March 31, more than a half-million copies of guideline documents had been disseminated by AHCPR and through collaboration with other PHS agencies, including the Centers for Disease Control and Prevention. AHCPR also operates a national publications clearinghouse through which research findings, assessments of health care technologies, clinical practice guidelines and other items are made available to providers, researchers, and the public.

The dissemination of other AHCPR-supported research findings has occurred through extensive efforts to publicize reports and guideline findings in the professional and lay press and news media. The AHCPR's User Liaison Program (ULP) has conducted AIDS workshops for State and local public officials that focus on the translation of research findings that will help them deal with policy and legislative issues. In 1993, ULP held a similar Workshop for Judges on HIV and Tuberculosis.

→ testing issues → in collab c other agencies?

SELECTED HIV-RELATED RESEARCH FINDINGS
AGENCY FOR HEALTH CARE POLICY AND RESEARCH

Quality of Care

- Chance of death from *Pneumocystis carinii* pneumonia (PCP) decreased when care was given at hospitals treating higher numbers of PCP cases. It was suggested that hospital experience may decrease mortality with this subset of patients with HIV disease. (Bennett, *J. Acquired Immune Deficiency Syndrome.*, 1992)

- Even after controlling for multiple patient-level and hospital-level variables, the relative risk of death was more than twice as high at hospitals with lower AIDS familiarity than at hospitals more experienced in AIDS care. Moreover, the better outcomes in high-experience hospitals did not appear to be the result of more intensive use of resources as measured by admission to the ICU, length of stay or cost. There is preliminary support for policies calling for the development of regional networks of HIV care, referral and provider education. (Seage, *J. Amer. Med. Assoc.*, 1992)

need translation to practice

- In a study of 289 patients with AIDS, only 38 percent had discussed preferences for life-sustaining therapy with their physicians, even though 72 percent said they wanted to talk about it. Patients who had been hospitalized were more likely to have discussed this issue, probably because physicians view these conversations as more pressing in the hospital setting. Physicians should take the initiative in introducing discussion of resuscitation options with their AIDS patients. (Haas, *Arch. of Inter. Med.*, 1993)

Health Care Outcomes

- A study in AHCPR's pharmaceutical outcomes program calls into question the value of early therapy with zidovudine (ZDT). For asymptomatic patients treated with 500 mg. of ZDT, a reduction in the quality of life due to severe side effects of therapy approximately equals the increase in the quality of life associated with a delay in the progression of HIV disease. (Lenderking, *N. Eng. J. Med.*, 1994)

- Patients with cytomegalovirus (CMV) retinitis often are not referred to an ophthalmologist until the condition threatens their sight. A primary care physician only can see the posterior one-third of the retina with direct ophthalmoscopy, but the specialist can use indirect ophthalmoscopy to diagnose the condition. The authors

recommend periodic screening of AIDS patients for CMV retinitis once patients' CD4 cell counts fall to 200, with screening repeated every 3 to 4 months. (Kupperman, *Amer. J. Ophthalmology*, 1993)

- In a comparison of the efficacy of specific diagnostic methods compared with ultrasonography to detect enlarged spleens in individuals with HIV infection, it was found that physical diagnostic techniques for detection of splenomegaly are relatively insensitive but specific. Using either percussion or palpation in conjunction with ultrasound increased diagnostic accuracy. (Tamayo, *J. Gen. Inter. Med.*, 1993)

- A new quality of life scale has been developed to address the particular problems of people with AIDS. Although symptoms are the most specific and most-often-used patient-reported measure of health status, patients' fatigue and ability to function are at least as important in evaluating quality of life. (Cleary, *Medical Care*, 1993)

Access to Care

- Differences were found between care received by men and women with PCP. Women with HIV were less likely to be white and less likely to have private insurance, and more likely to be admitted to a hospital through an emergency room, and receive care at hospitals with less experience in treating PCP. The differences relating to access to care--not having health insurance and being admitted through the emergency room--seemed to be associated with a greater likelihood of women than men dying in hospital. (Bennett, *J. Acquired Immune Deficiency Syndrome*, 1993)

- Although no racial differences were found in this pharmaceutical outcomes study regarding stage of HIV disease of subjects at presentation, there were racial disparities in receipt of therapy, with antiretrovirals received by 48 percent of eligible African-Americans and 63 percent of eligible non-hispanic whites. PCP prophylaxis was received by 58 percent of eligible African-Americans and 82 percent of eligible whites. The observation that African-Americans are significantly less likely than whites to receive antiretroviral or PCP prophylaxis at first presentation suggests a need for culturally-relevant interventions to ensure that uniform standards are applied. (Moore, *N. Eng. J. Med.*, 1994)

- Inpatient and outpatient service use increased over progressively lower levels of CD4 counts. White participants had more HIV clinic visits and fewer admissions than people of color. It was concluded that CD4

lymphocyte count is associated strongly with increased usage of health services. People of color with HIV disease are more likely than similar whites to be admitted to the hospital and less likely to use out-patient care. (Piette, *Amer. J. Public Health*, 1993)

Provider Issues

- Although primary care physicians believe they are at low risk of contracting HIV from their patients, for some physicians the fear of contagion takes a high emotional toll. Conflicts between fears and ethical responsibilities create intense personal dilemmas. Some physicians reported taking excessive precautions to prevent exposure to body fluids, while others took inconsistent or no precautions. (Epstein, *Family Medicine*, 1993)

- Many physicians were unable to identify universal precautions to prevent occupational transmission of HIV. Residency trained physicians expressed a greater comfort with discussing sexually-related topics with their patients than did non-residency trained physicians. Sixty-seven percent of the physicians reported never providing treatment to an individual with HIV disease. Residency trained and board certified physicians expressed a greater likelihood of providing treatment to HIV patients than non-residency trained and non-board certified physicians. (Ryan, *Archives of Family Medicine*, 1993; *Journal of AIDS*, 1992; *Journal of Family Practice*, 1991)

- A large and increasing number of primary care physicians and clinics provided ambulatory care for New York State Medicaid patients between 1983 and 1990. However, the percent of primary care providers--as a proportion of all physicians--declined over time, while the percentage of specialists and subspecialists increased. Most primary care physicians treated a small number of AIDS patients, and the level of "experience" did not increase over the eight years of the study. Large clinics may be reaching a threshold where staff will become overburdened. (Keyes, *AIDS and Public Policy J.*, 1993)

Costs and Financing of Care

- The HIV-infected patients with diarrhea miss twice as much work, socialize less, and decline more rapidly in health and functioning than those with HIV who do not have diarrhea. Care for patients with chronic diarrhea is costly--about 50 percent higher than for similar patients without diarrhea ($24,567 vs. $14,471), and

these patients need nearly 60 percent more health resources, including diagnostic tests and outpatient visits. (Lubeck, *J. Acquired Immune Deficiency Syndrome*, 1993)

- In hospitals which treated 30 percent of all AIDS patients alive during 1988, service utilization by other HIV patients was found to comprise a substantial portion of the total HIV burden and related costs. The average hospital was found to lose $204,000 a year treating uninsured persons hospitalized for AIDS, plus another $109,360 for treating HIV illness in uninsured patients. (Andrulis, *J. Amer. Med. Assoc.*, 1992)

- Insurance coverage of the HIV infected population varied widely by geographic location, although gay and bisexual men were most likely to have private insurance coverage. People in the South had a greater chance of losing private insurance and less chance of gaining public Medicaid insurance than people in the Northeast. In all regions studied, uninsured PWA's seemed to have less access to medical care. (Fleishman, *Inquiry*, 1993)

- Hospital care for IDU's with AIDS is likely to be more expensive than for non-IDU homosexual AIDS patients, and policy-makers are urged to incorporate this information in planning for AIDS care. In addition, instruments to assess severity of illness should incorporate information on intravenous drug use. (Seage, *J. Acquired Immune Deficiency Syndromes*, 1993)

- Persons with AIDS were 2.7 times more likely to lose full-time employment over a 6-month period than seronegative persons, and loss of employment was strongly associated with both loss of health insurance and loss of income. Twenty-seven percent of PWA's in this relatively affluent subject population reported that financial difficulties prevented them from seeking care. Given that the problems experienced by most persons infected by HIV are considerably more severe than those in this study population, the imperative for action is great. (Kass, *J. Acquired Immune Deficiency Syndromes*, 1994)

- Although one-time mandatory HIV testing of surgeons and dentists, with mandatory restriction of those found to be HIV-positive, is more cost-effective than other policies, the cost-effectiveness varies tremendously under different scenarios, especially when different levels of practitioner seroprevalence and transmission risk are assumed. For example, under a medium seroprevalence and transmission risk scenario, testing of all surgeons might avert 25 infections at a total cost of $27.9 million. However, the incremental cost-effectiveness per patient infection averted ranges from $28.9 million under a low-

risk scenario, to $81,000 saved under a high-risk scenario. (Phillips, *J. Am. Med. A.*, 1994)

AHCPR

Area: Prevention

GOAL: Demonstrate Computer Support Impact on AIDS Patients

Objective	Action Steps	Programs					Unmet needs
		Descriptions	Resources		Populations Served	Constituent Involvement	
			FY 1995	FY 1996 (proposed)			
Determine the Impact of Computer Support on AIDS Patients	Computer Support Demostration Project	Provide in-home computer systems to advanced AIDS patients to measure effects on use of prophylactic treatments, quality of life	$430,440	390,000	Patients with advanced AIDS	NA	NA

AHCPR

Isn't this CDC ?

Area: Prevention

GOAL: REDUCE THE NUMBER OF NEW INFECTIONS

Objective	Action Steps	Programs					Unmet needs
		Descriptions	Resources		Populations Served	Constituency Involvement	
			FY 1995	FY 1996 (proposed)			
Reduce the number of new infections by 10% by the year 1997.	Peer-based counseling for at-risk youth.	Program xxx targeting at-risk youth.	$13 million	$15 million	young gay men 15-25	programs funneled through community planning process	Program only reaches one-half of target population; could be funded at $25 million.

AHCPR

Area: Prevention

GOAL: Determine Cost Effectiveness of Preventing AIDS Complications

Objective	Action Steps	Programs					Unmet needs
		Descriptions (Clinical + Cost Effectiveness studies Grant)	Resources		Populations Served	Constituency Involvement	
			FY 1995	FY 1996 (proposed)			
Evaluate Cost Effectiveness of Strategies for Preventing OI	Collect clinical and cost data from randomized trials and observational cohorts	Embed clinical and cost data into comprehensive decision-analytic, cost effectiveness model.	$198,541	$225,000	Patients with AIDS	NA	NA

AHCPR

Area: Prevention

GOAL: REDUCE THE NUMBER OF NEW INFECTIONS

Objective	Action Steps	Programs					Unmet needs
		Descriptions	Resources		Populations Served	Constituent Involvement	
			FY 1995	FY 1996 (proposed)			
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AHCPR
Area: Prevention
GOAL: Disseminate HIV/AIDS Treatment Information

Objective	Action Steps	Programs					Unmet needs
		Descriptions	Resources		Populations Served	Constituency Involvement	
			FY 1995	FY 1996 (proposed)			
Provide Telephone and Computer Access to Accurate HIV/AIDS Treatment Information	AIDS Treatment Information Service	1-800 number with trained reference specialists respond to specific requests for approved treatment information	$41,000	$53,000	Primary care practitioners, case managers, allied health professionals HIV+ indiv. and affected community	PHS interagency project incorported input from HIV+ indiv. and constituency groups	State-of-the-art treatment guidelines on advanced HIV disease

Provide Accurate Information to Service Providers, Consumers on Treatment of early HIV Disease	Distributed 1.5 million copies of AHCPR Clinical Practice Guideline for Evaluation and Management of Early HIV Infection	Guidelines developed by panel of experts using literature review format	$30,000	$30,000	Clinical Practitioners and HIV+ individuals	Panel of Clinical experts	Updating Guidelines as New Information Emerges
Provide Effective-ness Dissemi-nation Strategies for HIV Education CBOs	Assess effective and ineffective dissemin-ation strategies used by CBOs	Examine oganizational strategies used by several CBOs in SF	$198,000 (from 1994 funds)	0	HIV Education CBOs	CBOs	NA

Provide Information on Use of AZT for Prevention of Perinatal Trans-mission of HIV to Consumers	Development of Consumer Guide on Use of AZT for Prevention of Perinatal Trans. of HIV	Guide will discribe recommend-ations of PHS Task Force on Use of AZT based on ACTG 076	$75,000	0	Pregnant women and women of child-bearing age infected with HIV	HIV infected women and advocacy groups have been involved in the develop. and review of the guide.	NA

AHCPR
Area: Prevention
GOAL: Disseminate HIV/AIDS Treatment Information

Objective	Action Steps	Programs					Unmet needs
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