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I. SPECIAL REPORT

Federal Funding For Health Services Research On AIDS, 1986-1991

by Karen A. Rudzinski, Katherine M. Marconi, and Martha M. McKinney

Between 1986 and 1991 the U.S. Department of Health and Human Services (HHS) awarded almost $43 million for extramural research on the costs of delivering care to people infected with the human immunodeficiency virus (HIV), the organization and accessibility of HIV-related services, the quality of medical care, and other aspects of HIV health service delivery. More than 100 evaluation and research studies were funded by five HHS agencies during this time period. This UpDate reviews the research supported by these agencies and tracks federal funding for HIV-related health services research over the five-year period that preceded the full implementation of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990.

Study methods. This analysis of the first generation of HIV-related health services research focuses on extramural studies funded by five HHS agencies between January 1986 and December 1991: Agency for Health Care Policy and Research (AHCPR); Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA); Health Care Financing Administration (HCFA); Health Resources and Services Administration (HRSA); and National Center for Nursing Research (NCNR). We reviewed all HIV-related research and evaluation grants and contracts from these agencies to identify health services research projects. Because the focus of the study was health services research, we excluded prevention-related studies funded by the Centers for Disease Control and Prevention (CDC). HIV drug treatment and etiology studies were not defined as health services research unless they addressed patient adherence to treatment plans or the organization and delivery of HIV-related services.

We derived a list of potential projects based on interviews with project officers from the five agencies and reviews of their research grants and contracts. A computerized information system for tracking federal grants-IMPAC-provided financial information and award dates. Project applications were used to confirm that a study addressed HIV-related services and to code study characteristics. Through this review process we identified a total of 106 evaluation and research projects.

We gathered information on study outcomes (for example, cost and financing, quality of care, and access to care); the date and length of the award; the award amount; the institution receiving the award and its location; and the characteristics of the study, including its unit of analysis, methodology, and location and the populations studied. A typology of health services research, originally developed by an AHCPR working group, was modified to classify each health services research study in terms of study pur-

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pose, methodological intent, and level of analysis.¹

### Study Findings

**Funding trends.** Federal investments in health services research on HIV and acquired immunodeficiency syndrome (AIDS) began in 1986, when HCFA allocated $145,000 in general research revenues to fund a study of projected Medicaid costs for AIDS from 1986 through 1991.² One year later HHS earmarked $1 million for extramural health services research on HIV/AIDS. The dearth of information on HIV service delivery, particularly on the cost and financing of AIDS care, prompted HHS to allocate an additional $500,000 for health services research in that same year. In the late 1980s HHS agencies also held a series of conferences to define their health services research agenda.

During 1987 more than half of the federal funding for HIV-related health services research went for the development of a series of methodologies to estimate (1) the costs associated with health personnel training, the direct delivery of care, and voluntary HIV counseling and testing; and (2) the cost-effectiveness of alternative therapies and different organizational arrangements for the delivery of care. AHCPR modified some of these methodologies and fielded in 1989/1990 a large-scale prospective cohort study, known as the AIDS Cost and Service Utilization Survey (ACSUS), to create a longitudinal database on the use and costs of HIV-related medical and support services.³

The $42.7 million allocated to the 106 projects over the five-year period represents about 2 percent of the annual HHS budget for HIV/AIDS; Exhibit 1 shows the distribution of new awards over the period 1986-1991. Funding peaked in 1989 with the initiation of thirty-six extramural evaluation and research projects. These studies accounted for about one-third of all projects funded during the five-year period. By 1991 new federal investments in health services research on HIV/AIDS had dwindled to eighteen projects, despite the emphasis of the (1990) Ryan White CARE Act on evaluating the quality and appropriateness of medical and support services.

**Comparisons by agency.** The fifty-six research studies funded by AHCPR between 1986 and 1991 accounted for about half of the total projects funded and almost 60 percent of the total funds awarded during the five-year period (Exhibit 2). Although the costs of these projects ranged from $6,000 to almost $5 million, their median cost ($86,000) was considerably less than for projects funded by three other HHS agencies. Evaluation and research studies supported by ADAMHA accounted for 11 percent of the funded projects and almost 19

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**Exhibit 1**


<table>
<thead>
<tr>
<th>Year</th>
<th>Number of new awards</th>
<th>Percent of new awards</th>
</tr>
</thead>
<tbody>
<tr>
<td>1986</td>
<td>1</td>
<td>100%</td>
</tr>
<tr>
<td>1987</td>
<td>0.9</td>
<td>9%</td>
</tr>
<tr>
<td>1988</td>
<td>6</td>
<td>18%</td>
</tr>
<tr>
<td>1989</td>
<td>5.7</td>
<td>18%</td>
</tr>
<tr>
<td>1990</td>
<td>18.9</td>
<td>36%</td>
</tr>
<tr>
<td>1991</td>
<td>17</td>
<td>34%</td>
</tr>
</tbody>
</table>

Source: HHS Grants and Contracts.

Note: HIV is human immunodeficiency syndrome; AIDS is acquired immunodeficiency syndrome.
Funding Source Of HIV/AIDS Research Projects

<table>
<thead>
<tr>
<th>Agency</th>
<th>Number of projects</th>
<th>Percent</th>
<th>Total costs (thousands of dollars)</th>
<th>Median cost (thousands of dollars)</th>
<th>Cost range (thousands of dollars)</th>
</tr>
</thead>
<tbody>
<tr>
<td>AHCPR</td>
<td>56</td>
<td>52.8%</td>
<td>$24,808</td>
<td>$86</td>
<td>$6–$4,461</td>
</tr>
<tr>
<td>HRSA</td>
<td>15</td>
<td>14.2%</td>
<td>3,462</td>
<td>201</td>
<td>50–407</td>
</tr>
<tr>
<td>NCNR</td>
<td>12</td>
<td>11.3%</td>
<td>4,847</td>
<td>360</td>
<td>75–817</td>
</tr>
<tr>
<td>ADAMHA</td>
<td>12</td>
<td>11.3%</td>
<td>7,954</td>
<td>546</td>
<td>15–2,305</td>
</tr>
<tr>
<td>NIDA</td>
<td>1</td>
<td>0.9%</td>
<td>502</td>
<td>502</td>
<td>_a</td>
</tr>
<tr>
<td>NIMH</td>
<td>11</td>
<td>10.4%</td>
<td>7,450</td>
<td>589</td>
<td>15–2,305</td>
</tr>
<tr>
<td>HCFA</td>
<td>11</td>
<td>10.4%</td>
<td>1,625</td>
<td>53</td>
<td>13–649</td>
</tr>
<tr>
<td>Total</td>
<td>106</td>
<td>100.0%</td>
<td>$42,694</td>
<td>$182</td>
<td>$6–$4,461</td>
</tr>
</tbody>
</table>

Source: HHS Grants and Contracts.

* Not available.

percent of the total funds awarded. All but one of these projects were funded by the National Institute of Mental Health (NIMH).

HRSA funded fifteen studies over the five-year period that evaluated different aspects of its HIV service delivery programs. The HRSA evaluation projects accounted for 14 percent of all funded studies but only 8 percent of the total funds awarded, reflecting the limited funding that is available for evaluation research. About one out of every nine studies funded between 1986 and 1991 was sponsored by the NCNR at a total cost of $4.8 million. Although HCFA did not receive any specific appropriations for HIV-related research, it used $1.6 million in general research revenues to fund eleven extramural studies.

Purpose Of The Funded Research

Approximately 88 percent (93) of the 106 research projects funded between 1986 and 1991 directly addressed the cost, quality, or accessibility of HIV care. Among the other topics addressed were (1) the HIV-related knowledge, attitudes, and behavior of the general public; (2) legal and ethical issues surrounding the care of people with HIV/AIDS; (3) HIV counseling and testing; and (4) methodology development.

Exhibit 3 classifies dollars spent on these 106 evaluation and research projects by their three main purposes. Projects can be counted more than once. Fifty-four (51 percent) had a primary, secondary, or tertiary interest in examining the cost and financing...
aspects of delivering HIV-related care. In thirty of these studies, cost and financing issues were the primary focus. Although funding for the thirty-nine studies addressing quality of care ($26.1 million) slightly exceeded funding for studies addressing cost and financing issues ($23.5 million), quality of care tended to be of secondary or tertiary importance. Sixteen studies (15 percent) addressed access to care, but only six of these studies made access the primary area of research focus.

**Cost and financing.** HIV-related studies were assigned to the category of cost if they focused on inpatient, outpatient, or long-term care; informal health resource use; or associated costs. Charge and payment studies also were assigned to this category. These studies typically analyzed relationships between variables such as alternative practice settings, resource use, the cost of HIV/AIDS care, and method of payment for care. Many of the studies conducted small population-based analyses of the HIV-related medical care provided in health facilities, such as public hospitals, or in specific metropolitan areas or states. A few large-scale studies covered multiple geographic areas, such as a study of the cost of HIV care in eleven communities with Robert Wood Johnson Foundation-funded AIDS Health Services Programs; an analysis of the costs of HIV care in Los Angeles, San Francisco, and San Diego; and a twenty-site study comparing the patterns of resource use among hospitalized patients in designated AIDS units versus scattered beds.

**Quality of care.** Studies were assigned to the category of quality when they examined (1) the relationship between service delivery and quality indicators such as morbidity and mortality rates, hospital readmission rates, severity of illness, and functional status; (2) the extent to which services are delivered in accordance with medical standards; or (3) subjective assessments of quality of care. Examples include RAND's studies of the relationship between patient volume and clinical outcomes in hospitals treating persons with a first diagnosis of *Pneumocystis carinii* pneumonia; a large-scale study of the number and appropriateness of provider referrals to drug clinical trials; an analysis of how physicians' use of an AIDS-specific, knowledge-based medical record system affects the quality of care; and a meta-analysis of therapeutic interventions for HIV that provides a framework for assessing health care quality.

**Access to care.** HIV-related studies were assigned to this category if they assessed the availability of service providers, the frequency of service use, and/or the level of clients' satisfaction with the accessibility of services. Only sixteen studies focused on access issues. Although the cost range for these studies was much lower than for studies in the other two categories, the median amount awarded was considerably higher. Examples include an ethnographic study that examined the processes that health professionals undergo as they learn to manage their fears of occupational HIV contagion, and several mail surveys or personal interviews with nurses and/or primary care physicians to examine how HIV-related knowledge, attitudes, and risk perceptions relate to willingness to care for patients with HIV/AIDS. While many of the large-scale studies on cost and service use collected data on clients' satisfaction with services and their unmet service needs, these studies did not investigate the access barriers faced by HIV-positive people who have no source of medical care.

### Level Of Analysis

Federally funded health services research on HIV/AIDS can be classified by level of analysis. Studies of individual attitudes and/or behavior accounted for 80 percent of the funded projects and 91 percent of the total funds awarded. Almost three-quarters of the eighty-five individual-level studies focused on HIV-positive persons exclusively or in combination with formal and informal health care providers or patients with other medical conditions. Another 22 percent of the individual-level projects studied formal health care providers, informal care providers, or both. Only 6.5 percent focused strictly on women and children.
Studies with organizations, or community or state systems, as the unit of analysis accounted for only 11 percent of all funded projects and less than 3 percent of the total funds awarded. The median amount awarded for individual-level studies ($224,000) was almost three times greater than the median award for organizational studies ($84,000) and four times greater than the median award for interorganizational and community-level research ($56,000).

**Conclusion**

Investment by HHS in the first generation of health services studies of HIV/AIDS peaked prior to biotechnological advances in treatment and epidemiological changes in the populations affected by the disease. This investment trend holds true for all major research categories, including the cost and financing of HIV services. Consequently, it is understandable why a survey conducted by the U.S. Congress Office of Technology Assessment (OTA) found that HIV/AIDS health care organization and delivery had benefitted the least from health services research.8

Despite the limited history and scope of health services research on HIV/AIDS issues, the evaluation and research studies have provided valuable descriptive information, primarily concerning trends in the cost and financing of HIV care. Data from HIV/AIDS cost and service utilization studies have been used in federal budget deliberations and in the development of the Ryan White CARE Act. A few studies addressing clinical decision making are being published, and survey methods and questionnaires have been developed and tested.

In the second decade of the HIV epidemic, opportunities exist to revive and redirect federal funding for health services research. The research, evaluation, and assessment program (Sec. 2673) of Title IV of the Ryan White CARE Act (which is now unfunded), NIH and AHCPR research mandates, and HRSA and HCFA evaluation funds present opportunities for HIV-related health services research. Seizing these opportunities for critical analysis of access and quality of care for different populations, as well as the other dimensions of our HIV health services research typology, can make substantial contributions to improved HIV/AIDS care and to our understanding of the societal effects of chronic illness.

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NOTES

1. Drawing on the discussion at a working group of health services researchers convened by AHCPR's Office of Program Development in late 1990, agency staff developed a three-level matrix classifying health services research in terms of outcomes (access, cost, and quality), level of analysis (clinical, institutional, system, and environmental factors), and methodology (methods development, data development, theory building/hypothesis testing, evaluation, and dissemination).


