



## MEETING SUMMARY AND REPORT

### Developing an HIV Health Services Research Agenda

A Meeting Supported by

The Agency for Healthcare Research and Quality<sup>1</sup>

and

The Henry J. Kaiser Family Foundation<sup>2</sup>

February 11, 2005  
Washington, DC

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A joint project of The George Washington University School of Public Health and Health Services Department of Health Policy and the GW Forum for Collaborative HIV Research.

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## **Developing an HIV Health Services Research Agenda**

### **A. Overview.**

On February 11, 2005, 29 individuals representing academia, federal and state government, HIV community advocates, pharmaceutical companies, and foundations met to formulate a health services research agenda in the area of HIV care, quality, and financing. (See Appendix A for a list of attendees.) In convening this conference, HIV researchers at George Washington University (GW) sought to promote coordination and collaboration opportunities in HIV-related health services research by maximizing the utility of currently funded research and exploring new opportunities for research partnerships. GW had two principal objectives: First, to identify the nature and scope of currently funded HIV health services research to assess gaps in research, and second, to assist federal, academic, and industry researchers to design and undertake health services research that is relevant to consumers of HIV care, their clinical and other care providers, institutions serving the HIV-infected community, health insurers and purchasers, governmental policymakers, and other stakeholders. (See Appendix B for the agenda for the meeting.)

The meeting was designed by a planning committee representing a broad group of stakeholders (See Appendix A). In support of the principal objectives described above, the planning committee designed the meeting to focus specifically on the following area of inquiry: what are the unanswered questions in health services research that are critical to policy making today. The planning committee was also very aware of the limited funding available for health services research and hoped that the meeting could also identify how existing data gathering and analytic resources can be best leveraged to address critical questions.

The meeting attendees agreed that current HIV health services research is building on a relatively rich base of work, especially given the relatively recent development of the specialty of HIV health services research. However, attendees also agreed that this base did not, as of yet, include an ongoing infrastructure for conducting HIV health services research and that many of the critical studies undertaken in the past, while producing valuable findings and bases for further research, were not current enough to reflect the realities of today's epidemic in the U.S. (See Appendix C for a summary of key questions raised by recent research.) Looking forward, the meeting attendees reached a general consensus that HIV health services research should:

- Provide timely data that reflects the changing nature of the epidemic and the constantly evolving structure and financing of care provided for people with HIV.
- Be sufficiently transparent that policy makers, community-based organizations, and providers can access new findings and data rapidly.
- Be directly relevant to the needs of policy makers, community-based organizations, and providers.

This document provides a summary of the meeting and is organized in two parts:

- first, a discussion of the key issues facing the field of HIV health services research of HIV health services research identified by the participants; and

## **Developing an HIV Health Services Research Agenda**

second, identification of critical research questions that attendees felt HIV health services research should be addressing in the near- and long-term.

### **B. Key Issues Facing the Field of HIV Health Services Research**

One of the important conclusions of this meeting was an understanding among participants that, given the lack of funding for HIV-related health services research researchers and policy analysts need to rely on a variety of sources for data that might drive a health services analysis. In other words, there are multiple sources of data that are collected for purposes other than health services research that can be used to better understand issues of access, quality, and financing in HIV care and treatment. For example, expanded surveillance studies, while technically conducted as part of epidemiologic analysis, may contain data ripe for analysis by health services researchers. Thus all those designing data collection instruments, whether epidemiologists, behavioral researchers, clinical researchers, or program evaluators should assess their data collection instruments keeping in mind the potential for multiple uses of those data – and consult with health services researchers and health policy analysts to assure the broadest potential utility of the data. Such interdisciplinary collaboration can provide significant new avenues for analysis and leverage multiple efforts.

There was considerable expression of frustration by meeting participants about the gap in our knowledge of what is currently happening in HIV health services, especially concerning questions relating to access and quality (e.g., the attributes of those entering care, the stage of disease when individuals in different subpopulations enter care, the attributes of those not in care, how care is being financed for different groups, differentials in access to standard of care). The nature of the HIV epidemic has evolved so rapidly – both in terms of the scope of who is affected by the disease and the nature of treatment interventions – that the community’s need to rely on data older studies, particularly the HIV Care and Services Utilization Study (HCSUS) collected in the 1990s paints an inadequate picture for policy makers and forces reliance on anecdotal information, even in the context of major policy decisions such as the reauthorization of a \$2 billion-a-year program such as the Ryan White CARE Act. One potential new avenue for research of great interest among meeting participants is the US Centers for Disease Control and Prevention’s new Morbidity Monitoring Project (MMP), as potentially filling part of this gap. The MMP is a nationally representative sample of HIV-infected adults in care, which through medical record abstraction and interviews, will monitor clinical outcomes, quality of care, and HIV risk behaviors. It will also try to identify met and unmet needs for HIV care and prevention services. A substudy will also look at HIV-infected adults out of care to determine why these individuals are not in care and monitor HIV risk behaviors.<sup>3</sup>

Participants identified some critical attributes for the collection and analysis of any data set hoping to be of use for health services policy and research purposes:

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<sup>3</sup> Greenberg, A. New Approaches to Tracking the HIV/AIDS Epidemic in the United States. Presentation at National HIV Prevention Conference, June 13, 2005, Atlanta GA.

## Developing an HIV Health Services Research Agenda

*Data collection efforts must relate to both the short-term and long-term need for understanding of critical health services issues. Data should be released for interim analyses to meet real-time planning, quality management and policy needs.*

There was a broad recognition among researchers and policy analysts participating in the meeting of the need for more timely access to data. Policy decisions are on a calendar that is often different from the timeline of surveillance or health services research. Researchers need to be flexible and willing to provide early access to data and interim analyses that will be relevant to these policy decisions. This makes the data collection more useful and, not insignificantly, may, if found useful to real-time policy decisions, create a larger constituency of support for more health services research.

*The level of analysis of data must go beyond the national level to include state and local analyses whenever possible.*

The nature of the epidemic can vary dramatically from state to state and even in localities within a state. For the data to be useful in influencing the design and implementation of programs (whether for care and services or prevention) geographically specific data must be made available. This may require somewhat larger local samples than needed for a study that only seeks a nationally representative sample; but this would be a less costly investment (in dollars and human resources) than states and localities having to design and implement their own data collection. It should be noted that as more and more demands are made on health departments and health care providers to participate in data collection, their willingness to participate will depend on the ultimate utility of the data to *their* planning, programmatic and quality management needs. This was perceived by participants as a basic issue of respect for those participating in research.

In addition, given the decentralized nature of the US health care system, without state and local level data, a true understanding of the system of care and differentials in access and quality will not be learned. National-level data will not reveal geographic variations in access due to different state or local level program designs in Medicaid and the Ryan White CARE Act, for example.

*Similarly, the level of analysis must also examine subgroups of populations, e.g. country of origin within minority groups.*

Participants reported (particularly providers) that there were insufficient data to determine differences in access within minority groups. Anecdotal and small-set data were offered to suggest that entry and adherence to care may differ based on country of origin (e.g., US-born blacks may differ from Caribbean-born blacks). While this is an issue that has been long-recognized in the development of prevention services, this has been less studied in terms of health services. Thus, to the degree financially feasible, data collection must recognize the potential for these differences within minority groups.

## **Developing an HIV Health Services Research Agenda**

Participants also identified a number of methodological and implementation issues associated with broader data collection and analysis and related to HIV health services research in particular. These included:

- An obligation to coordinate between new and old studies (e.g., the new CDC Morbidity Monitoring Project and the AHRQ-funded HIV Research Network), both as a form of verification and to avoid duplication of effort. (Some of the same providers may be asked to participate in each study; assuring that this is not overly burdensome and that data collection requirements are as similar as possible will assure greater adherence to both studies and a greater willingness of providers generally to participate in future studies.)
- The need to encourage data sharing across health department data sets. This is a particular concern at the state level, where HIV surveillance and epidemiology data often cannot be studied with Medicaid claims data. There are financial, practical, and legal (e.g., understanding of HIPAA requirements) obstacles to these collaborations. However, overcoming these obstacles would dramatically improve our understanding of HIV health services.
- The need to encourage mixed methods of research, i.e., combining qualitative and quantitative methods. This is an area that HRSA is spear-heading in some of its work with Special Projects of National Significance (SPNS) grantees; but broader acceptance of this approach is needed in the health services research field. Indeed, a number of clinicians and community representatives at the meeting raised the important issue of needing a method to capture the qualitative experiences of community-based providers to help identify new trends and areas for research.
- The need for more operations and implementation research. Participants felt that in addition to describing issues of access and financing and looking at the outcomes of particular programs, there is a need to better capture the relationship between how services are operationalized and implemented and outcomes.
- The need to look at private health care systems and data sets as potential sources for data and research, with a particular focus on maximizing efficiencies, integrating care, and increasing access.
- Much of health services research (and good surveillance and epidemiology research as well) relies on the collaboration of clinicians and clinical researchers. Training and mentoring of clinicians to be researchers and/or an early warning system for health services researchers should be explored. This would require making the case to clinicians that health services research is relevant to their needs and participation in it will build their professional credibility. Similarly, those conducting clinical research or developing large databases of HIV-positive cohorts for epidemiological or treatment research purposes need initiation in the concept of expanding their focus to include health services research.

Two other important points were raised during the discussion that related to more effective use of existing data. First, from health departments to community-based

## **Developing an HIV Health Services Research Agenda**

organizations, opportunities to collect more data exist, but they often lack the infrastructure to collect and/or analyze these data. A relatively small investment in personnel and hardware provided health departments and community-based providers might dramatically increase the amount of data available for health services researchers and policy analysts.

Second, we lack an ongoing communication mechanism among health services researchers, policy makers, health departments, community organizations, and providers. Each is framing questions, collecting data, and/or making decisions without the full benefit of the knowledge of the others. There is rarely a health services policy or research component to national HIV meetings and there is no mechanism in place to promote communication. This results in studies being designed without full benefit of input from those with real-world experience with a problem (see discussion above regarding integration of qualitative experience of clinicians) and/or policy decision being made without full benefit of the data that may be available to inform the decision.

### **C. Critical Research Questions Identified for Additional Research Effort**

Attendees were keenly aware of the need to focus on issues that were timely to the policy making process – that health services researchers, for example, already had data or studies that could be relevant to both the current debates on the future of Medicaid (given its critical importance in financing care for people with HIV) and reauthorization of the Ryan White CARE Act. Among the critical research questions related to accessing, financing, and quality of HIV care that would be relevant to policy makers and community organizations were:

- Issues related to the reauthorization and improvement of the Ryan White CARE Act:
  - Which aspects of the Ryan White CARE Act model work best? There are a number of evaluations that have been performed; more may be needed. But integrating what is known in a manner accessible to policy makers is needed.
  - What are core services for people with HIV? One critical issue of contention in the management of the CARE Act program in a time of tight fiscal constraints is whether a core set of services can be defined for people with HIV. Existing health services research could inform this discussion; as jurisdictions begin to adopt different definitions of core services prospective evaluations of the impact of these different approaches could inform future policy decisions. In particular, there was interest in how HIV care for substance users should be defined, the role of support services (i.e., which support services mattered most), and the need for mental health services.
- Issues related to forecasting demand and describing those who are not in care. While directly related to the CARE Act, these are broader systemic questions.

## Developing an HIV Health Services Research Agenda

- Can health services researchers assist in forecasting the demand for services based on current epidemiological data?
- Can health services researchers design studies that will help describe those who are not in care so that outreach programs can be targeted to those individuals? With increased concern about individuals entering care late in disease progression, finding those with HIV earlier can have major public health and individual health outcomes implications.
- Will there be enough providers to meet the need for those not in care if they enter the system? Several meeting participants expressed concern about anecdotal evidence that many HIV experienced providers are leaving the field without well-trained successors to replace them. If demand continues to increase, will the provider base be there? If not, what can be done (through medical education, financial incentives, etc.) to increase the supply of providers?
- Issues related to entitlement programs. Spending on HIV-related care is far greater in Medicaid and Medicare than in the CARE Act, though the latter often gets more attention. Relatively little research has been conducted on the entitlement programs and their impact on access and quality of care for people with HIV. Among the core questions raised by meeting participants were:
  - The need to monitor the impact of the new prescription drug benefit on HIV-positive Medicare beneficiaries. This may be a case of integrating HIV-related issues into larger studies of the new program, rather than designing an HIV-specific study.
  - The need to better understand the Medicaid population as it relates to HIV, both in terms of those with HIV and when and how they access Medicaid, but also those at-risk for HIV and the opportunity to integrate HIV prevention into Medicaid clinical services.
  - The need for state-level analyses of quality of care in Medicaid programs, given the variation in eligibility, benefits, and delivery systems across the states.
- Issues related to disparities. There needs to be more detailed understanding of the scope and nature of disparities (see earlier discussion of the need for greater subgroup analysis). Among the questions raised that might assist our understanding of racial/ethnic disparities in HIV care are:
  - What are the various points in the “life cycle” of disease and in a patient’s interaction with the system throughout this cycle at which disparities might occur - at time of diagnosis, referral and entry into care, type of care received, experience of care, insurance coverage, retention in care, etc.?
  - How do patient preferences and provider attitudes affect disparities?
  - What other factors may play a role in alleviating or exacerbating disparities, such as access to clinical trials, co-morbidities, financing structures and institutions, rate of diffusion of new technologies (e.g., a newly approved antiretroviral or diagnostic)?
- Issues related to the ethics of rationing in public programs. As more and more jurisdictions place eligibility and benefits restrictions on Medicaid and CARE Act beneficiaries, it is important to understand how different jurisdictions are making

## **Developing an HIV Health Services Research Agenda**

- decisions and what changes to programs they are implementing, with a particular focus on the public health and individual health implications of these varying decisions.
- Issues related to delivery systems. As HIV treatment changes, as the populations in care expand or change, health services research can use past studies and prospective studies to inform some key questions, including:
    - How do HIV care models transition to a chronic disease model? How does an HIV model differ from traditional chronic disease models?
    - What are best models for integration of HIV prevention into treatment settings?
    - How do HIV services and other critical services become integrated (e.g., mental health, substance abuse, other viral infections such as HCV)?

### **D. Next steps**

Meeting participants recognized that they had identified a very long list of structural issues regarding how HIV health services research might be conducted as well as a quite comprehensive list of substantive issues that require further study. Individual participants, and relevant funding agencies in attendance, agreed that this discussion was an important step in moving the field forward and would help guide future funding decisions. But the level of funding available is still quite limited.

One immediate next step is to continue the discussion, both among those concerned about HIV health services research issues and with the broader HIV community. To that end two specific actions are being taken:

- A listserv, managed by the GW Department of Health Policy, has been created to facilitate dialogue within the health services research and health policy community. Individuals can join the listserv by going to [hermes.gwu.edu](http://hermes.gwu.edu), clicking on LIST ARCHIVES, scrolling down to HIVHSR and clicking on HIVHSR; they will be given the option to join or leave the list. The e-mail address for the listserv is [hivhsr@hermes.gwu.edu](mailto:hivhsr@hermes.gwu.edu).
- This report will be disseminated by the GW Forum for Collaborative HIV Research, which reaches a broad base of both clinical researchers and policy makers, thus extending the reach of this discussion.



Appendix A

Developing an HIV Health Services Research Agenda

Participant List  
February 11, 2005

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## Developing an HIV Health Services Research Agenda/Appendices

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**Appendix B**

**Developing an HIV Health Services Research Agenda**

A Meeting Supported by  
The Agency for Healthcare Research and Quality  
and  
The Henry J. Kaiser Family Foundation

February 11, 2005

Location:  
Barbara Jordan Conference Center  
Kaiser Family Foundation  
1330 G Street, NW  
Washington, DC

- 10:00-10:15: Welcome and Introductions  
Welcoming remarks:  
Ruth J. Katz, JD, Dean, George Washington University  
School of Public Health and Health Services  
Introductions:  
Jeffrey Levi, GW
- 10:15-10:30 Why we are here (brief background regarding genesis of this meeting)  
Jeffrey Levi, GW  
Jennifer Kates, Kaiser Family Foundation
- 10:30-11:00 What is happening now – initial presentations  
HIVNet: Richard Moore  
HRSA: Lois Eldred  
CDC Morbidity Monitoring Project: A.D. McNaughten  
NIH: Dianne Rausch (NIMH)
- 11:00-11:30 Open discussion on what's happening now
- 11:30-12:00 What we need to know – five minutes (each) from different perspectives:  
Providers: Valerie Stone; Keith Rawlings (invited)  
Consumers: Anne Donnelly (invited); Dawn Averitt (invited)  
Health departments: Bruce Agins, NY State AIDS Institute;  
Murray Penner, NASTAD
- 12:00-12:30 Open discussion on what we need to know

## Developing an HIV Health Services Research Agenda/Appendices

- 12:30-1:00 Break for lunch
- 1:00-1:30 Lunch discussion – lessons from the non-HIV world of health services research  
Marsha Lillie-Blanton, Kaiser Family Foundation
- 1:30-2:30 Open discussion of the questions we need answered
- 2:30-2:45 Break
- 2:45-3:45 Focused discussion by category of questions raised during the day  
Objective will be to:
1. Prioritize
  2. Assess whether there are data available to answer the questions
  3. Assess who might fund these studies
  4. Determine if there are potential collaborations among attendees or others to assure this work might move forward
- 3:45-4:00 Closing and next steps  
How do we keep talking among ourselves?  
Who else should be part of this discussion?

*This meeting is a joint project of the GW Department of Health Policy and the GW Forum for Collaborative HIV Research.*

## Appendix C: Background on State of HIV Health Services Research

*The following is drawn from text submitted to AHRQ in support of the conference grant that funded this meeting.*

This is a critical time in HIV health services research. Numerous factors related to the HIV epidemic require an assessment as to whether new or different health services research questions must be addressed in order to improve health outcomes, strengthen quality measurement and improvement, and identify strategies to improve access, foster appropriate use of services, and reduce unnecessary expenditures. As can be seen from the discussion below, the challenges associated with the HIV epidemic address all of the priority populations identified in the Program Announcement: “low income groups; racial and ethnic minority groups; women; children; the elderly; individuals with special health care needs, including individuals with disabilities and those who need chronic care and end-of-life health care; and individuals living in inner-city, rural, and frontier areas.” Among the critical factors needing examination or re-examination are (italics reflect AHRQ research interests as reflected in the Program Announcement):

- HIV infection prevalence rates continue to rise, particularly among some populations and geographic areas of the US. New infection rates are rising steadily among some segments of the population, particularly among women, youth, low-income groups, and racial and ethnic minority groups.<sup>4</sup> The implications of the changing demographics of HIV for *access* to life-saving treatments and *outcomes* require further exploration.
- A growing percentage of HIV-infected individuals are multiply diagnosed with severe and persistent mental illness, drug addiction, and other infectious diseases such as Hepatitis C infection.<sup>5</sup> Many HIV-infected individuals have experienced lifelong social disenfranchisement, housing instability, and inadequate access to

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<sup>4</sup> Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report 2002*;14. Also available at: <http://www.cdc.gov/hiv/stats/hasrlink.htm>.

<sup>5</sup> Andersen, R., Bozzette, S., & Shapiro, M. (2000). Access of vulnerable groups to antiretroviral therapy among persons in care for HIV disease in the United States. *Health Services Research*, 35(3), 389-416.; Sullivan, G., Koegel, P., Kanouse, D. E., Cournos, F., McKinnon, K., Young, A. S., et al. (1999). HIV and people with serious mental illness: The public sector's role in reducing HIV risk and improving care. *Psychiatric Services*, 50(5), 648-652.; Bing, E. G., Burman, M. A., Longshore, D. , et al. (2001). Psychiatric disorders and drug use among Human immunodeficiency virus-infected adults in the United States. *Archives of General Psychiatry*, 58(8), 721-728.; Burman, M. A., Bing, E. G., Morton, S. C., et al. (2001). Use of mental health and substance abuse treatment services among adults with HIV in the United States. *Archives of General Psychiatry*, 58(8), 729-736; Gottesman, I., & Groome, C. (1997). HIV/AIDS risks as a consequence of schizophrenia. *Schizophrenia Bulletin*, 23, 675-684.;Centers for Disease Control and Prevention. (2002, May). *Drug-associated HIV transmission continues in the United States*. Atlanta, GA:Author.; Centers for Disease Control and Prevention. (2001, July 13). *Prevalence of Hepatitis C virus infection among clients of HIV counseling and testing sites - Connecticut, 1999: Vol. MMWR 2001* (pp. 577-581). Atlanta, GA:Author.; Sherman, K. E., Rouster, S. D., Chung, R. T., & Rajicic, N. (2002). Hepatitis C virus prevalence among patients infected with Human Immunodeficiency Virus: A cross-sectional analysis of the US Adult AIDS Clinical Trials Group. *Clinical Infectious Diseases*, 34, 831-837.

health care.<sup>6</sup> As a result, anecdotal reports suggest that HIV-infected individuals commonly enter treatment in clinical and social crises that require intensive resources before stabilization can occur.<sup>7</sup> Surveillance reports indicate that a growing number of individuals are entering HIV care with AIDS or other manifestations of highly advanced HIV disease.<sup>8</sup> Addressing these issues will affect *health outcomes, foster appropriate use of services, and strengthen quality measurement and improvement.*

- New treatments have changed disease progression dramatically.<sup>9</sup> While HIV remains a fatal disease, individuals receiving optimal therapy may live in a chronic disease state for many years. The growing number of HIV-infected individuals with relatively high resource requirements is reported to be significantly challenging the HIV care system.<sup>10</sup> Greater understanding is needed as to the implications of this change on how care should be organized, delivered, and financed to better identify *strategies to improve access, foster appropriate use, and reduce unnecessary expenditures.*
- Some data suggest that there are payer, geographic, and racial or ethnic disparities in utilization of recently introduced protease inhibitors and other antiretrovirals (ARV).<sup>11</sup> There is evidence that mortality rates are increasing among some

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<sup>6</sup> Health Resources and Services Administration. *ADAP Fact Sheet*. Retrieved February 3, 2004, from <http://hab.hrsa.gov/programs/factsheets/adap1.htm>; Chillag, K., Bartholow, K., Cordeiro, J., Swanson, S., Patterson, J., Stebbins, S., et al. (2002). Factors affecting the delivery of HIV/AIDS prevention programs by community-based organizations. *AIDS Education and Prevention, 14*(3), 27-38.; Cunningham, W. E., Andersen, R. M., Katz, M. H., et al. (1999). The impact of competing subsistence needs and barriers on access to medical care for persons with human immunodeficiency virus receiving care in the United States. *Medical Care, 37*(12), 1270-1281.

<sup>7</sup> Burrage, J., & Porche, D. (2003). AIDS services organization partnerships: A method to assess outcomes of community service organizations for vulnerable populations. *The Journal of Multicultural Nursing and Health, 9*(1), 7-12.

<sup>8</sup> Neal, J. J., & Fleming, P. L. (2002, February). *Frequency and predictors of late HIV diagnosis in the United States, 1994 through 1999*. Paper presented at the meeting of the 9th Conference on Retroviruses and Opportunistic Infections, Seattle, Washington.

<sup>9</sup>Centers for Disease Control and Prevention. (2003). *HIV/AIDS Surveillance Supplemental Report* (pp. 1-19). Atlanta, GA:Author.; Freedberg, K. A., Losina, E., et al. (2001). The cost effectiveness of combination antiretroviral therapy for HIV disease. *New England Journal of Medicine, 344*(11), 824-831.; Goetz, M. B., Morreale, A. P., et al. (2001). Effect of highly active antiretroviral therapy on outcomes in Veterans Affairs Medical Centers. *AIDS, 15*(4), 530-532.

<sup>10</sup> This is reflected in the increased demand for AIDS Drug Assistance Program services and resulting waiting lists. See MD Davis, et al. National ADAP Monitoring Project Annual Report, Washington, DC: Henry J. Kaiser Family Foundation, 2003; and National Alliance for State and Territorial AIDS Directors, *The ADAP Watch*, at [www.nastad.org](http://www.nastad.org). Accessed January 28, 2004.

<sup>11</sup>Cunningham, W. E., Mosen, D. M., Morales, L. S., Andersen, R. M., Shapiro, M. F., & Hays, R. D. (2000). Ethnic and racial differences in long-term survival from hospitalization for HIV infection. *Journal of Health Care for the Poor and Underserved, 11*(2), 163-178. Crystal, S., et al. (2001). Initiation and continuation of newer antiretroviral treatments among Medicaid recipients with AIDS. *Journal of General Internal Medicine, 16*(12), 850-859.; Keruly, J. C., Conviser, R., & Moore, R. D. (2002). Association of medical insurance and other factors with receipt of antiretroviral therapy. *American Journal of Public Health, 92*(5), 852-857.; Helsin, K. C., & Cunningham, W. E. (2001). African Americans and AIDS: Issues



segments of the HIV-infected population. Racial and ethnic disparities are reported at a time when public funding for HIV care and treatment are at an all-time high. Factors contributing to racial disparities require careful exploration by health services researchers, to *support improvements in health outcomes* for all affected by HIV.

- The HIV-infected population is “aging.” There are increasing numbers of older Americans living with HIV, both due to a rise in new infections among those over 50 years of age and because those diagnosed in their younger years are living longer.<sup>12</sup> This has implications for *improving access to care*, both in terms of how care is delivered and how it is financed. The addition of the Medicare prescription drug benefit is just one issue that will dramatically affect access to care for this population.
- The field of HIV clinical research treatment is highly dynamic. New therapeutics and treatment strategies are being reported in the clinical literature in rapid succession. The translation of new HIV clinical knowledge into practice has been challenging. Physicians report difficulties in keeping up with state of the art care. Approaches used to disseminate HIV clinical knowledge, such as Public Health Service (PHS) guidelines, appear to be best accepted or used by physicians who have small to moderate size HIV practices. These physicians tend to treat relatively newly infected patients who are not educated about the various treatment options available to them. The patients may also be reluctant to initiate therapy due to misinformation or denial. HIV experienced physicians report that HIV clinical meetings are their most useful source of updated HIV treatment information but do not have enough time to attend them. Physicians practicing in large HIV practices report that they are persistently challenged by their patients to provide them with the latest, state of the art therapeutics and treatment regimens available.<sup>13</sup> Disparities in the quality of HIV care have resulted from the variability of clinical knowledge and its application among various HIV-infected

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in Access to Care. *Minority Health Today*, 22-32.; Anderson, K. H., & Mitchell, J. M. (2000). Differential access in the receipt of antiretroviral drugs for the treatment of AIDS and its implications for survival. *Archives of Internal Medicine*, 160, 3114-3120.; Bing, E. G., Kilbourne, A. M., & Brooks, R. A. (1999). Protease inhibitor use among a community sample of people with HIV disease. *Journal of AIDS and Human Retrovirology*, 20(5), 474-480.; Cunningham, W. E., Markson, L. E., & Anderson, R. M. (2000). Prevalence and predictors of highly active antiretroviral therapy use in patients with HIV infection in the United States. *Journal of Acquired Immune Deficiency Syndromes*, 25, 115-123.

<sup>12</sup> Linsk, N. L., Fowler, J. P., & Klein, S. J. (2003). HIV/AIDS prevention and care services and services for the aging: Bridging the gap between service systems to assist older people. *Journal of Acquired Immune Deficiency Syndromes*, 33(Suppl. 2), S243.; Mack, K. A., & Ory, M. G. (2003). AIDS and older Americans at the end of the twentieth century. *Journal of Acquired Immune Deficiency Syndromes*, 33(Suppl. 2), S68.; Kun, K. E., & Schwartz, R. W. (1998). Older Americans with HIV/AIDS. *SIECUS Report*, 26(2), 12-14. Crystal, S., Akincigil, A., Sambamoorthi, U., Wenger, N., Fleishman, J. A., Zingmond, D. S., et al. (June 2003). The diverse older HIV-positive population. A national profile of economic circumstances, social support and quality of life. *Journal of Acquired Immune Deficiency Syndromes*, 33 (Suppl. 2), S76-S83.

<sup>13</sup> Hidalgo, J. *A Survey of Physicians Practicing in HIV Clinical Settings: Adoption of National HIV Antiretroviral Guidelines*. Harwood, MD: Positive Outcomes, Inc. 2003.

- populations.<sup>14</sup> Health services research can contribute to *improved health outcomes* through a better understanding of *decision-making at all levels of the health care system*.
- There are growing state-by-state variations in public health financing systems, in part fueled by significant drops in state and local revenue.<sup>15</sup> Contraction of financing for insurance and for safety net programs has a significant impact on HIV-infected populations, as well as their providers. People living with HIV are disproportionately dependent on the public sector to finance their care, even those who are newly diagnosed with HIV. Most of the data relating to the role of the public sector in financing HIV care comes from studies undertaken in the mid-1990s. As states make dramatic changes in their Medicaid and other medically needed programs in the context of severe budget shortfalls, new analysis is required to determine the impact of contracted public financing, its impact on beneficiaries and their health care providers, and the impact of state-by-state *differences in delivery modalities and financing arrangements on access to care and health outcomes*.
  - As the HIV epidemic has grown and diffused throughout the US, a large complex HIV delivery system has evolved. Efforts have been made to increase available and accessible care.<sup>16</sup> These efforts have often been undertaken without planning to ensure that needed services are located among populations in need, that duplication is minimized, and that cost-effective care is provided in an efficient manner. Attempts to coordinate care are often impaired by time and staff constraints, territoriality, vast numbers of organizations with which to coordinate, and poor articulation of roles and responsibilities by funders. Priority setting for HIV funding has tended in many communities to be based on a system that was established ten to twenty years ago, at a time when a “death and dying” care model was appropriate. Insufficient infrastructure has been funded to support the more relevant chronic disease model that exists in HIV today. Mature AIDS service organizations are reported to be experiencing challenges in reengineering

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<sup>14</sup> Levi, J., Parrish, B., and Miller, V. Quality of HIV Care – Closing the Gap. Forum for Collaborative HIV Research, George Washington University School of Public Health and Health Services, Washington, DC. 2003.

<sup>15</sup> Smith, V., Ramesh, R., Gifford, K., Ellis, E., Wachino, V., & O'Malley, M. (2004, January 28). *States respond to fiscal pressure: A 50-state update of state Medicaid spending growth and cost containment actions*. Washington, DC: Kaiser Family Foundation. See also Levi, J., Hidalgo, J., & Wyatt, S. (2000). The impact of state-by-state variability in entitlement programs on the Ryan White CARE Act and Access to services for underserved populations. In C. Ryan (Ed.), *Directions in HIV Service Delivery and Care: A Policy Brief* (Vol. 2, pp. 15-20). Rockville, MD: Health Resources and Services Administration.

<sup>16</sup> Davis, M. D., Aldridge, C., Kates, J., & Chou, L. (2003, April). *National ADAP Monitoring Project*. Washington, DC: Kaiser Family Foundation.; Levi, J., & Kates, J. (2000). HIV: Challenging the health care delivery system. *American Journal of Public Health, 90*(7), 1033-1037.; Surapruik, A., Blum, N., O'Neill, J. F., & Marconi, K. (2000). Improving HIV/AIDS services through palliative care: An HRSA perspective. *Journal of Urban Health: Bulletin of the New York Academy of Medicine, 77*(2), 244-254; Hecht, F. M., Wilson, I. B., Wu, A. W., Cook, R. L., & Turner, B. J. (1999). Optimizing care for persons with HIV infection. *Annals of Internal Medicine, 131*(2), 136-143.

themselves to provide relevant, cost-effective care that meets the complex needs of today's HIV-infected care consumer. HIV providers report that they are expected to "do more for less," without the needed organizational tools and financial resources to reshape their agencies. A better understanding is needed regarding the systems of care that have been established, as well as their outcomes and cost-effectiveness. This improved understanding will help to inform the design of innovative *strategies to improve access* as well as planning, organizing, and financing of HIV care.

This is a good time to assess the health services research agenda to be sure that our research accounts for these important changes in treatment and delivery as we study access and quality of HIV care. The volatility in the HIV epidemic as well as in the care and delivery system described above suggest that this is a particularly important moment to assess the research agenda. The federal government spent over \$8.8 billion in FY 2003 in financing HIV care and treatment in the United States.<sup>17</sup> This amount is expected to be even higher in FY 2004. The federal government, therefore, has a direct stake in knowing the impact of this investment and whether it succeeds in addressing key challenges associated with HIV care (e.g., racial/ethnic disparities, geographic diffusion of quality care models). We believe that this can only be accomplished through a focused health services research agenda. There has been limited funding for investigator-initiated HIV health services research in recent years. We hope this conference will be able to better define the outstanding research questions and promote interest among potential funders in supporting such research.

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<sup>17</sup> This reflects spending on the Ryan White CARE Act, Medicare, and the federal share of Medicaid. Source: FY 2003 Moyer Material submitted by the Office of the Assistance Secretary for Budget, Technology and Finance, US Department of Health and Human Services, February 25, 2002.