REPORT: ASSESSMENT OF MEDICAL CARE
FOR HIV PATIENTS IN THE GREATER HARTFORD EMA

Prepared by Goff Brown Associates, LLC
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The reauthorization of the Ryan White Care Act requires that 75% of Ryan White Title I funding be allocated to identified core services beginning March 1, 2007. Many of these core services center around medical care. The Ryan White Planning Council contracted with a consultant, Goff Brown Associates, LLC, to undertake a survey of medical providers to obtain their input specifically around medical practice for HIV care. The consultant and staff developed a brief questionnaire to administer. Telephone interviews were scheduled for the week of January 8-12, 2007. The Ryan White staff identified sixteen facilities that provide medical care in the EMA. A provider was identified at each facility to be interviewed. Thirteen providers responded and were scheduled. Two were unavailable at their scheduled time, one cancelled and, in one case, the interviewer could not keep the rescheduled appointment. Nine providers were interviewed. One response was submitted in writing.

Dr. Kenneth Abriola	CT Health Care Associates	Glastonbury
Dr. Kevin Dieckhaus	UCONN Division of Infectious Diseases	Farmington
Dr. M. Huddleston	Community Health Center	Meriden
Dr. Carola Marte	Community Health Center	Meriden
Dr. Ellen Neuhaus	Rockville General Hospital	Rockville
Dr. Jack Ross	Hartford Hospital	Hartford
Dr. Juan Salazar	CCMC	Hartford
Seja Fishman	St. Francis Hospital	Hartford
Dr. Pooja Tolaney	Charter Oak Health Center	Hartford
Kathy Tummillo	St. Francis Hospital/ Burgdorf Clinic	Hartford

There were nine questions asked during the telephone interviews. The questions focused on issues of both primary and infectious disease care for HIV patients, services at their respective facilities, and issues with the medical field in general as they relate to HIV care. See Attachment 1 for the questionnaire. Additionally, each facility was asked to submit a demographic report. Four responded, three adult providers all located outside of Hartford and one that treats children and youth. This data cannot be considered typical of the HIV/AIDS patient within the EMA due to the limited number of obtained responses. The data is attached to this report in Attachment B.

PRIMARY AND INFECTIOUS DISEASE CARE

Both primary care and infectious disease care are provided at all responding facilities. In some cases, it is the same physician provider; in others, the care is separate. This largely depends on the structure of the HIV program within the medical setting.

Primary care for people with HIV has the same requirements as primary care for anyone else. However, most physicians indicated that primary care for HIV patients is additive and that the physician must be more vigilant for screening co-morbid issues. HIV patients progress more quickly with other illnesses and with people living longer with HIV, there are more incidences of co-morbid conditions such as diabetes, hypertension, cardiac disease, renal failure and cancer.

Having one physician serve as both primary care physician and infectious disease physician works until the disease becomes complex. Then, HIV treatment issues tend to overtake the primary care due to time utility issues. For this reason, it may be better for the patient to have separate primary care and infectious disease physicians to ensure that all aspects of the patient's physical care are attended to. However, all respondents felt it is better to have both the primary care and infectious disease care on site, or at least in close proximity for better access and improved communication.

Most physicians responded that they experience problems in keeping patients engaged. The only doctor who indicated that this was generally not a problem was in private practice.

Most cited problems of mental illness, active substance use and incarceration (revolving door) as key to patients not staying engaged. Other issues cited included homelessness, child care, denial and stigmatization followed by single citations of violence/domestic violence, fear of immigration, and not having insurance.

Two physicians said that it is individual make-up of the patient that kept them from getting engaged, e.g., they don't make good medical choices, or that their lives are so complex that medical care just doesn't stay a top priority. Another indicated that responsibility is less in the hands of the patient and so there is a sense of entitlement meaning that the patient doesn't feel a need to be responsible for keeping appointments unless it is a crisis. This creates a no show rate that can range from 20% or more daily.

Transportation was cited as problematic in eastern Connecticut where transportation via public bus is inadequate. While the facility is on a bus line, points of origin may not be. Other transportation problems include getting to appointments too late to be seen or finding that they may wait up to an hour after being seen to be transported home.

One physician worked with children and youth. There are seldom problems engaging children since they work with the entire family unit. However, as youth get older, it becomes harder. As patients enter young adulthood, there is a need for medical and social case management to effectively transition them to adult care.

The responding physicians were satisfied that their facilities were doing a good to excellent job in caring for HIV patients in both primary and infectious disease care. There was consistent response in having a comprehensive, coordinated range of services on site to make it easier for the patient to access needed services. Psychiatric services, substance abuse treatment and medical adherence all need to be on site and accessible for patients.

The big issue for the physicians was the lack of specialty care for HIV patients. Those mentioned included orthopedics, ophthalmology, neurosurgery, dermatology, and gastrointestinal. When a physician is able to get a patient seen, the waiting lists are often 4-6 months or more and the referral is accepted based on the personal/professional relationship the physician has with the referral. However, when HIV patients do not show, the referral doctor's practice becomes unwilling to accept any further referrals. When probed, indication was that it was a financial issue – no shows and low reimbursements from the federal entitlements impacted their practice financially.

Due to low reimbursements, many physicians are no longer accepting Title XIX or SAGA in their practices. In some instances there is no available gynecology service for female HIV patients. One physician, however, stated that perhaps physicians don't realize that money is available for their services through Ryan White funding and perhaps there should be more advertising to this effect.

Most physicians said that having "medical extender" staff more available in their facilities would improve care. Specifically, medical case management and medical adherence were mentioned most often, along with a need to recapture patients who don't show (medical outreach). Quality care for HIV patients is being seen every three months. Currently, practices do not have the manpower to, on an ongoing basis, follow-up the no-shows, who then don't reappear until there is a crisis.

While resources were limited for their HIV practices, some physicians identified the manner of funding as problematic. One physician indicated that operating an HIV clinic is not financially remunerative, and, as a result, it is difficult to argue for increased staff resources from the parent organization. However, some clinics do not pursue grant funds because they don't necessarily fund what is needed in the specific clinic practice. One facility has opted to not pursue any grant funds and is satisfied with this arrangement feeling that it allows him to provide the care they believe is best without the strings of government funding.

There was consistency of message regarding who delivers care for HIV patients. Some didn't see a primary care physician as being able to deliver HIV care. All expressed a requirement for being trained in infectious disease and being current in HIV care. The field has the fastest shifting paradigm in the medical arena. There needs to be enough of a mass of patients for a physician to remain current. Simply seeing 2-3 patients with HIV will not provide the physician with enough impetus for continuing education on HIV care.

It was noted that HIV as a specialty is not an attractive option for medical students. When selecting specialties, there are more lucrative options. One physician stated that her income is 40% less than her physician husband simply because of their specialty choices.

Another systemic issue is related to federal guidelines for doctors and patient caps. One felt that the current patient volume caps are too high for physicians who do both primary

care and infectious disease care. Another systemic issue relates to medical coding and flow charts for information sharing on patients across systems. As an example, there are individuals who live in eastern Connecticut who obtain their ongoing medical care in Hartford. Yet, when an emergency arises, they are transported to Rockville Hospital. No information is available on the patient making it difficult to treat the person well. It should be noted that this was not only a problem for the eastern part of the EMA, but was identified as an issue in the Hartford area when there are separate primary care physicians not affiliated with infectious disease physicians.

IMPROVING MEDICAL OUTCOMES

As would be expected, issues of active substance use and mental illness were cited most often as barriers to having poorer medical outcomes. This was followed by jail/incarceration and homelessness.

However, two physicians indicated that socio-economic status was not necessarily an indicator of poorer outcomes. Rather, it is more a factor of being able to make good medical choices for themselves. To that end, one noted that the system needs to motivate people to be more educated on the importance of their care, following a model such as that in diabetes care, to help patients understand the importance of their treatment plan.

When asked what could be done at their facilities to improve medical outcomes, in no particular order, the following were identified:

- More nurse outreach
- More mental health services available on site
- Nutrition care – more dietician services
- Mid-level support for physicians (Nurse practitioners, APRNS) who could handle stable patients, allowing physicians to concentrate on those with more need
- Increase medical adherence staff. Open caseloads of 140-190 patients is simply too high
- Outpatient/inpatient nurse liaison
- Assistance with required paperwork to allow APRN staff to be more focused on medical care

When asked what could improve medical outcomes within the medical field, in general, responses were varied:

- Better communication between outpatient and inpatient venues. There seems to be a disconnect between health clinics and the hospitals. How could key information be summarized in a standardized way to provide to hospitals when patients needing inpatient care?

- Better education of medical doctors. Most are “clueless” about HIV. They need to be educated about early symptoms of HIV and need to have testing become part of the routine primary care screenings to promote early diagnosis. For example, CCMC identified six young people in the last three years, one from sexual abuse.

- Need more access to mental health, on site. One physician felt there may be too many case managers –some patients have 2-3 case managers whre there should only be one.

- Will need more physicians trained in HIV. Treatment for HIV is fastest evolving in medicine now. There is need for dedicated teaching and learning time for doctors to keep current.

- Transitioning back to housing/the community. As people age and drugs fail, more dementia will be seen. More services will be needed to address this. Peter's Retreat, Tabor House and Mercy Housing were all cited as doing tremendous work and as models for services.

- Spend down issues prevent some from getting medications. Patients have to pay up front and can't afford it so they become non-adherent.

- Get rid of CT needing consent for HIV testing – this is a barrier. Testing needs to be universal.

- More comprehensive insurance to reinstate things like eye exams, dental exams

USE OF INCREASED FUNDING FOR MEDICAL CARE

The most often cited needed service was mental health treatment followed by medical adherence programs. Substance abuse treatment was mentioned frequently. However, one physician stated that patients needed more than counseling and were asking for inpatient treatment as ways to remove themselves from the environment and triggers for use.

It was suggested that the Ryan White Planning Council look at program outcomes and build upon those that have successful medical outcomes. Potential models included Peter's Retreat which has a combination of housing, support and access to medical care, a former program at Trinity Hill, intensive case management at Chrysalis Center, and medical adherence at UConn Health Center as examples.

Another approach physicians were interested in is for the Planning Council to work with existing facilities to identify what could facilitate their being able to provide better medical care and issue an RFP for this instead of for a particular service. Perhaps the medical facilities could pull form a menu of approved core services and develop proposals to enhance their delivery system to ensure comprehensive, coordinated care is available and accessible, on site. The more places people have to go for care, the more chance for deterioration.

One provider stated that the Planning Council/Grantee should demand better service for their funds. A specific example was transportation. In the Tolland area, public

transportation is inadequate. The service currently in use may bring patients too late to be seen. Patients have had to wait one hour to get ride home. If a person becomes acutely ill and there is no prearranged transportation, the result is an emergency room visit. Consider alternatives - Hockanum Valley Van Fleet might be a better resource in Tolland area.

Build better coordination for information flow across facilities and communities. Develop an intermediary service that can assist in coordinating services, particularly sub-specialties, with the HIV clinics.

More funding is needed for specialty care. For example, one physician reported that there is a one year wait list for pain management; 4-6 month waits for care for orthopedics and GI/colonoscopy.

Attention should be placed on home health care as well. As patients get older and deterioration sets in, the field needs to explore how more patients could be kept home longer, which would be a more cost effective option. In one cited example, despite a supportive family environment and willingness to keep the individual home along with home nursing care, the patient had to be transferred to a nursing home. A couple of physicians mentioned being able to provide home IV services as a cost-effective service.

Data collection is a problem. There is no universal paperwork system for medical and non-medical services that works. How can data be collected from medical providers that meets data needs and is not overwhelming? For example, in the clinic, nurses may make 30 calls a day and each has to be tracked. The current method is time consuming and takes the nurse away from patient care. Additionally, data collection across the titles is problematic – how could a more consistent format be developed across the Titles?

Medical case management was mentioned. However, one physician felt that there were too many case managers with some patients having two or three case managers, when the design should be only one. There needs to be better use of case management funds to ensure that each patient has only one case manager.

Attachment A

Greater Hartford EMA Ryan White Planning Council: MEDICAL PROVIDER INTERVIEW QUESTIONS – FINAL

1. Do you provide primary medical care as well as infectious disease care for your patients with HIV? If no, how do your patients obtain primary care?

2. From your perspective, what constitutes primary care for person with HIV? How does that differ from regular primary care for persons without HIV?

3. Do you experience problems with keeping patients engaged in medical care? If yes, what factors prevent them from obtaining medical care from you?

4. How could infectious disease care for HIV patients be improved at your facility? In general?

5. How could primary care for HIV clients be improved at your facility? In general?

6. Do any particular groups of HIV patients at your facility have poorer medical outcomes (CD4s, viral load, hospitalizations, mortality, opportunistic infections) than other groups? If yes, what are the groups with poorer outcomes? What are the reasons?

7. What could be done at your facility to improve medical outcomes of HIV patients?

8. What could be done in the medical field overall and in our area in particular to improve medical outcomes for HIV patients?

9. If there were increased funding for medical care for HIV patients, what would your top priority be and why? How might you put it in place? What do you think it would take to accomplish this?