Hepatitis C Leadership Committee Meeting

Monday, December 03, 2012

In Attendance

 Donna DeRoo, Priscilla Essert, John Capitman, Janice Mathurin, Carol Sipan, Theresa Hughes, Jena Adams, Ora Murray, Pam Madala, Don Peters, Mary Gish, Lynne Ashbeck, Kweku Middleton

Teleconference Attendance

 Rachel McLean and Shirley Barger

Introductions and Discussion of Committee Charge

All in attendance introduced themselves. Dr. John Capitman welcomed all and explained the purpose of the meeting is to identify the necessary steps to be taken to produce a preliminary plan that addresses the Hepatitis C epidemic in the Central San Joaquin Valley. Donna DeRoo explained that the current funding from Gilead Health Sciences is through spring 2013 and the need to complete the project by then. Theresa Hughes provided more background on the project, how it grew out of work in other parts of California and awareness of the special needs of the Valley. She also explained how the report would be used to prioritize and support applications to multiple funding sources to support follow-through activities. With these considerations in mind, all in attendance agreed the plan we would develop should address: a) the context and current status of viral hepatitis (not just Hep C) from perspectives of economics, epidemiology, current care options, and social context, b) development of a limited number of high priority specific process and goal objectives for a regional response and c) some preliminary indications of approaches to implementation.

Review and Discussion of Input from the November Summit

Capitman presented a summary of the input and discussion from the November summit on 4 topics:

1. Why do we need a regional plan?
2. What are the primary values and goals to guide the plan?
3. What should be included in the regional plan:
4. Who should be included in the planning process?

With respect to the need for a regional plan, Summit participants noted the following:

* Size and scope of problem, potential economic impact but lack of data
* Bring awareness of issue….promote prevention
* Need for collaborative and regional approach…because of mobile population and multiple overlapping and linked systems
* Changing policies and programs for incarcerated and post-prison populations
* Changing politics around needle exchange

Committee members endorsed these rationales for the regional plan, and indicated that additional factors that should be noted, include:

* Implementation of the Affordable Care Act in the year 2014.
* Primary focus on access to care and economics.
* Linkage with HIV and Hepatitis B

Several additional themes about the need for the report were also highlighted by committee members:

* Because Hepatitis C is a silent epidemic, dialogues have not been established concerning the virus and ways to prevent and treat it. All segments of the population need to be included in this dialogue so that no population is left out. Need to look at VA models. Hepatitis C is at epidemic proportions in the Vietnam Veteran population, however, the level of care in the VA population is very high.
* Although the November summit focused on Hep C only, there is a need to broaden the focus to all forms of viral hepatitis, including Hep B. Lynne Ashbeck pointed to the interest within the Hmong community locally with Hep B and in replicating Bay Area hospital initiatives around this condition.
* Ongoing development and debate about Hepatitis screening and treatment have clouded professional understanding. There is an emerging debate about whether or not general screening of baby boom populations is needed or justifiable. Similarly, past treatment regimens have been very difficult and expensive for patients and there is little new awareness of better treatments. More generally, there is just an enormous need for physician education about this topic. At the same time, there may be opportunities to work with insurers, health plans and large practices to alter protocols to encourage more screening and treatment.
* While Los Angeles and San Francisco have plans no great examples of regional models exist. Rachel McLean noted that there is a statewide plan for viral hepatitis prevention. surveillance, education/prevention, and treatment. She planned to share this document with the group. Committee members highlighted the need for alignment between the Valley plan and statewide efforts .

Capitman then provided a set of recommendations from the November summit about the goals and values that should be reflected in the regional plan, including:

* Importance of awareness and overcoming stigma and shame---breaking the silence---for effective prevention, management and treatment
* Some important steps can be made without new funding, but an adequately comprehensive will require new resources
* Building community support for prevention, screening, management of HCV and social/economic/educational supports for patients
* Focus on actionable plans……identify what is feasible
* Value of professional education and dialogue
* Promote the quality of life and respect the dignity and self-worth of each individual
* Providing the most positive outcomes and support for HCV patients and families in the long and short term is important
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* Palliative is important.
* Focus on serving all population groups impacted by HCV with evidence based and culturally responsive services.

Committee members responded positively to these goals and did not indicate that any were off track. Committee members highlighted several additional goals and values.

* Provide linkage to Veterans Administration, Kaiser Permanente, managed health plans, medical groups, and large systems to engage them in adopting protocols for Hepatitis screening, prevention, education, management and treatment.
* Provide linkage to the Affordable Care Act.
* Provide linkage to HIV/AIDS and STD prevention, testing, and management.
* Need to engage providers and get them to conduct testing. (Both primary care and specialist physicians need to be targeted for awareness and education because lack of testing is perceived as a major challenge for the region).
* Discuss current debate about recommendations that all baby boomers be tested for the Hepatitis C Virus. Insurance carriers have given a grade “C” to the Hepatitis C Virus making it a low priority for preventive services.

Committee members also discussed several themes that seemed relevant to articulating goals and values for the regional viral hepatitis preliminary strategic plan:

* The plan should encourage development of sustainable infrastructure across the continuum of care to ensure that appropriate care transitions throughout the course of disease progression and treatment.
* The regional plan should emphasize the value of regional plan with local footprint, a regional strategy with support for local implementation.
* The personal income and economic well-being implications of viral hepatitis need to be highlighted as well as broader community economic costs.
* The document cannot highlight enough the importance of education and early intervention.
* There is an urgent need for support groups for persons engaged in treatment because of complexity and side effects. Such groups can help patients and providers understand and recognize variations in disease manifestations and providers need to know enough to manage reactions to disease.
* We should seek alignment with others and related work and avoid starting new initiatives. The report should highlight how existing programs and policies can serve as the basis for an improved regional response.
* The report should address the apparent ongoing crisis in federal funding for Hepatitis related interventions. Because Hepatitis C is a silent epidemic, dialogues have not been established concerning the virus and ways to prevent and treat it. All segments of the population need to be included in this dialogue so that no population is left out.

Discussion of Next Steps

The group reviewed the list of participants recommended for the planning process from the summit in comparison to those who had agreed to participate so far.

* Health care system representatives
* Public health, behavioral health, social service county agencies
* Public health, behavioral health, social service provider agencies
* Correctional systems representatives (county and state)
* Health care professionals (doctors, nurses, promotoras) and alternative health/complimentary health providers
* Probation officials
* Potential funders
* HIV/STD and Women’s Health experts/advocates
* Diverse patient representatives

On reviewing these lists, Theresa Hughes summarized the discussion by noting that the group still needs representation from Hispanic, Hmong and Native American groups, drug users, and women’s health advocates, persons infected with Hepatitis C. Among the specific groups mentioned to approach for their engagement were: Planned Parenthood, BWOPA – Black Women’s Organization for Prison, West Care. Committee members agreed to forward names of people they know or other organizations that could be approached about engagement.

The group discussed the need to better describe the efforts currently going on to address viral hepatitis in the region and how to ensure that all those groups who are involved are also engaged in the planning process. There was a consensus recommendation that even if the current funding does not support this kind of broad outreach, that we might see the report being developed as a beginning point for growing the network and increasing engagement.

Capitman, DeRoo, and Hughes agreed to develop and share with the committee a draft of the introduction and context sections for the report based on the discussion.

The group discussed the timing of two additional meetings. At the second meeting, the group would review the draft introductory materials, report outline, specific recommendations, and key additional resources. At third meeting, the group would review drafts of remaining report sections and make final decisions about recommendations and a dissemination plan.

Capitman suggested that committee members look at list of initiatives/topics derived from the Summit. Several committee members indicated that addressing all these issues might make it hard to identify key recommendations for the report. The committee also agreed that our goal is to develop a living, breathing preliminary plan that is flexible and can be changed as necessary.

All agreed that the report should highlight a small number of key areas for next steps and outline other issues that will need to be addressed through subsequent planning and policy development.

* Several members noted that raising the level of public and professional awareness on Viral Hepatitis is one of these key goals.
* Focusing attention on prison populations and the need for more targeted programming that looks at inmates that are being released from prison and in all systems associated with the parole system. The report needs to support advocacy for changes in screening of inmates going in and coming out of the system who are infected with the Hepatitis C virus.
* The report needs to pinpoint shortages in data and also what we know about which communities are most at risk for negative consequences of viral hepatitis. There is a need for more assessment and mapping to identify Hepatitis C infected individuals; who they are where they reside. To tell these stories adequately may require establishing systems to intercept those potential patients and determine how intersecting public systems can most effectively respond.

The group determined that a next meeting, with somewhat more time should occur on Wednesday, January 30th from 9 am – 1pm. Ora Murray will send out a meeting proposal and hold the date notice. Ms Murray will also seed confirmation for participation in the third meeting on or around February 26th, 2013.