MHS Molecular HIV Surveillance(?) and Community Engagement

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The Environment in 2012

- Few community advocates and clinicians were aware that public health officials in some parts of the United States were using reported laboratory data (e.g. viral loads) to find out-of-care individuals, reach out to them, and offer services to re-link them to care.
- Those who did know were trepidatious at best.
- We (Project Inform) saw promise in this approach, but worried about the consequences if the community wasn’t consulted early and had the opportunity to shape these programs.
- Big question: Could we reach consensus?
HIV Surveillance Think Tank

- Held November 6 & 7, 2012
- ~30 community advocates and public health officials
- Three fundamental questions:
  - Is the use of collected laboratory (e.g. surveillance) data a promising approach to care re-linkage and retention?
  - Can the benefits outweigh the risks? If so, then how?
  - Is it ethical to use surveillance in this way? Is it ethical not to?
  - Should programs of this type move forward, provided that safeguards are in place?
Strengths of the Group

• Truly diverse – represented multiple constituencies and demographics who had at least some background and knowledge of the issue

• Public health officials presented from CDC, HRSA and local health departments

• Smaller size allowed for a high level of interactivity and discussion

• Diversity of view points:
  • At the outset there were a number of participants who had strong concerns about these approaches. One remarked in a survey, “No way!”
Challenges Posed to the Group

• Define policies and procedures for each type of re-linkage activity to reduce risks and enhance benefits
• Define stakeholders who should be consulted during the planning and execution of activities
• Describe what meaningful engagement would look like if we recommend that additional jurisdictions consider this approach
• Recommend policies and procedures that should guide implementation
Challenges Posed to the Group (cont.)

- Identify actions and priorities for advocates and others to forward these issues on a national level
- Develop and vote on a consensus statement regarding the use of surveillance data and other data for care linkage and retention
- Identify issues for further follow-up and exploration
Highlights Relevant to This Discussion

Pros of using surveillance:

• Addresses linkage failures in addition to falling out of care
• Maximizes resources
• Using peers and near-peers could reduce stigma, but…

Cons:

• Some community advocates and providers entirely opposed in 2012 w/out peer approach
• Great fears of harm from criminalization, stigma
• No patient permission
Signs of Meaningful Engagement

- Transparency
- Effective communication and education
- Conducted at the most formative stages – allows input to be incorporated
- Conducted during signing off on a new process
- Not siloed (multiple stakeholders consulted together)
- Offer a safe space for Q&A to identify concerns and problems
- Look at the potential good and who accrues positive impacts
Consensus Statement

• End goal was a consensus statement from all stakeholders, and that was achieved:

“The benefits [to more active uses of collected data] potentially outweigh the risks -- so that we encourage local jurisdictions to actively engage stakeholders in considering the use of surveillance data, along with other tools, to systematically increase access to care, ensure better linkages to services, and improve retention in care.”
Using Surveillance and Other Data to Improve HIV Care Linkage and Retention

A report from a Think Tank convened by Project Inform, held November 6 & 7, 2012 San Francisco, California

To access the full report:
Follow-up Consult in 2014

- Diverse regionally
- Focus on implementation

Findings:
- Great regional variation
- Lots of work to clean up data, with limited numbers of individuals re-linked to care
- Challenges with community engagement as defined by 2012 Think Tank in some geographic areas
- Great challenges (impossibility?) to use peer model
But Molecular HIV Surveillance (MHS) and Data 2 Care (D2C) Are Not the Same
D2C and MHS: Similarities

• Relies on laboratory values collected to guide healthcare decisions to inform active public health strategies
• One of the goals is to re-link out-of-care individuals to achieve viral suppression - MHS can prioritize D2C efforts
• Possibility that most people don't know data is shared in this way
• Concern among people with HIV, and especially among legal advocates, about privacy, stigma and possible ethical problems
D2C and MHS: Differences

- MHS data is more easily misunderstood
  - D2C - Use of viral load and CD4+ count to guide health decisions relatively standard and well known
  - MHS - HIV resistance testing alone remains difficult to explain. Use of the same sequence data for cluster analysis (both technology and use of technology) is very difficult to grasp

- MHS establishes link between two individuals living with HIV

- MHS raises the specter of attributing directionality – the risk for harmful consequences from this much higher
So…

- Be transparent
- Conduct multi-stakeholder engagement early and report back at regular intervals to community and others
- Don’t assume that the community representatives you have access to are the right ones
- Be willing to scale back or go slow
- Demonstrate how the health department will evaluate activities