Lessons

Characteristics of the jurisdiction matters – all “best practices” have to be triaged especially by size
Lessons

• Defining Linkage is still problematic
  • One vs two (or three) visits
  • What indicates secure vs insecure “attachment” to care

• Whose definition of linkage
  • Patients consider them linked/engaged
  • Providers consider themselves linked or not
  • Surveillance definitions of linkage

• Measures for surveillance data CD4 thresholds
  • CD4/viral load test often same day, part of dx workup—count as linkage?
  • Hard evidence of linkage

• We don’t use the same metrics across DOHs, studies

• Cascade data presentations varied in how calculated
Lessons

Notification-Linkage-Engagement-Retention is a process

- Cascade important for research and surveillance, but a public health tool
  - Provider/public health, cross-sectional/static
  - Need patient/dynamic perspective

- Segmenting the process of linkage-engagement-retention on the ground may work against ultimate goal, reduction of viral load

- Need to give up the separate reimbursement and see it as a process
Lessons

- Health Care Best Practices
  - Medical home for primary HIV care may be a best practice
  - Private providers often neglected in research and intervention

- Who is the advocate for the patient
  - After linkage, usually the medical care site
  - Before the linkage, not clear

- Support providers who are uncomfortable in notification challenges
Lesson

Confirmatory test is a barrier to linkage

- National policy issue
- HRSA: Use Ryan White Part A funds if confirmatory test negative (Houston)
- Accept parallel rapid tests?
- International models for point of test confirmation
- Delay in initiating ARV until confirmatory test
- What national policies need changing?
Shared Information Systems
Public Health Information Exchange

LAPHI

- Rationale: many without recent CD4/viral load test are in health care system
- Match positives to surveillance data base in real time
  - Alerts provider to verify HIV status, check on engagement in care
  - Try to re-engage in care
  - Evidence of considerable success
- Depends on surveillance system, IT and confidentiality
Health Information Systems

- Ability to communicate and track in real time whether people are coming to appointment
- Can access these data to ID positives not in care
- Can see number of tests overall to provide real denominator
- Different hospital EMRs don’t talk to each other – regional systems overcome this
- Tension in confidentiality re: large data bases
- Resource intensive
Confidentiality and Privacy

- Surveillance data for tracking only – can we use for individual patient tracking?
- Information exchanges have a lot of individual data – who should have access?
- Community consultation needed
- HIPAA limitations when care providers and care providers try to work together
- Can shared information systems still be helpful without very detailed information
- National advocacy for structural and policy change in use/access of data systems
**RESEARCH**

- Explore use of Regional Health Information System and electronic health records in conjunction with surveillance to better understand cascade, linkage and engagement.
- Define a minimum set of variables that are needed to need specific goals for cascade.
- Study impact of policy and legal changes in what data can be shared, who can gain access.
Lesson
(Research?)

Social Marketing and Education Campaigns

• Perhaps it is time to move $ from PR campaigns on testing
• Emphasize importance of linkage and being in care
• Explain benefits of care
• Address misinformation
RESEARCH

Navigation Models

- Describe and compare variety of models
  - Roots in STD/STI experience
  - Case management and social work models
  - Peer Models
  - Surveillance vs shoe leather
RESEARCH

Notification Process

• First step linkage
• Emotional reaction to test result
  • Need protocols for counseling?
  • Depends on whether results a surprise
  • Depends on whether patient seeks test or is offered test
• Are providers reluctant to test and link because they are uncomfortable with notification
RESEARCH

Stigma is one of the large barriers to linkage

• Community stigma still there
  • Fear of casual contagion
  • Taking meds, seeing a doctor
  • Seek care outside their neighborhood

• Emerging stigma reduction practices on the ground may be practical, feasible, not resource intensive but are they effective

• Stigma hard to change

• Public and social marketing campaigns against stigma needed – but how evaluate?
RESEARCH:

Affordable Care Act

- What evidence is needed for policy makers?
- Capture units for improving outcomes
- Need for wrap-around services and how to defend it (shift from Ryan White to Medicaid/Medicare)
- Primary care/pharmacy models vs medical home model
- What aspects of medical home are needed?
RESEARCH

Linkage Practices

- Cost effectiveness and incremental effectiveness of linkage practices,
  - need to model linkage
  - who pays for what and for who

- Role of community engagement and using community advice

- Compare different models re: linkage, comprehensive case management, navigator

- Implementation science: Role of procedures and checklists in intervention implementation and monitor fidelity

- Preparation for care intervention
Incentives

For different things -- testing, link for one/two visits, to start ARV, for reduced viral load

Need to parse benefits of incentives for each behavior
  - Incentivize repeat testing may be wasteful
  - Incentivize linkage/engage/adhere

Is it sustainable?

Should we use incentives for linkage
Research

Cascade as a process

- Outcome: viral suppression
  - Not just linkage but engagement
  - Is this the same set of predictors?
  - Cascade models show retention the biggest problem but reflects larger social predictors
    - Mental illness
    - Homeless
    - Substance use