Linkage

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

RESEARCH

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