BALANCING PATIENT PRIVACY WITH HEALTH SYSTEMS DATA INTEGRATION AND COORDINATION: HIV CONSIDERATIONS

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AGENDA
WHO DOES MICHIGAN SHARE WITH?

• Overview and Michigan law
• Controls
• For care
• To have good prevalence estimates
• When legally required
• For research
• For prevention
• All with a mindset of ethics and integrity
HISTORY

- Michigan has always had a strong HIV surveillance program
- Former AIDS Director and current AIDS Director are former epidemiology and surveillance managers
- Integrated Program Collaboration and Service Integration (PCSI) policies
- Integrated data sharing oath
- Directors are well-versed in data use agreements and IRB
- Surveillance manages STD and HIV partner services data systems
- Strong support of public health attorneys
- Strong research collaborations
- Michigan local health departments are “home-rule” jurisdictions
(1) All reports, records, and data pertaining to testing, care, treatment, reporting, and research, and information pertaining to partner notification under section 5114a, that are associated with the serious communicable diseases or infections of HIV infection and acquired immunodeficiency syndrome are confidential. A person shall release reports, records, data, and information described in this subsection only pursuant to this section.

(2) Except as otherwise provided by law, the test results of a test for HIV infection or acquired immunodeficiency syndrome and the fact that such a test was ordered is information that is subject to section 2157 of the revised judicature act of 1961, 1961 PA 236, MCL 600.2157.

(3) The disclosure of information pertaining to HIV infection or acquired immunodeficiency syndrome in response to a court order and subpoena is limited to only the following cases and is subject to all of the following restrictions:

   (a) A court that is petitioned for an order to disclose the information shall determine both of the following:

      (i) That other ways of obtaining the information are not available or would not be effective.

      (ii) That the public interest and need for the disclosure outweigh the potential for injury to the patient.

   (b) If a court issues an order for the disclosure of the information, the order shall do all of the following:

      (i) Limit disclosure to those parts of the patient's record that are determined by the court to be essential to fulfill the objective of the order.

      (ii) Limit disclosure to those persons whose need for the information is the basis for the order.

      (iii) Include such other measures as considered necessary by the court to limit disclosure for the protection of the patient.

(4) A person who releases information pertaining to HIV infection or acquired immunodeficiency syndrome to a legislative body shall not identify in the information a specific individual who was tested or is being treated for HIV infection or acquired immunodeficiency syndrome.
• (5) Subject to subsection (7), subsection (1) does not apply to the following:

• (a) Information pertaining to an individual who is HIV infected or has been diagnosed as having acquired immunodeficiency syndrome, if the information is disclosed to the department, a local health department, or other health care provider for 1 or more of the following purposes:

  • (i) To protect the health of an individual.
  • (ii) To prevent further transmission of HIV.
  • (iii) To diagnose and care for a patient.

With this clause we do not require consent to share laboratory data
We still have consent for Ryan White and AIDS Drug Assistance Program (ADAP)
Michigan HIV Surveillance program encourages the use of data in order to use resources effectively and reduce duplication of services, however, we are conservative in granting access to databases

- eHARS access is limited to HIV and STD surveillance staff
  - Further restricted by utilization of user roles (admin, full, read-only)
- Michigan has a robust ELR database (LMS) that is a very good proxy for lab data post-2012 but with no clinical or behavioral data
  - LMS access has been granted to a handful of HIV/STD prevention staff to inform partner services, and to HIV care staff to provide documentation for drug assistance programs
  - LMS access has been granted to several local health departments to facilitate case reporting
- Michigan HIV Surveillance shares liberally with any jurisdiction that has verified “ownership interest” in a case
  - Extends to counties within Michigan or non-Michigan cities/states
Michigan HIV Surveillance shares data to improve/expedite HIV care guided by a minimum necessary principle

**WHO:**
- The definition of a provider in Michigan includes physicians, nurses, infection control practitioners, and pharmacists
  - Providers can be in Michigan or out of Michigan
- Michigan LHDs or Non-Michigan HDs – when a patient is diagnosed in, currently lives in, or receives care in their jurisdiction
- ADAP
- Care Coordination sites – can run their own Data to Care projects using surveillance-generated not in care lists
- We don’t share with AIDS service organizations (ASOs)

**WHAT:**
- Anything in eHARS, testing or partner services databases, and/or CAREWare regardless of time or location
  - For example a current provider could receive information about ARV 10 years ago in another state
Michigan HIV Surveillance routinely exceeds all data completeness benchmarks as measured by 1302/1802

- Conduct routine matches with a number of internal MDHHS partners such as: Vital records, TB, Hep C, STD, Corrections, ADAP, Medicaid
- Contract with commercial people-search engines for updated demographic data: Lexis/Nexis and now TLO
- Perform annual social security and National Death Index death matches for vital status
- Limit duplication by performing
  - Interstate: routine interstate duplication review, cumulative interstate duplication review and out of state calls daily
  - Intrastate: locally-developed SAS programming
**PURPOSE – FULFILL LEGAL OBLIGATIONS**

- Michigan HIV Surveillance staff routinely (daily) perform eHARS record searches to fulfill the requests of law enforcement in the form of Subpoenas and Requests for Information - come directly to us from MDHHS Legal via Third Party Liability Electronic Database.

- If a record is found is eHARS information released is heavily redacted to eliminate risk/behavioral data.
Michigan HIV Surveillance has a long history of partnering with clinical and academic researchers

- For the past 5 years we have completed at least 5 data use agreements/data sharing agreement/memorandum of understanding per year with in-state and out of state researchers
- Each agreement is reviewed by the MDHHS compliance office to ensure that it meets department wide security and confidentiality standards
- Each agreement is run through the MDHHS IRB (AIDS director is a voting member)
- Notable examples in recent years
  - University of Michigan – transmission dynamics
  - British Columbia Center for Excellence – deep/next gen sequencing
  - Wayne State University – integrase resistance and the use of biologics
  - Los Alamos National Laboratory – molecular cluster analysis
  - Michigan State University – staging of HIV at diagnosis
PREVENTION

• Includes of course Data to Care (D2C)
  • Based off labs with heavy emphasis on integrated data
  • STD, TLO, etc.
• D2C RX (D2C using pharmacy claims)
• Molecular HIV Surveillance investigations
• D2PrEP (using STD surveillance data to provide active HIV pre-exposure prophylaxis (PrEP) referrals)
• De-centralized model-data given to local health departments not AIDS Service Organizations
  • MDHHS disease intervention specialists only conduct syphilis PS and rural HIV
INTEGRITY AND ETHICS

- Community engagement
- Branding
- Transparency - MHS isn’t just D2C
- Seek legal input
- Seek IRB and DUA compliance
- Focus groups and community advisory boards
- Diverse workgroups - surveillance, Ryan White, training, partner services
- Pilot
  - slow build, work out the kinks
NEXT STEPS

- We share a lot across systems but this isn’t efficient
- Many people involved in the process
- Manual processes have more chances for mistakes
- What we want to do: connect to health information exchange, MDHHS data warehouse
THANK YOU FOR YOUR TIME....

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