Expanding Data Sources and Partnerships Beyond Your Health Department: Rhode Island and the Providence VA Medical Center

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NASTAD National HIV and Hepatitis Technical Assistance Meeting

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Overview of Presentation

• Why we sought a collaboration with the VAMC
• Initial efforts to collaborate
• What got in our way
• How we overcame it
• What value it added to our program
- **Population** – 1.05M
  - 43rd nationally
  - 2nd most densely populated

- **Land Size** 37 miles x 48 miles

- **Race/Ethnicity**
  - 81% White
  - 12% Hispanic
  - 6% Black/African American

- **1 Health Department**

- **1 VA Medical Center**

- **1 area code 😊**
HIV in Rhode Island

Newly Diagnosed Cases of HIV, Rhode Island, 2008 - 2017

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Cases</th>
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<tbody>
<tr>
<td>2008</td>
<td>122</td>
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<td>2016</td>
<td>69</td>
</tr>
<tr>
<td>2017</td>
<td>81</td>
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Roughly 2,800 PLWH in Rhode Island
Based on individuals diagnosed with HIV infection through 12/31/2016 and living as of 12/31/2017, and residing in Rhode Island (based on most recent residence).

Based on HIV surveillance data reported through 03/14/2018. Data are provisional and subject to change.

*Estimate of undiagnosed population based on HIV surveillance data reported through 07/05/2017.
HIV 90-90-90

FAST-TRACK CITIES: ENDING THE AIDS EPIDEMIC
Cities Achieving 90-90-90 Targets by 2020

PARIS DECLARATION
1 December 2014

4. Use our AIDS response for positive social transformation

Our leadership will leverage innovative social transformation to build societies that are equitable, inclusive, responsive, resilient and sustainable. We will integrate health and social programmes to improve the delivery of services including HIV, tuberculosis and other diseases. We will advance human rights, gender equality, the rights of people living with disabilities

5. Build and expand an appropriate response to local needs

We will develop and promote services that are innovative, safe, acceptable, equitable and free of stigma and discrimination. We will encourage and foster community leadership and engagement to build demand and deliver services that are responsive to local needs.

6. Mobilise resources for integrated public health and development

In order to achieve the 90-90-90 targets for an AIDS-free generation, we will make a strong commitment to financing public health, as a sound investment in the future of our countries and the health of our people. We will ensure that the commitments of Heads of State, Governments and international financial institutions result in increased domestic resources and allocate additional funding and support to end the AIDS epidemic by 2020.

7. Units are leaders

We commit to develop and sustain partnerships with a network of key stakeholders in order to create the Declaration a reality. Working in a spirit of shared responsibility, we will regularly monitor our progress and adjust our responses to the pace, context and new evidence. We will work together to develop, support and improve our programmes, policies and data about all key tests and actions that can be improved. We will report annually on our progress.

90% of people living with HIV knowing their HIV status

90% of people knowing their HIV status on treatment

90% of people on treatment with suppressed viral loads
Surveillance Advancements & Identifying The Problems

- Electronic lab reporting (ELR) reduced data entry burden
  - eHARS data became complete and timely

- eHARS Not-In-Care (NIC) list generated – Dec 2016
  - 800 individuals identified as not-in-care – Nope. Wrong.

- Facebook, Accurint Lexis Nexis, interjurisdictional record searches, provider calls used to figure it all out!

- Substantial reporting gaps identified
History of RIDOH and VAMC Collaboration

• Recognized that the VAMC has no requirement to report to RIDOH... but:

  – Some previous RIDOH and VAMC data-sharing existed

  – eHARS populated with some VAMC diagnoses

  – HIV Partner Services Program had received referrals from VAMC for PS outreach

• ID providers work at both VAMC and largest HIV provider (The Miriam Hospital Immunology Center)
Issues with RIDOH – VAMC Reporting

• Only reported suspected new diagnoses

• Did not report in-state or out-of-state migration

• Did not report ongoing lab results as part of routine HIV care
August 2017: RIDOH-VAMC Meeting

• Met with ID Section Chief and primary HIV medical provider at the VAMC

• Discussed:
  – Partner services
  – Return to care program
  – 90-90-90 / Fast Track Cities Initiative
  – Reporting

• Providers onboard for reporting

All set to move forward and then…

… The Privacy Officer
Concerns of the Privacy Officer

• Believed only diagnosing lab results were reportable
  – Did not included routine CD4 and viral load reporting

• Concerned RIDOH request went beyond the “Standing Request For Information”
  – What is a Standing Request For Information?

• Concerned about mail transmission of data
• PRIVACY AND RELEASE OF INFORMATION (VHA Directive 1605.01)

• https://www.va.gov/vhapublications/ViewPublication.asp?pub_ID=3233

**c. HIV Reporting.** Information relating to an individual's infection with HIV may be disclosed to a Federal, State, or local public health authority that is charged under Federal or State law with the protection of the public health pursuant to a standing written request letter. A Federal or State law must require disclosure of the information for a purpose that is authorized by law and a qualified official of the public health authority must make a written request for the information.

(b) Specify the public health reporting required and the State law mandating such reporting,

(c) Be signed by a qualified representative of the State agency requesting the information, and

(d) Be valid only for 3 years and then it must be reissued.
Standing Request For Information

- A letter from DOH to VA:

- Asking VA to provide DOH with as much data as possible to help us satisfy our legal obligations

- Setting forth the legal obligations to indicate the legitimacy of need and assurances of confidentiality

- Acknowledging that we will not use the data except for the reasons described in the letter
Resolutions

• Provided:
  – Rhode Island General Law language
  – Rules and Regulations pertaining to the reporting of infectious diseases
  – Statement by the State Epidemiologist

• Developed secure fax reporting

• Developed clinic workflows to ensure routine reporting
  – Decided on quarterly reporting process

• Data started flowing Q4 2017
Value-added – CD4 and Viral Loads

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<td>2018</td>
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<tr>
<td>total</td>
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Case-finding & Care Status

23 unreported PLWH immigrated to RI

3 new, unreported RI diagnoses

18 people on NIC list that were really in care
Conclusions

• VAMC may be seeing PLWH that have been unreported to DOH, or are thought to be out of care

• Proper data sharing requires a documented “Standing Request For Information”
  – IT ISN’T DIFFICULT!

• Three groups are critical for success:
  – The VAMC Privacy Officer
  – Infectious Disease Providers
  – Infectious Disease Clinic Staff

• Accurate estimates of a state-wide care continuum require resolving reporting gaps like with the VAMC
Thank you!

Shout out to Drs. Melissa Gaitanis and Amanda Noska at the Providence VA Medical Center for their commitment to HIV surveillance and prevention & to Richard Rowe for supporting RIDOH in developing and implementing inter-agency reporting.

Special thanks to the RIDOH HIV Surveillance Team (Guillermo Ronquillo, Anna Civitarese, and Alex Montufar) for rolling with the punches as we identified more and more reporting gaps