DD19-1906 Capacity Building for Sickle Cell Disease Surveillance

Session 3: Establishing a State Surveillance Program Team

December 5, 2019
The Core Surveillance Team

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Core Surveillance Infrastructure

- **Human Resources**
  - **PI (up to .5 FTE, depending on experience):** Build relationships with data stewards, program, & legal staff including HIPAA privacy officers. This person will need to have an unwavering positive attitude and a lot of perseverance.
  - **Data Analyst (.2 to 1.0 FTE):** Experience working with large administrative data sets and experience with probabilistic matching were the most important skills for us. Less “hands on” work until the data are received but then could work full-time on this for close to a year…data cleaning and matching.
  - **Program Coordinator (.5 FTE):** Depends on the stakeholders, meetings, and administrative tasks necessary, good understanding of lead entity policies and processes related to contracting, subawards, data sharing agreements, etc.
  - **Consulting Staff (PRN):** Clinical expertise, for example to interpret NBS lab results, etc.

- **Financial Resources**
  - RuSH project provided $500,000/year to each state to build the infrastructure

- **Data Infrastructure**
  - Minimally, a HIPAA secure server and software capable of running linking/matching algorithms (I would start with what is familiar and already available given the lead entity—where the data will physically sit not who technically “owns it”)
Lead Entity: Administrative/Legal Infrastructure

- Initially, GA surveillance led by the Georgia Department of Public Health with State legislation in place to report cases of SCD for individuals under 18 years of age.
  - DPH IRB exemption
  - GSU/GHPC coordinated the surveillance under a sub-award which included a business associate agreement.

- Surveillance now led by Georgia State University’s Georgia Health Policy Center (GSU/GHPC) as “an entity acting under a grant of authority” from the State Public Health Authority.
  - This can be done through an MOU, letter from the State Health Officer, Business Associate Agreement, etc. whatever your State prefers.
  - Minimally necessary data/variables to accomplish surveillance but must include PHI
  - GSU IRB exemption

- Lesson Learned—Approach the administrative infrastructure with a sustainability plan in place at the onset.
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Resources/Team for SCD Surveillance
California Sickle Cell Data Collection Program
Considerations for Resources

- Infrastructure – each has different costs, strengths, weaknesses
  - Contract organization
  - University
  - DPH or other state agency
  - Non profit (clinical or other)

- Human Resources
  - Cost of labor and expertise in your area
  - SF Bay Area vs Birmingham or Indianapolis

- Indirect Costs

- Other External Costs
  - Paying for data
  - Paying for IT systems/support/data storage
Considerations for Resources

- Goals of State Surveillance
  - Support to state and local programs with data
  - Publications
  - Expansion into other relevant areas (e.g., Thalassemias, SCT surveillance)
  - Health education and outreach
California 2010-2012 (RuSH)

- 1.0 FTE Program Management
- 1.0 FTE Data Analyst/Developer
- 0.25 FTE PI (in kind)
- 1.0 FTE Program Coordination (split .50/.50 between two centers)
- 0.20 FTE Site PIs (in kind)
- $500,000/year
  - FTE
  - Site based meetings
  - Travel to Atlanta
  - Hardware
  - Budget for data
California 2012-2014 (PHRESH)

- 1.0 FTE Program Management
- 1.0 FTE Health Educator
- 0.10 FTE PI (in kind)
- $200,000/year
  - FTE
  - Some travel
California 2015-present (SCDC)

- 1.0 FTE Program Management/PI
- 0.25 FTE Health Educator
- 1.0 FTE Data Analyst
- 0.25 FTE Data Linkage
- 0.10 FTE Biostatistical Support
- 0.50 FTE Program Support
- $350,000-400,000/year
  - $50,000-100,000 for data
  - Travel
  - Rent/Infrastructure
California Current Other Support

- Tracking California
  - Many programs and grants (partial FTE for numerous staff)

- State Funding
  - Increased capacities for analyses/publication, health education
  - More data

- SCDC Capacity Building
  - Scaling up data linkage system
  - TA for other states
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