DD19-1906 Capacity Building for Sickle Cell Disease Surveillance

Session 6: Stakeholder Engagement for Collecting Individual-Level, Identifiable Data for a Rare Disease

February 20, 2020
Starting with Stakeholder Engagement

California Sickle Cell Data Collection Program
One Model of Implementing a Surveillance System

- Get a lot of funding
- Convene a panel of experts (may be omitted if time is short)
- Gather a lot of data on people
- Publish your findings

- (Never work in surveillance again)
A Better Model

- Recognize that the community of persons impacted by this disease has been under-resourced, lied to, and mostly ignored
- Recognize that there is a lot of frustration and anger about this
- Find ambassadors, and use connections to listen
- Listen to all stakeholders, not just the easy ones
- Listen to what the problems and the history are
- Talk together about how you might solve problems with data
- Build trust and respect
- AND THEN...
A Better Model

- Get some funding
  - Share it if possible
- Convene a panel of stakeholders with some technical assistance experts
- Gather a lot of data on people
  - Talk with stakeholders about what the data mean
  - Talk with stakeholders about how to best use the data
- Use your findings to shine a light on problems that can be fixed

- (Grow your collaborative network, get more funding, and do more!)
Concerns from Stakeholders in Early Program Development

- Advocates, persons with disease or their families
  - Privacy invasion
  - Using data for purposes not helpful to them
  - Why is tax money being used for this and not more direct help?

- Health care providers
  - Privacy invasion for their patients
  - Data are wrong – not clinical data, too many errors
  - We already know everything you’ll find
  - Why is money being used for this and not to support our clinical care?

- CBOs/state agencies
  - We’re already doing this (esp. if have registry)
  - Why is money being used for this and not to support or work?
Maintaining Stakeholder Engagement
Georgia Sickle Cell Data Collection Program
A Framework for the Dissemination and Implementation of Patient-Centered Outcomes Research

### We compensate stakeholders for...

<table>
<thead>
<tr>
<th>Providing and/or recruiting SCD community perspective and input</th>
<th>Disseminating information and materials to the SCD community</th>
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<tbody>
<tr>
<td>• Participating in program strategy and proposal development</td>
<td>• Liaison so SCD community is aware of available data; on board with SCDC</td>
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<td>• Input on analyses and uses for data</td>
<td>• Disseminating patient educational information</td>
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<td>• Conducting surveys to answer specific questions to guide use</td>
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<td>• Helping develop or reviewing and editing patient-facing materials</td>
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<td>• Providing patient perspective on other materials</td>
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We foster relationship by…

<table>
<thead>
<tr>
<th>Relationship-building</th>
<th>Considerations</th>
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<tr>
<td>• Providing local data; other info</td>
<td>• Providing support as needed, e.g. with federal funding rules, IRB, contracts/consulting agreements</td>
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<td>• Making introductions (e.g. help recruit speakers)</td>
<td>• Accommodating health needs of team members</td>
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<td>• Advising informally (e.g. on sustainability)</td>
<td>• Watching for fairness/loyalty concerns</td>
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<tr>
<td>• Cross-publicizing news and events</td>
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<tr>
<td>• Showing up where appropriate</td>
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<tr>
<td>• Passing along funding opportunities</td>
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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.