Data Linkage Strategies and Methods to Advance Youth Suicide Prevention

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Suicide prevention programs have limited ability to study long-term outcomes under the current funding structure.

Several unanswered questions remain regarding the effectiveness of youth suicide prevention efforts.
– National, state, and community data systems could be linked to existing data from suicide prevention efforts in order to study the longer-term and broader intervention impact at low cost.

– Initiatives in place to facilitate linkage (e.g., expansion of EHR, state HIE, APCD, PCORnet, etc.)
SCOPE OF THE REVIEW

To provide an objective description of the state of the science on data linkage strategies and analytic approaches in youth suicide prevention research including limitations, barriers, challenges, gaps and opportunities for future data linkage approaches.

Universal, selective and indicated interventions were examined including individual, community, and policy-level approaches as well as those targeting outcomes other than suicidal ideation, attempts, and suicide.
Key Questions

Key Question 1: What national, state, and community data systems can be linked to existing data from suicide prevention interventions in order to add possible value for stakeholders, and what methods are available to link the data systems?

Key Question 2: Which statistical methods are reliable and valid for analyzing linked national, state, and community data systems and suicide prevention data to avoid misleading conclusions?
- What are potential sources of bias for these statistical methods?
- What are the advantages and disadvantages of these different methods?

Key Question 3: Which statistical methods are reliable and valid for understanding possible moderators in suicide prevention programs to improve targeting interventions to populations?

Key Question 4: Given the current state of research, what types of methodological/analytic advances would promote further evaluation of youth suicide prevention efforts (e.g., new approaches to data linkage, increased use of common data elements, approaches to intervention harmonization) and facilitate intervention selection and implementation decisions by local community and state-level policy makers?
KEY QUESTION 1

What national, state, and community data systems can be linked to existing data from suicide prevention interventions in order to add possible value for stakeholders, and what methods are available to link the data systems?
PICOTS description of inclusion criteria for suicide prevention studies and data systems

<table>
<thead>
<tr>
<th>Population(s)</th>
<th>Received intervention: ages 0-25 (longitudinal follow-up past age 25 is acceptable)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention(s) (used for studies)</td>
<td>Behavioral, community, clinical/medical, policy level including studies promoting wellness targeting suicide ideation, suicide attempt, and suicide, or any combination of these interventions and outcomes.</td>
</tr>
<tr>
<td>Comparison(s) (used for studies)</td>
<td>Any intervention (including usual care).</td>
</tr>
</tbody>
</table>
| Outcome(s) (the primary and intermediate outcomes) | Primary outcome of interest:  
- Suicide ideation, reported within 12 months of data collection  
- Suicide attempt, any time point post intervention  
- Suicide, any time point post intervention  
Intermediate outcomes (if primary outcome is present), at any time-point post intervention:  
- Psychiatric and substance abuse disorders  
- Service use (e.g. ER visit) for psychiatric/substance abuse disorders  
- Graduation rates  
- Incarceration rates  
- Violence (both perpetrator and victim)  
- Social support and connectedness  
- Access to lethal means  
All outcomes were limited to standardized measures. |
| Timing | Publication date: 1990 or later. |
| Setting | Studies taking place in the United States only: Schools, home, primary care, emergency department, military bases, Indian reservations, juvenile justice systems, child welfare systems, suicide hotlines, other community settings. |

* Suicide ideation reported over the last 12 months reduces the potential for recall bias and provides more relevant information for current prevention and intervention.6, 7  
ER=emergency room
# SEARCH METHODOLOGY

<table>
<thead>
<tr>
<th>Key Question</th>
<th>Search Method</th>
<th>Search Criteria‡</th>
<th>Search Engines or Data Sources</th>
<th>Number of Raters/Coders</th>
<th>Data System Identification</th>
<th>Statistical Method Identification</th>
<th>Moderator Identification</th>
</tr>
</thead>
</table>
| KQ1          | Systematic Literature Review | PICOTS‡ | • PubMed      
• Cochrane 
• Campbell 
• CINAHL 
• PsycINFO 
• ERIC | 2 | Yes | - | - |
| KQ2          |             |                  |                               | 2 | - | Yes | - |
| KQ3          |             |                  |                               | 2 | - | - | Yes |
| KQ1          | Environmental Scan (Web) | PICOTS‡ | • Google      
• Yahoo 
• Bing 
• SPRC, AFSP, AAS websites | 1-2 | Yes | - | - |
| KQ1          | Targeted Search.§ | PICOTS‡ + Location | Selected state, city and local government personnel | 1-2 | Yes | - | - |

*KQ4 is not included in this table because it reflects a synthesis of opportunities and challenges based on the results of KQ1-3†Inclusion and exclusion criteria are the same for all searches.*
CRITERIA FOR INCLUSION OF DATA SYSTEMS

In addition to PICOTS criteria, data system:
• still in existence and underlying data are available and accessible in digital format
• can be shared and acquired by others for research purposes
• system collects and contains at least one of the primary outcomes
TARGETED SEARCH
CA, OR, DE, MD, IL, WI

Selection criteria:

(1) the state has an active SAMHSA state Garrett Lee Smith youth suicide prevention grant;

(2) geographic location and low suicide rate state bordering a high suicide rate state;
Suicide rates among persons aged 10-24 years by state -- United States, 2012-13 (U.S. avg 8.1)

Rates per 100,000 population

- 3.4 to 7.0
- 7.1 to 8.1
- 8.2 to 10.0
- 10.1 to 23.2

Source: Centers for Disease Control and Prevention (CDC) vital statistics
RESULTS – SYSTEMATIC REVIEW

Identified 59 studies of suicide prevention
# RESULTS – DATA SYSTEMS

<table>
<thead>
<tr>
<th>Phase</th>
<th>Potential Data Systems Reviewed</th>
<th>Data Systems Excluded</th>
<th>Unique Data Systems Identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematic Review (included articles)</td>
<td>71</td>
<td>64</td>
<td>7</td>
</tr>
<tr>
<td>Systematic Review (excluded articles)</td>
<td>125</td>
<td>83</td>
<td>43</td>
</tr>
<tr>
<td>Environmental Scan (Google, Yahoo, Bing)</td>
<td>477</td>
<td>425</td>
<td>52</td>
</tr>
<tr>
<td>Environmental Scan (other/directed)</td>
<td>254</td>
<td>226</td>
<td>28</td>
</tr>
<tr>
<td>Targeted Search</td>
<td>133</td>
<td>110</td>
<td>23</td>
</tr>
</tbody>
</table>

Total Data Systems Identified: 103
# STUDIES LINKED TO DATA SYSTEMS

(N=6 of 59)

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Suicide Prevention Approach</th>
<th>Data System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collins, 2008</td>
<td>Mood Stabilizer Treatment via Oregon Medicaid claims data</td>
<td>Oregon vital statistics data</td>
</tr>
<tr>
<td>Cooper, 2006</td>
<td>Availability of mental health and suicide services by county</td>
<td>Colorado Trauma Registry, Colorado death certificate data</td>
</tr>
<tr>
<td>Farmer, 1996</td>
<td>Multi-component SP</td>
<td>Galveston County Jail medical records and hospital records</td>
</tr>
<tr>
<td>Gardner, 2010</td>
<td>Suicide risk screening in primary care</td>
<td>Nationwide Children’s Hospital electronic health records</td>
</tr>
<tr>
<td>Olfson, 2003</td>
<td>Antidepressant medication treatment by region</td>
<td>CDC WONDER compressed mortality data</td>
</tr>
<tr>
<td>Walrath, 2015</td>
<td>SAMHSA-Funded Garrett Lee Smith gatekeeper training sessions</td>
<td>CDC WONDER compressed mortality data</td>
</tr>
</tbody>
</table>
RESULTS – DATA SYSTEMS
(n=153)

Geographic Coverage

- US - national 37%
- US - regional (e.g., east coast) 12%
- US - state level (e.g., Maryland) 63%
- US - smaller than state level 41%

*Do not add up to 100% because some data systems provide both state and national data
RESULTS – DATA SYSTEMS (n=153)

Level of Information Available for This Data System

- Data exist and can be acquired (free or for a fee) 90%
- Data are publicly available and can be downloaded 75%
- Data can be acquired but requires an automated registration 1%
- Data can be acquired if confirmed by a person (e.g., needs email communication) 79%
- Data dictionary or code book is accessible 48%
RESULTS – DATA SYSTEMS (n=153)

Data System's Primary Use

● Research (e.g., academic, pharma) 19%
● Clinical care / operations 11%
● Administrative services (e.g., census) 29%
● Public health (e.g., surveillance) 52%

Ongoing with Prospective Data Collection 94%
KEY FINDINGS

– To date, very few studies have used data linkage approaches for merging suicide prevention program data to community, state, or national data systems.
– This is likely due to cost, feasibility of accessing data systems, and restrictions regarding sharing PHI.
  • Many potentially linkable datasets offer the possibility of linkage at the individual patient level (78%), but ethical or legal barriers may prohibit linkage at this level.
KEY FINDINGS

– Most linkable datasets have outcomes related to suicide (71%); fewer datasets include suicide ideation (29%) or attempt (54%).

– 90% of the 153 data systems identified are accessible for a fee or free; but only 48% have a data dictionary available.

– Only 27% of the studies we identified reported on outcomes longer than one year post-intervention.
GAPS AND OPPORTUNITIES

– Longer-term results could be obtained by linkage of prevention efforts to existing data systems.
– Linkage to accessible, current surveillance data could help to address the lack of studies testing the impact of early intervention on risk for suicide attempt and suicide