



## Pathways to Prevention:

Weighing the evidence. Identifying the research gaps. Determining next steps.

# A Report From the Federal Partners Meeting of the National Institutes of Health Pathways to Prevention Workshop: Advancing Research To Prevent Youth Suicide

Wednesday, April 19, 2017

### Sponsored by:


National Institute of Mental Health (NIMH)  
National Institute on Drug Abuse (NIDA)  
National Center for Complementary and Integrative Health (NCCIH)  
National Institutes of Health Office of Disease Prevention (ODP)

### Summary

The Office of Disease Prevention's (ODP) Pathways to Prevention (P2P) program promotes the use of evidence-based practices to address complex public health issues by identifying research gaps and weaknesses in methodological and scientific approaches in topic areas. The goals of the P2P workshops are to shape a research agenda, develop an action plan, and synthesize and interpret the current evidence through an accompanying systematic review conducted by an Evidence-based Practice Center supported by the Agency for Healthcare Research and Quality's (AHRQ) Center for Evidence and Practice Improvement.

On March 29 and 30, 2016, the National Institutes of Health (NIH) held the [Pathways to Prevention Workshop: Advancing Research To Prevent Youth Suicide](#). Along with the ODP, this workshop was co-sponsored by the [National Institute of Mental Health \(NIMH\)](#), the [National Institute on Drug Abuse \(NIDA\)](#), and the [National Center for Complementary and Integrative Health \(NCCIH\)](#). After weighing the data from the [evidence review](#), expert presentations, and public comments, an unbiased, independent panel prepared [a report summarizing the P2P workshop and making recommendations](#) for future research priorities.

As the final step in the P2P program process, the ODP convened a meeting on April 19,



2017, with representatives of federal agencies (the Federal Partners) to identify strategies to address the recommendations in the P2P workshop panel final report. This document summarizes the discussions and action items identified at the Federal Partners Meeting.

## Background

In 2014, suicide was the second leading cause of death among youth (10- to 24-year-olds) in the United States, resulting in 5,504 deaths. Suicide rates increased by 24% from 1999 through 2014.<sup>1</sup> Many risk factors, precipitating events, and environmental circumstances contribute to suicidal behavior. Suicide attempts and deaths have many costs: emotional, psychosocial, economic, and societal.<sup>2</sup> Several groups are at increased risk for suicidal behaviors, including Alaska Native and American Indian youth, young adults with substance use problems, children of depressed parents, and youth and young adults who identify as a sexual or gender minority.

One of the challenges in suicide prevention research is that the primary outcome of interest is dependent on multiple variables and, depending on the target population, suicide often occurs at a low frequency, making examination of risk in higher risk subgroups (e.g., racial, ethnic, sexual and gender minorities) difficult because the studies lack sufficient power to accurately determine the effectiveness of the intervention on attempts or suicide deaths. Because suicidal behavior is often dependent on multiple variables, it may be that interventions addressing suicide risk factors have benefits for suicide reduction, but these potential benefits have not been examined in great depth, nor does the larger community know of these potential benefits. Because suicide ideation and behavior are low base-rate behaviors, pooling datasets from individual intervention studies and data

surveillance systems would be an important approach to better understand the effectiveness of prevention strategies on outcomes such as suicide, suicide attempts, and suicide ideation, particularly for high-risk subgroups (e.g., racial, ethnic, sexual, and gender minorities). If this approach proves fruitful, it may provide evidence for the importance of intervening early to prevent later suicide ideation and behaviors. Preventing attempts and self-harm ideation would potentially result in a reduction in deaths, as well as reductions in health care and the societal burden associated with suicidal behavior.

## P2P Workshop Key Questions

To help close research gaps related to youth suicide and to assess the scientific evidence, NIMH, NIDA, NCCIH, and the ODP sponsored the March 29–30, 2016, P2P Workshop: Advancing Research To Prevent Youth Suicide. The workshop evaluated the current state of knowledge on youth suicide and identified opportunities for future research. Specifically, the workshop sought to address the following questions:

- How can national, state, and community data systems be linked to existing data from suicide prevention efforts in order to add possible value for stakeholders? What methods are available to link the data systems?
- Which statistical methods are reliable and valid for understanding possible mediators and moderators in suicide prevention programs to improve targeting interventions to populations?
- Which statistical methods are reliable and valid for analyzing linked national, state, and community data systems and suicide prevention data to avoid misleading conclusions?
- 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 policymakers?

- What is the way forward that will help the suicide prevention research community realize the potential benefits of early prevention? What are the immediate and longer-term research investments needed to accomplish this?

## Systematic Evidence Review

A systematic evidence review of the scientific literature, guided by the key questions, was conducted by the Johns Hopkins University Evidence-based Practice Center through a contract with AHRQ to facilitate the workshop discussion and was published in December 2016 in the [Annals of Internal Medicine](#). The key findings from this review include:

- Few community, state, and national datasets are currently amenable to data linkage.
- Most of the linkable datasets have outcomes related to suicide, but fewer have information on suicide ideation and suicide attempts.
- Ethical and legal barriers may hinder the linkage of datasets at the individual level.
- Few datasets allow for study of the high-risk populations mentioned above.
- Lack of code books, data dictionaries,

and a standard set of data elements limit the feasibility of data linkage.

- Of the six studies that used outside data systems, all focused on the main effects of the interventions; none studied treatment effect heterogeneity or the impact of moderators.

Four next steps were recommended in the review:

1. Harmonization of interventions (to allow combinations for statistical power)
2. A national repository for suicide outcomes
3. Guidelines on data linkage methods and procedures
4. A technical support center to assist researchers, health systems, and others with methods and procedures for data linkage

The systematic evidence review also compiled an inventory of available datasets, which may serve as a potential starting place for future data linkage efforts.

## P2P Workshop Panel Report

The workshop's independent panel developed a final report on the P2P workshop. The workshop panel is a multidisciplinary body of non-federal representatives, who are experts in related fields. They are selected by the federal scientists who plan the workshop in conjunction with the ODP. The [final report](#) summarized key findings and research needs outlined in the systematic evidence review and discussed at the workshop, and provided recommendations to move the field forward. The workshop panel report made three recommendations:

- I. Enhance data systems to improve the ability to identify persons at risk for suicide by increasing the number of

available datasets and their accessibility, increasing data linkages, and developing methods to identify short- and long-term risk factors.

- II. Improve design and analysis by establishing common measures, performing longitudinal studies, and designing methods to draw valid conclusions to inform policy and practice.
- III. Build and strengthen the research and practice community by increasing research of policies and interventions to reduce access to the means of suicide, creating a “menu” of evidence-based suicide prevention programs, and disseminating evidence-based practices and modifiers of its effectiveness, as well as aggregated data (from above) for use in community prevention planning and evaluation.

## Federal Partners Meeting

The ODP convened a meeting on April 19, 2017, with the Federal Partners to strategize how to address the recommendations from the P2P workshop panel final report (see Appendix for list of attendees). The objectives of the Federal Partners Meeting were to (1) prioritize research and programmatic ideas and (2) identify products and action items for collaboration among the Federal Partners.

This report summarizes the discussions and action items identified at the P2P Federal Partners Meeting on Advancing Research To Prevent Youth Suicide.

## Summary of Discussion of P2P Workshop Panel Recommendation I: Enhance Data Systems To Improve the Ability to Identify Persons at Risk for Suicide

**Background:** The workshop panel highlighted the need for better data systems to identify those at risk and to advance knowledge about the risk and protective factors associated with youth suicide. Limited integration and access to data systems make it difficult to provide adequate surveillance for those at risk for suicidal behavior. The P2P workshop panel found limited availability of data systems that could potentially be used to examine risks and outcomes, citing only 6 out of 153 studies that can link national, state, and community data systems to existing prevention effort data. Two examples include [Walrath et al.](#),<sup>3</sup> using SAMHSA Garrett Lee Smith grantee data, and [Gardner et al.](#),<sup>4</sup> which used electronic health records. The workshop panel indicated surveillance is also impeded by a lack of standardized measures generalizable across settings, communities, and cultures to identify high-risk persons. The workshop panel recommended developing and implementing standardized measures (e.g., code books, data dictionaries) as well as implementing the consistent use of cause-of-injury codes for suicide reporting.

**Specific Areas of Research Focus:** The Federal Partners identified several priority areas in which to implement the P2P workshop panel recommendations. The discussion focused on the need to better identify suicidal youth at different ages and at different levels of risk, as well as to identify or assess youth who have been exposed to suicide.

The Federal Partners also discussed how to address an increased need for accessibility and integration between datasets. This was discussed in terms of both surveillance and secondary analysis for risk/protective factors for youth suicide. The Federal Partners identified several federal data repositories containing data directly related to suicide or adverse childhood experiences (ACEs), which

are strongly correlated with increased risk of attempted suicide,<sup>5</sup> and noted that integrating relevant portions of these datasets would help achieve the workshop panel recommendations. Datasets include:

- [National Library of Medicine's Inventory of Stored Data](#): includes data from, for example, the Eunice Kennedy Shriver National Institute of Child Health and Human Development's [Data and Specimen Hub \(DASH\)](#) program and the Adolescent Medicine Trials Network
- [National Archive of Criminal Justice Data](#): database of computerized crime and justice data for investigator-initiated research projects
- [National Data Archive on Child Abuse and Neglect \(NDACAN\)](#): collects datasets from researchers and federal sources to allow secondary analysis by researchers
- Substance Abuse and Mental Health Services Administration (SAMHSA): data from grantees of [Systems of Care Cooperative Agreement](#) and [Garrett Lee Smith Suicide Prevention](#) grants
- Army Study to Assess Risk and Resilience in Servicemembers ([Army STARRS](#))
- [Data from Tufts University](#) on potential positive and protective factors from the [4-H program](#) of the United States Department of Agriculture's National Institute of Food and Agriculture (NIFA)
- Administration for Children & Families' (ACF) Children's Bureau [case data](#) on adopted and foster children
- State and private organizations:
  - California, Colorado, Maryland, and Vermont participate in

programs in which local-level data on suicide behavior are collected

- [San Diego-based Community Health Improvement Partners](#) programs and Annie E. Casey Foundation's [Kids Count](#) program are private groups collecting ACE and suicide information
- [Inter-University Consortium for Political and Social Research](#): University of Michigan-based consortium for the collection, preservation, and dissemination of data from social science research that can be searched with keywords.

### Opportunities for Collaboration Among Federal Agencies, Resource Development, and Next Steps:

The Federal Partners highlighted several challenges that need to be addressed to improve surveillance systems, including the:

- Difficulty of adding questions regarding suicide to existing surveys
- Inability to pair surveillance data with long-term mortality data at the individual level, which limits the identification of risk/protective factors
- Policy barriers to collecting, storing, and cleaning data.

The Federal Partners discussed creating a working group, modeled after the NIH's former Community Epidemiology Workgroup (CEWG; now the National Drug Early Warning System [NDEWS]), to share information and data. The CEWG was a NIDA-led effort composed of a group of drug abuse experts who met semiannually on emerging issues, including monitoring drug trends, in sentinel sites in the United States (additional information on [CEWG/NDEWS](#)).

To address the challenges outlined above, as well as to integrate data collection activities, the Federal Partners suggested the following next steps:

- Work with the [NIH Office of Behavioral and Social Sciences Research](#) to establish a suicide epidemiology workgroup that, as a collaboration between state and federal agencies, will look at key issues related to suicides (e.g., clusters, community response) and share data and exchange information.
  - Share and upload suicide data to [Data.gov](#), a federal repository for federal public datasets.
  - Work with SAMHSA to:
    - Assess the feasibility of a data center to compile and house data on youth suicide, child and family well-being, and mental health.
    - Establish an inventory of available datasets with data relevant to suicide prevention.
  - Work with the following groups on opportunities and processes for utilizing relevant data sharing, re-analyzing data, and promoting data linkages across their data systems and national program evaluations:
    - ACF – for example, [foster care](#) and child welfare data from national surveys and program initiatives; youth-focused prevention initiatives
    - Department of Justice – [multiple datasets](#) for [juvenile justice programs](#)
    - NIDA – for example, datasets from prevention interventions with data sharing plans, or included in the [National Addiction Program & HIV Data](#)
- [Archive Program repository and Criminal Justice Drug Abuse Treatment Studies](#) programs
  - Anne E. Casey Foundation [Kid’s Count](#) and [Community Health Improvement Partners programmatic data](#)
  - SAMHSA – data from grantees of [Systems of Care Cooperative Agreement](#) and [Garrett Lee Smith Suicide Prevention](#) grants
  - Centers for Medicare & Medicaid Services (CMS) – Child Health Insurance Program ([CHIP](#)) and health interview data
  - Centers for Disease Control and Prevention’s National Violent Death Reporting System (NVDRS) data on suicides.
- Examine potential ways to match data elements across databases (“crosswalk”) that could be used for linking to suicide outcomes.
  - Work with the Department of Education, ACF, and the Department of Justice to add appropriate questions about suicide and ACEs to existing surveys, such as for foster care reporting and in juvenile justice.
  - Develop “best practices” such as the use of common data elements that could be used at the federal, state, or local levels; for example, within:
    - Federal grant programs such as SAMHSA Systems of Care and Garrett Lee Smith Memorial Suicide Prevention Program, NIFA’s Cooperative Extension System program, Army STARRS program, NDACAN, and Indian Health Service programs
    - State surveys of youth and evaluations of state-level

programs, for example, [Communities That Care](#) (Washington State)

- Private groups, for example, [Community Health Improvement Partners](#), [Annie E. Casey Foundation](#), [Black Dog Institute](#) (New South Wales, Australia).
- Utilize new approaches in data mining of social media and search engine analytics to monitor suicidal behavior using techniques from grants from the CDC and the NIH Collaborative Research on Addiction initiative.
- Work with the CDC's NVDRS to determine best practices for utilizing this data system.

## Summary of Discussion of P2P Workshop Panel Recommendation II: Improving Design and Analysis

**Background:** Increasing access and integration to datasets is the first step to detecting those at risk for suicidal behavior and studying the underlying causes; however, better tools and methodologies are necessary to analyze the data and extrapolate findings to different communities. The P2P workshop panel recommended establishing measurements and modeling techniques at multiple levels (from biological to environmental), assessing risk/protective behaviors across longitudinal and developmental changes, promoting data integration and linkage to mortality data, and applying recent advances in inferential methods to strengthen valid interpretation of non-randomized controlled trial data.

### Opportunities for Collaboration Among Federal Agencies, Resource Development, and Next Steps:

Discussion among the Federal Partners focused on the methodologies to leverage newly accessible datasets and to integrate data sources. As discussed before, operationalizing a shared definition of exposure in treatment and risk assessment is necessary to advance the field. The Federal Partners also discussed the concept of “exposure” to either suicide/risk factors or exposure to intervention/protective factors.

Connectedness and self-regulation were discussed as factors that may be protective against or decrease risk for suicide ideation. Consideration of exposure across different developmental periods is also necessary. To aid in modeling risk and protective factors, the Federal Partners suggested adding relevant language to existing Funding Opportunity Announcements (FOAs) or developing new areas as follows:

#### Theoretical frameworks

- Exposure to risk/protective factors
- Comprehensive approaches to suicide prevention
- Developmental stage theories to best inform future interventions
- Psychometric validation of common items on the Youth Risk Behavior Surveillance System
- Intervention optimization
- Social determinants of health.

#### Data analysis

- Secondary data analysis of newly accessible data
- Combining different datasets for analysis
- Linking mortality data to existing datasets, with technical assistance seminars on how to navigate the privacy and application processes

- Exact proportion of disability and quantify burden of disease
- Effect of interventions on mortality
- Using the NIH's *All of Us* questions to harmonize findings from other surveys and to crosswalk data
- Methods to best solicit, translate, and report feedback to and from stakeholders.

## Summary of Discussion of P2P Workshop Panel

### Recommendation III: Building and Strengthening the Research and Practice Community

**Background:** The workshop panel emphasized the development of a robust research and practice community. This would foster the initiation of data linkages, implementation, and dissemination, and aid in surveillance. The P2P workshop panel also recommended education of families, agencies, and communities in the use of datasets and interventions, helping to further expand the research and practice community. The workshop panel recommended two broad areas of focus: (1) collaboration across the full spectrum of stakeholders, including researchers, public health officials, providers, and policymakers; and (2) joint efforts to limit access to means of suicide, develop menus of effective interventions, and disseminate aggregated data on what works (and factors that influence effectiveness). The workshop panel also recommended providing education, training, evidence-based practice information, and resources to stakeholders in communities, researchers, methodologists, and practitioners. This is to foster collaboration and provide training in interventions and methodologies for testing hypotheses, and disseminate information on evidence-based interventions and implementation.

**Specific Research Focus Areas:** In considering the recommendations of the workshop panel, the Federal Partners identified several areas on which to focus their efforts. As discussed earlier, establishing a federal workgroup for data sharing, coordination, planning, and dissemination of information would aid development of a stronger research and practice community. A similar workgroup for youth suicide prevention would also provide a cross-sector forum for researchers to come together with community partners and policymakers. The Federal Partners also discussed policy research and policy approaches to suicide prevention, including efforts by the Robert Wood Johnson Foundation and Healthy People 2020 to monitor policies on training, education, and suicide means restriction. In addition, there is a need for monitoring health benefits of policy changes, such as the link between same-sex marriage laws and decreases in LGBTQ youth suicide attempt rates. The Federal Partners recognized that efforts to increase data linkages also come with ethical, legal, and policy issues related to patient data which must be addressed before linkages can occur. The discussion also focused on several efforts to build local and regional capacity. The Federal Partners agreed on the following next steps:

### Opportunities for Collaboration Among Federal Agencies, Resource Development, and Next Steps:

- Build capacity:
  - Train local-level practitioners and policymakers in effective collection and use of surveillance data.
  - Train researchers in linking studies to administrative data on mortality using insight from experts.



- Develop a national prevention system (long-term goal) to promote dissemination and implementation of prevention interventions that impact risk and protective factors for suicide.
- Meet with organizations such as the Anne E. Casey Foundation to discuss the feasibility of a public-private partnership similar to its Kids Count program and to learn more about how it engages in policy matters
- Work with the Council of State and Territorial Epidemiologists to determine what data it collects on suicide.
- Support the creation of two CDC “technical packages” (a CDC effort to assemble the best evidence-based practice into packaged strategies coupled with the evidence and implementation approaches) in:
  - Navigating privacy, ethics, and legal issues related to the use of administrative data
  - Supporting the translation and implementation of prevention efforts in communities.
- Use the CDC’s NVDRS process to establish ready-to-use datasets that support community partners and policymakers in making informed decisions.
- Use the Health Resources and Services Administration’s child death review to support communities in monitoring and acting in response to child deaths.
- Develop dashboards, potentially through small business grants, that allow communities to assess the impact of individual-level to policy-level intervention programs on risk and protective factors for suicide.

## Concluding Remarks

While the Federal Partners Meeting represents the conclusion of the P2P program activities related to youth suicide prevention research, efforts to decrease youth suicide are ongoing. This report presents a set of prioritized research and programmatic strategies that could be advanced through collaborations across the federal government and with private-sector partners. As a resource for the larger youth suicide research community, the report will be publicly available and distributed to key stakeholders, as well as to the public-private partnerships such as the National Action Alliance for Suicide Prevention.

The Federal Partners have already taken steps toward addressing the recommendations outlined above. This includes a roundtable discussion about the P2P Workshop and Federal Partners Meeting at the Society for Prevention Research annual conference on May 31, 2017. They have also released two FOAs specifically addressing the needs outlined above. The first Request for Applications (RFA) titled [Addressing Suicide Research Gaps: Aggregating and Mining Existing Data Sets for Secondary Analyses \(RFA-MH-18-400\)](#) is aimed at integration and analysis of existing basic, clinical, intervention, and social media data to identify potential biological, experiential, and other predictors and moderators of suicide risk. The other RFA titled [Addressing Suicide Research Gaps: Understanding Mortality Outcomes \(Ro1\) \(RFA-MH-18-410\)](#) seeks to support efforts to link research data to mortality data to better understand the risk/preventive factors, as well as the burden of, suicide among people seen in structured health care settings. These are the first in a series of steps the Federal Partners are committed to take to address the need to advance research to prevent youth suicide.



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