Meeting Summary

PCORI Stakeholder Workshop on Suicide Prevention

December 17-18, 2019

Summary

On December 17-18, 2019, the Patient-Centered Outcomes Research Institute (PCORI) convened a two-day stakeholder workshop on suicide prevention in Arlington, Virginia. It hosted 12 participants on the first day, including 2 researchers and 10 patients and patient advocates, including persons with lived experience and advocacy and community-based organization representatives.[1] On the second day of the meeting, 37 individuals participated; this included 11 of the attendees from the first day, in addition to 3 policymakers, 6 payers, 7 clinicians, 1 hospital/health system representative, 2 purchasers, 5 additional researchers, and 2 additional patient advocates.

PCORI convened the meeting to gather stakeholder input on its future investments in real-world evidence-building initiatives around suicide prevention. Both days of the meeting began with an overview of PCORI's current exploration of the topic to date and key areas of potential investment, which are:

- Crisis settings (e.g., psychiatric emergency departments, mobile crisis units)
- Brief interventions (e.g., safety planning, motivational interviewing)
- Treatments to prevent crisis, increase patients' coping skills, and improve quality of life (e.g., suicide-specific cognitive behavioral therapy)

Participants provided feedback on each of these areas and discussed several priorities:

- Prioritizing patient-centered outcomes research (PCOR) related to quality of life and reasons for living
- Addressing systemic/structural factors, particularly through community-based interventions
- Culturally tailoring settings and interventions to meet the preferences of individuals
- Educating clinicians and building system capacity for connecting at-risk individuals to preferred services

The following two sections provide an overview of PCORI's mission and background on the key areas of potential investment related to suicide prevention that PCORI identified. The remainder of the document synthesizes participants' feedback.

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[1] Throughout the two-day meeting, participants used the broad term *lived experience* to refer to firsthand experience with suicide. Attendees who identified as having lived experience provided input from their personal perspectives and from the perspectives of the organizations that they represented.

PCORI and Suicide Prevention Research

On both days, meeting participants introduced themselves and facilitators provided an overview of PCORI's research focus, their approach to engaging stakeholders, and the range of evidence products PCORI can provide. PCORI funds comparative clinical effectiveness research (CER), which focuses on producing findings that help patients/consumers, clinicians, purchasers, and policymakers make specific care decisions. PCOR is CER that considers patients' needs and preferences and the outcomes that are most important to them. PCOR engages patients in planning and conducting studies, as well as in disseminating the results. In determining which investments to pursue, PCORI seeks stakeholder input on which research products meet their needs and how best to make trade-offs between speed and certainty when producing evidence. PCORI typically does not fund epidemiological studies or those that are exploratory in nature.

During the first day, participants discussed the use of the term *patient* when referring to patient-centered outcomes research. One patient advocate noted that the use of the term *patient* might indicate a preference toward funding traditional mental health interventions, and another participant commented that the use of the term *patient* suggests that suicide is solely a clinical problem, when there are other factors, such as living conditions, that need to be considered. Meeting facilitators clarified that their interest in obtaining input on potential CER topics or questions extended beyond traditional interventions (e.g., PCORI is also interested in comparisons of treatments or intervention that are widely used), and that while randomized controlled trials produce strong evidence, they were open to other types of studies, such as observational studies.

On both the first and second days of the meeting, facilitators described two PCORI-funded suicide prevention studies currently underway. One is currently comparing inpatient psychiatric treatment with intensive outpatient psychiatric treatment for adolescents who are evaluated in the emergency department for suicidality. The second is comparing safety planning with an enhanced approach that consists of safety planning plus structured follow-up.

Suicide Prevention–Background

On both days, meeting facilitators provided background on suicide prevention based on their review of the literature and preliminary conversations with stakeholders. They presented statistics on the rising rates of suicide and the extent to which rates vary by gender identity, race/ethnicity, age, and geography (i.e., urban vs. rural). They listed several populations of interest, identified by background research and stakeholder input prior to the meeting, including transgender individuals, American Indians/Native Alaskans, rural populations, non-Hispanic Whites, men, and African-American teenagers. One patient advocate noted that veterans should also be prioritized.

Recognizing that suicide prevention is a broad field, meeting facilitators focused the discussion around three areas that they identified prior to the meeting as having potential for PCORI investment: crisis settings, brief interventions, and treatments. Across these three areas, meeting facilitators presented their early learnings:

- **Crisis settings:** There is strong concern from the patient community about taking those in crisis to the emergency room, as it can be a traumatic experience. Alternatives include psychiatric emergency departments, psychiatric urgent care clinics, and mobile crisis units.
- **Brief interventions:** Patients considered at risk may receive a brief intervention in a clinician's office, emergency department, or other setting. Brief interventions could include safety planning, or safety planning in addition to reasons-for-living planning.
- **Treatments:** There are some evidence-based treatments for preventing suicidal crisis, improving coping skills, and reducing suicidality and depression. Examples of these include suicide-specific cognitive behavioral therapy, dialectical behavioral therapy, and medication. Many patients endorse peer respite programs, which are voluntary short-term overnight programs offering community-based, nonclinical crisis support by people with lived experience; preliminary studies suggest good outcomes.

Suicide Prevention–Discussion

Participants provided feedback related to the areas of interest that PCORI identified prior to the meeting, focusing on outcomes and considerations important to participants. As described below, community-based interventions, cultural tailoring, clinician education, and system capacity building emerged as key strategies for improving outcomes.

Crisis Settings–Avoiding Trauma and Prioritizing Outcomes Related to Quality of Life

The importance of addressing problems associated with admission of people in crisis to an emergency department was discussed. Several participants discussed the reluctance to engage with the healthcare system, based on negative and traumatic experiences. Reducing stigma, racism, coercion, and especially the involvement of law enforcement emerged as important goals, as these factors have resulted in individuals' lack of trust in clinicians and systems.

Across both days of the meeting, patient advocates strongly emphasized the need to address the lack of trust in clinicians/systems among patients. This lack of trust causes those at risk to avoid disclosing suicidal thoughts or attempts for fear of losing control. Participants shared that those who consider or attempt suicide frequently experience a loss of power, particularly in clinical settings, where individuals can often experience coercion, including from those who mean to help. For example, individuals may be forced to complete a safety plan as a condition of avoiding hospitalization. People may be admitted against their will and wait times for admission are often extremely long (days). In addition, the involvement of law enforcement or child welfare services can result in a loss of control and trauma. Some crisis hotlines are not transparent about whether they will call the police, which can hinder trust. However, one participant indicated that in some areas law enforcement is the only available option to address crises.

Patient advocates expressed interest in research on interventions that increase the trust level of patients, by, for example, avoiding the involvement of law enforcement, and helping individuals stay in the community (as opposed to hospitalizing them). Participants suggested that PCORI may consider studying the impact of crisis units dispatched without law enforcement as compared to those that are accompanied by law enforcement, and outcomes for people who call a crisis line managed by peers or nonpeers.

Training of clinicians was discussed as a way to address these concerns (see also under Treatments). Training of law enforcement members was also discussed: a participant shared her experience that members of law enforcement may view crisis management negatively and may not be active participants in such training.

Training and building capacity among clinicians emerged as a key way of addressing challenges related to trust and connecting individuals to needed services. Patient advocates described how clinicians often react out of fear when dealing with suicide. Concerns about liability were discussed as an important factor for clinicians. Participants across various stakeholder groups agreed that educating clinicians to help them feel more in control in these situations could better position them to empower patients and connect them to services. Educational strategies that increase cultural competency and help clinicians share decision making with patients (e.g., those related to medication discontinuation among pregnant women) could be good starting points. A participant shared that in her experience the use of peers for suicide hotlines was associated with much reduced turnover. Researchers and patient advocates recommended that PCORI support research around the comparative effectiveness of various training programs and use of peers versus nonpeers.

Patient advocates strongly endorsed study outcomes associated with improving quality of life and reasons for living. Throughout both days of the meeting, patient advocates described a disconnect between these outcomes and those that are commonly emphasized in research studies, such as decreased mortality rates. Patient advocates endorsed upstream outcomes related to improving lives and making life worth living, and also suggested medication tapering as an outcome. Meeting participants endorsed various primary prevention outcomes, such as improvements in daily functioning, social determinants of health, autonomy, social support, hope, and preparedness to cope with future challenges related to suicide.

Summary of Participant Recommendations on Increasing Trust Among Patients

- Support research evaluating interventions that increase patients’ trust levels in clinicians and systems by
  - Avoiding the involvement of law enforcement (e.g., dispatching social workers instead of police in times of crisis)
  - Training clinicians
  - Using clinicians that are also peers for vulnerable communities
  - Matching individuals to services and care that meet their preferences
- Support research on models of peer support. This could include investigating effective models of training for support staff or comparing the effectiveness of different kinds of peer support
- Include outcomes related to quality of life, reasons for living, social determinants of health, social support, skills to manage suicidal ideation, autonomy

Brief Interventions

In response to PCORI's Suicide Prevention Background presentation on day 1, participants discussed that suicide is not a condition like heart disease, but rather, an outcome or sometimes a response to the conditions in which people are living—such as intergenerational trauma and social determinants of health. By treating it like a medical condition, researchers or clinicians may be more apt to pursue medical solutions rather than those that address upstream factors. Patient advocates noted that many interventions, such as safety planning, place the emphasis or responsibility on the individual when there may be structural factors (such as homelessness, violence, and lack of connectedness) that are directly related to individuals' desire to live. On day 2, some clinicians advocated for means restriction (e.g., reduced access to firearms) as an important evidence-based systemic intervention and called for more research in this area. One patient advocate noted that this approach may reduce mortality but will not reduce suffering. Some patient advocates felt that means restriction and safety planning strategies should not supersede efforts to address other factors related to individuals' quality of life.

Treatments–Addressing Upstream Factors via Community Based Interventions and Cultural Tailoring

Patient advocates indicated that clinicians and systems commonly lack the capacity to connect individuals to services meeting their preferences. They called into question the value of screening and assessments in the absence of patient-centered resources and treatments to connect people once they screen positive. Some clinicians, researchers, and a few patient advocates emphasized the need for research to determine optimal screening instruments and practices for healthcare settings. They said that in the meantime, risk assessments could be helpful starting points for identifying individuals' needs and for engaging with individuals who might be hard to reach (e.g., those who use emergency rooms as their primary source of care). Patient advocates emphasized the need to improve the care individuals may need and increase the capacity of systems and clinicians to connect individuals to such care before implementing screening and risk assessment interventions. Some clinicians offered that pediatric practices with integrated behavioral health services allow for screening and an immediate connection to a behavioral health specialist, but that optimal screening instruments and schedules require more research.

Related to system capacity building, participants discussed the importance of more research on the most effective models for peer support. Building capacity among support staff is also important. Research efforts could focus on optimal training approaches for peer-support staff and the comparative effectiveness of different types of peer support. Research on patient choice and efforts to match patients with their preferred services could also be fruitful.

Community-based approaches and cultural tailoring were discussed as key ways of addressing systemic factors that impact quality of life.

On day 2, meeting facilitators asked participants for examples of community-based suicide prevention approaches, such as interventions that take place in nonclinical settings (e.g., schools, churches, community-based organization, etc.), and that incorporate cultural sensitivity, community connectedness, and identity awareness. In response, one patient advocate who works with indigenous youth described a video messaging model used by their organization to connect indigenous youth to peers in times of crisis. This model is part of a holistic, strength- and hope-based strategy that connects indigenous youth to their culture. This patient advocate underscored the importance of addressing structural/systemic issues, like colonialism, the harm caused by medical institutions, and the lack of resources (i.e., healthcare facilities) on reservations.

Several participants, including researchers and patient advocates, agreed that outcomes may be improved by better tailoring care for specific populations, including African Americans, indigenous and LGBTQ populations, teenagers, and others. For example, to tailor mental health care for indigenous populations, they should consider a holistic model that includes the whole person—mind, body, and spirit—and recognizes systemic issues.

Participants recommended that PCORI support research that compares outcomes from culturally tailored approaches to approaches without such tailoring. For example, one patient advocate recommended that PCORI consider funding a study that explores the difference in outcomes for those who access traditional care versus those who access care from clinicians and staff who have received LGBTQ cultural competency training. Another patient advocate suggested comparing outcomes for hotlines using peers with those using nonpeers. One researcher commented on methodology of research studies on suicide prevention, noting that randomized encouraged design should be considered as an alternative to randomized controlled trials. Additionally, another researcher suggested studying how to better translate interventions to rural communities.

Researchers and patient advocates noted that many community-based programs lack the capacity to evaluate their outcomes, making it difficult to demonstrate their effectiveness and, therefore, difficult to implement the practice more widely. One patient advocate who helps operate a peer respite program reported that her organization has limited capacity to serve those in need relative to nearby psychiatry centers and explained that they do not have the resources to demonstrate outcomes. On day 1, patient advocates discussed the variability in community-based programs and supported their evaluation, adding that those programs should be assessed based on the extent to which they help individuals stay in the community and impact individuals' reasons for living.

On day 2, participants from various stakeholder groups highlighted a range of systems approaches that they thought are promising. Some examples of these included:

- Community hubs/town halls to educate a diverse array of community stakeholders in risks and treatments for people with suicidal ideation
- School-based approaches, including sports programs that offer opportunities for diverse groups (e.g., co-ed, all male, all female)
- Supportive, safe spaces for young people
- Communitywide mental health reporting system to connect indigenous youth to trained outreach staff

Summary of Participant Recommendations on Community Interventions and Cultural Tailoring

- Evaluation of hope-based, strength-based strategies for connecting indigenous youth to peers and trained support staff
- Evaluation of community-based programs, including peer respite programs, based on the extent to which they help individuals stay in the community and avoid crisis care and hospitalizations and impact individuals' reasons for living
- Research comparing the effectiveness of culturally tailored interventions. Examples of cultural tailoring that were discussed included:
    - Increasing LGBTQ competency among clinicians and those responding in crisis situations
    - Inviting the practice of culturally specific coping strategies, like spiritual exercises, into clinical settings
- Delivery of interventions in rural settings
- Support research on models that increase the capacity of clinicians and systems to connect individuals to the services they need or prefer and ensure this capacity is in place before instituting risk assessment and screening interventions