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Work in Progress and Lessons Learned

Leveraging Community-Engaged Research to Address Adolescent Depression with Pennsylvania Public Schools and Communities

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ABSTRACT:

Background: The prevalence of adolescent major depressive disorder rose from 8.3% in 2008 to 14.4% in 2018, and suicide is now the second leading cause of death among US adolescents.

Objective: Describe the process of community engaged research (CEnR) methods used to develop a randomized clinical trial (RCT) comparing the effectiveness of school-based universal depression screening on depression identification and treatment engagement, compared to standard symptom-based depression recognition.

Methods: We engaged stakeholders with personal or professional expertise and schools enrolled in the study. Qualitative methods aimed to elucidate barriers and opportunities during RCT development.

Results: Stakeholders were instrumental in all phases of RCT development. Qualitative feedback from participating schools, students, and parents informed RCT development and implementation.

Conclusions: Inclusion of CEnR methods provided opportunities to collaboratively address barriers to RCT design and implementation with school communities. This dialogue was invaluable in establishing relationships to further address mental health and other controversial adolescent health topics in future research.

KEYWORDS: Community-based Participatory Research, Community Health Research, Mental Health Services, Adolescent Health Services, Health Outcomes, Mood Disorders, Mental Disorders Diagnosed in Childhood

The prevalence of adolescent major depressive disorder (MDD) increased from 8.3% in 2008 to 14.4% in 2018.[1] Paralleling the rise in MDD is an increase in adolescent suicide,[2] the second leading cause of death among United States (US) adolescents in 2018.[3] Universal MDD screening is recommended in clinical settings by the United State Preventive Services Task Force,[4] however there is historically poor adolescent adherence to recommended annual preventive care.[5] Our team is currently conducting a randomized clinical trial (RCT) entitled Screening in High Schools to Identify, Evaluate and Lower Depression (SHIELD).[6] The intent of the SHIELD RCT is to evaluate the effectiveness of school-based screening for adolescent MDD comparing universal versus symptom-based screening. SHIELD is based on the premise that adolescents spend a large amount of their time in school,[7] and schools are already tasked with other health-related screenings (e.g. vision, hearing) that may impact a student's academic success.[8]

While the rising rates of adolescent MDD and suicide have led to efforts to increase awareness of the importance of mental health, significant stigma persists.[9-11] Conducting an RCT evaluating school-based depression screening, with the potential to identify a larger number of adolescents at risk for depression and suicide, not only required agreement from school administration, but also necessitated buy-in from parents and participating adolescents. Community-engaged research (CEnR) methods have previously been used to address depression stigma among African-American adults as well as Latino adolescents.[12-15] In this case, multifaceted stakeholder engagement involving the study team, community stakeholders and participating schools was used to provide the critical links to successfully develop this RCT on adolescent depression in the school setting.

Objectives

The objective of this manuscript is to describe the process of CEnR used to develop and implement SHIELD, an RCT comparing the effectiveness of depression identification and treatment engagement with school-based universal depression screening versus standard symptom-based depression recognition.

Methods

The development of partnerships and engagement strategies for all partners was guided by the key principals for CEnR as described in Israel et al, [16, 17] which include recognizing the community as a unit of identity, building on strengths and resources in the community, facilitating collaborative partnerships, integrating knowledge and action, promoting co-learning, using a cyclical and iterative process, addressing health from both a positive and ecological perspective, and disseminating findings. Below the history and growth of the partnership are detailed highlighting the key principles of CEnR.[16] Both the SHIELD RCT and qualitative components described were approved by the Penn State College of Medicine Institutional Review Board.

Partnership Development

To balance the perspectives of individuals, families, and community voices, we engaged both schools interested in participating in the RCT and mental health community stakeholders to inform the development of the RCT (*recognize community as a unit of identity; address health from both positive and ecological perspectives*). Dr. Sekhar (PI) initiated engagement of both groups in 2016 to discuss the concept of school-based mental health screening based on experiences in the pediatric clinical setting. In some instances these were cold emails sent as initial queries. For example, Dr. Sekhar reached out directly to several members on the Pennsylvania (PA) Student Assistance Program (SAP) website introducing herself as a general pediatrician and briefly outlining her research background and interests. The student assistance program (SAP) is responsible for supporting the SAP framework in all PA school districts to address barriers to academic success through referrals to school or community-based follow-up services. SAP leadership was willing to set up a phone call for an initial discussion. In another case, Dr. Sekhar reached out to parent contacts via her prior research work based on their affirmative response regarding willingness to be contacted for future research. Parents and professional stakeholders subsequently provided suggestions for peers who might be willing to participate. Thus, an initial group of stakeholders was convened for a one-time community engagement studio[18] to refine the concept for the research study and address concerns from stakeholders and the school community. When the research project was funded in 2018, a formal stakeholder advisory board (SAB) was developed to ensure applicability of the RCT to the target audiences and provide pathways for dissemination of study feasibility and study outcomes. Some of the original stakeholders from the community engagement studio transitioned into SAB. These stakeholders then provided recommendations for additional stakeholders, specifically linking the study team to adolescents in a high school-based mental health awareness club, contacts at the state government level, and representatives from PA SAP (*build on strengths and resources in the community*). The final SAB was comprised of adolescents, parents, mental health professionals (e.g., psychologist, psychiatrist), and primary care clinicians, in addition to professionals from schools, mental health organizations, and suicide prevention organizations (Table 1).

Table 1. Current Stakeholder Advisory Board Members

Group represented	Number of Stakeholders	Name and affiliation/expertise
Adolescents	2-3	High School-based club to promote mental health awareness has at least two students participate at each meeting
Parent	1	Local community member who is also a parent, youth group leader, and president of a grass-roots initiative to reduce mental illness stigma and combat teen suicide
Suicide/Mental Health Organizations	2	Present and founder of a local foundation created and dedicated to a family member who died by suicide Executive Director of statewide, student initiated program founded to raise awareness of youth mental illness
Pennsylvania (PA) Student Assistance Program (SAP)	2	SAP regional coordinators.
Medical Experts	4	Clinicians representing primary care, psychiatry, and adolescent medicine specialties
State Agency	1	Project Director for PA's Garrett Lee Smith Youth Suicide Prevention Grant
School representatives	3	School nurse and two school counselors

The study team identified schools interested in the RCT based on previous research and programming relationships.[19-22] In addition, stakeholders suggested potential school districts based on their own connections. Study team members met with school representatives to discuss the proposed RCT and associated qualitative study elements, and requested commitment from the school for the three-year study (Figure 1).

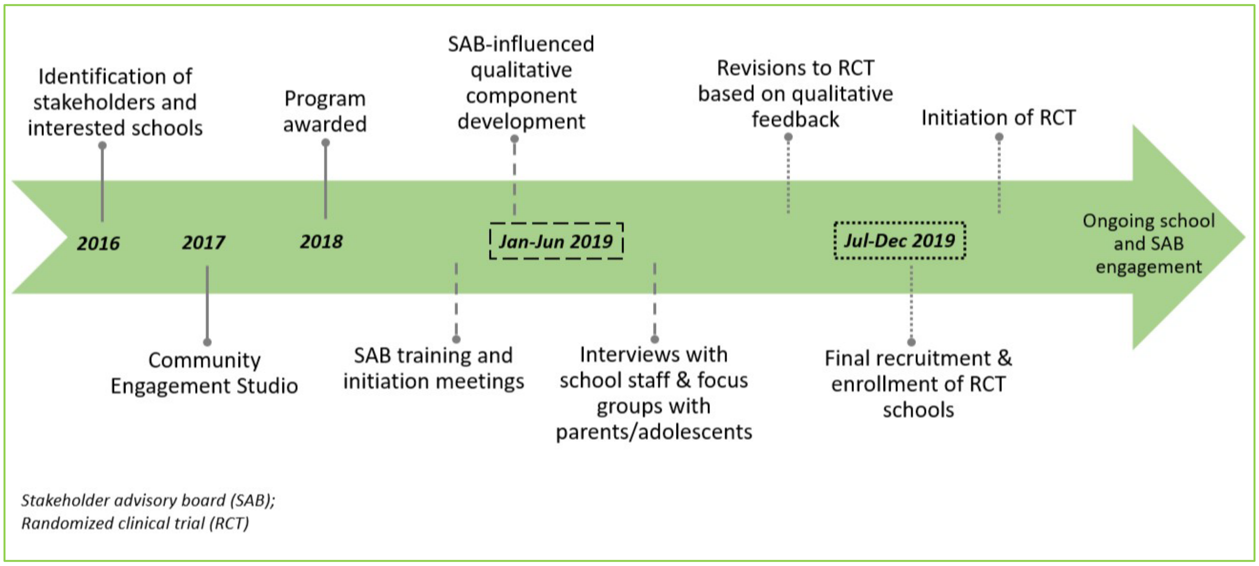


Figure 1: Timeline of Engagement Events to Develop Partnerships and the Randomized Clinical Trial

Stakeholder and School Engagement

Different from CEnR that exclusively partners with a group of advising individuals outside of the research, this study prioritized partnerships with both an external SAB and also engagement with the schools interested in enrolling in the research study.[6] This organization (Figure 2) allowed for objective, general perspectives from community experts in the mental health arena and specific feedback from the school communities most affected by study outcomes and feasibility in the school setting to influence the research activities (*integrate knowledge and action*). The SAB members were also well-positioned by this arrangement to guide dissemination of study results to participating schools by helping the research team appropriately frame and explain findings. A member of the study team functioned as the community engagement coordinator and was responsible for liaising between the research team and SAB.[23] This format provided stakeholders a point person outside of the immediate team and created a safe space to voice any concerns related to the research or team. The community engagement coordinator was responsible for overseeing and coordinating all engagement activities and application of the principals of CEnR (*facilitate collaborative partnerships*).

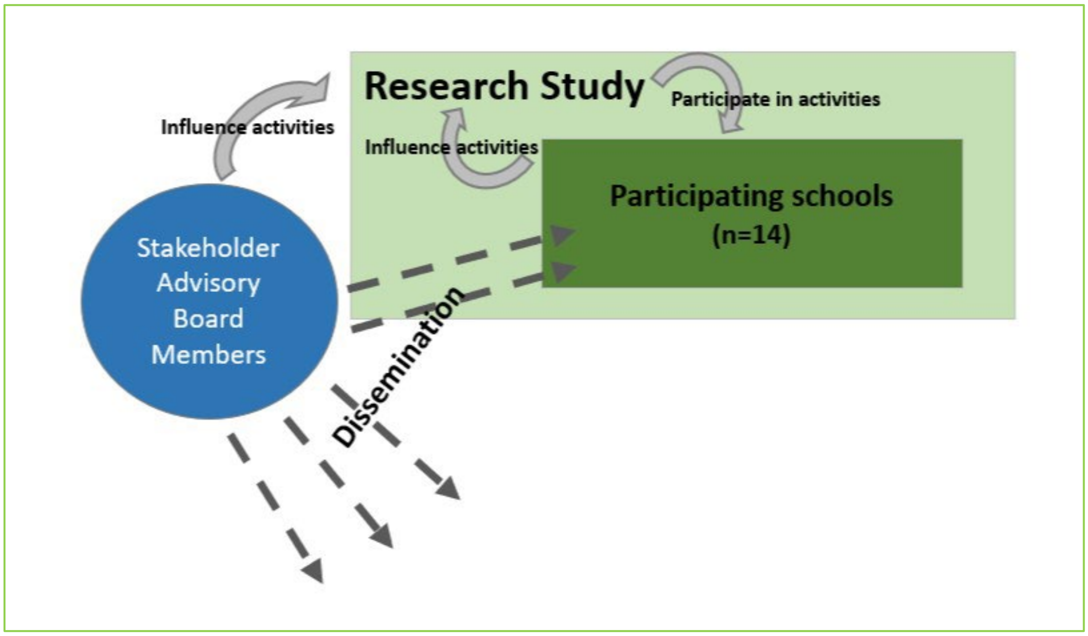


Figure 2: Interaction of Study Partners with Study Activities

SAB members agreed to meet four times per study year, three virtually and once in-person (*facilitate collaborative partnerships*). Stakeholder meetings were initiated in February 2019. Education and training was provided to members of the SAB on the research process and the overall proposed RCT design, and stakeholders shared their vision of how their perspectives and experiences could benefit the project, along with their goals for engaging (*promote co-learning*). Study team members and SAB members mutually agreed on the scope and roles of SAB members (*facilitate collaborative partnerships*), including finalizing RCT development, advising on qualitative engagement with schools across the study period, and ongoing dissemination efforts.

Due to limited instances of engagement of adolescents in CEnR,[24, 25] the inclusion of adolescents and adults on the SAB required thoughtful consideration to ensure a platform for the adolescent voice, particularly among medical and mental health professionals. Adolescents on the SAB (from a school-based mental health club at a single high school) shared participation responsibilities and thereby ensured continuity of the adolescent voice, despite busy schedules and matriculation over the study period. In addition, their attendance at live meetings was always accompanied by a faculty advisor. Students also occasionally opted to discuss items offline with peers in their student group and respond to requests in a collective way. This arrangement allowed for consistent, reliable participation of adolescents on the SAB. However, recognizing these adolescents might not be representative of other teenagers, additional perspectives were sought in the qualitative components of the study detailed below.

Each stakeholder was compensated for their participation unless prohibited by their position in state government. In addition, academic stakeholders benefitted from opportunities for collaboration and scholarship. Adolescents who participated were offered recognition (e.g., recommendation letter) to support college or job applications. School partners were offered free access to the Question, Persuade, Refer suicide triage training.[26, 27] Parents, who were largely impacted by youth mental illness either personally or professionally, and representatives from suicide prevention and mental health organizations, were provided a platform to raise awareness for their missions and share their lived experiences.

Intervention Development

The community voice was important in development and initiation of a RCT of this scale focused on adolescent depression, particularly when obtaining support and participation from schools[28] who served predominantly low-income communities and minority populations.

Through the described community engagement studio, stakeholders from schools and community groups discussed the screening concept and concerns about research logistics, refining the concept to improve feasibility in the school setting and chances of project funding. Upon securing program funding in 2018, the study team engaged the SAB to guide the development of a qualitative formative data collection strategy to better understand the school environment where the proposed research would take place and inform the final plans for intervention (*integrate knowledge and action*). SAB members worked with the study team to develop interview guides for interviews with school staff to understand what processes would facilitate the screening events, and focus group guides for focus groups with adolescents and parents in the target communities to gather community perspectives on barriers to school-based depression screening (Figure 1).

Thirty-minute semi-structured interviews were conducted with 19 school staff, in addition to eight, 60-minute adolescent focus groups with a total of 52 participants and six, 60-minute parent focus groups with a total of 36 participants. The adolescent focus group participants were distinct from those on the SAB. All interviews and focus groups were recorded, transcribed, and analyzed using descriptive content analysis, as described in Stuckey et al.[29] This type of analysis is appropriate when existing theory or research is limited. We avoided using preconceived (a priori) categories for coding, instead allowing the categories and names for categories (codes) to flow from the data.[30] Data analysis begins with reading all data repeatedly to obtain a sense of the whole meaning of the text.[31] Then data are read word by word to derive codes that can be organized into categories based on how different codes are related and linked. This forms an outline of an initial coding scheme ("codebook").[32, 33] Definitions for each category and codes are developed for transparency and ease of coding. The qualitative researcher (Dr. Stuckey) and PI (Dr. Sekhar) reviewed and approved the codebook. Two coders completed 20% of the transcripts to obtain reliability (kappa) between the coders, ensuring a similar understanding and consistent application of the codebook. Upon reaching an acceptable kappa (>0.8), the coders independently coded the remainder of the data.

In addition, the research team met with key personnel from each participating school to map out available resources and outline possible screening procedures. Information gained from engagement activities with school representatives, parents, and adolescents was applied in the final iteration of the RCT procedures.

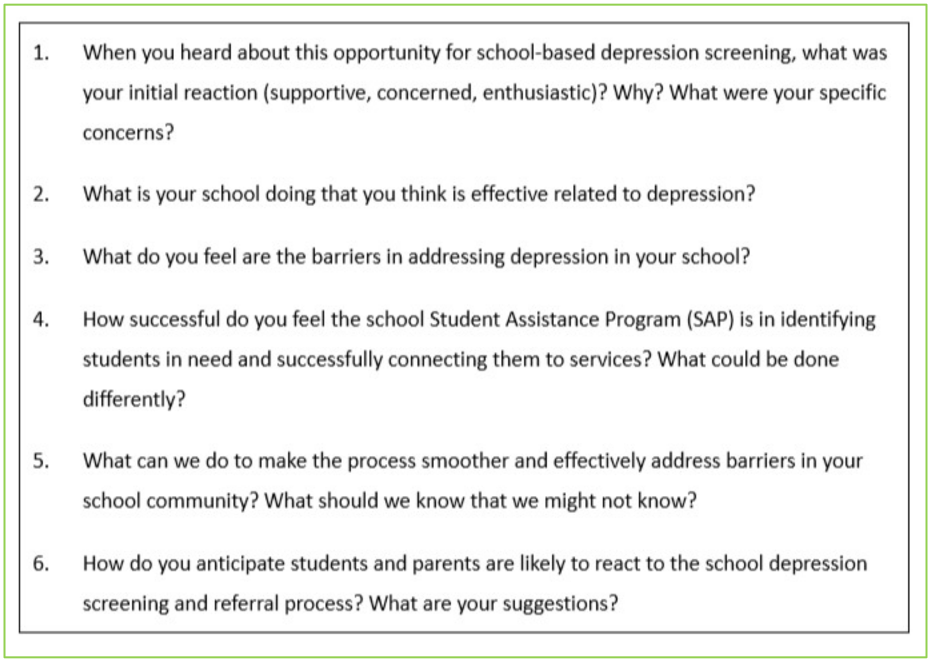
After finalizing the development of the RCT, stakeholders transitioned their focus to support ongoing dissemination of study progress through the development of a biannual study newsletter (*disseminate findings*). The stakeholder driven publication highlights our stakeholder partners, provides study updates and disseminates information about mental health to our partnering schools and communities on a quarterly basis.

Results and Lessons Learned

Stakeholder Engagement

The stakeholder voice was an important part of the study long before a formal notice of award. When initial study reviewers expressed concern that adolescents might not take a depression screen seriously and that some individuals might not be forthcoming on screening tools, stakeholder participants collectively countered that this should not be prohibitive and did not diminish the importance of providing the opportunity for disclosure. Stakeholder feedback was valuable in addressing reviewer concerns with a community voice and ultimately securing funding. Stakeholders were also integral in leveraging their networks and relationships with schools to assist the study team in identification of schools interested in the RCT (*facilitate collaborative partnerships*). In some instances, stakeholders were physically present at initial conversations with schools to help plan and troubleshoot concerns of school leadership.

Stakeholder involvement in the development of interview (Figure 3) and focus group guides helped to ensure the study team was asking the right questions to identify perceptions of mental health among adolescents and parents, and also perceived feasibility of proposed study activities among school representatives. For example, stakeholders suggested edits to improve non-stigmatizing language across all interview and focus group guides. Specifically for adolescent focus groups, one stakeholder suggested the use of storytelling, “it’s great to ask them: ‘Could you tell me about a time when…’” Other stakeholders advised a slower entre into sensitive questions, offering, “start by asking questions about ‘you and people you know at your school’ to ease the fear of talking about themselves.” Adolescent stakeholders also provided feedback on the demographic questionnaire and recruitment materials that accompanied the qualitative interviews and focus groups, such as revised demographic categories for gender and sexual orientation, and recruitment flyer wording that was better suited for community members, as opposed to more traditional clinical research participants.



1. When you heard about this opportunity for school-based depression screening, what was your initial reaction (supportive, concerned, enthusiastic)? Why? What were your specific concerns?
2. What is your school doing that you think is effective related to depression?
3. What do you feel are the barriers in addressing depression in your school?
4. How successful do you feel the school Student Assistance Program (SAP) is in identifying students in need and successfully connecting them to services? What could be done differently?
5. What can we do to make the process smoother and effectively address barriers in your school community? What should we know that we might not know?
6. How do you anticipate students and parents are likely to react to the school depression screening and referral process? What are your suggestions?

Figure 3: Sample School Staff Interview Guide Developed in Partnership with Stakeholder Advisory Board

In addition to RCT design and school partner recruitment, stakeholders were also engaged in early dissemination activities, such as the design and development of the study newsletter at the first in-person SAB meeting. “One thing I’ve really liked about participating…is how you handled…the meeting, employing things like icebreakers and gallery walks, seating people so they could form connections. I really think that helped to keep me engaged in this process,” said one stakeholder. Stakeholders provided content for each newsletter issue and served as editors. Newsletters were developed and distributed to participating schools two times per year and stakeholders were also encouraged to disseminate through their networks (*integrate knowledge and action*).

School Engagement

Focus groups and interviews with students, parents, and school staff provided an opportunity for the study team to understand attitudes toward mental health within the school community prior to implementing the RCT and guided small, but impactful changes in the plans for study implementation procedures (*integrate knowledge and action; promote co-learning*). Student focus group data advised that screening activities be completed in a quiet and private location to prevent students from reading one-another's responses. Thus, students were deliberately seated in an auditorium or in a classroom that could accommodate adequate spacing between them. Participants also proposed the use of the term "mood screener" rather than "depression screen." Interviews and planning meetings with staff indicated the need to develop clear documentation and communication plans for student follow-up and day-of-screening plans, such as location for student participation and internet access for completion of the screening tool. One staff member said, "it's important to know the process or the procedure that we have to follow if we find out that a student is a threat to him or herself." In addition, it was strongly suggested that schools consider implementing extra counseling support on screening days to reduce burden on traditional triaging processes, as one staff member stated, "I'm also a little bit worried that…we're going to be really overwhelmed that day" and another indicated the need "to have counselors on-hand for the influx that may happen once [the screening is] done." Staff interviews also revealed staff opinions that most parents and students had "a general lack of understanding about mental health needs," suggesting "any information that we can get to students, the community and even the staff would be helpful." These ideas were echoed in responses by parents and students in the focus groups, described fully by Stuckey et al.[29]

Lessons Learned

Stakeholders were instrumental in all phases of the RCT development, however these engagement efforts were not without challenges and opportunities for improvement. First, effectively engaging SAB members via web-meeting required thoughtful consideration of the topics presented for discussion. Varied stakeholder backgrounds and participation preferences made general discussion of complex topics challenging. As such, the meeting format was adjusted to focus on pointed requests and feedback on pre-formed options. For example, rather than a broad discussion of possible topics for the newsletter, the team presented potential options and gave participants the opportunity to comment or add others. Stakeholder engagement that required more thoughtful feedback or brainstorming was transitioned to email requests or reserved for in-person meetings. In addition, scheduling conflicts among some SAB members resulting in difficulty attending meetings. Members were consulted about mechanisms to best engage them. Two opted to preferentially participate with newsletter content and academic publications. A third withdrew from active participation, but requested to be included on email communication.

To enhance co-learning and maximize the benefits of the cyclical process of partner feedback and partnership improvement, additional evaluation strategies will be integrated into remaining study years. For example, we plan to conduct annual surveys to be completed by both our stakeholders and study team. The study team will be asked to assess the value of stakeholder feedback on key study milestones. Stakeholders will be asked to share 1) their perception of the value their feedback had on key study milestones and 2) the personal/professional value of their participation on the SAB. The survey tools will be updated annually to reflect appropriate study milestones. Feedback will be used to revise the engagement strategy for subsequent years. Additionally, annual qualitative and quality improvement checkpoints will be integrated to ensure the study is adapting to knowledge available through school partners as their school-based experiences evolved over time. For example, in the final year of the study, adolescents, parents and school staff will engage in additional qualitative opportunities to provide feedback on their experiences with the RCT (*promote co-learning; cyclical and iterative process*).

In addition to activities planned from outset, we have identified several opportunities for ad hoc stakeholder engagement. For example, qualitative results from the adolescent focus groups were presented to the SAB and paired with a discussion about the most appropriate method for dissemination to our partnering schools. This resulted in a plan to engage stakeholders in the development of a qualitative "brief" for a lay audience. The brief is intended to be a short, visually appealing, easily understood summary of the academic manuscript results. Our SAB members are well-positioned to guide us in this effort (*integrate knowledge and action; disseminate findings; integrate knowledge and action*).

Conclusions

While prior literature has described 1) engagement with adult and adolescent populations to address depression stigma,[12, 34, 35] 2) CEnR with adolescent minority populations on other stigmatizing health issues,[36, 37] and 3) CEnR with schools,[34] our engagement efforts highlight a unique marriage of these applications in a partnership between academic researchers and community stakeholders seeking potential solutions to address the controversial topic of adolescent depression.

Partnerships established with stakeholders and schools have already led to additional mutually beneficial opportunities. Future discussions within the SAB will focus on the development of a research agenda based on stakeholder interests, as described by Gaglioti et al, in addition to their role in supporting the RCT.[38] We anticipate the community dialogue around mental health may also provide the impetus for future opportunities to address adolescent depression. One stakeholder shared, “I think one ‘effect’ of these efforts is that it is starting conversations about mental health/depression/suicide…and leading to important community conversations…on this topic.” For researchers studying other stigmatizing adolescent issues, such as youth suicide, immunization, racial disparities, or obesity, SAB involvement is invaluable in opening dialogue with those who think differently than like-minded academic colleagues. Our partnerships placed accountability on the research team to address the challenges of practically applying the study protocol in real world settings. As researchers investigate potential solutions to controversial health topics in supportive, controlled, academic settings, it will be even more important to prioritize the knowledge and experience of community members in exploring the application of results that may vary when applied in community settings.

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