

ADOLESCENT HEALTH NETWORK DEVELOPMENT TOOLKIT



Welcome to the Adolescent Health Network (AHN) development toolkit! We created this toolkit for health researchers or institutions who are interested in developing their own AHN.

The goal of this toolkit is to streamline your network development process by utilizing our previously-developed templates, logistical considerations and lessons learned.

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Section 1

INTRODUCTION

The Value of Stakeholder Input
The Penn State AHN

INTRODUCTION



THE VALUE OF STAKEHOLDER INPUT

Health research and programming designed FOR a population rather than WITH a population can result in outcomes that lack value and relevancy. When initiatives include the input of the target population, there is a greater likelihood of a successful outcome. Though young, adolescents can provide an important “voice” as stakeholders in research. The Penn State AHN and this toolkit were sponsored by the Patient-Centered Outcomes Research Institute®. PCORI® strives to improve healthcare delivery and outcomes and help people make informed healthcare decisions by including patients, caregivers and the broader healthcare community in the research process.

THE PENN STATE AHN

The Penn State AHN connects health researchers to trained adolescent stakeholders, or “teen experts”. The Penn State AHN, currently comprised of 12 schools and nearly 50 adolescents from across Pennsylvania, uses virtual meeting tools to connect health researchers with adolescents from schools who participate in the AHN. A school staff advisor supervises participating adolescents’ completion of an online stakeholder training and serves as a local champion and contact. As participating adolescents graduate, incoming underclassmen join the “club”, creating an enduring framework to consistently engage adolescents as stakeholders.



Section 2

DEVELOPING AN AHN

General Structure of the Penn State AHN

Partners in the Penn State AHN

Stakeholder Guidance when Developing an AHN

Planning for your AHN

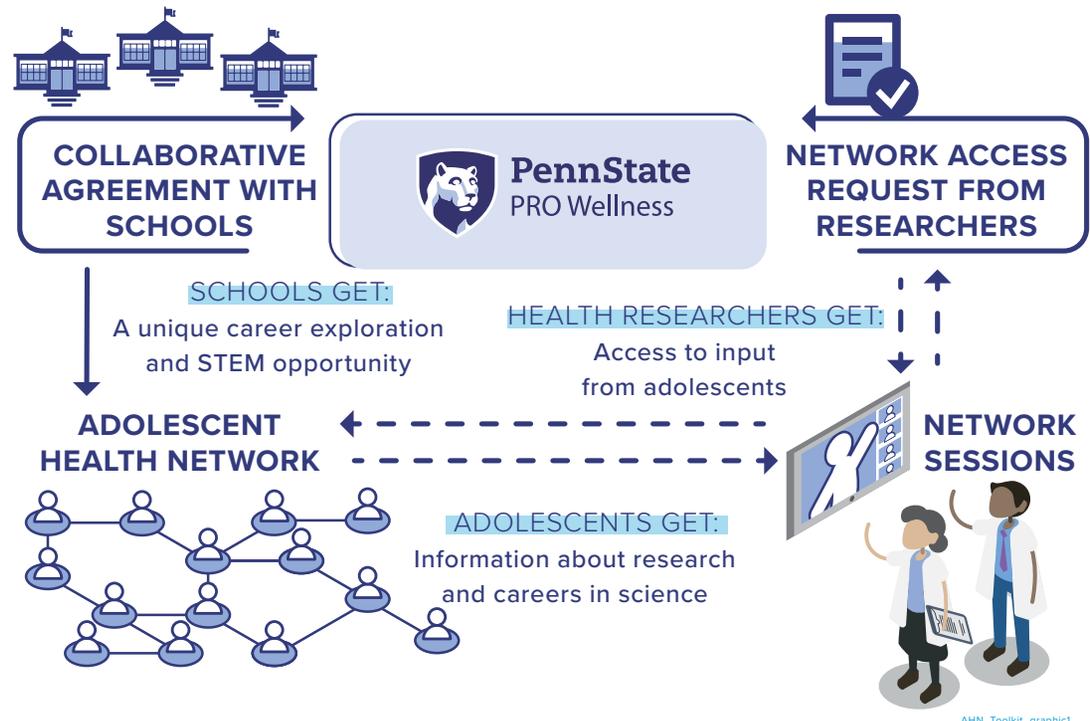
DEVELOPING AN AHN

Developing an AHN requires thoughtful planning to ensure adolescents can comfortably share their unique perspectives. In addition, health researcher partners should be able to easily access the AHN and be supported in preparing their research questions for adolescent engagement. By investing in the infrastructure up front, partners will have fewer barriers to successful engagement. This section provides a general overview of the Penn State AHN, including details on the involved partners as well as prompts as you map out your own AHN.

GENERAL STRUCTURE OF THE PENN STATE AHN

The Penn State AHN was built on our history of partnering with Pennsylvania schools. This history and our affiliation with an academic medical center created a natural bridge between adolescents and health researchers. Schools serve as the “access point” for enrolling adolescents into the network. Participation functions similarly to a school club or career enrichment opportunity. Each participating school appoints one advisor who recruits adolescents and facilitates communication between the AHN team and participating adolescents.

Once educated on the basics of the stakeholder role and community-engaged research via an online training, adolescents sign up for 5-6 sessions per school year and use real-life experiences to advise health researchers. In return, participating adolescents gain exposure to various health topics and careers in health and research fields. As adolescents graduate, they are replaced by underclassmen. An AHN does not have to be set up via school partnerships, but in general, an AHN should have a strong relationship formed with organizations who can facilitate adolescent engagement.



AHN_Toolkit_graphic1_

DEVELOPING AN AHN

Health researchers interested in accessing adolescent feedback through the AHN complete a network access request form. The form requests basic information along with a brief lay summary of the research topic. The lay summary is what is shared with adolescents as they sign up for a session. The Penn State team reviews the form, may offer suggestions to researchers to clarify the lay summary, and then facilitates scheduling the session. Health researchers are given access to training materials and templates to support a successful session.

Additional details on training materials and session logistics are detailed in subsequent sections.

PARTNERS IN THE PENN STATE AHN



Schools

Schools serve as the access point for adolescents. As participating adolescents graduate they are replaced by incoming underclassmen.

School Advisors



A school employee is identified as an advisor, and serves as the main point of contact between the Penn State AHN team and participating adolescents. In the Penn State AHN this is typically a school counselor or enrichment teacher. Advisors recruit adolescents from their high schools to participate in the network. In addition, advisors take turns participating in the AHN sessions. The role of the session advisor is to be an advocate for all adolescents participating in the sessions, and if warranted, escalate concerns about the conversation or information shared by any adolescents (i.e., harm to self or others).

Adolescents



Adolescents participate as stakeholders, NOT as research subjects. The Penn State AHN adolescents participate in an online training to learn more about community-engaged research and their stakeholder role, along with sample scenarios to prepare them for conversations that may occur in the AHN sessions. The online format is practical, as our AHN includes participants from schools statewide. Adolescents who meet participation requirements may receive a letter confirming participation, upon request, to be used for college and career applications.

Health Researchers



Health researchers, or teams conducting adolescent health research, who have an identified need for adolescent feedback are eligible to access the AHN. Health researchers prepare for their session(s) by accessing curated templates, resources and trainings on community-engaged research and lead their session(s) with participating AHN adolescents.

DEVELOPING AN AHN

STAKEHOLDER GUIDANCE WHEN DEVELOPING AN AHN

Community groups and individuals can provide feedback regarding how a program will be received, how information is collected, best practices, cultural competency, communication strategies, implementation recommendations and potential partners.

The Penn State AHN was developed with guidance from a Stakeholder Advisory Board (SAB) comprised of health researchers, adolescents, school representatives and parents. The guidance from the SAB member perspectives was critical when designing the framework for the AHN and selecting the information outlined in this toolkit. It may be helpful to have relevant stakeholders for your AHN weigh in as you develop similar components.



Engaging stakeholders:

- Identify existing groups, spaces, community collaborations or coalitions that are in place within your community to leverage your project and create opportunities for alignment.
- If you don't have existing relationships in place, be mindful of walking into a new space and stating what you need, and be prepared to offer your support first.
- Leverage relationships that you do have to open additional doors and shared spaces.
- Utilize existing communication pathways—fit your project into these. For example, advertising via existing newsletters distributed by research organizations.
- Once you have established trust and rapport and your partners agree to connect you to other stakeholders or participate in your project, ensure that you have consistent and clear communication regarding progress in the project and final results.



Where to find stakeholders:

When thinking of community stakeholders, everyone is a potential partner...

- Local school districts
- Faith leaders and groups
- Grassroots organizations
- Local coalitions
- Corner stores
- Chamber of Commerce
- Parent Groups (PTO)

DEVELOPING AN AHN

PLANNING FOR YOUR AHN

To determine your target adolescent and researcher populations, start by asking the following questions:

WHY

Why should we involve adolescents in the research process?

Stakeholders can enrich your work and share thoughtful insight that may be missed.

WHO

Who has the perspective we need?

Consider who is impacted by your research, both immediately and downstream, and the demographic makeup of your ideal population. It may be helpful to reach out to other groups within your institution who have experience working with the community. For example, a Clinical and Translational Science Institute.

WHERE

Where will we find the ideal population to serve in our network?

Schools and community organizations who engage with adolescents on a daily basis may be a good place to create relationships.

WHEN

When in the research process should adolescents be engaged?

Adolescents can have valuable input on all aspects of the research lifecycle. Consider ways to prepare your network participants to engage at each part of the process. Prepare participating researchers to create context needed for including the adolescent voice, as well.

HOW

How should the network operate?

Consider the format your network will use to connect adolescents and researchers (i.e., virtual, in person), and what resources they may need to be fully engaged. Utilize opportunities to hear from your partners about what works best for them.

WHAT

What is expected of network partners?

Establish a clear purpose and well-defined procedures for participating adolescents and interested health researchers.



Section 3

RECRUITMENT

Schools

Adolescents

Health Researchers

Sample AHN Development and Recruitment Timeline

RECRUITMENT

Establishing an AHN may not always result in an “if you build it, they will come” scenario. Recruitment of adolescents via schools or community organizations and health researchers can be challenging. Guidance is provided below based on experience gained while building the Penn State AHN.



SCHOOLS

Schools are ideal partners for accessing youth. Unfortunately, partnerships with schools can be challenging to navigate due to competing priorities, responsibility to protect students and limits on staffing and time. Previously-established relationships with schools can be helpful to leverage when initiating conversations with potential school partners.

Consider the following when initiating a new partnership or relationship with a school district:

- Unless you have a personal relationship with a superintendent, don't start at the top. Try to open the door with a connection to someone who could benefit directly from your program. A school counselor, health or science teacher, or depending on the size of the district, a data coordinator or research coordinator.
- Be mindful of testing schedules, breaks from school and other pertinent schedule conflicts and how your project could be impacted.
- If you do not have an existing relationship with the school or district, it is highly recommended that you meet with them first to determine what their needs are and how your organization can support them.
- Be mindful of how frequently you are trying to gather student or parent/guardian responses. It may seem like you are not requesting information that would take a significant amount of time, but the school or district could receive requests from other research groups at a higher frequency and schools are sensitive to not overtaxing their students and families.
- By connecting with the district research coordinator, you might be able to build into your project additional questions or opportunities to engage stakeholders that would directly benefit the district.

The Penn State AHN used [two recruitment flyers](#), one for the school advisor and the other for adolescents, plus [an informational letter when contacting schools](#).

RECRUITMENT

Once a school is contacted and interested in the opportunity, clearly communicate the expectations and benefits for all parties. Our team uses a memorandum of understanding ([MOU](#)) that outlines the roles and responsibilities of the schools and the Penn State AHN team. Each MOU is signed by a school representative and the lead on our Penn State AHN team. As part of signing the MOU, the school identifies their school advisor for the AHN, who serves as our primary contact.

As noted previously, if schools are not a realistic option in your area, consider other youth-focused organizations. Most of the strategies detailed will still apply.



ADOLESCENTS

The Penn State AHN relies on school advisors to identify interested adolescents following completion of the MOU. As the Penn State AHN was established, the initial goal was to include 2-3 adolescents from a wide variety of schools. In reality, advisors found 4-5+ adolescents were interested, so we adjusted by recruiting more adolescents from a smaller number of schools. A drawback to school advisor-initiated recruitment is that selected adolescents are often the “superstars” in their schools, or those always willing to engage. However, it is the Penn State AHN team’s intention to leverage the positive experiences of these adolescents to support recruitment of initially more reluctant peers in subsequent years (i.e., snowball recruitment). Alternately, based on your needs, you may choose to cast a broader net with recruitment via your community partner.

Once identified, school advisors submit contact information for their adolescents, who are then email a [form](#) to verify their participation and acquire parent consent for program participation (for those participants <18 years-old). Adolescent and parent forms are provided, including a [clear description](#) of the program requirements (i.e., participate as stakeholders, attending 5-6 sessions/year, complete evaluation forms, etc.).

RECRUITMENT



HEALTH RESEARCHERS

The Penn State AHN gladly accommodates health researchers both within and outside of Penn State. In addition, researchers at all levels from students/trainees to faculty professors are welcome to engage the network.



Consider the following when connecting with health researchers:

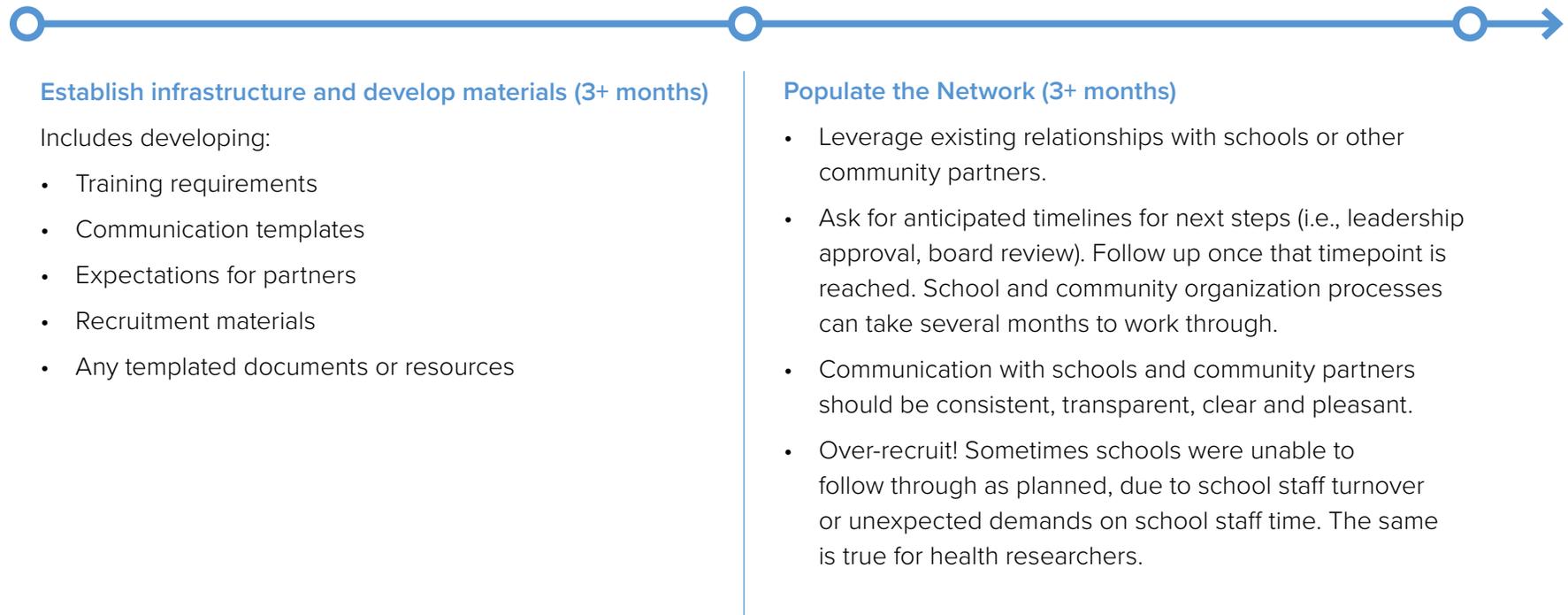
- Start at home. The Penn State AHN is promoted through several Penn State-specific research channels and networks, such as the Clinical and Translational Science Institute. These networks are helpful because the recipients (i.e., clinician researchers, health researchers) already “speak the language” and understand how having youth input could help their research.
- Leverage external connections with colleagues from education and training programs, previous organizations and professional networks. These individuals can be contacted with [a well-crafted email](#) explaining the purpose of the developed AHN.
- Put the value of adolescent stakeholder input in context. Researchers who may not initially understand if the AHN is right for them can benefit from a video clip or conversation about their research where the AHN team can provide a tangible example of how (and why) the adolescent voice could improve research. For example, if a researcher is experiencing difficulty recruiting for a study, the AHN may be able to help create a different, more adolescent-friendly explanation for the study to improve initial interest among the target population.
- Consider partnering with your organization’s marketing team to support marketing and promotion for your network. Whether you are developing an AHN for members of your own institution or with a broader focus, the recruitment strategy for engaging health researchers should outline the benefits of utilizing the AHN and have an easily accessible entry point. Early interactions with interested researchers should clearly communicate the process, capabilities and expectations.

The Penn State AHN utilizes a web-based network access request form to receive inquiries from health researchers. A link to the form is included with the recruitment email. A [30-minute meeting](#) is then scheduled to facilitate interested researchers in identifying how best to utilize the AHN to support their research, establish a date and time for an AHN session and introduce participating researchers to the templates, resources and training available to help them prepare for their session.

RECRUITMENT

SAMPLE AHN DEVELOPMENT AND RECRUITMENT TIMELINE

Allocate 4-6 months to both develop the AHN infrastructure and establish your partnerships.





Section 4

AHN PARTNER PREPARATION

Shared Resource Portal

School Advisor and Adolescent Training

Health Researcher Training

AHN PARTNER PREPARATION

To maximize the interaction between the AHN and health researchers, all participants should feel comfortable and confident in their roles. This can be achieved by proper training for those involved. The Penn State AHN provides partners with a central, web-based location to access all AHN training materials and resources, along with clear timelines for each partner's responsibilities.

SHARED RESOURCE PORTAL

The web-based shared resource portal provides easy access to all resources any AHN partners need to participate or engage with the AHN. We utilize OneDrive, but similar platforms (i.e., Google, Dropbox) would serve a similar function.

The shared resource portal contains two main sections:



Files for ADOLESCENTS & SCHOOL ADVISORS

This section includes training resources for school advisors and adolescents engaging in the AHN. Example materials include recruitment flyers, the parent information letter, training materials and video tutorials. Adolescents and advisors can also access links to the platform used to register for AHN sessions.



Files for HEALTH RESEARCHERS

This section contains all session preparation templates and training materials. Example materials include network engagement strategies, sample session agendas, checklists, training materials and video tutorials.

AHN PARTNER PREPARATION

SCHOOL ADVISOR AND ADOLESCENT TRAINING

To prepare network adolescents to feel confident in attending sessions and sharing their opinions as research stakeholders, the project team uses the following training process:

1. [Pre-training Survey](#)
Purpose: Determine adolescents’ baseline knowledge of stakeholder-engaged research
2. [Review Network Logistic Presentation](#)
Purpose: Provide an overview of the AHN goals, expectations and session logistics
3. [View Mock AHN Session Video](#)
Purpose: A brief, 2-minute video demonstrating a session
4. [FYREWorks Training](#)
Purpose: A self-guided (~1 hour) web-based training to establish knowledge about community-engaged research. This training resource is freely accessible and was previously developed by a PCORI™-funded program.
5. [Post-training Survey](#)
Purpose: Determine knowledge gained from FYREWorks training and confidence to participate as a stakeholder
6. **Debrief**
Purpose: Meeting between advisors and their participating adolescents to ensure understanding of the training and AHN participation expectations. A Penn State AHN project team member attends upon request.

School advisors are also encouraged to complete the adult track of the FYREWorks training materials to best support their participating adolescents. All participants are requested to complete the training obligations within one month of their participation verification (reference table at right).

ADOLESCENT TRAINING TIMELINE				
Tasks	Week One	Week Two	Week Three	Week Four
<i>Adolescent identified and contacted</i>	✓			
<i>Pre-training survey</i>		✓		
<i>Network logistic presentation</i>			✓	
<i>Mock video</i>			✓	
<i>FYREworks training</i>			✓	
<i>Post-training survey</i>				✓
<i>Debrief</i>				✓

AHN PARTNER PREPARATION

HEALTH RESEARCHER TRAINING

Health researchers who engage with the AHN have a varying degree of background knowledge and experience in community-engaged research. To prepare health researchers for their role in planning for and hosting an AHN session, we curated a series of optional resources and training materials.

1. [Health Researcher Session Prep Checklist](#)
Purpose: Outline session preparation timelines and expectations
2. [Session Agenda Template](#)
Purpose: Supports health researcher planning for one-hour session
3. [Successful Engagement Strategies Guide](#)
Purpose: Provides strategies for planning and executing AHN sessions to maximize adolescent discussion and feedback
4. [Mock AHN session video](#)
Purpose: A brief, 2-minute video demonstrating a session
5. [PCORI Research Fundamentals training](#)
Purpose: Overview of stakeholder-engaged research for unfamiliar health researchers



Section 5

AHN SESSION LOGISTICS

Pre-Session Activities

In-Session Activities

Post-Session Activities

AHN SESSION LOGISTICS

PRE-SESSION ACTIVITIES

Health researchers

Pre-session activities are initiated with the submission of an AHN network access request form. Health researchers provide a lay summary; a 200-word paragraph highlighting why the researcher requests adolescent feedback. The Penn State AHN team reviews researcher summaries to ensure appropriate wording for an adolescent audience. Brief, clear summaries are most successful in soliciting adolescent participation. Session registration and lay summary details are posted to the shared resource portal approximately 4 to 6-weeks prior to a session. Health researchers complete trainings (as needed) and prepare for their session using the templates and resources in the shared resource portal. Health researchers share any pre-reading materials (<30 minutes for adolescents to review) for participating adolescents at least 2 weeks before the session. The Penn State AHN team utilizes [checklists](#) to track partner responsibilities for each session and ensure clear expectations for all AHN partners.

CLICK TO VIEW

[Email to Health Researcher Regarding Network Access Request Form Submitted](#)

[Email to Health Researcher Regarding Session Preparation Steps](#)

[Email to Health Researcher 1 Week Prior to Session](#)

Adolescents and advisors

The Penn State AHN team works with each health researcher to establish a session date and time, acquire the lay session summary and open adolescent and advisor session registration. All sessions are listed in the shared resource portal with a link to a session-specific Signup Genius registration form. Adolescents and advisors are emailed when new sessions are listed. In some cases, health researchers solicit registration from specific groups of adolescents relevant to the work, for example, student athletes, or those of a certain gender.

The Penn State AHN team manages registration and communication with all adolescents and advisors, including reminder emails and text message reminders enabled through the Signup Genius platform. Pre-reading materials (if available) are provided approximately one week prior to the session.

4-6 weeks before session	3 weeks before session	2 weeks before session	1 week before session	Week of session
1) Establish session date/time 2) Health researcher provides lay summary of project via the network access request form	1) AHN team opens adolescent/advisor registration 2) Health researcher prepares for session	Health researcher provides pre-reading materials	AHN team distributes pre-reading materials to registrants	AHN team sends reminders to registrants

AHN SESSION LOGISTICS

IN-SESSION ACTIVITIES

Each session generally includes a Penn State AHN team facilitator, the primary health researcher plus one additional member of their team, one school advisor and 6-10 adolescents. The Penn State AHN facilitator initiates all web-based sessions ([see guide](#)), facilitates introductions and shares housekeeping items (i.e., cameras, chat). The remainder of the session time is facilitated by the health researcher, who leads the discussion using their completed session agenda template. The final 10 minutes of each session are reserved for the health researcher to share their professional journey and allow adolescents to ask questions about their profession and research experience. After the session, a OneDrive folder is created by the Penn State AHN project team facilitator to temporarily store the session audio and chat box files.

POST-SESSION ACTIVITIES

Following each session, the Penn State AHN team facilitator distributes post-session surveys to the participating advisor and adolescents. Within 48 hours of the session, the AHN team emails the participating researcher with a private link to an audio-only recording of the session and a post-session survey. Sixty days after the session, the participating researcher is emailed to confirm retrieval of the audio-only recording and to request completion of a 60-day post-session follow-up survey. Additional details about evaluation are included in Section 6.

CLICK TO VIEW

[Follow-up Email for Adolescents Who Participated in a Session with a Health Researcher](#)

[Follow-up Email for Advisors Who Participated in a Session with a Health Researcher](#)

[Follow-up Email for Health Researchers Who Hosted a Session](#)

[60-day Follow-up Email for Health Researchers Who Hosted a Session](#)



Section 6

DATA MANAGEMENT AND EVALUATION

Data Management

Evaluation Tools

DATA MANAGEMENT AND EVALUATION

The data tracked for an AHN is largely dependent on what information is needed for reporting to AHN program supporters/funders. At minimum, your network should collect contact information and demographic information about school/adolescent partners and interested health researchers. In addition, data that describes the experiences of each of the network partners is important to support program improvement.

DATA MANAGEMENT

The Penn State AHN utilizes(1) [REDCap](#) for data tracking. The Penn State AHN is evaluated using the RE-AIM model, which involves the assessment of five aims (reach, efficacy, adoption, implementation, and maintenance) at multiple levels (individual, organization, community) (2). In addition, Kirkpatrick’s Four Levels of Training Evaluation are used to assess the stakeholder-engaged research training provided to adolescents and researchers (3-5).

project-redcap.org

The Penn State Clinical and Translational Science Institute, Pennsylvania State University CTSA, NIH/NCATS Grant Number UL1 TR002014

[REDCap data dictionary files available upon request.](#)

EVALUATION TOOLS

	Pre-training survey (CLICK BOXES TO VIEW)	Post-training survey (CLICK BOXES TO VIEW)	Post-session survey (CLICK BOXES TO VIEW)	60-day post-session survey (CLICK BOXES TO VIEW)
<i>Adolescents</i>	✓	✓	✓	
<i>Advisors</i>			✓	
<i>Health Researchers</i>			✓	✓



Section 7

LESSONS LEARNED AND OPPORTUNITIES

LESSONS LEARNED AND OPPORTUNITIES

Each AHN will be unique and tailored to the target population of stakeholders and researchers it is designed for. However, developing and managing a successful AHN will not be without challenges and opportunities. Below is a list of additional lessons learned when building the Penn State AHN.



Identifying session days/times

Identifying session days and times while considering a variety of adolescent, school advisor and health researcher schedules presented challenges. We surveyed AHN advisors and adolescents to understand their general availability (i.e., mornings, evenings, weekends). The team then identified the top 3-4 time slots and days to host sessions. These days/timeframes were shared with researchers to guide session scheduling. This information should be collected several times per year, as availability may be impacted by school schedules and seasonal involvement in extracurricular activities.



Student compensation

Monetary compensation can be a great incentive for adolescents, but was not available through our AHN due to impacts on sustainability. Partnering adolescents suggested a [letter confirming participation](#) for college and career applications and verification of volunteer hours.



Session “no shows”

There will inevitably be times when adolescents have to cancel their session registration with short notice. We generally counted on 1-2 “no shows” per session, and over-recruited to offset this challenge. Reminder emails and text messages are helpful strategies to improve attendance.

NOTE: Text messages are helpful reminders to students.

LESSONS LEARNED AND OPPORTUNITIES



Managing grievances

It is vital to have a clearly outlined process for grievances to be raised by any partner and for the process to report the grievance to be tailored according to the nature of the grievance. The Penn State AHN utilizes three processes:

Adolescent/Parent Grievances with Health Researcher Sessions or Processes:

Grievances brought forth by adolescents or their parents are directed first to the school advisor. If warranted, the school advisor completes a [grievance report](#) for the project team's review. If requested, a meeting is scheduled to discuss.

Health Researcher Grievances with Sessions or Processes:

The health researcher completes the grievance report for the project team's review. If requested, a meeting is scheduled to discuss.

Grievances with Penn State AHN Team:

The Penn State Clinical and Translational Science Institute (CTSI), Community Engagement Core (CEC) serves as the third-party contact for any grievances with the Penn State AHN team. This includes any grievances brought forth by adolescents, parents, school advisors or health researchers engaging with the project. Grievances are sent directly to the CTSI CEC for appropriate processing.



Appendix

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REFERENCES

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