



PRIORITIZING RESEARCH APPROACHES TO MEANINGFULLY IMPROVE ADOLESCENT HEALTH

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Prioritizing Research Approaches to Meaningfully Improve Adolescent Health

Adolescence—broadly defined as the period between ages 10-24—is a time of significant biological, psychological, and social change. During this stage, young people grow into their adult bodies and brains while transitioning into adult roles in society. Research from the fields of medicine, public health, and social sciences has played an important role in helping those who care about and support young people understand this time period. In particular, research has increased people's awareness of the brain development that occurs during this time and how efforts to support health overall can lead to a triple dividend of benefits for adolescents' health today, their health in adulthood, and the health of future generations.¹⁻³ Research also has led to advancements in prevention and treatment efforts, including the development of the cancer preventing HPV vaccine and the identification of programs that effectively address health issues.⁴

The ability of research and data to deepen understanding and inform action is a key reason the Office of Population Affairs (OPA) named supporting, translating, and disseminating research as one of eight goals in Take Action for Adolescents[™], OPA's national call to action to promote adolescent health and well-being (see call out box).⁵ Additionally, as new knowledge emerges and societal contexts evolve, answered questions often give rise to new ones. For example, data on the health status of adolescents shared by the Centers for Disease Control and Prevention and the Surgeon General highlight needs in youth mental health, including the impact of social media on mental health; firearm violence; and other areas of health.⁶⁻⁹

Take Action for Adolescents™

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Developed in 2023 by the Office of Population Affairs (OPA) outlines eight inter-related goals that change-makers can work toward to improve the health of adolescents. One of the eight goals of Take Action for Adolescents is to support, translate, and disseminate research.

This document is OPA's latest effort in supporting adolescent health research efforts at the national level. It was originally conceptualized as a research agenda that could provide direction for those studying adolescents and their health. Following a similar process to the development of Take Action for Adolescents, OPA reviewed existing literature and frameworks and consulted with a variety of experts, including adolescent health and medicine researchers, youth-serving professionals, researchers whose work extends beyond health, and adolescents themselves (see Appendix A: Approach Overview and Appendix B: Approach for *Prioritizing Research Approaches to Meaningfully Improve Adolescent Health*). These efforts highlighted that the topics traditionally thought of as constituting adolescent health (e.g., mental health, nutrition, physical activity, sexual and reproductive health, and substance use) remain salient. Technology, the complex interplay between social service systems, environmental challenges, and identity were also areas of interest and need across researchers, practitioners, and adolescents.

However, OPA found through its conversations with various stakeholders that even more salient than any single topic, set of topics, or questions, those engaged in adolescent health were invested in talking about the research process itself.

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Framing the research priorities: Refining the process for building and sharing evidence

The benefit of research is in its ability to help people better understand the world around them by collecting and analyzing evidence. Evidence, in its broadest sense, is any type of information or data that supports or refutes a proposition, theory, or hypothesis. It has played a crucial role in science and has been used to establish facts, draw conclusions, recommend policies, and inform programming aimed at improving health and well-being, including that of young people.

What counts as evidence varies by discipline and context and has evolved over time, as new research methods and new frameworks for interpreting concepts have developed. This has been true for the field of adolescent health. Evolutions in adolescent health research have included the shift toward seeing quantitative and qualitative approaches as complementary rather than conflicting methodologies, the inclusion of strengths and assets in addition to risks, and looking across levels of influence in a young person's life (i.e., the individual, family, community, etc.). Such paradigm shifts have consistently resulted in a broader, more nuanced understanding of adolescent health, and have led to more rigorous investigation.

Adolescent health research as a field is increasingly recognizing the limitations of traditionally used methodologies generally bucketed as quantitative, qualitative, and mixed methods. Some of this shift is driven by the diversity of adolescents' experiences and perspectives, which requires similarly diverse and adaptable tools to accurately study their well-being. This shift also reflects how the field has begun and needs to continue addressing the issues where knowledge, expertise, and perspectives of some groups was or is discounted while those of a more traditional expert group are uplifted. In particular, credibility is gatekept from groups like children, Indigenous peoples, those experiencing economic deprivation and poverty, those with disabilities, and many others.¹⁰⁻¹⁴ As researchers work to expand the methodologies used and the people engaged in the research process, attention is also shifting to how to better communicate research results to build trust and maintain engagement.

OPA's conversations with researchers, practitioners, and young people mirrored these ongoing shifts in the field. Participants highlighted challenges such as perceived mismatches between what gets explored in research versus the information communities need; siloed research publications that do not fully show how systems and health outcomes interact; and a lack of clear, digestible findings that can guide action. Even as they discussed these challenges, participants shared potential solutions such as time and effort to have more community participation and strengthening dissemination efforts. It is these conversations in addition to the efforts already underway that have led to the guiding principles of this document. Ultimately,

researchers, youth, and practitioners want research that is more collaborative, embraces complexity, and is transparent.

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Figure 1: Priorities for shaping adolescent health research

This document is meant to serve as a toolkit, providing a range of promising approaches to the research process that researchers, funders, and others might consider as they continue to build the field of adolescent health. Research has real life constraints; it will not always be possible for researchers to adopt all the strategies discussed below. Researchers' expertise will influence when and how they engage with these priorities, and which strategies make the most sense for their work.

Defining the priorities

This section defines the three overarching research priorities that emerged in conversations with experts. Within each priority, its value to the quality, acceptability, and reach of the research is discussed. Following the definitions, specific strategies—with supporting resources—that researchers have used to implement the priorities successfully into their research processes and teams are detailed. This list of strategies is not exhaustive; rather it provides some concrete examples researchers can draw upon as they carry out their own work.



Priority 1: Ensure the research process for adolescent health is **collaborative**.

In many research settings, the individuals who determine and fund research topics, who conceptualize and conduct a research study, and who interpret and disseminate the research findings do not reflect the identities and voices of the communities being studied.¹⁵ With this approach, researchers and evaluators are often positioned as detached observers who maintain a distance from teens and the communities they study. This detachment means researchers frequently overlook invaluable insights from people with deep lived experience who, despite their expertise, lack decision-making power within research institutions and processes.

Priority 1 emphasizes making research more collaborative; that is, making sure that people invested in the outcomes of the research are involved in the decision-making around the research process itself.

In addition to researchers, this includes adolescents themselves, along with parents and caregivers, practitioners, and other community members who know and care about the wellbeing of adolescents.¹⁶ Collaborative research (sometimes called participatory research) emphasizes co-creation and mutual learning, and also encompasses the need to engage people with diverse social, cultural, economic, and political perspectives—across characteristics such as race and ethnicity, gender, immigration status, class, religion, geography, age, or political beliefs. Research teams should consider whose perspectives will inform and strengthen the research, and not shy away from including perspectives that might be challenging.¹⁷

When executed with intention and quality, collaborative research can help ensure that the most relevant research questions about adolescent health are being studied and that the research carried out is internally and externally valid.^{18,19} In other words, collaborations can produce research that accurately measures what it intends to measure (internally valid) and that is generalizable to the greater study population and/or other populations (externally valid).^{20,21}





In fact, recognizing that this type of collaboration is important for high-quality research, federal regulations require that community members sit on institutional review boards (IRBs), which oversee and monitor human subjects research projects.²² Collaborative research teams can also help expand who knows about the research, which can make it more actionable.²³

Importantly, however, there continues to be a general distrust in public health research—

both in how it is carried out and in how the findings will be used. This is particularly prevalent in more marginalized communities who, as has been well documented, have experienced significant breaches of trust and direct and indirect harms from clinical and public health research.²⁴⁻²⁶ Despite improvements in ethical guidelines around carrying out research in ways that minimize harms, these harms do still happen.²⁷ Engaging in collaborative research—and sharing decision-making around the research process with the communities being studied—is one way to help build trust in the research process and in research findings.^{28,29}

Building collaborative research teams and research processes requires time and intentional effort, especially since many researchers lack experience or training in this area. It can be challenging - but far from impossible - to meaningfully engage adolescents.³⁰ They face unique barriers to participating as decision-makers, including logistical hurdles, age-related biases, and researchers' limited capacity to share decision-making responsibilities effectively.³¹ Importantly, collaborative research only works if researchers also critically examine and address their own positions and the inherent power dynamics that may influence the research process and outcomes. However, by actively engaging with youth, their parents and caregivers, and community members, research can produce more accurate, socially relevant, and meaningful findings that genuinely reflect the lived experiences of diverse adolescents.

Case Study

In the <u>A Crecer (To Grow) study</u>, youth advisors provided input on recruitment materials, allowing the study to reach its ambitious recruitment targets. Collaboration from youth and trusted community-based organizations also contributed to the study having a high level of support among a community (undocumented families) that may otherwise be wary of participation.

Strategies that support this priority

Many of the strategies in this section focus on engagement of adolescents specifically because it was an identified area of needed capacity building. Information about collaborating with

adults across sectors and roles overlaps with and is addressed through the strategies and resources in Priority 2.

Increase researchers' capacity to engage adolescents at different stages of the research process.

Provide formal training to adult researchers.

The lack of comprehensive guidance on youth-engaged research, the need to train researchers on youth-engaged approaches, and inadequate funding for this training are three barriers to conducting youth-engaged research. Even among a group of researchers with an expressed interest in conducting youth-engaged research, many reported <u>uncertainty</u> about how to do so. Therefore, prioritizing the time and financial resources for training is essential from the beginning. Build time and resources into project timelines and budgets to provide relevant training opportunities so that academic researchers can learn how to work with adolescent co-researchers. The Knowledge Works and Wested YPAR (Youth-led Participatory Action Research) guidebook includes a three-session educator fellow training and the Youth-Nex project has developed a YPAR readiness self-assessment tool.

Many academic researchers also need support learning how to work effectively with community members, parents or caregivers, and practitioners. Boursaw et. al. write, "As <u>community and academic partners</u> develop shared research interests and goals, these individuals and groups must learn to traverse the dynamics of power relationships, community mistrust due to research abuse by academic institutions, and often-changing priorities to achieve shared project outcomes." <u>The Community Health</u> <u>Equity & Engagement in Research (CHEER) Toolkit</u> offers

Youth-led Participatory Action

Research (YPAR): Youth-led Participatory Action Research (YPAR): YPAR is a particular type of youth-led research that recognizes youth as experts and focuses on identifying solutions to problems and disseminating the findings to key decisionmakers in order to prompt action. Here are several welldeveloped resources to promote YPAR from universities around the country that could be useful:

- <u>University of California</u> <u>Berkeley</u>
- <u>University of California</u> <u>Davis</u>
- <u>Colorado School of</u>
 <u>Public Health</u>
- University of Virginia
- <u>Knowledge Works and</u>
 <u>Wested</u>
- <u>Youth Participatory</u> <u>Research: A Review of</u> <u>Reviews and Practice</u> <u>Guidance</u>

practical guidance for <u>communicating honestly and effectively</u> in a bi-direction manner and <u>building nimbleness into project timelines</u> is essential.

Provide training to adolescent researchers.

Build time and resources into project timelines and budgets to provide relevant training opportunities for adolescent researchers to practice skills. For example, youth can lead analysis groups where they work with qualitative data to interpret key learnings, drawing on their own lived experiences to refine and reframe. It is important for adult researchers to ensure that adolescent researchers have had adequate scaffolding and opportunities to practice research skills prior to engaging in youth-led analysis. Researchers can draw on existing resources to do this. For instance, Knowledge Works and Wested created a comprehensive <u>YPAR guidebook</u> for high school students. Lesson 21 of this resource provides guidance on how to build data analysis skills among adolescents, who can also lead reflections on data trends. Encouraging young people to connect quantitative data trends to driving factors based on their lived experiences. Lesson 5 in the guidebook outlines an activity to support adolescents and researchers in discussing how their identities can help them bring unique insights to the research and Lesson 14 focuses on youth as leaders and resources. These conversations are especially critical when the research focuses on marginalized communities. The guides and toolkits in the text box above include activities that can be adapted by research teams to ensure adolescent researchers have opportunities to acquire and practice research skills prior to applying those skills to an adolescent health research project.

Take steps to recruit a representative group of youth and plan for potential transitions in and out of the group.

Consider over-recruiting adolescent researchers, especially if the project will occur over several years, to account for possible attrition as young people transition to other work or educational opportunities. Include youth who represent the study population of interest, including youth who do not have formal leadership roles or prior experience with research. This <u>YPAR guide</u> outlines a five-step process for conducting youth-engaged research that includes worksheets, and pages 19 and 20 focus on how to recruit adolescent researchers.

Incorporate researcher-led consultations.

Researchers work with young people to present and refine existing analysis to ensure framing aligns with young people's perspectives and experiences. In addition to the resources highlighted in the Youth-led analysis groups section above, <u>Lesson 6</u> in the Knowledge Works and Wested YPAR guidebook provides guidance on youth-adult power sharing which can be helpful framing for research-led consultation sessions.

Ensure the project is adolescent-friendly from start to finish.

Broadly speaking, to be adolescent friendly means <u>reducing barriers</u> to participation that adolescents might face. Engage adolescents as early as possible to optimize their contributions to the project. Include a position on the research team who serves as a dedicated facilitator of adolescent engagement; this person can serve as bridge between academic and adolescent researchers and can advocate for processes that align with adolescent assets and needs. Build in flexibility in your timeline and budget to accommodate adolescent researchers' feedback. This video from the Hub for Justice-Centered Youth Engagement at the Colorado School of Public Health has <u>strategies for virtual meetings</u>; many of the strategies are applicable to inperson meetings as well. Other ways to be adolescent-friendly have been <u>described</u> by experienced researchers and include the following:



- Structure meetings to be adolescent-friendly and seek ongoing feedback. Create synchronous and asynchronous opportunities for youth to provide feedback in order to accommodate their often-busy schedules. Ensure that meetings are structured around the needs of adolescent researchers when feasible rather than expecting them to adapt to adult-centric processes. These can include logistical considerations, such as scheduling around school and related commitments. It can also involve considering youth's experience and comfort. While not talking down to youth, also do not assume they have existing understanding of research methods including operations, terminology, and concepts. It is important to intentionally make space for youth to gather and share their thoughts during discussions as some adolescents may, at first, be intimidated by speaking in a group with adult researchers. Adult researchers should also solicit feedback from the youth they are in partnership with. Schedule pre- and post-meeting sessions with adolescent researchers to ensure they understand their role in the meeting and to get feedback on how the meeting went once it is over. Youth-Nex has developed an "exit ticket" that can be used to obtain feedback from adolescent researchers.
- Establish adolescent-friendly, inclusive team norms and expectations. Be clear with adolescent researchers about the objectives of the project and its expected impact. Establish clear roles and expectations, both for the adolescent researchers and the adult researchers. The <u>YPAR Hub</u> at UC Berkeley has resources that can help establish a youthfriendly culture including activities focused on team building, youth-adult power sharing, and understanding oppression. The <u>High School YPAR Research Course</u> has lessons on social identities and youth-adult power sharing. Addressing identity is particularly important for studies that focus on marginalized communities.
- Compensate adolescent researchers for their time and expertise. Remember, adolescent researchers are not study participants, they are research team members and should be compensated accordingly. Consider additional forms of recognition in addition to monetary compensation that are relevant for adolescents such as community service hours, course credits, certificates, and letters of recommendation. This compensation guide from the Children and Youth with Special Health Care Needs National Research Network includes guidance to inform budgeting for adolescent engagement in research.

Ensure research protocols support recruitment of research participants that align with your research questions and intended study population.

Consult with adolescents to identify barriers to participation and potential solutions.

Adolescents face some similar barriers to adults when it comes to participation in research, such as study materials that are difficult to understand, unreliable transportation, or limited access to internet. However, <u>adolescents may experience additional barriers</u> including the need to juggle school and extra-curricular activities with study participation or navigating the requirements for <u>parental consent</u>. Parental consent can be particularly challenging for studies that focus on <u>marginalized communities</u> or sensitive topics, such as behaviors that may be perceived as risky. Researchers conducting such studies should consider consulting with



adolescents and/or trusted community organizations to identify and address barriers to participation.

Identify effective digital recruitment strategies for intended study populations.

In a study of <u>adolescent perceptions of health research</u>, researchers found that adolescents preferred recruitment via social media with messages tailored to their motivations. Studies also suggest that social media recruitment may be particularly effective for recruiting adolescents from <u>sexual and gender minority communities</u>. However, because social media recruitment may <u>result in different samples</u> compared to in-person strategies, researchers should consider consulting with adolescents to identify digital strategies aligned with the preferences of the intended study population to help researchers develop tailored approaches.

Provide meaningful incentives for adolescent participation in research.

A recent review of the use of incentives in child and adolescent research found that the majority of studies conclude that <u>incentives improve recruitment and retention</u>. However, there are some unique ethical considerations. For example, there may be concerns about caregivers pressuring adolescents to participate in order to obtain the incentive. While research has found monetary incentives to be more effective than alternative rewards, researchers may consider consulting with adolescents who meet study eligibility criteria to inform their decision about the use of incentives.

Implement practices that cultivate relationships between adolescent study participants and the research team.

Ensuring that adolescents experience <u>study staff as respectful and genuine</u> can help to build the sort of trust that is necessary for adolescents to join a study, especially when it comes to longitudinal studies. Ensuring that any study staff who will engage with adolescents have the knowledge and skills to build rapport with adolescents and their families is critical. With respect to retention, it is helpful when communication between data collection sessions is consistent, genuine, and respectful.

Prioritize coproduction of research into the study whenever possible.

Engaging adolescents as co-creators of research, rather than merely as subjects, has numerous benefits when done well. This is especially true for studies that focus on adolescents with marginalized identities or that address sensitive topics. The <u>Research Prioritization by Affected</u> <u>Communities (RPAC)</u> is a strategy for setting research priorities over two sessions that considers positionality. RPAC involves a literature review that is driven by discussions during the first session that informs ranking and prioritizing of research questions in the second session. YPAR is another youth-specific method to engage adolescents as co-researchers.



Priority 2: Ensure the research process for adolescent health embraces **complexity**.

Adolescent health is an expansive concept which encompasses a wide range of topical domains. Indeed, the World Health Organization's definition of health encompasses "physical, mental and social well-being and not merely the absence of disease or infirmity."³² The health of adolescents is also dynamic, reflecting the remarkable physical, cognitive, and social development that adolescents experience at this stage of life.³³ That said, the health of adolescents does not occur in isolation—rather, it is strongly linked to health at earlier stages in the life course and, in turn, helps set the stage for health and wellbeing into adulthood.

The factors shaping adolescent health are also expansive.³⁴ Any one health outcome may be impacted by, for example, an adolescent's biological makeup and other existing health conditions; by their health-related behaviors; and by the many systems they and their families or caregivers must navigate to meet basic needs, such as health care, education, housing, or workforce systems. Additionally, broader social, economic, environmental, political, and cultural contexts play a critical role in shaping the environments in which adolescents live and grow.

Importantly, there is now substantial evidence that adolescent health results from an interaction of these factors across the life course, extending back to conception and pre-conception.^{35,36} The science of epigenetics, for example, has confirmed that even gene expression can vary depending on contextual conditions.³⁷ While a focus on the interplay of individual and contextual characteristics is broadly warranted, such approaches are especially critical when seeking to answer questions related to health and how health outcomes vary for different demographic groups.

Priority 2 focuses on encouraging researchers to think expansively about how to carry out research in a way that considers the complex, interconnected, and dynamic realities of adolescent health and well-being.



Many of the experts we spoke with raised concerns that much of the research in adolescent health is not designed to acknowledge or account for these types of complexity; as a result, there are critical gaps in our knowledge, including in more fully understanding what types of health promotion interventions work for what populations and in which specific contexts.³⁸ They emphasized how addressing the complexity in health requires, at least to some degree, a re-evaluation of the data and scientific methods used to generate evidence on health and health promotion.

Below, we present a set of strategies that research teams might use as they work to embrace complexity in the building of evidence in adolescent health research. This means being open to new conceptual frameworks, new data sources, and new (or new to you) research methods and technology. When done well, embracing complexity is likely to lead to the development of more nuanced research questions, more valid studies, and greater clarity within studies about their contributions as well as their limitations.

Strategies that support this priority

Use frameworks and models that acknowledge the complexity of adolescence.

Below are some frameworks and models that are commonly used—sometimes in isolation but often in combination—to inform adolescent health research:

- The <u>Life Course Health Development</u> framework emphasizes that health is a consequence of multiple influences over time and that health trajectories are the result of cumulative risk and protective factors.
- Ecological models such as the <u>social-ecological model</u> and the <u>biopsychosocial model</u> highlight the many different levels of influence on health. While not unique to adolescence, this model has been applied by many researchers to emphasize individual, interpersonal, organizational, community, and <u>societal influences</u> on adolescent health.
- Intersectionality is a framework that describes how discrimination and oppression that adolescents with multiple marginalized identities experience can create <u>overlapping</u> <u>systems of disadvantage</u> which is critical for addressing health inequities. Researchers must be thoughtful in applying intersectionality to <u>avoid common challenges</u> that can undermine its value.
- <u>Social Determinants of Health</u> is a framework that focuses on structural factors that influence adolescent health, including systems (e.g., education and healthcare) as well as societal factors such as income inequality and discrimination.
- Asset-based frameworks such as <u>Developmental Assets</u> and <u>Positive Youth</u> <u>Development</u> emphasize a strengths-based approach to understanding adolescent health and well-being.
- Implementation science frameworks such as the <u>Consolidated Framework for</u> Implementation Research (CFIR) and behavior change models such as <u>social cognitive</u> theory and <u>self-determination theory</u> can inform how studies that examine the impact of interventions collect and analyze data to assess mechanisms of change.

Select methods and measures that are appropriate for both the research question and the study population.

To produce research findings that can be applied to real-world challenges, researchers should identify research methods that account for the complex and interconnected influences of individual, interpersonal, system, and societal factors. Research teams should be intentional in determining whose perspectives influence conceptualization of the study, which measures to use, and how to analyze data. Below are some strategies to consider.

 Prioritize research methods that take a strengths-based approach and bring different cultural perspectives of data. Research teams



should think critically about <u>what counts as evidence</u> and consider methods that acknowledge expertise and wisdom within marginalized communities. This should include <u>examining all aspects</u> of the study to assess whether study structures and protocols adequately address issues of power and discrimination. This UN <u>resource</u> <u>guide and toolkit</u> for practitioners, policy makers, experts, and advocates outlines eight intersectionality enablers and includes tools and examples that research teams can use to guide their efforts.

- Take a complex systems perspective. Methods and <u>frameworks</u> that help researchers apply <u>complex systems perspectives</u> can strengthen the potential for studies to support population-level health improvement by moving from an individual-focused approach to one that recognizes the interconnections between multiple levels of influence. Collaboration is also key when using a systems approach, as engaging <u>key stakeholders</u> better informs an understanding of how multiple systems might interact to influence adolescent health interventions.
- Account for the <u>social determinants of health</u> (SDOH), especially the influence of discrimination. Health researchers are increasingly applying <u>social determinants of health</u> research methods that account for the ways in which societal organization and systems (e.g., education, healthcare, etc.) influence individual health. The <u>PhenX SDOH</u> <u>Collection</u> includes data protocols to measure individual and structural factors that shape behaviors and health outcomes. Researchers should thoughtfully consider the measure they use to assess discrimination. For example, including <u>measures of societal racism</u> as opposed to individual experiences with racism can result in different findings. See the strategy on using frameworks for more on intersectionality.
- Develop and implement innovative methods. Innovation may include the application of existing methods to new settings or the development of new methods. For example, <u>participatory approaches</u> and <u>qualitative methods</u> are not new, but may be innovative in areas of research where their application is not widespread. <u>Harmonization</u> of multiple



existing adolescent health indicators to improve the ability of research to facilitate robust comparisons across time and locations is another example of innovation from existing tools. <u>Artificial intelligence</u> (AI) and other technology advancements—and their <u>ethical use</u>—warrant attention both as innovative research methods and as emerging <u>research topics</u>.

Work across disciplines and sectors.

To more fully address or acknowledge the complexity inherent in adolescent health, researchers will need to incorporate knowledge and expertise from diverse disciplines and establish partnerships across multiple sectors. Different disciplines bring varied understandings about adolescent health that can strengthen study design and enhance interpretations, while engaging stakeholders across multiple sectors can facilitate actionable recommendations. Below are strategies for research teams to consider:

- Build the capacity of team members to engage in interdisciplinary research. Effective interdisciplinary research requires more than a diverse range of expertise; it also requires skills and competencies related to research methods, communication, and interaction with others. Team functioning should be tended to across all stages of the study. This field guide for Team Science from the National Institutes of Health—a new version of which is currently under development—provides practical strategies for interdisciplinary research teams. The Maternal and Child Health (MCH) Navigator considers interdisciplinary and interprofessional team-building as a critical skill for public health leaders; see Competency 10 for a host of resources to build foundational and advanced skills on this topic.
- Establish cross-sector research partnerships. Adolescent health is influenced by the many systems with which they and their families interact, including education, healthcare, housing, etc. Establishing research partnerships with public agencies and private organizations in these sectors (e.g., schools, health care providers, etc.) can build capacity for all involved and address complex questions about adolescent health at a large scale. Research teams should consider strategies to assess the <u>outcomes and</u> <u>impacts</u> of research partnerships. Participatory research is another form of partnership; see the strategies in Priority One for more information.





Priority 3: Ensure the research process for adolescent health is **transparent**.

A lack of transparency in the research process can negatively impact the quality and value of science.³⁹ Research transparency can be conceptualized in many ways, but generally involves practices such as clear disclosure of underlying theories and hypotheses; thorough description of research methods, measures, and analyses; reporting of all results, regardless of conformance with hypotheses; and declaration of real, perceived, or potential conflicts of interest.⁴⁰⁻⁴²

While researchers receive training on - and most strive to uphold - rigorous research methods and reducing threats to study validity, these are not the only issues affecting science today. Over-reliance on certain demographics in adolescent health research has often resulted in a focus on white, educated, urban youth, decreasing the generalizability of findings, and neglecting the unique health needs and challenges faced by adolescents from more marginalized backgrounds and environments.⁴³ Researchers' tendencies to favor evidence that confirms their preconceptions can lead to biased data interpretation and reporting. Further, like other sciences, public health is not free from unscientific practices such as p-hacking (resulting in false positive results), cherry picking of results, and data falsification.⁴⁴⁻⁴⁶ To address these issues and strengthen the field, researchers should prioritize transparency in all aspects of their work.

A lack of transparency in the research process—and in the communication of research findings—also helps to drive mistrust in science among the public. Although most people report relatively high levels of confidence in scientists to act in the public's best interest, mistrust in science and scientists remains quite high.⁴⁷ According to the Pew Research Center, in 2024, almost one-quarter (23%) of surveyed Americans reported little or no trust in scientists – far greater than in the pre-pandemic period (13%).⁴⁷ Trust in doctors has also declined since 2020.⁴⁸ While the COVID-19 pandemic exacerbated mistrust in science, mistrust existed long before—

particularly in communities that feel they do not have a say or participate in research such as communities of color or rural communities.⁴⁹

Today, the downsides of mistrust in science are greater than ever, as those skeptical of traditional scientific research now have a wider selection of alternatives. Greatly increased access overall to information at all points in the spectrum from factual, to unproven, to disproven has led to an explosion in lay "research", often resulting in unscientific understandings

of a phenomenon.⁵⁰ Increasingly, people are turning to large language models such as ChatGPT to learn about a topic, often using them as a substitute for a traditional web search. In doing so, however, they are also exposed to incorrect statements and "hallucinations," where the Al interface generates statements that may appear to summarize scientific research but are actually fabricated, based on statistically probable text patterns.⁵¹ Furthermore, perceptions that research is biased, influenced by conflicts of interest, difficult to access or interpret, or otherwise flawed create real or perceived barriers to the consumption and application of scientific knowledge.

Priority 3 focuses on encouraging researchers to engage in processes that make research more transparent—that is, that help ensure more people understand the research process, methods, findings, and implications for action.

Open Science provides a well-developed framework for achieving this goal. The Center for Open Science defines open science as ensuring that research is transparent, shared, and inclusive.⁵² UNESCO writes "Open science is a set of principles and practices that aim to make scientific

Case Study

A key goal of open science is ensuring that research findings are relevant and accessible to policymakers, practitioners, community members, and youth themselves. Researchers from California State University, Monterey Bay partnered with the Gonzales Youth Council to study the mental health needs of Latinx youth. After surveying high school students, they developed a youth-friendly, onepage summary as well as a "From Youth for Youth" video. The youth researchers presented the findings to Monterey County Board of Supervisors. Their advocacy led the city council and the school district to jointly fund a school-based mental health clinician.

research from all fields accessible to everyone for the benefits of scientists and society as a whole.⁵³ Open science is about making sure not only that scientific knowledge is accessible but also that the production of that knowledge itself is inclusive, equitable and sustainable." Applying open science principles – described in the strategies below – across the lifespan of a study, from design to dissemination, can promote the well-being of adolescents by broadening access to scientific knowledge and resources. If done well, this can accelerate the identification and uptake of effective innovations.



Strategies that support this priority

Apply open science principles.

The principles of <u>open science</u> focus on (1) ensuring that data is more widely available (and openly shared, if possible), (2) research teams are described clearly and financial commitments are declared, and that (3) research processes (including recruitment, retention, community engagement policies, and other elements) and methods are described in detail. These principles are intended to make research and research products more <u>transparent</u>, <u>usable</u>, <u>and freely</u> <u>available</u>.

- Ensure that study structures and protocols align with open science principles. Study teams should consider adopting various practices to promote transparency and accessibility. In addition to the practices listed below, the <u>Center for Open Science</u> offers multiple resources to support open science practices across the research lifecycle (i.e., discovery, planning, conducting, reporting) through free, open-source project management and collaboration tools.
 - **Pre-registration of study protocols.** Registries to consider include <u>Registry of Efficacy and Effectiveness Studies (REES)</u>, the <u>Open Science Framework</u> (OSF), <u>ClinicalTrials.gov</u>, <u>AEA Registry</u>, <u>AsPredicted</u>, and trial registries in the <u>WHO Registry Network</u>.
 - Data management and stewardship. Aligned with data security and human subjects protections, make plans to make data available for further investigation. This includes datasets as well as algorithms and code. The <u>FAIR Principles</u> are a widely cited set of principles regarding data transparency endorsed by a diverse set of stakeholders.
 - **Publication in open access journals.** A key aspect of open science is ensuring broad access to study findings. Research teams should consider publishing in journals that provide free access. The <u>Directory of Open Access Journals</u> includes a list of open access journals.

Implement science communication best practices.

To ensure adolescent health research is transparent, it must be accessible to a wide set of audiences, including the communities in which studies are conducted.

- Build the capacity of researcher team members to communicate to a wide range of audiences. Few researchers receive training in how to communicate findings to policymakers, practitioners, community groups, or adolescents themselves. The American Association for the Advancement of Science (AAAS) has a <u>communication</u> <u>toolkit</u> that addresses communication for a variety of audiences. Several other discipline-specific associations and universities offer trainings and courses dedicated to science communication.
- Use plain language and share findings in ways that are actionable, as appropriate. <u>Plain</u> <u>language</u> is a set of guidelines to support clear writing to better reach audiences. These principles include using active voice and words that distinguish between requirements and recommendations. Adolescents and practitioners noted in their conversations with



OPA that research results were often hard to find and hard to understand or apply to daily life. While not every research finding leads to a clear course of action, researchers should draw connections across findings to contextualize data and what it means whenever possible.

- Engage adolescents themselves to communicate research findings. Engaging adolescents in dissemination can enhance the science communication skills of adult and adolescent researchers. The <u>YPAR Hub</u> at the University of California Berkeley and the University of Virginia's <u>Youth-Nex project</u> provide practical strategies and resources, including several examples of youth-friendly dissemination products including social media campaigns, documentaries, and websites.
- Share study findings with the community where the research was conducted. Research teams should communicate study findings in ways that are <u>aligned with community</u> <u>norms and values</u>. For example, engaging with communities in a dialogue about adolescent health research findings, as opposed to merely reporting out results, can help to <u>build trust</u> among adolescents and community stakeholders, especially in marginalized communities that may have been harmed by research.

Build evidence on the cost of implementing interventions in real-world settings.

A final component of transparency is ensuring that consumers of research understand the practical implications of the findings, particularly for implementation or application. While economic analysis in public health has become <u>more common</u> in recent years, and <u>policymakers</u> often apply cost-benefit analysis to select public health interventions, clear communication about costs remains rare in adolescent health research. Further, cost or implementation data shared in a study may reflect a controlled, ideal-case scenario quite unlike how interventions may be implemented in real-world settings. Factors such as recruitment, follow-up, staffing, or other supports may vary outside the study context. Experts in our group discussions discussed the importance - and difficulty - of communicating effectively what study findings imply about real-world implementation, how to replicate those findings, and the critical need for funding to support these efforts.



How the priorities support one another

Independently, incorporating each of these research priorities will strengthen the work done by those in the adolescent health field. However, they are more powerful together; each priority supports the others, and by making efforts to incorporate all three, researchers will develop more rigorous, credible, and impactful work.

Collaboration and complexity.

Adolescent health issues are complex, with many interrelated risk and protective factors. Similarly, siloed approaches to addressing these issues are less effective than collaborative ones. Collaborative research that engages a variety of stakeholders, including young people themselves, allows for a more advanced perspective on adolescent health issues. Complexity also supports collaboration. As the field calls for different research methods, or the inclusion of previously excluded groups into the research process, the value of collaboration becomes more fundamental to the rigor of a study.



Those working on collaborative research will have more capacity to be effective messengers of the work, as they are already practiced at communicating across diverse groups. Meanwhile, transparency can create a culture of information-sharing and that emphasizes the value of trustworthiness. To this end, research done in collaboration will have a wider range of relevant information they can share, including greater ability to secure data-sharing permissions. Unlike outsider researchers – those "doing research on" other populations – collaborative researchers will be able to proudly state that the work was done with the deep engagement of key stakeholders.

Complexity and transparency.

Researchers who engage with complex adolescent health questions, but neglect transparency, are unlikely to find their work has the intended impact. Complex but opaque research may be seen as esoteric and inaccessible at best, or at risk of fraud at worst. Meanwhile, research that embraces complexity *and* transparently describes its methods, strengths, limitations, and contributions to our understanding of adolescent health is likely to be recognized as advancing the field forward.

How the priorities were developed

These priorities were developed through an iterative, multi-stage process to gather input on the future of adolescent health research. It included an artificial intelligence-assisted review of published research as well as facilitated conversations with groups of researchers, practitioners, and adolescents themselves. While conversations with a different set of individuals might have yielded a slightly different set of priorities, the overall themes are aligned with recommendations for advancing adolescent health research that have been published in other reports. See Appendix A for more details on the process.



Phase 1: AI-Assisted Analysis of the Research Landscape

Discussions with Adolescent Health Researchers

Phase 2:

Phase 3a: Discussion with Adolescents

Phase 3b: Phase 3c: Discussion Discussion with Other Practitioners Researchers

with

Conclusion

This brief provides a framework for researchers to advance adolescent health in partnership with adolescents, as well as parents, caregivers, practitioners, and community members through three interconnected priorities: collaboration, embracing complexity, and transparency. By implementing these priorities, researchers can support the work of Take Action for Adolescents[™] while ensuring their work is more inclusive, comprehensive, and impactful. The purpose of these priorities is to ground researchers in the approach to research, rather than focusing on specific content, as the variety and rapid evolution of research topics make it difficult for any single document to address them all. The principles, however, are applicable across topics, methods, and purposes to ensure that research is as robust, valid, and understandable as possible.



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Appendix A: Approach Overview

Researchers, youth, and practitioners want research that is more inclusive, transparent, and examines how systems shape adolescent health and development. This will require changing research processes to emphasize collaboration and better dissemination.



The Office of Population Affairs (OPA) released Take Action for Adolescents[®]: A Call to Action for Adolescent Health and Well-Being in October 2023. One of the goals of Take Action for Adolescents is to support, translate, and disseminate research. The AI and engagement findings described on this poster will inform a guide for improving and advancing adolescent health research. The guide will be shared with those invested in the production of research. Scan the QR code below to learn more and stay informed of this work.



An Iterative Process to Gather Input on the Future of Adolescent Health Research



Appendix B: Approach for Developing Prioritizing Research Approaches to Meaningfully Improve Adolescent Health

The development of the research priorities discussed in this document is the outcome of an iterative, three-phase process to gather input on the future of adolescent health research.

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Phase 1: Al-assisted analysis of the research landscape

To conduct a large literature review on recent adolescent health research, an artificial intelligence (AI) method was used for screening articles and cluster analysis.

Five journals were selected for screening: *Pediatrics*, the *American Journal of Public Health* (*AJPH*), the *Journal of Research on Adolescence (JRA*), the *Journal of Adolescent Health (JAH*), and the *Lancet Child and Adolescent (the Lancet*). These five journals were chosen for their focus on adolescents, high impact factor scores (based on number of times selected articles were cited in recent years), and the fact that they approach health from medical, public health, and developmental perspectives. The articles reviewed were primarily from the past decade (2013–2023). A total of 5,896 articles were pulled.

From this pool of articles, an AI-driven process was developed to screen articles for inclusion. Criteria included: reporting results from a research study (including secondary data analysis and reviews); focusing on adolescents (defined as ages 10-24); and studies were conducted in the U.S., Australia, the U.K., and other countries with economic and healthcare treatment options similar to those in the U.S.

The AI screening process played a crucial role in identifying and organizing relevant articles to be analyzed using cluster analysis. The process to build the AI model included several steps:

- 1. **Al Training:** Consistent with standard practices, the research team manually reviewed approximately 200 articles. About one quarter of these articles were selected to serve as a training set for fine tuning the Al through a process called prompt engineering.^{1,2}
- Testing Al Accuracy: The Al model was tested on the remaining 150 manually reviewed articles to ensure reliability. The accuracy rate of the model was 97.33% (146/150 articles correctly classified).
- 3. **Screening:** The refined AI model screened all 5,896 articles identified in the initial search to determine their relevance based on the predefined inclusion criteria.
- 4. Keyword and Summary Extraction: The AI model extracted keywords, summaries of the articles, and main findings. Using this data, it created semantic embeddings— representations of the articles based on their titles, keywords, and summaries—and clustered them based on similarities.

Ultimately, 3,292 articles were used in the cluster analysis. Following the clustering process, the research team labeled the clusters based on their content and organized related clusters into broader themes. This resulted in six main clusters, further subdivided into 16 subclusters, providing a detailed map of current adolescent health research and its key areas of focus (see Appendix A).

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Phase 2: Discussions with adolescent health researchers

OPA presented the results of the cluster analysis during a session at the 2024 Society of Adolescent Health & Medicine (SAHM) Annual Meeting. Attendees were asked to provide feedback on the clusters, specifically what might be missing from what the AI model identified from the published research. Attendees were also asked about innovative methodologies in adolescent health research, implications for practitioners, translation of research to practice, and pertinent gray literature. Following the SAHM meeting, additional discussions were held to solicit feedback from researchers leading adolescent health-focused research centers and/or research agendas.

Key insights gained from these discussions included:

- The clusters developed by the AI model only reflected a subset of research. Other biomedical journals or journals from other disciplines could yield additional or broader clusters.
- **Recognition of the overlap among clusters is critical.** Health outcomes are interrelated and things like development and health care use span across outcomes.
- More work is needed to examine how systems shape adolescent health and development (e.g., social determinants of health, racism, culture, families, technology).
- More positive frameworks are needed. Researchers emphasized the importance of youth agency, positive youth development, and assets-based approaches
- Researchers identified potential research infrastructure improvements, including enhanced collaboration among researchers and with youth, funding, and dissemination as initial gaps.

Phase 3: Facilitated discussions with young people, practitioners, and other researchers

Based on feedback from Phase 2, modified clusters and questions about collaboration within research were discussed in facilitated sessions with young people, practitioners and other researchers.

Phase 3a: Discussion with young people

Child Trends, on behalf of the OPA, met with 15 former and current members of Youth Engaged 4 Change (YE4C), the Editorial Board for the Interagency Working Group on Youth Programs. During the meeting, the group discussed potential topics that an adolescent health research agenda or framework could cover and processes that might strengthen participation in and use of research by young people.

The YE4C participants emphasized the need for continued efforts to support and improve adolescent health, highlighting numerous questions that research could address. They discussed the diverse experiences of youth, shaped by factors like race/ethnicity, health status, gender identity, sexual orientation, immigration status, and geography. Participants highlighted systemic challenges affecting adolescent health and stressed the importance of greater youth engagement and empowerment.

In addressing systemic challenges, YE4C participants noted that more cross-cutting studies that link different health outcomes together and/or explore more deeply the intersections between topics could be helpful. Youth engagement and empowerment included but was not limited to allowing youth to advocate for themselves and having their thoughts and opinions taken seriously. It also included a strong interest in intergenerational understanding and partnership.

Trust was interwoven throughout the discussion and is a complex topic. Participants noted issues of adults' trust in youth, which affects youth's trust in adults. Participants also discussed the trustworthiness of information, citing concerns about misinformation and the lack of accessibility of research journals to young people. Overall, participants highlighted the importance of creating a more inclusive, collaborative, and trust-based approach to addressing adolescent health challenges.

Phase 3b: Discussion with practitioners

The Adjacent Possible and Child Trends, on behalf of the OPA, facilitated a virtual humancentered design activity and discussion with youth-serving practitioners. The session's objectives were to learn about practitioners' use and perceptions of research, to understand what information practitioners want and need from research to support their work, and to learn ways to better connect research to practice in support of adolescent health.

Participants highlighted several key themes and concerns related to integrating research into practice. Mental health emerged as a high priority across youth-serving organizations and initiatives. Participants noted that more communication is needed within and between researcher and practitioner spaces to build mutually beneficial collaboration and facilitate timelier and more meaningful ways to bring research into practice.

Practitioners expressed interest in learning about and engaging in a range of evidence that comes from research, from descriptive to rigorous. They understand the caveats that come with descriptive or suggestive findings, but they do not want to discount them, particularly when information is needed quickly. They noted that the long timelines of research are a barrier to receiving and using information. By the time research has been published through official channels, the topic is often outdated; having informal networks of practitioners and researchers would allow for more meaningful and timely collaboration and access to new information.

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Participants emphasized that research needs to be packaged to improve clarity and accessibility for practitioners and to provide practical information that translates research evidence into readily applicable guidance.

Funding was identified as a significant barrier, particularly the availability, structure, and flexibility of resources. Participants pointed out that relationship-building efforts, which are critical to successful researcher-practitioner partnerships, require ongoing funding throughout the lifecycle of projects, not just during their initial phases. These insights underscore the need for systemic changes to improve the timeliness, relevance, and applicability of research in addressing pressing issues within youth-serving spaces.

Phase 3c: Discussion with other researchers

The Adjacent Possible and Child Trends, on behalf of the OPA, facilitated a virtual humancentered design activity and discussion with researchers. The session's objectives were to: identify priorities for adolescent health and well-being research; understand what collaboration looks like among researchers and between researchers and practitioners and youth, and the facilitators and barriers to collaboration; and to learn about supports for research to improve outcomes for youth.

Participants noted the following topics need further research: school climate, academic achievement, and pathways to career and college; meaning and purpose among adolescents, and agency as a protective factor; identity (sexual orientation, gender identity, race and ethnicity); and methodologies for youth to co-design research and its impact. They noted that research on youth tends to focus too much on deficits and negatives, risks, and resilience rather than on strengths, youth agency, joy, and addressing the issues that demand resilience.

Collaboration with researchers in other disciplines, practitioners, and youth is very important. However, participants expressed there are many barriers to collaboration, especially limited funding and lack of intentional spaces and structures to support meaningful collaboration. Most funding mechanisms, including grants, do not account for the time and resources it takes to build trust between researchers and youth, which significantly hinders the ability to meaningfully co-create research. Funding was a key issue for virtually everything participants discussedthere are many things that researchers are passionate about and want to be doing, and that they know would serve their field and their focal populations, that they cannot do without funding.

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Participants noted the importance of breaking down silos between research and practice. They would like to see a far-reaching effort to synthesize and translate research into a common language that is accessible for all who might benefit from it, and to re-evaluate structures that determine what counts as legitimate research and evidence.

Strong silos within health research (physical and mental) and between health research and social determinants of health cause disciplinary divides. Participants wanted a shared language and structured opportunities to talk 'with' and not 'at' other researchers in small group settings or networks. They also suggested that incentives and intentional frameworks or structures for cross-disciplinary collaboration would help.

Citations

- 1. Vabalas, A., Gowen, E., Poliakoff, E., & Casson, A. J. (2019). Machine learning algorithm validation with a limited sample size. PloS one, 14(11), e0224365.
- 2. Perez, E., Kiela, D., & Cho, K. (2021). True few-shot learning with language models. Advances in neural information processing systems, 34, 11054-11070.