

UNDERSTANDING YOUTH DATA COLLECTION IN KANSAS

Key takeaways from a collaborative stakeholder convening

On Tuesday, Dec. 12, the Kansas Health Institute (KHI) hosted an event focused on understanding youth-related data collection in Kansas, the policies that impact data collection and the practical uses of data collection in program development. The convening was held in a hybrid format, gathering over 140 individuals from across Kansas. Participants included state agencies, local health departments, parents or legal guardians, community organizations, schools, researchers, policymakers and mental health professionals.

Opening Insights

The event commenced with opening remarks by Kari Bruffett, President and CEO of KHI. Following the opening, the attendees watched a video, *Understanding Perspectives* on Youth Data Collection in Schools, produced by KHI. In the video, a diverse group of stakeholders — including school administrators, students and local public health officials — offered unique insights into issues surrounding youth student data and school-administered surveys. Their perspectives covered the purpose of these surveys, experiences in completing them and potential areas for improvement. The video set the stage for the convening.

Background Presentation

Next, Cynthia Snyder, M.A., Senior Analyst at KHI, discussed the history of policy issues impacting student data collection from a national and state perspective.

National policy discussions concerning student information first emerged in 1974 with the enactment of the Family Educational Rights and Privacy Act (FERPA). In Kansas,



the Student Data Privacy Act was enacted in 2014. Prior to the Student Data Privacy Act, parents or guardians had the option to "opt out" of non-academic assessments. Under this opt out system, students were automatically considered participants in non-academic assessments unless their parents or guardians explicitly stated their refusal or withdrawal. This means that, by default, all students were included unless a specific request to opt out was made. The Student Data Privacy Act requires written consent of a parent or guardian to participate in an assessment of the student's physiological or emotional state. With the enactment of the Student Data Privacy Act, Kansas transitioned to an "opt in" system, mandating that parents or guardians must explicitly provide written consent for their children to participate in non-academic assessments. The adoption of the opt in system under the Student Data Privacy Act presented significant obstacles to gathering student data for non-academic surveys such as Kansas Communities That Care (KCTC) and the Youth Risk Behavior Survey (YRBS).

The second key piece of legislation related to student privacy and parental consent in Kansas was passed in 2022. With Senate Substitute for House Bill 2567, Section 27, schools were required to notify parents or guardians no more







Understanding Policy-Related Perspectives Panel.

than four months before each assessment, providing details on its content and consent process. This new requirement further complicated the data collection process for non-academic surveys.

As a result, the YRBS couldn't publish statewide estimates in 2015, and similar issues may arise in 2023 due to a lack of sample size, meaning not enough students completed the survey. Similarly, the KCTC saw a decline in participating school districts and students in 2015 and 2023.

Panel and Roundtable Discussions

After the background presentation, panel and roundtable discussions ensued. Stakeholders had an opportunity to discuss the implications of these policies and the importance of collecting reliable student data in Kansas to address the needs of schools and allocate resources more effectively.

Applications and Utilization of Youth Data Panel

The first panel (pictured above) discussed topics related to student data instruments and how the student data is used in Kansas. The following panelists participated in the discussion:

- Steve Corbett, M.A., Ph.D., Senior Epidemiologist, Kansas Department of Health and Environment
- Monica Kurz, M.S.W., Vice President of Policy & Prevention, HeadQuarters Kansas
- Babalola Faseru, M.B.Ch.B., M.P.H., Professor of Population Health, Family Medicine and Community Health, University of Kansas Medical Center
- Chrissy Mayer, Chief Community-Based Services Officer, DCCCA

During the discussion, panelists frequently referenced the Youth Risk Behavior Survey and the Kansas Communities That Care survey, including their reliability, validity and safety. Similar to the background presentation on student privacy legislation, the panelists emphasized balancing the need for parents to make informed decisions about students' participation in surveys and the necessity of gathering meaningful data. The panelists stressed that data is crucial for supporting educational programs, identifying emerging trends and effectively allocating resources, ultimately serving the health and well-being of students.

Understanding Policy-Related Perspectives Panel

The second panel (pictured above) discussed issues related to policy, and how state agencies and school boards responded to changes in the policy. Panel members were:

- Kent Reed, M.Ed., School Climate and Wellness Program Manager, Kansas State Department of Education
- Andy Brown, M.S.W., Deputy Secretary for Programs, Kansas Department for Aging and Disability Services
- Melanie Jack, J.D., Assistant Attorney General, Kansas Attorney General's Office
- Angie Stallbaumer, J.D., Deputy Director and General Counsel, Kansas Association of School Boards

Panel members discussed key considerations for schools and school boards, underscoring the complexities and unintended consequences of recent legislative changes on data collection, privacy and health equity. Panel members discussed the impact of data gaps on understanding community needs and allocating resources. Melanie Jack from the Kansas Attorney General's Office outlined the process of handling student privacy complaints, noting a low number of complaints have been received. The Student Data Privacy Complaint Form is available on the Kansas Attorney General's website.

Roundtable Discussion

Discussion continued with both virtual and in-person roundtables facilitated by KHI staff. Participants self-selected into groups to reflect on the day's discussions and identify strategies that could address the issues raised, such as increasing participation and other strategies for collecting meaningful data. The roundtable discussions covered a range of topics, including data collection and administration, policies and regulations, as well as program development and innovation. Despite the diversity of topics, the conversations in all three areas converged on similar concerns and proposed next steps. Consequently, the insights and recommendations are presented collectively, reflecting the interconnected nature of these themes.

Overall, participants in the roundtable discussions expressed concerns about navigating the complexity of implementing the Student Data Privacy Act in schools, especially when it intersects with mental health professionals assessing student risk. Specific issues were raised including trust and understanding among stakeholders, awareness and relevance of youth data collection, and the data collection process. Securing parental consent within a four-month window, and needing to opt-in, were seen as significant barriers to collecting data.

Key Takeaways

Working with Stakeholders

Build trust through education and engagement.

Participants emphasized the importance of fostering understanding among parents and students about how data is being utilized, recognizing this as a fundamental element in building trust. When community members including students, teachers and parents, have a clear understanding of how data is being used to improve the well-being of students and the community at large, their engagement is more likely. To enhance this understanding, it will be critical to conduct multifaceted educational efforts and engage with community-based organizations that utilize the data for survey promotion.

Share survey insights with students and parents.

Another suggested strategy was to share the survey results in aggregate with students and parents when the data become available. After reviewing the data, the school could consider engaging parents and students in conversations about developing solutions to the identified issues.

Data-Driven Decision Making

Cultivate a culture of data-based decision making. Participants emphasized the importance of using positive survey trends in messaging, as well as the concerning trends. Enhancing the understanding of the importance of developing and establishing baseline data and systematically monitoring trends were identified as essential elements in the creation of a culture of data-driven decision making.

Addressing Concerns

Address parents' and students' concerns.

Participants acknowledged that parents and students have concerns about privacy, accuracy and relevance. Parents feel strongly about being informed and involved in what their children are exposed to in schools. Parents emphasized the significance of being the primary source of information and guidance for their children. Providing information about the surveys that address specific concerns, as part of the consent process, is likely to increase participation.

Communicate with teachers and administrators about concerns. Participants also acknowledged that teachers and administrators have some of the same concerns as parents regarding accuracy and relevance, and the additional constraint of time during the school day. Communicating with teachers and administrators about key aspects of survey administration, the value of the information and the importance of their role in the process could further increase participation.

Communication

Empower student leadership. Participants saw students as potential champions for peer education and survey participation. Collaborating with student organizations such as Resist Chapters and HOSA for peer-driven health messages may be another opportunity to address student concerns.

Communicate the value of student data to legislators. Include student voices in the messaging. Participants saw the value of letting legislators know how their communities' schools and programs use data in their districts. Student voices were seen as vital, both through the survey instrument and their discussion with policymakers, to knowing what students need.

Engage in public service announcements. Participants saw several opportunities to educate students, parents, teachers and community members on the importance of youth data, such as public service announcements at sporting events and other widely attended activities or through promotional items that displays positive messaging.

Improving the Process

Make the data collection process more streamlined. Participants discussed options to make the process more effective and less burdensome to administer, including moving to phone-based, de-identified survey links. Participants expressed concerns about survey length, repetitiveness and the importance of questions.

Find out what is working. Participants wanted more information from other states, or other communities in Kansas, on effective communication and other strategies to promote successful data collection.

Looking Ahead

Brandon Skidmore, Vice President of Health Systems, Sunflower Foundation, ended the day by sharing his thoughts on the conversation around youth data collection and its impact on health in Kansas. He emphasized the need to zoom out and look at the





Americans are living shorter, less healthy lives. These behaviors as an adult start early in life. If we are going to get in front of those issues, we have to have a better and more complete picture of what we're dealing with."

- Brandon Skidmore. Vice President of Health Systems, Sunflower Foundation

concerning trends for the nation as a whole, as well as Kansas compared to other states. Skidmore highlighted the decline in health status over the years and its farreaching consequences on economic well-being and workforce challenges. He also stressed the importance of data in driving community health improvement, enabling proactive planning and empowering communities by providing valuable benchmarks. Skidmore pointed out that more efforts are required to engage parents and communities, address the gap in understanding and participation, and align resources with policy changes.

ABOUT THE EVENT RECAP

The convening and associated products are based on work done by Cynthia Snyder, M.A., Valentina Blanchard, M.P.H., L.M.S.W., Hina Shah, M.P.H., and former KHI employee and consultant Ivan Williams, M.B.A., under contract with the Kansas Department of Health and Environment (KDHE). The Kansas Health Institute (KHI) maintains editorial independence for these products. Any views expressed by KHI staff do not necessarily reflect the views of KDHE and their partners. It is available online at khi.org/articles/understanding-youth-data-collection-in-kansas

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KANSAS HEALTH INSTITUTE

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