

Opponent Testimony for SB 234
Committee on Public Health and Welfare
March 19, 2023

Chair and Members of the Committee,

I am submitting this testimony in opposition of SB 234 in my role as director of the University of Kansas, Center for Public Partnerships and Research (CPPR). We strongly support data privacy and protection standards and the intent of the bill. As proposed, the legislation's specificity and restrictions, however, will make it challenging for communities to continue to use IRIS and other systems. We offer recommendations under which we could support this bill.

CPPR builds and implements tools and resources that help children and families have better access to services designed to support their health and well-being. In 2017, we built IRIS – a web-based closed-loop referral tool designed to support bi-directional referrals for services (e.g., healthcare, public health, social supports, education, early childhood, housing, transportation) between providers within a community catchment area. IRIS has been active in Kansas for seven years. IRIS is supported by an evidence-informed implementation framework that leads community champions and partners through adaptive processes, policies, and procedures to better coordinate services and ensure individuals have equitable access.

Families recognize and experience high quality coordination among partners in a community, including when staff communicate across agencies and organizations and depend on organizations to know when to refer and understand services across the community (Ervin, 2004). Individuals and families who have positive experiences with coordination are more likely to participate in services and perceive them as useful. IRIS was built on the premise of family choice and the protection of data.

There are currently nine IRIS networks in Kansas, spanning 21 counties and 542 partner organizations. These cross-sector community networks include health systems, community based early childhood service providers, mental and behavioral health organizations, and public health departments. With support from Kansas state agencies, these robust and engaged community networks have connected more than 15,000 Kansas families to services through more than 23,000 referrals.

The IRIS referral workflow contains multiple checkpoints to ensure that client consent has been obtained. IRIS users are required to affirm that they have received appropriate consent from the individual being referred. First, prior to entering any personally identifying information (PII), staff must affirm that the individual provided consent for their PII (name, date of birth, phone number) to be shared through IRIS. Additionally, staff must affirm that they received appropriate consent for each referral. IRIS provides resources to guide the development of consent practices that align both with IRIS best practices and any applicable privacy laws and/or confidentiality regulations.

The IRIS community-driven networks matter for Kansas because:

- Through local control and collaboration, communities have addressed client consent and data privacy through MOUs, mutual client consent forms and practice, data use agreements, local governance, and referral tool consent check.
- Local communities are best suited to determine how and what data is valuable for them and how to apply client consent protocols and data privacy protections that address applicable privacy laws and/or confidentiality regulations specific to each organization.
- Communities achieve better health and well-being outcomes for their members when they know and understand the array of services received by individuals and the multiple touchpoints within their referral network.
- Kansas communities use this community-level data to make decisions about how to engage families and improve services and access.

Before exchanging a single referral, IRIS community partners establish community-driven and community specific standards for how they will implement the platform, including how they will address client consent, data ownership, and data governance. Some communities develop a shared written client consent document, others agree to minimum expectations for client consent while allowing individual organizations to follow consent protocols that meet their specific regulatory standards.

We respectfully propose that the bill be amended to:

- Ensure that the proposed law does not disrupt established child care, mental health, public health, family support, and prevention services referral networks.
- Allow a grace period for existing closed-loop referral networks to review the law and make needed changes to get into compliance.
- Encourage coordination between referral platforms (IRIS, findhelp, Unite Us, Community CareLink, 1-800-CHILDREN) and using Application Programming Interfaces (APIs) to maintain community investments in existing practices.

Thank you for the opportunity to provide written testimony on SB 234. We have included a description of the IRIS network and our data privacy standards. Again, we strongly support data privacy and protection standards and would like to be part of a cohesive strategy that honors the community work and state investments that have already established a strong referral system. We look forward to partnering with other developers and community partners to develop these standards.

Sincerely,



Jackie Counts
Director



Growing a Connected Network Around a Family

A simple, data-driven communication tool paired with community generated solutions.



14,707
KANSAS FAMILIES

Unduplicated number of individuals who were the subject of at least one referral in IRIS.



23,259
REFERRALS

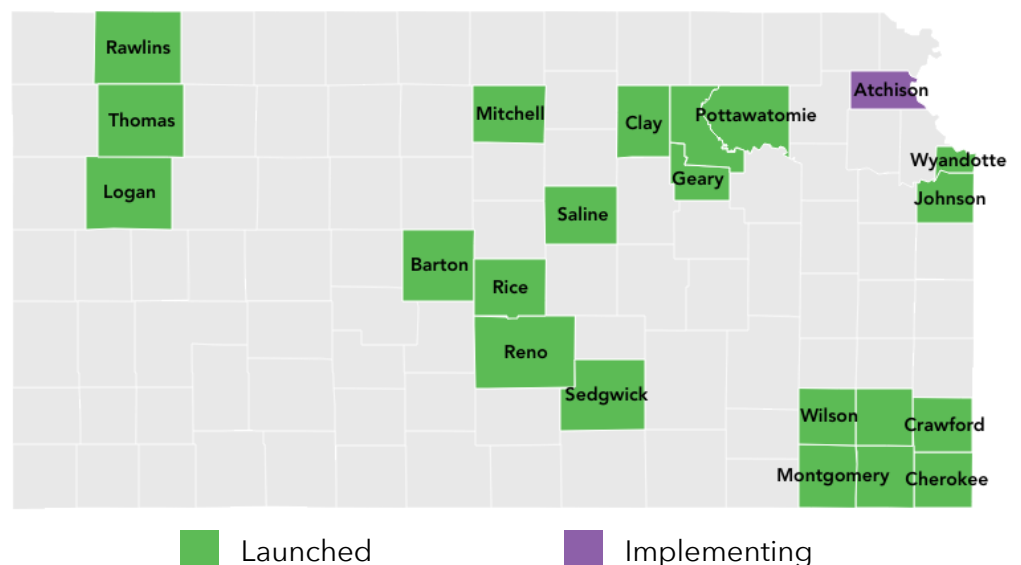
Many families were involved in multiple referrals.



42.6%
ENROLLED IN SERVICES

Families connected with needed services in IRIS communities.

COMMUNITIES	LAUNCH	CHAMPION
Atchison County	Implementing	Atchison County Housing Authority
Barton & Rice Counties	6/3/19	Barton County Health Department
Cherokee, Crawford, Labette, Montgomery, Neosho, & Wilson Counties	12/11/17	Four County Mental Health & My Family-Cherokee County
Clay, Geary, Riley, & Pottawatomie Counties	5/27/22	Clay, Riley, & Pottawatomie County Health Departments, Delivering Change
Jackson (MO), Johnson, & Wyandotte Counties	3/11/22	Jackson County Health Department, Johnson County Department of Health & Environment, Community Health Council of Wyandotte, Connections
Mitchell County	11/15/19	Mitchell County Regional Medical Foundation
Reno County	10/1/18	Hutchinson Community Foundation
Saline County	9/30/19	Saline County Health Department
Sedgwick County	3/4/19	Sedgwick County Health Department
Thomas, Logan, & Rawlins Counties	10/20/21	Northwest Kansas Educational Service Center



The Clay County IRIS Community merged into the Geary, Riley, & Pottawatomie Counties' Community on February 15, 2023.



IRIS Data Privacy Standards

WHAT IS IRIS?

The Integrated Referral and Intake System (IRIS) is a web-based communication tool used for sending, receiving, and updating information about referrals. IRIS is managed by the Center for Public Partnerships and Research at the University of Kansas. Each IRIS network is made up of a group of organizations and their staff (users) who send and receive referrals to one another. Each network is supported by one or more local user(s) with access to all referral information, known as the Data Manager.

WHAT INFORMATION IS SHARED IN IRIS?

Information entered and stored in IRIS includes client contact information (first and last name, birth date, phone number, and/or e-mail address), other details needed to make a referral, and referral results. Client contact information can be seen by all users in the IRIS network. Details about each referral can only be seen by the Data Manager(s) and the users at the organization sending or receiving the referral.

HOW IS DATA PRIVACY MANAGED?

Before joining an IRIS network, each partner organization must affirm that families will be given the choice to consent for their personally identifying information to be shared. All IRIS users must treat personal data in IRIS as private and clients must consent before their personal information is entered and before every referral. While procedures for gaining consent lie outside of IRIS and are the responsibility of each organization, IRIS provides resources to guide the development of consent practices that align both with IRIS minimum standards and any applicable privacy laws and/or confidentiality regulations.

The IRIS tool meets applicable law to reasonably maintain the privacy and security of personal information. Safety measures include regular audits, mandatory IRIS staff training, policies requiring appropriate handling of secure information, encrypting data while at rest and during transmission, housing data on HIPAA-compliant cloud storage solution, and single-user logins.