

Tackling Tough Public Health Problems through Cross-Sector Data Collaborations

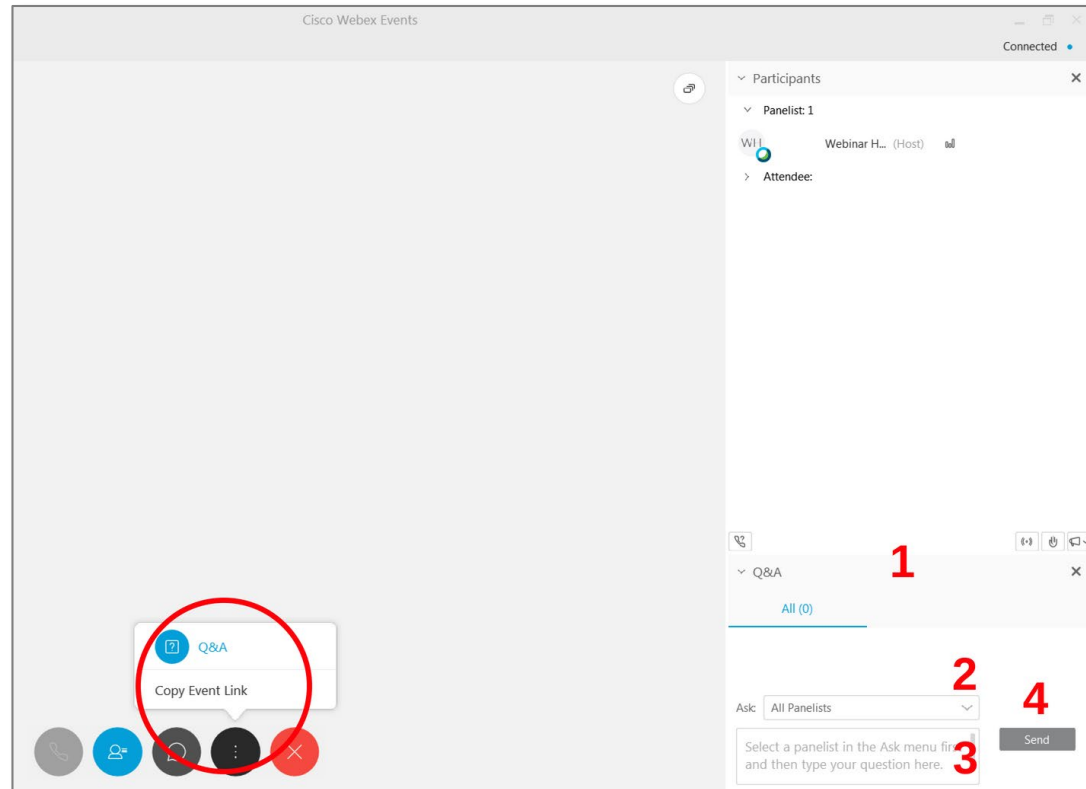
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Presenter



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- Research interests/areas of expertise:
 - Public Health Data
 - Adults at Risk
 - Maternal and Child Health
 - Statutory and Regulatory Public Health

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 - Social Justice
 - Cross-Sector Data Sharing
 - Collaboration Building



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for Public Health Law

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Tackling Tough Public Health Problems Through Cross-Sector Data Collaborations

Jennifer Bernstein, JD, MPH
Deputy Director, Network for Public Health Law
Mid-States Region

So much data

Screening

- » Childhood lead screening
- » Newborn screening for metabolic diseases
- » Early hearing detection & intervention
- » Vision & hearing screening of school children

Health Plans

- » Medicaid
- » State Children's Health Plan
- » County Health Plans

WIC

Regulatory

- » Restaurant inspection reports
- » Septic, wells, other permits
- » Clean indoor air act
- » Burning ordinances
- » Asbestos contractors
- » Lead abatement contractors
- » Health facilities

Vital Records

- » Birth records
- » Death records
- » Marriage records

Registries

- » Cancer
- » Birth defects
- » Traumatic injuries
- » Immunizations

Disease Surveillance

- » Infectious disease reports
- » Syndromic surveillance
- » Hospital acquired infections

Clinical Services

- » Child & maternal health
- » Immunization
- » Dental clinics
- » School-based clinics
- » FQHCs or CHCs

Emergency Preparedness

- » Health alert networks
- » Volunteer registries
- » Vulnerable people registries

And growing

- » **Amount of data**
- » **Sources of data**
- » **Data sharing partners**
- » **Ways to transfer and exchange**
- » **Linkages with other information**
- » **Creation integrated databases**
- » **Retention, reuse, and further sharing of the information**
- » **Creation of public datasets**

So many laws

Data Protection and Disclosure Laws

+ frequent condition for receiving funds

Federal

- **HIPAA**
- **FERPA**
- **WIC**
- **Title X family planning**
- **Cancer registries**
- **Substance abuse treatment**
- **Federally supported research**
- **Social Security Act**

State

- **Health information**
- **Disease surveillance**
- **Registries**
- **Vital records**
- **Screening**
- **Drug monitoring**
- **Medicaid**
- **Clinical services**
- **Social security #**
- **Open records**

Law governs every aspect of data

Collection

Use

Sharing

Protection

Law friend or foe?

- How does law help us to do our job?
- How is law a barrier?

General barriers to exchange

- » **State law applies – variation among states**
 - » **General vs. specific authority to exchange data**
 - » **Scope of sharing: prerequisites, conditions & limits**
 - » **Within a state – applicability of multiple laws, need to harmonize**
 - » **Variety and changing systems, manner of exchange, technological capability**
- Growing complexity, multiple points of data transfer, HIE laws

Navigating the law

Creative Solutions:

- Create exceptions in agreement to accommodate certain parties
- Meet legal requirements of most restrictive party's law
- Change in law or regulation to accommodate sharing
- Have party with greatest authority act as a data clearinghouse

The Patchwork US Privacy Framework

Cason D. Schmit

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FEARLESS ON EVERY FRONT

Presentation Overview

- Outline
 - Ethical context for using existing data for public health purposes
 - [2017 WHO Guidelines on Ethical Issues in Public Health Surveillance](#)
 - Overview of federal privacy laws
 - Implications for leveraging existing data for public health purposes
 - International model (GDPR)
- Objectives:
 - Compare federal data protection laws across sectors.
 - Analyze how different federal data protection laws facilitate or impede the use of cross-sector data for public health purposes.

Resources to Navigate Federal Data Protection Laws

- 22 Snapshots of different federal laws protecting data
- Annotated list of resources and guidance
- Coming Soon: Interactive online database of legal data sharing resources

https://www.networkforphl.org/topics_resources/topics_resources/health_information_and_data_sharing/federal_privacy_laws/?blm_aid=21653



Abbreviations

- 42 C.F.R. Part 2 - Substance Abuse and Mental Health Services Administration Confidentiality Provisions
- CIPSEA - Confidential Information Protection and Statistical Efficiency Act of 2002
- FERPA - Family Educational Rights and Privacy Act
- HIPAA - Health Insurance Portability and Accountability Act
- HHS - Department of Health and Human Services
- IDEA - Individuals with Disabilities Education Act
- NSLP - National School Lunch Program
- SBP - School Breakfast Program
- SMP - Special Milk Program for Children
- Title X - Population Research and Voluntary Family Planning Programs
- WIC - Women, Infants, and Children Supplemental Nutrition Program
- SNAP - Supplemental Nutrition Assistance Program
- VA - US Department of Veterans Affairs



WHO guidelines on ethical issues in public health surveillance

Ethical Foundations for Public Health Data Use

A Public Health Ethics Lens



WHO guidelines on ethical issues in public health surveillance

Ethical Data Use for Public Health

- Guideline 1. **Countries have an obligation to develop appropriate, feasible, sustainable public health surveillance systems.** Surveillance systems should have a clear purpose and a plan for data collection, analysis, use and dissemination based on relevant public health priorities.

Obligation to conduct public health surveillance



WHO guidelines on ethical issues in public health surveillance

Ethical Data Use for Public Health

- Guideline 11. Under certain circumstances, **the collection of names or identifiable data is justified.**
- Guideline 12. Individuals have an obligation to contribute to surveillance when reliable, valid, complete data sets are required and relevant protection is in place. **Under these circumstances, informed consent is not ethically required.**

Justification for collecting Identifiable data

Informed consent is not always ethically required



WHO guidelines on ethical issues in public health surveillance

Ethical Data Use for Public Health

- Guideline 14. With appropriate safeguards and justification, **those responsible for public health surveillance have an obligation to share data** with other national and international public health agencies.

Obligation to share data with public health

- Guideline 16. With appropriate justification and safeguards, **public health agencies may use or share surveillance data for research purposes.**

Use data for research purposes

Federal Data Protection Laws and Cross Sector Data Sharing

- Federal agencies collect and use data for a variety of programs and initiatives across sectors.
- This data has significant potential to inform public health activities.

Legal Variation

- Unfortunately, there are different federal data protection frameworks depending on
 - Person or entity
 - Nature of the data
 - Why it was originally collected
 - Intended use or purpose

(A few) Federal Data Protection Laws

Federal Legal Framework	Citations	Sector	Focus
42 C.F.R. Part 2	42 U.S.C. § 290dd- 2, 42 C.F.R. Part 2	Health Care	Mental/Behavioral Health
Child and Adult Care Food Program	42 U.S.C. § 1758(b)(6); 7 C.F.R. §§ 226.2, 226.23	Social Service	Nutrition Programs
CIPSEA	44 U.S.C. § 3501 Note Sec. 501, et al.	Population data	Statistical Data
Confidentiality of Certain VA Medical Records	38 U.S.C. 7332; 38 C.F.R. §§ 1.460-1.499	Veterans	Health Care
VA Medical Quality Assurance Records	38 U.S.C. § 5705; 38 C.F.R. §§ 17.500-17.511	Veterans	Quality Assurance
FERPA	20 U.S.C. § 1232g; 34 C.F.R. Part 99	Education	Student Records
Head Start	42 U.S.C. § 9801, et seq.; 45 C.F.R. § 1303 Subpart C	Education	School Readiness
HHS Privacy Act Regulations	5 U.S.C. § 552a; 45 C.F.R. Part 5b	Federal Health Plans	Health Care
Higher Education Act	20 U.S.C. § 1092b; 34 C.F.R. Part 5b	Education	Student Loans
HIPAA	42 U.S.C. § 1320d et al., 45 C.F.R. Parts 160 and 164	Health Care	Services and Payment
Homeless Management Information Systems	42 U.S.C. § 11360a; 24 C.F.R. §§ 578.7, 578.57, 578.103	Social Service	Homelessness
IDEA, Part B	20 U.S.C. § 1400; 34 C.F.R. Part 300	Education	Disability Programs
IDEA, Part C	20 U.S.C. § 1400; 34 C.F.R. Part 303	Education	Early Intervention Services
Medicaid Information Safeguards	42 U.S.C. § 1396a(a)(7); 42 C.F.R. Part 431, Subpart F	Federal Health Plans	Participant Information
NSLP and SBP	42 U.S.C. § 1758(b)(6); 7 C.F.R. §§ 245.2, 245.6	Social Service	Nutrition Programs
Protection of Pupil Rights Amendment	20 U.S.C. § 1232h; 34 C.F.R. Part 98.	Education	Data Collection
SNAP	7 U.S.C. Ch. 51; 7 C.F.R. § 272.1	Social Service	Nutrition Programs
Special Milk Program	42 U.S.C. § 1758(b)(6); 7 C.F.R. §§ 215.2, 215.13a, 245.6	Social Service	Nutrition Programs
Summer Food Service Program	42 U.S.C. § 1758(b)(6); 7 C.F.R. §§ 225.2, 225.15	Social Service	Nutrition Programs
Title X	42 U.S.C. Ch. 6A, Subch. VIII; 42 C.F.R. Part 59, Subpart A	Social Service	Family Planning
VA Claims Confidentiality Statute	38 U.S.C. § 5701; 38 C.F.R. §§ 1.500-1.527	Veterans	Claims
WIC Confidentiality Provisions	7 U.S.C. § 2018; 7 C.F.R. § 246.26	Social Service	Nutrition Programs

How is identifiable information defined?

Federal Legal Framework	Not Defined	Unspecified information about individuals	Direct Identifiers	Indirect Identifiers	Deduction/Inference	De-identification Standards
42 C.F.R. Part 2			X		X	Yes
Child and Adult Care Food Program		X				Aggregate or summary data
CIPSEA			X	X	X	No
Confidentiality of Certain VA Medical Records			X		X	No ^{1, 3}
VA Medical Quality Assurance Records			X ¹	X ¹		No
FERPA			X	X	X	Yes
Head Start		X	X			No
HHS Privacy Act Regulations			X			No
Higher Education Act	X					No
HIPAA		X			X	Yes
HMIS		X	X	X		No ³
IDEA, Part B			X		X	No
IDEA, Part C			X	X	X	No ³
Medicaid Information Safeguards			X ²			No
NSLP and SBP		X				Aggregate or summary data
Protection of Pupil Rights Amendment		X	X			No
SNAP	X					No
Special Milk Program		X				Aggregate or summary data
Summer Food Service Program		X				Aggregate or summary data
Title X		X				Aggregate or summary data
VA Claims Confidentiality Statute	X ¹					No ^{1, 3}
WIC Confidentiality Provisions		X				No

¹ VA guidance applies the HIPAA identifiability standards

² States have flexibility to determine what information is protected.

³ Federal de-identification guidance exists.

Identifiability Defined by Deduction or Inference

- FERPA
 - “information that, **alone or in combination, is linked or linkable** to a specific student that **would allow a reasonable person in the school community**, who does not have personal knowledge of the relevant circumstances, to identify the student with **reasonable certainty**.”
- 42 CFR Part 2
 - “information by which the identity of a patient... **can be determined with reasonable accuracy** either directly or by reference to other information.”
- HIPAA
 - “a **reasonable basis** to believe the information **can be used to identify** the individual.”
- CIPSEA
 - “**permits** the identity of an individual to whom the information applies to be **reasonably inferred** by either direct or indirect means.”

The Problem with Inference or “Reasonable Person” Identifiability

- Actually very difficult to apply
- Safe harbor de-identification standards (e.g., HIPAA) are low risk and easy to use



Federal Legal Framework	Data Use Exceptions	
	Public Health	Research
42 C.F.R. Part 2	No	Yes
Child and Adult Care Food Program	No	No
CIPSEA	No	Yes
Confidentiality of certain (VA) medical records	Yes	Yes
VA Medical Quality Assurance Records	Yes	Yes
FERPA	No	Yes ¹
Head Start	No	Yes
HHS Privacy Act Regulations	No	Yes ²
Higher Education Act	No	Yes ³
HIPAA	Yes	Yes
Homeless Management Information Systems	No	Yes
IDEA, Part B	No	Yes ¹
IDEA, Part C	No	Yes ¹
Medicaid Information Safeguards	No	No
NSLP and SBP	No	No
Protection of Pupil Rights Amendment	No	No
SNAP	No	No
Special Milk Program	No	No
Summer Food Service Program	No	No
Title X	No	No
VA Claims Confidentiality Statute	Yes	Yes
WIC Confidentiality Provisions	No	No

Data Use Exceptions for Public Health and Research

¹ Limited to educational studies

² Several HHS components list research as a permitted purpose

³ Restricts non-governmental research

But that's not all...

- Tremendous variation and complexity in state laws dealing just with health information



EDITOR'S CHOICE

Falling short: how state laws can address health information exchange barriers and enablers FREE

Cason D Schmit ✉, Sarah A Wetter, Bitu A Kash

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Published: 02 November 2017 **Article history** ▼

Public Health Reports

Transitioning From Paper to Digital: State Statutory and Regulatory Frameworks for Health Information Technology

Cason Schmit, JD, Gregory Sunshine, JD, Dawn Pepin, JD, MPH, more...

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First Published August 16, 2017 | Research Article |



<https://doi.org/10.1177/0033354917722994>

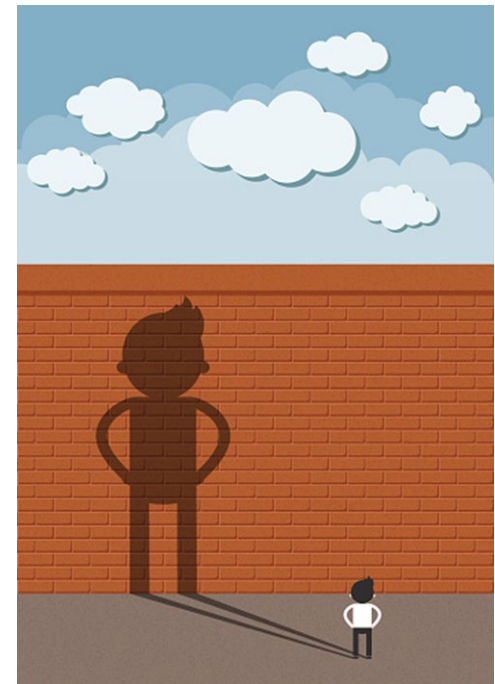


Persistent Data Sharing Barriers

- Unfortunately, effectively leveraging this cross-sectoral data for public health purposes has remained elusive in part because the **United States lacks a unified framework for sensitive data protection** (i.e., privacy, confidentiality, and security).
- Legal data sharing barriers can be both real and perceived
 - Real legal barriers → a law restricts a use or disclosure
 - Perceived legal barriers → belief that a law prohibits a use or disclosure
 - BOTH are actual barriers!

Implications of Legal Uncertainty

- Precautionary data stripping
 - I.e., removal of useful data elements
- At best, legal uncertainty increases transaction costs for data sharing
- At worst, legal uncertainty impedes legal data uses

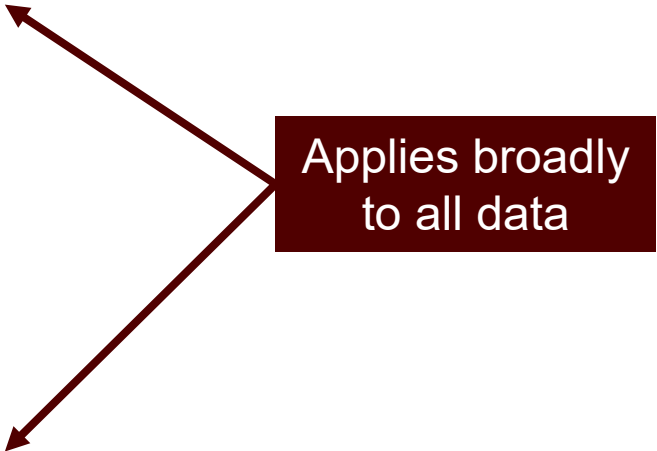


Model for an alternative approach

The European Union's General Data Protection Regulation (GDPR)

GDPR(EU)

- “[A]ppplies to the processing of **personal data** ... which form part of a filing system or are intended to form part of a filing system. ”
- “**personal data**’ means any information relating to an identified or **identifiable natural person**; an identifiable natural person is one who **can be identified, directly or indirectly, in particular by reference to an identifier...**”



Applies broadly
to all data

GDPR and Public Health

- Recital #54
 - “The processing of special categories of personal data **may be necessary for** reasons of public interest in the areas of **public health without consent** of the data subject”
- Article 9
 - “1.Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data ..., [health data or sexual activity data] shall be prohibited.
 - **2.Paragraph 1 shall not apply** if one of the following applies: ...
 - **(i) processing is necessary for reasons of public interest in the area of public health**”

GDPR Article 5: Principles relating to processing of personal data

- “Personal data shall be: ...(b) collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes;
- further processing for archiving purposes in the public interest, **scientific or historical research purposes or statistical purposes shall**, in accordance with Article 89(1), **not be considered to be incompatible with the initial purposes**”



Conclusions

- Inconsistent federal statutes and regulations place different restrictions on how sensitive administrative data can be used.
- Understanding these federal laws is critical to understand how to leverage cross-sectoral data for public health purposes.
- The EU GDPR provides a workable model for a unified approach to data protection while permitting data to be used to promote population health.
- What are the ethical implications of the US data protection framework?

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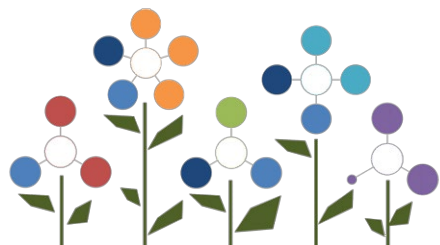


Criminal Justice- Behavioral Health System Review

Data Collaboration with Public Health, Fire, EMS, Hospitals and Law Enforcement

Partnership for a Healthy Community: Tri-County Community Health Improvement Plan

- Four Core Priorities:
 - Behavioral Health
 - Healthy Eating Active Living
 - Cancer
 - Reproductive Health



Partnership for a Healthy Community

Why Behavioral Health?

Perceptions of Health In Our Community

#1 Mental Health

Ranked the **highest** health issue within the community

72%

Of tri-county residents report overall good mental health, less than National Goal 80%.

8.4% (WC), 10% (TC), and 17.8% (PC) reported **more than 8 days of "not good"** Mental Health per month



37% reported the reason being unable to afford co-pay.



Drug Abuse, Anger/Violence & Alcohol Abuse ranked in the Top 4 perceived Unhealthy Behaviors.

59 Drug-Induced Deaths within the tri-county in 2014.

40 # of Suicide Deaths in 2014

In 2012, the suicide rates for PC(12.2), WC (12.8) and TC (15.4) were **above** the state rate (10.1).



Ratio of Population to Mental Health Providers

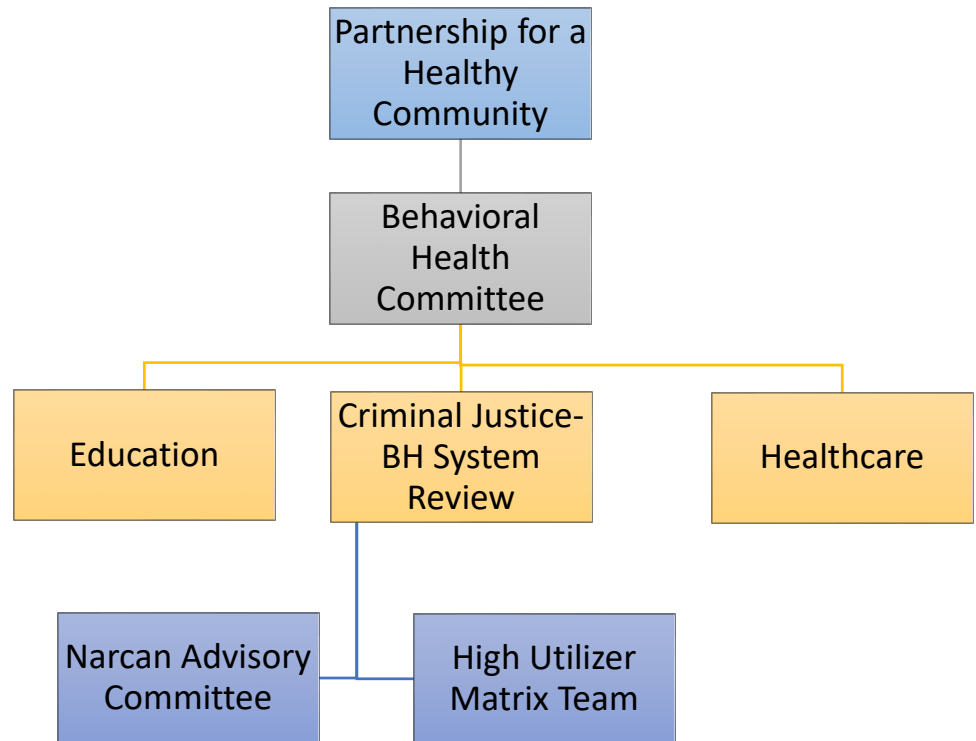
Peoria County: 490:1; Tazewell County : 690:1, Woodford County: 3,560:1



Behavioral Health

GOAL	Improve Mental Health through prevention and access to services for the residents of the tri-county region.	Reduce Substance Abuse among tri-county residents, especially youth.
Objective 1	Increase the proportion of adults reporting good mental health from 72% to 80% by 2019.	Reduce the rate of drug-induced deaths with the tri-county region by 10% from 16.3 per 100,000 tri-county residents to 14.7 per 100,000.
Objective 2	Reduce the suicide rate by 10% for the 11.0 deaths per 100,000 within the tri-county to 9.9 deaths per 100,000 tri-county residents.	Increase the percentage of 12th graders within the tri-county that disapprove the use of marijuana by 20% from 63% to 83%.
Strategy 1	Behavioral Health Primary Care Integration	Reduction of Opioid Abuse
Strategy 2	Culturally adapted healthcare	Behavioral Health Primary Care Integration
Strategy 3	Mental Health Benefits Legislation	Justice System Level Interventions
Strategy 4	School-based Social and Emotional Instruction	Targeted truancy interventions
Responsible Leaders	Behavioral Health Steering Committee Supporting County Health Department - Peoria City/County Health Department	

Organizational Structure



Why Participate?

Fire

Emergency Department

Judge (Problem-Solving Courts)

Probation

Jail

Police

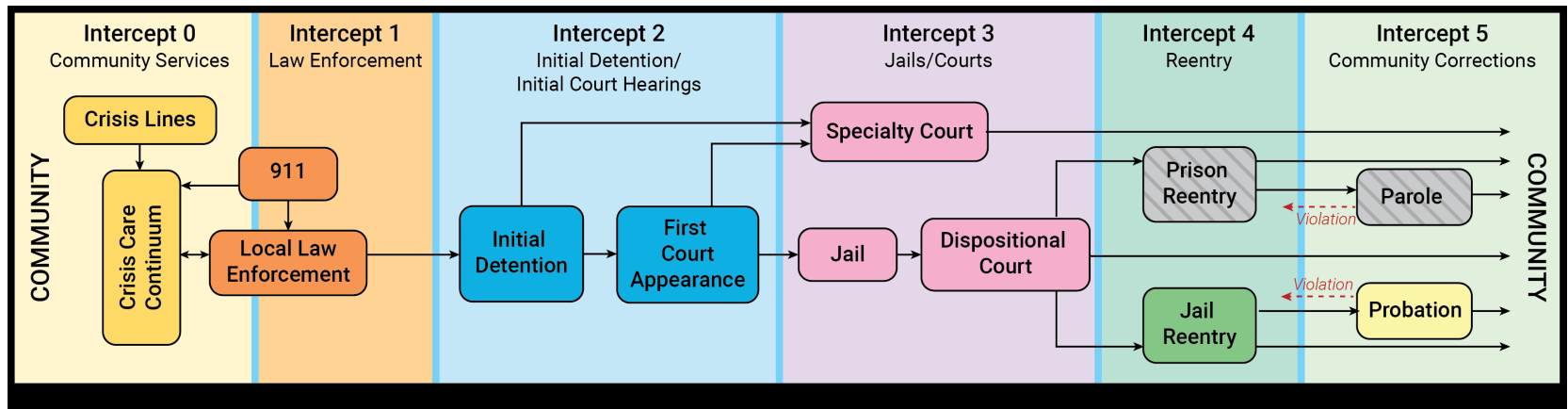
Health Department

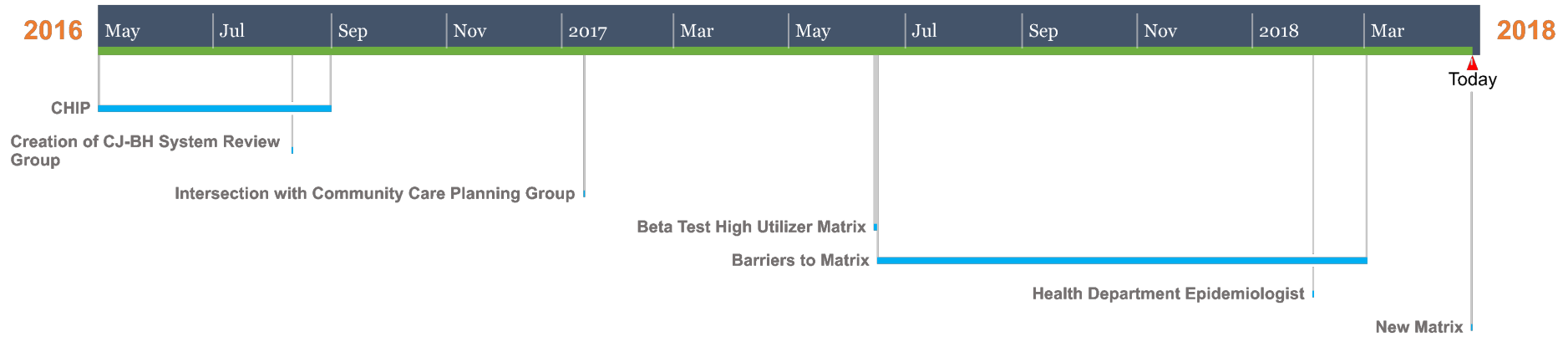
Homeless Services

Common Story

- M. Hendrickson found trespassing, 911 called
- Behavior warrants transport to area hospital
- Release from hospital to county jail for arrest
- Initial hearing
- Release with notice to appear
- M. Hendrickson found trespassing
- Arrested for failure to appear and trespassing
- Initial hearing/courts
- Released
- M. Hendrickson demonstrating erratic behavior
- 911 contacted
- ERS respond and take to ED
- Released
- M. Hendrickson agitated at OSF- ED

CJ-BH System Review





Timeline

Information Sharing

First and Last Name
DOB
Agency Identifier
Number of
Contacts
Charges (jail)
Zipcode



315 HIGH UTILIZERS

- Peoria County Jail – 250
- Human Service Center – 29
- AMT – 22
- Peoria Fire EMS – 11

- ❖ **Purpose 1:** Develop Community Care Plan to manage treatment options and prevent further use of emergency resources.
- ❖ **Purpose 2:** Identify financial impact of the broken system on the community as a whole

Data Sharing Matrix Visual

Client	Peoria County Jail	EMS (Fire)	EMS (AMT)	HSC	Total
A	8			6	14
B			25	39	64
C	6		23	10	39
D		16	34	6	56
E	13		25		38

Data Sharing Matrix Cost

Peoria County Jail	EMS (Fire)	EMS (AMT)	HSC	OSF ED	UP ED
\$134,000	\$10,885	\$169,708	\$152,500	\$2.1 M	\$575,207

Total Cost in 2017: \$3,008,434

Next Steps: Community Investment

Primary Response

- Expand capacities to engage at initial points of response, including on the street, availability at hospitals, and “sitters”

Case Management

- Individual to coordinate with healthcare and social services agencies to provide follow-up, linkage to resources, and support for certain cases.

Information Sharing Technology

- Develop technology to increase quantity, quality, and frequency of data sharing between community agencies to support informed interventions.

Contact Information

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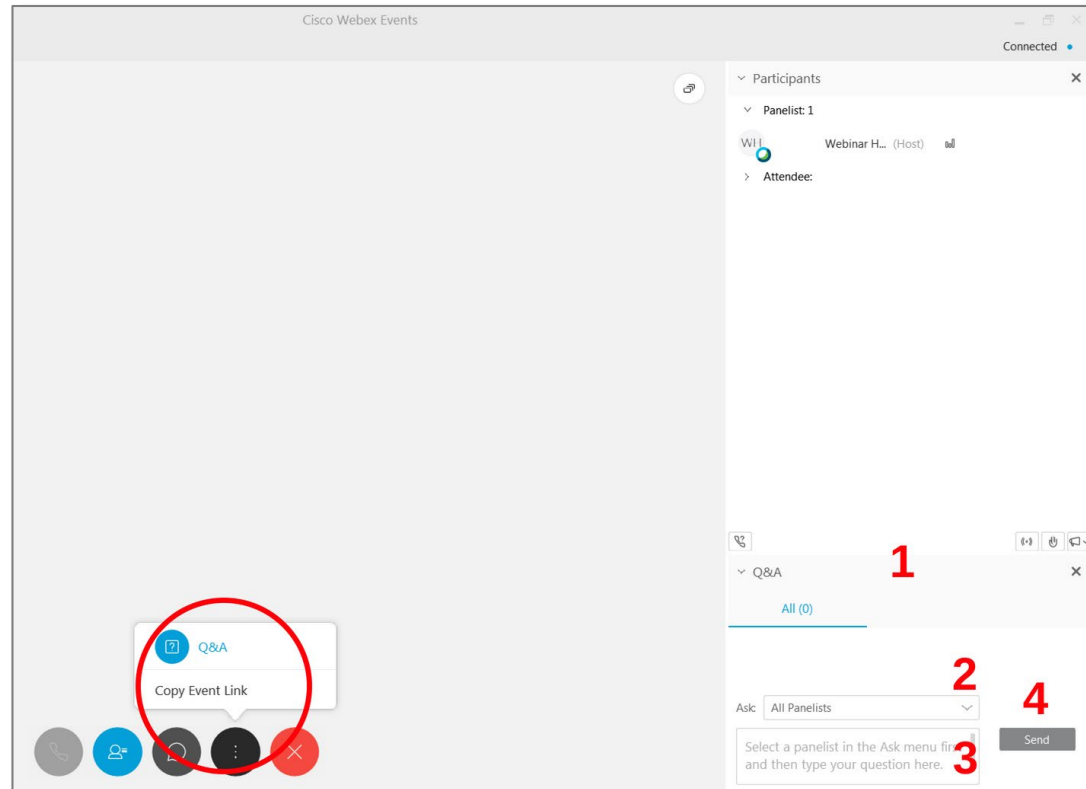
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