



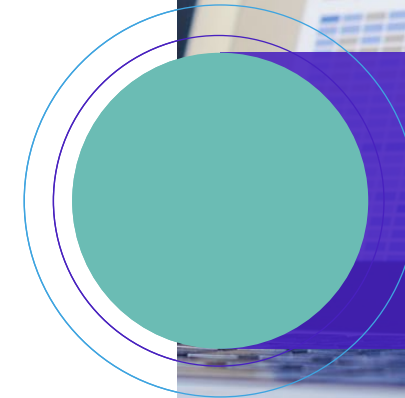
Navigating the Digital Frontier:

The Role of Lawyers in Data Sharing and Integration

Deja Kemp, JD

Director of Legal Policy

Actionable Intelligence for Social Policy (AISP)



URL or other link here optional

TELL US IN THE CHAT:
What do you hope to
get out of today's
training?



Agenda

- Introductions and Overview of AISP & DISC
- Overview Administrative Data
- Role of Lawyers
- Legal Risk
- Ethical Use
- Questions

What We Do

- **Convene** and advocate on behalf of communities that are sharing and using cross-sector data for good
- **Connect** to innovations, best practices, and research and funding opportunities that support ethical data sharing
- **Consult** with data sharing collaborations to build the human and technical capacity to share data and improve lives

Why We Do It

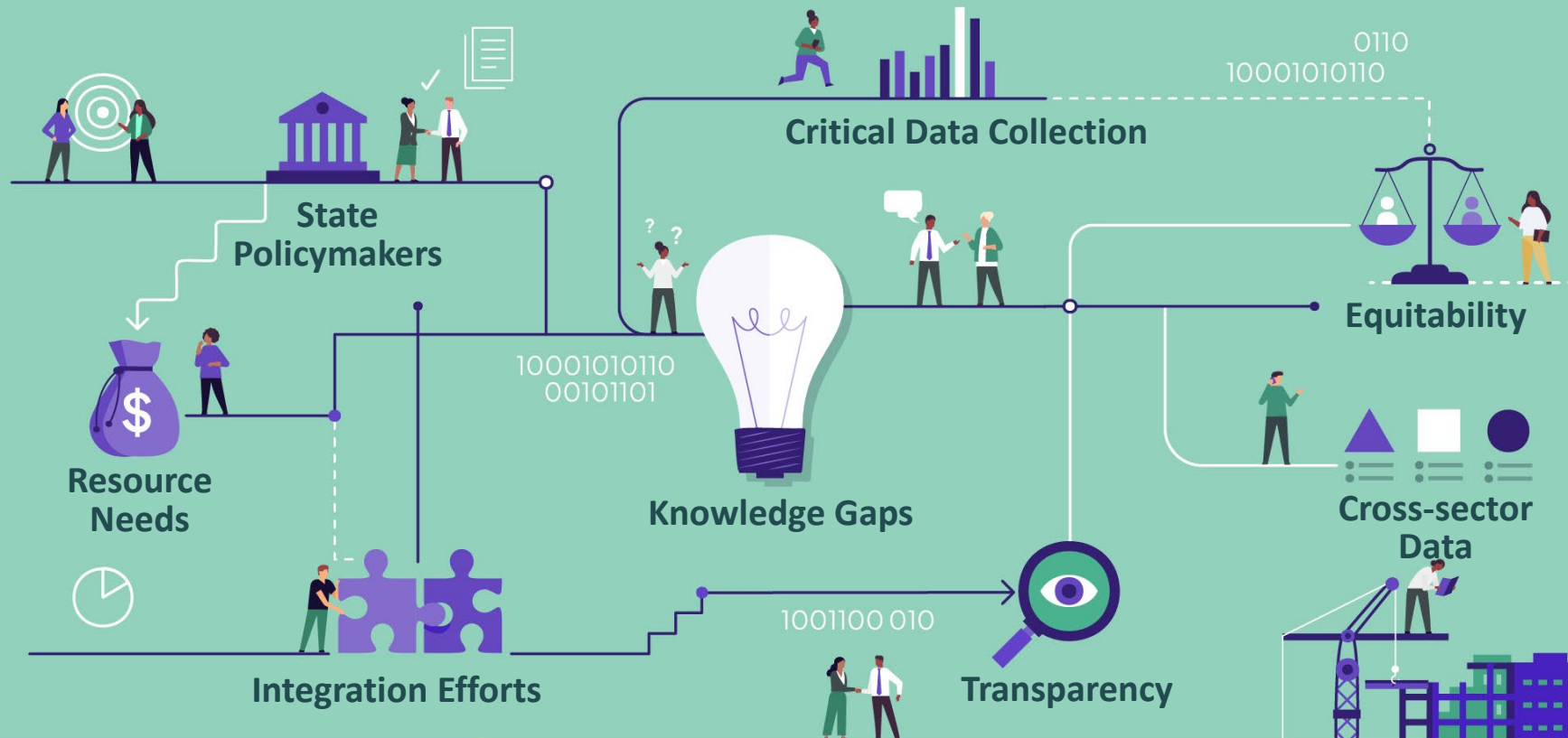
When communities bring together cross-sector data safely and responsibly, policy-makers, practitioners, and schools are better equipped to:

- Understand the complex needs of individuals and families
- Allocate resources where they're needed most to improve services
- Measure long-term and two-generation impacts of policies and programs
- Engage in transparent, shared decision-making about how data should (and should not) be used

www.aisp.upenn.edu



The Data Integration Support Center (DISC) at WestEd provides expert integrated data system planning and user-centered design, policy, privacy, and legal assistance for public agencies nationwide.



Our roles



We are:

Data evangelists

Connectors, community builders, thought partners, cheerleaders, and data sharing therapists

Focused on ethical data use for policy change



We are not:

Data holders or intermediaries

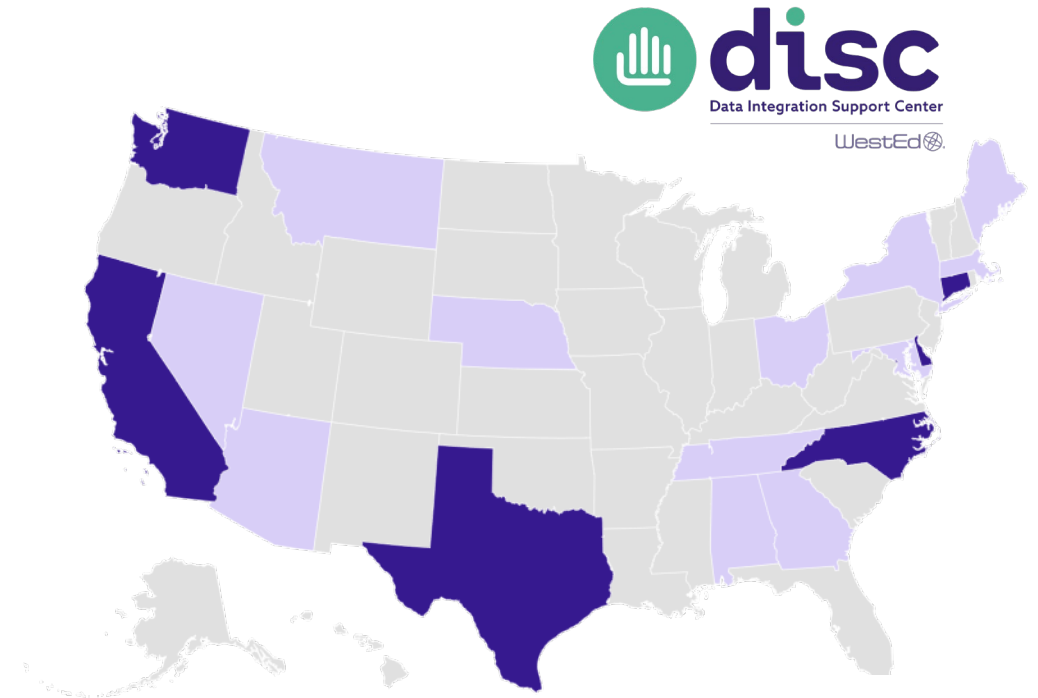
A vendor or vendor recommender

Focused on academic research

Our Networks



● Network Sites ● Developing Sites



● Intensive TA support ● Moderate TA support

What we do

AISP

IDS Peer Network

Guidance & Standards

Training & Consulting

Advocacy & Communications

Multi-site Research

DISC

Planning & User-Centered Design

Legislative Analysis

External Legal Support

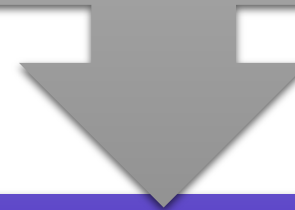
Privacy

System Security

Our approach



Data sharing is as relational
as it is technical.



We don't just need to integrate
data;
we need to integrate people.

ESSENTIAL QUESTIONS



What are administrative data and how are they used in integrated data systems (IDS)?



How can lawyers contribute to the ethical use of data within IDS?



What role do lawyers play in safeguarding privacy and data protection within IDS?



What are the potential legal risks and liabilities associated with integrated data systems that lawyers should advise their clients and organization of?

Administrative Data

What are administrative data?

Administrative data

- Data collected by government agencies in the normal course of delivering social services and programs
- Can also be repurposed to support evaluation, analysis, and research



DEPT. OF JOURNAL MISFEITS
MILLION-DOLLAR MURRAY

Why problem-life decisions may be better to solve than to manage.

BY MALCOLM GLADWELL

Money Murray was a bear of a man, an
iron master, an football and lawyer,
and when he fell down—which he
did nearly every day—it could take two
or three grown men to pick him up. He
had straight black hair and a stern face. On
the street, they called him Murray. He
was wearing most of his teeth. He had a
wooden smile. People loved Murray.

Somehow people at Home DEP, which is
to walk through the aisles and finish
off the half-empty glasses of beer left
at the gaming tables.

"If you see on a screen, you could pick
him up several times a day," Patrick
O'Regan, who is a deputy cop in down-
town Reno, said. "And he's gone on
some amazing stunts. He would get

"Blame, you know you know us," and
he'd say, "I know"—and go back to
smoking it."

"I've been a police officer for fifteen
years," O'Regan's partner, Steve Johns,
said. "I picked up Murray up about sev-
eral times."

Johns and O'Regan pleaded with
Murray to quit drinking. A few years
ago, he was assigned to a treatment pro-
gram in which he was under the super-
vision of counselors, and he failed. He
got a job and worked hard, but when the
program ended, "When he graduated
out, he had no one to support us, and he
needed that," O'Regan said. "I don't
know whether it was his military back-
ground. I suspect that it was. He was a
good cook. One time, he accumulated



The homeless man "Murray" problem, a day that was further down the road of the world was. Photograph by John Gagliardi.

His chosen drink was vodka. Beer
he called "house pin." On the streets
of downtown Reno, where he lived, he
could buy a two-hundred-and-fifty-
milliliter bottle of cheap vodka for a
dollar fifty. If he was lucky, he could
go for the seven-hundred-and-fifty-
milliliter bottle, and if he was lucky he
could always do what many of the other

picked up, get drunk, then get back
and a couple of hours later and start up
again. A lot of the guys on the street
when they were drinking, they got to
sleep. They are so incredibly drunk, so
tired, so alone. Murray was such a
character and had such a great sense of
humor that we couldn't get past that.
Even when he was alone, we'd say,

endings of every five thousand dollars.
Rising up for weeks regularly. Did ev-
erything he was supposed to do. They
said, "Congratulations," and put him
back on the street. He spent that six
thousand in a week or so."

Others, he was too intoxicated for the
drink took at the job, and he'd get sent
to the emergency room or either take



Million Dollar Murray

Researcher quoted extensively in this article is Dennis Culhane, the co-founder of AISP.

Read, [Million Dollar Murray, The New Yorker, 2/13/2006](#)

Don't worry,
I'm not going
to read this to
you.



“In the nineteen-eighties, when homelessness first surfaced as a national issue, the assumption was that the problem fit a normal distribution: that the vast majority of the homeless were in the same state of semi-permanent distress. It was an assumption that bred despair: if there were so many homeless, with so many problems, what could be done to help them? Then, fifteen years ago, a young Boston College graduate student named Dennis Culhane lived in a shelter in Philadelphia for seven weeks as part of the research for his dissertation. A few months later he went back, and was surprised to discover that he couldn't find any of the people he had recently spent so much time with. “It made me realize that most of these people were getting on with their own lives,” he said. **Culhane then put together a database—the first of its kind—to track who was coming in and out of the shelter system. What he discovered profoundly changed the way homelessness is understood.** Homelessness doesn't have a normal distribution, it turned out. It has a power-law distribution. “We found that eighty per cent of the homeless were in and out really quickly,” he said. “In Philadelphia, the most common length of time that someone is homeless is one day. And the second most common length is two days. And they never come back. Anyone who ever has to stay in a shelter involuntarily knows that all you think about is how to make sure you never come back.”

WHEN PEOPLE HAVE A HOME

They spend **less time** in



hospitals,
police
custody
& shelters

10 people + 10 homes

6 months

SAVED

\$668,000



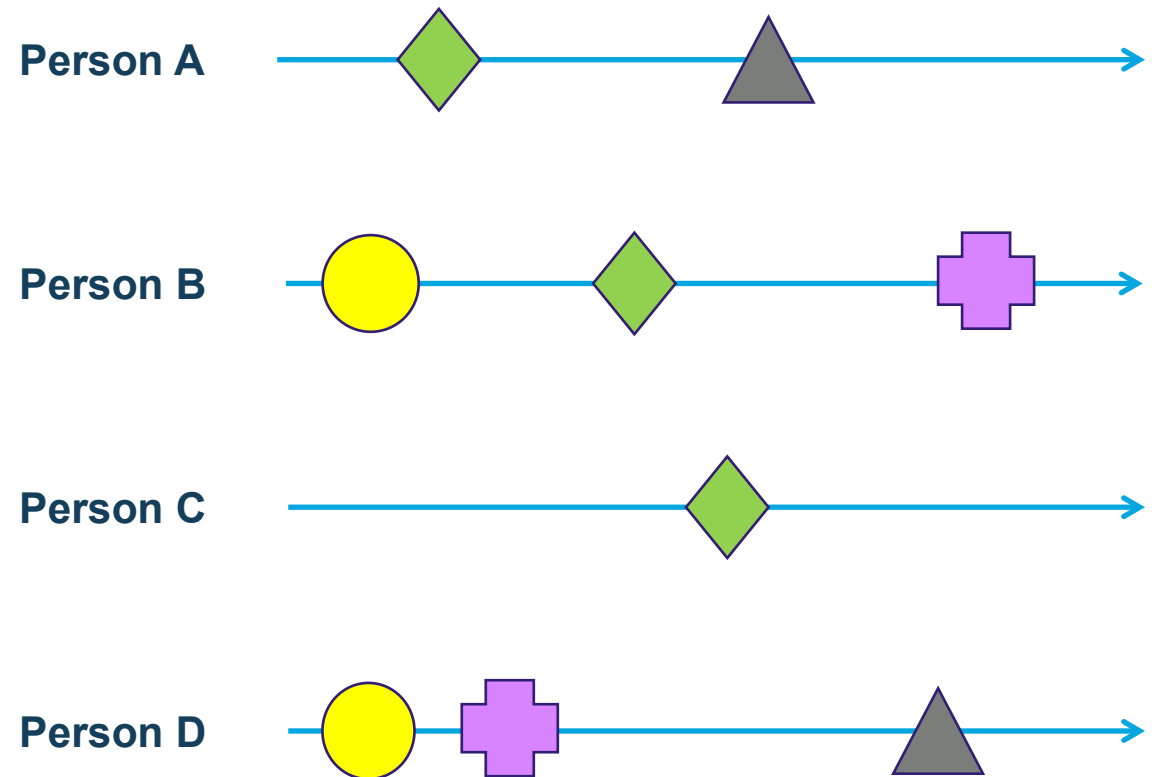
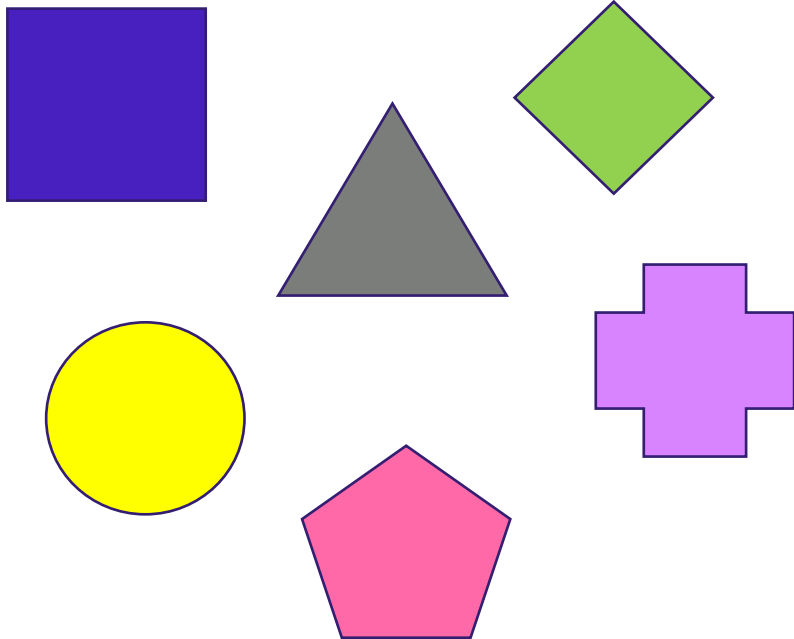
Housing First
Think about it.


upstream

Housing First is an initiative led by the United Way Saskatoon and area. Data provided by the United Way.

What is the difference?

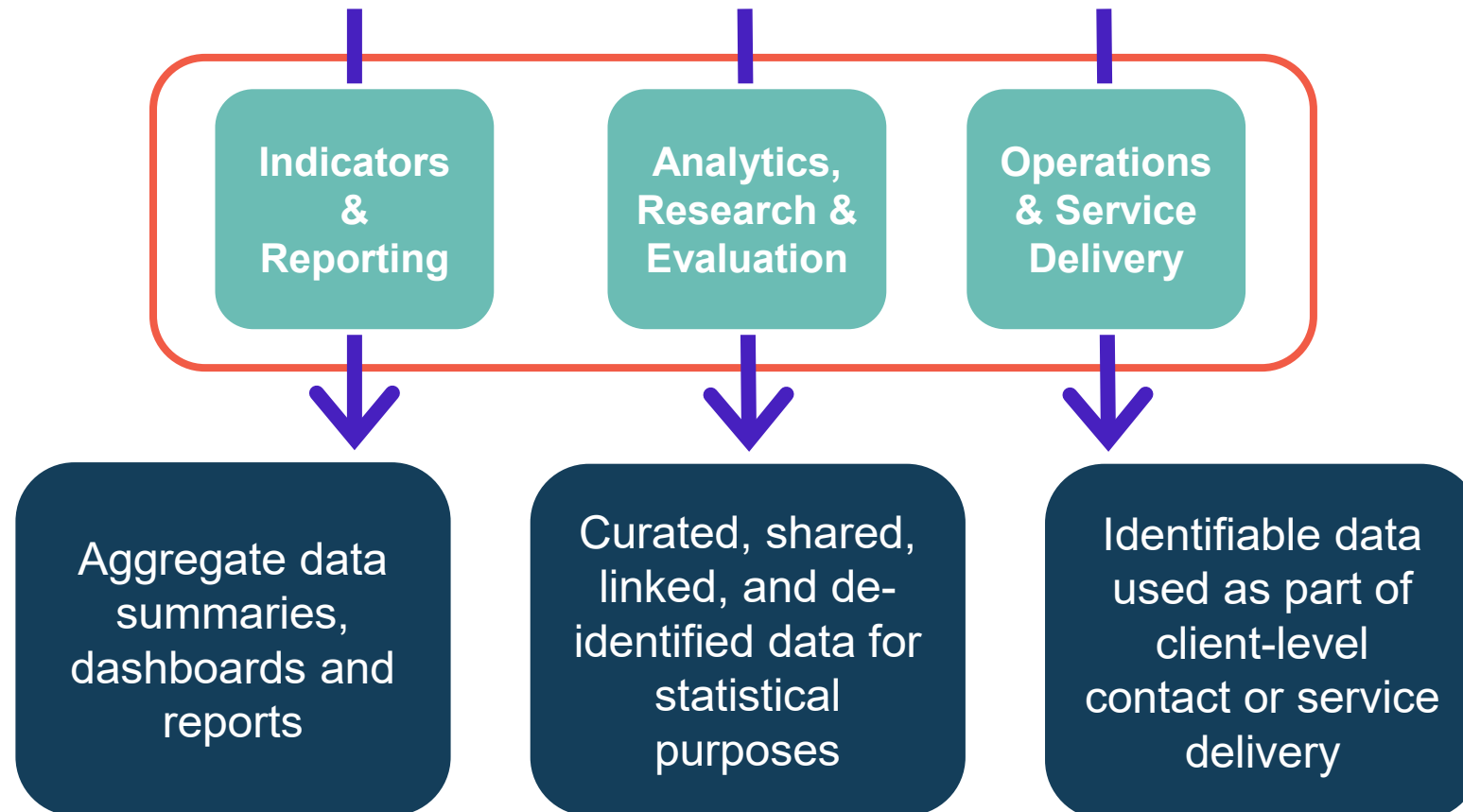
SHARED ADMINISTRATIVE DATA SET



When we bring data together, we can better:

Understand	Understand the complex needs of individuals and families
Allocate	Allocate resources where they're needed most to improve quality and equity of services
Measure	Measure long-term impacts of policies and programs
Engage	Engage in transparent, shared decision-making about how data should (and should not) be used

Common Uses for Data Sharing & Integration



The Power & Promise of Integrated Data

Early Childhood IOWA

Early Childhood Iowa
Statewide
Needs Assessment
2019

"Every child, beginning at birth, will be healthy and successful."

This publication was made possible by the Preschool Development Grant Birth to Five (Grant Number 9079030-01-00) from the Office of Child Care, Administration for Children and Families, U.S. Department of Health and Human Services as part of a grant totaling \$2,393,139 with 0% financed with non-governmental sources. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Office of Child Care, the Administration for Children and Families, or the U.S. Department of Health and Human Services.

CHARLOTTE-MECKLENBURG
FAMILY HOMELESSNESS
SNAPSHOT
2014-2015

March 2017

Data Brief: An Assessment of Opioid-Related Deaths in Massachusetts 2013-2014

Massachusetts Department of Public Health POSTED: SEPTEMBER 2016

INTRODUCTION

Since 2000, opioid-related deaths have increased in Massachusetts by 350%. The recent rate of increase is several times faster than anything seen before with every community in Massachusetts impacted by the current opioid epidemic. In 2013-2014 alone, opioid-related deaths were recorded in two-thirds of the cities and towns in Massachusetts.

Understanding the causes and deadly impacts of this issue can be a challenge. In the face of this public health crisis, the Commonwealth of Massachusetts has taken an unprecedented look at the available data on opioid-related deaths.

CHAPTER 55

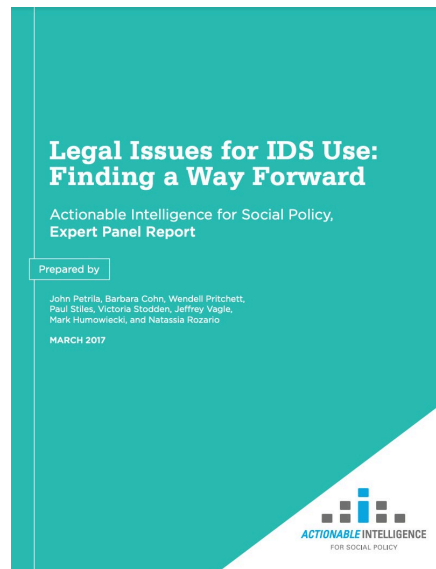
Chapter 55 of the Acts of 2015 (Chapter 55) was passed by the Massachusetts Legislature and signed into law by Governor Charles D. Baker in August 2015. This new law permits the linkage and analysis of different government data sets to better understand the opioid epidemic; guide policy development; and help make programmatic decisions. Importantly, in addition to providing insight into the current opioid epidemic, this effort also marks the beginning of how government, academia, and private industry can and should collaborate to answer complex health questions. This new model of cooperative data analysis has the potential to become the standard in Massachusetts and across the United States. The Chapter 55 project represents a process that should be continued, adapted, and refined as new public health challenges and new collaborators emerge.

What do lawyers
have to do with this?

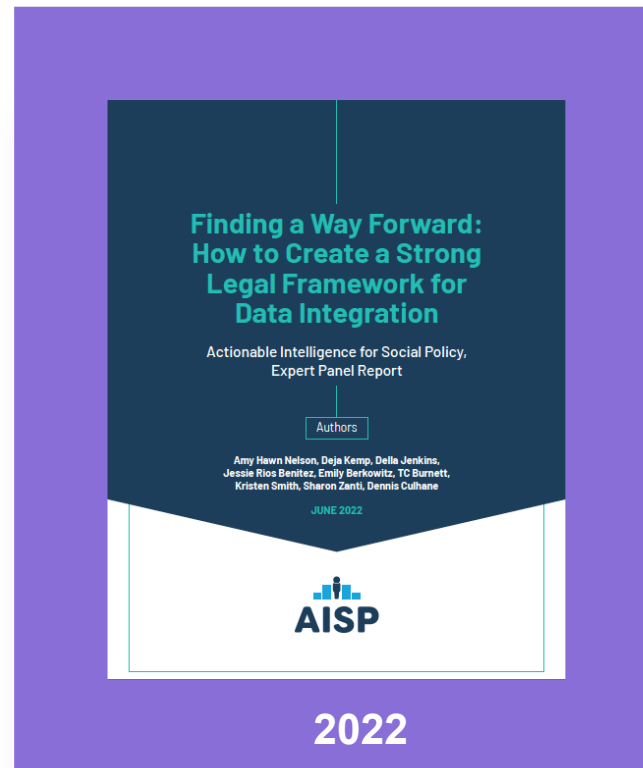
Quality Framework for IDS

Governance	Data governance is the people, policies, and procedures that support how data are used and protected.
Legal	Whether data can be shared legally depends on why you want to share, what type of information will be shared, who you want to share with, and how you will share the data. Legal agreements should reflect the purpose for sharing, document the legal authority to serve that purpose, and ensure that data sharing complies with all federal and state statutes.
Technical	Technical components are created to support analytics and insights that can help further improvements in policies, practice, and outcomes.
Capacity	Data sharing capacity refers to the staff, relationships, and resources that enable an effort to operate governance, establish legal authority, build technical infrastructure, and above all else, demonstrate impact.
Impact	All components of quality—governance, legal agreements, technical tools, and staff capacity—exist to drive impact.

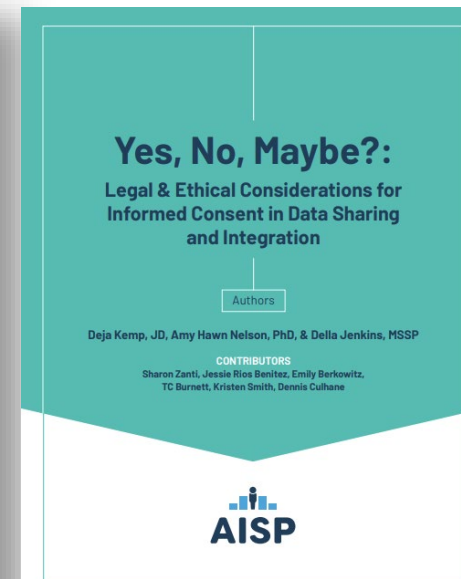
Legal Publications



2017

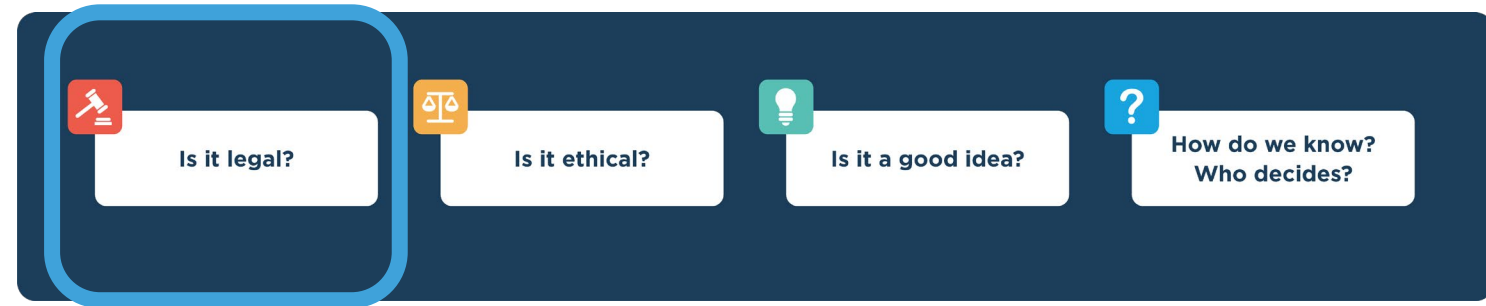


2022



2023

Why: The Four Questions



Lawyer's Role



Draft, review and negotiate data sharing agreements, licenses and MOUs



Counsel clients on legal risks associated with data sharing and integration



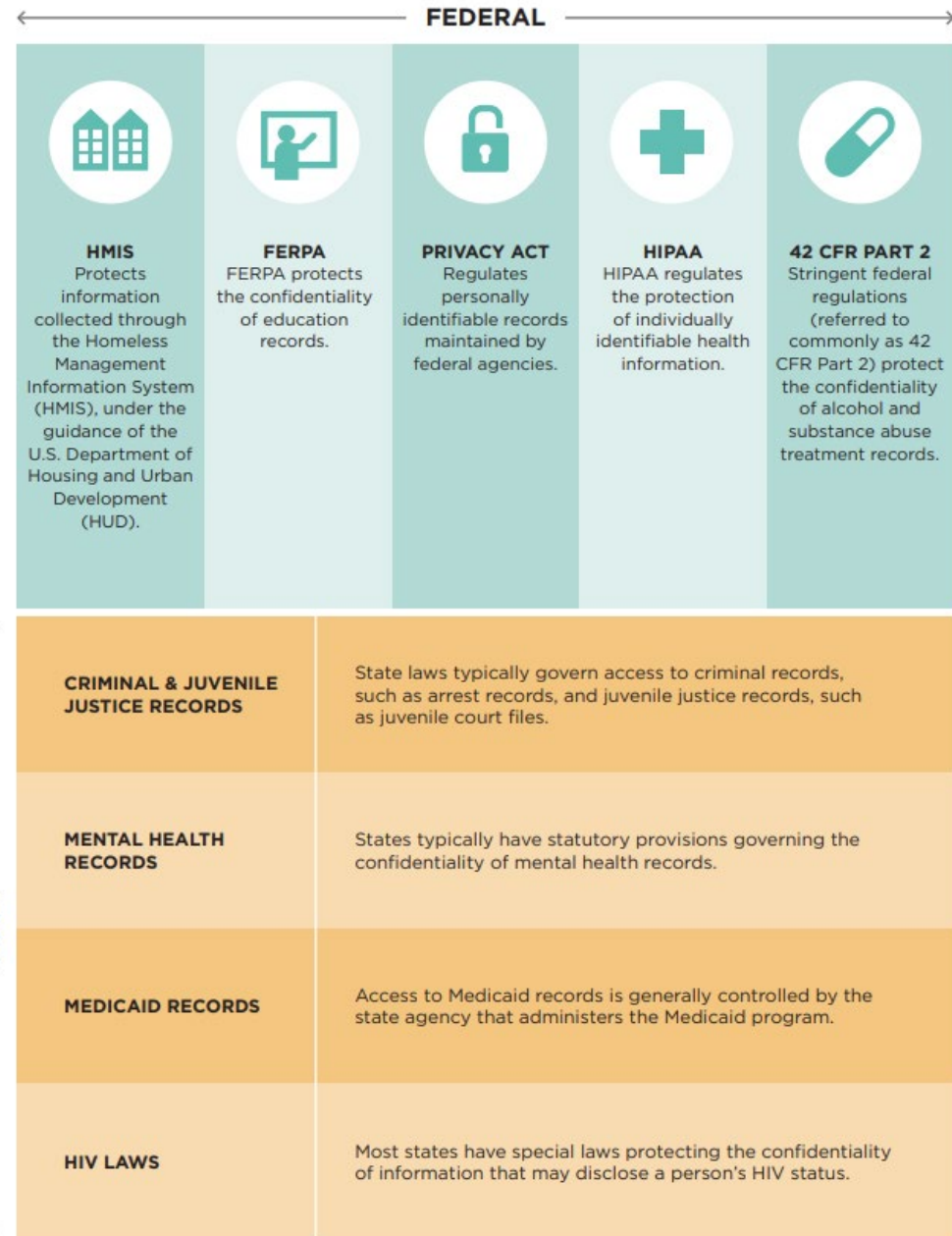
Provide advice and guidance on state and federal laws impacting data sharing and integration



Defend organization from lawsuits and enforcements actions because of data sharing and integration

Primarily being called on to resolve issues related to disclosure (Access & Use)

State & Federal Laws



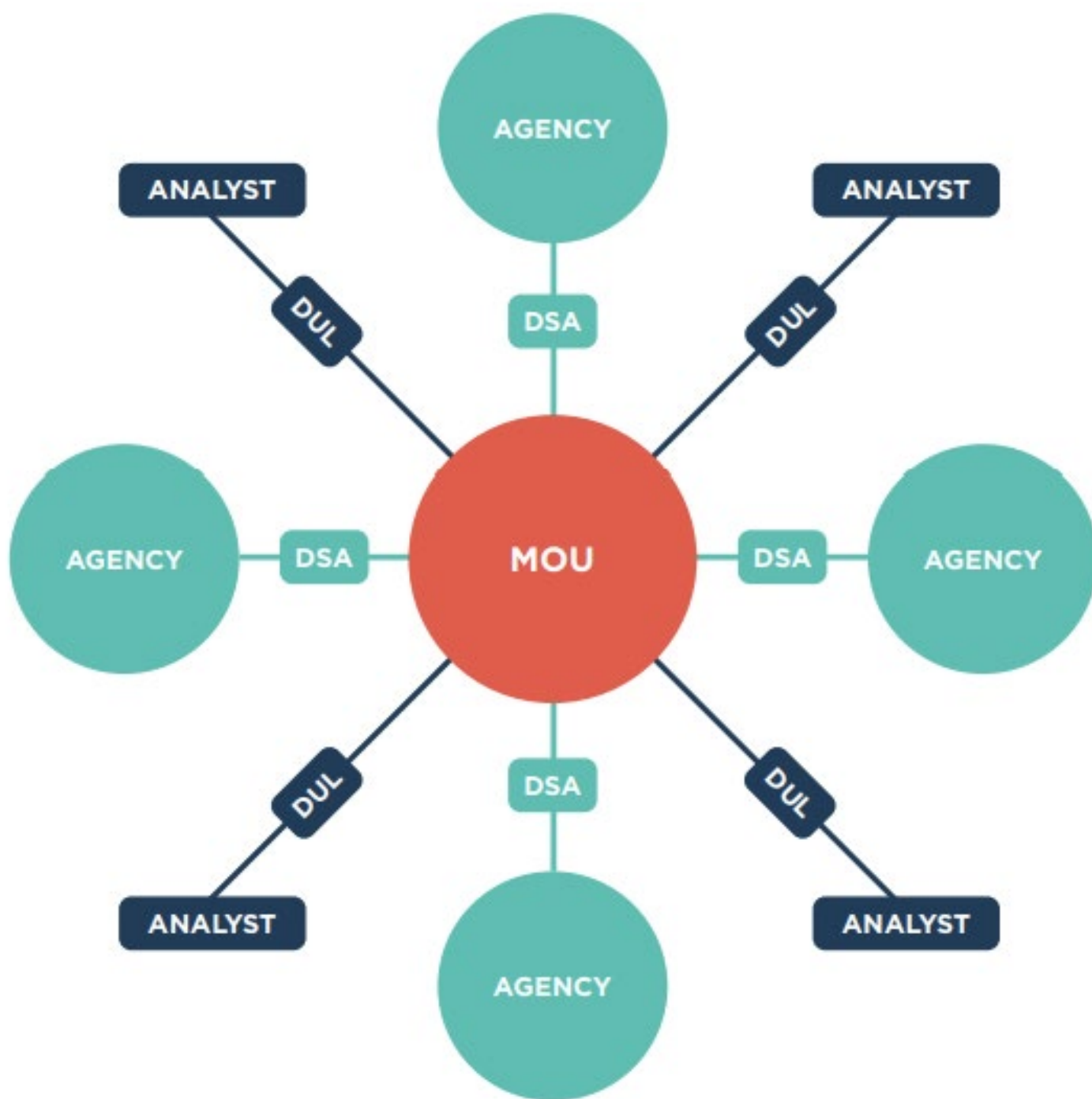
Authority and Access

Open Data	Restricted Data	Unavailable Data
Data that can be shared openly, either at the aggregate or individual level, based on state and federal law.	Data that can be shared, but only under specific circumstances with appropriate safeguards in place.	Data that cannot or should not be shared, because of legal restriction or another reason (e.g., data quality concerns).



How: The Legal Agreements

FOUNDATIONAL LEGAL AGREEMENTS			
LEGAL AGREEMENT	PURPOSE	PROCESS	SIGNATORY
Memorandum of Understanding MOU <i>Overarching process document signed on by all data partners</i>	The MOU documents the purpose and governance process. The MOU will be signed by all data partners as they enter the collaboration. The MOU references the DSA, DUL, and relevant policies, and procedures for data access and use.	Drafted in partnership with legal counsel from all participating data partners	Lead agency/ies + all data partners
Data Sharing Agreement DSA <i>Agency-specific to how data will be used for integration</i>	The DSA includes the specific terms and conditions that govern how data are transferred, stored, and managed when shared and integrated. The DSA references the MOU and the DUL. This document is specific to data held by a data partner.	Template is drafted in partnership with legal counsel from all participating data partners. Completed according to specific data assets of the data partner. Reviewed and updated annually, or as agreed upon.	Lead agency/ies + data partner
Data Use License DUL <i>Data use-specific once data has been integrated</i>	The DUL outlines the role and responsibilities of the data recipient. The DUL is often executed after the Data Request Form is approved. The Request Form and/or DUL should include: purpose, data fields, anonymization procedures, dissemination plan, and timeline of project completion. A DUL must be executed prior to data access.	Template is drafted in partnership with legal counsel from all participating data partners. Once data request is approved, a DUL is executed.	Lead agency/ies + data recipient



We suggest agreements that are:

- Tiered
- Standardized but flexible
- Transparent and comprehensible

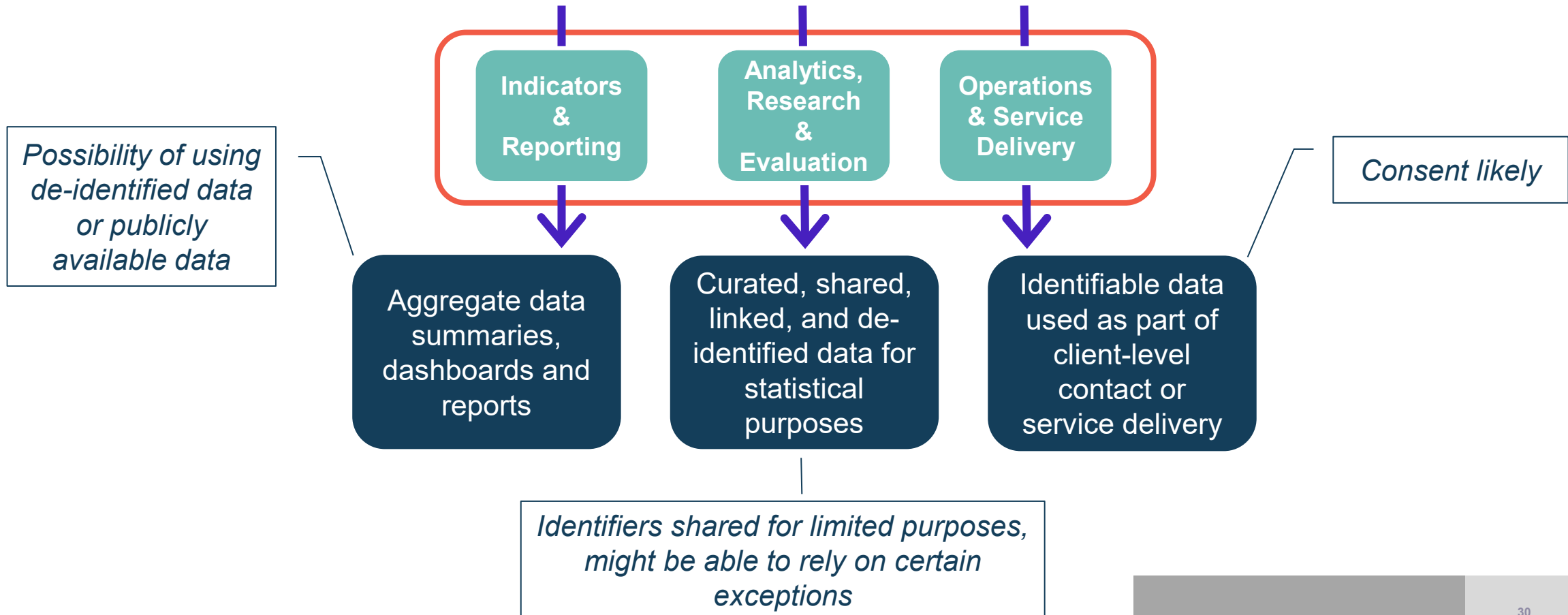
Questions that a lawyer might help resolve...

Can a SEA share K-3 data with Head Start to evaluate efficacy of Head Start in preparing students for school?

Could a patient's initials or the last four digits of their SSN be disclosed under HIPAA?

Could a health care provider share PHI with an HMIS to identify individuals for care coordination?

Lawyers inform on legality of use



Legal Risks

What are the potential legal risks of data sharing and integration?



Risk of Unauthorized Disclosure

- Breaches
- Security Incidents
- Re-identification

Misuse

- Data used for different purposes other than allowed under law and/or contemplated under agreements

Financial Penalties

- Enforcement Actions
 - State & Federal Investigations
 - Loss of funding
 - Penalties
 - Cost of corrective actions (notices, credit monitoring, etc.)

How can lawyers help their clients avoid liability?



Mitigate

Well drafted agreements that allocate risk

Properly insured

Incident Response Plans & Procedures



Prevent

Routine risk assessments and audits

Routine legal trainings

Data Minimization & De-Identification Protocols



Respond

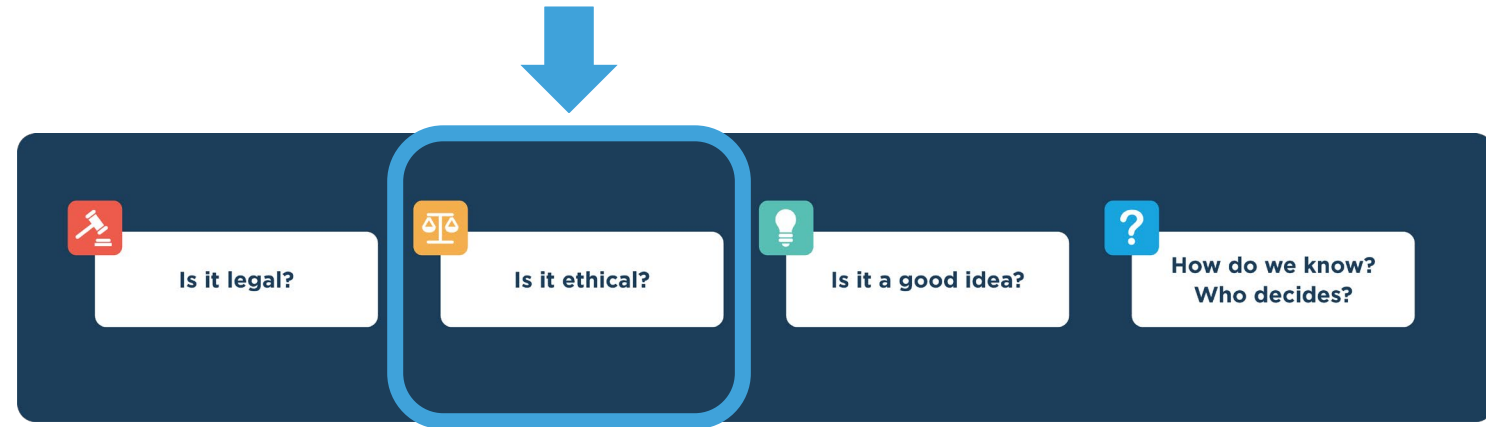
Investigate to determine scope & impact

Preserve evidence

Work with team to ensure no additional data loss or unauthorized access

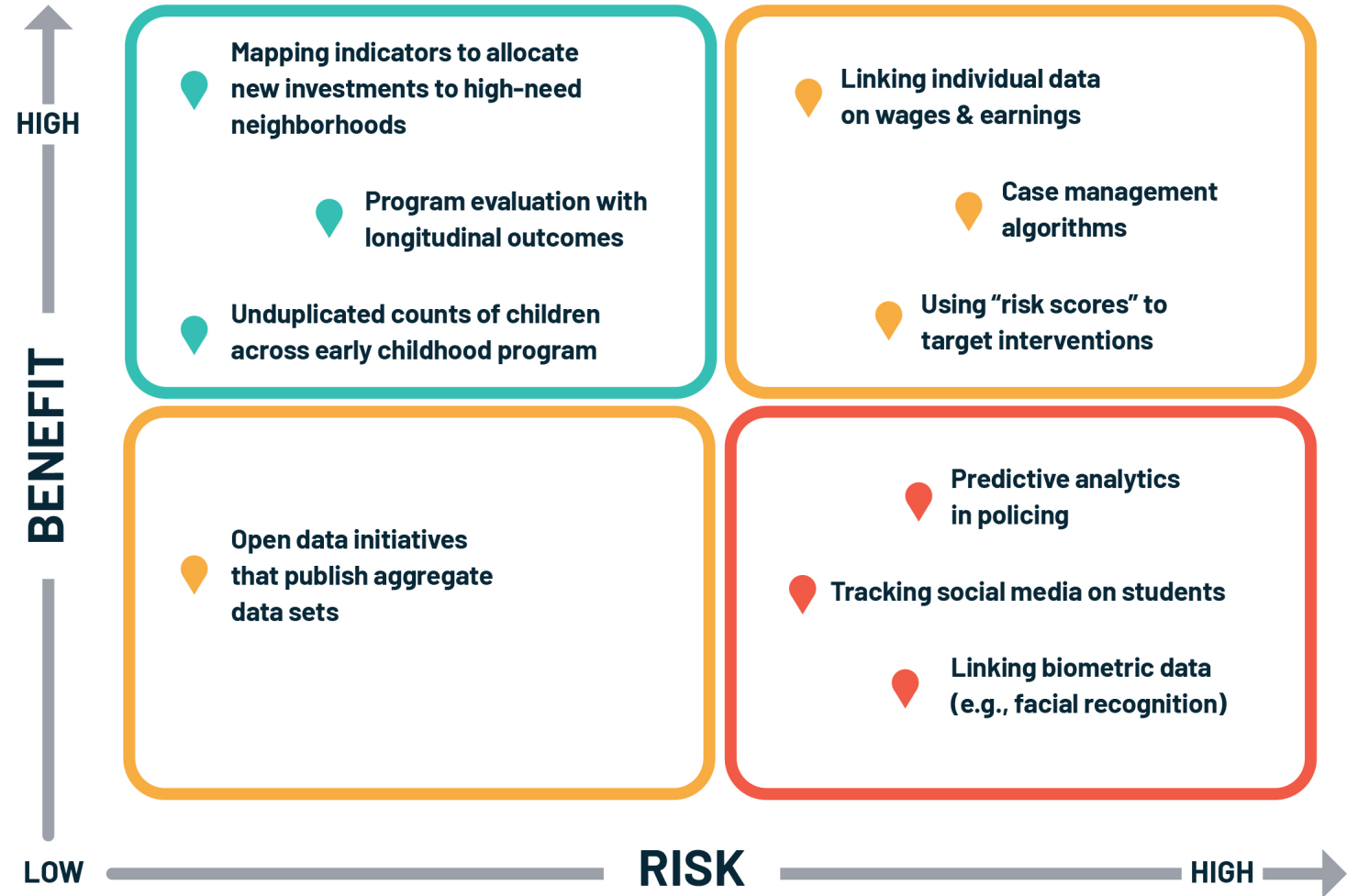
Ethical Use

Why: The Four Questions



2. IS THIS ETHICAL?

Social License, Risk v. Benefit



Ethical Problems

- Erasure
- Surveillance
- Comprehension
- Undue Influence
- Coercion

RESPECT FOR PERSONS	JUSTICE	BENEFACTENCE
Privacy must be protected	Risks and benefits must be fairly distributed	Benefits must outweigh risks

Racial Equity & Consent

The New York Times

Indian Tribe Wins Fight to Limit Research of Its DNA

Give this article Share Bookmark 321

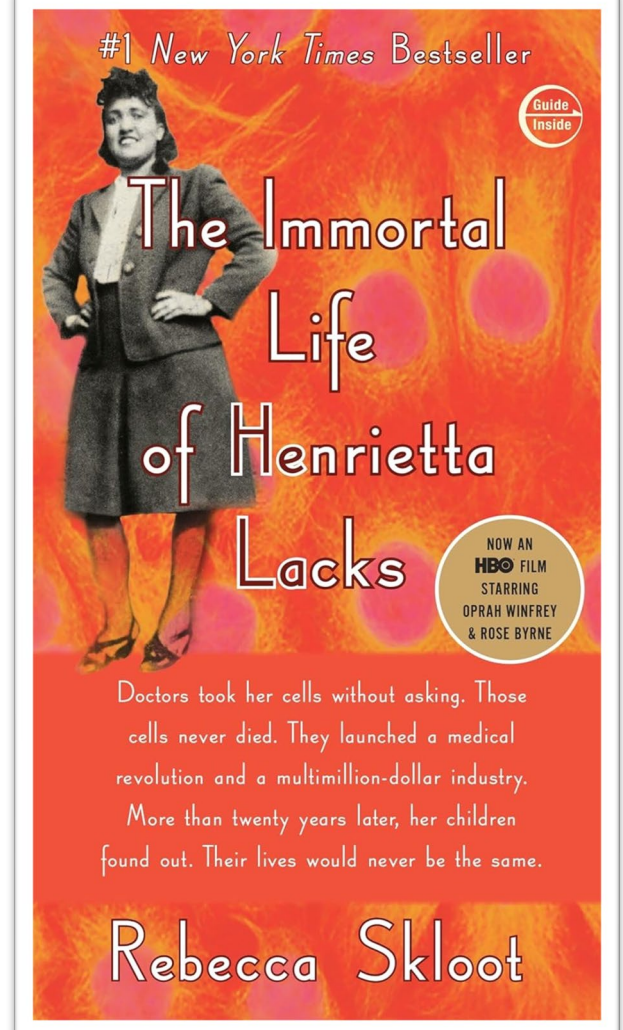


Edmond Tilousi, 56, who can climb the eight miles to the rim of the Grand Canyon in three hours.
Jim Wilson/The New York Times

By **Amy Harmon**
April 21, 2010

[See how this article appeared when it was originally published on NYTimes.com.](#)

SUPAI, Ariz. — Seven years ago, the [Havasupai Indians](#), who live amid the turquoise waterfalls and red cliffs miles deep in the Grand Canyon, issued a “banishment order” to keep Arizona State University employees from setting foot on their reservation — an ancient punishment for what they regarded as a genetic-era betrayal.



#1 New York Times Bestseller

Guide Inside

The Immortal Life of Henrietta Lacks

NOW AN HBO FILM STARRING OPRAH WINFREY & ROSE BYRNE

Doctors took her cells without asking. Those cells never died. They launched a medical revolution and a multimillion-dollar industry. More than twenty years later, her children found out. Their lives would never be the same.

Rebecca Skloot

ELEMENTS	DESCRIPTION	PRACTICAL EXAMPLES
Not Passive or Implied	Consent should be affirmatively given, allowing participants to actively ask questions and seek clarification.	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Opt-Out⁵⁹
Willingly Given	The participant should have full mental capacity to provide consent, and consent should be given without undue pressure, coercion, or force. The participant should be in a position to freely decide whether to permit sharing data.	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Allow adequate time for prior review <input checked="" type="checkbox"/> Participant sign “on the spot” without time for review
Understandable	The information should be given in plain language, in terms that the subject population understands. Further, the process should ensure that all risks and benefits are disclosed.	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Plain language <input checked="" type="checkbox"/> Specific <input checked="" type="checkbox"/> Brief <input checked="" type="checkbox"/> Broad or vague language <input checked="" type="checkbox"/> Legalese <input checked="" type="checkbox"/> Lengthy and dense
Revocable	The instrument should clearly state that consent can be withdrawn at any time for any purpose.	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Language that suggests the consent exists in perpetuity <input checked="" type="checkbox"/> Time-bound <input checked="" type="checkbox"/> Clear instructions for how to revoke or terminate consent
Not Conditioned on a Benefit	The instrument should make clear that refusing to consent will result in no penalty or loss of benefits.	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Penalties or loss of benefits for refusing to give consent
No Exculpatory Language	The instrument should not contain language that purports to waive or appears to waive a participant’s legal rights or appears to release the institution or its agents from liability or negligence.	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Release or any language that has the effect of freeing an entity from liability, negligence, fault, guilt, or blame

Consent Framework

How can lawyers contribute to ethical use?

- **Data minimization**
- **Data destruction/disposal guidelines**
- **Informed consent**
- **Ensuring data not misused or used for discriminatory purposes**

Questions?

Closing Reflections

TELL US IN THE CHAT:
What is one thing you are
taking away from this training
today?



Thank you.

Deja Kemp, JD

AISP Director of Legal Policy
dejak@upenn.edu

A Project of
WestEd 



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