



Data 101 for Lawyers: Navigating the Data Life Cycle

Kim Paull

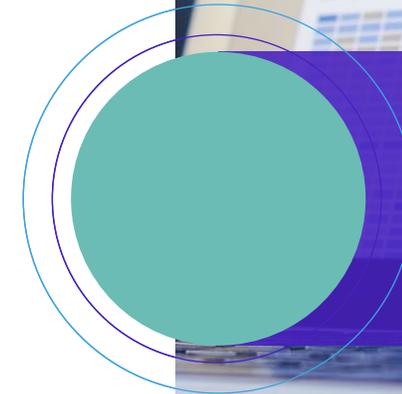
Director, Health Equity Clinical
Programs

Blue Cross Blue Shield of Rhode
Island

Amy Hawn Nelson

Director of Training and
Technical Assistance

Actionable Intelligence for Social Policy





Welcome!

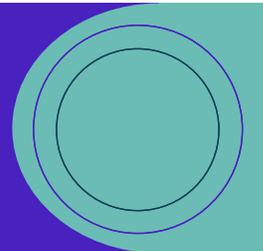
Add to the chat:

- Name & organization
- On a scale of 1-10, how much is data, or questions about data, part of your regular work?
- If you could have a job for exactly 1 week, and not a day more, what would it be?



Do the numbers speak for themselves?

What stories can data tell us about our communities?
How can data be used to share power?



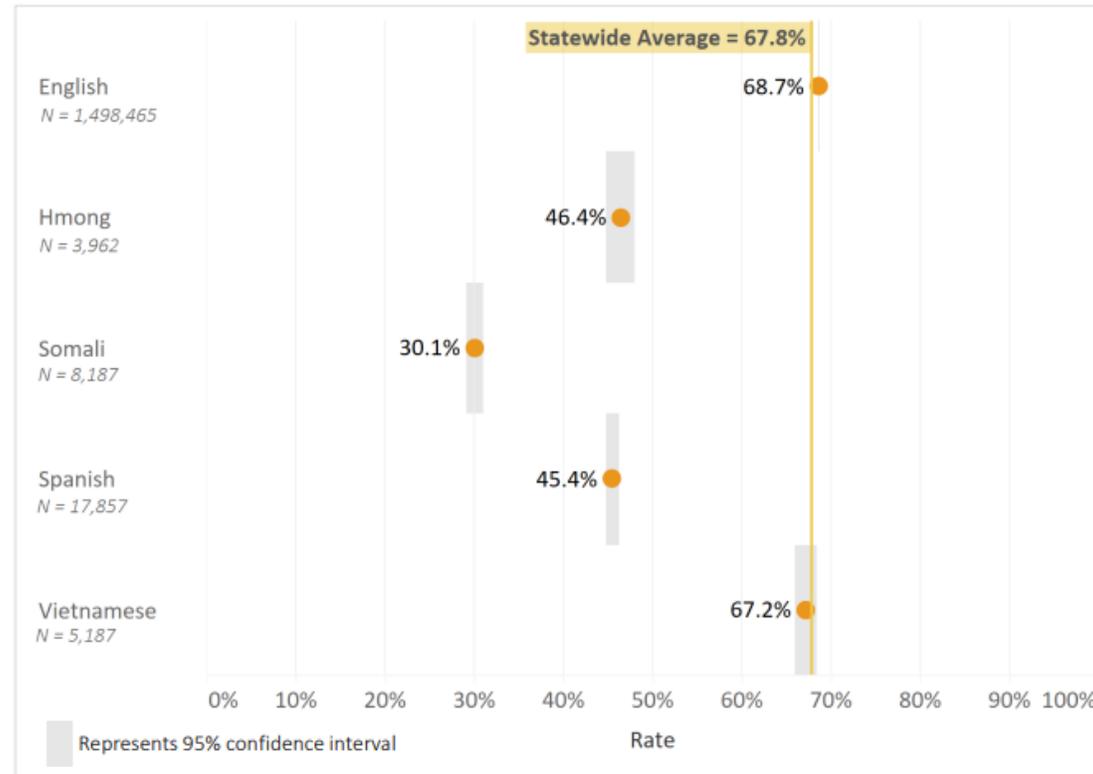
Data can tell stories and build power with communities

What story can these data tell and how can it support equity?

COLORECTAL CANCER SCREENING

Preferred Language Summary

2022 measurement year

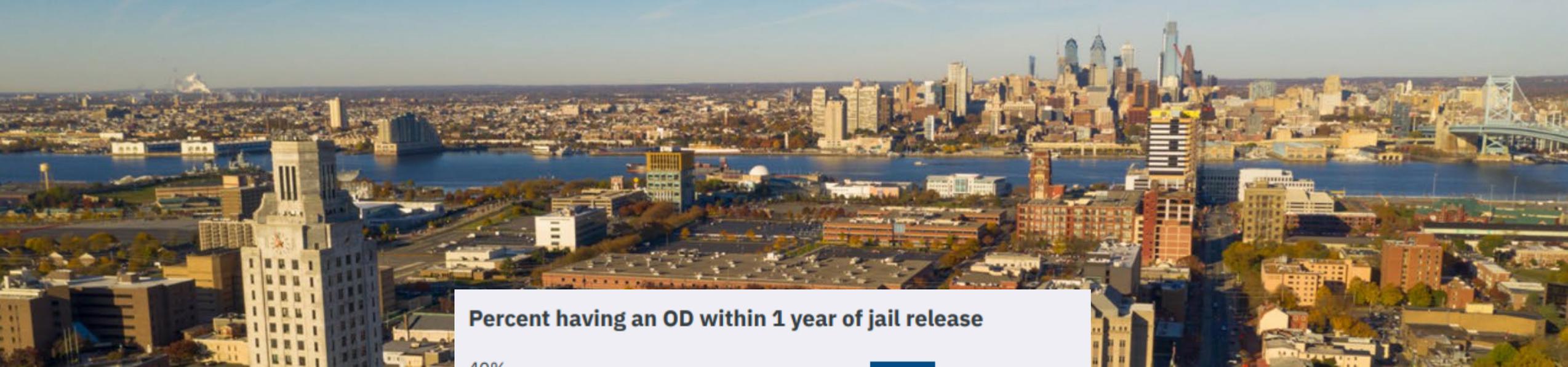


Patients who prefer to speak English, Hmong, Somali, Spanish, or Vietnamese make up 99% of the eligible population for the Colorectal Cancer Screening measure.

Compared to the statewide average for Colorectal Cancer Screening, patients who prefer to speak:

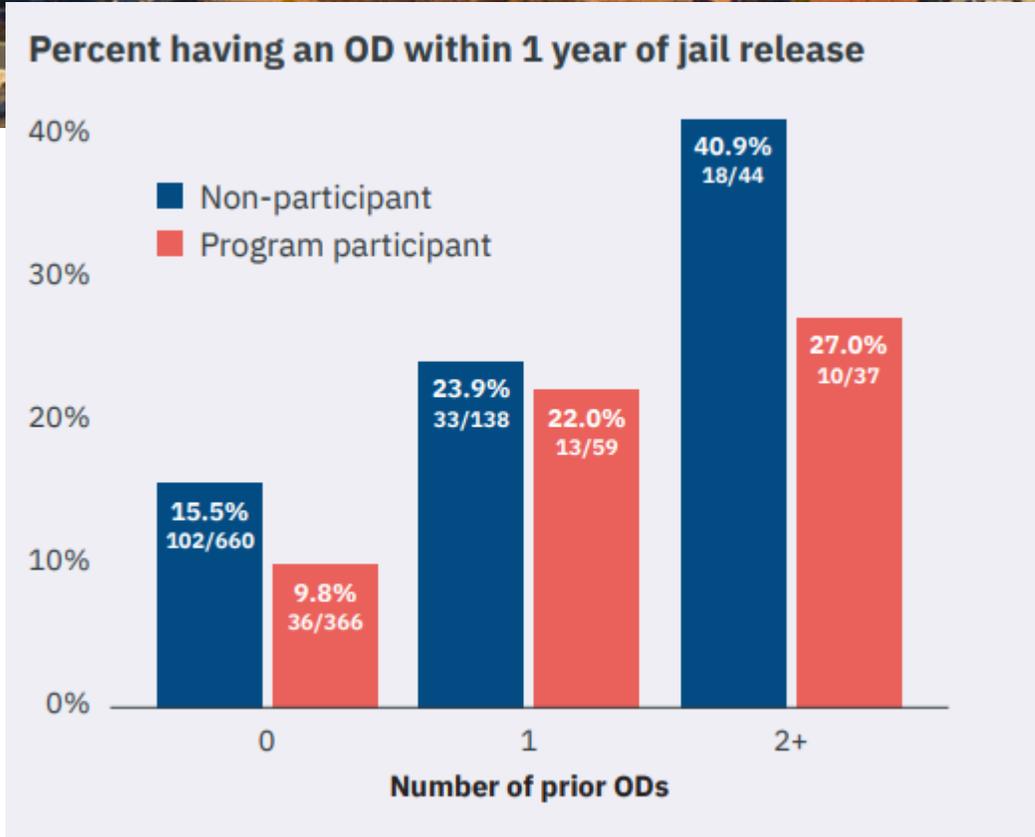
↓ Hmong, Somali, or Spanish have significantly lower rates of screening.

↑ English have significantly higher rates.



2. Analysis suggests that CCCF’s MOUD program was successful in reducing overdoses among individuals leaving the jail.

Among a subset of individuals incarcerated in the facility who had an opioid-use diagnosis based on hospital records, **10.0%** of MOUD program participants and **14.5%** of non-participants had an overdose 180 days after a jail release, and **12.8%** of program participants and **18.2%** of non-participants had an overdose within 365 days of release. Based on multivariable regression analyses, program participants were **41.2% less likely** to experience an overdose within 180 days of a jail release and **38.5% less likely** to experience an overdose within 365 days. Program participants were also less likely to have more than one overdose within one year of jail release.



4. A racial imbalance in who received treatment was evident.

Whereas 37.2% of incarcerated individuals who may have been eligible for treatment based on the Clinical Opiate Withdrawal scale were of Black, non-Hispanic race, 26.7% of those receiving treatment in the CCCF were of similar race. Individuals of White, non-Hispanic race were more likely to participate in the MOUD program, representing 55.6% of participants despite comprising 44.4% of those who were potentially eligible. This imbalance may have resulted from bias on the part of jail staff or race differences in experiences and preconceptions that may lead some people to be less amenable to program participation.

< Unaccompanied Youth >



In 2022, they co-planned a 2022 youth-focused PIT Count. The Count was named “Reach One, Teach One,” because it aimed to “give a voice to youth experiencing homelessness – a population that is often hesitant to share their housing status and experience homelessness in ways that differ from the traditional perception of sleeping on the street.”

In addition to enumerating youth experiencing homelessness that fall within the federal definition of the U.S. Department of Housing and Urban Development (HUD), “Reach One, Teach One” also engaged youth who experienced other forms of homelessness, collecting information to inform local efforts to combat youth homelessness.

“Reach One, Teach One” also helped raise awareness of the issue of youth homelessness in Charlotte-Mecklenburg. In 2023, the YAB supported the development of the youth questions that were included in the 2023 unsheltered PIT survey.



Empowering Change:
The Charlotte-Mecklenburg Youth
Action Board’s Journey to End Youth
Homelessness - Mecklenburg County –
Housing & Homelessness Dashboard

mecklenburghousingdata.org

How do those stories share, or withhold, power from community?



Share Power With

- Populations in the data are included throughout the data life cycle, especially while planning
- Questions and collection, data use and dissemination serve community-defined need

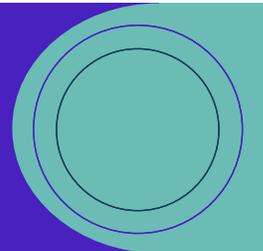
Withhold Power From

- Data collected from people and re-used without context or co-created purpose
- Analyses reinforce harms, retraumatize, or siphon resources



Administrative data use cases

How are data currently used by your client or in your organization?



Key Terms

Administrative Data: Data collected during the routine process of administering programs.

Administrative Data Reuse: Using administrative data in a way not originally intended, e.g., for research.

Examples:

- Program eligibility, enrollment, use
- Demographic, location info
- Medical claims
- Taxation and work records
- Vital records
- Criminal justice and involuntary engagement

Most data requests aren't fancy...



- Simple Excel sheet with two linked datasets
- One number asked by an Executive
- Validating data quality and reliability



Administrative Data Reuse: Examples

- Research
- Program Evaluation
- Budget Planning
- Equity Analysis
- Community power building and power sharing

**What cases have you
encountered recently?**

Requestor for Data Access and Use	Data sharing and integration needed to...	Questions to Guide Data Request Pathways
Epidemiologist with local Health Department	...Evaluate the health outcomes related to a local policy that has been implemented	Operational
Epidemiologist within NCDHHS DPH	...Better understand effects of county-based restrictions on rates of infection	Operational
Community Collaborative	...Better understand population-level outcomes for NC residents	If a strategic partner,* this would be operational. If not, this could be a public record request.
Community advocate	...Better understand the lived experiences of NC residents	If a strategic partner,* this would be operational. If not, this could be a public record request.
Department of Justice and DHHS Attorney	...address a legal matter	Legal purposes
Consulting vendor	...Complete the terms of their service agreement to conduct work on behalf of NCDHHS	Operational
Legislative Staffer	...Better understand current problem for draft legislation	Legislative request
Program evaluator	...Evaluate the effectiveness of a program	If a strategic partner,* this would be operational. If not, this could be a public record request.
Director of a large regional non-profit	...Better understand the backgrounds, experiences, and future outcomes of service recipients	If a strategic partner,* this would be operational. If not, this could be a public record request.
Business unit leadership	...Better understand cross-enrollment between programs	Operational
Internal audit for Office of Internal Auditor	...Conduct an audit	Audit purposes
State audit for Office of State Auditor	...Conduct an audit	Audit purposes
University-based researcher	...Better understand whether certain characteristics or experiences are predictive of later outcomes	Research
Deputy Director of another state department	...Better understand policy levers to improve outcomes with a population by incorporating outcome data from NCDHHS for predictive models	Operational
Media outlet	...inform the public of an emerging public health issue	Public records request
Staffer at the Governor's Office	...Draft a strategy to target new investments in X for the residents who are most in need of support	As a strategic partner,* this would be operational.



Use Case Examples from NC DHHS

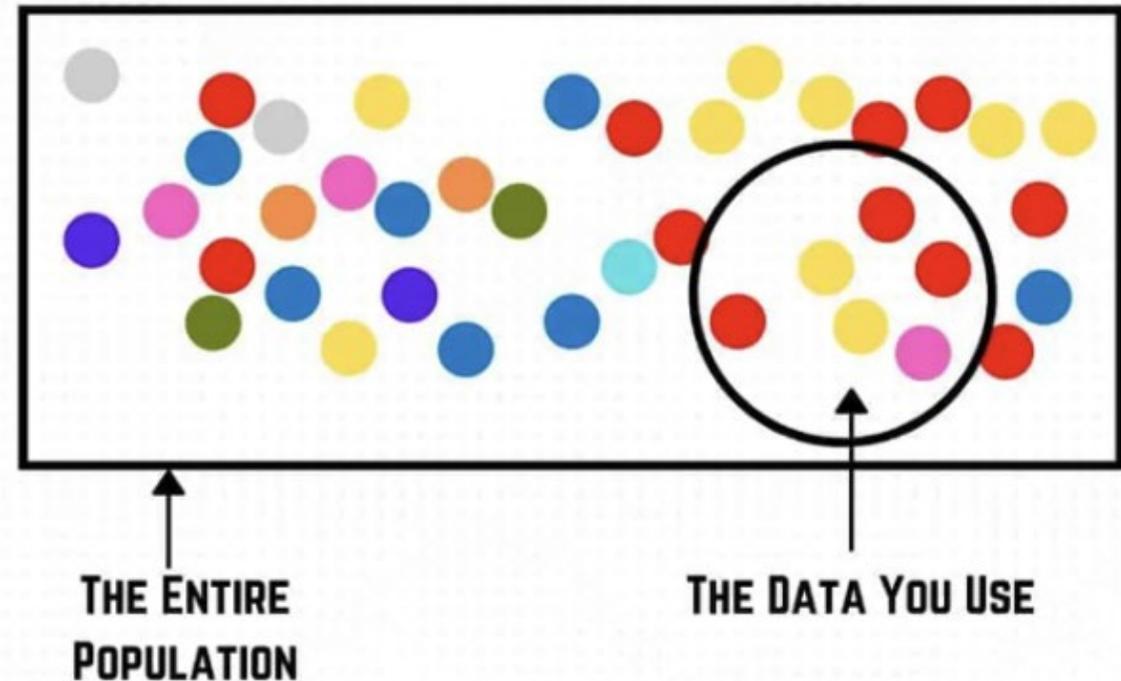
[See Appendix for questions to guide data request pathways, NCDHHS Data Sharing Guidebook](#)

Administrative Data Reuse can describe a *population*

Otherwise, studies or use cases reflect a *sample*.

Considerations:

- Bias
- Consent



What is a correct match? What is an incorrect match?

Source System 1		Source System 2		Source System 3	
Adelia	Jenkins	Della	Jenkins	A.	Jenkins
Amy	Hawn	Amy	Hawn Nelson	Amy	Nelson
Erin	Jimenez	Aaron	Jimenez	Aaron	Jimenez
Abigail	Aguilar-Morales	Abbey	Perez-Morales	Abbie	Perez
Lei	Chan	Li	Chen	Lei	Chen
ZsaShane	Saint James	Zsashane	St. James	Zsa Shane	James
Katie	Smith	Katherine	Smith	Kate	Smith
Salim	Abu Nadal	Salime	Nadal	S	Abu Nadel
Liu Yang	Chiyuan	Liu-Yang	Chih Yuan	Liu	Yuan

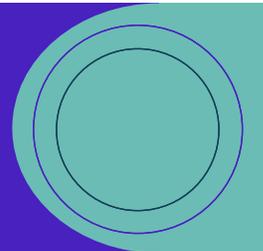
Linked data also involves correctly matching across systems with differing identifiers

- Critical to understand the quality of data, identifiers, and matching algorithm



The Law + Data Life Cycle

How does the law impact the use of data across the data life cycle, if at all?



Steps of the Data Lifecycle

Planning – Guide all future work, including ensuring a legal and ethical framework

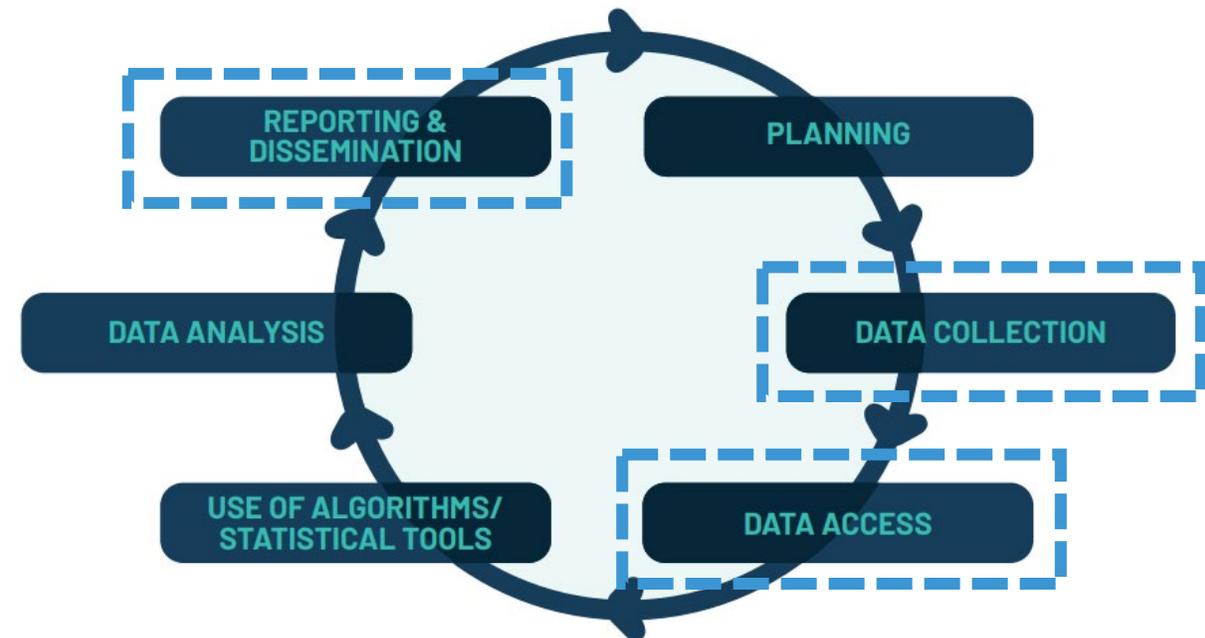
Collection –Gathering information to inform the study of a program, policy, or problem

Access – Practices regarding who can securely obtain, view, or use data; when it can be used; and for what purpose

Use of Tools – Quantitative and software tools that data into information

Analysis – Data are explored to develop findings, interpretations, and conclusions

Dissemination – Findings from the data are communicated internally or externally



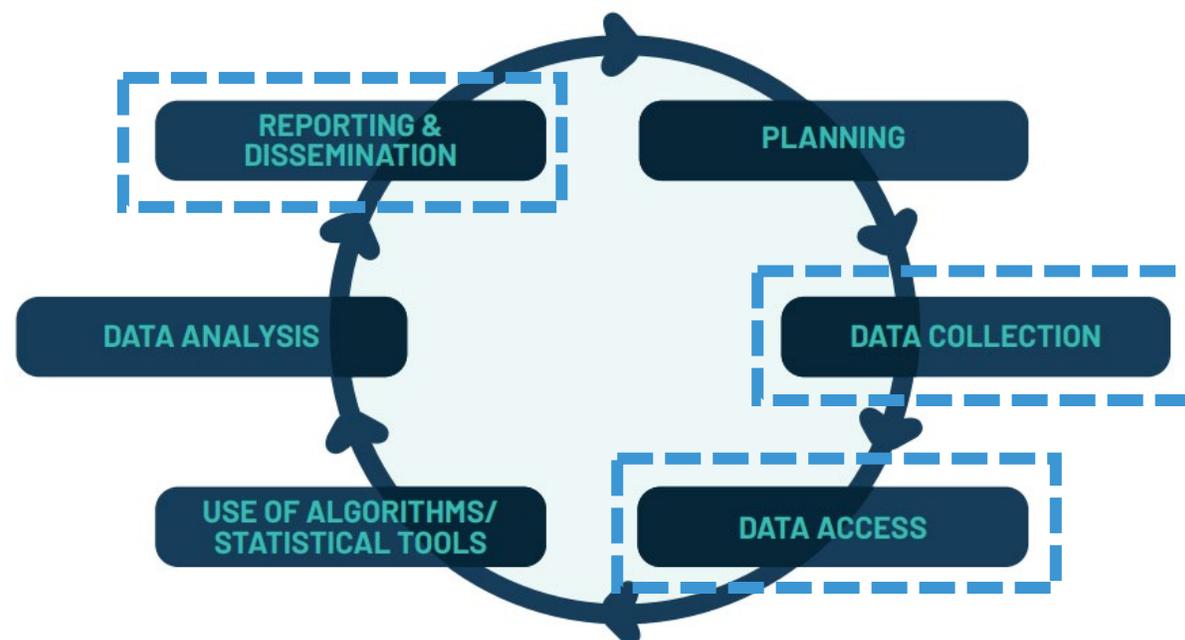
Centering Racial Equity Throughout Data Integration (AISP)

Steps of the Data Lifecycle

Collection – Privacy, security

Access – Consent, HIPAA, FERPA, etc.

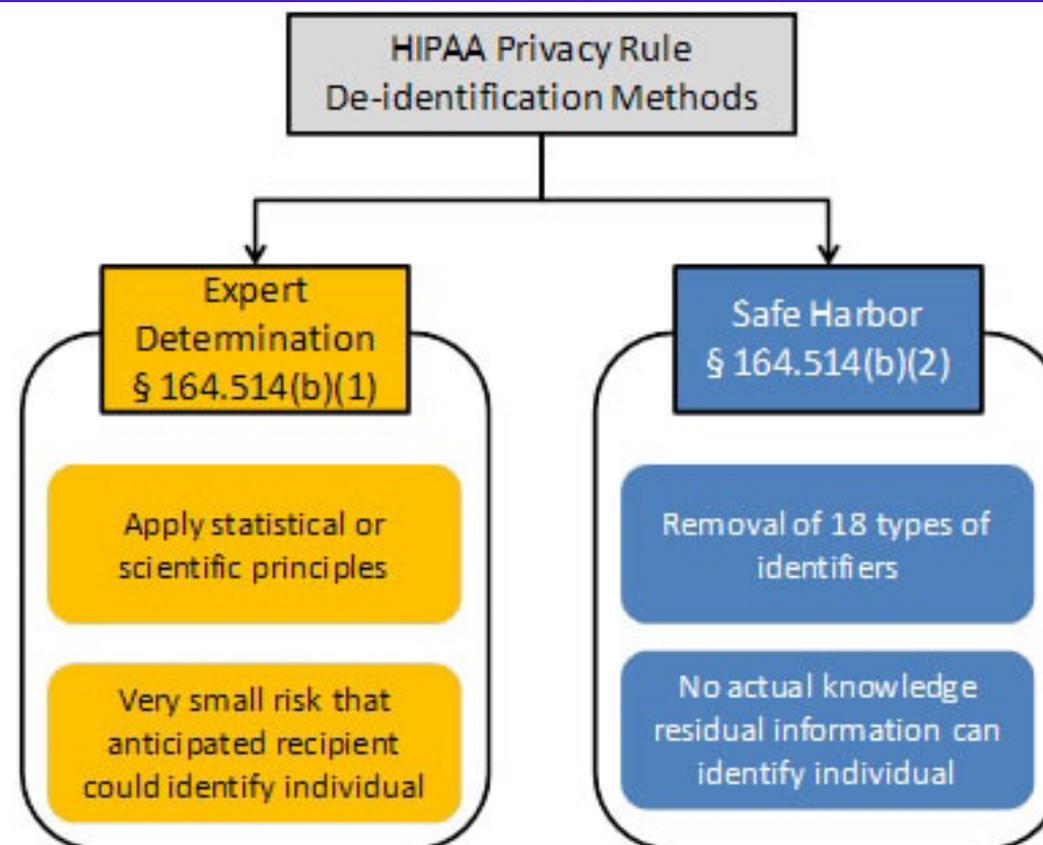
Dissemination – Ensure no re-identification; “small cell rules”



Key Terms

De-Identified Data:

- Data in which personally identifiable information is removed
- Commonly relied upon for administrative data re-use
- NOT covered by HIPAA Privacy Rule; Data Use Agreement, BAA not required



Limited Data Set

Includes zip codes, dates of service, and re-coded (scrambled) medical record numbers

- is PHI
- is NOT de-identified
- regulated by HIPAA privacy rule

FEDERAL

 <p>HMIS Protects information collected through the Homeless Management Information System (HMIS), under the guidance of the U.S. Department of Housing and Urban Development (HUD).</p>	 <p>FERPA FERPA protects the confidentiality of education records.</p>	 <p>PRIVACY ACT Regulates personally identifiable records maintained by federal agencies.</p>	 <p>HIPAA HIPAA regulates the protection of individually identifiable health information.</p>	 <p>42 CFR PART 2 Stringent federal regulations (referred to commonly as 42 CFR Part 2) protect the confidentiality of alcohol and substance abuse treatment records.</p>
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CRIMINAL & JUVENILE JUSTICE RECORDS	State laws typically govern access to criminal records, such as arrest records, and juvenile justice records, such as juvenile court files.
MENTAL HEALTH RECORDS	States typically have statutory provisions governing the confidentiality of mental health records.
MEDICAID RECORDS	Access to Medicaid records is generally controlled by the state agency that administers the Medicaid program.
HIV LAWS	Most states have special laws protecting the confidentiality of information that may disclose a person's HIV status.

RELEVANT LAWS



Consent to use and disclose data varies by law and context.

The default rule is that **identifiable information** cannot be shared or disclosed unless consent is obtained, or an enumerated purpose or exception exists.

FERPA EXCEPTIONS

PII can be shared without consent to...



School Official: Perform an institutional service or function that an employee would otherwise perform (34 CFR §§ 99.31(a)(1), 99.7(a)(3)(iii))



Studies: Conduct a study to develop, validate, or administer tests, aid programs, or improve instruction (34 FR § 99.31(a)(6))



Audit & Evaluation: Audit or evaluate a federal or state education program (34 CFR §§ 99.31(a)(3), 99.35)

HIPAA EXCEPTIONS

PHI can be shared without authorization for...



TPO (Treatment, Payment, Operations): Treatment, payment, and health care operations activities (45 CFR 164.502)



Public Health Activities: Preventing or controlling disease, preventing child abuse and neglect, FDA monitoring, preventing communicable diseases, medical surveillance for work-related injuries and public health authorities (45 CFR 512(f))



Health Oversight: Legally authorized health oversight activities, including audits and investigations necessary for oversight of the health care system and government benefit programs (45 CFR 512(a))



Research: For research if IRB approves a waiver of authorization or in preparation for research if certain elements are met. (45 CFR 502(d) and 164.514(a)-(c))



Serious Threat to Health or Safety: To avert serious threat to health or safety (45 CFR 512(j))



Key Exceptions to Consent

[Yes, No, Maybe? Legal & Ethical Considerations for Informed Consent in Data Sharing and Integration \(AISP\)](#)

Consent vs. Authorization

Table 1: Differences between Consent and Authorization	
CONSENT	AUTHORIZATION
The Privacy Rule allows, but does not require, consent to share PHI for treatment, payment, and health care operations. ¹⁶	The Privacy Rule requires authorization to disclose PHI for purposes not otherwise allowed by the Rule. ¹⁷
Covered entities that elect to use consent have complete discretion to design a process that best suits their needs. ¹⁸	An authorization has specific elements (requirements include description of PHI, purpose for disclosure, person authorizing disclosure, expiration date, etc.) that must be included to comply with HIPAA or there is a risk of disclosing information without proper permission. ¹⁹

Consent: What counts?

Figure 3: FERPA Elements for Consent



Required elements of the written consent under FERPA²³ include:

- Signature and date
- The purpose of the disclosure
- Description of the records that may be disclosed
- The name of the party or class of parties to whom the disclosure may be made

Figure 4: HIPAA Elements for Authorization



- Description of the PHI to be used or disclosed
- Name of the person or persons authorized to make the disclosure
- Identity of the party or class of parties to whom the disclosure may be made
- Description of the records that may be disclosed
- The purpose of the disclosure
- Expiration date or event
- Signature and date
- Statements that include: 1) a right to revoke consent; 2) assurances that treatment, payment, and enrollment eligibility are not affected; and 3) risk of redisclosure

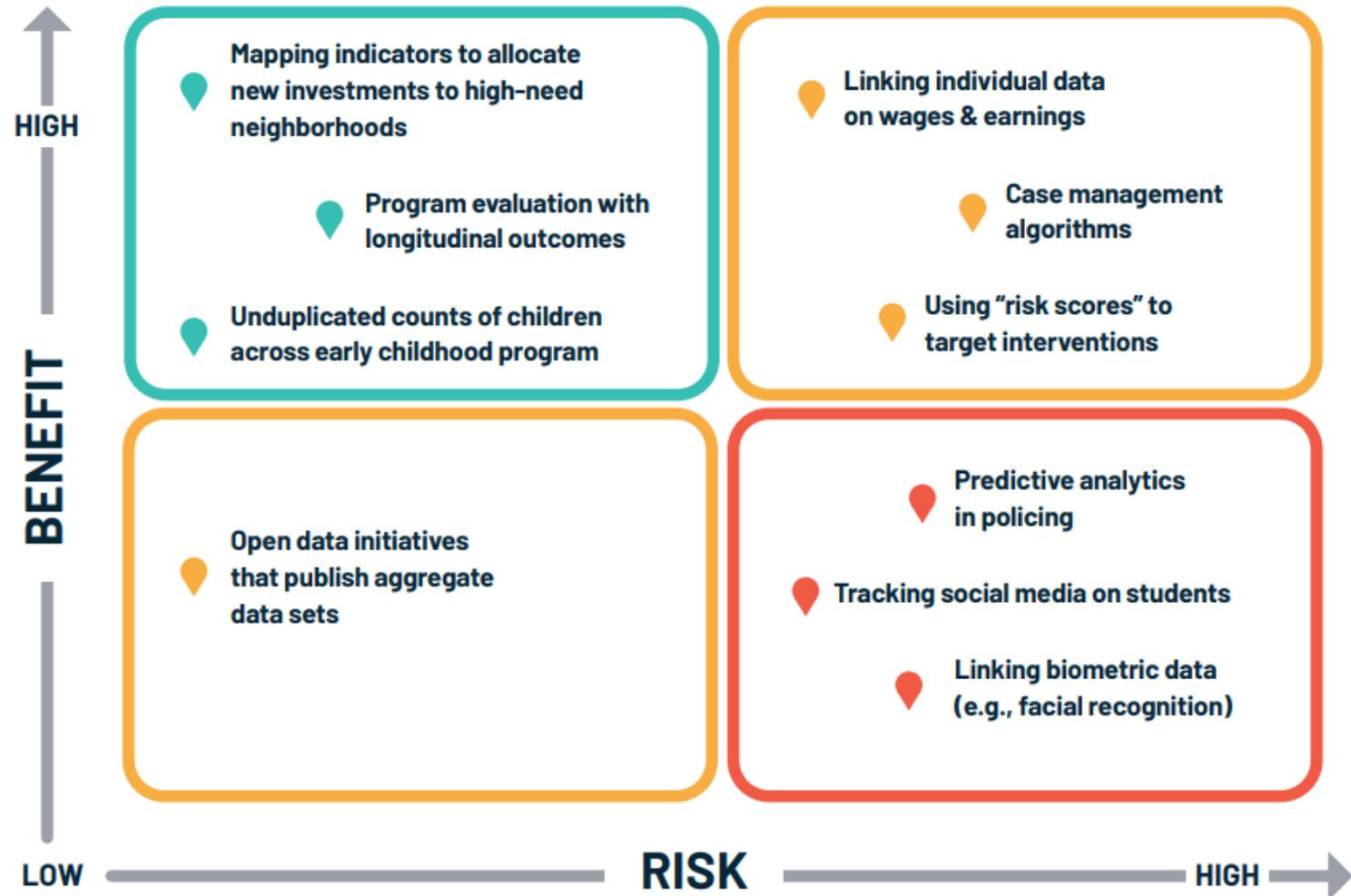
Data Access by Type

Data access generally refers to practices regarding who can securely obtain, view, or use data; when it can be used; and for what purpose.

OPEN DATA	RESTRICTED DATA	UNAVAILABLE DATA
<p>Data that can be shared openly, either at the aggregate or individual level, based on state and federal law. These data often exist in open data portals.</p>	<p>Data that can be shared, but only under specific circumstances with appropriate safeguards in place.</p>	<p>Data that cannot or should not be shared, either because of state or federal law, lack of digital format (paper copies only), or data quality or other concerns.</p>

Is it legal?
 Is it ethical?
 Is it a good idea?

How do you know
 and who decides?





Thank you!

AISP:

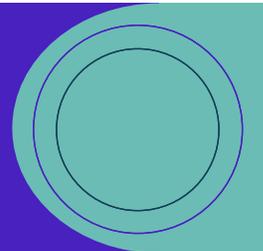
KimPaull@gmail.com, AHNelson@UPenn.edu
or visit AISP.Upenn.edu

DISC:

info@DISC.WestEd.org or visit
DISC.WestEd.org



Appendix



Questions to Guide Data Request Pathways

1. Does the request support work in alignment with **strategic priorities of NCDHHS?**

If yes or no, proceed to Q2. Note that requests may be prioritized based upon alignment with priorities.

2. Is this an operational request—related to ongoing work of NCDHHS—that supports **business intelligence with a NCDHHS Division or Office, department and/or strategic partner (under current agreement with NCDHHS), including local Offices?**

Is this request for data from a specific Division/Office? If yes, contact that Division/Office directly (See [Guidebook, pg.6](#)). Does this request involve data from multiple Divisions/Office? If yes, please contact dataoffice@dhhs.nc.gov. And see the [Operational Data Request Form](#).

If no, proceed to Q3.

3. Is this request for research purposes?¹

If yes, are you DPH staff? You may need to submit an application to [DPH IRB](#).

If yes, are you working in collaboration with NCDHHS staff or a consultant of NCDHHS for research purposes? If yes, Institutional Review Board review and approval may be required. Contact dataoffice@dhhs.nc.gov.

If no, proceed to Q4.

4. Is this request for audit purposes, including the **NCDHHS Office of the Internal Auditor (OIA), the NC Office of the State Auditor (OSA), or NC Office of State Budget and Management?**

For OIA, right of data access for audit purposes is reinforced by NCGS § 143B-216.50 and the OIA Charter. OIA shall have access to any records, data, or other information of the Department the Internal Auditor believes necessary to carry out the Internal Auditor's duties.

If yes, but not OIA, contact the applicable Division Director, Data Owner, and/or Designee for approval, as well as the NCDHHS Privacy and Security Office and OIA, before fulfilling the data request.

If no, proceed to Q5.

5. Is this a Public Records Request for Data Access and Use?

Y N Is this request for a nonprofit or community-based organization without a current agreement with NCDHHS?

Y N Is this request from a media source?

Y N Is this request from a commercial entity that is not operational (See Q1)?

If yes to any of the above questions, then this is a Public Records Request.

Y N Does the Public Records Request involve any analysis? (e.g. any data manipulation beyond a data system query of existing record that is held within NCDHHS servers)

If yes, data access is permissible but not required. NCDHHS is required to produce data as it exists at the time of the request but is not required to create data.

If this is a Public Records Request, contact public.records@dhhs.nc.gov.

If no, proceed to Q6.

6. Is this a legislative request?

Y N Is this request from or on behalf of a legislative member, committee, or Division (e.g. the Fiscal Research Division)?

If yes, contact DHHSlegislativeaffairs@dhhs.nc.gov.

If no, proceed to Q7.

7. Is this a request related to legal affairs?

Y N Is this request related to a subpoena, court order, discovery, litigation, investigation?

Y N Are you making a request on behalf of the NC Department of Justice?

Y N Are you making this request on behalf of a legal team?

If yes, contact the relevant Legal Counsel

If no, proceed to Q8.

8. Does this request involve interdepartmental data sharing (beyond NCDHHS) related to children and youth?

Y N Is this request related to children age birth-5? If yes, contact ECIDS, <https://www.ecids.nc.gov/ecids/ecids/researchers/datarequests>

Y N Is this request related to the integration of Early Childhood Data, Student Data, and Workforce Data? If yes, contact ELDS, through GDAC, <https://it.nc.gov/services/data-analytics/nc-government-data-analytics-center>

If no, proceed to Q9.