



# Data Ethics: Confidentiality, Sharing Sensitive Data, Consents, Agreements, Federal & State Laws

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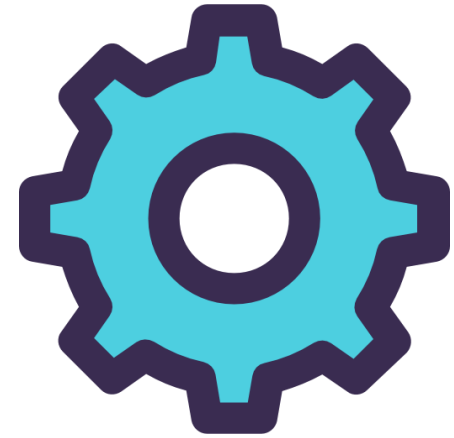
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*National Harbor, MD*

*July 2019*

# Overview of Session

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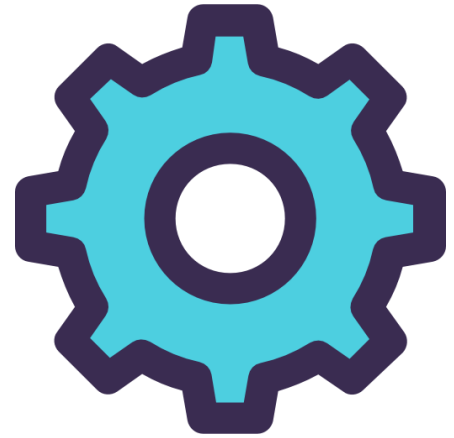


- Statement of problem
- Major regulations
- Stakeholder descriptions and interests
  - Different needs, concerns, knowledge
  - Strategies for addressing partner questions and requests
- Audience sharing

# Hopes and Fears

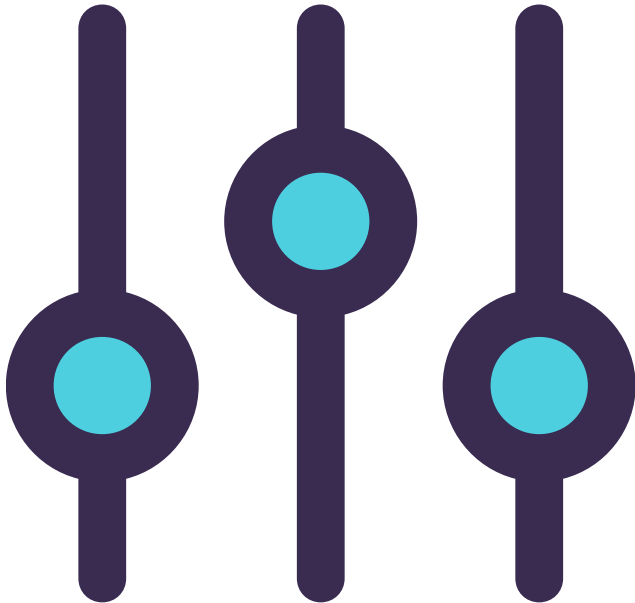
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- Who is in the room (roles and program types)
- Concerns and questions



# Statement of Problem

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Who, What, Why?

# Who needs data and why?

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- Treatment court team members
  - Appraise participant progress in treatment & compliance with program conditions
  - Program monitoring and feedback
- External evaluators and researchers
  - Provide programs and funders with feedback
  - Learn more about what works and what doesn't
  - Help guide difficult decision-making

# Why should programs share data?

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- Internal data sharing:
    - Improve treatment court process
    - Better serve all participants
  - External data sharing:
    - Using evaluation feedback to modify program practices is related to:
      - 85% reductions in recidivism
      - 100% increases in cost savings
- (Carey, Mackin, & Finigan, 2012)



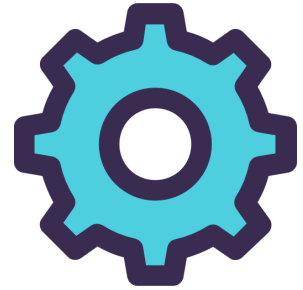
# What data do we need to share?

- Internal data sharing:
  - Assessment results
  - Attendance
  - Drug & alcohol test results
  - Treatment plan goals and counseling regimen
  - Evidence of symptom resolution, treatment-related attitudinal improvements
  - Attainment of phase requirements



# What data do we need to share?

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- Internal data sharing:
  - Compliance with electronic monitoring, home curfews, travel limitations, etc.
  - Adherence to MAT
  - Procurement of unauthorized medications
  - Commission of arrests or new offenses
  - Menacing, threatening, or disruptive behavior

(Adult Drug Court Best Practice Standards, Vol. II, 2015)

# What data do we need to share?

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- External data sharing (for evaluation):
  - Participant names and identifiers
  - Treatment court program data
  - Administrative records
  - Treatment records
  - Participant & stakeholder feedback

Note: all records must be at the individual level!

# Why is getting data so complicated?

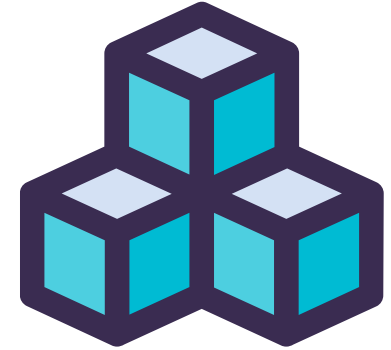
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- Growing concerns over identity theft or misuse of information
- Federal and state laws protect personal health information (PHI)
- Lack of knowledge of appropriate information-sharing protocols

# Statement of Problem

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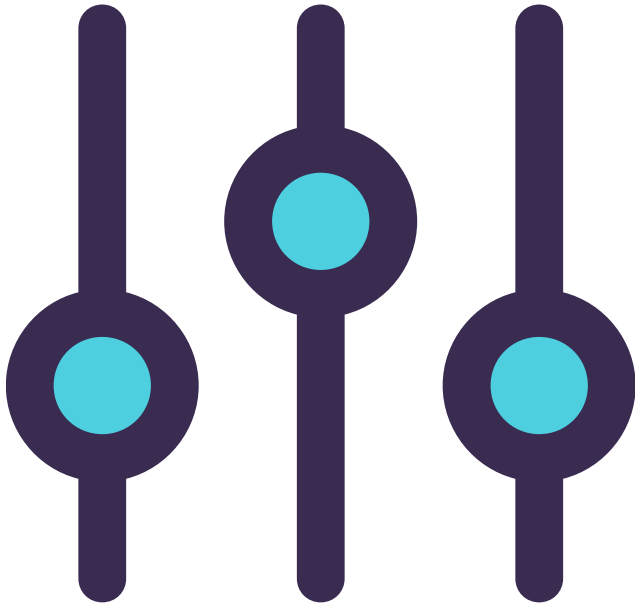


How do we:

- Access the information we need,
- Protect participant privacy, and
- Reassure agency staff and stakeholders?

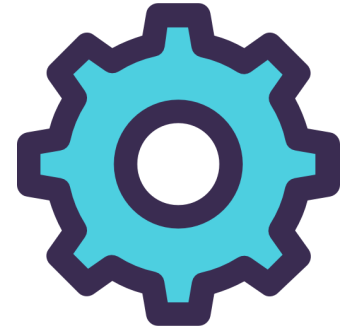
# Major Regulations

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# Key Terms

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- IRB = Institutional Review Board
- PHI = Protected health information
- Data-sharing agreement or MOU = Agreements between entities on how and what data will be shared

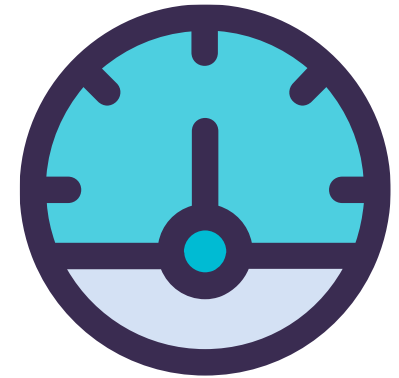
# Federal Regulations

- HIPAA
  - What's it stand for?
  - Health Insurance and Portability and Accountability Act of 1996
  - Governs use and disclosure of PHI
- 42 CFR Part 2
  - Code of Federal Regulations
  - Also protects disclosure of PHI



# Federal Regulations

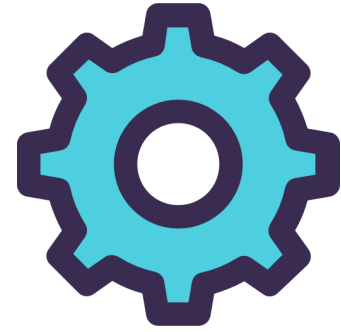
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- Both apply to treatment courts
  - HIPAA more directly applies to treatment providers or agencies
  - 42 CFR Part 2 applies more generally to the treatment court program
- Both are highly concerned with information related to substance use treatment
- Both are used by non treatment providers as standards for information protection

# Federal Regulations

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- Changes to the “Common Rule”
  - 2018 Common Rule has been adopted by 15 federal agencies (not including NIH)
  - Only impacts research and evaluation activities subject to IRB review
    - Consent form needs to state clearly and early the research purpose/risks/benefits
    - Consent form needs to indicate whether and when study results will be shared with the participant
    - Eliminates annual IRB review for “minimal risk” studies
    - Single IRB for multi-site studies

# State Statutes

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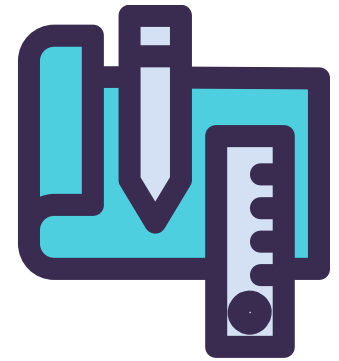


- If state confidentiality laws are less restrictive than federal regulations, the federal regulations stand
- However, states may impose more restrictive confidentiality laws

Source: 42 CFR § 2.20

# Variance in State Statutes

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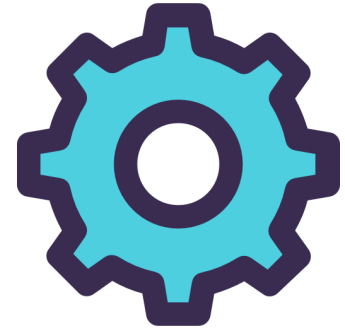


- Most states have statutes governing substance use records (which generally approximate federal regulations)
- Several states permit broader disclosure:
  - Kansas, Mississippi, New Hampshire
- Some states statutes are more narrow
  - Pennsylvania, Michigan, New Jersey, Missouri

Source: Institute Of Medicine, 2006

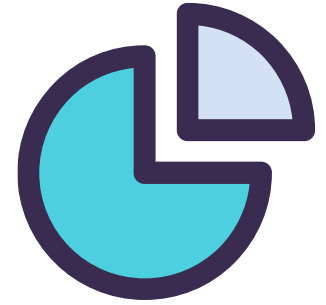
# Degrees of Confidentiality

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# Common Misconceptions

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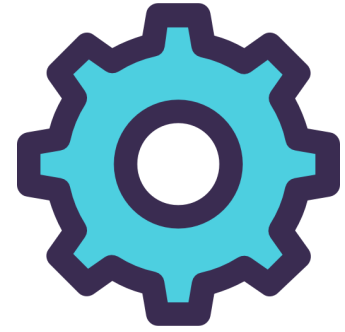
1. Treatment providers are prohibited from sharing information related to substance use and mental health treatment.

According to 42 CRF Part 2, this is *partly* true:

Must have a voluntary, informed, and competent waiver of a participant's confidentiality and privacy rights (or court order)

# Common Misconceptions

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2. Treatment courts (and other agencies) can only share de-identified information, or else the researcher needs signed consent forms from each participant.

# Common Misconceptions

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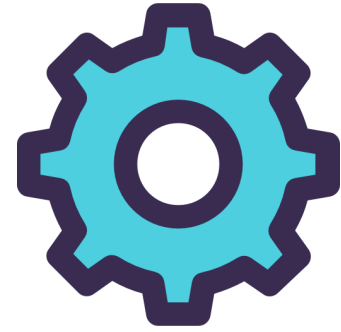


According to 42 CFR Part 2, this is *partly* true:

- Yes, 42 CFR Part 2 allows entities to share de-identified information (removing names, etc.) in the absence of signed consent forms
- But there are exceptions:
  - Research, audits, and evaluation (among others)
  - Must be a qualified researcher
  - Must have IRB approval

# Common Misconceptions

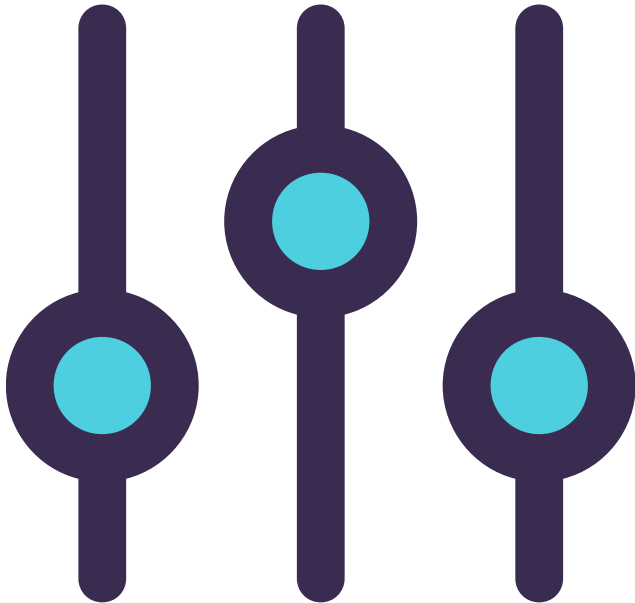
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- Similarly, HIPAA also makes exceptions:
  - Must have research approved by IRB
  - Must have HIPAA waiver
- HIPAA waiver granted if:
  - No more than minimal risk to participant
  - Research could not be practicably performed without waiver
  - Research could not be practicably performed without PHI

# Stakeholder Descriptions and Interests

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# Interested Parties

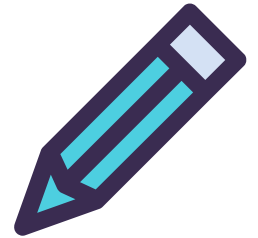
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- Program participants
- Program staff
- Corrections/probation/  
law enforcement/court
- Treatment  
providers/agencies
- IT/database staff
- Child welfare agencies
- Juvenile justice agencies
- Tribes/tribal organizations
- Funders

# Key Considerations

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- NADCP recommends internal data sharing under the following circumstances:
  - MOU signed by each member/agency, specifying what information will be shared
  - Participants provide voluntary and informed consent to release information within team
  - Defense attorneys clearly communicate with participants about what information will be shared

(NADCP Standards Vol. II, 2015)

# Key Considerations

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- All information sharing (internal & external) should be governed by signed agreements:
  - Expand beyond legal requirements and address *purposeful* data sharing
  - List information and the way it might be shared with research and evaluation:
    - Mental health diagnoses and treatment
    - Information about substance use disorders
    - Alcohol & drug treatment information
    - Child well being
    - Education, employment and other outcomes

# Critical Partners for Outcomes

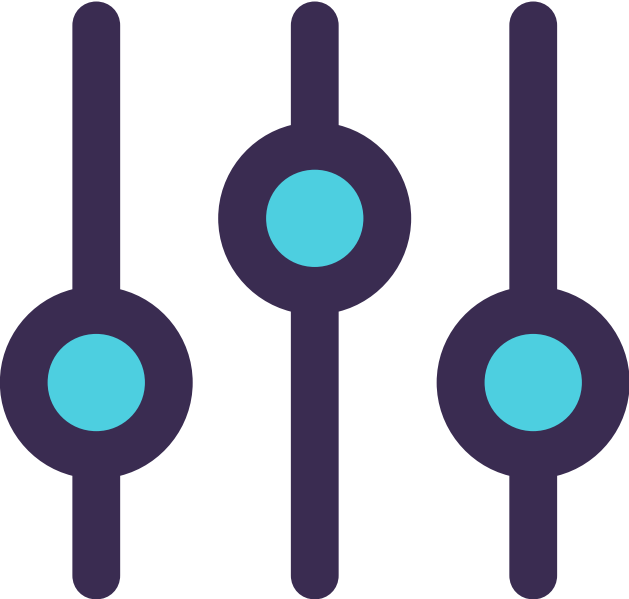
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- Participants
- Program Staff
- Treatment Providers
- Funders
- IT/Database staff
- Child Welfare
- Court
- Corrections
- Probation
- Law enforcement



# Audience Sharing

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# Other Considerations & Strategies





Thank you so much for  
your participation!

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