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TEXAS ACCOUNTABLE COMMUNITIES FOR HEALTH INITIATIVE

Data, Data Agreements, and Information Exchange Technology

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Learning objectives

1 Understand and be able to explain the importance of data in running a successful ACH

2 Understand the need for (and be able to establish) legally binding data agreements with ACH partners and participants

3 Recognize the importance of information exchange among ACH partners and participants and be a well-informed consumer when researching and/or selecting an information exchange platform for your ACH

Data – What do we mean by data?

Data – a collection of facts, such as numbers, words, measurements, observations, or just descriptions of things

Data – units of information, often numeric that are collected. In a more technical sense, data are a set of values of quantitative or qualitative variables about one or more persons or objects
– *Wikipedia*

Data – facts about something that can be used in calculating, reasoning, or planning
– *Merriam-Webster dictionary*

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Data – Why use data?

- What gets measured gets managed…
- Good data allows organizations to establish baselines, benchmarks, and goals to know how one is doing to keep moving forward

Data can:

- Facilitate informed decisions
- Serve as an early warning system
- Help you get the results you want
- Stop the guessing game
- Back up your arguments
- Keep track of it all

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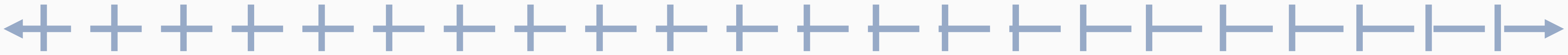
Data – Types of data

Quantitative – data that deals with numbers and things you can measure objectively; examples include height, length, temperature, volume, and prices

Continuous – data that can be divided and reduced to smaller and smaller levels



Discrete – a count that can't be made more precise; typically, it relates to integers; examples include the number of children or pets in your family

Data – Types of data

Qualitative – data that deals with characteristics and descriptors that can't be easily measured numerically, but can be observed; sometimes referred to as attributes; examples include smells, tastes, attractiveness, likes

- *Binary* – data that takes one of two mutually *exclusive categories*; examples include:
  - good/bad
  - true/false
- *Ordinal* – data which are assigned to *named categories* that have some kind of *natural order*; examples include:
  - short, medium, tall
  - 1 to 10 scale
- *Nominal* – data which are assigned to *named categories* that *do not have an implicit or natural value or rank*; examples include:
  - colors
  - types of dogs
  - some types of demographics

Data

Data can be used in many ways; some of the more important being to monitor an organization’s:

Performance

- Goals
- Operational or financial progress
- Programs’ success
- Patient/resident experience

Operations

- Programs and participation
- Processes and workflows
- Workforce

Finances

- On-going operations
- Long-term sustainability

Data – Data used to monitor and manage performance

Goals

- Goals come in all types and sizes. A goal is an **outcome** that you want to achieve – not to be confused with an **output** that are the actions or items that contribute to achieving an outcome
- Generally, in setting goals you begin with what you ultimately want to accomplish by when, and then work backward to define what will be needed to accomplish the goal. The designation of the outputs in a temporal sequence are called **objectives**
- Goal = Outcome with a timeline vs. Objective = Outputs with a timeline
- Short-term vs. long-term goals

SMART Goals

Specific

Measurable

Actionable

Relevant

Time-bound

Data agreements – Non-HIPAA governed agreements

- Non-HIPAA Applicable – Agreements between parties that describe the collection, sharing, or reporting of *non-HIPAA protected data*
- These agreements cover the sharing of data that does not trace back to a patient's record or other sources of *individually identifiable health information*
- Such agreements, sometimes described as data flows, can identify how data is collected, transmitted, analyzed, evaluated, and reported. They can also describe how data will be shared between entities from an operational perspective

Data agreements – Non-HIPAA governed agreements

- At a minimum, an ACH should establish such documents and execute them with all network partners and participants. Because these are simple descriptors and do not include individually identifiable health information, such Agreements can sometimes be drafted by non-legal personnel, though it is always recommended that your legal counsel review all such documents

Data agreements – HIPAA governed agreements

- HIPAA – *Health Insurance Portability Accountability Act* (1996) A federal law that required the creation of national standards to protect sensitive patient health information from being disclosed without the patient's knowledge or consent.
- The HIPAA Privacy Rule – Issued by HHS to implement the requirements of HIPAA, it covers the use and disclosure of individual's *protected health information (PHI)* by covered entities.
  - Dual objectives – protect individuals' data while allowing the flow of health information needed to provide quality care for the individual and protect the public health

Data agreements – HIPAA governed agreements

- ***Protected Health Information (PHI)*** – any information about health status, provision of healthcare or payment for healthcare that is created or collected by a covered entity and can be linked to a specific individual
- HIPAA defines 18 elements as PHI – things like name, SSN, address, telephone number, e-mail address, etc. [See Appendix 1 for a complete list of all 18 elements]

Data agreements – HIPAA governed agreements

- ***Covered entities*** – the following organizations engaging in electronic transactions involving claims, benefit eligibility, referral authorizations, etc. are subject to the Privacy Rule
    - Healthcare providers
    - Health plans
    - Healthcare clearing houses
    - Business associates
- ***Business associate*** – a person or organization using or disclosing individually identifiable health information from a covered entity to perform services for a covered entity

Data agreements – HIPAA governed agreements

- ***Business Associate Agreement (BAA)*** – a contract between the covered entity and business associate that establishes assurance the business associate will only use PHI for those purposes the business associate was engaged for by the covered entity
- A BAA is a useful tool for apportioning liability. Modifications to HIPAA in 2013 made business associates directly liable for misuse of PHI

Data agreements – HIPAA governed agreements

- ***Data Use Agreements (DUA)* –** an agreement between a covered entity and a researcher, with "research" being defined as "*any systematic investigation designed to develop or contribute to generalizable knowledge*"
- The Privacy Rule permits a covered entity to disclose a *limited data set* with certain entities for research purposes, public health activities, and healthcare operations, without obtaining patient approval

Data agreements – HIPAA governed agreements

- ***Limited Data Set (LDS)* –** LDS files contain PHI, but they do not contain any of 15 specific direct identifiers as they relate to the individual, or his/her relatives, employers or household members
- A LDS may include only the following
  - Dates (birth, death, admissions, etc.)
  - City, State, Zip code
  - Age
- A DUA must be entered into *before* there is any disclosure or use of a LDS

Data agreements – Data use agreements (DUA)

Must contain the following provisions:

1

Establish permitted uses of the data

2

Identify who may receive or use the data

3

Prohibit the recipient from using or disclosing the data, except as permitted by the agreement

4

Require the recipient to use appropriate safeguards to prevent unauthorized use or disclosure not contemplated by the agreement

5

Report to the covered entity any use or disclosure of data not provided for in the agreement

6

Require the recipient to ensure that any agents including subcontractors, to whom it discloses the information will agree to the same requirements

Data agreements – Data agreements

- Some important considerations/recommendations:
  - Whenever possible, get the patient's *informed consent* to use/share the data – no matter what kind of data
  - Working out the terms of a DUA usually takes more time and effort than anticipated, start the process early
  - Consider if *de-identified data* or *aggregated data* will meet your needs…at least as a first pass
  - Never share any data with anyone unless you have an agreement that covers all applicable elements of a DUA [See Appendix 2] in place first – consult your legal counsel about intra-company data sharing
  - If you receive a data agreement, read every word of it and send it to your legal counsel for review immediately

Information exchange technology – ACH technology plan

- An ACH should not be established without the governance group and backbone creating a technology strategy/plan even if it will not launch at implementation
- The technology plan should tie directly to the unified goals and targeted condition(s) selected to drive the ACH initiative
- While a comprehensive technology plan will cover data, data agreements, and information exchange technology, the following slides will focus exclusively on *information exchange platform* technology – IT systems that allow network participants to work together seamlessly by sharing relevant information

Information exchange technology – Information exchange platforms

- The technology infrastructure for an ACH is a critical component enabling stakeholders to achieve their clinical and social goals
- The technology infrastructure creates an integrated electronic platform to exchange clinical and social information securely between healthcare providers, CBOs and other ACH network participants *irrespective of individual platform*
- The path to an effective and efficient information exchange platform entails six steps
  1. Define underlying business requirements (i.e., what [business] we do)
  2. Determine system requirements (i.e., what the system must do)
  3. Define system requirement functionality (i.e., how must it do it)
  4. Select vendor
  5. Implement the platform and develop user support (help) strategy
  6. Ensure the platform is sustainable

Information exchange technology

Step 1

Define underlying business requirements

1. Understand the number and function of the organizations that will be involved
2. Understand factors that can impact adoption and widespread use of the platform
   - Availability of IT resources
   - Skill level of end-users
   - Perceived value to end users
3. Understand the system users and their functionality needs (i.e., case manager, administrator, program manager, etc. and their data access needs

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Information exchange technology

Step 2

Determine system requirements

1. Inventory all technology and data storage/sharing platforms at network sites
2. Identify clinical and CBO needs to obtain a consensus list of “must-have” system technology requirements that constitute a “minimally viable product” that is acceptable to both clinical and CBO participants. Some examples might include:
   - Capture personal and demographic information
   - Make eligibility determination
   - Query service eligibility and availability
   - Make referrals
   - Receive referrals

Information exchange technology

Step 3

Define system requirement functionality

- This step provides an opportunity to define specifically and precisely the system requirement functionality so as to address:
  - How each network participant will use the requirement
  - How the network participant's programs and workflows will interact with the technology
  - What information should be collected as part of the requirement, including any data forms

Note – to the extent that the requested system requirements/ functionality is unique, you should expect: 1) some amount of pushback from the vendor; 2 an up-charge; 3) a delay in the build time

Information exchange technology

Step 3

Define required system functionality

- Two of the most important system functionality elements to define involve *making referrals* and *receiving referrals* – these merit a little extra attention
- Making referrals – the platform should provide *closed-loop referrals*, meaning the referring entity receives information on the outcome of their referral including:
  - Receipt of referral?
  - Was appointment made? Kept?
  - Type and description of service provided?
- A network participant should be able to make a referral *even if they are not on the common network platform*…*this is important*… ignoring this situation quickly decreases the size and impact of your network!

Information exchange technology

Step 3

Define required system functionality

- Receiving referrals – the receiving entity should be able to get referrals from other network participants *even if they are not on the common network platform…this is important*…ignoring this situation quickly decreases the size and impact of your network!

Note - today virtually all platforms include some form of *Referral Directory,* that provides contact and program information on participating network organizations. Some even provide information on program providers that are not part of the network!

Note – make use of *existing referral directories* whenever possible and *keep your directory updated...this is important*

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Information exchange technology

Step 4

Selecting a vendor

- There are many vendors offering information exchange platforms in the market today
- Most platforms are either referral focused, case management focused or both
- The differences between vendor’s platforms are typically quite small – most differences are in customer service and back-end reporting
- Prices vary depending on your requirements and timeline, but most vendors offer non-profits a sizable discount

Information exchange technology

Step 5

Implement the platform and develop user support (help) strategy

- A good vendor will be with you every step of the way and will take responsibility for setting up all technical infrastructure including linkages to other platforms and platform QA
- In most cases, the vendor’s QA only goes so far, and it becomes the responsibility of the backbone or network administrator to do their own QA…*skip this step at your own peril!*
- Vendors typically include some level of training along with the implementation process
- It is typically up to the backbone or network administrator to set up (often with the vendor’s participation), on-going user support (help)

Information exchange technology

Step 6

Ensure the platform is sustainable

- Finally, even with large discounts, platforms aren't cheap. There are the upfront costs to acquire and implement the platform as well as annual license fees and on-going expenses to maintain the platform
- Therefore, the governance group working with the backbone must determine ways to generate financial funding for, and support of, the platform…along with all other ACH functions!

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Information exchange technology

- Some important considerations/recommendations:
  - An information exchange platform is an indispensable asset for an ACH
  - While it doesn’t need to be up and running when the ACH goes live, the sooner the better
  - You don’t necessarily need the Cadillac of platforms as most will get the job done; keep financial sustainability of the platform forefront in your mind
  - Having good support from the vendor is invaluable
  - Make sure the platform supports solid back-end reporting
  - The platform is important, but it’s nothing without the <u>full support and effective functioning of the network</u> – relationships matter!

Session summary / conclusions

Big picture…

- Data is important – get it right and you increase your chances for success; don’t be afraid to seek external help
- Success will mandate sharing data; if you are going to share healthcare data, always have a solid DUA approved by your legal counsel in place to save your bacon should anything so south
- Information exchange platforms look big and scary – don’t let that dissuade you…get the right platform, but first get the right network

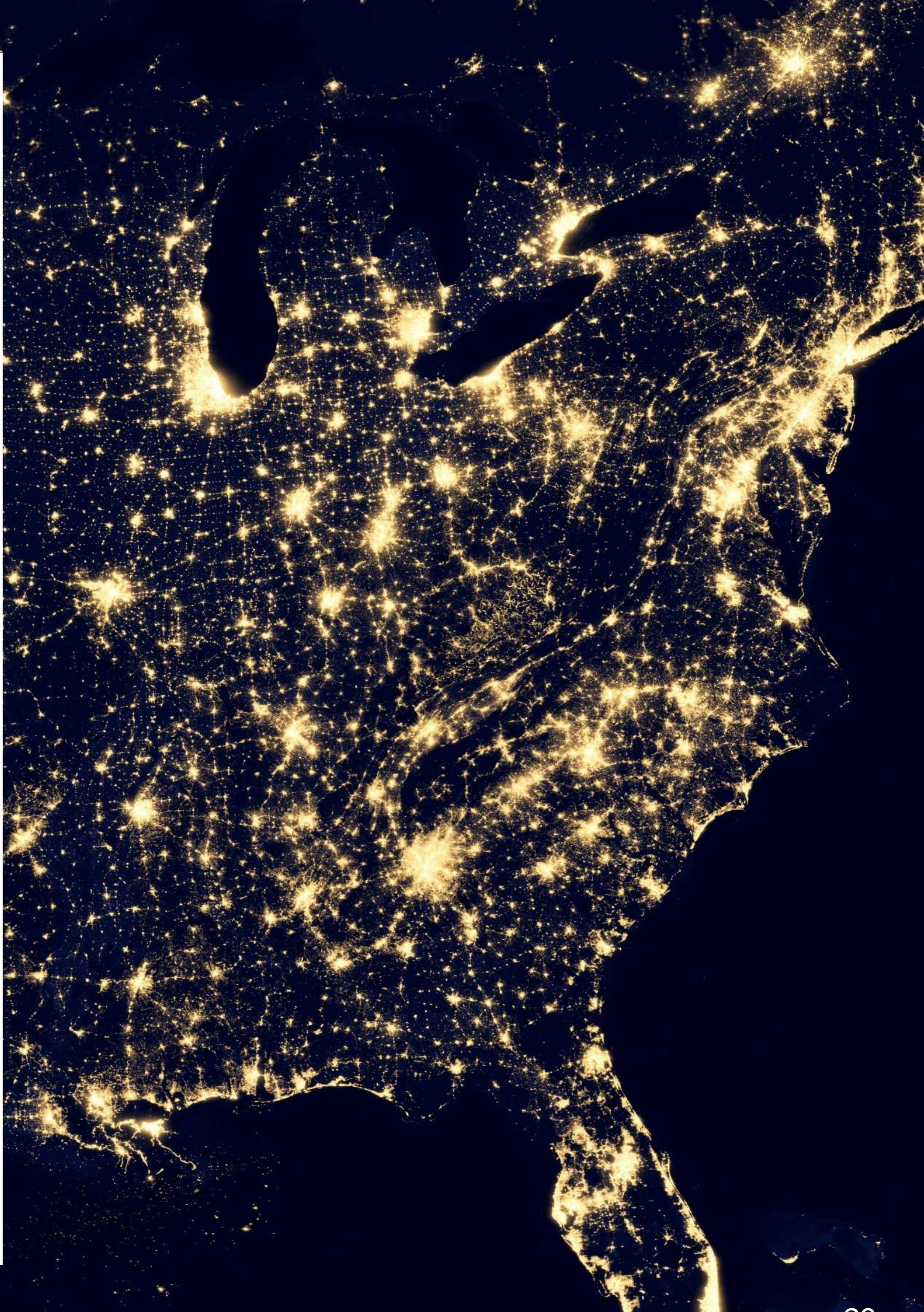

Photo by NASA on Unsplash

Appendix 1 – Protected Health Information

- Names
- All geographic subdivisions smaller than a state
- All elements of dates (except year)
- Telephone numbers
- Fax numbers
- E-mail addresses
- SSN
- Medical record numbers
- Health plan beneficiary numbers
- Account numbers
- Certificate/license numbers
- Vehicle identifiers including license plate numbers
- Device identifiers/serial numbers
- Web universal resource locators (URLs)
- Internet protocol (IP) numbers
- Biometric identifiers (fingerprints, voiceprints, blood type)
- Full-face photographic images
- Any other unique identifying number

Appendix 2 – Elements of a DUA

Name

Legal authority for data use

Program authority for data use

Purpose

Background

Mutual interest of entities

Responsibility of entities

Funding information

Costs and reimbursement

Custodian of the data

Agency point of contact (Project Officer)

Data Security procedures

Inspecting security arrangements

Data transfer, media and methods for the exchange of data

Reporting requirements

Records usage, duplication, re-disclosure restrictions

Record keeping, retention, and disposition of records

Potential work constraints

Ownership

Conditions for reporting results and public release of data

Policy and procedures for releasing data to researchers

Penalties for unauthorized disclosure of information

Terms of the Agreement

Constraints, including performance standards, DUA review procedures, audit clause

Definition of a breach

Liability issues