2025 PUBLIC HEALTH LAW CONFERENCE

Connection. Collaboration. Community.

Advancing Health Equity Through Community Information Exchanges (CIEs)

Presented by the Network for Public Health Law

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The Network for Public Health Law

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About the Network for Public Health Law

Provides visionary leadership in the use of law to promote, protect and improve health and advance health equity.

Works with local, tribal, state and federal public health officials and practitioners, as well as attorneys, policymakers, advocates and community organizations.

We provide information, resources, consultation and training, as well as opportunities to connect.

The Fine Print

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Which of the following best describes your background?

0	State health department
0	Local health department
0	Tribal health department
0	Community-based organization
0	Social services agency
1	Legal nonprofit
1	Other

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PHLC CIE Presentation

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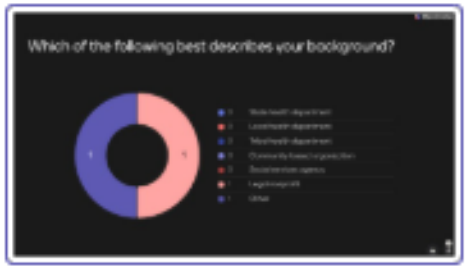

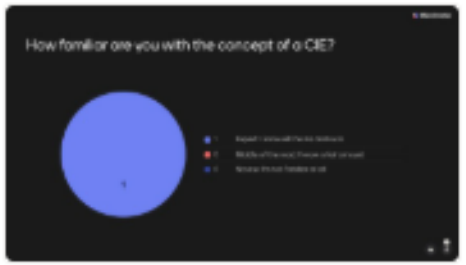

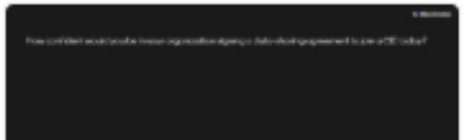

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How familiar are you with the concept of a CIE?

1	Expert: I know all the ins and outs
0	Middle of the road: I know a fair amount
0	Novice: I'm not familiar at all

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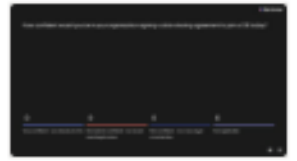

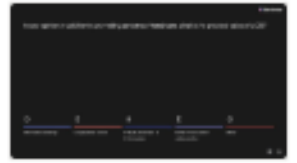

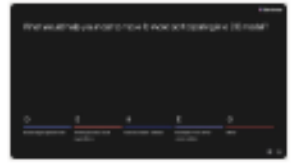

What is a Community Information Exchange?

A Community Information Exchange™ (CIE) is a community-governed system to facilitate data sharing among local health and social services providers and community-based organizations to promote more holistic and coordinated care.

CIE Purpose and Goals:

- Improve access to services and care continuity for people with health and health-related social needs
- Reduce the burden on individuals navigating fragmented and complex systems of care
- Advance health equity by addressing health needs driven by structural oppression

What problems do CIEs aim to address?

Example: Disconnected Services for Addressing Housing-Related Health Problems

A single parent and their two young children live in an unsafe housing unit with poor ventilation and exposure to mold and pests. The family makes numerous visits to a local health clinic because the children are suffering from asthma. A health care provider suspects the asthma is exacerbated by the poor housing conditions and refers the family to a housing services organization that provides medically necessary housing accommodations to eligible families. The parent works full time during the organization's business hours and must leave work early to visit them, which means foregoing pay for the afternoon and paying for transportation. When they arrive, they're told that the housing services organization does not have capacity to conduct intakes that afternoon. Further, it needs documentation from the health care provider, such as diagnoses and medical histories, and other eligibility information that the parent does not have on them at that time. This delays potential interventions to address the children's asthma (which worsens in the meantime) and further burdens the parent by requiring that they make another trip to the organization during work hours.

Common Features of a CIE

- Backbone organization
- Community-driven infrastructure
- Agreement structure formalizing relationships and terms
- Consent-based use and disclosure
- Technological infrastructure for data exchange
- Longitudinal record
- Closed-loop referral functionality
- Notifications and alerts

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In your opinion, what is the greatest value of a CIE?

0	0	0	0	0
Information sharing	Longitudinal record	Individual access to information	Better cross-sector collaboration	Other

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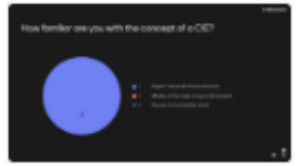

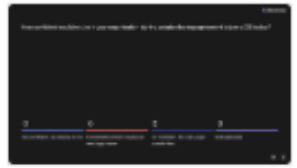

Revisiting Example

Disconnected Services for Addressing Housing-Related Health Problems

- Health care provider can reach out to housing services organization to schedule appointment and provide relevant information
- Housing services organization has access to select health data, as well as other relevant data (e.g., past services, eligibility information) through the CIE portal
- Health care provider is made aware of the referral outcome and can follow up accordingly

Legal and Policy Considerations

- Myriad legal requirements governing use and disclosure of data
- Differing consent requirements
- Complex agreement structure
- Concerns about risk in novel data sharing arrangements
- New compliance burdens

- Policy decisions related to:
  - Data elements and sensitive data
  - Permitted uses
  - Data access
  - Individual rights and access
  - Data retention
  - Participant selection

CIE Consent Models

Meghan Mead, Deputy Director| Network for Public Health Law

Consent as the Foundation of CIEs

- Information sharing in a CIE is predicated upon individual consent
- Differs from other types of data sharing that rely on legal exceptions
- Can simplify the legal framework, but raises expectations for robust consent model or consent utility
- Evaluate CIE partners, data types, and sensitive data

Why Consent Matters

- Cornerstone of trust and effective data sharing
- Balances service coordination with individual privacy
- Need to consider legal, ethical, technological, and procedural issues

Best Practices for Consent

✓ Consent must always be voluntary, no coercion

✓ Confirm capacity to consent (age, competence, state law requirements)

✓ Clarity! Forms should be clear, plain language, and accessible

Best Practices for Consent

✓ Informed! Specify what data is shared, with whom, and for what purpose

✓ 🔒 Obtain consent for highly sensitive data separately (mental health, HIV, SUD)

✓ Consent must be revocable at any time, with clear expiration terms

Best Practices for Consent

✓Consent must be unambiguous and affirmative

✓ Long form vs. short form

✓ Comply with any affirmative representations

✓ Evaluate material changes

Key Features in CIE Consent Models

- ✓Voluntary – no losing access to services or treatment
- ✓Clearly state purpose: “referrals, coordination, reducing duplication”
- ✓Make sure recipients clearly delineated (by category or by name)
- ✓Explain the type of information that will be shared

Key Features in CIE Consent Model

- ✓Rights of revocation and clear expiration timelines
- ✓Clients' rights section (voluntary, right to access copy of form)
- ✓Tiered consent options (basic vs. sensitive info; by provider)

Key Features in CIE Consent Models

- ✓Sensitive data may require separate, affirmative consent
- ✓Some models have multi-party/joint consents
- ✓Balance detail and readability (2–4 pages typical)
- ✓Short forms with optional detailed addenda

Key Learnings – Process & Procedures

✓Offer multiple methods: electronic, paper, possibly telephonic

✓Train staff and provide scripts/FAQs to explain CIE to clients

✓Develop uniform documentation across partners

At the end of the day:

- ✅ Robust consent model fosters trust, equity, and compliance
- Build on existing partner expertise, streamline across the CIE
- Keep forms understandable, voluntary, and adaptable
- Consent should empower individuals while enabling coordination

This is hard to do!

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Advancing Health Equity Through Community Information Exchanges Developing a Legal Framework

The Network for Public Health Law

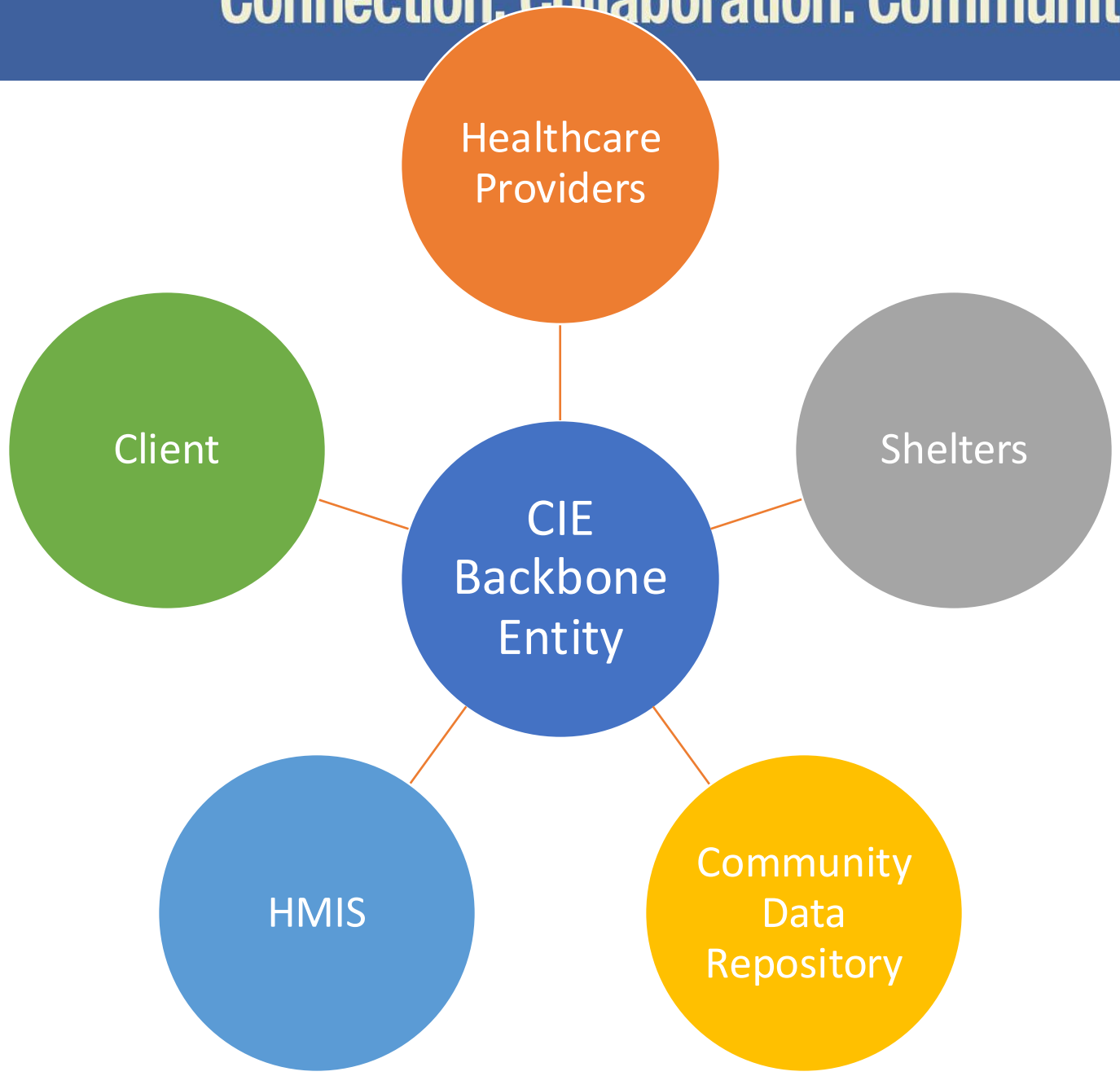
Community Information Exchanges

A Community Information Exchange, or CIE, is a network of health and social service organizations and agencies that develop shared governance to support the needs of community members.

Community Information Exchanges

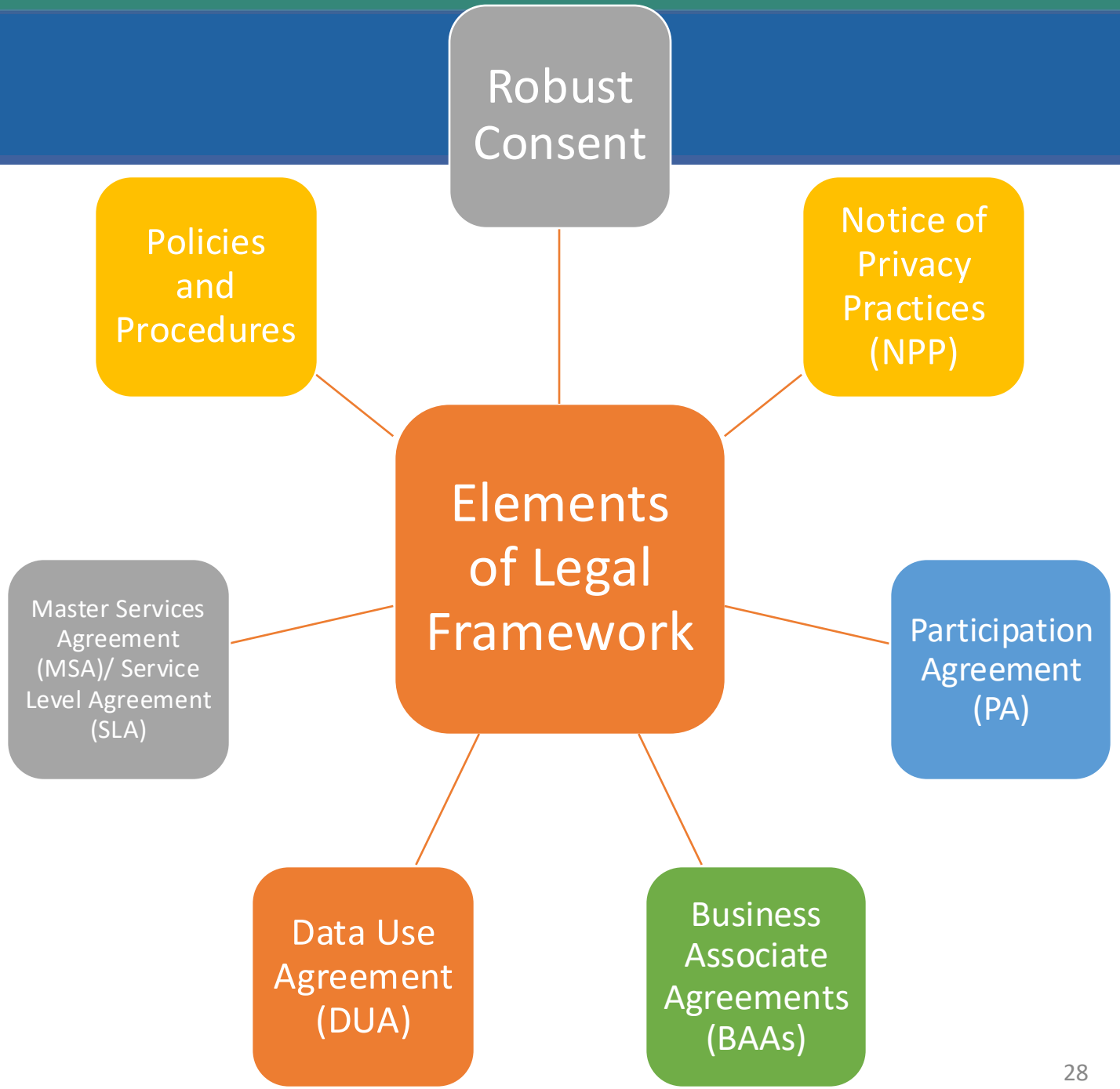
Serves as a care management hub, allowing participating providers to deliver more responsive, more effective community care planning for people who face multiple, often related, challenges (for example, food insecurity, unstable housing, and access to health care).

Sample Data Flows

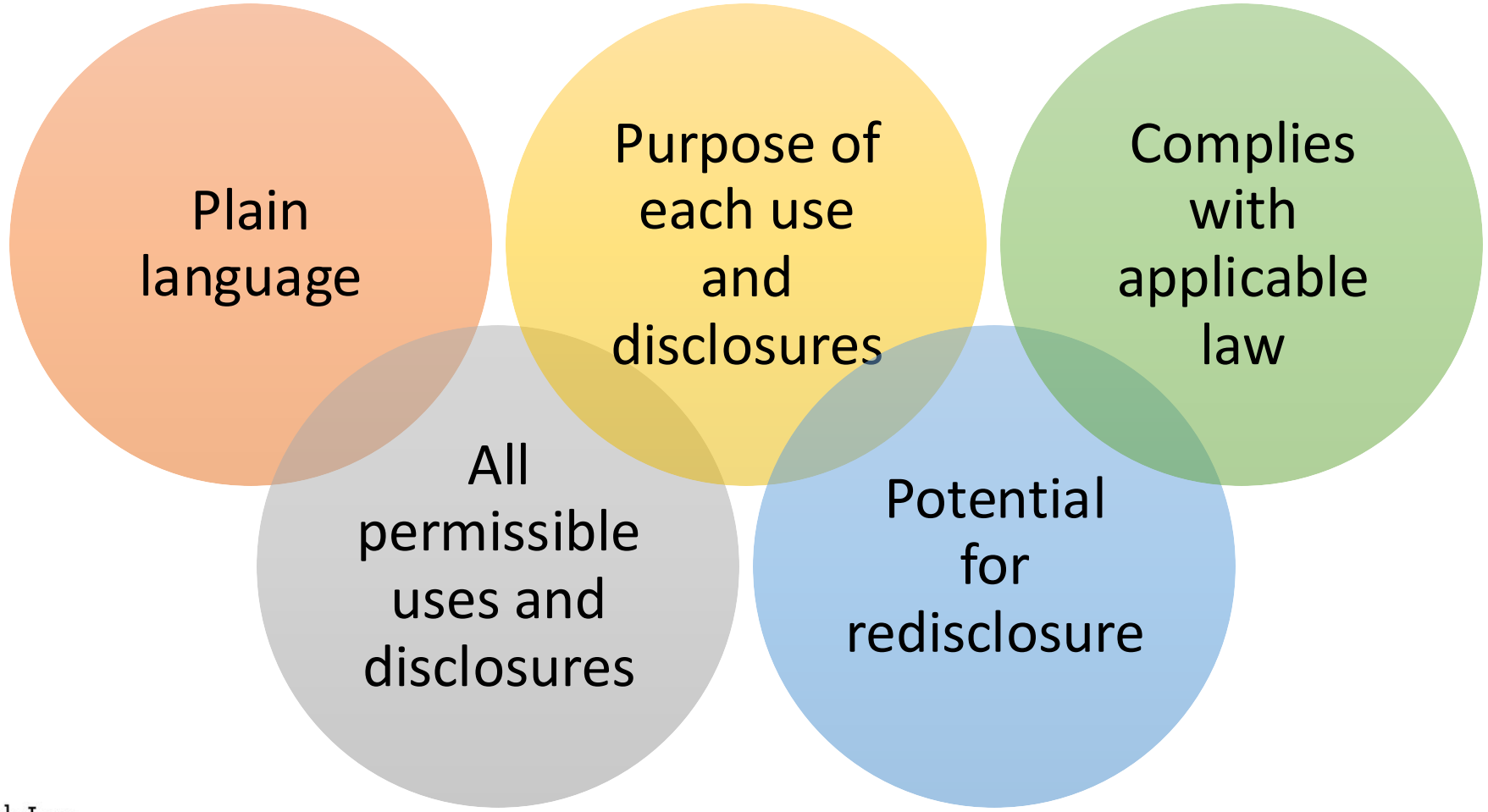


Framework Goals

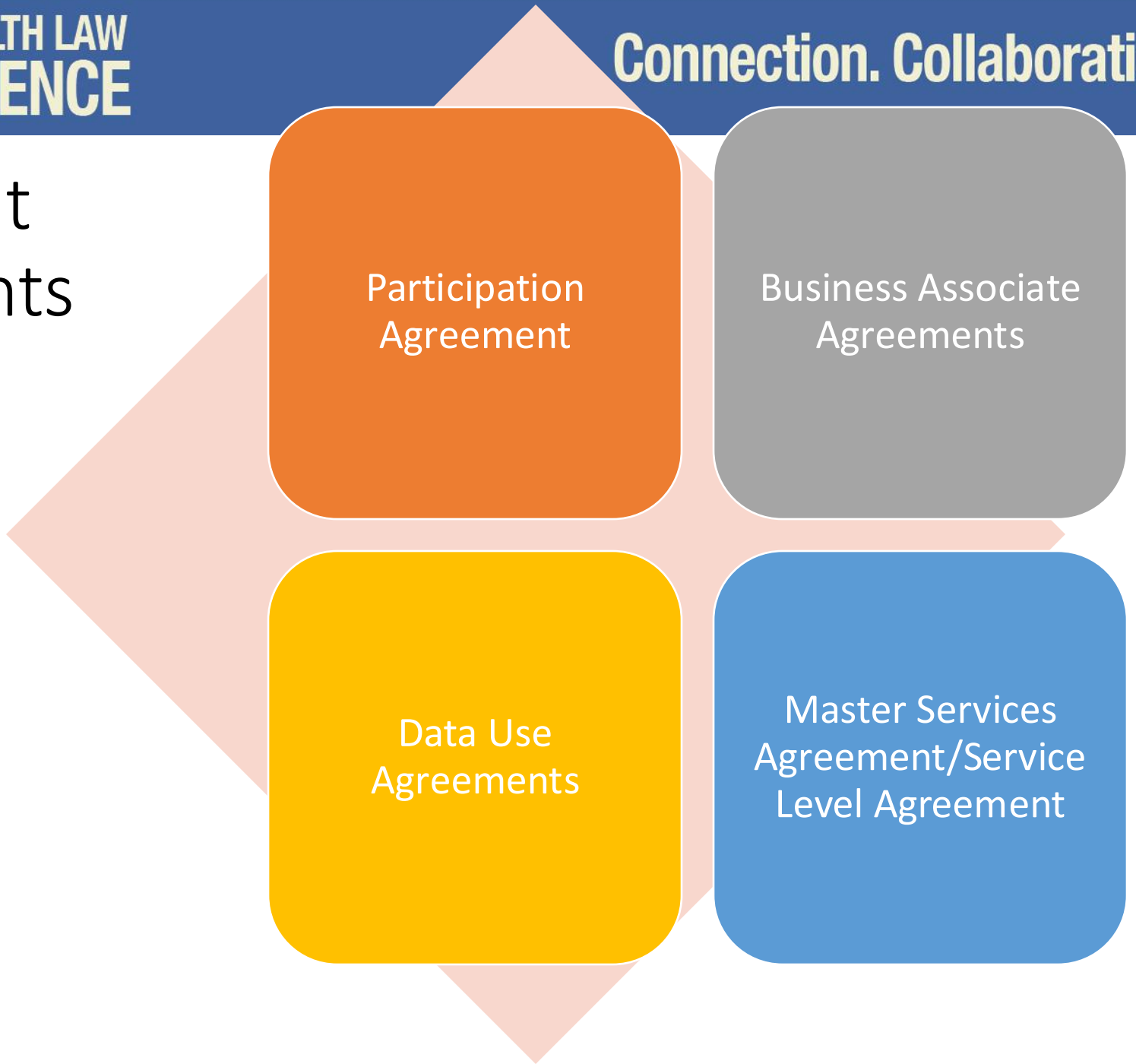
- Facilitating Data Exchange
- Data Protection
- Consent
- Transparency and Accountability


Robust Consent
Policies and Procedures
Notice of Privacy Practices (NPP)
Elements of Legal Framework
Master Services Agreement (MSA)/ Service Level Agreement (SLA)
Participation Agreement (PA)
Data Use Agreement (DUA)
Business Associate Agreements (BAAs)

Key Features of a Notice of Privacy Practices



Participant Agreements



Participation Agreements Key Components

- Rights and Obligations Regarding Participation
- Responsibilities of the Parties Regarding Data
- Permitted Purposes of CIE
- Types of Data Permitted
- Acknowledge CDR, APIs, MPI
- Information Security

Business Associate Agreements

Business Associates Include

(i) Health Information Organization… or other person that provides data transmission services with respect to PHI to a CE and that requires access on a routine basis to such PHI

Sample Authorities Granted by Business Associate Agreement to CIE

- Manage authorized requests for, and disclosures of, PHI among participants in the CIE
- Create and maintain a community data repository (CDR)/longitudinal record
- Release PHI from longitudinal records on behalf of the CE to authorized persons
- Create and maintain a master patient index
- Standardize data formats
- Facilitate the identification and correction of errors in health information records
- Provide a record locator or patient matching service

Sample Components of Data Use Agreement

- Rights and Responsibilities of the Parties Re Data
- Responsibility for Consent
- Data Elements
- Manner Data to Be Provided
- How Data May be Used
- Incorporation of Data
- Information Security
- Limits on Access by Third Parties
- Subsequent Disclosures

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Mentimeter

How confident would you be in your organization signing a data-sharing agreement to join a CIE today?

0	0	0	0
Very confident - we already do this	Somewhat confident - but would need legal review	Not confident - too many legal uncertainties	Not applicable

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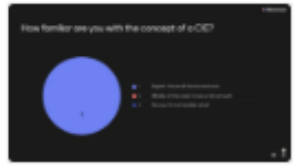

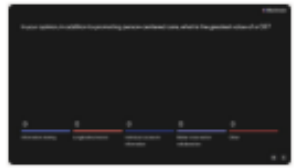

Recommended Data-Related Policies and Procedures

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What would help you most to move forward participating in a CIE model?

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Model legal agreements	Training on laws and regulations	Clear consent policies	Examples from other communities	Other

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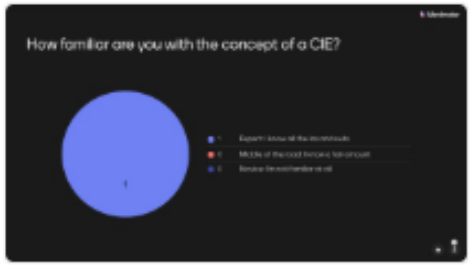

THANK YOU

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