Sharing Data for Whole Person Care

Dr. Kathleen Clanon
Cristi Iannuzzi
Chuck McKetney
Vanessa

• 47 years old
• Into music and art
• Living with her Mom
• Disabled by HIV and hepatitis

Loss of her mother results in a catastrophe……. Vanessa ends up homeless on the street. She has 41 ED and PES visits in the next six months…
Collaboration on a new level

Epic is a major assist in connecting many of the physical health organizations in Alameda County.

CHR adds mental health, addiction treatment, housing, EMS, jail health, benefits status and more.
Definitions

✓ **Social/Health Information Exchange or SHIE**
  ✓ A community of organizations sharing data under a set of agreements (i.e. according to federal and state regulations), and
  ✓ A platform to **keep data secure**, **manage who can see what**, and **match identity** when different data streams describe one person.

✓ **Community Health Record or CHR**
  ✓ The first tool drawing from the SHIE rolled out in September.
  ✓ The CHR allows providers to view a thin, timely slice of client utilization, diagnosis, and who else is working with them.
Demonstration of the CHR

Anonymized data from CHR Demo
Layers of privacy protection

✓ **Information Sharing Authorization** to identify what the consumer has agreed can be shared, with whom it can be shared, and when it has expired or been revoked

✓ **User authentication and Attribution** allows us to ensure that care managers only access information for someone they are authorized to see

✓ **Legal framework** includes a health data repository data sharing agreement that governs sensitive datasets inside and outside the privacy law
How the CHR is being used...
Community Health Record

• **Current Status:**
  - 44,874 people’s records are in the system
  - 101 people in 12 organizations trained and using the CHR
  - 307 consumer records viewed
  - 33 Information Sharing Agreements (ISA) signed

• **Most Cited by Users so Far:**
  - “Finding our my client has a housing case manager I didn’t know about!”
  - “Getting forms filled out and shared electronically to help with housing.”

“...it has caught on in such enthusiasm and excitement throughout our programs – staff and managers are literally buzzing with how helpful, user friendly, etc. it has been with more and more people wanting access…This access will literally save lives and help us help the community, so thanks!”

- Jaime Almanza
  Executive Director
  Bay Area Community Services (BACS)
Types of Available Data

**Whom We Are Serving:**
- Provider organizations and names of case managers and other care givers
- Services provided
- Population
  - Demographics (Age/Gender/Race)
  - Specified Subset
    - (HIV/TAY/Homeless/Veterans/SPMI)
    - Case Managed (yes or no)
- Housing status
- Medical and Mental Health Diagnoses

**Where They Get Care:**
- Emergency Department
- Inpatient
- Outpatient
- Psych Emergency
- Jail (future)
- EMS (future)

**What Services They’re Receiving:**
- Enrollment in programs

**Service enrollment and outcomes:**
- By client
- By provider

*New Connections: Health, Mental Health, Housing and more able to see the whole person….*
Example: What medical or mental health services are homeless people receiving, from which organizations?
When a consumer enrolls in case management, ED and PES usage drops.
The Information Sharing Authorization
What is the ISA?

• 3 ½ page Authorization for services and programs in Alameda County
• Initial use by Care Connect Care Coordinators
• Signed and dated by client or authorized individual (personal representative)
• Valid for 1 year period
• Modifiable/revocable at any time
• Stored in the CHR

Authorization for Sharing Your Protected Health and Personal Information

Client Name: ___________________________ Date of Birth: ____________
Client ID: ________________________________

The County of Alameda (the “County”) is asking for your authorization to allow sharing of your protected health information and other personal information (“information”). If you agree, information will be shared with (to and from) the County and the following types of organizations to help coordinate your care, resources, and human services.

- Physical and mental health
- Health plans
- Jail Health Services
- Crisis response
- Social Services Agency
- Housing supports
- Community services, for example, County Foodbank, County Library, legal services

Sharing information makes it easier to see if you are eligible for resources. It also allows you to get services and take part in programs run by the County and other organizations in Alameda County to improve your health (‘services’ and ‘programs’). This includes programs and services like Alameda County Care Connect (Care Connect), Healthcare for the Homeless, and Everyone Home.

Signing this Authorization Form (“Form”) is your choice. No matter what you choose, it will not change your ability to receive medical services, treatment, or public human services.

If you sign this Form, you are authorizing your information to be shared with (to and from) the County and the types of organizations shown above. It will be used to see if you are eligible for other resources, help link you to them, and help coordinate between them.

If you do not sign this Form, you can still receive medical services, treatment, or public human services. This may keep you from being able to fully take part in certain programs within the County for coordinating care.

How will sharing benefit me? If you allow your information to be shared, those serving you will be able to
Background on Information Sharing Authorization Form Development

Agreement by Data Sharing Sub-Committee to model after LA County form

Drafted form for Care Connect internal review/edits

Literacy consultant review and edits to ensure 8th grade reading level

Inside and outside Counsel review and edits

Two separate consumer feedback forums
Approximately 50 leadership representatives from:

- HCSA: Care Connect, County Counsel, EMS, Public Health
- Health Plans
- Hospitals
- CBO Providers
- SUD Providers
- Housing
- Social Services
- Sheriff
- Probation
- Legal Services
- Drug Court

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<thead>
<tr>
<th>Workgroup Meetings:</th>
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<tbody>
<tr>
<td><strong>1&lt;sup&gt;st&lt;/sup&gt; October 16, 2018:</strong></td>
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<tr>
<td>• WPC Overview</td>
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<td>• Initial Brain Storming Questions</td>
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<td><strong>2&lt;sup&gt;nd&lt;/sup&gt; October 23, 2018:</strong></td>
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<td>• Gallery Walk: Group responses/concerns on specific topics</td>
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<td><strong>3&lt;sup&gt;rd&lt;/sup&gt; November 27, 2018</strong></td>
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<tr>
<td>• HIE Best Practices Experts,</td>
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<td>• UA Form Edits based on feedback</td>
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<td>• Gallery Walk Response Document</td>
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<td><strong>4&lt;sup&gt;th&lt;/sup&gt; March 26, 2019</strong></td>
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<tr>
<td>• Present UA approved by Data Governance</td>
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<td>• Discuss workflow</td>
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Some controversies along the way…..

- “Pick list” design was desired by many, but technically and programmatically difficult.
  - Current best practices is to provide list of organizations covered by form but not to allow individuals to pick specific organizations for data sharing
  - May create gaps in individuals’ records – potential patient safety issue
- **Eliminated Probation and Sheriff** from organizations included due to stakeholder concerns about potential misuse of data
- Added Jail Health Services
- Not possible to include SUD sharing consent on same document
- MANY different County Counsels had different opinions….
- Name of the game:
  - Moving at the speed of trust.
  - Relentless incrementalism.
Universal Authorization Workflow

Two means of capturing consumer authorization:

1. In-person – electronic (unless consumer declines)
   - User walks through UA with consumer
   - Consumer makes selections on data sharing and “signs” electronically
   - System automatically populates record with consumer data sharing choices
AUTHORIZATION FOR SHARING YOUR PROTECTED HEALTH AND PERSONAL INFORMATION

Client Name: Lautt, Mina  Date of Birth: 1929-09-21  Client ID: Unknown

If you are working through this form with the consumer and wish to have them sign electronically, allow them to select the first option. Otherwise, choose the second option below.

☐ I am the consumer named in this document and agree to record and sign this authorization electronically.

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If you sign this Form, you are authorizing your information to be shared with (to and from) the County and the
Universal Authorization Workflow

Two means of capturing consumer authorization:

2. In the field – paper

- User provides paper form to consumer to sign
- Completed form is sent to AC3 Operations (per initial workflow design)
- System automatically populates record with consumer data sharing choices
Universal Authorization Workflow

• **UA may only be in-person**
  - Consumer may download the form from the website, but would need to bring it in-person
  - A legal guardian or representative may sign on behalf of the consumer – may not be a case manager, member of the care team, or other employee of the organization

• **Modifications to data sharing preferences would follow the same process**
  - Treated as a new authorization
AC SHIE: Data Governance

**Phase I: Technical and Legal Foundation**  Aug17-Jan 2018
- Participants: Program, compliance, IT representatives, and legal experts from County, AHS, CHCN, Alliance
- Products: Data Sharing Agreement, procedures, and plans for Universal Authorization document

**Phase II: Ground Work for Governance Charter, Membership and Supports**  Sept 18-Feb 19
- Participants: County departments, HIE experts, legal
- Products: Draft charter, proposed membership and structure of Data Governance ongoing, materials and questions for Steering Committee

**Phase III: Decisions and Direction Setting**  Data Governance Committee (DGC), first meeting February 7, 2019
Next Steps

• Campaign to get ISAs signed
• Roll out to non-HIPAA entities – should they see the same info, or a limited view?
• Hospital engagement
• Jail and probation as partners
• SUD and MH using different systems