Client Empowerment: Engaged Care through Connected Records

Karis Grounds
2-1-1 San Diego

Susan Millea, PhD
Children's Optimal Health

Melissa Moorehead
All In: Data for Community Health
Client Empowerment:
Engaged Care through Connected Records

Susan Millea, Ph.D.
Children’s Optimal Health
San Diego 211 Community Information Exchange Summit
San Diego, California
April 24, 2019

www.cohtx.org smillea@cohtx.org
• Health care systems: struggle to coordinate care and engage patients and care givers
• Education systems: struggle to coordinate services for students and engage parents/families
• Understanding child well-being involves health, school systems, social supports, equity issues

• How do we leverage advancements in technology and communications to create an integrated data ecosystem?
Community Data Ecosystem for Children: Multiple cross-sector collaborative projects

• Early Childhood Results Count!
  • Early identification of children with developmental delay, linkage to appropriate care
    • Closed loop referral system
    • Medical providers, Early Childhood providers, 211 UWATX, Aunt Bertha
  • STATUS: Addressing MOA and consent issues, data gov, planning for pilot

• STORY App
  • Parent/patient-centric integrated system for children with medical complexity
  • Value based health care
  • STATUS: Being deployed, identifying superusers

• Community School Model for a Campus-Coordinated Health System
  • Health equity challenges impact school success
  • Wrap around family services, school health, mental health, FQHC Clinics
  • STATUS: Concept submitted for review
Community Information Exchange
Core Components

Network Partners
Collective approach with standard Participation Agreement, Business Associates Agreement and participant consent with shared partner governance, ongoing engagement, and support.

Shared Language (SDoH)
Setting a Framework of shared measures and outcomes through 14 Social Determinants of Health Assessments and a Risk Rating Scale: Crisis, Critical, Vulnerable, Stable, Safe Thriving

Bidirectional Closed Loop Referrals
Updated resource database of community, health, and social service providers. Ability to accept/return referrals and to provide outcomes and program enrollment.

Technology Platform and Data Integration
Technology software that integrates with other platforms to populate an individual record and shapes the care plan. Partners access the system. System features include care team communication feeds, status change alerts, data source auto-history and predictive analytics.

Community Care Planning
Longitudinal record with a unified community care plan that promotes cross-sector collaboration and a holistic approach.
Client Record Sample

Client Profile
- Demographic and important information about the client

Domains
- Examples like Housing, Food & Nutrition,
- Categorization of Needs (SDOH) & Risk Level
- Shared Assessments and Values across agencies

Care Team
- Case Managers working with client across agencies
- Contact Information

Referrals & Program Enrollment
- Agencies or programs client is referred
- Connection to Services

Alerts
- Notification of emergency services & jail
- Ability to notify Care Team Members of changes

Feed
- Ability to communicate with Care Team members (twitter-like feed)
People and Process
Why build the STORY App?

Physicians: Hospitals, Specialty Clinics

Home Health Nursing

Durable Medical Equipment

PT/OT/Speech Therapists

Insurance Providers

School Nurses

Photos: Physiciansnews.com, phoenikhomehc.com, stcharlesrehabilitation.chsli.org, varietyst.org, medium.com, texaschildrenshealthplan.org
Why include the patient perspective?

Need: Systems level changes that help people, not just providers

Parent Identifies
11 Systems
(not just hospitals and clinics)
44 Providers/Programs
How did you build the STORY App?

Knowing Users vs Speaking to Users

You probably do know your users, so work that relationship during the UX (re)design process. Here’s 3 good times to talk:

- Discovery ➔ Strategy ➔ Design
- Research ➔ User Testing ➔ Concept Validation
- Prototype ➔ Test ➔ Revise ➔ Pilot/Deploy
What were key successes/challenges?

**Successes**
- Desktop
- Mobile
- DPT
  - DME, Nurse, OT/PT
- Shared Care Plan
- Child’s Story
- Data Core
- Utilization Data
  - Value based care

**Challenges**
- Bureaucratic complexity
  - Needing national approvals
  - Multiple committees
  - Inertia
- Multiple Tech Systems
  - Hospital EMR
  - Clinic EMR(s)
  - Home Nursing
  - Durable Medical, PT/OT
- Business negotiations, trust
  - Small, facile developer
  - University data backbone
  - Research Medical School
People and Processes
Importance of Participant Portal

• Person-Centered Model

• Community-owned data (ability to consent and revoke)

• Tracking who is helping me (Referrals, Programs, Care Teams)

• Empowerment (access and collection)
Collective Development

Feedback from Community Partners (on behalf of clients/patients)

- System wide Person-Centered
- Helpful for uploading/storing documents
- Ability to choose to create profile and consent
- Information requested vs. needed

Feedback from Participants

- User interface—easy to use, looks good, intuitive
- Support themselves or others within network
- Update own information
- Too much information (asks for too much)
- Track services they have access
  - Examples of testing sites: Library, Mental Health & Addiction Services, Senior (Grandparents Raising Grandchildren)

Chief Compliant:

- How much is too much?
- Expectations different in clinical vs. social services
- User Interface/Utilization

Success:

- True Client Empowerment and Access to Information
- Shared Communication
- Limited Patient Portal for social services vs. EHR/medical
Technical and Legal Development
What is the STORY App?

• It is **NOT** an Electronic Medical/Health Record, HIE, CIE

• **STORY is a platform independent solution**
  • Entities continue to use their existing record systems
  • Creates a ‘Curated STORY’ of the person
    • Collating essential details from across key persons involved in care
    • STORY view is tailored to user needs (MD, Nurse, Therapist, Parent)
    • Best practice guidance via physician order sets, care plans
  • Parent controls consent, who has access
  • Holistic time-series view of the patient’s health
  • Aggregates utilization data across patient, provider, site, etc.
    • Essential for developing value-based health care
Technical Development and Data Governance

- Innovative, facile developer
  - Intellectual Property protection
  - Patenting
- Based on Fast Health Interoperability Resource (FHIR)
- Application Programming Interfaces (APIs)
- Ascension/Seton (national health system)
  - Required multiple reviews/approvals from local to national
  - Hospital and Clinic EMRs are different
- Trusted 3\textsuperscript{rd} party for back end (Dell Medical School)
  - BAAs, DUAs
- Data Governance issues TBD
26-week premie
Congenital heart disease
Congenital brain malformation
Cerebral Palsy

Blindness
Epilepsy
G-tube dependent
Please talk to Blake & include him in plan.

Please don’t grab his hands, since he is blind, his hands are his eyes. You can do hand under hand to show him items by touch.

Please tell him simple instructions before placing blood pressure cuff or starting assessment.

Blake says Hi/Hey, uses happy/unhappy sounds; He is learning 3D symbols for Go, Stop, Like

He pushes or throws items for refusal.

He bites hands when excited or frustrated. We use chewelry or toys for re-direction.
• This is REALLY Great for kids with multiple disabilities! I carry a notebook to all appointments that’s hard to keep up to date. Doing this on my phone would be so much easier.

• I have providers in different cities/health systems. I want to include all providers to keep them all informed.

• I’d like to be able to print pages from my phone. Forms in medical offices don’t have enough space to write all hospitalizations, meds, etc. I could print the page and they would have it.

• Ability to add video clips is great. Then the psychiatrist/psychologist can see the behaviors I describe.
Technical and Legal Development
Technology/Building Portal

Goal: Access, empowerment and participant involved with their care

• View into the CIE with ability to set-up account on their own
• Aggregates both social and medical information
• Holistic view of access to services, resources and people
• Interface pulls select data from full community portals
• Provide insights from their perspective
**Technology Platform**

**ETL**

1. Reads data from a database
2. Converts the data for the new database
3. Loads into the new database

**MDM**

- Master Data Management
- Detects and merges duplicate records
- Ensures the accuracy, completeness, and consistency of multiple domains of enterprise data

**CIE**

- Shared client record
- Alerts
- Single Sign on

**API**

- Food
- Jail
- EMS
- Housing (HMIS)

**File upload**

**XLS**

**Community Information Exchange**
Resource Database
Hub for social and health sites and providers

- Shared taxonomy language for referrals (AIRS)
- Dedicated resource staff
- Regular updates made to resources
- Standards to listings and requirements
- Inclusion/Exclusion Criteria
- Linked to health conditions
- Tracks resource availability and unmet needs
Participant Portal

Pulls relevant information from Community Portal to Patient Portal
- Only specifically identified fields
- Reformatted language to be personal and relevant

My Profile & Settings
- Who you are?
- Demographics and Contact Information

My Summary
- Ability share thing about myself
- Things I need help or support with
- Challenges
Care Team
- Case Managers who I am working with

Referrals & Program Enrollment
- Agencies or programs client is referred
- Connection to Services

Eligibility
- Programs I may be eligible for
Resources I like:
- Ability to Favorite programs
- Learn more about eligibility
- Empowerment

*Use media features that are to familiar to participant “Facebook like or favorite”
Use, Outcomes, Next Steps
Use, Outcomes, Next Steps

Front End Implementation

Use and Outcomes

• Desktop is deployed
  • Clinicians can use
  • Cost savings from Durable Medical Equipment
• Mobile version moving from pilot testing to full deployment
  • Positive responses from pilot parents

Next Steps

• 10 Superusers targeted among parents, buddy system
• Assess what will make mobile use ‘sticky’, tool for daily use
Use, Outcomes, Next Steps

Back End: Data Core/Dell Medical School

Use and Outcomes

• Cloud Forest Data Environment fully functioning
• Data mirrored in Dell Medical School Data Core

Next Steps

• Enhance data flows into DMS Data Core
• Add EMR Aggregators, extends EHR systems that can be included
• Address Data Governance for research, community learning
Use, Outcomes, Next Steps

Insights: Utilization and Care Transformation

Use and Outcomes

• Seeking to give parent/caretaker equivalent status with medical team
• Payer data is incorporated
• Utilization analyzed by patient, provider, site, clinic, procedure

• Next Steps
• Improving turnaround time in accurate payer data (current 2 month delay)
• Cost analysis
• Value-based care
Use, Outcome and Next Steps
State of Participant Portal

Use and Outcomes:

• Still in demo site, testing with more participants before launch
  • Homeless/Housing Instability is crucial

• Meaningful Launch—ensure buy-in

Next Steps:

• Data Analytics on Utilization (consents and data sharing)

• Evaluation on Client Empowerment and impact on care by using app
Thank You!

Podcast link

Dr. Susan Millea (Left) and Dr. Rahel Berhane (Right)
Thank you!

Karis Grounds
Vice President of Health and Community Impact
kgrounds@211sandiego.org