HCBS Personal Health Record: If you build it, will they come?

HCBS Conference
August 29, 2017
SESSION OBJECTIVES

• Share the experience of three states that have worked on implementing HCBS-oriented Personal Health Record (PHR) tools

• Report lessons learned and effective strategies from these states’ demonstrations
  – Focus areas include vendor selection, user interface design, data sources to populate the PHR, and HCBS user adoption and training
TODAY’S PANELISTS

- Kathleen Tucker
- Tom Gossett
- Bonnie Young
- Shane Owens
- Eric Roley
- Matt Vedal
AGENDA

• Background of the Centers for Medicare & Medicaid Services (CMS) Testing Experience and Functional Tools (TEFT) Program

• Overview of HCBS PHR Demonstrations

• State Experiences
  – Minnesota
  – Georgia
  – Colorado

• Questions and Discussion
TEFT BACKGROUND AND HCBS PHR ACTIVITIES

Kathleen Tucker
The Lewin Group, TEFT Evaluation
TEFT BACKGROUND

• CMS established TEFT in 2014 in response to the Affordable Care Act. TEFT is unique because of:
  – The focus on experience
  – The development of a standardized assessment across Medicaid HCBS programs
  – The integration of health and social service information delivered to the individual via technology using a PHR
  – The coordination of health and HCBS information exchange between an individual’s providers

<table>
<thead>
<tr>
<th>State</th>
<th>Experience of Care Survey</th>
<th>Functional Assessment Standardized Items</th>
<th>Personal Health Record</th>
<th>eLTSS Plan</th>
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<td>New Hampshire</td>
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*Louisiana and Minnesota field tested Experience of Care Survey in Round 1

For more information please visit https://www.medicaid.gov/medicaid/ltss/teft-program/index.html
TEFT PHR ACTIVITIES

• Do you personally have an electronic tool you use to:
  – Schedule doctor’s appointments
  – Refill prescriptions
  – Pay medical bills
  – Enter medical or non-medical information
  – Manage health information

• If yes, you may be using a patient portal or a PHR.

• A patient portal differs from a PHR in that a patient portal is often “tethered” (linked) to one provider’s Electronic Health Record system.
  – With a patient portal, the individual often does not have the same level of control over the data as with a PHR.
TEFT PHR ACTIVITIES

- A PHR is a tool used by individuals to maintain and manage their health information in a private, secure, and confidential environment. A PHR gives an individual control over sharing their health information with their care team.

- TEFT combines social service information with medical and health information into a single electronic system controlled by the individual
  - However, many HCBS systems still rely on paper-based communication between a provider and beneficiary
  - TEFT offers an opportunity for states to examine their HCBS systems and begin to use electronic means (i.e., PHR) for communication and information sharing
PHR CONSIDERATIONS FOR HCBS GROUPS

- TEFT states have used focus groups and user testing, among other methods, to determine specific considerations for HCBS users

<table>
<thead>
<tr>
<th>Features</th>
<th>Accessibility</th>
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<tbody>
<tr>
<td>- Medical and social service information is presented without technical</td>
<td>- Supports integration with assistive technology (e.g.,</td>
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<tr>
<td>jargon</td>
<td>screen readers)</td>
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<tr>
<td>- PHR access via web page on computer and mobile phone</td>
<td>- Strong visual help cues to enter information</td>
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<td>- Training videos/help screens</td>
<td>- Error messages appear in plain language with</td>
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<td>- Allows beneficiaries to update/store electronic documents to the PHR</td>
<td>suggested course of action</td>
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<td>(e.g., advanced directives)</td>
<td>- Definitions available by right-clicking or hovering</td>
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<td></td>
<td>over a word (e.g., “tool tip”)</td>
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## Types of PHR Solutions for HCBS Groups

- TEFT states decided between purchasing an off-the-shelf PHR model or creating a custom-built system

### Off-the-shelf PHR Model
- Often requires the release of a Request for Proposals (RFP)
- A more static software package with little room for customization
- Ability to quickly implement within a system and population
- TEFT States: CT, MN

### Custom-built System
- Requires more time spent in the planning and design phases
- Allows more room for customization and integration with different IT systems
- TEFT States: CO, GA, KY, MD
## WHERE ARE WE NOW?

<table>
<thead>
<tr>
<th>Component</th>
<th>Y1: April ‘14 to March ’15</th>
<th>Y2: April ‘15 to March ’16</th>
<th>Y3: April ‘16 to March ’17</th>
<th>Y4: April ‘17 to March ‘18</th>
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<tbody>
<tr>
<td>PHR</td>
<td>PHR Planning (States)</td>
<td>PHR Design (States)</td>
<td>PHR Implementation (States)</td>
<td>PHR Evaluation (Lewin)</td>
</tr>
<tr>
<td></td>
<td>CO, CT, GA, KY, MD, MN</td>
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KEY ACTIVITIES SUPPORTING TEFT’S PHR DEMONSTRATIONS

• PHR Planning
  – PHR environmental scans and review of state information systems
  – Stakeholder engagement and design planning to identify features and functions for the PHR
  – Procurement and requirements gathering for PHR configuration

• PHR Design
  – Working with vendor on usability and accessibility
  – Understanding specifically how the PHR system will securely integrate with other IT systems

• PHR Implementation
  – User acceptance testing and user and stakeholder training
  – Phased releases and refinements for the PHR
  – Monitoring PHR adoption and usage (e.g., state led focus groups, Lewin PHR User Survey)
TEFT PHR ACTIVITIES

- TEFT states are implementing the PHR at different stages throughout the TEFT Demonstration
  - Next, we will hear from three TEFT states about their experiences completing the PHR component: Minnesota, Georgia, and Colorado.

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STATE TEFT PHR EXPERIENCE: MINNESOTA

Tom Gossett
Minnesota Department of Human Services
MINNESOTA’S GOALS

Prove we CAN share information from DHS systems in a way that is:

**Accessible**
- For seniors
- For people with disabilities

**Useful**
- For beneficiaries/legal representatives
- For case managers

**Securely Available**
- Where beneficiaries access the Internet
- Through a mobile-first platform
MINNESOTA’S CURRENT STATUS

MN Implementations:

Collaborative #1 - Otter Tail County
- Online since October, 2016
- 19 Beneficiaries/Legal Reps
- 12 Case Managers
- 27 Provider Staff
- 3 State Staff

Collaborative #2 - Southern Prairie
- Online by January, 2018
- Projected users – 40 Beneficiaries/legal representatives

Collaborative #3 - TBD
- Contracting in process
HOW DID MINNESOTA PLAN TO ATTRACT PHR USERS?

• State planning
  – Request for Proposals for PHR Community Collaboratives (2 rounds)
    • Collaboratives made up of multiple organizations serving people on Medical Assistance (Medicaid)
    • Collaboratives would contract with a vendor of an existing PHR
    • Collaboratives would engage and support beneficiaries who would use the PHR

• Stakeholder engagement
  – Beneficiaries/Legal Representatives:
    • Collaboratives included the County Human Services agency which provides case management for MA beneficiaries
    • Case Managers recommended likely PHR users to the Collaborative
    • Collaborative staff reached out to beneficiaries/legal representatives asking them to participate, and providing training and support throughout
WHAT WAS IMPORTANT IN THE HCBS PHR DESIGN?

• Stakeholder engagement to gather feedback
  - DHS project sponsors (senior managers) and staff
  - MN.IT @ DHS Staff
  - DHS aging & disability program administrators
  - MDH Office of Health Information Technology staff
  - County and MCO (Lead Agency) Case Managers
  - ADRC director & staff
  - Acute and Post-Acute Care providers
  - HCBS associations and providers

What We Learned:
  - Confirmation of the value of PHR
  - Case Manager info is key
WHAT WAS IMPORTANT IN THE HCBS PHR DESIGN?

- Requirements gathering & vendor selection

MN created a detailed business requirements workbook (composed of 266 specific requirements) that was included in the RFP and used for scoring proposals.
HOW DID THE MINNESOTA PHR IMPLEMENTATION GO?

- Stakeholder engagement & rollout

**Identify**
Providers/Case Managers identify likely participants

**Contact**
Collab. staff call potential users, explain PHR, confirm participation

**Train**
Collab. staff provide one on one training for users, share access to written and video materials online

**Onboard**
Tech staff adds user record to Aggregator, creates PHR record and invites the user to use the PHR system

**Support**
Collab. staff are available to users, conduct Focus Groups to gain user feedback, etc.
USER FEEDBACK

Bene/Legal Rep Focus Group

Provider/Case Manager Focus Group

Lewin Survey through PHR Message
WHAT IS MINNESOTA’S PERSPECTIVE ON “IF YOU BUILD IT, WILL THEY COME?”

• Sustainability
  – MN’s focus has been to use this demonstration as a way to learn lessons about how to electronically engage beneficiaries
  – We do not intend that the PHR will live in its current form beyond the end of the TEFT grant
  – Mechanisms for aggregating DHS data will live on for other uses

• Recommendations for others interested in adopting
  – Don’t underestimate the work that it will take to aggregate data from source systems
  – Talk to lawyers early and often
  – Start simple and build from there
STATE TEFT PHR EXPERIENCE: GEORGIA

Bonnie Young
Georgia Department of Community Health, Division of Health Information Technology

Shane Owens
Georgia Tech Research Institute
GEORGIA’S GOALS AND CURRENT STATUS

GOALS FOR PHR DEMONSTRATION

1. Support clients with care-related decisions
2. Support care team effectiveness and communication

CURRENT STATUS

– PHR Demonstration and Tool has been approved by:
  • Georgia Tech’s Institutional Review Board (IRB)
  • State of Georgia - Georgia Technical Authority
  • Department of Community Health Business Associate Agreement (BAA) with GTRI
– First phase of pilot in progress
– Full deployment will occur by November 1, 2017
STAKEHOLDER ENGAGEMENT

Medicaid Waiver Members (Clients)

Care Team Members
- Case Managers/Care Coordinators
- Service Providers/Formal Caregivers
- Family Members/Informal Caregivers
HOW DID GEORGIA PLAN TO ATTRACT PHR USERS?

1. **DCH Working Group**
2. **Field Research**
   - (Shadowing & Interviews)
3. **Workshops**
   - (Service Provider Conference)
4. **Case Manager Engagement**
WHAT WAS IMPORTANT IN THE HCBS PHR DESIGN?

- **Stakeholder Engagement**
  - Understand what data matters
  - Understand what functionality matters

- **Paper Prototype**
  - Understand how to organize the data

- **User Testing**
  - Understand interaction design
WHAT WAS IMPORTANT IN THE HCBS PHR DESIGN?

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# POTENTIAL FEATURES FOR CONSIDERATION

<table>
<thead>
<tr>
<th>Feature</th>
<th>Notifications of Changes</th>
<th>Mobile</th>
<th>Printable</th>
<th>High Impact</th>
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<td>Supporting Resources (FAQs/Member Forum)</td>
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## ANALYSIS

<table>
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<tr>
<th>In/Out of Health System Notifications</th>
<th>Waiver Waiting List Status &amp; Time Estimate</th>
<th>Caregiver Onboarding Notes</th>
<th>Condition Management Modules</th>
<th>Appointment Status Notifications</th>
<th>Service Provider Scheduling Management</th>
<th>Static Supporting Information Resources</th>
<th>Eligibility Status Change Notifications (include Anticipated)</th>
<th>Service Provider Finder &amp; Ratings</th>
<th>Waiver Program Updates &amp; FAQs</th>
<th>Service Record Info / Transition Info</th>
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## ANALYSIS

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<td>Static Supporting Information Resources</td>
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<td>Service Record Info / Transition Info</td>
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<td>Appointment Status Notifications</td>
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## WORKING GROUP DECISION

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<td>In/Out of Health System Notifications</td>
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<td>Appointment Status Notifications</td>
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DESIRED OUTCOME: EMPOWERMENT

Medicaid Members:
• Empowering members to take control of their health by facilitating communication of care needs with the care team

Care Team:
• Empowering care team members by providing useful and timely information to facilitate better care decisions
VENDOR SELECTION FACTORS

1. Pilot Demonstration = Test Innovation
2. Flexibility of Design/Development
3. Contracted Project Timeline

DECISION:
Build pilot product “in-house” using sister agency, Georgia Tech
WHAT WAS IMPORTANT IN THE HCBS PHR DESIGN?

**Stakeholder Engagement**
- Understand what data matters
- Understand what functionality matters

**Paper Prototype**
- Understand how to organize the data

**User Testing**
- Understand interaction design
PAPER PROTOTYPE

Jakes’s Homescreen

CARE TEAM

Jake Smith
CCSP Client
Care Coordinator

Joy Harris
Legacy Link
CCSP Care Coordinator

Susan Johnson
Right at Home
Caregiver

Frank Miller
Visiting Nurse
Home Health Provider

Jane Smith
Daughter
Lives with Member

Arnold Henry

Things to Look Out For

Health
- COUGH: if he has a cough, contact him physician immediately.

Appearance
- MESSY HAIR: if his hair is particularly messy, he could be having an episode of depression. Call Jane for ideas.

Personality
- IRRITABLE: if he becomes very irritable, he may not have taken his meds.

Today, Jake feels...

- “Horrible!”
- “I woke up 3 times last night.”
- “He’s doing OK.”
- “He may be cranky today so please be patient with him.”

Jake Needs
- Ibuprofen

Support Recommendations

Overall
- Appreciates Arriving on-time
- Frustrated By Being talked to like a child

Bathing
- Appreciates Being quick
- Frustrated By Having to be helped

Toileting
- Appreciates Giving me privacy
- Frustrated By Having to be helped

Medicaid Eligibility
- 97 Days Remaining

Waiver Eligibility
- 12 Days Remaining

Last Visit To Doctor
- 2 Days Since

View Past Days

#HCBS2017 | 36
UPDATED DESIGN

Keys for Caring

Support recommendations

How I enjoy my life
- I like to sleep in until 11
- I like books, but can't read anymore
- I like visiting with my family
- I knit often

What I'd like to be able to do
- Walk further
- Fix myself easy meals or snacks

Service recommendations

Personal Support Services

Bathing Tips
- I appreciate privacy
- I don't like when people are too rough

Light housekeeping Tips
- I like to have my dusting done weekly
- I don't want you to clean my jewelry

Adult Day Health
- No Recommendations

Emergency Response Services
- No Recommendations
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PHASE I PILOT – MVP TESTING

SCOPE:

– **Member Login:**
  • Allows the member to have secure access to their information via the computer or mobile device.

– **Member Profile:**
  • Allows member to record information that would be important to share with their service providers, family, etc.

– **Printing of Member Profile:**
  • Ability to print member profile information in order to share with their service providers, family, etc.

(MVP – Minimum Viable Product)
## FULL VERSION KEY FEATURES

<table>
<thead>
<tr>
<th>Feature</th>
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<tbody>
<tr>
<td>Provide access to any care team member</td>
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<tr>
<td>Provide daily updates to care team members</td>
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<tr>
<td>Caregiver onboarding notes</td>
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<tr>
<td>Eligibility status change notifications</td>
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<tr>
<td>Access to care team contact information</td>
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<tr>
<td>Updates to care team members about changes to care</td>
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<td>Ability to update their own information</td>
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<td>Educational resources to beneficiaries</td>
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<td>Service overview and preferences</td>
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<td>Validation of medical information</td>
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<tr>
<td>Audit logging of all information updates</td>
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MPOWER

THE POWER OF TEAMWORK
MPOWER is a mobile and desktop app built to connect Medicaid clients and care teams in powerful new ways. With the ability to personalize care, provide timely service information, and maintain a network of trusted supporters, MPOWER is working to redefine team-based care and collaboration.

BE INFORMED
Easily coordinate with care team members, service providers, and loved ones through daily client updates.

Daily updates are communicated whenever and however you want them, whether through email, phone call, or text messages.

STAY IN CONTROL
MPOWER works at home or on the go, and it's designed to reduce confusion and offer clear, useful features.

Service preferences, like client priorities and homebase details, provide smoother experiences for clients and care teams alike.

FEEL PROTECTED
Privacy options give clients control over who can access their information and who should be reached in times of need.

REST Assured
Every care team member has access to up-to-date client information, ensuring that checking on clients is always possible and quality of care is always consistent.

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WHAT IS GEORGIA’S PERSPECTIVE ON “IF YOU BUILD IT, WILL THEY COME?”

- **Sustainability**
  - Depending on outcome of the pilot, considering including future funding
  - Will embed lessons learned into other IT projects

- **Recommendations for others interested in adopting**

  Engage Your IT Department EARLY

  User Input Is Critical
STATE TEFT PHR EXPERIENCE: COLORADO

Eric Roley - TEFT Project Coordinator
Matt Vedal - PHR Project Manager
Colorado Department of Health Care Policy and Financing
COLORADO’S GOALS AND CURRENT STATUS

• Goals for YR 3: Design and field test PHR amongst 50 LTSS clients

• Where are we today? Around 10 clients signed up and ready to participate as of July 2017

• PHR Platform ready for production and testing, in web and mobile applications

• CO hasn’t reached initial desired number of participants, but has successfully worked with vendors to design platform and is ready to begin testing
RECRUITING CLIENT PARTICIPANTS

State planning

- Planned Stakeholder focus groups at 5 regions across state
- Engaged Providers and Case Management agencies to develop client recruitment strategy

Stakeholder engagement

- Conducted focus groups to elicit feedback and inform community of progress
  - Groups consist of case managers, clients and other parties interested in PHR development
- Developed and distributed questionnaire for potential clients who are willing and able to participate in the PHR Pilot
- Conducted live demo of PHR
ENVIRONMENTAL SCAN

- Clinical and non-clinical data important in PHR
- PHR training for LTSS clients/providers

DATA ELEMENTS

- Client demographic info
- ULTC Assessment
- Service Plan
- Hospital ADT Data
- Next steps…more data?
COLORADO PHR IMPLEMENTATION

• Stakeholder engagement
  – Completed 2 rounds of stakeholder meetings
  – 1st round served as reintroduction to TEFT, PHR activities
  – 2nd round included live demo, walkthrough of PHR
  – Focused on engaging TEFT stakeholders, looking for client participants and eliciting feedback

• Rollout
  – Colorado is ready to begin testing the PHR with LTSS clients
  – Small sample size to start with, hopefully lessons learned can guide action for longer term sustainability
COLORADO’S PERSPECTIVE ON “IF YOU BUILD IT, WILL THEY COME?”

Sustainability

- Colorado looking to expand PHR past TEFT grant.
- Hope to take feedback and lessons learned and incorporate into Medicaid PHR.

Recommendations for others interested in adopting

- Lots of community feedback is necessary.
- Must work with LTSS stakeholders to determine most effective ways to implement PHR in LTSS population.
- Work closely with vendors, data teams and other technical experts to manage expectations and create process for exchanging information.
CONTACT INFORMATION

Thank you!

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