State Health Policy Consortium

AMIA Final Report on the Development of Technical Assistance and Educational Materials to Support Consumer-Mediated Exchange

Final Report

Prepared for

Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
300 C Street SW
Washington, DC 20201

Prepared by

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State Health Policy Consortium

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Executive Summary

To move toward health care transformation, the Office of the National Coordinator for Health Information Technology (ONC) has a strategic goal to empower individuals to improve their health and the health care system through health IT. With the growth in adoption of electronic health records (EHRs) since the Health Information Technology for Economic and Clinical Health (HITECH) Act in 2009, data to support patient empowerment is becoming more available. Access to and use of this data will enable patients to participate more actively in their own health care decisions and manage conditions, and allows, their information to be shared and managed among providers who use different electronic systems or are in different geographic areas. The concept of consumer-mediated exchange (CMx) supports patient engagement and helps overcome traditional concerns about exchange such as consent management and state differences in disclosure laws.

In 2013, the American Medical Informatics Association (AMIA)—along with its subcontractors Koss on Care, LLC, and Barsch & Company (collectively, the AMIA team)— were contracted to lead a project titled *Attitudes: Development of Technical Assistance (TA) and Educational Materials to Support Consumer-Mediated Exchange*. This effort was one of several projects referred to collectively as the PHR Ignite Consortium, which investigated the value of CMx in the U.S. health care environment. These projects, supported by RTI International through the State Health Policy Consortium (SHPC) project and funded by ONC, were designed to develop a framework to advance CMx use by patients and providers to improve health outcomes.

The *Attitudes* project was designed to characterize patient, caregiver, and provider attitudes toward and opinions about CMx and rural care coordination for patients with chronic illnesses. The project sought to explore the challenges of rural care coordination and the range of CMx activities occurring in rural communities. The information obtained during this project supported development of a framework for technical assistance (TA) for CMx.

ES.1 Methodology

The AMIA team held open format roundtable discussions focused on either patient or provider reactions to various use cases and also conducted some individual interviews. Facilitators for the roundtables used two stories to stimulate discussion about care coordination for a patient with chronic illness. The *Today Story* described current exchange efforts and the *Future Story* envisioned how a similar series of events could be different when CMx was introduced into the health care environment. These stories provided a framework for an open discussion among the participants about the current conditions of chronic care management in rural settings and the potential for CMx to improve care management.

In addition to the roundtable discussions, the AMIA team conducted nine individual discussions with four patients, four providers, and a group of three vendor representatives to explore participant perspectives on the role of CMx in rural chronic care coordination and capture their recommendations for technical assistance and training.

ES.2 Synthesis and Analysis of Discussion Data

The AMIA team grouped key findings from the roundtables and interviews into topic areas to organize the information and identify the following themes: barriers to care coordination, barriers to CMx adoption and use, anticipated benefits of CMx, and recommendations about TA.

ES.2.1 Barriers to Care Coordination

The team assessed which barriers to care coordination could be mitigated by CMx and considered these the strongest candidates for education and awareness building. Barriers to care coordination included the following factors:

- lack of information and data-sharing between patent and provider,
- poor patient/provider communication,
- consumer health literacy,
- needs of unique patient populations,
- lack of EHR interoperability,
- provider attitudes and motivation,
- lack of patient motivation/engagement, and
- lack of provider reimbursement.

Both patient and provider participants agreed that the inability to share clinical information and data among providers and patients is a prominent barrier to care coordination, which could be improved by widespread use of CMx.

ES.2.2 Barriers to Consumer-Mediated Exchange

Barriers to CMx were also assessed and included the following:

- provider organization commitment,
- privacy and security,
- lack of CMx provider buy-in,
- HIPAA interpretation,
- information overload,
- patient/provider CMx technology competency,

- provider workflow and workload,

- lack of access (connectivity and affordability),

- needs of unique patient populations,

- EHR/CMx interoperability, and

- provider reimbursement policy.

Of these, patient and provider participants agreed that the lack of CMx technology competency among providers and patients is the largest barrier to CMx. The ability to customize solutions for specific patient populations and to reduce concern about information overload were also major opportunities for which appropriately implemented solutions could help to improve the adoption and use of CMx.

ES.2.3 Anticipated Benefits of Consumer-Mediated Exchange

Benefits of CMx identified included:

- improved information access and sharing,

- more accurate records,

- improved patient visit utilization,

- improved provider workflow,

- improved connection with social infrastructure services,

- improved patient and provider communication,

- improved EHR vendor interoperability,

- increased patient engagement,

- increased control in one's own medical care,

- increased ability to care for patients in between visits and to more effectively support homebound patients, and

- secure communications between the patient/caregiver and the medical team.

ES.3 Recommended Framework for TA to Advance CMx

Based on the analysis of barriers and benefits provided by CMx, five core TA framework components are recommended. Each component is described in detail in this report, along with suggestions for tailoring each component to patients, providers, vendors, and other stakeholders, as appropriate.

Planning and organizational support: Provider organizations should be provided with TA to help support organizational planning that includes CMx considerations. The TA should stress the importance of creating a CMx plan consistent with the shared perspectives of providers, patients, and commitment from leadership to achieve buy-in.

Readiness assessment: Provider organizations should seek to understand what barriers they will face in pursuing adoption of CMx, including an assessment that reviews policies, processes, technology, and culture to help determine how best to approach the adoption of CMx and what fundamental organizational or structural changes may be needed prior to adoption.

Design and implementation alternative guidance: Roundtable and interview participants identified the need for varied design and implementation models for CMx initiatives based on organizational and community differences. Provider and vendor organizations need TA to understand the value in providing multiple types of CMx platforms and customizable programs. TA should guide project plans and show how CMx models and implementation can be tailored to the needs of an organization or community.

Education and awareness: All stakeholder groups agreed that using CMx could be beneficial. Case studies and lessons learned relevant to a stakeholder's local setting should be available to communicate the value of CMx and local user feedback. Provider education and awareness must be geared to address provider skepticism and overcome common barriers to effective care coordination and CMx implementation (e.g., current workload and workflow, lack of interoperability among EHR systems). Nonetheless, many providers acknowledged that the industry is moving toward CMx, and some provider participants want to see CMx capabilities implemented in their own clinical settings. TA begins by supporting early education and awareness building and then transitioning to assistance for CMx use.

Training: TA should support the targeted piloting and full implementation of CMx by training and supporting both provider and patient participants. The training should be tailored to the needs of the individuals and be designed to fit within the constraints of their work and lives. Because CMx implementations must be tailored to local settings, training should be customized to the local CMx solution.

ES.4 Future Considerations and Conclusions

The roundtable discussions and individual interviews, along with the subsequent analysis, uncovered additional issues that, while not directly related to recommendations for CMx TA, are relevant to planners and implementers of a CMx TA program.

Limitations of TA: Some barriers to effective CMx adoption are more feasible to overcome than others. If policies and program design do not address perceived and real barriers to CMx adoption, TA will have limited impact. Planners should concentrate on those barriers that can be reasonably overcome within available resources and authority, initially focusing effort on those barriers (identified in this report) that are most likely to be overcome or resolved and whose resolution will have the greatest impact.

Detailed development of TA materials and methodology: All materials should be developed with input from organizations that have operationalized patient access and use of their EHR information for at least a year to draw lessons learned from real-world experience.

TA program design: This report establishes the initial framework to inspire formal TA program design. This program design and implementation depends on funding and whether the TA will support all potential sponsors of CMx or start with the rural communities explored in this project. The program design could have various formats including:

- communities of practice with shared tools and resource development;

- cooperative agreements for rural communities conducting CMx pilots;

- a knowledge center with tools and resources that hosts periodic workshops; and

- a national initiative with incentives for certain measureable CMx outcomes.

Test and pilot of the TA program: A TA plan resulting from the framework and training recommendations in this report should be piloted and evaluated with a small number of participating CMx sites.

Knowledge management and knowledge sharing: As TA is implemented, a repository of lessons learned and case studies should be maintained through a CMx knowledgebase to inform strategic planning and to assist participants in their own CMx efforts, whether they be independent initiatives or developed as part of an ONC-led program.

Support for CMx technical assistance: A centralized, national TA effort will produce the strongest effects. Support for such an effort could be supported through an appropriate Federal government program, or a convener such as a large not for profit or consortium of community based organizations aligned with the mission of ONC's Consumer eHealth Program. Centralizing programmatic activities—such as strategic planning, project management, contract operations, and outreach—under a single organizational authority will ensure the greatest net effect across the various individual communities involved in the TA effort.

Research: Additional research is needed on the following topics:

- Pilot the fundamental components of a TA program among provider organizations and in their clinical settings.

- Assess existing pilots for lessons learned that could aid CMx planning efforts.

- Explore the factors associated with unmotivated patients (as serious and powerful barriers to patient CMx adoption) to ascertain what components of motivation could be improved through CMx training and systems.

- Conduct CMx-related qualitative research to attain greater academic community participation, develop a broader CMx research literature base, and develop expertise in this area.

- Compare and contrast the attitudes and opinions of urban patients and providers about CMx with this report's findings regarding rural communities.

- Research systems analysis principles to provide recommended best practices regarding CMx workflows, roles, and compensation models that are feasible within existing constraints.

The results and analyses from this project highlight many potential opportunities and benefits offered by CMx of health information to improve care coordination, using the example of rural patients with chronic illness as a baseline. The barriers and benefits to CMx identified help to shape a comprehensive and evidence-based TA design. The framework and suggested actions for developing a successful education and TA program to support CMx of health information provide a starting point to create and implement such a program.

1. INTRODUCTION

To move toward health care transformation, the Office of the National Coordinator for Health Information Technology (ONC) has a strategic goal: to empower individuals to improve their health and the health care system through health IT. With the growth in adoption of electronic health records (EHRs) since the Health Information Technology for Economic and Clinical Health (HITECH) Act in 2009, data to support patient empowerment are becoming more available. Access to and use of these data will enable patients to participate more actively in their own health care decisions and condition management, and will also allow their information to be shared and managed among providers who use different electronic systems or are in different geographic areas. The concept of consumer-mediated exchange (CMx) supports patient engagement and helps overcome traditional concerns about exchange such as consent management and state differences in disclosure laws.

In 2013, the American Medical Informatics Association (AMIA)—along with its subcontractors Koss on Care, LLC, and Barsch & Company (collectively, the AMIA team)—were contracted to lead a project titled *Attitudes: Development of Technical Assistance (TA) and Educational Materials to Support Consumer-Mediated Exchange Project*. This effort was one of several projects referred to collectively as the PHR Ignite Consortium, which investigated the value of CMx in the U.S. health care environment. These projects, supported by RTI International through the State Health Policy Consortium (SHPC) project and funded by ONC, were designed to develop a framework to advance the CMx use by patients and providers to improve health outcomes.

The project was specifically designed to characterize patient, caregiver, and provider attitudes and opinions about CMx within the context of rural care coordination for patients with chronic illness. The project sought to explore the challenges of rural care coordination and the range of CMx activities occurring in rural communities. The information obtained during this project was used to develop a framework for technical assistance (TA) to improve adoption of CMx.

No standard definition of CMx exists. For this project, the AMIA team used the following characterization:

- CMx refers to patients' ability to aggregate and control the use of their health information among providers.[1]

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[1] ONC (2013). *Consumer-mediated exchange*. From the ONC Policy Committee Presentation. Retrieved from: http://www.healthit.gov/providers-professionals/health-information-exchange/what-hie.

- Patients can maintain control over where their data is housed and who sees the data, including the right to add or revoke access for individuals serving as a proxy, or to move their data from one PHR system to another.

- The types of applications that support CMx vary, and include personal health records, patient portals and electronic storage devices, but all seek to foster health information collection and sharing across diverse EHR systems.

Based on the findings of this project, systems interoperability continues to be a significant barrier to improved care coordination. The ability for CMx to aggregate and share patient information across disparate systems is increasingly critical for care coordination and is especially salient in rural settings given the challenges of access to care and specialists. The extended timeline for Meaningful Use Stage 2 and 3 incentives suggests that additional means for electronic exchange of patient information can be explored.

Discussions conducted during this project included 11 open format roundtable discussions (six with providers and five with patients and caregivers), one group discussion with vendors, and eight individual discussions (four patients and four providers) to delve more deeply into the role of CMx in rural chronic care coordination and explore TA and training. Finally, the contract sought to develop a TA framework to advance the adoption and use of CMx drawing from the lessons learned through the lens of rural care coordination for patients with chronic illness.

This report summarizes and analyzes the findings from these discussions, describes the TA framework, discusses the basis for the framework design and its components, and highlights potential prerequisites and further considerations to implement TA consistent with the framework and project findings.

2.   METHODOLOGY

The overall methodology for this research project was qualitative and designed to gain insights into attitudes and opinions that should inform a TA framework to promote adoption of CMx.

2.1   Outreach, Site Selection, and Individual Discussant Selection

The outreach methodology was designed to include a broad spectrum of patient, caregiver, and provider perspectives. The team provided a scenario focused on a chronically ill patient living in a rural area. This focus was also likely to produce specific and salient accounts of the importance of care coordination and CMx. Individuals meeting at least one of three following criteria were sought for their participation in patient and caregiver roundtable discussions:

- rural patients with chronic illnesses
- family caregivers of rural patients with chronic illnesses
- patient advocates supporting improved care coordination for rural patients with chronic illness

For ease of reference, when the term "patient" is used, it includes all three perspectives listed above. Provider perspectives were sought from many clinicians and professionals who are substantively involved in care delivery and coordination for rural patients with chronic illnesses. Outreach included primary care and family practitioners, physician specialists, nurse practitioners, care managers, physician assistants, pharmacists, health navigators, social workers, psychotherapists, and hospital outpatient services. For ease of reference, when the term "provider" is used, it includes this wide range of roles.

2.2   Roundtable Discussion Structure

The structure of the roundtable discussion sessions included two fictitious stories (see Appendix A). One describes how care coordination for a patient with chronic illness works in today's health care environment (the *Today Story*). The second story envisions how a similar series of events could work differently 2 years from now in an environment where CMx is widely used to facilitate communications among patients, caregivers, and providers (the *Future Story*). These stories, along with the ONC's Health IT for You video[2] for the consumer sessions, provided a framework for an open discussion among the participants about current conditions of chronic care management in rural settings and the potential for CMx to improve care management.

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[2] ONC (2012). *Health IT for You: Health IT for You: Giving You Access to Your Medical Records.* Video. Retrieved from: http://www.youtube.com/watch?v=UMiPW831b1o

Where possible, these discussions were conducted in person—one or two facilitators on site and the other team member(s) on the phone served as passive observers. The facilitators encouraged free and open discussion among the participants, requested clarification when needed, and otherwise avoided influencing the discussion other than to keep the conversation on topic. At one site (that included two separate roundtable discussions for patients and providers), Spanish translation services were secured for the largely Spanish-speaking participants.

In total, 11 roundtable discussions were completed—six with providers and five with patients and caregivers—from September through December 2013. These discussions included 104 attendees from 13 states; Table 2-1 summarizes these discussions.

2.3   Key Individual Discussion Structure

Discussions with key individuals were structured to more thoroughly explore participant perspectives on the role of CMx in rural chronic care coordination and their recommendations for TA and training. A provider and patient interview guide and background survey were developed to support the discussions. Follow-up interviews were conducted with four patients and four providers. With one exception, all individual discussion participants had participated in a prior group discussion. The discussion with key individuals representing vendors was conducted as a small group discussion due to an opportunity to talk to representatives from three different PHRs in one meeting. All of the vendors represented have stand-alone personal health record solutions that can serve as a platform for CMx.

Table 2-2 summarizes the nine discussions with key individuals.

Table 2-1. PHR Ignite Objective 3 Roundtable Discussions

ID[a]	Roundtable Discussion Type	Location	States or Native American Nation (NAN) Lands Represented	Languages Supported during Discussions	# of Participants	Sponsor	Date of Occurrence
C1	Patient	DC	TX, AL, CO, IN, WI	English	5	The Office of the National Coordinator, U.S. Dept. of Health and Human Services	09/16/13
C2	Patient	AZ	AZ	Spanish, English	14	The Regional Center for Border Health, Inc.	11/15/13
C3	Patient	MO	MO	English	9	Missouri Oncology Society	11/26/13
C4	Patient	MT	MT	English	6	NW EHR Collaborative, Inc. & HealthShare Montana	12/04/13
C5	Patient	NE	NE	English	18	Columbus Community Hospital & NE Health Information Initiative	12/10/03
P1	Provider	NC	NC, IN	English	11	Community Care of North Carolina	10/22/13
P2	Provider	Tele-conference	NAN lands in AZ, NM, AK, & East of the Mississippi R.	English	8	Indian Health Service (IHS)	11/13/13
P3	Provider	AZ	AZ	Spanish, English	15	The Regional Center for Border Health, Inc.	11/15/13
P4	Provider	Tele-conference	MO	English	6	Missouri Oncology Society	11/19/13
P5	Provider	MT	MT, ID	English	8	NW EHR Collaborative, Inc. & HealthShare Montana	12/04/13
P6	Provider	NE	NE	English	4	Columbus Community Hospital & NE Health Information Initiative	12/10/13

[a] The ID field indicates the unique code assigned to a roundtable discussion. "C" indicates a patient or "consumer" roundtable discussion and "P" indicates a provider roundtable discussion.

Table 2-2.   PHR Ignite Objective 3 individual Discussions

Individual Discussion Type	States Represented	Languages Supported during Discussions	Date of Occurrence
Patient	WI	English	11/26/13
Patient	AZ	Spanish, English	12/19/13
Patient	NE	English	12/23/13
Patient	MT	English	12/27/13
Provider	MO/KS	English	11/12/13
Provider	MO	English	12/14/13
Provider	AZ	English	12/19/13
Provider	MT	English	12/20/13
Vendors	N/A	English	12/12/13

3. DISCUSSION SYNTHESIS AND ANALYSIS

In total, 14 primary themes were identified during the during the patient and provider roundtable discussions. Some themes can be considered subsets of others but were highlighted because discussion participants specifically emphasized them.

3.1 Methods

As part of the thematic review of the patient roundtable discussions, 72 key takeaway statements from the project's five patient roundtable discussion summaries were grouped by the story of discussion (*Today Story* or *Future Story*) and reviewed for recurring themes. Statements with shared topical relevance were grouped within candidate themes and 14 themes were identified, as shown in Table 3-1. Each theme is marked under one of four columns to indicate whether it emerged during the Today and/or Future story and whether it was voiced by providers and/or patients. The themes (in the table) are not rank ordered in importance or priority. Appendix B provides the details underlying each theme, including general patient and provider reactions along with their associated key takeaways. Also, the supplement to this final report provides considerable detail about the stakeholder discussions that underlie this analysis. Some key takeaways apply to more than one theme and are listed in several thematic categories. In addition, facilitators developed a set of 20 archetypes during the analysis phase to communicate representative voices of existing or potential CMx of health information roles identified during discussions. These archetypes define practical target audiences for TA and provide a valuable resource for the planning phase. A description of these CMx Archetypes is included in Appendix C.

Table 3-1.   Primary Themes from Patient and Provider Roundtable Discussions

Primary Theme	Provider Today Story Reactions	Provider Future Story Reactions	Patient Today Story Reactions	Patient Future Story Reactions
1. Accuracy of the *Today Story*	X	N/A	X	N/A
2. Care coordination and health care system engagement challenges	X	X	X	X
3. Rework and inefficiencies in health care operations	X	—	X	X
4. (Provider/patient) engagement & communication challenges	X	X	X	X
5. Lack of information sharing, EHR system interoperability, and medical record access	X	X	X	X
6. Population-specific considerations	X	X	X	X

(continued)

Table 3-1. Primary Themes from Patient and Provider Roundtable Discussions (continued)

Primary Theme	Provider Today Story Reactions	Provider Future Story Reactions	Patient Today Story Reactions	Patient Future Story Reactions
7. Perceived benefits of CMx	—	X	—	X
8. Barriers to CMx technology adoption	—	X	—	X
9. Patient privacy and security concerns	—	X	—	X
10. Payment reform	—	X	—	—
11. Perceived impact of CMx to health care operations	—	X	—	—
12. CMx implementation considerations and recommendations	—	X	X	X
13. Leveraging nontraditional providers and caregivers to support CMx	—	X	X	X
14. Perspectives on telehealth remote monitoring technologies in the home	—	X	—	X

3.2 Summary of Key Takeaways

The unanimity about the need for leadership at the local level, provider education, and buy-in underscore that the success of CMx depends, in part, on clinicians becoming comfortable with EHRs and CMx. Training, CMx design, and implementation must be tailored to the characteristics of the community, organization, CMx application, and providers and patients. Stakeholders generally agreed that CMx has many potential benefits, but the most salient benefits tend to vary based on the stakeholder's perspective.

The Potential of CMx

Providers and patients tend to be more consistent than vendors about how CMx use might improve interactions between patients and providers. The core differences among the perspectives tend to align with their fundamentally different roles and may be more of a matter of emphasis. Notably:

- Patients readily perceived CMx as a means to address many of their rural care coordination challenges. They commonly envisioned the benefits of CMx in their own personal care contexts. They emphasized privacy and security and the importance of linking patients and family caregivers to available social infrastructure and support services in their communities.

- Providers generally emphasized the challenges to CMx adoption that they perceived more than the benefits. They largely remained skeptical of its benefits and expressed a need for evidence of its efficacy. They commonly voiced concerns over CMx

implications to workflow, funding, and interoperability, although most patients and the vendors recognized the importance of addressing these issues on behalf of providers.

▪ Vendors emphasized the importance of a structured approach to CMx adoption, including conducting a pilot. Vendors discussed their observations that most patients have no prior experience with the technology with which to make informed decisions to participate in CMx and providers, for the most part, have very minimal experience with CMx.

Organization and Planning

The shared stakeholder perspectives about leadership, commitment, and the importance of provider buy-in suggest an initial CMx TA component focused on *organization and planning*. The vendors' emphasis on targeted planning and piloting reinforced this need. The provider with the most PHR and patient engagement experience was adamant about the importance of planning at the organization level for CMx-focused projects.

One provider was a strong advocate for evaluating requirements for an organization to fully embrace CMx. The unanimous recommendation for provider buy-in also supports an organization's need for understanding what barriers they will face in pursuing adoption. These early requirements suggest that some type of *readiness assessment* to examine policies, processes, technology, and culture would help determine how best to approach adoption of CMx including changes needed to facilitate success. A second provider indicated its vendor had conducted this type of assessment on the organization's behalf.

The vendors were not as clear about the need for a readiness assessment step as a formal requirement, which may be due to a sales mentality that encourages working with any organization able to commit funding and leadership. The vendor would then help address any anticipated or unanticipated barriers. Nevertheless, vendors were clear on the need for a targeted pilot and an early planning step in which barriers are assessed and a priority value proposition for CMx is defined.

Focus on Local Context and Individual Needs

Stakeholders consistently held the perspective that CMx design, implementation, and training must be tailored to the local setting. This view suggests that TA should include advice and models for *CMx design alternatives*. Providers and provider organizations have varied needs, as do differences target patient populations. This suggests that a single TA design model should have multiple components which can be tailored depending on the intended use of CMx and should focus on individualizing plans for implementation.

Education and Awareness/Training

The consistent and strong recommendation for leadership, commitment, and provider and patient buy-in suggests the final areas of greatest need are *education and awareness* and *training*. The roundtable and the individual discussions demonstrated that, prior to any

training, providers and patients need basic education to build awareness and comfort about use of CMx and HIE generally. All patient/provider discussion group participants noted that the discussions raised their awareness of possibilities with CMx. Patients and providers alike said they had not previously thought about the benefits and the discussion helped them realize how some of the biggest challenges in care coordination could be addressed. Ultimately, whether to engage in CMx is an individual, local decision, and those who need this capability the most may be the least likely to understand its impact on their health care.

Most participants had little awareness of CMx prior to engaging in discussions. Upon first hearing about the CMx concept, they were often negative or skeptical. All participants had some specific recommendations on what approaches would work best in education and training. Participants agreed that the training should be tailored to individuals' needs and designed to fit within the constraints of their work and lives; they recommended hands-on and one-on-one training as needed.

Final Key Concepts

Development of the themes from the roundtable discussions concluded by identifying the following key concepts to shape CMx TA framework and recommendations:

- Improve the communication skills of patients and caregivers (e.g., adult parents caring for their elderly parents and children) to more effectively communicate important information with their providers. Improved communications could improve the value of patient-provider interactions.

- Develop strategies to address provider skepticism and their stated major barriers, both real and perceived.

- Address patient privacy and security concerns through technology improvements, training, and awareness.

- Increase patients' willingness to more actively manage their medical care and overall personal health.

- Develop strategies to help patients keep better track of their care.

- Increase the overall health literacy of patients, particularly about the purpose of tests and the reduction of unnecessary tests.

- Address population-specific training needs, particularly for the elderly, those who speak English as a second language, and those with low technology familiarity.

- Acknowledge the generally higher receptivity of patient participants (as compared with provider participants) to CMx when developing adoption, training, and TA plans.

- Leverage rural area stakeholders in CMx training and TA, such as employers, local hospitals, patient advocacy organizations, and professional medical associations.

- Incorporate existing and emerging health care support roles in a patient's continuum of care.

- Leverage existing benefits expressed by patients using telehealth remote monitoring technology in the home.

- Improve or avoid disruption of provider workflow and resolve concerns over information overload.

- Set reasonable expectations for patient-provider communications in a CMx environment (e.g., reasonable response times for electronic messages).

- Develop both patient- and provider-focused strategies to reduce redundant paperwork and tests.

- Develop executive- and policymaker-level strategies to increase the interoperability of EHR systems.

3.2.1 Exploration of Barriers, Benefits, and TA Topics

Barriers to Care Coordination

In examining the role of education and TA in advancing CMx, the authors assessed barriers to care coordination and the degree to which CMx could overcome these barriers.

These barriers to care coordination are illustrated in Figure 3-1. The diagrams were created as an exercise for the authors to begin to categorize the data into themes relevant to constructing a technical assistance framework. They may also provide value for those interested in analyzing similar factors related to their local environment. Moving from left to right on the on the x-axis indicates increasing impact of overcoming the barrier to care coordination. Moving from down to up along the y-axis depicts the increasing ability of CMx to play a role in overcoming the barriers. Barriers reported by patients are shown in circles while providers are shown in diamonds, and the importance given to the barrier as outlined in the analysis of data is designated by the relative size of the icon.

While the positions of the icons and their relative sizes are based primarily upon the analysis described in detail in Appendix A, the placement of each theme on the scale of impact and ability to overcome barriers was determined through the subject matter expertise of the researchers to interpret the findings of this project. While it does not provide a definitive answer, this rigorous analysis of the quantitative data can provide valuable insight for prioritizing the investment of effort with each stakeholder audience.

Figure 3-1.   Assessment of Barriers to Care Coordination

High Impact to Care Coordination, High Ability for CMx to Overcome Barriers

The top right quadrant indicates barriers that will have both a high impact if they are overcome and a high likelihood for CMx to support the changes needed. These include:

- ▪ Lack of Patient/Provider Information/Data Sharing,

- ▪ Poor Patient/Provider Communication,

- ▪ Consumer Health Literacy, and

- ▪ Needs of Unique Patient Populations.

Low/High Impact to Care Coordination, Low Ability for CMx to Overcome the Barrier

Both the left and right quadrants on the bottom indicate barriers that may have greater or lesser overall impact on care coordination, but that have a low likelihood of being affected by the proliferation of CMx specifically. These include:

- Lack of EHR Interoperability,

- Provider Attitudes & Motivation,

- Lack of Patient Motivation/Engagement, and

- Lack of Provider Reimbursement.

Barriers to CMx

Figure 3-2 focuses on barriers to CMx. The icons are again sized according to the relative importance of the issue to the stakeholder each icon represents. Patients are again represented by circles, providers by diamonds and, in this and subsequent graphics, the vendor perspective is represented by squares. Similar to the previous figure, icons along the x-axis indicate the increasing impact of overcoming the barrier to adopting CMx; the y-axis position indicates the increasing ability of TA to overcome this barrier to CMx.

Figure 3-2.   Assessment of Barriers to Consumer-Mediated Exchange
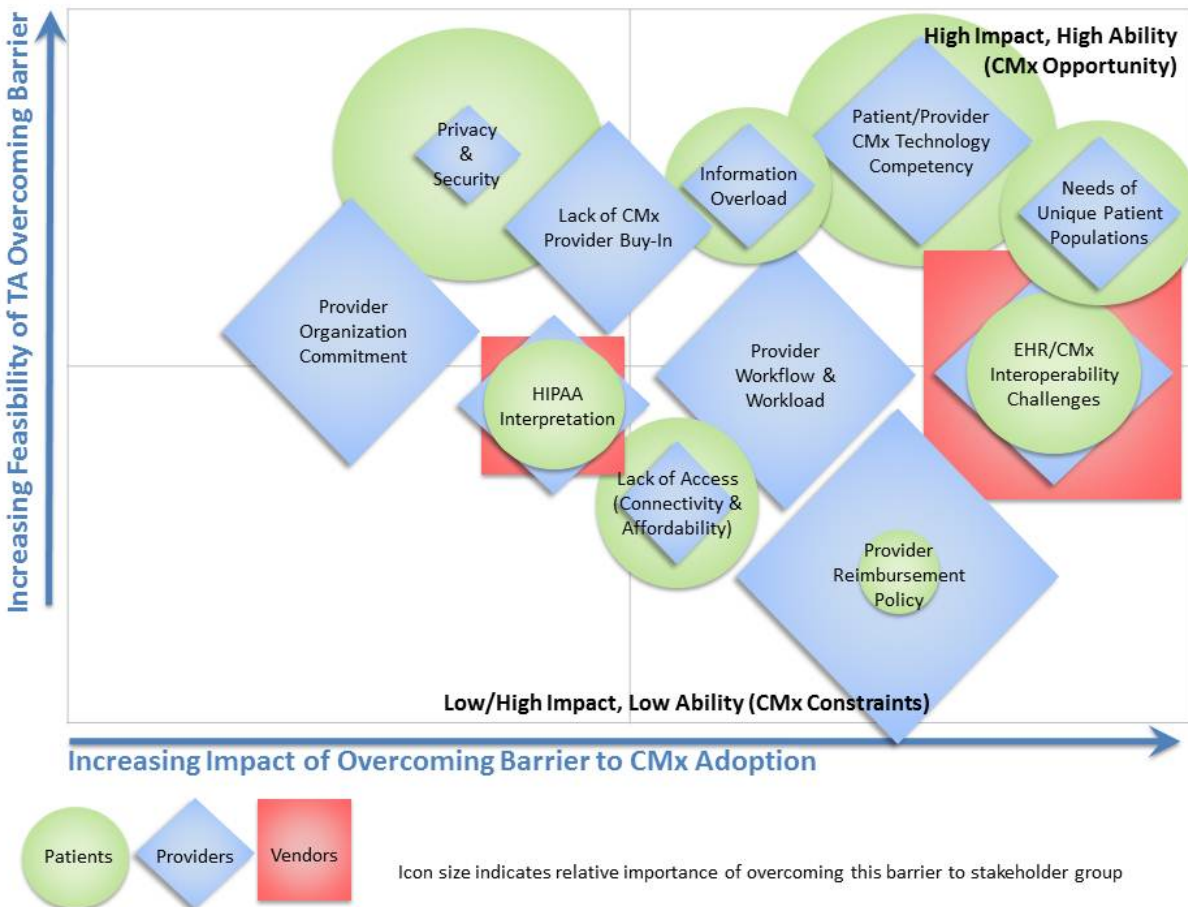
High Impact of CMx, High Ability for TA to Overcome Barriers

Barriers shown in the upper right quadrant are the strongest candidates for TA because they have the highest opportunity of being overcome along with the growth of CMx. These include:

- Patient/Provider CMx Technology Competency,
- Information Overload, and
- Needs of Unique Patient Populations.

Lower Impact of CMx, but High Ability for TA to Overcome the Barrier

The items in the upper left quadrant are also barriers that a TA initiative could help to overcome, but that have lower impact to affect the growth of CMx, including:

- Privacy and Security,
- Lack of CMx Provider Buy-In, and
- Provider Organization Commitment.

Low/High Impact of CMx, but Lower Ability for TA to Overcome the Barrier

Overcoming the barriers in the lower left and right quadrants may be better addressed through interventions other than TA, such as policy guidance, standards development, payment reform, or regulatory interventions. These include:

- HIPAA Interpretation,
- Lack of Access (Connectivity & Affordability),
- Provider Workflow & Workload,
- EHR/CMx Interoperability Challenges, and
- Provider Reimbursement Policy.

Benefits of CMx

Discussion participants commented that CMx has numerous benefits. In general, patients and providers believe that CMx has the ability to create care coordination benefits by addressing certain barriers. Figure 3-3 focuses on the benefits of CMx. As before, patients, providers and vendors are each assigned a shape (circle, diamond, and square, respectively) and the size of the shape indicates the stated benefit to overcoming a barrier to the widespread use of CMx. Moving from left to right on the on the x-axis indicates increasing impact to improving care coordination issues. Moving from down to up along the y-axis depicts the increasing ability of CMx to fulfill that benefit.

Figure 3-3. Assessment of Benefits of Consumer-Mediated Exchange

High Impact on Care Coordination, High Ability for CMx to Fulfill Benefit

Items included in this the top right quadrant indicate those benefits reported by the study participants that have the greatest likelihood to fill a gap they were able to identify between the Today Story and the Future Story and would also support improvements in overall care coordination. These include:

- Improved Patient Visit Utilization (fewer visits, fewer trips),

- More Accurate Records,

- Improved Information Access and Sharing (improved medication management, more timely and cost-effective referrals, reduced medical errors, fewer redundant medical labs/tests, improved emergency care, reduced paper/redundant documentation), and

- Improved Workflow.

Lower Impact on Care Coordination, but High Ability for CMx to Fulfill Benefit

The items in the upper left quadrant are benefits as stated by the participants which would be supported by the growth of CMx. While these are still worthwhile benefits from both the patient and provider perspective, they would likely have less overall impact on improving care coordination specifically than other benefits identified. These include:

- Increased Patient Engagement,

- Increased Control and Participation in One's Own Medical Care (or Care of Another),

- Secure Communications with the Medical Team, and

- Care for Patients In-Between Visits & Support to Homebound patients.

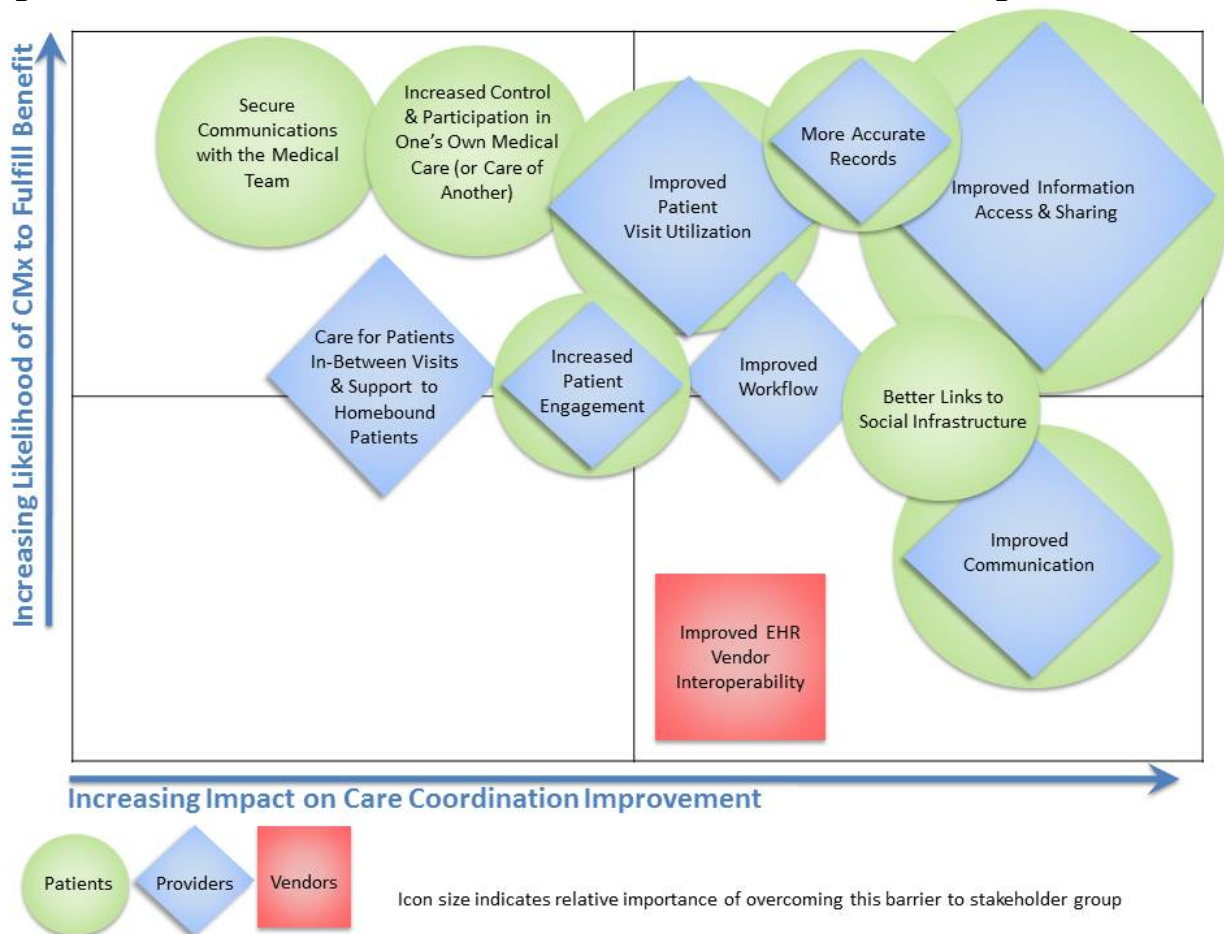**High Impact on Care Coordination, but Lower Ability for CMx to Fulfill Benefit**

Overcoming the barriers in the lower left and right quadrants may be better addressed through interventions other than TA, such as policy guidance, standards development, payment reform, or regulatory interventions. These include:

- Improved EHR Vendor Interoperability,

- Improved Communication, and

- Better Links to Social Infrastructure (Social Services, Local Community Services).

3.3 Policy Considerations and Potential Prerequisites to TA Development and Success

Consumer-mediated exchange (CMx) has the potential to yield tremendous benefits to patients and providers through improved care coordination. However, a successful TA and education initiative must be built with structural barriers in mind. The following are policy considerations that could increase the overall success of CMx.

Provider incentives/reimbursement: All stakeholder groups indicated a need for provider incentives, and most providers recommended a new reimbursement code for the use of CMx as an initial step to accommodate traditional payment models. At a minimum, guidance and clarification about how the cost of CMx adoption and use fits within existing reimbursement and new care payment models would be useful. If CMx cannot be financially supported in the context of fee-for-service payment, incentives or reimbursement could be considered for underserved communities, implementing new models of care.

Interoperability and standards: Representatives from all stakeholder groups raised concerns about current EHR interoperability and the likelihood that CMx would face the same challenges. Meaningful Use Stages 2 and possibly 3 aim to further advance interoperability, but a minimum set of CMx interoperability standards would facilitate the likelihood of CMx adoption and use. The issue of interoperability between EHRs and PHRs needed to facilitate CMx raise questions about how organizations can identify and support

CMx applications or systems that connect with third party systems. Defining minimum specifications or baseline functionality that CMx applications should use could foster adoption of CMx.

CMx demonstration program funding: Funding could spur implementation of pilots that demonstrate and measure the benefits and impact of CMx. Early pilots in areas with broad EHR adoption that show successful CMx implementations addressing care coordination barriers are a critical first step to advance general education, awareness, and provider buy-in. These pilots can also help test and improve CMx tools and TA efforts, as well as identify national and local champions.

Technology access: Patients and providers emphasized rural constraints regarding broadband access, technology access, and patient access to end-user devices. The desire to expand CMx provides an additional argument for extending the availability of broadband and technology access. Guidance on existing programs that support the expansion of technology infrastructure and CMx program models that provide patients with better access their data will be critical in rural areas. Programs designed to address the recognized gaps include public and private initiatives to accelerate broadband and technology access. These programs could be listed in an online resource that catalogs the range of resources available.

The extent to which these considerations are addressed will affect the receptivity and success of TA. More details regarding these limitations are discussed in Section 5: *Further Considerations and Conclusions*.

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4. RECOMMENDED FRAMEWORK FOR TECHNICAL ASSISTANCE TO ADVANCE CONSUMER-MEDIATED EXCHANGE (CMX) FOR RURAL PATIENTS WITH CHRONIC ILLNESS

The group discussion and interview topics that were consistently emphasized across stakeholders helped define the core components of the following TA framework. In addition, the AMIA team drew from its depth of expertise in health policy, federal acquisitions program management, technology strategic planning, TA and training for considerations and models that help shape the TA framework.

4.1 Guiding Principles for TA and Training Framework Design

The following observations are based on the perspectives of patients, providers, and vendors that guided the design of the CMx TA and training framework:

- Patient CMx participants highly value training that improves their CMx technology familiarity, health literacy, and communication skills.

- Providers value TA training and assistance that offers opportunities for first-hand observation of CMx in practice, improves their CMx technology familiarity, instills a collaborative culture of care among providers, facilitates TA when needed, and enhances provider/patient communication skills.

- Vendors would likely value information about the latest in CMx policy, CMx-use mandates established by payers, and CMx implementation best practices.

As a result of these observations, the following guiding principles for CMx TA and training framework design were established:

For patients:
- Focus on improving patient and family caregiver CMx technology familiarity, communication skills, and health literacy.

For providers:
- Focus on improving provider CMx technology familiarity, a collaborative culture of care, and patient engagement communication skills. Provide opportunities for first-hand observation of CMx in practice. Provide professional assistance when needed during CMx implementations.

For CMx vendors:
- Make vendors aware of the latest CMx policies, emerging employer/payer CMx use mandates, and best practices for CMx adoption and implementation.

4.2 TA Core Component Detailed Discussion

Based on the analysis of barriers and benefits provided by CMx, five core TA framework components are recommended:

- planning and organizational support,

- readiness assessment,

- design and implementation alternative guidance,

- education and awareness, and

- training.

Each recommended core component of the TA framework is discussed in the following sections. Within each component the discussion addresses the rationale, and suggested approaches for the component. This provides a starting point for shaping the content of a TA program; however, a comprehensive effort to implement such a program should include a validation of the goals, and should also review the policy, development, and research considerations discussed elsewhere in this report.

4.2.1 Planning and Organizational Support

This TA component supports organizational planning consistent with the shared stakeholder perspectives about leadership, commitment, and the importance of provider buy-in. This initial phase of CMx adoption is the logical time for the lead organization(s) to identify leaders of the project or program, begin building a foundation for provider buy-in, and set the likely goals of initial CMx adoption.

Needs and Rationale

Providing resources that help organizations think through the core requirements of CMx is a first step in determining the technological and workflow requirements that provider organizations and community partners need. Support for initial discussions and early strategic thinking could help organizations solidify their interest and identify organization and community champions.

Suggested Approach

Planning and organizational support includes developing tools and resources to help organizations envision the role of CMx for a target patient population, and the resources required for their organization or community to adopt and use CMx to improve care coordination (see Table 4-1).

For community-based CMx initiatives, local community engagement should occur during the Planning and Organizational Support component. For CMx solutions undertaken internally by provider organizations, community engagement could occur in a later component, such as Readiness Assessment.

Table 4-1.   Resources for Planning and Organizational Support

Stakeholder	Resources
Organizations Supporting CMx Initiatives	▪ Provide planning resources for identifying lead organization(s) and organization champions. ▪ Provide descriptions of CMx design and implementation alternatives developed for the TA program (TA Component 3). ▪ Provide descriptions of alternative staffing models for CMx implementation and training models that identify CMx-related roles and technology options. ▪ Provide early education and awareness templates and materials similar to those discussed in TA Component 4 that are tailored to organization leaders and administrators. Examples include fact sheets, case studies, and FAQs that position the use of CMx. The education materials should have an overview of program initiatives for organizations' leaders and include methods to capitalize on existing non-CMx programs and infrastructure or leverage other programs (e.g., state/national disaster recovery efforts). ▪ Employ teleconferences and Webinars; identify early adopters willing to host on-site observers as ways to introduce a planning and organization toolkit. ▪ Develop strategic planning session facilitation tools to support the discussion of priority CMx goals, organizational opportunities and challenges, including a review of case studies, lessons learned exemplars, sample project plans, and an introduction to readiness assessment. The graphics in Figures 3-1 to 3-4 (Section 3.3.1) to position stakeholder barriers and benefits could be used as a prioritization tool. ▪ Develop resources that identify different approaches for early involvement of providers and patients or patient advocates (e.g., community health workers, social workers, health navigators). ▪ Develop resources to help organizations canvass target patients and providers and hold exploratory meetings about CMx approaches for a pilot project. ▪ Develop materials that identify funding options. Briefing materials should be developed to educate stakeholders on how CMx initiatives can be funded through available funding programs and existing reimbursement mechanisms. These materials should include context-specific return-on-investment examples. ▪ Develop tailored materials for employers and payer organizations as potential providers or facilitators of CMx and engage them as other community-based supporters. ▪ Engage and involve local stakeholders and resources unique to each community. The sponsoring organization may want to include representatives of potential partners early in the deliberation process.

Stakeholders recommended many community-based organizations or venues that could conduct outreach, education, or training including: libraries, senior centers and other senior oriented organizations, churches, behavioral health and mental health service organizations, local health departments, community health centers, public health organizations, schools and school districts, local hospitals, local Chambers of Commerce, retirement centers, local Meals on Wheels programs, retired teachers organizations, nonprofit, community-based organizations, the business community, employers, Veteran Affairs Administration satellite offices, the post office and other government offices, retiree service groups, health fairs, high school sports venues, local radio stations, and local newspapers.

4.2.2 Readiness Assessment

Organizations should develop an understanding of the barriers they will face in pursuing adoption of CMx. They should perform an assessment that reviews policies, processes, technology, and culture to determine how best to approach the adoption of CMx and what fundamental organizational or structural changes may be needed before adoption.

Needs and Rationale

Several CMx barriers described in the analysis suggest a need for TA around readiness assessment including: cultural barriers, process and policy barriers, the need for provider buy-in, and anticipated provider resistance. Although vendors suggested that readiness assessment did not require a formal step, organizations that have implemented patient portals and PHRs underscored the need to assess barriers to adoption and to evaluate what will work best in each organization's environment.

Varied policies, processes, technology, and funding contexts require a tailored understanding and consideration of how best to approach CMx. The readiness assessment process should also be designed to help foster needed provider buy-in; allow early identification and vetting of concerns and challenges; support the development of pilot goals and parameters; and involve future participants and anticipated community partners in the pre-implementation phase of CMx assessment.

Suggested Approach

This TA component should provide tools and resources that help organizations systematically identify needs, gaps, and barriers related to CMx adoption and use. The TA will ideally make this process less onerous and guide the resolution of anticipated barriers (see Table 4-2).

Table 4-2.   Resources for Readiness Assessment

Stakeholder	Resources

Organizations Supporting CMx Initiatives	▪ Create a checklist of policies and procedures for review that includes: HIPAA and state privacy and security requirements; processes for patients requesting EHR information electronically; processes and policies for accepting updated patient record information from outside sources, including the patient.
	
	▪ Review and potentially update policies on providing appropriate health information access to designated caregivers on behalf of their patients. Organizations should review the policies and process about the identification and inclusion of informal caregivers.
	
	▪ Conduct a workflow and organizational assessment to review the roles, processes, systems, and organizational capabilities in the local setting. Provide models and suggested workflow approaches that have worked in comparable environments. Describe the benefits and value of establishing dedicated CMx roles and responsibilities.
	
	▪ Determine minimum technology functionality by developing a minimum set of requirements or specifications that will support CMx. Provide resources that help organizations consider what functionality they should enable and how they would make it available at a minimum level and at how it may become enhanced over time.
	
	▪ Provide tools to evaluate readiness of a target patient and provider population for a focused pilot. Highlight targeted readiness considerations; e.g., if the focus is on medication reconciliation and medication management, consider the following questions:
	  – What is the target network of provider organizations that will ideally be involved?
	  – Which pharmacies, including hospital pharmacies, will be involved?
	  – Can outside organizations such as payers, a regional or statewide health information exchange, or a national network provider such as Surescripts provide more comprehensive information?
	  – What e-prescribing practices need to be improved?
	  – How will the organization handle controlled substances?
	
	▪ Identify any baseline technical considerations, given potential target patients or focused uses. The readiness assessment considerations for unique patient populations could include likely end-user technologies, the need for texting functionality, multiple languages, disability access, etc.
	
	▪ Provide sample budgets for pilot and full implementation phases. Identify funding options or provide examples of such options that acknowledge expected barriers and constraints. Other examples include the following:
	  – Provide reimbursement guidance on how development, implementation, or operations costs can be covered through existing funding mechanisms.
	  – Make the sample project plans available for the readiness assessment, which will also help organization consider their resource and funding needs.

4.2.3 Design and Implementation Alternatives and Guidance

Organizations will need TA support to enable varied platforms and customizable programs, most likely with multiple components that fit the local needs and targeted CMx uses.

Needs and Rationale

Roundtable and interview participants clearly stated that varied design and implementation models are needed for CMx initiatives based on organizational and community differences. Project participants noted that different technology environments, both internal and external to a sponsoring organization, could influence the CMx approach. Vendors noted that all provider organizations may need to have implemented EHR systems that are Meaningful Use Stage 2 certified. Critical access hospitals might benefit from CMx as both a patient engagement solution and to support exchange between inpatient and outpatient settings when separate EHR systems are used.

Suggested Approach

This TA component includes providing resources that help organizations consider different models for implementing CMx. The models should include: technological solutions for both infrastructure and end-user technologies; staffing and CMx design models that could help overcome some of the technological and human barriers to CMx adoption; and implementation models that offer distinct training approaches. TA should also guide project plans and show how CMx models and implementation can be tailored to the needs of a given organization or community (see Table 4-3).

Table 4-3.   Resources for Design and Implementation Alternatives and Guidance

Stakeholder	Resources
Provider Organizations	▪ Develop alternative design and implementation options for technology with varied staffing and available or potential funding and reimbursement mechanisms. These options could include models for:
	− Single provider organizations (e.g., hospital, physician office)
	− Multiple provider organizations (e.g., hospital and physician network, multiple hospitals)
	− Community-based initiatives (combined health and social service model or expanded health services model)
	− Mediated CMx design—Suggested component of designs in which someone could act as an intermediary or proxy for individuals not comfortable using technology.
	− Examples of operational design and technology platforms—no one technology or platform should be preferred or required, but design options have different project planning and implementation requirements and costs. Developing resources to help organizations understand these differences will streamline the CMx selection and implementation phase.
	▪ Provide model contracts or general guidance on contracting principles. Having sample contracts that map to the model design and implementation plans will help streamline acquisition processes.
	▪ Provide templates for a staged implementation project plan to support design and implementation, applying system analysis and design principles as appropriate. Sample staged project plans could address identification of priority target CMx uses, selection of a technology platform, pilot scoping, participant identification, user testing (providers and patients), along with a method for addressing finding from the user testing phase, participant training, pilot initiation, pilot evaluation, development of recommendations for broader rollout based on pilot results.
	▪ Full CMx implementation planning to help organizations expand the use of CMx and consider additional target uses beyond the pilot phase. If the pilot had a narrow target patient population, parameters for expanding to additional target populations or perhaps expanding new functionality to the initial target population could be an interim step.
	▪ Programmatic and project management aids—These aids can be offered in a standardized format, but should be customizable to suit the diverse needs and unique settings of local stakeholders.

4.2.4 Education and Awareness

CMx is an emerging concept; therefore TA is needed to support education and awareness building before undertaking a CMx implementation. While most participants were not familiar with the concept of CMx specifically, when they discussed the functionalities associated with it they were enthusiastic about the idea. For example, once explained, many participating providers acknowledged the likely emergence of CMx, and some provider participants expressed a desire to see CMx capabilities implemented in their own clinical settings. Support for general education and awareness would be a significant contributor to supporting the proliferation of CMx

The education and awareness component of a CMx TA framework should consist of two phases of provider and patient engagement. The first phase should concentrate on

education and awareness to create a more receptive CMx environment. The second phase
would include more formal training tailored to the specific CMx design and focused use.

The education and awareness core component is essential to inform the public, health care
providers, payers, and other stakeholders about the benefits of CMx. Effective outreach to
educate potential participants in CMx is one of the most important facets of the TA and
training framework. Patient participants in the discussion frequently voiced the need for in-
person education and awareness activities with CMx stakeholders to establish trust. This
face-to-face interaction should introduce health IT and CMx concepts to develop an
understanding of the current health IT landscape and this technology's potential.

All stakeholder groups generally agreed during discussions that at least some benefit could
be derived from CMx. In general, patients readily grasped the value of CMx and could
envision how it might improve their current health care situation. Patients were the most
vocal stakeholder group, commonly relating examples of how they or someone they knew or
cared for could benefit from CMx.

Providers were the least enthusiastic when CMx benefits were explored. Although many
providers were somewhat optimistic, some simply could not see CMx effectively
implemented in their current environment in light of workload and compensation challenges.
Provider education and awareness could be geared to address provider skepticism and
common barriers to effective care coordination and CMx implementation (e.g., current
workload and workflow, lack of interoperability among EHR systems).

Outreach products and approaches should be cross-cutting, addressing the needs and
interests of various CMx stakeholders. Case studies and lessons learned relevant to a
stakeholder's local setting should be available to communicate the value of CMx and local
user feedback. The following discussion provides considerations and suggested approaches
for engaging providers and community partners; patients and families; and employers and
payers in effective education and awareness activities.

Providers and Community Partners

Needs and Rationale. To address skepticism about the usefulness and effectiveness of
CMx adoption in their clinical environments, providers should be given a high-level
introductory education on CMx and opportunities to participate in onsite training to see the
technology firsthand. Case studies and use cases should be provided to demonstrate CMx
benefits and improved care in realistic settings. Models of care should be provided, where
the application of CMx fits well within reasonable workflows. CMx provider leaders and
champions should support awareness activities; one CMx provider highly recommended
such participatory introductory experiences to increase provider receptivity and buy-in.
Providers should be given the opportunity to raise questions and voice their concerns about
CMx; they should also be able to get personal feedback from professional peers who have

used CMx and can speak at their level. The professional feedback and perspectives of this stakeholder group must be heard. All stakeholders stated that provider education and buy-in are critical success factors for CMx. Therefore, education and awareness efforts should focus on building trust in the value of CMx and permitting providers to make their own feasibility and utility judgments.

Suggested Approach. Introductory videos or Webinars can provide an overview of the current state of health IT adoption. The importance of information access in improved care coordination should be highlighted and potential CMx roles should be outlined. Education and awareness products should be designed to help position CMx to improve care coordination and patient engagement. This introductory-level education can be available at a national, state, and community level.

An added approach is to provide opportunities for first-hand observation of CMx such as road shows of simulated CMx environments, and shadowing experiences at existing CMx sites. Provider champions who can speak to other providers' questions and concerns should attend and support these observation sessions.

Education and awareness activities could potentially be supported through the nation's regional extension centers (RECs). Given the historical involvement of RECs to support providers in health care technology efforts, a CMx outreach role is a logical progression and leverages the existing reach and ties of RECs with their local provider communities. CMx support by RECs could also serve as a funding mechanism for their long-term sustainability.

Patients and Families

Needs and Rationale. Most patients and family participants had little or no exposure to CMx and many had limited exposure to EHRs. Patients consistently indicated they had limited understanding of health IT until they participated in the discussion sessions. Most were initially skeptical or negative, but after hearing about health IT and discussing it, many gained confidence and interest in CMx. Outreach should be designed to address different patient characteristics and backgrounds, initially targeting interested and willing patients. Providers of CMx should also specifically tailor CMx awareness communications to engage uninterested or unmotivated patients. High-level education should address the needs of family caregivers, recognizing their unique role in supporting their loved ones and fulfilling many of their care coordination responsibilities.

Suggested Approach. Develop videos, pamphlets, and other materials that providers can make available in their offices. On the basis of positive feedback from many patient roundtable discussion participants, the *Health IT for You* video is recommended for use in outreach. Public service announcements and materials for town meetings should also be considered. Additional components include: (1) provide opportunities for first-hand observation of CMx, such as road shows of simulated CMx environments or CMx simulators

available at health fairs and other community events; and (2) engage local recognized leaders through local community advertising and outreach (e.g., local radio and newspapers).

Although RECs have historically supported provider communities exclusively, service scope could be expanded to assist patients and their caregivers in CMx education and awareness efforts. Similar to the provider discussion, expanding services to reach additional CMx stakeholders could increase the reach and longevity of RECs and leverage their core competencies as valuable conduits for health care technology outreach and support.

Employers and Payers

Employers and payers were noted in roundtable discussions as significant CMx stakeholders. One rural hospital executive emphasized the need to engage employers, emphasizing that they play a significant role in supporting the well-being of their employees. One provider representing a health care payer system saw significant value in CMx and felt its use could be incentivized similar to existing performance-based incentives (e.g., getting discounts on health insurance if periodic check-ups are performed). Employers and payers could fulfill critical roles as initiative funders, offering incentives to their employees and beneficiaries for participating in CMx. Payers could mandate provider CMx use and establish reimbursement policies they deem appropriate. Tailored outreach should educate employers and payers on CMx efforts and the roles they can play so that they may be supportive of such initiatives and offer their constituents the opportunity to participate.

4.2.5 Training

Training is one of the most essential core components of CMx to ensure its successful long-term use in patient and provider settings. Training helps the CMx participants to transition from introductory education and awareness to formal, rigorous preparation to ensure CMx users effectively employ its capabilities in their local contexts. Because CMx implementations should be tailored to local settings and applications, training should also be customized to the local CMx solution. TA for implementation-related training should be developed in modules, addressing what will be needed for the two core target CMx participants—providers and patients—and the unique roles they play.

Providers and Community Partners

Needs and Rationale. Training for providers and community partners should be delivered in a staged format. A CMx pilot, and ultimately a full implementation, requires training that helps organizational leaders, community advocates, and providers gain sufficient comfort in CMx capabilities. Provider buy-in and trust in the effectiveness of CMx systems depend on how successfully CMx implementations are integrated into provider workflows. Attaining this trust and comfort level will serve as a catalyst for providers to recommend CMx use among their patients and family caregivers.

Guided by the CMx TA and training framework design principles established in Section 4.1 (Guiding Principles for Technical Assistance and Training Framework Design), training for providers and community partners should focus on familiarizing them with CMx technology, improving patient engagement and communication skills in a CMx environment, improving provider and organizational motivation to engage in CMx-related activities and foster a more collaborative culture of care. Training should be provided in multiple modes, including classroom and online training, and address methods to ensure that technology does not diminish human interaction in medical care.

Suggested Approach. Training should be provided in a staged fashion, targeted to organizational leaders/champions and provider participants. It should be tailored to each medical team role and should be suited to the stage of CMx implementation (e.g., pre-pilot launch, pilot, post-pilot expansion, and rollout).

Training should be provided in multiple modes. Role-specific training should be designed according to a user's CMx responsibility within the provider organization. Examples include training programs for the CMx executive leader, CMx program manager, and CMx provider (defined specifically by medical team role). All providers and organization office staff members need, at minimum, a high-level introductory CMx module.

To minimize personnel time for training-related tasks, a train-the-trainer approach is recommended. In this format, a small number of internal provider organization CMx trainers are identified and attend formal training at a central location. Upon successful completion of training, they return to their organizations and serve as training leaders, performing CMx training and bringing their peers' skills up to the demanded level of proficiency. While efficient and cost-effective, the success of a train-the-trainer approach depends on the effectiveness of the centralized training and the proficiency attained by the internal organizational trainers. Therefore, organizational decision makers must take great care in assigning personnel to an internal CMx trainer role. If provider organization decision-makers determine that a train-the-trainer approach will not be effective, a professional trainer-in-the-field format should be considered.

To address provider concerns and professional culture barriers, provider champions should participate in CMx training with their peers. One provider discussant who is an experienced CMx proponent highly recommended that multiple champions participate, cautioning that a sole champion will often not be sufficient to gain strong buy-in among provider peers. Provider training should be designed to capitalize on common provider didactic and hands-on training norms, possibly presented in a fashion similar to a *morning report*—a training format familiar to providers. Provider CMx trainees and pilot participants should be afforded the opportunity to share their personal experiences, techniques, and lessons learned as they begin to incorporate CMx use within their daily work activities. Finally, training should be scheduled to align with work demands and provided with minimal disruption.

Potential venues and partners for provider CMx training could include RECs, academic institutions, and other formal training programs. As highlighted in the *education and awareness* core component of the framework, RECs could also conduct formal training in addition to outreach activities. ONC could engage academic medical institutions, collaborating to incorporate CMx principles into their formal medical training curriculum. CMx-focused credentialing programs could also be developed over the long term and advanced CMx programs could be tailored to care specialties.

Lessons learned from Indian Health Service (IHS) roundtable discussion participants stressed the need to provide forums for advice sharing among organizations and for leading CMx organizations to mentor newly participating organizations. Such collaboration could be facilitated through periodic CMx meetings and conferences, where case studies and frequently-asked-questions can be voiced and where mentoring, forums, lessons learned, and knowledge management activities could be conducted. These gatherings could also be leveraged to inform the ongoing development of the CMx training materials.

Health Navigators, Lay Health, Tech Support, and Train-the-Trainer Resources

Needs and Rationale. Discussion participants emphasized the significant role health navigators, health *promotores*, social workers and other lay health workers play in supporting a patient in meeting their rural chronic care issues. These professionals and volunteers can fulfill critical intermediary roles, aiding patients to put CMx into context and to bridge their health literacy gaps. Some of these roles represent standalone professions that can fulfill an enhanced service role beyond the scope of CMx. These health workers should also be considering during discussions about reimbursement strategies for CMx. These staffing roles can also extend clinical resources and connect patients to needed social services resources and infrastructure. Training for these professionals should be provided in classroom and online training modes. Training should be role specific, appropriate to one's CMx responsibilities.

Patients and Families

Needs and Rationale. Among stakeholder groups, patients, and their family members responded most enthusiastically to the capabilities and benefits of CMx. This enthusiasm should be capitalized by developing engaging CMx training tailored to the diverse characteristics of patient populations.

The majority of patients and many providers emphasized that patients must become comfortable with the use of CMx. CMx should be positioned in the context of a patient's health and medical care and training should be tailored to patients' needs and characteristics.

Guided by the CMx TA and training framework design principles established in Section 4.1, training for patients and family caregivers should focus on familiarizing them with CMx

technology, improving their provider-engagement communications skills, and health literacy. Role models and mentors should be available and remain accessible during training. Training should be provided in a staged format in the classroom, online, and one-on-one. Training should involve a patient's family and caregivers as appropriate, but particularly for patients that are less comfortable with technology.

Suggested Approach. Training should be adapted specifically to the CMx platform available to the patient. Training design should be customized to the needs of special populations, such as the elderly, those with no technology familiarity, and those who speak English as a second language. Tailoring should address the age, language, technology familiarity, availability, memory, and attention-span needs of the attendees. Trainers should be professional, patient, and willing to repeat training when needed.

Online training should be modular so that it can be tailored to the needs of the local community and consist of core topics so that it is relevant and flexible to meet the unique mix of technology systems and workflow needs of the entities involved. Modules should be created based on general appeal and usefulness, where a recognized user benefit is generalized for other CMx users. The CMx training process does not need to include computer and internet fundamentals, but should take into account that all participants should have a certain baseline skill set needed to take the training. For that reason, it may be important to partner with community groups that provide basic computer trainings ahead of the trainings to provide those skills, taking into account the fact that many participants specifically noted that lack of basic computer literacy was a barrier and providing this as an introduction prior to the full CMx training. Example modules for the CMx training could include the following: CMx technologies overview; CMx use (by user task); telehealth and CMx; privacy and computer security. Sample course offerings could include: *How to Keep Your Information Secure); How to Use CMx to Support your Situation and Care Needs; Medication Accuracy and Multiprovider Access*; *Correcting your Medical Records through CMx*; *Emergency Access for You and Your Family*; and *Managing a Chronic Illness*. Providers and health care organizations should be able to assess the training needs of the patient (and family caregiver) and develop a customized program, selecting among available online modules and "prescribing" them.

Training should be role-specific. Example roles include patient, family caregiver, and peer (e.g., cancer support group buddy). Mentoring and peer resources should be made available to complement formalized training. Patient videos could be developed, highlighting how CMx made a critical difference in personal care. Advanced programs could be tailored for patients/caregivers of a specific disease.

Potential venues and partners for patient and family member training could include social service and community partners that already engage patients and families such as: health fairs, libraries, organizations catered to seniors, churches, behavioral health and mental

health service organizations, local health department, local hospital, retirement centers, and Veteran Affairs Administration satellite offices.

Patient, family, and caregiver availability for CMx training was highlighted as a significant barrier. Therefore, training should be available at times and in delivery modes that are adapted to participant availability and personal work commitments.

5.   FURTHER CONSIDERATIONS AND CONCLUSIONS

The recommendations presented in this final report establish the core components of a CMx TA framework. These components are broad and more work is required to translate these recommendations into the programmatic detail that framework implementers need. The following further considerations have been provided to focus planners and implementers on topics relevant to implementing TA.

5.1   Limitations of TA

Some of the barriers to effective CMx adoption identified in this report are more feasible to overcome than others. If policy and program design does not address the major barriers to CMx adoption, TA will have limited impact. Each identified barrier should be addressed as part of a formal strategic planning strategy. Planners should concentrate on barriers that are susceptible to training and can be overcome given available resources and authority. For example, addressing the lack of patient and provider familiarity with CMx technology is a realistic barrier to mitigate through formal training. In contrast, a strategy exclusively focused on the issue of provider payment reform is likely to have minimal impact on advancing CMx adoption in the short run due to its low feasibility.

5.2   Detailed Development of TA Materials and Methodology

Development of TA materials and methods will require further consideration and testing. All materials should be developed with input from organizations that have embraced patient access and used their EHR information for at least a year in order to capture lessons learned from real-world experiences. Ideally, organizations will also have embraced open platforms that enable CMx across provider systems.

5.3   TA Program Design

This report establishes the initial framework to design a structured in TA program. Additional work to fully develop a TA Program for CMx might include: creating a strategic plan, identifying leadership roles and responsibilities for TA program execution, budgeting and identifying funding for personnel and resources, developing a project management plan and resources.

TA program design depends on the amount of funding allotted and whether the TA is intended to support all potential sponsors of CMx or whether it would perhaps start with individual communities such as rural areas. The program design could take on a variety of formats including:

- communities of practice with shared tools and resource development;
- cooperative agreements for rural communities conducting CMx pilots;

- ▪ a knowledge center with tools and resources that hosts periodic workshops; and

- ▪ a national initiative with incentives for certain outcomes.

5.4 Test and Pilot the TA Program

Ideally, the TA and training framework recommendations provided in this report should be piloted and evaluated with a small number of sites. Findings from these TA program trials could help to further refine these recommendations.

5.5 Knowledge Management and Knowledge Sharing of CMx

Case studies are recommended to develop a knowledge base to inform strategic planning and assist participants in their own CMx efforts. This knowledge acquisition could be performed as periodic site visits to pilot sites or as a required step of project closeout activities.

Knowledge management activities should be a part of a national CMx TA program to support knowledge sharing across consortium/program participants. National meetings should include the periodic review of lessons learned and provide continuous learning for CMx participants.

If a national CMx program is pursued or funded participants should be required to contribute to knowledge management efforts for CMx. Such contribution may be incorporated as a commitment for funding as part of incentives provided to participants. Contributing to a lessons-learned repository and participating in case study efforts are examples of recommended knowledge management activities. If knowledge management participation is mandated, training and resources should be provided for the formal (and likely part-time) role of a CMx knowledge management analyst within a participating organization.

Legal concerns with an organization's participation should be addressed through program design. Any lessons-learned system should be designed to support a collaborative environment where cross-organizational information sharing is encouraged and the intellectual property of organization-specific solutions is protected.

5.6 Support for CMx Technical Assistance

Implementation for CMx TA requires a concerted effort from a strong centralized source to be successful. This support can come from a variety of sources such as ONC, other Federal partners, larger non-profit and community based organizations, vendors, large provider organizations, patient advocacy organizations, and other health care and consumer focused organizations. The absence of strong leadership would be a major barrier to the successful implementation of a CMx TA framework, especially in the current context which fails to align the core components of CMx with the prevalent reimbursement model.

5.7 Additional Research

Numerous opportunities exist for additional research to further define and reinforce the TA and training framework presented in this report. Opportunities and recommendations for further research include the following:

- Pilot the fundamental components of a TA program among provider organizations and in their clinical settings.

- Evaluate basic and enhanced CMx functionalities.

- Assess existing CMx implementations and pilots for lessons learned that could aid CMx planning efforts.

- Pursue research to investigate whether certain CMx design and implementation models have greater applicability or broader appeal.

- Establish guidelines for CMx pilot candidates that are likely to succeed. If candidate guidelines are developed, TA resources could be prepared accordingly.

- Conduct additional research on the Indian Health Service CMx implementation lessons learned, which may provide additional insights for a national CMx outreach and implementation strategy.

- Explore different TA needs among patient populations with a focus on the elderly, patients whose primary language is not English, and patients with specific chronic illnesses.

- Further explore health literacy challenges in the context of chronic illness and rural care coordination to develop effective health literacy improvement mechanisms within CMx training and systems.

- Explore the factors associated with unmotivated patients (lack of motivation is a serious and powerful barrier to patient CMx adoption) to ascertain what components of motivation could be improved through CMx training and systems.

- Conduct further research about attitudes of providers in medical specialties not originally engaged with this project. Conduct further research into understanding rural and frontier areas to identify issues and strategies to inform CMx design.

- Apply systems analysis principles to develop recommended best practices regarding CMx workflows, roles, and compensation models that are feasible within existing constraints.

The results and analyses from this project highlight many potential opportunities and benefits that CMx offers to improve care coordination for rural patients with chronic illness. As discussed in the TA framework and core component sections of the report, several policy considerations are prerequisites for successful TA. The barriers and benefits to CMx identified by stakeholders should shape the TA design. Engaging the academic community to produce more CMx-related qualitative research will support the development of a broader literature base and develop expertise in this research area.

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Appendix A:
PHR Ignite Consumer Stories

A.1 *Today Story*

U.S. health care providers, patients, and their caregivers are increasingly using computers and information technology to manage health information. Patients and their families and doctors, nurses, and other clinicians (for example, pharmacists and specialists) are trying to help improve health outcomes and health care by sharing electronically stored health information with everyone involved in your care, including you and your family. Federal and state governments are providing substantial funding to encourage use of computers, but the numbers of doctors and nurses using computers and the ways they use computers varies dramatically.

The following story is about a fictitious patient, Patrick Nelson, who currently lives in a rural community and has a chronic condition. Chronic conditions are illnesses or disabilities that require ongoing health care and include cancer, heart disease, and diabetes. This is a general story in which you can substitute the types of specialists and services used to treat the chronic illness you, or the patient you represent, are managing (e.g., oncologist and radiation oncology services for cardiologist and radiation).

1. Patrick goes to see Doctor Miller because his medications are not helping as much as they used to. Dr. Miller has recently installed an electronic health record (EHR) system that the office is now using.

   a. Nurse Williams asks Patrick for new or updated insurance information and to fill out forms about his medical history and current health concerns.

   b. Nurse Williams reviews the forms, asks a few questions, and checks Patrick's weight, blood pressure, and temperature.

   c. Dr. Miller reviews Patrick's information on the forms, asks a few questions about his written answers, and gives him a physical exam.

   d. Nurse Williams draws blood to order blood tests from the lab.

   e. Dr. Miller refills one prescription and prescribes a new medication to replace one that no longer seems to be effective.

   f. The nurse orders the lab tests and prescriptions electronically using the EHR.

   g. Dr. Miller recommends a check-up with a specialist and some x-rays.

2. Patrick leaves with a receipt for paying today's bill, two written referrals for the x-rays and specialist, and some educational information about the new medication and Patrick's chronic condition.

3. Patrick goes home and stops at the pharmacy to pick up his prescriptions. Patrick waits 30 minutes for the prescriptions to be filled.

4. Dr. Miller's office calls Patrick with his lab results and sends a copy in the mail.

5. Patrick schedules the referral appointments. The radiology and specialized treatment services are not near each other and Patrick has to make appointments on two different days.

6. Next week, Patrick travels an hour to the radiology center for the x-rays.

    a. He fills out more forms about insurance, his medical history, and his current health problem.

    b. The x-rays are taken and he is given the x-ray films or a CD to take back to Dr. Miller.

7. Patrick returns home with the x-rays and waits for his next appointment.

8. A week later, Patrick travels 2 hours to a treatment center.

    a. He fills out more forms about his insurance, medical history, and current health problem.

    b. Patrick remembered the educational information from Dr. Miller and the x-rays from the radiology center, but forgot his latest lab results.

    c. Nurse Davis and Dr. Jones review the information, ask follow-up questions, and give Patrick a physical exam.

    d. They perform some tests and draw blood to have some of the same lab tests ordered by Nurse Williams during his visit to Dr. Miller's office.

    e. Patrick receives new prescriptions and educational materials about the new drugs.

    f. Dr. Jones also refers Patrick to a nutritionist because she thinks his condition is related to his weight.

9. Patrick returns home with more information and questions about how the information fits with his prior treatment plan (that Dr. Miller hadn't changed other than changing his medication). He's also not sure how the new medication should be taken with his other medication.

10. Patrick thinks about scheduling a follow-up visit with Dr. Miller, but feels that he has missed too much work. He decides to wait to see how the new medications work and how he feels before seeing Dr. Miller again and puts off scheduling a visit to the nutritionist. Patrick takes all three medications and doesn't feel good after taking them. Patrick decides to hold off on the taking the newest medication.

11. A month later, while on a fishing trip, Patrick has to go to the ER because he experiences some shortness of breath. When asked about all of his medications, he's not very sure about what medications and dosages he is taking. He worries about whether they will give him something that will conflict with his regular medicines.

A.2 *Future Story*

The next fictional story is again about Patrick Nelson, 2 years from now when he and his family have a personal health record (PHR) that he uses on his iPad. His health information is securely stored and maintained in such a way that he and his family can understand the information. Patrick can also send and receive information with his care team: all the doctors, nurses, clinics, and hospitals Patrick uses for his health care. Patrick is monitoring his weight and blood pressure with a scale and blood pressure cuff that communicate

wirelessly with his iPad which, in turn, sends the information to Dr. Miller. This information is updated daily to both his PHR and his care team's EHR record of Patrick. For ease of comparison, the same situations from the earlier story occur 2 years later, but with the use of the PHR on his iPad.

1. Patrick has an appointment with Dr. Miller's office to check how he is managing his illnesses.

   a. Patrick electronically provides insurance and health history information using his iPad and Dr. Miller's office receives it the day before the appointment. Nurse Williams reviews the daily weight and blood pressure trends that Patrick recorded at home, and takes some notes to follow up on when he sees Patrick tomorrow.

   b. Nurse Williams reviews the updated information conducts the preliminary checkup, weight, blood pressure, and temperature.

   c. Nurse Williams and Dr. Miller examine Patrick, order lab tests on the blood, and prescribe two medications: one a refill, the other new.

   d. Tracking information regarding the lab tests ordered and the two prescriptions are securely sent to Patrick's PHR, which he can access through his iPad.

   e. Patrick is referred for x-rays and a medical exam. The referral information is electronically sent to the radiology center. Dr. Miller's office also electronically sends Patrick a list of suggested specialists and he, in turn, sends an electronic appointment request to Dr. Jones. Patrick authorizes secure electronic transfer of his medical information to Dr. Jones, once he selects him as his specialist.

2. Patrick leaves with updated information on his iPad, including the new educational information.

3. Patrick is notified on his iPad that his prescriptions are ready and he picks them up.

4. Dr. Miller's office receives the lab results and reviews them, then releases them to Patrick's PHR. Patrick receives a notification on his iPad that his results are available. The results include a note from Dr. Miller's office that includes an explanation of the results in language that he can understand. He feels that he has a sense of what the results mean and starts to consider some ideas for how he can make them better by exercising more and changing some of his eating habits.

5. The next week, Patrick travels an hour to the radiology center for the x-rays.

   a. The center has already electronically received his updated information from Dr. Miller's office. No additional forms are required.

6. A radiologist reviews the images and forwards them to Dr. Miller, who then releases the x-rays to Patrick's PHR in a secure fashion. A week later Patrick travels 2 hours to the treatment center.

   a. Patrick's updated information has already been provided before his appointment, including his latest lab test results. Dr. Jones has reviewed Patrick's health information, including the information he records daily at home (his weight and blood pressure). Dr. Jones notices that the medication appears to be working well to help Patrick control his blood pressure.

   b. Nurse Davis and Dr. Jones review the information, ask follow-up questions, and give Patrick a physical exam.

c. They do some tests and only order new blood work based on Patrick's examination.

d. Patrick receives another new prescription. Education materials about the new drug are sent to his iPad with a reference to his current medication and how to take the new prescription along with his other two prescriptions.

e. Dr. Jones also refers Patrick to a nutritionist because she thinks his condition could improve if he gets closer to his ideal weight.

f. Dr. Jones' office shares the findings from the exam and the additional lab results electronically with Patrick and Dr. Miller's office.

7. Patrick returns home with the information from all three of his latest visits. He has some questions about how the new instructions from Dr. Jones fit with his current treatment plan and he electronically sends his questions to Dr. Miller's office.

8. Patrick thinks about scheduling a follow-up with Dr. Miller's office and whether he has time to see a nutritionist. He decides to wait.

9. Dr. Miller's office receives the results of the x-rays and the nutritionist's referral. The office calls Patrick to discuss the results and encourage him to schedule a follow-up in the next 3 weeks. Nurse Williams also answers the questions Patrick had sent earlier about Dr. Jones' instructions for him and how they would impact his treatment plan. Dr. Miller also sends a message to Patrick's PHR message screen, saying, "Nurse Williams can provide the needed nutrition guidance to reduce the number of appointments Patrick needs to make."

10. Patrick is always able to share information securely with health care providers or family and friends when he wants them to have the information. Authorizing other people to see his information—while controlling exactly what part of his information they can see—allows Patrick to safely share his information to help support his ongoing health care needs. He can also set rules for how his information can be accessed in a medical emergency.

Appendix B:
Detailed Results from Roundtable Discussion Thematic Reviews

B.1 Thematic Review of Patient Key Takeaways

As part of the thematic review of the patient roundtable discussions, 72 key takeaway statements from the project's five patient roundtable discussion summaries were grouped by the story of discussion (*Today Story* or *Future Story*) and reviewed for recurring themes. Statements with shared topical relevance were grouped within candidate themes and 14 themes were identified (see Table 3-1 in Section 3). Below, the primary themes of general patient and provider reactions are listed along with their associated key takeaways. Some key takeaways apply to more than one theme so they are listed in several thematic categories. Primary themes are listed in the same order as Table 3-1, though not every theme is represented in this section; some themes emerged exclusively from the provider discussions and are presented in the section that follows. The source of each key takeaway is cited in brackets using the following notation: *[Table 1 Discussion Summary Reference Code, Key Takeaway Number]*. The takeaway numbers are referenced in the individual roundtable discussion summaries, which are not included in this summary document.

B.1.1 Themes of General Patient Reactions to the Today Story

Theme 1: Accuracy of the Today Story
1. General agreement on the accuracy of the *Today Story*, although several participants noted their experiences have sometimes been worse. *[C3, #1]*
2. Agreement that the *Today Story* is typical and highlights many rural care coordination issues. Concern focused on the challenges of travel (and related travel expenses), time from work, and limited access to medical treatments and specialists. *[C4, #3]*

Theme 2: Care Coordination and Health Care System Engagement Challenges
1. Many barriers to patient care coordination with or without IT, perhaps most notably access to care. *[C1, #2]*
2. Examples of where rural care coordination works better. *[C1, #3]*
3. Numerous personal stories from participants that commonly involved (a) missing medical information or lack of access to a patient's medical records by caregivers who need it, (b) prescription errors, (c) care coordination errors, and (d) lack of effective medication reconciliation leading to adverse drug interactions. *[C2, #1]*
4. Participants highly valued the role of the Regional Center for Border Health's health *promotores* (health promoters). *[C2, #3]*
5. Frustration with poor care system had provided in the past until patients found the Center. *[C2, #4]*
6. Frustration over travel challenges, medication management, and lack of coordinated care in rural areas. *[C3, #2]*
7. Frustration with medication errors. *[C4, #1]*
8. Agreement that the *Today Story* highlights many rural care coordination issues. Concern focused on the challenges of travel (and related travel expenses), time from work, and limited access to medical treatments and specialists. *[C4, #3]*

9. General frustration over the lack of care coordination and travel burden involved in seeking care. *[C5, #1]*
10. Importance of maintaining a personal notebook to keep track of all care performed. *[C5, #2]*
11. Strong agreement about the value of a nurse navigator or liaison to coordinate and support a patient's medical care. *[C5, #3]*
12. Concern about the overwhelming patient burdens of chronic illness care, especially burdens for elderly patients. *[C5, #4]*
13. Biggest problem in the *Today Story:* patient's information was not shared; caregivers were not talking to each other. *[C5, #5]*

Theme 3: Rework and Inefficiencies in Health Care Operations

1. Frustration about having to fill out the same medical information multiple times during a medical visit. *[C3, #3]*
2. Frustration with redundant lab work and medical tests. *[C4, #2]*
3. Frustration with redundant medical paperwork. *[C4, #4]*

Theme 4: Provider Engagement and Communication Challenges

1. Inability to access care records often the result of providers denying the patients access. *[C2, #2]*
2. Poor provider communication with patients and among providers involved in a patient's care. *[C4, #6]*
3. Concern about providers' unwillingness to listen to patients. *[C4, #7]*
4. Concerns over the modern medical culture and the general attitudes of professionals in health care. *[C4, #8]*

Theme 5: Lack of Information Sharing, EHR System Interoperability, and Medical Record Access

1. Inability to access care records often the result of providers denying the patients access. *[C2, #2]*
2. Concern that electronic medical systems do not talk to one another. *[C3, #4]*
3. Standardized patient medical history accessible nationwide would be beneficial. *[C3, #5]*
4. Disappointment in the "panacea" promise of EHRs. *[C3, #6]*
5. Concern over rural and urban medical facilities not sharing their electronic medical records with one another. *[C4, #5]*
6. Biggest problem in the *Today Story:* patient's information was not shared; caregivers were not talking to each other. *[C5, #5]*

Theme 6: Population-Specific Considerations

1. Concern about the overwhelming patient burdens of chronic illness care, especially burdens for the elderly patient. *[C5, #4]*

Theme 12: CMx Implementation Considerations and Recommendations

1. Patients have varied comfort levels with technology; often dependent on culture and demographics. *[C1, #1]*
2. Participants highly valued the role of the Regional Center for Border Health's health *promotores* (health promoters). *[C2, #3]*
3. Standardized patient medical history accessible nationwide would be beneficial. *[C3, #5]*
4. Strong agreement about the value of a nurse navigator or liaison to coordinate and support a patient's medical care. *[C5, #3]*

Theme 13: Leveraging Nontraditional Providers and Caregivers to Support CMx

1. Participants highly valued the role of the Regional Center for Border Health's health *promoters* (health promoters). *[C2, #3]*
2. Strong agreement about the value of a nurse navigator or liaison to coordinate and support a patient's medical care. *[C5, #3]*

B.1.2 Themes of General Patient Reactions to the Future Story and the Health IT for You Video

Theme 2: Care Coordination and Health Care System Engagement Challenges

1. Worry about lack of coordination and information sharing among rural and urban providers/specialists concerning a patient's care. *[C3, #5]*
2. Significant concern about the quality of care provided in rural areas. *[C3, #10]*
3. Strong agreement about importance of having copies of all specialists' medical notes sent to one's primary care provider. *[C5, #8]*
4. A widespread lack of acknowledgement of a patient's mental health during chronic illness care, especially cancer care. *[C5, #10]*

Theme 3: Rework and Inefficiencies in Health care Operations

1. Frustration with redundant medical tests. *[C4, #2]*

Theme 4: Provider Engagement and Communication Challenges

1. Use of this technology as an aid, not as a replacement, for face-to-face interaction. *[C3, #9]*
2. Perceived value in the technology to help patients prepare for their clinic visits and address the "biggest problem": patients who do not ask questions. *[C4, #6]*
3. Concern about physician unfamiliarity with computer technology and a loss of face-to-face interaction due to the computer in the exam room. *[C5, #2]*
4. Concern about increased risk of elder and child abuse as a result of increased computerization of patient care. *[C5, #6]*
5. Personal health records should not replace face-to-face interaction with one's caregiver. *[C5, #7]*

Theme 5: Lack of Information Sharing, EHR System Interoperability, and Medical Record Access

1. Ensuring that caregivers who need access to a patient's medical records can get them is more important than where the medical records electronically reside. *[C2, #1]*
2. Having such a medical record system is valuable, especially when medical emergencies occur when patients are out of town. The system could provide vital information to providers on behalf of patients who are incapacitated or unable to effectively communicate. *[C2, #2]*
3. Worry about lack of coordination and information sharing among rural and urban providers/specialists concerning a patient's care. *[C3, #5]*
4. "All electronic medical record systems have to talk to each other." (patient perspective) *[C3, #12]*
5. Perceived value in a medical record that can follow patients wherever they go, especially if they are injured and incapacitated. *[C3, #14]*

Theme 6: Population-Specific Considerations

1. Elderly patients generally unfamiliar with information technology. *[C3, #2]*
2. Mixed perspectives (positive and negative) about the value of home-based telehealth remote monitoring technology. Some elderly participants perceive it as an unnecessary burden. An urban adult child caregiver perceived value in being aware (via remote technology) of the health of his rural parent. *[C3, #6]*
3. Concern over a lack of computer literacy among the public, especially the elderly. Not everyone will be able to effectively use the technology depicted in the *Health IT for You* video. *[C5, #1]*
4. Need for the elderly to maintain control of their medical care. *[C5, #5]*
5. Strong agreement about the importance of social interaction and advice sharing among the chronically ill, especially cancer patients. *[C5, #9]*
6. Education for elderly patients so they can direct their care to a greater degree. *[C5, #12]*

Theme 7: Patient-Perceived Benefits of CMx

1. Having such a medical record system is valuable, especially when medical emergencies occur while out of town. The system could provide vital information to providers on behalf of patients when they are incapacitated or unable to effectively communicate. *[C2, #2]*
2. Perceived value in a medical record that can follow patients wherever they go, especially if they are injured and incapacitated. *[C3, #14]*
3. Perceived value in a CMx health information capability. *[C4, #3]*
4. Perceived value in ability to send questions to medical staff and have an ongoing electronic conversation. *[C4, #4]*
5. Less frustration for patients; more likely to comply and carry through with care. [C4, #5]
6. Perceived value in the technology to help patients prepare for their clinic visits and address the "biggest problem": patients who do not ask questions. [C4, #6]
7. General agreement that the most valuable benefit of CMx health information technology is its ability to aid in maintaining the continuity of care with a permanent (nonrotating) provider. [C4, #8]
8. Perceived value in personal health records being available to caregivers for a patient that is incapacitated. [C5, #3]
9. Strong perceived value of personal health record access and use by adult caregivers of elderly parents. [C5, #4]

Theme 8: Barriers to CMx Technology Adoption

1. Many barriers to patient care coordination with or without IT, perhaps most notably access to care. *[C1, #2]*
2. Participants were optimistic about technology presented in the *Future Story* and the *Health IT for You* video but had questions about how they could access and use it. Many stressed that they did not possess computers or Internet access and were concerned about their lack of familiarity with information technology in general. *[C2, #5]*
3. A general lack of computer use and Internet access in rural areas. *[C3, #1]*
4. Elderly patients generally unfamiliar with information technology. *[C3, #2]*
5. "Who is paying for it?" *[C3, #4]*
6. "Communication has to become more affordable." *[C3, #11]*
7. Concern about lack of computer literacy among the public, especially the elderly. Not everyone will be able to effectively use the technology depicted in the *Health IT for You* video. *[C5, #1]*

Theme 9:   Patient Privacy & Security Concerns

1. Privacy concerns related to EHRs. Big brother government concerns. *[C3, #7]*
2. General distrust in the reliability and security of information technology. *[C3, #8]*
3. Concern about personal privacy as it relates to personal health records. *[C4, #1]*
4. Concern about an increased risk of elder and child abuse as a result of increased computerization of patient care. *[C5, #6]*
5. Significant concern over the security of EHRs. *[C5, #13]*

Theme 12: CMx Implementation Considerations and Recommendations

1. The *Future Story* is too focused on the traditional provider care delivery model. *[C1, #1]*
2. The future model needs to go beyond just giving patients "data"; information needs to be actionable. *[C1, #3]*
3. Ensuring that caregivers who need access to a patient's medical records can get them is more important than where the medical records electronically reside. *[C2, #1]*
4. Importance of leveraging the health supporter role and clinic-facilitated support groups to provide training and TA. *[C2, #3]*
5. The approach depicted in the *Future Story* is "burdensome for the specialist." *[C3, #3]*
6. Use this technology as an aid, not as a replacement, for face-to-face interaction. *[C3, #9]*
7. "All EHR systems have to talk to one another." *[C3, #12]*
8. For any CMx health information technology, there must be guarantees that the medical staff will read a patient's inputs, that they won't be ignored. *[C3, #13]*
9. Emphasis on the importance of provider training. *[C4, #9]*
10. Concern about physician unfamiliarity with computer technology and a loss of face-to-face interaction due to the computer in the exam room. *[C5, #2]*
11. Concern about an increased risk of elder and child abuse as a result of increased computerization of patient care. *[C5, #6]*
12. Personal health records should not replace face-to-face interaction with one's caregiver. *[C5, #7]*
13. Strong agreement about the importance of social interaction and advice sharing among the chronically ill, especially cancer patients. *[C5, #9]*
14. Education for elderly patients so they can direct their care to a greater degree. *[C5, #12]*
15. An expressed need to have precise control over sharing one's personal health information. *[C5, #14]*

Theme 13: Leveraging Nontraditional Providers and Caregivers to Support CMx

1. Leverage the health supporter role and clinic-facilitated support groups to provide training and TA. *[C2, #3]*
2. Strong perceived value of personal health record access and use by adult caregivers of elderly parents. *[C5, #4]*

Theme 14: Perspectives on Telehealth Remote Monitoring Technologies in the Home

1. Telehealth remote monitoring technology in the home was perceived as valuable for a number of participants. Benefits were: a sense of security, the ability to more effectively control their medications and health, and time savings. *[C2, #4]*
2. Mixed perspectives (positive and negative) about the value of home-based telehealth remote monitoring technology. Some elderly participants perceive it as an unnecessary burden. An urban adult child caregiver perceived value in being aware (via remote technology) of the health of his rural parent. *[C3, #6]*

3. Perceived value in telehealth remote monitoring technology in the home and remote clinic visits performed from the home. *[C4, #7]*
4. Perceived value in telehealth remote monitoring technologies in the home. *[C5, #11]*

B.2 Thematic Review of Provider Key Takeaways

Using the same methodology employed in the thematic review of the patient roundtable discussions in the beginning of Appendix A, 79 key takeaway statements from the project's six provider roundtable discussion summaries were grouped by the story of discussion (*Today Story* or *Future Story*) and reviewed for recurring themes.

B.2.1 Themes of General Provider Reactions to the Today Story

Theme 1: Accuracy of the Today Story

1. The *Today Story* is very accurate; in fact, aggravatingly so! *[P1, #1]*
2. The discussion participants generally found the story accurate, although perhaps still more advanced than their environment from a technology standpoint. *[P4, #1]*
3. General agreement that the *Today Story* is typical and highlights many rural care coordination issues. *[P5, #1]*
4. General agreement that the *Today Story* highlights many rural care coordination issues. *[P6, #1]*

Theme 2: Care Coordination and Patient Health Care System Engagement Challenges

1. Care coordination is very complex and no infrastructure is in place to support it. Significant contributing actors across the continuum of a patient's care often remain outside of the medical conversation associated with a patient's care. *[P1, #2]*
2. A culture change across health disciplines is required to improve care coordination. *[P1, #3]*
3. Patient disorientation within the health system is prevalent and often overlooked. Adding another actor into the mix (e.g., a care coordinator) can increase a patient's frustration. Out-of-network information sharing and the timely receipt of out-of-network care documentation remain significant issues. Patients commonly return to primary care before the arrival of out-of-network care documentation, resulting in continuity of care challenges (e.g., refilling medications provided out of network). Coordination of care across [Native American] Nation boundaries is key. *[P1, #4]*
4. Financial management of one's medical care costs is a significant and often overwhelming burden for patients and their family members. More effort must be devoted to reducing the complexity of claims, simplifying billing language, and assisting patients in vital cost-benefit medical decisionmaking. *[P1, #5]*
5. Behavioral health significantly complicates information exchange among providers. Significant restrictions on the exchange of patient behavioral health information remain widely unknown among medical professionals. *[P1, #6]*
6. Out-of-network information sharing and the timely receipt of out-of-network care documentation remain significant issues. Patients commonly return to primary care before the arrival of out-of-network care documentation, resulting in continuity of care challenges (e.g., refilling medications provided out of network). Coordination of care across [Native American] Nation boundaries is key. *[P2, #2]*
7. For effective care coordination, schedulers should be considered a part of the medical team and schedule care with patient input. *[P2, #3]*

8. In rural settings, patients frequently make tradeoffs between work priority and medical care. *[P2, #4]*
9. Coordination of care is very important in rural settings, especially in extremely rural and frontier settings. *[P2, #5]*
10. Patient referral tracking remains a difficult challenge. *[P3, #1]*
11. Patients in the Arizona/Mexico border area are highly mobile, seeking medical care on both sides of the border. Providers have no insight into care provided across the border, which complicates medication reconciliation and continuity of care. *[P3, #3]*
12. The complexity of care and multiple tests, including duplicate tests performed in the same week by different providers, is a common issue in cancer treatment. *[P4, #2]*
13. General agreement among participants that patients commonly return from a referral to a specialist before the specialist responds with feedback. *[P5, #6]*
14. Recognized need for improved rural patient care coordination, with emphasis on increased sensitivity to patient travel burdens, maximizing care events during visits and reducing the need for multiple trips. *[P6, #3]*

Theme 3:   Rework and Inefficiencies in Health Care Operations

1. The complexity of care and multiple tests, including duplicate tests performed in the same week by different providers, is a common issue in cancer treatment. *[P4, #2]*
2. General frustration with redundant patient medical paperwork. *[P5, #4]*
3. General frustration with redundant medical tests and their additional cost to the patient, insurance companies, and the health care system overall. *[P5, #5]*
4. Patient frustration over redundant paperwork. *[P6, #4]*

Theme 4:   Patient Engagement and Communication Challenges

1. The patient should be asked to identify potential barriers to intended care, so that they may be adequately addressed before the care is implemented. *[P3, #4]*
2. Patients expressed need for greater ownership of their own care. *[P5, #2]*
3. Communication challenges between patients and their providers / caregivers include a lack of provider communication skill and patients' reluctance to communicate their medical concerns. *[P5, #3]*
4. The importance of recognizing the role of behavior in a patient's chronic illness. *[P5, #7]*
5. Concern over patients' ability to effectively communicate important medical information. *[P6, #5]*

Theme 5:   Lack of Information Sharing, EHR System Interoperability, and Medical Record Access

1. Behavioral health significantly complicates information exchange among providers. Significant restrictions on the exchange of patient behavioral health information remain widely unknown among medical professionals. *[P1, #6]*
2. Out-of-network information sharing and the timely receipt of out-of-network care documentation remain significant issues. Patients commonly return to primary care before the arrival of out-of-network care documentation, resulting in continuity of care challenges (e.g., refilling medications provided out of network). Coordination of care across [Native American] Nation boundaries is key. *[P2, #2]*
3. The *Today Story* is isolating, with minimal information exchange among providers. *[P3, #2]*
4. Lack of interoperability and information sharing among EHR systems. *[P6, #2]*
5. Difficulty with surgeons' access to patient images and x-rays taken from nonintegrated, rural facilities. *[P6, #6]*

6. A lack of important information sharing between specialists and primary care providers/hospitalists. *[P6, #7]*

Theme 6: Population-Specific Considerations

1. Behavioral health significantly complicates information exchange among providers. Significant restrictions on the exchange of patient behavioral health information remain widely unknown among medical professionals. *[P1, #6]*
2. Some of the Indian Health Service (his)-related feedback suggested the *Today Story* is outdated or more aptly applies to older patients less inclined to use technology, perhaps because IHS has more available technology. *[P2, #1]*
3. Out-of-network information sharing and the timely receipt of out-of-network care documentation remain significant issues. Patients commonly return to primary care before the arrival of out-of-network care documentation, resulting in continuity of care challenges (e.g., refilling medications provided out of network). Coordination of care across [Native American] Nation boundaries is key. *[P2, #2]*
4. In rural settings, patients frequently make tradeoffs between work priority and medical care. *[P2, #4]*
5. Patients in the Arizona/Mexico border area are highly mobile, seeking medical care on both sides of the border. Providers have no insight into care provided across the border, which complicates medication reconciliation and continuity of care. *[P3, #3]*
6. The complexity of care and multiple tests, including duplicate tests performed in the same week by different providers, is a common issue in cancer treatment. *[P4, #2]*
7. The importance of recognizing the role of behavior in a patient's chronic illness. *[P5, #7]*

B.2.2 Themes of General Provider Reactions to the Future Story

Theme 2: Care Coordination Challenges

1. General frustration about the challenges of rural patient referrals and difficulty attaining medical test results. Provider-patient communication norms worsen the situation (e.g., patients do not question when providers order redundant tests because they think the reordering is done for a reason). *[P5, #4]*

Theme 4: Patient Engagement and Communication Challenges

1. General frustration about the challenges of rural patient referrals and difficulty attaining medical test results. Provider-patient communication norms worsen the situation (e.g., patients do not question when providers order redundant tests because they think the reordering is done for a reason). *[P5, #4]*

Theme 5: Lack of Information Sharing, EHR System Interoperability, and Medical Record Access

1. Lack of PHR standardization and many available EHR platforms available for patient use leaves providers incapable of engaging patients effectively in CMx. *[P1, #3]*
2. A significant national effort should be undertaken to ensure all EHRs can exchange a patient's data. *[P3, #4]*
3. Provider systems are still very hard-pressed to share information. *[P4, #3]*
4. Perceived value in a centralized EHR system to be accessible nationwide. The pros and cons of national EHR approaches were discussed, including the negative impact on care when a centralized system goes down. *[P5, #1]*
5. Expressed need for health care organizations to use the same EHR. *[P6, #9]*

Theme 6: Population-Specific Considerations

1. Literacy and technology familiarity remain significant barriers to CMx technology adoption by the elderly. *[P3, #5]*
2. Oncology is viewed as having greater complexity (by far the most devastating diagnosis, frequency of visits, changing treatment, and complex medication) that makes patient and provider challenges even greater. *[P4, #4]*

Theme 7: Provider-Perceived Benefits of CMx

1. CMx of health information presents the opportunity to manage patient care between visits. *[P1, #2]*
2. CMx offers the potential for a more seamless presurgical experience. *[P6, #5]*

Theme 8: Barriers to CMx Technology Adoption

1. Technologies must be built with mechanisms to improve the accuracy and consistency of patient-generated health information and data. *[P1, #4]*
2. Connectivity remains an issue in rural areas. Some rural patients would not be able to access CMx health information technology if it were available. *[P1, #6]*
3. The depicted care model is highly dependent on the patient's motivation. *[P2, #1]*
4. Patients must be able to correct and contribute to their medical records. *[P2, #2]*
5. The patient in the story seems unusually motivated and tech savvy. *[P3, #1]*
6. Literacy and technology familiarity remain significant barriers to CMx technology adoption by the elderly. *[P3, #5]*
7. Willingness, desire, and ability to engage electronically will be varied and difficult for rural patients and older patients.
    a. Many patients want the clinician to be in control.
    b. Affording and using the technology is a challenge.
    c. Having Internet access is a challenge. *[P4, #1]*
8. Perceived value in the role of an EHR system in helping patients take greater ownership of their care. Benefits, such as electronic reminders and improved patient engagement / behavioral health, were discussed. *[P5, #2]*
9. General patient inability to afford electronic devices and Internet access. The technology has to be affordable, available, and ready to use. *[P5, #3]*
10. Concern that clinicians focus more on the data rather than the patient. *[P5, #8]*
11. It is unrealistic to assume every patient or household will own an electronic device to participate in CMx of health information. *[P6, #1]*
12. The level of technology familiarity required is unrealistic, especially among the elderly and those without a technology background. *[P6, #2]*
13. Lack of patient appreciation for the time constraints in clinic visits. *[P6, #4]*

Theme 9: Patient Privacy and Security Concerns

1. Some participants agreed that health information privacy and security standards must meet or exceed those used in electronic banking. *[P2, #3]*
2. Protection of patient information must be addressed in any implementation. *[P3, #7]*
3. General patient concerns over health information privacy and data theft must be addressed. *[P5, #5]*

Theme 10: Payment Reform

1. There is tremendous resistance to adopting any new workflows or patient-engagement requirements without compensation. A significant restructuring of provider workflow and reimbursement is required to facilitate the adoption of CMx of health information activities. *[P1, #1]*

2. Providers aren't compensated for CMx activities. A clinic participating in such activities requires more technically proficient staff, which increases organizational costs. *[P3, #2]*
3. The need for provider payment reform with compensation focused on outcomes. *[P5, #9]*
4. Payment reform is required for CMx, to include a billable care management task for CMx activities. *[P6, #7]*

Theme 11: Perceived Impact of CMx to Health Care Operations

1. CMx of health information presents the opportunity to manage patient care between visits. *[P1, #2]*
2. The game (health information exchange/increased availability of data to patients) is being played with or without us. *[P1, #8]*
3. Providers aren't compensated for CMx activities. A clinic participating in such activities requires more technically proficient staff, which increases organizational costs. *[P3, #2]*
4. The health promoter role provides a significant patient engagement, patient education, and medical team support capability for a medical organization. *[P3, #6]*
5. Clinician are concerned about losing the needed human touch and interaction in care. *[P4, #2]*
6. Perceived potential for unlicensed health care roles in a CMx of health information environment (e.g., health coaches, community health workers). *[P5, #6]*
7. Perceived value in a home visit as a part of a patient's overall health care support. *[P5, #7]*
8. Significant concerns over workflow impacts due to CMx. *[P6, #3]*
9. CMx offers the potential for a more seamless presurgical experience. *[P6, #5]*

Theme 12: CMx Implementation Considerations and Recommendations

1. A collaborative culture must exist for CMx of health information to work. *[P1, #5]*
2. Focus your priorities on (a) managing medications, (b) engaging early adopter patients, and (c) introducing change while addressing compensation and workflow impacts. *[P1, #7]*
3. The perceived value of RECs as a venue for CMx of health information was mixed (pros and cons). *[P2, #4]*
4. Forums for technology implementation mentoring exist within IHS. *[P2, #5]*
5. Participants perceived the following significant priorities must be addressed for any CMx of health information undertaking: patient motivation, lack of education, and medical team support during new technology implementation and rollout. *[P2, #6]*
6. Design new technology rollouts for highly heterogeneous health care systems. A standardized offering should have the capacity for tailoring to local needs and requirements. *[P2, #7]*
7. Medical team training should be hands-on and in the field. In addition to supplying the device and the manual for a technology rollout, users need support in their initial attempts and learning. *[P2, #8]*
8. Have a few individuals at high-performing implementation sites mentor their peers at other sites. Provide ready access to subject matter experts whenever necessary. *[P2, #9]*
9. The implementation of this technology seems easy, but is likely very complex and costly. *[P3, #3]*
10. Primary care is the driver for CMx. *[P6, #6]*
11. The medical home model may be effective way to support CMx. *[P6, #8]*
12. Medicine needs a paradigm shift so as to focus more on preventive and holistic care. *[P6, #10]*

13. Employers play a significant contributing role in their employees' health and should be stakeholders in CMx. *[P6, #11]*

Theme 13: Leveraging Nontraditional Providers and Caregivers to Support CMx

1. The health promoter role provides significant patient engagement, patient education, and medical team support capability for a medical organization. *[P3, #6]*
2. Perceived potential for unlicensed health care roles in a CMx of health information environment (e.g., health coaches, community health workers). *[P5, #6]*

B.3 Thematic Review of Individual Roundtable Discussion Summaries

In addition to the thematic review of key takeaway statements of the 11 discussion summaries, the team did a more thorough search for themes in the detailed text of each summary. This review considered the frequency with which a theme was documented within the individual roundtable discussion summaries, thus characterizing their degree of emphasis. Two groupings of the resulting analysis are presented: themes emphasized among patients and themes emphasized among providers. Themes common to both groups are emphasized in **bold text**. Themes are listed by descending order of frequency. The sources of each theme are cited in brackets use the discussion summary reference codes found in Table 3-1.

- **Access to data.** *[P1,P2,P3,P4,P5,P6,C1,C2,C3,C4,C5]*

- **Many barriers are unique to rural populations.** *[P1,P2,P3,P4,P5,P6,C1,C2,C3,C4,C5]*

- **Patient engagement/motivation.** *[P1,P2,P3,P4,P5,C1,C2,C3,C4,C5]*

- **Culture shift required (collaborative approach to care, technology, etc.).** *[P1,P2,P3,P4,P6,C1,C2,C3,C4,C5]*

- **Travel constraints/time associated with unnecessary trips to providers.** *[P1,P2,P4,P5,P6,C1,C2,C3,C4,C5]*

- **Need for PHR standardization/solution for lack of interoperability among EHR systems.** *[P1,P2,P3,P4,P5,P6,C1,C2,C3]*

- **Privacy issues/trustworthiness of patient health records.** *[P1,P2,P3,P4,P5,C1,C3,C4,C5]*

- **Digital divide: access and literacy.** *[P1,P2,P3,P5,P6,C1,C2,C3,C5]*

- **Unrealistic expectation of technology access and literacy.** *[P1,P2,P3,P4,P6,C1,C2,C3,C5]*

- **Education about value and benefits to new processes and technology is essential.** *[P1,P2,P5,P6,C2,C3,C4,C5]*

- **Cost.** *[P1,P2,P3,P4,P5,C3,C4,C5]*

- **Value of CMx technology as a time saver for patients and providers and care givers; also mitigates errors.** *[P2,P4,P5,P6,C2,C3,C4,C5]*

- **Telehealth perspectives (positive and negative).** *[P2,P3,P5,P6,C2,C3,C4,C5]*

- **Redundancy of paperwork and tests.** *[P1,P4,P5,P6,C2,C3,C4]*

- **Concern that overuse of technology will break down human interaction.** *[P1,P4,C3,C4,C5]*

- Efficiency (could be improved through technology/EHRs, etc.). *[C1,C2,C3,C4,C5]*

- Communication/collaboration necessary between patients and providers. *[C1,C2,C3,C4,C5]*

- **Reimbursement structure: payment reform and performance-based compensation.** *[P1,P5,P6,C3]*

- Accuracy issues with CMx. *[P1,P2,P3,P5]*

- No current structure in place that supports patient care coordination. *[P1,P2,P3,P5]*

- Education about the value and benefits to new processes and technology is essential. *[P1,P2,P5,P6]*

- Coordination of care across borders. *[P1,P2,P3,P5]*

- Incentivize patients and providers. *[P1,P2,P3,P5]*

- No compensation structure in place for electronic communication. *[P1,P3,P5,P6]*

- **Value of health promotores (promoters)/advocates and their need for data access.** *[P3,C2,C5]*

- Behavioral health. *[P1,P3,P5]*

Appendix C:
CMx Archetypes

After consideration of the attitudes and opinions participants expressed in the project's 20 discussions, the following archetypes have been created. The discussion facilitators developed these interpreted statements of the archetypes to communicate representative voices of existing or potential CMx of health information roles identified during discussions. Review of the archetypes is valuable to identify and envision CMx needs, roles, and potential reactions to adoption efforts.

Rural Patient—General

- Coordinate my care and optimize my rural travel, maximizing each visit and eliminating unnecessary trips.

- Eliminate redundant paperwork. Empower me to fill out a document once, so that it can be shared electronically by all my caregivers.

- Help me avoid costly and redundant labs and tests.

- Enhance the quality and duration of my face-to-face exchanges with my providers and caregivers during clinic visits. Allow me time to focus on my concerns with my provider, and to express and discuss what really matters in my care.

- Ensure my electronic medical records can be accessed by those who need them during emergencies.

- Empower me to set permissions and restrict who can access my electronic medical records, to include insurance companies and individuals (e.g., specialists, family members). Permit me to set these permissions on a content-level basis.

- Ensure my electronic medical records are protected with the highest level of security available (including the security of both health organizations and my personal home applications/services).

- Help me to manage the often overwhelming financial aspects of my care, including billing, problem resolution, and tradeoff decisionmaking between treatment alternatives and their associated costs.

- Help me to take greater ownership of my care, and to improve my understanding of medicine and my overall health literacy.

- Help me to leverage telehealth technology in the home (after any mandatory face-to-face visits) to maintain the continuity of care with my providers and specialists, without the risk of relationship loss due to professional rotations.

Patient—Elderly

- Help me to manage and overcome the overwhelming burden of chronic illness care (e.g., multiple medications throughout the day, multiple appointments, documentation, billing, and frequent travel).

- Help me to use CMx of health information technology to the extent that I wish. I am overwhelmed by technology and have had limited experience with it.

- If I do not wish to use CMx, provide someone to act on my behalf or let me maintain the traditional health care approaches that I am familiar and most comfortable with (e.g., paper records, prescription refills by voicemail, telephone calls to my receptionist and nurse). If I am overwhelmed by technology and cannot use it, then provide resources to help me (e.g., voice commands, support from artificial intelligence, health advocate/coach support).

- Empower me to maintain control over my medical care. I want to remain *in charge* of this important aspect of my life. Permit me to extend portions of control to those in my family (or other supporters) to the extent that I see fit. Tailor CMx of health information to my personality type (e.g., Type-A, high detail-driven versus big picture thinker).

- Provide training in line with my mental age, education, literacy level, attention level, and memory.

- Give me support and encouragement from elderly role models who successfully use CMx technology.

- Provide professional, culturally sensitive training in my primary language.

- Help me to stay informed and understand changes to health care laws, regulations, policies and how they affect me and my family members.

- Help me to maintain my privacy and the privacy of my electronic medical records.

- Address my concerns about government and commercial interference in my life (e.g., changing health care policy and unsolicited ads based on my health conditions).

Patient—Cancer

- Provide me mental health support when I need it. Help me to cope with the shock of my diagnosis.

- Empower me to share my advice and experiences with other cancer patients.

- Maximize my personal and face-to-face interactions to maintain the human touch in my care and recovery. Ensure my interaction with my caregivers is in no way diminished by the increased computerization of health care.

Patient—Border

- Permit any caregiver access to my electronic medical records to whomever needs it. Wherever my mobile work commitments take me, make sure my records are available.

- Help me to keep track of my medications and their dosages and permit this information to be readily sharable with any caregiver who needs it.

- Improve the fundamentals of my care, such as medication reconciliation and information sharing among providers and facilities.

Patient—Medications

- Help me to better manage and know my medications.

- Empower me with telehealth remote monitoring technologies in the home to record my health trends for the purpose of disproving the need for costly, recurring prescriptions and adjusting my medications appropriately.

Adult Child or Parent/Sibling Caregiver

- Empower me to participate in and contribute to the care of my elderly parent(s) while at the same time respecting their need for control.

- Empower me to participate in and contribute to the care of my children and siblings.

- Empower me with access to my distant/rural parents' telehealth home-based remote monitoring health measures so that I may keep current on their health status and any alerts (e.g., weight, medication adherence, blood pressure/sugar).

Provider—General

- Give me truly interoperable EHRs if you want to improve care coordination.

- The value of CMx looks promising, but you can't expect me to adopt this new technology without changing how I'm compensated.

- Compensate me and my medical staff for any CMx of health information activities.

- I remain very concerned over how CMx would negatively impact my workflow, and the workflow of my staff. I am anxious about the likelihood of information overload and real-time communication expectations on the part of my patients.

- Ensure that my workflow is enhanced, not diminished, by CMx health information activities.

- Help me to eliminate redundant labs and tests.

- Help me to coordinate the care of my patients and to be informed of all activities and tests performed by other providers. Ensure that I always know about the latest happenings and results.

- Usher in a culture change in health care so that other caregivers are more receptive to sharing information and collaborating in the care of my patients (e.g., care plan reconciliation across all of a patient's morbidities).

- Provide me with adequate training and first-hand observation experiences to realize the benefit of and effectively use CMx of health information technology in my organization.

- Empower me with tools and techniques to increase my patients' adoption of CMx health information technology.

Provider—Serving Border and Snowbird Patients

- Help me to keep track of my mobile and seasonal patients and the status of their referrals.

Provider—Cancer Specialist

- Help me to empower my patients to take more control over their care.

- Help me to maintain and improve the cancer treatment I and my team provide.

- Help me to support patients and families when they are faced with the shock of a cancer diagnosis.

- Help me to maintain the continuity of the complex, travel-intensive, long-term care of my cancer patients.

- Empower me to mitigate the many medication reconciliation issues common to oncology. Help me to effectively manage complex, often-changing medication treatments/protocols. Help me to avoid adverse drug reactions.

- Help all providers to collaborate and remain on the same page for our patient since no single provider is in charge in cancer treatment. Empower us with the ability to collaboratively perform care plan reconciliation among multiple providers.

- Help me to address the heavy travel burdens of care. Empower me with sophisticated scheduling capabilities so that a complex care plan schedule can be designed to make the most of every patient visit and can reduce the number of overall trips.

- Help me to streamline my clinic visits so that exam room time is focused on face-to-face time with my patients, focusing on what matters to them most.

Provider—Rotating

- No matter where my rotation takes me, permit me to support a CMx patient panel so that my CMx patients never lose the continuity of their chronic illness care.

- Empower me to be my rural patients' permanent provider. Provide me telehealth capabilities so that my CMx patients are given the continuity of care they deserve.

Provider—Orthopedic Surgeon

- Empower me with a more seamless presurgery experience.

- Arm me with the most current medical record information to make successful *fitness for surgery* assessments of ER hip fracture patients.

Provider—Home Health Aide

- Empower me with tools to view and contribute to a patient's primary care medical records. Let me send electronic messages to patients' providers to communicate medical updates or anything warranting immediate attention.

- Help me to reduce my chances of being surprised when I perform a home visit. Help me to overcome the challenges for missing, fragmented, or inconsistent medical record documentation available to me.

ER Medical Personnel and First Responders

- Empower us with immediate access to a patient's primary care medical record so that we may avoid adverse drug reactions and interactions, be aware of any

complicating medical conditions, and be aware of any unique treatment considerations or important information indicated by the patient or the primary care provider.

Patient Advocate / Health Promoter "Promotore" / Family Care Coordinator / Health Coach

- Include me in the patient's care coordination cycle. Consider me a part of the medical team.

- Empower my intermediary role between patient and clinician, communicating medical concepts in a language patients understand and updating providers on important patient feedback that needs to be taken into account for effective clinical decisionmaking.

- Help me more effectively coordinate with those who support my patients in the local community (e.g., social services, family members, patient advocacy organizations).

- Provide me with tools to help patients connect the dots between their behaviors and their health through the visual display of their health trends.

Clinic Scheduler

- Include me in the patient's care coordination cycle. Consider me a part of the medical team.

- Empower me to schedule care events to maximize visit utilization (e.g., integrated care events on a single day), to reduce the number of required visits, and to satisfy the availability needs of the patient.

Clinic IT Staff

- Consider me a part of the medical team, available to train patients on technology-related matters (e.g., personal health records, device use, security recommendations, hands-on training).

CMx Vendor

- CMx of health information is a public health imperative! Technology is available today to empower patients and providers to more effectively coordinate care.

- The lack of EHR system interoperability is a critical barrier for CMx adoption. We understand the competitive and proprietary issues surrounding EHR software, but there should be some generally accepted set of patient medical record information that can be exchanged regardless of platform. Interoperability will likely not occur without a government or payer mandate.