March 2014

State Health Policy Consortium

Stakeholder Findings Regarding Rural Care Coordination for Patients with Chronic Illnesses and the Potential Role for Consumer-Mediated Exchange (CMx)

Supplement to AMIA 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

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1. SYNTHESIS

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.

This supplement to the full Final Report on the Development of Technical Assistance and Educational Materials to Support Consumer-Mediated Exchange provides extensive detail around the discussions from which the final analysis and technical assistance framework was drawn. For more information, please reference the full final report.

1.1 Roundtable Discussions: Patient and Provider Attitudes and Opinions

A thematic approach to synthesize roundtable discussion findings was undertaken to a) organize the essential issues communicated by roundtable discussion participants in a common-sense manner understood by clinical professionals, policymakers, and laypersons alike and b) facilitate the strategic planning of consumer-mediated exchange (CMx) implementation considerations along a theme-by-theme basis.

The thematic review pursued two courses of assessment: a key takeaway review and a detailed discussion summary text review. A key takeaway is a point of significance identified by facilitators for a specific roundtable discussion and is listed in its discussion summary. First, we reviewed the 151 key takeaway statements that came out of the provider and patient discussions for the *Today Story* and the *Future Story*. For some patient roundtable discussions, feedback from the *Health IT for You* video was included along with the *Future Story* feedback. Second, we conducted a detailed review of each discussion summary's descriptive text to determine the degree to which the participants emphasized specific themes. Though both review methods are subjective in nature, good agreement was found between the two methods.

After completing the two forms of thematic review, we analyzed the results to distill them into primary themes and narrative descriptions of those themes. The narrative descriptions of the themes are derived directly from the thematic review content but presented in a more synthesized form and are infused with paraphrased comments from the participants to provide context for the results.

In total, 14 primary themes were identified during the patient and provider roundtable discussions. Table 1-1 summarizes the primary themes and indicates the part of the roundtable discussion (*Today Story* or *Future Story*) in which the themes occurred. Some themes can be considered subsets of others but have been made distinct because participants emphasize them specifically. The themes are not rank ordered in importance or priority.

The following primary theme discussion provides greater context and qualitative descriptions of each theme. As discussed previously, these themes emerged from an abstraction of the individual roundtable discussion summaries. Their true origins are the personal and, at times, emotional experiences of the patients, caregivers, and providers as they related their struggles in receiving or providing quality care when information did not flow effectively. Paraphrased comments from individual participants are included in some theme descriptions. Comment specifics, such as names and locations, have been redacted to preserve individual privacy. These individual comments are presented in italics.

Table 1-1. 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*	●	N/A	●	N/A
2. Care Coordination and Health care System Engagement Challenges	●	●	●	●
3. Rework and Inefficiencies in Health care Operations	●	—	●	●
4. (Provider/Patient) Engagement & Communication Challenges	●	●	●	●
5. Lack of Information Sharing, EHR System Interoperability and Medical Record Access	●	●	●	●
6. Population-Specific Considerations	●	●	●	●
7. Perceived Benefits of CMx	—	●	—	●
8. Barriers to CMx Technology Adoption	—	●	—	●
9. Patient Privacy & Security Concerns	—	●	—	●
10. Payment Reform	—	●	—	—
11. Perceived Impact of CMx to Health care Operations	—	●	—	—
12. CMx Implementation Considerations and Recommendations	—	●	●	●
13. Leveraging Nontraditional Providers and Caregivers to Support CMx	—	●	●	●
14. Perspectives on Telehealth Remote Monitoring Technologies in the Home	—	●	—	●

Note: — means no data

Throughout the remainder of this report, we provide call-out boxes depicting archetypical stakeholder voices. These archetypes are further described and listed in their entirety in Appendix C: *CMx Archetypes* of the final project report.

1.1.1 Theme 1: Accuracy of the Today Story

This theme captures participant feedback on the accuracy of the *Today Story* as it relates to their personal experiences with health care. In the *Today Story* (see Appendix A of the full final project report), a fictitious patient named Patrick struggles with medications, tries to navigate three providers with some electronic health record (EHR) technology, and decides against taking a new medication. The story ends with Patrick in the emergency room (ER).

Patients and providers across all discussions consistently stated the story was very accurate—particularly in terms of the challenges in care coordination and the difficulties patients face when trying to navigate the range of treatments across providers and the distances they needed to travel to most providers. The Indian Health Service (IHS) provider roundtable (P2) was perhaps the one exception where participants stated they have more EHR connectivity to date and felt that the technological representation in the story was a bit behind the times. Participants in other roundtables, however, stated that their communities had even less technology than depicted in the *Today Story.*

Patients voiced concerns focused on the challenges of travel (and related travel expenses), time away from work, and limited access to medical treatments and specialists. One patient said, "You should just substitute my name for Patrick's." Several patients indicated their challenges are worse than depicted. One provider said, "The *Today Story* is very accurate; in fact aggravatingly so!"

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

This theme captures participant comments associated with challenges of effective care coordination. This theme is commonly associated with primary care provider coordination of patient care with specialists and includes issues with medication, referrals, the receipt of consult notes and test results, care plan reconciliation, and basic awareness of patient status while in the care of a specialist or hospital system. This theme also accounts for comments associated with patient challenges with effectively engaging or participating in the health care system that are not necessarily associated with care coordination.

Patients' reactions to the *Today Story* highlighted this primary theme in many ways. First, patients related numerous personal stories that commonly involved issues such as

- missing medical information;
- the lack of access to a patient's medical records by caregivers who need it;
- prescription errors;
- care coordination errors; and
- the lack of effective medication reconciliation leading to adverse drug interactions.

> *Suffering from a fall and back injury while out of town, I didn't have any of my medications or medication documentation in my possession. My wife had to drive 50 miles roundtrip from the hospital to our home to retrieve my medication documentation. My doctor couldn't be reached for information because the injury occurred on a non-workday. Even after my wife returned*

> *with documentation, I was not permitted to receive medications until the following day.*

Patients discussed their struggles to access needed care—particularly from qualified specialists. Every patient expressed frustration about travel burdens and time away from work and family. One woman made the difficult choice of living apart from her husband to ensure she received needed specialty care.

Most discussions underscored the overwhelming patient and caregiver burdens associated with managing the care required for chronic illness through multiple providers, especially for elderly patients.

The following is a specific example from the Nebraska patient roundtable discussion that emphasizes the overwhelming nature of chronic illness care for the elderly:

> *I value technology and medicine but, even with a nurse navigator, for a lot of people it's just too much. An elderly relative of mine more or less just kind of gave up due to the overwhelming burdens associated with care—taking medications roughly seven times a day and too much time spent on doctor visits.*

Patients told a set of more positive stories regarding rural care coordination involving unique staffing positions in certain care settings. These individuals helped patients with care coordination. Specifically, a U.S.-Mexico border health clinic's health *promotores* (Spanish for "promoters") and nurse navigators, or liaisons affiliated with other clinics, help patients keep track of their care, sometimes schedule appointments, and often check on the patient's status in between visits. One patient participant stressed that his health promoter provided him education and talked to his doctor on his behalf (e.g., to talk about his medications). He appreciated the promoter's willingness to be available whenever he was needed. The participant valued the care he received from the health promoter to such a great extent that he considered the supporter almost as family. Participants also raised the point that community health workers could fulfill health supporter roles on a volunteer basis.

Rural Patient – General

- Coordinate my care and optimize my rural travel, maximizing each visit and eliminating unnecessary trips.
- Enhance the quality and duration of my face-to-face exchanges with my providers and caregivers during clinic visits. Allow me the time to focus on my concerns with my provider; 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.

Provider reactions to the *Today Story* also highlight this primary theme with similar and different perspectives. Providers regularly mentioned the challenges of referrals and medication reconciliation, particularly with providers that were out of network. Providers noted patients often came for a return visit before the needed documentation from referrals arrived. Behavioral health was often mentioned as an area in which referral information or simple lack of awareness of the care could cause care coordination challenges.

Some providers noted that they and their peers are not sufficiently sensitive to the travel burdens of patients and should try to reduce the need for multiple trips. Several providers noted that improved care coordination would require a cultural change for some providers.

Providers noted that health care and the financial components of health care coverage are complex and overwhelming for patients and families and add to the difficulties of navigating needed care.

1.1.3 Theme 3: Rework and Inefficiencies in Health Care Operations

This theme captures participant comments related to unnecessary redundancy in information requirements, unnecessary duplication in testing, and other process inefficiencies in health care delivery.

Patients and providers across all discussion sessions made similar remarks that the duplicative information processing—such as the recounting of medical and medication histories or the completion of insurance and Health Insurance Portability and Accountability Act (HIPAA)-related forms—required at most if not all visits was a waste of time and source of frustration. Patients highlighted that they were required to complete the same paperwork numerous times—often on the same day and in the same provider facility (e.g., different departments in the same hospital even with a shared EHR system).

Patients and providers discussed redundant testing as a very common problem. The causes for redundant testing were many and included the following:

- lack of access to recent test results
- patients characterized as reluctant to bring up the point of a redundant test because they did not want to question the provider’s authority to issue the test again or they lacked the health literacy or terminology awareness to understand that the test was a duplicate
- the slow response or unwillingness of specialists to share results
- cancer treatment and time-sensitive decisions requiring the test

Patients and providers agreed that duplicate testing was burdensome and costly.

1.1.4 Theme 4: Provider/Patient Engagement and Communication Challenges

This theme captures participant comments associated with issues, errors, or challenges with effective communication between patients and providers (or other medical personnel).

Patients frequently discussed the difficulties they had in communicating with their doctors and other medical staff in the office. They often felt doctors did not listen to patients. In one case, where the diagnosis was a rare autoimmune disorder, a patient went for years with providers misdiagnosing and at one point assuming she was a chronic hypochondriac. One patient noted that as a patient you have about 10 seconds to make an impression on the doctor at which point they categorize you as a certain type of patient.

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.

Several patients felt the changes in modern-day medical culture have turned medicine into a financial business and have changed the way providers and patients interact. Many patients also noted that patients—particularly elderly patients with complex chronic illness—are often afraid to question the doctors; they trust the doctors to make the right decision and often just want to be told what they need to do.

Providers also highlighted the challenges to patient communication and engagement, regularly citing patient challenges in effectively communicating their health status and asking questions about their care. This general lack of health literacy among patients was a concern frequently expressed by providers. It emphasizes the need for patient health literacy to be addressed in CMx education, awareness, and training efforts. Providers highlighted that many patients do not want to be engaged in their care or take responsibility for the behaviors that affect their health. Some providers echoed the statements of patients about provider communication skills and their inability to help patients understand their health needs.

Discussion of engagement and communication challenges in relationship to the *Future Story* focused on two main concerns: communication regarding patient education and the importance of not substituting technology for needed face-to-face interaction. Patients emphasized the importance of finding ways for providers or other staff in the provider organization to help patients understand and gain a certain comfort level with the use of CMx. Patients and providers discussed the critical importance of face-to-face visits even when technology is in place. Providers—including care managers and therapists—said there is an important need for human contact to help address continued communication challenges that only get discussed when the provider can see the expressions and body language of the patient.

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

This theme captures participant comments associated with the lack of information sharing between providers and among medical teams and personnel, the lack of interoperability of EHR systems within and across health care organizations, and the inability of a provider or patient to access medical records when needed.

Patient – Border

- Permit any caregiver access to my electronic medical records who 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.

Patients' discussions of the *Today Story* highlighted that patients agree their providers do not communicate with each other and either do not share needed information or fail to share it in a timely manner. Patients noted that, even with EHRs, their providers did not share information—often because the different EHR systems could not or would not exchange the information. This problem is worse between specialists and primary care and even worse if the provider is in another state or country. Patients also discussed providers' unwillingness to share the records and results with the patient, who could in turn share the information with other providers.

Providers reiterated their concerns about the difficulties involved in receiving the results of referrals from specialists. They added that, although EHR adoption continues to grow, the lack of interoperability between systems means there is little or no improvement in care coordination.

Patients and providers both discussed the importance of having EHR systems and tools for CMx that are able to talk to each other in the future. Providers commented that, similar to EHRs, personal health records (PHRs) are not standardized and that the range of CMx solutions may not be able to connect or share with the many EHR systems. Some providers discussed the pros and cons of having a centralized medical record system that would be accessible nationwide and the negative impact if such a system went down.

Patients repeatedly said that caregivers, formal and informal, need access to their medical records and that access is more important than where the records reside. Many patients emphasized the value of access to the information in the event of an emergency.

1.1.6 Theme 6: Population-Specific Considerations

This theme captures participant comments concerning specific patient populations or demographics such as the elderly, the Native American population, and those with specific illnesses such as cancer. This theme serves to aggregate all population-specific comments, which, although smaller in number, indicate that patient characteristics play an important role in care coordination for rural patients.

The patient population distinctly discussed in most patient and provider sessions was the elderly. The burdens of managing chronic illness were viewed as being especially challenging for the elderly. Some examples included trying to remember medications, reconciling advice from different providers, and having the endurance to make daylong trips to see specialists. The elderly were usually identified as the patients least willing to question their providers or provide information if not asked. For instance, older patients were reluctant to relate health issues during clinic visits. Patients and providers both characterized the elderly as the least likely to use CMx.

Patient –Elderly

- Help me to manage and overcome the overwhelming burden associated with chronic illness care.
- I am so overwhelmed by technology and have had limited experience with it over my life. Help me to use consumer-mediated health information exchange technology to the extent that I wish.
- 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. If I am overwhelmed by technology and cannot use it, then provide resources to help me.

> *When my father goes alone to get a checkup, he won't tell the medical staff how he is really doing. I see this mentality in many of his generation.*

Patients and providers stated that patient populations being treated for behavioral health conditions, such as depression, had additional challenges in terms of sharing information and managing medications. Providers recognized a common lack of understanding among their professional peers about the restrictive nature of patient behavioral health information and the inability to share information needed to support another provider's care efforts.

Providers discussed patients in more remote or frontier regions of states as having even greater care coordination challenges. The difficulty of care coordination across the U.S.-Mexico border was discussed during the Arizona session. The enormous distances to reach care in Alaska were highlighted during the IHS provider discussion.

Several discussion sessions focused on cancer care as having unique considerations because of the devastating nature of the diagnosis, the complexity of care, and at times the frequency of treatments. The unique patient population focus came up repeatedly during the *Future Story* discussion regarding barriers to adoption and the importance of tailored education and training to help address the unique needs of the cancer community.

1.1.7 Theme 7: Perceived Benefits of CMx

This theme accounts for comments where participants communicated perceived value or benefit in the potential of CMx capabilities.

Patients across all discussions saw the value of CMx in helping address the many challenges of rural chronic care coordination. Patients highlighted the importance of access to information during emergencies—particularly if the patient is incapacitated. Many patients and caregivers felt the informal caregiver's access to the information, or the adult child's access on behalf of elderly parents, is very important. Patients said they thought the availability of information from CMx would help them prepare for provider visits and feel less frustrated when trying to follow their treatment plans. Some patients expressed value in being able to identify and correct errors in their medical records and test results.

Many patients indicated that the ability to send their providers questions and have a remote conversation would be very helpful and would address the challenge of trying to get in touch with their doctors.

Providers saw the value of CMx in better managing patient care between visits and in addressing some of the gaps in care coordination. One provider characterized the *Future Story* as utopian but then went on to focus on the barriers to realizing the vision. A hospital specialist and an orthopedic surgeon both saw the value in creating a more seamless presurgical experience.

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.

1.1.8 Theme 8: Barriers to CMx Technology Adoption

This theme captures participant comments related to their perceived barriers to CMx technology adoption. This theme is related to *Theme 12: CMx Implementation Considerations and Recommendations* but has been made distinct for its significance and comment frequency.

Patients regularly discussed the lower levels of technology access and use in rural communities and for elderly populations. Patients and providers both mentioned that many geographic regions still do not have Internet access and certainly not broadband access and that ubiquitous broadband access would be important for CMx adoption. Many patients stressed that they were not comfortable with technology—some said they are not likely to use it; they also commented that their children are more comfortable with technology and could perhaps help.

Both patients and providers asked who would pay for the technology patients would be using.

Providers' most common reaction to the *Future Story* was to ask who will pay for the added time and costs providers incur to support the use of CMx and the impacts on their practice. Providers regularly noted that the future vision would take much longer than 2 years to achieve.

Patients and providers discussed health literacy and technology literacy as likely barriers to the adoption and use of CMx. Several discussions emphasized the importance of information being provided in a manner that patients could understand if it was going to help them better manage their care and health. Providers reemphasized that patient engagement in their care and their use of CMx is highly dependent on the patient's motivation. Many patients are perceived by their providers as unwilling to engage.

Some providers acknowledged the value of patients being able to correct and contribute to their medical record but worried about the information accuracy and consistency of patient-generated data.

Providers also noted that some providers are not motivated to coordinate care or support a more patient-centered care model and that without payment and care delivery reform the technology will not make the difference.

1.1.9 Theme 9: Patient Privacy and Security Concerns

This theme captures participant comments associated with concerns related to personal privacy, security, and access associated with their personal health information (PHI) in both electronic and paper form.

Patients and providers raised concerns about how the *Future Story*—with expanded use of technology—would address concerns about privacy and security. Patients regularly identified fear of how the information would be used and related concerns as reasons why some patients would be reluctant to engage. Nevertheless, most patients with chronic illness stated that the need to readily share health information was greater than any fears they had regarding privacy and security. Several patients noted that we really cannot do much about hackers and the lack of privacy in today's world. Some patients raised concerns about how the government would use the information. One participant believed their health information was being sold to device

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

makers because he was inundated with information about hearing aids and Medicare coverage.

Providers indicated the privacy and security requirements for CMx should meet or exceed the levels used for banking and that CMx implementation had to address patient privacy and security concerns.

1.1.10 Theme 10: Payment Reform

This theme captures provider feedback on the need for new compensation models and payment reform that accounts for CMx-related care delivery activities.

Providers are tremendously resistant to adopting any new workflows or patient-engagement requirements without compensation. Providers emphasized the need for significant restructuring of provider workflow and that reimbursement is required to facilitate the adoption of CMx activities. Many providers identified performance-based compensation—including patient-centered medical home and accountable care organization models—as being more supportive of CMx than traditional payment models. In the fee-for-service world, most providers stated there should be a reimbursement code or some other means to charge for the provider's time required to support CMx.

> *I think it really boils down to payment reform. I mean, you can be as idealistic as you want, but if you're going to ask doctors to work even harder, to spend more time in the office doing more things, to make less money, that isn't going to go over very well. Right now, we're basically paid for what we do in the exam room. If we're not seeing someone in the exam room, we're suffering.*

1.1.11 Theme 11: Perceived Impact of CMx to Health Care Operations

This theme captures provider comments on the envisioned impact of CMx on their existing health care operations, including their workflow and medical team personnel. This theme is a companion to *Theme 8: Barriers to CMx Technology Adoption* that was more patient focused.

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), reduce the number of required visits, and to satisfy the availability needs of the patient.

In general, providers responded with notably more apprehension than optimism concerning the impact of CMx adoption within clinical practice. Numerous providers expressed concern that introducing CMx within their work settings would harm existing workflows. Demands on clinic personnel to respond to electronic messaging and the anticipation that patients would grow to expect responses in near real-time were serious concerns. Providers were very concerned about the risk of information overload, which could seriously hamper effective and timely medical decisionmaking.

Providers recognized that not embracing and evaluating the appropriate application of CMx technologies could result in losing the ability to influence how CMx is adopted in one's community. One physician cautioned that strong external forces, such as health plan organizations, could direct the course of CMx without the medical community's input. He related how a large state employee health plan organization implemented numerous CMx capabilities—some more effective than others—in response to the local medical community's inability to respond to the needs of its employee constituents. He underscored that this was a missed opportunity for the medical community to successfully advance CMx for both patients and providers. Other providers emphasized how patients were assembling on their own through social networks to exchange advice and satisfy important health support needs the medical community was not supplying.

Positive impacts of CMx, while communicated less frequently than the negative impacts, were also emphasized among provider participants. They recognized the opportunity for CMx to engage patients and manage their care in between visits. Providers found patient reminders for medications and other health activities—such as check-ups—as valuable benefits of CMx. Other providers emphasized the value of leveraging in-between-visit patient data and making it actionable to inform medical decisionmaking. Providers expressed value in telehealth remote monitoring technologies in the home for their ability to alert caregivers to serious medical conditions and to provide clinicians access to daily patient health trends. It is significant that some participants spoke about CMx without differentiating it from remote monitoring—indicating strong interconnectedness between these two technological concepts.

In hospital settings, providers saw value in the potential for CMx to streamline the presurgery workflow of surgeons. They also envisioned improvements to hospital scheduling, such that rural patient visits could be planned to perform multiple care events on a single day to reduce travel burdens.

1.1.12 Theme 12: CMx Implementation Considerations and Recommendations

This theme captures participant considerations and recommendations communicated about any envisioned future CMx implementation and related training and technical assistance. Patients and providers alike were vocal in sharing numerous opinions and recommendations concerning how CMx should be implemented.

Patients stressed that a CMx rollout should be tailored to the user's technology comfort level, cultural background, and demographics. Early adopters were encouraged as candidates for initial rollout participants. In addition to tailoring, patients recommended that

CMx activities include an education focus for the elderly that encourages them to take a more directive role in their care.

Some patients emphasized the importance of having one's medical history available anywhere in the country such that first responders and providers could be aware of a patient's medical background immediately.

Integrating nurse navigator, health *promotores*, community health worker, and liaison roles within a CMx system was emphasized by many patients as highly valuable. Patients recognized doctors have limited time and that other staff in the providers' offices could help patients use CMx.

Patients commented on the potential burden that CMx-related activities could place on their providers. Primary care providers seeing 30 to 40 patients a day were likely to find it difficult to respond to the electronic messages of their patients. This opinion mirrors providers' concern about the negative impacts of CMx on their workflow (see *Theme 11: Perceived Impact of CMx to Health Care Operations* above). This shared concern suggests that efforts be made to minimize the burdens placed on providers through CMx implementation. Patients also expressed concern about their providers' unfamiliarity with technology and recommended they receive CMx training to use it effectively.

Patients emphasized the importance of face-to-face interaction with their providers in the exam room and cautioned that it should not be replaced by CMx. They also strongly advocated for CMx systems that provide assurance that their electronic messages are read by their providers and nurses. Anxiety over increased computerization of care and an anticipated decrease in interaction with patients led some patients to express concern that an increase in elderly and child abuse could occur.

Some patients strongly desired precise control over access to their medical record as a feature of CMx implementations. They stressed the importance of the system being designed so that it allows a user to restrict electronic medical record (EMR) access on a content and individual basis. Patients also expressed a desire to restrict third-party organization access to portions of their medical records, including insurance companies.

Providers stressed the need for a cultural change toward increased provider collaboration and a more holistic approach to care (e.g., medical home model) as preconditions for a large-scale CMx effort. Some providers also envisioned implementations being carefully orchestrated in parallel with compensation and workflow improvements. Providers strongly recommended medication management as a focus area for CMx because medication errors affect the greatest number of patients and providers nationwide. Other providers stressed that primary care should be the primary driver for any widespread CMx endeavor.

IHS providers related a number of implementation lessons and recommendations concerning technological improvements. They recommended establishing forums for mentoring with a few high-performing sites taking the lead, providing strong support (especially hands-on training in the field) to medical teams during rollout, designing implementations with the capacity for tailoring to address unique local needs, and providing ready access to subject matter experts when necessary. They stressed that implementations should be designed to engage and educate the unmotivated patient. Existing IHS training facilities and support staff roles were valued as contributors for a CMx rollout.

Providers stressed that CMx undertakings should embrace employers for their significant and contributing role in advancing their employees' health. Current health care incentive programs offered by employers (e.g., health care premium discounts for completing recommended checkups and screenings) could be leveraged to introduce employees to CMx technology.

1.1.13 Theme 13: Leveraging Nontraditional Providers and Caregivers to Support CMx

This theme captures participant comments on significant care coordination roles individuals filled in a traditional or nontraditional health care setting. This feedback includes considerations and recommendations for roles in envisioned future CMx implementations.

Several patients identified the value of distinct staffing roles in helping them better understand their health and care needs as previously mentioned under *Theme 2: Care Coordination and Health Care System Engagement Challenges*. Patients suggested these roles should be leveraged as part of CMx training and technical assistance (TA). Health *promotores* and patient navigators, who were sometimes nonclinicians, were two such positions patients and providers saw as potentially playing a role in CMx education and in providing assistance in using CMx.

Providers who had support from staffing resources like *promotores* and care managers often indicated the staff plays an important role in patient engagement and education. Some providers recognized potential roles in CMx environments such as health coaches or community health workers assisting patients with using CMx.

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

This theme captures positive and negative comments by participants regarding telehealth remote monitoring technology in the home.

Many patients saw value in remote monitoring technologies to help them better manage their chronic illnesses. An adult caregiver of his aging parents saw great value in being able to know his parents' important health metrics like blood glucose or blood pressure. Some patients were mixed about the value, and some elderly patients saw the technology as a burden. Although not as prevalent a discussion among providers, one provider saw it as an effective means to track a patient's health status and as a potential incentive to encourage patients to be more engaged. The IHS provider discussion underscored the value of both remote monitoring and telehealth (videoconferencing)—particularly extremely remote locations such as many parts of Alaska.

Adult Child or Parent/Sibling Caregiver

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

1.2 Individual Interviews

The following discussion is a synthesis of the eight patient and provider individual discussions that occurred following roundtable discussions. Findings are grouped and discussed along patient and provider discussant groupings, beginning with an overview of participant backgrounds and followed by perceived benefits of CMx, barriers to care coordination and CMx, and positive and negative lessons learned.

1.2.1 Patient Interview Findings

Patient Backgrounds

Individual discussions with patients indicated they represented many diverse backgrounds and consisted of the following: a health information technology-savvy patient and patient advocate from rural Wisconsin, a native Spanish-speaking patient of senior age from rural Arizona, a rural Nebraska patient and retired health department professional, and a patient from Montana. All participants were women and are estimated as being in their late forties or older. In total, the participants sought care for the following chronic illnesses: arthritis, chronic urinary tract infection, diabetes, heart disease, high blood pressure, high cholesterol, neuropathy, sleep apnea, Sjögren's Syndrome, and traumatic brain injury (TBI). Participants who related the number of providers involved in their care indicated as few as three and as many as five. Two participants were family caregivers: One cared for her aging parents until their passing. Another supports her chronically ill sister in her home. Information technology familiarity among the participants was wide ranging, from no familiarity whatsoever to the use of complex information technology systems in a professional setting. Only one of the participants possessed personal experience with CMx technology, but she was discussing her perspective as a caregiver and patient advocate for patients in Wisconsin who did not have CMx experience.

Benefits of CMx

Patient participants expressed a significant number of perceived benefits associated with CMx. It was perceived as a potential mechanism to fill gaps in a much-needed health care support infrastructure. The Wisconsin patient advocate felt that CMx could help patients and providers identify and capitalize on key health care and support resources available in their local rural communities. An example of a perceived benefit was CMx's ability to help a provider connect a patient to local social workers and informal social support networks.

The Montana participant placed great value in CMx as a means to help patients identify and correct errors in their medical records. She related a personal near-miss with an incorrect medical diagnosis to emphasize her point:

> *The results of a bone density test were used to diagnose me with a serious illness and to prescribe me a significant, long-term medication. I requested a copy of the test results and they were illegible! Even another medical professional couldn't interpret the results! I was shocked at how a provider could have written a prescription based on an illegible test. CMx could have helped me to find and correct this error before a serious medication was prescribed to me.*

One participant valued the seamless nature of EMR systems used at the ER and the pharmacy. Simply by providing her name, her medical records and latest prescriptions could be readily accessed.

Multiple participants placed value in CMx to empower adult children to act as proxies for their adult patients. A recurring point of emphasis was CMx's ability to make a patient's medical records available to relatives and caregivers to support effective information sharing and medical decisionmaking. This benefit resonates with many related instances of adult children acting as caregivers of their parents (or siblings) in rural settings.

Patient – Cancer

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

Other CMx benefits expressed by participants included the following:

- a means to address the challenges of distance and the delays associated with rural care and information sharing
- the ability to access one's medical records electronically and to explore their medical information to the desired level of detail (e.g., big picture vs. high detail)
- the ability to help patients communicate and share information more effectively with caregivers involved in their care
- a way to empower patients to communicate their needs to their providers

Participants thought the following target patient populations would benefit most from CMx: cancer patients, Baby Boomers and their children, patients requiring swift medical care, incapacitated patients (where family members and caregivers could act on their behalf), patients requiring the support of family caregivers, patients undergoing surgery, the chronically ill, developmentally disable patients living in group homes, patients released from state mental health institutions, and patients released from prison (and their family members). The Arizona participant thought U.S.-born, native English speakers possessing computer/Internet literacy would benefit most from CMx. This point is discussed in further detail in the *Barriers to CMx* section of the Final Report.

Barriers to Care Coordination and CMx

Rural care coordination issues are tightly interconnected with CMx barriers. The biggest barriers to effective rural care coordination expressed by patient participants were the following:

- a lack of Internet access (connectivity)
- access to care/availability of providers particularly specialists
- significant time and resources required to travel long distances to attain care from multiple providers at different locations
- a lack of information sharing among a patient's providers; organizational bottlenecks in the flow of information
- a lack of health literacy
- patient education level in general
- the need for medical interpretation and advice
- the language barrier (for non-native English speakers)

The following paraphrased story emphasizes a participant's distance and time challenges with respect to rural care coordination:

> *While supporting the care of my sister for a life-threatening chronic illness, we had to travel to specialists at a hospital 100 miles away. It took an entire month for her to be initially seen. When they wanted to have tests performed 'as soon as possible,' it was another two-and-a-half weeks before they were taken. This waiting time is hard on patients and their families.*

These rural care coordination challenges are further exacerbated by one interviewee's emphasis on the general lack of urgency associated with care and difficulty with doctors effectively listening to their patients. This laidback nature requires patients to be very serious about their care visits.

The biggest barriers to patient use of CMx were the following:

- a lack of Internet access (connectivity)
- a lack of access to a computer or other electronic CMx device (affordability of the technology)
- the cost of the computer and Internet access
- learning how to use CMx technology/training
- concerns over the privacy and protection of one's EMR information

A recurring perceptual barrier expressed by participants was that rural CMx user candidates think that they cannot successfully participate in CMx—that it was not meant for them. This perception was observed most notably in two individual interviews. The Montana discussant reflected on the low attendance at the recent patient roundtable discussion held in her town—despite local advertisement and outreach for the event. She emphasized the challenge associated with getting local residents to participate in such opportunities:

> *It's going to be a real challenge to access the people that you need to in this area. When you undertake outreach and send out advertisements they might think, "Oh, I'm not smart enough to even know what they're talking about" or "I don't know if it would be of benefit to us."*

The Arizona discussant said she would likely not be one to benefit most from CMx—a native Spanish speaker without any computer familiarity. Instead, she pointed to U.S.-born, native English speakers who were technology literate as those most likely to benefit.

Multiple interviewees raised concern about the privacy and security of PHI associated with a CMx implementation. Participants expect that patient information must be carefully protected. When asked to clarify the trade-off of CMx use versus the potential risk to one's personal privacy and security, one participant recognized that CMx consumers would likely embrace it despite the risk to personal privacy. She agreed that she would feel more comfortable knowing that the highest standards of security were used, which met or exceeded those of the banking industry.

The biggest CMx provider barriers to CMx adoption identified by patient participants were current workload and provider reluctance to participate in CMx (and EMR systems in general). One participant related her providers' frustration about the demands associated with existing EMR systems. She indicated that one specialist was intentionally "dragging his feet," keeping his paper medical record system and would likely retire before adopting an EMR system.

Positive and Negative Lessons Learned

Patient participants indicated some positive lessons related to, but not necessarily directly involved with, CMx. The Wisconsin patient advocate related a number of grassroots initiatives that capitalized on local community resources and emphasized the importance of bridging existing programs for an overall improvement in health outcomes. She emphasized how an interfaith caregivers alliance enabled local care advocates to be better supported with integrated resources and helped them organize local rural patient support groups. The Nebraska participant related the success of tools made available to department of health Prevention Coordinators for the *Tobacco Free Nebraska* program and emphasized that CMx resources could be modeled after this program. The Arizona participant emphasized how her exposure to CMx concepts during the roundtable discussion that she attended improved her awareness and understanding of provider use of EMRs in the exam room.

A number of negative lessons potentially related to CMx were also expressed by the patient participants. The Wisconsin patient advocate related how the *Wounded Warrior Caregiver Project* experienced challenges in adequately engaging social workers and other trusted communication channels, or go-betweens, to engage family caregivers. She also emphasized that many innovative health improvement programs remain isolated and unable to connect to, and benefit from, other existing initiatives. The Nebraska discussant stressed how constant changes to Medicare and Social Security have left the public generally concerned about any new change related to health care (e.g., a CMx policy or rollout). The Montana participant emphasized that significant distances and time delays continue to hinder rural care and the coordination of serious chronic illness. The current failure of information to flow across care organizations may pose significant challenges to information flow in a future CMx implementation.

1.2.2 Provider Interview Findings

Provider Backgrounds

Provider interviewees represented many diverse clinical backgrounds and consisted of the following: a male health information technology-savvy primary care provider and CMx proponent from western Missouri who practices within a large health care organization spanning 22 counties in western Missouri and eastern Kansas, a female oncologist and internist with a suburban private practice in eastern Missouri, a male social worker who leads a team of health *promotores* (promoters) in a border health clinic on the Arizona/Mexico boundary, and a female registered nurse and privately practicing home health aide serving the "old olds" of western Montana. Three participants were

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 performing a home visit. Help me to overcome the challenges for missing, fragmented or inconsistent medical record documentation available to me.

seasoned health care professionals with many years of experience and likely 50 years of age or older. One participant was likely within the first 10 years of his profession and less than 40 years of age.

Health characteristics of patients commonly served by the participants included the following: Alzheimer’s, cancer, chronically ill, chronic obstructive and pulmonary disease (COPD), diabetes, homebound, lacking in self-management skills, obesity, physically/mentally disabled, and rheumatoid arthritis.

CMx familiarity among the participants was wide ranging, from using no CMx capability whatsoever to the use of dedicated patient-centered CMx capabilities as a part of daily practice. Three participant organizations received meaningful use Stage 1 incentives and will apply (or have already applied) for meaningful use Stage 2 incentives by April 2014. Three providers used EHR systems that offered a patient portal or other CMx-related capability to their patients.

Benefits of CMx

Provider participants highlighted a number of benefits associated with CMx. One provider, who uses CMx in his practice, saw the greatest value in coordinating patient care between visits. He also felt that involving patients with complex care needs in CMx increases the accuracy of medical records. He indicated a huge increase in the accuracy of records when his patients participated in CMx and actively corrected their records. Another provider saw a patient’s ready electronic access to their medical records as a significant benefit. Another remarked that the greatest value of CMx is a patient’s ability to simply know her medications.

Two providers indicated that their clinic workflows had become more efficient. They noted that patient phone calls (e.g., related to lab work) had gone down when they began using CMx. One provider remarked that patients value secure communications with their providers over any other portal function.

One participant envisioned that a CMx solution supported by a) labs taken in the home and b) telehealth remote monitoring technology in the home may reduce the number of weekly clinic visits required for a patient.

Provider – Cancer Specialist

- Help me to empower my patients to take more control over their care.
- Help me to support patients and families when 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.
- Since no single provider is in charge in cancer treatment, help all of us to collaborate and remain on the same page for our patient. Empower us with the ability to collaboratively perform care plan reconciliation among multiple providers.
- 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.

The Arizona provider stressed the importance of CMx to provide patients the ability to "connect the dots" between their behaviors and their health through visual display of their health trends. Through the use of a *Health Diary* CMx capability, a health *promotore* could help patients make important behavioral health connections:

> *So say 3 months ago you weren't doing any exercise. With the intervention … with the health education we provided you with, with your own effort to exercise more, your new lab work came in and this is what it's showing now. So we try to connect the dots. Everybody knows that exercise is healthy for you, but unless you personalize it [to] an individual and you show it to them in such a way that they can visualize that the effort that they were doing 3 months ago is now producing fruit … is now giving them a positive outcome … that's the whole concept of this system.*

The Montana provider saw the greatest benefit in a home health aide's ability to view and contribute to a patient's primary care medical record and to send electronic updates to the patient's provider to communicate medical updates warranting immediate attention. Ready access to a homebound patient's records may assist home health aides to reduce their chances of being surprised during a home visit (i.e., due to fragmented, missing, or inconsistent medical record documentation provided).

Providers thought the following target patient populations would benefit most from CMx: 60- 70-year-old joint replacement (possibly 50- to 60-year-olds as well) patients; transplant patients; COPD patients; post-stroke patients; mentally ill patients; physically disabled patients; head-injured patients; patients on chronic coagulation medication who require monitoring; long-term breast cancer patients; those transferring home for home health care; those on multiple medications who have multiple comorbidities and see multiple doctors; those with long-term chronic illness (e.g., diabetes and hypertension); and the "younger, computer-savvy population." One provider thought all patients would benefit from CMx. Another thought the following circumstances would be most helpful for chronically ill rural patients to electronically share their health information: situations in which patients migrate, hospital visits or any other changes in care settings, a change of primary care provider, when seeking second opinions, when discussing medical decisions with loved ones, and when loved ones or caregivers make decisions for patients.

Barriers to Care Coordination and CMx

The biggest barriers to effective rural care coordination expressed by provider participants were the following:

- logistical challenges associated with care—travel, access to care, and priorities in daily living (e.g., making trade-offs between farm responsibilities and medical care)
- a lack of communication and EHR system interoperability among care settings and providers

- language barriers between patients and their providers
- a lack of patient familiarity with computer technology
- health care not being patient centered
- a lack of patient engagement in their care
- a lack of continuity of care

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 participants listed the following as the biggest barriers to rural patient use of CMx:

- a lack of Internet access (connectivity and affordability)
- a lack of access to a computer or other electronic CMx device (affordability of the technology)
- a lack of information technology familiarity and training
- a lack of responsibility or incentive to engage in their own care
- concerns over the safety, protection, redundancy, and security associated with a patient's EMR information
- work schedule and high worker mobility (e.g., migrant worker or frequent traveler)

The biggest barriers to provider use of CMx were related as the following:

- a lack of EHR system interoperability and information sharing among providers and their health care organizations (Reconciling records across systems is very time consuming and costly.)
- an overzealous interpretation of HIPAA regulations, which limits information sharing
- health care organization policies and procedures that limit patient and caregiver access to information
- physicians not accepting a culture of shared collaborative care
- unwillingness on the part of providers/specialists to promote CMx technology
- concern over the lack of useful information provided electronically by patients concerning their health (i.e., garbage in/garbage out) and clinician concerns that patients are put in a position of thinking they are the doctor
- the high cost of CMx systems and the lack of funding to support such technology
- CMx training demands for medical personnel
- a lack of payer incentives or mandates to require CMx use or provider-specialist communication norms (e.g., returning a patient to primary care provider with notes)

One provider emphasized that clinician motivation to improve communication among providers and specialists was influenced by the lack of incentives or legislative mandates:

> *There's just no incentive for specialists to share information with referring providers. You treat someone, you get paid the same amount whether or not you provide the patient's primary care provider a report or not. So what incentive is there for that specialist to exchange information?*

Providers emphasized that CMx adoption barriers are reasonably clear and center around the following core issues: rural care coordination challenges, a lack of computer/Internet access and the means to afford it, a lack of interoperability and information sharing, patient-provider communication barriers, a lack of appropriate skill and education, and a lack of motivation on the part of patients and providers.

Positive and Negative Lessons Learned

Providers indicated a number of positive lessons related to CMx. The Arizona provider emphasized the success of embedding social workers' and health *promotores'* roles within a clinic's daily operations. The border clinic's *Health Diary* CMx tool is successfully used as a discussion aid by *promotores* to help patients make connections between their behaviors and their health. Health *promotores* play an important intermediary role—conveying important health-related information between patient and provider and helping patients make sense of their medical records. Integrating health *promotore* support with a social worker offered the benefit of advanced services to patients. The participant also indicated that the *Health-E Arizona* program may possess existing CMx training materials that may be leveraged. The Missouri primary care provider emphasized the importance of large touch-screen monitors in the clinic exam room. The monitors served as a discussion aid to help patients update their medical information and engage more effectively with their providers. He also stressed that the biggest driver of patient adoption of PHR use is from their providers' encouragement to use the service. He also strongly believed that CMx electronic messaging with patients was less time-consuming than phone calls. The Missouri oncologist emphasized that her EHR permits her to get more done in a patient visit.

Some negative lessons were also related by providers. The Missouri primary care provider emphasized that problem lists and diagnoses documented in patient medical records are practically useless. He estimated that 40% of clinician data are tenuous at best because the data are driven by billing rather than patient accuracy. The Missouri oncologist struggled with getting her patients to sign up for her practice's patient portal within the required 48-hour sign-up time window. She also expressed a need for more patient education and a need to teach her patients how to use a patient portal effectively. She found it difficult to get providers more broadly involved with CMx-related efforts.

Positive lessons highlighted efficiencies in care through EHR use, the value of incorporating social worker and health *promotores* roles within traditional clinic operations, and ability to leverage discussion aids (in the form of CMx interfaces and patient exam room monitors) to improve patient-provider communication.

Negative lessons emphasized challenges with the usefulness of EMR documentation, patient use of portals and CMx technologies available to them, and the need for more provider involvement in CMx-related activities.

1.2.3 Vendor Group Discussion

Vendor Solutions Overview

A group interview with PHR vendors representing *Microsoft HealthVault*, *NoMoreClipboard,* and *Humetrix iBlueButton* was undertaken as the result of a discussion held at the cross-team State Health Policy Consortium—PHR Ignite meeting on November 20, 2013.

All of the vendor solutions can support stand-alone CMx and the following information storage and sharing: medications, lab results, visit summaries, immunizations, treatment plans, billing and payment information, health metrics (e.g., weight, blood pressure), and educational materials. Two of the three solutions support secure messaging. All of the vendor representatives were strong advocates for the value of PHRs and consumer-mediated exchange.

Benefits of CMx

Vendor representatives highlighted numerous benefits of CMx. The greatest benefits of CMx identified by the vendor representatives were the following:

For Patients:

- Maintaining detailed and complicated information particularly for complex chronic illness
- Aggregating information across multiple providers and multiple locations, particularly among providers without exchange capabilities
- Managing health information for family and loved ones, including moms acting on behalf of family members and adult children in their fifties and beyond supporting adult children and aging parents and increasingly addressing greater personal health needs
- Introducing CMx at certain health and health care milestones, when perhaps individuals are most ready (e.g., life events such as a newborn or recent severe diagnoses such as cancer, Medicaid/Medicare enrollment)
- Being prepared for doctor visits and emergencies
- Tracking and sharing health metrics
- Providing secure messaging between patients and their providers and caregivers
- Helping connect the dots between Blue Button and other forms of trusted exchange and the gaps among providers who cannot exchange, or are not exchanging, patient information

- "Comprehensive claim data (such as Medicare Blue Button data) used by mobile PHRs … provide[s] for extremely useful medical history [information] available anytime and anywhere"

For Providers:

- Increasing information exchange among providers (one participant offered that only one in three Medicare providers can exchange information with other Medicare providers)
- Improving patient satisfaction
- Meeting meaningful use patient engagement criteria
- Sharing information with patients
- Collaborating with patients

Provider – Serving Border and Snowbird Patients

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

Barriers to Care Coordination and CMx

Vendor representatives highlighted the following most significant barriers to care coordination and CMx:

- Uncommitted or disengaged providers
- Traditional culture of medical practice, workflows, and provider attitudes that encourage provider passivity and failure to support patients
- The belief that rural patients do not use or will not buy the technology (providers often stereotype their patients)—one participant noted this was very narrow minded and biased
- Organizations that do not have a focused purpose or clear vision for use of the information CMx makes available to patients—general data availability is not enough
- Insufficient education, training, and time devoted to how the solution is initially piloted (to include sufficient time allocated for trial and error)
- Providers understanding of CMx and being willing to "do their part" to help share information with patients and encourage patient use
- The lack of Direct server PHR/Blue Button trust bundle provisioning[1] among Meaningful Use 2 (MU2)-certified EHR systems
- Lack of provider organization understanding that "enabling EMR-to-PHR exchange using Direct with Blue Button+ apps is allowed under HIPAA and is an efficient way to meet MU2 requirements for patient engagement and e-health record access."

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[1] For more information on trust bundle provisioning, please visit the following URL: http://www.directtrust.org.

Positive and Negative Lessons Learned

A number of positive CMx lessons were highlighted by the vendor participants. They include an American Heart Association (AHA) hypertension program, the importance of engaging large patient advocacy groups, and the prescribing of CMx to patients by their providers.

In 2008, the AHA launched a multiyear program deliberately to address hypertension management. At first, the initiative started with a small number of closely held programs and then grew to a wide-spanning program that focused on training health care workers. AHA ultimately developed a tool-based program that could be tailored to different African American religious communities using volunteers and community members to undertake hypertension management, training, and routing to health care professionals. This program was lauded as very successful and led by highly enthusiastic volunteers.

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).

Engaging with large patient advocacy groups was highlighted as valuable to change provider perspectives, especially because of their trusted leadership role among patients and providers. Vendors encouraged the Office of the National Coordinator (ONC) to leverage the support of the 115 consumer groups that collaborated with the *National Partnership for Women and Families* on MU2 comments and patient engagement. One vendor recommended engaging the Consumer Partnership for eHealth (a coalition of 150+ patient organizations and consumer groups).

One vendor noted repeated successes with organizations in which providers are in essence willing to *prescribe* the use of CMx. The provider support and endorsement of CMx, coupled with a resource that helps patients set up and get comfortable with this new technology, can be the difference between 5% and 40% adoption.

Unsuccessful CMx projects were indicated as those that do not have a specific consumer use case or where the value is not well marketed to consumers or encouraged among providers (e.g., grants that demonstrate successful data exchange, but nothing more).

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2. KEY TAKEAWAYS

2.1 Patient and Provider Attitudes and Opinions

The roundtable discussions were highly engaging and permitted the documentation of insightful, first-hand attitudes and opinions from patients and providers representing many diverse rural care settings that led to identifying the 14 primary themes listed in Table 1-1.

Patient participants envisioned a number of ways in which CMx could improve their care. Patient participants largely expressed optimism in the prospect of CMx technology to improve the management of their chronic conditions in rural settings. Some of the most frequently envisioned benefits were improving care coordination among multiple providers; eliminating redundant paperwork and tests; reducing travel associated with more efficient care; catching and correcting errors in their medical records; and improving communication with one's provider during clinic visits, focusing on the things that matter most in their care. This optimism was offset, however, by reasonable concern over a number of factors associated with CMx adoption. Patient participants reiterated the concern heard from provider participants that many rural patients simply could not afford the required technology and broadband access—or were otherwise inadequately familiar with technology—to reap its greatest benefit. They also raised issues with care coordination, challenges associated with distance in rural settings, and redundant paperwork and tests as major concerns in today's care delivery environments. Careful consideration of how to bridge technology gaps and discomfort will be important for CMx.

In contrast, providers tended to emphasize the challenges to CMx. They clearly communicated their concern over a lack of interoperability among EHR systems. Increased interoperability was frequently cited as an essential prerequisite for improved care coordination and effective CMx adoption. Participating providers also emphasized payment reform and the need for performance-based compensation. Providers voiced significant concern that the costs associated with electronic equipment and Internet access would prevent many rural patients from effectively participating in any future CMx endeavor. Significant concern over impacts to existing workflow, a lack of compensation of CMx-related activities, the likelihood of increased patient-provider communication expectations, and a risk of information overload left many providers unconvinced of the likelihood of near-term CMx adoption or its overall benefit to health care. It is significant that provider feedback concerning care coordination issues, interoperability challenges, and concern over possible negatives aspects of CMx largely overshadowed the relatively sparse number of positive comments concerning the potential for CMx. The leap from modern-day health care to a setting supported by CMx was perceived by some participants as so significant that a cultural change within medicine was required. Because of this general expression of resistance on the part of many provider participants concerning CMx adoption, more effort will likely have to be focused on provider engagement in any envisioned CMx undertaking.

Concerning patient-provider communication, both patient and provider participants expressed the need to improve communication surrounding one's care, though patients placed greater emphasis on this than providers. Providers emphasized the need for increased patient health literacy to improve the effectiveness of interactions with their patients. Incorporating improvements to patient-provider communication and interaction is recommended as a core area of emphasis for CMx.

Patients and providers expressed significant concern about the state of privacy and security related to EHR systems. Any future CMx implementation should address this concern through the implementation of carefully developed technology and policy strategies.

Despite these concerns, the patient participants' ready optimism to grasp the concepts of CMx and their capacity to envision improvements to modern-day health care, that they might experience for themselves and for those they care for, warrants further investigation into the appropriate application of CMx capabilities for the advancement of the U.S. health care system.

2.2 Individual Interviews

The input from patient and provider individual discussants was reviewed for key takeaways. The review identified any new themes that emerged distinct from the group discussions. The individual interviews were uniquely suited to ask specific questions and follow up for clarity on participant responses. The analysis concentrated on aggregating and synthesizing the specific input individuals provided on how to advance CMx with respect to TA and training.

2.2.1 Patients

Patient interviewees related numerous recommendations for the successful implementation of CMx. Recommendations primarily surrounded the following themes: outreach and awareness, training, patient privacy and security concerns, and the capitalization and integration of existing resources and programs.

Outreach and Awareness:

- Start with a trusted source/leader in the community who knows how to engage patients and families. Engage well-liked medical leaders in the local community to be proponents for CMx. Work with local social service and health leaders, such as social workers, people already working to address gaps in rural services.
- Start with early adopters of patient engagement such as patient-centered medical homes or primary care practitioners.
- Outreach should be personal, performed face to face, and communicated clearly.
- Local CMx outreach efforts should start with the patients. Reach people personally in small groups.
- When engaging providers, do so personally and according to their availability.

- Specifically target the senior, Spanish speaking, chronically ill, low technology familiarity population in any future CMx undertaking. Help potential participants overcome their perceptual biases and realize that they can successfully participate *before disqualifying themselves.*
- Make Medicare and Social Security beneficiaries, especially the elderly chronically ill, aware of health policy and regulatory changes and how they directly affect them.

Training:

- Deliver education to patients and providers through trusted channels of communication—existing support groups, local media, newspapers, and radio stations.
- Consider the health *promotores*[2] as facilitators of CMx training.
- CMx training should be specifically tailored to the age, language, technology familiarity, availability, and memory/attention needs of the attendees. Trainers should be professional, patient, and willing to repeat training when needed.
- Provide an appropriate role model for trainees to emulate.
- Provide mentors who are available to answer any ongoing CMx-related questions.
- Provide the CMx media/equipment and training for economically challenged areas.
- The training needs to help patients know what to do with the information.
- Provide training to help providers with their need for paper medical records.
- Aid the patient and provider in determining what would be helpful and appropriate to be shared electronically.

Patient Privacy and Security Concerns:

- Address patient privacy and security concerns related to EMRs. Design CMx with security and redundancy/disaster recovery best practices in mind.

Capitalization and Integration of Existing Programs:

- Support and enhance the critical components of working rural social infrastructure models.
- Better integrate existing resources (e.g., siloed federal, state, and local social/health services programs) while addressing gaps in infrastructure and funding. Build out the existing community and rural infrastructure.

The following community organizations and resources were recommended for outreach by patient discussants: libraries, organizations catered to seniors, churches, behavioral health and mental health service organizations, local health department, local hospital, Chamber of

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[2] A health *promotore* (Spanish for health "promoter") is the local term used by an Arizona border clinic for a family care coordinator role.

Commerce, retirement centers, Veteran Affairs Administration satellite offices, retiree service groups, local radio stations, and local newspapers.

Participants did not specify any particular criteria for selecting communities for CMx outreach. In general, participants emphasized embracing communities that were simply motivated and willing to participate.

2.2.2 Providers

Providers who participated in the individual discussions offered a number of recommendations for the successful implementation of CMx. Recommendations primarily surrounded the following themes: initial implementation steps, outreach, CMx funding and payment reform, training, provider-patient communication, EHR interoperability, and patient privacy and security.

For the first steps of CMx implementation, one should start with a thorough review of policies and procedures within the provider organization and make sure everyone is on board. A critical mass of champions must be developed in an organization to promote provider utilization of CMx. Providers need to be educated to help them understand that CMx will mean less work for them. Lastly, the entire medical care-giving team needs to be involved. Medical teammates beyond the clinic’s doors should be supported in a CMx system. Rural home health aides can contribute positively to CMx activities, providing important updates to providers on their homebound patients.

Provider discussants made numerous outreach recommendations. Significant emphasis was placed on reaching individuals at the local level and engaging them one-on-one. Employers and health system payers were also considered vital participants in a CMx endeavor. Multiple participants recommended starting CMx education and awareness with children, making the concept familiar and integrating it within community social activities. One participant stressed the importance of planning for the long term, engaging nursing and medical schools. Few criteria were recommended related to community characteristics recommended for effective CMx engagement. One participant emphasized the importance of engaging a community with an educated population. Town institutions such as active town halls, churches, and schools were other recommended institutions for engagement. It was stressed that communities lacking these institutions and services could still be engaged, but it would likely take longer for outreach to be successful.

Funding to implement CMx and provider compensation reform were significant topics highlighted during individual interviews. Participants felt the CMx approach to care and records would not be sustainable unless more payment models covered the costs associated with CMx or paid similarly to accountable care organizations. Providers need to be incentivized to participate in CMx by either getting rid of fee-for-service compensation or including payment for virtual visits to providers through current reimbursement models. Payers were encouraged to mandate the use of CMx through incentives and policy reform. The Arizona provider stressed that funding should be made available for CMx roles, such as the health *promotores*, to provide dedicated training and support to patients to help them make sense of medical information:

> *It's not enough to just provide information. You have to help individuals make sense of it and that's the key role of what a promotore does. That's what we do. We help people make sense of their medical information here within the clinic and that's such a big thing that needs to happen. You need to be able to not just provide information but help people understand it and a lot of that happens through lay health professionals because people feel more comfortable with them and when you're more comfortable you tend to learn a little bit better.*

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.

Providers stressed that CMx training was extremely important for effective implementation. They were mixed on whether the focus of training should be placed on patients or providers, but all participants agreed that they both needed adequate training. Those who stressed provider training emphasized the need for providers to effectively engage their patients with CMx technology, that it should complement, not dominate, a clinic visit. Providers should also be given the opportunity to participate in hands-on training so they can see the benefits of CMx firsthand. Those who emphasized patient training stressed the need to teach them how to use a patient portal, to teach electronic communication norms (e.g., what health-related information is or is not useful to provide electronically to one's provider), and to improve patients' overall patient health literacy. Most felt patient training should be undertaken in the provider's office and that a nurse practitioner or an RN assistant could offer this training. One provider stressed that patient training should focus on using the computer, comprehending medical language, and understanding lab results. Prescribing CMx training in a modular format was recommended. When implementing training in a provider organization, one provider encouraged using a train-the-trainer approach. In such a format, a few assigned personnel could receive formal training and then return to their work environments and train teams to implement training across an organization.

Provider participants recommended the following community organizations and activities to help patients learn about and use CMx: senior centers; the local *Meals on Wheels* program; local colleges; libraries; community health centers; public health organizations; schools and school districts; high school sports venues; retired teacher service organizations; any nonprofit, community-based organizations; the business community; community health fairs; U.S. Post Office and other government offices; and employers.

Effective patient-provider communication was recognized as a key component of CMx training and implementation. Patients should be engaged in a dialogue to help them understand the context of the information they are receiving and how to use it effectively in their medical care. Patient engagement also needs to acknowledge and support the cultural values of rural and frontier patients (e.g., the fierce independence noted by the Montana provider of rural and frontier Montanans).

Numerous provider discussants stressed the importance of EMR system interoperability among rural providers, specialists, and health care organizations. Many perceived it as a prerequisite for successful CMx implementation. Legislation was recommended as a means to require EHR/CMx systems to interoperate with one another. Payers were also highlighted as having an important role, where mandating information sharing could set the stage for an effective CMx implementation.

Patient PHR privacy and security were emphasized by most participants as being essential for an effective CMx implementation. Privacy and security measures consistent with the highest industry standards used and cross-industry best practices (e.g., banking) should be leveraged.

2.3 Vendor Group Discussion

We reviewed feedback from PHR vendor group discussion participants for key takeaways. The discussion brings a new perspective to the project distinct from patient and provider individual discussions.

All three PHR solutions can be used as stand-alone applications that could serve as CMx platforms and are being used for this purpose in today’s market. The vendor or solution role is, by its very nature, focused on successful implementation; thus, much of the vendor input concentrated on implementation.

CMx Vendor

- Consumer-mediated health information exchange 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 is exchangeable irrespective of platform. Interoperability will likely not occur without a government or payer mandate.

Vendor participants agreed that the biggest factors in successful implementation are having the lead organization committed to the implementation and ensuring the providers are well educated on the value of CMx and well trained on how to encourage and educate their patients.

All vendor representatives agreed that it is equally important to have a specific health outcome and value proposition for the initial use of CMx and to undertake a pilot that demonstrates the benefit before rolling out the technology in a less targeted way. Case studies were noted as valuable but only helpful to a point. Vendors emphasized that provider and patient participants need to see and trust that it works.

Each vendor representative identified characteristics that were most likely to yield successful CMx implementations. All agreed that patients with complex care needs are one of the most important characteristics. Additional characteristics discussed mirrored the CMx benefits and included (or highlighted) the following:

- organizations managing multiple providers and many locations
- ability to engage patients or their caregiver when they have been recently diagnosed (e.g., cancer)
- certain chronic illnesses—diabetes, renal failure, advanced heart or liver failure
- moms managing family health needs and adult children helping aging parents
- adults in their fifties who are helping their adult children manage and navigate health care and who are helping their aging parents manage complex care needs
- patients who are encouraged by their doctors to use CMx services
- patients being able to share health metrics or values with a health coach and knowing they will be notified or called if there are concerns (this capability was highlighted for rural patients)
- ability to enable mobile technology, specifically cell phones
- internally funded projects usually indicate organizational buy-in
- organizations seeking to manage patient populations on a larger scale that recognize the value of tools that help patients manage their care
- thoughtful focus and design of the pilot implementation so everyone can see the technology work (i.e., firsthand observation in a real-world care setting)
- provider organizations willing to assign someone to train the patient, help them use it, and gain familiarity with the technology

One of the vendor representatives mentioned the following most notable differences and opportunities regarding rural implementation of CMx:

- It is important to enable mobile devices to help overcome care challenges due to distance.
- Implementation should focus on using technology for a specific illness (e.g., diabetes).
- Rural doctors are more likely to say their patients are not going to use the technology.
- Participants in rural areas are a bit more willing to experiment than those in other nonrural areas.
- Critical access hospitals (CAHs) that qualify for MU2 incentives are a good lead organization for CMx. CAHs often have two EHRs (inpatient and outpatient), and they do not want to impose two incompatible patient portals on their patients.
- On average, rural provider and patient populations are less tech-savvy and require more training.
- Once trained, rural patients often become the most enthusiastic users.
- Marrying CMx and telemedicine may have an even greater impact in rural communities.
- The potential role of EMT and EMS providers and the need for access to health information during an emergency or regional disaster should be considered.

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.

All vendors agreed that leadership is an important ingredient in successful implementation. Local leaders can help promote CMx and make it successful. The leaders mentioned included political leaders, community patient advocates, religious leaders, public health officials, emergency medical societies, and local and national disease organizations such as the AHA. Vendors emphasized that leaders should be individuals who have embraced patient-centered care and the use of CMx.

Recommendations on training generally mirrored the recommended characteristics of successful implementation. Leadership, both organizational and community based, must support training. Providers need to be on board. Provider education and a clear purpose for the use of CMx should enable success. Vendors indicated that achieving Meaningful Use Stage 2 would reduce the amount of effort required to achieve successful CMx, but Stage 2 is not necessary. One participant noted a CMx platform implemented once for multiple providers would save time and money in comparison to each provider having to stand up and support their own patient portal. The PHR vendor representatives stated that EHR patient portals are often limited in functionality and hard to use. One participant emphasized the importance of informing patients of their right to access their health records in an electronic format (i.e., HIPAA Omnibus rule).

Additional considerations for training highlighted the importance of thoughtful pilot design to show the value of CMx and to address anticipated provider concerns. Organizations and CMx advocates need to anticipate that providers will have many questions and concerns. It is important to stage projects (i.e., take a crawl, walk, run approach). Specifically start by sharing targeted information (e.g., certain lab values) before opening the floodgates. This approach helps allay concerns and gain provider and patient comfort with the technology. Stakeholder and provider education coupled with the piloting and staging of the project will help advance successful CMx adoption. Having an assigned role within the provider organization that aids patients in setting up accounts and serves as a PHR educator was consistently referenced as another key to success.

The role of the Centers for Medicare & Medicaid Services (CMS), the Department of Health and Human Services (HHS), and ONC was emphasized in the vendor discussion. CMS and ONC were seen as important in helping advance the use of CMx by demonstrating how CMx can support interoperability and cost-effective compliance for MU2 patient engagement. Vendors also asked that CMS provide policy guidance and clarification about how CMx use and support fits into existing payment structures and new reform models. One participant stressed that it is a *public health imperative* to not delay CMx with or without the availability of certain technology or infrastructure. The participant supported this perspective by referencing the following statement in a letter from the Consumer Partnership for eHealth to CMS and ONC leadership:

> *"It is incumbent to CMS and HHS to inform patients and their family caregivers and health care providers of the availability of such CMx tools … for them to make practical use of the Medicare Blue Button to enhance patient safety and care coordination."*

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3. COMPARE AND CONTRAST

The commonly shared perspectives across all three stakeholder groups engaged during roundtable and individual discussions—patients, providers, and vendors—are reassuring, although perhaps constrained by the structure of today's care delivery system.

The unanimity around the need for leadership and provider education and buy-in underscores that CMx's success depends on clinicians gaining great comfort with EHRs and CMx. The need to tailor training, CMx design, and implementation to the unique characteristics of the community, organization, and providers and patients acknowledges the local nature of health care delivery and community relationships. Reaching individuals, collectively and individually, requires accommodating the local environment. In general, stakeholder agreed that CMx offers many potential benefits, including unique or added benefits for improved chronic care for rural patients. What the most salient benefits are tends to vary based on the stakeholder's perspective.

Providers and patients distinct from vendors tend to be more consistent about how using CMx might improve interactions between patients and providers (e.g., helping improve communication), although vendors may avoid the topic to reassure both parties they are not interested in disrupting the relationship.

The core differences among the perspectives tend to align with their fundamentally different roles and may be more of a matter of emphasis. Of note:

- 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 offered their perceived challenges to CMx adoption more so than the benefits. They largely remained skeptical of its benefits and expressed a need for evidence of its efficacy. They commonly voiced concerns about CMx implications for 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 felt most patients have no prior experience with the technology to make informed decisions to participate in CMx and providers, for the most part, have very minimal experience with CMx.

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

One provider was a strong advocate for evaluating what will be required for an organization to fully embrace CMx. The unanimous recommendation for provider buy-in also supports an organization's need for understanding what barriers the organization will face in pursuing adoption. These early requirements suggest that some type of *readiness assessment* that examines policies, process, technology, and culture would help determine how best to approach the adoption and whether any fundamental changes are needed prior to adoption. A second provider indicated their 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. This may be due to a sales mentality that would encourage working with any organization able to commit the funding and leadership. The vendor would then help address any anticipated or unanticipated barriers. Nevertheless, vendors were very clear on the need for a targeted pilot that would suggest an early planning step in which barriers are assessed and a priority value proposition for CMx is defined.

The consistent perspective across all stakeholders that CMx design, implementation, and training need to be tailored to the local setting suggests that TA should include advice on and perhaps models for *CMx design alternatives*. The varied needs of providers and provider organizations and the variations in target patient populations suggest that a single design model could also have multiple components depending on the intended use of CMx.

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 advance awareness and build a sufficient level of comfort regarding the potential use of CMx and how electronically shared health information is or is not being used today. All of the patients and providers that had participated in the discussion groups noted how helpful the discussions were in making them aware of what is possible. Patients and providers alike said they had not thought of many of the benefits that were delineated during the conversation, and it helped them realize how some of the biggest challenges in care coordination could be addressed. The Arizona discussant's perception that one cannot successfully participate in CMx warrants significant attention for any considered rollout. *Those who need this capability the most may prematurely disqualify themselves from participating even when CMx technology and support are made available.*

Before participants had been part of the discussion, they often had very limited awareness. Upon first hearing about the CMx concept, they were often negative or skeptical.

As discussed above, all participants had some specific recommendations on what approaches would work best in starting an education and training initiative. The common characteristics of these recommendations involved tailoring the training to the needs of the individuals, designing the training to fit within the constraints of their work and lives, and having hands-on and one-on-one training as needed.