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**Implementing a Community Referral Platform:
Recommendations From a Real-World Implementation
Experience**

Qualitative Findings

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Executive Summary

The conditions in which people are born, live, learn, work, play, worship and age strongly influence health outcomes and quality of life.¹ Research has shown that social risk factors impact health care quality,² cost, use and patient outcomes.³

Organizations are increasingly using community resource referral platforms in their work to address social determinants of health (SDOH) for their populations. These are commonly designed with two primary purposes:

1. Provide an up-to-date resource directory that can be filtered to target different geographic regions, services offered and eligibility criteria, and
2. Track referrals and “close the loop” to know the referral outcome: Did the patient use the service and what was the result?

There are many community resource referral platforms on the market⁴ and the journey to implementation is not straightforward. This catalog of implementation challenges and recommendations is designed to be a guide for organizations following a similar path.

Organizations should consider the lessons learned and recommendations herein when planning to implement a community resource referral platform. Issues fell into 10 categories: HIPAA; Part 2; patient consent; trust/relationships; consistent engagement; data availability; vision/goal alignment; system integration; workflow alignment; and education. A summarized version is available below in Table 1.

Table 1: Summary Table of Lessons Learned and Recommendations

Lesson Learned	Recommendation
1. There were few clear benefits to CBOs for adding new workflows, which affected the rate of uptake.	1.1 Provide access to the platform, workflow consultation, implementation support and ongoing support at no cost to CBOs.
	1.2 Provide funding or other benefits to organizations, such as CBOs, that will likely not receive financial benefit from the platform.
	1.3 Ensure the team works to gain a clear understanding of the CBO's goals and needs.
	1.4 Work with CBOs to identify reasons that will motivate them to participate.
2. CBOs considered the platform supplemental rather than necessary for workflows.	2.1 Consider CBO needs and how the platform can address them; market the platform accordingly.
3. CBOs need to focus limited resources on activities with the greatest value for and highest impact on clients/patients.	3.1 Host co-design sessions to engage CBOs and understand their goals for the platform.
	3.2 Build capacity in CBOs to be able to accept more referrals.
4. Electronic messaging didn't initiate and develop working relationships across organizations.	4.1 Develop new workflows and relationships across organizations prior to technology launch.
	4.2 Drive platform engagement by ensuring that specific use cases cannot be completed in any other way.
	4.3 Ensure CBO leadership conveys to staff the importance of using the system and explains how it will impact work.

¹ Office of Disease Prevention and Health Promotion. (2020). *Healthy People 2020*. Retrieved December 14, 2020, from <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health>

² HHS. (2017). *Report to Congress: Social Risk Factors and Performance under Medicare's Value-Based Purchasing Programs*. United States Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Washington, DC: United States Department of Health and Human Services.

³ NASEM. (2016). *Accounting for social risk factors in Medicare payment: identifying social risk factors*. National Academies of Sciences, Engineering and Medicine (NASEM). Washington, DC: The National Academies Press.

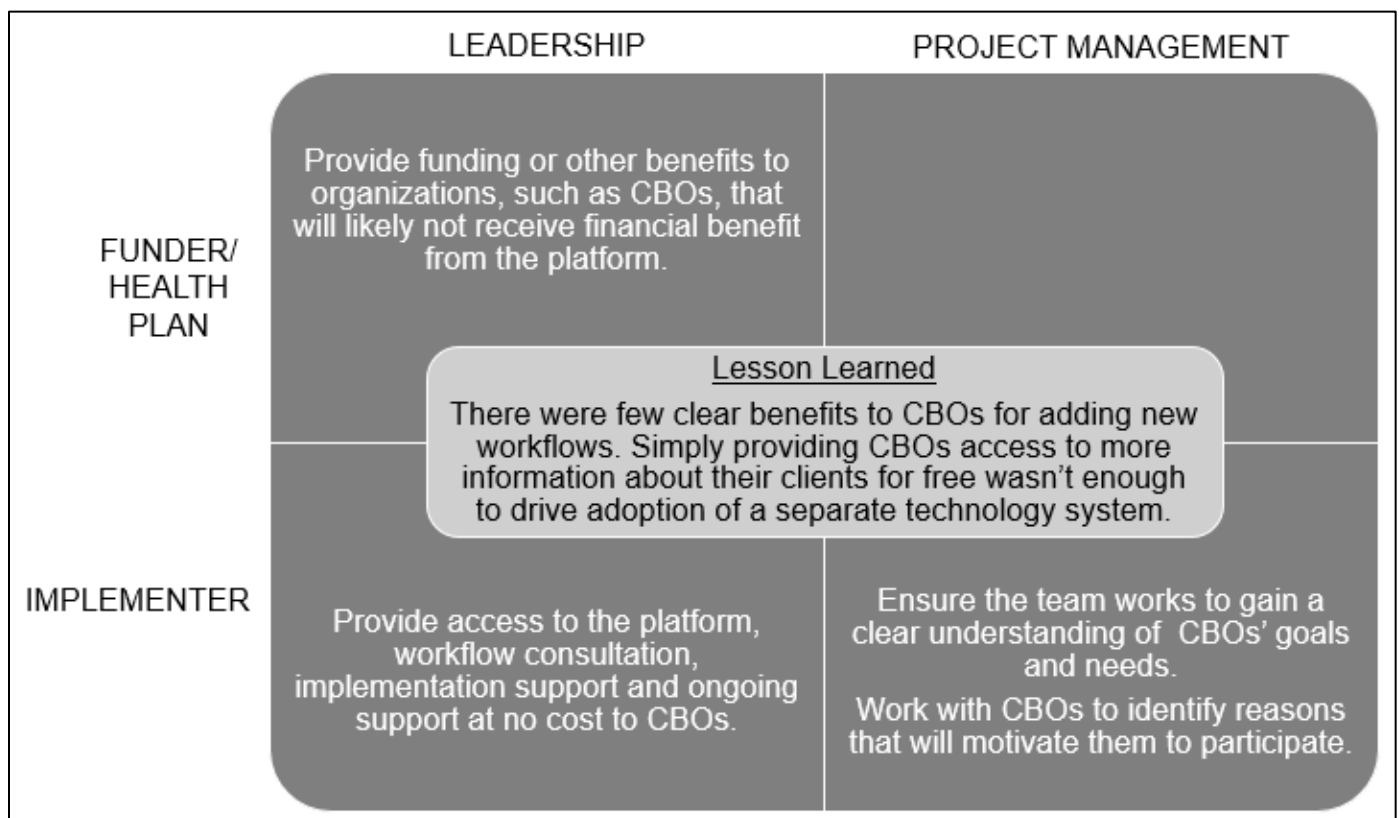
⁴ Cartier, Y., Fichenberg, C., & Gottlieb, L. (2019). *Community Resource Referral Platforms: A Guide for Health Care Organizations*. *SIREN*. Retrieved from <https://sirenetwork.ucsf.edu/sites/sirenetwork.ucsf.edu/files/wysiwyg/Community-Resource-Referral-Platforms-Guide.pdf>

Lesson Learned	Recommendation
	4.4 Facilitate face-to-face or webcam-enabled case conference meetings to help build trusting relationships between organizations that share care for large numbers of patients.
5. End users' patient privacy concerns can derail uptake of new technology.	5.1 Train all relevant staff members about HIPAA compliance in conjunction with or prior to technology platform training. 5.2 Ensure that staff feel comfortable with the features and functionality of the platform as well as the new workflows.
6. Asynchronous electronic communication wasn't initially trusted for high-stake, time-sensitive communications.	6.1 Ensure the platform triages messages to an appropriate individual regardless of staff schedules. 6.2 Publish transparent statistics showing average response times overall and by organization for different types of messages. 6.3 Identify a platform champion at each organization who is trusted by end users.
7. Consistent CBO legal counsel engagement prevents rework.	7.1 Explicitly discuss how to engage CBO counsel throughout the project. 7.2 Prepare short project updates for and meet with CBO legal counsel to discuss concerns that arise. 7.3 Address privacy, security, Part 2 and patient consent early in the design process. 7.4 Provide consistent staff communication about consent, authorization and Part 2 provisions. 7.5 Consider a data sharing agreement for all the organizations sharing data. 7.6 Include the funding health plan's legal team in all legal discussions.
8. Data not being available when staff expects it to be can lead to mistrust in the platform.	8.1 Increase the percentage of CBO patients and clients in the platform to improve its value as a tool for CBO staff. 8.2 Prioritize new platform implementation at CBOs with a high percentage of patients and clients from the plan, to enhance platform value for CBO end users. 8.3 Advise patients on how to renew their coverage, especially if platform inclusion depends on health insurance coverage. 8.4 Integrate data into organization's primary computer system when possible. 8.5 Educate end users on the sources of data in the system.
9. Staff are unlikely to use multiple applications without a compelling use case.	9.1 Identify platforms currently used in the community to avoid redundancies when possible.
10. Sporadic involvement of key decision makers meant revisiting issues and decisions and slowed progress.	10.1 Remind members periodically why they committed to this effort and why it is important, and what the effects are when they aren't there to lead.
11. Staff members' concerns can't be addressed if leadership doesn't know about them.	11.1 Ensure open communication between leadership and staff. 11.2 Reach out to organizations or specific users with reduced platform usage to understand and resolve barriers. 11.3 Include end users on the advisory committee.
12. CBO staff includes part-time employees and volunteers, making consistent engagement, communication and training challenging.	12.1 Integrate platform training into staff onboarding and ongoing professional development plans.
13. Staff and leadership turnover affected CBO participation, project decision	13.1 Create a memorandum of understanding covering transition planning in case a specific leader or project manager leaves the organization. 13.2 Build a professional pipeline and career ladder for staff in key roles.

Lesson Learned	Recommendation
making and implementation speed.	13.3 Educate staff frequently about the project's purpose and how it will benefit patients and clients.
	13.4 Fund additional training and development programs for care management and care coordination.
14. Unintentional inequities can arise in a multiorganizational governance structure.	14.1 Define equitable processes to allow everyone to participate.
15. Extensive experience implementing similar platforms at medical homes and hospitals did not translate as well as anticipated to the CBO environment.	15.1 Build extra time into the project plan even if you are experienced at implementing similar technologies in health care settings.
	15.2 Consider providing customized training for each organization, delivered by an experienced care coordinator.
	15.3 Partner with an organization that has significant relationships with intersectoral partners, which will help engage CBO participants.
16. The platform should reflect both CBO and medical home workflows and terminologies.	16.1 Ensure CBO end users need to see their workflows and experience reflected in the platform.
17. It is important to include an evaluation plan, key metrics and a way to share findings with the broader community in every implementation project.	17.1 Determine the expected impact of the platform. Select metrics and a method to measure a baseline rate and track progress.
	17.2 Share your experience and join the conversation at our Digital Measurement Community discussion, found at: https://www.ncqa.org/digital-measures/ .

Each lesson learned is associated with one or many recommendations and is targeted to specific organization types and staff types as shown in Figure 1 below.

Figure 1: Recommendations to address a lesson learned, for various audiences



How to Use the Companion Documents

In the Executive Summary:

Figure 1 describes how lessons learned link to one or more recommendations, targeted to specific staff types and organizations.

Table 1 provides a brief overview statement of each lesson learned and recommendation, as well as the organization and staff types who might benefit most from the information.

In the full White Paper:

Some issues require up-front thinking to plan for during the project. A sample implementation timeline is provided in Table 2 and each lesson and recommendation is coded for when it is most useful during implementation.

Tables 3 and 4 contain more detailed information about lessons learned and recommendations.

Lessons and recommendations are targeted to different roles (e.g., leadership, project managers, end users) and different organization types (e.g., funders, implementors, community-based organization staff, medical home staff). Each is coded for the type of participant who will find the information most useful.

Appendix A provides additional information about Community Resource Referral Platforms.

Appendix B provides additional information about the Reference Implementation studied, and methods used.

In the Associated Excel Files:

Lessons Learned and Recommendations are able to be filtered and sorted by role, organization type, issue type, and milestone.

Implementing a Community Referral Platform: Recommendations From a Real-World Implementation Experience

Introduction

The conditions in which people are born, live, learn, work, play, worship and age strongly influence health outcomes and quality of life.¹ Research has shown that social risk factors impact health care quality², cost, use and patient outcomes.³ Early studies showed strong links between patient-reported social risk factors and health status⁵ and health care utilization.⁶ Previous research showed that the presence of a social risk factor affects the patient's risk for inpatient and emergency department (ED) utilization, independent of medical risk.⁷

Organizations are increasingly using community resource referral platforms in their work to address social determinants of health (SDOH) for their populations. These software solutions are commonly designed with two primary purposes:

1. Provide an up-to-date resource directory that can be filtered to target different geographic regions, services offered and eligibility criteria, and
2. Track referrals and “close the loop” to know the referral outcome: Did the patient use the service and what was the result?

Purpose

We anticipate that organizations embarking on a journey to implement a community resource referral platform will use this document as a guidebook along the way. The lessons and recommendations draw primarily on the experience of one organization and community, but discussion with additional researchers demonstrates applicability beyond the studied setting.

The reference implementation was intended to connect medical homes that have an existing care management system to community-based organizations (CBO) for collaborative care management, including closed-loop referrals and a community services resource directory. Refer to Appendix B for information

⁵ Ippolito, M., Lyles, C., Prendergast, K., Marshall, M., Waxman, E., & Seligman, H. (2016). Food insecurity and diabetes self-management among food pantry clients. *Public Health Nutrition*, 1-7.

⁶ Fitzpatrick, T., Rosella, L., Calzavara, A., Petch, J., Pinto, A., Manson, H., & Wodchis, W. (2015). Looking beyond income and education: socioeconomic status gradients among future high-cost users of health care. *American Journal of Preventive Medicine*, 49(2), 161-171.

⁷ Jones, A., & Lulias, C. (2017). Prioritizing care coordination for patients who need it most. In M.H. Network (Ed.), *HIMSS Conference 2017, February 20, 2017*, p. Session 302. Orlando, FL.

Community Resource Referral Platforms

Referral platforms have nine common features, described below. Refer to Appendix A for more information.

1. The **resource directory** tracks resources available to patients or members.
2. **Referral tracking** is the ability to facilitate a hand-off between the medical home and CBO and track the outcome.
3. A **social risk screening** program generates data about relevant risks in the population and can inform decisions about resources that might address social risk.
4. **Care coordination** is the deliberate organization of patient care activities and sharing of information among persons involved in a patient's care, with a goal of safer, more effective care.
5. **Bidirectional communication** technology allows asynchronous and secure referrals with warm hand-off components, reducing time waiting on the phone or leaving messages.
6. **Reporting and analytics** capabilities allow organizations to track volume and type of care management, for whom and by whom, and allow insight into how these activities affect clinical outcomes or other measures of quality.
7. **Systems integration** allows availability of data from a community resource referral platform in other organizations' primary computer systems and vice versa.
8. **HIPAA/data security**. The HIPAA Security Rule protects individuals' electronic personal health information that is created, received, used or maintained by a covered entity, and requires protection of patients' electronic PHI through appropriate administrative, physical and technical safeguards.
9. **Consent tracking and authorization**. Some platforms track patient consent or authorization and allowed use or disclosure of information. The Privacy Rule permits tracking of consent for use and disclosure of PHI for treatment, payment and health care operations.

on the specific implementation studied, including goals, setting and our study methods.

We outline key steps in a general project timeline based on this implementation and provide lessons learned and associated recommendations. We indicate staff type, organization type, issue type and milestones associated with each, to guide readers to the types of lessons and recommendations most relevant to them.

Using This Tool

Our intention is that organizations considering implementing a community resource referral platform will use the experiences detailed in this project to inform planning for their own projects.

How to Use the Project Timeline

The general project timeline in Table 2: Milestones is based on the reference implementation studied and highlights key milestones. The reference implementation had three phases:

1. Allow CBOs to search for information about patients, including medical home name; care manager name and contact information; historical health information, including emergency and inpatient visit information; past procedures; and medication fill information.
2. Allow bidirectional communication between CBOs and medical home care managers, which includes, but is not limited to, referrals.
3. Integrate a community services resource directory.

It is important to note that the two key community resource referral platform functionalities were implemented in phases 2, and 3, but referrals were not necessary to start bidirectional communication. Not all organizations will choose to follow this path or implement this specific set of functionalities, but the lessons learned and recommendations throughout will be applicable to many implementations. The reference implementation did not depend on new referrals to start interactions and collaborations, which may differ from other software solutions.

As is typical with a transformation effort, this project took significantly longer than originally planned, due to unexpected challenges. We adjusted the project timeline several times and have outlined key implementation milestones on an example timeline, for illustration.

How to Use Lessons Learned

Lessons learned throughout implementation are captured in relation to each milestone, based on occurrence. They may provide insight into and help organizations prepare for their own challenges. Each is a brief vignette about a challenge that arose, the circumstances and the people and organizations involved. Each involves one or more issue type, staff type and organizational type and is coded to reflect these links.

Figure 2: Categories Applied to Lessons Learned

Issue Type		Staff Type	Organization Type
HIPAA Concern	Part 2 Concern	Leadership	Funder
Patient Consent	Trust/Relationships	Project Management	Implementer
Consistent Engagement	Data Availability	End User	Community Based Organization
Vision/Goal Alignment	System Integration		Medical Home
Workflow Alignment	Education		

About Issue Types

Each issue type has a unique background and presents unique challenges.

There were three types of data sharing and privacy concerns that arose in this project, related to HIPAA, substance use disorder treatment and patient consent. It should be noted that although not raised in the interviews, domestic violence and undocumented status may present privacy concerns in other settings.

HIPAA Concerns. The Health Insurance Portability and Accountability Act of 1996 (HIPAA)⁸ included provisions that required adoption of national standards for electronic health care transactions and code sets, unique health identifiers and security. Congress recognized that advances in electronic technology could erode the privacy of health information, and consequently incorporated provisions that mandated adoption of federal privacy protections for individually identifiable health information. This issue type includes whether sharing or receiving patient information from another provider or organization complies with HIPAA requirements.

Part 2 Concerns. Title 42 of the Code of Federal Regulations (CFR) Part 2: Confidentiality of Substance Use Disorder Patient Reports (“Part 2”) places additional safeguards around patient information related to substance use disorders and treatment. Patient information is protected under Part 2 when it is held by an entity that is a part of a federally assisted program and treats substance use disorder. Treatment information that is protected by Part 2 may only be disclosed with the patient’s written consent.⁹ Similar to HIPAA concerns, Part 2 concerns look at whether sharing or requesting information that may be related to substance use disorders and/or treatment is acceptable.

Patient Consent. The Privacy Rule permits, but does not require, a covered entity to voluntarily obtain patient consent for permissible uses and disclosures of protected health information (PHI) for treatment, payment and health care operations.

HIPAA “authorization” is required by the Privacy Rule for use and disclosure of PHI not otherwise permitted by the Rule. Where the Privacy Rule requires patient authorization, consent is not sufficient to permit a use or disclosure of PHI unless it also satisfies the requirements of a valid authorization. An authorization is a detailed document that gives covered entities permission to use PHI for specified purposes, which are generally other than treatment, payment or health care operations, or to disclose PHI to a third party for an identified purpose, as each is specified by the individual.¹⁰

Patient consent addresses whether a patient has given consent for information to be shared with other providers and organizations for routine treatment, payment and health care operations. Consent may be limited to certain information, staff or organizations or may be general consent to share as the provider feels appropriate. Different types of information also require different consent (e.g., Part 2). Patient authorization can be tracked using one form.

Trust/Relationships. This issue type was coded when interviewees brought up concerns that a certain level of trust and working relationship must be developed between staff from different organizations in order for them to feel comfortable sharing information and receive timely, accurate responses to questions, referrals or requests.

⁸ Office of the Assistant Secretary For Planning and Evaluation. (1996). *Health Insurance Portability and Accountability Act of 1996*. Retrieved from: <https://aspe.hhs.gov/report/health-insurance-portability-and-accountability-act-1996>

⁹ The Office of the National Coordinator for Health Information Technology & Substance Use and Mental Health Services Administration (SAMHSA). (n.d.) *Disclosure of Substance Use Disorder Patient Records: Does Part 2 Apply to Me?* Retrieved from: <https://www.samhsa.gov/sites/default/files/does-part2-apply.pdf>

¹⁰ U.S. Department of Health and Human Services (HHS). (2013). *What is the difference between “consent” and “authorization” under the HIPAA Privacy Rule?* Retrieved from: <https://www.hhs.gov/hipaa/for-professionals/faq/264/what-is-the-difference-between-consent-and-authorization/index.html>

Consistent Engagement. Concerns included ensuring that the right people are at the table and stay at the table throughout the project, as well as ensuring equitable participation by different types of stakeholders.

Data Availability. Data availability encompasses both ensuring that information on the appropriate patients or clients is found on the platform and having the expected types and amount of information available, with high levels of accuracy.

Vision/Goal Alignment. This includes ensuring that all participants understand why the project is happening and feel they will benefit significantly from the work and resources they put into the project. The goals and benefits for a medical home may be different from those of CBOs; this should be reflected in the work.

System Integration. This issue type addresses how to best integrate the new platform and data into an organization's current system.

Workflow Alignment. Related issues address a new platform's compatibility with the user's current workflow and whether it provides a benefit or creates a burden for the user. Users are less likely to use a burdensome platform, despite its potential benefits.

Education. Education issues encompass project participants' knowledge about why the project is happening and its significance, and how to use the platform. Issues also include understanding HIPAA and Part 2 compliance and how an organization meets those requirements.

About Organization Types

Lessons learned and recommendations are targeted to staff of four organization types: the funder, the implementer, CBOs and medical homes.

Funder. In the reference implementation studied, development and implementation of the care coordination and community resource referral platform was funded by the health plan CountyCare,¹¹ a Medicaid Managed Care plan operated by Cook County Health.¹²

A health plan is the legal entity that issues a contract for insurance for a defined population or that contracts with an employer to provide services for a self-insured population. It provides services through an organized delivery system that includes ambulatory and inpatient health care sites through a comprehensive health care benefits package. The plan follows a process for monitoring, evaluating and improving the quality and safety of care provided to its members.

Implementer. This is the organization designing, providing training for and implementing the community resource referral platform and associated technologies. In the reference implementation studied, *Medical Home Network*¹³ was the implementer.

Community Based Organizations. A CBO is a public or private nonprofit organization that represents a community, or a significant segment of a community, and works to meet community needs. CBOs work at a local level to improve life for residents.

In this reference implementation, CBOs interviewed included a home health care organization; organizations dedicated to addressing the physical and social needs of people with HIV; behavioral health organizations; and comprehensive health service organizations that provide physical health, mental health and social services to their patients or clients.

¹¹ Cook County Health. (2018). *About CountyCare*. Retrieved from: <http://www.countycare.com/about>

¹² Cook County Health. (2018). *Homepage*. Retrieved from: <https://cookcountyhealth.org/>

¹³ Medical Home Network. (2020) *Homepage*. Retrieved from: <https://www.medicalhomenetwork.org/>

Medical Home. The American Academy of Pediatrics introduced the medical home concept in 1967. Medical homes are physician practices that deliver advanced primary care, with the goal of addressing, integrating and promoting high-quality health care.¹⁴ Leading medical professional societies released the Joint Principles of the PCMH in 2007.¹⁵ NCQA released its Patient-Centered Medical Home (PCMH) Recognition program—the first evaluation program in the country based on the PCMH model—in 2008.¹⁶

About Staff Types

Lessons learned and recommendations are targeted to two staff roles: leadership and project management. Although end users may not be in a position to directly utilize them, they are likely to be affected by and may benefit from their implementation.

End User. CBO and medical home staff who use the platform to perform care management duties.

Leadership. Leadership at the CBO, medical home, implementation and funder organizations in charge of communicating with staff and setting the direction for initiatives at their organization.

Project Management. Project management represents general implementation of project managers at the implementer organization and implementation of individual project leaders at each CBO and medical home.

How to Use Recommendations

Recommendations are based on their relation to lessons learned. They are coded by type of challenge and by staff and organization types that may benefit from them.

In general, stakeholders should review lessons learned and recommendations tagged for their stakeholder type. We recommend that implementers review recommendations relevant to all stakeholder groups, as they may need to facilitate other stakeholders' review and implementation of recommended practices.

Stakeholders may also be interested in reviewing all lessons learned and recommendations relevant to a certain issue type, a particular organization type or for a certain project milestone.

Future Implications

This project illuminated challenges shared by many organizations trying to implement analogous changes with similar stakeholders. We cataloged lessons learned, their context and recommendations to prevent or mitigate these challenges in future projects.

A common theme was that challenges could be more easily mitigated if there was funding; for example, to allow extra time to be built into a project plan, additional technical support, increased iterative design with stakeholder participation and more equitable participation models.

Additional challenges experienced by CBOs, which affect projects like this one, are also related to chronic underfunding of social services, including higher workforce turnover and a large part-time and volunteer workforce. Providers and CBOs will remain hard-pressed to solve systemic problems themselves; the ecosystem requires additional policy and funding to support coordinated aid.

¹⁴ American Academy of Pediatrics. (2020). *Medical Home*. Retrieved from: <https://www.aap.org/en-us/professional-resources/practice-transformation/medicalhome/Pages/home.aspx>

¹⁵ American College of Physicians. (2007). *Joint Principles of a Patient-Centered Medical Home Released by Organizations Representing More Than 300,000 Physicians*. Retrieved from: <https://www.acponline.org/acp-newsroom/joint-principles-of-a-patient-centered-medical-home-released-by-organizations-representing-more-than>

¹⁶ National Committee for Quality Assurance (NCQA). (2020). *NCQA PCMH Recognition: Concepts*. Retrieved from: <https://www.ncqa.org/programs/health-care-providers-practices/patient-centered-medical-home-pcmh/pcmh-concepts/>

Findings

Tables 2–4 contain milestones, lessons learned and recommendations.

Milestones

Sample project milestones outline generalized timelines that future platform implementers could consider when planning a project. Some steps (2.2, 2.3, 2.5) occurred later in the studied project than described in the sample timeline, but lessons learned indicate that holding them earlier may have prevented project delay; based on project experience, we recommend holding them before business requirements and legal sign-off.

Table 2: Project Milestones

Phase	#	Milestone	Quarter	Description
Phase 1: CBO View Only	1.1	CBO discovery sessions	Q1	Conduct discovery sessions with CBOs to understand existing workflows and technologies and establish a working relationship with CBO leadership. This work will inform how best to convene the Advisory Committee and create the necessary relationships before its formation.
	1.2	CBO Advisory Committee stakeholder meeting	Q1	Convene a CBO Advisory Committee representing CBOs of different sizes, geographical locations, focus areas and funding sources to provide input and co-design the process and platform.
	1.3	Legal sign-offs	Q2	Ensure a legal agreement is in place between the technology implementor and new user organizations before system use occurs.
	1.4	Training on search functionality for CBOs	Q2	Train end users to search for patients/clients and view existing data such as medical home name and care manager contact information.
	1.5	Search functionality live for CBOs	Q2	Launch search functionality access for CBO staff.
Phase 2: Bidirectional Communication	2.1	Continue stakeholder meetings and co-design sessions with CBOs and medical homes	Q2-Q3	Conduct Phase 2 platform functionality design sessions to add bidirectional communication functionality.
	2.2	Part 2 Protections Meeting	Q3	Meet with leadership for CBOs that interact with data under Part 2 protections, including CBO legal counsel, to ensure understanding of how Part 2 protections will be upheld.
	2.3	Patient Consent and HIPAA Authorization Process Meeting	Q3	Meet with CBO leadership and CBO legal counsel to ensure understanding of how patient consent and HIPAA authorization will be tracked and honored.
	2.4	Finalize Phase 2 business requirements	Q3-Q4	Work with CBO Advisory Committee, medical homes and care management organizations to create final platform requirements, including Part 2 consent form and HIPAA authorization if necessary.
	2.5	Legal sign-offs	Q4	Secure legal sign-offs for data sharing from all entities, including the technology implementor, medical homes, CBOs and the funding health plan.

Phase	#	Milestone	Quarter	Description
	2.6	Bidirectional communication workflow launch	Q5	Start with a “soft launch” of the workflow with CBOs and medical homes through existing communication capabilities (phone or secure email) and document communications in a shared template before launching the bidirectional platform.
	2.7	Platform development and testing	Q6	Complete technical development and testing processes for the bidirectional platform based on business requirements developed throughout the stakeholder process and with learnings from the workflow launch.
	2.8	User training	Q7	Train end users on using the bidirectional platform.
	2.9	Bidirectional communication platform launch	Q7-Q8	Launch bidirectional communication functionality for CBO and medical home staff.
Phase 3: Integration with Community Services Resource Directory	3.1	Design decision: Buy or build community services resource directory	Q6-Q7	Establish whether project participants will create a community services resource directory and associated technology as part of this implementation or whether it will be more effective to partner with another organization to integrate an existing resource directory into the technology platform.
	3.2	Continue stakeholder meetings and co-design sessions with CBOs	Q8	Conduct Phase 3 platform functionality design sessions to determine how best to integrate referral resource directory functionality and content.
	3.3	Finalize Phase 3 business requirements for integration of community services resource directory	Q9	Collaborate with CBO Advisory Committee, medical homes and care management organizations to create final platform requirements.
	3.4	Platform development and testing	Q10	Complete technical development and testing processes for the integrated referral resource directory based on the business requirements developed throughout the stakeholder process and with learnings from the workflow launch in Phase 2.
	3.5	User training	Q11	Train end users on using the integrated referral resource directory.
	3.6	Community services resource directory functionality launch and roll-out	Q11-12	Launch referral resource directory for CBO and medical home staff.

Lessons Learned

The information in Table 3 was drawn primarily from interviews conducted evaluating the reference implementation as described in Appendix B, but also incorporates information from discussions with fellow RWJF S4A grantees.

<p>Definitions</p> <p>Reference implementation: The primary project implementation studied in this evaluation.</p> <p>Participating organizations: Organizations involved in the project that exchange information on the platform (CBOs, medical homes).</p> <p>Platform: The care coordination and community resource referral platform studied.</p> <p>Technology implementation team: Organizational staff responsible for implementation of the platform.</p>

Table 3: Lessons Learned

Lesson #	Lesson Learned	Context	Milestone	Recommendations	Issue Type	Staff Type	Organization Type
1	There were few clear benefits to the CBOs for adding new workflows, which affected uptake.	This project was funded by the health plan, but simply giving CBOs access to more information about clients for free wasn't enough to drive adoption. Additionally, a focus on workflows to allow medical home referrals to CBOs can make it difficult for CBOs to integrate the system into their own workflows.	1.1, 1.2, 2.1, 3.2	1.1,1.2,1.3,1.4	Vision/ Goal Alignment, Workflow Alignment	Leadership, Project Management	Funder, Implementer
2	CBOs saw platform functionality as supplemental rather than necessary to the workflow.	The sponsoring health plan, as well as already-connected medical homes, saw the new platform as a way for medical homes to make referrals and connect patients to CBOs and get information back from CBOs, but CBOs didn't see medical homes as their primary way connecting to new clients, so this new communication method wasn't seen as critical to the workflow.	1.1, 1.2, 1.4, 2.1, 2.8	2.1	Vision/ Goal Alignment	Leadership, Project Management	Funder, Implementer
3	CBOs have limited resources and must prioritize activities that they see as having the greatest value and highest impact on clients/patients.	Medical homes want to be able to close the loop on referrals. Lack of capacity and incentives for CBOs mean lack of impetus to change and incorporate additional items or processes to workflows, such as an external bidirectional message center.	1.1, 1.2, 2.1, 3.1, 3.2	3.1, 3.2	Vision/ Goal Alignment, System Integration	Leadership	Implementer, Funder

Lesson #	Lesson Learned	Context	Milestone	Recommendations	Issue Type	Staff Type	Organization Type
4	CBO end users did not feel comfortable sending electronic messages about patients/clients to another participating organization if there was not an existing working relationship.	Previously, referrals from medical homes to CBOs were primarily cold hand-offs with little or no communication. CBO staff were not accustomed to providing patient-specific information to external organizations.	21.5, 2.6, 2.9, 3.1, 3.6	4.1, 4.2, 4.3, 4.4	Trust/ Relationships, Vision/ Goal Alignment	Leadership, Project Management	Implementer, CBO, Medical Home
5	Despite leadership approval, CBO staff had concerns about whether they were permitted to send and receive messages with information about patients/ clients to staff at other participating organizations.	The technology implementation team worked extensively with CBO leadership to get approval for data sharing between their staff and medical home staff, but staff remained concerned about sharing patient information with other organizations.	1.2, 1.4, 2.1, 2.3, 2.4, 2.6, 2.7, 2.8, 2.9	5.1, 5.2, 5.3	HIPAA Concern, Trust/ Relationships, Vision/ Goal Alignment, Workflow Alignment, Education	Leadership, Project Management	Implementer, CBO, Medical Home
6	End users wanted to know that colleagues receiving messages check the platform regularly and provide a timely response.	End users were concerned that sending an electronic message to an unknown colleague, rather than phoning, might delay or prevent them from getting the information they need to help the patient/client.	2.1, 2.7, 2.8, 2.9	6.1, 6.2, 6.3	Trust/ Relationships, Vision/ Goal Alignment, Workflow Alignment, Education	Leadership, Project Management	Implementer, CBO, Medical Home
7	CBO legal counsel was not engaged until late in the process. Once engaged, disagreements arose about what constitutes compliant data sharing, leading to redesign and rework on previous decisions.	CBO legal counsel was often pro bono, after-hours support shared between an array of legal experts. Lack of early and frequent engagement of CBO legal counsel led to concerns, such as Part 2 provisions and collecting and storing patient consent for information sharing, not being raised until Phase 2 of the platform was ready to go live, significantly delaying the roll out of Phase 2.	1.1, 1.3, 2.2, 2.3, 2.5, 2.6, 2.8, 2.9	7.1, 7.2, 7.3, 7.4, 7.5, 7.6	HIPAA Concern, Part 2 Concern, Patient Consent	Leadership, Project Management	Implementer, CBO, Medical Home, Funder

Lesson #	Lesson Learned	Context	Milestone	Recommendations	Issue Type	Staff Type	Organization Type
8	Patient/client information being unavailable in the platform when staff expects it to be there can lead to mistrust in the platform.	CBO end users found the ability to view information about patients'/clients' medical home and care manager useful, but sometimes this information wasn't available on the platform or the patient's profile did not appear. Three circumstances drove these perceived gaps in data:1. The platform studied included only members of one local Medicaid Managed Care plan. This plan covered a majority of medical home patients, but for CBOs the percentage of patients in this plan was lower. 2. Medicaid Managed Care in IL requires all members to have a yearly renewal of eligibility ("redetermination"). Administrative lags can cause members to fall out of coverage as non-renewal, due to members not understanding the process or not receiving the paperwork due to an address change. Even though benefits are likely to be reinstated when the administrative process completes, this gap in coverage means that member information is available on the platform until coverage is reinstated. 3. In order for the patient's care manager to be listed in the system, the care management team must manually add the manager's name. If this step has not been completed, the CBO only sees the general contact information for the patient's assigned care management entity and medical home.	1.1, 1.2, 1.4, 2.1, 2.7, 2.8, 3.2, 3.4	8.1, 8.2, 8.3, 8.4, 8.5	Data Availability, Vision/ Goal Alignment, System Integration, Education	Leadership, Project Management	Funder, Implementer, CBO, Medical Home
9	If there are multiple competing platforms, the one used the most frequently is often the one that is preferred. Staff benefit from consistent workflows and not having to switch between competing applications.	CBOs in this locality are connected to multiple, similar platforms in addition to the one in this research project. One CBO indicated that it preferred the alternative platform because more of patients were represented and more consistent information was available.	1.1, 1.2, 1.4, 2.1, 2.7, 2.8, 3.1, 3.2, 3.4	9.1, 9.2, 9.3, 9.4, 9.5, 9.6	Data Availability, Vision/ Goal Alignment, System Integration, Workflow Alignment, Education	Leadership, Project Management	Funder, Implementer, CBO, Medical Home

Lesson #	Lesson Learned	Context	Milestone	Recommendations	Issue Type	Staff Type	Organization Type
10	Sporadic involvement of key decision makers meant revisiting issues and decisions and slowed progress.	Organizations made a commitment to participate on the platform project advisory committee and have their leaders engage in the platform co-design process. But after a few months, the project team found that members who had agreed to participate no longer prioritized these meetings in their schedules or would send another team member in their place.	1.1, 1.2, 2.1, 3.2	10.1	Trust/ Relationships, Consistent Engagement, Vision/ Goal Alignment	Leadership	Funder, CBO, Medical Home
11	Staff members' concerns can't be addressed if leadership doesn't know about them.	At some CBOs, there was disconnect between leadership, the project owner and the end user's enthusiasm for the platform, with leadership expressing strong support but end users indicating little value and use. In a notable example, a CBO leader told interviewers how great the platform was and how much of an impact it had made. The project owners expressed concern. The primary end user indicated that they hadn't used the platform for several months. Many concerns expressed by the end user could be easily addressed but had not been relayed to anyone, despite the user indicating that they trusted and liked the project staff.	1.1, 1.2, 1.5, 2.1, 2.6, 2.8, 2.9, 3.5, 3.6	11.1, 11.2, 11.3	Consistent Engagement, Vision/ Goal Alignment	Leadership, Project Management	Implementer, CBO, Medical Home
12	CBO staff included part-time employees and volunteers, which made consistent engagement, communication and training challenging.	Finding a time for training that works for everyone, as well as staff being able to retain detailed procedures and steps for a process they may not do frequently, can be a challenge.	1.4, 2.8, 3.5	12.1	Consistent Engagement, Vision/ Goal Alignment, Education	Leadership, Project Management	Implementer, CBO, Medical Home
13	Staff and leadership turnover affected CBO participation, project decision making and implementation speed.	Turnover affects the project's leadership, sponsorship, buy-in, training, and communication strategy. CBO leadership indicated that medical organizations are beginning to take on some work traditionally done by CBOs, such as case management, care coordination and social services referrals, which limited the applicant pool for staff and leadership with these skill sets. As a result, staff turnover has increased over the past few years across CBOs.	1.1, 1.2, 1.4, 2.1, 2.8, 3.2, 3.5	13.1,13.2,13.3,13.4	Vision/ Goal Alignment, Education	Leadership, Project Management	Funder, CBO, Medical Home, Implementer

Lesson #	Lesson Learned	Context	Milestone	Recommendations	Issue Type	Staff Type	Organization Type
14	Unintentional inequities can arise in a multi-organizational governance structure.	Some participants on the advisory committees or governance council can do so during working hours and be paid for their work; other organizations or community members may not be able to be compensated for that time.	1.1, 1.2	14.1	Trust/ Relationships, Consistent Engagement, Workflow Alignment	Leadership, Project Management	Implementer, Funder
15	Extensive experience implementing similar platforms at medical homes and hospitals did not translate as well as anticipated to the CBO environment.	Many have found* that system implementation was slower and more complicated than anticipated in CBO environments. * https://sirennetwork.ucsf.edu/sites/sirennetwork.ucsf.edu/files/wysiwyg/Community-Resource-Referral-Platforms-Guide.pdf	1.1, 1.2, 1.4, 1.5, 2.8, 3.2, 3.5	15.1,15.2,15.3	Trust/ Relationships, System Integration, Workflow Alignment, Education	Project Management	Implementer
16	To drive adoption at CBOs, the platform needs to reflect their workflows and terminologies and not be medical home-centric.	This platform was originally conceived to serve medical homes and hospitals and is oriented toward the medical profession, their workflows and terminology.	1.1, 1.2, 2.1, 3.2	16.1	Vision/ Goal Alignment, Workflow Alignment	Project Management	Implementer
17	Evaluation of this project reinforced the importance of having an evaluation plan, key metrics and a way to share findings with the broader community.	As recommended by SIREN in its 2019 report*, it is important to evaluate the impact of community resource referral platforms and continue to share learning with the broader community. * https://sirennetwork.ucsf.edu/sites/sirennetwork.ucsf.edu/files/wysiwyg/Community-Resource-Referral-Platforms-Guide.pdf	1.2, 2.1, 3.2	17.1,17.2	Vision/ Goal Alignment	Project Management	Implementer

Recommendations

The information in Table 4 was drawn primarily from interviews conducted evaluating the reference implementation as described in Appendix B, but also incorporates information from discussions with fellow RWJF S4A grantees.

Table 4: Recommendations

Recommendation Number	Recommendation	Associated Lesson	Milestone	Issue Type	Staff Type	Organization Type
1.1	Provide access to the platform, workflow consultation, implementation support and ongoing support at no cost to CBOs.	1	1.2	Vision/ Goal Alignment, Workflow Alignment	Leadership	Implementer
1.2	Provide funding or other benefits to organizations, such as CBOs, that will likely not receive financial benefit from the platform. Funding should be provided by the organization accruing the primary financial benefit from platform use or other benefits for adding new workflow.	1	1.2, 2.1, 3.2	Vision/ Goal Alignment, Workflow Alignment	Leadership	Funder
1.3	Create a platform that provides significant functionality to CBOs, independent of medical home referrals, allowing CBOs to derive more value from the platform.	1	1.1, 1.2, 2.1, 3.2	Vision/ Goal Alignment, Workflow Alignment	Project Management	Implementer
1.4	Work with CBOs to identify reasons that will motivate them to participate. Medical homes are often paid to utilize these platforms and systems or there is a financial incentive through value-based payment to reduce admissions or readmissions and improve SDOH. CBOs generally do not have the same alignment of incentives.	1	1.1, 1.2, 2.1, 3.2	Vision/ Goal Alignment, Workflow Alignment	Project Management	Implementer
2.1	Consider the CBO's needs and how the platform can address them; market the platform accordingly. Consider messages such as, "You can use this resource to help reconnect your patients with their medical home."	2	1.1, 1.2, 1.4, 2.1, 2.8	Vision/ Goal Alignment	Leadership, Project Management	Funder, Implementer
3.1	Host co-design sessions to engage CBOs and understand their goals for the platform. <i>Do the CBOs want more referrals? Is this how they want to receive them? Do they have the staff capacity to take on this work? How will it affect their patient outcomes?</i> Create a platform that provides significant functionality to CBOs, independent of medical home referrals, allowing CBOs to derive more value from the platform.	3	2.1, 3.1, 3.2	Vision/ Goal Alignment, System Integration	Leadership	Implementer
3.2	Build capacity in CBOs to be able to accept more referrals. http://systemsforaction.org/projects/strengthening-carrying-capacity-local-health-and-social-service-agencies-absorb-increased/meetings/webinar-strengthening-carrying-capacity-local-health-and-social-service-agencies-absorb-increased	3	1.1, 1.2, 2.1, 3.1, 3.2	Vision/Goal Alignment, Workflow Alignment	Leadership	Funder

Recommendation Number	Recommendation	Associated Lesson	Milestone	Issue Type	Staff Type	Organization Type
4.1	Utilize a soft launch to assist in development of new workflows and relationships between organizations. While first using the platform or shortly before implementation, the medical home and CBO staff can meet in person, use video chat or calls to discuss patients and referrals rather than relying on the system as the sole form of communication while building relationships.	4	2.6	Trust/ Relationships	Project Management	Implementer
4.2	Co-create use cases with CBO and medical home staff to drive workflows for specific use cases. Platform engagement will be highest if there are use cases that cannot be completed any other way; for example, requiring referral forms, consent forms or returning visit notes to be filled out on the platform. Funder leadership and participation in co-design can help set appropriate requirements and drive this engagement.	4	2.6, 3.1	Trust/ Relationships, Vision/ Goal Alignment	Project Management	Implementer
4.3	Communicate to staff the importance of using the system and how it will impact the CBO's work. This will help staff feel more comfortable using the system and see the importance to patients.	4	1.5, 2.6, 2.9, 3.6	Vision/ Goal Alignment	Leadership	CBO
5.1	Hold an education session for all relevant staff members about HIPAA compliance in conjunction with or before technology platform training. Training should be co-led by the organization's legal counsel and health plan legal counsel and have clear support from organization leadership.	5	2.8	HIPAA Concern, Education	Project Management	CBO, Medical Home
5.2	Communicate frequently and transparently with staff, ensuring that staff are comfortable with the features and functionality of the platform and the new workflows.	5	1.2, 1.4, 2.1, 2.3, 2.4, 2.6, 2.7, 2.8, 2.9	Trust/ Relationships, Vision/ Goal Alignment, Workflow Alignment, Education	Leadership	CBO, Medical Home
5.3, 4.4	Facilitate face-to-face or webcam-enabled case conference meetings during the pilot phase for all participating organizations to help identify appropriate workflows, facilitate collaboration on shared patients/clients and help build a trusting relationship between organizations that share care for large numbers of patients.	5,4	2.6	Trust/ Relationships	Project Management	Implementer, CBO, Medical Home
6.1	To ensure that messages are responded to quickly even if a user is unavailable, the platform should be able to triage messages.	6	2.1	Workflow Alignment	Project Management	Implementer
6.2	Publish transparent statistics showing average response times overall and by organization for different types of messages.	6	2.7, 2.8, 2.9	Trust/ Relationships, Workflow Alignment	Project Management	Implementer
6.3	Identify a platform champion at each organization. End users with concerns or resistance to the platform can converse with a colleague rather than having to address concerns only with leadership or the project management team.	6	2.1, 2.8, 2.9	Vision/ Goal Alignment, Education	Leadership	CBO, Medical Home

Recommendation Number	Recommendation	Associated Lesson	Milestone	Issue Type	Staff Type	Organization Type
7.1	Discuss explicitly with CBOs how best to engage their legal counsel, especially if counsel is pro bono.	7	1.1, 1.3, 2.2, 2.3, 2.5	HIPAA Concern, Part 2 Concern, Patient Consent	Leadership, Project Management	Implementer, CBO
7.2	Engage CBO legal counsel throughout the entire process by preparing short project updates for CBO leadership to share with legal counsel and by holding meetings or calls for legal counsel to discuss concerns that arise.	7	1.3, 2.2, 2.3	HIPAA Concern, Part 2 Concern, Patient Consent	Leadership, Project Management	Implementer, CBO
7.3	Address privacy, security, Part 2 and patient consent for information sharing across organizations with CBO legal counsel early in the design process.	7	1.3, 2.2, 2.3	HIPAA Concern, Part 2 Concern, Patient Consent	Leadership, Project Management	CBO
7.4	Provide consistent communication and training for staff on topics such as consent, authorization and Part 2 provisions, with examples of information that may and may not be shared, and with whom, under specific circumstances. Clear and consistent messaging through a fact sheet is more effective than each organization having its own interpretation and guidance.	7	2.2, 2.3, 2.6, 2.8, 2.9	HIPAA Concern, Part 2 Concern, Patient Consent	Leadership, Project Management	Implementer, CBO
7.5	Consider a data sharing agreement for all organizations sharing data, negating the need for patient consent that addresses care coordination activities as permitted under HIPAA and Part 2 and clarifies the role and responsibilities of the CBO.	7	1.3, 2.2, 2.3, 2.5	HIPAA Concern, Patient Consent	Leadership, Project Management	Funder, CBO, Medical Home, Implementer
7.6	Include the funding health plan's legal team in all legal discussions. Health plan legal approval is necessary to implement a consent process for plan members.	7	1.3, 2.2, 2.3, 2.5	Patient Consent	Leadership, Project Management	Funder, Implementer
8.1, 9.1	Participating organizations can request health plans whose members they care for to join the platform effort. If additional health plans contract to have their members included, CBOs would see a larger percentage of patients/clients represented on the platform, potentially increasing its value.	8,9	1.1, 1.2	Data Availability, Vision/ Goal Alignment	Leadership, Project Management	CBO
8.2, 9.2	Prioritize new platform implementation at CBOs with a high percentage of patients/clients from the plan; this may enhance the platform's value for CBO end users.	8,9	1.1, 1.2, 2.1	Data Availability, Vision/ Goal Alignment	Leadership	Funder, Implementer
8.3, 9.3	If inclusion in the platform depends on plan enrollment, advise patients how to renew coverage if it has lapsed. A patient that cannot be found in the platform but should have coverage can prompt to have the patient call and as about the status of their health insurance coverage.	8,9	1.4	Data Availability	Project Management	Implementer, CBO, Medical Home
8.4, 9.4	Integrate data into the organization's primary computer system when possible, such as medical home EHRs and hospital ED tracking boards, to allow customizations such as displaying an icon for patients and alerting end users to check for additional information in the platform.	8,9	2.1, 2.7, 3.2, 3.4	System Integration	Project Management	Implementer, CBO, Medical Home

Recommendation Number	Recommendation	Associated Lesson	Milestone	Issue Type	Staff Type	Organization Type
8.5, 9.5	Educate end users on the sources of data in the system. End users and participating organizations should understand why there is information on some patients and not on others.	8,9	1.4, 2.8	Data Availability, Education	Project Management	Implementer, CBO, Medical Home
9.6	Identify platforms currently used in the community to avoid redundancies when possible.	9	1.1, 1.2, 2.1, 3.1	Vision/ Goal Alignment, System Integration, Workflow Alignment	Project Management	Funder, Implementer
10.1	Convey the project's vision and purpose and the steps necessary for success at the kick-off meeting, while key decision makers are there. Revisit this conversation periodically with individuals or the full group if members begin to disengage, send other staff members in their place or as organizational leadership changes. Remind members about the commitment they made, why it is important and the effects when they aren't there to lead.	10	1.1, 1.2, 2.1, 3.2	Trust/ Relationships, Consistent Engagement, Vision/Goal Alignment	Leadership	Funder, CBO, Medical Home, Implementer
11.1	Ensure open communication between leadership and staff. Use anonymous surveys, frequent check-ins during staff meetings and 1:1 check-ins to understand challenges for staff; acknowledge and address each issue as it arises.	11	1.5, 2.1, 2.6, 2.8, 2.9, 3.5, 3.6	Consistent Engagement, Vision/ Goal Alignment	Leadership	CBO, Medical Home
11.2	Run periodic reports to monitor platform usage and provide these to organization leadership. Proactively reach out to organizations or users who have stopped using the platform to understand barriers and work with them to address barriers.	11	2.9	Consistent Engagement, Vision/ Goal Alignment	Project Management	Implementer
11.3	Include end users on the advisory committee to ensure that their perspectives are elevated.	11	1.1, 1.2	Consistent Engagement, Vision/ Goal Alignment	Project Management	Implementer
12.1	Ensure that platform training is integrated into staff onboarding and ongoing professional development plans. On-demand trainings or a train-the-trainer model can ensure that training is available without being an ongoing duty of project management.	12	1.4, 2.8, 3.5	Consistent Engagement, Vision/ Goal Alignment, Education	Leadership, Project Management	Implementer, CBO, Medical Home
13.1	Create a memorandum of understanding (MOU) that will create a plan for the project team in the event a leader or project manager leaves the organization. The MOU should document a transition plan for the incoming staff member so they can quickly get up to speed on the project and plan. This helps ensure that the success of the project doesn't depend on individual relationships.	13	1.2	Consistent Engagement	Leadership, Project Management	Implementer, CBO
13.2	Work across participating organizations to build a professional pipeline for staff in key roles. Developing a clear career ladder can help mitigate staff turnover; developing a professional pipeline can help strengthen CBOs.	13	1.2,1.4, 2.8, 3.2, 3.5	Consistent Engagement, Education	Leadership, Project Management	Funder, CBO

Recommendation Number	Recommendation	Associated Lesson	Milestone	Issue Type	Staff Type	Organization Type
13.3	Educate staff frequently about the purpose of the project and how it will benefit patients/clients.	13	1.2, 1.4, 2.8, 3.2, 3.5	Vision/ Goal Alignment, Education	Leadership	CBO, Medical Home
13.4	Fund additional training and development programs to increase the pipeline of trained individuals with the skill sets to do manage and coordinate care at CBOs.	13	1.1, 1.2, 2.1, 3.2	Vision/ Goal Alignment, Education	Leadership	Funder
14.1	Define equitable processes that allow everyone to participate. Consider how to equitably compensate people and organizations that want and need to be represented on shared governing bodies but don't have a budget or funding source.	14	1.1, 1.2	Trust/ Relationships, Consistent Engagement, Workflow Alignment	Leadership, Project Management	Funder, Implementer
15.1	Build extra time into the project plan even if you are experienced at implementing similar technologies in health care settings.	15	1.2, 2.1, 3.2	System Integration, Workflow Alignment	Project Management	Implementer
15.2	Consider customized training for each organization, delivered by an experienced care coordinator. CBO staff typically have less familiarity with computerized patient records than medical home staff. Differences among organizations may be significant enough to create a need for customized workflows for each organization and the population they serve.	15	1.4, 2.8, 3.5	Education	Project Management	Implementer
15.3	Partner with an organization that has significant relationships with intersectoral partners, which will help engage CBO participants.	15	1.1, 1.2	Trust/ Relationships	Project Management	Implementer
16.1	Ensure that CBO end users need to see their workflows and experience reflected on the platform, including their terminology. For example, medical professionals work with patients, but CBOs often work with clients/customers. Using general terminology that reflects different workflows can help diverse user groups be served by the same platform.	16	1.1, 1.2, 2.1, 3.2	Vision/ Goal Alignment Workflow Alignment	Project Management	Implementer
17.1	Determine the expected impact of the platform. Select metrics and a method to measure a baseline rate and track progress.	17	1.2, 2.1, 3.2	Vision/ Goal Alignment	Project Management	Implementer

Recommendation Number	Recommendation	Associated Lesson	Milestone	Issue Type	Staff Type	Organization Type
17.2	<p>Share your experience and join the conversation at our Digital Measurement Community discussion.</p> <ol style="list-style-type: none"> 1. Go to: https://www.ncqa.org/digital-measures/. 2. Click the blue “Get Access” button on the top right. 3. Click “Create Account” on the bottom right, enter information, and click “Submit” button. 4. Scroll down to mid-page and click on “View Community Forum”. 5. Click on “Latest” to find “<i>Implementing a Community Referral Platform</i>” post or Click on “<i>Digital Innovation</i>” underneath category on the left to locate “<i>Implementing a Community Referral Platform</i>” or search “<i>Implementing a Community Referral Platform</i>” in the search bar on the right-hand side of the banner. 6. Once post is located, comment by clicking “<i>Reply</i>” on the bottom right of the post. 	17	NA	NA	Project Management	Implementer

Appendix A: More About Community Resource Referral Platforms

Key Functionality

There are two key functionalities of community resource referral platforms: Resource Directories and Referral Tracking.

- *Resource Directory* The resource directory tracks resources available to patients/members. The database may track key features such as geographic area, services offered, hours of operation, public transportation accessibility, eligibility criteria for services and availability of appointments. Community based organizations (CBO) that provide resources and services to underserved populations might frequently change offerings due to funding fluctuations, so it is vital that this information be updated frequently. Some directories allow feedback if a user finds out-of-date information is found.

Some resource directories are public facing, others are available only to staff with secure logins. Some allow staff to provide patients or members with a personalized view of resources that are most appropriate for them.

- *Referral Tracking.* A key component of community resource referral platforms is the ability to facilitate a hand-off between the medical home and the CBO. Traditionally in clinical care, a warm-handoff is a transfer-of-care conversation that happens in person, in front of the patient.¹⁷ A referral platform can use technology to maintain the benefits of a warm hand-off, even though the face-to-face aspect is not practical in cross-organization hand-offs such as referrals. A warm hand-off allows patients to ask questions or clarify information and facilitates a relationship between the two care organizations and the patient.

Not all CBOs require referrals or are used to receiving them from clinical practitioners. CBOs may also be unused to providing information back to clinical practitioners about the outcome of the referral.

The second key component of referrals is the ability for a closed-loop referral platform.

Challenges in the outpatient referral and specialist consultation process are well documented, including lack of timely and complete communication between the specialist and the requesting physician.^{18,19,20} Similarly, when patients are referred to CBOs, often little follow-up information about the patient visit or the result goes back to the referring practitioner. The practitioner can follow up with the patient directly, but the chance of the patient falling through the cracks increases when no follow-up information is provided to the referring practitioner.

¹⁷ Agency for Healthcare Research and Quality (AHRQ). (n.d.). Warm Handoffs: A Guide for Clinicians. Retrieved from: <https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/patient-family-engagement/pfprimarycare/warm-handoff-guide-for-clinicians.pdf>

¹⁸ Gandhi, T. K., Sittig, D. F., Franklin, M., Sussman, A. J., Fairchild, D. G., and Bates, D. W. (2000). Communication breakdown in the outpatient referral process. *Journal of General Internal Medicine* 15(9), 626-631.

¹⁹ Forrest, C. B., Glade, G. B., Baker, A. E., Bocian, A., Von Schrader, S., and Starfield, B. (2000). Coordination of specialty referrals and physician satisfaction with referral care. *Archives of Pediatrics and Adolescent Medicine* 154(5), 499-506.

²⁰ Stille, C. J., Jerant, A., Bell, D., Meltzer, D., and Elmore, J. G. (2005). Coordinating care across diseases, settings, and clinicians: a key role for the generalist in practice. *Annals of Internal Medicine* 142(8), 700-708.

In addition to the resource directory and referral tracking, community resource referral platforms often include the following functions:²¹

- **Social Risk Screening.** A social determinants of health (SDOH) assessment program generates data about what SDOH factors are relevant in the population and can inform decisions about where resources might address SDOH. Individual assessment can be defined as “the systematic gathering and synthesizing of information about and with a client in a manner that serves to promote effective treatment.”^{22,23,24} A population assessment systematically assesses significant characteristics and needs. Assessment of SDOH factors in the population of interest is key to understanding what needs can be addressed.
- **Care Coordination** is deliberate organization of patient care activities and sharing of information among persons involved in a patient’s care, with the goal of safer, more effective care. This requires the patient’s needs and preferences to be known ahead of time and communicated at the right time to the right people. This information should be used to provide safe, appropriate and effective care to the patient.²⁵

Care coordination is a focal point of our nation’s ambulatory health information technology (IT) framework. Care coordination synchronizes delivery of health care from multiple providers and specialists.²⁶

- **Bidirectional Communication.** Technology allows asynchronous referrals with warm hand-off components. Medical home and CBO staff often meet with patients and may not be immediately available to take a phone call from a colleague, which can result in delays while waiting on hold or “playing phone tag.” Secure digital communication via a referral platform means that providers can share detailed information about a patient and the patient’s needs with colleagues, who can ask questions when it is convenient for them, reducing time spent on the phone or leaving messages.
- **Reporting and Analytics** capabilities allow organizations to track the volume and types of care management activities, for whom and by whom, and may also allow insight into how activities affect outcomes or other measures of quality.
- **Systems Integration.** It is often useful for data from a community resource referral platform to be available in other organizations’ primary computer systems such as EHRs, case management systems or ED tracking boards. Even a simple step such as displaying an icon in a primary computer system to indicate that a patient has additional information on the platform can alert the end user to check the community resource referral platform.

²¹ Social Interventions Research and Evaluation Network (SIREN). (2019). Community Resource Referral Platforms - Lessons from Early Health Care Adopters [Webinar]. SIREN <https://www.youtube.com/watch?v=4CGLSmqCChM&feature=youtu.be>

²² Cohen, R. J., Swerdlik, M. E., & Smith, D. K. (1992). Psychological testing and assessment: An introduction to tests and measurement (6th ed.). Mayfield Publishing Co.

²³ Hepworth, D., & Larson, J. A. (1990). Direct social work practice: Theory and skills (3rd ed.). Wadsworth.

²⁴ Artz, S., Nicholson, D., Halsall, E., Larke, S., & Sonya, B. (2007). Need and risk and how to tell the difference. E-Journal of the International Child and Youth Care Network (CYC-Net), 96. <https://www.cyc-net.org/cyc-online/cycol-0107-artz.html>

²⁵ Agency for Healthcare Research and Quality (AHRQ). (2018). *Care Coordination*. Retrieved from <https://www.ahrq.gov/ncepcr/care/coordination.html#:~:text=Care%20coordination%20involves%20deliberately%20organizing,safer%20and%20more%20effective%20care.>

²⁶ NEJM Catalyst. (2018). *What is Care Coordination?* NEJM Catalyst Innovations in Care Delivery. Retrieved From: <https://catalyst.nejm.org/doi/full/10.1056/CAT.18.0291>

- **HIPAA/Data Security.** The HIPAA Security Rule²⁷ establishes national standards to protect individuals' electronic personal health information created, received, used or maintained by a covered entity. The Security Rule requires protection of patients' electronic protected health information (known as "ePHI") through appropriate administrative, physical and technical safeguards to ensure the confidentiality, integrity and security of this information.²⁸
- **Consent Tracking and Authorization.** The Privacy Rule permits, but does not require, a covered entity to voluntarily obtain patient consent for uses and disclosures of PHI for treatment, payment and health care operations.

HIPAA "authorization" is required by the Privacy Rule for use and disclosure of PHI not otherwise permitted by the Rule. Where the Privacy Rule requires patient authorization, consent is not sufficient to permit use or disclosure of PHI unless it also satisfies the requirements of a valid authorization. An authorization is a detailed document that gives covered entities permission to use PHI for specified purposes, which are generally other than treatment, payment or health care operations, or to disclose PHI to a third party for an identified purpose, as specified by the individual.²⁹

Additionally, Title 42 of the Code of Federal Regulations (CFR) Part 2: Confidentiality of Substance Use Disorder Patient Reports ("Part 2") places additional safeguards around patient information related to substance use disorders and treatment. Patient information is protected under Part 2 when it is held by an entity that is part of a federally assisted program and treats substance use disorder. Treatment information protected by Part 2 may only be disclosed with patient's written consent.⁹

Some platforms can track specific consent or authorization forms signed by the patient, making it permitted use or disclosure readily apparent.

Other Approaches to CBO Referral Facilitation

Many vendors' electronic platforms serve as complete or partial community referral resource platforms; many were compared in a 2019 report compiled by SIREN.⁴ In addition to the functionality offered by various platforms, potential implementers should also consider vendor responsiveness, level of implementation support and platform cost when selecting a platform.

Alternative approaches also providing these functionalities. Some EHR vendors are beginning to offer these functions and connectivity as native to their products.

Community information exchanges are ecosystems of intersectoral community partners that share information on through a standardized data collection language.³⁰ This model generates information transparency and strengthens partners' capacity to strategize care planning for their community.³¹ These systems may also include some features of a community referral resource platform.

The Pathways Community HUB Model³² helps communities work together to support vulnerable populations. Twenty-one evidence-based, standardized pathways address risk factors that are barriers to achieving health. HUBs often have a community resource referral platform to facilitate their work.

Additionally, some organizations are designing systems with community resource referral functions from the start, with increased interoperability as an all-inclusive goal.

²⁷ U.S. Department of Health and Human Services (HHS). (2020). *The Security Rule*. Retrieved from <https://www.hhs.gov/hipaa/for-professionals/security/index.html>

²⁸ American Medical Association (AMA). (n.d.) *HIPAA Security Rule and Risk Analysis*. Retrieved from <https://www.ama-assn.org/practice-management/hipaa/hipaa-security-rule-risk-analysis>

²⁹ U.S. Department of Health and Human Services (HHS). (2013). *What is the difference between "consent" and "authorization" under the HIPAA Privacy Rule?* Retrieved from <https://www.hhs.gov/hipaa/for-professionals/faq/264/what-is-the-difference-between-consent-and-authorization/index.html>

³⁰ About NIEM. (2016). *NIEM | National Information Exchange Model*. Retrieved from: <https://www.niem.gov/about-niem>

³¹ What is CIE? (n.d.). 211 San Diego Community Information Exchange. Retrieved May 8, 2020 from <https://ciesandiego.org/what-is-cie/>

³² Pathways. (2019). *Homepage*. Retrieved from <https://pchi-hub.com/>

Appendix B: Project Details and Setting

In 2014, Medical Home Network (MHN), a Chicago-based provider collaborative, established an accountable care organization (ACO)³³ in the Medicaid managed care environment, with the goal of transforming care delivery. Its unique care management model uses technology in the primary care setting to track where patients receive care. Medical home-based care managers work with patients to manage their health by identifying social risks and providing resources and support. As of March 2019, more than half of ACO members (53,000 of 111,000) identified at least one social risk factor.

In partnership with Cook County Health System (CCH), MHN is developing CommunityCare Connect, a connectivity platform for care managers in primary care medical homes and staff at community-based organizations (CBO; also referred to as “social service agencies”) that work with Medicaid beneficiaries. The platform supports bidirectional communication and collaboration on patient needs that are addressed outside the primary care setting.

The platform has three features that support medical home care managers and CBOs. The first is an ability for connected CBOs covered under HIPAA to search for relevant patient information—including claims history and care management information. This access allows CBO staff to better understand a patient’s unique situation and health history, resulting in care that is most appropriate for the patient.

The second feature is bidirectional messaging between medical home care managers and participating CBOs. MHN recognized at the project’s outset that not every CBO needs bidirectional communication with medical homes or will use the platform to access patient health information, but there is value for medical home care managers in knowing if their patient completed a referral to a CBO.

The third feature integrates the platform with an online community services resource directory, enabling care managers to identify organizations that best align with patients’ needs, including convenient hours and locations. Medical home care managers can then close the referral loop with patients through a phone call or text message, rather than relying on CBO staff to log into the system to communicate the information.

Project Goals

The primary care medical home model is often associated with a reduction in health care utilization, including decreased utilization of unnecessary services such as visits to the ED and in-patient hospitalization stays.³⁴ Prior analysis has shown that digitally connecting the medical home and the inpatient and ED settings for purposes of care management decreases patient utilization.³⁵

Connecting medical homes to CBOs allows staff to collaborate on caring for persons who are treated by both organizations. Providing CBO and medical home staff with context about a patient allows interventions to be tailored more closely to the patient’s needs. Providing medical home staff insight into the CBO’s actions allows improved referral patterns and supports the patient in seeking further assistance and care.

Medical home care managers can be most effective with access to infrastructure to manage, facilitate and track referrals. Medical home care managers can partner with their peers at CBOs more easily if they have access to shared documentation, bidirectional communication and consistent data collection

³³ MHN ACO. (n.d.). *Homepage*. Retrieved from <http://mhnaco.org/>

³⁴ Nielson M, Gibson A, Buelt L, Grundy P, Grumbach K. (2015). *The Patient-Centered Medical Home's Impact on Cost and Quality: Annual Review of Evidence 2013-2014*. The Patient-Centered Primary Care Collaborative Publication.

³⁵ Art, J. (2019, November 18-19). *Behavioral Health Integration: Moving Beyond the Collaborative Care* [Conference presentation]. MHN Ideas Exchange 2019, Chicago IL, United States. <https://medicalhomenetwork.org/exchange>

across organizations. This helps promote shared accountability and can prevent patients and clients from falling through the cracks.

It should be noted that the platform, as conceived and executed in the reference implementation, contains both common functionality for a community resource referral platform and additional care coordination functions that may not be included in all such platforms.

This project had three distinct phases, as described in Table 5.

Table 5: Project Phases

Phase #	Phase	Participants	Functionality
1	Patient Search Rolled out to CBOs	CBOs: Behavioral Health Consortium and HRS Home Health	View of patient data: <ul style="list-style-type: none"> • Medical home name • Care manager name and contact information • Historical health information: <ul style="list-style-type: none"> ○ ED and inpatient visit information ○ Procedures, medicines
2	Bidirectional Communication	Additional CBOs Care management entities (CME)	<ul style="list-style-type: none"> • Message center • Message assignment
3	Community Services Resource Directory Link	Additional Care Management Organizations Patients-may participate in two-way texting	<ul style="list-style-type: none"> • Consent upload and verification • System integration with contracted community services resource directory

Project Setting

NCQA originally proposed this project as a means of understanding the effects of connectivity between medical homes and CBOs. It was designed to leverage an existing initiative between CountyCare (a Medicaid health plan) and MHN to connect primary care medical homes in the CountyCare network with CBOs. This work focused on low-income, high social-risk Medicaid recipients in Cook County, Illinois, a group with social needs, such as food insecurity, that are addressable by CBOs and are known to affect health outcomes.

The study group included all CountyCare Medicaid managed care members enrolled at MHN Accountable Care Organization (ACO) sites, representing about 110,000 patients in a primarily urban setting, with low socioeconomic status and a high rate of limited-English proficiency.

There is a high rate of social risk in this population. One in five surveyed CountyCare members reported concern about a “place to sleep tonight or in the near future.” Almost one-third of CountyCare patients with four social risk factors have had an IP visit and 85% have had an ED visit.

MHN had previously implemented a platform to connect medical home providers with hospital staff, capture care planning and care management information and document health risk assessments for ACO patients. The community referral platform was a logical next step to connect CBOs to the existing network.

Methods

In order to understand the roadblocks, resultant delays and lack of uptake, integration and utilization of the platform, the team conducted a series of interviews with relevant stakeholders from CBOs and medical homes.

Stakeholder Identification

The team identified three staff types for CBOs and medical homes that could provide relevant insights:

1. Leadership: Organization leaders who were typically involved in the project at a high level. They may have approved the use of the platform and view it as worthwhile to integrate, but are not involved in its day-to-day implementation or utilization.
2. Project Managers: Medical home or CBO staff who helped design, implement and integrate the platform across the organization, likely to have been trained in its use but typically don't use it on a day-to-day basis.
3. End Users: Medical home or CBO staff who were asked to integrate the platform into their day-to-day workflow.

Interview Process

We recruited interviewees from November 2019–February 2020, working with MHN. The team identified medical home and CBO staff who 1.) fit the leadership, project manager or end user role; 2.) were currently employed at a CBO or medical home; 3.) had exposure to or experience using the platform; 4.) were available for a half-hour interview in person or over the phone between November 2019 and February 2020.

We identified over 30 stakeholders across 10 organizations. Of these, 23 stakeholders from 8 organizations participated in an interview.

In addition to interviews with CBO and medical home staff, three key staff members from MHN and one key staff member from CCH were recruited and interviewed to share their experiences with platform implementation.

Over four months, half-hour, semi-structured interviews were conducted in person or over the phone by two team members. Each stakeholder was interviewed individually, with the exception of two stakeholders from the same organization who were interviewed together. Each interview was recorded and stakeholders were compensated for their time.

Although interview guides varied depending on the organization and interviewee staff type, the overall goal was the same: understand the individual's experience with the platform. Interviewee questions included why they thought their organization joined the project, what their overall experience was using the platform, if they had data privacy concerns (specific to Part 2), how the platform impacted their workflow, advice they would give to other organizations going through a similar process and their training experience.

Interview guides for CCHS and MHN staff were similar, with the overarching goal of understanding their experiences with the platform; questions varied by staff type. Interviewees were asked about their overall experience with the platform, how they identified members of the steering committee, anticipated challenges and data and privacy concerns they experienced.

Identify Key Themes and Lessons Learned and Develop Recommendations

After interviews were complete, we reviewed notes from each. Key themes were identified and recorded in a table to understand their frequency and what type of staff and type of organization were more (or less) likely to align with the themes. We used key themes to formulate lessons learned and develop recommendations presented below.

We also conducted two discussions—one webinar and one in-person discussion—with additional RWJF S4A researchers and included their lessons learned and recommendations where they added to those in the study project.

Limitations

This study posed two key limitations. First, it primarily reviewed one reference implementation project. Interviews were conducted with participants who could meet with the research team during the interview period; interview contacts were facilitated by the technology implementation team for the project. Because of the small sample size per organization (one–four interviews from each), it is possible that findings do not fully represent each organization’s experience. Second, because the reference implementation platform studied had experienced limited uptake at the time of the interviews, some staff had limited experiences to share about using the platform. For some organizations, platform training had taken place several months prior, making it more difficult for interviewees to recall experiences.

In addition, there is a significant change to the landscape on the horizon. The Office of Civil Rights (OCR) has issued a Notice of Proposed Rulemaking (NPRM) to amend HIPAA to remove barriers to care coordination. This change supports the reference implementation project goals to remove HIPAA concerns that currently constrain communication between CBOs and medical homes and other providers.

One primary goal of the NPRM is to improve information sharing for care coordination and case management. OCR proposes an amendment to the definition of health care operations to expressly state that individual-level care coordination and case management are permitted uses and disclosures of PHI, with the requirement for individual consent or authorization. The NPRM also intends to clarify that permitted use allows disclosure of PHI to CBOs, home and community-based service providers, social service agencies and similar third parties, whether or not the provider is a “covered entity” under HIPAA.

OCR notes in the NPRM that HIPAA already allows information sharing needed for care coordination and care management as part of treatment by providers and for health care operations. Because social services are not always viewed as part of a treatment plan, some covered entities incorrectly believed that information sharing with a CBO was not permitted. This confusion was due to the syntax of the regulations, which suggested that only population-based activities were permitted. The NPRM clarifies HIPAA guidance and proposes modifications to the Privacy Rule to facilitate beneficial activities at both the individual and the population level.

Although publication of the Final Rule is months in the future, the release of the NPRM will start to have an immediate effect on the project by clarifying for covered entities, CBOs and other health care organizations that sharing of PHI for care coordination is a permitted activity as part of both treatment and health care operations. Clarification of the permissible and beneficial role of CBOs in health care will improve care coordination initiatives.