Lucile Packard Foundation
for Children's Health

Report

Achieving Care Integration for Children with Medical Complexity:

The Human-Centered Design Approach to Care Coordination

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Executive Summary

Health care delivery for children with medical complexity (CMC) remains fragmented, which limits the potential to achieve optimal health and developmental outcomes. Traditionally, care coordination is initiated and managed within a single practice or entity, resulting in duplication of effort and persistence of unmet family needs. This project utilizes human-centered design (HCD) to rethink the process of care coordination for CMC. The goal is to design an approach to care integration across all sectors of care and support to achieve optimal health and wellbeing for the child. Through a series of HCD steps, the project reached the following conclusions:

1. Coordinated care **can** be a predictable "designed" pathway of care across multiple sectors of care, including medical, education, financial, and community services.
2. Building effective care coordination pathways and processes with a cross-sector collaborative approach results in care integration.
3. Care integration for CMC requires a series of feedback loops across the multiple services sectors, and a care coordinator's task is to actively manage the processes of the feedback loops.

The essentials to successful care integration for CMC are (1) a cross-sector data and information platform with a shared plan of care; (2) a playbook of jointly designed, predictable care pathways; and (3) a designated care coordinator who is responsible for managing information flow and feedback. HCD methods can bring together a coalition of cross-sector stakeholders to pilot test the proposed elements of care integration.

Introduction

Children with medical complexity (CMC) are characterized by multiple chronic conditions, a high level of health care need, and high family need for support and services.[1] Coordinating their multiple services is an essential part of their care but too often falls on their families to provide. Even when care coordination is available, it rarely achieves integration of services. Better models of care coordination that meet the needs of CMC and their families, and also providers and payers, are needed. This paper describes the application of Human-Centered Design (HCD) principles to creating better care coordination for CMC. An Expert Working Group, representing family partners, providers, hospitals, and care systems, imagined and designed a system in which care coordination for CMC – addressing medical, educational, and social needs – could be integrated and delivered effectively.

The Human-Centered Design Approach to Care Coordination

The term design is often associated with the visual aesthetics of a product. However, *design* can also be applied to a service or experience. The experience of using a product or service is affected not only by how well the product works and meets the needs of all users, but also how enjoyable or desirable a product is. The product should appeal to emotions, predictability, and ease of use.

The current system of care for CMC is not *"designed"* for CMC and their families. Reports illustrate the system as stressful, unpredictable, and not easy to navigate. One likely reason is that care coordination efforts for CMC often originate from individual organizations. A clinical provider's office may provide case management with a defined medical focus. However, that narrow focus risks failing to address the contributions of education, legal, or financial sectors that are essential to support the overall health and wellbeing of the child and family.

The field of HCD centers the thinking of a product or service squarely on the users' needs, behaviors, and experiences. A well-designed service works in a predictable manner, improves experiences, and appeals to the user's emotions. For this project, we used the methodologies of HCD to take a "fresh look" at care coordination for CMC, utilizing strategic design methods (see Appendix 1 for terms). The desired state for the user is care integration that meets all the needs of the user, whether it be medication, transportation, school, or social. To achieve this idealized service model may require disruption of the current system.

Figure 1. Disruption in Other Business Sectors

There are many examples of disruption in other sectors of business that have reimagined existing methods and altered the prevailing lens through which the business was viewed. One historical example is Henry Ford and the assembly line, which disrupted the automobile industry from predominantly hand-built, expensive coaches to transportation devices at far lower cost. The result of this disruption was vehicles produced for many more people and alteration of the personal transportation landscape. A current example is Amazon, which is disrupting retail not only by the use of online shopping, but also by using algorithms to suggest products and allowing online reviews, which streamlines the user experience.

Four Steps to Applying Human Centered Design to Care Coordination for CMC

HCD uses a methodology called the four "D's": Discover, Define, Design and Deliver.

1. **Discover** is a deep dive into understanding the issues, emphasizing the "user journey." Discover entails both a detailed literature review and broad stakeholder input. The key aspect of Discover is the generation of empathy for the user. Empathy is important to develop key insights to the user experience.
2. **Define** is the organization, analysis and synthesis of the information and insights identified in the Discover phase.
3. **Design** is when the team turns insights into ideas and evaluates potential solutions. A cross-disciplinary team is encouraged to brainstorm and draw ideas from other fields. Frameworks of care are developed in the Design phase.
4. **Deliver** is the product of a Roadmap for implementing solutions and a learning space for testing (prototyping) new ideas and initiatives.

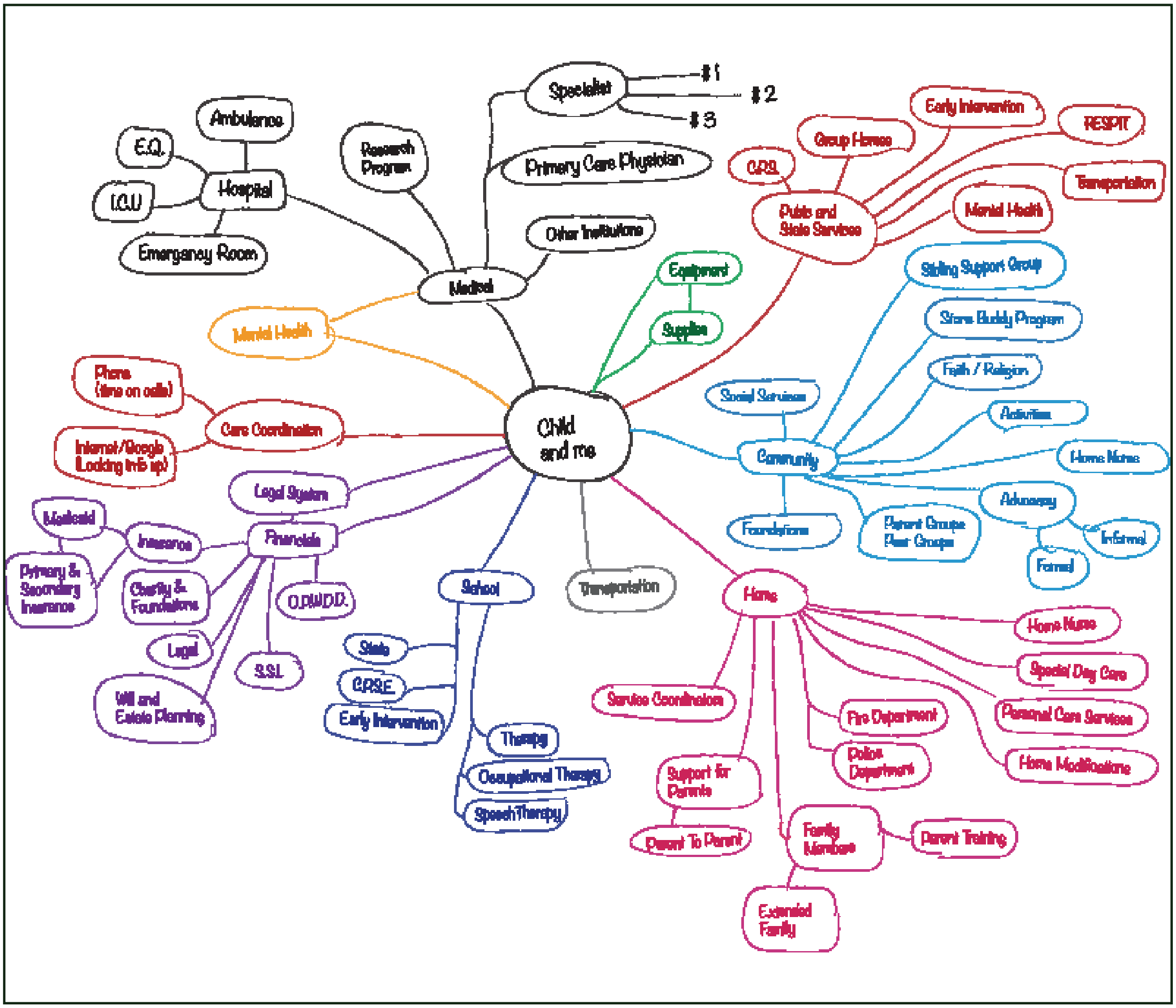
Step 1: Discover What Is Care Coordination and How To Do It

Existing Literature: A review of existing care coordination frameworks helped the Expert Working Group understand needs and opportunities. Reviewed frameworks included the American Academy of Pediatrics (AAP), the Agency for Healthcare Research and Quality, and the Case Management Society of America. The AAP definition emphasizes formal assessments, team-based activity, and addressing "interrelated, medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes."[2] No existing care coordination framework is specific to CMC.

Focus groups were held to understand specific "pain points" in a multiple-system perspective. We held two family, one community-service provider, and one physician focus groups, consisting of six to ten participants each. Participants represented a wide range of training, experience, socioeconomic background and medical condition. The focus groups began with two exercises that grounded the discussion in users' journeys and the components needed to facilitate the journey across care sectors. The two exercises were:

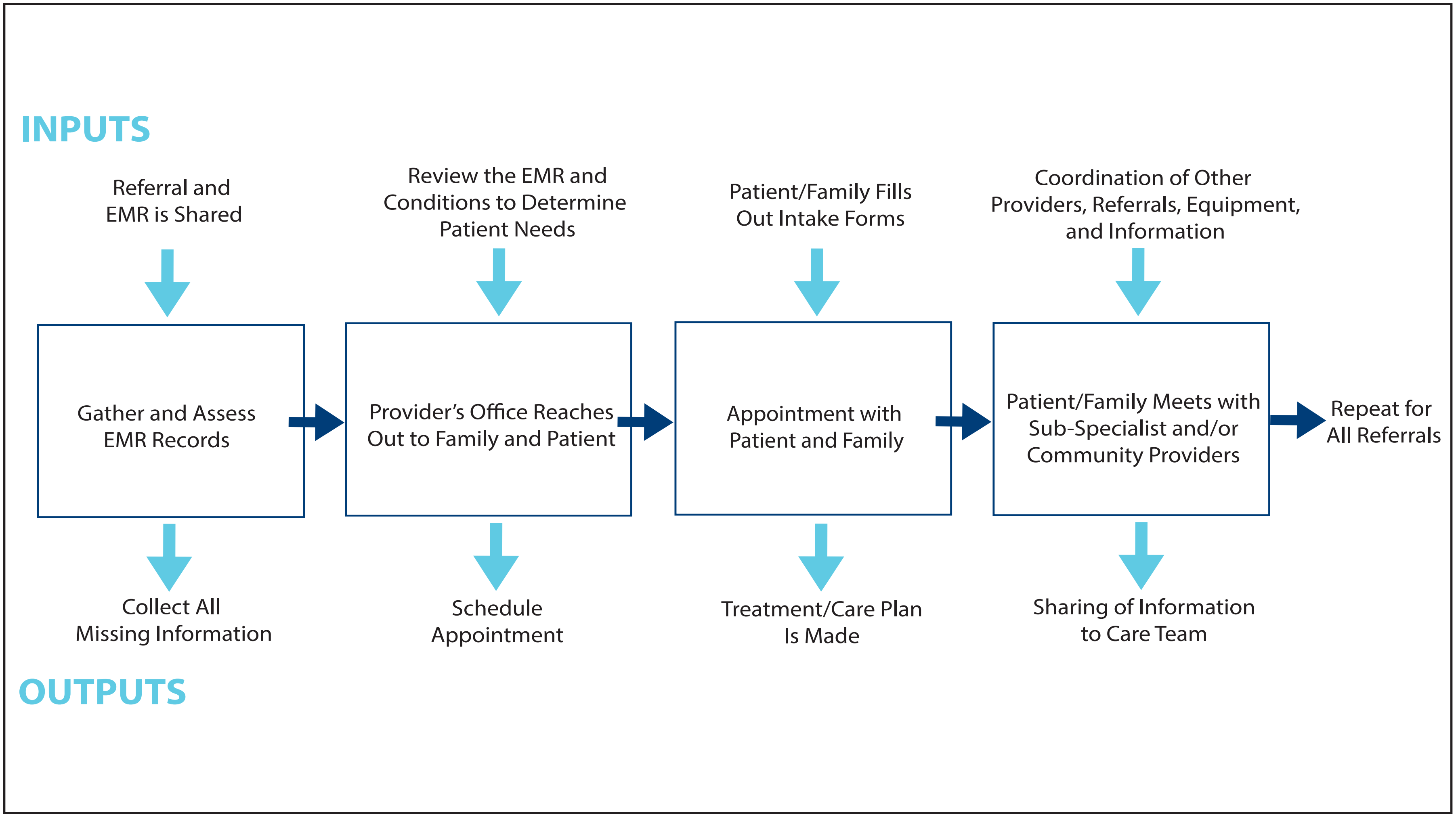
- **Care mapping – the "what"**: a tool that visually depicts the care complexity described by the family of a child with medical complexity. Participants were asked to describe all services the children and their families currently use, from home to school to clinical settings, from doctors to pharmacies to therapies and support groups. Care mapping has been previously described;[3] depicted in Figure 2 are the multiple services identified by the two family focus groups.

Figure 2. Care Mapping Exercise Composite Results



- **Service mapping – the "how"**: a tool that investigates "how" each step in a journey is enabled.[4] Participants described the processes that both enable a step to move forward (input) as well as the result of a step (output) (See Figure 3 on the next page). Service mapping complements the care map by examining the sequence of steps and user interactions necessary for each step to succeed.

Figure 3. Service Mapping Composite Result



Inputs = resources and processes that enable a step to occur.

Outputs = results of that step that also enable the journey to move forward.

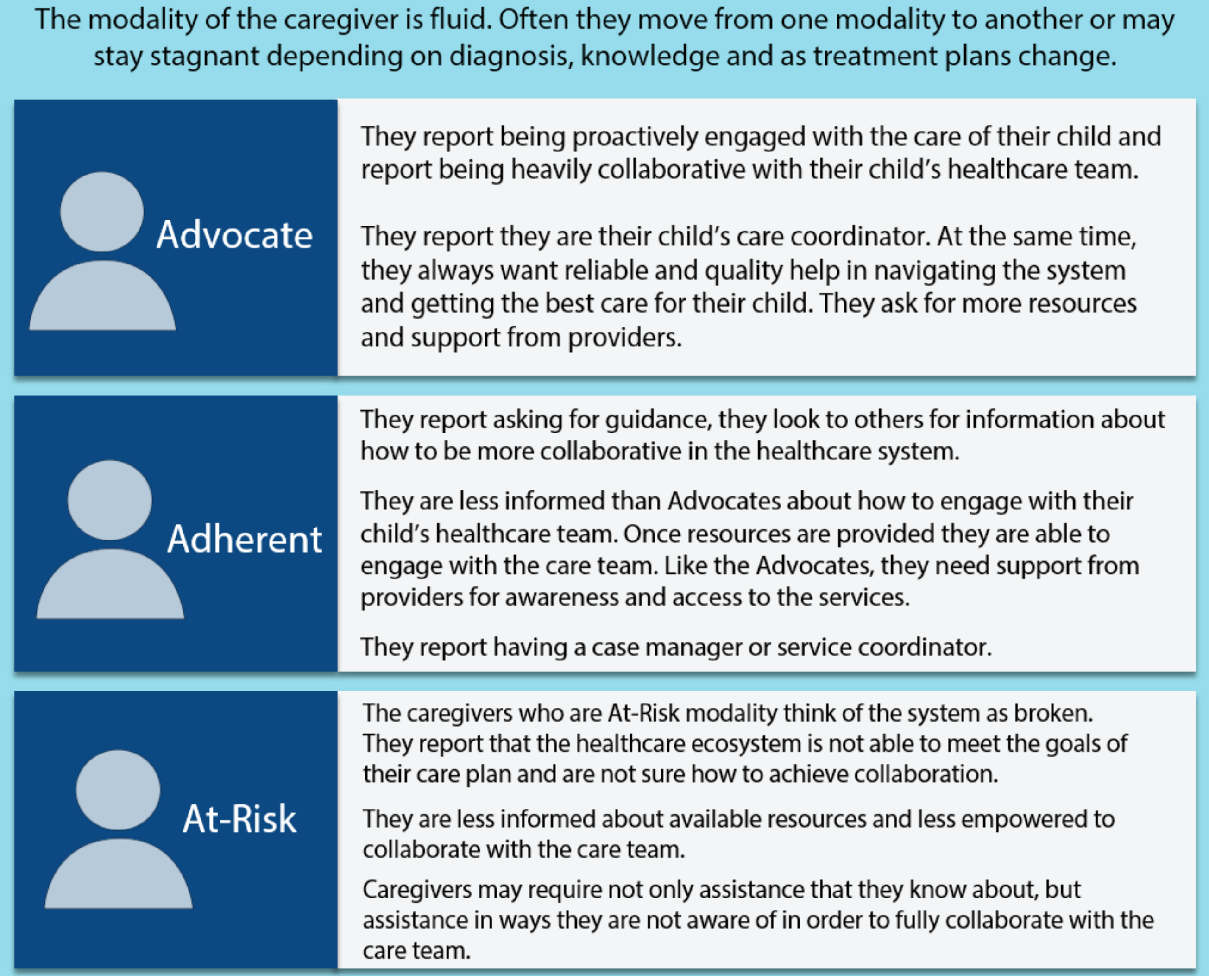
Grounding the focus groups in care mapping and service mapping allowed a broader discussion by highlighting places where infrastructure and processes do not support care delivery. The focus group discussion (Appendix 2) emphasized concerns about uneven care quality, sub-standard information transfer across settings, and resulting family and provider burdens.

Design Thinking Workshop: The Expert Working Group convened at a one-day meeting and were asked “How might we ensure that CMC receive coordinated care, resulting in care integration?” The workshop intended outcomes were:

1. Participants’ views of the problem are altered by looking outside the healthcare industry for inspiration.
2. Participants apply a human-centered approach to CMC care coordination to generate ideas to be used in the Define and Design phases.

Workshop participants were guided by three personas described in Figure 4. The personas were based on focus group input. Considerations included different social, demographic, and cultural needs; motivators and observed behaviors; and patterns of current or potential use of services.

Figure 4. Synthesized Personas Created for the Design Workshop



The modality of the caregiver is fluid. Often they move from one modality to another or may stay stagnant depending on diagnosis, knowledge and as treatment plans change.

Advocate	They report being proactively engaged with the care of their child and report being heavily collaborative with their child’s healthcare team. They report they are their child’s care coordinator. At the same time, they always want reliable and quality help in navigating the system and getting the best care for their child. They ask for more resources and support from providers.
Adherent	They report asking for guidance, they look to others for information about how to be more collaborative in the healthcare system. They are less informed than Advocates about how to engage with their child’s healthcare team. Once resources are provided they are able to engage with the care team. Like the Advocates, they need support from providers for awareness and access to the services. They report having a case manager or service coordinator.
At-Risk	The caregivers who are At-Risk modality think of the system as broken. They report that the healthcare ecosystem is not able to meet the goals of their care plan and are not sure how to achieve collaboration. They are less informed about available resources and less empowered to collaborate with the care team. Caregivers may require not only assistance that they know about, but assistance in ways they are not aware of in order to fully collaborate with the care team.

Two design thinking exercises were used:

- *Analogous Inspiration*: describe examples of cross-sector integration from fields outside of health care. Examples such as AirBNB, Amazon, and UBER address user needs by influencing behavior, generating emotions, and engaging the user.
- *Ideating a Design Solution*: create a care plan that can be used by all sectors. Using an experience-based approach, two ideas were generated: (1) Community-based, cross-sector partnerships integrating social and other support services. (2) Investment portfolios based on user defined objectives and goals, overseen by a professional manager.

Step 2: Define Desired Core Attributes of Care Coordination for CMC

Existing Literature highlighted several attributes of care coordination: (a) Care coordination is a specific set of partnering activities to achieve a state of care integration; (b) a family-centered approach is foundational to effective care coordination; (c) cross-sector relationships are important; and (d) infrastructure planning and tools to facilitate implementation are recommended. A recent review of care coordination further outlines current thinking.[3]

Focus Groups recommended the following themes and requirements for effective care coordination:

- Family needs are best met through (1) a team-based approach to care; (2) centralized resources for self-management; (3) consistent and reliable information transfer among providers and families; and (4) support for families that addresses social factors impacting health.
- Community-based service providers' needs can be met with (1) established and reliable communication channels among providers; (2) consistent quality of care delivery; and (3) sufficient resources to support all identified family needs.
- Healthcare professionals' needs are met by assuring (1) streamlined and effective transfer of information among care team members; (2) incorporation of social determinants of health in care planning; and (3) timely and adequate payment for services.

The Design Thinking Workshop consolidated these and other observations about solutions and barriers for care plans to provide the basis for the third step, the design phase of this project. The steps in a consolidated approach include:

- A team-based care approach across *all* sectors of care and life.
- A planned approach to care, with proactive identification of met and unmet user needs, and defined care pathways to health and well-being.
- The active management of information transfer among multiple system partners, with simultaneous feedback and feed-forward loops.
- Consistently high quality of care among multiple system providers.
- Centralized and individualized information and guidance for the child and family.

Step 3: Design the Key Components of Care Integration for CMC

Using the focus groups and Design Thinking Workshop insights, we created a care ecosystem framework of integrated care (See Appendix 3). The framework illustrates the design of key components of care integration for CMC. Activities and interactions throughout the care continuum are depicted. A cross-sector interaction might be among medical, educational, and pharmaceutical services. An internal organizational interaction might be between specialists and a primary care physician. The individual level could include planning and in-person visits among parents/CMC and providers. Tools, resources and relationships that support care integration are noted throughout.

Three foundational components of an effective ecosystem are recommended: Platform, Playbook, and Care Coordinator.

- **Platform** – A platform allows shared access to patient information, data, and care plans. It is centralized, and accessible by the care team including team members from a variety of sectors, caregivers and CMC. While no perfect platform system currently exists, foundational components may include the Shared Plan of Care template[5], with a medical summary and negotiated care plan components between family and providers; a common electronic health record (EHR); and data sharing agreements to facilitate communication.
- **Playbook** – A playbook contains descriptions of jointly designed and standardized pathways of care across the care continuum. A pathway of care depicts how a child and family move through and across sectors of care. A designed and standardized pathway includes expectations for timing of feedback and outcome measurement across and within systems. Feedback and feed-forwards loops, including documentation of family concerns and satisfaction, are parts of the playbook. Automatic referrals to home care agencies and co-management protocols between primary and specialty care are examples of activities that would be included in the playbook.
- **Care Coordinator** – A care coordinator, typically but not always an individual, is a single access point through the system that ensures care through the system according to design. While typically called a “coordinator,” the individual is actually “curating” the experience by managing the process and information flow to maximize quality and efficiency of services for CMC. The coordinator specifically manages the feedback and feed-forward loops of information within and outside the care team. The information flow helps the users (CMC and family) move along the pathway of care.

The ideal care system promotes integration of care by utilizing a centralized access platform that contains health and social records. The platform facilitates designed – i.e. predictable and standardized – pathways of care among all users.

In summary, a designed system of care integration emphasizes (a) a platform of tools and resources, (b) a playbook of planned pathways of care, and (c) a care coordinator to “curate” information transfer, learning loops, and team-based care. The platform, playbook, and care coordinator may be individualized for the organization(s) and system, but all need to be integrated in a predictable process for the user.

Step 4: Deliver the Necessary Tools to Implement a New Care Coordination System

Many current systems rely on families of CMC to perform care coordination and "curate" the process of information transfer and sharing among entities. The designed ecosystem changes the system from one reliant on families to a designed, supported system for the user. The Roadmap to Integrated Care (See Appendix 4), which provides steps towards implementation of integrated care, is based on the experience of previous examples of disruptive innovation[6,7] and includes three key components:

Care Integration which requires multiple organizations to jointly design and deliver care. A cross-sector guiding coalition for CMC is necessary to lead transformation efforts. Visible leadership from key stakeholders may include families, a children's hospital, primary care, social service providers, community-based organizations, payers, and leaders who are able to implement changes across systems. The guiding coalition should brainstorm and identify their **ecosystem** of care for CMC, based on the available resources to support care, including the playbook, platform, and coordinator. The voices of the patient and family is essential to identifying facilitators of care who are likely to promote positive outcomes.

Level-setting entails the adoption of common platforms, metrics and pathways. Teams must know how and what information flows across sectors, up and down within organizations and among providers and families. Partners in information technology, electronic health records, and/or bioinformatics may be key to creating and adopting common metrics and pathways. The participants of the system must learn and improve from its processes such as through Plan-Do-Study-Act cycles. Common performance metrics across sectors can provide valuable information to guide system improvements.

Since each organization and system challenges are unique, an **adaptive framework** entails pilot testing the designed care pathways and information flow. Initially the care pathway can be "prototyped" on a small group of users. "Prototyping" may be a term familiar to consumers who understand it to mean a product is still under development. Results can appropriately modify and adapt the cross-sector, data-sharing components to achieve care integration.

Conclusion

The health and wellness of CMC requires addressing multiple sectors of care and the information flow between the sectors. The use of human-centered design can result in the necessary disruption that integrates system thinking and incorporates a holistic approach that addresses user needs and experiences. A designed cross-sector approach to care that incorporates assessments, tools, and “curating” of information flow can lead to the desired state of care integration. The necessary disruption requires a cross-sector coalition willing to pilot test changes across systems.

Opportunities and challenges include the lack of interoperability of electronic health records and the lack of cross-sector data systems. Leadership needs to consider the number and composition of cross-sector organizations willing to “prototype” care pathways, including families, health care, education, and social services. It is essential that financial models are able to support a cross-system of care approach, as payment models are currently siloed and largely remain fee-for-service for CMC care delivery. Moving CMC care integration away from these isolated pathways and towards a fully integrated system of care will hinge upon exploration of value-based payment models.

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Appendix 1: Strategic Design Terms

Ecosystems are frameworks that consider and incorporate all aspects of the environment in which patient care exists, including home, clinical settings, and social determinants of health. Multiple levels of an ecosystem include networks connecting individuals, organizations and systems. Defining ecosystems improves our understanding of care delivery and communication challenges within and across sectors of care.

Feedback/Feed-forward Loops exist when information regarding the delivery of healthcare services are shared among stakeholders with the purpose of impacting service delivery. Feedback shares information with a referring source. Feed-forward shares the same information with a future provider. Loops describe how information flows back and forth, affecting decision-making and performance in an incremental manner.

Guiding Coalition is the team of process owners for a systems change process, such as discovery and implementation of new approaches to care system delivery. Guiding coalitions can consist of leadership and staff at all levels who can work within or across systems. Membership should include representatives from each stakeholder interest.

Modality is the caregiver's/patient's state-of-being/emotional state and their attributes or needs at a specific time and space within the care process. A caregiver's modality may be different at the time of diagnosis compared to two years afterwards when immediate medical needs may have transitioned to educational and financial needs.

Patient Journey is the representation of how patients navigate, move through, and engage the health care system, including the emotional state throughout the care process. This includes accessing and utilizing services, and communication of relevant information.

Personas are representations of social, demographic, cultural, motivators, and health needs to gain insights of user needs, behaviors and goals. Personas are essential to understanding how users interact with their system of care.

Platform refers to a central repository of all the components of care, patient and provider-related information that is accessible to the patient and care team. The platform should facilitate communication and connectivity of patient information to improve health outcomes and effective use of resources. Data sharing across sectors and systems, privacy and security are paramount.

Playbook includes the planned and provided services along care pathways for each individual patient throughout their journey. Clinical and non-clinical pathways should be documented and archived for reference and use.

Prototype is an opportunity to model or test a proposed solution to the identified problem/challenge on a small scale. The prototype is modified based on testing and performance utilizing data and quality improvement methods.

Roadmap provides the general directions that guide participants through the necessary activities to improve the delivery process and outcomes; the "how." It is a plan that guides the actual implementation process, identifying potential barriers, pain points, pathways, and deliverables. It also indicates where there are opportunities to recalibrate the plan and include additional stakeholders.

Systems Thinking is the examination and mapping of the interactions, relationships, and "causality" among all parts of a system, and their connectivity to support the delivery and utilization of patient care and other related activities.

Appendix 2: Focus Groups

Four focus groups were held in June and July of 2017. There were two caregiver, one community-based provider, and one physician focus groups. Each group had six to ten participants recruited by purposive sampling, through listservs, fliers, and targeted mailing. The final groups included:

- Families: range of diagnoses, ages, medical conditions, services received, race/ethnicity, and demographic backgrounds
- Community-based providers: child care, early intervention, pharmacy, and home health
- Physicians: primary care (including private practice and children's hospital-based), complex care, specialty care, intensive care, and emergency room

After introductions, two moderators led each group through care mapping and service mapping exercises (samples below). Subsequent questions focused on the user journey and shared experiences, particularly the emotions, behaviors, and actions of a daily journey or activity of a child with medical complexity.

The focus groups were approved through the Institutional Review Board of the University at Buffalo.

Relevant Themes:

Family: Inability to Navigate Care Ecosystem

"There is not a central database or repository, there is no one singular entity or even all the organizations together ... and that is an ongoing need"

"Sometimes [I am] on the phone from 8 o'clock in the morning until 5 o'clock at night just trying to coordinate all of this. It's the phone calls..."

Family: Lack of Peer Connection

"They're the only people who really understand, truly, what we're going through."

Family: Coordinating and Directing Care

"I went through six or seven service coordinators all of which didn't know anything. Honestly, they'd come to my house and I'd tell them what we needed and whatever else, and they'd be like, "Oh, I don't think we can do that," or "Oh, I don't think that's possible." I'd be like, what do you mean it's not possible? Do you know what I mean?"

Community Providers: Lack of Communication

"And all of a sudden you have a child come to school with a G-tube but that child eats for you at lunchtime every day. And you're like, why does this child have a G-tube?...we see a different child within programs and we probably could have avoided this G-tube if there was better communication."

Community Providers: Uneven Quality

"I think the parents are at the mercy of whomever they reach out to first. So the quality of all is not all equal, and the knowledge of all is not equal….some entities do a better job at that, like, triage, then others, and some know more about where to send parents."

Physicians: Transfer of Information

"Usually you open up the records and you have no idea what you're looking for, and it's kind of like a box of chocolates, because once you open it up you have no idea what you're getting. Sometimes some places send us the last visit and sometimes there's no medical history in it, and a copy of the vaccines. Some places send you every visit they've ever had…"

Physicians: Social Determinants of Health

"if you're going to have CF, it's much better to do it in an upper-middle class family than a lower socioeconomic group. You're just going to do better. You'll know how to problem-solve, you'll know how to work the system, and if the system is complex … If you're stressed out and trying to figure out how to keep the air conditioning running and keep food on the table, your ability to then follow up on the care needs of your child are not going to be…"

Appendix 3: Description of the Ecosystem Framework (Figure 5)

The Ecosystem Framework is a top-level framework that represents the different levels of care integration for the CMC. The framework captures all the steps, actions, and supporting functions to deliver needed care by the interconnected organizations and providers.

Provider Journey –Three levels of steps taken by providers.

> Cross Sector – steps used to communicate and ensure information flows across different care sectors, such as health care, behavioral health, education, and legal.
>
> Internal Organizational – steps used to communicate and ensure information flow across a specific system, such as the PCP and specialists.
>
> Individual Level – steps used to communicate and ensure information flow between an individual provider and the patient.

Patient Journey – Steps taken with an individual service provider. At the patient level, many steps may happen in sequence or concurrently with other providers.

Supporting Functions

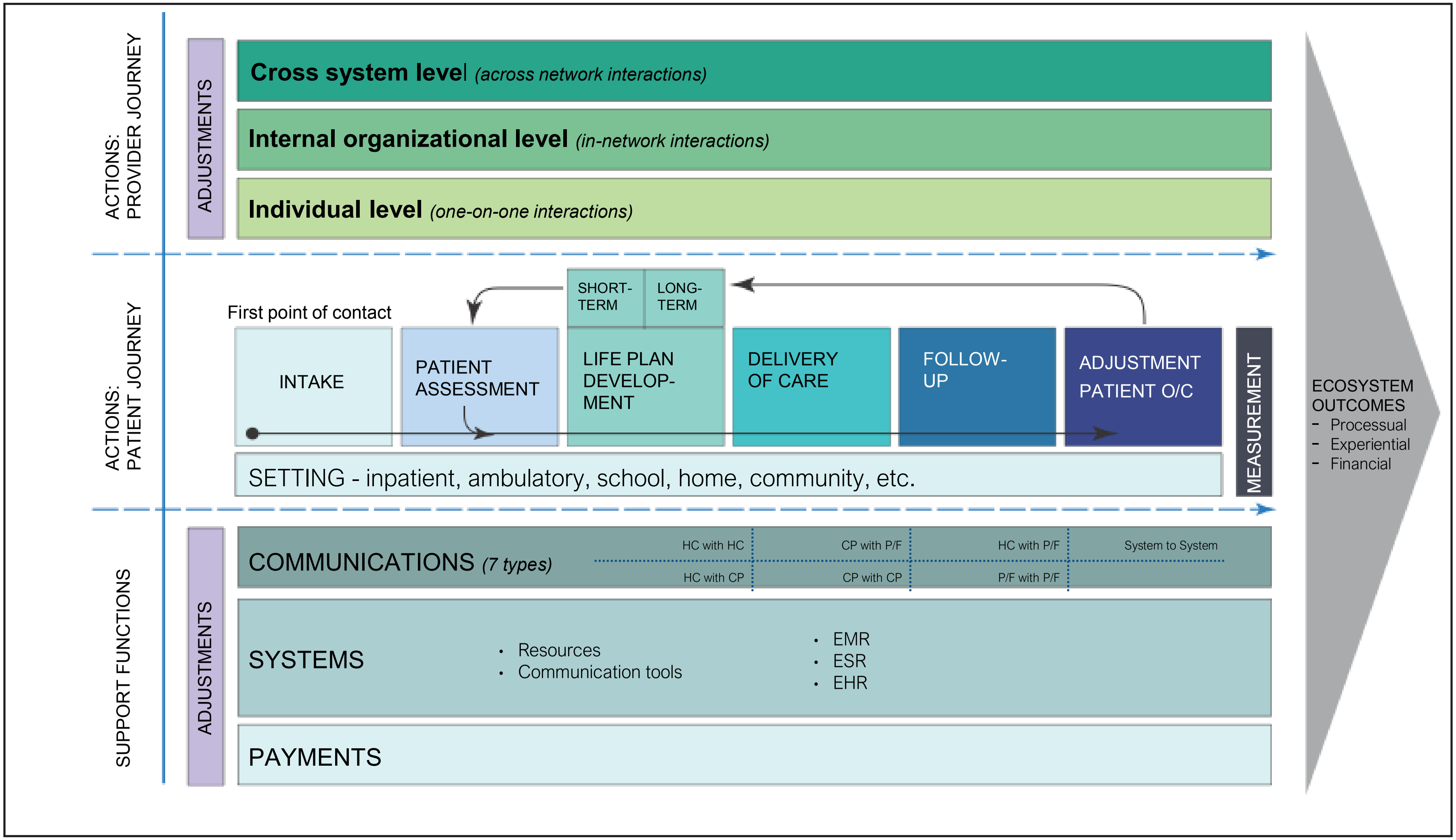
These infrastructure components are needed to support the actions of coordinated care for CMC.

> Communications – infrastructure that facilitates communication among stakeholders, including feedback and feed-forward loops
>
> Systems – infrastructure that facilitates the transfer of information among stakeholders
>
> Payments – support for the infrastructure, including adequate payments

Measurements and Adjustments

Data-driven outcomes are necessary to evaluate (1) the patient's and family's experience receiving care, and (2) the effectiveness of the system in delivering integrated care to the CMC.

Figure 5. Ecosystem Framework of Care for Children with Medical Complexity

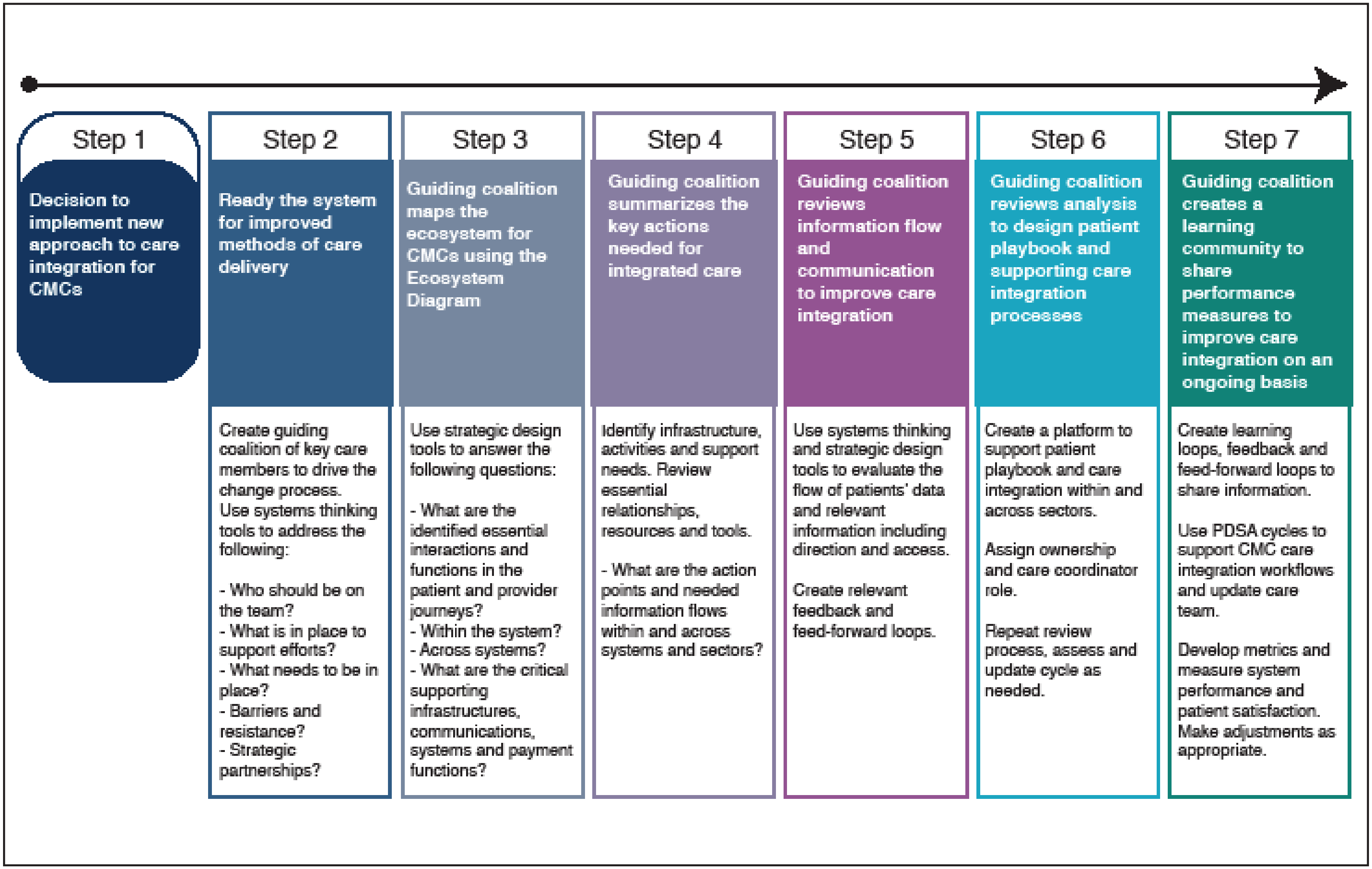


Healthcare (HC); Community Provider (CP); Patient & Family (P/F);
Electronic Medical Record (EMR); Electronic Social Record (ESR) Electronic Health Record (EHR)

Appendix 4: Roadmap

The Care Integration Roadmap: Detail (Figure 6) can be introduced to guide the implementation of the new initiative, identifying support to sustain the improvement, building in the requisite review processes, and reinforcing sustainable integrated care delivery. It includes a step-by-step process of evaluation, each component building on the information shared and knowledge developed, moving the organizations toward the desired care integration. Thus, the Care Integration Roadmap not only provides the user with the model, but also provides guidance on implementing this new approach. The overall intended outcome is an improved care experience for all participants.

Figure 6. Roadmap for Implementation of User-Oriented Care Integration: Detail



Step 1	Step 2	Step 3	Step 4	Step 5	Step 6	Step 7
Decision to implement new approach to care integration for CMCs	Ready the system for improved methods of care delivery	Guiding coalition maps the ecosystem for CMCs using the Ecosystem Diagram	Guiding coalition summarizes the key actions needed for integrated care	Guiding coalition reviews information flow and communication to improve care integration	Guiding coalition reviews analysis to design patient playbook and supporting care integration processes	Guiding coalition creates a learning community to share performance measures to improve care integration on an ongoing basis
	Create guiding coalition of key care members to drive the change process. Use systems thinking tools to address the following: - Who should be on the team? - What is in place to support efforts? - What needs to be in place? - Barriers and resistance? - Strategic partnerships?	Use strategic design tools to answer the following questions: - What are the identified essential interactions and functions in the patient and provider journeys? - Within the system? - Across systems? - What are the critical supporting infrastructures, communications, systems and payment functions?	Identify infrastructure, activities and support needs. Review essential relationships, resources and tools. - What are the action points and needed information flows within and across systems and sectors?	Use systems thinking and strategic design tools to evaluate the flow of patients' data and relevant information including direction and access. Create relevant feedback and feed-forward loops.	Create a platform to support patient playbook and care integration within and across sectors. Assign ownership and care coordinator role. Repeat review process, assess and update cycle as needed.	Create learning loops, feedback and feed-forward loops to share information. Use PDSA cycles to support CMC care integration workflows and update care team. Develop metrics and measure system performance and patient satisfaction. Make adjustments as appropriate.

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