

Holistic Care Coordination in Kansas

Environmental Scan and Literature Review



Authors

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Executive Summary

Holistic care coordination (HCC) is a patient-focused approach that considers the physical, emotional, and social aspects of a patient and family when providing services and supports in the development of a healthcare plan.¹ Healthcare providers and care coordinators often work as a team to assess the medical, behavioral, educational, social, developmental and financial needs of a patient and family in order to achieve optimal health.^{2,3}

The Kansas Department of Health and Environment (KDHE) Title V Maternal and Child Health Services Program partnered with the Kansas Health Institute on this study to explore how the HCC model could be expanded across primary care and maternal and child health programs in Kansas. This report provides insights into current HCC services in Kansas and aims to inform future improvements to HCC policy and practice across Kansas. This report is structured under four components including a literature review and environmental scan, survey of care coordination providers, interviews with insurance providers, and focus groups with parents. Key findings are discussed in more detail below.

Key Finding 1: Opportunities to Improve Communication Between Patients and Care Teams

Effective communication between healthcare providers and parents is crucial for parental satisfaction and meeting their child's care needs. The survey found that 75 percent of healthcare providers developed shared plans of care, with 90 percent of those providers working closely with families and over half communicating with parents at least every 30 days. However, the parents in the focus groups indicated that there was often inconsistent and unclear communication from the care team or their designated care coordinator. Based on recommendations from the literature, parents, provider's care coordinators, and Medicaid managed care organizations (MCOs) and insurance companies, communications with patients and their families could improve by using a patient-centered approach, using a single point of contact to build trust and rapport, and using modes of communication (in-person, telephone, electronic) that meet the patient and family's needs.

Key Finding 2: Challenges with Billing for Holistic Care Coordination

Representatives from MCOs and the health insurance companies interviewed primarily stated that they provide holistic care coordination directly to their members as a value-added service. Holistic care coordination was not viewed as something healthcare providers could bill for, except among those enrolled in alternative payment models, like value-based care. This is reflected in the survey data that show fewer than half of healthcare providers and less than a quarter of local health departments could bill for at least some holistic care coordination services. The literature review showed that some states, such as Kentucky, North Carolina, and Alabama, allowed for time and administrative components of holistic care coordination to be reimbursed.

Key Finding 3: Capacity of Healthcare System and Access to Holistic Care Coordination

The interviews with MCOs and health insurance companies, and the survey of healthcare providers and local health departments, suggested that there is a relatively high capacity for holistic care coordination in Kansas. The capacity of the healthcare system and access to HCC services are critical factors for effective care coordination. The MCOs and private health insurance plans employ care coordinators and use sophisticated tools to identify and work with families. The survey found that nearly 75 percent of healthcare providers had a designated care coordinator, except for respondents from local health departments. Interviews with MCOs revealed efforts to expand internal capacity for HCC through training, expanding referral networks and improving programs to include addressing social determinants of health. However, parents still reported several challenges with their care coordination, including a lack of knowledge about available services, insufficient follow-up and unclear plans of action. The literature review found that care coordinators manage large and medically complex caseloads, experience poor relationships with physicians, and have trouble reaching parents, which may explain some of these issues. HCC is a strategy to address the fragmentation of healthcare, but needs adequate system and provider capacity to be beneficial.

Key Finding 4: Health Equity

The literature review found that states incorporate equity into HCC programs and practices by completing cultural competence organizational self-assessments, using non-traditional and culturally competent providers like doulas or community health workers and administering provider trainings on culturally and linguistically appropriate care. Insurance companies and MCOs interviewed also discussed cultural competency and meeting member's linguistic needs. However, parents said there was a lack of cultural sensitivity in HCC services for their children, describing challenges in cultural-specific access and language barriers specifically for Spanish speakers. Parents also said the services they received were not sensitive to special needs, particularly for their children with autism or who are deaf. Both survey respondents and interview participants described using social determinants of health (SDOH) to identify patients for HCC services. Interview participants also described using SDOH and demographic data to prioritize members experiencing greatest inequities for HCC services.

Introduction

The Kansas Department of Health and Environment (KDHE) and the Kansas Health Institute (KHI) conducted the first phase of the environmental scan that focuses on assessing existing holistic care coordination (HCC) services, programs, and payment models. As defined in the Holistic Care Coordination Environmental Scan Request for Proposal (RFP), an effective HCC model focuses on all aspects of family life, allowing for stronger supports around cross-system navigation and addressing the primary needs identified by the family, including physical, social and emotional health services, housing, education, legal and financial aid. This report seeks to identify and understand the current environment of holistic care coordination practices and programs for Kansas residents who are pregnant or in their postpartum period, or who are children, primarily those age 0-8. Specifically, KDHE indicates five overall study aims:

Aim 1: Conduct national environmental scan of care coordination models and related billing practices across states.

Aim 2: Conduct environmental scan of care coordination services delivered across public health and private health systems across Kansas.

Aim 3: Assess coverage related to care coordination services by the top five insurance companies serving Kansas families.

Aim 4: Assess primary care and public health provider experience with providing care coordination services to pediatric populations in Kansas.

Aim 5: Assess the patient experience with receiving care coordination services in Kansas.

Both the environmental scan and literature review will aid in the development and execution of the following research activities:

- Develop a survey of organizations that are part of the public health and private health systems to identify HCC services delivered

An effective holistic care coordination (HCC) model focuses on all aspects of family life, allowing for stronger supports around cross-system navigation and addressing the primary needs identified by the family, including physical, social and emotional health services, housing, education, legal and financial aid.

across both systems and to understand provider experiences with delivering these services.

- Conduct key informant interviews (KIIs) with the top five insurance companies and all three Medicaid managed care organizations (MCOs) in Kansas to assess insurance coverage of HCC services.
- Assess patient experience with receiving care coordination services in Kansas and other states by conducting focus groups with parents/guardians of children age 0-8 who are receiving care coordination services or have received these services in the past 12 months and individuals who are receiving prenatal or postpartum care or have received these services in past 12 months.

Findings from the focus groups with Kansas residents who are parents of children age 0-8, pregnant or postpartum, key informant interviews with insurance companies and MCOs, and the survey of individuals who provide care coordination services are summarized in this technical report along with results from the literature review and environmental scan. Potential next steps for KDHE's consideration are included as well. For this study, public health system providers include local health departments, KanCare MCOs, hospitals (e.g., University of Kansas Health System, Children's Mercy), federally qualified health centers (FQHCs), and primary care providers (e.g., family physician practices, pediatricians).

This report focuses on holistic care coordination for Kansas residents who are pregnant or in their postpartum period, and children age 0-8. It does not focus on administrative case management, which provides eligibility and enrollment assistance to individuals who have been found functionally eligible for the brain injury, physical disability, and frail elderly waivers and the Program of All-Inclusive Care for the Elderly (PACE). This report also does not address OneCare Kansas, a Medicaid option providing coordination of physical and behavioral healthcare with long-term services and supports for people with chronic conditions, nor does it focus on targeted case management as provided in the intellectual and developmental disabilities waiver or the serious emotional disturbance waiver.

This document contains a glossary of terms used throughout the report in *Appendix A*.

Research Approach

This study has four components including a literature review and environmental scan, survey of care coordination providers, interviews with insurance providers and focus groups with Kansas residents who are parents of children age 0-8, pregnant or postpartum. The research approach for each component is presented at the beginning of its corresponding section. The appendices contain more details about the methodologies used for the literature review (*Appendix B*), survey (*Appendix C*), interviews (*Appendix D*) and focus groups (*Appendix E*). Questionnaires for the survey, interviews and focus groups are available [here](#).

Approach To a Novel Recruitment Challenge

During this study, the KHI team encountered a novel recruitment challenge in which many ineligible individuals repeatedly sought to participate in the focus groups or the provider survey through deception in an attempt to meet inclusion criteria. Due to evidence of suspicious activity while recruiting for focus groups, recruitment was paused on November 3, 2022, prior to conducting any focus groups, and KHI strengthened the recruitment approach to screen and remove potential scammers and ensure protection of confidentiality of focus group participants. Recruitment resumed with these strengthened screening processes on January 9, 2023. These efforts were taken to ensure participants and their confidentiality were protected from ineligible individuals. The provider survey encountered similar exposure to suspicious activity. In response, KHI adapted the filtering approach used prior to survey analysis to remove responses from respondents who did not meet eligibility criteria. Details on this approach are included with research methodologies for the survey (*Appendix C*) and focus group (*Appendix E*) components.

Literature Review and Environmental Scan

The environmental scan and literature review were developed to support research activities through examining publicly available information from state websites, state policies and supplemental literature. The summaries below were developed from compiled evidence and state-specific examples of care coordination services and programs.

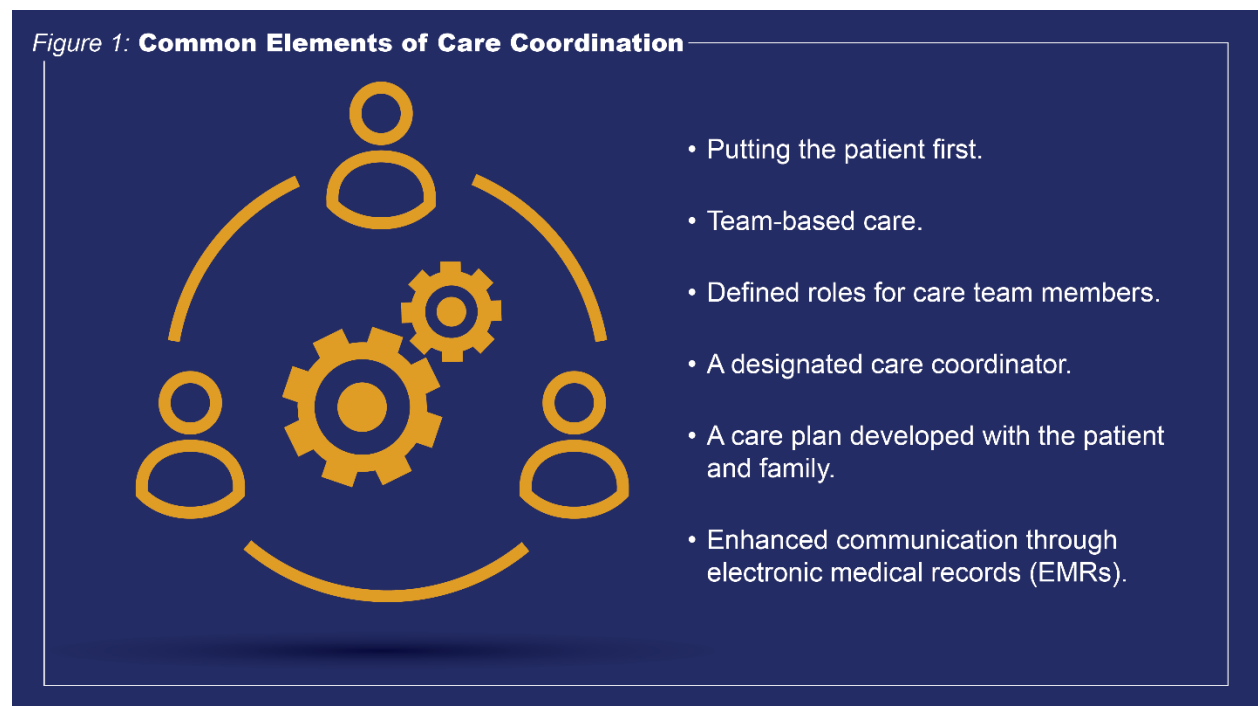
Key Findings

Findings from the environmental scan and literature review submitted to KDHE are summarized below. These summaries are high-level and include information that emerged as common themes and considerations from the full environmental scan and literature review.

Definition and Key Elements of Holistic Care Coordinationⁱ

Holistic Care Coordination is a patient-focused approach that considers the physical, emotional, and social aspects of a patient.⁴ Healthcare providers and care coordinators often work as a team to assess a child's and family's needs to achieve optimal health by addressing medical, behavioral, educational, social, developmental and financial needs.^{5,6}

Common elements of care coordination are shown in *Figure 1*.^{7,8}



Barriers to implementing holistic care coordination include limited staffing capacity, care coordination not being a reimbursable service or activity and inadequate communication channels.⁹

ⁱ Section summarizes [Question 1](#) (Appendix B).

Care Coordinator Experiences with Holistic Care Coordinationⁱⁱ

Findings on physicians' experiences in providing care coordination are limited and focus on the experiences of care coordinators working with families with children who have complex medical conditions (CMCs).¹⁰

The findings on care coordinator experiences focus on barriers and challenges, as shown in *Figure 2*.^{11,12,13}



Parent Experiences with Holistic Care Coordinationⁱⁱⁱ

The literature focuses on patient and family satisfaction with components of care coordination. Parents and caregivers noted a need for increased parental involvement and communication from providers, to be viewed as experts in their child's care, increased information sharing and a clearer understanding of the role of care coordinators.¹⁴ Communication was identified as a key indicator of care coordination experiences and additional indicators include parental satisfaction and quality of life (QOL) of the caregiver, which was measured by the number of days mentally unhealthy or anxious.^{15,16} Studies showed that having a supportive and knowledgeable care

ⁱⁱ Section summarizes [Question 2](#) (Appendix B).

ⁱⁱⁱ Section summarizes [Question 3](#) (Appendix B).

coordinator was associated with higher QOL and fewer mentally unhealthy days for caregivers.^{17, 18}

Holistic Care Coordination Policies^{iv}

States have implemented policies related to care coordination that are included in state legislation, Medicaid program guidance and state agency rules and regulations currently in practice. Efforts to accomplish policies may be state or organization led. Common care coordination policy areas identified across states aim to integrate siloed provider data and payment systems to allow for collaboration,¹⁹ establish task forces and committees to address issues related to care coordination and maternal health,²⁰ adopt regulations to allow flexibility in how certain communities are served, and enhance coverage and benefits for home visiting services.^{21, 22}

Holistic Care Coordination Billing Practices^v

Care coordination billing, payment and funding practices are shifting from fragmented care between multiple providers and care settings to an integrated ecosystem. For this shift to take place, states are structuring their benefits and payment models to allow for coordinated care between multiple providers.²³ Some models are transitioning from the traditional fee-for-service (FFS) payment models to bundled payment strategies and alternative payment models (APMs). The FFS payment structure rewards providers for performing procedures and services, but often fails to reimburse for care coordination to prevent gaps in care, resulting in duplication of services and redundancy of care by other providers for the same patient.^{24, 25}

Care coordination activities may not yet be considered services to some payors. In the FFS model, care coordination would require providers to conduct potentially non-reimbursable activities (e.g., care team meetings, patient self-management education, care coordination, data analysis, communication with other clinicians and closed-loop referrals). Some state billing models allow for some or all time and administrative components of care coordination to be reimbursable.²⁶

^{iv} Section summaries [Question 5](#) (*Appendix B*).

^v Section summarizes [Question 6](#) (*Appendix B*).

Addressing Social Determinants of Health and Equity^{vi}

Social determinants of health (SDOH) play a crucial role in affecting health outcomes and must be considered for care coordination to be holistic. SDOH are the conditions in the environments where people are born, live, learn, work, play, worship and age that affect health, functioning, and quality-of-life outcomes and risks.²⁷ A 2017 Colorado survey indicated that over two-thirds of healthcare organizations in the United States screen for SDOH as part of ongoing care management.²⁸

The application of an equity lens for care coordination aims to improve health equity and ensure that efforts to increase patient safety and healthcare quality do not inadvertently increase inequities among specific populations with higher rates of health inequity.²⁹ Ensuring health equity requires an in-depth understanding of populations of focus and how best to serve them. See *Appendix A* for full definition of health equity and populations of focus. This involves an understanding of the populations and serving them using culturally competent providers³⁰ and non-traditional providers³¹ (e.g., doula and community health workers), administering provider training for culturally and linguistically appropriate care, and conducting cultural competence organizational self-assessments.³²

Survey of Care Coordination Providers

The purpose of this survey was to measure the extent of services across the six domains of HCC ^{vii} (*Figure 3*, page 8), and to identify issues with billing and overall needs.³³ The target population included individuals who provide, or are knowledgeable of, care coordination services provided by their organization or practice for children age 0-8, prenatal, and postpartum populations in Kansas. The survey was disseminated through professional associations and coalitions between October 26, 2022, and January 3, 2023. Respondents were asked to identify the primary location of their practice. Respondents were excluded from the analysis if they did not consent, did not serve the target population, indicated their practice was not located in Kansas, or were suspected of fraudulent activity. The survey methodology is described in greater detail in *Appendix C*.

^{vi} Section summarizes [Question 7 and 8](#) (*Appendix B*).

^{vii} Each domain description is summarized from [Question 4](#) (*Appendix B*).

Figure 3: Six Domains of Holistic Care Coordination



Key Findings

The findings from the survey are summarized below. For each section, key findings are presented first and a narrative summary of the data is presented second.

Overview of Survey Respondents

Key Findings

The survey respondents represented a variety of types of organizations, roles, and geographic regions throughout Kansas. However, the overall sample (n=81) was relatively small, and pediatrician (2.5 percent) and OB-GYN (3.7 percent) practices appeared to be underrepresented compared to other types of healthcare providers. This could affect the validity and generalizability of the results considering that the focus of this project was on HCC services for pediatric, pre-natal, and postpartum populations. Nevertheless, the survey provides important insights into HCC practices among healthcare providers (HCPs) and local health departments (LHDs) in Kansas.

Summary of the Results

A total of 81 valid responses were received. Approximately half of the respondents were from HCPs (49.4 percent). This included FQHCs (8.6 percent), family practice clinics (14.8 percent),

pediatrics clinics (2.5 percent), OB-GYN clinics (3.7 percent), and hospitals (19.8 percent). The next largest group of respondents were from LHDs (42.0 percent). The most common roles held by respondents included administrator (29.6 percent), nurse (22.2 percent), care coordinator (13.6 percent), social worker/case manager (11.1 percent), and community health worker (9.9 percent). Most respondents identified as female (87.7 percent) as well as non-Hispanic (86.4 percent) and white (79.0 percent). About 9 out of 10 respondents reported working with children age 0-2 (90.1 percent) and 3-5 years (88.9 percent). More than 6 out of 10 respondents reported working with individuals receiving prenatal care (64.2 percent) or postpartum care (69.1 percent).

Domain 1: Screening, Identification, and Assessment

Screening, identification, and assessment are considered a foundation for HCC. A variety of tools and methods are available to identify, assess, and evaluate patient's needs throughout a continuous process.

Key Findings

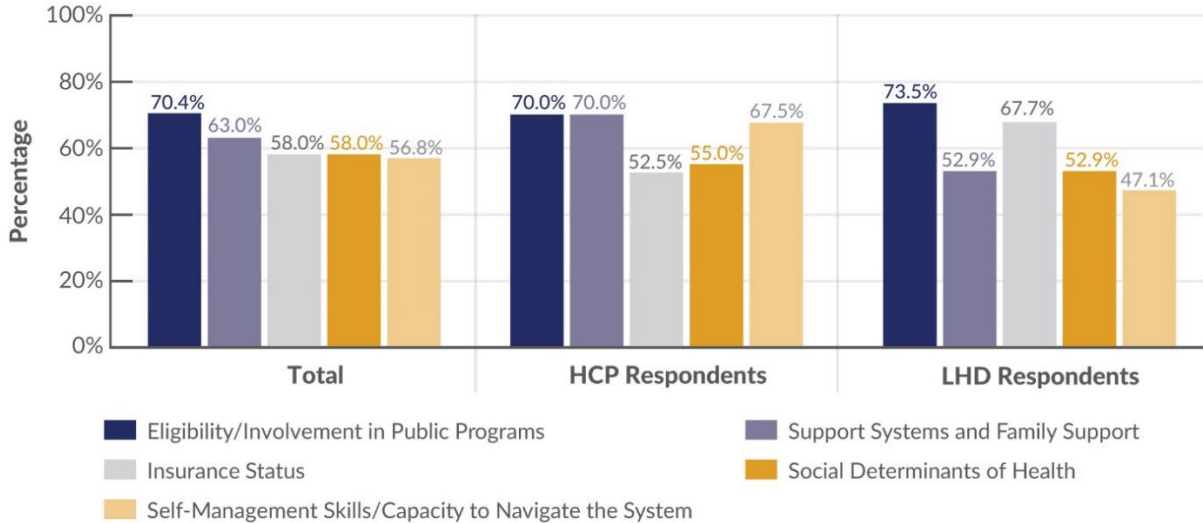
The most frequent considerations for additional support that would be beneficial to patients/families were related to the patient's family and public support systems, insurance status, and social determinants of health. By including numerous factors in their process for determining if HCC is needed, respondents' organizations may provide a more robust means for identifying people in need of HCC.

Summary of the Results

More than half of the survey respondents indicated that the following considerations were used to determine if additional support would be beneficial to the patient/family: (1) eligibility for and involvement in public programs (70.4 percent), (2) availability of support systems, including family support (63.0 percent), (3) insurance status (58.0 percent), (4) social determinants of health (58.0 percent), (5) the patient's self-management skills/capacity to navigate the system (56.8 percent), (6) unmet needs for services and support (54.3 percent), (7) health status of the caregiver and family members (54.3 percent), and (8) health literacy and health education needs (51.9 percent). Demographic (28.4 percent) and involvement in the justice system (29.6 percent) were indicated the least frequently.

Among HCP respondents, the three leading considerations used to determine if additional support would be beneficial to the patient/family cited most frequently included: (1) eligibility for and involvement in public programs (70.0 percent), (2) availability of support systems, including family support (70.0 percent), and (3) the patient’s self-management skills/capacity to navigate the system (67.5 percent). Among LHD respondents, the three leading considerations used to determine if additional support would be beneficial to the patient/family cited most frequently included: (1) eligibility for and involvement in public programs (73.5 percent), (2) insurance status (67.7 percent), and (3) unmet needs for services and supports (58.8 percent). Information about the top five considerations used by respondents to determine if additional services would be beneficial to the patient or their family is provided in *Figure 4*.

Figure 4. Top Five Considerations Used to Determine if Additional Services Would be Beneficial to the Patient or Their Family



Note: Total Respondents = 81; Healthcare Provider Respondents = 40; Local Health Department Respondents = 34. HCP = Healthcare Provider; LHD = Local Health Department; Respondents could select all that apply. Source: Kansas Health Institute analysis of Survey of Care Coordination Providers.

Domain 2: Shared Plan of Care

A shared plan of care is a living document to establish a partnership and assure the care being provided meets needs and ensures accountability from providers, patient, and family.

Key Findings

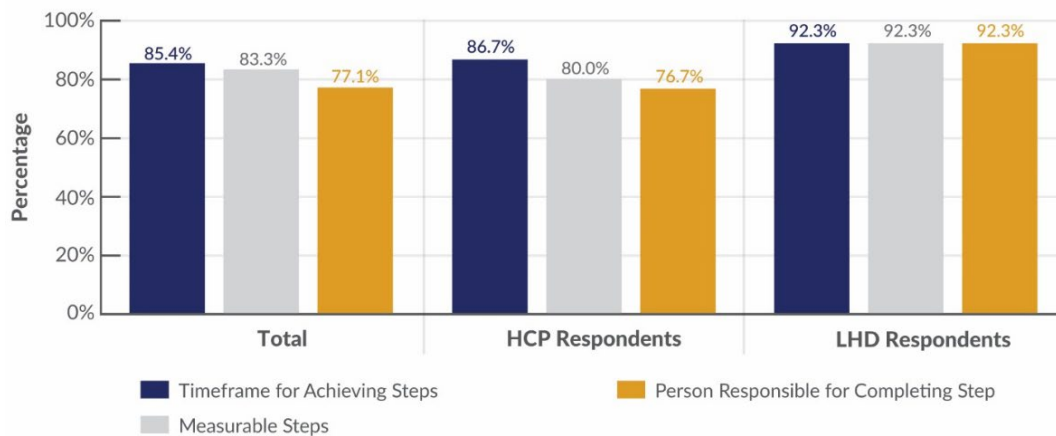
- Seventy-five percent of HCP respondents used a shared plan of care. Most of the HCP respondents that used a shared plan of care worked with patients and families to develop the plan (90.0 percent).

- Many HCP respondents who used a shared plan of care reported the following components were included in the patients care plans: Time frames for achieving steps (86.7 percent), measurable steps (80.0 percent), and person responsible for completing steps (76.7 percent). This suggests that most HCP respondents are providing robust care plans for patients.
- Nearly 4 in 10 (38.2 percent) LHD respondents used a shared plan of care. While LHDs provide many clinical preventive services they do not typically operate as a patient’s medical home. This could explain why the use of shared plans of care is low among LHDs.

Summary of the Results

A majority of survey respondents indicated using a shared plan of care (59.3 percent), including 75.0 percent of HCP respondents and 38.2 percent of LHD respondents. Almost all respondents who reported using a shared plan of care also reported that they work with patients/families to develop care goals (89.6 percent). Components of patients’ care plans include measurable steps (83.3 percent), a time frame for achieving steps (85.4 percent), and a person responsible for completing each step (77.1 percent). Over one-third (35.7 percent) of respondents reported reviewing and updating care plans more frequently than every 30 days, followed by every 3-4 months (25.0 percent) and every 1-2 months (20.8 percent). Information about the components included in patients’ care plans is provided in *Figure 5*.

Figure 5. Components of Patients Care Plans



Note: Limited to respondents that stated that their organization uses shared plans of care. Total Respondents = 48; Healthcare Providers Respondents = 30; Local Health Department Respondents = 13. HCP = Healthcare Provider; LHD = Local Health Department; Respondents could select all that apply.
 Source: Kansas Health Institute analysis of Survey of Care Coordination Providers.

Respondents were also asked to write what role they thought patients and their families should have in developing a care plan. Responses for this open-ended question reflected that patients and their families should have a “primary” or “active” role. Responses also indicated that patients and their families should “contribute to decision making,” “determine what is favorable and affordable,” and “decide what their personal goals are.”

Domain 3: Team-Based Communication

Team-based communication is needed between providers, patients, and families to establish and maintain the care plan and care partnership. Those on the care team must be timely, efficient, respectful, and culturally sensitive.

Key Findings

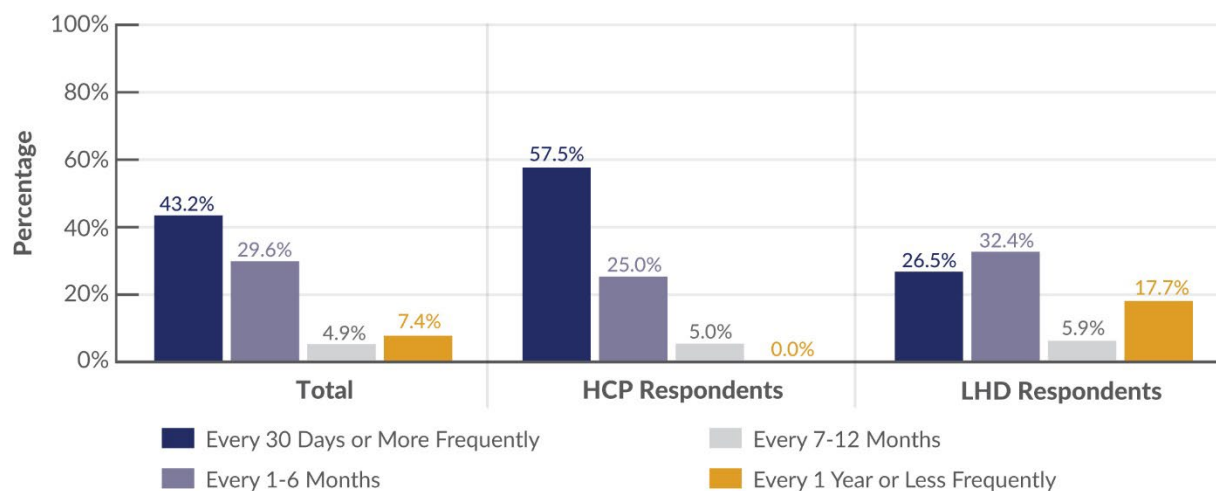
- More than half (57.5 percent) of HCP respondents stated they communicate with patients and families at least every 30 days. Communications appeared to take place primarily in-person or over the phone, potentially allowing for discussion and questions.
- More than half (57.5 percent) of HCP respondents stated they communicate with other members of the care team at least every 30 days. Among the HCP respondents, electronic health records (EHRs) were used most frequently (67.5 percent), in addition to in-person (42.5 percent) and telephone (37.0 percent) communications.
- Relatively few challenges were identified communicating with members of the care team, other than staff time (42.0 percent).
- Most respondents (81.5 percent) indicated that their organization refers patients to community-based organizations. Communications with community-based organizations appeared to be relatively frequent, with 39.5 percent communicating at least every 30 days and 29.6 percent communicating every 1-6 months.

Summary of the Results

The most common way respondents indicated that patients should contact their care team was using the main office number for their facility (72.8 percent). Using the direct phone number (48.2 percent) or email address (40.7 percent) for members of the patient’s care team were also cited by a substantial number of respondents, but not a majority.

Respondents indicated that care plans were shared with patients most commonly through in-person communication (61.7 percent) and over the phone (39.5 percent). Electronic health records were used to share care plans with patients among 42.5 percent of HCP respondents and 8.8 percent of LHD respondents. Most respondents also reported communicating with patients/patient’s families every 30 days or more frequently (43.2 percent) or every 1-6 months (29.6 percent). Information about the frequency respondents communicated with patients or their families is provided in *Figure 6a*.

Figure 6a. Frequency of Communications with Patients or Their Families



Note: Total Respondents = 81; Healthcare Provider Respondents = 40; Local Health Department Respondents = 34. HCP = Healthcare Provider; LHD = Local Health Department; Respondents could select all that apply.
 Source: Kansas Health Institute analysis of Survey of Care Coordination Providers.

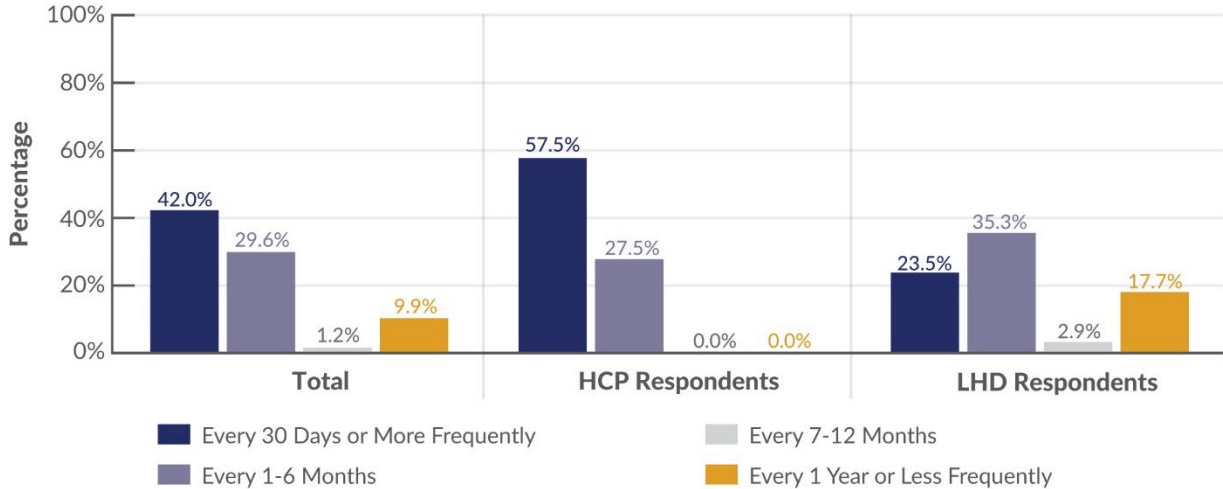
Respondents were asked how their organization promoted trust between the patient and their care team. Common responses to this open-ended question were related to empathy, confidentiality, respect, support, follow through, communicating in-person, and building rapport and relationships.

A majority of HCP respondents had an EHR (72.5 percent) and used an EHR to share care plans with care team members (67.5 percent). Half of LHD respondents (50.0 percent) had an EHR and 20.6 percent used an EHR to share care plans with care team members.

Respondents were asked which EHR systems their organization used. The most commonly cited EHRs among HCP respondents were Athena Health, Cerner, and eClinicalWorks (ECW). The most commonly cited EHRs among LHD respondents were Nightingale Notes, Patagonia, KIPHS, and Cure MD.

Respondents also reported communicating with other care team members every 30 days or more frequently (42.0 percent) or every 1-6 months (29.6 percent). *Figure 6b* provides information about the frequency respondents communicated with members of the care team. Most respondents also reported referring patients to community-based organizations (81.5 percent). The leading challenges for communicating patient care needs to other care team members include staff time (42.0 percent), obtaining patient consent (27.2 percent), data protection (25.9 percent), and reimbursement for this time (25.9 percent).

Figure 6b. Frequency of Communications with Members of the Care Team



Note: Total Respondents = 81; Healthcare Provider Respondents = 40; Local Health Department Respondents = 34. HCP = Healthcare Provider; LHD = Local Health Department; Respondents could select all that apply.
 Source: Kansas Health Institute analysis of Survey of Care Coordination Providers.

Domain 4: Individual and Family Empowerment

Individual and family empowerment may occur by encouraging growth from ongoing assessment, engaging families in self-management practices, and instilling a sense of self-efficacy.

Key Findings

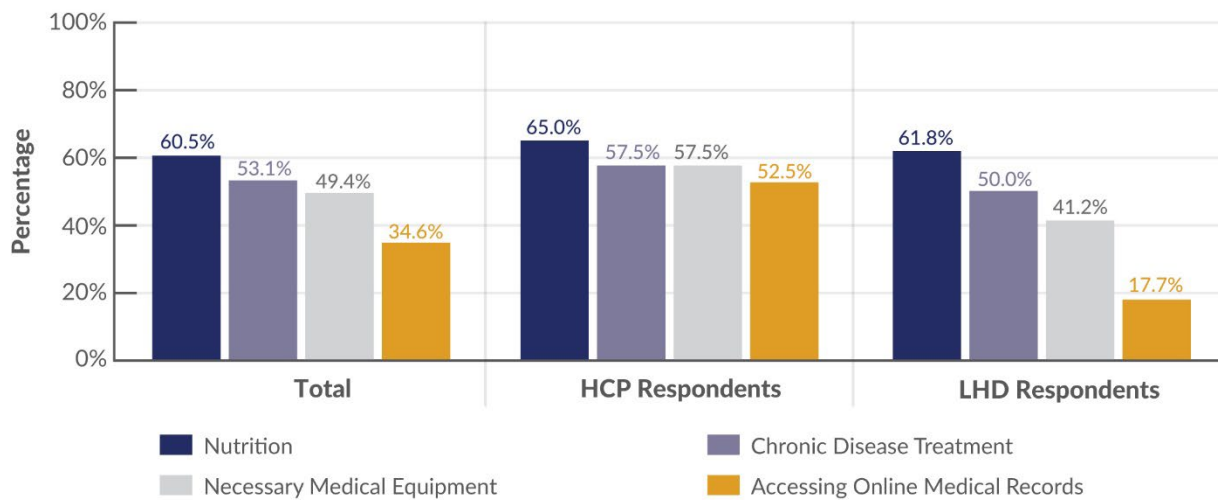
- More than half of respondents stated their organization offers or refers patients to education or self-management trainings on nutrition (60.5 percent) and on understanding the treatment of chronic conditions (53.1 percent).
- Four out of 10 respondents indicated that their organization always or often connects patients with peer supports (always=16.1 percent and often=25.9 percent). Peer

supports can include parent and youth mentors, support groups, family advocacy groups, internet-based patient communities and condition-specific organizations.

Summary of the Results

To assess this domain, respondents were asked if they offered or referred patients to specific education or self-management trainings, with the most common responses related to nutrition (60.5 percent), understanding the treatment of chronic conditions (53.1 percent), understanding how to use necessary medical equipment (49.4 percent) and accessing online medical records, patient portal, or care plans (34.6 percent). More than half of HCP respondents offered or referred patients to education or self-management training about nutrition (65.0 percent), understanding the treatment of chronic conditions (57.5 percent), understanding how to use necessary medical equipment (57.5 percent) and accessing online medical records, patient portal, or care plans (52.5 percent). For LHD respondents, education and self-management training on nutrition (61.8 percent) and understanding the treatment of chronic conditions (50.0 percent) were most common. Information about the education or self-management training that respondent’s organizations offer or refer patients to is presented in *Figure 7*.

Figure 7. Education or Self-Management Training Offerings or Referrals



Note: Total Respondents = 81; Healthcare Provider Respondents = 40; Local Health Department Respondents = 34. HCP = Healthcare Provider; LHD = Local Health Department; Respondents could select all that apply.
 Source: Kansas Health Institute analysis of Survey of Care Coordination Providers.

Respondents indicated that the frequency their organization connects patients with peer support was: (1) always (16.1 percent), (2) often (25.9 percent), or (3) sometimes (23.5 percent). Fewer

respondents indicated that their organization rarely (14.8 percent) or never (4.9 percent) connects patients with peer support.

Domain 5: Care Coordination Workforce

The care coordination workforce can consist of those with varying degrees, credentials and life experiences that may be valuable for care coordination.

Key Findings

- A large proportion of HCPs had a designated care coordinator (72.5 percent) and many of these HCPs required credentials for care coordinators (72.4 percent), such as a bachelor's degree, community health worker certification, and registered nurse licensure. However, only 3 in 10 (29.4 percent) LHDs had a designated care coordinator and 4 in 10 (40.0 percent) of these LHDs required credentials for care coordinators.
- Training required most often for care coordinators included relationship building with families (35.8 percent); identification of family strengths, priorities, and goal setting (35.8 percent); community-based resource provision (35.8 percent); and health literacy (34.6 percent). Training viewed as most helpful for care coordinators included health insurance policies and procedures (28.4 percent), relationship building with families (27.2 percent) and motivational interviewing (24.7 percent).

Summary of the Results

About half of all respondents reported having a designated care coordinator (53.1 percent). Many HCP respondents had care coordinators (72.5 percent). Fewer LHD respondents had care coordinators (29.4 percent).

Among the respondents indicating that they had a designated care coordinator, the most common job titles of the person who coordinates patient care were care coordinator (32.6 percent), care navigator (20.9 percent) and community health worker (16.3 percent). About one-fifth (18.6 percent) of respondents reported

A large proportion of healthcare providers had a designated care coordinator (72.5 percent) and many of these healthcare providers required credentials for care coordinators (72.4 percent).

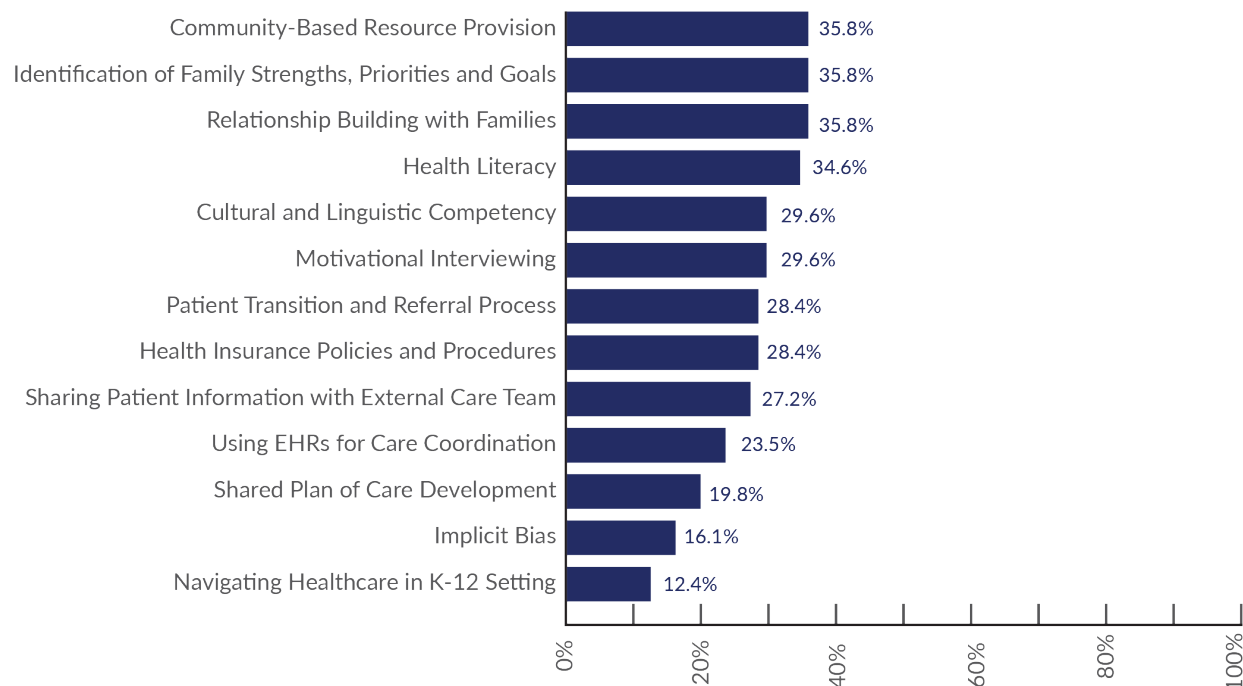
job titles (e.g., targeted case manager) other than those available in the question. Seven in 10 (72.4 percent) HCP respondents indicated that their organizations required care coordinators to have credentials, but only 4 in 10 (40.0 percent) LHD respondents indicated that their departments required credentials for care coordinators. Among the 28 respondents that said their organization requires credentials for care coordination, the most common responses were related to educational degree requirements (32.1 percent), such as a bachelor's degree (17.9 percent). Other required credentials included registered nurse licensure (25.0 percent), social work licensure (14.3 percent), certifications (e.g., community health worker) (14.3 percent), and training (e.g., CPR) (10.7 percent). About 1 in 4 of these respondents (28.6 percent) reported more than one credential requirement for care coordinators.

Respondents were asked which types of training were required for care coordinators. They were also asked to indicate the top three most helpful types of training. The most commonly required types of training were relationship building with families (35.8 percent), identification of family strengths priorities and goal setting (35.8 percent), community-based resource provision (35.8 percent), and health literacy (34.6 percent). The most commonly cited trainings viewed as most helpful were health insurance policies and procedures (28.4 percent), relationship building with families (27.2 percent), motivational interviewing (24.7 percent), and community-based resource provision (24.7 percent).

Respondents from HCPs indicated that motivational interviewing (30.0 percent), relationship building with families (27.5 percent), and health insurance policies and procedures (27.5 percent) were the most helpful training. Respondents from LHDs indicated that community-based resource provision (38.2 percent); health insurance policies and procedures (29.4 percent); identification of family strengths, priorities and goals (23.5 percent); and navigating healthcare in educational K-12 settings (23.5 percent) were the most helpful trainings.

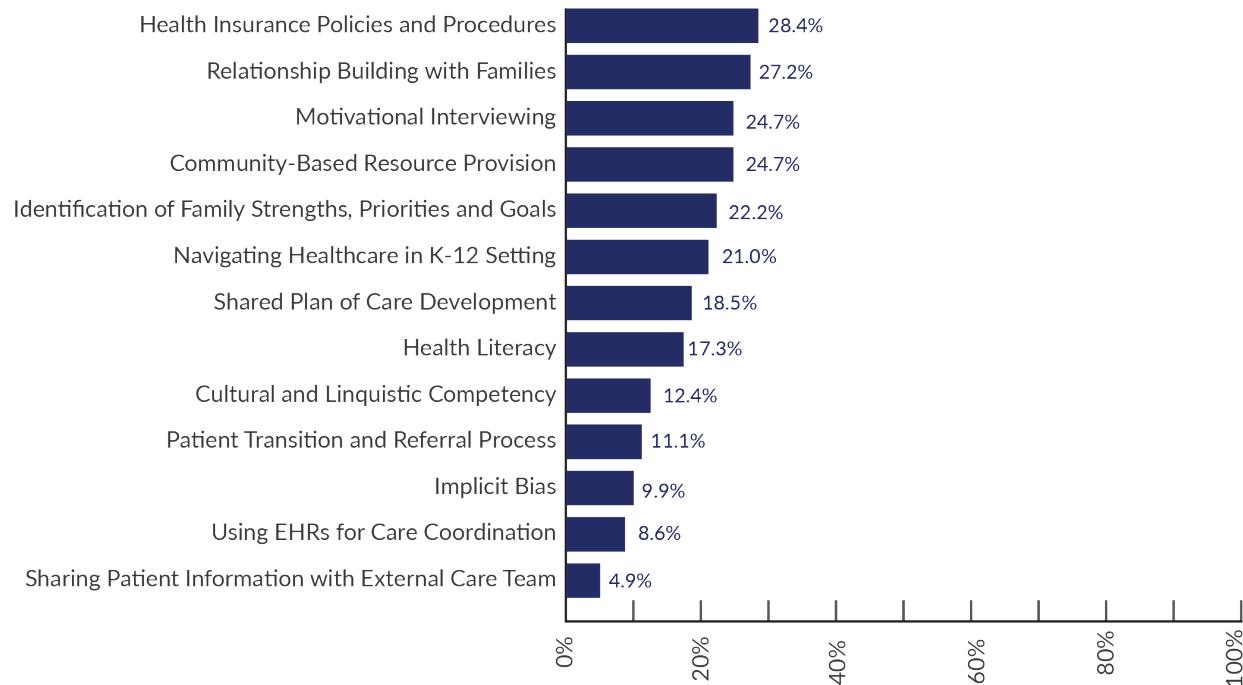
Information about the training required by organizations for care coordinators is presented in *Figure 8a* (page 18). Information about the training viewed as most helpful for care coordinators is presented in *Figure 8b* (page 18).

Figure 8a. Training Required by Organizations for Care Coordinators



Note: Total Respondents=81, Respondents could select all that apply. EHRs = Electronic Health Records.
 Source: Kansas Health Institute analysis of Survey of Care Coordination Providers.

Figure 8b. Most Helpful Training for Care Coordinators



Note: Total Respondents=81; Respondents could select up to three responses. EHRs = Electronic Health Records.
 Source: Kansas Health Institute analysis of Survey of Care Coordination Providers.

Domain 6: Care Transitions

Care transitions are an important aspect of healthcare and a patient's life. Examples include children transitioning to a new provider, a new town or into adult care. "Warm handoffs" are defined as a handoff that is conducted in person, between two members of the healthcare team, in front of the patient (and family if present).

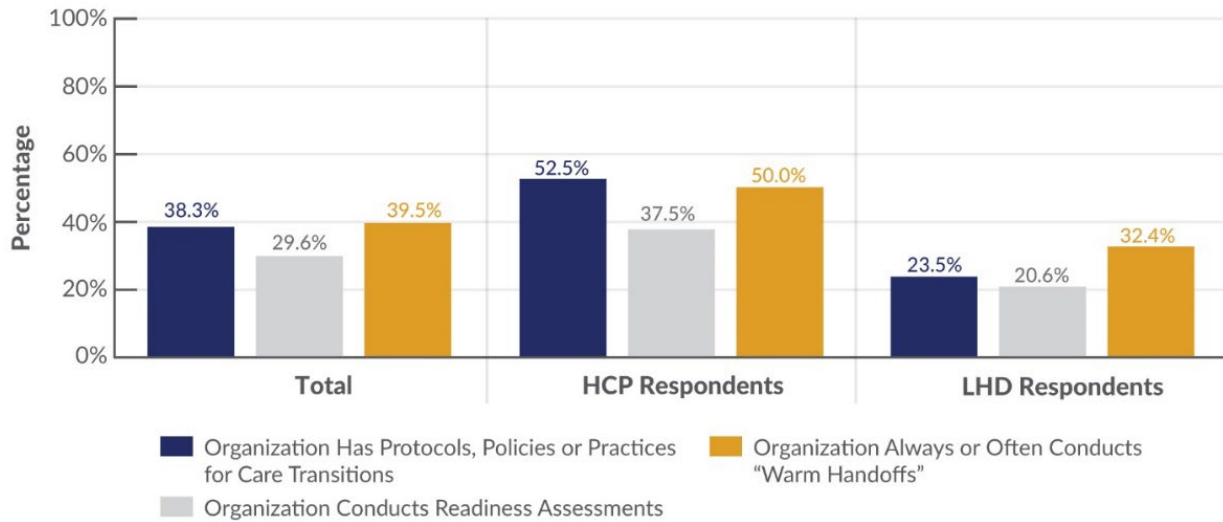
Key Findings

- Fewer than half of the respondents indicated that their organization had protocols, policies or practices related to care transitions (38.3 percent) or conducted readiness assessments (29.6 percent).
- Nearly 4 in 10 respondents (39.5 percent) indicated that their organizations always or often provided "warm handoffs."

Summary of the Results

Fewer than half (38.3 percent) of the respondents indicated having organizational protocols, policies or practices related to care transitions. Slightly over half (52.5 percent) of HCP respondents indicated that their organizations had protocols, policies or practices related to care transitions in place while less than a quarter (23.5 percent) of LHD respondents indicated that these were in place for their departments. Only 29.6 percent of respondents indicated that their organization conducted readiness assessments, 37.5 percent for HCP respondents and 20.6 percent for LHD respondents. Nearly 4 in 10 respondents indicated that their organizations always (11.1 percent) or often (28.4 percent) provided "warm handoffs," while 2 in 10 rarely (11.1 percent) or never (9.8 percent) provided "warm handoffs." Information about care transitions is presented in *Figure 9* (page 20).

Figure 9. Care Transitions



Note: Total Respondents = 81; Healthcare Provider Respondents = 40; Local Health Department Respondents = 34. HCP = Healthcare Provider; LHD = Local Health Department; Respondents could select all that apply.
 Source: Kansas Health Institute analysis of Survey of Care Coordination Providers.

Billing for Care Coordination Services

HCPs and LHDs may seek reimbursement to pay for the HCC services that they provide. This section aims to identify restrictions to billing for HCC and how payment structures could be improved to support HCC services.

Implications and Key Insights

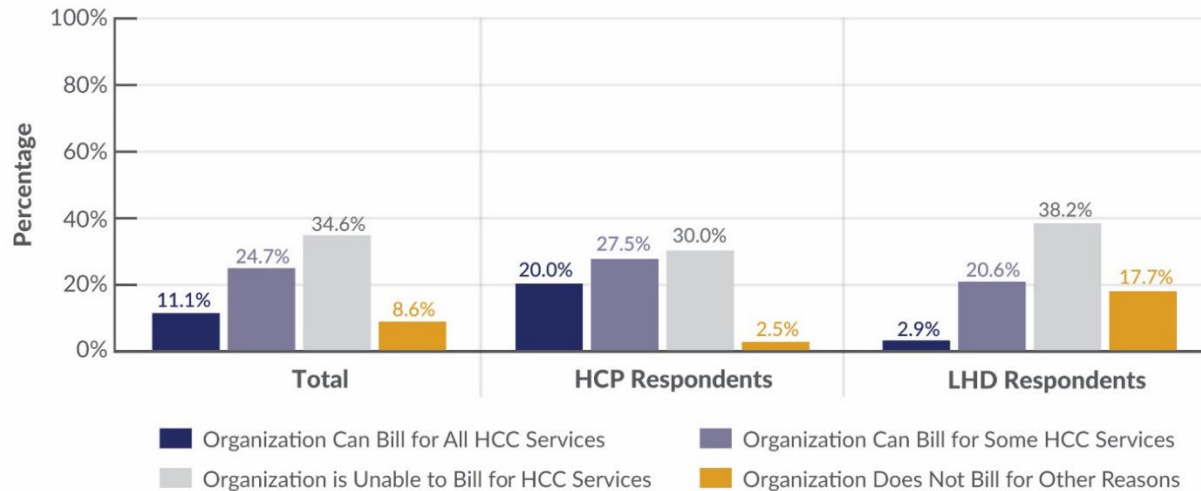
- Nearly half of HCP respondents could bill for all (20.0 percent) or some (27.5 percent) care coordination services.
- Among LHD respondents, only a quarter could bill for all (2.9 percent) or some (20.6 percent) care coordination services.

Summary of the Results

Relatively few respondents indicated that they could bill for all care coordination services (11.1 percent) or some care coordination services (24.7 percent). Among HCP respondents, 47.5 percent could bill for all (20.0 percent) or some (27.5 percent) care coordination services, and among LHD respondents, only 23.5 percent could bill for all (2.9 percent) or some (20.6 percent) care coordination services. Among the respondents able to bill for at least some HCC services, 60.0 percent had no restrictions on the amount of time they could bill for care

coordination. This was the same for HCP respondents and LHD respondents. Information about billing for HCC is presented in *Figure 10*.

Figure 10. Billing for Holistic Care Coordination Services



Note: Total Respondents = 81; Healthcare Provider Respondents = 40; Local Health Department Respondents = 34. HCP = Healthcare Provider; LHD = Local Health Department; Respondents could select all that apply.
 Source: Kansas Health Institute analysis of Survey of Care Coordination Providers.

Respondents were asked about restrictions on the amount of time they can bill for care coordination. Responses to this open-ended question included: (1) “40 hours/week,” (2) “no restrictions,” (3) “We are only able to bill one visit per trimester and one postpartum visit,” and (4) 240 billable units for one consumer each year.

Respondents also were asked what types of care coordination services should be covered that are not currently covered by private insurance or Medicaid managed care. Care coordination (care management, care meetings, etc.) and community health workers were cited most frequently. A care coordinator working for a hospital discussed the lack of payment for HCC, saying:

“When I receive a consult, our organization is not paid for my services regardless of the amount of time or effort it takes to provide a plan of care with the patient. At times it takes more than one day, and I am continuing to follow up.”

Respondents also were asked about what changes to billing practices would assist with their provision of care coordination services. Again, care coordination and community health workers

were cited most frequently. In relation to this question, a care coordinator working for a hospital said:

“I believe that care management hours should be allowed to be billable in a hospital or clinic setting. I am [a] care manager for the entire hospital and service all areas when consulted. I also service the clinics affiliated with our facility. It is a specialty that requires quite a bit of time management.”

Respondents whose organization did not bill for care coordination services were asked why their organization did not bill. Although the number of responses was limited, a few respondents highlighted that their organization serves uninsured and low-income populations, which was the reason given for not billing for such services. One LHD respondent said:

“The population that has the need for these services are often the most financially vulnerable. Billing or even discussion of billing will trigger obstacles to service provision.”

Overall Needs

A variety of factors can facilitate or impede the provision of HCC across Kansas. In the survey, respondents were asked about factors relevant to organizational capacity, partnering, and coordinating services between organizations, patient needs, and public policy.

Implications and Key Insights

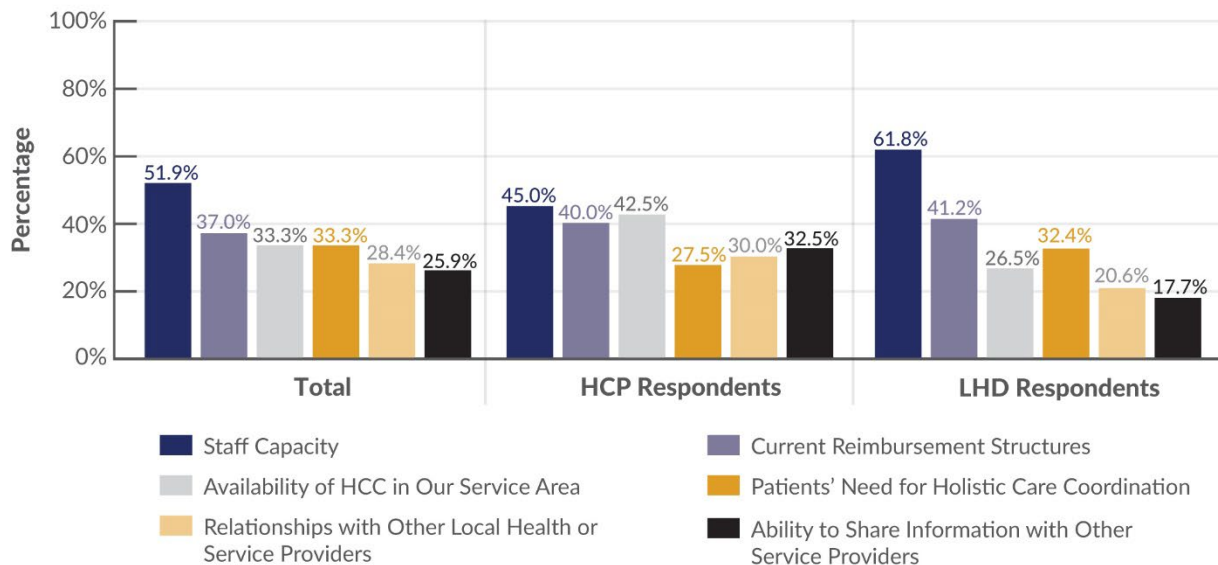
- Staff capacity (51.9 percent) and current reimbursement structures (37.0 percent) were the most commonly cited factors affecting their organization’s decision to expand care coordination services.
- Answers to open-ended questions noted that lack of payment for community health workers, absence of expanded insurance coverage, and lack of information sharing between healthcare providers were barriers to providing HCC services. The message appeared to be that more resources are needed for their organizations to expand HCC services. One respondent suggested that partnerships could be a solution to expand and improve HCC and that policymakers should incentivize these partnerships.

Summary of the Results

Respondents were asked what the three most important factors were to their organization’s decision to expand care coordination services. The four most frequently indicated factors were

staff capacity (51.9 percent), current reimbursement structures (37.0 percent), patients' needs for those services (33.3 percent), and current availability of care coordination services in our organization's service area (33.3 percent). Staff capacity was the leading factor indicated by HCP respondents (45.0 percent) and LHD respondents (61.8 percent). Additionally, current availability of care coordination services in our organization's service area was indicated by 42.5 percent of HCP respondents followed by current reimbursement structures (40.0 percent). For LHD respondents, current reimbursement structures (41.2 percent) and patients' need for those services (32.4 percent) were also two of the three most important factors. Information about the most important factors to respondent's organization's decision to expand care coordination services provided in *Figure 11*.

Figure 11. Most Important Factors Related to Our Organization's Decision to Expand Care Coordination Services



Note: Total Respondents = 81; Healthcare Provider Respondents = 40; Local Health Department Respondents = 34.
HCP = Healthcare Provider; LHD = Local Health Department; Respondents could select all that apply.
Source: Kansas Health Institute analysis of Survey of Care Coordination Providers.

Respondents were asked what state- or local-level policy changes would assist with their provision of care coordination services. Common responses to this open-ended question included: community resources, payment for community health workers, expanded insurance coverage, and information sharing between healthcare providers. One social worker working in a family practice suggested that policymakers should encourage local partnerships.

Respondents also were asked if there were any other ways that care coordination can be improved across Kansas. Common responses to this open-ended question included: improved payment, ability to bill for community health workers, and improved sharing of information.

Interviews with Insurance Providers

The goal of the interviews with insurance providers, including private health insurance companies and Medicaid MCOs, was to gain an understanding of HCC services currently being provided to pediatric patients age 0-8 and individuals receiving prenatal and postpartum care enrolled in private health insurance plans and those enrolled in KanCare. Detailed methodology for the interview component is described in *Appendix D*.

Key Findings

The following key findings were identified during the analysis of interviews. Themes were identified across all questions asked of insurance providers and were summarized into key cross-cutting themes (*Figure 12*).



Holistic Care Coordination Model and Purpose^{viii}

KHI provided the following definition of HCC to participants.

Key elements of holistic care coordination include: (1) team-based with designated and well-defined roles for all members of care team; (2) a sole, identified, care coordinator serving as point person to family; (3) patient- and family-centered care plan developed in collaboration with provider to establish care goals and adjusted as needed; (4) enhanced communication (emphasis on electronic medical records) between care team, community services, families and patients; (5) connects complex medical needs and social determinants of health such as economic stability, food insecurity, and access to housing; and (6) recognizes role and burden (cost, time, emotional health, etc.) on families caring for these patients.

MCOs and private insurance companies expressed agreement for the definition in practice; however, one private insurer explained they utilize the Case Management Society of America (CMSA) standards of practice which uses different words but shares the same functional definition in practice. Participants also stressed an increased focus beyond “the basics of a care management program” to include a holistic, whole person approach that involved medical care, behavioral health, and social determinants of health needs.

The key purposes of HCC identified by participants included helping members navigate healthcare, improving member outcomes, decreasing hospitalizations, controlling costs of care and providing wrap-around support. One MCO also highlighted the purpose of educating families around managing family members’ care. Most participants described the fragmentation or siloed nature of healthcare and identified members benefit from assistance in navigating this system.

The key benefits of HCC identified by participants included that it addresses member needs, improves member outcomes, increases cost-savings and benefits their business.

The key benefits of HCC identified by participants included that it addresses member needs, improves member outcomes, increases cost-savings and benefits their business.

^{viii} Note: Theme summarized from six interviewee responses across [Questions 1, 2, 3, 4, 11 and 13](#).

Participants described how providing HCC aligns with their mission with one MCO saying “That’s why we’re here. That’s what we do.” MCOs further described that they provide HCC because it is the “right thing to do,” increases member access to preventive care, which decreases hospitalizations and allows them to balance costs within limited Medicaid funding, describing it as a “win-win” for the company and the state. Two of the private insurance companies also said HCC helps control costs for the company.

Representative Quotations

“We know that behavioral health and medical care go hand-in-hand. And then we know that social determinants play a huge role in someone’s outcomes, either, you know, medically or behaviorally or just in their life in general. And so we know and have recognized that all of these things are intertwined. And for us to separate them or try to separate them doesn’t make sense.” – MCO

“I think a really good point that we try to do on a continuous basis is we try to break down those silos. We know that our healthcare system is very siloed by default, and so we try to open up those lines of communications between providers, but also even just within our own healthcare organization and other healthcare organizations.” – MCO

“We want to make sure the people are receiving the right care at the right time at the right place. And if you’re doing that, then you help the state control costs for the program over time.” – MCO

“Our goals are twofold, to improve member health and quality of life and lower healthcare cost.” – Private Insurance Company

Identification of Members for Holistic Care Coordination^{ix}

Participants explained that they use multiple approaches to identify members for HCC services, with one MCO saying they use a “no wrong door approach.” The most common methods to identify members involved reviewing member data and analytics, including results from health assessments and other evidence-based screeners, claims information, and referrals from

^{ix} Note: Theme summarized from six interviewee responses across [Questions 2, 3, 4, 5, 7 and 9](#).

members themselves, providers, or employers. For data-led approaches to identification, participants discussed how the results of the member health assessments and claims data are incorporated into predictive, proprietary algorithms that could assess and stratify members by risk level. One MCO specifically highlighted improvements to their algorithms used to identify members for HCC. Identification of children for care coordination used similar approaches; however, one MCO noted that they also utilize an inpatient transition of care assessment to identify members age 0-8 for care coordination services after a hospitalization.

Identification of pregnant members was noted as a challenge by both MCOs and insurance companies because they are often reliant on provider notification of the pregnancy, often by completion of a form. However, respondents did identify strategies, including reviewing claims data for pregnancy tests and eligibility reports for Medicaid. Another strategy shared was to incentivize providers to notify the company of a pregnancy or to provide cash incentives to members for communicating pregnancies to the company and completing a risk screener.

Some eligibility restrictions do exist. Both MCOs and private insurance companies described how care coordination services are available specifically for members. Private insurers noted that some employers restrict service options, such as telehealth, on their employee health plans, which can result in limits to the care coordination services available to these members.

Participants explained that they use multiple approaches to identify members for HCC services, with one MCO saying they use a “no wrong door approach.”

Representative Quotations

“We also are able to see claims that are coming in for our members, and we have some special algorithms that help when I was talking about identification. So, those claims are, kind of, brought into this algorithm along with some other things, like demographics, and that sort of thing to, kind of, assign how at-risk is this member, how many needs do we think this member might have so that we can help stratify and prioritize who should we reach out to first, who might have the greatest need to try to help allocate, you know, our resources in the best way that we can.” – MCO

“If they [providers] complete a prenatal form for our member, if they are in acknowledgment even our behavioral health providers, because we know a lot of, you know, women who are single mothers or sometimes within therapy and doing some stuff with behavioral health providers. So, if the mother indicates that she is pregnant, but, like, [Insurance Company] doesn't know yet, if they complete a form, if the provider completes the form and lets [Insurance Company] know that the mother is expecting, then that goes straight to our health side case management” – MCO

“At any point in time, a member can call into member services and self-refer into one of our programs, or a provider in the community or anyone else in the community could refer a member into one of our programs” – Private Insurance Company

Prioritization of Members for Holistic Care Coordination and Equity Considerations^x

Participants discussed prioritizing members for HCC based on need and equity considerations. Both an MCO and private insurance company explained that they evaluate members using social determinants of health to identify and prioritize needs “specific to that member.” Private insurance companies highlighted other needs used to prioritize members for HCC services, including cost, risk stratification and existence of chronic conditions or depression in pregnant individuals. Participants also discussed imbedding equity considerations into their collection of data to understand and address member needs, particularly for members in population groups or living in regions experiencing inequities and greater disparities. Two participants discussed the collection of race and ethnicity data as a recent effort to better understand member needs. For one participant, this was described as a new initiative because they have previously not collected member outcome data for race, ethnicity, and language. Three participants mentioned they address equity specifically through maternity programs and support focused on pregnant moms and women of color. Two MCOs said that they noticed worse birth outcomes for “black and brown moms” and referenced programs they utilize to help improve their outcomes. Participants specifically highlighted maternal morbidity as a concern, with one private insurer explaining their company sets a goal to reduce maternal morbidity among their members by half.

^x Note: Theme summarized from six interviewee responses across [Questions 1, 9 and 10](#).

Another approach discussed was looking at data from their population health assessment to understand the geographic regions with greatest need to better address inequity between regions. An MCO and private insurance company discussed how they have identified specific counties where health outcomes are worse than other counties in their service areas and are developing programming to address these members' needs. The private insurer said that they can even see health disparities within zip codes in different areas and use this geographic level for their algorithm assessing member risk level. Another private insurer, while discussing how they will tailor HCC services based on member need in different areas, chooses to address equity by focusing on their entire member area. However, this participant did discuss how the rural areas they serve often lack more health access and are less likely to be invested in by national nonprofits who support development of infrastructure related to SDOH needs. In these cases, the company prioritizes supportive efforts to build this infrastructure for their members.

Representative Quotations

“We know that maternal mortality and morbidity is higher in the African American population, for example. And so trying to put programs into place that will help address that so that we can make sure that there is more health equity, at least within the Medicaid population.” – MCO

“We look at things like gender, and race, and language, and demographic, all of that information. And we see what portion of our population falls into that, and then what's the disease burden for each of those segments of the population, and that just helps us inform our programs for the next year.” – MCO

“But we're in the process of actually obtaining ethnicity data. It's not something that we, as a company, even have. So there is a corporate-wide project to go after the race, ethnicity and language data. So you can rest assured that we're not targeting anybody, either positively or negatively, because we don't have the data.” – Private Insurance Company

“Generally speaking, our members are identified through an internal algorithm where we risk stratify those into either a high, a moderate, or a low category. We prioritize our outreach to those members that are deemed high, and as we work through those, we obviously go down the pipeline right to our moderates and our lows.” – Private Insurance Company

Holistic Care Coordination as a Value-Added Service^{xi}

In general, MCOs and private insurance companies discussed care coordination as a value-added service. The companies described value-added services as those provided directly by the insurance company at no cost to the member and said they do not receive claims related to these services. One MCO described value-added service as overhead, calling it the “cost of doing business with us.” However, two private insurance companies did provide a distinction between their value-added services and their value-based services. Value-based programs involved direct contracts with primary care providers in which the provider, plan and member collaboratively developed a customized care plan and the provider completes specific care coordination tasks towards performance measures outlined within the care plan. Value-based programs do generate claims and are considered billable services. The only other restriction mentioned within value-based programs was that there are different reimbursement rates based on the position title of the person submitting the claim. For example, different reimbursement rules for physician assistants versus physicians.

Value-added services tended to be program and population specific. When asked to describe what HCC services are offered to children age 0-8 and for individuals receiving prenatal and postpartum care, the participants identified two main considerations used to make these determinations. First, participants identified that they made service decisions based on health risk or member needs. These needs were often identified using claims data (diagnoses codes and cost) or results from comprehensive assessments. However, two participants also said they used the shared care plan to identify services that were most important to the member and other members of the care team to prioritize service provisions. The second consideration mentioned by respondents was that company’s capacity related to their available programs and departments also affected the kinds of services that could be provided to different populations.

Populations needed to be eligible for existing programs based on their diagnosed health conditions or age. One MCO participant also noted that the MCO contract with the state can determine which programs are available to participants and that the

The companies described value-added services as those provided directly by the insurance company at no cost to the member and said they do not receive claims related to these services.

^{xi} Note: Theme summarized from six interviewee responses across [Questions 1, 2, 3, 4, 5, 7 and 9](#).

MCO also utilizes evidence-based and national guidelines to make determinations on the types of services they provide throughout their programs. Another private insurer also said that members on employers' health plans may find their services limited if their employer has not selected the specific "add-on" including, for example, the company's extended maternity services. Participants describe regular evaluation of the programs and member health to identify if programs are sufficiently addressing needs or if a new program should be created to support members with specific chronic conditions. One MCO said the approaches they use to evaluate member need and their existing programs have improved over time.

Representative Quotations

"I was just going to say it's overhead cost for us, right? It's a value-add that we bring to this population to help serve them. And selfishly it does help us meet financial targets too, because if we can, you know, help a member not utilize the emergency room inappropriately or manage their health better so that they're not getting admitted to the hospital, that also helps not only us but the state of Kansas financially as well. We all know that Medicaid has limited funding. And so that's kind of how that kind of plays in. But when you're talking about, like, who pays for it, I think we're paid a capitated rate and, like, we do with those funds what we do. So, our case management, you're right, there's no claim. It's the cost of doing business for us." – MCO

"I mean, there's no cost to the member to participate in any of our programs. They're just offered as part of our, you know, broader product offering. So, there's no claim from a care manager or from an M.D. or anything. Zero cost to the member." – Private Insurance Company

"I'll say it this way. A value-based contract is a little bit like velvet gloves. And they're mutually agreed-upon measures that the provider and the plan are going to go after." – Private Insurance Company

"Well, you know, we have set programs, right? We think in mostly complex, and then, we think in chronic disease. And that would become disease specific. Now, we don't have a program for every disease that's out there. And so that becomes the category for an "other," should that come up" – Private Insurance Company

"I mean, each year, we evaluate them [service offerings] and determine, is it useful or if it needs to retire or sunset," – MCO

Building a Care Team^{xii}

Participants mentioned expanding care teams including the incorporation of community health workers and additional subject matter experts across different healthcare sectors. Participants described a care team with specific roles related to care coordination, with two participants sharing that they employ teams with the specific role of care management of members. One private insurance company further clarified that they also hire nurses with specialized expertise related to pediatric and maternity care for their care management teams. One MCO, when discussing the role of the care team further, explained that they empower their care teams to “assist the member with all aspects of their life.” Two participants also described the role of the care coordinator as a creative problem solver. This specifically related to how the MCO and private insurance company’s care coordinators were tasked with meeting member social determinants of health needs when limited community resources exist. This was described by one participant as “creative accounting” in which the care coordinators connect members with resources to free up money for the member’s other needs. Two participants also explained that a change in recent years has been an increased focus on relationships and building trust with members. One MCO shared that providing members with a single point of contact to their care team allowed case management to be more effective because of the relationship and trust built between the member and the care coordinator. A private insurance company also talked about how their company focused on motivational interviewing to help increase trust and willingness of members to share information with the care team.

Care teams also included the member and their family. Two participants described the development and modification of a shared care plan, describing the process of working with the member and their family, providers and other members of the care team to develop goals that address the members’ needs. A private insurance company said their team will create custom goals with the members and also prioritizes recognizing member progress on the care goals.

^{xii} Note: Theme summarized from six interviewee responses across [Questions 1, 2, 3, 4, 9 and 16](#).

Representative Quotations

“We have purposely focused on hiring nurses on our team that have that pediatric experience and that have that maternity experience, have the NICU experience. And that is something we've just done in the last few years in order to provide that real care management experience for those patients, for the parents, because, you know, they look to us to be the expert when they call the nurse.” – Private Insurance Company

“When we started this holistic approach, our members knew they had one point of contact, they had a relationship with that one point of contact, and they had that trust built. And so we have seen a lot more effectiveness with the case management aspect because of that trust that we have built by having that one point of contact.” – MCO

“So since then, like, we've been able to integrate with our different subject matter experts within the company and really come together as an integrated care team to provide that holistic approach to the member, and that did not exist five years ago. It certainly didn't exist 10 years ago.” – Private Insurance Company

“Our social workers get very creative. You know, maybe the member can't pay the utility bill. Well, we can't just, you know, hand you cash for your utility bill. But maybe we help offset your grocery bill by having you go here and that frees up more money to pay your utility.” – Private Insurance Company

“We want to do what we can creatively to have members have access to basic needs. So, they will do any...I mean, if it means partnering with a food bank, maybe doing an event, bringing that in, those kind of things. – MCO

Investment into Internal Capacity^{xiii}

Participants described efforts to expand their internal capacity through staff training, expansion of referral networks, and improvement of existing HCC programs. One MCO mentioned staff training related to health equity and multiple participants discussed a priority of cultural competency trainings for their staff with one private insurance company saying that it was an

^{xiii} Note: Theme summarized from six interviewee responses across [Questions 6, 9, 10 and 14](#).

accreditation requirement to customize care appropriately to different cultures instead of a “one-size-fits-all approach.” One MCO also talked about how they also have cultural competency requirements for providers that they contract with to ensure that members needs are met. Another MCO discussed how they prioritize assigning members to service coordinators who “grew up in” the member’s community. Two private insurance companies also provided a similar example of where their care coordinators may need to apply cultural competency describing cultures where a husband or family patriarch must be present for them to speak to female members, describing steps they take to ensure they receive proper consent.

Participants said another change to care coordination in recent years was the expansion of their community referral networks and care teams. Private insurance companies and an MCO discussed developing their referral networks and expanding their ability to refer members to community-based organizations. One participant detailed how their care teams develop and share lists of community-based resources they have referred members to in the past and are exploring a closed-loop referral system to track success rates in these referrals. They also talked about prioritizing hiring case managers locally in order to increase familiarity with the local resources.

Participants also explained that they offer translation services to members. The most common manner discussed was telephonic translation or a “language line” that was free to members to use. Participants also shared that if a member needs a translator present with them for their appointment, they can also arrange in-person translation at no-charge if they are provided advance notice. Additionally, a participant shared that they prioritize provision of member material in multiple languages.

A final way participants described building internal capacity related to the evaluation and modification of their programs. Participants described evaluating the performance of their HCC services using member outcome and need data. One MCOs discussed conducting a population health assessment of members to understand whether the programs had met their goals and identify remaining member care gaps. Another MCO said they utilize the Healthcare Effectiveness Data and Information Set (HEDIS) measures to understand the performance of their programs across domains of care. Two participants described that they also evaluate the program success using claims and diagnosis data to understand changes in expense, type and frequency of claims, looking for outcomes such as decreased pediatric hospitalizations and member expenses appropriate to their health maintenance requirements. Another way

participants evaluated care coordination was through member surveys either quarterly or after every episode of care to understand the performance of their HCC services.

Representative Quotations

“We have done some trainings, again, internally on cultural competency with our staff to help them better understand when they're working with a member who has a different belief system or value system than maybe that they currently...that they have so that they can effectively work with that member.” – MCO

“We have a health equity subcommittee that we do here at [Insurance Company]” – MCO

“We've had some health equity training series this year. I think we've had four where we've brought in special speakers to talk about various topics with all of the team so that they can have some exposure to that and education” – MCO

“We have our interpreters that we can use, that we can communicate with the members in a way that they will be able to understand. So, you know, if we have a member that doesn't understand how the medical system works in the United States because they're from another country, well, you know, we're able to walk that family through it to help them in a more appropriate fashion.” – MCO

“You know, some cultures, they have to have the husband and the wife on the phone, right? And if we're going to get the husband on the phone and we're talking about the mom or the wife, we've got to make sure that we've got consent. But we certainly do have workflows and processes to ensure that we're capturing whatever the member's needs are in that space” – Private Insurance Company

Perspectives on a Payment Model and Policy Recommendations^{xiv}

Two MCOs said that the current payment model for HCC services under Medicaid should not be changed and all current components of HCC within the contracts should be maintained. One MCO also said they appreciated current flexibility existing within the model because it allowed them to quickly adapt their programs to member needs as necessary. Additionally, two

^{xiv} Note: Theme summarized from six interviewee responses across [Questions 16 and 17](#).

participants said a future payment model of HCC should focus on incorporating both social determinants of health and behavioral health needs of members. One MCO shared this has grown as a focus in HCC but should continue to be expanded. One private insurance company said that the behavioral health piece “gets forgotten” and should be used in combination with social determinants of health in HCC, describing these components as “key” to holistic care coordination. Two participants also said that it was important for a team-based care model to be incorporated into an HCC payment model with allowance to diversify members of the care team from multiple different specialty areas for a “one-stop shop” to meet member needs.

Two participants indicated that increased funding to providers and HCC programs could be an improvement to a payment model. The MCO discussed increasing access to services in general and funding to these Medicaid programs. The private insurance company discussed how they’ve found success with increasing funding to clinics in their value-based programs in exchange for reaching specific quality levels. The clinics have then reinvested this money into growing their capacity to provide additional HCC services to meet their members’ needs. Two participants also discussed that resource shortages of people and facilities present a challenge that needs to be addressed in order to serve more members. A private insurer also expressed concerns about shortages in mental health resources. The participant also said that providers are stretched too thin to help with care navigation but was concerned that hiring certified nursing assistants and community health workers to do work previously completed by registered nurses was a mistake because of lower licensure requirements and qualifications.

Related to broader policy action around holistic care coordination, an MCO and private insurance company offered slightly different viewpoints on state requirements around HCC services. Both the MCO and private insurance company discussed how flexibility is essential to holistic care coordination services because flexibility allows them to adjust to address member needs as they arise. The MCO also shared that being overly prescriptive can cause challenges with their accreditation if the state’s requirements don’t match what is required for their accreditation and said they appreciated that there was an open line of conversation with the state about the contract, member needs and priorities. However, the MCO did suggest additional structure to support populations with dual eligible special needs plans saying that because “Kansas

Flexibility is essential to holistic care coordination services because flexibility allows them to adjust to address member needs as they arise.

hasn't taken the stance of you have to select the same company for both your Medicaid and your Medicare," there can be additional challenges in providing care coordination to meet members' needs. The private insurance company said that some additional requirements could be helpful for care coordination in Kansas, such as requiring accreditation or adding a requirement for a specific component that the state felt was important. For example, the private insurer recommended requiring human interaction with members for care coordination.

Representative Quotations

"I would say that the pieces of the care model that I've discussed today, that we currently have in place, I would think you would want in any care management program. So, screening, assessment, person-centered planning, addressing social determinants of health, caregiver support. I mean, all of that, all the things that we're currently doing I think are important. I don't think we're doing anything in care coordination right now that isn't impactful and important to what we're doing. So, I would think that they would want those same things." – MCO

"I think the state's done a really nice job setting up the contract to allow the managed care companies to develop a model for care management that's going to work best for members, right? I mean, there's some structure to it, but there's also some flexibility so that we have some agility to come up with a program that's going to be, like I said, rural. We want to be local, right? That's really important to us. So, I think the state's done a nice job outlining the structure around care management and what we're tasked to do as a managed care company but allowing us to do it in the way that we feel like we can be agile and make adjustments along the way." – MCO

"I appreciate more flexibility... I mean, it really comes down to those programs too where we really need to be reactive of what our population needs are at the time." – MCO

"I think the continued expansion of the social determinants of health and integration of behavioral health is important, that we continue to focus on those things as part of holistic care coordination. And I think that what I said that's really grown in the last few years and, you know, we have a lot of things planned and looking forward into the years to come around that. And I think that that will continue to be super important, to not be a medically focused care management program but that you're really looking at all of the members' needs and trying to

kind of meet them where they're at and help them with some of those basic needs. And then, you build that relationship to be able to help them with their healthcare needs.” – MCO

“I would think that we would want and should advocate for more prescript... I don't want to say prescriptive, because I want us to be able to be thoughtful of the member's needs and be iterative and improve on ourselves. But I do think that there should be a requirement for some type of human interaction. If you're a member at risk or in need, you need to have access to a person, right? So, I mean, I think that that is something that I would say we should really advocate for.” – Private Insurance Company

Policy Review Findings

During the interviews, representatives of the insurers consistently noted that a description of care coordination services is not included in their health insurance plan documents because those services are not a part of their health plan benefits, but instead are provided to all enrollees as a “value added” set of services that are designed to meet the unique needs of their enrollees. While the insurer representatives were agreeable to verbally sharing a description of the numbers and types of care coordination services they provide to their enrollees, written documentation detailing those services was not made available. Interviewees advised that detailed information about their company’s care coordination program is not publicly available, but is contained in internal company documents that are available to company representatives and employees responsible for identifying enrollees who may benefit from the various types of services offered by the insurer. The insurer representatives consistently expressed satisfaction with those internal programs, which are regularly evaluated and modified to meet the changing needs of their enrollees.

Detailed information about the insurers’ care coordination services, as briefly described on their public websites, also is presumably made available to their enrollees. Interested individuals are encouraged to contact the insurers directly for additional information about the types of care coordination services that are available to enrolled members, including:

- Case management – assistance with coordination of services and benefits for complex medical conditions;

- Disease management – coaching to help manage conditions like asthma, chronic obstructive pulmonary disease (COPD), diabetes, heart disease, high blood pressure, high cholesterol;
- Wellness management – tools to manage stress, become tobacco-free or lose weight;
- Behavioral health, depression management programs;
- Lifestyle programs;
- Transitions of care program – moving back home from a healthcare setting;
- End of life care program; and
- High-risk pregnancy care.

A review was conducted of the official, publicly available documents associated with the solicitation and award of contracts to the MCOs, including the request for proposal (RFP), the proposals submitted by companies submitting bids in response to the RFP, and the final contracts between KDHE and the MCOs. The scope of work (SOW) for the RFP includes a section related to service coordination that all bidders were asked to consider and respond to when submitting their bids. Section 5.4.1 of the SOW addresses “Service Coordination” and indicates that “CONTRACTOR(S) shall be responsible for Service Coordination and continuity and continuation of care by establishing a set of Member-centered, goal-oriented, culturally relevant, and logical steps to ensure that a Member receives needed services in a supportive, effective, efficient, timely, and cost-effective manner.” This section specifically states that “[c]ase management, disease management, discharge planning, and transition planning are elements of Service Coordination for Members across all providers and settings” and that “Service Coordination shall also assist Members with addressing Social Determinants of Health and Independence.” Finally, this section states that “CONTRACTOR(S) shall develop and implement a comprehensive Service Coordination program” that meets certain goals and objectives, as described in the section. In addition, the section also states that the service coordination program shall include a number of elements, such as a “process for screening and assessing Members, process for identifying and enrolling Members into the program, monitoring and oversight processes of Member’s services and health and welfare, and a process for effectively communicating with the Member, their family, PCP, other Providers and members of the Member’s interdisciplinary team.” Many other requirements, including which groups of members

are required to be enrolled in service coordination and how the contractor will work with providers and community organizations are included in the section. The RFP also includes “Attachment L,” which is titled “Service Coordination Matrix” and provides bullet point descriptions of types of MCO service coordination and community service coordination that bidders were asked to respond to in their proposals.

The proposals submitted by all seven companies that submitted bids in response to the RFP, which include numerous and various types of documents, all include a response to the Service Coordination section of the RFP, typically in the “Technical” portion of each bidder’s proposal, which is a document, hundreds of pages in length, that responds to each section of the RFP’s SOW.

In the final contracts between KDHE and the MCOs, Section 2.11 indicates that the state will develop a service coordination “strategy” with the contractors “no later than April 1, 2019.” Documents describing these strategies, assuming they were developed in accordance with the contract, were not available on the Department of Administration website noted above. However, a document entitled “[Health Plan Highlights for 2023](#),” that describes “extra services [Members] can receive in KanCare” is available on the KanCare website. In addition, flyers describing benefits and services provided by each of the KanCare MCOs for 2023 also are available on the KanCare website for [Aetna](#), [Sunflower Health Plan](#) and [United Healthcare](#).

Focus Groups with Kansas Residents Who are Parents of Children Age 0-8, Pregnant or Postpartum

The goal of the focus groups was to gain an understanding of the experiences of Kansas residents who are parents of children age 0-8, pregnant or postpartum with receiving holistic care coordination. Due to evidence of suspicious activity that strongly suggested fraudulent eligibility activity, KHI paused recruitment and strengthened the approach to screen and remove ineligible participants and protect the confidentiality of focus group participants. A total of 417 respondents replied to the initial screening survey; however, after initial screening only 15 parents and two pregnant individuals were eligible. Following secondary screening and the informed consent process, only seven parents were eligible to participate. Because no one who was pregnant was eligible to participate after secondary screening, only parent focus groups were scheduled. However, during the parent focus groups, some participants did discuss their

experiences with care coordination during pregnancy. Detailed methodology for the focus group component is described in *Appendix E*.

Overview of Participants

There were seven participants across the two focus groups. All participants identified as mothers and were between the ages of 32-47. The participants had from one to four children. All participants had at least one child age 0-8, but child ages ranged between 3 months old and 16 years. Five participants had more than one child age 0-8. One participant disclosed that they were a foster parent and two participants disclosed that they are registered nurses.

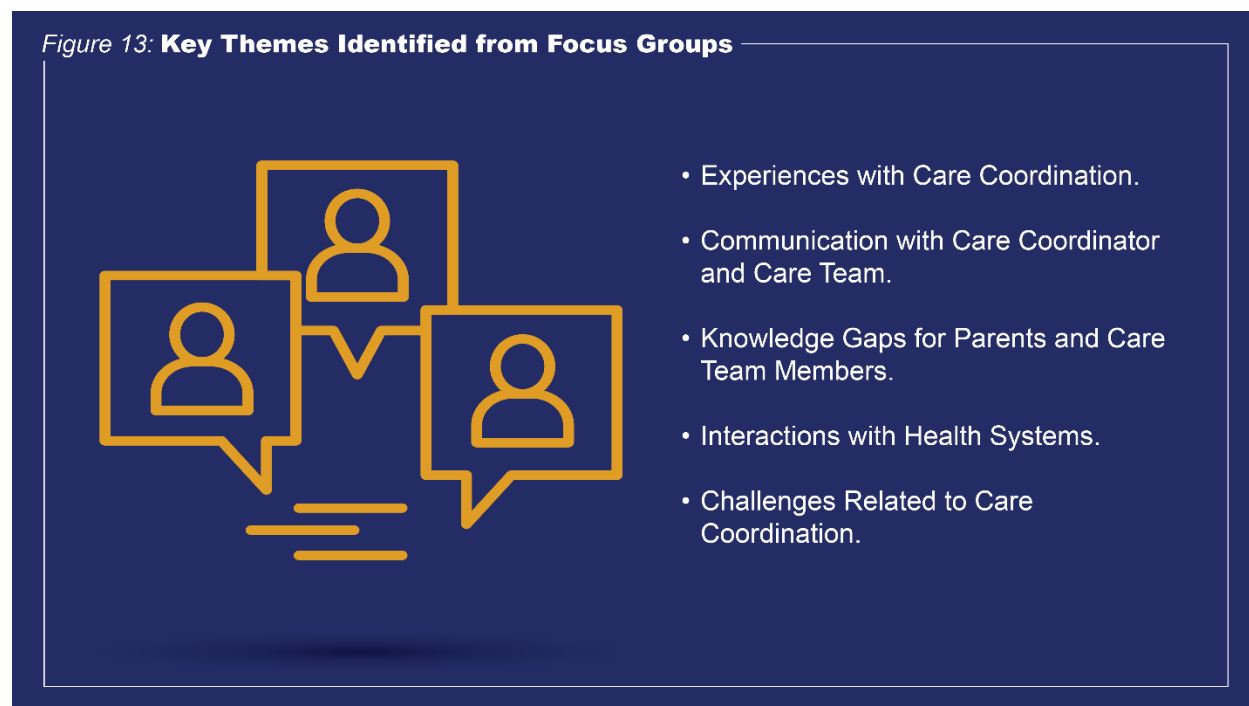
Participants lived in six counties across the following KDHE 2022-2023 Health Preparedness Regions. Two participants lived in the same county.

- Kansas City Area Coalition
- East Central Kansas Public Health Coalition
- Northeast Corner Regional Initiative
- Central Kansas Region
- Kansas South-Central Metro
- Lower 8 of Southeast Kansas

In the past 12 months, participants said their children had received preventative/well care (e.g., checkups) (six participants), specialty medical care (three participants), mental health services (two participants) or other services (one participant). The participant who selected other services said their child received speech therapy. In the past 12 months, participants said their children had primarily received care within Kansas. One participant described their child receiving care from Oklahoma as well. Five participants said that a designated care coordinator had helped coordinate their child's healthcare needs in the past six months. Two participants said they had received this help from a designated care coordinator within the past seven to 12 months. When asked which health insurance their children were covered under, four participants provided names of private insurance companies, two participants said Medicaid, and one participant provided an insurance provider specific to military or uniformed service members.

Key Findings

The following key findings were identified during the analysis of focus groups. Key themes were identified because they were most frequently mentioned by participants during the two focus groups (*Figure 13*).



Experiences with Care Coordination^{xv}

Parents described experiences with care coordination that varied in type and quality. Care coordination was defined as any activity associated with a patient's care coordination or provider/personnel involvement with care coordination. All parents experienced care coordination at some level (e.g., child is in Parents as Teachers program); however, most participants were mothers of children with either a chronic or short-term condition who were introduced to care coordination through their children's care. Most of the parents had children with complex health needs. Three participants mentioned that they had a child with hearing challenges and speech difficulties. At least one of the parents discussed their child having both conditions. A parent, different than those listed above, discussed care coordination received

^{xv} Note: Theme summarized from two focus groups across [Questions 1, 3, 5, 10, 11 and 19](#).

during their child's hospitalization and said they had a good experience with Parents as Teachers program.

Overall, parents' perceptions of the quality of these experiences were varied. Five participants shared at least one negative experience that they or their child faced when receiving care coordination. Three participants shared positive experiences related to care coordination or services. The Parents as Teachers program was the most mentioned program with mixed (positive and negative) experiences. One of the four parents was a parent teacher. Another one of the parents mentioned that they loved their parent teacher and that they are lucky.

Representative Quotations

"I think that's the struggle in some places. If you'll have some of those workers that, like, she'll go above and beyond to help your child, but then you have other workers that are just like, 'Well, I don't know what to do.' So, you just figure that out on your own." -Parent

"The Parents as Teachers, I just wanted to speak to that because I completely understand your frustration as a parent because I am a parent just like you guys, and it's such a crime. I hear that all the time. People are like, 'I didn't even know you existed. I didn't even know I was eligible.' And I myself didn't even know about Parents as Teachers until the birth of my son almost two years ago. Our social worker at the hospital told me about it, and we need to do a better job at getting the word out. I will say the wait time of three months is very typical right now." -Parent

"We've had a worker in the past that she made goals generic, that fit every child. It was not based on that child. But that's why I, kind of, chuckled because I'm like, at the beginning, no, it wasn't towards my priorities. Now it's changed because we are like, "No, my child is not the same as Johnny down the street." - Parent

Communication with Care Coordinator and Care Team^{xvi}

Parents described many difficulties with communicating with their care coordinators and members of the care team. Communication was defined as the transfer of information between care team, patients and/or individuals involved in service provision or delivery. Overall, 5 of 7 participating parents said they had no idea how to communicate with a coordinator or a service provider. Parents described how after initial contact with a care coordinator, they did not receive a call back, did not know the next steps or did not know what to do next for their child's care.

Three parents had mentioned that they had no idea when they would hear back about eligibility, assessment, enrollment or how their child is doing as they are receiving services. Some parents discussed that they have called for services or have been referred to a program and they do not know where they are in the process or they did not hear back. Three parents noted positive experiences with communication with care coordinators, even if they had experienced poor communication at some point of their child's care. For parents who were in contact with their care coordinator, methods of communication included phone, text, email, WhatsApp, online portals and flyers. Respondents preferred texting as the most effective form of communication. For Spanish speakers, leaving voice memos on WhatsApp was the preferred method of communication according to one of the parents who is also a parent teacher.

Parents repeatedly mentioned feeling like their care coordinators and providers did not listen to them or their child's needs, making the care more difficult for them and their children. Although three parents said they believed the care team did share information and documents with each other, three other parents said that they did not know whether this is occurring, with one parent

describing how she felt she was “explaining everything all over again” to each provider. As part of communicating about their child's care, parents discussed becoming advocates for their children. Four parents said they had to step up and advocate for their children when they felt their care needs were not being met. Two parents said they

Four parents said they had to step up and advocate for their children when they felt their care needs were not being met. Two parents said they did not know to advocate in the beginning. One parent now teaches other parents as a parent educator to advocate for themselves and their children.

^{xvi} Note: Theme summarized from two focus groups across [Questions 1, 3, 6, 7, 8, 9, 12, 13, 14, 16, 18, and 19](#).

did not know to advocate in the beginning. One parent now teaches other parents as a parent educator to advocate for themselves and their children. Examples of instances where parents advocated for their children included when a provider misdiagnosed a participant's child or when the parent had to seek out additional services out-of-state or services that were not previously offered to their child. Another example parents provided was needing to advocate for providers to give additional information such as next steps or timelines. Parents also discussed cultural sensitivity of services. One focus group shared that there was nothing done related to cultural sensitivity for their children's care coordination. The second focus group had a lot of discussion around both language, cultural and access barriers to services specifically for Spanish speakers.

Parents recommended that improvements to communication around care coordination including improved follow-up communication and providing parents a clear timeline, direct communication options like text or WhatsApp that allow them to directly reach their care team, and better communication between providers who are part of the care team so they can more effectively coordinate patient needs.

Representative Quotations

"So, there wasn't even a courtesy email to say, "Hey, we remember you exist." - Parent

"And we only know too with the school... I'd have to call the school secretary to be able to... I don't have any way to get in touch with our speech therapist who does all of our stuff for my oldest. I guess I would call the school secretary. I have no idea how to communicate with her." - Parent

"Our case manager through [community-based organization] was always available to us via text or phone call." - Parent

"After the initial visit with the county nurse, like I said, we had no communication. So, like, I kind of forgot about it. I don't even know...to be honest, I know she's a county nurse, but I don't know where her office is or how to get a hold of them. Like, even today, I wouldn't know how to get a hold of them if I needed to reach back. And I don't even know where she's from. I'm assuming like the health department or something, but I don't know." - Parent

Knowledge Gaps for Parents and Care Team Members^{xvii}

Parents identified gaps in knowledge for themselves and other members of the care team in identifying appropriate methods of contact, resources and services. Parents indicated that they did not know about resources available to their children, how to understand their children's eligibility for these services and programs, how to find contact information of service providers, or how to communicate their children's needs to providers and members of the care team. This theme also applied to participants who realized members of their care team lacked knowledge of resources to refer them. Two participants are registered nurses and they both said that as nurses, they coordinate the care of their patients. One of them expected that teachers should know more about the school system and coordinating services, and the other is shocked that she knows so little about services for her child, except for breastfeeding services offered through the hospital. One of the parents mentioned that her provider did not tell her that she was eligible for transportation assistance based on her insurance. Three participants mentioned that providers do not listen to them or their child's needs, making the care more difficult for them and their families.

Representative Quotations

"Like, if my daughter has a speech impediment, who do I call? Do I call her doctor or do I have to call private insurance to set up a speech therapist at the school? Like, is a private school going to...is that still state-covered? Like, nobody knew anything. Like, we didn't know that we qualified for Parents as Teachers with our little ones because I thought you had to make under a certain amount of money. And they were like, "No, everybody in the state qualifies." - Parent

"I know, like, in my area, I travel a lot to go to different doctors. And I know on the back of our Medicaid card, it does say that, you know, there's help with transportation. The doctor's office has never told me about it. I know when I signed up for the insurance, it was probably in the brochures that they give you or they mail you. But I was never told by the doctor, you know, 'Hey. We know you're having to drive out of town. Insurance will help you with this if you need help with it.' I had to find out on my own in regards to that." – Parent

^{xvii} Note: Theme summarized from two focus groups across [Questions 1, 3, 6, 7, 9 and 18](#).

Interactions with Health Systems^{xviii}

Parents involved with HCC services discussed difficulties in navigating different levels of the health systems including providers, private insurance companies, MCOs and the school systems. Interactions with health systems refers to any federal, state or local health system or programs as well as hospital systems. One type of health system interaction that parents found challenging was navigating their child’s care with their insurance provider or MCO. Two parents mentioned that their child had limited availability of services or challenges with finding in-network providers, saying there is only one provider that will accept the insurance in their town. Two parents mentioned that their child had limited availability of services or challenges with finding in-network providers, saying there is only one provider that will accept Medicaid insurance in their area. One parent described how using Medicaid for their vision care was a positive experience. One parent tried to apply for Medicaid, and they have not been successful.

Three parents also discussed billing and medical insurance. Billing and insurance refers to any mention of bills or invoices received by patients regarding their care. Unexpected bills were the unanticipated receipt of a medical bill or having a medical bill much higher than expected. Two parents had unexpected medical bills. Parents discussed receiving unexpected bills for services or tests ordered from their provider, and their experience with MCO care coordinators. Parents described how their insurance coverage did not cover some of the services or tests their providers instructed them to seek. One parent described a situation in which the state of Kansas sent a list of required specialists the parent needed to see and it was challenging because this was all out-of-pocket and no financial assistance was provided, but that not going would be classified as “medical neglect” of their child. One parent also spoke about her experiences with unexpected bills during a high-risk pregnancy, saying that the insurance coverage was not explained in advance. Another parent mentioned that when she was pregnant, she did her due diligence and found out that she needed a “shot” (vaccine). She notified the nurse and the nurse told her that her state insurance did not cover it. The parent told the nurse

One type of health system interaction that parents found challenging was navigating their child’s care with their insurance provider or MCO.

^{xviii} Note: Theme summarized from two focus groups across [Questions 1, 3, 6, 12, 15, 16, 17, 18 and 19](#).

that she had private insurance that should cover the vaccine. The nurse apologized and the doctor was upset at the nurse.

For interacting with healthcare systems, parents recommended that they receive resources and information regarding service availability, eligibility, contacts and timelines. Two parents recommended a resource list be given to parents at the birth of their child. Two parents suggested it would be important to educate care coordinators, service providers and teachers on the resources available so that they can be knowledgeable and inform parents about these resources. One parent also said it would be helpful to know what resources were available in the surrounding areas, not just in their town.

Two parents suggested it would be important to educate care coordinators, service providers and teachers on the resources available so that they can be knowledgeable and inform parents about these resources.

Representative Quotations

“I would really like it if there was more of a team effort between... It seems like our school district is really struggling to provide the services that she needs, and I wish there was more coordination between them and us and just the rest of our care team to try and meet the goals of... You know, she's starting to have behaviors related to communication. So, if she can't communicate, she gets angry, and it's hard to address those when none of her care team are responding.” - Parent

“Just for the lack of availability or accessibility when your child's sick and you want that immediate care. It always has me constantly looking for other pediatricians. The pediatrician, she's great, she's nice, she listens. You know, everyone in the office is nice, but the fact that I can't see you when I truly need to, that's a point of contention.” - Parent

“The way their office is set up, if your child is sick, you have to call them at 8:00, and that means all the parents are calling at 8:00. And there's, like, a 30-minute wait. And then you just have to be able to...you'll have to wait and see who canceled and then fill in. But I mean, that's not feasible. That means you take the whole day off of work in hopes of...I mean, you're going to do it for your child, regardless, but in hopes of that there is an open spot available for

you. And if you have both of them sick, you have to...if both of them are sick, then okay, one may be able to get in at 8, but the other one may not be able to get in until, like, 2 or 4. So, they don't have it set up where there is a doctor that will handle sick walk-ins. - Parent

Challenges Related to Care Coordination^{xix}

Parents discussed many challenges they faced related to their child's care coordination including difficulties with communication with care coordinators and care team about their child's care, availability of in-network providers, and accessing services. Challenges were any difficulties or barriers faced by parents, children, or the care team. Five parents discussed communication challenges related to service provision and the availability of services and described confusion about next steps or a lack of follow-up following initial contact with a care coordinator. Another problem was once the contact was made with a specific service, parents said they did not get a call back, did not know the next steps or did not have an idea about what to do next. Three participants mentioned that providers do not listen to them or their child's needs, making the care more difficult for them. Three parents also mentioned that they had no idea when they would hear back about eligibility, assessment, enrollment, or how their child is doing as they are receiving services. Some parents discussed that they have called for services or have been referred to a program and they don't know where they are in the process and they do not hear back.

For service availability, the largest challenge parents reported was not knowing what resources are available. Parents also discussed variability in the services as well, saying that the same program or service can be great somewhere else and poor in a different place. Two parents mentioned that their child had limited availability of services or challenges with finding in-network providers saying there is only one provider that will accept the insurance in their town. One parent mentioned that because the only provider that accepts her insurance is fully booked, she has to take her child out of town for care and was frustrated because this required her to take the day off work and she did not want to. Two parents also said that their child's pediatrician is unable to see their child during an emergency or when they really need to. One parent was in tears sharing her story of wanting to breastfeed but due to the child's condition,

^{xix} Note: Theme summarized from two focus groups across [Questions 1, 2, 3, 6, 10, 14, 15, 17, 18, and 19](#).

delay in services being provided, and work-related barriers, she was unable to breastfeed her premature baby.

Service availability was discussed by four parents, particularly services that were sensitive to special needs. It was important for parents in the focus groups to share their challenges and their expectations when it comes to disability friendly services. Participants specifically mentioned a need for services sensitive to children with autism and children who are deaf. One parent discussed a barrier to accessing these services is limited in-network providers under her insurance. Another parent described a negative experience with a provider who was not sensitive to her child's needs.

One parent mentioned a positive experience with a care coordinator who went out of their way to learn the sign for bubbles to communicate with her child.

Participants specifically mentioned a need for services sensitive to children with autism and children who are deaf.

Representative Quotations

"We've tried because of the hearing loss to apply for Medicaid. And we've tried and tried in every which way, and it's not in the cards for us." – Parent

"That's what I'm currently doing right now for eye doctor. I got a message from my daughter's teacher, saying that she's complaining about headache...you know, she's...and that stuff's blurry. So, we only have one eye doctor here in town that takes state insurance. So, I'm going to be looking after we get off the phone here. I'm going to be reaching out, trying to find me an eye doctor for my youngest, that is also autism-friendly, that works good with kids. So, that's what... I mean, I just got that message earlier. So, here we are again, you know, the one dentist and the one eye doctor in this town that takes our insurance. So, availability, you know, it would be nice if it was accepted at more places." - Parent

"And then another thing that we're having...what we are struggling with is when we did receive a flyer or information, them getting back in touch with us has been a struggle. Like, they'll send out something that's like, "Oh, we'll contact you in a week to set this up." And then it's just no response. I'm calling them and I'm not getting any answers." - Parent

“I did receive from the state of Kansas. They did send me an option to join a parent group and I tried. And the woman that I went to email, she had sent me the steps to do it. And I have never heard back about getting into a parent program. I reached out to people from friends of friends to, kind of, make my own support group, but I never received any word back after I applied for it.” - Parent

Next Steps

This report provides an evaluation of HCC services in Kansas through the perspectives of published literature, providers of care coordination, insurance providers and parents of children age 0-8 who have received care coordination services. This report aims to inform future work and policy development related to improving HCC services in Kansas. In addition to the information provided in this report, the project team plans to conduct an additional four focus groups with Kansas residents who are parents of children age 0-8, pregnant or postpartum in 2023. Three of these focus groups will be conducted in Spanish. Findings of these focus groups will be reported as an addendum to this report.

Appendix A: Glossary

Care Coordinator: A care coordinator is a professional working within the care team to provide person-centered resources, services, and supports to meet an individual's needs, schedule appointments, coordinate between specialists and physicians, and monitor an individual's progress.³⁴

Care Management: The set of routines (including programs and systems) aimed to help manage patients' health and medical conditions. Combines elements of case management and disease management into an overall rubric of "care management." Largely involves providers working directly with patients.³⁵

Complex Care: Complex care is a person-centered approach to address the needs of people whose combinations of medical, behavioral health, and social challenges result in extreme patterns of healthcare utilization and cost.³⁶

Coordinated Care: The overall objective of improving health outcomes by providing high-quality care, ensuring that care from disparate providers is not delivered in silos, and eliminating redundant healthcare system costs.³⁷

Children and Youth with Special Health Care Needs (CYSHCN): Those who "have or are at increased risk of having a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."³⁸

Children with Medical Complexity (CMC): CMCs are defined as children with multiple chronic medical conditions and functional limitations that require regular healthcare services and often experience frequent hospital readmissions and require the care of multiple community and hospital-based providers.^{39, 40}

Health Equity: In an applied method, refers to a state "when everyone has a fair and just opportunity to be as healthy as possible." This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and healthcare.⁴¹

Holistic Care Coordination: A patient- and family-centered approach of coordinating care based on the "whole person" with an understanding of physical, emotional, and social aspects. Patient and family-centered approach that utilizes team-based and assessment activities

designed to meet the needs of children and youth while enhancing the capabilities of families. It utilizes a holistic approach that looks at all the needs of the child and family that may affect the child's health and well-being by addressing interrelated medical, behavioral, educational, social, developmental, and financial needs to achieve optimal health.

Social Determinants of Health (SDOH): Are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.⁴²

Medical Home: A model or philosophy of primary care that is patient-centered, comprehensive, team-based, coordinated, accessible, and focused on quality and safety.⁴³

Patient Navigation: Care coordination services are often referred to as patient navigation in the pregnant and postpartum population.

Population of Focus: Populations that are at a higher risk for poor health as a result of the barriers they experience to social, economic, political and environmental resources, as well as limitations due to illness or disability. Populations may include racial and ethnic groups, including persons of Black, American Indian or Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander races and persons of Hispanic ethnicity; rural/urban residents; children; pregnant individuals; persons who are LGBTQIA+; older adults; persons with chronic illnesses; persons with housing instability or who are homeless; immigrant populations; displaced persons; persons with limited English proficiency; persons with low literacy; persons with low income; persons with disabilities; and others.⁴⁴

Appendix B: Literature Review Research Methodology

Question	Methods	Sources	Criteria	Search Terms and Phrases
1. What is the definition and key elements of a holistic care coordination model?	The literature review identified articles with a definition of holistic care coordination.	Sources included the Kansas Department of Health and Environment (KDHE), National Academy for State Health Policy (NASHP) and JAMA Pediatrics.	Studies published between 2016 and 2022. Literature that was reviewed to provide a definition of holistic care coordination did not specify an age range.	Holistic care coordination definition, integrated care coordination definition, care management definition
2. What has been the experience of care coordinators with providing holistic care coordination services to children with complex medical conditions?	The literature review identified peer reviewed, qualitative studies on experiences of care coordinators and healthcare providers (physicians and nurses) providing holistic care coordination.	Studies were accessed via PubMed, Journal of the American Medical Association (JAMA) and Google Scholar.	Studies published between 2016 and 2022. Study population: parents of children age 0-8 and individuals receiving prenatal or postpartum care	Care coordinator experience, provider experience and holistic care coordination
3. What has been the experience of parents/guardians of children between 0 and 8 years old with receiving holistic care coordination services?	The literature review identified studies that focused on parent satisfaction with components of care coordination.	Studies were accessed via PubMed, JAMA and Google Scholar.	Studies published between 2016 and 2022. Study population: parents of children age	Parent satisfaction and holistic care coordination

Question	Methods	Sources	Criteria	Search Terms and Phrases
			0-8 and individuals receiving prenatal or postpartum care	
<p>4. What are the elements of holistic care coordination programs that serve children age 0- 8 and prenatal and postpartum population in other states?</p>	<p>The KDHE Holistic Care Coordination Toolkit lists the six national standard domains as best practices for providers to create holistic care coordination models. The domains include:</p> <ol style="list-style-type: none"> 1. Screening, Identification, and Assessment 2. Shared Plan of Care 3. Team-Based Communication 4. Individual and Family Empowerment 5. Care Coordination Workforce 6. Care Transitions <p>The search identified state programs that include elements that align with one or more standards. For a description of each domain, see</p>	<p>To identify states with holistic care coordination programs, sources from NASHP, Kaiser Family Foundation (KFF) and Centers for Medicare and Medicaid Services (CMS) were reviewed. Further program information was identified from state websites.</p> <p>To identify more states not directly referenced by NASHP, KFF and CMS, a Google search was conducted using relevant search terms listed under the “Search Teams and Phrases”</p>	<p>State programs were selected and included based on their alignment with the six national standard domains.</p> <p>Study population: parents of children age 0-8 and individuals receiving prenatal or postpartum care</p>	<p>Holistic care coordination models, state holistic care coordination standards, state maternal and child holistic care coordination, person-centered care coordination, patient-centered care coordination, pediatric service coordination, integrated care coordination, pediatric comprehensive healthcare, state programs for holistic care coordination, care coordination screening, care coordination transitions, shared plan of care for care coordination, care coordination</p>

Question	Methods	Sources	Criteria	Search Terms and Phrases
	KDHE's Holistic Care Coordination Toolkit.	column, which focused on surrounding states, such as Nebraska, Oklahoma, Colorado, Iowa, Texas and Missouri.		communication practices.
5. What policies are implemented in states to support holistic care coordination models?	Policies from various states across the country, such as state legislation and initiatives to support, improve and expand holistic care coordination practices were evaluated and included in the environmental scan.	Policy information was identified from NASHP, CMS and KFF. Further state policy information was identified from state websites.	Care coordination policies were evaluated and selected based on being referenced by NASHP, KFF and CMS. Policies were selected based on their ability to meet the selected definition of holistic care coordination. Findings and policies must be representative of parents of children age 0-8 and individuals receiving prenatal or postpartum care	State policy for holistic care coordination, state policies and postpartum care coordination, state policies and pediatric care coordination
6. What are the defined billing	Reviewed state and program websites,	Many state websites	Study population:	Medicaid and holistic care

Question	Methods	Sources	Criteria	Search Terms and Phrases
practices associated with holistic care coordination programs?	NASHP, CMS, KFF and PubMed to identify billing practices associated with holistic care coordination.	included information for both providers and consumers for how care coordination is paid for. If state websites did not include billing information, a search was conducted using resources from NASHP, CMS, KFF and PubMed to access supplemental information.	parents of children age 0-8 and individuals receiving prenatal or postpartum care	coordination, billing for holistic care coordination, payment models of care coordination, patient-centered medical home model, billing practices for holistic care coordination
7. Out of the states reviewed, what states have been referenced in research as examples of having holistic care coordination models that address social determinants of health?	Databases (see column two for more information about sources) were used to locate states referenced in literature for addressing or incorporating social determinants of health into care coordination practices.	A search was conducted using Google Scholar, PubMed and Kansas State University (KSU) Academic Library to identify states that integrated social determinants of health into care coordination models.	Study population: parents of children age 0-8 and individuals receiving prenatal or postpartum care	Social determinants of health and care coordination

Question	Methods	Sources	Criteria	Search Terms and Phrases
<p>8. How do holistic care coordination models include an equity lens?</p>	<p>Search was conducted using the listed search terms and phrases to identify states that prioritized and incorporated an equity lens into care coordination models.</p>	<p>A search was conducted using PubMed, KSU Academic Libraries, NASHP, CMS and KFF. Once referenced states and relevant programs were identified, information was pulled from state websites.</p>	<p>Study population: parents of children age 0-8 and individuals receiving prenatal or postpartum care</p> <p>Search focused on care coordination models that discussed strategies to address the needs of populations of focus. Population of focus is defined as populations that are at a higher risk for poor health as a result of the barriers they experience to social, economic, political and environmental resources, as well as limitations due to illness or disability. See full definition in Appendix A.</p>	<p>Equitable maternal care coordination, equitable pediatric care coordination, health equity and postpartum care coordination, health equity and prenatal care coordination, equitable care coordination practices</p>

Appendix C: Survey Methodology

A survey of healthcare providers and local health departments was used to measure the extent of services across the domains of Holistic Care Coordination (HCC) in Kansas, as well as how these services are operationalized. Barriers and facilitators also were assessed. The target population included individuals who provide, or are knowledgeable of, care coordination for children age 0-8, prenatal, and postpartum populations. The survey was intended to be disseminated to individuals working for local health departments, hospitals, federally qualified health centers (FQHCs), family practice, and obstetrics and gynecologists (OB-GYNs). The survey was disseminated to the target population through professional associations and coalitions. Organizations that disseminated the survey included: (1) Kansas Association of Local Health Departments, (2) Kansas Academy of Family Physicians, (3) Kansas Hospital Association, (4) Community Care Network of Kansas, and (5) Kansas Statewide Farm Worker Program. The Kansas Academy of Pediatrics declined to disseminate the survey due to internal policies against disseminating third party surveys. The American College of Physicians declined to disseminate the survey because their members do not serve pediatric, prenatal, and postpartum patients. In addition, the Kansas Department of Health and Environment (KDHE) approached the following organizations to disseminate the survey: (1) Kansas Community Health Worker Coalition, (2) KDHE Special Health Care Needs Care Coordinators and Satellite Offices, (3) Perinatal/Infant Health Consultants, and (4) Kansas Academy of Pediatrics. But it is unknown to KHI if these organizations disseminated the survey.

Data Collection and Analysis

The survey questionnaire was organized around the six domains of HCC (*Figure 3*, page 8), respondent characteristics, billing, and overall needs. Questions focused on identifying elements of each domain, how organizations operationalized these elements, as well as barriers and facilitators. The survey was developed in collaboration with KDHE's Title V Maternal and Child Health (MCH) Services Program. A pilot test was conducted with a pediatrician and changes were made to the questionnaire based on the feedback. The survey was programmed into Qualtrics web-based survey collection tool. It was disseminated on October 26, 2022, and ended on January 3, 2023. Over this timeframe, the project team sought additional organizations to disseminate the survey further and sent follow-up requests to the initial organizations asking them to complete the survey. The project team also developed approaches to deter and identify potential fraudulent respondents. The survey was closed after follow-up

dissemination and a declining number of responses. Data were downloaded from Qualtrics and saved in an Excel file on a secure drive at the Kansas Health Institute (KHI) that was accessible only to the survey project team. After conclusion of the project, the survey data was shared with the KDHE project team using a secure file transfer.

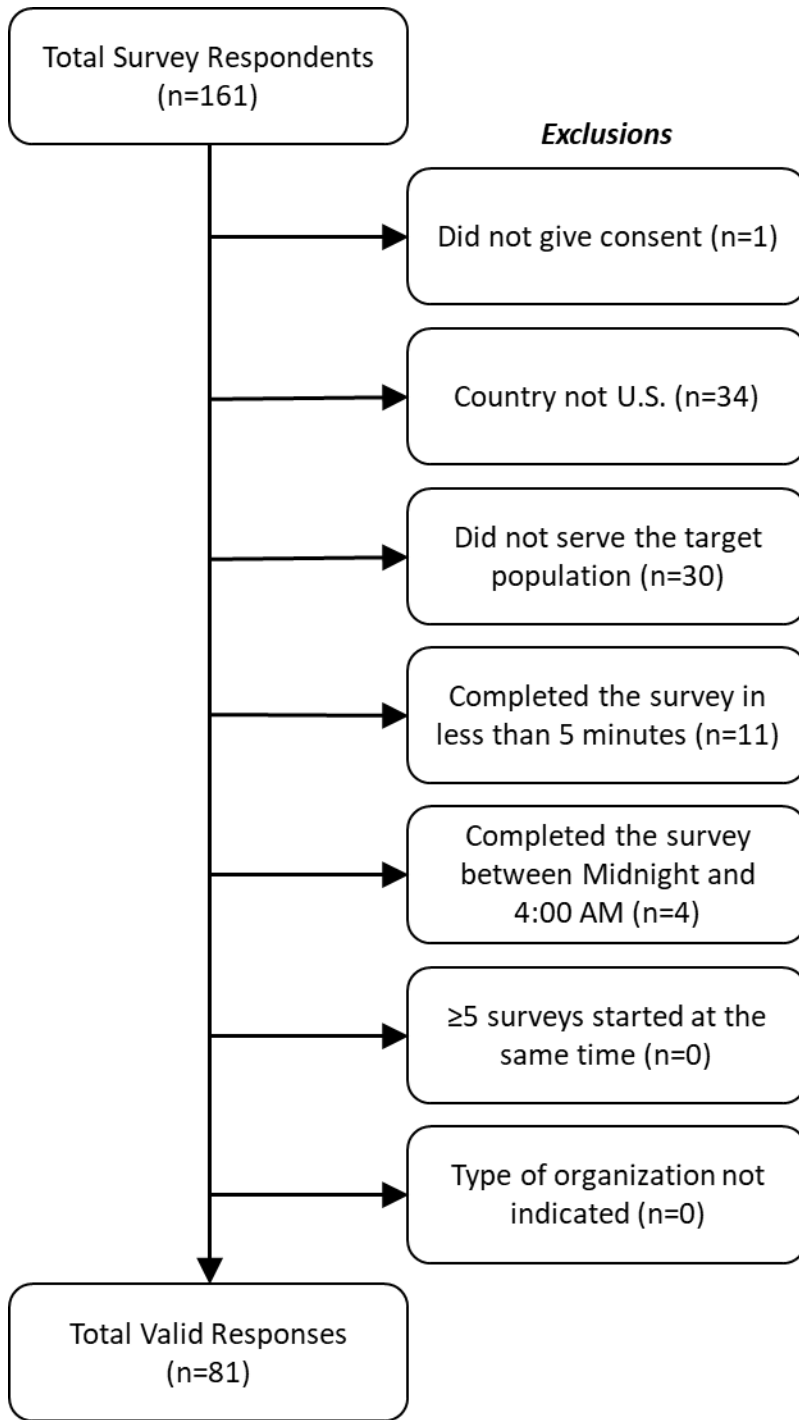
Responses were excluded for the following reasons:

1. Respondents did not consent.
2. Respondents were identified as being from outside the U.S. based on their IP address.
3. Respondents did not indicate serving children aged 0-8, prenatal or postpartum populations.
4. Respondents completed the survey in less than 5 minutes (note that Qualtrics estimated the survey to take approximately 20 minutes).
5. Respondents completed the survey between 12:00 AM and 4:00 AM Central Time.
6. Five or more respondents started the survey in a five-minute timespan.
7. Respondents did not indicate the type of organization they worked for.

Exclusions were used to ensure that respondents consented to ethics approval, served the target population, and to account for potential fraudulent behavior that was observed in the focus group portion of the overall study. The exclusion process is shown in *Figure C-2* (page C-3).

Statistical analysis was conducted in SAS v9.4. Frequencies and percentages were calculated for each quantitative question. Out of the 161 respondents, the denominator included all valid responses (n=81) except for questions involving skip logic. Responses to open-ended questions are summarized in the report and are provided verbatim in the appendix. The results are presented for all valid respondents (n=81), as well as separated into local health departments (LHDs, n=34) and healthcare providers (HCPs, n=40). HCPs include FQHCs, family practice, pediatrics, OB-GYN practices, and hospitals. Seven respondents answering other organization types were included in all valid respondents but not in either LHDs or HCPs.

Figure C-2: Exclusion Flow Chart



Appendix D: Interview Methodology

Research Approach

As defined in the Holistic Care Coordination (HCC) Environmental Scan Request for Proposal (RFP), an effective HCC model focuses on all aspects of family life, allowing for stronger supports around cross-system navigation and addressing the primary needs identified by the family, including physical, social and emotional health services, housing, education, legal and financial aid. To better understand how health plans, including Medicaid managed care organizations (MCOs) and private health insurance companies support HCC for Kansas residents who are pregnant or in their postpartum period, or who are children age 0-8, the Kansas Health Institute (KHI) interviewed key informants from the three MCOs and the largest private health insurance companies serving Kansas. The original focus was to identify which HCC services are covered by these health plans. However, KHI learned that a broader exploration may provide important information since covering benefits was only a small piece of how MCOs and private health insurance companies supported HCC. A more robust exploration of issues related to how health plans support HCC in Kansas is provided in this report.

Target Population and Interview Process

KHI requested interviews with representatives from the top five largest private health insurance companies in Kansas and the three KanCare MCOs. Among the participating health plans, the representatives either agreed to participate in the interview or identified more appropriate key informants from their organization. The health plans were allowed to identify the number of individuals to participate in the interviews. KHI sent the key informants consent forms once all the informants were identified from each organization. KHI scheduled the interviews after receiving all the consent forms from each organization. Interviews were conducted with 18 key informants from three MCOs and three private health insurance companies. The number of participants in each interview ranged from one to six. All interviews were conducted remotely using Zoom web-conferencing software. Interviews lasted between 70 to 90 minutes. The interview team included a primary interviewer and an observer. The interviewer managed the meeting, and the observer took notes and asked follow-up questions. The interviews were recorded. Key informants were asked for approval before starting the recording. The interviewer and observer discussed opportunities to improve the interview process following each interview.

Data Analysis

Interviews were recorded and then transcribed. Transcripts were analyzed using NVivo 12 qualitative data analysis software to assist with analysis. Interviews were read by the research team and then open-coded. The coding followed a systematic, iterative process involving 1) Initial a priori coding by interview guide sections and question number; 2) Open coding line-by-line of all transcripts. During this process, the research team listened to the audio recordings; 3) Secondary coding of nodes within each a priori code in NVivo to create themes; and 4) Themes were then summarized and exported from NVivo for review and discussion by the research team. During this process, analytical memos were maintained in NVivo to describe steps of analysis and reasons for thematic creation.

The research team determined that themes must be discussed in more than one interview. For this report, the research team conducted additional theme creation across questions to provide overall key findings from the interviews. Based on information learned during the six interviews, KHI staff also conducted a review and analysis of documents and information provided on public websites that described or served as the basis for the holistic care coordination services being provided by the insurance companies and MCOs to the pediatric, prenatal and postpartum patients that were the focus of this research. For the private insurance companies this documentation primarily consisted of public information on their company websites that was used to inform their existing enrollees and potential enrollees about the types of care coordination and value-added services that were or would be available to them once enrolled. For the MCOs, an official state agency website provided numerous documents and information describing the types of care coordination services that the MCOs were expected to provide, along with additional rules and requirements regarding how the services were to be provided. A summary of the documents and publicly available information was prepared by KHI staff for presentation in the final technical report.

Appendix E: Focus Group Methodology

As defined in the Holistic Care Coordination (HCC) Environmental Scan Request for Proposal (RFP), an effective HCC model focuses on all aspects of family life, allowing for stronger supports around cross-system navigation and addressing the primary needs identified by the family, including physical, social and emotional health services, housing, education, legal and financial aid. To better understand the experience of Kansas residents who are parents of children age 0-8, pregnant or postpartum, the Kansas Health Institute (KHI) conducted focus groups with participants from around the state.

Target Population and Interview Process

The target populations for these focus groups included:

- Parent/guardians age 18 years of age or older of a child (children) age 0-8 who are currently receiving or have received HCC services during the past 12 months in Kansas and/or other states.
- Individuals age 18-44 years who are currently receiving or have received HCC prenatal services during the past 12 months in Kansas and/or other states.
- Individuals age 18-44 years who are currently receiving or have received postpartum HCC services during the past 12 months in Kansas and/or other states.

Focus group eligibility also required that participants live in Kansas, were able to understand and speak English, could participate remotely over Zoom or phone and could provide informed consent of their own volition.

Participants were recruited using Kansas Health Institute (KHI) and Kansas Department of Health and Environment (KDHE) statewide networks of community, medical and public health partners to share announcements of the focus group opportunity with the community members they serve via emails and social media. Potential participants were then screened for eligibility by the KHI research team. Focus group recruitment began on November 1, 2022. Due to evidence of suspicious activity while recruiting for focus groups, recruitment was paused on November 3, 2022, and resumed on January 9, 2023. Suspicious activity strongly suggested fraudulent eligibility activity and as a result, KHI strengthened the recruitment approach to screen and remove ineligible participants and protect the confidentiality of focus group participants.

Recruitment was closed on February 7, 2022. A total of 417 respondents replied to the initial screening survey; however, after initial screening only 15 parents and 2 pregnant individuals were eligible. However, following secondary screening and the informed consent process, only 7 parents were eligible to participate.

KHI scheduled the focus groups with participants after receiving their informed consent documents. Because no one who was pregnant was eligible to participate after secondary screening, only parent focus groups were scheduled. However, during the parent focus groups, some participants did discuss their experiences with care coordination during pregnancy.

Two focus groups were conducted. Both focus groups were conducted remotely using Zoom web-conferencing software. The focus groups lasted 60 minutes. Two KHI team members conducted the focus groups. The focus groups were recorded and then transcribed for analysis.

Data Analysis

Interview transcripts were analyzed using Dedoose qualitative data analysis software to assist with analysis. Interviews were read by the research team and then open-coded. The coding followed a systematic, iterative process involving 1) Initial a priori coding based on interview guide sections and questions; 2) Open coding line-by-line of all transcripts. During this process, the research team listened to the audio recordings; 3) Secondary coding of nodes within each a priori code in Dedoose to create themes; and 4) Themes were then summarized and exported from Dedoose for review and discussion by the research team. During this process, analytical memos were maintained in Dedoose to describe steps of analysis and reasons for thematic creation.

Appendix F: Endnotes

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