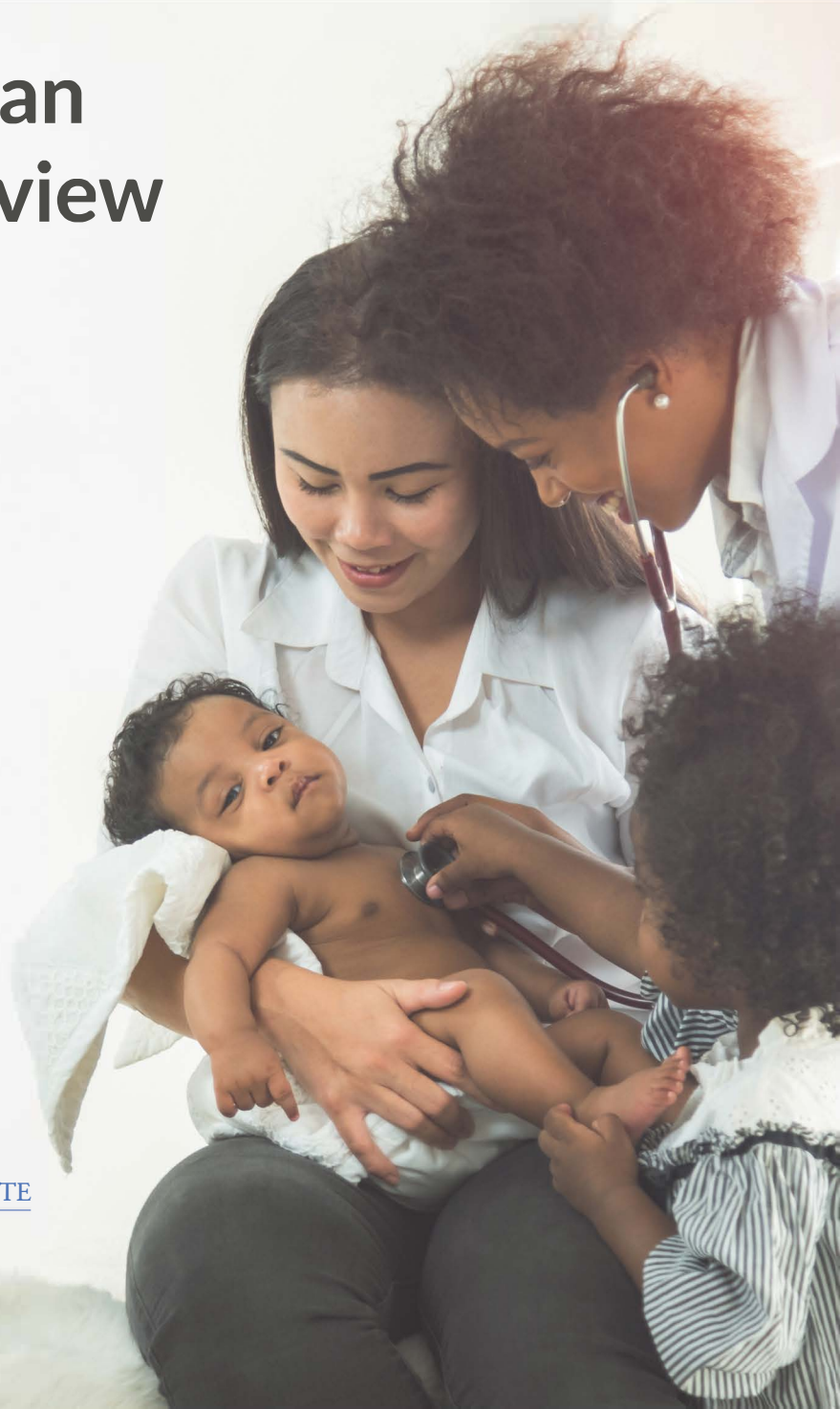
April 2023

Holistic Care Coordination in Kansas

Environmental Scan and Literature Review (Questionnaires)



Kansas Department of Health and Environment

KANSAS HEALTH INSTITUTE
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Contents

Holistic Care Coordination Provider Survey Questionnaire

Please note that the question numbers appear out of order in the questionnaire. This is because Qualtrics assigns a question number at the time questions are created. Questions were added and rearranged after the pilot test. The questions ordering provided below aligns with how the questionnaire was presented to respondents.

Holistic Care Coordination Survey

Anonymous Care Coordination Provider Survey
Do you provide any of the following services?

Services: *Care coordination, care navigation, case management, screenings, closed-loop referrals, patient care/action plans, family-centered planning and/or supported transfers/transitions of care*

We would like to hear from you. On behalf of the Kansas Department of Health and Environment (KDHE), the Kansas Health Institute is administering a survey of providers and public health workers that administer the above services. KDHE is seeking to better understand your experiences with **providing care coordination services (sometimes also referred to as care navigation or case management) to pediatric patients (aged 0 – 8 years) or patients receiving prenatal or postpartum care across Kansas.** This survey was approved by KDHE Institutional Review Board (IRB).

We are asking that one person per organization, facility or agency complete this survey. If you are not familiar with the procedures and practices related to the above services at your organization, please share this survey with another provider, administrator, care coordinator, or care navigator at your organization who would be able to speak to the procedures.

There is no physical, psychological, or social risk associated with this study. In general, the questions asked are not sensitive in nature. For those working in regions with few health providers, there is a minimal risk that county-level geographic information presented as a map could be linked to specific facilities. To address this minimal risk, we will only present information in aggregate. Your answers will not be connected to your name or your organization/agency. Your responses will be kept completely confidential and compiled with other responses. The survey data will be shared with the KDHE. Your participation in this survey

is voluntary and there will be no penalty or loss of benefits if you refuse to participate. You can choose to skip questions that you don't feel comfortable answering and you can stop at any time.

Your perspective is valuable. The survey should take you 15-20 minutes to complete. To know how far you have come in a survey, please refer to a progress bar at the top of each page. We encourage you take this survey on a computer rather than a mobile device.

If you have any questions or concerns regarding this survey, contact Samiyah Para-Cremer at sparacremer@khi.org.

3. INFORMED CONSENT
   By clicking the button below, you acknowledge: Your participation in the study is voluntary. You are 18 years of age or older. You are aware that you may choose to terminate your participation at any time for any reason.
   a. I consent, begin the survey (1)
   b. I do not consent, I do not wish to participate (2)
4. Which of the following best describes the type of organization you currently work for?
   a. Federally qualified health centers (FQHC) (1)
   b. Family practice (2)
   c. Pediatrics practice (3)
   d. Obstetrics and gynecology (OB-GYN) practice (4)
   e. Hospital (5)
   f. Local public health department (6)
   g. Other (Please list)
5. Which of the following best describes your role at your practice?
   a. Care coordinator (also referred to as care navigator, patient coordinator, or care manager) (1)
   b. Physician (2)

c. Nurse (3)

d. Doula/midwife (4)

e. Administrator (5)

f. Social worker or case manager (6)

g. Patient advocate (7)

h. Community health worker (8)

i. Other (Please list) (9)

6. In which county is the primary location of your practice? [County List Dropdown Menu]

7. How many full-time employees (FTEs) currently work at your practice? (Please round the FTE number to the nearest integer without the thousands separator.)

8. What is your gender identity?

    a. Male (1)

    b. Female (2)

    c. Non-binary (3)

    d. Other (Please list) (4)

    e. Prefer not to say (5)

9. Are you of Hispanic, Latinx, or Spanish origin?

    a. Yes (1)

    b. No (2)

10. What is your race? *(Please select all that apply)*

    a. White (1)

    b. Black/African American (2)

    c. American Indian or Alaska Native (3)

d. Asian (4)

e. Hawaiian or Pacific Islander (5)

f. Other (Please list)) (6)

g. Prefer not to say (7)

11. Do you provide services to any of the following populations? *(Please select all that apply)*

    a. Children aged 0-2 years (1)

    b. Children aged 3-5 years (2)

    c. Children aged 6-8 years (3)

    d. Individuals receiving prenatal care (care received during pregnancy) (4)

    e. Individuals receiving postpartum care (care received in 12 months after giving birth) (5)

    f. None of the above (6)

This section asks about how your organization identifies patients (age 0-8 and individuals receiving prenatal or postpartum care) who may have unmet health needs due their social, financial, and other circumstances.

13. Which of the following considerations do you use to determine if additional support would be beneficial to the patient/family? *(Please select all that apply)*

    a. Insurance status (1)

    b. Eligibility for and involvement in public programs such as Medicaid, the Supplemental Nutrition Assistance Program (SNAP) and the Special Supplemental Nutrition Program for Women, Infants, Children (WIC) (2)

    c. Whether the patient is involved in the justice system (3)

    d. Involvement in the child welfare or foster care system (4)

    e. Education needs (K-12) (5)

f. Language needs and preferences (6)

g. Health literacy and health education needs (7)

h. Social determinants of health (housing, food insecurity, etc.) (8)

i. Preferred method of communication (e.g., phone, e-mail, in person) (9)

j. Demographics (including race and ethnicity) (10)

k. Availability of support systems, including a family support network (11)

l. Unmet needs for services and support (12)

m. The patient's self-management skills and capacity to navigate care systems (13)

n. Health status of the caregiver and family member(s), if applicable (14)

o. Complexity of patient conditions (15)

p. Presence of frequent hospital admissions or emergency department visits (16)

q. Other (Please List) (17)

Sometimes, in order to coordinate care, the patient and/or family creates a care plan, together with one or more healthcare providers. It can be created for people with any health condition. The care plan covers the patient's needs and goals for healthcare and identifies any gaps in care coordination. The plan may set goals for the patient and the patient's providers. Ideally, it anticipates routine needs and tracks current progress toward a patient's goals. This plan is often called a shared care plan or a plan of action.

This section asks about how your organization develops these care plans for patients age 0-8 or individuals receiving prenatal or postpartum care.

55. Do you develop care plans for your patients?

a. Yes (1)

b. No (2)

15. When developing a patient care plan, do you work with the patient and their family to develop care goals?
    a. Yes (1)
    b. No (2)
16. What role should patients and their families have in developing a care plan?
17. Which of the following components do patients' care plans include? *(Please select all that apply)*
    a. Measurable steps (1)
    b. Time frame for achieving steps (2)
    c. Person responsible for completing that step (3)
    d. Other (Please list) (4)
18. On average, how frequently are the care plans reviewed and updated?
    a. More frequently than every 30 days (1)
    b. Every 1-2 months (2)
    c. Every 3-4 months (3)
    d. Every 5-6 months (4)
    e. Every 7-12 months (5)
    f. Less frequently than annually (6)

When a patient is receiving care from multiple providers, facilities or social services (their care team), a care team member may facilitate communication between these groups to help enhance understanding and avoid duplication of efforts. A care team includes the patient's primary care provider, other primary care professionals, and other healthcare professionals who care for them. It also includes people who are not primary care professionals—for example, the patient or people in the patient's life such as family

members or friends that help the patient get the care they need to feel better or stay healthy.

This section asks about your organization's communication with patients (age 0-8 or individuals receiving prenatal or postpartum care) and other members of a care team.

20. Do you have a designated care coordinator (sometimes also referred to as a patient navigator or care manager) that serves as a patient's first point of contact regarding their care?
    a. Yes (1)
    b. No (2)
21. What job title does your organization give for this designated person who coordinates patient care?
    a. Care coordinator (1)
    b. Care navigator (2)
    c. Patient coordinator (3)
    d. Patient advocate (4)
    e. Community health worker (5)
    f. Other (Please list) (6)
22. Does your organization require any credentials (degrees or certifications) to coordinate patient care?
    a. Yes (1)
    b. No (2)
56. What credentials (degrees or certifications) are required of the person coordinating patient care?
23. Which of the following does your organization provide to the patient and/or the patient's family to get in contact with members of their care team? *(Please Select all that apply)*

a. Main office number for our facility or organization (1)

b. Direct emails for members of their care team (2)

c. Direct phone numbers for members of their care team (3)

d. Emergency numbers for contacting care team outside of business hours (4)

e. Direct message options through the electronic health management system (5)

f. Other (Please list) (6)

24. Does your organization use an electronic health management system (I.T. system for tracking and sharing electronic medical records)?

    a. No (1)

    b. Yes (2)

25. What is the name of the electronic health management software you use?

26. How does your organization typically share care plans with **the patient**? *(Please select all that apply)*

    a. Phone (1)

    b. Fax (2)

    c. Mail (3)

    d. In-person (4)

    e. Electronic medical records (5)

    f. Other (Please list) (6)

50. How does your organization typically share care plans with **other members of the care team**, especially those in external organizations? *(Please select all that apply)*

    a. Phone (1)

    b. Fax (2)

c. Mail (3)

d. In-person (4)

e. Electronic medical records (5)

f. Other (Please list) (6)

27. Have any of the following been a challenge when communicating patient care needs to other care team members? *(Please select all that apply)*

    a. Interoperability (ability for IT systems for the different organizations to access the same records or software) (1)

    b. Data protection (2)

    c. Obtaining patient consent (3)

    d. Cost of electronic management software (4)

    e. Time of staff (5)

    f. Reimbursement rates for this time (6)

    g. Other (Please list) (7)

28. On average, how frequently do you communicate with **patients and/or patient's families** about the care they receive?

    a. Every 30 days or more frequently (1)

    b. Every 1-6 months (2)

    c. Every 7-12 months (3)

    d. Every 1 year or less frequently (4)

29. On average, how frequently do you communicate with **other care team members** about the care patients receive?

    a. Every 30 days or more frequently (1)

    b. Every 1-6 months (2)

c. Every 7-12 months (3)

d. Every 1 year or less frequently (4)

30. Some patients may require community support for housing, food or other unmet needs. Does your organization ever refer patients to community-based organizations to support these needs?

    a. Yes (1)

    b. No (2)

31. On average, how frequently do you communicate with **community-based organizations** about patient needs?

    a. Every 30 days or more frequently (1)

    b. Every 1-6 months (2)

    c. Every 7-12 months (3)

    d. Every 1 year or less frequently (4)

Relationship building is a central component of care coordination efforts in which a care team helps assist patients with accessing and understanding the care they receive. This section asks about your organization's perspective on the relationship building between patients (age 0-8 or individuals receiving prenatal or postpartum care), patient's families and the care team.

52. How does your organization promote trust between the patient and their care team?

53. Does your organization offer or refer patients or their families to any of the following education or self-management training? *(Select all that apply)*

    a. Nutrition-related education (1)

    b. Understanding how to use necessary medical equipment (2)

    c. Accessing online medical records, patient portal or care plans (3)

    d. Understanding and treatment of chronic conditions (4)

e. Other (Please list) (5)

f. None, we do not offer patients or their family education or self-management training (6)

54. Peer supports can include parent and youth mentors, support groups, family advocacy groups, internet-based patient communities and condition-specific organizations. On average, how frequently does your organization connect patients with peer supports?

    a. Always (1)

    b. Often (2)

    c. Sometimes (3)

    d. Rarely (4)

    e. Never (5)

This section asks about the training and credentials your organization expects of someone coordinating or managing care for patients (age 0-8 or individuals receiving prenatal or postpartum care) as well as the reimbursement and payment options available to those performing care coordination. If you are the person who coordinates care at your organization, please answer the following questions as they relate to yourself.

33. Which of the following trainings topics does your organization **currently require** for the person(s) who coordinates patient care? *(Please select all that apply)*

    a. Relationship building with families (1)

    b. Motivational interviewing (2)

    c. Identification of family strengths priorities and goal setting (3)

    d. Cultural and linguistic competency (4)

    e. Implicit bias (5)

    f. Health literacy (6)

    g. Health insurance policies and procedures (7)

h. Sharing patient information with external care team members (8)

i. Using electronic health records for care coordination (9)

j. Shared plan of care development (10)

k. Community-based resource provision (11)

l. Patient transition and referral process (12)

m. Navigating healthcare in educational K-12 settings (13)

n. None of the above (14)

34. Of the following trainings, which **three trainings would be most helpful** to your organization's care coordinator(s) in the future? *(Please select up to three)*

a. Relationship building with families (1)

b. Motivational interviewing (2)

c. Identification of family strengths, priorities, and goal setting (3)

d. Cultural and linguistic competency (4)

e. Implicit bias (5)

f. Health literacy (6)

g. Health insurance policies and procedures (7)

h. Sharing patient information with external care team members (8)

i. Using electronic health records for care coordination (9)

j. Shared plan of care development (10)

k. Community-based resource provision (11)

l. Patient transition and referral process (12)

m. Navigating healthcare in educational K-12 settings (13)

n. Other (Please list) (14)

34. Is your organization able to bill for care coordination services?

    a. Yes, for all services (1)

    b. Yes, for some services (2)

    c. No, unable to bill for services (3)

    d. No, we do not bill for other reasons (4)

36. Does your organization have any restrictions around the amount of time you can bill for care coordination (sometimes also referred to as care management) services for patients?

    a. Yes (1)

    b. No (2)

37. Please describe any restrictions on the amount of time you can bill for care coordination services for patients?

57. Why does your organization **not bill** for care coordination services?

38. What care coordination services **are not currently covered** by private insurance providers or Medicaid managed care organizations (MCOs) that you believe should be billable services in the future?

39. What changes to billing practices would assist with your provision of care coordination services?

This section asks about your organization's practices related to care transitions for patients age 0-8 or individuals receiving prenatal or postpartum care. Care transitions refer to the transfer of care between and within medical, behavioral health, social service, education, and justice systems.

41. Does your organization have protocols, policies or practices related to care transitions?

    a. Yes (1)

    b. No (2)

    c. Unsure (3)

42. Readiness assessments are tools that help inform transition procedures based upon a patient and patients' family's preparedness for the care transition. Does your organization conduct a readiness assessment?

    a. Yes (1)

    b. No (2)

    c. Unsure (3)

43. "Warm handoffs" are when a member of the care team meets with care coordinators or providers who will oversee the patients' future care after a transition. On average, how frequently does your organization do "warm handoffs"?

    a. Always (1)

    b. Often (2)

    c. Sometimes (3)

    d. Rarely (4)

    e. Never (5)

This section asks about your organization's overall experience with providing care coordination services to patients age 0-8 and individuals receiving prenatal or postpartum care.

46. Which of the following would be the three most important factors to your organization's decision to **expand** care coordination services? (Please select 3 factors)

    a. Current reimbursement structures (1)

    b. Staff capacity (2)

    c. Established relationships with other local health organizations and service providers (3)

    d. Patients' need for those services (4)

    e. Current availability of care coordination services in our organization's service area (5)

f. Access to mechanisms (IT, electronic medical records, technology, etc.) to share information with other service providers (6)

g. Other (Please list) (7)

h. None of the above, we have not considered expanding care coordination services (8)

47. What state or local level policy changes would assist with your provision of care coordination services?

48. Are there any other ways that care coordination can be improved across Kansas?

Insurance Company and Managed Care Organization Interview Questionnaire

Goal: Understand what holistic care coordination services (also sometimes referred to as care management or care navigation services) are considered a covered benefit for pediatric patients age 0-8 under private health insurance plans and KanCare, the types of services provided, and whether these types of services are subject to cost sharing.

When we ask questions related to KanCare, we are speaking about Kansas Medicaid and Children's Health Insurance Program (CHIP). If your answer differs between those covered by Medicaid and CHIP, please specify the program you are referring to in your answer.

Participants: Participants are representatives of one of the following:

1. Five largest insurance companies in Kansas (by market share)
2. Three managed care organizations (MCOs) in Kansas

Prep and Policy Review: Prior to the interview, the following questions will be answered using publicly available data and email communication with interviewees. If any of these questions remain unanswered, they will be asked during the interview:

- Where is the company's corporate headquarters?
- What is their service area?
- Do they have enrollees in all 105 Kansas counties? If not, in how many counties do they have enrollees?
- What type of insurance company are they? (From the Kansas Insurance Department website.)
- How many covered lives do you have in the state?
- How many of those covered lives are pediatric patients age 0-8?
- How many of those covered lives receive prenatal or postpartum care?
- What were the most common types of holistic care services covered for children age 0-8 provided between September 1, 2021, and August 30, 2022?

- For the most common types of holistic care services for children age 0-8 you identified previously, what percent of the costs were shared by patients?
- What were the most common types of holistic care services covered for individuals receiving prenatal and postpartum care between September 1, 2021, and August 30, 2022?
- For the most common types of holistic care services for individuals receiving prenatal and postpartum care you identified previously, what percent of the costs were shared by patients?

BEGINNING OF SEMI-STRUCTURED INTERVIEW GUIDE (90 Minute Interview)

Introductions

Hello. Thank you for taking the time to speak with us about care coordination you cover for children 8 years old or younger, as well as people receiving prenatal and postpartum care. Sometimes care coordination is also referred to as care management or care navigation services. Your information will help us better understand what types of services are available in Kansas and how care coordination can be improved. Before we begin, I have a few housekeeping items:

- Has everyone sent us their signed informed consent form? If you haven't, we'll have to ask you to leave the Zoom meeting.
- We will also be recording this meeting to support our analysis of the interviews. Is that okay?
- Before we begin, do you have any questions for us?

Questions

1. How would you describe "holistic care coordination"? (Prompt them to define)
2. For the purpose of this interview, we are defining key elements of holistic care coordination as (paste into the chat):
    a. Team-based with designated and well-defined roles for all members of care team,

b. A sole, identified, care coordinator serving as point person to family,

c. Patient and family centered care plan developed in collaboration with provider to establish care goals and adjusted as needed,

d. Enhanced communication (emphasis on electronic medical records) between care team, community services, families and patients,

e. Connects complex medical needs and social determinants of health such as economic stability, food insecurity, and access to housing, and

f. Recognizes role and burden (cost, time, emotional health, etc.) on families caring for these patients.

How would you describe “holistic care coordination”? (Prompt them to define)

3. How does [insurance provider/MCO name] determine what holistic care coordination services are covered for pediatric patients 8 years old or younger?

    a. How was covered services determined for prenatal and postpartum patients?

4. How have the holistic care coordination services offered as covered benefits changed over time?

    a. Probe: Have the number of claims for pediatric holistic care coordination increased, remained the same or decreased during past five years?

    b. How have the number of claims changed for prenatal and postpartum care coordination during past five years?

    c. Probe: How have the types of claims covered for these services changed over time?

5. What limitations or restrictions apply to holistic care coordination services benefits for pediatric patients 8 years old or younger? (If prompted, can specify time or charge based limitations)

    a. … and what limitations or restrictions apply for prenatal and postpartum patients?

6. What training is available to [insurance provider/MCO name] staff related to addressing holistic care coordination claims?

7. How does [insurance company/MCO] promote care coordination services available to pediatric patients 8 years old or younger?
    a. How are these services promoted to prenatal and postpartum patients?

Health equity means that 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 (Robert Wood Johnson Foundation). Health equity is achieved when every person has the opportunity to "attain his or her full health potential" and no one is "disadvantaged from achieving this potential because of social position or other socially determined circumstances." Health inequities are reflected in differences in length of life; quality of life; rates of disease, disability, and death; severity of disease; and access to treatment.

8. Thinking about care coordination services for pediatric patients 8 years old or younger, how does [insurance company/MCO] incorporate equity considerations?
    a. … and how is equity incorporated for prenatal and postpartum patients?
9. How do care coordination services vary based on the cultural or linguistic needs of [insurance provider/MCO name] enrollees?
    a. Probe: Does [insurance provider/MCO name] reimburse providers for the cost of employing and making translators available to their patients?
    b. Probe: Are additional services available to patients with greater needs?
10. For what reasons does [insurance company/MCO] have covered benefits for holistic care coordination services for enrollees?
11. What are the potential benefits for pediatric patients 8 years old or younger of providing coverage for these services?
    a. … and for prenatal and postpartum patients?
12. What are the potential benefits for [insurance company/MCO] of providing coverage for holistic care coordination services to pediatric patients 8 years old or younger?
    a. … and to prenatal and postpartum patients?

13. How does [insurance provider/MCO name] evaluate those benefits to patients?
    a. … and benefits to the [insurance provider/MCO name]?
14. How does [insurance provider/MCO name] assess the cost-benefit of covering holistic care coordination services?
15. What components would be essential to include in a payment model for care coordination for the state of Kansas?
16. What should be improved about holistic care coordination in Kansas?
    a. What policy changes would be helpful to increase access to care coordination services for patients 8 years old or younger?
        i. … and policy changes to increase access for prenatal and postpartum patients?

Thank you so much for speaking with us about how [insurance provider/MCO name] supports care coordination for children 8 years old or younger, as well as people receiving prenatal and postpartum care. This will go a long way in helping improve care coordination services throughout Kansas. Please feel free to follow up with us if you have any questions.

Parent Focus Group Screener Questionnaires

Adapted Screener to Prevent Eligibility Fraud

1. INFORMED CONSENT: By clicking the button below, you acknowledge: Your participation in the screening survey is voluntary. You are 18 years of age or older. You are aware that you may choose to terminate your participation at any time for any reason.

    a. Yes,

    b. No *Skips to end of survey*

Block Title: How did they hear about it?

2. How did you hear about this focus group opportunity?

    a. _____

Block Title: Contact information

Text: Please provide your contact information. If the survey indicates you may be eligible to participate in the study, we will contact you with more information. **All information you provide will be kept strictly confidential.**

3. First name:

    a. _____

4. Last name:

    a. _____

5. Phone number:

    a. _____

6. Email address:

    a. _____

TEXT: Home Address. If eligible and you choose to participate in a focus group, a gift card will be mailed to your home address after the focus group meeting.

7. Address Line 1:
    a. _____
8. Address Line 2: (OPTIONAL)
    a. _____
9. City
    a. _____
10. State
    a. _____
11. Zip code
    a. _____

Block Title: Focus Group Interest

12. We are conducting focus groups with two separate groups. If eligible, which focus group would you prefer to participate in?
    a. **Parent focus group** discussing my child's care coordination services (Completes Parent Block ONLY)
    b. **Pregnant individual focus group** discussing care coordination I received during and after pregnancy and my baby's care coordination services (Completes Pregnancy Block ONLY)
    c. **Neither**. I know longer wish to participate in either focus group. *Skips to end of survey*

Block Title: Parent Focus Group

13. In 2-3 sentences, please describe why you want to participate in the **parent focus group** discussing your child's care coordination services?

a. _____

14. What year were you born? [drop down format with years between 2010 and 1955]

15. How many children live in your household? [Drop down format – only accept numbers]

16. Are you the parent or legal guardian of the child(ren) living in your household?

    a. Yes

    b. No *Skips to end of survey*

17. How old are your children? [open response]

    a. _____

18. In the past 12 months, which of the following, if any, describe medical services your child(ren) have received? (Please select all that apply)

    a. Preventative/well care (e.g., checkups)

    b. Specialty medical care

    c. Mental healthcare

    d. Assistance with transportation or utilities (for household)

    e. Other, please describe _____

    f. None of the above

    g. Prefer not to say

19. In the past 12 months, in which states did your child(ren) receive these services? (Please list all states in which they received services)

    a. _____

20. In the past 12 months, what health insurance, if any, covers most of your child(ren)'s medical care?

    a. _____

21. Have your child(ren) ever had a designated care coordinator (sometimes referred to as care coordinator, navigator, community health worker, case manager) or a care coordination team who coordinated their healthcare needs?

    a. Yes

    b. No *Skips to end of survey*

    c. Don't know

22. For which of the following did your child have a designated individual who consistently provided assistance or worked with others to provide assistance to meet your child's healthcare needs?

    a. Scheduling appointments with other healthcare providers

    b. Understanding medical bills

    c. Paying medical bills

    d. Scheduling transportation to appointments

    e. Picking up medication

    f. Other (appear logic – shows next question if selected)

    g. None of the above

23. In what other ways did a designated individual assist with meeting your child's healthcare needs? *Question skipped if Other is not selected.*

    a. _____

24. When was the last time a designated care coordinator helped coordinate your child's healthcare needs?

    a. Within the past 6 months

    b. Within the past 7-12 months

    c. Within the past 13-18 months

d. Within the past 19-24 months

e. Within the past 25-30 months

f. Within the past 31-36 months

g. More than 36 months (3 years ago)

25. In 2-3 sentences, please describe why the topic of care coordination is important to you.

    a. _____

Block Title: Pregnant Individual Focus Group

26. In 2-3 sentences, please describe why you want to participate in the **pregnant individual focus group** discussing care coordination you received during and after pregnancy and your baby's care coordination services?

    a. _____

27. What year were you born? [drop down format with years between 2010 and 1955]

28. Have you ever received healthcare or health related services for pregnancy or care after giving birth?

    a. Yes

    b. No *[Skips to end of survey]*

    c. Prefer not to say *[Skips to end of survey]*

29. When was the last time you received healthcare or health related services during pregnancy or postpartum care after giving birth?

    a. Within the past 6 months

    b. Within the past 7-12 months

    c. Within the past 13-18 months

    d. Within the past 19-24 months

    e. Within the past 25-30 months

f. Within the past 31-36 months

g. More than 36 months (3 years ago)

30. Which of the following, if any, best describe the services you received in the past 12 months? (Please select all that apply)

    a. Preventative/well care (e.g. checkups)

    b. Specialty medical care

    c. Mental healthcare

    d. Assistance with transportation or utilities (for household)

    e. Other, please describe _____

    f. None of the above

31. In the past 12 months, in which states did you receive healthcare or health related services? (Please list all states in which you received services)

    a. _____

32. What health insurance, if any, covers most of your medical care?

    a. _____

33. Have you ever had a designated care coordinator (sometimes referred to as care coordinator, navigator, community health worker, case manager) or a care coordination team coordinate your care needs?

    a. Yes

    b. No *Skips to end of survey*

    c. Don't know

34. For which of the following did you have a designated individual who consistently provided assistance or worked with others to provide assistance to meet your healthcare needs?

a. Scheduling appointments with other healthcare providers

b. Understanding medical bills

c. Paying medical bills

d. Scheduling transportation to appointments

e. Picking up medication

f. Other (appear logic – shows next question if selected)

g. None of the above

35. In what other ways did a designated individual assist with meeting your healthcare needs? Question skipped if Other is not selected.

    a. _____

36. When was the last time a designated care coordinator helped coordinate your healthcare needs?

    a. Within the past 6 months

    b. Within the past 7-12 months

    c. Within the past 13-18 months

    d. Within the past 19-24 months

    e. Within the past 25-30 months

    f. Within the past 31-36 months

    g. More than 36 months (3 years ago)

37. In 2-3 sentences, please describe why the topic of care coordination is important to you.

    a. _____

Parent Focus Group Questionnaire

Notes for introductory section/discussion:

Thank you for participation, including background on the focus group and why it is being conducted:

- 60-minute discussion about experiences with care coordination,
- Review of consent and confidentiality, and
- KHI contact information for post focus group questions/comments/concern.

Key Definitions: There will be definitions throughout the guide as you go along, but first here are some initial key definitions and acronyms we will use regularly:

Care coordination: this refers to healthcare that is provided in a planned way that meets the needs and preferences of the patient across multiple providers or community organizations. When care is coordinated well, the patient and his or her doctors, nurses, other healthcare providers, family, and other caregivers all know who is responsible for different parts of the patient's care, and they communicate with each other so that everyone has the information they need.

Care team: this includes your primary care provider, other primary care professionals, and other healthcare professionals who care for you. It also includes people who are not primary care professionals — for example, yourself or the people in your life such as family members or friends that help you get the care you need to feel better or stay health.

Care plan: Sometimes, in order to coordinate care, the patient and/or family creates a care plan, together with one or more healthcare providers. It can be created for people with any health condition. The care plan covers the patient's needs and goals for healthcare and identifies any gaps in care coordination. The plan may set goals for the patient and the patient's providers. Ideally, it anticipates routine needs and tracks current progress toward a patient's goals. This plan is often called a care plan or a plan of action.

Part I. Experience with Care Coordination Services

First, we would like to ask you a few questions about your experience with your care coordinator or a care coordination team. [Note for the focus group conducted with individuals who are

receiving or have received some of the services outside of Kansas: First, we will focus on your child's/family experience with the care coordination services in Kansas. Given that your child is receiving or has received services outside of Kansas, we will also ask a few questions about your experience with care coordination of out-of-state services.]

1. How well are your child's needs being met by the care coordination you are receiving?

   Probe: Is your child's care coordinated in a way that makes things easier for you/your family? Why or why not?

2. What are the top priorities of your care coordinator/care coordination team as related to meeting your child's care needs?

   Probe: What other priorities would you like your coordinator/coordination team to establish?

3. How would you describe your experience working with your care coordinator/care coordination team to meet your child's care needs?

   Probe: What could care coordinator/care coordination team do to improve your experience?

   Probe: What role should a care coordinator have in meeting your child's care needs?

   Probe: What skills and knowledge would be helpful to have for care coordinators?

4. What role do you usually play in coordinating care for your child?

   Probe: What role should parents/guardians like yourself play in the care coordination process?

5. How involved do you feel in the decisions about your child's care plan*?*

   Probe: How would you like to see parents/caregivers be involved in the development of the child's care plan?

6. How did your care coordinator help your child and family receive resources or services you needed in Kansas?

   Probe: Did your care coordinator connect your family with any community resources such as transportation, utilities or other? If so, which ones?

Probe: What could have care coordinator/care coordination team done to improve your experience?

Questions for the focus group conducted with individuals who are receiving or have received some of the services outside of Kansas.

6.1 How did your care coordinator help your child and family receive resources or services outside of Kansas? (If applicable)

Probe: What worked well? What did not work well?

Probe: What could have care coordinator/care coordination team done to improve your experience?

Part II. Communication Between Parents/Guardians and Care Coordinator/Care Coordination Team

In this section, we will ask you a few questions about your experience communicating with your care coordinators, the care coordination team and providers.

7. How would you describe your experience communicating with your care coordinator/care coordinator team?

   Probe: What is helpful? What is not helpful?

8. In general, when you communicate with your care coordinator/care coordination team, do you feel like you get the information you need to understand and participate in your child's care?

   Probe: What could your care coordinator/care coordination team do to help you understand better?

9. How do the modes of communication used by your care coordinator/care coordination team meet your needs?

   Probe: How would you prefer to receive communication?

10. What suggestions do you have for improving communication between you and your care coordinator/coordination team?

Key definition – Culturally Sensitive Services: When providers approach families without judgment or ideas about what their cultural beliefs are without knowing the family, the family will feel valued and comfortable when accessing services.

11. What has been your experience with culturally sensitive services?

    Probe: Please share positive and/or negative experiences regarding availability/accessibility of culturally sensitive services.

Part III. Communication Between Individuals Involved in Care Coordination Team

12. How effectively does your care coordinator communicate the information to other members of the care coordination team in Kansas?

Questions for focus group conducted with individuals who are receiving or have received some services outside of Kansas.

12.1 How effectively does your care coordinator communicate the information to providers outside of Kansas?

13. How well do your child's different Kansas providers communicate and share information with each other?

13.1 How well do your child's Kansas providers communicate and share information with providers outside of Kansas?

14. What suggestions do you have for improving communication between the members of your care coordination team?

Part IV. Assistance in Navigating Medical Bill/Healthcare Coverage

15. Have you had an unexpected medical bill for services recommended by your child's care coordination team? If yes, ask Q. 23.

16. What steps did your care coordinator/care team take to help you resolve the issue?

17. What other assistance have you received from your care coordinator/care coordination team to help you understand what services are covered under your insurance and potential out-of-pockets costs? What was helpful? What was not helpful?

Part V. Recommendations

Finally, we would like to ask you for any additional suggestions for improving care coordination in Kansas.

18. What should be the top 3 priorities for improving care coordination in Kansas?

19. Please share any other experience and feedback you think relevant to our discussion today.