

KMMC Consumer Engagement Report
Results of Fall, 2019 Consumer Engagement about KanCare Experiences
January 21, 2020

Background and Goals. The KanCare Meaningful Measures Collaborative (KMMC) consumer engagement process was conducted from August, 2019 to November, 2019. This consumer engagement process served as a follow-up to the initial KMMC consumer engagement effort conducted in the Spring, 2019. The purpose was to engage KanCare members regarding their experiences with KanCare. Such feedback helps with priority setting and informing the KMMC's direction and focus. In addition, during the fall, 2019 emphasis was placed on expanding the opportunity to obtain feedback from additional KanCare consumers.

Reviewing/Coding Process. Ten organizations participating in the KMMC expressed interest in helping engage consumers, with five organizations being able to participate based on their availability. The five participating organizations were asked to use the same set of nine interview questions so that there would be consistency across populations (See Appendix for list). Interview questions were similar as the initial phase in Spring, 2019 with some changes based on direction from the KMMC. Input was gathered from over 135 Kansas consumers/persons served using listening sessions, telephone and in-person interviews, including mothers, mental health consumers, older adults, and individuals contacted by managed care organizations (MCOs).

Consumer responses were sent to the Community Engagement Institute (CEI) at Wichita State University where they were organized into a master document of all responses, while also ensuring that responses did not identify a specific individual. A small group of five volunteer KMMC members reviewed the responses. They divided the questions and were asked to consider and note the following as they reviewed consumers' responses:

- Were participant responses consistent with the previous themes developed in the Spring, 2019?
- Did any new themes or ideas emerge based on participant responses?
- Were there any responses that connected to one of the 3 identified priority areas: Network Adequacy, Pregnancy Outcomes, or Care Coordination

At least two volunteers reviewed responses to each question. Volunteer KMMC members met via conference call several times to discuss their insights and suggestions. Volunteer KMMC members recognized that codes and themes were not always distinct or separate. Therefore, participants' comments sometimes were "coded" under multiple themes.

Key Findings. The following report provides a summary of the collective insights from this process. Several of the key findings, include:

- In general, there were **similar themes and ideas as generated by the Spring, 2019 administration.** Additional examples and nuances were recognized for **Communication** and **Availability of Services.**
- There was consensus as to one new theme or idea: **Eligibility.**
- Reviewers provided several **considerations for future consumer engagement.**

Consistent Themes and Ideas. Several of the primary themes and ideas from the initial consumer engagement process (Spring, 2019) were also well represented by participants in the current consumer engagement phase. See the appendix for example responses that represented each of these themes. More specifically the following areas appeared regularly throughout participants' responses.

- Affordability/Coverage of Services
- Availability of Services
- Communication

While mentioned less frequently, the following themes were also mentioned.

- Transportation
- Living in Community, Independence, Quality of Life

Finally, while there were examples of the following items, they were not mentioned as often.

- Respect/Consumer Treatment
- Disparities
- Outcomes
- Consumer Feedback/Engagement

It is important to note that given the open-ended nature of the questions, a lack of response in a particular area does not necessarily mean it is less important to KanCare members.

Connection between Affordability & Availability. Reviewers recognized that participants' responses regarding affordability/coverage of services and availability of services sometimes were connected as both ideas were mentioned by the same participant or that the issues were hard to tease apart. Below are several participant statements that reflect this connection.

Q: What matters to you (or people receiving similar services to you) about the KanCare program?

- Adequate access to competent health care.
- Having competent doctors, finding someone who could handle a high-risk pregnancy, knowing that expenses were covered.
- Being able to see a doctor when I need to and getting the medication I need. Those are all good things. I couldn't pay for it otherwise because of my disability.

Q: What problems have you experienced with Medicaid (KanCare)?

- Finding competent providers who accept it. There aren't many high-risk doctors who will take it.
- Paying hundred of dollars for caregiver. The high cost of caregiver leave very little for other expenses.

Q: What benefits have you experienced with Medicaid (KanCare)?

- It helps with medical needs and it's been wonderful. It helps with medicines and medical bills. There is no way she would be able to afford to see the doctor without the help.

Noteworthy Nuances Related to Themes. Reviewers noted there were some ideas mentioned with enough frequency that they could possibly represent a new theme or idea. Reviewers discussed the need for these ideas to be mentioned frequently enough and/or be distinct from existing ideas or themes created in the Spring, 2019. Ultimately the reviewers determined that the following ideas were important nuances to existing themes but did not warrant completely new themes.

Availability of Services. Reviewers recognized that some participants' responses connected availability of services to other ideas, such as quality, network adequacy, and/or having a choice of providers. While each of these could be considered slightly different items, reviewers decided to keep them together under the larger header of "Availability of Services". Several examples are provided that highlight this connection:

Q: What matters to you (or people receiving similar services to you) about the KanCare program?

- Adequate means sufficient coverage to manage health.

Q: Is there anything that keeps you from getting your KanCare services? If yes, what keeps you from getting services?

- There was a lack of high-risk providers.

Q: Is there anything you would change about your KanCare services? If so, what would you like to change?

- It would have been nice to have more doctors to choose from. I noticed that some providers pushed me away because I had KanCare. I've heard that recipients with KanCare get cheaper vaccines than people with Blue Cross Blue Shield or other insurance.

Communication. While some communication comments focused on the personal or "human connection", other participant comments focused on the paperwork, forms, and related information received about KanCare. Several examples are provided that highlight the connection to the broader theme of communication:

Q: What matters to you (or people receiving similar services to you) about the KanCare program?

- Getting the correct information when you call in.

Q: What problems have you experienced with Medicaid (KanCare)?

- Lack of literature to make informed decisions about which to choose.

Q: Is there anything you would change about your KanCare services? If so, what would you like to change?

- Would like an assistant to help with paperwork and understanding services.
- We get a lot of unnecessary papers in the mail and it's just a waste. I think they need to switch to email or phone. That would help with cost of postage too.

New, Distinct Area: Eligibility. While it may have been mentioned during the initial consumer engagement process in the Spring of 2019, reviewers did note there were multiple responses related to eligibility for KanCare. Reviewers agreed that while this issue could be related to some of the existing themes, it was distinct, mentioned frequently, and important enough to note separately. Several example comments illustrate this idea.

Q: What matters to you (or people receiving similar services to you) about the KanCare program?

- Too hard to qualify
 - Having a stable eligibility program.
 - She is afraid of getting denied someday.
 - That I stay eligible for it.
- Q: What benefits have you experienced with Medicaid (KanCare)?

- Getting approved for it helped decrease my stress

Q: Is there anything you would change about your KanCare services? If so, what would you like to change?

- I wish coverage lasted longer.
- I think the cut off period after my baby is born is too short. I think that should be extended to a year and a half after having the baby. They need to extend it because parents can't take care of their kids if they themselves are in pain.
- I think they need to make the coverage last longer than 6 weeks after having a baby.
- Once assessed as being medically needy and your income does not change, you should be able to count on Medicaid services.

Q: What do you wish you could tell the Governor about KanCare?

- Don't change the program, where it makes it hard for people to get in or stay enrolled.
- The process of paperwork to determine eligibility and yearly paperwork to maintain eligibility takes far too long to receive in the mail. It takes 14 days to get from Topeka. That's just ridiculous.
- Fix the clearinghouse application process.

No Concerns, No issues. It is worth noting that some questions elicited a number of participants stating they had “no issue or no concerns” related to KanCare. Reviewers recognized that in the future it may be useful to provide those administering the survey additional follow-up questions or probes to determine the nature of these responses.

Finally, it is useful to note that the themes that were mentioned by participants were not always negative or a concern. Some participants, especially when asked certain question (See question 3) mentioned the issue as something that was going well or that was important to him/her.

Process Recommendations for Future Consumer Engagement.

Reviewers also recognized there were ideas or considerations for consumer engagement in the future. These include:

- Follow-up questions or training if the respondent/participant says “no issue or concern” as described above.
- Additional training for reviewers so that there is consistency in “coding” responses. The KMMC may want to consider how precise or critical it is that reviewers have a high consistent reliability of coding participants’ responses. For example, some areas such as transportation are fairly easy and consistently coded. Other comments, especially when nuanced or describing a complicated issue were more difficult for reviewers to code the same way. Additional training would take more commitment from the reviewers.
- It may be interesting to examine the connection between consumer feedback gathered via KMMC engagement process and other feedback, surveys, or data gathered from other sources.

- It may be helpful to explore additional approaches and factors that can impact consumer engagement. The current KMMC volunteer reviewers noted:
 - Does there need to be consistency in administration procedures recognizing that some settings or approaches can potentially impact consumers' responses.
 - Is it possible to administer questions in multiple languages?
 - Should some questions be short-answer or likert/ratings? Could the questions be framed to the existing priority areas/issues and participants asked to rate their importance.
 - Should some questions be removed if they are not generating many meaningful responses? For example, during the current administration the following questions did not generate as much feedback as others:
 - Is there anything that keeps you from getting your KanCare services? If yes, what keep you from getting services?
 - Is there anything you would change about your KanCare services? If so, what would you change?
 - Is there anything you think is important to keep the same about KanCare services? If yes, what would you think is important to keep the same?

Related, it may be helpful to explore whether these (and all) questions were fully understood by participants.
- Finally, it is important to note that given the methods used these responses do not necessarily reflect the views and experiences of all KanCare members as we are working with a sample of convenience.

Relation to Network Adequacy, Pregnancy Outcomes, or Care Coordination

Reviewers were asked to highlight participants' responses that related to Network Adequacy, Pregnancy Outcomes, or Care Coordination. Below are examples of participants' comments related to each.

- Network Adequacy
 - Q: What matters to you (or people receiving similar services as you) about the KanCare Program?
 - Provider access.
 - Provider lists are not always communicated.
 - Sufficient number of providers to offer choice in care.
 - Q: Is there anything that keeps you from getting your KanCare services? If yes, what keeps you from getting services?
 - Lack of access to a diversity of DME providers.
 - Unable to find a care worker who can travel and do overnight stay in order to get son to KC metro area for medical care.
 - Q: Is there anything you would change about your KanCare services? If so, what would you like to change?
 - More providers.
 - Difficult to find providers for 18-65 years of age.
- Pregnancy outcomes
 - Q: What problems have you experienced with Medicaid (KanCare)?
 - Had to wait for approval for prenatal visit and nausea meds.

Q: What matters to you (or people receiving similar services as you) about the KanCare Program?

- Having competent doctors, finding someone who can handle a high-risk pregnancy.

Q: Is there anything you would change about your KanCare services? If so, what would you like to change?

- I think the cut off period after my baby born is too short. I think that should be extended to a year and a half after having the baby.
- They need to make the coverage last long than 6 weeks after having a baby.

Q: Is there anything you think is important to keep the same about KanCare services? If yes, what would you think is important to keep the same?

- Well child check-ups should not change.

- **Care Coordination**

Q: What matters to you (or people receiving similar services as you) about the KanCare Program?

- The help I'm getting from my caseworker.
- I think the help I'm getting from my caseworker who helps me with paperwork and understanding the differences between Medicaid and Medicare.
- Assistance when encountering barriers to health care.

Connecting with KanCare Members. Consumers/Persons served were asked two questions about how they preferred to receive information and how to get ideas and opinions from people who use Medicaid.

- How would you prefer to receive information (telephone/letter/email) about Medicaid in Kansas?
 - Responses predominately indicated a preference for mail or letters. Other suggestions were via email, telephone, or in-person when possible.
- What is the best way to get ideas and opinions from people who use Medicaid? How can we get more people involved?
 - Comments suggested respondents were open to a variety of approaches to gain ideas and opinions. These included:
 - Surveys (mailed, emailed, or online)
 - Interviews (phone or in-person)
 - Social media/apps/Facebook
 - Meetings, advisory groups, committees

APPENDIX

Consumer Engagement Questions:

1. What matters to you (or people receiving similar services to you) about the KanCare program?
2. What problems have you experienced with Medicaid (KanCare)?
3. What benefits have you experienced with Medicaid (KanCare)?
4. Is there anything that keeps you from getting your KanCare services? If yes, what keeps you from getting services?
5. Is there anything you would change about your KanCare services? If so, what would you like to change?
6. Is there anything you think is important to keep the same about KanCare services? If yes, what would you think is important to keep the same?
7. What do you wish you could tell the Governor about KanCare?
8. How would you prefer to receive information (telephone/letter/email) about Medicaid in Kansas?
9. What is the best way to get ideas and opinions from people who use Medicaid? How can we get more people involved?

Summary Consumer Answers:

The KMMC design team reviewed answers from all consumers and grouped them into themes. The themes are presented in the first column in the table below, with examples of consumer answers that fit the theme in the second column.

Affordability/Coverage of Services

Q : What matters to you (or people receiving similar services to you) about the KanCare program?

- People are able to get services even if they are not financially stable.
- Not having extra medical bills to pay.
- Co-pays are not always affordable.
- Coverage of Dr. visits and hospital coverage. Would have had to pay a lot of money without Medicaid.

Q: What benefits have you experienced with Medicaid (KanCare)? They pay for my eye care and glasses.

- It pays for my doctor's visits. I only get \$800 a month. I could never pay for it. Without Medicaid I'd be dead.
- Help with medical bills.

Q: Is there anything you would change about your KanCare services? If so, what would you like to change?

- To receive dental
- Would like to see that Medicaid expanded their dental benefits.

Q: What do you wish you could tell the Governor about KanCare? It helps people pay for what they need.

- ER copay is covered and that's a big help.
- Please cover all our needs. Dentist most of all. Our teeth make us very sick.

Availability of Services

Q: What matters to you (or people receiving similar services to you) about the KanCare program?

- Provider Access
- Adequate access to competent health care
- Adequate means sufficient coverage to manage health

Q: What problems have you experienced with Medicaid (KanCare)?

- Has been denied multiple times for medical equipment, also having problems with Medicaid being inconsistent with what they pay for.
- Things that she needs like compression stockings are not approved. Also diabetic shoes are not approved. There are things that she thinks Medicaid would pay for like incontinence meds but they won't pay for them.

Q: What benefits have you experienced with Medicaid (KanCare)?

- Access to a specialist.

Q: Is there anything that keeps you from getting your KanCare services? If yes, what keeps you from getting services?

- There was a lack of high-risk providers
- There is nothing keeping me from getting my services
- Member's son requires total care around the clock. Unable to find a care worker who can travel and do overnight stay in order to get son to KC metro area for medical care. Has been trying for 12 months to arrange trip to KC.

Q: Is there anything you would change about your KanCare services? If so, what would you like to change?

- It would have been nice to have more doctors to choose from. I noticed that some providers pushed me away because I had KanCare. I've heard that recipients with KanCare get cheaper vaccines than people with Blue Cross Blue Shield or other insurance. (Note: Also related to Network Adequacy)
- Better dental coverage for adults because dental care is just as important and can lead to many health problems if not taken care of.

Respect/Consumer Treatment

Q: What matters to you (or people receiving similar services to you) about the KanCare program?

- No one to talk to about the services. Need to be able to go talk to someone in person. It's dehumanizing.
- They treat her right and while she believes some people abuse it, she doesn't.
- Members would like more information about how meals and lodging works and who they can talk to when they need to set up. They often do not know the right questions to ask when talking to the transportation number.

Q: What benefits have you experienced with Medicaid (KanCare)?

- Staff, even though often providing less than accurate information, is very kind and respectful at the MCO.

Q: Is there anything you would change about your KanCare services? If so, what would you like to change?

- Make sure to do right by each person.

Living in Community, Independence & Quality of Life

Q: What matters to you (or people receiving similar services to you) about the KanCare program?

- It has been wonderful, it matters that she can live in a nice place and the assistance is terrific (answered by sister).
- Having someone to clean, do laundry, set up meds w/o help. She would have a dirty apartment. Paying for medications and the rest of the medical bills.
- Being able to have medical nurse aids at home so she can be at home instead of a hospital.

Q: What benefits have you experienced with Medicaid (KanCare)?

- She received a medical aid after her bac surgery so she could go home instead of staying at the hospital.
- Pays for assisted living.

Q: Is there anything you think is important to keep the same about KanCare services? If yes, what would you think is important to keep the same?

- Services let her stay home.

Q: What do you wish you could tell the Governor about KanCare?

- We need help with gas money to maintain transportation so I can stay independent.

Communication

Q: What matters to you (or people receiving similar services to you) about the KanCare program?

- Getting the correct information when you call in.
- Lack of information, contact, approvals.
- I think the help I'm getting from my caseworkers who helps me with paperwork and understanding the differences between Medicaid and Medicare. And answers questions she has.
- Members would like more information about how meals and lodging works and who they can talk to when they need to set up. They often do not know the right questions to ask when talking to the transportation number.
- Need more helpful people answering the phones with regard to the Pharmacy Help Desk.
- Not being treated badly for being low income or disabled.

Q: What problems have you experienced with Medicaid (KanCare)?

- Not able to get a hold of them on the phone.
- Bad communication, unrealistic return dates for information.
- Lack of literature to make informed decisions about which to choose.

Q: What benefits have you experienced with Medicaid (KanCare)?

- Getting approved for it helped decrease my stress. The nurse helpline was helpful because when I called to see if I should go to the ER or not, they would tell me what was covered and what wasn't.

Q: Is there anything you would change about your KanCare services? If so, what would you like to change?

- It is impossible to get through to speak to someone – even Dr's have trouble
- We get a lot of unnecessary papers in the mail and it's just a waste. I think they need to switch to email or phone. That would help with cost of postage too.

- Having a number where you can easily speak to an actual person during the application process.
 - He has many issues with how he is treated at this assisted living facility. Stating that he has to constantly argue for things that he needs. He also has problems with Medicaid not paying for Doctor visits unless medicare does.
 - Clearer website from MCOs.
- Q: What do you wish you could tell the Governor about KanCare?
- Please do a better job at informing people of all the resources available to them.
 - So far they're treating her alright but she says they send her too many redundant letters.
 - The process is cold and cumbersome and there is a great lack of communication, inability to get clear answers and I challenge the Governor to go to the KanCare clearinghouse voicemail tree and see what she thinks about navigating it.

Transportation

Q: What matters to you (or people receiving similar services to you) about the KanCare program?

- Transportation services
- Transportation matters
- Expressed the need for more transportation, personal trips, and more flexibility with drivers. For example, if a person wanted to stop by the grocery store on the way home from an appointment, the driver should let them. Or be able to stop at pharmacy on the way home from doctor, but they won't allow, stating member would have needed to make that stop a part of the transportation request when scheduling the trip.
- Member cited an incident about transportation from one city to another due to location of a provider. The driver did not provide round trip service back to the original city. Member had to find another ride to get back home after the visit.

Q: What problems have you experienced with Medicaid (KanCare)?

- Transportation, because of no driver available, or not dependable, cancel last minute, access

Q: What benefits have you experienced with Medicaid (KanCare)?

- They pay for rides to and from my doctor visits if I need it. They paid for my glasses. We've called the nurse line a couple times in the past.
- They paid for my rides to doctor visits. I didn't have to pay for any medications when I took them.
- Mileage for trips to Doctor. Doesn't have to pay for in-home services anymore which helps with bills.
- I have had appointments in Hays and Colby and I like the transportation they provide.
- Mileage reimbursement makes a big difference in getting members to the provider office for well checks.
- Transportation services have increased my ability to see recommended specialists.

Q: Is there anything that keeps you from getting your KanCare services? If yes, what keeps you from getting services?

- Limited times that she can get rides provided. There are no doctors in Derby that accept Medicaid so it takes a long time to drive to Doctor appointment in Wichita.

- Lack of understanding how transportation benefit works. How to get meals and lodging when needing to travel a greater distance to see a doctor.

Q: Is there anything you think is important to keep the same about KanCare services? If yes, what would you think is important to keep the same?

- Keep transportation. Nothing else that I can think of.
- Having rides offered to members for appointments. Brought up local small town has a new cab service and they should join the list of KanCare transportation providers.

Q: What do you wish you could tell the Governor about KanCare?

- There is waste, especially in transportation services. I have had people from Wichita drive up to Lawrence to take me to an appointment in Topeka. Eliminate those wastes without eliminating the very vital transportation services will save a lot of money.

Disparity of Services (likely due to location or network adequacy)

Q: Is there anything that keeps you from getting your KanCare services? If yes, what keeps you from getting services?

- Overall lack of caregivers (Care Attendants) for members and families. No pool of individuals as an “emergency” back-up when care attendant calls in sick or unable to get there if member self-directs. No temporary agency for caregivers in our area. Seems one provider has different structure that provides help.

Q: Is there anything you would change about your KanCare services? If so, what would you like to change?

- No gap in coverage after retirement.

Outcomes

Q: What matters to you (or people receiving similar services to you) about the KanCare program?

- Competent doctors, finding someone who could handle a high-risk pregnancy.
- High quality doctors
- Having good doctors

Consumer Feedback/Engagement

Q: What matters to you (or people receiving similar services to you) about the KanCare program?

- Lack of information, contact, approvals

Q: Is there anything you think is important to keep the same about KanCare services? If yes, what would you think is important to keep the same?

- Keep consumer advisory committees with enhancements