Background:

In January-February 2019, Stakeholder Working Group (SWG) members submitted individual questions about KanCare via an online survey. The questions could relate to specific "domains" (e.g., quality of care) included in the KanCare annual report or could be other questions of interest about KanCare. More than 90 questions were submitted.

In February-March 2019, three partner organizations conducted a consumer engagement pilot with 56 consumers. Each organization asked consumers a set of seven questions, with some adding additional questions. The SWG design team then analyzed consumer responses and grouped them into themes. The full pilot results and themes can be found here: https://www.khi.org/assets/uploads/news/14860/2019.05.17_consumer_engagement_pilot_themes.pdf

In April 2019, SWG leadership sorted similar consumer engagement themes and individual SWG questions into groups. For each grouping, leadership drafted "consolidated questions" to draw together common ideas, which were reviewed and modified by the full SWG in May 2019. The SWG settled on 19 consolidated questions.
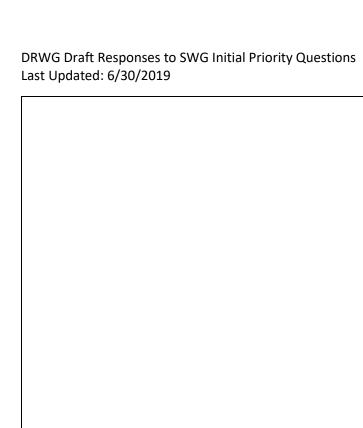
At the end of May 2019, the SWG completed a survey to assess the consolidated questions against a set of seven criteria previously developed by the SWG. Criteria included items such as "important to consumers," "actionability" and "number of people impacted." The survey results were then reviewed by the SWG on June 13, 2019. In that meeting, the SWG used the survey results to prioritize the consolidated questions by splitting them into two tiers. While all questions were considered important by the SWG, the consolidated questions in the first tier (9 questions total) represent the initial priority questions for review by the DRWG.

This document includes the 9 first tier of consolidated questions (bolded and marked with a "C" before their question number) and the underlying consumer engagement themes (bulleted with "Consumer Engagement Theme" before the theme) and individual questions (bulleted with "SWG" before the question number) for context. The consolidated questions are sorted by how they scored in the May 2019 survey completed by the SWG, with the consolidated question with the highest score listed first, and the question with the lowest score listed last.

At the July 1 meeting, DRWG members will discuss an initial assessment of existing measures and data sources that could address the SWG questions.

Table 1. **Enrollee Treatment**

Consolidated Question & Individual Questions and Consumer Engagement Themes	Existing Measures/Data Sources
C14. Enrollee Treatment. Are KanCare enrollees satisfied with the way they are treated and the degree to which they understand and can make decisions about their services?	**Potential Data Sources:** • CAHPS • HCBS CAHPS • MH Survey • National core indicators for aging and disability adults consumer surveys • National core indicators for adults with I/DD age 18 and older • KDADS NF satisfaction survey
• Consumer Engagement Theme: Living in Community, Independence, & Quality of Life	

• Consumer Engagement Theme: Respect/Consumer Treatment	**Potential Measures:**
	CAHPS: Adult, Child, Children with Chronic Conditions
	• How Well Doctors Communicate composite score, includes:
	  ○ Explains things in a way that was easy to understand
	  ○ Listened carefully to you
	  ○ Showed respect for what you had to say
	  ○ Spend enough time with you

• Consumer Engagement Theme: Communication	
• SWG 44. Cultural knowledge of medical providers.	

• SWG 69. Are enrollees treated with respect by providers and MCOs?	• Shared Decision Making composite
	  ○ Did you and doctor/provider talk about reasons: might want to (and might not want to) take a medicine
	  ○ When talking about starting/stopping medicine, did doctor/provider ask you what you thought was best for you

• SWG 70. Do enrollees feel safe when receiving care?	

• SWG 71. Do enrollees feel that providers and MCOs are available to answer their questions	• Customer Service composite:
	  ○ Health plan gives the information or help you needed
	  ○ Health Plan treat you with courtesy and respect

• SWG 9. How aware of their benefits are KanCare enrollees?	
• SWG 17. How many youths transitioning into adulthood reapply for services once they reach adulthood?	**HCBS CAHPS** Provider Staff Communicate and Treat You
• SWG 6/13: How easy is it to access and understand KanCare Services?	• Personal Assistance/BH staff/Homemakers treat you with courtesy and respect
• SWG 6/13: Are people getting informed about community-based supports like peer support that are alternatives to the mainstream model?	• Staff treat you the way you want them to
• SWG 6/13: Are people getting informed consent? (i.e., do people know that many medical treatments do more harm than good?)	

	- Staff explain things in a way that is easy to understand
	- Staff listen carefully to you

- Staff explain things in a way that is easy to understand
- Staff listen carefully to you

Choosing Services

- Did your service plan include none/some/most/all of the things that are important to you

  Personal Safety

- Did anyone paid to help you:
  - Take your money or things without asking you first
  - Yell, swear or curse at you
  - Hit or hurt you

  (Each of these have f/u questions to whether someone worked with them to help fix the problem.)

Community Inclusion and Empowerment

- Get together with family members/friends who live by when want to
- How often could do things in community you like
- Did you need more help than you get to do things in your community
- Did you take part in deciding what you do with your time each day and when

Employment

Questions for people wanting to work regarding barriers and getting help

MH Survey (Adults and Youth)

- Participation in Treatment Planning (choosing goals and services)
- Cultural Sensitivity to race, religion, language etc.
- I would recommend my MH providers to a friend/or family member
- Service quality and appropriateness
- Social Connectedness – encouraged to use consumer run programs (support groups, drop-in centers, crisis phone line etc.)
- I do better in school and/or work
- My housing situation has improved
- I am better able to do things I want to do
- I feel I belong in my community

National Core Indicators for Aging and Disability Adults Consumer Surveys

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- Proportion of Seniors and Adults with Disabilities Whose Services Meet All of Needs and Goals
- Percent of People Reporting that Staff Treat Person with Respect

National Core Indicators for Adults with I/DD Age 18 and Older
- Proportion of Kansans Who Believe They Can Make Choices and Decisions
- Percent of People Reporting that Staff Treat Person with Respect

KDADS NF Satisfaction Survey
- Percent of residents rating their nursing home a 9 or 10 (out of 10)
- Percent of residents who would recommend the nursing facility to friends/family as a place to live
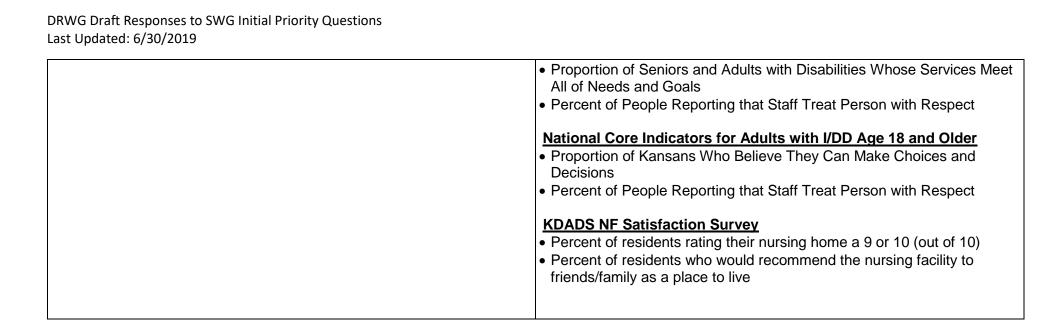
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Table 2. **Application processing**

Consolidated Question & Individual Questions and Consumer Engagement Themes	Existing Measures/Data Sources
C15. Application Processing. What are the barriers to having an application processed in a timely manner?	**Potential Data Sources:** • Insert data source here
• SWG 2. If the application is taking more than 45 days, what are the reason(s) for the delays.	**Potential Measures:** • Insert measure here
• SWG 3. What are the barriers to completing application review within the allowed time frame?	
• SWG 4. What are the patient characteristics for those that take longer than 45 days? For example, are there more patients in a certain geographic area, indicating a need for eligibility outreach? Is there a higher volume of patients with applications for patients for certain waivers, etc.	
• SWG 8. How many are processed with no changes from year to year, especially those in long term care services?	
• SWG 57b. How many individuals receiving HCBS fail to complete reassessments in a timely manner?	

Table 3. **Quality Assurance**

Consolidated Question & Individual Questions and Consumer Engagement Themes	Existing Measures/Data Sources
C3. Quality Assurance. Are quality assurance measures in place to ensure that individuals receive the level of services they need?	**Potential Data Sources:** • HEDIS • CAHPS • HCBS CAHPS • MH Survey
• Consumer Engagement Theme: Living in Community, Independence, Quality of Life	
• 67. Are people achieving their vision of a "good life" under KanCare?	**Potential Measures:**
• 68. Quality of life measures should assess the delay of complications from life either through conditions, disorders, disease or aging. I do not know enough about the data set to propose a specific question.	**HEDIS** • Preventive measures (vaccinations, well care, screenings) • Treatment quality (diabetes; prenatal/postpartum care; BH measures; etc)
• 51. Are people with more significant disabilities more likely to remain in nursing homes vs in the community? Has this changed from pre-KanCare trends?	**CAHPS** • Ease of getting care, tests, treatment needed • Getting an appointment with a specialist as soon as needed
• 33. What are the health care conditions that are impacted by personal care assistance; i.e. capability to self-administer drugs.	**HCBS CAHPS** • Getting personal assistance/BH/Homemaker services as long as supposed to and as needed (including getting food, taking medicine, getting dressed, bathing, toileting, homemaking)
• 10. How does the number of individuals self-directing their care compare to pre-KanCare?	**MH Survey** • MH providers willing to see me as often as I felt necessary
• 5. For individuals deemed eligible for HCBS in home supports, what is the number of approved plans of care with 20 or fewer hours per week attendant care services?	• I was able to get all the services I thought I needed • During a crisis, able to get needed services
• 88. Does KanCare/HCBS support community involvement and social supports?	

Table 4. **Care Coordination**

Consolidated Question & Individual Questions and Consumer Engagement Themes	Existing Measures/Data Sources
C13. Care Coordination. Are care coordination services (i.e., any services to help coordinate care; not limited to MCO-defined services) available for consumers who need it? Are care coordination services effective for those who have received them?	**Potential Data Sources:** • CAHPS • HCBS CAHPS • KanCare 2.0 eval design includes study of Care Coordination **Potential Measures:** **CAHPS** • Doctor informed and up-to-date about care received from other providers • For CCC: anyone from health plan, doctor's office/clinic help coordinate child's care among different providers or services. • For CCC: Did you get help needed form child's doctors or providers in contacting child's school or daycare.
• SWG 22. Are there common characteristics associated with children/youth entering psychiatric treatment residential facilities (PRTF)? Who's being screened out from entering PRTFs?	
• SWG 56. Who is helping children/youth with behavioral health conditions receive services, such as getting into psychiatric residential treatment facilities (PRTF)?	**HCBS CAHPS** • <u>MCO Care Coordinator</u>: ○ Do you who MCO CC is ○ Could you contact them when needed ○ Work with you when asked for help getting or fixing equipment ○ Help in getting changes in service, or help getting places or finding a job ○ Rating of help received from MCO Care Coordinator ○ Would you recommend this care coordinator • <u>Targeted Case Manager </u>for I/DD Waiver, include all the same questions as those for the MCO Care Coordinator
• SWG 59. I think there are a lot of questions surrounding coordination of care, especially with regard to LTSS (re: I/DD waiver). Is coordination of care best implemented on an MCO level or on a local level via Targeted Case Manager like in the I/DD waiver?	
• SWG 61. Who is ensuring follow-up visits when transitioning between types of care (for example; inpatient, specialty care, or post-partum)?	
• SWG 64. It might be important to determine how many of the youth with behavioral health conditions are in state custody (DCF/Corrections) and who helps coordinate THOSE services vs. youth with behavioral health conditions NOT in custody, etc.	
• SWG 39. How do results provided in the Mental Health Survey correlate to services provided?	

Table 5. **Social Determinants**

Consolidated Question & Individual Questions and Consumer Engagement Themes	Existing Measures/Data Sources
C4. Social Determinants. What KanCare social determinants data do we have? What do the KanCare data tell us about the social determinants of health, and their impact on enrollees?	**Potential Data Sources:** • MH survey • MCO Health Risk Screenings data
• Consumer Engagement Theme: Transportation	
• 89. How do social determinants of health including: Income and social status Employment and working conditions Education and literacy Childhood experiences Physical environments Social supports and coping skills Healthy behaviors Access to health services Biology and genetic endowment Gender Culture Impact health outcomes/treatment/enrollment/etc.?	**Potential Measures:** **MH Survey** Child: living setting (includes foster home, crisis shelter, homeless, correctional facility, etc.) **MCO Health Risk Screenings Data**
• 90. Do enrollees have access to safe housing? Do enrollees need help finding work (combine social determinants with employment domain)? Do enrollees have access to a network of caring friends or family? If not, what would help?	
• 91c. Are there differences in rates/frequencies for various SDOH by region of the state, rural/urban, etc.	
• 92b. Are there regional differences in SDOH data and how is this being communicated?	
• 93. How available is transportation in your community to social activities, church, etc.? (In other words, not medical appointments) How available is safe and affordable housing?	
• 94. What housing data is available to compared to the chronic conditions metrics? (What is the relationship between housing status and chronic conditions?)	
• 95. Financial hardships around older Americans who need services.	

Table 6. **No Access**

Consolidated Question & Individual Questions and Consumer Engagement Themes	Existing Measures/Data Sources
C8. No Access. What are the outcomes associated with individuals who cannot access care?	**Potential Data Sources:** • Insert data source here
• N/A. (This question was added in a later SWG discussion.)	**Potential Measures:** • Insert measure here

Table 7. **Pregnancy Outcomes**

Consolidated Question & Individual Questions and Consumer Engagement Themes	Existing Measures/Data Sources
C7. Pregnancy Outcomes. How does KanCare impact pregnancy outcomes? (maternal mortality, infant mortality)	**Potential Data Sources:** • Insert data source here **Potential Measures:** • Insert measure here
• 81. What is the frequency of low-weight births?	
• 82. How does the frequency of low-weight births relate to when eligible mothers began receiving health care?	
• 83. What are the outcomes associated with low-weight births?	
• 84. What are the inputs associated with low-weight births? How does racism relate to low-weight births/preterm births/infant mortality?	
• 85. How many babies are born with neonatal abstinence syndrome?	
• 85b. It would be good to have maternal mortality information, as well.	
• 85c. Overall mortality and premature death - all ages is good to know; how does this compare to the general population?	

Table 8. **Network Adequacy**

Consolidated Question & Individual Questions and Consumer Engagement Themes	Existing Measures/Data Sources
C11. Network Adequacy. What is the network adequacy in KanCare, relative to a benchmark (e.g., contract standard)? If network adequacy is below the benchmark, why? • Consumer Engagement Theme: Availability of Services • Consumer Engagement Theme: Disparity of Services • 37b. How does reported network adequacy relate to individuals' experiences accessing care? • 38. What is the percentage of individuals in different counties on home and community based services (HCBS) waivers over time? • 43. What percentage of individuals receiving HCBS report access to adequate health and dental services? • 45. Equity of care. (Does access to/quality of care vary by demographic?) • 46. How does access to care in Kansas compare to other state Medicaid plans? How do the reimbursements in Kansas compare to other state Medicaid plans? • 47. What is the true network adequacy for providers serving KanCare? For example, how many dentists do we truly have that provide dental services to individuals on KanCare? What is the available panel spots for patients seeking care - do they really have choice? Do we have sufficient level of Behavioral Health Consultants to meet the full need - and if not, why are plans not willing to credential new providers because their "networks are full?" • 48. Do patients have access to the care/services they need within the area as required by network adequacy? The number of available panel spots for patients seeking care.	**Potential Data Sources:** • Medicaid claims • Medicaid beneficiary data set • National provider identifier (NPI) registry • Annual MCO on-site reviews • Quarterly MCO Network Adequacy Reports • CAHPS supplemental questions (some questions vary by MCO) • MCO Surveys (e.g., appointment standards access, after-hours access) • Mental Health Member Survey (Mental Health Statistics Improvement Program) • SUD Member Survey **Potential Measures:** **MCO Network Adequacy Report/Claims Data/Beneficiary Data:** • Number of counties with access to 2 or more HCBS providers and at least 1 HCBS provider, by MCO and provider type o Indicates increase or decrease from previous year • % covered within network adequacy standards, by provider and county type • Average distance to provider, by provider and county type • Number of providers/number of locations, by MCO and provider type • Number of counties with 0% access, by MCO and county and provider types • Number and % of members not within access distance by MCO and provider type • Provider panel by MCO and provider type (reported as open, closed or accepting only existing patients)

• 48b. Do all patients have a choice of providers? Do MCO limits on credentialing providers (behavioral health) limit access to care?	**CAHPS**
	• Provider After-Hour Access: no consistent template for reporting by MCOs; some summary survey results
	• % of beneficiaries reporting after-hours access (varies by CAHPS question and MCO)
	• % of providers compliant with appointment access
	• % of beneficiaries reporting appointment availability (varies by CAHPS question and MCO)
	• Access to Care CAHPS questions: % of beneficiaries reporting access, by group (adult, general child, chronic condition child); reported 2014-2017
	    o In the last 6 months: When you needed care right away, how often did you get care as soon as you thought you needed?
	    o In the last 6 months: How often was it easy (for your child) to get the care, tests, or treatment you (your child) needed?
	    o In the last 6 months: Not counting times you needed care right away, how often did you get an appointment for (your child) for a check-up or routine care at a doctor's office or clinic as soon as you thought you needed?
	    o In the last 6 months: How often did you get an appointment (for your child) to see a specialist as soon as you needed?
	
	Mental Health Survey
	• % of beneficiaries reporting on specific statements
	    o I was able to see a psychiatrist when I wanted to
	    o I was able to get all the services I thought I needed
	    o My family got as much help as we needed for my child.
	    o My mental health providers were willing to see me as often as I felt it was necessary
	    o Services were available at times that were good for me
	    o During a crisis, I was able to get the services I needed

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- o During a crisis, my family was able to get the services we needed
- o Medication available timely
- o My mental health providers returned my calls in 24 hrs

SUD Survey

- % of beneficiaries reporting access in response to specific questions
  - o Is the distance to travel to your counselor a problem or not a problem?
  - o Were you placed on a waiting list?
  - o If you were placed on a waiting list, how long was the wait?
  - o Urgent problem: How satisfied are you with the time it took to see someone?
  - o Urgent problem: Were you seen within 24 hours, 24-48 hours, or did you have to wait longer than 48 hours?
  - o Did you get an appointment as soon as you wanted?

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Table 9. **Setting of Choice**

Consolidated Question & Individual Questions and Consumer Engagement Themes	Existing Measures/Data Sources
C2. Setting of Choice. Does KanCare improve enrollees' ability to live independently in the community setting of their choice?	**Potential Data Sources:** • Insert data source here **Potential Measures:** • Insert measure here
• Consumer Engagement Theme: Living in Community, Independence, Quality of Life	
• 67. Are people achieving their vision of a "good life" under KanCare?	
• 68. Quality of life measures should assess the delay of complications from life either through conditions, disorders, disease or aging. I do not know enough about the data set to propose a specific question.	
• 51. Are people with more significant disabilities more likely to remain in nursing homes vs in the community? Has this changed from pre-KanCare trends?	
• 33. What are the health care conditions that are impacted by personal care assistance; i.e. capability to self-administer drugs.	
• 10. How does the number of individuals self-directing their care compare to pre-KanCare?	
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