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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 discussed an initial assessment of existing measures and data sources that could address the SWG questions.

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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? Consumer Engagement Theme: Living in Community, Independence, & Quality of Life Consumer Engagement Theme: Respect/Consumer Treatment	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: Communication SWG 44. Cultural knowledge of medical providers. SWG 69. Are enrollees treated with respect by providers and MCOs? 	Potential Measures: CAHPS: Adult, Child, Children with Chronic Conditions How Well Doctors Communicate composite score, includes:
 SWG 70. Do enrollees feel safe when receiving care? SWG 71. Do enrollees feel that providers and MCOs are available to answer their questions SWG 9. How aware of their benefits are KanCare enrollees? 	 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 Shared Decision-Making composite
 SWG 17. How many youths transitioning into adulthood reapply for services once they reach adulthood? SWG 6/13: How easy is it to access and understand KanCare 	 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 Customer Service composite:
 SWG 6/13: Now easy is it to decess and understand realization. SWG 6/13: Are people getting informed about community-based supports like peer support that are alternatives to the mainstream model? 	 Health plan gives the information or help you needed Health Plan treat you with courtesy and respect HCBS CAHPS Provider Staff Communicate and Treat You
SWG 6/13: Are people getting informed consent? (i.e., do people know that many medical treatments do more harm than good?)	 Personal Assistance/BH staff/Homemakers treat you with courter and respect Staff treat you the way you want them to 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:
- o Take your money or things without asking you first
- o 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? Which application(s) specifically?	Potential Data Sources: KEES (Kansas Eligibility and Enforcement System) KanCare Ombudsman Annual Report
SWG 2. If the application is taking more than 45 days, what are the reason(s) for the delays.	Potential Measures: KEES
 SWG 3. What are the barriers to completing application review within the allowed time frame? 	Number of KanCare Applications and Reviews >45 days KanCare Ombudsman Annual Report
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.	Medicaid Eligibility Issues - % to total issues and count May include: Medicaid renewal, spend down issues, HCBS eligibility issues Note: can be broken out by MCO
SWG 8. How many are processed with no changes from year	KMMS (Kansas Modular Medicaid System)
to year, especially those in long term care services?	Number of waiver participants who were determined to meet level of care requirements to receive HCBS services
SWG 57b. How many individuals receiving HCBS fail to complete reassessments in a timely manner?	Number of waiver participants who were determined to meet level of care requirements to receive HCBS services

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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:
 Consumer Engagement Theme: Living in Community, Independence, Quality of Life 	HCBS CAHPSMH Survey
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? 	 <u>CAHPS</u> 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
 10. How does the number of individuals self-directing their care compare to pre-KanCare? 	supposed to and as needed (including getting food, taking medicine, getting dressed, bathing, toileting, homemaking)
 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? 	MH Survey MH providers willing to see me as often as I felt necessary I was able to get all the services I thought I needed
88. Does KanCare/HCBS support community involvement and social supports?	During a crisis, able to get needed services

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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 HEDIS
 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)? 	MCOs Potential Measures: CAHPS Doctor informed and up-to-date about care received from other providers
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?	 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 61. Who is ensuring follow-up visits when transitioning between types of care (for example; inpatient, specialty care, or post-partum)? 	MCO Care Coordinator: Do you who MCO CC is
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.	 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
 SWG 39. How do results provided in the Mental Health Survey correlate to services provided? 	 Would you recommend this care coordinator Targeted Case Manager for I/DD Waiver, include all the same questions as those for the MCO Care Coordinator
	 KanCare 2.0 Evaluation Study – to be approved yet by CMS Overall Service Coordination Strategy of integrating physical and behavioral health services: study of intervention group (members meeting a Health Risk Assessment threshold and



- receiving intensive service coordination) and comparison groups.
- OneCare Kansas program: study of intervention group (members eligible for OneCare Kansas and opting to participate) and comparison groups.
- Value-Based Provider (VBP) Incentive Program study of intervention group (members seen by providers who participated in VBP program)
 - Potential Care Coordination measures:
 - Annual Dental Visits (HEDIS)
 - Adults' Access to Preventive/ Ambulatory Health Services (HEDIS)
 - Adolescent Well-Care Visits (HEDIS)
 - Follow-Up After Mental Health Hospitalization (HEDIS)
 - Initiation and Engagement of Alcohol and Other Drug Dependence (HEDIS)
 - Anti-Depressant Medication Management (HEDIS)
 - ED visits, observation stays, or inpatient admissions for following conditions (Administrative) that could be sign of chronic concerns not well managed/coordinated:
 - Diabetic Ketoacidosis/ Hyperglycemia, or
 - Acute severe asthma, or
 - Hypertensive crisis, or
 - Fall injuries, or
 - SUD, or
 - Mental health issues
 - Outpatient or professional claims for following conditions (Administrative) that could be sign of chronic and/or preventive care not well managed/coordinated:
 - Diabetic retinopathy, or
 - Influenza, or
 - Pneumonia, or
 - Shingles
- Emergency department visits (Administrative)
- Inpatient Admissions, excluding maternity admissions (HEDIS)

HEDIS

HEDIS gaps in care reports may capture follow-up visits and
transitions in care
MCOs
 MCOs are gathering information about children waiting for
PRTF placement for KDADs
 Will include the number waiting, length of wait and what
services are being provided while the child is waiting
(56, 64, 22).
[30, 04, 22].

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	Potential Data Sources: • MH survey
 social determinants of health, and their impact on enrollees? 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 	 MCO Health Risk Screenings data US Census Bureau (Q95) US Interagency Council on Homelessness Quality of Life assessments Z-Codes
health services Biology and genetic endowment Gender Culture Impact health outcomes/treatment/enrollment/etc.? • 90. Do enrollees have access to safe housing? Do enrollees need help finding work (combine social determinants with	Potential Measures: MH Survey Child: living setting (includes foster home, crisis shelter, homeless, correctional facility, etc.)
 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 	 MCO Health Risk Screenings Data Questions include – feeling safe in the home; require assistance
SDOH by region of the state, rural/urban, etc.92b. Are there regional differences in SDOH data and how is	with housing; require assistance with obtaining food. (90, 93, 94)
 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? 	 US Census Bureau (Q95) Poverty rate (community or specific geographic level)

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•	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.

US Interagency Council on Homelessness

• Homeless rate (community or specific geographic level [91c, 94]

Quality of Life assessments

- Assessment includes a variety of measures.
- Assessment is conducted by member self-report, annually.
- Assessment informs PCSP (patient-centered services plan) at both an individual and population level to assess efficacy.
- Questions include, "Do you feel safe in your home?"

Z-Codes

 Z-codes in the ICD system can be used to identify social determinants attached to specific services at the member level. Still working with providers to add z-codes to claims.

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: MCOs Provider Network Reports Claims MMIS Demographics and Eligibility Data
N/A. (This question was added in a later SWG discussion.)	Potential Measures: • [Insert measure(s) here]

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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) 81. What is the frequency of low-weight births? 	Potential Data Sources:
82. How does the frequency of low-weight births relate to when eligible mothers began receiving health care?	Low birth weight Prenatal and postpartum 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? 	

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Table 8. Network Adequacy

Consolidated Question & Individual Questions and Consumer Engagement Themes	Existing Measures/Data Sources
	Potential 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 	 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)
 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 	 Mental Health Member Survey (Mental Health Statistics Improvement Program) SUD Member Survey Waiting List numbers by waiver type
 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? 	 HEDIS and NCQA Quality Compass Comparisons KDHE master Medicaid provider list based on the Managed Care final rule and requirement for all Medicaid providers to have a KMAP number.
 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 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 Indicates increase or decrease from previous year County type Average distance to provider, by provider and county type Number of providers/number of locations, by MCO and provider type
48b. Do all patients have a choice of providers? Do MCO limits on credentialing providers (behavioral health) limit access to care?	 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

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 Provider panel by MCO and provider type (reported as open, closed or accepting only existing patients)

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)
 - Question may include length of time to schedule appointment with specialist.
- Access to Care CAHPS questions: % of beneficiaries reporting access, by group (adult, general child, chronic condition child); reported 2014-2017
 - In the last 6 months: When you needed care right away, how often did you get care as soon as you thought you needed?
 - In the last 6 months: How often was it easy (for your child) to get the care, tests, or treatment you (your child) needed?
 - 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?
 - 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
 - My family got as much help as we needed for my child.

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	 My mental health providers were willing to see me as often as I felt it was necessary Services were available at times that were good for me During a crisis, I was able to get the services I needed During a crisis, my family was able to get the services we needed Medication available timely My mental health providers returned my calls in 24 hrs. SUD Survey % of beneficiaries reporting access in response to specific questions Is the distance to travel to your counselor a problem or not a problem? Were you placed on a waiting list? If you were placed on a waiting list, how long was the wait? Urgent problem: How satisfied are you with the time it took to see someone? Urgent problem: Were you seen within 24 hours, 24-48 hours, or did you have to wait longer than 48 hours? Did you get an appointment as soon as you wanted?
	 HEDIS Access/Availability of Care and NCQA Quality Compass Comparisons Adult's Access to Preventive/Ambulatory Health Services Children and Adolescents' Access to Primary Care Practitioners Annual Dental Visit Initiation and Engagement of Alcohol and Other Drug Abuse or Dependence Treatment Prenatal and Postpartum Care Use of First-Line Psychosocial Care for Children and Adolescents on Antipsychotics

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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: Health Screening and Health Risk Assessment Data MMIS Member demographics, enrollment, and encounter data MCO Service Coordination information KanCare 2.0 Evaluation Study – to be approved by CMS Did provision of supports for employment and independent living to the KanCare 2.0 members with disabilities and behavioral health conditions who are living in the community improve their independence and health outcomes? Study population: Members living in the community and receiving behavioral health services or HCBS services in the Physical Disability, Intellectual or Developmental Disability, and Traumatic Brain Injury waiver programs who opted to receive service coordination and were identified as potentially requiring employment or independent living supports. Intervention Group: those in study population receiving supports
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.	 Comparison Group: those in study population that didn't receive supports.
	Potential Measures:
 10. How does the number of individuals self-directing their care compare to pre-KanCare? 	KanCare 2.0 Evaluation Study: Final list of outcomes will be determined based on data availability:
 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? 	 Current employment status # of members who felt they were employed based on their skills and knowledge (If employed) Increased stable housing – # of addresses member lived in the past year. Decreased current legal problem (e.g., probation, parole, arrests)
88. Does KanCare/HCBS support community involvement and social supports?	
	# of days in the community

 # of members worried about paying bills Decreased ED visits
Decreased inpatient hospitalizations