Residents’ Views about Health Care in Maryland’s Mid-Shore Region: A Focus Group Study

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This is one of six Technical Reports prepared for the Maryland Health Care Commission by the University of Maryland School of Public Health and the Walsh Center for Rural Health Analysis at NORC at the University of Chicago as part of their study, entitled Health Matters: Navigating an Enhanced Rural Health Model for Maryland, Lessons Learned from the Mid-Shore Counties.
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For their time and many thoughtful comments: the 45 Mid-Shore residents who participated in the focus groups
Executive Summary

REPORT SUMMARY

This report covers one component of a larger project authorized in Senate Bill 707 (SB707: Freestanding Medical Facilities—Certificate of Need, Rates, and Definition) to examine challenges to health care delivery in the five Mid-Shore counties (Caroline, Dorchester, Kent, Queen Anne’s, Talbot) and to provide input to the state of Maryland’s Rural Health Care Delivery Workgroup. The Maryland Health Care Commission (MHCC) requested the University of Maryland School of Public Health, in partnership with the Walsh Center for Rural Health Analysis at NORC at the University of Chicago, to conduct the study and to work in parallel with the workgroup and the MHCC.

This focus group study involved conducting five focus groups, one in each county of the Mid-Shore, with a total of 45 individuals from the Mid-Shore area. These lively discussions were audio-recorded and transcribed. The transcriptions plus additional information captured in writing at the sessions (a total of 275 pages) were reviewed in depth by the research team, coded for key points and analyzed.

The report largely follows the question structure used during the focus groups. However, to more easily fit the focus group findings into the larger framework of the full project, the second part of this executive summary reframes the findings to match the structure of the full project report.

The next section of the report provides focus group background and describes procedures and methods, including obtaining institutional review board approval, recruiting participants, carrying out the focus groups and analyzing the results. It is followed by a section on participant characteristics, including demographic information, health care coverage and backgrounds of participants.

Focus group findings are covered in depth in the next and largest section, arranged by the question posed and by common themes voiced by the participants, including quotations that support these themes. The strengths of Mid-Shore health care and challenges identified by participants are covered. Participants’ views of the future of health care, both what they look forward to and what worries them, are then addressed. Participants were also asked to work in smaller groups to identify and describe a health service that would be important to their families. They proposed a dozen such service ideas. The findings section also includes participant recommendations and suggestions for the MHCC.

In the next section, the focus group research team provides perspectives on the findings. The team points out that the findings yield the perceptions, views and opinions of the participants, and the team also suggest areas for local and state assistance, in some cases reflecting the national health care debate.

Limitations are reviewed in a brief section, followed by a section listing seven major project recommendations by the focus group team. A final section provides a content overview of this report and lists next steps.
FOCUS GROUP FINDINGS REFRAMED FOR THE CATEGORIES OF THE FULL REPORT

The order of the “findings” section later in this report follows the structure of the focus group questions. However, to better align with the full report on rural health, the findings below follow the broad categories of the full report, along with additional topics that emerged from the group discussions. Note that at times participants spoke both positively and negatively about the same topics, which is the nature focus group research.

Health and Health Care

Health insurance and costs: All five groups discussed this topic. Participants in four groups (Caroline, Kent, Queen Anne’s, Talbot) said they had good insurance coverage, but at the same time individuals in all five groups mentioned cost and coverage difficulties. “It’s the deductibles that’s killing the people,” said one participant (Dorchester). People in two groups (Dorchester, Talbot) looked forward to possible lower rates in the future, and individuals in another group (Caroline) looked forward to care integration as required by Maryland’s All-Payer Model (U.S. Centers for Medicare and Medicaid Services, 2017) if implemented as intended. People in all five groups worried about possible loss or insufficiency of insurance coverage in the future. “Plain and simply a lot of people [will be] losing their insurance,” expressed another participant (Caroline). The groups recommended that insurance be made affordable and be expanded; they also suggested that the state subsidize the costs of providing care in rural areas.

Specialty care: Participants in all five focus groups said that specialty care is either lacking or far away. One participant noted, “There are very few specialty options on the Shore, so you end up traveling a long distance” (Caroline). People in two groups (Caroline, Kent) suggested that specialists be made available in innovative ways, such as coming periodically to satellite offices or via telemedicine.

Mental, behavioral and substance use care: Participants in three focus groups (Caroline, Kent, Queen Anne’s) said that mental, behavioral and substance use care is lacking in the Mid-Shore area, and participants in two groups (Caroline, Queen Anne’s) said it needs to be accessible and affordable. One participant described, “What happens now if you have a mental health crisis, generally, you end up in the criminal justice system” (Queen Anne’s). Three service ideas were suggested, including standalone inpatient facilities (Kent), more holistic care that includes a variety of approaches (Caroline) and more resources for both outpatient and inpatient care (Caroline).

Need for care coordination, case management and patient navigation: Participants in three groups (Caroline, Queen Anne’s, Talbot) discussed ways to help individuals get their health care needs met. Explained one participant, “I feel like there should be someone in the health care system that’s following people around to make sure they’re getting the resources that they need . . . just that whole improvement on follow-up care and continuity of care” (Caroline). Participants spoke of the need to improve treatment and coordination with insurance issues following a car accident. (Queen Anne’s).

Care in general: Participants in three groups (Caroline, Dorchester, Kent) felt they received good health care. One stated, “I got an actual diagnosis and follow-up care with my primary care doctor” (Caroline).
At the same time, some of the same participants said the quality of care was poor (Caroline, Dorchester, Queen Anne’s). Less regulation may improve care, according to Queen Anne’s participants. Some thought doctors’ offices needed more support so doctors do not perform administrative tasks. “Let doctors be doctors,” expressed participants in Caroline. Focus group members were worried about having enough care for the future needs of subpopulations, such as children, young people, pregnant women and seniors (Caroline, Dorchester, Queen Anne’s, Talbot). People in four groups (Caroline, Dorchester, Queen Anne’s, Talbot) had suggestions for better supporting, recruiting and retaining doctors.

Emergency care: Participants in two focus groups (Dorchester, Kent) were pleased with their emergency care. Said one, “The ER doctor realized what a sick person really looks like. And then he was able to coordinate the testing, the monitoring and getting him [my teenage son] out of there” (Dorchester). Participants in one county (Dorchester) promoted the need for improved and enhanced ambulance services, including equipping them to provide immediate care and stationing them near population centers.

Doctor-patient communication: Participants in all five groups described times when doctor-patient communication was very good. One stated, “I love and trust my doctor” (Caroline). At the same time, people in four of the groups (Dorchester, Kent, Queen Anne’s, Talbot) said providers could be rude and impersonal. Noted one, “I just felt that he [the doctor] had no empathy at all” (Talbot).

Timeliness: Participants spoke of positive and negative issues regarding timeliness. Some could get timely appointments (Caroline, Queen Anne’s, Talbot) and some reported efficient visits (Caroline, Dorchester, Talbot). Even so, people in three groups reported waiting too long to get an appointment or sitting too long in the waiting room, then having too little time with the doctor (Caroline, Dorchester, Talbot). One person said, “I’ll spend 50 minutes waiting . . . then I literally get four minutes with my provider” (Caroline).

Health literacy: Participants in one group (Talbot) spoke about people having difficulty understanding their health, insurance and the health care system. For example, a participant explained, “I work for social services . . . a lot of the folks that I service are undereducated. They don’t understand health care now, much less even have any idea what’s going to happen when it changes.”

Health Care Workforce Capacity

Doctor turnover and quality: Participants in four groups (Caroline, Dorchester, Queen Anne’s, Talbot) mentioned that doctors are restricted by rules and regulations and do not have enough staff assistance. They recommended some ways to support, recruit and retain doctors. One participant commented, “I think we need to do better at getting quality doctors here. But then also having a facility to provide quality, handling of their patients” (Dorchester).

Supporting the health care workforce: Participants in four groups (Caroline, Dorchester, Queen Anne’s, Talbot) suggested that the workforce be enhanced (increase staffing), that the working environment be improved, and that more training be provided. They spoke about the need to have nurse or health worker home visits to enhance care (Kent). A participant added, “In-home care. Nurse- or health worker-based in-home care . . . I think it fits many different needs” (Kent).
**Efficient office staff and operations:** Participants in three groups (Kent, Queen Anne’s, Talbot) had good things to say about the workflow in their doctors’ offices.

**Nonphysician health care providers:** Individuals in four groups (Caroline, Dorchester, Kent, Talbot) talked about the effectiveness of nonphysician health care providers, such as nurse practitioners (NPs). One said, “My NP before she left was fabulous” (Caroline).

**Lost jobs and bad working conditions:** Participants in two groups (Queen Anne’s, Talbot) discussed lost jobs and bad working conditions, especially for health care workers left behind following job cuts. One described, “It’s horrible for the people that work there. They’re short-handed. They don’t have enough help” (Queen Anne’s).

**Technology Support**

Participants in three groups (Caroline, Dorchester, Talbot) brought up challenges created by technology, such as patient portals that do not communicate with one another, loss of eye contact when doctors write on laptops, and uninformed use of technology, such as when office staff are not aware of the office website. About her appointment, one participant agreed, “A little too fast and a little too much time spent typing things in the computer” (Talbot). Telemedicine/telehealth received mixed reviews, and one participant noted it was more acceptable with a provider already known to the patient (Caroline). Several technology-related service ideas were presented, including using nurse specialists by phone (Kent), having medical specialists work via telemedicine (Kent), and developing a communication system that connects all patient’s doctors, labs and other services (Talbot).

**Economic Development**

Participants welcomed facility changes when they expanded services, such as a new urgent care center in Caroline County. However, facility changes worried participants in four groups (Caroline, Dorchester, Kent, Queen Anne’s) when there was either a reduction in services or a possible closure. People in two groups (Caroline, Kent) recommended keeping or adding facilities and services. Service ideas related to facilities included standalone facilities for mental health care (Kent), a small “destination” hospital (Kent) and a network of clinics located where there is a lack of hospitals (Kent). Participants in one focus group were concerned about the economic impact of health care changes on the local college and the senior population. In reference to losing the local hospital, one participant said, “This would be a very severe economic issue were it [the hospital] to fall through” (Kent).

**Transportation**

Participants in four groups (Caroline, Dorchester, Kent, Talbot) thought transportation could be improved for both regular and emergency purposes.

In terms of regular care, participants in three groups (Kent, Queen Anne’s, Talbot) said that some care was in good locations. People in two groups (Caroline, Kent) said there were transportation difficulties getting to doctors’ appointments. One person said, “It’s a distance to drive, and that’s a problem when you can’t drive or have no car to drive” (Caroline). One service idea was an improved medical transportation system (Talbot).
For emergency care, participants in two groups (Caroline, Kent) discussed difficulties with transportation. Participants suggested improving and enhancing ambulance services, including equipping them to provide immediate care and stationing them near population centers (Dorchester). A participant added, “I have a friend whose husband, a doctor, died while waiting for [an ambulance], one wasn’t available” (Dorchester).

Vulnerable Populations

Focus group participants discussed their concerns about several subpopulations as reflected below.

**Children**: A lack of pediatricians was cited by participants in two groups (Kent, Queen Anne’s). Participants in one group (Caroline) cited a need for more mental health providers in the schools. One said, “A lot of anxieties, depression, those types of things they start [in school]” (Caroline). People were worried about children’s health if the hospital is closed. (Kent).

**Young adults**: Participants in one group (Talbot) thought that young adults were not making a living wage early in their careers. One participant said, “We’re living in a different world with our young people today” (Talbot). In Kent, people were worried about the health of young people if the hospital closed.

**Pregnant women**: Participants in three groups (Dorchester, Kent, Queen Anne’s) spoke about a lack of obstetricians and, with the relocation of the maternity ward, long distances to travel to deliver babies. One said, “Now in this area, if you’re having a baby you have to go either to Easton, or across the bridge to Annapolis, which is in the northern end of the county and is well better than an hour drive without bridge traffic” (Queen Anne’s). A participant in Kent expressed concerns about “the woman that’s pregnant and worried where is she going to deliver” if the hospital closes.

**Seniors**: People in one focus group (Kent) said it works well to have an inpatient facility near a nursing home. However, a participant in this same group said that doctors are not attracted to a small, elderly community. Worries related to older adults included Medicare running out of money or costing more were cited by participants in two groups (Queen Anne’s, Dorchester). In one group (Dorchester), participants believed the increase in older adults will lead to more disease, such as heart attacks and strokes. In another group (Caroline), participants said older adults will need more services and their working families will not be able to help. Participants in a third group (Kent) noted palliative care is needed to take better care of people at the end of life and avoid excessive expenditures. People in this group (Kent) also said that rural characteristics include being “poorer, sicker, distant, older.”

**Low-income individuals**: Participants in one group (Talbot) said that those with low incomes do not spend much on insurance and then are surprised by high costs later. One explained, “My biggest worry is that a lot of them, because they’re all low-income families, they choose their health care based on price. They don’t even know what they’re getting” (Talbot). Participants in all five groups were worried that people would lose insurance, including individuals with low incomes.

**Individuals with disabilities**: Participants in one group (Talbot) had an extended discussion about lack of accessibility for those with physical disability due to heavy, nonautomatic doors for entry into medical buildings and offices, inaccessible examination tables and scales, and poorly placed curb cuts. This group (Talbot) also said that people with intellectual disabilities need more help at the doctor’s office.
with communication, forms and insurance. On a positive note, participants in one group (Caroline) affirmed deaf consumers were “getting . . . interpreting service through telehealth.”

**Non-English speakers:** This topic was raised in one group (Queen Anne’s) in which a participant’s relative needed help with Spanish for health and insurance issues. He said, “She did find a friend that speaks Spanish” (Queen Anne’s).

**People needing mental, behavioral and substance use care:** Care for these individuals is lacking in the Mid-Shore region, according to participants in three groups (Caroline, Kent, Queen Anne’s). People in two groups (Caroline, Queen Anne’s) said care must be accessible and affordable. Participants suggested standalone mental health inpatient facilities (Kent), more holistic care (Caroline) and “more resources and services for outpatient and inpatient care for mental health, behavioral health” (Caroline).

**Other Topics Mentioned by Focus Group Participants**

Additional topics that do not fit the full report categories arose from focus group discussions.

**Empathy for Mid-Shore residents:** Participants in four groups (Caroline, Kent, Queen Anne’s, Talbot) wanted the MHCC to try to better understand the Mid-Shore and those who live there. In one group (Kent), participants asked leaders to remember what the word “rural” means: “poorer, sicker, distant, older.” In three groups (Caroline, Queen Anne’s, Talbot) participants said the commission should keep listening to and talking with people in the Mid-Shore area. People wanted to be listened to now, for the commission to “pay attention” (Queen Anne’s), because during previous listening sessions on local health care, they were “sold a bill,” and health services and jobs were lost (Queen Anne’s). Participants cited this negative experience as a reason it was difficult to recruit focus group participants (Queen Anne’s).

**Accountability:** Participants in three groups (Caroline, Dorchester, Talbot) mentioned accountability, asking that grants and programs be monitored and rules be enforced. One asserted, “The Parity Act is not being enforced for substance abuse services” (Caroline).

**Decision making:** Participants in two groups (Kent, Talbot) discussed how decisions should be made, with people asking that decision-making be clear and focused and that decisionmakers be diverse. One participant said, “Right now, we have a bunch of wealthy white men making decisions on health care for this country” (Talbot).

**New approaches to solutions:** Two groups (Caroline, Kent) recommended that the commission consider different ways of doing things, including collaborating across state lines (with Delaware), using public/private partnerships for challenges like medical transportation and “thinking outside the box,” not just adding to what is already being done. For example, a participant in Kent suggested, “Doesn’t seem likely that the hospitals are going into the bus system. But you don’t hear anything about public/private partnerships of bringing those two industries together to try to solve some of these problems to their mutual benefits. If I was to speak to the commission, I would say . . . look at partnerships.”
Focus Group Background, Project Overview, Procedures and Methods

A NOTE ABOUT FOCUS GROUPS

Focus groups are a qualitative research method that, when rigorously designed, provide an opportunity to observe and record participants’ perceptions, opinions, beliefs, and attitudes about a research topic (Henderson, 2011, Creswell, 2014). They can offer information about how people form opinions and how open they are to new ideas. They lead to narrative information that offers insight and direction, not quantitative measures. Focus groups are not designed to obtain consensus among participants or offer a single answer to questions. They may be used independently or in conjunction with quantitative research methods to provide exploratory findings that help develop quantitative measures. They can also further understanding about quantitative research findings. As all research methods have strengths and limitations, a mixed methods approach that uses multiple data collection methods can provide a more complete understanding than can be achieved by one method alone (Cresswell, 2014, P. 4).

Please note that focus groups are not intended to yield findings that can be generalized to a larger population.

PROJECT OVERVIEW

This report covers one component of a larger project authorized in Senate Bill 707 (SB707: Freestanding Medical Facilities—Certificate of Need, Rates, and Definition) to examine challenges to health care delivery in the five Mid-Shore counties (Caroline, Dorchester, Kent, Queen Anne’s, Talbot) and to provide input to the state of Maryland’s Rural Health Care Delivery Workgroup. The MHCC requested the University of Maryland School of Public Health in partnership with the Walsh Center for Rural Health Analysis at NORC at the University of Chicago to conduct the study and to work in parallel with the workgroup and the MHCC.

The goals of the focus groups were to gain insight into the health care perceptions and behaviors of consumers living within the five-county area and to understand their views, opinions and preferences for a regional health care system. The premise of the focus groups was to gather direct feedback on the views and opinions about issues related to the needs, wants, availability and accessibility of health care for consumers in the five-county area. These consumers are the key constituency served by the MHCC, and a vital source of knowledge about the health care issues that are most important to them. Focus groups were selected as a method of inquiry because they are well-suited to gaining insight into the personal experiences of individuals.

Between March 2 and April 3, 2017, five focus groups were held in public libraries in each of the five Maryland Mid-Shore counties: Caroline, Dorchester, Kent, Queen Anne’s and Talbot (Table 1). Focus group topics addressed assets and challenges related to health care in the region as well as defining characteristics of improved health services and recommendations for the MHCC. A total of 45 Mid-Shore residents participated in the focus groups (6 to 11 participants per group). Participants were recruited in partnership with the University of Maryland Cooperative Extension Service through trusted local health and human service organizations and by social media, phone, email, newspapers, radio and word of mouth. Recruitment announcements explained the purpose of the focus groups and told participants they would be provided a light dinner and $25 as a token of appreciation for their participation.
It is important to note that the results of the focus groups reflect the perceptions of some community members, but may not necessarily represent all community members in the Mid-Shore region.

**PROCEDURES AND METHODS**

Five focus groups, each lasting 90 minutes, were held in public libraries—one group in each of the five Mid-Shore counties. All the focus groups were conducted in English and facilitated by a trained moderator with extensive experience in qualitative research methods. The only people in each room were the moderator, two note takers, and the focus group participants. All focus group discussions were audio-recorded, transcribed verbatim and analyzed for common themes. (See Focus Group Findings.)

**Institutional Review Board Review**

The research methodology was submitted to the University of Maryland Institutional Review Board (IRB) and approved. It included the fact that participants who agreed to participate in the focus groups would read and sign a consent form that also requested their approval for being audio-recorded.

**Recruitment**

The focus groups targeted community members residing in the zip codes comprising hospital service areas for the three hospitals serving the region; these are in Cambridge (Dorchester County), Chestertown (Kent County), and Easton (Talbot County). In partnership with Mid-Shore staff from the University of Maryland Cooperative Extension Service, which conducts community outreach events throughout the year and maintains a list of key community stakeholders, the focus group research team developed recruitment materials (flyers, emails and phone messages) that were shared with key local health and human service organizations for dissemination among their clients. For two of the focus groups (Dorchester, Queen Anne’s), research staff members handed out flyers in person at various local establishments frequented by members of the community. Recruitment was also conducted through social media, newspaper announcements, radio (in Dorchester County) and word of mouth. Potential participants contacted the research team on a dedicated telephone line or email address and left a message with their contact information. Research staff then contacted each potential participant to determine whether he or she fit eligibility criteria, which included:

- being 18 years or older,
- speaking and understanding English,
- residing or working in any of the five counties in the Mid-Shore region, and
- being willing to share personal views and experiences on health care in the Mid-Shore area.

Research staff explained the scope and purpose of the study as well as the focus group format and logistics to eligible participants. As each focus group session approached, the research team sent reminder emails to those who signed up to reiterate the day and time, location, directions and processes. Please note that participants chose the most convenient available location, which may have been close to their jobs or homes. Thus, some groups had participants who lived in a county that differed from the one in which the discussion group was located.
Upon arrival, each participant reviewed the informed consent form, had an opportunity to ask questions and signed it. They completed a demographic information form prior to the start of the focus group discussion. The collected information provided additional context to the responses during analyses and included participant age, race/ethnicity, gender, language(s) spoken at home, zip code, health insurance type, and use of hospital, health facilities, and health services in the past year (Table 2).

**Focus Group Questions and Procedures**

The moderator guide was developed with input from University of Maryland team members, representatives of the Walsh Center, and key staff members of the University of Maryland Cooperative Extension Service. The guide was written to focus on answering the following two research questions:

1. How do Mid-Shore residents view their current health care services? What works well? What needs improvement?

2. What suggestions do Mid-Shore residents have for providers and policymakers to improve their health care services (regarding access, quality, proximity, cost, etc.)?

After participants signed in, signed the consent form, completed the demographic information form and were provided dinner, the moderator introduced the structure and guidelines of the focus group. (See Table 3.)

Participants were first asked to share their names, the county where they live, and who and what lives with them (including pets), and their first memory of going to the doctor, dentist or other health care provider. Participants were then asked to reflect on a recent or particularly memorable health care experience, first by sharing the details of the experience and then by writing down their thoughts in three categories: 1) what works well, 2) what needs improvement, and 3) suggestions for making the experience better. This exercise set the stage for a discussion on the strengths and challenges of the current health care system as experienced by the participants. The next question asked participants to think about the future of health care and share their thoughts about changes that they would like and those that worried them. After this discussion, participants were divided into two or three teams for an exercise to provide recommendations to the MHCC regarding a chosen health service important to the group. Teams were asked to write down features of the chosen health service that were most important and what they would like to see improved. Following this exercise, the moderator facilitated a discussion of each group’s ideas and asked for their recommendations for the MHCC. Each focus group concluded with participants’ final thoughts about the group discussion.

**Focus Group Analysis**

For this project, transcripts of the recordings were professionally prepared. The research team then organized the transcripts for review. They developed a set of codes (a code book) for labeling portions of text from a combination of the focus group structure and initial readings of the five transcripts (approximately 250 pages). The team reviewed another 24 pages of written comments that were captured from participant notes on sticky pads and activity sheets and from researcher notes on easel pad sheets during the focus group discussions.

The code list went through several iterations based on team discussions and on multiple readings of the transcripts. Four members of the team reviewed a 28-page sample of one of the transcripts to see how
consistent interpretations were and how the coding process might be adjusted. Note: Although one lead coder managed the coding, the team regularly discussed the findings, the coding process and the resulting report narrative weekly or biweekly from April through July 2017.

Given the tight project deadlines, the team chose to hand code the data versus coding with software. Hand coding involved applying codes in a systematic, line-by-line process, and creating tallies for the findings that could easily be reported in an initial presentation prepared in mid-May for the full research team. This material was also used for a presentation to the commission in late May. These tallied findings provided a scaffolding on which the team built the findings section of the focus group report for an early June 2017 draft. As the report evolved toward mid-July, topics and subtopics were created within the structure of the focus groups. In the report, each topic and subtopic uses introductory narratives explaining the findings then provides verbatim quotations to support the narrative. In reporting the findings, a “weight of evidence” approach was used when possible. That is, in each section, topics covered by all five focus groups were reported first, followed by those discussed by four groups, then three groups and so forth. At least one quotation was generally provided for each group that weighed in on a given topic. These quotations—the participants’ own words, their own voices—are the essence of this focus group report.

Please note that qualitative data analysis software programs follow the steps conducted in hand coding. These software programs help manage data; however, the coder(s) are responsible for making the many coding decisions involved in data analysis. Unlike quantitative data analysis, the software program does not conduct the analysis.

Participant Characteristics

There were two sources of information on the characteristics of the individuals who participated in the focus groups. One was a demographic questionnaire that they filled out at the beginning of the session. This information is reflected in the first two subsections below.

The second source was information that participants volunteered during recruitment, via email, the phone or at the sessions. This information is covered in the third section below.

FOCUS GROUP PARTICIPANT DEMOGRAPHIC INFORMATION

A total of 45 individuals participated in the five focus group discussions, which were held in each of the five Mid-Shore counties (Table 1). The Caroline, Dorchester and Kent groups all consisted of participants who lived in those respective counties, while some of the participants who attended the Queen Anne’s and Talbot focus groups lived in a different county. A majority of the participants (64% or 29 participants) were female, while the remaining 16 participants (36%) were male. Nearly half of all participants were 65 years or older. Six participants (13%) were 75 years or older, and 16 participants, (35%) were between the ages of 65 and 74, representing the largest age group. Seven participants (15%) were between the ages of 55 and 64, and six participants (13%) were between the ages of 45 and 54. Seven participants (15%) were between the ages of 35 and 44, and only 3 participants (7%) were between the ages of 25 and 34. (No one was younger; the age requirement was age 18 or older.) Thirty-eight participants (84%) identified as White or Caucasian, five (11%) identified as Black or African-
American, one (2%) identified as Hispanic, and one (2%) identified as Other. Consistent with the eligibility criteria, 43 participants (96%) spoke English at home, one (2%) spoke English and Spanish, and one (2%) participant did not respond to this question.

**FOCUS GROUP PARTICIPANT HEALTH INSURANCE COVERAGE AND HEALTH SERVICE UTILIZATION**

Eighteen (40%) of the 45 participants had public insurance, while 17 (38%) had private insurance. Another eight participants (18%) had both public and private insurance, one participant (2%) had insurance through the exchange, and one participant (2%) did not respond to this question. Of the 25 participants (56%) who had some form of public insurance, 22 (85%) had Medicare. Participants were also asked what hospital they or their family members had used in the past year. Memorial Hospital at Easton was the most-used hospital (13 participants and/or their family members) followed by University of Maryland (UM) Shore Regional Health at Chestertown (Chester River Hospital Center) (12 participants and/or their family members) and UM Shore Regional Health at Dorchester (Dorchester General Hospital). (8 participants and/or their family members). Other hospitals that were used included Anne Arundel Medical Center (7 participants and/or their family members), Johns Hopkins (4 participants and/or their family members), Peninsula Regional Medical Center (3 participants and/or their family members) and other area hospitals (1 each in Washington, DC, Annapolis and Baltimore). Finally, when asked about other health facilities and services used in the past year by participants and/or their family members, participants indicated that pharmacies were the most used (43 participants and/or their family members) followed by private doctor’s offices (40 participants and/or their family members) and private dental offices (36 participants and/or their family members). Equal numbers of participants and/or their family members used the emergency room and urgent care clinic (20 participants and/or their family members, respectively), while 14 participants and/or their family members used an ambulatory surgery center. Other services used ranged from disability/rehabilitation/aging services to emergency medical services (911), and mental health services (7 participants and/or their family members each, respectively). Table 2 provides a full listing of health facilities and services.

**FOCUS GROUP PARTICIPANT BACKGROUNDS**

People were asked to participate in the focus groups to reflect on their personal health experiences. However, during the recruitment and focus group processes, many people volunteered information about their backgrounds. In the following list of backgrounds (below), some people may be represented by more than one role or type of experience. Some are retired from their professions. This list combines information from all five groups. Note that this background information was not requested as part of the demographic survey and may not fully represent all participants.

Professional backgrounds represented include:

- Nurses with experience in critical care, home care, hospice, mental health and acute care (four), as well as two nurses with experience in public health and community health
- Professionals in behavioral and mental health (four)
- Local health department staff (three), including people working in wellness or with people with cognitive disabilities
• Health care consultants (three)
• Case managers (two) working with discharge planning or with low-income individuals
• Insurance professionals (two), a patient navigator and a regional manager
• Health foundation volunteers (two)
• Family doctor
• Hospice volunteer
• Human resources manager
• Government administrator
• Health services administrator
• School social worker
• Lawyer who runs a legal clinic
• Seller/inventor of medical equipment
• Local University of Maryland instructor
• Office manager

In terms of personal backgrounds, participants discussed many types of acute and chronic illnesses. One participant had used mental health services; one was in a wheelchair. Numerous participants had loved ones with a variety of health issues, including a parent of a child with a rare condition; a parent of a child with a fatal cancer; a parent of two children with chronic conditions; a parent of two individuals addicted to heroin; and a parent of young adults who could not afford health insurance. At least three people had loved ones (wife, sister, fiancé) injured in car accidents, and two participants had been injured in car accidents. Participants had experience with loved ones or friends who needed emergency care.

Focus Group Findings

The focus group findings are based on data collected from two sources: spoken comments of participants (captured by transcriptions of the sessions) and written comments captured by research team members on easel pads or by participants on “sticky notes” before the discussion under Question 1 or on activity sheets before the discussion under Question 3.

The structure of each focus group was previously described and is provided below.

The focus group findings reported below largely follow the focus group structure. The participants’ many recommendations and suggestions for the MHCC are combined into one recommendations section along with a large table that includes both individual recommendations and suggestions as well as health service ideas in response to Question 3.
FOCUS GROUP STRUCTURE

Introductions/Icebreaker

Question 1: Last Health Care Visit or Another Health Care Visit
  What worked well
  What didn’t work well
  Suggested improvements

Question 2: Thinking About the Future, What Changes Would You Like? What Worries You?

Question 3: (Group Activity) Choose a Type of Health Service Important to You and Your Family, Describe the Features You Want to See

Last Word: Recommendations for the Maryland Health Care Commission

Takeaway Thoughts

The moderator began each group with an icebreaker in which she asked group members to give their first name, the county where they live, who and what lives with them (including pets), and a childhood memory of going to the doctor, dentist or other health professional.

After participants answered these questions (including memorable doctor and dental visits and youthful illnesses and episodes), the moderator led the participants through a series of questions and activities that produced the following findings (Tables 4-7).

Note: Focus groups yield descriptive results and comments of participants. Unlike surveys, which lead to one answer to a question, focus group results can lead to multiple answers and, as shown below, both positive and negative comments on the same topic.

QUESTION 1: LAST HEALTH CARE VISIT OR ANOTHER HEALTH CARE VISIT

Participants were asked to briefly describe a recent health care experience. Some mentioned routine visits to eye doctors, the dentist, a family or primary care doctor for a routine physical, or (for family members of two participants) follow-up care after a car accident. One participant saw a nurse practitioner for quarterly diabetes check-ups. Visits to specialists were mentioned, including an endocrinologist, an “RA” (rheumatoid arthritis) doctor, a dermatologist and a dermatological surgeon. One participant was going to a “doc in the box” until she had time to research a new primary care doctor. One had grown up on a farm where they were trained to take care of themselves.

The wife of one participant had received an in-home visit from a nurse to provide an eight-hour infusion. Some participants mentioned getting preventive care such as a flu shot or a colonoscopy. One referred to same-day knee surgery. Another had a triple bypass in the past year.
Participants went to “urgent care” for bronchitis and for an ankle sprain. Also, a participant had taken her adolescent son to the emergency room, where they did tests and determined he needed higher-level care, so he was sent by medevac to “University Hospital.”

Many more care examples are described in the sections that follow. Participants were asked to take a few minutes to use “sticky notes” to record what went well with their recent health care experiences, what had not gone well and suggested improvements. They then talked about many of these points. All points made orally or in writing were captured by the research team via transcription of the recorded discussion or typing of the notes written on sticky notes by participants or on easel pads during the discussion or in conversation notes by research team members.

In the sections that follow:

- Comments are arranged by theme, with those themes mentioned by the most groups listed first.
- A “show of hands” was often, although not always, used by the moderator when there appeared to be many people making the same comment. (This approach was used to help the discussion move on to other points.)
- Comments marked as “note” were written down on a sticky note or easel pad; otherwise all comments were oral as captured by a digital audio-recorder and then transcribed.

**STRENGTHS: WHAT WORKS WELL IN MID-SHORE HEALTH CARE**

After reflecting on recent health care experiences and jotting down their thoughts, participants in all groups had many good things to say about local health care.

**Good doctor-patient communication (5 groups)**

Participants in all five counties had positive comments about communication and relationships with their doctors:

*I love and trust my doctor. She’s been my primary care doctor for many, many years, and we know each other. So, that’s what works well. I don’t get the doctor du jour.* (Caroline)

*Just the experience at the colonoscopy, they made me feel really comfortable there, at ease, told me what to expect.* (Caroline)

*I appreciate the doctor comes in and . . . that there’s communication between the patient and the doctor. The doctor doesn’t know it all until he listens to his patient. It distracts you from your problem. It gives you a more soothing feeling as far as . . . he doesn’t know everything. He doesn’t give you that opinion that he knows everything.* (Dorchester)

*Show of hands on liking interaction with your doctors: 8 of 11 participants (Dorchester)*

*The doctor gave me options when I didn’t like what he first suggested, options are good.* (Talbot)

Another participant with a very ill baby said:

*It seems like when you have a doctor that cares, it means a lot. . . It means a lot because I have a doctor that if I call him and I leave him a message, he’ll get back to me.* (Dorchester)
Effective nonphysician health care providers (4 groups)

Other types of providers, particularly nurse practitioners (NPs), were very much appreciated as well and were mentioned by participants in the Caroline, Dorchester, Kent and Talbot groups:

My NP before she left was fabulous, always excellent care, always kept up with it, knew our personalities well to know what was just a phase and what was actually a problem that needed to be addressed. She really knew us well. (Caroline)

My husband had a recent hospital experience and it all went very well. . .  [the nurse] took a good half hour and talked about what we needed to do . . . Very good instructions. (Dorchester)

But I think the part [of my appointment] that worked well is that an NP took my case and was able to handle it and prescribe the correct medicine. (Kent)

I got a follow-up call to ask, “How are you feeling?” It was the NP this was impressive. (Talbot)

Good insurance coverage (4 groups)

Participants in the Queen Anne’s, Caroline, Kent and Talbot groups praised their insurance coverage and efforts to make accessing care easier:

I have good insurance coverage. (Caroline)

Coverage by my insurance was great. I didn’t need pre-approval to see specialists. (Queen Anne’s)

[My insurance company] is fantastic insurance. I had a brain tumor, and it cost my family nothing, and I can’t imagine what that stay was. I was in the hospital for a week and a half, plus the surgery, and my son had a tumor removed, and it’s just fantastic insurance. (Queen Anne’s)

When it was time to leave the office, they just submitted it to the insurance company, didn’t ask for any copay. They just said we’ll see how it pans out. (Talbot)

Getting an appointment in a timely manner (3 groups)

Participants in the Queen Anne’s, Caroline and Talbot groups described positive experiences scheduling appointments:

My doctor was very responsive. When I called and told them there’d been a car accident, I didn’t go by ambulance to the hospital. And they were like, “Come right in.” There were no questions asked. They found an appointment for me and got me in immediately. (Caroline)

I got an appointment quickly when I called with my concern. (Talbot)

Efficient medical visits (3 groups)

Efficient, often very helpful, appointments were praised by participants in the Caroline, Dorchester and Talbot groups.
My actual time at the office for the visit was minimum. They got me in and seen, and I was out, on my way again. (Caroline)

Fast and complete exam, spent adequate time which goes together. (Dorchester)

They saw me right on time, I did not have to wait. (Talbot)

I was seen in a very timely manner. (Talbot)

Good care received (3 groups)

Participants in the Caroline, Dorchester and Kent groups had good things to say about the care they received:

I go to my primary care, whom I love, every three months. And it’s supposed to be for diabetes follow-up… and it’s kind of like I summarize what I’ve done, and got all my results, and we go over them. So, it’s much more than just diabetes follow-up. (Caroline)

I got an actual diagnosis and follow-up care with my primary care doctor. (Caroline)

One thing I liked is that my doctor is very proactive in prevention. (Dorchester)

I went to the urgent care center with a sprained knee. And what worked well was that they took an image of the knee and saw that it wasn’t broken. I already had crutches, but it [was] a success in terms of… finding out what was wrong and finding—ruling out more serious things being wrong. (Kent)

[My rehab care] was personal, it was involved with me as an individual. I got the pain medication when I needed it. They didn’t wake me up in the middle of the night. (Kent)

Good location of care (3 groups)

Individuals in the Queen Anne’s, Kent and Talbot groups had positive comments about the location of their care:

I liked the location. One office is about three minutes from my house out in the middle of the sticks. (Queen Anne’s)

What has worked very well is that my parents in a nursing home, they’re 92 and 95 now, have, because they have a local inpatient facility, have been able to have immediate care from the nursing home whenever pneumonia, little strokes, little edema kinds of things. When things get out of hand for the nursing home, they have an inpatient facility three blocks away that they can go to and then come back. (Kent)

The endocrinologist in Easton comes up here to Chester River, and it’s at least once a month, it may be twice a month… I can see her on schedule without effort… I can just about walk. (Kent)

For me [for my rehab care], it was being in the community and a different sensitivity. (Kent)

The medical office was close to work and home. (Talbot)
Efficient medical office staff and operations (3 groups)

Participants in the Queen Anne’s, Kent and Talbot groups praised office staff and how medical offices and operations were run:

Efficient office staff. (Queen Anne’s)

I go through the infusion outpatient center here at the hospital. And it all is extremely efficient, very well trained, professional staff. (Kent)

Quick and efficient service, friendly doctor and staff. And the reminder call. (Talbot)

Helpful emergency care (2 groups)

Emergency care was praised by participants in the Dorchester and Kent groups:

The ER [emergency room] doctor realized what a sick person really looks like. And then he was able to coordinate the testing, the monitoring and getting him [my teenage son] out of there. (Dorchester)

It took many hours before the [ER] doctor came...but when the doc came he was great. (Dorchester)

[My wife] woke up in the middle of the night and she could not speak and she was confused. I got her quickly to the emergency room where we were treated right here, treated...diagnosed very quickly but they said they couldn’t help her because they needed more tests, they needed more machines, they needed specialists. So, they called around to the different hospitals... (Kent)

CHALLENGES: WHAT DOESN’T WORK WELL IN MID-SHORE HEALTH CARE

Reflecting on the same recent health care experiences, participants were asked to describe what did not work well. Note: Participants mentioned that some aspects of the same service worked well and other aspects did not.

Insurance, costs, coverage difficulties (5 groups)

Participants in all five county sessions had negative comments about insurance coverage and the cost of care:

It’s the deductibles that’s killing the people. They have insurance, they’re paying through the nose for it... But they can’t use it, not when you’ve got a $12,000 deductible. (Dorchester)

Show of hands on insurance hassles: 5 of 10 participants (Kent)

I spent five times more time at the office trying to clear up insurance issues and explain insurance issues than I spent there for the illness. And it’s remarkable to me how fractured—I mean, I have [a common kind of insurance] so it’s not [a] mysterious out-of-the-box type of situation... But if you’re really sick and you’re having trouble just trying to get through it, to spend literally five times more time on the insurance than the visit. (Kent)

Insurance coverage was seen as a challenge for mental health care:
We need... parity of payment so specialty providers will be able to financially sustain serving the Caroline County substance abuse, mental health and behavioral health services that we need... But there’s supposed to be a law that says that there’s parity between payments, and it’s just not enforced. (Caroline)

One participant said that in an emergency, his wife had to go to a faraway hospital by helicopter; his son later helped negotiate the cost.

We got a bill for the helicopter, $45,000 over the $12,000 that Medicare had paid... In any health care system that we arrive at, does this kind of trap should be included? (Kent)

For people in the Queen Anne’s and Caroline County groups, insurance comments were related to follow-up care for themselves or family members involved in car accidents (five of a combined 15 participants discussed car accidents between the two counties).

She had a car accident... like three months ago, four months ago, something like that. But she went to the hospital in [another area] because the accident was down that way, and when they release her, and when she’s coming here, and she has been trying to get help for like therapies, and stuff. But they won’t help her because the insurance on the car don’t want to pay, like because I had full coverage on the car – right? – insurance, but with [a car insurance company]. And the other guy who hit my car in the back, he did have insurance, too. But when she is like trying to get help, they wanted her to pay, and she don’t have the money to pay... She did find a friend that speaks Spanish, and it’s a lawyer, and call, and they ask for all the paperwork she have... She was crying in nighttime, because she had a pain. (Queen Anne’s)

Mine was a billing issue. I was self-pay because it was an automobile accident. But then I got an EOB [explanation of benefits] from my insurance company where they billed them as well. So, I’m still working through the kinks on that one. (Caroline)

In [other state] [after my car accident] I had no true exam, no testing, no real diagnosis after a car accident, didn’t really have any follow-up care back home until symptoms got worse. It was a worry of cost in the hospital setting, and then getting back home it was trying to find the right providers for therapy, for specialties. (Caroline)

Specialty care: Lacking or far away (5 groups)

Another topic that came up in every group was specialty care, most commonly that it was lacking or far away:

Locally here, we no longer have the same-day surgery services. So, I had to go all the way to Cecil County to have my knee surgery. [It took] an hour and 10 minutes. (Queen Anne’s)

There are very few specialty options on the Shore, so you end up traveling a long distance, and I mean a long distance, to get to that broader training because those that are specialty on the Shore leave because they aren’t up-to-date on the newest practices or what’s happening. (Caroline)

My wife early this week [mid-March] came down with a very serious sinus infection and her nose was totally blocked, one ear is totally blocked. So, she called all the sinus specialists and made sure—none of them could see her before May even... wouldn’t even try to work her in before May. So, we’re going to Johns Hopkins tomorrow. But that’s... if you want a good specialist and you
want them in short order, you’re not going to find them locally in most cases. They’re just not here. (Kent)

There are no pediatricians here. There are no obstetricians here. (Kent)

We’ve lost, I think, a couple of cardiologists just within the last couple of months . . . We’re not attracting people because it’s a small community, it is an elderly community. (Kent)

One participant did mention that some specialists were too focused:

It really seems like everyone’s gotten so specialized that they can’t step back, and see the picture. (Queen Anne’s)

**Doctors: Restricted, not supported enough (4 groups)**

Participants in the groups held in Queen Anne’s, Caroline, Dorchester and Talbot mentioned that doctors need more support:

We talked about a broad amount of things, but they all really kind of fall under “let doctors be doctors.” If they’re going to be a primary care doctor, let them coordinate the services. Let them have the time, and the appropriate payment to be the doctors. And it’s not happening. (Caroline)

A variety of restrictions were described:

Doctors are afraid to write prescriptions for people, even if they think, “Yeah, maybe you need this. Nah, I don’t want to risk anything.” So, getting the care, because the doctors are probably – and not unjustifiably – scared. (Queen Anne’s)

For years I’ve been hearing from physicians that, “I’m thinking about getting out of medical practice, because I’m dealing more with paper and the government than I am with patients.” And I think deregulation will help that a lot. (Queen Anne’s)

I think that there is very real concern about physicians about doing anything off-book a little bit, because of their exposure legally. (Queen Anne’s)

But the biggest problem is all the constraints that they’ve got shoved on them. Whose instructions, whose standard of care do they follow? It used to just be the AMA [American Medical Association]. Now it’s the insurance company, it’s the drug company and it’s the local hospitals . . . And if you’ve got four different standards of care all crashing around you and your only concern is the patient, it’s tough. (Dorchester)

**Facilities: Changing, closing, lacking (4 groups)**

Actual or potential negative changes in facilities (reductions in services and possible closures) and lack of facilities were mentioned by participants in the Queen Anne’s, Caroline, Dorchester and Kent groups.

We used to have a full hospital in Chestertown, and with the transition when the University of Maryland took it over, they lost pediatrics, they lost maternity, they lost same-day surgery. They just keep losing services. (Queen Anne’s)
I've lived in the county 37 years, and I've seen the access to those kinds of facilities go down instead of up. (Queen Anne's)

It used to be a country hospital. It was Chestertown Hospital, and then it was called Queen Anne’s Hospital. And then when Shore Health came in, and the university took it over, they had listening sessions similar to this, and brought in people from the community, and sold the bill that this is going to be wonderful because we’re going to have all these specialists that you’ve never had access to. And they’re going to be able to come in here once a month, and you’ll have all these new services. And that didn’t happen. (Queen Anne’s)

They’re two counties in the state that don’t have hospitals. The only two [Caroline and Queen Anne’s]. (Caroline)

I moved here 10 years ago because, when I retired, there was a facility available. (Dorchester)

They’ve already taken a maternity ward. . .when Cambridge became part of the University of Maryland health system, maternity went to Easton. (Dorchester)

Location: Inconvenience, seasonal traffic (4 groups)

Participants in the groups held in Queen Anne’s, Caroline, Dorchester and Kent counties had comments about driving distances for care and about seasonal traffic and the difficulty of crossing the Bay Bridge:

Now in this area, if you’re having a baby you should go to either Easton, or across the bridge to Annapolis, which is in the northern end of the county, and is well better than an hour drive without bridge traffic. [In the summer] you may as well get a boat and swim, or something. (Queen Anne’s)

And like all four of my children were born in Chestertown. My daughters don’t have that opportunity. They should go an hour and 15 minutes away to have a baby. (Queen Anne’s)

Travel time 45 minutes one way. It’s just too far. (Caroline)

Have places [for health care that are] closer. It doesn’t really concern me because I have a lot of people’s support, but you can see, especially in this county, that it is a problem. (Caroline)

Show of hands on distance issues: 9 of 9 participants (Caroline)

My concern is . . . 20 minutes from Cambridge to Easton on a good day. Not in the summertime. And if you’re living in the south Dorchester area, you’re an hour to hour and 15 minutes. And they’ve already taken a maternity ward-- when Cambridge became part of the University of Maryland health system, maternity went to Easton and the doctor that argued it in Sailwinds Park down here said, “I can drive there any time in 15 minutes.” Well, I don’t know what helicopter he takes, but it ain’t a regular car. I’m sorry, he’s wrong. (Dorchester)

[In summer] you always have to deal with the bridge and you never know what you’re going to get. (Kent)

Essentially good care is an hour away. And for either acute emergency or, as you point out, I just need to see the doctor and I can’t get there, right? (Kent)
Impersonal or rude care (4 groups)

In the Queen Anne’s, Dorchester, Kent and Talbot groups, examples were given of impersonal or even rude care:

Nurses were gossiping. (Queen Anne’s note)
The surgeon was a complete and total jerk, and I was awake during the biopsy and he yelled at everybody who was in the operating room, was incredibly rude and dismissive. And I was frightened and it really frightened me even more to have him be treating people in such a disrespectful way. (Dorchester)
Doctor and nurse were impersonal and spent short time with patient. (Kent note)
Show of hands on impersonal care: 3 of 10 participants (Kent)
I just felt that he [the doctor] had no empathy at all. (Talbot)
More empathy for patient or find a new career. (Talbot note)

Mental, behavioral, substance use care: Lacking (3 groups)

In the Queen Anne’s, Caroline and Kent groups, there were substantive discussions about the need for behavioral and mental health care:

What happens now if you have a mental health crisis, generally, they end up in the criminal justice system, and they have to develop a record there before the mental health programs will pick them up? (Queen Anne’s)
A lot of times that’s what it is they do because they aren’t getting the treatment they need. They self-medicate, which drinking is, and then they drink and are disorderly, and they go off to jail. (Queen Anne’s)
You’re not going to get a psychiatrist full time in this area. . . you’re not going to draw many psychiatrists over here, given the population, I don’t think on the Mid-Shore. (Queen Anne’s)
I was surprised that none of our topics came out to be that drugs are an issue . . . We’ve got heroin pouring into the county, but I don’t know of any treatment facilities in the county. (Queen Anne’s)
There is no [substance use] treatment facility in Caroline County; there are no recovery houses in Caroline County. (Caroline)
So, more of these [mental health] services, so more accessibility. . . We definitely need more psychiatrists. (Caroline)
We need [mental health] providers in the schools as well, [where] a lot of anxieties, depressions, those types of things they start. . . We have providers, but we need more providers. (Caroline)
The amount of resources and clinics for outpatient and inpatient care for these services, examples like Suboxone, methadone services . . . We need more resources and services for outpatient and inpatient care for mental health, behavioral health. Caroline County does not have no inpatient/outpatient . . . They don’t even have ILPs [independent living programs], specifically Caroline County has three level-one facilities. That’s it . . . There’s no day programs. There’s no MAT [medication-assisted treatment] . . . You’ve got to go out of county for a DWI [driving while intoxicated] program. (Caroline)
Mental health is not here at all. I think it’s either in Cambridge or in Dorchester....it would be an hour and half to drive for mental health care. (Kent)

Providing alternative approaches to mental health care and perceiving it as a health condition were important to participants:

And nobody really ties that [alternative approaches] back into something for a mental health client. A follow-up with any medications, just like with any other kind of care, there needs to be a follow-up there. Don’t just throw people on pills, and not follow up with it. And to add other therapies, and kind of like with the holistic health care approach, and kind of a way to get rid of the stigma of someone seeking mental health services. It’s gotten a lot better, but it’s still there. But a way to make it seem that depression is the same as having diabetes. It’s still a mental health condition or a health condition. It’s not just mental health. (Caroline)

Primary care providers were said to have an important “first line” role in mental health care:

Not only is there a lack of doctors, but then those that are there being able to access them, though. That was a very broad encompassing of, and I would say for, opiates and mental health. Primary care is the first line of defense. They should be the first ones recognizing it, seeing it, making the referrals and going forward, not writing more and more prescriptions on the issue, but when people aren’t being seen, when they aren’t accessing it. (Caroline)

As with other care, they said, coordination is needed but is lacking:

You go around and around and around, or you have to go somewhere else. If you go to substance abuse services, and you’re required to get a Hep [hepatitis] C test to see. . .because you were an injection user, you can’t do it there. You’ve got to go somewhere else to do it, and they won’t do it. There’s no coordination of care around. (Caroline)

Participants said distance is especially challenging for mental health care:

Distance – having them accessible to and across the board, so we could get rid of this wait list problem, because having to follow up for care, and a lot of mental health services you need routine follow-up, multiple times a month, multiple times a week. So, to be driving hours is problematic for most people in a rural area. (Caroline)

**Time: Too long to wait for an appointment, too little time for care (3 groups)**

Participants in the Caroline, Dorchester and Talbot groups had negative comments about time—that it can take too long to get an appointment, too long to wait in the waiting room, or too little time at the appointment.

*My doctor only works part time and she had two family emergencies, and my every three-month appointment was cancelled twice. . . It was rescheduled further apart – further out than when I wanted it.* (Caroline)

*I’ll spend 50 minutes waiting and waiting and waiting for my time, and then I literally get four minutes with my provider to explain my problem.* (Caroline)
Why can’t they schedule people a little better? . . . I’m averaging now, no matter whom I go to except for one physician, a one-hour wait, as it was this morning. (Dorchester)

Show of hands on waiting a long time in the doctor’s office: 9 of 11 participants (Dorchester)

The wait time from the time I called for an appointment to get in was months. So, granted, this was dental, but there’s a lot of other specialists and what-not in mental health that it’s very much that way. Long wait lists or times to get in for an appointment. (Talbot)

I feel like I’m being rushed. This was a primary care visit, so it’s a little different than a specialty care, and she’s been my doctor for a while. I think she’s competent, but I always feel like it’s rushed. Got 10 or 15 minutes with you tops and boom, boom, boom. Just goes down her list of questions, and the actual physical exam is very, very quick probably because she knows I’m okay. But, I feel like it’s a little less thorough, you know, just looking at your eyes, your ears, your mouth, checking your parts they’re supposed to check. A little too fast. (Talbot)

Mine is access to services, a timely access to services and I think being on the rural Eastern Shore, we wait and wait and wait. [In] the job that I’m dealing with, who needs to get into Kennedy Krieger, it’s already been almost a year. You know, we wait forever to be able to get quality services. (Talbot)

Medication costs: High (3 groups)

Individuals in Queen Anne’s, Kent and Talbot mentioned the high costs of medication and the prices set by drug companies:

I know it is a concern for many people, and that is the cost of medication . . . And there doesn’t seem to be as much regulation among the drug companies. For example, in recent months, where the episode where EpiPens all of a sudden jumped up to $600 for one EpiPen when it had been much less than that. . . And I know for many people, getting their medications is a tremendous burden when there’s multiple illnesses that they’re dealing with and treatment modalities. So, how are we going to improve access to medications at a cost that people can afford? (Queen Anne’s)

Show of hands on drug prices being unaffordable: 4 of 10 participants (Kent)

Insulin that I use daily is $600 a [one-ounce] bottle . . . It used to cost like $10. . . (Kent)

Technology challenges: Patient portals, doctor distraction, poor use, telemedicine (3 groups)

Participants in Caroline, Dorchester and Talbot had a variety of negative comments about the use of technology.

Some had negative things to say about the use of patient portals, either for lack of information sharing or for difficulty getting something done that way:

Multiple patient portals. Every single doctor has a different patient portal with a different login, and a different password. They don’t communicate with each other . . . [there are] the different ones at different places that can’t see the same thing, but you should bring everything, because they don’t share the things back and forth. (Caroline)
And talking about what didn’t work well, this was not with the dermatologist but with my primary care. They have started a patient portal where you can go online to request like prescription refills. . . . I put it in and then I had to call and then I had to get the pharmacy to call. It took me almost 10 days to get a refill on a prescription, and I’m like you can take that patient portal and send it overseas because I didn’t care for it at all. . . . I mean, I understand that we’re in the technology age and I do understand the need for it and stuff, but it hasn’t shown me a whole lot yet. (Talbot)

Participants said that computers reduced doctor-patient contact:

A little too fast and a little too much time spent typing things in the computer. Relatively good eye contact, but it’s really hard with all the electronic health records and stuff now that they’re clicking away while they’re talking to you, making sure they’re taking care of clicking everything in versus just sitting with you and talking with you. Those programs have gotten better, but they’re still. . . . I think it still creates a wall between you and the provider. (Talbot)

Another comment was that hospitals and offices were not making good use, or were not aware, of the technology they had:

But certainly that [use of electronic records] was not my experience when I went to the emergency room with a friend who was very ill. They asked us repeatedly for all this information. (Dorchester)

Well, I went to this dentist website and emailed him because I lost my initial paperwork I’m supposed to take and I thought, well, maybe I’ll find it online. And it wasn’t, so I emailed them to ask if they could email it to me before I went. When I got to the office and I hadn’t gotten it, I just told them, I said, “I’m really sorry I didn’t bring my paperwork.” I said, “But I sent you an email.” And they were like, “Well, where’d you send it to?” And I said, “From your website.” And they’re like, “Oh, there’s a place on our website that you can email?” (Talbot)

While telemedicine was often mentioned in a positive way, it was not uniformly embraced:

Horrible, horrible, horrible. I work for mental health. We had telemed. It was horrible. Doctors sat at a desk at Sheppard Pratt, and you saw the bottom of [their] head. “Yeah, and how’s he doing? Okay.” You know? It was horrible. We had two practitioners, and it turned out financially not to be a viable thing, because we got billed for their telemed time if the patient didn’t show. (Caroline)

I would say that there has to be a relationship. I’m fine with it once I have a relationship with a doctor or a specialist, if they came here physically one time, a regular time, but I’m not going to start off on teledem with somebody that I have never actually developed a relationship with. I’m not going to trust them with our health that way. (Caroline)

Quality of care: Poor (3 groups)

Poor quality of care was mentioned by participants in the Queen Anne’s, Caroline and Dorchester groups:

The first thing that comes to mind for me is a couple of years ago I was misdiagnosed at a local doctor’s office. Apparently, I had asthma, and they diagnosed me with anxiety. . . . and decided to put me on anxiety medications, and it didn’t help my breathing at all. (Queen Anne’s)
So, my surgeries have been done in Anne Arundel County [across the bridge], or Christiana [in Delaware]. I have to go that far to get what I consider to be adequate surgery and health care. (Queen Anne’s)

Just physicians that actually listen to you try to diagnose any issues. (Queen Anne’s)

We had a car accident in [another state] . . . it’s been well over a year. We’ve got to figure out what exactly is going on with her with the photosensitivity, with the constant migraines. For the past weeks, she had a constant headache that [has] not broke. And we cannot find good health care for her as far as finding a cure, finding an answer to the issues. (Queen Anne’s)

So, I kept telling [the doctor] my baby was sick, he kept telling [me] my baby was fine, I worry too much…. And come to find out, my baby had cancer. And he never took and sent me for x-rays or anything and it broke my heart. He didn’t even call to see how she was and she died. (Dorchester)

I had the experience with the dermatologist in Easton. I had, it’s like a pimple on the side of my face that wasn’t healing. In fact, it was getting larger. And I went to this dermatologist and he said, “It’s cancer. But I don’t need to take it out, I’ll just give you a shot,” or he gave me medication or something. . . . Well, I went back and continued working, and it got bigger, and it was itching, and I thought there’s something wrong. So, I went to another dermatologist, and he said it has to come out right away. And so, he made an incision and took it out, sewed me up. And I was fine. But if I had not gone to a second dermatologist, goodness knows what would have happened. (Dorchester)

Quality measures should be more relevant to care for sick people:

And for the staff that’s there, there’s not enough to make those patient satisfaction surveys be what they need to be. If you’re going to get the answers you want on that, you need people that are going to fluff your pillow, bring you your juice, tuck you in at night, and don’t worry about the person that needs CPR [cardiopulmonary resuscitation] next door . . . And you need that quality of care for what you’re seeking. I mean, people in the medical system are generally sick. We need services to make us better. We don’t need services to have us at a spa. And there’s a disconnect there [between patient satisfaction surveys and good quality care], a huge disconnect. (Caroline)

Care coordination/case management/patient navigation: Needed (3 groups)

Care coordination, case management and patient navigation efforts that help patients get what they need to be healthy were mentioned by participants in the Queen Anne’s, Caroline and Talbot groups:

Coordination of care is not happening, because of – whether it be time, or lack of interest to do it, or lack of training of what it is. . . . because primary care used to be you had your family doctor, and they took care of everything, and now they have to refer out to so many different things, but they’re not coordinating all of that care. They’re not coordinating those prescriptions back and forth. They’re giving you a name and sending you out the door. (Caroline)

Participants talked about going from doctor to doctor:

There are a lot of things I’ve gone to multiple offices for and end up going out of county, going across the bridge, down to Salisbury into Delaware for quality health care. And I don’t feel that’s the way it’s supposed to be. (Queen Anne’s)
There’s been a lot of times I’ve been pushed off, even at my own primary care when I went there and wasn’t able to see my doctor because she’s off on Fridays. I saw another doctor because I had a pain in my side. He’s pushing it off as constipation; turn around, and decided, like well, “How about you go over to the ER [emergency room] and have them check you out?” So, I went from the doctor’s office right across the street to the ER in Grasonville or Queenstown. As soon as I got in there wasn’t five minutes to say, “You have appendicitis.” I wait probably an hour. Then they transport me over to Easton, and I had to sit in Easton overnight before they can get me into surgery the next day. I’m like, “Okay, I went to three different facilities for appendicitis, and it took the second one to find out and the third one to actually do something about it.” . . . That’s kind of my issue. You have to bounce around a lot before you get where you need to go. (Queen Anne’s)

In terms of complex care, others said:

There’s not like a case management for highly difficult or specialized type cases. So, I’ve been to more doctors’ appointments since I’ve been here in Maryland than I can even count. I guess I could look back at my calendar. But one week I had 10 doctor appointments, and I do have a job. . . . My wife can’t drive, so she’s got to somehow get to some appointments, but it’s we go to this neurologist: “I can’t help you.” We go to another neurologist: “I’d love to treat you because you’re interesting to me, but I probably won’t be good for you.” And we have four neurologists that have passed us around. And so, we’re like, “What do we do?” (Queen Anne’s)

. . . They’ve even said with the changes in health care that people are supposed to have case managers to deal with chronic illnesses, chronic disease prevention. A lot of them can’t afford to bring in somebody to refer them to in their office to talk about chronic disease prevention. They can’t afford to do that. The doctors’ offices can’t afford to have a person there to teach their patients and to have . . . a referral system. They do it themselves. (Talbot)

Regardless, we’re definitely seeing the need for the patient navigation for us to be able to tell them how to call. Getting a colonoscopy is no easy business. It’s one thing to say I need an appointment for a breast exam or a mammogram or my annual. It’s another thing to say you need pre-screening, then you need prep instruction. Then you call them two days before so they know what to do for that prep. And then they go for their colonoscopy. Do they have transportation to and from? I mean, it’s a much bigger picture. (Talbot)

Where patient navigation was available, participants said doctors’ offices should share patient information:

Some providers, and this just adds to ongoing problems, some of the providers say, . . . “We’re not going to give you any information on the patients that you just patient navigate because you’re not paying for anything. So, we don’t owe you their results.” (Talbot)

Although most comments about coordination and navigation referred to health care, there was also a call for helping coordinate insurance coverage. This was especially true for follow-up care for car accidents.

She had a car accident . . . she went to the hospital in [another area] because the accident was down that way, and when they release her, and when she’s coming here, and she has been trying to get help for like therapies and stuff. But they won’t help her because the insurance on the car don’t want to pay, like because I had full coverage on the car – right? – insurance, but with [a car insurance company]. And the other guy who hit my car in the back, he did have insurance too, but
when she is like trying to get help, they wanted her to pay, and she don’t have the money to pay. (Queen Anne’s)

Some participants were health care providers, and they were aware that not all of their time was billable:

I, as a mental health provider, have billable service pressure. So, phone calls I can’t bill for, case management I can’t bill for, all that kind of stuff . . . We have to make money to support the practice, and I’m just always conscious, not as dramatic as it sounds, but I’m conscious that we need billable services. Yes, I can talk to this teacher, and get it done, but I’ve got to get a kid, so I can get them in my office, and work with them, which needs to happen . . . There’s a lot of behind-the-scene stuff that we can’t bill for. (Caroline)

Transportation difficulties for regular and emergency care (2 groups)

Negative comments about transportation were made by Caroline and Kent participants. Some applied to getting to regular care:

It’s a distance to drive, and that’s a problem when you can’t drive or have no car to drive. I medically couldn’t drive because I had a concussion, and I didn’t have a car to drive because my car was crashed. (Caroline)

If you have private care, you can’t get assisted transportation. If you have state care, you can get transportation, but not if you have a family. So, if I’m at home with my child I cannot get a ride to my doctor’s appointment because I have a child, and they can’t ride in the car. So, people don’t make appointments because of lack of transportation, lack of the ability to get to primary care, where it is, and that’s even if they go locally, let alone the amount of time that it would take to go to any kind of specialty or other places. I’ve done this recently because it’s what I do. An Uber ride from Goldsboro to Easton, which is fairly reasonable for a doctor’s office, is $35 one way. So, you wonder why people don’t access the care that’s available. (Caroline)

Say you’re just sick, but you don’t need an ambulance. There is no public transportation. So, the only way . . . and if you’re elderly, and if it’s at night, and elderly people have difficulty driving at night . . . you’re really, really in a problem situation. (Kent)

When they cannot get to regular appointments, some people wait until their conditions worsen:

And then what do they do? They wait ’til they get sicker. They call 911, and they get an ambulance to Delaware to the emergency room or wherever. (Caroline)

Participants commented about emergency transportation:

Particularly in our area for ambulances, it’s the emergency units and they’re volunteers and if they have to go to Easton . . . and two of them often have to go. You know, they don’t have that many that can do a long ride like that and take four hours. (Kent)

So, some publicly supported arrangement so there were more of them [ambulances] and more flexibility . . . and that’ll become even more acute when the hospital goes away, right? (Kent)
Workforce issues: Lost jobs or bad working conditions (2 groups)

Queen Anne’s and Talbot participants described loss of jobs and poor working situations:

“When services were reduced,] the other thing they did is they came in, and they got rid of all the LPNs [licensed practical nurses], and you had to be an RN [registered nurse], and people that had worked there their whole lives basically were let go, because the university standards were that – and no one knew any of that. So, you had people losing their jobs in the community, and the services just aren’t there anymore. (Queen Anne’s)

My one daughter is an RN at the ER there now, and it’s horrible for the people that work there. They’re short-handed. They don’t have enough help. There are 12-hour shifts turning into 15- and 16-hour shifts. They’re not getting a chance to pee, to eat, to anything. And the quality of the care here is worse than it was 10 years ago. (Queen Anne’s)

If we’re lucky, the provider stays. But our providers change constantly because they can’t afford to stay here. (Talbot)

Disability issues, particularly access to care (1 group)

Accessibility for individuals with physical disabilities was discussed at length by participants in the Talbot group, who also mentioned the challenges of health care for individuals with Intellectual disabilities.

Accessibility is more than parking spots, but sometimes even that is not done correctly:

Urgent care, there's no curb cut. So, if you park in handicapped spots here . . . The curb cut is all the way down at the very first building. That drives me wild. (Talbot)

One participant was in a wheelchair and explained the troubles she had getting to the doctor and during the visit:

When I first started with the family physician that I’m no longer seeing, to get in their building, you open one door and then there’s like a breezeway, and you have to open another door to get in. And I explained that I was having such a terrible time because the doors were so heavy, and it’s two doors at each . . . They said that they couldn’t afford to fix the door. So, their solution was that when I come, I call from my car and let them know I’m out there, and someone will come out and open the door for me. (Talbot)

This same practice also had exam tables that did not lower and scales that did not work for wheelchair users:

I would just echo [what she said] about access and just amazing how if you have rehab facilities [that] don’t have automatic doors. And I was at aqua care today and people hold it open for you, I'm in a walker. But until a little less than a year ago, I was wheelchair bound. I had to take a wheelchair wherever I went. And it was very frustrating. I just can’t believe this facility doesn’t have automatic doors. The orthopedic center doesn’t have automatic doors. And they say, “Well, here’s a wheelchair.” We did call the office, he’s like a mile and a half to the orthopedic center, it's like a mall, it’s this huge, cavernous . . . and the wheelchair they had had bad wheels, and it was really large and I had to really get my arms out here to wheel it. (Talbot)
The Talbot group discussed the need to address people with intellectual disabilities.

I work with disabled folks, they're mostly intellectually disabled. And I know exactly what you’re talking about. I have folks that I have to bring them to the doctor so that I can re-say what the doctor says so they can understand it. I fill out their forms for them. I know that doctors can't do everything, but for folks that need that kind of help, I feel like they should give it. I do. I don’t mind doing that, I'm not supposed to do it at work, but I want them to get the care. It’s a shame.

(Talbot)
Health literacy: Challenges understanding health issues, health insurance (1 group)

The Talbot group discussed challenges of understanding health issues as well as health insurance coverage and costs. Most individuals who addressed these topics were in a role where they helped others and spoke on behalf of their clients in addition to making comments about their own health care experiences.

As an example of a health issue, they said patients with diabetes were not always clearly told they have the disease:

*And one of the big problems we have is we’re trying to get people in for a pre-diabetes education, and I find that the providers, they may tell them that their blood sugars are high, and here, we’re going to put you on this medication and I’ll retest your blood sugar in three months. Have any questions been answered or asked? No. And then we call them to bring them into a class. I know this is an aside. We call them to bring them into a class and we know what their blood sugar level is. We don’t say, “Oh, you’re in a diabetic range, did you know that and are you in care?” They say, “Oh, I just have a high blood sugar and they’re going to test me again in three months.” And we’re like, “No, honey, you have diabetes.” We feel like saying, “No, you have diabetes, and you should be talking to a case manager about what you should be doing for your diabetes.” Not “Here’s a pill, watch your diet, we’ll see you in three months.” And that’s kind of what I get from my primary is that I’m not getting some targeted questions answered and resources. (Talbot)*

The complexity, costs and coverage of insurance can be hard for some people to understand. Three Talbot participants spoke about this:

*I work for social services . . . And the one issue I worry about is a lot of the folks that I service are undereducated. They don’t understand health care now, much less even have any idea what’s going to happen when it changes . . . And my biggest worry is that a lot of them, because they’re all low-income families, they choose their health care based on price. They don’t even know what they’re getting. They don’t. Most of them probably have no clue or okay, you say I got to have this, give me the one at the bottom. They choose the cheap one, and then by the time they get to the doctor, they’re surprised when the co-pay is $75, $100 or $200 dollars and they’re like, “It was just a check-up.” You chose that. (Talbot)*

*I work in human resources, and just like he said, the majority of my time, when I have a new employee or open enrollment, it’s explaining the health care plan. And I just have two and I have to spend probably 40 minutes a person at times explaining to them the differences. And they’re like, “Well, what should I do?” (Talbot)*

*My folks are different because they don’t have the cognitive abilities to remember it [insurance coverage, health care], to understand all the steps. So, we do a lot of breaking everything down, and we’re not frontline workers. But because there’s nobody else, we do that. (Talbot)*
QUESTION 2: THINKING ABOUT THE FUTURE, WHAT CHANGES WOULD YOU LIKE?
WHAT WORRIES YOU?

In introducing the topic of change, the moderator talked about uncertainty in the future of health care. She mentioned talk of potential changes to the Affordable Care Act, also called Obamacare. She also mentioned possible changes in the Mid-Shore region. She said that sometimes people look forward to changes and sometimes people worry. She asked participants to describe what changes they looked forward to and what worries they had.

CHANGES PARTICIPANTS WOULD LIKE OR LOOKED FORWARD TO

There was a variety of responses in different groups to this question.

Lower rates: Health insurance and health care (2 groups)

Dorchester and Talbot participants mentioned health care possibly becoming more affordable:

The Affordable Care Act is not working. (Dorchester)
Affordable is not affordable. (Dorchester)

Lower rates? . . . I’ve heard that’s what the intention is, to make . . . insurance more affordable. I would look forward to that. (Talbot)

So, if there are some changes in the Affordable Care Act and people start to lose their coverage, we’re right there to pick them up. So, it’s a good thing and a bad thing. It’s showing what works and what doesn’t work for the system. You speak to hopefully lower rates; wouldn’t that be nice? But unless we start looking at a universal health care type of situation, those insurance companies are still going to battle it out and those rates are still going to. . . there has to be a buy-in in order for rates to drop. That’s just math. So, I’m looking forward to keeping my job. Is that selfish? And helping as many people as I can. (Talbot)

Revitalization of our hospital (1 group)

Kent participants were looking forward to hospital improvements:

I’m looking forward to a revitalization of our hospital that’s been drained off by Easton for its own purposes. And so like [another participant] said, she goes . . . a regular person comes here all the time so she can schedule it for those. You can’t have all the specialists here, but if there are enough of them coming on a regular basis, so that you can set up regular appointments, rather than having to go to Easton just for a regular infusion or testing or something. There should be some sort of determination of what’s needed here. (Kent)

A new facility for urgent care, dialysis (1 group)

Caroline participants were enthusiastic about a new facility that was being built:

They just broke ground recently on the new facility that they’re going to be building. I’m not sure exactly what is going in there. I know my doctor’s office is moving over there. I know there’s going to be a diagnostic center. (Caroline)
Dialysis is going to be there [in the new facility being built] as well. (Caroline)

I don’t know how long it’s going to take for this facility to be built, but it’s a very much-needed addition to our county. (Caroline)

And they’re talking about a pilot project for an emergency room of sorts. And the entire second floor is supposed to be available for specialty care, and like visiting doctors, and such. (Caroline)

And the good thing is, obviously, that one [the new facility] and the one in Queen Anne’s County is right off the highway. (Caroline)

If it mirrors them [if the new facility mirrors the one in Queenstown], that’s going to be really nice. . . . Mostly because it’s the two counties in the state [Caroline and Queen Anne’s] that don’t have hospitals. The only two. (Caroline)

Less regulation (1 group)

Participants in Queen Anne’s saw the benefits of less regulation:

I don’t know if it’s an over-regulation thing that’s going on, so people are. . . maybe that should do with some of the intimidation that I feel that doctors are experiencing. Maybe if we. . . who knows, maybe in the future if Obamacare does go away. . . I don’t know if that has anything to do with what we’re experiencing in Maryland, because that’s federal, and my experience is between the states. So, it may be more of a Maryland-specific thing. (Queen Anne’s)

Well, we may end up seeing. . . still seeing the short wait times, because people won’t be as regulated, so you’ll see a proliferation, a potential proliferation of doctors in the areas. (Queen Anne’s)

For years I’ve been hearing from physicians that, “I’m thinking about getting out of medical practice, because I’m dealing more with paper and the government than I am with patients.” And I think deregulation will help that a lot. (Queen Anne’s)

All-payer model, if there is follow-up on integration of care (1 group)

A participant in Caroline described possible benefits of the Maryland all-payer model and whether it would lead to better follow-up care and care integration.

I haven’t seen a whole lot of local participation, and what’s happening with it, but the requirements of it address several of the suggestions that we were talking about—of giving that doctor that requirement to do more follow-up, more integration, and such, so that people are. . . have a more continuous circle of care. The way that it looks on paper looks very good. I’m excited about that change. I’m nervous about its rollout, and how it happens, because if there isn’t a lot of local participation in it, then how do we know how it’s going to rollout? Is it going to roll out without any transition model? But what it looks like, and what it’s supposed to be doing is moving towards some of those positive changes. [Moderator: Are you concerned about it in hospitals?] I’m concerned about it, because the planning comes from hospitals. So, the hospital, itself, is supposed to be the planning entity for the local, and Caroline doesn’t have a hospital, so we’re lumped into another location. So, that’s where my concern lies with the local, because the planning it’s happening on behalf, of as part of the rollout, but without that hospital is it truly the representation of what is needed locally? (Caroline)
Technology: Telemedicine innovations (1 group)

Those in Kent were optimistic about the effective use of telemedicine:

*I mean, sure, it’s not either/or. But I think there’s a lot of supplementary things that can be done and will be done in five years from now, eight years from now, in telemedicine.* (Kent)

CHANGES THAT WORRY PEOPLE

The groups tended to be more unified in the changes they worried about:

People losing their insurance or it is insufficient (5 groups)

Loss or inadequacy of health insurance in some form was a worry for all five groups.

*I’m just worried at how many more doctors’ appointments and copays I’m going to have to pay until somebody is able to help my family.* (Queen Anne’s)

*Plain and simple, a lot of people [will be] losing their insurance. I should be okay. That doesn’t mean a lot of other people are going to be okay. I’m extremely concerned about that. . . With the Affordable Care Act being changed, or whatever they decide to do with it, seeing how it’s just starting to roll out, and we’re still starting just to see it, what if it is. . . now, it might not be, but what if it is 10 to 20 million people that lose their insurance that just got it, or lose it for some other reason? That is unacceptable in a country living today. It’s unacceptable. So, there’s got to be a way to fix that.* (Caroline)

And I’m worried for my sister. Her husband is a contractor in another county, but with the Obamacare, their health insurance was like $1,000 something a month, which was manageable. It went up – I saw the bill – I have a picture of the bill – $10,000 a month. . . . So, they have no health insurance, and they paid the penalty, and they pay privately. And I don’t know what the new one is going to do, but if the first one was supposed to make it better, there’s going to have to be some serious change, and I’m just worried for them. My niece has Down’s syndrome, and she has four other children that need health insurance. (Caroline)

*Show of hands that people have concerns about what will happen [after changes in the Affordable Care Act]: 6 of 9 participants* (Caroline)

*More concern to me is that a lot of our people that are addicted right now are getting the Medicaid assistance through Obamacare.* (Caroline)

*Now, my health insurance is doubled from what it was prior since Obamacare, and I have private insurance through my company. So, I’m on both ends of that, because I fight for the addict, and I want them to have the coverage.* (Dorchester)

*But if you’re going to have an insurance policy or an insurance premium, whether it’s an existing one or the new one that they’re working on, whatever they have, the person, the individual person has to pay, has to be something that’s logical. A friend of mine whose husband had a Ewing’s sarcoma for about two years and as bad as that is, she never met the deductible. She constantly was out of pocket. She’s in bankruptcy.* (Dorchester)
The long-term status of Medicare was a worry for some participants:

_I think at our age we’ve gone on Medicare now, and you hear rumblings about the Medicare Trust Fund running out of money soon. And I guess we’re concerned about what is the transition if Medicare does pull out? How do retired folks then deal with paying for their medical care? (Queen Anne’s)_

_I’m just concerned about the cost of insurance. In my case, Medicare serves as supplemental insurance I’m thinking of because it goes up and up and up and up. And I worry that one day I won’t be able to afford it . . . I’m sure every senior worries about it, too, unless they’re part of the two percent who are extremely wealthy. (Dorchester)_

Reductions in Medicaid were worrisome:

_Well, that scares me as well because for me, I pay for my insurance for myself through my job. But my youngest two, they’re covered by Medicaid. And my youngest one, his medicine alone, one medicine, a little eye drops like this for 30 days, if I didn’t have insurance for him through Medicaid, it would be $300. I can’t afford his medical bills. I always worry every single year, and it’s coming up when I recertify. I’m like holding my breath until I get a letter saying, “. . . You’re still able to have coverage for him.” Every year, I’m like, okay, because my daughter, cool, because she doesn’t have any issues. She’s like me, she doesn’t really get sick. But for him, I’m like seriously holding my breath every year, like I hope they never say I’m not. . . I’m denied for him because I don’t know what I’m going to do, honestly. I make okay money but it’s like I cannot afford $300 meds every month. (Talbot)_

**Enough care for future needs of subpopulations (4 groups)**

Participants in Queen Anne’s, Caroline, Dorchester and Talbot expressed worries about the care of certain populations:

_And I’m thinking again, in particular, about the younger people, the kids, the woman that’s pregnant and worried where is she going to deliver. And all these are still part of my thoughts about the hospital and the community. (Kent)_

Participants in these four counties were particularly worried about the growing number of seniors and the resulting increases in health challenges:

_Like I understand like we’re getting old, and we would like to have people around to help everything we need for when we’re becoming sick, and stuff like that. . . (Queen Anne’s)_

_Dorchester County is on a par, I think, with Baltimore City as far as income and a lot of health risk. We also are a county that has, if not the highest rate of senior citizens, certainly one of them, which means lower income for lots of people so they’re eating lots of carbs and not necessarily healthy foods. So, they’re getting fatter, obesity, sedentary lifestyle, et cetera. So, we’re into heart attacks and strokes. (Dorchester)_

Worries about the health and well-being of young adults were described in the Talbot group:

_And yes, it’s nice that kids can stay on parents’ health insurance until they’re 26, except parents have to pay thousands of dollars a month to be able to keep them on, which I don’t know about_
most young adult parents, but mine didn’t pay for their own insurance. They didn’t pay rent, they couldn’t provide that income to cover that. And we’re living in a different world with our young people today. They’re not, you know, they’re not making a living wage as early as they used to. So, I definitely worry about the young adults, too, that by the grace of God, the young kids have been covered and I think will continue to be covered. But it’s those young adults that . . . and then the elderly that get cut off. (Talbot)

Losing services and jobs in health care (including patient navigators) (3 groups)

Participants in Caroline, Dorchester and Talbot were worried about losing services and losing health care jobs:

“When Obamacare came into play, I lost my job as a medical billing auditor, because they didn’t have the funds anymore, because the way that, I guess, the system works, somebody has to lose. . . So, it was us in the billing departments for the hospitals. I worked for Medicare, Medicaid, Blue Cross, United Health Care, all the big companies. So, I was at the top of the realm and fell. So, I’m also worried that if it continues, or if it picks up in the same way, and we add more people onto Medicaid, that that’s going to be the spiral again. (Caroline)

My concern would be here in Cambridge I’d hate to see us lose our emergency capability. I don’t know what that 20-minute drive up there means in terms of lives, but at my age . . . it is nice to have emergency service. (Dorchester)

Now, my health insurance is doubled from what it was prior [to] Obamacare, and I have private insurance through my company. So, I’m on both ends of that, because I fight for the addict, and I want them to have the coverage to get what they need as far as medical treatment, but yet, I’m on the other hand, because I’m a worker. (Caroline)

So, if there are some changes in the Affordable Care Act and people start to lose their coverage, we’re right there to pick them up. So, it’s a good thing and a bad thing. It’s showing what works and what doesn’t work for the system. You speak to hopefully lower rates; wouldn’t that be nice? But unless we start looking at a universal health care type of situation, those insurance companies are still going to battle it out and those rates are still going to . . . there has to be a buy-in in order for rates to drop. That’s just math. So, I’m looking forward to keeping my job. Is that selfish? And helping as many people as I can. (Caroline)

The other thing with Medicaid possibly changing the way it is now, we also worry because lots of us now bill Medicaid instead of working on grants. So, sure we worry about our jobs. You know, I’m pre-retirement age so, you know, all of my eggs are in that basket now. But what’s going to happen to the 55 people that are on my caseload? (Talbot)

Doctors: Leaving or low quality (2 groups)

In the Queen Anne’s and Caroline groups, participants expressed dismay at doctors leaving the area or about the quality of some doctors who stay in the area:

What we had 30 years ago, our local community recruited a young doctor here, and like paid off his student loans, and built him a little shack that he worked out of, and everything. . . . He stayed six-seven years, but then his malpractice insurance was too expensive, and he went back to New York . . . So, kind of like you’re talking insurance for people, like with the doctors, which kind of
ties in. You were talking more writing prescriptions, but like the doctors can’t afford to be in practice. There are a lot of doctors giving up their practice because they can’t afford their malpractice insurance, particularly obstetricians. (Queen Anne’s)

The impacts of it [doctors leaving] are felt probably much more starkly on the Eastern Shore than over in the mainland. (Queen Anne’s)

And they probably can’t charge as much, and don’t have as much patients here to cover that. So, that may be a major thing that’s keeping them from coming here or staying here. (Queen Anne’s)

Caroline County is a rural place, so our community health provider has accessed the available HRSA [Health Resources and Services Administration] opportunities to get doctors’ loans paid off. But what that means is they don’t stay. They’re brand new. They’re green. They haven’t had all of the extensive experience, and they stay for a couple of years after you develop your relationship, and they’re gone. The intention is keeping them here, wanting them to stay once they have their money paid off, ... They should stay for two years. That’s it. The two years, and they can have $50,000 paid off, and that’s what they do. So, two years, and they’re gone. ... One of the things we talked about was they need to be able to stay and finding ways to do that. (Caroline)

Some participants were blunt about the quality of some doctors:

We just do not have the resources, ...we don’t have good doctors like they said that even stay. We get these hand-me-downs. I always said it’s the rejects from across the bridge, that come over here, and they have no clue. They haven’t lived here. They don’t know here. (Caroline)

Economic impact of health care changes: Could be negative (1 group)

Participants in Kent expressed worries that the lack of or closing of facilities and services could adversely affect the local economy. They thought that a hospital and mental health services located nearby were important.

We want to have inpatient service. Take the college, take Heron Point [a retirement community]. You know, economically, people don’t go to nursing homes unless there’s a full-service hospital nearby. For the college kids, there’s probably a high level of usage, I don’t know if the hospital. ... the one thing that’s missing from here that’s needed is mental health care, and that’s not here at all. ... I think it’s either in Cambridge or in Dorchester. ... it would be an hour and half to drive for me. (Kent)

When one participant said he thought college students “are too healthy a cohort” to need a hospital, another said, “But it’s important to the parents who fund the students coming here to have health care here.”

There was also a discussion of a dilemma of losing patients then losing services then possibly losing businesses, families, and the local college.

Well, but this is a chicken and egg problem that we just touched on. The loss of inpatient will lead to thinning out of the facility here, has a knock-on effect to businesses and families coming in, okay? So that we have not addressed the economic issue here at all. It hasn’t been part of the topic. (Kent)
We have problems of the medical [services] and problems with the school . . . that have real economic issues. And this would be a very severe economic issue were it [hospital] to fall through. (Kent)

**QUESTION 3: (GROUP ACTIVITY) CHOOSE A TYPE OF HEALTH SERVICE IMPORTANT TO YOU AND YOUR FAMILY, DESCRIBE THE FEATURES YOU WANT TO SEE**

This part of the focus group process asked participants to suggest and describe examples of services that would be helpful. To begin, the moderator described the role of the Maryland Health Care Commission in planning health services in Maryland and providing information to consumers. She asked the group to imagine that the commission had asked them for advice to help design better health services for county residents.

She divided each group into two or three teams and asked each team to choose and discuss one health service that was important to them and their families. She gave examples such as seeing the family doctor or a specialist, going to the emergency room, or being a hospital patient. They could build on an example they had discussed earlier or choose something new.

The teams had about 10 minutes to consider the services that were important to them and features they would like to see. They could describe a type of doctor or dentist or other health professional, the location, how long the wait was for an appointment. Features might involve technology or the need to recruit doctors and other professionals. See Appendix D for the Activity Worksheet the groups used for this exercise.

Each group reported on their ideas for services and important features. The services were not intended to be the most important services needed in the Mid-Shore region, but should be considered examples of what is needed. Service ideas ranged from specific details to general concepts.

**Standalone mental health facilities (Queen Anne’s)**

Citing a “void for acute mental health care on the Shore,” this team suggested there be at least two standalone mental health facilities, staffed by physician assistants and nurse practitioners, with psychiatrists available by telemedicine. The facilities would each have 10-20 beds with a couple of beds allocated for the “mandatory 72-hour hold” and others for extended care.

**Improved post-motor vehicle accident treatment and coordination of insurance issues (Queen Anne’s)**

The basic idea is to stop medical bills from going to collection agencies while legal issues related to the car accident are getting resolved and to help provide money for treatment while the legal issues continue. The team wants coordination for both the insurance and health care services.

**More accessible and holistic mental health services (Caroline)**

The team said there should be more accessibility, more psychiatrists and other therapies. This team also suggested a more holistic approach to addressing mental health.
Substance abuse, mental health and behavioral health services: More resources for outpatient and inpatient care (Caroline)

The team spoke about the need for substance abuse and mental and behavioral health services. “We need more resources for outpatient and inpatient care for mental health and behavioral health.”

Primary care supports (Caroline)

The team spoke about the importance of adequate office support to “let doctors be doctors” and spend time with patients. They saw doctors doing tasks that other office staff could do. Participants recommended giving doctors adequate time, payment and residency training. They also mentioned the need to provide transportation to enable people to access care.

Improved cost and availability of services (Dorchester)

The team asked, “What is the greatest need?” and said, “Some sort of minimum care or availability.”

Improved and enhanced ambulance services (Dorchester)

Suggestions included equipping ambulances to enable treatment right away when possible. Also, ambulances should be located near population centers. In terms of emergency calls, they pointed out that on parts of the Mid-Shore, like Hooper’s Island, 911 calls go to the Western Shore (that is, across the Chesapeake Bay).

Outpatient infusion center (Kent)

The team’s message was to maintain this existing center with high-quality staff, services and pharmacists.

Ideas for improved access and lowered costs (Kent)

Ideas included:

- Nurse specialists by phone
- Medical specialists by telemedicine
- A network of clinics located where there are no hospitals (they mentioned a comparable program in rural Connecticut)
- Nurse/health worker home visits

A small “destination” hospital (Kent)

The team said a small hospital should be located by homes and nursing homes. It would include infection control, palliative care, and oncology and would enable isolation for epidemics. The hospital could have a medical specialty focus and be a “destination hospital” that would draw people to come.
Medical transportation system (Talbot)

This idea is for improved transportation for appointments, possibly using the bus system. The bus would come to your home; you would call the day before. There would be education on how to use the system, and the support of public officials would be sought.

Improved specialty care communication, including with other parts of the health care system (Talbot)

This team suggested ways to improve communications between specialists and with other facets of health care, such as vendors and laboratories. It would include a communications system or network to share results and other information and would be accessible to all doctors treating the same patient so they can coordinate the care.

PARTICIPANT RECOMMENDATIONS AND SUGGESTIONS FOR THE MARYLAND HEALTH CARE COMMISSION

The groups were vocal about good elements of care as well as features that did not work well, and they offered a wide array of ideas. They offered their views when the focus group moderator asked for suggestions related to recent visits, for service ideas and for recommendations to give the commission. Ideas were also offered by participants throughout each 90-minute section. Their recommendations and suggestions are combined here. They are grouped by theme and the order is based on the numbers of groups mentioning that theme. (See Table 7.)

Insurance: Make it affordable, expand it, subsidize rural areas (5 groups)

All five groups had suggestions about insurance coverage and costs. Affordable insurance and health care was a common idea:

I would like for the Maryland [Health Care] Commission to work with the insurance commissions to ensure that everyone has access to reasonable health care insurance at a cost that is affordable. Right now, insurance premiums are exorbitant for many many people, and the alternative to that is that they don’t have any insurance. So, I think that we need to make insurance accessible and affordable. (Queen Anne’s)

Expanding insurance coverage was also suggested. Examples include medical record reviews and alternative therapies for pain:

I think the other thing would be expanding on what insurance pays for. I made an appointment today in Washington, DC, for my son for a second opinion on something because I have to make an appointment, and go physically for him to get paid. [The doctor] cannot get paid to review everything that’s been done from Baltimore to Rockville to Salisbury, and all the way around, and give that opinion unless I take my son out of school for the day for the two-hour drive to take him over, and be seen, just for him to review the files. He’s not even going to do anything other than review the file. . . . He should be able to be paid to make that review as an appointment, even if he did telehealth to talk with me about it, but I mean I have to take him [my son] basically to do nothing else, other than look at the files of another doctor and give a second opinion. (Caroline)

Insurance needs to also cover some of those alternative therapies, and alternative choices [for pain] as opposed to just paying for that prescription. (Caroline)
Participants suggested that insurance coverage be “logical” as well as predictable:

...if you’re going to have an insurance policy or an insurance premium, whether it’s an existing one or the new one that they’re working on, whatever they have, the person, the individual person has to pay, has to be something that’s logical. A friend of mine whose husband had a Ewing sarcoma for about two years and as bad as that is, she never met the deductible. She constantly was out of pocket. She’s in bankruptcy. (Dorchester)

My suggestion is that these auxiliary services [emergency transportation] are really controlled in a better way so that the patient has some idea [of costs]. (Kent)

They also said care should precede payment for complex post-accident issues:

Nobody [insurance companies] wants to pay up front. So, we realize there’s legal issues involved. But it seems that there should be a priority of care over billing . . . some of these medical expenses should be able to be worked out after that fact when that happens anyway. (Queen Anne’s)

They should not be sending medical bills to collections for accidents and things like that when there’s still litigation and negotiations pending. They should look for a way to be able to work out insurance coverage, and who is ultimately responsible for the medical bills, and not make the patient, somehow, miraculously come up with lots of money for treatment when there should be, ultimately, someone that’s liable, an insurance company that ends up on the hook then. (Queen Anne’s)

There were also suggestions for what government should do, including subsidizing care, particularly in rural areas:

Have our insurances to compete across state lines to reduce the cost. (Dorchester)

I’d like the government to stop squabbling over the health insurance or health protection and come to a good conclusion. (Dorchester)

[I recommend] picking up Medicare costs after the federal government drops them. . . . [if Medicare and Medicaid go away, then it should be a state responsibility]. (Kent)

If there was some sort of fund that where people who could not afford secondary insurance could get it because they’re going home sick . . . they can’t care for themselves. (Talbot)

If rural health care facilities have financial issues because they’re smaller for whatever reasons, and that’s one of the reasons we hear, then the states should be willing to subsidize the services in rural areas. So, large hospitals maybe have the volume, hospitals here don’t have the volume. Or if you want to pay for a specialist, it costs money to pay for a specialist that maybe a bigger hospital can support and a smaller hospital can’t. So, the state should, to ensure good healthcare throughout the state, should provide a financial basis for rural healthcare. (Kent)
Doctors: Support them, recruit them (4 groups)

Participants from the Queen Anne’s, Caroline, Dorchester and Talbot groups thought there should be more support for the work of doctors, whether it was support for existing doctors or for finding and retaining good doctors:

*We talked about a broad amount of things, but they all really kind of fall under “let doctors be doctors.” If they’re going to be a primary care doctor, let them coordinate the services. Let them have the time and the appropriate payment to be the doctors. And it’s not happening.* (Caroline)

Lessening the burden of paperwork, rules and regulations was mentioned:

*I would tell the Maryland Health [Care] Commission to stop scaring doctors to the point where they’re afraid to give their patients the quality and type of treatment they need.* (Queen Anne's)

*I would like them to be capable of spending more time. . . they have guidelines from the insurance companies that that’s the max time [10-12 min] they’re allotted. I guess I was just looking for more of a kind conversation.* (Talbot)

One area of support that was discussed related to computerized records, providing help and having a system:

*My primary care doctor, who hates computers, is required to do electronic medical records. And I really think she needs like a right-hand person to do whatever the garbage is, and then she can be with the patient, because when I go see her I bring hard copies to her of like all my EMGs [electromyograms], or this doctor I saw, and get them to scan it at the front desk, and hand her the copies, so she doesn’t have to go searching through the computer.* (Caroline)

*Maybe a communication system. . . .network. . . we were kind of thinking like the specialists. . . well, our primary should have some way of communicating with the specialists as far as referral systems, sharing results. I shouldn’t have to chase my results.* (Talbot)

Another area of support was assistance with prescriptions:

*And she [the primary care doctor] has to do so much that somebody else . . . She doesn’t need to be calling in a prescription. The nurse could, that kind of thing.* (Caroline)

Others said there should be more support staff per provider:

*More staff per provider in the office, the medical offices. It’s just not enough people. Roles aren’t matching with the productivity of the medical practice at all. It’s more work and more possible medical mistakes because of the confusion of how staff are placed and how many staff are placed in offices per provider, per patient . . . It needs the staff onsite to provide care. It needs to be equivalent with the providers in the office and the patients that are being seen.* (Caroline)

Participants mentioned doctor training and retention:

*The second thing that we talked about was training and residencies. Caroline County is a rural place, so our community health provider has accessed the available HRSA [Health Resources and Services Administration] opportunities to get doctors’ loans paid off. But what that means is they don’t stay. They’re brand new. They’re green. They haven’t had all of the extensive experience, and they stay for a couple of years after you develop your relationship, and they’re gone. So,*
figuring out a way to bring in some more of those trainings, or send out some of those doctors to other residencies, because medical care is... it’s changing so fast, and green and untrained doctors are not able to access it for the best for the rural people. (Caroline)

The groups had ideas about recruitment:

I would suggest that somebody recruit these people, go to like third-year med students, actually second-year med students, before they’re like finding a place to live, and psychiatry programs. I went and spoke at a psychiatry program in Baltimore, second-year residents, so they can start thinking about what they want to do and educate them about places that are available in Caroline County. (Caroline)

Get a recruiter and give the links—places to shop, visit, the beach. (Caroline note)

Keep spouse happy and doctor will stay. (Caroline note)

I think we need to do better at getting quality doctors here. But then also having a facility to provide quality handling of their patients. (Dorchester)

Take action on the high rate of turnover. (Talbot note)

Health care workforce: Enhance, improve the environment, train (4 groups)

Participants in Queen Anne’s, Caroline, Dorchester and Kent suggested various improvements for the health care workforce.

For example, there were suggestions to make more use of various types of nonphysical health care providers:

Referring to pharmacists, because there’s so many things and medications that a pharmacist can help with that even the doctor really doesn’t have quite the same level of knowledge as a pharmacist. So, I think it would be good if they would refer more people to pharmacists. (Dorchester)

Trying to incorporate the use of case managers. (Caroline)

My most recent experience with the health care system was last week when a nurse came to our home to give my wife an eight-hour infusion, which happens every three weeks. And it’s a very good experience because, A) she doesn’t have to go sit in a hospital for eight hours. And since she has immune compromise, being in a hospital is the last place she wants to be. And this nurse is a very good nurse. She doesn’t just give the infusion, she takes her vitals, she talks to her about her diabetes, she encourages her on her exercise, she deals with the whole person. And what’s remarkable about it is not only is it a positive experience, but it costs Medicare a third of what it would cost if she had the same service in a hospital. And it’s, to me, a very powerful example of how the service model makes a huge difference... And many of the chronic disease problems that we have as the dominant problem in the country at the moment need behavior changes. And behavior change works much better when you have regular contact with a caregiver even if it’s a nurse or a health worker. (Kent)

Nurse- or health worker-based in-home care... I think it fits many different needs... But it’s particularly useful for chronic conditions or for prenatal, right?... Well, it’s just that there aren’t... there’s no OBs [obstetrics] locally, and you have to drive an hour. Wouldn’t it be much better if a nurse came and saw you every couple weeks or every month and did the same thing the OB would...
do, right? And the same is true if you’re a diabetic or if you have substance abuse problems and you need to... or you need to change your diet, right? All of those things are actually more effectively done by a person with some emotional skills than by a busy professional who’s got five minutes for you, right? (Kent)

Service ideas under Question 3 from Kent County participants included using nurse specialists by phone and having nurses or health workers make home visits.

Paying for key functions, like ambulance staff, was a suggestion:

We don’t have volunteer police. Why do we have all these volunteer ambulance drivers?... Ambulances should be staffed so that you don’t have to send one from Cambridge to Hooper’s Island and then back and then to Easton or back to PRMC [Peninsula Regional Medical Center] when the hospital’s on code red. (Dorchester)

The negative consequences of job cuts made a few years before were very clear:

My one daughter is an RN [registered nurse] at the ER [emergency room] there now [after all LPNs, [licensed practical nurses] were let go], and it’s horrible for the people that work there. They’re short-handed. They don’t have enough help. There are 12-hour shifts turning into 15- and 16-hour shifts. They’re not getting a chance to pee, to eat, to anything. And the quality of the care here is worse than it was 10 years ago. (Queen Anne’s)

Participants urged a show of kindness by health professionals, which suggests a need for training:

I was going to say my recent experience in emergency room, I would say that all the staff should be aware that when you’re dealing with the public, we should try and be kind and not irritable because when you arrive in emergency room and you think you or the friend you’re with is really ill and they’re short-tempered and dismissive, it makes you feel a lot worse. And our experience... I think it was the nurse who... the intake nurse who was kind of... she was just kind of unpleasant and it made a very bad impression. And when you’re worried, something like that makes you even more concerned and stressed out... And if the person you’re dealing with is pleasant, if they could just make an effort to be civil and pleasant, it makes all the difference in the world, it really does. (Dorchester)

Improve bedside manner and be personal. (Kent note)

Transportation: improve for both regular and emergency care (4 groups)

Groups in Caroline, Dorchester, Kent and Talbot offered a variety of suggestions for improving transportation for medical appointments and in emergency situations.

Some recommendations related to solutions for regular transportation needs for health care:

Have more accessible services in Caroline County that not only have the providers, but are transportation accessible. (Caroline)

Say you’re just sick but you don’t need an ambulance, there is no public transportation. So, the only way... and if you’re elderly, and if it’s at night, and elderly people have difficulty driving at night... you’re really, really in a problem situation. (Kent)
When responding to Question 3, Talbot participants suggested a system of medical transportation.

A number of suggestions were made related to emergency transportation, particularly via ambulances, including providing more equipment and locating them near “population centers.”

I’d [tell] the Commission to take into consideration the unique transportation challenges we have on the Eastern Shore, particularly as it relates to emergent and critical care. Route 50 and the bridge can be a bottleneck at times. And if you have an emergent or critical case, you can’t get to where you need to go. (Queen Anne’s)

Have well-equipped ambulances that can respond to emergencies . . . they should have the equipment on board so they can begin treating people right away for things like stroke and heart attacks. (Dorchester)

And then also, because our population is very rural and very dispersed, that they need to have ambulances . . . stationed in places where they can get to population centers easily and to have the equipment and staff readily available to do that in order to respond to emergencies. (Dorchester)

So, some publicly-supported arrangement so there were more of them [ambulances] and more flexibility in that because . . . that’ll become even more acute when the hospital goes away, right? (Kent)

One service idea fleshed out by the Dorchester group was improved and enhanced ambulance services.

**Empathy for those in the Mid-Shore region: Show empathy, continue to engage (4 groups)**

Participants in Queen Anne’s, Caroline, Kent and Talbot wanted the commission to try to understand the Mid-Shore and those who live there:

I think you can’t just look at the population of the Eastern Shore, and then put that into a formula to get the number of facilities and the services, as you can where you don’t have that type of [transportation] challenge. (Queen Anne’s)

Put yourself in our shoes, and just think about all the things that we have to deal with as far as health care for our families and how much it costs. (Talbot)

They said the commission should remember what the word “rural” means:

I don’t know who the guy was [at a public meeting]. He was [there] when they asked for questions from the floor. And he says, “You’ve forgotten the word ‘rural.’ All your discussions, you’ve forgotten the word rural.” And the rural characteristics. And the rural characteristics are poorer, sicker, distant, older. (Kent)

Participants said the commission should keep listening to and talking with people on the Mid-Shore:

I just wanted to say that I hope that everything we say in here, and everything we didn’t say, I hope they pay attention. (Queen Anne’s)

Keep these meetings going. This was very, very informative. (Caroline)

I am thankful that someone is interested in hearing what we have to say, and maybe it will spur something. (Caroline)
We need more of these talks. We need to get more people from the community involved. (Caroline)

I think that the dialogue still has to keep going. . . And we have to pursue, we have to persist, we have to enlist, we have to resist. . . we can’t just sit back and wait for it to happen. (Talbot)

The takeaway is that there is a lot of energy right now around solving problems in health care and it’s a good time to put it [to] good use to see if we can find some solutions. (Caroline)

Several participants essentially said, “Listen to us this time.” Some participants described in detail previous “listening sessions” held a few years ago. They were “sold a bill.” Services and jobs were lost. They spoke of longstanding anger in the community and a sense of betrayal from this experience:

Many people from the community were very active when they had these listening sessions, and I personally knew somebody on the board, who was a good friend, and they sold us this bill that all these wonderful things were happening, and they didn’t. (Queen Anne’s)

[It call it] the ugly time because people felt betrayed. When you had lived here, and you had all of these services. (Queen Anne’s)

They came in, and they got rid of all the LPNs [licensed practical nurses], and you had to be an RN [registered nurse], and people that had worked there their whole lives basically were let go, because the university standards were that. . . and no one knew any of that. So, you had people losing their jobs in the community, and the services just aren’t there anymore. (Queen Anne’s)

The people that came to the listening sessions and shared their ideas, and one of them was even an ER [emergency room] doc there at the sessions that was very active, and came to these sessions, and asked specific questions about, “What are we getting? What are we losing?” “Oh, you’re not losing anything. We’re enhancing services. This is going to be wonderful for your community. . .” (Queen Anne’s)

And they had several of these listening sessions in each community around the counties in Kent and Queen Anne’s. And I attended the one in Centreville’s Firehouse, and there was probably 75-80 people from the community there . . . And that was just that one session, and they had them in each town. And we were told this. And then some of the people in the community that worked at the hospital were saying, “Well, that’s not what we’re hearing. So, then you started asking more questions. You would go to this first. . . just like here [the focus groups]; it’s a series. (Queen Anne’s)

So, you’d go to this one, and then you’d go to another one, and they’re still telling you, “Oh, no. We’re bringing all these services and specialists in.” And it never happened. (Queen Anne’s)

So, when I was asking people to come here [the Queen Anne’s focus group]? “Hell no. They don’t care what I think. They just do what they please. They asked my opinion, and they don’t care.” (Queen Anne’s)

We’ve had these conversations for years, and the Shore has posted higher percentages of needs for years and years, but not the actual numbers. Numbers are higher on the Western Shore, but the percentage of these needs have always been higher on the Shore, and here we are having the same conversation again. So, I’d like to be hopeful about it, but I take away disappointment, because we’ve talked about this a long time. . . . I’ve been in the field 15 years. We’re still talking about it. Nothing changed. (Caroline)
Technology: Use to improve coordination, care (4 groups)

Participants in the Caroline, Dorchester, Kent and Talbot groups made a number of suggestions regarding the effective use of technology.

One suggestion was an information system that worked between doctors’ offices:

*Maybe a communication system... network... we were kind of thinking like the specialists... well, our primary [care provider] should have some way of communicating with the specialists as far as referral systems, sharing results. I shouldn’t have to chase my results.* (Talbot)

A common safety check—asking one’s name and other information—had not been explained and led to frustration:

*I felt that certainly on the basis of my recent emergency room experience, that the information on patients should be computerized so that you don’t have the experience of being asked three or four different times by different people what your name is or your age or your address or that. They should just be able to hit a key on the computer and have all that information. But I think it would save money, and it would save time.* (Dorchester)

Participants said there should be help for creating visit records:

*About the technology... the doctor should be looking at you, and somebody else should be back there typing.* (Talbot)

*One suggestion that I thought of when we was talking, I’ve had the same experience watching doctors watch the screen and half talk to me. And I feel like it’s not their fault, it’s the nature of the... but voice recognition software really would play a big role for that. If they could just talk to the screen, then they could keep their eye on you... or even just as you’re answering the questions, your answers are recorded. I mean, technology can help.* (Talbot)

They indicated that telemedicine could be very helpful, including enabling contact with more specialists and reaching certain populations:

*How about a word about telemedicine? That’s something that I think is really helpful, could be helpful, to a community like this, and an investment that would make sense... I don’t know a lot about it, but as I understand it, you have a much lower level person and that person is connected with, say, Johns Hopkins or somewhere else by all the technology we have today. And I would say that is something that I would hope to see more of... [Moderator: So, bringing the specialists, even though they’re not physically here?] Precisely, precisely. I mean, sure, it’s not either/or. But I think there’s a lot of supplementary things that can be done and will be done in five years from now, eight years from now, in telemedicine.* (Kent)

*I think there is a place for telehealth, but you have to find that medium. We use it for deaf services, for interpreting in the mental health industry, and it’s working wonderfully, and it is helping the deaf consumers on the Eastern Shore who need an interpreter for their mental health services. They’re getting that interpreting service through telehealth.* (Caroline)
Coordination/case management/patient navigation: Help individuals get what they need (3 groups)

Participants in Queen Anne’s, Caroline and Talbot had suggestions for how better coordination and patient navigation would improve care:

Someone to advocate for me, or my family member. As a nurse, I know I’m essentially my dad’s case manager. He doesn’t understand the medical system. He would have been so far gone by now if he didn’t have me. I don’t feel like I should have to be a nurse at home. I feel like there should be someone in the health care system that’s following people around to make sure they’re getting the resources that they need, and this provider is talking to this provider, especially when you’re traveling three hours away for here, there, and everywhere, just that whole improvement on follow-up care, and continuity of care. (Caroline)

I would certainly say that if insurance companies could figure out a way, especially through primary offices, to have some type of outpatient educator or patient advocate...that they can supply... But then they need somewhere, some resource, for patient advocacy and patient navigation to make sure that people are following up, that they do understand the testing that they need to have done or explaining procedures and such that they may not necessarily have time to do. (Talbot)

(Patient navigation) would be a good office in the health departments. (Talbot)

In the case of care following a car accident, there was an expressed need for coordination of both care and insurance coverage. After a detailed discussion of this topic in Queen Anne’s, the moderator summarized:

So, we have you want to stop these [medical] bills from going to collection while this is going on with legal issues, and help provide money for treatment while the legal issues are going on, and you said coordinating both the insurance and health care services? Answer: Yeah. (Queen Anne’s)

Accountability: Monitor, oversee programs, enforce the rules (3 groups)

A few participants in Caroline, Dorchester and Talbot wanted there to be more accountability and oversight.

A Caroline participant mentioned enforcement of the Parity Act so there would be parity of payments for mental health providers. Another Caroline participant mentioned the Maryland all-payer model and the need for hospitals to implement it so it would lead to better follow-up care and care integration.

There were other comments indicating participants’ concerns about accountability, questioning whether public funds were being used as intended:

I am going to be blunt... These block grants that are given to rural counties, they need to be monitored. They need to be held accountable when money is given from the government, it needs to be monitored by the government... The example is when money is given they need to be held accountable. Are there services being provided? Are they being provided well? Are they following the original grant of when they received the money? Why they even asked for the money? I feel as though that is not being followed... That’s just my personal opinion, and people are applying for grants for money purposes, and for show without... that’s why we have these loopholes. It
may not be that the money is not actually there, but is it being monitored to see that it’s going where it’s supposed to go? I feel there’s a loophole somewhere. (Caroline)

More auditing. (Caroline)

[There’s] no auditing, no accountability, you know, you’re just renewing these grants. A lot of these grants are just renewable, so, let’s apply – we got it for five years, and let’s keep on going. Unfortunately, accountability has to come into play somewhere. (Caroline)

I would like some overview of nursing homes so that the people in there are being taken care of for their benefit and not for the benefit of stockholders. (Dorchester)

Loosen up those purse strings. . . Put money to programs that work. (Talbot)

Specialists: Need more, provide in innovative ways (2 groups)

The topic of specialists was a recurring theme; participants in Caroline and Kent had several suggestions:

More specialists on the Shore. . . closer and more of them. (Caroline)

[Provide] greater access to specialists, and closer. (Caroline)

We need more doctors, primary care and specialists, behavioral health, substance use, more services across the broad spectrum. (Caroline)

All hands about needing dental services: 9 of 9 (Caroline)

All hands about needing more specialists: 9 of 9 (Caroline)

The groups had suggestions for how local communities could access specialists:

I think it’s disappointing that more professionals, MDs particularly, don’t come here. . . There are not enough people. So, that’s why I thought the idea of having people come occasionally. . . rather than just moving in and setting up a practice. (Kent)

I was going to say for location my suggestion was actually satellite and telecom offices because several of the specialists I’ve been to are not here as far as an office, but they collaborate with another doctor, and come once a month for that particular specialty or something. (Caroline)

Either we need better telemedical access to specialists so you don’t have to drive, and some people can’t drive, or we need a good local transport system, right? (Kent)

Mental, behavioral, substance use care: Make it accessible, affordable (2 groups)

Between the Queen Anne’s and Caroline groups there were three service ideas for mental and behavioral in- and outpatient care in response to Question 3.

Several other suggestions were made by participants in these groups:

There used to be services in Caroline County, and more specifically they need to take insurance, or have like some kind of sliding scale, and not be just pay-for-service. . . To have mental health services. (Caroline)
More of these [mental health] services, so more accessibility. . . We definitely need more psychiatrists. (Caroline)

We need [mental health] providers in the schools, as well, [where] a lot of anxieties, depressions, those types of things they start. . . We have providers, but we need more providers. (Caroline)

Distance. . . having them accessible to and across the board, so we could get rid of this wait list problem, because having to follow up for care, and a lot of mental health services you need routine follow-up, multiple times a month, multiple times a week. So, to be driving hours is problematic for most people in a rural area. (Caroline)

To allow these complementary therapies to be included with insurances, even other things like acupuncture, massage, exercise, ways to have that included as part of your preventative health care, or management for mental health problems, because it’s proven in research that exercise can help decrease the risk for anxiety and depression. (Caroline)

We need more resources and services for outpatient and inpatient care for mental health, behavioral health. (Caroline)

Well, we need . . . parity of payment. So, specialty providers will be able to financially sustain serving the Caroline County substance abuse, mental health and behavioral health services that we need. . . the Parity Act is not being enforced for substance abuse services. (Caroline)

The Caroline group offered solutions to the opioid problem:

Require proof of effort before prescription. We are still in the midst of the opiate crisis that we have, and pushing, pushing, pushing pills. I have had a hard time even convincing my doctor to refuse pills. “I’ll call it in for you, anyway, just in case you need it.” . . . And I’m not talking about one doctor, multiple doctors. I think there should be a requirement of proof of effort for behavioral changes or integrated referrals to integrated health before prescriptions . . . Or how the doctor has even tried other things first, has made referrals . . . physical therapy instead of meds . . . complementary care . . . or given suggestions of personal education opportunities prior to prescriptions. (Caroline)

Facilities and services: Keep, add (2 groups)

People in Caroline and Kent had several suggestions for facilities and services. People in Caroline said there should be more doctors and services, especially for seniors:

With more people being insured, the doctor shortages, we need more doctors out there. And also, just back on the seniors, the senior citizens, I think, need more services, too, because there’s a lot of people that can’t help. . . families that are working that can help support them through what they need. (Caroline)

Palliative care is needed:

It’s just so distressing to think that so much money is spent in the very last months of life on Medicare patients who, if you ask them before they got sick, would never have ever wanted such a thing. And so, we need a palliative care unit where there’s good counseling . . . right now if you go to hospice, you have to forego all treatment even though in experimental situations where patients don’t have to give up their chemotherapy or their radiation, but they get hospice services, they use less, they give it up better, they have happier outcomes. . . And I think that would be a
good role for these inpatient beds, with the whole range of services. But counseling, being able to talk about what do you really want. (Kent)

People in Kent were especially concerned about losing their local hospital:

All hands: keep my hospital: 10 for 10 participants (Kent)

But I think there’s still a place for a stepped-down hospital and I’m happy that there’s so much support for that. And that’s what I’m going to take away. (Kent)

I wish the commission would say, “We’re going to keep the hospital. How are we going to do it?” And I wish that the University of Maryland had that and your idea, make it an area of specialty. . . - if you start with that, I think the hospital would stay open and be successful. (Kent)

Kent participants also contributed several services ideas in the Question 3 discussion, including keeping a high-quality outpatient infusion center, putting a clinic network in a location where there are no nearby hospitals, and having a small focused hospital near homes and nursing homes.

Quality: Make it the priority (2 groups)

Individuals in the Queen Anne’s and Caroline groups had suggestions about quality, especially in terms of making it a priority:

I feel that they need to know above all legal, government and whatever other issues that go on behind the scenes, quality of care needs to come first. (Queen Anne’s)

Less quota and quantity versus more quality for health care. (Caroline)

Decision making: Be clear, ensure diversity (2 groups)

People in the Kent and Talbot groups addressed a need for both clarity and diversity in decision making around health (i.e., decisionmakers need to reflect diverse community members).

But I’m afraid. . . I’m too afraid they will fudge with, “Here are seven, you decide.” . . . But they should be objectively coming up with. . . we’ve listened to everybody, we’ve looked at everything. And these kind of issues we’re talking about, here’s the model . . . It’s supposed to come from them. (Kent)

My concern to them [the commission] is give us clarity. Don’t come throw seven different options and choices. That’s not their job. Their job is to wrestle it to the floor. . . But what I’m worried about is I don’t see them driving toward conclusion. That’s my concern. (Kent)

That we need to make sure that those people who are making decisions about our healthcare, that there is diversity. . . Because right now, we have a bunch of wealthy white men making decisions on health care for this country. (Talbot)

Education: On health, insurance, the health care system (2 groups)

Participants in Dorchester and Talbot had recommendations for education on health topics and on insurance and the health care system:
And that there also needs to be education so that people are more aware of what the symptoms are. I know that women, for example, experience heart attack in very different ways than men do. But I’m not sure I could tell you what those ways are and would recognize it in myself. [Another focus group member] had the experience of having a stroke and not recognized that it happened. And so, she accidentally did the right thing and cured herself... Education about warning signs. (Dorchester)

I would say central access, like he was saying education, but organizing education for the general public around health care and health care systems. To have a place to go to get answers. (Talbot)

I would say find a way to educate on these new health care things. If you can’t educate everyone, put persons in place that can explain a little better. (Talbot)

I would like to see education as far as all of the programs that we’ve talked about. Because I think there’s a lot of misunderstanding about the people that we pay for out in our society. (Talbot)

Drug prices: Control them (2 groups)

Suggestions addressing high drug prices were made by groups in Queen Anne’s and Dorchester:

*Improve access to medications at a cost that people can afford. (Queen Anne’s)*

I would like someone to address the issue of the drug companies. There are drug companies that are price gouging and are a monopoly on (drugs) and they’re jacking prices way up like the Naloxone. . . . that counteracts the effect of drug overdoses. That company has recently raised their prices because now all the states and counties are buying it and stocking their ambulances with it so they’re viewing it as a great opportunity to raise the price. (Dorchester)

Just for a moment on the drug situation, over the years I’ve been trying to figure out myself. Congress can’t do it. If you believe in a capitalist country, which we are so far, you got to be very careful of squashing people who come up with good ideas. The drug companies, if you shortened the time that they had protection, you might call it copyright and paper right, but if you cut back from 10 years and an ability to redo to maybe four years, and then it can go to generic, that’s going to be, in theory, you’re not taking the capitalism away from it. You’re merely saying, “Hey, you got a good idea, but you’re going to have a limited time that we can protect you with it.” And that probably could get through legislative groups by saying you just can’t protect yourself indefinitely. But they’ve got to get a return. You know, it costs millions of dollars to do those developments. In all fairness, there are some costs. And others are gouging, yes. (Dorchester)

New approaches to solutions: Collaborate, partner, think “outside the box” (2 groups)

Caroline and Kent participants had suggestions for how the commission could approach problem solving.

Caroline County participants urged collaboration across the state line, that is, between Maryland and Delaware, especially with respect to emergency care and care for substance use:

*Caroline County borders two-thirds of Delaware, the north end of the county, and the south end of the county for EMS [emergency medical system] services have to be transferred to the nearest hospital, and it is in Delaware. So, we can’t capture data [on] what actually happens, because the majority of people either go seek private pay care there, or you can’t go to something that is close*
by. . . Caroline County has Level 1 opiate services, and there is a Level 2, Level 2.5, 2.7 that is 10 miles away in Delaware, and we have to send people to Baltimore City, to Cumberland to be able to get equivalent services that are right next door to them, which, by the way, they aren’t successful discharging from those services unless family members participate at that distance. But the services that are right next-door are not able – the two states can’t work on some sort of a collaboration between the two? (Caroline)

Figure out . . . that . . . we are not on an island of Maryland, but that the state line actually is there, and people drive through it all the time . . . There’s no coordination across the [Delaware] state line, but Caroline County borders two-thirds of the state. (Caroline)

A Kent participant offered a collaborative way to look at transportation issues:

. . . the government isn’t really [good] at a lot of things. It can spend a lot of money at them, but they aren’t always that good. But some of the most successful things that I was ever involved in involved public/private partnerships. And the one thing you don’t hear in this whole health discussion, you hear transportation’s a tremendous problem. Doesn’t seem likely that the hospitals are going into the bus system. But, you don’t hear anything about public/private partnerships of bringing those two industries together to try to solve some of these problems to their mutual benefits. If I was to speak to the commission, I would say that a look at partnerships, especially public/private partnerships, is probably their only hope to deal with these problems that are outside the medical system but are so impactful on the medical system that they may drive it to its knees financially. (Kent)

The Caroline group also urged the commission to “think outside the box” in terms of coming up with solutions:

The most important recommendation [is] to think outside of the box. It tends to be that fixes are tacked one onto the next of what exists and what was broken already. We’re going to fix it by adding to this piece, or not. And look outside of the box at the problem as a whole. Because adding more substance abuse services is wonderful, but not if there isn’t the rest. It doesn’t help to throw the money at it . . . So, maybe addressing transportation (had) a larger effect. . .

(Caroline)

Discussion/Research Team Perspectives on the Focus Group Findings

The purpose of this section is to identify broad themes that emerged from the focus group findings to assist policymakers, program planners and others to better understand and address the health care needs and priorities of residents from the five Mid-Shore counties. Not only did the findings from the focus groups reflect the perceptions, views and opinions surrounding health care in the Mid-Shore region, they also highlighted issues for state and local assistance. Some issues are outside of the scope of this project but are part of the national debate on how health care is financed, managed and delivered.

In general, focus group participants described needs specific, and often unique, to their rural communities. These discussions reflect the notion that efforts to address such needs must strike a balance between individual county needs and a regional approach. This echoes the recognition in the rural health literature that a “one-size-fits-all” approach to health care policies and reforms is often ineffective despite commonalities across rural areas (Kenny et al., 2013). The possible closure of the
Chestertown Hospital provided the impetus for this study (Shaum, 2016), and participants shared that the needs of rural communities must be supported even, as the Kent group discussed, if their hospitals do not have the volume of patients that large hospitals [in urban areas] do. One participant said, “The state should, to ensure good health care throughout the state, provide a financial basis for rural health care.” As discussed, longstanding negative feelings among residents who felt ignored in previous public discussions impacted our ability to recruit participants. Focus group participants, who recalled prior apparently unheeded “listening session” efforts concerning health care needs, urged the MHCC to pay attention to what the current groups were saying and to continue the conversation. A number of themes voiced by focus group participants pointed to broader state and national challenges that go beyond county issues; we refer to these as “state of health care” issues seen through the rural health perspective.

When reflecting upon “what works well” and “what does not work well” in the Mid-Shore health care system, participants’ comments focused on the challenges residents face when interacting with various aspects of the system. Considering this imbalance between positive and negative comments, it is important to adopt a strength-based approach that leverages existing community resources to address population health needs, as suggested in the 2005 Institute of Medicine (IOM) report’s action plan for quality-focused, rural community health systems (IOM, 2005).

Poor alignment between the health care system and patient-centered health needs is another major theme that emerged from discussions in all five groups. Specific concerns included insurance coverage and affordability issues, the lack of care coordination, access issues for specific populations, and the dichotomous role of technology in facilitating or complicating health service delivery. “Patient-centered care,” defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions,” was proposed by the IOM (2001, p. 6) as one of six specific aims to improve the U. S. health care system. Participants from all five groups called for improvements in various aspects of Mid-Shore health care and provided many examples of situations in which their health care experiences did not meet their needs. From high deductibles and drug prices to disjointed care following car accidents, to impersonal or rude care, to uncoordinated care, to challenges in access to mental and behavioral health services, it is clear that policy, program planning and implementation must adopt a more patient-centered approach to better meet the needs of these rural populations.

Overall, the scarcity of resources in the rural setting was a recurring theme in all group discussions. This phenomenon is well documented in the rural health literature (Ricketts, 2000). Participants in the five Mid-Shore counties noted workforce shortages, particularly in specialty providers, obstetric and emergency care providers, and mental and behavioral health providers as well as shortages in staff to support doctors in general. Lack of emergency and nonemergency transportation services also impacted the accessibility of health care services, and poor-quality care by providers related to workforce recruitment and retention challenges.

When asked to provide recommendations to the MHCC on ways to improve the health care system, participants stressed the importance of continual community engagement. In the words of one Talbot participant, “I think that the dialogue still has to keep going.” This continuity is recommended in the
IOM report on rural health (IOM, 2005). The community participation approach is not without challenges, as detailed in the rural health literature (Kenney, Farmer, Dickson-Swift, & Hyett, 2015), and focus group participants mentioned the need for diversity in decision making. The five groups all wanted to be better understood and, essentially, to be treated with increased empathy. A variety of recommendations were proposed, ranging from asking that the state play an active role in ensuring adequate health care services to public-private partnerships and collaborations across state lines, to enhancements to the health care workforce especially geared toward the training and quality of nonphysician providers.

Participant recommendations that address the “state of health care” issues encompassed two of the three factors cited by Epstein and colleagues as essential to achieving patient-centered care at the national level (Epstein, Fiscella, Lesser & Strange, 2010). These factors are: “an informed and involved patient and family, receptive and responsive health professionals who can focus on disease and knowing the patient, and a well-coordinated and well-integrated health care environment that supports the efforts of patients, families, and their clinicians” (p. 1492). Participants recommended improving the health care environment, including reforms in the areas of drug pricing, health insurance and reimbursement for care coordination services. They also mentioned reforms that better address mental and behavioral health challenges and nonpharmaceutical interventions. Other areas for potential improvement related to the need for: an informed and involved patient and family; greater health literacy in the general population (participants referred to a lack of understanding), particularly about specific health conditions; and more information on health insurance and the health care system. Finally, participants brought attention to the needs of vulnerable populations including older people, people with disabilities, young people, caregivers, those at the end of life and others. All of these recommendations reflected “state of health care” issues that, while not unique to the rural health communities in the Mid-Shore (Epstein et al., 2010), have far-reaching impact on health care experiences at the individual patient encounter level (Raja, Hasnain, Vadakumchery, Hamad, Shah, & Hoersch, 2015).

LIMITATIONS

While these results present rich findings from a variety of community members living and/or working in the five Mid-Shore counties, not all subpopulations were represented. A number of groups had wait lists, but recruitment was difficult at times due to poor prior experiences with similar “listening session” efforts. Our ability to conduct more than one focus group per county, and conduct groups in Spanish, was limited by resources available. Time constraints also limited the duration of our recruitment efforts and our ability to recruit participants from communities that are difficult to reach (e.g., the uninsured, individuals without email or phone access, individuals not already connected to service providers through whom recruitment materials were disseminated). As a result, people from populations facing certain health care barriers were not present. These barriers include primary care access via health centers or local health departments, linguistically appropriate care for non-English speakers, access to social services for those with complex needs, veterans’ health care access and other issues. To address these limitations, stakeholder interviews, another component of this study, included experts serving difficult-to-reach populations. These interviews obtained experts’ views about the current rural health
landscape in the Mid-Shore region specific to these populations. In addition, focus group participants included professionals working with some of these populations, and they spoke about their clients’ difficulties.

PROJECT RECOMMENDATIONS

Based on the focus group findings and the research team’s perspectives on these findings, we offer the following recommendations.

1) **State and county governments need to be involved in addressing regional and local unmet health care needs in rural areas.**

   Focus group participants clearly spoke about their rural health community health care needs that must be met, even if, for example, “rural health care facilities have financial issues because they’re smaller for whatever reasons” (Kent). The 2016 Maryland General Assembly initiated this project through Senate Bill 707 because of the strong community outcry when a hospital system wanted to close a local hospital. The health service needs of rural communities require special attention, and a market economy approach may not work in rural regions (i.e., closing a hospital because it is not profitable). If a hospital or other health care facility closes in a more resource-rich area, other services may be available to address the resulting gap. The impact of closing health care facilities in a rural area with scarce resources can negatively impact the people and communities in that region. State and county government may need to step in to address unmet needs. For example, communities may need to develop public/private partnerships when health care resources are scarce or the state may need to “subsidize the [health] services in rural areas” (Kent).

2) **Program planners need to consider individual county needs while improving the regional Mid-Shore system.**

   Focus group participants alluded to the idea that it is not economically feasible to have comprehensive, expensive health care services in each individual community. There needs to be a focus on a regional health care system. At the same time, critical individual county needs should be considered when a regional system is developed. For example, participants expressed frustration in local areas lacking critical, high-quality, reliable obstetrics and emergency services. Program planners can consider approaches to meet at least some health care services that do not include a full-service hospital (e.g., telemedicine that expands the capacity of local providers; expansion of nonphysician providers including nurses, nurse practitioners, physician assistants, and others; and the use of trained peer support providers and community health workers who can supplement physician and nurse services).

3) **Program planners need to acknowledge longstanding community feelings about not being heard or understood and continue to involve the community in planning.**

   Focus group participants were vocal in expressing their feelings about not being heard in the past when other health care town hall meetings were held years before in the Mid-Shore region. They also felt that planners needed to have a better understanding about and empathy for rural health
needs, stating “put yourself in our shoes. . . (regarding) health care for our families” (Talbot) and reminding planners that rural populations are. . .“poorer, sicker, distant, older” (Kent). While events took place several years ago, participants’ feelings today influence local residents’ current views. Participants explained that residents’ feelings influenced their decisions regarding participation in the focus groups (i.e., some people did not want to attend as they did not feel their voices were heard in the past). Others chose to attend in an effort to express their views. When asked about their recommendations for planners and policymakers, they wanted continued input. “Keep these meetings going (Caroline).” “The dialogue still has to keep going . . . we can’t just sit back and wait for it to happen” (Talbot).

4) Program planners can use a “community asset” approach and build on the service and community characteristics that work well.

Focus group participants spoke of health service features that work well, and many features that need improvement. To avoid being overwhelmed by limited resources and unmet needs, communities can build on existing successes while addressing areas that need strengthening. For example, the Mid-Shore region is comprised of engaged communities with people who have significant personal and professional experiences. Despite focus group participants’ feelings about not being heard in previous regional health care system planning, they were passionate about expressing their views and contributed to thoughtful, substantive discussions. They wanted to continue participating in community efforts to improve their health services. In addition, the Mid-Shore region is home to many retirees from the Washington, DC area who have extensive professional experience. Their expertise and energy are strong community assets.

5) Program planners can create an ongoing community partnership approach to identify and address needed services.

Focus group participants expressed concerns about the future of their health services and worry that existing problems may get worse. They spoke about the uncertainty of health care reform and its impact on rural areas as well as concerns that their voices would not be heard again. An ongoing community structure to include residents (i.e., ongoing and long-term, not just every few years) would build on the residents’ strong sense of engagement and could assist policymakers and program planners in effectively addressing resident concerns and needs.

6) State and local organizations need to focus on patient-centered care by implementing existing policies and programs that support this service model.

Focus group participants identified problems that point to the need for patient-centered services. The concept of patient-centered services is not new (IOM, 2001); however, this paradigm has only been introduced to health care in recent years. It takes time for a new approach to be implemented in local and state planning and become a norm in health services and programs. Participants discussed health care services that did not work well. Many are examples of lack of patient-centeredness, such as: inconvenient locations, long waits and too-short visits, inaccessible facilities
for people with disabilities, technology that interferes with patient-physician communication, and difficulties with transportation to regular and emergency care. A paradigm shift that truly puts people at the center of health care requires intentional effort, time, money, education, oversight and the involvement of all stakeholders, particularly those directly affected. Activities to achieve this outcome might include quality improvement guidelines that emphasize patient-centered services, monitoring and oversight that enforce these guidelines, consumer and patient advisors and advisory boards, and provider training and continuing education.

7) There is a role for state and national recommendations to address rural health needs such as those in the Mid-Shore region.

Many problems discussed in the focus groups are related to the state of health care today and require solutions that extend beyond the Mid-Shore. For example, participants discussed the scarcity of local mental and behavioral health resources and the current opioid addiction crisis affecting rural areas. These problems are, in part, related to national and state issues such as implementing parity regulations addressing equal insurance coverage for mental and physical health services and implementing national and state policies that encourage integrating primary and behavioral health care. Other examples requiring state and federal solutions include adequate insurance coverage (e.g., the continued need for affordable insurance policies with reasonable deductibles and copays) and payment for care coordination. In addition, the scarcity of well-trained primary care physicians and specialists requires state and federal solutions. For example, initiatives that recruit and retain physicians, expand their capacity and include loan repayment programs; support and training for new physicians via telemedicine; Area Health Education Center training programs; as well as nonphysician, peer support and community health worker programs. State solutions may involve Maryland state government and professional associations (i.e., those representing Maryland hospitals, insurers, physicians, and other providers) working together and coordinating with national initiatives. It is important to note that local public and private efforts are also needed to improve workforce recruitment and retention.

Summary and Next Steps

As part of a larger study of rural health care in the Mid-Shore region of Maryland’s Eastern Shore, the University of Maryland School of Public Health, in partnership with the MHCC and the Walsh Center on Rural Health Analysis at NORC at the University of Chicago, conducted focus groups in the five counties that comprise the Mid-Shore region. These discussion groups, which took place between March 2 and April 3, 2017, were intended to gain insight into the health care perceptions and behaviors of consumers living in this region and to understand their views and opinions about a regional health system. The focus groups were held in public libraries in five counties: Caroline, Dorchester, Kent, Queen Anne’s and Talbot. A total of 45 people from the Mid-Shore region participated and were highly engaged in discussing their health care. Focus group topics included: strengths and challenges related to health services in the region, thoughts about the future of health care in the area and recommendations for the MHCC, including ideas for needed health services. Focus group discussions were audio-recorded and transcribed. Participants’ written materials from focus group exercises and discussions were also
transcribed. The research team developed a code book and hand coded and analyzed approximately 275 pages of data.

When focus group participants were asked to discuss aspects of local health care that worked well and did not work well, participants reported satisfaction with the following features (the number in parentheses indicates the number of groups that commented on each feature): good doctor-patient communication (5), good insurance coverage (4), timely appointments (3), efficient medical visits (3), good care (3), good location (3), efficient office staff and operations (3), and helpful emergency care (2). In addition to these positive comments, participants noted many other features that needed improvement. (Sometimes participants provided both positive and negative views about the same topics, reflecting their mixed experiences.) They reported challenges in the following areas: high insurance costs and limited coverage (5), limited specialty care (5), lack of support for doctors (4), changing or closing facilities (4), long driving distances and seasonal traffic (4) impersonal or rude care (4), limited mental and behavioral health and substance use services (3), too-long waits for too-short appointments (3), high medication costs (3), technology challenges (3), poor quality of care (3), need for care coordination (3), transportation difficulties for routine and emergency care (2), lost jobs or bad working conditions (2), inaccessibility of care for people with disabilities (1), and difficulty understanding health issues and health insurance (1).

Participants were also asked to think about the future of health care in the Mid-Shore region and possible changes they would like as well as potential changes that worry them. They discussed the following potential positive changes: lower health care costs, revitalization of a local hospital, a new urgent care facility, less regulation, integrated care evolving from the Maryland all-payer model, and telemedicine innovations. Potential future changes that worried participants included: insufficient or no health insurance; availability of adequate future care for subpopulations such as children, pregnant women, young people and the elderly; lost health care services and jobs; doctor turnover and poor-quality doctors in the region; as well as the negative economic impact of closing health care facilities.

When asked to describe health care services and related features that were important to them and their families, three participant teams for the service exercise chose mental health and substance use services and facilities out of a dozen topics chosen by as many teams. Other teams chose the following services: treatment and insurance coordination following car accidents; adequate office support for primary care offices; adequate care for basic needs; improved and enhanced ambulance services; an outpatient infusion center; care innovations (such as nurse calls or visits, access to specialists by telemedicine and a clinic network); medical transportation for appointments; a small “destination” hospital; and specialty care with improved communication. Participants had many specific ideas for designing these services.

Focus group participants were also asked to make recommendations to the MHCC, and they had many, including: Insurance: make it affordable, expand it, subsidize rural areas (5); Doctors: support them, recruit them (4); Health care workforce: Enhance, improve the environment, train (4); Transportation: Improve for both regular and emergency care (4); Empathy for those in the Mid-Shore region: Show empathy, continue to engage (4); Technology: Use to improve coordination, care (4); Coordination/case management/patient navigation: Help individuals get what they need (3); Accountability: Monitor, oversee programs, enforce the rules (3); Specialists: Need more, provide in innovative ways (2); Mental,
behavioral, substance use care: Make it accessible, affordable (2); Facilities and services: Keep, add (2); Quality: Make it the priority (2); Decision making: Be clear, ensure diversity (2); Education: On health, insurance, the health care system (2); Drug prices: Control them (2); and New approaches to solutions: Collaborate, partner, think “outside the box” (2).

After considering the extensive amount of information that participants provided about a wide range of topics, the research team developed the following recommendations to address health care services in the Mid-Shore region:

1) State and county governments need to be involved in addressing regional and local unmet health care needs in rural areas.

2) Program planners need to consider individual county needs while improving the regional Mid-Shore system.

3) Program planners need to acknowledge longstanding community feelings about not being heard or understood and continue to involve the community in planning.

4) Program planners can use a “community asset” approach and build on the service and community characteristics that work well.

5) Program planners can create an ongoing community partnership approach to identify and address needed services.

6) State and local organizations need to focus on patient-centered care by implementing existing policies and programs that support this service model.

7) There is a role for state and national recommendations to address rural health needs such as those in the Mid-Shore region.

The research team greatly appreciates participants’ time and active participation in the focus groups. It is an honor and obligation to represent their views in this report. They devoted their time to discussing this important topic that greatly impacts the health of their families and communities. They expressed the importance of engaging the community in an ongoing basis when making decisions about regional health care services. In the words of one Caroline County participant, “I’m thankful that someone is interested in what we have to say, and maybe it will spur something.” A Talbot County participant requested, “The dialogue still has to keep going.” It is our hope that this study is the beginning of an ongoing partnership between engaged community members, program planners and policymakers to address the health care needs of the Mid-Shore region in the best approach possible.
References


TABLES

Table 1: Focus Group Dates, Locations and Participant Counts
Table 2: Focus Group Participant Demographics
Table 3: Focus Group Guidelines
Table 4: Strengths: What Works Well in Mid-Shore Health Care
Table 5: Challenges: What Doesn’t Work Well in Mid-Shore Health Care
Table 6: Changes Participants Would Like/Look Forward To; Changes That Worry Participants
Table 7: Recommendations, Suggestions and Service Ideas for the Maryland Health Care Commission
### Table 1: Focus Group Dates, Locations and Participant Counts

<table>
<thead>
<tr>
<th>County</th>
<th>Date</th>
<th>Location</th>
<th>Number of Participants</th>
<th>Number of participants from county</th>
</tr>
</thead>
<tbody>
<tr>
<td>Queen Anne’s</td>
<td>3/2/2017</td>
<td>Queen Anne's County Public Library - Centreville Branch</td>
<td>6</td>
<td>5 Queen Anne’s; 1 Caroline</td>
</tr>
<tr>
<td>Caroline</td>
<td>3/7/2017</td>
<td>Caroline County Public Library - Denton Branch</td>
<td>9</td>
<td>All 9 from Caroline</td>
</tr>
<tr>
<td>Dorchester</td>
<td>4/3/2017</td>
<td>Dorchester County Public Library - Central Library</td>
<td>11</td>
<td>All 11 from Dorchester</td>
</tr>
<tr>
<td>Kent</td>
<td>3/23/2017</td>
<td>Kent County Public Library - Chestertown Branch</td>
<td>10</td>
<td>All 10 from Kent</td>
</tr>
<tr>
<td>Talbot</td>
<td>3/30/2017</td>
<td>Talbot County Free Library - Main Library</td>
<td>9</td>
<td>5 Talbot, 3 Caroline, 1 Dorchester</td>
</tr>
</tbody>
</table>

### Table 2: Focus Group Participant Demographics – (Aggregated across all 45 participants)

<table>
<thead>
<tr>
<th>Age</th>
<th>Race / Ethnicity</th>
<th>Gender</th>
<th>Language(s) spoken at home</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>25-34 yrs (6.7%)</td>
<td>38 White (84.4%)</td>
<td>29 Female (64.4%)</td>
</tr>
<tr>
<td>7</td>
<td>35-44 yrs (15.6%)</td>
<td>5 Black/African-American (11.1%)</td>
<td>16 Male (35.5%)</td>
</tr>
<tr>
<td>6</td>
<td>45-54 yrs (13.3%)</td>
<td>1 Hispanic (2.2%)</td>
<td>43 English (95.6%)</td>
</tr>
<tr>
<td>7</td>
<td>55-64 yrs (15.6%)</td>
<td>1 Other (2.2%)</td>
<td>1 English &amp; Spanish (2.2%)</td>
</tr>
<tr>
<td>6</td>
<td>65-64 yrs (35.6%)</td>
<td></td>
<td>2 left blank (2.2%)</td>
</tr>
<tr>
<td>6</td>
<td>75 yrs+ (13.3%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Health Insurance Type

- 17 Public (37.8%)*
- 18 Private (40.00%)
- 8 Public and Private (17.8%)*
- 1 Insurance through Exchange (2.2%)
- 1 left blank (2.2%)

*Public Insurance Types (25 total)

- 22 Medicare
- 1 Medicare & other
- 1 Amerigroup
- 1 Other

#### Hospital used in the past year by self / family (some participants checked more than one)

- 13 Memorial Hospital at Easton
- 12 Chester River Hospital Center
- 8 Dorchester General Hospital
- 7 Anne Arundel Medical Center
- 4 Johns Hopkins
- 3 Peninsula Regional Medical Center
- 1 Sibley (DC)
- 1 Annapolis
- 1 Baltimore
- 1 “Depends”
- 6 Left blank

#### Other health facilities / services used in the past year by self / family (some participants checked more than one)

- 43 Pharmacy
- 40 Private doctor’s office
- 36 Private dental office
- 20 Emergency room
- 20 Urgent care clinic
- 14 Ambulatory Surgery Center (outpatient or same-day surgery center)
Table 3: Focus Group Guidelines

<table>
<thead>
<tr>
<th>DISCUSSION GROUP GUIDELINES</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Please talk <strong>one at a time</strong>.</td>
</tr>
<tr>
<td>2) Speak in a loud voice so we can hear you. (for recording)</td>
</tr>
<tr>
<td>3) Avoid side conversations with people sitting next to you. (Often the best comments, I want to hear them)</td>
</tr>
<tr>
<td>4) Please allow everyone to speak before jumping in again. We want everyone to have a chance to speak.</td>
</tr>
<tr>
<td>5) Allow for <strong>different points of view</strong>. There are no wrong answers.</td>
</tr>
<tr>
<td>6) Say what you <strong>believe</strong>, regardless of whether others agree with you.</td>
</tr>
<tr>
<td>7) Cell phones ringers off, please (I understand emergencies)</td>
</tr>
<tr>
<td>8) <strong>Only one person up or out</strong> of the room at a time.</td>
</tr>
<tr>
<td>9) <strong>Please say your first name before you speak.</strong></td>
</tr>
</tbody>
</table>

7 Disability / Rehab / Aging services
7 Emergency Medical Services (911)
7 Mental health services
5 Clinic affiliated with a hospital
4 Local health department
4 Primary care community clinic
3 School-based health center
2 Adult day care
2 Physical therapy
1 Home health care
1 Hospice care / services
1 Medical transportation (not for an emergency)
1 Skilled nursing facility
1 Other: specialist
1 Other: rheumatologist
1 Other: podiatrist
1 Other: OB/GYN
1 Other: lab
1 Other: integrated care
1 Other: home infusion services
1 Other: cardiologist
1 Other: hospital outpatient
Table 4: Strengths: What Works Well in Mid-Shore Health Care

<table>
<thead>
<tr>
<th>Local Health Care Strengths</th>
<th>Groups Where Mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good doctor-patient communication</td>
<td>All 5FG</td>
</tr>
<tr>
<td>Effective nonphysician health care providers</td>
<td>4FG:CDKT</td>
</tr>
<tr>
<td>Good insurance coverage</td>
<td>3FG-QKT</td>
</tr>
<tr>
<td>Getting an appointment in a timely manner</td>
<td>3FG-QCT</td>
</tr>
<tr>
<td>Efficient medical visits</td>
<td>3FG-CDT</td>
</tr>
<tr>
<td>Good care received</td>
<td>3FG-CDK</td>
</tr>
<tr>
<td>Good location of care</td>
<td>3FG-QKT</td>
</tr>
<tr>
<td>Efficient medical office staff and operations</td>
<td>3FG-QT</td>
</tr>
<tr>
<td>Helpful emergency care</td>
<td>2FG-DK</td>
</tr>
</tbody>
</table>

NOTE: Letters identify the county: Q=Queen Anne’s, C=Caroline, D=Dorchester, K=Kent, T=Talbot

Table 5: Challenges: What Doesn’t Work Well in Mid-Shore Health Care

<table>
<thead>
<tr>
<th>Challenges: What doesn’t work well in Mid-Shore Health Care</th>
<th>Groups Where Mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance, costs, coverage difficulties</td>
<td>All 5FG</td>
</tr>
<tr>
<td>Specialty care: Lacking or far away</td>
<td>All 5FG</td>
</tr>
<tr>
<td>Doctors: Restricted, not supported enough</td>
<td>4FG-QCDT</td>
</tr>
<tr>
<td>Facilities: Changing, closing, lacking</td>
<td>4FG-QCDK</td>
</tr>
<tr>
<td>Location of care: Inconvenience, seasonal traffic</td>
<td>4FG-QCDK</td>
</tr>
<tr>
<td>Impersonal or rude care</td>
<td>4FG-QCK</td>
</tr>
<tr>
<td>Mental, behavioral, substance use care: Lacking</td>
<td>3FG-QKT</td>
</tr>
<tr>
<td>Time: Too long to wait for an appointment, too little time for care</td>
<td>3FG-CDT</td>
</tr>
<tr>
<td>Medication costs: High</td>
<td>3FG-QCD</td>
</tr>
<tr>
<td>Technology challenges: Patient portals, doctor distraction, poor use, telemedicine</td>
<td>3FG-QCT</td>
</tr>
<tr>
<td>Quality of care: Poor</td>
<td>3FG-QCD</td>
</tr>
<tr>
<td>Care coordination/case management /patient navigation: Needed</td>
<td>3FG-QCT</td>
</tr>
<tr>
<td>Transportation: Difficulties for regular and emergency care</td>
<td>2FG-CK</td>
</tr>
<tr>
<td>Workforce issues: Lost jobs or bad working conditions</td>
<td>2FG-QT</td>
</tr>
<tr>
<td>Disability issues, particularly access to care</td>
<td>1FG-T</td>
</tr>
<tr>
<td>Health literacy: Challenges understanding health issues, health insurance</td>
<td>1FG-T</td>
</tr>
</tbody>
</table>

NOTE: Letters identify the county: Q=Queen Anne’s, C=Caroline, D=Dorchester, K=Kent, T=Talbot
<table>
<thead>
<tr>
<th>Changes Participants Would Like or Look Forward to</th>
<th>Groups Where Mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Lower rates?”: Health insurance and health care</td>
<td>2FG-DT</td>
</tr>
<tr>
<td>Revitalization of our hospital</td>
<td>1FG-K</td>
</tr>
<tr>
<td>A new facility for urgent care, dialysis</td>
<td>1FG-C</td>
</tr>
<tr>
<td>Less regulation</td>
<td>1FG-Q</td>
</tr>
<tr>
<td>All-payer model, if there is follow up on integration of care</td>
<td>1FG-C</td>
</tr>
<tr>
<td>Improved health care</td>
<td>1FG-D</td>
</tr>
<tr>
<td>Technology: Telemedicine innovations</td>
<td>1FG-K</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Changes that Worry Participants</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>People losing their insurance or it is insufficient</td>
<td>All 5FG</td>
</tr>
<tr>
<td>Enough care for future needs of subpopulations (younger people, kids, pregnant women, seniors, young adults)</td>
<td>4FG-QCDT</td>
</tr>
<tr>
<td>Losing services and jobs in health care (including patient navigators)</td>
<td>3FG-CDT</td>
</tr>
<tr>
<td>Doctors: Leaving or of low quality</td>
<td>2FG-QC</td>
</tr>
<tr>
<td>Economic impact of health care changes: Could be negative</td>
<td>1FG-K</td>
</tr>
</tbody>
</table>

NOTE: Letters identify the county: Q=Queen Anne’s, C=Caroline, D=Dorchester, K=Kent, T=Talbot
### Table 7: Recommendations, Suggestions and Service Ideas for the Maryland Health Care Commission

<table>
<thead>
<tr>
<th>Recommendations and Suggestions for the Maryland Health Care Commission</th>
<th>Groups Where Mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance: Make it affordable, expand it, subsidize rural areas</td>
<td>All 5FG</td>
</tr>
<tr>
<td>Doctors: Support them, recruit them</td>
<td>4FG-QCDT</td>
</tr>
<tr>
<td>Health care workforce: Enhance, improve the environment, train</td>
<td>4FG-QCDK</td>
</tr>
<tr>
<td>Transportation: Improve for both regular and emergency care</td>
<td>4FG-CDKT</td>
</tr>
<tr>
<td>Empathy for those in the Mid-Shore region: Show empathy, continue to engage</td>
<td>4FG-QCKT</td>
</tr>
<tr>
<td>Technology: Use to improve coordination, care</td>
<td>4FG-CDKT</td>
</tr>
<tr>
<td>Coordination/case management/navigation: Help individuals get what they need</td>
<td>3FG-QCT</td>
</tr>
<tr>
<td>Accountability: Monitor, oversee programs, enforce the rules</td>
<td>3FG-CDT</td>
</tr>
<tr>
<td>Specialists: Need more, provide in innovative ways</td>
<td>2FG-CK</td>
</tr>
<tr>
<td>Mental, behavioral, substance use care: Make it accessible, affordable</td>
<td>2FG-QC</td>
</tr>
<tr>
<td>Facilities and services: Keep, add</td>
<td>2FG-CK</td>
</tr>
<tr>
<td>Quality: Make it the priority</td>
<td>2FG-QC</td>
</tr>
<tr>
<td>Decision making: Be clear, ensure diversity</td>
<td>2FG-KT</td>
</tr>
<tr>
<td>Education: On health, insurance, the healthcare system</td>
<td>2FG-DT</td>
</tr>
<tr>
<td>Drug prices: Control them</td>
<td>2FG-QD</td>
</tr>
<tr>
<td>New approaches to solutions: Collaborate, partner, think “outside the box”</td>
<td>2FG-CK</td>
</tr>
</tbody>
</table>

### Service Ideas Offered by Focus Group Participants

<table>
<thead>
<tr>
<th>Service Ideas Offered by Focus Group Participants</th>
<th>Groups Where Mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standalone mental health facilities</td>
<td>1FG-Q</td>
</tr>
<tr>
<td>Improved post-motor vehicle accident treatment and coordination of insurance issues</td>
<td>1FG-Q</td>
</tr>
<tr>
<td>More holistic and accessible mental health services</td>
<td>1FG-C</td>
</tr>
<tr>
<td>Substance abuse, mental health and behavioral health services: More resources for outpatient and inpatient care</td>
<td>1FG-C</td>
</tr>
<tr>
<td>Primary care supports</td>
<td>1FG-C</td>
</tr>
<tr>
<td>Improved cost and availability of services</td>
<td>1FG-D</td>
</tr>
<tr>
<td>Improved and enhanced ambulance services</td>
<td>1FG-D</td>
</tr>
<tr>
<td>Ideas for improved access and lowered costs: Nurse specialists by phone, medical specialists by telemedicine, a network of clinics located where there are no hospitals, nurse/health worker home visits</td>
<td>1FG-K</td>
</tr>
<tr>
<td>Outpatient infusion center</td>
<td>1FG-K</td>
</tr>
<tr>
<td>Improve access to care and lower the cost of care through innovations</td>
<td>1FG-K</td>
</tr>
<tr>
<td>A small “destination hospital”</td>
<td>1FG-K</td>
</tr>
<tr>
<td>Medical transportation system</td>
<td>1FG-T</td>
</tr>
<tr>
<td>Improved specialty care communication, including with other parts of the health care system</td>
<td>1FG-T</td>
</tr>
</tbody>
</table>

**NOTE:** Letters identify the county: Q=Queen Anne’s, C=Caroline, D=Dorchester, K=Kent, T=Talbot
APPENDICES

A – Recruitment Flyer

B – Focus Group Moderator’s Guide

C – Demographic Questionnaire

D – Activity Worksheet for Question 3
HELP IMPROVE HEALTH CARE IN THE MARYLAND MID-SHORE

DISCUSSION GROUP: Rural Health Needs and Opportunities in the Maryland Mid-Shore Region

Are you 18 years or older? Do you live in any of the Mid-shore Counties (Kent, Caroline, Queen Anne’s, Talbot, or Dorchester) and speak English? Come talk to us about health care.

The Maryland Health Care Commission is sponsoring a study about rural health on the Eastern Shore and is looking for your ideas! As part of the study, you are invited to join a small group of community members to share your views about an improved health care system in this region.

The feedback from the groups will be anonymous and will be used to develop recommendations to improve the current healthcare delivery system. In appreciation for your time and sharing your thoughts, you will receive light dinner and $25.

<table>
<thead>
<tr>
<th>Group 1 (Queen Anne’s)</th>
<th>Date/Time</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1 (Queen Anne’s)</td>
<td>Thursday, March 2 6:00-8:00pm</td>
<td>Queen Anne’s County Public Library - Centreville Branch 121 S. Commerce St Centreville, MD 21617</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group 2 (Caroline)</th>
<th>Date/Time</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 2 (Caroline)</td>
<td>Tuesday, March 7 6:00-8:00pm</td>
<td>Caroline County Public Library - Denton Branch 100 Market Street Denton, MD 21629</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group 3 (Dorchester)</th>
<th>Date/Time</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 3 (Dorchester)</td>
<td>Tuesday, March 14 6:00-8:00pm</td>
<td>Dorchester County Public Library - Central Library 303 Gay St. Cambridge, MD 21613</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group 4 (Kent)</th>
<th>Date/Time</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 4 (Kent)</td>
<td>Thursday March 23 6:00-8:00pm</td>
<td>Kent County Public Library - Chestertown Branch 408 High Street Chestertown, Maryland 21620</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group 5 (Talbot)</th>
<th>Date/Time</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 5 (Talbot)</td>
<td>Thursday, March 30 5:30-7:30pm</td>
<td>Talbot County Free Library - Main Library 100 West Dover Street Easton, Maryland 21601</td>
</tr>
</tbody>
</table>

Interested in participating? Want more information?
Call 443-863-8992 or email MidShoreDiscussionGroupStudy@gmail.com

This study is being funded by the Maryland Health Care Commission and conducted by researchers at the University of Maryland College Park School of Public Health and at the NORC Walsh Center for Rural Health Analysis at the University of Chicago.

It has been reviewed and approved by the University of Maryland College Park Institutional Review Board.
Appendix B: Focus Group Moderator’s Guide

Interviewer/Moderator’s Guide for Rural Health Study

Topic: Improving Health Services in the Mid-Shore Region

DATE: March 2, 2017

A. **INTRO:** (5 min) Hello. My name is Lori, and I am the moderator for today’s discussion. The topic is “Improving Health Services in the Mid-Shore Region.” We’re discussing your experience going to the doctor, dentist, hospital, emergency room, and other places where you take care of your health.

**Purpose:** You’ve seen a handout describing the project purpose. Any questions about what you’ve read?

**AGENDA** You will be doing a few things today: participating in a group discussion, listening to new ideas, and writing down your own thoughts. Everyone is invited to speak, and there are no wrong answers. I’d like to hear different viewpoints, and have a free-flowing discussion.

**Moderator:** I work for the University of Maryland, School of Public Health in College Park. It’s an hour away from the other health professional schools in Baltimore. I conduct research about health, often about aging. I’ve lived in Maryland for a long time; however, my Midwestern accent is from Michigan, where I grew up.

**ACKNOWLEDGE:** Thank you very much for being here tonight. I appreciate you taking time to come here.

**DISCLOSURES:**

1) You’ve met my team member(s) when you arrived today. They’re here to learn from you. They’ll take notes so we don’t miss anything you say. I’ll ask them if there are any questions
they would like me to ask when we are getting close to the end of the session

2) This session will be recorded so I can write an accurate report without taking notes while we talk. The report won’t include any names because what you say is important, not who said it. We won’t share the recording with others.

3) We will only use first names when we speak during our discussion. We won’t share your names with others.

PERMISSIONS: You should feel comfortable excusing yourself at any time to use the restroom or get food and drinks. However, I ask that only one person leave the room at a time.

GUIDELINES: I’m going to pass out a sheet with guidelines for today’s discussion.

10) Please talk **one at a time**.
11) Speak in a loud voice so we can hear you.
12) Avoid side conversations with people sitting next to you.
13) Please allow everyone to have a chance to speak first before jumping in again; we want to allow equal time for everyone.
14) Say what **you believe, regardless of whether** others agree with you. We want different points of view -- there are no wrong answers.
15) **Only one person up or out** of the room at a time.
16) Please say your first name before you speak.

IRB CONSENT:

B. SELF INTRODUCTIONS: Please introduce yourself and tell us your first name and …

(5 - 7 min)

Icebreaker/Transition Questions

1. **Introductions/Ice breaker** (5 – 7 minutes)
1. First Name
2. County where you live
3. Who/what lives with you (pets, plants, other things important to you)?
4. Thinking back to your childhood, what is your first memory of going to the doctor, dentist, or other health professional?

**Main Questions**

**Questions 1-5 (45 min)**

(20 minutes)

1. Next, we’ll talk about your current experience going to doctors, dentists, clinics, other health professionals, and hospitals. For example, it might be your last health care visit or another health care experience that stands out in your memory.

   a) First, tell us a little about the visit or experience (e.g. where was it? What type of health professional did you see? What was your experience?)

   b) In the next few minutes, you will have a chance to write down your thoughts about: 1) what worked well during this experience, 2) what needed improvement, and 3) your ideas to make the experience better.

**NOTE:** If you need any assistance getting your thoughts down on paper, please let me know.
EXERCISE DIRECTIONS:

- TEAM INSTRUCTIONS: Write Directions on Easel in advance

- Pass out post its, each person takes several green, yellow, and blue post its.

i. Use the Green post its to write down what worked well during the experience? What did you like?

ii. Use the Yellow post its to write down what didn’t work so well during the experience? What needed improvement?

iii. Use the Blue post its to write down your suggested improvements. What would make the experience better for you?

iv. Write down as many as you can in the next 2-3 minutes.

v. Please write clearly and in big letters so we can read them. One thought on each post it.

vi. When you’re done, we’ll put the post its on the easel and discuss your ideas.
-TEAM INSTRUCTIONS:

-We'll put each person’s post-its in a group.
-Give each grouping a name (e.g. bad back, heart specialist).
-We’ll see green, yellow, and blue post its for each person.
-Need to have sheets of paper taped to places near the easel so we can read them easily.

Team members: Sort post-its into groupings for each person

-While team sorts into groups by person, take a break, stretch

DISCUSSION

Ask for volunteers to begin discussing their experience

QUESTION 2 (5 MIN)

2. There is uncertainty about the future of health care right now with talk of changes to the Affordable Care Act, known by some people as “Obamacare.” And there is talk of changes in the Mid-Shore Region separate from the federal law. Some people look forward to changes, while others are worried. Some worry about losing insurance, especially people who are sick and may not qualify for new insurance.

(5 minutes)

a) When thinking about the future of health care in the Mid-Shore region, what changes would you like? What worries you? Think about health care for you, your family, your community.

PROBE  What have you seen, read, heard or been told about future changes?
PROBES:
- Changes in insurance?
- Hospital closures?
- Hospital jobs leaving the area?
- Longer distances to services?
- Difficulty for specific health problems such as mental health, addictions, care for the elderly, help for kids and adults with disabilities,

QUESTION 3 (WITH EXERCISE) 15 MIN

3. The Maryland Health Care Commission is a state agency that plans health services in Maryland and provides information to consumers (like you) and policymakers. The Commission has asked you for advice to help design better health services for QAC residents. This is your chance to tell the Commission what is important to you and your family. Of course, we know that policymakers and planners have limited resources and need to make decisions within their budgets.

EXERCISE INSTRUCTIONS (15 minutes)

- Handout with instructions and a worksheet, YELLOW highlighters

(15 minutes, if there is time, each team picks 2 service types)

NOTE: If you need any assistance getting your thoughts down on paper, please let me know.
- Divide the group in two teams (each half of the table is a team).
- Choose a health service that is important to you and your family, one that your group wants to discuss (such as seeing your family doctor or a specialist, visiting an emergency room, being a hospital patient).
  - You might build on an example that you discussed earlier or pick a new experience.
- In the next few minutes, describe what health services are important to you and your family and what features you would like to see.
  - EXAMPLES: type of doctor, dentist, other health professional, where it’s located, how long you wait for an appointment, etc.)
- There are no right or wrong answers – your team’s job is to describe what is important to you.
- You can think about technology that might help (such as telemedicine/distance medicine that could remotely bring health services to rural areas).
- You can think about ways to attract more doctors, dentists, and other health professionals to QAC.
- If your team finishes the first health service before the time is up, please select a 2nd service area to address.
- 
- **You will use a work sheet that has 2 columns:**
  - 
    **Type of Service**  
    Service features that are important to you and your family
- When you finished your work sheet, please use the YELLOW highlighter to mark the 3 features that are the most important to you.
- **DISCUSSION: EACH GROUP PICKS SOMEONE TO TALK ABOUT THEIR IDEAS**
- After each team finishes, a team member will describe your service(s).
  **TEAM:** We’ll collect work sheets.
QUESTION 4 (5 MIN)

4. Now that you’ve told the Commission what is important to you, let’s think about how you would like your county and Mid-Shore leaders to make these decisions.

-After hearing your suggestions about the kind of health care services that are important to your community, how would you like your county or Mid-Shore leaders to make recommendations to state policy makers? (2 minutes)

PROBES: What would this step look like in your community? Who would need to talk with whom?

QUESTION 5 (5 MIN)

5. You get the last word (5 minutes)

You get the last word. What is the most important recommendation you would give the Maryland Health Care Commission?

Give time to write their thoughts.
Each person has a chance to speak.

C. We have about 10 minutes remaining, and I’d like my team members to let me know if there are any additional issues they would like us to discuss.

TEAM MEMBERS: Pass cards with clearly printed questions to me.

D. Closure (2-3 min)
The discussion time is almost over. I’d like each one of you to tell me one thought you are taking away from today’s discussion. Who would like to share these thoughts in about 15 seconds?

TEAM MEMBER WRITES ON EASEL

We have discussed a great deal about health and health care today, and I’ve learned a lot.

Thank you very much for coming here tonight. We appreciate you sharing your valuable thoughts. We’ll be sure to include them in the project report.

Please stop at the door on your way out for your gift card – a small way of showing our appreciation for your time and effort.
<table>
<thead>
<tr>
<th>Rural Health Discussion Group Participant Background Information Form</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Name (first &amp; last):</strong></td>
</tr>
<tr>
<td><strong>Zip Code:</strong></td>
</tr>
<tr>
<td><strong>Age:</strong></td>
</tr>
<tr>
<td>- 18-24 years old</td>
</tr>
<tr>
<td>- 25-34 years old</td>
</tr>
<tr>
<td>- 35-44 years old</td>
</tr>
<tr>
<td>- 45-54 years old</td>
</tr>
<tr>
<td>- 55-64 years old</td>
</tr>
<tr>
<td>- 65-74 years old</td>
</tr>
<tr>
<td>- 75 years or older</td>
</tr>
<tr>
<td><strong>Race / Ethnicity:</strong></td>
</tr>
<tr>
<td>- White</td>
</tr>
<tr>
<td>- Hispanic / Latino</td>
</tr>
<tr>
<td>- Black / African American</td>
</tr>
<tr>
<td>- Native American / American Indian</td>
</tr>
<tr>
<td>- Asian / Pacific Islander</td>
</tr>
<tr>
<td>- Other: ____________________________________________________</td>
</tr>
<tr>
<td><strong>Gender:</strong></td>
</tr>
<tr>
<td>- Male</td>
</tr>
<tr>
<td>- Female</td>
</tr>
<tr>
<td>- Other: ________</td>
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<tr>
<td><strong>Health Insurance:</strong></td>
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<tr>
<td>- Private</td>
</tr>
<tr>
<td>- Insurance through exchange (Maryland Healthcare)</td>
</tr>
<tr>
<td><strong>Language(s) spoken at home:</strong></td>
</tr>
<tr>
<td>- English</td>
</tr>
<tr>
<td>- Spanish</td>
</tr>
<tr>
<td>- Other: ____________________________________________________</td>
</tr>
<tr>
<td><strong>Which hospital(s) do you / your family go to if you are sick?:</strong></td>
</tr>
<tr>
<td>- Dorchester General Hospital</td>
</tr>
<tr>
<td><strong>In the last year, if you or a family member have used any of the following health facilities / services, please check the box(s) below:</strong></td>
</tr>
<tr>
<td><strong>Facility type / Service type</strong></td>
</tr>
<tr>
<td>Private doctor’s office</td>
</tr>
<tr>
<td>Pharmacy</td>
</tr>
<tr>
<td>Private dental office</td>
</tr>
<tr>
<td>Primary Care Community Clinic</td>
</tr>
<tr>
<td>Emergency room</td>
</tr>
<tr>
<td>Clinic affiliated with a hospital</td>
</tr>
<tr>
<td>Emergency medical services (911)</td>
</tr>
<tr>
<td>Medical transportation (not for an emergency)</td>
</tr>
<tr>
<td>Urgent Care Clinic</td>
</tr>
<tr>
<td>Local health department</td>
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<tr>
<td>School-based health center</td>
</tr>
<tr>
<td>Ambulatory surgery center (outpatient or same-day surgery center)</td>
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<tr>
<td>Mental Health services</td>
</tr>
<tr>
<td>Skilled Nursing Facility (short- or long-term nursing home)</td>
</tr>
<tr>
<td>Adult Day Care</td>
</tr>
<tr>
<td>Disability / Rehab / Aging services</td>
</tr>
<tr>
<td>Home Health care</td>
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<tr>
<td>Hospice care / services</td>
</tr>
<tr>
<td>Case management services</td>
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<tr>
<td>Other: ____________________________________________________</td>
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<td>Other: ____________________________________________________</td>
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<td>Other: ____________________________________________________</td>
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<tr>
<td>Other: ____________________________________________________</td>
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<tr>
<td>Other: ____________________________________________________</td>
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</tbody>
</table>

**PARTICIPANT BACKGROUND INFORMATION FORM**

Initials ______ Date ________
Appendix D: Focus Group Activity Worksheet for Question 3

**Activity: Important Health Services for You and Your Family**

The Maryland Health Care Commission has asked for your advice to help design important health services for you and your family. This is your chance to tell the Commission what is important to you.

**Activity Instructions**

- Choose a health service that is important to you and your family, one that your group wants to discuss (such as seeing your family doctor or a specialist, visiting an emergency room, being a hospital patient). You might build on an example that you discussed earlier or pick a new experience.
- In the next few minutes, describe what health services are important to you and your family and what features you would like to see (e.g. type of doctor, dentist, other health professional, location, wait time for an appointment, etc.)
- There are no right or wrong answers – your team’s job is to describe what is important to you.
- You can think about technology that might help (such as telemedicine/distance medicine that could remotely bring health services to rural areas).
- You can think about ways to attract more doctors, dentists, and other health professionals to your county.
- If your team finishes the first health service before the time is up, please select a 2nd service area to address.

<table>
<thead>
<tr>
<th>Health Service Area</th>
<th>Important Service Features</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
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<tr>
<td></td>
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