

DEPARTMENT OF HEALTH AND HUMAN SERVICES
ADVISORY COMMITTEE ON MINORITY HEALTH (ACMH)

**Omni Shoreham Hotel
Washington, DC 20008**

July 21-22, 2015

Committee Attendees

Roderick K. King, MD, MPH, FAAP (Chair)
Arthur Chen, MD
B. Ashleigh Guadagnolo, MD, MPH
Paul Juarez, PhD
Beverly L. Malone, PhD, RN, FAAN
Cynthia Mojica, PhD, MPH
Sela V. Panapasa, PhD
Rea Pañares, MHS
Isabel Scarinci, PhD, MPH
Roland J. Thorpe, Jr., PhD

Federal Staff

J. Nadine Gracia, MD, MSCE, Deputy Assistant Secretary for Minority Health, U.S. Department of Health and Human Services
Rashida Dorsey, PhD, MPH, Director, Division of Policy and Data, Office of Minority Health, U.S. Department of Health and Human Services (Designated Federal Officer (DFO), ACMH)
Minh Wendt, PhD, Public Health Advisor, Division of Policy and Data, Office of Minority Health, U.S. Department of Health and Human Services (Alternate Designated Federal Officer, ACMH)

Invited Presenters

Debra J. Barksdale, PhD, Professor and Director, Doctor of Nursing Practice Program, University of North Carolina at Chapel Hill
Bruce Cohen, PhD, Massachusetts Department of Public Health
Tawara D. Goode, MA, Assistant Professor and Director, National Center for Cultural Competence, Georgetown University
Audrey M. McDowell, MS, Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services
Barbara Richards, MPP, Director, Division of Business and Data Analysis, Center for Medicaid and Chip Services, Center for Medicare & Medicaid Services (CMS)

DAY ONE – Tuesday, July 21, 2015

Call to Order

- Roderick K. King, MD, MPH, Chair

Dr. King called the meeting to order and welcomed committee members and staff. He noted that this was a transformational time for minority populations and a transformational moment in health care, because recent tragedies related to race and color created a new dialog. This presents an opportunity for the committee to move its agenda forward and improve health and health care for minority populations.

Following a round of introductions, Dr. King reviewed the agenda for the meeting.

OMH Welcome and Updates

- J. Nadine Gracia, MD, MSCE, Deputy Assistant Secretary for Minority Health, U.S. Department of Health and Human Services

Dr. Gracia provided an update on OMH activities. Key points were as follows:

- 30th Anniversary of the Heckler Report: OMH hosted a Health Equity Summit on April 27 with more than 250 guests, including HHS Secretary Sylvia Burwell, former HHS Secretaries Margaret Heckler and Louis Sullivan, former Surgeon General David Satcher, and former Congressman Louis Stokes. The event highlighted the impact of the Heckler Report and its continued importance going forward, as well as created a resurgence of interest in the report. Beyond the Health Equity Summit, OMH has and continues to coordinate and/or participate in several conferences and events throughout 2015 in commemoration of the 30th anniversary of the Heckler Report.
- Men's Health: OMH has been actively working on its increasing portfolio related to men's health. OMH released a data brief on demographic and health profiles for adult males, ages 19 to 64, by race and ethnicity as well as a data brief with disaggregated data on health status among Hispanic and Latino males. OMH hosted a webinar on advancing health equity for boys and men of color that addressed social determinants such as incarceration, education, and employment. ACMH member Roland Thorpe, PhD., was a speaker for the webinar. OMH co-hosted a Men's Health Roundtable on male pre-conception care and reproductive life planning, along with the National Collaborative for Health Equity, the American Public Health Association, the Men's Health Network, and the CDC Division of Reproductive Health.
- National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (National CLAS Standards): OMH has been updating existing resources at www.thinkculturalhealth.com, including the e-learning program for nursing and the language assistance guide. OMH recently announced a new e-learning curriculum, *Promoting Healthy Choices and Community Changes*, which is designed for promotores de salud. The curriculum is available in English and Spanish and can be used by promotores at any level of experience. Participants receive a certificate of completion for each module of the curriculum. In March, Dr. Gracia participated virtually in the fifth annual Health Equity Forum in Nova Scotia. Canada is in the process of adapting the

World Health Organization health equity standards and was interested in learning about the framework that HHS developed to look at cultural and linguistic competence.

- Higher Education Technical Assistance Project (HE-TAP): The OMH Resource Center (OMHRC) launched HE-TAP in response to President Obama's higher education agenda for the U.S. to have the highest proportion of college graduates in the world by 2020. The project will help institutions of higher education, including minority-serving institutions, become more competitive for federal grants and other resources. OMH is hosting five workshops to share resource development strategies. Dr. Gracia encouraged committee members to help publicize the workshops and/or to participate in the programs themselves. Information is at www.minorityhealth.hhs.gov/HETAP.
- Tribal Health: Dr. Gracia met with tribal leaders at the Wind River reservation in Wyoming to learn about health challenges and critical needs of the Northern Arapahoe and Eastern Shoshone tribes. Colleagues from the Indian Health Service, the Substance Abuse and Mental Health Services Administration, and the Department of Justice also participated. Tribal leaders recognize that they need to partner with more agencies. Suicide and hopelessness are key issues for tribal youth, and unemployment on the reservation is a major social determinant. The visit also included a cultural exchange.
- My Brother's Keeper (MBK): More than 230 communities across the country have accepted the MBK Community Challenge. Dr. Gracia has spoken at MBK local action summits in California, Pennsylvania and Massachusetts. The MBK Alliance is a new, independent organization of private-sector leaders who are committed to the goals of the initiative and dedicated to providing opportunities for boys and young men of color (www.mbkalliance.org).
- Other activities:
 - Dr. Gracia represented HHS on the U.S. delegation for the Universal Periodic Review of the Human Rights Council in Geneva. The delegation responded to questions from 122 member states regarding issues such as police brutality and discrimination in communities of color, immigration, equal access to health care, and reproductive health.

Discussion

1. *Dr. Scarinci stated that historically black colleges and universities (HBCUs) would benefit from the HE-TAP and offered to host a workshop in Alabama.*
 - Dr. Gracia said she would put Dr. Scarinci in touch with OMHRC to discuss opportunities for the next round of in-person workshops.
 - Dr. King stated that HBCUs in Florida and Georgia would also be interested.
2. *Dr. Panapasa raised several issues. She noted that the data brief on Hispanic males highlighted the broad diversity within minority populations and asked if OMH was planning to do similar work focusing on other populations. She asked if Dr. Gracia planned to work with other tribes and whether Alaska natives factored into that work. She also noted that the Minority Data Center at the Inter-university Consortium for Political and Social Research (ICPSR) could be a potential resource for HE-TAP.*
 - Dr. Gracia stated that additional data briefs will be published on an ongoing basis and noted that heterogeneity of data was a focus of one of her blog posts. She offered to put

Dr. Panapasa in touch with OMHRC to discuss how the ICPSR Minority Data Center could assist the HE-TAP initiative. She noted that OMH's portfolio includes addressing the health status of Alaska Natives. The following staff specifically work on American Indian/Alaska Native health: (1) the OMH policy lead for American Indian and Alaska Native (AI/AN) health serves as the Executive Secretary of the American Indian/Alaska Native Health Research Advisory Council that recommends tribal health research priorities to HHS, and (2) the Native American capacity building specialist at the OMH Resource Center works with tribes across the nation.

3. *Ms. Pañares expressed interest in additional information on MBK. She asked how OMH was taking advantage of the critical conversation that was currently taking place about race and urged the committee to consider its role in that conversation.*
4. *Dr. Chen stated that the Heckler Report was an important starting point for recognizing and addressing health disparities in this country, which is an ongoing struggle. He would welcome a conversation about building a successful movement that could keep these issues alive over the long term.*
5. *Dr. Juarez stated that the current emphasis on minority health, including local efforts to promote health in all policies, presents an opportunity to generate momentum at the federal level. He suggested that the committee look at new initiatives in economic development and housing and find ways to incorporate a focus on health.*
 - *Dr. Gracia noted that the National Partnership for Action to End Health Disparities (NPA) was making strides to address equity in all policies. Members of the Federal Interagency Health Equity Team (FIHET) have been looking at how to bring equity into the programs and policies of agencies across the federal government.*
6. *Dr. Malone noted that she visited a community health center in Indian Country where the majority of the care was provided by a nurse practitioner who was from that culture. She urged Dr. Gracia to promote nurse practitioners and nursing education when she makes presentations on cultural competency.*

Medicaid and CHIP Data Update

- **Barbara Richards, MPP, Director, Division of Business and Data Analysis, Center for Medicaid and CHIP Services, Centers for Medicare & Medicaid Services (CMS)**

Ms. Richards provided an update on efforts to improve access to Medicaid and CHIP data. She noted that, in 2012, CMS recognized that improving the Medicaid and CHIP data environment was an agency priority in order to meet the needs of data users, manage the implementation of the Affordable Care Act and state Medicaid and CHIP programs, and strengthen access to data for CMS and program administrators.

Medicaid and CHIP Business Information Solutions (MACBIS) is a new platform that integrates multiple CMS legacy systems in four functional areas (program data, operational data, financial data, and pharmacy data). CMS is moving toward more robust data, data validation, business intelligence and reporting, and comprehensive data integration, including state data. CMS is moving from quarterly to monthly submission of operational data.

The new operational data system, T-MSIS, has more than twice as many data elements as the old system (550+ versus 200+). New data validation requirements will provide a feedback loop to improve data quality. Robust data analytics will offer data integration and can be accessed by states. The new system is in start-up mode, and CMS is expanding the capacity of the Division of

Business and Data Analysis. T-MSIS includes three new data files (provider, managed care plan, and third-party liability) that will help CMS look at delivery system reform and access to care. It also includes all files from the legacy system (inpatient claims, long-term care claims, prescription claims, other claims, beneficiaries, and encounters).

The new system will enhance the ability to analyze data related to enrollment, access to care, quality of care, consumer satisfaction, delivery system, and payment.

- Enrollment: Supports analysis of demographic data, enrollment trends over time, and comparison of the newly eligible populations to other Medicaid enrollees. The data dictionary includes the Office of Management and Budget (OMB) expanded categories for race and ethnicity. CMS is asking states to report these data and is working with states to address limitations in what they can provide.
- Access to care: Supports analysis of geographic distance between beneficiaries and the closest Medicaid providers, adequacy of states' managed care provider networks, provider supply and providers who are submitting claims, and service utilization trends. CMS would like to incorporate geo-spatial mapping in the future.
- Quality of care: Supports analysis of state reporting on child and adult health care quality measures for claim-based measures, utilization patterns for certain conditions and preventive screenings, and trends for beneficiaries with high costs and high needs.

Discussion

1. *Dr. Juarez asked what the unit of analysis would be for geographic areas. He noted that researchers have to be able to look at a geographic area in order to link claims data to population health. It would be helpful if Medicaid claims data could be linked to other types of data that are reported by census tracts or Zip codes.*
 - Ms. Richards said CMS is still working on this issue and was open to ideas. The unit of analysis would need to reflect the fact that Medicaid is administered by states.
2. *Dr. Guadagnolo stated that it might be useful to have a connector that would make it possible for researchers to use geographic information from individuals who are eligible for both Medicare and Medicaid (dual eligibles). She asked when data would be available to researchers and the public at large.*
 - Ms. Richards said that CMS would release the information through public use files as quickly as possible. She estimated that it would be early 2016 before CMS had data from all 50 states and the District of Columbia; they would then have to conduct a quality review. She noted that not all states would be able to provide all 550 data elements. CMS would provide Meta data that would indicate which data states were unable to report and when they would be able to provide those data.
3. *Dr. Panapasa emphasized that the committee needs good, reliable, and accurate data on the minority populations it is charged to address. The identifiers in the data dictionary for race and ethnicity, as presented, did not reflect the OMB categories for Native Hawaiians and Pacific Islanders. Census 2020 might include a new category (Middle Eastern/North African). At a minimum, CMS should be in compliance with the new OMB categories.*
 - Dr. Dorsey stated that the presentation slide was not an accurate reflection of the data elements and assured Dr. Panapasa that CMS was compliant with the OMB standards.

- Ms. Richards stated that CMS can update the data dictionary over time. She noted that any changes that are made must be implemented across 50 states and the District of Columbia.
 - Dr. Dorsey stated that OMH participates in an interagency work group that advises OMB on collection of data on race and ethnicity. However, the changes they propose would not be implemented until the 2020 census.
4. *Dr. Mojica asked how CMS would ensure that states provide quality data.*
- Ms. Richards stated that CMS was working one-on-one with states and was developing a mapping process to track what data each state can provide, what they are unable to provide, and when they anticipate they could provide missing data. They were also developing a framework for assessing the quality of data and would create a feedback loop to follow-up with states. The new platform includes front-end validation requirements that must be met before data files are accepted. That process will be automated and will be reviewed by internal staff who know the state programs.
5. *Dr. Chen asked how closely CMS was working with states that are not moving quickly to provide claims data. He noted that Community Commons publishes a wide range of data sets that can be used by the general public and experts (www.communitycommons.org).*
- Ms. Richards replied that CMS staff have a wide range of training and skills related to data, and her division was developing tools to meet them where they are. She noted that the Center director was a strong advocate for making data accessible and usable.
6. *Dr. King asked how the committee could support this work going forward.*
- Ms. Richards said that CMS would welcome suggestions regarding how they could do a better job of making data available. She noted that she was working closely with Dr. Cara James at the CMS OMH regarding this issue as well as with Dr. Dorsey and Dr. Gracia.

Health Care Delivery System Reform

- Debra J. Barksdale, PhD, Professor and Director, Doctor of Nursing Practice Program, University of North Carolina at Chapel Hill

Dr. Barksdale discussed patient-centered care and its benefits for minority populations. To set the context for her presentation, she described her research showing that perceived stress was correlated with hypertension among African Americans and other research showing that provider factors, including race and perceived prejudice, impact adherence to treatment.

The Institute of Medicine defines patient-centered care 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.”

Patient-centered health care addresses the patient’s health care needs and preferences and is appropriate and cost effective. It is based on five principles: respect, choice, empowerment, patient involvement in health policy, and access, support, and information.

The benefits of the patient-centered approach include improved clinical outcomes, decreased costs, and improved patient satisfaction. Patients report better recovery, better emotional health, and fewer tests and referrals.

The challenge of patient-centered care is how to balance respect for patients with the professional responsibility to use expertise to translate clinical science into better population health.

The Patient-Centered Outcomes Research Institute (PCORI) was authorized by Congress in September 2010 as part of the Affordable Care Act. Its mission is to help people make informed health care decisions and improve health care delivery and outcomes by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader health care community.

PCORI's goals are to increase the quantity, quality, and timeliness of research information; speed the implementation and use of evidence; and influence research funded by others.

PCORI's work answers patients' key questions: What should I expect will happen to me? What are my options, and what are the benefits? What can I do to improve the outcomes that are most important to me? How can clinicians and the care delivery systems they work in help me make better choices?

PCORI's priorities are assessment of prevention, diagnosis, and treatment options; improving health care systems; communication and dissemination research; addressing disparities; and accelerating patient-centered outcomes research and methodological research. Health professionals have a role in influencing health care delivery systems. That role may include science/discovery, practice, and education; leading new models of care; and educating current and future generations.

The documentary, *The Waiting Room*, provides many examples of what needs to change (<http://www.whatruwaitingfor.com>).

Expanding the range of providers and including patient navigators would help to increase patient-centered care.

Key questions that health professionals should ask as they attempt to reconcile the need to respect and honor patients' preferences, needs, and values with their professional obligation to deliver evidence-based care include: What are the ethical considerations? What are the financial implications? What is the impact on our professional egos? What are the professional risks/liabilities? What are the risks/liabilities to the organization?

Discussion

1. *Dr. Juarez stated that the current debate regarding immunization was a good example of the balancing act between patient preferences and provider expertise, especially when patients base decisions on information from the Internet.*
 - Dr. Barksdale replied that health care providers will play a greater role in helping patients sort out the wide range of information and will add the human touch. The immunization issue is complicated, because it involves both individual rights and public safety.

2. *Ms. Pañares asked how the committee could work on the spectrum of population health issues that Dr. Barksdale presented.*
 - Dr. Barksdale stated that the committee can have a significant influence on population health and the social determinants of health. She encouraged the committee to focus on one or two priorities.
 - Dr. Malone stated that health care providers have a responsibility to take a leadership position on issues of public health.
3. *Dr. Panapasa asked how PCORI addresses the need for good, representative data in order to address gaps and barriers.*
 - Dr. Barksdale stated that PCORI did a fair amount of meta-analysis in its early days. She encouraged the committee to inform PCORI about what types of data are needed to improve health care for minority populations, and she offered to provide contact information for key individuals at PCORI.
4. *Dr. Chen noted that the health care industry is relying heavily on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) to measure the extent to which care is patient-centered. He suggested that it would be helpful if PCORI could provide guidance regarding the types of questions that are included in this instrument.*
 - Dr. Barksdale offered to find out whether PCORI was involved with CAHPS and, if not, would refer them to OMH to follow up on Dr. Chen's suggestion.
5. *Dr. Scarinci noted that patients' preferences are often based on education. She expressed concern that differential care based on those preferences might increase disparities and asked how providers could address that risk.*
 - Dr. Barksdale noted that many health care decisions are based on emotions. Providers have to walk a fine line between honoring a patient's wishes and being responsible without being paternalistic.
 - Dr. Chen agreed that patient-centered, culturally competent care is complex, and it requires a significant amount of time. A shift to outcomes-based or value-based reimbursement would be helpful, but productivity will always be a concern.
 - Dr. Malone stated that patient-centered care is about providing patients with options and letting them make decisions.
 - Dr. Scarinci said that the health care system would always be concerned about costs.
6. *Dr. Juarez noted that quality of care is another factor, especially for underserved populations. The fact that providers offer different levels of care to different types of patients is well documented.*
 - Dr. Barksdale referenced her experience providing pro bono care at a homeless shelter and noted that patients receive substandard care because resources are limited. This is a systems issue.
7. *Dr. Mojica referenced Dr. Barksdale's recommendation to expand the range of providers. She noted that Medicaid will provide reimbursement for community health workers (CHWs), but there is no funding allocated for those services.*
 - Dr. Barksdale noted that a recent meeting on care transition at the National Institute of Nursing Research discussed the role of patient navigators. In some cases, navigators may need more advanced training than CHWs typically have, which might impact reimbursement.
8. *Dr. King stated that patient-centered care requires a fundamental behavior change on the part of providers and leaders. Up until now, there has been no accountability for providers,*

leaders, and health care to make that change. He emphasized the need to include the consumer voice to help drive behavior change.

Affordable Care Act Marketplace Enrollment Updates

- Audrey M. McDowell, MS, Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services

Ms. McDowell provided an update on health insurance Marketplace enrollment and retention of coverage. She began by noting that ASPE recently published zip code-level enrollment data through February 22, 2015; county-level data broken out by race and ethnicity and other characteristics; and an update on the overall impact of the Affordable Care Act on health insurance coverage. Those documents are available in a special section of the ASPE website (<http://aspe.hhs.gov/health/reports/2012/ACA-Research/index.cfm>). CMS also publishes quarterly updates on Marketplace enrollment.

Marketplace enrollment data:

- The total number of Marketplace plan selections increased by 46 percent (from 8.0 million to 11.7 million) between the end of the 2014 Open Enrollment Period (OEP) and the 2015 OEP. Enrollment in states using the HealthCare.gov platform increased by 62 percent. Enrollment in state-based marketplaces that used their own platform increased by 11 percent. Those states also participated in Medicaid expansion, which could impact their enrollment.
- Re-enrollees comprised almost half of all Marketplace plan selections during the 2015 OEP.
- The race/ethnicity distribution of consumers selecting (or being automatically reenrolled into) plans in the HealthCare.gov states was similar in both 2014 and 2015. It is important to note that race and ethnicity data were self-reported, and consumers were not required to provide that information.
- Individuals who were African-American or Latino, young adults, those who did not have financial assistance, and/or had lower net premiums were more likely to be new consumers during the 2015 OEP.

Overall effectuation rates for HealthCare.gov states:

- At the end of the 2014 OEP, 5.4 million individuals selected a Marketplace plan and paid the first month's premium, representing a 79 percent effectuation rate.
- There were 8.8 million Marketplace plan selections at the end of the first quarter of 2015, representing an 85 percent effectuation rate.
- Effectuation rates for 2014 and 2015 were consistent with industry expectations.
- Data on effectuated coverage were not broken out by race and ethnicity.

Research questions regarding retention of coverage:

- How did Marketplace plan selection and retention patterns change between the 2014 and 2015 coverage years?
- To what extent do selection and retention of coverage appear to vary by gender, race/ethnicity, financial assistance status, and other characteristics?
- To what extent does Marketplace plan switching vary by those characteristics?

Retention of Marketplace coverage:

- About 5.6 million individuals selected a Marketplace plan during the 2014 OEP. Of those, 83 percent (4.7 million) still had an active plan selection at the end of the 2014 OEP; 67 percent still had an active plan selection at the end of the 2014 coverage year; and 65 percent still had an active plan selection at the end of the 2015 OEP.
- Individuals were more likely to retain their coverage if they were older, had lower net premiums, had financial assistance, and/or were White. There is a need to better understand factors that contribute to retention.

Marketplace plan switching between 2014 and 2015:

- About 1.2 million individuals switched Marketplace plans between 2014 and 2015 in the HealthCare.gov states. Switchers represented 54 percent of active re-enrollees and about 29 percent of all re-enrollees (both active and automatic).
- Plan switching in HealthCare.gov states was higher than in some other markets.
- Individuals were more likely to switch Marketplace plans if they were older, had lower net premiums, were Latino or White, and/or had financial assistance. There is a need to better understand factors that contribute to switching.

The 46 percent increase in total plan selection indicates that the Marketplace has not yet reached steady-state enrollment. There are some differences across sub-groups (race/ethnicity, financial assistance status, net premium) in terms of retention and switching patterns. There is a need to better understand the needs and preferences of individuals who currently have coverage as well as those who may have applied for coverage but chose not to select a plan. There is also a need to better understand factors that contribute to decisions to switch plans.

Discussion

1. *Dr. Thorpe asked if the data represented statistical differences.*
 - Ms. McDowell replied that ASPE had not yet performed a statistical analysis of the data.
2. *Dr. Thorpe asked if there were any differences in enrollment rates between African American men and women. He also asked whether anyone had looked at the intersection of race, gender, and geography.*
 - Ms. McDowell said ASPE was currently determining the validity of the data and had not conducted the level of analysis proposed by Dr. Thorpe. She noted that ASPE did not see significant differences by meta-level, although people with catastrophic coverage were more likely to keep their plans.
3. *Dr. Scarinci said the congruence between retention and switching plans suggests that engagement might be a factor. She suggested that it would be interesting to compare that pattern to utilization data.*
 - Ms. McDowell stated that utilization data were not available. That information would have to be obtained from the various insurance plans.
4. *Dr. Juarez asked if ASPE planned to make the enrollment data available to the public.*
 - Ms. McDowell replied that ASPE would release a summary report of the plan switching analysis. ASPE would conduct some quality control before the retention data would be released.

5. *Dr. Panapasa noted that the report did not capture data on the various racial and ethnic populations who were eligible but did not enroll. She suggested that some of those individuals might move to states where they could obtain coverage.*
 - Ms. McDowell stated that the plan switching analysis looked at how many people changed counties or states. The number of people who changed states was very small. She noted that Marketplace enrollment was a small part of the overall impact of the Affordable Care Act on insurance coverage. About 16.4 million uninsured people have gained health insurance coverage since the enactment of the Affordable Care Act; about 14.1 million of that number obtained coverage since the beginning of the OEP. The un-insurance rate declined by 5.3 percent among Whites, 9.2 percent among African Americans, and 12.3 percent among Latinos. This reflects the impact of the Marketplace, Medicaid expansion, and the ability of young adults to remain on their parents' plans.
6. *Dr. Chen asked if there was any analysis on the proportion of eligible applicants who enrolled in state-based Marketplaces versus the HealthCare.gov platform. This information could demonstrate the effectiveness of outreach activities in states with their own exchanges.*
 - Ms. McDowell stated that most of ASPE's analysis was focused on the HealthCare.gov states. She would look into whether ASPE had conducted an analysis of state-based Marketplace enrollment.
 - Dr. Panapasa said that state-level comparisons would be valuable.
7. *Dr. Juarez asked when state-level data would be available.*
 - Ms. McDowell said the March 2015 enrollment report included some state-level data. In 2014, ASPE published a state-level flat file that included all of the variables. A similar file for 2015 would be published once the data have been reviewed for quality. She would notify Dr. Dorsey when the file is posted on the ASPE website and data.gov.
8. *Dr. Juarez asked if there were any templates to assist with enrollment of special populations, such as youth leaving foster care or individuals transitioning out of prison.*
 - Ms. McDowell said she was not familiar with enrollment and outreach for special populations.
 - Dr. King suggested that the committee could invite speakers to address that issue at future meetings.

National Committee on Vital and Health Statistics (NCVHS) Updates

- Bruce Cohen, PhD, Massachusetts Department of Public Health

Dr. Cohen provided an overview of the NCVHS, areas where the activities of NCVHS converge with the mission of OMH and the ACMH, and activities of the NCVHS subcommittee on Data Access and Use.

NCVHS was established in 1949 and is one of the oldest statutory public advisory bodies to the HHS Secretary. Its work is organized around four core areas: standards; data access and use; population health; and privacy, confidentiality, and security.

NCVHS has increased its focus on community use of health data and recently added a working group on Data Access and Use. The workgroup has greater flexibility than the committee, because members do not have to go through the process that is required for the federal advisory committee.

NCVHS has looked closely at how they disseminate their findings. All meeting announcements, letters to the Secretary, reports, tools, and other resources are available at the committee's website (www.ncvhs.hhs.gov).

NCVHS and OMH priorities could align in a number of ways:

- Focus on federal initiatives to collect and disseminate more detailed data
- Encourage more community-focused initiatives and policies
- Protect and secure data for individuals and communities
- Develop and use data collection standards
- Extend vision beyond medical care to include broader public health issues (e.g., social determinants and inequality).

NCVHS and OMH priorities converge in several areas:

- Privacy: NCVHS focuses on making the uses and users of health data more transparent; protecting people from uses that could stigmatize individuals or communities; and improving individual access to their own information in order to improve their own health.
- Standards: Transaction standards, code sets, identifiers, and operating rules facilitate the transmission of and effective use of data. They also support capturing more granular data for analysis that can help reduce health disparities, and they support measurement of health care policy advances.
- Population health: Communities need more granular local data and the skills to use them so they can identify determinants of inequity. Social determinants of health need to be defined consistently and operationalized. This is a critical time for HHS to provide strategic support for community data engagement.

The NCVHS Population Health subcommittee has focused its efforts on developing communities as learning systems for health. The NCVHS report, *The Community as Learning System: Using Local Data to Improve Local Health*, was published in 2011. In 2014, NCVHS sponsored a roundtable on Supporting Community Data Engagement that brought together community leaders, health data connectors, and health data suppliers. A key theme concerned the expanding drive for health equity within communities and its implications for data access and use. NCVHS produced a report based on the roundtable findings and submitted a set of recommendations to the Secretary. Recommendations focused on the need to help local communities access and use available data and tools. One such tool is the NCVHS *Community Data Stewardship Toolkit*, which can be used to educate community members and leaders on appropriate practices for collecting, storing, preserving, disseminating, and publicizing health data.

Dr. Cohen's own research has focused on the importance of collecting and disseminating detailed race and ethnicity data to address disparities issues.

Potential areas for collaboration between NCVHS and OMH include:

- More participation by OMH colleagues in NCVHS workshops, hearings, and meetings
- Joint projects
- NCVHS use of OMH networks for outreach to a broader audience

- OMH input for NCVHS planning processes.

Dr. Cohen and NCVHS would welcome the committee's thoughts and suggestions.

Discussion

1. *Dr. Malone stated that nursing is moving out of the hospital and into the community, with an emphasis on keeping people healthy. The presentation did not discuss providers, but nurses would be a natural fit for a community-based initiative. Dr. Malone noted there were no nurses on the NCVHS.*
 - Dr. Cohen replied that a key unintended consequence of health care reform in Massachusetts was the realization that providers could make more money if they kept people out of hospitals. Incorporating a variety of providers in community networks is an important aspect of that strategy. The lack of nurses on the NCVHS was duly noted.
2. *Dr. Juarez noted that the University of Tennessee Health Science Center was developing databases and tools to help communities collect and use data, including a mapping tool (www.immemphis.com). He asked if NCVHS had considered developing mapping tools to make data available and accessible.*
 - Dr. Cohen replied that providing easy ways for people to visualize data can have a major impact. NCVHS has repeatedly encouraged the federal government to develop simple, interactive Web-based query systems that people can use to generate data about their own communities. Many states have developed such systems. The National Environmental Public Health Tracking Network has developed environmental and health mapping tools. There should be a more unified approach, so each state, community, or health care system does not have to reinvent the wheel.
3. *Dr. Panapasa commended the NCVHS for its attention to data granularity and asked whether they supported that level of granularity for collection of birth and death data.*
 - Dr. Cohen stated that Massachusetts has collected birth data for 35 racial and ethnic groups for 20 years, including 10 different sub-groups of Chinese. Analytic issues should not impede the collection of meaningful data on ethnicity groups, isolated linguistic groups, and other groups that have not been captured before.
4. *Dr. Panapasa asked if the NCVHS considered faith-based groups as community resources.*
 - Dr. Cohen agreed that those groups are crucial partners in some communities.

National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (National CLAS Standards) and Delivery System Reform

- Tawara D. Goode, MA, Assistant Professor and Director, National Center for Cultural Competence, Georgetown University Medical Center

Ms. Goode presented a conceptual framework for a cultural competence model, defined linguistic competence, and explored the role of the National CLAS Standards within the context of health care delivery system reform and the Affordable Care Act. She began by noting the proliferation of terms related to cultural competence, many of which are used interchangeably, and she emphasized that cultural awareness is not the same as cultural competence.

There are five key elements of cultural competence at the organizational level:

- Value diversity

- Conduct self-assessment
- Manage the dynamics of difference
- Institutionalize/imbed cultural knowledge
- Adapt to diversity (values, policies, structures, and services).

Those elements must be manifested at every level of an organization or system, including policy making, administration, practice and service delivery, patient and family, and community. They must be reflected in the organization's attitudes, structures, policies, practices, and services.

Linguistic competence is the capacity of an organization and its personnel to communicate effectively and convey information in a manner that is easily understood by diverse groups, including persons of limited English proficiency, those who are not literate or have low literacy skills, individuals with disabilities, or those who are deaf and hard of hearing. It requires organizational and provider capacity to respond effectively to the health and mental health literacy needs of populations served. It also requires policies, structures, practices, procedures, and dedicated resources to support this capacity.

There is a clear role for the National CLAS Standards in health care delivery system reform. A literature review conducted by Ms. Goode identified 15 different areas of bias in health care.

Ms. Goode reviewed the five priority areas for health care delivery system reform outlined in the Affordable Care Act and identified the CLAS standards that would address issues related to cultural competency within each priority:

- Payment Reform: Standards 5, 9, and 11
- Primary and Preventive Care: Standards 3, 4, 11, and 13
- Measuring and Reporting Quality: Standards 10, 11, and 15
- Administrative Simplification: Standards 9 and 11
- Health Information Technology: Standards 1, 12, and 13.

Discussion

1. *Dr. Juarez asked how the Affordable Care Act addressed cultural and linguistic competency.*
 - Ms. Goode replied that 18 provisions of the Affordable Care Act are related to cultural and linguistic competency. Federal civil rights laws also provide protections. However, many states do not require health care providers to ensure language access.
2. *Dr. Chen noted that California requires hospitals to provide interpretation. However, the availability of interpreter phones does not mean that patients will use them. There is a need for good policies and practices to ensure that patients understand what is happening and get what they need.*
 - Ms. Goode agreed that California has been a leader in this regard, but resources must be allocated. She noted that linguistic competency and cultural competency are not identical.
3. *Dr. Panapasa stated that health literacy is another issue. Many minority populations do not understand how to navigate the health care system.*
 - Ms. Goode noted that the framework she proposed includes health literacy as a component of linguistic competency.
4. *Dr. Malone stated that cultural competency often makes things easier in the long run, but at the beginning it can be awkward for both patients and providers.*

5. *Dr. Chen stated that, on the surface, risk assessments can identify factors that are more challenging. Over time, risk factors decline as a result of good primary care. In those mature settings, providers are often penalized for taking the time to provide high quality care.*
6. *Dr. Panapasa noted that Standard 11 references demographic data. She asked if the National CLAS Standards include a provision to ensure that data are not restrictive.*
 - Ms. Goode stated that “demographic data” is an umbrella, and organizations are free to determine what they will include. Sometimes, the data elements are not sufficient to identify the social determinants of health or the multiple cultural identities that impact health outcomes. For example, people with disabilities are rarely included in demographic data.
7. *Dr. Juarez said there was a need for an index to measure the extent to which individuals are impacted by various “isms.” He asked what incentives would help providers understand and measure whether they are making a difference.*
8. *Dr. Malone stated that “magnet” hospitals attract patients and providers by including the community in determining what services to provide.*
9. *Dr. Chen asked for examples of best practices of changes in organizational culture.*
 - Ms. Goode stated that Kaiser was doing a good job of embedding cultural competence in policies and practices and supporting personnel in this area. They have established Centers of Excellence for specific diseases and population groups that can serve as incubators for developing and disseminating new practices. The role of leadership is important. Health care organizations should get their board of directors on board and get leaders to acknowledge their role. The Robert Wood Johnson Foundation funded a project that required the CEO to be on board and attend meetings on cultural competence. It is important to think about who will be the messenger to promote the concept.

Committee Business

Dr. Gracia provided an update on the House and Senate Appropriations Committee reports for proposed FY 2016 appropriations.

Committee members discussed the presentations:

- Dr. Chen thought it would be useful to have examples of how organizations like Kaiser implement organizational change and create performance indicators to establish accountability
- Dr. Mojica observed that Dr. Cohen’s presentation included a list of NCVHS deliverables. It would be helpful to have a similar list for ACMH.
- Dr. King noted that NCVHS has multiple subcommittees, with clear responsibilities for each. He supported the proposal to collaborate with NCHVS.
- Dr. Malone stated that some form of partnership with PCORI would be good for both parties.

Dr. King asked committee members to review the presentation materials and think about potential topics for recommendations to Dr. Gracia.

Public Comment

Dr. King opened the floor for public comments. No comments were offered.

Wrap Up

Dr. Dorsey noted that the meeting materials included three additional examples of ACMH products, including letters and reports. She stated that the deliverables from this meeting should be submitted in early September. OMH could provide a technical writer to assist with references and formatting. The content would need to be provided by committee members.

Committee members discussed options and process for using a technical writer.

Dr. Guadagnolo reviewed the status of deliverables from the previous meeting.

Dr. King asked committee to review the draft deliverables.

DAY TWO – Wednesday, July 22, 2015

Call to Order and Remarks/Reflections

- Roderick K. King, MD, MPH, Chair

Dr. King invited committee members to share their reflections on the first day of the meeting.

- Dr. Malone stated that it would be important for the committee to find balance—or finding a middle point between extremes—in developing its recommendations.
- Dr. Juarez noted that the presentation on the National CLAS Standards provided a good framework to link the standards to health care system reform.
- Dr. Scarinci felt it would be important to align the committee’s recommendations with a framework that was endorsed by all HHS agencies. She would support a recommendation in response to the request from PCORI.
- Dr. Thorpe pointed out that minority health and health disparities are two different things. The committee needs to use the terms correctly and follow the mandate established by Congress.
- Dr. Juarez stated that lumping everything into “disparities” does a disservice to minority health. Minority health is about increasing health status of a minority group. The overall health of all groups can be improved without reducing disparities between groups. A comparison group is essential in order to determine disparities.
- Dr. Malone said that, as a clinician, she wants to ensure that theoretical work gets to the people who need it.
- Dr. King highlighted the “both/and” nature of this discussion. Demonstrating and defining disparities in health outcomes created momentum for minority health; the focus has shifted to interventions for targeted populations, building on the health disparities but no longer making comparisons. Public health law has not caught up with the shift. The committee can use the definitions to drive the language that is used in the field.
- Dr. Dorsey commented that the work of OMH is largely programmatic and is targeted to address identified disparities for which there is an evidence base. She suggested that the committee look at the OMH mission statement and the ACMH charter.
- Dr. Juarez noted that the National Institutes of Health (NIH) recently issued a request for information regarding disparities. This is an opportune time for ACMH to provide input.

- Dr. King noted that NIH is the driver for research on health disparities and minority health within HHS.
- Dr. Chen emphasized the importance of addressing the National CLAS Standards. The standards are well crafted, and they should be implemented and disseminated as widely as possible. There is a need for goals and objectives for each standard. The committee's recommendations should narrow the gap in health outcomes, and the National CLAS Standards are an excellent framework to get there. Dr. Chen noted that Barbara Richards' comments underscored the variable levels of awareness within HHS and in the field. The committee should look at how OMH develops leadership strategies that will improve the ability to promote health equity and reduce disparities at the implementation level.
- Dr. Malone stated that without research, there would be nothing to translate into practice, but practice is deeply important. The committee has an opportunity to balance those two aspects.
- Dr. Panapasa noted that references to data were a common thread across all of the presentations. The implications for good data and evidence-based information are significant. Many important decisions regarding race and ethnicity questions for the 2020 census are being made now. Researchers across the country are already doing the work to disaggregate the data. At a minimum, there should be a count of public hospitals that are implementing the National CLAS Standards, and which elements they are implementing, in order to understand the challenges. Technology will make it easier to obtain and analyze the data.
- Dr. Juarez said he reviewed the Medicaid brief and was reminded of how complex the program is. It is difficult to compare administrative data across 51 independent programs and to integrate administrative data with other types of data. A core data set and common definitions would be important. There is a need to balance researchers' need for granular data with practitioners' ability to collect the data.
- Dr. Thorpe noted that the new Medicaid infrastructure will not be useful if the states are unable to interface with it.
- Dr. Panapasa observed that the multi-racial population is the fastest growing demographic, but it was not mentioned in any of the presentations.
- Dr. King agreed that the multi-racial population has implications for data analysis, but it has deeper implications for how people define themselves culturally. It would be interesting to discuss this issue at a future meeting.
- Dr. Thorpe stated that speakers should be asked to frame their presentations within the context of minority health.
- Dr. Malone raised the issue of multiple roles and how the health care environment treats people differently, depending upon their occupation. That dynamic becomes even more powerful when occupation is combined with color.

Committee Business

Dr. King identified three tasks for this portion of the meeting:

- Finalize the charge of the Data Subcommittee
- Finalize Medicaid data memo
- Finalize health care system reform memo.

Dr. Dorsey made the following announcements:

- Members of ACMH and other OMH advisory committees are not impacted by the OPM data breach. However, members who serve on committees for other federal agencies should contact OPM if they have not received a letter.
- Committee members should submit their receipts for travel expenses within five business days following the meeting.

Dr. King stated that the NCVHS focus on “practical, thorough, and timely recommendations” would be a good standard for ACMH to adopt. Emphasis on balance, which was a theme of the discussion this morning, provides healthy tension between both sides.

Data Subcommittee

Dr. Thorpe presented the proposed charge for the subcommittee:

- Conduct an inventory of datasets within HHS and other federal agencies that provide useful information related to the health of racial and ethnic minority populations.
- Provide recommendations on approaches to better assess the health of racial/ethnic minorities and to link health, ecological, and administrative data at a local level.
- Data disaggregation and increased availability and quality of data on hard-to-survey (HTS) racial and ethnic minority pops
- Methods that enable the use of health data at small geographic areas.

Committee members discussed the draft charge:

- Dr. Thorpe stated that the first bullet might duplicate work that has already been done and would probably be eliminated.
- Dr. Scarinci suggested revising the 1st bullet so it is appropriate.
- Dr. Dorsey noted that a FIHET subcommittee compiled a compendium of federal datasets and offered to provide a copy of the document once it is completed to use as a starting point.
- Dr. King suggested changing “conduct an inventory” to “examine the inventory.” He also suggested removing it from the charge and making it an activity.
- Dr. Mojica suggested separating the two issues in the 2nd bullet.
- Dr. Juarez made three suggestions: 1) Add “health disparities” to the first section of the 2nd bullet; 2) specify the purpose of linking various types of data; and 3) Add verbs to the 3rd and 4th bullets.
- Dr. Panapasa suggested revising the 4th bullet to include data collection.
- Dr. King proposed to add an activity for the ACMH to partner with NCVHS, with the Data Subcommittee to take the lead.

Committee members approved the revised charge, as follows:

- Provide recommendations on approaches to better assess the health of racial/ethnic minorities and identify health disparities.
- Provide recommendations to link health, ecological, and administrative data at a local level to better assess changes in the health of racial/ethnic minorities and health disparities.
- Provide recommendations on data disaggregation and increased availability and quality of data on hard-to-survey (HTS) racial and ethnic minority populations.

- Provide recommendations on methods that enable the collection and use of health data at small geographic areas.

Committee members approved the following activities for the subcommittee:

- Examine the inventory of datasets within HHS and other federal agencies that provide useful information related to the health of racial and ethnic minority populations
- Partner with the Population Subcommittee of the National Committee on Vital and Health Statistics (NCVHS).

Dr. King confirmed that the members of the data subcommittee include Dr. Guadagnolo, Dr. Juarez, Dr. King, Dr. Panapasa, and Dr. Thorpe. Other ACMH members are welcome to join, and the subcommittee can invite external experts to participate in its activities.

Subcommittee members agreed to finalize the language of the charge. Dr. Thorpe agreed to take the lead on developing a draft memo to Dr. Gracia proposing the formation of a Data Subcommittee and to circulate it to ACMH members for review. Dr. Dorsey agreed to talk to the DFO of the NCVHS regarding the proposed collaboration.

The committee agreed on the following timeline:

- Draft memo to subcommittee: August 10
- Subcommittee comments: August 17
- Draft to full committee and Dr. Dorsey: August 24
- Comments from full committee and Dr. Dorsey: August 31
- Final memo to Dr. Gracia by the week of September 7.

Medicaid Data Memo

Committee members discussed the draft memo:

- Dr. Scarinci suggested that someone with expertise on how to capture data should review the memo in light of Ms. Richards' presentation. She also felt that the memo should include some short-term goals.
- Dr. Juarez stated that the memo should request that data be captured, with a focus on core data, common meta data, definitions, and missing data sets. The objective is to create a structure that makes Medicaid data usable for researchers.
- Dr. Guadagnolo noted that CMS made a significant effort to ensure that Medicare data are available for researchers; a similar effort was not made for Medicaid. The point of the memo is to emphasize the importance of making Medicaid data accessible and useable for researchers. There was no expectation that the data would be standardized, but it should be a priority to make them available. Ms. Richards did not provide enough information to formulate short-term goals.
- Dr. Guadagnolo noted that Medicare created encrypted beneficiary IDs. As they develop the infrastructure, CMS should make sure Medicaid data can be as nimble, not just claims data. Organizations and researchers should not have to wait until all states are on board to be able to access the data warehouse.
- Dr. Juarez stated that the introduction could be clarified to provide the context for how Medicaid has evolved over time from a maternal/child program to a safety net program as different populations were added. He agreed to draft that section.

- Dr. Malone suggested that the memo should be reduced to two pages.
- Dr. Mojica asked if the committee wanted to be more specific regarding the types of recommendations OMH should provide to CMS.
- Dr. Dorsey noted that CMS controls the data. The recommendations should provide a clear rationale, while allowing OMH flexibility to implement them.
- Dr. Juarez stated that the purpose of making data available is to make it possible to monitor changes in minority health and health disparities.
- Dr. Malone expressed concern that the first recommendation implied that OMH has the authority to make Medicaid data available.
- Dr. Mojica suggested removing the first sentence and the comparison to what was accomplished for Medicare and revising the recommendation to be less directive.
- Dr. Juarez recommended breaking the second recommendation into sub-bullets.
- Dr. Chen stated that Medicaid data would supplement data that are not captured through public health data and would be helpful in surveillance.

The committee revised the draft in real time, and Dr. Thorpe sent the revised draft to committee members for review. Committee members agreed to submit comments by July 28 so the memo could be submitted to OMH by July 31.

Health care System Reform Memo

Dr. Dorsey noted that the committee was required to discuss the recommendations in a public forum. The memo could be drafted through conference calls following the meeting.

Dr. King noted that the draft memo was based on the National CLAS Standards as a starting point. He asked if the committee still wanted to use that framework.

Committee members discussed the memo and raised the following points:

- The National CLAS Standards memo and the population health memo could be combined under the umbrella of health systems transformation to reflect the recognition that population health includes upstream components.
- Population health requires the integration of many different systems, including education, justice, and economic development.
- Those who are incarcerated are part of the community system. The memo could recommend that OMH work with the Department of Justice to increase the cultural competence of the prison system.
- The memo could incorporate the model presented by Ms. Goode to demonstrate that the National CLAS Standards encompass all areas of delivery system reform.
- Include a recommendation on portability and interoperability of electronic health records (e.g., every person has a “Smart Card”).
- Use Massachusetts state health care reform as a model.

Committee members agreed upon four major recommendations:

- Use the National CLAS Standards as a frame for culturally competent health system reform

- Expand the definition of population health, using the Affordable Care Act as a broad umbrella
- Revisit systems of payment reform to look at how risk impacts providers serving populations with significant health disparities
- Place a greater emphasis on data and health information technology.

Committee members agreed upon the following timeline:

- Conference call to revise the memo: August 5
- Formal submission to Dr. Dorsey: August 12
- Memo forwarded to Dr. Gracia for review: August 18
- Memo submitted to Dr. DeSalvo: September 2

Ms. Pañares agreed to take the lead on finalizing the memo. Other writers include Dr. Chen, Dr. Malone, Dr. Mojica, and Dr. Scarinci.

Closing

Dr. King thanked committee members and staff for a productive meeting.

The meeting was adjourned at 1:00 p.m.

ACTION ITEMS

WHAT	WHO	WHEN
Connect Dr. Scarinci with OMHRC to discuss HE-TAP workshops	Dr. Dorsey	TBD
Connect Dr. Panapasa with OMHRC to discuss how the ICPSR Minority Data Center could assist HE-TAP	Dr. Dorsey	TBD
Notify Dr. Dorsey when state-level enrollment data have been posted on the ASPE website	Ms. McDowell	TBD
Provide ACMH with the compendium of federal datasets compiled by the FIHET	Dr. Dorsey	TBD
Contact the DFO of the NCVHS regarding the proposed collaboration with ACMH	Dr. Dorsey	TBD
Finalize the Data Subcommittee charge	Data Subcommittee	TBD
Memo to Dr. Gracia proposing the formation of a Data Subcommittee	Dr. Thorpe (lead) Data Subcommittee ACMH members	<ul style="list-style-type: none"> • Draft to subcommittee: August 10 • Subcommittee comments: August 17 • Draft to full committee and Dr. Dorsey: August 24 • Comments from full committee and Dr. Dorsey: August 31 • Submit to Dr. Gracia: Week of September 7
Medicaid Data memo	Dr. Thorpe (lead) ACMH members	<ul style="list-style-type: none"> • Comments to Dr. Thorpe: July 28 • Submit to Dr. Dorsey: July 31
Health care System Reform memo	Ms. Pañares (lead) Dr. Chen Dr. Malone Dr. Mojica Dr. Scarinci	<ul style="list-style-type: none"> • Conference call: August 5 • Submit to Dr. Dorsey: August 12 • Forward to Dr. Gracia: August 18 • Submit to Dr. DeSalvo: September 2