



National Institute of
Diabetes and Digestive
and Kidney Diseases



**National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
National Kidney Disease Education Program (NKDEP)
Health Information Technology (IT) Working Group**

Using Health IT to Identify and Manage Chronic Kidney Disease (CKD) Populations

**John Edward Porter Neuroscience Research Center (PNRC-II), Building 35A
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Draft Summary

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Welcome

Andrew S. Narva, M.D., NIDDK, NIH

Robert A. Star, M.D., NIDDK, NIH

Dr. Andrew S. Narva welcomed the participants to the meeting. He introduced Dr. Robert A. Star, Director of the NIDDK Division of Kidney, Urologic, and Hematologic Diseases, who extended his welcome, as well as that of NIDDK Director Dr. Griffin P. Rodgers, to the meeting attendees. Dr. Star cited his experience 40 years ago, when he first attended a class in medical informatics taught by Dr. G. Octo Barnett. Twelve years ago, when he assisted in developing the clinical part of the NIH Roadmap, Dr. Star also sought to address the intractable problem of capturing information from routine medical practice for use in medical research and improving population health.

Researchers have begun to address the issue of using routine medical data in substantive ways. Increased interest in pragmatic trials has coincided with interest in decreasing the costs of clinical trials and research. The NIDDK is developing a portfolio on implementing and disseminating pragmatic trial research. These studies depend on capturing information on routine care using electronic health records (EHRs) and developing computerized phenotypes. In addition, two of the NIH Collaboratory projects are renal studies. The NIH also has embarked on a “big data” initiative, the success of which depends on harvesting clinical information. Reservations about EHR data persist, however, including questions about its accuracy, missing data, statistical techniques and the ability to follow patients across health care settings.

Dr. Star expressed his gratitude to Dr. Narva, Ms. Jenna Norton and the planning committee for their efforts in preparing for this meeting, which included construction of a wiki to share information. He anticipated stimulating and productive formal and informal discussions throughout the meeting.

Meeting Overview and Objectives

Uptal D. Patel, M.D., Duke University School of Medicine

Dr. Uptal D. Patel thanked all the participants for their attendance. He noted that early in his training as a nephrologist, he would hear patients say, “Doc, why didn’t someone tell me sooner?” Patients needed help navigating the health care system, and the health information of too many patients was lost. Methods were needed to better identify and manage populations with CKD.

Dr. Patel recognized the efforts of the NKDEP Health IT Working Group to address these needs. To advance population health management approaches to improve kidney health, the NIDDK planned to host this conference to identify best practices for using the wealth of information within existing EHRs and health IT systems to deliver optimal care and manage CKD patients in real time. Many strategies have been developed in isolation, but this meeting provides an opportunity to share best practices and learn from others in the field. Dr. Patel indicated that at this meeting, presenters and participants will review challenges and opportunities to facilitate additional broad-scale population efforts for research and clinical care for kidney disease, as well as develop a repository to aggregate shared strategies and resources. This repository will take the form of a wiki, an enduring platform to share ideas, code, case histories and resources.

Keynote: Overview of Challenges in Electronic Health Records-based Population Health Management

Neil R. Powe, M.D., M.P.H., M.B.A., University of California, San Francisco

Dr. Neil R. Powe provided an overview and surveyed the challenges of population health management using EHRs. From 1990 to 2010, the rates of diabetes-related complications (acute myocardial infarction, stroke, amputation, end-stage renal disease [ESRD] and death from hyperglycemic crisis) decreased, showing progress in caring for patients. Scientific knowledge and understanding have grown enormously, but closing the gap between understanding and clinical practice has remained a problem. Population health management and the use of EHRs have the potential to close this gap. Dr. Powe indicated that he will discuss the population health management framework; steps and examples in EHR-facilitated population health management; accelerating and sustaining uptake in a complex environment; and alignment, accountability and culture change.

The goals of population health management include to improve and maintain health across the full continuum of care, reduce disparities within the population, and enhance value and minimize the need for expensive interventions. The elements of population health management are evidence-based, patient-centered, cost-effective interventions; the use of data to provide consistent, proactive preventive and chronic care; and incentives for quality of care and efficiency. The challenge of population health management is combining the elements of individual health solutions into a whole that is more effective than the individual elements themselves.

Meaningful use of EHRs was established as a national priority by the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act. The Office of the National Coordinator (ONC) administers the health IT certification program, and the Centers for Medicare and Medicaid Services (CMS) established an EHR incentive program. The two key pillars of meaningful use are (1) improving population and public health and (2) reducing health disparities. Meaningful use was designed to be implemented as a phased approach: Stage 1 defines the data that should be collected by EHRs, stage 2 is improvement of care processes, and stage 3 is improvement of care outcomes.

The framework for population health management integrates risk management and population health. The framework recognizes that human health is affected by multiple types of interventions and policies

(regulatory, economic, technological, clinical and community action-based). Outcomes that are important include improved mean quality and length of life, as well as decreased disparities in mortality and quality of life. Determinants of health (biology and genetics, environment and occupational setting, and social and behavioral) are complex and contribute unequally to different clinical problems. Risk management involves using health risk policy analysis and health risk science to determine which specific interventions and policies improve public health. EHRs can be used to establish which populations are at risk and implement appropriate interventions.

The steps for population health management include monitoring and identifying populations to stratify risk, implementing health management interventions, and tracking performance and quality measures. EHRs play a role in population health management interventions through population monitoring and identification using patient registries, health information exchanges and surveillance systems; health management interventions, including patient registries, health coaching, patient portals, virtual consultations, clinical decision support tools and telemonitoring; and tracking performance and quality measures. The Kidney Awareness Registry & Education (KARE) Study, which demonstrated the beneficial effect of a primary care registry on CKD management, is an example of population monitoring and identification using EHRs to create electronic patient registries. Registry challenges for CKD care include misclassification issues because of a lack of consensus regarding the factors to use to identify CKD patients; lack of generalizability because of the increased likelihood of identifying patients that seek care more often; lack of data accessibility because of the dispersion of CKD-related data throughout the EHR database; and the complexities of CKD, including different treatment recommendations for different stages and etiologies of CKD and different comorbidities underlying CKD. Population health surveillance involves collecting, analyzing and disseminating health data to enable identification of public health trends. An example is the Centers for Disease Control and Prevention (CDC) CKD Surveillance System. Surveillance system challenges include difficulty with identifying and acquiring data sets, issues of interoperability, incomplete data sampling that may affect the generalizability of results, exclusion of important health indicators, and unreliability of data.

Dr. Powe provided examples and discussed challenges of using EHRs for health management interventions in CKD. Patient navigators help patients overcome individual barriers to care, enhance care team communication and facilitate patient engagement. The Cleveland Clinic implemented a CKD patient navigator program in 2015. Challenges include a lack of standards for developing and designing program components, the dependence of effectiveness on patient engagement, and costs that may prevent access for safety net and vulnerable populations. Self-management portals and electronic personal health records (ePHRs) are a growing aspect of EHRs that are designed to educate patients, provide patients with a way to communicate securely with their doctor, and foster patient engagement with treatment plans. Examples include My KidneyCare Center, a kiosk portal at a predialysis clinic waiting room; the My Kidney Care smartphone app; and OpenNotes, a web-based self-management portal. Challenges for patient portals and ePHRs include demographic disparities in ePHR adoption, the possibility for increased patient harm, privacy issues and the potential for increased mistrust. Clinical decision support tools provide reminders, alerts and real-time guidelines to the care team. These tools are useful for problem list documentation, automated outreach and “in reach,” as well as computerized provider order entry. Challenges associated with using these tools include the possibility of medication ordering errors from eliminating human roles, the time needed to keep the tools up-to-date, alert fatigue, infrequent documentation of CKD, possible bias in problem list documentation, and the inability to improve outcomes with documentation alone.

Regarding tracking performance and quality measures, health information exchanges (HIEs) are key tools to enhance care coordination by allowing health data to flow between different delivery settings, fulfilling a vital need because many patients receive care from multiple locations; health information organizations bring together multiple stakeholders to exchange clinical information electronically. HIE challenges include market forces, inadequate funding, policy challenges (i.e., “meaningful use” requires only having

the capability to exchange data), concerns about privacy and security, technical challenges with large-scale data aggregation and integration, and the need to involve payers.

Dr. Powe outlined the actions that need to be taken to accelerate and sustain EHR-based population health management:

1. Build the case for better health, experience and value.
2. Build provider trust in data completeness, accuracy, consistency and risk prediction.
3. Redesign workflows in organizations to act on data.
4. Address privacy and security protections.
5. Recognize the digital divide and address disparities for vulnerable patients.
6. Create sustaining partnerships with outside entities.
7. Incorporate the patient's voice.
8. Build expertise in IT, data management and analyst/statistician staff, which can be a financial challenge.
9. Promote accountability.

Accountability, alignment and change in culture must be promoted. Actions to take that will create catalytic but supportive business, clinical and regulatory environments include continuing EHR meaningful use incentives, establishing rules of engagement and governance of HIEs, and creating more "e-quality" measures generated from EHRs, such as those of the National Quality Forum. Accreditation and certification need to be aligned; for example, hospitals demonstrating meaningful use will be more likely to receive new residency slots under new Graduate Medical Education legislation, and meaningful use could be aligned with board recertification (e.g., the American Board of Internal Medicine's self-assessment modules that test doctors' ability to use EHRs for population health management). In addition, the National Committee for Quality Assurance's Patient-Centered Medical Home criteria are aligned with meaningful use, and the Joint Commission on Accreditation of Healthcare Organizations has been contracted to investigate unfavorable health IT-related events and develop remedies.

Dr. Powe concluded by again sharing the population health management framework, indicating that during this meeting, different aspects of the framework will be discussed and examples of those aspects provided.

Patient Perspectives

Richard Knight

Mr. Richard Knight shared some of his history as a patient, which provided the motivation for his current advocacy activities. In 1996, his application for life insurance was denied, and he was advised to see his doctor. When he met with his primary care doctor, he was told that he had protein in his urine and that some insurers will not offer life insurance to people with that condition. His doctor did not tell him that it was an indication that he had kidney problems. From 1996 through 2004, Mr. Knight was under the care of a primary care doctor. He had regular blood tests performed. Once, when the results of a blood test were lost, he was refused a retest on the grounds that his insurance might not pay for it. He eventually saw a urologist because his brother was having prostate problems. The urologist called him and after asking

whether he was under the care of a physician, told him the result of his creatinine test, which was 13.5 mg/dL, and advised him to go directly to the emergency room. Because he felt no symptoms and was operating his own business, Mr. Knight finished work that day before going to the hospital. A catheter was inserted and dialysis was started at the hospital.

Mr. Knight stated that his story illustrates the need for better preventive care if one goal in CKD care is to increase the use of arteriovenous fistulas (AVFs) for dialysis. He directed his remarks in particular to primary care physicians (PCPs). When he took his medical records—which he had difficulty securing—to a specialist, the specialist confirmed that as an African American male with high blood pressure, his care should have been more aggressive.

Mr. Knight was on dialysis from 2004 through 2006. In 2006, a friend who was a perfect match donated a kidney for him. Mr. Knight noted that in Washington, D.C., a disproportionate number of African Americans are on dialysis and need a kidney. While on dialysis, Mr. Knight maintained his activities although he was told that he should go on disability. He also learned that dialysis patients are perceived as unable to understand more than basic information about their condition. Mr. Knight was helped by the example of a friend who was on dialysis for 31 years. He learned that patients need to educate themselves about their condition. In his work as a liaison to Capitol Hill, he also learned about the importance of lobbying to prioritize funding.

EHRs and patient portals are very helpful to patients. As medical information is translated for patients, soliciting patient input is important. Often, the type of information that is sought by patients is that which is available only through the doctor's portal, not the patient's portal.

Mr. Knight thanked the participants for the opportunity to speak to them and expressed his appreciation for their efforts, which will have a positive impact on the CKD community.

Moderated Panel 1: Population Health Management in Public Systems

Moderator: Kevin Abbott, M.D., M.P.H., NIDDK, NIH

Panel Introduction

Kevin Abbott, M.D., M.P.H., NIDDK, NIH

Dr. Kevin Abbott introduced the panel of speakers from Canada, the Veterans Affairs (VA) system and CMS. Dr. Abbott, previously with the Department of Defense (DoD), observed that the DoD is the closest program to a national medical system that exists in the United States. The presentations focused on strategies, challenges and facilitators for CKD population health management efforts in public systems.

Alberta Kidney Disease Network

Brenda Hemmelgarn, M.D., Ph.D., University of Calgary

Dr. Brenda Hemmelgarn presented a review of the strategies for kidney-related population health management adopted by the Alberta Kidney Disease Network (AKDN) in the hope that they will serve to inform the working groups and spark discussion. Alberta is a province in western Canada, with a population of 4 million adults. The researchers in the AKDN studied the implementation of estimated glomerular filtration rate (eGFR) reporting across the province and the impact it had on nephrology visits and health care resource use. Reporting eGFR increased nephrology visits in patients with values less than 60 mL/min/1.73 m² and even more so in patients with values less than 30. An initial peak in visits that declined over time was observed in both cohorts, suggesting that to increase referrals, additional information beyond eGFR results might need to be provided. In the next phase, the AKDN group performed a cluster-randomized, controlled trial, in which they randomized a cluster of general

practitioners' practices in three health regions of the province: two rural regions and one urban region. They compared the standard prompt to a more detailed, laboratory results-based prompt and measured clinical composite and standard-of-care outcomes. No differences in the clinically relevant composite endpoint over a median of 2.1 years were found. Additionally, referrals to a nephrologist for eGFRs of less than 30 mL/min/1.73 m² were not significantly different. Although they might have potential, single-faceted interventions did not achieve the desired effects. Therefore, interventions that were multifaceted, as well as more interactive, were tested.

The CKD Clinical Pathway was a more interactive approach. First, the researchers worked closely with PCPs to develop a guideline that would be more applicable to the local setting. Translating knowledge into action involves identifying problems, adapting knowledge to local content, assessing barriers, designing and implementing interventions, and evaluating and sustaining knowledge use. This framework was used to tailor the intervention to the needs of the PCPs. Some of the features the physicians deemed important were effective use in point-of-care assessments and easy access to information. The AKDN assembled key stakeholders, including members from the IT community, to design the pathway. The CKD Clinical Pathway is open access and is available online (www.cdkpathway.ca). Some of its key features were designed based on input from PCPs to enhance the efficiency in care. Several challenges for the CKD Clinical Pathway have been identified, including dissemination and uptake among physicians and planning for sustainability. Lessons learned from developing the CKD Clinical Pathway include that an integrated approach is important, implementation takes both time and a variety of resources, and it is important to consider scale and dissemination.

Dr. Hemmelgarn summarized that the AKDN is located in a geographically defined population, has partnerships with other stakeholders to integrate clinical care practices, and has taken advantage of pragmatic interventions. However, challenges to the AKDN include being faced with outcomes that are limited by the data sources available, the inability to target a higher risk population, and the need for multipronged strategies and approaches.

Population Health Management at the Veterans Health Administration

Theresa Cullen, M.D., M.S., Regenstrief Institute

Dr. Theresa Cullen presented on health IT and the functionalities that have proven most important. Population health is the key to achieving health equity. Some recommended stages of public health management for CKD within health IT that she deemed critical include the following: (1) the patient and health care team should direct requirements; (2) software design should be consistent with living digital design principles; (3) data should be available; (4) electronic specifications for clinical quality measures should be adaptable, yet quality based; (5) the knowledge display should prompt appropriately without overload; (6) clinical reminders and action plans should be driven by understandable, weighted logic; (7) architectural design should result in public health management at the same time as clinical care delivery; and (8) data should be acquired, shared, aggregated and analyzed.

Much of Dr. Cullen's experience with CKD has been with the Indian Health Service (IHS), and she highlighted the improvements in CKD care that they were able to achieve at that organization. IHS delivered integrated health care successfully to almost 2 million patients in 36 states; designed a health IT system initially for patients within the context of a community; and designed a health IT system that was enhanced for patients, communities and population health management. What has worked best with the IHS has been public health management that was driven by a need for efficiency and impact.

Dr. Cullen stated that within the Veterans Health Administration, they successfully deliver integrated health care to 6 to 8 million patients throughout the United States. The VA has a health IT system designed initially for patients that is currently being enhanced. Public health management at the VA is driven by a need for efficiency and impact. The Veterans Health Administration's Kidney Data System

details the state of kidney disease in the VA patient population. The goals of the system are to provide data to multiple stakeholders and identify areas for improving care for acute kidney injury (AKI), CKD and ESRD. Care has been improved through public health management, involving health care teams, and improving dialysis.

In closing, Dr. Cullen opined that another registry is not what the CKD field needs. The focus instead should be on the following: (1) patient, provider, community and population views; (2) specific and consistent electronic definitions; (3) active electronic taxonomy curation within the health IT system; (4) clinical reminders within multidisease states; (5) actionable data presentations at the point of care; and (5) interoperability and data sharing. Dr. Cullen stressed that the opportunities are optimal for the CKD community to position itself with health IT.

Health Information Technology Barriers to Quality Improvement

Joel Andress, Ph.D., CMS

Dr. Joel Andress presented on barriers and solutions to data issues in quality measures, surveying the importance of quality measure development, limitations and opportunities for improvement, the ESRD Measure Evaluation Quality Initiative, patient-oriented measures, and e-measures. CMS has long played a leadership role in quality measurement and public reporting for dialysis facilities. This endeavor has provided CMS with the opportunity of shaping the quality measurements field.

The development of new quality measures should be evidence-based, a transparent process with public comment, able to recognize the critical role of technical expert panels, and finalized with rule making. CMS' approach to developing measures is cyclical. CMS has developed a strategy for managing measures planning called the Measures Management System Model. The four major components of the model system that are most relevant for CKD are the following: (1) CMS measure priorities planning; (2) measure conceptualization, specification and planning; (3) measure implementation selection and rollout; and (4) measure use evaluation and maintenance.

CMS' quality strategy goals are relevant to ESRD, particularly the goals of making care safer (e.g., reducing infections), engaging patients and families, promoting effective communication and coordination of care, and promoting effective prevention and treatment of chronic disease. Quality measures include the population included in the measure; how frequently an event occurs; criteria for exclusion from a measure; and risk adjustment, which account for factors outside a facility's control. CMS has developed clinical measures specifically related to ESRD issues, including hemodialysis adequacy, peritoneal dialysis adequacy and vascular access, among others.

The measure evaluation criteria consist of importance, scientific acceptability, feasibility, usability and harmonization. Challenges to data collection for measure development include the potential data burden itself of collecting new data to support new measures and the use of different IT systems and platforms by providers for collecting and submitting their data. The timeliness of Medicare administrative claims data can pose challenges. The proposed solutions to data collection and measure development that the CKD community might consider include implementing measures without testing; requiring reporting of data through existing programs to support testing; and leveraging new programs for data collection, as seen in the CMS Innovation Center's Comprehensive ESRD Care Payment Demonstration. Moving forward, consideration should be given to the availability of data to support the testing of new measures. Successful testing also relies on a greater balance of stakeholder input at critical stages in measure development.

Dr. Andress stated that the ESRD Measure Evaluation Core Initiative is one preliminary attempt to address the challenges to data collection for measure development. The ESRD Quality Measure Testing Plan is currently in the development phase and is a process whereby researchers can engage in testing not

only the feasibility of collecting new data but also the validity and reliability of measure constructs built out of those data elements. The plan will be a volunteer program in which CMS will work with the dialysis facilities to collect data for two phases, alpha and beta testing. Alpha testing is small-scale and will identify and troubleshoot feasibility issues regarding the collection of data elements. Beta testing will partly depend on the quality measure collection tool for the Consolidated Renal Operations Web-Enabled Network (CROWNWeb), which allows collection on a voluntary basis of data elements that the CMS measure developers at the University of Michigan will define and make available to facilities in the network.

In closing, Dr. Address identified two classes of measures that require additional development: patient-oriented measures, where CMS will be studying avenues for developing new patient-centric measures in the coming year, and electronic clinical quality measures (e-measures), where interoperability is not yet in place.

Moderated Discussion

Dr. Abbott asked Dr. Hemmelgarn to explain why nephrology referral rates were less than 50 percent. Dr. Hemmelgarn explained that the researchers are exploring the reasons for suboptimal referral rates; referrals need to be facilitated, and tools need to be put in place to do so.

Dr. Abbott noted that EHRs often are implemented as top-down systems and asked the panel members about approaches to engage providers more directly in the systems to improve care. Dr. Cullen suggested that users should help design systems. Functionality could be added so that providers can customize their own panels of patients on which to run quality measures. Quality measures should be reported on a health care team basis, rather than by provider. Dr. Address noted that quality measures provide gross information about the care provided but do not provide feedback on changes that might be made to improve care. For example, readmission rates do not contain information about comorbidities of patients. He advocated for reporting quality measures by care team, because team members are jointly responsible for the care of patients. In addition, he noted that reporting readmissions by hospital can be misleading because patients do not always return to the same hospital.

Dr. Abbott recalled Mr. Knight's history of an 8-year gap when he should have been under the care of a nephrologist. Given that a significant proportion of patients start dialysis without ever having been seen by a nephrologist, Dr. Abbott asked the panelists what could be done to improve communication between patients and providers. Dr. Hemmelgarn responded that health portals provide information, but they also can be used for two-way communication between patients and providers. Dr. Cullen stated that all patient notes, including mental health notes, are now open at the VA. This initiative was part of an effort to educate and engage patients, which is seen as critical. Investigations are ongoing about which formats—for example, audio recordings, provider notes, and videos—patients prefer for educational material. Mobile technologies are being developed to interact directly with patients. Dr. Address stated that when developing quality measures around interacting with patients, the interactions need to have a product (e.g., medication management) that quality measures can capture, rather than being represented as just a check box.

Dr. Narva commented that readmission was considered an ideal quality measure because of the expense it represents and ease of collecting data, but its use as a quality measure met significant resistance. Dr. Address replied that the implementation of the measure was part of the reason it met resistance; the dialysis community was not part of the discussion, and providers responded that readmissions could occur for reasons other than the care that they had provided. When developing quality measures for CKD care, the broader community—including nephrologists, data experts, nurses, federal partners and patients—

needs to be engaged. CMS will benefit from greater feedback from the community through public comments and advisory panels.

Audience Questions to the Panel

A participant asked Dr. Hemmelgarn whether she is collaborating with the Canadian Primary Care Sentinel Surveillance Network, which spans the country and multiple EHR systems. Dr. Hemmelgarn clarified that the Network integrates electronic records within primary care settings across Canada; each primary care setting is considered a node of the Network. She is collaborating with the Network on ways to enhance the referral process and apply a risk prediction tool for ESRD to use for referrals.

A participant asked whether the CKD Clinical Pathway is stand-alone or integrated into the EHR system. Dr. Hemmelgarn responded that the decision was made to make CKD Clinical Pathway publicly available; the next phase will be to integrate the tool into patients' care plans and evaluate its effectiveness in a cluster-randomized, controlled trial.

In response to a question about whether the CKD Clinical Pathway is aimed at the PCP or the patient, Dr. Hemmelgarn replied that when it was first developed, the CKD Clinical Pathway was focused on the provider, but in the next stage of its development, the focus will be on tools to help patients in different stages manage their CKD. Patients particularly are interested in gaining access to their laboratory results, which is not common in Canada. Dr. Cullen noted the patient interest when the VA opened provider notes to patients prospectively starting in January 2015. Observing whether patients with abnormal laboratory results will be motivated to change their behavior now that they have access to those results will be instructive.

A participant commented that registries have the positive effect of creating a community for patients and asked Dr. Cullen why she had advocated for "no more registries." Dr. Cullen clarified that she was advocating for moving beyond registries. Currently, access to primary data is limited in registries. Registries will be more useful in the long term if the data contained within them could be queried independently.

A participant asked for more details about the DoD's EHR system. Dr. Cullen responded that the DoD had acquired a proprietary system. The system was designed to change the graphical user interface to increase the functionalities it provides. Usability remains an issue for many systems. The VA's goal is to have interoperability at the point of care.

A comment was made that providers should not be "graded" on a curve. Absolute achievements should be made public to motivate improvement. Dr. Andress responded that measures evolve over time. He recognized that improvements could be made in describing the quality of care that dialysis facilities provide. Greater engagement by stakeholders will allow measures, such as the star ratings of dialysis facilities, to better communicate quality of care to patients.

A participant asked Dr. Hemmelgarn about the effectiveness of efforts to follow up with patients once they are engaged with the CKD Clinical Pathway. He cited a study in which he is engaged that makes a CKD-enhanced chart available to the patient. Dr. Hemmelgarn responded that evidence is lacking about how to engage patients. Evaluation of effectiveness is critical. Dr. Cullen added that factors by which to stratify patients (e.g., age, race, sex, internet access) are not known.

Dr. Patel asked the Panel members to comment on the challenge of using EHRs for purposes for which they were not designed. Dr. Hemmelgarn responded that engaging stakeholders during the development EHR systems is needed. Dr. Cullen added that stakeholders have to be very clear about what they need.

The Federal Government also can have a role in establishing standards for EHR systems. Dr. Abbott commented on the need to curate referrals so that borderline cases do not overwhelm the system.

Mr. Knight observed that early intervention by physicians can result in significant cost savings in CKD care. He advocated for a patient-centered focus, which he speculated might be achieved only through legislation to change the reimbursement model.

A participant observed that better communication is needed between PCPs and specialists, as well as between patients and providers. Comorbidities also complicate the care of patients with CKD. Dr. Cullen replied that interoperability is a transcendent issue because, as seen at the VA, a large fraction of patients receive care in multiple settings.

Moderated Panel 2: Population Health Management in Vertically Integrated Systems

Moderator: Alan S. Go, M.D., Kaiser Permanente

Panel Introduction

Alan S. Go, M.D., Kaiser Permanente

Dr. Alan S. Go began the panel by stating that vertically integrated systems potentially take a different approach to population health management of CKD. They benefit from greater integration between the provider and payer.

Population Health Management at Kaiser Southern California

Mark P. Rutkowski, M.D., Kaiser Permanente

Dr. Mark P. Rutkowski began with a motivational song about the complexities of CKD care. Kaiser's overall population management strategy for CKD is that a majority of CKD Stage 1 through 3 patients need to be fully integrated with all other population care efforts; only a subset of CKD Stage 1 through 3 patients with a compelling need are seen by nephrology; and CKD Stage 4 and 5 patients need a multidisciplinary and systematic approach by nephrology to optimize care and prepare for renal replacement therapy.

Decisions based on eGFRs or CKD staging need to be supported by accurate and specific data. As an example, it is preferable to use race-adjusted eGFRs rather than report eGFRs for black and non-black races. EHRs provided opportunities for clinicians to update the race being used for the correction of future eGFRs at the point of care in order to improve the accuracy. (The updated race also can be used to recalculate eGFRs for staging retrospectively.) An additional way to improve accuracy is that the race used for the eGFR is shown on the patient portal so that the patient also may notify the provider if this is inaccurate, which is the same idea as open notes improving charting accuracy. The eGFR appearing on the patient portal also illustrates the downstream data implications of many decisions made upstream. For example, an eGFR at the Kaiser Permanente Southern California laboratory is considered an "interpretation" rather than a "normal or abnormal result" so it is not flagged as abnormal when it appears on the portal. This prevents the concern generated by minor fluctuations in GFR and allows clinician to put GFR level in perspective for the patient.

Developing the staging algorithm for the CKD registry required extensive discussion. Staging ultimately considered the chronicity of GFR test results, GFR values, other markers for CKD (e.g., proteinuria), and consideration of the effect of age on GFR. Some patients were excluded from the CKD registry and instead classified as having chronic reduced GFR Stage 3 because of the staging algorithm, which considered age and other markers for CKD. The specificity of CKD staging prevents including patients

with chronic reduced GFR Stage 3, who are numerous but low risk, in best-practice alerts; the registry is highly specific so that efforts to care for high-risk patients are prioritized.

An important issue is which CKD patients need to see a nephrologist. Examples were shown of decision support messaging in EHR when a referral is placed for a CKD 4/5 or for a CKD 3 patient that incorporates concepts of the etiology of renal disease, level of albuminuria, and rate of GFR loss. One point of interest was how to track patients who have chosen no future dialysis. If, after discussion with the patient by either the PCP or nephrologist, a shared decision has been made not to initiate dialysis, then the provider is encouraged to place a specially designed code on the problem list: “Shared decision made to not initiate or discontinue dialysis.” This problem list code then can be easily used by the population management data system to modify the population efforts for this CKD subset. For example, if the PCP has entered this problem list code, then outreach for a referral to nephrology will stop, although the PCP could initiate a referral if still needed.

Population management involves data integration with the medical record at the point of care, the problem list, and best-practice alerts. The CKD staging, including whether on dialysis or with transplant, from the population management system feeds back into the EHR medical record system on population management summary sheet, as well as via a dynamically updated health maintenance modifier (HMM) in the Epic EHR. This functionality then can be used in best-practice alerts, with examples shown of reminders to avoid a peripherally inserted central catheter (PICC) and write a “Save the Veins” order to post as appropriate bedside signs.

Patients identified by the creatinine safety net were not limited to the elderly; they included a significant number of patients younger than 40. Because a filter was used, a large number of low-risk, elderly patients were not included in the cohort, and the outreach effort could be focused.

Including a chronicity algorithm led to greater data consistency in the CKD staging. The usefulness of this chronic stage assignment, akin to the concept of baseline renal function, has many uses. Data were shown of the last chronic CKD stage before the patient progressed to ESRD. Only a small percentage of patients were classified as chronic reduced GFR Stage 3 prior to ESRD; most patients were Stage 4 or 5. Data were shown of the percent of patients seen by nephrology prior to ESRD by prior CKD stages.

Metrics are used to determine success in optimal starts of ESRD. The optimal start metric includes credit for home dialysis, starting dialysis with an AVF, and preemptive transplants. The denominator used is the number of patients with CKD Stage 4 or 5 as the last chronic stage prior to progressing to dialysis. In data from 2011, starting dialysis was four times more likely than dying in 1 year for patients who were CKD Stage 4c (chronic GFR 15 to < 20) or 5 (chronic GFR < 15). For Stage 4 or 5 patients younger than 65, the focus is on early kidney transplant listing prior to dialysis. Potential progressors to CKD Stage 4 or 5 are identified preemptively for follow-up by a nephrologist or PCP.

Key CKD data from Kaiser Permanente Health Connect (KPHC), Kaiser’s EHR system, are being captured by the Renal Patient Life Course Questionnaire to eliminate data entry in other databases and allow data to be entered at the point of care. Much of the data for the Monthly Nephrology Quality Update email, which is directed to the nephrology team, is derived from variables in the Renal Patient Life Course Questionnaire. An example was shown of how the data can be used to allow renal social workers to follow up on patients who are unable to make a renal modalities decision or who are on the no dialysis pathway by choice. The data from the Renal Patient Life Course Questionnaire can be used to generate a report that shows the progress over time in regard to optimal start preparation.

The patient portal includes a Personal Action Plan, which has a subsection for CKD 4/5 patients. Patients can view the trends in their GFR test results and can see where they are in the preparation for ESRD. The Personal Action Plan also contains links to resources for patient education.

Dr. Rutkowski concluded with a final verse of the song about CKD, describing the advantages of an optimal start for patient outcomes.

Population Health Management at Geisinger Health System

Evan Norfolk, M.D., Geisinger Medical Center

Dr. Evan Norfolk reviewed the Geisinger Health System model for population health management of CKD. With almost 500,000 members, Geisinger is the largest rural health care system in the United States. Geisinger has implemented the Epic EHR system in its ambulatory clinics and inpatient services since 1996 and 2007, respectively. All Geisinger inpatient facilities and medical groups, as well as many private practitioners with EHRs who share Geisinger patients, are connected by Geisinger's EHR system. The Geisinger model includes patient-centered primary care; integrated population management; creation of a medical neighborhood; delivering quality care as measured by patient satisfaction, comprehensive chronic disease-bundled metrics and preventive care metrics; and value-based reimbursement.

Geisinger hypothesized that the traditional mode of care in anemia management, erythropoiesis-stimulating agent (ESA) oversight and management primarily by physicians, was not leading to optimal care. The fundamental design for a new mode of care was for a nephrologist and pharmacist to jointly develop protocols for ESA and iron treatment. Comparing data for protocol and non-protocol patients, protocol patients reached hemoglobin goals more quickly and remained within hemoglobin goals longer. Protocol patients also remained within transferrin saturation (TSAT) goals longer and were more likely to have ESA treatment administered at home than in the clinic. In addition, protocol patients had an expanded dose interval and required lower total doses, resulting in estimated annual cost savings per patients of almost \$4,000.

Geisinger implemented nephrology-specific care bundles to manage CKD. Geisinger has a large population of CKD patients, with approximately 2,900 adult patients with a GFR less than 30 mL/min/1.73 m² and 15,000 to 20,000 adult patients with a GFR less than 60. To close care gaps, EHR alerts to PCPs and a CKD bundle were implemented for CKD Stage 4 and 5 patients, and EHR alerts to PCPs were implemented for all nondiabetic patients with proteinuria. After implementing the CKD bundle, care of CKD Stage 4 and 5 patients improved in terms of reduced hypertension, near-universal twice-yearly assessment of renal function, increased annual assessment of urine protein, and increased administration of the influenza vaccine. Other measures improved by the CKD bundle included increased administration of the Pneumovax vaccine, as well as increased rates of testing for phosphorus, hemoglobin and parathyroid hormone (PTH).

CKD/ESRD patients at Geisinger tend to be older and sicker, having an average age of 65.9 years, seeing approximately seven different classes of medical providers per year, and having 13 different prescriptions. Reasons for readmission for ESRD patients include congestive heart failure, access failure and sepsis. Transition opportunities include fluid overload, vascular access, medication-related problems, dietary-related problems and end-of-life care.

To assist with transitions of care, ESRD patients at Geisinger are matched to a case manager. Case managers are trained and supervised by the nephrology practice. The goals of the case manager program are to optimize medical management while the patient is hospitalized; coordinate care after discharge; prevent emergency department visits, admissions and unnecessary readmissions, thus reducing costs; enhance patient and provider satisfaction; and enhance communication. Case managers interact most frequently with higher risk patients, such as new start and post-discharge patients, and they interact with patients at the dialysis unit, via telephone call and via home visits. Case managers collaborate with providers to manage comorbid conditions, provide medication reconciliation, optimize medication, and identify and facilitate support services. Types of intervention also include identifying psychosocial and physical barriers to care and developing interventions to address those barriers, as well educating patients

on self-monitoring and self-management strategies. Case managers meet weekly with nephrologists and the program director to review individual patients, admissions and emergency department visits. Case managers and/or the program director also meet monthly with hospitalists, and the program director meets regularly with emergency department staff. The results of the program in its first year were reductions in admissions, emergency department use, avoidable readmissions and per member costs.

Given the program's success with dialysis patients, a similar case manager program was established for CKD patients. Case managers assist with management of signs and symptoms of CKD, including volume status, weight, diuretic therapy, blood pressure management, dietary education and anemia management. CKD case managers facilitate decision making on ESRD choices and identify psychosocial barriers to care, developing interventions for those barriers. In the first 5 months of the program, reductions were realized in admissions, emergency department use and readmissions. In the future, Geisinger plans to expand the number of care managers and focus more on patient education, looking at straightforward interventions, such as nonsteroidal anti-inflammatory drug (NSAID) use.

Geisinger also plans to develop a CKD population program. The program will take the form of a computerized database of every CKD patient served by Geisinger. The CKD population electronic dashboard will assist in early identification of clinical problems, assist in referrals and track outcomes, with the goal of decreasing the rate of progression, as well as increasing the percentage of patients starting dialysis as an outpatient and starting with a mature AVF. Other data-driven reports will include a census of (1) patients with an eGFR less than 25 mL/min/1.73 m² and their AVF access status and (2) PICC line placement in hospitalized patients with a GFR less than 30.

Population Health Management at the Mayo Clinic

Amy W. Williams, M.D., Mayo Clinic

Dr. Amy W. Williams stated that in preparation for bundled reimbursement, the re-engineering dialysis (RED) program at the Mayo Clinic was designed to manage all care required by patients with ESRD and improve the value of care delivered to patients on dialysis, representing a system that is financially responsible and meets external metrics. In the patient population at the Mayo Clinic, a small fraction of the patients with multiple chronic conditions was found to represent a large fraction of Medicare spending. The Mayo Clinic, therefore, dedicated significant resources to re-engineer dialysis. Achieving population health at every level of the care pyramid was based on improving the patient experience through evidence-based practices. The RED roadmap addresses the top of the pyramid and is a long process that includes defining metrics, addressing the needs of at-risk patients, supporting shared decision making, addressing transitions in inpatient care, educating patients, and disseminating best practices. Accountable care must address the continuum of care—from CKD through ESRD decision making, dialysis and end-of-life care—and must involve an extended team of providers.

Using observations and interviews, the Center for Innovation developed different personas representing the patients with ESRD cared for at the Mayo Clinic. Each persona had a different disease trajectory that included many transitions of care, each requiring support to be successful. The five key patient needs, as seen through the eyes of the personas, included (1) shared decision making, (2) collaboration and empowerment, (3) open and honest communication, (4) improved education, and (5) clarified external relationships. Patients were concerned primarily with the cost of care, but they also wanted to know about survival rates for different modalities, as well as roles and responsibilities for themselves, family members and their care team. The main lesson that was learned from the patients was “Patients don't get vacations.” It is the job of the care team to evaluate the burden to the patient, assess the patient's capacity to cope with the burden, and decrease the burden of the patient's disease.

Project RED developed a set of best practices for different steps in the disease trajectory. These best practices describe support for the patient at different stages and transitions of care. Standardization,

collaboration and communication were found to be key to smooth transitions. Examples include patient preference-focused educational materials, EHR alerts for referrals when GFR is less than 25 mL/min/1.73 m²; EHR tools to communicate care plans; an electronic evidence-based practice CKD care algorithm; a standard CKD visit template; and expanded multidisciplinary care teams that include pharmacists, who round with the care teams for dialysis patients. Educational materials and decision aids that are available to patients on the Mayo Clinic intranet include AskMayoExpert, which has information on CKD, and patient materials that the physician can provide to the patient in an office visit. A decision aid was created to help patients decide on modality, which patients reported was important to them. The CKD care algorithm takes the form of a decision tree that has different steps for patient evaluation, testing and referral and provides information about needed laboratory tests and what the test results mean. Standardization of hospital care and of the hospital care team included admitting patients to a designated inpatient unit and standardizing order sets. A consistent, integrated flow of information was achieved by multiple measures, including daily meetings of inpatient and outpatient ESRD care teams, participation of nurses in dismissal rounds, and just-in-time patient educational materials. IT resources were used to smooth transitions. The diffusion matrix is a dynamic tool to ensure that the care team is implementing the measures that it is supposed to. Each cell in the matrix is “clickable” to reveal progress and determine barriers to implementation, allowing optimal allocation of resources.

The results of implementing Project RED include significantly reduced avoidable use of emergency and inpatient services, decreased in-hospital dialysis runs, significantly decreased hospital starts, medication therapy management (MTM) estimated total cost-of-care savings of approximately \$3,000 per patient per year, and a significantly decreased 30-day readmission rate. The Mayo Clinic plans to sustain the gains realized through Project RED by creating an oversight and reporting structure and continuing support from leadership. Lessons learned regarding what is essential for success include understanding the needs of the patient, receiving support from top leadership, managing knowledge across the system, establishing common expectations and defining accountability through stakeholder engagement, and implementing accountability and the use of metrics.

Moderated Discussion

Dr. Go asked the panel members to describe the most significant barriers to EHR-based population health management of CKD. Dr. Williams replied that smaller clinics and dialysis units lack sufficient resources. Dr. Norfolk cited disparities in accessing EHRs. Drs. Rutkowski and Norfolk cited a need for more staffing to leverage IT solutions.

Dr. Go inquired about the scalability of IT solutions to smaller patient populations. Dr. Williams observed that the Mayo Clinic’s dialysis population was small—only about 500 patients—although it serves a large area. Having multiple sites requires a diffuse IT solution. The advantages of being a single site include no conflicting priorities.

Dr. Go asked whether serving larger populations, which have sicker patients, represents a scalability problem. Dr. Norfolk responded that streamlining Geisinger’s approach has been challenging. Dr. Rutkowski stated that Kaiser’s biggest challenge has been integrating CKD/ESRD care with other disease efforts, such as diabetes.

Dr. Go inquired about a structured approach to CKD/ESRD care. Dr. Williams responded that decreasing the need for patients to come in to see providers improves outcomes and decreases the burden on the system. Dr. Norfolk noted the advantages of patients being able to have multiple appointments on the same day. Dr. Rutkowski stated that CKD Stage 4 or 5 patients can be resistant to treatment because they are asymptomatic; having care givers to lead them through their care is needed.

Dr. Go asked whether the leadership of the panelist's organizations are likely to be amenable to conducting randomized, controlled trials of interventions. Dr. Williams responded that no randomized, controlled trial was conducted for Project RED, but randomized, controlled trials were conducted for other communities of practice. Dr. Norfolk stated that the primary focus of Geisinger's leadership has been to establish the interventions and demonstrate cost-effectiveness. Dr. Rutkowski added that to conduct a randomized, controlled trial of an intervention, integrating researchers into the effort at the beginning will be key.

Audience Questions to the Panel

In response to a question by Dr. Patel about cost savings, Dr. Rutkowski stated that Kaiser had compared the costs of an optimal versus a non-optimal start. Dr. Williams stated that as a single system, the Mayo Clinic can determine which measures produce the greatest cost savings, although those measures might not be most important for improving patient care.

A question was asked about how to measure such patient-centered outcomes as control and continuity of care. The questioner asked whether these outcomes could be included in a patient's EHR. Dr. Williams responded that patient-centered outcomes were encompassed by the five patient needs as seen through the eyes of the personas. Dr. Rutkowski added that making the transition to dialysis but still being able to continue to work is an important patient outcome that could be measured.

A participant asked Dr. Rutkowski about the rationale for excluding older patients from the CKD cohort. Dr. Rutkowski responded that none of the CKD Stage 4 or 5 patients were excluded based on age, but for Stage 3 patients, the issue of inclusion is more complicated because GFR decreases with age for patients with the same CKD risk. Once patients progress farther, they are actively managed. In addition, elderly patients have been shown to progress more slowly.

In response to a question posed to Dr. Williams about replicating the intervention of depicting personas of ESRD patients, Dr. Williams affirmed that the designer is replicating the work elsewhere.

Dr. Go asked whether the Mayo Clinic is focusing only on renal care of ESRD patients. Dr. Williams responded that initially care focused on ESRD, but the need to start intervening earlier has been recognized. In addition, the Mayo Clinic is taking some of the same approaches to intervention for liver and heart failure.

Dr. Paul Eggers, NIDDK, recognized that progress was made by the three vertically integrated systems in achieving optimal starts for dialysis patients, but what really is optimal is no start at all. A metric is needed for preventing transition to dialysis. Dr. Rutkowski responded that when Kaiser began its management of CKD patients, the problem of an optimal start was thought to be easy to fix, but that was not the case. He agreed with the need for a metric to measure progression and survival in treating patients with CKD, for whom an optimal start is only a small part of the problem. Dr. Norfolk added that working toward best practices will help delay progression.

A participant asked what would be the best way to extend the results of the three systems to the rest of the United States. Dr. Rutkowski recommended reporting GFR consistently, establishing realistic guidelines that are feasible for every system, and establishing consistent metrics that will provide targets for all providers. Dr. Norfolk stated that leveraging what patients want in EHRs will be important. Dr. Williams advocated for knowledge management. All providers need to understand best practices and have the right information for patients.

A participant commented that efforts need to be made upstream in kidney disease. Registries and case management will be important for cost containment. Dr. Narva responded that kidney care needs to be

made part of routine care in the primary care setting, particularly for patients with diabetes. He cited the success of the IHS in decreasing ESRD incidence.

Moderated Panel 3: Population Health Management in Private Sector and Research

Moderator: Paul Drawz, M.D., University of Minnesota

Panel Introduction

Paul Drawz, M.D.

Dr. Paul Drawz introduced the session, which highlighted three approaches to population health management research through the use of health IT tools in clinical trials addressing CKD and comorbidities across multiple health systems.

ICD-Pieces

George “Holt” Oliver, M.D., Ph.D., Parkland Center for Clinical Innovation

Dr. Oliver gave a presentation on a CKD pilot study that used the Improving Chronic Disease Management with Pieces™ (ICD-Pieces™) tool, a technology developed and disseminated by a nonprofit organization specializing in the research and development of clinical prediction systems. Four health systems cooperated to conduct a clustered, randomized clinical trial of CKD patients who had other comorbidities, such as diabetes and hypertension, with a clinical support model called the Chronic Care Model enhanced by technology support (Pieces) compared with the standard of care. A secondary aim of the research was to develop and validate predictive models for risks of hospitalizations and cardiovascular events for patients with coexistent CKD, diabetes and hypertension and to predict risk of 30-day readmissions for patients who are hospitalized.

The Chronic Care Model integrates health systems and the community with the aim of increasing productive interactions between a proactive practice team and informed, activated patients and, ultimately, improving health outcomes. It includes better educating patients to support self-management, educating physicians about CKD care prior to referral, and providing scientific updates relevant to patient care (e.g., serum creatinine standards, use of eGFR). Dr. Oliver described several studies that used electronic data to predict risks and future clinical events. One study used EHR-based multi-condition models to predict the risk of 30-day readmission or death; data from the EHR were used to stratify patients into risk categories.

The pilot study in which ICD-Pieces™ identified patients who had been underdiagnosed for CKD, leading to follow-up interventions for the patients by the PCP, illustrated the utility of this collaborative care model in a resource-constrained system. The pilot demonstrated that application of this model improved the percentage of patients at goal for systolic and diastolic blood pressure and angiotensin-converting enzyme inhibitor/angiotensin II receptor blocker (ACEI/ARB) treatment, which helps slow the progression of CKD, as well as a significant improvement in blood pressure for patients receiving statins. Challenges and limitation of predictive modeling activities include the interventions needed for the highest risk patients; changes in the health environment, including EHR data models, clinical interventions and populations; the tensions between clinical and social risk; and integration of inpatient and outpatient workflows.

Dr. Oliver’s pilot is enrolling patients with the triad of CKD, hypertension and type 2 diabetes. Patients are excluded if they are outside ages 18 to 85, have CKD stage 5, or are opted out by the physician or patient. The primary outcome is the 12-month hospitalization rate, and a secondary outcome is 30-day readmission, emergency room visits, cardiovascular events and deaths. The Collaborative Care Model comes from using a set of policies and order sets to enable mid-institution employees to support the

Model with their PCPs, such as through educational materials, training manuals and notifications to the provider to follow up with glycemic control, lipid management or blood pressure control. Processes for the delivery of education materials also are being shared with physicians to provide a model for delivery of quality education materials to the patients in a systematic way.

Population Health Management at the Cleveland Clinic

Sankar Navaneethan, M.D., Baylor College of Medicine

Dr. Navaneethan described Cleveland Clinic's efforts in population health management through an EHR-based registry. The Cleveland Clinic health system serves 1.5 million people who primarily live in the region surrounding Cleveland, Ohio, through the Cleveland Clinic main hospital, eight community hospitals and 15 community-based health centers. Cleveland Clinic has used the EHR system Epic since 2002 for patient scheduling and order entry, progress notes, result review, medication management, and communication among providers and with patients. Its CKD registry is operated by clinical, biostatistical and electronic research staff and now includes more than 95,000 patients. Patients are selected through a careful process, and EHR validation is performed by two investigators in two stages that include the review of 20 randomly selected EHR-generated charts both to assess appropriateness of ICD-9 codes with kidney diseases and comorbidity conditions and to exclude the presence of a specific comorbidity that may have been falsely claimed to be present. Dr. Navaneethan reviewed the Cleveland Clinic's structure surrounding the CKD registry, including linkages with data sources, identification of patients for other clinical trials, and quality improvement projects.

A key focus of the Clinic is to transform registry data into knowledge. Its registry data are useful for research, patient care and providers. Examples of kidney research projects that have used the data are associations of metabolic syndrome and ESRD/death in CKD, the significance of CKD in pulmonary arterial hypertension, the role of an implantable cardioverter defibrillator in CKD, and the use of the renal resistive index in CKD. With support of an NIDDK R34 grant to improve outcomes for CKD patients through clinical translational research, researchers are conducting a randomized, controlled trial that includes an EHR-based, enhanced personal record that will use electronic communication to disseminate CKD stage-specific goals of care and CKD education to improve outcomes for CKD Stage 3b and 4 patients. Cleveland Clinic's CKD registry also assists recruitment efforts by identifying patients who meet specific inclusion or exclusion criteria for studies. It includes an option to provide the study coordinator with the schedule of patients' visits to their provider, thus saving resources and coordinator time.

Challenges for an EHR-based registry encompass implementation and maintenance issues, such as the design and funding of the registry, as well as harmonizing the priorities of the team members and having all use the same vocabulary. A clear data dictionary, definitions and an understanding of what to include in the data collection also are needed. Obstacles to maintaining such a registry include the need for sustenance or support for team members, understanding by the legal team of data-sharing needs for collaborative research, the loss of State Systems Development Initiative (SSDI) data linkage, and structural changes within the health care system. The registry would need to be refined over time and new variables to the registry validated. Procedural data may require expertise in natural language processing, and quality assurance would be an ongoing process. To conduct an EHR-based clinical trial, an enhanced personalized health record within the EHR would be needed, as well as an encounter for patient navigators and a focus on "MyChart for all" across the system.

Dr. Navaneethan summarized that EHR-based registry development is possible with the assistance of a multidisciplinary team. EHR-based registries can be used for outcomes research, recruitment for clinical trials, and quality improvement projects. In addition, efforts are needed to accommodate changes in the

health care system and institutional policies, as well as other changes that could affect the sustenance of institution-based registries.

Institute for Clinical Evaluative Sciences: Kidney, Dialysis and Transplantation

Danielle Nash, Ph.D. (candidate), Institute for Clinical Evaluative Sciences

Ms. Nash gave a presentation on how the Institute for Clinical Evaluative Sciences (ICES) uses health information technology to identify and manage CKD populations through its Kidney, Dialysis and Transplantation (KDT) Research Program. Begun in 1992, ICES is a Canadian nonprofit organization that engages research, data, and clinical communities. The organization provides more than 50 databases containing Ontario's health-related data, which include physician billings, hospital visits, prescription drugs, demographics, clinical registries, and local laboratory data. The organization continues to expand its partnerships with Ontario's leading health research institutes. The KDT Program includes 16 core investigators across the province; 10 analysts and other staff; and provincial government partners, including the Ontario Renal Network and Trillium Gift of Life Network (Ontario's organ and tissue donation agency).

ICES facilitates the use of administrative data for research. Ontario operates under a single payer health care system funded by the provincial government, with prescription drug coverage for individuals 65 years and older and other qualified patients. All Ontario residents have a health plan number used for all health care encounters. ICES' databases include data for more than 13 million people over more than 25 years (1988–2015). The data are de-identified and checked for accuracy, captured at the individual level with high retention, and comprehensive and longitudinal. The data sources can be linked to the patient at various levels, such as population and geography through postal codes, health care providers through the physician identifier, and hospitals and dialysis facilities through the facility identifier. Researchers can access data through a special designation under Ontario law to access personal health information without patient consent for the purposes of analysis, evaluation, and compilation of statistical information about the health care system. They have a responsibility to protect the data, which is ensured through compliance audits conducted every 3 years, confidentiality and nondisclosure agreements, reporting aggregate results only, and other policies and procedures. Only a few individuals at ICES have access to identifying information for purposes of data linkage.

Challenges and solutions to using administrative data for research involve the validity of data, consistent definitions, and data storage and processing speeds. Although some data elements, such as dialysis and prescription drug information, are easily captured, data about CKD and AKI diagnoses often are underrepresented. Researchers performed validation studies on some of these coding algorithms using linked laboratory data. CKD validation found that it was detecting a difference in eGFRs but missed approximately one-third of patients with CKD. Because validations cannot be performed for every condition, physicians, hospital coders, and other clinical experts are relied on to provide advice on coding algorithms. The KDT Research Program developed and continues to maintain a KDT Variable Library covering more than 80 common diagnoses and procedures to ensure consistency of definitions for a number of conditions, exposures, baseline characteristics and outcomes across its studies. To handle the challenges of storing "big data," ICES transitioned to a new SAS platform environment and hosts a data repository that contains more than 3 terabytes of data. Ms. Nash noted the extensive time (i.e., on the order of hours or even days) that running a SAS program can take, depending on the number of records available, particularly laboratory or pharmaceutical data. With laboratory data available for nearly the entire province of Ontario, future KDT Program plans include accurate provider-wide CKD studies and cluster randomized trials for dialysis facility interventions. Other opportunities involve multi-province data sharing and replication of studies, as well as international data sharing with the Chronic Kidney Disease Prognosis Consortium.

Moderated Discussion

Dr. Drawz asked the panelists about barriers to integrating research into population health management efforts that might arise from simultaneously implementing and studying interventions, particularly securing institutional review board (IRB) approval. Dr. Oliver responded that because the ICD-Pieces™ study was a pragmatic trial, the burden on providers, patients and health systems was minimal. The issue of consent, however, still is under discussion with the IRB. Dr. Navaneethan replied that with a smaller number of patients than the ICD-Pieces™ study, securing consent from participants in the Cleveland Clinic study is feasible; he and his colleagues are in the process of doing so, but IRB approval is recognized as a burden for these types of studies. Ms. Nash stated that an ICES cluster randomized study was framed as an educational intervention provided to facilities and, therefore, patient consent was not needed.

Dr. Drawz inquired about additional data to which the researchers would have liked to have access. Dr. Navaneethan cited hospitalization records. He observed that the difficulty in obtaining these data points to the need to secure data agreements up front. Ms. Nash indicated that the researchers would have liked to have access to data on race, smoking status, and quality of life. She indicated that they have discussed potential collaborations with other Ontario ministries to obtain some of the data they need, including information from the school board. Dr. Oliver would have liked feedback from patients on what information they had retained, which is not captured in the medical record.

Audience Questions to the Panel

The topic of data validation was discussed. An audience member asked whether mechanisms exist to validate data with clinicians before it is de-identified. Ms. Nash responded that data validation has been possible with clinical registries but not larger data sets. Dr. Oliver replied that in his study, physicians check the data periodically, and an effort is made to use only the parts of the EHR that are most reliable. Data are “cleaned” through use by clinicians, a participant noted; the more the data are used, the more accurate they are. Data accuracy also can be assessed by comparing data among practices to identify outliers. A comment was made that changing the form of data can introduce inaccuracy; raw data should be used whenever possible.

A participant asked about how practice is transformed at the same time research is conducted. A comment was made that the step wedge approach has gained wide acceptance. Rather than randomize practices for interventions, interventions are phased in over time, with practices that are still on the wait list for interventions serving as controls until the intervention is implemented.

The issue was raised of using data that have been collected over a long time period, during which conditions may have changed. Ms. Nash acknowledged that changes occur that complicate data interpretation, such as Canada’s switching in 2002 from International Statistical Classification of Diseases and Related Health Problems 9th Revision (ICD-9) codes to ICD 10th Revision (ICD-10) codes, but data collection periods can be adjusted so as not to include older data with harmonization issues (e.g., using only post-2002 data). For rare diseases and outcomes, older data might be needed, but researchers who use older data should understand how they might have changed over time. Stratifying by year can help track changes over time.

Dr. Patel asked about what infrastructure the panelists had used to improve clinical care. Dr. Navaneethan responded that an enhanced version of MyChart had been used as an intervention. Dr. Oliver noted that if an intervention requires maintenance of a platform, a business case will have to be made to continue supporting the effort after research funding is exhausted.

A comment was made that registries can be used to recruit for randomized, controlled trials. The PCPs of eligible patients can be contacted about interventions and given the option to enroll in the trial.

Moderated Panel 4: Population Health Management Health Information Technology Tools and Solutions

Moderator: Clement J. McDonald, M.D., National Library of Medicine

Panel Introduction

Clement J. McDonald, M.D., National Library of Medicine

Dr. Clement J. McDonald provided background about medical informatics standards currently in use by laboratories. Health Level Seven (HL7), now released as version 2, is used to deliver orders to referral and local laboratories and send results back to the requesting system. Logical Observation Identifiers Names and Codes (LOINC), supported by all the major referral laboratories, provides identifiers for individual laboratory tests. Meaningful use regulations stipulate that EHRs must support LOINC. The Unified Code for Units of Measure (UCUM) is a standard for identifying units of measure. LOINC and UCUM codes are part of the character string used to report laboratory results in an HL7 message.

National Health Information Technology Standardization Activities

Kensaku Kawamoto, M.D., Ph.D., University of Utah Health Sciences Center

Dr. Kensaku Kawamoto reviewed national health IT standardization activities. Health IT has the potential to help improve CKD care, particularly through clinical decision support (e.g., automated identification of patients with CKD, provider and patient care reminders, referral facilitation). Advanced clinical decision support is not widely available, but could be facilitated by standards-based interoperability. Recent clinical decision support standardization efforts include Health eDecisions, an effort to develop and validate standards for clinical decision support interoperability, and the Clinical Quality Framework, sponsored by the ONC and CMS, which aims to develop and validate harmonized standards for clinical decision support and electronic clinical quality measurement.

Dr. Kawamoto advanced three clinical decision support interoperability paradigms: a standard knowledge artifact, a standard patient evaluation service, and standard “apps” (e.g., CKD Management Dashboard). A standard knowledge artifact (i.e., write once, interpret anywhere) is written in a standard format and conveys information from the artifact supplier to the artifact integrator. Examples might be an order set or rules to identify a subgroup of patients that are written in a standard format. Interoperability is achieved when everyone agrees to use exactly the same format. For a standard patient evaluation service (i.e., write once, use anywhere), the clinical decision support guidance requestor supplies the data to the clinical decision support guidance supplier, which has built the logic needed to interpret the data and returns the requested guidance. A number of service suppliers—such as OpenCDS, Immunization the Calculation Engine, the CDS Consortium, and Evinance (for oncology)—already exist, and service consumers include Epic, the Veterans Health Administration, eClinicalWorks and Elekta Mosaic. Standard apps require an interoperability layer because EHR systems differ considerably from one another. Even systems from the same vendor may be customized and require an interoperability layer. ClinKB and MPages are examples of vendor-specific apps for Epic and Cerner, respectively, but the number of cross-vendor approaches, such as Substitutable Medical Apps & Reusable Technology (SMART) on Fast Healthcare Interoperability Resources (FHIR), are growing.

The three clinical decision support interoperability approaches are promising for CKD. Although likely to prove difficult, developing a common patient data model will be critical to achieving interoperability. CKD could provide an example of how to apply these approaches to standards-based clinical decision support and quality improvement. Interoperability will ensure that best practices in CKD population

health management are disseminated broadly and systems do not duplicate efforts already undertaken by others.

Fast Healthcare Interoperability Resources

W. Ed Hammond, Ph.D., FACMI, Duke Center for Health Informatics

Dr. W. Ed Hammond began his presentation about FHIR with a discussion of the standards required to support population health management. Functionalities required include aggregation of data across multiple sources because patients get care in different settings; aggregation of data across a variety of EHR systems, including different versions of systems from the same vendor; accommodation of a variety of sources of data; incorporation of a variety of terminologies; creation and management of registries; and unification of a variety of stakeholders who have different requirements and different motivations. Health indicators include multiple kinds of data beyond clinical: behavioral, genetic, socioeconomic and environmental. Barriers to interoperability include tracking patient identity across multiple heterogeneous databases; accommodating small health care settings, where many patients receive care, as well as large ones; accommodating a variety of clinical settings; creating both public and private partnerships; interfacing with governments at city, county, state and national levels, which is particularly challenging because states each manage health care data differently; achieving semantic interoperability; creating business cases that demonstrate true value to all participants to motivate health care providers to embrace interoperability; and resolving privacy issues, yet uniquely identifying patients.

FHIR offers many advantages that promote interoperability. These advantages include that FHIR is relatively easy and low-cost to learn, scalable from simple to complex, flexible, free and open-source, and built using modern technologies. FHIR is service-driven, allowing the user to send only the data he or she wants to send, and permits transporting data at all levels of granularity. FHIR's design philosophy focuses on implementers, targets common scenarios, uses cross-industry technologies (e.g., XML, JSON, HTTPS, OAuth), supports human readability, and supports multiple paradigms and architectures.

FHIR is a set of modular components called “resources.” The resources refer to each other using internet addresses, and the resources are what is exchanged between systems. More than 150 resources have been defined, examples of which are “patient,” “practitioner,” “allergy intolerance,” “family history,” and “care plan,” and more are being added by users as needed. Parties exchanging data define the way they want to use resources and relations among resources using profiles. Examples of profiles include issuing a referral of a patient to another facility; populating a registry; supporting an HIE; reporting an adverse event; ordering a medication; and providing data to a clinical decision support algorithm. The same content can be shared in different formats, termed paradigms. For example, a laboratory result can be received in a message and packed in a discharge summary document.

Different systems—including commercial systems, home-grown systems, vendors and implementers—will be brought together on an open platform architecture using FHIR. Dr. Hammond predicted that smart phones apps will be developed that will bring the patient into the information and communication network, and these apps hopefully will be shareable across systems.

Office of the National Coordinator for Health Information Technology

Kevin Larsen, M.D., ONC for Health IT

Dr. Kevin Larsen provided a policy perspective on health IT. The vision of the Learning Health System is to make patient care, decision support and research equivalent, except for differences in scale. Individual EHR records are connected with population health and research through data input, but the flow of information from research to patient care also is facilitated. Interoperability needs to be established between physicians, as well as among different types of entities. As with the dashboard of a car, feedback

from health care quality measures needs to be fast and reliable. The batch processing model for health care feedback is not useable.

The driver to achieve this vision is the migration to value-based payments. The Department of Health and Human Services (HHS) is committed to a multiyear plan for linking payments to quality. By 2018, alternative payment models (i.e., bundled payments) are targeted to represent 50 percent of all Medicare payments, and almost all payments will be value-based. Unified outcome measures that can be combined in an interoperative way will be needed, with EHRs as the primary reporting platform. A recent article outlined the vision for the future of federal policies on quality measures. Measures will drive improvement and value-based purchasing, as well as inform consumers (e.g., in their choice of physicians and treatments), which is more difficult to achieve.

CMS establishes the Medicare policy for meaningful use, which is an incentive policy to induce providers to install and use EHR systems. ONC regulates the standards for what EHR systems can and need to do, determining if EHR systems meet those standards and assuring purchasers that their system has been tested. EHR systems are certified as distinct modules, characterized by task: (1) capturing raw data; (2) sending data to a secondary system (e.g., a patient registry); and (3) sending data to CMS. The goal is for ONC to certify modules and for users to assemble a system from those certified modules to meet their health IT requirements. The Common Clinical Data Set represents the key health data that health IT systems must collect and use, including such data as patient name, sex, date of birth, ethnicity, problems, medications, laboratory tests, care team members, immunizations, plans of treatment, and goals. Similar to how Google, Amazon and credit card companies analyze data “on the move,” the goal for health IT is to perform analytics on health data “in motion,” rather than first grouping, storing, cleaning and modifying data before analyzing them (i.e., data “at rest”).

ONC oversees HIEs. Michigan Direct Gateway™ (MiDiGate™) is an example of a central HIE system that processes data from eight different HIEs, including eligible providers and hospitals. An interface generates standards-based data from these sources and sends the data to MiDiGate™. MiDiGate™ extracts the data, checks it (e.g., queries when a patient has a new provider), allows providers to see data in near real time, and manages the data needs of such users as the state of Michigan’s health department, data warehouses, and the Federal Government.

For example, currently, data standards have been developed that allow data sharing between hospitals. Different federal agencies (e.g., CMS, U.S. Food and Drug Agency [FDA], CDC), however, still ask to receive data in historic formats that are not compatible with one another. The goal is to standardize data format requirements across federal agencies. Ideally, common data elements will be used across patient registries, clinical databases and research databases, and it is anticipated that these data elements will continue to evolve.

The Stage III meaningful use rule was published recently. Under the Medical Care Recovery Act (MCRA), Medicare is incorporating the meaningful use program into other quality use programs. ONC has released a request for information on the policies that should be established for health IT systems. The goal of the request for public comments is to receive feedback on how to use public policy to advance the use of health IT.

Audience Questions to the Panel

A participant commented that in certain states, payers—including CMS—are prohibited by law from gathering laboratory data on patients. Dr. Larsen responded that for certain reportable conditions, providers are required to send laboratory results to the state health department. Also, some states have HIEs that integrate many sources of data. Complications arise, however, when managing consent to provide access to data for a wide range of downstream users.

In response to a question from a participant about contacting CMS to have access to data about the population of patients with CKD, Dr. Larsen stated that CMS intentionally does not collect certain types of data because concern exists regarding CMS' becoming a large, nationwide data warehouse.

Dr. Abbott asked about inducements that might be effective if Congress mandates interoperability. Dr. Hammond proposed that the appropriate LOINC be associated with laboratory tests when they are performed and remain associated with test results. Dr. Larsen stated that many stakeholders believe that the drive toward value-based payment, rather than any federal mandates, will drive systems toward interoperability. Some states already mandate interoperability. Dr. Kawamoto observed that the lack of institutional incentives to spend money on interoperability is a problem because the benefits of interoperability are very widely distributed, making individual institutions reluctant to bear the entire financial burden of making systems interoperable.

A participant asked about the benefits that will derive from the Common Clinical Data Set. Dr. Larsen responded that ONC ensures that health IT systems certified for meaningful use can submit data in the form of the Common Clinical Data Set. The Common Clinical Data Set is most meaningful, however, if it is linked to a data model. Dr. McDonald added that most clinical data are sent as a complete record, not as a field. Dr. Kawamoto stated that ensuring data are captured for all fields will be important. Problem lists, for example, are notorious for not being well maintained.

A question was asked about transferring records of patients between systems in instances when only a few patients are moving. Dr. Hammond responded that FHIR is designed to facilitate moving data among systems. Having a common set of data elements to which all systems map will facilitate moving records, although determining what to move still will be difficult. The key will be to have agreement on which elements are included for a given disease. Dr. McDonald suggested that regional health systems will facilitate exchange of patient information. Dr. Larsen advocated for a relationship solution, whereby a telephone call to find out what information is needed facilitates data exchange. The role of the regional aggregator (e.g., HIE), mentioned by Dr. McDonald, will be to help the two systems exchange data securely. Dr. Kawamoto commented that it is not in the interest of a service provider to invest funds in facilitating the transfer of data to a different institution. An incentive structure will be needed to induce providers to focus on issues of interoperability.

A participant expressed doubt about whether it would ever be in the interest of an EHR vendor to make a system that everyone could use. Dr. Larsen commented that in some cases no intent exists to impede interoperability, but in others, systems are intentionally built to make it difficult to share data. He predicted that as the health care system moves toward risk-based models, interoperability will be seen increasingly as a shared business risk. When partnerships are formed among providers, an immediate incentive is created to share data. Data sharing does not occur readily, however, among competitors. Dr. McDonald added that establishing standards historically has been the role of government and predicted that interoperability will be achieved through government mandates.

A participant suggested that interoperability be made part of the certification process. Dr. Larsen replied that the certification process balances flexibility and usability. ONC tests the "shrink-wrapped, off-the-shelf product," not the system as it is deployed in the field. He noted that the Certification Test Procedures for Meaningful Use will be made available soon for public comment at the Federal Government's health IT website (www.healthit.gov). ONC will be seeking input from the public on how the certification process can be improved and what tools should be used to test systems for certification. Dr. Hammond added that whether two systems are interoperable is no longer a question with a simple positive or negative answer; levels of interoperability exist.

Dr. Patel noted that as patients become more mobile, a national system for interoperability will become more necessary. Dr. Larsen responded that currently, HIEs have been implemented unequally and

heterogeneously. He offered the Chesapeake Regional Information System for our Patients (CRISP) in Maryland and the District of Columbia as an example of an HIE that provides high-quality information. The Epic network also is rated highly for interoperability by its customers. Dr. Hammond stated that as data from systems begin to be used, meaningful activities will move systems in the direction of interoperability. Examples of successful activities that benefit from data interoperability are the Patient-centered Clinical Research Network (PCORNet) and Clinical Data Research Networks. Dr. McDonald noted that as HIEs have become larger, privacy scrutiny has increased, making certification more difficult.

A participant asked about best practices around HIEs. Dr. Larsen stated that ONC provides policy and technical assistance to state governments regarding establishing HIEs. He observed that establishing an HIE requires funding; finding providers who are interested in investing in joining an HIE can be difficult. Successful HIEs that tend to have a multi-stakeholder business model.

A participant observed that payers—not physicians—have been the primary beneficiaries of “big data” because of a reduction in the costs of duplicate tests. Dr. Larsen observed that patients benefit as well. Establishing HIEs requires a community of trust. Dr. Hammond noted that HIEs offer the opportunity to improve the quality of care provided by measuring such quality metrics as infection rates at facilities. Providers can be resistant, however, to airing information that they might view as detrimental to their reputation, rather than an opportunity to improve.

Adjournment

Dr. Patel thanked the panel members and the participants for a day of active discussion. The topic of the first day of the meeting had been current activities in health IT. The second day will be devoted to discussing the desired directions for health IT and how to move in those directions.

Dr. Patel recommended that participants join the wiki, on which are posted details of the cases that were highlighted during today’s meeting and other information related to the day’s discussions.

Friday, October 23, 2015

Welcome and Breakout Group Charges

Andrew S. Narva, M.D., NIDDK, NIH

Uptal D. Patel, M.D., Duke University School of Medicine

Dr. Narva welcomed the participants to the second day of the meeting. He stated that the morning’s breakout group session will be the key part of the meeting. The session will allow participants to suggest steps in the path toward change. He expressed his hope that after the end of the meeting, the participants would continue to work as a community to make progress. Dr. Patel indicated that participants who want to continue the conversation started at the meeting should contact him and share their contact information.

Dr. Patel expressed his gratitude to the participants, speakers and moderators for an engaging discussion. The previous day’s presentations depicted the range of efforts in health IT for population health management. In addition to sharing and learning, innovation is needed. To address the burden of CKD, mild and moderate disease needs to be managed. Innovation tends to occur through such “unholy” alliances as Apple and music, Microsoft and gaming, and the National Aeronautics and Space Administration (NASA) and Legos. Dr. Patel asked participants to approach the problem from a radically

different fashion and address a “moonshot” goal of eliminating kidney disease altogether. He requested that the breakout groups consider common goals and brainstorm two or three concrete deliverables.

Dr. Patel posed the following questions to the breakout groups:

- Where are we now? What is essential for population health management of CKD?
- Where do we want to be?
- What steps are necessary to get to where we want to be?

Simultaneous Breakout Groups: Blueprint for Population Health Management

The participants met in simultaneous breakout groups to discuss the blueprint for CKD population health management using health IT.

Breakout Groups Report Back

Defining the Population and Identifying Cases: Computable CKD Phenotypes and Outcomes

Moderator: Kensaku Kawamoto, M.D., Ph.D., University of Utah Health Sciences Center

Presenter: Blake Cameron, M.D., Duke University

Dr. Cameron reported for the CKD computable phenotype and outcomes group. Dr. Cameron began by describing the current challenges in identifying patients with CKD using EHRs. First, multiple barriers (technical, administrative, and political) exist that preclude ready access to quality EHR data and interoperability among data systems. Second, there is lack of consensus for a standardized CKD phenotype definition. Third, CKD identification and treatment may be perceived as low priority by health systems.

Dr. Cameron outlined the group’s desired future state. EHR data will be readily accessible for population health management and outcomes analysis. A standardized CKD definition will be in place. Registry tools and health management resources will exist. Patients who are at risk of CKD and its complications will be screened and treated. Process interoperability will be achieved across EHR platforms and health systems.

The breakout group identified the following deliverables needed to facilitate more widespread population health management for CKD:

1. Core of standardized EHR-based phenotype definitions for CKD. The focus of standardization should address core problems (“low-hanging fruit”) such as diabetic and hypertensive kidney disease rather than edge cases. A manuscript on common definitions might be prepared.
2. Business/policy case for relevant stakeholders to prioritize CKD.
3. Collaborative repository to aggregate knowledge and disseminate best practices, including code, tools, and standards-based algorithms. The NKDEP population health management wiki might serve as a start for the repository.

Risk Stratification: Identifying a Target Population

Moderator and Presenter: Paul Drawz, M.D., University of Minnesota

Dr. Drawz described the current status of risk stratification for people at risk for developing CKD, people with undiagnosed CKD, and patients with CKD at risk for progression. Ironically, it is the payers, who have access to limited data such as ICD-9 codes rather than laboratory results, who are using risk stratification to manage care. Evidence supporting risk stratification in the general population based on GFR and urine albumin is insufficient. Providers are not ordering urine albumin testing, even in patients with reduced GFRs. Machine learning for risk stratification has been implemented only on a pilot scale. Risk prediction models, such as the progression to kidney failure model developed by Dr. Navdeep Tangri and colleagues (2011), exist that are machine learning algorithms that use laboratory data and other factors as inputs.

The group identified key barriers to risk stratification. Proteinuria may be a better risk factor than GFR, but only a fraction of patients with risk factors are being screened for proteinuria. Patients with diabetes are more likely to be screened, especially for proteinuria, than those with hypertension. Evidence supporting screening of CKD is lacking in such at-risk populations as patients with hypertension—much less in the general population—as outlined by the U.S. Preventive Services Task Force.

Dr. Drawz highlighted goals for risk stratification. Risk scores need to be integrated to facilitate provider and patient decision making. Patients need to be identified who need nephrology referrals, therapy, general healthy-behavior counseling, and ESRD planning.

The approaches to achieving these goals were discussed by the group. Communication plans are needed between patients and clinicians to ensure that patients receive the appropriate laboratory tests and treatment (i.e., urinary albumin and ACEI/ARB prescriptions). The kidney care community could learn from diabetes and cardiovascular disease, for which A1C tests and treatment with aspirin, respectively, are almost universal. Laboratories and pharmacists could become more involved in triggering orders for urine albumin testing, recommending urine albumin testing at GFRs less than a triggering value or recommending testing when patients fill orders for a statin or an ACEI/ARB, respectively. Alerts regarding the need for urine albumin testing could be sent by pharmacists to PCPs. Defining CKD by objective criteria could lead to populating problem lists automatically. Quality measures could be implemented to increase urine albumin testing and prescription of ACEIs/ARBs. A decision support tool built into the EHR system that calculates the risk of ESRD in 1, 5, and 10 years might be helpful for physicians and patients.

In the future, other factors might be included in risk stratification. Apolipoprotein L1 (*APOLI*) testing for African Americans might be implemented. A more realistic description of racial admixtures based on self-report might aid in risk prediction. Consideration of the socioeconomic factors that contribute to CKD risk, which is captured by self-reported race, is likely important in risk prediction.

The breakout group identified the following deliverables needed to facilitate more widespread population health management for CKD:

1. Patients at risk need to be tested for proteinuria, particularly to predict progression and cardiovascular disease risk, as well as to identify patients with proteinuria who would benefit from treatment with ACEIs/ARBs.
2. Risk stratification tools are needed to identify patients who should be treated with statins and/or ACEIs/ARBs.

3. Risk stratification tools should be embedded within EHRs in order to inform CKD-related discussions and decisions by providers and patients.

Care Management Solutions and Tools: Improving Care

Moderators: Mark Rutkowski, M.D., Kaiser Permanente, and Susan Crowley, M.D., F.A.S.N., Veterans Health Administration

Presenter: Susan Crowley, M.D., F.A.S.N., Veterans Health Administration

Dr. Susan Crowley reported on the group's discussion of care management tools from the provider's viewpoint. The group had begun with a recapitulation and inventory to identify issues and recurring themes. Data flow was judged important. Primary care providers need better access to laboratory results from dialysis. Laboratory reports with longitudinal trends are needed to support the PCP's decision making, and analytics are needed to interpret the data. Data need to be aggregated and comparable across settings. Data need to be accessible from one place. Care and data should be integrated to decrease rates of acute dialysis and readmissions. Mirth, an open-source data integration tool, can be used to accept and exchange data.

CKD needs to be managed upstream. Current care management does not consider CKD care in its own right. Care bundles could target CKD. Nephrologists could interface more with PCPs to provide recommendations.

The group identified issues around patients. Patients need more input into program design. Public understanding of care management is lacking. Patients with advanced CKD need to be engaged better.

Better evidence is needed. Resources are being invested in the reimbursement model, rather than patient-centered outcomes. The value of following clinical guidelines and processes should be defined.

New data streams should be explored. Capturing patient compliance and adherence data is needed. Performance measures for CKD should be developed. Data are needed on patient outcomes.

The group discussed analytics. Statistical models do not use the wealth of data currently stored and collected in EHRs. Better access is needed to real-time data for research purposes. A CKD application that tracks fistula placement and central venous catheter (CVC) rates should be developed. Analytic systems that connect to real-time data and present model output to providers are needed. Small data that focus on the patient should be captured. Easily accessible model output at the point of care is needed.

The group had several recommendations for the future of care management solutions and tools. "Unholy" and "holy" alliances, such as those with dialysis providers and those resulting from broad patient outreach, will need to be formed. Better evidence-based guidelines will be needed. The group suggested the formation of a work group to harmonize CKD guidelines and recommendations. A better understanding of what variables are most relevant to patient-centered outcomes also will be needed.

Dr. Rutkowski added that the breakout group had benefited from experience with difference aspects of care management solutions and tools, and sharing interests had been the most valuable part of the session.

The breakout group identified the following deliverables needed to facilitate more widespread population health management for CKD:

1. Real-time, continuous, important data and analytics to tease out the most important thing for a population to do.
 - a. Part of daily rounds could be a huddle to use an analytics dashboard.

- b. Real-time data and analytics could be built into the workflow.
2. Accurate software that “reads the provider’s mind” to know how he or she wants to see the data and fits into the clinical workflow.
 - a. The software also should read patients’ minds to understand what is most important to them.
 - b. A common care plan should be designed to mesh these priorities so that interventions are aligned.
3. Panel management perspective at the provider level.
4. Assessment of which outcomes are most important to patients to focus on the clinical management of the individual patient.
5. Centralized collection of data.

Engaging Patients and Providers: Information Exchange

Moderators: Ebony Boulware, M.D., M.P.H., Duke Center for Community and Population Health Improvement, and Richard Knight

Presenter: Ebony Boulware, M.D., M.P.H., Duke Center for Community and Population Health Improvement

Dr. Ebony Boulware described barriers to engaging patients and providers. Information on the patient often is not accessible, even to the provider. The use of tools by providers often is suboptimal, and patients become the center of information sharing. Structural issues lead to fractured care, and few incentives exist to create a uniform, streamlined structure of care. Health care culture needs to be based more on patient outcomes. The problem of engaging patients and providers has been articulated well, but no solutions are being identified. Patients have different desires and degrees of educational need. To involve CMS in patient and provider policy, evidence needs to be developed. Documentation can be irrelevant. Patient demographics (e.g., elderly patients with ESRD) can be challenging. Cultural barriers to providers’ adopting a shared care plan exist.

The group had identified goals for engaging patients and providers. The patient’s voice should be reflected in the EHR. The patient should receive comprehensive care from a collaborative care team. Patients should have a comprehensive care plan, instead of plans that are fractured among specialties (e.g., nephrology, cardiology).

To achieve these goals, support and tools need to be widely available. Research is needed to identify the best paths to achieving patient and provider engagement goals. Dashboards can provide information to patients and providers, including alerts for sentinel events, and can help interoperability. Integrated, standards-based care plans need to be developed. Virtual roundtables of all providers involved in a patient’s care could be established to develop the care plans. These plans should be extensible beyond care for kidney disease and, most important, patients need to agree to them. Care plans should include patient goals. A care plan pathway should be developed that the patient needs to agree to at several points along the development path. Patients need to be engaged directly in their care goals, using technologies like gaming. Smart phones and gaming could be used to educate patients in a way that does not overload them with information. The family needs to be engaged as well. Trust needs to be established between patients and providers, because patients often do not understand what they do not understand.

Health IT can encourage patient-physician partnerships. Partnerships can be encouraged through a shared care plan. Visual tools on the dashboard should be the default for encounters. Health promoters, health educators and clinical social workers can interact more personally with the patient.

The breakout group identified the following deliverables needed to facilitate more widespread population health management for CKD:

1. Dashboard with patient and provider accessibility.
2. Integrated, comprehensive, patient-centered care plans.
 - a. CKD care plan requirements should be electronic and informed by experts.
 - b. Care planning should include lay health providers.
3. Direct patient-engagement tools (e.g., gaming, Swedish rheumatology registry)

Closing Comments

Uptal D. Patel, M.D., Duke University School of Medicine

Robert A. Star, M.D., NIDDK, NIH

Andrew S. Narva, M.D., NIDDK, NIH

Dr. Patel thanked the participants for an engaged discussion and, in particular, expressed his appreciation for the input provided by non-nephrologists and patient representatives. He noted the following four themes that had emerged as ways to advance the use of health IT to identify and manage CKD populations:

1. Care plan. Focus was placed on a care plan as a mechanism for moving forward. Including the patient's voice in the plan was suggested as important. The details of the technical pieces that need to be included also had been discussed.
2. Dashboard. A dashboard will allow existing data to be better prioritized for care delivery. It could include a risk stratification feature to ensure improved care for the highest risk patients.
3. Business and policy case. The case must be built for a variety of care settings and stakeholders, including small, independent practices; large medical centers; accountable care organizations; and commercial payers. Partners exist that might help building the case.
4. Collaborative space. The wiki serves as a beginning for developing a collaborative space.

Dr. Star presented some commonalities from the meeting's discussion and presentations. The patient's voice needs to be heard in the EHR, as well as all aspects of CKD care. A computable phenotype or phenotypes is needed that will be consistent across health care settings. Laboratory results, including creatinine levels and eGFR, can be used to help determine CKD phenotypes. Dashboards should be developed to visualize data for individuals and populations. Other requirements for furthering CKD population health management using health IT include direct patient engagement tools, quality measures, and development of a business case. Dr. Star thanked the participants for a very productive meeting, as well as the organizers for successfully bringing together a group of people to think about important issues in CKD care.

Dr. Narva congratulated the participants on a productive meeting that had met all expectations. He thanked the participants for attending and the individuals who had assisted in planning the meeting, particularly Ms. Norton, Dr. Patel and Ms. Eileen Newman.

Meeting materials will be posted on the wiki. These will include a meeting summary and the speakers' presentations, as well as contact information for individuals who want to continue to collaborate on advancing CKD population health management using health IT.