



**Kidney Interagency Coordinating Committee
and Urology Interagency Coordinating Committee Meeting**

**Addressing Scientific and Systems Challenges in Transitioning from Pediatric to Adult Care for
Individuals with Childhood-onset Kidney and Genitourinary Conditions**

Natcher Conference Center, Room D
National Institutes of Health
Bethesda, MD
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Meeting Participants and Summary

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Welcome and Introductions

Tamara Bavendam, M.D.

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH)

Susan Mendley, M.D.

NIDDK, NIH

Dr. Susan Mendley welcomed members and attendees to the NIDDK Kidney Interagency Coordinating Committee (KICC) and Urology Interagency Coordinating Committee (UICC) meeting. She noted that Dr. Andrew Narva, former KICC Executive Secretary and director of the National Kidney Disease Education Program, retired from the NIDDK in August 2019. She expressed appreciation to Dr. Narva for his services. Dr. Mendley reminded participants that the KICC was mandated by Congress in 1987 to meet yearly; however, because of the enthusiasm, the structure changed from a *pro forma* meeting to one that meets twice yearly and provides an active forum for communication among federal agencies working in kidney disease. The aim is to encourage cooperation, communication, and collaboration among all federal agencies engaged in kidney research and related activities.

The NIDDK hosts an online resource—the Federal Chronic Kidney Disease (CKD) Matrix—that summarizes CKD-related activities and conveys the multifaceted and interconnected federal response. Dr. Mendley remarked that a joint KICC-UICC meeting provides an added holistic view of health. Although the approaches differ between the two groups, their challenges are similar. One such example is the transition from pediatric to adult care for young adults with a complex, rare disease. The aim is to share learning experiences between the two groups. Dr. Mendley invited meeting attendees to introduce themselves.

Dr. Tamara Bavendam also welcomed everyone and noted the larger-than-usual attendance in having the UICC join the KICC. She reviewed the NIDDK-sponsored February 2015 workshop titled “Research Needs for Effective Transition in Lifelong Care of Congenital Urinary Conditions,” which conveyed how a group of multidisciplinary attendees thought about transitions in health care for individuals with congenital genitourinary conditions. She emphasized that that meeting resulted from discussions between pediatric and adult urologists who were trying to address transition of care issues but lacked a platform to have a common conversation. Nephrologists also were in attendance, and the agenda included a session dedicated to transitions and adult health care in which women with spina bifida shared their perspectives. Experts in the field presented on engagement of male adolescent patients, intellectual and developmental disability, and self-management. The detailed minutes of the meeting can be accessed from the NIDDK website: https://www.niddk.nih.gov/news/meetings-workshops/2015/transition-lifelong-care-congenital-genitourinary-conditions_02-2015

Dr. Bavendam explained that most urologic conditions, congenital and acquired, require lifelong care. Many of the decisions on management of lower urinary tract issues are protected, and there is a joint connection between neurology and nephrology that begins prenatally. The February 2015 meeting participants identified the epidemiologic, outcomes, and clinical care research needs, many of which were related to preservation of renal function: renal outcomes are a topic the KICC also has spent time understanding. The proceedings of the meeting were published in the May 2017 issue of *Urology* and helped to focus attention in this area. Subsequently, the Society of Pediatric Neurology has included talks on care transitions in their annual meeting list of topics. Transitional care was discussed also at the June 2015 UICC meeting. Dr. Bavendam welcomed the opportunity to revisit this topic.

Challenges in Transitioning to a Transitional Care Program for Urologic Patients

Michael Hsieh, M.D., Ph.D.

The George Washington University (GW)

Dr. Michael Hsieh presented on transitional care for urologic patients. He began by reviewing the survival rates for persons with spina bifida. From 1983 to 2002, the 1-year survival rates for children born with spina bifida improved steadily; this was observed across ethnic groups and for all ages. A medical triumph and the most compelling data are the results showing an 80 percent increase in survival among these patients from the 1960s to 2014. Spina bifida patients are living longer and neurologic bladder issues require specialized adult care. Other conditions—such as epispadias, vesicourethral reflux, and ureteropelvic junction obstruction—also may require specialized care in adulthood. Dr. Hsieh explained that female spina bifida patients, for example, may have transitional urology issues; he posed the question of who will care for these patients as they age. A patient could potentially have up to five different procedures extending from childhood to adulthood, such as a ventriculoperitoneal shunt, bladder augmentation, and Mitrofanoff appendicovesicostomy. Risks associated with bladder augmentation in this and similar patients have been linked to increased incidences of cancer resulting in lifelong surveillance. Furthermore, prior procedures may affect these patients' ability to have children.

Regarding training, some residency programs require residents specialized in adult urology to gain experience in working with pediatric urology patients, but the depth is not significant. Similarly, pediatric urologists, although they have fellowships and certificates of qualification, receive little training in the care of adults with urological conditions. Dr. Hsieh noted general challenges of transitional care (e.g., issues of insurance, independence, and sexuality), as well as the urology-specific challenges and the cancer-related issues. Transitional care is an ongoing discussion on the national level. A clinician should consider the lifelong urologic care that encompasses many domains, including the neurocognitive, bladder and bowel, and sexual function/fertility/body image domains. Several areas of research—epidemiology, outcomes, clinical directed care, self-management, and system issues—can be developed from these care domains.

Dr. Hsieh highlighted several resources and initiatives to help pediatric urologists transition their patients. Got Transition® (gottransition.org), a cooperative agreement between the Maternal and Child Health Bureau (MCHB) and The National Alliance to Advance Adolescent Health, puts forth a recommended health care timeline. Transitional activities begin at adolescence and extend to ages 23 to 26. Dr. Hsieh emphasized that transfer of care and transition are unequal. A Joint Children's National Hospital–GW venture, the Clinic for Adolescent Pediatric-Onset Urology (CAPITUL), was started in 2014 and is the first dedicated transitional urology program in the mid-Atlantic region. CAPITUL interfaces with regional medical centers and practices, especially those in rural areas. In addition to infants, children, and adolescents, adults with pediatric onset urologic disorders are seen at CAPITUL.

Four models of transitional urology programs are being used across the country: (1) a separate freestanding children's hospital with a pediatric urologist on staff and adult hospital with an adult urologist; (2) an integrated health system in which the children's hospital is a component of the adult hospital, with pediatric and adult urologists in close proximity and communication (e.g., University of California at San Francisco); (3) a central urologist with privileges at both the freestanding children's and the adult hospitals (e.g., CAPITUL); and (4) an integrated health care system attended by a central urologist (e.g., Cleveland Clinic). Regardless of the model, Dr. Hsieh noted the challenges that he and other urologists transitioning patients in the mid-Atlantic regions face. The insurance (e.g., Maryland and

Virginia Medicaid) is accepted at Children's National Hospital but not the adult hospital—in this case, GW. Other challenges include the strain of having sexuality discussions as parents stay close to the patient and the Washington, D.C. Board of Health restriction on not allowing patients less than 18 years of age to be operated on in adult hospitals. Finally, reimbursements from transitional urology alone cannot sustain an active clinical practice.

Dr. Hsieh concluded that transitional urology is an important but new field. Many socioeconomic and regulatory barriers to successful transition of patients from pediatric to adult care setting remain.

Discussion

- Dr. Robert Star sought clarity on the insurance acceptance issues with GW patients. Dr. Hsieh clarified that the Maryland and Virginia Medicaid policies do not allow adult patients to seek transitional care services from an out-of-state hospital—in this case, GW. The Centers of Excellence such as Children's National Hospital is an exception but only covers pediatric patients. An alternative strategy has been to arrange for care at a GW satellite location in Maryland.
- Dr. Marie Ferris asked whether a patient's readiness to transition has been measured. Dr. Hsieh replied that questionnaires sometimes are used to assess readiness but noted that his major concern is adult patients whom he sees at GW for the first time with worsened urologic disorders and renal insufficiency.
- Dr. Maria Mann asked about the interactions with primary care physicians (PCPs) given the rare diseases these patients experience. Dr. Hsieh explained that a number of his pediatric patients have PCPs that will continue to provide services after a patient's care transition. Generally, care remains fragmented. Dr. Rohan Hazra suggested discussing the entire spectrum of care for pediatric patients, including other specialties such as internists. Dr. Hsieh stated that an ideal PCP would be a Med-Ped physician (i.e., double-boarded in internal medicine and pediatrics), which is rare.
- In response to a query by Dr. Bavendam on how frequently he interfaces with a nephrologist in CAPITUL, Dr. Hsieh pointed out that nephrology has not been an issue; most patients he sees who have chronic renal insufficiency are already receiving nephrological care.
- Dr. Star asked how well patients were responding to transitional care and called attention to the NIDDK CKD electronic (e)-Care Plan, which might be applicable in this context. Dr. Hsieh explained that socioeconomic factors affect a patient's overall response. The patients who transition well are those with medically conscientious families who keep meticulous records and are up to date on the medical conditions; medical literacy at the patient level also plays a key role. Dr. Mendley added that disease duration would need to be considered. The NIDDK CKD e-Care Plan was designed to address active patients and is not necessarily a model for the long term. She asked what could be structured differently in the current health care system to alleviate having to invent a smaller initiative to facilitate transitional care and how other federal agencies could help. Dr. Hsieh replied that having a universal electronic health record (EHR) would be ideal. He noted that innovative strategies—such as a working medical bracelet/USB drive, which includes a PDF of a patient's medical procedures—are useful. Optimizing billing for patients with complex medical conditions also would be helpful.

- When asked about any Medicaid changes that the Centers for Medicare & Medicaid Services (CMS) could inquire of the mid-Atlantic states, Dr. Hsieh noted that enabling Maryland and Virginia Medicaid patients with lifelong urologic issues to transition to the CAPITUL program would be a worthwhile goal. Dr. Mann pointed out that the Advancing Care for Exceptional Kids Act (commonly called the ACE Kids Act) is a federal law being implemented across children's hospitals and is relevant to this meeting.

Health Care Transition to Adult-focused Services: Lessons from the Field

Maria Ferris, M.D., Ph.D., M.P.H.

University of North Carolina at Chapel Hill (UNC) Health Care

Dr. Ferris provided an update on health care transition (HCT) lessons from the field and began by describing a signature program, the UNC Self-management and Transition to Adulthood with Rx=Treatment (STARx). Founded in 2006, the mission of STARx is to teach, enhance, and promote self-management for transition readiness for patients ages 12 to 29. The STARx research team collaborates with institutions worldwide and has translated its tools into several languages. Dr. Ferris emphasized that HCT is a process that involves adolescents and emerging adults, their parents, and providers—the goal is to be successful. Regarding the state of HCT, evidence shows that adult patients, regardless of their condition, generally are unprepared for the changeover in health care. Reports indicate that families of children with chronic conditions (e.g., CKD, diabetes mellitus [DM], or inflammatory bowel disease [IBD]) have higher levels of stress (emotional, physical, and financial) and increased marital distress.

Dr. Ferris summarized a series of studies in adolescents and young adults (AYAs) with CKD and end-stage renal disease (ESRD). Functional magnetic resonance imaging, used to evaluate the visual working memory of pediatric patients with CKD, showed decreased activation in the parietal lobe and prefrontal regions compared with non-CKD patients. AYA patients with early-age diagnosis and CKD onset have increased cognitive impairment issues compared with late-onset CKD. Dr. Ferris noted that the UNC Department of Pediatrics begins the transition process when a patient reaches 12 to 14 years of age; this is routine in most children's hospitals. The transition process ends when the patient continues in an adult-focused health care setting.

The UNC STARx program developed measurement tools to help patients beginning at 12 to 14 years of age transition the health care system. The TRxANSITION Index™ is provider-administered and is based on a 10-point grading scale evaluating three focus areas covering all aspects of an HCT (e.g., type of illness, nutrition, and ongoing support). The STARx Questionnaire is a self-administered disease-neutral report assessing self-activation, efficacy, and direction. Dr. Ferris remarked that to her surprise, the majority of adolescent patients with multiple conditions, when surveyed, preferred to learn about their health disorder from a parent first and from their health care provider second. Although patients gained more knowledge about their condition from their provider, the information did not necessarily increase their adherence to treatment. Data recently published using the TRxANSITION Index to evaluate AYA patients in the UNC Health Care system longitudinally showed that patients could understand the illness and medicines at a young age, but self-management skills were not established until age 20. The study also showed that parents needed to be educated about their child's condition and transition readiness.

Recognizing that no forum existed for researchers to discuss and share knowledge on HCT, Dr. Ferris organized the International and Interdisciplinary HCT Research Consortium (HCTRC) and helped to establish annual meetings. The HCTRC later designed an HCT Model consisting of four domains—individual, family and social support, health care system, and environment—to better understand the state

of the research and successful transition outcomes. Dr. Ferris summarized research findings in each of the four domains:

- **Individual domain**—In the AYA population, age predicts health self-management and readiness, females have knowledge of plans for higher education, and males make their own appointments and routinely communicate with their doctor. Caucasians scored better on transition compared to other races. Deficits in executive function associate with reduced readiness in patients with chronic conditions. Fifty percent of the Pediatric Heart Transplant Transitioning to Adult Care (commonly called TRANSIT) study participants transitioned better after an intervention.
- **Family and social domain**—A positive correlation was observed between family cohesion and transition readiness. Independence in keeping doctor appointments and knowing more about medicines was observed in youth from a two-parent household.
- **Health care domain**—Among Medicaid beneficiaries, low transition rates associate with increased emergency room (ER) visits and medicine non-adherence.
- **Environment domain**—An assessment by ZIP code showed that in communities with higher percentages of females, the patient transition readiness was higher. An increase in the poverty level associates with a decrease in patient readiness.

Dr. Ferris detailed the impact of the UNC STARx interventions. The TRxANSITION Passport (i.e., Nephrology Medical Passport™), which supports communications between the patient and providers in the clinic or ER, contains details about diagnosis, medicines, and insurance. Passport usage was similar among the more affluent patients who had IBD and private insurance compared with the mostly minority patients who had CKD and were on private insurance. Dr. Ferris advocated for using plain language when teaching parents and families, as well as answering questions and using teach-back approaches. She described her use of a simple approach, Kidney Klues Cards, to capture the patient’s voice and highlighted the use of other interventions, including Planet K and Planet T1D (Type 1 DM) mobile applications (apps).

Discussion

- Dr. Abbott asked who is accountable for entering and updating the Passport data. Dr. Ferris explained that at her practice, a coordinator manually updates the Passports using Microsoft Word and noted that her group is collaborating with the UNC Department of Computer Sciences and student programmers to develop a Passport app that patients will be able to access in the future.
- In response to a query by Dr. Star on the use of EHRs to populate the Passports, Dr. Ferris pointed out the challenges to having the STARx Questionnaire incorporated into the “MyChart” online patient portal—similar to that of the existing Patient Health Questionnaire 9, which is used for adults. Dr. Abbott noted that the primary care manager most often is responsible for uploading new tools, such as questionnaires, to MyChart and would be the person to contact.
- Dr. Jesse Roach asked about the policy or timeframe in a transition that a urologist begins seeing patients alone, without a parent present, for office visits. Dr. Ferris replied that the UNC Health Care policy is to separate patients from their parents at age 12 during office visits to allow candid discussions on sexuality and gender issues.

- Dr. Star inquired about a CMS quality metric for HCT office visits. Dr. Roach explained that some medical practices potentially could see this use of a quality metric as an added burden. He will make sure that CMS has these followup discussions.

Transition to Adult Health Care: A 2019 Snapshot

Marie Mann, M.D., Ph.D., M.P.H.

Health Resources and Services Administration (HRSA)

Dr. Marie Mann presented on HRSA's approach to transitioning youth from pediatric to adult health care. She elaborated on the HCT theory, evidence, and developments; the national performance measure (NPM) and performance results; Got Transition/the National Resource Center (NRC); and HCT improvement strategies. Dr. Mann reminded participants of the common properties (e.g., timespan, the process, awareness levels, and critical milestones) that all transitions, including pediatric-to-adult HCT, share. These properties should be considered in research and in establishing health care programs. The goal is to prepare youth and families for HCT and provide them with the knowledge, skills, and support needed throughout the transition process. The evidence shows that positive outcomes, especially for youth with special health care needs, are achieved best in a structured HCT process. Dr. Mann emphasized that health care systems need to be receptive to this type of HCT process and observant of necessary improvements.

Regarding HCT developments, the 2018 Clinical Report issued by the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and American College of Physicians (ACP) recommends using the Six Core Elements of Health Care Transition™—a structured HCT approach that can be customized for use in various settings for all youth and young adults. The Title V Maternal and Child Health (MCH) Services Block Grant Program grantees—as well as large systems of integrated care, children's hospitals, and disease-specific programs—are gaining experience in using and evaluating the Six Core Elements. In parallel, an increasing number of Title V MCH programs across the United States and territories support care coordination and implementation of evidence-informed approaches to HCT.

Dr. Mann reported that HCT has been identified as an NPM (i.e., NPM 12) for the 59 State and Territorial Title V MCH programs that serve mothers, children, and families. As of 2018, 36 State Title V MCH programs have selected HCT as a performance measure and are working to promote and advance HCT for youth both with and without special health care needs; however, performance lags. According to the 2016 National Survey of Children's Health (NSCH), programs are indicating that only 17 percent of youth with special health care needs and 14 percent of youth without special health care needs are meeting the performance measurement requirements. Got Transition/NRC, a cooperative agreement between HRSA/MCHB and the National Alliance to Advance Adolescent Health, has been in place since 2013 and is in effect until 2023. Got Transition, supported by six onsite staff, an executive team that includes family and young adult representatives, and several external advisory groups, aims to improve the ability of youth and young adults to manage their own health and effectively use health services, and to promote a structured process for transition preparation, transfer of care, and integration into adult-centered care. Got Transition's activities include assisting pediatric and adult practices to implement the Six Core Elements of HCT; assisting health delivery systems, health professional training programs and state agencies to implement the Six Core Elements; expanding youth, young adult, and family engagement in HCT; advocating for policy improvements in HCT; and keeping the Got Transition website current.

Dr. Mann detailed the HCT improvement strategies. She reiterated that the AAP/AAFP/ACP Clinical Report on Transition was updated and published in the November 2018 issue of *Pediatrics* and calls for all AYAs to receive transition services from health care professionals that continue into adulthood. The Clinical Report also makes available a sequential set of age-based steps for transition planning, transfer, and integration into adult care based on the Six Core Elements of HCT. In closing, Dr. Mann emphasized

the importance of incorporating transition into the medical home model of care and adolescent well visits. The HCT needs are twofold: (1) to focus on both pediatric and adult health care systems and (2) to involve parents/caregivers and AYAs in transition improvement planning and as team members in quality improvement efforts.

Discussion

- When asked whether the NPM requirements are focused on the individual or a team, Dr. Mann responded that the NPM on transition is applicable to the State Title V MCH programs. The three questions that make up of the NPM 12 are embedded in the NSCH, which Title V MCH programs use for benchmarking. These data are included in their annual state reports.
- Participants discussed cost-effectiveness and cost savings. For instance, integrated health delivery systems are incentivized to control cost. Some children's hospitals became interested in transition after observing the high ER use by patients 19 to 26 years of age. It is noteworthy that organizations or agencies implementing a program or intervention often are not the ones benefiting from the cost savings. Thus, the success and value of HCT should not necessarily be defined by cost savings in ER visits. It may take several years before the consequences of a good transition are manifested in the life of the young adult.
- In response to a question from Dr. Hazra on the percentage of the research agenda that should focus on healthy AYAs, Dr. Mann explained that adolescent development studies, including studies that address adherence to care and self-care skill development, may be helpful, as well as studies that examine transition outcomes and long-term outcomes of young adults.

Agency Updates

Agency for Healthcare Research and Quality (AHRQ): Evidence-based Practice Center Systematic Review

Christine Chang, M.D., M.P.H.

AHRQ

Tariq Shafi, M.D., M.H.S. (by WebEx)

University of Mississippi Medical Center

Dr. Christine Chang explained that the AHRQ project, a systematic review (SR) of ESRD in the Medicare population, was first described at the September 2018 KICC meeting and was conducted in collaboration with the Johns Hopkins University Evidence-based Practice Center. She invited principal investigator, Dr. Tariq Shafi, to present his report of the findings. Dr. Shafi noted that the full report has not cleared the AHRQ peer-review process and that today's update will not contain any study conclusions. The goals of the SR were to examine the effects of more frequent (or longer) hemodialysis on clinical outcomes and quality of life (QOL) and to summarize the instruments used to assess QOL and symptoms in ESRD patients.

Dr. Shafi provided background and rationale for the ESRD SR. The Medicare ESRD legislation was passed in 1973, and the standard practice for hemodialysis (dialysis) was three times per week and treatment lasted for 8 hours per visit. The treatment technique became more efficient over the past 45 years; in 2019, the U.S. dialysis time is approximately 3.5 hours. Because the kidneys work around the clock, whether more frequent or longer dialysis could improve clearance and outcomes is the research question being addressed. To begin the review process, a technical expert panel was established to discuss

the decisional dilemmas from the clinical, patient, and payor perspectives. The analytic framework is examining the frequency and duration of dialysis in U.S. Medicare ESRD population. The SR focused on four key questions: Questions 1–3 captured data on study characteristics and comparison with the general U.S. ESRD population, frequent dialysis, and longer dialysis. Question 4 collected data on QOL instruments and symptoms. Patient data were grouped into two categories: usual care (three times per week, fewer than 4 hours per treatment) and longer duration (three times per week, 4 hours or longer per treatment).

Dr. Shafi detailed the literature search results. The search returned 206 publications that matched the review criteria; 36 were related to dialysis frequency, 180 were related to QOL, and there was overlap. Methods included bias of risk assessment and strength of the evidence. There were 12 observational clinical trials and two randomized control trials (RCTs) on characteristics: usual care predominated. One hundred and sixty studies (21 RCTs and 139 observational trials) collectively used 123 QOL instruments. Of the 123 instruments, 16 were developed in a dialysis population, and 10 had been validated. Dr. Shafi summarized the comprehensive list of preliminary research recommendations on the existing data, human subject studies in dialysis, and biomarker studies.

Discussion

- Dr. Abbott asked about the frequency of checking residual renal function at the start of the dialysis across the studies. Dr. Shafi explained that residual renal function was checked infrequently in the studies.
- Given the challenge to encourage patients to consider home dialysis, Dr. Star suggested scanning the SR publications to identify the various study recruitment approaches. He also noted that the location (home or clinic) in which the QOL instruments are administered could affect baseline measurements.

CMS: Novel Payment Models for Improving CKD and ESRD Care in Medicare Patients

Tom Duvall, M.B.A.

CMS

Kathleen Blackwell, M.P.H.

CMS (by WebEx)

Mr. Tom Duvall reviewed the CMS efforts to implement the July 10, 2019, Executive Order on Advancing American Kidney Health and provided an update on other CMS activities. Further details will be reported at a future meeting.

Adjournment

Dr. Mendley thanked the presenters and attendees for their participation and adjourned the meeting.