Data Technical Workgroup

The Data Technical Workgroup will be responsible for supporting the data needs of the CCS Redesign Stakeholder Advisory Board (RSAB) and the data needs of the RSAB Technical Workgroups (TWG) relative to their specific topic area. These TWGs include:

- Eligibility / Health Conditions;
- Outcome Measures / Quality;
- Provider Access and Provider Network;
- County / State Roles and Responsibilities; and
- Health Homes / Care Coordination / Transitions.

The Data TWG will be responsible for providing the RSAB with descriptive data regarding all aspects of the CCS program, for example: cost utilization data for diagnostic and treatment services; utilization data by provider type; utilization data by diagnosis; analysis by region; administrative costs; and, to the extent possible, data regarding other services provided to CCS eligible children such as Medical Therapy Program, behavioral health, in home support service costs, etc. The Data TWG will also provide descriptive data requested from other TWGs as well as provide analysis of specific data areas requested by TWGs determined to be necessary for them to complete their work.

TWGs will communicate and work in collaboration with the Data TWG to ensure that data needed to inform their research and recommendations are made available, if such information is accessible. The Data TWG will also assess potential for further data development in the future, based on unmet information needs they or other TWGs identify.

This TWG will be co-chaired by Lee Sanders, MD, Stanford University, Dylan Roby, UCLA Center for Health Policy Research (UCLA), and Brian Kentera, Department of Health Care Services (DHCS).

The final list of topics will be identified and prioritized by the RSAB workgroup members and in conversation with other workgroups and their needs, but suggested areas for exploration include:
• Identifying and prioritizing specific data needs in issue areas determined by RSAB workgroups
• Accessing and including denied and unpaid claims in the aggregate CCS claims data to better understand variations in eligible diagnoses and claims authorizations across county CCS programs
• Assess potential for future development of a provider-sourced data warehouse (similar to Cincinnati Children’s Hospital's i2b2) for CCS providers to share de-identified data and compare and track outcomes over time
• Analyze potential for cost containment based on utilization of services
• Make projections about potential impacts on cost and utilization of any prospective changes to the program proposed by other technical workgroups
Eligibility / Health Conditions Technical Workgroup

The role of this technical workgroup will include an initial system-level scan of how medical eligibility is determined by CCS Medical Directors and staff across counties to look at patterns in eligibility determination. The TWG should also rely on the work of other organizations such as the Children’s Regional Integrated Service System, as they have put considerable effort into standardizing the medical eligibility process across counties. The overarching goal of this TWG will be to make recommendations to the RSAB and ultimately to the DHCS to bring CCS medical criteria up-to-speed with the needs of California’s Children and Youth with Special Health Care Needs (CYSHCN) population, the evidence-base for accounting for medical complexity and acuity of need, and the Affordable Care Act’s trend toward expanding access to health care across the country.

This TWG will be co-chaired by Bob Dimand, MD, DHCS and Neal Kohatsu, MD, DHCS.

The final list of topics will be identified and prioritized by the TWG members, but suggested areas for exploration include:

- Researching standardized validated assessment/eligibility determination tools in specific counties and other states and their potential for State-wide applicability
- Exploration of current CCS case mix and denied eligibility claims in comparison to current eligibility criteria, to establish if such criteria meet the needs of California’s CYSHCN population. If relevant, development of new eligibility guidelines
- Accounting for acuity of need on a regular basis, to ensure that enrollees’ level of care coordination and oversight adjusts to changing needs as children age
- Inclusion of prenatal and neonatal screening protocols for more rigorous case finding
Outcome Measures / Quality Technical Workgroup

A general consensus expressed by the RSAB is the need to establish baseline measures for quality of care and improved outcomes for CCS enrollees. This workgroup will coordinate with the data workgroup to 1) decide what data are needed to establish this baseline and consistent evaluation of progress, 2) determine if the data are readily available, and if they are, 3) consult the literature on benchmark outcomes to design a plan to track the CCS program’s progress toward such goals over time. If the data are not available, it will be up to this workgroup to make recommendations for establishing the necessary infrastructure to begin data collection.

This TWG will be co-chaired by Linette Scott, MD, DHCS and Joseph Schulman, MD, DHCS.

The final list of topics will be identified and prioritized by the workgroup members, but suggested areas for exploration include:

- Establish a baseline from which to assess need for quality improvement
- Establish benchmark outcomes, modeled on existing standards (for example, the California Perinatal Quality Care Collaborative)
- Goal-setting and metrics for measuring progress toward those goals over time
- Potential for interpreting data, identifying deficiencies, and translating to systems- and facility-level quality improvement projects
- Conduct a literature review on measures for assessing cultural competence and patient experience of care; devise recommendations for incentivizing health plans for meeting patient-centered quality of care metrics
- Facilitate a focus group with parents/caregivers of CCS enrollees to understand the patients’ definition of “quality care” and their experiences in the existing CCS program
- Exploration of other states’ attempts to achieve the “triple aim” of health reform - improving quality, efficiency, and outcomes - in their programs for CYSHCN, in comparison with California and across counties
Provider Access and Provider Network Technical Workgroup

The CCS program has established standards for all pediatric specialty and sub-specialty care across the State that will be maintained in any organized delivery system developed through the redesign process. The focus of this workgroup will be to explore further potential for expanding the CCS network of providers, consider ways to address geographic disparities in access and provider shortages, look at managed care access standards, and consider provider credentialing and access standards for an organized delivery system under CCS redesign. In addition, DHCS and UCLA will encourage coordination with Janet Coffman and her team at UCSF, who have conducted significant research on the supply of pediatric specialists in California, provider access issues, and potential for workforce development.

This TWG will be co-chaired by Nick Anas, MD, Children’s Specialty Care Coalition and David Banda, DHCS.

The final list of topics will be identified and prioritized by the workgroup members, but suggested areas for exploration include:

- Provider paneling, current certification criteria (for hospitals, individual providers, and special care centers) and potential for expanding
- Setting and maintaining standards of care and provider networks across the State, and requirements of health plans and any CCS organized delivery system for evaluating and maintaining those standards
- Access to specialty providers in rural counties, and potential for scheduling multiple same-day appointments for long-distance travel or providing additional travel resources to families/caregivers
- Potential for incorporating telemedicine and home-based health care into enrollees’ care plan for care maintenance
County / State Roles and Responsibilities Technical Workgroup

The CCS program is administered in a partnership arrangement between the State and counties. Over many decades this relationship has become increasingly complicated as counties and the State have attempted to accommodate changes in the program resulting from federal requirements associated with Title V, Title XIX, Title XXI and legislative adjustments. While changes to the program have been implemented statewide, some operational changes have been implemented or modified from county to county which impact various areas such as funding, service authorization, and eligibility determination. This TWG will be tasked with assessing areas for improved consistency and clarity of roles and coordination.

This TWG will be co-chaired by Judith Reigel, County Health Executives Association of California, Anastasia Dodson, DHCS and Louis Rico, DHCS.

The final list of topics will be identified and prioritized by the workgroup members, but suggested areas for exploration include:

- Assessment of current distribution of roles and responsibilities between the State, county CCS programs, and State regional offices, and development of a comprehensive Memorandum of Agreement/governance plan delineating these responsibilities
- Assess service authorization authority, responsibility, and oversight, including durable medical equipment (DME), in an effort to simplify the process and reduce delays in access to care and equipment for enrollees
- Consideration of the sustainability of counties’ “maintenance-of-effort” requirements
- Special consideration for the unique needs of small “dependent” counties
- Surveying county CCS programs to evaluate staff roles and responsibilities, to confirm the roles and definitions of CCS case managers, and the needs assessment tools they use for enrollees
Health Homes / Care Coordination / Transitions Technical Workgroup

Implementation of health homes and increasing care coordination between all partners is an essential component of CCS redesign. This includes not only improving communication and coordination between primary and specialty care providers, but also oral, mental and behavioral health, the school-based Medical Therapy Program (MTP), physical and occupational therapy, regional centers, home- and community-based health care services, pharmacy and DME, transition to adult care, etc. The array of services required to adequately care for CYSHCN has led to the creation of the “patient navigator” or “care coordinator”, to help enrollees and their parents/caretakers navigate through the health care system and access the care they need in a coordinated and timely manner. The task of this workgroup is to develop specific recommendations for implementing health homes for CCS enrollees.

This TWG will be co-chaired by Jessica Schumer, MD, UCLA Center for Healthier Children, Families & Communities, Jill Abramson, MD, DHCS and Hannah Katch, DHCS.

The final list of topics will be identified and prioritized by the workgroup members, but suggested areas for exploration include:

- Electronic Health Records: Current capacities, baseline needs for optimal performance and interoperability across domains
- MTP: Details of how the Program currently operates, health home components, program eligibility and variations from CCS program eligibility, level of coordination with county CCS programs, health systems, and health plans, ensuring that the MTP is included in any redesigned CCS organized delivery system
- Self-management services and education, and gaps in availability for CCS enrollees
- Assessment of counties’, health systems’, and health plans’ current use of “patient navigators/advocates” and care coordinators, as well as necessary background/qualifications for navigators and care coordinators
- Parent/caregiver perspective on issues of systems navigation, medication management, and in-home resources to identify areas of need and potential for improvement
- Development of standards for case managers
- Transition to adult care
• Palliative care
• Specific areas of need for CCS-only children, with regard to providing a “health home” in the absence of Medi-Cal or other sufficient primary care coverage