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May 26, 2015

Anastasia Dodson
Associate Director for Policy
California Department of Health Care Services
1501 Capitol Avenue
Sacramento, CA 95814

Dear Ms. Dodson,

On behalf of CCHA, I am writing to provide comment on the quality metrics and outcomes measurements presented to the Technical Work Group on Outcome Measures/Quality of the Regional Stakeholder Advisory Board on CCS Redesign. Specifically, CCHA wishes to provide:

- Suggested principles on quality and outcome measures for the CCS Program;
- Comments on the metrics presented to the TWG during the first webinar on April 10th, 2015;
- Feedback on the "Care Coordination Measures Feedback Form" provided to the TWG during the May 7th, 2015 webinar (see attached Form).

CCHA is concerned about the Department's recent focus on "Care Coordination Measures," because it represents a narrower way to assess quality than what was discussed during the April 7th webinar. During the April webinar, the TWG discussed considering important aspects of the health care delivery system for children with CCS-eligible conditions, including access, barriers to access, capacity of the pediatric network and other services. The group agreed to look at data available through existing sources, including CMSNet, the Title V Needs Assessment Process, CPQCC quality/outcomes data, and VPN data that will soon be available from PICUs statewide. Using Electronic Health Record (EHR) Meaningful Use data to develop short/long term quality and outcomes measures for care coordination was discussed but not in detail. Thus, we were surprised that the Care Coordination Measures feedback document presented to TWG members on May 7th reflects predominantly measures that tie to EHR. We would urge the Department to look at other priority areas beyond care coordination and use of HER, particularly measures that were discussed during the TWG's first webinar.

Guiding Principles for Identifying Quality and Outcome Measures for CCS

Below are some guiding principles developed in consultation with our hospital quality experts for the Department to consider as the TWG discusses quality and outcome metrics for CCS:

1. The establishment of outcome measures or quality metrics for the CCS population should be an iterative process that is not limited to these few TWG meetings. If the Department wants to develop meaningful measures of quality for this complex population, more ongoing consultation and refinement with stakeholders will be necessary.

2. The TWG and Department should establish a framework to evaluate quality and outcomes, in order to develop meaningful measures that support improvement in the program. This framework must encompass more than the sharing of medical information between physicians and facilities; it should extend to encompass the family experience of the program.

3. To the maximum extent possible, measures should be developed out of data that is already being collected in order to minimize cost, avoid duplication, and eliminate provider confusion. It may eventually be necessary for new data sources to be developed in order to ensure robust quality metrics for CCS. However, this will have a cost that should be accounted for by the State; providers cannot be expected to shoulder the burden. Any new data sources should also be carefully analyzed to ensure that the information being sought is not already being reported.

4. All medical outcomes measures should be consistent with American Academy of Pediatrics and specialty medical association guidelines as appropriate. For example, measurements of the age of annual primary care visits, frequency of regular dental care visits, etc., have established clinical guidelines that should be followed by providers.

5. A tool should be identified to capture behavioral/mental health information and access to care for CCS patients. CCS children, particularly those with several co-morbid conditions may have mental/behavioral issues secondary to their CCS diagnosis. In order to properly treat the whole child, those conditions and the child's access to treatment should be evaluated along with their physical health issues.

6. Any data source, tool, or measurement used to evaluate quality and outcomes should be appropriate to the pediatric CCS population. For example, Leapfrog is used to evaluate General Acute Care hospital safety but their survey is not accurate for children's hospitals since they do not have a pediatric computerized provider order entry validation test.

Comments on the Metrics Presented to the TWG During the April 10th, 2015 Webinar

For the purposes of the first TWG meeting, the Department provided two documents identifying potential quality metrics, one titled "Assessing Health Care Systems Serving Children and Youth with Special Health Needs" and another authored by the Stanford CPOP listing suggested quality domains and indicators available through existing paid claims data. CCHA has the following feedback on the two documents:

Assessing Health Care Systems Serving Children and Youth with Special Health Needs

The metrics presented in this document are too general and will not be applicable equally between facilities. The data would be difficult to collect, particularly since it is unclear who would be filling out the survey instrument as it is presented. The measures proposed in the document need to be defined for clarity. For these reasons, CCHA would submit that these measures should not be used by the Department for the purpose of evaluating CCS quality and outcomes measurement, particularly if the data would be tied to reimbursement.

Stanford CPOP Suggested Quality Domains and Indicators

Although paid claims data can be used to develop useful metrics, we submit that there are some metrics (pharmacy, lack of OP visit after hospital discharge) which can be influenced by issues that are beyond the control of the provider or facility. For example, if a family is poor they may not be able to fill every prescription. Or, the patient's family situation may be volatile and thus, compliance with physician instructions is low. Finally, the complexity of the CCS population can bias ED physicians and sometimes families toward IP admission even if the condition can be managed comfortably by the primary care physician. Care must be taken to interpret the data correctly, for the good of the patient and the provider. Below, we have provided feedback on some of the specific measures proposed in the CPOP document:

1. Measures #1 (annual primary care visit) and #3 (regular dental care) would be useful for determining clinical quality/outcomes as long as they are revised to reflect AAP/specialty specific guidelines.

2. If readmissions are going to be used as a quality metric, Measure #8 (no unplanned 30 day readmission) should be amended to apply to "same cause" readmissions and shorten the window from 30 to 7-14 days.

3. Measures #9 – 15 do not need to be measured individually as they are implicit in Measure #8.

Feedback on the "Care Coordination Measures Feedback Form" Provided to the TWG During the May 7th, 2015 Webinar

Per the Department's request, we have submitted our responses to the "Care Coordination Measures Feedback Form." Please see the attached for our detailed responses.

In general, CCHA would like to express its concerns with the Department's sole focus on care coordination as a measure of quality/outcomes for the CCS population. While issues regarding care coordination are certainly important, the CCS program was designed to ensure that children with rare or complex health conditions obtain access from highly trained specialists. Thus it would seem of utmost importance to measure whether or not the program is achieving this critically important goal. Similarly, patient and family satisfaction must be an important indicator of the quality of any program. Such measures must be included in any set of quality/outcome measures for CCS that is promulgated by the Department.

In addition, all of the measures proposed in the Form are drawn from problematic data sources. The NS-CSHCN is not a reliable data source for CCS children due to the significant difference between socio-economic status of CCS families and those that participate in the National Survey. The Title V CCS physician survey is only taken every five years and in order to continue using the data, it would be necessary to develop a way to more frequently/continuously collect the survey information. In order to develop meaningful measures from the data sources identified on the Form, CCHA believes that the Department would need to engage an independent contractor to standardize/tailor existing survey tools for CCS administrators, providers, and families.

In closing, CCHA recommends that the Department work with the TWG to identify new and broader metrics of quality and outcomes that are pediatric specific and appropriate for CCS.

Thank you for the opportunity to comment on these measures.

Sincerely,

Ann-Louise Kuhns
President & CEO
California Children's Hospital Association

Attachment

Department of Health Care Services
California Children's Services (CCS) Redesign

Outcome Measures/Quality Technical Workgroup (TWG)
May 7, 2015 webinar
Care Coordination Measures Feedback Form

TWG/ RSAB Member Name and Organization: _____Ann Kuhns/CCHA_____

Email: ___akuhns@ccha.org_____ **Date:** _____5/26/2015_____

***Stakeholder feedback is due Tuesday, May 26, 2015. Please email your feedback to** chpr_ccs@em.ucla.edu **and** ccsredesign@dhcs.ca.gov

I. Care Coordination Measures

TWG-proposed priority area	Measures from Existing Data Sources	Stakeholder input Please address the following questions: • Are these the appropriate measurements? • What changes are suggested? • What additions are suggested?
1) Existence of care plan	**CCS administrative data**: At least 1 visit coded for "care coordination" per year. **Title V CCS Family Survey:** Parent/caregiver provided with or want care plan for child?	CCHA supports these measures, as long as they are refined to reflect the percentage of goals in the care plan that are met.
2) Existence of EHR	**Title V CCS Administrator Survey:** Impact of EHR on access to and sharing of information regarding CCS clients with other providers serving the same clients	This measures EHR use, which is not synonymous with care coordination.

3) Usage of electronic patient information portals	**National Survey – Children with Special Health Care Needs (NS-CSHCN):** Likelihood that parent/caregiver would use a website to help arrange or coordinate care.	Seems like it would be difficult to measure and not clear that this improves care coordination for a child.
4) Usage of EHR incentive payments	**No existing measures identified.**	This has nothing to do with anything other than use of HER incentive payments. Doesn't measure quality or care coordination.
5) Meaningful use of EHR	**Title V CCS Physician Survey:** Importance of additional resources to becoming a primary medical home for CCS clients [rank order], including: EMR system that links with pediatric subspecialty providers.	Not clear what this actually is. Also, similar to above, not clear that this measures quality or outcomes in a meaningful way.

6) Provider-to-Provider communication (Including Integrated EHR)	**Title V CCS Physician Survey:** Significance of barrier to providing quality care: PCP's ability to access electronic information from specialty providers serving the same CCS children.	Please resubmit these with numbers, since it's hard to provide feedback on these 7 distinct measures without numbers. Some of these measures would seem of questionable validity and subject to a lack of interrater reliability. For example, "frequency of feeling that PCP and specialty provider were working together…" -- Feeling? Similarly, how to measure "frequency of communication…" is this a perception or a normative value? Also, relative to measures of discharge delays…does this measure lack of care coordination or lack of resources (e.g., inpatient mental health, home health care).
	Title V CCS Physician Survey: Frequency of communication with other providers (and type of provider) serving the same CCS clients.	
	Title V CCS Physician Survey: Importance of additional resources to becoming a primary medical home for CCS clients [rank order], including: Ability to conduct informal consults and make contact with subspecialty providers (email, phone, telemedicine).	
	Title V CCS Family Survey: Frequency of	

6) Provider-to-Provider communication (Including Integrated EHR), continued	feeling that PCP and specialty provider were working together to care for child in last 12 mos.	
	Title V CCS Administrator Survey: Frequency of discharge delays because of lack of care coordination or DME access	
	Title V CCS Administrator Survey: Frequency of CCS provider's communication with: PCPs, Special Care Centers, regional centers, schools, MTPs, community based organizations	
	NS-CSHCN: Parent/caregiver's satisfaction with providers' communication with each other and with outside services (school, early intervention, child care providers, vocational education,	

	rehabilitation programs)	
Uncategorized Care Coordination Measures from existing sources	**NS-CSHCN:** Is there someone who helps parent/caregiver arrange/coordinate care; if yes, who; need for additional assistance coordinating care; overall satisfaction with care coordination received	
Additional comments or suggestions from TWG for Care Coordination Measures		We are concerned that the focus of the quality and outcomes workgroup has become entirely centered on care coordination. Much of the goals of CCS are really around access to high quality specialty care for unusual diseases and conditions. By focusing on care coordination, it appears that you only want to measure the thing that will give the Department the outcome it wants: Folding CCS into Medi-Cal managed care. This seems biased. Also, there seems to be too much focus on EHR use, as if that's a proxy for care coordination. Is that so? Are there studies to back up that presumption?

*****PLEASE NOTE: Stakeholder feedback is due Tuesday, May 26, 2015. Please email your feedback to chpr_ccs@em.ucla.edu and ccsredesign@dhcs.ca.gov**