

May 26, 2015

From: Laurie A. Soman

To: chpr_ccs@em.ucla.edu; Dodson, Anastasia (EXEC-DIR)@DHCS; Rico, Louis (CMS)@DHCS; CCS Redesign (CMS)@DHCS

cc: CRISS Steering Committee (mkmcgrath1254@aol.com; jduenas@supportforfamilies.org; Chris.Dybdahl@santacruzcounty.us; culluma@sutterhealth.org; terricowger@aol.com; kcarlsen@placer.ca.gov; barellano@ccha.org; Cutcher, Greg @San Francisco County; Mwolfe@co.humboldt.ca.us; kking@careparentnetwork.org; louis.girlingmd@acgov.org; wendy.longwell@rfenc.org; pmarks@familyvoicesofca.org)

Subject: Feedback on RSAB Outcome Measures/Quality Technical Workgroup

Dear DHCS and UCLA folks—

I'm writing to comment on the feedback form on Care Coordination Measures and to make several recommendations to the Outcome Measures/Quality Technical Workgroup about possible ways to strengthen our process. I thought we had a productive first meeting of the group, but I found our second call confusing, amplified by the "Care Coordination Measures" distributed for feedback. I don't understand why the group's work is focusing on discussing what are labeled "Care Coordination Measures" after our discussion on the first call. In addition, I don't think the "Care Coordination Measures" are strongly linked to quality or outcomes or speak to care coordination for children with special health care needs. Let me start by restating what I thought we agreed to in the first workgroup call:

- In addition to looking at specific clinical outcomes and indicators, we agreed to consider important aspects of the health care delivery system for children with special health care needs, including access, capacity of the pediatric network and other services, and barriers.
- We agreed to look at what kinds of data already are available through existing sources, including CMSNet, Business Objects, and CCS County Performance Measures, as well as the surveys conducted as part of the Title V Needs Assessment Process.
- We agreed that it would be critical to consider the CPQCC quality/outcomes data as well as the VPN data that soon will be available from PICUs statewide. As I understand it, even though the data may not be limited solely to CCS-enrolled children, the care delivered in NICUs and PICUs is driven by the quality standards of the CCS program and thus is relevant to assessing the quality and impact of the program.

In contrast to the agreement during the first call on a broad array of quality/outcome indicators, the care coordination measures that we've been asked to review mostly concern the presence and use of electronic health records (EHR) and are the kind of components that are being or will be addressed via managed care plans for their enrollees. EHR implementation is an important starting point in approaching care coordination and should be assessed as a tool for contributing to better coordination, but its use alone isn't a measure of actual coordination. In addition, there appears to be little in the measures that is specific to care coordination for children with CCS conditions or that would evaluate the nature or extent of value added from the CCS program.

Recommendations

I have some specific comments about the suggested measures and data sources and their applicability to CCS, but first I want to make more general recommendations for our workgroup in approaching measuring quality and outcomes for the CCS program and the children served by it.

1. First and foremost, I think we need to agree on a framework for evaluating quality and outcomes, from which specific measures would flow. This was discussed during the first meeting but not addressed in our second call. The framework should include compilation of baseline data on quality and outcomes in the program as it is now, as well as attention to periodic collection and analysis of new data, e.g. periodic surveys of CCS families, state and county program staff, and providers, on a more frequent schedule than the Title V Needs Assessments conducted every five years. These surveys should be designed, administered and analyzed by entities independent of the state to ensure neutrality. Collection of baseline data and periodic data updates is particularly important if systems changes are made to the CCS program, since frequent periodic evaluation will be required to ensure that changes made have positive impact on quality and outcomes.
2. I strongly recommend that we return to discussing a range of factors with impact on quality and outcomes, such as:
 - access to appropriate and timely care;
 - clinically oriented metrics, including identification of one or two measures appropriate to individual Special Care Centers such as clinical measures for diabetes or cardiac conditions; and
 - measures keyed to CPQCC and PICU data.

Measures should be specific to children and youth with special health care needs. This discussion should be part of development of the evaluation framework, including a clear statement of what we want to measure and the rationale for those metrics.

3. Before agreeing on measures for care coordination, we should agree on a definition and operationalization of care coordination that includes but extends beyond the sharing of medical information among specialists, hospitals and PCPs. For example, we should address the importance of:
 - a care plan addressing the whole child and developed in partnership with the family;
 - coordination with other critical agencies used by CCS children such as regional centers, special education, and mental/behavioral health services;
 - effective transition from the pediatric to the adult health world; and
 - family perceptions of and satisfaction with levels of care coordination.
4. The evaluation framework should have built-in capacity for growth and commitment to continuous quality improvement through expanded outcome measures as new program and systems improvements are agreed on and implemented.

In addition to my comments above, I have some reservations about the data sources proposed in the feedback form:

- As noted above, the Title V surveys should be repeated on a more regular basis than every five years in order to provide actionable information. The surveys should continue to be managed by an entity independent of the state and their results should be released on a timely basis to the public.
- As we've discussed before, the National Survey data on children with special health care needs are not reliable sources of information on CCS children and their families or for evaluation of CCS quality or outcomes. To recap, the surveys are not limited to children

with CCS-eligible conditions nor are they specific to the low-income, Medi-Cal-eligible children who comprise the vast majority of CCS enrollees. The income differences alone make the National Survey data particularly unreliable in assessing such factors as access to and use of web-based devices or portals. Surveys of families of current CCS enrollees, such as those conducted in the current Title V process, would be far more appropriate for making these assessments.

I hope these comments are helpful and I thank you for the opportunity to provide them. I look forward to the chairs of the Quality/Outcomes Workgroup reconvening the group to develop an evaluation framework and set specific next steps leading to development of measures that will assess the quality and outcomes for this very vulnerable population of children.

Laurie

cc: CRISS Steering Committee

Laurie A. Soman
Director, CRISS Project
Director, Alameda County Medical Home Project
Senior Policy Analyst
Lucile Packard Children's Hospital
725 Welch Road, M/C 5524
Palo Alto, CA 94304
Phone/Fax: 510-540-8293
Lsoman6708@aol.com/Lsoman@stanfordchildrens.org