

## Key Informant Interviews Subcommittee

CCS Title V Needs Assessment  
Key Informant Interview Subcommittee Meeting  
Oct. 7, 2009  
8:00 AM

Conference Call Number: 1-877-675-1807  
Participant Code: 648955

Online meeting page: <http://fcm.fhop.na4.acrobat.com/interviews/>

### AGENDA

1. Welcome and Introductions
2. Goals for today
  - a. Identify topic areas to be asked about in the interview
  - b. Determine list of key informants to be interviewed
3. Develop a list of topic areas and potential questions to ask interviewees
4. Brainstorm organizations/individuals/interest groups to be interviewed
5. Next Steps
  - a. FHOP will draft interview guide and email to participants for review
  - b. Schedule follow-up teleconference to discuss draft interview guide

CCS Title V Needs Assessment  
Key Informant Interview Subcommittee  
Conference call and online meeting  
Oct. 7, 2009, 8:00 AM

### Meeting Notes

#### Attendees:

Kathy Chance, DHCS CMS  
Marian Dalsey, DHCS CMS  
Stephanie Dansker, UC Davis Medical Center  
Katie Gillespie, FHOP  
Mary Goldberg, DHCS CMS  
Mara McGrath, CRISS  
Gerry Oliva, FHOP  
Jennifer Rienks, FHOP  
Tara Robinson, Family Voices  
Jeannine Rodems, California Academy of Family Physicians  
Cheryl Sparks, Blue Cross

- The meeting was held via conference call with an accompanying online meeting page.
- After a welcome and introductions, Jennifer Rienks reviewed the goals for the meeting.

- The group will meet 3 or 4 more times to identify organizations/individuals/interest groups to be interviewed, to discuss the draft interview guide, and to review information gathered in the interviews.
- On the online meeting page, the group viewed the document “CCS Issues Raised and Questions Posed by the CCS Title V Stakeholders, the HMA Report and the CHCF Issue Brief”. Jennifer explained the document and then the group reviewed each of the issues/questions, discussing which topics to address in key informant interviews.
- It was suggested to start by summarizing the positives of the CCS program and ask interviewees for additional examples as well as suggestions for data to illustrate the positives.
- It was discussed to not ask for additional issues or problems because many issues and problems have been identified through the various statewide efforts and the key informant interview group will identify which need further exploration through interviews. In the interviews, the question can be framed as “how does [this issue] play out in your work?”.
- Please see the working document, “CCS Issues and Questions for Key Informants” for specific issues to consider addressing in interviews.
- We did not make it through all of the issues. We will meet on the phone and online again next Wednesday, October 14, at 1pm. Before this meeting, review the working document, “CCS Issues and Questions for Key Informants”. Send FHOP a list of suggested key informants, based on the issues and questions. We will discuss these on the call next week.

CCS Title V Needs Assessment  
Key Informant Interview Subcommittee Meeting  
Oct. 28, 2009  
3:00 PM

Conference Call Number: 1-877-675-1807  
Participant Code: 648955

Online meeting page: <http://fcm.fhop.na4.acrobat.com/interviews/>

AGENDA

1. Welcome and Introductions
2. Review and discuss interview guide
3. Discuss Piloting interview tool - need 2 volunteers to be "interviewed"
4. Next Steps

**Focus Groups Subcommittee**

CCS Title V Needs Assessment  
Focus Group Subcommittee Meeting  
Oct. 12, 2009  
10:00 AM

Conference Call Number: 1-877-675-1807

Participant Code: 648955

Online meeting site: <http://fcm.fhop.na4.acrobat.com/focusgroups/>

AGENDA

1. Welcome and Introductions
2. Goals for today
  - c. Determine who will be asked to participate in focus groups
  - d. Identify potential locations for focus groups and enlist help coordinating focus group logistics
3. Brief review of FHOP timeline and progress on data collection efforts and how they are interdependent
4. Overview of purpose of focus groups- what kind of information we are looking for from these groups? Discussion of what types of individuals would be best able to can give us data not available from other sources
5. Brainstorm potential organizations/individuals/interest groups to partner with in recruiting participants and conveying focus groups
6. Determine which organizations/individuals/interest groups will be contacted for participation
7. Identify who can help with coordinating the various focus groups and locations for focus groups
8. Next Step
  - e. FHOP and subcommittee members will follow-up on contacting identified organizations/individuals/interest groups to invite participation and plan logistics
  - f. Schedule follow-up teleconference to discuss progress

Title V CCS Needs Assessment  
Focus Group Subcommittee  
Conference call and online meeting  
Oct. 12, 2009, 10-11:30AM

**Attendees**

Dini Baker, CHOC  
John Barry, CCS Shasta County  
Kathy Chance, DHCS CMS  
Stephanie Dansker, UC Davis Medical Center  
Katie Gillespie, FHOP  
Mary Goldberg, DHCS CMS  
Mara McGrath, CRISS  
Gerry Oliva, FHOP

Jennifer Rienks, FHOP  
Debbie Ruge, CCS LA County  
Pam Sakamoto, CCS Solano County  
Katie Schlageter, CCS Alameda County

## Call notes

### 1. What types of individuals would be best able to can give us data not available from other sources?

#### Who are potential organizations/individuals/interest groups to partner with in recruiting participants and convening focus groups?

- Family Groups
- Medical Therapy Program – parents? chiefs, admins/providers?
  - southern counties and northern counties
- Some ready-made focus groups through CRISS subcommittees
  - family centered care (family resource centers, CCS reps, medical therapy program reps)
  - medical therapy program group
  - claims group
  - medical eligibility group (CCS medical consultants)
- at hospitals, family advisory councils
  - Family Partners groups in Orange County - Dini (Spanish speakers)
- Contra Costa – Spanish speaking group, Joan Crook
- families who use services but are not in CCS? For example, Lucile Packard group?
- Children’s Hospital LA, large parent group – also Spanish speaking, especially in cancer group
- Partnership Health Plan of California, convenes focus groups (Solano, Napa, Yolo, Sonoma) (CCS group held 2 years ago, DME a few years back) – CCS contact, Michele Dernay
- LA County CCS – Family Group, majority from medical therapy program
  - for a provider group, could invite other counties
- MTP supervisors group, meeting on Dec 7 (Northern CA)
  - Southern CA also has a group
- CCS: Bay Coastal Administrators, meet monthly (12-14 counties)
  - meetings: Oct 22, Nov ?, Dec ? ; at State building in Oakland
  - Similar meeting in Northern CA – Sacramento?
    - typically meet in Dec but travel issues
    - Could get more rural counties
    - John Barry will follow up
  - Similar meeting in Southern CA?
- Admins/chiefs outside of CCS – hospital administrators, division chiefs, who represent children’s hospitals, CCHA
- American Academy of Pediatrics
- CCS Medical providers

- any specialty meetings
  - Neonatology Day in Southern CA in Nov
- Hospitals may have contracted specialty care provider groups and have monthly meetings
  - CHOC (Could have 4 focus groups)
  - Kaiser?
- Jeff Gould, perinatal quality care improvement group
  - meet 3-4 times a year
- High risk infant follow-up program meeting, Sacramento, Nov 9
  - have monthly coordinator conference calls (1<sup>st</sup> Thursday of the month)
  - nurses, psychologists, PT, physicians
- Primary care providers in rural communities?
  - group to develop questions for survey?
- issues for primary care in general and finding/using a medical home
  - (-primary care from subspecialists)
- Explore with:
  - AAP?
  - mix primary care and subspecialists?
- Durable medical providers
  - CAMPS, Bob Ackerman - key informant interview better than focus group?
- People doing the day to day work
  - Nurse case managers – can they be grouped?
  - Orange County, PH Nurses do CCS and meet regularly
  - LA County, CCS Nurses meet monthly (Debbie Ruge)
  - Alameda County CCS Nurses – 12 nurses
  - Solano, 3 nurses

**2. Which organizations/individuals/interest groups should be contacted for participation?  
Who will help with contacting organizations/groups about possibilities for  
conducting/coordinating a focus group?**

1. MTP administrators
2. MTP clients
3. Specialty providers
4. Primary care
5. Administrators and medical chiefs
6. Case management (CCS Nurses)
7. CCS Administrators: Dependent Counties –
  - a. Eligibility (medical consultants) – group with Administrators
8. Family groups: Family Partners –

**3. Questions to ask when contacting groups or agencies about the possibility of a focus group:**

- The groups will be: 8-12 participants, face-to-face, 1.5-2 hours
- Ask about dates; location, assistance recruiting participants, possible room space, possible refreshments
  - For patient/family groups, also ask about: possible travel reimbursement, possible childcare, possible stipend

**4. Next meeting:**

-Will schedule over meeting wizard

Title V CCS Needs Assessment  
Focus Group Subcommittee Meeting  
Oct. 22, 2009  
9:00 AM

Conference Call Number: 1-877-675-1807

Participant Code: 648955

Online meeting site: <http://fcm.fhop.na4.acrobat.com/focusgroups/>

AGENDA

1. Overview of follow-up responses after last call - identify gaps or contact that still need to be made
2. Can we combine any groups?
3. Finalize list of focus groups and who will help with hosting and logistics
4. Plan for next call and development of focus group guides

Title V CCS Needs Assessment  
Focus Group Subcommittee Meeting  
Oct. 22, 2009  
9:00 AM

Conference Call Number: 1-877-675-1807

Participant Code: 648955

Online meeting site: <http://fcm.fhop.na4.acrobat.com/focusgroups/>

Attendees: Cheryl Sparks, Anthem Blue Cross; Debbie Ruge, LA CCS MTP; Dini Baker, CHOC; Mara McGrath, CRISS; Kathy Chance and Mary Goldberg, DHCSMS; Gerry Oliva, Jennifer Rienks, and Katie Gillespie, FHOP.

AGENDA

5. Overview of follow-up responses after last call - identify gaps or contact that still need to be made
6. Can we combine any groups?
7. Finalize list of focus groups and who will help with hosting and logistics
8. Plan for next call and development of focus group guides

Focus Groups Follow-up

1. MTP administrators  
(MTP clients – combine with Family group)
2. Specialty providers
3. Primary Care
4. Administrators and medical
5. Case management (CCS Nurses)
6. CCS Administrators: Dependent Counties
7. Eligibility (medical consultants)

8. Family groups: Family Partners

[Notes removed to protect identities of participants]

CCS Title V Needs Assessment  
Focus Group Subcommittee Meeting  
Nov. 24, 2009  
10:00 AM

Conference Call Number: 1-877-675-1807

Participant Code: 648955

Online meeting site: <http://fcm.fhop.na4.acrobat.com/focusgroups/>

AGENDA

9. Welcome and Introductions

10. Goals for today

- g. Update status of scheduling focus groups with groups selected for participation.
- h. Review initial list of topic to be explored in focus groups

11. Update on scheduling focus groups

12. Review list of potential topics to explore with various focus groups. List of potential topics suggested by stakeholders and or identified in the key informant interviews as common themes for additional exploration

13. Next Step

- i. FHOP will draft focus group discussion guides based on analysis of the key informant interviews and feedback from focus group subcommittee
- j. Schedule follow-up teleconference to review discussion guides

Title V CCS Needs Assessment  
Potential Topics for Focus Groups

Category/Group	Suggested Topic to Cover
MTP Administrators	<ol style="list-style-type: none"> <li>1. Do we need to redesign the MTP to make it more efficient and effective? If yes, then how? [prompt – eligibility? Service delivery?]</li> <li>2. Review literature? Research? on best practices. ... How can data collection, outcome measures, and research on best practices be used in MTP? Program planning and clinically. Increase use of validated instruments.</li> <li>3. How to deal with not enough county therapists and vendors not wanting to do the work because of low reimbursement rates?</li> <li>4. Do you perceive that schools and MTP are duplicating services? Are the recommendations for the relationship between Education and MTP? Confusion about who is responsible for services with school providing OT and PT and billing Medi-cal and CCS providing the same services</li> <li>5. Should state do more data collection and measurement of functional changes? -- What data should be collected and how to collect it to capture this information?</li> </ol>

MTP	Same as above
Specialty Providers	<ol style="list-style-type: none"> <li>10. What are the most significant barriers to provider participation in CCS? Strategies to overcome? (break into 2 questions) (incorporate #1-3)               <ol style="list-style-type: none"> <li>1. (Specialty physician shortage issue – rates and delays for authorization</li> <li>2. (What incentives could be used to capture new specialty physicians?</li> <li>3. (How to do more training for primary care or specialty providers? How to engage providers?</li> <li>4. What would it take to inspire interest in providing quality care and contributing to the well-being of with these kids? --- get rid of/reword: how to market the program to providers who are not currently participating?</li> <li>5. What would you need to be able provide a medical home for these kids? --Would you want to incorporate into your practice? What could be done to improve communication with the Medical Home physicians – and any other components?</li> <li>6. What would it take to induce primary care MDs to provide a medical home to and provide good care to CCS kids? ---Do providers think medical home should be integrated into specialty practice, or not integrated? (reword/combine 5 and 6)</li> <li>7. Should health plans be required to provide the same coverage/standards of care that CCS provides for kids that have private insurance or don't qualify for CCS (for all Health Plans – or managed care medicare?) (is this question best for this group? –being asked in multiple groups)</li> <li>8. Should state do more data collection and measurement of outcomes? –What kinds of outcome information should the State be collecting?</li> <li>9. Should CCS program try to get out from under EDS? (ask another way – should CCS providers be reimbursed in another way? What are challenges billing? What is a better way?)</li> <li>10.</li> </ol> </li> </ol>
Medical Consultants	<ol style="list-style-type: none"> <li>1. Ideas for how to improve timely authorization process for DME – (also ask of MTP chiefs)</li> <li>2. How to do more training for providers? How to engage providers?</li> <li>3. How could authorization process for services be improved?</li> <li>4. How to reduce inter-county variations?</li> <li>5. (Do they do anything about providers and enforcement of standards? Do they do any enforcement of standards with primary care providers in their communities?) Could you envision your role changing to assist with enforcing standards?</li> <li>6. Common application process – is there ways of improving eligibility determinations?</li> <li>7. Provider barriers to participating in CCS? Strategies to overcome? -also ask question from Specialty Care group about how to recruit and market</li> </ol>
Hospital Administration and Health Plans	<ol style="list-style-type: none"> <li>1. How could health plans help facilitate timely access to equipment and services given the state CCS delays in authorization for these?</li> <li>2. Issues in coordinating care in CCS kids when patient is carved out? How to overcome barriers to coordination?</li> <li>3. Prompt:Would it improve care to carve in of whole child when they have a complex CCS-eligible medical conditions?</li> <li>4. How is care coordinated when there is not a carve out? Is there a problem getting access to specialty care when carved in? Do they get to appropriate specialty care?</li> <li>5. Should health plans be required to provide the same coverage that CCS provides for privately insured kids that don't meet CCS financial</li> </ol>

	<p>qualifications?</p> <ol style="list-style-type: none"> <li>6. Treating the whole child – creating a whole child system for complex CCS cases?</li> <li>7. What would it take for the health plans to do case management and what should it consist of? How to provide families with social support?</li> <li>8. Common application process – is there ways of improving eligibility determinations?</li> <li>9. Should CCS program try to get out from under EDS?</li> <li>10. Strategies for better enforcement of state CCS standards with providers of high level and low level care?</li> </ol>
<p>CCS Administrators and Case Managers</p>	<ol style="list-style-type: none"> <li>1. How to improve timely authorization process for DME?</li> <li>2. How to reduce inter-county variations?</li> <li>3. Should health plans be required to provide the same coverage that CCS provides for kids that don't qualify?</li> <li>4. Are there county-level models that make authorizations more efficient? Prompts In county, case management people work directly with financial eligibility people to improve the authorization process. Nurse managers aren't doing as much of the clerical work (Katie add to this...)</li> <li>5. How could case management be improved?</li> <li>6. Should there be standardized case management protocols? Would they help to reduce perceived inter-county and intra- county variation</li> <li>7. Common application process – are there ways of improving eligibility determinations?</li> <li>8. How much variability is there in the amount and quality of case management in different counties?</li> <li>9. Would providing medical case management through the regional medical centers/Special Care Centers be more efficient and effective? (would it be more efficient to have direction and authorization at Special Care Centers and not be done by the counties?) (should there be regional standardization?) (is this question about efficiency and effectiveness or variability?) (question is about medical practice and about authorization process)</li> </ol>
<p>Transition Age Youth</p>	<ol style="list-style-type: none"> <li>1. Transition issues – how can we improve transition?</li> <li>2. Challenges in finding an adult provider that can care for CCS condition?</li> <li>3. What has made it easier – what has made it harder?</li> <li>4. Did you have transition team?</li> <li>5. What worked with your transition planning?</li> <li>6. Who helped you with your transition?</li> <li>7. What did you experience in transitioning to an adult provider?</li> <li>8. What other kinds of non-medical services do they need and what is their experience in trying to get these services?</li> </ol>
<p>Families</p>	<ol style="list-style-type: none"> <li>1. Social support and case management – we've heard counties are losing social workers and county Case Managers can only do basic medical case management – how is this impacting families?</li> <li>2. CCS pays for in-home support services – how is this process working for families? What suggestions do you have?</li> <li>3. Access to and satisfaction with primary care providers in the local community? Suggestions?</li> <li>4. What areas do parents want to have input into? What would make care more family centered?</li> <li>5. Barriers to care?</li> <li>6. Do you have adequate access to DME? Prompts Delays in getting equipment serviced? Suggested solutions?</li> </ol>

	<p>7. Are there gaps in services? Delays in services? 8. With staffing cuts, do county CCS staff have enough time to provide an opportunity for parent input?</p>
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CCS Title V Needs Assessment  
Focus Group Subcommittee Meeting  
Jan 20, 2010  
Noon – 1pm

Conference Call Number: 1-877-675-1807  
Participant Code: 648955  
Online meeting site: <http://fcm.fhop.na4.acrobat.com/focusgroups/>

AGENDA

1. Welcome and introductions
2. Update on progress
3. Review focus group draft topics/questions for:
  - a. Hospitals and Health Plans
  - b. Transitioning Youth
4. Begin review of summary of finding for focus groups already conducted (this topic will also be continued on a later call after completion of 3 more focus groups)

Category/Group	Suggested Topic to Cover
Hospital Administration and Health Plans	<p>11. How could health plans help facilitate timely access to equipment and services given the state CCS delays in authorization for these? (question kind of confusion, shouldn't be the first question. Qs 2 and 3 are more general Is it asking about what they can do or asking about if they can identify issues? (need to know what vendors the health plans are using or need denial with initial request)</p> <p>12. Issues in coordinating care in CCS kids when patient is carved out? How to overcome barriers to coordination?</p> <p>13. How would it improve care to carve the whole child out of the managed care plan when they have a complex CCS-eligible medical conditions?</p> <p>14. How is care coordinated when there is not a carve out? Is there a problem getting access to specialty care when carved in? Do they get to appropriate specialty care?</p> <p>15. Should health plans be required to provide the same coverage that CCS provides for privately insured kids that don't meet CCS financial qualifications?</p> <p>16. Would it help to create a separate delivery system to care for the whole child if they have a complex CCS condition? (similar to 3? (intended to be separate questions – looking at it from 2 perspectives. Is there a way to reword it? Carving out whole child vs enrolling in a specialty plan.</p> <p>17. What would it take for the health plans to do case management and care coordination and what should it consist of? How to provide families with social support? (Plans will need more staff to do case management, or else change definition of</p>

	<p>case management                  (There is inconsistency in care coordination in Medi-Cal health plans, and it falls to the hospitals; suggestion to have a standard or expectation of what case management is                  (Would plans be willing to implement case management standards developed by CCS                  (Plans – can do case management/care coordination for clients who are not CCS because paid, but for CCS, not being paid because a carve out                  18. Are there ways of improving eligibility determinations?                  19. Should CCS program try to get out from under EDS?                  (a leading question, no opened ended. Reword – what is impression of EDS and how it works?                  (what about the issue with EDS changing, to ACS –comment: doesn't make any difference what the entity is, using same computer system, just matters what rules they have to follow)                  20. Strategies for better enforcement of state CCS standards with providers of high level and low level care?                  (this question is preferred over 9)</p>
<p>Transition Age Youth</p>	<p>9. Transition issues – how can we improve transition?                  10. Challenges in finding an adult provider that can care for CCS condition?                  11. What has made it easier – what has made it harder?                  12. Did you have transition team?                  13. What worked with your transition planning?                  14. Who helped you with your transition?                  15. What did you experience in transitioning to an adult provider?                  16. What other kinds of non-medical services do they need and what is their experience in trying to get these services?</p> <p>-Should we add something about if they have experienced barriers in getting care? Any gaps in care? (a prompt for 2 or 7)                  -Not covered: technically people are adults at 18, CCS until 21. We have inconsistency in who tries to transition by 18 and by 21. Different providers have different thoughts on this. And if they have more than one condition, may be transitioned at different times for different conditions. (a probe/prompt for 7)                  -Move question #1 to end.                  -5 then 4 and 6 under it.                  -Start with #7</p>

**Survey Subcommittee**

**CCS Needs Assessment  
Survey Workgroup Conference Call  
March 9, 2010, 11 AM  
Agenda**

Conference line: 1-877-675-1807

Participant code: 648955

Online meeting page: <http://fcm.fhop.na4.acrobat.com/surveys/>

1. Introductions and purpose of today's call
2. Goals of conducting the surveys – what do we want to know more about?
  - a. Built on key informant interviews and focus groups

-Comment from Sarah Swaney – to address age/grade level for questions

-Comment from Diana Obrinsky – question about appropriateness of questions, the length makes it confusing and who the questions will be targeting. Suggests a broad approach, more open ended, and not drilling down from the start. Also, who at the hospitals will be targeted.
3. Review topics areas covered in the surveys of:
  - a. Families
  - b. Medical providers, administrators, health plans
4. Review of questions on survey for DME providers
5. Review of questions on survey for families
6. Review of questions on survey for Medical providers, administrators, health plans
7. Plan next steps
  - a. Pilot testing
  - b. Survey Distribution

## Data Work Group

CCS Title V Needs Assessment  
Data Subcommittee Meeting  
Oct. 15, 2009  
9:00 AM

Conference Call Number: 1-877-675-1807

Participant Code: 648955

Online meeting site: <http://fcm.fhop.na4.acrobat.com/dataworkgroup/>

### AGENDA

1. Welcome and Introductions
2. Project background for those who didn't attend Sept 9<sup>th</sup> meeting, deliverables, timeline and overview of primary data collection in interviews, focus groups and surveys
3. Goals for today
  - k. Review list of data requested and reviewed in 2005
  - l. Review list of suggested data for 2009
  - m. Identify potential future data presentations
  - n. Plan next steps
4. Review list of data requested, received, and reviewed in 2005 and confirm which data we want to review from 2009
5. Review and clarify list of recommended data sources from Stakeholder meeting and brainstorm additional sources
6. Discuss current and past work being done by stakeholders and others regarding CCS or children with special health care needs that could be shared with the stakeholder group
7. Plan next steps

Title V CCS Needs Assessment  
Data Subcommittee Meeting  
October 15, 2009, 9:00 AM

### NOTES

- After a welcome and introduction, Jennifer Rienks from FHOP provided a brief overview of the Title V CCS Needs Assessment process and the role of the Data Workgroup within that process.
- There were four goals for the meeting:
  - o. Review list of data requested and reviewed in 2005
  - p. Review list of suggested data for 2009
  - q. Identify potential future data presentations
  - r. Plan next steps
- i. The group reviewed the list of data requested, received, and reviewed in 2005. There was discussion about the definitions of difference indicators and a suggestion to include an explanation of what it is and how it is measured for each indicator. The group agreed to review the same data from 2009 and make comparisons where it is possible.

- ii. Then the group review and clarified the list of recommended data sources compiled from Stakeholder meeting and brainstormed additional sources. The notes from the discussion are pasted below.
- iii. During the needs assessment process, FHOP is coordinating webinars to present current and past work regarding CCS or children with special health care needs. FHOP has been in touch with Kathy Smith, Melissa Rowan, and Christy Bethell about doing presentations. The group suggested contacting Tom Klitzner, Greg Janos, Jeff Gould, Paul Wise, and Steve Barrow, and people representing programs in other areas, such as Denver and Houston.
- iv. For next steps, there was discussion of creating subgroups from Data Workgroup to focus on OSHPD data and on Claims data.
- v. Another conference call meeting will be scheduled for early November. A Meeting Wizard invitation will be sent out. A list of meetings for the Data Workgroup, as well as other subcommittees, and the webinars is available at:  
[http://fhop.ucsf.edu/fhop/htm/ca\\_mcah/title\\_v/cshcn\\_t5\\_new.htm#ev](http://fhop.ucsf.edu/fhop/htm/ca_mcah/title_v/cshcn_t5_new.htm#ev)

### Suggested Data to Examine for CCS Title V Needs Assessment

(Notes from call are in green)

#### Data on Screening

- Rates / utilization data of newborn hearing screening and are receiving follow up care – can get program data showing what happens in certified hospitals
- Rates on expanded metabolic and genetic newborn screening

#### Data on Outcomes

- LA County CCS data base – length of stay
- Discharge logs/interviews/focus group about why kids are not discharged
- Cystic Fibrosis Foundation Data – nutrition and outcomes; National Quality Improvement Project – Tara Lannon;
- NICU Data:
  - California Perinatal Quality Care Collaborative (CPQCC) – clinical information; Jeff Gould; clinical quality initiatives; regional variation
  - Infection control outcomes – Paul Kurtin
- California Hospital Assessment and Reporting Taskforce (CHART) data – general pediatric measures
- Judith Baker, Hemophilia data – some on CDC website
- Increasing referrals to CCS programs – OSHPD for hospitalization; CMS net trends
- Office of Statewide Health Planning and Development (OSHPD) discharge abstracts
  - Admission and readmission rates by condition
  - Paul Wise's hospital discharge data analyses
  - Rehospitalization data and link to A1C levels (diabetes) – not in OSHPD because outpatient - Hospitalization and first diagnosis?, diabetes association
  - Length of Stay by condition – compare between Medi-Cal and other insurance types
- Functional Improvement Score (FISC)/ Neuromotor Impairment Severity Scale (NISS) data (Dr. James Boyd, CCS MTP, has developed tools for outpatient rehab; but usable for outcomes?)
- Rehab improvement data (data source?)
- Standards – how they impact care (data source?) – Quality Care data in CA vs. other states; Kaiser, Shriners' Hospital (not CCS in LA)

Data on access to services and physician availability

- List of paneled providers
- Claims data
  - Claims paid data can be used to identify who the physicians are that are taking care of CCS clients by specialty type
  - EDS/claims data – considering carve outs
  - subsample of counties - who is taking new patients
- Utilization data – use State data on # of authorizations that are actually billed to get an idea of services rendered and not rendered for authorizations sitting in the system
- Time between medical determination eligibility to referral to authorization
- CCS kids access to care by diagnosis to a specialty care center appropriately (data source?) – look at service authorizations; health plan data on referrals
- CMS Net
- ACMS data (CMS Net in Los Angeles County)
- High Risk Infant Follow Up (HRIF)/Metabolic services etc., covered by Private Insurance and paid by CCS (data source?) – CPQCC, started in April
- How many people are not billing for services they have provided (data source?) – ask in focus groups
- County Organized Health System (COHS) data – w CCS carved in (Santa Barbara, San Mateo, partnership health plan (Yolo, Napa, Solano)) – Paul Wise data; payment problems in Partnership Health Plan; look at fiscal issues

Other Data for issues or problems

- Private Insurance/Medical Therapy Program
- Post audit reviews (more info on this?)
- Anecdotal case stories (has someone already collected these?)

Data from Families

- National Survey of Children with Special Health Care Needs (NS of CSHCN), and “cross walking” to other data
- Exit surveys (data source?)
- Satisfaction surveys (data source?)
- Family Voices survey
- Interviews (Who are the interviews of?) on electronic Service Authorization Requests (SARs)
- Access to specialists, wait times – survey, focus groups (compare to CCS data)

Excluding conditions – how many kids would be impacted, fiscal issues  
Enrollment versus expensive, why increasing costs – and compare to costs of care

Title V CCS Needs Assessment  
Administrative Data Workgroup  
Dec 17, 2009, 9 a.m.

Attendees: Marian Dalsey, Kathy Chance, Brenda Washington, Rachel Luxemburg, Farra Bracht, Tom Klitzner, Mary Jess Wilson, Jennifer Rienks, Katie Gillespie

Conference call number: 1-866-718-6728  
Participant code: 9131842  
Online meeting page: <http://fcm.fhop.na4.acrobat.com/dataworkgroup/>

1) Welcome and Introductions

- 2) Overview of Administrative Data Sources and Available Data Elements
  - a) CMS Net
    - Data dictionary was sent out.
    - CMS Net has referrals, eligibility, and authorization data
  - b) Claims Paid
    - MIS-DSS
    - EDS claims data and eligibility data
      - Issue discussed regarding costs to treat different conditions. One caution that you need to know more, about diagnoses and co-morbidities to be able to compare cases. A second comment that ICD9 codes are limited. Also kids may have 6 diagnoses but can only 4 or 5 in CMS Net.
  - c) SUR – Surveillance and Utilization Review System
    - What's been spent by code and by fiscal group, paid and denied claims, can look by provider and by county; 6 years of data (revolving); might be easier to pull from than Claims Paid
- 3) Review current data request for administrative data
  - a) Access to Care -
  - b) Access to Specialty Care
  - c) Transition to Adulthood
  - d) Prevalence of Outcomes
  - e) Developmental Screening
  - f) Foster Care
  - g) Family Roles

Comments in Data Request file. While reviewing data, a reminder to consider whether the information will help make decisions for priorities for the Branch.
- 4) Potential Additional data questions – other suggestions?
  - a) How many children fall into each of the eligible condition categories and what are the cost associated with each condition? (already under Prevalence and Outcomes)
  - b) What are the total costs of caring for a CCS child – including both the CCS condition and non-CCS costs (will be addressed in data analysis for waiver process.)
  - c) How does the cost of care for a CCS child in FFS Medi-Cal compare with Medi-Cal managed care? (will be addressed in data analysis for waiver process. Will be only for Medi-Cal, not Healthy Families)
  - d) How do length of stay and expenditures for hospitalization vary across hospitals for specific conditions for children under 1. (has to be on back burner, some may come out with waiver)
  - e) How much is spent treating infants between 23-26 weeks? Average per infant and mean, mode, and median (cannot do this, without chart review)

Other data questions?

- Do we have someone looking at OSHPD? Yes being done as part of redesign, Paul Wise will be working on.
- A lot of phrases about the existing data source, and it is not a research database but a case management data base, and paid claims are only ones that have gone through the system

- 5) Next Steps
  - Pull the requested data. On the next call, we will begin looking at the data.

CCS Data Committee  
Hospital Discharge Workgroup Conference Call  
Agenda

1. Welcome and Introductions

2. Data Analyses for the Redesign
  - a. Paul Wise working with Claims Paid data
  - b. Jeff Gould working with CPQCC Data
  - c. Identify ways to share these analyses with the CCS Stakeholders
3. Discussion research that has been done or is currently being done on CSHCN and access/financing/outcomes issues using:
  - a. hospital discharge data
  - b. other data sources
  - c. review of selected research abstracts
  - d. selection of what to share with stakeholders and how to show
4. Next Steps

Title V CCS Needs Assessment Data Committee  
Hospital Discharge Workgroup Conference Call  
January 26, 2010

Notes

5. Welcome and Introductions

Present: Paul Wise, Paul Kurtin, Farra Bracht, Marian Dalsey, Kathy Chance, Mary Goldberg, Hallie Morrow, Jennifer Rienks, Katie Gillespie

6. Data Analyses for the Redesign
  - a. Paul Wise working with Claims Paid data
  - b. Jeff Gould working with CPQCC Data
  - c. Identify ways to share these analyses with the CCS Stakeholders

Notes:

- i. FHOP shared documents from the State on the redesign: the Scope of Work for Analysis of CCS Expenditure Data (being completed by Paul Wise) and the Scope of Work for Analysis of CCS NICU data (being completed by Jeff Gould).
- ii. Paul Wise and Marian Dalsey reviewed the purpose and plan for the analysis of expenditure data.
- iii. A question was asked about why the NICU data analysis is separated out from analysis of the other CCS data. It was explained that Jeff Gould will be working on creating a better picture of what's happening to infants in the NICU. For example, when they are admitted, how many infants have a CCS eligible condition, how many develop a CCS eligible condition, and how many are eligible by acuity or some other factor and when they leave the NICU they are no longer eligible.
- iv. Paul Wise commented there will be coordination of the analyses to approach the CCS expenditure data and the NICU data in similar ways.
- v. The best way to share these data with the Needs Assessment Stakeholder Group was discussed. In order to consider some of the preliminary results for setting priorities at the Stakeholder meeting in May, it will be more useful to share results before the meeting, perhaps through webinar(s).

7. Discussion research that has been done or is currently being done on CSHCN and access/financing/outcomes issues using:
  - a. hospital discharge data
  - b. other data sources
  - c. review of selected research abstracts
  - d. selection of what to share with stakeholders and how to show

Notes:

- Paul Wise shared that they have been working on how kids with chronic disease are utilizing facilities, looking at hospital data. For example, variation in using specialty care facilities by county, diagnoses, age group, etc. They are expected to be published in spring. He also shared that they have been going in depth for CF, rheumatology conditions, cardiac issues, and cancers to see what hospitals are being used for care, looking at factors such as saturation of the system, insurance provider, and other demographics. He said he has presented this information before and could do a webinar for the group.
  - We reviewed and discussed some of the articles listed in the CCS data articles working draft. FHOP will follow up with a couple of authors about sharing results with the Stakeholder group.
8. Next Steps
- Coordinate with Paul Wise on using the CCS data analysis for the needs assessment process.
  - Set up a few webinars to share results.

Title V CCS Needs Assessment  
Data Work Group  
Thursday, April 29, 2010

**Call Notes**

Attendees: Katie Schlageter, Francine Crockett, Pat Glass, Norma Stephenson, and Diana Obrinsky (Alameda County); Pam Sakamoto (Solano County); Tom Klitzner (UCLA Pediatrics); Laurie Soman (CRISS); Tara Robinson (Family Voices); Shelley Rouillard (MRMIB); Mary Goldberg, Kathy Chance, Traci McCarley, Rachel Luxemburg, and Brenda Washington (State CMS); Jennifer Rienks and Katie Gillespie (FHOP).

The following documents were sent out before and discussed on the call:

Excel files:

- Special Care Center data by County
- Primary care provider addresses
- CCS Administrative Time Tables
- CCS Diagnosis data
- CCS Medical Expenditures
- CCS Deaths 2008, 2009

Maps:

- CCS Active Cases 2009
- CCS Active Medi-Cal Cases 2009
- Percent of CCS Medi-Cal Clients
- Percent of CCS Only Clients
- Percent of HF Clients

Discussion:

Two broad goals for the call: to discuss the best ways to present this data to the larger Stakeholder group; and to talk about some of the issues that the data raise to prepare for the Stakeholder meeting.

Special Care Center data by County

- Referenced the email comments from Mary Jess Wilson about reasons for variation between counties and discrepancies between State and County generated data.

- Tom gave the example of congenital health disease: some forms do not require significant care coordination, but they are eligible; also, suggested to look at counties with at least 50 cases
- Diana noted the low the numbers for LA and suggested cautions for looking at the data, and specifically making conclusions about small counties and small numbers
- Pam commented that HMO kids are eligible for some benefits, but special care services are covered by HMO
- Tom asked what questions we want to answer with these data. For example, is there county by county variation in kids who need services (because if there are data issues happening in all counties, then can compare counties), suggested a County needs at least 50 cases
- Shelley suggested looking at rural county issues and mapping where special care centers are located
- Diana said she was more interested in why kids do not have authorization than between county variation, in order to identify potential areas for improving authorization. For example, is it HMO and not a problem or is it transportation. To do this, could link case number to chart, and Counties could check on why.
- Pam noted there could variation by Counties with managed care
- Diana noted that pulling and doing a hand count of Alameda records found 81% authorized to SCC compared to 72% in table.
- Tom suggested doing some scatter plots, for example by rural and urban to look at numbers and compare.
- Jennifer asked if this document should be shared with the larger Stakeholder group – general consensus yet. Also she asked for/summarized reasons for variation (to be prepared for discussion at May meeting): county's exposure to CCS only; Medi-Cal managed care; transportation issues; clinical diagnoses; regional variation based on how special care centers are organized (is the doctor the child needs at the SCC or separate).
- Diana addressed the issue of special care centers not functioning at true special care centers, noting that because of defunding, the State cannot enforce collaboration at SCCs.
- Tom did a quick tally and found the average for California to be about 60%. He suggested looking for significant deviations from 60% to identify counties that appear to be doing well or not so well, and then go to them and ask what they are doing. For example, could ask if there is a best practice we can learn to improve authorization.

#### Primary care provider addresses

- If "missing", there is no PCP of record in CMSnet
- Did LA and Lassen get switched?
- Jennifer asked about reasons for variations – is it administrative/record keeping?
- Shelley noted that kids on Medi-Cal cannot find a PCP who will take it
- Laurie gave the example of Contra Costa, which has Medi-Cal managed care
- Traci shared that the PCP field is not required, and cannot make it required because Counties would object
- Francine noted that the missing number is consistent with the number having CCS-only in Alameda, and that the special care center often serves as the primary care provider
- Brenda shared that is PCP is SCC, it can be entered in the field

#### CCS Administrative Time Tables

- Discussed the many tabs included in file. Where there is not LA data, it is excluded. These are from calendar year 2009. Dependent counties are highlighted, and for these counties, eligibility is determined at the State office. Where there were multiple requests, used first request.
- Jennifer asked about variation.
- Pam reminded us to consider the process for determining eligibility. It can take up to 3 requests to parents to get release of records.
- Tom noted the data suggest the need for a process that is efficient but also reduces variation

- Laurie shared that authorization delay is an indication of an administrative problem, not necessarily that kids aren't getting care, because they may receive care without payment.
- Kathy noted that it used to be deliver care, then get authorization. But not anymore.
- Jennifer asked about multiple requests in the system, for example, for wheelchairs. Pam gave the example of a wheelchair needing a growth adjustment may require multiple parts, and each part is coded.
- Francine addressed the issue of choosing only the first referral. For example, the case may not be open because it is inappropriate or denied. Several months later, referral is used to get approved (for kids with open cases).
- Laurie asked if we can look at these numbers over time to identify trends.
- Tom shared that he does not see a lot of kids coming in this delayed and wasn't sure how useful or relatable this document would be for physicians.
- Laurie mentioned the issue of time to get service (versus authorization). Could look at how much it affects child's care and how it affects admin/providers.
- Brenda said it would be a big job to match authorization to claims paid

#### CCS Diagnosis data and Death data

- Jennifer wanted to know if these categories need more explanation/detail – general consensus of yes.
- Specifically for primary diagnosis, group asked about mental illness.

#### Maps

- Quick look at maps. Discussed offering data in tables and in visual form at meeting.

#### General data work:

- Jennifer shared that FHOP is working on analyzing data from the surveys. We hope to send out data sheets and summaries May 3<sup>rd</sup> or 4<sup>th</sup>.
- Tara asked if the summary of the Family Survey would be available in a family friendly format. Jennifer said FHOP would work on it, but may not be able to get to it until after the May meeting.