

Outcome/ Data Analysis Subcommittee Meeting
3/15/07 10:00 AM to 1:00 PM

ITEM	DISCUSSION	ACTION
<p>Chester Randle, M.D., Chief, Program Development Section Introductions</p>	<p>Committee Members who were present (in person or on phone) Ann Pomper: Hospice of Santa Cruz Christy Beaudin: Chief Quality Officer-CHLA Devon Dabbs: Children’s Hospice & Palliative Care Coalition Lori Butterworth: Children’s Hospice & Palliative Care Coalition Jenny Mann Francis: U.C. Davis Medical Center Joan Tanzer: George Mark Children’s House Joyce Shefren: Pathways Home Health, Hospice & Private Duty Margaret Clausen: California Hospice Organization Christy Torkildson: George Mark Children’s House Elana Evan: Children's Comfort Care Resource Program, UCLA Samuel P. Yang: CA Department of Developmental Services Lorry Frankel: Packard Children’s Hospital Jan Burrow: Nurse Consultant, CMS Branch Carmen Romo: Research Analyst, DHS, MCP-RDB Jo Monday: Research Analyst , CMS Branch Belva Kinstler, Manager, CMS Branch</p>	

<p>Update</p>	<p>References Submitted to the Subcommittee Summary sheet of PedsQL tool Abstract on Impact on Family Scale, J of Developmental and Behavioral Pediatrics 24(1):9-16 Feb 2003</p> <p>Florida Waiver has references to Tools – these will be released after they submit their final report Quality of Life Pain and Symptoms Family Stressors Provider Satisfaction Survey</p> <p>Lori and Devon are going to meet some of the staff of the Florida Palliative Care waiver on 3/27-28. They plan to get copies of their assessment tools for our Subcommittee.</p> <p>Dr. Randle has contacted Dr. Ahmad, Epidemiologist, from the Maternal, Child and Adolescent Health/Office of Family Planning Branch for State assistance with study design.</p>	<p>Christy to email Dr. Randle another family assessment tool that was written by Dr Worden</p>
<p>Update, cont.</p>	<p>Subcommittee consensus on measurements.</p> <p>Determine the impact of the provision of Coordinated Care via the waiver on the following: Patient Quality of Life Family Satisfaction Development of goals of care Control of Pain and Symptoms Reduction of E.D. visits and Hospitalizations</p> <p>Discussion of comparison group Discussion about the value of tracking medical error Discussion about collecting anecdotal experiences about the family and possible use of a Family Journal.</p> <p>NHPCO tracks quality of care but may be too large for our purposes</p>	

Federal Waiver Reporting Requirements

Number of persons served
Diagnoses of persons including ICD-9 codes
Paid Claims for waiver services

Information needed to determine Effectiveness of the Waiver

Quality of Life Scale (probably PedsQL)
Pain and Symptom Scales
School Attendance (see Florida Waiver)
Consider Stein & Jessup 1985 Impact on Family Scale
Family Functioning assessment (Margaret Clausen knows of one)
Economic Impact on Family (see Florida Waiver and Hayes study)
Provider Satisfaction Survey (see Florida Waiver)
to assess Hospices, Special Care Centers, local CCS offices, and
Care Coordinators

Discussed how frequently the QOL scale should be performed

Options

1. Literature review of frequency for similar families
2. Every 3 months to 1/yr
3. Determined by phase of child's illness (i.e. at time of diagnosis, the time of deterioration, bereavement, recovery etc)

The goal should be to use the same scales that other states are using to improve consistency of evaluations.

Determine Enrollment Effectiveness

The waiver will require the following:

- # of CCS Clients potentially eligible for the Waiver
- # of CCS Clients offered enrollment into the pilot project
- # of CCS Clients who were offered enrollment and accepted

Next Steps	The subcommittee would like to see what “Plan of Care” information Hospices are currently collecting.	Christy will get the Plans of Care from the Northern California Collaborative and Elana will get the Plans of Care from the Southern California Collaborative. They will request the Plans used for adults and children. Dr. Randle to email Subcommittee the Peds QL website so members can review the Tool.
Next Meeting	<p>General Pediatric Palliative Care Stakeholder Meeting April 10, 2007 10:00 AM to 3:00 PM</p> <p>Outcome/ Data Analysis Subcommittee Meeting April 18, 2007 10:00 AM to 1:00 PM</p>	