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California Pediatric Palliative Care (PPC) Waiver: Evaluation Report

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UCLA CENTER FOR
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Glossary and Definitions

Acronym	Term
ACA	Affordable Care Act
CCS	California Children's Services
CCSNL	California Children's Services nurse liaison
CDPS	Chronic Illness & Disability Payment System
CMS	Centers for Medicare & Medicaid Services
ED	Emergency department
DHCS	Department of Health Care Services
F-CAP	Family-centered action plan
HRQOL	Health-related quality of life
IP	Inpatient
LOC	Level of care
OP	Outpatient
PedsQL	Pediatric Quality of Life Inventory
PFC	Partners for Children
PEPM	Per enrollee per month
PPC	Pediatric palliative care
RX	Pharmacy
UCLA	University of California, Los Angeles Center for Health Policy Research

California Pediatric Palliative Care (PPC) Waiver: Evaluation Report

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Executive Summary

Introduction

In 2006, California passed the Nick Snow Children's Hospice and Palliative Care Act (bill number AB 1745). The law enabled the California Department of Health Care Services (DHCS) to develop a pediatric palliative care pilot program for children eligible for full-scope Medi-Cal to be delivered concurrently with curative care and regardless of the child's life expectancy. California's pediatric palliative care initiative was implemented through the Centers for Medicare & Medicaid Services (CMS) §1915(c) waiver option, which allows states to explore the provision of long-term care services in both home- and community-based settings. The waiver program encourages testing of innovative strategies to reduce the need for costly institution-based care and to increase quality of care and life through more extensive care coordination and therapeutic services. In line with these goals, DHCS designed the Pediatric Palliative Care Waiver to improve the quality of life for children and their families through the provision of supportive home-based services, and to minimize hospitalization and length of stay through the use of community-based care. A three-year pilot program, known as Partners for Children (PFC), was approved in 2008 and the first children were enrolled in January 2010.

The state contracted with the University of California, Los Angeles Center for Health Policy Research (UCLA) to provide an independent evaluation of the operational, financial, clinical, and humanistic outcomes of the waiver.

Findings

The findings presented in this report are based on claims and quality assurance data provided to UCLA by DHCS from 2007 through 2012, as well as data UCLA collected from surveys of families and providers who participated in PFC.

Operational

DHCS served as the administrative authority over PFC and the primary waiver liaison with CMS. Quality assurance activities included onsite program compliance reviews, level-of-care (LOC) determination reviews, health and welfare assessment reviews, comprehensive care plan reviews, provider qualification reviews, and financial audits. Over the three-year course of the program, DHCS identified a number of deficiencies, most frequently pertaining to the LOC determination component. Care plans were another source of deficiency. DHCS staff attempted to prevent deficiencies and address existing ones by providing technical assistance and training, reviewing corrected care plans and LOC forms, and clarifying program policies through official program notices.

The percentage of enrollees using PFC services was used as an indication of engagement with the program. Expressive therapies, including music, massage, and art therapies, were all utilized by at least 40% of enrollees. Less utilized services included pain and symptom management, home respite, and play therapy.

Over the three-year pilot period, 151 children enrolled in PFC. The average enrollment duration was about 11 months (328 days).[1] Of the 151 total enrollees, 132 spent at least 60 days in the program and were included in the cost analyses. Enrollees were most likely to be male and Latino. The most frequent primary diagnoses included neurologic conditions and cancers.

Financial

Comparing the health care costs of enrollees in the two years leading up to enrollment with costs while enrolled demonstrated substantial savings, including:

- Mean reduction of $3,331 per enrollee per month (PEPM) based on paid claims analysis. This reduction was driven by a major decrease in inpatient care costs of $4,897 PEPM, an indication of the success of PFC in providing home- and community-based services instead of costly hospital-based care.
- Mean reduction of $3,133 PEPM when including the estimated unpaid claims related to program services.
- Mean reduction of $2,154 PEPM when including the estimated unpaid claims and administrative costs of the pilot.
- Return on investment of $2.20 for every dollar spent on PFC ($1.20 when including unpaid claims and administrative costs).
- Nearly $7 million in health care costs avoided as a result of PFCs bending of the cost trend from two years prior to enrollment through the pilot period.

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[1] This includes time from enrollment to disenrollment as well as time from enrollment to the end of the study period for individuals who remained enrolled in the pilot when it ended in December 2012.

- Estimated potential savings of more than $12 million if PFC enrollment were to increase to 200 participants and continue for another three years.

A difference-in-differences approach comparing pre-post enrollee costs to pre-post costs of a control group with similar disease severity would have been ideal, but PFC enrollees proved to be a unique group for which a comparable set of children could not be identified. Nonetheless, the magnitude of the savings shown in the pre-post analysis suggests that PFC was financially successful.

Utilization

Utilization measures also demonstrate PFC's success, including:

- A nearly 50% reduction in the number of inpatient days PEPM from 4.2 prior to enrollment to 2.3 during the pilot period.
- A major decrease in the average length of stay for each hospitalization, from 16.7 days pre-enrollment to 6.5 days during the pilot period.
- Overall increase in the number of outpatient visits PEPM from 35 to 39, an indication of improved care coordination and the substitution of hospitalizations with outpatient and home-based care.
- Small reductions in emergency department use, from 0.23 PEPM to 0.20 PEPM, and ED visits leading to hospitalizations, from 0.15 PEPM to 0.12 PEPM.

Humanistic

Providers were largely satisfied with PFC overall, though satisfaction varied by provider type and numerous barriers to care provision were reported. California Children's Services nurse liaisons (CCSNLs), who were responsible for the authorization of all services at the county level, demonstrated greater satisfaction than hospice and home health agencies, which were the main providers of home-based care. All of the CCSNLs and agency/hospice providers believed that PFC services were helpful in reducing family stress and worry, and increasing family confidence about their ability to care for their child.

Referring physicians were generally positive about PFC, but a broader survey of California Children's Services (CCS) paneled physicians in counties participating in PFC suggested that program visibility was a problem and may have been a barrier to program referral. Nearly two-thirds of physician respondents reported no familiarity with PFC. In addition to the widespread lack of knowledge, physicians reported the following barriers to care:

- Patient/family perceived stigma associated with palliative care
- Family unwillingness to participate
- Physician uncertainty about the most beneficial plan of action

- Burdensome paperwork
- Belief that PFC participation interferes with curative care

CCSNLs echoed some of these barriers, including stigma, incorrect referral by physicians due to lack of knowledge of program eligibility requirements, and paperwork. Further perceived barriers to care once enrolled in the program included family inability to acknowledge the life-threatening nature of their child's illness, conflict among family members about treatment goals, agency staff shortages, and communication problems based on language differences.

The most pervasive barrier for hospice/home health agencies was the low reimbursement rate for many PFC services. This issue may have been partially ameliorated for the future by the consideration in December 2012 of a roughly $300 PEPM increase in service reimbursement for participating agencies.

Satisfaction among family member caregivers was consistently high. Caregivers reported that PFC services were helpful in reducing or controlling their child's pain and other symptoms. Participation in the program also helped reduce caregivers' trouble sleeping and feeling worried about their ability to manage their child's health. All 50 surveyed caregivers said they would recommend PFC to a family member or friend who had a child with a life-limiting condition.

Conclusions and Recommendations

UCLA's evaluation of this program demonstrates positive results in achieving the Institute for Healthcare Improvement's Triple Aim of improved care, better health, and lower costs.(1) Analysis of the three-year PFC pilot suggests that California's Pediatric Palliative Care Waiver demonstrated a cost-effective way to provide home-based palliative care to children with life-threatening conditions that was satisfying to most enrollees' primary caregivers and their health care providers. PFC enrollment led to health care cost savings of $3,331 PEPM on paid claims, and overall savings of $2,154 PEPM when including all estimated administrative costs of the pilot. The lack of a comparison group makes it difficult to eliminate other possible explanations for these cost savings, but an examination of the source of the cost savings speaks directly to the goals of PFC. Most of the savings were the result of the dramatic decrease in inpatient and a relatively smaller increase in outpatient costs. This major shift – from costly inpatient care to more coordinated and less expensive outpatient care – is the result of PFC's home-based care model. Overall savings totaled nearly $7 million, an indication of the potential continued cost effectiveness if PFC were to expand to more counties and eventually statewide.

Beyond its financial success, PFC achieved important utilization changes and received high satisfaction scores from caregivers, who reported improvements in their children's pain and other symptoms as well as their own experience and quality of life. PFC providers also expressed widespread satisfaction, though their concerns highlight important areas for improvement moving forward. Concerns about reimbursement rates among hospice and home health agencies would be particularly important if enrollment in PFC increases. The lack of knowledge about PFC among prospective referring physicians is a concern and underscores the importance of increasing program visibility.

Based on these issues, UCLA offers the following recommendations:

- Assess continuously the financial viability of providing services to PFC enrollees for hospice and home health agencies to ensure a sufficient supply of providers. This will be particularly important if enrollment in PFC increases.
- Increase the visibility of PFC among prospective referring providers to increase enrollment.
- Grow operational capacity and strategy to match program expansion. This can be achieved by building on existing partnerships and develop new ones among the state and county CCS programs, specialty care centers, other medical and community services, and hospice and home health agencies.
- Share best practices among program partners to seek ways to simplify referral protocols across medical settings and enrollment procedures at the county level.
- Assess enrollment processes and procedures to minimize the time between referral and enrollment.
- Support providers in educating families to reduce perceived barriers to enrollment and receipt of services.

PFC gained program status and was extended for five years, to 2017, at the end of the pilot period. As the program grows to include more providers and enrollees, operational capacity and strategy must grow with it.

Introduction

According to the Institute of Medicine, pediatric palliative care seeks to relieve symptoms associated with a serious medical condition or its treatment, and to enhance the quality of life for children and their families by addressing their unique psychological, social, and spiritual needs.(2) Based on a similar definition, the American Academy of Pediatrics recommended in 2000 that pediatric palliative care begin upon the diagnosis of a child's life-threatening condition and continue for the duration of the disease, alongside curative care or life-saving treatment.(3)

Children ages zero through 20 have age-specific diseases, and consequently have age-specific treatment goals and needs. From the time of diagnosis with a life-threatening disease and as a supplement to clinical treatment, pediatric palliative care provides children with holistic care that considers every aspect of the effect the diagnosis will have on the child's and family's physical, psychological, and spiritual health.(4) For the child, palliative care may include pain and symptom management resulting from disease and treatment side effects, and child life counseling and expressive therapies that provide the child with coping mechanisms and tools for self-expression. For the family, palliative care may include training on how to navigate the health care system, make the best treatment decisions, provide optimal care for their child, and bereavement counseling before and after the passing of a child. Having the option to continue palliative care during treatment can alleviate the pain and side effects that a child may have to endure during continued treatment and also reduces the dilemma parents face when weighing treatment and the pain of their child.(2)

Pediatric Palliative Care Waiver Background

In response to the need for comprehensive pediatric palliative care, California passed the Nick Snow Children's Hospice and Palliative Care Act (AB 1745) in 2006. The law enabled DHCS to develop a pediatric palliative care pilot program offering hospice-like services for children eligible for full-scope Medi-Cal to be delivered concurrently with curative care and regardless of the child's life expectancy. The last feature was a departure from the federal Medicare stipulation that pediatric hospice care only be covered during the last six months of life.

California's pediatric palliative care initiative was implemented through the CMS §1915(c) waiver option, which allows states to explore provision of long-term care services in home- and community-based settings. The CMS waiver encourages testing of innovative strategies to reduce the need for costly institution-based care and to increase quality of care and life through more extensive care coordination and therapeutic services. In line with these goals, DHCS designed the Pediatric Palliative Care Waiver to improve the quality of life for children and their families through the provision of supportive home-based services, and to minimize hospital stays through the use of community-based care. A three-year pilot program, known as Partners for Children (PFC), was approved in 2008 and the first children were enrolled in January 2010.

In the interceding years, numerous other initiatives made portions of concurrent care standard for children with life-threatening conditions. In 2007, children enrolled in the CCS program became eligible for case management to integrate curative and palliative care (though not for all of the therapeutic and counseling services covered by PFC). On a federal level, the Concurrent Care for Children Requirement (CCCR Section 2302) of the 2010 Patient Protection and Affordable Care Act (ACA) cemented in law concurrent pediatric and curative care for ill children, thus sparing families the difficult choice to forego all curative treatment before receiving hospice benefits. Despite these developments, PFC retained unique characteristics that are still not in place in all state Medicaid programs. Perhaps most notably, the ACA did not change Medicaid's stipulation that children have no more than six months to live before gaining eligibility for palliative care benefits. PFC provided access to comprehensive in-home palliative care services as early as at the time of diagnosis and throughout the course of the disease as long as the child met the necessary level of care (described below).

The program was a collaboration among DHCS' CCS program at the state and county levels, specialty care centers where children receive curative treatment, and local licensed private home health agencies, hospices or contracted agencies that decided to voluntarily participate in the program. Eleven counties participated in PFC. Five – Alameda, Monterey, Santa Clara, Santa Cruz, and San Diego – joined in the first year of the program (2010). Four others – Marin, Orange, San Francisco, and Sonoma – were added in the second year (2011). Los Angeles and Fresno counties joined in 2012, the third and final year of the pilot program.

On December 28, 2012, CMS granted PFC a five-year extension that allows the program to continue through March 2017. However, this report covers the pilot period only, from January 2010 through December 2012.

Covered services

PFC provided the following palliative care services:

1) Comprehensive care coordination.
2) Expressive therapies, including art, music, play, and massage for the child.
3) Family education, including instruction on providing care and operating medical equipment.
4) Respite care in and out of the home to provide needed rest for the primary caregivers.
5) Family counseling and bereavement counseling.

6) Pain and symptom management.

Participating hospice and home health agencies also operated 24/7 on-call nursing support services to provide advice on urgent care questions and to further facilitate access to care. Where applicable, these services were available to a denominated "family unit," which varied by the individual case and could include parents, legal guardians, siblings, and significant others.

Care coordination

Each child and family was assigned a care coordinator and a multidisciplinary team of providers at the contracted care agency. Within 48 hours of a child's assignment to an agency, the care coordinator contacted the child and family to start developing the Family-Centered Action Plan (F-CAP), a comprehensive care plan that highlighted each child's and family's needs and desires. F-CAPs were to be completed within 14 days and were one of the waiver's main tools in limiting the need for hospitalizations while improving quality of life. They allowed the care coordinator to manage most aspects of the child's care with the child's and family's self-reported needs in mind, relieving the family of many duties. F-CAPs were designed to be updated at least bimonthly to ensure the accuracy of information on demographics, medical diagnosis and condition, physical assessment, pain assessment, nutritional risk screening, information on family composition, spiritual/religious affiliations and cultural issues, and the risk/home environment. Additionally, all family members, including the child, were asked about their perceptions of the illness and health care goals. The F-CAP was translated to accommodate Spanish-speaking families.

CCSNLs were ultimately responsible for approving F-CAPs. CCSNLs were also responsible for authorizing all services at the county level and ensuring that waiver services met the needs of enrolled children and families and program requirements. In conjunction with the hospice/home health agency, CCSNLs were responsible for monitoring hospice/home health care coordinators' comprehensive coordination of enrollees' care.

The hospice/home care agency care coordinator, either a registered nurse or medical social worker, coordinated all medical and community services for the child, accompanied the child and family to scheduled appointments, and generally facilitated communication between the family and all service providers. In addition to 22 hours of initial assessment services, the program covered 4 to 12 hours of case management hours per month.

Eligibility and enrollment

Children and their families either self-referred to PFC or were referred by a physician, another health care provider, such as a hospice or home health agency, or a CCSNL. To be enrolled in the PFC program, children and young adults had to be 20 years of age or younger, live in one of the 11 participating counties, and have full-scope, no share-of-cost Medi-Cal and a CCS-eligible, life-threatening condition. Eligible children also had to meet the necessary level of care (LOC), by which a physician had to declare, on the required Physician Referral Form, that a child was at risk of having at least 30 inpatient days during the subsequent 12 months as a result of his/her qualifying condition if the child did not enroll in PFC. CCSNLs ultimately determined eligibility in all cases, at times with the assistance of county CCS medical consultants or a PFC program physician to establish the LOC requirement. If a CCSNL determined a child was eligible, the child and family completed paperwork to select a hospice or home health agency and connect with a care coordinator.

If there were no participating hospices or home health agencies available in the county of residence at the time of referral, otherwise eligible children were placed on a waiting list. Some counties that participated in the waiver and set up other structural components of PFC never enrolled any children because the county was unable to contract with a local hospice or home health agency (see Exhibit 3 for the distribution of county of residence of all enrollees).

Once enrolled, a child could be disenrolled for any of the following reasons:

- There was a significant positive change in health status, such that the child no longer meets the LOC requirement,
- The child moved to a county that did not participate in PFC,
- The child or family decided to withdraw from the program unilaterally,
- The child was hospitalized for 30 days continuously (for more information on the “30-day rule,” see the Program Design section below),
- The child lost eligibility for full-scope, no share-of-cost Medi-Cal,
- The participant/family/home environment posed a health and safety risk to PFC providers and 30 days passed without successful remediation,
- The child/family missed three confirmed appointments for PFC services despite CCSNL and care coordinator efforts to accommodate the family,
- The child enrolled in another CMS §1915(c) waiver (simultaneous enrollment in multiple waiver programs is not permitted),
- The child turned 21 years of age, or
- The child died.(5)

If eligible to later re-enroll in the program, the child and family were required to complete the enrollment process from the beginning.

Review of Pediatric Palliative Care Literature

The estimated prevalence of children with life-threatening illnesses worldwide is 10-16 per 10,000.(6) In the U.S., this translates to approximately 500,000 children, of whom 50,000 die annually.(4, 7-9) Because life-threatening illnesses in children are much rarer than in adults, families often find themselves financially and emotionally unprepared to deal with the illness. Pediatric conditions are also different from the more prevalent terminal illnesses in adults and may require different modalities and plans of care, in particular more aggressive care up to the end of life.(10) Length of illness varies widely in children because of differential development and resilience, and end-of-life care can extend over many years and through several developmental phases. (10-12)

Pediatric palliative care is a much newer phenomenon than the adult version, and there are few models of care and even fewer analyses of the cost, clinical, and quality-of-life effectiveness of pediatric palliative care programs. Though the palliative care model for end-of-life care has traditionally centered on outpatient hospice care, caring for children with life-threatening illness may be more resource-intensive than for the elderly, and hospices may not be willing or prepared to care for a population with potentially different needs from their usual patient population (13, 14). According to a 2007 survey of 378 hospices, about 78% accept pediatric patients (15, 16). Among the 20-25% of hospitals in the U.S. that maintain palliative care programs, the proportion with pediatric components is unknown (17, 18).

The needs of children and families dealing with life-threatening and life-limiting illnesses have been increasingly recognized by states and Medicaid through cost-neutral waiver programs, including those in Florida (the first, in 2005), Colorado, and California.

Home-based care

In the face of rising health care costs, there has been growing interest in moving more patient care out of hospitals and into the home. These efforts to facilitate the delivery of pediatric palliative or hospice care may enable a larger percentage of terminally ill children to receive care in their own home.(19) As home health technologies develop, so does the range of services. A growing body of evidence suggests that the location in which children receive palliative care has serious implications. When palliative care is provided in the home, parental satisfaction appears to be high, and subsequent adaptation and outcomes for parents and siblings can improve.(20-22)

Cost

The most established home-based pediatric palliative care (PPC) program, Florida's Medicaid pediatric palliative care program, estimated that a model combining medical and palliative treatments in inpatient, outpatient, and hospice settings could expect to spend $110,000 per infant and $62,000 per child at baseline in the last year of life (23). Preliminary data from

Colorado’s program calculated savings of $15,000-20,000 per enrollee per year by eliminating preventable emergency department and hospital visits (24).

In 2006, Massachusetts created the home-based Massachusetts Pediatric Palliative Care Network, operating through hospices statewide. The costs to providing hospices per child for one year of care in 2010 ranged widely, from $1,520-$7,421, and depended in part on per-child overhead costs of hospices, not including medications, equipment, or other personnel such as personal care assistants and home health aides who may have been covered by private insurance or Medicaid. (25)

Barriers to care

Physicians have reported several perceived barriers to palliative care for children, including uncertain prognosis, family hesitation to acknowledge an incurable condition, communication problems, including, but not limited to, language barriers, time constraints, and insufficient staff education and expertise about palliative care.(26) Other perceived barriers include false hope for cure, inappropriate continued use of advanced life-saving technology, limited financial resources for specialized pediatric care, limited access to specialty care in rural areas, ethical and legal issues, inappropriate eligibility criteria, fragmented care, inadequate assessment and management of symptoms, lack of research on pediatric palliative care, and lack of training and expertise even in pediatric oncology.(4, 27-31) Despite formal training, physicians in one study said they do not feel adequately prepared to care for children with terminal conditions.(32)

Technology has improved the survival likelihood of pediatric patients with complex medical disorders and rare conditions who might not have previously survived, but many of these children are still prone to repeated life-threatening or life-limiting complications.(33) Indeed, advances in pediatric care have led to an increase in the prevalence of children with life-threatening conditions.(34) Despite technological improvements, there are several potential barriers to supporting a critically ill child in a home environment, including lack of health care providers experienced in home extubation, inaccessibility of pediatric critical care transport teams, medical equipment for transport and use in the home, supportive hospice services, difficulties in insurance payment for transport and procedures performed in the home, and lack of long-term home care support if the child survives his/her illness longer than expected.(35)

Pediatric Palliative Care Outcomes – Determining Effectiveness

Previous research has measured the effectiveness of palliative care interventions in improving outcomes related to patient symptom burden, provider satisfaction, reduced percentage of patients dying in-hospital when desired, pain and symptom control, reduced resource use, increased family satisfaction, and the successful transitioning of patients to less intensive sites of care.(36-44) However, most of this clinical effectiveness research focuses on adults and there is a lack of outcomes-based research dedicated to pediatric programs and interventions. For example, symptom-related interventions are rarely studied in pediatric end-of-life care despite evidence that pediatric oncology patients experience symptoms that are different from, and more intense than, those experienced by children dying of other diseases.(45)

Initial attempts to measure outcomes in PPC have revealed many complexities. Complications can arise from the short life spans of many PPC patients, potentially small and geographically dispersed patient samples, identifying a comparison group with a similar level of severity, identifying the right instruments for measuring costs and benefits, variability in outcomes due to the wide range of diseases and the variation in prognoses of those diseases, and moral and ethical debates about whether effectiveness studies should even be conducted for PPC recipients facing end-of-life care (46).

Health-related quality of life (HRQOL) has been proposed as a tool for measuring PPC outcomes, but selecting the best instrument is complicated. Children in PPC programs present with a variety of diseases, making generic measurement preferable. These generic HRQOL instruments assess physical, emotional, and social constructs, but often miss less generalizable domains like pain, fatigue, depression, spirituality, social interaction, and desire for autonomy. Many studies have used the Pediatric Quality of Life Inventory Generic Core Scale (PedsQL) in asthma, cancer, heart disease, rheumatology, and diabetes patients.(47-52) However, there are other indications that standard quality-of-life instruments such as PedsQL lack validity for measuring health-related quality of life in children with life-limiting conditions.(53)

Family support

Research findings underscore the importance of considering the needs of all family members when providing care to children. Care teams should pay particular attention to parents with depressive symptoms, who in some cases can receive supportive care through their children's pediatric palliative care programs. Parents are generally more involved as direct caregivers and decision makers than in the adult setting.(53) When a child becomes fatally ill and dies, parental grief is more intense than the grief experienced in response to other forms of loss such as the death of a spouse or friend, and this intense grief can affect parental health outcomes, including increased mortality in bereaved parents.(54, 55)

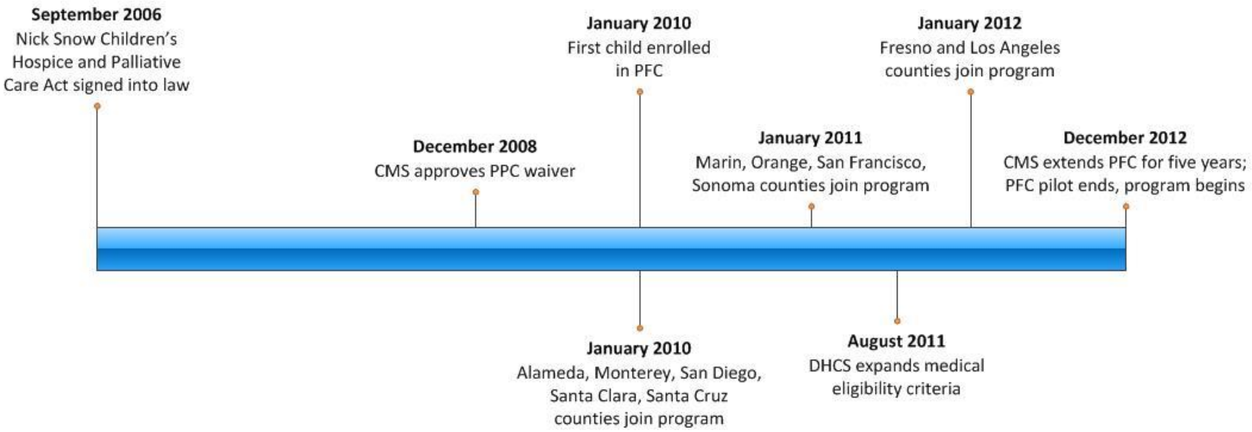
To assist patients and their families through the palliative care process, promoting shared decision-making among patients, caregivers, and doctors can better inform all parties about the risks and benefits of health care interventions and offer them an opportunity to make an informed choice.(56) Evidence suggests that compared to their counterparts, patients who engaged in shared decision-making had greater patient-doctor communication and higher satisfaction with their doctors, improved adherence with treatment regimens, and a greater sense of personal control and self-esteem.(57-60) In addition, shared decision-making is associated with better quality of life or self-reported health status.(60, 61)

Program Design

PFC waiver service agencies had to be licensed hospice agencies or home health agencies. The care team generally consisted of referring physicians, CCSNLs, agency care coordinators, child life specialists, massage therapists, art therapists, music therapists, home health aides, licensed clinical social workers, marriage and family therapists, and licensed psychologists.

PFC was designed, in part, to provide in-home services. As such, a "30-day rule" was implemented whereby children who were hospitalized for 30 or more consecutive days were automatically disenrolled from the program. These children were generally eligible to re-enroll once they were discharged from the hospital, but they were not considered part of PFC during the period of extended hospitalization. The purpose of the rule was to temporarily disenroll children who could not utilize PFC's in-home services rather than to exclude severely ill children. To reflect the spirit of the rule in the cost analysis, we attempted to prevent an undercounting of the costs associated with these extended hospitalizations by including all costs for children who had multiple enrollment periods, including the time between enrollment periods, if the original disenrollment was the result of the 30-day rule.

Exhibit 1: Timeline of Waiver Implementation



Evaluation Design

AB 1745 mandated an evaluation of the PFC program. DHCS contracted with UCLA to conduct the evaluation with the following goals in mind:

1) Assess the impact of the program on financial outcomes, including return on investment (ROI) and cost savings, and projections for future program savings, if any, in the budgets of state and local governments if the PFC program were expanded statewide.
2) Provide an estimate of whether the actual total expenditures for home- and community-based waiver services and other Medi-Cal services provided to individuals

under the PPC Benefit Waiver program fall below or exceed 100 percent of the amount that would be incurred in the absence of the waiver.

3) Assess humanistic outcomes, including child and family quality of life and satisfaction with the program.
4) Evaluate operational factors in program administration through providers' assessment of the ease of navigating the program, referring patients, and providing services.

The results described in this report assess the main components of the evaluation – operational quality assurance and financial, utilization, and humanistic outcomes.

Design

The cost analysis utilizes a pre-post design in which the health care claims costs up to 24 months prior to PFC enrollment were calculated on a per enrollee per month (PEPM) basis and compared to the PEPM costs of enrollees during their time in PFC. In the absence of an appropriate control group (described in greater detail in the Limitations of Financial Outcomes section below), the two-year pre-enrollment period served to stabilize the cost trend prior to program participation. The extended pre-enrollment period minimizes the potential for major events that led to referral and enrollment in the program disproportionately affecting the pre-enrollment period and inflating cost savings in the post period through a bias in the timing of referral.

Humanistic outcomes were measured by pre-post analysis of family quality-of-life and satisfaction measures included in the family surveys designed by UCLA and administered to enrolled children's primary caregivers by CCSNLs. UCLA provided CCSNLs with training on survey administration to ensure reliability of results.

Data sources

The evaluation analyses were conducted using data from Medi-Cal claims files, CCS enrollment files, F-CAP files, and survey data collected by DHCS from questionnaires designed by the UCLA evaluation team. The pre-enrollment period for each child was the 24 months prior to their first enrollment in PFC. Given that the first child enrolled in PFC in January 2010, we used claims data from as early as January 2008 and up to the end of the pilot period in December 2012. Enrollment files applied to the same period as the claims data. F-CAP and the survey data on family satisfaction and quality of life were collected on a continuous basis by CCSNLs and transmitted to UCLA via DHCS from the beginning of enrollment in January 2010 through December 2012. Other survey data, including UCLA questionnaires for CCSNLs, provider agencies, and CCS physicians, were collected through SurveyMonkey. For a more detailed explanation of the development of the questionnaires and survey processes, see Appendix A: Survey Methodology.

A six-month run-out was applied to the claims data, such that any claim with a check (payment) date more than six months from the service end date was dropped. The run-out period was necessary due to the standard delay between service provision and claim payment in Medi-Cal. We also allowed an extra three months to account for the lag caused by Medi-Cal claims file production. The claims data for the final analyses in this report were obtained in October 2013, accounting for the run-out and lag on claims up to December 2012, when the PFC pilot ended.

Over the course of the program, concerns were raised by provider agencies and DHCS that claims related to PFC services may have been systematically denied and thus did not appear in the paid claims file DHCS was contracted to deliver to UCLA. As such, DHCS investigated separately the unpaid or denied claims pertaining to PFC enrollees and provided an overall estimate of the amount of unpaid claims. This number was added to the total program cost as a lump sum and was included in the post-enrollment costs.

DHCS also provided UCLA a separate estimate of the administrative cost of PFC to the state via reports that each participating county submitted declaring the amount spent on PFC-related staff and activities. These estimated annual expenditures were also included as a lump sum in the post-enrollment costs.

Findings

Operational

Waiver Quality Assurance

DHCS served as the administrative authority over PFC and the primary waiver liaison with CMS, including submission of CMS Form 372, the annual report required of all CMS home- and community-based services waivers. The quality assurance information reported here is based on DHCS' final CMS Form 372 of the waiver period, submitted in December 2012. DHCS monitored the implementation and administration of PFC by CCS' county-level programs via DHCS' Children's Medical Services Branch, which includes CCS. Quality assurance was handled through "a system to monitor quality control, provider standards, care plans, and services provided to clients to ensure that the health and welfare needs of individuals served in the PPCW [were] continuously met and protected," as mandated by CMS quality assurance guidelines. DHCS performed onsite program compliance reviews, level-of-care (LOC) determination reviews, health and welfare assessment reviews, comprehensive care plan reviews, provider qualification reviews, and financial audits as part of its quality assurance and improvement responsibilities. County CCSNLs held monthly phone calls with enrolled children and their families to ensure satisfaction, discuss health and welfare issues, and review reasons for program disenrollment.

Over the three-year course of the pilot, DHCS identified a number of deficiencies, most frequently pertaining to the LOC determination component of its quality control efforts. While DHCS did not provide specific numbers of different types of deficiencies, county CCSNLs were found to be significantly noncompliant in submitting completed LOC forms in a timely manner and in reporting the date of the LOC determination. CCSNLs were also found to be noncompliant in requiring providers to complete appropriate sections of care plans and documenting monthly calls to families to ensure services were received as expected.

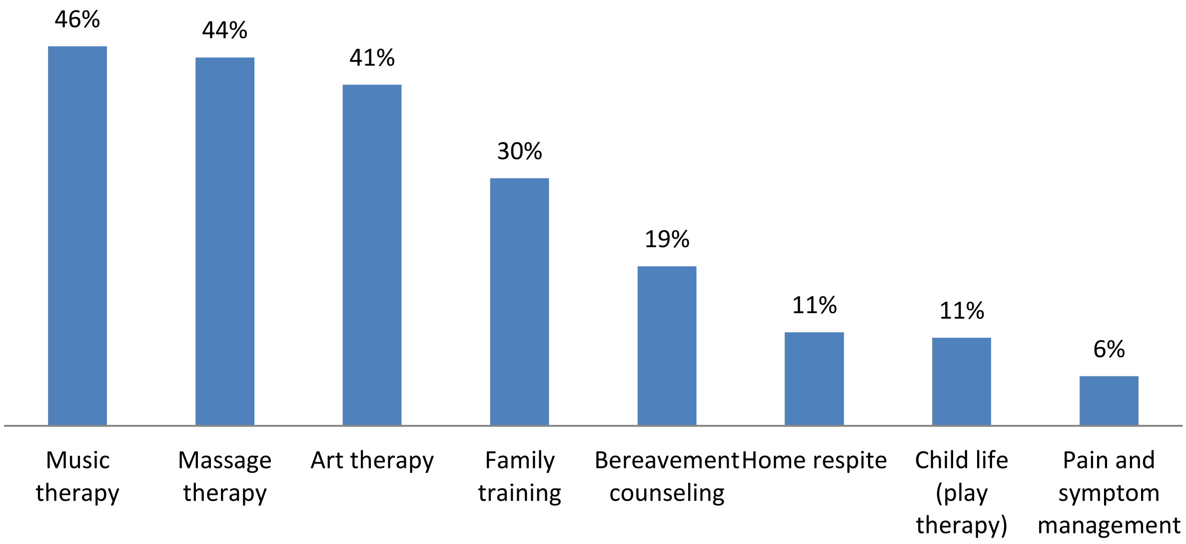
Care plans were another source of deficiency. Providers did not address or complete some health and safety assessments, physicians did not sign care plans in a timely manner, providers did not always forward care plans to CCSNLs, who in turn did not always submit care plans to DHCS, and families were sometimes excluded from multidisciplinary team meetings. Hospice and home health agencies were also found deficient in submitting completed provider applications, including documentation of participating staff.

DHCS attempted to prevent deficiencies and address existing ones through technical assistance, reviews of corrected care plans and LOC forms, and clarifications of program policy through official program notices. At the beginning of the waiver period, DHCS trained all CCSNLs, their backups, and other interested county administrators on all aspects of their PFC-related scope of work, including overall expectations, F-CAP, case management, health and welfare monitoring responsibilities, and database use. DHCS also conducted monthly conference calls with CCSNLs in all participating counties and quarterly calls with hospice and home health agencies to discuss ongoing concerns.

PFC Service Requests

The percentage of enrollees requesting PFC services provides an indication of engagement with the program. Other than care coordination, which was provided continuously, expressive therapies were the most requested services (Exhibit 2). Music, massage, and art therapies were all requested by at least 40% of enrollees. Less frequently requested services included pain and symptom management, home respite, and play therapy. PFC services were the principal source of the concern about systematic denial of claims described above, so the claims data on these services were considered unreliable. The data reported here are from F-CAP results logged in the PFC database maintained by DHCS throughout the pilot period, which indicate services requested but not services utilized.

Exhibit 2: Percentage of PFC Enrollees Requesting Program Services, 2010-2012



Source: UCLA analysis of F-CAP results in DHCS PFC database.
Note: N=151

Demographics

Over the three-year pilot period, 151 children enrolled in PFC. The overall program population was diverse in terms of age, race/ethnicity, county of residence, and primary diagnosis (Exhibit 3). Enrollees were most likely to be ages 6-10 (32%), male (56%), and Latino (59%). More than one-third of enrollees lived in San Diego County (34%). Neurologic disorders (27%) were the most frequent primary diagnoses of enrolled children, followed by cancers (22%) and pulmonary disorders (11%). The mean number of days enrolled in PFC was 328, or approximately 11 months.

Exhibit 3: Demographic and Descriptive Characteristics of All PFC Enrollees, 2010-2012

	n	%
Total	**151**	
Age		
Less than 2	17	11
2-5	32	21
6-10	48	32
11-15	26	17
16-20	28	19
Gender		
Male	85	56
Female	64	42

	n	%
Missing	2	1
Race/Ethnicity		
Latino	89	59
White	14	9
Asian/Pacific Islander	8	5
Black	5	3
Other/Missing/Unknown	35	23
County of residence*		
San Diego	52	34
Los Angeles	27	18
Monterey	24	16
Orange	19	13
Santa Cruz	12	8
Sonoma	10	7
Other**	8	5
Primary diagnosis		
Neurologic	44	29
Cancer	33	22
Pulmonary	16	11
Neuromuscular	15	10
Cardiac	14	9
Transplant	13	9
Metabolic	8	5
Other***	8	5
Average length of enrollment (days)	328	

Source: UCLA analysis of PFC enrollment data provided by DHCS.
*Total adds up to 152 because one child lived in two participating counties while enrolled.
**Other includes Fresno, Marin, San Francisco, and Santa Clara counties, which are condensed here for confidentiality reasons because of small population size.
***Other includes gastrointestinal conditions and enrollees whose primary diagnosis was "Other and unspecified postsurgical nonabsorption."

The cost analyses in this report are based on a subset of the PFC population that was enrolled in the program for at least 60 days, which DHCS and UCLA hypothesized was the minimum amount of time needed for the program to have an effect on utilization. There were 132 children enrolled for at least 60 days for whom complete claims data were available. This group's demographic and other descriptive information is presented in Exhibit 4. The overall demographic, geographic, and disease distributions are similar to those of the overall enrollee population. The mean enrollment period of nearly one year (361 days) was about one month longer than in the overall enrollee population.

Exhibit 4: Demographic and Descriptive Characteristics of PFC Enrollees Included in Cost Analyses (Minimum 60-Day Enrollment), 2010-2012

	n	%
Total	**132**	
Age		
Less than 2	14	11
2-5	28	21
6-10	42	32
11-15	23	17
16-20	25	19
Gender		
Male	75	57
Female	57	43
Race/Ethnicity		
Latino	79	60
White	11	8
Asian/Pacific Islander	6	5
Black	5	4
Other/Missing/Unknown	31	23
County of residence*		
San Diego	48	36
Los Angeles	26	20
Monterey	18	14
Orange	17	13
Santa Cruz	9	7
Sonoma	9	7
Other**	6	5
Primary diagnosis		
Neurologic	39	30
Cancer	27	20
Neuromuscular	15	11
Pulmonary	14	11
Transplant	12	9
Cardiac	11	8
Metabolic	6	5
Other***	8	6
Average length of enrollment (days)	361	

Source: UCLA analysis of PFC enrollment data provided by DHCS.

*Total adds up to 133 because one child lived in two participating counties while enrolled.

**Other includes Marin, San Francisco, and Santa Clara counties, which are condensed here for confidentiality reasons because of small population size.

*** Other includes gastrointestinal conditions and enrollees whose primary diagnosis was “Other and unspecified postsurgical nonabsorption.”

Financial Outcomes

Cost Savings and Return on Investment

PFC lowered the per-enrollee per-month (PEPM) cost of providing care to the 132 children enrolled in the program for at least 60 days by $3,133 (Exhibit 5), based on pre-post analysis of paid claims and an estimate of incorrectly denied claims for PFC services. This figure does not include the administrative cost to DHCS of running the program or the roughly $300 PEPM increase in service reimbursement for participating agencies that was proposed in late 2012, near the end of the pilot period. While this increase was not in effect during the pilot period, it has since been recognized as a necessary part of providing appropriate care to PFC enrollees because it attempts to ensure a sufficient supply of provider agencies by making PFC care provision financially viable. The increase should be included in future calculations to more closely reflect the expected program cost moving forward. Incorporating the $300 PEPM reimbursement increase and the administrative cost to DHCS of running the program, the pre-post savings would be $2,154 PEPM.

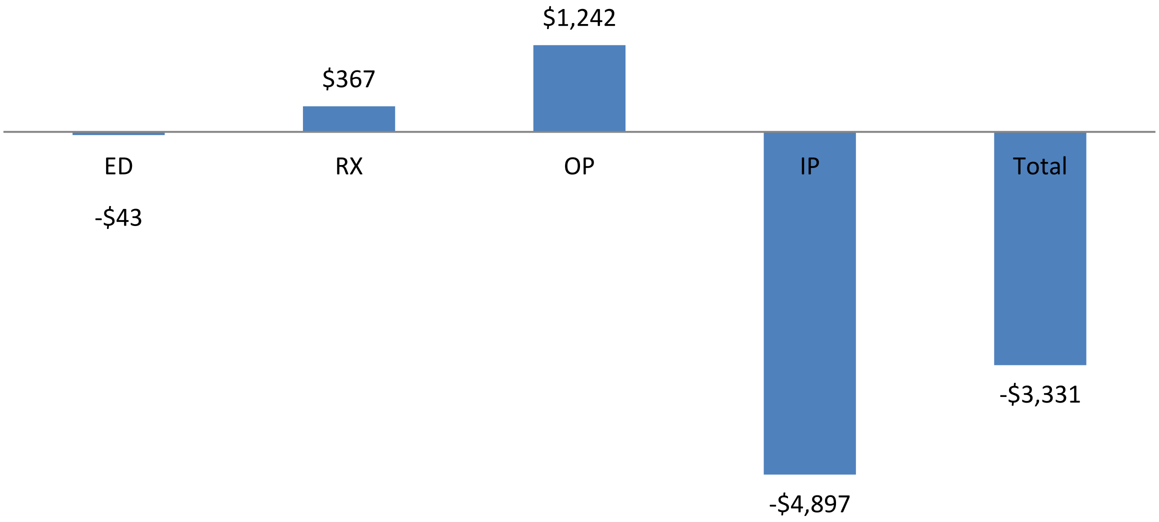
Exhibit 5: Pre-Post PEPM Cost Comparison of PFC Enrollees, 2008-2012

	Number of children	Enrollee months	Total cost	Average PEPM
Pre	131	2,830	$44,270,682	$15,643
Post	132*	1,736	$21,718,677**	$12,511
		Pre-post difference in PEPM =		**$3,133**

Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data, and DHCS reporting of unpaid claims and program administrative costs.
*There is an additional child in the post period because one enrollee entered PFC at birth and did not have any pre-enrollment period.
**Costs in the post period include all paid claims and DHCS’ estimates of unpaid claims for PFC services.

Examining costs by service type, most of the savings were realized through a reduction in inpatient (IP) care costs of $4,897 PEPM, with an additional small decrease in emergency department (ED) care costs (Exhibit 6). In line with PFC’s goal of providing more care in the home and community settings, the reduction in inpatient care costs was accompanied by an increase in outpatient (OP) services of $1,242 PEPM and a smaller increase in pharmacy (RX) services of $367 PEPM. The net savings underscore the financial benefit of programs such as PFC that move care from the relatively costly IP setting into home- and community-based care.

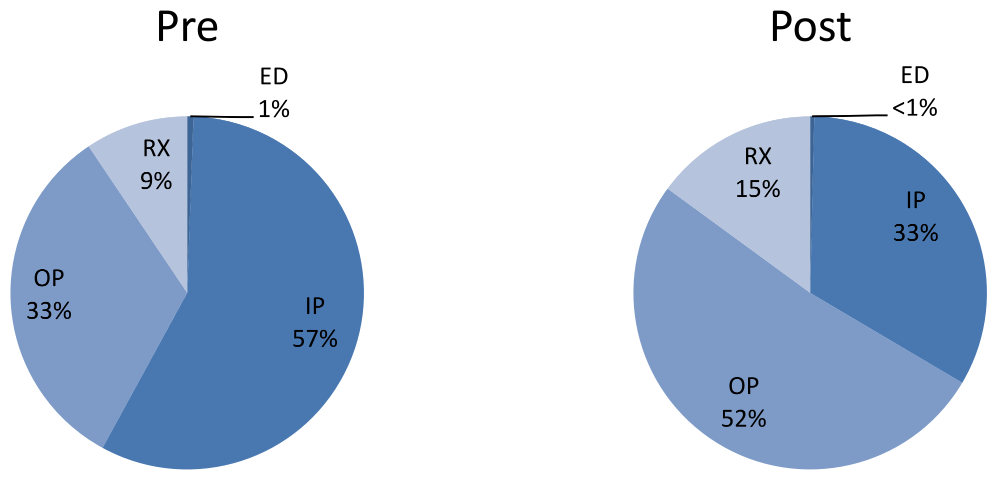
Exhibit 6: Pre-Post Change in PEPM Cost of PFC Enrollees, by Service Type, 2008-2012



Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data.
Note: ED = emergency department; RX = pharmacy; OP = outpatient; IP = inpatient.
Note: The total savings of $3,331 is higher than the savings cited in Exhibit 5 because these numbers include only paid claims and do not account for unpaid claims, which were provided by DHCS in a lump sum and could not be disaggregated by service type.
Note: Long-term care was examined as a separate service type but was too small to report separately and was included in the IP service category.

The proportion of costs attributable to IP care dropped from more than half in the pre period (57%) to one-third in the post period (33%; Exhibit 7). The proportional decrease in IP service costs was accompanied by an increase in the proportion of OP service costs from 33% pre-enrollment to 52% post-enrollment, and a proportionally similar increase in Rx service costs. ED costs were small compared to the other service types and did not change substantially between the pre and post periods as a proportion of total PEPM costs.

Exhibit 7: Comparison of the Distribution of PEPM Cost of PFC Enrollees in the Two Years Prior to Enrollment and During Enrollment, by Service Type, 2008-2012



Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data.
Note: ED = emergency department; RX = pharmacy; OP = outpatient; IP = inpatient.

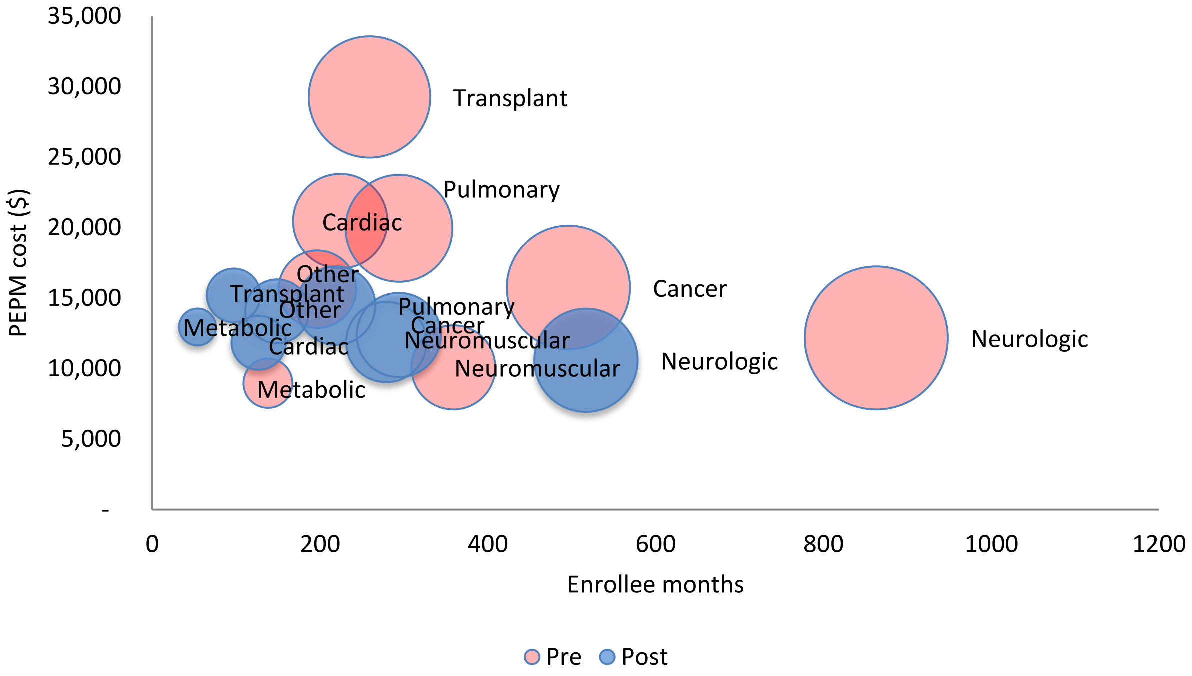
The change in costs differed according to enrollees' primary diagnoses. Children enrolled in PFC as a result of a transplant or cardiac or pulmonary condition showed marked PEPM cost savings from the pre-enrollment to post-enrollment periods, including more than $14,000 PEPM savings for transplant-related enrollees (Exhibit 8 and Exhibit 9). Enrollees with cancer or a neurologic condition showed more modest savings, while those with neuromuscular and metabolic conditions exhibited mean cost increases from the pre to post periods. In terms of overall cost (the diameter of the bubbles in Exhibit 9), enrollees with neurologic conditions represented the largest proportion of cost in the pre- and post-enrollment periods, in part because they comprised the largest diagnosis category and had the most enrollee months.

Exhibit 8: PEPM and Total Cost of PFC Enrollees, by Diagnosis Category, 2008-2012

	Pre			Post		
	Enrollee months	**PEPM ($)**	**Total cost ($)**	**Enrollee months**	**PEPM ($)**	**Total cost ($)**
Cancer	496	15,743	7,808,732	294	12,392	3,643,203
Cardiac	224	20,444	4,579,498	127	11,839	1,503,570
Metabolic	138	8,955	1,235,782	54	12,959	699,785
Neurologic	863	12,174	10,506,547	517	10,584	5,471,897
Neuromuscular	359	10,084	3,620,031	279	11,893	3,318,137
Pulmonary	294	19,941	5,862,682	219	14,473	3,169,486
Transplant	259	29,255	7,577,151	97	15,188	1,473,264
Other	197	15,636	3,080,259	149	14,056	2,094,336

Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data.

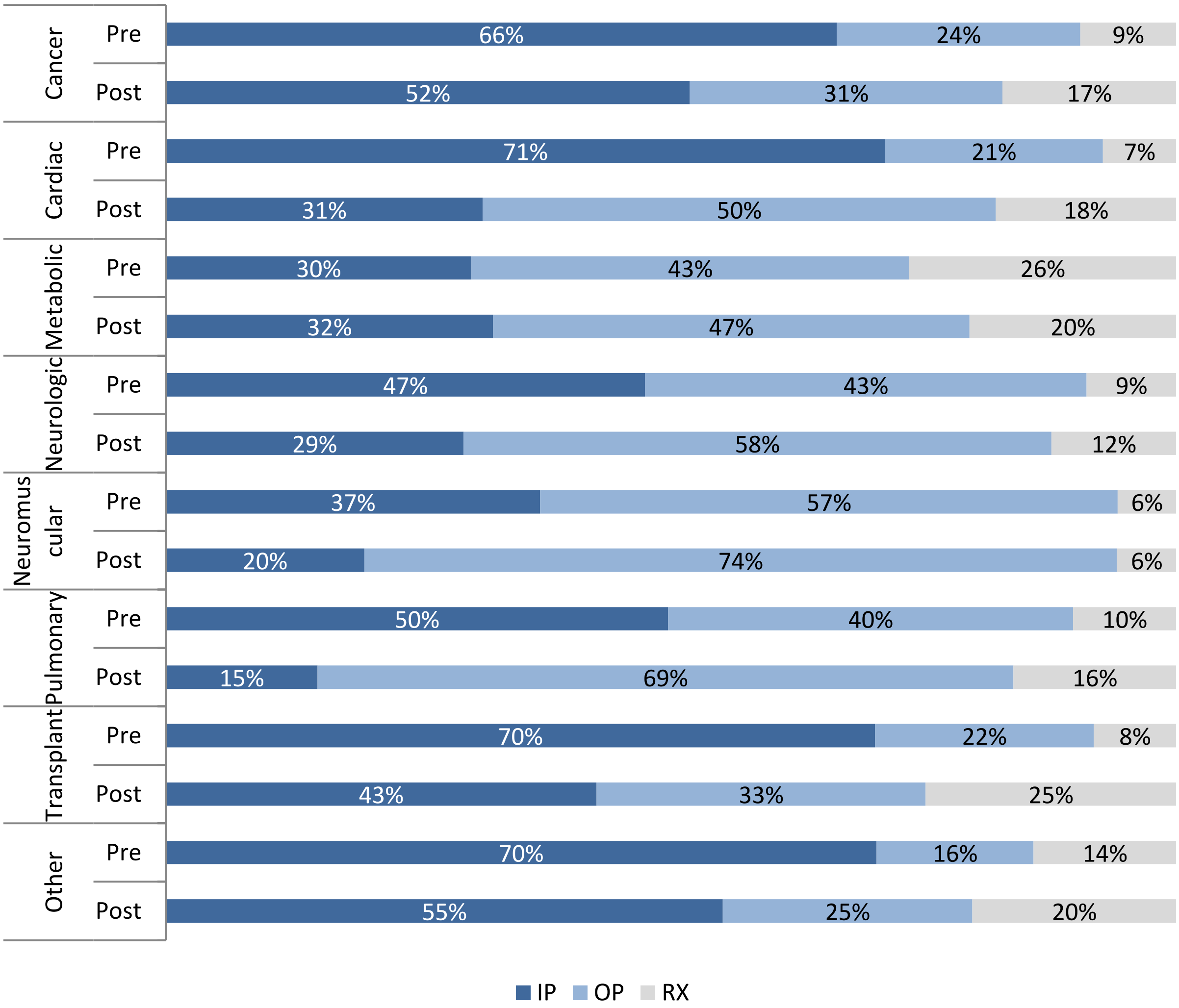
Exhibit 9: PEPM and Total Cost of PFC Enrollees, by Diagnosis Category, 2008-2012



Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data.
Note: Bubble size represents total cost for the diagnosis category.
Note: Other includes gastrointestinal conditions and enrollees whose primary diagnosis was "Other and unspecified postsurgical nonabsorption."

The cost savings by diagnosis category are most evident in the reductions in IP costs from pre- to post-enrollment. Enrollees with transplants or cardiac or pulmonary conditions all reduced the proportions of their costs attributable to IP services by at least 27% and as much as 40% in the case of those with cardiac conditions (Exhibit 10). However, a reduction in the proportion of costs associated with IP services did not necessarily guarantee overall cost savings, as evidenced by enrollees with neuromuscular conditions, who had a 17% reduction in IP services but whose total average costs nonetheless increased slightly from pre- to post-enrollment. This may have been caused in part by the costly nature of OP services for neuromuscular conditions.

Exhibit 10: Cost Distribution of PFC Enrollees, by Type of Service and Diagnosis Category, 2008-2012



Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data.
Note: IP = inpatient; OP = outpatient; RX = pharmacy.
Note: ER percentages were not included due to small size.
Note: Other includes gastrointestinal conditions and enrollees whose primary diagnosis was “Other and unspecified postsurgical nonabsorption.”

The return on investment (ROI) of PFC was $2.20 (Exhibit 11). That is, for every dollar that was spent on the program, the state and federal governments (because the pilot was jointly funded) recouped the original dollar and saved an additional $1.20.

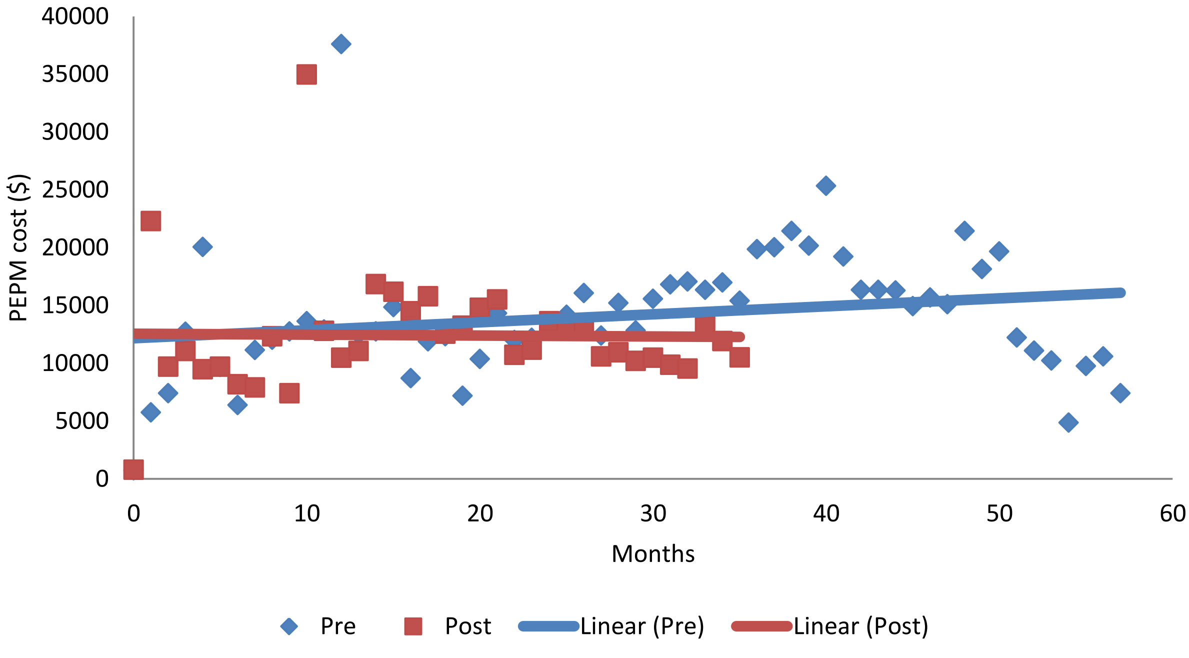
Exhibit 11: Return on Investment of PFC Program, 2010-2012

Type of Savings/Cost	Value ($)
Gross program savings (PEPM savings * Total enrollee months)	5,438,178
Total program cost (($300 PEPM reimbursement increase * Total enrollee months) + Administrative costs)	1,697,996
Net savings (Gross program savings – Total program costs)	3,740,182
Return on investment (Net savings/Total program cost)	2.20

Cost Avoidance

A comparison of the cost trends between the pre- and post-enrollment periods shows that PFC contributed to a slowing of the cost increases among enrollees (Exhibit 12). If the cost trajectory for the pre-enrollment period had continued post-enrollment, costs for providing care to the 132 children enrolled for at least 60 days during the three-year pilot period would have been an estimated $28.3 million,[2] as opposed to the actual pilot period paid claims cost total of $21.4 million, a difference of $6.9 million.

Exhibit 12: Pre-Post Trend Analysis of PEPM Cost of PFC Enrollees, 2008-2012



Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data.

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[2] This estimate is based on a quadratic trend of PEPM costs of PFC participants prior to their enrollment in the program. The trend analysis employed a Poisson model. The choice of a quadratic trend was based on empirical evidence seen in the data and provides a more conservative cost estimate.

Projected Future Program Savings

Given PFC's conversion from pilot to program status and the five-year extension of the program, it is important to consider the potential future savings PFC could generate if it were to increase enrollment in currently participating counties and/or expand statewide. To project future savings, two major assumptions were made. First, the administrative cost of running the three-year pilot period was assumed to carry over to future three-year periods, with the addition of the $300 PEPM increase in service reimbursement for participating agencies. Second, the pre-post PEPM savings for the three-year pilot period were assumed to continue forward at the same three-year rate. Under these assumptions, if 200 children enrolled in the program for three years, the total cost would be $3.3 million and the gross savings generated from the $3,133 PEPM would total $22.6 million, resulting in three-year savings of $19.3 million.

Limitations of Financial Outcomes

The analyses presented here suggest that PFC was highly successful from a cost-savings perspective. However, the strength of the results is limited by the pre-post design utilized. This methodology did not allow for consideration of environmental or historical factors, including other changes in policy, reimbursement, provider supply, or inflation, all of which could have contributed to changing Medi-Cal and CCS costs over the period of the PFC pilot. A difference-in-differences approach, in which the enrolled children would be compared over the same time period to a similar group of CCS-eligible children (claims on all CCS children were available to the evaluation team) who did not enroll in PFC, would have controlled for these outside factors by comparing the pre-post change in the enrolled group to the pre-post change in the control group.

While a difference-in-differences approach would have been preferable to the pre-post design, UCLA was unable to identify an appropriate control group, mainly because the level of disease severity of PFC children prior to enrollment was substantially greater, on average, than any other group of children identifiable through the CCS program. UCLA attempted to compare the enrolled children to the sickest children in CCS using health care costs as a proxy for severity, but even limiting the potential control group to the top 1% of CCS children nonetheless resulted in average costs that were an order of magnitude lower than those of the enrolled group. The evaluation team conducted extensive ICD-9 and CPT code mining to attempt to determine potential control children's level of severity, but the costs remained substantially lower than those of enrolled children. Children who were on the waiting list at some point during the program but never enrolled in PFC appeared to be a promising control group because they had met the criteria for program eligibility, but sensitivity analyses showed them to be a highly unstable group in terms of cost. Given that they were never enrolled in the program, the cut point for their pre-post comparison had to be determined arbitrarily, and slight modifications in the selected date led to drastically different results.

The most rigorous attempt to identify a control group involved a search of the entire CCS population to find matched controls for the children enrolled in PFC. This process utilized the Chronic Illness & Disability Payment System (CDPS), a diagnostic classification system that predicts expenditure levels for specific disease categories.(62) In consultation with medical experts, UCLA grouped enrolled children's primary and secondary ICD-9 codes into broader disease categories according to the CDPS system. CDPS codes generally range from "extra low" to "extra high," with slight variations across disease categories. UCLA compiled a list for each PFC enrollee of all disease categories of at least "medium" severity that appeared in the three months prior to enrollment and then searched the entire CCS database to identify children who had the same CDPS codes in any given three-month period in the claims file, which ran from 2007 to 2012. CCS children also had to roughly match PFC children on age (a proportional calculation such that matched children could not be more than 25% older or younger than enrolled children). This diagnosis-based matching strategy left a substantial number of PFC enrollees with no exact matches in the entire CCS population. Despite the exact matches on CDPS diagnoses and age for the remaining enrollees, the PFC group still had PEPM costs that were about 50% greater than those of the control group (Exhibit 13). Furthermore, the PFC children for whom matches could not be found tended to have higher costs than the rest of the PFC group, suggesting that the highest-cost children were the hardest to match.

The results are fairly consistent with at least some of the limited data available from previous studies summarized in the literature review above, specifically Colorado's Medicaid-based pediatric palliative care program. Extrapolating PFC's savings of $2,154 PEPM, the average annual savings per child are close to $26,000, while estimates for Colorado's program range from $15,000 to $20,000 per enrollee per year.(63)

Exhibit 13: Results of CDPS and Age Matching with Comparison of Matched and Unmatched Enrolled Children, 2009-2012

	Matched				Unmatched			
Group	**Avg. PEPM (pre)**	**Avg. PEPM (post)**	**Difference**	**n**	**Avg. PEPM (pre)**	**Avg. PEPM (post)**	**Difference**	**n**
All enrolled	16150	13301	-2849	69				
All matchable enrolled	14934	13607	-1327	59	26564	18821	-7743	10
All matchable controls	10010	8043	-1967	242*				

NOTE: All controls matched on age (25% flex)

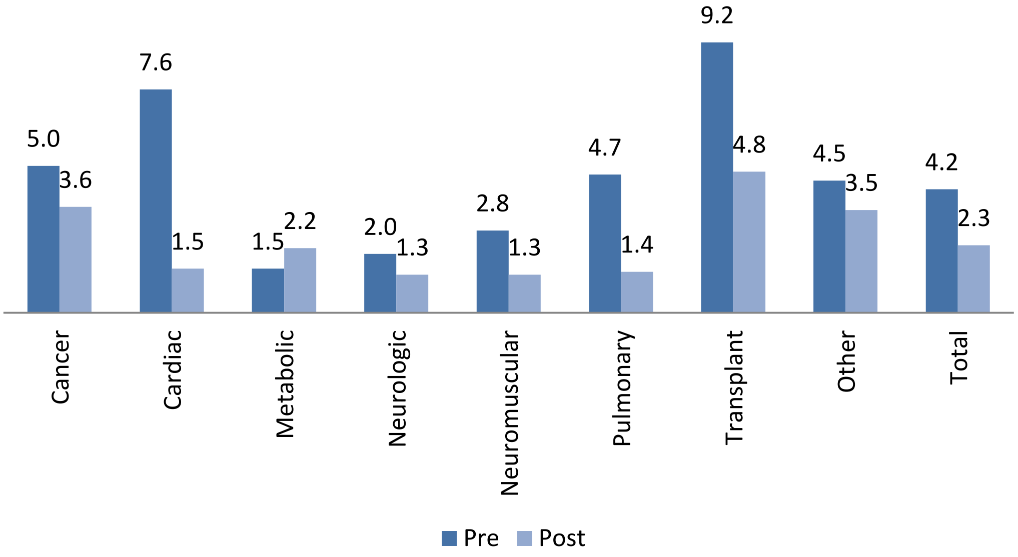
NOTE: There are 69 enrollees rather than the 132 in the final cost analyses because the attempt to find a control group occurred prior to receipt of the final data set in order to determine the cost analysis strategy. Given the impossibility of matching some enrollees from the outset, UCLA determined it was unnecessary to conduct additional matching analysis with the final group of 132.

*Control group calculations are based on the average PEPM of 500 repetitions of randomly selecting up to five controls (where possible) for each enrolled child from the 9,879 eligible matches

Utilization Outcomes

The drastic reduction in inpatient (IP) services described in the Demographics section led to a nearly 50% reduction in the average number of IP days per month among program enrollees, from 4.2 to 2.3 (Exhibit 14). The reduction was driven by major changes in the three primary cost-saving diagnosis categories – cardiac, pulmonary, and transplant. The average number of hospitalizations was also reduced in the program period, from 0.26 PEPM prior to enrollment to 0.20 PEPM during the program.

Exhibit 14: Mean Number of Inpatient Days PEPM, Pre- and Post-Enrollment, by Diagnosis Category, 2008-2012

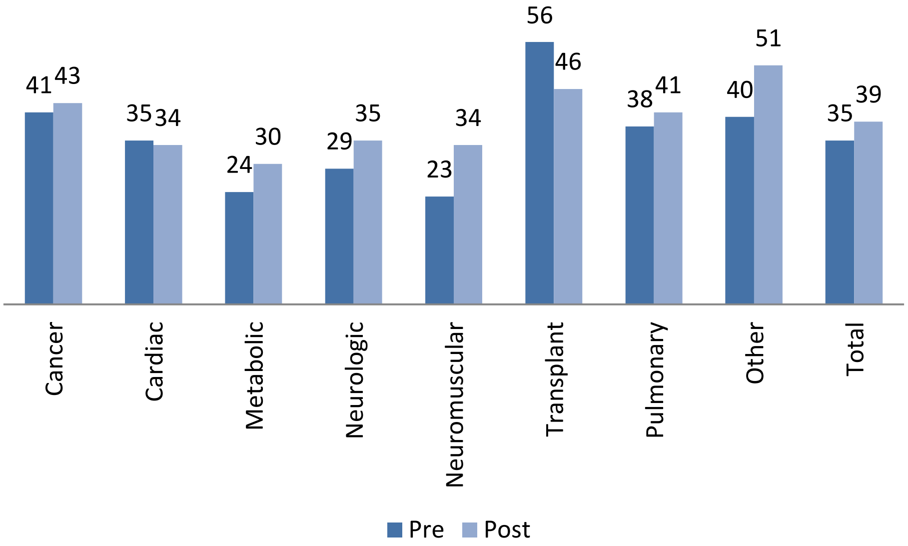


Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data.

In addition to reducing the need for hospitalizations through enhanced care coordination and the 24/7 nurse line, PFC also reduced the amount of time enrollees spent in the hospital on each visit from an average of 16.7 days prior to enrollment to 6.5 days while in the program (data not shown). Further, the 30-day readmission rate (hospital admission within 30 days of the previous discharge) was reduced from 45% of admissions to 37% of admissions (data not shown). The decrease in the latter may be partially explained by the more intensive care coordination provided to PFC enrollees.

As was the case with the financial outcomes, in which reduced IP costs were associated with increased OP costs, the decrease in the time PFC enrollees spent in the hospital was accompanied by an increase in the average number of OP visits from 35 PEPM prior to enrollment to 39 PEPM while enrolled in the program. There was wide variation in the change in OP visits across the different principal diagnosis categories (Exhibit 15).

Exhibit 15: Mean number of Outpatient Visits PEPM, Pre- and Post-Enrollment, by Diagnosis Category, 2008-2012



Source: UCLA analysis of MIS/DSS claims, MEDS and CMS Net data.

While ED use was relatively minor compared to IP and OP throughout the pre-enrollment and pilot period, there were slight reductions in average ED use and the average frequency of ED visits leading to hospitalization. The former dropped from 0.23 visits PEPM in the pre-enrollment period to 0.20 during enrollment, and the latter from 0.15 PEPM to 0.12 PEPM, respectively. Children with severe illnesses such as those that qualified enrollees for PFC are often admitted directly into the hospital, bypassing the ED, which may explain the relatively low overall ER use of a group of children with life-threatening diseases.

Underscoring the severity of the conditions of many PFC enrollees, 20 of the 132 children who enrolled in PFC for at least 60 days passed away prior to the end of the pilot period in 2012. Of these enrollees, nine had a primary diagnosis of cancer, seven had neurologic conditions, three had pulmonary conditions, and one had a primary cardiac condition (data not shown).

Humanistic Outcomes

Beyond the cost analysis and process evaluation, UCLA measured humanistic outcomes of PFC, including CCSNL, provider, and family satisfaction with PFC and enrolled child and family quality of life. UCLA conducted this component of the evaluation using original questionnaires designed by the evaluation team. CCSNL and provider surveys were conducted online using SurveyMonkey. Family satisfaction and quality-of-life surveys were administered by the CCSNL in the corresponding county, either in person or over the phone. For a detailed description of the data collection methodology utilized in this survey, see Appendix A: Survey Methodology.

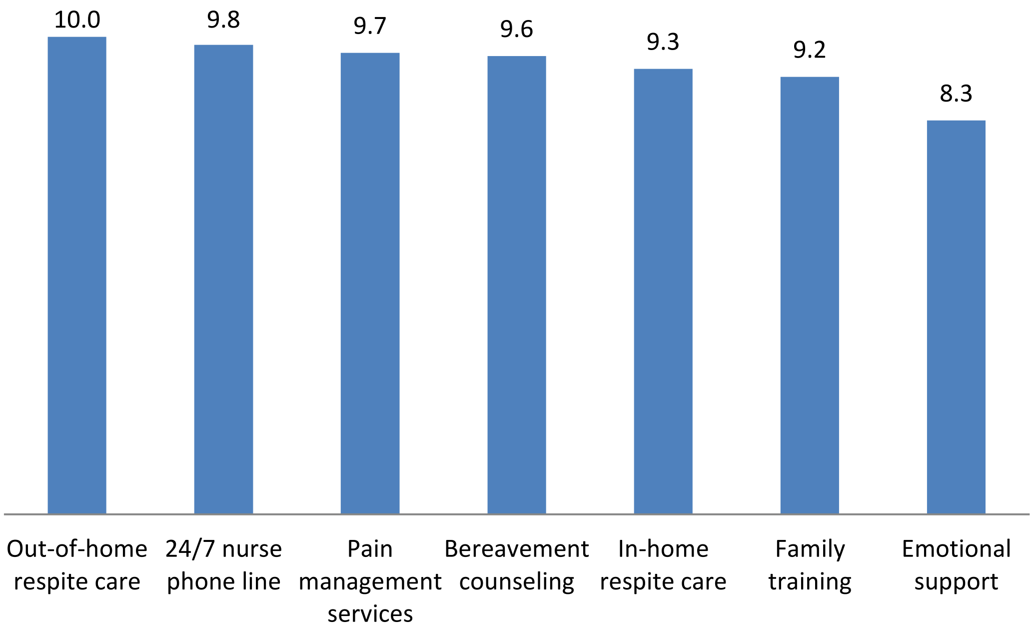
Provider and CCSNL Satisfaction

UCLA conducted surveys with CCSNLs, participating hospice and home health agencies, and CCS paneled physicians to gauge program outcomes from the perspective of the providers most involved in enrollees' and providers' PFC experience. All surveys were administered using SurveyMonkey's SSL encryption feature to protect the confidentiality of participants.

CCSNLs

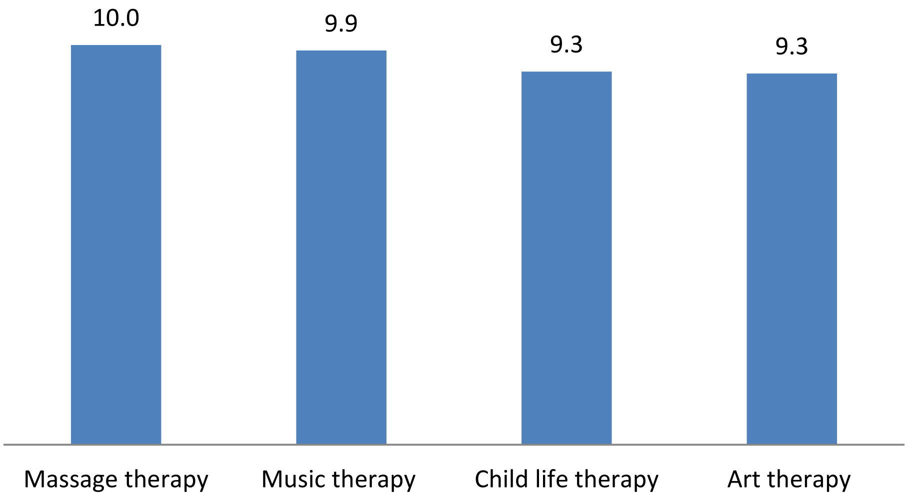
CCSNLs, the main PFC liaisons to enrolled children and their families, demonstrated high satisfaction with the quality of the program and its services. All nine CCSNLs responded to UCLA's survey and gave the waiver services overall a mean quality score of 9.8 out of 10. Ratings for individual services varied slightly and ranged from 8.3 to 10 (Exhibit 16 and Exhibit 17).

Exhibit 16: Average CCSNL Ratings of Select Waiver Services, 2011



Source: UCLA CCSNL survey.

Exhibit 17: Average CCSNL Ratings of Therapeutic Services, 2011



Source: UCLA CCSNL survey.

These scores were particularly relevant given the value that CCSNLs placed on individual services. When asked to rate the importance of each service for enrolled children and their families on a five-point scale from unimportant to very important, all CCSNLs said that pain and symptom management and counseling were very important, and the majority (at least 7 of 9) said that massage, music, and art therapy, family training, and in-home respite were very important. Six of the nine CCSNLs indicated that care coordination, child life therapy, bereavement services, the 24/7 nurse line, and out-of-home respite care were very important services (data not shown).

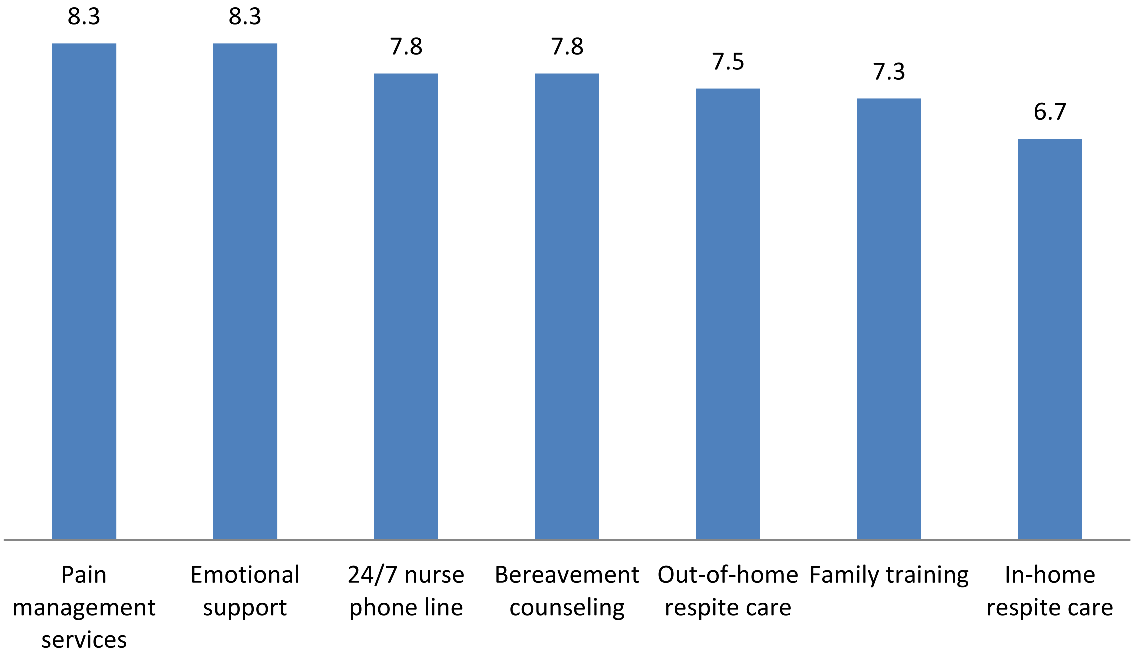
CCSNLs provided critical insight into the functioning of the program. The majority said that care coordination was an essential component of PFC that provided emotional and logistical support to families. Examples of important care coordination tasks included obtaining the right medications, acquiring and providing needed repair for durable equipment, such as hospital beds and wheelchairs, organizing transportation, and coordinating financial assistance and respite for parents. CCSNLs felt that some parents would not have been able to effectively coordinate the care of their child on their own given the complexity of most children’s conditions. They believed that care coordination saved money and time and allowed for quick resolution of issues to the benefit of the patient, family, and health system.

All of the CCSNLs believed that the program services were helpful in reducing family stress and worry and increasing family confidence about their ability to care for their child. In open-ended questions, CCSNLs said that parents felt “less alone” and “grateful” knowing that someone else knew about their child's condition, listened to their concerns, and could help with any issue that arose. The 24/7 nurse phone line was viewed by CCSNLs as another important resource to alleviate parents' stress and worry, as well as an effective service to reduce health care costs by preventing unnecessary ED visits and identifying problems early on in the home to prevent longer hospital stays.

Hospice and home health agencies

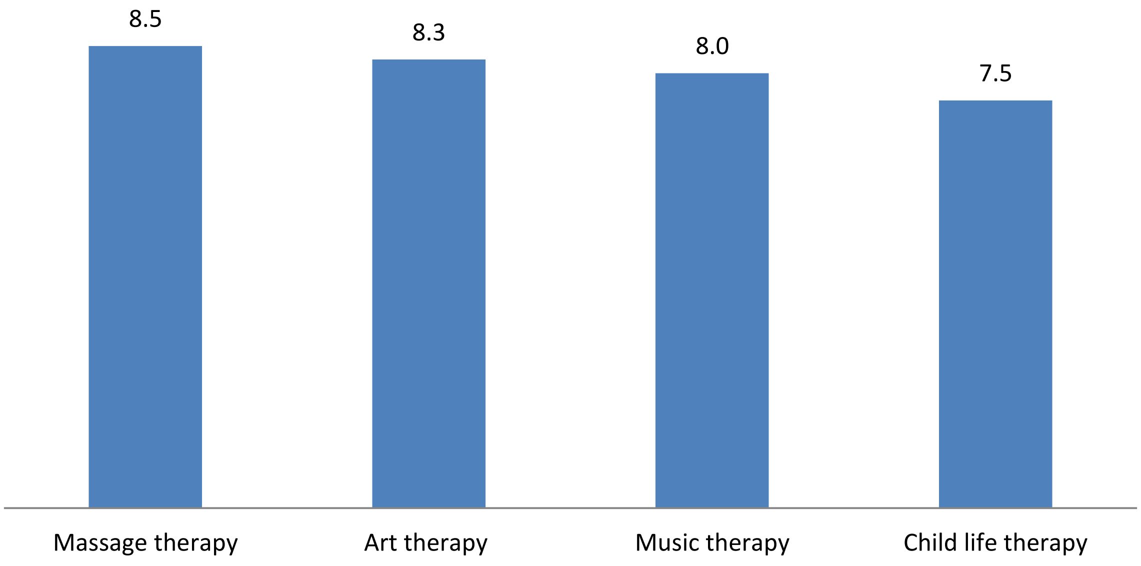
Hospice and home health agencies showed lower satisfaction than CCSNLs with the quality and utility of program services, but the scores on the 10-point rating scale were nonetheless high. Representatives of the four agencies that responded (of five total participating agencies at the time of the questionnaire) gave PFC program services an overall rating of 7.8. Ratings for individual services varied and ranged from 6.7 to 8.3 (Exhibit 18 and Exhibit 19).

Exhibit 18: Average Hospice and Home Health Agency Ratings of Select Waiver Services, 2011



Source: UCLA hospice and home health agency survey.

Exhibit 19: Average Hospice and Home Health Agency Ratings of Therapeutic Services, 2011



Source: UCLA hospice and home health agency survey.

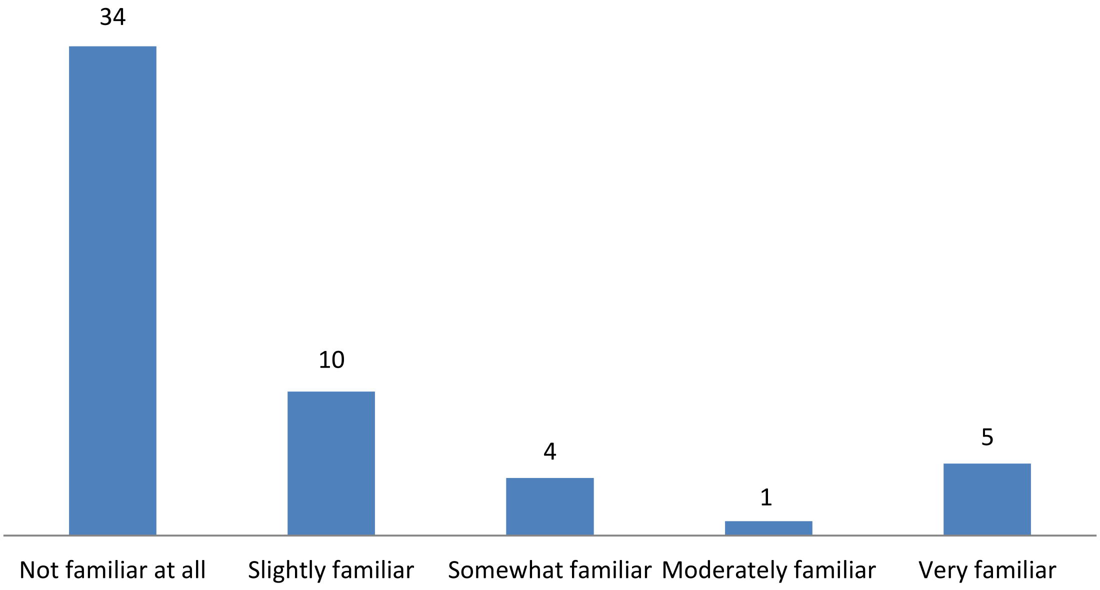
Hospice/home health agency providers all agreed that care coordination, massage therapy, pain and symptom management, bereavement services, art therapy, and music therapy were either very important or important services, while counseling, family training, and the 24/7 nurse line were considered to be of at least moderate importance.

All of the hospice/home health agency providers believed that the program services were helpful in reducing family stress and worry and increasing family confidence about their ability to care for their child. Like CCSNLs, agency/hospice providers suggested that care coordination and the 24/7 nurse phone line were particularly helpful in reducing family stress and worry. Family training, pain and symptom management, and emotional support were also credited with increasing confidence of families in caring for their child.

Physicians

Fifty-four CCS paneled physicians completed a survey about their knowledge, experience, and opinions of PFC (descriptive characteristics of respondents available in Appendix A, Exhibit 1). Based on their responses, program visibility appeared to be a problem. Thirty-four of the 54 respondents, or 63%, reported no familiarity at all with PFC (Exhibit 20). Among the 20 physicians who expressed at least some familiarity, only 13 were somewhat familiar with the eligibility criteria and only 11 had previously referred children to PFC. In considering how best to disseminate information about PFC and other palliative care programs in the future, respondents who had previously referred children to PFC were asked how they learned about the program. Ten of the 11 learned from another physician, seven from another employee at their institution, three from social workers, two each from grand rounds and the original program request for action, and one each from CCSNLs, the physician's own patient, advocates, and CCS workgroup meetings.

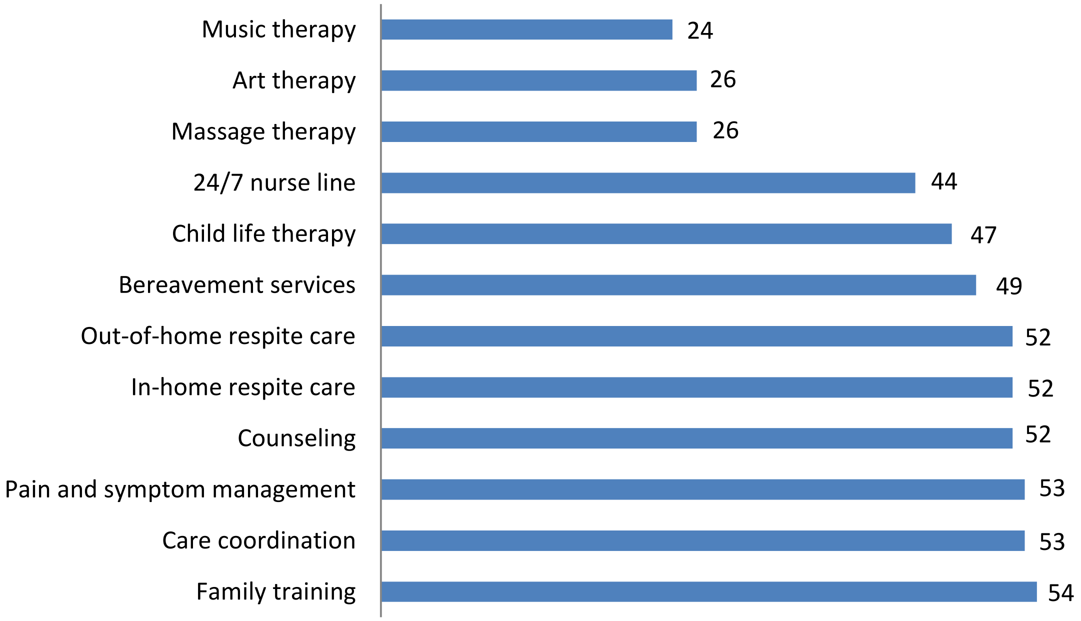
Exhibit 20: Number of CCS Physicians with Knowledge of Partners for Children, by Level of Familiarity, 2013



Source: UCLA physician survey.
Note: Based on a total of 54 responses.

Respondents were asked to rate the importance of providing individual PFC services to children with life-threatening or life-limiting illnesses (Exhibit 21). Family training was deemed the most important service, with all 54 respondents saying training was important or very important. Care coordination and pain and symptom management were considered nearly as important (53 each), followed by counseling and in-home and out-of-home respite care (all 52), bereavement services (49), child life therapy (47), a 24/7 nurse line (44), massage therapy (26), art therapy (26), and music therapy (24).

Exhibit 21: Number of CCS Physicians who Consider PFC Services Important, by Type of Service, 2013

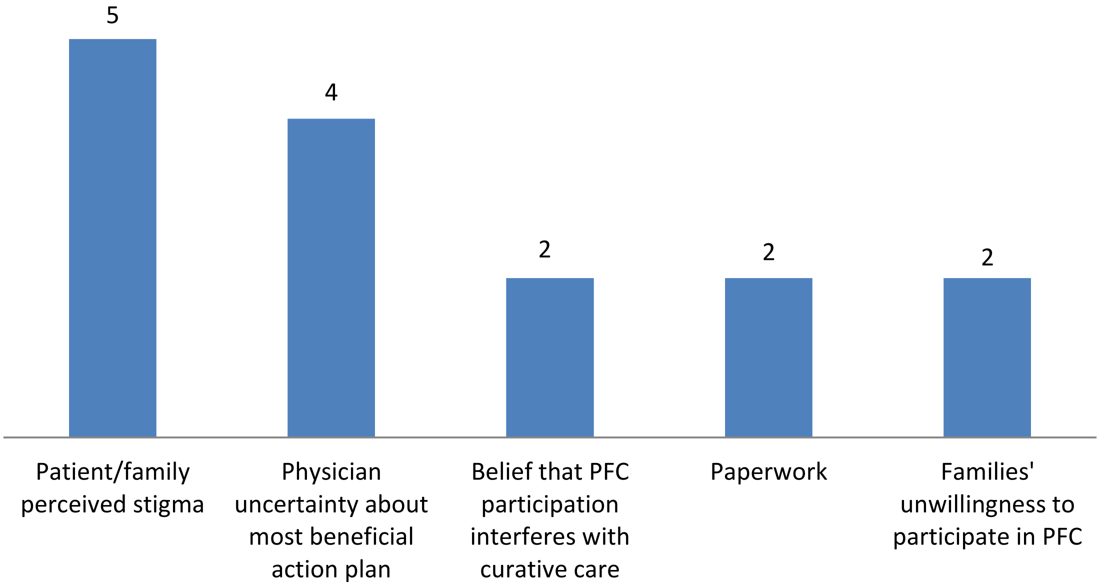


Source: UCLA physician survey.
Note: Includes all physicians who considered each service to be “important” or “very important.” Based on a total of 54 responses.

Physicians varied in the timing of referral to palliative care relative to a child’s diagnosis. Twenty-four respondents (44%) said they were most likely to refer patients at the end of life, while 20 (37%) said they were most likely to refer early or in the middle of the child’s diagnosis. Among those who had previously referred patients to PFC, six of the 11 (55%) said they were most likely to refer early or in the middle of diagnosis.

Referring physicians also varied widely in the number of referrals they made to PFC. Two of the 11 respondents referred a single patient, while four others referred at least 10 and as many as 30 children. One possible cause of variation in the frequency of referrals was physicians’ reaction to the referral process. Nine of the 11 referring physicians said the process was at least slightly effective, but had multiple comments about how to improve it, including shortening the process and expanding the program to absorb more frequent referrals. Respondents were also critical of the eligibility and enrollment process, which four physicians said was too lengthy and rigid. Specific barriers to care noted by referring physicians included the stigma associated with terms like hospice, end-of-life care, and palliative care (5), uncertainty about whether a patient would benefit more under the standard concurrent care program or PFC (4), the belief that participation in PFC would interfere with a patient’s curative care (2), paperwork (2), and the family’s unwillingness to participate in PFC services (2; Exhibit 22). Many of these barriers are consistent with those found in previous research, as summarized in the Barriers to care section of the Review of Pediatric Palliative Care Literature.

Exhibit 22: Number of Referring Physicians with Perceived Barriers to Care, by Type of Barrier, 2013



Source: UCLA physician survey.
Note: Based on a total of 11 responses from physicians who had previously referred patients to PFC. Physicians were allowed to select more than one response.

Despite these barriers, seven of the 11 referring physicians said they were likely or extremely likely to continue to refer patients to PFC, and the eighth respondent was unlikely to continue only because PFC had temporarily stopped in the county where the provider practices. Willingness to continue participating in the program may have been tied to broad satisfaction with care coordination and other services. Eight of the 11 referring physicians said PFC coordinated enrollee care well or very well. Six respondents credited PFC with improving communication between themselves and others providers, particularly hospice/home health care agencies and other non-physician staff. Of the eight referring physicians who responded to questions about the usefulness of individual PFC services, all found the care coordination and family training services at least somewhat useful, followed by the 24/7 nurse line, bereavement services, and pain and symptom management (7), in-home and out-of-home respite care, music therapy, massage therapy, and child life therapy (6), and art therapy (5).

Enthusiasm about future participation in PFC extended to those physicians who had no previous experience with the program. Non-referring physicians received background information on PFC as part of the survey if they claimed no previous familiarity with the program. Of the 41 respondents who said they were unfamiliar with PFC, 32 (78%) said they were likely to refer patients in the future and 25 said they had patients at the time of the survey who they believed met the PFC eligibility criteria.

Barriers to enrollment and provision of services

Eligible children were not always referred to PFC, and children and families who were referred to PFC did not always enroll in the program. While it was impossible to determine the reasons for refusing enrollment, UCLA surveyed CCSNLs and providers to understand their perspectives on barriers to enrollment and barriers to providing care once families were enrolled.

At least five of the nine responding CCSNLs considered lack of family knowledge about program services and unwillingness to allow service providers into their homes as barriers to enrollment. They also identified the stigma of terms like hospice, end-of-life care, and palliative care and the perception that PFC services would interfere with curative care as additional barriers.

CCSNLs also identified logistical issues, including incorrect referral by physicians who were unaware of the full-scope Medi-Cal requirement and lack of referral of eligible children because of physician misunderstandings about the difference between concurrent and palliative care. From both the physician and the CCSNL perspective, the amount of paperwork required to refer and screen potentially-eligible children was prohibitive. PFC administrators attempted to mainstream the process, but CCSNLs continued to view paperwork as a barrier in enrolling children and providing timely care. The mean time elapsed between referral and enrollment was 76 days, or about 2.5 months.

Once enrolled, CCSNLs also noted a number of barriers to coordinating and providing services. Seven of the nine CCSNLs believed that families were not ready to acknowledge that their child's condition was life-threatening and considered this a barrier to care. At least five of the nine respondents identified conflict among family members about treatment goals, staff shortages, insufficient family knowledge about program services, language barriers, and stigma as further barriers to care. At least three of the nine respondents also cited as barriers conflict between staff and family about treatment goals, conflict among staff about treatment goals, communication difficulties between staff and families, children's reservations or concerns, and cultural differences.

Providers at hospice/home health agencies echoed many of the concerns of CCSNLs, and three of four responding providers also considered children's own reservations or concerns to be a barrier to care. The most pervasive barrier to care for hospices and home health agencies, however, was the low reimbursement rate for many services. Providers indicated that reimbursement rates for in-home respite care were too low and that there was an insufficient supply of available service providers to offer out-of-home respite care. All four of the responding agencies said they received lower reimbursement for PFC enrollees than through other funding services for four of the eleven main program services – art, music, and massage therapy, and the 24/7 nurse phone line. Three of the providers said that care coordination and pain and symptom management services were also reimbursed at lower rates than other funding sources. Reimbursement rates were unanimously noted as a potential barrier for program sustainability.

Family Satisfaction

Of the 151 children who enrolled in PFC, 107 had caregivers who completed at least one survey, an overall participation rate of 71%. Given the goal of measuring the effect of PFC services over time, only caregivers who had at least two responses were included in the satisfaction and quality-of-life analyses. For caregivers to have completed at least two surveys, children had to have been enrolled for at least six months (enough time to complete a baseline and initial follow-up survey). There were 102 children who met this criterion. Of their 102 caregivers, 50 responded to at least two surveys, for a 49% response rate at first follow-up. Of the 50 caregivers included in the analysis at first follow-up, 36 had children who were enrolled for at least one year, the minimum time necessary to complete a second follow-up survey. Eighteen of the 36 completed a second follow-up survey, for a 50% response rate at one year. A small number of caregivers completed additional follow-up surveys, but their numbers were too small to report. Demographic and descriptive characteristics of the 50 caregivers included in the analysis and their children are shown in Exhibit 23.

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Exhibit 23: Demographic and Descriptive Characteristics of PFC Enrollees and Their Primary Caregivers Included in Family Satisfaction and Quality-of-Life Analysis, 2010-2012

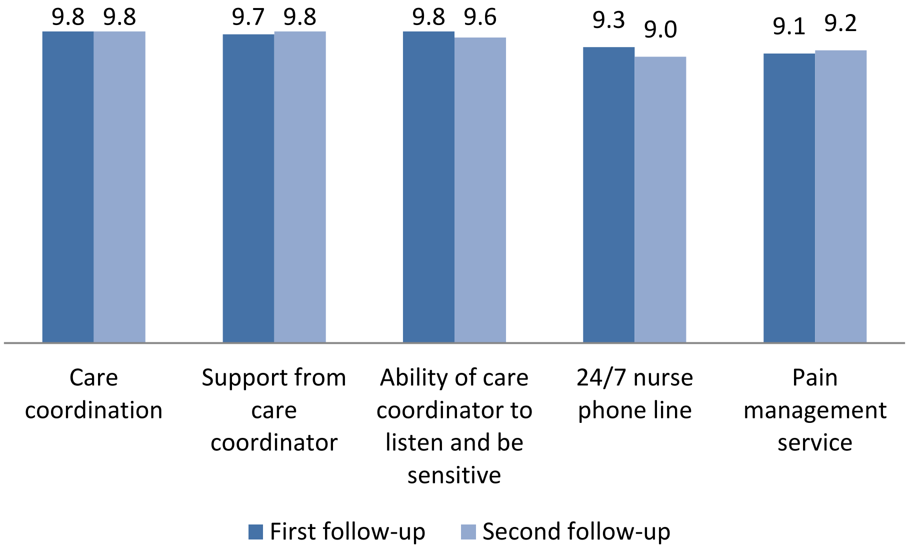
	n	%
Total	50	100
Characteristics of Children		
Age		
2-5	10	20
6-10	24	48
13-20	16	32
Gender		
Male	34	68
Female	16	32
Race/Ethnicity		
Latino	34	68
White	5	10
Other	10	20
Missing	1	2
Primary diagnosis		
Neurologic	19	38
Cancer	9	18
Pulmonary	8	16
Neuromuscular	5	10
Other*	7	14
Missing	2	4
Characteristics of Caregivers		
Marital status		
Married/Living with partner	28	56
Never married/Separated/Divorced/Widowed	18	36
Missing	4	8
Number of children under 18 in household		
1	11	22
2	12	24
3	13	26
4+	10	20
Missing	4	8

Source: UCLA family satisfaction and quality-of-life survey and DHCS PFC database.
*Other includes metabolic, gastrointestinal, transplant, and cardiac.

Satisfaction among caregivers was consistently high. The waiver services overall garnered average ratings of 9.6 on a 10-point scale in the first and second follow-up surveys.

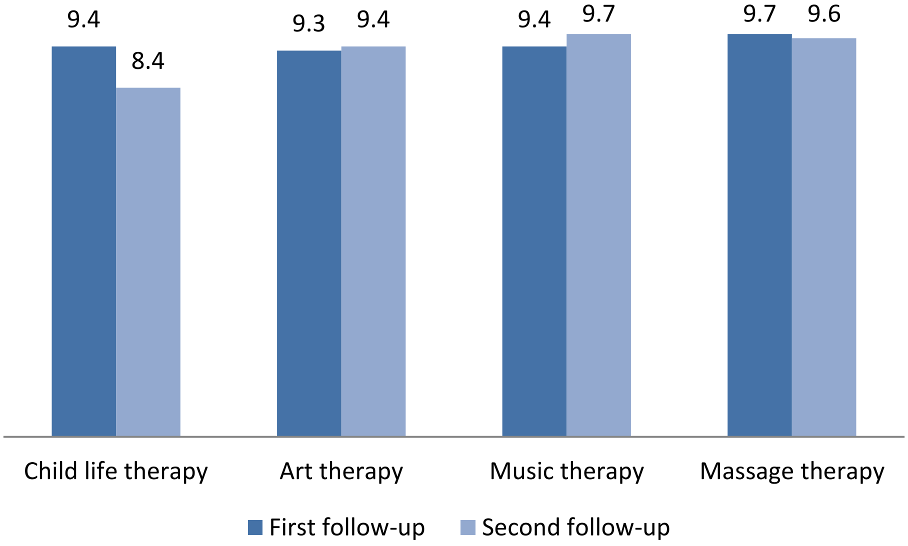
Individual services also received high scores from enrollees' caregivers (Exhibit 24). Care coordination, a central component of the PFC model, received overall average ratings of 9.8 at first and second follow-up. More specifically, caregivers' sense of support from their care coordinator and perceptions of the care coordinators' ability to listen and be sensitive to the family's needs scored at least 9.6 at all points. Clinical services, such as a 24/7 nurse line for health consultation and the program's pain management service, received slightly lower scores, but were still more than 9 at all points. Therapeutic services, including child life, art, music, and massage, also received high scores throughout the first year of follow-up (Exhibit 25).

Exhibit 24: Average Caregiver Ratings of Care Coordination and Clinical Services, at First and Second Follow-up Surveys, 2010-2012



Source: UCLA family satisfaction and quality-of-life survey.
Note: Forty-eight of the 50 caregivers who completed the first follow-up survey answered the care coordination questions, 13 answered the nurse phone line question, and 19 answered the pain management question. Seventeen of the 18 caregivers who completed a second follow-up survey answered the care coordination questions and five answered the nurse phone line and pain management questions.

Exhibit 25: Average Caregiver Ratings of Therapeutic Services, at First and Second Follow-up Surveys, 2010-2012



Source: UCLA family satisfaction and quality-of-life survey.
Note: Of the 50 caregivers who completed the first follow-up survey, 15 answered the child life therapy question, 21 answered the art therapy question, 36 answered the music therapy question, and 39 answered the massage therapy question. Of the 18 caregivers who completed a second follow-up survey, nine answered the child life therapy question, seven answered the art therapy question, 13 answered the music therapy question, and 16 answered the massage therapy question.

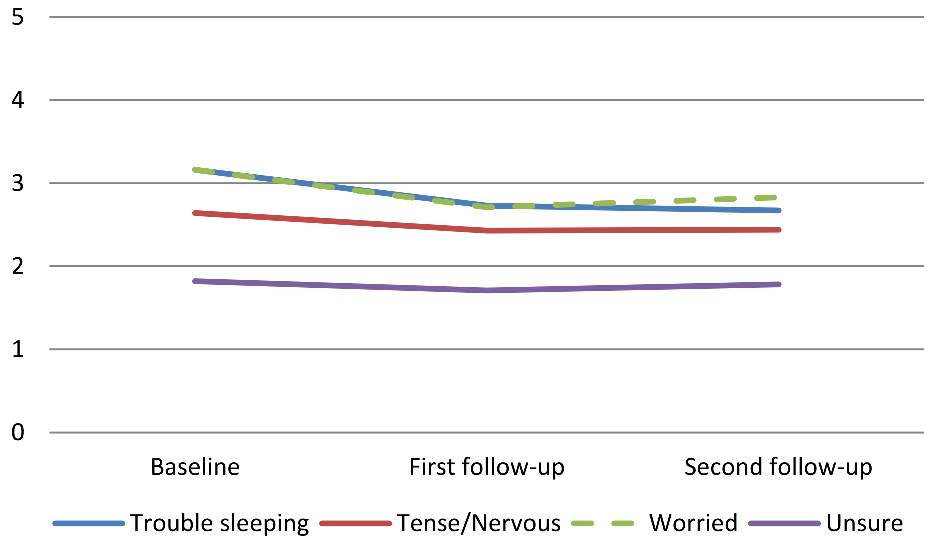
Child and Family Experience and Quality of Life

Enrolled children were not asked any questions directly, but caregivers were asked if PFC services helped them reduce or control their child's pain and other symptoms. On a 10-point scale, the services received an average rating of 8.6 for pain control/reduction and 9.3 for management of other symptoms. While caregivers' perception of a child's pain is a subjective measure, previous research suggests that it can be accurate in populations of chronically ill children.(64, 65)

Given evidence that standard quality-of-life instruments, such as PedsQL, lack validity for measuring health-related quality of life in children with life-limiting conditions,(53) a panel of pediatric palliative care physician experts was assembled to support the development of an original survey tool to measure enrollee and family experience and quality of life. In consultation with the panel, UCLA opted to ask explicit questions about aspects of stress and worry rather than administer longer questionnaires that may have been a burden on families.

Caregiver experience and quality of life was operationalized using four potential aspects of the experience of caring for a child with a life-limiting condition – trouble sleeping, feeling tense or nervous, being worried about their ability to manage their child's health, and feeling unsure about their ability to manage their child's health. Specific questions were included in the baseline and follow-up surveys to measure change over time in the frequency of feeling each aspect on a five-point scale ranging from never to always. Exhibit 26 shows the average frequencies of symptoms in the overall caregiver population. Trouble sleeping (3.16 to 2.73) and feeling worried about the ability to manage their child's health (3.16 to 2.71) both show marked declines between the baseline and the first follow-up surveys that are largely sustained in the second follow-up survey. The caregiver population mean scores for feeling tense or nervous and feeling unsure about their ability to manage their child's health varied slightly, but remained essentially flat over the three surveys.

Exhibit 26: Average Frequency of Caregiver Experience and Quality-of-Life Aspects, Baseline through Second Follow-up, 2010-2012



Source: UCLA family satisfaction and quality-of-life survey.

Caregivers were further asked if they thought specific PFC services contributed to reductions in stress and worry, and increases in confidence, related to their child's care. In 97% of the cases (counting each survey separately), care coordination, family training, the 24/7 nurse line, and pain and symptom management services were considered helpful in all of the quality-of-life areas. In 95% of the cases, child life, art, music, and massage therapies were also helpful in reducing stress and worry.

One hundred percent of the surveyed caregivers said they would recommend PFC to a family member or friend who had a child with a life-limiting condition.

Conclusions and Recommendations

Analysis of the three-year PFC pilot suggests that California's Pediatric Palliative Care Waiver demonstrated a cost-effective way to provide home-based palliative care to children with life-threatening conditions that was satisfying to most enrollees' primary caregivers and their health care providers. PFC enrollment led to savings of $3,133 PEPM compared with the two years pre-enrollment for the 132 children who spent at least 60 days in the program. When including the administrative cost of running the pilot and the $300 PEPM increase in service reimbursement for participating agencies, partially a result of DHCS' acknowledgment of early signs of cost savings at the end of the pilot period, savings were still more than $2,000 PEPM.

The lack of a comparison group makes it difficult to eliminate other possible explanations for these cost savings, including historical trends in health care costs, but an examination of the source of the cost savings speaks directly to the goals of PFC. Most of the savings were the result of the dramatic decrease in inpatient costs by $4,897 PEPM, accompanied by a relatively smaller increase in outpatient costs of $1,242. This major shift, from costly inpatient care to more coordinated and less expensive outpatient care, is the result of PFC's home-based care model. Overall savings in terms of costs avoided had the pace of costs prior to enrollment continued into the pilot period totaled nearly $7 million, an indication of the potential continued cost savings if PFC were to expand to more counties or even statewide.

Beyond the financial outcomes, PFC achieved important changes in health care utilization, including shorter inpatient stays and less time spent in the hospital, on average. The pilot was also viewed favorably by enrollees' primary caregivers, who reported that PFC helped them reduce or control their children's pain and other symptoms, as well as improve quality-of-life indicators for themselves, such as trouble sleeping and feeling worried about the ability manage their children's health. The objective evaluation of the program demonstrates desirable results in achieving the Institute for Healthcare Improvement's Triple Aim of improved care, better health, and lower costs.(1)

Providers participating in PFC also expressed widespread satisfaction with the pilot, although their concerns highlight important areas of improvement to maximize the reach and effectiveness of the pediatric palliative care model moving forward. Concerns about reimbursement rates among hospice and home health agencies may have been somewhat addressed by the $300 PEPM increase in service reimbursement for participating agencies, but there may still be trepidation in signing on to provide services. There was a widespread lack of knowledge about PFC among prospective referring physicians in the CCS pool of providers that may have limited the program's enrollment numbers in the pilot period. CCSNLs and referring physicians considered the PFC paperwork process to be burdensome, and more than two months passed on average between referral to PFC and enrollment in the program. Providers also noted many barriers to enrollment at the family level, including stigma associated with palliative care, the inability of family members to acknowledge the life-threatening nature of their child's illness, and conflicts among family members about treatment goals.

Based on these conclusions and remaining concerns, UCLA offers the following recommendations:

- Assess continuously the financial viability of providing services to PFC enrollees for hospice and home health agencies in order to ensure a sufficient supply of providers. This will be particularly important if enrollment in PFC increases. Additional, thorough cost analyses of service provision to children by participating agencies are needed to potentially adjust reimbursement. This would allow vendors to sustain operations and limit undue fiscal strain. Beyond service costs, participating agencies incur additional costs such as provider training to the unique needs of children enrolled in PFC, billing, and other administrative expenses. Additional reimbursement to support administrative costs may be crucial to recruit and retain provider agencies. Given the evidence of cost savings of this program, enhanced reimbursement would likely still be cost effective.
- Increase the visibility of PFC among prospective referring providers to increase enrollment. Given recognized barriers to referral, including lack of knowledge among physicians about income eligibility requirements and the difference between concurrent and palliative care, provider education efforts should be increased. Education of providers on the potential benefits of referring children and families early in the care process is especially important. Starting care early for eligible children improves the experience of children and their families, and could contribute to lowering the cost of care.
- Grow operational capacity and strategy to match program expansion. This can be achieved by building on existing partnerships and developing new ones among the state and county CCS programs, specialty care centers, other medical and community services, and hospice and home health agencies.
- Share best practices among program partners to seek ways to simplify referral protocols across medical settings and enrollment procedures at the county level. This would be especially helpful for adult hospice and home health agencies that are interested in expanding care for children but face difficulties in managing the resulting costs. DHCS should continue its ongoing conference calls with all providers and use this venue for best practice sharing.
- Assess enrollment processes and procedures to minimize the time between referral and enrollment. The mean time elapsed between referral and enrollment was 76 days, or

about 2.5 months. DHCS should consider the reasons for this delay and address them appropriately.

- Support providers in educating families to reduce perceived barriers to enrollment and receipt of services. DHCS should continue efforts to address concerns expressed by families, including language barriers and concerns about accepting the nature of their child's life-threatening condition. It is also important to develop and implement processes that facilitate open and productive communication between family members and staff regarding treatment goals and support in conflict resolution.

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Appendices

Appendix A: Survey Methodology

Primary Caregiver Survey

We created an original survey instrument (text available in Appendix C) to evaluate families' satisfaction and quality-of-life experience with PFC. Questions gauged caregivers' perceptions of how program services affected their child's health and well-being, and the caregivers' ability to manage their child's life-limiting condition. Caregivers were interviewed upon their child's enrollment in the program and at subsequent six-month intervals as long as their child remained enrolled in PFC. CCSNLs served as survey administrators and generally contacted families by phone to conduct the survey or schedule a time to meet in person to complete the survey. If CCSNLs were unable to communicate with a member of the family after three attempts on different days and times, the family was considered to have missed that survey but was still eligible to complete a survey six months later if their child remained enrolled in the program.

CCSNL Survey

We created an original survey instrument (text available in Appendix C) to evaluate knowledge and perceptions of the PFC program among CCS Nurse Liaisons (CCSNL). Using our state contacts, we identified and gathered contact information for CCSNLs, all of whom worked closely with specialty care centers in the 11 participating California counties. We contacted the CCSNLs between January and February 2012 to confirm their email information. We distributed the survey along with an email invitation through SurveyMonkey and allowed CCSNLs up to eight weeks to complete and return the survey. Of the 17 who ostensibly received the invitation, nine completed the survey, for a response rate of 53%.

Hospice and Home Health Agency Survey

We created an original survey instrument (text available in Appendix C) to evaluate knowledge and perceptions of the PFC program among management personnel at CCS provider agencies (hospices and home health agencies). At the time of the survey administration (November-December 2011), there were five agencies participating in PFC. We contacted the organizations by telephone during daytime hours to obtain email addresses for the most appropriate potential participants, in order to send the e-mail based survey. We distributed the survey along with an email invitation through SurveyMonkey and allowed provider agencies six weeks to complete and return the survey. Four of the five agencies responded to the survey, for a response rate of 80%.

Physician Survey

We created an original survey instrument (text available in Appendix C) to evaluate knowledge and perceptions of the PFC program among CCS paneled providers. Using a publicly-available list of CCS physicians (http://www.dhcs.ca.gov/services/ccs/scc/Pages/SCCName.aspx), we identified 2,079 potential survey participants. All physicians on the list were affiliated with specialty care centers in participating counties. Between March and August 2012, we contacted physicians' offices and medical centers by telephone during daytime hours to obtain email addresses for as many potential participants as possible in order to send the email-based survey. Once we had eliminated duplicate names, retirees, and physicians whose email addresses were unavailable or who had previously opted out of our online SurveyMonkey delivery method, we were left with a sample of 694 physicians. We distributed the survey along with an email invitation through SurveyMonkey in January 2013 and allowed physicians until March 2013 to complete and return the survey. Of the 694 physicians who ostensibly received the invitation, 54 completed the survey, a response rate of 7.8%. The specialty and practice characteristics of the responding physicians are described in Appendix A, Exhibit 1.

Appendix A, Exhibit 1: Specialty and Practice Characteristics of CCS Physician Respondents, 2013

Specialty area	**n**	**%**
Pediatrics	30	61%
Cardiology	13	27%
Neurology	4	8%
Pulmonology	4	8%
Hematology/Oncology	3	6%
Medical genetics	3	6%
Nephrology	3	6%
Gastroenterology	2	4%
Endocrinology	1	2%
Rheumatology	1	2%
Craniofacial plastic surgery	1	2%
Hospice and palliative care	1	2%
Otolaryngology	1	2%
Pathology	1	2%
Radiology	1	2%
Physiatry	1	2%
Adolescent medicine	1	2%
Surgery	1	2%
Psychiatry	1	2%
Sleep disorders	1	2%
Total	**74**	

Practice setting	n	%
Academic medical center	45	90%
Hospital and out-patient	14	28%
Private practice	4	8%
Total	**63**	

Source: UCLA physician survey.
Note: Respondents were asked to select all specialty areas and practice settings that apply. Percentages are based on the total number of respondents for the given question (not the total number of respondents for the overall survey). Forty-nine physicians responded to the question about specialty area, and 50 responded to the question about practice setting.

Appendix B: Data Preparation Methodology

Enrollment

Enrollment status was determined by the PFC database file sent by DHCS. We implemented a minimum 60-day continuous enrollment rule and dropped all children who had been enrolled for less than 60 days from the analyses. We further dropped children whose enrollment data were inconsistent, including those who had two enrollment dates but no disenrollment date, those whose enrollment and disenrollment dates were conflicting (disenrollment date prior to enrollment date), and those whose enrollment dates were missing.

In order to more accurately calculate per-enrollee-per-month (PEPM) costs, we assigned enrollment status on a daily basis to be able to calculate per-enrollee-per-day (PEPD) costs for services that ran across two months. We manually changed the status in the partial months after a child was disenrolled because enrollment status was only updated at the beginning of every month. For example, a child disenrolled on May 10 initially appeared to be enrolled until June, so we converted the child's status to disenrolled for May 11-31 to calculate PEPD. We then linked the cleaned PFC database file to the CCS eligibility and claims data files, also received from DHCS.

Claims

The claims required significant cleaning, including moving incorrectly placed decimal points (discovered upon comparison with adjustments that nearly matched the original claims) and inconsistent dates between original claims and adjustments (in which case we replaced the adjustment dates with the original claim dates). Adjustments that did not match any original claim were dropped. The total cost of a claim after adjustment was distributed evenly across the total number of days for the given service based on the original claim's start and end dates (for example, a service costing $100 over five days was assigned a per-day cost of $20). Finally, we created an indicator variable to show if the claim date occurred prior or subsequent to enrollment.

Calculating PEPM from PMPD

To calculate PEPM for individual months, we divided the aggregate cost of all services provided to all children enrolled in PFC in the given month (using the daily cost calculations described above) by the number of children enrolled at any point during that month. This monthly PEPM is shown in Exhibit XX. To calculate the PEPM cost over the course of the entire program, we summed the costs for each month and divided the total by the total number of enrollee months.

Appendix C: Data Collection Instruments

Primary Caregiver Survey – Baseline

Date Today MM/DD/YYYY:

County Name:

Child CIN:

Nurse Last Name:

Child CCS:

Nurse First Name:

Parent First Name:

1. Basic demographic information
   1_a. What is your relationship to the child?

[INTERVIEWER NOTE: CHECK THE ANSWER THAT APPLIES. IF OTHER, PLEASE SPECIFY]

MOTHER	1
FATHER	2
FOSTER MOTHER	3
FOSTER FATHER	4
OTHER. SPECIFY: ___________________	5
REFUSE	98
DO NOT KNOW	99

1_b. Including the child who receives services, how many children under the age of 18 live in your household?

____________ [NUMBER]

REFUSED 98

DON'T KNOW 99

1_c. Including yourself, how many people live in your household?

____________ [NUMBER]

REFUSED 98

DON'T KNOW 99

1_d. Are you married, living with a partner, widowed, divorced, separated, or never married?

MARRIED	1
LIVING WITH A PARTNER	2
WIDOWED	3
DIVORCED	4
SEPARATED	5
NEVER MARRIED	6
REFUSE	98
DO NOT KNOW	99

1_e. Is there another person who is closely involved in the care of your child?

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

[INTERVIEWER NOTE: IF R INDICATED YES PLEASE ASK QUESTION 1_f. FOR ALL OTHER ANSWERS SKIP TO QUESTION 1_g.]

1_f. Who is that caregiver?

THE CHILD'S OTHER PARENT	1
THE CHILD'S OTHER FOSTER PARENT	2
THE CHILD'S STEP PARENT	3
THE CHILD'S GRANDMOTHER OR GRANDFATHER	4
THE CHILD'S UNCLE OR AUNT	5
THE CHILD'S OLDER BORTHER OR SISTER	6
OTHER. SPECIFY: ___________________	7
REFUSE	98
DO NOT KNOW	99

[INTERVIEWER NOTE: FOR THE FOLLOWING SET OF QUESTIONS: IF R INDICATED ANOTHER PERSON INVOLVED IN THE CHILD'S CARE, PLEASE ASK ABOUT THE RESPONDENT AND THE OTHER CAREGIVER. IF R IS DOES NOT REPORT ANOTHER CAREGIVER, ASK ABOUT RESPONDENT ONLY]

1_g. Are you male or female?

[INTERVIEWER NOTE: CHECK THE ANSWER THAT APPLIES. IF OTHER, PLEASE SPECIFY]

MALE	1
FEMALE	2
OTHER. SPECIFY:_________________	5
REFUSE	98
DO NOT KNOW	99

1_h. How old are you?

_____________ [AGE NUMBER 0-99]

REFUSED 98

DON'T KNOW 99

1_i. Are you Latino, Chicano or Hispanic?

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

1_j. *[INTERVIEWER NOTE: ASK ALL RESPONDENTS. IF RESPONDENT SAID YES TO PREVIOUS QUESTION, USE THE BEGINNING IN THE { } BELOW]*

{You said you are Latino, Chicano or Hispanic. Also} please tell me which one of the following you would use to describe yourself. Would you primarily describe yourself as White, Black or African American, American Indian or Alaskan Native, other Pacific Islander, Native Hawaiian, or other/multiple?

[INTERVIEWER NOTE: IF R GIVES AN "OTHER" RESPONSE, SPECIFY. IF R GIVES MULTIPLE RESPONSES, PLEASE SELECT "OTHER" AND SPECIFY]

WHITE	1
BLACK OR AFRICAN AMERICAN	2
ASIAN	3
AMERICAN INDIAN OR ALASKA NATIVE	4
OTHER PACIFIC ISLANDER	5
NATIVE HAWAIIAN	6
OTHER OR MULTIPLE. SPECIFY: ____________________	7
REFUSED	98
DON'T KNOW	99

1_k. What is your highest level of education?

NO FORMAL EDUCATION	1
GRADES 1 THROUGH 8	2

GRADES 9 THROUGH 11	3
HIGH SCHOOL GRADUATE	4
SOME COLLEGE	5
COLLEGE GRADUATE	6
POST COLLEGE (17+ YEARS)	7
OTHER. SPECIFY: ___________________	97
REFUSED	98
DON'T KNOW	99

1_l. Do you work?

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

[INTERVIEWER NOTE: IF R SAYS YES PLEASE ASK THE FOLLOWING QUESTION AND RECORD THE NUMBER OF HOURS. IF NO, SKIP TO QUESTION 1_hS TO REPORT ABOUT OTHER CAREGIVER OR IF NO OTHER CAREGIVER SKIP TO QUESTION 2]

1_m. How many hours a week do you work?

____________ NUMBER OF HOURS OF WORK A WEEK]

REFUSED 98

DON'T KNOW 99

[INTERVIEWER NOTE: FOR THE FOLLOWING QUESTIONS: IF R INDICATED ANOTHER PERSON INVOLVED IN THE CHILD CARE, PLEASE ASK ABOUT THAT CAREGIVER. IF RESPONDENT DOES NOT REPORT ANOTHER PRIMARY CAREGIVER, SKIP TO QUESTION 2]

{Now, please answer about the other person involved in your child care}

1_g_S. Is the other caregiver male or female?

[INTERVIEWER NOTE: CHECK THE ANSWER THAT APPLIES. IF OTHER, PLEASE SPECIFY]

MALE	1
FEMALE	2
OTHER. SPECIFY:________________	5
REFUSE	98
DO NOT KNOW	99

1_h_S. How old is the other caregiver?

____________ [SPOUSE'S/PARTNER'S AGE]

REFUSED 98

DON'T KNOW 99

1_i _S. Is he/she Latino, Chicano or Hispanic?

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

1_j_S. *[INTERVIEWER NOTE: ASK ALL RESPONDENTS. IF RESPONDENT SAID YES TO PREVIOUS QUESTION, USE THE BEGINNING IN THE { } BELOW]*

{You said the other caregiver is Latino, Chicano or Hispanic. Also} please tell me which one of the following h/she would use to describe him/herself. Would he/she primarily describe him/herself as Native Hawaiian, Other Pacific Islander, American Indian, Alaska Native, Asian, Black, African American, or White?
[INTERVIEWER NOTE: IF R GIVES AN "OTHER" RESPONSE, SPECIFY. IF R GIVES MULTIPLE RESPONSES, PLEASE SELECT "OTHER" AND SPECIFY]

WHITE	1
BLACK OR AFRICAN AMERICAN	2

ASIAN	3
AMERICAN INDIAN OR ALASKA NATIVE	4
OTHER PACIFIC ISLANDER	5
NATIVE HAWAIIAN	6
OTHER OR MULTIPLE . SPECIFY: ____________________	97
REFUSED	98
DON'T KNOW	99

1_k_S. What is the other caregiver's highest level of education?

NO FORMAL EDUCATION	1
GRADES 1 -11	2
HIGH SCHOOL	3
SOME COLLEGE	4
COLLEGE GRADUATE	5
POST COLLEGE (17+ YEARS)	6
OTHER. (SPECIFY: ____________________	97
REFUSED	98
DON'T KNOW	99

1_l_S. Does the other caregiver work?

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98

DON'T KNOW	99

[INTERVIEWER NOTE: IF R SAYS YES PLEASE ASK THE FOLLOWING QUESTION AND RECORD THE NUMBER OF HOURS. IF NO, SKIP TO QUESTION 2]

1_m_S. How many hours a week does he/she work?

____________ NUMBER OF HOURS OF WORK A WEEK 0-99]

REFUSED 98

DON'T KNOW 99

2. Sometimes parents may feel stress related to the care of their child.

2. a. They may feel that they have a hard time falling asleep or staying asleep. How often would you say you feel this way?

Never	Occasionally	Sometimes	Most of the time	All the time	Refuse	Don’t know
1	2	3	4	5	98	99

2. b. They may feel nervous or tense. How often would you say you feel this way?

Never	Occasionally	Sometimes	Most of the time	All the time	Refuse	Don’t know
1	2	3	4	5	98	99

3. For each of the following services, please indicate if you agree with the following statement: “I think that this service will be **helpful** in reducing stress related to the care of my child”

[INTERVIEWER NOTE: PLEASE REPEAT THE STATEMENT AS NEEDED. PROBE: “do you agree with the statement that (fill in the blank) will be **helpful** in reducing stress related to the care of your child?”*]*

		Disagree	Agree	Not Applicable	Refuse	Don’t know
3.a.	Care coordination	1	2	97	98	99

3.b.	Family training	1	2	97	98	99
3.c.	In-home respite care	1	2	97	98	99
3.d.	Out-of home respite care	1	2	97	98	99
3.e.	Child life therapy	1	2	97	98	99
3.f.	Art therapy for the child	1	2	97	98	99
3.g.	Music therapy for the child	1	2	97	98	99
3.h.	Massage therapy for the child	1	2	97	98	99
3.i.	24/7 nurse line	1	2	97	98	99
3.j.	Availability of bereavement services	1	2	97	98	99
3.k.	Pain and symptom management	1	2	97	98	99

4. Sometimes parents may feel worried about managing their child's health. They may have a hard time keeping their mind on other things they are supposed to be doing such as work, household chores, or paying bills. How often would you say you feel worried related to managing you child's health?

Never	Occasionally	Sometimes	Most of the time	All the time	Refuse	Don't know
1	2	3	4	5	98	99

5. For each of the following services, please indicate if you agree with the following statement: "I think that this service will be **helpful** in reducing worry related to the care of my child"

[INTERVIEWER NOTE: PLEASE REPEAT THE STATEMENT AS NEEDED. PROBE: "do you agree with the statement that (fill in the blank) will be **helpful** in reducing worry related to the care of your child?"*]*

		Disagree	Agree	Not Applicable	Refuse	Don't know
5.a.	Care coordination	1	2	97	98	99

5.b.	Family training	1	2	97	98	99
5.c.	In-home respite care	1	2	97	98	99
5.d.	Out-of home respite care	1	2	97	98	99
5.e.	Child life therapy	1	2	97	98	99
5.f.	Art therapy for the child	1	2	97	98	99
5.g.	Music therapy for the child	1	2	97	98	99
5.h.	Massage therapy for the child	1	2	97	98	99
5.i.	24/7 nurse line	1	2	97	98	99
5.j.	Availability of bereavement services	1	2	97	98	99
5.k.	Pain and symptom management	1	2	97	98	99

6. Sometimes parents may feel that they are **not** confident with handling the care of their child's condition. They may feel like they do not have the ability to manage the care for the child, get the right help, or even know who to ask for help. How often would you say you feel **unsure** about your ability to manage the care for your child?

Never	Occasionally	Sometimes	Most of the time	All the time	Refuse	Don't know
1	2	3	4	5	98	99

7. For each of the following services, please indicate if you agree with the following statement: "I think that this service will be **helpful** in making me feel more confident in my ability to manage the care for my child"

[INTERVIEWER NOTE: PLEASE REPEAT THE STATEMENT AS NEEDED. PROBE: "do you agree with the statement that (fill in the blank) will be **helpful** in making you feel more confident in your ability to manage the care for your child?"*]*

		Disagree	Agree	Not Applicable	Refuse	Don't know

7.a.	Care coordination	1	2	97	98	99
7.b.	Family training	1	2	97	98	99
7.c.	24/7 nurse line	1	2	97	98	99
7.d.	Pain and symptom management	1	2	97	98	99

8.

a. Have you been using any other types of support including religious, spiritual, or cultural resources, as well other social-emotional support sources such as counseling, to help you deal with your child's condition? For example, prayer, meeting with clergy, psychological counseling.

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

[INTERVIEWER NOTE: IF YES, PLEASE CONTINUE TO b]

b. If yes, please list the types of support you use (e.g.: support group, meditation, prayer, novinas, etc.): ____
____
____

9. Do you feel knowledgeable about community resources available to you and your child that can support you and your child during this time?

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

10. Using any number from 0 to 10 where 0 is the worst possible and 10 is the best possible, what number would you use to rate the support you received from the following *[INTERVIEWER NOTE:*

PLEASE MAKE CLEAR THAT THESE QUESTIONS RELATE TO SERVICES THAT ARE ***NOT*** *PART OF THE HOME HEALTH /HOSPICE AGENCY.]*

Type of Support	Rate support 0-10	Not applicable/did not use support	Refuse	Do Not Know
10a. Spouse/partner		97	98	99
10b. Grandparents of child		97	98	99
10c. Other Family members		97	98	99
10d. Family friends		97	98	99
10e. Primary care doctor		97	98	99
10f. Other doctor		97	98	99
10g. Nurse		97	98	99
10h. Social worker		97	98	99
10i. Teachers, counselors, or others at your child's school		97	98	99
10j. Religious clergy or other religious support		97	98	99
10k. Support groups run by agencies such as the American Cancer Society		97	98	99
10l. Other. Specify:_________________		97	98	99

11. Notes:

[INTERVIEWER NOTE; PLEASE WRITE HERE NOTES SUCH AS ANY COMMENTS MENTIONED BY R DURING THE INTERVIEW]

____

Primary Caregiver Survey – Follow-up

Date Today MM/DD/YYYY:

County Name:

Child CIN:

Nurse Last Name:

Child CCS:

Nurse First Name:

Parent First Name:

[INTERVIEWER NOTE: PLEASE INSTRUCT THE RESPONDENT TO THINK ABOUT THE PAST MONTH WHEN ANSWERING THE FIRST FOLLOW-UP AND THREE MONTHS WHEN ANSWERING THE NEXT FOLLOW-UPS]

1.

a. [INTERVIEWER NOTE: PLEASE INDICATE IF THE RESPONDENT IS THE SAME RESPONDENT WHO ANSWERED THE BASELINE SURVEY BY INDICATING YES OR NO HERE. IF RESPONDENT IS THE SAME, PLEASE MARK "YES" AND SKIP TO QUESTION 2. IF RESPONDENT IS DIFFERENT, PLEASE ASK QUESTION 1.b.]

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

b. If no, what is your relationship to the child?

[INTERVIEWER NOTE: CHECK THE ANSWER THAT APPLIES. IF OTHER, PLEASE SPECIFY]

MOTHER	1
FATHER	2
FOSTER MOTHER	3
FOSTER FATHER	4
OTHER. SPECIFY: ___________________	5
REFUSE	98
DO NOT KNOW	99

2. When you were first told about the Partners for Children Program, were you given a list or told what services are available to you?

YES	1

NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

3. Using any number from 0 to 10 where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate all of the services you or your child received through the Partners for Children Program.

*[INTERVIEWER NOTE: PROMPT: "*When we say services, we mean services that your child or other family members received through the Partners for Children program/HOME Health agency/Hospice Agency including care coordination, family training, in-home and out-of-home respite care, child life therapy, as well as art, music or massage therapy**.** "]

[INTERVIEWER NOTE: IF A SERVICE IS NOT OFFERED IN YOUR COUNTY PLEASE DO NOT ASK ABUT THE SERVICES AND MARK "NOT APPLICABLE/NOT OFFERED"]

c. The waiver services overall

______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES...96

NOT APPLICABLE/NOT OFFERED...97

REFUSED 98

DON'T KNOW 99

d. How care was coordinated for your child by the care coordinator

[INTERVIEWER NOTE: IF R DOES NOT UNDERSTAND, PROBE: "care coordination refers to the way the care coordinator refers you to the service providers and makes sure that your child and your family get the services you need"]

______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES...96

NOT APPLICABLE/NOT OFFERED...97

REFUSED 98

DON'T KNOW 99

e. The support you received from your care coordinator

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES..96

NOT APPLICABLE/NOT OFFERED..97

REFUSED 98

DON'T KNOW 99

f. The support you received from other staff in the agency
[INTERVIEWER NOTE: PLEASE SPECIFY THE NAME OF AGENCY]

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES..96

NOT APPLICABLE/NOT OFFERED..97

REFUSED 98

DON'T KNOW 99

g. The care coordinator's ability to listen to your child and your family and be sensitive to the needs of you child and your family

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES..96

NOT APPLICABLE/NOT OFFERED..97

REFUSED 98

DON'T KNOW 99

h. Family training

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES..96

NOT APPLICABLE/NOT OFFERED..97

REFUSED 98

DON'T KNOW 99

i. In-home respite care

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES..96

NOT APPLICABLE/NOT OFFERED..97

REFUSED 98

DON'T KNOW 99

j. Out-of-home respite care

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES..96

NOT APPLICABLE/NOT OFFERED..97

REFUSED 98

DON'T KNOW 99

k. Child life therapy

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES..96

NOT APPLICABLE/NOT OFFERED..97

REFUSED 98

DON'T KNOW 99

l. Art therapy for child

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES..96

NOT APPLICABLE/NOT OFFERED..97

REFUSED 98

DON'T KNOW 99

m. Music therapy for child

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES...96

NOT APPLICABLE/NOT OFFERED...97

REFUSED 98

DON'T KNOW 99

n. Massage therapy for child

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES...96

NOT APPLICABLE/NOT OFFERED...97

REFUSED 98

DON'T KNOW 99

o. 24/7 phone line with a registered nurse through the agency

[INTERVIEWER NOTE: PLEASE SPECIFY THE NAME OF AGENCY]

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES...96

NOT APPLICABLE/NOT OFFERED...97

REFUSED 98

DON'T KNOW 99

m.1. The pain and management service

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES...96

NOT APPLICABLE/NOT OFFERED...97

REFUSED 98

DON'T KNOW 99

p. The emotional support your child received while using the services

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES...96

NOT APPLICABLE/NOT OFFERED...97

REFUSED 98

DON'T KNOW 99

q. The emotional support you or other family while using the services

_______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES...96

NOT APPLICABLE/NOT OFFERED...97

REFUSED 98

DON'T KNOW 99

4. Using any number from 0 to 10 where 0 is the lowest amount possible and 10 is the highest amount possible, what number would you use to answer these two questions:

a. How much did the waiver services help you reduce or control your child's pain?

_______________ RESPONDENT'S NUMBER FROM 0 (LOWEST) TO 10 (HIGHEST)

DID NOT USE SERVICES...97

REFUSED 98

DON'T KNOW 99

b. How much did the waiver services help you manage your child's other symptoms that come from being sick?

_______________ RESPONDENT'S NUMBER FROM 0 (LOWEST) TO 10 (HIGHEST)

DID NOT USE SERVICES...97

REFUSED 98

DON'T KNOW 99

5. Sometimes parents may feel stress related to the care of their child.

5. a. They may feel that they have a hard time falling asleep or staying asleep. How often would you say you feel this way?

Never	Occasionally	Sometimes	Most of the time	All the time	Refuse	Don’t know
1	2	3	4	5	98	99

5. b. They may feel nervous or tense. How often would you say you feel this way?

Never	Occasionally	Sometimes	Most of the time	All the time	Refuse	Don’t know
1	2	3	4	5	98	99

6. For each service, please indicate if you agree with the following statement: “The service was helpful in reducing stress related to the care of my child”

[INTERVIEWER NOTE: PLEASE REPEAT THE STATEMENT AS NEEDED. PROBE: “do you agree with the statement that (fill in the blank) service was helpful in reducing stress or tension related to the care of your child?”]

		Disagree	Agree	Did Not Use This Service	Service Not Applicable	Refuse	Don’t know
6.a.	Care coordination	1	2	96	97	98	99
6.b.	Family training	1	2	96	97	98	99
6.c.	In-home respite care	1	2	96	97	98	99
6.d.	Out-of home respite care	1	2	96	97	98	99
6.e.	Child life therapy	1	2	96	97	98	99
6.f.	Art therapy for child	1	2	96	97	98	99
6.g.	Music therapy for child	1	2	96	97	98	99
6.h.	Massage therapy for child	1	2	96	97	98	99
6.i.	24/7 nurse line	1	2	96	97	98	99
6.j.	Bereavement services	1	2	96	97	98	99
6.k.	Pain and symptom	1	2	96	97	98	99

	management						

7. **Sometimes parents may feel worried about managing their child's health. They may have a hard time keeping their mind on other things they are supposed to be doing such as work, household chores, or paying bills. How often would you say you feel worried related to managing you child's health?**

Never	Occasionally	Sometimes	Most of the time	All the time	Refuse	Don't know
1	2	3	4	5	98	99

8. For each service, please indicate if you agree with the following statement: "The service was **helpful** in reducing worry related to the care of my child"

[INTERVIEWER NOTE: PLEASE REPEAT THE STATEMENT AS NEEDED. PROBE: "do you agree with the statement that (fill in the blank) service was helpful in reducing worry related to the care of your child?"]

		Disagree	Agree	Did Not Use This Service	Service Not Applicable	Refuse	Don't know
8.a.	Care coordination	1	2	96	97	98	99
8.b.	Family training	1	2	96	97	98	99
8.c.	In-home respite care	1	2	96	97	98	99
8.d.	Out-of home respite care	1	2	96	97	98	99
8.e.	Child life therapy	1	2	96	97	98	99
8.f.	Art therapy for child	1	2	96	97	98	99
8.g.	Music therapy for child	1	2	96	97	98	99
8.h.	Massage therapy for child	1	2	96	97	98	99
8.i.	24/7 nurse line	1	2	96	97	98	99
8.j.	Bereavement services	1	2	96	97	98	99
8.k.	Pain and symptom	1	2	96	97	98	99

	management						

9. Sometimes parents may feel that they are NOT confident with handling the care of their child's condition. They may feel like they do not have the ability to manage the care for the child, get the right help, or who to ask for help. How often would you say you feel unsure about your ability to manage the care for your child?

Never	Occasionally	Sometimes	Most of the time	All the time	Refuse	Don't know
1	2	3	4	5	98	99

10. For each service, please indicate if you agree with the following statement: "The service was **helpful** in making me feel more confident in my ability to manage the care for my child"

[INTERVIEWER NOTE: PLEASE REPEAT THE STATEMENT AS NEEDED. PROBE: "do you agree with the statement that (fill in the blank) service was helpful in making you feel more confident in your ability to manage the care for your child?]

		Disagree	Agree	Did Not Use This Service	Service Not Applicable	Refuse	Don't know
10.a.	Care coordination	1	2	96	97	98	99
10.b.	Family training	1	2	96	97	98	99
10.c.	24/7 nurse line	1	2	96	97	98	99
10.d.	Pain and symptom management	1	2	96	97	98	99

11.

a. Have you been using any other types of support including religious, spiritual, or cultural resources, as well other social-emotional support sources such as counseling, to help you deal with your child's condition? For example, prayer, meeting with clergy, psychological counseling.

YES	1

NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

[INTERVIEWER NOTE: IF YES, PLEASE CONTINUE TO b]

b. If yes, please list the types of support you use (e.g.: support group, meditation, prayer, novinas, etc.): ____

12.

a. Have you been using any type of community support for you or for your child that may be available to you **IN ADDITION TO** services you received through this program? For example: programs offered by the American Cancer Society.

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

[INTERVIEWER NOTE: IF YES, PLEASE CONTINUE TO b]

b. If yes, please list the resources you use or have used ____

13. What words would you use to describe how the waiver services have helped your child?

[INTERVIEWER NOTE: PLEASE WRITE THE RESPONDENT'S ANSWER]

____

14. Would you recommend this program to another family member or friend if their child had a similar situation?

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

15. What would you change about Partners for Children program?

[INTERVIEWER NOTE: PLEASE WRITE THE RESPONDENT'S ANSWER]

____

16. Are there any other services you would desire to have offered along with the services you received?

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

17. Would you like to receive the following services:

[INTERVIEWER NOTE: IF OTHER, PLEASE SPECIFY]

a. Counseling by a social worker or psychologist

YES	1

NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

c. Other (specify): ____
d. Other (specify): ____

18. **Using any number from 0 to 10 where 0 is the worst possible and 10 is the best possible, what number would you use to rate the support you received from the following during the past three months**
[INTERVIEWER NOTE: PLEASE MAKE CLEAR THAT THESE QUESTIONS RELATE TO SERVICES THAT ARE ***NOT*** *PART OF THE WAIVER.]*

Type of Support	Rate support 0-10	Not applicable/did not use support	Refuse	Do Not Know
18.a. Spouse/partner		97	98	99
18.b. Grandparents of child		97	98	99
18.c. Other Family members		97	98	99
18.d. Family friends		97	98	99
18.e. Primary care doctor		97	98	99
18.f. Other doctor		97	98	99
18.g. Nurse		97	98	99
18.h. Social worker		97	98	99
18.i. Teachers, counselors, or others at your child’s school		97	98	99
18.j. Religious clergy or other religious support		97	98	99
18.k. Support groups run by agencies such as the American Cancer Society		97	98	99

18.l. Other. Specify:_________________		97	98	99

{We have just a couple more questions to ask}

19.

a. Do you work?

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

[INTERVIEWER NOTE: IF R SAYS YES PLEASE ASK THE FOLLOWING QUESTION AND RECORD THE NUMBER OF HOURS. IF NO, SKIP TO QUESTION 17c.]

b. How many hours a week do you work?

_____________ NUMBER OF HOURS OF WORK A WEEK]

REFUSED 98

DON'T KNOW 99

c. Is there another person who is closely involved in the care of your child?

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

[INTERVIEWER NOTE: IF R INDICATED YES PLEASE ASK THE FOLLOWING QUESTIONS. FOR ALL OTHER ANSWERS, SURVEY IS FINISHED.]

d. Who is that caregiver?

THE CHILD'S OTHER PARENT	1
THE CHILD'S OTHER FOSTER PARENT	2
THE CHILD'S STEP PARENT	3
THE CHILD'S GRANDMOTHER OR GRANDFATHER	4
THE CHILD'S UNCLE OR AUNT	5
THE CHILD'S OLDER SISTER OR BORTHER	6
OTHER. SPECIFY: __________________	7
REFUSE	98
DO NOT KNOW	99

e. Does the other caregiver work?

YES	1
NO	2
NOT APPLICABLE	97
REFUSED	98
DON'T KNOW	99

[INTERVIEWER NOTE: IF R SAYS YES PLEASE ASK THE FOLLOWING QUESTION AND RECORD THE NUMBER OF HOURS. IF NO, SURVY IS FINISHED.]

f. How many hours a week does he/she work?

_____________ NUMBER OF HOURS OF WORK A WEEK]

REFUSED 98

DON'T KNOW 99

20. Notes:
[INTERVIEWER NOTE; PLEASE WRITE HERE NOTES SUCH AS ANY COMMENTS MENTIONED BY R DURING THE INTERVIEW]

____

[INTRVIEWR NOTE: THE FOLLOWING TWO QUESTIONS SHOULD BE ASKED ONLY OF FAMILIES WHO HAVE RECEIVED THE SPECIFIC SERVICE]

Only for families that transitioned:

21. Using any number from 0 to 10 where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate the transition services you received

______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES...97

REFUSED 98

DON'T KNOW 99

Only if family is receiving bereavement services:

22. Using any number from 0 to 10 where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate the bereavement services your family received

______________ RESPONDENT'S NUMBER FROM 0 (WORST) TO 10 (BEST)

DID NOT USE SERVICES...97

REFUSED 98

DON'T KNOW 99

CCSNL Survey

Today's date
[0_Date]
MM/DD/YYYY 00:00:00
[automatically generated by survey monkey]

1. The Partners for Children (PFC) program is currently in effect in 11 California counties. You have been identified as a California Children's Services (CCS) Nurse Liaison (CCSNL) providing palliative care to pediatric patients in one of these 11 counties. In which county do you currently provide pediatric palliative care as a CCS Nurse Liaison? (please check only one response)

[1a_cnty]
[1] Alameda
[2] Fresno
[3] Los Angeles
[4] Marin
[5] Monterey
[6] Orange
[7] San Diego
[8] San Francisco
[9] Santa Clara
[10] Santa Cruz
[11] Sonoma

[0] Other
[9999] Don't know
[9998] Don't want to answer
[1b_otxt] If Other please specify [TEXT]

The following questions are designed to gain an understanding of your perceptions and use of palliative care services in your pediatric practice.

2. How do you define palliative care? (Check all that apply)

[2a_sup] [1] Supportive care
[2b_dm] [1] Disease
management **[2c_sm]** [1] Symptom
management
[2d_supc] [1] Care when cure is not the goal
[2e_ql] [1] Care that improves quality of life
[2f_op] [1] Outpatient
care **[2g_ip]** [1] Inpatient
care **[2h_all]** [1] All
[2i_dk] [1] Don’t Know
[2j_refus] [1] Don’t want to
answer **[2k_oth]** [1] Other (please
specify)
[2l_otxt] If Other please specify [TEXT]

3. How much do you agree with the following statement: “In general, physicians and patients have misperceptions about what palliative care is” (Please check only one response per row)

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don’t know	Don’t want to answer
Physicians **[3a_mdmis]**	[5]	[4]	[3]	[2]	[1]	[9999]	[9998]
Patients **[3b_ptsmis]**	[5]	[4]	[3]	[2]	[1]	[9999]	[9998]

4. How important do you think it is to provide each of the following services to children with life-threatening or life-limiting illnesses and their families: unimportant, of little importance, moderately important, important, or very important? Please check only one response for each service type (row))

Service	Unimportant	Of little importance	Moderately important	Important	Very important	Don’t know	Don’t want to answer
Care coordination **[4a_cc]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Family training **[4b_ft]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
In-home respite care **[4c_iresp]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Out-of home respite care **[4d_oresp]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]

Child life therapy **[4e_life]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Art therapy for the child **[4f_art]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Music therapy for the child **[4g_music]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Massage therapy for the child **[4h_massg]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
24/7 nurse line **[4i_nl]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Bereavement services **[4j_brv]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Pain and symptom management **[4k_pain]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Counseling **[4l_counsl]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Other (please specify) **[4m_o]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
If Other please specify **[4n_otxt]**				[TEXT]			

The following questions are designed to gain an understanding of your experience with the referral process for the Partners for Children program.

5. Have you screened any patient referrals for the Partners for Children program? (Please check only one response) **[5_scrn]**

[1] Yes...CONTINUE TO **QUESTION 8**
[2] No ....CONTINUE TO **QUESTION 6**
[9999] Don't know ....CONTINUE TO **QUESTION 16**
[9998] Don't want to answer..CONTINUE TO **QUESTION 16**

6. You answered that you have not screened any patient referrals for the Partners for Children program. Please tell us the reason(s) for this. (check all that apply)

[6a_new] [1] I'm new to this position ....CONTINUE TO **QUESTION 29**
[6b_nopv] [1] No providers set up for the program ....CONTINUE TO **QUESTION 29**
[6c_norf] [1] Doctors have not referred patients ....CONTINUE TO **QUESTION 7**
[6d_dk] [1] Don't know ....CONTINUE TO **QUESTION 29**
[6e_rfs] [1] Don't want to answer ....CONTINUE TO **QUESTION 29**
[6f_oth] [1] Other ....CONTINUE TO **QUESTION 29**
[6g_otxt] If Other please specify [TEXT]

7. Physicians do not always refer eligible families to the Partners for Children program. We would like to know your perception. We have listed six statements that may explain why some patients are not referred by their doctor. Please read each statement below and rate how much of a barrier to referring families to the Partners for Children program each is- sue is: an extreme barrier, a moderate barrier, somewhat of a barrier, or not a barrier? (Please check only one response per statement (row))

	An extreme barrier	A moderate barrier	Somewhat of a barrier	Not a barrier	Don't know	Don't want to answer
Doctors do not know about the program. **[7a_norefxp]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Doctors know about the program but believe it will interfere with the patient's curative care. **[7b_ norefxp]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Doctors know about the program but are uncomfortable referring to the program because of the stigma associated with terms such as hospice, end of life care, and palliative care. **[7c_ norefxp]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Doctors are not always sure if the patient will benefit more from hospice under concurrent care or from Partners for Chil- dren program care. **[7d_ norefxp]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Doctors are not referring patients because of the amount of paper work required. **[7e_ norefxp]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Doctors are not referring because they believe families will not be willing to participate in the services. **[7f_ norefxp]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Other **[7g_ norefo]**	[4]	[3]	[2]	[1]	[9999]	[9998]
If Other please specify **[7h_otxt]**				[TEXT]		

8. You answered that you have screened patient referrals for the Partners for Children program. Approximately how many patient referrals combined have you screened for the Partners for Children program since the beginning of the program in your county? (Please enter the number in the textbox provided below. If you don't know enter 9999. If you don't want to answer enter 9998.)
[8_scrn]
Please enter number here [NUMBER]

9. Can you please tell us how many referrals have been initiated under the following circumstances? (Please enter the number in the textboxes provided. If you don't know enter 9999. If you don't want to answer enter 9998.)

[9a_dr]	[NUMBER]	Doctors initiated referrals
[9b_nrs]	[NUMBER]	You or another CCS nurse contacted the doctor to suggest a potentially eligible patient following case mining
[9c_fam]	[NUMBER]	Families heard about the program through word of mouth and asked their doctor to them
[9d_oth1]	[NUMBER]	Other (please specify, followed by the number without comma)
[9e_oth2]	[NUMBER]	Other (please specify, followed by the number without comma)

10. Of the referrals you've screened, how many children have been determined by the State to be eligible for the Partners for Children Program? (Please enter the number in the textbox provided below. If you don't know enter 9999. If you don't want to answer enter 9998.)
[10_elig]
Please enter number here [NUMBER]

11. How long after the initial referrals from physicians do children typically start receiving services? (please check only one response)
[11_dtosrv]
[1] Less than 1 week
[2] 1 to 2 weeks
[3] 2 to 4 weeks
[4] 4 to 6 weeks
[5] More than 6 weeks
[9999] Don't know
[9998] Don't want to answer

12. Can you please describe the typical referral process from beginning to end? Please include everything from the time the physician refers the family to the time at which the providers deliver services.
[12_refprc]
[TEXT]

13. Physicians do not always refer eligible families to the Partners for Children program. We would like to know your perception. We have listed six statements that may explain why some patients are not referred by their doctor. Please read each statement below and rate how much of a barrier to referring families to the Partners for Children program each is- sue is: an extreme barrier, a moderate barrier, somewhat of a barrier, or not a barrier? (Please check only one response per statement (row))

	An extreme barrier	A moderate barrier	Somewhat of a barrier	Not a barrier	Don't know	Don't want to answer
Doctors do not know about the program. **[13a_drdk]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Doctors know about the program but believe it will interfere with the patient's curative care. **[13b_intf]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Doctors know about the program but are uncomfortable referring to the program because of the stigma associated with terms such as hospice, end of life care, and palliative care. **[13c_ stig]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Doctors are not always sure if the patient will benefit more from hospice under concurrent care or from Partners for Chil- dren program care. **[13d_ unc]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Doctors are not referring patients because of the amount of paper work required. **[13e_ pap]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Doctors are not referring because they believe families will not be willing to participate in the services. **[13f_unwil]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Other **[13g_ o]**	[4]	[3]	[2]	[1]	[9999]	[9998]
If Other please specify **[13h_otxt]**				[TEXT]		

14. Please tell us about any ways you think the referral process can be improved or changed to better meet the needs of pa- tients? CCS Nurse Liaisons? (Optional)
[14_refrec]

15. Some eligible families can't be referred to the Partners for Children program because of the lack of providers. Do you know of at least one case in which a family was eligible for the Partners for Children program but could not be referred because of the lack of providers?
[15_lkprov]
[1] Yes
[2] No
[9999] Don’t know
[9998] Don’t want to answer

The following questions are designed to gain knowledge about enrollment in your primary county of service.

16. Please complete the following sentence: “The number of enrolled families in the program for my county program has been…”
[16_numenr]

[1] Lower than expected
[2] About what was expected
[3] Higher than expected
[9999] Don’t know
[9998] Don’t want to answer

17. Eligible families referred to the Partners for Children program do not always enroll. We would like to understand the possible barriers families face when making this decision. We have listed five statements that may explain why families do not enroll in the program. Please read each statement below and rate whether you feel this to be an extreme barrier,
a moderate barrier, somewhat of a barrier, or not a barrier to enrollment. (Please check only one response per statement
(row))

	An extreme barrier	A moderate barrier	Somewhat of a barrier	Not a barrier	Don’t know	Don’t want to answer
Families are hesitant to join the program because they think it will interfere with their children’s curative care. **[17a_intf]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Families are hesitant to join the program because they are uncomfortable with the stigma 8associ- ated with terms such as hospice, end of life care, and palliative care. **[17b_stig]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Families are hesitant to join the program because they have insufficient knowledge about the bene- fits of the services. **[17c_insf]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Families are seeking other services. **[17d_osvc]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Families are unwilling to have service providers come to their home. **[17e_unwil]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Other **[17f_o]**	[4]	[3]	[2]	[1]	[9999]	[9998]
If Other please specify **[17g_otxt]**			[TEXT]			

The following questions are designed to gain an understanding of the utilization and quality of services offered through the Partners for Children program.

The next several questions concern the services available to children and their families in the Partners for Children program. The services referred to are care coordination, family training, in- and out-of-home respite care, child life therapy, art, music and massage therapy for the child, a 24/7 nurse phone hotline, bereavement services, as well as pain and symptom management.

18. We would like to know how frequently each service available through the Partners for Children program is used. How often do patients in the program typically receive the following list of services: is that never, rarely, sometimes, often, or always? (Please check only one response for each service type (row))

	Never	Rarely	Sometimes	Often	Often	Service not available	Don't know	Don't want to answer
Care coordination **[18a_cc]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Family training **[18b_ft]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
In-home respite care **[18c_iresp]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Out-of home respite care **[18d_oresp]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Child life therapy **[18e_life]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Art therapy for the child **[18f_art]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Music therapy for the child **[18g_music]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Massage therapy for the child **[18h_massg]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
24/7 nurse line **[18i_nl]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Bereavement services **[18j_brv]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Pain and symptom management **[18k_pain]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]

19. How many of the families currently enrolled in the program have received at least one session of the bereavement ser- vices? (Please enter the number in the textbox below. If you don't know enter 9999. If you don't want to answer enter
9998.)

[19_numbrv]

Please enter number here [NUMBER]

20. Please rate the quality of each service offered through the Partners for Children program. Based on your experience/assessment, using any number from zero to 10 where zero is the worst possible and 10 is the best possible, what number would you use to rate each of the services provided to families through the Partners for Children program? (Please check only one response for each service type (row))

	0	1	2	3	4	5	6	7	8	9	10	Service was not used	Service was not available	Don't know	Don't want to answer
Waiver services Overall **[20a_all]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]
Family training **[20b_ft]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]
In-home respite care **[20c_iresp]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]
Out-of-home respite care **[20d_oresp]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]
Child life therapy **[20e_life]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]
Art therapy for the child **[20f_art]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]
Music therapy for the child **[20g_music]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]
Massage therapy for the child **[20h_massg]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]
24/7 phone hotline with a registered nurse through the agency **[20i_nl]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]
Bereavement counseling **[20j_brv]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]
Pain and symptom management **[20k_pain]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]
Emotional support to families while using services **[20l_supp]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[9996]	[9997]	[9999]	[9998]

21. We would like to understand how helpful the available services are in reducing stress for families as related to the care of their children. For each service offered through the Partners for Children program, please indicate if you agree with the following statement: "The service is helpful in reducing stress for families related to the care of their children." Do you strongly disagree, disagree, neither disagree nor agree, agree, or strongly agree? (Please check only one response for each service type (row))

	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Service not available	Don't know	Don't want to answer
Care coordination **[21a_cc]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Family training **[21b_ft]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
In-home respite care **[21c_iresp]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Out-of home respite care **[21d_oresp]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Child life therapy **[21e_life]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Art therapy for the child **[21f_art]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Music therapy for the child **[21g_music]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Massage therapy for the child **[21h_massg]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
24/7 nurse line **[21i_nl]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Bereavement services **[21j_brv]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Pain and symptom management **[21k_pain]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]

22. Can you please tell us about the ways any of the services reduced stress for the families? You may use anecdotes (but please do not mention the patients' names), or just comment in general. (Optional)
[22_lsstr]

23. We would like to understand how helpful the available services are in reducing worry for families as related to the care of their children. For each service offered through the Partners for Children program, please indicate if you agree with the following statement: "The service is helpful in reducing worry for families related to the care of their children." Do you strongly disagree, disagree, neither disagree nor agree, agree, or strongly agree? (Please check only one response for each service type (row))

	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Service not available	Don't know	Don't want to answer
Care coordination **[23a_cc]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Family training **[23b_ft]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
In-home respite care **[23c_iresp]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Out-of home respite care **[23d_oresp]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Child life therapy **[23e_life]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Art therapy for the child **[23f_art]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Music therapy for the child **[23g_music]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Massage therapy for the child **[23h_massg]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
24/7 nurse line **[23i_nl]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Bereavement services **[23j_brv]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Pain and symptom management **[23k_pain]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]

24. Can you please tell us about the ways any of the services reduced worry for the families? You may use anecdotes (but please do not mention the patients' names), or just comment in general. (Optional)
[24_wry]

25. We would like to understand how helpful the available services are in making families feel more confident in their ability to manage care for their children. For each service offered through the Partners for Children program, please indicate if you agree with the following statement: "The service is helpful in making families feel more confident in their ability to manage care for their children." Do you strongly disagree, disagree, neither disagree nor agree, agree, or strongly agree? (Please check only one response for each service type (row))

	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Service not available	Don't know	Don't want to answer
Care coordination **[25a_cc]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Family training **[25b_ft]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
In-home respite care **[25c_iresp]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Out-of home respite care **[25d_oresp]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Child life therapy **[25e_life]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Art therapy for the child **[25f_art]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Music therapy for the child **[25g_music]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Massage therapy for the child **[25h_massg]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
24/7 nurse line **[25i_nl]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Bereavement services **[25j_brv]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]
Pain and symptom management **[25k_pain]**	[1]	[2]	[3]	[4]	[5]	[9997]	[9999]	[9998]

26. Can you please tell us about the ways any of the services helped families feel more confident in their ability to manage care for their children? You may use anecdotes (but please do not mention the patients' names), or just comment in general. (Optional)
[26_conf]

This section is designed to gain an understanding of your overall experience with the Partners for Children program.

27. Barriers to managing enrolled families in the Partners for Children program are varied. Examples of barriers include lack of family confidence, conflicts and communication difficulties among family members and/or providers, and also staff shortages. Below we have listed 12 possible barriers. Please read each statement below and rate how much of a barrier you perceive each issue to be in regards to managing enrolled families in the Partners for Children program: an extreme barrier, a moderate barrier, somewhat of a barrier, or not a barrier? (Please check only one response per state- ment (row))

	Not A Barrier	Somewhat of a Barrier	A Moderate Barrier	An Extreme Barrier	Not applicable	Don't know	Don't want to answer
Family confidence/buy-in							
Family not ready to acknowledge the life-threatening condition **[27a_ notrdy]**	[1]	[2]	[3]	[4]	[9997]	[9999]	[9998]
Children's reservations or concerns **[27b_ chld]**	[1]	[2]	[3]	[4]	[9997]	[9999]	[9998]
Families uncomfortable with thought of using services because of stigma associated with terms such as hospice, end of life care, and palliative care **[27c_ stig]**	[1]	[2]	[3]	[4]	[9997]	[9999]	[9998]
Family misunderstanding that services are concurrent and do not inter- fere with curative care **[27d_ mis]**	[1]	[2]	[3]	[4]	[9997]	[9999]	[9998]
Families have insufficient knowledge of benefits of the services offered through the program **[27e_ insf]**	[1]	[2]	[3]	[4]	[9997]	[9999]	[9998]
Conflicts							
Conflict among family members about treatment goals **[27f_ famconfl]**	[1]	[2]	[3]	[4]	[9997]	[9999]	[9998] [1]
Conflict between staff and family about treatment goals **[27g_ stfamconfl]**	[2]	[3]	[4]	[9997]	[9999]	[9998] [1]	[2]
Conflict among staff about treatment goals **[27h_ stfconfl]**	[3]	[4]	[9997]	[9999]	[9998]		
Communication							
Communication difficulties between staff and families **[27i_ comun]**	[1]	[2]	[3]	[4]	[9997]	[9999]	[9998]
Language barriers **[27j_ lang]**	[1]	[2]	[3]	[4]	[9997]	[9999]	[9998]
Cultural differences **[27k_ cultr]**	[1]	[2]	[3]	[4]	[9997]	[9999]	[9998]
Other							
Staff shortages **[27l_ stfnum]**	[1]	[2]	[3]	[4]	[9997]	[9999]	[9998]
Other **[27m_o]**	[1]	[2]	[3]	[4]	[9997]	[9999]	[9998]
If Other (please specify) **[27n_otxt]**				[TEXT]			

28. On average, how much time do you devote to the Partners for Children program, for all cases, each week? (Please se- lect only one response)
[28_time]

[1] Less than 10 hours
[2] 10 to 19 hours
[3] 20 to 29 hours
[4] 30 to 39 hours
[5] 40 or more hours
[6] Don’t know
[7] Don’t want to answer

This section will help us gain demographic information necessary to evaluate the effectiveness of the program.

29. What is your gender? (please check only one response)
[29a_gen]

[1] Female
[2] Male
[3] Don’t want to answer
[0] Other
[29b_gen] If Other please specify [TEXT]

30. Which one or more ethnic or racial categories would you use to describe yourself? (check all that apply)

[30a_wht] [1] White
[30b_blk] [1] Black or African American
[30c_as] [1] Asian
[30d_ai] [1] American Indian or Alaska Native
[30e_pi] [1] Other Pacific Islander
[30f_hi] [1] Native Hawaiian
[30i_hisp] [1] Latino or Hispanic
[30g_dk] [1] Don’t know
[30h_ref] [1] Don’t want to answer
[30j_otxt] If Other please specify [TEXT]

31. What is your age range?
[31_age]

[1] 29 years or under
[2] 30-39 years
[3] 40-49 years
[4] 50-59 years
[5] 60-69 years
[6] 70-79 years
[7] 80 years or over
[9998] Don’t want to answer

32. What year did you complete your nursing training? (Please enter a four digit year (YYYY) in the textbox below. If you don't know enter 9999. If you don't want to answer enter 9998.)
[32_nrs]
Please enter a four digit year here (YYYY) [NUMBER]

33. How long have you been a registered nurse (RN) case manager with CCS?
[33_dccsnl]

[1] Less than 1 year
[2] More than 1 year but less than 2 years
[3] More than 2 years but less than 3
years [4] More than 3 years but less than 4
years
[5] More than 4 years but less than 5 years
[6] More than 5 years
[9999] Don’t know
[9998] Don’t want to answer

34. When did you begin providing palliative care to pediatric patients as a CCS Nurse Liaison within one or more of the eleven counties? (Please enter the date(s) below. If you don't know please enter 01/01/1199. If you don't want to answer enter 01/01/1198) If you don't know please enter 01/01/9999. If you don't want to answer enter 01/01/9998)
[34_dtsrt]
Please enter date here [MM/DD/YYYY]

35. How many years experience do you have working with pediatric patients? (Please enter the number in years in the text-box below. If you don't know enter 9999. If you don't want to answer enter 9998.)
[35_yrsxp]
[NUMBER]

You have now completed the survey. Thank you very much for your participation.

Hospice and Home Health Agency Survey

Today's date **[StartDate]**
MM/DD/YYYY 00:00:00
[automatically generated by survey monkey]

1. The Partners for Children program is currently in effect in 11 California counties. Your agency has been identified as serving the CCS population in at least one of these 11 counties. If your agency serves more than one county, please select the county which you primarily serve, followed by the second, and, if applicable, third county from the dropdown menus. In which county/counties do you currently serve the CCS population? (please select all that apply)

County Name (Primary)
[Cnty1_1a] [1]
Alameda [2]
Fresno
[3] Los Angeles
[4] Marin
[5] Monterey
[6] Orange
[7] San Diego
[8] San Francisco
[9] Santa Clara [10]
Santa Cruz [11]
Sonoma
[12] Other
[13] Don't know
[14] Don't want to answer

County Name 2
[Cnty2_1b] [1]
Alameda [2]
Fresno
[3] Los Angeles
[4] Marin
[5] Monterey
[6] Orange
[7] San Diego
[8] San Francisco
[9] Santa Clara [10]
Santa Cruz [11]
Sonoma
[12] Other
[13] Don't know
[14] Don't want to answer
[15] Not applicable

County Name 3
[Cnty3_1c]
[1] Alameda
[2] Fresno
[3] Los Angeles
[4] Marin
[5] Monterey
[6] Orange
[7] San Diego
[8] San Francisco
[9] Santa Clara [10]
Santa Cruz [11]
Sonoma
[12] Other
[13] Don't know
[14] Don't want to answer
[15] Not applicable

If Other (please specify). If you selected "Other" from more than one dropdown menu, please specify below in the following format: Other1 / Other2 / Other 3
[CntyOth_1d] [TEXT]

2. What is the legal name of your agency/agencies as registered with the Medi-Cal program?

Please enter name here
[AgncyNm_2a]

The following questions are designed to gain an understanding about your agency.

3. Please identify your agency type? (please check all that apply)

[hospice_3a]	[1]	Hospice Agency
[homeh_3b]	[1]	Home Health Agency
[agncyoth_3c]	[1]	Other
[agncyothtxt_3d]		If Other please specify [TEXT]

4. What is your title? (please check all that apply)

[adm_4a]	**[1]**	Administrator
[nurse_4b]	**[1]**	Service Coordinator: Nurse
[sw_4c]	**[1]**	Service Coordinator: Social Worker
[oth_4d]	**[1]**	Other
[othtxt_4e]		If Other please specify [TEXT]

5. Which of the following pediatric services does your agency offer? (Please check all that apply)

Service	Do not offer	Offer	Don't Know	Don't want to answer
Care Coordination **[cc_5a]**	[0]	[1]	[9999]	[9998]
Family training **[ft_5b]**	[0]	[1]	[9999]	[9998]
In-home respite care **[iresp_5c]**	[0]	[1]	[9999]	[9998]
Out-of-home respite care **[oresp_5d]**	[0]	[1]	[9999]	[9998]
Child life therapy **[life_5e]**	[0]	[1]	[9999]	[9998]
Art therapy for child **[art_5f]**	[0]	[1]	[9999]	[9998]
Music therapy for child **[music_5g]**	[0]	[1]	[9999]	[9998]
Massage therapy for child **[massg_5h]**	[0]	[1]	[9999]	[9998]
24/7 nurse line **[nl_5i]**	[0]	[1]	[9999]	[9998]
Bereavement services **[brv_5j]**	[0]	[1]	[9999]	[9998]
Pain and symptom management **[pain_5k]**	[0]	[1]	[9999]	[9998]
Counseling **[counsl_5l]**	[0]	[1]	[9999]	[9998]
Other **[oth_5m]**	[0]	[1]	[9999]	[9998]
If Other (please specify):__________ **[othtxt_5n]**			[TEXT]	

The following six questions will ask you about the number of nurses, social workers, individual care coordinators your agency has and whether they have three years or more of pediatric experience. You will be asked to enter the numbers in the textboxes provided. If you don't know please enter 9999. If you don't want to answer please enter 9998.

6. How many individual nurses does your agency have working with Partners for Children clients (please count all LVN/LPN/RN nurses)? (If you don't know please enter 9999. If you don't want to answer please enter 9998.)
   Please enter number here ____________________ [Number]
   [NmNrs_6a]

7. Of the total number of individual nurses your agency has working with Partners for Children clients (the number you entered above), how many have 3 years or more of pediatric experience? (If you don't know please enter 9999. If you don't want to answer please enter 9998.)
   Please enter number here ____________________ [Number]
   [NmNrsExp_7a]

8. How many individual social workers does your agency have working with Partners for Children clients? (If you don't know please enter 9999. If you don't want to answer please enter 9998.)
   Please enter number here [Number]
   [NmSocWrk_8a]

9. Of the total number of individual social workers your agency has working with Partners for Children clients, how many have 3 years or more of pediatric experience? (If you don't know please enter 9999. If you don't want to answer please enter 9998.)
   Please enter number here [Number]
   [NmSocWrkExp_9a]

10. How many individual care coordinators does your agency have working with Partners for Children clients? (If you don't know please enter 9999. If you don't want to answer please enter 9998.)
    Please enter number here [Number]
    [NmCc_10a]

11. Of the total number of individual care coordinators working with Partners for Children clients (the number you entered above), how many care coordinators in your agency have 3 years or more of pediatric experience? (If you don't know please enter 9999. If you don't want to answer please enter 9998.)
    Please enter number here [Number]
    [NmCcExp_11a]

12. Please rank the importance of the following service types for children with life-threatening illnesses and their families: are they unimportant, of little importance, moderately important, important, or very important? (Please check only one response for each service type(row))

Service	Unimportant	Of Little importance	Moderately important	Important	Very important	Don't know	Don't want to answer
Care coordination **[cc_12a]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Family training **[ft_12b]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
In-home respite care **[iresp_12c]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Out-of-home respite care **[oresp_12d]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Child life therapy **[life_12e]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Art therapy for the child **[art_12f]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Music therapy for the child **[music_12g]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Massage therapy for the child **[massg_12h]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
24/7 nurse line **[nl_12i]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
bereavement services **[brv_12j]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Pain and symptom management **[pain_12k]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Counseling **[counsl_12l]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Other **[oth_12m]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
If Other (please specify) **[othtxt_12n]**				[TEXT]			

The following questions are designed to gain an understanding about your agency's experience providing palliative care to pediatric patients.

13. Has your agency served this population (children 20 years or younger) prior to this program?
[srvdpop_13a]
    [1] Yes
    [2] No
    [3] Don't know
    [4] Don't want to answer

14. How much of a difference is there in serving children with life-threatening or life-limiting illnesses compared to adult and elderly populations with these illnesses? (Please check only one response)
[difadlt_14a]
    [1] No difference ....(SKIP TO **QUESTION 16**)
    [2] A slight difference .... (SKIP TO **QUESTION 15**)
    [3] Somewhat of a difference .... (SKIP TO **QUESTION 15**)
    [4] A moderate difference .... (SKIP TO **QUESTION 15**)
    [5] An extreme difference .... (SKIP TO **QUESTION 15**)
    [6] Don't know .... (SKIP TO **QUESTION 16**)
    [7] Don't want to answer..................................(SKIP TO **QUESTION 16**)

15. You answered that there is a difference between serving children and adult or elderly populations with life-threatening or life-limiting illnesses. Please describe some of the differences between serving children with life-threatening or life- limiting illnesses compared to adult and elderly populations with these illnesses.
[difadlttxt_15a] [TEXT]

16. Do you agree with the following statement: "There is adequate training available for this agency that provides palliative care to children 20 years and younger?" (Please check only one response)
[agrtrain_16a]
    [1] Strongly disagree
    [2] Disagree
    [3] Neither agree nor disagree
    [4] Agree
    [5] Strongly agree
    [6] Don't know
    [7] Don't want to answer

17. What training opportunities would you like to see offered in the future? (Optional)
[traintxt_17a][TEXT]

The following questions are designed to gain an understanding about your experience with the services offered through the Partners for Children program.

18. How familiar are you with the Partners for Children program? (please circle only one response) **[fmPPC_18a]**
    [1] Not familiar at all ....(SKIP TO **INFO PAGE 19**)
    [2] Slightly familiar........................ (CONTINUE TO **QUESTION 19**)
    [3] Somewhat familiar .... (CONTINUE TO **QUESTION 19**)
    [4] Moderately familiar .... (CONTINUE TO **QUESTION 19**)
    [5] Very familiar .... (CONTINUE TO **QUESTION 19**)
    [6] Don't know...(SKIP TO **INFO PAGE 19**)
    [7] Don't want to answer ....(SKIP TO **INFO PAGE 19**)

19. Is your agency currently set up to provide services for the Partners for Children program? **[setup_19a]**
    [1] Yes ....(CONTINUE TO **QUESTION 20**)
    [2] No... (CONTINUE TO **INFO PAGE 19**)
    [3] Don't know .... (CONTINUE TO **INFO PAGE 19**)
    [4] Don't want to answer ....(CONTINUE TO **INFO PAGE 19**)

20. Has your agency provided services to any enrolled patients and their families enrolled in the Partners for Children program? **[provd_20a]**
    [1] Yes ....(CONTINUE TO **QUESTION 21**)
    [2] No.. (CONTINUE TO **QUESTION 40)**
    [3] Don't know .... (CONTINUE TO **QUESTION 40**)
    [4] Don't want to answer ....(CONTINUE TO **QUESTION 40**)

The next several questions concern the services available to children and their families in the Partners for Children program. The services referred to are care coordination, family training, in- and out-of-home respite care, child life therapy, art, music and massage therapy for the child, a 24/7 nurse phone hotline, bereavement services, as well as pain and symptom management and counseling.

21. How often do families take advantage of the services your agency offers through the Partners for Children program: Is that never, rarely, sometimes, often, or always? (Please select only one response for each service type (row))

	Never	Rarely	Sometimes	Often	Always	Service not offered	Don't know	Don't want to answer
Care coordination **[cc_21a]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Family training **[ft_21b]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
In-home respite care **[iresp_21c]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Out-of home respite care **[oresp_21d]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Child life therapy **[life_21e]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Art therapy for the child **[art_21f]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Music therapy for the child **[music_21g]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Massage therapy for the child **[massg_21h]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
24/7 nurse line **[nl_21i]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Bereavement services **[brv_21j]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Pain and symptom management **[pain_21k]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]

22. How many of the families currently enrolled in the programs have received at least one session of the bereavement services? (Please enter the number in the textbox below. If you don't know enter 9999. If you don't want to answer enter 9998.) Please enter number here
[fambrv_22a]

23. We would like to understand how helpful the available services are in reducing stress for families as related to the care of their children. For each service offered through the Partners for Children program, please indicate if you agree with the following statement: “The service is/was helpful in reducing stress for families related to the care of their children.” Do you strongly disagree, disagree, neither disagree nor agree, agree, or strongly agree? (Please circle one response for each service)

	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree	Service not offered	Don’t know	Don’t want to answer
Care coordination **[cc_23a]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Family training **[ft_23b]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
In-home respite care **[iresp_23c]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Out-of home respite care **[oresp_23d]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Child life therapy **[life_23e]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Art therapy for the child **[art_23f]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Music therapy for the child **[music_23g]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Massage therapy for the child **[massg_23h]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
24/7 nurse line **[2nl_3i]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Bereavement services **[brv_23j]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Pain and symptom management **[pain_23k]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]

24. Can you please tell us about the ways any of the services reduced stress for the families? You may use anecdotes (but please do not mention patients’ names), or just comment in general. (Optional) **[redstrtxt_24a]**

25. We would like to understand how helpful the available services are in reducing worry for families as related to the care of their children. For each service offered through the Partners for Children program, please indicate if you agree with the following statement: “The service is/was helpful in reducing worry for families related to the care of their children.” Do you strongly disagree, disagree, neither disagree nor agree, agree, or strongly agree? (Please circle one response for each service)

	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree	Service not offered	Don’t know	Don’t want to answer
Care coordination **[cc_25a]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Family training **[ft_25b]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
In-home respite care **[iresp_25c]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Out of home respite care **[oresp_25d]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Child life therapy **[life_25e]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Art therapy for the child **[art_25f]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Music therapy for the child **[music_25g]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Massage therapy for the child **[massg_25h]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
24/7 nurse line **[nl_25i]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Bereavement services **[brv_25j]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Pain and symptom management **[pain_25k]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]

26. Can you please tell us about the ways any of the services reduced worry for the families? You may use anecdotes (but please do not mention patients’ names), or just comment in general. (Optional) **[wrytxt_26a]**

27. We would like to understand how helpful the available services are in making families feel more confident in their ability to manage care for their children. For each service offered through the Partners for Children program, please indicate if you agree with the following statement: “The service is/was helpful in making families <u>feel more confident in their ability to manage care</u> for their children.” Do you, disagree, neither disagree nor agree, agree, or strongly agree? (Please circle one response for each service)

	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly Agree	Service not offered	Don’t know	Don’t want to answer
Care coordination **[cc_27a]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Family training **[ft_27b]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
In-home respite care **[iresp_27c]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Out of home respite care **[oresp_27d]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Child life therapy **[life_27e]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Art therapy for the child **[art_27f]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Music therapy for the child **[music_27g]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Massage therapy for the child **[massg_27h]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
24/7 nurse line **[nl_27i]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Bereavement services **[brv_27j]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]
Pain and symptom management **[pain_27k]**	[1]	[2]	[3]	[4]	[5]	[97]	[9999]	[9998]

28. Can you please tell us about the ways any of the services helped families feel more confident in their ability to manage care for their children? You may use anecdotes (but please do not mention patients’ names), or just comment in general. (Optional)
[conftxt_28a]

29. Please rate the quality of each service offered through the Partners for Children program. Based on your experience/assessment, using any number from zero to 10 where zero is the worst possible and 10 is the best possible, what number would you use to rate each of the services provided to families through the Partners for Children program? (Please check only one response for each service type (row))

	Worst possible 0	1	2	3	4	5	6	7	8	9	Best possible 10	Service not offered	Don't know	Don't want to answer	
Waiver services overall **[waivsrv_29a]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]	
Family training **[ft_29b]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]	
In-home respite care **[iresp_29c]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]	
Out of home respite care **[oresp_29d]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]	
Child life therapy **[life_29e]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]	
Art therapy for the child **[art_29f]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]	[0]
Music therapy for the child **[music_29g]**	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]	[0]	[1]
Massage therapy for the child **[massg_29h]**	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]			
24/7 hotline with a registered nurse through the agency **[nl_29i]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]	
Bereavement counseling **[brv_29j]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]	[0]
Pain and symptom management **[pain_29k]**	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]		
Emotional support to families using services **[counsl_29L]**	[0]	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]	[10]	[97]	[9999]	[9998]	

The following questions are designed to gain an understanding of any possible barriers associated with delivering palliative care services to pediatric patients and working with the Partners for Children program.

30. Have reimbursement rates affected your decision to participate in the Partners for Children program? (Please check only one response)
[rates_30a]

[1] Yes .... (CONTINUE TO **QUESTION 31**) [2]
No... (CONTINUE TO **QUESTION 32**) [3]
Don't know .... (CONTINUE TO **QUESTION 32**) [4] Don't
want to answer .... (CONTINUE TO **QUESTION 32**)

31. You answered that reimbursement rates have affected your decision to participate in the Partners for Children program. Please tell us how the reimbursement rates have affected your decision to provide services. (Optional)
[ratestxt_31a]

32. For each service, please indicate if you have found the reimbursement rates to be: lower than other funding sources, about the same as other funding sources, or higher than other funding sources. (Please check only one response for each service type (row))

	Lower than other funding sources	About the same as other funding sources	Higher than other funding sources	Other sources do not fund this service	Do not provide this service	Provide these services but don't know	Don't want to answer
Care coordination **[cc_32a]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Family training **[ft_32b]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
In-home respite care **[iresp_32c]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Out-of-home respite care **[oresp_32d]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Child life therapy **[life_32e]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Art therapy for the child **[art_32f]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Music therapy for the child **[music_32g]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Massage therapy for the child **[massg_32h]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
24/7 nurse line **[nl_32i]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Bereavement services **[brv_32j]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Pain and symptom management **[pain_32k]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]

33. We are interested in finding out the reasons your agency may not provide specific services. For each of the following services your agency DOES NOT PROVIDE, please tell us the reason. Is it because the reimbursement rates are too low, a lack of service provider in the area, or other? (Please check all that apply per service type (row))

	Reimbursement rates are to low	Lack of service in the area	Don't know	Don't want to answer	Other
Family training **[ft_33a]**	[1]	[2]	[9999]	[9998]	[0]
In home respite care **[iresp_33b]**	[1]	[2]	[9999]	[9998]	[0]
Out of home respite care **[oresp_33c]**	[1]	[2]	[9999]	[9998]	[0]
Art therapy for child **[art_33d]**	[1]	[2]	[9999]	[9998]	[0]
Music therapy for child **[music_33e]**	[1]	[2]	[9999]	[9998]	[0]
Massage therapy for child **[massg_33f]**	[1]	[2]	[9999]	[9998]	[0]
Bereavement services **[brv_33g]**	[1]	[2]	[9999]	[9998]	[0]
Pain and symptom management **[pain_33h]**	[1]	[2]	[9999]	[9998]	[0]

34. If you indicated other reasons, aside from reimbursement rates and/or a lack of service in your area, why your agency does NOT provide one or more of the services, please specify the reason your agency does not provide this service in each respective textbox below.

Family training **[ft_34a]**	[TEXT]
In home respite care **[iresp_34b]**	[TEXT]
Out of home respite care **[oresp_34c]**	[TEXT]
Art therapy for child **[art_34d]**	[TEXT]
Music therapy for child **[music_34e]**	[TEXT]
Massage therapy for child **[massg_34f]**	[TEXT]
Bereavement services **[brv_34g]**	[TEXT]
Pain and symptom management **[pain_34h]**	[TEXT]

35. Barriers to working with enrolled families in the Partners for Children program are varied. Examples of barriers include lack of family confidence, conflicts and communication difficulties among family members and/or providers, and also staff shortages. Below we have listed 12 possible barriers. Please read each statement and rate how much of a barrier you perceive each to be in regards to working with enrolled families in the Partners for Children program. Is it an extreme barrier, a moderate barrier, somewhat of a barrier, or not a barrier? (Please check only one response per statement (row)).

	An Extreme Barrier	A Moderate Barrier	Somewhat of a Barrier	Not A Barrier	Not applicable	Don't know	Don't want to answer
Family confidence/ buy in							
Family not ready to acknowledge the life-threatening condition **[notrdy_35a]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]
Children's reservations or concerns **[chld_35b]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]
Families uncomfortable with thought of using services because of stigma associated with terms such as hospice, end of life care, and palliative care **[stigma_35c]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]
Family misunderstanding that services are concurrent and do not interfere with curative care **[mis_35d]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]
Families have insufficient knowledge of benefits of the services offered through the program **[noknow_35e]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]
Conflicts							
Conflict among family members about treatment goals **[famconfl_35f]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]
Conflict between staff and family about treatment goals **[stfamconfl_35g]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]
Conflict among staff about treatment goals **[stfconfl_35h]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]
Communication							
Communication difficulties between staff and families **[comun_35i]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]
Language barriers **[lang_35j]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]

Cultural differences **[cultr_35k]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]

	An Extreme Barrier	A Moderate Barrier	Somewhat of a Barrier	Not A Barrier	Not applicable	Don’t know	Don’t want to answer
Other							
Staff shortages **[stfnum_35L]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]
Other **[oth_35m]**	[4]	[3]	[2]	[1]	[97]	[9999]	[9998]
If Other please specify **[othtxt_35n]**	[TEXT]						

This section is designed to obtain your suggestions and feedback for the Partners for Children program.

36. Are there any other medical needs or support services families have that this program hasn’t met? (Please circle only one response)
[unmet_36a]
[1] Yes .... (CONTINUE TO **QUESTION 37**) [2]
No... (CONTINUE TO **QUESTION 38**) [3]
Don’t know .... (CONTINUE TO **QUESTION 38**) [4] Don’t
want to answer .... (CONTINUE TO **QUESTION 38**)

37. You answered that there are other medical needs or support services families have that this program hasn’t met. What are these needs and which services might help address these needs?
[unmettxt_37a] [TEXT]

38. We are trying to identify best practices to share with others who provide similar services to children with life threatening illnesses. Do you have any tips or suggestions for them? Can you identify any techniques or strategies that have been beneficial to you while working with families in the Partners for Children program?
[tpstxt_38a] [TEXT]

39. We are interested in learning how having multiple family members involved in the care of children impacts the services delivered through this program. For example, have you found that other family issues come up, or that having multiple family members makes your job more difficult or easier? Please describe the role family dynamics has played in your ability to provide services to the children and families. **[faminvtxt_39a]** [TEXT]

You have now completed the survey..................................... (CONTINUE TO **END**)

The following questions are designed to gain an understanding of any possible barriers associated with delivering palliative care services to pediatric patients and working with the Partners for Children program.

40. Have reimbursement rates affected your decision to participate in the Partners for Children program? (Please circle only one response)
[rates_40a]
[1] Yes .... (CONTINUE TO **QUESTION 41**) [2]
No.. (CONTINUE TO **QUESTION 42**) [3]
Don't know .... (CONTINUE TO **QUESTION 42**) [4] Don't
want to answer ....(CONTINUE TO **QUESTION 42**)

41. You answered that reimbursement rates have affected your decision to participate in the Partners for Children program. Please tell us how the reimbursement rates have affected your decision to provide services. (Optional)
[ratestxt_41a]

42. For each service, please indicate if you have found the reimbursement rates to be: lower than other funding sources, about the same as other funding sources, or higher than other funding sources. (Please check only one response for each service type (row))

	Lower than other funding sources	About the same as other funding sources	Higher than other funding sources	Other sources do not fund this service	Do not provide this service	Provide these services but don't know	Don't want to answer
Care coordination **[cc_42a]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Family training **[ft_42b]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
In-home respite care **[iresp_42c]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Out of home respite care **[oresp_42d]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Child life therapy **[life_42e]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Art therapy for the child **[art_42f]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Music therapy for the child **[music_42g]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Massage therapy for the child **[massg_42h]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
24/7 nurse line **[nl_42i]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Bereavement services **[brv_42j]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]
Pain and symptom management **[pain_42k]**	[1]	[2]	[3]	[4]	[97]	[9999]	[9998]

43. We are interested in finding out the reasons your agency may not provide specific services. For each of the following services your agency DOES NOT PROVIDE, please tell us the reason. Is it because the reimbursement rates are too low, there is a lack of service providers in the area, or because of other reasons? (Please check all that apply per service type (row))

	Reimbursement rates are to low	Lack of service in the area	Don't know	Don't want to answer	Other
Family training **[ft_43a]**	[1]	[2]	[9999]	[9998]	[0]
In home respite care **[iresp_43b]**	[1]	[2]	[9999]	[9998]	[0]
Out of home respite care **[oresp_43c]**	[1]	[2]	[9999]	[9998]	[0]
Art therapy for child **[art_43d]**	[1]	[2]	[9999]	[9998]	[0]
Music therapy for child **[music_43e]**	[1]	[2]	[9999]	[9998]	[0]
Massage therapy for child **[massg_43f]**	[1]	[2]	[9999]	[9998]	[0]
Bereavement services **[brv_43g]**	[1]	[2]	[9999]	[9998]	[0]
Pain and symptom management **[pain_43h]**	[1]	[2]	[9999]	[9998]	[0]

44. If you indicated other reasons, aside from reimbursement rates and/or a lack of service in your area, why your agency does NOT provide one or more of the services, please specify the reason your agency does not provide this service in each respective textbox below.

Family training **[ft_44a]**	[TEXT]
In home respite care **[iresp_44b]**	[TEXT]
Out of home respite care **[oresp_44c]**	[TEXT]
Art therapy for child **[art_44d]**	[TEXT]
Music therapy for child **[music_44e]**	[TEXT]
Massage therapy for child **[massg_44f]**	[TEXT]
Bereavement services **[brv_44g]**	[TEXT]
Pain and symptom management **[pain_44h]**	[TEXT]

You have answered that you do not know about the Partners for Children Program or that your agency does not currently work with the program.

Let us tell you a little bit about this program. The purpose of the Partners for Children program is to provide pediatric palliative care services to children who have a CCS eligible medical condition with a complex set of needs. Eligible children and their families have the benefits of comfort care at home while continuing curative treatment. Unlike with hospice, eligible children will not need to be in the last six months of life to participate.

The waiver is based on the principle that if curative treatment is provided along with palliative care, there can be an effective continuum of care throughout the course of the medical condition.

The objective is to minimize the use of institutions, especially hospitals, and improve the quality of life for the participant and family (siblings, parent/legal guardian, and significant others).

Examples of the services available include: care coordination, family training, in-home respite care, out of home respite care, child life therapy, art therapy for the child, music therapy for the child, massage therapy for the child, 24/7 nurse line, bereavement services, pain and symptom management.

To be eligible for the program, a child needs to meet all of the following:
Live in a county that is participating in the program
Be eligible for full scope Medi-Cal
Be 20 years of age or younger
Have an eligible condition

The following is a list of medical conditions that may qualify a child to receive services:

Neoplasm *ICD9 Codes 140208, 235238, 239*
Neoplasm, Stage 3 or 4
Any neoplasm not responding to conventional protocol (at least one relapse)
Central nervous system tumors

Cardiac *ICD9 Codes 745, 746, 747.1, 747.2, 747.3, 747.4*
Major cardiac malformations for which surgical repair is not an option or awaiting surgery or transplant
Severe anomalies of Aorta and/or Pulmonary Arteries
Heart Failure ICD9 Codes 428.0 428.99

Pulmonary
Cystic Fibrosis with multiple hospitalizations or emergency department visits in the previous year ICD9 Codes 277
Pulmonary hypertension ICD9 Codes 416.0 416.8
Refractory pulmonary hypertension ICD9 Code 416.0
Pulmonary hemorrhage ICD9 Codes 770.3, 786.31
Chronic or severe respiratory failure ICD9 Codes 518.81, 518.83, 518.84

Immune
AIDS with multiple hospitalizations or emergency department visits in the previous year ICD9 Code O42
Severe Combined Immunodeficiency Disorder ICD9 Code 279.2
Other severe immunodeficiencies ICD9 Codes 279

Gastrointestinal
Chronic intestinal failure dependent on TPN ICD9 Code 579.3
Other severe gastrointestinal malformations ICD9 Codes 751.1, 751.2, 751.3, 751.5
Liver failure in cases in which transplant is not an option or awaiting transplant ICD9 Codes 570, 572.8, 751.61

Renal
Renal failure in cases in which dialysis or transplant are not an option, or awaiting transplant ICD9 Codes 585.6, 586

Neurologic

Holoprosencephaly or other severe brain malformations requiring ventilatory or alimentary support with at least four hospitalizations or emergency department visits in the previous year ICD9 Code 742.2

CNS injury with severe comorbidities ICD9 Codes 851 854, 952

Severe cerebral palsy/HIE with recurrent infections or difficulttocontrol symptoms ICD9 Codes 343, 768.7

Batten Disease ICD9 Code 330.1

Severe neurologic sequelae of infectious disease or trauma ICD9 Codes 323.6, 331.4, 342, 344, 851 854, 952

Metabolic

Severe and progressive metabolic disorders including but not limited to: leukodystrophy, TaySachs disease, and others with severe comorbidities ICD9 Codes 330.0, 330.1, 330.8

Mucopolysaccharidoses that meets Level of Care criteria below ICD9 Code 277.5

Neuromuscular

Muscular dystrophy requiring ventilatory assistance (at least nocturnal BiPAP) ICD9 Codes 359.0, 359.1

Spinal muscular atrophy, Type I or II ICD9 Codes 335.0 335.19

Other myopathy or neuropathy with severity that meets Level of Care criteria below ICD9 Codes 334, 335.2, 335.8, 335.9, 336

Other conditions that meet Level of Care criteria below, including but not limited to:

Severe epidermolysis bullosa ICD9 Code 757.39

Severe osteogenesis imperfect ICD9 Code 756.51

Congenital infection with severe sequelae (e.g. CMV, HSV, toxoplasmosis) ICD9 Codes 771.0, 771.1, 771.2

Postorgan transplant with complications ICD9 Code 996.8

Other nonlisted conditions will be given ICD 9 code on case by case basis

For more information about the program, please visit the Partners for Children website at:
http://www.dhcs.ca.gov/services/ppc/Pages/default.aspx

Physician Survey

Today’s date
[0_Date]
MM/DD/YYYY 00:00:00
[automatically generated by survey monkey]

1. The Partners for Children program is currently in effect in eleven California counties. You have been identified as providing care to the CCS population in one of these eleven counties. If you practice medicine in more than one county, please select the county in which you primarily practice, followed by a second, and, if applicable, third county from the drop-down menus. In which county/counties do you currently practice medicine? (please select all that apply)

County Name (Primary)
[1a_Cnty1] [1]
Alameda [2]
Fresno
[3] Los Angeles
[4] Marin
[5] Monterey
[6] Orange
[7] San Diego
[8] San Francisco
[9] Santa Clara [10]
Santa Cruz
[11] Sonoma
[12] Other
[13] Don't know
[14] Don't want to answer

County Name 2
[1b_Cnty2] [1]
Alameda [2]
Fresno
[3] Los Angeles
[4] Marin
[5] Monterey
[6] Orange
[7] San Diego
[8] San Francisco
[9] Santa Clara [10]
Santa Cruz
[11] Sonoma
[12] Other
[13] Don't know
[14] Don't want to answer
[15] Not applicable

County Name 3
[1c_Cnty3]
[1] Alameda
[2] Fresno
[3] Los Angeles
[4] Marin
[5] Monterey
[6] Orange
[7] San Diego
[8] San Francisco
[9] Santa Clara [10]
Santa Cruz
[11] Sonoma
[12] Other
[13] Don't know
[14] Don't want to answer
[15] Not applicable

[1d_otxt] If other [TEXT]

The following questions are designed to gain an understanding of your perceptions and use of palliative care services in your pediatric practice.

2. How do you define palliative care? (check all that apply)

[2a_sup]	[1]	Supportive care
[2b_dm]	[1]	Disease management
[2c_sm]	[1]	Symptom management
[2d_supc]	[1]	Care when cure is not the goal
[2e_ql]	[1]	Care that improves quality of life
[2f_op]	[1]	Outpatient care
[2g_ip]	[1]	Inpatient care
[2h_all]	[1]	All
[2i_dk]	[1]	Don’t Know
[2j_refus]	[1]	Don’t want to answer
[2k_otxt]		Other (please specify) [TEXT]

3. How important do you think it is to provide each of the following services to children with life-threatening or life-limiting illnesses, and their families: unimportant, of little importance, moderately important, important or very important? (please check only one response for each service type (row) below)

	Unimportant	Of little importance	Moderately important	Important	Very important	Don't know	Don't want to answer
Care coordination **[3a_cc]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Family training **[3b_ft]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
In-home respite care **[3c_iresp]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Out-of home respite care **[3d_oresp]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Child life therapy **[3e_life]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Art therapy for the child **[3f_art]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Music therapy for the child **[3g_music]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Massage therapy for the child **[3h_massg]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
24/7 nurse line **[3i_nl]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Bereavement services **[3j_brv]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Pain and symptom management **[3k_pain]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Counseling **[3l_counsl]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
Other (please specify) **[3m_o]**	[1]	[2]	[3]	[4]	[5]	[9999]	[9998]
If Other please specify **[3n_otxt]**				[TEXT]			

4. When a child is diagnosed with a life-threatening illness, at what point are you most likely to refer them to palliative care if available? (please check only one response)
[4a_tmref]
[1] Early in diagnosis [2]
Middle of diagnosis [3]
End of life
[4] Don't know
[5] Don't want to answer
[0] Other (please specify)
[4b_otxt] If Other please specify [TEXT]

The following questions are designed to gain an understanding about your familiarity and usage of the Partners for Children program.

5. How familiar are you with the Partners for Children program? (please check only one response)
[5_fmpcc]
[1] Not familiar at all ....(SKIP TO **PAGE 12**) [2]
Slightly familiar .... (CONTINUE TO **QUESTION 6**) [3]
Somewhat familiar .... (CONTINUE TO **QUESTION 6**) [4]
Moderately familiar.................... (CONTINUE TO **QUESTION 6**) [5] Very
familiar .... (CONTINUE TO **QUESTION 6**) [6] Don't
know ....(SKIP TO **PAGE 12**) [7] Don't
want to answer ....(SKIP TO **PAGE 12**)

6. Please tell us how you learned about the Partners for Children program. (check all that apply)

[6a_lrnpcc] [1] Another physician
[6b_lrnpcc] [1] Another employee (not a physician) in your office/institution
[6c_lrnpcc] [1] Grand rounds
[6d_lrnpcc] [1] California Children's Service Nurse Liaison
[6e_lrnpcc] [1] A patient **[6f_lrnpcc]**
[1] Don't know **[6g_lrnpcc]** [1] Don't
want to answer
[6h_otxt] Other (please specify) [TEXT]

7. We would like to understand how familiar providers are with services provided by the Partners for Children program. By services we mean care coordination, expressive therapies, family training, respite care, bereavement counseling, and pain and symptom management available to children and their families and/or caregivers in the Partners for Children program. How familiar are you with the services available through the Partners for Children program? (please check only one response)
[7_fmsvc]
[1] Not familiar at all
[2] Slightly familiar
[3] Somewhat familiar
[4] Moderately familiar
[5] Very familiar
[6] Don't know
[7] Don't want to answer

8. How familiar are you with the eligibility criteria for the Partners for Children program? (please check only one response)
[8_fmelg]
[1] Not familiar at all ....(SKIP TO **PAGE 12**) [2]
Slightly familiar....................................... (CONTINUE TO **QUESTION 9**) [3]
Somewhat familiar .... (CONTINUE TO **QUESTION 9**) [4]
Moderately familiar .... (CONTINUE TO **QUESTION 9**) [5] Very
familiar .... (CONTINUE TO **QUESTION 9**) [6] Don't
know..(SKIP TO **PAGE 12**)
[7] Don't want to answer..(SKIP TO **PAGE 12**)

9. Have you referred any patients to the Partners for Children program? (please check only one response)
[9_ref]
[1] Yes.. (CONTINUE TO **QUESTION 10**) [2]
No .... (CONTINUE TO **QUESTION 29**) [3]
Don't know .... (CONTINUE TO **QUESTION 29**) [4]
Don't want to answer............................ (CONTINUE TO **QUESTION 29**)

10. How many unique patients have you referred to the Partners for Children program? (Please enter the number in the textbox provided below. If you don't know enter 9999. If you don't want to answer enter 9998.)
[10_nref]
Please enter number here [NUMBER]

11. Of the children you've referred, how many have been determined to be eligible for the program? (Please enter the number in the textbox provided below. If you don't know enter 9999. If you don't want to answer enter 98.) **[11_nrefelg]**
Please enter number here [NUMBER]

12. How effective is the referral process? (please check only one response)
[12_refect]
[1] Ineffective
[2] Slightly ineffective
[3] Slightly effective [4]
Effective
[5] Don't know
[6] Don't want to answer

13. Please tell us about any ways you think the referral process can be improved or changed to better meet the needs of patients? Providers? (Optional)
[13_imrftxt] [TEXT]

The following questions are designed to gain an understanding about your experience working, communicating, and coordinating care with other professionals for patients in the Partners for Children program.

14. After a patient is accepted into the program which of the following do you expect to occur: (please check only one response)
[14a_xpt]
[1] You will still be highly involved in the coordination of patient care
[2] The CCSNL/provider will take over the coordination of patient care
[3] You will continue to be involved in patient coordination of care in collaboration with the CCSNL and the provider
[4] Don't know

[5] Don't want to answer
[0] Other (please specify)
[14b_xptotxt] If Other please specify [TEXT]

15. In general, please describe your involvement in coordinating care for your patient following a referral. Please use a typical case if you have had more than one referral. (please check only one response)
[15a_inv]
[1] You were/are still highly involved in the coordination of patient care
[2] The CCSNL/provider took over the coordination of patient care
[3] You continued to be involved in patient coordination of care in collaboration with the CCSNL and the provider
[4] Don't know
[5] Don't want to answer
[0] Other (please specify)
[15b_invotxt] If Other please specify [TEXT]

16. We are interested in knowing if the Partners for Children program had an effect on the quality of communication between you and other professionals. Has communication with the following professionals changed since the Partners for Children program was initiated? Has communication worsened, stayed the same or improved? (please check only one response per professional category (row))

	Worsened	Stayed the same	Improved	Don't know	Don't want to answer
CCS Nurse liaison **[16a_com]**	[3]	[2]	[1]	[9999]	[9998]
Home health care agency/hospice **[16b_ com]**	[3]	[2]	[1]	[9999]	[9998]
Other physician specialist **[16c_ com]**	[3]	[2]	[1]	[9999]	[9998]
Other non-physician staff **[16d_com]**	[3]	[2]	[1]	[9999]	[9998]
Other (please specify) **[16e_ com]**	[3]	[2]	[1]	[9999]	[9998]
If Other please specify **[16f_ otxt]**			[TEXT]		

17. Please tell us in what ways your relationship with any of the professionals listed above has changed since the initiation of the Partners for Children program? (Optional)
[17_rlchng] [TEXT]

18. How well do you believe the Partners for Children program coordinates care for the patient(s)? (please check only one response)
[18_cc]
[1] Very poorly
[2] Poorly
[3] Neutral
[4] Moderately well
[5] Very well
[6] Don't know
[7] Don't want to answer

The following questions are designed to gain an understanding about your perception of the effectiveness of the Partners for Children program.

19. Below you will find a list of services available to children and their families in the Partners for Children program. How useful was each of the services provided: not useful, slightly useful, somewhat useful, moderately useful or extremely useful? If the services were not used or not available please check the appropriate box. (please check only one response for each service type (row))

	Not useful	Slightly useful	Some-what useful	Mod-erately useful	Ex-tremely useful	Service was not used	Service not avai-lable	Don't know	Don't want to answer
Care coordination **[19_a_cc]**	[1]	[2]	[3]	[4]	[5]	[96]	[97]	[9999]	[9998]
Family training **[19_b_ft]**	[1]	[2]	[3]	[4]	[5]	[96]	[97]	[9999]	[9998]
In-home respite care **[19_c_iresp]**	[1]	[2]	[3]	[4]	[5]	[96]	[97]	[9999]	[9998]
Out-of home respite care **[19_d_oresp]**	[1]	[2]	[3]	[4]	[5]	[96]	[97]	[9999]	[9998]
Child life therapy **[19_e_life]**	[1]	[2]	[3]	[4]	[5]	[96]	[97]	[9999]	[9998]
Art therapy for the child **[19_f_art]**	[1]	[2]	[3]	[4]	[5]	[96]	[97]	[9999]	[9998]
Music therapy for the child **[19_g_music]**	[1]	[2]	[3]	[4]	[5]	[96]	[97]	[9999]	[9998]
Massage therapy for the child **[19_h_massg]**	[1]	[2]	[3]	[4]	[5]	[96]	[97]	[9999]	[9998]
24/7 nurse line **[19_i_nl]**	[1]	[2]	[3]	[4]	[5]	[96]	[97]	[9999]	[9998]
Bereavement services **[19_j_brv]**	[1]	[2]	[3]	[4]	[5]	[96]	[97]	[9999]	[9998]
Pain and symptom management **[19_k_pain]**	[1]	[2]	[3]	[4]	[5]	[96]	[97]	[9999]	[9998]

20. How helpful would you say the Partners for Children program is at managing needs and coordinating care for children with life threatening conditions? (please check only one response)
[20_cchelp]
[1] Not at all helpful
[2] Not very helpful
[3] Slightly helpful
[4] Helpful
[5] Very helpful
[6] Don't know
[7] Don't want to answer

21. Eligible families are not always referred to the Partners for Children program. We would like to understand the possible barriers a referring provider as yourself faces when making this decision. We have listed five statements that may explain why some providers do not refer their patients. Please read each statement below and rate whether you feel this to be an extreme barrier, a moderate barrier, somewhat of a barrier, or not a barrier. (please check only one response per statement (row))

	An extreme barrier	A moderate barrier	Somewhat of a barrier	Not a barrier	Don't know	Don't want to answer
Participating in the program will interfere with the patient's curative care. **[21a_intf]**	[4]	[3]	[2]	[1]	[9999]	[9998]
There is a stigma associated with terms such as hospice, end of life care and palliative care. **[21b_stig]**	[4]	[3]	[2]	[1]	[9999]	[9998]
It is uncertain whether a patient will benefit more from hospice under concurrent care or from Partners for Children program. **[21c_unc]**	[4]	[3]	[2]	[1]	[9999]	[9998]
The amount of paper work required is not manageable. **[21d_pap]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Families are not willing to participate in the services. **[21e_unwil]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Other (please specify) **[21f_o]**	[4]	[3]	[2]	[1]	[9999]	[9998]
If Other please specify **[21g_otxt]**			[TEXT]			

22. How likely are you to continue to refer patients to the Partners for Children program? (please check only one response)
[22_contref]
[1] Extremely unlikely
[2] Unlikely
[3] Likely
[4] Extremely likely
[5] Don't know
[6] Don't want to answer

23. For some referring providers the paperwork involved in the referral process is not a barrier, but for some it is. If paperwork will be mainstreamed and easier to handle, how likely are you to refer patients to the Partners for Children program in the future? (please check only one response)
[23_refutr]
[1] Extremely unlikely
[2] Unlikely
[3] Likely
[4] Extremely likely
[5] Don't know
[6] Don't want to answer

24. Do you believe you have any additional patients in your current practice that meet the eligibility criteria for the Partners for Children program?
[24_ptselg]
[1] Yes.. CONTINUE TO **QUESTION 25**) [2]
No .... CONTINUE TO **QUESTION 26**) [3]
Don't know... CONTINUE TO **QUESTION 26**) [4]
Don't want to answer............................. CONTINUE TO **QUESTION 26**)

25. You indicated that you believe you have additional patients in your current practice that meet the eligibility criteria for the Partners for Children program. How many additional patients do you think are eligible? (Please enter number below. If you don't know enter 9999. If you don't want to answer enter 9998)
[25_nelg]
Please enter number here [NUMBER]

26. Do you have any suggestions that would make Partners for Children a more effective and helpful program?
[26a_sug]
[2] No... CONTINUE TO **QUESTION 34**) [1]
Yes (please specify)............................... CONTINUE TO **QUESTION 34**)
[26b_sugtxt] If Yes please specify............................... CONTINUE TO **QUESTION 34**)

You have answered that you do not know about the Partners for Children program. Let us tell you a little bit about this program.

The purpose of the Partners for Children program is to provide pediatric palliative care services to children who have a CCS-eligible medical condition with a complex set of needs. Eligible children and their families have the benefits of comfort care at home while continuing curative treatment. Unlike with hospice, eligible children will not need to be in the last six months of life to participate.

The waiver is based on the principle that if curative treatment is provided along with palliative care, there can be an effective continuum of care throughout the course of the medical condition.

The objective is to minimize the use of institutions, especially hospitals, and improve the quality of life for the participant and family (siblings, parent/legal guardian, and significant others).

Examples of the services available include: care coordination, family training, in-home respite care, out-of home respite care, child life therapy, art therapy for the child, music therapy for the child, massage therapy for the child, 24/7 nurse line, bereavement services, and pain and symptom management.

To be eligible for the program, a child needs to meet all of the following:
Live in a county that is participating in the program
Be eligible for full scope Medi-Cal
Be 20 years of age or younger
Have an eligible condition

The following is a list of medical conditions that may qualify a child to receive services:

Neoplasm ICD-9 Codes 140-208, 235-238, 239
Neoplasm, Stage 3 or 4
Any neoplasm not responding to conventional protocol (at least one
relapse) Central nervous system tumors

Cardiac ICD-9 Codes 745, 746, 747.1, 747.2, 747.3, 747.4
Major cardiac malformations for which surgical repair is not an option or awaiting surgery or transplant
Severe anomalies of Aorta and/or Pulmonary Arteries
Heart Failure ICD-9 Codes 428.0 - 428.99

Pulmonary
Cystic Fibrosis with multiple hospitalizations or emergency department visits in the previous year ICD-9 Codes 277
Pulmonary hypertension ICD-9 Codes 416.0 - 416.8
Refractory pulmonary hypertension ICD-9 Code 416.0
Pulmonary hemorrhage ICD-9 Codes 770.3, 786.31
Chronic or severe respiratory failure ICD-9 Codes 518.81, 518.83, 518.84

Immune
AIDS with multiple hospitalizations or emergency department visits in the previous year ICD-9 Code 042
Severe Combined Immunodeficiency Disorder ICD-9 Code 279.2
Other severe immunodeficiencies ICD-9 Codes 279

Gastrointestinal
Chronic intestinal failure dependent on TPN ICD-9 Code 579.3
Other severe gastrointestinal malformations ICD-9 Codes 751.1, 751.2, 751.3, 751.5
Liver failure in cases in which transplant is not an option or awaiting transplant ICD-9 Codes 570, 572.8, 751.61

Renal
Renal failure in cases in which dialysis or transplant are not an option, or awaiting transplant ICD-9 Codes 585.6, 586

Neurologic
Holoprosencephaly or other severe brain malformations requiring ventilatory or alimentary support with at least four hospitalizations or emergency department visits in the previous year ICD-9 Code 742.2
CNS injury with severe comorbidities ICD-9 Codes 851 - 854, 952
Severe cerebral palsy/HIE with recurrent infections or difficult-to-control symptoms ICD-9 Codes 343, 768.7
Batten Disease ICD-9 Code 330.1
Severe neurologic sequelae of infectious disease or trauma ICD-9 Codes 323.6, 331.4, 342, 344, 851 - 854, 952

Metabolic

Sever and progressive metabolic disorders including but not limited to: leukodystrophy, Tay-Sachs disease, and others with severe comorbidities ICD-9 Codes 330.0, 330.1, 330.8
Mucopolysaccharidoses that meets Level of Care criteria below ICD-9 Code 277.5

Neuromuscular

Muscular dystrophy requiring ventilatory assistance (at least nocturnal BiPAP) ICD-9 Codes 359.0, 359.1
Spinal muscular atrophy, Type I or II ICD-9 Codes 335.0 - 335.19
Other myopathy or neuropathy with severity that meets Level of Care criteria below ICD-9 Codes 334, 335.2, 335.8, 335.9, 336

Other conditions that meet Level of Care criteria below, including but not limited to:

Severe epidermolysis bullosa ICD-9 Code 757.39
Severe osteogenesis imperfect ICD-9 Code 756.51
Congenital infection with severe sequelae (e.g. CMV, HSV, toxoplasmosis) ICD-9 Codes 771.0, 771.1, 771.2
Post-organ transplant with complications ICD-9 Code 996.8

Other non-listed conditions will be given ICD 9 code on case by case basis

For more information about the program, please visit the Partners for Children website at:
http://www.dhcs.ca.gov/services/ppc/Pages/default.aspx

27. How likely are you to refer patients to the Partners for Children program in the future? (please check only one response)

[27__refutr] [1] Extremely unlikely
[2] Unlikely
[3] Likely
[4] Extremely likely
[5] Don't know
[6] Don't want to answer

28. Do you believe you have any patients in your current practice that meet the eligibility criteria?
[28_ ptselg]
[1] Yes.. (CONTINUE TO **QUESTION 33**) [2]
No .... (CONTINUE TO **QUESTION 34**) [3]
Don't know.. (CONTINUE TO **QUESTION 34**) [4]
Don't want to answer............................. (CONTINUE TO **QUESTION 34**)

The following questions are designed to gain an understanding about the barriers providers may face when making the decision to refer children and their families to the Partners for Children program.

29. Eligible families are not always referred to the Partners for Children program. We would like to understand the possible barriers providers face when making this decision. We have listed five statements that may explain why providers do not refer their patients. Please read each statement below and rate whether you feel this to be an extreme barrier, a moderate barrier, somewhat of a barrier, or not a barrier. (please check only one response per statement (row))

	An extreme barrier	A moderate barrier	Somewhat of a barrier	Not a barrier	Don't know	Don't want to answer
Participating in the program will interfere with the patient's curative care. **[29a_intf]**	[4]	[3]	[2]	[1]	[9999]	[9998]
There is a stigma associated with terms such as hospice, end of life care and palliative care. **[29b_stig]**	[4]	[3]	[2]	[1]	[9999]	[9998]
It is uncertain whether a patient will benefit more from hospice under concurrent care or from Partners for Children program. **[29c_unc]**	[4]	[3]	[2]	[1]	[9999]	[9998]
The amount of paper work required is not manageable. **[29d_pap]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Families are not willing to participate in the services. **[29e_unwil]**	[4]	[3]	[2]	[1]	[9999]	[9998]
Other (please specify) **[29f_o]**	[4]	[3]	[2]	[1]	[9999]	[9998]
If Other please specify **[29g_otxt]**			[TEXT]			

30. How likely are you to refer patients to the Partners for Children program in the future? (please check only one response)
[30_ refutr]
[1] Extremely unlikely
[2] Unlikely
[3] Likely
[4] Extremely likely
[5] Don't know
[6] Don't want to answer

31. For some providers the paperwork involved in the referral process is not seen as a barrier, but for some it is. If paperwork will be mainstreamed and easier to handle, how likely are you to refer patients to the Partners for Children program in the future? (please check only one response)
[31_ refutr]
[1] Extremely unlikely
[2] Unlikely
[3] Likely
[4] Extremely likely
[5] Don't know
[6] Don't want to answer

32. Do you believe you have any patients in your current practice that meet the eligibility criteria for the Partners for Children program?
[32_ ptselg]
[1] Yes.. (CONTINUE TO **QUESTION 33**) [2]
No .... (CONTINUE TO **QUESTION 34**) [3]
Don’t know... (CONTINUE TO **QUESTION 34**) [4]
Don’t want to answer............................ (CONTINUE TO **QUESTION 34**)

33. You indicated that you believe you have patients in your current practice that meet the eligibility criteria for the Partners for Children program. How many patients do you think are eligible? (Please enter number below. If you don't know enter 9999. If you don't want to answer enter 9998)
[33_ nelg]
Please enter number here [NUMBER]

This section will help us gain demographic information necessary for a complete evaluation.

34. What is your gender? (please check only one response)
[34a_gend]
[2] Female
[1] Male
[3] Don’t want to answer
[0] Other (please specify)
[34b_gentxt] If Other please specify [TEXT]

35. Which one or more ethnic or racial categories would you use to describe yourself? (check all that apply)

[35a_wht] [1] White
[35b_blk] [1] Black or African American
[35c_as] [1] Asian

[35d_ai] [1] American Indian or Alaska Native
[35e_pi] [1] Other Pacific Islander
[35f_hi] [1] Native Hawaiian
[35g_hisp] [1] Latino or Hispanic
[35h_dk] [1] Don't know
[35i_ref] [1] Don't want to answer
[35j_otxt] Other (please specify) [TEXT]

36. What is your age range? (please check only one response)
[36_age]
[1] 29 years or under
[2] 30-39 years
[3] 40-49 years
[4] 50-59 years
[5] 60-69 years
[6] 70-79 years
[7] 80 years or over
[8] Don't want to answer

37. What year did you complete residency training? (Please enter a four digit year (YYYY) in the textbox below. If you don't know enter 9999. If you don't want to answer enter 9998.)
[37_resyr]
Please enter year a four digit year here [YYYY]

38. What is your board-certified specialty area (check all that apply)?

[38a_pc] [1] Primary Care
[38b_ped] [1] Pediatrics
[38c_fm] [1] Family medicine
[38d_im] [1] Internal medicine
[38e_onc] [1] Hematology/Oncology
[38f_card] [1] Cardiology
[38g_endo] [1] Endocrinology
[38h_neuro] [1] Neurology
[38i_pulm] [1] Pulmonology
[38j_neo] [1] Neonatology
[38k_gatro] [1] Gastroenterology
[38l_rhm] [1] Rheumatology
[38m_hep] [1] Hepatology
[38n_dk] [1] Don't know
[38o_refu] [1] Don't want to answer
[38p_otxt] Other (please specify) [TEXT]

39. What is your practice setting (check all that apply)?

[39a_amc] [1] Academic medical center
[39b_ppmg] [1] Private practice (including medical groups)
[39c_nah] [1] Non-academic hospital based only
[39d_op] [1] Outpatient based only
[39e_hspop] [1] Both hospital and outpatient

[39f_dk] [1] Don’t know **[39g_refu]** [1]
Don’t want to answer **[39h_otxt]**
Other (please specify) [TEXT]

40. How many Medi-Cal patients, aged 0-21 years, did you treat in your practice in the past 12 months? (Please enter the number in the textbox below. If you don’t know enter 9999. If you don’t know enter 9998.)
[40_nmedic]
Please enter number here [NUMBER]

41. Would you please estimate the proportion of Medi-Cal patients, aged 0-21 years, you treated in your practice in the past 12 months that are Managed Care? (please check only one response)
[41_pmedic]
[1] None
[2] up to 24%
[3] 25%-49%
[4] 50%-74%
[5] 75%-99%
[6] 100%
[7] Don’t know
[8] Don’t want to answer

You have now completed the survey. Thank you very much for your participation.