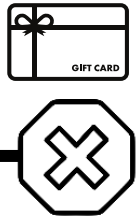


# AFFIRM California Study

**Goal: 50 completed surveys per site**



## **Eligibility:**

- English-speaking and Spanish-speaking adult caregivers of children and youth with special healthcare needs (CYSHCN)
- Caregivers will self-screen and provide implicit consent online before the survey

UCSF study team member will recruit caregivers in the waiting room.

Caregivers take brief 20 min. English or Spanish online survey on iPad or are given a QR code to complete on their device.

Each participant will receive a gift card (physical card or electronic code).

## Meet the UCSF study team



**Rachel Willard-Grace**  
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**Prospective Sites (agreements pending):** Loma Linda University School of Medicine; Community Regional Medical Center, Fresno; WellSpace Health; Salud Para la Gente; Family Health Care Network Kaiser Santa Rosa; UC Davis Glassrock Clinic  
**Funding:** Grant from Lucile Packard Foundation for Children's Health

# Frequently Asked Questions (FAQs)

## What are we trying to learn and how will results be used?

The AFFIRM California study will use a brief (20 minute) cross sectional online survey to assess Self-Management Support (SMS) that families of CYSHCN in California receive from their children's healthcare providers. Our goal is to identify opportunities to improve support so as to better guide programmatic and policy efforts.

The AFFIRM survey was co-designed with caregivers of CYSHCN to address the support needs that they felt were most impactful for their ability to care for their children.

## How would this impact the clinic?

Beyond the presence of UCSF staff in the waiting room for a few weeks, we would need a point of contact to coordinate securing clinic permissions for our staff to be on site and to coordinate the best days. We have allocated \$4,000 per site to help offset the costs of that personnel time.

We prioritize **not** interrupting clinic flow. We can provide links or QR codes for people to complete the web-based survey at the later time if needed, or our staff can meet with patients after their appointment to share study iPads for easy completion.

## How might this affect my patients?

There are no direct benefits for participation. However, **we will provide a \$50 electronic or physical gift card** as a thank you for the time required for participation. We can also provide resource sheets for families if desired.

We are also committed to sharing results back, not only with sites, but also with participants, through written summaries and report back webinars. The survey is **available in English and Spanish** and has an audio self-administration option for accessibility purposes.

## What are we requesting?

Permission for 1 to 2 UCSF study team members to recruit adult caregivers of CYSHCN from waiting rooms for 2-3 weeks.

Note: **No** sharing of patient-level data from clinic is required. We do **not** need clinic staff to engage in recruitment, consent, or survey administration.

## Are we evaluating existing clinic service?

No – data will not focus on individual sites or services, but is intended to garner information about the status of support for families of children with special healthcare needs across California.

## What is the timeframe of the study?

Data collection will take place from Summer 2024 – Spring 2025. The exact timeframe will be established based on preferences of each site. We anticipate that recruitment of 50 participants per site will take no more than 2-3 weeks.