



# Barriers and Facilitators of Personal Health Record Adoption: A study of Low-Income Families with Children with Special Health Care Needs



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## Introduction

*Who are children with special health care needs (CSHCN)?*

"Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally [McPherson et al., Pediatrics 1998]."

*Why families with CSHCN?*

Caregivers for CSHCN have especially demanding health information management needs and need to share information about their child with multiple health care providers - the PHR is a potentially useful tool to address this need.

*How can we ensure that all families benefit from this technology?*

We start by understanding the current situation of families, gauging the needs of the community, and informing both developers and users of the challenges and benefits that lie ahead. Ensuring that all families benefit will mitigate health disparities.

*Why Google Health?*

Lucile Packard Children's Hospital (LPCH) is partnering with Google Health to allow patients to import their children's records into the Google Health PHR. This presents a unique opportunity for patients to use this free tool for healthcare information management.

## Methods

**Focus group studies** and individual **usability studies** of the Google Health PHR were conducted in partnership with LPCH and two community support groups for families with CSHCN.

Usability studies were conducted using a developer testing version of Google Health with fictitious patient data imported from LPCH's Cerner electronic medical record. Short surveys were administered during focus group and usability studies.

*Subject recruitment criteria:*

- Use of public health insurance (Medi-Cal, CCS, HealthyKids or Healthy Families) was used as a proxy for low-income status.
- Focus groups: English, Spanish, Vietnamese, Cantonese speakers. Usability studies: English only.
- Participant age is between 18-45 years
- Participants are caregivers for a CSHCN between 0-21 years

## Abstract

This project explores the barriers and facilitators to adoption of electronic Personal Health Records (PHRs) in low income families/caregivers of children with special healthcare needs (CSHCN). General focus groups and usability studies of Google Health were conducted in English. These studies will help to understand: 1) the current methods by which caregivers manage healthcare information and 2) the knowledge, needs, and concerns of caregivers about PHRs. Preliminary results have shown that caregivers primarily use paper-based methods even though healthcare providers may not always give full copies of records. The PHR has potential to meet information management needs in families, but few families were aware of the PHR's availability. Reducing these barriers to PHR adoption will provide caregivers with a compelling electronic alternative.

## Preliminary Results

Preliminary results represent a subset of proposed studies: N=3 usability studies and Spanish and Cantonese focus groups.

*Thematic Quotes from Focus Groups:*

- "I keep all my records in a box at home."
- "I always need to ask my doctor for a copy of my [child's] record."
- "I keep records that I need in emergencies in a separate binder."

*Thematic Quotes from Usability Studies (N=3):*

- "I'm all for paperless."
- "[This] PHR would save me a lot of space!"
- "It seems pretty straightforward and easy to use. It's helpful to be able to track your information without having to deal with a lot of paperwork and documents."

*Descriptive Statistics of Spanish group (N=6):*

- 100% of subjects surveyed own a computer in their home.
- 100% of subjects surveyed have Internet access in their home.
- 83% of subjects surveyed maintain records for their child

*Cantonese group (N=16):*

- 100% of subjects surveyed own a computer in their home.
- 75% of subjects surveyed have Internet access in their home.
- 63% of subjects surveyed maintain records for their child.
- 50% of subjects expressed concern about electronic privacy.
- 37.5% of subjects surveyed felt comfortable using the Internet

## Preliminary Conclusions

- A **lack of awareness** of PHRs was noted in focus groups and usability studies: raising awareness will be key.
- Access to computers and the Internet are less significant barriers to use of an electronic Personal Health Record. Specific computer skills training is more appropriate.
- **Localization support:** linguistically appropriate tools are crucial for their effective use by non-English speakers.
- **Trust and privacy** remain as concerns for parents, but are outweighed by the potential benefits of PHRs.

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Information Management Strategies for Child's Check-ups  
(Cantonese focus-group, N=16)

