

# Feasibility of Providing Long-Term Follow-Up for Congenital Hypothyroidism Patients by Primary Care Providers in California and Hawaii

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# Background

- Increasing national attention on long-term follow-up of children diagnosed through newborn screening (NBS)
- HRSA grant 2013: Integrating Newborn Screening Long-Term Follow-up into Primary Care Practices
- California's long-term follow-up model: specialty care center-based
  - MSMS disorders: July, 2007
  - Endocrine disorders: November, 2011
  - Hemoglobin disorders: November, 2011

## Background

- Primary Congenital Hypothyroidism (PCH) affects 1 in 2,000 live births in California (CA)
- Most children with PCH need lifelong treatment
- Delayed or inappropriate treatment may cause severe neurocognitive disabilities
- PCH is easier to manage compared to other disorders screened for by NBS
- Little is known about the role of primary care providers (PCPs) in PCH management

# Background

- **The PCH Project:** a three-year grant funded by the Health Resources and Services Administration (HRSA) from 2013 through 2016
- **Participating states:** California and Hawaii
- **Target population:** PCPs and patients with PCH

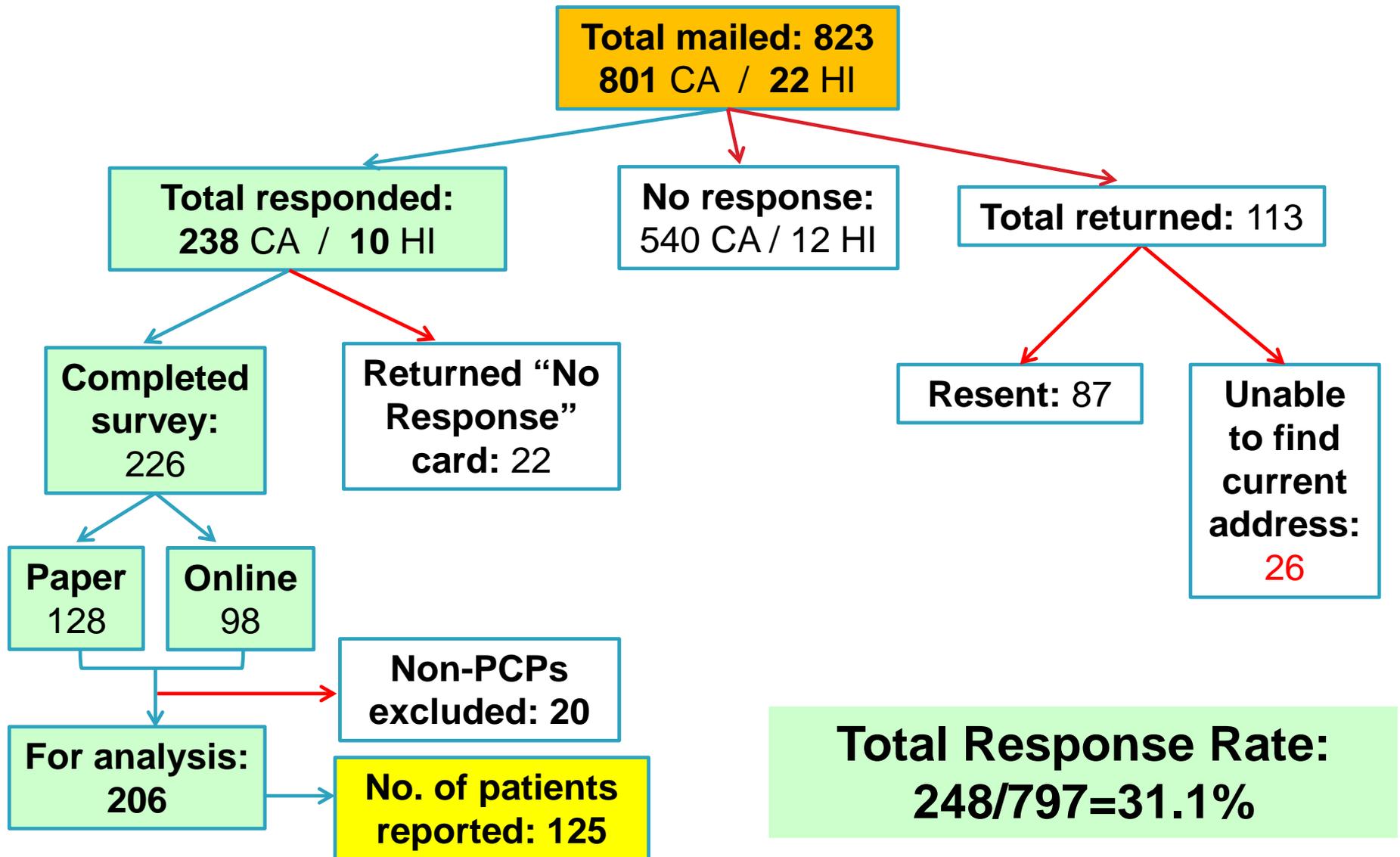
# Study Objectives

- 1) **Assess** the willingness and capability of PCPs to provide long-term care for patients with PCH and their needs for PCH-related continuing medical education
- 2) **Evaluate** the current case management patterns and clinical outcomes
- 3) **Assess** PCPs' willingness to obtain informed consent and provide data to the PCH Project long-term follow-up (LTFU) database
- 4) **Investigate** the practicality of providing real time LTFU data by PCPs and identify barriers incurred
- 5) **Improve** PCPs' knowledge on PCH and increase their capability of providing LTFU for patients with PCH

# Study Methods

- **Provider-Based Cross-Sectional Survey (CSS)**
  - Objectives 1–3, completed
  - All PCPs who were listed as contact doctor for  $\geq 1$  patients with PCH during 2009–2014 (N=823)
- **Two-Year Long-Term Follow-Up Data Collection**
  - Objective 4, in progress
  - Respondents to the CSS who indicated interest in LTFU
- **Post Follow-Up Survey**
  - Objective 4, to be implemented
  - PCPs who participated in the LTFU data collection
- **Continuing Medical Education about PCH**
  - Objective 5, to be implemented

# Response Rate

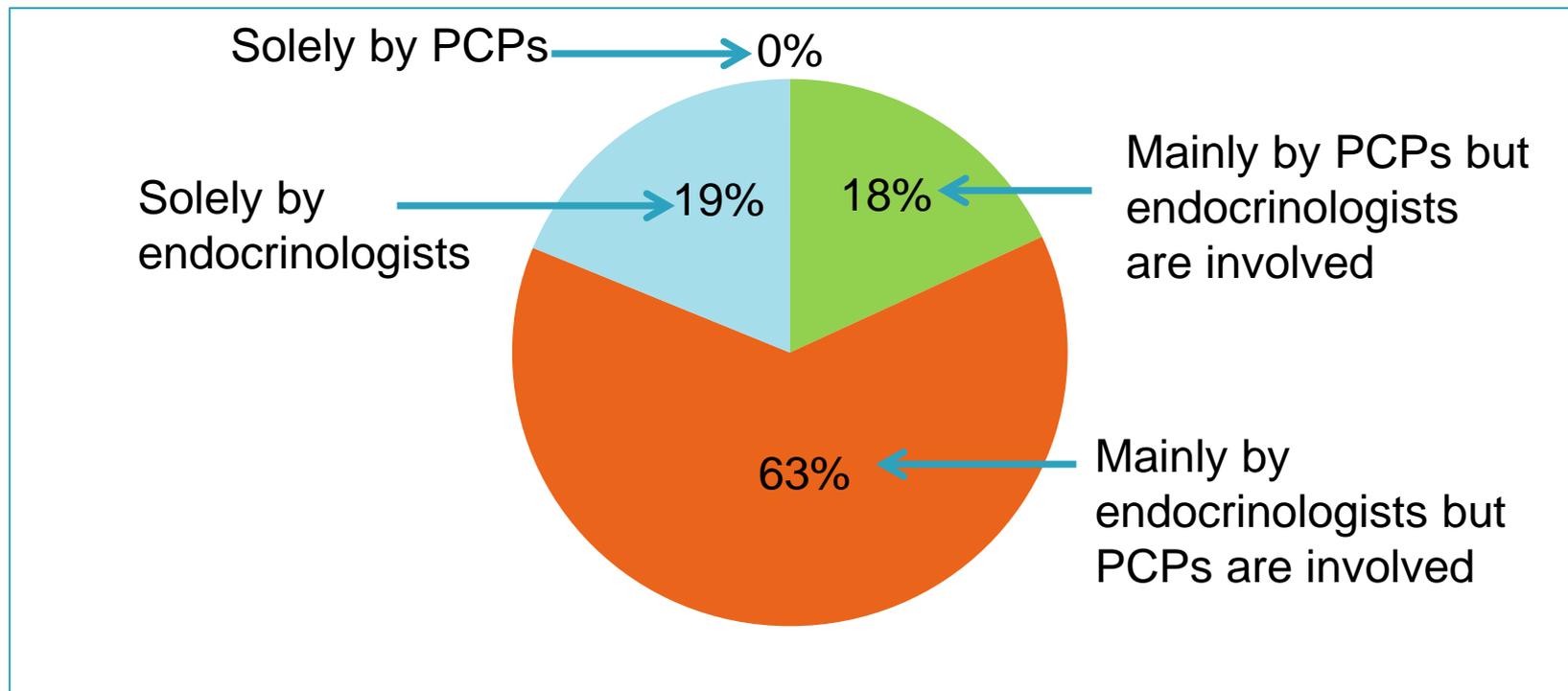


# Characteristics of the Responding PCPs

Characteristics	%	Characteristics	%
<b>Male sex</b>	51.0	<b>Type of Practice</b>	
<b>Race/ethnicity</b>		Private practice	45.1
Hispanic/Latino	7.1	Group practice	33.3
White	46.0	Hospital-based practice	4.4
Asian	37.9	HMO	3.9
Black	2.5	Community health center	13.2
Other	6.5	<b>Medical Specialty</b>	
<b>% of Hispanic patients</b>		Family Practice	8.2
<15%	23.1	General Pediatrics	91.8
15–29%	26.6	Other pediatrics	2.9
30–49%	16.3	<b>Years in medical practice</b>	
≥50%	34.0	Median (range)	18 (2, 43)

# Case Management Patterns

- **78.1%** PCPs reported currently caring for one or more patients with PCH
- Who usually manages the patient's PCH conditions?



# Case Management Patterns

- **90.7%** PCPs reported willingness to provide long-term care to new patients with PCH
- Perceived barriers for providing long-term care for patients with PCH

Barriers	%
Need guidance or support from endocrinologists	60.7
Not familiar with the PCH treatment guidelines	28.2
Need more staff time to coordinate care	15.0
Patients are not compliant with care	14.1
Don't have enough time	11.6
PCH long-term care is too complicated	10.2
Don't get enough reimbursement	10.2
Anticipate no barriers	19.9

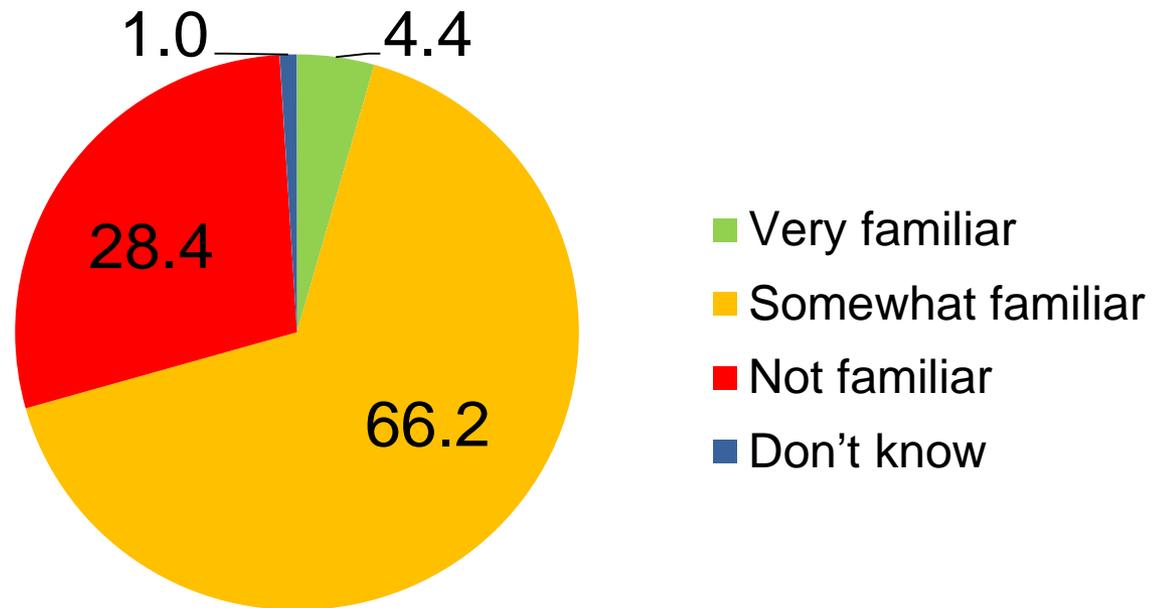
# Care Coordination

- **94.1%** of PCPs reported knowing a pediatric endocrinologist with whom they may consult for PCH
- Difficulties encountered when coordinating care with pediatric endocrinologists for patients with PCH

Difficulties Encountered	%
No difficulties	65.5
Some endocrinologists are hard to reach	<b>29.6</b>
Other (e.g., difficult to make referral, transportation, late response)	10.7
Some endocrinologists are hard to work with	4.4
Could not find endocrinologists to work with in my area	4.4
Some ask for compensation for phone consultation	0.5

# Knowledge on PCH Management

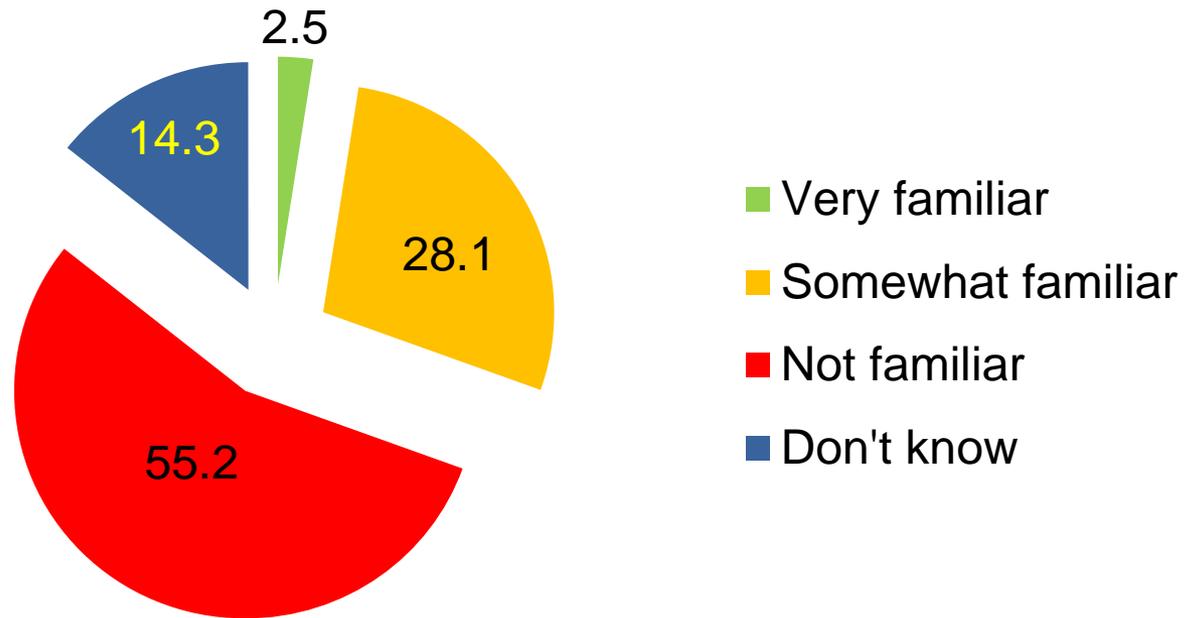
- Familiarity with the PCH-related treatment guidelines



- Only **49.1%** respondents correctly answered the recommended frequency of blood tests to monitor PCH patients over the patients' lifespan

# Knowledge on PCH Management

- Familiarity with Transient CH diagnostic indications



- Only **23.1%** know at what age to consider trying the patient off the levothyroxine treatment to rule out transient CH

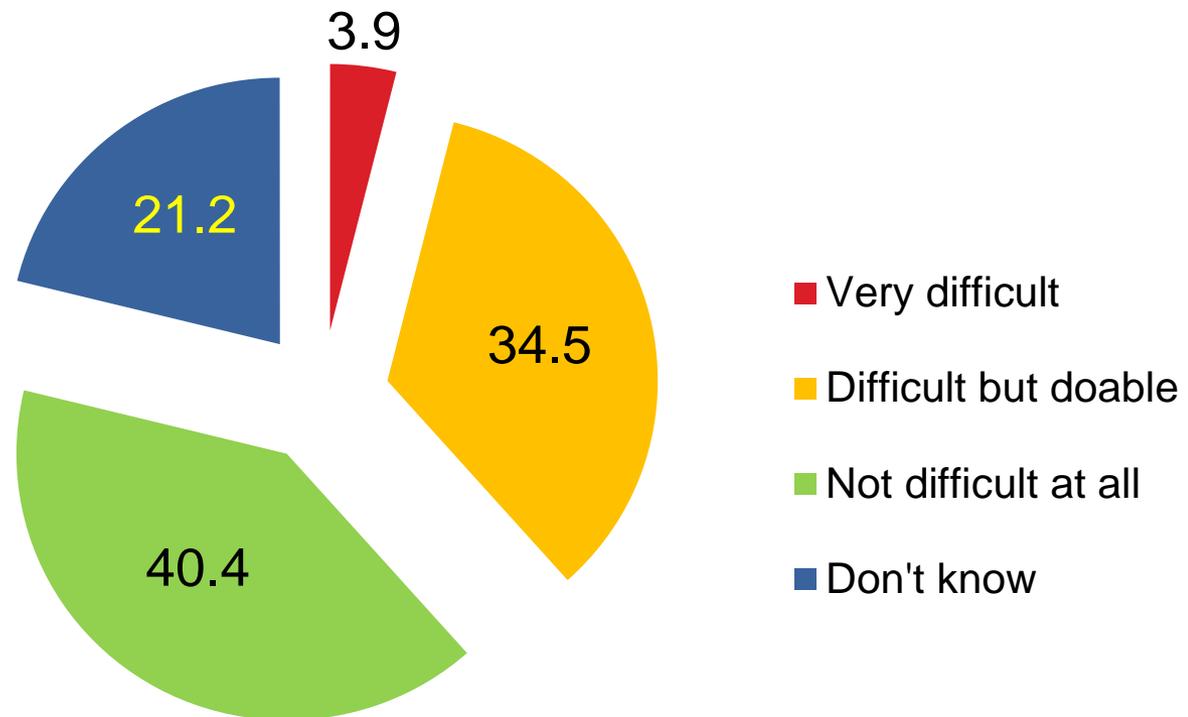
# Continuing Medical Education (CME) Needs

- **83.9%** of PCPs reported that they are likely or very likely to participate in CME on PCH LTFU if it is available
- Preferred format for CME

Preferred Format	%
Webinars	<b>61.2</b>
Grand rounds presentations	34.0
In-person classes	29.6
One-on-one consultation with Endocrinologists	19.4
Other	14.6

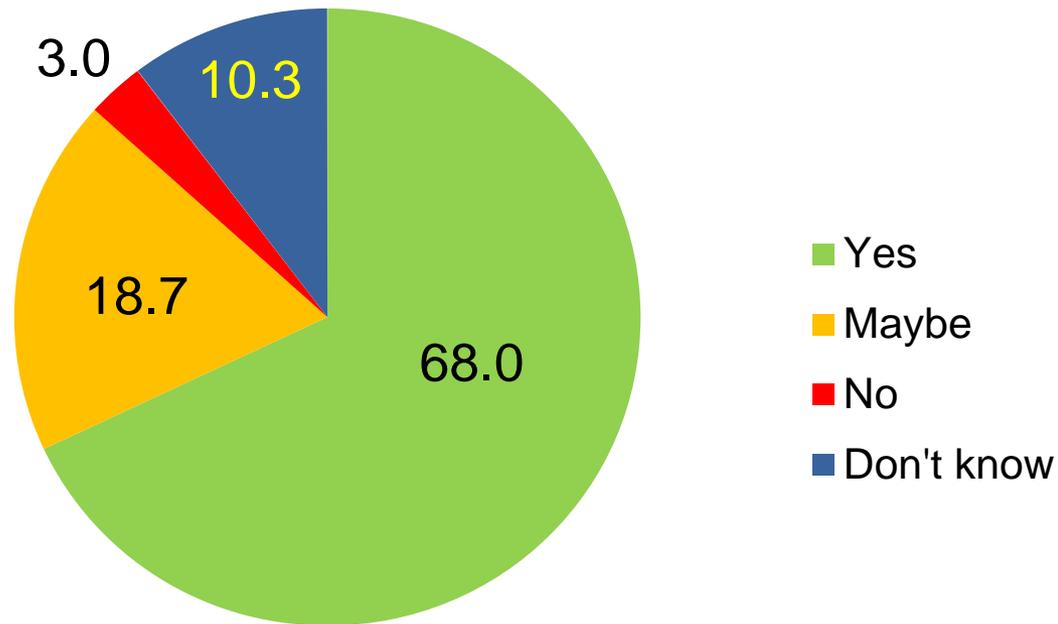
# Feasibility of Obtaining Informed Consent

- **76.3%** of PCPs reported willingness to obtain informed consent; only **5.4%** said not willing to do so
- Difficulty in obtaining informed consent from patients



# Feasibility of Providing LTFU Data

- Willingness to provide LTFU data:



- 35.0%** of respondents prefer web-based data collection forms, **35.5%** prefer paper forms, **22%** no preference

- Compensation required to provide Long-Term Follow-Up data

Compensation	%
\$50/patient/year	7.2
\$100/patient/year	21.6
\$150/patient/year	15.7
\$200/patient/year	20.9
No compensation is needed	<b>23.5</b>
Don't know/Other	11.1

# Reasons for Not Willing to Provide Long-Term Follow-Up (LTFU) Data

Reasons (N=27)	%
Don't have enough staff or time to enter data	37.0
Do not provide long-term care for patients' PCH	37.0
Have concerns over patient's privacy	18.5
The LTFU database is not relevant to clinical practice	7.4
It is not important to collect LTFU data for PCH	0
Other reasons	25.9

# Conclusions

- The majority of PCPs are willing to provide long-term care for patients with PCH
- There is a lack of knowledge about up-to-date PCH-related treatment and management standards
- Support from endocrinologists is needed for successful management of cases
- Most PCPs are willing to obtain informed consent from patients and provide long-term follow-up data with a reasonable compensation

# Acknowledgement

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