Clinical Sequence Evidence-Generating Research Consortium

**CSER Decliner Survey – Parental Decliner Version**

Proposed by: CSER Survey Measures & Outcomes WG

Version 1.2, Dated 5/2/2018

# Survey Measures and Outcomes

## [NECESSARY] DECLINER DEMOGRAPHICS

**Who are you?:**

* Patient
* Parent of patient

**Child Information**

Sex (1 item):

What sex were you assigned at birth, on your original birth certificate? (Check one)

🞏0 Female

🞏1 Male

🞏2 Prefer not to answer

OPTIONAL ADDITIONAL QUESTION FOR “TWO-STEP” APPROACH:

How do you describe yourself? (Check one)

🞏0 Female

🞏1 Male

🞏2 Transgender

🞏3 Do not identify as female, male, or transgender

Age (1 item):

What is your date of birth?

MM: \_\_\_\_ DD: \_\_\_\_ YYYY: \_\_\_\_\_\_\_\_

NOTE: Use date of survey completion to convert to age (in years) for sharing across sites. A birth date is identifying information and cannot be shared outside of a given site in date format

Language:

1. 1 Do you speak another language besides English?

🞏0 Yes [PRG: If selected, show next 2 Qs]

🞏1 No

1. How well do you speak English?

🞏0 Native English-speaker

🞏1 Very well

🞏2 Well

🞏3 Not well

1. What language do you prefer to speak with your child’s doctors?

🞏0 English

🞏1 Another language

🞏2 I am equally comfortable discussing my child’s medical care in both English and another language

OPTIONAL:

1. [PRG: If “another language” selected in Q3:] Please tell us which language you prefer to speak with your child’s doctors: [PRG: DROPDOWN LIST:] Spanish, Vietnamese, Chinese (Mandarin, Cantonese, or other Chinese language), Tagalog, German, French, Korean, Russian, Arabic, Other (please specify): [PRG: FREE TEXT]

**Parent 1 Information (Pediatric Patients Only)**

Sex (1 item):

What sex were you assigned at birth, on your original birth certificate? (Check one)

🞏0 Female

🞏1 Male

🞏2 Prefer not to answer

OPTIONAL ADDITIONAL QUESTION FOR “TWO-STEP” APPROACH:

How do you describe yourself? (Check one)

🞏0 Female

🞏1 Male

🞏2 Transgender

🞏3 Do not identify as female, male, or transgender

Age (1 item):

What is your date of birth?

MM: \_\_\_\_ DD: \_\_\_\_ YYYY: \_\_\_\_\_\_\_\_

NOTE: Use date of survey completion to convert to age (in years) for sharing across sites. A birth date is identifying information and cannot be shared outside of a given site in date format

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OPTIONAL:

1. [PRG: If “another language” selected in Q3:] Please tell us which language you prefer to speak with your child’s doctors: [PRG: DROPDOWN LIST:] Spanish, Vietnamese, Chinese (Mandarin, Cantonese, or other Chinese language), Tagalog, German, French, Korean, Russian, Arabic, Other (please specify): [PRG: FREE TEXT]

Income (2 items):

What was your household’s total family income (before taxes) from all sources in the last year? (Check one)

🞏0 $5,000 to $9,999

🞏1 $10,000 to $14,999

🞏2 $15,000 to $19,999

🞏3 $20,000 to $24,999

🞏4 $25,000 to $29,999

🞏5 $30,000 to $39,999

🞏6 $40,000 to $49,999

🞏7 $50,000 to $59,999

🞏8 $60,000 to $69,999

🞏9 $70,000 to $79,999

🞏10 $80,000 to $99,999

🞏11 $100,000 to $119,999

🞏12 $120,000 to $139,999

🞏13 $140,000 or more

OR USE BRIEFER ALTERNATIVE SET OF RESPONSES

🞏0 Less than $20,000

🞏1 $20,000 to $39,999

🞏2 $40,000 to $59,999

🞏3 $60,000 to $79,999

🞏4 $80,000 to $99,999

🞏5 $100,000 to $139,999

🞏6 $140,000 or more

How many people (children and adults) were supported by this income in the last year? \_\_\_\_\_

Education level (1 item):

What is the highest grade or level of school you completed or the highest degree you received? (Check one)

🞏0 No schooling completed

🞏1 Elementary school (kindergarden through 5th grade)

🞏2 Middle school (6th, 7th, or 8th grade)

🞏3 Some high school (9th, 10th, or 11th grade)

🞏4 12th grade, no diploma

🞏5 High school graduate (diploma or GED or equivalent)

🞏6 Some post-high school training (college or occupational, technical, or vocational training), no degree or certificate

🞏7 Completed occupational, technical, or vocational program, received degree or certificate

🞏8 Associate (2-year) college degree

🞏9 Bachelor’s degree (for example: BA, AB, BS)

🞏10 Master’s degree (for example: MA, MS, MEng, MEd, MSW, MBA)

🞏11 Professional degree (for example: MD, DDS, DVM, LLB, JD)

🞏12 Doctoral degree (for example: PhD, EdD)

OR USE BRIEFER ALTERNATIVE SET OF RESPONSES

🞏0 Less than high school (less than 9th grade)

🞏1 Some high school (9th to 12th grade), no diploma

🞏2 High school graduate (diploma or GED or equivalent)

🞏3 Some post-high school training (college or occupational, technical, or vocational training), no degree or certificate

🞏4 Associate (2-year) college degree, or completed occupational, technical, or vocational program and received degree or certificate

🞏5 Bachelor’s degree (for example: BA, AB, BS)

🞏6 Graduate or professional degree (for example: MA, MBA, JD, MD, PhD)

Insurance status (2 items):

Are you covered by health insurance or some other kind of health care plan? (Include health insurance obtained through employment or purchased directly as well as government programs like Medicare and Medicaid that provide medical care or help pay medical bills) (Check one)

🞏0 No

🞏1 Yes

IF YOU ARE COVERED: What kind or kinds of health insurance or health care coverage do you have? (Check all that apply)

🞏0 Private health insurance, employment based

🞏1 Private health insurance, directly purchased

🞏2 Government plan, Medicare

🞏3 Government plan, Medicaid

🞏4 Government plan, Military health care

🞏5 Other type of insurance (Please Describe): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

🞏6 No coverage of any type.

**Race and Ethnicity**

What category or categories best describe you? Check all that apply.

* American Indian, Native American, or Alaska Native
* Asian
* Black or African American
* Native Hawaiian/Pacific Islander
* White or European American
* Middle Eastern or North African/Mediterranean
* Hispanic/Latino(a)
* Prefer not to answer
* Unknown/none of these fully describe me

Variation across sites:

Sites may collect additional information on race ethnicity as long as the information can be summarized according to the categories shown in the ELSI and Diversity Measure. For example, a site may want to collect more detailed information on Asian ethnicity and may use additional categories to capture differences within the broader category.

**Parent 2 Information (Pediatric Patients Only)**

Sex (1 item):

What sex were you assigned at birth, on your original birth certificate? (Check one)

🞏0 Female

🞏1 Male

🞏2 Prefer not to answer

OPTIONAL ADDITIONAL QUESTION FOR “TWO-STEP” APPROACH:

How do you describe yourself? (Check one)

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Age (1 item):

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OPTIONAL:

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## [NECESSARY] DECLINER REASONS (Open Ended)

1. Please tell us why you decided not to join this study: [open response]

**Instructions for investigator: please select every box that corresponds to the reasons given for non-participation in the free text above.**

**Study**

* The study will take too much of my time/too busy/no time
* The study does not give me enough money for the amount of time it requires from me
* The study location or visits are not convenient for me/too far/unable to travel/no transportation
* I do not wish to give the study samples (blood, saliva, etc.)

**Privacy**

* Results are stored in my/my child’s electronic health record
* My/my child’s genetic results could be seen by:
  + The government
  + My employer
  + My insurance company
* My/my child’s genetic results could be used to discriminate against me/my child by my:
  + Health Insurance
  + Life Insurance
  + Long-Term Care Insurance
  + Disability Insurance
  + Other [Free Text]

**Health**

* I am overwhelmed by my own/my child’s health problems right now
* I do not want more testing than my own/my child’s doctor recommends
* I am too ill

**Do not want certain types of genetic results**

* Results that aren’t related to my own/my child’s health problems right now
* Results that only cause health problems in adults\*Kaiser remove\*
* Results that don’t affect my health but could be important for my children or other family members
* Results that are uncertain
* Results about conditions with no treatment

**Other**

* Religious/spiritual reasons
* Genetic test results may affect my family relationships
* I want my child to choose for him/herself when he/she is an adult \*Kaiser remove\*
* Not interested in [my child] participating in research (general)Not interested in [my child]participating in genetics research
* Too many other competing demands (caring for others, long work hours)
* Other [Free Text]
* **REFUSED TO ANSWER/NO REASON PROVIDED**

## [OPTIONAL] DECLINER REASONS (Multiple Choice)

1. [OPTIONAL] This list is from other patients/parents who decided not to join studies like this one. Did any of these reasons affect your decision not to join this study? Please choose up to three reasons.

* The things I/my child need to do to be in the study didn’t work well for me
* I have concerns about my privacy
* I am not interested in participating in research
* My/my child’s current health condition is all I want to focus on right now
* I don’t want genetic research results from this study
* I’m worried about how I will cope with the genetic information I might receive

# CHANGELOG

**VERSION 1.2**

**May 1st 2018**

* Added revised language preference questions

**May 2nd 2018**

* Added response items to optional reason for declining question(I have concerns about my privacy, I am not interested in participating in research)

**VERSION 1.1**

**March 28th 2018**

* Added single-item Race & Ethnicity question from Parent Baseline Measure Packet