****Clinical Sequence Evidence-Generating Research Consortium

CSER Parental Patient Measures – BASELINE

Proposed by: multiple CSER Working Groups

Version 1.5, Dated 7/16/2018

## Demographics

### Sex

What sex was your child assigned at birth, on the original birth certificate? (Check one)

🞏0 Female

🞏1 Male

🞏2 Prefer not to answer

OPTIONAL ADDITIONAL QUESTION FOR “TWO-STEP” APPROACH:

How does your child describe themselves? (Check one)

🞏0 Female

🞏1 Male

🞏2 Transgender

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

### Age

What is child’s 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. Do you speak another language besides English?
* Yes [PRG: If selected, show next 2 Qs]
* No
1. How well do you speak English?
* Native English-speaker
* Very well
* Well
* Not well
1. What language do you prefer to speak with your child’s doctors?
* English
* Another language
* 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]

### Income

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

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 (kindergarten 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

Is your child 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 YOUR CHILD IS COVERED: What kind or kinds of health insurance or health care coverage do the 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.

### Country of Origin

A major goal of this research is to increase diversity in genomic research so that new advances in genomic medicine are available to everyone. To do this, we need to understand how our participants identify with different racial and ethnic categories.

Where were you born? (country) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Estimated time to administer 00:01:20

### Access to care

1. Has there been any time in the last 12 months when you wanted or needed your child to see a doctor or health care professional and did not?

🞏 Yes

🞏No

    if yes:

2.  Why did your child not see a doctor or health care professional when you wanted or needed them to in the last year?

🞏 I could not afford it.

🞏 It was too difficult to get there.

🞏 I do not like doctors and avoid going.

🞏 I did not want to get bad news.

🞏 I did not have time.

🞏 I decided to take care of it on my own.

🞏 I decided to wait and see if the problem would go away on its own.

🞏 The doctor was not available to see my child.

### BRIEF Health Literacy Survey

*Citation: Chew, Lisa D., et al. "Validation of screening questions for limited health literacy in a large VA outpatient population." Journal of general internal medicine 23.5 (2008): 561-566.*

How often do you have someone (like a family member, friend hospital/clinic worker or caregiver) help you read medical materials?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Always | Often | Sometimes | Occasionally | Never |

2. How often do you have problems learning about your medical conditions because of difficulty understanding written information?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Always | Often | Sometimes | Occasionally | Never |

3. How often do you have a problem understanding what is told to you about your medical condition?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Always | Often | Sometimes | Occasionally | Never |

4. How confident are you filling out medical forms by yourself?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Not at all | A little bit | Somewhat | Quite a bit | Extremely |

### Subjective Numeracy Scale

*Citation McNaughton CD, Cavanaugh KL, Kripalani S, Rothman RL, Wallston KA. Validation of a Short, 3-Item Version of the Subjective Numeracy Scale. Med Decis Making. 2015;35(8):932–936. PMCID: PMC4592371*

 For each item, rate yourself on the scale from ‘Not at all good (1)’ to ‘extremely good (6)’

1. How good are you at working with fractions “Not at all good (1)’ to ‘extremely good (6)’

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Not at all 1  | 2 |  3 | 4 | 5  | Extremely good6 |

2. How good are you at figuring out how much a shirt will cost if it is 25% off? Not at all good (1)’ to ‘extremely good (6)’

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Not at all 1  | 2 |  3 | 4 | 5  | Extremely good6 |

3. How often do you find numerical information to be useful? ‘Never (1) to Very Often (6).”

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Never 1  | 2 |  3 | 4 | 5  | Very Often6 |

### Zip Code

What is your zip code? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

### Single item race measure with Hispanic ethnicity

What category or categories best describe your child? 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 my child

*Notes:*

If parents are completing forms in studies of children, information on race/ethnicity should be collected for each parent.

Sites may collect additional information on race ethnicity as long as the information can be summarized according to the categories shown in this 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.

## Health Care System Distrust Scale

*Adapted from: Shea JA, Micco E, Dean LT, McMurphy S, Schwartz JS, Armstrong K. Development of a revised Health Care System Distrust scale. J Gen Intern Med. 2008 Jun;23(6):727–732. PMCID: PMC2517896*

Prefacing Instructions:

By Health Care System we mean: hospitals, community clinics, and labs as well as organizations involved in health such as insurance companies and drug companies. We are not including people such as doctors, nurses, specialists, x-ray technicians, medicines, or office staff. We are just talking about the organizations.

**1) The Health Care System does its best to make patients' health better**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

**2) The Health Care System covers up its mistakes**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

**3) Patients receive high quality medical care from the Health Care System**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

**4) The Health Care System makes too many mistakes**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

**5) The Health Care System puts making money above patients' needs**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

**6) The Health Care System gives excellent medical care**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

**7) Patients get the same medical treatment from the Health Care System no matter what the patient's race or ethnicity**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

**8) The Health Care System lies to make money**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

**9) The Health Care Systemexperiments on patients without them knowing**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

## Quality of Life Ascertainment FOR ALL PATIENTS – Visual Analog Scale

*See Scale on next page*

****

* We would like know how good or bad your child’s health is TODAY.
* This line is numbered 0 to 100.
* 100 means the best health you can imagine.

0 means the worst health you can imagine.

* Mark an X on the scale to indicate how your child’s health is TODAY
* Now please write the number you marked on the scale in the box below

YOUR CHILD’S HEALTH TODAY=

How good is your child’s health TODAY

## Quality of Life Ascertainment FOR ALL PATIENTS - PedsQL Generic Core Scale

Due to survey licensure, we are unable to share copies of PedsQL surveys we are using, but will include the domain areas used in CSER (see below table).

More information about the PedsQL can be found on their website @ <http://www.pedsql.org/>. Some sample versions of these surveys can be found @ <http://www.pedsql.org/pedsql13.html>.

|  |  |  |
| --- | --- | --- |
| **CSER Use Case** | **English** | **Spanish** |
| Infant (1 - 12 months) | Parent Proxy: PedsQL™ Infant (1-12 months) | Parent Proxy: [SPANISH] PedsQL™ InfantSpanish version contains both Infant (1-12 months) and Infant (13 - 24 months) |
| Infant (13 - 24 months) | Parent Proxy: PedsQL™ Infant (13 - 24 months) |
| Generic Core Scale, Toddlers (age 2 - 4 years) | Parent Proxy: PedsQL Parent Report for Toddlers (ages 2-4) | Both Parent Proxy and Child Self Reports (if applicable): [SPANISH] PedsQL™ Generic Core ScalePlease note this Spanish version contains all age groups |
| Generic Core Scale, Young Child (5 - 7 years) | Parent Proxy: PedsQL Parent Report for Young Child (ages 5-7)Child Self Report: PedsQL Young Child Report (ages 5-7) |
| Generic Core Scale, Child (8 - 12 years) | Parent Proxy: PedsQL Parent Report for Child (ages 8-12)Child Self Report: PedsQL Child Report (ages 8-12) |
| Generic Core Scale, Teenagers (13 - 18 years) | Parent Proxy: PedsQL Parent Report for Teen (ages 13-18)Teen Self Report: PedsQL Teen Report (ages 13-18) |
| Cancer Module, Young Child (5 - 7 years) | Parent Proxy: PedsQL Cancer Parent Report for Young Child (ages 5-7) | Parent Proxy: [SPANISH] PedsQL™ Cancer ModulePlease note this Spanish version contains all age groups |
| Cancer Module, Child (8 - 12 years) | Parent Proxy: PedsQL Cancer Parent Report for Child (ages 8-12) |
| Cancer Module, Teen (13 - 18 years) | Parent Proxy: PedsQL English Cancer Parent Report for Teens (13-18) |