ScHARe
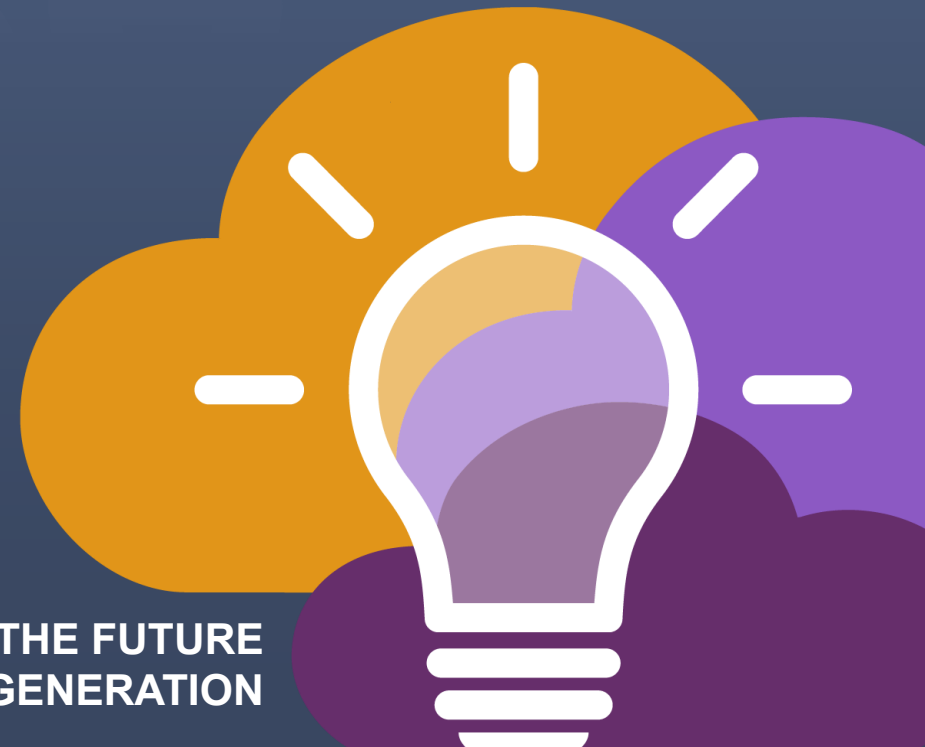
CDEs in Survey Format

BE A PART OF THE FUTURE
OF KNOWLEDGE GENERATION

ScHARe Core CDEs

NIH CDE Repository:
https://cde.nlm.nih.gov/home

NIH Endorsed

- Age
- Birthplace
- Zip Code
- Race and Ethnicity
- Sex
- Gender
- Sexual Orientation
- Marital Status
- Education
- Annual Household Income
- Household Size

- English Proficiency
- Disabilities
- Health Insurance
- Employment Status
- Usual Place of Health Care
- Financial Security / Social Needs
- Self Reported Health
- Health Conditions (and Associated Medications/Treatments)
- **NIMHD Framework***
- **Health Disparity Outcomes***] * Project Level CDEs

For FUNDED PROJECT DATA – CDEs Centralized for Interoperability and Data Sharing

1. **Age**

What is the person's age? (collapse data over 89 yrs old / 2 yrs and under, report in months-does not exclude asking full birthdate)

_____   ☐ years   ☐ months

Project 5 Covid-19 Age https://cde.nlm.nih.gov/cde/search?q=PROJECT%205&nihEndorsed=true

2. **Birthplace**

Where were you born?

☐   In the United States, including U.S. Territories (Puerto Rico, Guam, U.S. Virgin Islands, American Samoa and Northern Mariana Islands) (**Select from Drop Down-not doable on word doc**)

☐   Outside the United States (**Select from Drop Down-ISSO categories-not doable on word doc**)

PhenX – Birthplace https://www.phenxtoolkit.org/protocols/view/10201 *ADAPTED-Territoires with US; instead of seperate*

Source for PhenX : American Community Survey (ACS), 2008

3. **ZIP code (caveat collapse zip codes w less than 10)**

   What is your current postal ZIP code? _____

   Project 5 Covid-19 Address Postal Code https://cde.nlm.nih.giov/deView?tinyId=w BHatIMoA

4. **Self-Identification (This question's intent is to get at bare minimum of identification, which will be determined by the changes proposed by OMB. Study can collect details of Race and Ethnicity as preferred. This does not supplant other required R/E reporting. Awaiting OMB.)**

   Please select the racial category or <u>categories</u> with which you most closely identify. *(select all that apply)*

   ☐   American Indian or Alaska Native|

   ☐   Asian or Asian American

   ☐   Black or African American

   ☐   Hispanic or Latino

   ☐   Native Hawaiian or Other Pacific Islander

   ☐   Middle Eastern or North African (in current reporting tables will be reported as white)

   ☐   White

   ScHARe working group preference based on potential classifications in 2030 census https://www.npr.org/2021/09/30/1037352177/2020-census-results-by-race-some-other-latino-ethnicity-hispanic#:~:text=And%20under%20that%20combined%20question%2C%20the%20list%20of,federal%20agencies%20collect%20data%20on%20race%20and%20ethnicity.

Potential new approach!

5. **Sex**

What was your sex assigned at birth, on your original birth certificate?

☐ Female

☐ Male

☐ Intersex

☐ None of these describe me

☐ Prefer not to answer

PhenX Protocol - Biological Sex Assigned at Birth   https://www.phenxtoolkit.org/protocols/view/11601

All of Us Research Program, Participant Provided Information (PPI), 2018

National Academies Sciences, Engineering, Medicine report: Measuring Sex, Gender Identity, and Sexual Orientation
https://www.nationalacademies.org/our-work/measuring-sex-gender-identity-and-sexual-orientation-for-the-national-institutes-of-health
and All of Us
chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://allofus.nih.gov/sites/default/files/aou_ppi_basics_version.pdf

Potential new approach!

6. Gender

What is your current gender? [Select only one]

☐   Man

☐   Woman

☐   Non-Binary

☐   Transgender

☐   None of these describe me-I would like to consider additional options

Are any of these a closer description to your gender identity?

     [ ] Trans man/Transgender Man/FTM
     [ ] Trans woman/Transgender Woman/MTF
     [ ] Genderqueer
     [ ] Genderfluid
     [ ] Gender variant
     [ ] Questioning or unsure of your gender identity
     [ ] None of these describe me, and I want to specify _____

☐   Prefer not to answer

Potential new approach!

7. Sexual orientation

Which of the following best represents how you think of yourself? [Select only one]

☐   Lesbian

☐   Gay

☐   Straight, that is, not gay or lesbian, etc.

☐   Bisexual

If none of the above represents you, are any of these a closer description of how you think of yourself (drop down)

         [ ] Queer

         [ ] Polysexual, omnisexual, sapiosexual or pansexual

         [ ] Asexual

         [ ] Two-spirit

         [ ] Have not figured out or are in the process of figuring out your sexuality

         [ ] Mostly straight, but sometimes attracted to people of your own sex

         [ ] Do not think of yourself as having sexuality

         [ ] Do not use labels to identity yourself

         [ ] Don't know the answer

         [ ] No, I mean something else (optional free text) _____

☐   Prefer not to answer

8. Marital status

What is your current marital status?

- ☐ Married
- ☐ Living as married or living with a romantic partner
- ☐ Divorced
- ☐ Widowed
- ☐ Separated
- ☐ Single, never been married-not living with romantic partner
- ☐ Prefer not to answer

9. Education

What is the highest level of education you have completed?

☐ No formal schooling

☐ Primary/Grade/Elementary School (approximately grades 1st through 5th)

☐ Middle School/Lower Secondary Education (approximately grades 6th through 8th)

☐ Secondary/High School/Upper Secondary (grades 9th through 11th) without a high school diploma

☐ General Educational Diploma (GED)

☐ Secondary/High School/Upper Secondary (grades 9th through 12th) with a high school diploma

☐ Occupational/Technical/Vocational Programs/Short Cycle Tertiary Education - Associate's Degree (approximately 2 years)

☐ College/University/Bachelor's Degree/Equivalent Tertiary Education (approximately 3-5 years)

☐ Graduate/post-graduate degree/professional degree/ (JD, PhD, MD, EdD, Eng, Master's Degree, etc.)

International Standard Classification of Education (ISCED)
https://datatopics.worldbank.org/education/wRsc/classification#:~:text=The%20International%20Standard%20Classification%20of,revised%20in%201997%20and%202011
and
USA standards of Education https://nces.ed.gov/programs/digest/d01/fig1.asp

Unique – potentially mappable

Potentially mappable

10. Annual household income range

What is your annual household income from all sources within family, not including roommates?

- ☐ Less than $10,000
- ☐ $10,000-$24,999
- ☐ $25,000-$34,999
- ☐ $35,000-$49,999
- ☐ $50,000-$74,999
- ☐ $75,000-$99,999
- ☐ $100,000-$149,999
- ☐ $150,000-$199,999
- ☐ $200,000 or more

All of Us - Basic Information Survey https://allofus.nih.gov/sites/default/files/aou_ppi_basics_version.pdf

BRFSS = Behavioral Risk Factor Surveillance System (CDC)

11. Household family size

Approximately how many individuals (adult and children) does your household family income support?

- ☐ _____

Project 5 Covid-19 Shared Living Space Number of Individuals https://cde.nlm.nih.gov/cde/search?q=PROJECT%205&nihEndorsed=true

12. English proficiency

We are interested in your own opinion of how well you speak English. Would you say you speak English:

- ☐ Very well
- ☐ Well
- ☐ Not well
- ☐ Not at all
- ☐ Refused
- ☐ Don't Know

PhenX Toolkit - English Proficiency https://www.phenxtoolkit.org/protocols/view/270201

Regents of the University of California. (2019). CHIS 2018 Adult Questionnaire, question number "QA18_G8" is represented in this protocol as question 1. Retrieved from http://healthpolicy.ucla.edu/chis/design/Pages/questionnairesEnglish.aspx

13. Disabilities

Do you have a disability or have serious difficulty with any of the following? Select all that apply.

- ☐   Deafness or difficulty hearing
- ☐   Blindness or difficulty seeing
- ☐   Difficulty concentrating, remembering, and deciding
- ☐   Difficulty walking or climbing stairs
- ☐   Difficulty dressing or bathing
- ☐   Difficulty doing errands alone
- ☐   Not disabled