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Assessing consent for and response to health survey components in an era of falling response rates: National Health and Nutrition Examination Survey, 2011–2018

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Abstract

Response rates for national population-based surveys have declined, including the National Health and Nutrition Examination Survey (NHANES). Declining response to the initial NHANES interview may impact consent and participation in downstream survey components such as record linkage, physical exams, storage of biological samples and phlebotomy. Interview response rates dropped from 68% in 2011–2012 to 53% in 2017–2018 for adults age 18 and older. Response was higher for children (1–17 years) but with a similar downward trend (2011–2012, 81%; 2017–2018, 65%). Despite declining interview response rates, changes in consent and response rates for downstream components over time have been mixed. Among those interviewed, the examination response rate was over 93%, consent for record linkage was over 90%, and consent for storage of specimens for future research was over 99%. The availability of a blood sample for storage ranged between 60%–65% for children and 78%–85% for adults.

Keywords

Survey; Informed consent; Biorepositories; Linkage; Response Rate

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1 Introduction

The National Health and Nutrition Examination Survey (NHANES) is made up of several components that together are designed to assess the health and nutritional status of adults and children in the United States. NHANES is conducted by the National Center for Health Statistics of the U.S. Centers for Disease Control and Prevention (CDC). Since 1999, NHANES has been a continuous population-based survey of the civilian non-institutionalized population of the United States, with data released every two years. The survey is unique in that it combines interviews and physical examinations that include collection of biological specimens. The survey is composed of three stages: screening to determine eligibility; an in-home interview; and a physical exam and laboratory assessment in a mobile examination center (MEC). Informed consent is obtained (as required by the Department of Health and Human Services (HHS) regulations, 45 Code of Federal Regulations 46) and it can be used to measure willingness to participate in complex and time-consuming surveys like NHANES (Office for Human Research Protection, 2016). Consent and participation occur in sequential components during the survey process (Figure 1). Response rates in the NHANES survey among those sampled has been decreasing over time (NHANES, 2019b). Our objective was to evaluate if consent to participate in and response to the survey components declined during the same period of falling interview response rates. This includes consent to participate in linkage of data to other administrative sources and storage of biologic samples for future research. Consent for DNA collection is also collected but is not included in this report because DNA collection for genetic research was discontinued in 2012. Consent to the survey and to future genetic and non-genetic research was reported for previous NHANES cycles (McQuillan, Pan, & Porter, 2006; McQuillan & Porter, 2011; McQuillan, Porter, Agelli, & Kington, 2003).

This report provides information on consent and response by certain demographic characteristics from NHANES 2015–2018 and evaluates trends over time from 2011 to 2018, as the decline in response rates started during these years.

2 Methods

In this report, in-house consent data from 2011–2018 was analyzed to calculate consent and response. Consent was defined as respondents or parents/guardians who agreed to participate in the survey and the various components by providing a signature of informed content. Response was defined as the participation in a survey component identified by the availability of associated data. For the household interview, consent and response usually occur simultaneously, with the interview immediately following the informed consent process. However, the timing of consent and response differs for subsequent components. Detailed definitions for each measure of consent and response are given below.

2.1 Consent and Response variables

Household interview consent and response among those sampled.—Selected households receive an advance letter to introduce the survey and then an NHANES interviewer visits the selected household to screen those who live in that house. If one or more persons are identified as eligible through the screening, they are designated as a

sample person. The NHANES interviewer explains survey participation to the sample person and the sample person then agrees or declines to participate in the survey. Respondents who agree to participate in the survey then read and sign the Household Interview Consent Form. Parents/guardians provide consent for minors, and emancipated adolescents age 16 and older consent for themselves. Consent to the household interview is defined as respondents or parents/guardians who agree to participate by providing a signature of informed content. Once consent is obtained, the sample person is now considered to be a study participant and the interviewer proceeds with the administration of the household interview (Figure 1).

All study participants consent to the interview at the time of the interview. The interview response rate is calculated by the number who participated in the interview out of those who were sampled through the screening process.

Linkage consent among those interviewed.—NHANES requests the social security numbers from all survey participants during the household interview, including minors. The social security number is collected for the sole purpose of conducting potential data linkages, such as linking to vital statistics records (death certificates) and health and other related records (e.g., Medicare records). Consent for linkage is obtained by the participant checking a box on the household interview consent form. In this report we provide the percent who consented to linkage among interviewed participants.

Examination consent and response among those interviewed.—After the household interview is completed, consent for the exam component is sought from adult participants, and parental permission is sought for participants who are minors. Consent to the examination is defined as participants or parents/guardians who agree to participate in the Mobile Exam Center (MEC) examination by providing a signature of informed consent. Once parental consent is obtained, children aged seven years or older receive separate information on the exam and sign an assent form agreeing to the examination. Both parental consent and child assent are required for participation among children aged 7–17 years in the examination component while parental consent alone is sufficient for children 0–6 years of age. An appointment for an examination in the MEC is given to those who provide consent. The exam response rate is calculated by the number who participated in the MEC examination out of those interviewed (% examined/interviewed). This is often referred to as a conditional response rate, since the exam response is conditional on whether the participant has completed the household interview. Additionally, we provide the final examination response rate, which is the number who participated in the MEC examination out of those identified as eligible through the screening process (% examined/sampled).

Consent for storage of biological samples for future research out of those interviewed.—Immediately after consent has been obtained for the examination, participants are presented with the Consent/Assent and Parental Permission for Specimen Storage (serum, plasma and urine) and Continuing Studies consent form. The household interviewer asks the survey participant to read the questions and answers (Q&As) provided on the consent form and answers any questions about specimen banking and possible future uses of specimens. Participants are informed both in the consent form Q&A's and by the interviewer that the results of any future research will not be sent to them. Individual

consent is obtained from adults, parental consent for minors, and additional individual assent is obtained for minors age 7–17 years. Consent was defined as respondents or parents/guardians who agreed to participate in storage of biological samples for future research by signature, among those interviewed.

Response rate for consent for future research with participation in phlebotomy.—Survey participants one year and older are asked to participate in phlebotomy. There is no separate consent process for phlebotomy; it is covered in the examination consent. However, as with any exam component, participants may still participate in the exam but decline to participate in phlebotomy during the exam. We provide the percent who participated in phlebotomy and who consented to future research among those examined. Participants who had at least some blood collected are defined as having participated in phlebotomy.

Complete phlebotomy with collection of a pristine sample.—Collected blood samples are aliquoted into priority vials and frozen and sent for immediate testing. Priority vials are samples of serum, plasma and urine that are dedicated to the specific tests included in each cycle's laboratory component (e.g., complete blood count). After priority vials are filled with enough blood or urine volume, any excess specimens are aliquoted into storage vials and sent directly to the CDC Biorepository (CBR) for storage. These storage vials are called pristine samples since they are sent to the CBR at the point of collection and are never thawed before use in any other study. They are only available for participants aged 3 years and older who have a signed consent document for allowing future research use of their biological samples. Participants with enough sample to fill both priority and pristine vials are considered to have a "complete" phlebotomy. Since pristine samples are aliquoted last in the phlebotomy protocol and less blood is collected from children under age 12, there is a greater chance for insufficient blood for a pristine sample in children. Among participants one year and older, "residual" sera samples are those collected in priority vials tested at laboratories, and with enough sample remaining for future testing among participants who consented to future research. Therefore, these residual samples have been subjected to at least one freeze-thaw cycle before they are sent to the NHANES contract biorepository and are not considered pristine. This report focuses only on the pristine sample collection among participants aged 3 years and older because this population represents the primary future research storage collection for NHANES. Additionally, the intent of storing pristine vials is to have a pristine sample available to CDC in case of a public health emergency. As an example, the stored samples were used to provide a baseline estimation of population infection after the 2009

Influenza A/H1N1 pandemic (Reed, Katz, Balish, & Fry, 2012) an emerging pathogen. The percent of participants who consented to future research, completed phlebotomy and had a pristine sample, out of those examined is provided.

2.2 Survey Sampling

NHANES uses a complex, stratified multistage probability cluster-sampling design (Johnson, Dorhmann, Burt, & Mohadjer, 2014). Analysis for this report is based on four

two-year cycles from 2011–2012 through 2017–2018. This time period is included in these analyses since consent response rates have been published for previous survey years (McQuillan et al., 2006; McQuillan & Porter, 2011; McQuillan et al., 2003). In addition, in 2011 the survey began oversampling the non-Hispanic Asian population in addition to the oversample of non-Hispanic black and Hispanic persons in order to make reliable estimates for these subgroups.

Because we are measuring response and consent rates using data collected to monitor survey operations, sample weights and the complex sample design were not applied in our analyses and we did not produce nationally representative estimates.

2.3 Covariates

Data were examined for those participants age 1 year and older and grouped as age 1–5, 6–11, 12–17, 18–39, 40–59, and age 60 years or older (only those aged 3 years and older were used for examining collection of pristine samples for future research because storage samples were not collected for children under age 3). Race and Hispanic origin were based on self-report and categorized as non-Hispanic white, non-Hispanic black, non-Hispanic Asian and all Hispanic. Participants who did not self-select into these categories were classified as “other” race/Hispanic origin. Interviews were conducted in English and Spanish. Participants who did not speak either language used a family member or a local interpreter to translate the interview from English. Additional variables examined included gender, birth place (defined as U.S. born [born in the 50 US states or DC] or non-U.S. born [not born in the 50 states or DC]), poverty index (calculated by dividing family income by a poverty threshold specific for family size using the U.S. Department of Health and Human Services’ poverty guidelines and categorized as either below poverty level or at or above poverty level), and educational level of the participant (for those aged 18 or older) or the head of household (for participants aged 1–17 years) (measured as the last year of school completed and self-categorized as having less than a high school education, having completed high school or a general equivalency diploma, or having more than a high school education).

2.4 Analysis

All percentages and 95% confidence limits were calculated using SUDAAN statistical software without weights and specifying simple random sampling for the design. Trends over time were evaluated using estimates from four 2-year cycles from 2011 to 2018. In the 2011–2012 cycle non-Hispanic Asians were oversampled in the survey for the first time. Estimates by demographic subgroup were presented for the last 4-year period (2015–2018) to present the most recent results using a larger analytic group to increase statistical stability. Differences between subgroups, pairwise differences between survey cycles and linear trends over time were evaluated by examining p-values from a Student’s T-test from a linear contrast procedure in SUDAAN. A p-value < 0.05 was considered statistically significant. No adjustments for multiple comparisons were made.

3 Results

3.1 Trends in Interview and Conditional Examination response rates

Figure 2 presents the overall response to the survey interview over time for the four 2-year survey cycles between 2011–2018 for children age 1–17 years and adults age 18 years and older. Among children sampled for NHANES, those who participated in the interview decreased from 81% in 2011–2012 to 65% in 2017–2018. Among adults, the interview response rate was 68% in 2011–2012 and 53% in 2017–2018. Similarly, among children sampled, the percent who participated in the examination decreased from 78% in 2011–2012 to 60% in 2017–2018. Among adults, response to the examination among those sampled decreased from 65% to 50% during the same time period.

The exam response rates among those interviewed (i.e., the conditional exam response rate) was high, above 90%. However, the percentage decreased over time from 96% in 2011–2012 to 93% in 2017–2018 for children and from 96% in 2011–2012 to 94% in 2017–2018 for adults ($p < 0.001$ test for linear trend over time for both).

3.2 Differences in examination response rates by demographic categories

Differences in exam response rates among those interviewed were calculated by demographic categories for the most recent 4-year time period (2015–2018) for children age 1–17 and adults age 18 and older (Table 1).

Among children, participation in the examination among those interviewed was 95% overall and increased with age ($p < 0.001$ test for trend), was higher among those born outside the U.S. (97%) compared to those U.S. born (94%, $p < 0.001$), was higher among those who completed the interview in a language other than English (96%) compared with English (94%, $p = 0.030$), and higher among those who lived below compared with at or above the poverty line (97% versus 95%, $p = 0.001$). Participation did not vary by gender, race and Hispanic origin or education of the head of household.

Among adults, participation in the examination among those interviewed was 95%, and higher among those age 40–59 (96%) compared with those age 60 and older (94% $p < 0.001$) or age 18–39 years (95%, $p = 0.004$). Participation also varied by race and Hispanic origin, higher among non-Hispanic black (96%) compared with non-Hispanic white (95%, $p = 0.003$), all Hispanic (95%, $p = 0.027$) or non-Hispanic Asian (94%, $p < 0.001$) persons. Participation in the examination did not vary by gender, U.S. birth status, language of the interview, poverty level, or individual education.

3.3 Trends over time for consent to data record linkage and biological samples for future research

Figure 3 presents the percentage of children and adults who consented to record linkage, and who consented to sample storage for future research out of those interviewed.

For both children and adults, over 90% of those interviewed provided a social security number and therefore consented to future record linkage to other health data sets. Linkage consent among children was 91% in 2011–2012 and 92% in 2017–2018 and there was no

consistent linear trend over time ($p > 0.05$ for test for linear trend) (Figure 3). Among adults, linkage consent increased over time from 91% in 2011–2012 to 94% in 2017–2018 ($p < 0.001$ for test for linear trend) (Figure 3).

At least 99% of those interviewed consented to the collection and storage of biological samples for future research among both children and adults (Figure 3). Variation in consent over time was very small (< 1%) ranging from a high of 99.5% for children in 2011–2012 and 99.8% for adults in 2013–2014 and a low of 99.0% among children and 99.1% among adults in 2017–2018 ($p < 0.01$ for test for linear trend for both). Note that this consent was obtained before examination and phlebotomy participation.

3.4 Differences in consent to data linkage by demographic categories

Among children age 1–17 years in 2015–2018, consent to record linkage among those interviewed was 92% overall and increased with age ($p = 0.006$) (Table 2). Consent to record linkage was higher for non-Hispanic white (95%) compared to Hispanic (93%, $p = 0.007$), non-Hispanic Asian (92%, $p = 0.047$) and non-Hispanic black persons (88%, $p < 0.001$). Consent was also higher when comparing non-Hispanic Asian ($p = 0.002$) and Hispanic ($p < 0.001$) to non-Hispanic black persons. Consent to record linkage did not vary by U.S. birth status, language of the interview, or poverty level but was higher among those whose head of household had a high school diploma (94%) compared to those with more than high school (92%, $p = 0.019$) and higher among females (93%) compared to males (92%, $p = 0.034$).

Consent to data record linkage among adults age 18 and older in 2015–2018, was 94% overall and increased with age ($p = 0.009$, linear test trend). Consent again varied by race and Hispanic origin and as among children was higher among non-Hispanic white (96%) compared to Hispanic (93%, $p < 0.001$), non-Hispanic Asian (92%, $p < 0.001$) and non-Hispanic black persons (91%, $p < 0.001$). As among children, consent was also higher among non-Hispanic Asians ($p = 0.033$) and all Hispanics ($p < 0.001$) compared to non-Hispanic black persons. Consent to data record linkage among adults did not vary by language of the interview, poverty level, or individual education but was higher among males (94%) compared to females (93%, $p = 0.022$) and higher among U.S. born (94%) compared to those born outside the U.S. (92%, $p < 0.001$)).

Consent to use of biological samples for future research was over 99% for both children and adults interviewed, with little variability by demographic characteristics therefore estimates of consent by cofactors were not presented.

3.5 Trends over time for participation in phlebotomy and for complete phlebotomy with the collection of a pristine sample for storage for future research

Figure 4 presents the percentage of examined children and adults who consented to future research and participated in phlebotomy as well as those who completed phlebotomy with enough blood for collection of a pristine sample for future research for participants age three and older.

Participation in phlebotomy and with consent to future research among those examined was lower in children (range 79%–82%) than adults (range 95%–96%) but there was no consistent linear trend over time for either.

Among children (age 3–17 years) 60% to 66% of those examined consented to future research and had complete phlebotomy with collection of a stored pristine sample. For adults, although the percentage who had a pristine sample fluctuated between 78% and 85% and differences between cycles were almost always statistically significant, there was no consistent trend over time.

3.6 Differences in participation in phlebotomy and the collection of a pristine sample for storage for future research by demographic categories

Table 3 presents the characteristics of those who participated in phlebotomy and Table 4 the characteristics of those who had complete phlebotomy with collection of a pristine storage sample for the 2015–2018 cycle.

Participation in phlebotomy among examined children (age 1–17) in 2015–2018 was 80% overall and increased with age from 69% among those age 1–5 to 89% among those age 12–17 ($p < 0.001$). Having any phlebotomy was higher among Hispanic children (85%) compared to non-Hispanic white, black, and Asian children (78%, 78%, 71% respectively ($p < 0.001$ for all comparisons). Differences between non-Hispanic white and non-Hispanic black children compared to non-Hispanic Asian children also reached statistical significance ($p = 0.003$ and $p = 0.002$ respectively). Phlebotomy was higher (88%) among those interviewed in a language other than English compared with those interviewed in English (78%, $p < 0.001$), higher among those living below the poverty line (82%) compare to those living at or above poverty (79%, $p = 0.005$) and higher among those whose head of household had less than a high school education (83%) or just a high school education (81%) compared to more than a high school education (78%, $p < 0.001$ and $p = 0.018$ respectively). Phlebotomy among children did not vary by gender or U.S. birth status.

Participation in phlebotomy among examined adults was 95% overall and increased with age ($p < 0.001$). Variations were found by race and Hispanic origin, and there was greater participation in phlebotomy among both non-Hispanic white (96%) and Hispanic (97%) adults compared with non-Hispanic black (93%) adults ($p < 0.001$ for both comparisons) and non-Hispanic Asian (93%) adults ($p < 0.001$ for both comparisons). Similar to children, phlebotomy was higher (97%) among those interviewed in a language other than English compared with those interviewed in English (95%, $p < 0.001$). In contrast with children, phlebotomy was higher among those living at or above poverty (96%) compared to those who live below (94%, $p = 0.004$). Participation in phlebotomy did not vary by gender, U.S. birth status, or individual education level.

Complete phlebotomy resulting in collection of a pristine sample for children ages 3–17 was 62% overall and increased with age from 51% to 70% ($p < 0.001$) (Table 4). Complete phlebotomy was higher among non-Hispanic white (66%) and Hispanic children (66%) compared to non-Hispanic black (57%) and non-Hispanic Asian (52%) children ($p < 0.001$ for all comparisons).

Complete phlebotomy for children ages 3–17 was higher among those who completed the interview in a language other than English (68%) compared to those who completed it in English (61%, $p < 0.001$) as well as higher among those whose head of household had just a high school education (65%) compared with more than a high school education (61%, $p = 0.005$) but did not vary by gender, U.S. birth status, or poverty level.

Among adults, 79% had complete phlebotomy resulting in collection of both priority and pristine samples. This increased with age ($p < 0.001$). Complete phlebotomy for adults was highest among non-Hispanic white (86%) and Hispanic (82%) adults and lowest among non-Hispanic black (68%) and non-Hispanic Asian (74%) adults ($p < 0.001$ for all pairwise comparisons between these 4 groups). Complete phlebotomy was higher among those interviewed in a language other than English (83%) compared to those who were interviewed in English (78%, $p < 0.001$) as well as higher among those living at or above poverty (81%) compared to those living below poverty (78%, $p = 0.024$) but did not vary by gender, U.S. birth status, or individual education level.

4 Discussion

Information on consent for the storage of biologic samples for future research in the NHANES survey has previously been published (McQuillan et al., 2006; McQuillan & Porter, 2011; McQuillan et al., 2003). These previous publications provide information on both non-genetic and genetic NHANES consent. The current data analysis included response and consent rates from the four 2-year cycles from 2011 to 2018 because survey response rates started to decline during these survey years. This paper extends our review of consent data beyond just the collection and storage of non-genetic biological samples for future research to other aspects of the consent process, such as the percentage of selected persons who were interviewed, the percent examined, the percent who consented to storage of their specimens for future research, and the percent who consented to linkage to other health related data sets. We have also looked at how many examined participants participated in phlebotomy and the percentage of survey participants who had enough blood collected to allow for storage of a pristine sample at the CBR.

From 2011–2012 to 2017–2018, NHANES has been experiencing a significant decline in both children and adults participating in the interview and the examination. Despite the declining response rates over time, there do not appear to be concurrent declines in consent to other requests of NHANES participation, including the linkage to other health data sets by social security number and the collection and storage of biological samples for future research using a broad consent model where future research was not defined and participants were told they would not receive any results from that research (NHANES, 2019a). Consent to data linkage increased among adults between 2011–2012 and 2017–2018. Other studies have demonstrated that a broad consent for biobank research was acceptable to the populations studied (Ewing et al., 2015; Kim et al., 2019; Sanderson et al., 2017).

Despite declining survey response rates over the time period analyzed in this report, consent and participation in the examination remained high for those who agreed to be interviewed

for both children and adults in most demographic categories, with percentages between 93 and 97 percent. Among adults, participation in the examination was higher among non-Hispanic black compared to non-Hispanic white, non-Hispanic Asian, and Hispanic persons. There were no race/ethnic differences among children. Children who were not born in the U.S. or who were non-English speakers, and who lived below the poverty level were more likely to have parental consent and provided assent to participate in the exam. There were no differences by interview language, U.S. birth status, or poverty status among adults.

Though close to 95% of all interviewed participants were examined, 80% of children and 95% of adults participated in phlebotomy. Participation in phlebotomy varied by age, race and Hispanic origin, education of the head of household, language of the interview, and poverty level among children. Younger children were less likely to have participated in phlebotomy (aged 1–5, 69%; 6–11, 80%) compared to children aged 12–17 years (89%). Hispanic children were more likely to have participated in phlebotomy compared to other race ethnic groups, while non-Hispanic Asian children were least likely to have participated in phlebotomy (all Hispanic 85%, non-Hispanic Asian 71%). There was less variation by demographic characteristics among adults in regard to participation in phlebotomy, but those aged 18–39 were less likely to have participated in phlebotomy (94%) compared to both older age groups, and non-Hispanic black and Asian persons (93%) who were also significantly less likely to have participated in phlebotomy compared to other race and Hispanic origin subgroups (96%–97%).

Though over 99% of all interviewed participants signed the consent allowing for the collection and storage of biological samples for future research, an analysis of the examination component data demonstrated that approximately 80% of children aged 1–17 years and 95% of adults among those examined in the MEC participated in phlebotomy. Despite these relatively high percentages having any phlebotomy, there were fewer examined individuals who had complete phlebotomy with enough blood collected to store samples in our biorepository. Overall, 62% of children and 79% of adults had pristine samples available for future research and this did not vary significantly over time. The lack of a pristine sample was related to younger age, being either non-Hispanic black or non-Hispanic Asian, and using English language for the interview, among both children and adults; as well as lower income among adults and lower education of the head of household among children. These data suggest that NHANES may need to review the blood collection protocol, consider increasing the volume of blood collected, and assess why there is a difference by race/Hispanic origin, income and education. Figure 4 demonstrates that between 2011–2012 and 2017–2018 approximately 35–40% of examined children and 15–22% of examined adults had an insufficient amount of blood collected to allow for storage of biospecimens. Although the survey also stores residual sera remaining from samples after priority laboratory testing is complete, the ability to store pristine samples is critical to the success of the NHANES biorepository program because many proposed studies require samples that have never been thawed.

NHANES, like many surveys, is increasingly challenged to maintain adequate response rates. Lower response rates may be associated with biased estimates that may not be representative of the US population (Czajka & Beyler, 2019; Williams & Brick, 2018).

Though participation has declined since the 2011–2012 survey cycle, those who do consent to and participate in the initial health interview generally consent to participation in other survey components as well as use of data for other purposes: the examination, biospecimen collection, storage for future research and linkage to other health-related data sets. However, falling survey response rates may have an impact on the yield of data from NHANES as having fewer participants will result in less available biologic samples for future studies, and less data available for linkage since fewer people are participating in the survey compared to earlier survey cycles. Having biological samples available to the public for future research studies from this survey is one of the goals of NHANES. Evaluating the survey data demonstrated that although 99% of participants consented to biospecimen collection and storage for future research during the household interview, additional work is needed to increase both participation in phlebotomy and complete collection during phlebotomy to assure that there is enough blood collected for each participant in all age groups to provide pristine samples for public health emergencies and for future research studies. The NHANES program is currently modifying field operations to increase survey participation, including the development of improved outreach materials and enhanced recruitment protocols.

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The National Health and Nutrition Survey non-public Administrative data was used in the analyses in this paper. That data will be available upon request. To request the use of the data please contact: https://wwwn.cdc.gov/dcs/ContactUs/Form. The analysis of the data used SAS programing with no available replicating files since the data is administrative data. As above an investigator can replicate the data upon request using the contact provided above.

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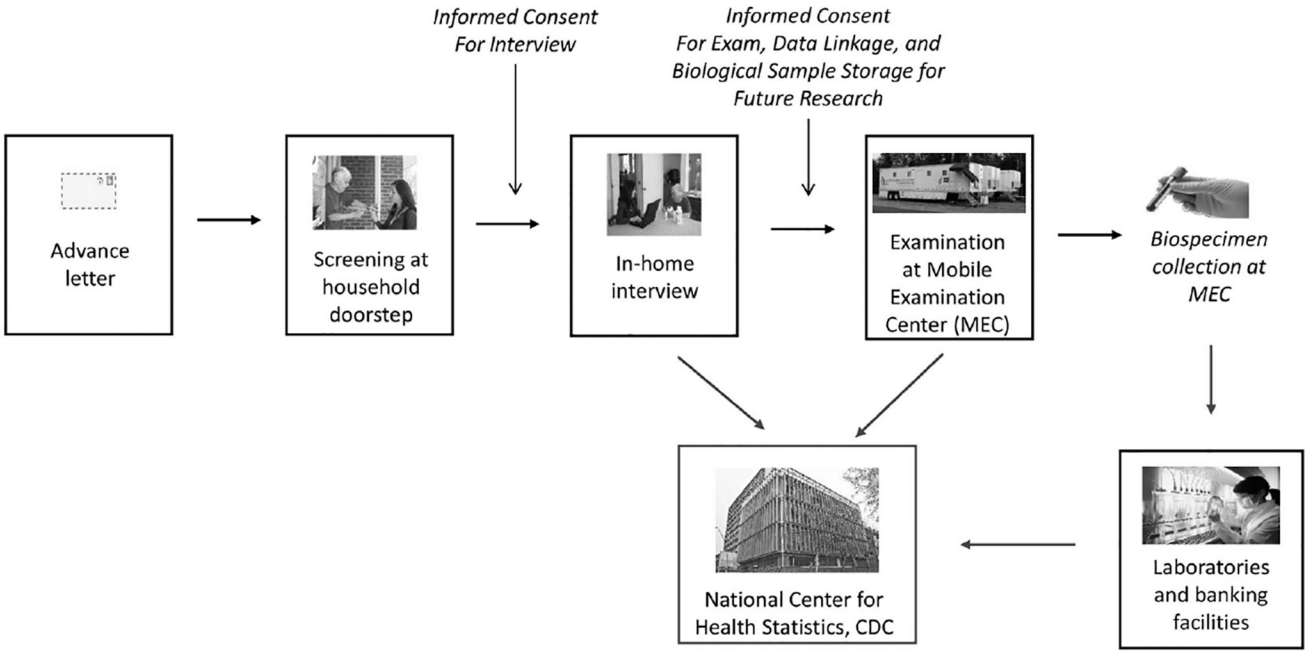

Figure 1.
NHANES data collection flow chart and when informed consent occurs in the process

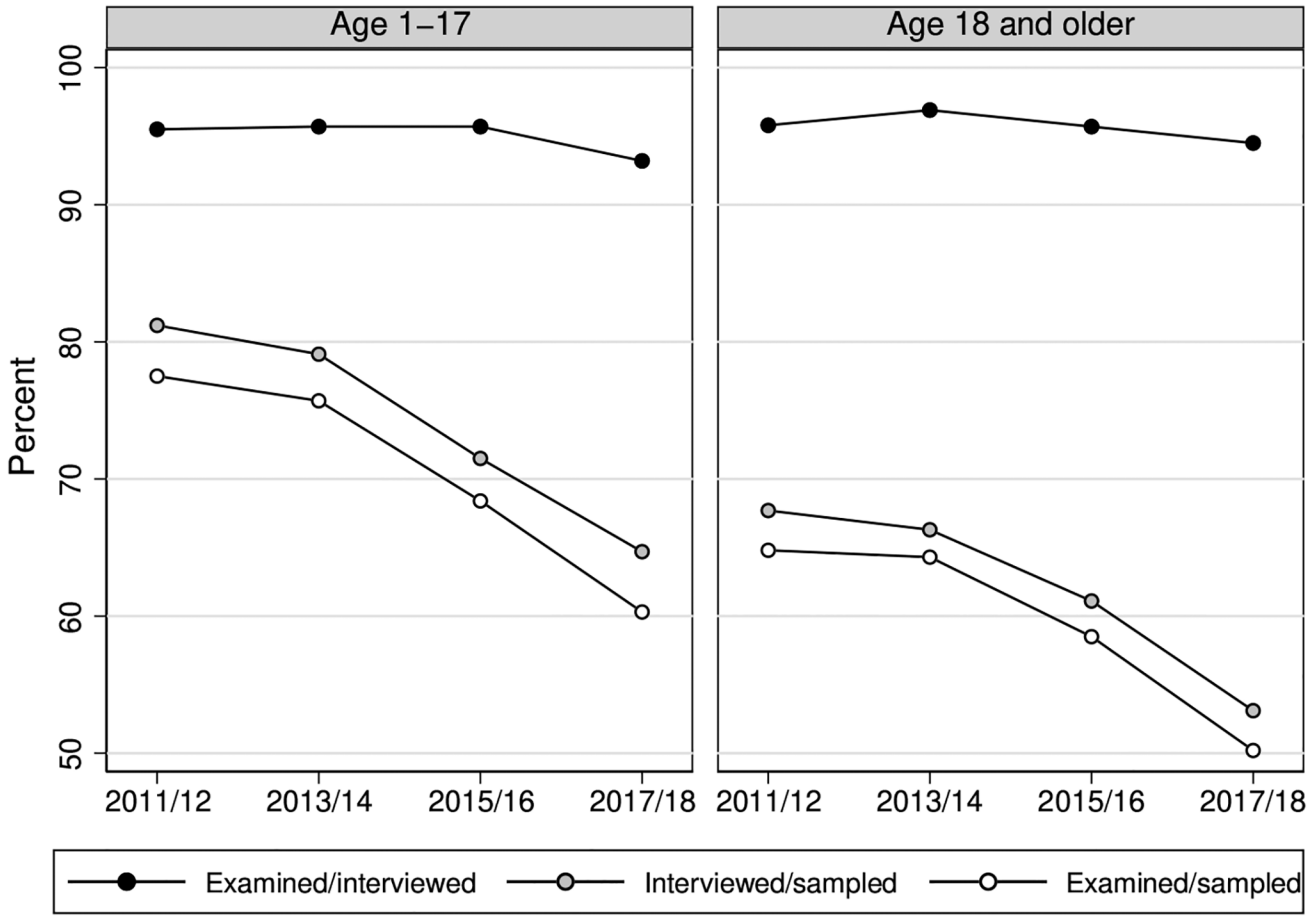

Figure 2.
Trends over time to interview and examination response

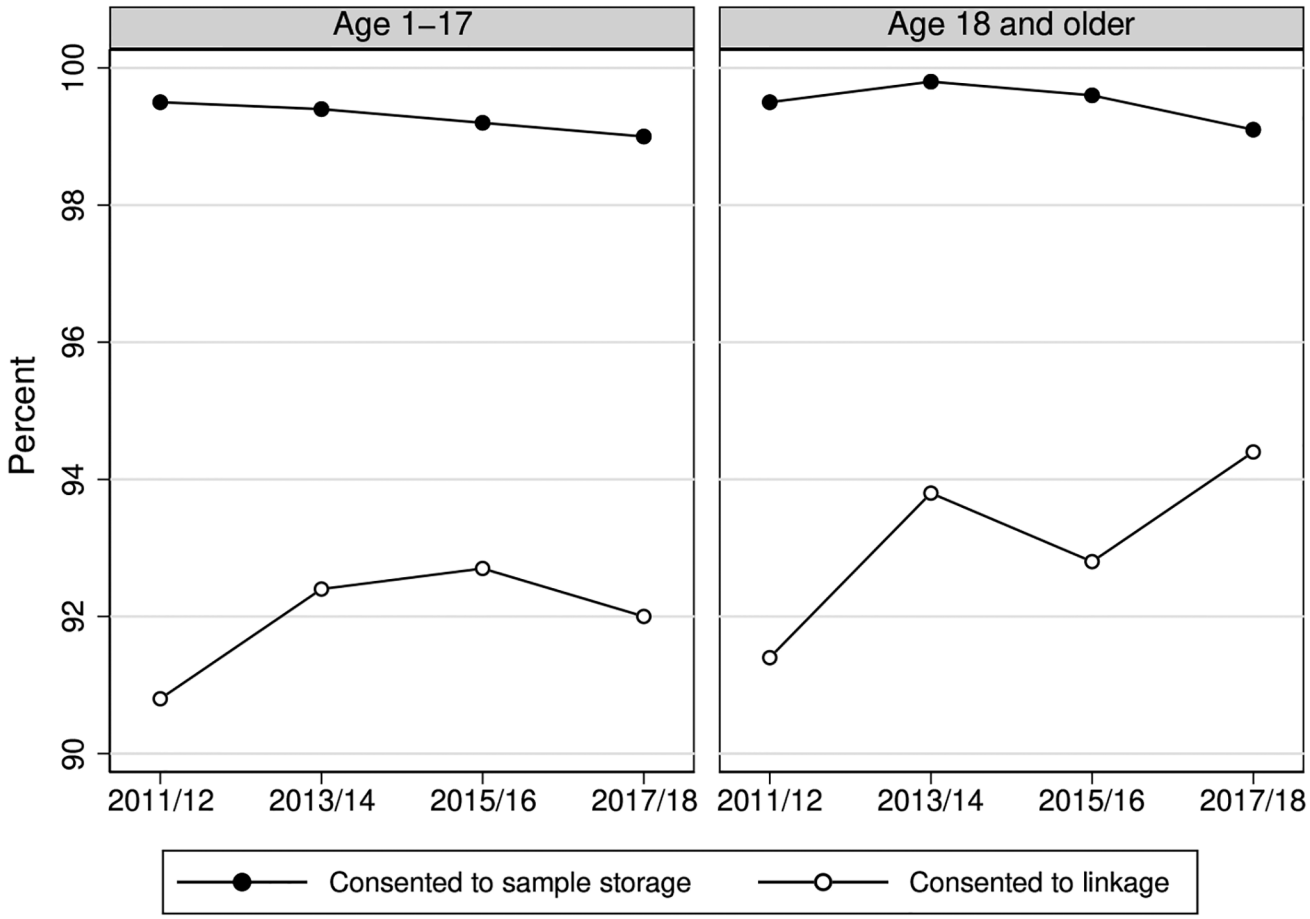

Figure 3.
Trends over time in consent to data linkage and consent to storage of sample for future research

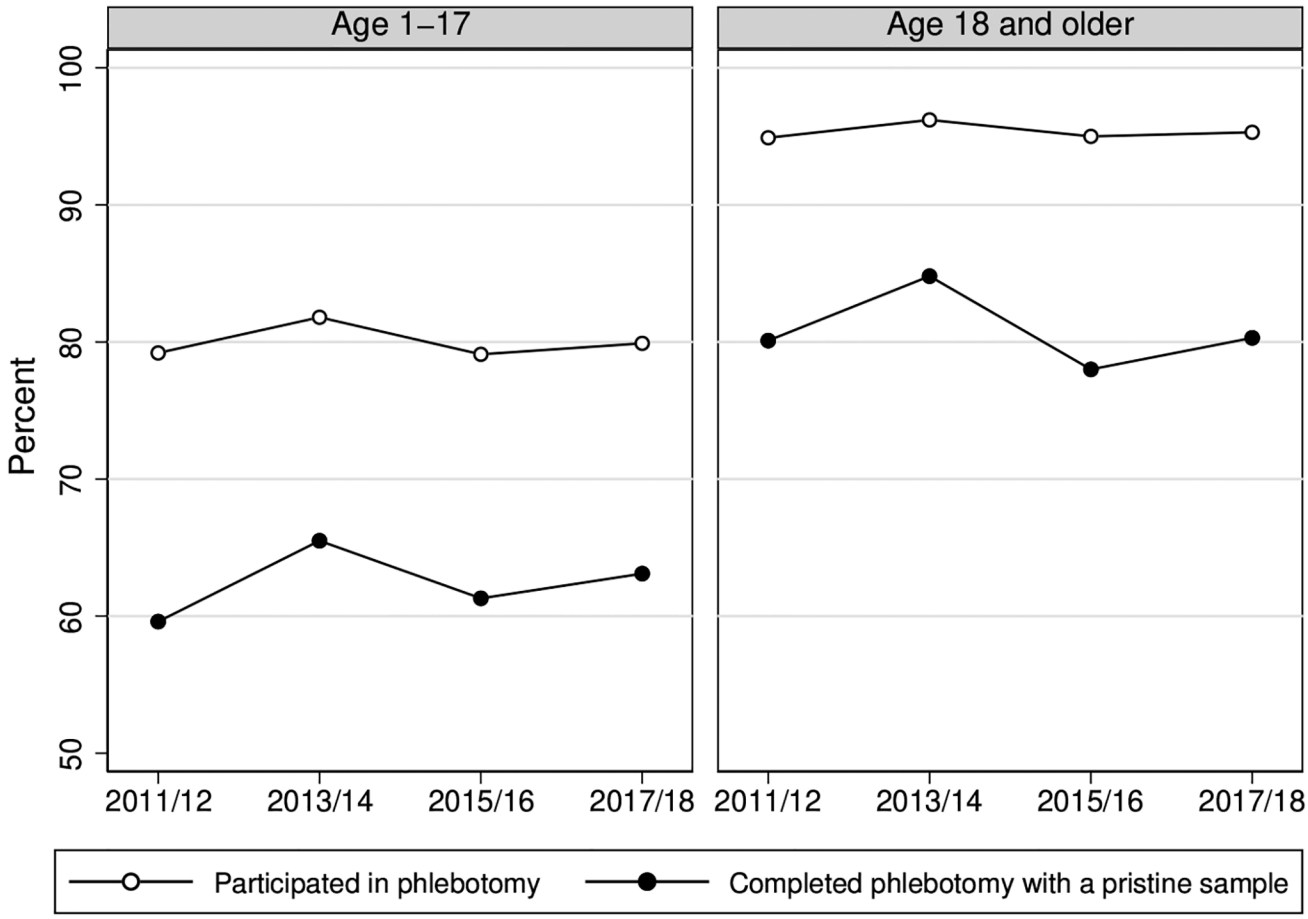

Figure 4.
Trends over time in participation in phlebotomy and completion of phlebotomy with collection of a pristine sample.

Table 1

Examination response rates among interviewed children (age 1–17) and adults (age 18 years or more) all and by demographic categories, NHANES 2015–2018

	Children age 1–17					Age 18 and older				
				95% C.I.					95% C.I.	
Demographic Characteristic	**Interviewed**	**Examined**	**%**	**Lower**	**Upper**	**Interviewed**	**Examined**	**%**	**Lower**	**Upper**
Age Group										
Young[a]	2227	2075	93.2[*,†]	92.1	94.2	4200	3982	94.8	94.1	95.5
Middle[b]	2447	2311	94.4[*]	93.5	95.3	3597	3459	96.2[*]	95.5	96.8
Old (ref.)[c]	1950	1877	96.3	95.3	97.1	4051	3827	94.5	93.7	95.2
Gender										
Male (ref.)	3347	3160	94.4	93.6	95.2	5727	5431	94.8	94.2	95.4
Female	3277	3103	94.7	93.9	95.4	6121	5837	95.4	94.8	95.9
Race and Hispanic origin										
Non-Hispanic white (ref.)	1996	1878	94.1	93.0	95.1	3946	3737	94.7[‡]	94.0	95.4
Non-Hispanic black	1501	1427	95.1	93.9	96.1	2608	2510	96.2[*,§]	95.4	96.9
Hispanic	1957	1851	94.6	93.5	95.5	3197	3039	95.1[‡]	94.3	95.8
Non-Hispanic Asian	613	577	94.1	92.0	95.9	1575	1476	93.7[‡]	92.4	94.9
Other	557	530	95.2	93.0	96.8	522	506	96.9	95.1	98.2
Birthplace[d]										
U.S. born (ref.)	6236	5885	94.4	93.8	94.9	8050	7661	95.2	94.7	95.6
non-U.S. born	387	377	97.4[*]	95.3	98.8	3794	3603	95.0	94.2	95.6
Language of the Interview										
English (ref.)	5825	5496	94.4	93.7	94.9	10378	9862	95.0	94.6	95.4
non-English	799	767	96.0[*]	94.4	97.2	1470	1406	95.7	94.5	96.6
Poverty Level										
At or above (ref.)	4201	3991	95.0	94.3	95.6	8142	7821	96.1	95.6	96.5
Below poverty	1719	1663	96.7[*]	95.8	97.5	2195	2112	96.2	95.3	97.0

Demographic Characteristic	Children age 1–17					Age 18 and older				
				95% C.I.					95% C.I.	
	Interviewed	Examined	%	Lower	Upper	Interviewed	Examined	%	Lower	Upper
Educational level[e]										
> high school (ref.)	3521	3353	95.2	94.5	95.9	6355	6060	95.4	94.8	95.9
High school diploma	1405	1331	94.7	93.4	95.8	2828	2687	95.0	94.2	95.8
< high school	1369	1313	95.9	94.7	96.9	2647	2506	94.7	93.8	95.5
Total	6624	6263	94.6	94.0	95.1	11848	11268	95.1	94.7	95.5

Response rates presented did not factor in screener non-response and were calculated for different age groups, therefore they differ from those found at: https://wwwn.cdc.gov/nchs/nhanes/ResponseRates.aspx.

[a] 1–5 and 18–39

[b] 6–11 and 40–59

[c] 12–17 and 60 or older

[d] Born in the 50 states or the District of Columbia is U.S. born.

[e] For children: Educational level for head of household

[*] $p < 0.05$ for difference in percent from subgroup to reference group within demographic characteristic.

[†] $p < 0.05$ for test for trend among age groups.

[‡] $p < 0.05$ for race and Hispanic origin subgroup when compared to non-Hispanic black reference group.

[§] $p < 0.05$ for race and Hispanic origin subgroup when compared to non-Hispanic Asian reference group.

"ref." indicates the reference subgroup for each demographic variable.

Table 2

Percent who consented to data linkage among interviewed children (age 1–17) and adults (age 18 years or more) all and by demographic categories, NHANES 2015–2018

	Children age 1–17					Age 18 and older				
				95% C.I.					95% C.I.	
Demographic Characteristic	**Interviewed**	**Linkage consent**	**%**	**Lower**	**Upper**	**Interviewed**	**Linkage consent**	**%**	**Lower**	**Upper**
Age Group										
Young[a]	2227	2026	91.0 *,†	89.7	92.1	4200	3903	92.9 *,†	92.1	93.7
Middle[b]	2447	2274	92.9	91.8	93.9	3597	3366	93.6	92.7	94.4
Old (ref.)[c]	1950	1819	93.3	92.1	94.4	4051	3821	94.3	93.6	95.0
Gender										
Male (ref.)	3347	3069	91.7	90.7	92.6	5727	5391	94.1	93.5	94.7
Female	3277	3050	93.1 *	92.2	93.9	6121	5699	93.1 *	92.4	93.7
Race and Hispanic origin										
Non-Hispanic white (ref.)	1996	1890	94.7 ‡,§	93.6	95.6	3946	3794	96.2 ‡,§	95.5	96.7
Non-Hispanic black	1501	1322	88.1 *,§	86.3	89.7	2608	2362	90.6 *,§	89.4	91.7
Hispanic	1957	1812	92.6 *,‡	91.3	93.7	3197	2982	93.3 *,‡	92.4	94.1
Non-Hispanic Asian	613	566	92.3 *,‡	89.9	94.3	1575	1456	92.4 *,‡	91.0	93.7
Other	557	529	95.0	92.8	96.6	522	496	95.0	92.8	96.7
Birthplace[d]										
U.S. born (ref.)	6236	5769	92.5	91.8	93.2	8050	7580	94.2	93.6	94.7
non-U.S. born	387	349	90.2	86.8	93.0	3794	3508	92.5 *	91.6	93.3
Language of the Interview										
English (ref.)	5825	5382	92.4	91.7	93.1	10378	9732	93.8	93.3	94.2
non-English	799	737	92.2	90.2	94.0	1470	1358	92.4	90.9	93.7
Poverty Level										
At or above (ref.)	4201	3952	94.1	93.3	94.8	8142	7718	94.8	94.3	95.3
Below poverty	1719	1609	93.6	92.3	94.7	2195	2067	94.2	93.1	95.1

Demographic Characteristic	Children age 1–17					Age 18 and older				
	Interviewed	Linkage consent	%	95% C.I. Lower	95% C.I. Upper	Interviewed	Linkage consent	%	95% C.I. Lower	95% C.I. Upper
Educational level[e]										
> high school (ref.)	3521	3246	92.2	91.3	93.1	6355	5945	93.6	92.9	94.1
High school diploma	1405	1321	94.0 *	92.7	95.2	2828	2651	93.7	92.8	94.6
< high school	1369	1265	92.4	90.9	93.8	2647	2479	93.7	92.7	94.6
Total	6624	6119	92.4	91.7	93.0	11848	11090	93.6	93.2	94.0

[a] 1–5 and 18–39

[b] 6–11 and 40–59

[c] 12–17 and 60 or older

[d] Born in the 50 states or the District of Columbia is U.S. born.

[e] For children: Educational level for head of household

[*] $p < 0.05$ for difference in percent from subgroup to reference group within demographic characteristic.

[†] $p < 0.05$ for test for trend among age groups.

[‡] $p < 0.05$ for race and Hispanic origin subgroup when compared to non-Hispanic black reference group.

[§] $p < 0.05$ for race and Hispanic origin subgroup when compared to non-Hispanic Asian reference group.

"ref." indicates the reference subgroup for each demographic variable.

Table 3

Percent who participated in phlebotomy among examined children (age 1–17) and adults (age 18 years or more) all and by demographic categories, NHANES 2015–2018

	Children age 1–17					Age 18 and older				
				95% C.I.					95% C.I.	
Demographic Characteristic	**Examined**	**Had Phlebotomy**	**%**	**Lower**	**Upper**	**Examined**	**Had Phlebotomy**	**%**	**Lower**	**Upper**
Age Group										
Young[a]	2075	1440	69.4[*,†]	67.4	71.4	3982	3728	93.6[*,†]	92.8	94.4
Middle[b]	2311	1861	80.5[*]	78.9	82.1	3459	3316	95.9	95.2	96.5
Old (ref.)[c]	1877	1675	89.2	87.8	90.6	3827	3680	96.2	95.5	96.8
Gender										
Male (ref.)	3160	2524	79.9	78.4	81.3	5431	5167	95.1	94.5	95.7
Female	3103	2452	79.0	77.5	80.4	5837	5557	95.2	94.6	95.7
Race and Hispanic origin										
Non-Hispanic white (ref.)	1878	1458	77.6[§]	75.7	79.5	3737	3603	96.4[‡,§]	95.8	97.0
Non-Hispanic black	1427	1115	78.1[§]	75.9	80.3	2510	2328	92.8[*]	91.7	93.7
Hispanic	1851	1572	84.9[*,‡,§]	83.2	86.5	3039	2938	96.7[‡,§]	96.0	97.3
Non-Hispanic Asian	577	411	71.2[*,‡]	67.4	74.9	1476	1377	93.3[*]	91.9	94.5
Other	530	420	79.3	75.5	82.6	506	478	94.5	92.1	96.3
Birth place[d]										
U.S. born (ref.)	5885	4680	79.5	78.5	80.6	7661	7283	95.1	94.6	95.5
non-U.S. born	377	295	78.3	73.7	82.3	3603	3437	95.4	94.7	96.1
Language of the Interview										
English (ref.)	5496	4300	78.2	77.1	79.3	9862	9364	95.0	94.5	95.4
non-English	767	676	88.1[*]	85.6	90.3	1406	1360	96.7[*]	95.7	97.6
Poverty Level										
At or above (ref.)	3991	3142	78.7	77.4	80.0	7821	7496	95.8	95.4	96.3
Below poverty	1663	1363	82.0[*]	80.0	83.8	2112	1990	94.2[*]	93.1	95.2

	Children age 1–17					Age 18 and older				
				95% C.I.					95% C.I.	
Demographic Characteristic	**Examined**	**Had Phlebotomy**	**%**	**Lower**	**Upper**	**Examined**	**Had Phlebotomy**	**%**	**Lower**	**Upper**
Educational level[e]										
> high school (ref.)	3353	2605	77.7	76.2	79.1	6060	5784	95.5	94.9	96.0
High school diploma	1331	1075	80.8 *	78.5	82.9	2687	2547	94.8	93.9	95.6
< high school	1313	1087	82.8 *	80.6	84.8	2506	2379	94.9	94.0	95.8
Total	6263	4976	79.5	78.4	80.5	11268	10724	95.2	94.8	95.6

Persons who participated in phlebotomy must also have consented to storage of a sample for future research.

[a] 1–5 and 18–39

[b] 6–11 and 40–59

[c] 12–17 and 60 or older

[d] Born in the 50 states or the District of Columbia is U.S. born.

[e] For children: Educational level for head of household

* $p < 0.05$ for difference in percent from subgroup to reference group within demographic characteristic.

† $p < 0.05$ for test for trend among age groups.

‡ $p < 0.05$ for race and Hispanic origin subgroup when compared to non-Hispanic black reference group.

§ $p < 0.05$ for race and Hispanic origin subgroup when compared to non-Hispanic Asian reference group.

"ref." indicates the reference subgroup for each demographic variable.

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Table 4

Percent who completed phlebotomy and provided a pristine sample among examined children (age 1–17 years) and adults (age 18 years or more) all and by demographic categories, NHANES 2015–2018

	Children age 1–17					Age 18 and older				
				95% C.I.					95% C.I.	
Demographic Characteristic	**Examined**	**Pristine sample**	**%**	**Lower**	**Upper**	**Examined**	**Pristine sample**	**%**	**Lower**	**Upper**
Age Group										
Young[a]	1088	554	50.9[*,†]	47.9	53.9	3982	3044	76.4[*,†]	75.1	77.8
Middle[b]	2311	1417	61.3[*]	59.3	63.3	3459	2699	78.0[*]	76.6	79.4
Old (ref.)[c]	1877	1306	69.6	67.4	71.7	3827	3174	82.9	81.7	84.1
Gender										
Male (ref.)	2650	1620	61.1	59.3	63.0	5431	4306	79.3	78.2	80.4
Female	2626	1657	63.1	61.2	65.0	5837	4611	79.0	77.9	80.0
Race and Hispanic origin										
Non-Hispanic white (ref.)	1521	1004	66.0[‡,§]	63.6	68.4	3737	3198	85.6[‡,§]	84.4	86.7
Non-Hispanic black	1224	698	57.0[*]	54.2	59.8	2510	1706	68.0[*,§]	66.1	69.8
Hispanic	1588	1042	65.6[‡,§]	63.2	68.0	3039	2497	82.2[*‡,§]	80.8	83.5
Non-Hispanic Asian	510	267	52.4[*]	47.9	56.8	1476	1092	74.0[*‡]	71.7	76.2
Other	433	266	61.4	56.7	66.0	506	424	83.8	80.3	86.9
Birth place[d]										
U.S. born (ref.)	4918	3070	62.4	61.1	63.8	7661	6089	79.5	78.6	80.4
non-U.S. born	357	206	57.7	52.4	62.9	3603	2827	78.5	77.1	79.8
Language of the Interview										
English (ref.)	4603	2817	61.2	59.8	62.6	9862	7744	78.5	77.7	79.3
non-English	673	460	68.4[*]	64.7	71.9	1406	1173	83.4[*]	81.4	85.3
Poverty Level										
At or above (ref.)	3396	2115	62.3	60.6	63.9	7821	6313	80.7	79.8	81.6
Below poverty	1372	894	65.2	62.6	67.7	2112	1657	78.5[*]	76.6	80.2

	Children age 1–17					Age 18 and older				
				95% C.I.					95% C.I.	
Demographic Characteristic	**Examined**	**Pristine sample**	**%**	**Lower**	**Upper**	**Examined**	**Pristine sample**	**%**	**Lower**	**Upper**
Educational level[e]										
> high school (ref.)	2800	1699	60.7	58.8	62.5	6060	4812	79.4	78.4	80.4
High school diploma	1108	725	65.4[*]	62.6	68.2	2687	2136	79.5	77.9	81.0
< high school	1152	731	63.5	60.6	66.2	2506	1959	78.2	76.5	79.8
Total	5276	3277	62.1	60.8	63.4	11268	8917	79.1	78.4	79.9

Persons with completed phlebotomy with a pristine sample.

[a] 1–5 and 18–39

[b] 6–11 and 40–59

[c] 12–17 and 60 or older

[d] Born in the 50 states or the District of Columbia is U.S. born.

[e] For children: Educational level for head of household

[*] $p < 0.05$ for difference in percent from subgroup to reference group within demographic characteristic.

[†] $p < 0.05$ for test for trend among age groups.

[‡] $p < 0.05$ for race and Hispanic origin subgroup when compared to non-Hispanic black reference group.

[§] $p < 0.05$ for race and Hispanic origin subgroup when compared to non-Hispanic Asian reference group.

"ref." indicates the reference subgroup for each demographic variable.