NATIONAL HEALTH AND NUTRITION EXAMINATION SURVEY (NHANES)

Consent/Assent and Parental Permission for Specimen Storage and Continuing Studies

Print name of participant _____ _____ _____
First Middle Last

Q **Why will a sample of blood and urine be kept for future health studies?**

A We will store some of the blood and urine from persons who are examined in NHANES for future health studies. These samples will be frozen and kept in a specimen bank for as long as they last. You can request that your samples be removed at any time. Your participation is voluntary and no loss of benefits will result if you refuse.

Q **What studies will be done with the samples?**

A At this time, no specific studies are planned besides the tests included in the NHANES exam. As scientists learn more about health and diseases, other studies will be conducted that may include stored samples. There can be many additional studies on these samples.

Assurance of Confidentiality: We take your privacy very seriously. All information that relates to or describes identifiable characteristics of individuals, a practice, or an establishment will be used only for statistical purposes. NCHS staff, contractors, and agents will not disclose or release responses in identifiable form without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and the Confidential Information Protection and Statistical Efficiency Act of 2002 (CIPSEA, Title 5 of Public Law 107-347). In accordance with CIPSEA, every NCHS employee, contractor, and agent has taken an oath and is subject to a jail term of up to five years, a fine of up to $250,000, or both if he or she willfully discloses ANY identifiable information about you. In addition, NCHS complies with the Federal Cybersecurity Act of 2015 (6 U.S.C. §§ 151 & 151 note). This law requires the federal government to protect federal computer networks by using computer security programs to identify cybersecurity risks like hacking, internet attacks, and other security weaknesses. If information sent through government networks triggers a cyber threat indicator, the information may be intercepted and reviewed for cyber threats by computer network experts working for, or on behalf of, the government.

Q **Who can use the stored samples for further study?**

A Researchers from Federal agencies, universities, and other scientific centers can submit proposals to use the stored specimens. These proposals will be reviewed for scientific merit and then by a separate board that determines if the study proposed is ethical. The NHANES program will always know which samples belong to you or your child, but we will not give other researchers any information that could identify you or your child.

Q **Will I receive results from any future testing of my specimens?**

A Science and medicine are continually advancing. New tests and new ways of looking at results will be developed in the future. We can't predict what tests will be done or what the results will mean for your health. The NHANES program will not contact you or your family with results from these future studies. We will describe the completed studies on our website. If you are interested in your results from any of these studies, you may call our toll-free number, 1-800 452-6115 to request your specific results as they come available.

Q **What are the benefits and risks for allowing my blood or urine sample to be used for future studies?**

A You will not directly benefit but these studies may eventually help the health of people in the future. The risk of giving a sample includes the minor risk associated with taking the blood sample. There may also be a risk that some people may use the information from these studies to exaggerate or downplay differences among people. The ethics board that will review all studies using these samples will attempt to prevent any misuse of the information gained from the NHANES samples.

Q **How can I remove blood or urine samples from the specimen bank?**

A In the future, if you want samples removed from the specimen bank, call us toll-free at 1-800-452-6115.

The results of continuing studies of your stored specimens may help find new ways to prevent, treat, and cure many diseases.

For **persons ages 7 and over,** check a box

- ☐ Yes, my blood and urine may be kept for future health studies, and I understand that I will not be contacted with the results from these studies
- ☐ No, my blood and urine cannot be kept for future health studies

For **parent/guardian of a child under the age of 18**, check a box

- ☐ Yes, my child's blood and urine may be kept for future health studies, and I understand that I will not be contacted with the results from these studies
- ☐ No, my child's blood and urine cannot be kept for future health studies

_____
Signature of participant age 7 or over Date

_____
Signature of parent/guardian of participant under 18 Date
(Unless the participant is an emancipated minor ☐)

I observed the interviewer read this form to the person named above and he/she agreed to participate by signing or marking this form.

_____ _____
Witness (if required) Date

Name of staff member present when this form was signed: _____

___ ___ ___ ___ ___ ___
SP ID