

**Attachment 8a**

**Participant Information Sheet:  
“ABOUT THE REQUEST FOR HOSPITAL RECORDS”**

## **ABOUT THE REQUEST FOR HOSPITAL RECORDS<sup>1</sup>**

### **BACKGROUND**

As part of the National Health and Nutrition Examination Survey (NHANES) Longitudinal Study, we will obtain more information about your hospitalization(s), such as the final discharge diagnoses and procedures performed. We hope to better understand medical problems, including diabetes and heart disease.

### **INFORMATION COLLECTED FROM PARTICIPANTS**

We will ask you for the name and contact information for all hospitalizations between the first time you participated in the NHANES survey and the date you authorize, or allow, us to contact staff at your hospitals.

### **INFORMATION COLLECTED FROM HEALTH CARE PROVIDERS**

We may ask your hospitals to send us the following documents:

- Hospital face sheet, which may include your name, address, dates of hospitalization, date of birth, discharge diagnoses, procedures performed during hospitalization, and special codes (ICD-9 and/or ICD-10 CM) related to discharge diagnoses and procedures
- Discharge Summary. Typically the discharge summary is written by your doctor and contains all the information about your hospitalization.
- Progress note from last day of hospitalization. Typically the progress note is written by your doctor and contains important information about your hospitalization.

For a small number of participants, we will ask your hospitals to send more documents, including progress notes for entire hospitalization; emergency room reports; admission notes; operative reports; pathology reports; radiology reports; EKGs; laboratory reports; and cardiac catheterization reports.

### **INFORMATION WE WILL SHARE WITH YOUR HEALTH CARE PROVIDERS**

By contacting the hospitals you tell us about, hospital staff will know you are a participant in NHANES. We will tell the hospital staff that they should not use this knowledge to obtain additional information

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<sup>1</sup> As part of the protocol stated for administering question HVQ.150, the Health Representative will review this information sheet with the participant prior to obtaining the signature for the HIPAA authorization form(s). The representative will verbally adjust the wording as needed if a proxy was used for the interview (for example, to replace the word “you” to the participant’s name).

This information sheet will not be presented with decedent proxy because a waiver of signed HIPAA authorization form has been sought for deceased participants.

about you through the released NHANES data or by using the NHANES data to link to other databases. We will also inform the hospital staff that any effort to determine your identity using the NHANES data is prohibited by the Public Health Service Act, and the Confidential Information Protection and Statistical Efficiency Act.

We will share your name, sex, and date of birth with your hospitals to help them identify you and send us back the correct information. We will not share other information from this survey with your health care provider.

## **QUESTIONS AND ANSWERS ABOUT THE HOSPITAL MEDICAL RECORDS CHECK**

### **Q: Why is the hospital medical record check important?**

**A:** We will use the data gathered in the study to help us better understand important health problems, including diabetes and heart disease. Even if you don't have any of these problems, your information will be important. We will look at your medical history data and the other data you provide in the survey to help us learn about factors that may, or may not, be associated with problems like diabetes and heart disease. Research from this study will provide valuable information for the public health community, health care providers, and doctors.

### **Q: Why do you need to contact my hospitals?**

**A:** Hospitals often have special codes related to discharge diagnoses and procedures. To have the same type of information for everyone, we need to contact hospitals directly.

### **Q: Will my information be kept private?**

**A:** We take your privacy very seriously. The information you give us will be used for statistical research only. This means that your information will be combined with other people's information in a way that protects everyone's identity. As required by federal law, only those NCHS employees, our contractors, and our specially designated agents who must use your personal information for a specific reason can see it. Otherwise, your data will only be shared after all information that could identify you and/or your family has been removed.

Strict laws prevent us from releasing information that could identify you or your family to anyone else without your consent. A number of federal laws require that all information we collect be kept confidential: Section 308(d) of the Public Health Service Act (42 United States Code 242m(d)), the Confidential Information Protection and Statistical Efficiency Act (CIPSEA, Title 5 of Public Law 107-347), and the Privacy Act of 1974, 5 U.S.C. § 552a. Every NCHS employee, contractor, research partner, and agent has taken an oath to keep your information private. If he or she willfully discloses ANY identifiable information, he/she could get a jail term of up to five years, a fine of up to \$250,000, or both.

In addition, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015. 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. The Act allows software programs to scan information that is sent, stored on, or processed through government networks in order to protect the networks. If any cybersecurity risk is detected, the information system may be reviewed for specific threats by computer network

experts working for the government (or contractors or agents who have governmental authority to do so). Only information directly related to government network security is monitored. The Act requires any personal information that identifies you or your family to be removed from suspicious files before they are shared.

**Q: What if I have more questions about the survey in the future?**

**A:** In the future, if you have questions about NHANES or if you change your mind and want to take back permission, please call us toll-free at 1-800-452-6115. Dr. Duong T. Nguyen of the U.S. Public Health Service is available to discuss any aspect of the survey. He can be reached at 1-800-452-6115, Monday - Friday, 7:30 a.m. - 4:30 p.m. EST. You can also get answers to your questions by writing to him at MS P08, 3311 Toledo Rd., Hyattsville, MD 20782). If you have a question about your rights in this research, please call the NCHS Research Ethics Review Board at 1-800-223-8118. Say you are calling about Protocol #XXXX-XX.