



## Issues in Returning Individual Results from Genome Research Using Population-Based Banked Specimens, with a Focus on the National Health and Nutrition Examination Survey: A Workshop Summary (Paperback)

By Committee on National Statistics, Steering Committee on the Guidelines for Returning Individual Results from Genome Research Using Pop, Division of Behavioral and Social Sciences and Education

National Academies Press, United States, 2014. Paperback. Condition: New. Language: English . Brand New Book. Population surveys traditionally collect information from respondents about their circumstances, behaviors, attitudes, and other characteristics. In recent years, many surveys have been collecting not only questionnaire answers, but also biologic specimens such as blood samples, saliva, and buccal swabs, from which a respondent's DNA can be ascertained along with other biomarkers (e.g., the level of a certain protein in the blood). The National Health and Nutrition Examination Survey (NHANES), sponsored by the National Center for Health Statistics (NCHS), has been collecting and storing genetic specimens since 1991, and other surveys, such as the Health and Retirement Study (HRS) funded by the National Institute on Aging, have followed suit. In order to give their informed consent to participate in a survey, respondents need to know the disposition and use of their data. Will their data be used for one research project and then destroyed, or will they be archived for secondary use? Sponsors of repeated cross-sectional surveys, such as NHANES, and of longitudinal surveys that follow panels of individuals over time, such as HRS, generally want to retain data for a wide range of secondary...



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