Cells and **Suppose** Should Biological Measures Be Included in Social Science Research?

Committee on Population

Caleb E. Finch, James W. Vaupel, and Kevin Kinsella, Editors

Commission on Behavioral and Social Sciences and Education National Research Council

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Preface

In 1997 the Committee on Population published *Between Zeus and the Salmon: The Biodemography of Longevity,* a volume that drew on various disciplinary perspectives to take stock of what demography and biology could tell us about the trajectory of human longevity. One prescient chapter, written by Robert Wallace, noted the need to explore the potential usefulness of collecting biological (and especially genetic) data in the context of large, population-based surveys.

As the 1990s drew to a close, it became increasingly clear that advances in biodemography require a greater ability to analyze the interactions of genes, the environment, and behaviors, which in turn require linked data on all three domains. Recent technical developments in the collection and analysis of biological data have made it much more feasible to collect such information in nonclinical settings. Given the financial considerations created by researchers' appetites for ever more complex data, and the finite amount of public money that will ever be devoted to data collection, there is mounting pressure for multipurpose household surveys to collect biological data along with the more familiar interviewer-respondent question-and-answer type of information.

Many surveys to date have collected some biological and/or clinical data. Before the pressure to collect biological data in social surveys becomes broad-based and overwhelming, those who fund, design, and analyze survey data need to think through the rationale and potential consequences. Thus it was that the National Institute on Aging (NIA), which funds many of the cutting-edge social science surveys in the United

States, asked The National Academies to organize a series of planning meetings, culminating in a workshop on "Collecting Biological Indicators and Genetic Information in Household Surveys," held in Washington, D.C., in February 2000.

Committee on Population workshops are designed to be stimulating fora for researchers and policy makers from a wide range of disciplines. This meeting brought together demographers, economists, epidemiologists, ethicists, molecular biologists, physiologists, geneticists, pathologists, and sociologists, in addition to representatives of numerous government agencies. The workshop and this resultant volume sought to address a range of questions. What can social science, and demography in particular, reasonably expect to learn from biological information? Which genetic, pedigree, historical, and environmental data ought to be collected in order to be most useful to a wide range of scientists? Are there likely to be unintended side effects of amassing biological data (for example, what will attempts to collect bioindicators do to survey response rates, or to the quality of self-reported data)? How might ethical duties to research subjects change with the collection of bioindicators? How will confidentiality issues be handled? The methodological challenges for marrying large population surveys to genetic hypotheses are complex and not easily solved, in part because extant surveys have been structured and funded to address a set of important nongenetic scientific questions.

This report summarizes the workshop presentations. The chapters were enriched by the free-flowing workshop discussion that helped to sharpen key concerns and expand the breadth of several papers. A special note of thanks in this regard goes to Raynard Kington, director of the National Health and Nutrition Examination Survey, who shared his knowledge of and visions for future survey research. The chapters were then peer reviewed, and we owe a debt of gratitude to the many individuals who generously gave of their time to review and further strengthen the contents of this volume. For their insightful and constructive remarks, we would like to thank George Annas, Lisa Berkman, Ties Boerma, Charles Boult, Joy Boyer, Wylie Burke, James Carey, James Curtsinger, Ronald Freedman, Leonid Gavrilov, Noreen Goldman, Evan Hadley, Jennifer Harris, Richard Havlik, Wendy Mack, Scott Pletcher, Karen Swallen, Marc Tatar, Elizabeth Thomson, Martin Vaessen, and several anonymous reviewers.

Our greatest debt is to Caleb Finch and James Vaupel, who not only cochaired the workshop and edited the volume, but also were instrumental in developing the workshop framework, identifying a stellar cadre of authors and reviewers, and guiding authors in their revisions. We also would particularly like to thank Richard Suzman of the NIA who, as the prime motivator of this endeavor, shared his expertise and consistently

PREFACE

challenged all involved to expand the boundaries of inquiry. The committee is grateful to a number of colleagues who worked with the cochairs and me on a steering committee to develop this project. These include demographers Douglas Ewbank, Beth Soldo, and Kenneth Wachter; three members of the National Research Council's Committee on National Statistics, William Kalsbeek, Thomas Louis, and Edward Perrin; and two members of The National Academies Board on Biology, Robert Sokal and Raymond White. Benjamin Wilfond of the National Human Genome Research Institute was especially helpful in providing initial guidance and information regarding ethical and legal issues that would need to be addressed.

Thanks are also due to staff and associates of the National Research Council. Brian Tobachnick coordinated the logistical and travel arrangements for the workshop and assisted with myriad aspects of manuscript preparation. Randi M. Blank edited the volume and made suggestions for the glossary. Christine McShane guided the manuscript through the publication process. Sally Stanfield and the Audubon team at the National Academy Press handled the technical preparation of the report. Kevin Kinsella directed the study and coordinated the review process. Development and execution of this project occurred under the general guidance of the committee's director, Barney Cohen.

> Jane Menken Chair, Committee on Population

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