Vaccine Safety Research, Data Access, AND Public Trust

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Expanding Access to Research Data Panel on Data Access for Research Purposes, Committee on

National Statistics, Division of Behavioral and Social Sciences and Education, National Research Council, 2005-11-11 Policy makers need information about the nation ranging from trends in the overall economy down to the use by individuals of Medicare in order to evaluate existing programs and to develop new ones This information often comes from research based on data about individual people households and businesses and other organizations collected by statistical agencies The benefit of increasing data accessibility to researchers and analysts is better informed public policy To realize this benefit a variety of modes for data access including restricted access to confidential data and unrestricted access to appropriately altered public use data must be used The risk of expanded access to potentially sensitive data is the increased probability of breaching the confidentiality of the data and in turn eroding public confidence in the data collection enterprise Indeed the statistical system of the United States ultimately depends on the willingness of the public to provide the information on which research data are based Expanding Access to Research Data issues guidance on how to more fully exploit these tradeoffs The panel s recommendations focus on needs highlighted by legal social and technological changes that have occurred during the last decade

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