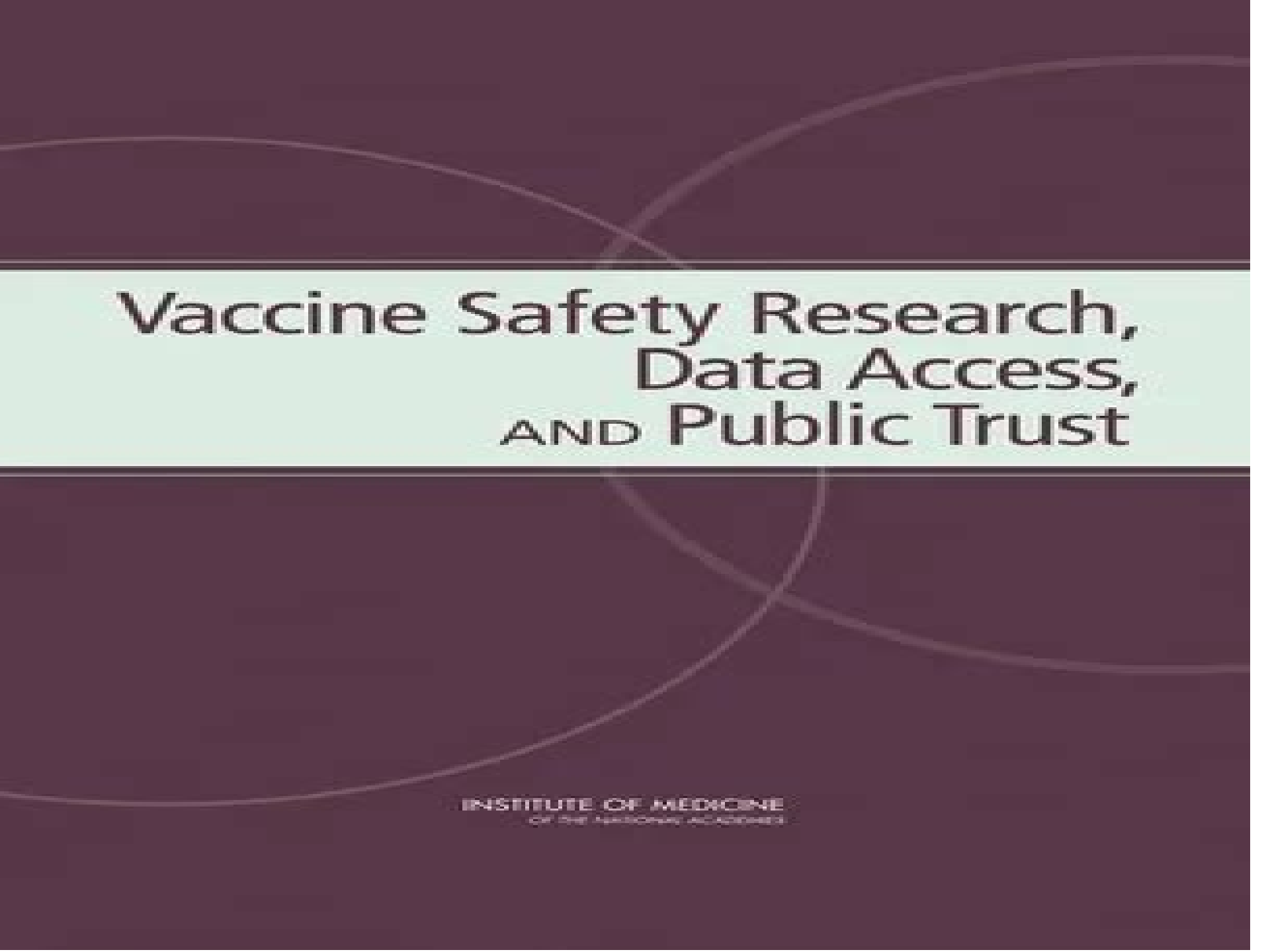


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Vaccine Safety Research, Data Access, and Public Trust Institute of Medicine, Board on Health Promotion and Disease Prevention, Committee on the Review of the National Immunization Program's Research Procedures and Data Sharing Program, 2005-04-29 The Vaccine Safety Datalink VSD is a large linked database of patient information that was developed jointly by CDC and several private managed care organizations in 1991 It includes data on vaccination histories health outcomes and characteristics of more than 7 million patients of eight participating health organizations Researchers from CDC and the managed care groups have used VSD information to study whether health problems are associated with vaccinations The subsequent VSD data sharing program was launched in 2002 to allow independent external researchers access to information in the database In this report the committee that was asked to review aspects of this program recommends that two new oversight groups are needed to ensure that the policies and procedures of the VSD and its data sharing program are implemented as fairly and openly as possible *Departments of Labor, and Health and Human Services, Education, and Related Agencies Appropriations* United States. Congress. Senate. Committee on Appropriations, 2007 Departments of Labor, Health and Human Services, Education, and Related Agencies Appropriations for 2007: Department of Labor United States. Congress. House. Committee on Appropriations. Subcommittee on the Departments of Labor, Health and Human Services, Education, and Related Agencies, 2006 *Departments of Labor, Health and Human Services, Education, and Related Agencies Appropriations for 2007* United States. Congress. House. Committee on Appropriations. Subcommittee on the Departments of Labor, Health and Human Services, Education, and Related Agencies, 2006 **Departments of Labor, Health and Human Services, Education, and Related Agencies Appropriations for 2008, Part 2B, 110-1 Hearings, ***, 2007 *Departments of Labor, Health and Human Services, Education, and Related Agencies Appropriations for 2008* United States. Congress. House. Committee on Appropriations. Subcommittee on the Departments of Labor, Health and Human Services, Education, and Related Agencies, 2007

Vaccine Safety Research, Data Access, and Public Trust National Academy of Sciences Board on Health Promotion and Disease Prevention, 2005 **Expanding Access to Research Data** National Research Council, Division of Behavioral and Social Sciences and Education, Committee on National Statistics, Panel on Data Access for Research Purposes, 2005-12-11 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 House Reports Congress,House, **Departments of Labor, Health and Human Services, and Education, and related agencies appropriation bill, 2006 : report together with minority views (to accompany H.R. 3010).** ,

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