

EXPANDING ACCESS TO RESEARCH DATA

**Reconciling Risks
and Opportunities**

**NATIONAL RESEARCH COUNCIL
OF THE NATIONAL ACADEMIES**

Expanding Access To Research Data Reconciling Risks And Opportun

Marcel Das, Peter Ester, Lars Kaczmirek



Expanding Access To Research Data Reconciling Risks And Opportun:

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

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, 2005-11-11 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

Improving Data to Analyze Food and Nutrition Policies National Research Council, Division of Behavioral and Social Sciences and Education, Committee on National Statistics, Panel on Enhancing the Data Infrastructure in Support of Food and Nutrition Programs, Research, and Decision Making, 2005-11-18 Several changes in the United States over the past two decades have implications for diet nutrition and food safety including patterns of food consumption that have produced an increase in overweight and obese Americans and threats to food safety from pathogens and bioterrorism The

changes raise a number of critical policy and research questions How do differences in food prices and availability or in households time resources for shopping and food preparation affect what people consume and where they eat How do factors outside of the household such as the availability of stores and restaurants food preparation technology and food marketing and labeling policies affect what people are consuming What effects have food assistance programs had on the nutritional quality of diets and the health of those served by the programs Where do people buy and consume food and how does food preparation affect food safety To address these and related questions the Economic Research Service ERS of the U S Department of Agriculture USDA asked the Committee on National Statistics to convene a panel of experts to provide advice for improving the data infrastructure on food consumption and nutrition The panel was charged to review data needs to support research and decision making for food and nutrition policies and programs in USDA and to assess the adequacy of the current data infrastructure and recommend enhancements to improve it The primary basis for the panel s deliberations given limited resources was a workshop on Enhancing the Data Infrastructure in Support of Food and Nutrition Programs Research and Decision Making which the panel convened on May 27 28 2004 This report is based on the discussions at the workshop and the deliberations of the panel The report outlines key data that are needed to better address questions related to food consumption diet and health discusses the available data and some limitations of those data and offers recommendations for improvements in those data The panel was charged to consider USDA data needs for policy making and the focus of the report is on those needs

Managing and Sharing Research Data Louise Corti,Veerle Van den Eynden,Libby Bishop,Matthew Woollard,2019-10-07 Written by experts at the UK Data Archive with over thirty years of experience in working with and teaching people to work with data this book is the globally reaching guide for any postgraduate student or researcher looking to build their data management skills Focused on both primary and secondary data and packed with checklists and templates it contains everything readers need to know for managing all types data before during and after the research process Building on foundational data management techniques it offers practical advice and insight into the unique skills needed to work with newer forms of data like social media and big data It also demonstrates how to Identify quality data that is credible ethically sound and available for use Choose and collect data suitable for particular research questions and project scopes Work with personal communal administrative and other sensitive and public data Make the most of metadata Visualise and share data using innovative platforms like blogs infographics and podcasts

Putting People on the Map National Research Council,Division of Behavioral and Social Sciences and Education,Committee on the Human Dimensions of Global Change,Panel on Confidentiality Issues Arising from the Integration of Remotely Sensed and Self-Identifying Data,2007-03-22 Precise accurate spatial information linked to social and behavioral data is revolutionizing social science by opening new questions for investigation and improving understanding of human behavior in its environmental context At the same time precise spatial data make it more likely that individuals can be identified breaching

the promise of confidentiality made when the data were collected Because norms of science and government agencies favor open access to all scientific data the tension between the benefits of open access and the risks associated with potential breach of confidentiality pose significant challenges to researchers research sponsors scientific institutions and data archivists Putting People on the Map finds that several technical approaches for making data available while limiting risk have potential but none is adequate on its own or in combination This book offers recommendations for education training research and practice to researchers professional societies federal agencies institutional review boards and data stewards

Proposed Revisions to the Common Rule for the Protection of Human Subjects in the Behavioral and Social Sciences

National Research Council, Division of Behavioral and Social Sciences and Education, Committee on Population, Committee on National Statistics, Board on Behavioral, Cognitive, and Sensory Sciences, Committee on Revisions to the Common Rule for the Protection of Human Subjects in Research in the Behavioral and Social Sciences, 2014-03-31 Proposed Revisions to the Common Rule for the Protection of Human Subjects in the Behavioral and Social Sciences examines how to update human subjects protections regulations so that they effectively respond to current research contexts and methods With a specific focus on social and behavioral sciences this consensus report aims to address the dramatic alterations in the research landscapes that institutional review boards IRBs have come to inhabit during the past 40 years The report aims to balance respect for the individual persons whose consent to participate makes research possible and respect for the social benefits that productive research communities make possible The ethics of human subjects research has captured scientific and regulatory attention for half a century To keep abreast of the universe of changes that factor into the ethical conduct of research today the Department of Health and Human Services published an Advance Notice of Proposed Rulemaking ANPRM in July 2011 Recognizing that widespread technological and societal transformations have occurred in the contexts for and conduct of human research since the passage of the National Research Act of 1974 the ANPRM revisits the regulations mandated by the Act in a correspondingly comprehensive manner Its proposals aim to modernize the Common Rule and to improve the efficiency of the work conducted under its auspices Proposed Revisions to the Common Rule for the Protection of Human Subjects in the Behavioral and Social Sciences identifies issues raised in the ANPRM that are critical and feasible for the federal government to address for the protection of participants and for the advancement of the social and behavioral sciences For each identified issue this report provides guidance for IRBs on techniques to address it with specific examples and best practice models to illustrate how the techniques would be applied to different behavioral and social sciences research procedures Handbook of Survey Research Peter V. Marsden, James D. Wright, 2010-04-28 With chapters on sampling measurement questionnaire construction and question writing survey implementation and management survey data analysis special types of surveys and integrating surveys with other data collection methods this title includes topics such as measurement models the role of cognitive psychology and surveying networks *Secret Science Reform Act of 2015* United

States. Congress. House. Committee on Science, Space, and Technology (2011-),2015 **Questions Surrounding the 'hockey Stick' Temperature Studies** United States. Congress. House. Committee on Energy and Commerce. Subcommittee on Oversight and Investigations,2006 *Improving Business Statistics Through Interagency Data Sharing* National Research Council,Division of Behavioral and Social Sciences and Education,Committee on National Statistics,Steering Committee for the Workshop on the Benefits of Interagency Business Data Sharing,2006-10-11 U S business data are used broadly providing the building blocks for key national as well as regional and local statistics measuring aggregate income and output employment investment prices and productivity Beyond aggregate statistics individual and firm level data are used for a wide range of microanalyses by academic researchers and by policy makers In the United States data collection and production efforts are conducted by a decentralized system of statistical agencies This apparatus yields an extensive array of data that particularly when made available in the form of microdata provides an unparalleled resource for policy analysis and research on social issues and for the production of economic statistics However the decentralized nature of the statistical system also creates challenges to efficient data collection to containment of respondent burden and to maintaining consistency of terms and units of measurement It is these challenges that raise to paramount importance the practice of effective data sharing among the statistical agencies With this as the backdrop the Bureau of Economic Analysis BEA asked the Committee on National Statistics of the National Academies to convene a workshop to discuss interagency business data sharing The workshop was held October 21 2005 This report is a summary of the discussions of that workshop The workshop focused on the benefits of data sharing to two groups of stakeholders the statistical agencies themselves and downstream data users Presenters were asked to highlight untapped opportunities for productive data sharing that cannot yet be exploited because of regulatory or legislative constraints The most prominently discussed example was that of tax data needed to reconcile the two primary business lists use by the statistical agencies *The Potential Consequences of Public Release of Food Safety and Inspection Service Establishment-Specific Data* National Research Council,Division on Earth and Life Studies,Board on Agriculture and Natural Resources,Committee on a Study of Food Safety and Other Consequences of Publishing Establishment-Specific Data,2012-01-14 The Food Safety and Inspection Service FSIS is the regulatory agency in the US Department of Agriculture that is responsible for ensuring that meat poultry and processed egg products produced domestically or imported into the United States are safe wholesome and properly labeled FSIS collects a voluminous amount of data in support of its regulatory functions but the two major types of FSIS data that are currently being considered for public release are sampling and testing data derived from standard laboratory tests and inspection and enforcement data derived from text written by inspectors Some of those data are already released to the public in aggregated form but not in disaggregated establishment specific form In recent years the Obama administration has implemented measures to facilitate openness in government including the requirement that federal agencies publish information online and provide public

access to information in a timely manner in a form that can be easily retrieved downloaded indexed and searched with tools that are available on the Internet and without the need for Freedom of Information Act FOIA requests The Potential Consequences of Public Release of Food Safety and Inspection Service Establishment Specific Data examines the potential food safety benefits and other consequences of making establishment specific data publicly available on the Internet The report includes how factors such as level of aggregation timing of release level of completeness and characterization of the data or context in which the data are presented might affect their utility in improving food safety The report also examines potential ways that food safety benefits and other effects of publicly posting the data might be measured

Federal Statistics, Multiple Data Sources, and Privacy Protection National Academies of Sciences, Engineering, and Medicine, Division of Behavioral and Social Sciences and Education, Committee on National Statistics, Panel on Improving Federal Statistics for Policy and Social Science Research Using Multiple Data Sources and State-of-the-Art Estimation Methods, 2018-01-27 The environment for obtaining information and providing statistical data for policy makers and the public has changed significantly in the past decade raising questions about the fundamental survey paradigm that underlies federal statistics New data sources provide opportunities to develop a new paradigm that can improve timeliness geographic or subpopulation detail and statistical efficiency It also has the potential to reduce the costs of producing federal statistics The panel's first report described federal statistical agencies current paradigm which relies heavily on sample surveys for producing national statistics and challenges agencies are facing the legal frameworks and mechanisms for protecting the privacy and confidentiality of statistical data and for providing researchers access to data and challenges to those frameworks and mechanisms and statistical agencies access to alternative sources of data The panel recommended a new approach for federal statistical programs that would combine diverse data sources from government and private sector sources and the creation of a new entity that would provide the foundational elements needed for this new approach including legal authority to access data and protect privacy This second of the panel's two reports builds on the analysis conclusions and recommendations in the first one This report assesses alternative methods for implementing a new approach that would combine diverse data sources from government and private sector sources including describing statistical models for combining data from multiple sources examining statistical and computer science approaches that foster privacy protections evaluating frameworks for assessing the quality and utility of alternative data sources and various models for implementing the recommended new entity Together the two reports offer ideas and recommendations to help federal statistical agencies examine and evaluate data from alternative sources and then combine them as appropriate to provide the country with more timely actionable and useful information for policy makers businesses and individuals

Proposed Revisions to the Common Rule National Research Council, Division of Behavioral and Social Sciences and Education, Board on Behavioral, Cognitive, and Sensory Sciences, Committee on Revisions to the Common Rule for the Protection of Human

Subjects in Research in the Behavioral and Social Sciences,2013-08-26 On July 26 2011 the U S Department of Health and Human Services issued an advance notice of proposed rulemaking ANPRM with the purpose of soliciting comments on how current regulations for protecting research participants could be modernized and revised The rationale for revising the regulations was as follows this ANPRM seeks comment on how to better protect human subjects who are involved in research while facilitating valuable research and reducing burden delay and ambiguity for investigators The current regulations governing human subjects research were developed years ago when research was predominantly conducted at universities colleges and medical institutions and each study generally took place at only a single site Although the regulations have been amended over the years they have not kept pace with the evolving human research enterprise the proliferation of multisite clinical trials and observational studies the expansion of health services research research in the social and behavioral sciences and research involving databases the Internet and biological specimen repositories and the use of advanced technologies such as genomics Proposed Revisions to the Common Rule Perspectives of Social and Behavioral Scientists Workshop Summary focuses on six broad topic areas 1 Evidence on the functioning of the Common Rule and of institutional review boards IRBs to provide context for the proposed revisions 2 The types and levels of risks and harms encountered in social and behavioral sciences and issues related to the severity and probability of harm because the ANPRM asks for input on calibration of levels of review to levels of risk 3 The consent process and special populations because new rules have been proposed to improve informed consent e g standard consent form consent for future uses of biospecimens and re consenting for further use of existing research data 4 Issues related to the protection of research participants in studies that involve use of existing data and data sharing because the ANPRM proposed applying standards for protecting the privacy of healthcare data to research data 5 Multidisciplinary and multisite studies because the ANPRM proposed a revision to the regulations that would allow multisite studies to be covered by a single IRB 6 The purview and roles of IRBs because the ANPRM included possible revisions to categories of research that could entail changes in IRB oversight

Secret Science Reform Act of 2014 United States. Congress. House. Committee on Science, Space, and Technology (2011-),2014 **Principles and Practices for a Federal Statistical Agency** National Academies of Sciences, Engineering, and Medicine,Division of Behavioral and Social Sciences and Education,Committee on National Statistics,2017-08-27 Publicly available statistics from government agencies that are credible relevant accurate and timely are essential for policy makers individuals households businesses academic institutions and other organizations to make informed decisions Even more the effective operation of a democratic system of government depends on the unhindered flow of statistical information to its citizens In the United States federal statistical agencies in cabinet departments and independent agencies are the governmental units whose principal function is to compile analyze and disseminate information for such statistical purposes as describing population characteristics and trends planning and monitoring programs and conducting research and evaluation The work of these

agencies is coordinated by the U S Office of Management and Budget Statistical agencies may acquire information not only from surveys or censuses of people and organizations but also from such sources as government administrative records private sector datasets and Internet sources that are judged of suitable quality and relevance for statistical use They may conduct analyses but they do not advocate policies or take partisan positions Statistical purposes for which they provide information relate to descriptions of groups and exclude any interest in or identification of an individual person institution or economic unit Four principles are fundamental for a federal statistical agency relevance to policy issues credibility among data users trust among data providers and independence from political and other undue external influence Principles and Practices for a Federal Statistical Agency Sixth Edition presents and comments on these principles as they ve been impacted by changes in laws regulations and other aspects of the environment of federal statistical agencies over the past 4 years

Social and Behavioral Research and the Internet Marcel Das, Peter Ester, Lars Kaczmirek, 2018-10-24 Highlighting the progress made by researchers in using Web based surveys for data collection this timely volume summarizes the experiences of leading behavioral and social scientists from Europe and the US who collected data using the Internet Some chapters present theory methodology design and implementation while others focus on best practice examples and or issues such as data quality and understanding paradata A number of contributors applied innovative Web based research methods to the LISS panel of CentERdata collected from over 5 000 Dutch households Their findings are presented in the book Some of the data is available on the book website The book addresses practical issues such as data quality how to reach difficult target groups how to design a survey to maximize response and ethical issues that need to be considered Innovative applications such as the use of biomarkers and eye tracking techniques are also explored Part 1 provides an overview of Internet survey research including its methodologies strengths challenges and best practices Innovative ways to minimize sources of error are provided along with a review of mixed mode designs how to design a scientifically sound longitudinal panel and avoid sampling problems and address ethical requirements in Web surveys Part 2 focuses on advanced applications including the impact of visual design on the interpretability of survey questions the impact survey usability has on respondents answers design features that increase interaction and how Internet surveys can be effectively used to study sensitive issues Part 3 addresses data quality sample selection measurement and non response error and new applications for collecting online data The issue of underrepresentation of certain groups in Internet research and the measures most effective at reducing it are also addressed The book concludes with a discussion of the importance of paradata and the Web data collection process in general followed by chapters with innovative experiments using eye tracking techniques and biomarker data This practical book appeals to practitioners from market survey research institutes and researchers in disciplines such as psychology education sociology political science health studies marketing economics and business who use the Internet for data collection but is also an ideal supplement for graduate and or upper level undergraduate courses on Internet research

methods and or data collection taught in these fields Research Methods for Public Administrators Gary Rassel, Maureen Berner, Jocelyn DeVance Taliaferro, Elizabethann O'Sullivan, 2016-10-04 Research Methods for Public Administrators introduces students to the methodological tools public administrators and policy analysts use to conduct research in the twenty first century Full of engaging examples and step by step instructions to illustrate common research methods and techniques this book provides future administrators with an unshakeable foundation in model building research design and statistical applications New to the Sixth Edition Sections addressing recent developments in research methods such as Big Data and Exploratory Data Analysis Expanded coverage of digital media including internet surveys and survey data collection by tablet computers Greater focus on qualitative research methods and their strengths and weaknesses relative to quantitative methods Updated study items knowledge questions homework exercises and problem assignments for each chapter **The SAGE Handbook of Survey Methodology** Christof Wolf, Dominique Joye, Tom W Smith, Yang-chih Fu, 2016-07-11 Survey Methodology is becoming a more structured field of research deserving of more and more academic attention The SAGE Handbook of Survey Methodology explores both the increasingly scientific endeavour of surveys and their growing complexity as different data collection modes and information sources are combined The handbook takes a global approach with a team of international experts looking at local and national specificities as well as problems of cross national comparative survey research The chapters are organized into seven major sections each of which represents a stage in the survey life cycle Surveys and Societies Planning a Survey Measurement Sampling Data Collection Preparing Data for Use Assessing and Improving Data Quality The SAGE Handbook of Survey Methodology is a landmark and essential tool for any scholar within the social sciences **Innovative Data Communication Technologies and Application** Jennifer S. Raj, Khaled Kamel, Pavel Lafata, 2022-02-24 This book presents the latest research in the fields of computational intelligence ubiquitous computing models communication intelligence communication security machine learning informatics mobile computing cloud computing and big data analytics The best selected papers presented at the International Conference on Innovative Data Communication Technologies and Application ICIDCA 2021 are included in the book The book focuses on the theory design analysis implementation and application of distributed systems and networks Communicating Science and Engineering Data in the Information Age National Research Council, Division on Engineering and Physical Sciences, Computer Science and Telecommunications Board, Division of Behavioral and Social Sciences and Education, Committee on National Statistics, Panel on Communicating National Science Foundation Science and Engineering Information to Data Users, 2012-03-07 The National Center for Science and Engineering Statistics NCSES of the National Science Foundation NSF communicates its science and engineering S E information to data users in a very fluid environment that is undergoing modernization at a pace at which data producer dissemination practices protocols and technologies on one hand and user demands and capabilities on the other are changing faster than the agency has been able to accommodate NCSES asked the

Committee on National Statistics and the Computer Science and Telecommunications Board of the National Research Council to form a panel to review the NCSES communication and dissemination program that is concerned with the collection and distribution of information on science and engineering and to recommend future directions for the program Communicating Science and Engineering Data in the Information Age includes recommendations to improve NCSES's dissemination program and improve data user engagement This report includes recommendations such as NCSES's transition to a dissemination framework that emphasizes database management rather than data presentation and that NCSES analyze the results of its initial online consumer survey and refine it over time The implementation of the report's recommendations should be undertaken within an overall framework that accords priority to the basic quality of the data and the fundamentals of dissemination then to significant enhancements that are achievable in the short term while laying the groundwork for other long term improvements

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