Record Nr. UNINA9910826074603321 **Titolo** Health data in the information age: use, disclosure, and privacy // Molla S. Donaldson and Kathleen N. Lohr, editors; Committee on Regional Health Data Networks, Division of Health Care Services. Institute of Medicine Pubbl/distr/stampa Washington, D.C., : National Academy Press, 1994 **ISBN** 1-280-21136-9 9786610211364 0-309-53821-1 0-585-00234-7 Edizione [1st ed.] Descrizione fisica 1 online resource (271 p.) Altri autori (Persone) DonaldsonMolla S LohrKathleen N. <1941-> Disciplina 651.5/04261 Soggetti Medical records - Access control Confidential communications - Physicians Medical informatics Lingua di pubblicazione Inglese **Formato** Materiale a stampa Livello bibliografico Monografia Note generali Bibliographic Level Mode of Issuance: Monograph Nota di bibliografia Includes bibliographical references p. (214-224) and index. Nota di contenuto Health Data in the Information Age -- Copyright -- Preface --Acknowledgments -- Contents -- Summary -- THE PROBLEM --INSTITUTE OF MEDICINE STUDY -- USES AND USERS OF INFORMATION IN HDOS -- Databases -- Key Attributes of Databases -- Other Characteristics of Databases -- Ensuring the Quality of Data -- PUBLIC DISCLOSURE OF DATA ON HEALTH CARE PROVIDERS AND PRACTITIONERS -- Key Factors in Public Disclosure -- Analyses and Disclosure of Results -- Describing Analytic Methods -- Minimizing Potential Harms -- Releasing Data -- STRENGTHENING QUALITY ASSURANCE AND QUALITY IMPROVEMENT PROGRAMS THROUGH DATA FEEDBACK -- CONFIDENTIALITY AND PRIVACY OF PERSONAL DATA --Privacy and Privacy Rights -- Privacy Rights -- Confidentiality --Security -- A National Identification System or Dossier -- Personal Identifiers and the Social Security Number -- An "Ideal" Identifier --Relevance to HDOs of Existing Laws on Confidentiality and Privacy --

Recommendations Regarding Protection of Patient and Personidentifiable Data -- Preemptive Legislation -- Data Protection Units --Release of Person-Identified Data -- Policies Relating to Access and Disclosure -- Universal Person-Identifiers -- THE FUTURE -- 1 Introduction -- ADVANCING THE PROSPECTS FOR COMPREHENSIVE HEALTH DATABASES AND NETWORKS -- The Problem -- The Opportunity -- HEALTH DATABASE ORGANIZATIONS -- THE INSTITUTE OF MEDICINE STUDY -- The Study Committee and Its Charge --Questions Confronting the Study Committee -- STUDY ACTIVITIES --ORGANIZATION OF THE REPORT -- COMMENT -- 2 Health Databases and Health Database Organizations: Uses, Benefits, and Concerns --DEFINITIONS -- Database -- Key Attributes of Databases -- Other Characteristics of Databases -- Data Network -- Health Database Organization -- The Concept of HDOs -- HDOs Under Development --THE BENEFITS OF HEALTH DATABASES -- Broad-based Benefits. Differential Benefits as a Function of Users and Uses -- USERS OF INFORMATION IN HDOS -- USES OF DATABASES -- Assessing Access to Care and Use of Services -- Assessing Costs and Identifying Opportunities for Savings -- Evaluating Quality and Outcomes of Care -- Hospital-specific Mortality Rate Studies -- Effectiveness and Outcomes Research -- Quality Assurance and Quality Improvement Programs -- Planning and Monitoring Patient Care -- Enhancing Administrative Efficiency -- Operating Managed Care Programs --Strategic Planning and Selective Contracting -- Strategic Planning --Selective Contracting -- Other Business-related Uses -- Tracking Injury and Illness, Preventive Care, and Health Behaviors -- Promoting Regional and Community Health Planning, Education, and Outreach --Health Planning and Education -- Community Outreach -- Other Uses for HDO Databases -- Comment -- ENSURING THE QUALITY OF DATA -- SUMMARY -- 3 Public Disclosure of Data on Health Care Providers and Practitioners -- PREVIOUS STUDIES -- IMPORTANT PRINCIPLES OF PUBLIC DISCLOSURE -- IMPORTANT ELEMENTS OF PUBLIC DISCLOSURE -- Topics for HDO Analysis and Disclosure -- Who Is Identified --Vulnerability to Harm -- Methodological and Technical Issues -- How Information Is Publicly Disclosed -- COMMITTEE FINDINGS AND CONCLUSIONS -- RECOMMENDATIONS -- Advocacy of Analyses and Public Disclosure of Results -- Minimizing Potential Harms -- Advocacy of Data Release -- Promoting Wide Applications of Health-related Data -- Requiring Recipients to Protect Data Privacy and Confidentiality --Using Valid Analytic Techniques -- Related Issues -- Privacy Protections for Person-identifiable Data -- Constrained Staff Capabilities -- Obligations to Correct Analyses or Retract Information -- STRENGTHENING QUALITY ASSURANCE AND QUALITY IMPROVEMENT PROGRAMS -- Data Feedback. Quality Assurance and Quality Improvement -- Privileging -- Peer Review Information -- Public Disclosure and Feedback -- SUMMARY --APPENDIX 3A -- Actual Numbers, Computed Values, and Risk Adjustment -- Certainty, Probability, and Correct Inferences -- The Educational Content of Public Information Dissemination -- 4 Confidentiality and Privacy of Personal Data -- HISTORICAL PERSPECTIVES AND GENERAL OBSERVATIONS ON DISCLOSURE OF INFORMATION -- SOURCES OF CONCERNS ABOUT PRIVACY AND THE CONFIDENTIALITY OF HEALTH RECORDS -- Health Care Records --Electronic Records -- DEFINITIONS -- Privacy -- Informational Privacy -- Recordkeeping Privacy -- Privacy Rights -- Balancing Benefits of HDOs Against Loss of Informational Privacy -- Federal and State Privacy Protection -- Confidentiality -- Confidentiality Obligations in Health Care -- Disclosure of Health Information -- Weaknesses of Legal

Protection for Confidentiality -- Security -- Health-Related Information -- EXPANDED DEFINITIONS -- HARM FROM DISCLOSURE AND REDISCLOSURE OF HEALTH RECORD INFORMATION -- Common" Disclosures -- Inadvertent Release -- "Routine" Releases or Uses in Accordance with Prevailing Practices -- Rerelease to Third Parties Without the Subject's Knowledge or Consent (Secondary Use) -- Covert Acquisition and Use of Data for Illegal or Unethical Purposes -- Release of Inaccurate Data -- PRIVACY INTERESTS AND HDOS -- Foreseen and Unforeseen Circumstances -- A National Identification System or Dossier -- Personal Identifiers and the Social Security Number -- An Ideal Personal Identifier -- Issues Relating to the SSN -- SSN Uses for Other Than Medical Payments -- Shortfalls of the SSN as an Identifier -- Confidentiality of Research Uses of HDO Databases -- RELEVANCE OF EXISTING LAWS TO HDOS -- Laws Governing Insurance Support Organizations -- Laws Governing Consumer Reporting Agencies. HDOs as Governmental Entities: General Confidentiality Protections in Public Law -- Constitutional Law -- Legislative Charter -- Freedom of Information Acts -- Fair Information Practices -- OPTIONS FOR PROTECTING PRIVACY AND CONFIDENTIALITY OF HEALTH-RELATED DATA IN HDOS -- Uniform Legislation -- Federal Preemptive Legislation -- Uniform State Legislation -- Options for Consent and Participation Rights -- HDO Access to Data -- Other Consent and Participation Rights -- Disclosure Options -- Disclosure-Oriented Options (Weak Options) -- Confidentiality-Oriented Options (Strong Options) -- Governance Options as an Approach to Privacy Protections -- State-Based Systems -- Private-Sector Systems -- Mixed Governance Systems -- Other Administrative Options to Protect Privacy and Confidentiality -- COMMITTEE RECOMMENDATIONS -- Overview and General Principles -- Preemptive Legislation -- Arguments for Federal Legislation -- Attaching Privacy Protection to Data -- Uniform Requirements -- Specific Elements of Federal Legislation -- Exemption from Compulsory Reporting and Compulsory Process -- Data Protection Units -- Establishing a Data Protection Board -- Developing Administrative Policies and Procedures -- Overseeing Data Integrity --Release of Person-identified Data -- Policies Relating to Access and Disclosure -- Consent -- Release of Person-identified Data -- The Standing of Other HDOs -- The Standing of Persons, Parents, and Legal Representatives -- The Special Standing of Research -- Special Patient Care Considerations -- Prohibition on Access to Person-identifiable Data -- Implications of Recommendations Denving Access -- Employer Access -- Universal Person Identifiers -- COMMENT -- The New Privacy -- SUMMARY -- References -- Appendixes -- A Fact-Finding for the Committee on Regional Health Data Networks -- PARTICIPANTS AND GUESTS AT COMMITTEE MEETINGS. Expert Presentations and Briefings -- Invited Guests and Observers --Institute of Medicine Staff -- SITE VISITS -- Memphis, Tennessee: July 26-28, 1992 -- Cleveland, Ohio: August 2-4, 1992 -- Des Moines,

Expert Presentations and Briefings -- Invited Guests and Observers -- Institute of Medicine Staff -- SITE VISITS -- Memphis, Tennessee: July 26-28, 1992 -- Cleveland, Ohio: August 2-4, 1992 -- Des Moines, Iowa: August 26-28, 1992 -- Seattle, Washington: September 9-11, 1992 -- Rochester and Albany, New York: September 21-23, 1992 -- Albany -- Rochester -- Basic Findings of Site Visits -- B Committee on Regional Health DataNetworks Biographical Sketches -- Glossary -- Acronyms -- Index.