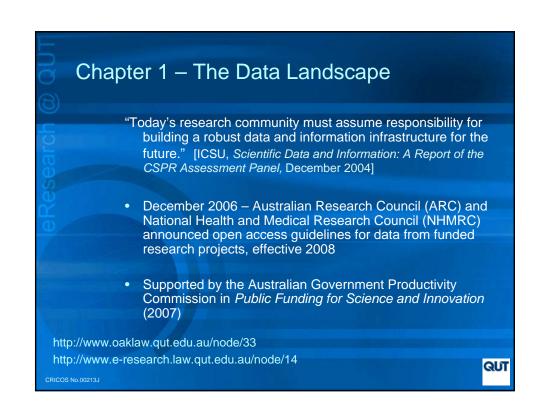




BUILDING THE INFRASTRUCTURE FOR DATA ACCESS AND REUSE IN COLLABORATIVE RESEARCH: An Analysis of the Legal Context - Examines the legal framework in which research data is generated, managed, disseminated, used - Provides an overview of the areas of law relevant to research data: - copyright, contract, confidentiality, privacy, public records, freedom of information etc - Explains current practices and attitudes to data sharing; considers open access policies developed at national and international levels - Provides practical guidance and recommendations on the development of appropriate legal frameworks for data management - http://www.oaklaw.qut.edu.au/node/33 - http://www.e-research.law.qut.edu.au/node/14



Chapter 1 – The Data Landscape

- Prime Minister's Science, Engineering and Innovation Council (PMSEIC),
 Working Group on Data for Science, From Data to Wisdom: Pathways for Successful Data Management for Australian Science (December 2006)
- Australian Government National Collaborative Research Infrastructure Strategy (NCRIS), Strategic Roadmap (2006)
- Australian Partnership for Sustainable Repositories (APSR), Sustainable Paths for Data-Intensive Research Communities at the University of Melbourne (August 2006)
- ,NHMRC/AVCC, Joint Statement and Guidelines on Research Practice Australian Code for Responsible Conduct of Research (2006)

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Chapter 2 - Key Concepts

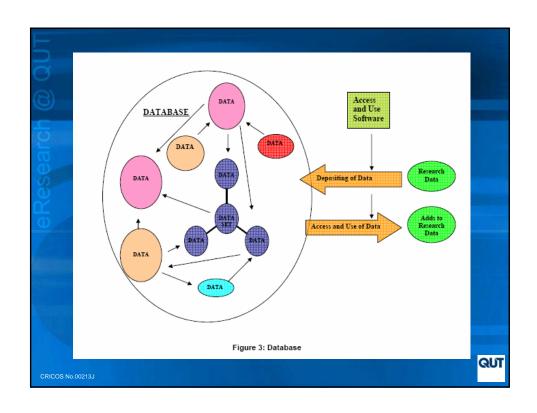
- Key terms and concepts:
 - "data", "dataset", "database"
 - "data" includes raw information, text, software, numbers, graphs, pictures, metadata and audio and video recordings
 - "ownership", "control", "access" and "use"
- Different parties may claim an interest in relation to data:
 - Researchers who generate or collect data, research funders, database managers, custodians and users
- Several areas of law impact on issues of data ownership, control, access and use:
 - copyright, patent, contract, confidential information and privacy

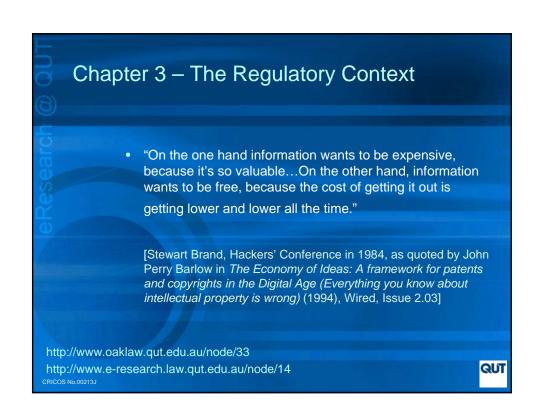
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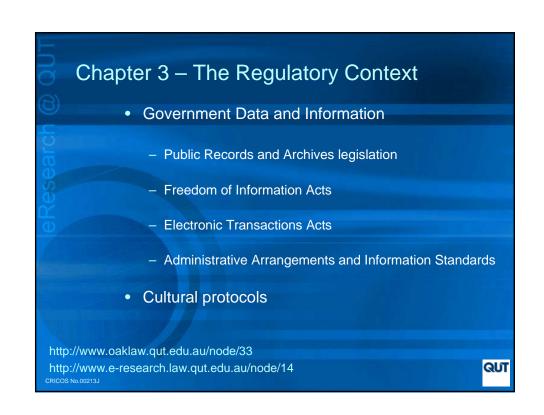
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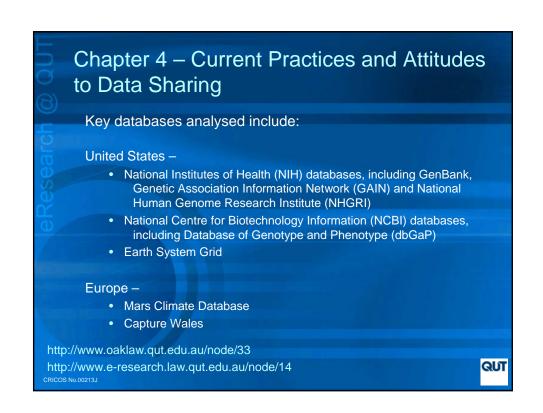


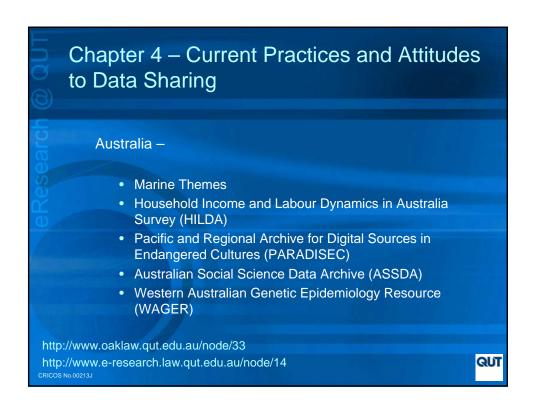


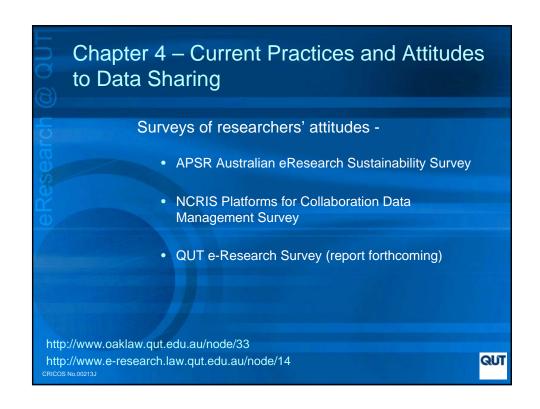
Chapter 3 — The Regulatory Context • Examines the regulatory context in which data is generated, managed and used • Particular focus on legislative and administrative provisions applying to data generated or held by public sector or publicly funded entities • Health information and personally identifying information – legal frameworks for information privacy - Competing considerations: advancement of medical research (aided by data sharing and data linking practices) vs. protection of patient anonymity and privacy • Privacy Act 1988 (Cth) and State legislation • Australian Law Reform Commission (ALRC) Issues Paper 31: Review of Privacy (2006) • ALRC Issues Paper 26: Protection of Human Genetic Information (2001) http://www.oaklaw.qut.edu.au/node/33 http://www.e-research.law.qut.edu.au/node/14

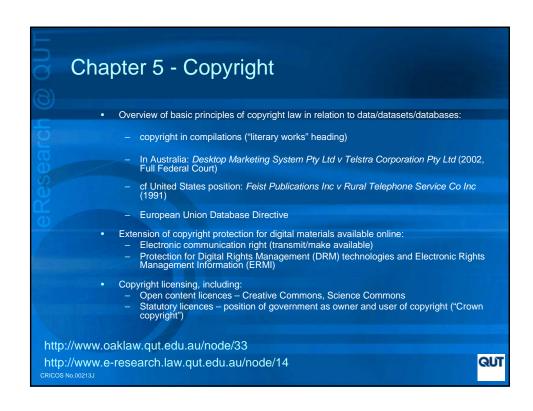


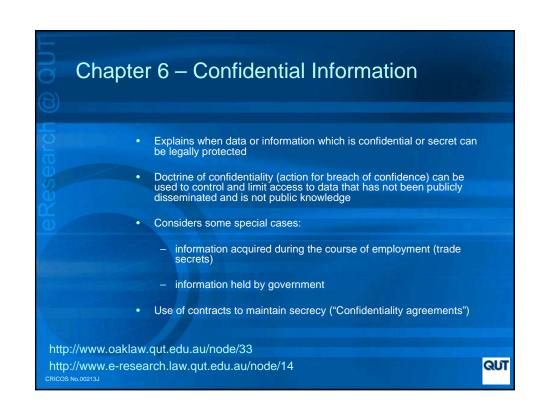
Chapter 4 – Current Practices and Attitudes to Data Sharing Surveys and describes examples of web-accessible United States, European and Australian databases with developed legal arrangements for providing access to and sharing of research data: analyses the various models of data ownership, control, access and use observed in the sample looks at general frameworks as well as subject-specific databases, especially collections of medical and genetic research data Considers the relevance of survey evidence of researchers' attitudes on accessibility and sharing of data to the development of systems for technical and legal management of research data http://www.oaklaw.qut.edu.au/node/33 http://www.e-research.law.qut.edu.au/node/14

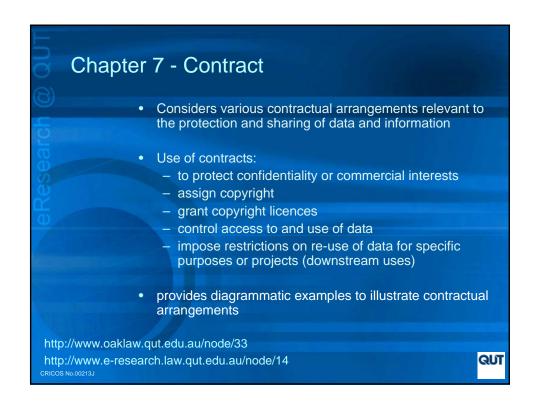


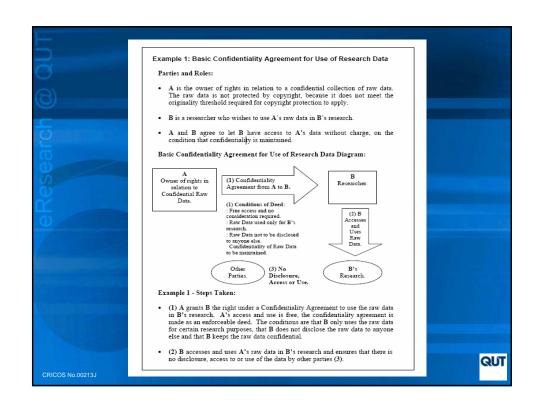


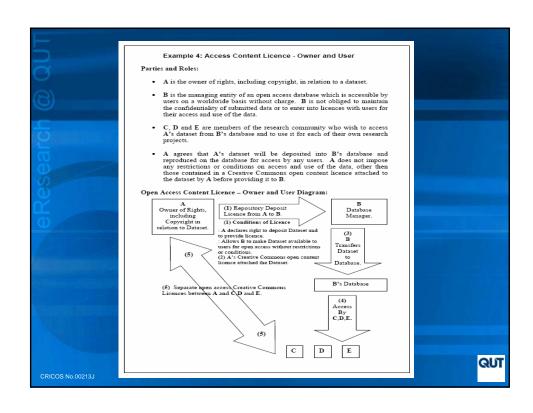


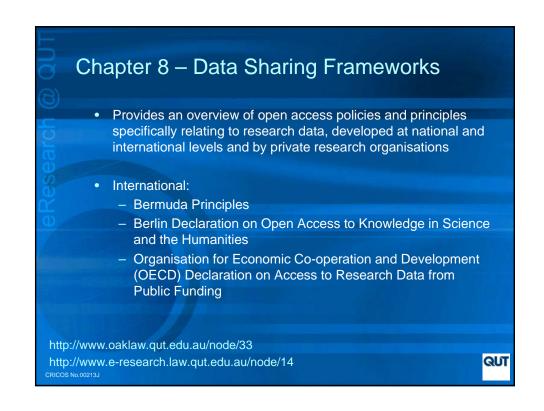




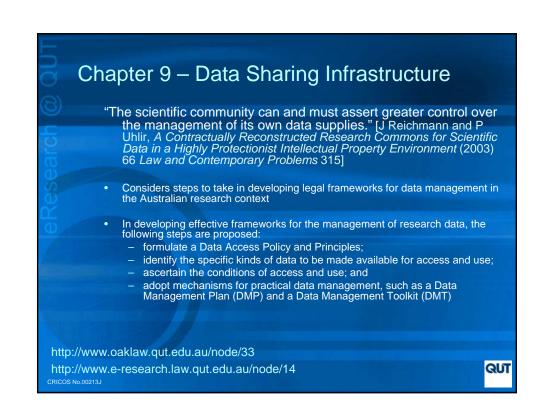




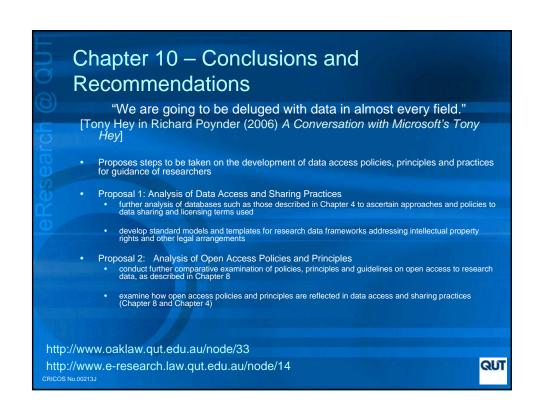




Chapter 8 – Data Sharing Frameworks • National - governments and public sector research funding bodies: - National Institutes of Health (NIH) Data Sharing Policy; and - Australian Research Council (ARC) and National Health and Medical Research Council (NHMRC) funding policies. • Private sector research organisations: - Wellcome Trust Position Statement (UK) http://www.oaklaw.qut.edu.au/node/33 http://www.e-research.law.qut.edu.au/node/14



Chapter 9 – Data Sharing Infrastructure Data Management Plan (DMP) – - how data is managed in accordance with relevant legal controls - how data is preserved and maintained and how this is funded - who is responsible for the management of data and the database Data Management Toolkit (DMT) – - guides researchers in the allocation and handling of data in accordance with the DMP - how to deposit data into the database - how to manage data in compliance with legal requirements http://www.oaklaw.qut.edu.au/node/33 http://www.e-research.law.qut.edu.au/node/14



Chapter 10 – Conclusions and Recommendations

- Proposal 3: Develop Data Access Policies and Principles and Model Data Management Plans, Toolkits and Templates
 - Policies and principles to provide clear statements on open access to research data
 - Data Management Plans (DMP) to assist in management, preservation and maintenance of data in accordance with relevant legal requirements
 - Data Management Toolkit (DMT) to provide practical guidance to researchers on how to collect, manage and deposit data
 - Template Access Agreements and Repository Deposit Licences consistent with the DMP and DMT

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