



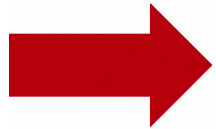
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Sharing Clinical Research Data

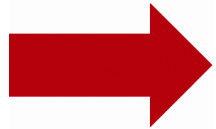
Session IV: Policy Incentives and
Cultural Shifts to Enhance Data
Sharing

Deven McGraw
Director, Health Privacy Project
October 5, 2012



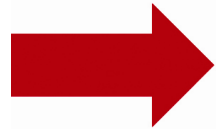
Fair Information Practices – Markle Common Framework (2006)

- Openness and transparency
- Purpose specification and minimization
- Collection limitation
- Use limitation
- Individual participation and control
- Data integrity and quality
- Security safeguards and controls
- Accountability and Oversight
- Remedies



ONC's Nationwide Privacy and Security Framework (December 2008)

- Individual Access
- Safeguards
- Correction
- Accountability
- Openness & Transparency
- Individual Choice
- Collection, Use and Disclosure Limitation
- Data Integrity & Quality



FTC's Report on Consumer Privacy (March 2012)

- Privacy by Design - Companies should promote consumer privacy throughout their organizations and at every stage of the development of their products and services
 - Incorporate substantive protections such as data security, reasonable collection limits, sound retention and disposal practices, and data accuracy.
 - Maintain comprehensive data management procedures throughout the life cycle of their products and services
- Simplify consumer choice (consider context, data sensitivity)
- Transparency – Companies should increase transparency of their data practices (and provide individuals with access to