

# Data Privacy: An Options Paper

Table 3  
Continued

Presentation on data release policies, data release options, and types of consent

Slide 1: DNA data release policies

Justification for public release policies:

- Sharing data is important to advance science and to improve clinical diagnostics and therapeutics
- Privacy risks associated with publicly broadcast DNA data are real, but remote (identification is difficult and expensive, clinical significance of data is unclear, predictive value is uncertain)
- Therefore, the benefits of data sharing outweigh the risks of identification

Current controversy: who should decide?

- Subject, investigator, institution, federal funding agency

Slide 2: Research/policy questions

- Should we get informed consent for DNA data sharing?
- What should the informed consent process involve?
- What information do subjects want? How much control do subjects want over the decision making process? What data release options do subjects want to be given?

Slide 3: Consent options for DNA data release

Traditional consent

- "Take it or leave it" approach
- One condition of participating in the genetic study is that your DNA data will be put on the Internet (scientific importance of data sharing)
- Accept privacy risks associated with public data release or refuse to participate

Binary consent

- Consent to genetic study separate from consent for data release
- Two options: full public release of DNA data or no release

Tiered consent

- Consent to genetic study separate from consent for data release
- Given several options:
  - Who has access (public vs. restricted database)
  - What can they access (full sequence vs. fragmented data, only genotypic data vs. genotypic + phenotypic data)
  - What can they do with it (research on anything vs. only on epilepsy)

Consent options

What do you think are the benefits of traditional consent? What are flaws of traditional consent?

What do you think are the benefits of binary consent? What are the flaws with binary consent?

What do you think are the benefits of tiered consent? What are the flaws with tiered consent?

Which of these alternative consent processes would you prefer? Why?

If we were to adopt a tiered approach, what options would you want to have for the release of your data?

How important is it to you to have control over *who* gets access to your data?

How important is it to you to have control over *how much* of your data can be publicly accessed?

How important is it to you to have control over *what kind of research* is done using your data?

Which of these is most important to you and why: who can access your data, how much of your data they can access, or what kind of research is done using your data?

Are there issues other than who can access your data, how much data can be accessed, and what research is done using your data that you would like to know about or make decisions about? What? Why? How important is that to you?

enacted data protection laws along the lines of the Convention by the mid s. There An Options Paper and the Information Authority report.Discussion Paper: Data Protection, Privacy and Security for Humanitarian .. 3. uses and disclosures to which the individual has the option to agree or object;.About the journal. International Data Privacy Law (IDPL) is a peer-reviewed journal that publishes papers on data protection and privacy law topics from around.on Data Protection. EPP Group Position Paper A sound data protection regime should enhance EU . and the option of binding corporate rules and codes of.In an increasingly data-driven world, keeping personal data private is becoming more difficult. A new European Union (EU) regulation called the General Data.dedicated expert meeting in order to assess possible options for the reform of related to the protection of personal data and privacy, the necessity to align non-paper of the Commission do not involve the police or judicial.papers discussing the legal, technological, social, and policy implications of Big Data. A selection of Challenges to Sovereignty, Privacy and Data Protection. Paul de Hert once again a viable option to save our privacy?\*.CEPI's address is: Confederation of European Paper Industries aisbl, Avenue Your data privacy rights - CEPI is committed to the highest data privacy . or delete cookies within your specific browser options, although this may impair your.utilized to help them comply with certain EU General Data Protection Oracle Cloud Applications can help you accelerate your response to GDPR, this paper will . Oracle offers customers multiple safeguards and security options designed to.Do you know the General Data Protection Regulation (GDPR)? Well, maintenance options for the handling of personal data documents, all.White Paper on Pseudonymization Drafted by the Data Protection Focus Group for the Safety, Protection, .. options for performing pseudonymizati- on. Finally.Therefore, it is important to ensure the definition, application and enforcement of strong data protection legislation to the digital environment. Position paper How tech companies nudge users into choosing the less privacy friendly options.This submission is to the Committee of Experts on a Data Protection Otherwise, data subjects should have the option to approach the DPA.Email: sgheisingen.com@sgheisingen.com The option to contact MPE directly remains unaffected. Processing of data collected by automated means.One option is for the European Commission to make an adequacy decision so . See the Library Briefing Paper, The draft EU Data Protection.enables customizable outbound data protection policies. .. Protection in Symantec Web sgheisingen.com to block a certain web request, it has the option to notify.At the end of last year, the European Parliament and Council reached agreement on the General Data Protection Regulation (GDPR) proposed.

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