Individual control of health data in the big data environment

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2017 This Is What Happens In An Internet Minute

Google
- 3.5 Million Search Queries
- 70,017 Hours Watched
- $751,522 Spent Online

Facebook
- 900,000 Logins

YouTube
- 16 Million Text Messages
- 4.1 Million Videos Viewed

Netflix
- 342,000 Apps Downloaded

Snapchat
- 1.8 Million Snaps Created

Instagram
- 46,200 Posts Uploaded

Twitter
- 452,000 Tweets Sent

Tinder
- 990,000 Swipes

LinkedIn
- 120 New Accounts Created

Amazon Echo
- 50 Voice-First Devices Shipped

Spotify
- 40,000 Hours Listened

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QB4. How much control do you feel you have over the information you provide online, e.g. the ability to correct, change or delete this information?

- Complete control
- Partial control
- No control at all
- It depends on the website or application (SPONTANEOUS)
- Don't know

Base: Respondents who provide personal information online (n=19,430 in EU28)
- 69% of people say that their **explicit approval** should be required in all cases before their data is collected and processed.

- Roughly seven out of ten people are concerned about their information being used for a **different purpose** from the one it was collected for.
Biomedical Big Data: New Models of Control over Access, Use and Governance;
Journal of Bioethical Inquiry, 2017
General Data Protection Regulation

Article 20. Data portability right

“[the] data subject shall have the right to receive the personal data concerning him or her, which he or she has provided to a controller, in a structured, commonly used and machine-readable format and have the right to transmit those data to another controller without hindrance from the controller to which the personal data have been provided”.

Department of Health Sciences and Technology
This includes all data observed about the data subject during the activities for the purpose of which the data are collected, such as a transaction history or access log. Data collected through the tracking and recording of the data subject (such as an app recording heartbeat or technology used to track browsing behavior) should also be considered as “provided by” him or her even if the data are not actively or consciously transmitted.
- **Shift:**
- Individual (data subject) acquires power **to** distribute
- Migration from paper to the digital
  - eIC tools
  - Online consent management
  - Dynamic consent
### From analog to digital?

#### Table 1. Components and Challenges of Informed Consent with Traditional Paper Forms and Electronic Methods.

<table>
<thead>
<tr>
<th>Component</th>
<th>Traditional Paper Informed Consent</th>
<th>Electronic and Digital Informed Consent</th>
<th>Challenges and Areas for Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclosure</td>
<td>Information is written, usually on paper. Discussion with investigator takes place, usually face to face</td>
<td>Consent can involve electronic information, multimedia information, video graphics, and interactive computer interfaces. Investigator can be remote in time or place from participant</td>
<td>All types of disclosure require determining the appropriate content (amount and complexity of information) for disclosure. User-friendly disclosure is needed. Amount and style of information tailored to electronic platforms need to be determined.</td>
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</table>
| Understanding      | Investigator and participant discuss information. Participant asks questions. Investigator assesses understanding, in some cases using questions, structured quizzes, other methods | Interaction can take place during disclosure. Questions and assessment of understanding are easily built in. Ongoing engagement is enabled. Links to additional information can be included. | Evidence indicates that people do not read click-through agreements on computers and mobile devices. Information should be engaging and user-friendly to promote reading and understanding. It may be difficult to assess capacity and understanding. Empirical evidence to date indicates that video and multimedia consent strategies have not resulted in consistent advantages or disadvantages with regard to participant understanding.

| Voluntariness      | Investigator asks participant to make a choice in a setting free from coercion and undue influence. Research team observes participant’s body language and any hesitation | Some electronic systems facilitate participant control. Participant can easily sign off or disengage. Participant can decline. | It may be difficult to assess voluntary choice without the clues of body language and tone. It may be difficult to verify the identity of the person consenting. Some data collection is passive. In some cases, contributing data is a required part of the arrangement. |
| Authorization       | Paper consent document is signed. Copies of document are kept in records. | Options might include clicking agreement or an electronic signature. Records of agreement are kept electronically. | It may be difficult to verify the identity of the authorizing person. |
Participant Centered Consent Toolkit

Sage Bionetworks developed and maintains the Participant-Centered Consent (PCC) toolkit.
Dynamic consent

Data Subjects can change their consent preferences

Data Controllers Use and Share your data, restricted by the Data Subject’s consent

Data Subjects are Notified and kept Informed of where and when their data was used.

https://www.hwcomms.com/DynamicConsent
Shift:

- Increased granularity
- Meaningful disclosure
- **Monitoring** of data uses
GOVERNANCE

Participatory schemes

Figure 1. Citizens aggregate data from different sources and make them available for precision medicine research through data cooperatives. Cooperatives offer new control mechanisms for individual data and new governance tools for aggregated data. *This figure is reproduced here as a prototype; it contains copyrighted material, and it cannot be published as such.*
- Shifts
- Citizen owned
- Federated system
- Augmented control
- Trend towards more individual control (not just in rhetoric)
- Innovative models face challenges
- More synergy in innovation around control could be more effective
- Meaningful individual control will be crucial for data access and sharing
“Big Data is not about the Data”
Gary King