eHealth, ethics and privacy
Data collection / generation challenge
Privacy challenge
Anonymity challenge
Ethics of care
communication
context & settings
context & settings
6 CHARACTERS REBOOTING MEDICINE AND HEALTH  O, 1, A, C, G, T

Accelerating Digital Technology

Super-Convergence

Reboot

Wireless Sensors & Devices

Mobile Connectivity

Social Networking

Genomics

Internet

Imaging

Data Universe

Health Information

Number of sequenced Human Genomes

PREVENTION

PREDICTION

MANAGEMENT

DIAGNOSIS

DISEASE

Based on the work of Dr. Eric Topol, author of "The Creative Destruction of Medicine: How the Digital Revolution Will Create Better Health Care"
Pew Research Internet Centre (2015)

Health & Fitness: 28,617 / 2.75%
Medical: 14,632 / 1.41%
What ethical obligations do researchers have to protect the **PRIVACY** of subjects engaging in activities in Internet spaces?

How is **CONFIDENTIALITY** and **ANONYMITY** assured online?

How is and should **INFORMED CONSENT** be obtained online?
Information privacy

Terms of use, privacy policy & permissions
Permissions
Permissions that access user information
EU – Draft of conduct

<table>
<thead>
<tr>
<th>Category</th>
<th>Average (mean) # of Permissions</th>
<th>Category</th>
<th>Average (mean) # of Permissions</th>
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<tbody>
<tr>
<td>Communication</td>
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<td>Education</td>
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<td>Business</td>
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<td>Family</td>
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<td>Lifestyle</td>
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<td>Health &amp; Fitness</td>
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<td>Role Playing</td>
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<td>Medical</td>
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<td>Music</td>
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<td>Productivity</td>
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<td>Transportation</td>
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<td>Racing</td>
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<td>Travel &amp; Local</td>
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<td>Simulation</td>
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<td>Finance</td>
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<td>Tools</td>
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<td>Books &amp; Reference</td>
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<tr>
<td>Adventure</td>
<td>5</td>
<td>Comics</td>
<td>4</td>
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</tbody>
</table>

Source: Google PlayStore, June 18-Sept 8, 2014.
Note: “Games” was expanded into its subcategories for this list. 8 apps did not have category information.

PEW RESEARCH CENTER
Private & public
“...privacy is a concept that must include a consideration of expectations and consensus.” (AoIR 2012)
Contextual integrity
Are we studying human subjects?

- A study of email communication
- Interviews in virtual worlds
- Forums, IM
- Web crawlers
- Third-party applications

- Large data pools. Eg. #hashtag in Twitter.
- Big social data
- The connection between the person and the object of research is indistinct.

INFORMED CONSENT

ANONIMITY

Aggregated data
Confidentiality & Anonymity
Data / human subjects
COMPLEX
EU - Draft of conduct
AoIR Research Ethics Guidelines (2012)
Ethics Resource Guide (COSMOS)
ETHICS OF CARE

Individuals

Socio-technical context

Circumstances
Thanks

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