

 <b>UOC</b> Universitat Oberta de Catalunya		<ul style="list-style-type: none"><li>• Students</li><li>• Researchers</li><li>• Media</li></ul>	<ul style="list-style-type: none"><li>• Alumni</li><li>• UOC Corporate</li><li>• Latin America</li></ul>
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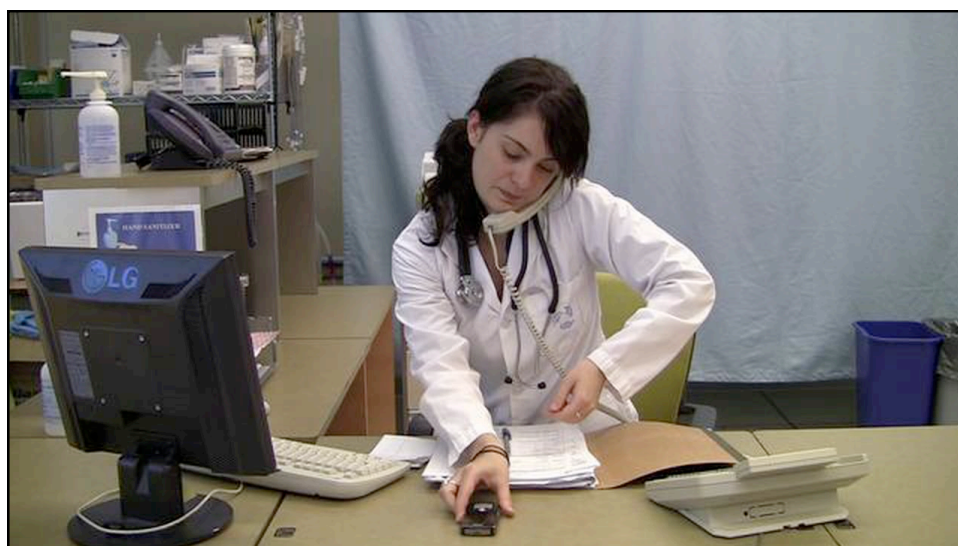
  

 	<h1>School of Social Sciences</h1>
	<h2>IME</h2> <p>Dr. Roser Beneito-Montagut Lecturer in Digital Social Sciences Cardiff University Researcher at CareNet Universitat Oberta de Catalunya</p>

The Hague, 10<sup>th</sup> May 2016

eHealth and data collection / data generation challenge  
Privacy challenge  
Anonymity challenge  
Ethics of care

The Hague, 10<sup>th</sup> May 2016



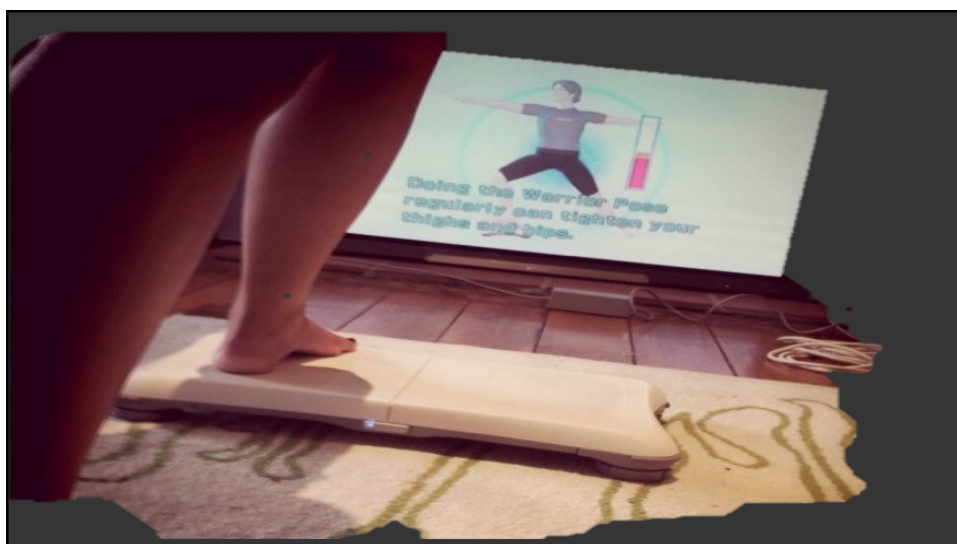
from UHN eHealth Innovation

communication



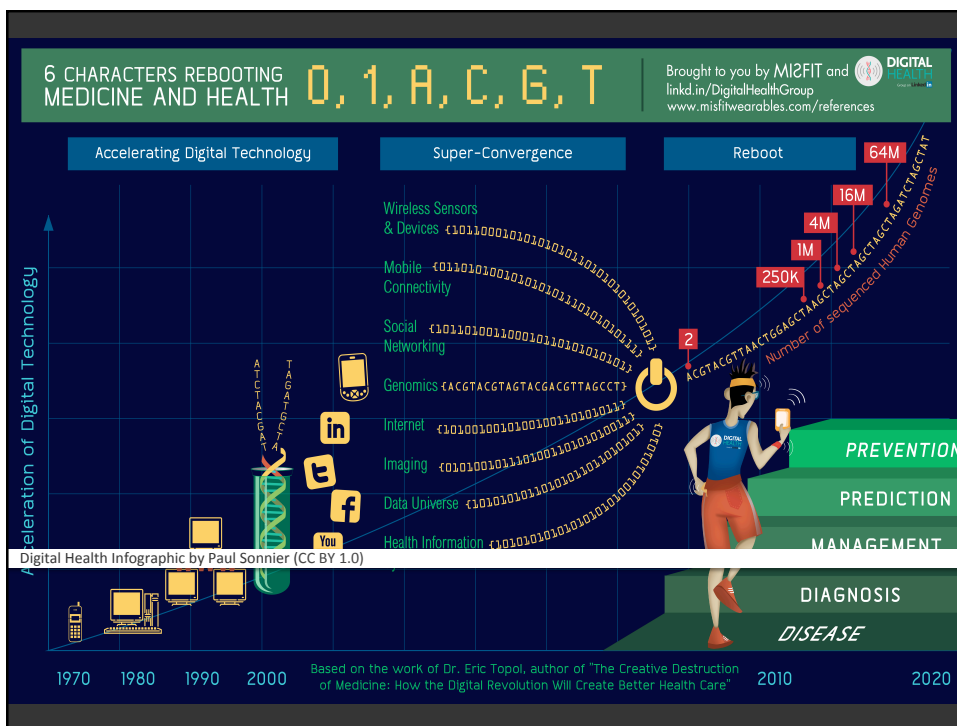
hGraph basics + multi screen by Juhan Sonin (CC BY 2.0)

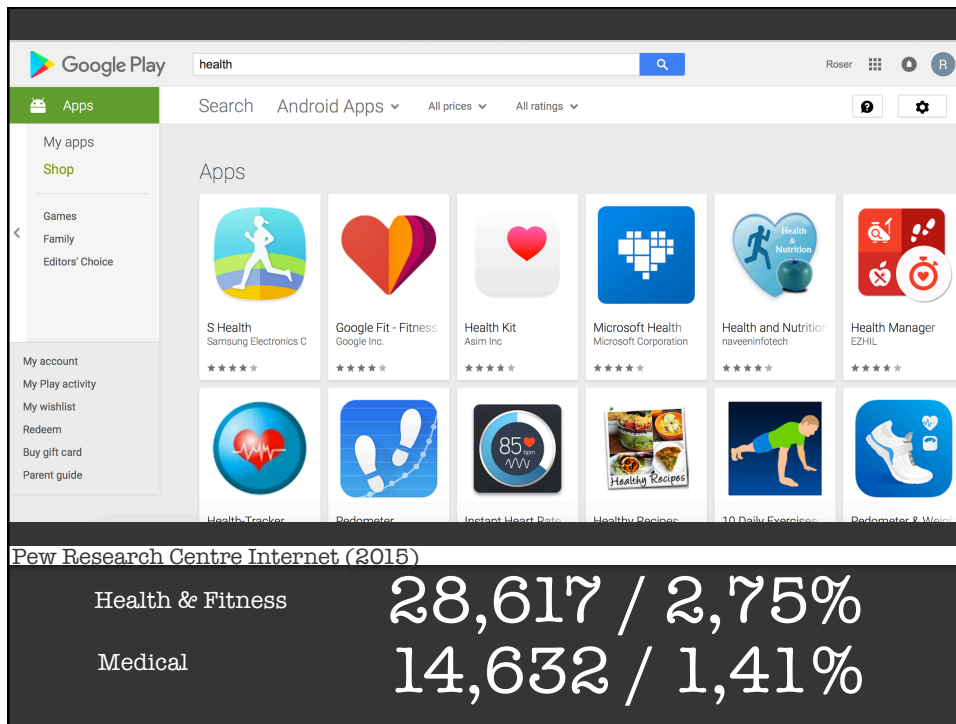
## context & settings



Exercise by Eric Veland (CC BY-NC 2.0)

## context & settings





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 should **INFORMED CONSENT** be obtained online?

researchers & data



<http://i.huffpost.com/gen/1897543/images/o-PRIVACY-facebook.jpg>

Terms of use, privacy policy & permissions

Permissions  
Permissions that access user information  
EU – Draft of conduct

#### App Permissions Vary a Bit by Category

Category	Average (mean) # of Permissions	Category	Average (mean) # of Permissions
Communication	9	Education	5
Business	8	Entertainment	5
Casino	7	Family	5
Lifestyle	7	Health & Fitness	5
Role Playing	7	Medical	5
Shopping	7	Music	5
Social	7	Productivity	5
Transportation	7	Racing	5
Travel & Local	7	Simulation	5
Finance	6	Tools	5
Media & Video	6	Trivia	5
Music & Audio	6	Weather	5
News & Magazines	6	Arcade	4
Photography	6	Board	4
Sports	6	Books & Reference	4
Strategy	6	Card	4
Action	5	Casual	4
Adventure	5	Comics	4

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

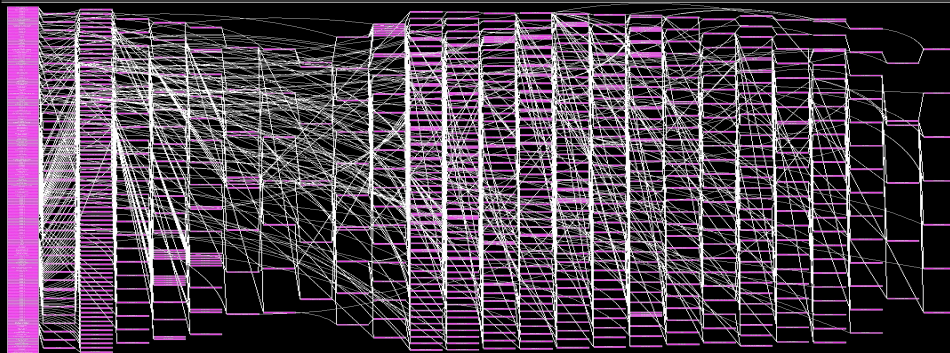
The central knoll at Tompkins Square Park CC BY-SA 3.0 David Shankbone

Private & public  
 "...privacy is a concept that must include a consideration of expectations and consensus." (AoIR 2012)  
 Contextual integrity

## Are we studying human subjects? Gaining access


<ul style="list-style-type: none"> <li>• A study of email communication</li> <li>• Interviews in virtual worlds</li> <li>• Forums, IM</li> <li>• Web crawlers</li> <li>• Third-party applications</li> <li>• Fake-profiles / socialbots</li> </ul>	<ul style="list-style-type: none"> <li>• Large data pools. Eg. #hashtag in Twitter.</li> <li>• Big social data</li> <li>• The connection between the person and the object of research is indistinct.</li> <li>• Third party applications</li> </ul>
<b>AUTOMATED METHODS OF DATA COLLECTION</b>	<b>NON- AUTOMATED METHODS</b>
<b>INFORMED CONSENT</b>	<b>ANONIMITY</b>

Aggregated data  
 Confidentiality & Anonymity  
 Data / human subjects



Johnclark.pba, CC-BY-SA-3.0

**COMPLEX**  
EU - Draft of conduct  
AoIR Research Ethics Guidelines (2012)  
Ethics Resource Guide (COSMOS)



Individuals

Socio-technical context

Circumstances

**ETHICS OF CARE**



**Thanks**

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