

Scientific Health Research

Legal aspects: Privacy



1-12-2016



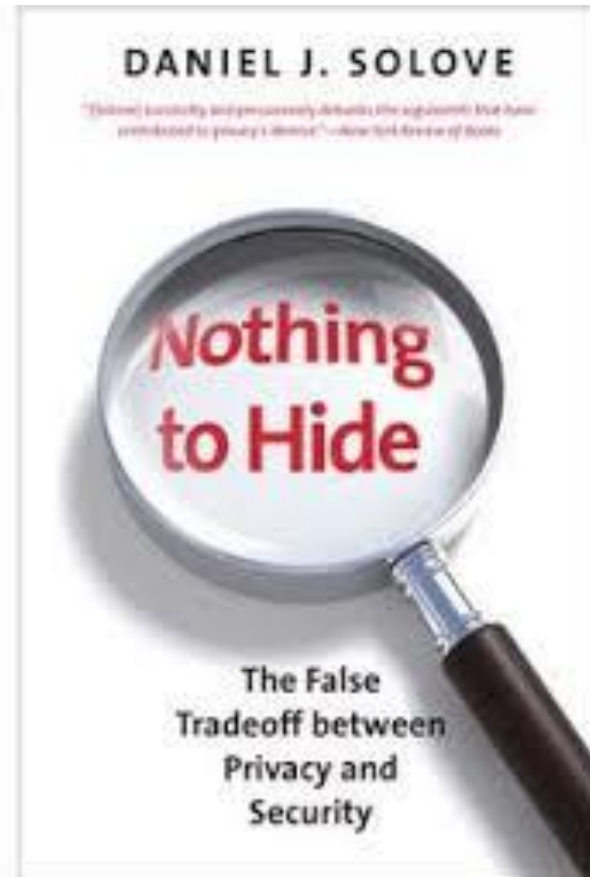
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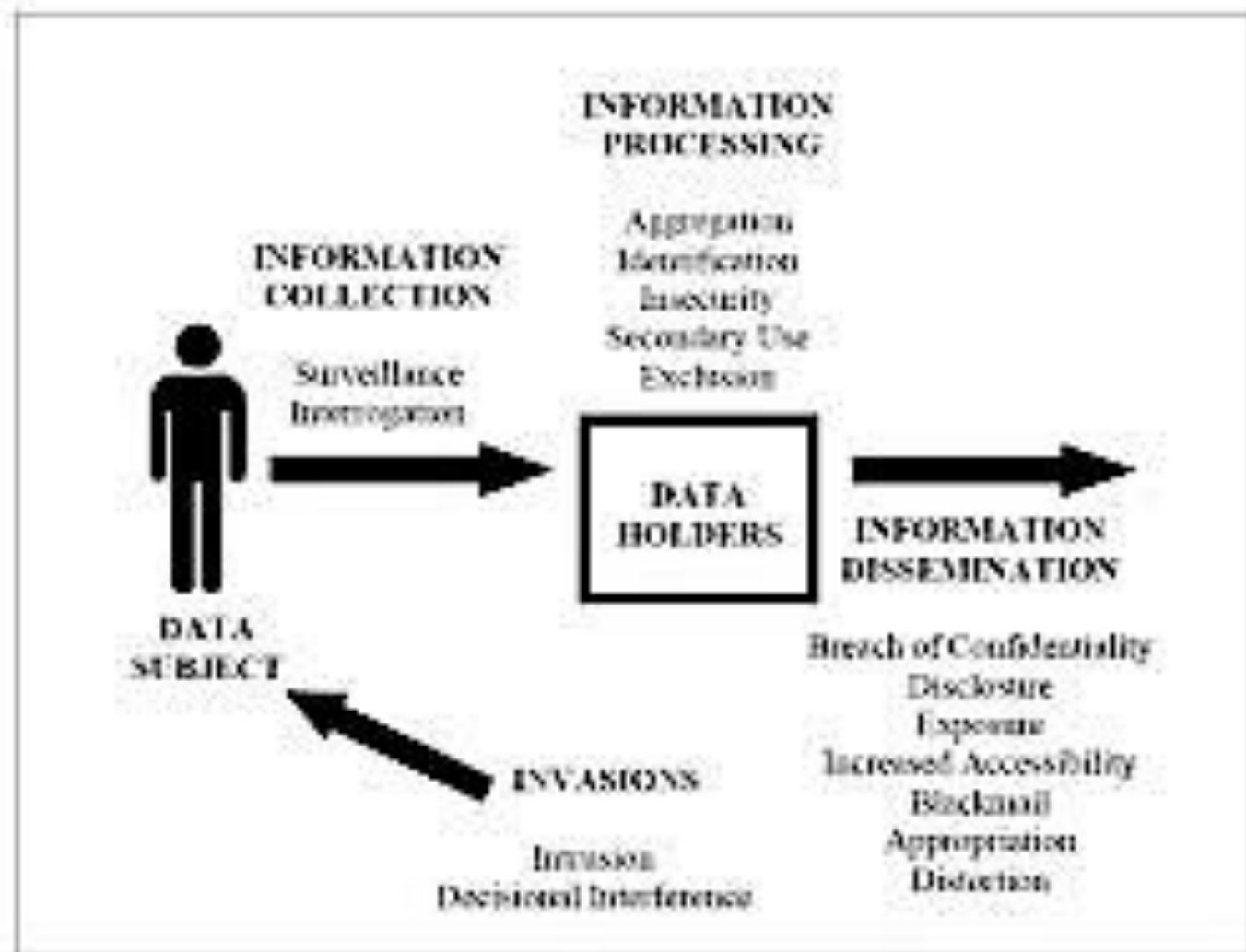
Marie-José Bonthuis

Who is

- IT Lawyer, PhD RuG
- UMCG, LifeLines,...
- Privacy, EPD, Ketens









Legal aspects

Which type?

- a) collecting new data for instance by questionnaires
- b) based on existing electronic health records
- c) based on your own patients (minimal restrictions)

Applicable law?

- personal data?
- consent?



Basics of privacy

- Protection of personal data;
=identifiable (direct/ indirect),
≠ not identifiable (anonymous)



coded?



pseudomized?



K-anonymity

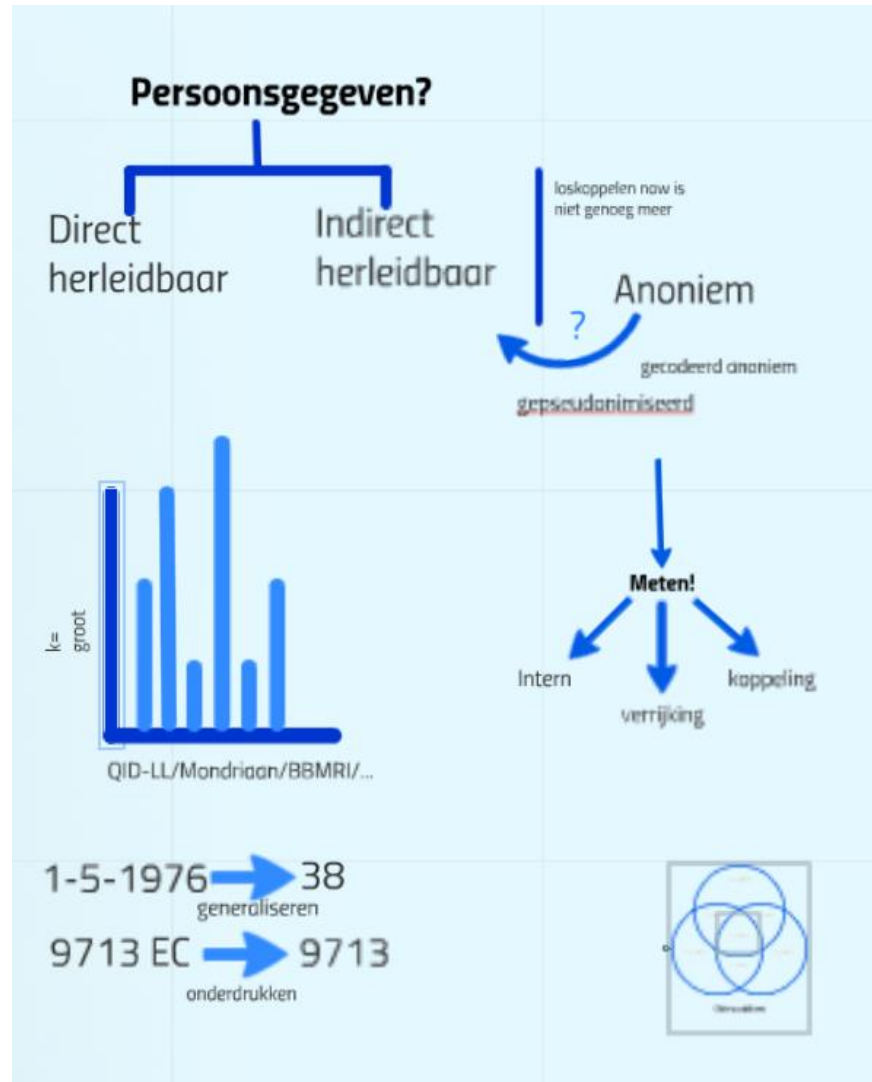


Table 3.2: Anonymity set size k for various (potential) quasi-identifiers

Quasi-identifier:	# of sets	Min.	1st Qu.	Median	Mean	3rd Qu.	Max.
PC4	388	2	3,278	7,090	7,188	10,300	22,330
PC6	66,883	1	24	35	41	50	1,322
PC4+DoB	2,267,700	1	1	1	1	1	42
PC6+DoB	2,759,422	1	1	1	1	1	5
PC4+gender	776	1	1,652	3,536	3,594	5,151	11,730
PC6+gender	133,012	1	11	18	21	25	954
gender+YoB	221	1	5,219	14,570	12,550	19,740	25,580
gender+YoB+MoB	2,699	1	397	1,177	1,028	1,594	2,326
gender+YoB+MoB+PC4 ^a	635,679	1	2	3	4	6	40
gender+YoB+MoB+municip. ^b	34,790	1	6	18	80	96	733
gender+DoB	71,318	1	21	40	39	54	571
gender+DoB+PC4	2,488,828	1	1	1	1	1	22
gender+DoB+PC6	2,766,475	1	1	1	1	1	4
town+gender	134	1	222	1116	20,700	3259	347,100
town+YoB	5,642	1	6	29	492	101	14,270
town+YoB+MoB	49,207	1	2	5	56	20	1,262
town+DoB	463,134	1	1	2	6	7	419
town+YoB+gender	10,492	1	4	17	264	60	7,515
town+YoB+MoB+gender	83,172	1	1	3	33	14	695
town+DoB+gender	697,875	1	1	2	4	5	226

^a QID_A , see Section 3.3.2.^b QID_B , see Section 3.3.3.



Contact

- m.j.bonthuis@umcg.nl
- bonthuis@itsprivacy.nl



Verder denken over Big Data in de Zorg
Digitale revolutie in de zorg denderd voort



Universitair Medisch Centrum Groningen





Literature

- Dutch Act on Medical Research Involving Human Subjects;
<http://www.ccmo.nl/attachments/files/wmo-engelse-vertaling-29-7-2013-afkomstig-van-vws.pdf>
- Medical Treatment Agreements Act (Dutch); <http://www.ccmo.nl/attachments/files/wgbo-pdf.pdf>
- Research Code;
<https://www.umcg.nl/SiteCollectionDocuments/English/Researchcode/UMCG-Researchcode,%20basic%20principles%202013.pdf>
- Biobank reglement (Dutch);
https://teamsites.umcg.nl/afdelingen/bvl/BioBanking/Gedeelde%20documenten/272510_Biobankreglement.pdf
- Dutch Data Protection Act (Dutch)
http://wetten.overheid.nl/BWBR0011468/geldigheidsdatum_19-08-2014
Guideline Good Clinical practice;
http://www.ich.org/fileadmin/Public_Web_Site/ICH_Products/Guidelines/Efficacy/E6/E6_R1_Guideline.pdf