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Frame of the cards: identical structure for each country

THEME	BIOLOGICAL IDENTITY	
Identification of technology	DNA database – company Genomac International, s.r.o.	
Technology used/tool (For each teams, a card pro tool)	DNA ANALYSIS/ DATABASE	
Country/ use area	Czech republic	
Frame of use	Commercial DNA paternity testing, DNA testing of genetic origin – GenoGraf, establishment of the Czech national genetic database	
Population concerned: target and age	Not publicised, in DNA paternity testing included parents with their (presumably) children.	
% of users/of young users	Unknown	
Trends (measured / supposed)	3000 Czechs agreed that their data are included in database by mid 2007 ¹ , there were 2000 genetic profiles in Czech national genetic database run by the company by march 2008. ²	
Known or potentials dangers /Risks	Company was fined 90000 Czech crowns after investigation of Czech DPA found out following misconducts: Company have not liquidated personal data nor DNA samples after finishing tests of paternity and genetic origin, documentation contained names, surnames, birth numbers despite the claims of the company it will for research purposes identify clients on by initial letters of their names and specific	

¹ see <http://www.genomac.cz/en/view.php?cisloclanku=2007080003>

² press release of the company, see <http://scienceworld.cz/biologie/ceska-narodni-genograficka-databaze-spustena-650>

	number of the client. DPA also found out that before the start of the inspection company didnot asked clients for their consent with proceession of their data nor their were informed about the extend in which their data will be processed. Company carried on paternity tests and tests of genetic origin without proper registration at the DPA. ³ DPA ordered company to liquidate all personal information processed in violation of law on data protection including DNA profiles and samples.	
Others		
Generated data bases		
Associated data base/ creation (a line pro database)	Company was founded in the fall of 2001 and from its early days involved in paternity DNA testing. ⁴	
What justifies the inscription in the file /Risks?	Person seeking testing sends DNA samples, in case of paternity test also of (presumed) child. / Free consent of a child (or any other second person whos samples are submitted) with proceession of his/her data is illusionary	
Purposes /contents, main data included / Risks?	DNA samples, other personal information of the subjects	
File masters? Risks?	Genomac International, s.r.o./ for risks see Known or potentials dangers	
Who accesses the files/ Sharing of the data base? Access limits? /Risks	Employees of the company/ not known/ see Known or potentials danges	
Data retention delays/ risks Right to be forgotten	According to the law 101/2000 on data protection controller is obliged to « preserve personal data only for a period of time that is necessary for the purpose of their processing. After expiry of this period, personal data may be preserved only for purposes of the state statistical service, and for scientific and archival purposes. When using personal data for these purposes, it is necessary to respect the right to protection of private and personal life of the data subject from unauthorised interference and to make personal data anonymous as soon as possible.» ⁵ For information on actual practice see Known or potentials dangers	
Rights to know or to modify data?	According to the law 101/2000 on data protection «In collecting personal data the controller shall be obliged to inform	

³ Czech Data protection authority Annual report 2008, http://www.uouu.cz/files/vz_2008.pdf

⁴ web pages of the company <http://www.genomac.cz/en/view.php?cisloclanku=2006040002>

⁵ Act no. 101 of April 4, 2000 on the Protection of Personal Data and on Amendment to Some Acts, art 5, par. e)

	<p>the data subject of the scope in which and the purpose for which the personal data shall be processed, who and in what manner will process the personal data and to whom the personal data may be disclosed, unless the data subject is already aware of this information. The controller must inform the data subject about his right of access to personal data, the right to have his personal data rectified as well as other rights provided for in Article 21.»⁶</p> <p>For information on actual practice see Known or potentials dangers</p>	
Covert purposes/ Risks/uncontrolled future evolution	see Known or potentials dangers/ risks of possible future genetic discrimination of the subjects whos DNA profiles or samples were compromised	
Others (interconnections...)		
Legislation in application		
Law /rules / others (?) (implemented for this data base or this technology)	<p>Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine⁷</p> <p>None specific national legislation with regard to DNA testing and databases.</p>	
Risks for freedoms despite the law		
If revision of the regulation: reasons? Result: improvement or aggravation (compared to the protection of the DP)	Necessary adoption of the new legislation acknowledged also in DPA annual report 2008	
Conformity with the European right (Charter of fundamental rights, directives...)		
Implementation (or not) of the legislation? / Risks		
Others		
This tools and young public or young adults		
How far are young people concerned?	Information on percentage of youngsters DNA profiles in a database is not available	
Awareness of issues or of risks	None research into the topic done so far, probably low	
Indifference or reaction	Indifferent	
Awareness campaigns/ results	Press release of the DPA, informing of the public about findings of the inspection,/ not measured, probably influencing	

⁶ Act no. 101 of April 4, 2000 on the Protection of Personal Data and on Amendment to Some Acts, art. 11, par. 1)

⁷ entered into force in the Czech republic 2001

	practice of other companies providing commercial DNA testing	
Good practises	Extensive privacy statement of another company providing commercial DNA testing on the web pages of the company. ⁸	
Campaign to be led. On which themes?	Informing youngsters of the meaning and importance of protection of their sensitive biological data and relevance of DNA profiles in that sense. Informing adults on the meaning of free consent with processing of the personal data with special relevance to their children, informing on risks of possible genetical discrimination.	
Others		
Conclusions		
Recommendations	Support DPA call for new legislation dealing specifically with DNA databases, establish expert group including privacy experts to start work on new legislation, public awareness campaign	

Podpořili nás:



Ministerstvo práce a sociálních věcí



Trust for Civil Society in Central & Eastern Europe



Open Society Fund Praha



Lichtenštejska a Norska v rámci



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⁸ http://www.dnatest.cz/cz/15_ochrana_soukromi_zakazniku/cz_privacy.asp#q3