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Frame of the cards: identical structure for each country

THEME	Biological identity	
Identification of technology	National health registers	
Technology used/tool (For each teams, a card pro tool)	Databases	
Country/ use area	Czech republic/ Prague	
Frame of use	Registers were established with the aim of registering and tracking patients with selected illnesses with serious social impacts, assessing of diagnostic and treatment methods, analysing evolvments, causes and affects of illnesses and statistical health research.	
Population concerned: target and age	Patients with serious illnesses	
% of users/of young users	Unknown	
Trends (measured / supposed)	Stagnation of the ammounts of a data ¹	
Known or potentials dangers /Risks	„Czech DPA considers problematics of new legal norms related to health registers to be socialy underestimated. Ministry of Health have not accepted request of the DPA to clarify whole concept of the registers. DPA asked for clarification on data retention period in individual registers and explanation why is not (ulike in other EU countries) taken in account consent of the subject of the data. DPA have recommended that in the	

¹ from the response of the Institute of Health Information and Statistics of the Czech Republic to the request of Iuridicum Remedium of 2009/5/12

	respect to the extremely sensitive data processed in the registers were those subject of the more detail legislation by the law and not just ministerial decree or Attachment of a legal norm." ²	
Others		
Generated data bases		
Associated data base/ creation (a line pro database)	<i>National register of inpatients (NRHOSP), National register of women in childbed (NRROD), National register of newborns (NRNAR), National register of congenital defects (NRVV), National register of abortions (NRPOT), National register of physicians, dentists and pharmacutists (RLZF), National register of users of substitutive drugs (NRUSL), National register of oncological diseases (NOR)³, National register of vascular surgery (NRCCH)⁴, National cardio surgery register (NKCHR)⁵, National Register of Joint Replacements (NRKN)⁶, National Register of Cardiovascular Interventions (NRKI)⁷, National register of occupational deseases (NRNP), National Register of Persons Refusing Donation of Tissues and Organs Posthumously⁸, National register of IVF</i>	
What justifies the inscription in the file /Risks?	Medical statistics and research, state health policy, illness prevention /see Potential dangers	
Purposes /contents, main data included / Risks?	NOR ⁹ birth number, data on treatment and illness of the patient, personal and family anamnesis, data anonymised 25 years after the death of the patient. NRHOSP birth number, data on treatment and illness of the patient, personal and family anamnesis. Data anonymised 5 years after release from the hospital. NRROD Birht number of a mother, information on	

² Czech DPA Annual report 2008, p.91, translation F.P.

³ <http://www.ksrzis.cz/Pages/168-NOR-National-Register-of-Oncological-Diseases.html>

⁴ <http://www.ksrzis.cz/Pages/169-NRCCH-National-Register-of-Vascular-Surgery.html>

⁵ <http://www.ksrzis.cz/Pages/167-NKR-National-Cardiosurgery-Register.html>

⁶ <http://www.ksrzis.cz/Pages/171-NRKN-National-Register-of-Joint-Replacements.html>

⁷ <http://www.ksrzis.cz/Pages/170-NRKI-National-Register-of-Cardiovascular-Interventions.html>

⁸ <http://www.ksrzis.cz/Pages/173-NROD-National-Register-of-Persons-Refusing-Donation-of-Tissues-and-Organs-Posthumously.html>

⁹ according to Attachment to the Act no. 20/1966

http://www.pravnipredpisy.cz/predpisy/ZAKONY/1966/020966/Sb_020966_-----_.php

pregnancy, the treatment and state of health of mother and newborn baby. Data anonymised 10 years after delivery of a baby.

NRNAR

Birth numbers of mother and baby, and their health state. Data anonymised 10 years after delivery of a baby.

NRVV

Birth numbers of mother and baby with congenital defects (NRVV), data on treatment and illness of the child and mother, personal and family anamnesis, data anonymised 5 years after child reaches 15 years of age.

RLZF

Personal information of physicians, dentists and pharmacutists. Data anonymised 1 year after finishing of the practice of the medical personel.

NRPOT

Birth number of pregnant woman, personal anamnesis, data on health state of the woman, Data anonymised 10 after abortion.

NRCCH

Birth number of the patient, data on health state related to the illness, information on the treatment and its results. data anonymised 5 years after the death of the patient.

NKCHR

Birth number of the patient, data on health state related to the illness, information on the treatment and its results. data anonymised 20 years after the death of the patient.

NRKN

Birth number of the patient, data on health state related to the illness, information on the treatment and its results. data anonymised 5 years after the death of the patient.

	<p>NRNP</p> <p>Birth number, date of death, data related to the illness, data related to the occupation of the patient. Data are anonymised 40 let after file is established.</p> <p>NRKI</p> <p>Birth number, health state related to the illness, data on treatment and its results. Data anonymised 5 years after the death of the patient.</p> <p>NRUSL</p> <p>Birth number, nationality, health insurance number, data on health state of the patient and treatment and its results. Data are anonymised 20 years after establishment of the file.</p> <p>National register of IVF</p> <p>Processes only anonymised data of the woman subjected to In vitro fertilisation and anonymised data of the father.</p> <p>Data are submitted by individual medical facilities, data on first name, family name, birth number, date of birth, and permanent address are submitted from Central register of citizens of Ministry of Interior.</p>	
File masters? Risks?	Ústav zdravotnických informací a statistiky České republiky (ÚZIS ČR) – Institute of Health Information and Statistics of the Czech Republic	
Who accesses the files/ Sharing of the data base? Access limits? /Risks	«Access to the personal data in the register has processor, controller and relevant medical personell of the medical institution giving treatment to the patient relevant to the register. Relevant medical personell is a person appointed by the director or statutare representative of the medical institution and approved by the controller of the register.» ¹⁰	
Data retention delays/ risks Right to be forgotten	NOR ¹¹ birth number, data on treatment and illness of the patient, personal and family anamnesis, data anonymised 25 years	

¹⁰ Act no. 20/1966§ 67 d) art. 8)

¹¹ according to Attachment to the Act no. 20/1966

http://www.pravnipredpisy.cz/predpisy/ZAKONY/1966/020966/Sb_020966_-----_.php

after the death of the patient.

NRHOSP

birth number, data on treatment and illness of the patient, personal and family anamnesis. Data anonymised 5 years after release from the hospital.

NRROD

Birth number of a mother, information on pregnancy, the treatment and state of health of mother and newborn baby. Data anonymised 10 years after delivery of a baby.

NRNAR

Birth numbers of mother and baby, and their health state. Data anonymised 10 years after delivery of a baby.

NRVV

Birth numbers of mother and baby with congenital defects (NRVV), data on treatment and illness of the child and mother, personal and family anamnesis, data anonymised 5 years after child reaches 15 years of age.

RLZF

Personal information of physicians, dentists and pharmacutists. Data anonymised 1 year after finishing of the practice of the medical personel.

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Birth number of pregnant woman, personal anamnesis, data on health state of the woman, Data anonymised 10 after abortion.

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Birth number of the patient, data on health state related to the illness, information on the treatment and its results. data anonymised 5 years after the death of the patient.

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Birth number of the patient, data on health state related to the illness, information on the treatment and its results. data anonymised 20 years after

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Rights to know or to modify data?	<p>Subjects can ask controller (Ministry of health) to clarify on extend of their personal data processed. Specific information on content of a data they can obtain only from medical facility that submitted the data to the register.¹² Information on these rights are not publicly available to the subjects.</p>	
Covert purposes/ Risks/uncontrolled future evolution		
Others (interconnections...)		
Legislation in application		
Law /rules / others (?)	defined by Act no. 20/1966 Sb. on National Health Care, in wording of later	

¹² from the response of the Institute of Health Information and Statistics of the Czech Republic to the request of Iuridicum Remedium of 2009/5/12

(implemented for this data base or this technology)	amendments - §67c., Act no. 89/1995 Sb. on State Statistical Service, in wording of later amendments., Act no. 101/2000 Sb. on Personal Data Protection, in wording of later amendments,/ Ordinance of Ministry of health no. 552/2004 on transfer of the personal and other data into National health information system for the purpose of National health registers (Vyhláška č. 552/2004 Sb., o předávání osobních a dalších údajů do Národního zdravotnického informačního systému pro potřeby vedení národních zdravotních registrů.)/ Mandatory instructions of National Health Information Systems (Závazné pokyny NZIS)	
Risks for freedoms despite the law		
If revision of the regulation: reasons? Result: improvement or aggravation (compared to the protection of the DP)		
Conformity with the European right (Charter of fundamental rights, directives...)	Might contravene : Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (Council of Europe, CETS No. 108), The Czech Republic ratified the Convention CETS No. 108 on 9 July 2001 and it entered into force in the Czech Republic on 1 November 2001, 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 Biomedicine, Applies also: Position No. 3/2004 Personal Data Processing in the Context of Clinical Testing of Drugs and Other Medical Substances ¹³	
Implementation (or not) of the legislation? / Risks		
Others		
This tools and young public or young adults		
How far are young people concerned?	Number of youngsters among subjects of a data not revealed by the Institute of Health Information and Statistics ¹⁴	
Awareness of issues or of risks	None research made so far, probably very low	
Indifference or reaction	None	
Awareness campaigns/ results	None	

¹³ <http://www.uoou.cz/index.php?!=en&m=left&mid=02:109&u1=&u2=&t=>

¹⁴ from the response of the Institute of Health Information and Statistics of the Czech Republic to the request of Iuridicum Remedium of 2009/5/12

Good practises	None	
Campaign to be led. On which themes?	Awareness campaign on extend of data currently processed, importance of free consent with data protection and legislation change	
Others		
Conclusions		
Recommendations	Clarification of a concept of the registers. Inclusion of free consent of the patient with the procession of the data. Shortening of the data retention periods. For more see Czech DPA recommendations in Known or potentials dangers. ¹⁵	

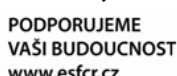
Podpořili nás:



Ministerstvo práce a sociálních věcí

Trust for Civil Society in Central & Eastern Europe

Open Society Fund Praha



Podpořeno grantem z Islandu,

Lichtenštejnska a Norska v rámci

¹⁵ Czech DPA Annual report 2008, p.91, translation F.P.

Finančního mechanismu EHP a Norského finančního mechanismu

prostřednictvím Nadace rozvoje občanské společnosti.