



COUNCIL OF EUROPE CONSEIL DE L'EUROPE

Strasbourg, 10 November/novembre2011

T-PD-BUR(2011)16Rev MOS

BUREAU OF THE CONSULTATIVE COMMITTEE OF THE CONVENTION FOR THE PROTECTION OF INDIVIDUALS WITH REGARD TO AUTOMATIC PROCESSING OF PERSONAL DATA [ETS No. 108]

LE BUREAU DU COMITE CONSULTATIF DE LA CONVENTION POUR LA PROTECTION DES PERSONNES A L'EGARD DU TRAITEMENT AUTOMATISE DES DONNES A CARACTERE PERSONNEL [STE n°108]

(T-PD-BUR)

Compilation of reports of T-PD representatives in other committees and *fora* as well as other events and conferences

Compilation des rapports des représentants du T-PD aux travaux d'autres comités et *fora* ainsi qu'à des événements et conférences

Secretariat document prepared by
DG I – Human Rights and Rule of Law

Document préparé par
la DG I – Droits de l'Homme et Etat de droit

INDEX / TABLE DES MATIERES

Report by Rita Vaitkevičienė further to her participation in the 6th meeting of the Group of Specialists on Predictivity, Genetic Testing and Insurance strasbourg, 13-15 April 2011..... 3

Rapport d'Hana Stepankova, suite à sa participation à la 4^{ème} Conférence Francophone et le Séminaire - Dakar (Sénégal) 19-21 septembre 2011.....8

REPORT BY RITA VAITKEVIČIENĖ FURTHER TO HER PARTICIPATION IN THE 6TH MEETING OF THE GROUP OF SPECIALISTS ON PREDICTIVITY, GENETIC TESTING AND INSURANCE STRASBOURG, 13-15 APRIL 2011

Strasbourg, 15/04/2011

Previous meeting: in Strasbourg, 5 – 7 October 2010

1. Welcome and Background

1.1. Prof. Carlos M. Romeo – Casabona (Spain), the Chairman of the Group of Specialists on Predictivity, Genetic Testing and Insurance (hereinafter – Group of Specialists) opened the meeting. The Chair welcomed members of the Group: Prof. Bernard Dubuisson (Belgium), Dr. Jacques Montagut (France), Prof. Aart Hendriks (the Netherlands) and Rita Vaitkevičienė (hereinafter – RV), representative appointed by the (TP-D) to participate in the work of Group of Specialists. He thanked all those who had made comments on the draft Green Paper or presented other contributions.

1.2. Ms Ayşegül Elveris, Secretary of the Group of Specialists presented the Agenda (enclosed). Preliminary Chapter, Chapter I and Chapter II of the draft Green Paper will be discussed and possibly finalised by Members of the Group of Specialists on 13-14 April and discussions on Chapter III are planned for 14-15 April. She also presented changes in the Draft Green Paper – an essential document which is to be discussed and compiled by the Secretariat – Mr Carlos de Sola, Head of Health and Bioethics Department and Mme Laurence Lwoff, Head of Bioethics Division and Ms Ayşegül Elveris. She also informed the meeting that Article 3 a. of Chapter II had been prepared with help of the T-PD Bureau.

2. Preliminary Chapter

According to the comments of the members of the Steering Committee on Bioethics, the Secretariat had made some changes in the Preliminary Chapter. All changes are related to the principles of private insurance and they have been taken into account by members of the Group of Specialists.

3. Paragraph 1 of Chapter 1

3.1. The discussions started about the heading of Chapter 1 which is as follows: “Collection and Processing of Health Related Data for Insurance Purposes”.

Prof. Aart Hendriks questioned why the word “collection” was set apart from “processing” which already includes collection.

Mr Carlos de Sola proposed to change word “processing” to “use”.

RV: as the definition of “automatic processing” provided in Article 2 item c of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (hereinafter – Convention ETS-108) does not include collection of data, only “storage of data, carrying out of logical and/or arithmetical operations on those data, their alteration, erasure, retrieval or dissemination” the wording of the heading might be left as it is but proposal of Mr Carlos de Sola to rename Chapter 1 as follows: “Collection and use of health related data <...> insurance purposes” is acceptable if these data will be used only by that particular company which collected them and never be transferred to third parties.

3.2. Small changes in Paragraph 1 item a., I: “Health related data can be demanded and collected the ...”

3.3. Some reservations were expressed regarding Paragraph 1 item a second sentence “by asking the applicant to fill <...> a lifestyle and/or <...>.”

All participants agree that question about lifestyle (smoking and etc.) following the Article 5 item b (legitimate purpose) might be included in to the questionnaire given to the applicant.

4. Paragraph 1 of Chapter 1

4.1.1. Paragraph 2 item a. i. (Health questionnaires)

Paragraph 2 item a. i. states that “considering in particular the sensitive nature of health-related data, this legal duty should however not put the applicants in a position where, for example through open-ended questions, they are incited to disclose information that are not relevant to the insurance contract”.

RV suggested to supplement this item with a the new sentence saying that any data collected by insurance companies should be adequate, relevant and not excessive in relation to the purposes for which they are collected.

4.1.2. Paragraph 2 item a. i. (Health questionnaires)

RV asked what would happen with the questionnaire and data which are filled in if parties did not enter into the contract or the person decided to revoke it.

Prof. Aart Hendriks thought that the data should be deleted, but Mr Carlos de Sola said that the data should be retained for a reasonable time period.

RV proposed a compromise: data might be retained for a reasonable time because the person has right to give a complaint or any party could go to court and these data may be used as evidence.

4.2. Paragraph 2 item a. ii. (Medical examinations)

Dr Jacques Montagut expressed his concerns regarding independence of doctors who are paid by insurance companies.

RV asked that attention be paid to the right of an individual to give or not to give consent (informed consent) for an additional medical examination. It was agreed that above mentioned provision be included in Paragraph 3 of Chapter 1 of the draft Green Paper.

4.3. Paragraph 2 item a. iii. (Communication of data by third parties to the contract)

Participants discussed details about the balance between the principles of medical confidentiality and legitimate purpose of insurers to obtain these data. It was proposed that any data transfer from the physician to the insurance company should be done by fulfilling mandatory obligations or by obtaining the consent of the patient.

RV noted that the two rights of the data subject are to be respected and guaranteed: the right to be informed and the right not to know.

5. Paragraph 2 of Chapter 1

5.1. Paragraph 2 item b. (With regard to the scope of data obtained)

Prof. Aart Hendriks and Dr Jacques Montagut raised questions about the scope of data requested, the data actually obtained for the risk assessment purpose. What would happen if collected data are not relevant to the insurance contract? What would be the procedure if, to save time, the applicant or the applicant’s physician sent the content of the applicant’s entire medical file to the insurer.

It was also agreed that genetic data should not be transferred to the insurer and he/she should have no right to process them even if these data had previously been received.

RV noticed that data received by the insurers concerning the applicant's health may not be relevant to the contract. It would be a reasonable measure to mention that any excessive data should be deleted and the sender (physician in that case) should be informed about data breaches. It was agreed to include the provision.

5.2. Paragraph 2 item f. (issues raised by the globalization of the insurance market)

Prof. Carlos M. Romeo – Casabona said that the Internet repositories (e.g. personal blogs, facebook pages) could provide information in relation to the health status of people but as this information may not be accurate and obtained from the internet, it could not be used for insurance purposes.

RV expressed an opinion that legislation should be technology-neutral if they are not regulated.. This is not a matter of the Internet, but the problem of the public disclosure of data. It was suggested to follow one of the personal data protection principles stating that data controller (the insurer) must guarantee data security and to implement appropriate technical measures intended for the protection of personal data against accidental or unlawful destruction, alteration and disclosure as well as against any other unlawful processing.

6. Paragraph 3 of Chapter 1

6.1. There were no comments on Paragraph 3 item a. (Legal framework)

6.2. Paragraph 3 item b. (General applicable principles)

Participants agreed to some general principles applicable to the collection and processing in the insurance field of health-related data. They are as follows:

- data can only be collected and processed with the free and informed consent of the insurance applicant;
- only data necessary for insurance purposes might be collected and processed;
- the data should be relevant to the contract;
- the data should be reliable;
- the principle of proportionality should be guaranteed.

RV proposed that the requirement to guarantee the data subject access to the information about the data relating to him/her which has been collected by the insurer should be included to the list of general principles. All participants agreed on this point.

6.3. Paragraph 3 item b. ii. (Specific options. Health questionnaires items 1, 2, 3, 4)

The meeting discussed the content of the questionnaire. It was agreed that the questions should be clear, concise and understandable. The information which is collected should be relevant to a contract which parties are going to enter.

RV noticed that health questionnaires should be covered by the general principles of data protection specified in Paragraph 3 item b. It was also important that completed questionnaire should not be transferred to the any third party and should be used only for the purpose it was created – for insurance purposes. Also the question about how much time these questionnaires should be stored by the insurance company if the individual filled in the questionnaire, made all other necessary steps, but

- the person didn't sign the contract;
- the insurer didn't signed,
- the withdrawal of the contract has been made.

How should personal data be processed? How long should they be retained?

The recommendation is to set a reasonable time for data retention terms, for example 6 months. The data could hardly be deleted immediately when relationships between parties have been

terminated, because any party may lodge the complaint or go to court. In this case some evidence might be needed.

6.4. Paragraph 3 item b. ii. (Specific options Medical examinations, items 5, 6, 7)

The meeting discussed payments for additional medical examinations.

RV emphasised that, as written, there were two concerns regarding medical examinations: people would possibly be discriminated against according to the quantity of data they provided. There would also be the possibility of indirect disclosure of personal data. For example, different price levels may be applied to the clients upon disclosure of their health status (indirect disclosure of personal data).

Another option was the respect of the right not to know (the person who chooses the right not to know will go to the insurer and will be asked for higher health insurance fees because he has some disease).

6.5. Paragraph 3 item b. ii. (Specific options. Communication of data by third parties to the contract, item 8)

The same approach as has been written in Paragraph 2 item b. of Chapter 1 shall be applied.

6.6. Paragraph 3 item b. ii. (Specific options. Communication of data by third parties to the contract, item 9)

The same approach as has been written in Paragraph 3 item b. ii. of Chapter 1 shall be applied.

6.7. Paragraph 3 item b. ii. (Specific options. With regard to access to and storage of data, item 10)

Proposal of RV for slight changes of item 10:

Insurers should establish rules (e.g. privacy codes, good practices, codes of conduct) which guarantee personal data protection and confidentiality of information (in accordance with domestic law). [These rules should be made available to the public].

6.8. Paragraph 3 item b. ii. (Specific options. Issues raised by the globalization of the insurance market, items 18-20)

RV: the data sharing between entities from different countries should follow the requirements of Article 2 of the Additional Protocol to the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data regarding supervisory authorities and transborder data flows: the transfer of personal data to a recipient who is subject to the jurisdiction of a State or an organisation which is not Party to the Convention only if that State or organisation ensures an adequate level of protection for the intended data transfer and if safeguards are provided by the controller responsible for the transfer and are found adequate by the competent authorities according to domestic law.

Paragraph 3 item b. ii (Specific options that may result from potential abusive conducts)

Data collected from Internet repositories without the knowledge and consent of the applicant cannot be used for insurance purposes [except for attempts to detect fraud].

RV said that any data from the public resources like internet, TV, newspapers and other media should not be used for insurance purposes.

Also for any personal data, processing should have a legal background and legitimate purpose.

7. Paragraph 1 of Chapter 2

In the last session of the first day of the meeting the following questions were addressed:

- the possibility to use family data and family history;
- the possibility to use predictive data for the purpose to reduce risk in underwriting of the insurance contracts.

- the possibility to use genetic data for insurance purposes.

An opinion was expressed about the fact that two different types of data might be treated as genetic data: genetic testing results and predictive data.

RV: Only in one European country - United Kingdom – is it allowed to use genetic data for insurance purposes. Others follow the Oviedo Convention which clearly states that genetic tests may be performed only for health purposes or for scientific research linked to health purposes or the restriction is settled in national legislation and there is no room for any other purposes. In some countries this issue is not regulated by separate laws but is included to the laws on Patients' rights.

14-04-2011

8. Chapter 3

Mr Carlos de Sola presented Chapter 3 (social aspects)

Because social aspects are not directly related with data protection matters and meeting discussions were more related to the issues of solidarity, only question about the individuals' access to the information was discussed. All participants agreed that individuals' consent is necessary and access to the information should be implemented. Discussions as regards use of genetics data were raised once again.

15-04-2011

9. Preliminary Chapter, Chapter 1, Chapter 2 and Chapter 3

All participants in the meeting once again examined all documents item by item before clarifying their positions. once everybody clarified his or her position.

10. Next meeting

RV felt that the first three chapters were almost finished and perhaps her attendance would not be needed in future.

RAPPORT D'HANA STEPANKOVA, SUITE A SA PARTICIPATION A LA 4ÈME CONFERENCE FRANCOPHONE ET LE SEMINAIRE – DAKAR (SENEGAL) 19-21 SEPTEMBRE 2011

L'Association francophone des autorités de protection des données personnelles (AFADP) s'est réunie durant 3 jours (19, 20 et 21 septembre 2011) pour la première fois sur le continent africain – à Dakar (Sénégal). La matinée du 19 septembre était consacrée aux projets des organisations régionales et à l'état des travaux de rédaction, de révision ou de modernisation des instruments juridiques internationaux de tous les acteurs de la protection de la vie privée. Les intervenants ont présenté les travaux récemment effectués : Acte additionnel de la Communauté Economique des Etats de l'Afrique de l'Ouest et Textes de l'Union Africaine (intervenant M. Mouhamadou Lo, Président de la Commission de Protection des Données Personnelles du Sénégal), Convention 108 du Conseil de l'Europe (Mme Hana Stepankova, Porte-parole du Bureau de la protection des données personnelles République Tchèque, 1ère Vice-présidente du T-PD), Directive de l'Union européenne (Mme Isabelle Falque-Pierrotin, Conseiller d'Etat, Vice-présidente de la Commission Nationale de l'informatique et des Libertés en France et Lignes directrices de l'OCDE (Mme Chantal Bernier, Commissaire adjointe au Commissariat pour la protection de la Vie Privée du Canada).

L'intervention sur la Convention 108 (et son Protocole additionnel) a décrit le processus de la modernisation de ce document pour qu'il réponde, après trente ans d'existence, aux attentes d'une protection des données moderne et efficace et assure suffisamment les droits des citoyens et citoyennes des pays membres du Conseil de l'Europe face à l'environnement informationnel et communicationnel contemporains.

Par ailleurs, Mme Marie Georges, expert scientifique du Conseil de l'Europe, a présenté le projet de partenariat entre la CEDEAO et le Conseil de l'Europe pour le renforcement des capacités aux fins de la mise en œuvre de l'acte additionnel adopté par la CEDEAO.

Pour conclure, la faculté de l'approfondissement de la protection des données personnelles et en même temps les avantages pour différents systèmes juridiques de la Convention 108 et de son Protocole additionnel modernisés, furent soulignés.