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**BUREAU OF THE CONSULTATIVE COMMITTEE OF THE CONVENTION  
FOR THE PROTECTION OF INDIVIDUALS WITH REGARD TO AUTOMATIC  
PROCESSING OF PERSONAL DATA**

**(T-PD-BUR)**

**OPINION ON THE DRAFT RECOMMENDATION  
ON THE USE FOR INSURANCE PURPOSES OF PERSONAL HEALTH-RELATED INFORMATION,  
IN PARTICULAR INFORMATION OF A GENETIC AND PREDICTIVE NATURE**

Directorate General of Human Rights and Rule of Law

At its last plenary meeting on 26-28 November, the DH-BIO decided to draw up a non-legally binding instrument on the use for insurance purposes of personal health-related information, in particular information of a genetic and predictive nature, in the form of a Recommendation of the Committee of Ministers to member States and to invite the T-PD to comment on the draft.

The Bureau of the Consultative Committee welcomes the opportunity given to comment the Draft Recommendation on the use for insurance purposes of personal health-related information, in particular information of a genetic and predictive nature. The Bureau has examined the proposed provisions and their compatibility with Council of Europe standards on data protection, in particular with the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (ETS No. 108, hereafter "Convention 108").

## **General comments**

A new recommendation should be in full compliance with the principles already set forth by the Committee of Ministers on the protection of personal data in this field, in particular with Rec(2002)9 on the protection of personal data collected and processed for insurance purposes<sup>1</sup>, Rec (97) 5 on the Protection of Medical Data<sup>2</sup>, Rec (92) 3 on Genetic Testing and Screening for Health Care Purposes<sup>3</sup>. Such documents should therefore not only be mentioned in the draft Recommendation, but also substantially considered in order to avoid any discrepancy with the existing legal framework on the protection of personal data in a sector that the Council of Europe – for the high potential risks of discrimination for individuals - has already considered as being particularly delicate.

One of the basic principles with respect to the protection of personal data in this field, is the general prohibition of the use of genetic data in the insurance sector, as stated in both international [see Article 14 of the UNESCO International Declaration on Human Genetic Data; Rec (92)3 (Principle 7)] and various national instruments. This principle of general prohibition should therefore be taken into consideration while drafting the new instrument.

It has been further noticed that data protection is not explicitly mentioned in the draft Recommendation and that privacy, confidentiality and security are only mentioned in paragraph 23 and with regard to internal regulations of the insurers. In view of the fact that the draft instrument deals with sensitive data, it is highly recommended that data protection is given a stronger role in the Recommendation and should be explicitly mentioned either in the Preamble or in Chapter I, and that further amendments be made to the draft as per the subsequent suggestions.

It is also proposed that more references to the relevant data protection rules / domestic laws of the member states be introduced.

Special attention should be paid to the fact that this draft Recommendation deals with information of a genetic and predictive nature and as a consequence the information

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<sup>1</sup><https://wcd.coe.int/ViewDoc.jsp?id=306221&Site=CM&BackColorInternet=C3C3C3&BackColorIntranet=EDB021&BackColorLogged=F5D383>

<sup>2</sup><https://wcd.coe.int/ViewDoc.jsp?id=571075&Site=CM&BackColorInternet=C3C3C3&BackColorIntranet=EDB021&BackColorLogged=F5D383>

<sup>3</sup><https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=573883&SecMode=1&DocId=601492&Usage=2>

provided involves not only test results but other sensitive data such as body samples and tissue. In terms of transparency regarding storage and erasing of data of a genetic and predictive nature, provisions should be taken into consideration in the draft and proposed provisions should be adapted accordingly.

It should also be underlined that there are no provisions with respect to the information to be provided to the insured persons. Furthermore, the possibility for the insured persons to provide additional information in the context of the negotiations with the insurer should also be introduced. Chapter VI could be supplemented with these elements and its title could be amended to reflect this broader scope "Information of the individuals, mediation (...)".

Finally, information kept for statistical purposes should be rendered anonymous and retained in a form in which identification of the persons is no longer possible.

### **Specific comments on the text**

#### Glossary:

Consistency of definitions between various Council of Europe's instruments should be sought and the definition of genetic data could be aligned with existing legal instruments such as Rec (97)5. Furthermore, the draft Explanatory report of the modernised Convention 108 which is currently under discussion could be taken as an example, even more so as the proposed definition is based on comments provided by the DH-BIO.

#### Preamble:

Rather than simply recalling Convention 108, it should be underlined that the processing of personal data should be carried out in compliance with the provisions of Convention 108 and the relevant recommendations of the Committee of Ministers in this field, in particular Rec(2002)9 , Rec (97) 5, Rec (92) 3 and Rec (2010)13 on the protection of individuals with regard to automatic processing of personal data in the context of profiling<sup>4</sup>.

Moreover, more explanations should be given to the serious risks of discrimination (in terms of eligibility for the contract or price determination) coming from the use of genetic data in the insurance sector.

Para. 5 of the Preamble: a specific reference to Article 6 of Convention 108 should be added and it is therefore recommended to use the following wording: "Considering the sensitive nature of the personal information used in these contracts which deserves a special protection as provided for by Article 6 of Convention 108".

Para 12 of the Preamble - it is suggested to redraft as follows: "Considering the need for member states to take appropriate measures to establish a balance between the interests of parties to private insurance contracts relating to the health or length of life of an individual and the need to ensure respect for the fundamental rights and human dignity of insured persons". Moreover, the reference to "a regulatory or convention-based framework" is unclear in the preamble of the Recommendation.

Para 13 of the Preamble leaves some ambiguity whereas the use of health data in the insurance sector should be subject to strict requirements, in particular with respect to genetic data, as mentioned before. It is suggested to delete the para. 13 "Considering that obtaining these results may in certain cases require legislation or regulations, whereas in other cases

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<sup>4</sup><https://wcd.coe.int/ViewDoc.jsp?id=1710949&Site=CM&BackColorInternet=C3C3C3&BackColorIntranet=EDB021&BackColorLogged=F5D383>

dialogue between the relevant stakeholders, promoted by the public authorities, may [also] produce satisfactory results”.

## Chapter II

Title: “Collection and use of health-related personal information”: In this phase of the processing it is essential that data subjects are provided with the relevant information concerning the processing of their data, as stated, amongst others, by Rec(2002)9 (Principle 5).

Para 5: it is suggested to redraft to “[...] duly justified and if the person has been informed about the relevance to the risk and its justification”.

Para 11: information on other family members should not be collected or used for insurance purposes without the consent of those family members. It is therefore recommended to use the following wording: “The only permitted exceptions should be in cases where the information is relevant and where the family members concerned gave their consent [...]”.

Para 12: individuals concerned should be informed on the exceptions. It is suggested to add: “exceptions... and inform the individuals concerned”.

Para 19: “Personal information in the public domain should not be used by insurers to calculate risks or premiums [without being verified by appropriate evidence]”. It is suggested to delete the last words of the sentence: “without being verified by appropriate evidence”, which opens the possibility of using personal information in the public domain for insurance purposes. The collection of personal data by controllers from the public domain, such as Internet, is a challenging issue which raises serious concerns with regard to the respect for the principle of purpose limitation and compatibility of purposes<sup>5</sup>. Whatever the case may be, it should be recalled that according to Article 4.2 of Rec (2002)9 personal data processed for insurance purposes should, in principle, be collected from the data subject.

Moreover, the explanatory memorandum should specify that the public domain also includes social networks and forums. Furthermore, the collection of data from “closed” or restricted web pages also raises concerns.

It should be further noticed that the fact that the information entered the public domain legally or illegally is not a personal data protection and privacy issue (reference made to data protection in the Explanatory Note).

Para 22 “Option A: The use for insurance purposes of data obtained in a research context should not be permitted”. It is suggested to keep Option A which appears to be in line with the principle of purpose limitation and compatibility and with Rec(97)5 on medical data which provides that genetic data processed for treatment of diagnosis of the data subject or scientific research should only be used for these purposes (Principle 4.7).

Provision 23-26: It is recommended to move “Privacy – confidentiality – security”/ to the beginning of this chapter and add the following (in a new provision 23): “Insurers should respect data protection rules of the countries they are operating in at all time while collecting, storing and erasing sensitive data.”

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<sup>5</sup> See Article 29 Working Party’s Opinion 3/2013 [http://ec.europa.eu/justice/data-protection/article-29/documentation/opinion-recommendation/files/2013/wp203\\_en.pdf](http://ec.europa.eu/justice/data-protection/article-29/documentation/opinion-recommendation/files/2013/wp203_en.pdf)

Provision 23 (new 24) should read: "Insurers should adopt internal regulations and appropriate technical and organisational measures in accordance with the corresponding data protection rules of the countries they are operating especially in order to ensure and protect the security and confidentiality. Sensitive data should be stored separately from other data."

Further details on technical and organisational measures to be adopted with respect to traceability could be provided in the explanatory memorandum.

Para 24 "Period during which information may be stored". The conservation of data is provided for by Article 13 of Recommendation (2002)9 which, amongst others, states that where personal data are no longer necessary for the accomplishment of the purpose for which they were collected, including to refuse insurance coverage, they should be deleted. If they must nevertheless be kept for purposes provided for by law, they should be kept separately and be accessible only for those purposes subject to appropriate safeguards.

It is further proposed that at the expiration of the contract, the data is stored in an intermediate database with limited access for the sole purpose of allowing the action assured by the insurers. It is therefore not necessary to keep the data in a live database. This provision should be at least referred into the explanatory memorandum.

Para 25: Regarding the storage of information the proposed provision 25 is acceptable. Where an application for insurance has been rejected, it is recommended that sensitive data be erased right after rejection.

"Existing predictive data" para 29-32. From the explanatory note, it is understood that this section refers to those domestic laws permitting the use of existing genetic data. It should be pointed out that, as provided for by Principle 7 of Rec (92)3, insurers should not have the right to require genetic testing or to enquire about results of previously performed tests, as a pre-condition for the conclusion or modification of an insurance contract.

Indeed, the use of genetic data as such, whether or not related to existing information, presents extremely relevant risks for individuals, namely discrimination, which largely justifies a prohibition of their use in the insurance sector. In addition, Rec(97)5 provides that genetic data processed for treatment of diagnosis of the data subject or scientific research should only be used for these purposes (Principle 4.7).

If the reference to the possibility that some states may permit the use of existing data is deemed to be necessary, it should be clearly stated that processing of genetic data in the field of insurance should be prohibited in principle and only authorised under really exceptional circumstances, clearly provided for by law. This was the position adopted also by Article 29 Working Party in its Working Document on genetic data. It should finally be recalled that most of EU Member States have strict regimes in this respect.

Para 33 "Non-genetic predictive data". In terms of potential discrimination risks, this category of data is also very sensitive and due attention should be paid therefore be paid to Rec(2002)9 and Rec (2010)13 on profiling, addressing in particular the risks raised by purely automated decisions.

Para 34: the Explanatory Note does not appear to be related to the provision of para. 34, which refers to the update of data.

Para 35: This paragraph seems to introduce restrictions on the information to be provided to the insured person as it requires that information should be provided "at the request of the

insured." Automatic provision of information by the insurer would be more in line with the right of information.