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Addendum III

STEERING COMMITTEE FOR HUMAN RIGHTS

(CDDH)

Daft Recommendation on the processing of personal health-related data for insurance purposes, including data resulting from genetic tests

(as adopted by the CDDH at its 85th meeting, 15-17 June 2016)

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Preamble

I. The Committee of Ministers, under the terms of Article 15(b) of the Statute of the Council of Europe,

II. Considering that the aim of the Council of Europe is to achieve a greater unity between its members, in particular through harmonising laws on matters of common interest;

III. Recalling the principles laid down in

- the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (“the Convention on Human Rights and Biomedicine”) (ETS No. 164) and in
- the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (ETS No. 108);

IV. Taking into consideration

- Recommendation (2002)9 on the Protection of Personal Data collected and processed for Insurance Purposes;
- Recommendation (97)5 on the Protection of Medical Data;

as well as the European Social Charter and the European Code of Social Security;

V. Bearing in mind the significant expansion of private insurance contracts covering risks related to an individual’s health, physical integrity, age or death;

VI. Considering the sensitive nature of the personal health-related data processed in these contracts;

VII. Taking into account developments in the field of genetics, in particular the prospects of obtaining data more and more easily on the genetic characteristics of individuals, the analysis of which may be particularly complex;

VIII. Bearing in mind the risks of an incorrect or excessive interpretation of these data regarding the state of health of the persons concerned in the – sometimes very distant – future;

IX. Convinced of the social importance in each country of appropriate cover of certain risks related to health, physical integrity, age or death;

X. While recognising the insurer’s legitimate interest in assessing the level of risk presented by the insured person;

XI. Aware of the role that voluntary private insurance can play in supplementing (and occasionally replacing) cover of these risks by the social security scheme or other public or compulsory insurance;

XII. Convinced, moreover, of the social importance, which varies from country to country, of cover of risks related to death, insofar as insurance may be a precondition for access to certain financial services;

XIII. Emphasising the need to strike a fair balance between the constraints relating to the nature of the private insurance contract, the protection of the individual interests of the insured persons and consideration of the social importance of certain risks;

XIV. Considering the need for member States to take appropriate measures to ensure respect for the fundamental rights of insured persons in regard to private insurance contracts relating to a person's health, physical integrity, age or death; to provide a regulatory or convention-based framework for the processing for insurance purposes of health-related personal data, in particular predictive data whether or not of a genetic nature, and to promote the insurability of individuals presenting a higher health risk, especially with regard to the social importance of coverage for certain risks;

XV. Considering that obtaining these results may in certain cases require legislation or regulations, whereas in other cases dialogue between the insurers, patient and consumer representatives, health professionals, the competent authorities and other relevant stakeholders may produce satisfactory results;

XVI. RECOMMENDS that the governments of member States implement the provisions of this Recommendation.

Chapter I - General provisions

Object

1. Member States should take appropriate measures to ensure respect for fundamental rights of persons, without discrimination, in the context of the insurance contracts covered by this Recommendation.

Scope

2. This Recommendation applies to personal and group insurance contracts with the objective to insure the risks linked to a person's health, physical integrity, age or death.

3. None of the proposed measures of this Recommendation should be interpreted as limiting or otherwise affecting the possibility for any member State to grant the insured person a wider measure of protection.

Definitions

4. For the purpose of this Recommendation:

- "insured person" refers to the individual whose risks are covered by the contract, whether in the process of being drawn up or concluded;
- "insurer" refers to both insurance and re-insurance companies;
- "third party" is any natural or legal person other than the insured person or the insurer;
- "examination" includes any non-genetic or genetic test;
- "genetic test" refers to a test involving analysis of biological samples of human origin, aiming at identifying the genetic characteristics of a person which are inherited or acquired during early prenatal development;
- "health-related personal data" refer to all personal data related to the health of an individual;
- "processing of personal data" means any operation or set of operations which is performed upon personal data.

Chapter II - Processing of health-related personal data

Principle 1 – Insurers should justify the processing of health-related personal data.

5. Health-related personal data should only be processed for insurance purposes subject to the following conditions:

- the processing purpose has been specified and the relevance of the data has been duly justified;

- the quality and validity of the data are in accordance with the generally accepted scientific and clinical standards;

- data resulting from a predictive examination have a high positive predictive value; and

- processing is duly justified in accordance with the principle of proportionality in relation to the nature and importance of the risk in question.

6. Health-related data from family members of the insured person should not be processed for insurance purposes, unless specifically authorised by law. If so, the criteria laid down in paragraph 5 and the restriction laid down in paragraph 17 have to be respected.

7. The processing for insurance purposes of health-related personal data obtained in the public domain, such as on social media or internet fora, should not be permitted to calculate risks or premiums.

8. The processing for insurance purposes of health-related personal data obtained in a research context involving the insured person should not be permitted.

9. Questions posed by the insurer should be clear, intelligible, direct, objective and precise. Insurers should provide easy access to a contact person, having the requisite competence and experience, to address any difficulties of understanding in regard to the documents for the collection of health-related personal data.

Principle 2 – Insurers should not process personal health-related data without the consent of the insured person.

10. Health-related personal data should not be processed for insurance purposes without the insured person’s free, express and informed, written consent.

11. Health-related personal data should in principle be collected from the insured person by the insurer. The transmission of health-related personal data by a third party should be made subject to the insured person’s consent.

Principle 3 – Insurers should have adequate safeguards for the storage of health-related personal data.

12. Insurers should not store health-related personal data which is no longer necessary for the accomplishment of the purpose for which it was collected. They should, in particular, not store health-related personal data if an application for insurance has been rejected; or if the contract has expired and claims can no longer be made. An exemption can be made if further storage is required by law.

13. Insurers should adopt internal regulations to protect the security and confidentiality of the insured person’s health-related data. In particular, health-related personal data

should be stored with limited access separately from other data and data kept for statistical purposes should be anonymised.

14. Internal and external audit procedures should be put in place for adequate control of the processing of health-related personal data in regard to security and confidentiality.

Chapter III - Specific provisions on genetic tests

Principle 4 – Insurers should not require genetic tests for insurance purposes.

15. In accordance with the principle laid down in Article 12 of the Convention on Human Rights and Biomedicine, predictive genetic tests must not be carried out for insurance purposes.

16. Existing predictive data resulting from genetic tests should not be processed for insurance purposes unless specifically authorised by law. If so, their processing should only be allowed after independent assessment of conformity with the criteria laid down in Paragraph 5 by type of test used and with regard to a particular risk to be insured.

17. Existing data from genetic tests from family members of the insured person should not be processed for insurance purposes.

Chapter IV - Provisions on risk assessment

Principle 5 – Insurers should take account of new scientific knowledge.

18. Insurers should regularly update their actuarial bases in line with relevant new scientific knowledge.

19. On request of the insured person, the insurer should provide relevant information and justification to that person regarding the calculation of the premium, any additional premium or any total or partial exclusion from insurance.

Chapter V —Social importance of coverage for certain risks

Principle 6 – Member States should facilitate risks coverage that is socially important.

20. Member States should recognise the social importance of coverage for certain risks and should, where appropriate, take measures to facilitate affordable access to insurance coverage for persons presenting an increased health-related risk.

Chapter VI - Mediation, consultation and monitoring

Principle 7 – Member States should ensure adequate mediation, consultation and monitoring.

Mediation in disputes between insured persons and insurers

21. Member States should ensure that mediation procedures be set up, where they do not exist, to ensure fair and objective settlement of individual disputes between insured persons and insurers. Insurers should inform all insured persons about the existence of these mediation procedures.

Collective consultation between parties

22. Member States should promote consultation between insurers, patient and consumer representatives, health professionals and the competent authorities, to ensure a well-balanced relationship between the parties and increase transparency vis-à-vis the public.

Monitoring of practices

23. Member States should ensure independent monitoring of practices in the insurance field in order to evaluate compliance with the principles laid down in this Recommendation.