

COUNCIL OF EUROPE



CONSEIL DE L'EUROPE

Strasbourg, 9 October 2014

Restricted
DH-BIO (2014) 14

Committee on Bioethics (DH-BIO)

Draft Recommendation on the processing for insurance purposes of personal health-related data, in particular data resulting from genetic tests

revised by Mrs Doris Wolfslehner (Austria), Rapporteur,
in the light of the comments made by delegations and by the Bureau

Delegations are invited to examine the revised draft Recommendation with a view to a preliminary exchange at the 6th plenary meeting (12-14 November 2014) and to send to the Secretariat (DGI-CDDH-Bioethics@coe.int) their written comments by 28 November 2014.

Preamble

Chapter I
General provisions

Chapter II
Processing of health-related personal data

Chapter III
Specific provisions on genetic tests

Chapter IV
Provisions on risk assessment

Chapter V
Socially important risks

Chapter VI
Mediation, consultation and monitoring

Preamble

1. The Committee of Ministers, under the terms of Article 15(b) of the Statute of the Council of Europe,
2. 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;
3. Taking into consideration, in particular:
 - 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”) of 4 April 1997;
 - the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data;
 - the European Social Charter and the European Code of Social Security;
4. Bearing in mind the significant expansion of private insurance contracts covering risks related to an individual’s health, physical integrity or life expectancy;
5. Considering the sensitive nature of the personal data used in these contracts;
6. 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, while the analysis of which may be particularly complex;
7. 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;
8. Convinced of the social importance in each country of appropriate cover of certain risks related to age or health, such as illness, invalidity, retirement and dependence;
9. 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;
10. Convinced, moreover, of the social importance, which varies from country to country, of cover of other risks such as death, insofar as this may be a precondition for access to certain services, which in some cases may be essential, such as professional loans or loans to obtain one’s main residence;
11. Emphasising the need to strike a fair balance between, on the one hand the constraints relating to the nature of the private insurance contract and the protection of the individual interests of the insured persons and, on the other, consideration of the social importance of certain risks;
12. 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 length of life; to provide a regulatory or convention-based framework for the collection and 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 cover of socially important risks;

13. Considering that obtaining these results may in certain cases require legislation or regulations, whereas in other cases dialogue between the relevant stakeholders, promoted by the public authorities, may [also] produce satisfactory results;

14. **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 the fundamental rights of persons, without discrimination, in the context of the insurance contracts covered by this Recommendation.

Scope

2. This Recommendation applies to personal insurance in which the risk to be insured is linked to a person's health, physical integrity, age or length of life.

3. None of the proposed measures of this Recommendation shall 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 concerned by the risk covered by the contract, whether in the process of being drawn up or concluded;
- "third party" is any natural or legal person other than the insured person;
- "insurer" refers to both insurance and re-insurance companies;
- "examination" refers to any non-genetic or genetic test and / or examination;
- "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 concerning the health of an individual;

Chapter II – Processing of health-related personal data

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

5. Member States should take appropriate measures to ensure that:
- Health-related personal data for insurance purposes are only collected if their relevance to the risk in question has been duly justified;
 - Health-related personal data are only collected if duly justified in accordance with the principle of proportionality in relation to the nature and importance of the risk in question;
 - Health-related personal data are only collected if the quality of the data is in accordance with the generally accepted scientific standards;

- Health-related personal data resulting from an examination with predictive value is only collected if the data have a high/significant positive predictive value.
- 6. The collection of data on family history for insurance purposes should not be permitted, unless authorized by domestic law. In this case, the criteria as provided for in Paragraph 5 of this Recommendation should be met.
- 7. Questions posed by the insurer are to be clear, intelligible, direct, objective and precise. Insurers should in addition take appropriate measures to verify that the documents for the collection of health-related personal data are correctly understood by insured persons and should provide easy access to a contact body or person of the insurer, having the requisite competence and experience, to address any difficulties of understanding.

Principle 2 – Insured persons should have control over their health-related personal data.

- 8. Health-related personal data processed for insurance purposes should, in principle, be collected from the data subject. If the data subject consents for a third party to provide the data, the insured persons should always have control over any data concerning him/her that is submitted to the insurer.
- 9. The only admissible third party to transmit health-related personal data are medical doctors or health professionals. Data sought from or communicated by a medical doctor or health professionals should satisfy the criteria set out in Paragraph 5 of this Recommendation and should be transmitted through the insured person or with the insured person's written consent.
- 10. The use 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.
- 11. The use for insurance purposes of health-related personal data obtained in a research context should not be permitted.

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.
- 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 separately from other data with limited access and data kept for statistical purposes should be anonymised.
- 14. Internal and external audit procedures should be put in place for adequate control of health-related personal data.

Chapter III - Specific provisions on genetic tests

Principle 4 – Genetic tests should not be required 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 should not be carried out for insurance purposes.
16. Existing predictive data resulting from genetic tests should in principle not be used for insurance purposes. If authorized by domestic law, the criteria as provided for in Paragraph 5 of this Recommendation should be assessed by an independent body.
17. Existing data from genetic tests from family members should not be used 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 data bases in line with any new scientific knowledge.
19. The insurer should provide precise information and justification to the insured person regarding the calculation of the premium, any additional premium or any total or partial exclusion from insurance.

Chapter V – Socially important risks

Principle 6 – Member States should facilitate the coverage of socially important risks.

20. Member States should, where appropriate, take measures to facilitate the affordable access to insurance coverage for socially important risks 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. Mediation procedures should be set up 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 dialogue 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 that an independent monitoring of practices in the insurance field be set up in order to evaluate compliance with the principles in this Recommendation.