EUROPEAN MALIGNANT HYPERTHERMIA GROUP (EMHG)

https://www.emhg.org

Life insurance and MH

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1. Context and objectives

General information

Life insurance (From Wikipedia) or life assurance (Commonwealth of Nations) is a contract between an insurance policy holder and an insurer or assurer, where the insurer promises to pay a designated beneficiary a sum of money upon the death of an insured person (often the policy holder).

The policy holder typically pays a premium, either regularly or as one lump sum. The benefits may include other expenses, such as funeral expenses.

Life policies are legal contracts and the terms of each contract describe the limitations of the insured events.

Often, specific exclusions written into the contract limit the liability of the insurer; common examples include claims relating to suicide, fraud, war, riot, and civil commotion.

Difficulties may arise where an event is not clearly defined, for example: the insured knowingly incurred a risk by consenting to an experimental medical procedure or by taking medication resulting in injury or death.

Differences between social and private insurance programs:

Private insurance

- Risks are classified, and grouped in homogenous groups (‘segmentation)
- Segmentation is used to select and assess the risks presented by individuals
- Insurance admission rules and premiums are adjusted accordingly
- Persons with too high a risk to be insured may be refused, or agreed to insure them only with certain exclusions (particular illnesses or disorders may be excluded)
- Additional conditions may be applied such as waiting period or excess fee

Social welfare scheme

- Principle of ‘social solidarity’
- Risks associated with health are spread among all or a significant proportion of members of a community
- The level of coverage and the associated rules are established for everyone
- Cover is financed through broad contribution-based mechanisms (professional revenues, income tax,….
- No underwriting and contributions do not reflect each person’s individual risk profile

Limitations of these guidelines

These lines of thought do not imply or consider:

- coverage of health risks by the national social security systems/social welfare schemes

- the obtained information thusfar only pertains to the countries of the European community
- recruitment or promotion of employees, nor fitness for duty in armed forces
- MH-susceptibility of anaesthesia is being considered; not other *RYR1*-myopathies

Definitions

(excerpt from Recommendation CM/Rec (2016)8 of the Committee of Ministers to the member States):

- ‘Insured person’ refers to the individual whose risks are covered by a contract
- ‘Insurer’ refers to both insurance and re-insurance companies
- ‘Reinsurance’ An insurance company concludes a reinsurance agreement in order to share or transfer risks in the event of there being a higher claim rate than anticipated (implicating that international industry- and legal practices have to be applied).
- ‘Third party’ is any natural or legal person other than the insured person or the insurer (eg family doctor)
- ‘Examination’ includes any test, genetic or otherwise
- ‘Genetic test’ refers to a test invoving analysis of biological samples of human origin, aiming to identify the genetic characteristics of a person that 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

2. Questions arising in regard to MH-susceptibility:

1. Should MH-susceptibility as clinically proven in a proband and/or predictive data (IVCT and/or genetic tests) be reported by the applicant to the insurer?
    - as underwriting requires applicants to give an accurate and complete description of the risk characteristics to be covered ('good faith' concept – 'legal duty' in most European countries)
    - recognizing the insurer's legitimate interest in assessing the level of risk presented by the insured person (actuarial fairness)
    - but being in conflict with the right of privacy and self-determination (and the right not to know) Convention on Human Rights and Biomedicine (ETS 164, Oviedo, 04.04.1997).
2. Can MH-susceptibility lead to in an increase of the premium?
3. Can MH-susceptiblity limit the liability of the insurer? Could it lead to termination of insurance? Can it lead to any total or partial exclusion from insurance?
4. Do you as a professional have to (or can you) warn other family members of the risk of MH?
5. Can you as a professional be asked to communicate to the insurer information from the patient's medical file with his/her consent?.

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3. Legislative documents

In order to formulate an advice 3 'legislative documents" have been consulted. Relevant excerpts from the following documents

1. Recommendation CM/Rec (2016)8 of the Committee of Ministers to the member States. “On the processing of personal health-related data for insurance purposes, including data resulting from genetic tests”.

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

- *The processing purpose has been specified and the relevance of the data has been duly justified*
- *Processing is duly justified in accordance with the principle of proportionality in relation to the nature and importance of the risk in question (data must be relevant to the risk to be covered).*

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

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

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

- *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.*
- *Existing predictive data resulting form genetic tests should not be processed for insurance purposes unless specifically authorised by law.*
- *Existing data from genetic tests from family members of the insured person should not be processed for insurance purposes.*

2. Consultation document on predictivity, genetic testing and insurance. Elaborated by the Steering Committee on Bioethics (CDBI) 2012

Chapter 1: Collection and use of health-related personal data for insurance purposes.

- *Insurers, in pursuing the best possible assessment of the risks which prospective clients carry, are interested in all data likely to provide information on their future health.*
- *Underwriting a contract is based on the knowledge and experience of underwriters and medical doctors who give their evaluation on the basis of ratings suggested in the underwriting manuals.*
- *Underwriting manuals are up-to-date, evidence-based rating guidelines suggested for the assessment of different risk factors. These guidelines are usually produced by reinsurers using data from clinical and insurance literature, as well as the findings of experience studies analysis.*
- *Issue raised with the above statements: what data are to be obtained from insurance applicants are opaque, and how the information collected is translated into the actuarial language that serves as a basis for calculating the risk and the premium is unclear.*

Chapter 2: Specific aspects of genetic predictive and other predictive data.

- *Definition of genetic test: Tests involving analysis of biological samples of human origin and aimed specifically at identifying the health-related genetic characteristics of a person that are inherited or acquired during early prenatal development. Analysis refers to chromosamal analysis, DNA or RNA analysis, and analysis of any other element enabling equivalent information to be obtained, i.e. information that is directly linked to the genetic characteristics of the person concerned. This is the case in particular with analysis of gene expression products.*

- *Diagnostic testing is used to diagnose or rule out a specific genetic or chromosomal condition when a particular condition is suspected based on clinical symptoms.*
- *By contrast, predictive testing is used on individuals in apparent good health, to detect genetic alterations associated with a pathology that has not manifested.*
- *In the absence of symptoms, the results may possibly provide information on the person concerned's furture health. Their predictive value in relation to the development of diseases nonetheless remains extemely variable and, in the vast majority of cases, limited, owing in particular to the diversity of factors involved, non-genetic ones included, and to the complexity of their mutual interactions.*
- *Especially regarding risks to the protection of privacy and risks of discrimination this has prompted several states (Austria, Germany, France, Belgium, Norway, Spain, Switzerland) to define a specific legal framework, prohibiting or stringently and precisely limiting the use of the results of genetic testing for non-health purposes.*
- *Monogenic diseases for which genetic alterations on their own play a decisive part in the development of the disease, are very rare.*
- *It would be possible, in theory, for an insurer to use familial information provided to him by an insurance applicant to underwrite future applications from other members of his/her family. This practice is illicit since family members have not consented on this use of their data.*

3. International Academy of comparitive Law. The XXth International congress – Fukuoka, Japan 2018. Legal aspects of genetic testing regarding insurance and employment. National report for Belgium. Thierry Vansweevelt, Britt Weyts and Cindy Cornelis.

1. *The policyholder knows, consciously or unconsciously, more about his/her genetic risks than the insurer. Therefore the insurer is in a weaker position when concluding an insurance contract. He does not have the same information as the policyholder.*

2. *Art 58 and 61 of the Insurance Act 2014 prohibit any use of genetic information of testing in the context of insurance. Genetic data may never be communicated. The use of genetic information is prohibited to avoid any systematic prejudice against the 'genetically weak' and an improper risk selection by the insurer.*
3. *The ban applies to the policyholder, the insured, the physician and the insurer.*
4. *The prohibition will always apply, even when the policyholder agrees to use the data.*
5. *The Insurance Act 2014 applies to Belgian insurers, foreign insurers with an office in Belgium and foreign insurers that perform insurance activities in Belgium without having its office in Belgium.*
6. *Based on his/her right to self-determination, the patient is entitled to information about his/her state of health. This information also relates to genetic health.*
7. *The insurer is not entitled to a copy of the patient record. This is prevented by physician-patient confidentiality. If the insurer wants a certificate or declaration for concluding or executing the agreement, the insured can request a statement from his/her doctor who can deliver the statement to the patient. The insured person then decides for himself whether or not to give the declaration to the insurance company.*
8. *The insurer may not ask for genetic information, and the physician or policyholder may not disclose it. The patient's consent cannot exempt the physician from her/his duty of professional confidentiality and cannot cancel the unlawfulness of the violation.*
9. *The Insurance Act provides protection by introducing a complete and absolute prohibition on requesting and communicating genetic information in connection with the conclusion or performance of an insurance contract.*
10. *Every patient has the right to say that he/she does not want to be aware of his/her genetic information. By invoking his/her right not to know, the patient waives his/her right to health status information.*

11. *Based on the right not to know, no one can be forced to undergo genetic research.*
12. *In Belgium, lack of enforcement is a problem. In the context of insurance, there are no sanctions when the prohibition is violated.*

Recommendations

Insurers, in pursuing the best possible assessment of the risks which prospective clients carry, are interested in all data likely to provide information on their future health.

Underwriting a life-insurance contract requires applicants to give an accurate and complete description of the risk characteristics to be covered ('good faith' concept – 'legal duty' in most European countries). Providing genetic information however carries the of discrimination.

As underwriting of a life-insurance contract between an insurer and an applicant is best based on evidence-based rating guidelines derived from relevant clinical information (and currently no such guidelines exist) the EMHG has a clear intrest in expressing a clear point of view on this matter.

The following has been discussed within, and agreed upon by the EMHG

1. Individuals are entitled to know any information collected about their health, if they wish to know, but according to the "Declaration on the Rights of the Patient" adopted by the World Medical Association in 1981 and amended in 1995, the patient also has the right not to be informed on his/her explicit request, unless required for the protection of another person's life".
2. MH of anaesthesia is a metabolic syndrome limited to general anaesthesia and is entirely preventable if a non-triggering anaesthesia technique is used.

3. MH-susceptibility (actual MH-crisis in a proband) can be reported to the insurer by the candidate-policyholder if he/she whishes to do so.
4. The reliability, sensitivy and specificity of the IVCT are known and the scientific validity of this test as an indicator for MH susceptibility has been well established. MH-susceptibilty based on a positive IVCtest can be reported to the insurer by the candidate-policyholder.
5. MH-susceptibility of anaesthesia does not interfere with life expectancy as such.
6. MH-susceptibility of anaesthesia does not interfere with quality of life.
7. MH-susceptibility of anaesthesia does not lead to loss of autonomy, and does not incur chronic costs.
8. Taking into consideration pts 5 – 7 being diagnosed MH-susceptible on clinical grounds and IVCtests should not lead to an increase in premium nor exclusion from the contract.
9. In most countries the law prohibits an applicant disclosing the results of a genetic work-up on MH already undergone. Therefore genetic results should not be communicated to the insurer.
10. The insurer is not entitled to subject the concluson of an insurance policy to the holding of a predictive genetic test.
11. It is illicit for an insurer to use familial information provided to him by an insurance applicant to underwrite future applications from other members of his/her family.
12. Third parties – including IVCTests labs - are not allowed to confer information about MH to an insurer, even with the consent of the individual involved.

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Travel and MH- insurance, safety issue mainly if traveling to low-resource countries

1. The same recommendations formulated in regard to applicating for a life-insurance can be applied when taking out a travel insurance. The premium should not be raised for an individual with MH-susceptibility of anaesthesia in view of the preventable nature of the problem.
2. The EMHG (as do other instances) advises that needing anaesthesia in countries with poorly developed health care systems may entail more risks than in parts of the world with all possible resources. One of these several risks is MH-susceptibility, the prevention and treatment of which may be suboptimal in low resource countries (dantrolene/derivative often not available).
3. The EMHG provides up-to-date contact addresses including e-mail and telephone numbers of the MH-labs in the parts of the world where these exist. See www.EMHG.org
4. The EMHG advises MH-susceptible patients to undersign an insurance covering medical costs for transportation including repatriation when traveling to countries lacking the necessary resources to prevent or manage MH.
5. The patients should be readily identifiable as ‘MH-susceptible’ when traveling (warning cards or bracelets) and carry information about how to prepare safe anaesthesia, possibly in different languages