香港保險業聯會
The Hong Kong Federation of Insurers

Best Practice on Use of Genetic Test Results ("Best Practice")

1. Preamble

1.1 Formerly known as the "Code of Practice on Genetic Testing" ("Code"), the Code was first introduced in May 2000 by the Genetics Working Group formed by the Hong Kong Federation of Insurers ("HKFI"). The Code was later revised on 1 May 2005, and was endorsed by all Life Insurance Members ("LIMs") and General Insurance Members ("GIMs") of the HKFI.

1.2 In light of the medical advancement, particularly related to DNA technology since 2005, the Life Insurance Council ("LIC") in April 2017 began a review of the Code. Further, in December 2017, it has come to the HKFI's attention that the Hong Kong SAR Government had established a Steering Committee on Genomic Medicine ("Steering Committee"), comprising of experts from the academic, clinical and research sectors to map out strategies for developing genomic medicine in Hong Kong. The Steering Committee recommended that more specific regulatory measures against genetic discrimination in the context of insurance should be explored.

1.3 In November 2018, the HKFI, along with the Food and Health Bureau ("FHB") decided to take forward the recommendation of the Steering Committee. The HKFI believes the development of genomic medicine will have long term positive effects in advancing the development of medicines and in early treatment intervention. Genetic testing can also be a useful tool in the diagnosis, prevention and treatment of illnesses or diseases. Further, the public should not be discouraged from the benefits of genetic testing because of concerns over obtaining insurance coverage.

1.4 Member Companies are advised to read the Best Practice in conjunction with, without limitation, the relevant provisions of the Insurance Ordinance ("IO", Cap. 41), Personal Data (Privacy) Ordinance ("PDPO", Cap. 486), Disability Discrimination Ordinance ("DDO", Cap. 487), and Codes and Guidelines issued by the Insurance Authority (IA). Member Companies are reminded to comply with all applicable laws, codes and guidelines, including without limitation the aforementioned ordinances, codes and guidelines, in their practice.

2. Introduction

2.1 Many countries have introduced limitations (self-regulation or legislation) in recent years on the request and use of genetic test results by insurers for the purpose of assessing insurance applications.

2.2 Genetic testing awareness and advancement has been growing rapidly since the Code took effect in 2005. The HKFI believes this is the appropriate time to revisit the principles of insurance practice on the use of genetic test results to better protect the insuring public and to provide more clarity to the applicants and the insured persons about the practice of the insurance industry. The Best Practice defines the industry's position and sets out guidelines on the use of genetic test results to uphold the essential fundamentals of voluntary insurance. It is intended to strike an appropriate balance between the interests and standards of both insurers and customers regarding genetic testing and insurance.

3. Scope

3.1 The scope of this Best Practice covers issues on the use of genetic test results in relation to insurance activities, which include but are not limited to underwriting and claims assessment.

3.2 All Members of the HKFI are advised to adhere to the Best Practice. For the avoidance of doubt, the Best Practice only applies to the use of genetic test results in conducting insurance activities with existing and potential insured persons. It does not attempt to provide any advice on medical testing, medical treatment or other therapeutic purposes.

3.3 The Best Practice applies to all Hong Kong residents (including without limitation residents with valid working visa in Hong Kong).

3.4 Notwithstanding any provisions in the Best Practice, for Certified Plans under the Voluntary Health Insurance Scheme ("VHIS"), (a) no Predictive Genetic Test results can be requested by an insurer, and neither can any of such results be taken into account by an insurer, regardless of the level of coverage or medical conditions or genetic predispositions of the applicant or the insured; and (b) only Diagnostic Genetic Test results can be requested by an insurer in accordance with paragraph 5.2 of the Best Practice (see below). For avoidance of doubt, if the VHIS is attached as a policy rider, insurers shall comply with the relevant requirement of FHB and abide to the Best Practice for that part of the policy issued under a VHIS Certified Plan.

4. Interpretation

4.1 Genetic testing relevant to the insurance industry refers to the types of medical tests that analyse human DNA or chromosomes to detect changes or variations in the genetic material related to diseases[i]. The results of a genetic test may confirm a clinical suspicion, determine a person's susceptibility to a disease, or help predict a person's chance of developing or passing on a genetic disorder.

4.2 There are many different types of genetic tests available on the market. The most common tests[ii] include:

(a) Diagnostic Genetic Test

A diagnostic or confirmatory genetic test identifies or confirms a specific genetic or chromosomal condition in a symptomatic individual. A positive test result means the faulty gene or chromosomal abnormality causing the condition has been found. A negative test result means a faulty gene or chromosomal abnormality has not been found and the suspected condition can likely be ruled out.

(b) Predictive Genetic Test

A predictive or pre-symptomatic genetic test detects gene mutations or variations that increase the risks of developing disorders after birth, often later in life. These tests can be helpful, for example, to people who have a family history of a genetic condition but show no symptoms of the condition at the time of the testing. A positive test result means the faulty gene has been found and there is an increased probability that the individual will develop the condition. A negative test result means the faulty gene has not

been found and the individual has a lower probability of developing the condition.

A genetic test that may suggest susceptibility or relative risks of developing a disease based on a genetic variation can also be regarded as a predictive test.

(c) Carrier Test

Carrier testing is used to identify people who carry one copy of a gene mutation that, when present in two copies, causes a genetic disorder. This type of testing is offered to individuals who have a family history of a genetic disorder and to people in certain ethnic groups with a higher risk of specific genetic conditions. If both parents are tested, the test can provide information about a couple's risk of having a child with the genetic condition.

(d) Pharmacogenetic Test

This is a type of genetic tests that determines the influence of genetic variations on drug metabolism and response, and can guide individual drug dosage and selection.

(e) Prenatal Test

Prenatal genetic tests are used to detect changes in a fetus' genes or chromosomes before birth. This type of testing is offered to couples with a high risk of having a baby with a genetic or chromosomal disorder.

4.3 For the purpose of the Best Practice, "Genetic Testing" refers to Diagnostic Genetic Tests and Predictive Genetic Tests, since they are considered the most relevant by insurers in assessing insurance risks.

5. Genetic Testing and Underwriting

5.1 Insurers will not require, compel or pressure potential applicants to undertake genetic testing for underwriting purposes.

5.2 Without prejudice to paragraph 5.1 and subject to paragraph 5.3, in the event a Diagnostic Genetic Test has been conducted, insurers may request for the results of such Diagnostic Genetic Test for the purpose of underwriting.

5.3 In any event, insurers will not ask for the results of any types of genetic tests (Diagnostic or Predictive) for the purpose of underwriting if the genetic testing was conducted in the context of scientific research, including those in connection with the Hong Kong Genome Project.

5.4 Without prejudice to paragraph 5.1, for Life Insurance, and Critical Illness Insurance, subject to paragraph 5.3, in the event a Predictive Genetic Test has been conducted, insurers may request for the results of such Predictive Genetic Test as relevant for the purpose of underwriting, if both of the following criteria are satisfied:

(a) The sum assured in the policy is above the threshold listed in the Annex for the type of insurance applied on a per life basis, and
(b) The medical condition/gene requested is among those listed in the Annex.

5.5 For Life Insurance, and Critical Illness Insurance that do not satisfy the criteria listed in paragraph 5.4, and for all VHIS Certified Plans and other insurance plans, insurers will not ask for the results of any Predictive Genetic Tests.

5.6 Notwithstanding paragraph 5.5, insurers may use the results of a Predictive Genetic Test for underwriting purpose if the applicant voluntarily provides such information, and the information will result in a more favourable underwriting decision to the applicant. For example, if the applicant has disclosed his/ her family history of breast cancer, and voluntarily provides a negative test result for the BRCA 1 or 2 gene, the insurer may use the result for underwriting purpose.

5.7 Insurers will not ask or use the results of any genetic tests of a relative or family member of a proposed or existing insured person for the purpose of underwriting. However, for the avoidance of doubt, applicants or proposed insured persons are obliged to truthfully answer an underwriting question related to the medical history of family members.

5.8 Proposed or existing insured persons will not be required to disclose the results of a genetic test undertaken by another person.

6 Genetic Testing and Claims Assessment

6.1 If, at the underwriting stage the criteria set out in paragraph 5.4 are satisfied, the insurer requests for the Predictive Genetic Test results from a proposed or existing insured person, such person for any reason fails to disclose any of the results of the Predictive Genetic Test that has been undertaken, such non-disclosure may have an impact on the assessment decision at the claims stage.

6.2 If, at the claims stage, non-disclosure of the results of such Predictive Genetic Test is discovered, whether such non-disclosure will be considered as material will be based on:

(a) The relevant practice at the time of underwriting, and
(b) Whether the claimant's Predictive Genetic Test results were obtained exclusively in the context of scientific research (including those obtained under the Hong Kong Genome Project).

7 Protection of Personal Information

7.1 Insurers will comply with the Hong Kong PDPO and related codes of practice, guidance notes and guidelines with regard to the collection, access, storage and usage of genetic test data.

7.2 Insurers will not share the genetic information obtained from any person with any other insurance company without prior, explicit and informed consent of that person, unless the information is required for the purpose of reinsurance or for detection/prevention of insurance fraud, and such transfer of information is permitted under applicable laws.

8 Revision to the Best Practice, Threshold and the List of Medical Conditions in the Annex

8.1 The HKFI will monitor the development of genetic testing around the world, with reference to the recommendations made by reputable organizations such as the Genetic Alliance UK[iii], research findings from medical researchers and the Hong Kong Genome Project or overseas insurance bodies. The Best Practice will also be reviewed regularly, or whenever new technologies or regulatory requirements necessitate.

8.2 The HKFI will keep the FHB up-to-date when it amends the Best Practice, and the List of Medical Conditions in the Annex.

8.3 The HKFI has overall ownership and responsibility for managing the List of Medical Conditions in the Annex. The HKFI will:

(a) Use the following criteria when formulating the original List of Medical Conditions and when considering the addition/removal of any genetic mutation/diseases to/from the list:
   i. The decision is supported by sound actuarial or other data from a reliable source;
   ii. The decision is applicable to the Hong Kong market/population;
(b) Seek independent advice from appropriate medical specialists (to be determined);
(c) Provide the date of the medical condition added to/removed from the List for the avoidance of doubt;
(d) Consider the comments from the FHB as to the final recommendations; and
(e) Review the List of Medical Conditions in the Annex regularly.

9 Transitional Provision

9.1 The HKFI recognises that in order to adhere to the Best Practice, Member Companies may require time to revise their own policy documents, put in control and processes, and provide education and training to the staff and distribution channels. A transitional period of 10 months from the Commencement Date (i.e. from 1 June 2020 to 31 March 2021) will therefore apply to this Best Practice. In the meantime, Member Companies may continue to employ the current Code issued by the HKFI in May 2005.

10 Commencement

10.1 The Best Practice shall take effect from 1 June 2020.

May 2020

DISCLAIMER:	The Chinese version is a translation of the original in English. In case of any discrepancy(ies), the English original will prevail.

Annex

<table>
<tr><th>Type of Insurance</th><th>Threshold of sum insured in the insurance policy above which Predictive Genetic Test results may be requested</th><th>Medical Conditions for which Member Companies may ask for and take into account the Predictive Genetic Test results</th></tr>
<tr><td>Life Insurance</td><td>HKD 5,000,000</td><td rowspan="2">*^Early-onset autosomal dominant Alzheimer disease (EOAD)
*^Hereditary breast and ovarian cancer syndrome
*Lynch syndrome/Hereditary non-polyposis colorectal cancer
*Autosomal dominant polycystic kidney disease (ADPKD)
^Huntington’s Disease (HD)
^Hypertrophic cardiomyopathy (HOCM)</td></tr>
<tr><td>Critical Illness Insurance</td><td>HKD 1,000,000</td></tr>
<tr><td>VHIS</td><td colspan="2" rowspan="2">Predictive Genetic Test results will not be asked for, or taken into account, regardless the level of coverage.</td></tr>
<tr><td>All other types of insurance</td></tr>
<tr><td colspan="3">*Reference: https://www.cia-ica.ca/docs/default-source/2016/216002e.pdf
^Reference: https://www.cia-ica.ca/docs/default-source/2014/214082e.pdf

(As of April 2020)</td></tr>
</table>

[i] What is genetic testing? National Library of Medicine (US). 2017 Dec 6 [cited 2017 Dec 11]. Available from: https://ghr.nlm.nih.gov/primer/testing/genetictesting

[ii] What are the types of genetic tests: National Library of Medicine (US). 2017 Dec 6 [cited 2017 Dec 11]. Available from: https://ghr.nlm.nih.gov/primer/testing/uses

[iii] Genetic Alliance UK. 2017 Dec 6 [cited 2017 Dec 11]. Available from: https://geneticalliance.org.uk/

《使用基因測試結果最佳行業準則》（最佳行業準則）

1. 前言

1.1 《使用基因測試結果最佳行業準則》（《最佳行業準則》）原為由香港保險業聯會（保聯）組成的基因工作小組於 2000 年 5 月首次制訂的《基因測試守則》（《守則》），《守則》於 2005 年 5 月再作修訂，並獲保聯所有壽險及一般保險會員認可。

1.2 隨著醫學昌明，尤其是自 2005 年起，基因科技相關的發展一日千里，故壽險總會於 2017 年 4 月開始檢討《守則》；及至 2017 年 12 月，保聯得悉香港特別行政區政府成立基因組醫學督導委員會（督導委員會），滙聚學術界、臨床醫學界和研究界別的專家，專責勾劃發展香港基因組醫學的策略。督導委員會建議應該針對保險相關的遺傳基因歧視問題，探討推出更多具體的規管措施。

1.3 在 2018 年 11 月，保聯聯同食物衞生局（食衞局）決定著手推行督導委員會的建議。保聯相信基因組醫學的發展將對推動醫學發展，以至及早介入治療，具長遠且正面的影響。而基因測試在診斷、預防和治療疾病或病症上，更是相當有用的工具。此外，市民亦不應因為擔心能否獲得保險保障，而無法享受基因測試所帶來的裨益。

1.4 建議會員公司細閱本《最佳行業準則》，同時參閱（但不限於）《保險業條例》（香港法例第 41 章）、《個人資料（私隱）條例》（香港法例第 486 章）、《殘疾歧視條例》（香港法例第 487 章）中的相關條文，以及保險業監管局（保監）發出的守則及指引。提醒會員公司在執行時，須遵守所有適用的法律、守則及指引，包括（但不限於）上述法例、守則及指引。

2. 引言

2.1 近年，許多國家已經就保險公司要求索取及使用基因測試結果，作審核保單申請之用，推出限制措施（自律規管或立法）。

2.2 自《守則》於 2005 年生效以來，大眾對基因測試的認知大大提升，而基因測試亦有長足的發展，故保聯相信現正是合適的時候，重新檢視使用基因測試結果的保險市場慣例的原則，藉以為投保人提供更佳的保障，以及有助投保人及受保人對保險業的市場慣例有更清晰的了解。《最佳行業準則》釐訂業界的立場，並制訂使用基因測試結果的指引，以維護自願性保險的主要基礎。保聯亦希望藉此就基因測試和保險的課題上，在保險公司與顧客的利益和標準之間，取得適當平衡。

3. 適用範圍

註冊有限公司 Incorporated with limited liability
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3.1 本《最佳行業準則》的適用範圍涵蓋有關在保險活動上使用基因測試結果，包括（但不限於）核保和理賠。

3.2 謹此建議所有保聯會員公司遵守本《最佳行業準則》。為免疑慮，本《最佳行業準則》只適用於使用基因測試結果，以進行與現任及準受保人相關的保險活動；而並非擬就醫學測試、醫學治療或其他以治療為目的的方法，提供任何建議。

3.3 《最佳行業準則》適用於所有香港居民（包括［但不限於］在港持有有效工作簽證的居民）。

3.4 不論《最佳行業準則》任何規定，就自願醫保計劃認可產品：a）不論投保人或受保人所投保的保障級別、身體狀況或其遺傳易感性，保險公司均不能要求索取預測性基因測試結果，亦不能參考任何此等結果；b）保險公司只可以根據本《最佳行業準則》第 5.2 段（詳見下文），要求索取診斷性基因測試結果。為免疑慮，假如自願醫保計劃屬附加保障，則保險公司必須遵守食衞局發出的相關要求，並須遵守《最佳行業準則》有關自願醫保計劃發出的保單的相關部分。

4. 釋義

4.1 與保險業有關的基因測試指分析人類脫氧核醣核酸或染色體的醫學測試種類，以檢測與病症[i]相關的基因資料的變更或差異。基因測試結果或可核實臨床醫學上的懷疑、判斷某人對某種病症的易感性，或協助預測某人的基因將發展成為遺傳疾病或遺傳至下一代的機會。

4.2 市場上有許多不同類型的基因測試，最常見的測試[ii]包括：

(a) 診斷性基因測試

診斷性或確定性基因測試可鑑定或確定某位已顯露症狀人士的特定基因或染色體狀況。陽性測試結果指發現有問題基因或染色體異常引致病狀。陰性測試結果指並沒有發現存在有問題基因或染色體異常，可排除檢測人士懷疑患上病症的推斷。

(b) 預測性基因測試

預測性或症狀發生前基因測試用以偵測可增加出生後或隨後在人生中患上遺傳疾病風險的基因突變或變異。此等測試對家屬有遺傳病歷史，但在測試時沒有任何徵狀的人士有幫助。陽性測試結果指發現有問題基因，而檢測者日後發展為病症的機會率將增加。陰性測試結果指並沒有發現有問題基因或染色體異常，而檢測者日後形成病症的機會率相對較低。

根據基因變異而預測被檢者對某種疾病易感或相對風險的基因測試，亦可被視為預測性基因測試。

(c) 攜帶者測試

攜帶者測試指被測者携帶有一個基因突變，而當這個基因成對出現時則會發病。此類測試用於檢測具有遺傳病家族史的人士，以及具有較高特定遺傳病風險的某些族群人士。假如父母二人均接受測試，則測試可為夫婦二人日後懷有患上基因疾病子女的風險，提供資料。

(d) 藥物遺傳學測試

此類基因測試用於判斷基因差異對藥物代謝及反應的影響，並可為處方個人藥物劑量及選擇用藥作指引。

(e) 產前測試

產前基因測試用於孕婦分娩前偵測胎兒的基因或染色體改變，此類測試用於檢測有較高風險懷有基因或染色體異常胎兒的夫婦。

4.3 就本《最佳行業準則》而言，基因測試指診斷性基因測試和預測性基因測試，蓋此兩類測試是保險公司評估保單風險最相關的測試。

5. 基因測試及核保

5.1 保險公司將不會為核保而要求、迫使或強迫準投保人進行基因測試。

5.2 在不違背第 5.1 段及受制於第 5.3 段的前提下，假如投保人曾經進行診斷性測試，則保險公司可要求索取有關測試結果，作核保用途。

5.3 任何情況下，假如基因測試是作科研用途，包括與香港基因組計劃有關的測試，則保險公司將不會要求索取任何類型的基因測試結果，作核保用途（不論是診斷性或預測性的基因測試亦然）。

5.4 在不違背第 5.1 段及受制於第 5.3 段的前提下，就人壽保險和危疾保險，假如曾經進行預測性基因測試，則保險公司須同時符合以下兩項條件方可要求索取該預測性測試的結果，作核保用途：

(a) 投保的保單類別為終身保障，而保額超逾附件中臚列的保額門檻；以及

(b) 要求索取的有關病症 / 基因屬於附件中臚列的項目

5.5 就不符合第 5.4 段所列的條件之人壽保險和危疾保險，以及所有自願醫保計劃認可產品及其他保險產品，保險公司將不會要求索取任何預測性基因測試的結果。

5.6 儘管第 5.5 段所述，惟假如投保人自願提供相關的資料，保險公司也可使用預測性基因測試的結果進行核保，而相關的測試結果將對投保人的核保結果較為有利。舉例說：假如投保人披露了其家屬成員曾患乳癌的病歷，並自願提供測試 BRCA1 或 BRCA2 基因的陰性測試結果，則保險公司可使用相關的結果進行核保。

5.7 保險公司不會向準受保人或現任受保人索取或使用其親屬的任何基因測試結果，作核保之用。然而，為免疑慮，投保人或準受保人有責任如實回答有關家族成員病歷的核保問題。

5.8 準受保人或現任受保人不會被要求披露第三者已進行的基因測試結果。

6 基因測試與保險理賠

6.1 假如在核保階段中，符合第 5.4 段所列的條件，保險公司要求索取準受保人或現任受保人的預測性基因測試結果，而該人士因任何原因而無法披露曾經進行的任何預測性測試結果；該等未有披露的資料在理賠階段可能對理賠決定有影響。

6.2 假如在理賠階段，發現有未披露的預測性測試結果，將按以下原則，斷定該等未被披露的資料是否重要事實：

(a) 核保時慣用的相關原則，以及
(b) 索償人的預測性基因測試結果是否只可以從科研（包括從香港基因組計劃）中獲取。

7 保障個人資料

7.1 保險公司將遵守《香港個人資料（私隱）條例》和與收集、查閱、保存和使用基因測試資料相關的守則、指引和準則。

7.2 未得當事人在明確知悉的情況下表示同意之前，保險公司不會將獲取的基因資料與其他保險公司分享，除非該等資料必須用作再保險用途，或者用以偵測 / 預防保險詐騙，以及按相應的法例許可轉移該等資料。

8 修訂《最佳行業準則》附件中的門檻和病症名單

8.1 保聯將密切留意全球的基因測試發展，同時參考著名組織所作的建議，例如：英國基因聯盟組織（Genetic Alliance UK[iii]），由醫療研究員、香港基因組計劃或海外保險組織所作的研究結果等。本《最佳行業準則》將定期或按最新科技或所需的規管要求作出修訂。

8.2 如附件中的病症名單有所修訂，保聯將會向食衛局提供最新的修訂資料。

8.3 保聯擁有及負責管理附件中的病症名單，並將：

(a) 在制訂現有病症名單和考慮增刪病症名單中的任何基因突變 / 病症時，使用以下準則：
    i. 有合理的精算數據或來源可靠的其他數據支持該決定；
    ii. 該決定適用於香港市場 / 人口。
(b) 尋求相關專科醫生的獨立意見（有待確定）；
(c) 為免生疑慮，提供從病症名單中增刪病症的日期；

(d) 考慮食衞局的意見，並作為最終建議；以及

(e) 定期檢討附件中的病症名單。

9 過渡性條文

9.1 為了遵守本《最佳行業準則》，會員公司可能需要一段時間以完成修訂其保單文件、將之納入規管和行政程序，以及向職員及銷售團隊提供教育及進行培訓。因此，本《最佳行業準則》將於生效日起計 10 個月內訂為過渡期，即 2020 年 6 月 1 日至 2021 年 3 月 31 日。在此期間，會員公司應繼續沿用保聯於 2005 年 5 月發出之現有《守則》。

10 生效日期

10.1 《最佳行業準則》於 2020 年 6 月 1 日起生效。

2020 年 9 月

備註：此為中文譯本，如中、英文版本有任何抵觸或不相符之處，應以英文版本為準。

附件

<table>
<tr><th>保險類別</th><th>可要求索取預測性基因測試結果的保單保額門檻</th><th>會員公司可要求索取或參考預測性基因測試結果的病症</th></tr>
<tr><td>人壽保險</td><td>港幣 5,000,000</td><td rowspan="2">*^早發性常染色體顯性遺傳阿爾茲海默症
*^遺傳性乳癌及卵巢癌綜合症
*連氏綜合症/遺傳性非瘜肉結直腸癌
*體染色體顯性多囊性腎臟病
^亨廷頓舞蹈症
^增生性心肌病變</td></tr>
<tr><td>危疾保險</td><td>港幣 1,000,000</td></tr>
<tr><td>自願醫保計劃</td><td colspan="2" rowspan="2">不論哪種保障級別，保險公司均不可要求索取或參考預測性基因測試結果</td></tr>
<tr><td>所有其他保險險種</td></tr>
<tr><td colspan="3">*參考資料: https://www.cia-ica.ca/docs/default-source/2016/216002e.pdf
^參考資料: https://www.cia-ica.ca/docs/default-source/2014/214082e.pdf

(截至 2020 年 4 月)</td></tr>
</table>

[i] What is genetic testing? National Library of Medicine (US). 2017 Dec 6 [cited 2017 Dec 11]. Available from: https://ghr.nlm.nih.gov/primer/testing/genetictesting

[ii] What are the types of genetic tests: National Library of Medicine (US). 2017 Dec 6 [cited 2017 Dec 11]. Available from: https://ghr.nlm.nih.gov/primer/testing/uses

[iii] Genetic Alliance UK. 2017 Dec 6 [cited 2017 Dec 11]. Available from: https://geneticalliance.org.uk/