



Association of British Insurers

## **2008 COMPLIANCE REPORT AND DATA ANALYSIS**

# **ABI CODE OF PRACTICE, MORATORIUM AND CONCORDAT ON GENETIC TESTS AND INSURANCE**

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## INTRODUCTION

The Association of British Insurers (ABI) Code of Practice on Genetic Testing (the Code) sets out the standards governing insurers' access to, and use of, predictive genetic test results. Since the launch of the Code in December 1997, the industry has been self-regulated.

The ABI runs an annual exercise to check how member companies are complying with the Code, and the Concordat and Moratorium agreed with the Government. A further exercise is run each year on the statistical data of all cases where a genetic test result is disclosed to an insurance company.

In agreement with the Department of Health, the Human Genetics Commission has seen and commented on this report.

This paper summarises the 2008 results of these exercises and reports insurers' compliance with the Code, Concordat and Moratorium. The data analysis cannot be used for any other purpose, such as to identify trends in genetic testing because the data is not collected for that purpose and is therefore incomplete. The data is only compiled from people applying for long-term insurance and insurers do not request data on genetic test results that predict the likelihood of a condition developing, with the exception of Huntington's Disease for Life cover greater than £500,000.

**Part 1** of the paper reports on companies' compliance with the Code of Practice during 2008.

**Part 2** of the paper summarises the number and types of genetic test results that were disclosed to insurers during 2008.

## PART ONE

### COMPANIES' COMPLIANCE WITH THE CODE OF PRACTICE

Under paragraph 6 of the Code, the Chief Executive of each insurance company must certify annually to the ABI that their company has complied with the Code, and give details of how compliance has been achieved. This paper describes the process and the results in respect of the year 2008.

#### Summary of the results

The results of the 2008 compliance exercise indicate that all the ABI member companies for whom the Code was relevant were compliant with the Code during 2008.

#### Process

The ABI sent a questionnaire to all long-term protection companies in December 2008. All companies responded and Chief Executives signed a declaration that the answers accurately reflected their company's behaviour.

#### Results

All companies responded and the ABI received 55 returns, some of which covered more than one company, so in total 86 companies were reported. Of those, 8 were reinsurers and 5 were entirely closed to new business. The remaining 42 answered questions about their policy on genetic test results.

#### A. OVERALL APPROACH

A1 Question: Did you ask anyone to undergo a genetic test in order to obtain insurance?

All 42 respondents declared that they were complying with the provision at item 6 of the Code that "applicants will not be asked to, nor be put under any pressure to, undergo a predictive genetic test in order to obtain insurance."

A2 Question: Did you ask any applicants to disclose any genetic test results in 2008?

2 respondents said that they had asked applicants to disclose genetic test results during 2008. 40 respondents said that they had not asked any applicants to disclose any such results.

A2a Question: If 'yes' were the test results requested Diagnostic or Predictive?

2 respondents had asked 2 applicants to disclose genetic test results during 2008 that were Diagnostic.

A3 Question: Did you receive any genetic test results (positive or negative, predictive or diagnostic, relevant or irrelevant) during 2008?

30 respondents said that they had received at least one genetic test result during 2008. 12 respondents said that they had not received any such results.

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- A4 Question: Was it your policy during 2008 to take into account relevant negative/normal genetic test results, potentially overriding a rating due to family history?

37 respondents said it was their policy to take into account relevant negative/normal genetic test results. 5 respondents said this was not their policy, that is, they did not use such results. Insurance companies differ in their policies, ethos and composition, from Friendly Societies to banks and church initiated firms, specialist insurers to generalist insurers. The compliance exercise is undertaken to confirm compliance with the Code and does not seek the reasoning behind the insurer's policy decision.

- A5 Question: How did you publicise your policy on favourable genetic test results during 2008, as required under the concordat?

The majority of respondents used more than one method. 76.2% publicised their policy on favourable genetic test results on their application form. 45.2% used their website. 19% used advisers. 16.7% used other methods (for example, customer letters).

- A6 Question: Did you have a nominated genetics underwriter (NGU) during 2008?

All but 1 respondent indicated they had a NGU. In this case, the respondent did not medically underwrite and would not receive medical / genetic information.

- A7 Question: Did you have a backup NGU to cover absences of the NGU?

All but 1 respondent indicated that they had a deputy NGU during 2008. In this case, the respondent did not medically underwrite and would not receive medical / genetic information.

- A8 Question: Did you have systems in place to identify potential breaches of the Code and/or moratorium, to investigate them, and to rectify any actual breaches and ensure they could not recur?

All 42 respondents said that they had procedures in place to identify and investigate potential breaches of the Code, and to rectify any actual breaches they found.

- A9 Question: Was it your policy during 2008 to ignore all positive/adverse genetic test results, even where the use of those tests had been approved by GAIC (i.e. even those which you were permitted to use under the moratorium)?

14 respondents said it was their policy to ignore all positive/adverse genetic test results, even those that they would be allowed to take into account under the moratorium, whatever the source. 28 respondents said that this was not their policy. Please refer to Question A4 for further explanation.

### B. INSURANCE PRACTICE

- B1 Question: During 2008, did you use genetic test results in preferred lives underwriting?

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All respondents said they did not use genetic test results in preferred lives underwriting.

- B2 Question: Did you have procedures in place to monitor how your NGU complied with the Code?

All but 1 respondent had procedures in place to monitor how the Nominated Genetics Underwriter complied with the Code. In this case, the respondent did not medically underwrite and would not receive medical / genetic information.

- B3 Question: Did you have procedures in place to monitor how all other staff affected by the Code complied with it?

1 respondent did not have procedures in place to monitor how all other staff affected by the Code complied with it. In this case the NGU underwrote all applications and no other staff would be affected by this work. The respondent confirmed they did not receive nor use genetic test results.

### C. SECURITY AND CONFIDENTIALITY

- C1 Question: Did you have a written confidentiality policy in place during 2008? (If 'Yes', did your policy use the ABI guidelines in annex 3 of the Code as a benchmark?)

All respondents confirmed that they had a written confidentiality policy in place. 1 respondent said they had not used the ABI guidelines within the Code as a benchmark. The 1 respondent confirmed they did not receive nor use genetic test results in the underwriting process.

- C2 Question: Did you have procedures in place to ensure that sensitive personal information, including genetic test results, was only accessible to those staff who needed to see it?

All respondents confirmed that they had procedures in place to ensure that sensitive personal information, including genetic test results, was only accessible to staff that needed to see it.

- C3 Question: Did you have a procedure in place to monitor compliance with your company's confidentiality policy?

All respondents confirmed that they had procedures in place to monitor compliance with their confidentiality policy.

### D. EDUCATION AND TRAINING

- D1 Question: Did your compliance department have mechanisms in place to ensure that your NGU was fully aware of, and fulfilled, all of his/her responsibilities under Part 4 of the Code?

All but 1 confirmed they had mechanisms in place (either in the Compliance or another department) to ensure their NGU was aware of and fulfilled their responsibilities under the Code. The 1 respondent did not have an NGU because they did not medically underwrite and received no medical / genetic information. 5 respondents confirmed they had mechanisms in place that sat

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in areas other than the Compliance department i.e. Head of Customer Services / Underwriting, and independent audit process.

- D2 Question: Did you provide training and information to relevant staff, other than the NGU, to ensure that they could reasonably be expected to understand the Code as it applied to them, and their responsibilities under it?

All but 2 respondents provided training and information. 1 respondent did not use medical underwriting and would not receive medical / genetic information. 1 respondent did not receive nor use genetic information and had all applications underwritten by the NGU so other staff were not affected by this work.

- D3 Question: Did you nominate someone as the internal contact point for genetic queries?

All respondents nominated someone as the internal contact point for genetic queries.

- D4 Question: Did you have procedures in place to identify and, as necessary, incorporate into your underwriting process, relevant new information on genetics?

All but 3 respondents had procedures in place. The 3 respondents confirmed they did not receive nor use genetic test results.

### E. UNDERWRITING

- E1 Question: How did you communicate to customers and others your implementation of the genetics moratorium?

All but 2 respondents said they had communicated the ABI moratorium to their customers. The 2 respondents confirmed they did not use genetic information in the underwriting process and had not received genetic information. Because of the products offered, investment finance and group, the customers of the two respondents would not expect any medical underwriting. One respondent's main business is investment finance. The insurance is an added benefit for the investor and this is not medically underwritten i.e. the respondent takes the risk of insuring an individual without medical underwriting because the insurance is an extra for the customer. One respondent only writes life business for employee group policies that have no medical underwriting even though normal practice in group insurance is for amounts over group scheme 'free cover' limits to be individually underwritten. The respondent does not write for individual policies that would have medical underwriting.

There were multiple responses: 45.2% companies used their website, 85.7% used their applications forms, 66.7% used the GP Report, and 21.4% had used other methods, such as, letters to customers.

- E2 Question: Do you have a log, as required under the Code, that you always use to record the details of all genetic test results that were disclosed in connection

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with applications for insurance that you received during 2008? (Code, point 7.1)

All respondents that received genetic test results kept a log for 2008. 2 respondents did not routinely hold a log because they did not receive, and do not use, genetic test results. Of these 2 respondents, during 2008 1 respondent had outsourced the underwriting function to underwriters that do hold a log. 1 respondent will set up a log, in case genetic tests are inadvertently received.

### F. COMPLAINTS AND APPEALS

- F1 Question: During 2008, did your company's complaints procedure explicitly take account of the particular requirements within the Code for dealing with complaints relating to disclosure and use of genetic test results?

38 respondents stated that their complaints procedure had explicitly taken account of the requirements of the Code. 4 respondents did not receive nor use genetic information. The 4 respondents were compliant with FSA complaints requirements and were aware of, and would apply the requirements of the Code but had not explicitly detailed this.

- F2 Question: Who in the company would determine whether a complaint involved an alleged breach of the Code?

26 respondents said the NGU would be involved. 14 respondents said the Chief Medical Officer would be involved. 3 respondents said the Chief Executive Officer would be involved. 22 respondents said a combination of staff members, or another staff member would be involved. The other staff members were Chief / Senior Underwriter, Director / Head of Underwriting / Claims, Compliance Department, Quality Assurance and Complaints Department, Legal Officer, Genetics Compliance Officer, Director of Customer Care, Customer Relations Officer, Complaints Controller, and Head of Compliance and Technical Services.

- F3 Question: If a complaint under the Code exhausted your internal complaints procedure, was it your policy to send a final written decision letter?

42 respondents confirmed that if a complaint about an alleged breach of the Code had exhausted their internal complaints procedure, it was their policy to send a final written decision letter.

- F4 Question: At what stage did your complaints procedure require that a complainant was informed of their right to refer their complaint on to the independent adjudication process?

All respondents confirmed the complainant was informed of their right to refer a complaint at the latest when the company's final decision letter was provided. 7 respondents confirmed that a complainant would have been informed of their right when the complaint was first received.

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F5 Question: How many complaints under the Code did your company receive during 2008?

No complaints were received.

## PART TWO

### ANALYSIS OF GENETIC TEST RESULTS DISCLOSED TO ABI MEMBER COMPANIES

#### EXECUTIVE SUMMARY

The results of the 2008 survey indicate that:

- The number of all genetic test results disclosed in 2008, at 2191, was higher than in previous years. (table 1)
- The number of adverse/positive genetic tests used to predict future illness that was disclosed in 2008 was 391. This was higher than in 2007 at 271, 2006 at 203, and 2005 at 53. (table 7)
- The number of applications with adverse/positive genetic tests used to predict illness that were declined / postponed in 2008 was 54 (13.8% of 391). More people were declined / postponed in 2008 than in 2007 at 39 however, as a percent of the total adverse/positive tests used to predict illness received this was lower than in 2007 at 14.4% of 271. (table 7)
- The number of applications with adverse/positive test results used to predict illness that were accepted at ordinary rates in 2008 was 145 (37.1% of 391). More people were accepted at ordinary rates in 2008 however, as a percent of the total predictive adverse/positive test results received this was lower than in 2007 at 41.7% of 271. (table 7)

#### INTRODUCTION

1. The ABI Code of Practice on Genetic Testing (the Code) regulates the behaviour of insurance companies who belong to the ABI when dealing with any genetic test information disclosed to them by an individual applying for insurance. Insurers are bound by the Concordat and Moratorium, agreed with Government.
2. The Code requires that insurers maintain a log of applications that contain a genetic test result. The ABI collects this information annually to establish how many genetic test results are disclosed to insurers, and to establish how genetic test results affect the underwriting of insurance applications.
3. The data is collected via an electronic annual survey that is sent to all ABI member companies selling long-term insurance business.
4. The numbers below are small, compared to the overall levels of long-term insurance business carried out in the UK over the survey period. The industry sold over 2.5 million new protection products in 2008. Less than 0.09% of those policies included individuals for whom the insurer received a genetic test result. This percentage does not indicate the number of applicants who had a genetic test because applicants do not need to disclose genetic test results that predict the likelihood of a condition

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developing, with the exception of Huntington's Chorea for Life cover greater than £500,000.

### KEY RESULTS

- The total number of genetic test results disclosed to insurers in 2008 was 2191. There was an increase of 16.7% in the number of genetic test results disclosed to insurers from 2007 to 2008.

**Table 1 tests disclosed for all conditions - by year**

Year	Total number of tests disclosed to insurers	Number of tests for 'named' conditions	Number of tests for 'other' conditions
2008	2191	505	1686
2007	1871	443	1428
2006	1567	438	1129
2005	1322	373	949
2004	1061	348	713
2003	731	308	423
Total	8743	2415	6328

- The total number of test results in 2008 was made up of 505 test results for 'named conditions' and 1686 test results for 'other' conditions.
- The number of test results for 'other' conditions increased by 18.06% from 2007 to 2008, 26.48% from 2006 to 2007 and 9% from 2005 to 2006. Information about 'other' conditions is in paragraphs 28 - 30.

**Table 2 tests disclosed for named conditions - by year**

Year	Tests disclosed for named conditions						Total
	HD	BRCA	FAP	MD	MEN	HMSN	
2008	124	219	41	80	12	29	505
2007	132	163	47	74	9	18	443
2006	128	140	67	75	5	23	438
2005	123	127	42	55	4	22	373
2004	127	93 <sup>1</sup>	28	70	13	17	348
2003	116	61	44	69	4	13	307
Total	750	803	269	423	47	122	2414

**Table 3 test results - by named condition**

Condition	Test result			
	Total	Adverse (positive)	Favourable (negative)	Ambiguous
Huntington's Disease	124	32	90	2
BRCA1	111	48	60	3
BRCA2	63	26	37	0
BRCA not known if 1 or 2	45	5	34	6
Familial adenomatous polyposis	41	18	20	3
Myotonic dystrophy	80	35	44	1
Multiple endocrine neoplasia	12	9	3	0
Hereditary motor and sensory neuropathy	29	20	9	0
Total	505	193	297	15

<sup>1</sup> 2004 was the first year the category BRCA (not known if 1 or 2) was included

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8. The number of disclosed test results for Huntington's Disease reduced by 8 to 124 in 2008 from 132 in 2007.
9. The number of disclosed test results for all BRCA increased by 56 to 219 in 2008 from 163 in 2007.
10. While most results were favourable, the proportion of adverse results for named conditions increased from 119 adverse and 300 negative in 2007.

**Table 4 test results that were predictive, diagnostic, carrier, or 'don't know' - by named condition**

Named condition	Test result									
	Predictive		Diagnostic		Carrier		Don't know		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
Huntington's Disease	112	90.32%	9	7.25%	0	0%	3	2.41%	124	24.55%
Breast / ovarian cancer - BRCA1	98	88.28%	7	6.30%	2	1.80%	4	3.60%	111	21.98%
Breast / ovarian cancer – BRCA 2	57	90.47%	4	6.34%	1	0.90%	1	0.90%	63	12.47%
Breast / ovarian cancer – BRCA 1/2	35	77.77%	5	11.11%	1	2.22%	4	8.88%	45	8.91%
Familial adenomatous polyposis	24	58.53%	13	31.70%	1	2.43%	3	7.31%	41	8.11%
Myotonic dystrophy	38	47.50%	26	32.50%	14	17.50%	2	2.50%	80	15.84%
Multiple endocrine neoplasia	8	66.66%	2	16.66%	1	8.33%	1	8.33%	12	2.37%
Hereditary motor and sensory neuropathy	5	17.24%	24	82.75%	0	0%	0	0%	29	5.74%
Total	377		90		20		18		505	
	74.65%		17.82 %		3.96%		3.56%		100%	

11. For the named conditions, there was an increase in the number of predictive test results to 377 in 2008 from 356 in 2007.

**Table 5 predictive test results that were adverse, favourable, or ambiguous - by named condition**

Named condition	Test result		
	Adverse (positive)	Favourable (negative)	Ambiguous
Huntington's Disease	28	82	2
BRCA1	42	53	3
BRCA2	22	35	0
Not known if BRCA1 or BRCA2	2	29	4
Familial adenomatous polyposis	5	17	2
Myotonic dystrophy	6	32	0
Multiple endocrine neoplasia	6	2	0
Hereditary motor and sensory neuropathy	3	2	0
Total	114	252	11

12. For the named conditions, there was an increase in the number of adverse test results to 114 in 2008 from 77 in 2007 and a reduction in the number of favourable test results to 252 in 2008 from 263 in 2007 and ambiguous test results to 11 in 2008 from 16 in 2007.

## USE OF TEST RESULTS IN UNDERWRITING

**Table 6 underwriting decision by test result - for named conditions**

Underwriting decision	Adverse (positive)		Favourable (negative)		Ambiguous		Total	
	No.	%	No.	%	No.	%	No.	%
Decline/postpone	51	26.4%	32	10.8%	3	20.0%	86	17.0%
Accept at ordinary rates	46	23.8%	159	53.5%	2	13.3%	207	41.0%
Accept with loadings	63	32.6%	49	16.5%	8	53.3%	120	23.8%
Accept with exclusions	16	8.3%	18	6.1%	0	0.0%	34	6.7%
Offer revised terms	11	5.7%	26	8.8%	1	6.7%	38	7.5%
Application not completed	6	3.1%	12	4.0%	1	6.7%	19	3.8%
Pending - None selected	0	0.0%	1	0.3%	0	.0%	1	0.2%
<b>Total</b>	<b>193</b>	<b>100.0%</b>	<b>297</b>	<b>100.0%</b>	<b>15</b>	<b>100.0%</b>	<b>505</b>	<b>100.0%</b>

13. The underwriting decisions reflect factors other than genetic test results for the named condition, such as family history, personal medical history including other medical conditions and lifestyle factors such as smoking. This helps to explain why 32 of 86 applicants that were declined (37.2%) had favourable (negative) test results.
14. Of those applicants accepted at ordinary rates (207), 76.8% had favourable (negative) test results, 0.96% had ambiguous test results, and 22.2% had adverse (positive) test results.
15. Of those applicants accepted at or offered other than standard rates or terms (192), 48.4% had favourable (negative) test results, 4.6% had ambiguous test results, and 46.8% had adverse (positive) test results.
16. The percentage of applications that were declined increased by 6.2 to 17% from 10.8% in 2007. The percentage of applications with an adverse (positive) test result increased by 11.3 to 38.2% in 2008 from 26.86% in 2007. The percentage of applications accepted at ordinary rates reduced by 5.7 from 46.7% in 2007. The percentage of applications accepted with a loading decreased by 3.7% from 27.5% in 2007. The percentage of applications offered revised terms rose by 1 from 6.5% in 2007. The percentage of applications not completed declined by 0.9% from 4.7% in 2007.

**Table 7 underwriting decision for predictive adverse (positive) test results – for all conditions**

Underwriting decision	No. of results
Decline/postpone	54
Accept at ordinary rates	145
Accept with loadings	124
Accept with exclusions	30
Offer revised terms	24
Application not completed	14
<b>Total</b>	<b>391</b>

17. Table 8 refers to the year predictive tests were first taken. A total of 962 predictive test results were disclosed in 2008, for named and 'other' conditions. Of these, 70.0% (674) included the year the test was taken.

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**Table 8 year the test was taken – for predictive tests disclosed in 2008 – for all conditions**

Year	No. of results
1980-1994	50
1995-1999	109
2000-2004	214
2005-present	301
None selected	288
Total	962

**Table 9 route by which tests were first disclosed in 2008 – for all conditions**

Route	No. of results
Customer e.g. as part of their application form	605
GP e.g. as part of their GP Report	1501
Other medical adviser e.g. as part of their Independent Medical Report	24
Other	61
Total	2191

18. Most test results were disclosed by the GP (68.5%). The customers disclosed 27.6% of the test results. Both the application form and the GP Report form state that predictive genetic test results should not be disclosed. Other cases include e.g. the application form and the GP Report combined as the source of the disclosure.

### HUNTINGTON'S DISEASE (HD)

19. GAIC approved the use of positive predictive test results for HD for life insurance applications. Their use is subject to the £500,000 financial limit imposed by the moratorium.

**Table 10 HD type of test – by test result**

Type of test	Test result			
	Adverse (positive)	Favourable (negative)	Ambiguous	Total
	No. of results	No. of results	No. of results	No. of results
Predictive	28	82	2	112
Diagnostic	3	6	0	9
Don't know	1	2	0	3
Total	32	90	2	124

**Table 11 HD underwriting decision for favourable (negative) test results**

Underwriting decision	No. of results
Decline/postpone	7
Accept at ordinary rates	50
Accept with loadings	17
Accept with exclusions	4
Offer revised terms	6
Application not completed	6
Total	90

20. 77 of the 90 applications with favourable results (85.5%) were accepted or offered revised terms. 55.5% were accepted at ordinary rates, 30.0% were accepted with non-standard terms, and 6.7% were offered revised terms. 6.7% did not complete the application and 7.8% were declined or had their application postponed. People with a favourable result for HD could have

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other conditions that lead to non-standard terms being offered or the application being declined.

**Table 12 HD underwriting decision for adverse (positive) test results– by type of test result**

Underwriting decision	Type of test result			
	Predictive No. of results	Diagnostic No. of results	Ambiguous No. of results	Total No. of results
Decline/postpone	5	2	1	8
Accept at ordinary rates	1	0	0	1
Accept with loadings	17	1	0	18
Accept with exclusions	1	0	0	1
Offer revised terms	3	0	0	3
Application not completed	1	0	0	1
<b>Total</b>	<b>28</b>	<b>3</b>	<b>1</b>	<b>32</b>

21. Of the 28 adverse predictive test results, 22 were accepted or offered revised terms.

**Table 13 HD underwriting decision of ‘other than standard rates’ for adverse (positive) predictive test results, that were or were not affected by other factors**

Underwriting decision affected by other factors	No. of results	%
Yes	26	100
No	0	0
<b>Total</b>	<b>26</b>	<b>100</b>

22. 26 of the 28 adverse predictive test results had underwriting decisions that were affected by other factors. Of the remaining 2 decisions, 1 application was accepted at ordinary rates and the other application was not completed.

**Table 14 HD underwriting decision – by test result**

Underwriting decision	Test result			
	Predictive No. of results	Diagnostic No. of results	Ambiguous No. of results	Total No. of results
Decline/postpone	13	2	1	16
Accept at ordinary rates	48	3	1	52
Accept with loadings	32	3	0	35
Accept with exclusions	5	0	0	5
Offer revised terms	9	0	0	9
Application not completed	5	1	1	7
<b>Total</b>	<b>112</b>	<b>9</b>	<b>3</b>	<b>124</b>

23. 41.9% of all applicants who disclosed HD test results were accepted at ordinary rates, 12.9% were declined or the decision was postponed, 5.6% did not complete the application process and 39.5% were offered non-standard rates.

### FAMILIAL BREAST / OVARIAN CANCER

24. There were 219 test results for BRCA1, BRCA2, and BRCA (not known if 1 or 2) in 2008. There were no GAIC approved BRCA tests. Any test result disclosed to insurers was not taken into account. Where test results were disclosed a breakdown of underwriting decisions is shown in the tables below.

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**Table 15 BRCA1, BRCA2, BRCA (not known if 1 or 2) type of test – by test result**

Type of test	Test results			
	Adverse (positive)	Favourable (negative)	Ambiguous	Total
	No. of results	No. of results	No. of results	No. of results
Predictive	66	117	7	190
Diagnostic	8	7	1	16
Don't know	2	6	1	9
Carrier	3	1	0	4
Total	79	131	9	219

25. Of the 79 adverse results, 8 were diagnostic and 66 were predictive.

**Table 16 BRCA1, BRCA2, BRCA (not known if 1 or 2) underwriting decision for adverse (positive) predictive test results**

Underwriting decision	No. of results
Decline	11
Accept at ordinary rates	33
Accept with loading	28
Accept with exclusions	5
Offer revised terms	1
Application not completed	1
Total	79

26. Of the 79 adverse predictive test results, 34 had underwriting decisions at anything other than ordinary rates. For these, the underwriting decision could be affected by factors, such as personal medical history.

**Table 17 BRCA1, BRCA2, BRCA (not known if 1 or 2) underwriting decision - by type of test**

Underwriting decision	Type of test				
	Predictive	Diagnostic	Carrier	Don't know	Total
	No. of results	No. of results	No. of results	No. of results	No. of results
Decline	21	6	1	3	31
Accept at ordinary rates	93	3	1	2	99
Accept with loadings	45	7	0	4	56
Accept with exclusions	15	0	1	0	16
Offer revised terms	12	0	0	0	12
Application not completed	3	0	1	0	4
Pending/postponed	1	0	0	0	1
Total	190	16	4	9	219

### 'OTHER' CONDITIONS

27. The design of the questionnaire was such that less underwriting information was collected on 'Other' conditions. Of the 1686 'Other' conditions 585 test results were predictive and 821 test results were diagnostic.

28. The conditions within this group that had a large number of test results were Factor V Leiden with 272 test results and Haemochromatosis with 346 test results.

29. 394 test results were within the sub-category of 'other' where conditions were not identified; being listed as, for example, 'chromosome analysis', test for cancer', 'not clear but done due to pregnancy', 'unknown'.

## GENETIC TESTING AND INSURANCE

**Table 18 test results that were predictive, diagnostic, carrier, or 'don't know' – by 'Other' conditions**

	Predictive	Diagnostic	Carrier	Ambiguous	Total
Adult Polycystic Kidney Disease (APKD)	5	1	0	0	6
Antitrypsin - alpha	22	29	6	8	65
Alpha Thalassaemia	3	1	0	2	6
Alport's syndrome	4	2	0	0	6
Anderson Fabreys Disease	4	1	1	0	6
Balanced Recipricol Translocation	0	1	0	1	2
Muscular Dystrophy - Becker	2	4	1	0	7
Bowel cancer	41	6	1	1	49
Cadasil	2	4	0	0	6
Cerebellar Ataxia	1	2	0	0	3
Muscular Dystrophy - Charcot Marie Tooth disease	5	13	0	0	18
Congenital Adrenal Hyperplasia	0	0	0	0	0
Cystic Fibrosis	15	8	39	2	64
PMP-22 Gene	0	1	0	0	1
Muscular Dystrophy - Duchenne's	5	2	2	0	9
Dystonia	1	2	0	0	3
Factor V Leiden	116	131	4	21	272

## GENETIC TESTING AND INSURANCE

	Predictive	Diagnostic	Carrier	Ambiguous	Total
Familial Hypokalaemic Paralysis (FHP)	0	0	0	0	0
Familial Juvenile Hyperuricaemia	0	1	0	0	1
Muscular Dystrophy - Fascio scapulo humeral, FSH	0	1	0	0	1
Fragile X Syndrome	7	3	4	1	15
Friedreich's Ataxia	5	16	3	0	24
G6PD deficiency	0	0	0	0	0
Gardener's Syndrome	0	0	0	0	0
Gilbert's Syndrome	0	4	0	0	4
Haemochromatosis	107	200	20	19	346
HNPP	1	15	0	0	16
Hereditary Spastic Paraplegia - spastin	1	5	0	0	6
HLA	0	0	0	0	0
Hereditary Non-polyposis Colorectal Cancer (HNPCC)	22	5	0	1	28
Cardiomyopathy	4	7	0	0	11
Klinefelter's syndrome	0	1	0	2	3
Leber's optic neuropathy/atrophy	0	7	0	0	7
Long QT wave syndrome	2	5	0	0	7
Marfan's syndrome	4	9	1	0	14

## GENETIC TESTING AND INSURANCE

	Predictive	Diagnostic	Carrier	Ambiguous	Total
MTHFR	7	11	0	1	19
Muscular Dystrophy - not myotonic, Bethlem, myopathy, distal spinal, limb girdle	19	17	9	1	46
Neurofibromatosis	1	1	0	0	2
Ovarian Cancer	0	0	0	0	0
Polycystic Kidney Disease (PKD)	5	1	6	0	12
Porphyria	4	4	1	0	9
Pressure Palsies	0	0	0	0	0
Prothrombin	31	53	0	5	89
Retinitis Pigmentosa	0	0	0	0	0
Translocation - Robertsonian	0	0	1	1	2
Spinal Muscular Atrophy	0	0	0	0	0
Tay-sachs disease	3	0	5	1	9
Tuberous Sclerosis	2	4	1	0	7
Von Hippel-Lindau disease	10	10	1	0	21
William's syndrome	0	0	0	0	0
Wilson's disease	0	0	0	0	0
Hypercholesterolaemia - familial	1	3	1	1	6
Other	111	200	49	34	394
JAK	0	18	0	0	18
Translocation disorder	2	1	2	2	7

## GENETIC TESTING AND INSURANCE

	Predictive	Diagnostic	Carrier	Ambiguous	Total
Haemophilia	1	0	9	0	10
Adrenoleukodystrophy	1	0	0	0	1
Sickle Cell	3	1	1	1	6
Maturity Onset Diabetes of Youth (MODY)	0	0	0	1	1
Prostate Cancer	2	1	0	0	3
Turner's Syndrome	0	3	2	1	6
Gorlin's Syndrome	1	1	0	0	2
Thalassaemia	2	5	2	1	10
<b>Total</b>	<b>585</b>	<b>821</b>	<b>172</b>	<b>108</b>	<b>1686</b>