Response to the consultation by the Association of British Insurers on their Code of Practice for Genetic Tests

The BSHG welcomes the opportunity to respond to the consultation.

Our comments are as follows:

Section D 6. Principles on which the code is based.

We suggest that throughout the code a consistent terminology is used to describe in words the results of a genetic test and specifically the ambiguous terms ‘positive’ and ‘negative’ are not used and as suggested elsewhere in the text the terms ‘adverse’ or ‘mitigating’ are adopted.

We suggest the adoption of a term linked to the effect of a test on the interpretation of a pre-existing family history or symptom of an inherited condition for example in 6.2 and 6.3 delete (positive). Paragraph 6.2 would read:

‘Insurers may only take into account adverse results of those predictive genetic tests that the Genetics and Insurance committee (GAIC) has decided are technically, clinically and actuarially relevant.’

We suggest 6.4 reads:

‘…Insurers should publish their policy in respect of mitigating genetic test results.’

Section 11.5 This section would be clearer if the plural form is not used e.g. line 6 ‘applicants’ and line 7 ‘their.’ We suggest that ‘his or her’ is substituted.

Question 1. We agree with the statement in Question 1 that insurers may communicate directly to the applicant if the person has been counselled following the genetic test and the result is disclosed and its implications discussed with them.

Question 2. We agree that the arbitration process set out in annexe 4 is adequate.

Question 3. We agree that the timescale for the complaints procedure is reasonable.

Question 4. The role of the CMO is adequately described. We note bullet point 5 the requirement to consult a genetic specialist.