GenoMEL
the Melanoma Genetics Consortium

# GenoMEL's ethical guidance

GenoMEL is an international research consortium. It pools information, samples and other resources to increase our understanding of the genetics of melanoma. This document is intended as a general ethical guide, not as an alternative to detailed consideration of each individual research proposal. The relevant authorities overseeing such research must approve all research protocols.

1 Information sheets and consent forms should be clear and comprehensive.

2 Research participants should be offered general results. This can be via newsletters, the GenoMEL website or other means.

3 Research participants should be informed whether or not the researchers intend to offer any individual results from the research. Sometimes their ethical approval does not allow them to offer such results and sometimes they do not have the resources to do so. It is for individual research groups, with the help of their local ethics bodies, to decide if such feedback is appropriate.

4 For participants with whom direct contact is made, researchers must obtain informed consent to collect, store and use their information. In contrast, research involving information concerning people who have died, or involving pre-existing data may not require informed consent. The relevant regulatory authorities overseeing patient orientated research must approve such exceptions.

5 For participants with whom direct contact is made, researchers must obtain informed consent to collect, store and use their tissue samples (such as blood) for genetic research. The relevant regulatory authorities must approve any exceptions to this, for example research involving pre-existing samples.

6 Where possible, participants should be told how long their information/samples will be kept. This does not mean that there has to be a time limit on retention, only that the participant should receive such information.

7 All information and samples must be stored and protected appropriately – see the GenoMEL data protection requirements for details. Standard practice should be to link-anonymise* samples and data.

8 Participants should be advised that their data and samples might well be shared with other national or international groups. Where data and samples are shared internationally this should only be in a link-anonymised* way.

*When something is ‘link-anonymised’ it is known by a code. This means, for example, that a sample sent to another country will have a code written on it rather than a person’s name. The name of the person to whom the code refers stays with the original group of researchers.