



Genetic Alliance UK policy on good research practice

- 1.1 Genetic Alliance UK has adopted the UK Research Integrity Office's (UKRIO) Code of Practice for Research "Promoting good practice and preventing misconduct", published in September 2009 (the "Code"). The Code can be downloaded at www.ukrio.org.
- 1.2 All staff involved in research and its management are expected to uphold the Principles detailed in section 2 of the Code.
- 1.3 All researchers are expected to follow the "Recommended checklist for researchers" (on the inside front cover of the Code) when designing, conducting and finishing research projects.
- 1.4 Researchers and their managers will create a 'project file' for each new research project, which will be updated as the project progresses. The top paper will be the checklist. Corresponding documents or notes for each question on the checklist should be included in the project file (see Annex 1).
- 1.5 Genetic Alliance UK supports the principles of the "Concordat to Support the Career Development of Researchers: an agreement between the funders and employers of researchers in the UK" (the "Concordat"), published in 2008, while recognising that the size and resources of GAUK limit its ability to comply with all the specifics of the Concordat.
- 1.6 Genetic Alliance UK adopts the Code's definition of misconduct as detailed in section 3.16 of the Code. Genetic Alliance UK's procedure for dealing with allegations of misconduct in research is detailed in Annex 2.
- 1.7 Managers involved in research will use the procedure detailed in Annex 3 to identify, declare and address any conflicts of interest before any research project begins.



Annex 1

Documents and notes to be included in each project file along with the “Recommended checklist for researchers”.

Before conducting your research

Most questions in this part of the checklist can be evidenced by including in the file:

- the successful funding application.
- the ethics review application (NHS or university) (nb Q4c may require a separate note to be made if not all issues are covered in the funding or ethics applications)
- a note about any other guidelines the research will fall under, outside the ethics review.
- a note that the Genetic Alliance UK health and safety policy has been consulted, and the safety of the researcher has been addressed in the ethics review application.
- a note of which organisation is providing the funding, and stating that its monitoring requirements will be fulfilled. All Genetic Alliance UK accounts are audited.
- a copy of any related contracts (e.g. collaboration agreements with academic or other partners).
- a note of any conflicts of interest that have been identified and how they have been addressed (see Annex 3)

While conducting your research

Questions in this part of the checklist can be evidenced by adding to the file:

- notes from any progress meetings
- a note of how data is being stored.
- any formal progress reports.

When finishing your research

Include in the file copies of any publications arising from the research.



Annex 2

Genetic Alliance UK's procedure for dealing with allegations of misconduct (outlined below) is based on the UKRIO's "Procedure for the Investigation of Misconduct in Research".

- a) Allegations are formally reported to the Named Person (NP). The NP is the Director, Alastair Kent, unless he has any conflict of interest, in which case the Chair of Trustees will be the designated alternate.
- b) NP reviews allegations and takes any required actions to avoid risk to health and safety, patients etc, and refers to Genetic Alliance UK's disciplinary procedure (and other internal processes as required) if the Respondent is a Genetic Alliance employee. NP also ensures any contractual obligations to funding bodies, partner institutions etc are fulfilled (e.g. informing them of the allegations where appropriate).
- c) If the Respondent is not a Genetic Alliance UK employee, NP informs primary employer where appropriate.
- d) NP informs Respondent of the allegations against them and assesses the allegations.
- e) If the allegations appear to be upheld, NP convenes a meeting of the Genetic Alliance UK Board of Trustees. Trustees decide whether to dismiss allegations; refer to disciplinary or other internal procedure; address allegations via education, training and supervision; or investigate further.
- f) If Trustees decide further investigation is required, they may invite external expertise to participate as appropriate to ensure a comprehensive, fair and timely investigation is carried out. If the investigation uncovers evidence of misconduct by others or misconduct by the Respondent that is unconnected with the allegations under investigation, such allegations should be submitted to NP. Trustees decide what action to be taken if the allegations are upheld in part or in full. Any action should be in line with the Genetic Alliance UK disciplinary procedures.

Steps a through d should be completed in 10 working days.

Step e should normally be completed within 40 working days.

Step f will have no set timetable.



Annex 3

Genetic Alliance UK's procedure for identifying, declaring and addressing conflicts of interest

- A conflict of interest can arise where particular circumstances might affect an individual's judgement in making any decision that affects Genetic Alliance UK.
- Conflicts may arise due to personal, social, financial or business interests or ethical considerations, and be related to a variety of situations, such as the recruitment of staff, receiving funding from particular individuals or organisations, issuing contracts to suppliers of goods or services etc.
- Examples of conflicts of interest that might affect research at Genetic Alliance UK:
 - A part-time member of staff wishes to sign a consultancy contract with a pharmaceutical company which precludes work with other pharmaceutical companies. Genetic Alliance UK meanwhile accepts a research grant from a pharmaceutical company for a project in which the staff member will be involved.
 - A researcher has a financial interest in a company sponsoring his/her research project.
 - A staff member has a personal or family relationship with an individual applying for a research post.
- It is the responsibility of all staff and researchers to recognise and disclose activities which might give rise to conflicts of interest, or the perception of conflicts of interest (which can be as damaging) and to ensure proper management of those conflicts.
- Where deciding if a conflict of interest may arise is difficult, advice should be sought from the line manager or Director.
- Management of conflicts of interest in most cases may be limited to making a brief written declaration which is kept on file, but in some circumstances active management may be required, such as:
 - Not taking part in discussions or decisions relating to certain matters;
 - Not acting as supervisor to particular individuals;
 - Not taking part in certain projects;
 - Making a declaration to a particular sponsor or third party.
- In cases where the decision about management is difficult, they should be referred to the Genetic Alliance Board of Trustees.