

## Guidance for Applicants

The following sections provide additional guidance on specific topics that may be relevant to applicants.

### Invitations

Applicants requesting an introduction to Study participants have a wider responsibility when they or their staff are dealing with participants.

When a research study is approved to invite our participants to join their study, the invitation will be sent by Imperial College as correspondence from the Airwave PI. It will provide copies of, or pointers to, that study's REC-approved materials relating to the study. Should the participant wish to join the study, they will need to contact the Applicant directly.

### Feedback to Individual Participants

The content of any feedback sent by a study shall be stated clearly within the protocol of each study. In general, applicants are encouraged to make available measurements taken in the presence of the participants, such as height, weight, blood pressure, etc. They may also choose to disclose subsequent results, such as laboratory assays or the results of other analyses, if it is reasonably certain that the benefits of disclosure clearly outweigh any possible risks to the participants or their families. This will arise when three conditions are met:

- There is clear indication of an existing health problem.
- Any health problem identified would be amenable to referral to a relevant specialist.
- The participant has indicated beforehand that they wish to be notified if such a problem is identified.

In providing feedback, studies should present sufficient supporting information that the recipient can assess whether their result suggests that they should consult their primary care provider. Often this will be by providing the reference-range for the assay. Other information relating to the assay may also be provided, such as links to reliable resources on the Internet.

We want participants to be informed about the significance of their results, but researchers cannot take the place of primary care providers. We are not aware of all the factors affecting a participant's test results, and so we cannot give specific advice.

Applicants should make clear that participants will not be provided with feedback on assays, re-interpretations of results, or other assessments that may be conducted in the future.

### Feedback to Participants as a Whole

We are committed to communicating the outcomes of research to members of the cohort and the wider community. This means providing accurate, dependable, and engaging interpretations of research results that are accessible to a general audience with no specialist scientific knowledge.

The main purpose is to demonstrate to cohort members the value of the contribution they make in remaining active members, and to keep them informed of progress on the Study. We also aim to inform the wider public on the developments in science, given that most research is paid for by public money.

We therefore request that, at the conclusion of each research project, the PI writes a summary of their results for a general audience. The Airwave Study team may publish these reports on our website and in other general

communications, making modifications to improve clarity by agreement. Reasonable embargo conditions will be respected.

## Questions Relating to Invitations

In certain circumstances, a participant may respond to an invitation to join a particular study with questions relating to the reason for the invitation. This may happen, for example, where a study interested in a certain health-condition has invited participants whose existing genotype is believed to confer high susceptibility to the condition. Usually, the invitation will not disclose whether the invite is because they are part of the susceptible group or a control group. However, the invitee may already have reason to be concerned about their own susceptibility, perhaps because of diagnoses occurring to blood relatives.

In these cases, neither the applicant nor the Airwave Study itself should disclose further information regarding the reason that a participant was included as part of the invitation. This applies whether the participant chooses to join the study or not.

## Publications

As part of their substudies we expect applicants to place all research findings in the public domain via publication in peer-reviewed literature.

Pre-publication drafts of papers should be submitted to DAC for comment according to the terms of the Data Access Agreement of the TRE where the research was conducted. For researchers using CSRE – Imperial's local TRE – the DAC should be notified at least four weeks in advance of intended publication.

Applicants should notify the DAC if, in their opinion, there is a reasonable chance that their publication is likely to generate publicity amongst the wider public. DAC may then request the applicant provide a summary of their research in a form suitable for consumption by a lay audience via the Study website.

DAC may request the applicant delay submission of a publication for up to three months where, in its opinion, exceptional circumstances apply. Any such delay must be explained to the applicant in writing, and its duration must be no longer than is necessary.

## Acknowledgements

Whether or not members of the Airwave research team are co-authors on a paper, publications arising from the use of the Airwave study should acknowledge use of Study data and other resources, including the contribution made by funders. Please contact the secretary of the DAC for specific forms of words to use, which may vary according to the specific datasets used.

The cohort was established by multiple funders, and it is a requirement that their contributions, as well as that of the participants, are acknowledged in any papers published using our data or samples. Please write to the DAC Secretary for the form of words to use.

## Safe Outputs

Publications – including materials for internal consumption – and presentations must confirm to a disclosure control policy that ensures there is negligible risk of any member of the cohort being identified in results.

It is the responsibility of the researcher to produce safe outputs. Researchers must use their knowledge from the ONS Safe Researcher Training course (and other relevant training) to make a best endeavours

commitment to ensure analytical outputs are anonymous before submitting them for review. Tables highlighting fewer than 10 participants in any aggregated result should be suppressed.

Applicants should respect the consents provided by study participants. Applicants should respect any special conditions made by third parties who have contributed to the Airwave resource and from which the applicant's research has benefitted.

## Sharing Methods

Applicants may be asked to make available to the wider Airwave research community derived data, computer codes and other methods resulting from or generated by their work using Airwave data. Reasonable embargo periods will be respected, and research teams will be acknowledged by any subsequent researchers making beneficial use of their work.