

# DETERMINANTS OF ADOLESCENT (NOW ADULT) SOCIAL WELL-BEING AND HEALTH STUDY (DASH)

## GUIDANCE ON USE OF DATA BY EXTERNAL RESEARCHERS: COMPLETING THE APPLICATION FORM

### Section 1: The proposal

Please complete the data access application form and attach a 1-2 page proposal of your research plans, which specifies the research questions addressed, the analytical strategy and the set of variables to be used.

### Section 2: Research Governance

The MRC is working towards compliance with the Research Governance Framework. To this end, all projects drawing on the DASH data are required to identify the organisations and individuals who will hold key roles in the project's governance – the principal investigator, sponsor, employer and funder – and who will undertake the associated responsibilities as set out in the Framework. All projects employing DASH data will be jointly sponsored by the MRC SPHSU to ensure appropriate and ethical use. Collaborative projects analysing the existing DASH data do not require further ethical review; however, if this is a requirement of the applicant(s)' institution they are required to ensure such approval is gained.

Although the Unit Director, will formally act as sponsor, she will be supported in this role by the DASH Steering Committee and day-to-day responsibility for overseeing the use of the data will be delegated to a link person.

#### Link Person

One of the core [DASH researchers](#) will act as a link person for the project. If an application is not building on an existing collaboration, a link person will be identified by the Principal Investigator on the basis of interests, experience, capacity etc. This person will be responsible for providing the data, supporting analyses, contributing to publications and co-ordinating the feedback of findings and the return of the data at the end of the project.

### Section 3: Data requirements

Your proposal should specify the subset of variables required for the project. This should be documented as part of the application, and if further variables are required in due course this may require a further application. The data should not be used for any purpose other than stated in the proposal. An application for change or extension of use can be made to the Data Access Group via the link person.

Data provided for the use of external researcher(s) remains the property of the MRC at all times. The external researcher(s) will be responsible for maintaining secure storage of data or files provided, for ensuring the confidentiality of any personal information on these files, and for ensuring that no data are passed on to any third party at any time. No attempt should be made to identify individuals from the dataset.

The external researcher(s) will also be obliged to abide by the requirements of the SPHSU's policies on data protection and confidentiality and data management, by the [MRC's guide to the handling of personal information in medical research](#) and by the [MRC's guide to good research practice](#).

All data provided to external researchers are anonymised and the identity of the participants should not be disclosed. If this is not possible analyses must be conducted in-house. Applicants must not attempt to identify individual respondents. Data for each individual project will be supplied with a random ID number system so that data cannot be combined across different projects to create possible deductive disclosure possibilities.

External users of the data must adopt the same level of data security as is upheld within the Unit:

- DASH data and related syntax files should be stored on password protected network drives (to ensure regular back up and security). PCs should have automatic password lock features to ensure their security.
- All data transferred between SPHSU and external researchers, and vice versa, can be sent on a CD or data pen or by email. However, whatever mode of transfer adopted, all data transferred must be encrypted during transfer, and if posted should be sent by registered mail, couriered or hand delivered.
- If MRC data are to be stored on a laptop while held by external researchers, the device must be encrypted and password protected. In this case information on the encryption software should be included in your application.
- At the end of the project the dataset should be destroyed.

Please note it is not possible to share data on DASH participants obtained from the NHS with external researchers (such as inpatient records) unless they have received PAC approval for their use. Neither is it possible for external researchers to contact DASH participants except via the DASH team (and where respondents have given their consent) and with ethics committee approval.

## **Section4: Outputs**

### **a) Publications**

The Steering Committee are keen to see the work undertaken by or for external researchers leading to publications. Unless otherwise indicated, it will be assumed that this means joint publication with one or more members of the core DASH team (usually the link person). Normally, it will be the case that the external researcher takes the lead in writing up (literature review, etc.) and therefore is entitled to be first author(s). However, authorship should be discussed on a paper by paper basis and based on the Unit's policy on authorship (attached). Please note MRC policy requires all papers to be published in Open Access journals.

In exceptional circumstances, the link person and/or other DASH Steering Committee members reserve the right to disagree with the conclusions of the external researchers and withdraw their names from any publication. This would not necessarily preclude external researchers from publishing in their own right. Although we reserve the right to veto publication in certain circumstances, for example, to prevent deductive disclosure or if it is felt publication might jeopardise future waves of interviews, such consent will not be unreasonably withheld.

**All** presentations and publications based on DASH data, and any associated media contact, must have the **prior** approval of the Director of the Unit.

All publications based on analyses of the DASH must include an acknowledgement of the Study as follows:

*The DASH Study is funded by the UK Medical Research Council and the data were originally collected by the MRC Social and Public Health Sciences Unit (MC\_US\_5TK00\_DASH). Information on how to apply for access to the data can be found at: <http://dash.sphsu.mrc.ac.uk/Data-sharing.html> We are grateful to all the participants in the Study, to the survey staff who conducted the study and for the support of the community representatives. The data are employed here with the permission of the DASH Steering Committee (Project No. XXX). XXXX are also funded by the MRC (MC\_5TK00\_XXXX).*

#### **b) Derived variables**

Derived variables created by the external collaborator, which may be of wider value to users, should be returned to the study together with appropriate documentation (e.g. coding frames or syntax used).

### **Section 5: Monitoring Progress**

The link person is responsible for maintaining contact with the external researcher(s) and identifying and reporting back any problems encountered. The extent of involvement and/or frequency of contact will largely depend on the interest of the link person and the agreed working practices. In any case all projects will be reviewed by the Steering Committee on an annual basis.

### **Section 6: Agreement form**

The external researcher(s), their head of department and the link person should sign the attached agreement form, indicating they have understood and will meet these obligations.

Failure to uphold this agreement may result in further access to DASH data being denied.