

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

## Data Sharing Policy Version 1, November 2012

We are committed to maximizing the use of DASH data to advance knowledge to improve human health and welcome proposals for collaborative projects from bona fide researchers. Our policy reflects the [MRC guidance on data sharing](#). We have developed this data sharing policy with the aim of making data as widely and freely available as possible while safeguarding the privacy of participants, protecting confidential data, and maintaining the reputation of the study. We welcome comments on this policy.

**For further information contact: Seeromanie Harding, Principal Investigator, [s.harding@sphsu.mrc.ac.uk](mailto:s.harding@sphsu.mrc.ac.uk) or Oarabile Moloadi, research scientist, [o.moloadi@sphsu.mrc.ac.uk](mailto:o.moloadi@sphsu.mrc.ac.uk) A message can be sent to both of us simultaneously via [DASH@sphsu.mrc.ac.uk](mailto:DASH@sphsu.mrc.ac.uk)**

### BACKGROUND TO THE STUDY

The broad aim of DASH is to investigate the extent to which socio-economic, psychological, environmental and biological factors contribute to ethnic variations in health and well-being at different stages of the life course. It focuses on change and stability in key social and environmental influences on health e.g. economic disadvantage, racism, family life and social support, neighbourhoods.

DASH started in 2002/03 with 6643 11-13y olds (1236 White British, 725 White Other, 946 Black Caribbean, 1107 Black African, 493 Indian, 631 Pakistani and Bangladeshi, 937 Other) in 52 schools in 10 London boroughs. They were followed up (72% response rate) in 2005/06, at ages 14-16y.

The cohort is now in their early 20s and around 81% of the baseline sample has been traced via postal, electronic and web-based strategies, including social networking sites. DASH has had high response rates in conventionally thought 'hard to reach' populations, has a range of longitudinal social, psychosocial, and health measures, and has the largest longitudinal samples of ethnic minority young people in the UK. We are in the process of conducting a feasibility study to assess the possibility of a face to face follow-up in their 20s and how best to collect the data, including for the first time a range of bio-marker data.

Further information about the study can be found in the [DASH cohort profile](#) published in the International Journal of Epidemiology or on the [DASH study website](#).

Full variable level information from the study is available from the study team.

### 1. PRINCIPLES OF DATA SHARING

**1.1** Applications from bona researchers to use existing DASH data are welcome. All potential collaborators work with a link person, an experienced DASH researcher – to support their application and access to the data. It is

assumed such collaboration will lead to a joint publication. In line with MRC policy, all publications should be in Open Access journals.

**1.2** All collaborators are required to abide by MRC's policies on managing personal data, not pass on the data to a third party or attempt to identify individuals. At the end of the project all DASH data must be returned to the Unit and any copies destroyed. The confidentiality and potential for statistical disclosure of all data requests are assessed. Where potentially sensitive data are necessary, external collaborators will be required to conduct the analyses at SPHSU. Collaborative projects analysing the existing DASH data do not require further ethical review; however, if this is a requirement of the applicant's institution, then they are required to ensure such approval is gained.

**1.3** The following criteria are employed to consider applications: The research question(s) proposed should aim to develop understanding of how to improve human health, be of good scientific value and ethically and legally sound.

- The analytical techniques proposed should be appropriate and robust and DASH data should be able to address the question(s).
- The skills and experience of the applicant(s) should be appropriate to undertake the project.
- There should be an intention to publish the research findings for wider scientific scrutiny and benefit in open access journals.
- The DASH resources required to create the necessary dataset for the project should be reasonable.
- If the research question overlaps with an existing (external or internal) project, the researchers concerned will be encouraged to collaborate rather than make a separate application.

**1.4** No charge is made for providing data to external users. If a particularly time consuming request is received, for example, requiring inputting and coding of significant amounts of data, then external funding would need to be found to support such work.

## **2. GOVERNANCE FOR DATA SHARING**

**2.1** DASH has an external [Steering Committee](#) set up according to MRC guidelines i.e. it has formal terms of reference; more external than internal members and an independent external chair.

**2.2** The Steering Committee has oversight of the data sharing process. Applications to use the data are assessed and approved by the [study team](#) and Principal Investigator. Once approved internally the application is sent to the Steering Committee Chair for final approval.

**2.3** Applications which might be considered sensitive will be discussed by the full Steering Committee. If appropriate, additional external advice may be sought. If applicants wish to appeal against the decision on their proposal this will also be considered by the full Steering Committee. If applicants are still unhappy with the decision or process then the matter will be referred to the MRC Programme Manager within Head Office.

**2.4** An annual report is made to the Steering Committee of the external enquiries received, applications made and their outcome, progress with internal and external projects, publications produced, etc.

### **3. PROCESS OF DATA SHARING**

**3.1** A contact email address ([DASH@sphsu.mrc.ac.uk](mailto:DASH@sphsu.mrc.ac.uk)) is given on both the Unit and MRC gateway websites, while other publicity (e.g. the IJE cohort profile) contains the Principal Investigator's contact details. We endeavour to reply to an initial enquiry within one week.

**3.2** External users are required to complete an [application form](#) to access the data. The researchers concerned and the Head of the Department that will hold the data are required to sign the form to say that they will abide by the terms and conditions of use as set out in the declaration form and associated policies.

**3.3** Once an application has been received, it will be reviewed by the internal study group, and data security issues (e.g. confidentiality, possibility of deductive disclosure) will be discussed with the applicants. Data are not released externally if they allow the possibility of identification of individuals within the study. Potentially sensitive data e.g. schools, postcodes, are therefore only provided at a highly aggregated level. We aim to complete the review process in a month. Any issues will be discussed with the applicants so the application can be revised if necessary.

**3.4** The final decision to release the data is made by the Chair of the DASH Steering Committee and the Principal Investigator. Overall therefore the application process should be completed in six weeks.

**3.5** Once an application has been approved, the application is signed by the Principal Investigator and Unit Director and an approval letter is sent to the applicants which confirms the terms of the agreement.

**3.6** A dataset is then created for the project. Currently we estimate this will take a week per wave of data collected, although more time may be required if complex derived variables are requested which have not previously been constructed. A set of random ID numbers is allocated to the project and documented. This ensures that if external researchers have several ongoing projects they cannot combine datasets together in ways that could potentially lead to possible breaches of participant confidentiality.

**3.7** As well as a dataset we also provide external users with notes outlining key issues with variables requested, e.g. coding information, issues re. inconsistencies over time, medications that need to be considered for physical measures and biomarkers, information on inverse probability weights for drop out if appropriate.

**3.8** All data transfers are encrypted.

**3.9** External users with ongoing projects are required to provide an annual progress report once a year to the steering committee. When a project is completed, external users are required to return the dataset and any documentation on derived variables to the DASH Study and destroy all local copies.

### **4. DATA DISCOVERY**

**4.1** Information about the DASH Study is publicly available in a number of places at two levels.

**4.2** Descriptions of the overall study and its availability for data sharing as well as details on who to contact for further information are available in:

- [IJE cohort profile](#)
- the [DASH study website](#)
- the [MRC data gateway](#)

**4.3** We are working towards generating metadata for the main DASH questionnaires to DDI 3 standards. Once variables directly extracted from the questionnaires are fully documented to the desired standards, we will begin work on documenting core derived variables.

**4.4** The variable level metadata is available from the study team. Once the MRC Data Gateway has established a system for importing metadata our variable level information will also be deposited on that website.

**4.5** The [DASH Study website](#) contains the following:

- Information for participants, teachers, parents and researchers in four sections
- Contact area for respondents to update their address details or provide comments/make queries.
- Copies of information and consent forms, questionnaires and protocols, including those for the feasibility study currently in progress
- A full list of publications.
- Information on data sharing
- DASH [Facebook link](#)

**Seeromanie Harding and Oarabile Mloadi**  
**Principal Investigator of DASH and Research Data Scientist, November 2012**