

Wirral Child Health and Development Study

Data Access Policy and Procedures

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1. Purpose of the Wirral Child Health and Development Study (WCHADS)

The Wirral Child Health and Development Study (WCHADS) is a longitudinal cohort study which recruited pregnant women aged 18 years and above at their 20 week scan appointment, in the antenatal clinic at Arrow Park Hospital, Wirral, Merseyside, between March 2007 and December 2008. Just under 70% of eligible families kindly agreed to take part in the study at that time and we have continued to follow their progress over time. Detailed information has been collected on these women, their first born child, and their partners using self-completion questionnaires, interviews, developmental and observational assessments and experimental research procedures. Teacher informant data was also gathered on child social, academic, behavioural and mental health functioning in school was gathered at age 7 and 9 years of age. The study has been funded by the Medical Research Council throughout. Ethical approval for the study was obtained from Local NHS Research Ethics Committees.

The study was designed to examine prenatal and infancy origins of conduct problems in children. As is evident from several of our publications (e.g. Tibu et al 2014, Vidal-Ribas et al 2017), many of the findings, especially of sex dependent mechanisms, are also of potential relevance to adolescent depressive disorders. The data may therefore also be of interest to researchers wishing to investigate childhood origins of depression.

The study shares features with other longitudinal studies with measurement in pregnancy, such as ALSPAC and Generation R, but is distinctive in having many and repeated measures of observed child, parent and interactive behaviours, infant and child physiology, cognitive abilities, and social cognitions. An outline of the study design and of progress with data collection up to age 9 years can be found by clicking on 'progress' on the study home page. Publications can be found by clicking on 'study publications'.

2. Purpose of the WCHADS Data Access Policy

The purpose of this document is to describe in detail the general processes and procedures involved in accessing the Wirral Child Health and Development Study dataset (defined as samples or data already collected). We welcome proposals for collaborative and external projects for *bona fide* research. We make data as widely available as possible while strongly protecting confidentiality, and making sure that we maintain the reputation of the study, its funders and its participants (see the <u>MRC definition</u>; please contact us if you are in any doubt as to whether you fit this definition). All proposals are reviewed by the WCHADS Executive Committee

This data access policy is in-line with the benefits of data sharing that scientists and data managers value:

- Enabling new research questions to be answered in existing data
- Promoting collaboration between different research teams and diverse disciplines
- Sharing of knowledge about best methods for data collection, linkage and analysis
- Ensuring that collected data are cleaned, well documented, with value added
- Independently verifying established research findings
- Development and testing of new research methods
- Using to best effect the gift of data made by study participants
- Data sharing therefore represents an efficient use of public money and supports more timely scientific discovery.

3. Data access procedure: Overview

3.1. Specific opportunities and priorities for sharing

We are very interested to share data with teams or investigators with overlapping interests, who wish to take analyses in a new direction. For example a Henry Wellcome Postdoctoral Fellowship holder is using WCHADS data to examine distinct infancy predictors of callous unemotional traits and autistic spectrum traits. We have a major emphasis on callous-unemotional traits and on clarifying psychopathology phenotypes, and the additional interest in autism was very welcome. Similarly an MRC Clinician Scientist award holder will use WCHADS data on deprivation to examine the role of health inequalities in child mental health. We are also very interested to work up research questions jointly with investigators who may then go on to lead the writing up for publication. Conversely where we have data that can inform investigation in new areas we will be very happy to consider applications. An example might include questions about parenting taking advantage of our repeated observational measurement of mother-child interactions.

We have several times added new measures in response to approaches for collaboration. For example we added eye tracking at age 7 years, to improve our understanding of children's responses to emotional faces in the context of callous unemotional traits and autistic traits. We also developed a new cyber-ball peer rejection paradigm at age 9 years, to improve measurement relevant to resilience. No new measurement at age 9 years can be added now as data collection is underway. However an application for funding for age 11, 12 and 14 assessments focusing on the emergence of depression in early adolescence has been made. If that is successful data collection will start in September 2019, and we would be happy to discuss additional measures over the preceding months, mindful of the need to make sure we don't create an unacceptable burden for our families.

3.2. The WCHADS dataset

We encourage and facilitate collaborative data sharing by all 'bona fide' researchers from all disciplines across the world to maximise use of the dataset. The process for accessing data is the same for all, regardless of research area, institution, location or funding source, provided the proposed research is not being carried out for personal or commercial gain.

All data requests will be curated according to the specific proposal received. A list of approved collaborative and independent external project proposals is available on the website; applicants are encouraged to check this to avoid unnecessary duplication of requests. The website describes the dataset available and is a useful place to start to give you a good idea as to whether WCHADS would be potentially valuable in addressing your research question. You are encouraged to contact the PIs in the first instance to have an informal discussion to determine whether the data gathered to date is available and therefore a formal application should be submitted.

A Data Dictionary in HTML format is available on request which contains all of the meta-data from the questionnaire phases from parents, teachers and children and can be searched by phase, measure or informant. We also have a detailed Excel spreadsheet which summarises all interview, observational, experimental, genetic and physiological data (in addition to the questionnaires). A set of procedures manuals also describe the methods used during face-face assessments. All are available on request via email to the study on <u>first.steps@liverpool.ac.uk</u>. We would ask that you also have a short conversation with the study investigators prior to requesting these documents as this will help in the initial planning

stages to orientate you to possible relevant domains of measurement that we hold and the readiness of this data. These documents will only be provided to *bona fide* researchers who understand the sensitive nature of the information.

Access to WCHADS research data must be requested using the formal procedures described in this document and is subject to eligibility, the WCHADS funder's terms and conditions, existing ethical approvals for the study and University of Liverpool policies and procedures.

3.3. Consent and ethical considerations

Informed consent was obtained when participants were initially recruited and repeated consents have been taken at different time points during the longitudinal study. Permissions were gained with the following restrictions: 'Information will only be used by members of the research team and scientific research collaborators from other academic institutions approved by us'. The procedures and safeguards described in this document are designed to ensure that data is shared in line with this consent.

3.4. Requesting access to data

Researchers are required to complete an Application for Data Sharing form, which can be downloaded from the website or requested by emailing <u>first.steps@liverpool.ac.uk</u>. This proposal should have clearly stated aims and hypotheses and describe the relevant exposure, outcome and confounders that will be considered, justifying the data you require. For multiple projects you must submit multiple forms; one per project. You will get a response within two months of submission to inform you of the outcome and you will receive advice on the next stages. In some cases, approval may not be possible due to the lack of relevant data. Most proposals will be reviewed by the Executive Committee, including an Independent Access Advisor, a person separate and independent of the study that can provide an unbiased opinion. The rules of public accountability operate, such that an external advisor plays no part in decisions in which they have an interest by virtue of their professional or other relationships.

The Executive Committee also reserves the right to impose additional restrictions as appropriate. The Executive Committee reserves the right to check that all objectives in the original proposal are completed by cross reference to publications and make any additional analyses that were in the initial proposal but that have not been published via letters to journals and / or on our website, in order to avoid publication bias.

If a researcher is seeking funds for their research from a funding body, the Executive Committee must receive the completed Application for Data Sharing at least one month prior to the submission deadline. It may not be possible to approve those received less than one month before the submission deadline. It is the responsibility of the researcher to ensure compliance with their funder's terms and conditions with respect to their use of WCHADS data and samples.

Supervisors are ultimately responsible for their PhD students in the same way that PIs are responsible for their researchers. We request that any proposals for PhD projects are therefore submitted by the supervisor rather than the student themselves.

An amendment to your original proposal (to be submitted via the same method as your original proposal) must be completed if any of the following changes during the course of your approved project:

• Significant extension of research scope;

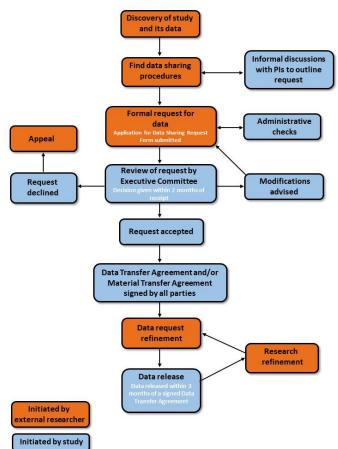
- End date;
- Researchers accessing the data;
- Change in institution;
- Any additional data required;
- Change of funding source.

3.5. Study response to a request for collaborative data access

You are strongly encouraged to make an informal approach to the study to discuss an independent project using WCHADS data or to discuss the possibility of a collaboration between the WCHADS team and yourself as a first step. This will ensure that the WCHADS dataset can feasibly be used to address the scientific question you would like to address. Information held on the study website and available on request regarding the scope of the WCHADS dataset can help inform this process. Once a formal request for data sharing has been made (i.e., Application for Data Sharing form submitted), the proposal will be reviewed by the Executive Committee within two months of receipt.

Once an application for data sharing has been approved, a Data Sharing Agreement must be signed by all parties. Data will be made available for sharing within three months of a signed data sharing agreement being completed.

The aim is to follow the process summarised in Figure 1 in line with MRC guidance.



Data-sharing request workflow

Figure 1. Summary of data access process

3.6. Conditions for secure management of confidential and sensitive information

All data from assessments are stored using a numerical identifier only and this data is secured in line with University of Liverpool and NHS guidelines. Data cannot be directly linked to identifying information held in the research base by anyone outside of the research team. Data are kept in locked, secure locations. All WCHADS data and associated study documentation is held on the Windows Managed Service in Liverpool University and is managed, stored and curated in keeping with the University's Information Security policy, which defines the preservation of confidentiality, integrity and availability and is informed by the principles set out in ISO 27001 and also complies with the Data Protection Principles set out in the General Data Protection Regulation (GDPR) EU2016/679. Formal security standards: General Data Protection Regulation EU2016/679, Data Protection Act 1998, MRC Information Security Policy, University of Liverpool Information Security Policy.

3.7. Charges for access to existing data and new data collection

WCHADS receives funding from the Medical Research Council to support core activities. This does not extend to providing support for additional individual projects and so the extent of the request for data will be considered and some proposals may be rejected due to lack of capacity to fulfil the request if funding is not available. A costing structure will be determined depending on the proposal. Once a proposal has been approved and the applicant informed of the cost these are **non-negotiable**.

If a researcher is seeking funds for their research from a funding body then you are strongly encouraged to include the costs of requesting data from the WCHADS dataset. Costs will be determined on a projectby-project basis and will reflect only the true costs to WCHADS of providing the datasets requested. Once a proposal has been agreed in principle an accurate costing will be provided. Data will not be provided until a data sharing agreement has been signed off by all relevant institutions.

3.8. Costs for grant proposals

If you are submitting a grant in order to cover the costs of the agreed research you must include fees for the curation of the WCHADS dataset that is in line with the Application for Data Access.

Any negotiations with funders regarding changes in requested funds must involve the PIs at all stages. The WCHADS team is happy to provide a letter of support once your research has been approved by us and the budget has been agreed.

3.9. Pre-access information

On occasion, researchers may require more detailed information than can be gleaned from the data dictionary for inclusion in grant proposals. These will be dealt with on case by case basis.

4. Management of the WCHADS dataset

The Principal Investigators of WCHADS are Professor Jonathan Hill and Dr Helen Sharp. Co-Investigators are Professor Andrew Pickles who is responsible for statistical analysis of WCHADS data, Professor John Quinn who is responsible for molecular biology work linked to the genetic material and Dr Chris Murgatroyd for who is responsible for epigenetic analysis of the genetic material. The various committees governing WCHADS are described below.

4.1. WCHADS Executive Committee (EC)

The sensitive nature of the data collected in WCHADS requires oversight from the PI group alongside an Independent Access Advisor. The WCHADS Executive Committee is responsible for the day to day management of the study and are responsible for safeguarding the data. The EC meets to consider the management of the study and publications, reviews all requests for data and makes decisions about access. The Executive Committee currently comprises Prof Jonathan Hill, Prof Helen Sharp, Prof Andrew Pickles, Prof John Quinn and Dr Chris Murgatroyd. The EC requests advice from the Independent Access Advisor where they are uncertain about a request, or consider there may be grounds to decline a request.

4.2. Independent Access Advisor

The Independent Access Advisor, Professor Barbara Maughan, provides an unbiased review where the EC requests assistance or there is the possibility of a request being declined.

4.3. Intellectual Property

The University of Reading and the University of Liverpool own the WCHADS datasets: any data generated and the biosamples collected. As such any formal requests to access the data must be made through the University of Liverpool and a data sharing agreement completed. Any data generated through an approved project must be returned to the dataset to encourage ongoing use by the research community.

5. Types of data and rules governing access

WCHADS collects data directly through questionnaires and a wide range of 'hands-on' assessments (cognitive, developmental, observational, experimental, and physiological). Data is derived from biological samples and other types of media collected, such as videos and audio files. An Excel spreadsheet is available which details the measures used and phases of study when individual measures were completed, and by which informant (child, mother, partner, teacher). Procedural manuals are also available which describe the methods used for laboratory based assessments during the study. A Data Dictionary is available which gives detailed measure and variable level information for all data collected via questionnaires. The scope of the dictionary is a work in progress and it will eventually include data collected from maternal interviews, child assessments and some other subsets of data which are currently summarised in the Excel spreadsheet. These documents are available on a request basis once informal discussions with the PIs have taken place and it is agreed that the scientific questions in your proposal might be addressed using the WCHADS dataset. The contents of the information gathered from families is sensitive in nature and so we do not make the full list of variables gathered publically available, rather this information is shared on request but limited to scientific researchers who will respect the nature of it. If you have any questions regarding data that is currently being collected or going through the preparation process, or general data queries, please email first.steps@liverpool.ac.uk. The study team are in the process of also uploading detailed metadata for the WCHADs study to the CLOSER DIRECTORY which is a searchable directory for studies on child development.

Proposals for access may be refused. Reasons for refusal include the following:

• Lack of availability of data/samples;

- Applicant not being a bona fide researcher (see Summary);
- The proposed work, in the view of the Executive Committee, risks bringing the study into disrepute;
- The proposed work risks disclosure of identifiable information relating to any individual participant;
- In the view of the Executive Committee there is a conflict of interest in relation to the proposed project.
- The proposed outputs of the project are outside the scope of the WCHADS ethical approval, funders' terms and conditions or the University of Liverpool's policies and procedures.

Any challenge against a refused proposal will be considered by the Independent Access advisor within a three month period.

5.1. Privileged use of data by the study team

The investigator team has privileged access to the study data for a period of 12 months following coding and cleaning. After this time period, formal requests for external projects using WCHADS data or collaboration with the WCHADS team on topics of mutual interest to the external researcher and the investigator team will be reviewed by the Executive Committee within two months of receipt. As outlined in Section 3.1 Specific opportunities and priorities for sharing, because of the focused hypothesis driven design of the study, and on the basis of previous experience, we expect requests commonly to be from researchers with similar or complementary interests. Where it is clear that a formal data sharing request is for a use that does not overlap with the study team's areas of interest, we will review the formal application as soon the relevant data is available for use (waiving the 12 month period of privileged access), and within the two month time-frame for review. Once an Application for data sharing has been approved, data will be made available for sharing within three months of a signed data sharing agreement being completed.

5.2. Questionnaire, assessment and biosample data

We ensure data collected by questionnaire and our hands-on assessments are made available as soon as possible after data coding and cleaning is complete (normally within 3 months). Non-genetic results obtained from biosamples can be made available as soon as all assays are completed. All potential identifiers will be removed from the dataset and disclosure risks will be considered. Data may be grouped where appropriate to preserve anonymity.

5.3. Genetic and epigenetic data

Maternal DNA was gathered from saliva once during the period of study. Child DNA has also been gathered and genotype data is available from the WCHADS participants for a number of candidate genes; DRD4, MAOA, 5HTTLPR and BDNF. GWAS analysis of WCHADS samples is not currently available. If you require bespoke genetics data not described above, please contact us prior to submitting a proposal to discuss your needs. Funding would have to be secured to facilitate further analysis of the genetic samples that have been gathered.

5.4. Accessing genetics data

Provision of genetics data requires a legally-binding agreement between the University of Liverpool and your host institution. This agreement is called a Data Transfer Agreement (DTA). An ethical amendment to approve the storage of WCHADS genetic samples at another location may also be required. For researchers based outside the University of Liverpool a Data Service Level Agreement (DSLA) is required. These forms differ in terms of the signatories required, not the access level received. A project specific appendix must be agreed before the agreements are signed. Genotype data cannot be released until fully completed forms have been received. Copies of the DTA and the DSLA are available on request from the Study Administrator and show the information that is required. Once your proposal is approved we will provide Word files with the specific appendix for you to complete, sign and return to us.

5.5. Potentially identifying data

Some of the data collected could allow study participants to be readily identified. These include personal details such as postcode and "free text" that could contain identifying information. The study team will not link any of these data directly to the WCHADS dataset. Instead a two-stage process is required if a researcher wishes to make use of any potentially identifying data. Firstly, the potentially identifying data are sent to researchers as a separate file with unique identifier but unmatched to any other data. Secondly, the researcher then derives any new variable that are less specific ensuring that they could not be used to identify an individual. These new variables are then returned along with accompanying documentation describing the derivation method(s) used to the appropriate data buddy. These new variables can then be added to the rest of the data request. Depending on the request, the Executive Committee may request that the researcher attend a meeting to explain their proposal in the context of the overall project and specific hypothesis being tested.

If a proposal requires detailed potentially identifying data (such as video files) to address a scientific question then a bespoke Material Transfer Agreement (MTA) must be completed before the data will be released.

5.5.1. Address data

The WCHADS team will not provide exact address or complete postcode data under any circumstances, due to issues of identifiability. Instead a range of derived administrative boundary variables are available. Each project proposal will be judged uniquely on its own merits and disclosure risk.

5.5.2. Free text data

Both questionnaires and interview datasets contain free text fields, where additional information not contained within the given tick box responses can be provided by the respondent. These data are not routinely coded and included in built/release files as different researchers may choose to use the data in different ways according to their specific needs. Researchers may request these text data and it will be provided once the appropriate charges have been paid. Researchers will be provided the text data with a unique 'TextID' attached that will not match to their existing dataset and given instructions on how to code the text data. Numerical variables returned can then be added to the existing dataset.

5.5.3. Date of birth

Complete dates of birth and other dates (e.g. interview date or questionnaire completion date) are not usually made available; only month and year are released as standard. The age at any data collection sweep is always computed and made available. Exact dates of birth will not be given to research collaborators. We recognise that there are times when this information is important for deriving variables such as season of birth variation in a particular measure. In these circumstances we will work with the researcher to correctly derive their variable as follows: (a) the researcher will be provided with a limited dataset containing a collaborator ID, pseudo date of birth, and any other essential data; (b) the researcher will use this dataset to write syntax that correctly generates any derived variables; (c) the researcher will send this syntax to the study team (in SPSS or Stata format) and (d) the WCHADS team will run the syntax to create the derived variables.

In situations where researchers provide a strong justification for needing complete date of birth throughout their main analyses (e.g. as a primary exposure, outcome or key co-variable) and the justification is agreed by the Executive Committee, a similar process to that described above will apply. Here the researcher would have to provide complete syntax for the all of their analyses in a form that the WCHADS team can use and the researcher would be provided with a full set of results. The real costs of doing this additional work will have to be paid in advance by the researcher and will vary on a case by case basis depending on the amount of work required by the WCHADS team.

6. Data Provision

6.1. The 'Data Buddy' process

When the Executive Committee has approved your project, a data buddy will be assigned to you. Your data buddy will assist you through the duration of your project; advising you on making your formal data request, administering the necessary paperwork (such as confidentiality forms and transfer agreements) and ultimately provide you with your dataset. They will not provide statistical, methodological or other support. Standard datasets are prepared within an agreed timeframe of all paperwork being completed; however some types of data may take longer.

6.2. Confidentiality form

Protecting the confidentiality of the study families is a primary concern of the PIs on the Executive Committee and the Independent Access Advisor. This is a particular issue as WCHADS is a regionally based study that recruited children born within a defined period. Bona fide research investigators and any member of their team who will directly access the data will be requested to adhere to a number of clauses regarding confidentiality (please see our confidentiality form – available on request).

6.3. Consent and Ethical considerations

The nature of consent at each phase of data collection has varied, meaning access to certain data may be restricted depending on the consent that has been given. This will be checked against the specifics of the proposal and made clear if any data falls outside the scope of the ethical permissions and/or consent.

6.4. Other paperwork

If a project requires genetics data, a Data Transfer Agreement (DTA) must be completed. This requires the signature of a legal signatory in the PI's institute. For other potentially clinically identifiable data a Material Transfer Agreement (MTA) may be required.

When a paper is submitted to the Executive Committee for approval a papers checklist (available on request) must be completed and sent with the manuscript.

6.5. Unique project identifiers

For each project a unique set of identifiers is created. If a principal investigator has more than one project, separate identifiers will be attached to each dataset relative to each project, thus datasets cannot be combined.

6.6. Secure data transfer

Data files will be transferred using the University of Liverpool's preferred data sharing tool DatAnywhere. Varonis DatAnywhere enables folders and files on a server to be securely synchronized with remote devices. Additionally, these folders and files can be shared with external users over the Internet (HTTPS). Data is transmitted securely over SSL and complies with all data governance and compliance procedures and policies. Data users will be assigned a password for a project when the first dataset is provided.

7. Summary of researcher responsibilities

This section summarises the main responsibilities of any researcher wishing to work with the WCHADS dataset. The same rules apply to all researchers regardless of whether they are a member of WCHADS staff, a new collaborator or a long-term collaborator.

7.1. Project proposals

It is important to note that the Executive Committee do not consider overlap when approving projects. It is up to the researcher to determine whether any project they are requesting data for is not already being worked on by any other researcher and to be aware of any other researchers who may be working in their area of interest. The Executive Committee may suggest possible collaborations but the researcher is under no obligation: this is a suggestion rather than a pre-requisite of project approval. Titles of all approved projects will be available online.

7.2. Data access

Researchers must adhere to the WCHADS access policy and confidentiality form at all times. Researchers must also comply with the terms of the WCHADS Data Transfer Agreements or Material Transfer Agreements where applicable. Current and future access is at risk if any researcher is found to be breaking these rules. In particular, data must NOT be shared with any other researchers. Serious breaches of data access rules will be prosecuted to the full extent of the civic or criminal law.

7.3. Confidentiality/Security Breaches

Any breaches of data security must be reported immediately to the PIs who will pass the issue on to the University of Liverpool Data Security Team for investigation and will inform the Local NHS Research Ethics Committee where appropriate. Examples of data security breaches include (but are not limited to):-

- Any unauthorised person (i.e. has not signed a data access agreement for the relevant data set) gaining access to WCHADS data;
- Sharing WCHADS data with unauthorised persons;
- Failing to ensure data are sufficiently encrypted during transport;
- Sharing login and/or password details that permit access to WCHADS data.

7.4. Derived variables

Any derived variables created as part of any research project must be returned to your data buddy with appropriate documentation; these will be incorporated in to the main dataset and made available to all researchers. If you fail to return any derived variables and we receive a specific request from another researcher to access that data, we will follow up with you again. We would expect you to return the relevant data to your data buddy (in order for the IDs to be replaced) within 8 weeks of completion of analysis. Failure to produce derived variables at this point may risk your future access to the dataset.

8. Publication

8.1. Peer reviewed papers and other research output

Sharing of WCHADS data is facilitated either for use in external projects or on a collaborative basis with the WCHADS PIs in line with ethical permissions. For external projects the WCHADS study and the work of the WCHADS team in data collection must be formally acknowledged. For collaborative projects the PIs must be included as co-authors on all publications arising from data gathered within the WCHADS study. All full papers must be sent to the WCHADS Executive Committee for approval (first.steps@liverpool.ac.uk) along with a completed papers checklist prior to journal submission. This includes any research output being placed in the public domain (for example working papers or non-peer reviewed papers). The Executive Committee will process all papers within four weeks of receipt. The Executive Committee will read all papers to check confidentiality is protected and to ensure that the paper will not bring the study into disrepute. The Executive Committee reserves the right to require that any paper which could potentially breach the confidentiality of any WCHADS participant(s) be withheld from submission for publication. The Executive Committee will work with the authors to overcome such breaches. If the researcher submits such publications regardless, the PIs will attempt to prevent publication.

The Executive Committee also provides advice and feedback to authors where we feel this may be helpful but their role is not to provide formal peer review: Under all circumstances the WCHADS Executive Committee reserve the right to submit letters or papers for publications in response to any paper to explain study procedures or to express a coherent scientific argument. A checklist of requirements for WCHADS papers along with some accompanying notes explaining these requirements and containing appropriate text to insert is available with the papers checklist. A completed checklist

must be included with each paper submitted for approval, please note this also applies to working papers. Researchers should let the Executive Committee know when a paper is accepted and send through an electronic copy of the final author accepted manuscript. A list of publications arising from the study can be found on the study website.

8.2. Open Access

8.2.1. Papers

WCHADS fully supports the Medical Research Council's (MRC) policies on open access. In summary, this means that if a) the specific research presented in a paper is wholly or partly funded by the MRC or b) any contributing author is wholly or partly funded by the MRC (via salary or fellowship/studentship) any publication must be made open access. It is the senior author's responsibility to ensure that any papers published comply with this policy. It is the responsibility of the grant-holder under part a) above or the individual author(s) under part b) above to cover the costs of making a publication open access. Please see the MRC website for more information.

Please note that secondary analyses of WCHADS data that is not funded by the MRC nor has any contributing author supported by the MRC does not need to comply with the MRC policy, however, WCHADS would encourage this wherever possible.

8.2.2. Journals

A number of journals request that datasets used in a publication are deposited in publicly available datasets. Our data management policy will not permit this and we therefore request that the following statement be used by researchers in such cases: "Data used for this submission will be made available on request to the Executive Committee (<u>first.steps@liverpool.ac.uk</u>). The WCHADS data management plan (available on request) describes in detail the policy regarding data sharing, which is through approved collaborative and protected access facilitated by the WCHADS research team, in line with original ethical permissions."

8.2.3. Grant applications

It has also come to our attention that some funders are also requesting that data be made publicly available. We recommend the same statement above is used in such cases.

8.3. Theses

We request that we are provided with an electronic copy of any theses that use WCHADS data as soon as possible after a degree is awarded.

8.4. Reports and other publications

We request that we are provided with an electronic copy of any reports and other publications that use WCHADS data as soon as possible.

8.5. Conference Proceedings

WCHADS do not need to see submissions to conferences.

9. The Media

All press releases on research arising from the study must be written in conjunction with the University of Liverpool and University of Reading's communications team. We reserve the right to publish press releases on certain articles and expect the lead author of the article to agree the press release with our University's public relations team and to be available to deal with media enquiries and interviews. We may also ask authors to prepare a précis of important papers and/or lay-summaries to include in reports to funders and future applications for future core funding.