

Yorkshire Health Study (YHS)

Confidentiality and Information Sharing

Produced by Amanda Loban, Data Manager, on behalf of the YHS management Group

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Background

The main functions of the YHS are to provide:

- Longitudinal observational data on a representative population based sample of adults.
- Up to date information to facilitate evaluation.
- A multiple trails facility for hypothesis testing.
- A recruitment facility for qualitative and quantitative research studies.

To fulfil these functions it is necessary to share data relating to research participants with other researchers and organisations. Such sharing must be handled appropriately in accordance with all applicable regulations. (See also the ScHARR Information Governance Primary Policy Number 001 and ScHARR Information Governance Supplementary Policy 003(a) Confidentiality and Information Sharing).

In addition, the information provided to participants with the questionnaires allows us to use the data to fulfil these functions (see Appendix 2).

Purpose

This document provides information on the types of data sharing that apply to the YHS and the processes put in place to safeguard this data.

Data sharing

Data relating to the YHS research participants is stored within a study database hosted on the University of Sheffield's secure server and access is restricted (See also CTRU SOP IS002 Computer System Security). Data is exported to the University network drive (N drive). Access is restricted to members of the YHS study team (see Appendix 1).

Sharing data to facilitate evaluation and research

Researchers may request data for a purpose which complies with the function of the YHS, i.e. to inform research which may help improve health, find best treatments and prevent illness; this includes use in the development and testing of tools that will be used to help inform healthcare decision making. The process of requesting data and assessing the suitability of the application is outlined in the collaborative studies process (see Appendix 3).

If the request is approved then data will be shared securely, as described below. All strong identifiers will be removed from the data provided (i.e. name, address, post code and date of birth). Age and postcode district replace date of birth and postcode where required. Without access to these strong identifiers the possibility of identifying an individual is minimised. It is also recommended that any free text fields be removed, as there is a chance that they could contain identifiable information; where free text fields are required safeguards taken to ensure confidentiality is maintained should be documented. Finally, datasets should be checked for any 'outliers', the checks made and steps taken as a result of those checks should be documented. In all cases only the minimum amount of data required for the research should be shared.

Data may be pseudonymised; the pseudonym is used to link individuals in different datasets. However, where possible it is recommended that the pseudonym is removed, i.e. if the data does not need to be linked back to the existing or follow up data.

The sharing of pseudonymised data will be reviewed once the new European Data Protection Regulation comes into force; currently the data protection act (DPA) does not prevent the use of pseudonymised data, so long as identification does not take place.

Data transfer internally

If the request is from a researcher within ScHARR then it is expected that they comply with the ScHARR Information Governance policies. It should be possible to share the data via an additional access restricted University network drive (i.e. not by giving access to the YHS network drive). If this is not possible then a data sharing agreement must be put in place to document the safeguards regarding the security and confidentiality of the data (Appendix 4).

Data transfer externally

If the request is from a researcher outside ScHARR a data sharing agreement must be put in place (Appendix 4).

Linking data to 'collaborative studies'

One of the functions of the YHS is as a recruitment facility (see Appendix 3 for a full outline of the process regarding collaborative studies). For approved studies, potential eligible participants within the cohort will be identified by the YHS data manager. These individuals will be invited to participate in the collaborative studies by replying directly to the researcher. A direct mail company may be used to contact the participants (see data processing). On occasion researchers may wish to link to data held by the YHS on the participants who have agreed to participate in their collaborative study. In these cases it is important to establish whether providing this information would make the data identifiable, i.e. do the researchers have the names and addresses of the people who've replied which they can then link via the pseudonym? If the data will be identifiable then the researcher must have made it clear in the information sheet, included when the individual is invited to take part in this collaborative research, that they wish to link to data held by the YHS. If the researchers do not collect names and addresses then the guidance under 'sharing information to facilitate evaluation and research' should be followed.

Data processing

In order to carry out mail outs (i.e. direct mail) and to keep the data up to date (i.e. to link to data regarding deaths and house moves) external companies may process the data. The data provided to carry out this processing is limited to names and addresses; it will not include any other sensitive information. An agreement will be in place regarding security and confidentiality of the data, this may form part of a contract or the template in appendix 5 may be used.

Appendix 1 – Yorkshire Health Study – Roles and Responsibilities

Latest version is stored in N:\projects\SYC\YORKSHIRE HEALTH STUDY\SOPS job descriptions etc

Copy for information:



YHS Roles & responsibilities 24.4.1

Appendix 2 – Summary of wording on letters, website and online survey

In HQ1 we have told participants that we will use their answers to 'help the NHS improve the long term health of people living in South Yorkshire' and it will be 'used only for research purposes'.

In HQ2 we similarly say we will use their answers to 'give an up-to-date picture of the health and wellbeing of local people and help us to find the best treatments to prevent and treat illness in the future'.

The information on the website for participants who sign up on line is also similar 'your answers will help us understand how we can improve the health of people living in Yorkshire and Humber'.

Appendix 3 – Collaborative studies process

Latest versions are stored in N:\projects\SYC\YORKSHIRE HEALTH STUDY\Collaborative studies\Collaborative studies YHS

Copies for information:



Appendix 4 – Example of data sharing agreement

Latest version is stored in N:\projects\SYC\YORKSHIRE HEALTH STUDY\Collaborative studies\Collaborative studies YHS

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Appendix 5 – Example of data processing agreement

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