

Macmillan Survivorship Research Group Data Access Policy

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Macmillan Survivorship Research Group

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1. Introduction

This document sets out the data access policy for datasets arising from studies conducted by the Macmillan Survivorship Research Group (MSRG). MSRG is hosted by Health Sciences, University of Southampton and is funded by Macmillan Cancer Support. Policies, forms and further information about accessing MSRG data are available at https://www.horizons-hub.org.uk/access_data.html. All completed forms should be submitted to msrg@soton.ac.uk.

2. Dataset Management

Professor Claire Foster is the MSRG Director. The management of datasets are the responsibility of the relevant Study Management Group with oversight from the Data Monitoring Committee or relevant study advisory committee. From time to time, advice may be sought from other key individuals. Proposals and papers will be considered on a monthly basis. Final decisions lie with the Director or the Chief Investigator of the project. The following sections describe the process of accessing and sharing data and the procedures in place to monitor output.

3. Sharing data with researchers

Data are made available through supported access rather than open access. Only fully anonymised data will be shared with researchers. We may charge investigators for costs incurred in providing a dataset. A list of approved research proposals utilising MSRG datasets is available at https://www.horizons-hub.org.uk/access_data.html.

4. Submitting a proposal

If you are interested in accessing a dataset, you should first submit the Preliminary Research Proposal Form. An MSRG Researcher will review this form and contact you for an informal discussion about your proposal. MSRG may put you in touch with other groups working in the same area to prevent duplication. If appropriate, the researcher will also provide the dataset code book.

Once you are ready to submit a formal proposal, you should complete the Research Proposal Form. You will receive a reply within one month to inform you of the outcome and to provide advice on the next stages. An estimate of the cost of sharing data will be provided if applicable. MSRG reserves the right to impose additional restrictions as appropriate.

If your research proposal is approved, you will have 12 months from the point of receipt of the dataset before applications from other groups to perform the same analysis will be considered.

5. Ethical approval

All proposals need ethical approval. You will need to provide evidence of ethical approval before data can be released. Data provided to external researchers will only include those participants who specifically consent to secondary data analysis.

For specific details about the ethical approvals in place for MSRG studies, please see Checklist for Papers using MSRG Datasets.

6. Contract

Before access to the data is provided, your institution will be required to sign a data sharing and confidentiality agreement with the University of Southampton.

7. Data Provision

When your project has been approved, an agreed dataset will be provided to you usually within a month of all paperwork being completed; however, some types of data may take longer. You will be responsible for notifying MSRSG if you experience any technical difficulties accessing the dataset once it has been sent.

You will not be provided with statistical, methodological or other support without prior agreement and this may incur costs.

8. Progress Report

If the project has not been completed within 12 months from the point of receipt of the dataset, the Research Progress Form must be completed. Progress will be reviewed and a decision made about whether the project can continue (with a new agreed time frame) or whether the project will terminate and the dataset returned as described in section 13, End of study.

9. Derived Variables

Any derived variables (such as data obtained as part of a new data collection exercise or newly derived variables coming from secondary analyses) created as part of any research project must be returned to the Data Monitoring Committee (msrg@soton.ac.uk) with appropriate documentation. By derived variables we mean new variables that have been derived using at least two existing variables (rather than simple recodes) or other variables that do not currently exist in the dataset that may be of use to other collaborators. These may be incorporated into the main dataset and, with appropriate permissions, be made available to other researchers once the protected period of approved use has ended. Failure to return derived variables may risk future access to datasets.

10. Paper submission and Publication

The Director and project Chief Investigator, and where appropriate one or more nominated member(s) of MSRSG, should be included as an author on any paper using MSRSG data. The designated author from MSRSG will read the paper to provide advice and feedback, check confidentiality is protected and to ensure that the paper will not bring MSRSG into disrepute.

All papers must be sent to MSRSG for approval at least 30 days prior to submission (msrg@soton.ac.uk), along with a completed Checklist for Papers using MSRSG Datasets. The MSRSG team will usually process all papers within one month of receipt.

Researchers should let MSRSG know when a paper is accepted and send through an electronic copy of the final published version (msrg@soton.ac.uk). If your work on the dataset was funded by bodies that require open access to publications arising from their funding, it is your responsibility to ensure papers are freely available.

All papers submitted will be sent to the study funders. We request that we are provided with an electronic copy of any reports and other publications that use MSRG datasets as soon as possible and within a month of completion. We request that we are provided with an electronic copy of any theses that use an MSRG dataset as soon as possible after a degree is awarded. We do not need to see conference submissions prior to submission but a copy should be sent to MSRG once accepted (msrg@soton.ac.uk).

11. Publicity policy

All press releases on research arising from the dataset should be seen and approved by the MSRG Director or project Chief Investigator, or their nominated representative (msrg@soton.ac.uk). We may, in partnership with the dataset funder, write press releases on certain articles and expect the lead author on the paper and host organisation's public relations team to be available to deal with media enquiries and interviews. We may also ask authors to prepare a précis of important papers to include in reports to funders and future applications for future core support.

The MSRG team will usually process all press releases within one month of receipt.

12. Intellectual property

Intellectual property in the data that make up an MSRG dataset is vested in University of Southampton and managed by MSRG. As such, any requests to access the data must be made through MSRG. Any data generated through an approved project must be made available to MSRG where it will form part of the dataset to enable it to be used by the research community. Any intellectual property generated using MSRG datasets ("Foreground IP") will belong to University of Southampton.

13. End of study

The end of the study is defined as when a paper has been accepted for publication or, at the end of the protected period of approved use, at the discretion of the MSRG Director or project Chief Investigator. The dataset, including any derived variables, should then be returned to MSRG and all local copies deleted unless permission is given in writing for data to be retained. An End of Study Checklist should be completed and returned to MSRG (msrg@soton.ac.uk).