Funder Requirements for Data Management and Sharing

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Project Purpose

The RDMSS Project is an infrastructure development project funded by the Wellcome Trust under the Institutional Strategic Support Fund. Its overall purpose is to develop and embed a RDM Support Service within the London School of Hygiene and Tropical Medicine, performing activities to enable and enhance data management practices. In its initial phase, the project is funded for one year (Jan-Dec 2012), with the potential for extension to three years (December 2014).

Introduction

This report provides an overview of funding agencies that support research projects at the London School of Hygiene and Tropical Medicine and explores the requirements and recommendations that they establish for data management and sharing. It serves a dual purpose, providing a summary of funder requirements for use by researchers wishing to understand their obligations for maintaining and sharing their data, and defines a set of requirements that should be met by the School to ensure it is able to support research activities.

Methodology

The information presented in this report was gathered from several sources using desk-based research methods. The list of funding agencies that support LSHTM researchers was constructed using information published on LSHTM Faculty and Project web pages[1], supplemented by additional details provided by the Research Grants and Contracts department. Information on funder requirements and recommendations for data management and sharing was obtained through a detailed review of their policy framework, grant submission systems, and funding advisory document. The author also drew upon earlier work performed by the Digital Curation Centre (Jones, 2009) and Research Information Network (2007) to catalogue funders' data plan requirements, using them as a guide to locate data policies.

Funders covered in this document

The first version of the funders list covers 17 agencies that have supported research activities performed by LSHTM during the past decade:

1. Action Medical Research (AMR)
2. Biotechnology and Biosciences Research Council (BBSRC)
3. Bill & Melinda Gates Foundation
4. Breast Cancer Campaign (BCC)
5. Cancer Research UK (CRUK)
6. Department of Health, UK (DoH)
7. Department for International Development (DfID)
8. Drugs for Neglected Diseases Initiative (DNDi)
9. Economic and Social Research Council (ESRC)
10. Engineering and Physical Sciences Research Council (EPSRC)
11. GlaxoSmithKline (GSK)
12. Medical Research Council (MRC)
13. Natural Environment Research Council (NERC)
14. Wellcome Trust
15. WHO - World Health Organization - TDR

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[1] http://www.lshtm.ac.uk/eph/ncde/groups/epigenetics/funders/index.html http://hivtools.lshtm.ac.uk/links_funders.htm, http://www.lshtm.ac.uk/itd/iid/research/index.html and http://www.lshtm.ac.uk/php/hsrp/studies/index.html

16. World Cancer Research Fund (WCRF)
17. National Health Service Technology Assessment (NHS HTA)

This list will be reviewed every six months to validate the accuracy of the information provided and add new funders as appropriate.

Definition of terms

The catalogue of funder requirements outlined in this report builds upon the requirement list developed by Jones (2009), extending it and redefining terms where necessary.

1. *Funder:* The name of the funding agency

2. *Data outputs covered:* Type and/or scope of data assets that are covered by funder data policies and/or recommendations.

3. *Data Plan Requirements:* Requirements to provide information on data management and/or sharing activities as part of the proposal to be submitted

4. *Funding arrangement for data management and sharing:* An indicator of the funder's willingness to support data management and sharing costs

5. *Documentation Requirements:* Documentation suggested by funders that shoule be provided to help researchers to access and use research data produced

6. *Retention Requirements:* An indicator of the minimum time period that data assets should be retained and the institutional agent that should be responsible

7. *Data Standards:* General or specific data standards or practices that should be adopted by the researcher when creating, managing, or sharing data

8. *Publication Requirements:* Information on the type of data to be published and timescales for making it available.

9. *Data Sharing Rights:* Funder statement on licence terms that should be applied to research data made available

10. *Designated Data Centre:* A data archive or service allocated by the funder that will be responsible for long-term curation, preservation, and where appropriate, publication of the research data.

11. *Monitoring:* Activities performed by the funder to monitor compliance against policy and steps that may be taken if the grant holder does not meet requirements

12. *Institutional Requirements:* Requirements established by the funder that apply to the host institution

13. *References:* References that provide further information on the funders' policies and procedures

1 Action Medical Research (AMR)

Data Outputs Covered:
All research outputs.

Data Plan Requirement

AMR does not require a data management/sharing plan.

Funding arrangement for data management and sharing

None stated

Documentation requirements

Clear and accurate records should be retained on procedures followed and approvals granted during research process, including interim and final results.

Retention requirements

Data should be retained for a minimum of ten years.

Data standards

None stated

Publication Requirements

Researchers are expected to make data available at the same time as research results are published. Publication may be delayed for a 'reasonable period', pending intellectual property protection, ethics approvals, or consents being obtained

Data sharing Rights

None stated

Designated data centre

None stated

Monitoring

None stated

References

Action Medical Research website < http://www.action.org.uk/ >

Institutional Requirements

Institutions should publish documents detailing the standards that they encourage to enable good research practice, as well as procedures for investigation research misconduct allegations.

Institutions should provide training for new researchers and students on data management, record keeping, data protection, Intellectual property management, and other research techniques.

2 Biotechnology and Biosciences Research Council (BBSRC)

Data Outputs Covered:

All research outputs

Data Plan Requirement:

A 'Statement on Data Sharing' plan is required for all applications

Funding arrangement for data management and sharing:

Funding for data management and sharing may be requested as part of Full Economic Cost for projects.

Documentation requirements:

Documentation should be created that describe the data's provenance and enable its content to be understood. Researchers are expected to make use of current guidance on best practice.

Retention requirements:

Data should be retained for a minimum of 10 years after completion of research project

Data standards:

Researchers expected to store data in accessible formats using established standards

Publication Requirements:

Researchers are expected to make data available at the same time as main findings of research are published or in line with best practice in field. Explicit reasons must be provided in Data Sharing Plan if data publication is not possible or appropriate. The BBSRC reserves the right to implement a more prescriptive approach to data sharing for specific research initiatives

Data sharing Rights:

IPR remains with investigator and institution. Data should be made available with as few restrictions as possible

Designated data centre:

No designated data centre. Deposition in an appropriate data archive or data enclave is encouraged. Alternatively, direct sharing by investigator or institution, or mixed mode sharing may be appropriate

Monitoring:

Compliance monitored through Final Report assessment procedure. Data sharing of previously produced research is taken into account when assessing future proposals

References:

BBSRC Data Sharing Policy. V1.1
< http://www.bbsrc.ac.uk/web/FILES/Policies/data-sharing-policy.pdf >
BBSRC Statement on Safeguarding Good Scientific Practice

< http://www.bbsrc.ac.uk/web/FILES/Policies/good_scientific_practice.pdf >

Institutional Requirements:

Institutions receiving BBSRC funding should possess guidelines setting out responsibilities and procedures for maintaining data.

3 Bill & Melinda Gates Foundation

Data Outputs Covered:

Final, annotated quantitative and qualitative datasets and accompanying information such as metadata, codebooks, data dictionaries, and questionnaires. Data may arise as a primary output of a grant, or as a product of other activities, such as program evaluations.

Data Plan Requirement:

A ‘Data Access Plan’ must be prepared for grants over $500,000.

Funding arrangement for data management and sharing:

Funding for data management and sharing may be requested as part of the project budget

Documentation requirements:

Documentation should be created that describe the data's provenance and enable its content to be understood. Researchers are expected to make use of current guidance and information on best practice.

Retention requirements:

None stated

Data standards:

Researchers should use standards appropriate to the subject domain.

Publication Requirements:

Data should be made available in a ‘timely manner’. The grantee may specify a time period for exclusive use of data (e.g. 12-18 months), after which the data will be made available for others. Alternatively, the data may be released with a Data Use Agreement, indicating that the user may analyse the data, but is not allowed to publish on topics related to the grantee's area of research. 3rd party proprietary data is not expected to be made available.

Data sharing Rights:

None stated

Designated data centre:

Deposition in a public access data archive or data enclave is encouraged. Alternatively, direct sharing by investigator or institution, or mixed mode sharing may be appropriate

Monitoring:

None stated

References:

Bill and Melinda Gates Foundation: Global Health Data Access Principles < http://www.gatesfoundation.org/global-health/Documents/data-access-principles.pdf >
Bill & Melinda Gates Foundation’s Data Access Principles: Frequently Asked Questions < http://www.gatesfoundation.org/global-health/Documents/faq.pdf >

Institutional Requirements:

None stated

4 Breast Cancer Campaign (BCC)

Data Outputs Covered:

All research outputs

Data Plan Requirement:

The Breast Cancer Campaign does not require a data management/sharing plan.

Funding arrangement for data management and sharing:

None stated

Documentation requirements:

None stated

Retention requirements:

None stated

Data standards:

None stated

Publication Requirements:

Encouraged to publish as early as possible, subject to IPR, confidentiality, ethical or consent status

Data sharing Rights:

None stated

Designated data centre:

None stated

Monitoring:

None stated

References:

None stated

Institutional Requirements:

None stated

5 Cancer Research UK (CRUK)

Data Outputs Covered:

All research data, including that not been used in a publication

Data Plan Requirement:

A ‘Data Management and Sharing Plan’ is required for all applications

Funding arrangement for data management and sharing:

Funding is not provided. CRUK consider timely and appropriate data management and sharing to be an integral component of the research process.

Documentation requirements:

Documentation should be created that describe the data's provenance and enable its content to be understood. Information on the encoding formats used for the data should also be provided. Researchers are expected to make use of current guidance and information on best practice.

Retention requirements:

Data should be retained for a minimum of five years following end of grant

Data standards:

The use of domain specific standards are recommended.

Publication Requirements:

Researchers are encouraged to make data available when research papers that report results are accepted for publication, in line with best practice in field, or after relevant patents are filed. Proprietary data or data covered by unsolvable confidentiality, ethical or consent issues do not need to be made available

Data sharing Rights:

IPR remains with institution, but grant CR-UK and/or designated recipients of CR-UK funding non-exclusive rights to use for non-commercial research

Designated data centre:

Deposition in an appropriate data archive or data enclave is encouraged. Alternatively, direct sharing by investigator or institution, or mixed mode sharing may be appropriate

Monitoring:

Funding committees monitor data management and sharing plans through grant review process and the grant closure report.

References:

Cancer Research UK: Policy on Data sharing and Preservation
< http://science.cancerresearchuk.org/funding/terms-conditions/funding-policies/policy-data-sharing/ >

Cancer Research UK: Data Sharing Guidelines
< http://science.cancerresearchuk.org/funding/terms-conditions/funding-policies/policy-data-sharing/data-sharing-guidelines/ >

Institutional Requirements:

None stated

6 Department of Health, UK (DoH)

Data Outputs Covered:

All publicly funded data

Data Plan Requirement:

The Department of Health does not require a data management/sharing plan.

Funding arrangement for data management and sharing:

Not stated

Documentation requirements:

Documentation should be created that describe the data's provenance and enable its content to be understood. Researchers are expected to make use of current guidance and information on best practice.

Retention requirements:

Health records retained in compliance with government legislation;

Data standards:

Open formats that allow linkages to be established between datasets

Publication Requirements:

Data should be published in a ‘timely manner’, subject to ethical & legal requirements

Data sharing Rights:

No statement on IPR of original item. Requirement to publish using open licence that authorises reuse

Designated data centre:

Data.gov and OpenlyLocal for open data

Monitoring:

Institutional audit

References:

NHS Information Risk Management
< http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/security/risk/ >
Data Protection Policy
< http://transparency.dh.gov.uk/dataprotection/ >

Institutional Requirements:

Data management systems for confidential data must comply with ISO/IEC 27001:2005 and ISO/IEC 27002:2005.

Encouraged to use open, linked data formats for publication.

Data that identifies one or more people should be encrypted with a recommended minimum key length of 256 bits, e.g. AES256, Blowfish

7 Department for International Development (DfID)

Data Outputs Covered:

All research outputs

Data Plan Requirement:

An ‘Access and Data Management Plan’ is required for all applications that possess a data component

Funding arrangement for data management and sharing:

Funding for data management and sharing may be requested as part of the project budget

Documentation requirements:

Documentation should be created that describe the data's provenance and enable its content to be understood. This will include a list of files in the set, how the data was collected, and which parameters have been used.

Retention requirements:

Retain and provide free access to raw datasets for minimum of five years after project completion. Project websites should be permanently archived on closure.

Data standards:

Recommend formats that can easily be transferred between different software applications, e.g. CSV for tabular data, ANSI SQL for databases, SPSS Portable or SAS transport for statistical files.

Publication Requirements:

Deposit raw and/or derived datasets in an open access discipline/institutional repository within 12 months of collection

Data sharing Rights:

IPR remains with host institution. DFID given an irrevocable worldwide licence to use all material produced through research. Encourage project outputs to be made available under licence that allows unrestricted access and reuse (e.g. Creative Commons Attribution)

Designated data centre:

Data should be deposited in an appropriate subject/institutional repository, such as those recommended by OpenDOAR and ICSU World Data System. Software to be submitted to an suitable sofware repository. Metadata record, papers & ‘small datasets’ should be published in R4D repository.

Monitoring:

None stated

References

Department for International Development. DFID Research Open and Enhanced Access Policy
< http://www.dfid.gov.uk/Documents/publications1/DFIDResearch-Open-and-Enhanced-Access-Policy.pdf >
DFID Research Open and Enhanced Access Policy: Implementation Guide
< http://www.dfid.gov.uk/Documents/publications1/DFIDResearch-Open-and-Enhanced-Access-Implementation-Guide.pdf >

Institutional Requirements:

None stated

8 Drugs for Neglected Diseases Initiative (DNDi)

Data Outputs Covered:

All research outputs

Data Plan Requirement

DNDi does not require a data management/sharing plan.

Funding arrangement for data management and sharing

Not stated

Documentation requirements

Research process should be documented in accordance with Good Lab Practice (GLP)

Retention requirements

None stated

Data standards

None stated

Publication Requirements

Results of work should be made "readily available and affordable in developing country".

Data sharing Rights

No statement on IPR of original item. Work may be placed in public domain in circumstances where IP acquisition is not necessary to promote its mission and goals

Designated data centre

None stated

Monitoring

None stated

References

DNDi's Intellectual Property Policy
< http://www.dndi.org/dndis-policies/intellectual-property-policy.html >

Institutional Requirements:

None stated

9 Economic and Social Research Council (ESRC)

Data Outputs Covered:

All research outputs

Data Plan Requirement:

A ‘Data Management and Sharing Plan’ is required for all projects that possess a data component

Funding arrangement for data management and sharing:

Funding for data management and sharing may be requested as part of Full Economic Cost for project

Documentation requirements:

Documentation should be created that provides information on origin, circumstances, processing/analysis and/or the researcher’s management of the data, among other items

Retention requirements:

Institutional retention requirements are not stated. Data should be deposited with ESRC data provider for purpose of long-term curation & preservation requirements

Data standards:

Refer to ESDS and UKDA guidance

Publication Requirements:

Deposited with ESRC data service providers within three months of the end of the grant. Waiver may be considered in exceptional circumstances

Data sharing Rights:

None stated

Designated data centre:

Economic and Social Sciences Data Service (ESDS)

Monitoring:

Review Data Management and Sharing Plan during project; withhold final award if data have not been offered for archiving to required standard within 3 months of the end of the award

References:

ESRC Research Data Policy
< http://www.esrc.ac.uk/about-esrc/information/data-policy.aspx >
ESRC Research Data Policy; ESRC Research Funding Guide; Data management plan: guidance for peer reviewers
< http://www.esrc.ac.uk/funding-and-guidance/guidance/applicants/research-funding-guide.aspx >

Institutional Requirements:

None stated

10 Engineering and Physical Sciences Research Council (EPSRC)

Data Outputs Covered:

All research data are covered by the policy. Non-digital data should be stored in a form that allows sharing on request (e.g. through digitisation).

Data Plan Requirement:

The EPSRC does not require researchers to submit data management or sharing plans in grant applications.

Funding arrangement for data management and sharing:

The institution should utilise received public research funding to support data management and sharing activities, making use of both direct and indirect funding streams as appropriate

Documentation requirements:

Documentation should be created that describe the data's provenance and enable its content to be understood. Researchers are expected to make use of current guidance and information on best practice. Persistent IDs should be assigned

Retention requirements:

Research organisations must store and preserve research data for a minimum of 10 years from the date that any researcher's ‘privileged access’ period expires or last date from which access to the data was requested by a third party

Data standards:

Refer to JISC, DCC and Information Commissioner's Office guidance

Publication Requirements:

Descriptive metadata should be created within 12 months of data being generated. Projects are encouraged to make research data available as early as possible

Data sharing Rights:

None stated for data. Researchers are expected to make publications freely available

Designated data centre:

Deposit with a suitable data archive

Monitoring:

Monitored on case-by-case basis. Unstated sanctions may be applied

References:

EPSRC Policy Framework on Research Data
< http://www.epsrc.ac.uk/about/standards/researchdata >

Institutional Requirements:

Institutions should provide resources to support the curation of publicly-funded research data throughout the data lifecycle. This includes the development of policies and procedures to manage research data holdings and handling third party access requests.

Access requests should be recorded, indicating when the data was requested.
Institutions should ensure that their researchers and research students have a general awareness of the regulatory environment and of the available exemptions which may be used, should the need arise, to justify the withholding of research data;

Institutions are expected to have a roadmap in place to ensure their policies and processes are in line with its policy framework on research data by May 2015.

11 GlaxoSmithKline (GSK)

Data Outputs Covered:

Research findings obtained from completed & abandoned projects

Data Plan Requirement:

GSK does not require researchers to submit data management or sharing plans in grant applications.

Funding arrangement for data management and sharing:

None stated

Documentation requirements:

GSK indicate that the process of performing research should be documented, encouraging grantees to use domain specific practices.

Retention requirements:

Subject to conditions of contract

Data standards:

Domain specific standards

Publication Requirements:

Pharmaceutical companies are legally required to disclose relevant data from clinical trials and other research to appropriate national or regional regulatory authorities as part of the medicine development and approval process. GSK posts protocol summaries on ClinicalTrials.gov and Clinical Study Register on study initiation. It also publishes summaries of study results on Clinical Study Register within 8-12 months of study completion. Some information may be withheld if it is considered to limit research patentability.

Data sharing Rights:

Subject to conditions of contract. Patents for 'radical' and 'incremental' research may be obtained. GSK support the use of clinical data in conformance to the WTO Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS), when it does not undermine Regulatory Data Protection (RDP)

Designated data centre:

None stated

Monitoring:

Report progress of clinical trials, but do not require explicit information on technology issues.

References:

Public Disclosure of Clinical Research
< http://www.gsk.com/policies/GSK-on-disclosure-of-clinical-trial-information.pdf >
GlaxoSmithKline’s Position: Regulatory Data Protection
< http://www.gsk.com/policies/GSK-on-regulatory-data-protection.pdf >

Institutional Requirements:

None stated

12 Medical Research Council (MRC)

Data Outputs Covered:

All research data

Data Plan Requirement

A ‘Data Management Plan’ is required for all projects that will produce data outputs

Funding arrangement for data management and sharing

Not stated

Documentation requirements

Projects are encouraged to use the Data Documentation Initiative (DDI) metadata standard

Retention requirements

Primary research data must be retained in their original form by the research institution that generated them for a minimum of ten years from completion of the project. Research records relating to clinical or public health studies should be retained.

Data standards:

The MRC recommend that grant holders refer to UK Data Archive, Inter-university Consortium for Political and Social Research (ICPSR), Inter-university Consortium for

Political and Social Research (ICPSR), Australian National Data Service and National Statistics Code of Practice for information on appropriate standards

Publication Requirements:

Data should be made available in a 'timely and responsible manner'. A limited period of exclusive use of data for primary research is considered reasonable.

Data sharing Rights:

The study must publish a Data-sharing policy establishing appropriate licence (e.g. Open Data Commons) for use of anonymised data

Designated data centre:

Research data should be submitted to the MRC Research Data Gateway

Monitoring:

None stated

References:

MRC policy on research data-sharing
< http://www.mrc.ac.uk/Ourresearch/Ethicsresearchguidance/datasharing/policy/index.htm >
MRC guidance on data management plans
< http://www.mrc.ac.uk/Ourresearch/Ethicsresearchguidance/datasharing/DMPs/index.htm >

Institutional Requirements:

None stated

13 Natural Environment Research Council (NERC)

Data Outputs Covered:

All research data

Data Plan Requirement:

A ‘Data Management Plan’ is required for all projects that will produce data outputs

Funding arrangement for data management and sharing:

Not stated

Documentation requirements:

Data should be catalogued according to the NERC profile of ISO19115:2003

Retention requirements:

Data and research materials should be preserved and made available for a minimum of 10 years after completion of the research. NERC indicate that research outputs of major importance may need to be retained for 20 years or longer

Data standards:

Specified in consultation with relevant data centre

Publication Requirements:

Project may define an embargo period of up to two years from end of data collection to enable researchers to analyse and publish findings. Potential data users encouraged to contact data creator to negotiate for earlier use.

Data sharing Rights:

IPR remains with host institution. NERC data centres are allocated a non-exclusive licence to manage and publish research data

Designated data centre:

Deposit with authorised NERC data centre (BADC, NGDC, NEODC, BODC, PDC, EIDC, UKSSDC, ADS). Catalogue record published through NERC Data Catalogue Service

Monitoring:

Ongoing monitoring. Grant holders who do not meet these requirements risk having award payments withheld or become ineligible for future funding

References:

NERC Data Policy
< http://www.nerc.ac.uk/research/sites/data/policy2011.asp >
NERC Data Policy Guidance
< http://www.nerc.ac.uk/research/sites/data/documents/datapolicy-guidance.pdf >

Institutional Requirements:

None stated

14 Wellcome Trust

Data Outputs Covered:

All data outputs, including records of interim results and final research outcomes

Data Plan Requirement

A ‘Data Management and Sharing Plan’ is required for applications to the Trust's biomedical sciences and medical humanities funding streams if the project will produce data outputs that have value to the research community in the short and/or long-term.

Funding arrangement for data management and sharing

Data management and sharing costs may be incorporated into the project budget.

Documentation requirements:

Documentation should be created that describe the data's provenance and enable its content to be understood. Records should be created and maintained that describe the procedures followed, approvals granted, and results (interim and final) found during the research process.

Retention requirements:

Data should be maintained in a secure environment for a minimum of 10 years

Data standards:

Formats and standards should be adopted that enable data outputs to be referenced, analysed and linked with other resources

Publication Requirements:

Data should, if possible, be made available at the same time as research papers on the findings are published. Data creators have the right to delay or limit data sharing to safeguard research participants or to address intellectual property issues. Any such restrictions should, however, be minimised and a clear statement provided on the reason for delays should be provided in the data management and sharing plan.

Data sharing Rights:

None stated

Designated data centre:

An appropriate subject or institutional repository should be used. A list of possible options may be found at < http://www.wellcome.ac.uk/About-us/Policy/Spotlight-issues/Data-sharing/Guidance-for-researchers/WTX060360.htm >

Monitoring:

Grant holders are encouraged to liaise with the funder to address data management issues. All grant holdess are asked to report back on their approach for disseminating their research as part of their end of grant report.

References:

Wellcome Trust: Policy on data management and sharing - August 2010
< http://www.wellcome.ac.uk/About-us/Policy/Policy-and-position-statements/WTX035043.htm >
Wellcome Trust: Guidelines on good research practice
http://www.wellcome.ac.uk/About-us/Policy/Policy-and-position-statements/WTD002753.htm

Institutional Requirements:

Data generated in the course of research should be kept securely in paper or electronic format, as appropriate.

Institutions should possess documentation establishing responsibilities and procedures for the storage and disposal of data and samples (including compliance with requirements of any ethics committee).

15 WHO - World Health Organization - TDR

Data Outputs Covered:

A definition of data outputs is not provided, but may cover all research data produced using project funding

Data Plan Requirement:

The Data management requirements vary between each funding call. Applicants are asked to describe the research lifecycle within their proposal, describing the technical and practical activities associated with data cleaning, monitoring, and verification.

Funding arrangement for data management and sharing:

Not stated

Documentation requirements:

No specific requirements are stated. However, the project will need to document their work in accordance with Good Clinical Practice.

Retention requirements:

None stated

Data standards:

None stated

Publication Requirements:

None stated

Data sharing Rights:

None stated

Designated data centre:

Selected datasets are published on the Global Health Observatory Data Repository (http://apps.who.int/ghodata/)

Monitoring:

None stated

References:

World Health Organisation < http://www.who.int/tdr/grants/en/ >

Institutional Requirements:

None stated

16 World Cancer Research Fund (WCRF)

Data Outputs Covered:

Definition of data outputs is not provided, but may cover all research data produced using project funding

Data Plan Requirement:

WCRF does not require researchers to submit data management or sharing plans in grant applications.

Funding arrangement for data management and sharing:

Funding is not provided for indirect costs, such as institutional overheads associated with data management

Documentation requirements:

None stated

Retention requirements:

In accordance with the UK Department of Health Research Governance framework, data collected in the course of research must be retained for an 'appropriate period' to allow further analysis by the original and/or other research teams (subject to consent)

Data standards:

Research Governance must conform with institutional policies on topic and/or UK Department of Health Research Governance framework

Publication Requirements:

In accordance with the UK Department of Health Research Governance framework, research findings and data relevant to findings must be "made available for critical review through accepted scientific and professional channels" and "made accessible" to those participating in the study, as well as other who could benefit from them. No time limit is stated.

Data sharing Rights:

IPR remains with the host institution. The WCRF reserve the right to make copies of data for national members

Designated data centre:

Research findings are added to the WCRF/AICR Continuous Update Project (CUP) database (http://www.wcrf.org/cancer_research/cup/)

Monitoring:

Funder requires report on project progress, but does not state an explicit requirements for the underlying dataset

References:

World Cancer Research Fund: Funded Research
< http://www.wcrf-uk.org/research/uk_funded_research.php >

Institutional Requirements:

Institution must possess policies on research governance

17 National Health Service Technology Assessment (NHS HTA)

Data Outputs Covered:

All outputs produced by the project

Data Plan Requirement

Applicants are encouraged to describe their approach to data sharing in the project proposal, plan and monthly reports. However, the application does not provide a formal template for the data management plan.

Funding arrangement for data management and sharing

Unstated

Documentation requirements

Documentation should conform to Department of Health (DoH) Research Governance Framework and Medical Research Council guidelines for Good Research Practice

Retention requirements

In conformance with MRC guidelines, primary research data must be retained by the producing research institution for a minimum of 10 years after project completion. Research records relating to clinical or public health studies should be retained for a minimum of 20 years.

Data standards

Projects must follow the Department of Health (DoH) Research Governance Framework and Medical Research Council guidelines for Good Research Practice

Publication Requirements

No time limit is stated. The NHS NTA request that they are provided with a copy of research outputs to be published at the time of submission or at least 28 before the publication date.

Data sharing Rights

IPR remains with the host institution. Monographs published by projects through HTA are covered by Crown copyright

Designated data centre

The HTA programme is working with the National Cancer Research Unit (NCRI) Informatics Initiative to formalise and co-ordinate data sharing efforts. Data may be deposited with a data enclave or data archive, or shared through an institutional website or through posting CDs . Investigators may wish to use a data-sharing agreement to define criteria for data access, including allowed use and confidentiality standards that should be met.

Monitoring

None stated

References

National Health Service Technology Assessment (NHS HTA)
< http://www.hta.ac.uk/funding/troubleshooting/index.html >

Institutional Requirements

None stated

References

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