Ongoing Repositories

This is a checklist of matters that should be considered when proposing to establish an ongoing data repository that will be available for future research.

An ethics application should address these matters and provide DOH HREC with the details of the proposed management of the repository.

Aims
Outline the aims of establishing an ongoing repository and the reasons why it is necessary.

Governance
Provide details of the ongoing ownership, management and governance of the data repository including the roles and responsibilities for the management of the information. The management structure must be independent of movement of personnel.

Consultation
Information must be supplied on the following questions:

- Has consultation with representatives of the relevant participant group(s) been performed?
- Will the relevant participant group(s) continue to provide advice and input on the use and management of the data repository?
- Has the proposal been informed by consultation with stakeholders and how will it ensure that it will continue to meet the needs of stakeholders?

Consent
Where consent of participants will be obtained please advise how the following matters will be addressed:

- the procedure for managing participants’ consent and ensuring that future research is within the parameters of the consent obtained
- the policies for collecting additional information, contacting participants and disclosing information to participants.

Access to Data
Provide details of the data access policy including:

- the types of research for which it can be used
- the access criteria applied to applicants to use data
- the terms and conditions of access
- who approves access or release of data
- whether the data can be used by researchers from other institutions
- what Human Research Ethics Committee (HREC) approval and other institutional approvals will be required for projects applying for access.
Benefit Sharing and Intellectual Property

How will the management of the repository ensure that:

- the beneficial use of repository is maximised
- the results of research are made publicly available regardless of outcomes
- the results of research are made available in a form accessible to the participant community?

Has consideration been given to the need for:

- a benefit sharing policy
- agreements relating to intellectual property rights
- a policy on the acknowledgement of the participants
- a policy on the acknowledgement of the data repository?

Security Policy

Provide details of the plan to ensure the protection of the information including:

- physical and environmental security
- human resources security
- communications and operational security
- access controls
- cryptography
- incident and breach management
- audit program.

Demise of Data Repository

Provide details of the plan for a situation where the data repository will no longer be maintained for example because funding is no longer available or it no longer meets the stakeholder’s needs. Specify the anticipated period of retention of the data repository and the measures taken to secure and dispose the information during this period.

For further information

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