## Auckland University of Technology Ethics Committee (AUTEC)

# Guide for drafting a Sensitive Data Safety **Management** Protocol

DEFINITION & PURPOSE:

Sensitive data is data that can be used to identify an individual, object or location and which has a risk of discrimination, harm or unwanted attention associated with it. Sensitive data potentially poses a substantial threat to those who are or who have been involved in it, especially if it is shared inappropriately, or if it falls into the wrong hands.

Areas in which research data is likely to be threatening include:

• Where research intrudes into the private sphere or delves into some deeply personal or emotional experience (e.g. experience of serious medical condition or disability,  sexual or religious practices, experience of abuse, death or violence);

• Where the study is concerned with deviant, illegal or objectionable behaviours (e.g. the data reveals information that is stigmatizing or incriminating);

• Where the study impinges on the vested interests of powerful persons or the exercise of coercion or domination (e.g. where the research is about social conflict or where participants may face political threat, discrimination or stigma).

The central issue for a sensitive data safety management protocol is the prevention of accidental disclosure of the identity of a participant or their personal information.

The following questions are to be used as a guide for writing the protocol as relevant to the context of the project.

### Project title and brief description:

#### Primary Researcher

#### Supervisor/s

### What data will be produced?

What physical data will you study? (e.g. identifiable medical records, questionnaires etc.)

What digital data will you generate? (e.g. field-notes, photographs, audio or video recorded interviews, etc.)

What file formats and software will you use?

How will data be structured and stored?

How much data you will produce over time – do you have enough storage?

Are you making full use of University provided, fully backed-up storage?

How will data generated in the field be saved to safe University storage? When will this occur?

Do you have a logical file naming convention and directory structure?

What quality assurance and back-up procedures are planned?

### What raw data is being collected and how will it be managed?

How will the raw data be collected?

Will any raw data be stored on portable devices (e.g. audio files on a mobile phone)?

How will the security of the temporary storage be assured?

Will the raw data be securely stored or transferred to a secure data repository?

Will the raw data be destroyed and if so, when and how?

### What are the ethical requirements for your data?

In what way is the data sensitive?

How and where is physical data (physical data/papers/records)? Is digitised data encrypted appropriately?

Will you anonymise / de-identify your data? How? When? What will happen to the identifiable information?

Does your research funder have specific data management and sharing requirements?

Should some data be destroyed? When and how? By whom?

How will the undertakings about consent, confidentiality, anonymisation and other ethical considerations given to participants be assured?

### What are the plans for data sharing and access?

Have you discussed data sharing with your research collaborators/ supervisor?

If your research involves people, have you obtained appropriate consent for data sharing?

Can your data be released immediately, or should you embargo (delay access to) the data? What data will you keep?

Will data be openly available to everyone or will there be access restrictions?

How long will / should data be available for? Will you use a data repository? Which one?

### What are your main data challenges? Who can help?

Do you need training or support? What is available?

What University policies are relevant to your project? Have you read and understood them?

Who is responsible for managing the data? What resources will you need?

Who is responsible for data at different stages in its lifecycle?

Are sufficient resources (skills, people, storage, technology) available to deliver your plan?

What will happen to the data if the Primary Research leaves mid-project?

### Don’t forget to update your data management plan regularly:

#### **Date for next review**