MOBILE ACQUIRED DATA TOP TIPS SERIES:
SECURITY AND INFORMED CONSENT

In Australia, human research is defined as “research conducted with or about people, or their data or tissue.” Thus, even a basic survey asking people about agricultural practices is considered human research. Before you commence any human research you need to obtain approval from a human ethics committee, both in Australia as well as in the project country. Below are some things to think about when preparing your ethics application and conducting research using apps for data collection.

DATA SECURITY

Ethics committees are concerned about the potential risk to participants’ privacy and confidentiality of their information and so want to know what measures you will take to protect study materials from misuse, loss, or unauthorised access during and after the project. Typically, this means:

- Removing identifiers (e.g. name, address, date of birth)
- Ensuring secure storage (e.g. locked filing cabinet, password protected files)
- Restricting access to appropriate personnel

In addition, when using apps that transmit data via the cloud, the committee will want to know where the surveys will be hosted, and whether there are any security, data ownership and privacy constraints associated with the survey host.

Things to consider when using apps for data collection:

1. Security of the platform:

- Familiarise yourself with the security protocols used by the makers of the app and incorporate a statement on the same into your ethics application. Provide a link to the website in case the reviewer wants more information. For example:

  Each phone will be enabled with password protection to restrict unauthorized access. Data stored on phones is protected using AES 256-Bit Symmetric Encryption and is erased from the phone after submission to the server. CommCare uses industry standard transmission encryption (HTTPS) to transfer data to and from the Dimagi server. All access to the cloud infrastructure is protected behind a firewall and require unique VPN access permissions. All data on the server is stored using AES 256-bit Symmetric Encryption.

- Regularly download and backup your data (independent of the above)

2. Security of the data collection devices:

- Enable full-device encryption (available for Android and iPhone platforms)
- Protect the devices with passwords
- Store devices in a locked cabinet when not in use
- Upload data to the cloud regularly so data isn’t lost if the device grows legs

3. Design of electronic form:

- If possible, do not collect identifying information from the electronic form (e.g. name, address). Use unique identifiers instead (for both research participants and enumerators). That way if data is lost or falls into the wrong hands, there really isn’t any concern about loss of confidentiality. Keep a separate (paper-based) log of participants so that you can follow-up or provide feedback to participants at a later date.
- Switch off GPS if geolocation data is not required for the project. If GPS data is required, carefully consider who will be able to access the data and strip GPS data prior to sharing the dataset, as needed.

DATA OWNERSHIP AND DATA SHARING

One of the advantages of using apps for data collection is the potential for near real-time sharing of data – whether this is with farmers, field researchers, project leaders or ACIAR. However, this changes how partners relate to the data and may impact relationships between partners. Under traditional, paper-based data collection systems, it is typically the in-country partners’ role to collect data and enter it into a database (see Figure). This process embeds a sense of data ownership to the in-country partner and there may be sensitivities around perceived loss of control of the data in the move towards use of apps. Further, real-time sharing makes it possible to monitor frequency of research activity (e.g. who is entering data and when). Enumerators and field researchers may see this as an attempt to “check-up” on their progress.

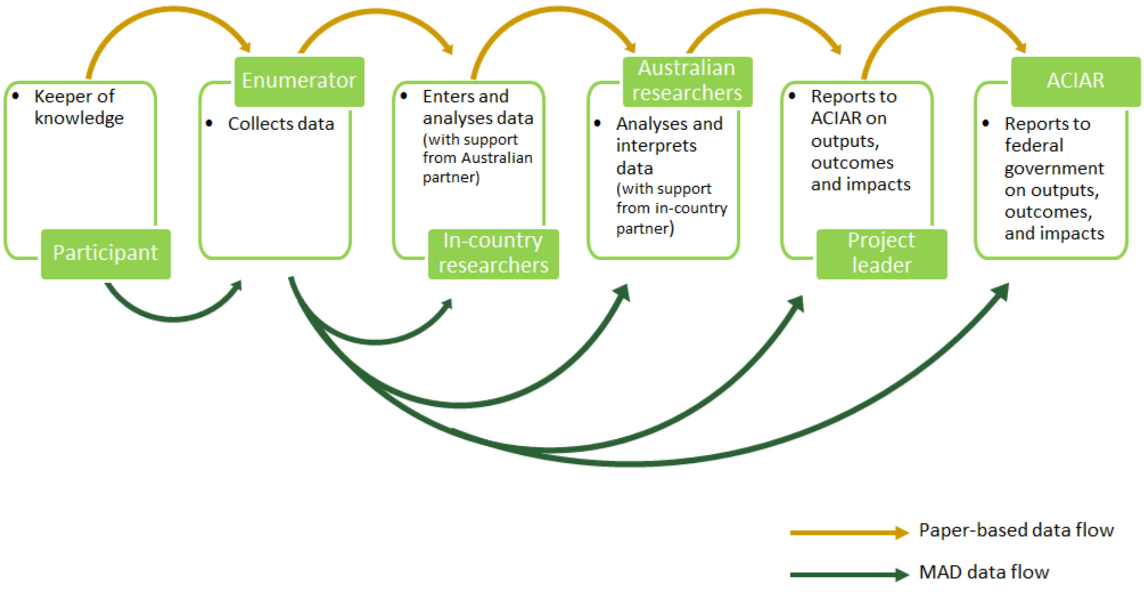
Keeper of knowledge
Participant
Enumerator
Collects data
Enters and analyses data (with support from Australian partner)
In-country researchers
Australian researchers
Analyses and interprets data (with support from in-country partner)
Reports to ACIAR on outputs, outcomes and impacts
Project leader
ACIAR
Reports to federal government on outputs, outcomes, and impacts
Paper-based data flow
MAD data flow

Figure 1. Data value chain using traditional, paper-based collection methods and MAD.

When adopting apps for data collection consider:

1. Engaging in discussions with senior in-country partners

- Proactively discuss these issues with in-country partners during the data sharing agreement process. Explain the proposed data flow and discuss any concerns of in-country partners. Help them understand the advantages that apps can offer the project, particularly those which benefit the in-country partners (e.g. higher data quality, reduced workload through avoiding data entry step). Incorporation of apps also offers immense capacity building opportunities for in-country partners. Once teams are trained they can use the platform for other projects – and put their institution ahead of the curve by using innovative methods

- Assign Form Administrator roles to senior in-country partners so that they can monitor the data at their discretion
- Send regular backups of the databases and data summaries to senior in-country partners to keep them engaged in the process

2. Engaging in discussions with enumerators and field researchers

- Use apps as an opportunity to engage enumerators and field researchers in the research process. Show them how you set the forms up, what the data looks like when it is sent up to the cloud, and what you do with it. This is an important
- Foster a culture of constructive feedback, providing feedback to enumerators on their performance. Some applications have the ability to monitor the time it takes enumerators to complete a survey. In the MAD pilot the project managers were able to use this to identify enumerators who were quickly moving through the survey and possibly missing important information.
- Invite feedback on the electronic forms and any challenges they are having with implementation in the field. Consider redesigning electronic forms to help with their workflow.

INFORMED CONSENT

The need to obtain consent is linked to the ethical principle of “respect for persons” meaning that people have the right to make decisions about their participation in research and do so based on a good understanding of what is involved. The need for consent extends beyond taking photographs; it should be sought any time a researcher wants to collect any data from a participant. Typically, ethics committees require a formal, written process of consent however in some contexts other formats, such as oral consent, may be approved by the committee.

Consider incorporating apps into the consent process by:

- Exploiting the interactive interface to share and discuss the project with potential participants prior to inviting them to sign the consent form
- Using the draw functionality to capture participant signatures, or in case of oral consent, the signature of the independent auditor-witness
- Using the audio or video functionality to document oral consent
- Incorporating form logic so than enumerators cannot proceed to ask questions without explicitly acknowledging that consent has been given

REPORTING ADVERSE EVENTS

Researchers are required to notify the relevant ethics committee if there is an adverse event or unanticipated problem (e.g. loss of research data, participant has a bad experience with a study procedure). In these cases, researchers may need to retrieve information about participants on short notice, which can be challenging if devices are regularly purged of records after data is uploaded to the cloud.

When using apps for data collection consider:

1. Reporting requirements

- What minimum data are you required to report in the event of an adverse event? Consider keeping this information in the participant log or other (paper-based) format so that in-country partners can retrieve it quickly.

2. Access to the data

- If paper-based logs will not be kept, consider who will need to access the data for reporting purposes and how they will access it. If data will be accessed by connecting the data collection device (e.g. tablet) to a computer, ensure that the file is easily interpretable. Alternatively, consider granting Form Administrator privileges to relevant people, so they can login and view the database online.