

# Priorities for Local AIDS Control Efforts (PLACE)

## DATA USE AGREEMENT

A data use agreement is recommended to ensure that the data are used to improve the program and that the participants cannot be harmed by the study, either individually or as a group. Generally, data use agreements are entered into by the funders of the study, the implementers of the study, and service delivery providers.

This data use agreement must be adapted to the situation. It should reflect the policies of the funder, the implementing organization and service delivery providers.

Protecting participants includes protecting the data after they are collected. Recommended elements of a data use agreement are below:

### **Protecting the Confidentiality of Personal Identifiers**

- Personal identifiers should not be collected from participants, but if they are, personal identifiers should be stripped from the data before they are shared. Personal identifiers are birthdays, residence, medical record number, national identification number, or any sequence of information that allows deductive disclosure of an individual.
- Under no circumstances should data with personal identifiers be shared outside the study team or emailed.
- Data should be transferred from the field to the research office through a secure server managed by the research team.
- GPS coordinates should be protected with the same level of confidentiality as personal identifiers.
- Data stored on a desktop in-country (if this applies) should be on a password-protected computer in an encrypted file. The computer should be in an office that can be locked and only limited staff should have access.
- If your data collection involves collecting or transferring data via mobile devices, those devices need to have encryption features activated (and the remote-wipe feature if relevant and an option).
- Photos that include people must only be used with the consent of the participants.

## Sharing Data

- Service delivery providers should be provided access to the data but the access should be within the context of a workshop that includes training on data confidentiality and how to interpret the data.
- Maps should be labeled so that key populations are not at risk. It is not ever permissible to publish a map of sex worker or MSM venues.
- Data use should involve representatives of the populations from whom the data were collected. For example, data use should engage managers of bars and clubs, members of sex worker organizations, and other groups that contributed to the study and should benefit.
- Publication of the findings should ensure that the primary aim of the publication is to improve the public health and the engagement of local stakeholders and groups affected by the results.
- It is reasonable to engage the Principal Investigator and the Steering Committee in the publication and interpretation of the findings.
- Data must never be used to harm populations or shame communities.
- Constructing a public use data set is recommended. The data set should include the data collection instruments, the protocol, the de-identified data, information about each variable and how it is coded, and sampling weights.

Signed: \_\_\_\_\_

Organization: \_\_\_\_\_

Date: \_\_\_\_\_

Signed: \_\_\_\_\_

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