Ensuring compliance with the LINKAGES Data safety and security checklist

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LINKAGES, funded by PEPFAR and USAID, is the largest global project dedicated to key populations—sex workers, men who have sex with men, people who inject drugs, and transgender people. The project is led by FHI 360 in partnership with IntraHealth International, Pact, and the University of North Carolina at Chapel Hill.

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Foreword

HIV service delivery programs must "do no harm" for both their project staff and program beneficiaries. The safe management of project data—which often contains highly sensitive individual beneficiary and community information—is part of that duty. To support implementing partners in the safe management of project data, the USAID- and PEPFAR-funded Linkages Across the Continuum of HIV Services for Key Populations Affected by HIV (LINKAGES) project developed an electronic Data Safety and Security Checklist designed to be used with the tips contained in this document. We offer these tools as working documents that can be downloaded and used to assist HIV program implementers, and especially those working with members of key populations—gay men and other men who have sex with men, people who inject drugs, sex workers, and transgender people—as they implement safe and high-quality programs.

Introduction

Data safety is vital for the protection of individual service users and project staff and for the integrity of the project. The confidentiality of service users is of paramount importance, both ethically and for the implementation of effective programs. Breaches in service user confidentiality can lead to blackmail, physical and/or sexual violence, job loss, loss of custody of children, and the widespread marginalization of service users, as well as a loss of trust in health care services that negatively affects service uptake. Breaches in data safety can harm implementers who are targeted for their involvement in service provision. For the project, a failure to protect data can result in an inability to provide appropriate services or report on activities. To protect service users' data, implementer

safety, and programmatic integrity, LINKAGES developed a list of actions that should be taken by implementing partners (IPs) collecting, managing, analyzing, and storing such data, referred to as the Data Safety and Security Checklist. IPs and strategic information (SI) backstops should use the checklist and this more detailed guidance on implementation to ensure adequate protective measures are in place.

The left column includes the checklist item from the Data Safety and Security Checklist and additional information on how to operationalize Please note: The checklist and this guidance document support data safety and security for HIV programs using paper and electronic data collection tools and databases. It does not cover communications transmitted and stored on online and mobile platforms such as Facebook or dating websites. Guidance for data safety in online HIV programming can be found in LINKAGES's Vision for Going Online.

that item. The right column includes example documents (or elements of such documents) to support operationalization. It also includes illustrative language in italics to help populate those documents. Illustrative language is meant only to help IPs think about the content of the documents and is not meant to be prescriptive.

Section 1. Paper Records

examples) of documents requiring safe rage with date of last review • Sign-in sheets • Clinical records • Outreach logs • Individual tracking data being used for microplanning
 rage with date of last review Sign-in sheets Clinical records Outreach logs Individual tracking data being
 scription of safe storage location and tections in place File cabinet with lock Only select staff have access to key, which cannot be duplicated
mes of staff with access to papered data and date of last review • Staff name, date access began, date ended • Date of last review med Data Safety Point of Contact abook which tracks access to safe rage location

- 4. Does the implementing partner have guidelines and protocols for handling individual records, including a list of staff responsible for moving data to safe storage?
 - An easy-to-use graphic depicts data movement (e.g., from peer educators to data entry personnel) and names each individual and their position; it refers to protocols for safe handling of individual records.
 - Each job description for positions that entail data handling contains specific responsibilities around data storage and record handling, including a confidentiality clause.
 - A confidentiality statement should be signed by all those named as having access to identifiable data, including paper- and electronic-based. An example of a confidentiality statement can be found in the <u>Program Monitoring Guide</u> (p. 22). These must be safely stored so they can be referred to as needed.
 - Staff responsible for data entry (i.e., when paper-based data is entered into an electronic format), such as a monitoring and evaluation (M&E) officer, should also be named and sign the confidentiality statement.

Graphic describing how data circulates within the organization and program

List of job descriptions that include safe data storage and record handling practices

- Peer outreach worker
- Peer navigator
- Drop-in center (DIC) manager
- Monitoring and evaluation (M&E officer

List of staff responsible for moving data with date that each person signed confidentiality agreement

Section 2. Electronic Data Systems

Instructions **Documents to support** operationalization (with illustrative examples) 5. Are all databases password protected? Log to track that all computers have Computers require passwords to open them; passwords, and all databases have databases should require an additional, separate passwords password. Ideally, there will also be an administrative access password separate from Date that passwords were last changed on computers where data is stored the user's password. A strong password will be around 10 characters Date that passwords were last changed or more and, where possible, always include on databases upper-case letters, lower-case letters, numbers, and symbols. Do not write down passwords to share them. Passwords should be changed every three months, with additional changes if security has been compromised or with staff departure.

¹HeartMob. Technical Safety Guide [Internet]. Hollaback!: 2019. Available from: https://iheartmob.org/resources/tech.

Systems to prevent sharing of passwords should be in place (two persons should not have the same log-in credentials). 6. Is access to passwords for databases and electronic Names of staff with access to electronic data controlled? data and dates that access began and ended Any data containing identifying information must be in a password- protected file, including when sent by email or uploaded to the Cloud. Describe who can access the database to enter data and to see the full database. Two different passwords are required for data entry versus access to the full database. 7. Are unique identifier codes (UICs) used instead of UIC generation guidance other identifying information such as client name? The process of developing UICs should follow the Program Monitoring Guide (p. 23). 8. Are electronic data securely backed-up and stored Describe backup either in the Cloud and/or on an external drive in a Cloud remote location outside of the implementing partner USB drive offices? CDThe IP should decide on whether to use Cloud or Date of last backup local storage based on local guidance from government and the cost of Cloud storage Describe data protection (which will depend on the size of data to be Password stored). Encryption Safe Cloud storage requires a password. If Safe location of hard drive possible, use an encrypted storage platform such as Google Drive. A portable backup storage device (e.g., a CD or USB drive) should also be password protected, and its location known only to those who have access to the full database. Data must be backed up weekly. Have a description of protections for backed-up data. 9. Does the implementing partner have a protocol for Illustrative language: changing passwords when staff depart? Whenever a staff member, consultant, or other individual with access to stored Each time a staff member with access leaves the data or the ability to enter data is fired organization, the password must be immediately or leaves the organization, his or her changed. If the staff person is being terminated, the password should be changed before the access will be terminated. If he or she decision to terminate is communicated to them. has a log-in name, the name will be deleted. In the case of firing, access to If a staff member is changing positions within data will be stopped before the decision the organization and will no longer have access is communicated to the employee. to the database, the password must also be changed immediately. 10. Is the implementing partner's database hosted on a Describe server protections in place, for secure web server? example:

- Whenever using an external cloud space to store data, the project should ensure that the web server is secured and has all the necessary security arrangements. Extra care should be taken if real time data collection is employed (e.g., DHIS2 tracker for individuals).
- Software used for cloud-based databases should automatically allow for encryption of data during transmission. DHIS2 meets this requirement.
- Use of a secure file transfer protocol (FTP) instead of plain FTP
- Use of a secure shell (SSH) instead of telnet
- Securing all web administration areas with secure sockets layer (SSL) (HTTPS)
- Securing your web forms with SSL (HTTPS)
- Use of firewalls on all endpoints, including servers and desktops
- 11. Is the implementing partner's database-hosting software updated whenever a new version or patches become available?
 - Particularly if the project uses real time data entry, make a provision for updating the system whenever a new version is available. Updates help execute new features of the software, including security protections.
 - Software updates often include patches.
 However, a stand-alone patch (or patches) may be released to fix critical security errors. These should also be employed immediately to avoid vulnerabilities.

Documentation can include a comparison of the current version of the software to the most recently released version.

Section 3. Data Sharing and Destruction Procedures

Instructions **Documents to support** operationalization (with illustrative examples) 12. Does the implementing partner have Guidance for Type 1 data sharing protocols/guidelines for sharing data? (illustrative language): When sharing information for data This protocol should provide guidance on the two analysis and reporting, no identifying types of data sharing that occur. information (e.g., service user name, email, address, phone number, date of Type 1: sharing for analysis and reporting birth) can be included. Information will When sharing information to individuals who are outside the project and/or who will not not be disaggregated to such a level that it becomes possible to identify an be providing services, identifying information should not be shared. This includes the individual. Information on location of service user's name, address, and telephone individuals, including hot spots, should never be shared beyond the project. number. Information that is disaggregated should not Data can be shared upon requests be disaggregated to the point where made to [insert staff person name and individuals could be identifiable. Locations of

KP members as a group should also not be shared. Sharing hot spot maps, even without street names, should not be done. More guidance specific to hot spot mapping and size estimation data collection and handling can be found in Mapping and Size Estimates of Sex Workers: Proceed with Extreme Caution.

- The process for requesting data and the format in which it can be shared (printed, electronic, as a summary report, etc.) should also be described.
- If there are concerns that Ministry of Health or other local officials will request identifiable data, this guidance will benefit from high level approval from the National AIDS Council or equivalent.
- Type 2: sharing to support service delivery in a way that benefits the individual service user (e.g., when someone is referred between facilities)
 - Describe that identifying information can be shared only with the informed consent of the KP member. Mechanisms in place to share information, such as accompanied referral or written referral slips, should also be described.
 - Describe ways in which job responsibilities and geographic areas of work will dictate the identifiable information that is shared with individual IP staff or volunteers. For example, peer educators will need to have information that corresponds to the type of services they provide within the communities where they work. However, they should not have information about individuals in communities beyond their geographic purview and should not have access to clinical results (such as HIV or sexually transmitted infection [STI] test results), or other information that a service user shared with health care workers (HCWs) or other program staff (such as experiences of violence) unless the service user has consented that this information can be shared.

title] as summary printed and/or electronic reports.

Guidance for Type 2 data sharing (illustrative language): Identifying information shared with service providers for the benefit of the service user (e.g., HIV status) requires the informed consent of the service user. This means the service user understands what will be shared, with whom, and why.

Peer educators will have access only to identifiable information that they collect or that corresponds to relevant service history (such as condom distribution) in those geographic areas where they work. They should not have specific individual's clinical results (e.g., HIV and STI testing results) or anything else disclosed to other project staff in confidence (e.g., experiences of violence) unless the individual has given informed consent for this to be shared. They may have aggregate data on incidents of violence at a hot spot in their geographic area to understand HIV vulnerability.

- 13. Does the implementing partner keep a list of individual(s) with the right to destroy data if its protection cannot be guaranteed due to an emergency?
 - Provide the names and positions of those who can destroy identifying data outside of

Names and positions of staff with right to destroy data

(illustrative language)

Destruction of data should be the last option and used only if there are no other alternatives to protect data. Data

compliance with donor specifications in case of an emergency (a general rule of thumb is to keep paper data for five years; for organizations with clinical files, follow Ministry of Health rules and policies regarding data storage). Clearly outline how such a decision can be made and by whom and have it reviewed and approved by the donor(s) to your program. can be destroyed if it is not possible to protect identifiable data (the program data is under threat). The decision that such a threat is imminent can be made by [name and title].

14. Is a protocol in place for the safe destruction of records?

- Each donor will have their own guidelines regarding how long paper and electronic records must be kept. Follow these guidelines unless there is an emergency that requires earlier destruction of data (see #13).
- Electronic data should be destroyed completely.
 Note that simply deleting a file does not destroy it. Choose from the destruction options described here:
 - https://studentprivacy.ed.gov/sites/default/files/resource_document/file/Best%20Practices%20for%20Data%20Destruction%20%282014-05-06%29%20%5BFinal%5D_0.pdf.
- If needed, paper records should be destroyed using cross-cut shredders, pulverizers, or incinerators.
- Destroy CDs, DVDs, and any magneto-optical disks by pulverizing, cross-cut shredding, or burning.
- The process of how data will be destroyed, including on what timeline, should be included.
 This can serve as the protocol.
- Each time data is destroyed the process for destruction should be described in detail and signed by the person who has destroyed the data.
- Review the protocol quarterly to ensure that it meets your needs and reflects your current staffing structure.

How long should paper data be stored?

How long should electronic data be stored?

Specific guidance from the Ministry of Health on the storage of clinical records

How paper-based records will be destroyed

How electronic records will be destroyed

Documentation of past data destruction, including date and method used

Section 4. Staff Training and Management

Instructions	Documents to support operationalization (with illustrative examples)
 15. Were all program staff trained in data confidentiality within the past year? Training should include skills building on how to encrypt and password protect electronic files. Training in confidentiality should cover Who will be responsible for collecting and recording information Where and how information will be collected and recorded How information will be stored Who will have access to the information, including what information will be shared within a facility or with third parties (such as providers within a referral network) The training will also describe the consequences of sharing identifying information. 	Training content developed List of trained staff with date of each person's training
 16. Are protocols in place to guide action in case individuals intentionally violate data confidentiality regulations? Intentionally violating data confidentiality regulations—for example, sharing a client file with another staff person who should not have access to it—will be grounds for employment termination. Large-scale breaches in confidentiality—such as sharing a database—or the use of client records for purposes such as blackmail will be prosecutable under local law as long as such action does not endanger the project or any of those it serves. Accidental breaches in confidentiality require retraining and may result in reduced staff responsibility (including less or no access to records). Violations of confidentiality should be documented, with outcomes recorded. Verbal disclosure of confidential client information—such as a peer educator disclosing a client's HIV status in conversation—should also be documented and include appropriate consequences, such as retraining or termination, based on the severity and intentionality of the disclosure. This document 	Record of breaches in confidentiality, including: date, person who committed breach, description of incident, outcome for the project, and disciplinary action taken against staff person Signed Oath of Confidentiality for each implementing partner staff

focuses on breaches involving written or
electronic data. For more on any breach of
confidentiality, refer to the Oath of
Confidentiality in the Program Monitoring
Guide (pg. 22), which should be signed by each
implementing partner staff who has access to
confidential information.