Privacy and Security Basics for Self-Management Participant Data Collection

Updated January 2016

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Training Overview

- Purpose of the Privacy Act
- Primary Features of the Act
- Who Needs Privacy Training?
  - Master trainers and program leaders or lifestyle coaches
  - Program coordinators
  - Anyone else involved with participant data collection or transfer
- Types of Information Protected by the Act
- Disclosure
- Safeguarding, Transporting and Disposing of PII
- Roles and Responsibilities
- Test Questions
- Certificate

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Privacy Act of 1974 Public Law 93-579 (5 U.S.C.A. 552a)

- Purpose: to protect records that can be retrieved by personal identifiers such as a name, social security number, or other identifying number or symbol.
- The act was created in response to concerns about how the use of computerized databases might impact individuals' privacy rights.
  - requires government agencies to show individuals any records kept on them
  - requires agencies to follow "fair information practices," when gathering and handling personal data.
  - places restrictions on how agencies can share an individual's data with other people and agencies.
  - lets individuals sue the government for violating of these provisions http://epic.org/privacy/1974act /

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Who Needs to be Trained?

- If your work involves the management of sensitive information, PII (Personally Identifiable Information), or protected health information, you need to ensure you are taking precautions to protect it from unauthorized access/disclosure, theft, loss and improper disposal.

Who Needs to Be Trained?

- Employees,
- Managers,
- Supervisors,
- Coordinators,
- Master trainers (MTs), and
- Lay leaders (LLs), including volunteers who are involved in the collection, handling, and/or data entry of Personally Identifiable Information (PII) on individuals participating in CDSME.

What Type of Training is Needed?

- Training for program coordinators and program implementers
  - The rights of individuals participating in CDSME
  - The appropriate protection of PII shared by CDSME participants at the workshop level
  - The appropriate storage and transfer of participant forms
- Training for individuals completing data entry and data transfer
  - The appropriate protection of PII shared by CDSME participants at the workshop level
  - The appropriate storage, transfer and destruction of data forms
  - Security requirements for electronic data transfer, storing and degaussing (destruction)

Types of Information Covered by the Privacy Act

- Sensitive: if the loss of confidentiality, integrity, or availability could be expected to have a serious, severe or catastrophic adverse effect on organizational operations, organizational assets or individuals.
- Protected Health Information: Individually identifiable health information that relates to a person's past/present/future physical/mental health, health care received, or payment.

http://irtsectraining.nih.gov/publicUser.aspx

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Information Protected by the Privacy Act

PERSONALLY IDENTIFIABLE INFORMATION (PII)

- Home address
- Home telephone number
- Complete date of birth
- Personal medical information
- Social Security Number (including just the last four digits of SSN)
- Personal/private information (if the information can uniquely identify the individual)
- Photographs
- Education records
- Financial transactions
- Employment history

Information Protected by the Privacy Act

PERSONALLY IDENTIFIABLE INFORMATION (PII)

"the term Personally Identifiable Information means any information about an individual maintained by an agency, including, but not limited to, education, financial transactions, medical history, and criminal or employment history and information which can be used to distinguish or trace an individual's identity, such as their name, social security number, date and place of birth, mother's maiden name, biometric records, etc., including any other personal information which is linked or linkable to an individual."

http://www.gsa.gov/portal/content/104276

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Disclosure

- No agency or person shall disclose:
  - any record
  - by any means of communication
  - to any person or another agency
  - without a written request or prior written consent of the individual to whom the record pertains
- "any means of communication" includes oral (phone, in-person), written and electronic (emails, faxes, texts, tweets, pins, etc.)

http://www.dodea.edu/upload/2011_patrainingslides.pdf

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Safeguarding PII

- PII must always be treated as “FOR OFFICIAL USE ONLY” and must be marked accordingly.
- This applies not only to paper records (including e-mail, faxes, etc., which must contain the cautionary marking “FOR OFFICIAL USE ONLY – FOUO”).
- All records containing PII should be stored in locked filing cabinets or other secure containers to prevent unauthorized access.
- Electronic records must be password protected and be transferred via encrypted e-mail.

Transporting PII

- Hand Carrying
  - Use a Cover sheet to shield contents
- Using Mail
  - Use manila or white envelopes
  - Mark the envelope to the attention of the authorized recipient
  - Never indicate on the outer envelope that it contains PII
- Using E-mail:
  - Password protect personal data placed on shared drives, the Internet or the Intranet
  - Use encrypted e-mail
  - Do not send PII to a personal, home or unencrypted e-mail address
  - Announce in the opening line of the text (NOT the subject line) that FOUO information is contained

http://www.dodea.edu/upload/2011_patrainingslides.pdf

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Disposing of PII

- A disposal method is considered adequate if it renders the information **unrecognizable** or **beyond reconstruction.**
- Disposal methods may include:
  - Burning
  - Melting
  - Chemically decomposing
  - Pulping
  - Pulverizing
  - Shredding
  - Mutilating
  - Degaussing (erasing from magnetic field or disc)
  - Deleting/Emptying Recycle Bin

www.dla.mil/.../Privacy%20Act%20103%20Safegarding%20Privacy%20

Your Role and Responsibility

- Take privacy protection seriously
- Respect the privacy of others
- Ensure messages, faxes and e-mails that contain personal information are properly marked and e-mail is encrypted
- Make sure you have consent forms in place for PII
- Don't share PII with individuals who are not authorized
- Have appropriate transfer, storage and disposal protocols in place for PII
- Do not e-mail PII to personal, home or unencrypted accounts

Your Role and Responsibility

- Advise all participants of their right to consent or refuse use of data about them
- Provide participants with a blank copy of the participant information form
- Read the leader welcome script

Stanford Program Master Trainers and Leaders

- Use the following Program Group Leader Script at a Class Zero pre-session or at the start of Session 1 and with any new participants who start at Session 2
  - The script explains why participant data is being collected and how it will be kept secure
- Emphasize that completing the participant info form is voluntary
  - Individuals may skip any questions they do not want to answer
  - Individuals may choose to not complete the form, but they can still participate in the program

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Leader/Lifestyle Coach Welcome Script

- This workshop is made possible by [*support from X funding agencies/ sponsors*].
- We hope that you will be willing to share information about yourself on the participant information form.
- This information is very valuable to us. We use it to learn who is taking the program and to improve our services. It also helps our funders show that they are spending their money wisely.
- Before you fill out the form, we want to explain how we will protect your information.

Leader/Lifestyle Coach Welcome Script

- At the top of the form, we ask for your initials. We only use these to match your information to an Attendance Log. This helps us to track how many times you come to class. **Please do not write your name on this form**.
- Any information you choose to share (minus your initials) will be entered into secure databases. Your information will be combined with information from other participants, and only combined information will be used. This information will not be linked to your name or initials in any way.
- We will follow very strict rules to protect your information and to keep it private. We will maintain these paper forms securely. After a trained person enters your information into a secure computer, we will destroy the paper forms.

Leader/Lifestyle Coach Welcome Script

- You do not have to complete the form. You may skip any questions that you do not want to answer. If you decide not to complete the form, you can still participate in this workshop.
- While filling out the form, you may ask us to explain any questions that you find confusing.
- **Thank you again for taking a few minutes to complete this important participant information form.**

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Your Role and Responsibility

- Collect participant information forms from individuals who choose to fill them out
  - Discourage people from writing their name on forms
  - Collect forms individually – don't allow them to be passed around
- Store forms in sealed envelope and give to your program coordinator

Non-Disclosure Agreements

- All individuals involved in providing self-management programs should sign Non-Disclosure Agreements
- All individuals involved in data collection, data transfer and/or data entry into Oregon Compass should sign Non-Disclosure Agreements
- Non-Disclosure Agreements should be sent to OHA. We will store them for three years as required by law.

Non-Disclosure Agreement Text

- I will not disclose any personally identifiable information provided by self-management workshop participants.
- I will follow all standard safeguards for protecting this information, including transmitting data forms in sealed envelopes and storing them in secure, locked locations; not sharing passwords non-approved users; and not leaving open computer screens in Compass unattended and/or accessible by non-approved users. I further agree to comply with all current Federal, state, and municipal laws governing protection of data entered into Compass.
- I understand that unauthorized disclosure of any sensitive participant data will result in termination of my access to Compass, and that other entities may subject me to disciplinary action as well as potential legal prosecution.

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Test Questions – Circle all correct answers

1. Information about an individual that is unique, or identifies or describes him or her (such as Social Security Number, medical history, date of birth, home address) is called:
   a. Interesting
   b. Record
   c. Data
   d. Personally Identifiable Information

Test Questions – Circle all correct answers

2. Disposal methods may include all except:
   a. Burning
   b. Shredding
   c. Tearing in half and putting in the garbage can
   d. Melting

Test Questions – Circle all correct answers

3. The leader / lifestyle coach script:
   a. Describes what participants will learn in the workshop
   b. Requests participants to share their birth date, address and sex
   c. Explains how participant privacy is protected and why data is being collected
   d. Emphasizes that participants are required to complete all survey forms

Test Answer Code

1. d - Personally Identifiable Information
2. c - Tearing in half and putting in the garbage can
3. c - Explains how participant privacy is protected and why data is being collected

Privacy and Security Basics Training Certificate

_____

(Name)

I have successfully completed the
Privacy and Security Basics Training for
Chronic Disease Self-Management
Program Implementation and Data Collection

_____

(Signature) (Date)

Congratulations!

Congratulations! You've completed the Privacy and Information Security Basics training.

Please print the certificate of completion (slide #27) and send the signed, dated original or a scan to OHA:

OHA/Oregon Public Health Division, attn: Self-Management Team
Health Promotion & Chronic Disease Prevention
800 NE Oregon Street, Suite 730
Portland, OR 97232
living.well@state.or.us
Fax: 971-673-0994

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