Patient Organization Training Framework

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Demographic Considerations

- Disease may impact motivation to attend training.
- Transportation may present a challenge to attend onsite location.
- Older individuals may face challenges using technology.
- Age and disease may impact dexterity and ability to interact with kinesthetic activities.
- Age and disease may impact ability to retain information.
- Age and disability may impact vision and ability to read text or graphics.

Needs assessment

Patients will want to know about health data that is relevant to them: (Hypothesized- further research may be needed)

- How to obtain it
- Their rights to obtain it
- Personal help troubleshooting their request for data
- How to interpret data *Further definition necessary*
- Address privacy issues around donating data for research
- Discuss insurance companies may use their data.

Learning objectives

1. Be able to explain the definition of Health Data
   a. Give examples of what Health Data are.
2. Know their right to:
   a. Request record and access certain health records
   b. The cost associated with receiving records
   c. The formats in which they can receive records
3. How to request data:
   a. Identify the different methods to obtain health records.
   b. Know where to find resources if they encounter challenges when obtaining data.
4. Be able to identify places where data go that are not HIPPA protected.
5. Understand how insurance companies can use health data and how they receive this data.

Consideration of learning styles

- Visual learner
  - Include graphics to illustrate where health data goes and not just narration.
- Auditory learner
  - Some portion of the instruction should involve the trainer orating key points.
- Kinesthetic learner
  - Provide an opportunity for a "hands-on" activity (
    - For example- a script that involves role play different parties involved in health data.

Delivery mode

1. FasterCures trains a member of a patient organization to provide lesson during support group meeting:
2. Online resources are, as well as teacher guides are accessible for patient organizations to learn how to conduct a training.
3. Online resources about health-data are referenceable directly by patient through the patient organization forums and website.

- A separate option to consider would be a web-based training.

Budget

- Estimated budget depends on implementation.

Delivery style

- Engaging
  - Change activity every 10 minutes:
  - Consider small breakout discussion groups.
  - Encourage attendees to develop a hypothesis then discover whether that is correct or not.
- Encourage recall and repetition in a fun way
  - Consider quizzing attendees on key concepts in a fun way
    - Examples include Jeopardy, headbands, or Pictionary.

Audience.

- Content should be prepared for both caregivers as well as patients.
- Possibly separated by groups for specific discussions

Time

- One time 60 minute training.
- A series of short follow up recall activities can also be included for groups that meet regularly to be conducted at future meetings.

Marketing

- Pre-made training descriptions and email messages that organizations can use to reach out to attendees.
- Pre-made graphics for organizations to include on social media event pages or their website.

Measuring effectiveness of training.

- Visitors count to website
- Post-training survey
- Recall percentage during activity