# Human Subjects & Ethics in Evaluation

Evaluation Lab ECHO Learning Community
November 19, 2019
Melissa Binder



### Human Subjects

#### Human Subjects Principles

Respect
Beneficence
Justice

#### **JUSTICE**

Goal is to improve program for participants

Strive to get multiple voices, from your less-satisfied participants as well as your fans

#### **BENEFICENCE**

There should be a good reason for every piece of information you collect

Don't be data-greedy

#### **RESPECT**

- 1. Full information
- 2. Voluntary participation
- 3. Confidentiality
- 4. Privacy

#### 1. Full information – at intake

- let participants know that their data may be used for evaluation and quality improvement
- note that evaluations report group averages and will never use a name or other identifying characteristics
- have participants sign a statement that they are ok with using their data for evaluation--it can be part of a general waiver

## 1. Full information – for focus groups, interviews and surveys

- explain the purpose for asking questions
- explain that quotes and stories will be used, but names will never be used without written consent

#### 2. Voluntary participation

Surveys, focus groups and interviews for evaluation should be voluntary

- allow people to skip questions in a survey
- or remain silent in a focus group

#### 3. Confidentiality

Don't publicly identify participants without their written consent.

Require written assurance that external evaluators and state agencies will preserve participant confidentiality

- Password protect files that you share
- Ask collaborators to agree in writing to password protect files and store on password-protected computers

#### 4. Privacy

Participants decide what they share for evaluation, with full information that you may share stories and quotes.

- Never identify anyone by name or identifying characteristics without their written permission

#### UNM Evaluation Lab focus group consent

We are interested in understanding how participants experience our programs, and that's what this focus group is about.

The focus group will take about an hour.

Your participation is voluntary.

We will take notes and record the discussion to make sure we understand what you said, but we are not going to keep names. If anyone would rather we not record, we won't!

We may use the information you share in a report with quotes, but, again, we won't use your name.





#### UNM EVALUATION LAB Informed Consent for Interviews 2018-2019 <check Learn for updates>

The Evaluation Lab works with organizations to help them figure out how they are doing and where they might improve. (organization) is interested in understanding how participants experience its programs, and that's why we are interviewing you. The interview will take about an hour. Your participation is voluntary and what you choose to share is totally up to you. A member of the research team will take notes and record the discussion to make sure we understand what you said. We won't share the recording with (organization). Once we have reviewed the recording to make sure our notes are accurate, we will destroy the recording. If you would rather we not record the interview, then we won't. We may share your story with (organization) and we may include your story in written reports. We won't use your name in the written reports, including reports that may be posted on the internet. If you have any questions about this evaluation project, or the Evaluation Lab, please feel free to call the Evaluation Lab Director, Melissa Binder, at (505) 277-3548. It's fine to record the interview Do not record the interview Name of Adult Participant Signature of Adult Participant Date Name of Research Team Member Signature of Research Team Member Date

#### **Evaluation Ethics**

#### Embrace the whole story

- be curious about how you can better achieve your mission
- hear from fans and less-satisfied
- report negative findings internally and to funders
- pluses and deltas
  - Credibility
  - Continuous quality improvement

#### Your ideas