

# Data Collection Best Practice: Informed Participation



The Massachusetts Collaborative for Action, Leadership, and Learning 3 (MassCALL3) and State Opioid Response – Prevention in Early Childhood (SOR-PEC) initiatives both require the collection of various types of information to inform the design and delivery of grant-related services. This information may be collected through structured interviews and focus groups with community members.

Grantees have an ethical obligation to ensure *informed participation*. This means that all involved individuals fully understand the purpose of the data collection activity and how the information being collected will be used.

**KEY ELEMENTS OF INFORMED PARTICIPATION.** Independent of the type of activity or the age of individuals to be engaged, the following information should be communicated to all participants either verbally or in writing in advance of data collection:

- **Purpose:** Why are data being collected?
- **Method:** What is the nature of the data collection activity (e.g., focus group, interview)? How will data be captured (notes, recorded, video)? Who will be collecting these data?
- **Identifiers:** Will any personally identifying information be collected and, if so, how will this information be treated in reports, presentations, or other data dissemination channels?
- **Data Use:** How will these data be used (e.g., internal planning, presentations, reports, PowerPoint)? Will participants have access to the final product?
- **Potential Impact:** Have you discussed how these data may impact the participants and/or their community (both positively and negatively)?
- **Rights:** Have you made clear that participants can end their participation at any time without penalty?

**INFORMED PARTICIPATION WITH ADULTS (18+).** In most cases, adults (18 years and older) can provide direct on-site verbal assent to participate in the data collection activity without further action.

**INFORMED PARTICIPATION WITH MINORS (Under 18).** *Best practice* is to first seek verbal or written permission from the minor’s parent, caregiver, or legal guardian. Once permission has been granted, the data collection team should also seek verbal assent to participate directly from the individual under 18 years of age.

**YOUTH HEALTH SURVEYS.** The guidance above is not intended to apply to youth health surveys, which are a different category of data collection. Grantees directly engaged in conducting youth surveys should adhere to best practice guidance from the MA Department of Elementary and Secondary Education, the Centers for Disease Control and Prevention, and other sources.

**ADDITIONAL SUPPORT:** If you are unsure as to how to proceed or encounter a situation that is not covered above, please contact your BSAS Contract Manager or CSPA TA Liaison for further guidance.