Attachment 7: Confidentiality and Participant Protection

1. Protect Participants and Staff from Potential Risks

The risks of participating in the Arkansas SOR 4 DHS/OSAMH grant project and performance assessment data collection are small relative to the benefits of providing substance use disorder prevention, harm reduction, treatment, and recovery support services. Participants and staff will not experience any more physical, medical, psychological, or social discomfort, nor legal risk, than what would naturally occur in their daily lives. Participation in performance and outcome assessments for all projects is voluntary. All participants are adults who will be asked various questions concerning their knowledge, opinion, and beliefs about opioid and stimulant misuse and use disorders, harm reduction, treatment, and recovery.

Risks for all participants will be minimized by providing informed consent prior to participation, allowing participants to stop at any time in the process, and ensuring confidentiality. However, in focus group settings, confidentiality cannot be guaranteed as researchers cannot guarantee that others in the group will respect the confidentiality of the group. Pseudonyms will be used to de-identify participants and other people, organizations, and places mentioned in all interview and focus group textual data collected for research. Participants will never be identified in reports or other public documents.

Participants and/or staff experiencing any adverse effects will be referred to an appropriate treatment center or service provider for guidance and/or assistance. Alternative treatments will be available upon request. Any adverse effects experienced by participants will be reported to the University of Wyoming IRB and follow IRB response protocol. Any problem that has led to an unexpected incident or unfavorable occurrence will be corrected as soon as practicable.

2. Fair Selection of Participants

All potential participants will be given the opportunity to voluntarily take part in focus groups or interviews pertaining to performance and outcome assessments. Any barriers to participation will be addressed based on the individual participant's needs and in compliance with the Individuals with Disabilities Act, (IDEA) 20 U.S.C. § 1401 et seq., Section 504 of the Rehabilitation Act (Section 504) 29 U.S.C. § 794; the Americans with Disabilities Act (ADA) 42 U.S.C. § 12101 et seq; and Arkansas state law.

3. Absence of Coercion

Incentives will be given to participants of vulnerable groups (e.g., pregnant parenting women in recovery, incarcerated parents) as a form of compensation for their time and effort and/or to help offset any barriers such as loss of income, transportation, or childcare. Incentives will be in the form of gift cards in the amount of $25. Gift card brand selection and delivery will be based on the protocols of the organization or facility collaborating with the evaluators and the needs of the participants.

Instructions given to potential participants will explain that participation is voluntary, and the ability to receive services or interventions is in no way dependent on participation. Staff will be informed that declining participation will not affect their employee standing,

compensation, or benefits in any way. Individuals will be informed that they may choose not to participate in the focus group or interview. Participants will be informed that they may choose not to answer any question and may end participation at any time without penalty.

Cultural competency strategies for communicating information to participants will include:

- Using clear and simple language to provide detailed and concrete instructions to minimize misunderstandings.
- Considering language preferences and proficiencies by using interpreters or translators when needed and speaking slowly and clearly.
- Acknowledging any power imbalances and encouraging a participatory approach where individuals feel empowered to express their thoughts and concerns.

4. Data Collection

Attachment 2 contains sample data collection instruments and protocols. We plan to collect data through interviews and focus groups with a variety of adults to examine process and outcome measures related to prevention, harm reduction, treatment, and/or recovery efforts in Arkansas. All participants will be asked various questions concerning their experiences, behaviors, and beliefs about opioid and stimulant misuse and use disorders, harm reduction, treatment, and recovery.

Research groups include:

- Program staff and service partners treating at-risk pregnant/early parenting women in treatment and recovery
- Young adults formerly in foster care in treatment and recovery
- College students participating in a collegiate recovery community

WYSAC will create focus groups and interview instruments that will be administered in person in a semi-private conference area or via a secure cloud-based internet platform. Attachment 2 of this proposal contains sample focus groups and interview instruments. The individuals who participate will be asked about their attitudes, beliefs, and behaviors concerning opioid and stimulant misuse and use disorders, harm reduction, treatment, and recovery. Interviews will take approximately 30 – 45 minutes. Focus groups will take approximately 60 – 90 minutes. The risk to participants will be no greater than what she or he might experience in everyday life. Identifiable information will never be collected from interviews or focus groups, and individuals may stop participating at any time without penalty.

5. Privacy and Confidentiality

Data will be collected during focus groups or interviews. Focus groups and interviews will take place in a) a semi-private conference area of the supporting vendor, or b) online via a secure cloud-based internet platform. All data collected will be digitally stored on password protected computers behind locked doors at the University of Wyoming. Consent forms will be stored separately in locked filing cabinets until the end of the project, after which they will be destroyed.

At WYSAC, only researchers involved in the project will have access to process measure and evaluation data. Only aggregate data will be made public in reports or presentations. Aggregated data will be provided to DHS/OSAMH to disseminate as they see fit. We expect that SAMHSA may also request access to certain data. Participant identity connected to data will not be collected in any interview or focus group.

6. Adequate Consent Procedures

Attachment 3 contains sample consent forms.

7. Risk/Benefit Discussion

Because there is minimal risk to both participants and staff involved, the potential for harm or discomfort anticipated for participants is not greater than what they would encounter in their everyday lives. Privacy concerns will be mitigated by employing strict data protection measures such as anonymization and secure data storage. Mild discomfort of participants will be managed by ensuring that they can skip questions or withdraw at any time without penalty. There will be no direct benefits to participants; however, performance assessments can offer substantial benefits to society and to the scientific community through the advancement of knowledge, leading to improved policies, services, interventions, and/or treatments.