

Client Consent Considerations

Through the act of coordinating referrals, IRIS networks collect, store, and share sensitive family information. Responsible stewardship of the family information in IRIS requires policies regarding how family information is collected, who has access to the information, and for what purposes. Client consent practices are foundational to maintaining data privacy in IRIS networks. Before their family's information is shared in IRIS, clients must understand what personal information will be collected and shared and how it will be used, have an opportunity to consider and ask questions, and voluntarily agree to provide the information. While the IRIS referral workflow contains checkpoints to confirm that client consent has been obtained, procedures for gaining consent lie outside of IRIS and are the responsibility of each organization.

COMMUNITY DISCUSSION

While each organization is ultimately responsible for developing and implementing their own consent practices, discussing consent during community meetings encourages organizations to learn from one another by sharing their own experiences and best practices. The following questions regarding consent may be answered at the organizational level but are also valuable topics of discussion among IRIS partners.

- What privacy laws and/or confidentiality regulations impact organizations' client consent?
- Can clients grant consent over the phone? What workflows support verbal consent?
- How will referrals be made if a client does not consent?
- Will information collected in IRIS be used for purposes other than coordinating services?
- Does the consent form expire?
- What happens if a client revokes consent?

In some cases, limits on the client information an organization can share will impact partners' workflows. The Local IRIS Leadership Team should work with the organization to communicate and address these implications with network partners and record workflows and expectations in Community Standards.

BEST PRACTICES

Organizations in your network are responsible for implementing consent practices that align both with IRIS best practices and any applicable privacy laws and/or confidentiality regulations (i.e. HIPAA, FERPA, 42 CFR Part 2, etc.). Organizations should involve staff well-versed in the rules and regulations when considering the impact on their consent processes, workflows, and ability to exchange client information. Some organizations may update an existing consent document to include IRIS-specific language or modify their notice of privacy practices; others may need to develop a new consent document, workflow, and staff training protocol.

Consent documents should use clear, easily understandable language and should be available in the languages spoken by the populations served.

Clients should actively consent to each of the following activities in IRIS:

- 1. Entering and storing basic family information (name and birthdate) within an electronic system viewable by other IRIS partners.
- 2. Making a referral to a specific partner organization which includes sharing family information to help the organization understand the client's needs (ex: household information, services requested, assessment results, other referrals, etc.) and how to best make contact.
- 3. Sharing the outcome of a referral with the referring organization.
- 4. Family information being viewable by one or more IRIS Data Managers, local program staff who may access client level data for technical assistance purposes.