

NEW YORK STATE OFFICE FOR THE AGING

2 Empire State Plaza, Albany, NY 12223-1251

Andrew M. Cuomo, Governor

An Equal Opportunity Employer

Greg Olsen, Acting Director

PROGRAM INSTRUCTION

Number 17-PI-02

Supersedes N/A

Expiration Date N/A

DATE: January 11, 2017

TO: AAA Directors, PeerPlace Champions, and NY Connects Coordinators

SUBJECT: Informed Consent: Questions and Responses

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ACTION REQUESTED:

Please review the questions and responses included in this Program Instruction (PI) concerning informed consent, and share the information with staff, providers of services, and users of the Statewide Client Data System.

RESPONSE DUE DATE:

No response is required.

PURPOSE:

The purpose of this PI is to provide responses to informed consent-related questions that the New York State Office for the Aging (NYSOFA) has received from Area Agencies on Aging (AAAs) and providers regarding specific circumstances and situations, in order to further clarify the consent processes described in 16-PI-16, "Statewide Client Data System: Informed Consent: Written and Verbal Consent Requirements, and How to Meet Them Beginning in the Go-Dark Period."

BACKGROUND:

As described in 16-PI-16, NYSOFA, AAAs, and all providers of services are subject to federal and state requirements, including the Older Americans Act (OAA), and must adopt and adhere to procedures protecting the confidentiality of all information gathered from individuals in the conduct of their respective responsibilities under the Act.

This includes obtaining the informed consent of an individual for the purpose of disclosing personal information to service providers for referral or any other purpose. In addition, other laws governing consent to capture, share, and disclose client information are applicable. The Statewide Client Data System incorporates consent processes that comply with the OAA and other laws governing consent to capture, share, and disclose client information.

The Questions and Responses in this document further clarify certain aspects of consent processes. Additional Questions and Responses will be provided in the near future.

INFORMED CONSENT: QUESTIONS AND RESPONSES

Q1. For existing clients, is consent to capture required only at the first re-assessment or at every annual re-assessment?

Response: Consent to capture must be obtained at every re-assessment, which will occur annually or when a change of circumstances occurs which warrants changes to/ additions to the care plan/service plan. Additionally, changes needed to the care plan/service plan may require consent to share and refer, should new referrals be necessary to meet needs, preferences, and goals. This requirement applies to new clients as well as existing clients at every annual re-assessment.

Q2. May a volunteer (who has no HCS account) complete the consent to capture process with clients on paper or by phone and provide this information to AAA Staff who then enter the data into the Statewide Client Data System and follow up with the client?

Response: Yes; volunteers can and should follow the same process that a paid employee does. Consent to capture can be captured by a volunteer, and data may then be entered into the Statewide Client Data System by AAA staff. If a volunteer, or employee without an HCS account, obtains consent in person they must obtain that person's written consent using the required forms. If consent is obtained by phone, they

must fill out a paper attestation form. All documents need to be uploaded and saved in the system.

This also applies to any subcontractors and service providers without an HCS account. Service Providers without HCS accounts may obtain informed consent from clients either in person or by telephone, as appropriate, with consent to be recorded in the Statewide Client Data System by an AAA employee with an HCS account. If consent is obtained in person, a written consent form must be completed. If consent is obtained over the phone, a paper attestation form must be completed and signed. All documents must be uploaded and saved in the system. Performance of the COMPASS (assessment) and all Cluster 1 services require written consent.

Q3. What if the client does not want to provide consent to collect their information or to refer them? May we give them the direct phone number for meals, for example? Can they “refer” themselves?

Response: Yes. If the client declines to provide consent to capture and/or disclose their information, you may give them the phone number for the service they may be calling about or which you identify based on discussion with them, so that they may follow up on their own. The worker can provide information to the client for his/her follow up; the worker is not able to follow up on the client’s behalf without the client’s consent.

Q4. What if the client refuses to give consent for I&A? Would they be able to be served? How would those clients be tracked?

Response: For Information and Assistance (I&A), the client record is established as a secure record and recorded as “Anonymous Anonymous.” The AAA or provider may still assist the client and provide them with information so that the client may do their own follow up. Consent needs to be obtained for all services that require an assessment.

Q5. May consent be obtained from individuals with Alzheimer’s or other dementia? What if I suspect they may lack capacity to consent?

Response: It is important to remember that an individual is presumed to have the ability to provide informed consent and that individuals with Alzheimer’s disease or other dementia may very well possess the ability to provide informed consent, or to consent to a family member or caregiver assisting them with understanding the information presented.

NYSOFA will be issuing additional guidance on informed consent in the near future.

Q6. May I make a referral to law enforcement or Adult Protective Services without informed consent?

Response: This is allowed in very limited circumstances.

NYSOFA will be issuing formal guidance on emergency situation disclosures in the near future.

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- PROGRAMS AFFECTED:**
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| <input checked="" type="checkbox"/> Title III-D | <input checked="" type="checkbox"/> Title III-E | <input checked="" type="checkbox"/> Title III-B | <input checked="" type="checkbox"/> Title III-C-1 | <input checked="" type="checkbox"/> Title III-C-2 |
| <input checked="" type="checkbox"/> EISEP | <input checked="" type="checkbox"/> NSIP | <input checked="" type="checkbox"/> CSE | <input checked="" type="checkbox"/> WIN | <input checked="" type="checkbox"/> Energy |
| <input checked="" type="checkbox"/> NY Connects:
Choices for Long
Term Care | <input checked="" type="checkbox"/> Other: All
workflow paths in
the Statewide Client
Data System | <input checked="" type="checkbox"/> Title V | <input checked="" type="checkbox"/> HIICAP | <input type="checkbox"/> LTCOP |

CONTACT PERSON:

TELEPHONE: