

Topic: Requests for additional Privacy Protections	Department: Entire Agency
Original effective date: 4/1/03	Last revision date: 3/20/23
Owner: VP for Quality and Compliance	Frequency of reviews: Annual
Internal/Regulatory Reference(s) (all that apply): 164.522	
Related documents/Links: Request for additional protections Form	

Policy: It is the policy of The Arc of Monroe to ensure that people have opportunities for privacy and that business, administrative and support functions promote personal and organizational outcomes.

Additional Information: Any person we support or their legal representative (“person” or “people we support”) has a right to request that The Arc restrict the uses and disclosures of PHI to carry out treatment, payment or health care operations (please cross reference the policy, [“Disclosures of Protected Health Information \(PHI\) for Treatment, Payment and Health Care Operations \(TPO\); Data Use Agreements and Limited Data Sets”](#)).

“Protected health information or PHI” is defined as information about people we support that relates to their past, present or future mental or physical health and also identifies them in some way. In addition to more obvious things such as treatment plans, service documentation, clinical assessment, etc., the following are also considered PHI:

- Initials of someone we support. If you share initials, you are sharing PHI. Reducing a name to initials does not protect it under HIPAA law.
- Pictures of someone we support. This includes any photograph that will identify the person in some way. This may be the case even if their face isn’t visible, but something distinctive about them is. It could also apply to pictures of the back of their head, side shots, other parts of their bodies that are distinctive, etc.
- Anything that describes someone in a way that makes it clear who you are talking about (such as a full physical description; or a combination of characteristics that are so unique as to effectively name the person). EXAMPLE: A short middle-aged woman with blazing red hair and right-side hemiparesis who goes to Henrietta Day Services.

This definition applies whether the information is written, spoken, signed, or in an electronic format – regardless of the language (e.g., English or any other language). You should presume that any information about people we support that you work with in your job is PHI and should be treated as such.

For the purposes of this procedure, “staff” includes employees, contractors, consultants, interns, students and volunteers. The VP for Quality and Compliance has primary responsibility for responding to requests for additional protections.

Denial of request:

The Arc is not required to agree to a requested restriction, except as indicated below. If we agree to a restriction, we are not permitted to use or disclose PHI in violation of that restriction unless the person is in need of emergency treatment and the PHI is crucial to that care. In those instances, we can disclose the PHI, however, we must request that the health care provider to whom we have disclosed it not disclose the information any further.

Required approval of request:

The Arc must agree to the request of restriction on the disclosure of PHI specifically to a health plan (e.g., a health insurance company) if the disclosure would be for the insurance company to pay for treatment that the person is:

- Paying for in full on their own;
- Paying for in full through another health insurance plan; OR
- Someone else has paid for the treatment in full.

Terminating a restriction:

The Arc may terminate a restriction or additional protection if:

- The person agrees to or requests the termination in writing;
- The person verbally agrees to the termination and the verbal agreement is documented; OR
- The Arc informs the person that we are terminating our agreement with the restriction. This does not impact the “Required approval of request” noted above and would only apply to any PHI created after this decision was shared with the person.

Procedure	
Task:	Responsible party:
General Guidelines	
1. People we support have the right to request additional protections or restrictions on how we use PHI for the purposes of treatment, payment or operations (please see the policy, “Disclosures of Protected Health Information (PHI) for Treatment, Payment and Health Care Operations (TPO); Data Use Agreements and Limited Data Sets”). They must make such a request in writing using the attached form (Request for Additional Protections).	People we support
2. If any staff member receives such a request, they must forward it to their manager immediately.	Staff
3. The manager needs to notify the VP for Quality and Compliance immediately.	Manager
4. After reviewing the request, VP for Quality and Compliance (or designee) may reach out to the person to clarify exactly what additional restrictions the person is requesting.	VP for Quality and Compliance or designee
5. The Arc will notify the person in writing of the decision to either accept or deny the request.	VP for Quality and Compliance
6. The Arc must maintain copies of all documentation related to the request for amendment, approval or denial, statement of disagreement, and agency rebuttal (or related summaries) for a period of 6 years from the date when the matter is resolved.	VP for Quality and Compliance

If we are granting the request in whole or in part:	
1. The VP for Quality and Compliance will inform the person that the request has been granted in whole or in part. If granted in part only, person will be informed as to which requests were approved and which were not. Please see the next section for denials.	VP for Quality and Compliance
2. The VP for Quality and Compliance will work with the designated program(s) or departments to implement the additional restrictions/protections.	VP for Quality and Compliance
3. Managers will be responsible for ensuring that all necessary staff understand the additional restrictions and how they are to be implemented.	Managers
If we are denying the request in whole or in part:	
1. If we are denying any part of the request, The Arc must provide a timely, written denial to the person.	VP for Quality and Compliance
Terminating a restriction:	
1. If we decide to terminating a restriction, we will notify the person in writing of our decision to do so.	VP for Quality and Compliance
2. This will include a statement that it will not affect PHI described the "required acceptance" above and will only apply to PHI created after this notification.	
Manager responsibilities:	
1. Managers have a responsibility to notify their Senior Director immediately if they receive a request for amendment to any PHI. This includes verbal requests made by people we support.	Managers
2. Managers will be responsible for fully implementing any additional restrictions that impact their program, including ensuring all appropriate staff are aware.	Managers
Senior Director responsibilities:	
1. Senior Directors have a responsibility to notify the VP for Quality and Compliance if/when a request for amendment is received.	Senior Director
2. Senior Directors may be asked to assist with and support their managers in implementing any additional restrictions that may impact their programs.	Senior Director
VP for Quality and Compliance:	
1. Acts as the agency's Privacy Officer	VP for Quality and Compliance
2. Responsible for administering the agency's HIPAA privacy policies and procedures.	VP for Quality and Compliance

3. Acts as a resource for staff in regards to proper implementation of the HIPAA privacy rule.	VP for Quality and Compliance
4. Has primary responsibility for responding to requests for additional protections/restrictions.	VP for Quality and Compliance

Document revision record:

Revision Date	Release Date	Reason for change	Approver
9/15/08	9/15/08	Reasons for change not documented	P Dancer
8/5/15	8/5/15	Reasons for change no documented	P Dancer
12/24/18	12/24/18	Reasons for change no documented	P Dancer
1/28/21	1/28/21	Transitioned to new procedural format and fleshed out procedure	P Dancer
3/20/23	3/20/23	Named referred-to policies and added links; fixed typos	ICC

REQUEST FOR ADDITIONAL PROTECTIONS FORM

The Arc of Monroe

See reverse side for instructions

Name of person: _____

Address: _____

City, State, Zip: _____

Date of Birth: _____

I am requesting additional protections/restrictions in the use and disclosure of my Protected Health Information (PHI) in The Arc of Monroe's Designated Record Set for the purposes of treatment, payment or healthcare operations, pursuant to HIPAA Right to Request Privacy Protection for PHI regulations, as indicated below.

Specific protections/restrictions requested: _____

If we agree to your request, please note that under HIPAA law, we are permitted to disclose PHI in violation of this request to a health care provider for the purposes of rendering emergency treatment. Such health care providers are not permitted to further disclose your PHI.

The Arc is required to agree ("required agreement") to requests restricting us from sharing PHI to a health plan/insurance company for services that will be paid in full by you, by another health plan, or by another person.

Any agreed-upon restrictions shall be in effect until:

- You request and agree that they should be terminated (may be done in writing or verbally); OR
- We determine that we will no longer agree to the restrictions. If this occurs, it will not impact the "required agreement" above and would only apply to PHI created after this decision was made.

Date/Time: _____ Signature: _____

Relationship to the person listed above:

☐ Self

Legal representative of this person (must use the first present on the following list):

- ☐ Court-appointed guardian
- ☐ Actively involved spouse
- ☐ Actively involved parent
- ☐ Actively involved adult child
- ☐ Actively involved adult sibling
- ☐ Actively involved family member

FOR ARC OF MONROE USE ONLY

Date received: _____ Request has been: ☐ Accepted ☐ Denied ☐ In whole ☐ In part

Additional comments: _____

Signature of VP for Quality and Compliance

Date

Instructions for completing the Request for Additional Protections Form

1. Please print legibly using dark permanent ink.
2. Sign and date the request.
3. Submit the completed and signed form to:
The Arc of Monroe
Attention: VP for Quality and Compliance
2060 Brighton-Henrietta Townline Road
Rochester, NY 14623.
4. You will be notified of the acceptance or denial of your request within 30 days.
5. If we accept the request for amendment, we will take steps to implement your requested restrictions. Please allow up to 60 days from the date of acceptance for these to be fully implemented.
6. If you choose to terminate your requested restrictions, please notify a manager in your program or you can contact the VP for Quality and Compliance at the address listed above. We prefer that you make such requests in writing, although this is not required.