

NJHIN Opt-Out Guidance for Unrepresented Patients/Residents

When New Jersey established the New Jersey Health Information Network (NJHIN) as the State's Health Information Exchange (HIE) in 2014, it adopted the Opt-Out model of patient consent to participation. The Opt-Out model is one in which the default for all patients is to participate within the HIE and, should a patient elect to Opt-Out, they must request that opportunity.

Unrepresented patients (incapacitated patients with no surrogate nor advance directive) present a unique privacy challenge within the Opt-Out approach. If the patient can not physically or mentally express a desire to Opt-Out, should the patient remain in the default state of consent granted to remain in the HIE.

NJII has examined this question and has determined the appropriate guidance is to leave the patient in the default state of consent granted, barring any evidence to the contrary. To validate an Opt-Out on behalf of an unrepresented patient in the state of New Jersey, a third party would be required to make that decision on behalf of the patient. Typically, decisions to make a proactive determination on behalf of a patient would be driven by one of the following standards:

- Advance Directive
 - This would be an inapplicable standard due to the patient's unrepresented nature
- Substituted Judgment
 - A reasonable approach to substituted judgment would be that patients would tend to choose the default setting for the State, in this case do not opt out. Objections to this could be contextual but as a broad rule, this would seem to lean towards the default.

- Best Interest
 - Physician approach
 - Our impression is that the large majority of physicians would recommend the default and not Opt Out
- Ethics Committee approach
 - I am not aware of any ethics committees weighing in on this subject but might be beneficial to review
- Guardianship approach
 - This would not be applicable since it is a generalized approach.

In each of these standards, we see the result is either a determination of keeping the default or not enough information to support an opt out. Since we do not see a clear path to an Opt Out decision, our guidance is to leave the patient in the default consent granted state.

For further questions:



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