

# **INTRASTATE AND INTERSTATE CONSENT POLICY OPTIONS COLLABORATIVE**

## **APPENDIX J: COMPARATIVE ANALYSIS REPORTABLE DISEASE**

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Health Information Security & Privacy

**COLLABORATION**



## Committee

HISPC Consent Policy Options Workgroup and NCHICA HIE Council's Policy Development Committee

## Scenario Five

**Reportable Disease.** In this scenario, 25-year-old male visits primary care physician for routine physical. Physician orders lab tests from clinical lab, which performs test and sends results to physician. Physician determines that consumer has HIV—a reportable disease—prescribes medication for consumer, and sends report of diagnosis to County Health Department, as required by law. County Health Department requests, and physician provides, information regarding consumer's past medical history and treatment. The health information includes records pertaining to the consumer's HIV infection.

## Assumptions

- The scenario involves exchange of health information contained in electronic health records (EHRs) that conform to nationally recognized standards and that can be created, managed, and consulted by authorized providers and staff both within health care organizations and across more than one health care organization.
- The scenario involves health care providers who are recognized as separate health care organizations.
- All of the requesting and responding providers in the scenario exchange health information with each other but are not necessarily participants in an HIO.
- If given a choice, the consumer is consenting to having some or all of his health information to be collected and stored in an EHR that conforms to nationally recognized standards and that can be created, managed, and consulted by authorized providers and staff both within health care organizations and across more than one health care organization.
- In the case of Opt In with Restrictions and Opt Out with Exceptions, health information that is protected by specific laws limiting access to the information, such as HIV positive status or test results, mental health or substance abuse information, either will be excepted from (carved out of) the EHR or restricted by the consumer.
- The providers will comply with mandatory reporting laws.
- The purpose of the exchange of health information is for treatment.
- Technology is able to carry out the requirements of the consent options.

## Instructions

List the most significant pros and cons with respect to the impact each of the five (5) consent policy options is likely to have on health care costs and quality of care, the business processes of the health care providers, consumer and provider trust in HIE, and legal liabilities of parties involved.

**Table J-1. Definitions**

Specific Issue	No Choice	Opt Out	Opt In w/Restrictions	Opt Out w/Exceptions	Opt In
Definitions	<p><b>Auto In.</b> Consumer's health information is automatically placed into an interoperable EHR without the consumer's prior permission and regardless of consumer preferences. Assumes that all of the consumer's health information, except as otherwise prohibited by law, will be accessible across more than one health organization.</p>	<p><b>Auto In with Choice.</b> Consumer's health information is automatically placed into an interoperable EHR without the consumer's prior permission. Assumes that all of the consumer's health information, except as otherwise prohibited by law, will be accessible across more than one health organization <i>unless and until the consumer chooses to opt out.</i></p>	<p><b>Auto Out with Granular Choice.</b> Consumer's health information is <b>not</b> automatically placed into an interoperable EHR without the consumer's prior permission. Assumes that none of the consumer's health information will be accessible across more than one health organization <i>unless and until the consumer opts in.</i> In addition, consumers may specify: (i) who may access their EHR, (ii) for what purposes the EHR may or may not be accessed, and/or (iii) what specific information may be placed in their EHR.</p>	<p><b>Auto In with Granular Choice.</b> Consumer's health information is automatically placed into an interoperable EHR without the consumer's prior permission. Assumes that all of the consumer's health information, except as otherwise prohibited by law, will be accessible across more than one health organization <i>unless and until the consumer chooses to opt out.</i> In addition, consumers may specify: (i) who may access their EHR, (ii) for what purposes their EHR may or may not be accessed, and/or (iii) what specific health information may be placed in their EHR.</p>	<p><b>Auto Out with Choice.</b> Consumer's health information is <b>not</b> automatically placed into an interoperable EHR without the consumer's prior permission. Assumes that none of the consumer's health information will be accessible across more than one health organization <i>unless and until the consumer opts in.</i></p>

**Table J-2. Quality of Care**

Specific Issues	No Choice	Opt Out	Opt In w/Restrictions	Opt Out w/Exceptions	Opt In
<p>Consumer wants effective treatment balanced with protection against unauthorized access to his/her health information.</p> <p>Provider wants to deliver effective treatment in the most timely and efficient way.</p>	<ul style="list-style-type: none"> <li>+ Maximum access to needed information should:</li> <li>+ improve quality of care</li> <li>+ decrease risk of harm due to errors</li> <li>+ maximize ability to provide continuity of care and coordination of care for appropriate treatment of consumer</li> <li>- No choice over who may use and exchange records may deter consumers from accessing health care providers, especially where sensitive information is concerned</li> <li>- Alternatively, consumers may not be truthful with providers if they know their information can be released without their consent.</li> </ul>	<ul style="list-style-type: none"> <li>+ Higher participation because few consumers opt out, so potentially greater quality of care</li> <li>+ Due to amount and accuracy of information, fewer duplicative tests and medication errors</li> <li>- Somewhat less volume of records available to providers because some consumers will choose to opt out</li> <li>- Some consumers may avoid seeking treatment.</li> <li>- With sensitive information, if consumer's only choices are to opt out or have all information included, consumers who opt out may see reduced quality of care, more duplicative tests and exams.</li> <li>- Some potential for errors due to smaller volume of information</li> </ul>	<ul style="list-style-type: none"> <li>+ Because this option provides consumers with the ability to restrict access to some but not all of their health information, consumers may be less likely to opt out, resulting in increased participation and relatively greater volume of records available for exchange.</li> <li>+ Relatively complete and accurate information</li> <li>+ Fewer duplicative tests and medication errors than with non-granular options</li> <li>- Likely somewhat less volume of records available to providers through HIE because some consumers still will choose to opt out for certain records</li> <li>- Lower quality of care for those consumers who do restrict access to some or all of their information</li> <li>- Potential for higher number of duplicative tests/medication errors for those restricting information</li> </ul>	<ul style="list-style-type: none"> <li>+ Because this option provides consumers with the ability to restrict access to some but not all of their health information, consumers will be less likely to opt out, resulting in increased participation and relatively greater volume of records available for exchange.</li> <li>+ Relatively complete and accurate information</li> <li>+ Fewer duplicative tests and medication errors than with non-granular options</li> <li>- Likely somewhat less volume of records available to providers through HIE because some consumers still will choose to opt out for certain records</li> <li>- If consumers choose to restrict access to needed health information, risk of increased errors and duplication of tests, etc.</li> </ul>	<ul style="list-style-type: none"> <li>+ Relatively high participation likely due to choice, leading to somewhat more information available to providers and higher quality of care than for more granular consent options</li> <li>- Less potential for increased quality of care when compared to no choice and opt out</li> <li>- Likely less volume of records, greater duplicate tests and medication errors</li> </ul>

Note: + = pro; - = con.

**Table J-3. Business Practice Impact**

Specific Issue	No Choice	Opt Out	Opt In w/Restrictions	Opt Out w/Exceptions	Opt In
Providers want HIE system that minimizes changes in work flow, minimizes investments in technology, decreases paperwork and administrative burdens, and results in quicker reimbursement.	<p><b>Physician</b></p> <ul style="list-style-type: none"> <li>+ Maximizes ease and efficiency of sharing health information that supports referral to clinical lab</li> <li>+ Most cost-effective because simple concept, so few dollars required for education</li> <li>+ No change in process of obtaining consent, so easy to administer</li> </ul> <p><b>Laboratory</b></p> <ul style="list-style-type: none"> <li>+ Maximizes ease and efficiency of responding to request for lab test and sharing of results</li> </ul> <p><b>Public Health Department:</b></p> <p><b>Physician</b></p> <ul style="list-style-type: none"> <li>- Maximizes burden to assure consumers that their health information is protected from unauthorized use, especially where sensitive information is concerned</li> </ul> <p><b>Laboratory</b></p> <ul style="list-style-type: none"> <li>- Maximizes burden to assure consumers that their health information is protected from unauthorized use</li> </ul> <p><b>Public Health Department</b></p> <ul style="list-style-type: none"> <li>- Most safeguards required to protect sensitive information from inappropriate release</li> </ul>	<ul style="list-style-type: none"> <li>+ The least complex of the options that permit consent, so fairly easy to administer</li> <li>- More burdensome to administer than no choice</li> <li>- Would need to maintain separate records for consumers who opt out</li> <li>- Would require consumer and staff education program about the consent option, which will increase costs to providers</li> </ul>	<ul style="list-style-type: none"> <li>+ Because more sophisticated technology is required, security of information may be greater.</li> <li>- Complex technology increases cost of technology</li> <li>- Complex consent options require greater staff and consumer education, as does the fact that information cannot be exchanged unless consumer opts in.</li> </ul>	<ul style="list-style-type: none"> <li>+ Because more sophisticated technology is required, security of information may be greater.</li> <li>- Complex technology increases cost of technology.</li> <li>- Complex consent options require greater staff and consumer education.</li> </ul>	<ul style="list-style-type: none"> <li>+ Still fairly easy and inexpensive to administer due to low complexity of consent option</li> <li>- Greater need to educate both staff and consumers regarding the benefits of HIE and the consequences of not choosing to opt in</li> <li>- Such education will be more time consuming and costly.</li> </ul>

Note: + = pro; - = con.

**Table J-4. Public Confidence—Trust in HIE**

Specific Issues	No Choice	Opt Out	Opt In w/Restrictions	Opt Out w/Exceptions	Opt In
<p>Consumers want to be informed about the policies and practices of the HIE and to trust that the HIE will abide by principles that limit the use and disclosure of their health information, and will comply with laws, regulations, standards, and policies that protect consumers' health information.</p> <p>Providers want other providers participating in the HIO to safeguard information and share information that is accurate, complete, and relevant to the purpose for which it is to be used.</p>	<p>+ Perception of public trust is dependent on the establishment and maintenance of trust relationships with consumers and among participating providers.</p> <p>- Consumers' perception of lack of right to privacy is likely to lead to low trust levels and possible refusal to seek treatment, give providers accurate and complete information, or participate in HIO.</p>	<p>+ Offering the consumer the choice to opt out likely will encourage more consumers to participate and build confidence and trust in HIE.</p> <p>- Because there is likely to be less consumer participation and thus less volume of records than with no choice option, records are likely to be somewhat less complete and accurate than if no choice, resulting in less confidence and trust in HIE among providers.</p>	<p>+ This option provides consumers with maximum control over use and disclosure of their health information and, accordingly, is likely to result in highest consumer level of trust in HIE.</p> <p>- Due to possibility of least access to complete records, this option may result in least trust among providers.</p>	<p>+ Because this option allows more consumer choice and control over the electronic disclosure of their health information, there is a greater likelihood of consumer confidence and participation in HIE.</p> <p>- Because this option allows more consumer choice and control over the electronic disclosure of their health information, the provider may not have access to the consumer's complete record, so provider's confidence in HIE likely will decrease.</p>	<p>+ More likely to increase consumer confidence because no information is exchanged unless consumers opt in.</p> <p>- Because of potential for lower consumer participation and lower volume of records, provider confidence in HIE is likely to be somewhat lower than for no choice or opt out.</p>

Note: + = pro; - = con.

**Table J-5. Savings/Health Care Cost Avoidance**

Specific Issue	No Choice	Opt Out	Opt In w/Restrictions	Opt Out w/Exceptions	Opt In
Providers and consumers want less paperwork, improved communication, reduced duplicative tests, increased accuracy and effectiveness of treatment, and long-term savings.	<ul style="list-style-type: none"> <li>+ Minimizes duplicative tests</li> <li>+ Most savings due to simplicity of administering and likely high volume of records</li> <li>- If consumer avoids seeking health care due to limited rights to privacy concerns, the consumer's health status may deteriorate, leading to higher costs.</li> <li>- Likely costly to educate consumers, especially where sensitive information involved</li> </ul>	<ul style="list-style-type: none"> <li>+ Because the opt out consent option is the least complex of the consent options, it is likely to be the least expensive to implement.</li> <li>- Opt out consent option will likely result in less participation and, thus, less volume of records available for HIE, resulting in less potential in cost savings when compared to no choice.</li> <li>- Providers will need to invest in consumer education programs to inform consumers about the benefits of HIE and the consequences of their choice.</li> <li>- Because the default is that health records are available for HIE, this option is likely to result in the highest level of volume than other consent options, resulting in higher cost savings due to reductions in paper work and redundancy.</li> </ul>	<ul style="list-style-type: none"> <li>- Least cost savings may be available due to potential for least volume of records available, maximum complexity of consent option, and maximum need for staff and consumer education.</li> </ul>	<ul style="list-style-type: none"> <li>- More costly due to complexity and low volume of records available for exchange.</li> </ul>	NA

Note: + = pro; - = con.

**Table J-6. Risks/Threats to Right to Consumer Privacy**

Specific Issue	No Choice	Opt Out	Opt In w/Restrictions	Opt Out w/Exceptions	Opt In
Risks/threats to right to consumer privacy	+ None - No choice results in a maximum perceived threat to consumers' right to privacy.	NA	NA	NA	NA

Note: + = pro; - = con.

**Table J-7. Liability and Laws**

Specific Issue	No Choice	Opt Out	Opt In w/Restrictions	Opt Out w/Exceptions	Opt In
Liability and laws	+ 10A NCAC 41A.0101 and NCGS §§ 130A-135 and -139 require physicians to report consumer's name and address to local health director, and there is safe harbor for doing so. - NCGS § 130A-143 provides that all information and records that identify a person with AIDS is "strictly confidential" and may not be released except with written consent, for purposes of public health, pursuant to subpoena or court order, or for statistical purposes if de-identified. - Accordingly, it would appear that consumer should consent for release of information to lab.	+ Less risk of liability for failure to comply with state and federal release of information laws because consumers can consent to or withhold consent for release of sensitive information. + Somewhat less volume of information in the EHR may lead to slightly less risk of malpractice liability than no choice option, because providers can only be held accountable to know information in their possession. + Less complex consent option may decrease the risk of inappropriate release of information.	+ Because consumers must permit the electronic disclosure of any of their health information, the risk of legal liability for violation of state and federal release of information laws is perhaps the lowest of all the consent options. + Possibly the smallest volume of information in the EHR may lead to the least risk of malpractice liability, because providers can only be held accountable to know information in their possession. - The complexity of this consent option may increase the risk of inappropriate release of information.	+ Less risk of liability for failure to comply with state and federal release of information laws because consumers can consent to or withhold consent for release of sensitive information. + Somewhat less volume of information in the EHR may lead to slightly less risk of malpractice liability than no choice option, because providers can only be held accountable to know information in their possession. - The complexity of this consent option may increase the risk of inappropriate release of information.	+ Less risk of liability for failure to comply with state and federal release of information laws because consumers can consent to or withhold consent for release of sensitive information. + Somewhat less volume of information in the EHR may lead to slightly less risk of malpractice liability than no choice or opt out options, because providers can only be held accountable to know information in their possession. + Less complex consent option may decrease the risk of inappropriate release of information.

Note: + = pro; - = con.