



STATE OF ILLINOIS  
HEALTH INFORMATION  
EXCHANGE AUTHORITY  
DATA SECURITY AND PRIVACY  
COMMITTEE

Report of Preliminary Findings and  
Recommendations

September 19, 2012

# Preliminary Findings and Recommendations

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## Preliminary Findings and Recommendations

The Illinois Health Information Exchange Authority (Authority<sup>1</sup>) Data Security and Privacy Committee (Committee<sup>2</sup>) has received oral and written testimony from over 30 stakeholders, organizations, subject matter experts and members of the general public regarding the privacy and security policies that the Committee should recommend to the Board of the Authority to govern the operations of the State-level health information exchange (ILHIE).<sup>3</sup> In addition, since its inaugural meeting on Feb. 8, 2012, the Committee has received analytical materials and other documents relating to the development and implementation of the ILHIE prepared by the State of Illinois Office of Health Information Technology (OHIT) and advisory work groups under the auspices of OHIT.<sup>4</sup> Following a review of these materials and discussions among the members of the Committee<sup>5</sup> and OHIT staff, a majority of the Committee members supports the presentation of the following Preliminary Findings and Recommendations to the Board of the Authority for its Sept. 19, 2012 meeting.

While the Committee believes that the Preliminary Findings and Recommendations reflect significant progress in the development by the Committee of key privacy and security policies for the consideration of the Board of the Authority, the Committee anticipates that additional Committee deliberations will be necessary or desirable. The development and implementation of the ILHIE is highly dynamic, as are the complex factors currently affecting the health care delivery system in Illinois, including factors relating to the privacy and security of electronic patient data which will be entrusted to the ILHIE. The Committee believes that in order to secure the success of the ILHIE, the Authority will need to assume a prominent role in the development and maintenance of public trust in Illinois regarding the nature, purposes and operations of the ILHIE. Such trust must be based on the assurance that the interests of patients in the privacy and security of their electronic health information is appropriately protected and balanced with the interests of other health care system stakeholders who will use the ILHIE to enhance patient treatment and safety, promote public health and control health care costs. The Committee is ready and willing to continue its support of the Authority's future deliberations and actions with respect to patient data privacy and security policies.

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<sup>1</sup> Detailed information available at: <http://www2.illinois.gov/gov/HIE/Pages/authority-index.aspx>.

<sup>2</sup> Detailed information available in Exhibit C and at: <http://www2.illinois.gov/gov/HIE/Pages/DataSecurityandPrivacy.aspx>.

<sup>3</sup> See Exhibits B and C.

<sup>4</sup> The Committee is grateful for the information and recommendations received from the ILHIE Legal Task Force workgroups (<http://www2.illinois.gov/gov/HIE/Pages/workinggroups.aspx>) and the OHIT Behavioral Health Integration Project (BHIP; <http://www2.illinois.gov/gov/HIE/Pages/BHIP.aspx>).

<sup>5</sup> See Exhibit A.

## Preliminary Findings and Recommendations

### CORE COMMITMENT TO PRIVACY AND SECURITY

1. In establishing the Authority to govern the operations of the State-level health information exchange (ILHIE), the Illinois General Assembly enunciated the Authority's core commitment "to ensure that the appropriate security and privacy protections apply to health information, consistent with applicable federal and State standards and laws".<sup>6</sup> The Committee believes that evolving health information technology will both enable and enhance the implementation of the Authority's core commitment to the privacy and security of patient health information.
2. The Committee's recent outreach to stakeholders for participation in the Committee's proceedings demonstrated the active interest of stakeholders in Illinois in the development and implementation of the ILHIE and the adoption by the Authority of patient data privacy and security policies to govern the operations of the ILHIE.

### THE IMPORTANCE OF INFORMATION SHARING

3. The health care delivery system in Illinois is complex. The successful treatment of a single patient involves multiple parties -- clinical treatment is delegated among multiple specialists; the location of clinical treatment is distributed among different types of facilities during a patient's course of treatment; and payment for a patient's treatment comes from multiple sources. The management of multiple parties and processes requires evaluation systems which measure and assess results. The sharing of patient clinical data is key for the operation and future success of the health care delivery system in Illinois. The ILHIE can play an instrumental role. The Committee recommends that the Authority adopt policies which encourage the exchange of patient health information and encourage the flow of patient health data into ILHIE for HIE purposes. Such HIE purposes, reflected in the enabling legislation of the Authority,<sup>7</sup> include the exchange of patient data for purposes of enabling patient treatment, payment, healthcare operations, public health functions permitted by law and medical research approved by an Authority-appointed Institutional Review Board (IRB).

### THE ROLE OF HIT TECHNOLOGY

4. The Committee recommends that the Authority adopt a multi-staged approach to the development and implementation of the ILHIE, and to the adoption, and periodic revision,

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<sup>6</sup> Illinois Health Information Exchange and Technology Act, 20 ILCS 3860/20(3).

<sup>7</sup> Illinois Health Information Exchange and Technology Act, 20 ILCS 3860/1 et. seq.

## Preliminary Findings and Recommendations

of corresponding patient data privacy and security policies to govern the operations of the ILHIE which are enabled by then current HIE technology. As health information technology advancements enable greater patient health information privacy and security functionality, the Authority should adopt and implement privacy and security policies that provide Illinois residents the greatest available degree of protection. The Committee recommends that the Authority adopt as its policy the periodic review and acquisition of health information technology advancements to enable the continued improvement of ILHIE's patient health information privacy and security.

5. To maximize the utility of the ILHIE to all residents of the State of Illinois, the Authority should seek to ensure the interoperability of the ILHIE with HIE systems being implemented across the United States, and in particular with those in Midwest States neighboring Illinois with which Illinois health care providers regularly exchange patient health information. To promote uniform national technical standards and legal policies which promote national HIE interoperability, the Authority should encourage federal government leadership in the adoption of national technical standards and legal policies, including patient data privacy and security policies.

### HARMONIZING ILLINOIS LAW

6. Illinois law regarding the disclosure of patient health information for the most part predates the adoption by health care providers in Illinois of electronic health information systems and the enactment of federal laws addressing patient health information privacy and security, principally embodied in regulations promulgated under the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"). In those instances where Illinois law is more restrictive than federal law, and such a divergence impedes the development and implementation of electronic health information exchange within Illinois or across State boundaries, the Committee believes that Illinois laws should be amended to facilitate the development and implementation of the ILHIE, and other methods be explored to address any affected interests that the statutory divergence was originally intended to address. In those instances where Illinois law is in principle not more restrictive than federal law but reflects differences in concepts and terms, the Committee believes that Illinois laws should be harmonized with federal law to help resolve existing uncertainty regarding the legal requirements applicable to health care providers in Illinois and their participation in the ILHIE. The Committee recommends that the Authority act to harmonize Illinois and federal health care privacy and security law, exercising its powers to enact regulations governing the operation of the ILHIE, and proposing the adoption by the Illinois General Assembly of relevant amendments to existing Illinois laws.

## Preliminary Findings and Recommendations

### MEANINGFUL USE INCENTIVES

7. The federal government has financially encouraged the widespread adoption of electronic medical record technologies, and the sharing of electronic patient health information through health information technologies, through the federal “Meaningful Use” EHR adoption incentive payment program.<sup>8</sup> The Committee recommends that the Authority in its implementation of the ILHIE enable the receipt by eligible Illinois health care providers of federal “Meaningful Use” incentive payments.

### EFFICIENCY

8. The Committee recommends that when adopting policies regarding the operation of the ILHIE, the Authority should take into consideration the consequences of such policies on clinical treatment workflows and administrative costs at the point of patient care.

### PUBLIC HEALTH

9. A significant additional anticipated benefit from the implementation of the ILHIE is the improved availability of health information for public health reporting and analysis by the Illinois Department of Public Health and other federal and local public health authorities. The Committee recommends that the Authority in its implementation of the ILHIE support the facilitation of public health reporting and ancillary medical research permitted by law to promote population health.

### BALANCING OF STAKEHOLDER INTERESTS

10. Multiple parties contribute to the creation of patient data and multiple parties have interests in the permitted use and sharing of such patient data, including: patients; providers; public and private payers; and public health authorities. The Authority’s policies regarding the operation of the ILHIE must reasonably accommodate these multiple interests, with the primary focus of all State health care initiatives being the patient. The Authority’s policies must balance the interests of multiple parties, while remaining true to the Authority’s core commitment to the privacy and security of electronic patient health care information. The engagement of patients in their own health care treatment decisions, including the sharing of their health information, on the basis of meaningful knowledge promotes public trust in the health care system and the role of the ILHIE, and ultimately contributes to improved patient health care outcomes.

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<sup>8</sup> Detailed information available at: <http://www2.illinois.gov/gov/HIE/Pages/EHRIncentive.aspx>.

## Preliminary Findings and Recommendations

### ENHANCING PATIENT PROTECTION: OPT-OUT POLICY

11. The use of health information technology in Illinois to securely facilitate the exchange of patient health information among unaffiliated providers is relatively new, and knowledge of the nature and benefits of HIE is not yet widespread among Illinois residents. The nature and benefits of the already functioning ILHIE Phase 1 Direct uni-directional secure “push” messaging, functionally similar to the sending of an encrypted email message with patient health information over the Internet between two known health care providers, at present are distinguishable from the nature and benefits of the proposed ILHIE Phase 2 bilateral query-response “pull” of patient health information from multiple providers for the benefit of multiple recipients. While current laws and policies may be adequate for the already functioning ILHIE Phase 1 Direct secure messaging, the Committee finds that an incrementally different set of laws and policies are appropriate for the proposed ILHIE Phase 2. Accordingly, the Committee recommends that the Authority offer Illinois residents additional patient data privacy protection by giving patients an “opt-out” choice to enable them to block the distribution by ILHIE of a patient’s data (other than as required by law).
12. Currently, health care providers generally are authorized under HIPAA to share a patient’s health information with others for purposes of treatment, payment or health care operations (commonly known as “T-P-O”), without the need of obtaining a patient’s prior authorization. Express patient authorization for disclosure of patient health information (“opt-in”) is currently required principally with regard to several categories of “specially-protected” patient health information under Illinois law, such as regarding HIV/AIDs, behavioral health, substance abuse and genetic testing data. The application by the Authority of patient authorization for the disclosure of all patient information on an “opt-out” basis would afford patients a greater degree of patient choice than currently required for the disclosure of data subject to the T-P-O exception, but without the degree of formal documentation required by an “opt-in” approach. An “opt-out” approach thus represents a “middle ground” between the no authorization/T-P-O approach and the “opt-in” patient authorization approach.
13. Empirical and anecdotal data presented to the Committee suggests that data collection systems that require collection of an affirmative authorization from the patient (“opt-in”) enjoy lower rates of patient participation than systems in which patient authorization is implied unless a patient expressly withdraws participation (“opt-out”).<sup>9</sup> To optimize the utility of the ILHIE and enhance the attainment of its anticipated benefits, the Committee

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<sup>9</sup> Re: Amount of Data Obtained Under Opt-In and Opt-Out Participation Models, available at: [http://www2.illinois.gov/gov/HIE/Documents/20\\_EmpiricalEvidenceReConsent%20Models072512\\_rev.pdf](http://www2.illinois.gov/gov/HIE/Documents/20_EmpiricalEvidenceReConsent%20Models072512_rev.pdf)

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recommends to the Authority the utilization of an “opt-out” approach to patient choice rather than an “opt-in” approach.

14. A majority of States that have considered patient authorization policies that apply to state-level health information exchanges have chosen the “opt-out” approach to patient choice. The adoption by the Authority of an “opt-out” approach to patient choice would be consistent with federal guidance and the apparent majority practice across the United States.<sup>10</sup> The “opt-out” approach has also been adopted by four active regional HIE initiatives in Illinois (Metro Chicago HIE; Central Illinois HIE; LincolnLand HIE; and Illinois Health Information Exchange Partners).
15. In order to enable the ILHIE to facilitate the transmission of patient health information to public health authorities, and to make patient health information potentially available in the event of a patient medical emergency (as defined by law), the Committee recommends that all patient health information be accessible to the ILHIE, but that its further disclosure by the ILHIE to authorized participants in the ILHIE be restricted by a patient’s decision to “opt-out”. The patient “opt-out” choice would therefore apply to restricting data distribution by the ILHIE, as opposed to restricting its collection by the ILHIE.

### OPT-OUT OVERRIDE/ BREAK-THE-GLASS

16. A patient that exercises the right to “opt-out” from further distribution by ILHIE of the patient’s health information to third parties (except as permitted by law), would be able to grant a specific provider recipient an authorization which permits the provider recipient to override the existing “opt-out” in order to access the information available to the ILHIE. By exercising an “opt-out” right and granting to selective provider recipients override access, a patient would enjoy considerable control with regard to the disclosure of the patient’s health information.
17. A principal benefit of the proposed approach allowing for the ILHIE to have access to patient data despite a patient’s restriction on its further distribution is the potential availability of such data in the event of medical emergency. As the law in Illinois is unclear regarding the permitted disclosure of patient health information in the event of medical emergency, the Committee recommends that the Authority act to clarify applicable Illinois law, whether through adoption of appropriate regulations or the enactment by the Illinois General Assembly of appropriate statutes.

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<sup>10</sup> See: Exhibit D; “Granularity of Patient Choice”, available at: [http://www2.illinois.gov/gov/HIE/Documents/4\\_BriefingSum\\_Pan2\\_071612.pdf](http://www2.illinois.gov/gov/HIE/Documents/4_BriefingSum_Pan2_071612.pdf); and “Patient Choice, Opt-in and Opt-out”, available at: [http://www2.illinois.gov/gov/HIE/Documents/3\\_BriefingSum\\_Pan1\\_071612.pdf](http://www2.illinois.gov/gov/HIE/Documents/3_BriefingSum_Pan1_071612.pdf).

## Preliminary Findings and Recommendations

### CONTINUATION OF “OPT-IN” UNDER CURRENT LAWS

18. Current Illinois law may restrict the ability of health care providers to make “specially-protected” patient health information available to an HIE without having obtained a patient’s prior “opt-in” authorization. (The principal categories of “specially-protected” patient health information in Illinois are: (i) mental health; (ii) substance abuse; (iii) HIV/AIDs; and (iv) genetic testing data.<sup>11</sup>) Until such time as Illinois laws are amended to clearly allow for the transmission of all patient health information to the ILHIE for HIE purposes (as recommended and discussed below), the initial ILHIE participants may be required to implement multiple-option patient choice and authorization collection procedures (to the extent practicable).

### ADMINISTRATIVE BURDENS

19. It is presumed that the implementation of an “opt-out” patient authorization approach would impose new administrative burdens on most health care providers that connect to the ILHIE, directly or indirectly, as well as corresponding operational responsibilities upon the ILHIE. It is anticipated that the administrative burdens may include (i) inclusion of a description of the ILHIE and the “opt-out” patient choice in the provider’s Notice of Privacy Practices distributed to patients, and (ii) distribution, collection and processing of “opt-out” forms or other electronic authorization procedures. The extent of the additional administrative burdens has not been quantified. The Committee recommends that the Authority seek to minimize administrative burdens at the point of care and explore solutions which enable the exercise by patients of their “opt-out” rights at their convenience.

### BARRIERS TO HIE IN CURRENT LAWS

20. It has been brought to the Committee’s attention that the Illinois Mental Health and Developmental Disabilities Confidentiality Act (MHDDCA<sup>12</sup>) contains ambiguous restrictions which can impede the exchange of patient mental health information through an HIE, even for patients who desire to be beneficiaries of health information exchange. The MHDDCA requires patient authorization with considerable specificity for authorizing the release of patient health information, it prohibits “blanket consent” and “advance consent”, and requires a durational limit on authorization. MC-HIE, a regional HIE initiative operating in Metropolitan Chicago, has determined that under current Illinois law it cannot accept

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<sup>11</sup> “Special Patient Data”, available at:

[http://www2.illinois.gov/gov/HIE/Documents/5\\_BriefingSum\\_Pan3\\_071412.pdf](http://www2.illinois.gov/gov/HIE/Documents/5_BriefingSum_Pan3_071412.pdf).

<sup>12</sup> 740 ILCS 110/.

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patient mental health information.<sup>13</sup> The difficulties that MC-HIE's participating HIE users have experienced in applying such a restriction effectively results in the complete exclusion from the MC-HIE of the medical information of any patient receiving mental health treatment services. Similar legal concerns are affecting the exchange of patient health information through the Central Illinois HIE.<sup>14</sup> Exclusion from health information exchange of any group of Illinois residents undermines the prospect of providing them coordinated patient care and other anticipated benefits from health information exchange.

21. The ILHIE also faces such barriers directly and indirectly, as the ILHIE is affected by data restrictions imposed by regional HIEs which are expected to connect to the ILHIE. Therefore, the Committee recommends that Illinois laws restricting the disclosure of certain categories of patient health information<sup>15</sup> be amended to clearly allow the transmission of all patient health information to the ILHIE for HIE purposes without the necessity of obtaining prior patient authorization, but subject to the patient's ability to "opt-out" from further disclosure by the ILHIE of the patient's health information. The Committee further recommends that patients with specially-protected patient health information be provided with meaningful disclosure regarding their "opt-out" right so as to promote their informed decision making. The Committee notes that Illinois laws currently require the provision to patients of adequate information to promote their informed decision making regarding a patient's right to decline ("opt-out") an HIV test.<sup>16</sup> The Committee recommends that provision of meaningful disclosure not unduly impose significant administrative costs or subjective obligations upon health care providers; an appropriate suggested detailed provision is attached.<sup>17</sup>

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<sup>13</sup> Testimony on behalf of MetroChicago Health Information Exchange, March 29, 2012, available at: <http://www2.illinois.gov/gov/HIE/Documents/MCHC%20Testimony%203-29-12.pdf>; "MetroChicago HIE, Testimony for the Illinois Health Information Exchange Data Security and Privacy Committee, July 17, 2012", available at: [http://www2.illinois.gov/gov/HIE/Documents/mchc\\_7-17-12%20testimony%20Final.pdf](http://www2.illinois.gov/gov/HIE/Documents/mchc_7-17-12%20testimony%20Final.pdf).

<sup>14</sup> <http://www2.illinois.gov/gov/HIE/Documents/CIHIE%20-%20%20Data%20Security%20-%20Privacy%20PublicTestimony%20Slides.pdf>.

<sup>15</sup> The principal categories of "specially-protected" patient health information in Illinois are: (i) mental health (Mental Health and Developmental Disabilities Confidentiality Act, 740 ILCS 110); (ii) substance abuse (Alcoholism and Other Drug Abuse and Dependency Act, 20 ILCS 301); (iii) HIV/AIDs (AIDS Confidentiality Act, 410 ILCS 305); and (iv) genetic testing data (Genetic Privacy Information Act, 410 ILCS 513).

<sup>16</sup> AIDS Confidentiality Act, 410 ILCS 305/3(d). See also "Providing and Documenting 'Meaningful Choice'", at: [http://www2.illinois.gov/gov/HIE/Documents/7\\_BriefingSum\\_Pan5\\_071412.pdf](http://www2.illinois.gov/gov/HIE/Documents/7_BriefingSum_Pan5_071412.pdf).

<sup>17</sup> "No covered entity may provide personally-identifiable clinical health information subject to this Act to a Health Information Exchange without providing the subject of the clinical health information or the subject's legally authorized representative the opportunity to expressly decline the further disclosure of the information by a Health Information Exchange to third parties, except to the extent provided by law. A covered entity may offer the subject of the clinical health information an opt-out opportunity to decline further disclosure by a Health Information Exchange, provided that the subject's decision is based on meaningful disclosure regarding the Health Information Exchange and the subject's decision is obtained without undue inducement or any element of force, fraud, deceit, duress or other form of constraint or coercion. A covered entity may rely upon the prior provision of

## Preliminary Findings and Recommendations

### FUTURE SEGMENTATION OF PATIENT HEALTH INFORMATION

22. Since the segmentation of specific categories of electronic patient health information within a particular electronic patient medical record is currently not yet reasonably technologically feasible, the Committee supports the launch of the ILHIE with an “all-data-in or all-data-out” patient choice. As HIE technology matures, however, the Committee recommends that the Authority introduce more granular patient choices, to allow patients to determine what health information patients wish to share with whom.

### DATA SECURITY PROTECTIONS AND ASSURANCE

23. The Committee recommends that the Authority adopt measures to build provider and patient trust in the ILHIE, which include: (1) monitoring; (2) enforcement strategies; (3) breach mitigation; and (4) public education. With respect to monitoring, the Committee recommends that the Authority should require Illinois custodians of electronic patient health information to report breaches of their electronic systems. The Authority can facilitate public reporting of breach incidents. The technical infrastructure of the ILHIE could allow for real-time network monitoring for privacy and security breaches, and potential breaches could be investigated by field audit teams. With respect to enforcement, the Authority should engage a Chief Privacy and Security Officer to (i) oversee and manage all enforcement monitoring and audits; (ii) manage a budget for enforcement activities and incentives for inter-agency cooperation; (iii) review all complaints against covered entities; (iv) manage the mitigation of breaches; and (v) direct public education. The Authority would

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meaningful disclosure to a subject by the covered entity or by its affiliated member of an integrated delivery network, which is documented in the subject’s medical record, or as otherwise permitted by the Illinois Health Information Exchange Authority, and such covered entity will not be required to provide meaningful disclosure anew, unless otherwise required by the Illinois Health Information Exchange Authority. "Meaningful disclosure" for purposes of this Act entails the provision of at least the following information to the subject of clinical health information or the subject's legally authorized representative: (1) a fair explanation of the Health Information Exchange, including its purpose and potential uses, and the fact that the Health Information Exchange will disclose the subject’s medical record to others unless the subject expressly opt-outs of further Health Information Exchange disclosure; and (2) a fair explanation of the procedures to be followed to withdraw consent to the further disclosure by the Health Information Exchange, except to the extent provided by law. The foregoing meaningful disclosure information may be provided in writing, verbally, or by video, electronic, or other means. The subject must be offered an opportunity to ask questions about the Health Information Exchange and the subject’s right to opt-out of further Health Information Exchange disclosure. Nothing in this Act shall prohibit a covered entity from combining meaningful disclosure information regarding Health Information Exchange or combining a form used to document a subject’s opt-out from Health Information Exchange disclosure with such information or forms used to inform the patient about the covered entity’s privacy practices, obtain consent for uses and disclosures of health information, obtain written consent for general medical care or any other medical test or procedure, provided that the combined information or forms make it clear that the subject may consent to general medical care, tests, or medical procedures without foregoing the subject’s opt-out rights to Health Information Exchange disclosure and clearly explain how the subject may opt-out of Health Information Exchange disclosure.”

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also coordinate interagency enforcement activities, and propose an increase in breach penalties under Illinois law to harmonize with a recent increase in breach penalties under federal law. With respect to breach mitigation, the Authority could monitor ILHIE user compliance with Corrective Action Plans arising from breach enforcement actions. With respect to public education, the Authority could (i) maintain a webpage focused on enforcement reporting results; (ii) host quarterly webinars on compliance topics; and (iii) engage in education outreach activities through education partners, such as non-profit community organizations.

### CONTROL OF DATA BY DATA CUSTODIANS

24. To the extent any data custodian has legal obligations relating to the disclosure of any patient health care information, including disclosure to the ILHIE, the data custodian bears the sole duty of complying with any applicable law. The Committee recommends that the Authority respect any grant under existing laws of discretionary authority to health care providers with regard to patient health records of which they are custodians, including the discretionary authority of providers to grant patient access to records<sup>18</sup>, accept patient corrections<sup>19</sup>, accommodate patient requests for data non-disclosure<sup>20</sup> and disclose information to the parents of a minor<sup>21</sup>. The Committee recommends that the Authority refrain from taking any actions which may interfere in the exercise by a health care provider of either health care judgment or legal compliance judgment in respect of any patient's health information. The Committee also recommends that the Authority refrain from taking any actions in respect of a patient record for which a health care provider's knowledge of the clinical context of the record is necessary or desirable, including action by the ILHIE to grant patient access to records, accept patient corrections, accommodate patient requests for data non-disclosure (other than a general "opt-out" request) or disclose information to the parents of a minor. The ILHIE should not undertake to make or influence decisions which in accordance with current laws should be made by the data custodian at the point of care.

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<sup>18</sup> HIPAA, §164.524(a)(2)-(3); Illinois Mental Health and Developmental Disabilities Confidentiality Act, 740 ILCS 110/4(a)(3) (access of parent or guardian to minor's mental health services record), 110/11(ii), (iii), (viii) (disclosures deemed necessary to protect a person against clear and imminent risk of harm)

<sup>19</sup> HIPAA, §164.526(a)(2)

<sup>20</sup> HIPAA, §164.522(a)(1)(ii)

<sup>21</sup> Illinois Consent by Minors to Medical Procedures Act, 410 ILCS 210/5 (regarding minor's treatment for drug and alcohol abuse or sexually transmitted diseases); Mental Health and Developmental Disabilities Code 405 ILCS 5/3-501(a)(parental notification of minor's psychotherapy treatment).

## Preliminary Findings and Recommendations

### NEUTRALITY ON MERITS OF DATA CUSTODIAN DISCLOSURE RESTRICTIONS

25. Unless a particular existing legal restriction on a data custodian's disclosure of patient health information affects the development and implementation of the ILHIE, the Committee recommends that the Authority refrain from taking any position with respect to the merits of any proposed or existing legal restrictions on a data custodian's disclosure of patient health information. While the Committee welcomes the testimony it received from stakeholders regarding the protection of a patient's reproductive rights decisions, the Committee recommends that the Authority should respectfully refrain from opining on a data custodian's existing or prospective legal obligations with respect to the custodian's disclosure of patient's decisions regarding reproductive rights or other medical treatment of minors.

### UNIQUE PATIENT IDENTIFIER

26. The Committee recommends that the Authority seek to have the ILHIE achieve the highest possible degree of patient record matching in order to minimize potential patient harms arising from the ILHIE's delivery to clinical personnel of erroneous information. In selecting and implementing the ILHIE's patient record matching system, the Committee recommends that the Authority exercise care in the use of personally-identifiable information as part of a patient's unique identifier.

### NEXT STEPS

27. An overview of the ILHIE's proposed patient authorization process and a graphical depiction of several examples of its application (use cases) are set forth in Exhibit E. The operational details of ILHIE's patient authorization management system need to be further developed by Authority staff in consultation with the ILHIE technology vendor.<sup>22</sup> A number of issues require further study and development, including the application of new patient authorization policies to legacy patient data, and the establishment of procedures which allow for patient revocation of prior preference choices.

28. The Committee recommends that the Authority will need to adequately publicize the patient data privacy and security policies that it adopts with relation to the operation of the ILHIE and the resulting patient rights. Adequate resources should be allocated to addressing the significant information gap regarding the nature, purpose and benefits of the ILHIE and its proposed patient consent policies that currently exists among health care providers in Illinois as well as the general public.

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<sup>22</sup> See Exhibit E.

## EXHIBIT A

### EXHIBIT A: MEMBERS OF THE DATA SECURITY AND PRIVACY COMMITTEE

1. Chair: Dr. Nicholas Panomitros – Attorney and Dentist in private practice; ILHIE Authority Board member
2. \* Jim Anfield – Senior Director Strategic Relationships, Blue Cross Blue Shield of Illinois
3. Leah Bartelt, Reproductive Rights Staff Counsel, Roger Baldwin Foundation of ACLU of Illinois
4. Elissa J. Bassler – CEO, Illinois Public Health Institute; ILHIE Advisory Committee member
5. David Carvalho – Deputy Director Policy Planning and Statistics, Illinois Department of Public Health; ILHIE Authority Board ex-officio member
6. Jennifer Creasey, Associate State Director of the Illinois Legislative Office of AARP
7. Jud DeLoss – Attorney in private practice; ILHIE Advisory Committee member
8. Dr. Carl Gunter – Director, University of Illinois Strategic Healthcare IT Advanced Research Projects (SHARPS) on Security
9. David Holland - VP/CIO, Southern Illinois Healthcare; ILHIE Authority Board member
10. Ron Isbell – Manager Network Infrastructure Data Security & User Access, Children’s Memorial Hospital
11. \*\* Dr. Edward Mensah – Program Director Public Health Informatics, University of Illinois at Chicago School of Public Health; ILHIE Authority Advisory Committee member
12. Pat Merryweather – Executive Director, Illinois Foundation for Quality Healthcare (IFMC-IL); ILHIE Authority Advisory Committee member
13. Harry Rhodes – Director Practice Leadership, American Health Information Management Association (AHIMA)
14. Tiefu Shen – Chief Division of Epidemiologic Studies, Illinois Department of Public Health
15. William Spence – CIO, Roseland Community Hospital
16. Timothy Zoph – Senior Vice President, Administration / CIO, Northwestern Memorial HealthCare

\* Mr. Anfield resigned from the Committee in mid-July 2012 due to a change in his professional employment duties.

\*\* Dr. Mensah recused himself in mid-August 2012 from active participation in the Committee’s deliberations due to his engagement to conduct on behalf of the ONC an assessment of OHIT’s compliance with the ONC’s grant requirements.

## EXHIBIT B

### EXHIBIT B: COMMITTEE CHARTER

- Resolution 2011-12, available at:  
[http://www2.illinois.gov/gov/HIE/Documents/Authority%20Docs/Resolution2011\\_12FINAL.pdf](http://www2.illinois.gov/gov/HIE/Documents/Authority%20Docs/Resolution2011_12FINAL.pdf).

### EXHIBIT B: COMMITTEE MEETING MINUTES

- Feb. 8, 2012, available at:  
[http://www2.illinois.gov/gov/HIE/Documents/DataSecurityPrivacyCom020812\\_MinutesFINAL.pdf](http://www2.illinois.gov/gov/HIE/Documents/DataSecurityPrivacyCom020812_MinutesFINAL.pdf).
- March 29, 2012 (draft), available at:  
[http://www2.illinois.gov/gov/HIE/Documents/DataSecurityPrivacyCom032912\\_Minutes050112.pdf](http://www2.illinois.gov/gov/HIE/Documents/DataSecurityPrivacyCom032912_Minutes050112.pdf).
- May 3, 2012 (draft), available at:  
[http://www2.illinois.gov/gov/HIE/Documents/DSPC%20Minutes%205%203%20%202012\\_DRAFT.pdf](http://www2.illinois.gov/gov/HIE/Documents/DSPC%20Minutes%205%203%20%202012_DRAFT.pdf)
- July 17, 2012 (draft), available at: [PENDING, to be posted]
- July 27, 2012 (draft), available at:  
[http://www2.illinois.gov/gov/HIE/Documents/DSPCminutes072712\\_draft083112rev.pdf](http://www2.illinois.gov/gov/HIE/Documents/DSPCminutes072712_draft083112rev.pdf)
- August 13, 2012 (draft), available at:  
[http://www2.illinois.gov/gov/HIE/Documents/DataSecurityPrivacyCom81312\\_Minutes\\_DRAFTrev090512.pdf](http://www2.illinois.gov/gov/HIE/Documents/DataSecurityPrivacyCom81312_Minutes_DRAFTrev090512.pdf)
- August 17, 2012 (draft), available at:  
[http://www2.illinois.gov/gov/HIE/Documents/DataSecurityPrivacyCom81712\\_Minutes\\_DRAFTrev090512.pdf](http://www2.illinois.gov/gov/HIE/Documents/DataSecurityPrivacyCom81712_Minutes_DRAFTrev090512.pdf)
- September 6, 2012 (draft), available at:  
<http://www2.illinois.gov/gov/HIE/Documents/MinutesDSPC.pdf>
- September 13, 2012 (draft), available at:  
[http://www2.illinois.gov/gov/HIE/Documents/DataSecurityPrivacyCom91312\\_Minutes\\_DRAFTrev.pdf](http://www2.illinois.gov/gov/HIE/Documents/DataSecurityPrivacyCom91312_Minutes_DRAFTrev.pdf)

## EXHIBIT C

### EXHIBIT C: LIST OF TESTIMONY AND MATERIALS RECEIVED

(available at: <http://www2.illinois.gov/gov/HIE/Pages/DataSecurityandPrivacy.aspx>)

#### February 8 Presentations

- Welcome & Agenda
- Committee Governance & Duties
- Committee Workplan
- Legal Task Force Overview & Status Report
- HealthShare Consent Management / Video

#### March 29, 2012 (Part of the BHIP First Statewide Meeting)

- Recommendations of the ILHIE Substance Abuse Subcommittee of the Legal Task Force
- Recommendations of the ILHIE Behavioral Health Work Group

#### March 29 Testimonies

- On behalf of the Prairie Center Health System, Mr. Eric Foster, Chief Operating Officer of the Illinois Alcohol and Drug Dependence Association
- On behalf of the Central Illinois Health Information Exchange, Dr. David Trachtenberg, its Chief Medical Informatics Officer and a practicing physician
- On behalf of the Metro Chicago Health Information Exchange, Mrs. Marilyn Lamar, Legal Counsel
- On behalf of the Mental Health Centers of Central Illinois, Mrs. Robyn Luke, Administrator
- On behalf of GROW in Illinois, Mr. Walter Blumenshine, Fieldworker for GROW in Illinois and a U.S. Armed Forces veteran

#### May 3 Testimonies and Public Comments

- Vicki Day – Nurse Practitioner, OSF St. James Hospital – John W. Albrecht Medical Center
- Harry Rhodes, MBA, RHIA – Director Practice Leadership, American Health Information Management Association (AHIMA)
- Donna Schnepf, MHA, RHIA – President, Illinois Health Information Management Association (ILHIMA); Sandra Joe, MJ, RHIA – President Elect, ILHIMA; and Deshawna Hill-Burn, Past President, ILHIMA
- Cindy Bracy – 1st Year Director of Legislation and Advocacy, ILHIMA; and Heather Shankland – 2nd Year Director of Legislation and Advocacy, ILHIMA
- Kim Baldwin-Stried Reich – ILHIMA Board Advisor and AHIMA Speaker-Elect

## EXHIBIT C

- Public Comment 1: Dietra Kulicke – Director, Marketing and Communication, Chestnut Health Systems
- Public Comment 2: Laura Knoblauch – Director, Illinois State University Student Health Services

July 17, 2012

- Chair Report
- ILHIE Update

Working Papers

- Patient Consent Policy Decision Tree
- Patient Choice: Options and Permitted Uses for Patient Data and Granularity of Patient Choice (overview)
- Briefing Summary - Patient Consent
- Patient Consent Models
- Briefing Summary - Granularity of Patient Choice
- Sensitivity of Patient Data: Safeguards for Certain Personal Health Information (overview)
- Briefing Summary - Special Categories of Patient Data
- Patient Choice and Consent: Operational Protocols (overview)
- Briefing Summary - Providing and Documenting "Meaningful Choice"
- Identity Management (overview)
- Briefing Summary - Patient Matching
- Fostering Public Trust in HIE: Enforcement and Mitigation Strategies & Security Compliance for HIEs (overview)
- Briefing Summary - Fostering Public Trust in HIEs
- Privacy Breach Enforcement

Regional HIE Testimony

- Marilyn Lamar, Metro Chicago Health Information Exchange
- David Miller, Central Illinois Health Information Exchange
- Steve Lawrence, LincolnLand Health Information Exchange/Illinois Health Information Exchange Partners

Public Testimony

- Marvin Lindsey, Community Behavioral Healthcare Association
- Ann Hilton Fisher, AIDS Legal Council of Chicago

## EXHIBIT C

- Peter Eckart, Illinois Public Health Institute
- Gregory Ignatius, Patient Advocate
- Colleen Connell, American Civil Liberties Union
- Kathy Chan, Illinois Maternal and Child Health Coalition
- Pamela Sutherland, Planned Parenthood of Illinois
- Mike Berry, HLN Consulting LLC
- Vik Bansal, Deloitte & Touche
- Patrick Gallagher, Illinois State Medical Society
- Lisa Gallagher, Health Information Management Systems Society
- Mary Rasmusson, Patient Advocate
- Robert Adams, Netsmart Technologies
- Drs. David Stumpf and Barry Hieb, Global Patient Identifiers Incorporated

July 27, 2012

- Behavioral Health Report - BHIP Summit Preliminary Findings
- Substance Abuse Report
- Genetic Testing Report
- AIDS Confidentiality Act Report

Working Papers

- Obtaining and Maintaining Consent - Operational Considerations
- Consent Models - Empirical Evidence
- Options for Storing Electronic Consent

Public Testimony

- Dr. Tom Mikkelsen, LincolnLand Health Information Exchange/Illinois Health Information Exchange Partners
- Dr. Fred Rachman, The Alliance of Chicago Community Health Services
- Esther Sciammarella, Chicago Hispanic Health Coalition
- Harry Rhodes, HIM Solutions - Testimony | PowerPoint Slides
- Ed Murphy, Central Illinois Health Information Exchange
- Dr. David Trachtenberg, Central Illinois Health Information Exchange
- Cynthia Bracy, Illinois Health Information Management Association
- Pat Schou, Illinois Critical Access Hospital Network

## EXHIBIT D

### EXHIBIT D: OVERVIEW OF SELECTED STATE-LEVEL HIE SYSTEMS

#### Consent Models/Process in Other States

##### **Maryland**

Stage 1: HIE will maintain a Master Patient Index (MPI) that contains a minimum data set to identify consumers - without consent.<sup>23</sup>

- Currently, the HIE does not exclude sensitive PHI, but it does not accept any health information from substance abuse or mental health providers.<sup>24</sup>
- Maryland Health Care Commission (MHCC) Policy on Sensitive Health Information and *Draft* Regulations require that participating organizations that have the technical capability to do so to allow consumers to request sensitive PHI be withheld from HIE. However, HIE's without this capability are to inform customers that they cannot selectively withhold PHI from the HIE but can opt out of HIE (which appears to be the case currently).<sup>25 26</sup>

Stage 2: Access to HIE [Opt-Out]

- Consumers are considered to be a participant in the HIE until they have explicitly opted-out.<sup>27 28</sup>
- Opt-out can be done by telephone, mail, fax or online<sup>29</sup>
- An HIE must require participating organizations to inform the consumer of their right to object prior to any initial query of the consumer's PHI<sup>30</sup>
- Exceptions:
  - 1) Direct point to point messaging
  - 2) Medical Emergency
  - 3) Public Health Reporting
- Draft regulations (not yet in final) provide that consent consistent with current law is required for sensitive PHI prior to disclosure of information to and through an HIE to an authorized recipient.<sup>31</sup> (Unclear whether opt in consent is then required for Special PHI)

##### **Minnesota**

Stage 1: Record Locator Service (RLS) [Opt-Out]

<sup>23</sup> Maryland Health Care Commission (MHCC) Health Information Exchange Approved Policies and Resolutions, p.

8; [http://mhcc.dhmfh.maryland.gov/hit/hiePolicyBoard/Pages/hie\\_pb\\_main.aspx](http://mhcc.dhmfh.maryland.gov/hit/hiePolicyBoard/Pages/hie_pb_main.aspx)

<sup>24</sup> <http://crisphealth.org/FAQs/tabid/110/Default.aspx>

<sup>25</sup> MHCC Approved Policies and Resolutions, p. 13.

[http://mhcc.dhmfh.maryland.gov/hit/hiePolicyBoard/Pages/hie\\_pb\\_main.aspx](http://mhcc.dhmfh.maryland.gov/hit/hiePolicyBoard/Pages/hie_pb_main.aspx)

<sup>26</sup> MHCC Draft Regulations, Regulation .04

<sup>27</sup> <http://crisphealth.org/FAQs/tabid/110/Default.aspx>

<sup>28</sup> MHCC Approved Policies and Resolutions, p. 7;

[http://mhcc.dhmfh.maryland.gov/hit/hiePolicyBoard/Pages/hie\\_pb\\_main.aspx](http://mhcc.dhmfh.maryland.gov/hit/hiePolicyBoard/Pages/hie_pb_main.aspx)

<sup>29</sup> <https://connect.crisphealth.org/>

<sup>30</sup> MHCC Approved Policies and Resolutions, p.7;

[http://mhcc.dhmfh.maryland.gov/hit/hiePolicyBoard/Pages/hie\\_pb\\_main.aspx](http://mhcc.dhmfh.maryland.gov/hit/hiePolicyBoard/Pages/hie_pb_main.aspx)

<sup>31</sup> MHCC Draft Regulations, Regulation .04

## EXHIBIT D

- Provider may release patient identifying information and location of patient records to an RLS without patient consent, unless patient elects to be excluded from HIE (**Opt-Out**)<sup>32</sup>

### Stage 2: Access to HIE [Opt-In with exceptions]

- Provider does not have access to RLS without patient's consent, which does not expire but can be revoked<sup>33</sup>
  - Exception in case of "medical emergency"<sup>34</sup> - "provider is unable to obtain the patient's consent due to the patient's condition or the nature of the medical emergency"<sup>35</sup>
- Provider may not release patient's health record without: (1) patient consent (**Opt-In**); (2) specific authorization in law; or (3) representation from another provider that he holds a patient consent<sup>36</sup>
  - Consent valid for one year<sup>37</sup>
  - Exception in case of "medical emergency when provider is unable to obtain the patient's consent due to the patient's condition or the nature of the medical emergency"<sup>38</sup>
    - **Note: MN recognizes emergency exception**
  - Exception for treatment disclosures "within related health care entities"<sup>39</sup>
  - Exception for disclosures to certain long-term care facilities<sup>40</sup>
  - **NOTE: MN does not recognize general T-P-O exception**

### New Mexico

#### Stage 1: Master Patient Index (MPI) and Record Locator Service (RLS) [Opt-Out]

- Provider may release "demographic information" and location of patient records to an RLS "in accordance with state or federal law" (i.e. without patient consent), unless patient elects to be excluded from HIE (**Opt-Out**)<sup>41</sup>
- Provider may release "information in an individual's electronic medical record" to an RLS or an HIE, unless Act provides otherwise (i.e. patient "opt-out")<sup>42</sup>

#### Stage 2: Access to HIE [Opt In]<sup>43</sup>

- Provider does not have access to RLS without patient's consent<sup>44</sup>
  - Exception in case of "treatment"<sup>45</sup>
  - **Note: NM recognizes Treatment exception**
  - Exception if "otherwise permitted by state or federal law"

<sup>32</sup> Minn. Stat. 144.293, subd. 8 (2009)

<sup>33</sup> Minn. Stat. 144.293, subd. 8 (2009)

<sup>34</sup> Minn. Stat. 144.293, subd. 8 (2009)

<sup>35</sup> Minn. Stat. 144.293, subd. 5 (2009)

<sup>36</sup> Minn. Stat. 144.293, subd. 2 (2009)

<sup>37</sup> Minn. Stat. 144.293, subd. 4 (2009)

<sup>38</sup> Minn. Stat. 144.293, subd. 5 (2009)

<sup>39</sup> Minn. Stat. 144.293, subd. 5 (2009)

<sup>40</sup> Minn. Stat. 144.293, subd. 5 (2009)

<sup>41</sup> NM Electronic Medical Records Act, sec. 6B, 6E

<sup>42</sup> NM Electronic Medical Records Act, sec. 6G2

<sup>43</sup> New Mexico Health Information Exchange Strategic and Operational Plans at <http://nmhic.org/supporting.files>

<sup>44</sup> NM Electronic Medical Records Act, sec. 6B, 6E

<sup>45</sup> NM Electronic Medical Records Act, sec. 6B

## EXHIBIT D

- Provider may release “information in an individual’s electronic medical record” to an RLS or an HIE, unless Act provides otherwise (i.e. patient “opt-out”)<sup>46</sup>
- Provider may release “information in an individual’s electronic medical record” to an RLS or an HIE for cases requiring “immediate medical attention”<sup>47</sup>
  - **Note: NM recognizes emergency exception**
- Specially-protected PHI subject to separate consent requirements (STDs, HIV/AIDS test results, viral hepatitis, genetics, mental health, substance abuse)

### Rhode Island

Stage 1: Disclosures to HIE [Opt In to enroll]<sup>48</sup>

- Patients to be provided with choice whether to participate in HIE<sup>49</sup>

Stage 2: Access to HIE [Opt-In with exceptions]

- Provider does not have access to HIE without patient’s consent<sup>50</sup>
- Patients to sign authorization form (**Opt-In**)<sup>51</sup>
- Maximum duration 24 months<sup>52</sup>
  - Exception in case of “emergency”<sup>53</sup>
    - **Note: RI recognizes emergency exception**
  - Exception in case of reports to public health authority<sup>54</sup>
  - Exception in order to “effectuate the operation and administrative oversight of the HIE”<sup>55</sup>

### New York

Stage 1: disclosures to HIE [No patient consent required]

- Provider may upload PHI to HIE without patient’s consent<sup>56</sup>

Stage 2: Access to HIE [Opt-In with exceptions]

- Provider does not have access to HIE without patient’s consent (**Opt-In**)<sup>57</sup>
  - Maximum duration 2 years<sup>58</sup>
  - Exception for peer-to-peer exchanges<sup>59</sup>

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<sup>46</sup> NM Electronic Medical Records Act, sec. 6G2

<sup>47</sup> NM Electronic Medical Records Act, sec. 6G1

<sup>48</sup> [http://www.currentcareri.org/matriarch/MultiPiecePage.asp\\_Q\\_PageID\\_E\\_26\\_A\\_PageName\\_E\\_PoliciesProcedures](http://www.currentcareri.org/matriarch/MultiPiecePage.asp_Q_PageID_E_26_A_PageName_E_PoliciesProcedures)

<sup>49</sup> Rhode Island Health Information Exchange Act of 2008, sec. 5-37.7-4(c)

<sup>50</sup> Rhode Island Health Information Exchange Act of 2008, sec. 5-37.7-7(a)(1)

<sup>51</sup> RI Regulations, sec. 2.2, 4.2

<sup>52</sup> RI Regulation 100, sec. 5B

<sup>53</sup> Rhode Island Health Information Exchange Act of 2008, sec. 5-37.7-7(b)(1); RI Regulations, sec. 4.3

<sup>54</sup> Rhode Island Health Information Exchange Act of 2008, sec. 5-37.7-7(b)(2); RI Regulations, sec. 4.3

<sup>55</sup> Rhode Island Health Information Exchange Act of 2008, sec. 5-37.7-7(b)(3); RI Regulations, sec. 4.3

<sup>56</sup> “Privacy & Security Policies and Procedures for RHIOs and their Participants in New York State, ver. 2.2”, sec. 1.2.4

<sup>57</sup> “Privacy & Security Policies and Procedures for RHIOs and their Participants in New York State, ver. 2.2”, sec. 1.1;

<sup>58</sup> Sec. 1.7.7

## EXHIBIT D

- Exception in case of public health reporting<sup>60</sup>
  - Exception in case of “emergency condition”<sup>61</sup>
    - **Note: NY recognizes emergency exception**
  - Exception “for the purpose of evaluating and improving RHIO operations”<sup>62</sup>
  - Exception for access to “de-identified data”<sup>63</sup>
- Additional requirements may be applied by RHIOs to “sensitive health information”<sup>64</sup>

### Virginia

(Appears there is no state HIE statute, and HIE is at early stage)

Stage 1: HIE will maintain a Master Patient Index (MPI) and a Record Locator Service (RLS) - without consent.<sup>65</sup>

- Some locator information will be stored centrally and other data will be accessible by edge servers maintained by participants that are accessible to HIE inquiries.<sup>66</sup>

Stage 2: Access to HIE [Opt-In]<sup>67</sup>

- Policy: Opt in model selected so that “complete data received through the COV-HIE, including special categories of data which cannot be exchanged through ... opt-out model”<sup>68</sup>
- Applies to all data (All in or All out)
- However, psychotherapy notes are never to be sent in response to a query.<sup>69</sup>
- HIE must secure consent of minor before exchanging minor’s Special PHI (separate consent). If not obtained, minor’s Special PHI must be excluded from response to query.<sup>70</sup>
- Decision to opt-in will be made at each entity (e.g. regional HIE, IDN) that participates in HIE.<sup>71</sup>
- Revocable any time<sup>72</sup>
- Exceptions:
  - 1) Medical emergency
  - 2) SSA query for determination of eligibility for disability benefits
  - 3) Public health reporting<sup>73</sup>

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<sup>59</sup> Sec. 1.2.1

<sup>60</sup> Sec. 1.2.2

<sup>61</sup> Sec. 1.2.3

<sup>62</sup> Sec. 1.2.5

<sup>63</sup> Sec. 1.2.6

<sup>64</sup> Sec. 1.4.2

<sup>65</sup> Commonwealth of Virginia Health Information Exchange (COV-HIE) Strategic Plan, Version 1.2, February, 2011, Sections 2.2, 2.3 [www.healthitcouncil.vi.virginia.gov/hits-devel/COV-HIE](http://www.healthitcouncil.vi.virginia.gov/hits-devel/COV-HIE)

<sup>66</sup> VA Strategic Plan, Sec. 2.8

<sup>67</sup> VA Strategic Plan, Sec. 2.3.3

<sup>68</sup> VA Strategic Plan, Sect. 2.5.3

<sup>69</sup> Connect Virginia Exchange Policies and Procedures Public Comment Draft, Policy No. CE-10 <http://www.connectvirginia.org/exchange>

<sup>70</sup> Connect Virginia Exchange Policies and Procedures Public Comment Draft, Policy No. CE-10

<sup>71</sup> VA Strategic Plan, Sec. 2.5.3

<sup>72</sup> Connect Virginia Exchange Policies and Procedures Public Comment Draft, Policy No. CE-8

<sup>73</sup> Connect Virginia Exchange Policies and Procedures Public Comment Draft, Policy No. CE-7

<http://www.connectvirginia.org/exchange> (Note: it appears ConnectVirginia is the same as what was previously referred to as COV-HIE but this would need confirmation)

## Health Information Exchange Patient Opt-Out Form



**CRISP**  
Enabling Health IT in Maryland

[En Espanol](#)

**This form is to be used by patients who do not wish to participate in Maryland's statewide Health Information Exchange (HIE).**

A Health Information Exchange, or HIE, is a way of sharing your health information among participating doctors' offices, hospitals, labs, radiology centers, and other health care providers through secure, electronic means. The purpose is so that each of your participating caregivers can have the benefit of the most recent information available from your other participating caregivers when taking care of you. When you opt out of participation in the HIE, doctors and nurses will not be able to search for your health information through the HIE to use while treating you. Your physician or other treating providers will still be able to select the HIE as a way to receive your lab results, radiology reports, and other data sent directly to them that they may have previously received by fax, mail, or other electronic communications. Public health reporting, in accordance with law such as the reporting of infectious diseases to public health officials, will also occur through the HIE after you decide to opt out.

For more information about opting out or rejoining the CRISP HIE, please visit [www.crisphealth.org](http://www.crisphealth.org), call 1-877-95-CRISP (27477), or email [hie@crisphealth.org](mailto:hie@crisphealth.org).

You have several options for opting out of the CRISP Health Information Exchange. Please select one below.

1. Complete the electronic form on this page.
2. Call 1-877-95-CRISP (27477).
3. Fax your completed form to 443-817-9587.
4. Mail your completed form to CRISP, 7160 Columbia Gateway Drive, Suite 230, Columbia, Maryland 21046.

For Options 3 and 4, please [click here to download the paper form](#).

### *Information for Patient Opting Out*

First Name\*

Middle Name

Last Name\*

Address Line 1\*

Address Line 2

City\*

State\* Maryland

ZIP Code\*

Primary Phone Number (xxx-xxx-xxxx)\*

Secondary Phone Number

Email

Date of Birth (mm/dd/yyyy)\*

Sex\* Male                      Female

Reason for Opting Out (optional)

If this form is submitted by someone other than the person named above, the person submitting the form hereby certifies that he/she is acting as (CHECK ONE):

Parent                      Legal Guardian                      Other

Specify relationship to the person named above

*Contact Information for Individual Completing This Form If Other Than Patient*

Name

Phone Number

Email

Phone

I would like to be notified of my participation choice in the following way (choose one)

Letter

Text Message

No Notification

\* Required

Secure Website

## How to Opt-Out or Back-In to the New Mexico Health Information Exchange

### NEW MEXICO HEALTH INFORMATION COLLABORATIVE (NMHC)

Not sure, need more  
information?  
Visit [www.nmhc.org](http://www.nmhc.org)  
Or call  
505-938-9999

Opt-Out  
Complete and mail the form  
below or online at  
[www.nmhc.org](http://www.nmhc.org)

Opt-Back In  
Complete and mail the form  
below or online at  
[www.nmhc.org](http://www.nmhc.org)

**You have a choice and can change your mind at any time.**

**Example – Decide to Opt-out:** If you fill out this form and mail or fax it in, the system will not allow access to any of your current or past medical information through the Health Information Exchange under any circumstances including an emergency situation. If you change your mind later and would like to reverse your decision you can **Opt-Back In** at any time.

#### I Choose to Opt-Out

#### I Choose to Opt-Back In

After you have made your selection by checking one of the boxes above, fill out this form and mail to the address below.

Last Name: \_\_\_\_\_ First Name: \_\_\_\_\_ Middle Name or Initial: \_\_\_\_\_

Date of Birth: (mm/dd/yyyy) \_\_\_\_\_

Street Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

Daytime/Work Phone #: \_\_\_\_\_ Cell Phone #: \_\_\_\_\_

Email Address \_\_\_\_\_ What is your gender (male/female) \_\_\_\_\_

When I have chosen to **Opt-Out** and sign and mail in this form, I understand that I am choosing for my health information not to be accessible in the NMHC Health Information Exchange network to anyone under any circumstances.

When I have chosen to **Opt Back In** and sign and mail this form, I understand that I am choosing for my health information to be available in the NMHC Health Information Exchange network to authorized users who have obtained my written consent.

Date: \_\_\_\_\_

\_\_\_\_\_  
Signature of Patient or Authorized Representative

**Mail this form to:**

**New Mexico Health Information Collaborative 2309 Renard Pl. SE, Suite 103 Albuquerque, NM 87106**  
Fax: 505-938-9940

## EXHIBIT E

### EXHIBIT E: OVERVIEW OF PROPOSED ILHIE PATIENT CONSENT MANAGEMENT POLICY

- I. “Two-stage” HIE
  - A. Stage 1 (Gateway 1): Release of PHI to ILHIE
    1. Description:
      - i. Health care facility’s release of patient identifying information to HIE (which will become part of MPI and/or RLS information held at HIE)
      - ii. Records are made accessible to HIE (gateway is opened)
  - B. Stage 2 (Gateway 2): Disclosure of data through ILHIE to HIE participants
    1. Description (generalized)
      - i. Query by provider
      - ii. Data collection, aggregation by HIE and disclosure to requesting provider (if query is allowed by HIE)
  - C. Consent requirements
    1. Opt-in consent for Special PHI for Stage 1 and Stage 2 disclosure (collected at Stage 1)<sup>74</sup>
      - Provider/facility whose records contain Special PHI (or contain both General and Special PHI), must obtain opt-in consent from the patient before it can release patient identifying information to the HIE and before it can make any of their records for this patient accessible to the HIE (before opening Gateway 1)(Stage 1) AND for the data to be aggregated by the HIE and disclosed to authorized HIE participants (Stage 2 disclosure).
      - If opt-in is not received, the entire record (both Special PHI and General PHI) for that facility cannot be made accessible by the facility/EMR to the HIE (no Stage 1 release – remains hidden from HIE)
    2. Opt-out consent for all patients (General PHI and Special PHI) for Stage 2 disclosure to authorized HIE participants

(No consent required from patients with only General PHI for Stage 1 release)
  3. All in/all out: consent is for all the records of a facility to be disclosed or all of that facility’s records to be “kept out”.

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<sup>74</sup> LEGAL COMPLIANCE. The data custodian (e.g. provider at point of care) is responsible for its compliance with all laws applicable to its release of information. For a partial listing of applicable federal and Illinois laws, see: “Patient Choice, Opt-in/Opt-out”, available at: [http://www2.illinois.gov/gov/HIE/Documents/3\\_BriefingSum\\_Pan1\\_071612.pdf](http://www2.illinois.gov/gov/HIE/Documents/3_BriefingSum_Pan1_071612.pdf).

## EXHIBIT E

### II. Potential Consent Process

#### A. At initial visit with a provider/facility that is an ILHIE participant:

1. Sensitive PHI patients – Opt-in option given: for patients whose record contains Special PHI or a combination of General PHI and Sensitive PHI, the facility gives the patient information about the HIE and a form giving the choice to affirmatively agree to allow her PHI from that facility to: (1) become accessible to the HIE (Stage 1); and (2) be disclosed to and through the HIE to participants (Stage 2).

- If the patient does not opt-in, the entire record (both General PHI and Sensitive PHI) and identifying information from that facility is to be excluded from Stage 1 (it is provider's/provider EMR's responsibility to determine if its records contain any Sensitive PHI and, if so, to make certain the entire record is kept inaccessible to the HIE); the HIE would not know of the record (as such, no Stage 2 disclosure, BTG disclosure, etc. could occur through the HIE for these records).
- This consent may need to be done separately for each facility with Special PHI
- This consent under current state law (i.e., Illinois' mental health records statute) would likely need some specificity/granularity such as designation of the sources of PHI and which recipients are permitted to receive/view the PHI.

2. All patients (General PHI and Special PHI) – Opt-out option given: the facility gives all patients information regarding the HIE and a form giving the choice to not have her PHI disclosed to HIE participants through the HIE and to not allow providers to have access (to not allow Stage 2 process).

- If patient with only General PHI does not opt-out, the patient is deemed to have consented to PHI disclosure through the HIE (Stage 2 disclosure) to all authorized PHI participants.
- Potential option: patient may choose to opt-out but authorize (on a form or online) a specific facility to have access to her records through the HIE until she revokes such authorization (give that facility override authorization).
- To be determined whether the patient can receive the opt-out information from the first HIE participant that she visits and can then be directed to a web portal to opt-out and the selection can be made available to other facilities/providers (such that the opt-out only needs to be selected once as opposed to each time the patient sees a new provider) or whether the patient needs to be presented with the opt out choice at each initial visit with a health care facility.

Operational considerations must be given on how to implement an opt-out model alongside an opt-in model.

3. Incomplete record: To be determined whether a patient with Special PHI chooses not to opt in for a facility and records are blocked from access by the HIE, the provider who queries the HIE and has access to some records are given an alert that it is not a complete record.

#### 4. Duration

- a. Opt-out consent (choosing not to opt out) does not expire
- b. If patient opts-out, she can opt back in at anytime
- c. Opt-in consent for Special PHI patients may require expiration date under state law

## EXHIBIT E

d. Both opt-out and opt-in consent revocable at any time (from that point going forward)

5. Incremental implementation

- Future step: an option to allow the patient to not opt-out but to exclude a specific facility such that data cannot be collected from that facility by the HIE during a query process.
- Future step: as data segmentation becomes more feasible, commercially reasonable implementation of more granular choices such as categories of data to restrict.

III. Post legislative change

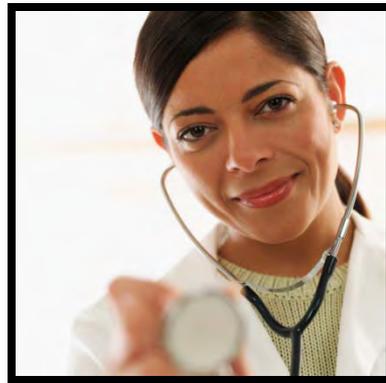
Effort will be made to amend state statutes to eliminate the requirement for opt-in consent for Special PHI such that the opt-out consent model could apply to all patients. This is a future step (not applicable to current implementation).

# Stage 1: Creation and Release of PHI

## Patient Presents at Primary Care Physician

1. Patient presents at Primary Care Physician

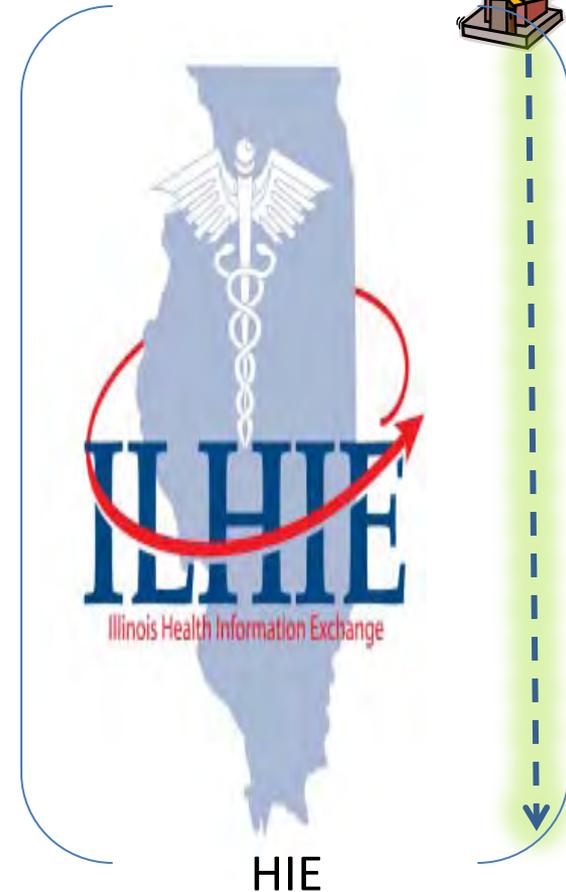
2. Provider describes HIE and offers opt-out



PCP's EHR

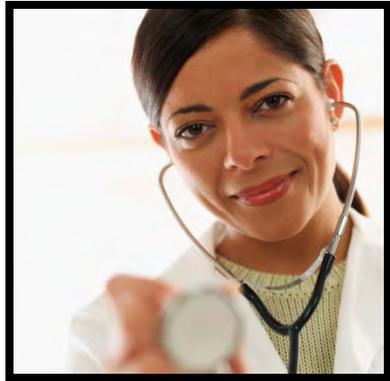


Gen PHI

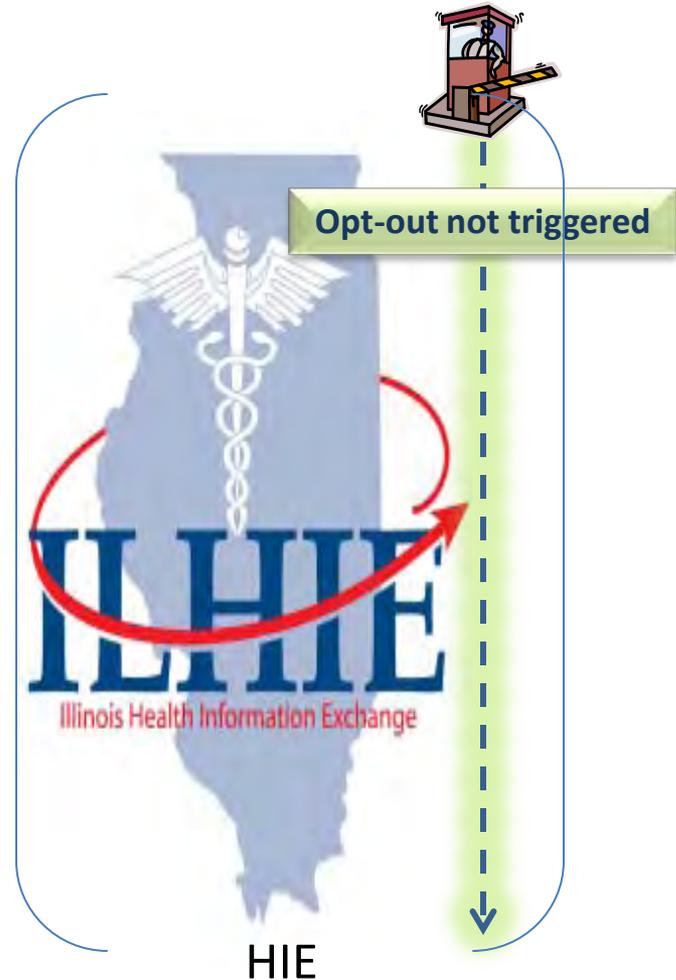


# Stage 1: Creation and Release of PHI Provider Obtains Consent

3. Patient does not opt-out



PCP's EHR

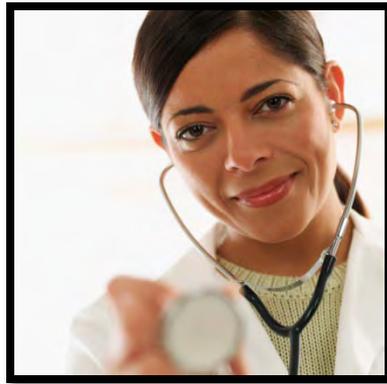


# Stage 1: Creation and Release of PHI

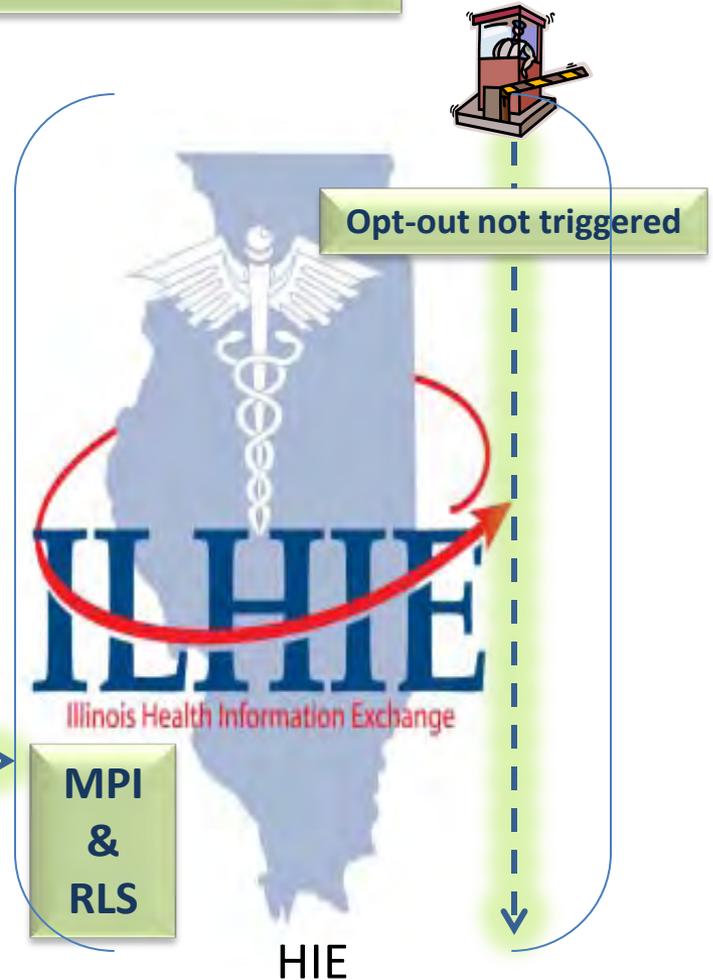
## Release of MPI and RLS

4. Patient demographic information sent to ILHIE

5. Patient data with PCP becomes accessible to ILHIE



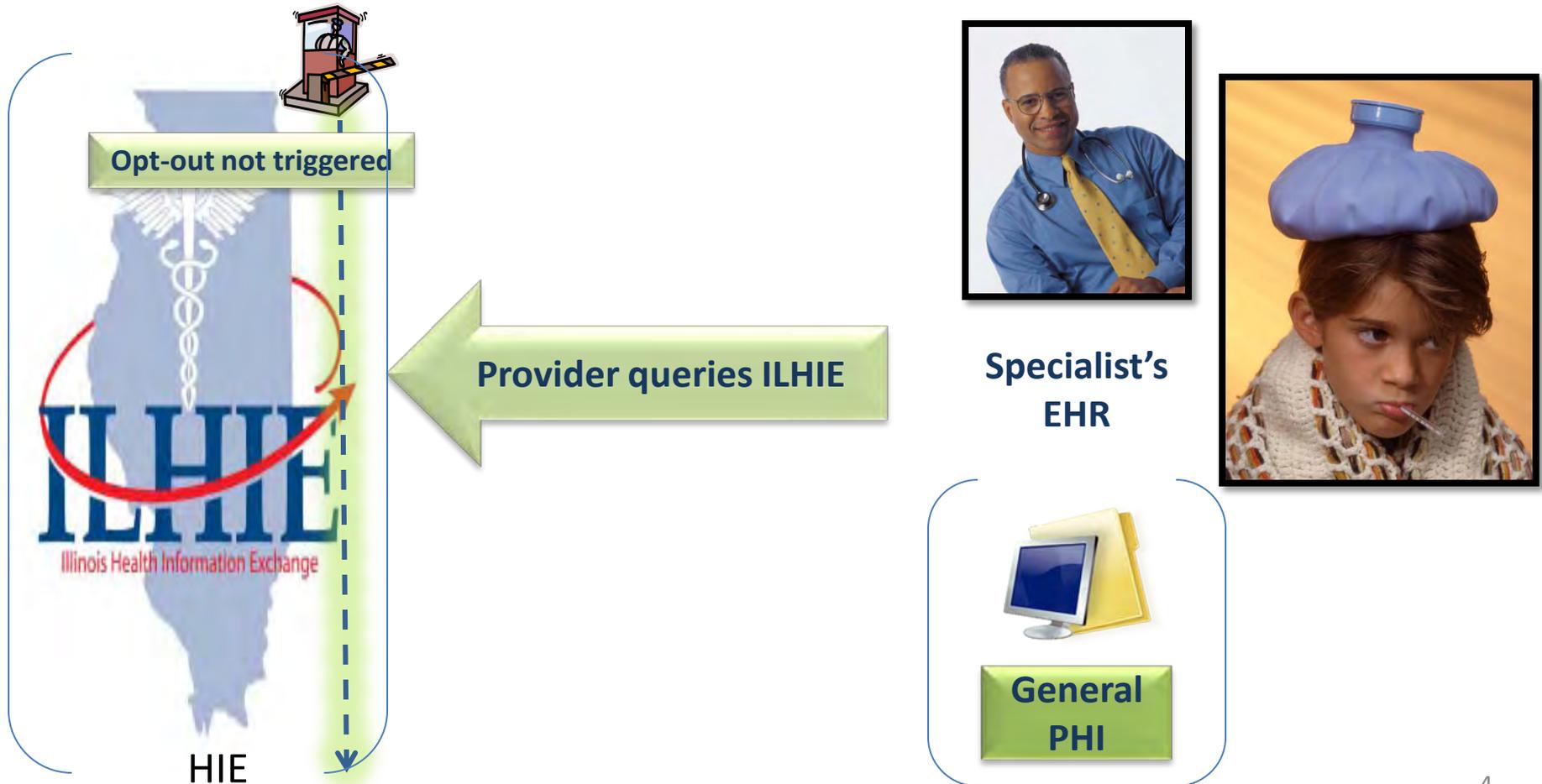
PCP's EHR



## Stage 2: HIE Query /Response Patient Presents at Specialist

1. Patient presents at ILHIE participating specialist

2. Participating specialist queries ILHIE for Patient's records

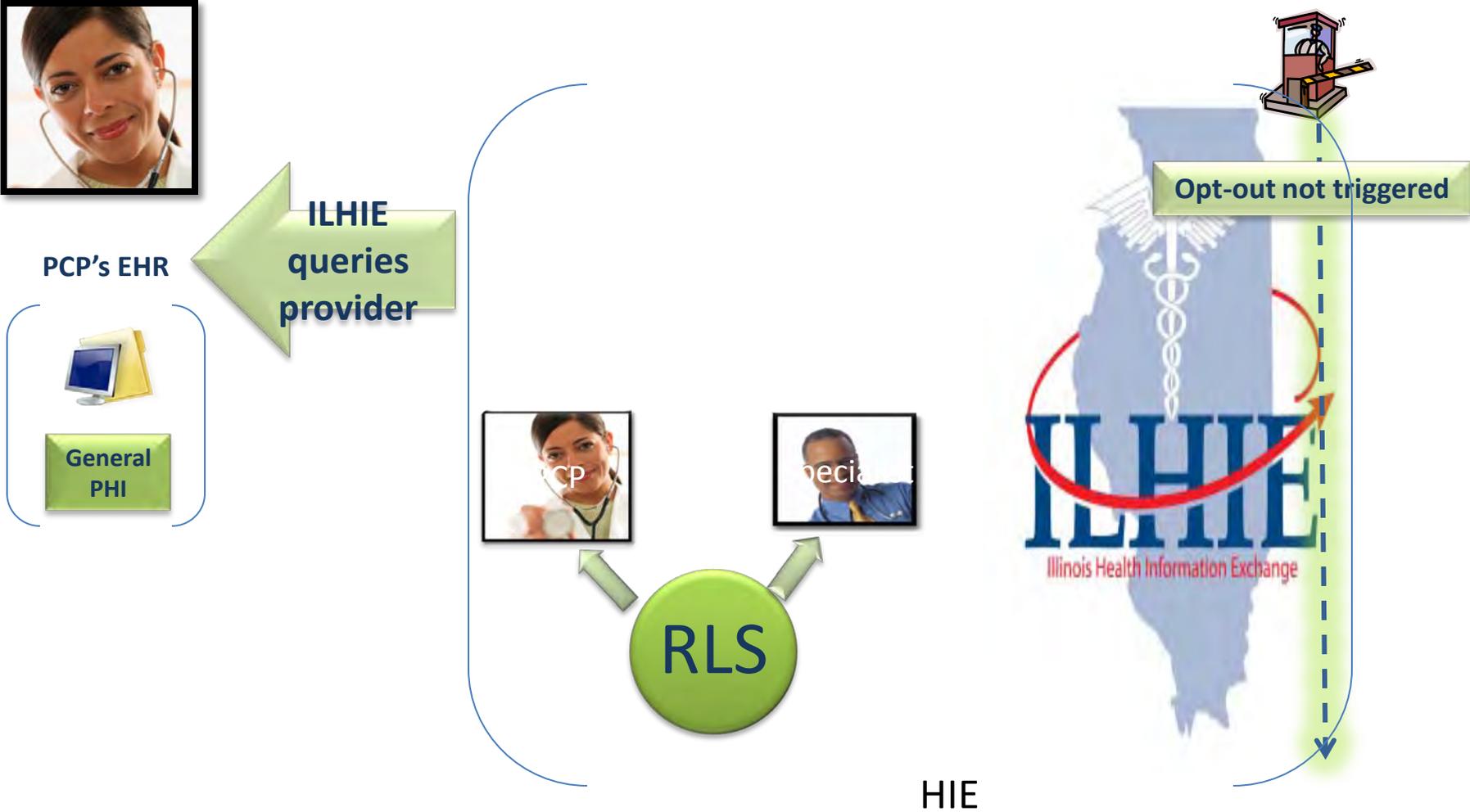




# Stage 2: HIE Query /Response

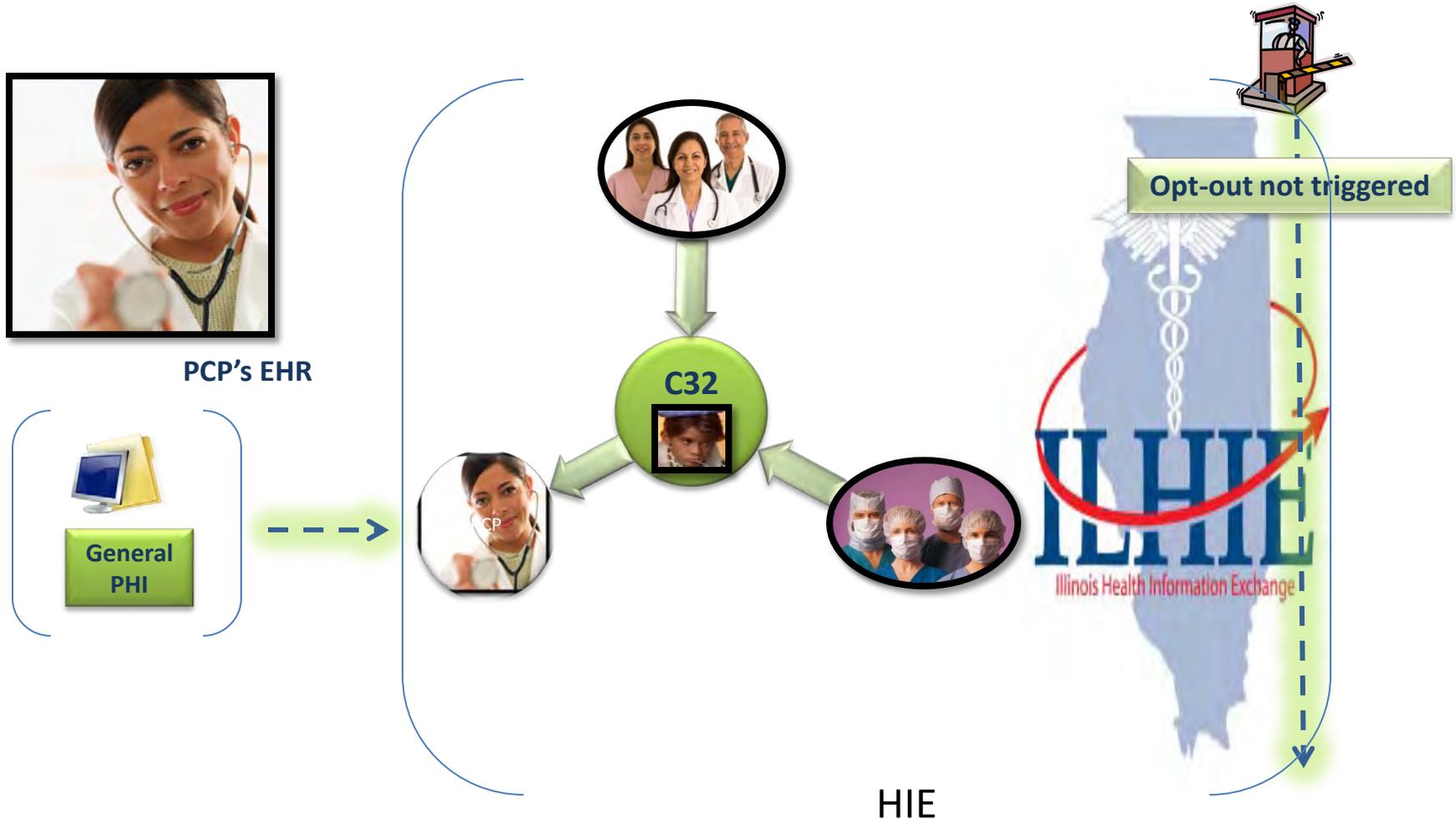
## HIE Query of Participating Providers

4. ILHIE queries providers listed in RLS for Patient's data



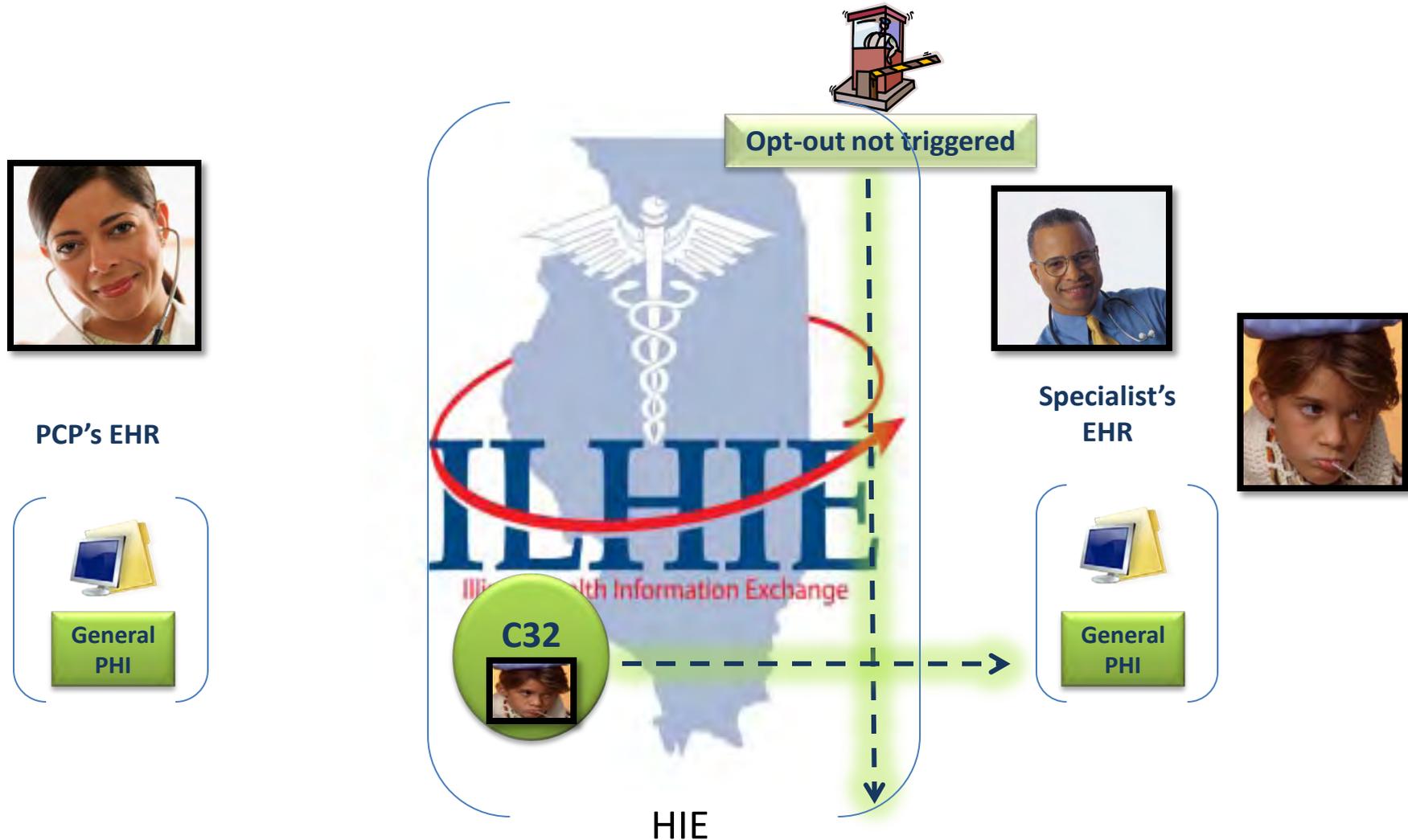
# Stage 2: HIE Query /Response Consolidated Patient Record (C32) Generation by HIE

5. ILHIE aggregates data received from providers



## Stage 2: HIE Query /Response ILHIE Delivers C32 to Participating Specialist

6. ILHIE delivers consolidated C32 to requesting participating specialist

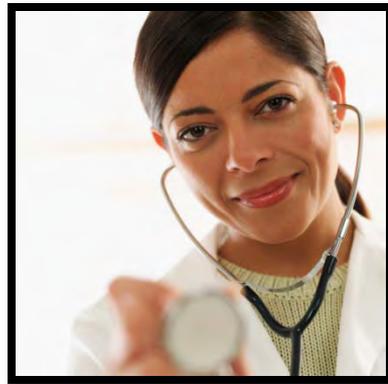


# Stage 1: Creation and Release of PHI

## Patient Presents at Primary Care Physician

1. Patient presents at Primary Care Physician

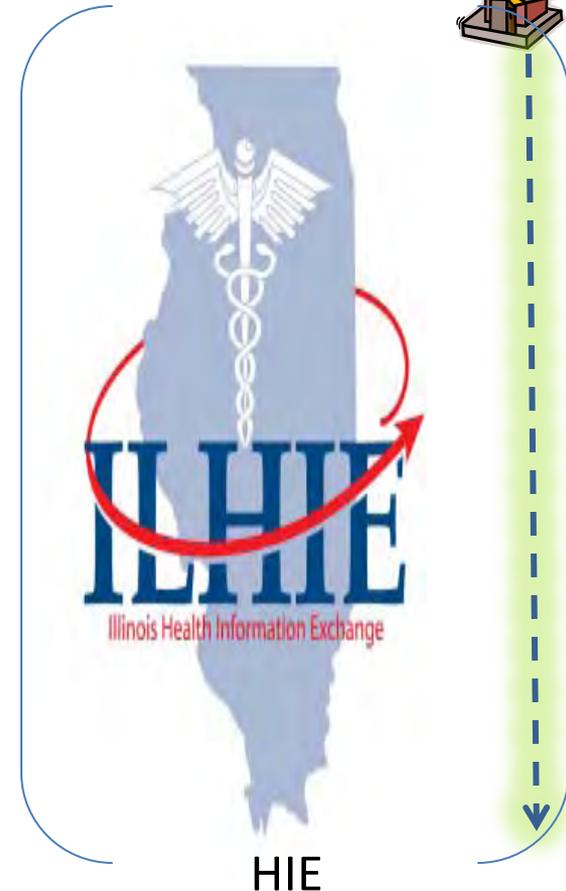
2. Provider describes HIE and offers opt-out



PCP's EHR

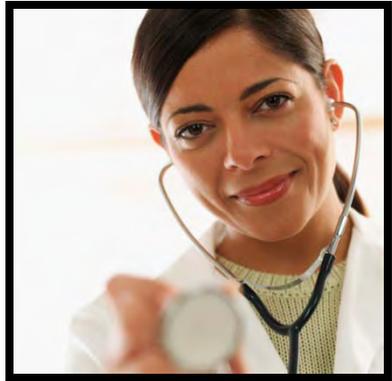


Gen PHI

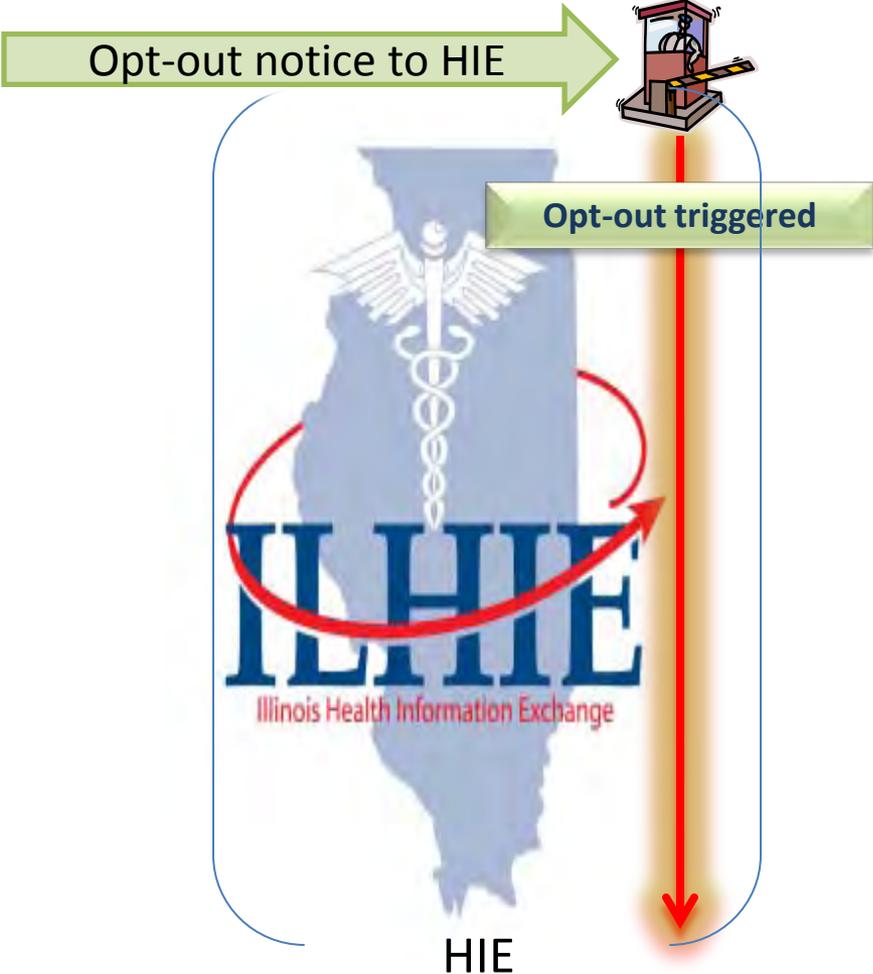


# Stage 1: Creation and Release of PHI Provider Obtains Consent

3. Patient exercises opt-out



PCP's EHR

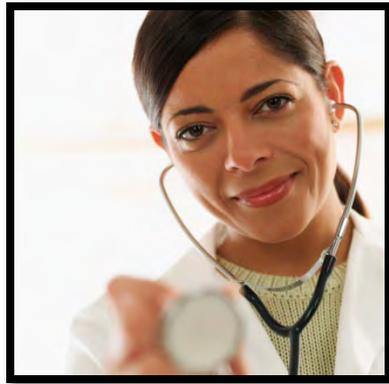


# Stage 1: Creation and Release of PHI

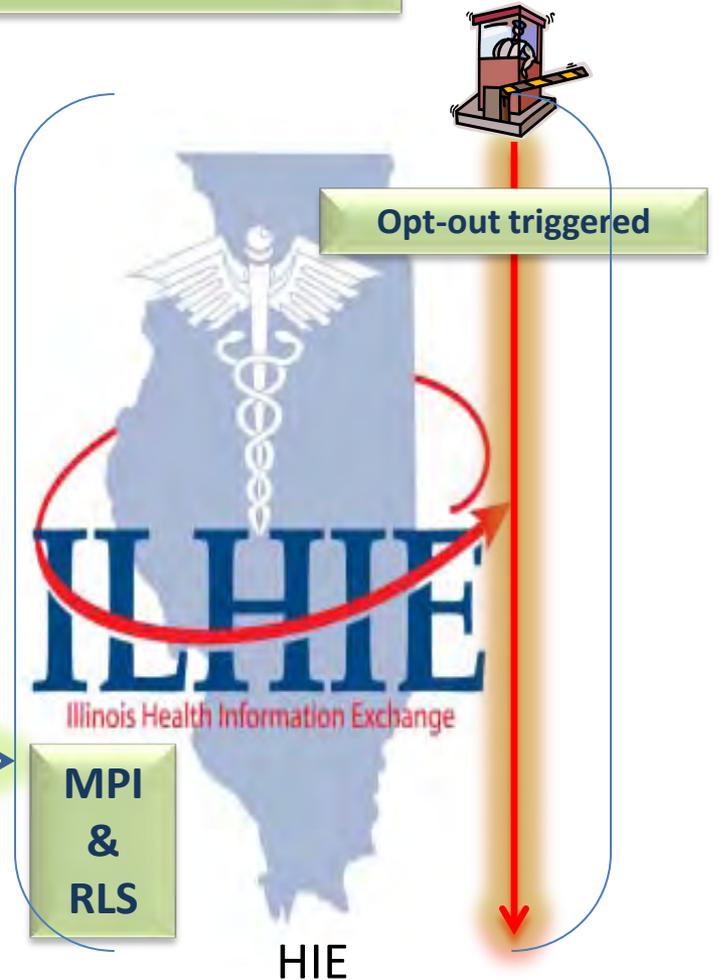
## Release of MPI and RLS

4. Patient demographic information sent to ILHIE

5. Patient data with PCP becomes accessible to ILHIE



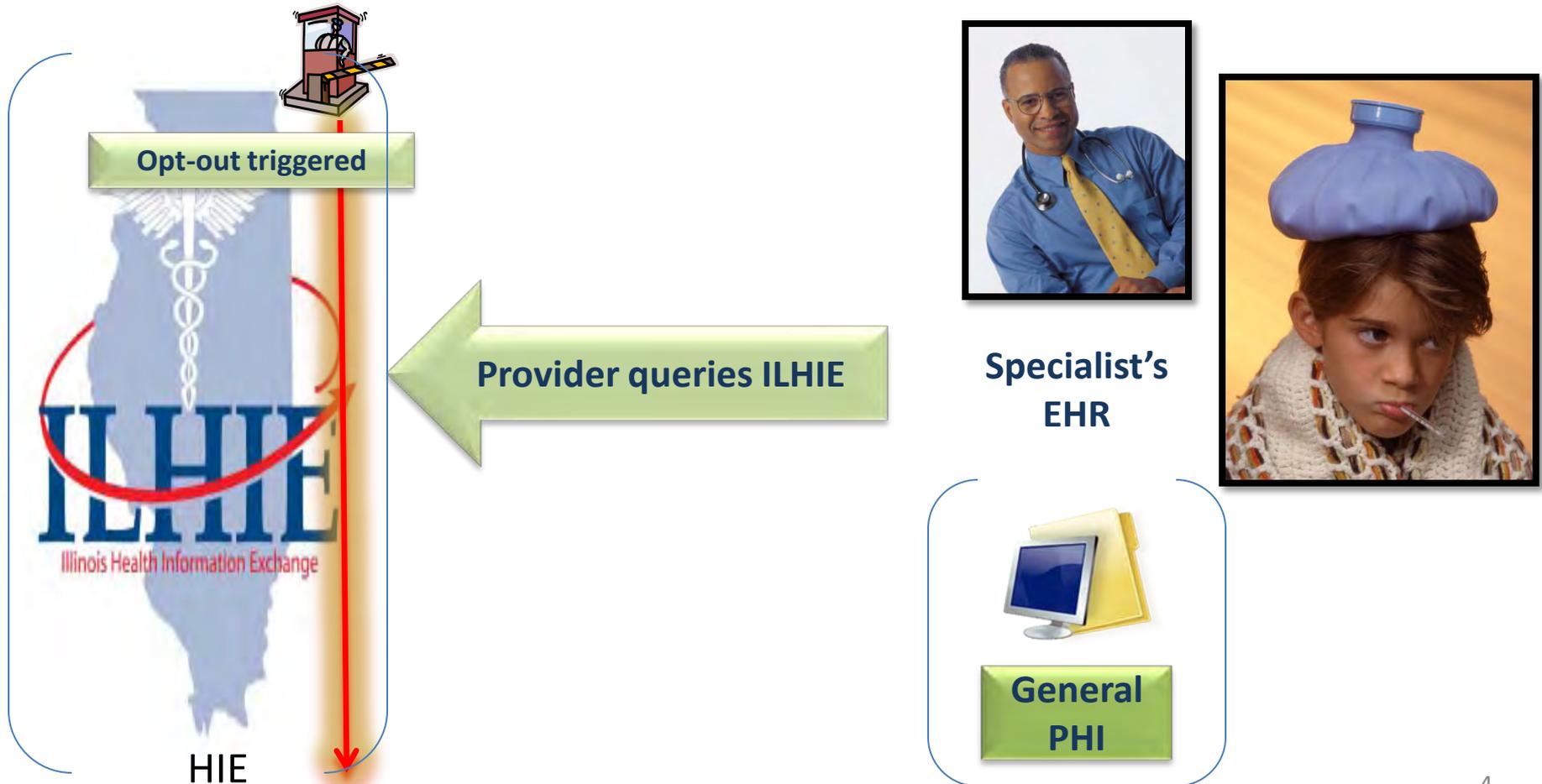
PCP's EHR



## Stage 2: HIE Query /Response Patient Presents at Specialist

1. Patient presents at ILHIE participating specialist

2. Participating specialist queries ILHIE for Patient's records



## Stage 2: HIE Query /Response HIE denies access to data

3. HIE returns "DATA NOT AVAILABLE" message



## Stage 2: HIE Query /Response Specialist “Breaks-the-glass” to access data

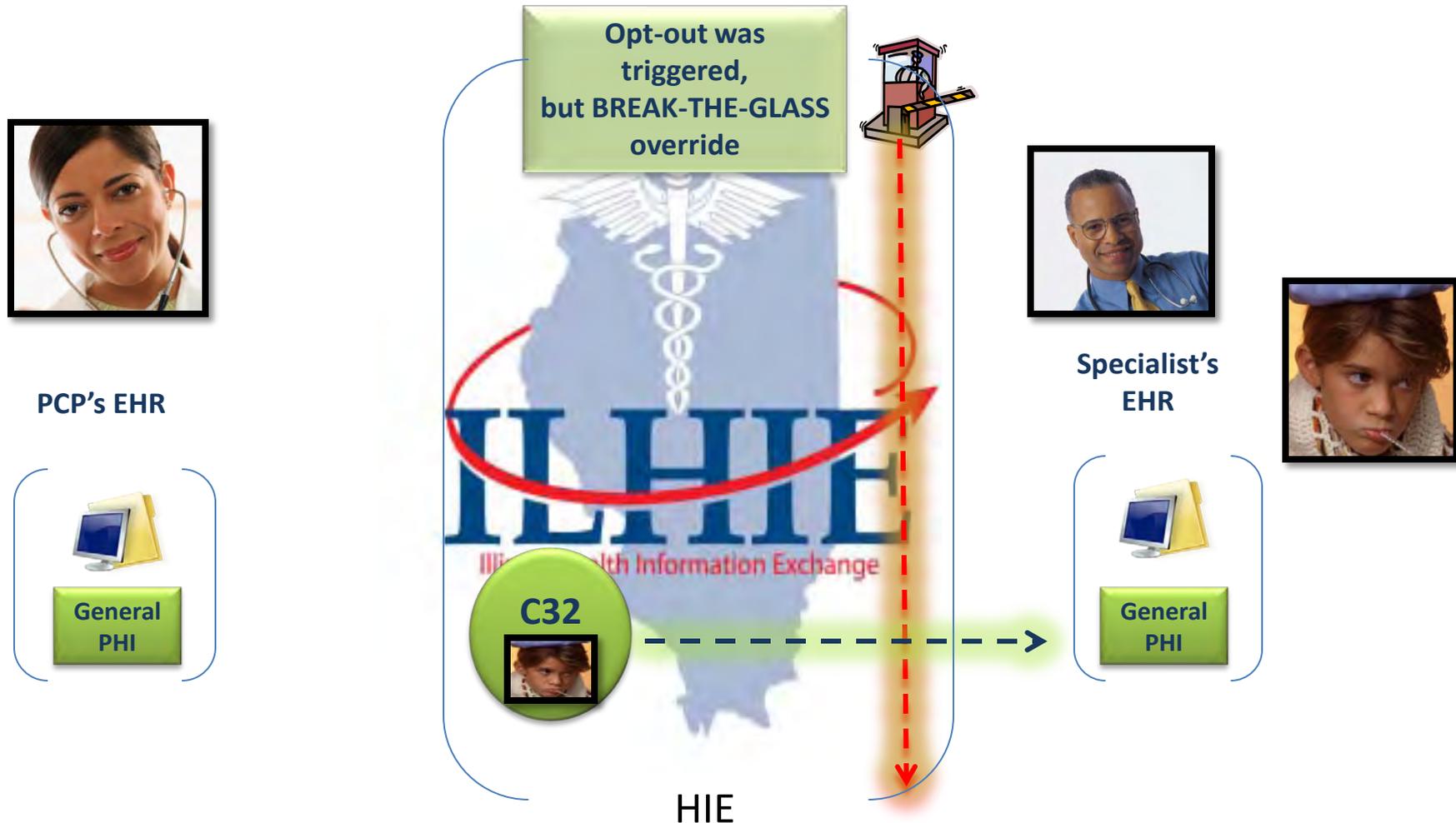
4. Participating specialist submits “BREAK-THE-GLASS” override to certify either:
- Patient medical emergency, or
  - Patient provided consent



## Stage 2: HIE Query /Response

### ILHIE Processes Query; Delivers C32 to Participating Specialist

5. ILHIE consults MPI and RLS;
6. ILHIE queries providers listed in RLS for Patient's data;
7. ILHIE aggregates data received from providers;
8. ILHIE delivers consolidated C32 to requesting participating specialist



# Stage 1: Creation and Release of PHI

## Patient Presents at Physician

1. Patient presents at Physician

2. Provider describes HIE and offers opt-out

3. Provider offers opt-in for Sensitive PHI



EHR



Gen PHI

Sensitive  
PHI



HIE

# Stage 1: Creation and Release of PHI

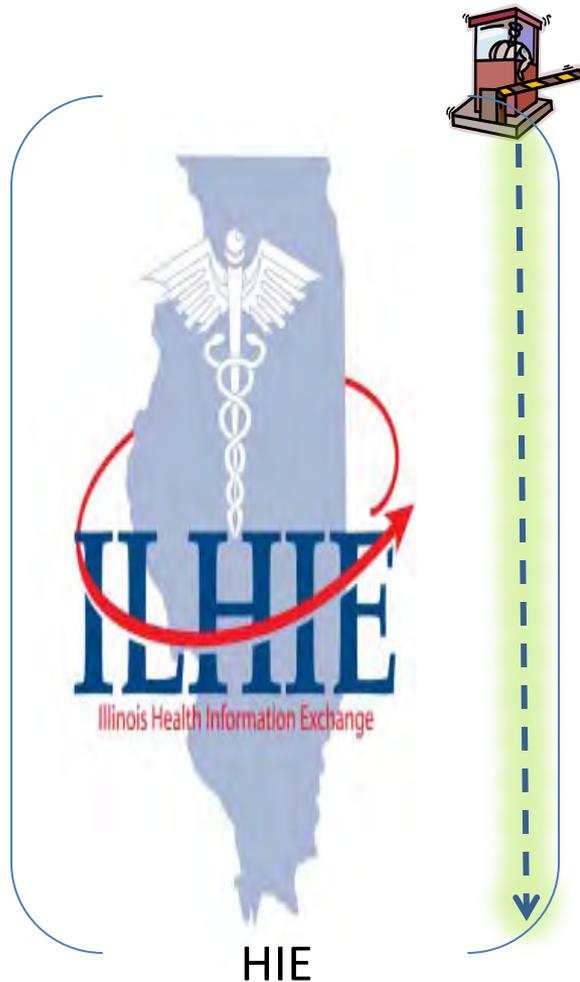
## Patient Presents at Physician

4. Patient does not opt-out

5. Patient agrees to opt-in for Sensitive PHI



EHR



# Stage 1: Creation and Release of PHI

## Release of MPI and RLS

6. Patient demographic information sent to ILHIE

7. Patient data becomes accessible to ILHIE



EHR



Gen PHI  
Sensitive PHI



MPI  
&  
RLS



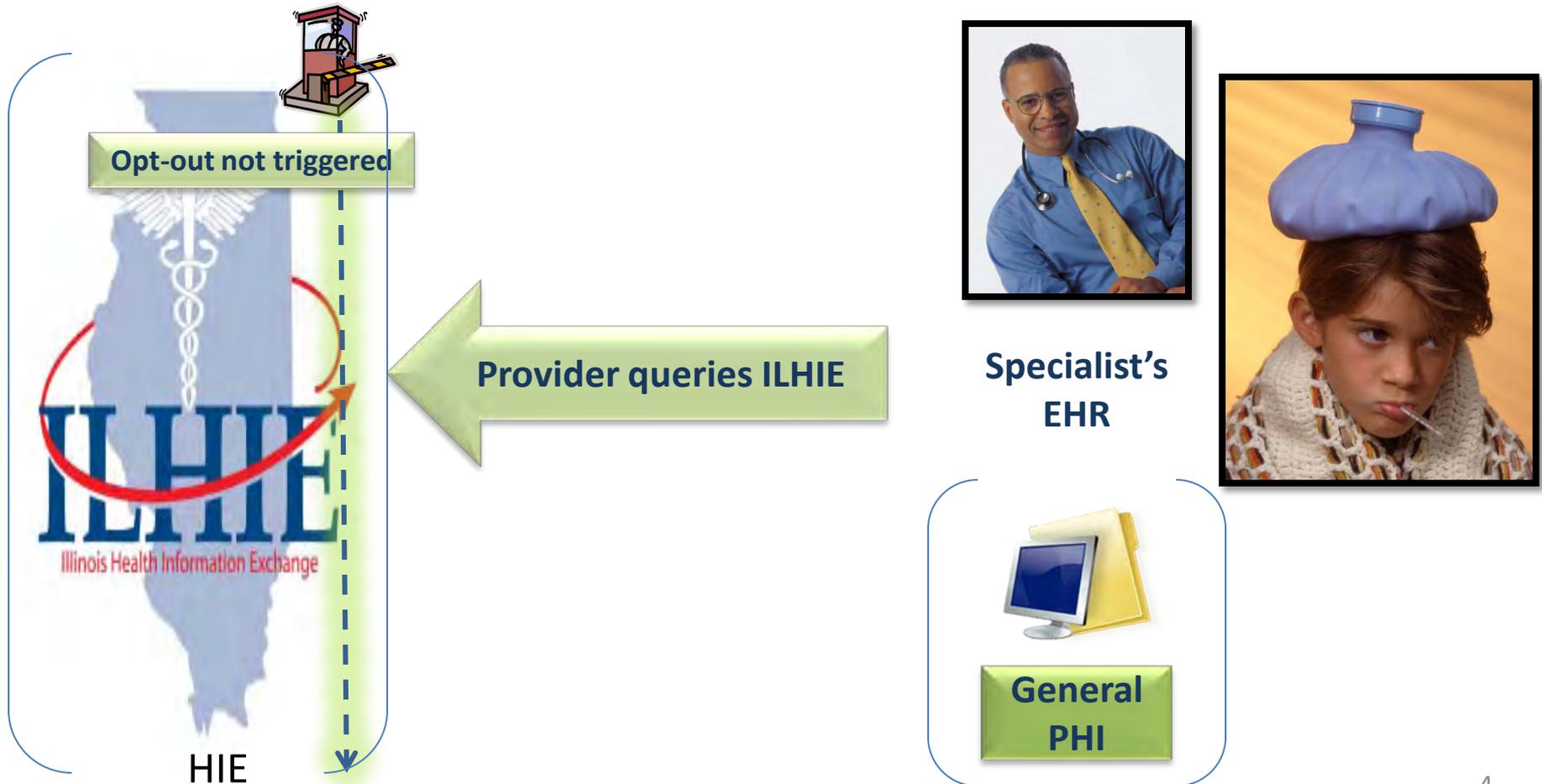
Opt-out not triggered

HIE

## Stage 2: HIE Query /Response Patient Presents at Specialist

1. Patient presents at ILHIE participating specialist

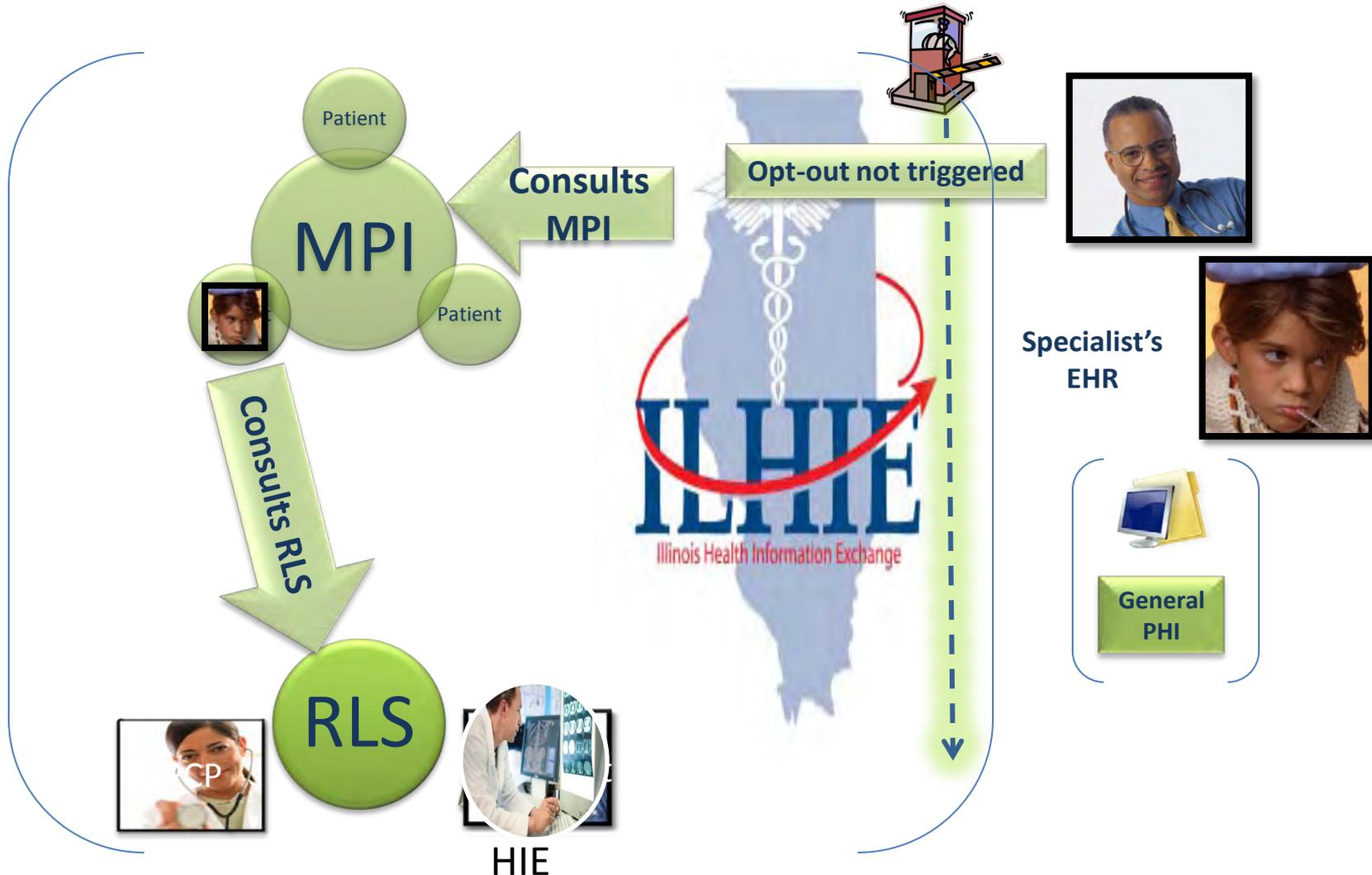
2. Participating specialist queries ILHIE for Patient's records



# Stage 2: HIE Query /Response

## HIE Consults MPI & RLS

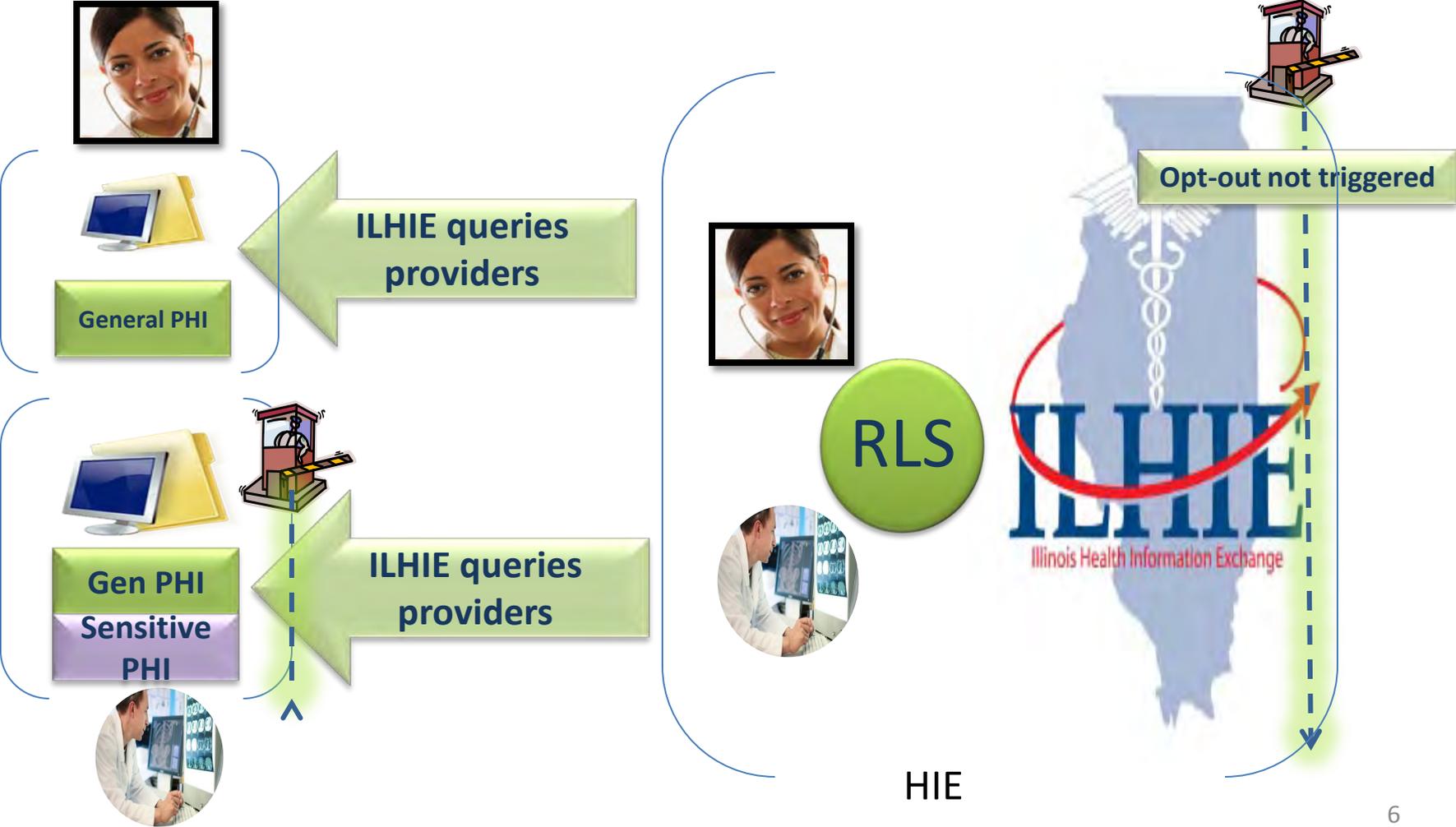
3. ILHIE consults MPI and RLS



# Stage 2: HIE Query /Response

## HIE Query of Participating Providers

4. ILHIE queries providers listed in RLS for Patient's data

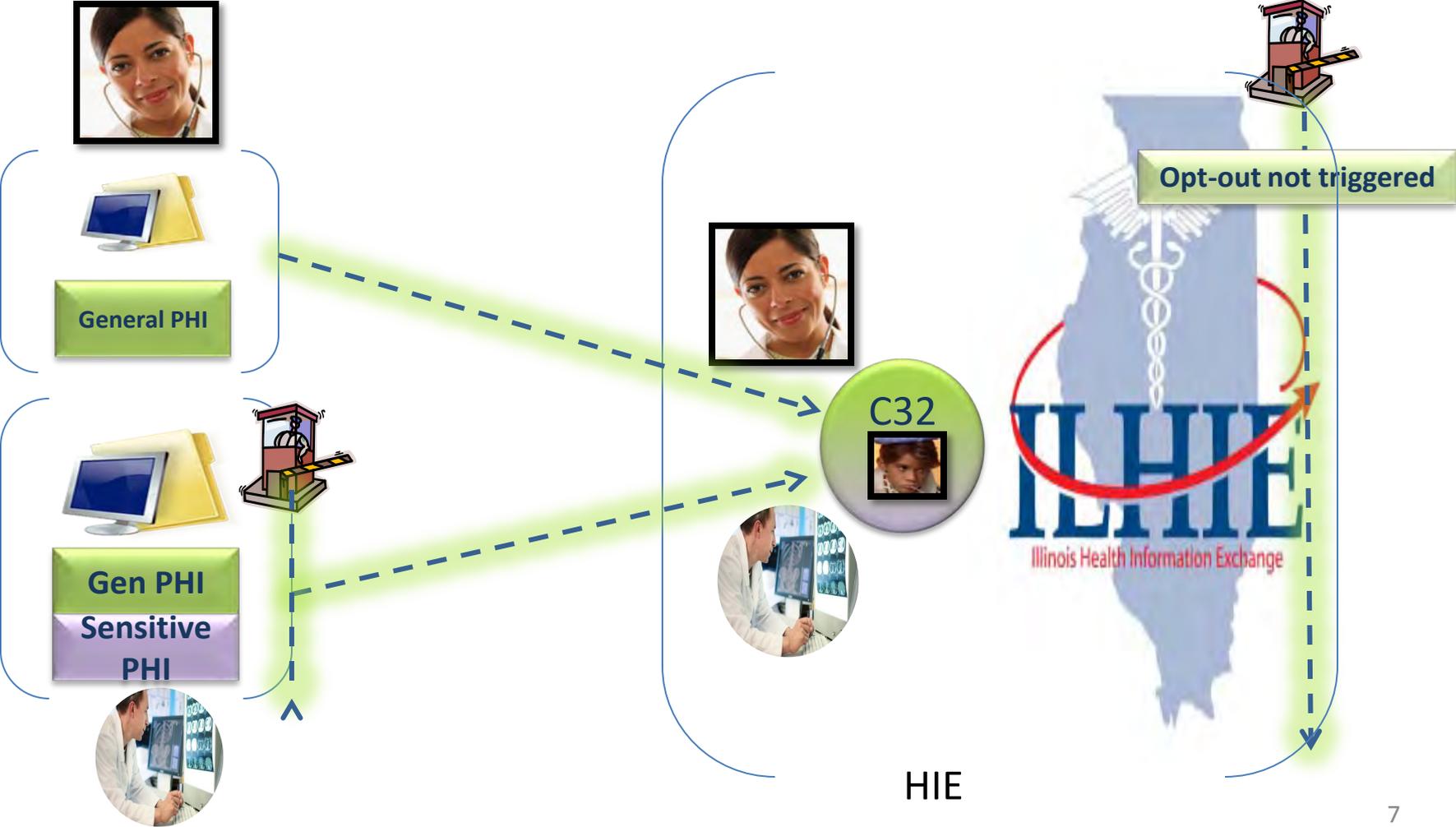


Use Case 3: Patient with Sensitive PHI Participates in HIE

# Stage 2: HIE Query /Response

## HIE Query of Participating Providers

5. ILHIE aggregates data received from providers

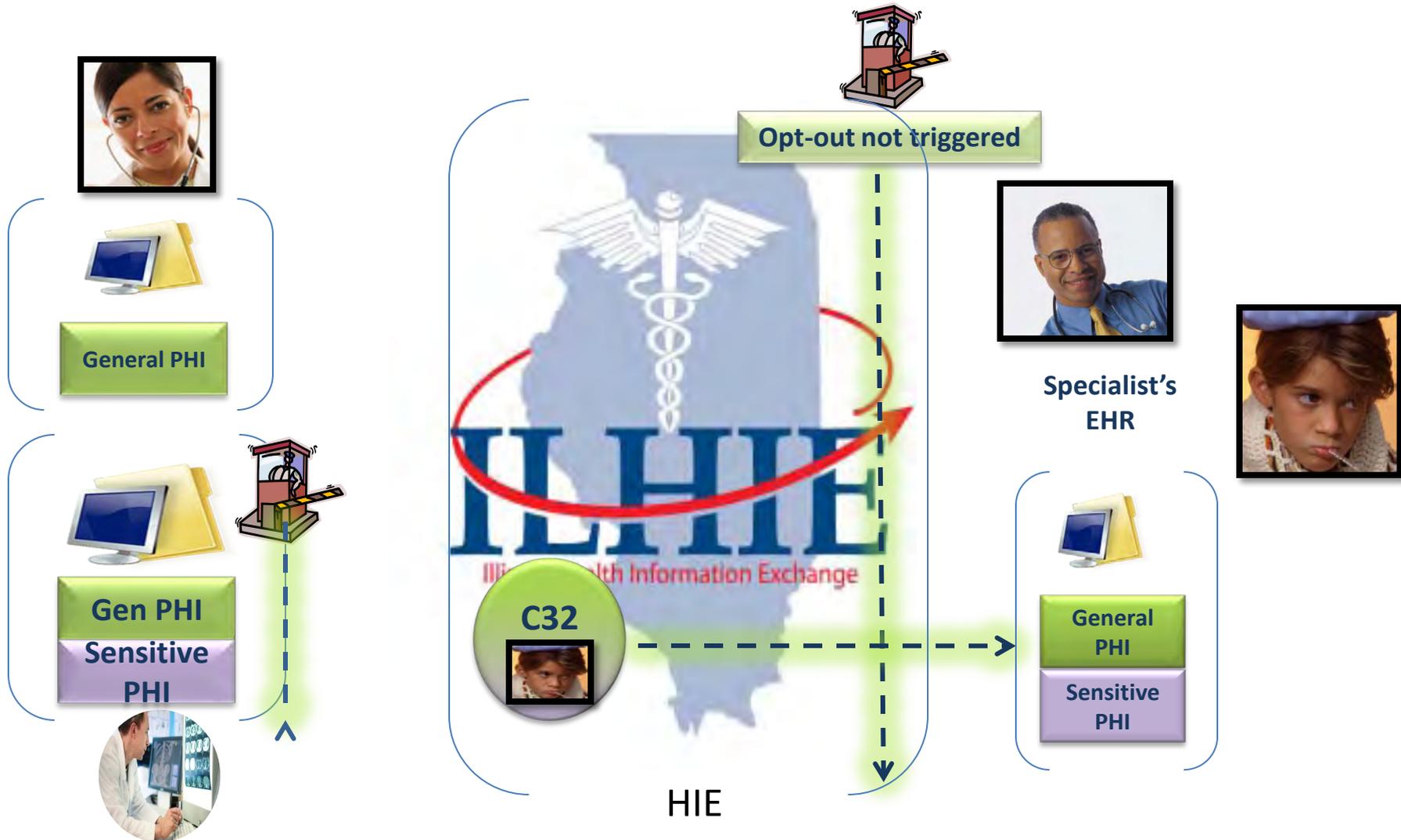


Use Case 3: Patient with Sensitive PHI Participates in HIE

# Stage 2: HIE Query /Response

## ILHIE Delivers C32 to Participating Specialist

6. ILHIE delivers consolidated C32 to requesting participating specialist



# Stage 1: Creation and Release of PHI Patient Presents at Physician

1. Patient presents at Physician

2. Provider describes HIE and offers opt-out

3. Provider offers opt-in for Sensitive PHI



EHR



Gen PHI

Sensitive  
PHI



HIE

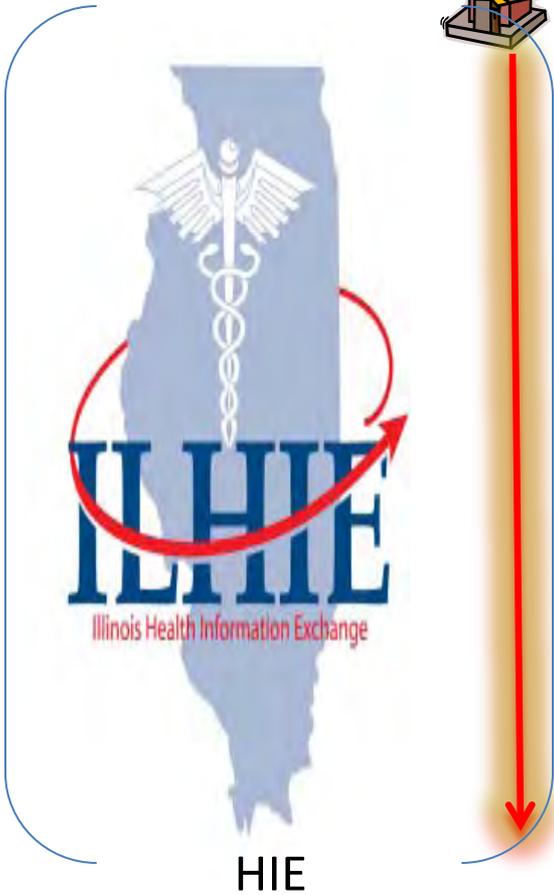
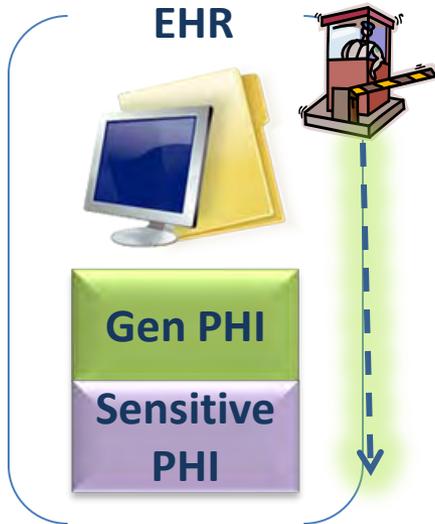
# Stage 1: Creation and Release of PHI

## Patient Presents at Physician

4. Patient opts-out (no disclosure by HIE)

5. Patient agrees to opt-in for Sensitive PHI

Opt-out notice to HIE



# Stage 1: Creation and Release of PHI

## Release of MPI and RLS

6. Patient demographic information sent to ILHIE

7. Patient data becomes accessible to ILHIE



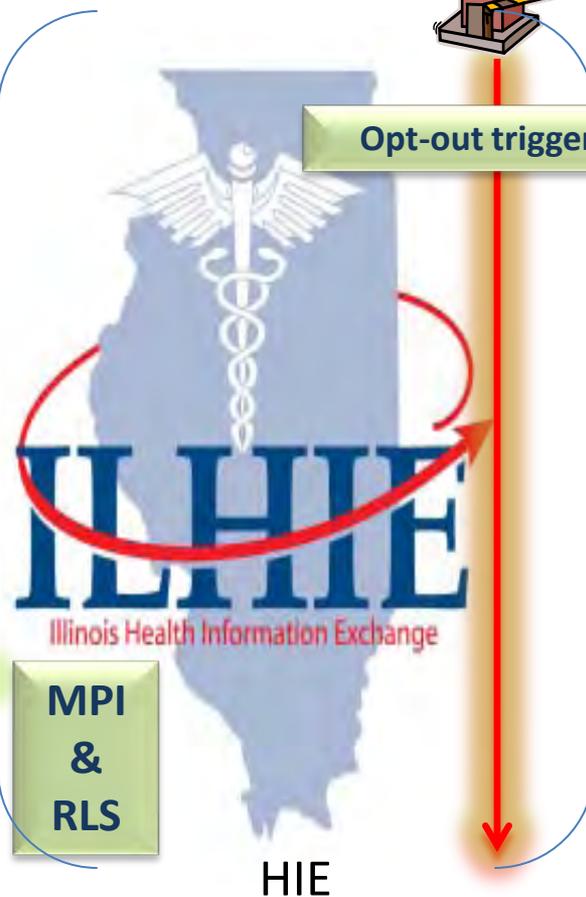
EHR



Gen PHI  
Sensitive PHI



MPI  
&  
RLS



Opt-out triggered

HIE



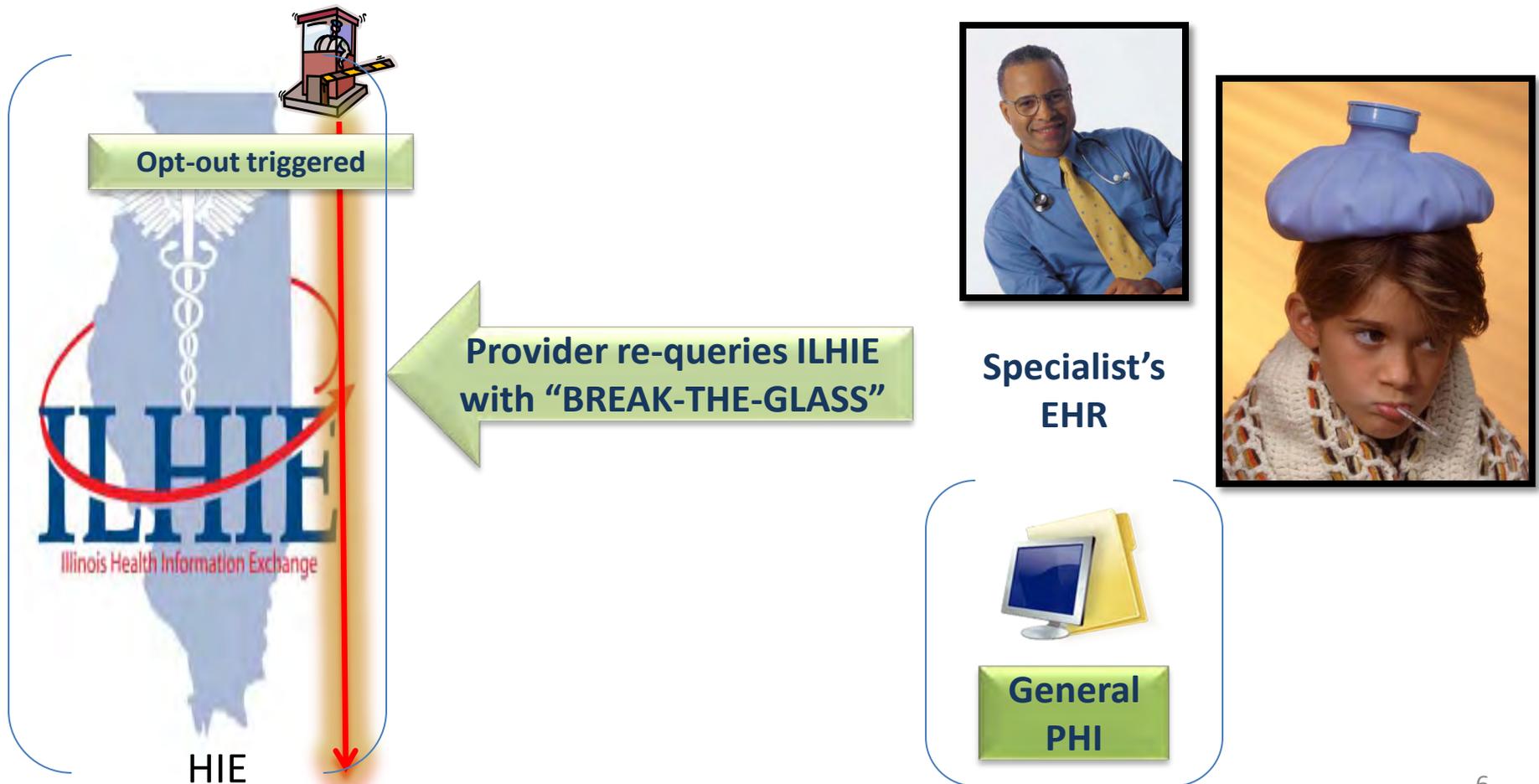
## Stage 2: HIE Query /Response HIE denies access to data

3. HIE returns "DATA NOT AVAILABLE" message



## Stage 2: HIE Query /Response Specialist “Breaks-the-glass” to access data

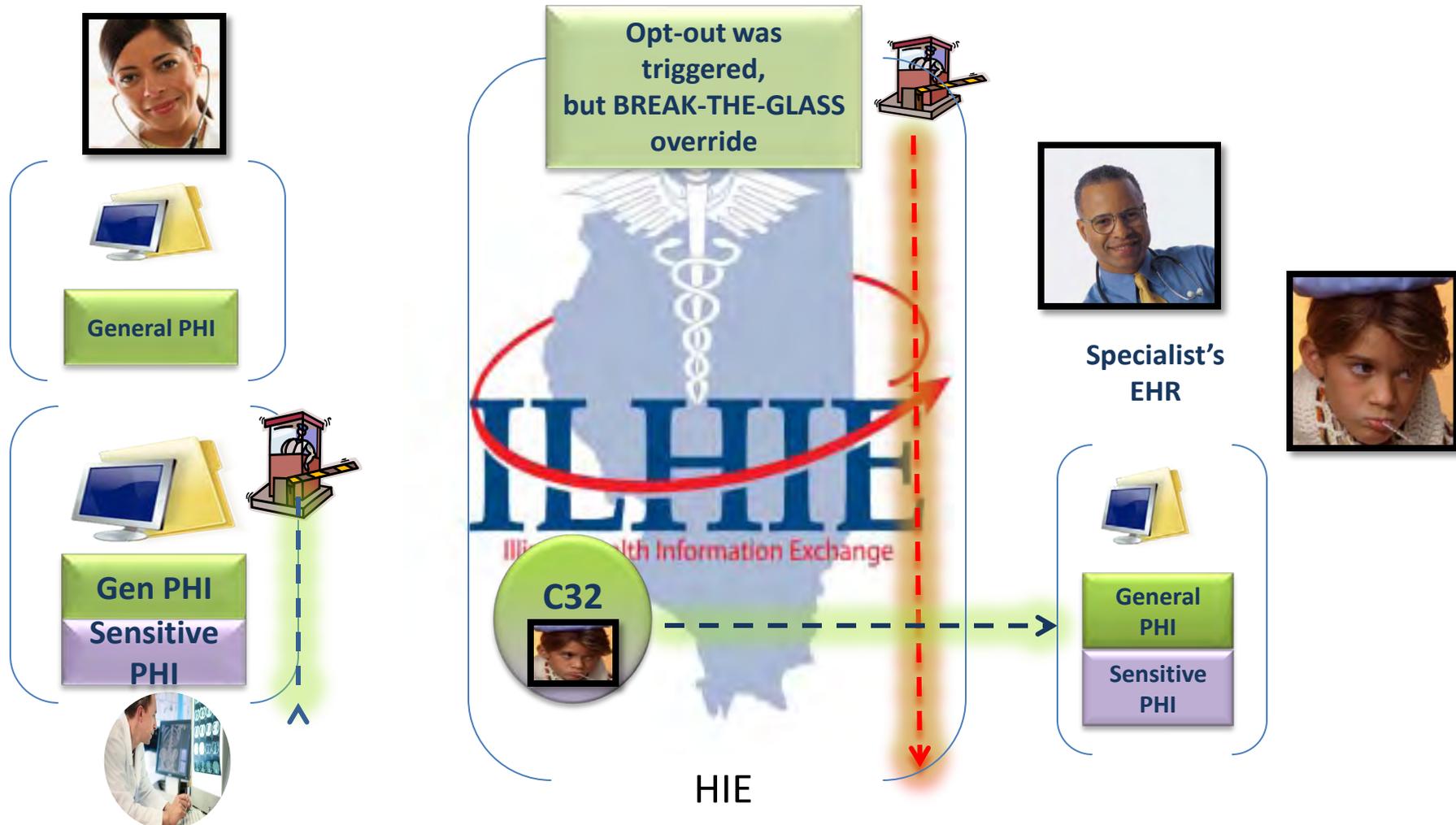
4. Participating specialist submits “BREAK-THE-GLASS” override to certify either:
- Patient medical emergency, or
  - Patient provided consent



## Stage 2: HIE Query /Response

### ILHIE Delivers C32 to Participating Specialist

5. ILHIE consults MPI and RLS;
6. ILHIE queries providers listed in RLS for Patient's data;
7. ILHIE aggregates data received from providers;
8. ILHIE delivers consolidated C32 to requesting participating specialist



# Stage 1: Creation and Release of PHI

## Patient Presents at Physician

1. Patient presents at Physician

2. Provider describes HIE and offers opt-out

3. Provider offers opt-in for Sensitive PHI



EHR



Gen PHI

Sensitive  
PHI



HIE

Use Case 5: Patient with Sensitive PHI declines HIE access to Sensitive PHI

# Stage 1: Creation and Release of PHI

## Patient Presents at Physician

4. Patient does not opt-out

5. Patient declines to opt-in for Sensitive PHI



EHR



Gen PHI

Sensitive  
PHI



Use Case 5: Patient with Sensitive PHI declines HIE access to Sensitive PHI

# Stage 1: Creation and Release of PHI

## Release of MPI and RLS

6. No patient demographic information sent to ILHIE

7. No patient data becomes accessible to ILHIE

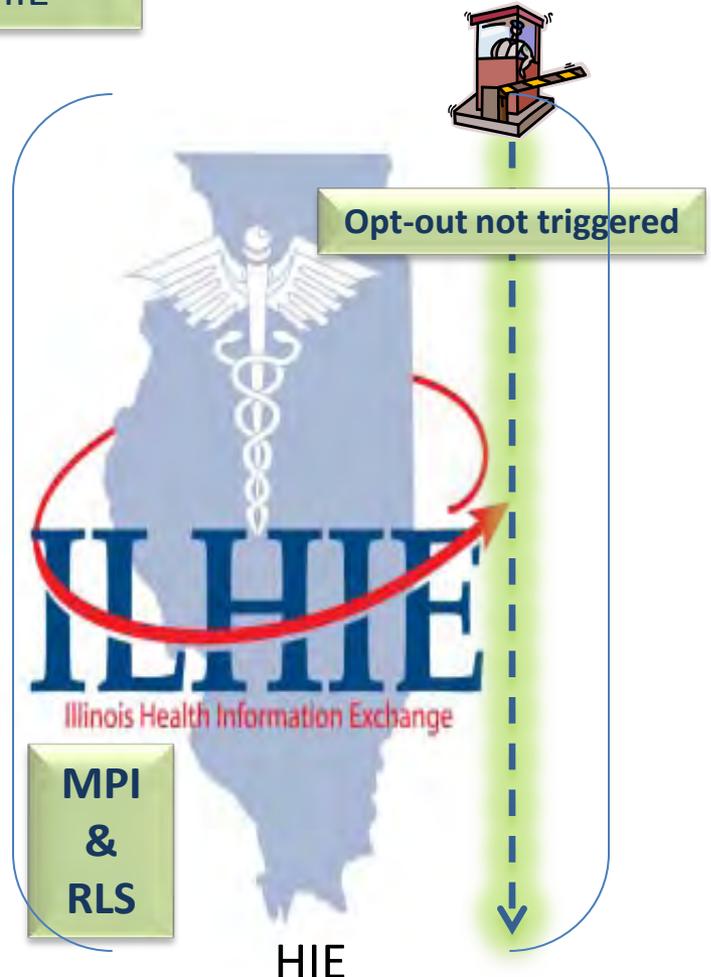


EHR



Gen PHI

Sensitive  
PHI

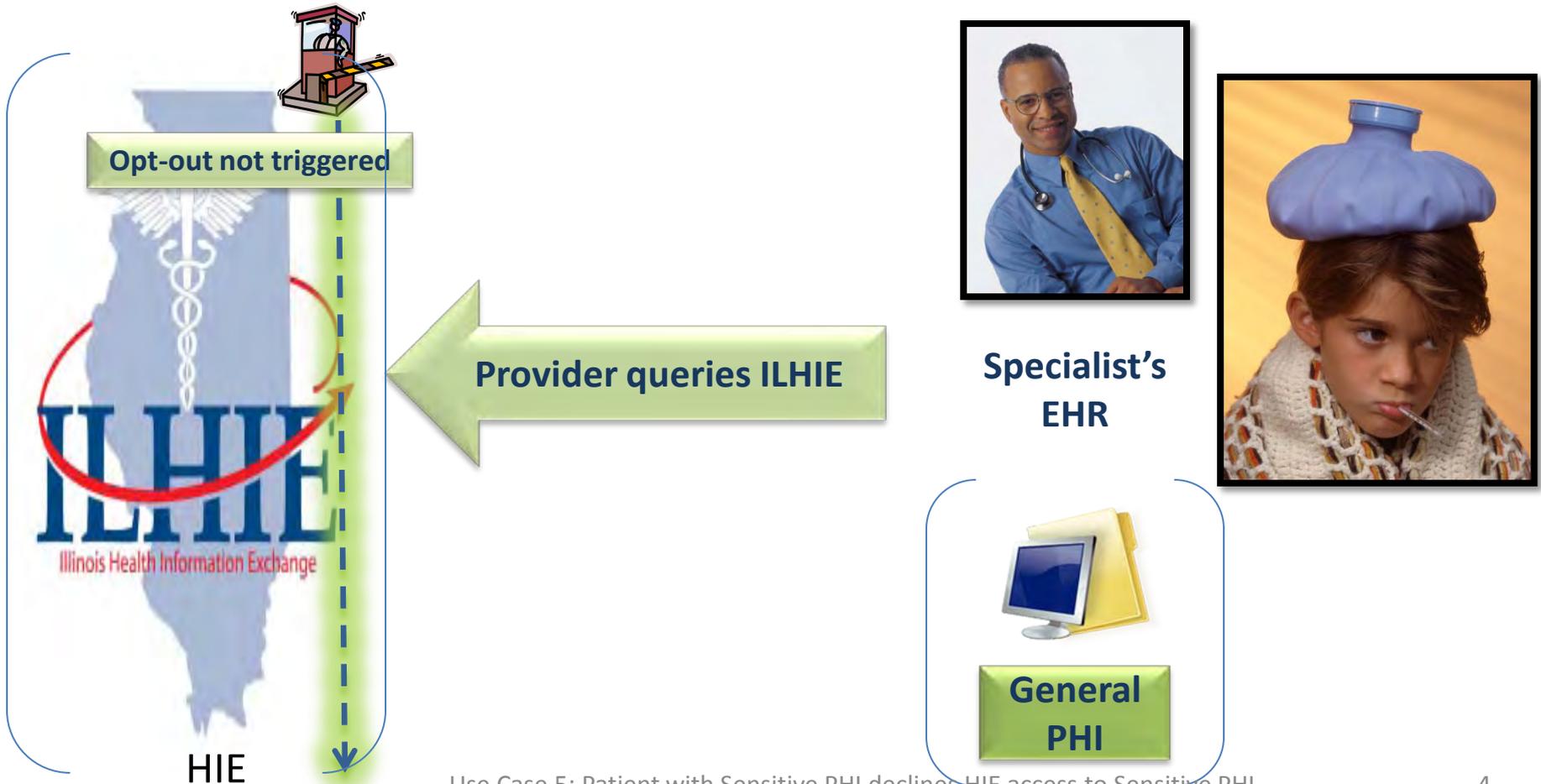


Use Case 5: Patient with Sensitive PHI declines HIE access to Sensitive PHI

## Stage 2: HIE Query /Response Patient Presents at Specialist

1. Patient presents at ILHIE participating specialist

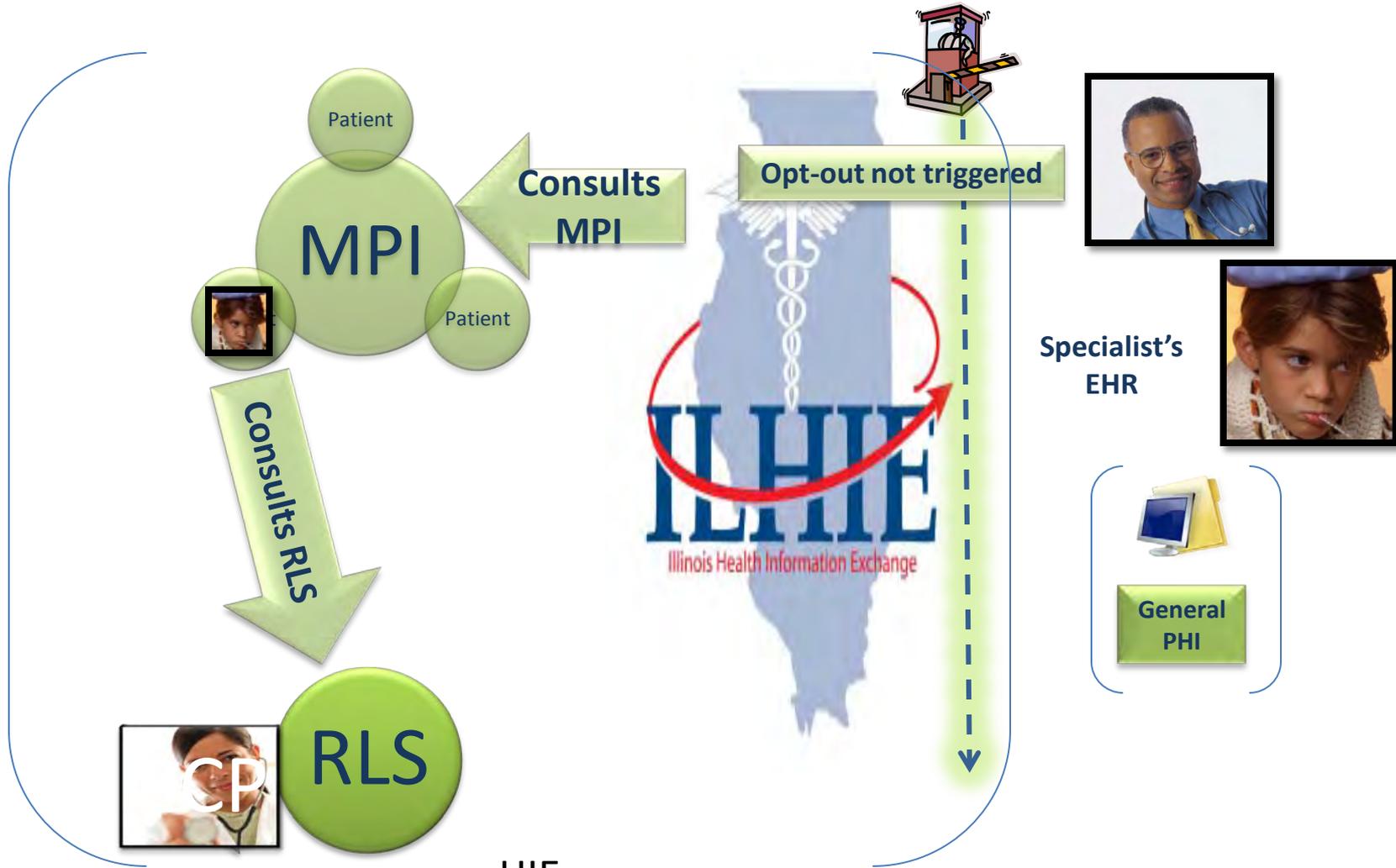
2. Participating specialist queries ILHIE for Patient's records



# Stage 2: HIE Query /Response

## HIE Consults MPI & RLS

3. ILHIE consults MPI and RLS

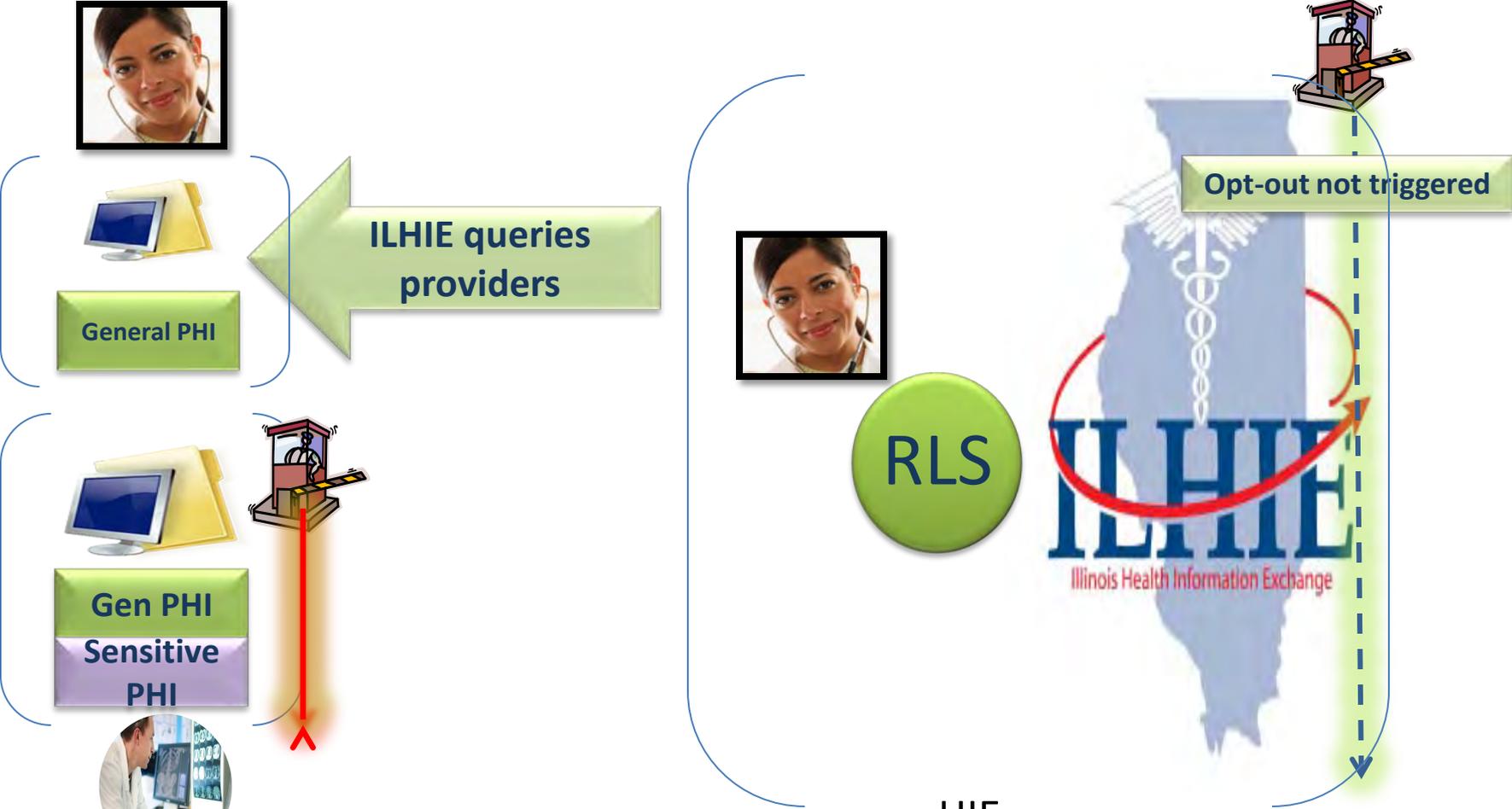


Use Case 5: Patient with Sensitive PHI declines HIE access to Sensitive PHI

# Stage 2: HIE Query /Response

## HIE Query of Participating Providers

4. ILHIE queries providers listed in RLS for Patient's data

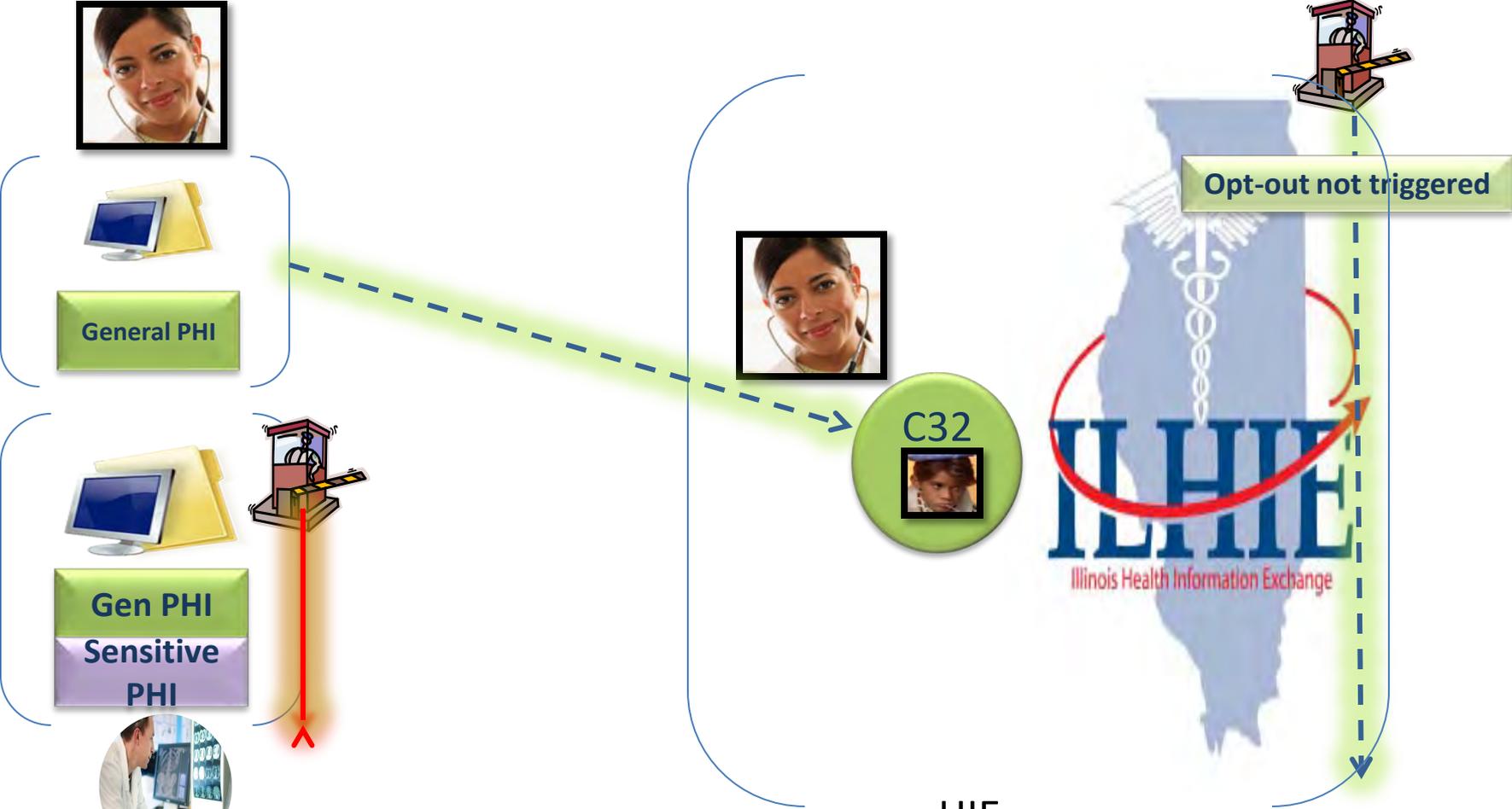


Use Case 5: Patient with Sensitive PHI declines HIE access to Sensitive PHI

# Stage 2: HIE Query /Response

## HIE Query of Participating Providers

5. ILHIE aggregates data received from providers

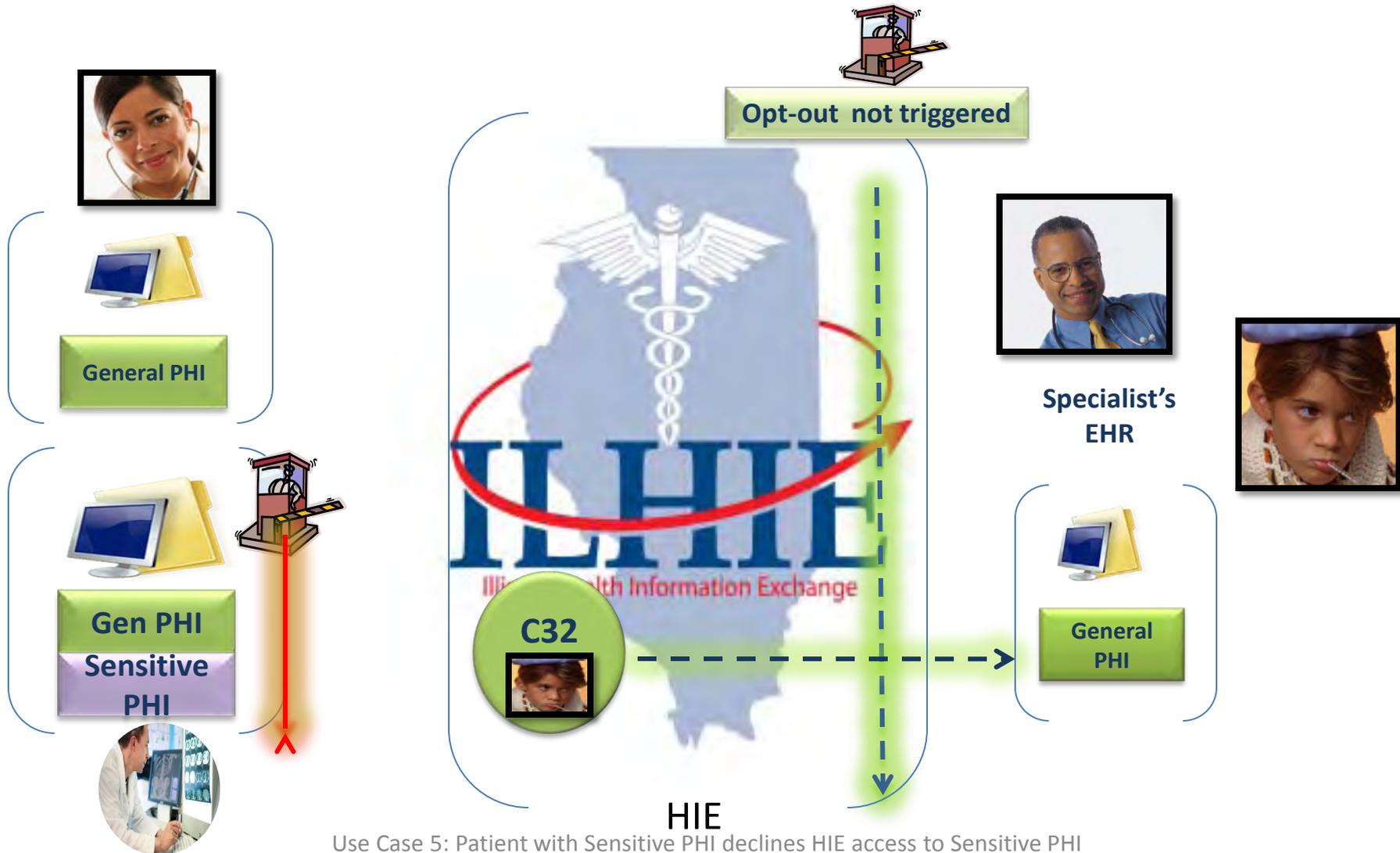


HIE  
Use Case 5: Patient with Sensitive PHI declines HIE access to Sensitive PHI

# Stage 2: HIE Query /Response

## ILHIE Delivers C32 to Participating Specialist

6. ILHIE delivers consolidated C32 to requesting participating specialist



Use Case 5: Patient with Sensitive PHI declines HIE access to Sensitive PHI