

ILHIE Authority Data Security and Privacy Committee

Briefing Summary: Panel #3 – Special Patient Data

To what extent should special types of “sensitive” patient data be treated differently for purposes of exchange through an HIE?

Federal Guidance

- Mental Health Data. The Federal HIPAA Privacy Rule currently requires patient authorization/consent for the disclosure of “psychotherapy notes”.¹
- Substance Abuse Data. The disclosure of data by a federally-supported substance abuse treatment facility is subject to regulations requiring patient authorization/consent.²
- Genetic Test Data. The collection and use by insurance payers of genetic information is subject to restrictions under the Federal Genetic Information Nondiscrimination Act.³

Illinois Status Quo: Mixed Opt-in/Opt-out for Special PHI

- Special PHI: opt-out
 - HIV/AIDs consent for testing: opt-out, except if for treatment or data is de-identified⁴
 - Immunization registry consent for inclusion: opt-out⁵
- Special PHI: opt-in
 - Mental health/behavioral health/developmental disability: opt-in, except therapist disclosures to staff⁶
 - Psychotherapy notes: opt-in⁷
 - Substance abuse: opt-in⁸
 - Genetic test data: opt-in, except if data is de-identified, or for program evaluation⁹
 - HIV/AIDs - consent for testing for insurance: opt-in¹⁰
 - HIV/AIDs – consent for disclosure of test results: opt-in, except if data is de-identified, or for program evaluation, or for public health¹¹

¹ HIPAA, 45 CFR §164.508(a)(2)

² 42 CFR Part 2

³ Pub. Law 110-223

⁴ 410 ILCS 305/4

⁵ 410 ILCS 527/15(a)

⁶ 740 ILCS 110/3, 5, 9

⁷ HIPAA, 45 CFR §164.508(a)(2)

⁸ 42 CFR Part 2

⁹ 410 ILCS 513/15, 30(a)

¹⁰ 410 ILCS 50/3(c)

¹¹ 410 ILCS 305/9