BARRIERS TO THE EXCHANGE OF PEDIATRIC HEALTH INFORMATION

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# TABLE OF CONTENTS

- Introduction ............................................................................................................. 3
- Minor Consent Background .................................................................................... 5
- Informed Consent and Patient Control of Health Information ................................ 6
- Unique Issues Related to Pediatric Health Information .......................................... 6
- NYS Law on Minors and Medical Treatment ......................................................... 7
- Circumstances in Which Minors can Consent to Their Own Health Care ........... 7
- Professional Responsibility of Providers ............................................................... 8
- New York State RHIO Consent Policy for Minors .............................................. 8
- Current State of Health Information Exchange .................................................... 9
- Minor Consent Tiger Team Approach ................................................................. 10
- The Challenge of a Potential Solution ................................................................. 11
- The Need for a National Solution ....................................................................... 12-13
- Endnotes .............................................................................................................. 14-17
- Glossary of Technical Terms .............................................................................. 18-19
- Tiger Team Listing ............................................................................................. 20-21
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NYeC Minor Consent Tiger Team

Introduction

A 15 year old visits her doctor for an annual physical and the completion of a form for her summer program. She has asthma which is well controlled. She has never consented for treatment or completed any legal authorizations as she is always accompanied by a parent. During this visit, while alone with the doctor, she mentions she is becoming more sexually active and wanted to discuss contraception and safe sexual practices. She is given a prescription for a birth control pill but asks that her parents not be told. She also asks that the prescription be given to her discreetly to be filled at a remote pharmacy rather than having the doctor electronically transmit the order to the local pharmacy as he will do with the asthma medication. In addition an HIV test is performed. The adolescent expresses concern that the counseling, focused exam, prescription, and the thankfully negative HIV test result be kept confidential. She understands that it is best that future medical providers and pharmacists know all the medications she is receiving, but she lives in a tight community where classmates work in the local chain pharmacy, and her parents’ friends are in the medical “business.” She is very concerned about her privacy.

Patients expect that their personal medical records will be kept strictly confidential. This level of trust is vital as it encourages patients to speak freely with their doctor. Such communication helps providers learn the critical information they need to properly diagnose and treat their patient. New York State law protects this expectation of privacy by restricting disclosure of medical information to third parties; allowing for such disclosure only when a patient consents to it. Adolescents who seek care independent from their parents, particularly sensitive reproductive-related health care, understandably have these same expectations and rights. However, ensuring confidentiality for these minor patients introduces a high level of complexity to handling patient health information in a way that protects confidentiality.

When parents consent to the treatment of their children, their children’s medical information is available to them; but when minors consent on their own, that information must be withheld from the parent absent the minor’s consent. If the parent in the scenario above wanted a copy of her daughter’s medical record, that confidential encounter and any ancillary services included with that encounter, such as the ordering of labs for HIV testing or a prescription for birth control pills, must be excluded from the record because the provider owes the minor a duty of confidentiality. When medical records are kept in paper form, a health care provider’s duty is clear—only information about care to which the parent has consented should be disclosed to parents. In the world of electronic health information exchange, absent technology that can segment data and accurately associate
subsequent ancillary procedures and results with an initial visit, there is currently no reliable way to prevent the parent from receiving health information related to minor consent – information that the parent should not receive without the minor’s consent.

The need to be able to segment or filter certain types of health information was affirmed by the passage of American Recovery and Reinvestment Act of 2009 (ARRA) and Health Information Technology for Economic and Clinical Health Act (HITECH). A provision in ARRA requires that upon patient request, services for which the patient has paid for out-of-pocket must not be divulged to their health insurer, as Congress recognized that some medical services are so sensitive that patients are willing to pay for them out-of-pocket to avoid disclosure to their insurance companies.

Currently, electronic systems do not have the technological capability to filter or segment health information in a manner that is consistent with current laws. In response to this technological deficit, the state and providers alike have grappled with the difficulty of ensuring compliance with state and federal laws like ARRA, laws protecting the disclosure of HIV/AIDS-related information, substance abuse treatment information, and mental health care information, and laws like the ones described below protecting the rights of minors to confidential care. To address the dilemma of protecting the confidentiality of minor-consented health information, New York State policies (Privacy and Security Policies and Procedures for RHIOs and their Participants in New York State Version 2.0) currently allow the state’s Regional Health Information Organizations (RHIOs) to refuse to exchange health information for children from the age of 10 until the minor reaches 18 and is considered an adult, a practice all RHIOs have adopted as they cannot ensure the privacy of this data.

This paper seeks to describe current laws that protect minors consenting to their own care, the barriers to exchanging health information for patients under 18, an interim solution reached by New York State and ideas developed by a “Tiger Team” of experts to come to a more effective solution.

A 13 year old boy is being treated for cancer. The treatment included radiotherapy and chemotherapy. During an interval when he is not receiving treatment and he is feeling well he visits his aunt in another part of the state while his parents take a well deserved vacation. Friday afternoon before a three day weekend he complains of a sore throat. His aunt spies a bruise on his arm, but he doesn't recall any injury. The boy feels “fine” and looks well. His aunt isn't alarmed but she is cautious and takes her nephew to the family's pediatrician. The boy makes an effort but he is unable to give a comprehensive medical history, and his parents are not readily reachable. A thorough exam with needed labs and chest X-rays are abnormal but the local physician is uncertain if the results represent *normal* findings for a child in his stage of treatment, or whether they represent an acute pathological process. Unable to quickly get records from the boy's regular treating physician coordinating the cancer treatment, the physician arranges for a specialist to see him in the morning after ordering a more extensive laboratory work up and a CT scan. No one slept well that night and the child continued his costly and intrusive work up in the morning. Even though the child and his parents would have been happy to have authorized participation in their RHIO to facilitate health data exchange, they were not given the opportunity in NYS as children of his age cannot participate at the present time because of the current inability to identify and segregate specially protected information.
Minor Consent Background

New York was one of 34 states and territories involved in the Health Information Security and Privacy Collaboration (HISPC), a national initiative that was funded by the U.S. Dept of Health and Human Services. The HISPC process was designed to examine how privacy and security laws would impact health information exchange within and across states.

A central finding of Phase I of HISPC was that strong policies that protect the privacy and security of health information are crucial to achieving interoperable health information exchange.

New York’s HISPC, Phase I analysis of the state’s health privacy laws resulted in its decision that an individual’s affirmative written consent would generally be required to authorize the electronic exchange of protected health information through the state’s RHIOs. Accordingly, the NY HISPC, Phase II focused on developing a standardized consumer consent solution that would be based upon a comprehensive set of health information privacy and security policies. The goal of this standardized process was to promote consistency across NYS RHIOs in obtaining consent and addressing consumer privacy concerns about electronic health information exchange.

Privacy and security policies for RHIOs and their participants in New York State were created through a Statewide Collaboration Process (SCP), a process that involved broad participation by a diverse set of stakeholders representing clinicians, provider organizations, payers, vendors, consumers and other interested parties. The SCP was facilitated by the New York eHealth Collaborative (NYeC), a public private partnership with the New York State Department of Health (NYSDOH) and the state’s designated entity. The activities of the SCP resulted in the development of technical specifications, functional requirements and privacy and security policies for RHIOs and their participants, collectively referred to as the Statewide Policy Guidance. The Privacy and Security Policies address issues around consent, authentication, authorization, access control, audit and breach.

One of the more difficult issues with which the privacy and security workgroup was faced was achieving consensus on how to protect minor patients’ confidentiality when consenting to their own care while still allowing the exchange of any pediatric health information.

The SCP convened a minor consent “tiger team” comprised of subject matter experts, including clinicians, lawyers, RHIO executives and other interested stakeholders in an effort to analyze the issue and make recommendations for a potential solution. Participants in the SCP believe that it is critical to facilitate the confidential exchange of pediatric health information, and the failure to arrive at a solution will effectively deny the benefits of health information exchange to an entire demographic of the state. This report is the work product of that team.


**Informed Consent and Patient Control of Health Information**

Informed consent by a patient is required under both common law and New York State law for treatment by a physician. Informed consent is a cornerstone of medical care and research in the United States. Providers bear the responsibility of educating patients on the benefits and risks of a given treatment, the likelihood of the treatment’s success, alternative treatments that may exist and the risk associated with no treatment at all.

Related to consent for treatment is the consent or authorization of release of information. Generally, patients can authorize the release of their medical records for treatment to which they consented, and the same is held true for treatment consented to by a minor patient when allowed by law.\(^2\) In addition, the Health Insurance Portability and Accountability Act (HIPAA) introduced the Privacy Rule.\(^3\) This created a federal floor for patient privacy, allowing states to adopt or retain more restrictive laws. The Privacy Rule allowed the release of patient health information for treatment, payment and healthcare operations, while requiring an authorization for release by a patient for other uses, such as research.

In addition to informed consent and the requirement for patients to authorize the release of their health information, significant changes to the HIPAA Privacy rule were included in the ARRA legislation (42 U.S.C. § 17935(a)). The new provision for Requested Restrictions on Certain Disclosures of Health Information requires that covered entities must comply with a restriction request by a patient for disclosures to health plans when the patient has paid for the service in full (45 C.F.R. §§164.522; 164.522 (i)). This new provision will have significant impact on health information exchange.

**Unique Issues Related to Pediatric Health Information**

Children as consumers of healthcare present unique challenges. Development from birth to adulthood requires frequent assessment of proper medications, anesthesia, and other treatments related to the child’s level of development. As children mature, their health needs vary greatly and the spectrum of potential disorders, diseases and concerns grows exponentially. Screening at all levels of development is strongly encouraged by providers, particularly in infancy when early intervention can make significant differences in later outcomes.

Overall, the vast majority of children are well, and therefore most children’s interactions with their health provider are related to preventative care, including immunizations. Parents and guardians are responsible for seeking and consenting to healthcare for their children in these circumstances. However, this role changes as pediatric patients grow into adolescents, when sensitive health issues such as sexual health are discussed privately between the minor patient and his or her health care provider. At times this care is provided by separate providers or clinics, but frequently these more sensitive interactions occur in the context of routine visits. This change presents challenges to parental access to medical information about their children.
NYS Law on Minors and Medical Treatment

Generally, under NYS law, minors may only receive medical treatment with the consent of their parents or custodians. However, New York has long recognized that minors, under certain circumstances, must have the ability to control certain aspects of their medical care and their medical information. A minor’s need for medical care or information gathered in the course of medical treatment may place them in conflict with their parent or guardian. This may arise when a minor seeks a specific form of medical treatment, such as reproductive care. But such situations may also be triggered by information gathered in the course of routine medical care to which the parent has consented. A parental consent or notification requirement or subsequent parental access to medical information may discourage the minor from seeking treatment or sharing necessary information with their health care provider, damage the minors’ relationship with their parent or guardian, or put the minor at risk of harm.

Consequently, all minors in New York have the right to consent to their own treatment in certain circumstances and for certain medical conditions, and state law also gives some minors the right to consent to all or almost all their medical care. When minors consent to their own medical treatment, they are then entitled to confidentiality of those records; providers may not disclose information about minor-consented treatment to parents or guardians unless they first obtain the minor’s consent to do so. In fact, all minors may have the right to voice an objection to the disclosure of medical information gathered in the course of their treatment when sharing that information with parents, guardians, or others would pose a threat to the minor’s well-being.

When it is the parent, and not the minor, who has the authority to consent to the minor’s care, information about the minor’s treatment usually may be disclosed to the parent. New York law, however, allows concern about detrimental effects on the health and well-being of a minor patient to trump the parent’s right to access. A health care provider must not reveal the information to a patient’s parents if he or she determines that disclosure would be detrimental to the provider’s relationship with the minor, or to the minor’s relationship with his or her parents. A provider may also withhold information from a minor patient’s parents if the minor is over twelve and objects to the disclosure. In such cases, the health care provider can rely on his or her judgment as to whether to disclose the information to the minor’s parent.

Circumstances in Which Minors Can Consent to Their Own Health Care

In New York, all minors have the authority to consent to their own treatment in a number of situations and, generally, to control access to information related to such treatment. By law, minors have the right to consent to care for the following health services on their own (without parental involvement or consent):

- Reproductive health care, including family planning (i.e., birth control and other contraception), emergency contraception, abortion, pregnancy/prenatal care.
including care during labor and delivery and care for sexually transmitted infections\textsuperscript{13};

- Mental health services under many circumstances;\textsuperscript{14}
- Certain alcohol and drug abuse services;\textsuperscript{15}
- HIV testing (although parental consent is generally required for a minor to receive medical treatment for HIV \textsuperscript{16}; and
- Sexual assault treatment.\textsuperscript{17}

Providers also can treat minors in an emergency without parental consent.\textsuperscript{18} In this instance, access to information may not follow consent. In the case of “emergency [care] which was the result of accidental injury or the unexpected onset of serious illness”, medical information can be disclosed to the parent or guardian,\textsuperscript{19} unless the disclosure would put the minor at risk.

Additionally, under NYS law, certain categories of minors have a broader right to consent to any and all medical care, and therefore, to the confidentiality that accompanies consent. Married minors,\textsuperscript{20} pregnant minors\textsuperscript{21} and minors who are parents themselves\textsuperscript{22} have a statutory right to consent. New York law also gives emancipated minors, the right to make their own health care decisions without the consent of a parent or guardian.\textsuperscript{23}

**Professional Responsibility of Providers**

All healthcare providers must keep their professional obligation to provide confidential care to minor patients. This profound responsibility is based in ethical values and legal principles. In fact, the health and well-being of minor patients depends on this trusted collaborative effort between healthcare providers and patients. Having this level of trust is important, because it is vital for minor patients to talk freely with their healthcare provider to be certain that there is a full understanding of the patient’s medical condition and concerns. The efficiency that technology brings to patient care must support these fundamental patient care tenets and protect minor patient rights to confidential care.

**New York State RHIO Consent Policy for Minors**

In order for a RHIO to provide access to health information about a minor, the RHIO must ensure that the minor has given consent to exchange any information relating to minor consent services (“minor consent information”). After careful analysis, the “Tiger Team” concluded that the only operational way to satisfy this requirement is that the RHIO must require provider organizations to obtain a minor’s consent to disclose minor consent information at the time the minor consent services are provided (see Section 1.5)
In order to consistently comply with this standard, participants of a RHIO, which could be a hospital, private practice, community health center or other entity, must have electronic health records (EHR) where providers and/or staff can distinguish between minor consent information and parental-consented information. Unfortunately, this technology, while arguably under development, is still in its infancy.

To address this lack of technology, the Privacy and Security Workgroup of the SCP worked with pediatricians specializing in adolescent medicine. After a number of discussions, the group arrived at the conclusion that as it is rare for young children to provide informed consent for treatment, health information could be exchanged for patients under the age of 10. After that time, no information about minors will be exchanged until the minor turns 18 and can provide consent as an adult. Second, provider organizations may access health information about minors in a medical emergency through the break the glass function without a minor’s consent.

This solution was recognized as insufficient, as there are important health and public policy goals that are served by ensuring meaningful health information exchange. Accordingly, the “Minor Consent Tiger Team” set about to develop a better policy that could accomplish both goals: allowing for exchange of minor’s health information while at the same time protecting the confidentiality of services to which minors consent on their own.

**Current State of Health Information Exchange**

While preparations are actively in progress, today’s data exchange cannot deliver many of the benefits anticipated by the designers and architects of the National Health Information Network (NHIN). There is still a gap between theory and practice, and that gap requires time to be bridged because experience is a required ingredient.

HL7 message standards provide the basis for communications, but there are significant challenges in data definition and workflow variations that impede exchange across the healthcare spectrum. The most frequently implemented data streams are Admissions, Discharges and Transfers (ADT), and laboratory data. There is wide variation in the handling of diagnoses, problems, procedures and allergies, among other things. The way that laboratory data is handled is probably the most mature and consistently implemented, but Logical Observation Identifiers Names and Codes (LOINC) implementations are not yet universal and other issues remain that affect data uniformity and presentation.

Many systems critical to local processes do not have outbound interfaces, requiring development or replacement. This includes inpatient medications, transcription systems, ancillary testing systems and others.
Developers of EHRs are under pressure to meet Certification Commission for Health information Technology (CCHIT) and ARRA requirements, but even if compliant releases are ready, many facilities are not ready to complete the upgrades. While vendors are developing modules to send and receive standards based documents (e.g., CCDs) there is very little field experience with this type of exchange and much remains to be worked out to support effective use.

As the new generation of data exchange is being implemented, organizations in New York are bound to the guidelines of the SCP and its Policies & Procedures (P&Ps). These P&Ps establish definitions and standards for data exchange in an effort to encourage support and manage such exchange. However, all involved recognize that the policies reflect current capability, not the final goal of full interoperability that will support improved patient care and patient safety.

**Minor Consent Tiger Team Approach**

After a thorough review and discussion of New York State law and the important public policy reasons supporting minors’ rights to seek and receive confidential health care, New York’s Minor Consent Tiger Team invited two ambulatory EHR vendors to demonstrate their current functionality for segmenting or filtering data. Both vendors had systems capable of filtering, or segmenting, information in the EHR at the encounter level. However, neither vendor demonstrated a capability to segment ancillary services such as prescriptions and laboratory results.

Looking for a potentially integrated solution, the team also invited vendors with consent management solutions to demonstrate how their systems interact with EHRs and HIE. The technology exists to allow patients themselves to decide which information can be seen by whom based on the encounter. If there are laboratory tests, prescriptions or other ancillary data associated with that visit that then occurs at a later date (a common event as patients will often undergo a laboratory test or fill a prescription days after the encounter) the only way this data can be separated is by selecting a date range. If the associated ancillary service occurs after the date range, the information is not protected or segmented.

Vendors associated with laboratories and radiology services were also invited to discuss their systems. The Tiger Team learned that there are currently no standards for how these results are entered into a patient’s EHR. Neither can these systems identify results that would be associated with the sensitive health visit of a minor patient.

The team also explored the idea of identifying those billing and diagnostic ICD-9 and CPT codes that may be associated with a sensitive health visit so that the encounter could be segmented or protected. However, in practice coding cannot be as precise or thorough as needed to detect all discussions and actions within an encounter, and this functionality would still not effect prescriptions, radiology results or laboratory orders or results.
The Challenge of a Proposed Solution

In order to apply the correct rules for privacy and security decisions the organization handling the data must be aware of who provided consent for treatment. This information is not routinely collected in an EHR or in a patient registration system. Collecting it is the first critical step in a series of steps necessary to solve this challenge. The next critical step is to pass this value in a required segment or field that ensures all downstream orders and results include this critical information.

HL7 transactions that form the basis of health information exchange offer the vehicle to enable appropriate management of minor patient consent. HL7 specifies a number of flexible standards, guidelines, and methodologies by which various healthcare systems can communicate with each other. Such guidelines or data standards are a set of rules that allow information to be shared and processed in a uniform and consistent manner. These data standards are meant to allow healthcare organizations to easily share clinical information. In reality, however, local implementations of HL7 transactions vary widely. An important aspect of the current collaboration is its potential to facilitate effective health information exchange by working towards greater specificity in HL7 transactions.

To solve the challenge of minor consent, we recommend establishing a standard for HL7 patient registration transactions to clearly state when a minor has provided consent for their own treatment.

One of two choices – either to add a field to the Patient Identification (PID) segment or to require the Consent (CON) segment as a part of every order and result transaction – should be implemented immediately. Another option to consider, given that the consent value is part of the visit information, is to convey the consent value via the Patient Visit (PV1) segment. But, like the CON, current implementations do not routinely include the PV1 with all downstream transactions. It is critical to protecting a minor’s confidential health information that all related labs and/or medication transactions generated after the initial event also reflect the nature of the consent.

Whether the PID, CON or PV1 segment is used, the critical component is to ensure that the consent value “sticks” to every order and every result generated from the treatment encounter. Results may be delayed by hours or days from the initial visit, but must still identify the consent value when the order message (ORU) is generated.

If a “Treatment Consent By” field is added to the PID or PV1 segment, values might include:

- Patient over 18 years
- Parent or Guardian for minor patient
- Patient under 18 years

Or, using Date of Birth (DOB) to determine age, more simply valued as:

- Self
- Parent or Guardian
Once the messages properly reflect the person who signed the consent it is possible for future handling of the data to be informed by that value.

Returning to our opening scenario, our 15 year old patient may consent for her own family planning services while continuing to go to routine clinician visits with her parents. A “mixed” visit may require the clinician to create separate visit records, but would enable accurate documentation of who consented for what services and appropriate control of subsequent access. Consent by her parents to allow providers to access their daughter’s medical data (such as the results of her annual exam or her asthma treatment) can only be applied to data resulting from interactions authorized with her parents’ consent. Any data on which the 15 year old directly consented requires her consent to exchange her health information through a RHIO.

The addition of the Treatment Consent By value to an appropriate HL7 message enables a data exchange or EHR to ensure that minor-consented services are not inadvertently disclosed based on a parent’s consent to access. With additional development, clinicians and health exchanges will be able to add functionality that allows the minor’s consent to enable sharing of the minor-controlled data.

**The Need for a National Solution**

New York is not the only state facing the dilemma of accommodating the competing needs of minors. Most states provide minors with the right to consent to some treatment, though the particulars of each state law vary greatly. The importance of a scalable solution that could be flexible to federal and state law requirements would have a highly beneficial impact on health information technology and exchange. Limitations of existing technology should not preclude the exchange of minor’s health information. While New York provides the platform for the further exploration of these issues, developments in both policy and technology will provide tremendous benefit nationally as other states implement systems of health information exchange. The resolution of this challenge has significant benefits. With further analysis and definition the concepts presented here present a resolution for similarly situated adult patients, such as those seeking treatment for conditions historically carrying a societal stigma – HIV/AIDS, mental health, substance abuse and sexually transmitted illnesses. It would be scalable to address the ARRA requirement to allow patients to pay-out-of-pocket for health services without disclosure to their insurance plan.

While the “tiger team” did not fully develop a solution, it did develop the concept of an HL7 segment that could act as a “sticky” flag, following ancillary data throughout the healthcare system. The development and rapid deployment of such a solution is critical at this time when the nation is undergoing a massive implementation of health information technology. Absent national guidance on this issue, there will be little incentive for EHR, HIE or other vendors to develop the technology that assures patient confidentiality.
While this paper does propose a potential technical solution for the problem, it is understood that other equally viable or even preferred solutions may be developed. What is absolutely required is that this problem be solved! To that end we call upon the Office of the National Coordinator for Health Information Technology, Centers for Medicare and Medicaid and other appropriate national authorities to assure:

- Meaningful use and other requirements for Certification of EHR, HIE and associated products and services must include the capacity to identify “sensitive” episodes of care and related services and allow for the control of their dissemination in an electronic exchange. Even if this must be phased in, it must be on the road map now to assure proper focus and enthusiasm to achieve a solution and implementation.
- National organizations responsible for the development and refinement of standards need to provide the necessary framework to support a solution. To the extent that additional input from the appropriate federal agencies can facilitate this, above and beyond the certification mechanism, it should be done.

We are convinced after delving into this issue for the past two years, that if the federal government begins to create standards and requirements, vendors will see the business case and provide the innovative technology that will solve this problem. However, without such leadership, the nation is embarking on the building of a national structure for data exchange largely non-compliant with current state and federal law, and which will not meet the public health and privacy concerns of its citizens.
Endnotes

1 See the HITECH Act, enacted as part of ARRA. This made some substantive changes to the HIPAA Privacy Rule (45 C.F.R. Part 160 and Subparts A and C of Part 164).

2 This is also the rule established under the federal alcohol and drug patient confidentiality law and regulations (42 U.S. C. § 290dd-2 and 42 C.F.R. Part 2). The person who has legal authority under state law to consent to alcohol/drug treatment is also the person whose consent to disclosure of information about that treatment is generally required before others may be given access to it. Thus, in a state like NY where a minor has the authority to consent to alcohol/drug treatment in certain circumstances, the consent of the minor is required to make any disclosure, including disclosures to the minor’s parent or guardian. (In states where parental consent to a minor’s alcohol/drug treatment is required, the consent of both the minor and the parent/guardian is required to make any disclosure).

3 See the HIPAA Privacy Rule, 45 C.F.R. Part 164.

4 See Bonner v. Moran, 126 F.2d 121, 122 (D.C. Cir. 1941) (“[T]he general rule is that the consent of the parent is necessary for an operation on a child.”); Alfonso v. Fernandez, 606 N.Y.S. 2d 259, 262 (App. Div. 2d Dep’t 1993) (recognizing the common law rule requiring parental consent of the provision of health services to a minor); In re Rosebush, 491 N.W. 2d 633, 683 (Mich. App., 1992) (“It is well established that parents speak for their minor children in matters of medical treatment.”)

5 As with adults, these rights may be exercised only by those individuals who have the capacity to consent – that is, who have the maturity and intellectual capacity to understand the risks and benefits of proposed and alternative treatments.


8 ld.

9 See Planned Parenthood of Central Missouri v. Danforth, 428 U.S. 52, 74 (1976) (“Minors, as well as adults, are protected by the Constitution and possess constitutional rights.”); Carey v. Population Servs. Int’l, 431 U.S. 678, 693 (1977) (“[T]he right to privacy in connection with decisions affecting procreation extends to minors as well as to adults.”). In addition, minors who receive health care through Medicaid and Title X may consent family planning services and supplies. Social Security Act Titles IV, XIX, XX; 42 U.S.C.A. §§ 300(a), 1396d(a)(4)(C) (2001) (“family planning services and supplies furnished (directly or under arrangements with others) to individuals of child-bearing age (including minors who can be considered to be sexually active) who are eligible under the State [Medicaid] plan and who desire such services and supplies”); 42 C.F.R. §§ 59.5(a) (“Each project supported under this part must…[p]rovide a broad range of acceptable and effective medically approved family planning methods (including natural family planning methods) and services (including infertility services and services for adolescents.”)), 440.240(b), 440.250(c) (2001) (“Family planning services and supplies must be limited to recipients of childbearing age, including minors who can be considered sexually active and who desire the services and supplies.”).
10 Emergency contraception is available to minors as is any other form of contraception. Thus, the Title X program requires that family planning clinics receiving federal funding offer EC on the same basis as any other safe and effective family planning method. Memorandum Re: Emergency Contraception from Thomas Kring, Acting Deputy Assistant Secretary for Population Affairs, US Department of Health and Human Services, to Regional Health Administrators (April 23, 1997)(on file with NYCLU). Further, the New York Departments of Health and Social Services have instructed hospital emergency rooms to offer EC to minor rape survivors within 72 hours of unprotected sex where medically appropriate. Department of Health, Department of Social Services, Child and Adolescent Sexual Offense Medical Protocol. (n.d.).

11 Planned Parenthood v. Casey, 505 U.S. 833, 899-900 (1992); Hodgson v. Minnesota, 497 U.S. 417, 458 (plurality opinion), (O’Connor, J., concurring) (1990); Planned Parenthood Ass’n, v. Ashcroft, 462 U.S. 476, 490-91 (1983); Akron v. Akron Ctr. for Reproductive Health, 462 U.S. 416, 439-40 (1983); Bellotti v. Baird, 443 U.S. 622, 643 (1979) (plurality opinion). In these cases, the US Supreme Court ruled that parental consent requirements for abortion are unconstitutional unless they provide an expeditious and confidential judicial bypass procedure. NY has made no provision for such a bypass procedure. Therefore, although no NY statute explicitly allows minors to have an abortion, minors in NY may get abortions without parental consent. In fact, NYS law expressly forbids the release of medical records pertaining to a minor’s abortion to the minor’s parents without explicit consent from the minor. (PHL) § 17 (McKinney 2001). In fact, anyone who unlawfully furnishes a report relating to a woman’s referral for or inquiry regarding abortion services, or anyone who requests or obtains such documents under false pretenses is guilty of a Class A misdemeanor. N.Y. (GB) § 394-e(4) (2001).

12 Minors may consent to medical, dental, health and hospital services relating to prenatal care, including labor and delivery services. N.Y. Pub. Health L. § 2504(3) (McKinney 2001).  

13 N.Y. Pub. Health L. § 2305(2) (McKinney 2001). NY expressly forbids the release of information regarding a minor’s treatment for Sexually Transmitted Infections (STIs) to parents and guardians without the patient’s consent. N.Y. Pub. Health L. §§ 17 (“[R]ecords concerning the treatment of [a minor] for venereal disease…shall not be released [by a physician or hospital] or in any manner be made available to the parent or guardian of such [minor].”), 2306 (McKinney 2001).

14 With regard to minor consent to mental health services, NY law distinguishes between outpatient and inpatient treatment. Generally, a minor of any age may seek outpatient mental health services without parental involvement if a parent or guardian is not reasonably available, or the provider determines that parental involvement would be detrimental to the course of treatment, or the parent or guardian has refused to give consent and a physician determines that treatment is necessary and in the best interest of the minor. N.Y. Mental Hygiene L. § 33.21(c) (McKinney 2001); 14 N.Y.C.R.R. § 587.7(a)(3)(iii) (2001). Where parents have refused to consent and a physician determines that the minor should receive treatment anyway, the physician must notify the parents of this decision, but only if clinically appropriate. N.Y. Mental Hygiene L. § 33.21(d) (McKinney 2001). A minor must be age 16 or over to consent to inpatient health treatment. N.Y. Mental Hygiene L. § 9.13(a) (McKinney 2001). If a minor has consented to inpatient treatment, parental consent for medication is not needed. N.Y. Mental Hygiene L. § 33.21(a)(1) (McKinney 2001). Additionally, sixteen- or seventeen-year-old admitted based on parental consent can give informed consent to medication where medication is in the minor’s best interests if: (1) a parent or guardian is not reasonably available, (2) requiring parental
involvement would have a detrimental effect on the minor or (3) the parent or guardian has refused to consent. N.Y. Mental Hygiene L. § 33.21(e)(2) (McKinney 2001).

15 NY law generally mandates that steps be taken to involve parents in a minor’s substance abuse treatment, N.Y. Mental Hygiene L. § 22.11(b) (McKinney 2001) (“[T]he important role of the parents or guardians shall be recognized...[and s]teps shall be taken to involve the parents or guardians in the course of [mental health] treatment.”). However, a minor can receive non-medical alcohol or substance abuse services (such as counseling) without parental consent or notification. Memorandum from Henry M. Greenberg, General Counsel, NYSDOH, to Dennis P. Murphy, Acting Director, Division of Family and Local Health 16 (June 29, 2000). Further, a minor may receive inpatient or outpatient medical treatment for alcohol or substance abuse without parental involvement if the provider cannot reasonably locate the minor’s parents or the parents refuse or fail to communicate with the provider, and the program director authorizes treatment; N.Y. Mental Hygiene L. § 22.11(c)(2) (McKinney 2001); or a physician determines that the involvement of the parent or guardian would have a detrimental effect on the course of treatment; or the parent or guardian refuses to consent and a physician believes that treatment is necessary to the child’s best interest; N.Y. Mental Hygiene L. § 22.11(c)(1) (McKinney 2001); 14 N.Y.C.R.R. 820.4(c) (2001). We note that the federal law and regulations governing confidentiality of alcohol and drug patient records, 42 U.S.C. § 290dd-2 and 42 C.F.R. Part 2, leave the issue of whether a minor can obtain health care or alcohol or drug treatment on his or her own (without parental notification or involvement), entirely to state law. See 42 C.F.R. § 2.14. In states like NY, which allows a minor to obtain alcohol or drug treatment on his/her own, then the federal regulations generally require the minor patient’s consent for any disclosure of information about the minor-consented alcohol/drug treatment to be made. The consent must be written and meet the requirements of 42 C.F.R. Part 2.

16 Under NYS HIV testing and confidentiality law N.Y. Public Health Law, Article 27-F, §§ 2780 et seq., any minor, regardless of age, who has “capacity to consent” is authorized to consent to (or decline) HIV testing on his/her own, without parental involvement or notification. The law defines “capacity to consent” as the ability to understand the nature and consequences of a proposed health care procedure (such as an HIV test) or a proposed disclosure of confidential HIV related information, and to make an informed decision concerning the proposed treatment or disclosure. See N.Y. Pub. Health L. § 2780(5) (defining “capacity to consent” to an HIV test or disclosure of HIV related information); and § 2781 (requiring that consent to HIV testing must be provided by individual with capacity to consent – which may be a minor who has capacity as defined above – or, if the test subject lacks capacity, by the person authorized by law to make health care decisions for the individual being tested.

17 A number of the services necessary for sexual assault treatment fall within the confidential reproductive services to which minors may give informed consent. These include pregnancy testing and counseling, administration of emergency contraception, STI diagnosis and treatment, HIV testing and, possibly HIV treatment. Minors may consent to rape crisis counseling. N.Y. C.P.L.R. § 4510(a)(3) (defining the rape crisis client, without regard to age, as “any person who is seeking or receiving the services of a rape crisis counselor for the purpose of securing counseling or assistance concerning any sexual offenses”) (emphasis added). They may also consent to forensic evidence collection. Department of Health, Department of Social Services, Child and Adolescent Sexual Offense Medical Protocol 33 (n.d.) (directing providers to obtain consent from sexual assault survivors, including capable minors, before collecting sexual offense evidence).


20 N.Y. Pub. Health L. § 2504(1) (McKinney 2001) (“[A] minor who…has married may give effective consent to medical, dental, health and hospital services for himself or herself, and the consent of no other person shall be necessary.”). Because the law applies to a minor who “has married,” a minor who is divorced should also be able to consent to his or her own care. As of yet, NY courts have not ruled on this issue.

21 N.Y. Pub. Health L. § 2504(3) (“Any person who is pregnant may give effective consent for medical, dental, health and hospital services relating to prenatal care.”


23 Under the Family Health Care Decisions Act adopted by New York in 2010, an “emancipated minor” is defined as either a person 16 or over and living independently from their parents, or a minor who is a parent him or herself. N.Y. Pub. Health L. § 2994-a(8) (2010). However, outside the context of health care decision-making for an incapacitated patient, emancipation is understood to be a much broader category. Under New York case law, a minor is deemed emancipated when they marry; when they enter the armed services; or if they become economically independent through gainful employment or the parents of the minor seeking emancipation have defaulted on their parental support obligations to the minor.
Glossary of Technical Terms

ADT – Admission, discharge, transfer is a message type used in Health Level 7 formatted communication

CCD - The Continuity of Care Document (CCD) specification is an XML-based markup standard intended to specify the encoding, structure and semantics of a patient summary clinical document for exchange. The patient summary contains a core data set of the most relevant administrative, demographic, and clinical information facts about a patient's healthcare, covering one or more healthcare encounters. It provides a means for one healthcare practitioner, system, or setting to aggregate all of the pertinent data about a patient and forward it to another practitioner, system, or setting to support the continuity of care. Its primary use case is to provide a snapshot in time containing the pertinent clinical, demographic, and administrative data for a specific patient.

CPT- The Current Procedural Terminology (CPT) code set is maintained by the American Medical Association through the CPT Editorial Panel. The CPT code set accurately describes medical, surgical, and diagnostic services and is designed to communicate uniform information about medical services and procedures among physicians, coders, patients, accreditation organizations, and payers for administrative, financial, and analytical purposes. The current version is the CPT 2010. CPT is currently identified by the Centers for Medicare and Medicaid Services (CMS) as Level 1 of the Health Care Procedure Coding System.

HL 7 - HL7 is an international community of healthcare subject matter experts and information scientists collaborating to create standards for the exchange, management and integration of electronic healthcare information. HL7 promotes the use of such standards within and among healthcare organizations to increase the effectiveness and efficiency of healthcare delivery for the benefit of all. HL7 is one of several American National Standards Institute (ANSI)-accredited Standards Developing Organizations (SDOs) operating in the healthcare arena. Most SDOs produce standards (sometimes called specifications or protocols) for a particular healthcare domain such as pharmacy, medical devices, imaging or insurance (claims processing) transactions. Health Level Seven’s domain is clinical and administrative data. HL7 specifies a number of flexible standards, guidelines, and methodologies by which various healthcare systems can communicate with each other. Such guidelines or data standards are a set of rules that allow information to be shared and processed in a uniform and consistent manner. These data standards are meant to allow healthcare organizations to easily share clinical information. HL7 version 2 defines a series of electronic messages to support administrative, logistical, financial as well as clinical processes. The HL7 Version 3 Development Framework (HDF) is a continuously evolving process that seeks to develop specifications that facilitate interoperability between healthcare systems.

ICD-9 - International Classification of Diseases, Clinical Modification (ICD-9-CM) is a classification used in assigning codes to diagnoses associated with inpatient, outpatient, and physician office utilization in the U.S. The ICD-9-CM is based on the ICD-9 but
provides for additional morbidity detail and is annually updated on October 1. It was created by the U.S. National Center for Health Statistics as an extension of ICD-9 system so that it can be used to capture more morbidity data and a section of procedure codes was added.

**LOINC - Logical Observation Identifiers Names and Codes (LOINC)** is a database and universal standard for identifying medical laboratory observations. It was developed and is maintained by the Regenstrief Institute, Inc., a US non-profit medical research organization, in 1994. LOINC was created in response to the demand for an electronic database for clinical care and management and is publicly available at no cost. It is endorsed by the American Clinical Laboratory Association and the College of American Pathologist. Since its inception, the database has expanded to include not just medical and laboratory code names, but also: nursing diagnosis, nursing interventions, outcomes classification, and patient care data set. **LOINC** applies universal code names and identifiers to medical terminology related to the Electronic health record. The purpose is to assist in the electronic exchange and gathering of clinical results (such as laboratory tests, clinical observations, outcomes management and research).
### Minor Consent Tiger Team Members

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