



Sharing Clinical Notes while Protecting Adolescent Confidentiality and Maintaining Parental Insight

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Abstract

Background The 21st Century Cures Act mandates sharing electronic health records (EHRs) with patients. Health care providers must ensure confidential sharing of medical information with adolescents while maintaining parental insight into adolescent health. Given variability in state laws, provider opinions, EHR systems, and technological limitations, consensus on best practices to achieve adolescent clinical note sharing at scale is needed.

Objectives This study aimed to identify an effective intervention process to implement adolescent clinical note sharing, including ensuring adolescent portal account registration accuracy, across a large multihospital health care system comprising inpatient, emergency, and ambulatory settings.

Methods A query was built to assess portal account registration accuracy. At a large multihospital health care system, 80.0% of 12- to 17-year-old patient portal accounts were classified as inaccurately registered (IR) under a parent or registration accuracy unknown (RAU). To increase accurately registered (AR) accounts, the following interventions were pursued: (1) distribution of standardized portal enrollment training; (2) patient outreach email campaign to reregister 29,599 portal accounts; (3) restriction of access to remaining IR and RAU accounts. Proxy portal configurations were also optimized. Subsequently, adolescent clinical note sharing was implemented.

Results Distribution of standardized training materials decreased IR and increased AR accounts ($p = 0.0492$ and 0.0058 , respectively). Our email campaign (response rate: 26.8%) was most effective in decreasing IR and RAU accounts and increasing AR accounts ($p < 0.002$ for all categories). Remaining IR and RAU accounts, 54.6% of adolescent portal accounts, were subsequently restricted. Postrestriction, IR accounts

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continued declining significantly ($p = 0.0056$). Proxy portal enhancements with interventions deployed increased proxy portal account adoption.

Conclusion A multistep intervention process can be utilized to effectively implement adolescent clinical note sharing at a large scale across care settings. Improvements to EHR technology, portal enrollment training, adolescent/proxy portal settings, detection, and automation in reenrollment of inaccurate portal accounts are needed to maintain integrity of adolescent portal access.

Background and Significance

Adolescence is a time of significant change and newfound independence. Medical visits during this time often focus on physical growth and development, social and academic achievements, emotional well-being, risk reduction, reproductive health, substance abuse, and injury prevention. To best discuss these sensitive topics, health care providers must ensure the confidential sharing of medical information with adolescents. Evidence has shown that ensuring this confidentiality encourages adolescents to disclose more during clinical visits.^{1,2} Support for adolescent access to health information has been voiced by multiple academic societies, including the Society for Adolescent Health and Medicine and the American College of Obstetrics and Gynecology,^{3–6} as well as by adolescents themselves.⁷ Differing state laws support adolescent consent and confidentiality for certain types of medical care.^{8,9} Although state laws and regulations can vary based on parameters such as age and medical services provided,^{8,9} the promotion of adolescent consent and autonomy for sensitive health care and protection of confidentiality for related electronic health information is a necessity.

With the passage of the 21st Century Cures Act in 2016 and the implementation of the Information Blocking rules in 2021,¹⁰ there has been a greater need to ensure adolescent confidentiality in the patient portal. The Cures Act mandates sharing electronic health information with patients.¹⁰ Those actors or entities that interfere with access, exchange, or use of electronic health information can be labeled “Information Blockers” and will be subject to disincentives in the future.¹⁰ Although there are allowable exceptions to withholding electronic health information from adolescents, the overall standard has been focused on sharing as much information as possible.^{10,11}

Despite this nationwide challenge, there is no consensus on best practices to achieve adolescent clinical note sharing. This is due to the wide variability in electronic health record (EHRs) functionalities, state minor consent and privacy laws, clinical needs and settings of health care providers, provider opinions regarding adolescent/parental access to confidential information, and variability in patient and proxy portal access policies.^{12,13} Additionally, concerns about unintended parental access to sensitive adolescent patient portal information make clinical note sharing adoption challenging.^{14,15} Numerous factors contribute to inaccurate portal registration for adolescents with parental contact information,

including nonstandardized and often complex portal registration processes, poor understanding of adolescent and proxy configurations, adolescent sharing of portal credentials, and parental coercion during the adolescent portal sign-up process.^{14,15} To ensure adolescent privacy, clinical notes cannot be shared without establishing portal account owners as adolescents. It is estimated that 64 to 76% of adolescent portal accounts may be accessed by parents or guardians.¹⁴ A recent study by Xie et al uncovered that 62% of adolescent portal accounts were inaccurately registered (IR) under parents or guardians.¹⁵ The correction of IR portal accounts is a necessary step toward achieving adolescent clinical note sharing.

NewYork-Presbyterian, Weill Cornell Medicine, and ColumbiaDoctors medical system is a health care system in the New York metropolitan area. The journey to clinical note sharing for this institution began with the establishment of a working group to achieve compliance with the 21st Century Cures Act. This multidisciplinary and interprofessional group was comprised of clinical informaticists, nursing and physician leaders, EHR analysts, registration and access team managers, as well as regulatory, compliance, health information management leaders, and legal stakeholders from all institutional entities. Given the complex nature of health information to be shared, it was necessary to assemble a diverse group of individuals with specialized expertise and skill sets.

The working group implemented adult portal laboratory and imaging result release and, subsequently, clinical note sharing for patients 18 years and older. Early on, it became evident certain patient populations faced unique challenges to clinical information sharing, including pediatric and behavioral health patients. Subgroups of experts were created for these patient populations. The Pediatric Information Sharing Workgroup was formed, with an initial focus on sharing clinical results and notes for pediatric patients from birth to 11 years old. After an extensive review of requirements, additional EHR configurations, and broad educational efforts with all pediatric clinical staff, clinical note sharing for patients 0 to 11 years old was achieved within 6 months. Efforts were then focused on the implementation of clinical note sharing for adolescent patients 12 to 17 years old and their proxies.

Objectives

The objective of this article is to describe the year-long process to implement clinical note sharing for adolescent patients, ages 12 to 17 years old, and their proxies across a large

multihospital health care institution comprising inpatient, emergency, and ambulatory settings. This includes the categorization of adolescent portal account registration accuracy, training efforts to standardize portal registration, and the implementation of proxy portal enhancements. A patient outreach email campaign was also developed to reregister IR and registration accuracy unknown (RAU) adolescent portal accounts. Following this campaign, restrictions were placed on IR and RAU accounts and adolescent clinical note sharing was implemented to the maximum degree given current technology limitations.

Methods

NewYork-Presbyterian, Weill Cornell Medicine, and ColumbiaDoctors health care system comprises 2 academic medical centers, 11 hospital campuses, and multiple large ambulatory care networks in the New York metropolitan area. These hospitals serve over 100,000 pediatric patients younger than 11 years old and over 30,000 adolescent patients 12 to 17 years old. This health care system utilizes EpicCare EHR and the MyChart patient portal system through the EpicCare EHR. Per New York State law, adolescents gain access to their patient portals at 12 years old.^{16,17} Parental access to patient health information lapses on a patient's 18th birthday as the patient is no longer considered a minor by New York State.^{16,18}

The Pediatric Information Sharing Workgroup first aimed to understand our baseline state of adolescent portal registration, including its accuracy and the amount of proxy portal assignments. A query was developed to investigate the accuracy of portal enrollment by analyzing patient email addresses used to register portal accounts. By comparing patient email addresses with patient first and last names as well as the first and last names of parents, proxies, guarantors, and emergency contacts, we categorized patient accounts (initial total $n = 24,871$) into one of three categories: (1) accurately registered (AR) portal accounts (initial $n = 4,967$ or 20.0% of total accounts); (2) IR portal accounts (initial $n = 8,788$ or 35.4% of total accounts); or (3) RAU portal accounts (initial $n = 11,116$ or 44.79% of total accounts). To minimize risk of confidentiality breaches for subsequent interventions, RAU portal accounts were treated as though they were IR. These accounts contained emails for which the ownership by parent or patient was not easily discernible (e.g., goldfish@xyz.com) or in instances where the first and last name of patient and parent matched (e.g., James Smith Jr. and James Smith Sr.). Email analysis for this query was chosen as it was the simplest query to build in a limited time frame for our group.

A two-sample z-test for proportions was used to quantify significance of intervention changes of portal registration category from intervention time to 2 months after intervention. Two-month intervals were used to track intervention progress as this provided adequate time for intervention implementation, while still providing at least one additional month postinterventions to track effects. Although not ideal, our implementation timeline to establish adolescent note

sharing and be in compliance with the 21st Century Cures Act required us to have shorter intervention intervals.

Patient demographic information, portal enrollment dates, and proxy assignment data were also collected. Portal enrollment data and accuracy at the registration employee and departmental level was collected to provide feedback to registration and access leadership. Proxy assignment data helped identify a new metric: proxy account per patient account (PAPA), defined as the number of proxy portal accounts for patients 12 to 17 years old divided by the number of patient portal accounts for the same age range. This metric was tracked throughout interventions as a secondary process measure, with a single proxy portal registered per patient on average resulting in a PAPA = 1.0, and two proxy registrations per adolescent on average resulting in a PAPA = 2.0. At the beginning of the project, the initial PAPA was 0.35.

While preparing our query, a separate working group was created with registration and access team leadership throughout all pediatric settings to obtain feedback regarding current adolescent portal registration practices. This group also served as a conduit to disseminate information to these high priority teams during all interventions. Differing practices and workflows were uncovered even within similar care settings, with several registration groups never conducting proxy portal assignments previously. In collaboration with this group and our training team, an instructional training document and a 10-minute video were developed, which outlined the importance of correct portal registration and the standard process for adolescent and proxy portal enrollment. A frequently asked questions document was also created with scripts for staff to use during the registration process with adolescents and parents. The training materials were compiled as an e-learning course and distributed by individual registration team managers across our institution. This training material distribution served as our first intervention.

Feedback from our clinical providers, leadership, and registration teams about overly restrictive configurations within proxy portal accounts led us to examine our proxy accessibility settings. Our settings were restricted in multiple ways, preventing proxies from accessing most patient information. Additionally, proxy access to patient information would also lapse when a pediatric patient became 12 years old. As a guiding principle, our team worked to grant proxies as much access as possible while still protecting adolescent privacy. Medical health information such as medications, problem lists, diagnoses, appointments, and laboratory and imaging results were reviewed, with viewability configured based on adolescent versus proxy access.

We created two new proxy types based on our review: Adult to Adolescent Proxy, No-Consent Required and Adult to Adolescent Proxy, Consent Form Signed. The former was provided by default to all parents of patients greater than 12 years old. This proxy type had limited viewability into sensitive adolescent information, including sexual history, pregnancy and sexually transmitted illness testing, and contraceptive medications. The determination of what constituted sensitive adolescent information was conducted via

an in-depth analysis by the Pediatric Information Sharing Workgroup in conjunction with institutional legal, privacy, and compliance officers. Gaps in proxy access were also eliminated at the 11 to 12-year-old birthdate. The Adult to Adolescent Proxy, Consent Form Signed proxy type was developed to allow parents full access to adolescent portal accounts for 2 years if the adolescent signed an electronic consent form. The consent form utilized contains a description as to what information is being released by signing the consent. The 2-year time interval was determined after discussion with pediatric providers, legal and privacy teams and was based on previous proxy lapse times utilized by our institution. To encourage adoption of these new proxy settings, standardized education was distributed to clinical, registration, and access staff. Education emphasized the enrollment of every new adolescent registrant with both an adolescent portal account and a proxy portal account. For patients deemed incapable of making medical decisions, a diminished capacity proxy configuration was also established prior to this initiative. This third proxy setting was also included in standardized training.

Once proxy functionalities were optimized, a patient outreach email campaign was launched with the goal of correcting the large number of IR portal accounts ($n = 12,027$ or 34.0% of total accounts at time of intervention) and RAU portal accounts ($n = 16,384$ or 46.3% of total accounts at the time). In this intervention, RAU portal accounts were treated as IR. Over the span of 1.5 months and on a rolling basis, 29,599 IR and RAU portal accounts were emailed a questionnaire. New IR and RAU accounts registered during the intervention time period were also included. Reminders were sent periodically about survey completion. Questionnaires informed parents and patients about statewide laws for access, federal mandates for adolescent clinical information sharing, and the proxy enrollment process. Portal account owners were asked to input email information of the adolescent patient and their parents. Questionnaires were

then processed by a third-party help desk team and re-registered appropriately. Questionnaires with inaccurate email responses noted by the help desk team (e.g., use of parental email for adolescent email or ambiguous email addresses) were escalated to registration staff at the patient’s primary care practice or the location where the patient was last seen. Registration staff members contacted these account holders via phone to address any concerns and to reenroll these accounts. Those accounts that reached no resolution were considered IR.

Following these reenrollment efforts and upon discussion with clinical, legal, and privacy leadership, remaining IR and RAU accounts were restricted from viewing any clinical information in the patient portal. This was done only after informing patients of these repercussions in the previous email campaign. To limit disruptions to care, restrictions took place over the span of 1 month and were conducted in batches, restricting accounts based on time of upcoming appointment and recent portal activity. Accounts were initially restricted for those with no recent portal activity for over 2 years and no upcoming appointments, then restricted based on last portal activity, and finally restricted to those with upcoming appointments. When accessing these restricted portal accounts, patients are directed to call help desk staff to reregister their accounts.

Once restrictions were in place, we distributed information to providers and staff about upcoming changes, conducted a town hall to answer any additional questions, and went live with clinical note sharing for our adolescent patients 12 to 17 years old on September 29, 2022. Post go-live portal registration accuracy was tracked to monitor and maintain intervention gains.

Results

During our initial query in December 2021, AR portal accounts were in the minority at 20.0% ($n = 4,967$) of total

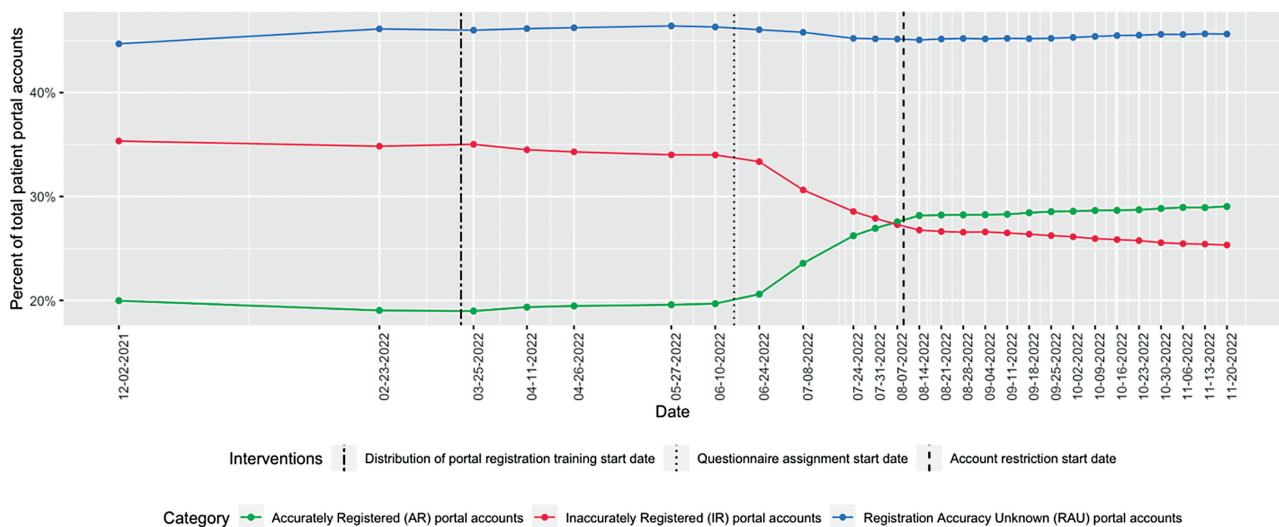


Fig. 1 Percentage of total adolescent patient portal accounts by category over time.

Table 1 Intervention significance by portal registration category

| Portal account category | Intervention 1: training distribution | | Intervention 2: questionnaire assignment | | Intervention 3: account restriction | | |
|---|---------------------------------------|--------------|--|----------------|-------------------------------------|------------------|----------------------|
| | March 25, 2022 | May 27, 2022 | June 10, 2022 | August 7, 2022 | August 14, 2022 | October 16, 2022 | p-Value ^a |
| N | 32,223 | 35,218 | 35,374 | 34,719 | 34,706 | 36,011 | |
| Accurately registered portal accounts | 19.0% | 19.6% | 19.7% | 27.6% | 28.2% | 28.7% | 0.147 |
| Inaccurately registered portal accounts | 35.0% | 34.0% | 34.0% | 27.3% | 26.8% | 25.9% | 0.006 |
| Accuracy unknown registered portal accounts | 46.0% | 46.4% | 46.3% | 45.2% | 45.1% | 45.5% | 0.260 |

^aTwo-sample z-test for proportions comparing immediately preintervention to 2-month postintervention. p-Values significant at 0.05 level marked in bold.

portal registered accounts, with IR portal accounts comprising 35.3% of total accounts (n=8,788), and RAU portal accounts comprising 44.7% of total accounts (n=11,116). In total, we classified approximately 80.0% of accounts as being IR or RAU.

At the time of our first intervention, distribution of standardized training, relative percentages of accuracy in registration remained largely unchanged (AR: 19.0%; IR: 35.0%; RAU: 46.0%). Two months following our distribution of training, we noted an increase in AR account percentiles (19.6%, p=0.049) and a decrease in IR account percentiles (34.0%, p=0.006; →Fig. 1 and →Table 1). The average PAPA had improved slightly from 0.36 to 0.39 (→Fig. 2).

With our second intervention, our patient outreach email campaign, a total of 29,599 patients were sent a questionnaire. A total of 7,936 patients completed the questionnaire (response rate: 26.8%), of which 3,658 responses (46.1%) required escalation and 630 questionnaires (7.9%) reaching no adequate resolution requiring restriction. In total, 25.0% of portal accounts (n=7,306) were reenrolled. Postintervention, a significant change in portal registration accuracy was noted, with AR accounts increasing to 27.6% (p<0.0001), IR accounts decreasing to 27.3% (p<0.0001), and RAU portal accounts decreasing to 45.2% (p=0.002), compared with 2 months after the first intervention. A crossing of percentile amounts of IR versus AR accounts was achieved approximately 2 months after our email campaign (→Fig. 1), denoting a higher percentage of AR portal accounts than IR accounts for the first time. Similar rates of change were noted at the individual department level across settings: in primary care practices (→Supplementary Fig. S1), in emergency rooms (→Supplementary Fig. S2, available in the online version), and in subspecialty practices (→Supplementary Fig. S3, available in the online version). PAPA improved from 0.42 to 0.53.

For our third intervention, we placed restrictions on remaining IR or RAU accounts. After a month, a total of 19,275 restrictions on portal accounts were placed, restricting 54.5% of total adolescent portal accounts at that time. Restricted accounts had limited access to portal functionalities and account owners were instructed to contact registration staff to reenroll their accounts. The number of IR portal accounts decreased 2-month postintervention start to 25.9% (p=0.006) of total registered accounts with a nonsignificant increase in AR portal accounts to 28.7%. RAU portal account percentages had remained relatively stable. PAPA had now approached 0.60.

Throughout the project lifecycle, overall registration accuracy was correlated with age, with younger patients having consistently higher percentages of IR accounts and older patients with higher percentages of AR accounts (→Supplementary Figs. S4 and S5, available in the online version).

As mentioned previously, to improve proxy assignment, proxy functionalities were expanded with an additional proxy tier added requiring the consent of the adolescent patient to grant full access to parents. A summary of functionalities released per proxy tier will be the subject of a subsequent article and are summarized briefly in →Table 2. Assignment of each proxy type increased through the initiative, reaching a total of over 22,000 proxies assigned, with the

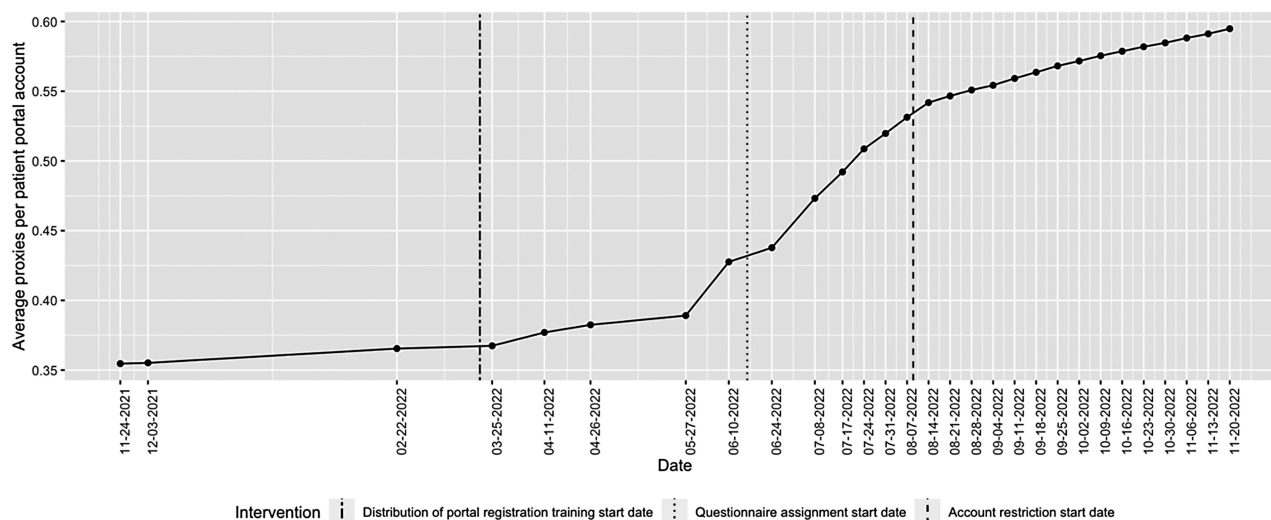


Fig. 2 Average number of proxies assigned per patient portal account over time.

Table 2 New proxy portal account viewability configurations

| Proxy type | Information viewable to proxy | Information not viewable to proxy | Length of access |
|--|--|---|---|
| Adult to adolescent proxy, no consent required | Most functionalities in patient portal, including basic laboratory and imaging results, medications, appointments, problem list, and diagnosis items | Adolescent-sensitive ^a information related to laboratory and imaging results, medications, appointments, problem list, and diagnosis items | Once assigned after 12 years old, does not lapse until 18 years old |
| Adult to adolescent proxy, consent form signed | Allergies, immunizations, medications, appointments, laboratory and imaging results, and most problem list, and diagnosis items | Adolescent-sensitive ^a information related to problem list and diagnosis items | Every 2 years requires consent by patient |
| Diminished capacity proxy | Allergies, immunizations, medications, appointments, laboratory and imaging results, and most problem list, and diagnosis items | Adolescent-sensitive ^a information related to problem list and diagnosis items | Does not lapse after assignment |

^aCriteria for adolescent-sensitive information was determined by the Pediatric Information Sharing Workgroup in conjunction with institutional legal, privacy, and compliance groups.

highest rate of increase seen in the Adult to Adolescent Proxy, No-Consent Required proxy type (→Fig. 3).

Diminished capacity proxy assignments significantly increased during our email campaign intervention ($p=0.03$) but remained unchanged during other intervention timeframes. The number of erroneous emails registered for portal accounts (e.g., none@none.com) also significantly decreased during our email intervention ($p<0.0001$) but remained relatively unchanged during other interventions (→Fig. 4 and →Table 3).

Discussion

A multifaceted approach with targeted interventions for staff, patients, and parents allowed our institution to reach a state of confidence from which we could safely implement adolescent clinical note sharing through the patient portal. This transformative process has improved confidential access to adolescent health information while maintaining parental insight.

The education efforts with registration and access teams were an important first step toward achieving our goal. Optimization of training with these teams has been utilized by other institutions to improve adolescent portal enrollment practices.¹⁵ Meeting frequently with registration and access leadership was crucial to understanding the scope of the issue at hand. Providing standardized training allowed the explanation of the importance of the cause. It also provided a way to distribute scripting and answers to frequently asked questions that would help in discussions with adolescents and parents during this potentially challenging transition time. Of note, are the gains noted after this intervention with improvements in IR and AR portal accounts. Although we cannot reliably attribute these changes to this single intervention alone, it does reemphasize the importance of developing training with those most involved with the process in mind. The PAPA score also increased during this time, denoting potential improvements to proxy assignments from education. A major challenge of this effort was staff turnover and the educational

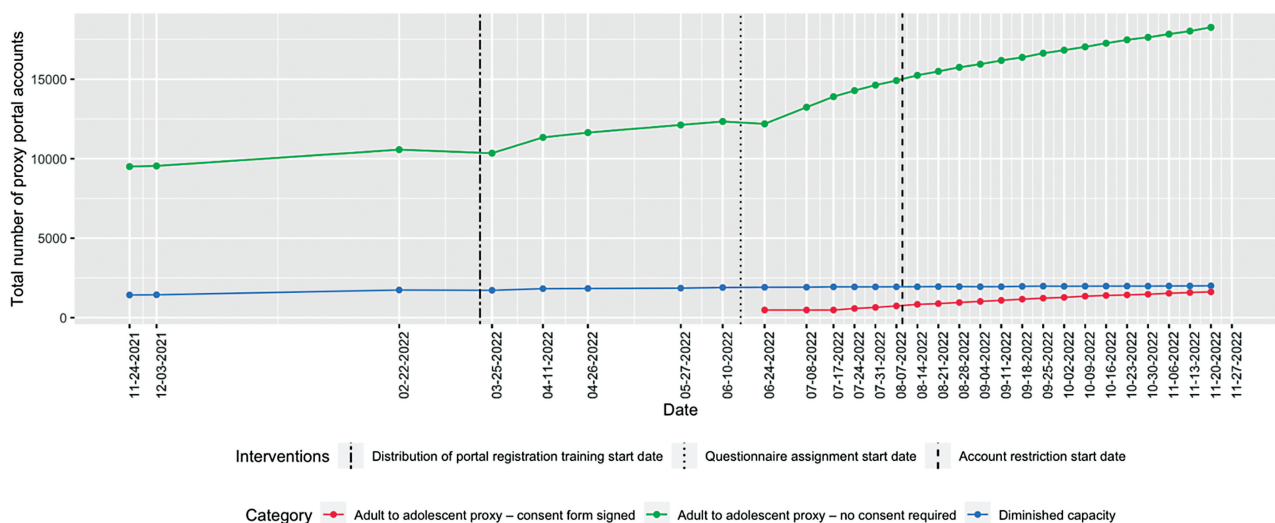


Fig. 3 Proxy portal account type enrollment over time.

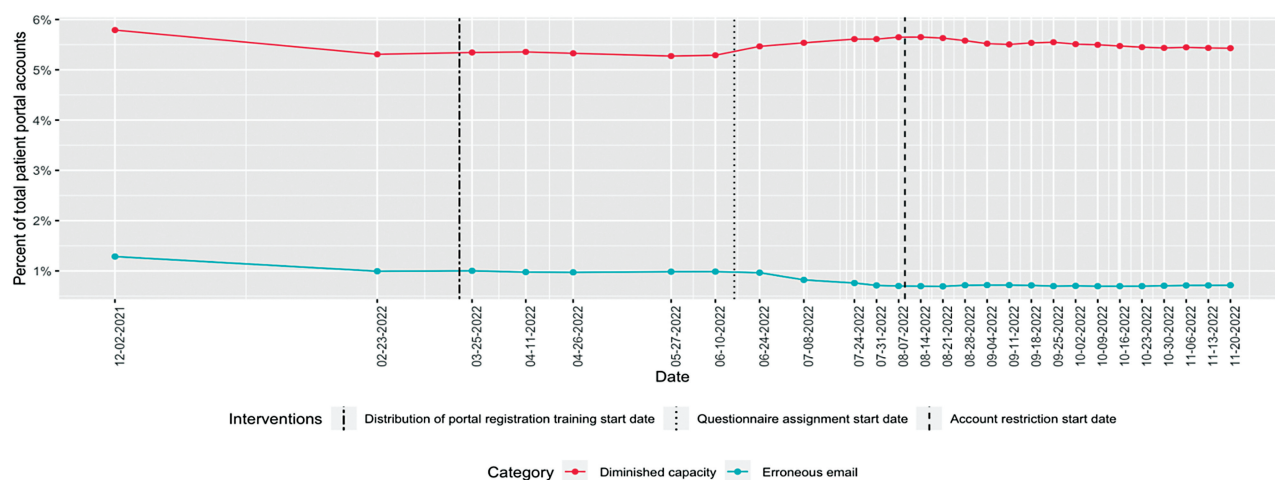


Fig. 4 Percentage of diminished capacity associated and erroneous email accounts relative to total adolescent patient portal accounts.

gaps in process knowledge that may occur because of it. To limit this concern, we are in the process of ensuring training modules for this workflow are provided to new hired staff. Additionally, short yearly refresher training modules are currently being explored.

Our second intervention, launching a patient outreach campaign, was the most impactful to achieve adolescent note sharing by maximizing AR accounts. With 25.0% of adolescent accounts reenrolled, this intervention effectively enabled the percentage of AR accounts to exceed the number of IR accounts. It also aided in a rapid increase in proxy portal enrollment after our proxy enhancements had been implemented. Additionally, this email campaign provided a conduit to inform parents and patients about current mandates and the importance of adolescent confidentiality and medical decision-making.

Preparation for this patient outreach campaign required approval and coordination with marketing, privacy, and legal teams. A large workforce needed to be trained and was devoted to manually reenrolling portal accounts in a short

period of time. Additional resources from our registration and access teams were also utilized to reregister patients with inaccurate questionnaire responses. This potential staffing necessity is a limitation to this intervention and may make it less feasible at other institutions. The 26.8% response rate does demonstrate potential utility of this approach to achieve adequate patient outreach and may represent a pathway for correction of larger EHR discrepancies in the future.

During our second intervention, another challenge noted was that many parents input another parental email address for their adolescent in an effort to circumvent our questionnaire, requiring manual review of answers. Inaccuracy in portal enrollment is a common and well-documented issue.^{14,15} We suspect this hesitancy to provide adolescent emails likely was secondary to the reasons previously described for inaccurate registrations.¹⁴ Gaps in understanding patient portal functionality by adolescents have been previously shown.¹⁹ We postulate that a longer standing and multimodal patient education campaign, with a devoted

Table 3 Diminished capacity and erroneous email changes over time

| | Intervention 1: training distribution | | | Intervention 2: questionnaire assignment | | | Intervention 3: account restriction | | |
|--------------------------------|---------------------------------------|---------------|----------------------|--|----------------|----------------------|-------------------------------------|------------------|----------------------|
| | March 25, 2022 | May 27, 2022 | p-Value ^a | June 10, 2022 | August 7, 2022 | p-Value ^a | August 14, 2022 | October 16, 2022 | p-Value ^a |
| N | 32,223 (100%) | 35,218 (100%) | | 35,374 (100%) | 34,719 (100%) | | 34,706 (100%) | 36,011 (100%) | |
| Diminished capacity assignment | 1,722 (5.3%) | 1857 (5.3%) | 0.693 | 1,871 (5.3%) | 1,961 (5.7%) | 0.038 | 1,961 (5.7%) | 1,971 (5.5%) | 0.312 |
| Erroneous emails in system | 323 (1.0%) | 347 (1.0%) | 0.853 | 349 (1.0%) | 243 (0.7%) | < 0.001 | 242 (0.7%) | 251 (0.7%) | 1 |

^aTwo-sample z-test for proportions comparing immediately preintervention to 2-month postintervention. p-Values significant at 0.05 level were marked in bold.

web site and patient information sessions for instance, may be helpful to decrease patient and parental hesitancy. Additionally, during our interventions, we found that framing both proxy and adolescent portal registrations as the default configuration at the portal transition age, simplifies and normalizes the discussion between registration staff and parents. In discussions with staff, this also decreased likelihood of forgetting proxy registration and emphasized adolescent medical decision-making during the encounter.

An extensive review of proxy access functionality should be viewed as an important prerequisite for any project aimed at adolescent portal medical information sharing. As mentioned, we utilized all proxy configuration enhancements possible to ensure parents had insight into their adolescent's health. There are unfortunately still technological limitations present that contribute to nonidealized viewing of patient information. For example, for certain data being shared (e.g., sensitive problem list items), it is not possible to differentiate between adolescent and proxy views, and therefore viewing was restricted from all parties (→Table 2). Additionally, clinical notes cannot be parsed into different views for adolescents versus proxies. Therefore, we employed an all-or-none approach to viewing clinical notes, with adolescents (and Adult to Adolescent Proxy, Consent Form Signed proxies) being able to view all clinical notes, whereas default proxies (Adult to Adolescent Proxy, No-Consent Required) cannot view any notes. No-Consent Required proxies are able to view nonsensitive laboratory work, problem list items, diagnoses, and appointment types. The determination of what constitutes sensitive adolescent information requires vetting from multiple teams, including providers, legal, and privacy and is likely variable across different states and health care systems.

An all-or-none approach to viewing adolescent clinical notes was utilized as it was deemed too difficult to parse out potentially teen-sensitive medical information from clinical notes using our EHR configuration. This did allow adolescents access to their notes, a functionality previously noted to provide adolescent satisfaction with medical care.⁷ Having proxy tiers and the ability for an adolescent patient to consent to allow access to notes did allow flexibility to those adolescents who wanted to share all notes with proxies. Having the ability to distinguish areas in a note as not to be shared with proxies, will allow for more nuanced clinical note sharing in the future with both adolescents and proxies.

This implementation process has several limitations that merit mention. Given the fast-paced nature of the interventions implemented, it should be noted that one intervention's change may not necessarily be reflected at the 2-month interval intervention endpoints being studied. This was a limitation in our efforts but is representative of conducting a real-life implementation to be in compliance with a government regulation. While we cannot conclude one intervention is better than another or compare longer-versus shorter-term effects of each intervention, the interventions cumulatively were effective in accomplishing our goal.

The query utilized to categorize portal account accuracy was created based on email analysis. Previously, many different methods of analysis have been used for this categorization. Xie et al, for example, used a combination of email analysis as well natural language processing to assess parental use of adolescent portals.⁹ In our case, an email analysis was simple to develop and conduct. Although efficient to create, there were limitations in our query. For example, RAU accounts are a byproduct of this email analysis. Although we saw significant changes in the amount of AR and IR accounts, a substantial percentage of RAU accounts still persisted after interventions. This persistence may be secondary to staff viewing ambiguous emails as potentially more correct than visibly inaccurately assigned accounts, like emails including a parent's first name. This may have brought less scrutiny to these specific portal accounts over time.

Considering RAU accounts as IR during interventions possibly overestimated the number of accounts requiring intervention. Our working group and clinical leadership decided to place restrictions on those RAU accounts after our second intervention, to reduce risk of potential breaches in confidentiality. RAU accounts will be tracked in the future and will be further analyzed using methods like natural language processing of portal messages to establish registration accuracy. These accounts will also be subject to upcoming interventions and technical guardrails aimed at improving adolescent portal registration.

Our Consent Form Signed proxy workflow still has room for improvement. Unintended consequences of utilizing consent signatures for proxy assignment we noted are issues with compliance on consent signatures and potential coercion by parents for full patient portal access. Using automatic assignment of the no-consent proxy type at the 12-year-old birthdate, along with additional patient and parent education, we hope to prevent parental coercion during enrollment and further ensure adolescents comprehension of consent signage. This will also increase default No-Consent Required proxy registrations compared with Consent Form Signed proxy registrations over time.

Diminished capacity proxy assignment also has the potential for improvement. There are concerns that there may be parents of diminished capacity patients that are still IR and primary account holders of adolescent portal accounts. Formal intervention processes have been proposed recently by Carlson et al to optimize diminished capacity proxy enrollment.²⁰ Currently, educational efforts are in place to increase assignment of this proxy type. Ensuring accurate enrollment of these portal accounts allows for proper access to portal information for these patients and proxies and prevents lapses in access to portal accounts during transition periods such as a patient's 18th birthday. It also aids in determining the overall complexity of our patient population.

Unfortunately, a main cause of inaccuracy in adolescent portal registration in our EHR has not yet been fixed. A single email field is used to register adolescent portal accounts. This email field does not specify whether it is for the parent or adolescent email address. There are also limited distinctions

between adolescent and parental phone numbers in the registration workflow. This allows for errors in information entry, subsequently leading to inaccurate portal accounts. Additionally, there are currently limited guardrails in the portal registration process to prevent registration with parent contact information. Given the priority of this topic, checks are now being built into the EHR system to ensure correct initial adolescent portal registration.²¹ Although these guardrails are important, most focus only on the new registration of adolescent portal accounts and do not aid in detection or re-enrollment of previous inaccurate accounts. Additionally, an unintended consequence noted after our intervention process was that the burden to check portal accuracy is placed on clinical providers now more than ever before. Further research and focused efforts should be placed on correcting adolescent portal accounts already IR, and into the automation of this process for large medical centers. This will hopefully decrease this additional burden on clinical providers over time.

Along with the technological optimizations, there is need for further education about adolescent consent and medical decision-making capabilities. Put into the context of state and national mandates, parents, adolescents, and clinical staff need to be aware of the importance of confidentiality in adolescent health. The more education, marketing, and publication about this topic the better. This will hopefully ease tensions around the transition to adolescent portal and medical decision-making autonomy and likely prevent potential breaches of confidentiality in the future.

As a next step, our focus is on a quality improvement cycle to provide standardized education and feedback to individual registration and access teams about their portal enrollment efforts. Standardized training will be assigned and tracked for these smaller registration groups and will be included in new hire curricula. Information regarding portal enrollment accuracy and training will be provided to registration managers at the departmental and individual registrar level. Additionally, new methods to assess RAU accounts, ensure enrollment of diminished capacity proxy accounts, and optimize overall portal registration accuracy are being tested. We will be working toward implementing new technology guardrails, proxy functionalities, and differential note sharing in hopes of continuing to ensure confidentiality for adolescents during this new digital age.

Conclusion

This study highlights the multistep intervention process our institution has taken to improve accuracy of registered portal accounts to support increased adolescent medical information access mandated by the 21st Century Cures Act. While this study has described successful strategies for identifying and correcting IR accounts, there is a need for additional methods to track inaccurate portal registration and automate correction. Technological limitations and realities of medical center practices must be taken into account in any future application of these methods. We will continue to optimize our proxy enrollment and adolescent portal

registration process to further support access while protecting confidentiality.

Clinical Relevance Statement

This study proposes a multistep intervention process medical centers can utilize for optimizing adolescent portal account enrollment on the path to adolescent clinical note sharing. This study highlights the necessity for improvements to EHR technology such as improved and more nuanced portal sharing settings, portal enrollment educational practices, and automation of processes to detect and reenroll inaccurate portal accounts to maintain the integrity of adolescent portal access.

Multiple-Choice Questions

1. What can be an effective tool for ensuring accurate adolescent and proxy portal account registration?
 - a. Ensuring a health information exchange is available at your institution
 - b. Ensuring provider satisfaction with the EHR
 - c. Standardized education that is distributed to registration and access teams
 - d. Verifying the mailing address of the patient

Correct Answer: The correct answer is option c. Standardized education is helpful to ensuring accurate adolescent and proxy portal account enrollment. Providing standardized training allows an explanation of the importance of adolescent confidentiality and proper portal enrollment. It also provides a way to distribute scripting and answers to frequently asked questions that would help in discussions with adolescents and parents during this potentially challenging transition time.

2. What is a contributing factor to the lack of consensus for best practices to achieve adolescent clinical note sharing?
 - a. Concerns about research data
 - b. Potential sharing of clinical notes to different countries
 - c. State law variability about adolescent consent and medical decision-making capabilities
 - d. Differing medical licenses of providers across state lines

Correct Answer: The correct answer is option c. At this time, there is limited consensus on best practices to achieve adolescent clinical note sharing. This is due to the wide variability in state laws, how EHRs function, different clinical needs and practice settings of health care providers, variety of provider opinions regarding adolescent/parental access to confidential information, and variability in patient and proxy portal access policies.

Protection of Human and Animal Subjects

This project was performed in compliance with the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects. All information regarding this project involved the

use of deidentified personal health information and was exempt from review by the Weill Cornell Medicine Institutional Review Board.

Conflict of Interest

None declared.

References

- 1 Ford CA, Millstein SG, Halpern-Felsher BL, Irwin CE Jr. Influence of physician confidentiality assurances on adolescents' willingness to disclose information and seek future health care. A randomized controlled trial. *JAMA* 1997;278(12):1029–1034
- 2 Lehrer JA, Pantell R, Tebb K, Shafer MA. Forgone Health Care among U.S. Adolescents: Associations between Risk Characteristics and Confidentiality Concern. *J Adolesc Heal* 2007;40(03):218–26
- 3 Gray SH, Pasternak RH, Gooding HC, et al; Society for Adolescent Health and Medicine. Recommendations for electronic health record use for delivery of adolescent health care. *J Adolesc Health* 2014;54(04):487–490
- 4 Carlson J, Goldstein R, Hoover K, Tyson N. NASPAG/SAHM statement: the 21st century cures act and adolescent confidentiality. *J Adolesc Health* 2021;68(02):426–428
- 5 Confidentiality in Adolescent Health Care. Confidentiality in adolescent health care: ACOG committee opinion, number 803. *Obstet Gynecol* 2020;135(04):e171–e177
- 6 Blythe MJ, Adelman WP, Breuner CC, et al. Standards for health information technology to ensure adolescent privacy. *Pediatrics* 2012;130(05):987–990
- 7 Huang JS, Yueh R, Ma S, Cruz R, Bauman L, Choi LJ. Adolescents' and young adults' satisfaction with and understanding of medical notes from a pediatric gastroenterology practice: a cross-sectional cohort study. *J Pediatr* 2019;215:264–266
- 8 Sharko M, Jameson R, Ancker JS, Krams L, Webber EC, Rosenbloom ST. State-by-state variability in adolescent privacy laws. *Pediatrics* 2022;149(06):e2021053458
- 9 Vukadinovich DM. Minors' rights to consent to treatment: navigating the complexity of State laws. *J Health Law* 2004;37(04):667–691
- 10 Federal Register. 21st Century Cures Act: interoperability, information blocking, and the ONC health IT Certification Program. Accessed October 1, 2022 at: <https://www.federalregister.gov/documents/2020/05/01/2020-07419/21st-century-cures-act-interoperability-information-blocking-and-the-onc-health-it-certification#h-141>
- 11 Pediatric Information Blocking Use Cases. Home. Accessed October 1, 2022 at: <https://www.aap.org/en/practice-management/health-information-technology/pediatric-information-blocking-use-cases/>
- 12 Ford CA, Bourgeois F, Buckelew SM, et al. Twenty-first century cures act final rule and adolescent health care: leadership education in adolescent health (LEAH) program experiences. *J Adolesc Health* 2021;69(06):873–877
- 13 Sharko M, Wilcox L, Hong MK, Ancker JS. Variability in adolescent portal privacy features: how the unique privacy needs of the adolescent patient create a complex decision-making process. *J Am Med Inform Assoc* 2018;25(08):1008–1017
- 14 Ip W, Yang S, Parker J, et al. Assessment of prevalence of adolescent patient portal account access by guardians. *JAMA Netw Open* 2021;4(09):e2124733–e2124733
- 15 Xie J, McPherson T, Powell A, et al. Ensuring adolescent patient portal confidentiality in the age of the cures act final rule. *J Adolesc Health* 2021;69(06):933–939
- 16 NY PHL §§ 2305, 2311, 2504, 2780(5), 2781, Ment Hygiene L § 33.21. Accessed November 26, 2022 at: <https://regs.health.ny.gov/content/section-234-minors>

- 17 Weiss Catherine B, Kwon E, Shapiro RA, et al. Teenagers health care and the law. 2018<https://www.nyclu.org/sites/default/files/thl.pdf>
- 18 Comp NY. Codes R. & Regs. Tit. 10 § 23.4, Adopted New York State Register March 18, 2016/Volume XXXVIII, Issue 20, eff.5/18/2016. <https://casetext.com/regulation/new-york-codes-rules-and-regulations/title-10-department-of-health/chapter-i-state-sanitary--code/part-23-sexually-transmissible-diseases/section-234-minors>
- 19 Miklin DJ, Vangara SS, Delamater AM, Goodman KW. Understanding of and barriers to electronic health record patient portal access in a culturally diverse pediatric population. *JMIR Med Inform* 2019;7(02):e11570
- 20 Carlson JL, Pageler N, McPherson T, Anoshiravani A. Providing online portal access to families of adolescents and young adults with diminished capacity at an academic children's hospital: a case report. *Appl Clin Inform* 2023;14(01):128–133
- 21 Xie J, Hogan A, McPherson T, Pageler N, Lee T, Carlson J. Creating a guardrail system to ensure appropriate activation of adolescent portal accounts. *Appl Clin Inform* 2023;14(02):258–262