Increasing Access to Medical Documentation for Hospitalized Children: A Qualitative Needs Assessment of Parents and Caregivers

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ABSTRACT

Background: Patients are increasingly engaged in the process of health care, including consumption of their own health data through patient portals and apps. The OpenNotes movement has also popularized the concept of making provider notes available to patients. However, the increase in patient access to their data has been largely restricted to adults in ambulatory settings. Parents/caregivers (PCs) of hospitalized children have unique needs, and their attitudes toward access to health information (HI) about those children are unknown.

Methods: Chronically ill children between 30 days and 8 years of age with respiratory or oncologic diagnoses who had at least 7 days of hospitalization within the past two years were identified and PCs were contacted by email. Participants underwent a semi-structured telephone interview on the subject of communication and access to HI in the hospital. The interviews were transcribed and coded, and major thematic concepts were identified.

Results: PCs of 13 patients (5 respiratory, 8 oncologic) agreed to participate and were interviewed. During the interviews, PCs reported that nearly all communication of HI was verbal, often delivered during times of high stress. Most participants used the patient portal to follow their child’s progress, but felt the portal was too limited. PCs universally endorsed a desire for more access to medical information while the child was in the hospital, but also cited potential downsides. PCs cited personal reference, quality assurance, consultation with outside experts, and increased sharing amongst family, friends, and social networks as uses for additional HI access. PCs wanted to read provider notes about their children, as they felt that reading clinical impressions and plans would help their understanding and engagement in the care process.

Conclusion: PCs of chronically ill children desire increased access to written materials and medical record data, especially in the high-stress inpatient setting. Expansion of portal access and inpatient OpenNotes-like initiatives may be beneficial in this population for quality assurance and patient/family satisfaction.

INTRODUCTION

Background

The process of health care delivery involves the creation of large amounts of data and information in the Electronic Health Record (EHR), especially in the hospital setting. Over recent decades it has become increasingly recognized that these data belong to patients, rather than providers, especially given that patient access to their records was enshrined in the Health Insurance Portability and Accountability Act (HIPAA) of 1996. Patients are increasingly accessing elements of their health records electronically through health portals, which provide patients with the ability to view variable amounts of their records, receive education, and communicate with providers, among other functions.[1,2] The OpenNotes (opennotes.org) movement has also led the way toward making provider notes directly and electronically accessible to patients.[3] Patients have reported that access to doctors notes improves understanding, doctor-patient relationships, and care quality,[4] though the relationship between access to health information and health outcomes has not been clearly established.[5,6] These advances in the patient access and experience have largely been realized without many of the potential downsides that were predicted, such as increased work for providers and increased anxiety among patients.[3,7,8]

However, not all patient populations have had equal opportunity to benefit from these advances. Hospitalized patients, in general, have much more limited access to their medical data during the course of hospitalizations than ambulatory patients.[9] Patient portals have been increasingly used among inpatient populations, but have been reported to have low levels of uptake by both patients and providers and often contain only a limited set of patient specific health data.[6,9,10] Access to provider notes for patients in the hospital is frequently completely absent, though there are several published studies describing generally positive experiences at individual centers.[7,11–13] Studies of ambulatory and inpatient adults have highlighted the fact that patients find increased access to medical data such as laboratory results, imaging studies, and provider notes to be beneficial.[11,13–16] Patients also report a desire to maintain the ability to access their data, even if they choose not to.[7]

Pediatric patients have also yet to fully benefit from increased access to information. Children are, by nature, most often dependent on parents and/or caregivers (PCs) for support and decision making. However, as children progress through adolescence to adulthood their independence, and therefore need for privacy and confidentiality, becomes more complex.[17] Caregiver relationships, such as separated parents and foster families, can also add complexity. For these reasons and others, health systems have been slower to adopt and promote programs that provide access to children's health data. This observation also applies to the hospitalized pediatric population, where many times PCs have no direct access to medical data for their children. However, communication is an important driver of satisfaction among PCs of seriously ill children,[18] and while PCs often receive verbal information during hospital rounds and conversations with providers, they are rarely fully engaged in the health care process with written or other materials during long periods of relative inactivity in the hospital.[19]

Some pediatric hospitals have reported introduction and evaluation of inpatient portal systems,[8,10,14,15,20] and unpublished reports of individual children's facilities that have allowed PCs to access some physician notes while in the hospital.[21] PCs have responded positively to such systems, allowing them to track test results and receive medical education, often through tablet-based interfaces during prolonged hospital stays.[16,20] However, the perceptions of PCs of hospitalized children surrounding the modalities and completeness of access to medical record information, especially related to access to and use of provider notes, are unclear.

Objective

The objective of this study was to assess parent and caregiver perceptions surrounding communication of medical information about their children while in the hospital, and to identify themes related to the need for increased access to medical data and documentation in the inpatient environment.

METHODS

Population

The study population consisted of parents or caregivers (PCs) of chronically ill, previously-hospitalized, pre-adolescent children. In order to avoid issues related to neonatal care and adolescent health and privacy,[17] only PCs of patients who were >30 days and < 8 years old at the time of the most recent hospitalization were included. PCs of patients with at least 7 days of hospitalization within the two years prior to the study were included, and PCs of patients known to be deceased were excluded. This study was limited only to PCs of patients with chronic respiratory disease[22] and/or oncologic/neoplastic conditions. These were chosen for feasibility and because they represent major proportions of the hospitalized pediatrics population both nationally[23] and at the study site. The initial study design planned for purposive sampling of at least five interview participants from each of the two disease categories.

Recruitment and Interviews

The invitation to participate in the study was sent to PCs via email, so PCs necessarily had at least one email address as a contact in the electronic health record. The email invitation described the study and invited PCs to respond to arrange a telephone interview. One email reminder was sent to non-respondents. Telephone interviews were conducted via a semi-structured interview guide, recorded, and transcribed by BO.

Data Collection and Analysis

Transcripts from PC interviews were reviewed by and were analyzed using a thematic analysis approach.[24] In essence, open coding was used to generate basic concepts using the participants' responses. These basic concepts were then iteratively refined into a set of core themes that could be used to appropriately frame the overall findings from the interviews. These core themes were applied back to the interview transcripts, identifying representative quotations that illustrate the themes. Transcripts were analyzed and coded using NVivo qualitative data analysis Software (QSR International Pty Ltd. Version 12, 2018).

After study enrollment, patient charts were reviewed and pertinent data related to demographics, hospital admissions, and diagnosis data were extracted and loaded, along with PC demographic data, into a RedCap database.[25] This research was reviewed and approved by the Oregon Health & Science University institutional review board. Each PC gave verbal, recorded consent both to participate in the audio-recorded interview process and for access by the research team to hospitalization and medical history information about his or her previously hospitalized child.

RESULTS

A total of 13 PCs were interviewed, including 5 from the chronic respiratory and 8 from the oncologic/neoplastic categories. Other characteristics of the patients are shown in **Table 1**. PC characteristics are shown in **Table 2**. All PCs interviewed in this study spoke English and were parents, in contrast to other family members or foster parents.

The interview transcript analysis revealed five major themes. These themes are detailed in **Table 3** and include: Modes of communication; Desire for increased access to information; Variation in health information use; Downsides to increased access to information; Provider Notes and Clinical Impressions. Each of the main themes is discussed in detail as follows.

Modes of Communication

Communication modes and timing can be quite variable in the hospital environment. PCs reported that they communicated with providers and staff in a variety of ways. Most prominent was direct, face-to-face verbal communication with doctors and nurses. PCs felt that, in general, the doctors were responsive and attentive, and that that they had opportunities to ask questions.

> *We found it helpful that [our doctors] were willing to answer any questions that we had and if we had questions that came up after rounds were done or something that needed a more in-depth conversation, um, we could generally speak with the nurse and the nurse would have the doctor come and talk to us, um, when things were a little bit less busy and we would be able to get all of our concerns answered. (PC #1)*

> *I did like the one on one time that the [doctor] would spend with us answering questions, um, without the rest of, without the residents or anything, like not in a group but just one on one. (PC #4)*

> *I think I did well with being able to sit down and have things explained to me. It's hard sometimes when there's a lot of medical jargon used, but most people that we spoke with were really good about kind of putting it in simpler terms or more layman terms that I could grasp a little bit easier (PC #7)*

Conversations also sometimes took place over the phone, as well as occasionally via email through the patient portal. PCs reported that nurses also provided some of the most valuable communication, often either supplementing the information from the physician teams or explaining it in terms that PCs could more easily understand.

> *I will say nurses are typically better at [putting things in simpler terms] than doctors. So a lot of times the doctor would come in and explain things and we would ask questions and stuff and then nurses could maybe translate a little bit better into human speak. (PC #7)*

> *. . . the other thing worth noting is a huge amount of communication that honestly is, has always been most valuable to us comes through the nursing staff. (PC #12)*

Other types of verbal communication included group or multidisciplinary meetings with provider teams as well as discussions with staff such as physical therapists and nutrition specialists.

Most PCs reported that they interacted with the medical teams during daily rounds, and that this opportunity worked well for them.

> *We always made sure we were there for [rounds] because it was always, we kind of felt like we got the plan for the day and we got the history of what had happened overnight and yesterday and got the plan for the day, at least the tentative plan so, me personally, I thought rounds were very helpful. (PC #2)*

> *When I could make it to the morning rounds with [my child] it was great because I got a daily dose of all the information, everything they were going to work on for her. (PC #9)*

> *I really did appreciate doing rounds in the morning . . . it was really nice to have that contact face to face with the team during rounds so that I was aware of the plan. (PC #10)*

At times, however, rounds could be intimidating to PCs due to the number of staff involved and the structured, didactic format.

> *You know at [the study hospital] as a teaching hospital, you know, as a parent of a patient it can be kind of cool but maybe a little overwhelming that the whole team of residents and med students come during rounds. Right? (PC #12)*

While PCs felt that direct verbal communication was an effective method, they also highlighted limitations and suggested other beneficial strategies. PCs reported that conversations and other verbal communications were often conducted during times of high stress, which led to decreased understanding and retention of the material. The high volume of information being communicated also could be overwhelming. Finally, PCs noted that they had trouble thinking of appropriate questions until later.

> *I think a lot of times when one of the doctors, depending on what was going on and depending on the situation a lot of time when the doctors explain things it's a little bit more high stress high emotional time, where maybe I don't think to ask some of the questions that I have or, you know, it's just there's a lot going on a lot of times when the doctors are talking, so sometimes it takes a little bit more time for me to think about the things that I wanted to ask or to come up with questions (PC #7)*

> *We go into these meetings as parents and you could have a 20-minute conversation with us and I might have gotten maybe 10 seconds worth of it and the rest of it just went over my head. Because it's just too much, you know. (PC #8)*
>
> *We received information many times in a kind of distress where, and that's because of the nature of things, hearing that your child has cancer or these different treatments are going to happen or how your child is doing. You hear this information in a time that it is, eh, that your, that my brain wasn't working that it's all emotional that the prefrontal cortex is not leading the brain and we hear that information and, and so I may never hear it again. (PC #13)*

Although some PCs were able to be present at the bedside nearly all the time, others had to leave for extended periods or had to depend on other caregivers for various reasons. This inevitably resulted in inconsistencies in how medical information was communicated and fractured connections between providers and caregivers. In addition, attempts to relay information between caregivers, such as parents caring for other children at home, could lead to omissions and misunderstandings.

> *. . . in the couple of days before she had her surgery that was when my [spouse] was up there and we were trying to decide what the best course of action would be and we had a couple of conference calls but the reception wasn't good, I was at home, trying to talk to them, but the phone was cutting in and out and, um, and I think that's why when I finally got up there why I had that last minute panic moment; because I wasn't, I didn't have, I don't think I got all of the information that I had needed beforehand because I was at home and my [spouse] is not great at relaying that information, taking what the doctor is saying and telling me. (PC #7)*

> *. . . my [spouse] did a couple nights with our son. And so that, and trying to get information from [them] is a little bit difficult (PC #10)*
>
> *. . . one of the things that [mom] and I really ran into was we were up there and not all, both of us were in the room at the same time, so one of us would have a conversation with the doctor and then the other would have a conversation with the doctor or a different doctor and we would have two totally different perspectives on what was happening or where things were going . . . (PC #11)*
>
> *I mean there's sometimes a little bit of a game of telephone, right? Um, and you know it's challenging to figure out, sometimes, if I've got one set of questions I'm really curious about, she's got another set of questions she's really curious about. How do we get those questions answered for each other? (PC #12)*

There were also concerns regarding potential limitations caused by linguistic and cultural differences between PCs and members of the treatment teams.

> *One of the things . . . that I could see affecting other people . . . that we have relationships with, is the lack of linguistic appropriate personnel . . . it wasn't only the linguistic part but also the acculturation level and the [particular] culture, we are used for the doctors to be very explicit and tell us all the things and it's not about a conversation that we're going to have and what is best for your kid, it's "I'm the doc and I'm the authority and this is what's going to happen." (PC #13)*

PCs mentioned that they sometimes received various types of non-verbal communication including printed reports, information sheets or handouts, and visual demonstrations of medical images such as x-rays and MRIs. One notable source of information cited by several participants was an extensive binder provided by the oncology department at the time of diagnosis of a malignancy. The binders detailed the treatment plan, provided information about the specific disease, profiled the treatment team, and gave PCs guidance in emergency situations. PCs who mentioned these binders found them extremely helpful.

> *. . . it may sound silly but it's a big size binder that's kind of our go-to to organize our brains . . . I can't overstate my appreciation for the binder. (PC #12)*

Similarly, other PCs who had experiences with communication via written or visual health information felt that it enhanced their experience and understanding in addition to the verbal communications that they all received.

Desire for Increased Access to Information

A major result of the interview analyses was that PCs were universally interested in having more access to information related to their child's health while they were in the hospital. As seen in the responses to two specific questions related to increased access in general and access to provider notes (**Table 4**), PCs answered in the affirmative and were generally unequivocal. Some seemed to feel as though having more access would be desirable:

> *There's been times, you know, where they've given so much information in a short period of time that I am not able to retain everything, so if I had access to that while I'm in there that would be very wonderful. (PC #5)*

Others were more emphatic that more information should be always be available:

> *I feel like as a parent, like, the most involved in his care, I feel like we have the right to everything. (PC #3)*

Nearly all (92%) of the PCs were active users of the patient portal application (Epic MyChart at the study site) (**Table 2**), both as a website and a mobile app, and many stated that they used it to review results, diagnoses, and medications, and to communicate with providers. However, multiple participants noted significant limitations with MyChart in terms of the usability of the system as well as the completeness and timeliness of the record set.

> *Yeah, and you know I think it's one thing to look in like MyChart thing, but that doesn't have all of her medical records. Like sometimes I just, I would like to see everything that's charted, everything that is discussed, I'm kind of a researcher. (PC #7)*

> *It's interesting that you have to request [medical records] though, that they're not just, like, available. You know? I mean they are, technically, but those are things you'd have to go ask for instead of just being able to pull up on MyChart. (PC #3)*

Variation in Health Information Use

PCs described a wide range of potential uses for medical information, and they also varied in the types of information they desired to access. PCs wanted to see some of the more standard aspects of the medical record, such as laboratory and pathology reports, imaging reports, medication prescriptions, and growth parameters. However, they also reported a desire to access images from radiology studies, and at least one PC mentioned wanting to view reports from multidisciplinary conferences.

Several of the participants, especially in light of the fact that their children have chronic diseases, tended to keep records of their own.

> *I always want to have the actual readouts from the scans, um, in physical copy for myself, which our doctors do for us. Um, even though, you know, I'm obviously not trained medical personnel, I can't interpret them, at*

> *least I have them for my records should I need them at some point. (PC #1)*
>
> *Yes, yeah I keep records of everything (PC #3)*

The aforementioned binders given to some of the oncology patients also included areas where PCs could track pertinent results as well as progression through treatment pathways, which was seen as beneficial.

> *[The binder] had this blank chart where, because he was getting blood tests, you know, daily at first and then weekly and monthly from there, and so there's a blank chart that you as a parent or caregiver can fill in to track your own child's blood tests that we actually like wrote in by hand for quite some time to be able to watch and track his blood counts. (PC #12)*

PCs felt that having more direct and complete access to medical information about their children would make their record keeping easier and more complete, which was already the case for some data available through the patient portal.

> *. . . actually they had all her medications on there, which was nice, because then I didn't have to keep track of them because I had them all written down and then every time they changed them I would write, I would change my list, but then I got signed up for the MyChart and I didn't have to do that, which was nice, because then they just changed it and it changed automatically. (PC #9)*

A common use that PCs mentioned for health information was to share the information with family members and other close relatives or friends. This was particularly true in certain cases when family members had special medical expertise or experience and could help with interpretation and explanation of results.

> *I mean I do have some people that, like family members and friends that are in the medical field that maybe could have helped translate things better to me, you know so I might have shared it in that regard. Like "hey, what does this mean, what is this" so I really could have grasped it. (PC #7)*

> *We also had an upper hand because my sister is an RN and did her internship up there on the hill on adult oncology . . . actually, at one point in time I did get, I went down the hill and got her records on disc and handed it over to my sister, that way she could pull it up on her computer and to be able to see, see the scans itself. So, you know, if there was a way, through a portal, to be able to access that. (PC #8)*

> *My aunts are both nurses and I wanted their opinion on it . . . so they could log in and see it and tell me what I should be asking and that kind of thing . . . it was nice because they could log in and see what [the medical team] were doing and tell me if I needed to be asking something else, if I needed to get her this, if I needed to ask the doctor "Well hey do this." (PC #9)*

However, some PCs simply wanted to be able to share accurate information about the health and progress of their child with family, either directly or through social media. PCs felt that more ready access to detailed health records could have been helpful in this regard as well.

> *We kept a blog to communicate, like . . . we kept a notes and blog where we communicate to the family, and sometimes you know we started to do the blog or tried to do the blog in very facts, and we would share our emotions and we would share the condition and what is happening with [patient name] at the health, medical level and a lot of times I'm just thinking "Am I making this up? What was the name? How do I explain*

> *this?" And so just if we will have that information it would have been easier. (PC #13)*

PCs had several other potential uses for medical information. Several PCs mentioned that they had challenges or delays related to releasing health information records to outside providers for second opinions or clinical trial participation, and direct access to those data could have expedited the process. Others mentioned that they were part of disease-specific social network groups where they would likely have used their child's information as a reference, both to ask questions and to share knowledge with others. Lastly, multiple PCs mentioned that they would have liked the ability to access images from radiology studies and procedures, as these visual records had an outsized impact compared with written reports.

> *I think just the visual cues, so just like looking at the images was really helpful cause when someone is trying to verbalize something in medical terms it's difficult to picture, so when they actually have the physical images in front of you it's easier to comprehend. (PC #4)*

> *You know, um, I think that one would have been a big one for us to be able to see the scans, have a printout, maybe, or a picture of it so that way we had something that we could look at, ok two hours later once we got something to eat "ok, let me look at it again." (PC #8)*

Downsides to Increased Access

Despite the fact that all participants desired more access to medical information, many did also cite potential "downsides" or unintended consequences to such access.

> *I don't know, I, it's hard to tell because we didn't have full access, but on the other hand it's also anxiety-provoking when you don't know. So I think*

> *having a good middle point there may be the most appropriate thing, but how do you decide what information is appropriate to share with the client or the patient that is not going to be anxiety provoking? It's going to be really hard, and especially because a lot is going to depend on who the patients are. (PC #13)*

This comment portrays how many of the PCs expressed their concerns. Most felt that their own particular situations would not be negatively affected but that others might, or that things could go poorly given the wrong circumstances.

> *Might potentially be upsetting to see something in a note that was of great significance if nobody had talked about it to them before. (PC #2)*

Multiple PCs commented that it could potentially be harmful to read medical details, especially important or meaningful details, in notes or records without having the opportunity to discuss them with the medical team. They suggested that this could lead to greater uncertainty and anxiety among PCs, and that it could lead them to make inappropriate conclusions without the benefit of medical advice.

Similarly, PCs felt that there was a chance, given increased access to notes and results, that PCs might feel an increased sense of pressure or responsibility for their child's medical care and decision making.

> *Also by having more information, I wonder, I don't know, but I wonder if we would have felt more sense of responsibility that we need to know more. (PC #13)*

The information could also foster obsessiveness among PCs, potentially making them feel responsible to make diagnoses or find new or untried treatments.

> *. . . you know, there is always that person who is going to be on WebMD and try to do the diagnose their child, you know, on their own, you know,*

> *and take that information and do 15,000 google searches and come up with the, uh, what their own deal is on that. (PC #11)*

In general, the concerns that PCs voiced regarding increased access to medical information about their children were centered around disruption of their emotional and psychological state or that of other families. In multiple interviews PCs highlighted that responses to increased access would likely vary between individuals. As an example, though the potential for increased anxiety was mentioned by a third of the participants, some had the opposite response to the stress of having a sick child in the hospital:

> *. . . it makes you a little crazy, I'll admit it. A little anxious, at least that's how I handled it. And, um, having more information calmed all that down, for me anyways, I don't know how other people handle it, but for me having information, knowing more, you know, didn't make me as scared. You know there's only so much you can do with information but it did help. (PC #9)*

Provider Notes and Clinical Impressions

Though PCs were explicitly asked for opinions related to access to doctors' or nurses' notes during the telephone interviews, several PCs also brought up the idea on their own. Several of the participants had previously been able to read physician notes, either through their own doctors' participation in OpenNotes-like programs or through medical record release requests, though none had been able to read notes about their children during hospitalizations. Several PCs stated a desire to have some written summary of daily progress and care plans, and others said they would like to have been able to read or review their providers' clinical impressions.

> *. . . I think the doctors, they tend to write up like progress notes and things like that. I think that would be helpful just to read like what they're thinking and what their plan is and, you know, there's been several occasions where there've been like mini meetings like case review meetings and things like that where they review [his] case and different people give their input. It would be nice to be privy to those notes I guess and just to be more included in his care. (PC #3)*

> *. . . just seems like sometimes we're rushed through the information that they're giving at morning report and just being able to sit back and look at the notes and go over "ok, that's what they were saying." That would be very helpful. (PC #5)*

> *. . . it would be helpful to have access to that because then you could pull [the notes] up and be like "ok so this is where the doctors are, this is what they think, this is where, um, this is you know what the conversation we've had on this stuff" so it works as a way to jog your memory and make sure you don't forget and miss stuff, you know. (PC #11)*

> *. . . we got access to the discharge plan and the discharge summary. But not having records of what are the impressions, the clinical impressions, the clinical decisions and things like that. And maybe they're kept very brief and there is not important information there, and maybe in some of the cases it would create anxiety but I think also getting a sense of what are the clinical impressions regarding the, how do you call it, the clinical impressions about how treatment, if it is working and will have been beneficial? (PC #13)*

Though PCs recognized the fact that medical documentation would likely contain large amounts of potentially inscrutable medical terminology, many PCs stated that they would find ways to overcome that barrier. Some felt that they had learned much of the terminology already, while others planned to ask questions, confer with friends or relatives, or use the internet to search.

> *After the amount of time that [name] was in treatment and all of the reading that I did when he was diagnosed and undergoing treatment I don't think that it would be that difficult for me to read the doctor's notes, um, largely because we got familiar with names, dosage, shorthand, complications, so many things about different treatments or medications or indicators during that time. (PC #1)*
>
> *I think that I was able to figure it out pretty well. I was able to track it pretty well, and for things that I didn't know I was able to look up, like using the internet exactly what a term meant or where that location was on the body, just those types of things. (PC #4)*
>
> *Some of it was, you know, just their daily rounds notes . . . that was pretty basic. Just "yeah, doing good, we need to get her eating, this, that." But you know, the more detailed ones, um, that's where my [relative] came in because of the lingo, of, kind of like when radiology reads a scan and how they perceive the imaging and their explanation can kind of, you know, really, anybody who doesn't know the medical terms can get lost real quick. (PC #8)*
>
> *I'd probably ask my [relative] or I'd look it up. I'd look up, like if there, that's what I did when I was in the hospital. If there was a medical term I didn't understand and there was no one around to ask I would google it like everybody does nowadays. (PC #9)*

Still other PCs acknowledged that they might not be able to figure out the meaning of some notes but still would like to be able to read them.

> *I would have, yeah. Uh, might not have made sense, but it would have been nice to know. (PC #8)*

When PCs were offered the possibility of reading provider notes during their child's hospitalization there was near unanimous general interest in the idea (see **Table 4**). PCs stated that the notes would likely have been helpful to gain a more complete understanding of their child's health, and that in many cases reading the notes could have helped them to ask better or more appropriate questions.

> *I would just feel more like prepared to ask questions and just feel more like I know what's going on and that I'm included in his care. (PC #3)*
>
> *. . . so that I could understand what they're seeing and if I have any questions then I would be able to ask them, you know? (PC #5)*
>
> *. . . at first we couldn't get everything straight, so if we would have had that access to you know what medications she's going to be getting, what the side effects are and so forth, and what they're looking out for that would have been very helpful cause mom and I like to do a lot of research ourselves, so. (PC #5)*
>
> *I'm a very visual, um, visual learner. If somebody is talking to me and telling me something I usually grasp the gist of it but if I'm reading things and really on my own, looking at something, I can understand it a million times better. (PC #7)*
>
> *I could have more information to communicate better with the doctors, say "I was reading this and this is the word used and does it mean this?" And they would say "yes, essentially, but" or they would say "yeah, that's what it means. So now you know." (PC #9)*
>
> *I think it might change it a little just in the aspect of potentially if I had questions [notes] might bring up questions that I didn't realize I had. If I wasn't particularly understanding something in specific, or what the plan*

> *was, I think if I was able to have [the note] in front of me it might spark some other questions related to it. (PC #10)*

PCs also noted that even though they felt that their medical providers were truthful with them, reading the full notes could possibly have revealed details that would have otherwise been withheld by the medical team because they were thought to be insignificant or potentially disturbing. Several PCs stated that they would rather know the entirety of the situation than have the information curated for them.

> *I mean, some people, you know, [they're] overwhelmed and they don't want to know too much, just enough to get by. But we want everything because that way we can help make the right decisions for her and we want to play a big role in her care as well as treatment, so, I mean, we want to be able to educate other people about it. (PC #5)*

> *I mean maybe other people want it sugar-coated but it helped me, like I said, it helped me to have the information and to have the truth. Because it doesn't help to give somebody hope when there's not hope. It doesn't help in that situation for me, it wouldn't have helped me for them to lie or, which I don't think they did, to just not give it to me straight, really." (PC #9)*

This was not universal, however, as at least one participant mentioned:

> *Sometimes denial can be healthy, and by not having, some aspects of denial can be healthy, and by not having full access there could be that aspect of denial. (PC #13)*

and another mentioned:

> *. . . sometimes it's better, you know, I work in politics, sometimes it's better not to know how the sausage gets made. (PC #12)*

PCs also felt that there were situations when being able to review notes would have allowed them to monitor for and correct errors in the medical record. None of the PCs mentioned any specific errors that they thought could have changed the overall outcome of their child's care. However, multiple PCs did mention errors or inconsistencies that they felt should have been corrected in order to have an accurate long-term medical record.

> *And again, several times the symptoms that they stated in her medical records that she was there for were incorrect about the projectile vomiting and things like that. So if I could have accessed those at the time I could have said "You know, this is not correct, this is not what I said," could have made like an addendum or something like that. (PC #4)*
>
> *. . . for instance there was times when, um, some information said during rounds wasn't entirely accurate to my knowledge. You know, so I was able to kind of correct that and like if something like that were to be placed in her medical file I mean I would be able to be like "Wait a minute, am I missing something or is this something that just got kind of put in there by accident or is it something I'm missing in her history?" (PC #6)*
>
> *I read through all of it and it was interesting because I did notice that some things that were in there, like, had never really been discussed with me and some things that I remember happening weren't in there so it seems a little bit incomplete to me, but I know part of that is just, you know, the nature of human error and human documentation, and things happen, and things get left out it's not always in there. (PC #7)*

An additional finding during the interviews was that PCs were, in many cases, unaware of their rights to access to their children's medical records and the processes to request that access. Several PCs mentioned HIPAA as a reason that medical information could *not* be released to them more easily, and several PCs reported that they were not aware of the ability to request records in a format of their choosing.

> *It's been difficult for them to get all the information that they needed from their original primary hospital to present to another oncologist . . . but, again, that may not be a possibility because of HIPAA. (PC #1)*
>
> *I mean I'm sure physicians notes are usually private for a reason. (PC #3)*
>
> *I don't know, I know there's a lot of concerns with HIPAA and things like that with making different medical records available but it seems like, it just seems like it should be a little bit easier to get at information as somebody that is allowed to have that information. (PC #7)*
>
> *. . . since so many things are digital now I just think well "how hard would it be, cause everything's computer charting," and I don't know anything about information technology, but I feel like it should be easier to put in a request and gain, like, electronic access to those records where I wouldn't have to have a paper copy unless I wanted it for some reason. But then I also, health record protection, information, protection of those records if they were electronically distributed I don't know what kind of security risks or security measures you'd have to take for gaining electronic access to a copy, but, for me I felt like an electronic copy would be much, easier for me. (PC #10)*

PCs generally mentioned that the process for requesting medical records, even for those who successfully did it, seemed more difficult than necessary.

> *It's interesting that you have to request them though, that they're not just, like, available. You know? I mean they are, technically, but those are things you'd have to go ask for instead of just being able to pull up on MyChart. (PC #3)*

> *I had to request [the medical records] way after the fact because I was curious what they said because there were a couple of things that happened that I wanted to kind of see about and cause stuff there kind of led to why we ended up where we ended up. But um, so I got those way, like months after the fact and I had to request them in writing and then they had to evaluate it and send it to me and that just seems like something that should be more readily available to parents and caregivers and, you know. (PC # 7)*

> *I did know that you can access it. Um, I was going to access some stuff one time and, I'm trying to remember, I think it felt like it was just kind of too much of a hassle, like I couldn't do it over the phone easily and I wasn't sure how much it was going to cost, and so I ended up just waiting until the next time that we went to the hospital . . . it just, I didn't feel like it was something that would be possible to access without actually going to the medical records department. It felt very cumbersome, the process felt very cumbersome to me. (PC #10)*

DISCUSSION

This study used qualitative analysis of telephone interviews with 13 PCs of chronically ill children to evaluate their experiences with communication of medical information and the need for expansion of direct access to medical data in the hospital. Through a thematic analysis approach, multiple themes were identified that seemed to apply broadly to the participants responses. There was near unanimous support from PCs for increased access to their children's medical records while in the hospital, including provider notes. Most PCs already used the patient portal, but felt it could be improved and expanded. PCs appreciated the verbal communications they received, but would prefer to have more written materials to use for reference in addition. Reasons and potential uses for increased information access varied widely and included personal interest, reference, research, sharing with family and social media, checking for errors, and obtaining second opinions. PCs identified miscommunications and anxiety as potential "downsides" of increased access to health information, but this did not prevent PCs from wanting the information. Interest in access to provider documentation, including progress notes, was a significant finding during the interviews. PCs anticipated that they would have more complete understanding of their children's health and progress and would be able to ask more informed questions after accessing notes. They also felt that provider notes would be a useful form of reference for record-keeping and consultation with others. Of note, many PCs were not fully aware of their rights to health record access and felt that the processes around that access were difficult to navigate.

These results are consistent with the findings of Kaziunas et al,[16] who studied unmet informational needs among a population of PCs caring for children after bone marrow transplant and identified the need for better access, especially to information related to lab tests and medications. Multiple other studies have examined the perceptions and potential effects of inpatient portal implementations. Though they generally agree with the results of this study, they also highlight issues related to uptake and usability of portals that are not addressed adequately here. Nonetheless, the conclusion that PCs generally desire and appreciate more access to medical information in the hospital is consistent across studies.

This study also highlights the interest among PCs in the relatively untested area of accessing provider documentation, such as progress notes, in the inpatient setting. Abundant data from the outpatient setting support the practice, but data are more limited in the inpatient setting. Studies to date suggest that adult patients are very interested in reading notes about themselves, that these patients may have multiple potential uses for the notes, and that adults are resourceful in facilitating their own comprehension of the content of notes.[7,11,12] These reports are all consistent with the results in this study, though this population of PCs of children has not previously been investigated. The interviews from this study also highlighted the perception among PCs that even if they wanted to access more records and notes about their children, legal and bureaucratic barriers would pose significant challenges in the process.

It is important to consider the potential negative implications of changing the way that PCs interact with information about their children while in the hospital. PCs identified multiple potential "downsides" to increased access to information, typically surrounding increased anxiety in general and situations in which information might be released before appropriate clinical counseling can be provided. Comprehension of clinical concepts and data by PCs is also important to consider. Though many of the participants felt that they could make sense of the data, some indicated the potential to "get lost real quick" among dense medical information. Linguistic and cultural issues were also mentioned by PCs as potential barriers to successful transfer of knowledge between providers and patients or families. These factors, including whether providers might change their habits in response to having patients and caregivers as a new audience for clinical notes,[26,27] should be considered in future studies.

There are several significant limitations to this study which generally arise from the limited size of the sample and the specific study population. In order to limit the impact of issues related to adolescent medicine and its associated ethical and legal challenges,[17] this study was limited to children under 8 years of age, and therefore the findings do not necessarily apply to older children. Similarly, the children in this study had chronic respiratory or oncologic conditions, and the opinions of PCs caring for those populations may not be generalizable to PCs of all hospitalized children. The study only involved PCs of children cared for at a single institution. Finally, this study did not evaluate the perceptions of clinical care providers. These limitations suggest a need for further validation of these results among a broader cohort.

CONCLUSIONS

This study used qualitative methodologies to identify five major themes related to communication of health information and attitudes toward increased access thereto among PCs of hospitalized children. PCs identified various valuable methods of communication of health information in the hospital, but indicated a need for more written reference material. They felt strongly that information access should be increased, and were interested in the opportunity to read provider notes and clinical summaries while their children were in the hospital. Many different potential use-cases for increased access were highlighted by participants including personal record keeping, sharing information among social networks, outside providers, and family members. Though potential negative impacts to increased access were noted, participants felt that, in general, they were outweighed by potential benefits. PCs desired to read provider notes about their children while in the hospital, and felt doing so would improve their understanding and engagement in the care process. These results suggest that, as in the ambulatory setting, inpatients and their surrogates desire and may benefit from increased access to health data and documentation while in the hospital including the ability to read notes and other documentation. Future pilot trials of increased patient portal access and OpenNotes-like documentation access for PCs of hospitalized children should address social, legal, and technical challenges to implementation, PC and clinician reactions and satisfaction, and potential impacts on health outcomes.

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TABLES

Table 1: Patient Characteristics

Disease Category (n)	**All (13)**	**Chronic Respiratory (5)**	**Oncologic/Neoplastic (8)**
Mean Age (months)	**33**	**23**	**40**
No. Female (%)	**9 (69)**	**5 (100)**	**4 (50)**
No. Admissions (range)	**6.7 (1-19)**	**2.2 (1-3)**	**9.5 (2-19)**
No. of Hospital Days (range)	**62 (10-128)**	**52 (11-125)**	**69 (10-128)**

Table 2: Parent/Caregiver Characteristics

	Parents Caregivers (n=13)
Mean Age in Years (range)*	**38 (28-52)**
No. Female (%)	**8 (62)**
No. with MyChart Account (%)	**12 (92)**
No. Accessed MyChart in Past Year (%)	**12 (92)**

* unable to obtain age data from 1 PC

Table 3: Main Themes and Descriptions

Theme	Description
Modes of communication	PCs cited and appreciated the frequent and varied forms of verbal communication (rounds, one-on-one, care conferences, etc.). Written and visual communication was highly valued (Oncology binders, imaging) when available, but was less often provided.
Desire for increased access to information	A desire for more access to health information, of various types, for their children was uniformly endorsed. Most PCs also said they would like to read provider notes from the hospital.
Variation in health information use	PCs described a wide variety of potential uses for health information including personal reference, disease tracking, quality assurance, expert consultation, and sharing within family/social networks.
Downsides to increased access to information	PCs identified potential downsides to unfettered access to medical information in the hospital including increased anxiety, confusion, obsessiveness, or excessive sense of responsibility.
Provider Notes and Clinical Impressions	PCs valued the ability to read provider notes, especially clinical impressions, summaries, and plans. Felt it could improve understanding and guide questions. PCs were resourceful in getting help to understand notes.

Table 4: Specific Responses to Questions about Increased Access

<table>
<tr><td colspan="3">Question 1: Would you have been interested in being able to directly access more information from the medical record about [child's name] while they are admitted to the hospital?</td></tr>
<tr><td colspan="3">Question 2: Would you have been interested in being able to read the notes by doctors or nurses while [child's name] was in the hospital?</td></tr>
<tr><th>Participant</th><th>Question 1 Response</th><th>Question 2 Response</th></tr>
<tr><td>1</td><td>“Absolutely, yes”</td><td>“Um, I think so.”</td></tr>
<tr><td>2</td><td>“Yes”</td><td>“Yes”</td></tr>
<tr><td>3</td><td>“Um. I don’t know”</td><td>“I think that would be helpful just to read like what they’re thinking and what their plan is.”</td></tr>
<tr><td>4</td><td>“Absolutely, yes.”</td><td>“Ohhh, yes. Absolutely.”</td></tr>
<tr><td>5</td><td>“That would be, yeah that would be very helpful.”</td><td>“Yeah. I would definitely”</td></tr>
<tr><td>6</td><td>“I do think that would have been more beneficial.”</td><td>“I think I would be interested in being able to read those”</td></tr>
<tr><td>7</td><td>“Mm hmm. Yeah.”</td><td>*</td></tr>
<tr><td>8</td><td>“Uh, my wife is saying yes.”</td><td>“I would have, yeah”</td></tr>
<tr><td>9</td><td>“I definitely would have.”</td><td>“Yeah. Yes”</td></tr>
<tr><td>10</td><td>“I, I would love that.”</td><td>“I personally would love it”</td></tr>
<tr><td>11</td><td>“Yes.”</td><td>“Right and yes, because, yes”</td></tr>
<tr><td>12</td><td>“Yeah I mean, sure, would I have been fascinated and interested in that, yes.”</td><td>*</td></tr>
<tr><td>13</td><td>“yes. Yeah”</td><td>“Yes”</td></tr>
</table>

* no response available for that specific question from the participant.

APPENDIX

Interview Guide

Telephone Interview Questionnaire:
Hello [Insert name of subject here], my name is Ben Orwoll. I am a pediatrician and researcher at OHSU. I appreciate your interest and willingness to participate in our study. The purpose of this telephone interview is to learn from your opinions and experiences while caring for a child in the hospital. We hope to use what we learn from you and others to improve the ways in which we share medical information with parents and caregivers in the hospital.

I just want to quickly remind you that we are audio recording this telephone survey, and so before we begin I would like to ask you to confirm your consent to participate.

Ok, great. Thank you.

As part of this project, we also request that you allow us to access and collect information from your child's medical record such as diagnoses and past hospitalizations. Our records show your child's name is [insert child patient name here]. Can you please describe your relationship to [Child first name] as well as [his/her] date of birth?

Do you have any questions about the data we are asking to collect? (answer questions)

Do you consent to the collection of medical data about [child's name]?

Thank you very much.

During the interview you do not have to answer any question that you do not feel comfortable answering. This interview should take between 15-30 minutes to complete. Any personally identifiable information that you provide as part of this interview will be kept private and will not be included in any future publication.

Do you have any other questions?

Thank you. We will now begin the structured interview portion of the survey:

1. I'd like to start by asking you to describe some of the ways that you received information about your [child name]'s health while [he/she] was in the hospital.

2. What were some of the things about how you received medical information that worked well for you?

3. What were some challenges you or other people caring for [child's name] faced in terms of understanding what was going on with [his/her] health in the hospital?

4. Do you have any thoughts on ways that providers in the hospital could improve how information is shared with families and caregivers? What suggestions do you have?

5. Would you have been interested in being able to directly access more information from the medical record about [child's name] while they are admitted to the hospital?
   - if so, what kinds of information would you have liked to access?
     - how would having this type of access been helpful?
     - are you the only one who would have used the information or would you have shared it with others?
   - (if not brought up by participant) Would you have been interested in being able to read the notes by doctors or nurses while [child's name] was in the hospital?

6. Are you aware of the OpenNotes movement or have you ever had the opportunity to read your own or [child's name]'s doctor's notes?
   - if yes, can you tell me about your experiences?

7. Do you or [child's name]'s other caregivers use the MyChart website or app to access information about [child's name]'s health?
   - if yes, what do you use it for? How could it be improved?
   - if no, were you aware of this service? What has kept you from using it?

8. Do you have any other thoughts or comments that you would like to add related to any of these topics?

Thank you very much for participating in this study. We will be continuing to collect and organize the responses from you and other participating fellows over the coming months. If you have additional questions, concerns, or would like to withdraw your consent to participate in this study at any time, please contact the study investigators. Our contact information can be found in the email invitation to the online survey or on the information sheet that was included with the study invitation.

Patient Identification Database Query (Oracle SQL)

```
/* this query will be designed to identify a cohort of patients who might participate in
a needs assessment for inpatient documentation access

The criteria to be used for eligibility will be as follows:
1. Caregiver is >18 years of age.

    (caregiver is eligible if the patient meets the following criteria):
    1.  Age of patient currently: <18 years
    2.  Age of patient at the time of most recent hospital admission at DCH: >30 days and
<8 years
    3.  At least one hospitalization of  7 days within the two years prior to the study
    4.  One or more of the following:
      a.       An encounter diagnosis or problem list entry for any Neoplasm (ICD-10
codes C00-D49)
      b.       An encounter diagnosis or problem list entry in the following ICD-10 Codes
for chronic pulmonary disease (10): I27.8, I27.9, J40.x-J47.x, J60.x-J67.x, J68.4, P27.x,
J68.4, J70.1, J70.3
      c.       An encounter diagnosis or problem list entry for presence of a
tracheostomy (ICD-10 code Z93.0) or an active LDA (line-drain-airway) entry for
tracheostomy
      d.       An encounter diagnosis or problem list entry for dependence on
supplemental oxygen (ICD-10 code Z99.81) or a ventilator (ICD-10 code Z99.1x)
    5.  An email address for the caregiver is available in the clinical demographic
information

Data collected during screening in the event of a screen failure will be destroyed
immediately, and none of those data will be exported from the clinical database.

Inclusion criteria will be as above, but in the event that insufficient subjects are
enrolled, criteria #3 will be adjusted to:  At least one hospitalization of  5 days
within the past 2 years.

Author: Ben Orwoll, MD
email: orwollb@ohsu.edu
Date: Winter, 2018

Update History:
20180212 - initial query
20180221 - updates to include more patient information, list of patients after IRB
approval
20180912 - updated criteria to include 24 months per new IRB and also to make sure that
all admissions are included in hosp-days count and age at last admit criteria
 */


WITH

  encounters
AS
  (SELECT pat.PAT_ID
  , pat.PAT_MRN_ID
  , pat.PAT_NAME
  , sex.NAME AS patient_sex
  , pat.GUARDIAN_NAME
  , status.NAME AS vital_status
  , CASE
      WHEN pat.EMAIL_ADDRESS IS NULL
        THEN 0
      ELSE 1
    END AS email_yn
  , pat.EMAIL_ADDRESS
  , hsp.PAT_ENC_CSN_ID
  , trunc((hsp.HOSP_ADMSN_TIME - pat.BIRTH_DATE)/365.25 * 12) AS age_at_admit_months
  , hsp.HOSP_ADMSN_TIME
  , trunc((HSP.HOSP_DISCH_TIME - hsp.HOSP_ADMSN_TIME) + 1, 0) AS HOSP_LOS -- rounding up
to nearest day
  FROM PAT_ENC_HSP HSP
  LEFT OUTER JOIN PATIENT pat
    ON pat.PAT_ID = hsp.PAT_ID
```

```
  LEFT OUTER JOIN ZC_SEX sex
    ON sex.RCPT_MEM_SEX_C = pat.SEX_C
  LEFT OUTER JOIN ZC_PATIENT_STATUS status
    ON status.PATIENT_STATUS_C = pat.PAT_STATUS_C
  WHERE rownum < 10000
    -- age at admission less than 8 years
    AND (hsp.HOSP_ADMSN_TIME - pat.BIRTH_DATE)/365.25 < 8
    -- age at admission > 30 days
    AND (hsp.HOSP_ADMSN_TIME - pat.BIRTH_DATE) > 30
    -- hospital LOS >= 7 days
    AND (HSP.HOSP_DISCH_TIME - hsp.HOSP_ADMSN_TIME) >= 7
    AND HSP.HOSP_ADMSN_TIME BETWEEN add_months(to_date('2018-09-01', 'YYYY-MM-DD'), -24)
AND to_date('2018-09-01', 'YYYY-MM-DD')
  ),

  hosp_info -- takes the patient IDs and links them back to all the hospital encounters
starting within the past 2 years
AS
  (SELECT distinct e.PAT_ID
  , COUNT(DISTINCT hsp.PAT_ENC_CSN_ID) AS no_hosp
  , SUM(trunc((HSP.HOSP_DISCH_TIME - hsp.HOSP_ADMSN_TIME) + 1, 0)) AS hosp_days --
rounding up to the nearest number of hospital days
  FROM encounters e
  INNER JOIN CLARITY.PAT_ENC_HSP hsp
      on hsp.PAT_ID = e.PAT_ID
  WHERE HSP.HOSP_ADMSN_TIME BETWEEN add_months(to_date('2018-09-01', 'YYYY-MM-DD'), -24)
AND to_date('2018-09-01', 'YYYY-MM-DD')
    AND hsp.adt_patient_stat_c IN (2, 3) -- only hospital encounters of status type
"admission" or "discharged" (no preadmits, leave of absence, or hospital outpatient
encounter)
    AND hsp.adt_pat_class_c = '1'
  GROUP BY e.PAT_ENC_CSN_ID, e.PAT_ID --, PAT_NAME, PAT_MRN_ID
  ),

  medhx
AS
  (SELECT DISTINCT hx.PAT_ID
     ,edg.CURRENT_ICD10_LIST
  FROM MEDICAL_HX hx
  INNER JOIN CLARITY_EDG edg
    ON edg.dx_id = hx.dx_id
  WHERE hx.pat_id IN (select pat_id from encounters)
  ),

  prob_list
AS
  (SELECT DISTINCT p.PAT_ID
    , EDG.CURRENT_ICD10_LIST
  FROM PROBLEM_LIST p
  LEFT OUTER JOIN CLARITY_EDG EDG
    ON EDG.DX_ID = p.DX_ID
  WHERE p.PAT_ID IN (SELECT PAT_ID FROM encounters)
  ),

  enc_dx
AS
  (SELECT DISTINCT e.PAT_ID
  , edg.CURRENT_ICD10_LIST
  FROM PAT_ENC_DX e
  LEFT OUTER JOIN CLARITY_EDG edg
    ON edg.DX_ID = e.DX_ID
  WHERE e.PAT_ENC_CSN_ID IN (SELECT PAT_ENC_CSN_ID FROM encounters)
  ),

  hsp_dx
AS
  (SELECT distinct enc.PAT_ID
    , edg.CURRENT_ICD10_LIST
  FROM HSP_ACCT_DX_LIST h
  LEFT OUTER JOIN CLARITY_EDG edg
    ON edg.DX_ID = h.DX_ID
```

```
  LEFT OUTER JOIN PAT_ENC_HSP enc
    ON enc.HSP_ACCOUNT_ID = h.HSP_ACCOUNT_ID
  WHERE enc.PAT_ENC_CSN_ID IN (SELECT PAT_ENC_CSN_ID FROM encounters)
  ),

  all_dx
AS
  (SELECT * FROM medhx
  UNION
  SELECT * FROM prob_list
  UNION
  SELECT * FROM enc_dx
  UNION
  SELECT * FROM hsp_dx
  ),

  lda -- checking for trach history
AS
   (SELECT DISTINCT enc.PAT_ID
--    , enc.PAT_ENC_CSN_ID
--    , lda.PLACEMENT_INSTANT as placement_datetime
--    , lda.REMOVAL_DTTM as removal_datetime
   --, lda.FLO_MEAS_ID
   --, lda.FSD_ID
--    , lines.NAME as lda_type
--    , lda.DESCRIPTION as description
   FROM IP_LDA_NOADDSINGLE lda
   INNER JOIN encounters enc
     ON enc.PAT_ID = lda.PAT_ID
   LEFT OUTER JOIN IP_FLO_LDA_TYPES types
     ON types.ID = lda.FLO_MEAS_ID
   LEFT OUTER JOIN zc_lines_group lines
     ON lines.LINES_GROUP_C = types.LDA_TYPE_OT_C

   WHERE (lda.REMOVAL_DTTM >= enc.HOSP_ADMSN_TIME
        OR lda.REMOVAL_DTTM IS NULL
        )
        AND lines.NAME IN ('Surgical Airway') -- tracheostomy
   ),

  eligible_patients_dx
  -- this table uses regular expressions to identify the varous ICD-10 codes that
represent the diagnoses of interest
AS
  (SELECT DISTINCT PAT_ID
   FROM all_dx
   WHERE
     (
       -- cancer diagnoses
       regexp_like(CURRENT_ICD10_LIST, '(^|\s)C') -- allows start of line or space then
Cxx
       OR REGEXP_LIKE(CURRENT_ICD10_LIST, '(^|\s)D(0|1|2|3|4)') --allows start of line or
space then D00-D49.xx
       -- chronic resp diseases
       OR regexp_like(CURRENT_ICD10_LIST, '(^|\s)I27.(8|9)$')
       OR regexp_like(CURRENT_ICD10_LIST, '(^|\s)J4(1|2|3|4|5|6|7)')
       OR regexp_like(CURRENT_ICD10_LIST, '(^|\s)J6(1|2|3|4|5|6|7)')
       OR regexp_like(CURRENT_ICD10_LIST, '(^|\s)J68.4$')
       OR regexp_like(CURRENT_ICD10_LIST, '(^|\s)P27.')
       OR regexp_like(CURRENT_ICD10_LIST, '(^|\s)J70.(1|3)$')
       OR regexp_like(CURRENT_ICD10_LIST, '(^|\s)Z93.0$')
       OR regexp_like(CURRENT_ICD10_LIST, '(^|\s)Z99.(81$|1)')
     )
  ),

  mychart_info
AS
  (SELECT MYPT_ID
  , myc.PAT_ID
  , myc.LAST_ACCESS_TIME
  , prxy.PROXY_PAT_ID
```

```
  , prxy.PROXY_LST_ACSS_DT
  , pat.PAT_NAME
  , pat.EMAIL_ADDRESS
  FROM MYC_PATIENT myc
  LEFT OUTER JOIN PAT_MYC_PRXY_ACSS prxy
    ON prxy.PAT_ID = myc.PAT_ID
  LEFT OUTER JOIN patient pat
    ON pat.PAT_ID = prxy.PROXY_PAT_ID
  WHERE myc.PAT_ID IN (SELECT * FROM eligible_patients_dx
              UNION
              SELECT DISTINCT PAT_ID FROM lda
      )
  ),

  eligible_pat_info_1
AS
  (SELECT DISTINCT e.PAT_ID
  , e.EMAIL_ADDRESS AS email
  , NULL AS disease_cat
    -- insert other blank fields here if needed
  , e.PAT_NAME AS patient_name
  , e.PAT_MRN_ID AS patient_mrn
  , e.patient_sex
  , max(e.age_at_admit_months) AS age_at_admit_months
  , NULL AS no_hosp
  , NULL AS hosp_days
--   , CASE
--       WHEN myc.pat_id IS NOT NULL
--         THEN 1
--       ELSE 0
--     END AS mychart_yesno
  , NULL AS mychart_accessed_yesno
--   , dx.CURRENT_ICD10_LIST
--   , CASE
--       WHEN lda.PAT_ID IS NULL
--         THEN 0
--       ELSE 1
--     END AS trach
  FROM encounters e
  INNER JOIN (SELECT * FROM eligible_patients_dx
              UNION
              SELECT DISTINCT PAT_ID FROM lda
      ) pats
    ON e.PAT_ID = pats.PAT_ID
--   LEFT OUTER JOIN mychart_info myc
--     ON myc.pat_id = e.pat_id
  WHERE e.vital_status = 'Alive' -- make sure that the patient is still alive
  GROUP BY e.pat_id, e.email_address, e.pat_name, e.pat_mrn_id, e.patient_sex
  ),

  eligible_pat_info_2 -- this patient info table adds in emails from the proxy's mychart
account if there was no email in the patient's file, and also pulls in information about
whether there is a mychart account and whether it has been accessed by the proxy (no
patients accessed their own mychart accounts, of course). It also adds in the hospital
information
AS
  (SELECT e.PAT_ID
  , CASE
      WHEN e.email IS NOT NULL
        THEN e.email
      ELSE myc.EMAIL_ADDRESS
    END AS email
  , e.disease_cat
  , e.patient_name
  , e.patient_mrn
  , e.patient_sex
  , e.age_at_admit_months
  , hosp.no_hosp
  , hosp.hosp_days
  , CASE
      WHEN myc.pat_id IS NOT NULL
```

```
        THEN 1
      ELSE 0
    END AS mychart_yesno
  -- checking whether the parent/caregiver had accessed the mychart within the past 12
months
  , CASE
      WHEN myc.PROXY_LST_ACSS_DT BETWEEN add_months(to_date('2018-09-01', 'YYYY-MM-DD'),
-12) AND to_date('2018-09-01', 'YYYY-MM-DD')
        THEN 1
      ELSE 0
    END AS mychart_accesssed_yesno
--    , myc.PAT_ID AS mycpat_id
--    , myc.PROXY_LST_ACSS_DT
  FROM eligible_pat_info_1 e
  LEFT OUTER JOIN mychart_info myc
    ON myc.PAT_ID = e.PAT_ID
  LEFT OUTER JOIN hosp_info hosp
    ON hosp.pat_id = e.pat_id
  WHERE e.age_at_admit_months <= 96 -- make sure that the max age at admit was 8 years
old or less
  )

SELECT pat_id
  , email
  , disease_cat
  , patient_name
  , patient_mrn
  , patient_sex
  , age_at_admit_months
  , no_hosp
  , hosp_days
  , mychart_yesno
  , max(mychart_accesssed_yesno) AS mychart_accesssed_yesno
FROM eligible_pat_info_2
GROUP BY pat_id
  , email
  , disease_cat
  , patient_name
  , patient_mrn
  , patient_sex
  , age_at_admit_months
  , no_hosp
  , hosp_days
  , mychart_yesno
```