

Seattle Children's to Establish Pediatric Health Information Exchange

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If you are a parent, the most important thing to you is the health of your child. I know this having children ranging in ages from 2 to 27 (yes, I'm a sucker for punishment). The most critical element in the care of your child, besides excellent clinical professionals, is information. For the longest time we, as parents, have searched the internet until we're blue in the face, scouring symptoms and potential cures for what ails our children. But there's always been one source of information that's not only been locked away from us, but also hard for providers to access in a timely manner. That's the data

contained in your child's medical record; be it at your child's general pediatric practice or at a specialist's office like Seattle Children's. This is about to change.

The Leadership and Board at Seattle Children's recognized this problem and decided to do something about it. We're in the beginning stages of setting up a pediatric health information exchange.

While you may be familiar with health information exchanges (HIE), this pediatric HIE (pHIE) will be one of the first of its kind to address the unique needs of children's health care. For example, many HIEs simply cut out the 13-18 year old population because of privacy issues related to the age of consent and other issues with certain data being viewable or not viewable by parents. In addition, there are other pediatric specific information needs, such as immunization history and coordinating care for children with special needs in schools. We're going to work through these issues and get this information to our patients and families. Children's, as the pre-eminent provider of pediatric specialty services in the Northwest, also faces the challenge

of distributing information over a wide geographic service area that includes Washington, Alaska, Montana, and Idaho. We intend to implement the HIE initially in the Puget Sound region and will expand from there.

Most HIEs focus on getting data to and from the care provider. This is essential in the care of our patients. Imagine, if your child were in the ED at Seattle Children's and he/she had a significant medication allergy documented in the pediatrician's office record. You would, of course, want the ED provider to be able to know about this allergy. Our HIE – the Pediatric Health Information Network (PHIN-like on the fish) will allow the provider to see those records. And, if you're the general pediatric provider that had one of your patients go to the Seattle Children's ED, you would want to know about that visit and all that happened during that visit. We can do that with the PHIN. Essentially, we're going to be leveraging the PHIN to eliminate those "blind spots" in the electronic medical record that exist today. That's what HIEs are supposed to do and that's what ours will do – unique for the population that most HIEs cut out.

But, that's not all (sounds like a late night infomercial)! What if the HIE wasn't just for eliminating the blind spots for the providers? What if the patient and family had access to pretty much the same HIE that the providers had access to, from a single trusted source? We could eliminate the "blind spots" for the patient and family as well. That way, if you had a child that went to a general pediatrician, then a specialist, then into surgery, then to homecare, then to home you could see your child's medical records across that whole continuum of care. No more "blind spots" in the medical information about your child.

It used to make providers a bit

nervous showing the patient and family their medical records. However recent studies, participated in by Seattle's Harborview Medical Center, show that it simply makes for better provider/patient communications and helps the patient feel more in control of their health (Bing: Ann Intern Med. 2012;157(7):461-470. doi:10.7326/0003-4819-157-7-201210020-00002). We think the PHIN will do the same.

Wait, there's more (to carry the theme)! What if you as the parent or the patient could actually enter data into your PHIN record? Imagine being able to comment on a note a provider wrote in the medical

record, being able to point out that your child was no longer taking a medication that's annotated in his/her record. Or, simply being able to email a provider, or perhaps chat on line....this is what we want the PHIN to do.

It's a bold vision but one that is within our grasp. It will take some time and we're just starting our first "baby" steps of this journey, but we really think this will open up a whole new world of transparency with the provider and patient. This will bring better information that will lead to better care for all our children.

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