



CHILD Registry Request for Proposal

Frequently Asked Questions

May 3, 2023

How does the AAP plan to get patient consent across variable participant consent policies?

Under the HIPAA Privacy Rule, the CHILD Registry is considered a Quality Improvement Activity. It allows permission to disclose protected health information in this capacity.

However, registry participants will be expected to follow their local Notice of Privacy Practices and it is included in standard legal agreements to participate in the registry.

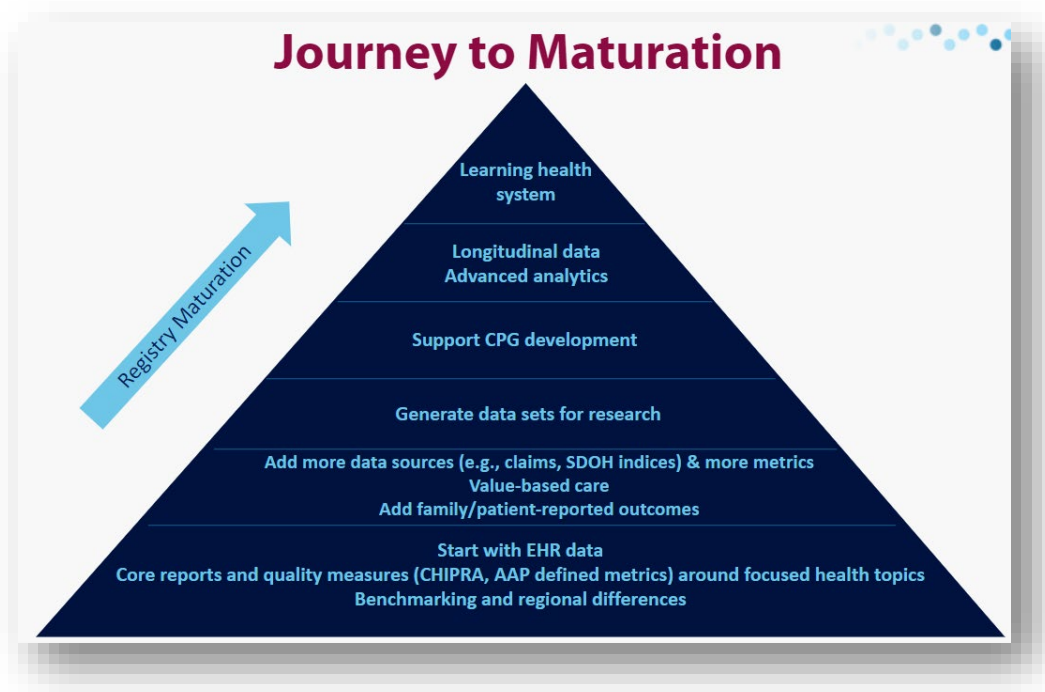
Can more information be provided regarding the CHILD Registry's intellectual property and the vendor's intellectual property?

AAP is the owner of all rights to the CHILD Registry, including the data, metrics/measures, algorithms, modeling, etc. The vendor would maintain their technical intellectual property on pre-existing products and services.

What is the prioritization of use cases and data sources for the registry?

Initially, the registry will mainly be used to support quality improvement projects and benchmarking performance at a local, regional, and national level.

EHR data will be the priority, followed by additional data sources as additional metrics and measures are defined (e.g., claims, public data sets (SDOH), patient-reported outcomes, etc.).



When does the AAP want the registry to go live?

AAP would like to pilot the registry from 2024-2025; soft go-live for the pilot program would be expected during this timeframe. AAP will launch the registry to all interested and approved participants in early 2026; final go-live would be expected then.

Are the short, medium, and long-term objectives expected to be deployed within the 5-year agreement or extended beyond the contract duration provided in the RFP?

The development of the registry’s objectives is expected beyond a 5-year timeframe, with most of the short and medium-term goals around data acquisition, including additional data sets outside of the EHR, benchmarking, quality improvement, and value-based care.

Can AAP provide a desired data model or details about the specific longitudinal data to be collected?

We are currently defining a core data set, using USCDI data classes and data elements as a baseline, and are identifying additional data elements commonly captured in pediatrics. We desire a FHIR data model to align with national interoperability efforts.

Will any data need to be migrated to the new platform?

No.



Can AAP provide clarification on the following requirements?

“The solution must distinguish between publicly available fields, restricted use fields, and private fields. The solution should distinguish between publicly available fields, restricted use fields, and private fields based on metadata configuration.”

These requirements refer to EHR fields. Some pediatric-specific EHRs have metadata around each field that determines the privacy setting for that field, e.g., genetic information. The need to compartmentalize certain information to only certain providers should be reflected in the CHILD Registry, if it is present in the EHR.

Has the AAP developed or identified specific patient-reported outcome measures?

No, the AAP has not yet developed patient-reported outcome measures. As noted in the Registry Maturation Model, this is not in the initial phase of the registry. We are seeking a vendor that has capabilities and experience in this.

How many measures, metrics, and indicators are tested and ready for deployment in the registry? How many are in the pipeline or not yet tested?

The CHILD Registry has identified measures from the CHIPRA core set that will be incorporated into the initial version of the registry. Additional registry metrics will be in alignment with AAP clinical guidance. We anticipate this will also be included in the initial version of the CHILD Registry.