Interoperability case study

National Children's Digital Health Collaborative

Overview

A child's health begins with the mother's health before conception, throughout pregnancy, and right up until birth. The importance and lifelong benefits for a child of capturing clinical information to support their care cannot be overstated. However, there are challenges associated with capturing relevant clinical and non-clinical information using current methods and systems, including lack of digitisation, efficiency issues, lack of longitudinal records and consumer experience issues.

In order to address some of these pressing challenges and issues with the current processes, the Australian Digital Health Agency partnered with eHealth NSW and the Sydney Children's Hospitals Network to establish the National Children's Digital Health Collaborative (the Collaborative), a national program which involves all jurisdictions.

The Collaborative started in 2017, when over 330 stakeholders participated in a series of national workshops to identify how digital technology could have a positive impact on Australian children and young people's health.

This consultation identified an opportunity for the parents of every child in Australia to have a comprehensive digital health record from the time they are conceived, through their critical first years and adolescence. This record was designed to be readily accessible by parents, healthcare providers and ultimately the individual throughout their life.

Progressing interoperability

A top priority for the Collaborative was to ensure this initiative was designed in line with the National Digital Health Strategy's key focus of progressing interoperability across the Australian healthcare system. Key components that have bolstered the interoperable capabilities of the record are:

- Solution infrastructure that supports the use of Fast Healthcare Interoperability Resources (FHIR) resources, leveraging the national terminology standards (SNOMED CT-AU), and the existing national terminology and FHIR validation server (OntoServer).
- Clinically relevant, reusable FHIR profiles that can be leveraged and refined by the broader Australian community.
- The ability for consumers to interact with their healthcare information through a user-friendly mobile application and for clinicians to interact with a patient's healthcare information through intelligent dashboards.
- Core architectural concepts that were explored in the technical design phase during the Proof of Concepts (PoCs) to enable the solution to be scaled nationally.

The solution could allow authorised users to configure and run reports on clinical interactions, subscriptions, lookups and other capabilities that use data to support quality improvement and better practice at the point of delivery, through decision support and risk stratification.

Australian Government
Australian Digital Health Agency

Scope and objectives

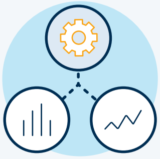
Four key initiatives were prioritised, scoped and proposed to the Agency Board for funding. All were successful and accepted. These include:

1. Digital Pregnancy Health Record (DPHR)
2. Child Digital Health Record 0-4 (CDHR 0-4)
3. Child Digital Health Record 5-14 (CDHR 5-14) (previously named Child Digital Health Checks)
4. Child Data Hub and Foundations Project

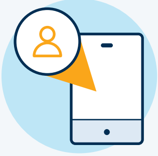
Together, these initiatives explore how digital health technology can:

empower families to be partners in their children's care with their healthcare providers

provide families with easy access to and control of their health information



integrate and better coordinate care for children and young people



enhance the quality of children's care through building a lifetime digital health record from conception

help improve the health and wellbeing of all Australian children

What was the result?

The Collaborative developed PoCs to test the ability to establish a digital pregnancy health record and child digital health record from pregnancy to birth and up to the age of 14.

These digital records leverage common infrastructure and processes, integrating with a variety of end user systems used by GPs, public hospitals and clinics. It enables consumers to interact with their healthcare information through a user-friendly mobile application and through intelligent dashboards.

The next phase for the digital health record is to consider the development of a national solution by transitioning learnings and components to new or existing national infrastructure, thereby significantly contributing to interoperability across Australia's health system.

What were the challenges?

Challenges that were experienced throughout the development of this solution included:

Use of interfaces for data exchange

Enabling jurisdictions to use existing interfaces to limit necessary changes to upstream systems rather than build out 'bypass' models was a requirement in the PoC.

System integration and privacy settings

Considering how this solution could integrate with other nationwide systems to protect certain information, and take into consideration what is visible, to whom, and what consent is required – for example, sexual health information, domestic violence, adoption, or children at risk.

Legal review of stakeholder partnerships

Formal data exchange agreements between private and jurisdictional providers are complex, requiring multiple party legal review and input. Considering how to define the partnership model for project participation and ongoing production support.

Policy and legislation

Ensuring national solutions consider all applicable policy and legislation across all jurisdictions where the solution will be deployed. Detailed policy and legislation review are required for successful national scaling.

Lessons learned

Standardise code sets and terminology

Where jurisdiction data sets differ, look to standardise terminology and code sets to reduce the need for translation/transformation services for information exchange.

Use community-based approach for FHIR development

The process of engaging the HL7 community in the development of FHIR resources is strongly recommended for national scaling.

Use discrete data elements

Discrete data elements are preferred over documents to ensure individual data elements can be used in a multitude of ways to future-proof the solution.

Embed clinical stakeholders in key delivery phases

Involve all impacted clinical resources in defining the requirements for profiles to be developed, as well as testing phases to ensure the solution is fit for purpose. This includes clinical terminologists, who are critical to ensure that national terminology standards are used appropriately.

Leverage existing interfaces to reduce upstream system modifications

Solutions should consider leveraging existing interfaces for data exchange to limit the necessary changes to upstream systems.

Access profiles for sensitive data and security front of mind

The interaction with consumer-sensitive data must be restricted and taken into consideration in what is visible, to whom, and what standard levels of consent are required across the national system.

The system needs to have the highest level of security to prevent the hacking of information that could lead to identity theft or access to personal information by third-party sources. Solutions must align to security standards set by the Agency when they are integrating with national services.

Allow significant time to formalise partnerships and information sharing agreements

Allow adequate lead time to formalise partnerships and data exchange agreements between multi-parties including jurisdictions, private providers and other state-based health services. The more parties involved, the more lead time may be required.

For any enquiries, please email interoperability@digitalhealth.gov.au