Our Vision
To create a longitudinal digital health record for every child born in Australia, spanning from conception to adulthood

Preconception
Digital Pregnancy Health Record

Pregnancy

Birth to early childhood (0-4 yrs)
Child Digital Health Record

Late childhood (5-14 yrs)
Child Digital Health Record 4-15

Adolescence to adulthood

Research into Longitudinal Child Digital Health Record

My Health Record
1. **Child Data Hub**
   The child data hub is the backbone of the NCDHC solution, providing:
   a. A repository to store child health data that does not exist in other national infrastructure (e.g., Child Health Assessment Results)
   b. Orchestration manages access to information including combining information from the data hubs internal repository with other information (e.g., My Health Record records), to provide a single point of access to all child health information.
   c. Business logic processing supports the generation of proactive event notification (such as overdue vaccinations)

2. **Digital Child Health API(s)**
   Digital child health API(s) represent a standardised approach to share child health data, providing the mechanism for transferring information between the Child Data hub, jurisdictional Systems, other provider and consumer systems/apps and the child health provider dashboard. It is expected that these API(s) will be based on the HL7 FHIR standard.

3. **National Interoperability API(s)**
   National interoperability API(s) enable the NCDHC solution to interoperate with other national infrastructure for enriching child health information with data from other national infrastructure and making child health data available to this infrastructure.

4. **Other National Infrastructure**
   Other national infrastructure represents existing and future national health infrastructure that the child data hub will interoperate with via National Interoperability API(s).

5. **Jurisdictional Systems**
   Jurisdictional systems provide jurisdictional users the capability of viewing and updating child health data. Ideally existing jurisdictional systems will be leveraged.

6. **Other Provider Systems**
   Other provider systems provide non-jurisdictional providers the capability of viewing and updating child health data. Ideally existing systems will be leveraged.

7. **Consumer Apps**
   Consumer apps will support user friendly access and updates to child health data by consumers.

8. **Health Provider Dashboard**
   A health provider dashboard will both:
   a. Support access to child health data by providers who do not have an IT system that interoperates with the Child Data Hub and,
   b. Be able to be embedded within compatible provider EMR systems to provide patient context aware display of child health data that is not natively valuable via there EMR (i.e., longitudinal child health data and/or an electronic representation of a child health “book”)

9. **Governance Operation and Support**
   The operation and support component represent the need to ensure that all components that make up the NCDHC ecosystem have appropriate governance, operation and support models and tools.
Data Hub

- The use of a discrete API Broker / Data Hub was included within the Collaborative Program Project Initiation (PID) Document. Benefits of the model include:
  - Minimize dependencies on changes to MHR for a limited scale pilot.
  - Allow learnings to feed into a business case, plan and design for a national rollout.
  - Allow flexibility in the use of contemporary integration standards and how vendors will build to the standards.
  - Allow testing of consumer and provider engagement models in a constrained environment.
  - Allow easy federation with other data sources (federated model) while providing a simplified access channel

- FHIR to both exchange and store data. Benefits of this include:
  - FHIR provides a flexible method for exchange of a wide range of health information.
  - The Data hub only needs to be able to understand the subset of data it needs to manage the flow of information (i.e. to manage authority and privacy). This allows easy changes to the clinical information with limited impact to operation of the data hub.
  - The Restful FHIR model being implemented within the Data Hub will allow flexibility in the use cases that the Data hub supports.
  - Allows the data to be presented easily in multiple ways (encounter based, longitudinal, domain focused)
  - Supports federation of data across multiple repositories with a shared indexing service
• Industry Standard Security - OAuth2/OpenID Connect + TLS:
  • Simple, understood implementation.
  • Ability to leverage existing authentication providers (NASH/PKI).
  • Simple to include additional authentication providers as required.

• Business Logic - intelligent automated actions based on data analytics.
  • Proactive notification of significant events

Sharing of information is a byproduct of care – not an action unto itself
Interoperability Patterns

• Supply
  • Document (composition) structure

• Retrieval
  • Source Document
  • Longitudinal Document
  • Summary View - Backend for Frontend (Questionnaire)
Collaborative adopted FHIR as the interoperable standard for implementation focusing on the following areas:

- **Structure:** FHIR profiles identified and drafted for the Collaborative leveraging both Australian and international standards following community lead standard process via HL7 Australia. This includes involvement of multiple stakeholders including eHealth NSW, HL7 Australia, Australian Digital Health Agency, clinicians and system vendors.

- **Terminology:** Use of SNOMED CT based National Clinical Terminology Service* as a source for shared interoperable terminology

- **Transport:** FHIR based Restful APIs published with adhering to the FHIR standard conformance requirements.

*The National Clinical Terminology Service (NCTS), operated by the Australian Digital Health Agency, is responsible for managing, developing and distributing national clinical terminologies and related tools and services to support the digital health requirements of the Australian healthcare community.

http://build.fhir.org/ig/hl7au/au-fhir-childhealth/
• The sharing of health information facilitated by the collaborative will be based on a series of health interactions.

• Health interactions represent a point in time exchange of information aligned with a function of care delivery or information management. Health interactions are designed such that:
  • They can be exchanged real-time or near real time.
  • They can mostly be transacted in any order with limited dependence on each other.
  • They are granular enough that they can be used across multiple different clinical processes or encounter types.
  • They represent both clinical and consumer focused actions.
  • They keep clinical context (Document Based Upload)
Penny was born today

Macular rash detected at birth

IM or IV injection, 8

Induced (No reason)

Normal Vaginal Birth

Blacktown Hospital

Penny has missed her 1

17:42 (5m)

Newborn Hepatitis B Vaccine Given, 8-May-2018

Newborn Examination Yes

Newborn Admission to Nursery No
• Using FHIR to both exchange and store data. Benefits of this include:
  • FHIR provides a flexible method for exchange of a wide range of health information.
  • The Data hub only needs to be able to understand the subset of data it needs to manage the flow of information (i.e. to manage authority and privacy). This allows easy changes to the clinical information with limited impact to operation of the data hub.
  • The Restful FHIR model being implemented within the Data Hub will allow flexibility in the use cases that the Data hub supports.

• Using a FHIR document structure allows individual pieces of atomic data to supplied as a “group”, These groupings allow:
  • Keeping context and allowing attestation in context.
  • Easy query and retrieval in multiple ways (encounter based, longitudinal, domain focused or atomic) while keeping traceability to the attested, supplied, “document”.
  • Original source “documents can be accessed to validate original source of truth.
Conceptual Provider Dashboard Design

**Patient Details**

**Penny June, LANE**
- Female
- 7-Jan-2018 (5m)
- Non Aboriginal or Torres Strait Islander

**Summary View**

**Birth & Newborn Examination**
- 7-Jan-2018 (5m)

**Health Encounter**

**Family History**
- 17-Feb-2018
- Penny’s family history recorded by GP
- Completed

**Emergency Presentation**
- 1-May-2018
- Penny presented at Mt Druitt ED with Granny
- Completed

**Health Check Missed**
- 3-Feb-2018
- Penny has missed her 1-4w health check
- Incomplete

**Emergency Dept**
- 2-May-2018
- Sever and harsh barking cough
- Completed

**Children’s Ward**
- 11-Apr-2018
- Repair fractured proximal humerus
- Completed

**WHO Birth-2Yrs (F)**

- Weight
- Length
- Head Circ.
- BMI

**Health Interactions**

<table>
<thead>
<tr>
<th>INTERACTION</th>
<th>DATE</th>
<th>SUMMARY</th>
<th>STATUS</th>
<th>ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaccination Up To Date</td>
<td>8-May-2018</td>
<td>Penny’s immunisation status is up to date</td>
<td>NEW</td>
<td>VIEW</td>
</tr>
<tr>
<td>Vaccination Reminder</td>
<td>7-May-2018</td>
<td>Penny’s 4 month immunisation is due</td>
<td>COMPLETED</td>
<td>VIEW</td>
</tr>
<tr>
<td>Emergency Presentation</td>
<td>1-May-2018</td>
<td>Penny presented at Mt Druitt ED with Granny</td>
<td>COMPLETED</td>
<td>VIEW</td>
</tr>
<tr>
<td>Family History</td>
<td>17-Feb-2018</td>
<td>Penny’s family history recorded by GP</td>
<td>COMPLETED</td>
<td>VIEW</td>
</tr>
<tr>
<td>Health Check Missed</td>
<td>3-Feb-2018</td>
<td>Penny has missed her 1-4w health check</td>
<td>INCOMPLETE</td>
<td>VIEW</td>
</tr>
<tr>
<td>Birth Discharge</td>
<td>10-Jan-2018</td>
<td>Penny discharged from Blacktown Hospital</td>
<td>COMPLETED</td>
<td>VIEW</td>
</tr>
</tbody>
</table>

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09:15 am | 23 May 2018

Embedded re-usable template/form

Birth-4 weeks Assessment

Last Name*: Last name
First Name: First name
IHI*: IHI
Date of Birth: DOB
Sex*: Male Female Other Unknown

Weight: kg Outcome Normal Review Refer

Comment:

Height/Length: cm Outcome Normal Review Refer

Comment:

Head Circum: cm Outcome Normal Review Refer

Preventive health: Influenza vaccination should be considered!
Opportunities for international Alignment

• Atomic Resource Structures and Terminology
• Exchange structure
• Anything Else?