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SUMMARY OF THE HEALTHY CHILD EVENTS SPECIFICATION REVIEW

DECEMBER 2018

Contents

1. Background
 2. Objectives for the work
 3. Project approach and process
 4. Outcome
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1. Background

PRSB had already published the Healthy Child Record Standard. It consisted of two documents:

- **Healthy Child Record specification** – this specifies the format of an electronic care record supporting the Healthy Child Programme, including the clinical sections and elements, which provide the standardised structure for that record.
- **Healthy Child Events Specification** (information model) – this provides the detailed content for the events, including values and business rules used to support the creation of the FHIR Events Catalogue for implementation of the standard.

The healthy child events specification had limited consultation during the original development of the healthy child record standard and it was noted that further work was required to define the use cases, provide clinical informatician review and broad consultation with clinical informaticians and system suppliers

This summary describes the further work that has been carried out to review the healthy child events specification, which was also part of gaining an Information Standards Notice (ISN) for the healthy child standard.

2. Objectives for the work

The objectives of this project were:

- Review of the child health events information models by clinical informaticians and suppliers to assure that they are suitable for recording on primary care, community and child health systems.
- The review to be sufficient in terms of breadth, depth and rigour to meet the needs of both the PRSB assurance processes and the information standards (ISN) process.

The scope of this project was:

- Review of the health child events information model and associated implementation guidance provided by NHS Digital.
- Review by clinical informaticians with an understanding of health visiting, school nursing, child health and general practice IT systems and a general understanding of the requirements for recording and information sharing to support delivery of the healthy child programme.
- Review by vendors of community health, child health and general practice systems
- Feedback to the NHS Digital business analyst team responsible for the information model, updating the model in an iterative manner.

3. Project approach and process

The core PRSB project team comprised:

- Project manager with experience of developing record standards and information models
- Clinical lead and clinical informatician from the RCPCH
- Clinical lead and clinical informatician from the RCGP
- Clinical advisor and clinical informatician from NHS Digital, nurse and member of e-health group at RCN

The key stages of the project were:

1. Conduct a mapping from the child health events information model provided by NHS Digital to the PRSB headings and information models, identifying any gaps and inconsistencies.

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2. An initial review of the child health events information model and mapping by a small core team of clinical informaticians supported by the HIU project manager to:
 - a. Agree general principles for the models, these were:
 1. *Alignment with the PRSB information models wherever these exist.*
 2. *Reference curated SNOMED CT ref sets only in the information models. Any other subsets should be included as examples only in the implementation guidance and the information models should reference SNOMED CT*
 3. *Reference current Data Dictionary terms*
 4. *Primary purpose is support for direct care.*
 5. *Clarity about which systems will be required to record or ingest the information associated with an event.*
 6. *Models should be generic, rather than hard-wiring in specifics (e.g. immunisation protocols or screening reviews). The specifics should be covered in implementation guidance.*
 - b. Assess the models against these principles and identify changes that need to be made in order to adhere to those principles prior to wider review.
 - c. Identify any models, which will not need review (as they have already successfully been through the FHIR® curation process).
 - d. Identify which models are suitable for review and which need further work (identifying the reason for additional work being required) before a review can be undertaken.
 - e. Advise on the way in which the review could be scheduled so that it would be manageable to those participating in it and would allow time for NHS Digital to update sections of the model where additional work is needed. This would include splitting up the model into manageable sections for reviewers.
 3. NHS Digital team updates to the model, based on core team feedback.
 4. A series of five review workshops held, led by NHS Digital and involving the core PRSB team, terminologists and data dictionary experts from NHS Digital.
 5. An introductory webinar for a wider group of clinical informaticians and suppliers. This explained how the information models would be used, the use cases to be supported and how these will be implemented. There were 21 attendees joining in addition to the project team and recording of the meeting was made available to those unable to join.
 6. Consultation process, as follows:

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- a. A 2 week on-line posting and review of the information models by clinical informaticians and suppliers.
 - b. Review of feedback by core team. Comments were sent by 6 reviewers submitting around 35 items of feedback.
 - c. Collation of feedback by core team and discussion of any outstanding issues in a webinar with the aim being to achieve consensus on a solution. The webinar was attended by 11 representatives (in addition to the project team). Feedback was discussed and addressed, resulting in either no change, clarification in the implementation guidance, or minor change.
 - d. NHS Digital update to final version of information model.
 - e. Updated model and summary of the process submitted for approval by the PRSB assurance committee.

The changes made to the events specification have also been reflected in an updated record specification with details of the changes provided in the release notes published with the updated record specification on the PRSB website.

Outcome

The PRSB assurance committee approved the process, the revised events specification and the changes to the record specification.

The Information Standards Notice (ISN) was approved.