



Information Requirements

Consumer Entered Health Summary

Version 1.0 - 23 November 2011

Final

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Document Information

Change history

Version	Date	Contributor	Comments
v0.01	15/9/11	Ann Stephens	Initial version, PCEHR Concept of Operations, September 2011
V0.02	23/9/11	Ann Stephens	Additional date fields
V0.03	28/9/11	Ann Stephens	Incorporate feedback and updated information
0.04	30/9/11	Ann Stephens	Feedback - word smithing
0.05	20/10/11	Ann Stephens	Feedback incorporated
0.06	23/11/11	Ann Stephens	Remove Gender Identity
1.0	23/12/11	Ann Stephens	Approved

Document authorisation

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Preface

Document Purpose

This document presents the information requirements for a Consumer Entered Health Summary.

The Consumer Entered Health Summary Information Requirements are a logical set of data items for use in the PCEHR and are therefore independent of any particular platform, technology, exchange format or presentation format.

Updates to this document will be published as additional package components are developed, with feedback from the sector.

Intended Audience

This document is intended for all interested stakeholders including:

- Consumers and consumer representatives
- Clinicians, such as general practitioners
- Software vendors developing eHealth system products
- Senior managers and policy makers, clinical experts, health information managers, IT operations and support teams, system integrators
- Stakeholders associated with the development and use of upcoming eHealth initiatives relating to 'continuity of care'
- Both technical and non-technical readers

Document Status

Final.

1 Introduction

1.1 Overview

This document presents the Information Requirements for Consumer Entered Health Summaries, as recommended for use in Australian eHealth systems.

The Information Requirements are the minimum set of data items that are recommended for implementation of the Consumer Entered Health Summary in the PCEHR.

1.2 Scope

The following statements regarding scope pertain only to the information requirement specifications herein and not more broadly to the PCEHR scope of work.

1.2.1 Scope Inclusions

The aim of a Consumer Entered Health Summary (CEHS) is to provide pieces of information about an individual's health, from the Consumer's perspective. The information held in a Consumer Entered Health Summary will vary depending on the individual.

1.2.2 Scope Exclusions

Information derived from clinical systems is out of scope for this document.

1.3 Purpose

The PCEHR System will provide an avenue for individuals to enter summary information into the PCEHR via the consumer portal, and printout this information.

In addition to their contact details, an individual can also provide a consumer entered health summary, which contains one or both of the following:

- Allergies (including the substance/medicine/device name and the reaction they have had to it)
- Medications (including the branded name of the product)

1.4 Exchange and Presentation Formats

The information presented here is defined at the information level, and is therefore independent of specific data exchange and presentation formats (e.g. HL7 v2.x or HL7 Clinical Document Architecture [CDA]).

The Information Requirements will be mapped to HL7 CDA exchange format and published following their endorsement.

The requirement that a particular piece of data be exchanged in a Consumer Entered Health Summary does not imply a requirement on the user interface. Some data elements (e.g. 'Document Originating System Identifier') are intended purely for purposes of internal processes within the receiving system. Similarly, other data elements (e.g. 'Date of Birth') have a number of different presentation options available (e.g. 'Birth Day' + 'Year of Birth' etc.), which are not considered here. The names given to data components and data items are in many cases not appropriate to be used as field labels on a user interface.

Implementations which modify the data item names in the 'Item' column of the following section to accommodate local practices (e.g. 'Person name')

represented as 'Patient Name') may still conform to this specification, but only if the meaning of the variables listed in the other columns are not modified.

The order in which the data items are listed in this document is not indicative of the order in which this data should be exchanged or presented to the user.

1.5 Adding Data

It is envisaged that the Consumer will enter data into the PCEHR system through a consumer portal. The consumer portal will provide a nationally operated portal to allow individuals to access their own PCEHR.

The consumer portal will support:

- Popular desktop web browsers, including, but not limited to Internet Explorer, Firefox, Safari and Chrome
- Links to the Australian Government funded healthdirect Australia consumer portal
- Context sensitive links to health literacy information from HealthInsite on www.healthdirect.org.au.
- Space within portal pages for information about current public health campaigns.

2 Core Components

2.1 Overview

The information components include:

Component
Individual
Author's Name (authorised representative)
Allergies and Adverse Reactions
Medicines
Document Control

Each component is described in terms of requirements and rationale.

Indicative samples for usage are included to provide additional clarity, but are not intended to be a prescription for display. All content in the samples is completely fictitious.

This is followed with a representation of the proposed data model for each.

2.2 Guide to this document

The proposed data model for each of the components is defined below, using the following columns:

- *Component*: A high level section or group of data elements
- *Item*: An individual data element or data group. A data item may be a single unit of data (e.g. "Date of Birth"), or a set of data that has a standard structure (e.g. "Address")
- *Type*: The type of data associated with the component or data item. Note that this may be a simple data type (e.g. text, date) requiring a single field, or a predefined structure requiring a group of fields. Refer to legend in section 2.2.1 below.
- *Number of Values Allowed*: The number of times that the given component/item may be included in a Shared Health Summary. For items, this is the number of times that the given item may be included, each time the component. Refer to legend in section 2.2.2 below.

The following legends are included to assist the reader with the content of the tables that follow.

2.3 Data Type legend

The following table provides a description of the various data types in use.

Datatype	Notes
Boolean	A Boolean value can be either true or false, or may be empty.
Codeable Text	Codeable Text is a flexible data type to support both free text and coded text.
Coded Text	Values in this data type must come from the bound value list, with no exceptions.
DateTime	DateTime is used for specifying a single date and/or time. It can indicate a level of precision, and define estimated or partial dates.
Integer	Whole numbers.
Quantity	The Quantity data type is used for recording many real world measurements and observations. Includes the magnitude, value and the unit.
Text	Free text string.
Time Interval	Time Interval contains a Start DateTime and (optionally) an End DateTime.
Unique Identifier	An identifier that uniquely identifies a given entity.

2.3.1 "Number of Values Allowed" legend

In order to facilitate understanding by non-technical readers, the standard notation for cardinality has been mapped to a more readable style, in the following ways:

- The value of "1" is technically represented as "1..1"
- The value of "1..Many" is technically represented as "1..*"
- The value of "0..Many" is technically represented as "0..*"

The following table provides a description of the options for Number of Values Allowed.

Value	Min	Max	Notes	Example
1	1	1	Must have 1 value and only 1	Vaccine Brand Name (i.e. per each immunisation record)
0..1	0	1	Does not need a value in every document, but when it does, it can only ever have 1	Medicine Additional Comments (i.e. additional comments are not required for all medicines)
1..Many	1	Many	Must have at least 1 value, and can contain multiples	Individual Address
0..Many	0	Many	Does not need a value in every CEHS, but when it does, it can contain multiples	Individual Communication Details

Supporting technical documentation (Structured Content Specifications and CDA Implementation Guide) fully complies with the standard technical notation.

3 Component: Individual

Description: The individual is the person about whom the healthcare event has been captured – that is, the subject of the information.

3.1 Requirements

Data item	Requirement statement	Rationale
Component	Each CEHS shall always contain information about the individual and shall always contain the following mandatory items.	A CEHS is only created pertaining to an individual and one cannot exist without that individual.
Person Name	The name of the individual shall be recorded in every CEHS. Multiple names for the individual are allowed.	Identification of the individual. Supports the indexing of clinical documents.
	The recording of individual name shall be consistent with Australian Standards of naming.	Allows interoperability. Eliminates ambiguity.
Person Identifier	Every CEHS shall contain the individual’s Individual Healthcare Identifier (IHI).	Allows interoperability. Eliminates ambiguity. Supports the indexing of clinical documents.
	A CEHS shall also be allowed to contain multiple identifiers for the individual.	Optionally the individual’s local identifier to support transition to the use of national identifiers.
Date of Birth	Every CEHS shall contain the individual’s date of birth.	Identification of the individual. Supports the indexing of clinical documents.
	An approximation for the date of birth shall be allowed (such as only the year, or the month and year) only when the exact date is not known. That is, when the exact date is known, the full date shall be provided.	The individual’s exact date of birth may not be known.
	When the date of birth is an approximation, an indication of such shall be included.	Eliminates ambiguity
Sex	The individual’s sex shall be recorded in every CEHS.	Identification of the individual. Supports the indexing of clinical documents.
	The individual’s sex shall be recorded using (and be restricted to) the Australian Institute of Health and Welfare Person—Sex Data Element Concept values.	Allows interoperability. Eliminates ambiguity.
Address	The individual’s address shall be recorded in every CEHS.	Identification of the individual.
	The recording of individual address shall be consistent	Allows interoperability. Eliminates ambiguity.

Data item	Requirement statement	Rationale
	with Australian Standards of address recording.	
	There shall be provision for recording the individual's address as not known or that they have no fixed address.	Individuals may not always have a fixed place of abode nor may the address be known in all cases.
Communication Details	The CEHS shall have the provision to record contact details for the individual.	Allows the individual to update their contact details.
	A value for individual's communication detail shall only be included when it is deemed to relevant/appropriate to do so (i.e. optional to include a value).	An individual's contact may not be available or appropriate to include.
	A CEHS shall be allowed to contain multiple individual communication details.	This allows recording of (for example) a home landline, a work mobile and an email address.
	The contact details record shall include provision for the medium (e.g. telephone, email), usage (e.g. home, work) as well as the actual details.	Allows interoperability. Eliminates ambiguity.
Indigenous Status	An indication of whether a person identifies as being of Aboriginal or Torres Strait Islander origin (or an indication of it being not stated etc.) shall be recorded in every CEHS.	Aborigines and Torres Strait Islanders are eligible for a range of specific services. This will contribute to improved data quality on indigenous health.

3.2 Samples & usage

1. The individual has only provided the least amount of information - that is, one address and no contact details. They have declined to state their Indigenous status.

INDIVIDUAL		
Name	Mr William SMITH	
IHI	8003600200002222	
Date of Birth	01/01/1946 (63 years) ¹	DOB Estimated? No
Sex		
Address	Residence: 20 Chapel Street, Lilydale, VIC, 3002	
Contact		
Indigenous Status	Not stated	

2. Later, the same individual provides more demographic information.

INDIVIDUAL		
Name	Miss Wilma SMITH	
IHI	8003600200002222	
Date of Birth	01/01/1946 (63 years)	DOB Estimated? No
Sex	Male	
Address	Residence: 20 Chapel Street, Lilydale, VIC, 3002 Postal: PO Box 123, Lilydale, VIC, 3002	
Contact	Home Phone: 03 3988 7156 Mobile: 0411 378 942 Email: mwsmith@internetprovider.com.au	
Indigenous Status	Neither Aboriginal nor Torres Strait Islander origin	

¹ The age of the individual would be a calculated value rather than being a separate data item.

3. Another Individual does not recall the exact date of their birth.

INDIVIDUAL	
Name	Mr Albert HENRY
IHI	8003600200003333
Date of Birth	1946 (63 years) DOB Estimated? Yes
Sex	Male
Address	Residence: 1 General Street, Broome, WA, 6725
Contact	Home Phone: 06 1212 1212
Indigenous Status	Aboriginal but not Torres Strait Islander origin

3.3 Proposed Data model

Data items	Data Type	Number of Values Allowed	Notes
Person Name	Person Name data group	1..Many	The individual's name, structured using a predefined type, consistent with Australian standards of naming (e.g. family name and first name etc.), as detailed in NEHTA's Participation Data Specification [PDS2011].
Person Identifier	Unique Identifier	1..Many	The unique identifier of the individual. This must include the individual's Individual Healthcare Identifier (IHI) and optionally the individual's local identifier.
Date of Birth	DateTime	1	The individual's date of birth. Where the exact date of birth is not known, this may be an approximation, which includes only the year, or the month and year.
Date of Birth Estimated?	DataGroup ²	0..1	The level of certainty or estimation of an individual's date of birth.
Sex	Coded Text	1	The sex of the individual. Sex is the biological distinction between male and female. Where there is an inconsistency between anatomical and chromosomal characteristics, sex is based on anatomical characteristics. ³
Address	Address data group	1..Many	The address of the individual, recorded in a structured format, consistent with Australian standards of address recording, as detailed in NEHTA's Participation Data Specification [PDS2011]. Where the individual's address is not known, the address line can be populated with text entry of "Individual has no known address." This may include "No fixed address" if appropriate.
Communication Details	Electronic Communication Details data group	0..Many	The individual's preferred means of contact should be included to facilitate clinical follow-up. Each Contact Details data item includes the medium (e.g. telephone), usage (e.g. home) and details. A value is not always required because it may not be available or appropriate.
Indigenous Status	Coded Text	1	A description of whether a person identifies as being of Aboriginal or Torres Strait Islander origin. Refer to the AIHW definition and code set. ⁴

² DOB Estimated is a datagroup consistent with AS5017-2006, with Yes/No Display.

³ Source of definition: Australian Institute of Health and Welfare; Person—sex Data Element Concept (METeOR identifier: 269716) <http://meteor.aihw.gov.au/content/index.phtml/itemId/269716> (accessed 19 May 2011)

⁴ Australian Institute of Health and Welfare, METeOR, Metadata Online Registry. Person—Indigenous status <http://meteor.aihw.gov.au/content/index.phtml/itemId/291036> (accessed 19 May 2011)

4 Component: Author's Name (Authorised Representative)

Description: The Authorised Representative is an individual who is authorised by the law of any jurisdiction to be able to act on behalf of an individual for healthcare purposes. This individual may author documents for the individual using the individual's Health Identifier.

4.1 Requirements

Data item	Requirement statement	Rationale
Component	Each CEHS shall contain the name of the author if they are someone other than the Individual.	A CEHS may be authored by an authorised representative of the individual. This author should be identified.
Author's Name (Authorised Representative)	The name of the Authorised Representative shall be recorded in the CEHS, when they author the consumer entered information for the individual.	Identification of the author who has represented the individual in the Consumer Entered document.
	The recording of author's name shall be consistent with Australian Standards of naming.	Allows interoperability. Eliminates ambiguity.
Person Identifier	The Consumer Entered Health Summary shall always record an identifier for an author when the author is not the Individual.	Eliminates ambiguity.
	A single identifier shall be the IHI of the author, whether or not they are the Individual themselves or their authorised representative.	Authorised representatives
Address	There shall be the provision to record the address of the author.	Should the author need to be contacted for clarifications.
	The recording of the address shall be consistent with Australian Standards of address recording.	Allows interoperability. Eliminates ambiguity.
	Multiple addresses shall be allowed.	Caters for the street address as well as the postal address.
Communication Details	There shall be the provision to record contact detail(s) for the author of the Consumer Entered Health Summary.	Downstream readers of the Record may need to contact the author.
	Multiple author communication details shall be allowed.	This allows relevant telephone numbers (i.e. daytime, after hours, mobile, etc.) and email addresses to be recorded for future reference.

4.2 Samples & usage

1. The author's name is recorded.

INDIVIDUAL	
Name	Mrs Wilma FLINT
IHI	8003602222222222
Address	Residential: 40 General Street, Brisbane, QLD 4001
Contact	Email : wllma@gmail.com Phone : 07 3998 7156

4.3 Proposed Data model

Data items	Data Type	Number of Values Allowed	Notes
Person Name	Person Name data group	1..Many	The author's name, structured using a predefined type, consistent with Australian standards of naming (e.g. family name and first name etc.), as detailed in NEHTA's Participation Data Specification [PDS2011].
Person Identifier	Unique Identifier	1	The unique identifier of the author; this must include the individual's Individual Healthcare Identifier (IHI). Where the author is an individual's Authorised Representative, this must be the Authorised Representative's IHI, even if they are a healthcare provider.
Address	Address data group	0..Many	The address of the author, recorded in a structured format consistent with Australian standards of address recording, as detailed in NEHTA's Participation Data Specification [PDS2011].
Communication Details	Electronic Communication Details data group	0..Many	The contact details for the author. The preferred means of contact should be included and should include at least one method of communication. Each Contact Details includes the medium (e.g. telephone), usage (e.g. work) and details.

5 Component: Allergies and Adverse Reactions

Scope: Allergies and Adverse Reactions component includes allergies and adverse reactions to all substances not just medicines. It may include food allergies, insect allergies as well as prescription and non-prescription medicines.

5.1 Requirements

Data item	Requirement statement	Rationale
Component	Information regarding Allergies and Adverse Reactions is optional for the Consumer entered health summary (CEHS).	Information regarding an individual's allergies and adverse reactions is vital to ensure high quality health care.
Agent Description	Allergy and adverse reaction listed in the CEHS shall contain a description of the causative agent.	This information will help an individual to record their health information related to allergies and adverse reactions.
Reaction Description	There shall be the provision for an allergy and adverse reaction record to include the description of the reaction that was caused by the aforementioned agent.	A description of the reaction allows better informed future management.
	There shall be the provision for more than one reaction to be recorded for a single agent, when appropriate.	An individual may experience multiple adverse reactions to a single agent.

5.2 Samples & usage

a) The individual volunteers information on any allergies and adverse reactions.

ALLERGIES / ADVERSE REACTIONS	
Agent	Reaction description
Penicillin	Rash; Nausea and vomiting
Nuts	Breathing problems

5.3 Proposed Data model

Data items	Data Type	Number of Values Allowed	Notes
<i>One (or more) reactions must be provided or a reason why no reactions are provided. That is, must have one of the following (a or b), but not both:</i>			
Allergies / Adverse Reaction	Group	0..Many	The data group of the known adverse reactions for the individual containing the relevant reaction details. Multiple reactions are allowed and the following 2 data items apply for each reaction added.
	Agent Description	Free Text	1 This free text data element is intended to summarise the agent or substance causing the allergy and/ or adverse reaction experienced by the individual. The agent must always be recorded.
	Reaction Description	Free Text	0..Many This free text data element is intended to summarise the signs and/ or symptoms experienced or exhibited by the individual as a result of the allergies / adverse reaction to the specific agent/substance.

6 Component: Medicines

Scope: The Medicines section should contain prescription medications, non-prescription, over the counter medications, medicines self-prescribed by the individual and complementary and alternative medicines.

6.1 Requirements

Data item	Requirement statement	Rationale
Item Description	Medicines listed in the CEHS shall include details that fully describe it, including the name of the medication, strength and dose form, where appropriate.	Helps ensure high quality health care. It is important to have a record of all medicines taken by the individual.
Dose Information	Medicines listed in the CEHS may include the dose instructions describing how the medicine is taken.	To indicate frequency and how and how much the consumer is taking in their own words.
Reason for Medicine	There shall be the provision for a medicine record to include the reason why the individual is taking the medicine.	It is important for healthcare providers to understand why the individual has taken the medicine.
Additional Comments	There shall be the provision for a medicine record to include additional information. This may include comments regarding medication duration.	Allows the consumer to enter addition information about the medicine.

6.2 Samples & usage

1. The individual reports taking a number of medications.

MEDICINES			
Medicine	Dose Information	Reason for Medicine	Additional Comments
Lasix tablet	1 tablet daily	Fluid retention	Prescribed by GP
Ventolin	Used when necessary	Asthma	Asthma is worse in springtime
St John's Wort	As directed on bottle	Depression	

6.3 Proposed Data model

Data items		Data Type	Number of Values Allowed	Notes
	Medicine	Group	0..Many	The data group for the medicines that the individual is known to be taking. Multiple medicines are allowed and the following data items apply for each medicine added.
	Item Description	Text	1	The details that fully describe a medicine, including the name of the medicine, strength, dose and form, where appropriate.
	Dose Information	Text	1	A description of how a particular product is taken from the individual's perspective. This may include the dose, frequency and any additional instructions required.
	Reason for Medicine	Text	0..1	The reason for the use of the medicine.
	Additional Comments	Text	0..1	Any additional information that may include comments regarding branding, medication duration, and other relevant information.

7 Component: Document Control

Description: This section describes information about the health summary document. Much of the information contained in Document Control is technical in nature and as such is not described here. Described below are those elements which have clinical relevance.

7.1 Requirements

Data item	Requirement statement	Rationale
Component	Each Health Summary document shall include metadata about the document.	Document management requirements.
	Document control information is predominantly technical and as such does not require display for end users.	
DateTime Input	The date/time when the CEHS document was attested (or finalised, or signed off) by the document author.	Clinical safety requirement to ensure that the reader knows exactly when the document was written.

7.2 Samples & usage

1. Document Header

A health summary may display various elements of the document control near the top of the summary.

INDIVIDUAL:	Mr William Dobel	DOB: 01/01/1931 (80 years)
CONSUMER HEALTH SUMMARY		Date Completed: 14/12/2012 12:30

7.3 Proposed Data model

Data items	Data Type	Number of Values Allowed	Notes
DateTime Input	DateTime	1	The date/time when the CEHS document was finalised, or signed off by the document author.

8 Technical Document Control Requirements

The following data items are included for completeness as they represent technical requirements to ensure correct identification of each document etc.

Data items	Data Type	Number of Values Allowed	Notes
Document Instance Identifier	Unique Identifier	1	The universally unique identifier of this instance of the Consumer Entered Health Summary document.
Document Set Identifier	Unique Identifier	1	The universally unique identifier of the set of documents related to the same healthcare encounter, of which the Consumer Entered Health Summary document is a versioned instance.
Version Number	Integer	1	The version number of the Consumer Entered Health Summary document instance.
Document Originating System Identifier	Unique Identifier	1	A universally unique identifier of the system used to create the Consumer Entered Health Summary document.
Business Document Type	Coded Text	1	The name of the Consumer Entered Health Summary document type used – e.g. 'Consumer Entered Health Summary'
Business Document Type Version Number	Integer	1	The version number of the Consumer Entered Health Summary document type used to create the Consumer Entered Health Summary.
Document Status	Coded Text	1	The status of the document
Language	Coded Text	1	The language primarily used within the document (e.g. 'en-AU')
Structured / unstructured clinical document flag	Coded Text	1	This document is a structured document with unstructured fields. This is a document which has all the above fields, and also contains additional unstructured data describing the relevant health details (e.g. medicines, allergies, etc.).

9 Known Issues

The following issue cannot be addressed in time for release 1, and will be dealt with post release 1.

Topic	Issue
Gender Identity	<p>It was requested that gender identity be included in Consumer Entered information, as the individual may identify as a different gender than their physiological sex. It was seen as important within the context of consumer entered information that an individual could record this type of information.</p> <p>However, in the context of the PCEHR the inclusion of this field was not deemed to be of critical importance, and would require a large amount of extra work that could not be done within short time frames of the PCEHR project.</p>