Acute rheumatic fever and rheumatic heart disease (clinical) DSS

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Identifying and definitional attributes

Metadata item type:	Data Set Specification
METEOR identifier:	401096
Registration status:	Health!, Recorded 27/03/2012
DSS type:	Data Set Specification (DSS)
Scope:	The Acute rheumatic fever and rheumatic heart disease (clinical) data set specification (ARF RHD DSS) describes data recommended for collection at jurisdiction level in relation to cases of acute rheumatic fever (ARF) and rheumatic heart disease (RHD). The content of the ARF RHD DSS is based on best practice for the diagnosis and management of ARF and RHD, as set out in the National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand publication "Diagnosis and management of acute rheumatic fever and rheumatic heart disease in Australia – an evidence-based review. 2006"
	RHD is manifested by chronic damage to heart valves caused by incidents of ARF. ARF is an auto-immune response to bacterial infection with group A streptococcus. RHD is rare in most affluent populations (including Australia) but is highly prevalent among Aboriginal and Torres Strait Islander people, primarily affecting young people.

Collection and usage attributes

Statistical unit:	A person either with or at risk of rheumatic heart disease (RHD).
Collection methods:	Primary data collection is by health service providers.
Implementation start date:	01/07/2011

Source and reference attributes

Submitting organisation:	RHDAustralia
Origin:	National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand 2006. Diagnosis and management of acute rheumatic fever and rheumatic heart disease in Australia – an evidence-based review.
Reference documents:	National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand 2006. Diagnosis and management of acute rheumatic fever and rheumatic heart disease in Australia – an evidence-based review. Viewed 22 February 2013,
	<http://www.heartfoundation.org.au/SiteCollectionDocuments/Diagnosis-Management-Acute-Rheumatic-Fever.pdf>

Metadata items in this Data Set Specification

Seq No.	Metadata item	Obligation	Max occurs
102	Person—person identifier, XXXXXX[X(14)]	Mandatory	1

    DSS specific information:

    This data element is to hold an identifier assigned at jurisdiction level for use in re-identification at source of de-identified personal records supplied to a national rheumatic heart disease data repository.

Seq No.	Metadata item	Obligation	Max occurs
103	Person—person identifier, rheumatic heart disease N(16)	Conditional	1

Conditional obligation:

Use of this data element is proposed as an interim arrangement pending implementation of a generic data element for national Individual Healthcare Identifiers for health information systems. Its use would also be subject to jurisdiction agreement.

Seq No.	Metadata item	Obligation	Max occurs
105	Person—coded identifier rheumatic heart disease, code [X(7)]	Conditional	1
112	Person (name)—family name, text X[X(39)]	Mandatory	2
113	Person (name)—given name, text X[X(39)]	Mandatory	1
114	Person (name)—alias, text X[X(39)]	Optional	1
121	Person—date of birth, DDMMYYYY	Mandatory	1
122	Date—accuracy indicator, code AAA	Mandatory	1

DSS specific information:

This data element is to be used in association with the *'Person—date of birth, DDMMYYYY'* and *'Person—date of death, DDMMYYYY'* data elements.

Seq No.	Metadata item	Obligation	Max occurs
125	Person—sex, code N	Mandatory	1
131	Person address cluster (rheumatic heart disease clinical)	Mandatory	2
1	Person (address)—address status, code N	Mandatory	1
11	Person (address)—house/property identifier, text X[X(11)]	Optional	1
12	Person (address)—street name, text A[A(29)]	Optional	1
13	Person (address)—street type, code A[AAA]	Optional	1
15	Person (address)—suburb/town/locality name, text A[A(49)]	Optional	1
20	Person (address)—Australian postcode, code (Postcode datafile) {NNNN}	Mandatory	1
135	Person—telephone number, text X[X(39)]	Mandatory	1
136	Person (telephone)—telephone number type, code A	Conditional	1
141	Discrete Indigenous community—Indigenous community identifier, N(8)A	Conditional	2
151	Person—Indigenous status, code N	Mandatory	1
153	Person—non-Indigenous target group for rheumatic heart disease control programs, code N	Mandatory	1

Conditional obligation:

This data element is recorded if the patient's Indigenous status is recorded as non-Indigenous via the *'Person—Indigenous status, code N'* data element.

Seq No.	Metadata item	Obligation	Max occurs
155	Person—country of birth, code (SACC 2011) NNNN	Mandatory	1
156	Person—Australian state/territory of birth, code N	Mandatory	1
161	Person—informal carer existence indicator, code N	Mandatory	1
163	Informal carer—relationship to care recipient, code N	Conditional	1

Conditional obligation:

This data element is to be recorded if the presence of informal carer is identified via the *'Person—informal carer existence indicator, code N'* data element.

Seq No.	Metadata item	Obligation	Max occurs
199	Person—consent to rheumatic heart disease register, code N	Mandatory	1
201	Service provider organisation cluster	Mandatory	2
1	Establishment—organisation identifier (state/territory), NNNNN	Mandatory	1
5	Establishment—organisation identifier (Australian), NNX[X]NNNNN	Conditional	1

Conditional obligation:

for national data set

11	Service provider organisation (name)—organisation name, text X[X(199)]	Mandatory	1
21	Service provider organisation (address)—Australian postcode, code (Postcode datafile) {NNNN}	Mandatory	1
301	Acute rheumatic fever diagnosis and notification KPI cluster	Mandatory	6
307	Patient—acute rheumatic fever confirmation status, code N	Mandatory	1
316	Patient—notification date, DDMMYYYY	Mandatory	1

DSS specific information:

Notification date is the equivalent of diagnosis date for acute rheumatic fever

324	Patient—rheumatic heart disease detection method, code N	Mandatory	1
349	Patient—acute rheumatic fever recurrence status, code N	Mandatory	1
351	Rheumatic heart disease diagnosis cluster	Mandatory	1

Conditional obligation:

If diagnosed with RHD

1	Patient—rheumatic heart disease diagnosis date, DDMMYYYY	Mandatory	1
13	Person—presence of mitral valve regurgitation, code N	Optional	1
14	Person—severity of mitral valve regurgitation, code N	Conditional	1

Conditional obligation:

Recorded if mitral valve regurgitation is present.

16	Person—presence of mitral valve stenosis, code N	Optional	1
17	Person—severity of mitral valve stenosis, code N	Conditional	1

Conditional obligation:

Recorded if mitral valve stenosis is present.

18	Person—presence of aortic valve regurgitation, code N	Optional	1
19	Person—severity of aortic valve regurgitation, code N	Conditional	1

Conditional obligation:

Recorded if aortic valve regurgitation is present.

21	Person—presence of aortic valve stenosis, code N	Optional	1
22	Person—severity of aortic valve stenosis, code N	Conditional	1

Conditional obligation:

Recorded if aortic valve stenosis is present.

Seq No.	Metadata item	Obligation	Max occurs
23	Person—presence of tricuspid valve lesion, code N	Optional	1
25	Person—presence of pulmonary valve lesion, code N	Optional	1
361	Acute rheumatic fever/rheumatic heart disease status cluster	Mandatory	1
1	Patient—rheumatic heart disease status assessment date, DDMMYYYY	Mandatory	1
2	Patient—rheumatic heart disease status, code N	Mandatory	1
5	Patient—antibiotics requirement for prevention of acute rheumatic fever, yes/no code N	Mandatory	1
7	Current pregnancy cluster	Conditional	1

Conditional obligation:

Data elements in this cluster are recorded if a woman is undergoing a pregnancy.

1	Female—pregnancy indicator (current), code N	Mandatory	1
2	Female—expected confinement date, DDMMYYYY	Mandatory	1
9	Person—international normalised ratio target range, code N	Conditional	1

Conditional obligation:

Recorded if anticoagulant treatment has been prescribed.

501	Physician review cluster	Optional	99

Conditional obligation:

alternately, reviews may be conducted from time to time by a Paediatrician or Cardiologist

1	Person—review due date (physician), DDMMYYYY	Optional	1
5	Person—review date (physician), DDMMYYYY	Conditional	1

Conditional obligation:

Recorded if review by a physician has been conducted.

502	Paediatrician review cluster	Conditional	99

Conditional obligation:

alternately, reviews may be conducted from time to time by a Physician or Cardiologist

1	Person—review due date (paediatrician), DDMMYYYY	Optional	1
5	Person—review date (paediatrician), DDMMYYYY	Conditional	1

Conditional obligation:

Recorded if a review by a paediatrician has been conducted.

Seq No.	Metadata item	Obligation	Max occurs
503	Cardiologist review cluster	Optional	99

Conditional obligation:

alternately, reviews may be conducted from time to time by a Physician or Paediatrician

Seq No.	Metadata item	Obligation	Max occurs
1	Person—review due date (cardiologist), DDMMYYYY	Optional	1
5	Person—review date (cardiologist), DDMMYYYY	Conditional	1

Conditional obligation:

Recorded if a review by a cardiologist has been conducted.

Seq No.	Metadata item	Obligation	Max occurs
511	Local medical officer/general practitioner review cluster	Conditional	1
1	Person—review due date (local medical officer/general practitioner), DDMMYYYY	Optional	1
5	Person—review date (local medical officer/general practitioner), DDMMYYYY	Conditional	1

Conditional obligation:

Recorded if a review by a local medical officer or general practitioner has been conducted.

Seq No.	Metadata item	Obligation	Max occurs
521	Echocardiographer review cluster	Mandatory	99
1	Person—review due date (echocardiographer), DDMMYYYY	Optional	1
5	Person—review date (echocardiographer), DDMMYYYY	Conditional	1

Conditional obligation:

Recorded if an echocardiogram has been conducted by an echocardiographer.

Seq No.	Metadata item	Obligation	Max occurs
531	Dentist review cluster	Mandatory	99
1	Person—review due date (dentist), DDMMYYYY	Optional	1
5	Person—review date (dentist), DDMMYYYY	Conditional	1

Conditional obligation:

Recorded if review by a dentist has been conducted.

Seq No.	Metadata item	Obligation	Max occurs
11	Person—dental fitness indicator, code N	Conditional	1

Conditional obligation:

Recorded if applicable following dental review.

Seq No.	Metadata item	Obligation	Max occurs
601	Antibiotic regimen (acute rheumatic fever) cluster	Mandatory	99

Conditional obligation:

Data elements in this cluster are reportable if antibiotic prophylaxis is prescribed (most cases).

Seq No.	Metadata item	Obligation	Max occurs
1	Patient—prophylaxis commencement date, DDMMYYYY	Optional	1

Seq No.	Metadata item	Obligation	Max occurs
2	Person—acute rheumatic fever prophylaxis expected cessation date, DDMMYYYY	Conditional	1
	Conditional obligation:		
	Recorded when a date to cease regular treatment can be estimated for the person according to evidence-based best practice.		
3	Patient—prophylaxis cessation date, DDMMYYYY	Conditional	1
	Conditional obligation:		
	Recorded when a person identified as requiring secondary prophylaxis treatment to prevent recurrent ARF, is ceased treatment according to evidence-based best practice.		
4	Patient—antibiotic agent prescribed, acute rheumatic fever code N	Conditional	1
	Conditional obligation:		
	Recorded when a person has been commenced on secondary prophylaxis treatment to prevent recurrent ARF.		
5	Patient—prescribed frequency of intramuscular antibiotic treatment, code N	Conditional	1
	Conditional obligation:		
	Recorded when a person is indicated to receive benzathine penicillin G to prevent recurrent ARF.		
605	Antibiotic administration event cluster	Conditional	99
	Conditional obligation:		
	Data elements in this cluster are reportable if an prophylactic antibiotic regimen is prescribed.		
1	Patient—antibiotic administration date, DDMMYYYY	Optional	1
11	Establishment—organisation identifier (state/territory), NNNNN	Conditional	1
	Conditional obligation:		
	Recorded if antibiotic administration date (acute rheumatic fever) is true.		
15	Service provider organisation (name)—organisation name, text X[X(199)]	Optional	1
21	Service provider organisation (address)—Australian postcode, code (Postcode datafile) {NNNN}	Optional	1
651	Person—influenza vaccine administration date, DDMMYYYY	Conditional	99
	Conditional obligation:		
	This data element is to be recorded if there are no known contraindications that prevent administration of the influenza vaccine to individuals indicated for vaccination, as described in the Australian Immunisation Handbook 9th Edition 2008.		

Seq No.	Metadata item	Obligation	Max occurs
652	Person—pneumococcal vaccine administration date, DDMMYYYY	Conditional	7

Conditional obligation:

This data element is to be recorded if there are no known contraindications that prevent administration of the pneumococcal vaccine to individuals indicated for vaccination, as described in the Australian Immunisation Handbook 9th Edition 2008.

Seq No.	Metadata item	Obligation	Max occurs
701	Rheumatic heart disease surgery cluster	Conditional	99

Conditional obligation:

Data elements in this cluster are reportable if the person has undergone surgery for cardiac valve repair or replacement.

Seq No.	Metadata item	Obligation	Max occurs
1	Rheumatic heart disease surgery—date surgical procedure recommended, DDMMYYYY	Optional	1
3	Rheumatic heart disease surgery—surgical procedure date, DDMMYYYY	Optional	1
5	Service provider organisation (name)—organisation name, text X[X(199)]	Conditional	1

Conditional obligation:

Recorded when surgery for rheumatic heart disease has been conducted.

Seq No.	Metadata item	Obligation	Max occurs
7	Valve procedure cluster	Conditional	4

Conditional obligation:

Recorded when surgery for rheumatic heart disease has been conducted.

Seq No.	Metadata item	Obligation	Max occurs
1	Rheumatic heart disease surgery—heart valve identifier, code N	Mandatory	1
2	Rheumatic heart disease surgery—heart valve procedure type, code N	Mandatory	1
3	RHD surgery—heart valve prosthesis identifier, code N	Conditional	1

Conditional obligation:

If procedure type is replacement.

Seq No.	Metadata item	Obligation	Max occurs
9	Rheumatic heart disease surgery—post-surgery survival indicator, yes/no/not stated/inadequately described code N	Conditional	1

Conditional obligation:

Recorded when surgery for rheumatic heart disease has been conducted.

Seq No.	Metadata item	Obligation	Max occurs
711	Anticoagulant treatment—commencement date, DDMMYYYY	Conditional	99

Conditional obligation:

Reported if a person has a specific condition associated with RHD that requires blood thinning treatment.

Seq No.	Metadata item	Obligation	Max occurs
721	Anticoagulant treatment—completion date, DDMMYYYY	Mandatory	3
725	International normalised ratio measurement cluster	Conditional	4

Conditional obligation:

<<< What determines the conditionality of this data element cluster? MMU 9/12/11 >>>

Seq No.	Metadata item	Obligation	Max occurs
1	Anticoagulant treatment—international normalised ratio measurement date, DDMMYYYY	Optional	1
2	Anticoagulant treatment—international normalised ratio level (measured), N[N.N]	Conditional	1

Conditional obligation:

Recorded when prescribed anticoagulant treatment is measured.

| 3 | Anticoagulant treatment—dose prescribed, total milligrams per 24 hour N[NN].N | Conditional | 1 |

Conditional obligation:

Recorded when anticoagulant treatment is indicated.

| 901 | Person—date of death, DDMMYYYY | Conditional | 1 |

Conditional obligation:

Recorded if the patient has died.

| 902 | Person—underlying cause of death, code (ICD-10 2nd edn) ANN-ANN | Conditional | 1 |

Conditional obligation:

Recorded if the patient has died.