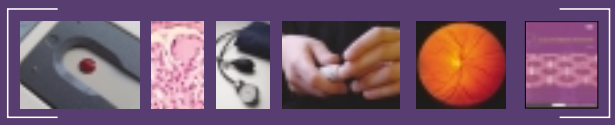
NHS SCOTLAND

SCOTTISH DIABETES CORE DATASET



JANUARY 2003

SCOTTISH EXECUTIVE

Working together for a healthy, caring Scotland

Scottish Diabetes Core Dataset

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FOREWORD

That rapid advances are necessary in the use of information technology to support clinical care is not in dispute. Nonetheless, many challenges remain and one such is the requirement to galvanise health professionals to develop appropriate and sensitive pathways of care. To support a pathway, agreement is essential upon the core information elements that must be shared amongst all those caring for the patient.

The Scottish Diabetes Core Dataset builds upon previous work to produce such a kernel. Datasets have hitherto been somewhat academic documents, mostly utilised for audit and research. The current work differs in that its prime purpose is to be incorporated into working clinical information systems used in the day-to-day care of patients with diabetes.

Scotland is fortunate in having a small and communicating band of professionals involved in the care of patients with diabetes. They have recognised the importance of a robust and reliable information infrastructure to support the *Scottish Diabetes Framework* proposals. This work is being carried forward by the Scottish Care Information Diabetes Collaboration (SCI-DC) and the Scottish Diabetes Core Dataset is the first fruit of this collaboration.

While its principal role is to support the creation of an electronic shared clinical record, such standardised data collection will fulfil all of the requirements of the Scottish Diabetes Survey and will support quality assurance of diabetes services. Thus managerial and ministerial requirements can be met as a by-product of clinical activity. It is envisaged that such an approach will become the norm in chronic disease management in Scotland.

Acknowledgements
The bulk of the work involved in revising and updating this dataset has been undertaken by Lorna Ramsay, Ewan Crawford and Rod Harvey. We are especially grateful to Donald Pearson (obstetrics), John Schulga (paediatrics) and Emma Shaw (dietetics) for making contributions from their specialist perspectives, and to Gillian Boyle and Pauline Mills (ISD) for their contributions to the Read Coding.

Dr Kenneth Robertson
Chairman, SCI-DC Steering Group
January 2003

INTRODUCTION

Recent years have seen major developments in diabetes services in Scotland. This record of innovation and action, combined with a growing recognition of the pressures being caused by the increasing prevalence of diabetes, led the Scottish Executive to highlight diabetes as a national priority in the Scottish Health Plan – *Our National Health: a plan for action, a plan for change.* The *Scottish Diabetes Framework,* published in April 2002, drew together the various strands of activity and set out a series of action points and milestones.

A critical part of the *Scottish Diabetes Framework* is the development and implementation of a robust clinical management system to support diabetes care. This is being taken forward as the Scottish Care Information Diabetes Collaboration (SCI-DC).

One of the core principles of information systems is compatibility and transferability of data. This necessitates agreement on the dataset – what data items should be collected and how these items should be defined. In September 2000 CRAG published, *A Report by the Working Group on IT to Support Shared Care in Diabetes*. A key deliverable of the working group, chaired by Dr Ewan Crawford, was to specify a core dataset suitable for sharing clinical information for the care of patients with diabetes, building on the SIGN minimum dataset and other published work. The report made clear that the dataset was only a starting point and that further development would be required to make it useable in clinical practice.

This document presents a further iteration of the diabetes dataset. Full account has been taken of the concerted effort now being made to improve the IM&T infrastructure for diabetes care in Scotland.

Purpose of the Core Dataset

The principal purpose of this dataset is for it to be implemented as part of the SCI-Diabetes Collaboration work. The details of this work have been published elsewhere (available on www.DiabetesInScotland.org) but the SCI-DC programme will offer diabetes IM&T solutions to regions based upon two elements – SCI-DC clinical and SCI-DC network.

Although it is expected that most areas will adopt the SCI-DC approach, this is not mandatory so publication of the core dataset is essential for the suppliers of other systems to ensure compatibility, and for the development of disease specific screens within primary care information systems. This will be the first detailed direct care dataset standard to be defined and implemented in Scotland.

Concept of Core Record

The aim is to create a core electronic record that resides on a central server (for each NHS Board area). Clinical staff with appropriate permission will be able to access the diabetes records of patients in their care wherever this care is delivered and view some or all of the contained information (see *Concept of Views of the Data* below). The core record will also be analysed to provide dynamic information for local audit and benchmarking as well as the details required for the annual Scottish Diabetes Survey.

By definition, this approach will generate a diabetes register that can also be used to furnish a call-recall system for diabetic eye screening.

Figure 1 makes it clear that the Scottish Diabetes Core Dataset does not, at present, incorporate all of the diabetes data that may be held on local systems which contribute information to the core record. This distinction is less obvious when the 'local system' actually constitutes browser access to the central record, but this architecture does not preclude there still being 'private' fields with only a subset being shared.

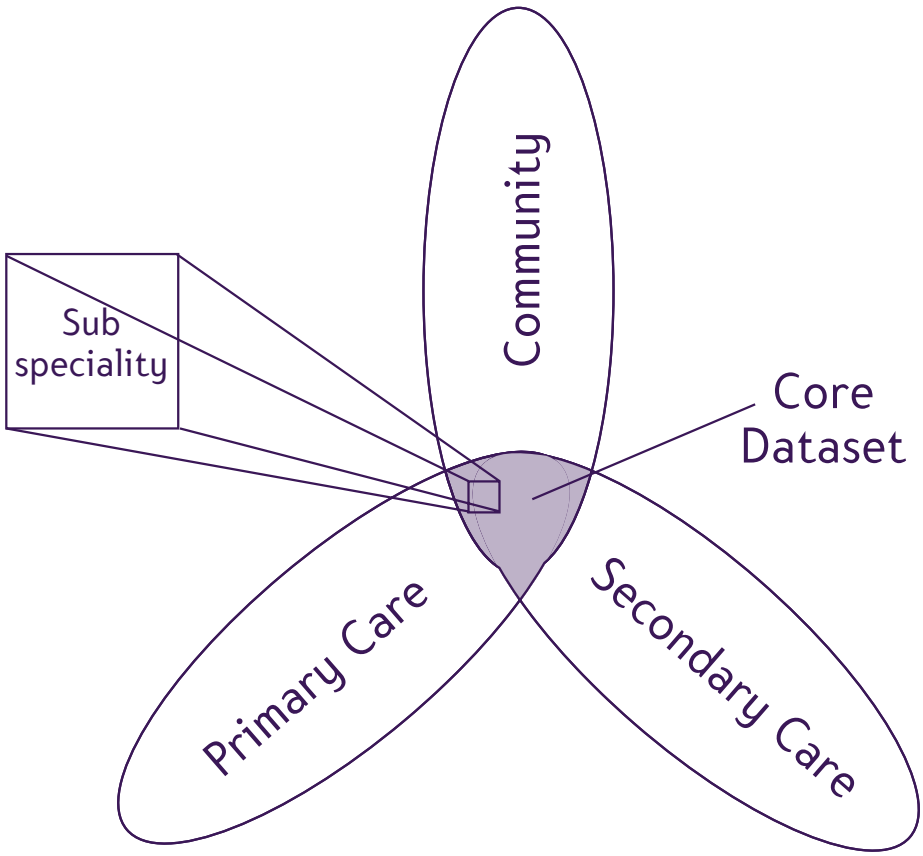

Figure 1: The Scottish Diabetes Core Dataset and the architecture of diabetes data

Thus, whether specialist data are held centrally or on systems in hospital or in primary care is irrelevant. What matters is the contribution to the core dataset and how this interaction is managed.

It is self evident that this dataset should not be construed as the entirety of data required for the care of a patient with diabetes. The test that was applied to proposed data items was, 'is this information essential to all those who may have to care for the patient without access to further information?'.

An obvious omission is the detail of Drug Therapy. Currently, this detail will be recorded on local systems but there is agreement that central recording should conform to the drug dictionary established for GPASS which is derived from the eVadis drug database supplied and maintained by ISD. The ultimate relationship to the evolving UK Clinical Products Reference Service (UKCPRS) remains to be seen.

Concept of Views of the Data

While this document details the elements of the Scottish Diabetes Core Dataset which potentially may be shared by health professionals, it is vital to understand that the actual data access that any individual obtains will be tailored and based upon function-related criteria (and patient preference). For example, a podiatrist would not be expected to have access to pregnancy-related information. This document is not about systems but suffice to say that the access control infrastructure will be managed at a local level.

Quite deliberately, no attempt has been made to apportion tasks to professional groups in relation to the population of the dataset. It is essential that local circumstances dictate best practice.

The inclusion of some sensitive data elements may cause concern. However, they need not be completed if patients would prefer this information to be maintained locally. These items are included in the dataset to allow sharing where this is deemed appropriate.

Summary of Changes

The current iteration has been coded (Read v2) to ensure compatibility with primary care systems. This is essential if these systems (principally GPASS) are going to be able to contribute to the dataset and/or incorporate elements from the dataset. Current national IM&T strategy suggests that there will be a transition to SNOMED-CT but this is not yet available in operational systems.

The original CRAG dataset comprised some 129 items while this version has 130. However, there have been significant changes to the Eye Screening section to reflect the work of the Health Technology Board for Scotland in preparation for a national diabetes eye screening programme. The pregnancy, childhood and dietetic sections have also been expanded but many of the items suggested by the subgroups set up to assist with the review process were felt to be too specialised for inclusion in the Scottish Diabetes Core Dataset. These items will, however, be incorporated within the SCI-DC development programme.

Next Steps

The immediate task is to roll out the SCI-DC elements across Scotland and to work with the SCI and GPASS teams and other suppliers (including CDSS) to facilitate contribution to this common dataset from all places from where diabetes care is delivered.

For NHS Boards, the Scottish Executive has made it clear in a recent circular – Developing services for people with diabetes, HDL (2002)81 – that all diabetes data collection systems in Scotland are expected, over time, to be compatible with this core dataset.

Developing the Dataset

It is self evident that diabetes does not occur in isolation and patients frequently may have other health problems e.g. cardiovascular disease. This poses real but surmountable challenges in relation to the evolution of integrated records – obviously data should be reusable so that once an item is collected, it is (potentially) available elsewhere.

In terms of dataset development, further additions and refinements will be made in the light of experience and to accommodate future data demands. Discussions with ISD are ongoing about how best to promulgate and maintain the diabetes dataset (and indeed other clinical datasets). In the meantime, SCI-DC will continue to provide the focus for dataset development. Comments about the dataset should be submitted to Dr Lorna Ramsay, Clinical Advisor, Data Intelligence Group, ISD Scotland, Trinity Park House, South Trinity Road, Edinburgh EH5 3SQ.

It is anticipated that this will be the last version of the dataset to be published in this way. In future, it is likely that the dataset will be made available only in electronic form.

EXPLANATORY NOTES

The following information explains the various columns within the Core Dataset, how they have been developed, how to use them, how they have changed from the CRAG Dataset (CRAG, September 2000), definitions, and future developments in clinical coding.

Content
The content of the CRAG Shared Care Dataset is largely maintained in this Core Dataset. Many of the field descriptions, parameters and field names are unchanged.

Layout
The Core Dataset retains the layout of the CRAG Dataset in that it has been set out in sections covering demographics, general data, diabetes control, cardiovascular disease, renal disease, feet, eye care, pregnancy, births and young diabetics.

New Read Codes
The development of this Core Dataset has required the NHS Information Authority in Birmingham, who provide support for Read Codes for the UK, to issue a substantial number of new Read Codes. Read Code Updates are produced every six months and the majority of the new codes were included in the March and September 2002 releases. The SCI Diabetes Collaboration Team is working to ensure that up-to-date releases of Read are implemented in diabetes systems supporting this dataset.

Fields without Read Codes
A small number of data items could not be Read coded. The majority of these are in the demographics section, e.g. previous surname, where their absence should have no effect.

Use of synonyms and Term Codes
Read codes have a 'preferred term' based on the wording thought to best describe the concept at the time the code was developed, and may have a number of 'synonymous terms' giving alternative ways of describing the same concept. For example: myocardial infarction (preferred) and heart attack (synonym). As far as possible, preferred terms (term code 00) have been used, but in some instances synonyms are used.

The preferred terminology changes over time such that a synonym may come to better represent prevailing medical language or knowledge. A good example of this is the change in classification of diabetes from Insulin-dependent and Non-insulin dependent diabetes mellitus to Type 1 and Type 2 diabetes mellitus. Read version 2 was developed when IDDM & NIDDM were the preferred terms. The Read classification regards Types 1 & 2 DM as synonyms for IDDM and NIDDM, although this has not necessarily been true in clinical usage. The current WHO classification of diabetes into Type 1 and Type 2 can be specifically coded within Read by tagging a two digit 'term code' onto the 5 digit Read codes for IDDM and NIDDM.

Laterality Codes
A column has been introduced to allow specification of laterality to certain data items where left or right is not specified in the Read code itself. These 'qualifiers' or 'attributes' can be tagged onto the Read code by the IT system.

Coding Comment Column
The coding comment column summarises the string of codes, values and text required to represent each data item. This is essentially for the benefit of system developers. In most circumstances clinical users would not be expected to need to refer to this column.

It is anticipated that IT system developers will probably want to automatically associate a date of entry with all Read Codes although this has not been specifically stated in the coding comments column. However, for many fields, the date of an event or investigation is required for clinical purposes and should be visible to the health care professional. This may not be the same as the date on which the data are entered on the system. In these instances the system must allow the health care professional to enter the appropriate date, and for these fields the coding comment column indicates the need to record a date.

Derived fields

In order to reduce duplicate data entry, a number of derived Fields have been introduced. For example, 'Year of first myocardial infarction' can be derived by the IT system selecting the earliest date from the 'Myocardial Infarction' field in which all MIs are recorded with a date.

Summary of major changes from CRAG dataset

A column is included detailing any changes made to the CRAG Dataset. The main changes are described below.

1. Fields removed. A small number of fields have been removed from the CRAG Dataset: Outcome of appointment; Planned review interval; Planned review date; Date of event; Referred to clinic nurse; Semi-quantitative 10-year CHD risk; and Person who interpreted eye examination.
2. Revised sections. The sections having undergone revision are: feet (amputation, sensation and ulceration fields); eyes (maculopathy, non-diabetic retinal lesions, laser therapy); pregnancy and births (children live & stillborn are now dealt with separately to abortions). The field 'Appointment with defined healthcare professional' has been divided into two: 'referral to defined healthcare professional' and 'seen by defined healthcare professional'.
3. New fields. A number of new fields have been added to the Core Dataset, particularly in the sections on eyes, young people with diabetes and dietary advice.

Definitions

Up-to-date definitions have been specified for data items where appropriate. As far as possible, definitions have been taken from published sources including the Definitions and Codes Manual NHSScotland (ISD, 2002); Report by the Working Group to Support Shared Care in Diabetes (CRAG, 2000); Management of Diabetes guidelines (SIGN, 2001); and Health Technology Assessment Report 1: Organisation of services for diabetic retinopathy screening (Health Technology Board for Scotland, 2002).

SNOMED-Clinical Terms

SNOMED-Clinical Terms (SNOMED-CT) is expected to replace Read Codes as the NHS preferred clinical terminology in the coming years, subject to successful evaluation and Scottish Executive approval. It will create a single unified terminology for use in acute and primary care, facilitating integration of computerised clinical information and is therefore an underpinning feature of the development of Electronic Patient Records and Electronic Health Records.

It is anticipated that some of the problems encountered during the production of this Read Coded dataset will be overcome once SNOMED-CT is introduced. This will be particularly beneficial in coding of the various specialist diabetic dataset modules proposed. The SCI-Diabetes Collaboration will consider migration to SNOMED-CT in due course.

DEMOGRAPHIC DATA

Reference number	Field name	Description	Parameter	Read term	Read code
1	PT_NHS	Community Health Index (CHI) number for Scotland	10 digits	Patient CHI number	915B.
2	PT_ID	Principal treating hospital patient number	14 characters	Patient hospital number	915D.
3	HOSP_ID	Principal treating hospital identifier	6 characters	Hospital reference number	9R6..
4	PRACID	General practice identifier	6-digit practice code		
5	GP_CODE	Registered GP identifier (GMC Code)	7 digits (GMC No. format)	General Medical Practitioner	03DC.
6	GPC_CODE	GMC Code of GP to whom correspondence should be addressed	7 digits (GMC No. format)		
7	SURNAME	Present surname	20 characters	Patient surname	9152.
8	FNAME1	1st forename	20 characters	Patient forename	9151.
9	FNAME2	2nd forename	20 characters		
10	OLDNAME	Previous surname	20 characters		
11	DOB	Date of birth	dd/mm/yyyy	Patient date of birth	9155.
12	ADDR1	Address 1	35 characters	Patient address	9153.
13	ADDR2	Address 2	35 characters		
14	ADDR3	Address 3	35 characters		
15	ADDR4	Address 4	35 characters		

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code + CHI number	n/a	Mandatory field. The Community Health Index (CHI) is a population register used for health care purposes. The CHI number uniquely identifies a person on the index.
00		Read code + hospital number	n/a	The hospital patient identifier is a code, which uniquely identifies a patient on the main index of a hospital (i.e. within the hospital health records system).
00		Read code + ISD location code	n/a	Each location in Scotland, at which events pertinent to the Scottish Health Service take place, is allocated a location code. Locations include hospitals, health centres, clinics, NHS board offices, private nursing homes, homes for the elderly, children's homes and schools. The code is a five-character code maintained jointly by ISD and GRO (Scotland).
		ISD reference file number (no Read code available)	n/a	Each GP practice (partnerships and single-handed) in Scotland is identified by a unique GP practice code. The practice code is a four-digit code plus a check digit with ranges of codes allocated to each NHS Board.
00		Read code + GMC Number	n/a	The GMC (General Medical Council) number is the personal identification number issued to each doctor/dentist by the General Medical Council/General Dental Council.
		GMC Number (no Read Code available)	n/a	See above.
00		Read code + text	n/a	Mandatory field. The surname of a person represents that part of the name of a person, which indicates the family group of which the person is part. It should be noted that in Western culture this is normally the latter part of the name of a person. However, this is not necessarily true of all cultures. This will, of course, give rise to some problems in the representation of the name. This is resolved by including with the name a preferred name format indicating amongst other things the order of various parts of the name.
00		Read code + text	n/a	Mandatory field. The first forename of a person represents that part of the name of a person, which after the surname, is the principal identifier of a person.
		No Read code available	n/a	A previous name is any name by which a person was previously known.
		No Read code available	n/a	This is any surname by which a person was previously known.
00		Read code + date	n/a	Mandatory field.
00		Read code + address	n/a	NHS standards for unstructured and structured addresses exist and are applicable in England and Scotland. (Refer to Defs Manual for details).
		No Read code available	n/a	
		No Read code available	n/a	
		No Read code available	n/a	

DEMOGRAPHIC DATA (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
16	PCODE	Postcode	8 characters	Patient postcode	9158.
17	SEX	Sex	Heading	Gender	1K...
			1 = Male	Male	1K0..
			2 = Female	Female	1K1..
18	ETHN_GP	Ethnic grouping	heading	Ethnic groups (2001 census)	9S...
			0 = White	White Scottish	9S13.
				White Irish	9S11.
				Other white British ethnic group	9S14.
				Other white ethnic group	9S12.
			1 = Black Caribbean	Black Caribbean	9S2..
			2 = Black African	Black African	9S3..
				Other black ethnic group	9SG..
			3 = Indian	Indian	9S6..
			4 = Pakistani	Pakistani	9S7..
			5 = Bangladeshi	Bangladeshi	9S8..
			6 = Chinese	Chinese	9S9..
				Other Asian ethnic group	9SH..
			30 = Other	Other ethnic group	9SJ..
				Other ethnic, mixed origin	9SB..
				Ethnic group not recorded	9SE..
19	STATUS	Current practice registration status	heading	Patient registration status	912..
			1 = On practice list	Patient registered by HB	912C.
			2 = Not on practice list	Patient not registered	9121.
20	DTDIAG	Date of diagnosis	dd/mm/yyyy	Diabetes mellitus	C10..
21	FASTING	Fasting venous plasma glucose at diagnosis	(nn.n) mmol/l	Plasma fasting glucose level	44g1.
22	2HRGLU	2-hour venous plasma glucose OGTT at diagnosis	(nn.n) mmol/l	120 minute plasma glucose level	44g6.
23	RANDGLU	Random venous plasma glucose at diagnosis	(nn.n) mmol/l	Plasma random glucose level	44g0.

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code + postcode	n/a	The postcode is a basic unit for identifying geographic locations. A postcode has two component parts: part one is the outcode, and part two is the incode. Refer to Definitions Manual for more details.
00		Read code heading	n/a	Phenotype at birth.
00		Read code	n/a	
00		Read code	n/a	
00		Read code heading	Updated from 1991 census to 2001	An ethnic group is a group of people having racial, religious, linguistic and/or other cultural traits in common. The ethnic group to which a patient belongs is judged by the patient. The standard 2001 OPCS classification of ethnicity is used here.
00		Read code	n/a	
00		Read code	n/a	
00		Read code	n/a	
00		Read code	n/a	
00		Read code	n/a	
00		Read code	n/a	
00		Read code	n/a	
00		Read code	n/a	
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00		Read code	n/a	
00		Read code	n/a	
00		Read code	n/a	
00		Read code	n/a	
00		Read code	n/a	
00		Read code heading	n/a	Required to record accurate prevalence data.
00		Read code	n/a	
00		Read code	n/a	
00		Read code + date	n/a	Day and month are not obligatory and where missing the format 01/01/2003 is recommended. Date of diagnosis does not apply to states of impaired glucose tolerance or impaired fasting glucose.
00		Read code + value + date	n/a	To ensure that a patient entered on the database has the appropriate diagnosis of diabetes mellitus, some measurement of blood glucose at diagnosis is required. Venous plasma sample must be used for this purpose. It is not essential that all 3 items are included, but at least one must be recorded. This should be interpreted according to the prevailing agreed UK classification of diabetes. In some cases, a random or fasting blood glucose will be sufficient; in others, the OGTT will be required.
00		Read code + value + date	n/a	Venous plasma glucose value two hours post 75g oral glucose.
00		Read code + value + date	n/a	

DEMOGRAPHIC DATA (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
24	TYPE_DM	Type of diabetes	1 = Type 1 Diabetes Mellitus	Type 1 Diabetes Mellitus	C108.
			2 = Type 2 Diabetes Mellitus	Type 2 Diabetes Mellitus	C109.
			3 = Impaired glucose tolerance	Impaired glucose tolerance	R10E.
			4 = Impaired fasting glucose	Impaired fasting glycaemia	R10D0
			5 = Gestational	Gestational Diabetes Mellitus	L1809
			6=Maturity onset diabetes of youth (MODY)	Maturity onset diabetes of youth	C10C.
25	HOSPCARE	Attendance at hospital diabetes clinic	Attended hospital diabetes clinic	Seen in diabetic clinic	9N1Q.
26	CARETYPE	Arrangement for formal diabetes care	heading	Diabetic monitoring	66A..
			1 = Primary care (GP) only	Diabetes: practice programme	66AP.
			2 = Hospital diabetic clinic only	Diabetes care by hospital only	66AU.
			3 = Shared between hospital diabetic clinic and GP	Diabetes: shared care program	66AQ.
27	CLINIC	Principal treating hospital diabetes clinic ID	6 characters	Attending diabetes clinic	9NM0.
28	DOD	Date of death	dd/mm/yyyy	Death	22J..
29	DEATHGRO	Cause of death	ICD 10 code	Cause of death	94B..
30	DEATHDIAB	Underlying cause of death	heading		
			1 = Directly related to diabetes		
			2 = Indirectly/ possibly related to diabetes		
			3 = Not related to diabetes		

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
12		Read code + Term code	n/a	'Preferred term' codes for types 1 & 2 diabetes should be available in the future through the new terminology SNOMED-CT. Secondary, other and unknown categories have not been included in the core dataset. 'Secondary diabetes' cannot currently be coded. It was considered that few or no patients should have 'other' or 'unknown' type of diabetes.
12		Read code + Term code	n/a	
00		Read code	n/a	Note this does not constitute a diagnosis of diabetes mellitus.
00		Read code	n/a	Note this does not constitute a diagnosis of diabetes mellitus.
00		Read code	n/a	
11		Read code + Term code	n/a	
00		Read code + date	Binary response in CRAG 'attends/does not attend' – see notes.	Binary response in CRAG 'attends/does not attend' could not be Read coded – considered positive response with date is appropriate for core dataset.
00		Read code heading	4 = Unknown in CRAG dataset – considered parameter should be known.	These data items should be recorded prospectively as intentions.
00		Read code	n/a	
00		Read code	n/a	
00		Read code	n/a	
00		Read code + clinic ID	n/a	
12		Read code + Term code + date	n/a	
00		Read code + ICD10 code	n/a	This field would be appropriately completed with ICD10 code by data linkage. From this, death due to coronary heart disease (a St Vincent target) could be ascertained.
		No Read code available	n/a	
		No Read code available	n/a	
		No Read code available	n/a	
		No Read code available	n/a	

GENERAL DATA

Reference number	Field name	Description	Parameter	Read term	Read code
31	WEIGHT	Patient weight	>0 – 300 kg (nnn.nn)	O/E – weight	22A..
32	HEIGHT	Patient height	>0 – 2.50 m (nnn.nnn)	O/E – height	229..
33	BMI	Patient body mass index	(nn.n) kg/m^2	Body Mass Index	22K..
34	SBP	Systolic blood pressure	(nnn) mmHg	O/E – Systolic BP reading	2469.
35	DBP	Diastolic blood pressure	(nnn) mmHg	O/E – Diastolic BP reading	246A.
36	SMOKER	Smoking status at date of contact	heading	Tobacco consumption	137..
			1 = Current smoker	Current smoker	137R.
			2 = Ex smoker	Ex smoker	137S.
			3 = Never smoked	Never smoked tobacco	1371.
37	STOPSMOK	Year patient stopped smoking	yyyy	Date ceased smoking	137T.
38	ALCHOHOL	Alcohol intake per average week	(nn) units	Alcohol consumption	136..
39	IMPOTENCE	Erectile failure		Impotence	E2273
40	G-DEPR-WB	General depressed wellbeing		General wellbeing schedule	3884.
41	D-DEPR-WB	Diabetes depressed wellbeing		Diabetes wellbeing questionnaire	3882.
42	SATIS-SERV	Satisfaction with service		Diabetes treatmt satisf quest	3883.
43	DIAB_REV	Diabetic review on this date	dd/mm/yyyy	follow-up diabetic assessment	66A2.

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code + value + date	n/a	Weight in kilograms taken without shoes.
00		Read code + value + date	n/a	Height in metres – measured without shoes. It is particularly important to measure regularly the height of children. In adults a single recording will usually be sufficient.
00		Read code + value + date	n/a	IT systems should calculate BMI automatically from the above fields as weight/height^2 (kg/m^2).
00		Read code + value + date	n/a	Systolic blood pressure in mmHg taken after 10 minutes sitting.
00		Read code + value + date	n/a	Diastolic blood pressure in mmHg taken sitting.
00		Read code heading	n/a	This field should be updated as appropriate.
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + year	n/a	Year of stopping smoking to be recorded as one or more events to allow valid recording over time of individuals who stop and restart.
00		Read code + value + date	n/a	Alcohol intake per average week measured in units (1 unit = 10g). Recording of a numerical value is prefered since recommended consumption limits are subject to periodic revision and may differ for pregnant women.
00		Read code + date	n/a	Failure to achieve/maintain erection sufficient for penetration. Data should remain confidential to treating physician. Refers to adult males only.
00		Read code + value + date	n/a	Two part questionnaire included as appendix in UK Diabetes Audit Working Group paper – 6 questions on general wellbeing and 6 specific to diabetes. (A dataset to allow exchange of information for monitoring continuing diabetes care, Wilson AE, Home PD *et al. Diabetic Medicine,* 1993; 10: 378-390.) SIGN guideline 55 on Management of Diabetes recommends that all people with diabetes should be screened for depression and offered appropriate therapy. Age appropriateness should be taken into account when using this parameter.
00		Read code + value + date	n/a	
00		Read code + value + date	n/a	Questionnaire (18 questions) included as appendix to UK Diabetes Audit Working Group paper.
00		Read code + date	Replaces CRAG 'annual review'.	This is no longer an annual review field since in practice most patients do not have a formal annual review appointment. The recurrent process measures, which should be monitored at least annually, tend to be performed at different episodes through the year. This achieves the same purpose provided each of these process measures has a date stamp.

GENERAL DATA (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
44	REF_HCP	Referral to defined healthcare professional	heading	Referral for further care	8H...
			1 = G.P.	Referral to G.P.	8H62.
			2 = Diabetologist	Referral to diabetologist	8H4F.
			3 = State registered dietitian	Refer to dietitian	8H76.
			4 = Diabetes specialist nurse	Referral to diabetic liaison nurse	8H7C.
			5 = Practice nurse	Referral to practice nurse	8H71.
			6 = Podiatrist	Referral to podiatry	8H7X.
			7 = Ophthalmologist	Ophthalmological referral	8H52.
			8 = Retinal screening programme	Referral to retinal screener	8H7n.
			9 = Diabetic foot screener	Refer to diabetic foot screener	8H7r.
			10 = Psychologist	Refer to psychologist	8H7T.
45	SEEN_HCP	Seen by defined healthcare professional at this event	1 = GP	Seen by General Practitioner	9N21.
			2 = Diabetologist	Seen by Diabetologist	9N2d.
			3 = Dietitian	Seen by Dietitian	9N27.
			4 = Diabetes Specialist Nurse	Seen by Diabetic liaison nurse	9N2i.
			5 = Practice nurse	Seen by Practice Nurse	9N22.
			6 = Ophthalmologist	Seen by Ophthalmologist	9N2e.
			7 = Optometrist	Seen by Optometrist	9N2V.
			8 = Retinal screening programme	Seen by Retinal screener	9N2f.
			9 = Podiatrist	Seen by Podiatrist	9N2Q.

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code heading	Replaces CRAG 'appointment with defined healthcare professional'. Separate 'Clinic nurse' category no longer included. Psychologist added.	Recorded each time a referral is made.
00		Read code + date		
00		Read code + date		
00		Read code + date	Replaces CRAG separate field for dietetic referral.	
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date	n/a	Revised since CRAG. This field records the profession of the person completing this health care contact and entering data.
00		Read code + date	n/a	
00		Read code + date	Replaces CRAG separate field for dietetic consultation.	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	

DIABETES CONTROL

Reference number	Field name	Description	Parameter	Read term	Read code
46	DRUGS	Hypoglycaemic drug therapy	1 = Insulin only	Diabetic on insulin	66A5.
			2 = Tablet only	Diabetic on oral treatment	66A4.
			3 = Insulin + tablets	Diabetic on insulin and oral treatment	66AV.
			4 = None	Diabetic on diet only	66A3.
47	CREAT	Serum creatinine	(nnnn) umol/L	Serum creatinine	44J3.
48	CHOL	Serum total cholesterol	(nn.n) mmol/L	Total cholesterol measurement	44PH.
49	HDL	Serum HDL cholesterol	(nn.n) mmol/L	Serum HDL cholesterol level	44P5.
50	TG	Triglycerides	(nn.n) mmol/L	Serum triglycerides	44Q..
51	ALBUSTIX	Albustix result	heading	Urine protein test	467..
			0 = not recorded	Urine protein test not done	4671.
			1 = negative	Urine protein test negative	4672.
			2 = trace	Urine protein test = trace	4673.
			3 = 1+	Urine protein test = +	4674.
			4 = 2+	Urine protein test = ++	4675.
			5 = 3+	Urine protein test = +++	4676.
52	MAVALUE	Numeric result of urinary albumin related to method used	heading	Urine protein	46N..
			1 = albumin concentration mg/l	urine albumin	46N4.
			2 = albumin creatinine ratio (ACR) mg/mmol	urine albumin:creatinine ratio	46TC.
			3 = timed overnight albumin excretion rate ug/min	overnight albumin excretion rate	44JG.
			4 = 24hr albumin excretion rate mg/24hrs	24hr urine albumin output	46N6.

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + value + date	n/a	
00		Read code + value + date	n/a	Serum total cholesterol can be either fasted or unfasted.
00		Read code + value + date	n/a	Serum HDL cholesterol can be either fasted or unfasted. HDL cholesterol is recorded in order to allow calculation of the 10-year CHD risk (along with smoking status, age, sex and BP) according to SIGN 40 guideline on Primary Prevention of Coronary Heart Disease.
00		Read code + value + date	n/a	
00		Read code heading	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code heading	n/a	Urine specimen to check for microalbuminuria may be collected in several ways depending on local preference. Staging definitions vary by method so values must be accompanied by statement of the method used.
00		Read code + value + date	n/a	Measured in first voided morning specimen.
00		Read code + value + date	n/a	Measured in first voided morning specimen.
00		Read code + value + date	n/a	Timed collection under 24 hours, often overnight.
00		Read code + value + date	n/a	

DIABETES CONTROL (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
53	MASTAGE	Albumin excretion (stages 1-4)	1 = Stage 1 (Normo-albuminuria)	urine protein normal	46N1.
			2 = Stage 2 (Micro-albuminuria)	Microalbuminuria	R1103
			3 = Stage 3&4 (Macro-albuminuria)	Persistent proteinuria, unspecified	K190X
54	GHB	Glycated haemoglobin (HbA1c)	0.0 – 30.0% (nn.n)	HbA1c – diabetic control	42W..
55	INJSITES	Injection sites abnormal		O/E – Injection sites abnormal	2F16.
56	SELF-MON	Self monitoring type	heading	Metabolic monitoring	8A1..
			1 = urine	Self-monitoring urine glucose	8A18.
			2 = blood	Self-monitoring blood glucose	8A17.
			3 = both	Self-monit. blood+urine glucose	8A19.
57	SEV_HYPO	Occurrence of severe (grade 4) Hypoglycaemic coma			C110.

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code + date	n/a	For cross comparison the value of albumin excretion by whatever method should be graded into three stages as recommended in SIGN 55 and SIGN 11 guidelines on Management of Diabetic Renal Disease. See table in guideline for staging definitions by method. The computer program should automatically grade the stage according to the method chosen. Neither microalbuminuria nor persistent proteinuria should be diagnosed on the basis of a single urine sample result.
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + value + date	n/a	Glycated haemoglobin refers to measurement of HbA1c (not HbA1).
00		Read code + date	Binary response in CRAG replaced by dated recording of abnormality.	Abnormal is defined as thickening on inspection or palpation.
00		Read code heading	n/a	Self monitoring refers to use of reagent strips for monitoring blood or urinary glucose (at least 1 test per week).
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	n/a	
00		Read code + date	Binary response in CRAG replaced by dated recording of abnormality.	Hypoglycaemia requiring external assistance or unconciousness/convulsion secondary to hypoglycaemia – record any episodes since last contact.

CARDIOVASCULAR AND RENAL DISEASE

Reference number	Field name	Description	Parameter	Read term	Read code
58	MI	Myocardial Infarct – date of	dd/mm/yyyy	Acute myocardial infarction NOS	G30z.
59	YRHYPTEN	Year of diagnosis of hypertension	yyyy	High blood pressure	G20..
60	YRCABG	CABG/coronary revascularisation procedure	yyyy	Coronary artery operations	792..
61	YRANGINA	Year of diagnosis of angina/CHD	yyyy	Ischaemic heart disease NOS	G3z..
62	YRMI	Year of 1st MI	yyyy		
63	STROKE	Stroke – date of	dd/mm/yyyy	Stroke and cerebrovascular accident unspecified	G66..
64	YRSTROKE	Year of 1st stroke	yyyy		
65	CLAUD	Intermittent claudication	dd/mm/yyyy	Intermittent claudication	G73z0
66	CHD_RISK	10-year CHD event risk from SIGN 40 & BCS algorithm	nn.n%	Framingham coronary heart disease 10-year risk score	3888.
67	YRDIALYS	Dialysis for renal failure	yyyy	Dialysis for renal failure	7L1A.
68	YRRTRNSP	Year of renal transplant procedure	yyyy	Transplantation of kidney	7B00.
69	YRRENAL	Year commenced renal replacement therapy	yyyy		
70	YRESRF	Year of end-stage renal failure	yyyy	End-stage renal failure	K050.

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code + date	CRAG 'on this date' specification removed.	SIGN 25 states: 'Record of recurrent infarction is used as an indicator of the success or otherwise of secondary prevention. In most situations a myocardial infarction will have occurred on a different date to the diabetic assessment. This will be accommodated by the use of event based files with a separate record, with appropriate date, for each episode of myocardial infarction.'
11		Read code + Term code + year	Changed from CRAG 'year of onset'.	Note that the definition of 'hypertension' is subject to periodic revision. The prevailing definition at the time of data recording should be used.
00		Read code + year	n/a	
00		Read code + year	Changed from CRAG 'year of onset'.	Year of clinical diagnosis of angina or objective evidence of coronary heart disease.
		Field to be derived from dataset	n/a	Year of onset of first myocardial infarction proven by ECG, cardiac enzymes or heart perfusion scan or other reliable methodology, but not on clinical features alone.
00		Read code + date	Changed from CRAG 'neurological deficit >24h'.	Event based record of each episode of cerebrovascular accident (stroke), defined as rapidly developing signs of focal (and/or global) disturbance of cerebral function lasting more than 24 hours or leading to death with no apparent cause other than vascular origin.
		Field to be derived from dataset	n/a	Year of onset of first stroke.
00		Read code + date	Changed from binary to event based.	Classical leg pain on exertion relieved by rest in either limb.
00		Read code + score + date	Semi-quantitative 10-year CHD risk removed – see note.	The absolute CHD risk for primary prevention can be calculated from the Framingham equation using the Excel macro available from the University of Manchester. This macro should be available with software application supporting the dataset therefore the CRAG semi-quantitative 10-year CHD risk field has been removed.
11		Read code + term code + year	Replaces CRAG 'year commenced renal replacement therapy'.	
00		Read code + year	Replaces CRAG 'year commenced renal replacement therapy'.	
		Field to be derived from dataset	n/a	
00		Read code + year	n/a	Year that either serum creatinine was chronically greater than 500umol/l (i.e. >500 umol/l on two occasions three months apart) or the patient was placed on permanent dialysis or received a renal transplant. This field could be automatically calculated by an IT system.

FEET

Reference number	Field name	Description	Parameter	Read term	Read code
71	FOOTRISK	Foot risk status	1/2/3/4	O/E – Right Diabetic foot at risk	2G5A.
			1/2/3/4	O/E – Left Diabetic foot at risk	2G5B.
72	AMPUT_L	Amputation, left lower limb – event	heading	Amputation of leg	7L06.
			1 = transfemoral	Amputation above knee	7L062
			2 = transtibial	Amputation below knee	7L064
			3 = forefoot	Amputation thro metatars bones	7L073
			4 = digit/metatarsal	Amputation of toe	7L08.
73	AMPUT_LD	Prevalent amputation status – left lower limb			
74	AMPUT_R	Amputation, right lower limb – event	heading	Amputation of leg	7L06.
			1 = transfemoral	Amputation above knee	7L062
			2 = transtibial	Amputation below knee	7L064
			3 = forefoot	Amputation thro metatars bones	7L073
			4 = digit/metatarsal	Amputation of toe	7L08.

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code + scale + date	Now has laterality. CRAG grading changed.	The SIGN 25 definitions used in CRAG have been updated with the SIGN 55 risk assessment criteria (adapted from Tayside Foot Risk Assessment Protocol). Foot risk status: Low risk 1 – Normal sensation AND good pulses, no previous ulcer, no foot deformity, normal vision; Moderate risk 2 – ANY OF loss of sensation, absent pulses (or previous vascular surgery), significant visual impairment, physical disability (e.g. stroke, gross obesity); High risk 3 – ANY OF Previous ulcer due to neuropathy/ischaemia, absent pulses and neuropathy, Callus with risk factor (absent pulse, neuropathy, foot deformity); Active foot disease 4 – Active foot ulceration, painful neuropathy which is difficult to control.
00		Read code + scale + date		
00	7NB32	Read code heading + Read code laterality	Amalgamates prevalent amputation status and amputation event fields from CRAG.	This field is event-based with an appropriately dated entry for each amputation episode. Amputation is defined as recommended in the SIGN guideline on Management of Diabetic Foot Disease as 'removal of forefoot or part of the lower limb'. This excludes loss of toes or single metatarsals, therefore the 4th category should be excluded from analyses based on this definition. Prevalent amputation status can be derived from this field by reference to the most recent event chronologically.
00	7NB32	Read code + Read code laterality + date		
00	7NB32	Read code + Read code laterality + date		
00	7NB32	Read code + Read code laterality + date		
00	7NB32	Read code + Read code laterality + date		
		Field to be derived from dataset		
00	7NB31	Read code heading + Read code laterality		This field is event-based with an appropriately dated entry for each amputation episode. Amputation is defined as recommended in the SIGN guideline on Management of Diabetic Foot Disease as 'removal of forefoot or part of the lower limb'. This excludes loss of toes or single metatarsals, therefore the 4th category should be excluded from analyses based on this definition. Prevalent amputation status can be derived from this field by reference to the most recent event chronologically.
00	7NB31	Read code + Read code laterality + date		
00	7NB31	Read code + Read code laterality + date		
00	7NB31	Read code + Read code laterality + date		
00	7NB31	Read code + Read code laterality + date		

FEET (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
75	AMPUT_RD	Prevalent amputation status – right lower limb			
76	PULSES_L	Any foot pulse – left	1 = Present	Foot Pulse left leg – present	24FB.
			2 = Absent	O/E – absent left foot pulses	24FA.
77	PULSES_R	Any foot pulse – right	1 = Present	Foot Pulse right leg – present	24EB.
			2 = Absent	O/E – absent right foot pulses	24EA.
78	FTMFIL_L	foot sensation to monofilaments – left	1 = Normal	10g monofilament sensation present	29B7.
			2 = Impaired	10g monofilament sensation absent	29B8.
79	FTMFIL_R	foot sensation to monofilaments – right	1 = Normal	10g monofilament sensation present	29B7.
			2 = Impaired	10g monofilament sensation absent	29B8.
80	FTVIBR_L	foot vibration sensation – left	1 = Normal	O/E – Vibration sense of left foot normal	29H7.
			2 = Abnormal	O/E – Vibration sense of left foot abnormal	29H6.
81	FTVIBR_R	foot vibration sensation – right	1 = Normal	O/E – Vibration sense of right foot normal	29H5.
			2 = Abnormal	O/E – Vibration sense of right foot abnormal	29H4.
82	FTSENS_L	foot sensation – left	1 = Normal 2 = Abnormal		
83	FTSENS_R	foot sensation – right	1 = Normal 2 = Abnormal		

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
		Field to be derived from dataset		
00		Read code + date		Foot pulses should be recorded as present if either one or both of the two major arteries (dorsalis pedis and posterior tibial) of the foot are felt upon physical palpation. The presence of pulses by Doppler ankle pressure should be interpreted with caution since normal readings may be recorded in the presence of medial arterial calcification and could be misleading.
00		Read code + date		
00		Read code + date		Foot pulses should be recorded as present if either one or both of the two major arteries (dorsalis pedis and posterior tibial) of the foot are felt upon physical palpation. The presence of pulses by Doppler ankle pressure should be interpreted with caution since normal readings may be recorded in the presence of medial arterial calcification and could be misleading.
00		Read code + date		
00	7NB32	Read code + Read code laterality + date	New field.	Test for detection of monofilament of 10 gram weight. Apply monofilament to 1st, 2nd, 3rd & 5th metatarsal heads and plantar surface of great toe. Failure to detect two or more stimuli represents abnormal sensation.
00	7NB32	Read code + Read code laterality + date		
00	7NB31	Read code + Read code laterality + date	New field.	See above.
00	7NB31	Read code + Read code laterality + date		
00		Read code + date	New field.	Test for perception of vibration of a 128 Hz tuning fork over the medial malleolus for 5 seconds or more.
00		Read code + date		
00		Read code + date	New field.	See above.
00		Read code + date		
		Field to be derived from dataset		The measurement of foot sensation should be carried out as recommended in the SIGN guideline on the Management of Diabetic Foot Disease. Foot sensation should be considered abnormal if monofilament and/or vibration sensation are impaired as defined above. This field can be derived by the IT system from the relevant fields.
		Field to be derived from dataset		See above.

FEET (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
84	CALLUS_L	Foot callus – left		Callosity	M201.
85	CALLUS_R	Foot callus – right		Callosity	M201.
86	FTDEF_L	Foot deformity – left		O/E – Left foot deformity	2G59.
87	FTDEF_R	Foot deformity – right		O/E – Right foot deformity	2G58.
88	NEWFTULC	New episode of foot ulceration	dd/mm/yyyy	Foot ulcer	M271.
89	ULCER_L	Prevalent ulcer status left foot		O/E – left foot ulcer	2G55.
90	ULCER_R	Prevalent ulcer status right foot		O/E – right foot ulcer	2G54.
91	YR1STAMP	Year of first lower limb amputation	yyyy		
92	PODIAT	Arrangement for podiatry attendance	1 = hospital 2 = community 3 = private state registered 4 = other 5 = none	Under care of podiatrist	9NN0.

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00	7NB32	Read code + Read code laterality + date	Binary response in CRAG replaced by dated recording of abnormality.	
00	7NB31	Read code + Read code laterality + date		
00		Read code + date	Binary response in CRAG replaced by dated recording of abnormality.	Foot deformity includes: toe abnormality (claw toe, hammer toe, over-riding toe); prominent metatarsal head; bunion; Charcot arthropathy; congenital deformity.
00		Read code + date		
11		Read code + Term code + date	Replaces CRAG 'year of observation of first foot ulcer'.	Where appropriate, this field should allow retrospective recording of year of observation of first foot ulcer on either foot as well as recording any subsequent new episodes of ulceration. Ulcer is defined as any break in the epithelium greater than a crack below the level of the malleoli. It is required as an indicator of possible risk of future amputation.
00		Read code + date	Binary response in CRAG replaced by dated recording of abnormality.	This field allows recording of observation of foot ulcer on date of episode for clinical care purposes – this may be a new ulcer or ongoing presence of previously noted ulcer.
00		Read code + date	Binary response in CRAG replaced by dated recording of abnormality.	See above.
		Field to be derived from dataset		SIGN definition = year of first amputation of forefoot or part of the lower limb. It excludes loss of toes or single metatarsals. This field could be derived by the IT system.
00		Read code + value + date		

EYE CARE

Reference number	Field name	Description	Parameter	Read term	Read code
93	VA_L	Visual Acuity – left (corrected)	4 characters	O/E – visual acuity L- eye	2B7..
			1 = 6/4	O/E – visual acuity L-eye = 6/4	2B7D.
			2 = 6/5	O/E – visual acuity L-eye = 6/5	2B71.
			3 = 6/6	O/E – visual acuity L-eye = 6/6	2B72.
			4 = 6/9	O/E – visual acuity L-eye = 6/9	2B73.
			5 = 6/12	O/E – visual acuity L-eye = 6/12	2B74.
			6 = 6/18	O/E – visual acuity L-eye = 6/18	2B75.
			7 = 6/24	O/E – visual acuity L-eye = 6/24	2B76.
			8 = 6/36	O/E – visual acuity L-eye = 6/36	2B77.
			9 = 6/60	O/E – visual acuity L-eye = 6/60	2B78.
			10 = 3/60	O/E – visual acuity L-eye = 3/60	2B7E.
			11 = CF (counts fingers)	O/E -L-eye counts fingers only	2B79.
			12 = HM (hand movements)	O/E – L-eye sees hand movements	2B7C.
			13 = PL (perception of light)	O/E – L-eye perceives light only	2B7A.
94	VA_R	Visual Acuity – right (corrected)	4 characters	O/E – visual acuity R-eye	2B6..
			1 = 6/4	O/E – visual acuity R-eye = 6/4	2B6D.
			2 = 6/5	O/E – visual acuity R-eye = 6/5	2B61.
			3 = 6/6	O/E – visual acuity R-eye = 6/6	2B62.
			4 = 6/9	O/E – visual acuity R-eye = 6/9	2B63.
			5 = 6/12	O/E – visual acuity R-eye = 6/12	2B64.
			6 = 6/18	O/E – visual acuity R-eye = 6/18	2B65.
			7 = 6/24	O/E – visual acuity R-eye = 6/24	2B66.
			8 = 6/36	O/E – visual acuity R-eye = 6/36	2B67.
			9 = 6/60	O/E – visual acuity R-eye = 6/60	2B68.
			10 = 3/60	O/E – visual acuity R-eye = 3/60	2B6E.
			11 = CF (counts fingers)	O/E – R-eye counts fingers only	2B69.
			12 = HM (hand movements)	O/E – R-eye sees hand movements	2B6C.
			13 = PL (perception of light)	O/E – R-eye perceives light only	2B6A.

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code heading		Visual acuity should be recorded in the corrected state.
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code heading		Visual acuity should be recorded in the corrected state.
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		

EYE CARE (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
95	RETINA_L	Retinal status – Left	heading	O/E – retinal inspection	2BB..
			R0 = No retinopathy	O/E – no left diabetic retinopathy	2BBK.
			R1 = Background diabetic retinopathy (BDR) mild	background diabetic retinopathy	F4200
			R2 = BDR moderate	Preproliferative diabetic retinopathy	F4202
			R3 = BDR severe	Preproliferative diabetic retinopathy	F4202
			R4 = Proliferative retinopathy	Proliferative diabetic retinopathy	F4201
			R5 = Enucleated	Enucleation of eyeball	72001
			R6 = Not adequately visualised	O/E – left retina not seen	2BBC.
96	RETINA_R	Retinal status – Right	heading	O/E – retinal inspection	2BB..
			R0 = No retinopathy	O/E – no right diabetic retinopathy	2BBJ.
			R1 = Background diabetic retinopathy (BDR) mild	Background diabetic retinopathy	F4200
			R2 = BDR moderate	Preproliferative diabetic retinopathy	F4202
			R3 = BDR severe	Preproliferative diabetic retinopathy	F4202

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00	Add 7NB32	Read code heading + Read code laterality	'BDR very severe', 'High risk proliferative retinopathy' and 'Advanced diabetic eye disease' now deleted.	This grading is consistent with the Scottish Diabetic Retinopathy Grading System produced by the Health Technology Board for Scotland (December 2002 amendment) and the Royal College of Ophthalmologists Report – Guidelines for Diabetic Retinopathy 1997. It replaces the grades recommended in SIGN 25. Due to restrictions with Read Codes, grades R2 & R3 are currently both mapped to preproliferative diabetic retinopathy since they require some form of action/referral.
00		Read code + date		
00	Add 7NB32	Read code + Read code laterality + date		
00	Add 7NB32	Read code + Read code laterality + date		
00	Add 7NB32	Read code + Read code laterality + date		
00	Add 7NB32	Read code + Read code laterality + date		
00	Add 7NB32	Read code + Read code laterality + date		
00		Read code + date		
00	Add 7NB31	Read code heading + Read code laterality	'BDR very severe', 'High risk proliferative retinopathy' and 'Advanced diabetic eye disease' now deleted.	This grading is consistent with the Scottish Diabetic Retinopathy Grading System produced by the Health Technology Board for Scotland (December 2002 amendment) and the Royal College of Ophthalmologists Report – Guidelines for Diabetic Retinopathy 1997. It replaces the grades recommended in SIGN 25. Due to restrictions with Read Codes, grades R2 & R3 are currently both mapped to preproliferative diabetic retinopathy since they require some form of action/referral.
00		Read code + date		
00	Add 7NB31	Read code + Read code laterality + date		
00	Add 7NB31	Read code + Read code laterality + date		
00	Add 7NB31	Read code + Read code laterality + date		

EYE CARE (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
			R4 = Proliferative retinopathy	Proliferative diabetic retinopathy	F4201
			R5 = Enucleated	Enucleation of eyeball	72001
			R6 = Not adequately visualised	O/E – right retina not seen	2BBB.
97	BLIND	Permanent blindness as defined	1 = Diabetic cause	Blindness, both eyes	F490.
			2 = Non-diabetic cause		
			3 = Blind, cause unknown		
			4 = Blind, potentially reversible cause		
98	YRBLIND	Year of onset of permanent blindness	yyyy		
99	MACULA_L	Diabetic maculopathy – left eye	M1 = Observable diabetic maculopathy left eye	Diabetic maculopathy	F4204
			M2 = Referrable diabetic maculopathy left eye	Advanced diabetic maculopathy	F4203
100	MACULA_R	Diabetic maculopathy – right eye	M1 = Observable diabetic maculopathy right eye	Diabetic maculopathy	F4204
			M2 = Referrable diabetic maculopathy right eye	Advanced diabetic maculopathy	F4203

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00	Add 7NB31	Read code + Read code laterality + date		
00	Add 7NB31	Read code + Read code laterality + date		
00		Read code + date		
00		Read code + value + date	Additional option 'potentially reversible cause' added. CRAG 'not blind' category omitted.	Permanent blindness is defined as permanent visual acuity corrected (i.e. wearing corrective lenses) of <3/60 (i.e. CF, HM or PL) in the better eye. Year of onset of permanent blindness can be derived from this field by IT system.
				Potentially reversible causes include operable diabetic cataract and vitreous haemorrhage.
		Field to be derived from dataset excluding option 4 ('potentially reversible cause')		
00	Add 7NB32	Read code + Read code laterality + date	The term 'early diabetic maculopathy' is now deleted.	This grading is based on the Scottish Diabetic Retinopathy Grading System produced by the Health Technology Board for Scotland December 2002 amendment.
00	Add 7NB32	Read code + Read code laterality + date		
00	Add 7NB31	Read code + Read code laterality + date	The term 'early diabetic maculopathy' is now deleted.	This grading is based on the Scottish Diabetic Retinopathy Grading System produced by the Health Technology Board for Scotland December 2002 amendment.
00	Add 7NB31	Read code + Read code laterality + date		

EYE CARE (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
101	ND_RET_L	Non-diabetic retinal lesions – left eye	heading	Retinal abnormality – non diabetes	2BBG.
			1 = Pigmented lesion	O/E – retinal pigmentation	2BB9.
			2 = Age-related macular degeneration	Unspecified senile macular degeneration	F4250
			3 = Drusen	Retinal drusen	2BBH.
			4 = Myelinated retinal nerve fibres	Myelinated retinal nerve fibres	2BBN.
			5 = Asteroid hyalites	Asteroid hyalitis	F4K24
			6 = Retinal vein thrombosis	Central retinal vein occlusion	F4238
102	ND_RET_R	Non-diabetic retinal lesions – right eye	heading	Retinal abnormality – non diabetes	2BBG.
			1 = Pigmented lesion	O/E – retinal pigmentation	2BB9.
			2 = Age-related macular degeneration	Unspecified senile macular degeneration	F4250
			3 = Drusen	Retinal drusen	2BBH.
			4 = Myelinated retinal nerve fibres	Myelinated retinal nerve fibres	2BBN.
			5 = Asteroid hyalites	Asteroid hyalitis	F4K24
			6 = Retinal vein thrombosis	Central retinal vein occlusion	F4238
103	CATART_L	Cataract observation – left eye	1 = Left cataract present	O/E – Left cataract present	2BT1.
			2 = Left cataract absent	O/E – Left cataract absent	2BT3.

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00	Add 7NB32	Read code + Read code laterality	New field.	The inclusion of these non-diabetic retinal lesions is consistent with the Scottish Diabetic Retinopathy Grading System produced by the Health Technology Board for Scotland 2002.
00	Add 7NB32	Read code + Read code laterality + date		
00	Add 7NB32	Read code + Read code laterality + date		
00	Add 7NB32	Read code + Read code laterality + date		
00	Add 7NB32	Read code + Read code laterality + date		
00	Add 7NB32	Read code + Read code laterality + date		
00	Add 7NB32	Read code + Read code laterality + date		
00	Add 7NB31	Read code + Read code laterality	New field.	The inclusion of these non-diabetic retinal lesions is consistent with the Scottish Diabetic Retinopathy Grading System produced by the Health Technology Board for Scotland 2002.
00	Add 7NB31	Read code + Read code laterality + date		
00	Add 7NB31	Read code + Read code laterality + date		
00	Add 7NB31	Read code + Read code laterality + date		
00	Add 7NB31	Read code + Read code laterality + date		
00	Add 7NB31	Read code + Read code laterality + date		
00	Add 7NB31	Read code + Read code laterality + date		
00		Read code + date		
00		Read code + date		

EYE CARE (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
104	CATART_R	Cataract observation – right eye	1 = Right cataract present	O/E – Right cataract present	2BT0.
			2 = Right cataract absent	O/E – Right cataract absent	2BT2.
105	CAT_EXT_L	Previous cataract extraction – left eye	yyyy	H/O: L cataract extraction	14NA.
106	CAT_EXT_R	Previous cataract extraction – right eye	yyyy	H/O: R cataract extraction	14N9.
107	VIT_L	Vitrectomy – left eye	yyyy	operation on vitreous body	7270.
108	VIT_R	Vitrectomy – right eye	yyyy	operation on vitreous body	7270.
109	LASER_LD	Laser therapy to left eye	dd/mm/yyyy	Laser therapy lesion of retina	72720
110	LASER_RD	Laser therapy to right eye	dd/mm/yyyy	Laser therapy lesion of retina	72720
111	LAS_SCARL	Laser photocoagulation scars – left eye		O/E – Laser photocoagulation scars	2BB0.
112	LAS_SCARR	Laser photocoagulation scars – right eye		O/E – Laser photocoagulation scars	2BB0.
113	LASER_LRE	Reason for laser therapy to left eye on this date	1 = Diabetic maculopathy		
			2 = Proliferative diabetic retinopathy		
			3 = High-risk non-proliferative diabetic retinopathy		
			4 = Non-diabetic reason		

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code + date		
00		Read code + date		
00		Read code + year	Binary response in CRAG replaced by dated recording of abnormality.	
00		Read code + year	Binary response in CRAG replaced by dated recording of abnormality.	
00	Add 7NB32	Read code + Read code laterality + year	Binary response in CRAG replaced by dated recording of abnormality.	
00	Add 7NB31	Read code + Read code laterality + year	Binary response in CRAG replaced by dated recording of abnormality.	
13	Add 7NB32	Read code + Term code + Read code laterality + date	Amended.	Record of each episode of laser treatment on left eye. CRAG 'Commencement of course of laser therapy' field removed. 'Year of commencement of first diabetes related laser therapy' field could be derived from dataset by IT system.
13	Add 7NB31	Read code + Term code + Read code laterality + date	Amended.	Record of each episode of laser treatment on left eye. CRAG 'Commencement of course of laser therapy' field removed. 'Year of commencement of first diabetes related laser therapy' field could be derived from dataset by IT system.
00	Add 7NB32	Read code + Read code laterality + date	New field.	The inclusion of this field is consistent with the Scottish Diabetic Retinopathy Grading System produced by the Health Technology Board for Scotland 2002.
00	Add 7NB31	Read code + Read code laterality + date	New field.	The inclusion of this field is consistent with the Scottish Diabetic Retinopathy Grading System produced by the Health Technology Board for Scotland 2002.
		No Read codes available		

EYE CARE (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
114	LASER_RRE	Reason for laser therapy to right on this date	1 = Diabetic maculopathy		
			2 = Proliferative diabetic retinopathy		
			3 = High-risk non-proliferative diabetic retinopathy		
			4 = Non-diabetic reason		
115	EYE_METH	Method of eye examination	heading	Visual testing	312..
			1 = Retinal photography	Retinal photography	58C1.
			2 = Dilated direct ophthalmoscopy	Direct fundoscopy following mydriatic	312E.
			3 = Slit lamp biomicroscopy	Slit lamp examination	312A.

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
		No Read codes available		
00		Read code heading		Retinal photography or slit lamp biomicroscopy used by trained individuals should be used in a programme of systematic screening. Dilated direct ophthalmoscopy should be used for opportunistic screening. CRAG 'Who interpreted findings of eye examination?' field removed.
00		Read code + date		
00		Read code + date		
00		Read code + date		

PREGNANCY

Reference number	Field name	Description	Parameter	Read term	Read code
116	PREG_NO	Pregnancy episode number	nn	Antenatal care: gravida No.	622..
117	PRE_PREG	Pre-pregnancy advice given		Pre-pregnancy counselling	676..
118	DEL_DATE	Date of delivery	dd/mm/yyyy	Birth of child	633a.
119	DEL_MODE	Mode of delivery of child(ren)	heading	Induction and delivery operations	7F1..
			0 = Normal spontaneous vertex vaginal delivery, occipito-anterior	Normal delivery NOS	7F19z
			1 = Cephalic vaginal delivery with abnormal presentation of the head at delivery, without instruments, with or without manipulation	Cephalic vaginal delivery with abnormal presentation of the head at delivery, without instruments NOS	7F18z
			2 = Forceps, low application, without manipulation, forceps NOS	Low forceps cephalic delivery	7F164
			3 = Other forceps delivery, forceps with manipulation, high forceps, mid cavity forceps	Other specified forceps cephalic delivery	7F16y
			4 = Vacuum extraction, ventouse	Vacuum delivery NOS	7F17z
			5 = Breech delivery, spontaneous, assisted or unspecified partial breech extraction	Spontaneous breech delivery	7F150
			6 = Breech extraction, NOS. Version with breech extraction	Breech extraction delivery NOS	7F14z

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code + value		Pregnancy recorded in chronological order e.g. in second pregnancy enter value '2'. System developers may wish to consider tagging this integer as a value to the Read codes recorded for items 117 to 121, to facilitate unambiguous association of these data with the relevant pregnancy episode.
00		Read code + date	Binary response in CRAG replaced by dated recording of abnormality.	Detail of what constitutes pre-pregnancy advice may vary by location and should be clarified at local level.
00		Read code + date	CRAG 'date of completion of episode' now divided into 'date of delivery' and 'number of aborted foetuses' with date.	Date of delivery refers to birth of a child of at least 24 weeks of gestation whether live or stillborn, i.e. a delivery requiring to be registered with GROS.
00		Read code heading	CRAG 'mode of delivery of foetus' excluding abortions which now have own field.	In the case of multiple birth, a mode of delivery should be recorded for each child.
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code		

PREGNANCY (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
			7 = Elective (planned) caesarean section	Elective caesarean delivery NOS	7F12z
			8 = Emergency and unspecified caesarean section	Delivery by emergency caesarean section	L3984
			9 = Other and unspecified mode of delivery	Other methods of delivery NOS	7F1Az
120	BNUMBER	Number of births in this pregnancy	heading	Outcome of delivery	633..
			1 = single birth	Single live birth	6331.
				Single stillbirth	6332.
			2 = twin birth	Twins – both live born	6333.
				Twins – 1 still + 1 live born	6334.
				Twins – both still born	6335.
			3 = triplet birth	Triplets – all live born	6336.
				Triplets – 2 live + 1 still born	6337.
				Triplets – 1 live + 2 still born	6338.
				Triplets – 3 still born	6339.
			4 = >3 births	Outcome of delivery NOS	633Z.
121	MATMORT	Maternal mortality		Death from sequelae of direct obstetric causes	L39B.
122	BOUTCOME	Outcome of liveborn child(ren)	heading	Outcome of delivery	ZV27.
			1 = Live birth	Single live birth	ZV270
			2 = Live birth (surviving > 1 year)	Live birth (surviving > 1 year)	633A.
			3 = Early neonatal death	Early neonatal death	Q48y6
			4 = Late neonatal death	Late neonatal death	Q48y7

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code		
00		Read code		
00		Read code		
00		Read code heading	CRAG 'number of births/ aborted foetuses' field excluding abortions which now have own field. Now encompasses stillbirths.	
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code + value		
00		Read code + date	Binary response in CRAG replaced by dated recording of abnormality.	
00		Read code heading	CRAG field 'foetal outcome' excluding stillbirths and abortions.	This field should be completed for each child and updated if the outcome alters.
00		Read code		
00		Read code		
00		Read code		Early neonatal death = Livebirth dying within the first 6 days.
00		Read code		Late neonatal death = Livebirth dying on or after the 7th completed day but before the 28th day.

PREGNANCY (continued)

Reference number	Field name	Description	Parameter	Read term	Read code
			5 = Postneonatal death	Postneonatal death	22J7.
123	GESTAGE	Gestational age for each child delivered	nn (weeks)	Length of gestation	62X..
124	MALFORM	Major malformation at birth or in 1st year of life		Congenital anomaly NOS	Pz...
125	NO_ABORT	Number of aborted foetuses in this pregnancy	n	Pregnancy with abortive outcome	L0...
126	TYP_ABRT	Type of abortion	1 = Spontaneous abortion	Spontaneous abortion	L04..
			2 = Legal abortion	Legally induced abortion	L05..
			3 = Illegal abortion	Illegally induced abortion	L06..
			4 = Other type of abortion	Pregnancy with abortive outcome NOS	L0z..
127	RSN_ABRT	Reason for termination	heading	Reason for termination of pregnancy	9Ea..
			1 = Abortion of dead foetus of multiple pregnancy ending before 24 weeks in which other babies liveborn	Continuing pregnancy after intrauterine death one fetus or more	L192.
			2 = Abortion induced for congenital malformation	Termination of Pregnancy: unborn child at risk from physical or mental abnormality or serious handicap	9Ea4.
			3 = Abortion induced for risk to maternal wellbeing	To prevent grave permanent injury to the physical/mental health of pregnant woman	9Ea1.
			4 = Abortion for any other reason	Unspecified abortion	L07..
128	GEST_ABR	Gestational age for each foetus aborted	nn (weeks)	Length of gestation	62X..
129	MALF_ABR	Major malformation in aborted foetus		Congenital anomaly NOS	Pz...

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code		Postneonatal death = Livebirth dying on or after the 28th day but before the end of the first year of life.
00		Read code + value	CRAG field 'gestational age' excluding abortions.	In the case of multiple birth, gestational age should be recorded for each child. Gestational age of stillborn child should be recorded here.
00		Read code	Binary response in CRAG replaced by dated recording of abnormality.	Major malformation detected at birth or during the first year of life is defined in SIGN 25 as one which results in death, requires major surgery, or has a major effect on the quality of life for the child.
00		Read code + value		Abortion is defined as loss of foetus before 24 weeks gestation.
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code heading		
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code + value		
00		Read code	Binary response in CRAG replaced by dated recording of abnormality.	

YOUNG DIABETICS AND DIET

Reference number	Field name	Description	Parameter	Read term	Read code
130	FHIST	Family history of Type 1 diabetes in 1st degree relative		FH: Diabetes mellitus	1252.
131	PUBSTAT	Pubertal status	1 = Pre-pubertal	O/E – Pre-Pubertal	22I8.
			2 = Pubertal	O/E – Pubertal	22I7.
			3 = Adult	O/E – Post-Pubertal	22I9.
132	SCHOOL	School name	35 characters	Schooling	13Z4.
133	TYP_SCHL	Type of school	1 = Nursery school	Nursery	13Z41
			2 = Primary school	Primary school	13Z43
			3 = Secondary school	Secondary school	13Z44
			4 = Further education	Further education	13Z45
			5 = Higher education	Higher education	13Z46
			6 = Special school	Child attends special school	13IE.
134	THYROTOX	Thyrotoxicosis		Thyrotoxicosis	C02..
135	HYPOTHYR	Hypothyroidism		Acquired hypothyroidism	C04..
136	TSH	Serum TSH level	(nn.n) mU/L	Serum TSH level	442W.
137	CYSTFIBR	Cystic fibrosis		Cystic fibrosis NOS	C370z
138	COELIAC	Coeliac disease		Coeliac disease	J690.
139	DIET_ADV	Dietary advice given	1 = Current dietary guidelines for diabetes	Pt advised re diabetic diet	8CA41
			2 = Weight management	Pt advised re wt-reducing diet	8CA40
			3 = Pregnancy	Diet in pregnancy advice	67A2.
			4 = Lipids	Pt advised re low-fat diet	8CA46
			5 = Low protein	Pt advised re low-protein diet	8CA4B
			6 = Low salt	Pt advised re low-salt diet	8CA48
			7 = Gluten free	Pt advised re gluten-free diet	8CA42

Term code	Laterality code	Coding comment	Changes from CRAG 2000	Definitions and note
00		Read code		The definition of type 1 diabetes for this purpose is a person requiring insulin <35 years of age.
00		Read code + date		Pubertal status is necessary as puberty alters glycaemic control and may influence comparison characteristics.
00		Read code + date		
00		Read code + date		
00		Read code + ISD location code	New field.	See reference number 3 note on ISD location codes.
00		Read code	New field.	
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code		
00		Read code + date	New field.	SIGN guideline 55 on the Management of Diabetes recommends that young people should be screened for thyroid disease at the onset of diabetes and at intervals throughout their lives.
00		Read code + date	New field.	
00		Read code + value + date	New field.	
00		Read code + date	New field.	SIGN guideline 55 on the Management of Diabetes recommends that patients with cystic fibrosis should be screened annually for diabetes from 10 years of age.
00		Read code + date	New field.	SIGN guideline 55 on the Management of Diabetes recommends that young people should be screened for coeliac disease at the onset of diabetes and at intervals throughout their lives.
00		Read code + date	New field.	
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		
00		Read code + date		

ANNEX A – SCI-DC – SCOTTISH CARE INFORMATION DIABETES COLLABORATION

The SCI-DC (Scottish Care Information – Diabetes Collaboration) Project aims to deliver effective information technology solutions to diabetes services in NHSScotland. The Scottish Diabetes Framework identified that well-managed, integrated diabetes care must be underpinned by effective information technology systems, and the SCI-DC Project was initiated to drive forward the IM&T milestones identified. The project aims to support the Scottish Diabetes Framework and the building of regional Managed Clinical Networks by the provision of supporting IT software and services. The project is funded for three years from April 2002.

SCI-DC is directed by a clinically-lead Steering Group with strong representation from both primary and secondary care. The SCI-DC Steering Group is chaired by paediatrician Dr Kenneth Robertson. This group reports to the Scottish Diabetes Group – the national steering group responsible for the implementation of the Scottish Diabetes Framework and for ensuring the co-ordination of national diabetes developments. It also reports to the IM&T Programme Board, the national planning and co-ordinating body for IM&T developments in NHSScotland, via the SCI Programme Board.

Project Management is provided by the Information Systems Support Group of the Information and Statistics Division of the Common Services Agency. The Project Team operates from the Clinical Technology Centre at Ninewells Hospital in NHS Tayside.

The SCI-DC project will be delivered in two phases. The first phase builds on the success of the Lanarkshire Diabetes System (LDS) and the Diabetes Audit and Research in Tayside Scotland (DARTS) systems and aims to maximise the benefits associated with these systems by making them freely available across NHSScotland. Some development work has been required to produce generic, robust and supportable production versions of these systems for national roll-out, and the resulting products are known as SCI-DC Clinical and SCI-DC Network, respectively. Central funding is available to assist with the procurement of hardware in support of the roll-out programme.

The SCI-DC products are complimentary, each with a different focus. SCI-DC Clinical is designed to provide hospital clinic-based support, delivering such features as the automatic generation of GP letters. An interface has been developed to take the clinical data captured by SCI-DC Clinical for automatic update of the patient record held on SCI-DC Network.

SCI-DC Network allows for the identification of all people with recorded diagnoses of diabetes in the area, and provides full support for the Scottish Diabetes Survey. Its regionally customisable web pages allow access to standardised treatment guidelines for decision support, and provide access to patient leaflets and local information such as clinic times and eye van schedules. SCI-DC Network allows for automated practice audit in support of clinical governance, and contains such features as graphical representation of laboratory results over time, allowing for longitudinal risk to be gauged and providing a focus for discussion with patients.

The first phase of the project has three main objectives. The first is to introduce widespread use of IT systems to diabetes services across Scotland in a short time frame. The second is to deliver the benefits and maximise the potential of systems which have been tried and tested in a clinical environment over a significant time period. The third is to pave the way for the introduction of enhanced clinical functionality to be offered by phase 2 of the project.

The second phase of the project develops and extends clinical functionality to provide more closely integrated and fully-functional IT solutions for the use of those involved in diabetes care. This phase builds on the functionality provided by SCI-DC Clinical and SCI-DC Network and extends it to ensure that it remains relevant, effective, forward-looking and sufficiently flexible to support different ways of working. The need for ease of access to integrated solutions, extended support for multi-specialty clinical care, and the facilitation of call-recall for diabetic retinopathy screening are all recognised as critical components of this second phase. The principal concept underpinning the SCI-DC initiative is the creation of a single shared electronic record for use by all involved in the care of patients with diabetes mellitus.

The roll-out phase of the project started in the summer of 2002. Implementation programmes are currently underway in four Health Board areas (October 2002), and implementation planning is in progress with those areas wishing to start implementation of the SCI-DC products in the coming year.

SCI-DC Steering Group also took responsibility for reviewing and updating the diabetes dataset. This has now been published as the Scottish Diabetes Core Dataset. SCI-DC products will continue to evolve and will be fully compliant with the national dataset. Although the use of the software produce by SCI-DC is not mandatory for health services in Scotland, it is expected that all data collection systems will, over time, be compatible with the core dataset.

More information about SCI-DC can be found on the website at www.DiabetesInScotland.org.
Contact with the project should be made through Julie Falconer, SCI-DC Project Manager, email julie.falconer@isd.csa.scot.nhs.uk or telephone 0131-551 8431.

ANNEX B – CLINICAL CODING IN THE NHS

Currently in Scotland, there are two main 'coding systems' – Read V2, used by GPs in Primary Care and ICD10/OPCS4 used in Secondary Care for recording information on diagnoses and procedures, mainly for central returns.

Read Version 2 – Full name is the Read Clinical Classification and it is a coded nomenclature of medical terms, designed specifically for use by clinicians in the day-to-day care of patients. They only exist as computer files, in the form of a medical thesaurus with which specially designed software can be used to look up the various terms. Version 2 evolved from an earlier '4-byte' version and developed into a hierarchical 5-level structure, containing approximately 100,000 preferred terms and a further 150,000 synonyms which are linked to the preferred terms.

Read V2 is mapped (where possible) to ICD9, ICD10, OPCS4 and British National Formulary (BNF). The codes are maintained and developed by the English NHS Information Authority (NHSIA) in Birmingham. In addition to GPs, V2 is being used in Scotland in Child Health systems and in Law Hospital.

Clinical Terms (Read V3/CTV3) – Version 3 was developed when it was realised that V2 could not be expanded enough to take into account the requirements of the different specialties of secondary care. In 1995, consultants in various specialties, nurses, PAMs and midwives were consulted (in Working Groups) to produce lists of appropriate terms which were designed to provide greater specialist detail and to encompass the wider domain of healthcare. The resulting thesaurus of clinical terms was much larger and had a much more complex structure than V2. It is currently used in many specialised systems (mainly in England) for recording clinical data about patients on a routine basis.

SNOMED-CT – In 1999, the NHSIA, joined together with the College of American Pathologists which produces SNOMED to develop a new clinical terminology, – a merger of the best features of SNOMED and CTV3, called SNOMED-Clinical Terms (SNOMED-CT). The first release is now undergoing formal evaluation and developers are beginning to consider implementation in supporting software applications. During the development period, support for V2 codes will be phased out. Migration for users of existing terminologies will require careful planning.

It is envisaged that SCT will be pervasive in all care settings across the UK over the next 5 to 8 years. Use of a common terminology will facilitate integration of clinical information into Electronic Health Records and improve appropriate sharing of clinical information. It describes all aspects of care, i.e. not just diagnoses and procedures.

ICD10 – The International Classification of Diseases and Related Health Problems is published by the World Health Organization and is used for epidemiological and research purposes internationally. It is a classification which groups like-diseases together into meaningful categories. A new version is published approximately every 15 years. Diagnostic information collected for in-patient and out-patient episodes throughout the U.K. is coded to this classification by trained clinical coders. This information, although used locally for planning and management, is also submitted to ISD to allow national data to be collected, analysed and published for research, planning and epidemiological purposes.

OPCS4 – The Classification of Surgical Operations and Procedures was until recently maintained by the Office of Population and Census, which has now been taken over by the National Statistics Office. This classification is used mainly in the UK for grouping together like-operations and procedures to allow comparative data to be collected. The current version was published in 1990 and as yet, there has been no action to update it, despite its failure to keep up with modern surgical techniques. As with ICD, patients treated at Secondary Care level have their operations and procedures coded to OPCS and the information is then submitted centrally to ISD.

Definitions

There are three distinct processes in information handling:

- Terming – for recording patient care
- Encoding – for statistics and management
- Grouping – for costing and other analysis.

Currently, each of the processes require different systems or 'languages', i.e. Read codes for terming, ICD/OPCS classifications for encoding and Healthcare Resource Groups/Diagnostic Resource Groups (HRGs/DRGs) for grouping. In due course, it is envisaged that SCT would be the common 'language' able to fulfil all of these roles when implemented in supporting systems.

'Terminology' is used in the sense of a body of specialised words relating to a particular subject. A 'Standardised Terminology' is a terminology comprising specialised words which its users have agreed are appropriate names for the concepts within their subject. Usually the terms will be arranged in hierarchy or hierarchies which represent current clinical opinion concerning for example, the relationships of diseases to one another, in respect of the system involved and the type of pathology. Where several terms can correctly be used to describe a given concept, all of these may be included and linked as synonyms. A 'Standardised Coded Terminology' is a standardised terminology in which alphanumeric (usually) ciphers have been attached to the agreed terms to assist with organisation, storage, transmission and analysis. The process of selecting a term from a Standardised Coded Terminology to describe a clinical concept is described as 'Terming'. Inserting the

attached code into a Clinical Information System is 'Coding'. These are *two logically distinct activities,* although in an automated system, the act of selecting a term may result in a code being automatically stored in a defined field. A clinical terminology can represent clinical information on all aspects of care including symptoms, signs, investigations, diagnoses, social care, etc.

A 'Classification' is the systematic arrangement of concepts such as diseases or drugs into categories according to shared characteristics. Each category is identified by a name or 'Rubric'. The Rubrics may have codes attached for the same reasons as with the terms described earlier. Allocating a concept to a category is 'Classifying'. Inserting the attached code into an information system is 'Coding'.

A 'Grouping system' is a type of classification with highly aggregated categories to which episodes of care may be assigned according to several attributes which have already been classified, such as operation, co-morbidity and age. Allocating a unit of care to a group is called 'Grouping'.

Further Information

For further information about the clinical coding in the NHS contact:

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ANNEX C – SOURCES OF USEFUL INFORMATION

Diabetes in Scotland
The Diabetes in Scotland website – www.DiabetesInScotland.org – includes a wide range of information about diabetes, in particular about centrally-funded initiatives such as the Scottish Diabetes Group, SIGN and SCI-DC. The site also includes publications including the Scottish Diabetes Framework and this dataset.

Scottish Diabetes Group
The Scottish Diabetes Group was set up by the Scottish Executive Health Department to support and monitor the implementation of the Scottish Diabetes Framework which was published in April 2002. The Group's remit is 'to act as a national steering group to co-ordinate and evaluate the implementation of the Scottish Diabetes Framework; to oversee the review and ongoing development of the national diabetes strategy; and to provide expert advice to the Department'.

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Also: **Diabetic Retinopathy Screening Implementation Group and Scottish Diabetes Survey Monitoring Group.**

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NHS Quality Improvement Scotland
NHS Quality Improvement Scotland was established on 1st January 2003, joining together five bodies – Clinical Standards Board for Scotland, Health Technology Board for Scotland, Clinical Resource and Audit Group (CRAG), Nursing & Midwifery Practice Development Unit, and Scottish Health Advisory Service.

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