DSC Notice: 07/2009
Date of Issue: May 2009

Information Standards Board for Health and Social Care
IMPLEMENTABILITY INTEROPERABILITY SAFETY

Sponsoring Organisation:	**Implementation Date: May Implement Immediately Full Implementation By:**	**1 April 2011**
Department of Health	**Subject:** **Data Standards: Diabetic Retinopathy Screening Dataset v3.6**	

DATA SET CHANGE NOTICE

This DSCN informs users of the approval of changes to an information requirement or information standard by the Information Standards Board for Health and Social Care (ISB HaSC).

This was approved by ISB HaSC at its meeting on 29 April 2009.

Summary:

This DSCN informs the NHS of required changes to the Diabetic Retinopathy Screening Data Set (DRSD) and should be read by all Diabetic Retinopathy Screening Programmes. It should also be read by all suppliers of Diabetic Retinopathy Screening systems.

The changes will support the information requirements for the following areas:

- key clinical data from primary care
- changes to policy and practice
- enhancements requested by users/NHS

These changes may be implemented with immediate effect. All Diabetic Retinopathy Screening Programmes must be fully conformant by 1 April 2011.

Note
This DSCN is in two parts:
Part 1 provides the detailed policy information underpinning these changes
Part 2 provides the definitional, technical and modelling details that will be included in the NHS Data Model and Data Dictionary – Change Proposal CP1047, these relate to the Diabetes Summary Core Data Set.

Data Sets / return affected:
Diabetic Retinopathy Screening Dataset (DRSD)

Related DSCNs:

19/2007

Impact of Change:

Service: Minor **System Suppliers:** Minor

The Information Standards Board for Health and Social Care (ISB HaSC) is responsible for approving information standards. Submission documents and the ISB HaSC Board output relating to the approval of this standard can be found at:

www.isb.nhs.uk/docs/diabetic/

DATA SET CHANGE NOTICE

Reference No:	**DSCN 07/2009**
Version No:	**v0.2**
Subject:	**Diabetic Retinopathy Screening Dataset v3.6**
Type of Change:	Change to an Approved Information Standard
Implementation Date:	Immediate
Business Justification:	The changes will support the information requirements for the following areas: ▪ key clinical data from primary care ▪ changes to policy and practice ▪ enhancements requested by users/NHS

Introduction

The purpose of this DSCN is to inform the service of the requirement for the changes to the Diabetic Retinopathy Screening Dataset (DRSD) NHS Information Standard to facilitate the provision of information in relation to the following areas:

- key clinical data from primary care
- changes to policy and practice
- enhancements requested by users/NHS

These changes will apply to all Diabetic Retinopathy Screening Programmes. They will also be relevant to all suppliers of systems used within Diabetic Retinopathy Screening Programmes.

These changes may be implemented with immediate effect. All Diabetic Retinopathy Screening Programmes must be fully conformant by April 1st 2011.

Background

The Diabetic Retinopathy Screening Dataset has been developed to support diabetic eye screening services, commissioning and planning agencies and national bodies in supplying and monitoring diabetic eye care. Its primary purposes are:

- to ensure that screening information is collected, recorded and transferred consistently according to documented, tested standards;
- to encourage and support a standardised approach to screening data collection across management software solutions;
- to support the collation of meaningful data for performance management and research;
- to provide a common interface to diabetes management and ophthalmology systems in support of co-ordinated patient care; and
- to facilitate alignment between the National Screening Programme for Diabetic Retinopathy and NHS Connecting for Health initiatives.

The dataset will directly support the clinical care of people with diabetes whilst they are under the care of a diabetic retinopathy screening programme.

Approved Changes to Diabetic Retinopathy Screening Dataset

Changes to the DRSD are outlined as follows:

1. Key clinical data from primary care

In 2006 the 'Do Once and Share: Diabetic Eye Disease Final Report' was published identifying a number of known issues and risks surrounding gaps in data communication and key risk factor data items relating to retinopathy. Specific data items were proposed and agreed by a multi-disciplinary expert reference group, which comprised 22 local and 26 national experts, plus a number of suppliers with a secondary (informing) role. Clinical leads, Optometrists, Ophthalmologists, Diabetologists, General Practitioners and persons with diabetes were fully engaged in this reference group. A full list of reference group membership can be found in section 12.1 of 'Do Once and Share - Diabetic Eye Disease', Final Report 2006, available at:

http://www.doas-ded.org/pages/article.asp?Sec=7&S=838&SS=838&PId=838

The Diabetic Eye Disease Action Team concluded that there is a need for "*a series of standardised care pathways that link primary care, screening and assessment / treatment in secondary care, and the datasets that should be used to record information in each care setting. Together, these deliverables constitute a foundation upon which national standardisation can be built.*"

Following this recommendation, clinical and key risk indicator data items have been added into the Data Set for the following uses:

1. Clinical data is required in order to identify patients whose screening interval can be increased with minimal risk. This provides benefit to both the patient and the screening programme.

2. Clinical data is required to ensure proposed treatment is appropriate on an individual basis by empowering clinicians with additional clinical information.

At the present time, users of the DRSD have no place to record clinical data items obtained from primary care in screening programme software management systems. The ability to record this data in a standardised way is imperative to ensure safety, comparability, and an accurate audit trail.

The data items are not mandatory and will only be completed where suitable manual or automatic processes exist. Information on suitable business process and changes to business working practice is published at: http://www.retinalscreening.nhs.uk.

New data items are as follows:

a. ***Blood Pressure***: New Data Items will allow the recording of Systolic Blood Pressure, Diastolic Blood Pressure and their observation dates.

b. ***Body Mass Index***: New data items Person Observation (Body Mass Index) and Observation Date (Body Mass Index) will support the addition of risk factor data.

c. ***Cholesterol***: New Data Items 'Person Observation (Serum Cholesterol)' and 'Observation Date' will allow the updated (repeated) recording of current Cholesterol level.

d. ***Contraindication to Mydriatic Agent***: New Data Items will enable the Screening Programme to receive prior information from Primary Care about the suitability of mydriatic agents, and an observation date. Accurate information will help the screening programme to make advance provision and save time during screening episodes, as well as improving the patient's experience. Primary Care is not expected to hold data regarding the patient *Reaction to Mydriatic Agent* as this is collected and recorded by the screening programme.

e. ***HbA1c***: New Data Items 'Person Observation (HbA1c Concentration)' and 'Person Observation (HbA1c Level mmol/mol)' (two reporting methods allows for both the current and

the new standard specific reference method to be used from 1st June 2009. Further information can be found at (http://www.diabetes.nhs.uk/) and 'Observation Date (HbA1c)' to aid in the diagnosis, assessment and treatment of diabetic eye disease, as well as supporting the monitoring of the patient care process.

f. ***Serum Creatinine****:* The Data Items 'Person Observation (Serum Creatinine)' and the 'Observation Date' will allow the updated recording of current Serum Creatinine level, and an observation date.

g. ***Smoking Status***: Data Item 'Smoking Status' and 'Observation Date' will allow the recording of current smoking status and an observation date.

h. ***Urinary Albumin***: The Data Items 'Person Observation (Urinary Albumin)', 'Testing Method (Urinary Albumin Level)', 'Albuminuria Stage' and 'Observation Date' will allow the updated recording of current Urinary Albumin level and an observation date. Albumin creatinine ratio is the appropriate measure of urinary albumin level.

i. ***GP Remarks – Clinical***: A new Data Item which will allow the GP to submit information pertinent to the screening of patients which cannot be recorded by any other method using the current DRSD. Although free text cannot be used for analytical purposes, this data item will enhance service delivery and the care pathway.

2. Changes to policy and practice

a. Registered Blind/Certificate of Vision Impairment (CVI)

In November 2003, the Department of Health, after consultation with a wide range of professionals, other government departments and voluntary organisations working in the field of visual impairment the process for registering a person blind was replaced with the introduction of the Certificate of Vision Impairment (CVI).

As a result the existing terms 'Partially Sighted' and 'Blind' have been replaced by the terms 'Sight Impaired' and 'Severely Sight Impaired' respectively.

Information on the change in process can be found at:

http://www.dh.gov.uk/en/Healthcare/Primarycare/Optical/DH_4074843

http://www.library.nhs.uk/Eyes/ViewResource.aspx?resID=102234

New Data Items have been included in the DRSD and the former Data Items retired.

b. Consent

It is an Information Governance requirement for Diabetic Retinopathy Screening Programmes to ensure consent for the transfer of patient information is explicitly recorded. The updated Consent group of Data Items makes provision for recording consent data for transfer of clinical data from Primary Care.

Information Governance guidance from the British Medical Association, General Medical Council and Patient Information and Advisory Group (PIAG) can be found at: http://www.retinalscreening.nhs.uk

c. Eligibility

Full details of eligibility criteria and for English National Screening Programme for Diabetic Retinopathy in the 'Exclusions: Excluding Patients from the NHS Diabetic Retinopathy Screening Programme Temporarily or Permanently v2.0' document published in 2006.

In order to support a clear and consistent method of recording of exclusions, the Data Items referring to eligibility have been revised. Further guidance relating to Eligibility and Exclusions and related working practice can be found at: http://www.retinalscreening.nhs.uk

d. Driving Fields

The Driving Fields Data Item was originally used to indicate the extent of visual field defects that might adversely affect an individual's driving ability.

Updated DVLA regulations state that driving fields must be tested following a rigorous procedure known as an Esterman test *"If a Visual field assessment is necessary to determine fitness to drive, DVLA requires this to be a binocular Esterman field"* (http://www.dvla.gov.uk/media/pdf/medical/aagv1.pdf)

The Driving Fields Data Item has been removed as it falls outside the scope of diabetic retinopathy screening.

e. Ethnic Category:

New Data Items will facilitate data analysis and monitoring of Ethnic Category data. Ethnic Category monitoring will enable better prevention of diabetic retinopathy and enhance the patient experience. There is a further general requirement for monitoring ethnicity so as to allow comparison of service provision and service needs, as well as to highlight any inequalities.

f. *Interpreter Required Indicator – Main Language*:

New Data Items of 'Interpreter Required Indicator' and 'Preferred Language' will ensure that all patients can understand and comply with the screening process regardless of their preferred language. This will facilitate better provision of service and ensure equality in access to screening and treatment regardless of preferred language.

3. Enhancements requested by users/NHS

These changes have been requested by users of the DRSD and are:

a. Right / Left Eye Quality of Image:

There has been a terminology change in the Diabetic Retinopathy Screening Workbook V4.2 (2008). This version of the workbook is in use throughout screening programmes. The terms 'unassessable', 'partially assessable' and 'fully assessable' were being used inconsistently by screening programmes and the change in terminology comes with detailed definitions to promote consistent use. These categories have now been revised for greater clarity and replaced with the terms: inadequate; adequate; and good.

b. Reaction to Mydriatic Agent:

The addition of these new Data Items will enable a Screening Programme to record information detailing adverse reactions to the mydriatic agent used during a screening episode, and will allow contraindications to mydriasis to be shared between screening services and healthcare professionals. This will improve patient safety and patient experience, and will allow screening programmes to make advance provision for patients unsuited to mydriasis. This data item will be collected by the screening programme, but it is important to share this information with primary care, particularly if the patient is subsequently seen by another screening programme or hospital eye department.

c. Right / Left Missing Eye:

New Data Items to will improve work flow because the current DRSD (and associated software) expects retinopathy grading information to be completed for both eyes. New Data Items for Missing Eye will allow for accurate recording and make the software more closely align with the actual grading process.

d. Date of New Patient Notification:

A new Data Item makes provision for a record to be kept of the date new patients are referred to the screening service. There is currently no record of this date. *Service Objectives and Quality Assurance Standards: Release 6.4. 24th September 2008* (available at http://www.retinalscreening.nhs.uk) states that "All newly diagnosed patients must be offered screening within three months of the programme being notified of their diagnosis". This additional data item is therefore required to ensure conformance to this Service Objective.

A summary of all of the changes to DRSD can be found in **Appendix 1**.

Further details of changes and guidance

Full details of all changes to the Diabetic Retinopathy Screening Dataset, as well as Guidance for Clinical and Administrative Users and Software Suppliers will be available on the English National Screening Programme for Diabetic Retinopathy website: http://www.retinalscreening.nhs.uk

Timescales for Implementation / Change **FRAMEWORK**		**Health and Social Care Personnel**	**Organisation**[1]	**IT Suppliers**[2]
Effective Date[3] "may use"		Immediate	Immediate	Immediate
Implementation Date[4] "must use"	***Collection Start Date***[5]	1 April 2011	1 April 2011	1 April 2011
Conformance Date[8] "must be used effectively and assessed for use"		1 April 2011	1 April 2011	1 April 2011
Superseded Date (of prior standard)[9] "stop using prior standard"		1 April 2011	1 April 2011	1 April 2011

Effects on Other Information Standards

There are no known effects on other NHS Information Standards as a result of these changes to the Diabetic Retinopathy Screening Dataset (DRSD).

Sponsor Details

Dr Rowan Hillson, National Clinical Director for Diabetes is currently reviewing the changes documented herein, before providing a sponsor's statement of support
Contact details:

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Further Information and Support

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The ongoing owner of the NHS Information Standard is:

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Appendices

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Appendix 1: Diabetic Retinopathy Screening Dataset (NWD) - Summary of Changes

New or changed data items or values are denoted as Blue. Removed/retired data items or values are denoted with a ~~strikethrough~~.

DRSD Data Item	Change Type	Description	Format	Proposed Value	Comments
Patient Data					
Ethnic Category	New Data Item	The ethnicity of the patient as specified by the patient. The first character will be from the code list in footnote 1. The second character is for local use.	an2	White [A] British [B] Irish [C] Any other White Background Mixed [D] White and Black Caribbean [E] White and Black African [F] White and Asian [G] Any other Mixed background Asian or Asian British [H] Indian [J] Pakistani [K] Bangladeshi [L] Any other Asian background Black or Black British [M] Caribbean [N] African [P] Any other Black background Other Ethnic Groups [R] Chinese [S] Any other Ethnic group [Z] Not stated [99] Unknown	
Interpreter Required Indicator	New Data Item	Records whether the patient (or patient contact) requires any additional interpretation.	n1	[0] No [1] Yes	
Preferred Language	New Data Item	The language with which the patient prefers to receive information.	n3	[1] Akan (Ashanti) [2] Albanian [3] Amharic [4] Arabic [5] Bengali & Sylheti [6] Brawa & Somali [7] British Signing Language	

DRSD Data Item	Change Type	Description	Format	Proposed Value	Comments
				[8] Cantonese [9] Cantonese and Vietnamese [10] Creole [11] Dutch [12] English [13] Ethiopian [14] Farsi (Persian) [15] Finnish [16] Flemish [17] French [18] French creole [19] Gaelic [20] German [21] Greek [22] Gujarati [23] Hakka [24] Hausa [25] Hebrew [26] Hindi [27] Igbo (Ibo) [28] Italian [29] Japanese [30] Korean [31] Kurdish [32] Lingala [33] Luganda [34] Makaton (sign language) [35] Malayalam [36] Mandarin [37] Norwegian [38] Pashto (Pushtoo) [39] Patois [40] Polish [41] Portuguese [42] Punjabi [43] Russian [44] Serbain/Croatian [45] Sinhala [46] Somali [48] Spanish [49] Swahili	

DRSD Data Item	Change Type	Description	Format	Proposed Value	Comments
				[50] Swedish [51] Sylheti [52] Tagalog (Filipino) [53] Tamil [54] Thai [55] Tigrinya [56] Turkish [57] Urdu [58] Vietnamese [59] Welsh [60] Yoruba [200] Other	
Diabetic Retinopathy Screening Programme (Date of new Patient Notification)	New Data Value	Date on which the local screening programme became aware of a patient requiring diabetic retinopathy screening	e-GIF Date		
~~**Registered Blind**~~	Remove Data Item	~~The date on which a patient was registered as blind.~~	~~e-GIF Date~~		
~~**Registered Partially Sighted**~~	Remove Data Item	~~The date on which a patient was registered as partially sighted~~	~~e-GIF Date~~		
Certified Severely Sight Impaired (Date)	New Data Item	To record the date on which a patient was certified as Severely Sight Impaired (previously 'Blind') by an ophthalmologist and received a Certificate of Vision Impairment (CVI).	e-GIF Date		
Certified Sight Impaired (Date)	New Data Item	To record the date on which a patient was certified as Sight Impaired (previously 'Partially Sighted') by an ophthalmologist and received a Certificate of Vision Impairment (CVI).	e-GIF Date		
Person Observation (BMI)	New Data Item	The recorded Body Mass Index (BMI) of the person. Derived from Height and Weight (kg/m2) as recorded in the patient record.	n3 (nn.n)		
Observation Date (BMI)	New Data Item	The date of observation of Body Mass Index (BMI)	e-GIF Date		
Systolic Blood Pressure	New Data Item	The recorded systolic blood pressure (mm Hg).	n3 (nnn)		

DRSD Data Item	Change Type	Description	Format	Proposed Value	Comments
Diastolic Blood Pressure	New Data Item	The recorded diastolic blood pressure (mm Hg).	n3 (nnn)		
Observation Date (Blood pressure)	New Data Item	The date of observation of blood pressure	e-GIF Date		
Person Observation (HbA1c Concentration)	New Data Item	The recorded glycated haemoglobin (%) This aligns with the Diabetes Control and Complications Trial (DCCT) definitions. This reference method will no longer be in use after 1 June 2011. (Since 2004 all labs must be IFCC compliant)	n4 (nnn.n)		
Person Observation (HbA1c Level mmol/mol)	New Data Item	The recorded glycated haemoglobin (mmol/mol). This aligns with the International Federation of Clinical Chemistry and Laboratory Medicine (IFCC) definitions and is the new standard specific reference method to be used from 1st June 2009. (Since 2004 all labs must be IFCC compliant)	n3 (nnn)		
Observation Date (HbA1c)	New Data Item	The observation date for HbA1c	e-GIF Date		
Person Observation (Serum Creatinine Level)	New Data Item	The recorded creatinine (µmol/L): Serum Creatinine using laboratory assay.	n4 (nnnn)		
Observation Date (Serum Creatinine)	New Data Item	The observation date for serum creatinine.	e-GIF Date		
Person Observation (Urinary Albumin Level)	New Data Item	The recorded result of the urinary albumin level; related to the method used.	n5 (nnn.nn)		
Testing Method (Urinary Albumin Level)	New Data Item	The method used to determine the recorded Urinary Albumin Level.	n2	[01] Albumin concentration (mg/L) [02] Albumin Creatinine ratio (mg/mmol) [03] Timed overnight albumin (ug/min) [04] 24hr albumin excretion (mg/24hr)	
Albuminuria Stage	New Data Item	The level of albuminuria in relation to risk of diabetic renal disease and/or cardiovascular disease.	n2	[01] Normoalbuminuria (Stage 1) [02] Microalbuminuria (Stage 2) [03] Macroalbuminuria (Stage 3 & 4)	
Observation Date (Urinary Albumin Level)	New Data Item	The observation date for urinary albumin.	e-GIF Date		

DRSD Data Item	Change Type	Description	Format	Proposed Value	Comments
Person Observation (Serum Cholesterol Level)	New Data Item	The Total Cholesterol Level (mmol/L)	n3 (nn.n)		
Observation Date (Serum Cholesterol)	New Data Item	The observation date for total cholesterol.	e-GIF Date		
Smoking Status	New Data Item	Records the current smoking status.	n1	[1] Current smoker [2] Ex smoker [3] Non-smoker history unknown [4] Never smoked [9] Not known	
Observation Date (Smoking Status)	New Data Item	The date on which smoking status was assessed.	e-GIF Date		
Contraindication to Mydriatic Agent	New Data Item	Records whether the patient has a predisposed contraindication to a mydriatic agent	n2	[01] Tropicamide 0.5% [02] Tropicamide1% [03] Phenylephrine 2.5% [98] Other dilation drops	
Contraindication to Mydriatic Agent (Name of Other Agent)	New Data Item	Records the mydriatic agent to which the patient has a known contraindication, if other specified.	an255		
Contraindication to Mydriatic Agent (Observation Date)	New Data Item	Records the date on which the contraindication to mydriatic agent was recorded	e-GIF Date		
GP Remarks (Diabetic Retinopathy Screening)	New Data Item	Remarks from the GP pertinent to the diabetic retinopathy screening of this patient.	an255		
~~**Consent Status (during invite)**~~ **Consent Status at Invitation Stage**	Data Item Name Change	Code indicating level of consent given by patient during invite for screening.	n2	[00] Consent not given [01] Consent given to hold and use screening details for operation of national screening programme [02] Consent given to hold and use screening details for operation of national screening programme and for research purposes	
~~**Consent Status Date (During Invite)**~~ **Consent Status at Invitation Stage (Date)**	Data Item Name Change	Date on which consent status was obtained (usually during screening appointment).	e-GIF Date		

DRSD Data Item	Change Type	Description	Format	Proposed Value	Comments
~~**Consent Code Taker (During Invite)**~~ **Consent Status at Invitation Stage (Recorder ID)**	Data Item Name Change	ID of person who obtained the consent status (usually during screening appointment).	an5		
Consent Status at Invitation Stage - Transfer of Clinical Information	New Data Item	Code indicating level of consent implied or expressed to screening programme in relation to transfer of additional clinical information.	n2	[00] Consent not given [01] Consent given to hold and use screening details for operation of national screening programme [02] Consent given to hold and use screening details for operation of national screening programme and for research purposes	
Consent Status at Invitation Stage - Transfer of Clinical Information (Date)	New Data Item	Date on which consent status was obtained (usually during screening appointment).	e-GIF Date		
~~**Consent Code Taker (During Invite)**~~ **Consent Status at Invitation Stage – Transfer of Clinical Information (Recorder ID)**	New Data Item	ID of person who obtained the consent status (usually during screening appointment).	an5		
Eligibility Recommendation Status (from GP)	New Data Item	A status indicator to record whether the GP currently deems this patient to be eligible for screening.	n2	[01] Active [02] Temporary Inactive [03] Permanent inactive	
Eligibility Recommendation Date (from GP)	New Data Item	Date from which this determination of eligibility is valid.	e-GIF Date		
Eligibility Recommendation Review Date (from GP)	New Data Item	Date at which this determination of eligibility expires.	e-GIF Date		
Eligibility Recommendation Responsible Clinician (from GP)	New Data Item	A record of the clinician that made the eligibility recommendation.	an255		

DRSD Data Item	Change Type	Description	Format	Proposed Value	Comments
Eligibility Recommendation Note (from GP)	New Data Item	Free text note with additional information from GP about determination of eligibility	an255		
Reason for Temporary Inactive Status (from GP)	New Data Item	Reason why GP has determined that a patient is ineligible for screening	n2	[01] Under ophthalmic care for diabetic retinopathy [02] Under ophthalmic care for eye condition other than diabetic retinopathy [03] Declined to participate in screening service [04] Learning or mental disability [05] Physical disability [09] Other reason	
Reason for Permanent Inactive Status (from GP)	New Data Item	Reason why GP has determined that a patient is ineligible for screening	n2	[01] Unable to perceive light in either eye [02] Declined to participate in screening service [03] Learning or mental disability [04] Physical disability [05] |Terminal Illness [09] Other reason	
Reason for Ceased Screening Status (from GP)	New Data Item	Reason why GP has determined that a patient is ineligible for screening.	n2	[01] Moved Away [02] Deceased [03] No longer categorised as diabetic [04] No current GP details [05] No current contact details	
~~**Eligibility for Screening (Diabetic Eye Screening)**~~ **Eligibility Recommendation Status (Diabetic Eye Screening)**	Data Item Name Change	A status indicator to record whether the screening service currently deems this patient to be eligible for screening.	n2	01 ~~Eligible for screening~~ Active ~~02 Ineligible for screening~~ [03] Temporary Inactive [04] Permanent Inactive [05] Ceased screening – move to archive list	

DRSD Data Item	Change Type	Description	Format	Proposed Value	Comments
~~**Reason for Ineligibility (Diabetic Eye Screening)**~~	Remove Data Item	~~Indicates why a patient is ineligible for screening.~~	~~n2~~	~~[01] Moved Away~~ ~~[02] Deceased~~ ~~[03] Under ophthalmic care~~ ~~[04] Blind – screening contraindicated~~ ~~[05] No longer categorised as diabetic~~ ~~[06] Declined to participate in screening service~~ ~~[07] No current contact details~~ ~~[08] Persistent DNA~~ ~~[09] Discharged for other reason~~	
Eligibility Recommendation Date (from Diabetic Eye Screening)	New Data Item	Date from which this determination of eligibility is valid.	e-GIF Date		
Eligibility Recommendation Review Date (from Diabetic Eye Screening)	New Data Item	Date at which this determination of eligibility expires.	e-GIF Date		
Eligibility Recommendation Note (from Diabetic Eye Screening)	New Data Item	Free text note with additional information from screening service about determination of eligibility	an255		
Reason for Temporary Inactive Status (from Diabetic Eye Screening)	New Data Item	Reason why screening service has determined that a patient is ineligible for screening	n2	[01[Under ophthalmic care for diabetic retinopathy [02] Under ophthalmic care for eye condition other than diabetic retinopathy [03] Declined to participate in screening service [04] Learning or mental disability [05] Physical disability [99] Other reason	
Reason for Permanent Inactive (Status – from Diabetic Eye Screening)	New Data Item	Reason why screening service has determined that a patient is ineligible for screening	n2	[01] Unable to perceive light in both eyes [02] Declined to participate in screening service [03] Learning or mental disability [04] Physical disability [05] Terminal Illness [99] Other reason	

DRSD Data Item	Change Type	Description	Format	Proposed Value	Comments
Reason for Ceased Screening Status (from Diabetic Eye Screening)	New Data Item	Reason why screening service has determined that a patient is ineligible for screening.	n2	[01] Moved away [02] Deceased [03] No longer categorised as diabetic [04] No current GP details [05] No current contact details [06] Refused demographic transfer but previously screened	
Screening Data					
Right Missing Eye	New Data Item	Indicates whether patient has had an eye removed by enucleation (accidental or surgical) and which eye.	n1	[0] No [1] Yes	
Left Missing Eye	New Data Item	Indicates whether patient has had an eye removed by enucleation (accidental or surgical) and which eye.	n1	[0] No [1] Yes	
Mydriatic Agent	Change Data Values	Records the type of mydriatic agent (eye drops) used to dilate the pupils prior to diabetic retinopathy screening.	n2	[01] Tropicamide 0.5% [02 Tropicamide 1.0% [03] Phenylephrine 2.5% ~~[98] Other dilation drops~~ [99] Other dilation drops	
Mydriatic Agent (Name of other agent)	New Data Item	Records mydriatic agent (eye drops) name where 'Other dilation drops' are used.	an50		
Reaction to Mydriatic Agent	New Data Item	Records whether or not there is an adverse reaction to the mydriatic agent.	n1	[0] No adverse reaction to mydriatic agent [1] Adverse reaction to mydriatic agent	
Reaction to Mydriatic Agent (Comments)	New Data Item	Free text description giving details of adverse reaction	an50		
~~**Driving Fields**~~	Remove Data Item	~~Indicates the extent of visual field defects for the purposes of driving.~~	n2	~~[01] Passed driving standards field defect test~~ ~~[02] Failed driving standards field defect test~~	

DRSD Data Item	Change Type	Description	Format	Proposed Value	Comments
Grading Data					
R Eye Quality of Image	Change Data Values	An indication by the grader of whether the quality of photographs allow the retinae to be sufficiently assessed.	n2	~~[00] Unassessable~~ ~~[01] Partially Unassessable~~ ~~[02] Fully Assessable~~ [00] Inadequate [01] Adequate [02] Good	
L Eye Quality of Image	Change Data Values	An indication by the grader of whether the quality of photographs allow the retinae to be sufficiently assessed.	n2	~~[00] Unassessable~~ ~~[01] Partially Unassessable~~ ~~[02] Fully Assessable~~ [00] Inadequate [01] Adequate [02] Good	
R Eye Screening Examination Outcome (Maculopathy)	Remove Data Value	The extent of maculopathy identified during grading.	n2	[00] M0 No Maculopathy [01] M1 Maculopathy ~~[02] CSMO~~	
L Eye Screening Examination Outcome (Maculopathy)	Remove Data Value	The extent of maculopathy identified during grading.	n2	[00] M0 No Maculopathy [01] M1 Maculopathy ~~[02] CSMO~~	

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Notes:

1. Relevant organisations are those organisations as defined in the standard who must take direct action to implement the standard
2. IT Suppliers are all suppliers to the organisations listed at [1] who supply functionality pertinent to that standard
3. **Effective Date** is the date from which a new standard can be used but may not be mandatory. This might facilitate piloting, for example, or enable time for system functionality development. At this point, ***you "may use" the standard*.**
4. **Implementation Date** is the point from which the new standard becomes mandatory. Ideally, it inherently implies organisations use appropriate systems i.e. the date is the same for organisations and suppliers. However, there maybe circumstances where interim workarounds are required i.e. the date is different for organisations and suppliers. At this date, ***you "must use" the standard***. Where the standard demands data is submitted centrally, sub components of implementation date (and possibly 'effective date') are:
    5. **Collection Start Date** – this is the date collection of data must begin
    6. **First Submission Date** – this is the date of first submission of data centrally
    7. **Reporting Period / Submission Cycle** – If the standard calls for further collection and submission at defined intervals, this cell provides text of the reporting period (e.g. calendar month, financial year) and the submission cycle (e.g. submit data monthly on the 10th working day of the subsequent month).
8. **Conformance Date** is the date from which the service and IT system suppliers must use the standard as envisaged i.e. using appropriate IT solutions rather than interim workarounds and, if the standard requires it, an independent, authoritative body or legitimate internal audit would conduct a conformity assessment with the expectation of full conformance by all relevant parties. It is the ***"must use standard effectively and assessed for use"*** date
9. **Superseded Date** of the prior standard sets the date at which the prior standard is replaced by the new standard i.e. the prior standard must no longer be used. This date will apply only where there was a pre-existing standard made redundant by the new standard. It might be different from preceding dates in the framework if, for example, a new and old standard run in parallel for a period. It is the date from which you ***"stop using the prior standard"***.

Change Request

NHS Connecting for Health

NHS Data Model and Dictionary Service

Reference:	Change Request 1047
Version No:	1.0
Subject:	Diabetes Summary Core Data Set
Effective Date:	1 April 2009
Reason for Change:	Change to data standards
Publication Date:	20 May 2009

Background:

Amendments are required to the Diabetes Summary Core Data Set to bring the definitions in line with the Diabetic Retinopathy Screening Data Set, which can be found at http://www.retinalscreening.nhs.uk.

This Data Set Change Notice updates these definitions as follows:

- Attribute ALBUMINURIA STAGE - The spelling for National Code 01 *Normalalbuminuria* is corrected to *Normoalbuminuria*
- Data Element URINARY ALBUMIN LEVEL TESTING METHOD - the units reported for this element have been corrected to match those already in use. Where screening centres use different units, the data is to be input into the Data Set using these correct units.

Summary of changes:

Attribute Definitions	
ALBUMINURIA STAGE	Changed Description
Data Elements	
URINARY ALBUMIN LEVEL TESTING METHOD	Changed Description

Date: 20 May 2009
Sponsor: Paul Croft, Standards and Classifications, NHS Information Centre for Health and Social Care

Note: New text is shown with a blue background. Deleted text is crossed out. Retired text is shown in grey. Within the Diagrams deleted classes and relationships are red, changed items are blue and new items are green.

ALBUMINURIA STAGE

Change to Attribute: Changed Description

The level of albuminuria in relation to risk of diabetic renal disease and/or cardiovascular disease. Identifies renal and cardiovascular risk for a PATIENT with diabetes.

National Codes:

~~01~~	~~Normalalbuminuria~~
01	Normoalbuminuria

02 Microalbuminuria
03 Macroalbuminuria

URINARY ALBUMIN LEVEL TESTING METHOD

Change to Data Element: Changed Description

Format/length:	n2
HES item:	
National Codes:	
Default Codes:	

Notes:
The method used to determine the PERSON OBSERVATION (URINARY ALBUMIN LEVEL).

The urine specimen used to check for albuminuria may be collected in several ways depending on local preference. Staging definitions vary by method so PERSON OBSERVATION (URINARY ALBUMIN LEVEL) must be accompanied by the method used.

Derive from the MEASURED OBSERVATION VALUE recorded for the MEASURED PERSON OBSERVATION TYPE 'Urinary Albumin level'.

The derived values are:
~~01 - Albumin concentration (µg/L)~~01 - Albumin concentration (mg/L)
~~02 - Albumin creatinine ratio (µg/mmol)~~02 - Albumin creatinine ratio (mg/mmol)
03 - Timed overnight albumin (µg/min)
~~04 - 24hr albumin excretion (µg/24hr)~~04 - 24hr albumin excretion (mg/24hr)

For enquiries about this Data Set Change Notice, contact datastandards@nhs.net

For enquiries about the Diabetic Retinopathy Data Set and Diabetes Summary Core Data Set, please contact enquiries@ic.nhs.uk