



Public Health England

Protecting and improving the nation's health

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Sarah Wilkinson
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NHS Digital
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17 August 2018

Dear Sarah,

I am writing on behalf of the Secretary of State for Health and Social Care ('the Secretary of State') to direct the Health and Social Care Information Centre, known as and referred to in this Direction as NHS Digital, to establish and operate an informatics system for the collection of information on patients eligible for diabetic eye screening.

The UK National Screening Committee has recommended to the Secretary of State and the NHS that systematic screening of people with diabetes is effective in supporting the early identification and treatment of diabetic eye disease in order to reduce sight loss.

The purpose of this Direction is to ensure that all eligible patients are invited for diabetic eye screening by Public Health England (PHE). "Eligible patients" is defined as persons registered with a General Practice in England who have a doctor-confirmed diagnosis of diabetes, are aged 12 years or over, and have not withheld their agreement to be invited for diabetic eye screening or are not otherwise ineligible to be invited for diabetic eye screening.

PHE is an executive agency of the Department of Health and Social Care. It fulfils the Secretary of State's statutory duties to protect health and address health inequalities, and executes the Secretary of State's power to promote the health and wellbeing of the nation. PHE's annual remit letter from the Parliamentary Under Secretary of State for Public Health and Primary Care sets out its responsibility for the national coordination and quality assurance of the population screening programmes in England. This includes the NHS diabetic eye screening programme, which provides diabetic eye disease screening to patients with diabetes.

This Direction is given to NHS Digital in exercise of the powers of the Secretary of State conferred by sections 254(1) and (6), and 304(9), (10) and (12) of the Health and Social Care Act 2012 ('the Act').

In accordance with section 254(2)(a) of the Act, the information to be obtained by complying with this Direction is necessary or expedient for the Secretary of State to have in relation to the exercise by the Secretary of State of the Secretary of State's functions in connection with the provision of health services in England, specifically the provision of the NHS diabetic eye screening programme.

This Direction is to be known as the NHS Diabetic Eye Screening Programme (Eligible Population Identification) Direction 2018 and comes into force on 01 October 2018.

Under section 254 of the Act, NHS Digital is directed to:

- Collect from all General Practices in England information as specified in Annex 1 of this Direction on all patients eligible to be invited for diabetic eye screening.
- Collect from all General Practices in England information as specified in Annex 2 of this Direction on all patients who have previously been eligible to be invited for diabetic eye screening but have since withheld their agreement or are otherwise now ineligible to be invited for diabetic eye screening.
- Collect this information on a monthly basis.

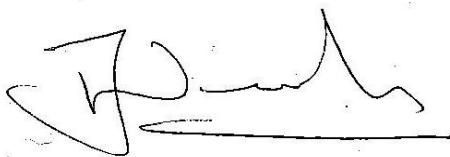
NHS Digital is directed in accordance with section 261(3) and 262(3)(a) of the Act to disseminate the information obtained by complying with this Direction and specified in Annexes 1 and 2 to PHE for PHE to use for the purpose of inviting eligible patients for diabetic eye screening.

NHS Digital is directed in accordance with section 260(1) and (2)(d) of the Act not to publish the information obtained by complying with this Direction.

The diabetic eye screening programme provides direct care to eligible patients so NHS Digital is directed not to apply national data opt-outs, as defined in the Upholding the National Data Opt-Out Direction 2018, to the information disseminated to PHE under this Direction.

In accordance with section 254(5) of the Act, NHS Digital has been consulted before this Direction has been given.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'John Newton', with a horizontal line underneath.

Professor John Newton
Director of Health Improvement

Annex 1: Information to be collected by NHS Digital from all General Practices in England for patients eligible to be invited for diabetic eye screening

NB. 'Eligible patients' is defined as persons registered with a General Practice who have a doctor-confirmed diagnosis of diabetes, are aged 12 years or over, and have not withheld their agreement to be invited for diabetic eye screening or are not otherwise ineligible to be invited for diabetic eye screening for one of the following reasons: they are no longer diabetic; they are aged under 12 years; they have de-registered with the General Practice; they are deceased; they have left the General Practice; they are not eligible for some other reason.

General Practice Extract Service data item name¹	General Practice Extract Service data item purpose
PATIENT.REFERENCE	One of the data items used to identify the person receiving healthcare and to inform the ongoing care process. This is a unique identifier which is used to identify individual patients. This unique identifier may be used to associate information extracted from the same General Practice about the same patient on different occasions. This will also be used as part of cohort identification when matching patient information within the PHE diabetic eye screening system.
PATIENT.NHS-NUMBER	This is the patient's NHS Number and is one of the data items used to identify the person receiving healthcare and to inform the ongoing care process. It will also be used to identify patients who have exited since last extract (e.g. no longer diabetic and age corrected as well as deceased and de-registered).
PATIENT.TITLE	This is to extract the title of the patient for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.FORENAME	This is to extract the forename of the patient for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.SURNAME	This is to extract the surname of the patient for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.DATE_OF_BIRTH	One of the data items used to identify the person receiving healthcare and to inform the ongoing care process. This will facilitate accurate identification of patient by care provider and exclusion from cohort where under 12.
PATIENT.DATE-OF-DEATH	One of the data items used to identify the person receiving healthcare and to inform the ongoing care process (data management, service

¹ The General Practice Extract Service informatics system will be used by NHS Digital to collect the information required by this Direction.

General Practice Extract Service data item name¹	General Practice Extract Service data item purpose
	delivery). It will also be used to inform screening programmes that no further care or correspondence should be planned or communicated.
PATIENT.SEX	One of the data items used to identify the person receiving healthcare and to inform the ongoing care process (data management, service delivery). This will facilitate accurate identification of patient.
PATIENT.ETHNIC	This is to extract the ethnicity of a patient which allows for analysis of ethnicity. It will also be used to evaluate patient experience. For example, the rate of development of diabetic retinopathy differs between ethnic groups, those in some groups will be at elevated risk, both at higher risk of having diabetic retinopathy when they are first screened and to progress to sight threatening diabetic retinopathy within a few years of diagnosis of diabetes.
PATIENT.FIRST-LANGUAGE	This is to identify the first language of the patient which is to be used as part of the patient's ongoing care process.
PATIENT.ADDRESS	This is to extract the full address of the patient for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching. This item is required in case data item below is missing from a patient record.
PATIENT.ADDRESS-1	This is to extract individual lines of the patient registered address for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.ADDRESS-2	This is to extract individual lines of the patient registered address for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.ADDRESS-3	This is to extract individual lines of the patient registered address for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.ADDRESS-4	This is to extract individual lines of the patient registered address for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.
PATIENT.ADDRESS-5	This is to extract individual lines of the patient registered address for communications purposes including posting of invitation to screening appointments, results, letters, etc. Patient identification and automated matching.

General Practice Extract Service data item name¹	General Practice Extract Service data item purpose
PATIENT. POSTCODE	This is the patient's postcode of current address.
PATIENT.GP	This is the GMP number of the patient's current registered doctor. To coordinate the ongoing care process (data management, service delivery). This will also be used by some screening programme systems to facilitate the link to the General Practice.
PATIENT. PRACTICE	This is the current General Practice code of where a patient is registered. This will provide a link to other PHE diabetic eye screening system GP data that includes General Practice address and contact details. It is required to identify the General Practice at which a patient is registered and to facilitate the communication of screenings results letters and to coordinate the ongoing care process.
PATIENT. PRACT- NUMBER	This is the practice number that is assigned to a patient within a practice and is one of the data items used to identify the person receiving healthcare and to inform the ongoing care process
PATIENT.PCG	This is to identify the responsible Primary Care Group (PCG)/Clinical Care Group (CCG) for a patient. Provides a link to other PHE diabetic eye screening system PCG/Clinical Commissioning Groups (CCG) data to identify the healthcare body responsible for providing diabetes services locally
PATIENT. ACTIVE	This item is to extract the current registration status of patients at a General Practice. This item is required in order to identify those patients that should be invited for diabetic eye screening. It is also to be used to identify those patients whose registration status has changed. Often as a consequence of this, the patient will have also left the screening programme cohort but this is not true in all cases, for example when a patient leaves a practice they do not leave the screening programme cohort until they re-register at another practice.
PATIENT. REGISTERED- DATE	Associated with PATIENT.ACTIVE data item to determine when a patient registered with a General Practice.
PATIENT. REMOVED- DATE	Associated with PATIENT.ACTIVE data item to determine when patient's General Practice registration ends.
JOURNALS. CODE	The SNOMED code indicating the nature of the characteristic, event or intervention as per the SNOMED code tables in the NHS Digital

General Practice Extract Service data item name¹	General Practice Extract Service data item purpose
	Business Rules for Patient-Level Data Extracts for the General Practice to Diabetic Retinopathy Screening (GP2DRS ²) documentation.
JOURNALS. DATE	Date to which the coded journal item applies. This is not the RECORD_DATE which records when the item was coded. For example, if a patient attended screening on '2014-03-05' and the code was entered into the system on '2014-06-30' this DATE will be '2014-03-05'.
JOURNALS. TIME	Time at which the journal item applied.

Annex 2: Information to be collected by NHS Digital from all General Practices in England for patients who have previously been eligible to be invited for diabetic eye screening but have since withheld their agreement or are otherwise now ineligible to be invited for diabetic eye screening

NB. 'Ineligible patients' is defined as defined as persons registered with a General Practice who have a doctor-confirmed diagnosis of diabetes, are aged 12 years or over, and have withheld their agreement to be invited for diabetic eye screening or are otherwise not eligible to be invited for diabetic eye screening for one of the following reasons: they are no longer diabetic; they are aged under 12 years; they have de-registered with the General Practice; they are deceased; they have left the General Practice; they are not eligible for some other reason.

Reason for patient being ineligible for screening	General Practice Extract Service data items (as listed in Annex 1) extracted for the patient
Patient withheld agreement to be invited for diabetic eye screening	PATIENT.REFERENCE PATIENT.NHS-NUMBER PATIENT.PRACTICE JOURNALS codes and date/time relating to patient withdrawal of agreement to be invited for screening
Patient no longer diabetic	PATIENT.REFERENCE PATIENT.NHS-NUMBER PATIENT.PRACTICE JOURNALS codes and date/time relating to patient diabetes diagnosis change
Patient date of birth now	PATIENT.REFERENCE

² General Practice to Diabetic Retinopathy Screening (GP2DRS) is the name of the Public Health England informatics system used to manage the information for the diabetic eye screening programme.

Reason for patient being ineligible for screening	General Practice Extract Service data items (as listed in Annex 1) extracted for the patient
under 12	PATIENT.NHS-NUMBER PATIENT.PRACTICE PATIENT.DATE_OF_BIRTH
Patient de-registered with General Practice	PATIENT.REFERENCE PATIENT.NHS-NUMBER PATIENT.PRACTICE PATIENT.ACTIVE
Patient deceased	PATIENT.REFERENCE PATIENT.NHS-NUMBER PATIENT.PRACTICE PATIENT.ACTIVE PATIENT.DATE-OF-DEATH JOURNALS codes and date/time relating to patient death
Patient left General Practice	All PATIENT data items listed in Annex 1 All JOURNALS codes and date/time relating to patient
Patient not eligible to be invited for screening for other reason	PATIENT.NHS-NUMBER PATIENT.PRACTICE