



Public Health
England



NHS Diabetic Eye Screening Programme

Collection of demographic information in
people registered with screening services

March 2017

Public Health England leads the NHS Screening Programmes

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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About PHE Screening

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better informed decisions. National population screening programmes are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the four UK countries. The Screening Quality Assurance Service ensures programmes are safe and effective by checking that national standards are met. PHE leads the NHS Screening Programmes and hosts the UK NSC secretariat.

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Introduction

Public Health England (PHE), as an executive agency of the Department of Health, must fulfil the Secretary of State's statutory duty to have regard to the need to reduce inequalities between the people of England ([Health and Social Care Act 2012](#)). PHE and the NHS must also fulfil the legal obligations of public sector equality duty set out in the [Equality Act 2010](#) and work to address discrimination and promote equality of opportunity so that everyone has the chance to enjoy good health.

From 1 April 2017 diabetic eye screening (DES) services will be able to record information on the nine protected characteristics described in the Equality Act 2010. Accessibility requirements can also be recorded in line with the [NHS Accessible Information standard](#). Fields relating to the screening of pregnant women with diabetes will be available in each of the DES software systems to make sure these women receive screening in line with [NICE guidance](#).

Collection of this information will enable DES services to demonstrate performance against inequalities CQUINs (commissioning for quality and innovation) if they are in place. The information will also provide local screening services with data to determine if access and uptake of screening is equitable across different groups and to identify where they need to make improvements if CQUINs are not in place. The collection of demographic data also allows evaluation of diabetic eye screening at a population level to drive improvements in national guidance and to better understand the epidemiology of diabetic retinopathy.

Protected characteristics

The nine protected characteristics are:

Characteristic	Database field	Definition	Default value
Age	Birth date	The date a person was born	Not applicable
Disability	Disability	Disability status of the patient as specified by the patient	No default value
Gender reassignment	Gender	As the patient wishes to portray themselves	Not known
Marriage and civil partnership	Marital/civil partnership status	The legal marital status of a person	Not known
Pregnancy and maternity	Multiple	N/A	N/A
Race	Ethnic category	The ethnicity of the patient as specified by the patient	Unknown
Religion or belief	Religion or belief	The religious or other belief system affiliation as specified by the patient	Unknown
Sex	Patient sex	Sex at birth	Not known
Sexual orientation	Sexual orientation	Sexual orientation of the patient	Unknown

The full definitions and coding options are available in the [DES dataset](#).

Sex and date of birth can be available in automated extracts such as the [GP2DRS](#) system. However, the majority of the information will need to be collected directly. This is so that the person with diabetes can consent for the member of staff to record the data as it is not required for their clinical care.

Collection of the above fields by services is currently voluntary. Local procedures should be in place to ensure staff are confident in asking for the information above sensitively and recording it accurately. The national programme is developing guidance and best practice on collecting demographic information to support those services which do not currently collect it.

There are multiple points of contact between the service and its users. Such as when a person calls to book an appointment or attends screening. Services will need to decide when the most appropriate time to collect the information is. Noting that additional time for the appointment may be required. The process may be different for new registrations with the service and existing service users.

The person with diabetes has the option of 'not stated', 'not specified' and 'not disclosed', if they prefer not to provide an answer for a particular field.

Disability is the only field which has no default option. It can be left blank if the person with diabetes has not been asked if they have a disability. An individual can have more than one disability recorded.

The information should be recorded as the person with diabetes specifies. The screening service staff should not enter what they think to be correct as this may not be how the person identifies themselves. People with diabetes may ask why you are collecting this information and how you will use it. The following are suggested responses to common questions:

Q: Why are we collecting this information?

A: We are collecting this information to make sure our service is accessible to everyone eligible for screening and that no group of people is disadvantaged. We can also make sure you receive information in a format that suits you best. The fields are the protected characteristics listed in the [Equalities Act 2010](#).

Q: Do I have to give you an answer?

A: No. We can record that you did not consent to provide the information. This means we know staff have asked the questions and you do not want to be asked again in the future. You can change your mind in future. You can also choose to provide information for some of the questions but not others.

Q: How is my information stored?

A: We store data on the screening service server. Only screening service staff can access the records. This may be the administrators responsible for managing appointments and the technicians who carry out the screening. Occasionally the people who manage the software will access the database. For instance, to test changes in data reports, ensuring people are counted accurately in each field.

Q: Who do you share my information with?

A: We will not share individual demographic information with anyone outside the screening service. We may group information together for people with the same protected characteristic to share with our commissioners and the screening quality assurance services. For example, this might be information like: '50% (4,550/9,100) of people with diabetes aged 12 to 18 years in our service attended screening in the past year'. We share this sort of information so we can identify if we need to make any changes to the way we provide our service.

Further information on the use of personal information in the screening programme is available on [gov.uk](#).

Accessible information

There are several fields in the **dataset** to ensure that requirements relating to how people with diabetes receive information are recorded.

These fields are:

- interpreter required indicator
- preferred language (written)
- preferred language (spoken)
- special requirements

There may also be software specific fields to support accessible information. You should consult your software supplier guidance on their use.

Collection of this information is voluntary within the software but we recommend that all services record the information for each person with diabetes in line with the accessibility standard. Interactive **e-learning** is available to support staff in applying and following the standard. A local process should be in place to document when and how the information is requested from service users.

As a default the interpreter required is set to 'no' and preferred language is set to English.

You can set the interpreter required indicator to 'yes' to flag if the person with diabetes needs an interpreter during appointments. A local procedure should be in place for the use of interpreters.

Makaton and British sign language can be recorded as a preferred spoken language.

You can use the special requirements field to capture any additional requirements a person with diabetes might have in terms of communication or access to the service. This can include the contact method and information format.

Pregnancy

Pregnancy is another protected characteristic within the Equality Act 2010. However, pregnant women have a specific **pathway** within diabetic eye screening as they are required to be screened more frequently. A specific set of fields relating to pregnancy is required to ensure the patient is managed appropriately.

These fields are:

- pregnancy status
- pregnancy notification date (date the pregnancy was notified to the service)
- estimated date of delivery
- pregnancy outcome
- pregnancy outcome date (date the outcome was notified to the service)

Women may inform the service that they are pregnant via telephone or during an appointment. Some services may have a notification process arrangement with maternity services and diabetes departments to ensure prompt notification. In the woman's record her pregnancy status should be set to 'pregnant' and the date recorded in the pregnancy notification date field. The woman should also be asked for the estimated date of delivery. This will help identify when a woman should be moved from digital surveillance back to routine digital screening. Software specific guidance on recording the information is available from the software suppliers.

When this information is added to the software the woman should be moved into the digital surveillance pathway and offered an appointment that occurs within six weeks of the notification date.

If the woman has had a routine digital screen in the three months preceding the notification, or if she notifies the service at the same time as attending a successful routine digital screening event, then she will not need to be offered a digital surveillance appointment that occurs within six weeks. Further screening should be undertaken in accordance with the **pregnancy pathway** and **NICE guidance**.

When a woman notifies the service that she is no longer pregnant you can record this by entering the date in the pregnancy outcome date field. This will move the woman from digital surveillance back to routine digital screening. Her recall date will be a year from her last scan in digital surveillance.

If the woman provides information on the outcome of her pregnancy you can record this in the pregnancy outcome field. It is not expected that services will request this information but it can be captured if provided. Completion of this field is voluntary and

information should only be entered with the woman's consent. The use of this field will allow the information to be collected consistently rather than being included in the patient notes.

The outcome of pregnancy can also be used to provide supporting information if a woman is moved off the pregnancy pathway before the expected date of delivery. You can use the information at programme board meetings when reporting on the standard of women being seen within six weeks of notification to the service. Women who have a termination of pregnancy or a have a miscarriage may not attend or cancel their first digital surveillance screen within six weeks. This is a valid reason why a service might not reach the acceptable threshold for the standard.