

What sort of information about me is held by the NHS DR Screening programme?

The only information that the programme will have about you at the beginning will be your name, date of birth, contact details, NHS number, details of your GP, information to help establish your preferred language and contact method and whether you might need large print documents and the fact that you have been diagnosed as having Type 1 or Type 2 diabetes.

Once you agree to have your eyes screened then it will be necessary to be able to check on the results on any previous screening event. It might be that the programme would like to have further information about your medical history relating to your diabetes (such as your blood sugar levels, blood pressure, foot checks, smoking history etc, but not sensitive information such as erectile dysfunction) so that those who are assessing you have a more complete picture about what is happening. When you confirm or attend your screening appointment it will be taken that you are consenting for that sort of data to be given to those involved in screening and assessment both in the programme and in the acute trust. However if you do not wish this further information to pass to the programme then you should let the programme staff or your GP know. This will not prevent your eyes being screened but would mean that staff are less able to assess your case as carefully. You can change your mind about this at any time.

Who will see information about me?

Those involved in the **administration** of the programme (normally based in a Primary Care Trust or a hospital): the details can be found on the letter accompanying this document.

Those who are carrying out the **screening process** (including putting in the eye drops, checking vision, taking your history, taking photographs of your eyes and grading the photographs). These are either staff employed by the PCT, acute trust or other NHS body OR are optometrists, self-employed ophthalmologists or staff employed by independent companies. The programme will provide you with a list of non-NHS personnel and companies if you are concerned in any way about who will see information about you and you should let the programme staff know if you have any particular concerns about any particular individual or company.

If your case is referred to the **hospital** for further assessment the information about you will be forwarded to the hospital so that those who will be looking after your case can have as much information about your history as possible.

In order to make sure that the programme is operating effectively from time to time its work is assessed by **clinical auditors** and others involved in **quality assurance**. They may need to have access to your data. In addition efforts will be made nationally to carry out research using fully anonymised data to try and identify as precisely as possible how best diabetes should be managed in the long term (some examples may be how many people have diabetic retinopathy in any area or how quickly it progresses in different groups of people). Any efforts to use any identifiable information would result in us working with the Patient Information Advisory Group to make sure that all necessary agreements are obtained.

Occasionally problems may occur in the software which is necessary to support the programme. Normally the software supplier will not need to see any information that is identified to a specific individual, but occasionally it may become necessary to supply basic information to ensure that the correct information is maintained by the programme securely. Software suppliers who work with the NHS are bound by requirements of confidentiality and should be supervised by NHS staff if they need to look at information that is linked to a named individual.

Your results and screening information will be sent to your GP.