EXCLUSIONS

EXCLUDING PATIENTS FROM THE NHS DIABETIC RETINOPATHY SCREENING PROGRAMME TEMPORARILY OR PERMANENTLY

Good Practice Guide
Version 2.0, March 2006

Contents

Review date 18th March 2007

1. INTRODUCTION

All people with diabetes of 12yrs and over should be sent an annual invitation for diabetic retinopathy screening. In a small number of circumstances, it may be appropriate to decide not to send a patient an invitation for diabetic retinopathy screening. This should only be done after a careful assessment of the person and their circumstances and this document aims to provide guidance on:

- how to identify those people with diabetes who should not be routinely invited for screening for diabetic retinopathy;
- how their status should be recorded; and
- the person who should be responsible for making this decision.

2. LIST MANAGEMENT

(a) Screening programme providers need to hold a complete and regularly updated list of people with diabetes in the population who are 12 years old or more, so that they can be systematically monitored with a view to offering them screening. This list is termed the **Full List.**

(b). All people with diabetes who will be called to screening annually are termed **Active**.
A small minority of people with diabetes on the **Full list** will not automatically be called to screening annually: these are termed **Inactive**. A person with diabetes on the **Inactive** list may have either **Temporary** or **Permanent** status.

(c) Placing a person with diabetes on the **Permanent Inactive List** will have the effect of stopping all invitations for diabetic retinopathy screening indefinitely. That patient's details should be moved to the **Permanent Inactive list** and no further invitations to screening should be sent**.** It should be remembered that the person can choose to resume participation in the screening programme at any time, when his or her status will revert Active.

(d) Placing a person with diabetes on the **Temporary Inactive List** will have the effect of stopping all invitations for diabetic retinopathy screening for a period of time determined by either by that person or by the healthcare professional (usually the ophthalmologist treating the person) This person's details should be moved to the Inactive list and be returned to the Active list only when that person with diabetes, or the healthcare professional has indicated that the person previously excluded should participate in the programme fully again. This will need to be action dated so that the programme can track the patient through year on year so he or she does not slip through the net.

(e) In the event that it is a voluntary opt-out that has led to the status of the patient being moved to the inactive list, the person with diabetes should give a clear indication as to whether the period of opt-out is one, two or more years. The inactive period should be recorded in the system and the software action-dated to prompt the administrator to recall the person to Active status, or to check whether it is appropriate to do so or not.

(f) Where a person with diabetes is given Inactive status, they should always be encouraged to consider Temporary Inactive status rather than Permanent Inactive status.

(g) When a person with diabetes is excluded from an offer of appointment for reasons that the patient is incapable of being treated, the ophthalmologist should record whether that patient should be placed on the Permanent inactive or temporary inactive list depending on the examination results and the programme and the GP should be informed in writing.

3. WHO CAN BE EXCLUDED?

The following groups of people may be excluded from offers of screening:

1. A person with diabetes who has made his or her own informed choice that he or she no longer wishes to be invited for screening; (**see Para 4a**)
2. A person with diabetes who is under the age of 12 years (in which case he or she should not have been referred to the programme until they have reached the eligible age)
3. A person with diabetes who does not have perception of light in either eye; **(See Para 5)**
4. A person with diabetes who is terminally ill; (**See Para 6)**
5. A person with diabetes has a physical or mental disability preventing either screening or treatment; **(See Para 7)**
6. A person with diabetes who is currently under the care of an ophthalmologist for the treatment and follow-up management of diabetic retinopathy, and then only for that period **(see Para 8).**

In all other circumstances, people with diabetes should be sent an annual invitation for diabetic retinopathy screening and given the opportunity to make their own informed choice about whether to accept on each and every occasion that screening is offered. It is the responsibility of the person with diabetes to decide whether to attend for screening, but the responsibility of the screening programmes to send an appropriate invitation. In cases where there is doubt over whether the person with diabetes should attend or not, they should be sent an invitation which they can choose to ignore or refuse.

It is NOT a reason to stop offering appointments to a person with diabetes simply because they have failed to take up the offer of screening on previous occasions, if the person with diabetes has also chosen to be screened privately, or if the person with diabetes only has a mobility problem.

It is NOT a reason to stop offering appointments to a person with diabetes simply because that a person is registered as blind or partially-sighted.

4a. INFORMED CHOICE

There will be people who ask not to receive future invitations for screening.

In these circumstances the appropriate health professional (normally GP or senior practice or diabetes specialist nurse**)** to whom the person with diabetes has made his/her wishes known should ensure that the person has received sufficient information to enable him or her to make an informed choice. That person should confirm his or her decision in writing. A copy of this document should be retained by the GP and a copy sent to the screening programme.

As diabetes is a life long condition it is prudent to encourage people who are thinking of excluding themselves from the programme to consider the possibility of excluding themselves only for a limited and specified period. Sometimes there are particular circumstances that make screening difficult for a patient at a particular time and these circumstances may resolve or otherwise be accommodated (temporary inactive list).

In either event the person with diabetes should confirm his or her decision in writing to the professional with whom they have been communicating. Screening programmes should encourage patients to discuss this with their GP but if they refuse, the screening programme should keep a record of the terms of the opt-out and a letter should be sent by the screening programme to the patient confirming the terms of the opt-out.

Those people who have only sought temporary exclusion should be placed on the **Temporary Inactive** list and have their details action-dated so that the programme administrator is reminded to return them to the Active list at the specified time.
Those people who wish to have no further invitations indefinitely should be placed on the **Permanent Inactive** list. It should be remembered that this person can choose to resume participation in the screening programme at any time, when his or her status will revert Active.

4b. CONSENT

THOSE UNDER THE AGE OF 18 YEARS

(i) All people aged 12 and over should be offered screening except on the rare occasion that the exclusions described in this document apply. However there are, very occasionally, issues about who has the capacity to make informed consent and who does not

(ii) Once children have reached the age of 16 they are presumed in law to be competent to give consent for themselves for their own medical and surgical treatment and for any associated procedures, including anaesthesia. They are deemed capable of signing consent forms for themselves. Nevertheless it is good practice to encourage competent children to involve their parents in the decision making process.

(iii) With regard to younger children, they are not automatically presumed to be legally competent to make decisions about their healthcare. However the courts have stated that those under the age of 16 years will be competent to give valid consent to a particular intervention if they have "sufficient understanding and intelligence to enable him or her to fully understand what is proposed". When making this decision both the complexity and the seriousness of the treatment involved should be taken into account.

(iv) If a child is not competent to give informed consent themselves then the consent of the person with parental responsibility should be sought. In these circumstances it is still good practice to involve the child in the decision making process.

Further Department of Health advice can be obtained on the website:

http://www.dh.gov.uk/PolicyAndGuidance/HealthAnd SocialCareTopics/Consent/
N.B. This link has recently been changed and we will forward the updated link when available.

5 BLINDNESS

The fact that a person is registered as blind or partially-sighted should NOT automatically result in an exclusion from the call/recall list and an offer of an invitation to screening. Many people who are registered blind have some residual vision. Treatment for diabetic retinopathy may enable those people to retain sufficient vision to live with some degree of independence and/or sustain quality of life benefits.

However if the person with diabetes has no perception of light in either eye, as identified by an Ophthalmologist (see section 8), he or she should be moved to the **Permanent Inactive** list.

6 PEOPLE WITH TERMINAL ILLNESS

People in this situation should be treated in the same way as people who are not terminally ill for as long as possible. This includes being invited to screening as long as they are well enough to participate. The ability to see can bring significant quality of life benefits towards the end of life. It is the decision of the person with diabetes whether to attend or not, and the guidance for Informed Choice (Para 4 (a) applies in these circumstances.

In special circumstances the GP may decide that invitations might be postponed or stopped depending on the individual person's situation if, in his or her judgement, an invitation to eye screening would cause unnecessary distress. As is usual in these circumstances, the GP would normally discuss this decision with the person's next of kin.

The GP should inform the screening programme whether the person is to be placed on the **Temporary Inactive** or the **Permanent Inactive** list. If the person is placed on the Temporary Inactive list the GP should indicate when the situation should be reviewed.

7 DISABILITIES

People with diabetes should NOT be removed from the Active list simply because they suffer from a disability which makes it more difficult to provide screening or treatment. ***Screening programmes are subject to the same regulations under the Disability Discrimination Act as other service providers and where mobility is the only issue novel solutions should be sought.***

However it may not be possible to screen a small number of people with diabetes due to learning or physical disabilities and this may prove to be an obstacle that cannot be overcome.

If it is not possible to screen a person with conventional screening methods, it may still be possible for an ophthalmologist to examine their eyes and in some circumstances to treat the patient (e.g. if the patient is treated under General Anaesthetic).

A person with diabetes should only be excluded from screening for reasons that the person with diabetes is incapable of being treated once that person has been examined by an ophthalmologist. The ophthalmologist should then confirm in writing to the GP and to the Screening Programme that the person with diabetes should be placed on the **Temporary Inactive** or the **Permanent Inactive** list and, if possible, indicate the appropriate period of suspension if placed on the Temporary Inactive list., and, in any event the programme administrator should action-date for review.

a. Learning or Mental Disability

Learning or mental disabilities alone are NOT a reason for excluding people from the programme. Efforts should be made with relatives, carers and other professionals to facilitate the explanation of the purposes of screening and the procedures to the individuals concerned.

There will, however, be a small number of people who are unable to comprehend the concept of participation in the programme and who become very distressed when the procedure is attempted. In these situations the screening activity should stop and their GP should be informed.

The GP should then refer the person to an ophthalmologist for assessment as to whether, should it become necessary, the patient could be effectively treated. The ophthalmologist may also wish to take into account the current retinopathy status (if examination, however limited, is possible) and the patient's life expectancy. If the ophthalmologist determines that it would be possible to treat the patient (if necessary under general anaesthesia) the responsibility for follow up and treatment of this person then passes to the ophthalmologist

and the Hospital Eye Service. Whilst the person with diabetes is under the care of an ophthalmologist their details should be placed on the **Temporary Inactive** list, and the ophthalmologist should indicate the appropriate period that applies, and the case action-dated by the programme administrator for review.
It should be remembered that mental disability may be a temporary condition, and this should be taken into account when determining which list that person with diabetes should be placed on, and for how long. If the ophthalmologist determines that the person with diabetes and mental disability is not currently capable of being treated their details should also be placed on the **Temporary Inactive** list and the GP should review this decision annually and the programme should note and action date so that this can be monitored year on year.

b. Physical disability

In some cases a physical disability, including medical conditions that prevent the head from remaining steady, may prevent a person from achieving a position where a retinal image of adequate quality cannot be captured. In these situations the screening activity should stop and their GP should be informed. Assuming the patient wishes to continue with screening, they should normally be referred to an ophthalmologist for assessment as to whether, should it become necessary, they could be effectively treated. As with people with mental disability, if the ophthalmologist determines that it would be possible to treat the patient (if necessary under general anaesthesia) the responsibility for follow up and treatment of this person then passes to the ophthalmologist and the Hospital Eye Service.

Whilst the person with diabetes is under the care of an ophthalmologist their details should be placed on the **Temporary Inactive** list and an action date noted so that the patient activity can be monitored year on year by the programme to ensure that the patient returns to the active list if the ophthalmologist confirms that this is acceptable.

In some cases the person with diabetes may be bed-bound or completely housebound. In these situations the GP should explain the situation to the person individually and he or she should only be placed on the **Temporary Inactive** list if the disabilities are unlikely to improve and with his or her consent. The person with diabetes should confirm his or her decision in writing, and this should be witnessed by the medical practitioner (or, with the GPs permission the Practice Nurse). A copy of this document should be retained by the GP and a copy sent to the screening programme. The GP should review this decision annually and if the situation improves transfer the patient to the Active list.

8 PATIENTS UNDER THE CARE OF AN OPHTHALMOLOGIST

a. Those under the care of an ophthalmologist for diabetic retinopathy

For the period of time when a person with diabetes is under the care of an ophthalmologist for the follow up and / or treatment of diabetic retinopathy their name may be placed on the **Temporary Inactive** list, and an action date noted so that the programme can monitor this

person's progress year on year. Secure processes need to be in place to ensure that the result of this examination with respect to the level of diabetic retinopathy (R0, R1, R2, R3, M0, M1, P0, P1 or unassessable) is reported to the Screening Programme.
If the patient has been placed on the **Temporary Inactive** list and is discharged their status should be returned to the **Active** list. The Programme needs to monitor this process regularly in conjunction with the Hospital Eye Service.

b. People with diabetes and eye conditions other than diabetic retinopathy

These patients require annual examination for diabetic retinopathy.

The first and preferred option is to place these people with diabetes on the **Full Active** list and call them to a separate screening examination using digital photography.

The second option is for the Clinical Lead for the Screening Programme to specify named ophthalmologists within an eye department who are competent to review diabetic retinopathy. In those circumstances people with diabetes who are **directly** under the care of one of those named ophthalmologists may be moved to the **Temporary Inactive** list. The programme administrator should action date the case for review and the ophthalmologist should provide to the screening programme with a report on the patient's retinal status which details the level of diabetic retinopathy (R0, R1, R2, R3, M0, M1, P0, P1 or unassessable).

9 OTHER SPECIAL SITUATION

a. Screening outside the NHS Diabetic Retinopathy Screening Programme

Patients who have had their eyes screened outside the NHS diabetic retinopathy screening programme remain eligible for screening and should NOT be excluded from the programme on those grounds. They should continue to be sent an invitation for screening at the routine interval so that they can decide whether or not to accept.

b. Those people with diabetes within residential care or institutional care (such as prisons)

People with diabetes within residential care or institutional care (such as prisons) remain eligible for screening and should NOT be excluded from the programme on those grounds.

SUMMARY

1. Care should be taken to distinguish between people who only seek to be excluded for a limited period of time who should be placed on the temporary inactive list and those who wish to be excluded permanently. A person should only be excluded from the Active list for diabetic eye screening call/recall if, providing the detailed advice in the relevant explanatory notes apply and he or she:

- **has made his or her own informed choice that he or she no longer wishes to be invited for diabetic eye screening.**
- **is under the age of 12 years.**
- **has no perception of light in either eye;**
- **is terminally ill and is deemed too unwell to participate;**
- **has a physical or mental disability that prevents either screening or treatment;**
- **is currently under the care of an ophthalmologist for the follow up and / or treatment of diabetic retinopathy, and then only for that period of time;**

2. People who make an informed choice that they no longer wish to be invited for diabetic eye screening and they make a written request that this should happen should be moved to the inactive list and invitations to screening should cease until the person makes a choice to participate in the programme again.

3. The following people should NOT be automatically excluded from diabetic eye screening call and recall:

- **people who have previously not taken up the offer of screening (even repeatedly);**
- **children 12 years and over but under the age of 18 years;**
- **people who are registered blind or partially sighted;**
- **people who are terminally ill;**
- **people who have physical disability;**
- **people who have learning or mental disabilities;**
- **people who have previously been treated for diabetic retinopathy;**
- **people who are under the care of an ophthalmologist for chronic eye disease management other than diabetic retinopathy;**
- **people with diabetes within residential care or institutional care (such as prisons).**

Only an ophthalmologist should decide whether or not a person with diabetes should be placed on the Inactive list because that person is not capable of being treated. However, with regard to other exclusions, it is recommended that only appropriate health professional (normally GP or senior practice or diabetes specialist nurse) should exclude a patient from the diabetic eye screening programme for reasons other than those given above. The GP will need to tightly control exclusion.

Patients should only be excluded from call and recall systems operated by PCTs or acute trusts, if valid reasons are cited, as defined by this document.

PCTs should be asked to audit the call/recall status of all people with diabetes aged 12 years and over who are excluded from the programme at least annually to verify that they have been excluded for valid reasons. Particular care needs to be taken when monitoring the level of exclusions from practice to practise so that evidence of anomalies can be carefully checked.