Referrals from diabetic eye screening to hospital eye services and associated failsafe

Guidance for diabetic eye screening programmes on failsafe required for screen positive referrals into hospital eye service

Version 1.0 / 22 January 2014
About the NHS Diabetic Eye Screening Programme

The NHS Diabetic Eye Screening Programme aims to reduce the risk of sight loss among people with diabetes by the early detection and treatment, if needed, of diabetic retinopathy. Screening using digital photography is offered every year to all eligible people with diabetes aged 12 and over.

The UK National Screening Committee and NHS Screening Programmes are part of Public Health England (PHE), an executive agency of the Department of Health. PHE was established on 1 April 2013 to bring together public health specialists from more than 70 organisations into a single public health service.

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To be read in conjunction with:
Service Specification No 22 NHS Diabetic Eye Screening Programme
(NHS England Publications Gateway Ref. No. 00728)

Crown Copyright 2014
Published January 2014
PHE gateway number: 2013425
About this publication

<table>
<thead>
<tr>
<th>Project / Category</th>
<th>Guidance</th>
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<tr>
<td>Document title</td>
<td>Guidance on referrals from diabetic eye screening to hospital eye services and associated failsafe</td>
</tr>
<tr>
<td>Version / Date</td>
<td>V1.0</td>
</tr>
<tr>
<td>Release Status</td>
<td>Final</td>
</tr>
<tr>
<td>Authors</td>
<td>Philippa Castell, Nina Cook, Sue Cohen, Lynne Lacey</td>
</tr>
<tr>
<td>Owner</td>
<td>Sue Cohen</td>
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<tr>
<td>Type</td>
<td>Guidance</td>
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<tr>
<td>Authorised By</td>
<td></td>
</tr>
<tr>
<td>Valid From</td>
<td>22 January 2014</td>
</tr>
<tr>
<td>Review Date</td>
<td></td>
</tr>
<tr>
<td>Audience</td>
<td>No restrictions once released</td>
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<td>Primary Care; Ophthalmologists; Diabetologists</td>
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### Amendment history

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<th>Author</th>
<th>Description</th>
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<td>V0.1</td>
<td>December 2012</td>
<td>Philippa Castell</td>
<td>First draft</td>
</tr>
<tr>
<td>V0.2</td>
<td>January 2013</td>
<td>Philippa Castell</td>
<td>Updated following comments from LR, WG</td>
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<tr>
<td>V0.3</td>
<td>February 2013</td>
<td>Philippa Castell</td>
<td>Updated following feedback from programme managers DT and SC</td>
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<tr>
<td>V0.4</td>
<td>February 2013</td>
<td>Philippa Castell</td>
<td>Updated following consultation from QA Team &amp; EP</td>
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<tr>
<td>V0.5</td>
<td>March 2013</td>
<td>Philippa Castell</td>
<td>Updated following consultation from external stakeholders</td>
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<tr>
<td>V0.6</td>
<td>March 2013</td>
<td>Philippa Castell</td>
<td>Draft for NDESP comment</td>
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<tr>
<td>V0.7</td>
<td>September 2013</td>
<td>Lynne Lacey</td>
<td>Updated following NDESP comment and organisational changes</td>
</tr>
<tr>
<td>V0.8</td>
<td>October 2013</td>
<td>Lynne Lacey</td>
<td>Updated following review by S Cohen and A Stevenson</td>
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Referrals from diabetic eye screening to hospital eye services and associated failsafe

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<td>November 2013</td>
<td>Lynne Lacey</td>
<td>Updated following review by M Harris</td>
</tr>
<tr>
<td>V1.0</td>
<td>January 2014</td>
<td>Lynne Lacey</td>
<td>Final version following NHS England and PHE Gateway process</td>
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**Review / approval**

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<tr>
<td>V1.0</td>
<td>Jan 2014</td>
<td>Sign off by Sue Cohen and Anne Stevenson</td>
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Executive summary

Guidance on referrals to hospital eye service from diabetic eye screening and associated failsafe

This guidance is provided to diabetic eye screening programmes (DESPs), providers of diabetic retinopathy secondary care ophthalmology services and commissioners of such services. It explains the process of referral from DESPs to ophthalmology services, responsibilities and the required associated failsafe.

For the purpose of this guidance, hospital eye services (HES) include any provision of specialist ophthalmology services for the assessment and management of patients with diabetic retinopathy.
Overview

Direct referral from DESP to HES is required for patients with a screen positive referral outcome grade (ROG) for diabetic retinopathy (DR).

Non diabetic retinopathy pathology falls outside the usual direct referral processes from DESP to HES. It is the responsibility of the patient’s GP for onward referral and management in line with local procedures. The referral of these cases may be managed/commissioned according to agreed local protocol. Failsafe arrangements will in consequence need to match the local protocol. In such cases patients remain within screening and will continue to receive yearly appointments unless the service records the results of a retinal examination by HES. While the patient remains screen negative the next screen may be deferred for a year. If referable DR is detected during a HES appointment then the screening service may record the finding, action it as for a screen positive event, suspend the patient from screening and continue with appropriate post referral failsafe.

HES should provide a designated diabetic retinopathy service as described in Royal College of Ophthalmology Guidance, and such provision should be appropriately commissioned.

The route/method of referral to HES, minimum dataset and acknowledgment processes should be locally documented in an agreed, dated, standard operating procedure (SOP) embedded within the local acute contracts. This will include an auditable acknowledgment of acceptance of the referral by HES, confirming the handover for clinical, administrative and failsafe responsibility.

Clinical responsibility within HES includes the responsibility for examination of the retina for diabetic retinopathy as part of ongoing care management for referred DESP patients. Responsibility for tracking patients from referral, follow up and discharge lies with the HES.

Data on the outcome of the referral and any ongoing management status of the patient should be provided to the DESP on a regular and timely basis to allow for reporting against national standards. This will include an annual status update on each patient indicating that the patient is still being managed for their diabetic retinopathy within HES and that the HES takes responsibility for the examination of the retina as part of their care management. An annual update on the retinal status in RxMx format is preferred but, if this is not available, confirmation of the date the patient was seen should be provided as a minimum.

On discharge from HES (either after non-attendance or after care/treatment) the DESP and GP should be notified. This process should be auditable.

It is noted that software changes may be required to fully implement this guidance.
Hospital eye services (HES) requirements for patients with diabetic retinopathy (DR)

The main aim of screening is to identify treatable conditions early in the disease, to ensure that screen positive patients are assessed, and where necessary treated in a way that improves their outcomes. This means that any HES providing assessment and management of patients referred from screening should provide high standards of organisation and care. The Royal College of Ophthalmology provides guidance on the provision of diabetic retinopathy services: Preferred Practice Guidance, September 2010 and Diabetic Retinopathy Clinical Guidelines, December 2012 (http://www.rcophth.ac.uk/).

A designated service for patients with DR within HES includes:

- Clinical leadership
- Appropriately trained and qualified clinicians and staff
- Access to technology, IT and equipment
- Administrative support with failsafe procedures to track patients through the service
- Capacity to meet national waiting time standards
- Close working relationship with the local DESP

Commissioners should ensure that any HES which accepts referrals for screen positive patients from screening can provide these aspects of service delivery. National commissioning guidance for the delivery of HES to these patients is to be developed. Until such time, local service specifications and contracts should follow the guidance from the Royal College of Ophthalmology and the linked quality standards.

Referrals from screening

Patients who are screen positive for diabetic retinopathy are referred with a referral outcome grade (ROG) that indicates the need for assessment.

This includes the following:

- R3A (active): Proliferative retinopathy
- R3S (stable): Treated proliferative retinopathy with no active lesions
- R2: Pre-proliferative retinopathy
- M1: Maculopathy

R3S, R2 and M1 will have either referral outcome grades for referral to digital surveillance clinics (managed by the DESP) or for referral to HES. The decision as to where the patient is best managed must be supported by local protocol developed by the DESP clinical lead, based on best evidence. Patients with a screen positive grade (R2, R3S, M1) who are not managed within HES should not be invited to routine screening, but invited to attend digital surveillance clinics.

Information on patients who are found to have other pathology (non-DR) detected by screening must be provided to the patient’s GP, and their onward referral/management will be as directed and agreed by local arrangements. The DESP must have a robust agreed protocol for the transfer of care for non DR referrals.

Referral process from DESP to HES

The referral will be generated by the DESP to the appropriate HES. It is important that both the patient and their GP have full information on the referral. Standard outcome letters and leaflets are available on the national website (http://diabeticeye.screening.nhs.uk) to assist in this process.

The referral letter/information provided from the screening service to HES will include the following minimum data items:

- Patient full name (P1.02, P1.03, P1.04)
- Patient NHS number (P1.01)
- Patient date of birth (P1.06)
- Patient GP details (1.8.3, 1.8.4, 1.8.5)
- Patient address (P1.07, P1.08)
- Patient contact number (P1.09)
- Patient screening outcome/reason for referral (S2 – visual acuity, G1.09, G1.10, G1.13, G1.14, G1.15, G1.16)
- Recommended timescale for appointment (urgent (within 2 weeks) or routine (within 13 weeks) 1.22.5:07/08, 1.22.6: 07/08 and 1.22.7:05/06)
Any information relevant to patient – for instance reaction to mydriatic agent, hard of hearing, attends with carer (P5.05, P5.06, S3.06 – if relevant to current referral). Codes relate to the diabetic eye screening programme dataset summary, October 2012 (http://diabeticeye.screening.nhs.uk/pathwaydocuments).

The referral from the screening service is performed on behalf of the patient’s GP. Local arrangements and a policy should be in place to ensure that this direct referral process is clear, incorporates failsafe and allows for the most appropriate HES appointment to be offered to the patient. If a patient requests and receives a referral outside the agreed process for the local DESP, the referral, subsequent follow-up and failsafe becomes the direct responsibility of the patient’s GP. Further information can be found in ‘Policy on Patient Choice and Transfer of Patients across Programme Boundaries’. (http://diabeticeye.screening.nhs.uk/pathwaydocuments)

Mode of referral

The mode of referral and its acknowledgement may vary between DESP and HES. The options may include direct links to software, letter, email, fax, phone or a combination of methods. It is local policy as to the best mode of referral, but the process must be auditable and ensure that the dated acceptance of the referral by HES and thereby the transfer of clinical responsibility to HES can be identified. The local policy for mode of referral should be signed off within the DESP and HES clinical governance structures. Any changes over time should lead to policy updates such that it is clear what arrangements were in place at any particular point in time.

On referral to HES by the referral outcome grader (ROG) the DESP should suspend the patient from its service, and the patient will not be invited for routine screening or surveillance. Programmes can utilise the national screening to treatment timeline tracker to monitor HES acceptance of the referral by ensuring the date the referral is confirmed as received in HES is recorded.

The DESP should provide a report at its quarterly programme board of any acknowledgments outstanding two weeks after referral, and on any resultant actions or the identification of potential barriers to meeting standards.

If acknowledgment of referral is not received from HES after reasonable attempts (letter B), then this should be escalated via local protocol to the patient’s GP for their follow-up action. The screening and immunisation lead may request details on these instances to follow up on actions taken by the GP.
Follow up of patients within HES and associated failsafe

The receipt of the referral from the screening service, its acknowledgement and ongoing tracking within HES, will be best served by a HES dedicated administration team as described in the Royal College of Ophthalmologists Preferred Practice Guidance, September 2010 (http://www.rcophth.ac.uk/).

The principles of patient tracking should be well established within secondary care providers, and it is these principles and methods that apply to referred patients. Identification of timeline breaches, and ensuring patients are not lost to follow-up are the responsibility of HES. Ensuring robust tracking systems are in place will secure maximum patient benefit from screening, and help reduce incidents and near misses. HES are responsible for providing initial information on referred patients, ongoing confirmation of patient treatment and discharge information to the DESP.

Template letters for the failsafe process have been provided in Appendix 1 and should be used by the DESP where appropriate. These can be amended in line with local policy for the arrangement of receipt of data. Breaches where acknowledgment of a referral or patient treatment status update is not received should be reviewed internally by the DESP on a monthly basis, and resultant actions reported at the DESP programme board where the screening and immunisation lead (or designated deputy) can follow up where appropriate.
<table>
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<th>Closing the loop</th>
<th>Failsafe process to ensure that the loop has been closed</th>
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| Ensure that patients referred urgently are offered and receive appointment within national quality standard time frames. | Referral acknowledged and accepted within HES. *(If not acknowledged Letter A and, if necessary, Letter B – Appendix 1 sent to HES)*<br>Recorded on timeline tracking (or equivalent). | Appointment offered and attended within time frame. *Data return from HES:*
  *Date acknowledgment received*
  *Date appointment(s) offered*
  *Date first appointment attended*
  Recorded on timeline tracking (or equivalent). | Acknowledgment for all patients referred *(HES responsibility to provide)*<br>Check that patients marked as urgent have appointment offered and attended in time frame (2 weeks achievable, 4 weeks minimum). |
| Ensure that patients referred routinely are offered and receive appointment within national quality standard time frames. | Referral acknowledged and accepted within HES. *(If not acknowledged Letter A and if necessary, Letter B – Appendix 1 sent to HES)*<br>Recorded on timeline tracking (or equivalent). | Appointment offered and attended within time frame. *Data return from HES:*
  *Date acknowledgment received*
  *Date appointment(s) offered*
  *Date first appointment attended*
  Recorded on timeline tracking (or equivalent). | Acknowledgment for all patients referred *(HES responsibility to provide)*<br>Check that patients marked as routine have appointment offered and attended in time frame (13 weeks achievable, 18 weeks minimum). |
| Follow-up of those who DNA HES apt (ensuring those not being seen in HES receive appropriate information about treatment and receive GP intervention) | HES advise patient DNA/discharged. Appointment(s) and final outcome recorded on timeline tracking (or equivalent). | Letter sent to GP from DESP on confirmation of discharge *(Letter C, Appendix 1)*. *Data return from HES:*
  *Date appointment(s) offered*
  *Date of discharge*
  Recorded on timeline tracking (or equivalent). | Patient not suspended within DESP software and managed as per local policy.<br>No patient should wait longer than 8 weeks (if urgent) or 36 weeks (if routine) without follow-up/investigation. |
| Ensure that patient has planned laser treatment within time frame | Patient listed for treatment at first visit is offered laser treatment within 2 weeks (urgent) or 10 weeks (routine). | Appointment offered and attended within time frame. **Data return from HES:**  
Date appointment(s) offered for first laser if listed at first visit.  
Date appointment attended for first laser.  
Recorded on timeline tracking (or equivalent) | Run checks to identify patients listed for laser with no date of laser entered on timeline tracking tool.  
Report data outcomes/breaches for escalation as per local policy. |

| Ensure that no patient is lost in the system and has either been followed up by HES or returned to DESP. | Patient should be under clinical responsibility of HES/GP or DESP. | Patient status* is known and recorded.  
Annual checks as part of audit of suspensions. | Patient status* should be completed on all patients referred. *(HES responsibility to provide).* Any overdue status should be investigated and resolved.  
Monthly report produced. If no information is provided to DESP after reasonable efforts to obtain information from HES, patient invited to surveillance. |

*Patient status can be either:*

- Patient under care of HES with planned appointment. The HES takes continued responsibility for examination of the retina in both eyes for diabetic retinopathy.

- Patient no longer under HES care and no planned appointments.
Data returns from HES to the DESP after direct referral

The screening service requires initial information returns from the HES to ensure that the overall failsafe is complete and to report on the national quality assurance standards for the screening service.

Data on all direct referrals from the DESP are required on the initial appointment relating to the referral:

- Date acknowledgment received
- Date appointment(s) offered
- Date first appointment attended
- Date appointment(s) offered for first laser if listed at first visit.
- Date appointment attended for first laser
- Date of discharge (or date when no future appointments are planned).

The DESP and HES should contractually agree the timeliness and method of communication of this data. It is the commissioner’s responsibility to ensure there is a contractually backed system of communication as referenced in the Royal College of Ophthalmologists guidelines (http://www.rcophth.ac.uk/)

Regular data requirement returns from HES to the DESP

For patients under the care of HES who are suspended within the DESP, patient status information for each individual should be returned by HES on a minimum 12-monthly basis to ensure that suspension of the patient is still appropriate. The DESP should review and audit all suspensions on an ongoing basis and the HES should actively provide information on patient status. An annual update on the retinal status in RxMx format is preferred but if this is not available, confirmation of the date the patient was seen should be provided as a minimum.

- Patient under care of HES with planned appointment. The HES takes continued responsibility for examination of the retina in both eyes for diabetic retinopathy.

- Patient no longer under HES care and no planned appointments.

The date and outcome of confirmation of status must be recorded within the DESP software and/or timeline tracking to provide auditable evidence, as determined by the DESP, of assessment/checks to the retina. An annual update on the retinal status in RxMx format is preferred but if this is not available, confirmation of the date the patient was seen should be recorded as a minimum.
The completeness, accuracy and timeliness of the data return must be monitored by the DESP on a monthly basis, presented at DESP programme board and fed back to HES as required. If information on a patient is not received after reasonable efforts, in order to assure clinical failsafe the patient must be invited to the DESP digital surveillance clinic for photography. This may result in a re-referral for the patient and commissioners will need to decide locally how this will be managed/commissioned. The cost of the surveillance appointment might be invoiced to the Hospital Eye Service department if this process is documented in contracts with HES, or payment for the patient episode could be withheld by the CCG.

**Management of patients discharged (or no further appointments planned) from HES**

HES must ensure that all patients with diabetes discharged from their care are identified to the patient’s GP and the DESP. Patients may be discharged due to non-attendance or after treatment for their DR is complete. In some cases it is acknowledged that patients are not always ‘officially’ discharged from HES but remain within ophthalmology with no appointments planned/scheduled. In these cases, HES should ensure that the DESP is made aware of the status of these individuals so that they can be managed appropriately within DESP.

For patients discharged after completion of interventional treatment, photography within three months of discharge should occur, so that a baseline image is obtained for future reference. Patients should be invited to a digital surveillance clinic for their next appointment. Patients with a R2, R3S or M1 grade will remain in digital surveillance if not referred to HES, and only returned to routine digital screening if R0/R1.

Patients identified at discharge by HES as unsuitable for digital imaging should be placed into a slit lamp biomicroscopy surveillance clinic for their next appointment. However, best practice for patients with R3S stable disease who are unsuitable for digital imaging is for continued management within HES rather than discharge.

For patients discharged after non-attendance the clinical responsibility lies with the patient’s GP. Letter C (Appendix 1) should be used by the DESP to highlight individual cases to the GP and encourage them to contact the patient and discuss the implications/risks of their non-attendance. If the patient agrees to attend another appointment, it is the GP’s responsibility for arranging this with HES, and advising the DESP of the outcome. The DESP should failsafe these patients after the GP has advised a referral has been made.

If the patient does not agree to attend a HES appointment after consultation with their GP and the DESP, and understands the risks of not attending, then the patient should be offered the opportunity to opt out of the DESP, which will prevent future invitations to screening, or the GP may decide that the patient should be excluded from screening as medically unfit (the patient may be terminally ill and not wish to attend hospital eye service appointments through a personal choice).

The DESP should provide a report at its quarterly programme board of the numbers of non-attenders and any resultant actions or identification of potential barriers. The screening and immunisation lead may request details to follow up on GP actions.
After discharge from HES and attempts made by the GP to encourage attendance, unless a signed opt out or exclusion form is received, the patient must be returned to the DESP and invited within 12 months of previous screening attendance to a digital surveillance clinic (as their last grade showed referable disease). Local policy may decide when the invitation to surveillance after discharge is generated. Patients who persistently DNA are at high risk and it should not be assumed that they will never attend in the future.

An audit trail for correspondence with the patient/GP in these circumstances should be held within the software using patient notes.
Appendix 1: Template letters

Letter A: Transferring clinical responsibility to HES. To be sent within one week of referral made but no acknowledgement.

Dear <<Consultant Name in HES>>

Patient Details <<NHS No, Name, Dob>>
<<Screening Date and Referral Outcome Grade>>

The above patient was seen in <<X>> Diabetic Eye Screening Programme (DESP) on <<date>> and an <<urgent/routine>> referral into <<XX>> Hospital Eye Service (HES) has been <<requested/made>>. Please acknowledge receipt of this referral via <<>>.

This letter is to confirm that by referral of this patient the DESP have transferred clinical responsibility for care of this patient for their diabetic retinopathy/maculopathy to yourself until such time that the patient is discharged from your care back to the DESP.

Please ensure that the DESP, patient and their GP are advised when the patient is discharged from HES (whether this be after assessment, treatment or non attendance).

The DESP will require information on the first appointment date given to this patient, the date of attendance, and the date of laser if this patient is listed for laser at their first appointment. This will allow national standards to be reported. Please ensure this information is returned to DESP via <<e-mail/fax/pt correspondence>>.

Please ensure that you return a patient status update to the DESP on an annual basis, confirming that the patient is still under your care with a planned appointment for examination of the retina in both eyes for diabetic retinopathy. This allows the DESP to ensure that the patient is still under your care for examination of their retina and is appropriately suspended from receiving DESP invitations for the following 12 months.

On informing the DESP that a patient has been discharged (or no further appointments planned), clinical responsibility will be transferred back to the GP and DESP.

If you have any queries then please do not hesitate to contact us,

Yours sincerely

Clinical Lead - DESP
cc Patient’s GP
Letter B: Ensuring referral received for transferring clinical responsibility to HES. To be sent within two weeks of referral made but no acknowledgement.

Dear <<Consultant Name in HES>>

Patient Details <<NHS No, Name, Dob>>
<<Screening Date and Referral Outcome Grade>>

The above patient was referred from Diabetic Eye Screening Programme (DESP) on <<date>> into <<XX>> Hospital Eye Service (HES). We are still awaiting acknowledgment of receipt of this referral. Please ensure acknowledgment is received by <<local process>>. Please note that if acknowledgment of referral is not received this will appear on an exception report provided to commissioners.

Clinical responsibility for care of this patient for their diabetic retinopathy/maculopathy has been transferred to yourself, until such time that the patient is discharged from your care back to the DESP.

Please ensure that the DESP, patient and their GP are advised when the patient is discharged from HES (whether this be after assessment, treatment or non attendance).

The DESP will require information on the first appointment date given to this patient, the date of attendance, and the date of laser if this patient is listed for laser at their first appointment. This will allow national standards to be reported. Please ensure this information is returned to DESP via <<e-mail/fax/pt correspondence>>.

Please ensure that you return a patient status update to the DESP on an annual basis, confirming that the patient is still under your care with a planned appointment for examination of the retina in both eyes for diabetic retinopathy. This allows the DESP to ensure that the patient is still under your care for examination of their retina and is appropriately suspended from receiving DESP invitations for the following 12 months.

On informing the DESP that a patient has been discharged and providing the required discharge photographs, clinical responsibility will be transferred back to the GP and DESP.
If you have any queries then please do not hesitate to contact us,
Yours sincerely

Clinical Lead - DESP
cc Patient’s GP
Letter C: Non-attendance letter escalated to GP. To be sent following notification of discharge from HES.

<<Patient Details >>

Dear <<GP>>,

<<XX>> DESP referred the above patient to <<XX>> Hospital Eye Service (HES) on <<date>> as an <<urgent/routine>> referral following national guidance for assessment and treatment of <<pre/proliferative>> eye disease which if left untreated can cause blindness.

Unfortunately they have been offered <<XX>> appointments within HES but have failed to attend. In line with HES policy they have been discharged and referred back to you as their GP. Please make contact with the patient and ensure that they understand the implication and risks of not being followed up at a specialist appointment. As this patient was referred from screening, they may not realise or perceive that they are at risk and have a potential problem which could be significant for their eye health.

If the patient is willing to attend another appointment then please re-refer this patient to HES and ensure the DESP is advised that a referral has been made. If the patient is not willing to attend then please advise the DESP of this outcome.

If any patient details are incorrect or the patient has moved from your practice or is being seen privately, then please advise us of this.

If you need any further information in regards to this patient please contact the DESP on the above,

Yours sincerely,

DESP Clinical Lead
cc Diabetologist
cc Ophthalmologist
Letter D: Audit confirmation of patient status updates from HES

Dear <<Consultant Name in HES>>

<<XX>> DESP referred the below patient<<(s)>> to <<XX>> Hospital Eye Service (HES). Clinical responsibility for the care of these patient(s) was transferred at the time of their referral. To date we have not received an annual patient status update on the following patients and request your attention in providing this information to us so that we can be assured that these patients are still under your care with a planned appointment.

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<th>Confirm not under care (patient discharged and is not due to be invited again by HES).</th>
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</table>

I can confirm that the HES takes responsibility for continued examination of the retina for diabetic retinopathy for those patients marked as still under active care, until such time that patient is discharged or no further appointments are planned, and the GP/DESP advised

Signed_____________________________
Date____________________

Please note that if information on a patient is not received after reasonable requests, in order to assure clinical failsafe the patient will be invited to the DESP digital surveillance clinic for photography. This may result in a re-referral for the patient which will have contractual and/or financial implications for the CCG. <<The cost of the surveillance appointment may be invoiced to your Hospital Eye Service Department>> (if specified in contract).

If you need any further information in regards to the above patient(s) please contact the DESP on the above,

Yours sincerely,
DESP Clinical Lead
cc Hospital Eye Service Manager
Letter E: No confirmation of patient status updates from HES

Dear <<Consultant Name in HES>>

<<XX>> DESP referred the above patient to <<XX>> Hospital Eye Service (HES). Clinical responsibility for the care of this patient was acknowledged and transferred at the time of their referral.

Despite <<2>> attempts at requesting information <<dates letters sent>> no information on their status has been returned and we cannot be assured that this patient is still under your care. We will therefore be inviting this patient to attend our digital surveillance clinic. This may result in a re-referral for the patient which will have contractual and/or financial implications for the CCG. <<The cost of the surveillance appointment may be invoiced to your Hospital Eye Service Department>> (if specified in contract).

Yours sincerely,

DESP Clinical Lead

cc Patient’s GP
cc Hospital Eye Service Manager
cc CCG Lead for Op
Appendix 2: Process flow charts

Process flow chart referrals and failsafe

- Patient identified as referable DR
  - Desp contact HES to advise DR referral appointment required.
- Patient suspended from DESP

**HES** - Hospital Eye Service
**DESP** - Diabetic Eye Screening Programme
**DR** - Diabetic Retinopathy

Letter A - Transfer of Clinical Responsibility to HES
Letter B - Ensuring referral received
Letter C - Gitation for patient non attendance
Letter D - Audit of suspensions
Letter E - Gation letter for no update from HES

*First
data(s) of patient offered consultation
Date of patient attended consultation
Date of first laser if at first consultation

DESP advised patient has been discharged from DR care in HES - follow local protocol for return to DESP.
Referrals from diabetic eye screening to hospital eye services and associated failsafe

Process flow chart for audit of suspensions

1. Referral to HES
2. Suspend patient in software
3. HES acknowledge referral
4. Audit of suspensions (ensure annual update received from date of suspension)
5. Status update received from HES
6. No response (after 3 weeks of 2nd letter) Send letter E, invite patient to surveillance and report to programme board
7. No response (after 6 weeks of initial letter) Re-send Letter D
8. NO Send Letter D (report breaches to board)
9. YES
   - Patient still under care of HES – continue suspension for next 12 months
   - Patient not under care of HES – remove suspension and return patient to DS/SLB

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