

Service Implementation - Do Once and Share

Diabetic Eye Disease Action Team

Final Report

Version 1.0

14 June 2006

Action Team:	Miss Clare Bailey (UBHT) Mr Robert Johnston (GHNHSFT) Dr Peter Scanlon (GHNHSFT) Dr Graham Wilson (C&T PCT)
Project Manager:	Christian Martin (GHNHSFT)
Project centre:	Gloucestershire Hospitals NHS Foundation Trust
SHA lead:	David Squire (AGW SHA)

Do Once and Share – Diabetic Eye Disease Final Report Version 1.0, 14 June 2006

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2	CFH-DOAS-DED-ADX	Do Once and Share – Diabetic Eye Disease: Final Report: Appendices	1.0

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1 Executive Summary

NHS Connecting for Health marks the start of a new era of healthcare informatics. No longer will information crucial to the effective care of patients be locked in filing cabinets or lost within bundles of hospital notes; no longer will high quality healthcare depend on the efficiency of administrators and the level of local expertise and enthusiasm. Information will be available when and where it is needed, through technology that enriches it and ensures that it can be used safely and effectively. For a series of key healthcare concerns, [Do Once and Share](#) reveals and describes this brave new world, in order that we might better understand the evolutionary processes that will be necessary as we move towards it.

This report presents the findings of a six month project to provide a real-world steer for the computer systems being developed to meet the needs of the NHS over the next ten years. The project, '*Do Once and Share* for Diabetic Eye Disease', aims to provide a foundation for the development of linked information subsystems in primary care, diabetic retinopathy screening programmes and hospital eye clinics. Its focus is on the delivery of open standards for the systematic recording and transfer of information to support the care process for diabetic eye disease.

The work was directed by an Action Team of four expert clinicians and a project manager, and informed by a Reference Group of 50 clinicians, service managers, IT system suppliers, voluntary organisations and patients. In order to achieve rapid progress, the Action Team was sponsored by and focused its activity on Avon, Gloucestershire and Wiltshire SHA. This provided a test-bed for the processes and standards defined ('Do Once ...'), which can now be extended nationally ('... and Share'). Accordingly, the Reference Group had particularly rich representation from Avon, Gloucestershire and Wiltshire, but involved key stakeholders from elsewhere to inform and validate the process and to secure links into institutions such as the various Colleges and national organisations.

Through a stakeholder conference in January 2006 and the subsequent development of an interactive online resource, information requirements for diabetic eye disease were defined and allocated to appropriate focus groups. Each group discussed any information subsystems currently used in the management and care of diabetic eye disease, and critically examined the processes by which information is currently recorded, shared and retrieved. Using the paradigm of [Imagine 2010](#), these ideas were collated and refined to describe a system, comprising:

- a summary care pathway for the management of diabetic eye disease [\[D1\]](#);
- a set of detailed care pathways for the detection, assessment and treatment of diabetic eye disease [\[D4\]](#);
- a series of datasets to support the systematic recording of information pertinent to diabetic eye disease [\[D6\]](#); and
- data exchange specifications to support reliable data transfer and sharing between information subsystems [\[D2, D3 and D5\]](#).

The work was informed, but not constrained, by the administrative structure, workforce, care processes and technical capability of today's NHS.

It is anticipated that the outputs from this project will be most useful for:

- a) information systems architects: the technical experts designing information systems for healthcare, both through NHS Connecting for Health and independently;
- b) service commissioners and managers: those tasked with transforming policy into practice, who need to understand the technical and practical context of the services for which they are responsible; and
- c) clinicians and patients: the stakeholders who wish to understand or influence the diabetic eye disease care process, and particularly the technical constraints which affect it.

1.1 Index of key findings

Finding	Proposed response	References
Lack of interoperability between information systems in primary care, screening and acute care	Datasets and data exchange specifications to facilitate interoperability	Section 5.3 O1 , O5 , O6 D2 , D3 , D5 , D6
Good data about referral patterns is not available	e-referral to hospital eye clinic allows source of referral to be recorded	O5 D1 , D2 , D3
Management of symptomatic presentation of diabetic eye disease can prejudice timely care	Standardised care pathways facilitate appropriate diagnosis and referral	O5 , O6 D1 , D2 , D4
Standard of care within hospital eye departments is variable and frequently falls short of benchmark standards	Standardised datasets at each stage of the care pathway within the hospital eye service and detailed decision support	O1 , O6 D4
Patients under care of hospital eye service are offered unnecessary screening	Electronic report based on clinical observations in hospital eye clinic to be deemed as annual screening with potential cost savings	O5 D1 , D4
Efficacy of local screening programmes is difficult to measure	Return to screening of visual outcomes recorded in hospital eye clinics and primary care	O1 , O6 D2 , D4 , D5
Efficacy of national screening programme is difficult to measure	Baseline visual impairment due to diabetic eye disease to be assessed, measured and monitored over time	O1 , O6 D3 , D5 , D6
Refinement of quality assurance criteria and service objectives for screening is necessary	Necessary metrics to be compiled nationally from data collected at point of care	O6 D3 , D5 , D6
Competing pressures between early systems delivery and alignment with NHS CfH systems	Universal standards for immediate adoption and subsequent strategic development	Section 5.3 O1 , O2 , O3 , O5 D10 , D11
The systems specified in the ICRS OBS do not meet various needs for diabetic eye disease	Requirement / provision gap analysis and amendments to ICRS OBS and related contracts	O4 D8 , D11

1.2 Consultation and validation

This work has been widely consulted amongst relevant stakeholders, both in Avon, Gloucestershire and Wiltshire and nationally. Comments, corrections and recommendations will be accepted and considered through the project website at <http://www.doas-ded.org>.

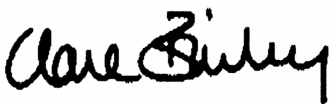
Following publication and initial review, this report will be submitted to the Royal College of Ophthalmologists, the National Screening Programme for Diabetic Retinopathy, and the National Institute for Health and Clinical Excellence (NICE) for approval as a national standard pathway for diabetic eye disease.

1.3 Recommendations

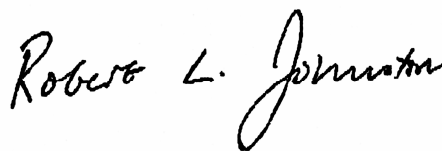
In addition to the national adoption of the care pathways, datasets and data collection processes proposed through this project, the Action Team recommends and requests:

- that resource be allocated to the review and occasional maintenance of the outputs from this project so that its relevance and utility can be maintained [10.1];
- that a Stakeholder Reference Group be established to inform and oversee development and implementation work on information systems for diabetic eye disease [10.1];
- that generic components for common information requirements such as access and consent be developed, published and maintained [10.2];
- that future Do Once and Share projects be supported by online information resources, terminology authoring resource and dataset authoring support [10.2];
- that further consideration be given to shared access to information for patients and clinicians [10.4].

We submit that this work accurately captures and details information system requirements for the effective detection and management of diabetic eye disease in England. Further, it contributes to the development of a framework for the ongoing development of co-ordinated standards to support diabetic eye disease, built on foundations of reorganisation-proof, patient-centred and joined-up healthcare. We commend it to those involved in the design and delivery of such systems.



Miss Clare Bailey



Mr Robert Johnston



Dr Peter Scanlon



Dr Graham Wilson



Christian Martin

2 SHA Executive Summary

This and the many other excellent Do Once and Share projects provide the tools to build something better than we have ever seen – a consistent, integrated health service firmly grounded in twenty-first century information technology. Do Once and Share is the first initiative from NHS Connecting for Health to engage large numbers of clinicians in the design of systems that will influence and improve clinical care through strategic national software solutions. This project provides an elegant example of how relatively simple systems could significantly improve the management of a common and debilitating condition across multiple healthcare sectors.

There is a clear need for coherent and connected information technology to support the detection and management of diabetic eye disease – this work coincides with:

- The evolution of systematic screening programmes and a concerted national move from paper to digital imaging and automated data transfer;
- The early development of NHS Connecting for Health solutions for screening; and
- A co-ordinated drive for IT to support the Diabetes NSF through the Diabetes Information Strategy Group.

This project will help to standardise processes and demonstrate how information flows can become more widely established to support excellent joined-up healthcare. There has long been widespread enthusiasm amongst Ophthalmologists and allied healthcare professionals in the Avon, Gloucestershire and Wiltshire region for developing high quality information systems and this work will help to inform other areas of the country where further progress is urgently needed.

I would like to make two recommendations to the recipients of this report: firstly, that some response is made, so that we can understand which parts of this work are likely to be realised through NHS Connecting for Health and which might benefit from further development whilst local understanding and enthusiasm is still available; and secondly, that the concept of a Stakeholder Reference Group (outlined in section 10.1 below) be formally adopted for all ‘Do Once and Share’ outputs, so that the beneficiaries of these systems can have an ongoing input into their development.

David Squire <david.squire@aqwsha.nhs.uk>
Associate Director of Clinical Governance
Avon, Gloucestershire and Wiltshire SHA

3 Action Team details

Action team name	Diabetic Eye Disease
Clinical lead	Miss Clare Bailey < clare.bailey@doas-ded.org >
Acute sector lead	Mr Robert Johnston < rob.johnston@doas-ded.org >
Screening lead	Dr Peter Scanlon < peter.scanlon@doas-ded.org >
Primary care lead	Dr Graham Wilson < graham.wilson@doas-ded.org >
Project manager	Christian Martin < christian.martin@doas-ded.org >
Location	Avon, Gloucestershire and Wiltshire SHA
SHA lead	David Squire < david.squire@agwsha.nhs.uk >
Start date	1 December 2005
Interim report date	14 February 2005
Final report date	14 June 2006
Project website	http://www.doas-ded.org

Miss Clare Bailey, Clinical Lead for the Action Team, is a Consultant Ophthalmologist at Bristol Eye Hospital, and the Royal College of Ophthalmologists representative on the Project Advisory Group for the National Screening Programme. She represented the Royal College during the consultation phases of the NICE guidelines for Type I Diabetes and will take this role in the forthcoming review of the NICE guidelines for Type II Diabetes. Clare published the results of the UK National Diabetic Retinopathy Laser Treatment Audit in 1998, which demonstrated wide variations in the adequacy of laser treatment of diabetic retinopathy.

Clare is supported in her clinical role by Dr Peter Scanlon, Mr Robert Johnston and Dr Graham Wilson. The project is being managed by Christian Martin.

Dr Peter Scanlon, an Associate Specialist in Ophthalmology, is National Co-ordinator for the English National Screening Programme for Sight-threatening Diabetic Retinopathy. Peter led a national procurement process for information systems for the Programme in 2003, resulting in national framework contracts for software to manage the diabetic retinopathy screening process. He also conducted a pilot study of ten existing screening services to inform the development of the eighteen Quality Assurance standards for the English Programme, and studied the ophthalmology workload of diabetic eye disease by conducting an audit of 3787 records relating to people with diabetes who attended an eye clinic over four years. This work informed the development of the Diabetic Eyecare Dataset by the NHS Datasets Group. Peter was a key participant in the consultation process that led to the recommended grading model for the English Screening Programme, subsequently adopted in the NICE guidelines for Type I Diabetes. He will also take part in the revision of the NICE guidelines for Type II diabetes.

Mr Robert Johnston is a Consultant Vitreoretinal Surgeon who specialises in the treatment of diabetic eye disease. He is also a director of a company that specialises in Ophthalmology EPR systems. His detailed knowledge of hospital IT systems and processes and his previous work on the Cataract National Dataset are being used to inform the project. Rob has

published widely on the benefits existing electronic record systems are already bringing to ophthalmology and has convened two national 'IT and Ophthalmology' conferences that have included all current suppliers of ophthalmology systems in addition to representatives from NHS Connecting for Health.

Dr Graham Wilson is a GP in Cheltenham and Diabetes Lead for Cheltenham & Tewkesbury PCT, which he represents on the Gloucestershire Managed Diabetes Network. He has worked extensively on patient pathways in diabetes, leading work with local primary care and specialist stakeholders to produce a local Integrated Care Pathway for Diabetes, and through this has an interest in electronic transfer of information for the improvement of patient care and audit. Graham is a GP advisor to the English National Screening Programme for Diabetic Retinopathy.

Christian Martin is project managing this Do Once and Share project. Christian has been working as National Technical Development Manager for the Diabetic Retinopathy Screening Programme for the last two years and has developed an in-depth knowledge of NHS IT systems and NHS Connecting for Health standards and processes. With Peter Scanlon, Christian has been working with the Map of Medicine team on standardised care pathways for Diabetic Retinopathy Screening. He is a PRINCE2 Practitioner.

4 Background

Diabetic eye disease is the main cause of blindness in the working-age population and can be treated effectively if detected at an early stage.

Although the incidence of diabetes (and therefore diabetic eye disease) is increasing, it is anticipated that systematic screening and early treatment of diabetic retinopathy will lead to a significant reduction in visual impairment and blindness caused by the condition. However, England is one of the first countries to offer free retinopathy screening to all people with diabetes, and many lessons have yet to be learned. Appraisal and refinement of screening and treatment models will require consistent measurement of disease progression and related visual impairment at an epidemiological level, and this in turn can only be achieved through the widespread use of standardised information systems.

4.1 Pathology, prevalence and treatment of diabetic eye disease

The most common diabetic eye disease is diabetic retinopathy. This occurs when blood sugar imbalance causes small vessels in the retina to weaken and develop tiny bulges that may leak or burst. In the advanced stages of the disease, insufficient bloodflow to the retina can cause the development of new vessels that bleed into the vitreous of the eye or damage the retina, often resulting in irreversible loss of vision.

Diabetic retinopathy will affect nearly all people with Type I diabetes and most people with Type II diabetes at some time in their lives. The condition has few noticeable symptoms until visual loss develops, but over 2% of people with diabetes will eventually become blind or severely visually impaired, and a far higher proportion in high risk groups such as those with long-term diabetes or high levels of glycosylated haemoglobin. Laser photocoagulation is

effective at slowing the progression of diabetic retinopathy but does not usually restore lost vision. However, examination of the retina is effective at detecting early signs of retinopathy before visual loss occurs. Annual screening (usually by digital fundus photography) and prompt treatment can prevent loss of vision in most patients.

More severe effects of diabetic eye disease, such as vitreous haemorrhage and tractional retinal detachment, may require surgical treatment.

4.2 Diabetic retinopathy screening

In 2003, the Delivery Strategy for the Diabetes NSF announced the introduction of a National Screening Programme for Sight-threatening Diabetic Retinopathy in England. This was supported by two national targets: “By 2006, a minimum of 80% of people with diabetes to be offered screening for the early detection (and treatment if needed) of diabetic retinopathy as part of a systematic programme that meets national standards, rising to 100% coverage of those at risk of retinopathy by end 2007”. Systematic screening programmes using digital fundus photography are being rolled out across England in support of these targets. The screening process is highly reliant on a series of information subsystems:

- The identification of people with diabetes to whom a screening invitation should be sent depends on diabetes registers stored on primary care information systems, which also hold disease management and risk assessment data;
- The capture, assessment and management of digital retinal images rely on information systems that link administrative and clinical functionality to data and images collected at the time of screening;
- The variety of sites and services involved in the management of diabetic eye disease, and the number of locations at which patient information is recorded or required, create a requirement for linked information subsystems both within and across healthcare sectors.

Much of the country has, or is developing, basic information systems to support the screening process. However, the ultimate effectiveness of the screening programme in terms of preserving vision cannot be properly assessed without the return of clinical data from hospital eye services following treatment. Further, the lack of consistent information standards to govern data collection and exchange across primary care, screening, and hospital eye services will hinder alignment with the strategic solutions proposed through NHS Connecting for Health.

4.3 Assessment and treatment in the hospital eye clinic

The introduction of a new screening programme will generally create an initial burden on the service to which it refers, and diabetic eye disease is no exception. As systematic screening for diabetic retinopathy becomes established across England, the balance between referrals to hospital eye services from screening programmes and from other sources will shift rapidly.

The challenge of managing this change at a local and national level will be compounded by:

- Widespread variation in commissioning progress, screening models and referral patterns;
- Resistance to the dual financial burden of screening and increased referral / treatment;
- Increased awareness of the condition and corresponding changes to the threshold at which referrals are made; and
- A lack of tools to measure the source of referrals and refine service models accordingly.

The management of diabetic eye disease in the hospital eye clinic, including referrals from screening services and symptomatic presentations of diabetic eye disease, generally follows local protocol. Few hospital eye services currently benefit from clinical information systems of any sort, let alone an effective shared patient record. This creates great difficulties in sharing assessment and treatment information with primary care and with screening programmes, and can result in unnecessary duplication of effort, patient anxiety and ultimately suboptimal patient care.

Although guidance on diabetic eye disease has been produced by NICE and through the Royal College of Ophthalmologists, this work has not yet resulted in a consistent national approach to the overall detection, care and management of diabetic eye disease.

The success of a national screening programme for diabetic retinopathy in terms of reducing blindness and visual impairment depends both on the efficient management of screening programmes and the delivery of optimal care in hospital eye services. Previous national audits have shown that the latter condition is not always being met. It is important that information systems being developed for the assessment and treatment of patients with diabetes in the hospital eye clinic will promote a universally high standard of care.

4.4 Scale of implementation

Diabetic eye disease is a common condition and its detection and management involves a large number of healthcare organisations and professionals. Whilst this presents both opportunities and challenges for the development of information systems, it emphasises the critical importance of early standardisation.

4.4.1 Patients

As of March 2006, there were 1,884,712 diagnosed cases of diabetes mellitus in patients aged 17 and over. Around 10% of these patients are likely to be under the care of a hospital eye service for diabetic retinopathy, and a further 1% will be ineligible for screening. Allowing for annual increase in diabetes prevalence of around 1.2%, NSF targets require that nearly 1.7 million realisable offers of screening be issued in 2007. In addition to this, a significant number of screening invitations will be issued to patients under the care of the hospital eye service, because there is no reliable information return to the screening programme to indicate that these patients have been adequately screened.

Approximately 40,000 patients referred to hospital eye services are found to have diabetic retinopathy each year. Data are not yet available to indicate how many of these patients have been referred from retinopathy screening programmes, but indications from established programmes are that roughly half of referrals to the hospital eye service originate from screening services.

4.4.2 Care settings and professionals

- Diabetes registers and summary clinical / risk management information are held by each of the 8,573 GP Practices in England.
- Not all diabetic retinopathy screening programmes have yet been defined, but it is likely that there will be between 100 and 105 programmes nationally by December 2007.
- Many referrals to the hospital eye service for suspected diabetic eye disease originate from community optometrists. Referrals are generally made through the patient's GP, but direct referral from optometrists is becoming increasingly common. Some optometrists are also involved in systematic screening programmes for diabetic retinopathy. There are 8,467 registered optometrists and Optometric Medical Practitioners in England, operating from 5,790 optometric practices.
- Referrals are made to around 120 NHS Trust-based eye services nationally, and assessment and treatment is carried out at most of England's 295 hospital eye clinics.

The following care settings can be part of the disease management pathway for diabetic eye disease:

- primary care
- screening management centres within and outside the NHS
- the constituent operational units of a screening programme, within and outside the NHS:
 - photography units
 - image grading centres
 - biomicroscopy assessment clinics
 - community optometrists
- eye clinics and ophthalmic assessment services based in acute care
- other relevant NHS and non-NHS care providers:
 - diabetology services
 - renal services
 - hospital optometrists
 - independent optometrists

4.4.3 Existing systems

The following information systems in current use in the NHS support processes or hold data pursuant to the care of diabetic eye disease:

- GP Practice Management Systems
- Diabetic retinopathy screening programme management software solutions
- Hospital PAS systems
- Ophthalmology Data Management Systems / Clinical EPR (very few):
 - Assessment clinic
 - Laser treatment clinic
 - Operating theatre

5 Project approach

Although there is no consistent national approach to diabetic eye disease, the delivery of digital screening programmes has generated a new interest in information subsystems for ophthalmology, and various initiatives are underway to solve some of the immediate problems outlined in this document. Without the rapid and concerted adoption of guidelines and information standards, current development work is likely to diverge, leading to a proliferation of non-interoperable local solutions. To minimise this risk, the project approach was as follows:

- The project scope was flexible enough to encompass and consolidate current development of information subsystems for diabetic eye disease, particularly as Do Once and Share provided the exposure and legitimacy of an NHS Connecting for Health project;
- Consultation and stakeholder engagement was as wide and open as possible, involving clinicians, patients, information experts and suppliers – though special care was taken to avoid advantaging any supplier who participated in the work; and
- Care pathways, datasets and data exchange specifications have been developed as open standards, freely available to any supplier wishing to implement them.

Engaging local and national representatives in the spirit of open co-operation has proven to be an effective way to make progress, primarily because the project aims to produce outputs that not only meet the strategic requirements of NHS Connecting for Health – encouraging early alignment towards an eventual goal – but also provide immediate value in this fast-evolving field.

5.1 Definitions and semantics

Many of the terms in this report have been defined in the glossary on page 47, and a broken underline indicates that a term should be read strictly according to its definition. As far as possible, terms follow their plain English meanings. However, a few require special consideration:

Much of the diabetic eye disease care process involves the detection and assessment of diabetic eye disease in people not otherwise under medical care. For simplicity, the term patient, which is defined in this document as ‘a person who receives medical attention, care or treatment’ will include these people.

Care pathway is a difficult concept, too often mistaken for inflexible process that denies patients access to tailored care. Following the *Do Once and Share* project for Diabetes, this document differentiates between:

- care components, elements that define what has happened or should happen to a patient; for example, a need, intervention or choice;
- care pathways, which are here defined as ‘descriptions of a structured process of care, setting out a consistent set of decisions and activities relating to one or more risks, issues or problems’; and

- care plans, the application or personalisation of one or more care pathways to a particular patient, leading to a sequence of planned activities for that patient.

This report describes a series of information subsystems. However, the system does not determine the care process: that is the prerogative of the patient and his or her condition. The patient is the focal concept across each deliverable of this project.

5.2 A time for change

This report describes information systems and processes that will support the future detection and management of diabetic eye disease. These future systems can be described with some certainty because they are already available – but not necessarily on a wide scale, or across the care spectrum, or organised in a way that allows their benefits to be realised.

The transition from free-form notes and fragmented paper records to structured, computer-based patient records will entail a significant cultural change. Accordingly, the care pathways and datasets that have been defined through this project do not necessarily reflect current practice. In general, the most significant deviations from current practice, such as the automatic grading of diabetic eye disease through the observation and recording of clinical signs, will go furthest to realise the benefits of information systems. In the context of diabetic eye disease, ophthalmologists will no longer revert to making an instant diagnosis with no record of the history, clinical observations or investigations behind that diagnosis.

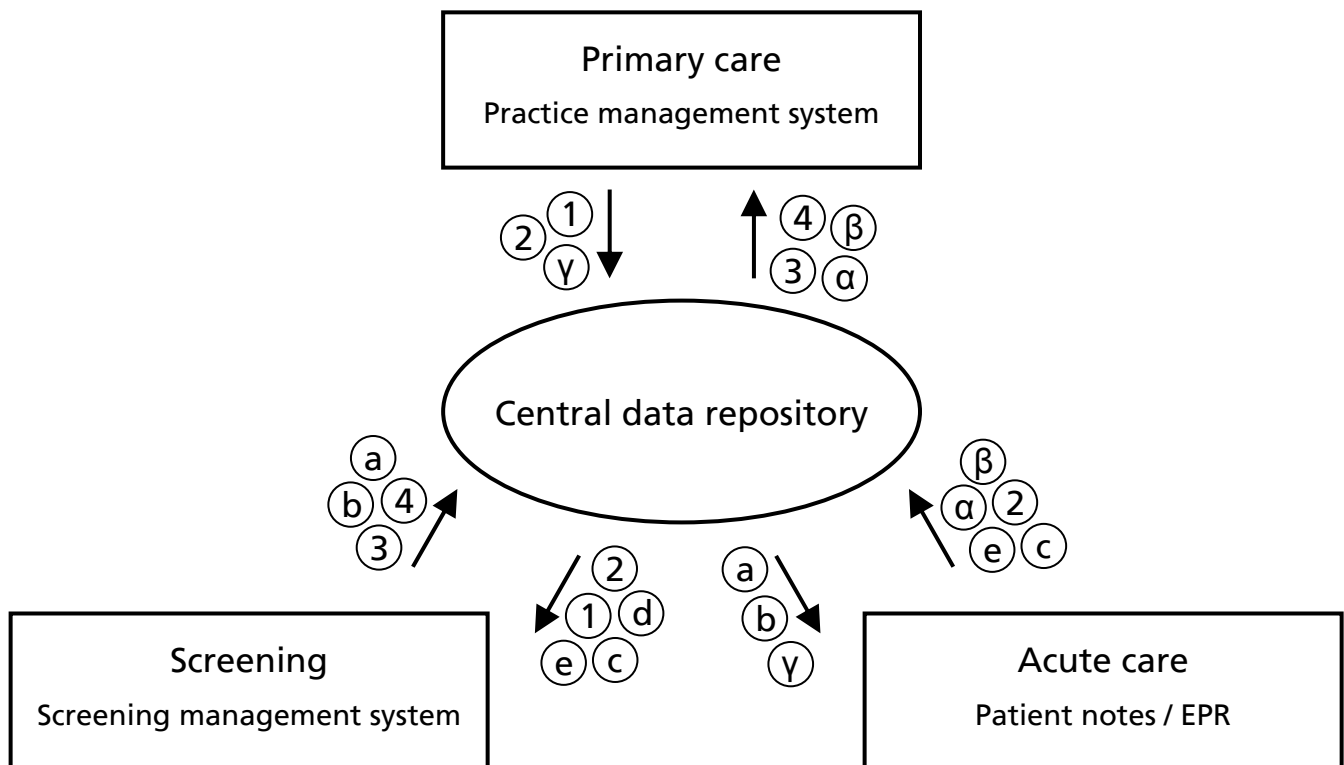
It is recognised that lack of familiarity with the tools and techniques of a digital era will be one of the greatest barriers to the adoption of the systems described by this project. Where possible, this has been mitigated by designing information standards that can be represented in a way which is recognisable to clinical users, for example by reflecting the layout of paper referral proformae on screen-based data entry forms. However, this is not always possible or desirable, and the general principle adopted is to favour appropriate functionality over familiarity, and allow NHS Connecting for Health to develop and test approaches to this significant and universal issue.

5.3 Platform independence

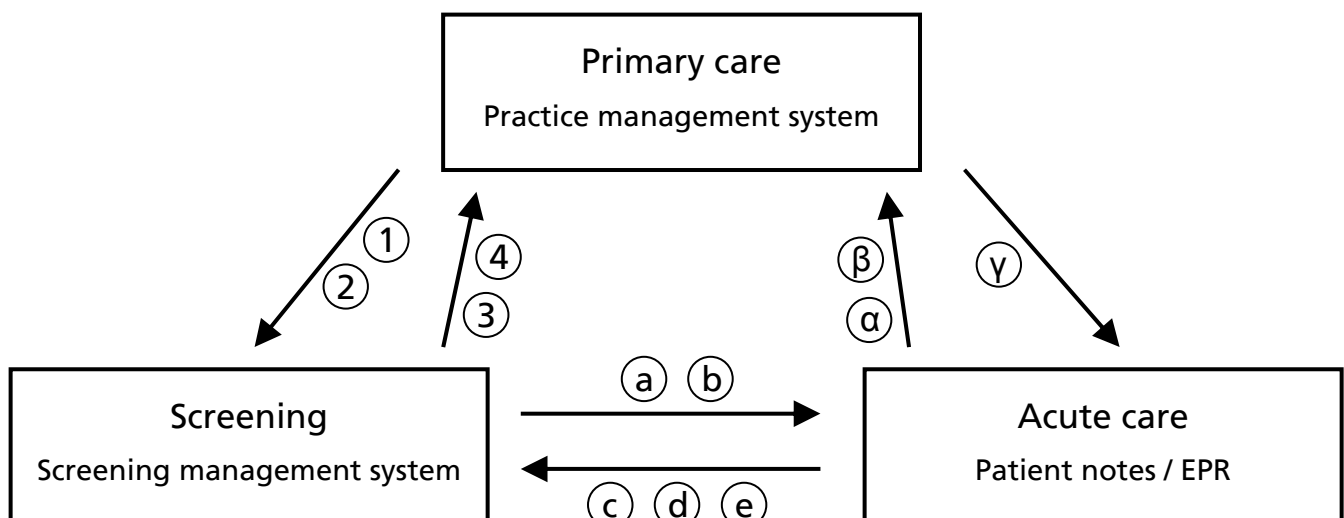
The tools most likely to enjoy a long and useful life are those which do not rely on assumptions about the environment in which they will be used. Recognising that it will be some years before reliable national IT infrastructure is in place, this project presupposes as little as possible about the information systems and processes that will be necessary to support the system of care that it describes.

Uncertainty as to how and when support for diabetic eye disease will be delivered creates an imperative to develop standards which will meet today's needs and can be built into today's IT solutions as well as informing the development of NHS Connecting for Health systems. Care for diabetic eye disease is likely to have evolved significantly by 2010, and it is more important to set the foundations for a culture of standardisation and interoperability than to concentrate on a future ideal. A key objective for this project, therefore, is the immediate and widespread publication of a series of information and process standards for adoption within existing systems and forthcoming 'interim' solutions, and for use as a development baseline for the strategic national architecture.

For example: the National Application Service Providers (NASPs) are contracted to deliver national information subsystems such as the Personal Demographics Service (PDS), a single national database of patient demographics, and the Personal Spine Information Service (PSIS), a central database of key health and care information. When they are fully operational, these systems will handle all requests for certain types of data, so information will be shared between primary care and the hospital eye clinic through a common subsystem:



In the meantime, the data to enable record sharing should be available, but may be distributed between a number of information subsystems:



Both of these models, and a variety of related hybrid approaches, have strengths and weaknesses. However, the bundles of data to be recorded and shared, the circumstances in which they should be transferred, and the processes within each service remain constant whichever model is adopted. The generic deliverables from this project support these and most other models of healthcare IT architecture. It is hoped, accordingly, that the standards:

- will be widely adopted by existing systems providers;
- will facilitate migration from existing systems to future systems;
- will survive some degree of administrative change; and
- will enable and encourage large scale interoperability.

6 Project objectives

6.1 Objective O1: standardisation

Develop a systematic approach to diabetic eye disease across primary care, screening and secondary care, which is consistent with other disease areas and can inform the development of NHS Connecting for Health solutions.

Status: Achieved

Date of completion: May 2006

References: Appendix C1

Where diabetic eye disease is detected by a screening programme, the majority of affected patients follow similar care plans, and good progress has been made on defining and disseminating care pathways and information standards for the diabetic retinopathy screening process. However, the management of diabetic eye disease in primary care and the hospital eye clinic both present wide variation in practice.

Primary care information systems hold structured information about diabetes diagnosis, clinical and risk factors. This information is usually current and accurate, but is not efficiently shared with screening programmes or secondary care. Further, the results of screening, assessment and treatment are rarely presented to the GP in a form that allows electronic transfer to the computerised patient record.

Very few hospital eye services have access to a clinical information system, relying instead on paper notes and local clinical protocol. Whilst this might not directly affect the quality of care offered, the burden of maintaining effective records in relative isolation is great, and effective audit from paper records can be difficult and expensive. Although procedures in the hospital eye clinic for the assessment and treatment of diabetic eye disease are well established, inconsistency in recording clinical data limits the utility of any records created. A tangible consequence of this is waste: in the absence of clear information to indicate that a patient is under the care of an ophthalmologist for the assessment of diabetic eye disease, the screening programme must issue an invitation

This project builds on work already done in Bristol and Gloucestershire to describe the operation of a series of standardised care pathways that link primary care, screening and

assessment / treatment in secondary care, and the datasets that should be used to record information in each care setting. Together, these deliverables constitute a foundation upon which national standardisation can be built.

6.2 Objective O2: stakeholder engagement

Secure local and national stakeholder engagement and establish a credible, informed body of clinicians to support the ongoing development of the NHS IT infrastructure.

Status: Achieved

Date of completion: February 2006

References: Appendix D, [Section 12](#), <http://www.doas-ded.org/team>

Despite the challenge of enthusing those with limited technical experience about systems design work, stakeholder engagement has been extremely strong and the level of support offered by clinicians across the care spectrum has been exceptional.

The project was steered by a Reference Group comprising a select multi-disciplinary team of clinicians, service managers, IT system suppliers, voluntary organisations and patients with current knowledge of the information needs for Diabetic Eye Disease and who stand to benefit from a concerted national drive for standardisation. Each area of England was represented, with 22 national and 25 local experts including representatives from the Royal College of Ophthalmologists, the Royal College of Physicians, the College of Optometrists, the Association of Optometrists, the National Screening Programme for Diabetic Retinopathy, Diabetes UK and the Royal National Institute for the Blind. Membership of the group is set out in [Section 12](#).

Wider stakeholder engagement has been secured through a series of presentations, articles and fliers, details of which are provided in Appendix D. The project has also engaged with the [National Library for Health](#) and will be featured in the forthcoming National Knowledge Week for Diabetic Eye Disease, as detailed in Appendix E.

The level of enthusiasm for this project, and the time that stakeholders were prepared to dedicate to the work, reflect an urgent need for interoperable IT solutions for diabetic eye disease and a widespread recognition of the benefits that such systems can bring to the care process. One of the recommendations from this project is the formation of a Stakeholder Reference Group to oversee the development and implementation of information subsystems for diabetic eye disease. It is anticipated that there will be no shortage of support for follow-on work amongst stakeholders who have contributed to this DOaS project.

6.3 Objective O3: provision of a focus for discussion

Provide a focal point for informed discussion about clinical processes relating to diabetic eye disease.

Status: Achieved

Date of completion: February 2006

References: <http://www.doas-ded.org/discussion>

A project website was been developed, with focus areas restricted to registered stakeholders and members of the Reference Group as well as an open forum. To maximise use of this resource, submission of comments and ideas is made as simple as possible: for example, comments posted to most pages of the website are displayed immediately for all to read. It is anticipated that this website will continue to be maintained by the National Screening Programme for Diabetic Retinopathy for as long as it continues to be useful.

It became apparent following the launch of the website that discussion about clinical processes would generally be limited to critical appraisal of the proposed outputs from the project, and particularly the care pathway diagrams. Whilst this was a useful way of capturing breadth of opinion, some degree of user-selected localisation (“show me comments for Avon, Gloucestershire and Wiltshire SHA”) would probably be more appropriate than a single national forum.

6.4 Objective O4: evolution of knowledge resources

Draw together Guidance, Expertise, Evidence and Knowledge in an open, accessible form (a GEEK resource) to encourage consensus on an appropriate national clinical pathway for diabetic eye disease.

Status: Achieved

Date of completion: May 2006

References: <http://www.doas-ded.org/knowledge>;
<http://www.library.nhs.uk/diabetes/Page.aspx?pagename=DR>

An interactive online resource was specified and deployed to allow Guidance, Expertise, Evidence and Knowledge to be posted and shared as easily as possible for the duration of this Do Once and Share project. It is anticipated that this website will continue to be maintained by the National Screening Programme for Diabetic Retinopathy until the relevant materials can be appropriately indexed within the [National Library for Health](#).

An online tool was developed to allow care pathways to be displayed and manipulated. It is anticipated that care pathways will be migrated to Map of Medicine when this becomes nationally available.

The Action Team engaged with the [Diabetes Specialist Library](#) of the National Library for Health to develop a library of significant articles, publications and guidelines relating to Diabetic Eye Disease. This will be used as the basis of the forthcoming National Knowledge Week for Diabetic Eye Disease. Excerpts from the library can be found at Appendix E.

6.5 Objective O5: information sharing

Identify and refine ways of linking together information sources with relevance to diabetic eye disease and express these in a consistent form to facilitate appropriate sharing of clinical data and a reduction in duplicate data entry.

Status: Achieved

Date of completion: May 2006

References: Appendices C2, C3, C5, C6

Systems for the care of diabetic eye disease have developed organically, and, in general, lack the ability reliably to share information. A prerequisite for effective information sharing is consistent information recording. The datasets delivered through this project will ensure that where information is recorded, it is done so consistently, and with sufficient context to be safe and meaningful. Each dataset has been cross-referenced and checked against other relevant datasets, and the Information Centre for Health and Social Care was engaged to ensure that existing standards are used where possible and to encourage consistency which will in turn facilitate data exchange.

Once agreed, datasets need to be presented to clinicians in a consistent and usable fashion. This will require consultation with clinicians to understand their needs, and software developers to understand how this can be delivered in the context of existing clinical information subsystems. It is unhelpful to present clinicians with information excessive to the patients needs at that point in the pathway; however, critical information such as consent status must appropriately be displayed and maintained.

6.6 Objective O6: monitoring and improving outcomes

Improve visual outcomes for patients with sight-threatening diabetic retinopathy in support of the targets set, but not yet reached, in the 1990 St Vincent Declaration unanimously agreed by Government Health Departments and patient organisations from all European countries, viz to reduce new blindness due to diabetes by one third or more.

Status: Achieved within the scope of this project

Anticipated completion: 2009

References: Appendix C

The overall aim of screening for (and subsequent treatment of) diabetic eye disease is to reduce visual impairment and blindness. In order to assess whether screening and treatment services are effective, both at an individual and a population level, the following are required:

- a) an accurate, consistent way of measuring visual function;
- b) identification of the cause of visual impairment or blindness; and
- c) records of visual function over time.

At an individual level, inconsistency in the recording of visual function, and failure consistently to record the cause and degree of visual impairment, can hinder the appropriate delivery of care and support. This is particularly true where vision is assessed and recorded at a number of locations, such as screening services and community optometrists, without the results being effectively shared.

At an epidemiological level, this problem is compounded, as the visual function of a given population can only be measured through research or through the use of information systems to collate and monitor levels and causes of visual impairment and blindness. In particular, an improvement in visual standards can only be assessed by reference to a reliable baseline.

The NHS has in the past relied on either paper-based audits or CVI ([Certificate of Vision Impairment](#)) registration rates. Currently, audits of work related to diabetic eye disease in hospital eye services are time-consuming, expensive and only cover a relatively small sample of patients, and a complete dataset is never available for all patients. Further, it is well known

that rates of CVI registration are variable and that overall there is significant under-registration (as much as 50%) of eligible individuals. Many people with diabetic eye disease have levels of visual impairment that do not meet those for CVI registration but that still affect their quality of life (for example, difficulties in reading or failure to meet the visual standards for driving). Audit of this level of visual impairment at a population level is almost impossible with existing paper-based systems.

The datasets proposed through this project enable continuous collection of visual impairment data, including an assessment of visual fields and whether observed visual impairment is due to diabetic retinopathy. For the first time, this will enable accurate and ongoing assessment of the true levels of visual impairment in people with diabetes. Because the information is collected at the point of care, the need for separate audit or registration is vastly reduced, and the quality and completeness of the data correspondingly improved. This data collection will hugely facilitate local and national service audit, so that screening programmes and hospital eye services can assess whether they are meeting quality assurance targets (such as waiting times for laser treatment).

6.7 Objective O7: sustainability

Establish a platform for the sustainability of this work.

Status: Achieved

Date of completion: April 2006

References: <http://www.doas-ded.org/knowledge>

This project has evoked widespread interest in the systematic specification and widespread availability of high quality systems for diabetic eye disease. Even should no further strategic systems development take place, an understanding of what is possible has now been firmly established, and it is anticipated that this Do Once and Share project will remain an important reference work for the development of systems for diabetic eye disease at all levels.

The Reference Group will be encouraged to continue this work beyond the end of the project, by transferring responsibility to colleagues if necessary. The project website, which includes functionality to submit comments and documents as well as an open discussion forum, will be maintained by the National Screening Programme for Diabetic Retinopathy for as long as it continues to be useful. When a sufficient body of knowledge and evidence has been established, subsets of information from the website will be migrated to other NHS knowledge resources such as the National Library for Health where they will continue to be maintained.

The Action Team has recommended (see section 10.1, below) that a Stakeholder Reference Group be established to inform and oversee the implementation of systems for diabetic eye disease. It is proposed that such a group will oversee a series of revisions to the outputs of this Do Once and Share group on the basis of:

- a) development and implementation constraints;
- b) implementation experience; and
- c) clinical and administrative developments in the intervening period.

7 Progress on deliverables

7.1 Deliverable D1: summary care pathway

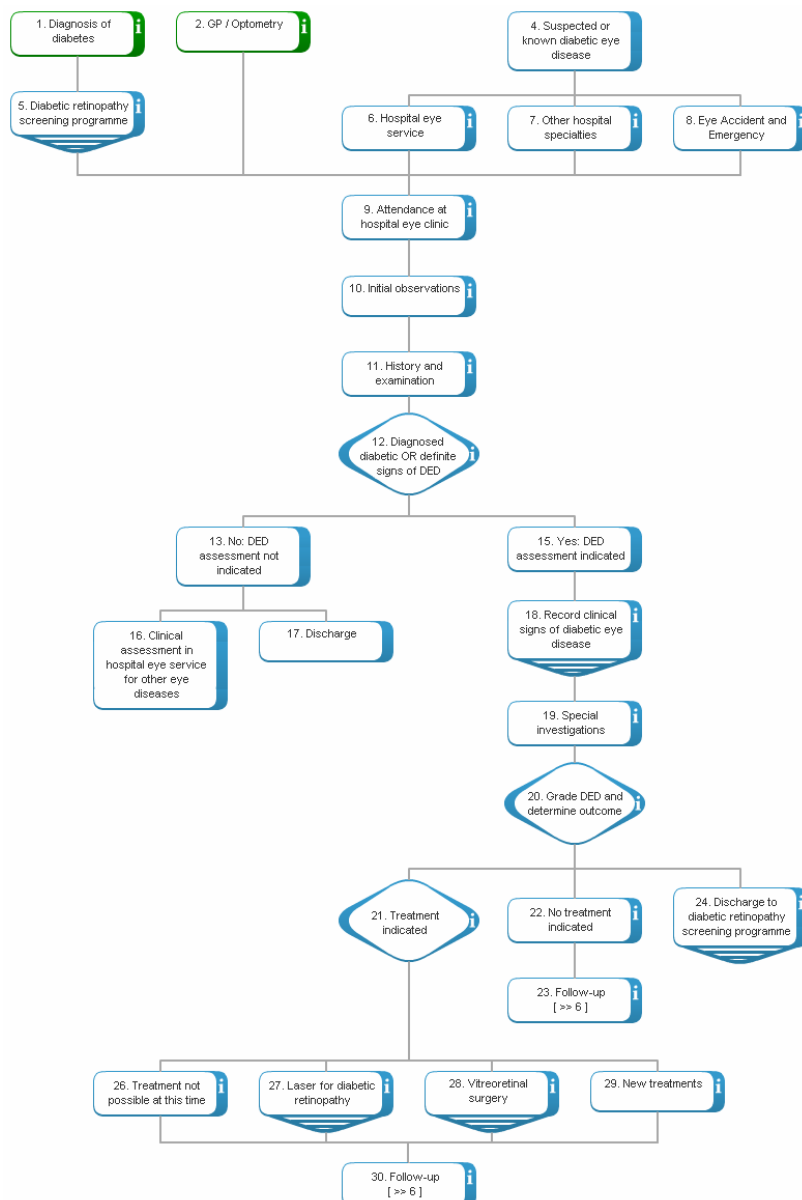
Build on work already done nationally and in Gloucestershire and work with other partners (including providers of evidence-based content services and clinicians experienced in data collection) to define a national pathway for the detection, assessment and treatment of diabetic eye disease.

Status: Complete

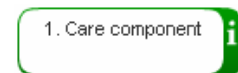
Date of completion: May 2006

References: Appendix C1, <http://www.doas-ded.org/care-pathway>

A summary care pathway for the management of diabetic eye disease has been devised and is attached and explained at Appendix C1.



The process represented by a care pathway generally starts at the top of the diagram and reads down. Each box in the care pathway is a 'node'. Green nodes relate to primary care; blue nodes relate to screening and secondary care.



A rectangular node represents a care component, usually a process or an activity.



A diamond-shaped node represents a decision with two or more alternative outcomes.



A node with a downwards chevron represents a link to another pathway, usually at a greater level of detail.

Just as the processes described by the care pathways in this project are unsuited to paper-based working, so too are the pathways themselves. After various attempts, the Action Team found that a 'flat' representation of the care pathway, as might be published in a report, was unhelpful, as it required too great a volume of explanatory notes and cross-references.

An interactive online tool was developed, allowing the user to navigate between related care pathways at various levels of detail, and facilitating the display of explanatory details and further information. The top-level view was designed to be as generic and simple as possible, such that it would be useful to each of the audiences described in section 1 above. Groups of care components, loops within a care pathway, subcategorisation and other aspects of process modelling have been omitted in the interests of simplicity but can be introduced if a generic requirement is identified.

Use of the pathways is self-explanatory; they are viewed through a [hypertext browser](#) so can be incorporated within a webpage and updated centrally. An **i** to the right of the node name indicates further information, and clicking the node will display an information panel that may contain links to other pathways or online resources. Some pathways, particularly those at a greater level of detail, contain dotted lines between nodes, indicating that a particular branch of the pathway is optional, according to local protocol.

It is anticipated that the care pathways described through this project will be migrated to the Map of Medicine or similar evidence-based content providers when these are widely available across the NHS. However implemented, care pathways have been designed to facilitate integration with the NHS Care Records Service and to take into account local variability in patterns of care.

7.1.1 Description of the summary care pathway for diabetic eye disease

The primary purpose of the [summary care pathway](#) is to provide information systems architects with a contextual framework to understand and implement the [datasets](#) that are defined for the various data collection processes relating to diabetic eye disease. The proposed care pathway is sufficiently generic to support all known management models for diabetic eye disease in England, but sufficiently detailed to support the design of new modular [information systems](#) for the NHS. Within the care pathway are links and references to more detailed [care pathways](#) for specific parts of the care process which are detailed in section 7.4.

The summary care pathway does not represent an exhaustive breakdown of all possible care processes, interventions and activities for patients with diabetic eye disease; neither is it a prescriptive guideline as to how eye services should be organised or managed. Whilst it may provide a useful summary of the clinical processes involved, it should not be used as a comprehensive clinical reference. As with any tool, it may be ineffective or potentially even damaging if used other than as intended by its designers.

7.1.2 National stakeholder involvement

This pathway was first proposed to a reference group of 50 expert stakeholders at the Reference Group conference on 17 January 2006. Since then, various iterations have been openly available on the [project website](#) and comments from stakeholders have been incorporated into the care pathway.

The care pathway was validated across all eye services in Avon, Gloucestershire and Wiltshire SHA by interviewing ophthalmologists and by following typical patient journeys. It has been widely discussed with national stakeholders and the Action Team knows of no management model for diabetic eye disease that cannot be described by the pathway.

7.2 Deliverable D2: data extraction from primary care

Define information requirements for the identification in primary care of people with diabetes for screening and convey demographic and clinical data (which might include diabetes management information such as blood pressures, HbA1c readings and renal data) to diabetic retinopathy screening programmes and clinical systems in use in hospital ophthalmology departments.

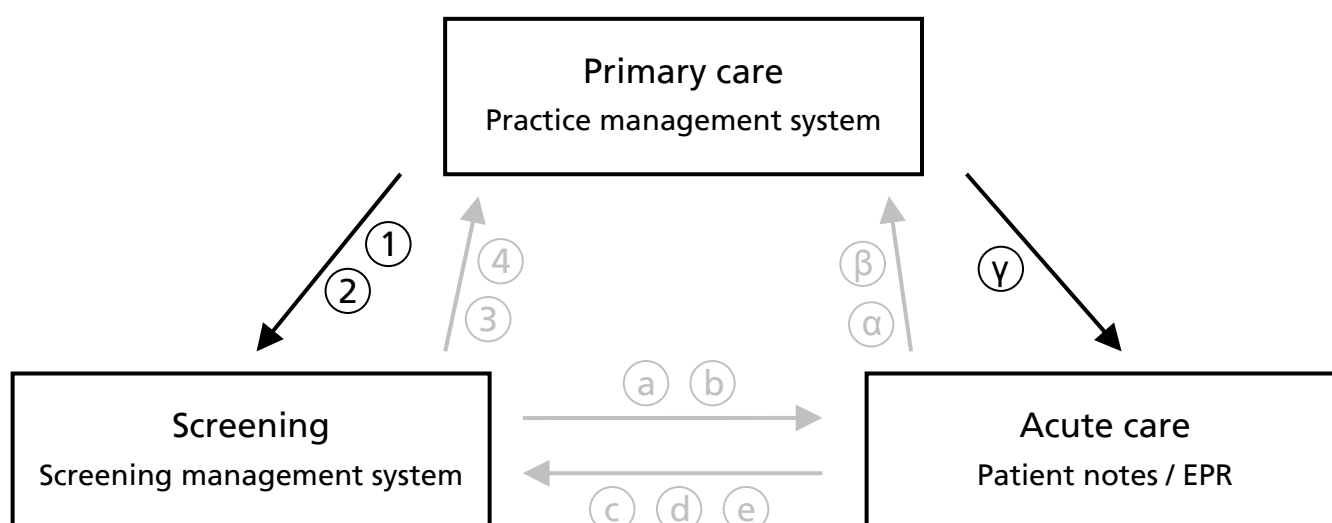
Status: Complete

Date completed: May 2006

References: Appendix C2, <http://www.doas-ded.org/a>

One of the two key targets in the [Diabetes NSF](#) is the development of practice-based registers of diabetes in primary care. Due in large part to the [Quality and Outcomes Framework](#) (QOF), high quality coded data about people with diabetes is available in the majority of GP Practice Management Systems. The main extensions required to transfer this information to screening programmes and primary care relate to consent and eligibility for screening, and are detailed in Appendix C2.

A primary care data exchange specification has been developed and discussed in detail with the Reference Group. The following interfaces have been considered (interfaces considered in relation to other deliverables displayed in grey):



1. Patient list (demographics, consent, eligibility for screening)
2. Clinical / risk indicators where consent has been obtained
- γ. Patient history for direct referral of diabetic patients

To maximise compatibility with existing systems, the specification is based upon:

- Demographic and coded clinical data available in any GP Practice Management System.
- The Diabetic Retinopathy Screening dataset, which is supported by all major diabetic retinopathy screening packages.

The data exchange specification is expressed in tabular form (Appendix C2.1) and as an HL7v3 Message Implementation Manual (Appendix C2.2), including storyboards, data transfer triggers and detailed message definitions. Information subsystems built around these specifications have the potential to deliver the following benefits:

- Comprehensive, accurate and up-to-date screening registers in diabetic retinopathy screening services
- Reduced administration demands and duplication of effort
- Less reliance on inefficient and error-prone paper processes and
- Availability of clinical / risk assessment factors to inform screening and subsequent assessment and treatment processes
- Improved returns and outcomes from screening services as a result of higher quality and reliability data from practice-based diabetes registers (for example, identification of unscreened population to be targeted in routine care situations)

7.2.1 Data transfer from primary care to screening

Following recommendations from the [Patient Information Advisory Group](#) (PIAG), two specifications for data extraction and transfer from primary care to screening programmes have been developed:

Dataset D2.1 Non-clinical patient information

The basic core of demographic information that must be conveyed to the screening programme in order to send an invitation for diabetic retinopathy screening, including:

- Name and contact details
- Communication requirements, e.g. preferred language
- Consent to transfer additional clinical / risk information
- Eligibility for screening

PIAG have advised that active consent from the patient is not required to transfer this information to a screening programme.

Dataset D2.2 Diabetic eye disease clinical / risk indicators

Additional clinical and risk indicators to aid in the diagnosis, assessment and treatment of diabetic eye disease, including:

- Diabetes type
- Registration of visual impairment and severe visual impairment
- BMI

- Blood pressures
- HbA1c history
- Renal functions
- Cholesterol
- Smoking
- Visual acuity

7.2.2 Data transfer from primary care to the hospital eye clinic

Referrals from primary care into the hospital eye clinic require additional clinical history and risk indicators, including:

- Non-clinical patient information, as defined in 7.2.1 above
- Diabetes eye disease clinical / risk indicators, as defined in 7.2.1 above
- Significant medical history
- Allergies
- Medications

This is a generic requirement, which has not been examined in detail through this project. It is understood that a GP Summary Specification is being developed by NHS Connecting for Health, and that this will be suitable to support referrals to the eye department and interventions to patients under the long-term care of an ophthalmologist. The only items of particular note that should be included within the GP Summary for assessment and treatment in the hospital eye clinic are allergies to topical mydriatic agents such as Tropicamide and Phenylephrine.

7.2.3 Non-biomedical data

In addition to demographic and clinical data relevant to the direct care of diabetic eye disease, primary care systems are also a potential source of non-biomedical information regarding knowledge, social, emotional and behavioural factors which might inform the provision of care. The diabetic eye is part of the wider condition of diabetes, so care for diabetic eye disease is likely to be divided across different healthcare sectors, clinics and care professionals. Whilst IT systems cannot provide a substitute for 'continuity of care', they can allow context – such as the degree of knowledge or understanding that a patient has about a process – to be shared amongst those involved in a patient's care. This is particularly important for patients being treated for diabetic eye disease, as treatment can be intensive and frightening. For the patient to feel that their care is under control, it is important that relevant information beyond basic administration, diagnosis and treatment indicators is available to all involved in the process.

A short 'patient profile', available to anyone involved in the care process and giving a summary of relevant non-clinical information agreed between patient and clinician, was proposed by the Reference Group as the most effective way to record and present key information. This summary could supplement structured information in the patient record. The risk of stereotyping a patient was recognised, and it was considered that the patient should choose the carers or groups of carers with whom the profile and other non-clinical information should be shared. General opinion, particularly from the Reference Group

representatives with diabetes, was that information should be shared in any way that might improve the standard of care, and that 'opt-out' from information sharing would be more effective than 'opt-in', but it was recognised that this is a wider problem that must be addressed at a higher level.

The bulk of non-clinical information is relevant across specialities and across health and social care sectors, and this requirement is therefore a generic concern for NHS Connecting for Health. However, a summary of non-biomedical factors relevant to the effective care of diabetic eye disease is provided at Appendix C2.3.

7.2.4 National stakeholder involvement

Strong representation from primary care on the Reference Group, under the direction of Dr Graham Wilson, primary care lead on the Action Team, has ensured a high level of involvement from GPs in this project. Data transfer from primary care information systems is amongst the least controversial of the developments outlined in this project, not least because such systems are already so well established in primary care.

7.3 Deliverable D3: screening → acute care data exchange specification

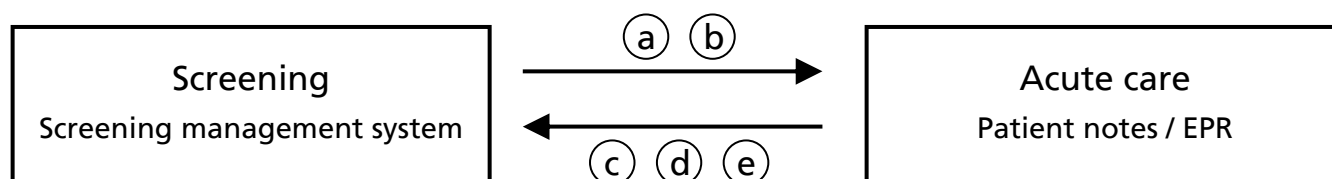
Specify an interface to pass patient information between diabetic eye screening services and acute care, which could be developed into a national data interchange standard.

Status: Complete

Date completed: January 2006

References: Appendix C3

The Diabetic Retinopathy Screening dataset, which is supported by all major diabetic retinopathy screening packages, makes provision for intraoperability: the ability to access screening information in hospital eye services through diabetic retinopathy screening management software. This project extends that specification to enable interoperability between screening systems and information subsystems in ophthalmology:



- a) Referral of patient with suspected diabetic eye disease
- b) Diabetic retinopathy screening history for diabetic patient
- c) Query to determine whether a patient referred other than from screening has a diabetic eye disease screening history (interaction (b) may be sent in response)
- d) Ophthalmology assessment of diabetic retinopathy / follow up / discharge
- e) Return of treatment data to screening programme

The data exchange specification is expressed in tabular form (Appendix C3.1) and as an HL7v3 Message Implementation Manual (Appendix C3.2), including storyboards, data transfer triggers and detailed message definitions.

7.3.1 National stakeholder involvement

The outputs from this deliverable are derived wholly from the Diabetic Retinopathy Screening dataset, which has undergone full national consultation through the NHSIA Datasets Team.

7.4 Deliverable D4: assessment and treatment care pathways

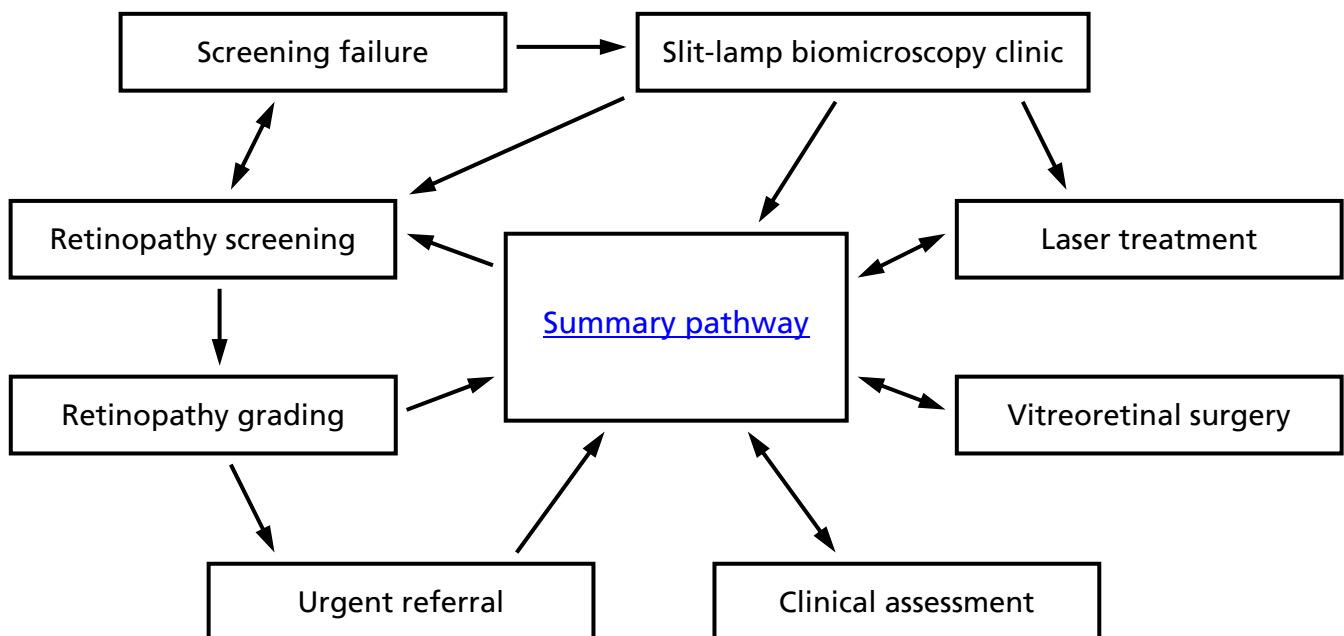
Refine the information pathway for the specialist assessment and treatment of diabetic retinopathy and to define clearly how this pathway can and should be 'localised' (including some reference to the degree of acceptable local variation). This work will be done in collaboration with providers of evidence-based content services and should extend the current work on data collection from diabetic retinopathy screening.

Status: Complete

Date completed: May 2006

References: Appendix C4, <http://www.doas-ded.org/care-pathways>

A series of detailed care pathways, for diabetic retinopathy screening and the assessment and treatment of diabetic patients in the hospital eye clinic, has been developed. The relationship between these pathways is as follows:



In support of each care pathway, datasets have been defined for:

- clinical assessment of diabetic eye disease in the hospital eye service: this dataset standardises the recording of the presence or absence of clinical signs of diabetic retinopathy and how these map to classifications of diabetic retinopathy (Appendix C4.9);

- b) laser photocoagulation treatment for diabetic retinopathy (Appendix C4.10); and
- c) fundus fluorescein angiography (Appendix C4.11).

7.4.1 Clinical assessment of diabetic eye disease in the hospital eye service

At present few if any hospital eye departments systematically collect data on patients with diabetic eye disease:

- during outpatient visits;
- when attending for laser treatment;
- when receiving other treatments; or
- when undergoing vitrectomy for diabetic eye disease.

Collection and audit of such data is vital to meet the demands of clinical governance defined in the NHS Plan (<http://www.nhs.uk/nhsplan/default.htm>) and to provide quality assurance of the diabetic retinopathy screening at a local and national level. All NHS organisations now have a statutory duty of 'quality' yet they cannot know whether they are delivering it unless systems are implemented which encourage appropriate care pathways and audit their effectiveness. Until such systems are implemented within the hospital eye service we will never know whether we have met the objective of screening and the St Vincent's declaration to reduce the incidence of blindness from diabetic retinopathy.

Diabetic retinopathy screening programmes aim to provide systematic annual screening to all eligible people with diabetes. Around 10% of people with diabetes attend the hospital eye service for the ongoing care and assessment of diabetic eye disease. Because there is no reliable information return to the screening programme to indicate that the level of diabetic eye disease in these patients has adequately been assessed, many of these patients also attend the screening service, resulting in inconvenience, anxiety and uncoordinated care. Each photographic screening episode costs around £25 per patient per annum, so for a screening programme serving a population of 20,000 the immediate saving of implementing an appropriate system in the eye clinic is around £50,000 per annum.

One objective of this DOaS project was to define minimum datasets to be collected in the hospital eye clinic and primary care to provide a high quality of care for the patient, allow audit of the quality of care and provide quality assurance of the screening service. The authors recognise that the implementation of these datasets will impose a change in working practices for many ophthalmologists but the consensus of opinion amongst the Reference Group was that this will be a change for the better by ensuring a systematic approach concentrating on recording the presence, absence and severity of specific clinical signs rather than only recording a diagnosis as is common practice at present. In addition to efficiently linking the eye clinic with screening this approach will allow immediate comparison of the efficacy of treatment by eye departments and regions with benchmark standards established in large randomised controlled clinical trials such as the ETDRS and DRS. We have consulted widely to ensure that the standardisation we seek to achieve with respect to the minimum datasets has broad agreement from medical retina specialists in the UK.

Ophthalmologists reviewing the associated dataset should concentrate on the 'Data recorded in HES' excel sheet and in particular the group of fields titled 'DR assessment' that lists all the

fields of clinical data collection and the data values within each field. The principle is that the ETDRS level of retinopathy and maculopathy is automatically defined with the minimum of data entry by recording the absence, presence and severity of specific clinical signs. The ETDRS level can then be translated into classification schemes which are less precise, such as the National Screening Committee classification of Diabetic Retinopathy, for return to screening or elsewhere.

A 'top down' approach has been taken to defining the level of retinopathy so that, for example if 'advanced diabetic eye disease' was identified then questions relating to this level (presence of iris neovascularisation, angle neovascularisation, etc) must be answered but details of other proliferative or non-proliferative features would be unnecessary as they would have no effect on ETDRS level, diagnosis, treatment or follow-up. This will optimise the number of data items that must be recorded for each eye of each patient. After discussion with the Reference Group, the Action Team decided to minimise the requirement for ETDRS reference photographs but thought that access to standard photographs 2a and 8a would be particularly helpful in determining the correct level of retinopathy.

This project has only considered data collection required for the assessment and treatment of diabetic eye disease and quality assurance of screening programmes. It must be emphasised that the data collection defined within this project must be programmed within a comprehensive clinical system for ophthalmology, catering for all ophthalmic subspecialties, when delivered by suppliers through NHS Connecting for Health. Patients with diabetic eye disease frequently have other eye conditions; diabetic retinopathy cannot be treated in isolation and healthcare professionals cannot be expected to use a multitude of different systems for different eye diseases.

It is also vital that decision support and risk outcomes analysis functions are built into any national solutions for diabetic eye disease. As an example of this the dataset includes the risk of progression to early or high-risk proliferative diabetic retinopathy for all levels of non-proliferative diabetic retinopathy.

Datasets for 'Patient data' and 'Return of data to screening' deal with additional data items that must be exchanged between diabetic retinopathy screening services and hospital eye services. These screens have implications on the data that must be collected within the HES ophthalmology clinical systems which must be carefully considered by programmers involved in implementing the datasets.

The design of the National Care Records Service is outside the scope for this project but we have taken steps to prove that what we suggest is practicable. A paper proforma of a draft of the assessment of 'Clinical Signs in Diabetic Eye Disease' (Appendix C4.9.9) was piloted in four medical retina hospital eye clinics (Moorfields, Bristol, Cheltenham, Gloucester) by numerous clinicians. Every clinician found the additional data entry requirements to be acceptable and that they did not significantly slow the progress of the clinic.

7.4.2 Laser photocoagulation for diabetic retinopathy

One previous paper-based national audit of diabetic retinopathy treatment has been organised by the Royal College of Ophthalmologists. This was expensive to perform and revealed widespread under-treatment by comparison with landmark trials and patchy

recording of data. Few, if any, eye departments in England currently record the details of all laser treatments electronically and have no automatic method of auditing the efficacy and complications of their treatments. Examination of clinical notes in different departments also reveals widespread variation in the level of detail recorded about laser treatment by individual doctors.

Audit based on information collected through a standardised care pathway at which collection of a minimum dataset is forced at every visit has great advantages over paper-based studies and is the only way that the impact of laser treatment on the incidence of blindness from diabetic retinopathy can be assessed. This is vital to meet the quality assurance outcomes of the screening programmes.

The aim of this part of the project was to define a minimum dataset that all departments must collect when treating patients with diabetic retinopathy using laser photocoagulation. The dataset deals with every step in the care pathway including:

- data to support listing of a patient for laser photocoagulation;
- process data fields (clinician, time, etc); and
- clinical fields (anaesthetic, laser, duration, power, etc).

It is vital that programmers are aware of all the necessary data fields and data items in addition to the clinical fields that are of most interest to clinicians.

Many of the fields of data collection in the laser treatment dataset are necessary for simple automated audits such as:

- interval between screening and being listed for laser;
- interval between listing for laser and laser treatment being performed;
- number of sessions of PRP / number of burns when completing a PRP; and
- acuity changes before and after laser treatment.

All of the above audits (and many others) will be immediately available to any department that implements electronic clinical systems in their eye department and when grouped with data from other departments will be able to provide quality assurance country-wide.

7.4.3 Fluorescein angiography and other special investigations

Various investigations are performed as part of the clinical assessment of diabetic eye disease. The most commonly performed include:

- Fundus fluorescein angiography;
- Optical Coherence Tomography (OCT); and
- Digital fundus photography within eye departments.

7.4.3.1 Fundus fluorescein angiography

Fluorescein angiography is an investigation where dye is injected into the patient's arm whilst a rapid succession of photographs is taken of the retina. The dye can be observed as it

circulates to the back of the eye, which can help to define the grade of diabetic retinopathy and response to treatment. The images are usually stored in digital photographic systems and these systems must be seamlessly linked with other information subsystems in ophthalmology. The project team have made a significant progress on defining a dataset to standardise the process of ordering, performing and interpreting the results of fluorescein angiography. A draft dataset is attached at Appendix C4.11.

7.4.3.2 Optical Coherence Tomography (OCT)

OCT is a non-contact retinal imaging modality for obtaining high resolution images of cross-sections of the retina or optic nerve head. It is increasingly becoming a standard tool for monitoring the stage and response to treatment of patients with diabetic retinopathy (as well as a wide variety of other retinal diseases). The OCT machine has numerous numerical and graphical outputs. It is vital that outputs from the OCT are not simply treated as images that are archived within a PACS system. Clinicians need access to the numerical data and will use this in a variety of ways, such as developing trend plots of central retinal thickness over time in patients with diabetic retinopathy, which is a key measure of response to treatment in patients with diabetic maculopathy. Technical specifications of interfaces with imaging modalities is beyond the scope of this DOaS project but the project group considered that it was important to emphasise that links with OCT machines were required for modern management of diabetic retinopathy.

7.4.4 New treatments

Many new treatments are currently being investigated for the management of diabetic retinopathy. These include:

- Intravitreal injections of steroids;
- Intravitreal anti-VEGF therapies; and
- Oral PKC inhibitors.

Although some of these treatments are being widely used for some grades of diabetic retinopathy none of them has so far achieved unequivocal evidence of benefit in randomised controlled clinical trials. At this stage it is therefore inappropriate to define care pathways and datasets for these therapies as part of this DOaS project. It is, however, likely that this will need to occur in the future once their clinical value is proven.

7.4.5 National stakeholder involvement

The care pathways and datasets delivered by this project have been jointly developed by the Diabetic Eye Disease Action Team and Reference Group, and have thus benefited from the scrutiny and suggestion of a large number of representative clinicians, patients, service managers and suppliers across England. Care pathways and datasets have been available from the project website for wider stakeholder consultation, and most care pathways have been 'field tested' by evaluating them against live clinics across Avon, Gloucestershire and Wiltshire.

7.5 Deliverable D5: assessment and treatment summaries for primary care

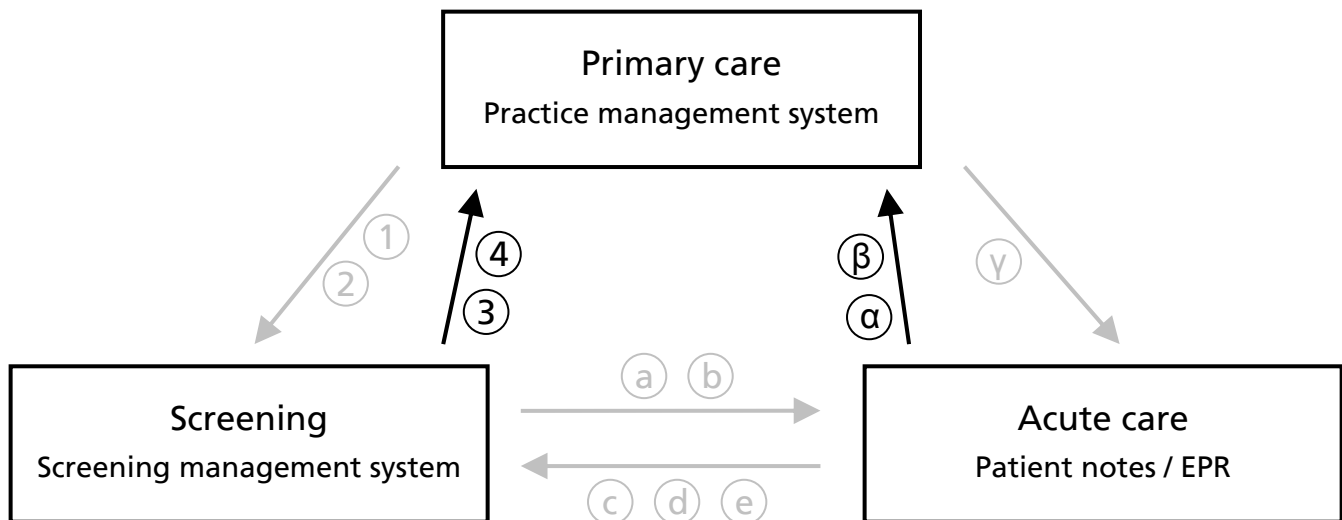
Specify an interface to pass summary assessment and treatment information to primary care systems from screening programmes and hospital ophthalmology systems.

Status: Complete

Date completed: April 2006

References: [Appendix C5](#), <http://www.doas-ded.org/f>

Various interfaces were considered for the return of data to primary care. For information relating to diabetic retinopathy screening, a series of data exchange specifications and associated HL7v3 messages was devised (Appendix C5.1). However, treatment and discharge summaries were identified as a generic need extending to all specialities and the detail was therefore considered to be outside the scope of this Do Once and Share project.



3. Report of screening event (Appendix C5.1.1)

4. Report of screening results / outcome (Appendix C5.1.2)

α. Treatment information

β. Discharge summary

Primary care recognises the value in receiving timely and accurate information on diagnoses, test results and procedures from provider organisations. Data transferred in this way are a significant asset in maintaining accurate and comprehensive records in supporting high quality patient care and clinical audit. Good progress has been made in agreeing the content and timing of such information exchange. Provided data primacy, clinical governance and consent issues are carefully managed, these data links also provide an opportunity to share updated demographics and other data to support the provision of care.

A number of drawbacks and potential clinical risks arise due to the lack of reliable interfaces between screening / acute care and primary care, including:

- potential inconsistencies between coding schemes; and
- timeliness / precision / accuracy / reproducibility of data.

There are examples of comprehensive, coded data exchange from specialist care to primary care, but these tend to be 'hard copy', therefore not directly transferable into GP Practice Management Systems (PMS). However, various successful interfacing projects suggest that electronic summaries from screening and secondary care have the potential to integrate successfully into practice management systems. Various information subsystems are already in place to transfer results of diagnostic tests automatically into Practice Management Systems, and those which are well established (such as pathology results) are reported by clinicians to be very successful.

The outputs of this project, and subsequent improvements to data exchange introduced as part of the National Care Records Service, have the potential to improve significantly the care offered by GPs to people with diabetes, through:

- Accurate, timely data assimilated directly into GP Practice Management Systems (PMS);
- Improved reliability and therefore clinical relevance of the primary care record;
- Information on retinal status assists in general management decisions in diabetes care;
- Accurate, real-time information on screening status will enhance routine diabetes care in Primary Care, for example by identifying unscreened patients to be targeted in routine care situations; and
- Reduced administration demands and potential coding errors at practice and screening level – less opportunity for mistakes or duplication.

Given accurate and timely transfer, screening and treatment results could usefully inform general diabetic care, allowing improved proactive care and audit. In primary care, diagnosis of diabetic eye disease is more important than information about its treatment, as it can support a diabetes risk assessment.

7.5.1 National stakeholder involvement

Strong representation from primary care on the Reference Group, under the direction of Dr Graham Wilson, has ensured a high level of involvement from GPs in this project. It is notable that the request for treatment and discharge summaries to be progressed as a generic workstream was made by the primary care focus group.

7.6 Deliverable D6: shared visual impairment dataset

Develop a method of recording comprehensive data on visual impairment amongst the diabetic population by linking visual acuity data from diabetic retinopathy screening programmes with visual acuity data from Hospital Ophthalmology Services.

Express required information collection and representation as a structured dataset.

Status: Complete

Date completed: January 2006

References: [Appendix C6](#), <http://www.doas-ded.org/datasets>

Appropriate standards for the measurement and tracking of visual acuity are well established; linking these with a cause of visual impairment is more complex. This project has developed a method of recording comprehensive data on visual impairment, including visual acuity as well as documentation of levels of visual field abnormality. Data from the hospital eye service will be returned to primary care and screening, so that there is comprehensive data collection for the whole population with diabetes. The classification systems used can be mapped between screening and secondary care.

7.6.1 National stakeholder involvement

The need for a shared visual impairment dataset is non-controversial. This component forms a key part of various other project deliverables which have undergone extensive consultation and stakeholder validation.

7.7 Deliverable D7: implementation guidance

Produce a “how to” handbook and communication plan – an actual handbook will not be needed but the project team will produce a summary report for wide circulation highlighting the rationale and features of the above products.

Status: Complete

Date completed: June 2006

References: Appendix C

This final report provides a comprehensive summary of the rationale and features of each project deliverable. Care pathways, datasets and data exchange specifications include explanatory notes and contextual notes / business rules to assist implementers. General design guidance is provided with each output and individual data items are annotated with implementation notes. The production of more specific guidance would require an understanding of the information subsystem development process, though this is perhaps a responsibility that could be adopted by the Stakeholder Reference Group proposed in section 10.1 below.

The Action Team have assumed ongoing responsibility for this work and should be the first point of contact for implementation queries. Contact details are provided in Section 3.

7.8 Deliverable D8: revisions to ICRS OBS

Recommend revisions to the system specification in Part II of the ICRS OBS.

Status: Complete

Date completed: May 2006

References: Appendix C8

A wide interpretation of the ICRS OBS would incorporate most of the functionality described through this project. The OBS makes no specific mention of ophthalmology, so to recommend general revisions to the system specification based around diabetic eye disease would be to change the character of the specification and potentially extend the scope of the service. Further, much of the OBS is drafted in general terms, such that the potential scope

of deliverables will depend to a large degree upon supplier responses, and the actual scope on NHS Connecting for Health strategic priorities and change control. Developments since the ICRS OBS was published have had no significant impact in this respect.

One exception, for which specific provision is made in the ICRS OBS, is screening for diabetic retinopathy. OBS section 103, 'Prevention, screening and surveillance', describes in detail various requirements for systematic screening programmes. The NHS Connecting for Health screening team (project executive Jeremy Thorp, project manager Dave Graham) has commissioned a review of these provisions. The Diabetic Eye Disease Action Team has participated in this review, and touchpoints to other relevant sections of the OBS have been identified. The first deliverable from this exercise is a detailed specification for an information system to support diabetic retinopathy screening, with a gap analysis against the provisions of the ICRS OBS. A table containing this information can be found at Appendix C8.

A potential omission in relation to diabetic eye disease is connectivity with various pieces of ophthalmic hardware (digital fundus cameras, OCT etc), and the acquisition, storage and management of digital images and associated diagnostic information. Ophthalmology is identified as a possible area for future development in section 115, 'Digital imaging', but no approach to ophthalmic imaging is specified and initial approaches to PACS teams suggest that ophthalmology is not a current priority.

Delivery timescales outlined in the OBS will require ongoing revision in the light of changing requirements and priorities, but it is for the directors of NHS CfH to determine how and when functionality to support diabetic eye disease should be scheduled.

7.9 Deliverable D9: publication and promotion of DOaS work

Feed back on developments to the relevant Royal Colleges, NICE Type II Diabetes Consultation, professional societies and other DOaS Action Teams.

Status: Well progressed; ongoing

References: Appendix D

The Reference Group has representation from the Royal College of Ophthalmologists, the Royal College of Physicians, the College of Optometrists, the Association of Optometrists, the National Screening Programme for Diabetic Retinopathy, Diabetes UK and the Royal National Institute for the Blind. Through their representatives, each of these organisations has been introduced to the aims of this Do Once and Share project and encouraged to contribute.

The professional body with most interest in this work is the Royal College of Ophthalmologists (RCOphth). The project will be presented at the RCOphth Medical Retina Group meeting, the main forum for ophthalmologists who treat patients with diabetic eye disease, in Oxford on 2 July 2006. It will also be presented at an RCOphth full-day seminar concerning diabetic retinopathy on 13 September 2006, and at an ophthalmic seminar at the Royal Society of Medicine in 2007.

Clare Bailey, clinical lead for the Action Team, sits on the Royal College of Ophthalmologists Professional Standards Committee as well as representing the College on the NICE Type I diabetes guidance consensus reference group and the Type II Diabetes Guideline Review

panel. She has led discussions on the project with the RCOphth Professional Standards Committee, and the outcomes of the project will be discussed again at their next meeting on 7 July 2006. She has also written an article in 'Eye News', which is sent to all ophthalmologists in the UK, encouraging readers to send comments and visit the project website. Clare continues to provide an excellent liaison between the Royal College and her clinical peers.

Peter Scanlon, screening lead for the Action Team, is also a member of the NICE Type II Diabetes review panel. It is anticipated that forthcoming NICE guidelines will align closely with recommended practice for diabetic retinopathy screening and with the outputs from this Do Once and Share project. With Rob Johnston, Peter is due to present the project at the North of England Ophthalmological Society Summer Congress on 7 July 2006.

NHS Connecting for Health National clinical leads have invited Rob Johnston to write an editorial for the BMJ on 'Do Once and Share & Ophthalmology'. If accepted, Rob intends to concentrate on the Diabetic Eye Disease Action Team and how data will flow between primary care, screening and secondary care.

Dr Graham Wilson, primary care lead, has established a network of interested colleagues in General Practice and has written articles for GP newsletters and magazines encouraging active participation in the Do Once and Share work.

Presentations have been given by members of the Action Team and flyers have been distributed at a number of relevant events, including the Royal College of Ophthalmologists Annual Congress in Manchester in May 2006, publicising the project and encouraging individuals to visit the website and send their comments.

Although a different approach is being taken by each of the eye-related Do Once and Share Action Teams ([Diabetic Eye Disease](#), [Glaucoma](#) and [Cataract](#)), close liaison between the project has been established and maintained. A workshop took place on 10 March 2006 for the three eye-related Do Once and Share Action Teams to discuss commonality of approach, under the auspices of the Royal College of Ophthalmologists. Christian Martin also sits on the Diabetes Information Strategy Group, the primary vehicle for taking forward the work done by the [Diabetes](#) Do Once and Share team.

This report will be presented to the Royal College of Ophthalmologists, NICE, and the National Screening Programme for Diabetic Retinopathy for approval as a national standard pathway for diabetic eye disease.

7.10 Deliverable D10: benefits statement

Provide a clear statement of the benefits of a system fit for purpose.

Status: Complete

Date completed: May 2006

The benefits of a system fit for purpose can be divided expressed in terms of improved efficiency, improved quality of care and improved service delivery.

7.10.1 Improved efficiency

- seamless sharing of patient data between the various professionals and care settings involved in this care pathway
 - reduction in time / risk of obtaining notes / records
 - reduction in time / error in duplicating assessments or measurements
- enhanced communications and understanding between patient and professional by providing ready access high quality supporting information and making the Patient Information Pathway a core part of the Electronic Patient Record
 - reduction in time to inform / re-inform patient
- providing educational and decision support to professionals in the clinical environment
 - reduction in time to educate / re-educate patient
- avoiding delays in referral between care settings, by providing immediate booking facilities

7.10.2 Improved quality of care

- enhanced communications and understanding between patient and professional by providing ready access high quality supporting information and making the Patient Information Pathway a core part of the Electronic Patient Record
 - improvement of information to support better self-management
- providing educational and decision support to professionals in the clinical environment
 - improvement in consistency of education / decisions

7.10.3 Improved service delivery

- assisting the ongoing process of audit, review and monitoring through well structured, comparable and readily accessible data
- providing better access for patients and professionals to research trials

7.10.4 Clinical overview

At present it is apparent to clinicians that in the absence of continuous electronic data collection it is not possible or practicable to feed back data on all patients to screening programmes as required by the Delivery Strategy for the Diabetes NSF. A number of different classification systems are used to determine the extent of diabetic retinopathy, no single one being used at all care settings across England. This work, by asking clinicians to record the lesions of retinopathy that they observe, will enable mapping across the different classification systems used, and individual clinicians will still be able to produce a summary grade of retinopathy according to their preferred classification system. Further, the process has been optimised to avoid unnecessary grading of minor pathologies where more serious diabetic eye disease is also present.

There is also a lack of good communication between primary care and some aspects of secondary care, such that when a patient attends for an eye clinic appointment it is often

difficult to ascertain important aspects relating to the patient's diabetes or blood pressure control which may have a significant bearing on the development and progression of eye disease.

There has already been considerable work into IT systems concerning diabetic retinopathy screening. This work builds on and integrates with this, and allows further communication between primary care, screening programmes and secondary care.

Overall this work will facilitate huge advances in the care of people with diabetes, as well as an ability to perform accurate quality assurance and audit, and to actively monitor clinical outcomes. Patients and professionals interested in improving diabetic eye disease services look forward to experiencing these benefits and hope that the outputs from this Do Once and Share project will provide a useful catalyst for the strategic systems development being undertaken by NHS Connecting for Health.

7.11 Deliverable D11: reports and recommendations

Status: Complete

Date of completion: June 2006

References: <http://www.doas-ded.org/project-documentation>

Progress reports as required in the terms of reference, including recommendations on the areas that require further work at the conclusion of the project.

Regular reports have been provided as required. Recommendations for future work are made in section 10, below.

8 Update on project constraints and risks

Risks and constraints were managed in accordance with PRINCE2 methodology. The main risks encountered during the project were:

R4: Availability of key resource [escalated to DOaS Programme Team 2/3/2006]

R6: Supplier representation on Reference Group [under ongoing consideration]

R7: Project budget not available as scheduled [resolved 31/1/2006]

The current Risk and Issue Register is attached at Appendix A2.

9 Details of any contingencies implemented

No contingencies implemented, other than as detailed in the Risk and Issue Register.

10 Future work / recommendations

10.1 Maximise utility of outputs and likelihood of realisation

This and all Do Once and Share projects necessarily describe tomorrow's healthcare processes and information systems by reference to today's practice. By the time the infrastructure and development resource and political will are available to implement what is described, the goalposts will have shifted: practice will have evolved, and the assumptions that we did not even realise we had made will no longer be valid. The information era is remarkably adept at changing our frame of reference.

Two approaches to mitigate this problem are suggested:

- a) **Act swiftly.** If, as the authors believe, this project describes improvements to the management of diabetic eye disease that are necessary, feasible and acceptable, then they should be independently validated and commercially appraised before one or more of these enabling factors is overtaken by the passage of time.
- b) **Keep up.** It is not proposed that this document and its appendices be rigorously maintained, as the changing tide of healthcare informatics will ensure that initiatives come and go. However, resource should be provided to carry out an annual update, and to participate in more focused specification of requirements when development and implementation efforts commence.

These responsibilities fall largely upon the commissioners of the Do Once and Share Programme. However, for the objectives of this project to be realised, its beneficiaries – patients, clinicians and managers – will need to assume a continuing role. The Action Team proposes that a Stakeholder Reference Group be established:

- to inform and oversee development and implementation work;
- to ensure that those delivering the NHS National Programme for IT fully understand the requirements of the NHS; and
- to react to design and implementation issues as appropriate.

The risks of development and implementation in a 'vacuum' are well understood, and although the Action Team has attempted to present the outputs from this project as clearly as possible, this is no substitute for informed supervision.

10.2 Apply generic solutions to generic problems

This project has identified a number of requirements and issues that are common across specialities and throughout the NHS. Whereas the Action Team can propose solutions to problems that are specific to diabetic eye disease, it is neither feasible nor helpful for us to attempt this for issues of much wider relevance. It may be that the development of appropriate standards and pathways is well progressed, but if this is the case then they should be published, indexed and maintained so that projects like this do not have to reinvent the wheel. Generic components of particular relevance to the care of diabetic eye disease include:

- appointment and referral management;
- access and other non-biomedical considerations;
- management of patient confidentiality and consent;
- medical summaries for assessment / treatment (including medications and allergies);
- discharge summaries, appropriate GP requirements (coded diagnoses, changes to current medication, risks that need modifying, date of next follow-up appointment, etc); and
- digital image management.

Further, access to generic tools such as online knowledge repositories, discussion tools and Map of Medicine would greatly improve the potential productivity of Do Once and Share projects and would encourage consistency and longevity of outputs.

10.3 Ratify outputs as maintained information standards

This DOaS project proposes a series of clinical pathways, datasets and data exchange specifications. Although these have been scrutinised and validated by a series of clinicians, patients and data experts, resource has not been available to:

- carry out clinical terminology mapping / authoring so that each of the datasets and data exchange specifications is supported by recognised and accepted clinical terminologies such as [SNOMED CT](#);
- supplement this work by ensuring that additional terms are defined in the [NHS Data Dictionary](#) and the [NHS dictionary of medicines and devices](#), as appropriate; and
- submit outputs for approval by the [NHS Information Standards Board](#).

Whilst potentially time-consuming, each of these processes will align the proposed standards for diabetic eye disease with other NHS information standards, and will strengthen the framework that supports their implementation. An important advantage of submission to the NHS Information Standards Board is that the standards will be baselined and systematically maintained, any agreed changes being recorded and informed to suppliers.

10.4 Provide patient and clinician access to data

Although this project has not explored patient access to data in detail, there is an increasing trend towards involving the patient at a much more fundamental level in their care. Empowering the patient – and providing the resources for patients to become fully involved in their own care – is key to good chronic disease management. We recommend that the potential for diabetic eye disease information to be shared electronically with the patient, alongside interpretative and educational resources, should be further investigated.

The same is true for other healthcare providers, and particularly those who work in other specialities. We have become accustomed to a culture of local ‘ownership’ of information, and any potential for better shared access to information should be exploited. The diabetic eye is part of the diabetic patient, and reliable information from diabetologists, renal specialists, podiatrists and other ophthalmologists will allow better informed and more appropriate care.

10.5 Proposal for project extension

A proposal has been submitted for a three month extension to the Do Once and Share Action Team for Diabetic Eye Disease, for the development and piloting of automated data exchange between GP systems and diabetic retinopathy screening systems. The proposal is outlined at Appendix F.

11 Additional information

The website, at <http://www.doas-ded.org>, is updated regularly with detail on each aspect of this Do Once and Share project. It is intended to be the primary repository of knowledge for diabetic eye disease information systems.

All of the specifications developed through this project are available, and will be maintained, through the website, and online resources such as clickable care pathways and HL7v3 Message Implementation Manuals can be accessed.

12 Stakeholder involvement

In addition to the Action Team, three categories of stakeholder are involved in this Do Once and Share project: Reference Group members, suppliers and self-nominated stakeholders.

12.1 Reference Group

A Reference Group was appointed, comprising a select multi-disciplinary team of clinicians, service managers, IT system suppliers, voluntary organisations and patients who have current knowledge of the information needs for Diabetic Eye Disease and who stand to benefit from a concerted national drive for standardisation.

Reference Group members were selected by the Action Team and invited by letter to participate in the Do Once and Share project. The role of the Reference Group is to drive the project towards delivering outputs which meet the needs of clinicians and patients, and to validate any deliverables before they are released for consultation or signed off.

Membership of the Reference Group, which comprises 22 local and 26 national experts, plus a number of suppliers with a secondary (informing) role, is as follows:

Name	Role	Remit
Mr Sahid Ahmed	Associate Specialist Diabetologist, Swindon	Local
Steve Aldington	Director, Retinopathy Grading Centre, Imperial College London	National
Mr Richard Antcliff	Consultant Ophthalmologist, Bath	Local
Dr Jonathan Bayly	General Practitioner, Stroud	Local
Lucy Beckett	Person with diabetes, nominated by Diabetes UK	Local
Eleanor Bell	Senior Project Manager, NHS Datasets Service, NHS Health and Social Care Information Centre	National
Mr Larry Benjamin	Consultant Ophthalmologist, Stoke Mandeville	National
Richard Bolton	Programme manager, Salisbury DR Screening Programme	Local

Mr Chris Canning	Clinical Lead, Do Once and Share Action Team for Cataracts	National
Sue Carter	Optometrist, Cheltenham General Hospital	Local
Lisa Charlton	Person with Diabetes; Trustee of RNIB	National
Steve Chave	Managing Director, Orion Imaging Ltd	Supplier
Dan Corfield	IM&T Manager, Cheltenham & Tewkesbury PCT	Local
Georgina Davis	Person with diabetes, nominated by Diabetes UK, Exeter	National
Mr Colin Dayan	Consultant Diabetologist, Bristol	Local
Ms Parul Desai	Clinical Lead, Do Once and Share Action Team for Glaucoma	National
Miss Cathy Egan	Consultant Ophthalmologist, Moorfields Eye Hospital	National
Verity Ellin	Screening programme manager, Bristol Diabetic Retinopathy Screening Programme	Local
Dr Roger Gadsby	General Practitioner, Nuneaton	National
Professor Edwin Gale	Professor of Diabetic Medicine, Bristol	Local
Dr Helen Gray	Consultant Diabetologist, Cheltenham	Local
Adam Gregory	IT Manager, Gloucestershire Hospitals NHS Foundation Trust	Local
Mr Rodney Grey	Consultant Ophthalmologist, Bristol	Local
Catherine Gualan	Co-ordinator, Service Development, Royal National Institute for the Blind	National
Mr Simon Harding	Consultant Ophthalmologist, Liverpool	National
Mark Histed	Screening programme manager and screener / grader, Gloucestershire Diabetic Eye Screening Service	Local
Dr Robin Hollands	General Practitioner, Underwood Surgery, Cheltenham	Local
Tom Humphreys	Project Manager, Avon IM&T Consortium	Local
Ewan Jones	Synergy Product Manager, iSOFT Ltd	Supplier
Rakesh Kapoor	Council Member, College of Optometrists, London	National
Anita Lightstone	Head of Service Development, Royal National Institute for the Blind	National
David MacVeigh	Council Member, College of Optometrists	National
Mrs Chitra Madhavan	Consultant Ophthalmologist, Swindon	Local
Mr Richard Newsom	Consultant Ophthalmologist, Southampton	National
Martin Norris	Healthcare Delivery Manager, Diabetes UK	National
Dr Mark O'Mahony	General Practitioner, Cadbury Heath Health Centre	Local
David Parkins	Council Member, College of Optometrists, London	National
Dr Paul Payne	General Practitioner, Gloucester Road Surgery, Bristol	Local
Dr Andy Rigby	General Practitioner, Tewkesbury	Local
Dr Tony Robinson	Consultant Diabetologist, Bath	Local
Dr Mike Robinson	Medical Director, In Practice Systems Ltd	Supplier
Alison Roe	Project Manager, NHS Datasets Service, NHS Health and Social Care Information Centre	National
Mr John Shilling	Consultant Ophthalmologist, Guy's and St Thomas' NHS Foundation Trust	National
Hayward Slater	Screening programme manager, Bath Diabetic Retinopathy Screening Programme	Local
David Stables	Medical Director, EMIS Ltd	Supplier
Mr David Steel	Consultant Ophthalmologist, Sunderland	National
Rob Stichbury	Managing Director, Digital Healthcare Ltd	Supplier
Mr John Talbot	Consultant Ophthalmologist, Sheffield	National
Mr David Taylor	Screening programme manager and principal screener / grader, North and East Devon Retinal Screening Service	National
Bridget Turner	Head of Healthcare Policy and Development, Diabetes UK	National
Trevor Warburton	Representative of the Association of Optometrists, Stockport	National
Craig Watson	Project Manager, NHS Datasets Service, NHS Health and Social Care Information Centre	National
Dr Bob Young	Consultant Diabetologist, Salford	National

12.2 Suppliers

The involvement of suppliers in this project is important, but must be managed sensitively – the work is being done on behalf of NHS Connecting for Health and both process and outputs must be free of bias which might hinder their legitimacy in the eyes of LSPs, NASPs and suppliers not involved in the development process. Accordingly, the role of suppliers involved in this work was strictly defined as follows:

“It is recognised that systems suppliers have a breadth of knowledge about NHS process and practice, and further that their practical implementation experience will provide a useful input to the development of standards. However, no supplier will gain any competitive advantage by virtue of involvement in the Do Once and Share work, and no supplier will be entitled to steer the scope or focus of the project or its deliverables. Further, no supplier may claim or imply that they are in any way preferred or advantaged, or that the NHS is endorsing their product or approach as a result of being involved in the project. Any standards developed through the Do Once and Share project will remain the property of the NHS and no supplier will be entitled to implement against them unless and until they are released into the public domain.”

Suppliers with a national market share of over 10% and a presence in Avon, Gloucestershire and Wiltshire SHA were invited to participate on the Reference Group. The following suppliers provided input to the project:

Supplier	Representative	Reference group
Digital Healthcare Ltd	Rob Stichbury	Yes
EMIS Ltd	David Stables	Yes
In Practice Systems Ltd	Mike Robinson	Yes
iSOFT Ltd	Ewan Jones	Yes
Orion Imaging Ltd	Steve Chave	Yes
Medisoftware Ltd	David Johnston	No

12.3 Self-nominated stakeholders

Any person or organisation reasonably expressing an interest in the project is welcome to view documents under development and provide feedback to the Action Team. Registration as a stakeholder was through the project website at <http://www.doas-ded.org/stakeholders>. Four self-nominated stakeholders registered during the project.

13 Clinical lead additional comments

No additional comments.

14 Do Once and Share programme comments

No additional comments.

15 Acknowledgements

As one of the final Do Once and Share projects from the first phase of the DOaS Programme, this project has benefited from the experience and advice of the pioneering Action Teams. In particular, the excellent work done by the Action Teams for Diabetes and Breast Cancer, both based in Northumberland, Tyne and Wear, has inspired the focus of this work and the presentation of its findings.

The Action Team would like to thank the many people who have contributed time and experience to this project, particularly the Reference Group, members of which have collectively donated thousands of hours of excellent work; Simon Knee for his excellent work on primary care data exchange; Donna Prentis for assistance with the presentation of care pathways; and Prarthna Pancholi for her ungrudging attention to the less glamorous aspects of project administration.

16 Sign off

SHA Lead	
Name:	David Squire
Signature:	
Date:	

DOaS Programme Manager	
Name:	Cathy Gritzner
Signature:	
Date:	

KPS Programme Director	
Name:	Muir Gray
Signature:	
Date:	

17 Glossary

The following glossary defines and explains terms as they are used in this document.

care component	Atomic concepts used to construct <u>care pathways</u> and <u>care plans</u> , such as needs, interventions and choices.
care pathway	A description of a structured process of care, setting out a consistent set of decisions and activities relating to one or more risks, issues or problems. A <u>care pathway</u> enables the variance between proposed and actual care to be audited.
care plan	The application or personalisation of one or more <u>care pathways</u> to a particular <u>patient</u> , leading to a sequence of planned activities for that patient.
data	Information recorded or stored in machine-readable form.
data item	A fragment of information about a person, observation or process.
dataset	A sequenced list of individual <u>data items</u> each with a clear label, definition and set of permissible values (codes and classifications) from which sets of <u>data</u> can be compiled. [http://www.icservices.nhs.uk/datasets/pages/default.asp]
DED	Diabetic eye disease, such as <u>diabetic retinopathy</u> .
diabetic maculopathy	<u>Diabetic retinopathy</u> affecting the <u>macula</u> .
diabetic retinopathy	A complication of diabetes, causing changes to the <u>retina</u> that may eventually result in reduced vision. <u>Diabetic maculopathy</u> is a type of diabetic retinopathy.
ETDRS	Early Treatment Diabetic Retinopathy Study: a leading trial which assessed the effectiveness of photocoagulation treatment for <u>diabetic maculopathy</u> .
fluorescein angiography	An investigation to assess blood circulation in the <u>retina</u> by tracing a dye which is injected into the bloodstream.
fovea	A small pit near the centre of the <u>macula</u> that contains the largest concentration of cone cells and is responsible for central vision.
fundus photography	Photography of the <u>retina</u> , usually using white or filtered light to illuminate the retina through the pupil.
grading	The systematic examination of images of the <u>retina</u> to detect features of <u>diabetic retinopathy</u> and classify according to their level of severity.
hypertext browser	Also known as a web browser, a computer application to display structured and linked text and images, particularly from the Internet. Internet Explorer and Mozilla Firefox are examples of common hypertext browsers.

information standard	An agreed specification of a set of <u>data items</u> to be used consistently for a specified purpose, usually in pursuit of commonality of process or <u>interoperability</u> . A <u>dataset</u> is an example of an <u>information standard</u> .
information subsystem	A computer-based system to achieve a defined task. Information subsystems may be hierarchical, so a subsystem can itself be a collection of <u>information subsystems</u> , together organised to achieve a particular task.
information system	A collection of <u>information subsystems</u> , together organised to achieve a particular task within a specified or inherent context.
interactive online resource	A website to which authorised visitors can submit documents and page content.
interoperable	See <u>interoperability</u> .
interoperability	An ability of two or more <u>systems</u> or components to exchange information and to use the information that has been exchanged.
laser photocoagulation	The application of controlled laser burns to the <u>retina</u> , primarily to slow the progression of <u>diabetic retinopathy</u> .
macula	The area near the centre of the <u>retina</u> at which visual perception is most acute.
macular oedema	Fluid accumulation in the centre of the <u>retina</u> due to diabetes.
open standard	A maintained <u>information standard</u> available to all suppliers to facilitate interoperation between <u>information subsystems</u> .
patient	A person who receives medical attention, care or treatment.
retina	The light-sensitive tissue that lines much of the back of the eye, in which nerve impulses are generated. From here they are relayed to the brain, where they are interpreted as vision.
shared patient record	Structured <u>data</u> about a <u>patient</u> stored on <u>information subsystems</u> that are accessible across health settings and specialities.
standardisation	The provision of agreed and appropriately precise criteria, rules and constraints to be used consistently for a specified purpose. <u>Standardisation</u> is generally a prerequisite of <u>interoperability</u> .
system	<ul style="list-style-type: none"> i) An <u>information system</u> or <u>information subsystem</u>. ii) A structured process with a start, an end, and defined rules and constraints. iii) A set of activities with a common aim and the means by which progress towards that aim can be assessed.
tractional retinal detachment	Elevation of the <u>retina</u> caused by fibrous membranes in the <u>vitreous</u> , most common in the advanced stages of <u>diabetic retinopathy</u> .

vitrectomy	A surgical procedure to remove the <u>vitreous</u> and any associated blood, which may be combined with the repair of retinal detachment and <u>laser photocoagulation</u> if needed.
vitreous	The clear gelatinous substance that fills the eyeball between the lens and the <u>retina</u> .
vitreous haemorrhage	Bleeding into the <u>vitreous</u> , which may impair vision or hinder treatment.