

**Monthly Listing ‘Everyone with Diabetes’ to Support Diabetes Eye Screening Direct Clinical Care.**

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| **Application made by:** | **Name** | **Organisation** | **Position** |
| Dr John Anderson | NE London Diabetes Eye Screening Programme | Clinical Lead |
| **Project details:** | **Project Name** | **Organisation** | **Objective** |
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**Amendment History**

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| Version | Date | Amendment History | Amended by: |
| 1.0 |  | First Draft | John Anderson |
| 1.1 |  | Second Draft | John Anderson and Louis Bolter |
|  |  |  |  |

**Review & Approval**

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| --- | --- | --- | --- |
| **Name** | **Title** | **Responsibility for this project** | **Date approved** |
| Paula Turnock | Project Manager - Endeavour | Technical Project Management |  |
| Renata Leppich | Programme Manager - Discovery | Programme Management |  |
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| Louis Bolter | Programme Manager NE London Diabetes Eye Screening Programme | Programme Manager |  |
| Bill Jenks | IT lead - WELC | Information Governance Review |  |
| Kambiz Boomla | Clinical Safety Officer - Discovery | Clinical Safety Review |  |
| David Stables | Trustee Endeavour Health | Scoping & Design Review |  |
| Luke Readman | CIO – WELC & Programme Chair | Final Review & Approval Sign off |  |

**Target Audience:** - All staff who are involved in the scoping; development and implementation of the project.

## Associated Documents:

(Attach technical specification)

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## Purpose of this Document

The purpose of this document is to outline the project objectives; scope and deliverables for the North East London Diabetes Eye Screening Programme me as part of the NHS Discovery Project, to ensure that the:-

* Scope is **in line with the overall objectives** of Discovery as a programme;
* Scope is **in line with local system priorities** and objectives (ie. Local Public Health / JSNA priorities, Local Digital Roadmap milestones or Sustainability & Transformation Plans);
* Issues of **data security, consent and information governance** can be robustly managed;
* Development and **delivery resources** are in place or can be identified and scheduled;
* Timelines for **benefit realisation / delivery** are realistic.

# Background

The Discovery Project has been shaped with four main aims:

* 1. To predict, anticipate or inform **individual** health needs from algorithms running in real time (or as near as possible) and to deliver the insight gained directly into the patient’s record across the whole of their pathway, whether in primary or secondary care or elsewhere, thus creating the opportunity to improve or prevent adverse outcomes.
  2. To expand the existing primary care informatics driven **population health** programme in east London, led by the Clinical Effectiveness Group at Queen Mary, to all health and care sectors.
  3. To enable the real time **reporting on programmes** by providers and commissioners supporting clinical improvement and new payment mechanisms. This would involve reporting on a pseudonymised or identifiable cut of the clinical data, as appropriate.
  4. To use data by third parties (commissioners, public health, and academics) **to support research, development and planning**, whether on consented identifiable data, or the pseudonymised dataset. East London would this become a research enabled community.

# Introduction

The North East London diabetes eye Screening Programme me undertakes photographic screening to detect diabetic eye disease, and to refer people with sight threatening disease to specialist care. It is part of the English National Diabetes Eye Screening Programme. Probably the most important part of the programme is maintaining an up-to-date list of everyone with diabetes registered at GP practices within the 7 CCGs within North East London.

In the past the CSU has provided a monthly list of 'everyone with diabetes' in inner north east London to the program. A similar monthly list has been provided by Simon Lam from the Business Intelligence Unit, currently representing Barking and Dagenham, Havering and Redbridge CCGs

The screening programme hopes that the discovery service can undertake similar provision into the future.

# Project Goals

The project goal is in line with the first of the 4 main aims of the Discovery Project. Specifically, the project under consideration is to provide close to real-time listing of 'everyone with diabetes' in GP practices in North East London. This listing will allow the program to recognise people with diabetes new to local GP practices who need to be offered diabetes eye screening in a timely manner. It will also allow the programme to recognise people with diabetes who have moved out of the area or died, to avoid inappropriate screening appointments being sent.

In addition the programme hopes that the listing will, in future, contain more detail about the Snomed codes defining diabetes, to allow it to analyse unusual cases where some doubt has been expressed about the security or timing of the diagnosis of diabetes.

# Scope & Benefits Realisation.

The eventual scope is to future proof the safe management of people with diabetes requiring eye screening across all of North East London. This will become particularly important if the CSU (which currently provides the North East London diabetes eye Screening Programme with a monthly inner NE London list of 'everyone the diabetes') should in future become unable to continue this work.

The benefit to the identified population is that of continuing to offer all people with diabetes in North East London a comprehensive and efficiently managed diabetes eye screening service, future proving current provision.

Development time is currently very flexible since the North East London diabetes eye Screening Programme is currently benefiting from its collaboration with the CSU in obtaining lists of 'everyone with diabetes'.

Once lists of ‘everyone with diabetes’ in inner NE London have been developed, validated and are reproducible, the hope is to later extend the more modern Snomed-based and information-rich data extraction process to outer NE London CCGs.

# Information Governance

This project involves the sharing of clinical data between the discovery project and the North East London Diabetes Eye Screening Programme me. Data will only be moved between these 2 entities using secure NHS data transfer processes (the current data transfer with the CSU uses the NHS.net email service). The patient identifiable data will not be shared further by either of the above entities.

The North East London Diabetes Eye Screening Programme is located within Homerton University Hospital NHS foundation trust. The trust has robust and comprehensive information governance processes in place.

# Benefits Case

The benefits apply to the first of the 4 main aims of the discovery project. Specifically, future proofing the provision of timely information concerning 'everyone with diabetes' to the diabetes eye Screening Programme me to allow clinical care to continue to be delivered in a safe and secure manner.

The principal benefit will be assuring that everyone with diabetes in North East London continues to receive high quality and timely access to diabetes eye screening

# Stakeholders / Interdependencies

The North East London diabetes eye Screening Programme me is funded by NHS England (London). In addition the program receives some funding from the seven CCGs in North East London to carry out optical coherence tomographic (OCT) screening of people with early diabetic maculopathy. It has no other funding sources.

The Screening Programme is based at the Homerton University Hospital NHS foundation trust. Data analysis is carried out by the Screening Programme’s data manager within the secure environment that the trust provides. Patient identifiable data is only stored on a secure server housed within the server room in the IT department at the trust. This same server runs the nationally mandated diabetes eye screening software.

The Diabetes Eye Screening Programme, would be willing participants in any communication plans and patient & public engagement plans that the discovery project undertakes. The programme regards communicating with the public about what happens to their data as an important part of its overall role.

# Risks

Currently a monthly list of 'is everyone with diabetes' in North East London is supplied by the CSU. Should the day to day feed from the CSU be discontinued, a risk to people with diabetes would emerge. The current proposal reduces the risk of this impacting on clinical service delivery.

The sharing of any information involving patient specific identifiers is a risk. This is mitigated by the robust information governance processes in place at Homerton University Hospital NHS foundation trust, the parent organisation holding the North East London diabetes eye Screening Programme contract.

# Measures of Success

Initial success will be tested by taking a subset of the dataset generated by the discovery service to each of three local GP surgeries with whom the service has good working relationships. In partnership with the surgery team we will then map the discovery service ‘list of everyone with diabetes’ against the practice list. Investigation of outliers in both lists will then be undertaken to validate both datasets.

The main measure of success of the project as a whole will be that no one living with diabetes in North East London will go without timely and appropriate access to diabetes eye screening. The project will contribute to maintaining a high uptake of screening, which has been associated with reduced rates of blindness in the target population.

# Technical Requirements

|  |  |
| --- | --- |
| **Information required from the applicant to inform the technical specification** | |
| Detail regarding subscribers and publishers.  This information is required to allow us to set up the User Manager in Discovery | Subscriber is the North East London Diabetes Eye Screening Programme me.  Data to be sent to: eyescreening@nhs.net |
| What are the cohort characteristics (e.g. patients on a specific care pathway; all patients; patients with a specific LTC etc.) | Al l patients with the long term condition of diabetes residing in whole or in part of the 7 CCGs within the NHS England NE London Area. |
| Detail the data specification (e.g. data specific to a LTC; care pathway; all GP consultations within a time range; all data within Discovery etc) | Demographic data and clinical data related all patients with the long term condition of diabetes currently registered with a GP in NE London |
| Will the data be hosted in Discovery, with access given to the applicant to the Discovery Data Service?  Or will the applicant host the data?  Please give details. | The NE London Diabetes Eye Screening Programme would be happy with any practical method of accessing the data which their service requires, and are happy to be guided by the Discovery team as to the most secure and efficient way of day to day access. |

# Activity

## Preparation & Planning

As part of the preparation and planning stage it is important to highlight:

* Unambiguous definition of what data is to be shared; where from/to and with whom.

The data definition comprises the following data fields for sharing between the discovery Project and the North East London diabetes eye Screening Programme me for all people with diabetes currently registered with a GP surgery in one of the 7 CCG is within North East London:-

[NHS number],  
[forenames],  
[Last name],  
[Title],  
[Date of birth],  
[Gender],

[Address line 1],

[Address line 2],

[Address line 3],

[Address line 4],

[Postcode],

[Mobile Phone No.],

[Date registered with practice],  
[Date registration with practice ended],

[Date of Death],  
[Date of diabetes diagnosis],  
[Diabetes type],  
[Ethnicity code],  
[Ethnicity description],

[Pregnancy code],  
[Date of Pregnancy code],  
[Practice code],  
[Practice name],  
[Latest HbA1c result],  
[Date of latest HbA1c result],

[Latest Blood Pressure result],  
[Date of latest BP result],

[CSV listing of SNOMED Diabetes-defining codes for patient],

[CSV listing of dates of SNOMED Diabetes-defining codes for patient],

[CSV listing of SNOMED Diabetes-eligibility codes for patient],

[CSV listing of dates of SNOMED Diabetes-eligibility codes for patient],

[CSV listing of SNOMED Ethnicity codes for patient],

[CSV listing of dates of SNOMED ethnicity codes for patient],

[CSV listing of SNOMED Deceased codes for patient],

[CSV listing of dates of SNOMED deceased codes for patient]

* Information Governance and Data Sharing Agreements

Information governance will be in line with the measures in place at the discovery project, and those of Homerton University Hospital NHS foundation trust.

The project will not begin operation until a data sharing agreement has been signed off by both the discovery project and the trust.

* Clinical Risk analysis

The clinical risk of failing to undertake data sharing is that people with diabetes may not receive diabetes eye screening in a timely and appropriate manner, with the potential that sight threatening eye disease could fail to be detected at the most treatable stage.

The clinical risks of undertaking data sharing are those of

1. data breach - mitigated by the information governance processes of both organisations
2. Incorrect management of the shared data resulting in incorrect identification of patient's -mitigated by the data management procedures and protocols in place in the North East London diabetes eye Screening Programme

* Technical Processes

The North East London diabetes eye Screening Programme me is happy to undertake technical processes in line with stipulations and regulations operated by the discovery Project.