



Insights for Care
Partners for Better Health



Do you suffer from diabetes?
Do you want to shape the future
of diabetes care?



MSD has fully funded this project which is a collaboration between MSD, Heart of England Foundation Trust, Lloyds Pharmacy and Birmingham Cross City CCG

Do you suffer from diabetes?

Do you want to shape the future of diabetes care?

Overview

Heart of England NHS Foundation Trust (HEFT) is excited to be partnering with local healthcare providers, as well as pharmaceutical and professional services companies, in a novel diabetes project ('Insights for Care'), which will use pseudonymised diabetes patient data to help us achieve better health outcomes in diabetes.

What do we hope to achieve with this project?

We have set ourselves a number of goals, which include:

- Undertaking world-leading research into the disease so that we can learn more about how the disease develops.
- Understanding how patients use NHS services and how we can improve access to these services for as many patients as possible.
- Identifying ways in which we can deliver better quality care to improve health outcomes for patients, including developing new interventions that aim to lower the risk of diabetes patients developing complications such as diabetic foot, deterioration of vision and chronic kidney disease, in a cost-effective manner.

Who is involved?

The project is a four-way partnership between:

- HEFT who will provide leadership to the project, as well as clinical input, academic oversight and technical support.
- Local participating GPs, who will also contribute with clinical input and leadership.
- MSD, a pharmaceutical company, who is funding this project. Whilst it has no access to individual or identifiable data and any research questions it suggests must be approved by a joint governance board including a patient representative, MSD hopes that this project can build its understanding of diabetes disease treatment.
- Lloyds Pharmacy, a supplier of medicines and services to the public, will work with partners to better understand how patients utilise pharmacy and collect medications.

What is our starting point?

We want to build a comprehensive database of information about patients with diabetes, and diabetes-related conditions and complications, over a number of years and across healthcare services (hospitals, GP surgeries, community care centres and pharmacies).

These data will be used to answer a number of research questions, which in turn will allow us to identify changes that should bring benefits to those living with diabetes. The local healthcare system will then be able to pilot and launch improved care models to demonstrate benefits to patients.

We will publish our findings in research journals and share these at academic conferences, so that a broader audience can learn from our research.

How will the data be collected?

Hospitals, GPs, community care centres and pharmacies already collect vital treatment data on various IT systems but these databases are not currently linked. We have reviewed these systems and identified the key data that we would need to extract to help us with this project.

These key data will be extracted within each setting of care by IT staff who understand data confidentiality and are accustomed to using clinical systems. Before this data is securely transferred to a special research database managed by Monitor Deloitte, the IT staff will carry out a number of processes to ensure it is not identifiable to anyone other than those responsible for direct care (e.g. NHS staff, Pharmacists). This process is also known as 'pseudonymisation'. Monitor Deloitte is a professional services firm who have been engaged by MSD to provide project management, technological and analytics support to Insights for Care. The data will also be encrypted on their secure server where access will be restricted to designated individuals.

What type of data will you collect?

The project will initially focus on patients receiving treatment for diabetes and diabetes-related conditions, before potentially expanding into additional diseases.

The data we collect will focus on disease characteristics (e.g. blood glucose), healthcare activity undertaken (e.g. lab tests, prescriptions), and patient outcomes (e.g. complications such as diabetic foot, deterioration of vision and chronic kidney disease).

How do I know my data is safe?

All data which could identify you will be removed whilst the data is still held within the NHS, and will be thoroughly checked before leaving the NHS database. Similarly, the same process for de-identification and quality control will be applied before any data leave Lloyds Pharmacies.

Once we have done this, it will be securely transmitted and stored within a system that is both physically secure from intruders and protected by firewalls to prevent access from outsiders. Access to the data will be restricted to a list of personnel approved by the NHS. In line with legal and regulatory drug safety reporting (i.e. Pharmacovigilance) obligations, MSD will be informed of any side effects related to MSD products and will be provided with reports containing only pseudonymised information.

These security provisions have been approved by HEFT's Information Governance Committee.

What if I do not want to participate?

If you would rather not participate in the project, please fill in the information below which will be used to ensure that your data will be excluded from all future analysis. You can choose to opt out at any time.

If you opt-out, your information will remain confidential and will not be used in any further future data analysis undertaken as part of this project. In order to ensure your data is successfully excluded, and not accidentally re-incorporated at a future date, we will maintain a list of the codenames for patients that have opted out – these codenames will be unidentifiable outside of the NHS.

Name: _____

Date of birth: _____

NHS Number: _____

Please give this completed form to your pharmacist

Dear Pharmacist, Please opt me out of this research project.

How do I know my data won't be misused?

Your data will only be used to answer specific research and service redesign questions that have been defined and approved by all members of a Governance Board. This Governance Board consists of members from all partner organisations, with additional patient and public health representatives. We have taken a number of measures to ensure compliance with national policy and legislation on patient privacy and data protection. At all times, your rights under the Data Protection Act will be upheld.

How will this benefit me?

The project will create a robust base by which we can assess the effectiveness of how diabetes is currently treated. We can then use this knowledge to improve clinical outcomes for patients by identifying specific patient groups that may benefit from different interventions and care patterns.

It will also help us to improve the coordination of care across services.

Where can I learn more?

If you have any questions or would like to find out more information please contact the HEFT call centre on 0121 424 3808 where we will be pleased to answer any queries you may have.

Thank you for helping us improve diabetes care