

Dear Group Practitioner,

SIRIUS – Gaucher Disease (Primary Care)

Introduction:

We at BARTS Life Sciences are writing to inform the Group Practitioners (GPs) in London NEL about a significant initiative in collaboration with the NEL ICB Data Service that involves the use of patient data for individuals at high risk of Gaucher Disease.

Purpose:

The aim of this project is through lab test results, presenting symptoms, SNOMED problems and diagnoses, demographic and administrative information this will be used to develop a query with high sensitivity and specificity at identifying the rare disease – Gauchers.

The clinical audit will use the data to identify rare conditions and partner to deliver patients reduced diagnostics journey times; NHS less reliance and less resources employed, allowing for more disease education and potential for further service enhancements of this through project experience.

How is the processing of information necessary to the work?

This initiative involves the sharing of pseudonymised patient data for the at-risk cohort, with the NEL ICB Data Service, who will link it with the identified GP and secondary data from the Data Discovery System (DDS)

The key aspects of this collaboration include:

Data Sharing: BARTS Life Sciences will share a cohort of pseudonymised patient data with NEL ICB Data Service.

Data Linking: NEL ICB will link NEL Patients with the respective symptoms mentioned with BARTS Life Sciences representatives, for the purpose of direct care. The data feeds will be updated regularly.

Outcome(s):

Proactive contact with at-risk residents will allow for the potential cohort to be assessed for Gaucher Disease and actions to be taken to allow the patient to start the journey for an improved experience of the system and help them become less reliant on the NHS and use the resources employed on disease education of individual health care professionals to make the diagnosis.

We have been working with the NEL Integrated Care Service IG Team and your Data Protection Officer to establish a Data Protection Impact Assessment (DPIA) and Data Sharing Agreement to facilitate this export and invitation. These were reviewed by the NHS North East London (NEL ICB) Data Access Group and approved by the NEL ICB) Information Governance Steering Group to provide you with reassurance.

Please could you take the following actions (once you receive the alert from the Data Controller Console) to confirm (as Controller(s)) that you are happy for the information about your patients to be shared with BARTS Life Sciences

1. Log on to the Data Controller Console
2. Review and accept the:
 - Data Protection Impact Assessment (DPIA), and
 - Data Sharing Agreement (DSA)
3. Update the Practice's Privacy Notice to include this processing.

Please note that by accepting the DSA on the Data Controller Console, you are responsible for:

- putting in place effective procedures to manage data subject access requests (from your patients) about the processing; and
- managing your own data breach(es).

Please contact your relevant Data Protection Officer If you have any information governance concerns.

Should you wish to discuss further about the programme, please contact jeni.mower@nhs.net

We look forward to welcoming you to the programme and thank you for your ongoing support

Best wishes,

Sophie Williams
Project Lead Barts Life Sciences