



NEL,
1 Lower Marsh,
London,
SE1 7NT

Email: NELCSU.foi@nhs.net

Dear Dr Bhatia

Reference: FOI.21.NEL049

21 June 2021

Re: Freedom of Information request

Thank you for your request under the *Freedom of Information Act 2000* (the Act). This response is provided on behalf of NHS North East London Clinical Commissioning Group (CCG). Your request along with the CCG's response is detailed below.

This request concerns your shared care record, *the eLPR - Discovery Data Service*, and specifically:

- **the disclosure of personal confidential information (clearly identifiable or pseudonymised) by contributing data controllers such as GP surgeries**
- **to a third party outside of the care team, i.e. a data processor (and so *access to that information by the data processor*)**
- **any onward disclosure to a sub-processor**
- **and its subsequent**
 - linkage
 - deidentification (anonymisation/pseudonymisation)
 - analysis/monitoring/audit of direct care
 - onward disclosure to “data recipients” or via a “data mart”
(in clearly identifiable/pseudonymised/anonymised formats)

by the data processor/sub-processor for secondary purposes - that is, purposes beyond direct medical care, such as planning, commissioning and “population health management” (or “analytics”).

The processing of such data derived from contributing data controllers - such as GP surgeries, hospital trusts, mental health providers, community providers, local authorities - for secondary purposes requires a legal basis to satisfy the common law of confidentiality (CLOC).

The absence of such a legal basis results in both a breach of confidentiality and a breach of Article 5(1)(a) of GDPR.

Processing in the absence of a CLOC legal basis is therefore, manifestly unlawful.

NHSX have written to you (and other similar schemes) concerning the absence of any such legal basis for secondary uses processing within your project.

Secondary uses processing by your project is not exempt from complying with the common law of confidentiality.

That letter is attached, [is in the public domain here](#), and was prompted by concerns raised by the National Data Guardian (NDG) about your project.

The secondary uses processing within your project predates COVID-19, and (as is clearly evident by your DPIA), is neither in part nor whole *solely* for COVID-19 purposes.

As detailed [within your DPIA](#):

- clearly identifiable, or pseudonymised, and so
- personal confidential information
- is disclosed from contributing data controllers
- to a data processor

Disclosure of such information, for such purposes, from contributing data controllers, is:

- neither a legal obligation, nor
- authorised under COPI 3(4), nor
- completely anonymised at source (prior to disclosure)

Pseudonymisation, as you know, neither renders personal data as non-personal, nor confidential information as non-confidential.

It is a security principle *only*.

Outside the Scope of the FOI Request – Explanatory Comment from CCG

May we start off by saying this FOI request makes the assumption that we are using personal confidential data for secondary uses without a legal basis and it also seems to conflate our two direct care systems the east London Patient Record (eLPR) and the Discovery Data Service (DDS).

In answer to the first assumption, there is currently only one live secondary use case of personal confidential data for either of those systems and that is for the East London Genes and Health project. This is a patient volunteered and fully consented project and is one of the world's largest community-based genetics studies, aiming to improve health among people of Pakistani and Bangladeshi heritage by analysing the genes and health of 100,000 local people. You can read more about it here

<https://www.genesandhealth.org/>

In NEL our core programmes are clinically driven and managed and they are primarily set up to support direct care and are not used for secondary purposes without our data controllers ensuring that there is a clear legal basis to do so. We have a principle that if data is to be used for secondary uses then it should be de-identified unless patient consent has been obtained or legal statute supports it. From your correspondence it is implied that our DPIAs do not make this clear enough and work is underway to review those to make sure they are fit for purpose and describe the situation properly. To help you understand the difference between the eLPR and DDS I will also give you a brief overview of these two level 1 and level 2 programmes to help give you a level of assurance about them.

For our level 1 programme, NEL's shared care record is built around our two Cerner Health Information Exchanges (HIEs) at Barts Health and Homerton, These HIEs pull data from other organisations that are connected in a single real time view of those records and once the shared view is closed no residual data remains. In other words when a professional is working in their practice or consulting room and clicks on the shared care record button in their main EPR (eg EMIS for a GP) the HIE then puts a call into the other systems that are connected (eg Cerner, RIO etc) and pulls out the records for that one patient and organises them in an HTML window. That HTML window is a view of the data only and the data itself

resides in the originating system and once that window is closed the data is no longer visible in that session. There is therefore no data that remains to be able to be processed or anonymised to use for secondary purposes.

For our level 2 programme, NEL is (along with SEL and NWL) developing the Discovery Data Service (DDS) which again is used primarily for direct care such as feeding the Child Health Information Service (CHIS). All data pushed into DDS is badged with the data controllership of the source provider which allows our providers and us to use the data under their data controllership. In other words any use cases for data held in DDS (be it for direct care or a secondary use) goes through strict clinical scrutiny and IG processes involving clinical and non-clinical representatives from the data controllers providing the data, and should that use case be approved, then DDS can exercise the use of that data down to each individual data controller level. No data is shared or used from DDS without the strictest assurance processes (including scrutiny of the legal basis). There is currently as mentioned above only one use of the data for secondary purposes where the data is identifiable (East London Genes and Health).

Accordingly, I would be grateful if you would provide me with the following information under FOI:

- 1. Has eLPR - Discovery Data Service now stopped processing personal confidential information for secondary uses, subsequent to the letter from NHSX and the concerns raised by the NDG?**

eLPR has never processed any data for secondary purposes. Discovery Data Service has one secondary use of data where personal confidential information is used and this is fully consented from the individual patients involved.

If not, and disclosure and processing continue, what is the legal basis for the disclosure of, and subsequent access to, personal confidential information for secondary uses processing (such as population health management) by contributing data controllers such as GP surgeries, and its subsequent linkage, deidentification, and analysis?

Not applicable

- 2. Is it the explicit permission of each individual obtained prior to disclosure?**

Yes, explicit permission is obtained from patients taking part in the East London Genes and Health project where this identifiable data is being used for secondary purposes.

3. Or has authority been specifically granted for all such processing under Regulation 5 of COPI 2002 (HRA/CAG approval)?

If so, please could you provide:

- The CAG approval reference
- Which classes of support has your project been granted

(<https://www.legislation.gov.uk/ukxi/2002/1438/schedule/made>), given that access to, linkage, deidentification, analysis, and further disclosure of, such information occurs

Not applicable

Further Comment Outside the Scope of the FOI Request

We would also note that our processes are aligned to those recommended by the London Information Governance Steering Group, and we work with the other ICSs in London to ensure that we support a consistent and robust approach to data protection for our patients within the region. The London Data Sharing Framework has been shared with both the ICO and the NDG, and we are working with both offices to ensure that the approaches undertaken are compliant with present standards. We have also held citizen engagement events that we have used to support the conversation with our population within London and these events and communications outputs are ongoing.

I hope that goes some way to assuring you of the confidence we have in our programmes in NEL. We are sorry you declined an invite to meet with our team to discuss this but trust this goes some way to answering your FOI request.

Copyright and Re-Use of Public Sector Information

NEL is a commissioning support unit hosted by NHS England. The CSU handles Freedom of Information requests on behalf of the NHS Clinical Commissioning Groups across London, Kent and Northampton.

The information supplied to you continues to be protected by the *Copyright, Designs and Patents Act 1988*. You are free to use it for your own purposes, including any non-commercial research you are doing and for the purposes of news reporting. Any other re-use, for example commercial publication and subscription charge, would require the permission of the copyright holder. This can be obtained via an application for an open government licence (OGL) under the *Re-Use of Public Sector Information Regulations 2015*.



Use of information expressly made available under this license indicates your acceptance of the terms and conditions as set out in the OGL.

To make an application for re-use you must:

- Make a request in writing to the address below,
- State the name of the applicant and an address for correspondence,
- Specify the document to be re-used,
- State the purpose for which the document is to be re-used

Email

NELCSU.foi@nhs.net

Postal address

NEL,
1 Lower Marsh,
London,
SE1 7NT

Website address

www.nelcsu.nhs.uk

For information where the copyright is owned by another person or organisation, you must apply to the copyright owner to obtain their permission to re-use. Further guidance for re-users can be found at:

<http://nationalarchives.gov.uk/documents/information-management/ogl-user-guidance.pdf>

NEL complies with the *Re-use of Public Sector Information Regulations 2015* and we encourage the re-use of the information that we produce, hold and disseminate. We are open and transparent, and treat all applications to re-use in a fair and non-discriminatory way.

Privacy Notice (formerly known as Fair Processing Notice)

We will record your contact and request details in order to monitor and improve the service we provide and in order to discharge our statutory obligations under the Act. This information will be handled in accordance with the NHS Confidentiality Code of Practice and the *Data Protection Act 2018*.

Using personal data we provide

You are required not to use personal data which is provided to you for electronic marketing (telesales, fax, e-mail) to our staff and comply with the Privacy and Electronic Communications (EC Directive)



Regulations 2003. Provision of such personal data in response to a Freedom of Information or Environmental Information request does not constitute consent from the individual concerned.

The *Data Protection Act* gives individuals rights to prevent processing likely to cause substantial unwarranted damage or unwarranted distress (section 10) and to prevent processing for the purposes of direct marketing (section 11). You should be aware that selling, giving or sharing of personal data could breach the *Data Protection Act*. NEL advises staff of their rights on behalf of Clinical Commissioning Groups.

Review procedure

If you feel that we have not met the requirements of the Freedom of Information Act 2000, you should contact the FOI Team at: NELCSU.foi@nhs.net

If you remain dissatisfied, you can ask us to review our decision by making a written request for an internal review. In order to assist with the review, you should include your address, a description of the original request and the reasons why you are dissatisfied. Please send this to:

Email

NELCSU.foi@nhs.net

Postal address

NEL CSU,
1 Lower Marsh,
London,
SE1 7NT

Website address

www.nelcsu.nhs.uk

The review will be handled by more senior staff who were not involved in the original decision. Although this will not apply to Section 36 claimed exemptions in accordance with Department of Health Directive, your request will still be reviewed. We aim to complete all internal reviews within 20 working days. If you then wish to appeal you should contact the Information Commissioner for an independent review at the following address:



Telephone

01625 545745

Postal address

The Information Commissioner,
Wycliffe House,
Water Lane,
Wilmslow,
Cheshire,
SK9 5AF

Website address

www.ico.gov.uk

Feedback

Your feedback is welcome to help us improve the service we provide. Please send comments or suggestions to our address.

Yours sincerely,

Freedom of Information Team

NEL