

Dated: March 17, 2020

For the attention of Chair of the Independent Inquiry

“Data sharing between the Lewisham and Greenwich Hospitals NHS Trust and Experian”

Sent by email to:

Board Secretary, Lewisham and Greenwich Hospitals NHS Trust
Comms Team, Lewisham and Greenwich Hospitals NHS Trust
National Director of Improvement, NHS England

Letter from use MY data

Introductory Note

We asked the members of the use MY data Advisory Group for views on the sharing of patient data by the Lewisham Hospital NHS Trust with Experian, which we have incorporated into this coordinated use MY data response.

As with any responses or letters that we collate on behalf of use MY data, these may contain contrasting views from Advisory Group members. It is inevitable that we will receive a range of views, and all these will be included. We have always seen our ability to represent contrasting views as a strength.

This is clearly a complex subject area, covering both the principle of using data to trace those without access to public-funded health services, and the actual practice of undertaking this function. Our response is limited to the latter point, and members have made some brief comments which we are highlighting to you which you might want to consider as part of your inquiry.

Whilst use MY data is focused largely on health data, our members have also provided letters and responses to the use and purposes of wider data, Artificial Intelligence, the Centre for Ethics, the National Data Guardian and the National Data Strategy.

We would be grateful if you could acknowledge receipt of this letter.

Observations

Our response is based on reporting of events in the media, and in particular within an article in the Health Service Journal on September 30, 2019 and subsequently on January 27, 2020. We are also aware of the Freedom of Information request which was submitted to the Trust by Phil Booth on October 2, 2019 and of the subsequent response from the Trust, which was dated November 28, 2019.

Our prime concern is that the trust did not disclose to patients that their personal information would be sent to Experian for the purposes outlined in the article.

If the Trust were to use data in this way, this should have been through a rigorous approvals process, including some form of review from patient representatives, as well as Information Governance and Caldicott expertise. It is not apparent that this took place and we would encourage you to seek clarity on this.

The Trust should also have been much more open, explicit and transparent with the public about this process, including the legal basis of the process and any rights of patients to object or opt-out, if these rights existed. There was a lack of transparency throughout.

We should also highlight the role of NHS Improvement. They sent out a suggestion to all Trusts that they should use Experian to explore whether service users are eligible for free care. Lewisham & Greenwich followed that advice but when this was challenged, NHS Improvement saw this as an NHS Trust issue (as the NHS Trust was the Data Controller) and were perceived to have stepped away from the problem.

We feel that NHS Improvement should have been clear from the outset about the legalities, negotiated standard contract wording and provided operational guidance including the need for transparency with patients. Only at this point should they have made the suggestion to NHS Trusts this was a course of action they could follow. This would have allowed all Trusts to implement the process successfully, and transparently.

We would consider that one of the jobs of national bodies is to use their expertise to provide clarity on complex legalities and implementation essentials and avoid the need for individual Trusts, which almost certainly lack experience and competence, to attempt to invent the process in multiple different ways.

Summary

We hope that the comments from use MY data are helpful.

We are happy to be contacted by the consultation team, and we are happy for our response to be shared as required by the consultation team. Our submission will also be added to the use MY data website (www.useMYdata.org.uk)

Any contact should be made through Alison Stone, use MY data Coordinator, at alison@usemydata.org.uk

About use MY data

use MY data is a movement of patients, carers and relatives

use MY data supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

use MY data endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.

use MY data aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

What we do

- ❖ We promote the benefits of sharing and using data to improve patient outcomes with sensible safeguards against misuse.
- ❖ We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
- ❖ We provide learning resources for patient advocates on patient data issues, including:
 - hosting workshops for patients and the public, focussing on topics related to patient data
 - a library of resources of data security, consent
 - narratives from individuals about how collecting, storing and using data can help patients.
- ❖ We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

www.useMYdata.org.uk
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 **@useMYdata**