



EMERGENCY LAPAROTOMY PATIENTS – HOW WE USE YOUR DATA

You have been given this leaflet because you, or someone you know, has recently had surgery to open the abdomen to find and fix any problems (a 'laparotomy'). These operations occur daily at hospitals across England and Wales. The NHS collect data about these operations and their outcomes to provide a national picture so that high standards can be maintained and, where necessary, improvements can be made. Your care team will enter data about your operation into something called NELA (the National Emergency Laparotomy Audit). The NELA team will only have access to data about your care in a 'pseudonymised' manner, which means that patients can only be identified by a unique computer-generated number; no personal identifiers like your name, are viewable by the NELA team. Your data is kept confidential and nothing will ever be published that could identify you. To prevent unauthorized access or disclosure of patient data, NELA have numerous physical, electronic, and managerial procedures to safeguard the information collected.

Can I ask for my data not to be collected through the National Data Opt-Out legislation?

In 2018, the NHS decided that people should have the right to 'opt out' of having their data included in such audits. However, the National Emergency Laparotomy Audit is exempt from this – losing even a small number of cases could provide the wrong picture about a hospital's performance. The national data opt-out is broad legislation that allows you to remove consent from having your data used for a variety of planning and research purposes.

Are there other options for withdrawing my information from the audit?

If you have a specific objection to having your data included in NELA, you can still withdraw your information from NELA. Send an email to NELA@rcoa.ac.uk and put 'patient request to opt-out' in the subject line or call the NELA team at 0207 092 1580. We will then contact your hospital to request that they do not enter your details into the audit. If your data has already been collected, we may be able to delete it if it has not already been used for audit analyses.

Where can I find out more?

You can find more information about NELA here: <https://www.nela.org.uk/Patient-Information#pt>, but if you have any specific questions or concerns about how NELA is going to use your data, you can email us at NELA@rcoa.ac.uk or call us on the NELA helpline at 0207 092 1580.

You can learn more about the national data opt-out scheme here: <https://digital.nhs.uk/services/national-data-opt-out>. Patients can view or change their national data opt-out choice at any time by using the NHS's online service (<https://www.nhs.uk/your-nhs-data-matters/>) or NHS App.