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## CURRENT ISSUES IN INFORMATION GOVERNANCE:

### National Data Opt-Out Policy implications for hospitals sending data to NICOR

#### Introduction

NICOR is required to comply with the laws and regulations that apply to protecting patient information collected for the purposes of the National Cardiac Audit Programme (NCAP). These are the UK General Data Protection Regulation (UK-GDPR), the Data Protection Act 2018 and the common law duty of confidentiality. The collection of data without patient consent within the NHS is covered in England and Wales by approval from the Secretary of State for Health and Social Care under Section 251 of the NHS Act 2006. Outputs from the NCAP never reveal the identity of any particular patient. Reports are based on aggregate summaries of data.

#### National Data Opt-Out Policy

The National Data Opt-Out Policy comes into effect in England on 30 September 2021. It is a legal requirement on all organisations that collect patient identifiable data to respect the wishes of patients who have opted out, so that their confidential patient information is NOT used for research and planning. Further information is available at the following link: <https://digital.nhs.uk/services/national-data-opt-out>. The NCAP falls within scope of the National Data Opt-Out policy.

As things stand, all health and care organisations are required to be compliant with the National Data Opt-Out Policy by 30th September 2021. Under this policy, prior to sending identifiable patient data to NICOR, hospitals are obliged to check against a national opt-out list held by NHS Digital to ensure that data are not sent to NICOR on patients who have registered to opt out. Similarly, NICOR has to check against the NHS Digital opt-out list when it onward shares any identifiable data.

#### Use of the NICOR database front end

Many hospitals enter data directly into the NICOR databases (for NCAP and other registries) at the point of care as it provides many advantages, including the rapid dissemination of changes to datasets. These data, in effect, are part of the individual hospital's record of that episode of care. However, by entering data into the NICOR databases prior to checking against the NHS Digital opt-out list, hospitals will not be compliant with the national opt-out by sharing data on patients who have opted out.

NICOR is currently exploring a number of different options to minimise any potential impact on existing data flows. One way to overcome this seems to be by setting up a data sharing agreement (DSA) between NICOR and each participating hospital that enters data directly into the NICOR databases. We have been working with our data controllers (Healthcare Quality Improvement Partnership and Barts Health NHS Trust) to develop an appropriate DSA. We will write to you to confirm once a DSA has been drafted. In the meantime please email Sam McAlister ([sam.mcalister@nhs.net](mailto:sam.mcalister@nhs.net)) at NICOR to confirm if your hospital is using or would like to use NICOR databases as front end and when the DSA is ready we will send you one for your hospital to sign.

Unfortunately once the national data opt-out comes into effect (30<sup>th</sup> September 2021), NICOR will be unable to receive data on patients who have opted out and is therefore unable to screen data on behalf of hospitals. The current advice is that hospitals should use a bulk upload to screen data for national opt-outs before submission to NICOR (removing data for patients who have opted out). Data for patients who have registered a National Data Opt-Out must not be entered onto the NICOR system.

In conclusion, the current situation is that from September 30<sup>th</sup> 2021:

- All Trusts in England participating in NCAP or the UK TAVI Registry must comply with the National Data Opt-Out Policy.
- Patient data submitted to NICOR is subject to the National Data Opt-Out legislation.
- Patient NHS numbers must be screened against the national opt-out list at NHS Digital prior to any data being entered into the NICOR IT platform. By submitting a record, a Trust is confirming that the NHS numbers have been screened and that the relevant patients have not opted out of including their data in NCAP.
- Trusts need to work with their local IG teams to ensure the necessary arrangements are in place to enable them to undertake the screening.
- Hospitals that use live data entry into the NICOR databases will need to consider adapting their current processes. Hospitals that first collect data in their own or in a commercial system must screen the data prior to uploading to NICOR.

We urge data to be uploaded to NICOR on a regular (preferably weekly) basis, such that each hospital can get the best benefit from the new data tools available, which provide instant feedback on a hospital's performance.

Thank you for your continued support.

Yours sincerely

A handwritten signature in black ink, appearing to read 'J. Chal', with a horizontal line underneath.

**James Chal**  
NICOR Chief Operating Officer