

05/11/2018

Dear colleague,

1 Trevelyan Square
Boar Lane
Leeds LS1 6AE

Introduction of the national data opt-out, replacing type 2 objections

0300 303 5678

Actions required:

- 1. Stop using type 2 objection codes on receipt of this letter**
- 2. Identify and share the information and guidance with appropriate healthcare staff**
- 3. Submit outstanding type 2 objections collection data using the Non-Digital Detained and Secure Estate Proxy Opt-out Form**

We are writing to you to inform you that we are now able to offer the national data opt-out to your patients in the Detained and Secure Estate. This opt-out enables patients to choose whether their confidential patient information is used for research and planning.

From the 5 November 2018 you will no longer need to register a type 2 objection for patients wanting to opt out. Instead you will need to complete and send a proxy form for each patient, to register their national data opt-out.

The national data opt-out replaces the previous type 2 objection code and healthcare professionals should not use this code after receipt of this letter. Instead, patients who want to register a national data opt-out need a healthcare professional to fill in a proxy form on their behalf. We have included a link to this form, along with guidance about who can complete it and how it should be filled in.

Up until now NHS Digital has automatically converted type 2 opt-outs to the national data opt-out, but from now we will no longer collect and convert these options so you **must not** use the type 2 code in SystemOne. Patient communication materials will be sent to each site during November 2018.

Please note that you will no longer see the national data opt-out in the patient's electronic health record. This information will be held nationally on the NHS Spine and will not be updated in the SystemOne prison module.

If your healthcare service has never submitted a type 2 objections data collection, then your patients' type 2 objections will never have been received by NHS Digital, so they cannot be converted or upheld. If you have any outstanding type 2 objections, then please submit them using the Non-Digital Detained and Secure Estate Proxy National Data Opt-out Form .

Please see overleaf for more information or visit: <https://digital.nhs.uk/national-data-opt-out>. You can also email enquiries@nhsdigital.nhs.uk or call us on 0300 303 5678.

Yours sincerely



Dr Manpreet Pujara
Deputy Chief Medical Officer

Enclosed:

1. Information and guidance document for healthcare staff
2. Non-Digital Detained and Secure Estate Proxy National Data Opt-out Form

Additional information about the national data opt-out

1. Why have you made this change?

This change is the result of an independent ‘Review of Data Security, Consent and Opt-outs’, which was conducted by Dame Fiona Caldicott and which recommended the introduction of a simple data opt-out. It has been put into policy by the Department of Health and Social Care to give people a clear choice on whether their confidential patient information is used for research and planning. A patient will be able state their preference once and be confident this will be upheld by all health and adult social care organisations (expected to be complete by 2020).

2. How will patients be able to set a national data opt-out in the Detained and Secure Estate?

The national data opt-out cannot be set through GP systems. GPs and other healthcare staff in the Detained and Secure Estate will be able to set a national data opt-out on behalf of a patient by completing a Non-Digital Detained and Secure Estate Proxy form and returning it to NHS Digital. This process for Detained and Secure Estate healthcare professionals to record national data opt-outs for their patients is available now. A copy of the form and guidance is enclosed in this letter and will be made available on our website.

3. What is a type 2 objection and how is it recorded?

The type 2 objection tells NHS Digital not to share a patient’s confidential information for purposes beyond their individual care. It is recorded in the SystemOne prison module patient record using the following code:

	CTv3	SNOMED CT	Rubric
Set Type 2	XaaVL	881561000000100	<i>‘Dissent from disclosure of personal confidential data by Health and Social Care Information Centre’</i>

4. How do I know if my patients have had their type 2 objection changed to the national data opt-out?

All Detained and Secure Estate healthcare services that have previously submitted a type 2 objections data collection to NHS Digital can be assured that their patients’ objections will have been automatically changed to the new national data opt-out.

If your Detained and Secure Estate healthcare service has never submitted a type 2 objections data collection, then your patients' type 2 objections will never have been received by NHS Digital, so they cannot be converted. Please use the Non-Digital Detained and Secure Estate Proxy National Data Opt-out Form to submit any outstanding type 2 objections.

5. Why is the type 2 code still available in the SystmOne prison module?

CTv3 codes are now 'legacy' terminologies. They were replaced by the SNOMED clinical terminology standard from 1 April 2018. As part of this process all existing CTv3 codes have been mapped to an equivalent SNOMED CT code so it is still possible to set type 2 objections after the SNOMED CT go-live date.

The intention is to withdraw the type 2 codes in November 2018, as part of the next planned SNOMED CT code release, though it may take several weeks for the GP system supplier to update the codes list within the SystmOne prison module.

6. What does withdrawal of the type 2 code mean?

SNOMED CT allows for codes to be removed from selection while still preserving the original code in the patient's electronic record, so it will still be possible to see type 2 objection codes that have previously been recorded in the patients record.

7. What else do I need to do for the national data opt-out?

The Royal College of General Practitioners (RCGP) has developed materials to support GPs, nurses and healthcare staff to understand more about the wider uses of data and the national data opt-out. These materials are available at: <https://digital.nhs.uk/national-data-opt-out>.

8. When will communications materials be made available?

For more information about the national data opt-out see: <https://digital.nhs.uk/national-data-opt-out>. We are developing communication materials for Detained and Secure Estate healthcare staff which will be sent out in November. They will also be made available on our website: <https://digital.nhs.uk/national-data-opt-out>.

Please advise staff in your Detained and Secure Estate healthcare service to use the form embedded in this letter to set a national data opt-out on behalf of your patients.

9. What about other patient opt outs and objections?

Any other types of opt outs or objections that are held in the patient's electronic record will still apply and it is for the Detained and Secure Estate healthcare service as the data controller to ensure these are applied where relevant.

10. What happens to type 1 objections?

The type 1 objection is intended to prevent the sharing of a patient's personal confidential information held by the Detained and Secure Estate healthcare service for purposes beyond the patient's individual care and is recorded using the following code:

	CTv3	SNOMED CT	Rubric
Set Type 1	XaZ89	827241000000103	<i>'Dissent from secondary use of GP patient identifiable data'</i>

As part of the review that identified a national data opt-out should be introduced, type 1 objections were considered, and it was agreed that they should continue to be respected until March 2020 when the Department of Health and Social Care will consult with the National Data Guardian on their removal.

General Data Protection Regulation / New Data Protection Legislation

11. How does this fit with the General Data Protection Regulation (GDPR) and new data protection legislation?

The national data opt-out was introduced on 25 May 2018. This coincided with new data protection legislation that came into force as part of the EU General Data Protection Regulation (GDPR). The national data opt-out is Government policy which works with GDPR and the Data Protection Act and is in addition to the data subject rights required by law.

12. Why introduce the national data opt-out at the same time as GDPR/new data protection legislation?

The new data protection legislation strengthens the requirements on data controllers to provide clear and concise information to patients about what data is collected and how it is processed by creating a legal duty of transparency as part of the requirement for fair and lawful processing of data. The national data opt-out supports this enhanced duty of transparency by providing access to materials and information that will help your Detained and Secure Estate healthcare service to explain to patients how their data is used across the health and care system and that they have a choice about how their confidential patient information is used for research and planning purposes.

13. Where can I find more information on GDPR/new data protection legislation?

Further information and guidance about GDPR for health and care organisations is provided by the Information Governance Alliance (IGA) and the Information Commissioner's Office (ICO).

<https://digital.nhs.uk/information-governance-alliance/General-Data-Protection-Regulation-guidance>

<https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/>