Applying patient opt-outs

Introduction

In order to maintain its audit functions to a high standard consistently and without the risk of reporting bias, the UKRR collects and processes confidential patient information without patient consent, having been granted permission to do so by the Health Research Authority's Confidentiality Advisory Group (HRA CAG). The HRA CAG receives its power to access and approve the use of confidential data without consent under section 251 of the NHS Act (2006).

A stipulation of processing confidential and personal patient information without their consent, both under the permissions granted by HRA CAG and the requirements of the Data Protection Act (2018) is that patients must be provided with the opportunity and the means to opt-out of their data being processed. Renal patients wishing to exercise their right to opt-out can do so by informing their renal centres, or, for patient in England, through the National Data Opt-out program managed by NHS Digital. The UKRR has produced a patient information leaflet that will be distributed by renal centres informing patients of how they can opt-out.

This document specifies the requirements for how renal centres should prepare data for submission for patients who have opted-out, de-identifying them so that their clinical data can be submitted without the UKRR being able to identify the patient.

Preparing data to submit to the UKRR

As stated in the introduction, when submitting data to the UKRR, opted-out patients should be de-identified and included in the submitted dataset. Doing this allows for the UKRR to continue to accurately count the number of patients being treated at renal centres in turn ensuring the validity of its audit.

When preparing data for submission, the renal unit/laboratory should ensure that all patients who have opted-out of having their confidential information being shared have been identified in line with their organisation's procedures. In England, this includes the requirement to check the opt-out status of patients held by NHS Digital as part of the National Data Opt-out program.

For each patient identified as having opted-out, the data manager (or member of staff responsible for submitting data) should replace any identifiers within the dataset with non-identifiable data in line with the instructions below.

UKRR data set v4.2 – CKD II-V and RRT data

Dataset for reference: UKRR data set 4.2

The following items shall only be sent where the patient has opted out of sending data to the UKRR. Where a patient has opted-out IDN05 should be set to "Y" flagging that the patient has refused consent. When IDN05 is set to "Y" then IDN05, IDN06, and IDN07 must be submitted to the UKRR.

Renal Association
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Name fields – IDN01 & IDN02

For patients where IDN05 has been set to "Y"

- **IDN01** (surname): shall be replaced by the word "CONSENT"
- **IDN02** (forename): shall be replaced by the word "REFUSED".
- **IDN08** (maiden surname or birth surname if different from IDN01): shall be replaced by the word "REFUSED"
- **IDN09** (Alias or alternative name that the patient is known by): shall be replaced by the word "CONSENT"

Date of Birth - IDN03 and Year of Birth IDN06

For patients where IDN05 has been set to "Y"

- **IDN03** (date of birth): cannot be transmitted if the patient has opted out of sending identifiable data and an additional item IDN06, containing the year of birth shall be sent, containing all 4 digits of the year born.
- **IDN06** (year of birth): should only be sent for an opted out patient, i.e. when the IDN05 flag is set to "Y".

Local Hospital Number, IDN04 and non-attributable unique identifier, IDN07

- **IDN04** (local hospital number) shall not be returned in the data extraction but a unique identifier shall be returned as IDN07.
- **IDN07** (opted out unique local identifier) is made up of PAT01 (hospital transmitting centre code) concatenated to an internal database number, i.e. locally non duplicable number, (in Proton the vrx internal database record number will be used).

  Example, Southmead Hospital in Bristol could send an IDN07 field of REE0117370, where REE01 is the NHS site code of the transmitting renal unit and 17370 is the internal database number.

  This item must be stored on the local system, to be used in the next data submission and must be accessible locally for reference if any data queries are required by the UKRR data team during their validation processes.

- **PAT13** (NHS number): is a unique identifying number and must not be sent
- **PAT12** (CHI number in Scotland): is a unique identifying number and must not be sent
- **PAT18** (H & C number in Northern Ireland): is a unique identifying number and must not be set

Address Lines PAT20, PAT21, PAT22 and Postcode PAT23

- **PAT20** (Address line 1) must not be sent
- **PAT21** (Address line 2) must not be sent
- **PAT22** (Address line 3) must not be sent
- **PAT23** (postcode) must be replaced by the first half of the postcode only

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Summary list of item changes

Field ID	Data Type	Mandatory	Description	Value for opted-out patient
IDN00	C10	Y	RR no – blank for new registrations	RR no – blank for new registrations
IDN01	C20	Y	Patient surname	"REFUSED"
IDN02	C20	Y	Patient forename	"CONSENT"
IDN03	D	Y	Date of Birth	Do not submit – Complete IDN06
IDN04	C15	Y	Local Hospital Number	Do not submit – Complete IDN07
IDN05	Code		Flag for Refused permission to send identifiable data to UKRR	Y
IDN06	N4		Year of birth if IDN05 set to "Y"	Year of Birth
IDN07	C20		Unique pseudonym for site use – combine site code with local record number	e.g. "REE0117370"
IDN08	C20		Patient birth name = name on birth certificate - also 'Maiden name'	"REFUSED"
IDN09	C20		Alias - other surname by which patient also known	"CONSENT"
PAT11	C15	Y	CHI number – Patients Registered in Scotland	Do not submit
PAT13	C12	Y	NHS Number	Do not submit
PAT18	C12	Y	H & C Number – Patients registered in the Northern Ireland	Do not submit
PAT20	C40		Address Line 1	Do not submit
PAT21	C40		Address Line 2	Do not submit
PAT22	C40		Address Line 3	Do not submit
PAT19	C40		Address Line 4	Do not submit
PAT23	P	Y	Postcode	Submit first half of the postcode e.g. "BS10"

All other data items should be submitted as normal.

Vascular access data

Paediatric Data via Filemaker

Laboratory AKI dataset

Dataset for reference: Laboratory AKI Dataset

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Where a patient has opted-out of having their confidential data sent to the UKRR; the following items should be changed or removed from the submitted data to de-identify the patient.

Data Item	Data Type	Description	Value for opted-out patients
NHS Number	String		Do not submit
Local Patient Identifier	String	Locally held unique identifier where the NHS number is not available	Unique pseudonym for site use – combine Lab ODS code with local record number e.g. "REE0117370"
Forename	String		"REFUSED"
Surname	String		"CONSENT"
DOB	String		Submit year of birth only: "YYYY"
Address 1	String		Do not submit
Address 2	String		Do not submit
Address 3 (Town)	String		Do not submit
Address 4 (County)	String		Do not submit
Postcode	String		Submit first half of the postcode e.g. "BS10"
Lab Code	String	ODS Code of Processing Lab	Do not submit – instead concatenate with unique patient reference to create Local Patient Identifier
Source of Request	String	ODS Code if possible or text	Do not submit

All other data items should be submitted as normal.

Creating the Local Patient Identifier

To create a unique Local Patient Identifier (to be used when an NHS no. is not available or cannot be submitted) the laboratory site should take their Lab ODS Code and concatenate it will to an internal database number, i.e. locally non duplicable number.

This Local Patient Identifier must be recorded on site as it will be used as a reference should the UKRR data team have queries as part of their validation processes. It should also be available as a reference for any future data submitted for that patient.