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IBD Registry, patient consent and the National Data Opt-Out

As you may know, there is a National Opt-Out being introduced enabling patients to opt out from the use of their data for research or planning purposes. From March 2020 all health and care organisations are required to be compliant with this national policy.

Patients who decide that they do not want their confidential patient information used for planning and research purposes may choose to indicate this via the National Opt-Out. For IBD teams submitting data to the IBD Registry, their data submissions are also subject to the National Opt-Out.

IBD teams will need to ensure their submissions to the IBDR are being sanitised using the national technical solution. Each Trust will have its own approach, and we suggest that may also be helpful to seek guidance from their local IG Lead/DPO and local IT/Data Administration/Information Teams to understand how your organisation is ensuring compliance with the National Opt-Out.

For patients who have requested the National Opt-Out, their patient information must not flow to the Registry.

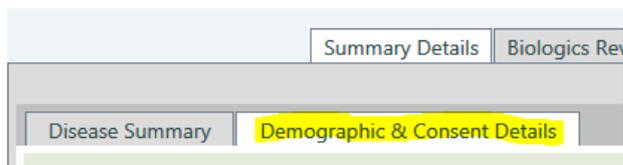
Two important notes:

- i) the opt-out only applies to data flowing to the Registry under a s251 exemption (i.e. where the patient's consent has not been sought). Patients who have consented for their data to flow to the Registry are not affected
- ii) IBD teams who are using tools such as the IBD PMS and Registry WebTool for clinical care are not affected by this (the opt-out only applies when data from these systems is submitted to the Registry).

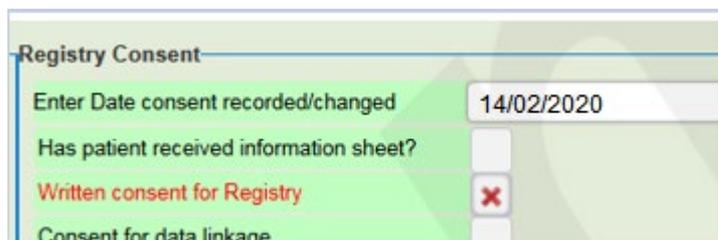
How to record patients' wishes to not submit their records to the Registry

The Registry's approved tools have the functionality built-in to exclude patients' files from being included in the extract for submission to the Registry. This exclusion may be for any number of reasons –the patient has withdrawn consent, patient has opted-out locally, or where the Trust has learnt that patient has opted-out nationally. The 'exclusion from submission' method is the same in all cases and is quick to implement. See below to see the simple steps involved:

On the WebTool – select the patient; on the Summary Details page click **Demographic & Consent** tab;



on the Registry Consent panel;



enter **Date**; click once or twice in **Written consent for Registry** until a **red cross** appears; then click **Save changes**; FINISHED

Having done this, the patient's record will not now appear in the files you extract for submission to the Registry, but you can still use and update their record to manage their IBD as part of routine clinical care.

For users of other data collection systems, go to the screen where you record the patient's consent and enter No (or N or red cross, as implemented locally) in the field for 'Consent for Registry'.

A general note on recording Consent

All sites are reminded of their responsibility to ensure that consent is recorded on the system in line with the decisions expressed by the patient on the consent form.

If this is not recorded as expressed, then the absence of consent recorded on the system may mean that data entered will then flow to the Registry under s251 and be used contrary to the patient's wishes.

For more information on how the National Opt-Out works with the Registry, contact: support@ibdregistry.org.uk

For information on the National Opt-Out go to: <https://digital.nhs.uk/services/national-data-opt-out>, or speak to your Trust Information Governance department.

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