

Patient Opt Out/Data purge approach

The purpose of this process is to set out how South London DSCRO notifies Concentra of dissenting patients.

Concentra will need to be notified of these dissenting patients so any existing records can be removed from their data files.

Assumptions

1. The Concentra tool is hosted within Brent CCG which is an ASH
2. Data is being used for direct patient care purposes only when an information sharing agreement has been signed. All other data is pseudonymised

NHS numbers can be sent to an ASH. The list will be created from the dissent codes as recorded on the EMIS and System1 systems.

This notification process will apply for each data flow each time it is received, processed and passed to Concentra

In proposed approach, the data flow is as follows:

Primary Purge

1. Data arrives at SECSU, they check for any “opt out” consent Read codes/CTV3 and capture a list of the NHS numbers that should be purged and the date the opt out was captured
2. South London DSCRO will only be purging records where there is an NHS number. Data sets with local IDs will not be linked and purged and will be orphaned records in the Concentra load.
3. The file will contain NHS number, date opted out and where applicable, date opted back in.
4. When the data processing & pseudonymisation process is complete, the data is passed to Concentra with the dissenting patients file.
5. South London DSCRO send the Full list of NHS numbers that should be purged (along with the dates the patient dissented). It was confirmed with David Stone that SECSU are allowed to send Concentra (Brent CCG) the list of NHS numbers. Concentra would expect this feed with every load of patient data (GP, SUS, Mental Health, SLAM, Community etc.).
6. South London DSCRO will hold the master list of dissenting patients. Concentra will delete their file. Holding the file is deemed to be processing the data and as the patient has opted out of data processing it is not appropriate for the file to be held by both South East CSU and Concentra.

Note: Concentra is not allowed to keep the list of patients’ that have opted out. Concentra will have to check the NHS number against all data sources and delete required records.

Secondary Purge

4. In the event that data was transmitted to Concentra (in previous or current loads), Concentra reference the list of NHS number who are marked as “Opt Out”, and fully delete this data (retrospectively) from all databases. For data not to reside in flat files, Concentra will have to delete whole files from the DW after processing. If a patient “opts back in”, there won’t be any historical data for that patient in the system.

- 4.1. Concentra performs a secondary check on the data loaded for specific “Opt out” Read codes and automatically raise an email alert if breaches are found. (SECSU.InformationGovernance@nhs.net)
- 4.2. No reporting on purged data required. Standard incident reporting (i.e. someone emails Concentra with GP dataset) is required as per the agreed contracts. However, Concentra can send an email reporting that the purge was complete (Email address required)
- 4.3. Concentra will do the checks against the full list of opt-out patients and by date, the process will check for patients that have been added to the list of Opt out NHS numbers since the last purge of data.
5. In the case where a user opts back in, South London DSCRO removes the NHS number from the list of opted out patients, or marks them with an Opt In date, they also no longer purge the data from the extracts, Concentra only receive data from that point forward (Incremental load). Concentra **cannot** reload history for a patient that opts back in, for feeds other than full history loads.
6. Concentra will use the Read codes listed in the appendix to check that there has been no data sent over from the South London DSCRO in error.
7. If any dissenting patients or sensitive data is found in the files from South London DSCRO, Concentra will raise an incident report with NWL CCG governance group and with South London DSCRO. This would be done via an email to: secsu.informationgovernance@nhs.net & (email for NWL)

Outstanding question:

- SECSU/Concentra to agree specification for NHS list of Opt Out patients.

Appendix

Read codes used for patient dissent.

Programme	Local/National	Read Code	Code Iteration
ICP/WSIC	Local	XaNwT	Declined consent to share data with specified 3rd party
ALL	Local National	XaQVo	Refused consent for electronic record sharing
SystemOne Sharing, CWHHE MOU	Local	XaKRw	Refused consent for upload to local shared electronic record
Summary Care Record	National	XaXj6	Express dissent for Summary Care Record dataset upload

Summary Care Record	National	XaKRY	Express dissent for Summary Care Record dataset upload
Care.Data	National	XaaVL	Dissent from disclosure of personal confidential data HSCIC
Care.Data	National	XaaVM	Dissent withdrawn disclosure personal confidential data HSCIC
WSIC, Care.data	Local National	XaZ89	Dissent from Secondary use of GP patient identifiable data
WSIC, Care.data	Local National	XaZ8A	Dissent withdrawn second use of GP patient identifiable data