

COST2CARE: Addressing the economic and human cost of hospital acquired and nursing-sensitive adverse events in older patients through optimal use of routine discharge data and measurement of missed nursing care.

PROCESS FOR WITHDRAWING FROM CHART REVIEW ELEMENT OF THE STUDY.

If for some reason an eligible current patient or member of the public expresses a wish that their hospital chart/notes would not be included in this study there is a clear process to be followed.

Posters in the hospital and the project website will provide details on how these patients or members of the public can make their wishes known.

Chart review process:

The participating Model 4 hospital will generate a random sample of charts for audit in accordance with the criteria set out in the study description, this process will be conducted under the guidance of the Healthcare Pricing Office. This sampling process will result in a list of hospital stays identifiable by the original (un-encrypted) MRN, episode number, admission date and time, discharge date and time which can be used to identify the charts or portions thereof for review. The un-encrypted MRN is required by the hospital and the chart review team for chart identification and retrieval. As the review is based on the physical chart it will not be possible to anonymise the chart when the review is taking place. The final piece of information which will be provided with the chart review sample, will be an encrypted MRN which is generated by the hospital HIPE manager in line with processes used by the HPO as part of their routine data processes.

The chart review team will be the only COST2CARE study team members who will have access to the unencrypted MRN. The chart review team from DCU will only have this information for the duration of the chart review. In the participating hospital, for analysis purposes the hospital discharge data set (HIPE) is linked with the patient charts based on patient identifiers. As soon as the files are linked (datafile containing random selection of patient discharge data from HIPE and the chart review data collected by research team) they are hashed by one-way encryption so that we know that they are retrieved from the same patient but that the patient ID is no longer retrievable. At this point the un-encrypted MRN will be removed from the excel file along with the admission and discharge dates and times to further ensure anonymity. The information can now be passed on to the wider study team (i.e. the chart review extracted data provided by the review team and the HIPE clinical details for the patient cohort) with only an encrypted MRN as the identifier.

The above arrangement ensures that the chart review team can identify and review the correct charts while ensuring that data shared to the wider team is anonymised. The wider DCU team will not be able identify an individual or their MRN based on the pseudonymised information returned by the review team. The chart review team will sign a non-disclosure agreement as discussed with the DPO at the participating hospital preventing them from retaining any identifying information. By doing this, the personal data of the participants will be secure as the researchers will have no way or reidentifying the participants once the data has been extracted.

Process for withdrawing from the study:

As the generator of the encrypted MRN, the hospital HIPE Manager will (in exceptional circumstances) be able to identify an original MRN from the encrypted MRN at any stage during the study. **However, the DCU team will not be able to do this.**

In the case that a data subject wishes to exercise their rights, the HIPE manager can accommodate this without the MRN being revealed to the DCU team. Such a query would result in the DCU team being advised that a particular record identified by the encrypted MRN should be removed from the analysis. See steps below:

Step 1

If a person believes they meet the criteria for inclusion, and does not want to be included in the study, but is unsure if the hospital where they were an inpatient is part of the study, they should contact the DCU team by emailing marcia.kirwan@dcu.ie. If they are confirmed to be eligible the DCU team will direct them to the hospital COST2CARE contact.

Step 2

The COST2CARE team at the hospital confirms the person meets the criteria and collects certain personal details from the person in order to identify the chart. This might include Name, Address, Date of Birth, Date of admission in 2022 and Date of Discharge. If MRN is known this should also be collected. If MRN is unknown the other details will enable identification of MRN.

Step 3

The COST2CARE team will notify the local HIPE manager of the request.

Step 4

The local HIPE manager will check if that person's chart has been included in the file of randomly selected charts identified for the review. If the person's chart has been randomly included in the file of 1000 patients, but not yet extracted by the Review Team, the relevant MRN will be removed by the HIPE manager from the 1000 selected for review.

OR

If on the other hand the chart review had already taken place when the member of the public requests removal through the COST2CARE team at the hospital as above, the HIPE manager can accommodate the request for withdrawal without the MRN being revealed to the DCU team. Such a query would result in the DCU team being advised that a particular record identified by the encrypted MRN should be removed from the analysis.

NOTE:

It is important to note that withdrawal from the study is possible at any point up to completion of data analysis. However, this can only be carried out through the process described above, as the DCU team will not be able to identify individuals in the anonymised datafile. Once final analysis is completed, and reports written, the research team will no longer be in a position to delete data from the final datafile.