

## Newborn Genetic Screening

### E. Screening data management

Data from the St Joe's Log form and NEC Screen Interview are entered into the Access database on a shared drive at L:\Daisy\Recruit.mdb. This database contains the tables, queries, forms, reports and macros that staff use to interact with the data. This database does not have a front-end and back-end, all objects are contained in this one database. New data entered into the recruit database is transferred to the St Joe back-end of the main study database (L:\dci\StJoeBe.mdb) on a weekly basis.

#### Database tables

There are two primary data tables: *tblStJoeLog* and *tblNecScreenInterview*. The primary key in *tblStJoeLog* is the mother's hospital ID. The hospital ID is specific for a given admittance to the hospital, if the same person is re-admitted to the hospital at a later time, they are assigned a new ID. The mother's hospital ID is also included in *tblNecScreenInterview*. These two tables are linked by the mother's hospital ID in a one-to-many relationship. A record cannot exist in *tblNecScreenInterview* unless a matching record already exists in *tblStJoeLog*. If a mother has twins there will be one record in *tblStJoeLog* and two records in *tblNecScreenInterview* – one for each twin. The primary key for *tblNecScreenInterview* is the DAISID – a unique ID assigned to each infant by the study recruiters.

There are 3 additional tables in the database that are created from Make-a-Table queries which are used to export data either to SAS or to the main study database.

#### Data entry

Data from St Joe's Log is entered into *frmDeStJoeLog*. This form is based on *qryStJoeLog* which selects only those records which have not been exported, but also allows the addition of new records. Skip patterns in data entry are controlled by *mcrStJoeLog*. The data entry form can be opened by pressing the 'St Joe's Log' button on the main switchboard.

Data from the NEC Screen Interview is entered into *frmNsi* which contains the subform *frmNecScreenInterview*. The main form is based on *qryNsi* which selects from *tblStJoeLog* only those records that have been assigned a DAISID and which have not been exported. The rationale here is that we do not want to update records in the recruit database which have already been exported to the main database. The subform is linked to the main form by the mother's hospital ID. Skip patterns in data entry are controlled by *mcrNsi* and *mcrNsi2*. The data entry form can be opened by pressing the "NEC Screen Interview" button on the main switchboard.

## Weekly data checks

These queries are activated by pressing the similarly named buttons on the Main Switchboard.

***qryCheckLogByLogdate:*** Based on *tblStJoeLog*. Requests that a start date and end date be entered and then displays all records where the contact date falls between the two dates given. This allows the recruit supervisor a means to quickly check whether or not data have been entered for the given time period.

***qryCheckDaisidInNsi:*** Based on *tblNecScreenInterview*. Requests that a start date and end date be entered and then displays all records where the contact date falls between the two dates given. This allows the recruit supervisor a means to quickly check whether or not data have been entered for the given time period.

***qryDaisidDoesNotMatch:*** Links *tblStJoeLog* to *tblNecScreenInterview* and lists any records where the DAISID given in the latter does not match the one in the former. The only cases where this should be true is when the infant is a twin or a triplet – these are excluded from this query.

***qryNoNsi:*** Links *tblStJoeLog* to *tblNecScreenInterview* by mother's hospital ID and lists any records where a DAISID was assigned in the former but no record exists in the latter. These are Interviews that need to be entered.

***qryNoSampleInfo:*** Based on *tblNecScreenInterview*. Lists records for infants born in the previous 90 days for which no sample data has been entered. These are records for which sample storage data need to be entered.

***qryPending:*** Based on *tblStJoeLog*. Lists records where interview is 'pending'. This list is given to the recruiters each week as a reminder of pendings that need to be resolved.

***qryRefusalReasons:*** Based on *tblStJoeLog*. Requests that a start date and end date be entered and then lists all records for which cord blood was collected but the interview was refused. Allows recruit supervisor to summarize reasons for refusal over a given time period.

***qryExportLogToSas:*** Links *tblStJoeLog* to *tblNecScreenInterview* by mother's hospital ID and lists all records that are contained in *tblStJoeLog* whether or not there is a matching record in *tblNecScreenInterview*. This is a Make-a-table query which makes the table *mktExportLogToSas*. The data is then transferred to a text file at L:\de\sas\recruit\recruit.dat by the macro *mcrExportLogToSas*. The SAS program generates the number of refusals and consents obtained from St. Joe's Hospital (see [Weekly Report Protocol](#)).

## Monthly data checks

***qryConsentCheckList:*** Based on *tblNecScreenInterview*. Requests that a start date and end date be entered and then lists all Interviews with a contact date between the two given dates. **This list is given to St Joe's Hospital so that they will know who they should have consent forms for.** This query is activated by pressing the 'St Joe's Consent' button on the Main Switchboard.

## Weekly Data Export

Data are exported from the recruit database to the main study database on a weekly basis. The recruit database is kept separate from the main database to decrease the number of staff members accessing the database at any one time. This is especially important with the recruit database because of the number of records in the tables (20,000+).

Pressing the 'Export Log' and 'Export NSI' buttons on the Main Switchboard invokes the macros *mcrSwitchMain.TransferLog* and *mcrSwitchMain.TransferNsi*. These macros create tables of data to be exported to the main study database and then updates the EXPORTED field to 'yes' for the same records.

The queries run are *qryMakeTableExportLog* and *qryMakeTableExportNsi*. These queries select records for infants born at least 10 days prior, where the interview is not 'pending', and where the field EXPORTED is 'No'. The criteria of born at least 10 days prior is there to give the recruiters time to complete all of the data entry required, including numbers of samples, etc. Records for 'pending' interviews are not exported since they have not yet been resolved, and records are only exported if they haven't been exported before. After the tables are made the queries *qryUpdateExportLog* and *qryUpdateExportNsi* are run. These queries update the EXPORTED field to 'Yes'.

After these export queries have been run the recruit database is closed and the St Joe backend of the main study database at L:\dci\StJoeBe.mdb is open. The tables, *mktExportLogToDaisy2* and *mktExportNsiToDaisy2* are deleted from this database and then imported from recruit.mdb. The queries, *qryAppendToStJoeLog* and *qryAppendToNsi*, are run which append the newly imported records to the existing St Joe Log and Nec Screen Interview tables.