



British Isles Network of Congenital Anomaly Registers

BINOCAR Standard Operating Procedure for The BINOCAR Annual Report

Instructions for the Registration and Surveillance of Congenital Anomalies in
England and Wales

Authors:

Anna Springett (BINOCAR Hub)
Elizabeth Draper (EMSYCAR)

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| Version number | Date | Comment |
|----------------|-----------------|--|
| 1.1 | 30 January 2015 | First version put together by AS, ED and the BINO CAR Management Committee |
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Background

The BINOCAR Hub annually produces a report to present the latest complete year's data. These reports include the prevalence, trends, prenatal diagnosis, terminations of pregnancy, infant mortality and prevalence by maternal age groups, geographical variation, a spotlight on a specific anomaly, and chapters on the two national disease specific registers.

The chapter on geographical variation reports data at the register level only. No smaller geographies are presented in this report. Reporting at a register level does not require any disclosure control however when presenting data on terminations of pregnancy by register a risk assessment and some disclosure control may be necessary (see BINOCAR SOP - Small numbers).

This SOP will go through the technical details of getting the data ready for analysis and well as how the report is put together.

Annual report timetable

| Task | Feb | Mar | Apr | | | | May | | | | Jun | | | | | Jul | | | |
|--|-----|--------|--------|--------|--------|--------|-------|-------|-------|--------|--------|------|------|--------|------|------|------|--------|--------|
| | | Wk 4 | Wk 1 | Wk 2 | Wk 3 | Wk 4 | Wk 1 | Wk 2 | Wk 3 | Wk 4 | Wk 1 | Wk 2 | Wk 3 | Wk 4 | Wk 5 | Wk 1 | Wk 2 | Wk 3 | Wk 4 |
| Register data sent to EUROCAT and the Hub | Red | | | | | | | | | | | | | | | | | | |
| Register data finalised by EUROCAT and sent to the Hub | | Orange | | | | | | | | | | | | | | | | | |
| The Hub drafts report | | | Yellow | Yellow | Yellow | Yellow | | | | | | | | | | | | | |
| Selected register leads comment on the drafts | | | | | | | Green | Green | Green | | | | | | | | | | |
| The Hub revises draft | | | | | | | | | | Yellow | Yellow | | | | | | | | |
| All register leads comment on the draft | | | | | | | | | | | Red | Red | | | | | | | |
| Management committee meeting to discuss issues & finalise report | | | | | | | | | | | | | Red | | | | | | |
| The Hub revises draft and produces summary & press release | | | | | | | | | | | | | | Yellow | | | | | |
| Funders & Caldicott Guardian to see report and press release | | | | | | | | | | | | | | | Blue | Blue | | | |
| The Hub makes any final changes to report, summary & press release | | | | | | | | | | | | | | | | | | Yellow | |
| Report launch | | | | | | | | | | | | | | | | | | | Purple |



Registers send their data to EUROCAT on the 15th February and send an update on the 15th October every year. This includes the latest data from twoth years previous (e.g. in 2014 the latest data will be from 2012). Any other year where the register has made changes to cases will also be sent. Once EUROCAT has received data from all of their registers across Europe they upload the data to a test website where they ask registers to confirm their data by checking their numbers by congenital anomaly and prevalence rates. Once the BINOCAR registers have confirmed their data it can be released to the Hub. This process can sometimes take up to 6 weeks from the 15th Feb/Oct.

The Hub are then given 4 weeks to get the data ready for, run the analysis and write the report. Once the first draft is ready, it is sent to a few of the registers leads including the chair and secretary of BINOCAR and the clinical register lead for their comments. They are given 3 weeks to send their comments back to the Hub. The Hub then has 2 weeks to make any changes to the report after these comments.

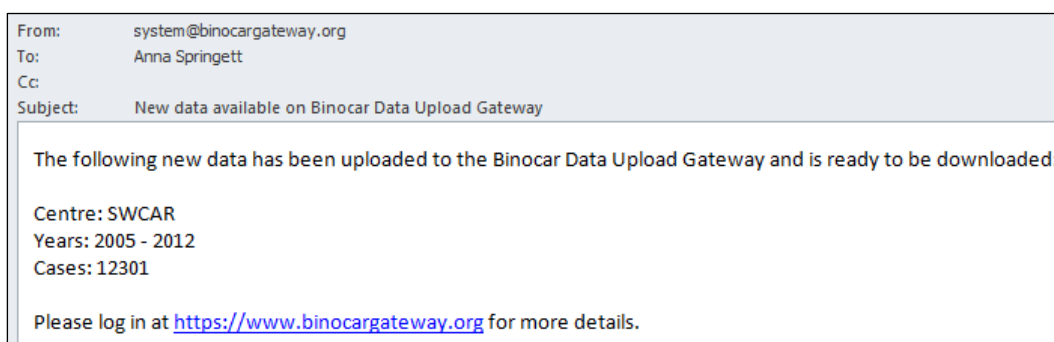
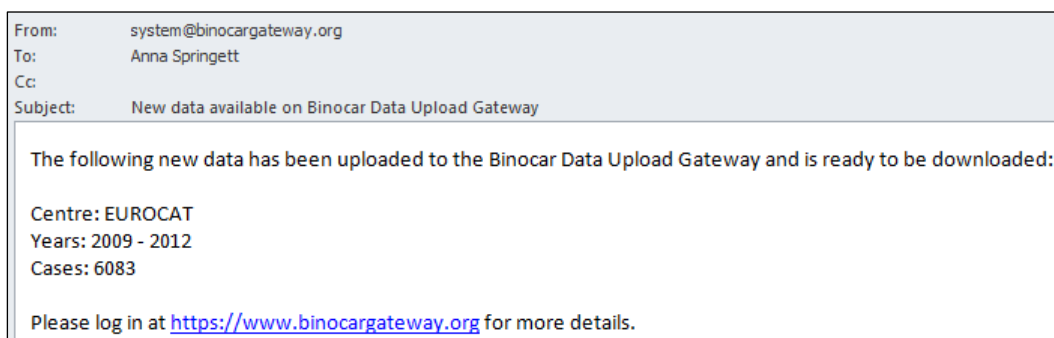
Once the second draft is ready the report is sent around to all registers for them to comment, they are given 2 weeks. After this a management committee meeting is held to discuss and resolve any issues raised by the registers and to finalise the report.

The Hub then has a week to make the changes and put together the final report, summary and with the help of the QMUL media team a press release. These are then sent to the funders of the registers and a Caldicott Guardian for their approval. If any changes are needed the Hub has a week to make them then the report can be launched. The QMUL media team sends the press release to the media and the report is added to the BINOCAR website. Any media requests are dealt with by the Hub.

Getting the data ready for analysis

On the 15th Feb/Oct the registers should be sending their latest completed year's data along with any other years where changes have been made to EUROCAT and to the BINOCAR Hub. See the BINOCAR Gateway SOP for the method of transferring the data and the Reporting using standardised methods and Extra BINOCAR variables SOPs for the variables and format the data should be sent in.

Anna Springett at the BINOCAR Hub will receive an email when EUROCAT have uploaded the register data and when the registers have uploaded their extra BINOCAR variables using the BINOCAR Gateway. The email will contain details of the register, years and number of cases that have been uploaded.

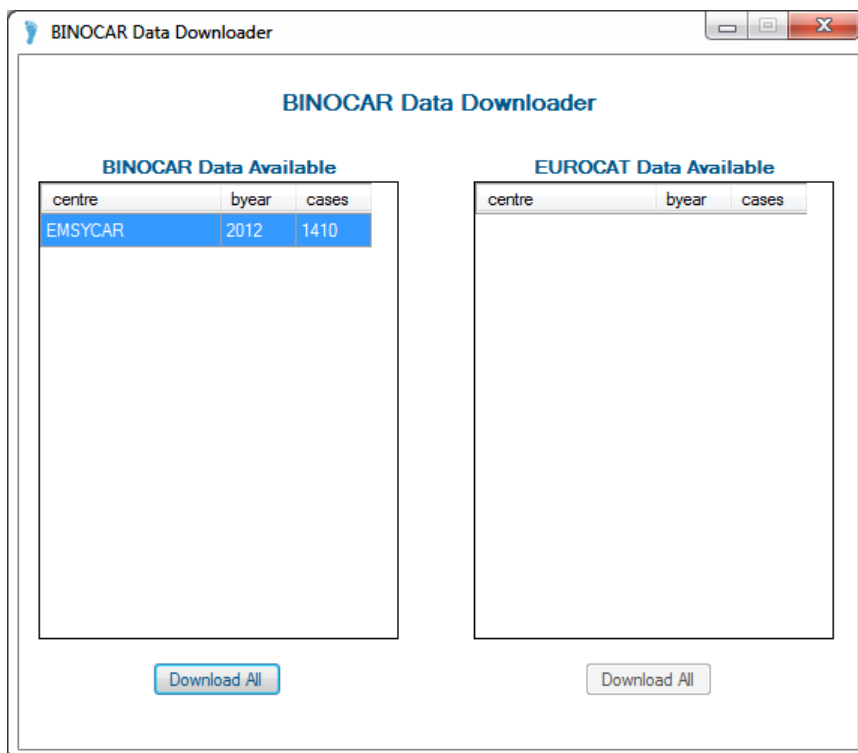
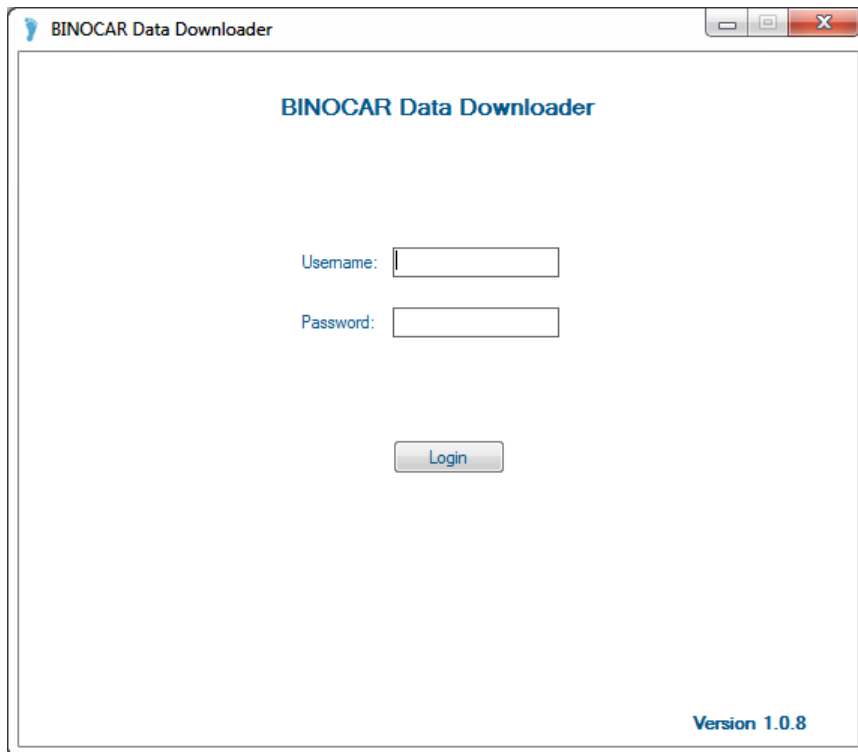


The dedicated server where the BINOCAR Hub is stored is turned off when not in use so that unnecessary backups are not being carried out. The server is not directly accessed; it can be accessed using the BINOCAR downloader program, the BINOCAR Management Program (BMP) and using commands in STATA. The BINOCAR server will need to be turned on for these processes to be carried out. The BINOCAR server will need to be turned off again after these processes have been carried out and a backup has been run. To turn the BINOCAR server on and off speak to the head of IT.

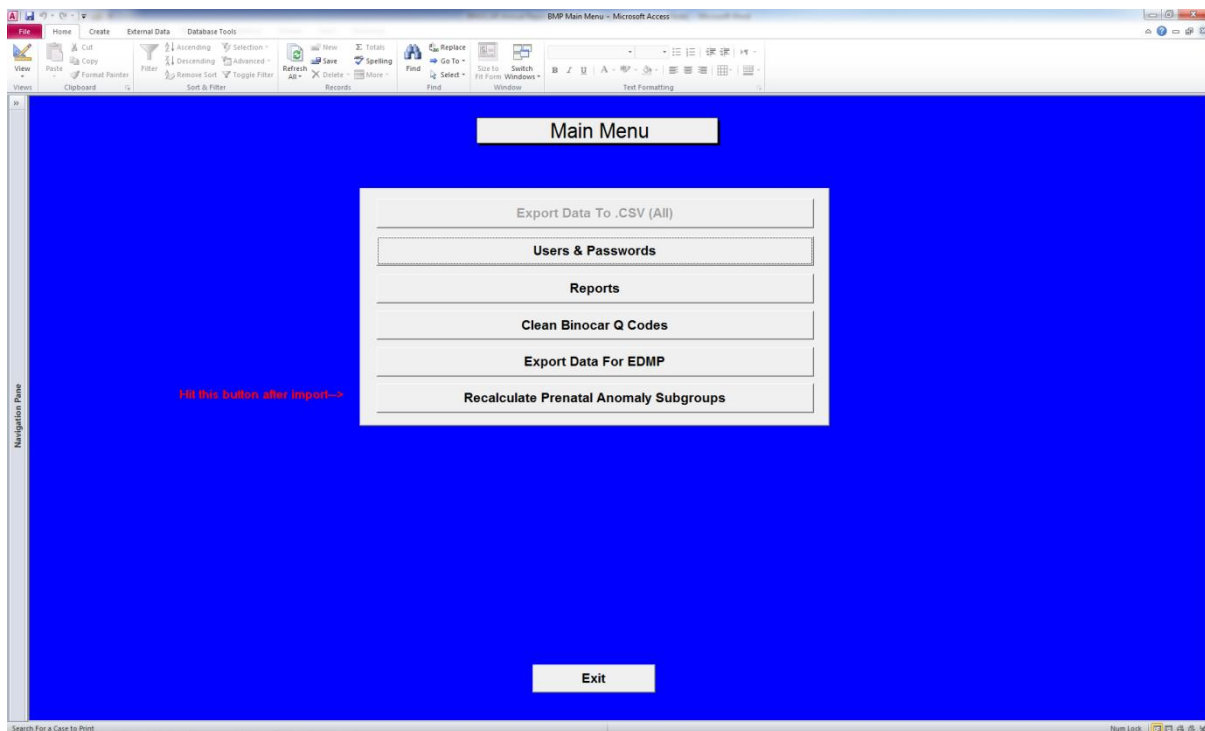
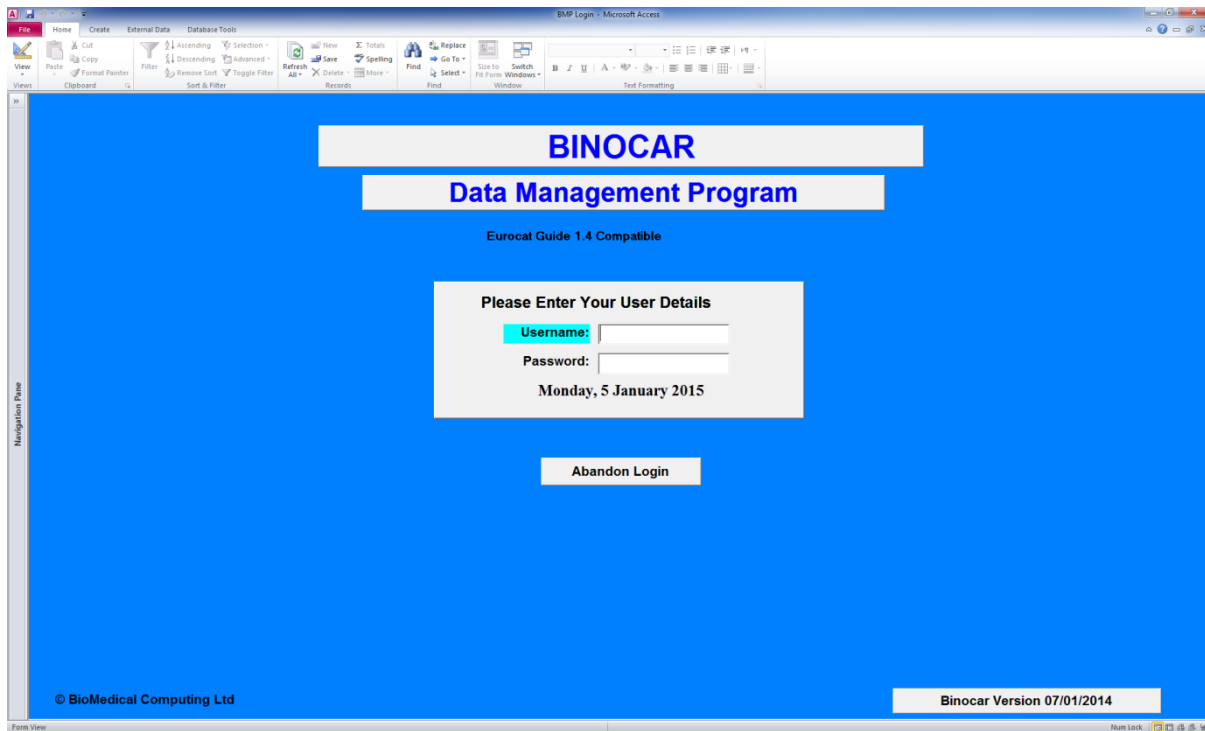
Bio-medical Computing Ltd have set up a BINOCAR downloader program that enables the data that has been uploaded to the BINOCAR Gateway to be downloaded in the correct format onto the BINOCAR server in the Hub. This download program can be downloaded to a PC using the following link:

<https://www.binocargateway.org/binocardownloader.exe>

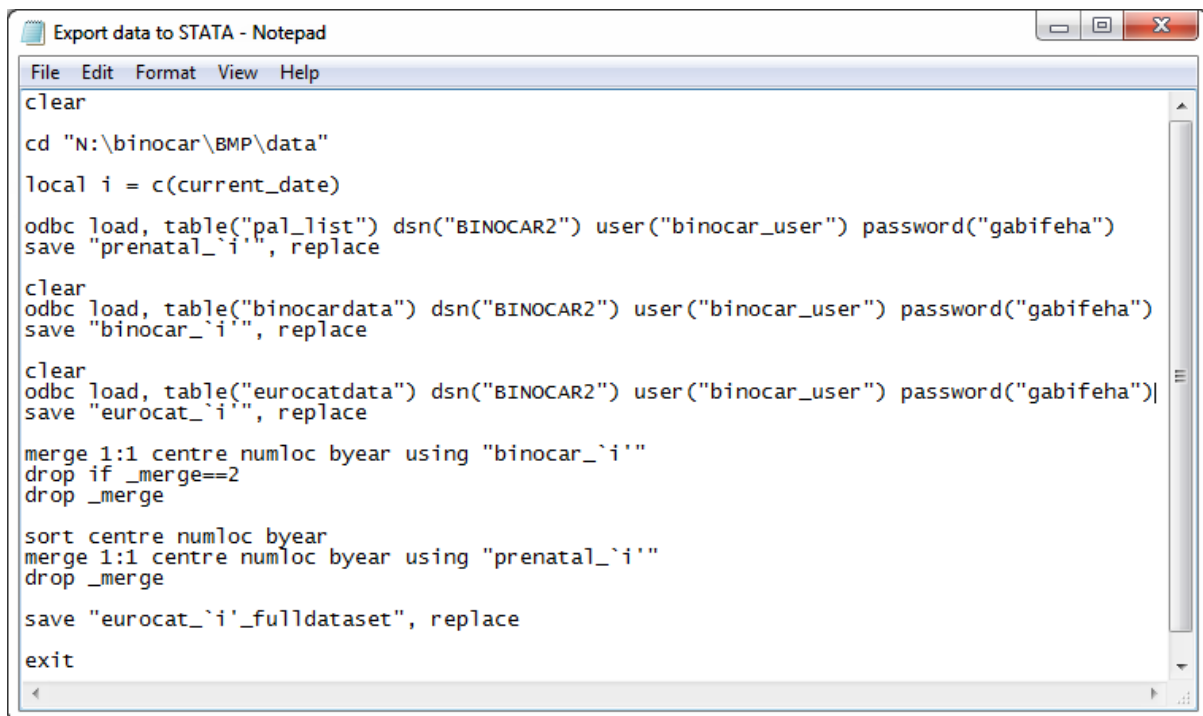
Open the downloader program saved on your PC and login using the username and password "m". A list of the data ready to be downloaded will be shown. The registers data on the left and the EUROCAT data on the right. Click the Download All button underneath the lists to download it to the BINOCAR server.



The anomaly binaries and prenatal anomaly binaries then need to be recalculated this can be done using the BINOCAR Management Program Access database that Bio-medical Computing Ltd have set up. This database can be obtained from James at Bio-medical Computing Ltd and is saved on the Projects drive of the Wolfson Institute Network. This program can also be logged into using the username and password “m”. Click the Recalculate Prenatal Anomaly Subgroups button, this takes a while but a box with the number of cases done will come up when it has finished.

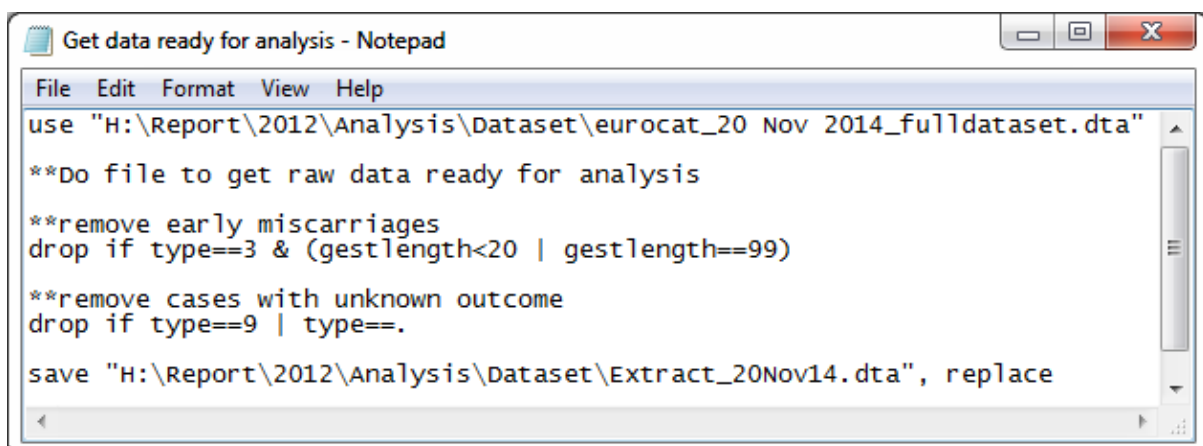


The data can then be exported from the database into STATA using a do file that imports the separate data tables from the server and saves them as STATA files and then merges all of the files together to create one final dataset to be used for the annual report analysis.



```
File Edit Format View Help
clear
cd "N:\binocar\BMP\data"
local i = c(current_date)
odbc load, table("pal_list") dsn("BINOCAR2") user("binocar_user") password("gabifeha")
save "prenatal_`i'", replace
clear
odbc load, table("binocardata") dsn("BINOCAR2") user("binocar_user") password("gabifeha")
save "binocar_`i'", replace
clear
odbc load, table("eurocatdata") dsn("BINOCAR2") user("binocar_user") password("gabifeha")
save "eurocat_`i'", replace
merge 1:1 centre numloc byear using "binocar_`i'"
drop if _merge==2
drop _merge
sort centre numloc byear
merge 1:1 centre numloc byear using "prenatal_`i'"
drop _merge
save "eurocat_`i'_fulldataset", replace
exit
```

Early miscarriages then need to be removed from the dataset and any cases with unknown outcome, using a STATA do file. This will then create a final dataset that will give the same numbers as the prevalence tables on the EUROCAT website. This dataset is now ready for analysis.



```
File Edit Format View Help
use "H:\Report\2012\Analysis\Dataset\eurocat_20 Nov 2014_fulldataset.dta"
**Do file to get raw data ready for analysis
**remove early miscarriages
drop if type==3 & (gestlength<20 | gestlength==99)
**remove cases with unknown outcome
drop if type==9 | type==.
save "H:\Report\2012\Analysis\Dataset\Extract_20Nov14.dta", replace
```