Working with data from the DNBC on the VDI – general information

If you are about to start working with DNBC data through a Virtual Desktop Infrastructure (VDI) on Aarhus University's server, please read this document carefully. In order to have access to the VDI you must complete and sign the form on page 4 and return it to the DNBC data manager at bsigdata@ph.au.dk

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Who may work with DNBC data?
Working with personal DNBC data requires permission from the DNBC Steering Committee, the Danish Data Protection Agency, DDPA (Datatilsynet) and – if biological material is involved - from the Research Ethics Committee (Videnskabsetisk Komité).

Only researchers from established scientific groups with a well-described research protocol will be authorized to work with DNBC data on the VID server at Aarhus University on the terms described below.

Master thesis students will have access to anonymized data only.Researchers based outside the EU may access anonymized data sets. If person-identifiable variables are needed, the institution in question and the Statens Serum Institut must co-sign an EU Data Processer Agreement

Login, UserID and Password
To access the VDI server, you must register with Aarhus University as a user. The DNBC Data manager will make sure your user account is opened when the form on page 4 of this document has been received.
The DNBC data manager will provide you with a UserID and Password. This information is personal and it is your responsibility to keep it confidential.

In order to access the server, please consult the VDI setup manual on the AU website

When your data set is ready, you will be able to access your personal folder.
If you need to share your data with e.g. students, a statistician or other colleagues, the person or persons must also be registered as user(s) with Aarhus University after reading and signing this document.
You will be asked to attend/complete a data security awareness course. This course could be taken on-line.
If you have not accessed your data for approx. 6 months, we will close your account for safety reasons.

Price and time period

The price of a standard user account is DKK **5.000 per year[1].** If you have more than one project, an additional folder will be established per project at an annual fee.
The cost of generating your project data set will be charged at our standard hourly rate. Please prepare your list of variables carefully, so that you do not need to consult our data managers again for additional variables.
Your dataset is available for a standard period of 2 years, or for the period corresponding to the time schedule stated in your authorisation from the DNBC Steering Committee and the Danish Data Protection Agency, DDPA. If you need to extend your access period, it is your responsibility to apply for an extension. When your Data Protection permission expires, we will automatically close your account.

Software

Once logged in you have access to a virtual Windows computer. SAS, SAS Enterprise Guide, STATA, SPSS, R, R Studio, MS Office, Notepad++ are available.
The DNBC team does not provide any software support. If you experience any problems with the connection or the server, please consult the VDI Setup manual or contact support at health.it@au.dk.
If you have problems with the data set, please contact the DNBC data management at bsigdata@ph.au.dk.

Data safety

Your data set is put together based on a need-to-know principle, e.g. you will only be given access to the variables that are necessary for your research project as described in the approved protocol. Data must not be passed on to a 3rd person without permission from the DNBC. Results from the project must not be published in such a way that the registered persons can be identified.

Your data set will include a unique DNBC key number.

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[1] It is possible to carry out a feasibility study without paying the full fee. The preparation of the necessary data for such a study will be charged at our standard hourly rate.

Once working through the VID, you are <u>not</u> permitted to export data or data sets, neither directly nor indirectly. Please see details on repatriation of data on page 4 of this document.

The log will be checked regularly. If we suspect that data has been exported without prior permission, the responsible researcher will be contacted. Unauthorized exports may result in the researcher losing his/her data access privilege.

Please stay updated at all times on the data protection policies applicable:
http://www.au.dk/en/informationsecurity/data-protection/

Own data/external registries
External data, e.g. data collected personally by researchers or data from other registries, may be uploaded to the VDI server for use in a DNBC project.

Such a data set should be uploaded securely – please ask the DNBC data manager for an upload guide. Data must include the necessary identifiers (Danish civil registry numbers or the like).

External data must comply with the same rules of discretion as DNBC data, i.e. open personal identifiers are not to be stored on our server. Once linked to the DNBC data, the open personal identifier will be removed from external data.

The DNBC accepts external data in SAS or STATA formats, unless otherwise agreed with the DNBC data managers.

External data not destined to be incorporated into the DNBC database must be covered by a Data Processor Agreement.

The handling of external data will be charged at our standard hourly rate.

Laboratory data and derived variables must be returned to the DNBC
If DNBC derived variables are considered to be of potential value to other researchers, the variables should be documented and returned to the DNBC or the algorithm used may be made available on the DNBC website (contact the DNBC secretariat at dnbc-research@ssi.dk)

If you work with biological material, laboratory results from bio-samples must always be returned to the DNBC databank. The index file that links the results to DNBC background data will not be handed over to the researcher before the laboratory results have been received.

Incorporation of external data, laboratory data and derived variables
When a project comes to an end, data may be stored at the Danish Data Archive or with the DNBC (for a limited period and additional charge).

External data collected by researchers may be incorporated into the DNBC database and be made available for other researchers if data is considered valuable and covers a large subgroup of the cohort population. For this purpose, the researcher who collected the data and the DNBC must apply for permission (videregivelsestilladelse) from the Danish Data Protection Agency, DDPA. If an external data set or laboratory data is incorporated, the quality and the status of data documentation of the variables are not the responsibility of the DNBC.

If you have used a complicated algorithm to generate a certain variable and this work could be useful for others we expect you to put this algorithm on the DNBC website (contact the DNBC secretariat at dnbc-research@ssi.dk)

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NOTE – RULES on DATA REPATRIATION from VDI

You are NOT allowed to:
- save data to other locations than your CryptShare
- e-mail, upload or transfer data from the VDI
- copy, cut or paste data from VDI
- print, make screen dumps or take photos of the screen
- make hand copies of data from the screen
- take out any microdata - like rows, cell- or key values

Data repatriations MUST be checked and allowed by:
- Niels-Søren Bøgh nsb@ph.au.dk
- Niels Henrik Bruun nhbr@ph.au.dk
- Lone Fredslund (BSIG data) lf@ph.au.dk

Data can leave the system in aggregated form ONLY if there is:
- at least the average of 5 persons
- no min, max, medias or percentiles
- no significant points in plots
- no micro data in axis in plots
- no missing values below at least 5 missing values per variable

Put data for repatriations in the folder:
..\hjemtagning\<Date (yyyy_MM_dd)>\<your files>

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Please print, fill in, scan and return this page to the DNBC Data Manager at
bsigdata@ph.au.dk

I hereby confirm that I have read, understood, and agree to adhere to the above mentioned rules for working with data on the DNBC VDI server at Aarhus University in connection with my DNBC project.

Project number:	I **2** I **0** I I I - I I I (yyyy-xx)
Project title:	
My name (printed):	
Project responsibility:	(Name of the "dataansvarlige" – the person who is responsible for the project. It may be you, but it may also be the person you work for)
I am:	□ a researcher □ a Phd-student □ a Master student/specialestuderende □ a "forskningsårs"-studerende □ Other: _____
I am affiliated with (name of institution):	
(for students): My advisor/vejleder is (name):	
Collaborator(s):	
Date:	I **2** I **0** I I I I I I I (yyyy/mm/dd/)
Signature:	

Please stay updated at all times on the data protection policies applicable:
http://www.au.dk/en/informationsecurity/data-protection/