

# Guidance in applying for data from Statistics Denmark (DST) within the auspices of Heart.dk.

First rule when applying for data from DST for a project within the auspices of Heart.dk, **ALL** communication with DST **MUST** be initiated through one of the administrators of Heart.dk which are the ones who manage the project database at DST. However, each individual researcher must design the application and all required documentation as shown in the instructions below. For any further questions, the researcher is asked to contact his/ her supervisor.

Application for DST depends on what is updated in the various project folders in the Heart.dk auspices at DST. Below is a description of what the researcher should describe in connection with the update of the project folder and then submit this to the administrators of the Heart.dk project database. There are also help links which can be used to formulate the description and to gain insight into what data is available through DST.

The links below give the individual researcher access to see what data is available under the various project folders under Heart.dk. There are also some folders with different instructions for how to work within Heart.dk. You can also get a copy of these folders with "Git". If you are familiar with "Git" you can use your regular program to clone with "<https://github.com/ctpteam/dst>"

If you are not familiar with "Git", the following is suggested:

1. Install R and Rstudio
2. Install "Git"
3. Open Rstudio
4. Select "new project"
5. Select "Version Control"
6. Select "Git". Repository must be filled in with "https://www.github.com/ctpteam/dst" and the bottom window is filled with the location on your PC where you want the folder with the information stored.
7. After completing the points above, you can periodically open Rstudio with the project and press "Pull" under the "Git" path to get everything updated.

Once you have accessed the contents of the various project folders through GitHub, you can examine which project folder contains most, if not all, of the data you need to carry out your project. However, should any updates be missing in the project folder that are appropriate for your project, follow the instructions below and complete the steps that fit with the update you desire for the project folder.

## Updating data in the project folder

If a researcher wants to update a project folder register data in relation to time, the researcher must provide a description of why this is necessary in relation to completing the research project. The researcher **MUST ALWAYS** examine how long the individual registers are updated and which is the latest version, this is done by first examining the setup file in the project folder, which can be found under the following path:

X:\Data\Rawdata\_hurtig\70+THE 4 NUMBERS GIVEN ON THE PROJECT FOLDER<sup>1</sup>

Below is a link to an overview of the registers and variables that can be applied for from DST, and by clicking on the different registers it can be seen when the individual register is updated to:

<http://www.dst.dk/extranet/forskningvariabellister/Oversigt%20over%20registre.html>

If the update of the project folder is an addition of additional variables and registers, the researcher must first examine whether they are already available in Heart.dk's project database (project folder 3573). In case that the data already exists in 3573, the researcher must provide a brief description (a few lines) of why the individual variables and registers are necessary for the completion of the research project.

However, if the desired variables and registers are not found, these must first be applied for in the Heart.dk's project database (project folder 3573), and then moved to the individual project folders under Heart.dk. However, this requires that the researcher submit a brief explanation (a few lines) as to why the individual variables and registers are necessary for the completion of the research project and submit these to the administrators of the Heart.dk project database.

Lastly the researcher who wants something updated must send an e-mail to the rest of the researcher on the given project folder and ask if they want something updated before contacting the project database administrators. An e-mail list of the uses on a given project folder can be found on FSE-BOA.

## Creating a new user

Creating a user on a project folder, whether it is a new or an existing user, requires first and foremost approval from either Christian Torp-Pedersen, Lars Køber, Gunnar Gislason, Henrik Enghusen Poulsen, Emil Fosbøl or Morten Schou. After being approved, the following information must be submitted to the Irene Simsby Weiss (irene.simsby.weiss.01@regionh.dk):

1. Number on the project folder
2. Researcher's name
3. Researcher's email address
4. Ident: on the researcher or an announcement for a new user creation
5. Mobile number
6. Name of the person who approved

Finally, it must also be stated whether the researcher should have repatriation rights, which also requires an approval of one of the seniors.

## Regarding access and login procedure

General access is described in the manuals that can be downloaded from:

<https://www.dst.dk/da> and <https://www.dst.dk/da/TilSalg/Forskningsservice/brug-af-forskermaskiner>

When you receive a password from DST, the email says "Server: SRVFSEGH1" but you can log in to any of the five servers. However, number one is closed.

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<sup>1</sup> The same 4 numbers to be written after ident when logging on to the server

Passwords may **NEVER** be shared. All habits from daily clinical practice needs to be forgotten in relation to DST.

## How to work under the project folders

In order to achieve the best research environment, with the most optimal driving time, ALL researchers must follow the instructions below regarding which hard disk; programs, temporary datasets, figures, tables, etc. should be stored on:

1. All researchers must store everything they generate on the F-drive
2. All researchers create a personal folder with their full name under the following path:
3. Z:\Data\Workdata\70+THE 4 NUMBERS GIVEN ON THE PROJECT FOLDER<sup>1</sup>\THE RESEARCHERS FULL NAME
4. After creating the researcher's "personal folder" under point 3, it is recommended that everyone create 3 folders under the personal folder with the following names: output (for tables and figures), data and program.
5. Even better the user may use the R-program `heaven::createProject("name")` to define default project folders
6. Similarly, the researcher must create a folder to be named with the email address that the individual researcher wants to repatriate to, the folder must be created under the following path:  
Z:\Data\Workdata\70+THE 4 NUMBERS GIVEN ON THE PROJECT FOLDER<sup>1</sup>\EMAIL ADRESS

## Export of data from project folders outside DST

In connection with export from one of the project folders, the elements that are exported must **ALWAYS** be looked through by at least two researchers, one of whom is the researcher him or herself and the other must be one with export rights on the individual project folder. The list of people who have export rights from the various project folders can be found under the folder "Persons with export rights" which the researcher has obtained through Git.

One of the safeguards against illicit exports is a requirement that the data to be exported must be placed in a folder named with the exporters e-mail address and placed under "EMAIL" on the Z-drive in the project.

The procedure **MUST** be complied to ensure that items containing microdata are not repatriated. In the worst case, it can cause **ALL** within Heart.dk to be logged out of DST for months. Below is a link to DST repatriation guidelines that **MUST** be read by **ALL** researchers:

<https://www.dst.dk/da/TilSalg/Forskningsservice/hjemtagelse-af-analyseresultater>

Always remember to forward the path to which the elements to be exported are located to the persons who are to examine and export the desired elements to the researcher.

## Moving codes between project folders

If a researcher has access to several project folders within Heart.dk, it is possible to have program/code pieces transferred between the project folders. However, it requires that they only contain codes and no

microdata and personal data. This means that before requesting a transfer from one of the Heart.dk project database administrators, the program must be checked by the researcher and the associated supervisor. After the program has been examined, the following information must be submitted to the administrators of the Heart.dk project database:

1. The path the program is to be moved from
2. The path where the program is to be moved to
3. The names of the researchers who have checked the program

The personnel at DST do not see the same drive letters as the users, and DST therefore requests that these requests are performed on the Z-drive

## Uploading external datasets to a given project folder

If a researcher needs to have external/ own datasets transferred to a project folder, the researcher is to upload the dataset/ datasets through the DST upload solution, which is located at the same location where you choose server on remote.dk. In addition, the researcher must submit the following information to the Heart.dk project database administrators:

1. Researchers ident
2. The date of when the data was uploaded
3. Name of the dataset/datasets
4. State which variables are to be encrypted by DST
5. State if the dataset/datasets contains free text fields
6. A brief description of what the datasets contain and why the data can be used to answer the purpose of the project folder. The purpose of each project folder is found in the approval under the various project folders that researchers have obtained through Git
7. Submit the relevant approvals in relation to the researcher's permission to use this external data
8. Submit a summary of the variables in the dataset/datasets
9. Finally, the researcher must confirm that he/she agrees to pay the expenses that come in connection with the addition of the dataset/datasets to the project folder. In this context, the researcher must provide information on where the bill should be sent to and the information on the invoice. As a minimum, the researcher must submit a GLN/EAN number, project account number as well as phone number, email address and name of the person who administered the project account.

Below are two links to more information about encryption and free text fields as well as a direct guide to how the actual transfer of data through the DST upload solution is made.

[https://www.dst.dk/-/media/Kontorer/13-Forskning-og-Metode/Eksterne\\_data\\_til\\_FSE\\_2019\\_Endelig.pdf?la=da](https://www.dst.dk/-/media/Kontorer/13-Forskning-og-Metode/Eksterne_data_til_FSE_2019_Endelig.pdf?la=da)

<https://www.dst.dk/ext/3942639397/0/forskning/Vejledning-til-upload-af-data--pdf>

## Addition of registers handled by the Danish Health Data Authority (Sundhedsdatastyrelsen - SDS)

If a researcher wishes to transfer some of the registers maintained by SDS or have additionally drugs/medicines added to a project folder, the researcher must follow the instructions found under the folder "Guidelines the Danish Health Data Authority (SDS) ". The researcher must be aware of having to pay for the costs that may arise in connection with the transfer of registers from SDS to DST. In addition to submitting the required documents as stated in the instructions to the Heart.dk project database administrators, the researcher must also provide confirmation that the researcher agrees to pay the expenses that may be associated with the transfer of the dataset/ datasets to the project folder.

In this context, the researcher must provide information about where the bill should be sent to and the information on the invoice. As a minimum, the researcher must submit a GLN/EAN number, project account number as well as phone number, email address and name of the person who administered the project account.

## Resetting a password

If a researcher has forgotten his password, it is possible to reset it. This is done in the same place as you choose server at remote.dk.

Click on the icon "Forgot Password" and a list of the project folders that the researcher has access to will appear, then click on the icon "Reset" and after a few minutes you will receive a new password on the associated e-mail address (i.e., the email address sent to DST in connection with researcher creation).

Below is a link to DST's own direct password reset guide:

<https://www.dst.dk/ext/9079468459/0/forskning/How-to-reset-your-password--pdf>

## Changing a password

Every three months, the researcher must change the password to the various project folders which researcher has access to before they expire. This is done in the same place as you choose server at remote.dk. Click on the icon "Change Password" and a new window will open where the researcher has to enter Domain/username (dstfse/ident<sup>1</sup>), current password and a new password.

Below is a link to DST's own direct password reset guide:

<https://www.dst.dk/ext/4136068151/0/forskning/How-to-change-your-password--pdf>

If a researcher fails to change the password before it expires, the researcher can use the reset password function instead as described above.

## Annual survey

We are obligated to check the users' need of access to data. This is done annually through a survey. Access to prescription medicine data? (LMDB) require an employment contract in a hospital, a university or in a

Patient Association. If you do not have an employment contract or if you fail to fill in the survey prior to the deadline, your access to DST will be closed.

## Approvals of the various project folders

Under each project folder is the individual approval of the project folder, which is notified through the Knowledge Center for Data Reviews in the Capital Region. Approval numbers appear in an approval letter and should normally appear under the section "Ethics" in an article.

Below is a suggestion for this section:

For this type of study informed consent or ethical approval are not required. In Denmark register-based studies that are conducted for the sole purpose of statistics and scientific research do not require ethical approval or informed consent by law. However, the study is registered and approved by the data responsible institute (Region Hovedstaden (Approval number: P-2019-XXX) in accordance with the General Data Protection Regulation (GDPR).

Best regards

The administrators of the Heart.dk project database