KØBENHAVNS UNIVERSITET

INSTITUT FOR FOLKESUNDHEDSVIDENSKAB

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Terms and conditions for the Public Health Database (FSD)

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Please note that there is a Danish version of this document. Should there be any discrepancies between the two, it is the Danish one that is the most up to date.

1. Database description

The Public Health Database (Folkesundhedsdatabasen/FSD) is a database linking a number of registers with data on each person living in Denmark since 1980 and onwards. The database is a shared infrastructure at the Institute of Public Health (Institut for Folkesundhedsvidenskab/IFSV) and the Research Unit for General Practice in Copenhagen (Forskersenheden/Research Unit) and is the data foundation for register-based studies. The goal behind the database is to investigate the health of the population, including determinants and consequences of diseases. It is possible to study both frequent and rare health conditions, as well as to look at the health condition of the entire population and the conditions of special subgroups, e.g. socioeconomic groups and immigrants. In addition, FSD aims to contribute to the development of new methods to describe the health of the population and to investigate the connection between determinants and health outcomes.

FSD has been created as a project database (project number: 704615) under the Research Scheme at Statistics Denmark (Danmarks Statistik/DST) and is located at DST on its own hosted server. In addition to register data, external data such as survey data and/or cohorts from research projects based at IFSV and other institutes are included. All projects under FSD must be reported by the project manager to the University of Copenhagen's (KU) register of personal data processing via PROJECT LIKE MINE.

FSD's secretariat is responsible for the day-to-day operations of FSD, including data management, documentation, coordination, data security courses and finances. The secretariat consists of a chair, vice chair, a secretary and 3-4 data managers.

IFSV's Head of Department together with the authorization responsible officer approves new projects and bigger updates with content change in the Purpose or Description of the project. The Head of Department and the authorization responsible officer approve FSD's internal data security rules.
Other discussions regarding, for example, finances and procedures for the database, can also take place with the head of department, and the person responsible for authorization. In addition, an expert group is associated with the FSD (Appendix D), which can advise the secretariat if necessary. In general questions and in cases of doubt, it is the department management that makes the final decisions.

2. Access to the database

Researchers who wish to set up a project in FSD need to contact the secretariat (FSD@sund.ku.dk) with a short project description. After this, a meeting with one of FSD's data managers may be arranged. The

project must fill in a special application form (the mini-protocol) and indicate the desired registers and variables in FSD's variable template. The mini-protocol and variable template can be found at N:\SUN-IFSV-FSD.
In Appendix A, the application and approval procedure are described in more detail.

In general, possible users of FSD are limited to:

- Students enrolled or researchers employed at IFSV and/or the Research Unit
- External researchers who participate in projects in collaboration with employees at IFSV and/or the Research Unit, and expert group members for the external cohorts that are included in FSD and who use FSD's data, including surveys and other external data that are part of FSD

The project manager must be employed at IFSV or the Research Unit. In addition, the project manager must be at associate professor or professor level or have a permanent employment contract at KU(cf. the rules for project managers on the Common Directory/Fællesfortegnelsen of KU).
To ensure that new users of the database comply with good data practice, the following rules apply to students and new/external researchers:

1. The researcher must complete a data security course offered by IFSV at Absalon. In addition, one must be certified annually by DST through DDV (Dansk Data Vindue) in order to access his/her project(s).

2. The researcher must be physically present at IFSV or the Research Unit when data is accessed for the first time. New and/or external researchers must physically be present at IFSV or the Research Unit for a minimum of 5 days in total, after which the researcher, if the secretariat finds it responsible, can "take his/her access home" to his/her own institution or home workplace. If the researcher is an experienced user of DST, they can be given a dispensation and have the number of days required to be present at either IFSV or the Research unit reduced. However, the researcher must always meet in person with either an experienced user or a data manager from the department. Dispensation can therefore never result in the user being completely exempt from physical attendance but will always be required to be present for at least one day.

3. Access to the server depends on which country you are in:

a. Denmark: You can immediately log in to DST from your computer and work as long as you comply with DST's rules on working at your workplace or home workplace
b. EU + EEA incl. UK: You must log in to the KU VPN before you can log in to DST. It is possible to use a computer that is not owned by KU
c. Other countries, e.g. USA: You may only log in from a KU computer and you must be employed/paid by KU

4. Access to the projects, when the administrative arrangements are in place.

a. The first time you log in to the projects, you do so in the company of a Datamanager or experienced register project user.
b. Instructions for accessing FSD's hosted server can be found on DST's website (Windows users).

Denmark's Data Window

Denmark's Data Window (DDV) is an application created by DST, which is used for the administration of research projects. In DDV, users can be associated with authorized institutions as well as projects created under the institutions.
DDV is used for creating new projects (ordering data), resetting existing projects (updating/expanding data and/or population), and approving and signing project settings. In addition, DDV can be used for uploading attachments, such as documentation of external data or detailed population descriptions, and downloading analysis results after they have been retrieved.
DDV is accessed via https://remote.dst.dk/ with your own DST ident and password, where it appears as a separate tab, just like FSE-upload, the research machine and FSD's hosted server "srvfsesundku2". You can read more about DDV here and find instructions here.

3. Guest researcher agreement and data processing agreement

It is the project manager's responsibility to ensure that the relevant agreements are in place with external researchers in the project group (e.g. guest researcher agreements and data processing agreements). The project manager must confirm to the FSD secretariat that the agreements have been concluded before access to the project folder on DST can be granted.
Upon termination of employment of UCPH employees and/or employment at the Research Unit (e.g. upon submission of a PhD thesis or upon change of job), a guest researcher agreement and a data processing agreement must also be signed if the researcher is to continue to have access to FSD.
Students at UCPH are also covered by the requirement for a guest researcher agreement and a data processing agreement.
The secretariat may close access to data at any time if the above agreements on employment and/or affiliation with UCPH do not comply with the described rules, but it is the project manager's responsibility to ensure that this is in order. Agreements can be found here and here.

4. Data security

All work with data must take place in accordance with applicable register legislation and DST's rules for **data security.** If DST's security rules are not followed, the **sanctions are significant:** It will usually

entail DST closing all access to FSD for a defined period of time. During this period, every FSD researcher will be excluded from accessing their project in the database. In case of repeated data security breaches, the sanctions are increased. It is the project manager's responsibility to ensure that the entire project group is familiar with the rules for data security when working on FSD's server at DST. The rules and recommendations below apply to authorized researchers working on FSD:

1. All new researchers who are to be associated with FSD projects must complete a data security course at FSD before getting access to the database. Project managers must also take the above course, even if they will not be authorized researchers on the project (applies to projects created after 31. January 2022).

2. It is not allowed to write notes off the screen or take screenshots. All results must go through DST's data extraction ("home sending") system.

3. IDs and passwords are personal and must not, under any circumstance, be lent to others. Violation of this rule results in the immediate revoke of access for every researcher at FSD for three months.

4. In case of a data security breach, DST and FSD's secretariat must be notified immediately. If it is DST who discovers a violation and notifies the researcher, the researcher must inform FSD. Everyone from the project group who has been involved in the breach must subsequently attend a data security course. If those involved do not participate in the first available data security course after the breach, the secretariat can temporarily close access to all the projects the parties involved have access to, until a data security course has been completed. The secretariat can close access to projects at any time if deemed necessary.

5. Deliberate or repeated breaches of data security rules will lead to exclusion from FSD and DST.

Extracting results via an FSD datamanager

1. When extracting data, results must be in a form suited for immediate publication. Output must be limited to what is relevant and necessary.

2. When extracting data, the researchers must specify how many files are involved, how many sheets there are in each Excel file and how many tables are in each sheet. The N number must also be clearly stated for each cell in the tables that are to be extracted.

3. In the case of larger and more labor-intensive material, the FSD data manager may require guidance from the project's researchers during the retrieval.

4. For projects with more than one researcher, a colleague (an authorized researcher with access to the same project) should check all files before submission

5. Data extraction must be ordered well in advance: at least a week in advance so that the FSD data manager is prepared and has time for the task.

The FSD secretariat recommends that researchers with data extraction rights follow the same procedures.

Researchers on FSD projects must – in addition to complying with the rules described in this document – familiarize themselves with and comply with other sets of rules that may apply at the institute, department or unit where the researcher is employed.

Note that the rules at DST are more restrictive than the current legislation.

5. Data extraction (home sending) permit

Data extraction permission can only be granted to employees of IFSV (Department of Public Health) and the Research Unit. However, an exemption for continued repatriation permission can be granted for emeritus researchers.

Authorized researchers without extraction permission can apply to the FSD secretariat for obtaining it. The researcher must be able to document having created files for extraction without comments from the person doing the extraction minimum 5 times up to the time of application. The FSD secretariat decides at a secretariat meeting whether data extraction permission can be granted.

A researcher loses their right to extraction if they transfer to a new position and is thus no longer employed at IFSV and/or the Research Unit. The right to extraction is transferred to a project participant who is employed at IFSV and/or the Research Unit, is part of the project group on the project in question and who has been approved by the secretariat as a data extractor. If this is not possible, the extraction is handled by an FSD data manager. In special cases, an exemption for continued repatriation permission can be granted for external researchers.

In case of longer absences or change of positions, the FSD secretariat will evaluate if the extraction permit is to be revoked.

6. Newsletter

The FSD secretariat prepares information letters that are sent out to the database's users when necessary. The information letters contain important information such as registry and other updates on the operation of the database. Users are expected to read these.

FSD also informs project managers about which authorized researchers have access to the project(s) they are responsible for. It is important that all researchers who have access to data have permission

to do so, the right agreements are in place and that there is a specific need for being able to access data.

7. Price policy for FSD projects

All new FSD projects are charged an amount depending on project-size for establishing the project and subsequently, an annual amount, for disk rent. The total amount paid for project creation in FSD goes to depreciation of the server, purchase of new disks, power, maintenance at DST, purchase of data from DST and the Health Data Agency (Sundhedsdatastyrelsen/SDS) as well as salary for the secretary of the FSD secretariat.
The amount does not cover the salary for the FSD data manager, whose task only involves helping to define the project's variable selection, extraction year and population limits.

Project size-dependent setup price:
The prices below can be changed if necessary, by the secretariat, after approval by the head of department. All prices when contacting the secretariat are indicative and it will always be the actual price for data extraction and invoicing that the projects must pay. The secretariat is not obliged to send out notifications of minor price increases, which for example. occur due to inflation or to follow the price increases of data boards e.g. Statistics Denmark. However, major price increases are notified so that the projects have the opportunity to reconsider before starting or updating. Projects will be encouraged at all times to apply for more funding than the estimated price given by the secretariat, to take into account any possible price increases.

Creation price depending on project size:
Calculation of estimated size:
A = Number of DST register variables (Dream counts in total for 1 variable)
B = Number of years (Last year minus the first year desired, regardless of whether each register exists for each year or not). Years before 1980 are disregarded, years that are not yet available are disregarded, and cumulative files (e.g. the Cause of Death Register/ Dødsårsagsregisteret) only count for the extraction year, although they may go way back in time.
C = Expected population size in thousands – if it is difficult to calculate, the FSD data manager can help.

Estimated size= (A*B*C) /100

Estimated size	Price group	Price for creation	Yearly disk rent
0-499	1	30.000 kr.	4.000 kr.
0-499 + particularly work-heavy tasks	1+	40.000 kr.	4.000 kr.
500-49.999	2	40.000 kr.	6.000 kr.

50.000+	3	50.000 kr.	8.000 kr.
		+ 2.000 kr. for LMDB* (all expenses to SDS (Sundhedsdatastyrelsen) are paid by the project)	
		+11.000 kr for STATA licence	

* Lægemiddeldatabasen = Medicine Database ** National Patient Register

Particularly work-intensive tasks for the FSD data managers can result in transferring to a higher price group. However, this only applies to setting up within the lowest price group. Work-intensive tasks can be e.g. a complex population extraction, addition of external dataset, purchase of new registers or need for SDS applications. Whether the creation is particularly work-intensive is assessed by the associated FSD data manager before the mini-protocol is forwarded to the steering committee for approval.
Project members can estimate the price themselves, but the final price is set by an FSD data manager. If the project's actual size after creation turns out to be smaller than estimated and thus falls into a lower price group, the price can be adjusted, based on an overall assessment by the FSD data manager.

Project price in subsequent years:
There is a set price for disk rental, regardless of whether data are used or not. This is size dependent - see the table above. Putting projects on hold is not possible.

Medicine data:
It costs DKK 2,000 kr. to order medicine data for a new project due to costs associated with FSD consulting on SDS applications, data extracts by FSD, as well as service and transfer fees at DST, including data checking. All expenses to SDS in relation with application handling are paid by the project.
For updates, a surcharge of DKK 2,000 is also paid for new LMDB approval to cover advice from FSD and costs for DST.

LPR3:
It costs DKK 5,000 to order LPR3

Updating projects:
An update of a project can be the addition of an extra year to existing registers, or the addition of new variables or registers.

The price depends on the size of the update, i.e. whether it involves changing the purpose of the project, how many registers have to be updated, how many years, etc. You can calculate an estimate via the price calculation excel sheet which can be found on N:\SUN-IFSV-FSD.

Softwares not included in KU's campus agreement:

STATA license: 10 000 kr. per project when it is created.
STAT can only be used in projects that have purchased a license.

Installing additional modules for R, SAS, Python or STATA:

Additional modules / packages can be installed free of charge on the two annual installation days. If you cannot wait until the next installation day, and the installation is approved by the FSD Secretariat, it can be done at your own expense outside of these days. In any case, you must contact an FSD data manager to install new data on the server. To DST, FSD pays wages per started hour.
As a rule, other statistical softwares cannot be approved.

Appendices

Appendix A. Guide for FSD projects

All documents are found here.

Creating a new project in FSD

1. Write to FSD@sund.ku.dk to inform them that you have a project coming up. Then, if necessary, schedule a meeting with an FSD data manager.
2. Remember to register for DST's or FSD's **course on data security**. All new researchers must attend a course before they can gain access to FSD.
3. Complete the mini protocol. Use the latest template at N:\SUN-IFSV-FSD and remember to **review and complete the checklist** (4th tab in the mini protocol).
4. Fill out the variable list, use the latest template at N:\SUN-IFSV-FSD. See available registers and variables in the file Variabelliste_DST. Use the control field and decide what to do with variables that do not exist in FSD. Make sure the years match exactly, as there are data discontinuities in some variables.
5. Send the mini-protocol and the variable list to FSD@sund.ku.dk.
6. When the mini-protocol and the list of variables are deemed to be sufficiently thorough, the secretariat sends the project to the steering committee for approval.
7. When the project has been approved by the steering committee, the secretariat sends the mini protocol to the project manager for their signature on the cooperation agreement.
8. The agreement is sent back to FSD (FSD@sund.ku.dk), which then obtains the signature from FSD's chairman.
9. After the approval of the steering committee, the project must be reported to the register of personal data processing at KU via PROJECT LIKE MINE.
10. The FSD data manager submits the project to Statistics Denmark (DST) and receives a project number. In case the project needs data from the Health Data Authority (SDS), an application must be submitted to them.
11. After DST approved the project proposal, it must be signed by the project manager, scanned and returned to DST.
12. When all permissions have been received, the associated FSD data manager can pull data for the project. Note that there may be a waiting time.
13. When the data is delivered, an invoice is sent to the project.
14. **Within four weeks after data delivery, the project must check that the ordered data sets have been well received.**

Authorization of a researcher

1. For a new researcher to be authorized, the person is required to complete the data security course. Therefore, contact someone in the FSD secretariat if you want to add a new researcher to the project.

2. The FSD secretariat will then request at DST that the person be associated as an authorized researcher to the respective project.

3. DST orders user and affiliation agreements for the researcher.

4. Rikke Lund (authorization officer) or the deputy approves the affiliation agreement and one of FSD's administrators will then set up the researcher's access in DDV.

5. The researcher receives an email from DDV stating that the affiliation agreement has been approved and including instructions on how the **researcher must approve the user agreement themselves.** The researcher receives access information and instructions for logging on to DST in a separate email.

Appendix B. Data from the Health Data Authority (Sundhedsdatastyrelsen /SDS)

If the project needs data from the Danish Health Data Authority (SDS), it can be added to the project. FSD must approve the project and association of the requested data from SDS before applying for data from SDS. In order to submit the application, the following must be ready:

- Project description
- Extract description
- Approval of the project from the data responsible institution (KU-SUND)
- Project number and contact person at DST

It is important to read the instructions for the project and extract description on SDS's website.

Reusing data from SDS
FSD contains copies of a number of SDS registers. In the file Variabelliste_SDS in the folder N:\SUN-IFSV-FSD there is an overview of them. There is also information on which populations the individual files are based on, as well as on which project the file was purchased for. Please note that some of the files may be of an older date and therefore are not necessarily up to date.

It is possible to reuse data from SDS, which is already available as copies either on FSD or on projects under FSD. To reuse data, do the following:
First of all, it must be approved by FSD that data is linked to the project
If data is owned by a specific project and not the main database, approval must be obtained from the project manager on the project. Reusing of data must be approved by KU-SUND. Use this template.
Whether an application has to be submitted to SDS for reusing or not, depends on the following:

- When reusing data owned by FSD, you must apply to SDS for permission to reuse data in your project.
- When reusing data owned by a project under FSD, you do not need to apply to SDS for permission to reuse data on your project.

In the register overview in Appendix C, you can see which SDS registers are owned FSD. There is help with the required attachments here.

Medicine data on DST
Medicine data is on the DST, but to use it, permission is needed from SDS.
There are more attachments and requirements for this application than for other data reusing. See guidelines here.

Purchasing new data from the Danish Health Data Authority (SDS)
In order for us to coordinate the purchase of new data, please inform your FSD data manager if you wish to purchase new data extracts from SDS.

If data is of general interest for several projects in FSD, the secretariat can decide that FSD pays for the purchase of data for the project. That is on the condition that permission is granted for data reuse in future projects in FSD.
It requires roughly the same attachments as data reusing, see here.

If you need to apply for several things, you can apply for both reusing / medicines and the purchase of new data in the same application.

Appendix C. Registers and cohorts in FSD

The newest version of the list of available registers and variables from DST are found here.

External data from the Danish Health Data Authority (SDS/Sundhedsdatastyrelsen)

- Cancerregisteret (CAR)
- Det Psykiatriske Centrale Forskningsregister (PSYK)
- Det Nationale Diabetesregister (NDR)
- Det Medicinske Fødselsregister (MFR)
- Register over stofmisbrugere i behandling (SIB)
- Det Nationale Alkoholbehandlingsregister (NAB)
- Yderregisteret (YDR) *)
- Abortregisteret (ABORT)
- IVF registeret (IVF)
- Sessionsregister

External data from the State's Archives which are administered under the archive law

- Multigenerationsregistret (MGR-lite)

Other external datasets (incl. surveys and biomarkers)

- The Metropolit Study (Metropolit kohorten)
- Copenhagen Aging and Midlife Biobank (CAMB)
- Danish Longitudinal Study on Work, Unemployment and Health, DALWUH (Marginaliseringsprojektet)
- Social Inequality in Cancer (SIC)
- The Copenhagen Primary Care Laboratory Database (COPLAB)
- The Danish Conscription Database (DCD)
- Survey of Health, Ageing and Retirement in Europe (SHARE) data for Danmark ("REGLINK-SHAREDK")
- Rigshospitalets Mor-Barn Kohorte
  The Copenhagen Multi-centre Psychosocial Infertility cohort (COMPI)
- The Well-being in HospitAL Employees study (WHALE)
- Den Landsdækkende Undersøgelse af Patientoplevelser (LUP)
- Bedre sundhed i generationer (BSIG)
- Sessionsregister fra Værnepligtsektionen ved Forsvarets personalestyrelse.
- Obligatoriske nationale test (Undervisningsministeriet)
- Ældredatabasen

*) The register is in FSD and therefore, if data are to be reused, an application must be sent to SDS.

Appendix D. Public Health Database Experts Group

Chair Stine Kjær Urhøj
Department for Epidemiology, IFSV, KU

Professor and vice-chair Christen Lykkegaard Andersen
Research Unit for General Practitioners, KU

Datamanager Charlotte Ørsted Hougaard
Department for Social Medicine, IFSV, KU

Datamanager Drude Molbo
Department for Social Medicine, IFSV, KU

Datamanager Dora Kovacs
The Copenhagen Health Complexity Center, IFSV, KU

Datamanager Mark Meisner Jensen
Department for Social Medicine/Research Unit for General Practice and Department for Epidemiology, IFSV, KU

Professor Theis Lange
Head of Institute, IFSV, KU

Professor Rikke Lund
Authorisation Responsible, Head of Department, Department for Social Medicine, IFSV, KU

Professor Naja Hulvej Rod
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Professor Marie Louise Nørredam
Department for Health Service Research, IFSV, KU

Professor Anne-Marie Nybo Andersen
Department for Epidemiology, IFSV, KU

Public Health Database Secretary
Bodil Marie Holst
Department for Social Medicine, IFSV, KU

Appendix E. Public Health Database Secretariat

In February 2025 the secretariat consists of:

Chair: Stine Kjær Urhøj (stur@sund.ku.dk)

Vice-chair: Christen BL Andersen (christen.andersen@sund.ku.dk)

Secretary: Bodil Marie Holst (bodil.holst@sund.ku.dk)

Datamanagers:
Charlotte Ørsted Hougaard (coho@sund.ku.dk)
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