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## 'Improved diabetes care for patients with type 2 diabetes and schizophrenia: An exploratory study using participatory design'

*A Data Management Plan created using DMPonline*

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### **Project abstract:**

The overall focus of the project is to strengthen the efforts of diabetes care among patients with schizophrenia and diabetes type 2. A large number of patients with schizophrenia simultaneously develop type 2 diabetes. This is attributed, among other things, to patients' lifestyle, reduced disease awareness and side effects to the medical treatment, most often leading to increased appetite and fatigue. On average, patients with schizophrenia live approx. 20 years shorter than the background population, i.a. as a result of the development of type 2 diabetes. Type 2 diabetes is a complex chronic disease that requires special attention for each patient, to delay and / or prevent diabetic complications. Although the link between having schizophrenia and the risk of developing diabetes type 2 is well documented, there is very scant research that is based on patient-centered approaches. The focus of the project will thus help to gain an understanding of the patients' challenges and in collaboration with the patients, help to improve the quality of care and treatment and improve the individual's living conditions. This patient group constitutes a particularly vulnerable group, which is why close cross-sectoral cooperation is needed around coherent processes. The purpose of this project is therefore to uncover current practices, including barriers and needs - and to develop a strengthened intervention for patients with schizophrenia and diabetes type 2 improving the patient's self-care and reducing organizational complexities. The approach is a participatory design consisting of three studies identifying the needs of patients, relatives and healthcare professionals and developing a new intervention in a joint effort.

**Last modified:** 28-10-2020

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## Data Collection

The project design consists of 3 phases or sub-studies. I will collect data systematically as listed below:

Sub-study 1:

Data will be field-notes from field observations and data from individual interviews with patients (15-20) (sound-files) and focus groups with health care professionals (2) (video/sound-files). The created data will be written in word documents and later analyzed qualitatively in NVivo software.

Sub-study 2:

Data will be created by different user activities (3 workshops) and interviews. Data collected during the workshops will be field-notes, artifacts, photos and recording. Also it will be analyzed qualitatively in NVivo software.

Sub-study 3:

The 3rd sub-study is the test and evaluation phase, which will be inspired by feasibility studies. Data will be collected both qualitative and quantitative by individual interviews, focus groups, questionnaires and patient records.

During the field studies I will use a manual logbook i.e. to describe considerations and behaviors and use these data to further develop thoughts and ideas. Also use drawings to illustrate thoughts and considerations and the organisational complexities of care and treatment for patients with schizophrenia and type 2 diabetes.

Transcriptions from individual and focus group interviews, notes from ethnographic field studies and workshops will be structured by the research software NVivo 10. The qualitative data will be stored in Sharepoint and OPEN but not data that include personal informations.

Data from the questionnaires will be analyzed in STATA using descriptive statistics.

Original field- notes from the manual logbook and the original consent statements will be stored in a locked archive at the institution.

## Documentation and Metadata

The metadata will also be stored in Sharepoint.

This could be data from the logbook such as definitions, methods, procedures, publications. This to make sure that data can be reusable.

## Ethics and Legal Compliance

The project will include data with personal informations.

All participants will receive oral and written information about the purpose of the project before informed consent is signed. All participants can withdraw their consent at any time without this affecting their treatment course. All sensitive personal data will be anonymised and stored in accordance with applicable legislation. The project is already registered at the Danish Data Protection Agency and notified to the Committee on Health Research Ethics in the Region of Southern Denmark. The project will be carried out in accordance with the Declaration of Helsinki

My data and software will be released under FAIR licenses. It cannot be completely open because of the amount of qualitative data.

Therefore I will make sure that all kind of data that is protected by the copyrights will be stored in the right platforms.

Also, according to IPR I have the responsibility to ensure that I'm not infringing the copyright by referring properly to avoid misconduct.

## Storage and Backup

The sensitive data stored will be named with a number for patients and a number for health professionals as well as a date.

All data will be stored in Sharepoints 'sikre projektrum' via Regional IT and OPEN.

Any copies of data will be stored on an encrypted flash drive and password secured laptop.

Make sure that only the necessary persons are required access, as my data contains human privacy.

So in relation to my project only my main supervisor and I can view the data due to confidentiality and human integrity. Again, I will use an encrypted flash drive and password secured laptop.

## **Selection and Preservation**

In relation to my funders and workplace i expect to store data and metadata that are of long-term value so that they can be preserved or reused in 10-15 years and made available if possible.

The valuable data will be deposited in "Rigsarkivet" or in Zenodo as well as in the institution at some kind.

## **Data Sharing**

Since I cannot share all qualitative data, I want to share processes, methods, metadata etc. in "Rigsarkivet" or Zenodo and in the institution, so that it becomes visible to other researchers to find and apply for data access.

Restrictions on data sharing is required when data contains subject privacy. My project will contain a lot of personal information as I'm doing a qualitative research in a clinical setting where patients and health care professionals are included. So, I will only share anonymised data and data that cannot be linked to any of the included participants.

## **Responsibilities and Resources**

I am the primary researcher and I'm therefor responsible for the data management. But my main supervisor of the PhD project will also have some insight of the data, why we have clearly defined roles and responsibilities.

I will use existing resources for data storage, such as Sharepoint, NVivo and OPEN and in long-term "Rigsarkivet" or Zenodo and in the institution. This project has a possible digital solution, which is not yet known. But i can be relevant to invite relevant stakeholders of software or/and technical expertise.