Plan Overview

A Data Management Plan created using DeiC DMP

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

Creator: Tanja Juhl Mikkelsen

Principal Investigator: Tanja Juhl Mikkelsen

Data Manager: Tanja Juhl Mikkelsen

Affiliation: Syddansk Universitet / University of Southern Denmark

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ORCID iD: 0000-0002-7218-6567

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.

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Data Collection

What data will you collect or create?

The project design consists of 3 phases or sub-studies. I will collect data systemticly 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 date 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 feasibilty studies. Data will be collected both qualitative and quantitative by individual interviews, forcus groups, questionnaires and patient records.

How will the data be collected or created?

During the field studies I will use a manual logbook i.a. 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 archieve at the institution.

Documentation and Metadata

What documentation and metadata will accompany the data?

The metadata will also be stored i Sharepoint.
This could be data from the logbook such as definitions, methods, procedures, publications. This to make sure that data can be resuable.

Ethics and Legal Compliance

How will you manage any ethical issues?

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

How will you manage copyright and Intellectual Property Rights (IPR) issues?

My data and software will be released under FAIR licenses. It cannot be completely open because of the ammount 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 reffering properly to avoid misconduction.

Storage and Backup

How will the data be stored and backed up during the research?

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.

How will you manage access and security?

Make sure that only the nessecary persons are required acess, 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

Which data are of long-term value and should be retained, shared, and/or preserved?

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.

What is the long-term preservation plan for the dataset?

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

Data Sharing

How will you share the data?

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.

Are any restrictions on data sharing required?

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 researh 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 includede participants.

Responsibilities and Resources

Who will be responsible for data management?

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 date,
why we have clearly defined roles and responsibilities.

What resources will you require to deliver your plan?

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.