Plan Overview

A Data Management Plan created using DMPonline

Title: The nursing telecoach: description and evaluation of a new function

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Project abstract:

General background research project

Since 2023, the Digital Health Centre (Digitaal Gezondheidscentrum, DGC) has supported people living with chronic illnesses through an integrated model that connects healthcare and the social domain. The DGC is a regional collaboration between the Red Cross Hospital (RKZ), Heliomare, General Practitioners Midden and Zuid Kennemerland, ViVa! Zorggroep, and the municipalities of Beverwijk, Heemskerk and Velsen. By the end of 2024, more than 1,500 patients with various chronic conditions had received care through the DGC. The model is built on three core pillars: telemonitoring, disease management, and prevention, all grounded in the philosophy of positive health. Through digital applications and integrated pathways, the DGC aims to bring care closer to patients, strengthen self-management and enhance collaboration across sectors.

A key function within the DGC is the nurse telecoach, a new professional role who supports patients from the six domains of positive health in understanding their condition, interpreting home measurements and enhancing their self-management skills. Each care pathway developed by a project team consisting of a nurse telecoach, nurse specialist, medical specialist, patient representative and digital innovator, is designed to provide structured, continuous, patient-centred support. By the end of 2024, the DGC included eleven specialised secondary-care pathways.

Moreover, the DGC aligns with the four principles of appropriate (value-based) care. First, the design of each care pathway aims to improve the cost-effectiveness of care while increasing value for patients. Second, the DGC provides patients with timely, reliable and relevant information, thereby enhancing disease insight, supporting self-management and contributing to shared decision-making. Third, frequent home measurements and digital questionnaires allow care to be organised as close to the patient as possible, enabling timely remote contact between patients and healthcare providers. Finally, the nurse telecoach addresses the patient’s overall wellbeing through structured health conversations based on the principles of positive health, bridging the medical and social domains. Accessibility is further enhanced by allowing patients to participate via smartphone, tablet or computer.

Problem Statement

Although the DGC has demonstrated clear benefits, the integrated and low-threshold

approach has also revealed previously under-recognised non-medical challenges such as financial concerns, social problems, and mental health difficulties that significantly influence disease trajectories, especially among patients with low socioeconomic status and limited health literacy. The region expects a 12% to 18% increase in the number of people with chronic diseases in the coming years, highlighting the urgent need to expand the DGC in terms of capacity and the number of care pathways developed.

Despite the rapid growth of the DGC and the role of the nurse telecoach, there is currently no supported insight into the effectiveness, evolution, or implementation of the DGC model and the nurse telecoach role. Additionally, the knowledge existing within the DGC has not yet been described in a structured manner, analysed and widely disseminated. Furthermore, there is no formal training or continuing education program for the nurse telecoach, presenting challenges for broader regional or national implementation. Therefore, the present PhD-research project aims to address these gaps and contribute to the evaluation and scaling up of the DGC.

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1. General features of the project and data collection

1.1 Project leader contact details

Tijn Kool, tijn.kool@radboudumc.nl 06-11531143

1.2 I have composed my DMP with the assistance of a data stewardship (or management) expert. List his or her name, function, organisation/department, phone number and email address.

- The expert is connected to my department or institution (please explain his/hr expertise related to data stewardship)

Mirjam Brullemans-Spansier
Central Data Steward
Technology Center Data Stewardship
Stafdienst Informatie Management
11-02-2026

1.3 In collecting data for my project, I will do the following:

- Generate new data
- Use existing data (please specify)

Clinical, anonomized data from the Electronic Health Record (EHR), patiënt reported data from the Patient Journey App platform (eg PAM questionnaire), app usage statistics from Patient Journey App platform (e.g. app opens, notifications received, information consulted).

1.4 In my research, I will use:

- A combination of quantitative and qualitative data

1.5 I will be reusing or combining existing data, and I have the owner's permission for that.

- Yes, I have permission to use the data

1.6 In collecting new data, I will be collaborating with other parties.

- Yes, the new data will be (partly) provided by a project partner or supplier

1.7 I am a member of a consortium of 2 or more partners. Clear arrangements have been made regarding data management and intellectual property. (also consider the possible effect of changes within the consortium on issues of data management and intellectual property)

- Yes, clear arrangements have been made regarding data management and intellectual property through a consortium agreement

Yes, clear arrangements have been made regarding data management and intellectual property through the ZonMW consortium agreement

1.8 I can give an estimate of the size of the data collection; specifically, the number of participants or subjects (“n=”) in the collection and its size in GB/TB

- Yes (please specify)

(Sub)Project	**Volume, N=**	**Storage space**
1- A review of the perception and experience of nurse-led telecoaching by telemonitoring nurses and patients with chronic diseases in promoting well-being, and which factors influence this process.	N/A	1-10GB
2- Nurse telecoaching in the DGC: a qualitative study of the experiences and perspectives of stakeholders in the DGC	±30 (new data)	1-10GB
3- Evaluation of the DGC: evaluation from the perspective of the patient, the healthcare providers involved, the business operations, and perspective from the healthcare organizations and the social domain in the region.	±1500 patients (existing data) and ± 30 other participants (new data)	1-10GB
4- Development of competency profiles and a matching educational program for nurses with vocational and higher professional education, translated into a blended learning curriculum.	±20 (new data)	1-10 GB

1.9 The following end products I will make available for further research and verification (please elaborate briefly)

- (Several versions of) processed data
- Data documentation
- Syntaxes

Final versions of data used for analysis, questionnaires/interview guides and anonymized processed data will be available for further research.

1.10 During the project, I will have access to sufficient storage capacity and sites, and a backup of my data will be available. (please elaborate briefly)

- Yes, I will make use of my institution's standard facilities for storage and backup of my data

Digital data will be stored on a secure, access-restricted servers of Radboudumc and RKZ. Recordings and transcripts will be stored securely on the server in the RKZ's healthcare innovation folder for 10 years after the study, back-ups will be stored on a secure RKZ hospital’s drive, and will be performed automatically by the RKZ ICT department every 5 hours.

After pseudonymization of the (qualitative and quantitative) data, data processing and analysis will take place in ATLAS.ti and SPSS, which is securely stored within the Radboudumc's DRE.

Moreover, interactive Studios offers a cloud-based platform. In line with ISO27001 and NEN7510, eCRF is stored in Patient Journey App when online/digital informed consent is applicable. Patient Reported (incl. surveys) data is stored in Patient Journey App. Usage data is stored in Patient Journey App. Data will be stored in the cloud, in a fully certified data center of Uniserver in Alkmaar and back-ups are made on a daily basis for a 14-day period. It is confirmed that the data will not leave the European Economic Area.

Furthermore, a digital Subject Identification Log will be stored at RKZ, separately from the research data and securely on the server in the RKZ's healthcare innovation folder.

2. Legislation (including privacy)

2.1 I will be doing research involving human subjects, and I am aware of and compliant with laws and regulations concerning privacy sensitive data.

- The Wet Medisch-Wetenschappelijk Onderzoek met Mensen (WMO, or Medical Research (Human Subjects) Act) does not apply to my project.
- Yes, I will involve human subjects in my research. I will comply with the Algemene Verordening Gegevensbescherming (AVG)

2.2 I will be doing research involving human subjects, and I have (a form of) informed consent from the participants for collecting their data.

- Yes, and this informed consent allows for the reuse of data (note that in the Code of Conduct for Medical Research, ‘reuse’ is also referred to as ‘further use’)

In the informed consent form, participants are informed about the possible reuse of their data for future projects. Participants can indicate in the consent form whether they agree with future reuse or not.

2.3 I will be doing research involving human subjects, and I will protect my data against misuse.

- Yes, the data will be pseudonymised. (please explain how this will be done, and by which organisation)

Prior to analysis, all extracted data will be pseudonymized, we will not have access to directly identifiable personal data and only the required data will be extracted from the Patient Journey App.

Qualitative data collected through interviews and focus groups will be pseudonymized. No names or directly identifiable personal details will be included in transcripts or analysis files, and audio recordings will be stored securely. Each participant will be assigned a unique study code (e.g. USER001).

2.4 I will stick to the privacy regulations of my organisation

- Yes

3. Making data findable

3.1 The data collection of my project will be findable for subsequent research. E.g., on a catalogue, a web portal, or through the search enginge of the repository (note: this is key item 3, which you should report to ZonMw at the end of your project).

- Yes, it can be found through the search engine of the archive or repository in which it is stored (please specify)

The Radboud Data Repository (RDR) will be used to guarantee long-term findability of the research data from this project.

3.2 I will use a metadata scheme for the description of my data collection (note: this is key item 7, which you should report to ZonMw at the end of your project).

- Yes, I will use a generic metadata scheme (please specify)

The RDR makes use of Dublin Core and DataCite metadata items.

3.3 I will be using a persistent identifier as a permanent link to my data collection (note: this is key item 1, which you should report to ZonMw at the end of your project).

- Yes, I will be using a persistent identifier (for instance a DOI code). Please specify which type of persistent identifiers you will use:

A DOI will be assigned to the metadata record of the dataset in the RDR.

4. Making data accessible

4.1 Once the project has ended, my data will be accessible for further research and verification.

- No (please explain)

After the project has ended, the data will not be made accessible. The dataset contains sensitive information from patients as well as operational and financial data from the Rode Kruis Ziekenhuis, which cannot therefore be shared openly.
However, to ensure findability, metadata describing the dataset will be made available and access to (subsets of) the data will be provided upon request by the principal investigator and/or relevant institutional stakeholders.

4.2 Once the project has ended, my data collection will be publicly accessible, without any restrictions (open access).

- No, there will be access restrictions to my data collection (please explain)

The data collection will not be made publicly accessible without restrictions after the project has ended. The dataset has sensitive patient group data, operational and financial information from the Rode Kruis Ziekenhuis. Data will be published/archived under 'closed access' conditions. Access to the data will be provided upon request by the principal investigator and/or relevant institutional stakeholders.

4.3 I have a set of terms of use available to me, which I will use to define the requirements of access to my data collection once the project has ended (please provide a link or persistent identifier; also note that this is a key item 4, which you should report to ZonMw at the conclusion of your project).

- Not yet, my institution will draft a set of terms of use with the help of a legal advisor

4.4 In the terms of use restricting access to my data, I have included at least the following:

- The approval of the participants allows for further research using this data set
- A steering committee, programme committee or project leader will be charged with approving data requests
- The reimbursement of costs, for example in obtaining the data
- The permitted period of use of the data set
- The manner in which the data set can be accessed
- Whether or not the data set may be linked with another data set (for reasons of privacy)
- The sharing of data for commercial purposes, taking into account the provisions of state aid law
- Collaboration in using the data set, including agreements on publication and authorship
- Agreements on methodology
- Conditions related to data security

5. Making data interoperable

5.1 I will select a data format, which will allow other researchers and their computers (machine actionable) to read my data collection (note: this is key item 5, which you should report to ZonMw at the end of your project).

- Yes (please specify)

For this project, the following preferred data format are used which will be usable in the long term:
- Word and other text documents are saved as.PDF files.
- Excel files are saved as .CSV files
- SPSS files (incl Castor export) are saved as .DAT/.SPS (syntax) files.

5.2 I will select a terminology for recording my data (e.g., code, classification, ontology) that allows my dataset to be linked or integrated with other datasets (note: this is key item 6, which you should report to ZonMw at the conclusion of your project).

- Yes, metadata standard (please specify)

Data will be recorded using commonly used standards and terminologies to enable linkage with other datasets.

- Use of standardized variable definitions and coding schemes.
- Use of validated and standardized questionnaires (such as Patient Activation Measure: PAM), and instruments based on the Positive Health framework.
- Use of standard units of measurement.
- Use of standardized codebooks and thematic labels.

5.3 I will be doing research involving human subjects, and I have taken into account the reuse of data and the potential combination with other data sets when taking privacy

protection measurements.

- Yes, the participants have given their permission for reuse of the data, and the data have been pseudonymised

6. Making data reusable

6.1 I will ensure that the data and their documentation will be of sufficient quality to allow other researchers to interpret and reuse them (in a replication package).

- I will perform quality checks on the data to ensure that they are complete, correct and consistent (please explain)
- I will document the research process (please explain)

The research process will be documented using standardized reporting checklists such as COREQ for qualitative research and STROBE for quantitative study.

Moreover, quantitative data will be checked for missing values, outliers, and coding errors. Qualitative transcripts will be checked with audio recordings to ensure accuracy.

6.2 I have a number of selection criteria, which will allow me to determine which part of the data should be preserved once the project has ended. (see also question 1.9 and 6.1)

- Yes

6.3 Once the project has ended and the data have been selected, I can make an estimate of the size of the data collection (in GB/TB) to be preserved for long-term storage or archival.

- Yes (please specify)

3-5GB

6.4 I will select an archive or repository for (certified) long-term archiving of my data collection once the project has ended. (note: this is a key item, which you should report to ZonMw at the conclusion of your project)

- Yes, and this archive has a data seal of approval (please specify the archive)

Patient Reported data is archived in Patient Journey App, App-usage statistics are archived in Patient Journey App.

Research data is archived at the local research network folder.
Moreover, digital pseudonymized data will be archived in the RDR of Radboudumc and raw data will be on a secure, password-protected RKZ hospital's drive for 10 years after completion of the study and access will be granted only to authorized members of the research team. And paper documents will be archived in a locked cabinet at the RKZ, accessible only to authorized researchers, for the duration of the legal retention period (10 years).

6.5 Once the project has ended, I will ensure that all data, software codes and research materials, published or unpublished, are managed and securely stored. Please specify the period of storage.

- Yes, in accordance with VNSU guidelines (please specify the number of years)

All data will be preserved for 10 years after completion of the study.

6.6 Data management costs during the project and preparations for archival can be included in the project budget. These costs are:

- Amount ..... (please elaborate)

Costs for data management (use of Castor EDC, server, use of full MS Sharepoint Teams location, RDR, standard DRE workspace) have not been budgeted for this project. These costs are covered by the department (overhead) or by the Radboudumc.
Collections in the RDR are free up to 200GB storage per year, per research project.

6.7 The costs of archiving the data set once the project has ended are covered.

- Yes (please elaborate)

See 6.6; costs are covered by the department (overhead) or by the Radboudumc.