
Impactful intelligent individual-driven connected health service for osteoarthritis self-management

A Data Management Plan created using DMPTuuli

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Project abstract:

Osteoarthritis (OA) is the most common, costly and the leading cause of chronic disability globally in individuals older than 70 years that can be better treated with help of self-management interventions. In the USA, OA is the highest cause of work loss and affects more than 20 million individuals, costing greater than US\$100 billion annually. Our national goals in healthcare are to increase citizen empowerment on their own care. Connected health solutions have the potential to increase access to healthcare services regardless of time and place and reduce costs. This will happen if the solutions are designed both to bring value for the patient along the care journey and to address the needs of all stakeholders. Business modelling and network orchestration have been widely used as a value capturing and value creation mechanisms to support network innovation. The current research lacks of patient centric business modelling and orchestration approaches that could enable novel service co-innovation in healthcare sector. The OACarePoC project aims to make multidisciplinary research that 1) identifies the currently unknown needs for the OA patient self-management that uses gamification to motivate patients, 2) generates novel ways to use network orchestration and new individual-driven business modelling approaches to facilitate innovation of an intelligent, coherent, individual-driven solution for OA self-management bringing added value to all stakeholders in the network, and 3) uses system dynamic approach and simulations to demonstrate its potential, systemic impact from medical, patient and business perspectives. OACare project will combine mixed methods within engineering, business and nursing sciences in a unique manner. The project will result better understanding of the gamification opportunities in the patient self-management, it will create a proof of concept of personalized OA service that supports OA self-management bringing increased quality of life to the OA patients and helping different care teams to make their care process more efficient without losing the quality of patient experience. It will help to make PoC of the service that bring OA patients as interactive partners in healthcare helping them to conduct interventions needed in their daily life. It will be a starting point for the identified stakeholder companies to be integrated to the developed OACarePoC with the patient centric business model helping them to get their solutions rapidly in the involved care organizations and faster to the international markets.

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1. General description of data

1.1 What kinds of data is your research based on? What data will be collected, produced or reused? What file formats will the data be in? Also give a rough estimate of the size of the data produced or collected?

Service blueprint technique and/or process mapping will be used to build a comprehensive understanding of the current treatment and care of OA. Additional researches will be implemented using systematic literature reviews and meta-analyses. Qualitative, semi-structured interviews will be conducted among patients (n=20-30, depending on saturation), healthcare professionals (n=20-30, depending on saturation) and different stakeholder organizations (20-30 people will be interviewed from different stakeholder organizations).

1.2 How will the consistency and quality of data be controlled?

All data will be audiorecorded and transcribed immediately by a transcription service provider. Analyses will be performed independently by two reviewers.

2. Ethical and legal compliance

2.1 What ethical issues are related to your data management, for example, in handling sensitive data, protecting the identity of participants, or gaining consent for data sharing?

The applicant is committed to complying with proper scientific practices, including intellectual property rights, data security and privacy. This study will be approved by the relevant centres during the autumn of 2020. The aim and the method of the study will be explained to the participants, and they will be also informed by a standard written information form (including aim of the study, recruitment, sampling, measurements and measurement times, participants rights, expenses and payments, possible benefits/risks, confidentiality, data management, contact details etc.). Written informed consent will be obtained from patients prior to inclusion in the study to ensure that the participation was voluntary (Declaration of Helsinki, 2013).

The research will generate written (study notes, meeting minutes) and audio material, and use material in electronic records (data obtained from experiments, measurements, workshops). All data will be treated as confidential and transcribed immediately by a transcription service provider. Physical data will be stored under lock and key at the Oulu University, and digital data will be stored on the research organizations' professionally maintained servers protected by passwords. All researchers processing the raw interview will sign a data processing agreement. Generated data will be stored for 5-10 years after completion of the research project. All data will be destroyed by the PI. Data will not be transferred outside the EU/ETA countries.

2.2 How will data ownership, copyright and IPR issues be managed? Are there any copyrights, licences or other restrictions that prevent you from using or sharing the data?

At the end, all data, excluding material and information to be considered crucially confidential, will be allowed for external researchers as required by the Academy of Finland. At this point, it is assured that any personal data that may allow identification of research participants is removed.

The researchers and partners will agree on the tasks, responsibilities and rights relating to data collection, management and use. The material produced by the participants are subject of copyright and therefore cannot be shared.

The research project will not use data which is covered by the Copyright, Designs and Patents or any other similar legislation.

The ownership of the potential inventions are subject to Finnish invention legislation. As permitted by Finnish legislation, protected inventions can be exploited for non-profit research with no authorization. Public research

organizations have processes in place so that the rights of results can be transferred to a start-up or existing companies.

3. Documentation and metadata

3.1 How will you document your data to make them findable, accessible, interoperable and reusable for you and others? What kinds of metadata standards, README files or other documentation will you use to help others understand and use your data?

The data will be saved using standard formats. In addition, all technical papers, theses, reports and presentations will be stored digitally using PDF format.

4. Storage and backup during the research project

4.1 Where will your data be stored, and how will they be backed up?

During the project the data will be stored digitally in the University of Oulu server systems that will be backed up nightly.

The analysis is being made using NVivo Server. The data is thus saved also in NVivo.

The researchers have access to all research data within their own research group, but access rights can also be restricted whenever needed, e.g., on the requirement of a collaborating party. Users' access rights are managed by the IT staff of the university.

4.2 Who will be responsible for controlling access to your data, and how will secured access be controlled?

The ownership and use right of the data remains in the possession of the researchers, controlled by the PI.

The transfer and production of data will be monitored throughout the project, particularly in interactive web-based networks

5. Opening, publishing and archiving the data after the research project

5.1 What part of the data can be made openly available or published? Where and when will the data, or their metadata, be made available?

A combination of Gold and Green Access strategies will be followed to maximize dissemination. The results of this research will be reported (as open access articles) in internationally recognized, high-impact journals in the business and medical fields and in national and major international conferences and seminars. Every year the project situation will be reported by the rules of Academy of Finland.

5.2 Where will data with long-term value be archived, and for how long?

Generated data will be stored for 5-10 years after completion of the research project.

6. Data management responsibilities and resources

6.1. Who will be responsible for specific tasks of data management during the research project life cycle? Estimate also the resources (e.g. financial, time and effort) required for data management.

The open access costs are included in the proposal budget