

1.0 Background

The development of mobile information technology, within the past 8-10 years, has enabled the possibility of obtaining personal data of a sort and to an extent not previously seen. This kind of data collection - or 'self-tracking' – is already well known from diet and exercise contexts where for instance calories, fluid intake, exercise forms, and training extent is being registered.

The global movement Quantified Self brings together people interested in using self-tracking and the thereby generated data to improve their performances and achieve greater insight into their own lives (1-4). Within the movement, gradually more people have used self-tracking to get health problems under control having experienced an insufficient health system. This especially applies to individuals with complex, chronic health problems manifested by uncharacteristic symptoms. Through self-tracking these individuals have gained insight into causal relations and have been able to change or remove the factors that have had a negative impact on their health (1,2,5,6). Furthermore, studies have shown a desirable effect when allowing specially trained coaches support patients and run the process of IT-supported self-tracking (7,8).

This pilot study will explore how self-tracking can be used in the investigation of complex health problems and to find ways to reduce symptoms and improve quality of life through a process that is individually designed. The investigation is carried out using a technology supported process in close collaboration with the selected patients and a health coach.

2.0 Purpose

The study aims to investigate:

- How patients' self-tracking can be used for data-guided health coaching in a clinical department
- How self-tracking can help to support and involve patients with serious and chronic diseases as part of their treatment
- Which questions that need to be clarified in order to design a larger study

The hypothesis is, firstly, that patients will achieve an increased understanding of their health situation and their own possibilities of influencing this situation. Secondly, the data will help create a greater sense of control and make it easier to live with a chronic disease, such as prostate cancer in the so-called *watchful waiting state*.

3.0 Method

Two patients will be selected (suffering from respectively *kidney stone attacks* and *prostate cancer*) and they will attend an individually customized coaching process with an urologist and a project nurse. The duration of this process will be approx. three months.

The patients will be equipped with either a smartphone or a smart watch in which the TOTTI-app and software components are installed. The TOTTI software's primary function is the patients' self-monitoring (self-tracking) of relevant subjectively experienced phenomena and activities such as meals, fluid intake, behavior, and physical and psychological symptoms. The selection of the tracked phenomena and activities will be agreed upon between the patient and the coaching project nurse in advance and then continuously adjusted as required.

Inclusion criteria: <ul style="list-style-type: none">• Patients with uncharacteristic symptoms• Patients with complex health problems	Exclusion criteria: <ul style="list-style-type: none">• Patients with dementia or other cognitive problems• Patients who have difficulties understanding Danish
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3.1 Self-tracking and coaching

In connection with an initial coverage of the individual patients' situation, one or more personal basis phenomena will be defined and these will be recorded throughout the entire self-tracking process. These basic phenomena will be tracked before the intervention with the aim of determining the patient's individual baselines. If a basic phenomenon exerts a negative impact on the patients' quality of life, for instance fatigue after meals, the goal will be to reduce the incidence. If a basic phenomenon affects the patient's situation positively, for example a sense of vigor, the goal will be to increase the incidence. The assessment of either negative or positive value of the various basic phenomena is determined by the coach in cooperation with the patient.

Data collected by the patient will be used to identify possible underlying factors causing his health problems. These insights are part of the process of finding the simplest and mildest intervention from which the patient can benefit. The setup of what the patient should be recording will be defined individually and then continuously adjusted. If possible, comparisons of blood test results before and after the self-tracking will be carried out to determine any significant changes in relevant biomarkers.

During the initial coaching session, the patient must install the appropriate TOTTI software components. The setup of the software is individual and adapted to the patient's illness and needs. Therefore the categories in the self-tracking app will be decided upon in cooperation between the

patient and the therapist.

After the first coaching session, the patient will track his data as agreed upon. Once a week, the project nurse will conduct a follow-up session and evaluation of the patients' data, together with the patient. This will be a weekly coaching session and the patient will also be offered a monthly consultation with the urologist.

3.2 Evaluation and data processing

As part of the evaluation, interviews with patients, the project nurse, the urologist and the consultant from TOTTI Labs will be carried out. For this purpose, an individually customized interview guide will be developed. All parties will be interviewed before and after the self-tracking and coaching process in order to uncover and document the following areas (point 2 applies solely to the patients):

1. Identification of expectations - and subsequent experiences with - the process and the use of the technology
2. Possible changes in the understanding of the patients' situation
3. Personal benefit of participation in the project

In addition, the Totti Labs consultant and the project nurse will evaluate the patients' data once a week, and the consultant will continuously be evaluating the coaching process with the project nurse. The project is furthermore guided and evaluated in an ongoing collaboration with Professor Jette Ammentorp from The Health Services Research Unit.

4.0 Continuous data processing and analysis

In the ongoing clinical work with the participants, the collected self-tracked data will be prepared and analyzed by using the IT system which provides a number of standard visualizations. If necessary, ways of analyzing and presenting the data that supports the patient and the coach's efforts will be tested in order to develop an understanding of the patient's health and the essential factors related.

4.1 Treatment of the data

The method for analyzing the tracked data will be decided on later in the process.

4.2 Qualitative analysis of focus group interviews

All of the interviews will be recorded, transcribed and analyzed according to Kvale's method of meaning condensation (9) and Malteruds systematic text condensation (10). Both methods provide an overview

of the text material and helps structuring empirical data. The systematic text condensation is used for descriptive analyzes of the uncovered phenomena.

5.0 Ethics

The pilot project will be reported to The Research Ethics Committee in the Region of Southern Denmark and the Danish Data Protection Agency for approval. The patients included will be informed about the project and the option of withdrawing from the project at any time without implications for treatment and care. They will also be informed that data is being anonymized and they are asked to sign a consent form before participating in the project.

6.0 Publications

At least one article is expected to be produced based on this pilot project. An example of a title could be: "From active surveillance to active survivor - self tracking in prostate cancer."

7.0 Perspectives

At the community level there is a need for cost-effective and scalable solutions to accommodate the challenges that chronic diseases provide. IT and coach supported self-tracking is a promising attempt well worth pursuing further. The sum of the improvements achieved for individual patients will contribute to reducing the social and economic costs generated by these disorders.

8.0 Timetable

March / April 2016	▪ Inclusion of patients
April 2016	▪ Preliminary meetings between patients, project nurse and specialist
May, June & July 2016	▪ Preliminary interviews conducted ▪ Self-tracking and coaching process is ongoing
August 2016	▪ Final interviews conducted
August-September 2016	▪ Finishing the aggregated data sets ▪ Transcription and analysis of interviews
October-December 2016	▪ Article writing

9.0 Organization

This project derives from The Health Services Research Unit and The Research Section of Urology in Lillebaelt Hospital, and is organizationally affiliated with Center for Health Sciences Research and Education / Institute of Regional Health Services Research, University of Southern Denmark.

The pilot project is being managed by a steering group set up by The Health Services Research Unit, involving:

- Professor, PhD, Research Leader Jette Ammentorp, Health Services Research Unit, Lillebaelt Hospital / University of Southern Denmark
- Professor, Research Leader Palle Jörn Sloth Osther, Department of Urology, Lillebaelt Hospital / University of Southern Denmark
- Entrepreneur, MSc.it., Thomas Blomseth Christiansen, TOTTI Labs and Consulting Blomseth
- Project Nurse, MNSc., Louise Favrholt Øbro, Department of Urology, Hospital Lillebælt
- Research Assistant, MHSc., Karin Yde Waidtløw, Health Services Research Unit, Lillebaelt Hospital / University of Southern Denmark

10.0 Economy

The pilot project is part of the InterReg project 'Prometheus', and acquires financial support through this. Prometheus is an EU-funded project and collaboration between partners from both Germany and Denmark. A detailed description of the project, its partners and objectives can be read here:

<http://www.interreg5a.eu/dk/projekte-ergebnisse/projektuebersicht/prometheus/>

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