AALBORG UNIVERSITY

Techno-Anthropology
Master Thesis

WHAT IS PRO?

An investigation of coherence in patient-reported outcomes in general practice as a social construction of technology

---

AUTHORS:
Anna Lei STOUSTRUP
Sisse Helena Faldborg JØRGENSEN

SUPERVISORS:
Jeppe ERIKSEN
Pernille S. BERTELSEN

JUNE 2019

AALBORG UNIVERSITY
STUDENT REPORT

Title sheet

Title: What is PRO? An investigation of coherence in patient-reported outcomes in general practice as a social construction of technology
Semester: 10th semester, master thesis
Project period: February-June 2019
ECTS: 30
Project group: 1

Authors
Anna Lei Stoustrup – 20103367
Sisse Helena Faldborg Jørgensen – 20134026

Supervisors
Pernille S. Bertelsen
Jeppe Eriksen

Extent of report
Number of pages: 72,6
Number of characters: 174.253
Number of appendices: 7

By signing this document, each member of the group confirms participation on equal terms in the process of writing the project. Thus, each member of the group is responsible for the all contents in the project.

Resumé

Patient-reported Outcomes (PRO) bliver i stigende omfang implementeret og benyttet i den danske sundhedssektor. Ved gennemgang af officielle dokumenter vedrørende PRO, er der ikke en umiddelbar konsensus angående hvad O'et i PRO bør oversættes til. Dette studie søger at afdække hvilke forståelser af PRO teknologien udvalgte aktører har konstrueret og hvilke implikationer dette måtte have. Undersøgelsen blev udført via den metodologiske tilgang *Social Construction of Technology* (SCOT), for at muliggøre en afdækning af de socialt konstruerede virkeligheder der er baggrunden for disse forståelser.

Kvalitative metoder er blevet anvendt for at afdække forståelserne, begyndende med en dokumentanalyse der afdækker relevante rapporter i relation til digital sundhed og PRO i en dansk kontekst, efterfulgt af semistrukturerede interviews og transskribering af videomateriale. Denne data er blevet kodet og analyseret gennem omhyggeligt udvalgte kriterier for at afdække *set of meanings*, *problems* og *solutions* blandt sociale grupper i henhold til SCOT-metodologien.

En analyse baseret på SCOT metodologien har vist, at varierende holdninger eksisterer blandt sociale grupper, med udgangspunkt i oversættelsen af O'et i PRO blandt aktører, videre gennem *set of meanings* i grupperne, resulterende i forskelligartede *problems* og *solutions* som disse grupper oplever i mødet med teknologien. Der blev ydermere fundet korrelation mellem problemerne blandt de sociale grupper.

Empirien har søgt at afdække årsagerne til disse forskelligartede forståelser af PRO teknologien og viste, at forståelserne blandt de sociale grupper er funderet i deres sociale konstruktion af teknologien, baseret på deres tidligere oplevelser med denne og anden sundhedsteknologi. Aktører, der tidligere har oplevet problemer i forhold til datadeling, er tilbageholdende med at anvende denne teknologi, hvor de, som udvikler teknologien og ikke har haft disse oplevelser har et positivt udgangspunkt.

De foreslåede *solutions* blev i diskussionen af resultaterne afdækket som komplekse i deres beskaffenhed, da de i løsningen af nogle gruppers problemer kan være årsag til dannelse af nye problemer hos andre.

Abstract

Patient-reported Outcomes (PRO) are increasingly implemented and used in the Danish healthcare system. When reading official documents about PRO it seems as though there are no definite consensus as to what the O in PRO should be translated as. This study seeks to uncover which varying understandings of the technology of PRO are constructed by actors, and what implications this might entail. The investigation was performed with the methodological approach of Social Construction of Technology (SCOT) in order to explore the socially constructed realities of these understandings of PRO.

In order to uncover these understandings, qualitative methods have been utilised, starting with a document analysis to uncover relevant reports on the topic of digital health and PRO in a Danish context, followed by semi-structured interviews and transcription of video material. The data has been coded and analysed through carefully chosen criteria in order to uncover the set of meanings of social groups, problems and solutions as per SCOT methodology.

An analysis based on the structure from SCOT methodology has found, that varying understandings indeed exist among the social groups, starting in the translation of O in PRO amongst actors, over the set of meanings amongst groups resulting in differentiating problems and solutions that groups experience with the technology. A correlation of problems was, however, detected between the social groups.

The empirical data has uncovered reasons for the varying understandings of the PRO technology and show, that the understandings of social groups are grounded in their own social construction, based on their experiences and history with the technology and health technology overall. Those with a history of problems with data sharing are watchful regarding participating in this initiative. Those who are employed to implement the technology nationwide and do not have previous negative experiences, have an understanding grounded in the benefits of the technology.

In the discussion of the results, the implications of the suggested solutions were found to be complex in nature, seeing as some solutions might create new problems while solving them for other groups.

Table of contents

1.0 Pre-understanding

This thesis came to be based on a continuous interest in health care technology and its interaction with its users. Patient-reported outcomes (abbr. PRO) is systematically collected data from patients regarding their state of health etc. directly from the patient without interpretation. (FDA, 2009) The technology will be expanded further on the term in chapter *2.1 Patient-reported outcome*s.

This will be our third time investigating PRO, which is a field that continues to spark both our scientific and personal interests. Previous endeavours include the opportunity to test a design game of our own production on a workshop in collaboration with the PRO secretariat and Bornholms Hospital(Christensen *et al.*, 2017). The design game was tested with both patients with osteoarthritis as well as health professionals of the hospital, to uncover insights from users to use in the continuous development of PRO tools. Secondly, another collaboration with the PRO secretariat, consisted of a stakeholder analysis to uncover the values of the most central stakeholders in the development process and analyse how these values might impact the development (Stoustrup and Jørgensen, 2019).

These project processes continued to provide knowledge as well as research questions and wonderings, primarily the question of how PRO is constructed socially among actors connected to the field. Initially, a lot of time was spent researching the term of PRO, which both satisfied the need for clarification as well as provided more confusion; a confusion that appeared to be a more general symptom of the technology. As it turns out, the understanding of what PRO actually is varies depending on who you ask and in what context. This seemed intriguing, seeing that the work with PRO is part of an effort to create greater coherence in the Danish health sector, a coherence that should make it easier to be a patient, especially a patient with one or more chronic illnesses, as well as a health professional. (Danish Ministry of Health, 2018)

In addition to this more academic interest in the subject, we also find ourselves to have a personal interest in this field. We have both had experiences with the Danish health sector, one of us as a patient only and one of us as both a health professional and a patient. Furthermore, we have both experienced past and current pregnancies, which have shown what it is like to be connected to the health system for an extended period. Through these personal insights, we have encountered the lack of coherence between sectors and know of the

frustrations it can entail as a patient and as a health professional. This has only proved to increase the motivation, regarding wanting to produce knowledge that can possibly contribute to a greater coherence in Danish health care.

This study deals with PRO as a technology as a whole, but has its focus on general practice, as this is the sector where we have noticed a significant difference in the understanding of the technology compared to other actors as well as difficulties in achieving the desired level of cooperation. (Stoustrup and Jørgensen, 2019) Furthermore, because general practice typically is the entry point to the rest of the health sector, one could argue, that it is significant to the public, that the way general practitioners understand and employ the technology correlates with the rest of the health sector (Pedersen, Andersen and Søndergaard, 2012).

2.0 Introduction

Through extensive research into the field of patient-reported outcomes, several actors connected to the field have been spoken to in order to uncover i.e. their values in relation to the development process. In this context it was found, that asking a simple question like "*What is PRO?*" delivers a multitude of replies, including a need for clarification on what context they should define PRO from. Previous work with PRO has shown, that there are a vast number of personal definitions and understandings of what the technology is, how it is supposed to be used, and what the purpose of it is.

A previous study prompted the following replies:

"*PRO is information given by the patient in relation to a course of treatment.*" - Ministry of Health
"*PRO for me is patient reported outcomes, meaning information about the patient's state of health.*" - Danish Health Data Authority
"*PRO is a very important measuring tool to take the temperature on how well the health sector contribute to patients' quality of life and functional ability.*" - Danish Patients
"*PRO is a way to add the voices of the citizens into the cooperation in the health sector, to secure that their own assessment of their situation is included and that you relate to this information in dialogue with them.*" - Local Government Denmark (KL)

Figure 1: Definitions of PRO as stated by stakeholders (Stoustrup and Jørgensen, 2019)

As these quotes show, they all centre around the notion that PRO is a means to collect data provided by a patient, but besides that, the definitions of what the purpose of that information is vary greatly. The continued spread of PRO means that more patients and health care professionals encounter the tools, which only increase the importance of a common understanding in order to navigate the tools in different contexts.

To observe how a chosen technology is understood and employed is an interesting activity. Technology is all around us and is an integral part of our everyday lives, so integral, that we often do not pay much attention to it. And it only keeps coming. One part of our society

that is greatly digitised is the health sector (Danish Ministry of Health, 2018). In a relatively small number of years the health sector has transformed from somewhat analogue, local hospitals to centralised super hospitals where technology plays a major part in the everyday treatment of patients. The digital strategy for the Danish health care sector describes the need of further digitisation, and thus, a coherence through the health care sector, i.e. "*(...) the need for coherence is presently becoming increasingly essential as multimorbidity is rising, putting increasing numbers of patients in contact with multiple segments of the health system.*" (Danish Ministry of Health, 2018) Fulfilling the need to better coordinate a patient's path through the entire health care sector in their course of treatment, seems to be one of the next big steps in the digitisation process. (Danish Ministry of Health, 2018) To achieve this coherence across sectors, it is crucial that the technology is developed, understood and used in accordance with the specific context it is to be used in regarding the needs of the different sectors. If there is not enough coherence, the technology, and ultimately, the overall goals, will be at risk of not being successful (Pinch and Bijker, 2012).

2.1 Patient-reported outcomes

Data reported directly from the patient is a phenomenon increasingly common in healthcare systems. The information may regard any aspect of a patient's health status; from biological and mechanical questions about symptoms, pain and functional ability to more psychosocial factors such as quality of life, satisfaction levels and health perceptions. (Black *et al.*, 2016; Yang *et al.*, 2018) Originally, patient-reported outcomes were invented for American drug trials to measure the effectiveness of medicine. Later, PRO has been used for monitoring patient's symptoms pre, post and during a medical, conventional or operational intervention. The most recent development within PRO, is that it can be used for decision support along with measurements of Health-Related Quality of Life. (Black *et al.*, 2016)

The many uses of patient-reported outcomes have entailed different abbreviations for the different uses. Patient-reported Outcomes are abbreviated "PRO", Patient-reported Outcome Measures as "PROM" and Patient-reported Experience Measures as "PREM" (Baldwin *et al.*, 2011; Munch-Petersen *et al.*, 2016). Some researches even argue for more denotations, like Patient-reported Information for further clarification of what type of patient-reported data is being used (Baldwin *et al.*, 2011).

This study will rely on the abbreviation *PRO* when referring to either PRO, PRO-data or PROM, unless referring to a specific wording used by an actor. In the report Program PRO, a Danish report written based on current evidence by 29 experts in the field with recommendations for the best implementation of PRO into the Danish healthcare system, the authors have created a figure to illustrate the different uses of patient-reported data, showing that the focus of the report is on PRO-data, not on PRO or PREM:

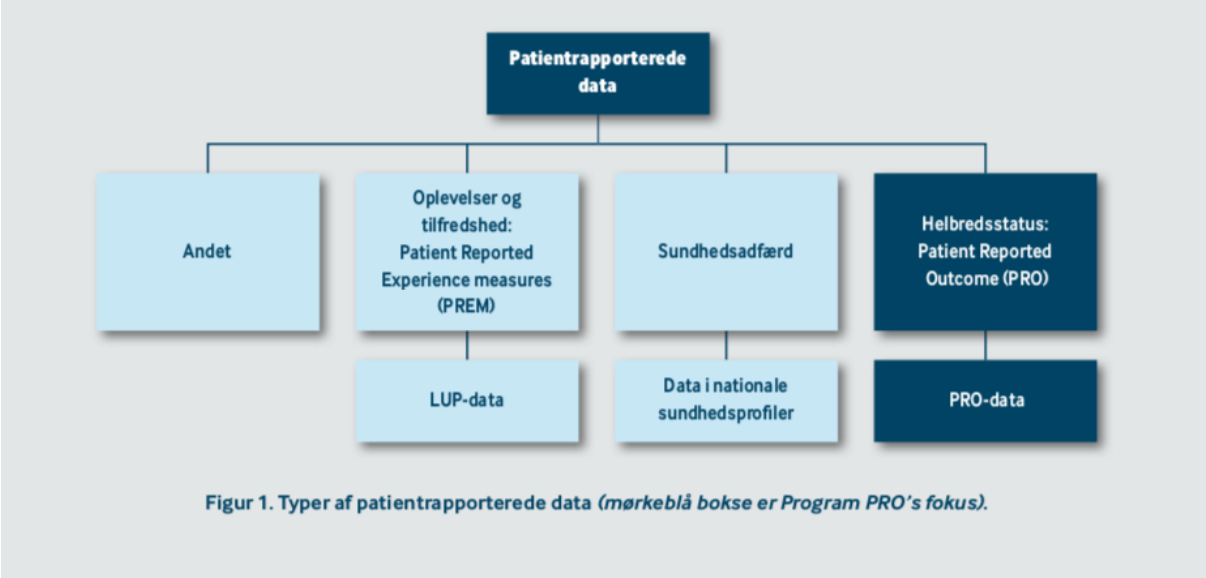


Figure 2: Uses of PRO (Munch-Petersen *et al.*, 2016)

PRO is defined by the U.S. Food and Drug Administration as *"(...) any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else."* (FDA, 2009). Program PRO formulates their definition of PRO as "*PRO-data (Patient-reported Outcome Data) is data about the patients' state of health, hereunder physical and mental health, symptoms, health related quality of life and functional level. PRO-data is reported directly from the patient."*

The usage of PRO has proposedly many appraised consequences. Among these are; improved efficiency in workflows, increased patient involvement and as an effect here from; increased patient-empowerment, increased dialogue and cooperation between patient and health professionals, higher level of satisfaction and better compliance. PRO can also be used as a monitoring- and screening tool for the patients' physical and mental status, where the patient regularly report any progress or decline in order for an algorithm or a health professional to assess, whether further action is needed or the patient benefits from the treatment (Greenhalgh, 2009; Philpot *et al.*, 2018).

Its origin in the quantitative world results in an understanding, that the PRO questionnaires should be standardised and preferably validated, but challenges can arise in relation to this. Since psychosocial factors, such as Quality of Life and Health-Related Quality of Life, are usually measured with qualitative questioning methods, there is a process of changing, creating, standardising and validating more quantitative questionnaires that are useful for the scope of PRO. (Black *et al.*, 2016)

Furthermore, there must be developed an entire infrastructure to accommodate the data from the questionnaires. Herein lies an obstacle towards creating interoperability between the questionnaires, where different metrics of measurements, different operating systems and in general different ways of developing questionnaires can be challenging. (Black *et al.*, 2016) The implementation of PRO in clinical settings does, however, propose some challenges. These are especially regarding resources, such as excess time expenditure, expenses in relation to implementation and use, apprehension towards misuse of data and doubts about definition, usage and effect (Black, 2013; Chenok *et al.*, 2016; Philpot *et al.*, 2018).

2.2 PRO in Danish general practice

Seeing that the scope of this study is on the understandings of PRO in general practice, this chapter will focus on the current status in that sector. PRO is currently being implemented across the Danish health sector (Danish Ministry of Health, 2018). Part of this implementation is happening in general practice, where validated questionnaires are converted from the traditional paper version to a new electronic version. In general practice it is used to systematically collect health data from patients, mostly through home monitoring of blood pressure and depression. With electronic questionnaires, this can be done from home instead of at the GPs office or in the waiting room. A benefit of using electronic questionnaires rather than paper is also, that the GP will be able to follow their patients' health status in real time, and the data will not be corrupted. In some cases, algorithms will be utilised to evaluate whether an intervention is needed. (MedCom, 2017)

The implementation in general practice is part of a three-year project launched by The Ministry of Health to test and spread the implementation of electronic PRO tools (MedCom, 2017). The PRO tool used in the project is WebPatient, which is an add-on to WebReq, a tool currently in use in general practice for requesting laboratory samples. During this three-year

period, WebPatient has been made available to all general practitioners (GPs) through WebReq, of which 63 % has used the tools at least once. The project had an original goal of a 65 % spread and has been extended till the end of 2019. (MedCom, 2017)

2.3 A timeline of PRO

As previously described, the world of PRO is rather complex, with many actors involved and sometimes intertwined. In order to better understand the field of PRO in a Danish context, an overall timeline of events and initiatives regarding PRO will be provided. A multitude of local initiatives exist, hence, not all will be mentioned here. When the national steering group for PRO was established, DKK 8 million was allocated to pool projects. A list of those can be found on the website for national PRO. (PRO-sekretariatet, 2019a) A deeper introduction of some of the relevant actors mentioned here can be found in the *Methods* chapter.

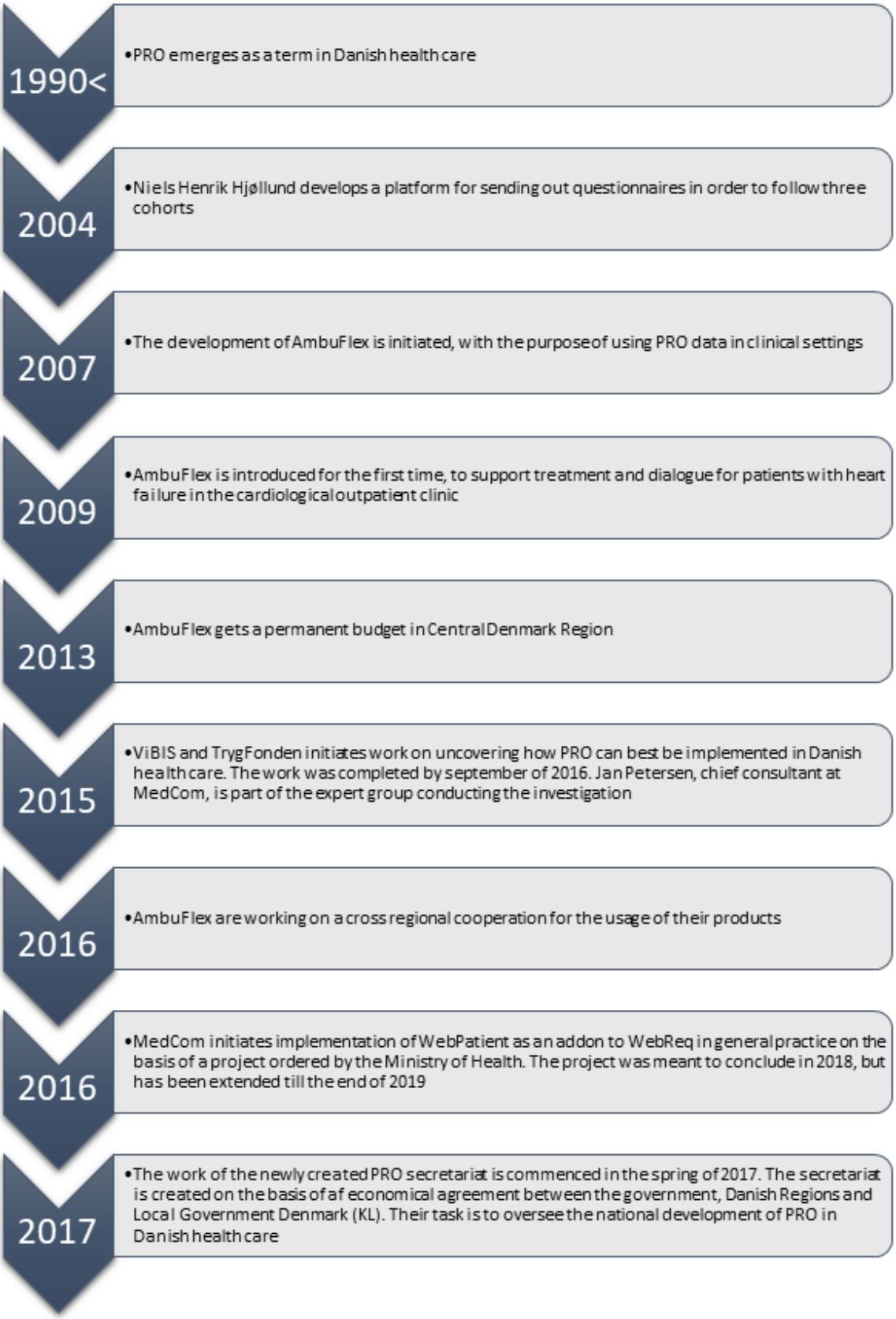


Figure 3: Timeline of PRO (Ambuflex, no date; Danske Patienter, no date; Rodkjaer *et al.*, 2015; PRO-sekretariatet, 2018a; MedCom, 2019b)

As seen in the timeline, PRO has been used in Danish health care for many years, though this has not been in a structured manner (Nielsen, 2015). Through the years, three starting points in the effort to create a more structured technology, have been commenced; researcher Niels Hjøllund initiated what would eventually become AmbuFlex in 2004, ViBIS lay the grounds for the national work with PRO with their report in 2015 and MedCom launches their implementation of PRO in general practice in 2016. None of these three initiatives are connected through the same infrastructure at this moment.

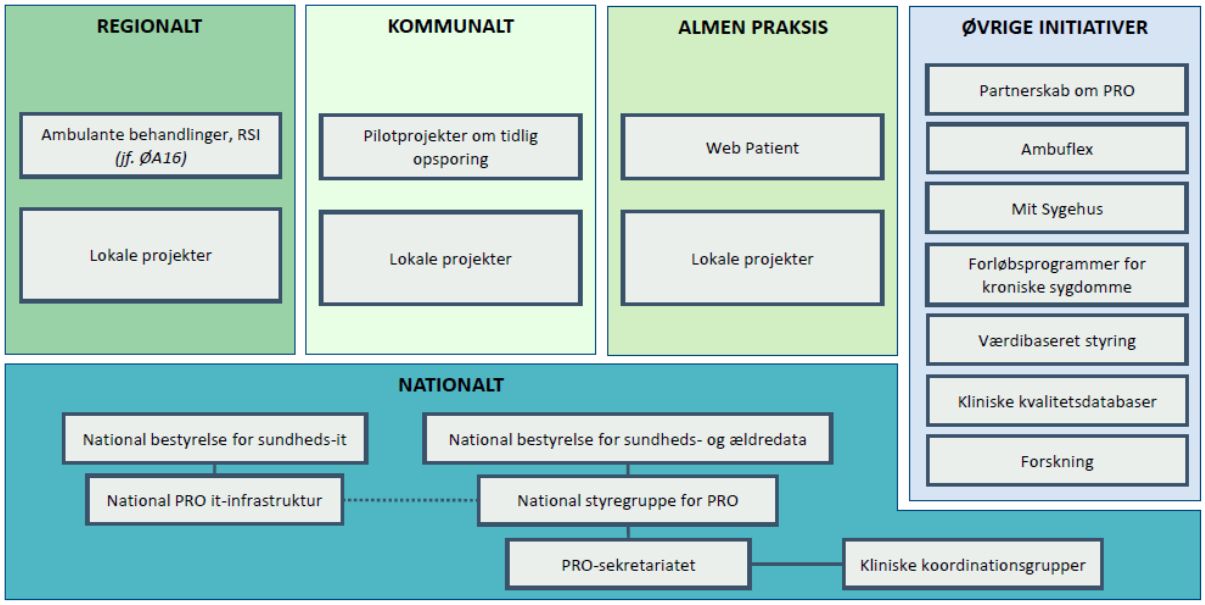


Figure 4: PRO landscape (PRO-sekretariatet, 2019b)

The above illustration shows an overview of the initiatives in a Danish setting. As it shows, there are a multitude of initiatives, which further means a multitude of understandings. This discovery leads the study on to the area of interest.

2.4 Area of interest

With the knowledge, that the PRO technology has many starting points and a large quantity of developers attached, it raises a curiosity if and how a national coherence is to be achieved. Previous studies into the field of PRO, as well as newer discoveries specifically with the use of PRO in general practice, has paved the way for a study into the various ways PRO is understood, developed and used across sectors in Danish health care. (Stoustrup and Jørgensen, 2019) With consideration for how the digital strategy for the health sector has a focus on coherence across sectors, in favour of the patients, especially those living with one or more chronic illnesses, it

seems curious to have different actors developing PRO tools. In addition to not being developed in the same manner, it seems that there is not complete coherence in the way the technology is understood by developers and users.

This seems concerning regarding the goal of achieving a complete coherence across sectors and the likelihood of all involved actors, developers as well as health professionals and patients, sharing a common understanding of what it is meant to do. For these reasons, this study will concern itself with an exploration of understandings of PRO and uncovering how actors perceive the technology, in an effort to determine how coherence across all sectors can be achieved.

2.5 Problem statement

Based on the above considerations, the following problem statement has been formulated:

> Which understandings of Patient-Reported Outcomes exist amongst relevant actors in the context of general practice in Denmark and what might the implications of these social constructions be?

3.0 Techno-Anthropological problems

This chapter will delve into the Techno-Anthropological competencies and how the problem statement displays a Techno-Anthropological problem. Furthermore, this study has a social constructivist approach, which will be expanded upon here as well as what the perceived ontology of the study is.

With Techno-Anthropology being an interdisciplinary study programme, it can be helpful in terms of reading and understanding this study to know, what thoughts have gone into the standpoint taken regarding this field. Below is an illustration of the Techno-Anthropological field, which centre on technology. This thesis will have PRO as a technology, and therefore PRO in its centre. In order to study the technology in a Techno-Anthropologic realm, it must be viewed from three angles, shown in the corners of the triangle; the users, the experts, and the artefacts. In this case, those in charge of developing and implementing PRO represents the experts, the PRO tools are the artefacts and general practitioners and other health professionals are the users. It can be argued, that patients are also users of this technology, but since the scope did not include patients, the focus will be on health professionals as users. The choice to exclude patients has been made, as the study primarily holds a focus on how the technology is understood through the eyes of those who are developing it. Seeing that an interest in the involvement of general practitioners and their understanding of the technology is what fuelled this study, the choice was made to include them and leave out patients, in order to set up limits to the extent of the study.

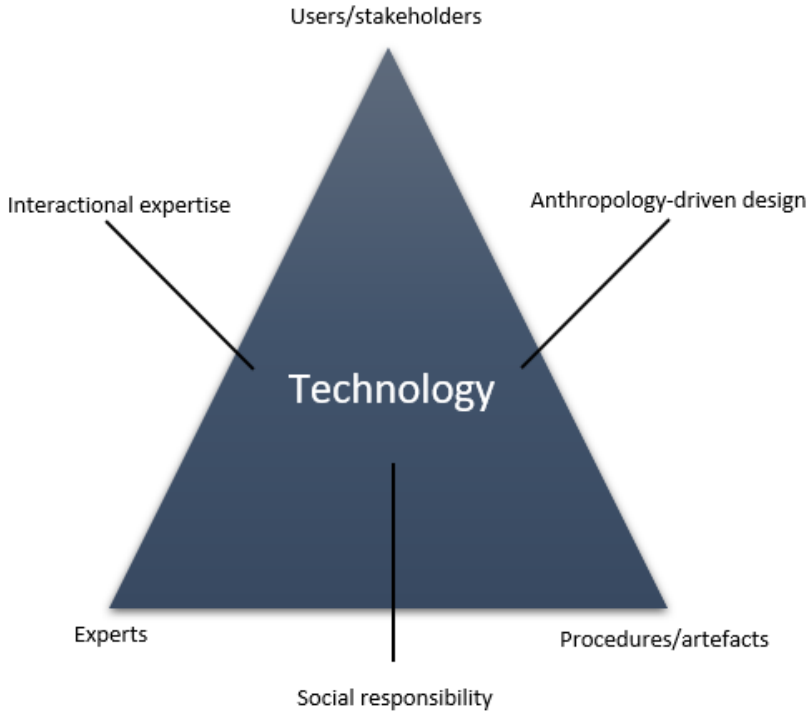


Figure 5: Techno-Anthropological Competences (Børsen and Botin, 2013)

The triangle displays the main research field of a Techno-Anthropologist. To illustrate this study specifically, a triangle with actors and artefacts of this scope is shown below.

Figure 6: Techno-Anthropological competencies in the scope of this study

To understand and study the relationships between these corners, the interfaces between them will be processed; the interactional expertise, anthropology-driven design and social responsibility. The first interface, the expert/user interface is about having interactional expertise. This competency will be the focus in this thesis, as it is the discipline of uncovering understandings of a technology and facilitate a common understanding between experts and users. This thesis came to be, due to an awareness of a lack of understanding between developers and users of PRO, as well as between the expert groups in between, and a desire to try to find a way to resolve this problem through a stabilization and ultimately a way to close the problems. These understandings are rooted in a social construction of the particular technology.

The second interface is the expert/artefact interface, which deals with social responsibility. Implementing a new technology in the Danish health care sector can be an overwhelming change in workflows and there needs to be an awareness of this when exploring reasons for discrepancies in the actors' understandings. What may seem like a suitable idea for one group of actors might seem like an enormous burden for other actors, rendering the importance of being aware of how to handle the cultural impact.

The third and last interface is the anthropology-driven design. A previous study had a focus on this user/artefact interface, where values of stakeholder in relation to the development and design of PRO tools were uncovered (Stoustrup and Jørgensen, 2019). For this thesis, a similar approach will be applied, as an analysis of actors' understandings of PRO can create awareness of how the design process can take these understandings into account in future development. (Børsen and Botin, 2013) For a problem to be of Techno-Anthropological relevance, it must be rooted in the central competencies as visualised in the triangle. In this study, the problem is rooted in uncovering understandings of a technology and relate them to their influence on a real-life setting.

3.1 Social constructivism

In social constructivism, reality is not a static construction but rather a dynamic frame of subjective understandings of what is true. It exists through constant interpretations by the actor, and the notion of what is true to one actor can be false for the next. When exploring technology, this way of approaching reality explains, why no one definition of a technology

exists. It will be understood differently by actors engaging with it, based on what pre-understandings and experiences the actors have and ultimately shape the changeability of the technology through the social phenomenon. (Fuglsang, Rasborg and Olsen, 2013) The problem formulation of this study centre on uncovering understandings of PRO technology, which are based in the experience of each actor and goes to show, how they hold varying understandings of the same technology and how these understandings can influence the way the technology is being developed and used.

The ontology of this study is based in the social constructivism. The field of research in this scope is the PRO technology and thus, how the actors understand this technology. In continuation hereof, the study accepts the implications of the technology of PRO as being real as well as the understandings created by the individual actors are. The epistemology is moreover how the knowledge of PRO is constructed through the reality of the actors. (Fuglsang, Rasborg and Olsen, 2013) Seeing that the study has its starting point in a hypothesis based on our pre-understanding of the field; that varying understanding of PRO in general practice exists, the study has a rationalist foundation and will explore if the hypothesis is true or not in a social constructivist manner (Ebdrup, 2014). By performing the study based on this deductive manner it is possible to explore if this hypothesis, that there are in fact different understandings, is true and what these understandings are.

4.0 Theoretical framework

This chapter will introduce the theoretical framework and methodology. The study will be framed through the social construction of technology (abbr. SCOT) which correlates with the social constructivist approach. Both frames assume, that understandings are based on the pre-existing knowledge, understandings and experience of the individual actors, where the social constructivist approach reasons for the human approach, SCOT reasons for the approach to the technology and the understanding of its development process.

4.1 The Social Construction of Technology

In our approach to investigate the development of the technology of PRO in general practice, it is useful to lean towards a theory that can explain how and why different groups influence this development. Therefore, the theory and methodology of SCOT has been chosen for analysis. SCOT views the development of technology as always dependant on cultural and societal trends, and not as independent ideas and developments more or less separated from these trends. Traditionally, technology is perceived as somewhat autonomous, meaning that it does not evolve only in relation to societal changes, it evolves on its own accord. SCOT disagrees with this notion. (Lauritsen, Olesen and Bruun Jensen, 2007)

SCOT explains the development of technology in a multidirectional model, where the steps into developing and advancing a technology is determined by the social groups that have influence on the technology. The multidirectional approach entails, that there at any point in the development of the technology, are multiple choices that could be made for the technology and thereby multiple outcomes and successes. Technology development is hereby not a linear model, where a need sparks an idea, which turns into a technology whose potential is expanded and refined with increasingly better models, but rather, the design of the technology is determined by the problems and solutions of the groups. This contradicts a classical linear view of technology development, and a case can be made, that when looking back at the development of a technology, the direction might seem linear with only the successful cases as points in the development, but in SCOTs view, this is not the case going forward with a technology. There are a multitude of choices at each step of the development, based on the needs and ideas of the groups, and a development of the technology does not

simply succeed over its competitors, because it is universally better, but because it solves the problems that the social groups experience with the technology. (Pinch and Bijker, 2012)

The concept of SCOT is often visualised by the development of a well-known everyday object; the bicycle. In a linear understanding of the development, it is most common to focus on the versions that were the most significant; from the Boneshaker to the Penny Farthing to Lawson's Bicyclette, but a multidirectional approach allows the researcher to explore, why some variations would succeed and some would fail. While the Penny Farthing did solve some of the comfort-problems relating to the Boneshaker, it was in many aspects not a very practical vehicle, and it could be outright dangerous if you were elderly and was deemed rather inappropriate for a woman or a child. But if you were a "*young man of means and nerve*", the Penny Farthing could transport you at great speed to your destination with its large front wheel. These different points of views are in SCOT referred to as "interpretative flexibility"; that the artefact has differentiating meanings in the social groups. At this point, attempts were made to accommodate the other groups needs by turning towards tricyclettes or building bouncing mechanisms into a bicycle with more symmetrical front- and back wheels, which before were very uncomfortable due to vibrations and not as fast as the Penny Farthing. At this point the technology will in SCOT-terminology be described as "unstable". A solution to the different problems was found by installing air-filled tires on bicycles with symmetrical wheels; at the same time making the bicycle much more comfortable and safe for women and elderly, but not posing a problem for the "*young men of means and nerve*" as the air-filled tires could provide speed comparable to that of the Penny Farthing, who therefore adopted the development of the technology. Even though some groups could still have problems with the new development, air-filled tires served a great role in terms of stabilizing the technology. (Pinch and Bijker, 2012)

The following illustration is an example of the linear understanding of technology development, which is usually used for describing the development of a specific technology. It is based on the notion, that development of technology follows a line of improving an idea with increasingly better iterations of the technology in order to unlock its best potential:

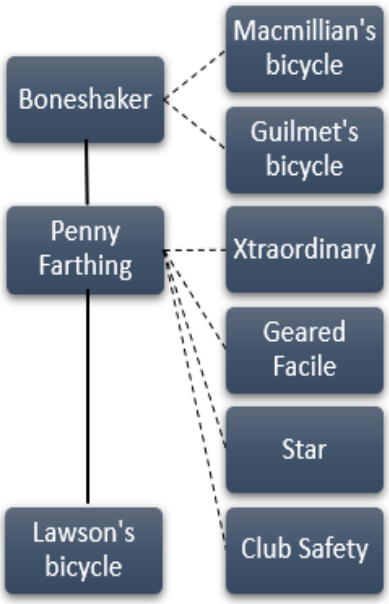


Figure 7: The traditional quasi-linear view of the developmental process of the Penny Farthing bicycle (Pinch and Bijker, 2012)

The following illustration shows how SCOT views the development; that different suggestions are being developed simultaneously, and sometimes incoherently, as based on the problems and solutions of the groups involved in the development. The further developments are then by SCOT not successful or unsuccessful correlating their ingenuity or unlocking of potential, but simply by what the groups accept as solutions to their problems with the existing technology.

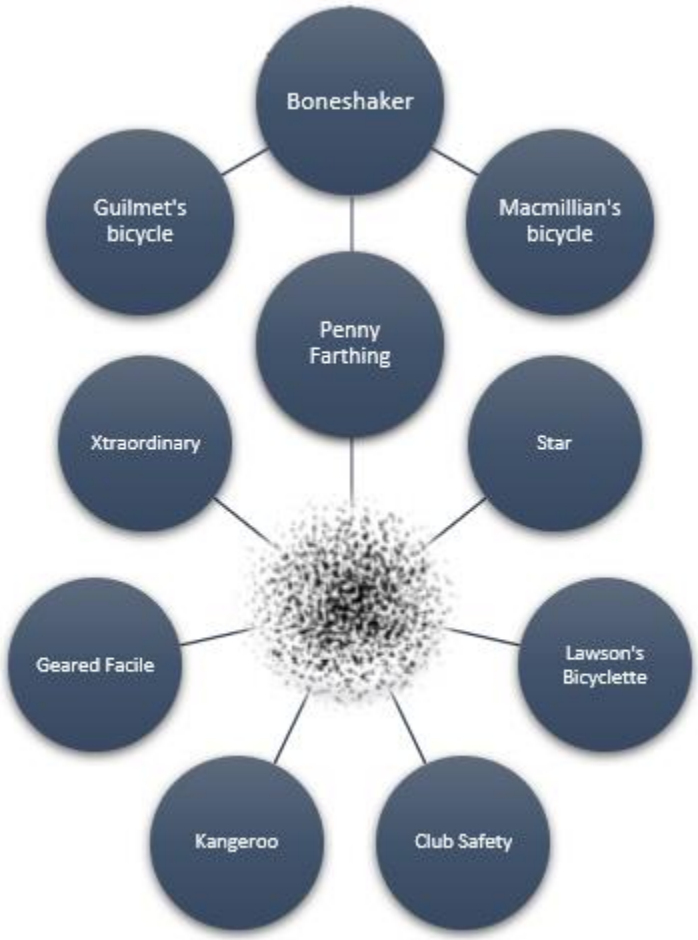


Figure 8: The development process of the Penny Farthing bicycle (Pinch and Bijker, 2012)

4.1.1 SCOT as a methodology

In the approach of SCOT, there is an interrelationship between technology, groups and problems. First, you have the technology; an artefact existing in the society. Next, you have social groups and lastly, you have problems. A problem is defined by "*when something constitutes a problem for a social group".* This, of course, entails defining a social group. A social group is an opposition to groups defined by organisations or institutions, such as the military or a company. It is defined by the notion, that all members have the same set of meanings in relation to the specific artefact. In the case of bicycle-development, groups could for instance be; female cyclists, older cyclist, male cyclists and anti-cyclists (further groupings inside these groups could also be relevant). (Pinch and Bijker, 2012)

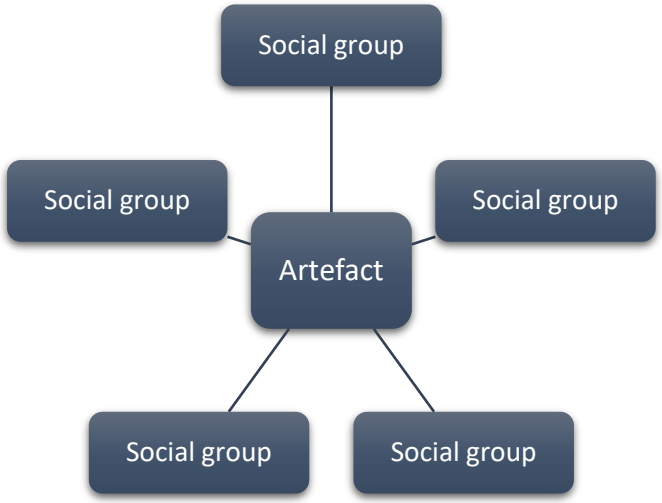


Figure 9: The relationship between an artefact and the relevant social group (Pinch and Bijker, 2012)

Hereby, it is possible to define the function of the artefact within the group. With detailed descriptions of the groups and the function of the artefact within the group, it is possible to understand the needs and challenges this group might experience with the artefact and thus, how the group constructs the technology. It is important to understand, that not only does the artefact have different meaning between groups, but that the groups based on this, influence the design of the artefact. This is the "interpretative flexibility" as mentioned earlier. (Pinch and Bijker, 2012)

After defining the social group, the next area of interest, in terms of understanding the interpretative flexibility, is, what these groups experience as problems with the artefact. (Pinch and Bijker, 2012)

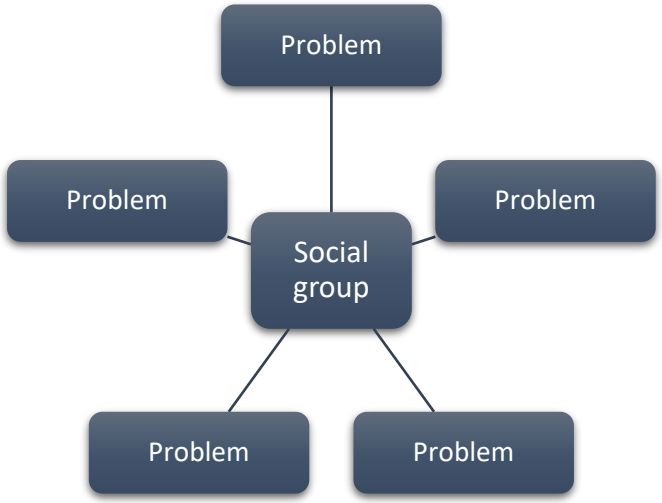


Figure 10: The relationship between one social group and the perceived problems (Pinch and Bijker, 2012)

The next step is to identify various solutions around each problem, formulated by the groups in order to stabilize the technology (Pinch and Bijker, 2012).

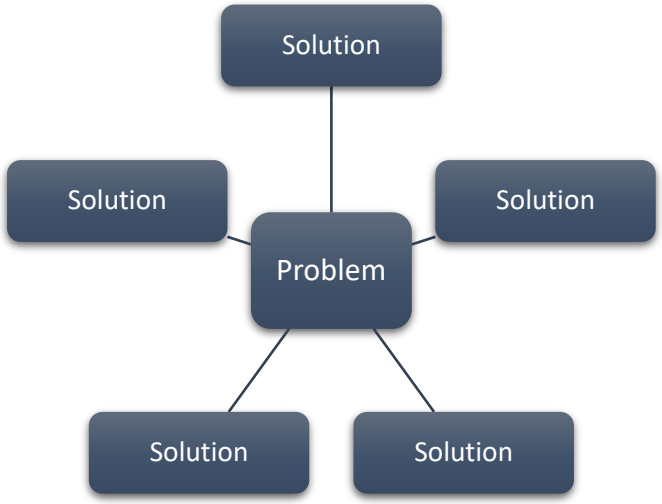


Figure 11: The relationship between one problem and its possible solutions (Pinch and Bijker, 2012)

To close the controversy between the groups regarding the artefact, is not necessarily to solve the problem. Pinch and Bijker describes two strategies for closure af a controversy. One so-called *"rhetorical closure"* where actors can attempt to convince another that a problem, in fact, is un-problematic. Another closure strategy is *"redefinition of problem"* where actors may try to solve a problem by defining it as something else entirely. The main thing is that the group

considers the problems to be solved or as insignificant and thereby the technology has reached the next level of stability. The closure or stabilization of a technology is rarely total and simultaneous, hence why the term "level of stability" is used. There still might be problems experienced in some groups. (Pinch and Bijker, 2012)

The following illustration shows a step-by-step guide on how to perform an investigation with SCOT methodology. Firstly, you must investigate the field in order to uncover knowledge from actors, who are divided into social groups. This knowledge is then organized by defining their problems and solutions. The next step is to analyse and condense the vast amount of data into concrete solutions that will close problems for the groups, and as a result stabilise the technology. The last step is to discuss the implications of the solutions and whether they might create problems for other groups. (Lauritsen, Olesen and Bruun Jensen, 2007) This thesis will follow the taxonomic structure of this figure.

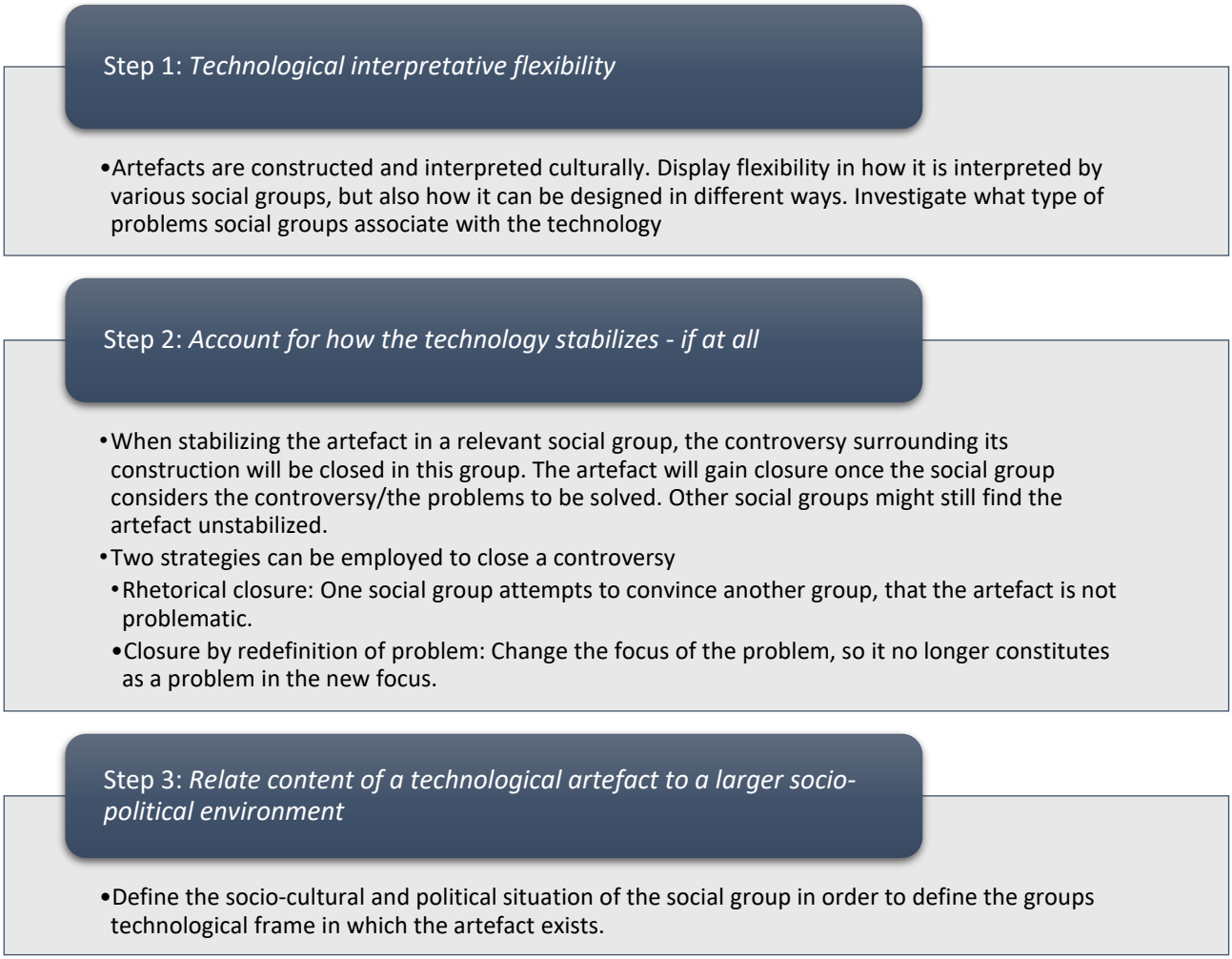


Figure 12: SCOT as a methodology

4.1.2 SCOT as a theory

To qualify SCOT as a theory; a way to understand and interpret the world, there is a need to investigate the interpretative flexibility of the groups further, and stabilization processes and understand why social groups construct technology in a certain way.

To do this, one of the creators of SCOT, Wiebe Bijker, has suggested the term *technological frame*, which is defined as:

> *"A technological frame includes all the elements that has influence on the interaction inside a relevant social group and leads to the attribution of meaning of technological artefacts - and thereby to the constitution of technology."* (Bijker, 1997; Lauritsen et al., 2007)

A technological frame consists of elements that will help the researcher understand the attitudes in the social groups. The elements could be; goals, problems, solutions, theories, tacit knowledge, test procedures, design methods, exemplary artefacts etc.. This knowledge will help the researcher understand the attitudes of the group when analysing the empirical data. A technological frame is individual for each group, and a term for the resources within the group in relation to the artefact.

At the same time, the term technological frame encompasses the resources an actor can use into changing and developing a technology, but also contains conservative and stabilizing thoughts and procedures about how a technology is constructed. The frame will guide the actor in their attitudes and actions and will contain both the central problems' relation to the technology and the strategies for solving them. At the same time, they are limiting in terms of what the actor cannot or think they cannot do.

When the case-studies are performed, the insights must be gathered into concepts in a "*theory of invention"*. Bijker has the following four demands for the concepts. They must:

1. Make it possible to describe both change and continuity
    a. *The technology should on one hand be viewed as a breach from former technology, but on the other hand the technological development should also be seen as a continued process from former practice*
2. Make it possible to perform a symmetrical analysis

    a. *The technology cannot be viewed only by itself, but must be attached to a social group*
3. Make an analysis on both an actor-level and a structural level
    a. *Even though the approach is based mostly on actors, it is important to remember that actors are bound by certain structures*
4. Not be based on assumptions about that is social and what is technical
    a. *These areas are not separate, but intertwined - technology is socially constructed and the social is technologically constructed* (Bijker, 1997b)

But SCOT should not be seen as a simple explanatory model regarding the interrelation between how the social constructs technology and reversely, how technology constructs the social. Bijker describes three different configurations of how a socio-technical ensemble can be, however not in their finished form:

1. The first is a scenario, where there is not one dominant technological frame to guide the actors' interactions. This scenario is dominated by innovation in light of the absence of structural mechanisms.
2. The second is a scenario, where one group can insist on their definitions of both problems and solutions. In this scenario the innovation will be moderated, and the development will follow somewhat conventional tracks.
3. The third is a scenario, where two or more groups are placed in each their different technological frame. In this situation there will be controversy between groups.

    (Bijker, 1997b)

Scenarios can help put the theory of technology into a larger societal context by defining how the strength-relationship between actors can be understood (Lauritsen, Olesen and Bruun Jensen, 2007).

5.0 Methods

The methodological framework of the study is SCOT, as described in the previous chapter. The methodology contains a sequence of steps, which can be utilised in order to provide a resolution to the problem statement. This study will seek out data to support a formation of social groups, uncovering of problems and attempts at stabilising the problems via defined solutions. The structure of this process will be depicted in a study design below. Furthermore, there will be a description of the methods used for the gathering of background information as well as data collection. Firstly, a description of the literature study will be presented. Secondly, relevant material will be presented and accounted for. There, we present the three main sources we have used to form our foundation of background knowledge and data needed for analysis; reports, interviews and video material. In combination, these three sources provide us with solid knowledge in the field of PRO in general practice.

5.1 Study design

Here will be a display of the study design, showing how the study will move from the gathering of empirical data, through the processing of set of meanings, social groups, problems and solutions, to the analysis and final discussion through a converging and diverging structure. This model will be reiterated through the report, in order to clarify what stage of the process the study has reached.

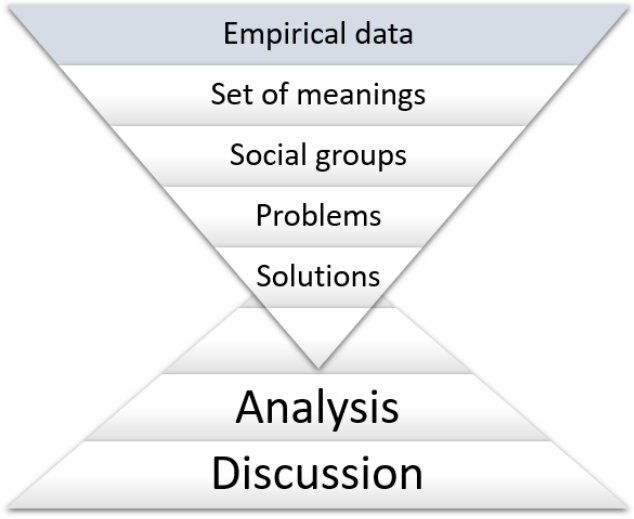


Figure 13: Study design; methods

As the illustration shows, this section of the study deals with the collection of empirical data.

5.2 Access to the field

Based in the background knowledge attained earlier in the study, as described in *2.1 Patient-reported outcomes* and *2.2 PRO in Danish general practice*, relevant actors were discovered. It was found, that MedCom oversees developing and implementing PRO in general practice, which identified them as a relevant actor in the landscape. This led to a contact being established to a representative in the organisation, who acted as gatekeeper and facilitated contact to the relevant actor for the PRO development. Thus, through the snowballing method, an actor for an interview was reached.

Through the Program PRO report, it was learned, that the PRO secretariat is a significant actor in the PRO field. A contact in the PRO secretariat was already established, which eased the process of gaining an interview with that organisation. Finally, contact with one or more general practitioners were needed, prompting a snowballing effort in our network to facilitate a contact. A gatekeeper was located as one of our supervisors was able to facilitate contact to a GP. Several other attempts at reaching GPs were not successful.

A gatekeeper is a person or an organisation standing in a position between the researcher and the field. The gatekeeper can in a figurative way open gates, to allow the researcher into the field and collect data. Simultaneously, a gatekeeper also controls if the researcher can get the access at all, and who the researchers should contact. This might be a deliberate choice on the gatekeeper's side, caused by the gatekeeper having their own agenda or not liking the scope of the project, but might just be caused by the gatekeeper having their own limits in regard to, who they know and have access to. (Lavrakas, 2008; SCHJØDT, 2019) Thus, a gatekeeper can either be of significant help to the study but can also affect it in a negative way. This means, that the researcher needs to be considerate of who the gatekeeper facilitates contact to.

The PRO-secretariat had the role of gatekeeper in previous projects; at the same time providing access, contacts and information, but also controlling who access was granted to, what extent of contact was acceptable and what topics and formulations could be used in the investigation (Stoustrup and Jørgensen, 2019). SCOT mentions snowball-sampling as the preferred method, when accessing the field, you wish to investigate. Snowball-sampling is a non-probability sampling technique with an object to reach otherwise hard-to-reach actors. The method consists of asking each participant if they can refer you to relevant actors inside

the field after an interview or another form of contact. When all actors begin referring to actors, that are already mentioned, you theoretically have reached a sufficient number of relevant actors of the field. (Lauritsen, Olesen and Bruun Jensen, 2007; Chromy, 2008). The contacts reached through "snowballing" are, as mentioned, not always representative of the entire field. Researchers must therefore be attentive towards this bias and preferably have several gatekeepers with altering opinions and positions in the field, to gain a true picture. (MØLLER, 2019)

In this case, the snowball-sampling was not as extensive, as there would be a great number of actors reached, if done like SCOT recommends (Lauritsen, Olesen and Bruun Jensen, 2007). This would pose a problem in terms of time management and gaining more data, than what would be realistic to process in the analysis. Furthermore, the scope was not to gain access to all relevant actors, but to gain access to those, who it was already presumed was able to give relevant information, enabling the answering of the problem statement. This, of course, leaves a bias - if we have only contacted actors, who would confirm the assumptions about the problem and prevent ourselves from gaining important insights, which there must be an awareness of when concluding from the empirical data.

5.3 Data collection

Data has been gathered from several sources. These consist of official reports, research papers, interviews and video material. In combination, these will provide thorough knowledge on the use and perception of PRO in general practice in a Danish setting, both historically, presently and forward-looking. First off will be a description of the method of obtaining knowledge and information about the scope of study, by in detail describing the initiating literature search, and the three additional sources of data that has been used; reports, semi-structured interviews and video material. These methods have been chosen in order to obtain a broad range of data to determine the set of meanings from the actors.

5.3.1 Structured literature search

In order to investigate pre-existing research into the field of the challenges of implementing PRO in general practice in Denmark, a structured search for research in this area is commenced. The method of detecting and selecting relevant studies are based on the method described by Preferred Reporting Items for Systematic Reviews and Meta-Analysis, abbreviated as PRISMA. PRISMA is a method developed specifically for identifying studies in the field of evaluating healthcare intervention (Moher *et al.*, 2009). The method consist of a thorough 27 step checklist for guiding a systematic review or a meta-analysis, but since this study is not a such, the steps for a general outline are used along with the visualisation tool, the PRISMA flowchart, in order to visualise the strategy for identifying, screening and excluding or including relevant articles (PRISMA, 2015).

A structured search for peer-reviewed articles on Aalborg University's database PRIMO is conducted. PRIMO is the university library's online database comprised of all physical texts and much of the electronic material that students can access. The database gives access to countless journals that publish peer-reviewed articles. Searches can be built and refined using sorting, special characters and combinations in the search engine. (AAU Library, no date)

The search string is an advanced search comprised of "patient-reported outcomes" AND "general practitioner", which prompted too many results.

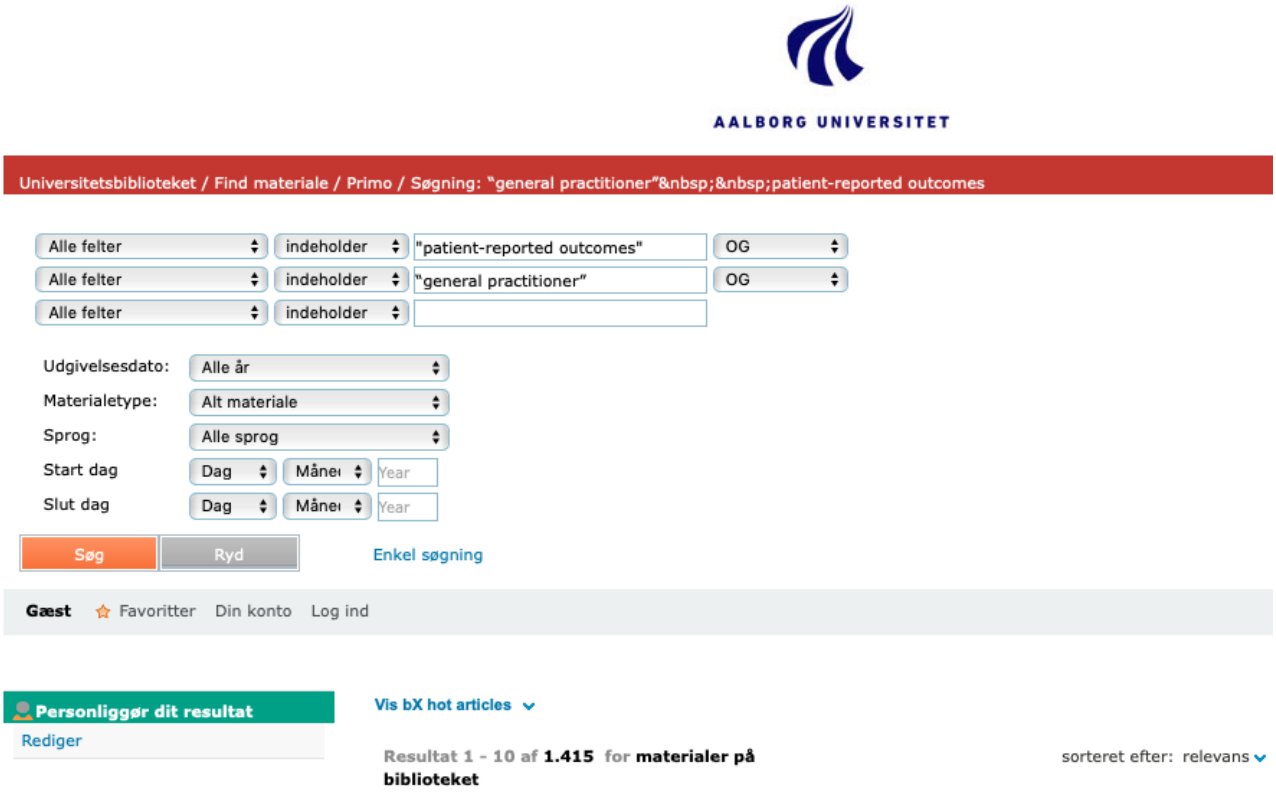


Figure 14: Search results

A new search string is therefore defined with "patient-reported outcomes" as a title-word and "general practitioner" as a word for all fields, meaning that articles are required to have "patient-reported outcomes" as a word in the title, but only "general practitioner" somewhere in the article's text. This choice was made to only retrieve articles that have PRO as a focused method/intervention, not only as a tool for obtaining information, as many researchers use it for, but do not evaluate whether the use of PRO in itself had an impact.

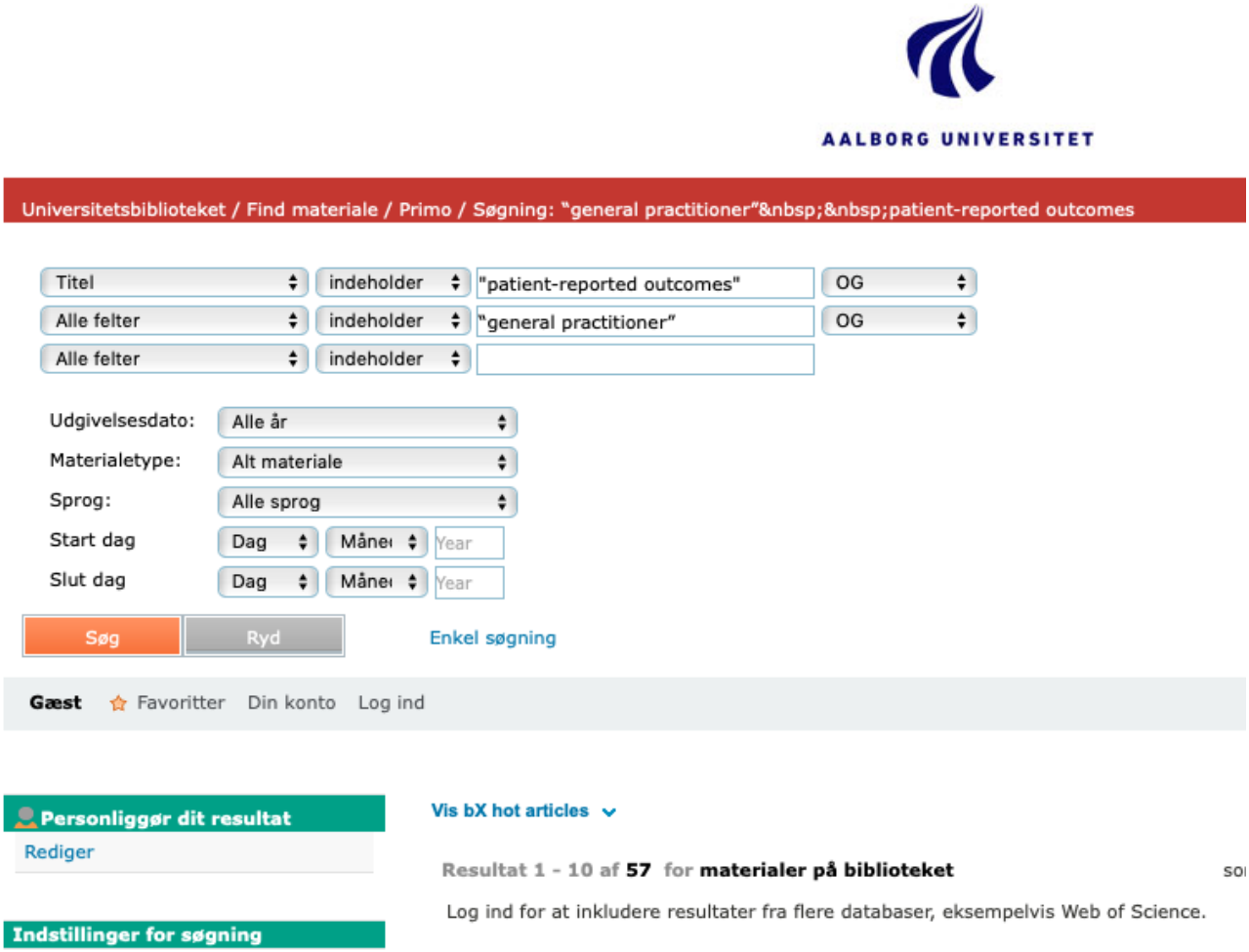


Figure 15: Search results

The search rendered 57 results, so this search is then combined with the search word "Denmark", seeing as the scope only concerns the Danish setup of three different sectors with general practitioners as a private agent. This search rendered four results and is filtered for peer-reviewed articles only, in order to keep a satisfactory level of academic unbiasedness. This rendered three results that are screened by reading abstracts to investigate, if the articles presented studies that has already investigated this field of interest or studies that are relevant for this study, providing background, methods or other insights.

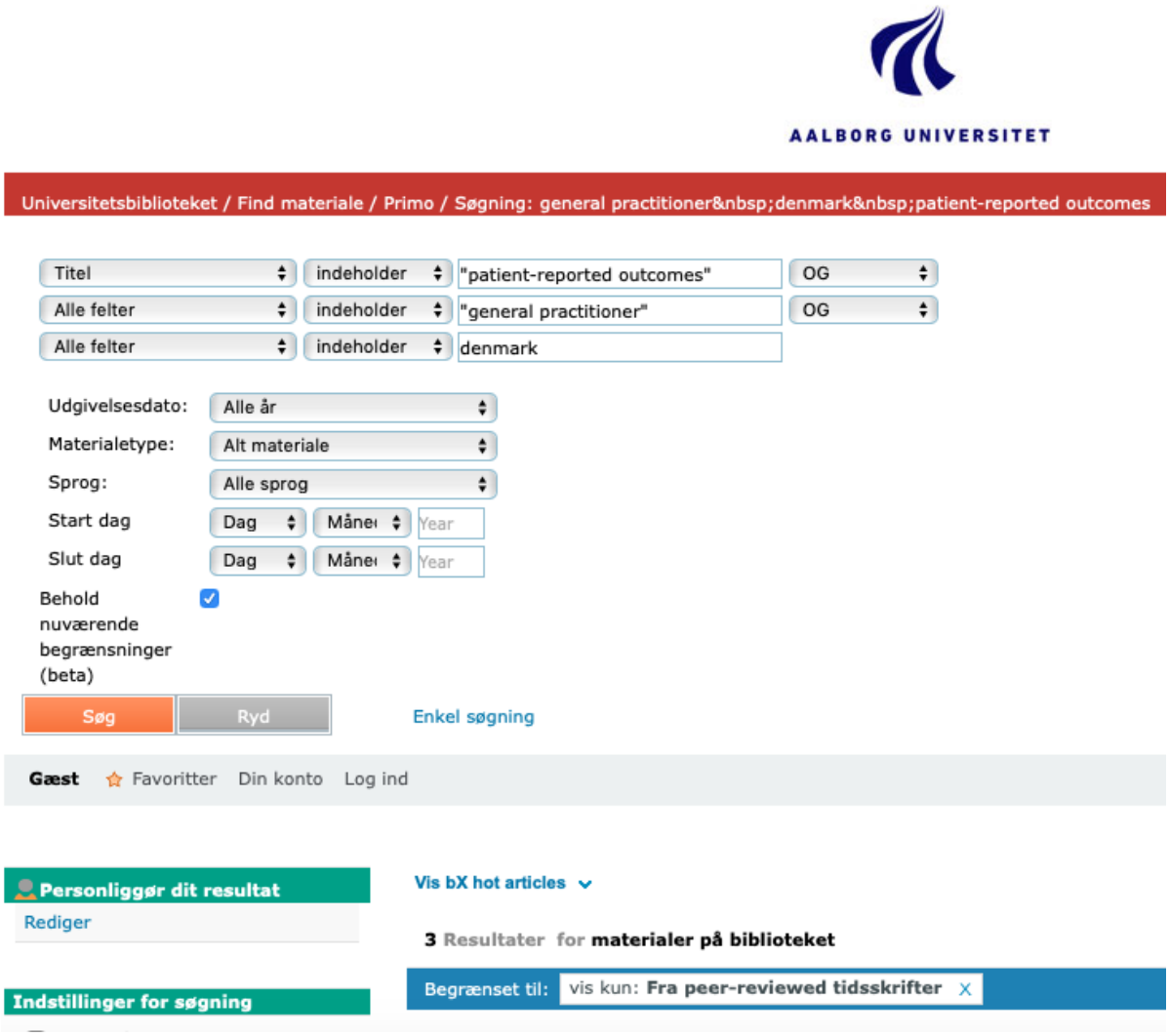


Figure 16: Search results

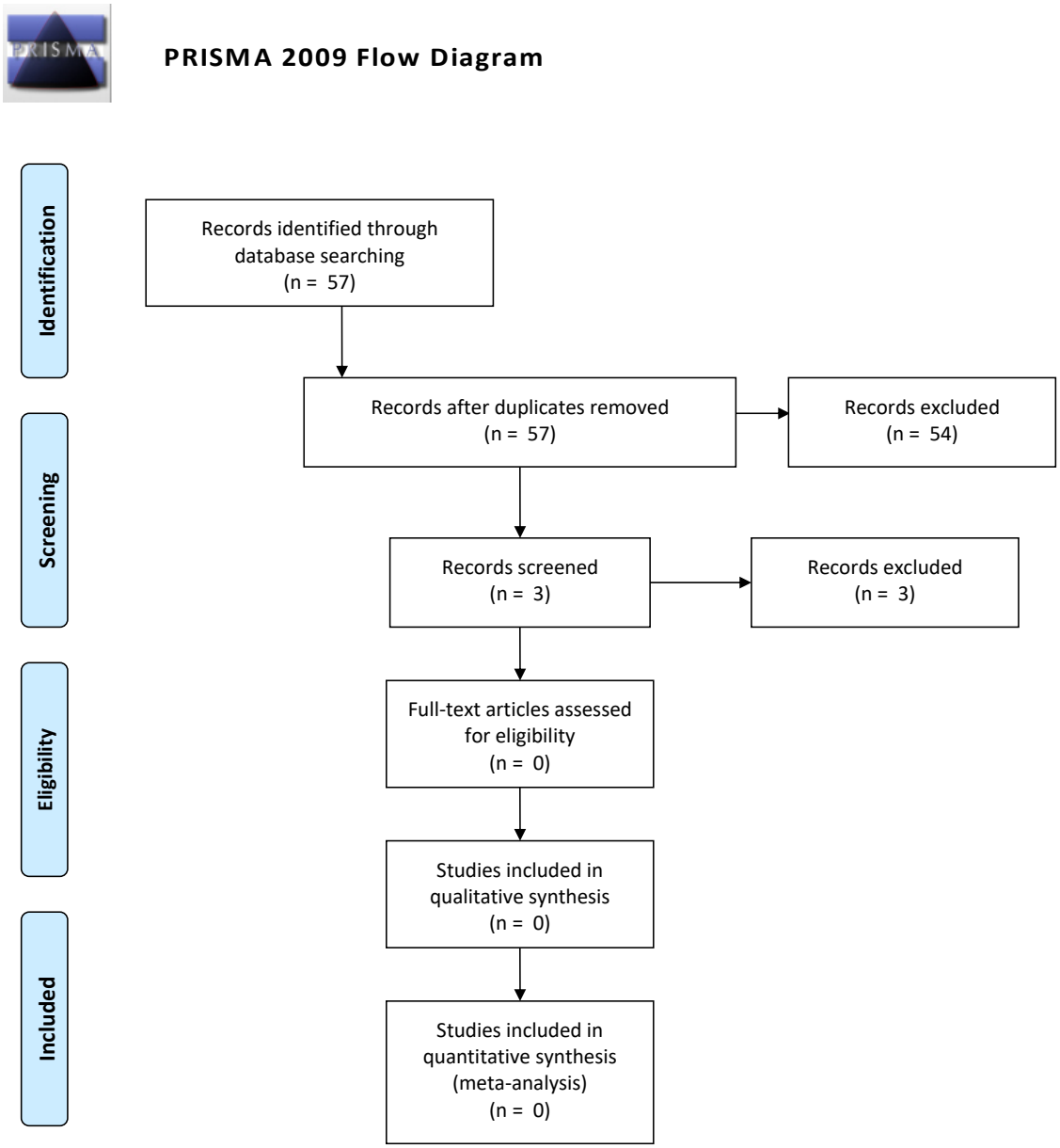
The abstracts are scanned for mentions of PRO in general practice.

Title, authors, journal, year	**Relevance for scope**
Health Care and Patient-Reported Outcomes Richard R. Rubin, Mark Peyrot, Linda M. Siminerio Diabetes Care Jun 2006	None. No mention of general practitioners in abstract.
Patient-reported outcomes at hospital discharge from Heart Centres, a national cross-sectional survey with a register-based follow-up: the DenHeart study protocol Berg SK, Svanholm J, Lauberg A, *et al* *BMJ Open* 2014	None. No mention of general practitioners in abstract.

AmbuFlex: tele-patient-reported outcomes (telePRO) as the basis for follow-up in chronic and malignant diseases Liv Marit Valen Schougaard, Louise Pape Larsen, Anne Jessen, Per Sidenius, Liv Dorflinger, Annette de Thurah, Niels Henrik Hjollund Quality of Life Research March 2016	None. No mention of general practitioners in abstract.

Figure 17: Relevance of reports

The structured literature search shows that no apparent research on the topic is available and underlines the relevance for this study, as there seems to be a gap in knowledge in this area. This also entails, that there is no standard for venturing into an investigation and analysis of understanding PRO in general practice in Denmark.



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Figure 18: PRISMA of structured literature search

5.3.2 Reports

In order to uncover different set of meanings towards PRO as a technology, reports are sought out from relevant actors regarding the development, implementation and vision for the use PRO in Denmark. Seeing that the literature study targeting knowledge on PRO in general practice in a Danish setting did not provide significant knowledge, attention is turned to a different type of literature, in order to find information on the scope. In order to seek out and make use of other reports, document analysis is employed as a method. Using existing documents for analysis purposes require an awareness of how these documents are collected, how are they are to be analysed systematically and how the results should be presented. A way of uncovering relevant documents is through snowballing, similar to the way you snowball through actors. A main document is selected and searched through for references or connections to other documents. In order to select the main document and to know what other documents are relevant, it can be helpful to determine a number of criteria. (Brinkmann and Tanggaard, 2010) To contribute to the scope, the criteria are as follows:

- Must be about PRO specifically or digital healthcare with relevance for PRO
- Must be in a Danish setting
- Must be from a reliable source

These criteria have led to a decision to the choice of the digital health strategy for 2018-2020, A Coherent and Trustworthy Health Network for All, published by the Ministry of Health as the main document. It is a report that concerns digital health in general in Danish health care, and has several references specifically to PRO. Furthermore, it describes the larger coherence in the health sector which PRO ultimately is meant to be a part of. Basing the search of reports upon the strategy, a reference to the National Targets for the Health System is encountered, which leads to the report covering these targets. The digital health strategy directly references the National Targets, which led to that report. Both above-mentioned reports are published by the Ministry of Health, who is one of the parties behind MedCom, who develops digital communication tools for the Danish health sector. MedCom has developed a module for using PRO in general practice in Denmark and recently published a report covering the evaluation of the process. In that report, a reference to Program PRO is found. Besides the Ministry of Health, Danish Regions and Local Government Denmark (KL) also participated in the production of the digital health strategy as well as the National Targets, and those two actors commissioned an

initiative on how PRO is used systematically in the health sector, leading the search to a report by PA Consult. Thus, our snowballing efforts ultimately led us to the following five reports on the development, use and plans for PRO in general practice in a Danish setting:

Name	Author	Year published	Type
A Coherent and Trustworthy Health Network for All. Digital Health Strategy 2018-2022	Ministry of Health, Ministry of Finance, Danish Regions and Local Government Denmark	2018	Tertiary
National Targets for the Health System 2018	Ministry of Health, Danish Regions and Local Government Denmark	2018	Tertiary
Evaluation of Patient-Reported Information (PRO) in General Practice	MedCom, Ministry of Health, PLO and CIMT	2019	Tertiary
Analysis of Patient-Reported Information (PRO)	PA Consult	2015	Tertiary
Program PRO - Application of PRO-data in quality development in the Danish Health Care System	TrygFonden and ViBIS	2016	Tertiary

Figure 19: Reports on PRO used in data collection

As the matrix shows, the chosen reports are all tertiary documents, meaning they have been written later than the contents occurred. For these reports it means, that they have been written after an intensive review of the information it contains and is not a product of what has happened in the moment the information was produced. Thus, it is significant to keep in mind, that this information is more processed than it would be, if it was statements presented in an interview or in a comment at a conference. A choice has been made though, to use the information from the reports equally with data derived from interviews and quoted from video recordings of conferences, due to an assumption that the information presented in the two second data sources are somewhat processed as well, seeing that those who have uttered it are employed by some of the same actors and thus presumably follow the general opinion of this actor. (Brinkmann and Tanggaard, 2010)

In snowballing, you should continue searching until no more new references appear, but in this case, a choice was made to stop prematurely, seeing that this selection of

reports appeared to contain enough data for this purpose. It is likely, that more documents could be uncovered through this method providing the study with a deeper perspective, but a limit needed to be set to accommodate the time needed for processing and analysis, thus, a conscious choice to not continue searching was made.

Insights on actors

Below is an overview of the actors behind the reports in order to create a context regarding who they are and what their affiliation to the field of PRO is. They are listed separately from the list of reports and videos, to make it easier for the reader to separate the information and avoid overly large matrices.

In SCOT terminology this is the first step of creating a technological frame for the social groups, as explained in chapter *4.1.2 SCOT as a theory*. Later, the technological frame will be expanded with the group's understandings of the technology; i.e. set of meanings, problems, solutions.

Actor	**Insights**
Ministry of Health	The task of the ministry is to assist the government in decision making regarding health and the elderly. They work to achieve a healthy Denmark with a focus on the citizens. (Sundhed- og Ældreministeriet, 2017) The ministry is head of a variety of departments, hereunder the Danish Health Data Authority and by extension, the PRO secretariat. The ministry is also one of three owners of MedCom. This means, that the ministry is head of two actors who develop and implement PRO tools in the Danish health care sector simultaneously.
Ministry of Finance	This ministry oversees economic politics, hereunder the financial agreements that affects the public strategies in Denmark, i.e. the digital health strategy. (Finansministeriet, no date)
Danish Regions	Interest organisation of the five regions in Denmark and employers' organisation. They work to promote and secure the interests of the regions, i.e. in matters of health care. (Danske Regioner, no date a)
Local Government Denmark	Interest organisation of the 98 municipalities in Denmark. Similarly, to Danish Regions, Local Government Denmark works to make sure the interests of the municipalities are considered. (Kommunernes Landsforening, no date)
MedCom	Non-profit organisation owned by the Ministry of Health, Danish Regions and Local Government Denmark (KL), who develops cross-sectorial digital communications solutions in the Danish health care sector. (MedCom, 2019a)

	They are in charge of the implementation of PRO in general practice through an addon to WebReq called WebPatient. This project is set to conclude by the end of 2019. (MedCom, 2017)
CIMT	CIMT (Centre for Innovative Medical Technology) is a collaboration between Odense University Hospital and University of Southern Denmark who perform research and innovation in the field of new medical technologies. (CIMT, no date)
PLO	Nationwide interest organisation of general practitioners. (PLO, no date)
PA Consult	Privately owned consulting agency with a focus of innovation. (PA, no date) The report used here is commissioned by the government, Danish Regions and Local Government Denmark and based on experiences on PRO within the framework of AmbuFlex. (PA Group, 2015)
TrygFonden	Non-profit organisation that works towards a safer Denmark independently as well as in collaboration with others. (TrygFonden, no date) In the report used for this thesis, they have collaborated with ViBIS. (Munch-Petersen *et al.*, 2016)
ViBIS	An organisation founded by Danish Patients to perform research and promote patient involvement in Danish health care. (Danskepatienter, no date a)

Figure 20: Insights on actors from reports

5.3.3 Interviews

In order to gain information on the understandings of PRO in general practice, a string of semi-structured interviews are performed. (Brinkmann and Tanggaard, 2010) Interviews are typically a good way of gathering data, seeing that you can gain a deeper understanding of actors and their opinions, which you would not be able to get through i.e. a quantitative methods or observations. In interviews, you have your actor in close reach and can adapt your line of questioning continuously through the interview process, if needed. This allows for a more open and engaging conversation compared to i.e. questionnaires, that are traditionally more closed off. Interviews can also prove to be a good tool for uncovering tacit knowledge, that would not come up in questionnaires (Brinkmann and Tanggaard, 2010). Also, it is a quicker way of gaining a large amount of data, which is an advantage when dealing with people who do not have a lot of time to spare. General practitioners are a group who can be very difficult to reach, mainly due to them being busy, so we are aware, that we may not be able to secure many interviews. Because of this, the rest of the data collection process works towards uncovering data that covers a wide spectrum of GPs, in order to get as broad a sense of the field

as possible, i.e. through interviews with other actors relevant for the field, here MedCom and the PRO secretariat. This, to gain as extensive an understanding as possible, but also to explore how those in charge of the development understand the technology. For this thesis, telephonic interviews with relevant respondents have been chosen, seeing that the logistics of face to face interviews is an obstacle due to distance.

Interview guide

For the interviews, the line of questioning will be based on defined terms from the SCOT terminology; *Set of meanings*, *Problems* and *Solutions*. When constructing the interview guide with these terms in mind, it is assumed that the best possible foundation to get the necessary information from the actors is achieved. The interviews will be performed with a very narrow number of representatives from a broad section of the PRO landscape relevant for general practice; the PRO secretariat, MedCom and general practitioners. It was also considered to interview representatives from the Ministry of Health, PLO, researchers and possibly other relevant actors as well, but ultimately decided against it due to a desire to speak to those directly involved with the implementation, rather than include actors who are more in the periphery. Also, reaching actors for interviews, transcribing it and processing data is a time-consuming process, so this decision has been made in order to focus on the most relevant actors and dedicate enough time to process the data properly. Seeing that data in this study is composited of data from interviews as well as data from reports covering a number of the other actors considered, as well as brief sections of video material, the study will ultimately have covered a large spectrum of the PRO landscape upon completion. Though the interview guides all have the same starting point in the SCOT methodology, the wordings will vary in order to accommodate the relevance of the individual actor (Appendix 2, 4, 6).

Insights on actors

As well as after presenting the chosen reports, there will be provided a short presentation of relevant insights on the actors selected for interviews, in order to provide more context.

Actor	Insights
PRO secretariat	The PRO secretariat is an administrative organ charged with supporting the national PRO steering group. They are located in the Danish Health Data Authority in the department of data quality and -content. They supervise the national work with PRO in the Danish health care sector. (PRO-sekretariatet, 2018a)
General practice	In general practice, GPs can request laboratory samples electronically through WebReq. (Dansk Medicinsk Data Distribution, no date b) MedCom has developed an addon to this program called WebPatient, which enables GPs to order home monitoring forms. Currently, WebPatient offer 14 questionnaires spanning from blood pressure measurements and headache journaling to Peak Flow measures and weight controls. These questionnaires are presented as PRO questionnaires. (Dansk Medicinsk Data Distribution, no date a)
MedCom	Non-profit organisation owned by the Ministry of Health, Danish Regions and Local Government Denmark (KL), who develops cross-sectorial digital communications solutions in the Danish health care sector. (MedCom, 2019a) They are in charge of the implementation of PRO in general practice through an addon to WebReq called WebPatient. This project is set to conclude by the end of 2019. (MedCom, 2019b)

Figure 21: Insights on actors from interviews

5.3.4 Video material

In addition to the interviews and chosen reports, the data will be supplemented with quotations and observations from carefully selected video material. These being the launch event of Program PRO and the MedCom conference covering the evaluation of their implementation of PRO in general practice. These two videos contain material which are found to be relevant for the scope. Video material can be viewed as either research film or ethnographic film, where research film displays the reality as undisturbed as possible and ethnography display a chosen narrative. Based on the way these videos are filmed, it is assumed that they are research film, as there is no obvious narrative to be observed. Nonetheless, there should always be an

awareness of a possible agenda when working with video produced by others (Pink and Pink, 2007). Both the MedCom videos as well as the video on Program PRO have been uploaded to YouTube on their respective channels, with no reference to other parties involved in the production. Hence, it is assumed, that they have recorded, edited and uploaded the material themselves.

Insights on actors

In this section, the actors encountered in videos will be described in order to provide a context for why we have engaged with them and why they are relevant for this thesis.

Actor	Insights
ViBIS	An organisation founded by Danish Patients to perform research and promote patient involvement in Danish health care. (Danskepatienter, no date a) The video material used in this report is from the launch of Program PRO in September of 2016. The video material used can be found online on ViBIS' website. (Danskepatienter, no date b)
MedCom	Non-profit organisation owned by the Ministry of Health, Danish Regions and Local Government Denmark (KL), who develops cross-sectorial digital communications solutions in the Danish health care sector. (MedCom, 2019a) They are in charge of the implementation of PRO in general practice through an addon to WebReq called WebPatient. This project is set to conclude by the end of 2019. (MedCom, 2017) The video material used as a source for this report is videos filmed at a MedCom conference which took place in February of 2019. They can be found online on MedComs website. (MedCom, 2017)

Figure 22: Insights on actors from video material

6.0 Results

The previous chapter dealt with the collection of data, which will be processed in this chapter. As the illustration below shows, this stage of the study will concern itself with the condensation and sorting of the data set and uncover the set of meanings of the actors, what social groups they are to be placed in and what problems and solutions are expressed by the groups.

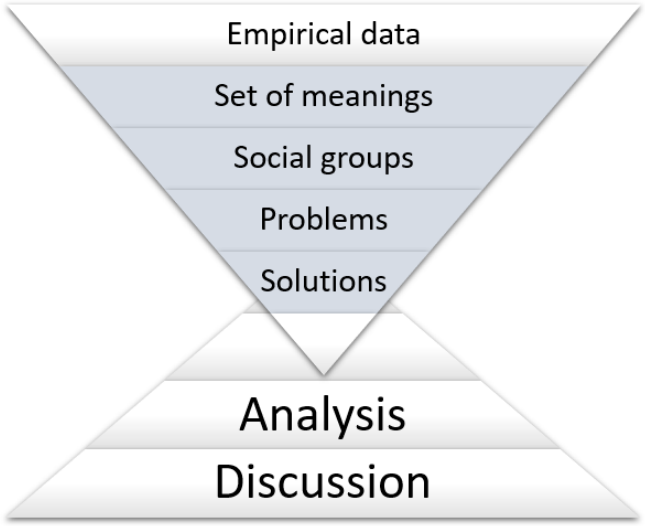


Figure 23: Study design; results

Results of the condensations will be presented in matrices for a better overview. The first matrix will be a display of the included actors and their set of meanings. The second will be a display of the problems expressed directly and indirectly by the actors, and thirdly, a matrix showing the potential solutions that have been defined by the actors.

6.1 Set of meanings

Below the actors present in all three sources of data are listed with their main set of meanings. The actors consist of authors of the reports that are included, individuals who have been interviewed and entities behind the video material used. Seeing that some actors are connected to several sources of information, they will have a set of meanings displayed, that is also connected to other actors. Also, some actors are co-authors of reports, and will thus share a set of meanings. It is not possible to distinguish, whether they have varying set of meanings as separate actors, when the knowledge is derived from a single source.

The set of meanings have been chosen based on a set of criteria. As with the document analysis conducted previously, the set of meanings will also have to adhere to a set of criteria in order to be deemed relevant for this study. The criteria are:

- Must concern the field of PRO
- Should preferably be about PRO in general practice specifically
- Must address opinions and understandings of what PRO is and should be used for

By reviewing the material carefully with these criteria in mind, a multitude of quotes, opinions, statements etc. were found. Seeing that including everything relevant would be chaotic and create matrices of immense size, the data has been condensed and is shown in the matrix below in an aggregated version. When processing the data further in the analysis, quotes will be included in their full extent, concurrent with the use of aggregated data.

Set of meanings
Actor: MedCom, PLO and CIMT From report: o PRO is a digitised solution of existing paper-based workflows o PRO should be validated questionnaires/measurements with underlying algorithms o Can increase efficiency in current workflows o Can improve data quality o Minimizes the risks of UTH o Improves patient involvement o In Denmark the understanding is that PRO is patient-reported information (oplysninger), not outcomes From interview: o The direct translation is patient-reported information o PRO is digitisation of already existing paper-based workflows and making those more efficient o PRO can be; measurement data, answers/questions, results for dialogue support - any data a GP would ask for during a consult. Basically, information you need in general practice that the patient is responsible to provide o PRO is beneficial for both patients and GPs since it will ease workflows and free time for conversation o PRO increases patient empowerment and involvement o PRO heightens quality of data o PRO could be a gift for GPs in easing workflows o PRO can reduce the risk of UTH GPs would like to contribute to the development of PRO, but are careful with sharing data
Actor: PRO secretariat

- Everybody talks PRO, but they talk about it from their own point of view
- PRO gives the patients more influence and ability to set the agenda
- Tips the power scale towards the patient
- Gives the patient more insight on their health status and possibility to prepare for the consultation
- Provides a more holistic view on the patient as a whole
- Would be a good supplement to referrals and when transferring between sectors
- Even though MedCom focuses on objective parameters it gives GPs experience in using patient-reported data which makes way for the national initiative with PRO
- When national PRO is developed, this should be used and not MedComs own questionnaires
- It is important for patients, GPs and the secretariat that there is not uncovered information that are not being used
- Many GPs would like to contribute to the national work with PRO

Actor: General practice

- PRO is the patient performing a measurement at home and provides them for the GP
- PRO only makes sense if it eases workflows
- That PRO is based on algorithms creates less grounds for flaws in data
- Practically impossible to implement across sectors, but could be useful if the home care personnel could fill out some data and this data would be attached to the journal
- Confidentiality is not a problem as all exchanges of data would be per agreement with the patient
- It is easier to use objective measurements than qualitative questionnaires, because you need further information when asking about i.e. QoL and the questionnaires does not allow this

Actor: Ministry of Health, Ministry of Finance, Danish Regions and Local Government Denmark

- Responses from patients on their own state of health
- Personalised approach to individual needs
- Support value-based health
- Screening tool for side effects and consultation needs
- Create data for research and quality assurance

Actor: ViBIS and TrygFonden

- PRO is data coming directly from the patient and is the patients' own experience of the treatment
- PRO is a tool to achieve a more coherent course of treatments across professions and sectors
- Only the patients know their result from the overall course of treatment, therefore only the patient can give this information
- PRO has a large potential to create a more patient-centered and patient-involved healthcare system
- PRO is about the outcome of the course of treatment and an expression of the patients' overall benefit of the treatment
- To unfold PROs full potential, it must be implemented throughout all sectors
- PRO can also be useful for quality development in the healthcare sector on an aggregated level

Actor: PA Consult

- Implementation of PRO will save a large amount of expenses in the healthcare sector. This potential is even larger if PRO is implemented across sectors
- The usage of PRO will ease workflows, because algorithms will sort patients into what further contact, or treatment is required
- PRO can support an increased sense of responsibility for the patients
- PRO can support an increased experience of quality in the course of treatment
- PRO can support better diagnosing and treatment
- PRO can support easier transfers through sectors

Figure 24: Set of meanings

The most significant finds in these set of meanings, are the very varying opinions on what PRO technology is and is supposed to do. The data shows how the different actors have their focus on diverse parts of the technology; some focus on benefits for patients, others on the economic gain. This shows, that differentiated understandings of the technology do indeed exist and that the amount of data gathered seems enough to determine what understandings there are and what that entails for the further development and use of PRO technology.

According to the set of meanings discovered here, three themes have been determined and will lay the foundation for the creation of the social groups in the analysis. The themes are:

- Type of data PRO encompasses
- Positive effects of PRO for the patient
- Contributions of PRO to the health sector

6.2 Problems

Following the same procedure as when determining the set of meanings, several criteria has been determined in order to locate the problems of the actors. These criteria are:

- Must express a difficulty the actors experience themselves, or know others do
- Can be assumptions of current or future difficulties
- Can be both specific problems or more overall difficulties

Following an examination of the material, with these criteria in mind, the condensed version of the results is presented below:

Problems
Actor: MedCom, PLO and CIMT • Different views of what PRO means • Not enough GPs in the field and this causes a worry in concern of being assigned further tasks • Those who do not use PRO are not being asked, both patients and GPs • PRO will entail more work for the patient • Not all GPs are positive towards learning new systems • GPs are reluctant to share data with other sectors • The PRO-secretariat is not cooperating with PLO • GPs do not see the meaning of contributing to developing very diagnose specific questionnaires • General practice cannot contribute with a representative for development of each questionnaire • WebReq is not a part of the national infrastructure (it is private) • No clarity on how the cooperation between the secretariat and MedCom should be
Actor: PRO secretariat • Everybody talks PRO, but we have different views on what PRO is • Not every relevant party is involved in developing PRO and this is a challenge in implementing PRO across sectors • GPs are not as used to interdisciplinary work as other healthcare professionals • GPs are not used to sharing patients' personal information • GPs might feel they are breaking confidentiality with patients when sharing information • GPs might not view all patient-reported information as valid • Challenging that different PRO tools are developed and implemented for the GPs and for the rest of the healthcare sectors • GPs don't know what to do with additional information from patients that they can't use in the current course of treatment • Not all GPs are interested in involving the patient more • Difficult for the secretariat to get access to GPs, even though some wish to participate
Actor: General practice • The technology can be overwhelming for some patient groups • The current questionnaires need supplementary questions to compliment current workflows • GP need an easier way of contacting the patient regarding their data • Does not find questionnaires besides blood pressure relevant • Additional work for patient to fill out by hand and electronically
Actor: Ministry of Health, Danish Regions and Local Government Denmark • Coherence should be achieved cross sectionally • More holistic approach to the patient • Increase in comorbidity and multimorbidity heighten need for coherence

- Patients need to trust that their data are kept safe and treated respectfully
- Greater need for geographical equality
- The health sector needs to be more professionally meaningful for health professionals
- Health sector needs to provide more quality for patients
- Treatment should have maximum value for money
- Treatment should entail more value and quality for the patients

Actor: Ministry of Finance

- Coherence should be achieved cross sectionally
- More holistic approach to the patient
- Increase in comorbidity and multimorbidity heighten need for coherence
- Patients need to trust that their data are kept safe and treated respectfully
- Greater need for geographical equality

Actor: ViBIS and TrygFonden

- Patients need easier transition between sectors
- Patients do not experience satisfactory coherence in the health sector
- Patients do not experience sufficient individualised treatment
- There needs to be more insights into a patients' full course of treatment

Actor: PA Consult

- Greater coherence in the switch between sectors
- Current workflows are too expensive
- Current workflows can be slow and have delays
- Paperwork can get lost in transitions

Figure 25: Problems

The main findings in the problems expressed were, that the technology is not suitable for all actors' needs at this stage, and there are some concerns for how it will affect patients in terms of ability to use the technology and how much work they need to put into it. There are also mentions of problems related to security and data sharing, which is rather significant in a technology aiming for cross-sectoral data sharing. These problems also show, that the actors do not share understandings of the technology, which leads the study on to the exploration of solutions to these problems.

6.3 Solutions

In order to uncover the solutions bought up by the actors, the data has been examined with the following criteria:

- Should mention a way to accommodate a problem, either by themselves or others
- Does not have to relate to a specific problem, but can be more overall
- Does not have to be about PRO specifically, but must be in close proximity

These criteria have led to the condensation of the following solutions:

Solutions
Actor: MedCom, PLO and CIMT • MedCom could facilitate how general practice should be involved in national PRO • GPs could have their own group for developing questionnaires for national PRO that were broader and less diagnose specific • Questionnaires that generate value for the GPs should be used be using those, they already use in paper-form • Practice would like to contribute, but only if it creates value for them • WebPatient is smart to use to support national PRO, because of the close connection to WebReq • Another platform for PRO could be the MinLæge app or KIH that are already existing platforms for sharing data between sectors • It is important to understand the GPs values and scepticisms in relation to sharing data considering the DAMD-situation • The best way of implementing new systems is to get some to use it and tell others about it
Actor: PRO secretariat • The perception of PRO is likely streamlined over time • GPs will in time realise that they can save time if patients do some of the work • "The family GP" culture will change over time and make way for new practices • Important to look at current workflows and recycle best practices when developing PRO • GP could gain greater influence on questionnaires if they participate more in the development • Finding solutions to symptoms of a more psycho-social character • The health sector needs to go through a journey of cultural change • GPs get accustomed to using questionnaires through MedComs work
Actor: General practice • Objective questionnaires are precise to work with regarding PRO • Ease GPs workload if home care could use PRO questionnaires
Actor: Ministry of Health, Danish Regions and Local Government Denmark • Improving electronic health records • New ways of using health information in health care communication • More interaction between GP and patient • Electronic records and algorithms will enable early detection and possibly prevent hospitalisation

- Better training in using digital solution can ease workflows
- Enable patients to follow their path though the health sector
- App can provide two-way communication between GP and patient
- PRO should be implemented across sectors to reach full potential
- PRO data should be presented through sundhed.dk
- Common infrastructure should be developed to connect local and regional PRO initiatives
- Municipalities, regions and GPs should work together to achieve full implementation of PRO
- Current work on easing data sharing between sectors should be completed

Actor: Ministry of Finance

- Improving electronic health records
- New ways of using health information in health care communication
- More interaction between GP and patient
- Electronic records and algorithms will enable early detection and possibly prevent hospitalisation
- Better training in using digital solution can ease workflows
- Enable patients to follow their path though the health sector
- App can provide two-way communication between GP and patient
- PRO should be implemented across sectors to reach full potential
- PRO data should be presented through sundhed.dk
- Common infrastructure should be developed to connect local and regional PRO initiatives

Actor: ViBIS and TrygFonden

- Implement PRO across sectors to reach full potential
- Heightened coherence can be achieved through more systematic sharing of data in the health sector
- PRO data can be used for quality development in the health sector

Actor: PA Consult

- Systematic use of PRO should be initiated to ease workflows and prevent unintended incidents
- Cross-sectional cooperation
- PRO should be seen in connection to other electronic initiatives in health care to ease workflows
- PRO can prevent loss of paperwork
- When developing PRO tools, it's important to incorporate current workflows to ease implementation

Figure 26: Solutions

Examining the solutions has shown, that the actors consider the technology from their individual point of view. It is interesting to see, how actors are more prone to think of the technology as a whole and consider the entire field when speaking of what it is and what it is meant to do, but when the topic falls on what problems it can entail and how they could be

solved, they centre on their own situation primarily. This follows the social constructivist approach and goes to show, how the technology truly is shaped through the experiences of the actors.

7.0 Analysis

Through the examination of the data and the presented results in the previous chapter, a multitude of interesting notions have been observed. It was found, that actors do indeed understand the technology based on their own experiences with the technology itself, but also with previous experiences in the field, related to the technology.

To reiterate the model of the study design, as shown below, the study has now reached the analysis part, which means that after several rounds of processing data in order to uncover knowledge and condense it in relevant themes, the data will now be processed in an expansive manner, to uncover what lies behind the condensed statements and what this means.

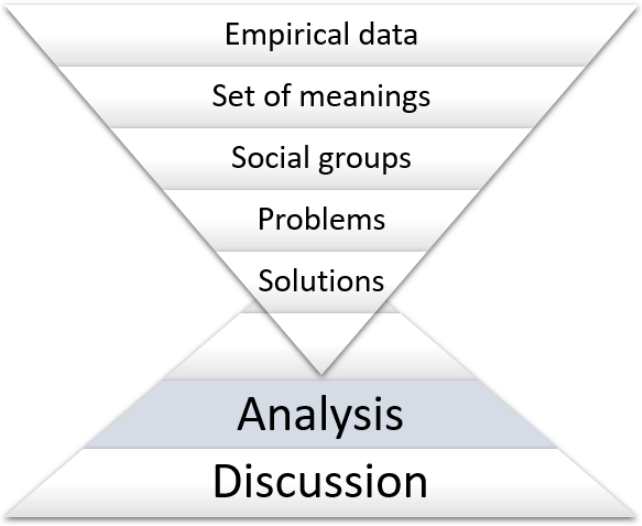


Figure 27: Study design; analysis

The analysis will be divided into four parts. Firstly, an analysis of the terminology used by the actors will be conducted. As mentioned, it was found in the data that the actors do not share understandings of the PRO technology. They have all constructed their own understandings. It could be assumed, that these understandings are rooted in the ways they denote PRO, as it seems as though they do not agree on something as seemingly plain as how to translate PRO into Danish. To gain a deeper understanding of this premise, it will be explored what terminology the actors use and what the words they use actually mean.

Subsequently, the social groups of the actors will be determined based on the three themes derived from the individual set of meanings. When social groups have been determined, the actors will henceforth only be referenced as their respective social group, as per SCOT.

Seeing that they are placed due to their individual understandings, it is assumed that they have a similar construction of what PRO is.

After the sorting into social groups, the problems identified in the previous chapter will be linked to these social groups, and then condensed into the most prominent problems. These problems will then be presented along with the groups attached to this problem. The study will not go further into analysing the problems individually in this section, this will be done along with the solutions. The analysis of the problems is constructed this way, in order to divide the analysis into more manageable parts, which allows for a more focused analysis. Seeing that the problems and solutions are closely linked, a decision has been made to combine the analysis of those two and thus analyse the problems along with the solutions.

When the presentation of the problems is complete, the analysis will move on to presenting the solutions provided by the social groups that can be connected to the problems. The solutions are not necessarily linked directly to the problems by the social groups. This is because the groups might not mention linked solutions directly, as it is assumed that the groups have not necessarily considered all possible solutions to a problem when stating it, but that does not mean that other statements cannot form the foundation for a suitable solution. Thus, statements linked to other topics will be connected to the expressed problems as well. This provides for a deeper understanding of the problems and how multiple angles can be engaged in order to seek out a solution.

7.1 Terminology

Before analysing the set of meanings of PRO, a look into the terminology used when talking about PRO will be commenced. A word can hold great importance to knowing what people mean, when they speak of something. Every word holds a set of connotations and using one word differently than intended can change the whole meaning of the sentence or a term. We believe, that in order to understand how an actor perceives PRO as a technology, we need to know what the words they use in fact mean. Because our scope is within a Danish context, we will use Danish and English words intertwined, as some use Danish translations and some stick to denoting it in English. To make reading of this easier, we will mark the words we are translating and analysing in cursive.

In the following matrix we will display the various ways actors denote PRO in order to account for their perception of the words and the technology.

Actor	Wording
Ministry of Health	Patientrapporterede oplysninger (Sundhedheds- og Ældreministeriet, 2019) PRO-data (Patient Reported Outcome data) (Sundhedheds- og Ældreministeriet, 2019) (Ældreministeriet, KL and Regioner, 2018; Sundhedheds- og Ældreministeriet, 2019)
PRO secretariat	Patientrapporterede oplysninger, patientrapporterede data and PRO-data (PRO-sekretariatet, 2018b, no date)
MedCom	Patientrapporterede oplysninger (MedCom, 2017)
PA Consult	Patientrapporterede oplysninger (PA Group, 2015)
ViBIS/TrygFonden	PRO-data and patient reported outcome-data (Munch-Petersen *et al.*, 2016)
Ministry of Finance	Patientrapporterede oplysninger (Finansminsteriet, 2016)
Danish Regions	Patientrapporterede oplysninger (Danske Regioner, no date b)
Local Government Denmark (KL)	Patientrapporterede oplysninger and PRO-data (Danish Ministry of Health, 2018)
CIMT	Patientrapporterede data (CIMT, 2019) Patientrapporterede oplysninger (MedCom, 2019b)
PLO	Patientrapporterede oplysninger and PRO-data (PLO, 2018)
General practice	Patientrapporterede oplysninger (Transcription, appendix)

Figure 28: Overview of denominations used by actors

Firstly, it should be noted, that even though we have listed a wording for general practice, this information is based on an interview with one general practitioner and cannot be considered the wording for all general practitioners. However, we choose to include this wording, as it complements the wording, we found at PLO, the organisation for general practitioners, and thus make the careful assumption that a portion of general practitioners are likely to use this particular wording as well. Also, it is worth noting, that some actors use varying types of

wording, i.e. the Ministry of Health used the first two types of wordings on the same page, showing that they do not stick to one perception of the terminology. The PRO secretariat uses the definition provided by ViBIS and TrygFonden and refer to it primarily as data but occasionally as *oplysninger*. Furthermore, they lean on the definition used by the FDA. (Sundhedsdatastyrelsen, 2017)

7.1.2 Outcome or information

Looking at the matrix we see, that only ViBIS and TrygFonden solely uses the wording PRO-data or sticks to *outcomes* rather than using the misleading translation *oplysninger*. Others who use *PRO-data* also use *patientrapporterede oplysninger.* According to the dictionary, *outcomes* do not translate into Danish directly as *oplysninger*.

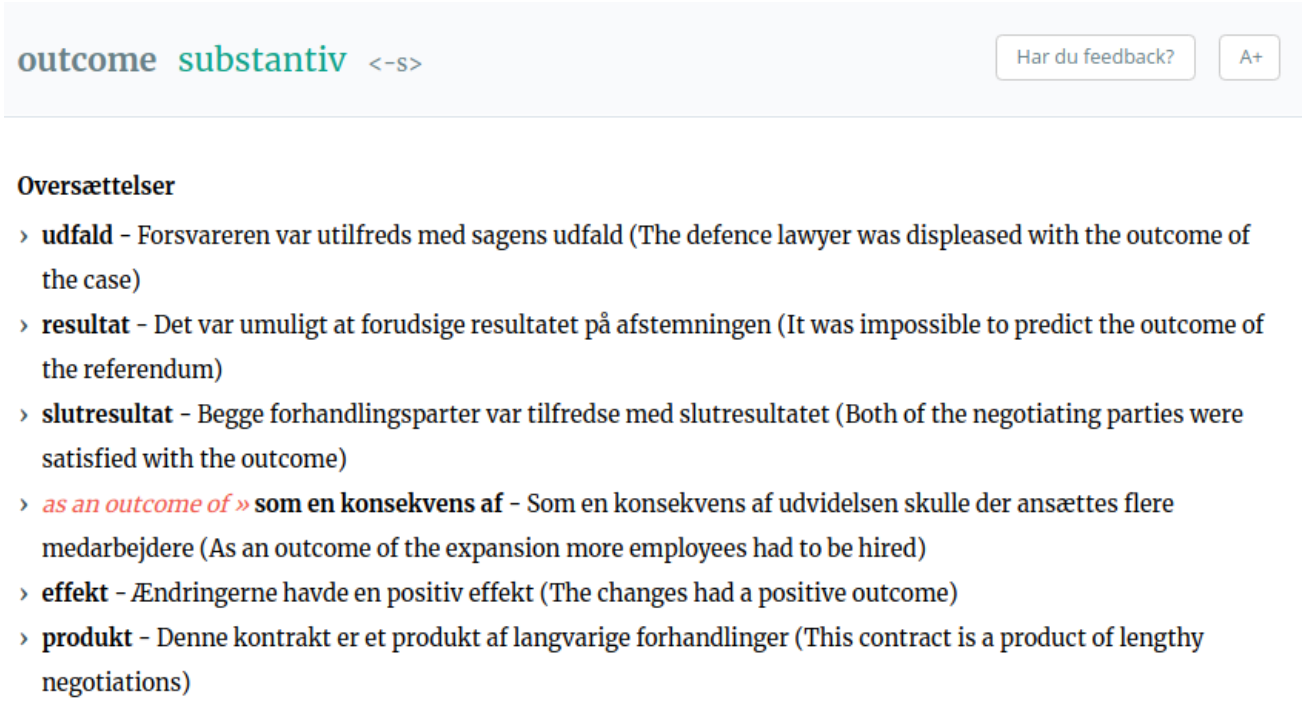


Figure 29: Screenshot of search result (Ordbogen.com, 2019).

As the illustration above shows, *outcome* translates to words such as *resultat*, *effekt* and *udfald*, which are words we associate to other connotations than *oplysninger*, which according to the dictionary translates into English to *information*.

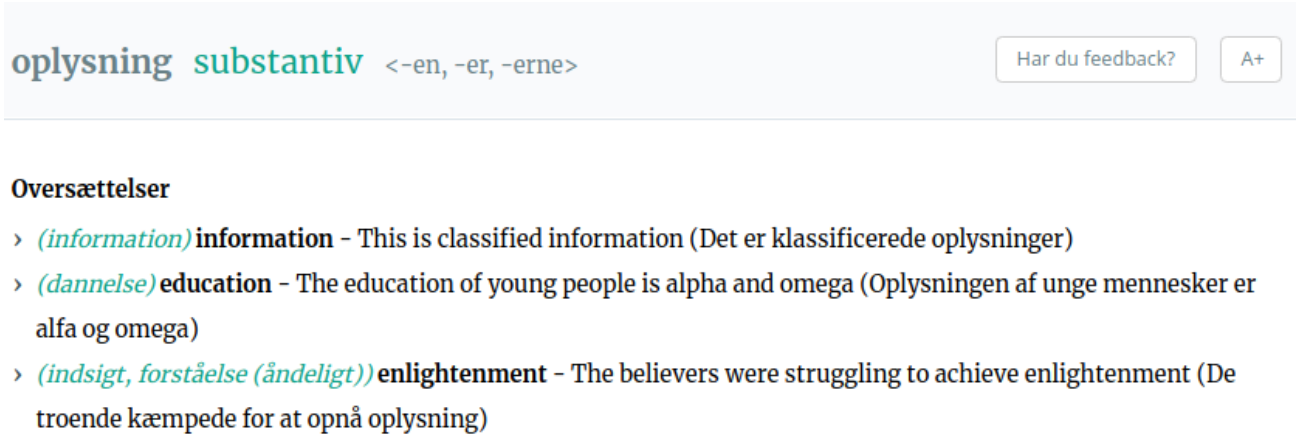


Figure 30: Screenshot of search results (Ordbogen.com, 2019)

It can be said, that *information* and *oplysninger* holds a broad range of connotations. Everything you are told is information, thus, it could be argued, that *oplysninger* would be a sufficient translation for *outcomes*. We would argue, however, that the Danish definition of PRO from Program PRO (Munch-Petersen *et al.*, 2016) is something else than just collecting objective information from patients, it is a matter of collecting a holistic image of the patient and thus achieving knowledge on multiple factors, which, we believe, falls more under the term *outcomes*, rather than *information*.

There seems to be an awareness of the problem, when you watch the MedCom Conference. A conversation between Mogens Hørder, Chairman of the expert task force behind Program PRO, and Jan Petersen, Chief Consultant at MedCom and member of the expert task force behind Program PRO occurs, where the following is said:

> *"I see that you perceive PRO as information that the patients generate and delivers to a system, that collects it. ... The way we otherwise work with PRO, and the way it is viewed in the literature, that PRO is more something to do with anxiety and depression, and not so much direct physical and biochemical measurements. ... Many seem to think, that P-R-O stand for "patient rapporterede oplysninger", but the O actually stands for outcome, and this is something else. ... At some point we have to agree on the issue of "what is PRO and what is PRO not".*
>
> \- Mogens Hørder
>
> "*It is a little curious, this translation of "PRO", because it is "patient-related outcome". It is very much based in the domain of quality development - PRO and PROM and so on - but I*

believe that because of the Danish translation - or mistranslation - we have a much broader understanding of it here in Denmark. … The standards MedCom have developed to exchange these things, we call them all PRO, even though it also includes measurement results. In Denmark we probably have a broader perception of PRO, as health-related information provided at the patient by the patient."

- Jan Petersen

This conversation is interesting in terms of investigating the different usages of definitions and understandings between different social groups that per definition in SCOT terminology have differentiating set of meanings regarding the technology.

7.2 Social groups

Based on the set of meanings provided directly from the actors and derived from other sources, they will be separated into their social groups as per SCOT methodology. A social group is defined as the members sharing a set of meanings in relation to PRO. Therefore, the expressed set of meanings in the collected data set will be examined, and an assessment will be made as to whether any actors share a set of meanings and thus are grouped together. The matrices containing the results have turned out rather extensive though condensed, which is why the focus will be on the most prominent themes, as mentioned in 6.1 Set of meanings.
The main themes discovered are:

- Type of data PRO encompasses
- Positive effects of PRO for the patient
- Contributions of PRO to the health sector

7.2.1 Type of data PRO encompasses

The first theme concerns what the actors have stated regarding what PRO actually is and what types of data it encompasses. Previously, we covered what words the actors use to denote PRO - here we will analyse further how they perceive the technology itself to define the social groups.

We commence the analysis with a statement by MedCom, as they are responsible for implementing PRO in general practice as well a part of the initial controversy regarding how

to define the technology. A notion which was scientifically intriguing in the first place. When asked what PRO in general practice is to them, the reply was:

> "*It is the direct translation: Patient-reported information*"
>
> - MedCom

This shows, that MedCom seem to have a firm conviction, that outcomes are translatable to information and that the two words do not hold separate meanings. They go on to elaborate, what they perceive as being information:

> "*(...) and information can be; measurement data, questions/answers (...) results regarding a desire for dialogue support - any data a GP would ask for during a consultation. It could also be measurements recorded over several days; i.e. blood pressure or fluid and flow of urine tables. Basically, information you need in general practice that the patient is responsible for providing*"
>
> - MedCom

Qua this quote, they elaborate on the types of information they consider the O in outcomes to be when speaking of general practice. They have a focus on objective types of data and therefore not the full spectrum of what PRO tools are established to provide both patient and health sector with. This places MedCom on one end of the dichotomy regarding PRO tools; is it a tool for objective data or a tool for objective *and* subjective data, i.e. a holistic approach?

The PRO secretariat places themselves on the other half of the dichotomy. They rely on the definition of PRO provided by the Program PRO project, and therefore their translation of O is outcome. The definition from Program PRO is:

> *"PRO-data (Patient-reported Outcome Data) is data about the patients' state of health, hereunder physical and mental health, symptoms, health related quality of life and functional level. PRO-data is reported directly from the patient."*
>
> - Program PRO

When asked what PRO is, the representative from the PRO secretariat is clear in their perception hereof:

> *"A possibility for the patient to give their view on their state of health."*
>
> - The PRO-secretariat

"By using PRO, you get an opportunity to get all the way around the patients and it won't be on the physicians' premise, what they believe is important to know something about".

- PRO secretariat

This expresses a more holistic approach to the tools. The secretariat argue, that *"depression (…) is real PRO-data"* thus, on the same time explicitly saying that some data are not, underlining their point of view that PRO-data should be about the patient as a whole and not focus entirely on objective data. The secretariat does not perceive PRO as being a tool for the patient to record and provide information which the physician requires for a specific purpose during consultations. It opens up for allowing the patient to be involved in deciding what they feel is important to provide additional information on. Back on the other side of the dichotomy, and in stark contrast to the view of the secretariat lies that of the general practitioner who was interviewed.

"Patient-reported information (oplysninger, ed.) *is when I ask the patient to make measurements at home and disclose them to me."*

- General practitioner

This resonates with the definition given by MedCom. Seeing that they develop PRO tools for general practice based on how GPs already use it, it makes sense for these two actors to place themselves on the same side of the dichotomy. The GP goes on to explain why they believe PRO should consist of objective measurement data rather than subjective:

"It is more logical for now. (…) You still have to have the talk all over again, so it does not make any sense. (…) In a questionnaire you ask certain things, but there are no additional questions. Therefore, it is more suited for something where you can say "I can do this, and I can't do that."

- General practitioner

The Ministry of Health, Ministry of Finance, Danish Regions and Local Government Denmark express an opinion, that PRO is data related to the patients' outcome of the course of treatment (Ældreministeriet, KL and Regioner, 2018; Danish Ministry of Health, 2018). This opinion was reverberated at the presentation of the Program PRO conference, where spokesperson for Health and Elderly for the party Venstre, Jane Heitman says,

"We need all that which can be measured and weighed, but what about those it is all about, namely the patient? We all too often forget to ask the patient themselves about subjects like well-being and functional level."

- Jane Heitman, Health and Elderly, Venstre

This aligns the opinions stated in two different sources by the Ministry of Health. In their report on Program PRO, ViBIS and TrygFonden state that PRO is data coming directly from the patient and is the patients' own experience of the treatment. They also state, that it is a tool used to achieve a more coherent course of treatment across professions and sectors. (Munch-Petersen *et al.*, 2016) This shows, that they also view the technology of PRO to be about more than measuring objective parameters to assist a patient in a consultation with their GP, but something that assists the patient's journey through the entire health sector. This shows, that the Ministry of Health follows the line of perception presented by Program PRO, and thus also the PRO secretariat. Furthermore, ViBIS resonates, that PRO is about the outcome of the course of treatment and an expression of the patients' overall benefit of the treatment. Only the patients know their personal result from the overall course of treatment, therefore only the patient can provide data on this.

When looking at use of words regarding these actors, though, it should be noted that while only ViBIS denotes PRO as outcome-data, the PRO secretariat and the Ministry of Health choose to denote it as outcome-data as well as information. This suggests, that even though the Ministry of Health use the term information, they use it in a broad sense to also include subjective data, unlike e.g. MedCom who only use information to mean objective, measurable information.

PA Consult do not elaborate on what specific type of data they believe, PRO should consist of, but they do translate PRO into *"Patientrapporterede oplysninger"*. Also, they focus on aspects like easing workflows, saving expenses and increasing patients' sense of responsibility and quality in their treatment. These are not aspects, that connect directly with the holistic treatment of the patient, but more to make their course of treatment more efficient, thus placing them in the vicinity of MedCom and the GP and thereby create a basis for assuming, that their set of meanings lie somewhat close to that of those two actors.

7.2.2 Positive effects of PRO for the patient

An important and recurrent theme when talking about PRO, is investigating the potential it holds for those it affects. P is for Patient and therefore the patient-perspective must be included when addressing PRO. The actors have all somehow talked about what PRO can do for the patient, but also what implementing PRO in a course of treatment might entail for the patient in a more negative sense.

When looking at the positive aspects, it is mentioned from both MedCom and the PRO secretariat that PRO improves patient involvement and can assist in transforming consultations with the GP to focusing on the patient as a whole, instead of primarily having a focus of obtaining data for a course of treatment. This correlates with the statements from the reports by MedCom, PA Consult and ViBIS, where they reach this conclusion from the evidence they investigate as well. The PRO secretariat further elaborates their view in the interview, that PRO can *"tip the power scale towards the patient"* by *"giving the patient the opportunity to set the agenda and impact their encounter with the healthcare sector."* The point of the actor is, that by using PRO, there will be an overall more holistic approach to the patient by *"getting all the way around the patient and not being on the premise of the physician."* Another actor names several factors that stand to be improved with the use of PRO. PA Consult mention in their report, that PRO can support an increased sense of responsibility for the patients as well as an increased experience of quality in the course of treatment. This could happen through better diagnosing and treatment and an easier transfer through sectors.

However, while MedCom does mention that PRO could have several positive consequences for the patient, such as improved involvement in their course of treatment and provide more time for the patient in consultations, if the practitioner can spend less time on administrative tasks, there is not much of a benefit for the patient according to the GP. To them, the most positive outcome is, that the patient does not have to transport themselves to the clinic or having the home carer collect data, perhaps in lieu of having the patient go to the GPs office.

The Ministry of Health describes a personalised approach to individual needs as a benefit for the patient. Besides this, they describe how the technology can be used as a screening tool, both in terms of looking for possible side effects and consultation needs. These statements from the ministry show, that they have considered many options for how PRO can be helpful to the complete patient journey. This supports the previous assessment, that the

Ministry of Health has a focus on subjective factors and the individual needs of the patient. Regarding this, they have similarities with MedCom, but not with the GP. This shows us a divide between MedCom and the GP in terms of what social group they belong in.

Another topic that several actors touched upon, in relation to how the technology of PRO could be beneficial for the patient, is the topic of data sharing, privacy and confidentiality. These topics are often up for debate in the media, where data sharing in the health sector is not necessarily seen as a good thing. There is an entire Facebook page dedicated to providing a critical voice in the matter (Patientdataforeningen, no date). The sharing of data does not seem to be a problem in the eyes of the GP, who states that confidentiality is not a problem as all exchanges of data would be per agreement with the patient. Seeing as we have only spoken to a single GP, this statement is to be considered very generalised and as only one voice out of roughly 3.400 general practitioners in the country ('PLO faktaark 2017 1.', 2017).

The PRO secretariat, who is not currently connected to the use of PRO in general practice, but are very much involved in the field as a whole, and thus are aware of certain aspects of the GPs attitudes towards the technology, state, that to their knowledge many GPs would like to contribute to the national work with PRO. This is also the sentiment of MedCom. As those currently in charge of PRO in general practice, they have presumably spoken to a larger number of practitioners about the topic and state, that the GPs would like to contribute to the development of PRO, but add, that they are careful with sharing data. Thus, they express a different perception of the general practitioner's willingness to share data, than the GP we spoke to. Seeing that GPs work alone or in smaller groups, it is to be expected, that they hold a great variety of personal opinions on this matter. This does tell us, though, that the general practitioners are mindful of the patients' data, some to the extent that they are not immediately ready to share patient data across sectors, others find it reasonable, seeing that they will only share it, if the patient in question has given their consent. Because of this, we make the assumption, that GPs, under the right circumstances, could be willing to share data, which is a fundamental part of what makes PRO a strong tool in the effort to create coherence in the health sector, and by extension ease patients' journey through the health sector, because their data are able to follow them through sectors.

The GP touches upon a more negative side of PRO. Namely the fact, that even though it can save time for the patient, if they do not need to show up to as many unnecessary consultations, it will entail more effort for the patient, by saying:

"It is a bit difficult towards the patients, because they actually end up doing double work (…) They do not log in (with NemID, ed.) *and type the actual result, but write it down and then later send it to me."*

- General practitioner

This perception is based on the GPs view on what PRO is meant for; the patients performing data collection at home, rather than having the GP do it in consultation. This perception, the GPs set of meanings, vary greatly from that of the PRO secretariat and ViBIS. What the GP references here, is a notion that has been discussed in relation to PRO before; that the act of having the patient produce data for their own course of treatment is not patient involvement, but rather patient work (Bygholm and Bertelsen, 2017). This notion is not mentioned by any of those in charge of developing and implementing PRO, so it is interesting to see, that practitioners and researchers are the ones to bring light to this matter. Having to perform these tasks require something else from the patients, rather than just showing up in a consultation. When using PRO in general practice in its current form, which is mainly performing home monitoring such as blood pressure, it is also required from the patient, that they understand how to use the monitoring instrument, how to record the data and how to fill out the questionnaire.

Another angle that could be a disbenefit to patients, is mentioned by the PRO secretariat. They state, that it is important for patients, GPs and the secretariat that there is not uncovered information that is not being used. By this, it is understood that patients should not perform tasks or fill out questionnaires, which will not be used directly in their current course of treatment. When delivering some sort of data, it will be expected that it will be brought up at a later event. If this does not happen, it might not be in the patient's favour.

7.2.3 Contributions of PRO to the health sector

When reading academic articles on PRO, it is often mentioned that PRO is not only beneficial for the patients, but also has the potential to form a multitude of positive aspects for the healthcare sector and its employees (Greenhalgh, 2009; Black, 2013; Philpot *et al.*, 2018). We see this as a recurring theme in our data as well. The general practitioner, as mentioned before, seems to have a very pragmatic approach to using PRO as a technology:

"We put power to it, so that they can deliver the information electronically. The home-monitoring questionnaires have been used for many years on general practice. The new element is that it is electronic."

- General practitioner

In this quote, they describe how PRO does not add a new dimension to work in the practice but can help turn an existing practice into something else, by making it electronic. The practice itself it not new, but they see a potential in the electronic transformation, as stated in the next quote.

"How can we make already existing processes more efficient, the paper-based PRO that already exists. How can we make this more efficient by relocate tasks to the patient?"

- General practitioner

"It (data, ed.) *will run more structured, in fixed frameworks, save time and will place themselves where it should be and not be lost or forgotten."*

- General practitioner

These quotes display how the general practitioner agree, that using PRO can benefit their daily work by digitising existing workflows. They also directly state, that PRO only makes sense if it eases workflows. This suggests, that in the eyes of the GP, PRO only has a justification as a technology that makes the workload for GPs smaller and their workflows more efficient. That perception seems shared by PA Consult, who states that the usage of PRO will ease workflows, because algorithms will sort patients into what further contact, or treatment is required. In relation to easing workflows, some actors also speak of how it can minimise errors. The GP mentions how the fact that PRO is based on algorithms, creates less grounds for flaws in data.

"*The benefit for me, is, that the average has been calculated and is transferred straight to my records. That means, that there is no risk of miscalculations and there no risk, that someone type in something incorrect.*"

- General practitioner

Here, the GP touches a subject that is also evident in the report from MedCom; that risks of errors, adverse incidents (UTH) and a fluctuating quality of data will be minimised when using PRO. In the Program PRO report, quality lifts due to PRO are also mentioned, but on a more structural level with PRO being described as a *"quality indicator in systematic quality development of treatment."* (Munch-Petersen *et al.*, 2016) In Program PRO quality development

is mentioned as "*Four principles of national distribution*", in three of four principles, indicating that the tool is being seen as something more than involving patients and improving workflows, but as a tool to aggregate data and use it for more than the individual patients' course of treatment. The Ministry of Health, Ministry of Finance, Danish Regions and Local Government Denmark also have this as a main point in their report, *A Coherent and Trustworthy Health Network for All*, rendering some of their set of meanings the same as that of ViBIS/TrygFonden. They say:

> *"By systematically and actively using PROs in the dialogue with the patient, the health system's actions can (...) support value-based health. (...) At the same time PROs create sound new data for research, quality assurance and tasks involving new governance models in the health system. Used correctly PROs are just as essential to the quality of treatment as clinical data."*
>
> - Ministry of Health et al.

This point is also underlined by the Minister of Health and Elderly, Sophie Løhde from the party Venstre.

> *"A clear requisite to create better quality is, of course, that we can assess the quality. Traditionally, we use clinical indicators of quality to measure quality. Typically, this is measurements of readmission or mortality. For a patient … the most important is survival, and most do, and then there is more a focus in the life lived. … Here* (with PRO, ed.) *we can, with the patients' own words, get … a more nuanced view upon, whether the treatment is successful for the individual patient."*
>
> - Sophie Løhde

This statement underlines, that the set of meanings of the relevant ministries are in line with that of the ones stated in Program PRO and goes beyond the direct benefit for patients and health professionals. Mentioning quality assurance and value-based health opens a conversation, which we have also mentioned before, which is the use of patient data for other purposes than the current course of treatment.

ViBIS believes that PRO has a large potential to create a more patient-centred and patient-involved healthcare system, but to unfold the full potential, it must be implemented throughout all sectors. They also state, that PRO can be useful for quality development in the

healthcare sector on an aggregated level. Seeing that ViBIS has written the report on Program PRO, which is the basis for the national work with PRO, it is assumed, that the authorities do not perceive the use of patient data outside their current course of treatment as problematic.
As the only actor mentioning it directly, one of the main points of the report from PA Consult is that the implementation of PRO can entail immense savings in the healthcare system. They add, that this potential is even larger if PRO is implemented across sectors. Other actors do agree, that PRO need to be a cross-sectorial technology in order to reach its full potential. The GP states, that implementing PRO across sectors is practically impossible, due to current rules on protection of data but could be useful if the home carers could fill out data and attach it to the patient's record. This shows, that the GP is willing to participate in the transfer of patient data, but as mentioned before, only when the patient has consented to this.

The PRO secretariat has had problems with engaging the GPs in the national work. This difficulty could be grounded in the perception from a GP, that it will simply be too troublesome to implement across all sectors. Finally, in order to reach the full coherence, the technology of PRO should be the same across sectors. As mentioned, the PRO secretariat coordinates the national work and implementation of PRO, which does not currently include general practice. Instead, MedCom is handling their current PRO infrastructure. This can be basis for some confusion as to how all PRO technologies can be completely coherent, but the PRO secretariat has some thoughts on the future of this. They currently have a positive attitude towards the different technologies, and state that even though MedCom focuses on objective parameters, it gives the GPs experience in using patient-reported data which makes way for the national initiative with PRO and add, that when national PRO is developed, this should be used and not MedComs own questionnaires.

7.2.4 Forming social groups

From their statements in our empirical data, social groups have been defined based on the stated set of meanings. During the analysis of these, three consistent set of meanings can be derived. The first represents the notion, that PRO tools are meant to collect objective information from patients to ease workflows for practitioners and make it easier to be a patient. This is also the social group who typically use the term *information* rather than *outcomes* or *outcome-data* regarding PRO. They do, however, mention several times in this group, that the implementation will entail positive outcomes for the patients in terms of empowerment and

increased involvement. In this social group MedCom, CIMT, PLO and PA Consult placed themselves. In this group we also find the only actor who mentions a possible beneficial economical outcome of using PRO; PA Consult. In the second group the general practitioner is placed. Their view on PRO is, that it is digitalisation of existing workflows and should work as a way to ease data gathering from patients. There is not a lot of focus on benefits for the patient or the health sector, and there does not seem to be an overall willingness to use the tools, unless they benefit the workflows in the clinic directly. The third group represents the opinion, that PRO technology is meant to better the quality of treatment, both on an individual and on an aggregated level. This group typically refer to PRO as O for *outcome* or *outcome-data*. This group contains the actors, who are most patient-oriented and understand PRO as something that will benefit both patient and health sector. They do not speak of economics, but of efficiency and coherence.

Actors	**Social group**	**Number**
MedCom, CIMT, PLO, PA consult	PRO is primarily a tool to ease workflows, but also entail positive outcomes for the patients and would be positive to implement across sectors.	A
General practice	PRO is a tool to ease workflows. It is objective *information* rather than *outcome data.*	B
PRO-secretariat, TrygFonden, ViBIS, Ministry of Health, Ministry of Finance, Danish Regions, Local Government Denmark	PRO is primarily a tool for improving courses of treatment for patients, but also for improving quality of treatments in the healthcare sector as a whole. The information is subjective outcome data and more than just information	C

Figure 31: Social groups

Henceforth, the groups will be referenced to by their given group letter only. Utilising a similar illustration from SCOT, show how the social groups are defined in this study:

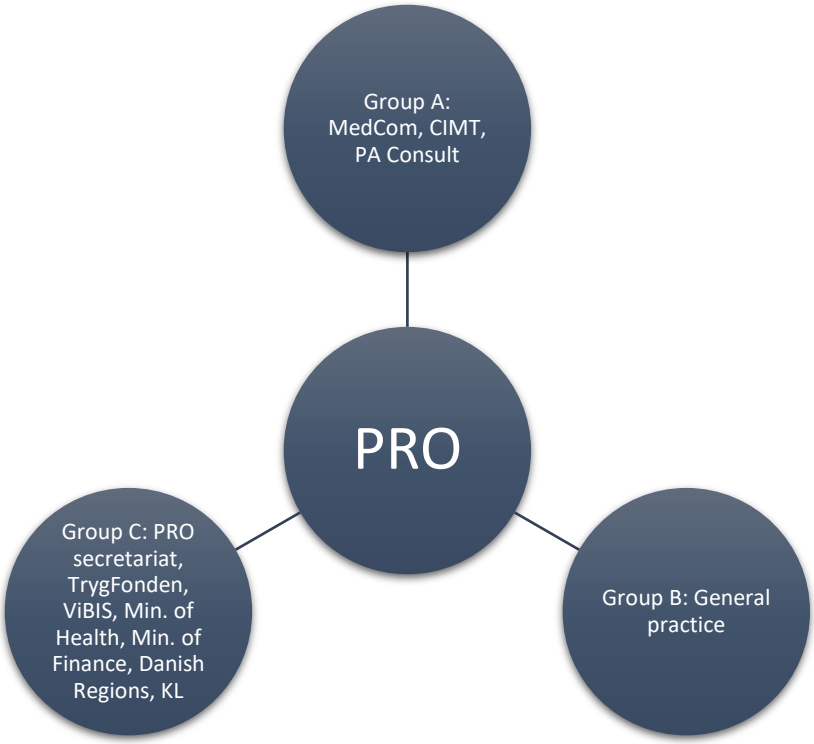


Figure 32: Social groups as per SCOT

The artefact is in the centre of the illustration in this study; the PRO technology, surrounded by the three groups and who they consist of. These three social groups depict the three versions of the technology constructed socially in the individual groups. Looking back at the PRO timeline, *2.3 A timeline of PRO*, we know, that the technology of PRO originated in different places and for different reasons and has been continuously developed as different strands of the same technology. It has been stated, that PRO has been used in Danish health care for more than 20 years, and the GP also states, that the use of patient-reported outcomes is not new. Patient-reported questionnaires have a long history in Danish health care, and this seems to be the form it still exists in as a social construction in group B, thus, this is also the construct they desire to keep developing, as they see no need to make fundamental changes to an already existing tool.

Groups A and C have adopted the more patient-oriented perception of the technology, even though they have constructed variations of the depth of the data collected, and the involvement of patients in their respective versions. Below is a depiction of the purpose of the three versions of the technology, as we see them constructed by each social group:

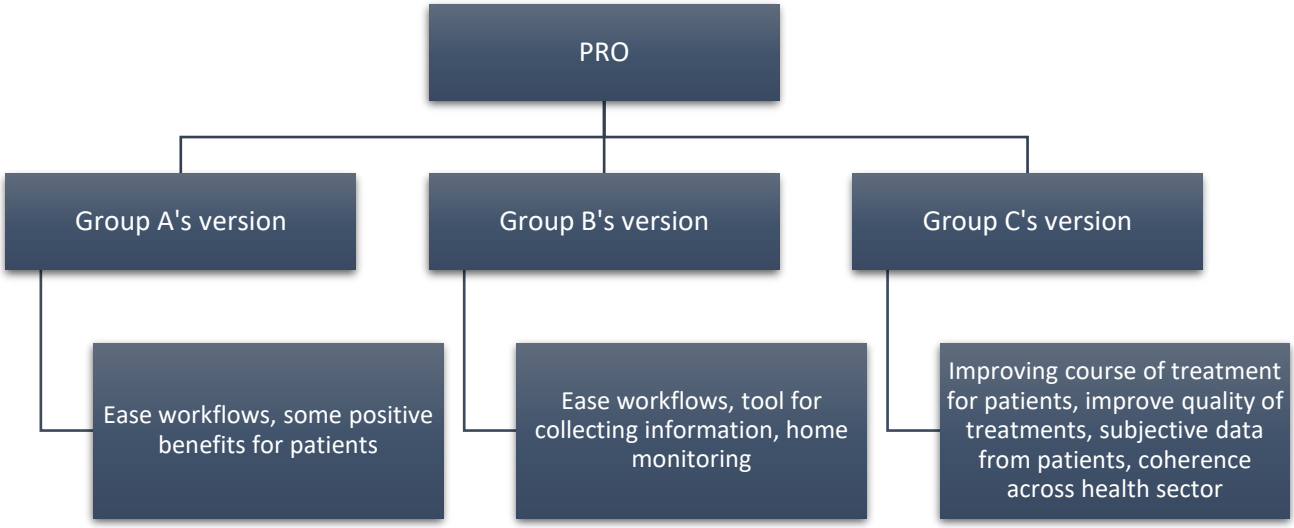


Figure 33: The development of PRO through the three social groups

7.3 Problems

As per SCOT, each social group who share a set of meanings also share certain problems with a technology. As shown above, the three versions of PRO have significant differences, thus, the social groups will also have greatly varying problems attached to their individual social construction of the technology. Examining the empirical data further, it will be uncovered what problems these social groups share. When placed in a social group, all actors are not bound to share every opinion and every problem, but they will overall have an aligned understanding of the technology.

In SCOT methodology, the problems of each social group are shown in illustrations below. Then, solutions for each problem will be identified. This study will take a slightly altered approach, as the groups have identified a great deal of problems among them. For this reason, there will be an initial display of what problems each group has identified, and these problems will then be condensed into five overall problems. Then, solutions for these five problems will be identified. By doing this, the study will be able to focus on the main problems posed by the social groups and provide a deeper understanding of those.

Group A find the following problematic:

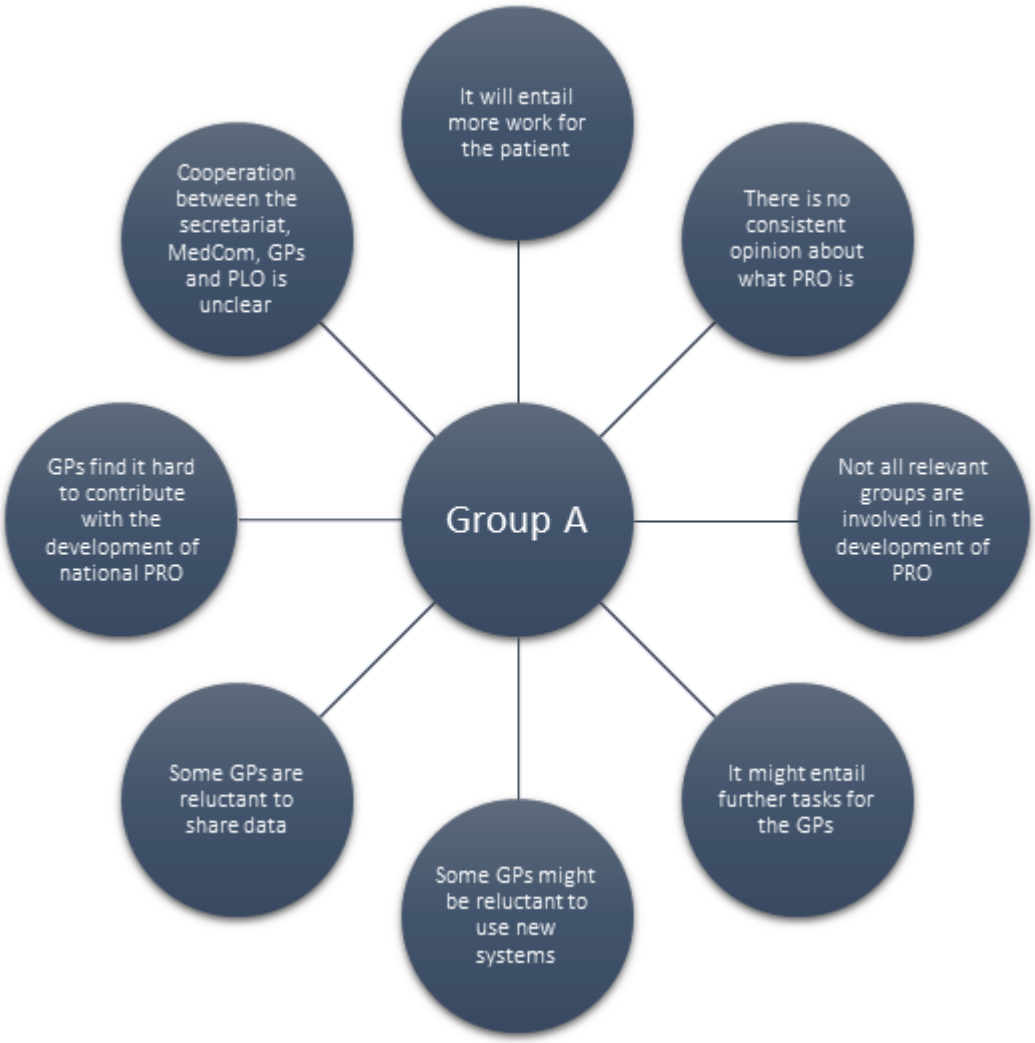


Figure 34: Problems stated by group A

The problems stated by group A show, that they have a focus on cooperation, both between GP and patient and GP and developers. They are considering the workflows of the GPs and worry how using the technology could affect their daily work in a negative way. They also mention how using PRO would mean more work for the patients.

Problems stated by group B:

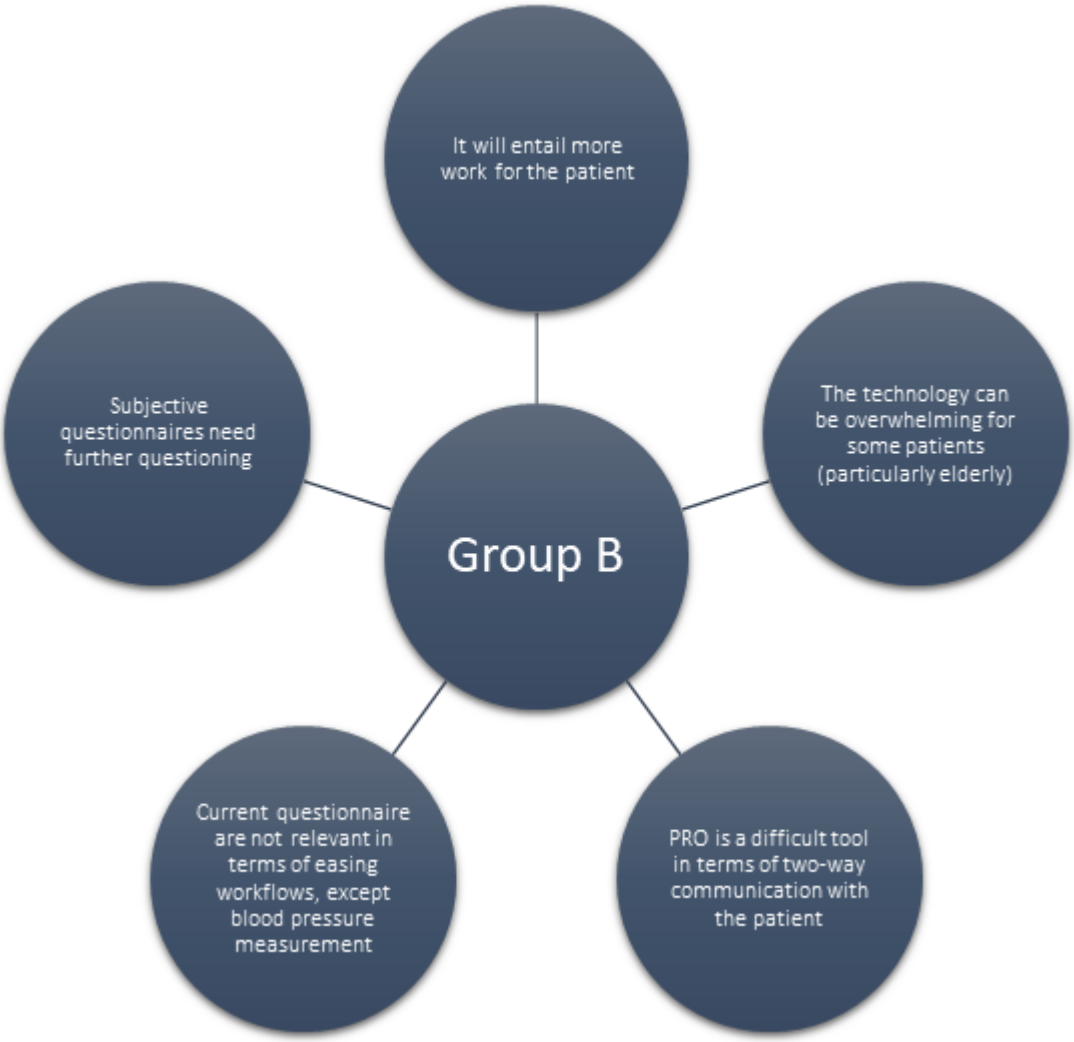


Figure 35: Problems stated by group B

In group B, the focus of the problems centre on how the tools can be difficult to accommodate in the daily workflows. They problematise the current form of the questionnaires and believe, like group A, that using them in daily routines would provide additional work for the patients, who might not all be comfortable with using the technology.

Group C:

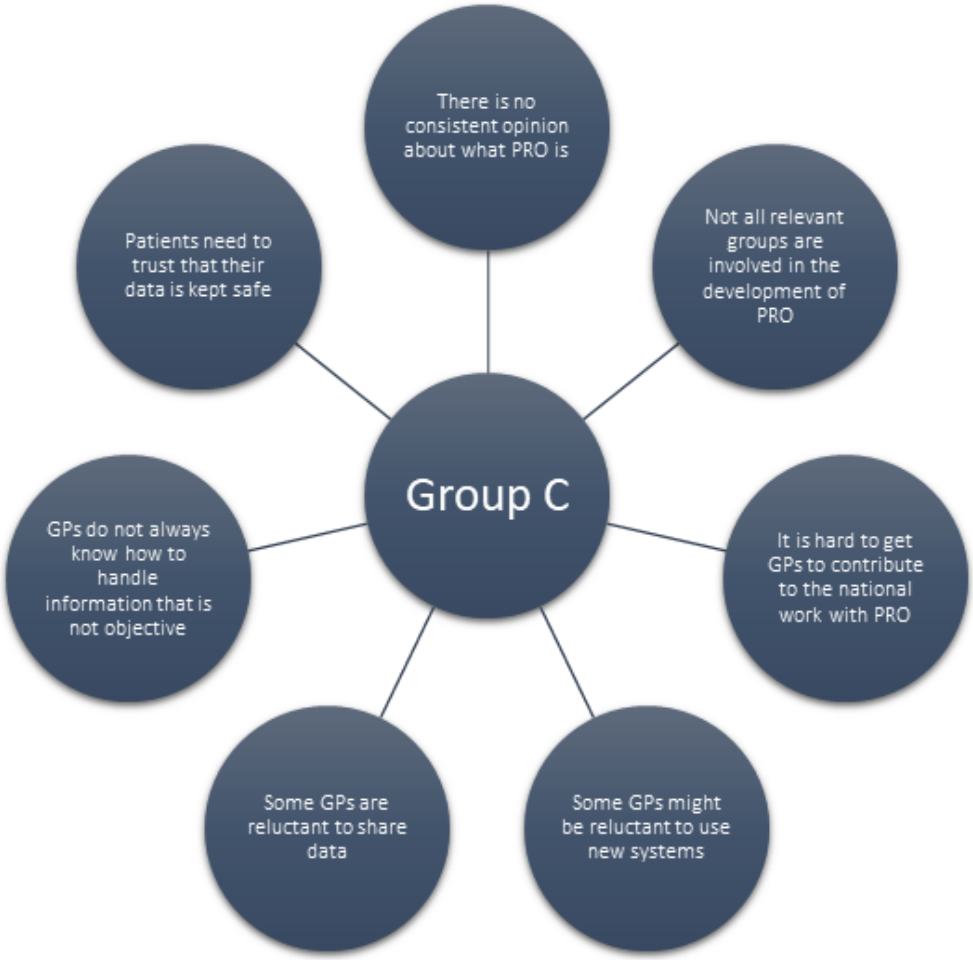


Figure 36: Problems stated by group C

Group C share their concerns regarding the cooperation between developers and GPs and are focused on how it can be difficult to engage the GPs in the work and how the technology in its current form does not seem to appeal to GPs. There are several pitfalls concerning sharing of data and how to handle subjective data from questionnaires.

A main point in the SCOT methodology is to shed a light on conflicts between social groups in relation to the technology. These problems and conflicts stated by the social groups form the basis of exploring solutions to a more stable construction of an unstable technology. As seen above, some problems recur in more than one social group, which ultimately eases the task of stabilizing the technology, as it will be easier to solve problems that the social groups agree upon. An example of a problem, which two social groups agree upon, is that both group A and group C find it problematic that:

- There is no consistent opinion about what PRO is
- Not all relevant groups are involved in the development of PRO
- Some GPs might be reluctant to use new systems
- Some GPs are reluctant to share data

Based on the above-mentioned problems identified by each group, and the awareness of some problems being reiterated by some groups, the following five main problems have been defined:

- Involving GPs in national PRO
- GPs reluctance towards implementing PRO
- GPs reluctance towards sharing data
- Increased demands for the patient
- Difficulty of implementing subjective questionnaires

7.3.1 Problem one: Involving GPs in national PRO

The first problem that will be processed, is the problem of involving GPs in the development of national PRO. This is a fundamental part of achieving the desired coherence across sectors. Group C especially are having difficulty with involving the GPs in the development process, where they attempt to accommodate the wishes and needs of the users of the technology. The problem is comprised and condensed of the following problems mentioned by the social groups:

Group A	GPs find it hard to contribute with the development of national PRO
Group A	Cooperation between the secretariat, MedCom, GPs and PLO is unclear
Group C	Not all groups are involved in the development of PRO
Group C	Difficult for the secretariat to get access to GPs, even though some wish to participate

Figure 37: Problem one

As seen above, both group A and C mention the problem of some actors having a difficulty of reaching the GPs. They also agree upon the difficulty in integrating GPs in the development of national PRO. They do, however, differentiate on the reason why, where group A argue that it

is difficult for GPs to see the relevance in their participation, group C argue that the problem lies with them having difficulty in obtaining access to the GPs.

> *"General practice cannot deploy a representative for each of the working groups* (in national PRO, ed.) *for the specific diagnoses … It would make sense for GPs to contribute with* (the development of, ed.) *more overall questionnaires."*
>
> - Group A

> *"I do not think it is the individual GPs. I think that many would like to contribute, but it can risk coming to nothing."*
>
> - Group C

7.3.2 Problem two: GPs reluctance towards implementing PRO

The second problem has a focus on the difficulty of not only reaching the general practitioners and evoke their interest and inclination in assisting in both the development process of the PRO tools themselves, but on the difficulty of having them see the benefits of using them and actually initiate the use of them in their daily workflow. It is comprised and condensed of the following problems generated by the social groups:

Group A	Might entail further tasks for the GPs
Group A	Some GPs might be reluctant to use new systems
Group C	Some GPs might be reluctant to use new systems

Figure 38: Problem two

7.3.3 Problem three: GPs reluctance towards sharing data

The third problem deals with the data sharing, that is an inevitable part of utilising the full potential of the PRO technology. It is comprised of the same problem iterated by two groups, as shown below.

Group A	Some GPs are reluctant to share data
Group C	Some GPs are reluctant to share data

Figure 39: Problem three

It is interesting to note, that where groups A and C both define a problem with the GPs unwillingness to share data, group B, the GPs themselves, do not see this as a problem:

"No, I do not think so (that sharing the patients' information could be problematic, ed.). *This is an agreement I make with the patient, that I attach "this". I do not attach anything I have not agreed on with the patient."*

- Group B

7.3.4. Problem four: Increased demands for the patient

This problem concerns itself with the patient and what it might entail for them in regard to an increase in effort, if the PRO technology is to be implemented across the entirety of the Danish health sector and be a stable part of the daily routine in consultations with health professionals. It is comprised of the separate problems stated below:

Group B	It will entail more work for the patient
Group B	The technology can be overwhelming for some patients (particularly elderly)
Group B	PRO is a difficult tool in terms of two-way communication with the patient
Group C	Patients need to trust that their data is kept safe

Figure 40: Problem four

7.3.5 Problem five: Difficulty of implementing subjective questionnaires

The fifth and final problem that has been condensed from the data set, is regarding the use of objective versus subjective questionnaires in general practice. The problem has been condensed though the following three individual problems:

Group B	Current questionnaires are not relevant in terms of easing workflows, except blood pressure measurement
Group B	Subjective questionnaires need further questioning
Group C	GPs do not always know how to handle information that is not objective

Figure 41: Problem five

7.4 Solutions

After presenting what problems have been posed by the various social groups, they will be reiterated when deriving solutions according to the SCOT methodology. The solutions are condensed from several statements, but will be expanded to include quotes, when relevant. Some of the problems have solutions posed directly by the group, but a lot do not have defined solutions. Nonetheless, by analysing the data set, it is possible to find solutions to some problems.

The solutions contribute to a stabilization of the technology. There might be conflicting solutions to overlapping problems, or solutions creating new problems for some social groups, while solving them for others. This will be elaborate upon in the discussion. Seeing that every group has their own social construction of what the technology is, no one solution will be suitable for the problems for all groups. The solutions will be represented under the relevant problem with a clear indication of what social group is the originator of the solution. This will create an overview of the solutions defined by the groups. Some solutions might be identified in relation to several problems, seeing that more than one problem can be derived from a piece of conversation with the same solution, or a single solution is deemed suitable for several problems, even if it has not been mentioned in direct connection with it. Some problems might have several solutions while some problems do not have any apparent solutions. This might be caused by the groups not seeing a solution to the problem, or that other groups simply do not recognise the problem as a problem.

The first step in stabilizing a technology in terms of solving the problems, is for the social groups to agree that there is a problem. If not, then in solving the problem you can possibly create other problems for the group not experiencing a problem. This will again make the technology unstable. Some problems can, as mentioned, be combined in the same area, and therefore their solutions are relevant to assess next to each other. In the next section, aggregated problems and the solutions that the groups define will be presented. The problems and solutions are presented in an illustrated manner in order to give better overview of the data. They will then be unfolded and analysed in textual form.

7.4.1 Solutions for problem one: Involving GPs in national PRO

These solutions touch upon some of the difficulties encountered, when attempting to involve GPs in the process. The defined solutions that relate to this problem are presented below.

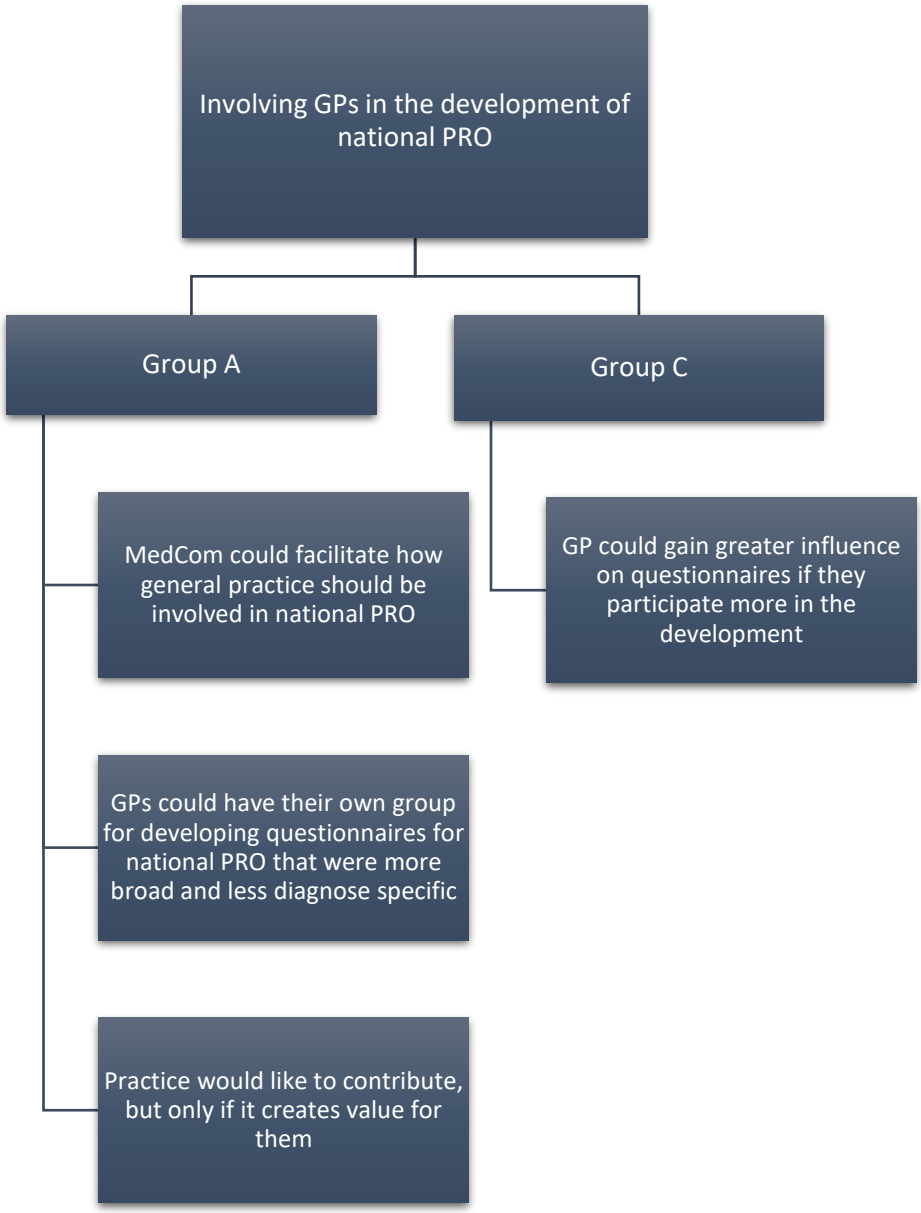


Figure 42: Solutions for problem one

The groups approach this problem from two very different perspectives; group A perceive the problem as being based in the GPs finding it hard to contribute, while group C, believe it is due to the difficulty of getting the GPs to contribute. They do agree that it is a problem, that the GPs are not more involved. Group A points out some practical solutions as to how you can involve

the GPs more, where group C seems to find themselves at a closed road in terms of gaining access to the GPs.

> *"We have to go through the front door. It starts with XXX* (organisation, ed.)*, then we are referred to XXX* (other organisation, ed.)*. The door has not completely opened yet."*
>
> - Group C, interview

A solution to this problem could be, that group A facilitates the contact as suggested by them and thus initiating a closer collaboration between the two groups developing the technology. Group A does not have a problem with accessing GPs in general, and describe the problems as being in terms of accessing the GPs who are not yet on board with PRO.

> *"We have gotten positive feedback from those who had already used PRO, but we have not asked those who will not use PRO (…)"*
>
> - Group A, Interview

The data shows, that group A are open for creating a sub-version of PRO tailored to the needs of GPs, which seems to be a solution that would suit the GPs, as they do not feel they will benefit much from the current version of the technology.

7.4.2 Solutions for problem two: GPs reluctance towards implementing PRO

This problem may seem simplistic in its form, but it seems to be a recurrent theme to engage the GPs enough in the technology, to motivate them to use it in their daily workflows. Below is an illustration of the solutions expressed by the groups through the data material.

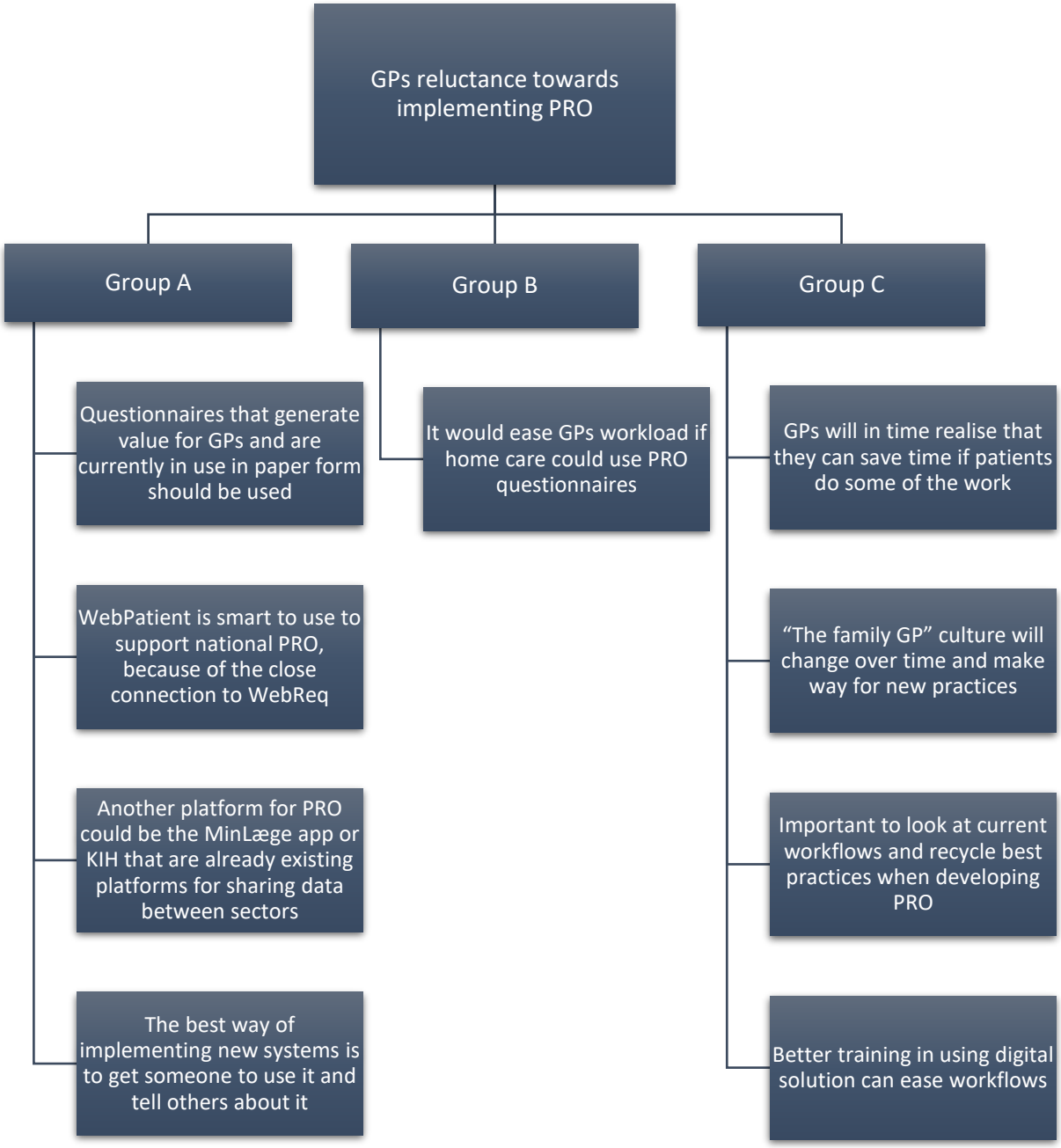


Figure 43: Solutions for problem two

The groups' solutions are reflections of their set of meanings. Group C see the future of PRO as being a cross-sectorial, grand scheme change of culture, where the patient gets to be more involved in their treatment and help set the agenda and is seen as an expert in their own health. This, as well as see the end-goal of both their own efforts, but also those of group A, should end up in all sectors using national PRO. Group C has a focus on the way using PRO tools in daily routines can ease workflows and free up time in the GPs timetables which are under great

pressure. Even though group C are developing the national version of PRO, that does not yet encompass general practice, they do not see it as a problem.

> *"It is good that you get some experience with using the questionnaires out there in the healthcare sector (…) but when we make the national* (PRO, ed.), *preferably, you should use that."*
>
> - Group C, interview

Group A, on the other hand, takes a more practical approach towards the best possible implementation of PRO in general practice. As they see it, the problem lies in the apparent incompatibility between the way national PRO is being developed currently and the way it makes sense to use in general practice. Where group C believes, that general practice needs to adjust to using the technology, group A is more focused on adjusting the technology to the actual needs of GPs. They aim to mould the PRO tools into something that the GPs can use directly in their practice without changing their existing workflows.

> *"Practice gets it how they like it and how they need it. They get it* (PRO, ed.) *as laboratory results."*
>
> - Group A, interview

Where group A has several practical solutions to their view of the problem, but group C argues for this cultural change, which certainly encompasses more than some practical changes in behaviour. Thus, there seems to be a significant discrepancy in the approach to including and accommodating GPs in the work with national PRO.

Group B did not touch upon the subject of how exactly they see themselves being more involved in the process of developing PRO, but takes on a more practical stance regarding how, it would be of use to them in their day to day work. The solution defined by group B is also a reflection of how far apart the groups are in their set of meanings. The GPs admit to seeing some relevance in some interdisciplinary usage of PRO but cannot see how it could be relevant or even possible to have this flow of data across sectors.

> *"It* (cross-sectorial sharing of data, ed.) *is impossible. There are great obstacles in doing this, so I do not think more about this."*
>
> - Group B, Interview

This, again, underlines that there is not full alignment in the set of meanings between the groups. When they are not standing on common ground as to what is the purpose of the technology, it presumably will be hard to create something together. The secretariat seems to be aware of this by acknowledging, that there is need for some cultural change.

"I think, it is a cultural journey, that the whole healthcare sector must undergo, this PRO."

- Group C, Interview

Yet, the development of national PRO continues without the GPs, even though it is considered a problem.

7.4.3 Solutions for problem three: GPs reluctance towards sharing data

Even though the problem is based in the same type of statement by two different groups, it is considered significant and a large part of why PRO has been constructed in different ways in the social groups. The opinions regarding the sharing of data, which is a fundamental part of especially group Cs understanding of the technology of PRO, seems to vary greatly, spanning from concerns to practical ideas on how data could be shared, in order for it to make sense to health professional and patient alike. Below is illustrated how the social groups perceive the topic of sharing data and how it should be solved according to them.

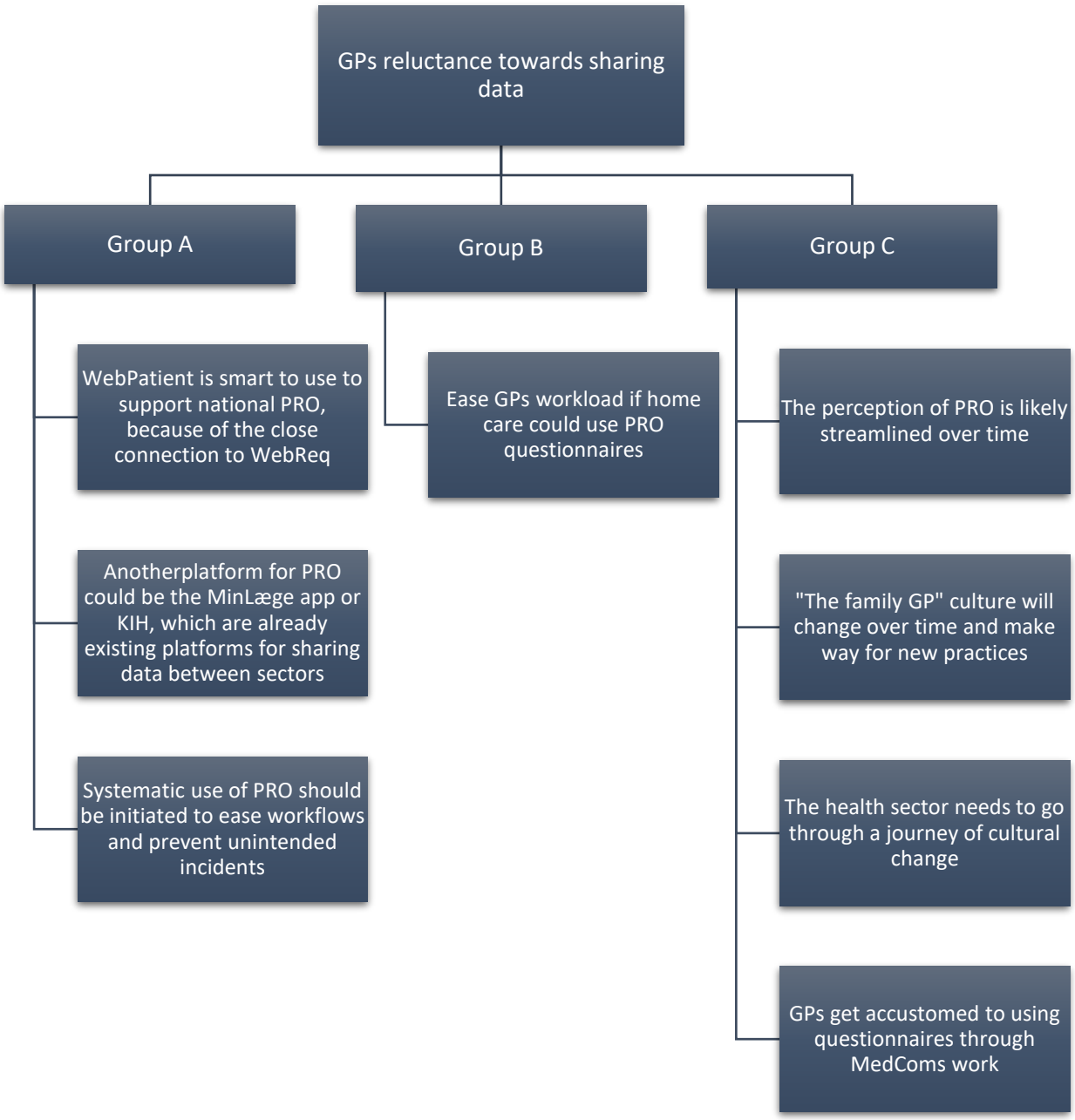


Figure 44: Solutions for problem three

When processing the data from all three groups, it is evident that the problem regarding sharing data is a two-sided one. One side is of a more practical nature and has a focus on if and how sharing of data across disciplines and especially across sectors is even technically possible, which, after all, is the grand idea of national PRO as stated in Program PRO (Munch-Petersen *et al.*, 2016). Group A has several suggestions as to how data could be shared and through which platforms. Their idea is to use already existing platforms like WebPatient, KIH (Klinisk

Integreret Hjemmemonitorering) or the newly developed app, Min Læge, because these systems already are prepared for sharing of data with the patient.

> *"The app, Min Læge, (...) runs on the PLSP* (Primærsektorens Leverandør Service Platform, ed.) *and is meant for sharing data with the patient. (…) the PLSP is very relevant. (…) data being put there could be shared with other collaborators or outside the primary sector."*
>
> *Group A, interview*

The other side of the reluctance towards sharing data could be grounded in ethical, historical and cultural causes within the realm of GPs. Ethically, it was mentioned in all groups, that in order to protect the patient, the GPs are careful not to share data on behalf of the patient, where there is not a clear agreement with the patient in place on where data goes.

> *"If they* (the GPs, ed.) *must share PRO-data with others, it is experienced like they have to hand over data, that the patient gave them. Some GPs talk about this confidential space."*
>
> - Group C, Interview

As mentioned earlier, group B agree with these statements and will only share data where there is a clear agreement with the patient, and they know the end-destination and usage of the data. Group B is not worried about the confidentiality if these measures are accounted for.

Closely related to the ethical reasons to the reluctance is the historical background for data-sharing in general practice. The actor from group A mentions the so-called "DAMD-case" from 2014, where it was discovered that a data-harvesting tool, Sentinel, had been collecting data from patients' journals without having obtained consent from the patients (Fischer and Tynell, 2014). This is, according to group A, a major reason for the reluctance towards sharing data amongst GPs.

> *"They* (the GPs, ed.) *do not want to end up in this situation again. (…) They would like to share data when relevant and where it makes sense, but to just open the gates and not really know, who they share they data with - they are careful about this."*
>
> - Group A, Interview

This explains the reluctance of the GPs; which group C does not seem to be particularly aware of. They do not perceive this historical cause to behind the reluctance, but seem to view it as having more cultural causes:

"There is not a tradition for GPs to share data to this degree, which is more of a tradition in the hospitals. I think this is one of the reasons for it being more difficult to reach general practice (…) You are not used to cooperation on that level. Not that you do not want to, but you are used to handling things yourself."

- Group C, interview

This shows, that group C has their focus entirely elsewhere regarding this problem. It does not show in the data, whether it is due to them not being aware of the situation and the following reservations or if they simply do not believe this to be the cause. It is also a possibility, however, that this is the knowledge group C has obtained from their interactions with GPs and therefore they pay particular notice to the matter regarding confidentiality and tradition in general practice. If their collaborators have not put emphasis on the past problematics of data sharing in general practice it explains why they have an entirely different response to the problem.

Group C goes on to explain, that GPs do not need the information as much as the physicians in the hospitals do and that this also could be a reason for the reluctance.

"(…) you are used to sitting with things yourself and therefore you, perhaps, do not need to secure information from elsewhere in the same extent as the hospitals."

- Group C, interview

The above standing underlines the importance of the statement from Group A, that *"It is important to understand the GPs values and scepticisms in relation to sharing data…" (group A, interview)*. GPs are more of an island, compared to hospitals; they are used to working more independently and not share a lot of data with others. This also means, that while they do not have a culture in data sharing, they also stand differently than health professionals in hospitals do, if the wrong data is shared or a mistake happens. If the GP does this, it is more likely to fall back on this individual and they can be held liable for the error, whereas hospitals operate in a larger setting and thus, maybe the blame will fall on an entire department of staff rather than just one person. It is worth noting though, that with all the documentation that exists in the health sector today, it is probable, that the error would be traceable, but it is also assumed, that if an error happens as part of a larger workflow, the blame will be divided onto more people.

This also provides an understand into why a GP is reluctant to place themselves in a situation, where they know difficulties can arise, particularly in relation to mishandling of

their patients' data. Especially, considering that they do not immediately see the great benefit for them in their workflows.

7.4.4 Solutions for problem four: Increased demands for the patient

For this problem, it is primarily group B who are represented regarding problems, while group C supplement with a problem regarding data security. This shows, that group B is mostly concerned with how utilising PRO in their daily routines most of all will affect their workflow as well as cause problems for the patients.

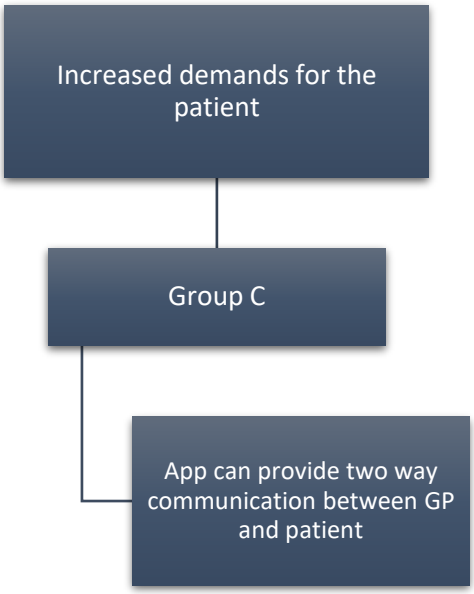


Figure 45: Solutions for problem four

The matter of why group B is mostly represented in the problems here, is, probably, seeing that the interview-guide had the relationship between PRO and GPs as a focus and did not dive much into the patient focus of the technology. Group C also does have the patient in focus throughout the data, based in the set of meanings, that PRO can be a tool to enhance the patient experience and quality of treatment in several ways. Group A merely mentions the positive sides of PRO for patients in short terms, as side notes to the main effect; making the existing workflows more efficient. A natural effect of this not being a subject, that the empirical data uncovers, is that there are not many problems and even fewer solutions defined. Seeing that using PRO entails an effort from the patient, we found it of importance nonetheless, and do see the relevance come through in the data where patients are mentioned, both in terms of how using PRO will affect them, but also how they will have to do more of the work.

The problems raised by group B can be understood by the set of meanings of that group towards PRO; if you only view PRO as a tool for pushing assignments from the practice to the patient in an effort to make workflows easier on the practitioner, it is not an astounding find, that you view this act as something that will burden the patient. If you, like group C, view PRO as a tool in benefit of the patients, then you are not likely to see many problems for the patients in this regard. Then, the problem, perhaps, is too slow and too little development and implementation of PRO. The problems raised by group B underline the arguments in the above-standing chapter; that some GPs view themselves as a sort of protector of both their own area but also the patient's data and rights. Their focus is more on the close relations between patient and GP and not so much on the healthcare system as a whole, which naturally is a focus from actors in group C, representing exactly this.

7.4.5 Solutions for problem five: Difficulty of implementing subjective questionnaires

Once more, the problem is dominated by group B, who do not see the subjective questionnaires as particularly useful in terms of easing workflows. It is their experience, there is not enough information in the questionnaires, to justify them standing alone or be of benefit in easing the workload for practitioners.

Group C supplements this sentiment by stating, that the GPs prefer to handle information that is directly relevant for their patient in their current course of treatment and which is obviously useful, without interpretation. Below is an illustration of the solutions expressed by the groups in relation to this problem:

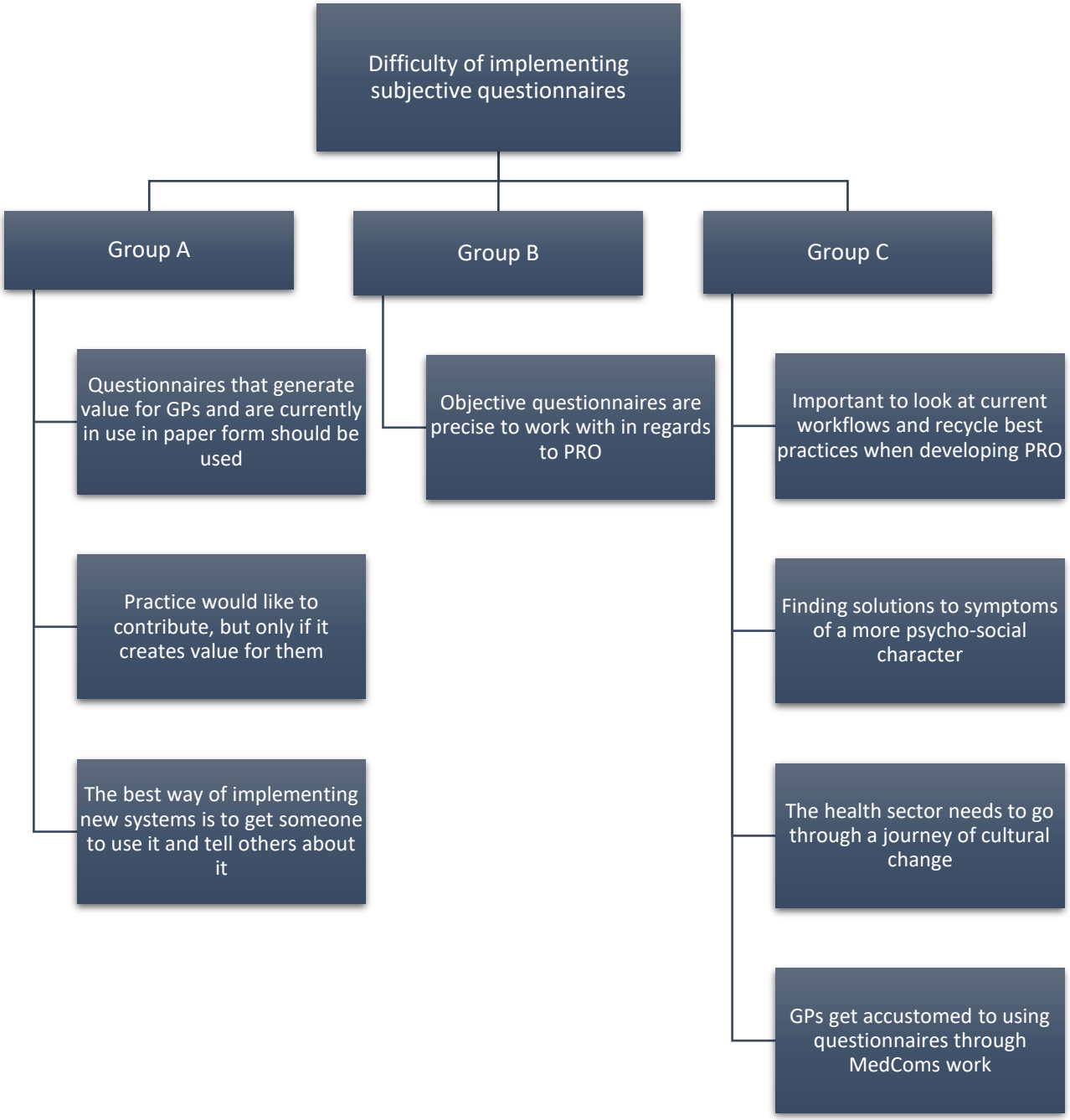


Figure 46: Solutions for problem five

This last problem once more shows these two sides of a singular problem, based in the set of meanings of the groups. The one side, representing group A and B, being more practically oriented; that PRO should be fitted into already existing workflows of the GPs by using the questionnaires or measurements, they already use.

> *"When we talk about implementing PRO in general practice, it is with this hat on: How do we make already existing processes more efficient. The already existing paper-based PRO*

process - how can we make it more efficient by actually move tasks out (to the patients, ed.)*."*

- Group A, Interview

The other side, represented by group C, do agree that when incorporating PRO for general practice, or any group of health professionals, it is beneficial to investigate and learn from existing workflows

"If you have these different options and all are equally good, then you might as well try to see the advantages in that (questionnaire, ed.)*. There is a questionnaire you use in general practice, and if it is the same, let us take it to get a link over there."*

- Group C, interview

They do, however, not seem too accommodating towards the thought of the GPs continuing to use PRO as primarily objective questionnaires, but hold the position, that the GPs should transition to use the more holistic questionnaires from the national work with PRO, once they are finished.

"When we make the national PRO, you should use this."

- Group C, interview

The group, as already mentioned above, has the view that in due time, a cultural change will happen and thereby national PRO will gain grounds into general practice and blend in seamlessly with their current workflows. It does, however, seem to be quite a leap from the GPs viewing PRO as they do now, to them seeing the benefits in using questionnaires for baseline and follow-up regarding the psycho-social aspects of the patients' life.

7.5 Summary of analysis

This section will provide a summary of the significant finds in order to understand the bigger picture of this study and the implications of the findings, as well as reiterate the important details of the analysis for the concluding parts of this study. The analysis commenced with an investigation of the terminology of the PRO term. It was found, that five actors use *information* only, when translating the word *outcomes* in Patient-Reported Outcomes into Danish; MedCom, PA Consult, the Ministry of Finance, Danish Regions and general practice. Two actors only use *data* or *outcome-data*; ViBIS and TrygFonden. The remaining five use *information* as well as

outcome-data; the Ministry of Health, the PRO secretariat, Local Government Denmark, CIMT and PLO. We found, that *information* and *outcomes* cannot be used interchangeably, as they do not mean the same. The data set has shown, that there is a correlation between how the actors denote PRO and how they understand the technology. For instance, general practice only perceives it as a tool for gathering objective information from patients and uses the term *information*.

Based on the set of meanings expressed by the actors, they were then separated into three social groups with those they share similar understandings with. Group A contains MedCom, CIMT, PLO and PA Consult. Group B consists of general practice and group C consists of the PRO secretariat, TrygFonden, ViBIS, Ministry of Health, Ministry of Finance, Danish Regions and Local Government Denmark. Each social group expressed several problems regarding the use of PRO in general practice. The problems related to a multitude of topics, such as the sheer difficulty of getting GPs involved, how the tools can benefit GPs in their workflow and if they will be helpful for patients, or only entail a higher level of effort from them.

The problems were divided into five primary problems; *Involving GPs in national PRO*, *GPs reluctance towards implementing PRO*, *GPs reluctance to share data*, *Increased demands for the patient* and *Difficulty of implementing subjective questionnaires*. The groups provided several possible solutions for the problems. Regarding the first problem, it was suggested that MedCom could facilitate the contact between the GPs and the PRO secretariat. Another suggestion was to develop a separate version of PRO for the GPs, to better suit their needs. The second problem could be solved by using already known questionnaires in general practice as well as utilising platforms they are already familiar with. Another solution suggested, was to make greater efforts to better understand the culture of the GPs when developing for them. For problem three, they suggested working on a cultural change in general practice, as they do not currently have a culture of sharing patient data on that level. The groups do not specify solutions regarding problem four, as this was not a focus in the data collection. However, some of the points they made were useful in order to look at possible stabilisation attempts, hence these will be treated in the discussion. Problem five could be solved by using questionnaires that were already in use in paper versions in general practice. They also suggest the use of objective questionnaires over subjective ones. Regarding the subjective questionnaires, they suggested to introduce ways to handle subjective data, i.e. refer patients to other actors who can address it.

8.0 Discussion

As the illustration shows, this will be the final step in processing the data. After several convergences, the data has been processed in the analysis, and will now be expanded further upon with a discussion of the solutions uncovered.

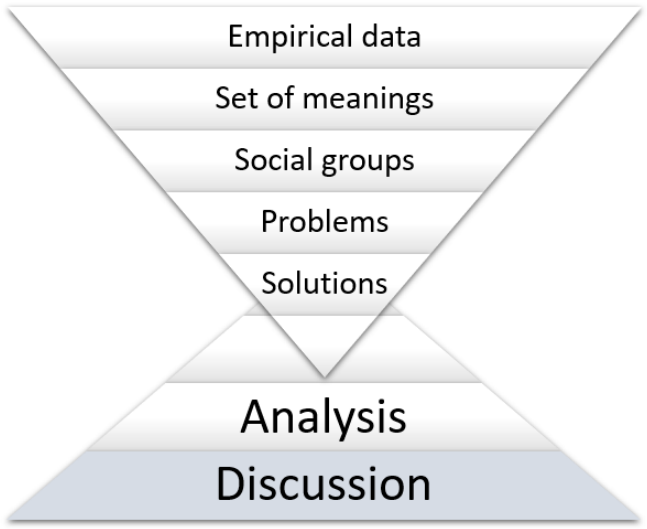


Figure 47: Study design; discussion

In this chapter, important topics in the findings of the study will be discussed along with critiques of the theory, methodology and methods used. Firstly, a discussion on the most significant findings will be commenced, regarding what was uncovered and how this could have implications within a larger context. Thereafter, a discussion of the theory and methodology of Social Construction of Technology will be performed regarding relevant strengths and weaknesses in this approach. Lastly, the methods used and how it affected the empirical data will be discussed.

8.1 Discussion of findings

The analysis of the set of meanings of the social groups uncovered five main problems connected to the PRO technology. Those five problems were: *Involving GPs in national PRO*, *GPs reluctance towards implementing PRO*, *GPs reluctance towards sharing data*, *Increased demands for the patients* and *Difficulty of implementing subjective questionnaires*. In this chapter, the solutions of these problems will be discussed thoroughly and suggestions for closure will be made. This discussion should be seen as our approach to the "*theory of invention"* as defined in

paragraph *4.1.2 SCOT as a theory*; a gathering of the insights uncovered in the study; the technological frames, the interpretative flexibility and the analysis of the groups' knowledge, set in relation to our world view as social constructivist, where technology is not only socially constructed, the social are also technologically constructed in a seamless and coherent web.

8.1.1 Problem one: Involving GPs in national PRO

A solution to the first problem defined, was to let MedCom facilitate contact to the GPs and to create a working group of GPs for developing questionnaires for PRO in general practice. This strategy would by Pinch and Bijker be defined as closure by redefining the problem; solving a problem by creating something else that could satisfy all groups. The air-filled tire for the bicycle provided both the comfort for the groups not agile or brave enough to use the Penny-Farthing, it also provided the young men with the speed to match their needs. As in that scenario, a workgroup of GPs could give them incentive to be involved in the national work with PRO, while at the same time create PRO questionnaires that would in fact be relevant for them and therefore more likely to be used by more GPs in their workflows.

An interesting dichotomy was raised in our empirical data; the GPs are difficult to involve, and the GPs find it difficult to contribute. Perhaps, this solution could lead to a closure of this problem. It would furthermore show an acknowledgement, that GPs are their own speciality and not just a general supplement for other physicians' specialities. A GP could rightfully ask, why questionnaires are being developed for a multitude of other specialties besides theirs. A problem with this solution is that, even though GPs are their own speciality, they do have some overlaps with other physicians' specialities and therefore it could be an immense challenge for the GP working group to develop GP-PRO-questionnaires for every diagnose. This advocates for PRO in general practice being of a more overall level; general well-being, overall functional level and abilities.

Another challenge with the solution of a closer collaboration between the groups, however, is that the set of meanings regarding PRO is not aligned between the groups. A fair assumption would be, that it would be difficult, even for group A, to get the GPs to contribute to a version of PRO that the GPs do not believe will benefit their workflows considerably. Currently, it is a setting that neither group A nor group B believe will be very fruitful for the GPs to contribute to. This problem is multifaceted in terms of getting all relevant actors involved in

the same solution. In order to stabilize this problem, it would require group C to be open for adjusting their technology to the needs of GPs.

Another issues, which was not present in the data, is the fact that the GPs are private actors in a public area and therefore their time is money in another way than the regional physicians. We do not know if this is an obstacle in the collaboration, but it seems like it could be part of the explanation. This problem could call for some degree of political action to encourage the GPs the be involved in the national work.

8.1.2 Problem two: GPs reluctance towards implementing PRO

Solutions for this problem was defined by the groups as committing to using questionnaires and platforms that the GPs already know. This was the solution from all groups, with the small disclaimer from group C, that when the national PRO is developed and fully launched, this should be utilised as the standard, perhaps implied "no matter what questionnaires this encompasses".

In order to stabilize this problem, it must first be clarified whether general practice should henceforth use the PRO tools as developed by MedCom or if they are to enter the national work with PRO down the line. As the situation is now, two separate actors simultaneously have designated general practice as their territory. It is understandable, that a lack of coherence exists in the field of PRO, when you have a national initiative that supposedly covers all sectors, except one, who uses their own version. If both actors agreed on this, however, it is likely that coherence and cooperation could exist, but to our knowledge, no moves have been made to join each other's initiatives.

This suggests, that general practice needs to be placed somewhere they will stay, and the PRO infrastructure will be able to accommodate them, regardless of where they are placed in the landscape. When that is clear, the developers need to have more awareness of the needs of GPs and GPs need to be more informed on how PRO can be of benefit to them. The solution of problem one, redefining the problem in order to close it, could very well be translated to this problem as well, as an argument could be, that tools developed with assistance of the GPs would seem more relevant and useful for other GPs.

8.1.3 Problem three: GPs reluctance towards sharing data

For this problem only vague solutions, such as assuming that a slow cultural change will likely increase the usage of PRO in the future, were suggested. The data shows, that GPs are not opposed to sharing data per se, but they are worried that it will do harm for patient along with themselves. This is important to be aware of in a development process of a technology, whose cornerstone is a shared infrastructure for data sharing among sectors. Thus, the stabilizing of this problem seems to be rooted in an openness about negative past experiences and a willingness to ensure, that history will not repeat itself, to secure data can be shared with proper consent and not fall in the wrong hands.

Tackling this problem puts the secretariat in a difficult situation in relation to using PRO for general quality development. You would have to attain very specific clearances from patients in order to use their information to anything else besides their own specific course of treatment and create a very transparent system. This, one could argue, would not be a negative approach for the problem of sharing data across sectors, since the patients should ethically by viewed as owner of their information and therefore should have the transparency of seeing where their information travels.

The problem therefore could be closed by applying the strategy of rhetorical closure, where one group must convince another that the technology is in fact un-problematic. The secretariat could do this by convincing GPs, that they will keep their promise towards the patients to keep the data safe and the GPs could do this by convincing the secretariat, that it will not be a problem to attain the needed permissions from patients in order to use the information for quality development.

8.1.4 Problem four: Increased demands for the patient

As stated, no real solutions were given regarding this problem which was mainly caused by the fact that our interview guide did not set out to uncover this subject specifically. We did, however, include the problem as the patients to great extent is the center of the whole technology and there were mentions of how it would affect them negatively workwise.

In order to stabilize the problem, we see the solution as a part of the solution to some of the other problems; that GPs should be more involved in the development. This problem cannot be put on the actual practitioners, as it seems the individual GPs do not seem

to be opposed to the technology of PRO per se, but more so are dismissive towards the extra work using it entails for both them and the patient, without having benefits that compensate for it. A closing strategy here could be one of a rhetorical nature, where the secretariat convinces the GPs that there, in fact, is no problem with an increase in patient work, as the benefits from this extra effort will simultaneously yield many positive effects for the patients.

Furthermore, if the GPs participate more in the preliminary workshops and general development of national PRO, they would be more likely to have a say in how the tools are developed because they would have better access to stating their opinions and describe how the tools would help or hinder their workflows.

8.1.5 Problem five: Difficulty of implementing subjective questionnaires

Solutions for this problem, as suggested by the groups, were to use familiar questionnaires for the GPs and then slowly wait for this cultural processing, that group C explain will solve many of the issues that national PRO are facing. In order for this problem to become closed, it seems as if the actors need to meet somewhere in a compromise, or, as stated in the fourth problem, that the GPs should provide more input to the development in order to have the technology better accommodated to their needs. It does not seem unrealistic to gain closure by redefinition with a version of the PRO tools, where GPs will have access to questionnaires that are relevant for them to use, but also to have them participate in a cross-sectoral collaboration, where they deliver objective as well as subjective data on patients when necessary and proper consent has been given.

This middle ground does create some potential issues among the actors. First, the secretariat might have some reservations about accepting a version of PRO, that to begin with is more *information* and less psychosocial factors or *outcomes*. Secondly, the GPs might experience problems regarding experience an increase in workload after implementing more subjective questionnaires with a psychosocial focus, seeing that as of right now, they do not always know what to do with that type of knowledge.

8.1.6 Denotation

As mentioned in our problem area and literature analysis, it was in our empirical data evident, that there are indeed different usages of what the different actors call PRO and that this

differentiating denotation in fact, is correlated to those actors' set of meanings. We uncovered, that the actors have fundamentally different perceptions of what the technology is, what it is supposed to do and how it can contribute to improving the health sector for healthcare professionals and patients. This entails, that when developing a technology with different set of meanings, the end-product will be understood very differently. Seen as an isolated technology, this is not at issue. There is a multitude of similar technologies developed from different set of meaning for specific users. The problem arises when the technology is meant to be implemented on a grand, national scale. General practice is an important actor in this infrastructure, seeing that patients typically begin their course of treatment with a visit to their GP.

As a solution in order to close this, perhaps, foundational problem, we suggest either one of two closure strategies, both closure by redefinition. One is an approach, where the developers agree upon an understanding of PRO and adjust their language and tools accordingly, or an approach of developing a denotation or stratification tool to more precisely denominate the different understandings of PRO. This would acquire some resources into the actors entering a collaboration of investigation like this; clarification of what is actually being used related to what is actually being said. For instance, an abbreviation for the term *"patientrapporterede oplysninger"/"patient-reported information"* could be PRI instead of PRO in order to distinguish the two. It appears the definition and distinction from Program PRO is not clear enough, when nobody really knows what you are asking, when you ask them *"what is PRO?"*

8.2 Methodological and theoretical approach

The approach of this study was, as mentioned, the methodological and theoretical approach of Social Construction of Technology. The methodology provided a thorough structure to the data collection process of developing an interview guide and thereby provided grounds for sorting and analysing this data and creating overview, structure and tangible conclusions. An obvious challenge when using one methodology, is the risk of getting too narrow-minded and losing some nuance in the attempt to make world to fit into a form that may or may not be an accurate display of the reality.

One could certainly argue, that when narrowing actors down to social groups you, at the same time as creating a more simplistic and understandable dataset, lose some nuance in terms of the small differences between actors inside a group. To overcome this challenge, we attempted to not include more actors than we believed we could manage in order to still extract each actor's most significant statements. This, on the other hand, entailed a narrower empirical field, which will be discussed in the next paragraph.

Another critique of the methodology is, that according to SCOT methodology, all actors/groups are viewed within a flat field of power-relations. No actor is weighted to be more or less influential, and there is no conversation about inflictor/inflicted; who does the technology otherwise affect and what are these consequences. This was evident in our data, when the groups were weighted equally, but there in fact was quite a bit of difference in actual influence between Groups A and C, who were somewhat equal, and Group B. Because this is not a congenital focus of the methodology, researchers must be aware of not overseeing those less influential actors and include them in the study as well, as we did with the GPs. In this study, the most significant group not incorporated in the scope is the patients. Leaving out patients in this study entails, that we do not get to hear how they understand the technology, what they considered problematic about it and how they would solve those problems. Thus, we are only able to attempt the stabilization of the technology among the largest influencers.

When going through the data material, there are a lot of references to the patients, what they want, what they need and what it should be like to be a patient in the Danish health system. We can only accept those opinions as the truths of those who speak of it, we are not able to challenge their views by supplementing them with statements from actual patients. In another study, it could be interesting to get their perspective on matters such and the treatment of their personal health data, how they feel about an increase in home monitoring and how it would make sense for them to use PRO when consulting their general practitioner.

The focus of SCOT is primarily on the technology and less on the consequences the technology can have in a broader setting, than that of the development and implementation of the technology. There is not a focus on the economic or ecological consequences of the technology and therefore it is not as sensitive to negative democratic or natural consequences as other methodologies and theories related to technology development, i.e. Public Engagement of Science, because the scope of that methodology is exactly that.

8.3 Methods

8.3.1 Uncovering solutions

A qualitative approach was chosen for collecting data for this study in order to gain nuanced and in-depth insights. The primary source of data came from semi-structured interviews and a document analysis. These two types of data were supplemented by a brief section of video analysis. The interview guide was produced with consideration for the SCOT framework, to secure that we would have the correct data for uncovering the actors' set of meanings, problems and solutions with a focus on uncovering tacit knowledge from the actors. We came to find, however, that it proved more difficult than expected to extract suggested solutions continuously to the problems we uncovered. By the end of each interview, we reviewed the problems we took notice of, and reiterated them to the actor, to make sure, that a solution would be provided for each problem. When condensing the data, we chose to include other types of problems than those we initially noted during the interview, which left us with problems with no defined solution. In some cases, it was enough to extract solutions from the interviews, but in other cases, this was not possible. To accommodate this, it could have been beneficial for the study to perform a number of follow up interviews. The method used can be criticized for being less representative of what solutions the actors would define, when being confronted with the problems condensed from all the material. Thus, conclusions made on this background should be somewhat careful, but an effort was made as not to articulate the findings as absolute truths.

8.3.2 Interviews

The interview part of the data collection consisted of three interviews with MedCom, the PRO secretariat and a general practitioner, respectively. Regarding the first two actors, we find it reasonable to assume, that the statements made by the actor represent the organisation. We do see a possible bias regarding the general practitioner we spoke to, as we only interviewed one. GPs are only able to represent themselves, as they are not as connected by the same organisation as the first two respondents were. This means, that we have been compelled to generalise a lot and assume, that the statements made by the GP we spoke somewhat cover the opinions of other GPs. We would have liked to perform more interviews with GPs in order to attempt to make more precise generalisations regarding GPs, but it has unfortunately not been

possible. On this matter, we can relate to the PRO secretariat having a hard time reaching general practice. Thus, we have performed the study with input from the one GP that we have but are aware that the statements made are indeed very generalised.

Our interview guide was created based on the methodology of SCOT in terms of uncovering set of meanings, problems and solutions. The questions were formulated in order to uncover explicit and tacit knowledge. This provided in depth uncovering in the processing of data in relation to set of meanings and problems, that we perhaps would not have uncovered if asking explicitly. However, it created a challenge in terms of uncovering solutions, as mentioned. Therefore, there could be more, or other solutions from the actors, that could be uncovered with further iterations of interviews.

The method of reaching actors in a stringent SCOT approach is to snowball through the field. This, however, was not our scope, as we already had an idea of what actors were relevant to reach. This can be argued to have affected our data, seeing that there might be actors important to the field, that we did not reach. In order to accommodate this bias, we have not formulated our findings as universally true for the entire field, but clearly state, that this is the reality of these specific actors.

The interviews were performed as telephonic interviews, which is a method that creates easier access to interviews, because it is less invasive for the actors in terms of fitting it into a busy schedule, furthermore, geography is no challenge. The downside is that you lose some nuance in terms of using and observing body language and perhaps using physical probes like pictures. In terms of uncovering the scope of this study, it was decided that telephonic interviews were sufficient as a method.

Following the interviews, they were transcribed. We made the choice, to omit some parts, i.e. if the actor spends some time looking for words, mumbling, saying "uhmm…" and the like. This was done to gain more clarity and due to those little nuances not being necessary for this study. Furthermore, certain things were said off the record and are thus not shown in the transcription. Redacted statements are replaced with "[Parts redacted – off the record, ed.]" This phrase is included because some statements are in the middle of other statements, for the reader to know why parts are missing or do not make sense. It is possible, that editing the transcription with these considerations can cause a bias, but we do not believe this is the case, due to nothing relevant being left out, unless it was off the record. We have made

the decision to make the transcription as clear and readable as possible, over including every word and mumble.

8.3.3 Considering agenda of material

When using reports and video material that we did not produce ourselves, it is important to be aware of the agenda behind the publication. Even though a video recording can seem like a simple, objective piece of data, it is not so. There will always be an agenda behind the angle it has been filmed from, the inclusions and, maybe more importantly, exclusions from the frame as well as the way it has been edited. We cannot know what happens outside the frame of the video, we cannot know what has been edited out and if certain sequences have been switched around.

We have chosen to include certain quotes from recordings published by others. These can only be considered true in the sense, that they are true in what we have observed ourselves on the recordings. Statements can be manipulated, so they should be included with some considerations. We must to the best of our abilities check who has produced the recording and with what purpose, and on that basis deemed them to be of a quality suitable for this study. We notice, for example, that the MedCom recording includes somewhat critical questions to their work and we see displays of body language in the background, which do not speak to MedComs benefit. These observations leads us to believe, that MedCom has not grossly edited the video to push their own agenda through, but has published it in a manner where it represents the reality of the actual conference, as more of a bystander, thus, we assume the content to be reliable for this use. Furthermore, the information from the videos were mostly in the report used complementing the primary sources of data; the reports and more so the interviews.

The same arguments go for the reports as for the recordings. When incorporating this material into the data one must be careful of the sender, the context, the political setting and so on and not consider the statements as the ultimate truth. We primarily used the reports for statements from an actor, so that the statements would be on behalf of that actor and not as much a representation of the truth as we see it.

8.4 Techno-Anthropological problems

In the beginning of this thesis, we argued that this study deals with a Techno-Anthropological problem, seeing as the scope was to shed a light on the influences that technology and humans have on each other, exemplified by the reality of PRO in general practice in Denmark. The study into uncovering understandings and discussing the implications of said understandings amongst actors touches the three interfaces of a Techno-Anthropological study by simultaneously delving into the interactional expertise of experts and users, into the social aspects of the implications of the technology as a result of the interface between experts and artefact/technology and lastly the methods of the study used to uncover the above mentioned interfaces being anthropological, as visualised by figure 47 below. PRO is indeed a technology and, albeit purely digital, it is very palpable and significant for the users of it, as it can change their (work)lives and the health sector in Denmark as a whole. Therefore, it is both highly relevant and possible to investigate as a Techno-Anthropological problem.

Figure 48: Techno-Anthropological competencies in the scope of this study

9.0 Conclusion

This chapter will conclude the study and an attempt at answering our problem statement:

> Which understandings of Patient-Reported Outcomes exist amongst relevant actors in the context of general practice in Denmark and what might the implications of these social constructions be?

Throughout the data collection and analysis, the focus has been on selected actors' understanding of PRO as a tool and as a technology in general. Through semi-structured interviews and an analysis of relevant reports with and by the actors, the three main social groups surrounding the technology have been defined. The study has found, that based on the empirical data it was possible to define three groups, who have their own overall understanding on what PRO is as a technology, as well as what it can do for both patients and the health sector. In outline, group A denotes PRO as *information* and perceives the technology as a systematic collection of information from the patient, which can be used to ease already existing, paper-based workflows and make these workflows more cost-effective. Group B also denotes PRO as *information* and primarily understand the technology as objective information delivered by the patient, mainly through home-monitoring to ease workflows in general practice. Group C denotes PRO mostly as *outcome-data* and perceives PRO as both objective and subjective data, which, collected through questionnaires to assist a patient in their course of treatment, can facilitate an individualisation of their treatment and provide dialogue support in consultations. This view supports a holistic approach to the patient and is also meant to enable the idea that the data should follow the patient through sectors, to ease their transition and to make workflows better for health professionals.

This shows, that we have managed to uncover varying understanding of PRO between actors using qualitative methods; semi-structured interviews and document analysis, supplemented by video material. Furthermore, the problems and solutions of the social groups have been investigated, showing, that some problems recur in more than one social group, but the reasons behind the problems vary between groups. Recurring and singular problems have been analysed and put in correlation to the solutions proposed by the social groups, in order to

evaluate whether it would be possible to stabilize the technology and create the needed coherence among actors. It was found, that singular interviews were difficult in terms of uncovering solutions, as many of the problems uncovered were tacit in the statements from the actors and only emergent in the analysis of the data. The study could therefore have benefitted from a second iteration of interviews with the actors.

It was possible to find seemingly suitable ways to stabilize the technology through an analysis the five problems, but whether a different version of PRO which accommodates these attempts at stabilization is possible cannot be known based on this data. Even though, the solutions seem to solve the problems here and now, it is plausible that they might create new problems or that the solutions are not possible to accommodate at all. The PRO tools are being developed as a part of a larger political strategy, so it is likely not possible to implement seemingly simple solutions and expect them to be met accordingly. That is, moreover, not the aim of the study; the aim through the study has been to uncover if these discrepancies of understandings exist and what the solutions to solve these problems could be.

Furthermore, we do believe, we have uncovered why these discrepancies exists. First and foremost, it seems rooted in the two vastly different manners it is currently being implemented in, respectively the national work with PRO and the work with PRO in general practice by MedCom. Secondly, in something as simple as a lack of communication between involved actors. Thirdly, the two implementation strategies are based on vastly different set of meanings with the national work with PRO, being based in the Program PRO report. This entails a heightened focus on patient involvement and – empowerment; a cross-sectoral tool and a tool for quality development. MedCom are basing their development and implementation on practical approaches to fit a single sector; the general practice. This entails that PRO by MedCom is developed as a tool to help make general practice more effective, not necessarily to make improved conditions for the patient or the healthcare sector as a whole.

Based on this study, it is possible to conclude that the field of defining in general practice in Denmark, is a complex construction, which require great concern for all involved actors. The solutions to problems might seem simple, but can be difficult to accommodate, since the implications of implemented solutions might entail unforeseen problems for other actors, while solving them for some.

10.0 Bibliography

1. AAU Library (no date) *Search technique*. Available at: https://www.en.aub.aau.dk/find-material/hints-search/ (Accessed: 6 June 2019).
2. Ældreministeriet, S., KL and Regioner, D. (2018) 'Nationale mål for sundhedsvævenet 2018', *Elektronisk publikation*, pp. 1–37. Available at: https://www.sum.dk/Aktuelt/Publikationer/Nationale-maal-sept-2018.aspx.
3. Ambuflex (no date) *Milepæle: historien om AmbuFlex*. Available at: http://ambuflex.dk/om-ambuflex/ (Accessed: 6 June 2019).
4. Baldwin, M. *et al.* (2011) 'Patient-reported outcomes, patient-reported information: From randomized controlled trials to the social web and beyond', *Patient*, 4(1), pp. 11–17. doi: 10.2165/11585530-000000000-00000.
5. Bijker, W. E. (1997a) *Of Bicycles, Bakelites, and Bulbs: Toward a Theory of Sociotechnical Change*. MIT Press (Inside technology). Available at: https://books.google.dk/books?id=IsbmwN8-m1cC.
6. Bijker, W. E. (1997b) *Of Bicycles, Bakelites, and Bulbs: Toward a Theory of Sociotechnical Change*. MIT Press (Inside technology).
7. Black, N. (2013) 'Patient reported outcome measures could help transform healthcare', *BMJ (Online)*, 346(7896), pp. 19–21. doi: 10.1136/bmj.f167.
8. Black, N. *et al.* (2016) 'Patient-reported outcomes: pathways to better health, better services, and better societies', *Quality of Life Research*. Springer International Publishing, 25(5), pp. 1103–1112. doi: 10.1007/s11136-015-1168-3.
9. Børsen, T. and Botin, L. (2013) 'What is techno-anthropology?' Kbh.: Nota (Serie om lærings-, forandrings- og organisationsudviklingsprocesser, vol. 3), p. 483 sider. Available at: https://nota.dk/bibliotek/bogid/633570.
10. Brinkmann, S. and Tanggaard, L. (2010) *Kvalitative metoder : en grundbog*. Kbh.: Hans Reitzel.
11. Bygholm, A. and Bertelsen, P. (2017) 'Patient at Work - In the Era of PRO.', *Studies in health technology and informatics*, 241, pp. 115–121.
12. Chenok, K. E. *et al.* (2016) 'Incorporating Patient-Reported Outcomes Into Health Care To Engage Patients And Enhance Care', *Health Affairs*, 35(4), pp. 575–582. doi: 10.1377/hlthaff.2015.1362.

13. Christensen, T. V. *et al.* (2017) *Uncovering knowledge from users and healthcare professionals*.
14. Chromy, J. R. (2008) *Snowball Sampling*. Available at: http://sk.sagepub.com.zorac.aub.aau.dk/reference/survey/n535.xml?term=snowball (Accessed: 6 June 2019).
15. CIMT (2019) *Evaluering af PRO i almen praksis*. Available at: https://cimt.dk/evaluering-af-pro-i-almen-praksis/ (Accessed: 6 June 2019).
16. CIMT (no date) *Centre for Innovative Medical Technology*. Available at: https://cimt.dk/gb/ (Accessed: 6 June 2019).
17. Danish Ministry of Health (2018) 'A Coherent and Trustworthy Health Network for All'. Available at: https://www.healthcaredenmark.dk/media/1611539/The-Danish-Digitalisation-strategy-2018-2022.pdf.
18. Dansk Medicinsk Data Distribution (no date a) *Web-Patient – enkel og sikker PRO for både dig og din patient*. Available at: https://www.dmdd.dk/web-patient/ (Accessed: 6 June 2019).
19. Dansk Medicinsk Data Distribution (no date b) *WebReq – hurtig og effektiv laboratorierekvirering*. Available at: https://www.dmdd.dk/webreq/ (Accessed: 6 June 2019).
20. Danske Patienter (no date) *Program PRO*. Available at: https://danskepatienter.dk/vibis/om-vibis/vores-projekter/program-pro (Accessed: 6 June 2019).
21. Danske Regioner (no date a) *Danish Regions*. Available at: https://www.regioner.dk/services/in-english (Accessed: 6 June 2019).
22. Danske Regioner (no date b) *Værdibaseret Sundhed*. Available at: https://www.regioner.dk/sundhed/tema-vaerdibaseret-sundhed (Accessed: 6 June 2019).
23. Danskepatienter (no date a) *About Danish Patients*. Available at: https://danskepatienter.dk/about-danish-patients (Accessed: 6 June 2019).
24. Danskepatienter (no date b) *Brug af PRO-data i praksis*. Available at: https://danskepatienter.dk/vibis/videoer-og-film-om-inddragelse/brug-af-pro-data-i-praksis (Accessed: 6 June 2019).
25. Ebdrup, N. (2014) *Sådan bruger du videnskabsteori*. Available at:

https://videnskab.dk/miljo-naturvidenskab/sadan-bruger-du-videnskabsteori (Accessed: 6 June 2019).
26. FDA, H. (2009) 'Guidance for Industry Patient-reported Outcome measures: Use in Medical Product Development to Support Labeling Claims', *Clinical/Medical Federal Register*, (December), pp. 1–39. doi: 10.1111/j.1524-4733.2009.00609.x.
27. Finansministeriet (no date) *Om os*. Available at: https://www.fm.dk/om-os (Accessed: 6 June 2019).
28. Finansminsteriet (2016) *Aftale om regionernes økonomi i 2017*. Available at: https://www.fm.dk/nyheder/pressemeddelelser/2016/06/aftale-om-regionernes-oekonomi-i-2017 (Accessed: 6 June 2019).
29. Fischer, A. and Tynell, J. (2014) *OVERBLIK Det handler data-sagen om*. Available at: https://www.dr.dk/nyheder/indland/overblik-det-handler-data-sagen-om (Accessed: 6 June 2019).
30. Fuglsang, L., Rasborg, K. and Olsen, P. B. (2013) *Videnskabsteori i samfundsvidenskaberne : på tværs af fagkulturer og paradigmer*. 3rd edn. Frederiksberg: Samfundslitteratur.
31. Greenhalgh, J. (2009) 'The applications of PROs in clinical practice: What are they, do they work, and why?', *Quality of Life Research*, 18(1), pp. 115–123. doi: 10.1007/s11136-008-9430-6.
32. Kommunernes Landsforening (no date) *KL - Local Government Denmark*. Available at: https://www.kl.dk/english/ (Accessed: 6 June 2019).
33. Lauritsen, P., Olesen, F. and Bruun Jensen, C. (2007) *Introduktion til STS : science, technology, society*. Kbh.: Hans Reitzel.
34. Lavrakas, P. J. (2008) *Gatekeeper*. Available at: http://methods.sagepub.com/reference/encyclopedia-of-survey-research-methods/n200.xml (Accessed: 6 June 2019).
35. MedCom (2017) 'Evaluering af Patientrapporterede oplysninger (PRO) i Almen Lægepraksis'. Available at: http://medcom.dk/projekter/pro-i-almen-laegepraksis.
36. MedCom (2019a) *Om MedCom*. Available at: https://www.medcom.dk/om-medcom (Accessed: 6 June 2019).
37. MedCom (2019b) *Patientrapporterede oplysninger (PRO) i almen praksis*. Available at: https://www.medcom.dk/projekter/pro-i-almen-laegepraksis (Accessed: 6 June

2019).

38. Moher, D. *et al.* (2009) 'Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement', *BMJ*. BMJ Publishing Group Ltd, 339. doi: 10.1136/bmj.b2535.
39. MØLLER, A. B. (2019) *Snowball sampling*. Available at: http://metodeguiden.au.dk/alfabetisk-oversigt/generelle-metodiske-overvejelser-og-problemstililnger/sampling-revised/snowball-sampling/ (Accessed: 6 June 2019).
40. Munch-Petersen, M. *et al.* (2016) *Program Pro - Anvendelse af PRO-data i kvalitetsudviklingen af det danske sundhedsvæsen [Program Pro - Use of PRO data in the quality development of the Danish health service]*.
41. Nielsen, M. L. (2015) *Ny professor sætter patientdata i system*. Available at: http://newsroom.au.dk/nyheder/vis/artikel/ny-professor-saetter-patientdata-i-system/ (Accessed: 6 June 2019).
42. Ordbogen.com (2019) *Ordbogen*. Available at: https://www.ordbogen.com/da/ (Accessed: 6 June 2019).
43. PA (no date) *About us*. Available at: https://www.paconsulting.com/about-us/ (Accessed: 6 June 2019).
44. PA Group, P. C. (2015) 'Analyse Af Patient-Rapporterede Oplysninger'.
45. Patientdataforeningen (no date) *Bevar Tavshedspligten*. Available at: https://www.facebook.com/BevarTavshedspligten/ (Accessed: 6 June 2019).
46. Pedersen, K. M., Andersen, J. S. and Søndergaard, J. (2012) 'General Practice and Primary Health Care in Denmark', *The Journal of the American Board of Family Medicine*, 25(Suppl 1), p. S34 LP-S38. doi: 10.3122/jabfm.2012.02.110216.
47. Philpot, L. M. *et al.* (2018) 'Barriers and Benefits to the Use of Patient-Reported Outcome Measures in Routine Clinical Care: A Qualitative Study', *American Journal of Medical Quality*, 33(4), pp. 359–364. doi: 10.1177/1062860617745986.
48. Pinch, T. J. . and Bijker, W. E. (2012) 'The Social Construction of Facts and Artifacts: Or How the Sociology of Science and the Sociology of Technology Might Benefit Each Other'.
49. Pink, S. and Pink, S. (2007) *Doing Visual Ethnography*. 1 Oliver's Yard, 55 City Road, London England EC1Y 1SP United Kingdom : SAGE Publications, Ltd. doi: 10.4135/9780857025029.

50. PLO (2018) *Høring over udkast til bekendtgørelse om registrering af den enkelte borgers patientrapporterede oplysninger (PRO-data) og selvmålte data i Nationalt patientindeks (NPI)*. Available at: https://www.laeger.dk/hoering-over-udkast-til-bekendtgoerelse-om-registrering-af-den-enkelte-borgers-patientrapporterede (Accessed: 6 June 2019).
51. PLO (no date) *Om PLO*. Available at: https://www.laeger.dk/om-plo (Accessed: 6 June 2019).
52. 'PLO faktaark 2017 1.' (2017).
53. PRISMA (2015) *Welcome to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) website!* Available at: http://www.prisma-statement.org (Accessed: 6 June 2019).
54. PRO-sekretariatet (2018a) *Om os*. Available at: pro-danmark.dk/da/om-os (Accessed: 3 January 2019).
55. PRO-sekretariatet (2018b) *PRO – patient reported outcome*. Available at: pro-danmark.dk/da/pro-english (Accessed: 3 January 2019).
56. PRO-sekretariatet (2019a) *PRO-puljeprojekter*. Available at: http://pro-danmark.dk/da/pro-landskab/pro-puljeprojekter (Accessed: 6 June 2019).
57. PRO-sekretariatet (2019b) *PRO i Danmark*. Available at: http://pro-danmark.dk/da/pro-landskab/pro-i-dk (Accessed: 6 June 2019).
58. PRO-sekretariatet (no date) *Forside*. Available at: http://pro-danmark.dk/da (Accessed: 6 June 2019).
59. Rodkjaer, L. *et al.* (2015) 'Patient- reported outcomes – a means of facilitating patient involvement', (July 2016), pp. 77–80.
60. SCHJØDT, U. (2019) *Gatekeepers*. Available at: https://metodeguiden.au.dk/alfabetisk-oversigt/generelle-metodiske-overvejelser-og-problemstililnger/gatekeepers/ (Accessed: 6 June 2019).
61. Stoustrup, A. L. and Jørgensen, S. H. F. (2019) *Incorporating user values in a technological innovation*.
62. Sundhed- og Ældreministeriet (2017) *Mission, vision og værdier*. Available at: https://www.sum.dk/Om-ministeriet/Mission-vision-vaerdier.aspx (Accessed: 6 June 2019).
63. Sundhedheds- og Ældreministeriet (2019) *Patientrapporterede oplysninger (PRO)*. Available at: https://sum.dk/Sundhed/Sundhedskvalitet/Patientrapporterede-

oplysninger.aspx (Accessed: 6 June 2019).
64. Sundhedsdatastyrelsen (2017) 'Bilag 6 : Begrebsramme for Den Nationale Arbejdsgruppe for PRO', pp. 2–3.
65. TrygFonden (no date) *TrygFonden - in English*. Available at: https://www.trygfonden.dk/english (Accessed: 6 June 2019).
66. Yang, L. Y. *et al.* (2018) 'Patient-reported outcome use in oncology: a systematic review of the impact on patient-clinician communication', *Supportive Care in Cancer*. Supportive Care in Cancer, 26(1), pp. 41–60. doi: 10.1007/s00520-017-3865-7.

11.0 Appendix

Appendix 1: List of illustrations

Appendix 2: Interview guide, PRO secretariat

Appendix 3: Transcription of interview with the PRO secretariat

Appendix 4: Interview guide, general practice

Appendix 5: Transcription of interview with general practice

Appendix 6: Interview guide, MedCom

Appendix 7: Transcription of interview with MedCom