PERSPECTIVES OF TELEHEALTH

A case study of telehealth for cystic fibrosis patients in the mist of COVID-19



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Resumé

Dette speciale er et casestudie om telemedicin til voksne med cystisk fibrose (CF) tilknyttet Enhed for Cystisk Fibrose under Infektionsmedicinsk Klinik på Rigshospitalet (herefter kaldet CF-centret). I samarbejde med CF-centret og Telemedicinsk Videncenter ved Region Hovedstaden var specialet tiltænkt som en kvalitetsundersøgelse og evaluering af dette telemedicinske initiativ for CF-patienter. Grundet de særlige omstændigheder for foråret 2020 blev vores indledende planer og metodiske overvejelser stærkt udfordret og skiftede kurs, da COVID-19 pandemien ramte Danmark og lukkede landet ned. Telemedicin er digitale og/eller mobile sundhedsydelser og behandling over afstand, hvilket i dette casestudie inkluderer flere underliggende egenskaber. Det telemedicinske initiativ til CF-patienterne indeholder hhv. en online eSundhedsplatform kaldet OpenTeleHealth, hvorpå medicinske værdier og data om patienter samt spørgeskema om symptomer står. Desuden telemonitoreringsudstyr til at måle omtalte medicinske værdier hjemmefra, dvs. patienten selv udfører målingerne; dette indeholder en iltmåler, et spirometer (måling af lungefunktion) og blodtryksmåler, som via Bluetooth overfører data til OpenTeleHealth, samt en tablet. Sidst består dette initiativ af telekonsultationer forestået via tabletten, hvor patient og behandler kan konsultere hinanden vedr. de monitorerede data og symptomer via video.

Indledningsvis afsøgte vi videnskabelige artikler på området for at sikre en grundlæggende videns base om CF, telemedicin og kombinationen af de to. Herudfra har vi udarbejdet et vidtspændende literature review. Desuden har vi gennem etnografiske metoder indhentet empirisk data til analysen. Vi har benyttet os af semistrukturerede interviews med CF-patienter, som vi var nødsaget til at foretaget via videoopkald grundet COVID-19. Desuden blev planerne om observation af telekonsultationer og udlevering af telemonitoreringsudstyr på CF-centret umuliggjort, da alle hospitaler i Danmark lukkede ned for ikke-akutte aktiviteter. Derfor tilføjede vi autoetnografi som metode til indhentning af empiri, dette er en metode hvor forskeren selv oplever og reflekterer løbende over oplevelser i feltet for at forstå kulturen heri. Hermed menes kulturen under COVID-19, hvor al kommunikation og kontakt til omverden forestås via digitale løsninger, ligesom telekonsultationer er digital kommunikation via video. For at sikre en tilbundsgående socio-teknisk analyse har vi brugt de teoretiske rammeværk af den hollandske Science & Technology forsker Jeanette Pols, hhv. hendes teori om Care at a distance, og Postfænomenologi (Postphenomenology, PP) af den amerikanske filosof Don Ihde og den hollandske teknologifilosof Peter-Paul Verbeek. Pols' teorier og PP, vurderer vi, går godt hånd i hånd til dette speciale, da Pols' teori er meget case specifik til telemedicin. Pols' teori bidrager desuden med et rammesættende og konkret værktøj til at analysere videokommunikation og teknologibrug til sundhedsydelser. PP går mere i dybden med selve menneske-teknologi interaktionen, hvori facetter som hvorledes teknologier medierer nye handlinger og opfattelser af verden, samt nye intentionaliteter formet gennem nye menneske-teknologi relationer analyses. Herved mener vi at have lavet en teknoantropologisk analyse med fokus på at lave en grundig undersøgelse af telemedicin til denne patientgruppe, deres brug af dette og hvorledes CF påvirker teknologiens brugbarhed. Dette er tiltænkt som et evaluerende bidrag til Rigshospitalets telemedicinske initiativ.

Resultaterne fra analysen er diskuteret ved brug af strategiteorien Triple Aim, som er en teori tiltænkt til innovation af sundhedsvæsenet gennem teknologiudvikling, samt teorien om Values that Matter (VtM), der inkorporerer værdi dynamikker i designprocesser. Disse teorier er benyttet til både en diskussion af analysen samt en generel diskussion af telemedicin i relation til at COVID-19 har bibragt et massivt fokus på potentialerne af telemedicin.

Vi har kunne konkludere at telemedicin til denne sygdomsgruppe er et positivt tiltag. Særligt grundet karakteren af CF og den kultur der findes i patientgruppen ift. egen sygdom og den signifikante behandlingsbyrde. CF er en kronisk, livsbegrænsende og meget altomsiggribende sygdom, der i høj grad påvirker hverdagslivet. CF-patienterne oplever en form for frihed-fra-sygdom gennem telemedicin, da det bevirker at patienterne selv kan holde øje med sygdomsforværringer og ikke skal afvente en behandler for at få bekræftet egne symptomer og helbred. Desuden opnås en nærhed på afstand for patienterne medieret af det telemedicinske udstyr. Dette er blot nogle af de afsluttende konklusioner, vi har gjort os i dette speciale. Vi har desuden påpeget flere opmærksomhedspunkter vedrørende telemedicin, da kontekst og patientgrupper i særlig høj grad har stor indvirkning på succesraten for implementering af telemedicin. Disse opmærksomhedspunkter ser vi yderst relevante i lyset af den telemedicinske trend, der er opstået under COVID-19. Supervisor: Lars Botin Aalborg University Copenhagen



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COVID19 and the consequences of the lock-down of society and the university since March 13, 2020 have had influence on which activities that have been possible to stage and carry out as part of the project work. More specifically, this means that activities have been limited to online activities, and that activities such as Lab activities; surveying activities; on-site ethnographic studies and on-site involvement activities have not been possible. When assessing this project, please bear this in mind.

Added here: the students' own reflections on the challenges they have experienced and how they have sought to overcome these.

COVID-19 has implied challenges in relation to conducting a case study in collaboration with the health care sector, respectively the Cystic Fibrosis Centre at Rigshospitalet and providers alongside with CF-patients affiliated. COVID-19 has made it impossible to conduct some qualitative research like observations of consultations at the CF-centre because of the hospital shutting down due to the national lockdown initiated 13th of March 2020. This, however, gave us the opportunity to discover the impacts of information and communication technologies (ICT) at first hand as we as researchers have been obliged to use video communication in our interviews with informants. Also, our meetings with our supervisor have been conducted via video communication. These activities have been incorporated throughout the thesis providing us with crucial embodied experience of communicating through a screen. Thus, we have seized the opportunities that emerged in the wake of the COVID-19 lockdown, e.g. that telehealth has merely become a public property and we have integrated this perspective of the COVID-19 pandemic in this thesis. This will be outlined further in various chapters when relevant throughout the thesis, especially in the Method chapter.

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1. Introduction

Cystic fibrosis (CF) is a chronic disease which impacts the life of the patient to a great extent:

"I use approximately 3-hours daily on treatment. And besides that, I exercise, because well it's a part of my medicine [...] I think I exercise approximately four times a week."

(Interview CFp1: 1)

In addition to medical and physical treatment, Danish CF-patients must attend consultations at one of the two national CF-centres once a month to various controls persisting throughout life (Rigshospitalet, 2018). Because the treatment is centralised, attendance consultations are often time consuming for CF-patients which can be added to the existing treatment burden of CF (CFF, n.d.(a)). To assist CF-patients in own disease management a technological initiative has been launched, respectively telehealth; a solution which should ease the distance between the persons involved and by that improve treatment adherence, overall health and quality of life (Rigshospitalet, 2018).

The term distance has been the pivot of Spring 2020 where several parts of society have been put on hold due to the COVID-19 lockdown - however not everything has been put to hibernation (Frydendahl & Høyer, 2020). Alongside the trees and flowers burst into bloom, there has been a blossoming in the utilization of information and communication technologies (ICT), like telehealth, to manage contact and business at a distance; online meetings on various workplaces and digital exams, just to mention a few (Hyldig, 2020; Steffensen, 2020). No doubt that the COVID-19 lockdown has been an eye-opener regarding telehealth:

"Corona virus has showed us that innovative health care technological solutions can be implemented in a heartbeat and additionally with a great effect for both the (health care, ed.) system and the patient."

(Rasbech, 2020)

The quote refers to health technologies, like telehealth, as a golden ticket, moreover the telehealth initiative for CF-patients could also be beneficial for CF-patients living close to the CFcentres (Rigshospitalet, 2018). This trend is backed up by the explosion in the use of video calls through the Danish health care video infrastructure, VDX: From 8,796 minutes/822 participants dispersed on 217 video calls on March 2nd 2020 to 389,400 minutes/19,187 participants dispersed on 6,835 video calls on April 16th 2020 (Medcom, 2020).

Therefore, it is relevant to scrutinise this area of utilising technologies in health care further in order to clarify nuances and carefully examine implications of this highly topical technological supplement to health care. Which implications does introduction of telehealth have on treatment of a chronic disease like CF, the patient-provider interaction and relationship, the patient experience of care and last, but not least; which values come into play or get eliminated with this technological setup. This will be examined in this thesis along with many other perspectives. The thesis will revolve around a CF-specific telehealth setup, however, the COVID-19 pandemic has highly influenced the methodologies and the results of these studies.

1.1 Problem area

Telehealth is an area which is incorporated in several strategies in society in relation to improvement of health care initiatives to various patient groups. Telehealth is often directed towards elderly and people suffering from chronic diseases (SST, 2020a). The benefits of telehealth are amongst others time savings for both the patient and the provider (SDS, 2018). Moreover, the promises of telehealth make the technological solution a potential answer to questions of how to reach patients in remote areas as the Danish hospitals are rather centralised (Finansministeriet, n.d.). Lastly, the digital element of telehealth could potentially offer patients more available public health services, thus securing that;

"[...] that one can continue on living an active life even though one suffers from one or more chronic conditions."

(SDS, 2018)

Telehealth has various constellations of which one is video consultations that is highly prioritized this spring because of the COVID-19 pandemic (Wentzer, 2020). A new initiative containing a video feature on an existing smartphone app called "Min Læge" (in English: My GP) is based on a temporary agreement between De praktiserende lægers landsorganisation (in English: The General Practitioners Association) and Danske Regioner (in English: Danish Regions) to secure consultations in these COVID-19 times (Wentzer, 2020; Aidt, 2020). Thus, the video consultation replaces a face-to-face consultation with own general practitioner (GP), and the consultation are said to proceed *"[...] easy and with no risk of contamination (of COVID-19, ed.)"* (Danske Regioner, 2020). Thus, securing a medically safe setting.

When using video consultations as a communication tool between providers and patients an awareness of the changed scope of communication. This is due to alterations like;

"Suddenly the nurse can only hear and listen and sometimes see but cannot use the additional senses. Hence, it requires focused competences, when they (the nurses, ed.) are not

in a physical proximity of the patient."

(Mammen, 2018)

For that purpose, one of Danish regions has created a guide which should ensure consultations of high quality when using video to communicate between provider and patient (Region Midt, n.d.). The development of such a guide indicates that applying video consultations and telehealth to health care could be more than merely a "plug'n'play" solution, which has to be carefully considered before implementing it into an existing treatment regime (Rigshospitalet, 2019).

Patients who suffers from pulmonary malfunction diseases like Chronic Obstructive Pulmonary Disease (COPD) seem to benefit from the use of telehealth as they experience shorter admissions at the hospital and an increased safety by being followed closer by the hospital staff (Danske Regioner, 2017). Thus, telehealth is predicted as "[...] the treatment of the future" for patients suffering from severe COPD (Danske Regioner, 2017). The telehealth equipment for COPD holds many similarities with the telehealth setup for CF-patients (Danske Regioner, 2017). As with the initiative involving patients with COPD, the telehealth initiative for patients with CF also involve technologies which enables the patients to do measurements at home, thus saving resources on transportation and decrease the number of outpatient visits at the CF-centre at Rigshospitalet (Rigshospitalet, 2018). Additionally, "[...] reduce the risk of the patient incurring additional bacteria. For patients with Cystic Fibrosis must not stay in the same room, as they are in high-risk of infecting each other [...]." (Rigshospitalet, 2018)

Thus, telehealth also reduces other practical and medical challenges when it is employed in the context of CF.

As CF is a congenital disease, the patients are being followed from an early stage in life: "You know each other, [chief physician] you see, is on the CF-ward, I have known her all my life. She was at Rigshospitalet, when I was born, [...]" (Interview CFp2: 11). The close relationship between provider and patient seems to;

"[...] be pivotal in order to organise and maintain the comprehensive treatment program for the individual patient."

(SST, 2020b: 24)

From this perspective a question emerges on how telehealth is perceived by the CF-patients when it becomes a supplement to their treatment and care.

Concurrent with the aspirations of telehealth presented above, telehealth could also potentially alter treatment regimes and care. These matters make the telehealth area extremely relevant, especially in a time of a pandemic where viable and prompt solutions are crucial for the general health care of a population. Therefore, due to the immediate straightforwardness of telehealth we find it paramount to study and furtherly delve into the potentials and challenges of telehealth. This will be conducted through a case study of CF-specific telehealth at Rigshospitalet in an imperative COVID-19 perspective.

1.2 Problem statement

How does telehealth mediate cystic fibrosis treatment, and what potential impact does telehealth have on the patient-provider relationship?

1.2.1 Research questions

- What is telehealth? How can telehealth be defined?
- How does the disease group and the treatment burden of CF influence telehealth?
- Which parameters are affected for the patient when using telehealth as a supplement to CF-treatment regimes?
- How can telehealth be evaluated?

1.2.2 Clarification of concepts

Concept	Definition
CF-centre	Rigshospitalet's unit for CF-treatment with CF-specialists
CFp1, CFp2, CFp3	Informants, all adults living with CF, short for Cystic Fibrosis patient [number]. For the sake of anonymity, the informants are being re- ferred to as CF-patients, however this is in no way to delimit them from being persons
Provider(s)	All health care professionals relevant for CF-treatment
Telehealth setup	Telehealth including both teleconsultation, eHealth platform and tele- monitoring
Tele-patient(s)	CF-patients using the telehealth setup as a supplement to their treat- ment regime
Tele-technologies	Technologies designed for and/or used for telehealth purposes

1.3 Literature review

In this section the main findings of our literature review will be presented. Telehealth shows great promise and potential, however it is not just a universal phenomenon or technology. Moreover, the disease, patient group and their relation to their providers have shown to be of great significance to the success rate for the telehealth.

This review will firstly go through the evolution of telehealth and move further to introduce different technological schemes of telehealth and the usability and possibilities of these. Then the review will present possible shortcomings and reasons for these in relation to telehealth and cover the impact on the patient-provider relationship according to the discoveries in the literature research. Lastly, prospective evaluation strategies are outlined with a recapitulation of the key discoveries in the review.

EXPANSION OF CF-SPECIFIC TELEHEALTH

The use of digital technology such as different kinds of telehealth solutions has increased in CF-treatment. This has been illuminated in a systematic review by Calthorpe et al. (2020) on the evolution of the use of CF-specific digital technology, in which 48 studies have been included from 1999 until 2019. The review states;

"Digital technologies present an opportunity to support and improve the lives of pwCF (people with cystic fibrosis, ed.). [...] Technology has been used with the aim of increasing accessibility to healthcare, earlier detection of pulmonary exacerbations and objective electronic adherence monitoring. It may also be used to promote adherence and self-management through education, treatment management Apps and social media."

(Calthorpe et al., 2020: 72)

The review by Calthorpe et al. (2020) presents a figure illustrating the expansion in the use of digital technology in CF over the last 20 years measured in number of publications. This shows a massive increase in publications in 2012; 6 publications that year compared to 0-2 publications/year the former years. With a distinct peak of publications in 2017 (12 publications), which have not been equal since (Calthorpe et al., 2020: 73, *Figure 1*). This mirrors the technological development at the time in reference to digital technology along with an increased interest and feasibility of telehealth in CF-treatment.

A key conclusion stressed in this article is that;

"The benefits of digital technology must be carefully balanced against the investment of time needed to use them. [...] Furthermore, the benefits of treatment should be of benefit to the

patient as well as the CF team." (Calthorpe et al., 2020: 76)

Hence, a possible evaluation focus must both include the patient group and the CF-treatment team. Moreover, the treatment burden in CF is very high, thus a telehealth supplement should strive towards limiting the already extensive treatment burden (Calthorpe et al., 2020).

There exist many kinds of telehealth initiatives presented in literature, among those home monitoring is an element highly represented in CF-specific telehealth. At the Cystic Fibrosis Centre of the Paediatric Hospital Bambino Gesù in Rome they have experience with using telehealth for follow-up with their patients from home since 2001, and they have done a feasibility study that investigated the effectiveness of telehealth for CF (Murgia et al., 2016). This study has examined the evolution of the Forced Expiratory Volume in the first second (FEV1) index through telehomecare; the FEV1 is used to monitor CF disease progression and evaluate therapeutic efficacy (Murgia et al., 2016; Szczesniak et al., 2017: 318). This study presents a statistically significant effectiveness of telemonitoring for CF-patients in relation to FEV1 index;

"[...] we found an average improvement of the FEV1 index for THC (telehomecare, ed.) patients (compared to the initial conditions of each THC patient) which could be considered significantly different from that of the control group."

(Murgia et al., 2016: 2)

The format of the telehomecare in this study is home monitoring of respiratory function linked up to a digital multi-parametric recorder with integrated saturimeter and a plug-in spirometer (Murgia et al., 2016; Bella & Murgia et al., 2009: 458).

FAVOUR ACCESSIBILITY IN TECHNOLOGY

Another approach and technology within CF-specific telehealth has been presented by Wood et al. (2017) in a feasibility study that investigated the integration of telehealth in CF-care. Wood et al. (2017) present a smartphone application to supplement the outpatient care of CF-patients, where the monitoring aspect is based entirely on the patient-reported symptoms which a CF-team receives and then decides what further actions should be pursued. The technology in this study is a smartphone application that is easy to access in the sense that if the patient has a smartphone it is applicable. As Wood et al. state in the article;

"One shortcoming of [...] previous studies was poor adherence to the monitoring system, which resulted, at least in part, from the equipment being large and bulky. The smartphone application described in this study overcame this limitation, as it was small and portable, and integrated easily with the lifestyle of adults with CF."

(Wood et al., 2017: 550)

The treatment burden of CF is significantly high as aforementioned, which has also been an important in-favour argument for introducing telehealth technologies in CF-treatment regimes, i.e. to ease treatment and self-management of disease for CF-patients (Calthorpe et al., 2020). Thus, the importance of incorporating the disease factors, such as treatment burden and lifestyle of people with CF, is paramount.

The communication platform and how to ensure a viable communication between CF-patients and their providers between consultations has been a focus in a feasibility study by Gur et al. (2016). In this study the intention behind the tele-technology is also a key focus in reference to making the technology easily integrable with everyday life of people with CF. Gur et al. have seeked to eliminate the knowledge gap intervening consultations for CF-patients, and thus performed a feasibility study to evaluate how technologies can be used to improve access to medical services and communication. The study presents the use of freely available technology, hence not for-purpose-developed technology, respectively introducing Skype and WhatsApp as communication platforms (Gur et al., 2016). Skype is a video and chat communication application, and WhatsApp is also a communication application including video and chat functions, which also contains several other functions like document sharing functions (Skype, n.d.; WhatsApp, 2020). Hence, both applications are applicable for everyone with access to a computer/smartphone and internet. In this study Gur et al. made use of these applications' communication features; "Skype-based online video chats and WhatsApp messages" (Gur et al., 2016: 489). Several difficulties emerged in this feasibility study, amongst others recruiting patients willing to commit to video chats, and problems with internet connection to ensure a stable communication connection (Gur et al., 2016: 491). Despite these challenges, the study concluded:

"[...] that they (Skype and WhatsApp, ed.) have the potential to improve some aspects of care of our patients. [...] The (CF-, ed.) team felt that the chats enabled better acquaintance with the patients, helped in planning adequate interventions and increased support." (Gur et al., 2016: 490, 492)

However, the study also stressed that due to its small patient number, the limitations of the study called for larger studies to conclude any further.

USABILITY OF TELEMONITORING

The large-scale randomised controlled trial (RCT) study by Lechtzin et al. (2017) is another example of an intervention study of home monitoring in CF. This study aimed to assess the usability of telemonitoring and whether early intervention and treatment of CF pulmonary exacerbations was beneficial (Lechtzin et al., 2017: 1145). The study population was divided 1:1 into two groups, a control group and an early intervention group.

"The EI (early intervention, ed.) arm participants used home-based spirometers and patientreported respiratory symptoms (using the Cystic Fibrosis Respiratory Symptom Diary [CFRSD]), completed twice weekly via the Viasys AM2 device [...] to identify and trigger the treatment of PEs (pulmonary exacerbations, ed.)."

(Lechtzin et al., 2017: 1145)

The telehealth system would alert the CF team if the measurements described in the quote above where triggered, and they could then initiate early treatment. This study;

"[...] demonstrated that home monitoring with spirometry and a symptom diary is feasible and effective for detecting more acute exacerbations at an earlier time period than usual care.

[...] but this (early interventions, ed.) did not result in slower decline in lung function."

(Lechtzin et al., 2017: 1150, 1144)

Along with positive results in relation to the Quality-of-Life surveys both trial groups were asked to fill out, the early intervention group declared significantly fewer respiratory symptoms than the participants in the usual care group (Lechtzin et al., 2017: 1149). The great treatment burden combined with a possible trial-burden, where the patient is required to adapt to new forms of treatment and perhaps comply with more self-management, is also an important notion in this article.

Saeed et al. (2020) has recently published a large systematic review with a primary focus on usability issues in telemonitoring in which they also present possible solutions found in scientific literature in relation to the presented issues. Their review investigates different telehealth applications; a variety of technological systems and artefacts, e.g. web-based monitoring systems, tablets for videoconferencing and wireless sensors, and different chronic diseases including CF (Saeed et al., 2020). The prevalent usability issues with telemonitoring systems were identified as "*(i) difficulty in using the system; (ii) a lack of user-friendliness; (iii) a lack of assistance with the system; and (iv) technical errors."* (Saeed et al., 2020: 275-276) The possible solutions identified all revolves around common parameters; heuristic

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evaluation, inclusion of key users (both patients and clinicians), design and development of robust systems, decreasing complexity and increasing user friendliness (Saeed et al., 2020).

SPECIALISED HEALTH CARE ACROSS DISTANCES

Telehealth shows great promise in relation to accessibility to health care, which has been assessed in an intervention study by Wood et al. (2016) on how to reach and secure treatment for CF-patients using telehealth in Western Australia. Rural and remote areas, hence major distances to CF-specialists can be a major contributor to low adherence and attendance in routine follow-ups at CF-centres (Wood et al., 2016: 673). This study revolves around a different kind of telehealth than the examples presented above, as this study presents a telehealth initiative where the patient attends their nearest hospital if they live >100km from a CF-centre. Consequently, this study does not include home-based monitoring, but video conferencing with the assigned CF team where the patient is based at a local hospital where a designated health professional ensures measurements before the video conference (Wood et al., 2016). These video conferences are by Wood et al. (2016) called telehealth clinics, and during this 12-month intervention study the participants only attended telehealth clinics, and traditional in-person clinics were only provided upon request.

The intervention with telehealth clinics were evaluated afterwards using two questionnaires, respectively the Telehealth Satisfaction Scale (TeSS); "*The TeSS is a 10-item questionnaire originally developed to assess patient satisfaction with telehealth in a rural memory clinic.*" (Wood et al., 2016: 674), and a for-purpose developed satisfaction survey.

The study achieved a positive result in relation to increased adherence to consultations, and concluded that;

"A total of 19 of the 21 participants (90%) attended four or more clinics during the intervention period, compared with four (participants, ed.) (19%) in the previous year." (Wood et al., 2016: 675)

Hence, there is a positive ripple effect in terms of adherence in rural areas when introducing telehealth according to this study. Nonetheless, telehealth has the possibility to impact the feasibility of CF-treatment and adherence, and it entails changes in standard procedures for both the patient and the clinician.

TELEHEALTH - PERHAPS NOT FOR ALL

As telehealth initiatives involve both the patient and the clinician in new ways, it is relevant to discuss the nuances and shapes of relationships that emerges in the wake of using telehealth technologies in treatment and care.

Antohe et al. (2017) open a discussion on the impacts of telehealth on the patient-provider relationship in their proceeding *"Telemedicine: good or bad or for whom?"*. In a medical perspective Antohe et al. claim that telehealth is inevitable because *"Telemedicine is widely looked as a resource with the potential to revolutionize access to care"* (Antohe et al., 2017: 49). Yet, it does not always mean that telehealth is for everyone as the title of the proceeding indicates. Hence, Antohe et al. point out that *"For those patients well known to their doctors, a virtual follow-up virtual visit can be benefit."* (Antohe et al., 2017: 50) As the quote suggests, specific precautions should be present in order to achieve the potential of telehealth.

Moreover, the telehealth set-up is usually placed in an already established relation between patient and clinician. This could suggest some limitations in telehealth, e.g. what Antohe et al. describe as 'no touch medicine', meaning "[...] that some symptoms, signs and diagnosis can be provided through telemedicine and some are not" (Antohe et al., 2017: 50). The signs referred to here could be body language as the physical meeting "[...] allows better assessment of nonverbal context of the examination" (Antohe et al., 2017: 51). Thus, a telehealth initiative could require novel ways of practicing the patient-provider relationship. In relation to this Antohe et al. (2017) also shed light on requirements to the patient's capability to identify and articulate anxiety, as this is harder to assess from a distance.

"The meaning of telemedicine must be reconsidered and actualized according to the new socio-technologic panorama." (Antohe et al., 2017: 51) When stating this, Antohe et al. refer to the infinite possibilities within telehealth, as well as the many parameters needed to be considered when seeking to analyse telehealth practice.

RE-CONCEPTUALISING THE PATIENT-PROVIDER RELATIONSHIP

A qualitative study by Gordon et al. (2020) is elaborating on the communication between patient and clinician when it is mediated through a video call. Although they describe a general satisfaction with the telehealth initiative among the patients, the study illuminates some of the challenges related to communication experienced by the patients (Gordon et al., 2020), as elaborated by one of the patients: "And you can't necessarily do anything, because you can't interject and stop them (the providers, ed.) because of the distance, you know?... I didn't even get an opportunity to express my opinions without having to talk over her."

(Gordon et al., 2020: 3-4)

Gordon et al. (2020) suggest several initiatives which include both patients and clinicians to prepare them for communication using video calls and cope with this rather new way of communicating. Thus, the clinicians are encouraged to develop *"webside manner" similar to bedside manner"* (Gordon et al., 2020: 5). Bedside manner refers to the clinician's ability to behave in a humanistic and empathic way, which is emphasized as an "essential skill for medical practice" (Weissmann et al., 2006: 661).

A large qualitative study conducted by Ignatowicz et al. (2018) is a part of a multi-sited study called 'the LYNC study' examining effects and impacts when using digital communication in relation to adolescents suffering from different chronic conditions including CF (Ignatowicz et al., 2018: 1-2). With an ethical point of view Ignatowicz et al. explore patients and specialist clinicians and their experiences with digital clinical communication through 129 semi-structured interviews.

"An overarching theme from the data was the need to re-conceptualise the patient-clinician relationship in the context of the use of digital communication."

(Ignatowicz et al., 2018: 3)

Three key themes were identified as important elements of such a re-conceptualisation; "*au-tonomy and control, defining the limits of duty of care, and communication and trust*" (Ignatowicz et al., 2018: 3) In the following the themes autonomy and control, and defining limits of duty and care will be elaborated further.

The theme regarding autonomy and control showed somewhat conflicting circumstances in how telehealth effects the empowerment of patients;

"Some clinicians described young patients becoming more dependent rather than less dependent because of the increased access to clinical support and advice provided by digital communication."

(Ignatowicz et al., 2018: 4)

The quote exemplifies unforeseen effects on the patient-provider relationship, here the patient becoming more reliant on the clinician, thus less independent in own treatment. Another theme is concerning the duty of care for clinicians. This theme highlights how digital communication makes it difficult for the clinician to define "*when a duty of care is established*" (Ignatowicz et al., 2018: 5), because communication via emails and text messages makes the clinician more reachable to patients. However, it can be unclear for the clinician how and when to react to such requests (Ignatowicz et al., 2018). The struggle related to when and how to respond can be understood in the light of duty of care being a *"key element of any relationship between a patient and their clinician"* (Ignatowicz et al., 2018: 7). As in the studies by Antohe et al. (2017) and Gordon et al. (2020), the study by Ignatowicz et al. supports the findings in relation to digital communication to improve communication and relationship between patient and clinician. Concurrent with these discoveries, it should be investigated further how digital communication affects the autonomy of the patient as it *"[...] is more complex than the current literature acknowledges."* (Ignatowicz et al., 2018: 7)

ADHERENCE TO TELEHEALTH

Communication between clinician and chronically ill patient can be essential in relation to patients being persistent in treatment adherence (Antohe et al., 2017: 1). Although it may not be the only circumstance affecting patient's adherence, as Murgia et al. (2016) state that:

"In our experience, one of the critical aspects in the follow-up of chronic patients is a poor adherence to therapy. We highlighted in time a significant increase in adherence to telemoni-

toring."

(Murgia et al., 2016: 2-3)

According to Murgia et al. (2016) telemonitoring might have the potential to evoke engagement in own treatment. However, to succeed in introducing patients to home monitoring, there is a need to investigate the socio-material settings in order to understand the;

"[...] activities of patients and their caregivers - and how those activities are supported by social and material arrangements - can result in insights for design of consumer health informatics technologies and infrastructural advancements."

(Novak et al., 2015: 145)

The quote is from the chapter *"Technology and the Ecology of Chronic Illness in Everyday Life"* by Novak et al. (2015) who emphasize the necessity towards a more context focused approach in understanding patients' capability to treatment adherence. By context Novak et al. (2015) refer to an increased attention towards everyday life activities.

Jarad and Sund (2010) have conducted a feasibility study focusing on the usability of home monitoring in relation to two different chronic respiratory diseases, respectively COPD and CF. The study involved mostly CF-patients, and

"[...] have examined the similarities and differences between COPD and CF-patients for daily recording and the effects on diagnosis of exacerbations and hospitalisation rates." (Jarad & Sund, 2010: 127) This study indicates that "*COPD patients were more likely to remain in the study and recorded more days than CF-patients.*" (Jarad & Sund, 2010: 130) Thus, a difference in adherence is present also when telehealth is introduced in treatment regimes. Jarad & Sund (2010) appoint the difference in adherence between the two groups to;

"[...] young CF-patients are less likely to adhere to any type of daily discipline. Daily monitoring may be more acceptable to older COPD patients with a less busy lifestyle."

(Jarad & Sund, 2010: 131)

Consequently, the lifestyle and median age of the patient group are of great importance in reference to adherence to supplements to treatment regime such as telehealth.

GAMIFICATION OF TELEMONITORING

Vagg et al. (2018) have conducted a pilot study on making self- and disease-monitoring mobile while engaging the patients in a positive, non-disease-oriented way, hereby acknowledging the busy lifestyle of younger adults with CF and potentially contribute to adherence: *"The proposed system incorporates a game where a user must blow into the microphone (on a smartphone, ed.) to control an object through obstacles. This Android app collects game performance data, well-being questionnaire data, and initial blow strength."*

(Vagg et al., 2018: 100)

Although there are good results using gamification to increase adherence in the area of paediatric treatment of patient with CF in relation to airway clearance, little to none investigation have been done with adult patients (Vagg et al., 2018). Yet there seems to be a motivation to use game apps across age, which argues for the importance of this pilot study (Vagg et al., 2018). Moreover, the results showed that;

"[...] patients found the app non-intrusive or demanding to their lifestyle, [...] they liked that the app icon and game style as it does not appear to be for their CF and as such each participant felt comfortable playing in front of friends or in public."

(Vagg et al., 2018: 104)

The significance of interventions being applicable to the everyday life of the patient is again illuminated, and not as such radiate disease even though the intervention is concerning self-management of treatment.

A more radical approach to investigate and potentially increase adherence to telehealth among CF-patients is presented by Zucco et al. (2018). This study contains machine learning and sentiment analysis in order to; "[...] make predictions to early detect patient dropout patterns and, providing the physician with this information, prompt action can be taken to prevent program abandon." (Zucco et al., 2018: 1735)

POTENTIALS OF TELEHEALTH IN CF-REGIMES

While the life expectancy of CF-patients has increased, new requirements to treatment and self-management have emerged, here telehealth could accommodate these new circumstances (Grzincich et al., 2010: 1; Jarad & Sund, 2010). Through a "[...] pilot trial of a home telemonitoring system involving 60 adult patients with cystic fibrosis" (Grzincich et al., 2010: 1) positive results have been found. Here 70% of patients were very engaged in monitoring their own health status and reported that they felt safe with the telemonitoring setup (Grzincich et al., 2010: 3). The telehealth equipment included a digital recording device which allowed the patients to perform spirometry tests, record oxygen saturation levels and complete an electronic symptom diary (Grzincich et al., 2010: 360). According to Grzincich et al. (2010), along with most of the literature presented in this review, there is a need for larger studies which among other things furtherly examine patients and their capability of maintaining long-term home telemonitoring.

Ketchell is also calling for larger studies that can confirm evidence linked to positive results of telehealth in CF-treatment (Ketchell, 2018). Here Ketchell proposes future research to be protocolled as Specific, Measurable, Achievable, Realistic and Time - in short SMART (Ketchell, 2018). SMART was developed in the early 1980's as a guide to do effective management and create quantifiable goals and objectives that helps a company in a certain direction (Doran, 1981). As SMART paves the way for a certain kind of data, it could delimit future research from including qualitative data, which gives insight to the everyday lives of patients, hence, key aspects like the use of telehealth equipment (Choyce et al., 2017). Moreover, SMART can be questioned in unpredictable settings like that of telehealth as;

"[...] innovative care practices are characterised by a process of identifying and adjusting goals, because participants are looking for ways to make new technologies work."

(Pols, 2012: 14)

In this review almost all literature on CF-specific telehealth cases articulate telehealth as a supplement to usual outpatient care. In recapitulation telehealth;

"[...] should not replace but rather act as an adjunct to face to face consultation time that also provides an interactive platform for health promotion and self-management." (Ketchell, 2018: 20)

Wong et al. articulate that;

"It must be anticipated that individual patients will adopt and use systems in ways that suit themselves and their lifestyles and not necessarily as anticipated by clinicians or information systems professionals [...]."

(Wong et al., 2015: 59)

Wong et al. (2015) discuss the potential challenges that arise with the use of Patient Centred Systems especially in relation to patients with COPD or CF. Thus, contributing with a critical, yet significant point concerning patients and possible assumptions related to their use of telehealth. Wong et al. are also debating self-management which telehealth initiatives have the potential to increase for the patients. Moreover, Wong et al. link self-efficacy with self-management; meaning that it is necessary for the patient to belief in own capability to do a certain action (Wong et al., 2015; Cambridge Dictionary, 2020). Hence, if the patient does not believe themselves to be capable of using the telehealth equipment and able to respond to possible change in health status, self-management will fail to happen (Wong et al., 2015; 57). Wong et al. (2015) are also questioning whether RCT's are the right approach for evaluating telehealth. Unlike the systematic review by Calthorpe et al. (2020), who see a need for more RCT's to validate findings in telehealth, Wong et al. doubts that;

"[...] the evidence produced (by RCT's, ed.) provides insight into the experiences, perspectives and/or outcomes valued by individual patients [...]."

(Wong et al., 2015: 58)

In the article "*Telemedicine is the way forward for the management of cystic fibrosis – the case against*" the eligibility of telehealth for patients with CF is highly questioned by a CF clinician. It is however important to point out, that the author behind this article declared that he himself did not have direct experience with telehealth. The clinician puts it very bluntly:

"Sadly, the facts are that, rather than showing clear patient benefit, the introduction of THC (telehealth care, ed.) programmes into CF care has been difficult, expensive in time for patients [...] The programmes have not been universally embraced by patients and the greatest concern is that they have rarely shown any clinical usefulness."

(Lenney, 2018: 22)

Without adopting the concerns stated by this clinician, this article contributes with perspectives that could be relevant to bear in mind when conducting fieldwork.

EVALUATING TELEHEALTH

The heterogeneously of telehealth is seemingly as high as conventional medicinal practice, both in reference to the technologies used, and the approaches and purposes for introducing telehealth, as elaborated above. Many questions are yet to be answered, in relation to; what telehealth is (classification), how it can and should be used (purpose and usability), which disease and target group it is viable for, etc. As a seminal article by Holle & Zahlmann states;

"With the rapidly increasing development of telemedicine technology, the evaluation of telemedical services becomes more and more important."

(Holle & Zahlmann, 1999: 84)

Despite the apparent possibility of being outdated, still many articles present assessments of specific telehealth initiatives, but none of them motions an exhaustive and all-around evaluation strategy for the purpose (see Wong et al., 2015; Wood et al., 2016; Calthorpe et al., 2020). A framework for assessment of telemedicine applications was presented by Kidholm et al. (2012), which was shorted MAST (Model for ASsessment of Telemedicine). The MAST model has been presented in other literature as an evaluation strategy applicable for evaluating telehealth, however it was initially introduced as an assessment model (Kidholm et al., 2010; PAHO, 2016):

"[...] for assessing the effectiveness and contribution to quality of care provided by telemedicine applications. [...] the model will form the basis for future decisions on whether or not to implement telemedicine services in healthcare systems and that MAST can help decision makers in choosing the most efficient technologies to be used in the most cost-effective

way."

(Kidholm et al., 2012: 44, 50)

The MAST introduces seven domains with key aspects for a multidisciplinary assessment of the transferability of the telehealth application in question, respectfully;

"1. Health problem and characteristics of the application, 2. Safety, 3. Clinical effectiveness,

4. Patient perspectives, 5. Economic aspects, 6. Organisational aspects, 7. Socio-cultural, ethical and legal aspects"

(Kidholm et al., 2012: 47, *Figure 1*)

Hence, the MAST introduces an all-encompassing and esteemed assessment model, and the domains presented in the model can arguably be utilised for evaluation purposes as well (Kidholm et al., 2017; PAHO, 2016).

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The World Health Organisation (WHO) has issued the '*Draft Global Strategy on Digital Health 2020–2024*', which also stresses the need for a unified evaluation strategy in relation to telehealth and describes the governance work in relation to this. Amongst other things the future work will focus on;

"Establishing a monitoring and evaluation framework that promotes continuous improvement of overall digital health ecosystem and feeds into public health initiatives is also warranted."

(WHO, 2020)

Because of the inherent interdisciplinarity in telehealth a generic evaluation standard is a tough nut to crack, as stated by Holle & Zahlmann;

"However, professional views of the aims and methods of evaluation are different from the perspective of computer science and engineering or from medicine and health policy." (Holle & Zahlmann, 1999: 84)

Holle and Zahlmann propose a greater focus on evaluation from the start of any telehealth project and/or study, i.e. implement an evaluation strategy in all phases of the study. The main deduction of the proposed evaluation phases by Holle and Zahlmann is the combination of evaluation on both the technical aspects, and the feasibility of the telehealth in terms of medical use and efficacy. Which is discussed in a newer systematic review by Nepal et al. (2014), who have reviewed 49 articles on telehealth regarding evaluation, state that;

"With the proliferation of telehealth, it is important not only to understand these properties (application, technology, and functionality, ed.), but also to define new properties to account for a wider range of context of use and evaluation outcomes."

(Nepal et al., 2014: 393)

Thus, Nepal et al. express some criticism of the high feasibility and technological functionality focus in many evaluation studies on telehealth scopes. They propose a comprehensive, multidimensional framework with various key dimensions, which

"[...] explicitly introduces the socioeconomic evaluation, the health services dimension, and the health services, discipline area of health, and context in which the services are being delivered."

(Nepal et al., 2014: 394)

Specifically, because telehealth is rather context-sensitive; it both constitutes most conventional medicine practice factors, as well as a technology aspect along with the tele-aspect, which introduces the possibility of time and place differences in the health care. An example on how to execute an evaluation study has been presented in a British pilot study on home monitoring of adults with CF. Here Choyce et al. (2017) present a study protocol for an RCT with an aim to protocol how to

"[...] assess whether this (home monitoring, ed.) results in differences in health-related quality of life over a 12 months period in adults with CF"

(Choyce et al., 2017: 2)

Hence, the study seeks to evaluate more qualitative aspects and prospects of telehealth, which has not been a common, singled-out priority in evaluating telehealth for CF according to our literature search. The study outlines that their focus is on doing "[...] a robust assessment of the patient experience." (Choyce et al., 2017: 6) Moreover, this protocol study states that;

"Novel means of using technology to improve the interaction between people with CF and their MDT (multidisciplinary team, ed.) provides a potential solution [...] The qualitative aspects of the trial are a vital component in allowing us to better understand the context in which the trial takes place from the patient perspective."

(Choyce et al., 2017: 5, 6)

Evaluation is a challenging task which according to Holle and Zahlmann (1999) should begin alongside the initiation of a project and follow the project cycle with clearly defined goals for the telehealth service. However, besides validating and ensuring that the technical solution works as intended, there is another very important aspect to track; evaluation and inclusion of the humans using the technology continuously.

LAST, BUT NOT LEAST

The literature search conducted for this thesis shows many small intervention and/or feasibility studies in relation to telehealth technologies used in CF-treatment regimes. In other words, there is a rather small number of RCT's and systematic reviews, which arguably can be seen as a generally low quality of evidence in reference to decisive conclusions on the use of telehealth in CF (Calthorpe et al., 2020). However, as Wong et al. (2015) opened a brief discussion on perhaps the methodology and protocols for studying telehealth setups should not only be limited to "classical" clinical research practice and RCT's. This is backed up by the points made by Choyce et al. (2017), who emphasise the essential element of patient perspectives and qualitative evaluation, which might not be illuminated in clinical trials.

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In recapitulation, the scientific literature in this review demonstrate a growing tendency of telehealth in CF-treatment regimes, which is owing to a combination of technological evolvement and a receptiveness in CF-treatment regimes (Calthorpe et al., 2020). A common agreement in literature is also that telehealth, no matter the technologies or setup, is a supplement to conventional outpatient consultations and treatment.

Especially telemonitoring holds a large part of the CF-specific telehealth applications. This often includes a home-based spirometer, an oxygen saturation gauge and a sort of respiratory symptom diary (Grzincich et al., 2010; Murgia et al., 2016; Lechtzin et al., 2017). The tendency of telemonitoring could be a result of the specific CF-characteristics, which encompass a congenital, chronic disease, i.e. the patients are laypersons at least in own disease and treatment, along with a high treatment burden and frequent consultations with CF-specialists (CFF, n.d.(b); Calthorpe et al., 2020).

A key issue in studies on CF-specific telehealth setups have shown to be adherence, this can possibly be ascribed to the evident treatment burden for people living with CF juxta-posed with the median age of CF-patients and the busy lifestyle appertaining that age group (Jarad & Sund, 2010; Novak et al., 2015; Lechtzin et al., 2017). Some studies have researched this phenomenon of adherence and tested more context-sensitive technologies of telehealth, where the general scope of the technologies is less distinctively medical, hence more adaptable to an everyday life of a CF-patient (Gur et al., 2016; Vagg et al., 2018; Saeed et al, 2020).

Another inevitable key aspect of telehealth is the patient-provider relationship as a shift in autonomy and control combined with a novel form of patient-provider communication is reconceptualised using technologies as mediator (Antohe et al., 2017; Ignatowicz et al, 2018). The build-in characteristic of distance in telehealth as technologies change the practice of health care, because telehealth distinct itself from the closeness of conventional care, what Antohe et al. (2017) states as 'no touch medicine'. This aspect of telehealth is also brought to attention by Gordon et al. (2020) with them stressing that a new form of 'webside manner', a digital alternative to bedside manner, should be included in telehealth prospects to ensure the clinician an attentive and empathic behaviour.

The "*socio-technical panorama*" (Antohe et al., 2017: 51) of telehealth require an interdisciplinary and exhaustive approach as well as evaluation strategy, which amongst other things should include all relevant actors (patients, clinicians, relatives, IT specialists etc.), socioeconomic relations, patient safety issues, medical effectiveness, ethical concerns etc. (Holle

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& Zahlmann, 1999; Kidholm et al., 2012; Nepal et al., 2014). Furthermore, evaluation of telehealth needs to be an iterative process and be included from start to finish of a telehealth project (Holle & Zahlmann, 1999).

2. Telehealth and Cystic Fibrosis

In this chapter we will attempt to define telehealth and describe the technologies of this thesis; the CF-specific telehealth initiative called OpenTeleHealth (OpenTele, OTH) for the telepatients at Rigshospitalet. Lastly, we will present the disease of CF, the patient group and the commonly studied limiting lifestyle aspects for people with CF.

2.1 Defining telehealth

Telehealth have historically been a definition conundrum, and there exists no one universally accepted definition (WHO, 2010; Mullin, 2018; EC, 2018). Nonetheless, we will here present a glossary of the different definitions presented by relevant authorities and scientific literature. Along with many others the WHO stresses that "*The many definitions highlight that tele-medicine is an open and constantly evolving science* [...]" (WHO, 2010: 9). The umbrella scope for telehealth and its alternate terms is ICT (Mullin, 2018), i.e. the use of ICT in health care service delivery.

TELEHEALTH

In many cases the terms telemedicine and telehealth are used interchangeably, however there is an overall agreement that telemedicine differs from telehealth in reference to which actors interact directly with the technologies. Since telemedicine in some definitions are closely related to the medical act and medical doctors. Whereas;

"[...] telehealth refers to both clinical and non-clinical applications in the way of education, administration, and research while telemedicine is often reserved for clinical, patient care ap-

plications."

(EC, 2018: 25)

Thus, telehealth can be perceived as a more generic term that refers to health-related procedures when comparing to telemedicine. The WHO definition of telehealth is also based in how it differs from telemedicine, which again "[...] distinguish telemedicine from telehealth with the former restricted to service delivery by physicians only" (WHO, 2010: 9). The Danish Health Data Authority (in Danish: Sundhedsdatastyrelsen, shortened SDS) recognises both the terms telehealth, telemedicine and eHealth, but defines the two first as literally the same, and the latter more unspecific as ICT used in health care, but primarily as health IT (SDS, n.d.). The SDS defines telehealth and telemedicine as health care provided without a physical meetup using ICT, where both the patient and provider participate in the

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use of ICT (SDS, 2015). Moreover, SDS has illustrated the hierarchy of telemedicine, under which telehealth and eHealth also refer to, in relation to e.g. other types of ICT and the use of telemedicine, as a diagram (see Appendix 4).

Telehealth is often the term used in literature, when presenting any variant of telemedicine including video, e.g. videoconference, video call etc. (WHO, 2010; EC, 2014; Coiera, 2015; AIHW, 2018).

One important characteristics of telehealth is the patient's active engagement with the technology, e.g. monitoring equipment, thus telehealth can sometimes be an interaction between patient and tele-technologies (DaCHI, 2015).

EHEALTH AND MHEALTH

Respectively, the terms eHealth and mHealth refers to electronic health and mobile health. Both falls naturally under the broader term of telehealth according to the Australian health informatics scientist Enrico Coiera (2015), and are defined by the European Commission (EC) as;

"[...] specific to the technologies used in delivering these (telehealth, ed.) services from distance: The Internet and mobile devices respectively (eHealth and mHealth, ed.)."

(EC, 2018: 26)

WHO has a greater focus on eHealth as a variant of telehealth, possibly because of their global health focus and their goal of achieving universal health coverage, as eHealth (and mHealth) are "[...] cost-effective and secure use of information and communications technologies in support of health and health-related fields" (WHO, 2020: 16).

According to the Danish Centre for Health Informatics (DaCHI) eHealth is a known telehealth term seen in a Danish context, which they define more broadly, i.e. very close to the above telehealth definitions, and claim that eHealth in a Danish context can be said to even be an umbrella term above telehealth (DaCHI, 2015).

TELEMEDICINE

Coiera broadly states that all "*Clinical communication technologies are often identified with the field of telemedicine*" (Coiera, 2015: 343). Thus, claiming that telemedicine can be perceived as the umbrella term for all health ICT services, here underlying telehealth, which Coiera however states to involve not only clinicians, but all health professionals (Coiera, 2015). In agreement with Coiera is the Dutch science and technology (STS) researcher

Jeannette Pols, who classifies telemedicine as "[...] technologically mediated communications between professionals" (Pols, 2012: 12).

WHO points to the inception of telemedicine; "[...] a term coined in the 1970s, which literally means 'healing at a distance'' (WHO, 2010: 8). The definition of telemedicine by WHO underpins that it is delivery of health care, where distance is a critical factor. Furthermore, WHO defines telemedicine as a medical practice that is ICT based and used by all health professionals to exchange information relevant for treatment, i.e. only health professionals are involved in the direct use of telemedicine (WHO, 2010; WHO, 2020).

Contrary to the definition by WHO, the EC defines it as;

"Telemedicine is the provision of healthcare services where traditional face-to-face patientdoctor interaction (or doctor-doctor) is replaced by over-distance interaction through use of ICT."

(EC, 2018: 25)

Thus, defining telemedicine as not limited to health professional interaction, but also between provider and patient.

The EC defines two domains within telemedicine services, which differ in the legal and organisational context surrounding them; i) medical act telemedicine, and ii) telemonitoring (EC, 2014: 5-6). The medical act domain refers to what the above-mentioned definitions also refer to, namely that telemedicine is a medical act performed by medical doctors (only) and "[...] practised over distance with the support of ICT" (EC, 2014: 5). Telemonitoring will be presented as a term by itself below.

In 2015 the DaCHI published a technical report in which they defined among others telemedicine along with telehealth, moreover, discussed the terms in a Danish context. The DaCHI report defines telemedicine in agreement with Coiera, Pols and WHO, i.e. ICT that supports communication between health professionals, where the patient is the object of diagnosis and decision-making (DaCHI, 2015). This report also underpin that the terms are found to be used somewhat at random in literature and often not clearly defined (DaCHI, 2015).

TELEMONITORING

The second domain within telemedicine services in reference to the definition by the EC (2014) is telemonitoring, and can be defined as follows;

"Telemonitoring: a major opportunity for chronic disease management. Telemonitoring is a telemedicine service aimed at monitoring the health status of patients at a distance." (EC, 2008: 4)

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Telemonitoring is presented to a high degree in general as a viable health care service to monitor chronically ill patients' vital signs in active collaboration between health professionals and patients. Coiera also points out that "[...] telemonitoring may thus substitute for conventional hospital outpatient or physician visits" (Coiera, 2015: 349). Which also underpins the possible proficiency of telemonitoring for exactly this target group, i.e. people living with chronic diseases.

Furthermore, Coiera lists the technical parameters of telemonitoring as "[...] a combination of audio, video and measurement data to monitor a patient's status remotely." (Coiera, 2015: 349)

Telemonitoring is a known health service in Australia, primarily due to the issue with securing health care and treatment to remote and rural areas. The Australian Institute of Health and Welfare (AIHW) has in their two-year-annual report on the deliverance of health care in Australia presented telemonitoring as;

"Tele-monitoring systems allow patients to take their own vital signs (for example, blood pressure), and then videoconference or secure message the information to their care coordi-

nators."

(AIHW, 2018: 396)

Therefore, as one of the few telehealth terms, telemonitoring is relatively unanimously defined as well as its prospects for use is agreed upon in literature as viable for especially monitoring collaboration with chronically ill patients.

TELECONSULTATION

Teleconsultations and telemonitoring often go hand in hand, as teleconsultation can be compared to conventional consultations with one significant difference in terms of distance between provider and patient. Coiera defines teleconsultations as being practiced using telephone, or other forms of voice calls, and video conferencing; "*Teleconsultation services (whether voice or video) can be used to provide information to patients [...]* (Coiera, 2015: 346). Moreover, Coiera describes the possible extension of remote monitoring when combining with teleconsultation; "Some of these interactions (conventional home visits from health care workers, ed.) can be substituted with a teleconsultation" (Coiera, 2015: 349). The EC definition is close to Coiera's definition: "Teleconsultation: in this case the doctor communicates remotely with the patient, using for example video conference (with dedicated software that ensures privacy), to hear the symptoms and make the diagnosis."

(EC, 2018: 67)

Furthermore, the EC identifies teleconsultations as a virtual health solution falling under the telemedicine umbrella and being a tele-expertise medical practice (EC, 2018). An alternate for teleconsultation is telehealth video consultations, where it specifically concerns videoconferencing with medical specialists (AIHW, 2018: 396).

2.1.1 Tele parlance

In this thesis we have chosen to use telehealth as the umbrella term comprehending all aspects of health services delivered using ICT for various reasons with basis in the above presented definitions. Particularly because most definitions of telemedicine classify it as the use of ICT between medical doctors. More precisely we will use the terms teleconsultations and telemonitoring, which both are telehealth services relevant for the case of CF-specific telehealth in this thesis, furtherly elaborated in the next section. In figure 1 we have illustrated the technical and interactional perspective of the CF-specific telehealth.



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Teleconsultation is the real-time interaction between provider and patient across distance supported by ICT. Whereas telemonitoring refers to an interaction between patient and technologies used for monitoring symptoms, hereby meaning monitoring equipment such as blood pressure apparatus or a spirometry. Lastly, eHealth refers to electronic and digital platforms mediated through a screen, i.e. tablet or computer, this is also where the monitored data from telemonitoring will appear and be presented for both provider and patient.

2.1.2 OpenTeleHealth: CF-specific telehealth

The technology of this thesis is a part of a telehealth initiative using OpenTele for home based telemonitoring and teleconsultations for CF-patients at Rigshospitalet. The technologies can be classified as being telehealth as it allows for both provider and patient to exchange vital information relevant for treatment based on remote monitored measurements across distance and time using ICT. OpenTele is a cloud-based e-health platform that can be used by patients via a web portal and an application on a tablet. The provider can access the patient's data and the remote monitored measurements performed by the patient via a web portal (OTH, 2020a), see the architecture in more detail in Picture 1.



PICTURE 1: OPENTELE ARCHITECTURE (OTH, 2020B)

Thus, the technology can be stated to perform both telemonitoring and teleconsultation as videoconferencing between patient and provider (OTH, 2020a; OTH, 2020b). This CF-specific telehealth includes a variety of Bluetooth-enabled equipment for home based telemonitoring performed by the patient; a small spirometer (for testing pulmonary function), an oxygen saturation gauge, a blood pressure apparatus, and an android tablet (Rigshospitalet, 2018; CF Centre Copenhagen, n.d.). The telemonitoring equipment can be seen in Picture 2 and is stored in a hard case as visualised in Picture 3.



PICTURE 3: TELEMONITORING EQUIPMENT



PICTURE 2: HARD CASE WITH CF-TELEHEALTH SETUP

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As illustrated in Picture 1 of the OpenTele architecture, the data gathered through homebased monitoring using the equipment described above will be transmitted via a secure encrypted wireless connection (CF Centre Copenhagen, n.d.).

Some important inclusion criterions for CF-patients to become tele-patients are;

"The patients must be able to handle basic functions on a tablet. They must be able to selfmonitor in relation to examination of own disease, comprising perhaps also produce a physical sample (e.g. a blood sample, urine sample, sputum sample etc.) and also be able to send in the test results to the hospital."

(Rigshospitalet, 2019: 2)

Before a teleconsultation the CF-patient is required to measure own medical values including the FEV1 (pulmonary function) using the telemonitoring equipment as well as answer an online survey on the eHealth platform regarding information on medication intake and score their own symptoms on a scale (Rigshospitalet, n.d.).

Besides, it is possible to do telemonitoring without transferring data to the CF-centre, which require login (Interview CFp3). Alongside video communication, the patients can communicate with the CF-centre through online messages via the OpenTele platform (Rigshospitalet, n.d.).

2.2 Cystic Fibrosis

CF is a progressive, life-limiting chronic disease and is characterised by mainly affecting the lungs, pancreas and digestive system as a defective gene leads to different glandular malfunctions (CFF, n.d.(b); Rigshospitalet, n.d.). In Denmark there are approximately 500 CFpatients and the median life expectancy is just above 40 years old and in chance of increasing due to research and treatment evolution (Sundhed.dk, 2019; Rigshospitalet, n.d.). Furthermore, an average CF-patient uses 1-3 hours daily on vital treatment in addition to the monthly outpatient control and hospitalisations, thus being a disease with a great treatment burden (CFF, n.d.(b); Grotenborg et al., 2019; CF Centre Copenhagen, n.d.). The daily resources spend on treatment is dispersed over various medical activities listed below (CFF, n.d.(b)):

- Intake of enzyme tablets before every meal.
- Daily intake of vitamins.
- Chest physiotherapy twice a day and when needed.
- Inhalation with medicine vaporisers once to three times a day. This is done after doing the chest physiotherapy.

Additionally, there is regular exercising to help loosen secretion in the lungs to prevent infections and germs (CFF, n.d.(b)). However, this cannot always be prevented which require treatment with antibiotic and often admission to the hospital in isolation for several weeks (CFF, n.d.(b)). The malfunction in pancreas also require awareness of nutrition and how to secure a sufficient intake of nutrients during a day (CFF, n.d.(b)). Lastly, there is the mental aspect in suffering from a life-shortening disease: "*How do you survive a fatal disease?*" (Interview CFp3: 14)

In Denmark there are two national CF-centres, one of those being the outpatient CF-centre at Rigshospitalet, which holds the highest number of CF-patients (Rigshospitalet, n.d.). The case study for this thesis is based on the outpatient CF-specific telehealth initiative, hence the adult CF-patients affiliated the CF-centre at Rigshospitalet (Rigshospitalet, 2018). This initiative replaces two monthly attendance consultations each quarter, which will then be performed using the telehealth technologies, and only one's each quarter the CF-patient visits the CF-centre for an attendance consultation (Rigshospitalet, 2018).

As touched upon in the literature review adherence is a known challenge when introducing telehealth to CF-treatment. A reason for this has also been studied in literature, and a main assumption concerns the existing significant treatment burden along with the low average age, which often conjuncts with an enterprising lifestyle.

"With life expectancy for these (CF, ed.) patients rising, there is need to investigate interventions for a CF adult that does not impede on their busy lifestyle."

(Vagg et al., 2018: 100)

Several examples in scientific literature have shown relatively large percentage of abandonment in telehealth pilot studies and initiatives all intended for CF-patients and easement of their treatment (Zucco et al., 2018; Choyce et al., 2017; Jarad & Sund, 2010). Concurrent with the somewhat unexpected, yet significant discovery by Jarad & Sund (2010) in their study on telemonitoring for patients with chronic respiratory disease, CF and COPD;

"A total of 32 (63%) CF patients and one (5%) COPD patient were withdrawn from the study due to lack of adherence [...] The difference in adherence may not be a reflection on telemonitoring itself. Rather, it may be that young CF patients are less likely to adhere to any type of daily discipline. Daily monitoring may be more acceptable to older COPD patients with a less busy lifestyle."

(Jarad & Sund, 2010: 130-131)

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A focal point here is to investigate, whether a potential lack of adherence is caused by specific parts of the overall telehealth process, or it is caused by the telehealth being another *"type of daily discipline"* (Jarad & Sund, 2010: 131). Moreover, Jarad & Sund (2010) provide us with nuances of the CF-patient group, helping us being aware of possible assumptions about this particular group and their approach to telehealth.
3. Methods

In this chapter we will describe the methods employed, as well as elucidate the reasons for applicating the methods presented below.

First, we will cover our literature research, primarily used to map the current scientific studies on telehealth and CF-specific health care using ICT, which has been described in the literature review. Next the process of gaining access to the field is described, which on account of the special circumstances due to the outbreak of COVID-19 have been challenged greatly (SST, 2020c). Hereafter we will outline the method of autoethnography and the field log, which provides the empirical material with our own experience of using video communication during the national lockdown. Lastly, the methodological course for interviews will be described along with a description of the further process of the empirical data gathered through interviews.

3.1 Literature research

The literature research has been directed by general searches for telehealth as well as searches for telehealth concerning chronic disease. Furthermore, searches have been made for telehealth for patients with CF.

At first, relevant databases were identified through the website of the university library with application of filters, which ensured a relevant selection of databases. Thus, IEE Xplore, Ebscohost, Web of Science, Cochrane Library, PubMed and the university's own database Primo have been the preferred databases throughout the literature search. Ideas of pertinent search words were exchanged and indexed in a table to open the subject on telehealth and to ensure a broad perspective on the field. Additional to the variation in search words filters were applied, thus the searches were mainly for peer reviewed material in Danish or English. Findings were organised in a matrix which created structure and an overview. Below is an explanation of the matrix, see Table 1:

Database	Search words and search filters	Total results	Search ID	Reference	Date of search

TABLE 1: LITERATURE SEARCH MATRIX

- Database: The chosen database, e.g. IEE Xplore or PubMed
- Search words and search filters: Chosen search words and operators, e.g. Telemedicine OR telehealth OR teleconsultations AND cystic fibrosis. Filters, e.g. only peer reviewed articles
- Total results: The total search results, e.g. 79
- **Search ID:** In order to make it easier to navigate between the selected material, every item was named with a search ID, e.g. 1.5
- Reference: The reference of the material
- Date of search: The date the search was conducted.

In addition to the various scientific materials based on the literature research, we have also been given access to unpublished background material regarding the telehealth setup at the CF-centre (see Appendix 5 and 6). The unpublished material has been fruitful as this has provided us with insight which otherwise would not have been available due to the COVID-19 lockdown, which will be explained later in this chapter.

3.2 Field work

In the following sections we will outline our field work approach and alterations of the original field work planned prior to the national lock down caused by COVID-19.

3.2.1 Multisited approach

The technological focal point of this thesis, i.e. telehealth, impacts several aspects of health care and society as described in the problem area. Thus, the technologies circulate among several sites. Therefore, the field work has been organised with inspiration from multisited ethnography, more specifically the approach of follow-the-thing developed by the American anthropologist George Marcus (Marcus, 1995). Although this approach encourages a broad-ened perspective on telehealth, as we follow the technologies on different sites, e.g. at home at the patient and again at the CF-centre, we discovered a sort of limitation. This limitation is caused by the omnipotent character of telehealth, as it is an ICT and thus also can be characterised as an Internet of Things (EC, 2019; Al-Majeed et al., 2015). Hence, it neutralizes sites and creates a mutual third area between the patient and the provider in their interaction with different aspects of the technologies. Therefore, it can also be argued that telehealth as Internet of Things technologies are multisited in itself.

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We began our following of telehealth by corresponding with Telemedicinsk Videnscenter (in English: Telemedical Knowledge Centre) in the Capital Region of Denmark, who paved the way for the collaboration with the CF-centre (Hult, n.d.). At the CF-centre we have had a close collaboration with the nurse in charge of distributing and coordinating the telehealth initiative. As we would follow telehealth by delving into patients' and providers' experience of and routines with telehealth, we would have to be consistent with rules of General Data Protection Regulation (GDPR) as well as ensuring the obligation to notify. Therefore, we contacted various authorities respectively De Videnskabsetiske Komiteer for Region Hovedstaden (n.d.) (In English: The Research Ethical committees in the Capital Region of Denmark) and Videnscenter for Dataanmeldelser (n.d.) (in English: The Knowledge Centre of Data Notification).

To explore how the telehealth equipment travelled from site to site, respectively from the CFcentre to the home of the patient we initially had planned observations of a consultation where the patient would be introduced to the telehealth equipment before taking it home. Moreover, we had planned observing teleconsultations to follow OpenTele at the CF-centre and to observe how the provider related to the patient through OpenTele. This we saw as an opportunity to get a step closer to the mutual third area emerging as a result of the interplay between the provider and the patient, as aforementioned. To make potential differences visible in conventional care compared to care at a distance, we had also planned to observe an attendance consultation at the CF-centre, thus rather paradoxically following the technologies in their absence.

These initial steps were taken in January and first of February before the outbreak of COVID-19 in Denmark the 27th of February, which came to impact the ensuing field work (SSI, 2020). Here the multisited approach came in our favour as this approach does not limit the fieldwork to one specific site (Marcus, 1995).

3.2.2 Methodological considerations and COVID-19

The restrictions put on by the state to reduce the breakout of COVID-19 have resulted in a slightly different process than we imagined and have challenged us in our professional creativity in how to engage with the field. This due to the provisional lockdown of the health care sector, including Rigshospitalet (Lottrup, 2020). Thus, the situation with COVID-19 at once narrowed down the fieldwork opportunities and we as researchers have had to rethink our

methodological project design. Moreover, due to the COVID-19 lockdown the outpatient consultations at the CF-centre have all been altered to teleconsultations to secure consultations (Mail from nurse, March, see Appendix 7). To follow the telehealth equipment, we asked a patient to take pictures of the equipment and send the pictures to us. As multisited fieldwork extends beyond pre-planned movements of investigation (Marcus, 1995), we turned the barriers, e.g. limited access to the CF-centre, into an opportunity to explore video communication through ourselves by applicating autoethnography, which will be elaborated on later.

We also found alternative ways to communicate with the informants about the statements of consents. After informing the informants of the purpose and use of their contribution over the phone, we sent them information forms about the thesis, asked them to read it carefully and then reply by mail regarding to what extent they gave their statement of consent (see Appendix 8A).

At the beginning of the lockdown the nurse's recruiting of informants have been paramount to the thesis. Moreover, to the extent it was possible, we have corresponded with the nurse to be in touch with the CF-centre, thus she has been a vital connection to the field.

3.2.3 Autoethnography

Due to the lockdown caused by COVID-19, we increasingly experienced that our internal face-to-face meetings had to be replaced by video calls through digital communication plat-forms and/or phone calls (Politi, n.d.). The alteration from face-to-face meetings to video calls appeared in some ways similar to teleconsultation without further comparison to the particular medical context of telehealth. To integrate our discoveries from using video communication, we have taken inspiration from autoethnography, which;

"[...] use personal experience to illustrate facets of cultural experience, and, in so doing, make characteristics of a culture familiar for insiders and outsiders."

(Ellis et al., 2011: 276)

Hence, perceiving ICT including video calls as utilised in the CF-telehealth setup as a cultural phenomenon in the sense that the technology constitutes a specific culture for interactions.

Autoethnography is a method where the researcher's personal experiences are scrutinised at first hand using all senses in order to understand the culture being studied (Adams et al., 2015). This requires an awareness of the balance between introspection which refers to the

researchers own experience, and extrospection referring to observations of the field, because it easily becomes blurred (Baarts, 2015). To handle this challenge a field log has been carefully filled in when we have had experiences or thoughts in relation to video communication with each other, informants or our supervisor (see Table 2, Appendix 10).

TABLE 2: FIELD LOG

Date	Context	Observation	Reflection	Next step	Theory

Besides providing us with an overview, the log contributed to a systematic frame of what was observed and the reflections upon that, albeit this separation can never be made completely. By organising the log chronologically, the log gives insight to the development of our own experiences, thus making a reflective space which also is a feature of doing autoethnography (Adams et al., 2015; Baarts, 2015).

The empirical result of autoethnography goes hand-in-hand with the main theory selected for the analysis, respectively postphenomenology (PP). This inaugurates a meta perspective, hence we as researchers take part in a micro-scale analysis of the human-technologies relation and how this relationship shapes our research and role as researchers (Rosenberger & Verbeek, 2015: 12). An underlying philosophy of autoethnography is an important recognition of;

"[...] the innumerable ways personal experience influences the research process [...], as a method, autoethnography is both process and product."

(Ellis et al., 2011: 274, 273)

Hence, the autoethnography method will assist us as researchers to include and recognise the influence of own experiences and thus understand the culture encompassing the technologies of telehealth, specifically video as ICT.

For this thesis the autoethnographic aspect will come into play when the focus is on teleconsultation. There will be no comparison to other aspects like the medical part of telehealth. Moreover, the autoethnography assists us in reflecting on own experiences and knowledge gained through digital distance and video communication.

3.3 Interviews

A main methodology employed for collecting empirical data has been semi-structured interviews. This method has been deliberately chosen as its structure is ambled to address specific topics related to the technology in question and use thereof. Semi-structured interviews also allow for the researchers to explore the informants' understanding and personal experience with the telemedicine initiative for CF-patients, thus leaving a potential to explore new meanings of telemedicine (Galletta & Cross, 2013). To ensure an interview structure that reflects and incorporates the purpose of our research, we have drawn up interview guides that is grounded in the research questions presented in a former chapter (see Appendix 8B).

The anthropologist James Spradley has singled out two major themes in interviewing; a reciprocal action between developing rapport with the informants, and eliciting information (Spradley, 1979). The distinct process of attaining meaningful information holds the key goal of interviewing, while the rapport process refers to;

"[...] a basic sense of trust has developed (between researcher and informant, ed.) that allows for the free flow of information."

(Spradley, 1979: 44)

When composing the interview questions and later conducting the interviews, we have held a particular attention to securing a harmonious flow in the interviews inspired by Spradley. The interview guides were thus designed to comply with the four stages of the rapport process; apprehension, exploration, cooperation and participation (Spradley, 1979). This assisted us as researchers to contemplate and discover new questions based on the informants' answers during the interview concurrent with following the overall purpose in the interview guide.

Our preliminary methodological scheme included interviews with both providers and patients, however, as elaborated on in the section *Field access* the worldwide pandemic and the following lockdown of the health care sector in Denmark eliminated the option to interview the providers.

Thus, we have conducted three interviews with patients affiliated the CF-centre at Rigshospitalet and due to the COVID-19 lock-down in Denmark all interviews were conducted via Skype with video and audio. We both participated, one acted as active interviewer and interacted throughout the interview with the informant via video and talk, while the other presented herself in the beginning of the interview with video and audio and hereafter shutting down video and audio. The passive researcher was responsible for the recording, securing

all topics in the interview guide were covered and for asking clarifying questions at the end of the interview.

The necessity of distancing ourselves as researchers due to the national lockdown and selfquarantine of CF-patients, hence the use of Skype, forced us to reflect additionally on our roles in the interview and the technical mediation of Skype as a communication tool. This included a meta-investigation in the sense that this thesis explores the use of ICT in medical practice and treatment of CF as well as the interaction and relation between provider and patient through technology. Combining this with us as researchers gaining insight through the explicit use of ICT (in this case Skype and video calls) to meta-investigate just that - the use of ICT/telehealth. We have throughout the semester written reflections on the investigation process in the field log (see Appendix 10), also on this specific topic, where one reflection was on the physical placement of the technological device securing the Skype connection (either computer or smartphone). The active interviewer found that placing her smartphone in an offhand strategic position to ensure best possible "eye contact" with the informant and being in eye level to both our surprise did not work. She found that the relation to the informant became instantly closer as she grabbed the smartphone and held it throughout the interview, thus creating a more hand-held and harmonious mediation of her participation in the interview (Appendix 10).

It is important to stress that the informants and patients as a whole cannot be generalised as a common actor with the same hopes, ambitions and experiences. This has been of great importance for us as researchers to keep in the back of our heads and we have experienced three very heterogeneous informants, both in terms of demography and in terms of their personal experiences with CF and CF-treatment. However, we have also seen a congruity in their statements regarding being a CF-patient, the telehealth setup and treatment burden amongst others. This will be elaborated further in the analysis chapter.

3.3.1 Coding in themes

All interviews were recorded and afterwards transcribed in full text and was translated as close to the word and meaning in the further coding process to English. Each informant was at the end of their interview presented with three options in reference to "keeping score" with their statements; to read the whole transcription and approve before further use, to read only the paragraphs we intend to use in the analysis, or to pre-approve our further use of their statements, thus decline to read the transcription. No informant expressed the need to see the transcriptions, and all informants declared to have complete confidence in our use of

their statements. This suggests that the rapport process reached the third step of cooperation between researchers and informants (Spradley, 1979). All informants have been anonymised in the transcriptions based on the following format; firstly, the role of the informants, e.g. CF-patient, and lastly sequentially numbered.

After transcription, we extracted the empirical data into table 3 below for further processing, i.e. coding of data. We have used the coding method of systematic text condensation in order to gain and extract as much knowledge from the data as possible (Brinkmann & Tanggaard, 2015).

TABLE 3: CODING IN THEME	S MATRIX
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Analysis of empirical data						
Transcript of interview se- quence	Systematic text condensa- tion	Categorisation, analysis and interpretation				

First round of interpretation and read-through of the transcribed interviews had the aim of identifying significant sections which afterwards was systematically condensated in the second column in table 3. Afterwards we made annotations of theory and analytical topic relevant for the condensed text sequence. This coding method enabled us to identify repetitions and regularities across the interviews, as well as compare and contrast the narratives and discourses of the informants to our existing knowledge based on discoveries in the literature review and relevant theories (Brinkmann & Tanggaard, 2015; Bazeley & Jackson, 2007). Thus, the coding supported us to analyse the empirical data gathered through interviews; by fracturing each element into themes and meaning units and finally gathering the "pieces" into a new recontextualised perspective (Bazeley & Jackson, 2007).

4. Theory

In this chapter we will elaborate on the theoretical framework for this thesis. We will draw on Pols and her theories on 'Care at a distance' as telehealth inevitably promises health care, however always at distance, thus this theoretical framework will be utilised to analyse this aspect of telehealth (Pols, 2012). Pols' theoretical framework will also be utilised to analyse the patient-provider relationship through technologies. Moreover, we will employ the theory of postphenomenology (PP) to analyse the mediation of telehealth both as technologies as well as a patient-provider interaction through a technological set-up (Rosenberger & Verbeek, 2015).

Lastly, we will discuss the discoveries of the analysis using perspectives from the Triple Aim framework developed by the Institute for Healthcare Improvement (IHI) (IHI, 2020a; Botin et al., 2015). This will be juxtaposed with perspectives on 'Values that Matter', a theory by Smits et al. (2019) on technology design with a focus on value dynamics.

These theories will be presented below and are all chosen because they contribute with essential nuances to the analysis and discussion of telehealth in relation to the case study of the CF-specific telehealth setup.

4.1 Care at a distance

As illustrated in figure 1 in the section *Tele parlance*, telehealth contains several interventions. Pols emphasises this framing of telehealth as she states that;

"[...] telecare equipment comes in many shapes and sizes, from webcams to monitoring devices. The various items are often lumped together as 'telecare' [...], as if they all do the

same thing." (Pols, 2012: 12)

Here she opens for the nuances and complexity of telehealth. Through her scrutiny of telehealth, Pols introduces terms that articulate what these interventions are about, especially regarding how communication and the use of telemonitoring impacts both the provider and the patient.

Pols uses the approach material semiotic, which;

"[...] stands for the idea that people and objects shape each other in mutual relations. Identities are situated; they are the result of specific relations within a situation."

(Pols, 2012: 17)

The embedded awareness in this approach sharpens the attention towards not only the context in which the relation is conducted. Moreover, the technologies or objects are being roused, so to speak, as stated by Pols: "Animals, plants and technology also 'let' humans into their environment or set the terms for living together with them." (Pols, 2012: 18) Thus Pols suggests that technologies are far from passive things just awaiting human commands. Moreover, the material semiotic approach emphasizes meanings and actions that occur in relation to the human-technology relation (Law, 2019: 1). Pols exemplifies this by describing how a doctor is constructed not only by wearing a white coat and a stethoscope around the neck. It is also the actions that the person does while wearing such a coat and stethoscope which construct 'the doctor', e.g. a situation where the doctor uses the stethoscope to examine a patient (Pols, 2012: 17). Likewise, it is the actions and meanings constructed in the use of technology which creates the purpose of the technologies, hence the meaning which is constructed to e.g. the stethoscope emerge from the situation in which it is used (Pols, 2012). This is also seen in relation to persons, thus "[...] identities change when the practices, relations, and attributes change [...]" (Pols, 2012: 17). Pols describes how the doctor turns into a parent, thus another identity is constructed, when (s)he is doing activities in relation to her/his children like picking them up from day-care (Pols, 2012: 17). This illuminates the perpetual mutuality that is embedded in the relational circumstances amongst technologies and humans according to a material semiotic theoretical framework.

4.1.1 Warm or cold (tele)health care

Pols frames the practice of long-distance care via telehealth in relation to patients suffering from chronic pulmonary diseases. Pols emphasises the ethical aspects of care, that being both telehealth and conventional health care (Amsterdam Universiteit, 2020). An ethical aspect that Pols discusses is warm hands in contrary to cold technologies in situations where devices and systems, like telehealth, supplement or fully perform health care (Pols, 2012). Pols states that the assumptions in this discussion is that "[...] medical technology is cold, rational and functional, whereas human care is affective and comforting" (Pols, 2012: 25). Thus, there is an underlying assumption towards care being divided into certain interventions containing certain effects. According to Pols the warm or cold effect of an intervention does not depend on the use of technological devices in the intervention. Rather the effect is a result of how well the intervention is adjusted to the situation and the need for care (Pols, 2012). Pols illustrates this by stating that;

"Empathy has a limit when a patient needs painkillers. Patients warmly welcome assumed cold interventions such as technical advice on how to use medication."

(Pols, 2012: 39)

This example illustrates that it is not a matter of whether to use technologies in care in general. If anything, it is about clarifying the needs of the patient and then chose the intervention which can accommodate these needs. Otherwise "*Supposedly warm interventions may go cold when they discourage a patient.*" (Pols, 2012: 39) This frames health care with nuances and make us strive even harder to be context-sensitive in order to do justice to both humans and technologies.

Pols states that ICT like webcams create new forms of communication between patients and providers. This will give rise to new routines for patients as well as providers alongside promises of potential efficiency and pitfalls in the health care (Pols, 2012). As aforementioned, Pols emphasizes the importance of focusing on the context of which the health care takes place when examining telehealth services because the technologies cannot be disconnected from *"the user group"* and *"the culture of use"* (Pols, 2012: 113).

Thus, when evaluating telehealth, the patient's situation can never be simplified to involve only the patient; it is necessary to include other entities as well (Pols, 2012). Pols exemplifies this with an example of webcam use in telehealth practice as a communication tool between provider and patient. Pols stresses different aspects of this sort of communication, e.g. how it differs from face-to-face consultations;

"Compared to a 'physical' home visit, webcam visits skip the ringing of the doorbell, the hanging up of coats and other material and physical rituals of admittance. The webcam brings the visitor into the patient's room with a click of the mouse."

(Pols, 2012: 113)

This touches upon changes in habits in the encounter. Hence the webcam and the technologies call for other ways to structure how the patient and provider meet each other even though the attendance consultation happens at the CF-centre and not in the home of the patient.

Pols introduces the term telepresence in relation to teleconsultations;

"The subjective experience of being together with a person in one place when one is geographically situated in another". (Pols, 2012: 100) It is paramount to be aware of the relational circumstances of which telepresence is based in. If the patient and the provider are foreign to each other the video call through teleconsultations will enhance this, and potentially contribute to an insecure and uncomfortable experience for the patient (Pols, 2012). Moreover, if this sort of communication is to make sense for the patient, it is important that the provider knows the patient's medical history and thus have a close relation to the patient (Pols, 2012).

4.1.2 Symptoms discovered using telemonitoring

In relation to chronic disease it is important for the patient and the provider to react on symptoms to avoid exacerbations (Pols, 2012). In this context telehealth can imply activities where the patient conducts telemonitoring through various measuring equipment. The use of telemonitoring can create a difference "[...] between what devices do and what people experience in their own bodies" (Pols, 2012: 67).

Pols brings a concrete example of such a situation with a patient suffering from heart failure, where a case of oedema can be a medical warning:

"Mrs Jansen: [...] See, my weight is usually between 62 and 63 kilos and one day it went up to 63.1, well, this one little ounce may be gone the next day, but me, I got called straight away. I think this is over the top."

(Pols, 2012: 66)

This example might show how the contact to the provider are constructed merely on the behalf of quantitative data which leaves the subjective, patient experience behind. This suggest that the objective medical data could question the experience of the patient (Pols, 2012). In addition to this the patient must translate the medical knowledge from the telemonitoring device into practical knowledge and hereafter try to balance this with "[...] disobedient bodies and competing values" (Pols, 2012: 95). Thus, telemonitoring come into play in the lives of the patients as a potential opponent to the subjective experience related to own disease. Furthermore, telemonitoring can also act as a source to essential knowledge which can contribute with important assistance to the provider.

Pols has inspired us to delve into what happens in the situation where telehealth becomes a part of the life of the people with CF. We will make use of the term telepresence to analyse the relation between the patient and the provider. Moreover, we will examine how data conducted through telemonitoring constructs care at a distance. Furthermore, we will make use

of Pols' vision regarding nuances on cold technology and warm hands to respond to the actual patient experience.

Pols assists us in taking important steps toward a clarification of the interplay between patient, provider and telehealth, moreover we see a need for an in-depth analysis to zoom in on the lived experience and practice with telehealth. Therefore, we have chosen a postphenomenological mediation analysis which highlights the human-technologies relation without making the technologies equal to human actors, and this theoretical framework will be elaborated on below.

4.2 Postphenomenology

PP positions itself within a combination of Science and Technology Studies (STS) and Philosophy of Technology, thus PP is;

"[...] bringing together the empirical orientation of STS on concrete case-studies with the conceptual and also normative orientation that are characteristic for philosophy of technol-

ogy."

(Rosenberger & Verbeek, 2015: 10)

The starting point of PP thus obligates the researcher to be significantly aware of what the field may bring of details and simple arrangements which could be crucial in understanding how technologies become inevitable in human existence. An important focal point in Philosophy of Technology is broadening the perspectives of technologies in a philosophical context (Franssen et al., 2018). Thus, the researcher;

"[...] must make technology a foreground phenomenon and be able to reflectively analyze it in such a way as to illuminate features of the **phenomenon of technology itself**."

(Ihde, 1993: 38; original emphasis)

To put it in other words, PP considers technologies to play a significant part in human existence.

PP is a theory which originates from phenomenology as PP explores how humans and technologies in close relationship shape each other (Rosenberger & Verbeek, 2015). PP and phenomenology share a curiosity in exploring the relation between human and technologies. However, PP distances itself from the main thought in phenomenology about how technologies distance humans from a sort of originality in life (Ihde, 2010). Reversely, PP concludes that *"Technologies, to be short, are not opposed to human existence; they are its very medium."* (Rosenberger & Verbeek, 2015: 13) The word medium, or *mediation*, is a central term in PP, and refers to how technologies mediate human life and influence how humans perceive the world they live in. The fundamental mediation illustrated by the founder of PP, the American philosopher Don Ihde, frames it:

Human - Technology - World

(Rosenberger & Verbeek, 2015: 14, 263)

The mediation can be exemplified with the case of Galileo's discovering of the moon's surface when he used the telescope. The constellation of Galileo with the telescope composed a possibility to Galileo to interpret the moon in a radically new way, thus he perceived the moon differently than before he used the telescope (Rosenberger & Verbeek, 2015: 12). The new constellation of Galileo with the telescope brought a new entity to life, hence Galileo became "*the observer*" and the moon became "*observable*" (Rosenberger & Verbeek, 2015: 19). This brings us closer to how PP arranges subject and object as "[...] constituted in their mediated relation" (Rosenberger & Verbeek, 2015: 12). The subject and object are never pre-given, but a result of human interaction with technologies in a specific situation (Rosenberger & Verbeek, 2015). This emphasises the mutual interdependence between human and technologies and how technologies should be understood through the relations to human practice.

4.2.1 Mediations

As aforementioned, mediation is a cornerstone in the theory of PP. The term can be illustrated through various mediations developed by Ihde and another key person in PP; the Dutch philosopher of technology Peter-Paul Verbeek (Rosenberger & Verbeek, 2015). Ihde introduced four types of meditations to PP, of which we will delimit us from elaborating on all four and only focus on one mediation relevant for this thesis, respectively the hermeneutic mediation (Rosenberger & Verbeek, 2012).

Concurrently with further development and expansion of technologies Verbeek argues that there is a similar need to expand the various mediations to explore how different technologies impact humans (Rosenberger & Verbeek, 2015: 20). Albeit the mediation created by Ihde emphasizes human-technology relations where the two entities merge, Verbeek goes a step further. This in order to help analyse human-technology relations where "[...] the physical boundaries between humans and technologies are blurred, and technologies merge with our bodies." (Rosenberger & Verbeek, 2015: 20) Verbeek introduces three new mediations, of which we will elaborate on two of them in the following sections; the augmented and the

immersion mediations, respectively. As the third mediation, the fusion mediation, refers to a hybrid entity where the human and the technologies become one (Rosenberg & Verbeek, 2015), which is not relevant in the case technologies of this thesis, and will therefore not be elaborated any further.

HERMENEUTIC MEDIATION

The hermeneutic mediation is developed by Ihde and relates the human to the world through data or numbers, which the human must be familiar with in order to interpret and thereof make sense of. Inde describes how a wristwatch is an example of a hermeneutic mediation if the carrier of the watch knows how to interpret the clock and understand what it means when the short hand points to 11 and the long hand points to 12, i.e. interpret that it is 11 o'clock (Rosenberger and Verbeek, 2015). Ihde frames this mediated relation as:

 $I \rightarrow (Technology - world)$

(Rosenberger & Verbeek, 2015: 17)

AUGMENTED MEDIATION

In the development of the augmented relation Verbeek build upon the work of Ihde, who originally had identified the embodiment relation and the hermeneutic relation as two of four basic mediation relations in PP (Rosenberger & Verbeek, 2015: 13).

The augmented relation is a combination of two relations, which Verbeek exemplifies with the use of Google Glass (Google Glass, n.d.):

"When using Google Glass, people both have an embodiment relation with the Glass itself, and a hermeneutic relation with its screen that offers a representation of the world." (Rosenberger & Verbeek, 2015: 22)

The mediated relation is illustrated as follows:

 $(I - Technology) \rightarrow World$ $\boxed{\searrow} (Technology - World)$ (Rosenberger & Verbeek, 2015: 22)

The mediation illustrates how the two relations, respectively embodiment relation and hermeneutic relation, are happening at the same time. Hence, the embodiment relation is the

human being embodied with the technologies (upper part of the relation) and in that way experiences the world through technologies. The hermeneutic relation is linked to how the user of the glass interprets the environment anew through the data provided by wearing the glass (lower part of the relation) (Rosenberger & Verbeek, 2015).

IMMERSION MEDIATION

The immersion relation is developed by Verbeek and revolves around technologies that "[...] *do not merge with the body but with the environment.*" (Rosenberger & Verbeek, 2015: 21), and is illustrated as follows:

I ↔ Technology/World

(Rosenberger & Verbeek, 2015: 22)

Moreover, the "[...] relation of "immersion," in which a technological background interacts actively with human beings" (Rosenberger & Verbeek, 2015: 21) is a more ambient relation than the two formerly presented relations. An example of this mediation is smart toilets which measures urine and faeces and on the basis of that creates data about the user of the toilet (Rosenberger & Verbeek, 2015). Thus, the smart toilet is utilised when the user has to go, likewise the smart toilet needs certain materials from the user to get activated. Through such relation the human can perceive the world and him/herself differently because they gain insight into how technologies experience them (Rosenberger & Verbeek, 2015).

4.2.2 Intentionality

The different kinds of mediations illustrate different ways of how humans are directed towards the world, and thus;

"In all of these new human-technology relations, new "intentional relations" between humans and the world come into being. [...] Human experience has an intentional structure: human beings are always directed toward reality. We cannot simply "see", but we always see something [...] We cannot understand human experience without taking into account this intentional directedness towards the world."

(Rosenberger & Verbeek, 2015: 21)

The directedness or intentionality should be understood as technologies always mediate humans towards a certain world which emerges as a result of how technologies organises the human's relation to its surroundings (Rosenberger & Verbeek, 2015). By emphasising the

ability of technologies to direct humans in a certain way, you could get the impression that technologies feature a human quality, respectively intentionality, which could create a sort of symmetry between humans and technologies. However, this is not the case according to PP; "[...] it does not claim that things can act just like humans do. [...] Rather, the question is: what kind of roles do objects play in agency?" (Rosenberger & Verbeek, 2015: 20)

As stated above, humans and technologies are not equal, however technologies actively impact the doings of humans to various degrees. Thus, technologies cannot on their own act in the world, but in relation with humans they become active as intentional influencers in how humans perceive and act in the world.

With hermeneutic mediation along with all the mediations introduced by Ihde the intentionality is mediated by the technologies themselves, whereas the intentional character in the mediated relations introduced by Verbeek "[...] takes on a different shape" (Rosenberg & Verbeek, 2015: 21) as stated by Verbeek.

Through the augmented relation Verbeek refers to the directedness towards the world as divided in two or "*bifurcated*", because the two relations, i.e. embodiment and hermeneutic relations, simultaneously augment the world view and act as;

"[...] a split in people's directedness at the world, because two parallel fields of attention emerge."

(Rosenberger & Verbeek, 2015: 22)

From the immersion relation the intentionality is "*bidirectional*", meaning that "[...] human beings are directed towards technologies that are also directed towards them." (Rosenberger & Verbeek, 2015: 22) Hence, the intentionality in an immersion mediation can take a reflexive and/or inducing character, as the human is faced with a possible new relation to themselves mediated by technologies (Rosenberger & Verbeek, 2015).

4.2.3 Multistability

To understand how technologies can mediate different relations, it is relevant to include the postphenomenological term *multistability*.

Multistability is a term central in the work of Ihde and refers to how to handle the non-neutrality of technologies (Rosenberger & Verbeek, 2015). Multistability evokes our attention to how technologies have *"multiple 'stabilities' or 'variations'"* (Rosenberger & Verbeek, 2015: 26), which Ihde illustrates as: "[...] a hammer is "designed" to do certain things—drive nails into the shoemaker's shoe, or into shingles on my shed, or to nail down a floor—but the design cannot prevent the hammer from (a) becoming an objet d'art (work of art, ed.), (b) a murder weapon, (c) a paperweight,

etc."

(Rosenberger & Verbeek, 2015: 26)

The different scenarios described in the quote, e.g. the hammer being used in the context of murder or in assisting to take charge of papers, illustrates the multistability of the hammer. Moreover, the example touches upon several ways on how the human in relation with the hammer can be configured both as a murder, a carpenter and a clerk. This illuminates that technologies "[...] are understood to potentially support multiple embodiment relations or hermeneutic relations (or other relations)." (Rosenberger & Verbeek, 2015: 26)

By applying this theoretical framework to the analysis, we will analyse features of the telehealth setup and through that, discover how telehealth shapes the existence of being a CFpatient. The mediations will help us clarify how telehealth shapes the CF-treatment and constitutes the subjectivity of the CF-patient. Meaning that we will look at potential alterations caused by telehealth in how the patient see him/herself in relation to CF and daily life. Intentionality is closely interwoven with the mediations; thus, we will scrutinise how telehealth influences CF-treatment and thereof investigate how the patient-provider relationship is reshaped through technologies. Lastly, we will analyse the multiple stabilities of telehealth as these stabilities illuminates the different routines and perceivings of the technologies which also shapes the relations.

The discoveries of the analysis will be discussed further within the frames of the Triple Aim refined by Botin et al. (2015) and the theory of Values that Matter by Smits et al. (2019), which will be presented in the following sections.

4.3 Triple Aim

The Institute for Healthcare Improvement (IHI) is an independent organisation based in the U.S., which with a global influence and collaboration is "[...] committed to redesigning health care into a system without errors, waste, delay, and unsustainable costs" (IHI, 2020b). The IHI proposed the Triple Aim in 2008; a strategic framework to achieve "[...] high-value goals of reliable and safe health care on a societal level." (Botin et al., 2015: 4) The Triple Aim seeks to simultaneously pursue the following three dimensions:

"Improving the experience of care, improving the health of populations, and reducing per capita costs of health care." (Berwick et al., 2008: 759)

Hence, a framework focusing on the individual patient experience, the overall population health status, and the per capita cost of health care, with a clear goal of increasing the quality and quantity of the two former and lowering the latter. The three dimensions are to a great extent to be pursued through new technological designs for health care with a proof of value in order to achieve the Triple Aim (Berwick et al., 2008).

In 2015 Botin et al. presented additional perspectives to the Triple Aim, thus introducing the Triple Aim framework on both the original societal perspective, and two new levels of Triple Aim perspectives; institutional and individual (see figure 2, Botin et al., 2015: 5, *Figure 1*). By dividing the Triple Aim into these stratified perspectives Botin et al. illustrates an extensive approach to break down the challenges in each level in order to achieve the Triple Aim. What Botin et al. refer to as the societal perspective is the actual Triple Aim as presented by the IHI.

The improvement challenges in the health care according to the Triple Aim focus on an institutional level are mainly concerned with change and actions in the health care organisation or hospital ward "[...] where health information technology mediates new roles" (Botin et al., 2015: 5).



Emancipation

FIGURE 2: THREE LEV-ELS OF THE TRIPLE AIM, RESPECTFULLY BOR-ROWED FROM BOTIN ET AL., 2015: 5, *FIGURE 1.*

The individual perspective refers to how the providers and patients must be assisted to obtain "[...] empowerment, emancipation and en-

hancement in relation to their health, well being and work practices" (Botin et al., 2015: 5) in order to make viable use of health ICT suchlike telehealth.

In this thesis we will use the stratified perspectives by Botin et al. on the Triple Aim framework to discuss the multiple perspectives of telehealth. These perspectives will contribute to the discussion of the technological reality of telehealth as experienced by the users, their use and the utility (Botin et al., 2015: 9). There are never only one side to a story, therefore several perspectives are required to properly evaluate technologies, hence the multiple stabilities of the telehealth will be discussed through multiple perspectives using the Triple Aim framework.

In relation to the institutional perspective are we unfortunately compelled to excluding Rigshospitalet as an institution and the CF-centre to this perspective, as described in the *Methods* chapter on COVID-19 we were not able to investigate this perspective fully. This is also present for the individual perspective, where only the patient aspect of this perspective will be discussed.

As delineated in the *Introduction*, we have discovered a growing tendency in the application of telehealth and especially teleconsultations because of the COVID-19 lockdown, such as teleconsultation with general practitioners. The universal aspirations emerged with COVID-19 in relations to telehealth could influence the use of telehealth to CF-patients as well (Mail from nurse, April, see Appendix 9). As covered in a former chapter CF is a complex disease with a diverse patient group, furthermore telehealth is rather nuanced and can take shape as many different technologies. Therefore, to furtherly ensure a robust discussion, a more context-sensitive approach is deemed needed to scrutinise values in the different perspectives, why we would like to introduce to Values that Matter in the following section.

4.4 Values that Matter

The theory of Values that Matter (VtM) is rather novel, which has been presented by Smits et al. (2019) including Verbeek. This framework is a methodological fusion of the mediation theory in PP and design for values, and *"[...] VtM allows for anticipating value dynamics."* (Smits et al., 2019: 396). Smits et al. identifies two value dynamics; value definition and value expression, which both emerge from the human-technology interplay.

Specifically, the dynamic of value definition outlines that;

"[...] a value is subject to the technologies that embody and express the value [...] (hence, ed.) the content of what constitutes the values is subject to the design itself."

(Smits et al., 2019: 397)

Thus, Smits et al. state that the values embedded in the design of the technology is not always equal to how the value is defined by the users, because of the reciprocal mediation between human and technologies as well as relations.

In addition, value expression relates to *"The way in which technology affects a value depends on users' perception and behaviour as a result of the technology"* (Smits et al., 2019: 397). Smits et al. exemplifies this through 'safe cigarettes' which originally should ensure a better health among smokers due to different features, that should result in a lower intake of nicotine, thus contributing to a better health. However, these features had quite the opposite effect as the smokers;

"[...] smoked more often, inhaled deeper and broke off filters [...] In the example, the value of health is not improved but threatened due to users' behaviour changes."

(Smits et al., 2019: 397)

Accordingly, how values are expressed through the technologies is based on the use and the users. The VtM consists of four phases; explore, conceptualise, anticipate and test, and is originally framed as a *pre*-implementation design methodology with the aim of;

"[...] developing designs that embody and anticipate important values. [...] First, it refers to the important contribution of values to life. Second, it stresses the context-dependence of values as the type of values result and depend on user-technology interactions." (Smits et al., 2019: 398)

Hence, the VtM is not directly applicable to use as an evaluation approach, as its theoretical framework is focusing on design of technologies for viable use with a primary focus on values. However, we see great potential and perspectives in the underlying philosophy of VtM, especially the value dynamics and the third phase of anticipation, will be used to discuss the discoveries of the analysis.

The anticipation phase of VtM is where the value dynamics come into play, as this phase aims "[...] at understanding the effects of the concept on value dynamics [...]" (Smits et al., 2019: 400). As described in the section on PP technologies are not neutral, thus the mediation of technologies has the potential to both impact humans and their lives as well as the interplay and relation between the providers and patients.

We will strive to conduct a nuanced discussion of the multiple perspectives of the CF-specific telehealth setup through the Triple Aim framework with a discussion on how the technologies of telehealth potentially mediate conflicting value dynamics across these perspectives. Thus, further examine the many facets of telehealth in the context-sensitive setting that is CF which entails a rather heterogeneous patient group.

5. Analysis

This chapter is divided into subchapters with the reasoning of starting with a broader perspective on the CF-specific telehealth where the theories by Pols will be employed to analyse health care practiced through technologies and the re-conceptualised patient-provider interaction. Hereafter we analyse the telehealth setup through PP, more specifically we will do a mediation analysis on how the technologies of teleconsultations, telemonitoring and the eHealth platform of OpenTele mediate health care. Next we will analyse how the intentionality of the technologies potentially shape the doings of CF-patients using the telehealth setup and how this change their perceptions of the world. Lastly, we will analyse the multiple variations of the telehealth setup, i.e. the multistability, as experienced by the patients and the immediate aspirations by the CF-centre.

By structuring the analysis as such we argue that the investigation of the telehealth setup include a techno-anthropological and exhaustive analysis, which illuminates complexity of the socio-technical interplay that is technologies, health care practice and patients. Hence, such an analysis can arguable be the groundwork for a holistic evaluation of the CF-specific telehealth setup at Rigshospitalet.

5.1 Technology-driven health care

Telemonitoring holds a substantial share of the telehealth introduced in CF-treatment regimes, as touched upon in the literature review. Amongst other employments telemonitoring is greatly used to detect pulmonary exacerbations earlier (see Murgia et al., 2016; Lechtzin et al., 2017; Calthorpe et al., 2020; Saeed et al., 2020). Although earlier interventions have shown great promise regarding pulmonary exacerbations, the study by Lechtzin et al. (2017) also concluded that earlier interventions did not show any effect on a slower decline of lung function. Hence, telemonitoring used to intervene earlier with pulmonary exacerbations in CF-regimes can be ascribed to quality of life for the patient, i.e. possible avoidance of hospitalisation and an intravenous (IV) treatment to fight an infection. This is consistent with the preliminary focus from the providers, which amongst other central objectives for patient experiences points towards;

"The opportunity to continuously monitor LFU (lung function, ed.) at home. Minimise the risk of cross-infections. Earlier detection of exacerbations".

(Rigshospitalet, n.d.: 2)

Along with a key aim published by the Telemedical Knowledge centre regarding this telehealth setup;

"That the patients via telemedicine experience an improved quality of life and freedom." (Telemedicinsk Videncenter, n.d.)

Thus, the providers also highlight the connection between minimising evolvement of exacerbations with quality of life for the CF-patients, in which the telemonitoring equipment is seen as key.

5.1.1 Illuminating nuances of symptoms

Generally, the CF-patients interviewed articulate telemonitoring as a positive supplement to their treatment regimes. How, when and why they make use of the monitoring equipment are however relatively heterogeneous, yet they have some uniform main features, which will be analysed in more details in a later section using PP.

Pols introduces a possible divergence within telemonitoring; disobedient bodies competing with values from monitoring equipment (Pols, 2012), i.e. the patient's own assessment of health status and symptoms versus what the measurements affirm. This potential bodily-technological incongruity is also experienced by the CF-patients, in the sense that;

"You know this when you have these kind of lungs (due to CF, ed.) - you **can feel** it! But then I tried to measure it (the lung function, ed.), because earlier I had tried to do a measurement and at that time the lung capacity seemed normal. And then it's just - then you don't have to think more about it (a possible exacerbation, ed.). But this time I **could see** that the capacity had decreased, and then I thought "I'll be damned!" [surprised]"

(Interview CFp1: 7, emphasis added)

You do not have to speak long with CF-patients to discover that they are laypersons in own disease in many ways, and the providers also show great respect for the "expert of own disease"-parameter of CF-patients. This can for one be seen in the modifications in the requirements in relation to the home-based telemonitoring executed by the patients, where the providers have a close collaboration with the patients rather than an "authority-subject relation" (Interview CFp1; Interview CFp2; Interview CFp3).

Another aspect of the telemonitoring is the patient experienced effect of these potentially conflicting measurements in reference to the patient's own bodily assessment. One of the CF-patients has deliberately opt out of reading the measurements, stating that;

"Well I'm the kind of a person that don't need those numbers [...] I don't need to know how low it (lung capacity, ed.) is, because it affects me too much mentally. So, I don't look at the when I blow - I don't look at the results. I just upload them. And then I have an agreement with them (providers, ed.) [...] If there is anything (more serious, ed.) then they can tell me, but they aren't to tell me how it looks."

(Interview CFp3: 4)

Hence, this patient refused to enter a possible dilemma of disobedient body versus affirmed technological measurements.

As long as the self-assessed respiratory condition is deemed as good, both CFp1 and CFp2 have a reduced use of the telemonitoring equipment outside of the required measurements before teleconsultations. However, when the patients experience a tough period in relation to their lung function and wish to keep track of small improvements which they cannot bodily assess, the telemonitoring option reassures them (Interview CFp1; Interview CFp2).

The use and reason for this is quite different from CF-patient to CF-patient according to our discoveries, and as touched upon in the literature review, the "[...] individual patients will adopt and use systems in ways that suit themselves and their lifestyles [...]" (Wong et al., 2015: 59). Such as CFp3 who deviates from reading and taking note of the values measured by the telemonitoring equipment in order to avoid possible anxiety-provoking news and hereby upholds a coping mechanism (Interview CFp3). CFp1 also makes use of the telemonitoring equipment to cope with own anxiousness, yet in a reverse way of CFp3's somewhat instrumental use excluding a hermeneutic interpretation of the measurements. CFp1 contradictory finds telemonitoring to be a;

"[...] resort for me, a good and healthy solution for me in relation to my health as well as in relation to my mental wellbeing."

(Interview CFp1: 4)

Whereas CFp2 is motivated by regarding the self-monitoring as;

"It's kind of become a sport to keep track of oneself. You sort of must. [...], it's a bit more fun to blow in this thing (spirometer, ed.), to get the information, so to speak."

(Interview CFp2: 3)

Thus, CFp2 makes a kind of gamification of the self-management of own disease through telemonitoring.

5.1.2 Warm care / cold technologies - or what?

Pols opens a discussion based in a Habermassian 'system world' approach regarding; "[...] the opposition between warmth and coldness, or care and medicine, [where] technology is especially cold."

(Pols, 2012: 25)

Thus, stating a common assumption that technological objects are cold (= bad), whereas warm hands are good as they tend to patients in an empathic and caring way. However, Pols also points out that an intentional warm action can be regarded as cold by the patient if it is discouraging to them (Pols, 2012). An inspection report by the Danish Health Authority on the national CF-treatment efforts states that many CF-patients find it challenging to travel to the CF-centres along with the already demanding treatment burden (SST, 2020b). This view is shared by the interviewed CF-patients, who point to the tiring aspect of CF-treatment and monthly outpatient controls at the hospital (Interview CFp1; Interview CFp2; Interview CFp3).

"[...] - I've frequented Rigshospitalet all my life, I really don't want to go there if I can help it. Unless it's absolutely necessary, then I must, that's just the way it is". (Interview CFp2: 8)

"Going back to this guilty conscience that I have had before where I perhaps frequented Rigshospitalet once, maximum twice, annually for controls, because I didn't want to blow (test for lung function, ed.), so I stayed away. [...] Well I'm the kind of person that rather not want to have anything to do with the hospital. But it's a prerequisite I must oblige to. That's why I think this telecommunication helps. Because it constitutes an extra contact to the hospital, that I wouldn't have had elsewise."

(Interview CFp3: 10)

The CF-patients here articulate the physical and digital distance of telehealth as a warm, caring initiative, because it complies with their hostility towards what the hospital evokes within them. The CF-patients - in each their way and reasons for this - all illuminates great side benefits of telehealth as it accedes to different personal and pragmatic needs of theirs. Despite what could be assumed, the CF-patients declare a sense of increased care across distances via this telehealth setup as they still are closely monitored;

"And they (the CF-clinicians, ed.) are fairly quick to say "Hey! Now it's time for a 14-days (IV, ed.) treatment, so you have to come to the hospital right away"

(Interview CFp2: 9)

"[...] so there is basically also a kind of care in it (telehealth setup, ed.). Ahm - or 'watching out for' which also is a value, one could say."

(Interview CFp3: 11)

Therefore, it can be argued that the telehealth setup with some patients and disease groups ensures more warm care, however not in a conventional "warm" way. As CFp3 concludes; "*And there is a greater - although I'm interested in the relational aspect - then this telecommunication still allows for me to better be me*." (Interview CFp3: 16) Thus, stating that CFp3's prioritization is as follows; person before CF-patient, which the telehealth technologies generate space for.

5.1.3 Proximity at a distance

The use of the webcam encompasses several possibilities along with points to pay attention to, as touched upon in the section *Problem area*. For example, how a screen affects how the provider is present in the encounter with the patient, which CFp2 articulates *"Well one might say that there is not the same personal contact."* (Interview CFp2: 10) This is elaborated by CFp1;

"You **will** get another feeling and another ... contact in the meeting with one's doctor, right? When you sit across from them. But. You get used to it, I would say [...]" (Interview CFp1: 10, original emphasis)

CFp1 and CFp2 both experience a change in the contact with the providers during teleconsultations. This is also an experience we have had at first hand by using Microsoft Teams (Teams) (Microsoft Teams, n.d.) during the COVID-19 lockdown:

"Something" happens when you are sitting in the same room and can have a spontaneous conversation. This "something" doesn't happen when you communicate through Teams and such like in relation to scheduled meetings." (Appendix 10, April 9, 2020, original emphasis)

Like CFp1 we have had difficulties with pinpointing it closer this alteration in contact via ICT, we attempt to explain it as a sort of quality and comfort which are absent in the encounter through the webcam and the screen.

Here lines can be drawn to the term telepresence introduced by Pols (2012). Telepresence outlines the patient's experience of proximity in the encounter with the provider when they are in different locations (Pols, 2012). As touched upon in the literature review, Gordon et al. (2020) suggest a digital counterpart to bedside manner, respectively 'webside manner', to ensure that the provider is attentive and empathic in the encounter with the patient. Yet,

'webside manner' is not self-sufficient; both Gordon et al. (2020) and Ignatowicz et al. (2018) stress that communication via webcam highly benefit from an already founded relationship between patient and provider. Again, Pols' theory on telepresence through the webcam becomes relevant because the term helps frame this and paramount area of telehealth. In the following CFp1 express the experience further:

"But I do not think that her (the clinician, ed.) focus is diminished regarding checking my values (medical values, ed.). [...] I only think that one can - I have experienced a sort of inatten-

tiveness."

(Interview CFp1: 11)

The CF-patients experience teleconsultations being practised a bit faster compared to attendance consultations (Interview CFp1; Interview CFp2; Interview CFp3). CFp1 presumes the rather speedy feature of the teleconsultation is caused by the providers having a mix of both teleconsultations and attendance consultations during a workday, which could affect the teleconsultation towards a more efficient format (Interview CFp1).

It can be argued that the focus is altered in teleconsultation towards an increased attention to the medical values rather than the relational, which CFp1 declares as;

"Sometimes one has to say "Hey hey I - Hey!" - that is, they (the providers, ed.) are very busy in moving on to the next..."

(Interview CFp1: 10)

This discovery is also seen in the study by Gordon et al. (2020), who describe how some patients find it difficult to take part in the dialogue in teleconsultations. Also, Antohe et al. (2017) emphasise that the patient must be more able to articulate concerns etc. in a webcam mediated meeting with a provider.

In addition, CFp3 brings similar reflections in relation to the interplay between patient and provider through a screen; *"It (the communication, ed.) becomes more factual of some sort and turns more into 'Is there anything you need?"* (Interview CFp3: 8-9) This quote is in line with CFp1's experiences and shows that the proximity is different from attendance consultations, as stated by CFp3; *"I have slightly more contact with them (the providers, ed.) when I am physically present"* (Interview CFp3: 15). Thus, the webcam and the tablet construct a sort of alteration which affect the patient-experienced proximity.

CFp3 emphasises that the relational focus in the context of CF-treatment has difficult conditions in general, which can be ascribed to the medical regime that, in the words of CFp3, is

"[...] far more result oriented" as opposed to focused on the relational (Interview CFp3: 14). This experience of the medical values being a sort of promoter in the conversation is articulated by CFp1 as; "When I don't upload anything (medical values, ed.), then they do not have anything to refer to." (Interview CFp1: 8) This discovery could explain why the CF-patients experience an alteration in the presence of the provider when it is governed by technologies.

Another aspect of telepresence is that it is dependent on other technologies, such like various telemonitoring equipment and internet connection. In the following, CFp2 describes an attempt to complete a teleconsultation;

"[...] mind you, it (the teleconsultation, ed.) took place over the phone because there - what do you call it - it (the tablet, ed.) did not work because there was no internet connection. So, you couldn't talk to them (the providers, ed.), but it might be my location, I think." (Interview CFp2: 2)

This example illuminates how a simple, yet essential condition enables or disables a teleconsultation, and hereby the telepresence of the provider; an unstable internet connection. During the lockdown caused by COVID-19 we have experienced how an unstable internet connection has great impact on our meetings with the supervisor through Teams;

"I find that when we have our meetings with [the supervisor], where we normally are seated at uni (university, ed.), all three of us are pretty much equal in the activity. During such a meeting through Teams, I found myself to become more passive, in a way." (Appendix 10, March 23rd, 2020)

This experience can be linked to how an unstable internet connection impacts the telepresence of the user as well.

As the telehealth initiative mainly is intended for patients living ≥20 kilometres from the hospital the internet connection could be a continual issue (Rigshospitalet, n.d.). In that context it could be relevant to look in the direction of the study by Wood et al. (2016) introduced in the literature review, where the telehealth setup revolves around telehealth clinics situated at local hospitals. Thus, CFp2 could go to the telehealth clinics which could ensure a robust internet connection and thus facilitate the necessary CF-specialist consultation. The above-mentioned conditions relevant for ensuring a viable teleconsultation, including enough telepresence and thus increasing the patients experience of proximity, could be perceived as challenging in the current scope of the telehealth. As described, it is the medical

values and factual questions which dominate the consultation and could thus minimize the

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focus on practising 'webside manner', also due to technical issues. This might argue for the importance of the patient knowing the provider prior to the teleconsultation as stressed by Pols (2012). In Pols' description of proximity in the encounter through webcam, Pols mentions how the webcam increases potential negative circumstances which can emerge in the encounter with an unfamiliar person. As exemplified by CFp1;

"It matters to me whether or not I know the clinician. And how well I know the clinician. If it is a clinician, who have only been here (at the CF-centre, ed.) for two years, then I don't listen as much as if it was a clinician who has been there for ten years [...]."

(Interview CFp1: 9)

What can be added to Pols' definition of telepresence is, in this case, the providers' medical experience with CF. If the provider has little medical experience with CF and the disease group, it can be argued that the patients withdraw from the teleconsultations by not being attentive. This discovery might be linked up with the CF-patient group being nearly laymen as delineated in the former subsection. As stated by Pols, it is important to see the telehealth setup in the culture of use and the users, which in this case is highly affected by the culture within the patient group; they are very well versed in their own disease and treatment.

5.1.4 The digital ringing on the doorbell

As introduced in the former section, Pols touches upon differences when using the webcam to communicate as oppose to face-to-face communication, thus behaviour that assists a sort of natural flow in the initial steps of an encounter is skipped when using a webcam (Pols, 2012). It can be interpreted that the webcam has a sort of suddenness when it is used as a communication tool. Pols gives an example where the starting point is a physical home visit which is being altered to a webcam visit, thus Pols' example relates very much to social norms when a guest enters a home. However, the webcam brings alterations not only in relation to preparation of medical values, but also in relation to requirements of behaviour related to attendance consultations. When patients meet for an attendance consultation;

"They are not allowed to stay in the same room and thus not wait in the same waiting room. Therefore, there is always focus on hygiene and on avoiding that the patients are gathered

in one room."

(SST, 2020b: 12)

Moreover, a \leq 45 minutes delay can be expected in relation to attendance consultations, where the patients must wear a facemask to minimize the risk of cross-infections which not only is "[...] very uncomfortable" (Interview CFp3: 8). It can also be experienced as rather

stigmatising by the patients (CF Centre Copenhagen, n.d.). Hence, the behaviour or circumstances in relation to the consultation at the hospital can be interpreted as rather unpleasant for some CF-patients. Contrary to these circumstances at the CF-centre, the webcam brings forth other requirements besides uploading medical values, suchlike:

"Charge the tablet before the teleconsultation [...] Remember that the clinician or nurse calls you 5 minutes before scheduled and asks you to log in."

(Rigshospitalet, 2019)

Albeit the teleconsultation is scheduled, it can be argued that the CF-centre is preparing the CF-patients for the teleconsultation by reminding them 5 minutes before it starts, thus they might alleviate the unexpectedness of suddenly appearing on the tablet.

In teleconsultation there is no need for a facemask because there is little to no risk of crossinfections and the potential wait is significantly decreased (Interview CFp3). These alterations are positively received by the patients who, on that background, seem to benefit from changing a visit at the CF-centre into a webcam "visit" from home (Finsenscentret, 2018: 15).

To recapture technology-driven health care calls for an attentive and constructive eye on the culture of the users, the use and usability of the technologies. Pols' claim of disobedient bodies competing with monitored data from telehealth equipment is also present here, where CFp1 describes a concrete case of this as examined above. The CF-patients are laypersons in own disease, and it could therefore be stated that they are well trained in assessing own symptoms. In relation to this the telemonitoring indirectly could act as an adverse catalyst and thus invert autonomy for the patient and their own capability of self-management and coping with own disease course.

The assumption of care only being warm in the present and proximate setting, concurrently technologies being cold and unable to mediate care is a faulty black and white oversimplification. Paradoxically the CF-patients experience an alternative care at a distance mediated through the telehealth setup and underpin that it is not directly comparable to the conventional outpatient care, but telehealth contributes with "something else". This "something" is experienced differently for each CF-patient but can be characterised as contributing with an inner peace and various space for action. Furthermore, there is an alteration in the presence of the provider when the consultation is conducted via telehealth, which affects the patients' experience of proximity. This could be due to several factors like medical values being the

promoter of the dialogue, and the provider's attentiveness might be prejudiced by considering the shift between patients at the CF-centre and tele-patients online. Moreover, the telepresence is also influenced by technological factors like a stable (or lack thereof) internet connection which could be an issue in remote areas. Last, but not least, it is crucial to consider the providers' medical experience with CF, as this can affect the patients' ability to act out telepresence in the encounter.

5.2 Technologies mediate a 'freedom-of-disease'

By applying the mediation theory of PP, we will delve into the different lives of the patients and explore how telehealth shapes the worldviews of the CF-patients. The mediation analysis will elaborate selected examples from the analysis conducted in the framework of Pols juxtaposed with other examples from the interviews.

5.2.1 Hermeneutic mediation

One of the crucial technological features of the telehealth setup is a visual presentation of medical values through the telemonitoring equipment, which entails a process of human interpretation of the technological lead. The hermeneutic mediation thus shapes the world as follows:

$$I \rightarrow (Technology - world)$$

(Rosenberger & Verbeek, 2015: 17)

There are several reasons for introducing CF-patients to telehealth, particularly telemonitoring could have the potential to be beneficial in relation to possible early treatment of exacerbations.

As delineated, the telehealth setup also entails telemonitoring where the CF-patients must be familiar with how to use the equipment and interpret the results. Prior to the use of the equipment the CF-patients have an introduction at the CF-centre;

"And then I was just acquainted with how to use the equipment and then my lung capacity was measured with their measuring equipment and afterwards on the telehealth equipment so we sort of could see how big the difference was on the same measurement. [...] That's all actually - it wasn't that hocus-pocus."

(Interview CFp1: 4)

This quote illuminates the underlying qualifications of the CF-patient in how to make sense of the medical values from the various parts of the telemonitoring equipment, thus it can be understood as a recurring point of departure for the hermeneutic mediation. The CF-patients must be familiar with the medical values means in order to be capable of reacting on changes, thus it can be argued that the briefing of the patients is merely medical and technical as they also learn how to login etc. (Interview CFp1). In the interpretation of data, the CF-patients must calculate the medical values with comparing them with the values from the fixed equipment at the CF-centre. This step seems not to be an issue to CFp1, who refers to the introduction as a rather straightforward procedure.

In the quote CFp1 is told to be aware of the levels for the medical values to which the CFpatient must react in a prerequisite manner to the interpretations. By introducing the CF-patient to react in a specific way to the medical values could illuminate a degree of a delegation of responsibility, hence the CF-patient obtains more responsibility in connection to be aware of and react on symptoms;

"Well, something I would normally maybe have talked to my CF-clinician about, I actually can control from home on my own and be in control of."

(Interview CFp1: 12)

The delegation of responsibility is an inevitable part of the self-management of telehealth which the CF-centre have tried to accommodate in the inclusion criteria of the telehealth initiative:

"They (the CF-patients, ed.) must be able to do self-monitoring in relation to basic examination of own disease, among these potentially also be able to produce a physical sample (i.e. a blood sample, a urine sample, sputum sample, etc.). [...] The patient must consider how it (telehealth, ed.) fits their everyday life [...]"

(Rigshospitalet, 2019)

The inclusions criteria should assist the providers in selecting the patients who can manage this responsibility by ensuring that the patients are able to do various measurements. In addition, there is a requirement for the CF-patients to reflect upon whether telehealth is a right supplement for them and how it will fit into their everyday lives. Here a line can be drawn back to the literature review and Wong et al. (2015) who presented a debate on self-management in telehealth, which the inclusion criteria symbolises a concern about and illuminates the CF-centre's attention on.

It can be argued that the CF-patients' introduction to the telehealth setup and the instructed point of departure for interpretation is rather result concentrated. Juxtaposed with the factual

character of the communication through the webcam might narrow down the CF-patients doings and perceivings in relation to how the cope with the medical values as touched upon in a former subchapter.

5.2.2 Augmented mediation

The augmented mediation adds another dimension to the human existence as this mediation to various degrees extend the human's perceivings of the world and through that also impacts their doings. The potentials of telehealth make it relevant to dive into the augmented mediation, as telehealth enables patients to monitor their lung capacity at home:

$$(I - Technology) \rightarrow World$$

 $\boxed{\searrow}$ (Technology – World)
(Rosenberger & Verbeek, 2015: 22)

The augmented mediation happens through the two mediations, respectively embodiment and hermeneutic, in a sort of parallel process (Rosenberger & Verbeek, 2015). The way both CFp1 and CFp2 handle their disease through the symptoms conducted through telemonitoring can be interpreted as augmented mediations which in different ways shape CFp1's and CFp2's handling of their disease and lives.

In addition to referring to the telemonitoring part as sport, which we interpret as a kind of gamification, CFp2 uses telemonitoring in relation to lung physiotherapy;

"You are not always equally motivated (to train the lungs, ed.) and you take the data, well then it (the tablet, ed.) tells you that now you will have to concentrate just a bit more." (Interview CFp2: 4)

The data monitoring can be interpreted as the embodiment mediation which extends CFp2's body, in this case CFp2's lung capacity, to medical values. CFp2 interprets and compares the medical values to the standards which have been introduced to CFp2 in the dispensing of the telemonitoring equipment. The interpretation of the data shapes CFp2 to put extra effort to the lung therapy, hence the augmented part of the mediation as CFp2's interplay with the telemonitoring extends CFp2's efforts in the lung therapy.

Besides using telemonitoring when wanting to keep an eye on potential improvements, CFp1 utilises the telemonitoring around activities where CFp1 is in doubt whether an activity impacts the lungs in a bad way.

"[...] I kept an eye on the lungs at home (through telemonitoring, ed.) and could actually see, alright it was actually also every time I had been with the [animal, ed.] that I discovered that it was a bit lower, my lung capacity. [...] And now it became rather figurative that I could see my measurements, that they had decreased. So, it's nice that I could cut back on things, which weren't good for me, which might elsewise would have taken me months to figure

out."

(Interview CFp1: 6)

By monitoring the lung capacity in relation to activities CFp1 discovers a decrease in the lung capacity because the lung capacity becomes visible through the medical values which can be interpreted as the embodiment mediation as the case with CFp2. Thus, decreasing lung capacity shapes the activity from being an additional choice to an opt-out after CFp1 interprets the medical values. CFp1 experiences this as merely a positive option to react faster on worsening activities. Having the possibility of monitoring the lungs independently has shaped not only what activities CFp1 is participating in, but the telemonitoring also plays a significant part when CFp1 is going to the CF-centre;

"I can now go there (to the CF-centre, ed.) and be calm and think "well I recently measured my lung capacity a week ago and it looked fine." So, if it is decreased, then it's related to the specific day, nothing about bad lungs [...]. I can go there without having a sweat [...], I'm not sitting there and feeling that I'm hyperventilating [...] Ah yes, it (telehealth, ed.) has been

amazing!"

(Interview CFp1: 15)

This exemplifies how the medical values comes into play in another way than in dialogue with the provider in the teleconsultation. Thus, the medical values which CFp1 has measured from home assists CFp1 in relating to the consultation at the CF-centre. Hence the monitored medical values and CFp1's interpretation thereof augment the patient's coping with the attendance consultations and possible "bad" results; thus, the result-oriented part of telehealth offers an augmentation in terms of a great mental assistance to CFp1.

5.2.3 Immersion mediation

Through the immersion mediation technologies relate to the human through an underlying character with a reference to smart-technologies, and in the case of telehealth the human-technologies interaction entails an interdependence in which an immersion relation emerges:

I ↔ *Technology/World* (Rosenberger & Verbeek, 2015: 22)

The immersion mediated can be exemplified in how CFp3 relates to the world by organising the information level of data as aforementioned in the subsection *Illuminating nuances of*

symptoms. By adding the possibility of only be informed in case of significant exacerbations, CFp3 relates to the world through a sort of supervision as the provider keeps an eye on the medical values and react on the patient's behalf if an exacerbation is occurring. It can be interpreted that CFp3's treatment of CF gets the same underlying character in situations, where CFp3 otherwise would have to handle the results bringing CF in the foreground that affects CFp3 in a negative way. Through telemonitoring CFp3 actively interplay with telehealth, simultaneously the agreement with the CF-centre assists CFp3 in using telehealth merely as a tool. This instrumentalization of the telehealth setup creates a distance to the disease which CFp3 needs in relation to being a person rather than fully a CF-patient, hence upholding the everyday life of CFp3 through this immersion relation with the technologies.

5.3 Adherence - a matter of technologies?

In the former section we analysed the mediated relations between human-technology-world, and these mediations can change the human's directedness towards the world. To investigate this further, we here analyse the technologically mediated character of intentionality and how this has affected the CF-patients' ability to adhere to own treatment.

As stated by Verbeek "Intentionality is not a bridge between subject and object but a fountain from with the two of them emerge" (Rosenberger & Verbeek, 2015: 12), hence the intentional relations can change in new technological mediations. Both CFp1 and CFp3 express a direct or indirect need to be "a good patient", i.e. a patient that adhere to treatment. The intentional relation towards this is shifted by the mediation of the telehealth setup. They articulate this as;

"And again, **I already was responsible before** I started telemedicine and was very knowledgeable about the medicine, but **have become more responsible** in regard to activities,

> [...], which I had not ascribed much meaning beforehand." (Interview CFp1: 12, emphasis added)

"And it (the telehealth setup, ed.) causes me to purely conscious wise act as a good pa-

tient"

(Interview CFp3: 9, emphasis added)

Hence, it can be argued that the intentionality of adhering to treatment can be mediated through the telehealth.

5.3.1 Induced intentionality

CFp3 describes a contrasting relation to own disease and treatment including consultations; "[...] all of my life I have thought of it (testing lung function, ed.) as being **one long performance** in having to create a curve which would enable me to say to them (the providers, ed.) that I didn't want as much medication as they wanted me to."

(Interview CFp3: 5, original emphasis)

As identified earlier CFp3 stresses the constant need for autonomy (Interview CFp3), hence a somewhat eternal clash between this need for autonomy and the reality constituted by CF as a chronic, life-shortening disease with an extensive treatment burden. In the abovementioned quote CFp3 articulates the attendance consultations as a lifelong performance, which might explain why CFp3 experiences a massive internal strain and anxiousness linked up with the CF-centre (Interview CFp3).

Before being introduced to telehealth, CFp3 tried to avoid going to consultations; "So over the last - hmm - last 10 years I haven't been particularly interested in attending a check-up" Interview CFp3: 3). As aforementioned this CF-patient has an agreement with the providers about how much in the loop CFp3 is regarding own medical values unless it is acute. However, it can be argued that CFp3 is assigned to the telehealth in the sense that CFp3 delivers data from own body directed towards and via the technologies, hence an unavoidable bidirectionality is constituted between them. Even though CFp3 is only to be informed about own data in case of more acute measurements, just these acute announcements take shape of an induced intentionality mediated by the tele-technologies, as CFp3 thereby is forced to reflect upon an unsolicited feedback (Rosenberger & Verbeek, 2015).

Adherence to treatment is a known issue within CF, including adherence to self-management of treatment and prevention activities, adherence to regular controls at a CF-centre as well as adherence in research studies involving e.g. telehealth technologies (see Wood et al., 2016; Wood et al., 2017; Antohe et al., 2017; Calthorpe et al., 2020). An initial aspiration by the CF-centre regarding low treatment and check-up adherence is mentioned as a side note under the intended professional qualities which they expect enabled by introducing telehealth to CF-treatment regimes. Propounded as a somewhat tentative question; "*Better monitoring of patients who otherwise are absent from medical check-ups?*" (Rigshospitalet, n.d.), thus asking a frequently asked question by many other researchers as presented in the literature review. In a feasibility study protocol by the CF-centre regarding introducing

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telehealth to CF-treatment regimes, they point to the findings of Knudsen et al. (2016) regarding adherence-correlations in CF, and states that;

"The CF treatment is time consuming, considerable and burdensome; a recent cross-sectional study (Knudsen et al., 2016, ed.) showed a low adherence to treatment among 74% of the young adult population in the clinic."

(CF Centre Copenhagen, n.d.)

Hence, again pointing to the inevitable treatment burden of CF as a presumably great contributor to low adherence rates.

5.3.2 Intentionality vs. treatment burden

CFp2 pinpoints the tiring aspect of the treatment burden of CF along with this burden not being an intermediate stage, but a lifelong burden for CF-patients;

"[...] there isn't any days where you shouldn't do it (adhere to treatment, ed.). You see, I have been - off course everyone have, well most CF-patients know perfectly well that there are some days where you're just not that motivated and then there is some time where you skip, but it comes back to bite you [...]"

(Interview CFp2: 9)

Thus, any kind of easement of the treatment burden should in principle be beneficial for the CF-patients. As presented in the literature review, an important facet to this is the weighing of technological benefits should also comply with the time used by the patients and providers when supplementing CF-treatment regimes with telehealth (Antohe et al., 2017; Calthorpe et al., 2020). Novak et al. (2015) also stress the exceeding need to have a context-sensitive approach in order to understand patients' capability to adhere to treatment.

For all the CF-patients interviewed the CF-centre and the providers affiliated are like a second family, however a "family" they prefer not to visit (Interview CFp1; Interview CFp2; Interview CFp3). CFp1 describes the attendance consultations before being introduced to telehealth as a very anxiety-provoking, monthly visit to the hospital, stating that the anxiousness also influenced the medical values;

"The body is tense, and you are completely strained, you are anxious, you are worried. Well I'm not - many are probably calm, but for someone like me who is mentally affected by my physical disease, then it's really hard and gave a misleading picture of how I actually had it down in the lungs, I think."

(Interview CFp1: 15)

A similar perception is shared by CFp3, who also describes attendance consultations as a hassle;

"Well just as I show up at - or before - or actually already as I leave home then a kind of moment occur within me regarding that I at any rate don't want to go there (the hospital, ed.). An anxiety and a kind of uncertainty - because after a long life of check-ups then I think - and it doesn't work like that when I sit here at home by myself and have telecommunication."

(Interview CFp3: 3)

Both CF-patients have experienced an induced intentionality with the previous attendance consultations, however mediated by the tele-technologies they are included in another intentional relation. A mutual constitution of the CF-patients and the tele-technologies emerge in a new reflexive intentionality triggered by the autonomy and freedom they experience with the telehealth regarding their frequent contact to the providers.

"Then there is this telecommunication, which makes up for a contact to Rigshospitalet (the CF-centre, ed.) which I beforehand wouldn't have had and that soothes my conscience." (Interview CFp3: 10)

"Now I go there (the CF-centre, ed.) and think "well I have just measured my lung capacity a week ago and it looked fine". [...] So I am much calmer now. [...] Oh yeah, but it's just been amazing! It has truly been a life saver. [...] It has resulted in some fun experiences which I'm also benefiting from i my subsequent check-ups."

(Interview CFp1: 15, 5)

Hence, the telehealth supplement to their treatment regime does not only affect them as patients and humans in private settings, but seemingly also entail a positive ripple effect on their attendance consultations.

5.3.3 Subtle intentionality

Besides mediating a wide-ranging intentionality which includes both mental facets of being a CF-patient with a chronic disease along with a positive intentionality of adherence regarding attendance consultations, telehealth also constitutes a more subtle intentionality;

"I'm not sure if it (telehealth, ed.) helps me, it helps to motivate oneself a little bit in the sense that the numbers (medical values, ed.) don't drop and becomes worse and worse. [...] Well just like I have to take my pills and other stuff but if it's positive, then it's just a bit more fun, you know [small chuckle] [...] There is nothing worse than having to go to Rigshospitalet because you know that you're ill [...] Now you can nip it in the bud, you might say." (Interview CFp2: 8-9)

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CFp2 here remarks that the telehealth setup in no apparent way increases the quality of life for the patient, however the statement also illustrates a subtle intentionality mediated through the interplay of patient and telehealth setup. This mediation grants the CF-patient a steadier, yet very subtle control with own disease course which is much less intrusive than a monthly travel to a regular check-up at the hospital. In the study by Vagg et al. (2018) a gamificated telehealth application was presented to increase adherence in monitoring of CF with a primary focus on "[...] not appear to be for their CF [...]" (Vagg et al., 2018: 104). Vagg et al. learned that this non-intrusive application was a viable way to ask CF-patients to selfmonitor without putting a strain on their lifestyle, which seems to be the case for CFp2 as well in reference to the quote above.

CFp1 repeatedly underpins the positive effect the telehealth setup has on own mental health and increased, yet subtle, option for autonomy;

"[...] to me it (telehealth setup, ed.) has given me a lot mentally, that being my mental wellbeing, that I can employ the measurements myself, not always having a doctor to measure my numbers at Riget (Rigshospitalet, ed.) in order to give me peace at heart about how I feel. I can do that myself."

(Interview CFp1: 12)

As experienced by CFp2, CFp1 here also point to the discrete intentionality of telehealth in reference to allowing CFp1 to manage own disease and peace at heart without having to consult a provider. Hence, we argue that a new reflexive intentionality is present in the human-technology relation due to the new mutual constitution of the CF-patient and their experience with own disease and world view.

So, is treatment adherence a matter of technologies? Some new intentional relations are certainly taking shape with the technological mediations of telehealth, mostly reflexive intentionality pointing towards an increase of adherence for the CF-patients, however also some relations that take character as induced intentionality as specifically experienced by CFp3.

5.4 The many stabilities of telehealth

The CF-patients have all received the same equipment which by default cannot be separated to contain just some of the parts, this became clear when one of the CF-patients told about the procedure when a part of the equipment was broken;

"[...] when a component doesn't work the whole (the telehealth setup, ed.) has to be replaced. The equipment has worked well, the tablet was just not working. [...] You see, I've retrieved six tele-equipment in three months."

(Interview CFp1: 16)

Thus, it is the same technical setup which was the focal point in the mediation analysis above. What we already have unveiled in the former analysis sections, is the diversity in the patient group in how the telehealth setup is utilised.

In the following, we will analyse and put words to the many stabilities of the telehealth setup to understand how the diversity of the technologies impacts the CF-treatment.

5.4.1 Framework of the telehealth setup

The mobile feature of the telehealth setup contrary to "[...] Rigshospitalet's rather large fixed measuring equipment [...]" (Interview CFp1: 5) had let to some doubt at first in relation to the accuracy of the measurements (Interview CFp1). However, the performance of the equipment conjured away these doubts; "[...] you could actually make your own measuring graph using this (telemonitoring, ed.) equipment" (Interview CFp1: 5). The possibility for making and interpreting the medical values as a graph stabilises the telehealth setup as a visual aid constituted through the hermeneutic mediation. This is an appreciated stabilisation which can be interpreted from the statement by CFp1 in the quote above.

CFp2 and CFp3 both refer to the equipment and the box in which it is placed as nice and of great material (Interview CFp2; Interview CFp3). As the equipment has a mobile feature and is part of a home environment and potentially other environments as well, the box is of specific significance;

"A flight case [...] It's some kind of box which is very robust because [...] you should be able to bring it with you if it's necessary. So, it (the telemonitoring equipment, ed.) is just in there.

[...] I don't want to have it laying out because it is to be kept clean and stuff like that." (Interview CFp2: 8)

Thus, the box constitutes and stabilises the telehealth setup as a mobile assistant to CFtreatment. The mobile feature has also been accommodated in the home based routine of teleconsultation; CFp3 places the box on the dinner table, opens the box and takes out the equipment which besides the monitoring technologies also contents a sort of tripod which "[...] you can put it (the tablet, ed.) on there." (Interview CFp3: 7). From these quotes it can be interpreted that much effort have been put into making the equipment accessible and user-friendly, which is a crucial point to consider in reference the patients' utilisation of telehealth as mentioned by Saeed et al. (2020) in the literature review. From our own experience with conducting interviews via Skype we discovered what impact it had when the device, in this case a smartphone, was put on "homemade tripod";

"At first I had put it (the smartphone, ed.) upon a box, so my hands were free but during the first interview the informant said the (s)he could not see my forehead, that the picture got cut

rather unfortunate [...]"

(Appendix 10, March 30th, 2020)

This was not a good solution, which emphasises the significance of the effort put into the whole telehealth setup - from the box to the tripod and, of course, to the specific measuring equipment. All these initiatives together stabilise the telehealth setup as a user-friendly mobile feature.

5.4.2 Telehealth in COVID-19 times

The mobile feature has contributed to several multistabilities of the telehealth equipment, also in relation to the COVID-19 lockdown;

"Those patients who are [already] set up in OpenTele, suddenly have the advantage of not missing out on monitoring their lung function, blood pressure, oxygen saturation and pulse. The other patients are missing out on this. I can only imagine how this (telehealth setup, ed.) gives them an extra safety in what to them must be an extraordinary unsafe situation." (Mail from nurse, March, see Appendix 7)

Thus telehealth is aspired to be constituted as an opportunity for the CF-patients to uphold a regular contact to the CF-centre and thus maintain treatment in the case of COVID-19, another stability of the telehealth comes into play during COVID-19; *"It (telehealth setup, ed.) has been a lifesaver"* (Interview CFp1: 5)

"Yes of course I think it's really nice to be let off of going anywhere now that they (the providers, ed.) have asked one not to and it - well - they really care about it (staying safe via selfisolation, ed.), I do as well of course [...]"

(Interview CFp2: 7)

Telehealth is a profound vital lifeline for CFp1 who refers to a situation where the spirometer was broken which let to CFp1 being very upset because the medical values produced from the spirometer significantly shape CFp1's relation to own disease and self (Interview CFp1). This situation underlines how important the spirometer is in stabilising telehealth as mean-ingful technologies for this specific patient group.

Telehealth is also stabilised as technologies assisting CFp2 in isolation which is an essential term in connection to COVID-19 and CF-patients being in great risk (Interview CFp2). Another stability of the telehealth setup can be interpreted to emerge from the quote where CFp2 articulates how the providers care about the isolation of the patients and other aspects of how telehealth can be beneficial to the CF-patients during COVID-19. Telehealth can be interpreted as an assistant to the providers because "*Then they (the providers, ed.) can better keep track of me*" and "[...] *keeping an eye on, that is what the hospital needs, right?*" (Interview CFp3: 10, 11).

5.4.3 An automatic assistant

The telehealth setup is in some human-technology relations stabilised as an automatic assistant. An example of this can be found in how CFp3 utilises the telemonitoring together with the agreement with the providers of only acute information being shared with the patient. Hence, stabilising the telehealth as an automatic assistant;

"And these data (telemonitored medical values, ed.) is transferred to the tablet and send these data to the clinician [...] It is transferred automatically. That is, oxygen saturation, blood pressure, lung function is transferred automatically. The only thing I have to type in, that is my weight."

(Interview CFp3: 2)

It is the Bluetooth and internet connection which are the technological focal point of mediating the telehealth setup as an underlying technological assistant as well as the providers accept CFp3's request regarding opting out of the non-acute information.

As mentioned earlier telehealth augment CFp2's effort when CFp2 is doing lung physiotherapy, and the patient also refer to the self-management as a sport (Interview CFp1: 3). This could stabilise the telehealth setup as a contest component, especially the spirometer, which motivates CFp2.

5.4.4 Technical obstacles

As illuminated earlier the telehealth setup is significantly depended on a stable internet connection. Various functions are impacted unfavourably in the case of internet outage:

"It (the tablet, ed.) would not connect to WIFI [...] so they (the providers, ed.) can't get the data but then – well then I've just walk a bit down the street and then the data got transferred

anyway, so it'll all work out in the end [small giggle]"

(Interview, CFp2: 6)

This quote frames several of the functions which stabilises the telehealth setup in ways that immediately are in contrast to several of the stabilities presented above. Here the telehealth setup is stabilised as technologies which oblige CFp2 to leave the home to enable a transfer of medical values. This stability opposes telehealth as an assistant which helps CFp2 to maintain isolation and, even more important, potentially not adhere to treatment though the CF-patient wants to.

An unstable internet connection or unpredictable instabilities could have unfavourable impacts on an immersed mediation of patient and tele-technologies as this is highly dependent on Bluetooth;

"I have often experienced that I had to manually type it (telemonitored medical values, ed.) in. So, the value is stated on the device, but it won't get transferred to the tablet." (Interview CFp1: 13)

This could potentially oblige CF-patients, like CFp3, to relate to the medical values and lose the opportunity to keep a distance to the medical values which might affect the mental health. Here there can be drawn a line to the study by Saeed et al. (2020) that points to the usability of telemonitoring being highly dependent on solid designed systems.

Teleconsultations mediated through video can be interpreted as a great part of several telehealth setup (Wood et al., 2016; Gordon et al., 2020; Gur et al., 2016). Likewise, to the situation with the failing transfer of medical values, the teleconsultation is also stabilised as an "old fashioned" conversation via a phone call as seen with CFp2 in this patient's attempt to do teleconsultations. This is also experienced by CFp1;

"Especially the situation where you are supposed to be on video with the clinicians. It often happens that they have had to surrender and say, "we'll call you" because they simply couldn't make it work."

(Interview CFp1: 13)

Teleconsultation conducted via the phone might narrow down the possibility for the provider to create proximity at the distance, as they would not be able to see the CF-patient, hence read body language and facial expressions.

5.5 Throw a stone in the water and a ripple effect will show

The nuances of telehealth could be said to have an interminable interface; however, one thing is certain; telehealth constitutes a changeability in many aspects of health care. Furthermore, telehealth as presented in this CF-specific case is to be perceived as a supplement to existing treatment regimes, and is in many ways non-comparable to conventional, outpatient health care.

Telehealth allows for a space for action and creates an opportunity for more freedom in and with own CF, which can be rare with an all-encompassing chronic disease like CF. As CFp3 puts it, "[...] *this telecommunication still allows for me to better be me*." (Interview CFp3: 16, emphasis added), hence touching upon the intrusiveness of CF on the person behind the patient.

5.5.1 Digital distance

No doubt that the online "meeting" between the patient and the provider is re-conceptualised in the sense that the preliminary steps of the meeting, i.e. the social norms constituting a face-to-face meeting, are skipped in teleconsultations. The suddenness of a teleconsultation is rather different than preparing to go the hospital for a monthly consultation. The initial steps of a teleconsultation are remarkably cut down in comparison to the preparations of an attendance consultation;

"It can be in the back of my mind before I have to go to Rigshospitalet. If one is to say that there is a start of the preparation, then it can take place a week before. And this (teleconsultations, ed.) takes place from the time I open my eyes in the morning."

(Interview CFp3: 7)

"- in a busy everyday life, it's nice that it's (teleconsultations, ed.) more flexible [...] [Before] I had to plan for an hour and a half drive there (to the CF-centre, ed.). Before you really got going and then had to use half an hour on finding a parking spot and then you have to go up and sit and wait. [...] It was often a real all-day project [...]"

(Interview CFp1: 12)

Here the CF-patients point to both mental and pragmatic preparations, and of the two the pragmatic preparations outweigh the mental - however not by much (Interview CFp1; Interview CFp2; Interview CFp3). An important factor of teleconsultations is telepresence as the digital distance is shortened by the technologies, however this kind of technological mediation cannot fully eliminate the physical distance. Therefore, the humans must be aware of this difference in telecommunication which requires an alternative (tele-)presence in order to

ensure a sense of proximity and empathy in the interaction (Pols, 2012). The CF-patients have all experienced the difference in the proximity and presence when comparing attendance- and teleconsultations. This comes down to both the providers' medical experience with CF in reference to how the CF-patients are able to enact telepresence themselves (Interview CFp1). Moreover, it revolves around how the CF-patient experiences the attentiveness of the provider mediated through a screen (Interview CFp1; Interview CFp2; Interview CFp3).

5.5.2 A necessary mediation

The stabilities of the telehealth setup have one thing in common; that they support the CFpatients in handling several aspects of their disease from visualising their lung capacity through graphs to be an underlying, necessary assistant in their contact with the CF-centre. Likewise, telehealth could be said to be stabilised as an assistant for the CF-centre as well, as telehealth enables the CF-centre to maintain treatment and contact to the patients when attendance consultations are not possible in situations like COVID-19 or with patients opting out of medical check-ups.

Despite potential challenges with telepresence, the CF-patients consider the telehealth setup as a caring technological mediation of the necessary contact and interaction with the CFcentre.

"It (attending the CF-centre, ed.) can affect me a lot mentally, so it has been a great relief for me to be able to measure it (lung capacity, ed.) without having to put pressure on my ward (the CF-centre, ed.). Just as much because [...] I would avoid going there and thus not putting myself in danger (of cross-infections, ed.)."

(Interview CFp1: 3)

"Well I can't answer for everyone else, but I think that most CF-patients feels the same: If it can be done over the phone, then you do it".

(Interview CFp2: 12)

"Well there is a kind of contact to what basically is my second home, you could say. So, in that, that there is a contact, there is a value. And also, an opportunity for dialogue." (Interview CFp3: 11)

There is an underlying controversy in living with CF as the CF-patients describe above; the treatment burden is perceived as a necessary evil for them in order to live longer and have

more quality of life than with an untreated CF. They are all referring to a fundamental desire of adhering to own treatment. Here telehealth performs as the extension the CF-patients either need in order to adhere or which eases their ability to adhere (Interview CFp1; Interview CFp2; Interview CFp3). The subtle intentionality mediated through the interplay with the telehealth allows for the CF-patients to steadily and almost unnoticeably oversee own course of disease. Due to the character of CF as a chronic and life-limiting disease the CF-patients cannot escape the disease and more often than not the treatment burden.

"[...] how are you to survive a critical, fatal disease with everything that encompasses, what kind of human being are you, how do you really embrace the massive anxiety it also entails to be a human being under those conditions."

(Interview CFp3: 14)

CFp3 describes the dilemma of having a fatal disease here above and what thoughts that can bring to mind. This basis term of being a CF-patient is not changed by implementing telehealth, however the scope of self-management of own disease and coping with the fact that CF is a life-limiting, chronic disease is experienced as changed by telehealth. For this CF-patient the telehealth introduces a more viable mediation of own disease and contact to the CF-centre, however still constituting the patient in an induced intentional relation as the disease cannot be eliminated.

5.6 No touch medicine in a no touch society

Due to the COVID-19 pandemic a universal health regulation has been announced which implicates that people are to keep physical distance to each other to avoid getting infected (Politi, n.d.), hence creating a 'no touch society'. In the literature review we presented the term 'no touch medicine' by Antohe et al. (2017) referring to telehealth.

The strategy for the literature research has primarily been based on an inspirational snowball-effect, meaning that we have let us inspire by terms in scientific literature to expand the search and embrace the nuances of telehealth. This has been beneficial in reference to establishing a robust foundation of the scientific field and research topics of telehealth and CF.

Furthermore, COVID-19 has greatly influenced our methodological space for action as described in the *Methods*. The COVID-19 reality has entailed an otherwise impossible experience and given us as researchers an exceptional reflection on the reality of living with CF and being obliged to communicate only via ICT. "So, the question is whether we as researchers aren't living in a "CF-reality" now, without any further parallels [...] during this COVID-19 pandemic and lock-down? [...] essential insights into an impossible reality which we without the COVID-19 pandemic with all likelihood never would have had the chance to get a sniff at or experience a fraction of ourselves."

(Appendix 10, April 28th, 2020)

This field log has been noted with a massive respect and no direct or further analogies to the actual reality of living with CF. There are not many favourable things to say about COVID-19, but it has been an eye opener for us as researchers in terms of telehealth and CF. Our reflections have contributed to an overriding guidance and comprehension of the communicative changes when mediated through a screen. Moreover, as the quote above tentatively states, it has given us the opportunity to "*get a sniff*" into the worldview of CF-patients (Appendix 10).

We have strived to gather as much detailed information about the use, users and usability of telehealth which the interviews with CF-patients have been paramount in attaining. The interviews have been conducted with the research questions as guiding points in order to carefully examine the CF-specific telehealth case study.

In order to scrutinise and navigate both the paradox, complexity and nuances of telehealth in a CF scope we have employed the theories of Care at a distance by Pols and PP by Ihde and Verbeek (Pols, 2012; Rosenberger & Verbeek, 2015). These theories complement each other well as described in the *Theory* chapter. Here Pols' theories of Care at a distance have contributed with a more case-specific framework in relation to telehealth and how the context of such technologies frames the use and users. The theory of PP has assisted this analysis in digging deep into the different relations constituted by the use of technologies. How these relations shape the worldview and doings as well as how the intentionality of humans are mutually constituted by technologies in their multiple stabilities. Hence, we have found that Pols and PP mutually constitutes a "silent collaborate P" in the analysis and investigation of telehealth, its use and implications on health care.

6. Discussion

In this chapter we will discuss the results of the analysis through the theories of Triple Aim and Values that Matter (VtM) (Botin et al., 2015; Smits et al., 2019). We will again emphasise that the VtM is developed to design technologies where value dynamics are to be examined and included in the design process. We employ the VtM to this discussion with great respect to the original framework and draw upon the component of value dynamics. We will take a critical look at telehealth along with the telehealth trend which arose with the onset of COVID-19. Moreover, we will discuss how this growing tendency potentially can impact the CF-patients and their treatment regimes along with a general discussion of telehealth as "the answer".

6.1 The golden ticket

Looking at telehealth from the societal perspective of the Triple Aim; the dimensions of improving patient-experience of care, improving the health of populations, and reducing the cost of health care per capita, this will at first glance be a match made in heaven. According to our analysis the overall patient-experience of own care is increased for the CFpatients mediated through the tele-technologies. Also, the CF-patients avoid the risk of cross-infections by not visiting the hospital each month. Additionally, the telemonitoring allows for the CF-patients and providers to track their health and disease course. Thus, potentially avoid acute exacerbations and increase health status and quality of life for these patients. In Denmark the (Diagnosis-Related Group) DRG-system is used to financially administer the finances of the national health care sector, which mirror the average costs in relation to different diagnosis-groups and the treatment of these (Hansen et al., 2020). The DRG 2020 rate for CF is DKK 71,306, whereas the DRG rates for telemedical treatment regimes generally are all below DKK 1,500 (SDS, 2020). Rigshospitalet has published an approximate cost for telehealth solutions;

"[...] the price falls somewhere between DKK 5,000-7,500 per equipment package plus roughly DKK 620 yearly expenses to a SIM-card per package."

(Rigshospitalet, 2019: 2)

Thus, the CF-specific telehealth setup could be said to reduce per capita cost greatly for treatment of CF-patients. Hence, we will argue that the original Triple Aim, i.e. the societal perspective, is granted with the telehealth supplement to CF-treatment regimes. Telehealth as seen through the seeming rose-coloured glasses of Triple Aim holds a strong argument in

terms of ensuring high-value goals for a sustainable health care sector. However, telehealth is not just a societal golden ticket, it entails many more aspects to point attention to.

6.2 Institutional immersion

We have not been able to investigate the institutional perspective as perceived by the CFcentre as explained earlier. However, we argue that the telehealth setup mediates new roles that have implications on the institutional perspective and practice of CF-treatment. The telepatients are constituted through the mediations of the tele-technologies, especially the interplay between the telemonitoring and eHealth platform, thus gets immersed into the institutional level of health care. This argument is based on the delegation of responsibility which is mutually constituted by the self-monitoring and the transfer of measurements through Opentele, as this is tasks conventionally practiced by a provider. Therefore, an immersion mediation shapes a bi-directedness as the patient's data is immersed in the health care practice, thus constituting the CF-patient in a new role that highly influences the patient-provider interplay. CFp1 frames this new role with its institutional perspective;

"Well, you also relieve them (the providers, ed.) a little when you can conjure something from home, in reasonable settings of course."

(Interview CFp3: 7)

Thus, articulating the patient role and responsibility as exceeding private settings and reaching into institutional settings. Hereby it can be discussed whether or not the patient still is constituted as a patient as the health care practice is divided between the hospital and home-based monitoring practiced by the patients themselves. A certain degree of professional autonomy can be argued to take shape in the home-based practice. With an intention of securing more personal autonomy in relation to own health through self-management, this newfound autonomy is based in health care practice. Can technologies mediate more autonomy for the patients without taking some from the providers? A limitation of this study is our missing link in the investigating of the CF-centre as an institution and the providers affiliated in order to research this question further. The earlier described parameter of "expert of own disease" is an advantage for this disease group because they are laypersons in CF already, thus this shift of roles and practices is not that alien to them.

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By introducing a telehealth setup - that in so many ways could be said to be a societal vision for health care systems with a 'Triple Aim-lense' - an intentionality based in societal objectives are embedded in the technologies. Pols refer to the societal perspective of telehealth as;

"To study the effectiveness of a telecare device departs from a deterministic idea of what technology is, making the part of users and contexts invisible because of their assumed irrel-

evance."

(Pols, 2012: 179)

Additionally, it is important to state that adherence to treatment in principle falls under improvement of population health, hence adherence could also be stated to have a societal perspective in mind. In the analysis we uncovered that an intentionality of adherence can be mediated by telehealth. Consequently, the tentative question asked by the CF-centre in regard to the possibility of better monitoring patients that elsewise would opt out of check-ups is somewhat replied to.

"That's why I think this telecommunication helps. Because it constitutes an extra contact to the hospital, that I wouldn't have had elsewise."

(Interview CFp3: 10)

Here CFp3 refers to an intentionality of adherence, that the patient would not have had if it had not been for the mediation of the telehealth. So, in a way a societal goal, i.e. implied improvement of (CF-)population health, is attained by introducing telehealth.

6.3 Dynamics of Cystic Fibrosis

We find the value dynamics essential to discuss in this context with reference to the quote by Pols above regarding the "*assumed irrelevance*" (Pols, 2012: 179) of the users and context, as our analysis have shown that especially these are of great relevance to the assessment of telehealth.

Telehealth is very nuanced both in terms of technologies and the use of telehealth itself. In addition to this we have found that the characteristics of the disease is extremely context-sensitive in reference to telehealth, both in relation to the disease itself and the patient group. Thus, we regard the users and their context as highly indicative for how the value dynamics come into play. The VtM theory;

"[...] stresses the context-dependence of values [as the] values result and depend on usertechnology interactions." (Smits et al., 2019: 398)

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A significant part of the context of CF is the intrusiveness of both the disease itself and treatment burden. Hence, as aforementioned any easement of the treatment burden should in principle have a great impact, which the CF-centre also emphasises;

"But all CF-patients affiliated Rigshospitalet who are deemed suitable and accepts the offer (of telehealth, ed.) will in principle experience an increased value with telemedicine [...]" (Rigshospitalet, 2018)

The abovementioned 'value' is stated by a provider; therefore, we assume the 'value' in question is referring to general health of the patients through persistent adherence. The CF-patients describe the providers as nearly having a greater need to monitor their disease than the patients' themselves;

"It (telehealth, ed.) makes my everyday life easier because I don't have to travel once a month or every second week **each time they (the CF-Centre, ed.) wish** to get some numbers (medical values, ed.) [...]."

(Interview CFp2: 8, emphasis added)

"But - well this keeping an eye on, that is **what the hospital needs**, right?" (Interview CFp3: 11, emphasis added)

The disease itself becomes trivial in the sense that CF is an inescapable embodiment of people living with CF, however *not* trivial in the sense that it becomes simple in any way. This can be seen in the quotes above, where the CF-patients articulate this paradox rather indifferently. The patient-provider relationship is for life, at least for the CF-patient. When introducing telehealth, the equation gets a new link that mediates the relation and hereby also the intentionality which most likely will reshape the institutional perspective as well. We will however stress that this aspect is to be further investigated before any conclusive remarks can be stated.

The CF-centre has described which values and how they anticipate that the patient will benefit from the telehealth supplement, and has amongst other things pointed to;

"[...] support patients with CF to take more ownership of their health care by offering the possibility of monitoring their lung function (FEV1), blood pressure and oxygen saturation at home. People with CF will still be monitored closely but will reduce the time spent on their outpatient visits and reduce the risk of cross-infections."

(CF Centre Copenhagen, n.d.: 1)

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Thus, making anticipations about future value dynamics where the mediated human-technology interaction is not visible, moreover these anticipations mirror the discussed societal perspective above. Considering the significance of a context-focused and nuanced outlook on the implications of telehealth a merely societal perspective is insufficient in evaluating a telehealth setup.

A basic term of CF is that the disease is chronic, and the treatment burden is significant, and as the CF-patients have remarked the constant worrying of own health is very intrusive on everyday life. Hereby making CF a highly negative facet in own life and the patients describe a hostility towards both own disease and the surrounding activities, i.e. both treatment and check-ups (Interview CFp1; Interview CFp2; Interview CFp3). The treatment activities, here-under consultations and monitoring of own symptoms, is changed by telehealth mediating these purposes and thereby influencing the intentionality of the patient.

The term freedom-of-disease points towards the CF-patients experiencing a more emancipated existence mediated through the telehealth. This highlights a shift in value dynamics in regard to the perception of own disease and therefore world view. Also meaning that the intentionality of adherence not only is ascribed to a societal perspective, but seemingly also to the individual level, yet based on other values. The subtle intentionality mentioned in the analysis is profound in relation to the CF-patients, as the intentional relation of adherence for the patients is merely a mean towards more emancipation. Whereas the intentionality of adherence for the providers is an aim in itself as their first job is to treat disease and increase population health (Rigshospitalet, 2020). However, it can then be discussed whether there is room for two diverse starting points in reference to a seeming uniform adherence intentionality. Furthermore, the patients' intentionality is mediated through technologies granted by the societal perspective, and again a discussion of whether this is at all feasible emerge. Any conclusions regarding this discussion should be based on more research and examination of this topic.

6.4 COVID-19 acting catalyst

Despite the rather limited number of informants a high degree of diversity of the users and use of the tele-technologies have been uncovered. Additionally, the multistability of telehealth in this CF-case shows a variety of perceivings and doings. This calls attention to the current situation of COVID-19, where telehealth has been distributed to several areas of health care (Medcom, 2020). To this, attention must be drawn to the acuteness caused by the COVID-19 lockdown, that require technologies like telehealth to solve both acute and more basic health care issues. It cannot be ignored, however, that there is a need for delve into the possible implications of introducing telehealth. The infectious enthusiasm towards telehealth could blind and thereby eliminate further examining of such implications. We here stress the necessity of including a great focus on context-sensitivity and herein anticipation of value dynamics. When throwing a stone, a ripple effect will show, yet it is crucial to discuss these ripple effects and not get blinded by the acuteness of COVID-19. We see a need for larger studies further investigating the implications of long-term telehealth applications. Especially if the aspirations of such is not to supplement outpatient care but to replace it entirely. Rigshospitalet acknowledges the possible shortcomings of telehealth, as it is perceived as a supplement to outpatient care. Hence, they recommend that attendance consultations for tele-patients is twice as long than regular attendance consultations (Rigshospitalet, 2019). CFp1 underpins this;

"It's 10-times easier that you can do it (teleconsultations, ed.) from home [...] and I basically had a lot of these [fast and uneventful attendance consultations]. No, it's (teleconsultations, ed.) not the same, but when I think about the alternative - if I don't feel the need for a more in-depth meeting, then it's (teleconsultations, ed.) fine".

(Interview CFp1: 10)

During the COVID-19 lockdown telehealth is no longer supplement to attendance consultations with own GP, i.e. teleconsultations have replaced the attendance consultation (SST, 2020d). The intentional values of rapidly introducing telehealth is based on quickly adapting to a critical situation, i.e. the COVID-19 pandemic. The Danish Organisation of GP's "[...] certainly sees a place for video consultations after the Corona crisis has ended." (Medcom, 2020) This calls for a discussion of the value dynamics, specifically the interplay of value definition and value expression, of telehealth in this context. A temporary solution is ascribed a certain value definition and the intentional relation of this temporality is also mirrored in the value expression. We argue that the provisional characteristics of telehealth in this case is not robust or particularly well suited for the long hold in itself. Because, as established telehealth is not just one technology for one setting or one patient group, hence the complexity and context of its intended use plays a crucial part in its applicability. We propose a discussion of the scope of telehealth as presented for the general public in these COVID-19 times and argue that this scope needs to be challenged and re-negotiated if a permanent aspect is intended.

6.5 Person over patient

Both CFp1 and CFp3 utilise the telehealth setup to counterbalance their own person to the patient aspect of themselves, i.e. create more space for the person "hosting" the disease rather than becoming merely the patient. CFp1 opts for telehealth and utilises the telemonitoring equipment several times a month to reassure oneself;

"But just knowing that I have the option (to monitor, ed.), that puts my mind to rest. But I can also actively opt to say that 'now I don't want to do a measurement'. [...] It has really given me so much! Previously, I was worried all the time, now I can get worried, but then think 'no, you know what, I can measure it (lung capacity, ed.) when I get home'. Then I can see how it

looks. It's really, really - healthy. It relieves so incredibly much. My mind, that is."

(Interview CFp1: 8, 12)

Hence, CFp1 actively uses the telemonitoring equipment in order to "dim down" the patient aspect of own person as it gives CFp1 a momentary freedom-of-disease. In other words, the telehealth contributes to a personal space for CFp1 which the constant worrying does not make room for.

In contrary CFp3 opts out of engaging with own monitored data constituted by CFp3's interaction with the technologies in order to leave room for own person. CFp3 stresses the importance of prioritising person above patient, and preferably CFp3 would opt out of being a patient as a whole;

"- well it's a condition I have, I would like to run away from it, but I can't [...] You know, it's an endless waiting for results and tests ceaseless. So, it's also a way in which the autonomous part of me says: "ARGGG! - please stop it!", but it's a condition. It's just that, which I resist sometimes."

(Interview CFp3: 15, 16)

CFp3 has also remarked that the telehealth setup better allows CFp3 to be authentic as the value dynamics constituted through the mediation between CFp3 and the telehealth creates space for CFp3's most oppressed values (Interview CFp3: 16). Hereby it can be argued that the value dynamics based on the human-technology interaction for both CFp1 and CFp3 allows for a certain degree of freedom-of-disease that in itself constitutes a momentary haven. It is however debatable whether there is room for an actual intentionality of the patient itself - or person living with CF - as the societal perspective and its intention of adherence makes a greater claim.

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The individual perspective of the Triple Aim framework aims to simultaneously enhance, empower and emancipate the individual, in this case the CF-patient. Again, a discussion on whether this at all is possible if the individual perspective is contrary to the societal perspective is re-opened. Can a person living with CF be free of the patient aspect to the degree they need and want to if the technologies introduced to mediate their treatment have an already established intentionality of adherence? The results of our analysis show that the CFpatients experience an indirect warm care which is not comparable to the warm human care of the providers. This being an alternative warm care in the sense that by distancing the CFpatients from facing their treatment burden and the anxiousness the hospital evokes in them, there is left room for a much-needed breather (Interview CFp1; Interview CFp2; Interview CFp3). Hereby we argue that a value dynamic including freedom-of-disease and autonomy prosper for the individual patient. The societal perspective and technologies in general can seem rather rigid, but as the example with CFp3 and this patient's agreement with the CFcentre shows, a needed flexibility comes into play. Key to the discussion of telehealth is the values expressed through the human-technology interaction, hereby meaning the patientexperienced care and how their value dynamics get influenced by technological mediated health care.

7. Conclusion

This thesis is a case study which examines a telehealth initiative for people with CF affiliated the specialised CF-centre at Rigshospitalet. More specifically, we have examined how telehealth mediates CF-treatment and what potential impacts telehealth has on the patient-provider relationship. Based on our exhaustive literature review the field of telehealth for CFpurposes have been mapped in order to secure fundamental knowledge. The scientific literature and research of this field shows an increasement in CF-specific telehealth both in terms of evolution and expansion within the last decade. The potentials of telehealth have prospered massively within many other areas of health care due to COVID-19, however the limitations and possible adverse effects of telehealth are still to be studied further. Our literature research illuminates many, yet often only feasibility studies of CF-telehealth pilots, and a very scarce number of larger studies of longer running projects (Calthorpe et al., 2020; see Literature review). The forces of telehealth are in many ways also its downfalls; telehealth is - both technological, usability-wise and regarding the intended patient group - infinitely diverse and nuanced. As stated by Antohe et al. (2017: 51) the "socio-technologic panorama" of telehealth is monumental. This could justify the many feasibility studies of CF-specific telehealth, as the context-sensitive nuances are essential to incorporate in the telehealth initiative and thus decreases the applicability to other contexts and patient groups.

The treatment burden of CF highly characterises the patient group and their everyday lives as the daily treatment, medicine and physical exercises take up several hours per day. This is an important contextual parameter of CF as a disease and in the culture of the patient group, hence a certain degree of awareness to this is crucial in relation to the telehealth setup being viable for CF-patients. Meaning that the benefits of introducing and using telehealth as a replacement or supplement to outpatient care have to outweigh the hassle of alterations in routines and division of responsibilities for both patient and provider. However, it is not merely a matter of resources. The telehealth setup mediates an interdependence based on the human-technology interaction which affects both treatment and the patient-provider relation. The tele-technologies also mediate a shift in autonomy, where a delegation of responsibility referring to the patient now monitoring themselves at home and thereby self-managing own disease constitutes a shift. The patient autonomy increases as they perform own treatment in the light of a professional autonomy, as discussed in the former chapter.

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The telehealth impacts the patient-provider interaction as an embedded feature of telehealth is securing health care at a distance, however the digital distance is still present despite the ICT eliminates the physical distance. We again stress that this digital distance is not to be invalidated, and as the Analysis has illuminated the relation and communication through a screen is not parallel to face-to-face meetings. Hence, the term telepresence by Pols (2012) situates this paradox and we have discovered that the CF-patients also experience a short supply of telepresence. The patients themselves find that they are not able to perform telepresence with a provider with little CF-specific medical experience. Furthermore, the patients generally articulate the teleconsultations as more effective and carried by a focus on medical values, not relational care (Interview CFp1; Interview CFp2; Interview CFp3). However, the complexity of telehealth again shows its face, as the CF-patients also describes the telehealth option as a caring initiative because it eliminates many anxiety-provoking aspects of CF-treatment and own disease. Pols refers to an oversimplification of "warm care" and "cold technologies", which in this case of CF-telehealth in many ways constitutes the opposite. We argue that this is highly due to the culture of the patient group and the characteristics of CF as a disease.

In the *Analysis* we have examined the human-technology relations of CF-patients and the telehealth setup using PP to fully investigate the implications and uses of telehealth in this context (Rosenberger & Verbeek, 2015). An important relation mediated by the telehealth setup is the intentionality of adherence, which is a key objective from the providers as treatment adherence is for now the only relief of CF impairment and thus increase quality of life for the patients (Rigshospitalet, 2018). However, due to the intrusiveness of CF many CF-patients experience a clash between wanting to be free of disease, incl. treatment burden, and exacerbations leading to a decline of lung function (Interview CFp2). Therefore, an indirect intentionality of adherence is also present for the CF-patients, as they are mutually constituted in an intentional relation between telehealth and the want of freedom-of-disease, which the telehealth setup creates space for through different mediations uncovered in the *Analysis* (Interview CFp1; Interview CFp2; Interview CFp3).

This thesis started out in a COVID-19 free-context and is now finalising in a highly influenced new COVID-19 reality, which also to a great extent is mirrored in the project. Telehealth shows massive potential for ensuring health care at a distance. However, the diversity and complexity of the technologies and usability of telehealth itself and the context of which it is

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employed in is of the essence to incorporate when considering telehealth as a viable solution. Many societal perspectives are granted by utilising telehealth as a technological supplement (or replacement) for conventional care, as discussed in the former chapter. The users and context of telehealth is never invisible and will inevitably influence the success rate of a telehealth application.

For CF-treatment the telehealth setup in this specific case study has shown more promise and relief than obstacles for the patients, despite technical difficulties with simple, yet significant features like WIFI connection. A momentary haven and freedom-of-disease is mediated by the telehealth setup, and as the initiative is perceived as a treatment supplement to quarterly attendance consultations it gives rise to more safety and comfort for the CF-patients. As concluded in former chapters, an alternative warm care is constituted by distancing the disease burden and the CF-patients from each other using this digital mediation.

8. Bibliography

Adams, T., Holman Jones, S. and Ellis, C., 2015. Autoethnography. New York: Oxford University Press, pp.1-45.

Aidt, G., 2020. *Min Læge App - Sundhedsdatastyrelsen*. [online] Sundhedsdatastyrelsen.dk. Available at: https://sundhedsdatastyrelsen.dk/da/registre-og-services/om-min-laege-app [Accessed 8 April 2020].

AI-Majeed, S.S., AI-Mejibli, I.S. and Karam, J., 2015. *Home telehealth by Internet of Things (IoT)*, 2015 IEEE 28th Canadian Conference on Electrical and Computer Engineering (CCECE), Halifax, NS, 2015, p. 609.**Finansministeriet, n.d.** *Ærø Kommune: Telemedicin Giver Bedre Velfærd På Tværs Af Sektorer.* [online] Finansministeriet. Available at: https://www.fm.dk/temaer/sammen-haengsreform/innovationsministeren-paa-danmarksturne/aerae-kommunes [Accessed 8 April 2020].

Antohe, I., Floria, M. and Carausu, E., 2017. Telemedicine: Good or bad and for whom?. In: E-Health and Bioengineering Conference (EHB). [online] IEEE. Available at: https://doiorg.zorac.aub.aau.dk/10.1109/EHB.2017.7995358 [Accessed 9 Feb. 2020].

Australian Institute of Health and Welfare (AIHW), 2018. Australia's health 2018, AIHW, Canberra, pp.395-396

Baarts, C., 2015. *Autoetnografi.* In: S. Brinkmann and L. Tanggaard, ed., *Kvalitative metoder*, 2nd ed. Hans Reitzels Forlag, ch.8.

Bazeley, P. & Jackson, K., 2007. *Coding Basics*. In: *Qualitative Data Analysis with NVivo*, Sage. pp.68-93

Bella S, Murgia F, et al., 2009. Five years of Telemedicine in Cystic Fibrosis disease. Clin Ter, 160(6), pp. 457-460.

Berwick, D., Nolan, T. and Whittington, J., 2008. *The Triple Aim: Care, Health, And Cost*. Health Affairs, 27(3), pp.759-769.

Botin, L., Bertelsen, P. and Nøhr, C. (2015). Challenges in Improving Health Care by Use of Health Informatics Technology. In: L. Botin, P. Bertelsen and C. Nøhr, ed., Techno-Anthropology in Health Informatics: Methodologies for Improving Human-Technology Relations. [online] IOS Press, pp.3-5, 7 Available at: http://ebookcentral.proquest.com/lib/aalborguniv-ebooks/detail.action?docID=2190956 [Accessed 19 Feb. 2020].

Brinkmann, S. and Tanggaard, L., 2015. Interviewet: Samtalen som forskningsmetode. In: S. Brinkmann and L. Tanggaard, ed., Kvalitative metoder, 2nd ed., Hans Reitzels Forlag, ch.1.

Calthorpe, R., Smith, S., Gathercole, K. and Smyth, A., 2020. Using digital technology for home monitoring, adherence and self-management in cystic fibrosis: a state-of-the-art review. Thorax, 75(1), pp.72-77.

Cambridge dictionary., 2020. SELF-EFFICACY | meaning in the Cambridge English Dictionary. [online] Available at: https://dictionary.cambridge.org/dictionary/english/self-efficacy [Accessed 3 Mar. 2020].

Choyce, J., Shaw, K., Sitch, A., Mistry, H., Whitehouse, J. and Nash, E., 2017. A prospective pilot study of home monitoring in adults with cystic fibrosis (HOME-CF): protocol for a randomised controlled trial. BMC Pulmonary Medicine, 17(1).

Coiera, E., 2015. Guide To Health Informatics. 3rd ed. CRC Press, pp.343-370.

Cystic Fibrosis Centre Copenhagen (CF Centre Copenhagen), n.d. Home Monitoring In Adults With Cystic Fibrosis — A Feasibility Study. Cystic Fibrosis Centre Copenhagen. [Unpublished study protocol, Appendix 5]

Cystisk Fibrose Foreningen (CFF), n.d.(a) *Telemedicin Til Voksne CF-Patienter – Et Pilotprojekt | Cystisk Fibrose Foreningen.* [online] Cystisk Fibrose Foreningen. Available at: https://cystiskfibrose/telemedicin-til-voksne-cf-patienter-et-pilotprojekt/ [Accessed 21 May 2020].

Cystisk Fibrose Foreningen (CFF), n.d.(b). *Medicin Og Behandling | Cystisk Fibrose Foreningen.* [online] Cystisk Fibrose Foreningen. Available at: https://cystiskfibrose.dk/livet-med-cystisk-fibrose/medicin-og-behandling/> [Accessed 31 March 2020].

DaCHI, 2015. Begreber, Værdier Og Metoder Til Belysning Af Bæredygtig Og Levedygtig Udvikling Og Indførelse Af Teleteknologi I Sundhedsvæsenet. DaCHI Technical Report no. 15-2. Aalborg: Dansk Center for Sundhedsinformatik (DaCHI), Institut for Planlægning, Aalborg Universitet, pp.6-13.

Danske regioner, 2017. *Danske Regioner - KOL-Patienter Er Tilfredse Med Telemedicin.* [online] Regioner.dk. Available at: https://www.regioner.dk/services/nyheder/2017/december/kol-patienter-er-tilfredse-med-telemedicin [Accessed 9 April 2020].

Danske Regioner, 2020. Danske Regioner - Snart Kan Du Gå Til Fysioterapeut, Kiropraktor Og Fodterapeut Uden At Tænke På Smittefare. [online] Regioner.dk. Available at: [Accessed 8 April 2020].

De Videnskabsetiske Komiteer, n.d. *De Videnskabsetiske Komitéer*. [online] Regionh.dk. Available at: <https://www.regionh.dk/til-fagfolk/Forskning-og-innovation/jura-og-data/De-Videnskabsetiske-Komiteer/Sider/default.aspx> [Accessed 31 March 2020].

Doran, GT., 1981. There's a SMART way to write management's goals and objectives. Management Review 70(11): 35-36

Ellis, C., Adams, T. and Bochner, A., 2011. Autoethnography: An Overview. Historical Social Research / Historische Sozialforschung, 36(4), pp.273-290

European Commission (EC), 2008. On Telemedicine For The Benefit Of Patients, Healthcare Systems And Society. COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIA-MENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COM-MITTEE OF THE REGIONS. Brussels: European Commission, pp.3-11.

European Commission (EC), 2014. Widespread Deployment Of Telemedicine Services In Europe Report Of The Ehealth Stakeholder Group On Implementing The Digital Agenda For Europe Key Action 13/2 'Telemedicine'. Brussels, pp.4-8.

European Commission (EC), 2018. Market Study On Telemedicine. Brussels, pp.25-110.

European Commission (EC), 2019. The Internet Of Things - Shaping Europe'S Digital Future - European Commission. [online] Available at: https://ec.europa.eu/digital-single-market/en/policies/inter-net-things> [Accessed 24 April 2020].

Finsenscentret, 2018. Værdibaseret Styring I Finsencentret 2018 Anbefalinger Og Præsentation Af Resultater. 1st ed. [ebook] København: Finsenscentret, pp.14-15. Available at: https://www.rigs-hospitalet.dk/presse-og-nyt/nyheder/nyheder/Sider/2018/december/vaerdi-kultur-og-mere-for-min-dre.aspx> [Accessed 26 April 2020].

Thesis by Trine Christensen Mayntzhusen & Marie Hasselbalch

Franssen, M., Lokhorst, G. and Poel, I., 2018. *Philosophy Of Technology (Stanford Encyclopedia Of Philosophy).* [online] Plato.stanford.edu. Available at: https://plato.stanford.edu/entries/technology/superior [Accessed 13 April 2020].

Frydendahl, L. and Høyer, A., 2020. *Væn Dig Til Videomøder Og Hjemmearbejde: Corona Maser Teknologi Ind I Arbejdsdagen.* [online] DR. Available at: ">https://www.dr.dk/nyheder/regionale/mid-tvest/vaen-dig-til-videomoeder-og-hjemmearbejde-corona-maser-teknologi-ind-i> [Accessed 20 May 2020].

Galletta, A. & Cross, W. E., 2013. *Mastering the semi-structured interview and beyond: from research design to analysis and publication.* New York: New York University Press, pp. 24, 45, 72

Google Glass. n.d. *Tech Specs – Glass*. [online] Available at: <https://www.google.com/glass/tech-specs/> [Accessed 14 April 2020].

Gordon, H., Solanki, P., Bokhour, B. and Gopal, R., 2020. "I'm Not Feeling Like I'm Part of the Conversation" Patients' Perspectives on Communicating in Clinical Video Telehealth Visits. Journal of General Internal Medicine.

Grotenborg, L., Katzenstein, T., Kocisko, M. and Pressler, T., 2019. ePS2.10 Home monitoring in adults with cystic fibrosis - a feasibility study. Journal of Cystic Fibrosis, 18, p.S44.

Grzincich, G., Gagliardini, R., Bossi, A., Bella, S., Cimino, G., Cirilli, N., Viviani, L., Iacinti, E. and Quattrucci, S., 2010. Evaluation of a home telemonitoring service for adult patients with cystic fibrosis: a pilot study. Journal of Telemedicine and Telecare, 16(7), pp.359-362.

Gur, M., Nir, V., Teleshov, A., Bar-Yoseph, R., Manor, E., Diab, G. and Bentur, L., 2016. The use of telehealth (text messaging and video communications) in patients with cystic fibrosis: A pilot study. Journal of Telemedicine and Telecare, 23(4), pp.489-493.

Hansen, N., Nielsen, C., Fjallsbak, E., Olsen, S. and Lauritsen, E., 2020. *DRG - Takster - Sund-hedsdatastyrelsen*. [online] Sundhedsdatastyrelsen.dk. Available at: https://sundhedsdatastyrelsen.dk/da/afregning-og-finansiering/takster-drg [Accessed 17 May 2020].

Holle, R. & Zahlmann, G., 1999. Evaluation of telemedical services. IEEE Transactions on Information Technology in Biomedicine, 3(2), 84–91.

Hult, C., n.d. *Telemedicinsk Videncenter*. [online] Regionh.dk. Available at: <https://www.regionh.dk/om-region-hovedstaden/denAdministrativeRegion/Center-for-Sundhed/det-naeresundhedsvaesen/Sider/Telemedicinsk-Videncenter.aspx> [Accessed 11 March 2020].

Hyldig, K., 2020. *Virtuel Kage Og Håndtegn Tager Toppen Af Trætheden*. [online] Kommunen.dk. Available at: https://www.kommunen.dk/artikel/virtuel-kage-og-haandtegn-tager-toppen-af-traethe-den [Accessed 14 May 2020].

Ignatowicz, A., Slowther, A., Elder, P., Bryce, C., Hamilton, K., Huxley, C., Forjaz, V., Sturt, J. and Griffiths, F., 2018. Ethical implications of digital communication for the patient-clinician relationship: analysis of interviews with clinicians and young adults with long term conditions (the LYNC study). BMC Medical Ethics, 19(1).

Ihde, D., 1993. Philosophy of Technology: An Introduction, New York: Paragon House, p. 38.

Inde, D., 2010. Stretching the In-between: Embodiment and Beyond. *Foundations of Science*, 16(2-3), pp.109-118.

IHI, 2020a. *The IHI Triple Aim* | *IHI - Institute For Healthcare Improvement*. [online] Available at: <http://www.ihi.org/Engage/Initiatives/TripleAim/Pages/default.aspx> [Accessed 10 April 2020].

Thesis by Trine Christensen Mayntzhusen & Marie Hasselbalch

IHI, 2020b. *History* | *IHI - Institute For Healthcare Improvement*. [online] Ihi.org. Available at: <http://www.ihi.org/about/Pages/History.aspx> [Accessed 20 April 2020].

Jarad, N. and Sund, Z., 2010. Telemonitoring in chronic obstructive airway disease and adult patients with cystic fibrosis. Journal of Telemedicine and Telecare, 17(3), pp.127-132.

Ketchell, R., 2018. Telemedicine is the way forward for the management of cystic fibrosis – the case in favour. Paediatric Respiratory Reviews, 26, pp.19-21.

Kidholm, K., Bowes, A., Dyrehauge, S., Granstrøm Ekeland, A., Flottorp, S., Kvistgaard Jensen, L., Duedal Pedersen, C. and Rasmussen, J., 2010. *The Model For Assessment Of Telemedicine (MAST) Manual*. The MethoTelemed project, European Commission, p.11.

Kidholm, K., Ekeland, A., Jensen, L., Rasmussen, J., Pedersen, C., Bowes, A., Flottorp, S. and Bech, M., 2012. A MODEL FOR ASSESSMENT OF TELEMEDICINE APPLICATIONS: MAST. International Journal of Technology Assessment in Health Care, 28(1), pp.44-51.

Kidholm, K., Clemensen, J., Caffery, L. and Smith, A., 2017. The Model for Assessment of Telemedicine (MAST): A scoping review of empirical studies. *Journal of Telemedicine and Telecare*, 23(9), pp.803-813.

Knudsen, K., Pressler, T., Mortensen, L., Jarden, M., Skov, M., Quittner, A., Katzenstein, T. and Boisen, K., 2016. Associations between adherence, depressive symptoms and health-related quality of life in young adults with cystic fibrosis. SpringerPlus, 5(1).

Law, J., 2019. *Material Semiotics*. [online] Heterogeneities.net, p.1 Available at: http://www.hetero-geneities.net/publications/Law2019MaterialSemiotics.pdf> [Accessed 24 March 2020].

Lechtzin, N. et al., 2017. Home Monitoring of Patients with Cystic Fibrosis to Identify and Treat Acute Pulmonary Exacerbations: eICE Study Results. American Journal of Respiratory and Critical Care Medicine. [Online] 196 (9), 1144–1151. [online]. Available from: http://search.proquest.com/docview/1961325356/.

Lenney, W., 2018. Telemedicine is the way forward for the management of cystic fibrosis- the case against. *Paediatric Respiratory Reviews*, 26, pp.22-23.

Lottrup, C., 2020. *Coronavirus: Til Patienter Og Pårørende På Rigshospitalet*. [online] Rigshospitalet.dk. Available at: https://www.rigshospitalet.dk/corona-paa-riget> [Accessed 31 March 2020].

Mammen, D., 2018. *Kræver Nye Kompetencer | Sygeplejersken, DSR*. [online] DSR. Available at: https://dsr.dk/sygeplejersken/arkiv/sy-nr-2018-2/kraever-nye-kompetencer [Accessed 9 April 2020].

Marcus, G., 1995. Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography. *Annual Review of Anthropology*, 24(1), pp.106

Medcom, 2020. *Medcom And Digital Support During Corona - Medcom.* [online] Medcom.dk. Available at: <https://www.medcom.dk/medcom-in-english/about-medcom/medcom-international/medcom-and-digital-support-during-corona?fbclid=lwAR3x1Kk4Lg4jlpq40X4sqxhJR-ZasxQCepZVBr4ptQtPnXgxXy-38ANeEC30> [Accessed 27 May 2020].

Microsoft Teams, n.d. *Chat, Meetings, Calling, Collaboration | Microsoft Teams*. [online] Products.office.com. Available at: https://products.office.com/en-us/microsoft-teams/group-chat-software [Accessed 15 April 2020].

Mullin, G., ed., 2018. Health Technology Sourcebook. 1st ed. Detroit: Omnigraphics, pp.9-27.

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Murgia, F., Tagliente, I., Zoppis, I., Mauri, G., Sicurello, F., Bella, F., Mercuri, V., Santoro, E., Castelnuovo, G. and Bella, S., 2016. Trend of FEV1 in Cystic Fibrosis patients: A telehomecare experience. In: IEEE Symposium on Computers and Communication (ISCC). [online] IEEE. Available at: https://doi-org.zorac.aub.aau.dk/10.1109/ISCC.2016.7543752 [Accessed 9 Feb. 2020].

Nepal, S., Li, J., Jang-Jaccard, J. and Alem, L., 2014. A Framework for Telehealth Program Evaluation. Telemedicine and e-Health, 20(4), pp.393-404.

Novak, L., Simpson, C., Slagle, J. and Mulvaney, S., 2015. Technology and the Ecology of Chronic Illness in Everyday Life. In: L. Botin, P. Bertelsen and C. Nøhr, ed., Techno-Anthropology in Health Informatics: Methodologies for Improving Human-Technology Relations. [online] IOS Press. Available at: http://ebookcentral.proquest.com/lib/aalborguniv-ebooks/detail.action?docID=2190956 [Accessed 19 Feb. 2020].

OpenTeleHealth (OTH), 2020a. Universal Telemedicine Service And E-Health Solution | Opentelehealth. [online] Available at: http://opentelehealth.com/product/ [Accessed 19 March 2020].

OpenTeleHealth (OTH), 2020b. Unique Clinical Workflow For Doctor-Patient Consultation. [online+image] OTH. Available at: http://opentelehealth.com/clinical-workflow/ [Accessed 19 March 2020].

Pan American Health Organization (PAHO), 2016. *Framework For The Implementation Of A Telemedicine Service.* [ebook] Washington, D.C.: Pan American Health Organization (PAHO), pp.63-67. ISBN 978-92-75-11903-7

Politi, n.d. Forlængelse Af Tiltag Mod COVID-19 | Coronavirus/COVID-19 | Danmark | Politi. [online] Politi.dk. Available at: https://politi.dk/coronavirus-i-danmark/forlaengelse-af-tiltag-mod-covid-19-i-danmark [Accessed 15 April 2020].

Pols, J., 2012. Care at a distance, 1st ed. [online] Amsterdam: Amsterdam University Press, pp.11-20, 25, 39, 66-67, 100, 107, 113, 179. Available at: https://www-jstor-org.zorac.aub.aau.dk/sta-ble/j.ctt6wp5zw [Accessed 23 Feb. 2020].

Rasbech, M., 2020. *Dansk Industri: Coronakrisen Viser At Fremtidens Sundhedsvæsen Er Digitalt.* [online] Altinget: sundhed. Available at: <https://www.altinget.dk/sundhed/artikel/dansk-industri-coronakrisen-viser-at-fremtidens-sundhedsvaesen-er-digital> [Accessed 14 May 2020].

Region Midtjylland (Region Midt), n.d. *Guide Til Den Gode Videokonsultation.* [online] Rm.dk. Available at: https://www.rm.dk/sundhed/faginfo/center-for-telemedicin/varktojer-og-viden/narvar-pa-afstand/> [Accessed 8 April 2020].

Rigshospitalet, **n.d.** VBS Telemedicin Projektet For Cystisk Fibrose Patienter. Rigshospitalet. [Unpublished report, see Appendix 6]

Rigshospitalet, 2018. *Patienter Med Cystisk Fibrose Kan Spare To Ud Af Tre Besøg.* [online] Rigshospitalet.dk. Available at: https://www.rigshospitalet.dk/presse-og-nyt/nyheder/nyheder/Sider/2018/november/cf-patienter-kan-spare-2-ud-af-3-besoeg.aspx [Accessed 9 April 2020].

Rigshospitalet, 2019. Kom Godt I Gang Med Telemedicin - Erfaringer Fra Infektionsmedicinsk Klinik. [PDF] København: Rigshospitalet. Available at: [Accessed 26 April 2020].

Rigshospitalet, 2020. Kernefortælling. [online] Available at: https://www.rigshospitalet.dk/om-hospitalet/strategi/Sider/kernefortaelling.aspx> [Accessed 27 May 2020].

Rosenberger, R. and Verbeek, P. ed., 2015. *Postphenomenological Investigations Essays On Human–Technology Relations.* 1st ed. London: Lexington Books, pp.10,12-14, 19-22, 25-26, 31, 261, 263.

Skype, n.d. Skype | Communication Tool For Free Calls And Chat. [online] Skype.com. Available at: https://www.skype.com/en/ [Accessed 9 March 2020].

Smits, M., Bredie, B., van Goor, H. & Verbeek, P-P., 2019. Values that Matter: Mediation theory and Design for Values. In: E. Bohemia, G. Gemser, N. Fain, C. de Bont & R. Assoreira Almendra, ed., Research Perspectives in the era of transformations: Conference proceedings. Conference proceedings of the Academy for Design Innovation Management, no. 1, vol. 2, Academy for Design Innovation Management, pp. 396-400, Academy for Design Innovation Management Conference 2019, London, United Kingdom.

Spradley, **J.**, **1979**. Asking descriptive questions. In: *The Ethnographic Interview*, 1st ed. Wadsworth Group, pp.44-61.

SSI, **2020**. *Udbrud Med COVID-19*. [online] Ssi.dk. Available at: <https://www.ssi.dk/ak-tuelt/sygdomsudbrud/coronavirus> [Accessed 31 March 2020].

Sundhed.dk. 2019. *Cystisk Fibrose - Lægehåndbogen*. [online] Available at: <https://www.sundhed.dk/sundhedsfaglig/laegehaandbogen/lunger/tilstande-og-sygdomme/oevrige-sygdomme/cystisk-fibrose/> [Accessed 21 March 2020].

Sundhedsdatastyrelsen (SDS). n.d. *Begrebsbasen*. [online] Available at: <http://sundhedsdata.iterm.dk/#results> [Accessed 10 March 2020].

Sundhedsdatastyrelsen (SDS), 2015. *NBS Telemedicinbegreber - Rapport Vedrørende Udarbejdelse Af Begrebssystem Og Definitioner.* [online] København: Sundhedsdatastyrelsen. Available at: <https://sundhedsdatastyrelsen.dk/da/rammer-og-retningslinjer/om-terminologi/nbs/om-arbejdsgrupperne/telemedicinbegreber> [Accessed 1 April 2020].

Sundhedsdatastyrelsen (SDS), 2018. *Telemedicin Og Telesundhed - Mere om telemedicin og telesundhed.* [online] Sundhedsdatastyrelsen.dk. Available at: <https://sundhedsdatastyrelsen.dk/da/rammer-og-retningslinjer/telemedicin-og-telesundhed> [Accessed 8 April 2020].

Sundhedsdatastyrelsen (SDS), 2020. DRG Takstvejledning 2020. [PDF] København: Sundhedsdatastyrelsen. Available at: https://sundhedsdatastyrelsen.dk/-/media/sds/filer/finansiering-og-afregning/takster/2020/takstvejledning-2020.pdf> [Accessed 17 May 2020].

Sundhedsstyrelsen (SST), 2020a. *5 Nye Sundhedsaftaler Skal Sikre Det Gode Samarbejde På Tværs Af SundhedsVæsenet I De Næste 4 År.* [online] Sst.dk. Available at: https://www.sst.dk/da/ny-heder/2019/5-nye-sundhedsaftaler-skal-sikre-det-gode-samarbejde-paa-tvaers-af-sundhedsvaesenet-i-de-naeste-4-aar [Accessed 8 April 2020].

Sundhedsstyrelsen (SST), 2020b. Eftersyn Af Indsatsen Til Personer Med Cystisk Fibrose. 1st ed. [ebook] København S: Sundhedsstyrelsen, p.12-24. Available at: ">https://www.sst.dk/-/me-dia/Udgivelser/2020/Eftersyn-af-indsatsen-til-personer-med-cystisk-fibrose-09012020.ashx?la=da&hash=9E95D690EC3C78CC69FF357358F2AD366B47E0C3>">https://www.sst.dk/-/me-dia/Udgivelser/2020/Eftersyn-af-indsatsen-til-personer-med-cystisk-fibrose-09012020.ashx?la=da&hash=9E95D690EC3C78CC69FF357358F2AD366B47E0C3>">https://www.sst.dk/-/me-dia/Udgivelser/2020/Eftersyn-af-indsatsen-til-personer-med-cystisk-fibrose-09012020.ashx?la=da&hash=9E95D690EC3C78CC69FF357358F2AD366B47E0C3>">https://www.sst.dk/-/me-dia/Udgivelser/2020/Eftersyn-af-indsatsen-til-personer-med-cystisk-fibrose-09012020.ashx?la=da&hash=9E95D690EC3C78CC69FF357358F2AD366B47E0C3>">https://www.sst.dk/-/me-dia/Udgivelser/2020/Eftersyn-af-indsatsen-til-personer-med-cystisk-fibrose-09012020.ashx?la=da&hash=9E95D690EC3C78CC69FF357358F2AD366B47E0C3>">https://www.sst.dk/

Sundhedsstyrelsen (SST), 2020c. *Retningslinjer For Håndtering Af COVID-19 I Sundhedsvæsenet.* [online] Available at: https://www.sst.dk/da/Udgivelser/2020/Retningslinjer-for-haandtering-af-COVID-19> [Accessed 30 March 2020]. **Sundhedsstyrelsen (SST), 2020d.** *Kontakt Til Egen Læge Under Epidemien Med Coronavirus/ CO-VID-19.* [PDF] Sundhedsstyrelsen. Available at: ">https://www.sst.dk/-/media/Udgivelser/2020/Co-rona/Informationsmateriale_kontakt-til-egen-l%C3%A6ge/SST-Covid-19-La-ege.ashx?la=da&hash=C7CC776F7B02BDEC412E727A2C8F83F3AA8C6915>">https://www.sst.dk/-/media/Udgivelser/2020/Co-rona/Informationsmateriale_kontakt-til-egen-l%C3%A6ge/SST-Covid-19-La-ege.ashx?la=da&hash=C7CC776F7B02BDEC412E727A2C8F83F3AA8C6915>">https://www.sst.dk/-/media/Udgivelser/2020/Co-rona/Informationsmateriale_kontakt-til-egen-l%C3%A6ge/SST-Covid-19-La-ege.ashx?la=da&hash=C7CC776F7B02BDEC412E727A2C8F83F3AA8C6915>">https://www.sst.dk/-/media/Udgivelser/2020/Co-rona/Informationsmateriale_kontakt-til-egen-l%C3%A6ge/SST-Covid-19-La-ege.ashx?la=da&hash=C7CC776F7B02BDEC412E727A2C8F83F3AA8C6915>">https://www.sst.dk/-/media/Udgivelser/2020/Co-rona/Informationsmateriale_kontakt-til-egen-l%C3%A6ge/SST-Covid-19-La-ege.ashx?la=da&hash=C7CC776F7B02BDEC412E727A2C8F83F3AA8C6915>">https://www.sst.dk/-/media/Udgivelser/2020/Co-rona/Informationsmateriale_kontakt-til-egen-l%C3%A6ge/SST-Covid-19-La-ege.ashx?la=da&hash=C7CC776F7B02BDEC412E727A2C8F83F3AA8C6915>">https://www.sst.dk/-/media/Udgivelser/2020/Co-rona/Informationsmateriale_kontakt-til-egen-l%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6gen/L%C3%A6ge/SST-Covid-19-La-egen/L%C3%A6gen/L%C3

Steffensen, J., 2020. *Uni-Studerende Skal Til Digital Eksamen: - Vi Skal Ikke Have En Sekunda-Corona-Årgang.* [online] TV2 Nord. Available at: https://www.tv2nord.dk/coronavirus/uni-studerende-skal-til-digital-eksamen-vi-skal-ikke-have-en-sekunda-corona-aargang [Accessed 14 May 2020].

Szczesniak, R., Heltshe, S., Stanojevic, S. and Mayer-Hamblett, N., 2017. Use of FEV1 in cystic fibrosis epidemiologic studies and clinical trials: A statistical perspective for the clinical researcher. *Journal of Cystic Fibrosis*, 16(3), pp.318-326.

Vagg, T., Tan, Y., Shortt, C., Plant, B. and Tabirca, S., 2018. MHealth and Serious Game Analytics for Cystic Fibrosis Adults. In: IEEE 31st International Symposium on Computer-Based Medical Systems (CBMS). [online] IEEE. Available at: https://doiorg.zorac.aub.aau.dk/10.1109/CBMS.2018.00025 [Accessed 9 Feb. 2020].

Videnscenter for Dataanmeldelser, n.d. *Videnscenter For Dataanmeldelser.* [online] Videnscenter for Dataanmeldelser. Available at: https://www.regionh.dk/til-fagfolk/Forskning-og-innovation/jura-og-data/Videnscenterfordataanmeldelser/Sider/default.aspx [Accessed 31 March 2020].

Weissmann, P., Branch, W., Gracey, C., Haidet, P. and Frankel, R., 2006. Role Modeling Humanistic Behavior: Learning Bedside Manner from the Experts. *Academic Medicine*, 81(7), p.661.

Wentzer, H., 2020. *Videokonsultationer: Genistreg Eller Åbning Af Pandoras Æske?*. [online] VIVE. Available at: https://www.vive.dk/da/udgivelser/videokonsultationer-genistreg-eller-aabning-af-pandoras-aeske-14878/ [Accessed 8 April 2020].

Whatsapp, 2020. *Features.* [online] WhatsApp.com. Available at: <https://www.whatsapp.com/features/?lang=en> [Accessed 9 March 2020].

World Health Organisation (WHO), 2010. *Telemedicine: Opportunities And Developments In Member States.* Global Observatory on eHealth (GOe) Survey. [online] pp.8-82. Available at: https://www.who.int/goe/publications/goe_telemedicine_2010.pdf [Accessed 10 March 2020].

World Health Organisation (WHO), 2020. Draft global strategy on digital health 2020–2024. [online] WHO

Wong, M., Almond, H., Cummings, E., Roehrer, E., Showell, C. and Turner, P., 2015. Patient Centred Systems: Techno-Anthropological reflections on the challenges of 'meaningfully engaging' patients within health informatics research

Wood, J., Mulrennan, S., Hill, K., Cecins, N., Morey, S. and Jenkins, S., 2016. Telehealth clinics increase access to care for adults with cystic fibrosis living in rural and remote Western Australia. Journal of Telemedicine and Telecare, 23(7), pp.673-679.

Wood, J., Jenkins, S., Putrino, D., Mulrennan, S., Morey, S., Cecins, N. and Hill, K., 2017. High usability of a smartphone application for reporting symptoms in adults with cystic fibrosis. Journal of Telemedicine and Telecare, 24(8), pp.547-552.

Zucco, C., Bella, S., Paglia, C., Tabarini, P. and Cannataro, M., 2018. Predicting Abandonment in Telehomecare Programs Using Sentiment Analysis: A System Proposal. In: IEEE International Conference on Bioinformatics and Biomedicine (BIBM). [online] IEEE. Available at: https://doiorg.zorac.aub.aau.dk/10.1109/BIBM.2018.8621481 [Accessed 9 Feb. 2020].

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