# Exploring the Potential for Technology to Improve Cystic Fibrosis Care Provision: Patient and Professional Perspectives

SUNIL RODGER, Open Lab, Newcastle University, UK
KENTON O'HARA, Microsoft Research, Cambridge, UK

Health care systems increasingly promote self-management of chronic conditions outside of traditional clinical environments, often through technologies which help to support patient self-care and engagement with medical professionals. We investigate specialist care provision in cystic fibrosis (CF), a life-shortening genetic condition, to understand the experiences of those living with it and of professionals who provide such care. Our work highlights how the motivations for the use of technology in this context are often intrinsically linked to the nature of CF itself and the constraints that the condition imposes on care provision. These include the high burden associated with self-management and clinic attendance; the ever-present risk of infection and a subsequent decline in health; and patients who are often very well-informed and actively engaged in their care. In exploring enablers and barriers to technology in this context, we highlight the importance of considering its integration into the chronic care cycles, practices, and structures of CF care.

CCS Concepts: • **Human-centered computing~Computer supported cooperative work** • **Social and professional topics~Remote medicine** • **Applied computing~Health informatics**

**KEYWORDS**

Chronic illness; cystic fibrosis; CF; chronic care cycles; collaborative activity system; care organization; self-management; patient empowerment; remote clinic; telemedicine.

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## 1 INTRODUCTION

Cystic fibrosis (CF) is the most common fatal genetic condition amongst northern Europeans, affecting over 10,000 people in the UK. A multi-system condition, patients particularly struggle to clear mucus from the lungs, leading to recurrent infections, progressive lung damage, and reduced life expectancy [15]. Maintaining health in CF requires adherence to a demanding daily regimen of self-care, and regular attendance at specialized outpatient clinics for routine monitoring by multi-disciplinary teams (MDTs). Visits increase in frequency and duration during CF exacerbations, which can lead to in-patient treatment and a long-term decline in health [20].

In recent years, as with other chronic conditions, there has been increased interest in the potential of home-based health monitoring devices and applications to facilitate long term care in CF. These devices range from consumer-based wearable activity monitors to more specialized home-based health monitors, such as spirometers, pulse oximeters, and peak flow meters. Combined together, such devices can capture important longitudinal information, patterns and insights about the patient condition that could inform both CF patients and clinical teams alike. Understanding the particular implications and opportunities for these technologies and the information they provide, requires acknowledging the close partnership between clinical teams and patients in chronic conditions. Chen [12] articulates the notion of a *chronic care cycle* which sets out the important interplay between home and clinic-based care, and the rhythmic nature of its organization. With this in mind, patient health information, wherever it is generated, is not just accumulated over time but rather is "integrated, compared and utilized" across repeated care cycles that comprise chronic disease management.

The significance of these chronic care cycles, though, is broader than considerations about the complementary nature of home and clinic-based information and the ways in which it might be better integrated. Rather, there is a more fundamental mutual interdependence in the ways that home-based and clinical care are structured and organized. Bardram et al [2] emphasize the need to consider these home-based self-monitoring technologies not just as single-user activities in patient self-management, but rather as part of a larger *collaborative activity system* that includes the patient and home setting and the clinician and clinic setting. While their focus was on the impact of home monitoring on the cooperation and organization of labor across a clinic-home activity system in hypertension care, these ideas are more broadly applicable to our thinking about the management of chronic conditions. They apply not just to the evaluation of technologies and their transformative impact on the organization of the activity system. Rather, they can also be a basis for looking at existing activity systems to identify the contextual factors that shape the cooperative organization of labor. This can help assess where there are opportunities for reconfiguring these cooperative systems of care, and where there may be potential barriers. However, it is also important to understand the context of specific chronic conditions, as each has its own particular set of concerns and is associated with a specific care management burden. These shape the distribution of care across patient and clinical teams, and the factors that may affect new or redistributed work arising from the introduction of technology.

In this paper, as part of a larger effort to develop technologies for improved CF care, we present a study of patients and clinical care teams. Our aims are to understand and articulate the lived experiences and cooperative organization of CF care as it is currently structured across clinic and home; the factors which shape current care practices; and the beliefs of patients and health care professionals underpinning these practices. In addition to elucidating these factors, we contribute an understanding of where the assumed benefits of technological deployments may be well-aligned with the redistribution of the cooperative work involved in chronic care provision, and where tensions may exist between these benefits and the additional work imposed in their use.

## 2 RELATED WORK

### 2.1 Technology in chronic health care provision

With increasing pressure on healthcare systems, driven by aging populations and more patients with chronic illnesses, researchers have been increasingly exploring new ways to configure health care outside of traditional clinical settings [46]. This shift is characterized by a move towards

technologically-enabled self-care and disease management at home, posing challenges for the co-ordination and design of health care systems and processes [26]. The active role of patients in their own care relies on information sharing with clinical teams to reach a consensus on treatment decisions, building on notions of shared decision-making [10,23,30] and patient-centered care [3,61] which are particularly important in chronic conditions [4,6]. Previous research has emphasized the importance of self-management and education alongside technological tools in supporting people living with chronic conditions such as asthma [36] and diabetes [24]. It has also documented how new technologies, such as electronic health records, can alter the clinician-patient interaction within clinics [51]. Such challenges are amplified with home-based technologies, which lead to new patterns of communication and divisions of labor between patients and professionals: what Bardram has described as a *collaborative activity system* in chronic health care [2]. These systems and technologies generate data which requires collaborative sense-making and interpretation in order to play a role in clinical practice [1]. Data 'co-interpretation' depends on aligning perspectives between patients, clinical staff, and other caregivers [44]. Information exchange can be compromised as patients and clinicians expect different forms of knowledge, and there is the need to bridge gaps in understanding rather than just share data [27]. These processes of information collection, synthesis and interpretation are particularly important in chronic conditions such as cystic fibrosis (CF), where clinical engagement is intermittent. Chen highlights how medical professionals and patients make sense of and utilize health information within and across temporal *chronic care cycles*, the sequences of routine hospital visits and subsequent periods of home care that define chronic conditions, and call for these to be considered in the design of future technologies [12].

Better understanding of the cycles of chronic illness might be fostered through tools and processes to support collaboration around health information generated by patients during these intervals between clinic visits. For example, collaborative interpretation of patient journals can improve comprehension and mutual trust between clinicians and patients [57]. However, each party has distinct yet overlapping expectations around the role of patient-generated data in the clinic [14]. Chung et al highlight the need to provide patients and health care providers with the ability to reach mutual goals, enable goal-orientated data collection, and tailor visualizations and other interfaces to support collaboration [14]. There are a range of challenges to the sharing and use of patient-generated data, such as that gathered via home-based and wearable technologies, with their successful integration into clinical workflows posing technical, organizational, and social issues [69]. These challenges will only increase with the uptake of technologies such as Apple Watch that increasingly monitor health parameters, and explicitly facilitate discussion of tracked metrics with clinical professionals [70].

Within broader research on personal informatics in HCI [24,40,53], patient-generated health data has been investigated in relation to self-discovery and curiosity amongst people living with chronic conditions [41]. Mamykina's analysis of sense-making practices around such data has identified how it may prompt behavior change in people living with chronic conditions through a cycle of perception, inference, and action [42]. However, the potential value of home-based and wearable technologies in this context is also influenced by how they are utilized within both the hospital and home phases of chronic care cycles, as well as how they affect interactions and care practices between patients and medical teams. Of particular importance in integrating home technologies into everyday chronic care routines are understanding patient motivations for their use [32]. Despite their potential, evidence of the effectiveness of mobile health interventions for chronic disease management is mixed [33]. A 2015 review found that previous studies of these technologies have privileged a medical perspective on chronic illness, overlooking how patients

integrate self-care into their daily lives; it suggested there were opportunities for research to focus on both the everyday life experiences of patients as well as how they collaborated with clinical teams in managing their health [47].

Collectively, this prior work underscores the need to understand not only patient motivations and practices around wearable and home-based technologies in the context of chronic illnesses, but also the perspectives of medical teams who deliver care for these conditions. It also emphasizes the importance of considering how these technologies (and the data they generate) might be integrated into and potentially transform existing structures of care provision in conditions such as CF. It is therefore essential to explore the nature and impact of the condition itself on patients and professionals, and how these factors influence the current organization of care, to understand how technologies may reshape this domain.

### 2.2 CF clinical care structure and technology

CF is the most common fatal genetic condition amongst northern Europeans, occurring in ~1 in 3000 births [50], and affecting over 10,000 people in the UK [21]. It is characterized by an inability to clear sticky mucus from the airways, which harbor chronic bacterial infection leading to bronchiectasis and progressive lung damage [15]. Other symptoms include pancreatic insufficiency, liver disease, and, in some cases, the development of CF-related diabetes. Care in this complex condition needs a holistic approach [37,60] delivered via multi-disciplinary teams (MDTs) at specialized CF centers [16], and supplemented by active self-management. Improvements in treatment have led to significant increases in life expectancy [15] but impose a significant burden of daily self-care on patients [56]. This includes nebulized drugs to suppress chronic infections, enzyme supplements to aid digestion, and specialized physiotherapy or physical activity. Some also manage CF-related diabetes or liver disease, and deal with mental health issues associated with living with a life-limiting condition [52]. People with CF attend clinic for routine follow-up at least every three months even when their health is stable [20]. During an exacerbation they may require more frequent clinic attendance, or an inpatient stay to receive intravenous antibiotics, with associated disruption and impact on their quality of life [8].

As treatment has become more complex, patients struggle with self-management [55]. Adherence is affected by a range of factors [39]: barriers include the burden of treatment, competing demands on their time, forgetfulness, an absence of perceived benefit, fatigue, and stigma; whilst facilitators include clinic attendance, reminders and support, and perceived benefits of treatment [28]. These factors highlight the importance of close collaboration between patients and clinicians in managing CF, combining regular in-clinic follow ups with home-based self-care. In addition, with increased life expectancy and treatment complexity, there has also been increased demand on specialized CF clinics [64], a trend that is anticipated to continue [31]. The physical segregation required to reduce the risk of cross-infection between patients imposes further constraints on the allocation of scarce resources including trained staff, consultation rooms, and equipment, and exacerbates the demand on clinics.

In this context, increasing the proportion of CF care undertaken outside of clinics may offer significant advantages. This would involve finding a sustainable balance between clinic-based care and patient self-management. Remote monitoring of key health metrics could reduce the need for patients whose health is otherwise stable to attend routine in-person clinics. Hospital-based telehealth, where local health professionals monitor patients and access the expertise of a CF center via videoconference, offers one alternative model of care [68]. Within the home,

smartphones can enable self-reporting of symptoms of respiratory exacerbation, to reduce delay to treatment [66,67]. The feasibility of video conferencing alongside remote data collection via 'non-connected' devices has also been explored [65], as have home-based lung function tests supported by regular telephone engagement with the clinical team [59]. These approaches have been shown to support improved adherence to treatment amongst patients [58].

These studies relied on patients manually reporting data from home monitoring devices to the MDT on a regular basis, and/or via occasional in-clinic data downloads. With increased technological capabilities, real-time tracking and data transmission to clinical teams has become feasible. Tracking lung function and self-reported symptoms via an internet-connected spirometer aided reporting of CF exacerbations, though adherence to daily monitoring was low [54]. Games helped to increase adherence to breathing exercises [5,48], including via remotely monitored data [62]. An iPhone tool to enhance CF-related knowledge, treatment adherence, and peer support amongst adolescents was well-accepted and regarded as useful [15], while a pilot study of smartphone-enabled home spirometry and symptom monitoring is ongoing [13].

Yet compared to other chronic conditions, there remains a scarcity of research on remote care technologies in CF and evidence for their efficacy is mixed. Most studies have focused on establishing feasibility, treatment adherence, and health outcomes. A 2012 systemic review found insufficient evidence to assess the benefits of telehealth in CF but concluded that it remained a promising area for future research [18]. Similarly, a review by Curley et al found that although feasible, uptake of telemedicine in CF was challenging due to poor adherence [19]. Despite this, there remains significant optimism around the use of these technologies in CF, due to the perceived benefits for both patients and clinical teams of changing the structure of care [38].

However, the needs and preferences of CF patients and clinical teams in relation to home-based or wearable technologies for this purpose have seldom been investigated. Where it exists, research has sought to understand user preferences for mobile apps to enable self-management. One study found that generic diet- or weight-based apps were badly suited to managing the condition, with patients preferring dedicated CF apps to support multiple aspects of self-management and minimize user burden [35]. Priorities included ease of access to information, automating everyday disease management activities, integrating with smartphone capabilities, improving communication with health care providers, and facilitating socialization with others with CF. Mixed opinions were expressed about gamification, while customization to meet individual preferences and CF management goals was desired.

A European project, MyCyFAPP, is currently trialing a clinic-linked self-management app and educational tools for CF patients to promote good nutrition and enzyme dosage [71]. In addition to noting homogeneity in CF care structure across European countries, it found that existing apps for CF self-management only partially meet user needs [43]. A user-centered development approach identified a range of factors in a health app ecosystem for CF, including a readiness for self-management, the diversity of user requirements (requiring personalization options), and the need for communication between patients and health care providers [27]. An investigation of gamification found that patients felt social interaction, empowerment, and progression through goals was important, alongside customization and adaptability to individual contexts [34]. Finally, co-design of concepts and user interface features emphasized the importance of setting clear expectations about data shared between patients and clinical teams [63]. Although full self-management of CF is not realistic [27], there is a need for tools to support both the remote care and self-management aspects of the condition. [43]. Yet there is currently little understanding of how patients and clinical teams conceptualize home-based and wearable technologies in the

context of the chronic care cycles involved in CF, nor of how these actors envisage such technologies restructuring care provision for CF in the future.

Due to the nature of CF – a chronic illness characterized by complex self-management and regular interaction with MDTs in specialized clinics – it offers a compelling context in which to investigate how home-based and wearable technologies might support cooperation and potentially redistribute care work between clinical teams and patients. Work to date has not investigated patient and clinical perspectives of how technology could support these processes. Understanding these perceptions in the context of the current structure of care provision also enables a consideration of how these technologies might be integrated into everyday life and how they may affect clinical practice and the delivery of care. This study therefore investigates how those living with CF, and the clinical teams who support them, envisage how technology might assist in managing the condition and transforming clinical interactions and wider care practices.

## 3 METHODS

### 3.1 Overview and data collection

Given our aim of understanding experiences of cystic fibrosis (CF) care from both patient and professional perspectives, as well as how technologies might change the structure of this care, we adopted a grounded theory approach to our research. Grounded theory is an inductive research method in which theoretical concepts are derived from the data through an ongoing, iterative process of data collection and analysis [11,17,29]. It provides a structured process of analysis that has been widely used in qualitative healthcare research as a way of understanding lived experiences [9]. It has also been increasingly applied in HCI and CSCW contexts, where it has particular value in guiding exploratory research such as this study [45]. We followed a constructivist approach to grounded theory outlined by Charmaz [11], which acknowledges the subjectivity associated with such an analysis and disavows universality of theories generated. It also concedes that total naivety to the research area is not only unrealistic but can be counterproductive [45:33].

Within an existing National Health Service (NHS) Quality Improvement programme, we conducted a qualitative contextual study at a specialist CF center in a UK hospital. This comprised five days of clinic observations, and semi-structured interviews with 8 patients (Table 1) and 10 multi-disciplinary team (MDT) members (Table 2). We structured our fieldwork to permit the concurrent, interrelated process of data collection and analysis necessary for grounded theory.

Initially, we undertook three days of observations in the CF clinic. We observed 10 consultations between different members of the multi-disciplinary care team and CF patients. During these sessions we observed the specifics of the interactions between the MDT and the patient, including the clinical tests which were performed, and the ways in which aspects of the patient's condition and self-management practices were presented, elicited, and understood. As patients accounted for their behaviors during these conversations, we were able to glean insights into their everyday experiences and challenges. In addition to the clinical consultations themselves, we were able to observe patient journeys through the clinic, including the practical ways in which these visits were organized and the social, spatial and technical factors which underpinned this organization. Between clinical observations we spent time in the MDT office, and were able to observe the 'backstage' aspects of clinic organization. In situ conversations with the MDT throughout the observation days provided additional explanation and detail to the behaviors we observed. The observations and in situ conversations were documented with hand-

written field notes, which provided sensitizing concepts [7] that guided our ongoing analysis, subsequent observations, and interviews.

As well as clinic observations, we conducted 18 interviews, which were audio recorded for transcription. Interviews lasted between 43 and 102 minutes (median 59). Open-ended questions were asked encompassing the following broad topics: their overall experience of living with CF (or providing care) and how it affected their everyday life; their experience of clinics and exacerbations; their thoughts on technology and how it might be used to change CF care; and their feelings about the data which such technologies might generate and how they would engage with it. The interviews provided an insight into how patients and care providers perceived their respective experiences and interactions, often clarifying, explaining, challenging, or contributing further nuance to things we had observed in clinic. Participants were given a £20 Amazon voucher on completion of the interview in compensation for their time. Interviews were informed by the observations and informal conversations with members of the MDT. The mean age of patients was 37.5 years (19-52), and of the MDT 40.3 years (24-54).

Table 1. Participant information (patients)

| ID | Occupation | Demographic | Telecare experience | Fitness Tracker Use |
|---|---|---|---|---|
| PAT1 | Housewife | Female, 30s | Yes | Yes |
| PAT2 | Office worker | Female, 40s | Yes | Yes |
| PAT3 | Retired office worker | Male, 50s | Yes | Yes |
| PAT4 | Office worker | Female, 50s | No | Yes |
| PAT5 | Office worker | Female, 20s | No | No [a] |
| PAT6 | Retired office worker | Male, 40s | Yes | No |
| PAT7 | Office worker | Male, 20s | No | Yes [b] |
| PAT8 | Apprentice | Male, < 20 | No | No |

[a] PAT5 said they could not afford a tracker, but wanted to use one

[b] PAT7 used the step counter on their phone, not a dedicated device

Table 2. Participant information (multi-disciplinary team)

| ID | Role | Gender |
|---|---|---|
| MDT1 | MDT member [a] | Female |
| MDT2 | MDT member [a] | Female |
| MDT3 | Clinician | Male |
| MDT4 | CF Specialist Nurse | Female |
| MDT5 | MDT member [a] | Female |
| MDT6 | CF Specialist Nurse | Female |
| MDT7 | Clinician | Male |
| MDT8 | MDT member [a] | Female |
| MDT9 | Clinician | Male |
| MDT10 | CF Specialist Nurse | Female |

[a] Our participants included one interviewee for each of several roles in the MDT (physiotherapist, dietician, staff nurse, and administrator). As part of the anonymization process, we have not identified these respondents individually by role.

### 3.2 Analysis

Data collection and analysis were conducted concurrently, with insights derived using a constant comparative process [11,17]. The lead author first conducted open coding of the

interview transcripts at a line-by-line level, labelling key concepts that had been discussed by participants with code-words. Tentative emergent themes were then identified through clustering related codes. Following Charmaz [11], we used a 'loose' axial coding approach to understanding the relationships between different codes and themes, and verified these through discussion within the research team. Memos were used throughout this process to aid our thinking about these codes and relationships.

This coding and analysis process was initially undertaken after the first three interviews had been conducted. The concepts and themes which emerged informed the focus of subsequent rounds of interviews and data analysis. At each stage, new codes and themes were integrated into the emerging analysis. Further interviews were conducted using a theoretical sampling approach, until data saturation was reached with no new codes or themes generated after three consecutive interviews. This iterative process resulted in three overarching themes: accommodating CF in everyday life; the challenges associated with CF clinics; and perceiving value in technology for CF care. These are discussed in further detail in the following sections.

## 4 RESULTS

### 4.1 Accommodating CF in everyday life

A central theme in our data, mentioned by all participants, concerns the impact of cystic fibrosis (CF) and how those with the condition negotiate its presence in their everyday lives. They explained the effort of self-management, the ways in which they used routines and technology in managing the condition, and the importance of not letting CF dominate their life. We explore each of these in turn below.

*4.1.1 Time and effort required for CF self-management.* When asked about the impact of having CF, patients emphasized the significant time and effort associated with managing the condition. They drew attention to how their treatments impacted on their everyday lives. Although treatment is individualized, PAT3's description of their daily routine gives an indication of a typical level of self-care amongst adults with CF:

> "I wake up at about six o'clock and spend the next hour, hour and a half doing puffers [nebulised drugs] and stuff, and then in the evening, the same again… I take two tablets twice a day, once first thing in the morning and once last thing at night … a tablet first thing in the morning for my hay fever… [and enzymes] with my meals… three times a day plus snacks, and that can vary between four and six or seven per meal depending on what the meal is… two different vitamins which is two tablets once a day" (PAT3).

Another explained how in addition to their medication and treatments, they tried *"to attend the gym five times a week as a form of exercise"* because they found specialized CF physiotherapy unhelpful in clearing their lungs of mucus (PAT5). Making time for such management practices was difficult for those in employment, particularly when the progressive nature of CF led to an increasing treatment burden as they got older:

> "I would get up at six o'clock in the morning, I would do two different nebulisers, then I would do physio, then I would do my next nebuliser and get myself sorted before going to work and doing an eight-hour day… [then] the same regime again in the evening. And

> gradually CF was taking more and more of a burden on me and I was finding that I was needing to do stuff in the afternoons as well" (PAT6).

The demanding nature of self-care work undertaken by CF patients meant that they often found it challenging to adhere to all the treatment recommendations made by the multi-disciplinary team (MDT). Creating consistent routines was acknowledged as being a useful way for patients to improve adherence, but this was not something that was always possible. For example, one patient explained how their job involved an unpredictable travel schedule. This created an irregular routine that made managing their CF challenging:

> "balancing the medication with a normal routine, especially with my occupation, I don't always have set times that I need to be in certain places, sometimes I stay away, sometimes I fly abroad, and so balancing the amount of medication I have to take with that kind of non-routine… can be quite difficult" (PAT7).

Similarly, another patient explained how her role as a working mother posed challenges in terms of 'juggling' her employment, childcare, and the additional work imposed by the demands of CF self-care. This was difficult because her days were never the same, and the performance of her care was something that she contingently managed and reprioritized in relation to other demands imposed by her myriad responsibilities. The extent to which patients are prepared to deprioritize their care work in the context of competing demands was well illustrated by the fact that she had experienced a significant health decline and needed to receive intravenous antibiotics, yet had postponed an appointment to visit the clinic to receive them because her child was at home on half-term school holiday. In postponing her appointment to look after her child, she presented a significant risk to her own health.

Clinical professionals recognized the existing burden of self-care on patients and their need to accommodate managing CF in their everyday lives. One MDT member likened what they were asking patients to do to "*having an extra part-time job on top of your job… it's a lot for them to do every day*" (MDT6). As such, clinical professionals accepted that patients balanced treatment adherence with other commitments and therefore found ways of adapting to the needs of individual patients, endeavoring to ensure good adherence while being realistic about people's priorities and capabilities. This required a flexible approach and also a personalized approach given significant diversity between individuals.

> "[some are] very, very adherent and will do absolutely everything… [others] will do absolutely nothing that we suggest… It is a real mixed bag" (MDT8).

Rather than considering solely what might be medically 'best' for a patient, one team member described how they often had to do *"a bit of negotiating and compromising and coming up with some sort of agreement that they're happy with"* (MDT5). This was aided by the trusting relationship that they built up with the patients over many years of regular clinic attendance, which was evident in the clinical interactions we observed. MDT members highlighted this relationship as being particularly important in understanding what made 'people tick'. Developing this trust and personal knowledge of the patient over time through the regular face-to face attendance in clinic is thus an important consideration in understanding and reconfiguration of care away from the clinic to more home-based solutions. They accepted, however, that the burden of care meant that some patients did not adhere well to their recommended treatments.

*4.1.2 Technology use in managing CF.* Recognition of these existing burdens of CF care work and challenges to adherence are an important consideration for how we think about any restructuring of the cooperative care process with home monitoring technology. Further insights into these concerns were observed in the ways that patients currently adopted existing forms of monitoring and app support into their CF self-care practices.

As well as the challenges of competing demands on adherence to care work, there are also cognitive challenges of remembering to perform these activities especially where these may be new, infrequent or irregular. Several patients were seen to use general purpose mobile phone reminders, especially for tasks which were new and/or irregular:

> "I used to take one [drug]… to harden my bones because of the osteoporosis that was to take once a week. How can you remember to take something once a week? So [that was] a calendar reminder, just because otherwise I'd never have taken it… [it's] trying to fit that into your schedule… the irregular stuff or the new stuff that you've just got that you haven't had to take before" (PAT3).

This illustrates one way in which patients used technology to better accommodate CF into their daily lives by reducing the burden associated with specific aspects of care. Another example was the use of body-worn glucose monitors by a number of patients to help manage their CF-related diabetes. These monitors simplified the collection of necessary care data and minimized the need for painful 'finger prick' testing [72]. As such these devices helped them integrate care into their routine. Another patient explained how their burden of logging of nutrition information to help them manage CF had been reduced by shifting from manual spreadsheet recording to more simplified scanning of food packets in the MyFitnessPal app. The primary purpose of this logging was to enable them to more accurately recount their diet when asked about it in clinic.

Some patients would use technology to record health data about their condition. Where this was for personal reflection, we saw some minimal manual logging activity. For example, one patient described how they used the Health app on their iPhone to manually record their lung function and weight that were taken at every clinic visit. They were not doing such logging on a daily basis. They described a process of reflecting on their health and its change over time. This change was used for motivational purposes and represented their ongoing desire to 'beat' CF:

> "You've got a little graph that you can follow… [my motivation was] to see the figures and know that I wasn't deteriorating… I was always told when I was little 'you won't make your teens', when I was in my teens 'you won't make your twenties'… I think in my head it's like, 'I need to beat it'" (PAT1).

While manual data logging was used in these circumstances, this was relatively infrequent and thus posed limited burden to the patient relative to its value. Other examples of technology based behavior and health logging by patients involved more passive forms of logging that were not demanding of patient engagement to collect the data. Four of the eight patients used some form of wearable activity tracker, while a fifth used their phone's built-in step counter. This allowed the patients to render their activity visible and reflect on their level of (in)activity. For CF patients, exercise is part of an important daily routine, contributing to a reduction in lung function decline, helping clear mucus build up in the lungs and facilitating better breathing. Exercise and activity can sometimes help compensate for physiotherapy exercises that would otherwise need to make up the care routine. By rendering these things visible, patients were more aware of their activity and able to better incorporate exercise and activity as part of normal everyday behavior.

As one explained, *"a lot of times we think we do more than we actually do… we don't realise how much time we sit on our bum in a day"* (PAT2). Some described using wearable trackers to set fitness goals, such as keeping their heart rate *"within a certain bracket, because then I know that I'm exercising"* (PAT1). Others valued how devices prompted them to take specific actions, with one describing how their FitBit:

> "says 'Oi, you ain't done any steps for the last hour, go and do 250 steps. You've only done two sets of stairs today'. So, I have been known just to… go up and down the stairs to get me stairs count for the day" (PAT3).

He denied the value of these prompts for *"anything like telling me to do exercise… I'm not using this to get me into being some sort of sporty Lycra-clad idiot"* (PAT3).

The significance of these particular forms of tracking technology lies partly in their ability to passively collect data without imposing additional burden on patients who are already managing significant burdens associated with the condition itself. This is a key consideration in any reimagining of the distribution of care work. Furthermore, it points to the importance of openness and adaptability in enabling care work to fit into individual patients' lives. Clinical professionals described how these fitness trackers enabled them to engage with patients in clinic through personalized exercise goals, grounded in a realistic appraisal of what might be feasible in patients' everyday lives. It allowed them to, for example:

> "start talking to [the patient] about 'Why don't you have a target instead of only doing 1,000 steps a day, why don't we see if we can build it up and have you doing 2,000 steps a day or more?'" (MDT5).

Activity tracking allowed for a large degree of flexibility and 'openness' in setting such goals collaboratively. One clinical professional explained how some patients preferred exercise to specialized physiotherapy, and suggested that fitness trackers were a useful tool to make health maintenance activity more meaningful for these patients. Another thought it was positive that some patients chose to initiate activity tracking themselves and brought the data to clinic, as it demonstrated engagement in managing their health. However, they admitted to being unsure how best to interpret such data clinically, echoing prior work on the need to bridge gaps in understanding such data between patients and clinical teams. These factors point to how this data is primarily of use to the patient, rather than to the clinical team. The collection of clinically meaningful data, that would better fit into ongoing work practices and chronic care cycles, would require further input and definition from the clinical team.

*4.1.3 Not letting CF dominate one's life.* Despite the considerable impact of CF on their everyday lives, interviewees were clear that they did not wish to be defined by the condition. Several described not disclosing that they had CF to other people, which has parallels in previous research by O'Kane which has noted the selective concealment of medical devices amongst those living with chronic health conditions as part of their self-presentation [49]. In part, this was related to our participants wishing to avoid disruption to their personal or work lives. However, for some patients, this non-disclosure extended to close friends, and in some cases aspects of the day-to-day management of CF were concealed even from partners:

> "[CF is] almost like… a different side of me that I like to bury away… When we're at home, we don't really talk about my condition that much, I don't talk about it at work … it's almost like a different person in a way… when I come to clinic it's just something that

> I like to get out of the way as quickly as possible and then return back to just being me again" (PAT7).

This issue was recognized by members of the MDT, with one noting that some patients *"essentially don't have CF when they're outside the hospital. They just don't want to engage, they don't want to think about it"* (MDT1). In turn, this could reduce adherence to treatment recommendations, and negatively impact their long-term health. Several interviewees said that they did not engage with online sources of peer support provided by charities, such as web forums. They characterized these disease-specific resources as unhelpful or negative, in contrast to more positive ways of interacting with other 'CFers' online:

> '[a CF forum] was the most depressing place in the world where everyone went to die, and that isn't the case anymore. People with CF can live long lives, and I think inspiring those people using Instagram… [it] is such a brilliant way for us now to be able to communicate" (PAT5).

Yet patients recognized the notion of being inspired by the achievements of others with CF as complex, for it carried an implicit comparison between themselves and others living with the condition. Given the variability of CF symptoms, not everyone felt comfortable doing this. One person described meeting someone whose young relative had CF:

> "I could tell when he started talking that she is really not a very well [child]… and she is really struggling… it is hard, I don't know if you should compare yourself to different people" (PAT4).

In spite of these efforts not to let CF dominate their lives, many patients described how the significant effort involved in self-management meant that it was a constant presence. One patient explained they were *"pretty much continually thinking about CF on a constant basis"* (PAT6). This was reinforced, as members of the MDT acknowledged, by the regular hospital visits associated with best-practice care for CF which constituted a form of 'institutionalization':

> "you are in out of that hospital as a paediatric patient for sixteen odd years and then as an adult almost lifelong. That can just be something that weighs down on patients, spending weeks and weeks in hospitals each year. Most… have to be reviewed at least every three months… it is a huge time commitment" (MDT9).

Of significance here is that care activities create a continued presence of CF in patients' lives. Any additional engagement burdens created through new forms of self-care activity come with the potential to add to this presence of the disease. Active monitoring may create engagement that contributes to the perceived presence of CF, and so may be a barrier unless it is offset through benefits elsewhere. Passive monitoring offers additional benefits here by avoiding engagement and allowing the disease to more easily 'disappear'. Of further interest are the ways in which clinic visits can add to the ever-present nature of the disease and potentially come to dominate the identity of the person as a CF patient. In this regard, understanding the ways in which patient work might offset the work associated with regular clinic visits may be of value in reducing the overall dominance of CF in people's lives. We turn now to consider this in further detail.

### 4.2 Challenges associated with CF clinics

*4.2.1 Burden of clinic attendance.* Even patients whose health is stable attend CF clinics at least every three months for routine monitoring by the MDT. We observed how they are segregated on

arrival at clinic, allocated a consultation room, and then visited by each member of the MDT in turn. Each health care professional recorded clinical data on a centralized electronic medical record system. This information was synthesized by the clinician, who was ordinarily the final team member to visit each patient and who co-ordinates their treatment.

With high clinic demand, and the unpredictable duration of each interaction, we saw how patients often had to wait to be seen by specific members of the MDT. One explained that

> "a lot of times you just sit there and it takes about three, four hours to see four people or something… you're in a room by yourself… [and] you get a bit bored" (PAT2).

The delay in being seen is additional to the travel time to get to the CF clinic, which can be substantial as they are typically regional specialized centers. The MDT acknowledged how the regular clinics associated with CF disrupted family life:

> "[it] is time off work for the parents, it is time away from school for the kids or… time away from university or… employment… it affects everyone within the family" (MDT7).

This burden is magnified if patients experience an exacerbation or infection. These can lead to an inpatient hospital stay of two weeks or more, to receive intravenous antibiotics and intensive monitoring. Even patients trained to self-administer these drugs at home must visit the clinic several times during an intravenous medication cycle to monitor their progress, as well as attend to the different dosage schedules of each medication:

> "one of the antibiotics you have to take every eight hours intravenously… you have to make up the medication then drip it through, so that's three times a day… the other antibiotic you take every 12 hours… [it] is quite time consuming" (PAT4).

Inpatient stays could also be part of a prolonged period of ill health, which could severely disrupt careers or education. One person described how they

> "would be in for two, three weeks, [then] home for say a month, a month and a half, and back in again… one year I spent a third of the year in hospital" (PAT1).

Finally, and understandably, patients generally did not enjoy attending hospital despite acknowledging its necessity. In addition to the inconvenience discussed above, hospitals sometimes held negative memories and associations. For some older patients, who remembered clinics pre-segregation, there was a sense of loss of community. Some patients also described experiences of losing friends or family members to CF, and as one of these people explained,

> "I've never been one for coming to hospital. I don't particularly like hospitals to be quite honest. They're not a great place to be, are they?" (PAT3).

For some people, their dislike of hospitals manifested in avoidance of the CF clinic, which in turn risked their long-term health.

*4.2.2 Risks of cross-infection.* A specific concern for CF patients is the risk of picking up an infection which can pose a serious risk to their health. Many patients' lungs are colonized by particular bacteria, and to prevent cross-infection it is important to avoid direct contact with other patients whose lungs may harbor different bacterial flora. Attending hospital can present a cross-infection risk, and as such there is an incentive to reduce these visits. This concern also has a significant impact on the organization of care, with efforts to reduce risk meaning that completely separate clinics are run for those with different 'bugs'. For example, we observed how those with

*Pseudomonas aeruginosa* attend clinic on a different day to those with *Burkholderia cepacia*. These necessary precautions can pose challenges to appointment scheduling and resource allocation.

Both patients and professionals discussed the risk of cross-infection. Although it was not the primary concern of patients, it did weigh on their minds as one explained:

> "[it is] a big thing. There are going to be other people here with other infections that you can catch. I know you can catch them anywhere, but if you can keep away from the chances of catching other things, that has got to be a good thing… this hospital is brilliant… they've got a very good hygiene level. But there's still that chance" (PAT1).

The MDT acknowledged that cross-infection was always a possibility, despite the rigorous infection control precautions we saw and were subject to in our observations of clinics. These included frequent sanitization and cleaning protocols, physically segregated clinics to ensure patients infected by different bacteria did not attend the same clinic session, and the isolation of patients from each other within the same clinic session. However, as one team member noted,

> "at the end of the day we're a hospital… we can do as much cleaning and cross-infection precautions as we like but there is still no 100% guarantee that there's no bugs" (MDT4).

In light of new disease-modifying drugs that are becoming available for CF, one clinician explained how cross-infection was a particular concern:

> "[it] is actually one of the biggest risks to patients because… they should come through from pediatrics in the future with clean lungs and if they then inherit a 45 year old bug that's had… a hundred courses of intravenous antibiotics and developed… resistance over years then that's just a disaster" (MDT7).

The risk of cross-infection also had a significant knock-on effect in terms of reducing the capacity of the clinic: the MDT could not schedule appointments for those with different bugs in the same clinic, nor could it substitute someone as easily if there was a late-notice cancellation. In addition, the need to thoroughly disinfect consulting rooms between each patient could compound the delays in clinics which have already been discussed. As such, one can see that there are clinical incentives to identify possible ways to reduce unnecessary hospital visits which are putting all patients at risk and creating a challenging operational burden on a system. Likewise, for individual patients, there are considerable incentives to reduce risks associated with hospital visits by minimizing unnecessary consultations. This points to a shared set of concerns around which care work redistribution could be reconfigured through remote monitoring and telecare.

*4.2.3 Context and trust in 'snapshot' clinical interaction.* One of the well-established concerns for clinicians in chronic care is that they typically only have an intermittent picture of patients' health and overall wellbeing. Clinicians in the MDT, in particular, explained how they did not always have a good handle on how patients were coping in their everyday lives, or of the wider factors which might be affecting particular patients. This was in part due to the nature of the clinical consultation. One respiratory physician explained how they would typically *"see people for a brief window of 15 or 20 minutes… and for the most part, you get a snapshot of how they've been"* (MDT3). These challenges have often been the basis for arguments justifying provision of more frequent longitudinal data through appropriate and clinically driven everyday health monitoring. While there may be certain merit in these arguments, there is a different point to be made here about the importance of developing a trusted relationship with the patients that enables the elicitation of important health and well-being information. One of the key challenges faced by

clinicians in the MDT as a consequence of minimized interaction with the patient was not the limited time to elicit information, but rather the limited opportunity to build trust with the patient that would encourage personal information disclosure. They felt that this could sometimes compromise the quality of their interaction with patients, who might be less forthcoming in discussing their condition if they felt they were letting someone down:

> "if you come to somebody who has expectations of you and if you haven't been meeting those expectations, you may or may not tell the full truth… what I can see on paper suggests to me that maybe somebody hasn't been doing their treatment, but they're telling me they have" (MDT3).

Of significance to our concerns here is that these deeper trust relationships with patients were distributed across the MDT as a whole, and that this becomes an important consideration in assessing opportunities for care work redistribution. Many team members we interviewed explained how it was the CF Specialist Nurses and other non-physicians who often knew the patients best, in part by having the opportunity to spend longer periods of time with them in clinic. Patients sometimes relied on these other members of the MDT as a *"psychological crutch… it will depend on whichever team member they trust"* (MDT1), sometimes disclosing things that were relevant to their care provision to other members of the MDT. The Specialist Nurse team, who were available for telephone consultation by patients, described how in light of these trusted relationships, most patients would proactively contact them if they had concerns or questions about their health. These other professionals therefore developed a good understanding of the contextual factors in patients' lives which in turn might affect their health, their adherence to treatment, or even their attendance at clinic. The collaborative nature of the work of the MDT, and the importance of being able to provide holistic care, was emphasized by all professionals interviewed. Understanding the impact of any care work redistribution, such as through remote monitoring and telecare, would need to give careful consideration to how such trusted relationships might be supported.

### 4.3 Perceiving value in technology for CF care

Both patients and clinical professionals felt that wearable and home-based technologies could fundamentally change the nature of CF care. They described this positively, framing perceived benefits in relation to the challenges mentioned above. They emphasized how remote monitoring might improve the timeliness and reduce the burden of CF care, by supporting interactions between patients and MDTs during the home phase of the chronic care cycle.

*4.3.1 Remote monitoring to improve the timeliness and reduce the burden of CF care.* Members of the MDT, explaining the cadence of regular CF clinics, highlighted the importance of early identification and treatment of a decline in a patient's health. One clinician anecdotally said that eight out of ten patients in a typical clinic were stable and well, but two should have attended hospital sooner for treatment. As such, clinicians perceived significant value in technology to remotely monitor core health metrics, such as measures of lung capacity, weight, and BMI, and allow early identification of those becoming unwell. These data could be collected via digitally enabled versions of existing clinical tools such as home spirometers and oxygen saturation meters, as well as through wearable technologies such as fitness trackers. Clinicians also expressed value in knowing the patient's CRP (a blood marker for infection), as well as how much sputum they

were producing and its consistency and color, though they acknowledged that collecting these data remotely would be more challenging and burdensome.

Clinicians explained how home monitoring through technologies like home spirometry and wearable technologies might enable both patients and the MDT to overcome the 'snapshot' phenomenon described above:

> "[Home-based self-care is] hugely, hugely valuable. I think it's the way forward for any chronic condition… on both sides of the doctor/patient divide there's probably a snapshot phenomenon that would really benefit from having… a look at what has been going on over the last week or the last month… The ability to step back, to take your head a little bit of out the fast lane I think would be really useful for patients, and obviously for us" (MDT3).

The benefit of these technologies was not simply that they enabled more frequent measurements than 'snapshot' clinics, but also that they might support patients in reflecting on their own health. One clinician noted that CF patients are sometimes desensitized to their symptoms, and don't always seek medical advice early enough. Technology could therefore:

> "[give patients] an ability to think about it more often… triggers a kind of symptom check to say 'Today, how am I compared to yesterday or last week?' and… review that data" (MDT3).

Clinical professionals suggested that most patients would respond to a decline in their health by getting in touch with the MDT for advice. However, they also sounded a note of caution, explaining how some might ignore data that suggested a deterioration, or even obsess over the data. They explained how in clinics, for example, they had to prevent some patients from repeating lung function tests to achieve a 'better' value. Clinical professionals thus explained how any use of these technologies must consider the individual responses of patients:

> "[some] can be quite anxious as it is… it would be quite difficult to help them to find [home monitoring] more empowering, because for a lot of the time they might feel quite overwhelmed anyway or quite anxious anyway… people are quite predisposed to one way or the other. People tend to be either quite keen to take control of their own care or they tend to be not so keen" (MDT8).

As already noted, clinical professionals expressed an acute awareness of the burden that clinics impose on patients. As such, they saw great potential for remote monitoring to reduce the frequency of in-person clinic attendance for stable patients. Their ideas about how this might reorganize CF care are discussed in more detail in the following section. However, their enthusiasm for such home-based or wearable monitoring technologies was tempered by their desire that these should not simply shift this 'clinical' burden onto patients in their own homes:

> "the point of the home monitoring is to improve patients' time commitments, isn't it? So you do not want them getting up and doing a million things based on a home monitoring system. You want them to live a normal life. That is kind of the main goal here, is to minimise their time in hospital, is to minimise their treatment needs so that they can live a relatively normal life" (MDT9).

Clinical professionals also acknowledged that some types of home-based monitoring would be more burdensome on patients than others, either due to the nature of the measure, or because the

frequency of data collection would not be practical. Individual health status and everyday commitments also came into this equation, as one clinician explained:

> "it would be very difficult to sell doing lung function, a blood test, a sputum weight and filling in the symptom score every day for someone… [who is busy and] who has not had an infection for 10 years but… much, much easier to sell that to somebody who has more time, who has much more to gain from it" (MDT3)

Patients were enthusiastic about the possibility of novel technologies that had potential to reduce the number of visits to the clinic and the time they spent in hospital, provided that it did not compromise the quality of care they received. They articulated this idea unprompted, noting that it would alter aspects of care provision and their interactions with the MDT. In this context, patients were positive about the potential role that wearable and home-based monitoring could play in future CF care, and there was no resistance to sharing such data with the clinic. Indeed, patients assumed that technologically-enabled home care would be well-integrated with wider clinical care provision, and took comfort in the idea that their health could be remotely monitored by their MDT:

> "As long as you know that you're still be[ing] monitored… and you can see that you're not deteriorating from doing it, that's got to be a bonus, hasn't it?" (PAT1).

Here, the patient is orienting to the notion of home monitoring as form of remote care rather than simply monitoring for self-management. That is, these technologies are assumed to be extending a watchful clinical eye over the patient rather than handing off care to the patient.

*4.3.2 Changing the nature of the clinical encounter.* In our discussions with participants, they expressed a variety of ideas about how wearable and home-based technologies might be integrated into future care provision for CF. These ideas fell into three core categories in terms of the ways that they envisioned a restructuring of the cooperative care activity system: (1) data augmentation of existing clinics, (2) remote triage, and (3) remote clinics.

In the data augmentation model, there is little change seen in the overall structuring of the chronic care cycle. Rather, the emphasis in these ideas was improving clinical decision making through the integration of high frequency longitudinal data collected through wearable or home-based monitoring. This would enable the MDT to build up a more holistic picture of a patient's health and avoid the 'snapshot' phenomenon already discussed. It might also permit the patient and/or the MDT to initiate an appointment sooner than the regular follow up schedule should the data suggest this was necessary, in much the same way as at present a patient who felt unwell would ring up to arrange an appointment.

A second possibility was a 'triage' based system: a video call scheduled with a CF Specialist Nurse prior to routine clinical appointments, augmented by remotely captured data, to determine whether they needed to come in at all for follow up or whether this could be safely postponed.

Finally, these technologies open up the possibility for fully remote clinics, in which patients who are stable could have routine appointments with the MDT entirely via video calls and remotely captured data. This could also enable clinics to be split so patients could arrange separate appointments with different members of the MDT. Both 'triage' and 'remote clinics' could increase operational flexibility, enabling more effective use of limited clinical resources.

It is worth emphasizing that none of the alternative models of CF care provision suggested by participants involve automated diagnosis or decision-making. Instead, the two novel forms of clinic discussed above involve using remote technologies to support the MDT in determining

whether someone is well enough to stay at home. As such, the ensemble of tools provides an evidence base that the clinical professional, through an initial consultation with the patient, can come to a judgement about the necessity of an in-person clinic visit. Given the close relationship between the MDT and their patients, and the knowledge that the team has built up about individuals, they would be able to make an informed decision about whether data is a reliable indicator of their health.

Regardless of the precise model of future care, certain concerns and priorities emerged amongst the MDT. As well as considering how technologies might increase the burden on CF patients at home, professionals were also conscious of how they might affect clinical consultation. Clinicians, responsible for care co-ordination, already synthesize and act upon a variety of data collected by the MDT during clinics. They thus expressed concern that novel technologies might contribute to 'data overload', and emphasized the importance of summaries to make this data useful within the clinic:

> "You are not going to want to sit there and go through three months of daily data … however the monitoring systems decide to go moving forward, summary data is going to be key" (MDT9).

Members of the MDT also explained how data gathered by monitoring technologies would sit alongside the 'subjective' conversations they had with patients in clinic. Despite valuing 'objective' data such as lung function scores obtained by validated clinical instruments, professionals also discussed how the information that they gleaned from patients within clinical encounters were significant in informing their practice.

Professionals highlighted that different types of clinical consultation would be more or less suited to remote clinics. It was considered particularly important, for example, that the comprehensive annual clinical reviews and follow-up appointments to discuss results with patients took place face-to-face. This was not only because certain types of monitoring such as blood tests or scans could only be done in person, but also because these consultations set up the collaborative healthcare plan between the patient and the MDT for the next year. By contrast, regular follow-up clinics were viewed as being more amenable to a remote clinic.

Some clinical professionals also discussed how CF clinics were under considerable resource pressure. With improved care, the number of adults living with CF in the UK is growing by the equivalent of a clinic every year, and the current structure of care is thus increasingly unsustainable. We observed the significant efforts made by the clinical team to ensure that their scarce resources were used most effectively, which could be challenging given the need for appropriate segregation. There was the perception that remote monitoring of CF patients would help to minimize the burden on clinics. For example, one health care professional explained how a remote clinic could enable more flexibility, because unlike in-person clinic slots, there would be no need to physically segregate those patients who were 'attending' virtual appointments.

However, while a remote appointment might be appropriate for a stable patient, someone experiencing a decline would inevitably need to attend clinic in person:

> "if someone is unwell then they need to be clinically seen… They need proper blood tests, they need their sputum analysed and they need treatment" (MDT9).

It was very apparent that members of the MDT did not believe that technology would obviate the need for attending clinics entirely, particularly for those who were unwell. For all the positive benefits they envisaged for remote clinics, they were explicit that they were not appropriate for every patient, nor in all clinical contexts.

## 5 Discussion

In this paper we have presented a study looking at the care system of cystic fibrosis (CF) and the ways it is distributed across patients and health care professionals working in a hospital-based multi-disciplinary team (MDT). We have highlighted how current care practices are both organized around and constrained by the nature of CF itself, most notably its progressive, multi-systemic nature, which necessitates regular clinic attendance alongside self-care at home. As such, the structure of care provision in CF conforms to the cyclical *chronic care cycles* of home- and clinic-based care described by Chen [12]. This concept is valuable in understanding how CF patients actively engage with and manage personal health information, often through technologies such as smartphone-based applications, and in making sense of this information through temporal comparisons such as 'how they felt during last week' or 'at this time last year'. These cycles also shaped patients' engagement with the MDT, in doing so helping to define the co-ordination and balance of CF care between the clinic and the home.

In CF, as with other chronic conditions, there is also an interest in understanding how personal monitoring technologies and applications might facilitate key aspects of this cycle to achieve better health outcomes. Such technologies could adopt many forms, from supporting patient self-management to enabling better remote monitoring by a clinician, and many configurations in between. Yet care provision in CF, shared as it is between patients at home and the MDT in the clinic, constitutes a form of what Bardram has described as a *collaborative activity system* [2]. The introduction of new technologies into this activity system will inevitably reconfigure it and redistribute cooperative care work between the clinical team and patient. Any shifts in the burden of care must be aligned with the perceived locus of values and outcomes realized for each actor in the system. While this is a general concern in chronic care management, there are specific and unique elements to different conditions that affect the ways that the care system is configured, and the burden-value dynamic entailed by any reconfiguration. In this regard, our concerns in this paper were with the specific circumstances of CF care management. Our aims were to understand current practices of patients and health care professionals, and the factors shaping them, to identify challenges in CF care and any opportunities for reconfiguring these practices through personal monitoring technology. Our findings expose the complexities associated with the activity system of CF care, rooted in the experiences of both patients and clinical professionals.

From a patient perspective, this study highlighted several important considerations when considering technology which might effect future reconfigurations of CF care provision. First, there is already a significant burden of care for CF patients in terms of their daily medication, physiotherapy and dietary monitoring that must be juggled in the context of other everyday responsibilities. While there is considerable variation among patients, adherence to these regimens is a negotiated concern that is adapted and reprioritized in light of these other factors. Such characteristics will likely extend to any health monitoring solutions as well, with several potential implications. Obtaining continuous data via a passive activity monitor may not be a significant burden, but actively obtaining daily spirometry, temperature, weight, and blood oxygen data (to say nothing of logging self-report symptom data) could impose considerable additional work for those living with CF. These activities would be likely subject to *negotiated* adherence, and so any proposed benefits would need to be robust to a degree of non-adherence and mindful of the significant care burden which already exists in this condition.

Likewise, our findings highlight how collecting such data might heighten the concerns patients expressed about feeling defined by CF, further challenging adherence unless data collection was sufficiently motivated. For example, if monitoring activities generate artifacts which encourage

reflection [14], this may be insufficient to sustain longitudinal daily monitoring for all but the highest-risk patients. Thus, the collaborative activity system of CF care relates not only to the division of labor for optimal health outcomes, but is entangled in a range of complex issues relating to the nature of the condition and the lived experience of the 'burden' it imposes on people's lives. This includes, for example, the extent to which they adopt or reject the identity of being a 'CF patient' in different contexts. Bardram highlights that homecare activities can heighten patients' self-consciousness about their condition [2] while Mamykina's work on sensemaking in chronic illness explores how 'breakdowns' and gaps in patients' understandings act as triggers for behavior change through a perception-inference-action cycle [42]. Yet our data shows how prompting patients to reflect on their health data has the potential to draw additional and at times unwelcome attention to their condition and its implications, increasing the dominance of CF their lives. While attentiveness to their health status may be clinically necessary in supporting self-care and disease management, this must be balanced with wider considerations about an individual's wellbeing.

These factors suggest a need for care when adopting technology to support these reflective practices in chronic, life-shortening conditions such as CF to ensure that issues relating to identity and emotional labor are carefully considered. A recognition that 100% compliance with treatment recommendations is unrealistic, adopting a non-judgmental approach, accepting compromise, ensuring carefully and effective communication, and tailoring treatment to daily lifestyles may all help in this context [22]. Such considerations should influence the design of future technologies in this space. For example, the notion of partial, rather than 'absolute', adherence should be sensitively built into the design of technologies to support those living with CF. For instance, approaches utilizing gamification for adherence (e.g. [34]) must be mindful of the many possible reasons people feel unable to adhere to treatment recommendations. Any proposed reconfiguration of CF care reliant upon sustained longitudinal monitoring must therefore be particularly sensitive to these experiential aspects of living with this complex condition.

However, our study suggests that some degree of monitoring burden may be accepted by CF patients on the condition that it formed part of an integrated effort to reconfigure the distribution of care in ways that reduce burden elsewhere. For example, monitoring may be more readily accepted if it facilitates the early detection of a health deterioration that reduces the burden of potential hospital visits or treatments through more proactive intervention. Recent work has suggested that AI could predict exacerbations of Chronic Obstructive Pulmonary Disease (COPD) [25], an approach which could reasonably be tailored to pulmonary exacerbations in CF which often result in hospitalization and health decline. Similarly, given the burden imposed by regular clinic visits on patients, in terms of time, effort and cross-infection risk, small bouts of active monitoring could be offset by care reconfigurations that reduced the overall burden on the patient. One example would be monitoring in support of a remote triage service, permitting a remote review by a CF nurse to determine whether patients needed to come into clinic for a more extensive MDT review. This approach, as discussed below, may enable alignment with the concerns and priorities of healthcare professionals.

From the perspective of MDT, a key issue was meeting increasing demand for their services. It was clear that clinics struggled to provide sufficient capacity to accommodate a growing population of adults living with CF. Some of this is common to healthcare systems in general, but our research highlights aspects that relate specifically to CF. The multi-system nature of the condition demands holistic, multi-disciplinary care, while the challenges of infection control lead to complexities of patient scheduling and separation that compromise the MDT's ability to adapt

to changing patient circumstances. Furthermore, the specific patterns of potential health deterioration experienced by CF patients, and consequent adverse outcomes if not treated in a timely manner, necessitate a very high frequency of chronic care cycles. Such frequency is necessary, to identify and treat patients who might be experiencing a decline in health, but we also observed frustration amongst both health care professionals and patients that many clinic visits serve primarily to confirm that someone is in good overall health.

Within this context, self-initiated patient-generated data might not be regarded as systematically beneficial to the organization of care. That is not to say that such data would not occasionally be useful as a self-explanation artefact in ad hoc aspects of the patient clinician interaction, but in and of itself, it would not address the key concerns of the clinic. Indeed, members of the MDT acknowledged that they had not yet identified how best to incorporate patient-generated data usefully and consistently into clinical practice. In this respect, our findings extend to CF prior research (e.g. Chung et al [14]) that documented challenges associated with integrating patient-generated tracking data into clinical consultations. The work associated with reviewing such data may challenge capacity-pressured clinics, ultimately limiting its value in CF care.

Likewise, although MDT-initiated patient-generated data may be more easily assimilated by clinicians, the additional burden it imposes on CF patients may present an uncomfortable shift in the distribution of care. In the context of CF, therefore, personal health monitoring technologies must meet the collaborative goals of both patients and the MDT in relation to both data collection and its use [14]. This is not meant as a general concern that may apply in the abstract to any chronic condition, but rather that these goals are understood and articulated by patients and clinical professionals in relation to the specificities of CF. Technologies must also attend to the cooperative aspects of the collaborative activity system in the specific context of CF care [2], which they will inevitably reconfigure, as well as the care work they will redistribute.

In light of this, we must consider areas of potential alignment of CF-specific goals between patients and the MDT that could be enabled through remote monitoring technology. Our findings suggest that one such area in CF care provision would be in reducing the number of 'unnecessary' clinic visits. This would benefit clinics by reducing the immediate demand on the MDT, as well as the demand induced by the complexities of cross-infection management. It would also align with the strongly expressed desire of patients to reduce the burden of clinics, by decreasing the frequency and duration of clinic visits and lengthening the 'home' phases of the chronic care cycle [12].

Our study highlights the significant intangible value CF patients built up through regular interactions with trusted members of the MDT. Such trusted relationships are an important part of the disclosure context essential to the holistic approach to patient care that is necessary in a complex, chronic condition such as CF. It is important that such features of this collaborative care system are not discarded with any enthusiasm to adopt models of care supplemented by remote technologies. In this respect, a shift to a predominantly virtual model of care may challenge the creation and retention of such trust relationships, in addition to any technical issues that may be encountered. Instead, where there appears to be a valuable compromise in chronic care redistribution in CF – in which shifts in work burden align with value to patients doing the new work – would seem to be in a triage-based model. This offers the ability for clinician-initiated, patient-generated data to support decision-making about the necessity of clinic attendance, finding an appropriate and individualized balance in the burden of care from the perspective of both the clinic and CF patients. Such an approach would be mindful of Bardram's suggestions that technology for homecare in chronic conditions support flexibility in patient-clinic cooperation, as

well as enable patient ownership and control over factors such as the data shared with the clinical team [2]. Our data further suggests that technology to support the collaborative activity system of CF care must support goals and priorities that are meaningful in the lives of individual CF patients.

## 6 Limitations

This paper presents a constructivist grounded theory of specialized care provision for cystic fibrosis (CF) and how it is perceived by those living with the condition and medical professionals who deliver specialized care at a single UK center. As such, despite reaching theoretical saturation within this setting, our findings cannot be considered generalizable to all CF patients or clinical teams in all cultural or healthcare contexts.

## 7 Conclusions

This study highlights the value tradeoffs which must be considered when designing technologies for collaboration in chronic health conditions such as CF. These cannot be assumed to be generic across all or even very similar conditions. Rather, we have to look at how specific aspects of the condition result in particular healthcare structures, and how technologies might facilitate their reorganization. Our data suggest that the nature of CF itself, and how it shapes current care practices, points towards areas of possible alignment between patients and the clinic in the collaborative activity system of care. In cystic fibrosis (CF), a key benefit of remote monitoring technologies is their potential to reduce the number of unnecessary hospital visits, benefitting both patients and clinical teams. Such benefits should not necessarily require fully remote clinics but might better be delivered through a 'triage' system as described above. This would seem to strike an appropriate balance in the redistribution of care work between the multi-disciplinary team (MDT) and patients, who already contend with the significant everyday burden of living with CF.

For technologies to support self-care and the wider activity system of chronic health care provision, to be successful in chronic conditions such as CF, they must be well-integrated and grounded in the lives of people living with those conditions. They must also attend to the nuances of the collaborative working practices between patients and their health care providers, and the particular structures of care provision which support these relationships. Drawing upon the experiences and perspectives of both patients and professionals, this study highlights a range of issues to consider in relation to CF, a condition in which technologies offer significant scope to transform the nature of care provision.

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