A CHECK LIST DESIGNED TO IMPROVE MEMORY RECALL AMONGST CF PATIENTS

Research paper

Twomey, Michael, University College Cork, Cork, Ireland, 91158761@umail.ucc.ie

Sammon, Dave, University College Cork, Cork, Ireland, dsammon@ucc.ie

Nagle, Tadhg, University College Cork, Cork, Ireland, t.nagle@ucc.ie

O'Raghallaigh, Paidi, University College Cork, Cork, Ireland, p.oreilly@ucc.ie

Abstract

When a Cystic Fibrosis (CF) patient/carer meets a doctor, it is the responsibility of the patient/carer to recall their medical history. Often the information imparted by the patient/carer is inaccurate due to their inability to remember their medical history accurately. Coupled with this, patients/carers often leave medical encounters unable to remember the information that has been imparted to them. These memory issues can seriously impede the doctor's ability to correctly diagnose and treat a CF patient and the patient's ability to adhere to the doctors' recommendations. This paper explores: "The Memory Recall of mild to moderate Cystic Fibrosis(CF) patients/carers in routine doctor's appointments and the impacts a simple artefact can have on memory recall, stress and empowerment". Using Design Science Research, the artefact designed, built and evaluated to address the problem is a pretotype (a paper-based prototype) in the form of a Check List. Rigorous evaluation by CF patients, carers and respiratory clinicians' points to the artefact's validity and shows its contribution to memory recall, a reduction in stress, and an increase in empowerment for both CF patients and carers. The insights gained from this research will be an essential precursor to the creation of an effective digital solution.

Key words: Design Science Research, Memory Recall, Cystic Fibrosis, Check List, Stress, Empowerment, Pretotype

1   Introduction

Cystic Fibrosis (CF) is an inherited chronic respiratory disease that primarily affects the lungs and digestive system. The underlying genetic defect is related to the cystic fibrosis transmembrane conductance regulator (CFTR), which leads to an imbalance in the exchange of salt and water across the cell membrane. This affects all mucus generating organs, including the pancreas, sinuses, and reproductive system (Ratjen et al., 2015). Although CF is a multi-organ disease, the cycle of inflammation coupled with infection and repeated pulmonary exacerbations primarily affecting the lungs is a major cause of morbidity and mortality (Ratjen et al., 2015). Coupled with the physical aspects of the disease, CF centred studies report rates of anxiety ranging from 30-33% among CF adults (Yohannes et al., 2012) and are 38% among CF carers (Besier et al. 2011).

The understanding and remembering of health information is a key component in healthcare management. The context of the medical appointment and of hospitals in general can render effective doctor–patient interaction difficult due to appointments often taking place under severe time pressures and under high stress levels (Ong et al., 1995). High levels of stress and anxiety in turn hinder recall of medical information (Ley, 1979; Shapiro, 1992). Encoding information at a time of distress and possible confusion can impair patients' capacity to recall information, as is inferred by studies of the harmful impact of stress on eyewitnesses (c.f. Deffenbacher et al., 2004). This papers objective is to explore: "The *Memory Recall* of mild to moderate Cystic Fibrosis(CF) patients/carers in routine doctor's appointments and the impacts a simple artefact can have on memory recall, stress and empowerment". We investigate how features, such as colour and information structuring (information organised or bound together in a meaningful way facilitating higher order cognitive representations), might be used in the design of an artefact to aid the memory recall of CF patients/carers. We do this exploration by means of Design Science Research using a Check List as a specific form of paper-based prototyping (referred to here as pretotyping).

In this paper we focus on the specific concept of memory recall rather than general communication between a doctor and CF patient or carer. While there are many studies (primarily by clinicians) on how well patients can recall what the doctor has imparted to them during their medical appointment, the uniqueness of our research is that it looks at the problem of memory recall from a CF patient/carer perspective. We examine the ability of the patient/carer to recall the health events they have experienced outside of the medical appointment setting and their ability to recall this information accurately when asked to do so by their clinician, which according to Cohen et al. (1995) and Martin (2014) has received a lot less attention in research.

A further uniqueness of this study is that the lead author draws on his own experience as a CF patient, living with the disease for over 46 years. These experiences significantly shape both the research and the design of the artefact.

The remainder of this paper is structured as following: a brief background of the study, followed by an outline of the development and evaluation of the artefact. We then highlight the key benefits and finally we conclude our paper with the limitations of this study and our contributions to knowledge.

2   Background to the Study

The main nexus of communication between the patient and the doctor is the medical appointment. The conversation in an appointment is bi-directional and consists of two important phases - the *Elicitation Phase* and the *Explanatory Phase*. Both phases can be problematic for the CF patient or carer in terms of their ability to remember information. In addition, we look at processing capacity, information structuring and colour and their impacts on memory recall.

2.1 Elicitation phase

The elicitation phase of the appointment is when the clinician interviews the patient/carer regarding their medical history, current wellbeing, current medication, and so on (Martin et al., 2014). This is the kind of detailed information that a doctor requires to formulate an accurate diagnosis and to engage in clinical decision-making (Cohen et al., 1995). This *"Clinical History and Interview"* stage accounts for 46% of the duration of a doctor's appointment (Bickley, 2013). Often times the information imparted by the patient/carer is inaccurate due to their inability to remember their medical history accurately (Cohen et al., 1995). Indeed, this inability to remember relevant clinical information often results in patients and carers becoming more anxious in what is already a demanding environment. This correlates well with our study of 305 CF participants in 2015, where 74% said they found *recalling their medical history at a doctor's appointment a stressful experience* (Twomey, 2015). The overall profile of a CF patient's condition is a key factor in their long-term care, quality of life and their life expectancy (Twomey, 2015). Imprecise data can have several pernicious effects on the treatment the patient receives. A misdiagnosis may see the likelihood of recovery substantially diminished, and an erroneous diagnosis of a serious illness can cause considerable mental distress, psychological problems or death (Personal Injuries Ireland, 2017).

2.2 Explanatory Phase

The second phase of the appointment is the explanatory stage, in which doctors engage in informing patients about diagnoses, further clinical options, self-management plans as well as general advice (Martin et al., 2014). Memory recall has been reported to be a predictor for adherence and other self-care behaviours such as lifestyle modification (McPherson et al., 2008). Research shows however that that the bulk of patients fail to recall the information they are given during their medical encounters leading to reduced health outcomes, diminished patient satisfaction and to clinician dissatisfaction (Schraa et al., 1982).

2.3 Processing Capacity

Human working memory is limited in the number of items it can hold. Processing capacity (e.g., processing speed, working memory) limits the efficacy of many knowledge processes (Chin et al., 2017). In his landmark analysis, Miller (1956) observed that humans can recall only seven plus/minus two units (or 'chunks') of information. Moreover, there also seems to be a linear correlation between the amount of information provided and the amount that can be recalled (Safeer et al., 2005). Predictably, the more information provided, the more information lost (ibid).

2.4 Information Structuring

Psychological theory and associated empirical findings suggest that information structuring can be an effective instrument in improving recall and comprehension (Ackermann et al., 2016). The relationship between structure and ensuing recall performance has hitherto been studied albeit in very diverse situations such as education and Schizophrenia (Epstein, 1967; Hannafin, 2004; Traupmann, 1975). In particular, information appears easier to store in memory when it is structured in a way that assists the recipients' organisation of it (Langewitz et al., 2015). From a cognitive perspective the advantages of information structuring seem to be in "chunking"; that is, low-level separate fragments of information are joined together into larger high level meaningful units (Miller, 1956). It also seems that implicit categorisation i.e. merely presenting the data in a logical order does not improve memory recall. By contrast, explicit categorisation does increase recall of medical information by patients (Kessel, 2003). Nevertheless, as patients age the organisation of data seems less important to memory function than the degree to which the information is consistent with their previously acquired knowledge and beliefs (Hess and Tate, 1991).

2.5   The Role of Colour

The role played by colour in augmenting our attention level is conclusive (Pan Y. et al., 2012; Eysenck M., 2009) as colours have an ability to attract our attention (Farley et al., 1976). The more attention dedicated to particular stimuli, the greater the probability that the stimuli will be transferred to longer lasting memory storage (Sternberg R. et al., 2009). Colour therefore has the capability to increase the prospect that environmental stimuli will be encoded, stored, and retrieved effectively. The selection of colours and the manipulative facets can, however, shape the degree to which colours can affect human memory performance (Dzulkifli et al., 2013). The right combination of colours is important because it can produce higher level of contrast, and this can affect memory retention (Dzulkifli et al., 2013). Colours can also impact the level of interest and also give rise to emotional stimulation which contributes to control activities that will subsequently improve memory execution (Kaya et al, 2004). Stimulation, especially emotional arousal, can play a vital role in retaining the information in the memory system. Indeed, colours can heighten the relationship between arousal and memory (Kaya et al, 2004).

3   The Check List and its Evaluation

Experts have long documented the capacity for human failure in complex environments (Arriaga et al., 2013). Check Lists are a conventional instrument for averting human errors in complicated, high intensity areas of effort (Borchard et al., 2012). In fields such as aviation or aeronautics the use of Check Lists is extensive and stretches back more than 30 years. Their use in the discipline of medicine is relatively recent, but they have proven to be very beneficial in preventing memory failures (Stock et al., 2015). For example, when implemented correctly, Check Lists can substantially diminish cumulative errors that lead to surgical omission and they can significantly augment patient safety (WHO, 2010). In January 2007, in an endeavour to tackle the safety of surgical care, the World Alliance for Patient Safety began efforts on the World Health Organisation's (WHO) Safe Surgery Check List (WHO, 2008). Haynes et al. (2009) conducted an investigation that discovered that surgical deaths were lessened by approximately one-half and surgical impediments were diminished by more than one-third when the surgical safety Check List was put into operation. As crisis-associated cognitive aids it made sense for our study to explore the use of a Check List to aid memory recall in the appointment setting. In our literature review we did not discover any research that focuses on the design or use of Check Lists for CF patients and carers (or for any other chronic illnesses).

Pretotyping is a paper-based approach developed by Alberto Savoia (2011) at Google to understand why products/services fail in their proposed settings despite being well designed. Like functional prototyping, pretotyping develops a scaled down form of a product. However in contrast to functional prototyping, which focuses on questions such as: "Can we make it?", "Will it function as anticipated?", "How economically can we make it?", pretotyping focuses on questions such as "Will people be attracted to it?", "Will they purchase it if we make it?", "Will they use it as we first thought?", "Will they continue to use it?" (Savoia, 2011). Pretotyping is useful in investigating the initial interest and actual usage of an impending digital solution by simulating its core experience (in our case within the medical appointment) with the smallest investment of time and money feasible. Pretotypes support the capture of distinctive insights from users of the pretotype within a given context and also help avoid "falling in love" with early solutions.

The prototype in this study takes the form of a Check List, designed for the CF patient/carer to fill out *before* and *during* the doctor's appointment. The prototype evolution took place over a ten-month period where the researchers adopted a Design Research (DR) approach to its design, build and evaluation. DR is essentially a problem-solving paradigm (Hevner et al., 2004). DR helps resolve new or *wicked problems* by crafting innovative artefacts (Peffers et

al., 2008). The Design and Build team consisted of a CF patient (the lead author), a CF respiratory clinician and two carers of CF children.

Evaluation Criteria for Each Version		
Criteria	Definition	Details
Completeness	Ensuring that all necessary (and appropriate) sections, including individual items/metrics required by a CF patient or carer at their medical appointment are included in the Check List.	We will seek to make sure that all key **CF related metrics** i.e. FeV1, medications, O2 saturation etc are included within the Check List. To do this we will need CF patients/carers that are using the Check List in real appointments, to tell us what is missing. We will also obtain advice from our clinicians. This makes sense as some health metrics can be more relevant with disease type, age and disease progression. For example, an adult with CF may have their cholesterol measured routinely, whereas with a child their height and weight metrics may be more important at a particular time.
Usability	The degree to which the artefact is able or suitable to be used in the medical appointment. How logical is it? How does it functions visually. Is it difficult to use? Is the CF patient or carer comfortable using it?	Cognition and emotion are tightly intertwined, which means the designer must design with both in mind (Norman, 2013). While the Check Lists purpose will be to aid memory recall, reduce stress and increase empowerment within a complex and demanding setting. We need to ensure that the Check List helps CF patients and does not hinder them within the appointment or after they leave the clinic. We will ask them for their feedback after using the Check List. We will ask them what issues they have, we will also ask them to rate the Check List in terms of ease of use, how well it functions from a visual perspective, how logical it is and if they are comfortable using it. This subjective feed back will be ascertained using a Likert scale, scaling responses from 1 to 5.
Robustness	The ability of the Check List to withstand or overcome adverse conditions, rigorous testing and to have CF patients and carers continue to engage and use the artefact within their medical appointments.	Much of the failure to achieve optimal health outcomes is often due to the failure of health actions themselves – that is, individuals' adherence (or nonadherence to healthy behaviours and treatment routines (Martin, 2014). We hope that our solution will really resonate with CF patients and carers and really take hold. That they will continue to use the Check List, as it satisfies their memory recall needs, is aligned with their goals and can become automatic with little or no effort. Therefore, our robustness questions will focus around their usage behaviour. Have they changed their behaviour moving from nothing or a diary to using the Check List? Do they continue to use it over time? Have they noticed changes in their own behaviour and what changes have they made?
Impact	We will require CF patients and carers subjective opinion on the effect the Check List has on their perceived stress levels, on their sense of empowerment and on their ability to remember during and after the medical appointment.	Over the last number of years, empowerment and empowerment-related themes, such as patient activation, enablement and involvement, have really come to the fore. In tandem with this our CF patients and carers report increased stress levels during and after their medical appointments due to memory recall issues making them feel inadequate, helpless and sometimes frustrated. Therefore, we will need to understand the effects that the Check List is having on these variables reported by patients as important to them. This will be done using a Likert rating scale (1-5). We will hope to achieve scores of 4 or 5 for both stress reduction , increased empowerment and improved memory recall.

Table 1 Evaluation Criteria

A core element of Design Research is the *evaluation* of the artefact being developed. The Check List in this study was evaluated in order to determine how well expectations (aiding memory recall both *during* and *after* a medical appointment) and intentions (reducing stress and increased empowerment) were meet. The full list of evaluation criteria is listed in Table 1. The participants in our evaluation group consisted of seven CF adult patients and eleven carers of CF children. The Check List evolved over three iterations, where each of the three versions of the Check List was *evaluated* in real life routine doctors' appointments by each of

our participating evaluators. Each participant was interviewed by the research team. In addition, expert opinion was sought from clinicians on the effectiveness of the Check List design and its subsequent use by CF patients or carers. Next, we describe each version of the Check List.

3.1   Check List Version 1

A design workshop was held in September 2016 by our Design and Build team. As recommended by experts in the area of Check List design (such as Michael Simmons and Ian Chew (2015)) we sought to make our Check List complete, usable, robust, and impactful. We also kept to the point, keeping the volume of information to a minimum as recommended by Baddeley (2007). Our focus was on ensuring the Check List was easy to use in the pressurised appointment environment. We sought to maximize patient comprehension and make the capture of health information as simple as possible (e.g. by decreasing reading level for those participants with a lower educational background), without missing key context and connotation (Schraa et al., 1982), affording cues of the most crucial steps (i.e. the killer items). See Table 2 below for the Design and build of each version.

Problem	"Exploring Memory Recall of mild to moderate Cystic Fibrosis(CF) patients/carer in a routine doctor's appointment"		
Design and Build	**Version 1**	**Version 2**	**Version 3**
	Date: Sept 2016	**Date:** Nov 2016	**Date:** March/April 2017
	This Check List (Appendix A-see Figure 1) was decided upon due to it suitability in complicated, high intensity areas of effort (Borchard et al., 2012) and due to its ability in preventing memory failures in medicine (Stock et al., 2015). It was agreed that when in the doctor's appointment communicating with a pen and sheet was more appropriate than having "one's head in an iPad" etc. The Design and Build team held several workshops which involved scenario type /role playing to augment our understanding of patient/carer behaviour and journey mapping to help visualise the patient's experience. Research literature was used to guide the Design and Build team in the creation of the Check List, in particular works by Borries Schwesinger (2010) a renowned expert in the field of form/visual creation. On release of the Check List a detailed Check List of usage instructions was given to each participant.	Following the evaluation of Version 1 the Design and Build team consulted with literature and several design and build sessions were held. The team applied their research findings regarding the use of colour in aiding memory recall (c.f. Wichman et al., 2002) and also as advised by Elliot et al., (2015) the team used combinations of colour to create higher levels of contrast, to influence memory. Missing CF related metrics were also added to achieve greater completeness. The Check List (see Appendix A-Figure 2) was again supplied with revised detailed usage instructions.	The main problem areas that were identified in Version 2, that of space and the absence of an emotional section (as requested by some of our participants) were addressed in Version 3. We sought advice from one of our clinicians on how we would address the request for an emotional section in the Check List. Check List Version 3 (see Figure 1) was released with revised usage instructions.

Table 2 Design and Build of each Version

Drawing on over 100 years of combined CF experience in the Design and Build team, we created defined sections/categories within our Check List, limiting pre-population to essential data, and consolidating other items of interest into a small number of fields to harness the power of structure as an aid to memory recall it (c.f. Langewitz et al., 2015). We designed the Check List around the communication clinical workflow of the medical appointment (i.e. the step by step data collection/ instruction process that a clinician engages in at a medical appointment) as outlined by Bickley (2013). This use of categorisation was first noted by Ley (1979) who recommended using explicit categorisation as an aid to memory recall.

We released Version 1 (see Figure 1- Appendix A) of the Check List together with detailed usage instructions to our eighteen CF patients/CF carers, who then used it at their subsequent medical appointments. We were interested in ascertaining how they would use the Check List

and most importantly how the Check List would meet the evaluation criteria and ultimately assist in increasing memory recall, reducing stress, and increasing empowerment.

3.1.1   Summary of Findings

Previous to our research only 17% of our participants were capturing their medical data at their medical appointments and none of them were using any applications as they felt that there was nothing available that matched the needs of a CF patient or carer. Our evaluation (see Table 4) shows 81% of participants reported an increase in memory recall as a result of using the Check List at their respective medical appointments. This was not altogether surprising as research has shown that better recall in structured conditions can be attributed to "chunking'': the ability to form high-level clusters of information from low-level individual elements (Gobet, 2001; Chen, 2005; Li, 2013). However, following our participant interview process we discovered that the monochrome of colour in the Check List was causing some issues. For example, a young mother (already in a heightened state of stress with a sick 3-year-old CF child) reported becoming distracted by her child's coughing spasm during an appointment and found it difficult to relocate her attention back to the correct section of the Check List. Our interviews also revealed that important CF related metrics such as blood sugars, bone density, and liver readings were omitted from the Check List.

3.2   Check List Version 2

Colour is believed to be the most significant visual experience to human beings (Adams et al., 1973). As mentioned the monochrome of colour was causing a usability issue for our CF patients and carers. Guided by the literature, the Design and Build team discovered not only how we might use colour better to solve our usability problem but also that colour could function as a powerful information channel to the human cognitive system and could play an important role in improving memory function (c.f. Wichman et al., 2002). The Design and Build team colour coded each section of the Check List using particular combinations of colour as advised by Elliot et al., (2015) and Schwesinger (2010). The right combination of colour is important because it can produce a higher level of contrast, and this can influence memory retention (Hall, 2004). In addition, the identified CF related metrics previously overlooked were added. At the end of November 2016, we released Version 2 (see Figure 2 – Appendix A).

3.2.1   Summary of Findings

In Version 2 there was a 19% increase in completeness (see Table 4). 72% of the evaluation group also commented positively on the bright pink and green colours at the end of the artefact. They felt that the use of colour in this way had aided their ability to recall information and had helped them avoid leaving an appointment without asking important questions or highlighting key concerns that the patient or carer had. This aid to the patients/carers memory recall is not surprising given the use of colour to treat patients with Alzheimer Disease (a neuro-degenerative form of dementia) which deteriorates memory capabilities (Dzulkifli et al., 2013). In 1976, Farley and Grant began experiments on the influence of colour on attention and discovered that coloured multimedia presentations resulted in better attention and memory performance. Colour was used in the Check List in order to draw the patient's attention to certain sections – such as the 'Questions for the doctor' and the 'Comments by the doctor'. The following comment made by one of the carers was also very encouraging "My son who is 13 years old can fill it out". This showed an increase in the usability of the Check List. "*For individuals to change their everyday behaviours it can be challenging, difficult to achieve, expensive and the impacts are often short-lived*" (Kvedar et al., 2015). Our Check List was demanding behavioural changes, which required doing *new things* (e.g. filling in certain sections of the Check List before the appointment, acting somewhat like a rehearsal for the appointment, which in itself aids memory recall (White et al., 1995)), *doing things better* (e.g. asking the doctor more questions to enable sections of the Check List to be completed during the appointment) and *halting* certain behaviours (e.g.

guessing/estimating in response to questions posed by the doctor at appointments due to an inability to remember facts).

The coded comments in Table 3 were made by some of the evaluators indicating increased empowerment and engagement (by the individuals in their own or their child's health). However, some limitations of the Check List were also being called out, including the need to capture data between appointments (for example in the home).

Impact Type	Participant Type	Example of quotes
Empowerment	Carer	*"Now I ask way more questions, and I feel I am getting way more out of my appointment with the doctor"*
Empowerment	Patient	*"It prompts me to ask about x-rays reading etc."*
Empowerment	Patient	*"For me it's the amount of preparing, looking over notes etc. I am forced to think more"*

Table 3 Patient comments at interviews following use of Version 2 of Check List

Other questions pointing to limitations in the current design included: How could insights be gained from all the Check List data collected? Where should completed Check Lists be kept? How should they be backed up? The Design and Build team agreed that it was now time to understand more about the real "impacts" that the Check List was having. In addition, it was decided that the time was right to comprehend what CF clinicians had to say about this new artefact within the appointment setting.

3.3 Check List Version 3

Further sections such as *emotional state* of our CF patients and carers were added to the Check List in Version 3 (see Figure 1) and the space issues identified were also addressed. Our evaluations for Version 3 (see Table 4) took place in late March/early April 2017. As a result of using the Check List and now being able to recall and relay information more easily, CF patients and carers felt *less stressed and more empowered*. This is discussed in greater detail in our next section where we present the key benefits of the Check List in relation to the research objective.

3.3.1 Summary of Findings

As per Table 4 our evaluations were looking more positive with higher levels of completeness, usability and robustness. The comments made in terms of the impacts the Check List was having (see Table 5 & 6) were both moving and very encouraging.

However, another challenge also came to the fore which hitherto had not being expressed but is not altogether surprising. What if a person does not have a printer or a colour printer? This would be solved by getting a booklet of Check Lists printed in colour (which could detach easily if required) which would then be given to each CF patient or carer for use.

3.3.2 Expert Clinical Opinions

We sought the views of two CF clinicians on Check List Versions 2 & 3 which had been used in appointments with them. One of the clinicians, who was head of adult respiratory medicine in his hospital commented "I think the Check List is a great idea and should really make a difference to appointments". Also, the lead author visited the Paediatric team in the same hospital in early 2017. Although initially cautious of the Check List (as had previously been reported by carers) and of supplying carers with medical information, the Paediatric unit are now actively providing carers with their child's medical data to help them record their medical data on their Check Lists. This is a big win as it shows great promise for much needed evidence of behavioural changes by some clinical stakeholders. Research shows that

even in successful hospitals, there are doctors who oppose partaking in Check List implementation primarily due to the perception that it takes up too much of their time (Leape L., 2014). It seems that the level to which a Check List can impact processes of healthcare and patient outcomes can hinge on attitudes and behaviours of all stakeholders (Rosen et al., 2014).

Check List Evaluations			
	Version 1	**Version 2**	**Version 3**
Completeness	We achieved 61% completeness regarding the key CF related metrics that needed to be recorded for recall purposes. There gaps identified were in the areas of urine tests, bone density, sugar levels etc. that reduced our Check List completeness.	We achieved high scores of over 80% (an increase of 19%) in completeness albeit with further work to be done in the area of medication and emotional state metrics.	We attained our 100% evaluation goals for completeness in terms of key information that needed to be recorded for *recall* purposes for CF patients and carers in their medical appointments.
Usability	100% of participants were comfortable using the sheet, but we identified a major usability issue regarding the uniformity of colour which was hindering the use of the Check List in the pressurised environment of the appointment. Participants reported having difficulty finding their way back to particular sections (quickly) if they were distracted in an appointment. 100% of participants claimed they were however comfortable using the Check List in their appointment.	We obtained scores of over 80% in usability, but space requirements were raised as an issue. As expected the use of colour to separate the sections really added to the usability of the Check List, where it was now found to be more logical, simpler to use and easier to find one's way back to a particular section if distracted at an appointment. 17/18 participants give a 4 or 5 out of 5 in a Likert Scale in terms of ease of use.	We succeeded in our evaluation goals for usability by attaining a figure of 95% in the pressurised environment of the medical appointment facilitating information recall during and after the medical appointment.
Robustness	There was recognition by 78% of participants that a change in behaviour would be required in using the Check List before and during their medical appointments. However 94% were commitment to this behaviour changes in the future if the issue of information recall and stress reduction was to be addressed using the Check List.	We achieved a high degree of robustness (albeit with some engagement techniques required for 3/18 of the Group). There was also a recognition by 83% of participants that they would need to change their behaviour in the future if the issue of memory recall and stress reduction was to be aided by using the Check List.	Regarding the robustness of the Check List 15/18 of participants were using the Check List in all their clinical appointments for information recall. The remaining 3 participants required the use of engagement techniques to keep involved.
Impacts	100% of participants felt that the Check List had aided them in some way in their respective medical appointments. 81% of participants report an increase in their ability to remember their medical history and what had happened at their respective appointments.	The were early signs of increases in empowerment and engagement by participants.	In Version 3 we sought to really understand the impacts that the sheet was making in appointments and on the CF patient/carers who had now been using the Check List (albeit in different forms) for almost six months. Impacts are really seen particularly in the **increase in memory recall**, a **reduction in stress** and an **increase in empowerment** that the patient /carer felt as a result of using the artefact and being able to *recall their medical information*.

Table 4 Evaluation Versions

4   Evaluated Impact of the Check List

All participants agreed that using the Check List in their medical appointments facilitated their ability to recall clinical information in their appointments. As we shall see this recall ability resulted in a number of further benefits for the CF patients and carers.

4.1   Improved Memory Recall

2 out of 18 of our participants stated that as a result of the Check List they had avoided a revisit to the doctor, as they had not left out any important symptoms when they went to their appointment. Others in the group supported this but felt that over the course of the 6 months

they could not say that they had definitely saved on a revisit to the doctor. In comparison, 16 of our participants said that as a result of using the Check List they had raised matters that were a cause of concern with their doctor. All 18 participants agreed that waiting to get in front of their doctor again to ask about something that was really worrying them about their own or their child's health was a huge strain to bear and that preventing such a situation from arising in the first place by using the Check List was a real benefit in terms of reducing this potential stress.

4.2   Reduced Stress

Stress was a particular concern for our participants which was deemed by all 18 to be augmented by their inability to remember their medical data. When asked "Did using the Check List help reduce your stress levels"? - all 18 said that it had with 13 rating this at 4 or greater on a Likert scale of 1-5 (where 1 - it had little effect on their stress levels and 5 it made a big difference to stress levels).

Table 5 augments our understanding of the impact that the Check List has on the perceived stress levels of our CF patients and carers. One mother elicited a very stressful afternoon that she experienced whilst in a doctor's appointment with her sick CF baby. She said that the Check Lists coloured sections really helped her to refocus on the appointment whenever she became distracted by the child (who was quite distressed and agitated at the time due to an infection) - see her comment in Table 5 (in bold).

Impact Type	Participant Type	Example of quotes
Reduced Stress	Carer	*"The Check List may seem a small thing for some, but for me it was huge, I was so worried about my little girl, anything that helps reduce that stress is amazing. I don't think people should really judge unless they have walked in my shoes"*
Reduced Stress	Carer	**"With the Check List for the first time I could really hear what the doctor was saying to me" (Mother of a CF child)**
Reduced Stress	Patient	*As a CF patient it's not easy, when I am at the appointment I feel my heart racing, I am stressed about what the doctor might say about my CF. The Check List won't take all the stress away, but it sure does help a lot. More than I thought it would to be honest. It's amazing what a bit of paper can do"*

Table 5 Check List Stress Impacts

4.3   Increased Empowerment

Health care is currently experiencing a paradigmatic change in the way patients are shifting from being submissive recipients to more independent, dynamic, and engaged participants (Snyder, 2016). Identified by the World Health Organization as an eminent priority subject matter to be pursued globally (Delnoij et al., 2013) patient empowerment referring to the set of self-determined actions based on patients' specific requirements for developing self-determination and expertise with their disease - has gradually become a key feature of a

Impact Type	Participant Type	Example of quotes
Empowerment	Patient	*"I feel at long last that I have a real voice in the what happens with my body. Before I felt voiceless, unheard, not comfortable speaking about my concerns. Now I have the courage to speak my mind. I can't believe how good it feels"*
Empowerment	Patient	*"The doctor assumes that the treatment he recommends is ok with me, he never really asks me. But now when I come with the Check List he knows I mean business, that I am serious about my CF, that I want to heard, I want to have my say. I think it has really helped our relationship"*

Table 6 Check List Empowerment Impacts

patient-centred approach to healthcare (Prigge et al., 2015). With regard to empowerment, the researchers sought to answer the question: "Did using the Check List give you a greater sense of empowerment"? Again all 18 participants answered yes albeit to varying degrees. Interestingly 15 participants gave a 4 or 5 when asked to rate the Check List on a Likert scale of 1-5 (where 1 it made very little difference to their sense of empowerment and 5 it made a big difference to their sense of empowerment) These findings are again reinforced by the comments in Table 6.
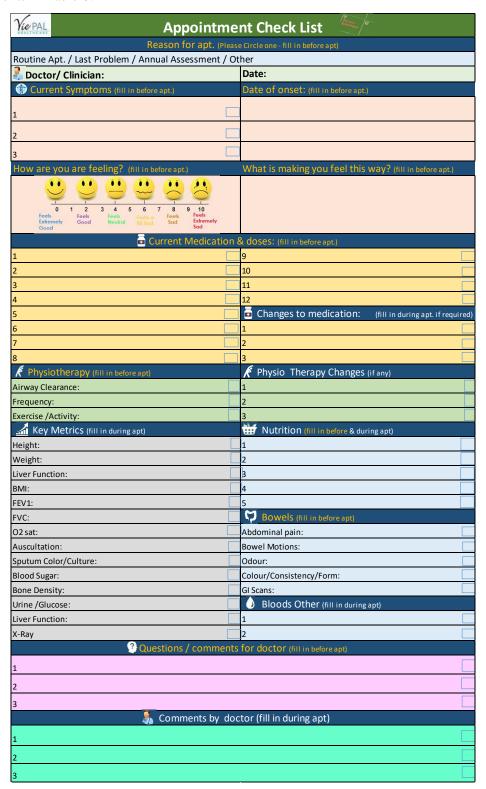
Appointment Check List

Reason for apt. (Please Circle one - fill in before apt)

Routine Apt. / Last Problem / Annual Assessment / Other

Doctor/ Clinician: | **Date:**

Current Symptoms (fill in before apt.) | **Date of onset:** (fill in before apt.)

1

2

3

How are you are feeling? (fill in before apt.) | **What is making you feel this way?** (fill in before apt.)

| 0 | 1 2 | 3 4 | 5 6 | 7 8 | 9 10 |
| Feels Extremely Good | Feels Good | Feels Neutral | Feels a lil Sad | Feels Sad | Feels Extremely Sad |

Current Medication & doses: (fill in before apt.)

1	9
2	10
3	11
4	12
5	**Changes to medication:** (fill in during apt. if required)
6	1
7	2
8	3

Physiotherapy (fill in before apt) | **Physio Therapy Changes** (if any)

Airway Clearance:	1
Frequency:	2
Exercise /Activity:	3

Key Metrics (fill in during apt) | **Nutrition** (fill in before & during apt)

Height:	1
Weight:	2
Liver Function:	3
BMI:	4
FEV1:	5
FVC:	**Bowels** (fill in before apt)
O2 sat:	Abdominal pain:
Auscultation:	Bowel Motions:
Sputum Color/Culture:	Odour:
Blood Sugar:	Colour/Consistency/Form:
Bone Density:	GI Scans:
Urine /Glucose:	**Bloods Other** (fill in during apt)
Liver Function:	1
X-Ray	2

Questions / comments for doctor (fill in before apt)

1

2

3

Comments by doctor (fill in during apt)

1

2

3

Figure 1 Check List Version 3

5   Conclusion

In conclusion, the lead author (a 46 years old CF patient) has used Design Science Research to investigate the memory recall problems that CF patients and carers have regarding their medical information in a routine doctor's appointment. An artefact in the form of a Check List has been designed, built and evaluated. Not only has the artefact augmented the understanding of memory recall within a medical appointment, it has also resulted in an artefact with important key benefits: improving the ability to recall key clinical data, reducing stress and increasing empowerment for CF patients and carers. However, we have also seen that there are still issues with this paper-based artefact that need to be explored, understood and resolved. Some outstanding questions include: How should we gain insights from all the data collected? How should we collect data between appointments?

This study has a number of limitations. The sample size is limited. Consequently, some of our qualitative findings demonstrated a strong trend but we would not claim that these results are statistically significance. We were the designers of the Check List and its evaluation, introducing the possibility of observer bias. To reduce the effect of this bias, interviews were conducted with consistent objective data collection tools in the form of an externally vetted questionnaire that was designed not to lead the participant. Furthermore, the key benefits illustrated by comments in Tables 5 & 6 above speak for themselves and leave little room for misinterpretation. Finally, the presence of a Hawthorne effect, namely that the robustness of the Check List was affected by the fact that the participants knew that they would be interviewed after each iteration and hence may have been more likely to use the Check List. But the longitudinal use of the Check List by CF patients and carers is intended to counterbalance this.

We have shown in our study how beneficial pretotyping is as a means to gauge initial user appeal and behaviour prior to the possible creation of any digital innovations. Unfortunately, in today's world there is real tendency to run to a digital solution before really understanding a problem within its unique environment or indeed before understanding the behaviours of the people for whom the solution is designed for. This all too often results in patients being expected to shoehorn into creations which are not fit for purpose, their particular disease or the actual environment they find themselves in.

From a practical perspective, as the Check List has been designed by CF patients/carers and clinicians for CF patients/carers this facilitates real specific CF related data recollection before and during a medical appointment. Which in turn improves memory recall, an essential ingredient for the CF patient or carer to ensure the successful outcome of their medical appointments. The Check List also helps CF research as it contributes to CF patients and carer's wellbeing and outcomes as the evaluations conducted have shown.

From an academic perspective, the Check List artefact is a new (in terms of structure, design and usage context) discursive template that facilitates a new patient led approach to tackling the problem of memory recall (from a patients/carers perspective) during and after medical appointments. This is invaluable as hitherto, no such tool existed for CF patients and carers to facilitate the act of remembering within a clinical encounter. Any research on memory (in clinical settings) seems to be conducted primarily by clinicians and to date we have not encountered any research conducted by an actual CF patient (or other patient type) who is actually living with the problem to be solved. The research therefore highlights the enriching insights and contributions to knowledge that both patients and carers can make to the health innovation arena.
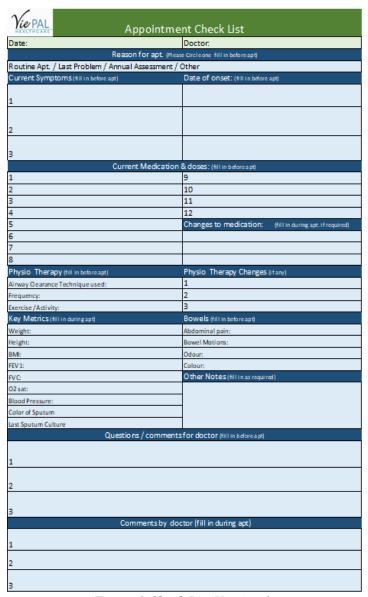
Appendix A

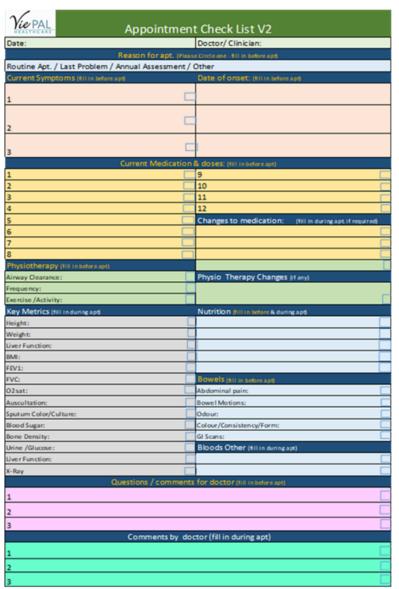*Figure 1 Check List Version 1*

Figure 2 Check List Version 2

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