Patient Access to their electronic patient record in secondary care: Results of a prospective, parallel, randomised open study

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Abstract

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Objective: The aim of this study was to evaluate the feasibility, benefits, technological usability, and acceptability to patients of providing secure access of linked secondary care in CF.

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Results: Ninety-one people with CF completed the study. Intervention n=45, median age 27.5 (IQR 12.0) years, 22 males. Control group n=46, median age 27.0 (IQR 15.0) years, 29 males. There was no effect of Patient Access on levels of anxiety (GAD-7), depression (PHQ-9), confidence in managing healthcare (PAM-13), level of trust in healthcare professionals (PEPPI), computer literacy, all symptom QoL scales and eight QoL domains (CFQ-R). Patient Access scored 86% for satisfaction, 82% for ease of use and 80% for usefulness (PHWSUQ). Of those who had EHR access, 98% agreed that access to EHR should continue.

Conclusions: This pilot study suggests that providing access to EHR in people with CF does not appear to have a negative effect and uptake by patients has been very positive. Prospective studies are needed to investigate the long-term effect of such interventions on objective health outcomes and how we can improve the functionality of such application from the patient perspective. Clinical Trial: ClinicalTrials.gov Identifier: NCT06122025

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PATIENT ACCESS TO THEIR ELECTRONIC PATIENT RECORD IN SECONDARY CARE: RESULTS OF A PROSPECTIVE, PARALLEL, RANDOMISED OPEN STUDY

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Trial Registration: ClinicalTrials.gov Identifier: NCT06122025

Keywords

Patient Access; anxiety; quality of life; questionnaires; electronic healthcare records

Introduction

Over the past decade, a revolution in technology has fundamentally changed the way people live and how they access information. This new digital age has resulted in an exponential growth in social media and online access to services such as banking and shopping. While digital technology can transform the way patients engage in health care, misinformation, misinterpretation, and information overload have the potential of negatively impacting on physical and mental health.

The NHS and other national health care services have recognised the importance of a more joined up working with an integrated approach to health care services. This has the potential to improve safety and efficiency, clinical standards and disease prevention and empowers users to take control of their own health [1–4].

The vision for primary care was that all citizens should have online access to their GP records by 2015 [5]. This vision has been successful and by 2017, 95% of GP practices were able to offer online access to detailed primary care records including test results. Since 2020, all health care users are now able to access the full record including note annotations. This new transparency in record sharing has met some resistance from health care professionals due to concerns that accessing unfiltered medical information may lead to increased workload, patient anxiety and potential litigation [3,6,7]. Equally some patients have expressed anxiety over the potential for breeches in security and confidentiality [2].

In contrast to primary care, full online access in secondary care is lagging; limited by the accessibility of platforms and the fragmentation and lack of digitised records.

In Leeds, the regional adult and paediatric cystic fibrosis (CF) services introduced a modified primary care electronic healthcare record (EHR) in 2007 and went paperless. This resulted in a dramatic improvement in efficiency while providing the benefits of primary care developments including full Patient Access to their records [8]. However, the multidisciplinary team had concerns that providing patients with full access to their records might increase anxiety and affect the way the team recorded information. Therefore, prior to opening the portal to all patients, we performed a pilot study to evaluate the feasibility, benefits, and acceptability to patients of providing secure access of linked secondary care in CF. We also wanted to explore technological usability and the impact of the shared records on communication and patient satisfaction.

Methods

Design

A prospective, parallel, randomised open study was conducted over six months between April 2018 and May 2019 (ClinicalTrials.gov Identifier: NCT06122025).

People with CF were recruited on a consecutive basis, either from outpatient clinics or as an inpatient on the Regional Leeds Adult CF Unit. Eligible people were identified using the Leeds Adult CF Unit electronic healthcare records (EHR; 8) Inclusion criteria consisted of diagnosis of CF (confirmed by the presence a CF phenotype with either two CF causing mutations or a single mutation with two positive sweat chloride (>60 mmol/L)), age 17 years or over, able to give written informed consent, and presence of an electronic healthcare record (EHR) system at the Regional Leeds Adult CF Unit. Patients were excluded if they were taking part in a clinical trial.

Once consented, individuals were allocated to either the intervention or control group (1:1 ratio) using a randomised sampling technique. Random sequenced numbers were generated (https://www.random.org/sequences/) with the smallest value of 1 and largest of 100, and even numbers assigned to the intervention.

The study was approved by London - Camberwell St Giles Research Ethics Service (17/LO/19; 26/11/2017).

Measures

A baseline questionnaire was used to collect demographic data including age and gender.

To evaluate the psychological impact, and effect on patient satisfaction, quality of life (QoL), patient and physician relationships, and pattern and rates of adherence to treatment, of having access to EHR in secondary care, the following questionnaires were completed at week 0, and again at week 26±1:

- GAD-7 (Generalised Anxiety Disorder-7); a validated questionnaire, further validated for use in CF, to assess level of anxiety (primary outcome measure) through seven items covering the preceding two weeks [9, 10].
- CFQ-R (Cystic Fibrosis Questionnaire-Revised; 11,12) to assess QoL (primary outcome measure),
- PHQ-9 (Patient Health Questionnaire-9); a validated questionnaire to measure severity of depression [13], further validated for use in CF [10].
- PAM-13 (Patient Activation Measure-13); a validated questionnaire to assess the knowledge, skills and confidence a person with CF has in managing their healthcare [14].
- PEPPI (patient and provider perceived efficacy in patient-physician interaction); a validated questionnaire to assess the participants' level of trust and interaction with their healthcare

professionals [15].

In addition, the following questionnaires were completed at week 0 and week 26±1, to evaluate the functionality of Patient Access, perceptions and engagement with Patient Access and Computer literacy:

- Perception of and intention to engage with Patient Access, to assess patients’ thoughts about having access to their medical records in terms of reasons for accessing the records, expected effect of having access to them, and barriers to acceptance. This questionnaire was based on a modified OpenNotes pre-survey [16] and the Physician and Patient Attitudes toward Technology in Medicine survey [17, 18].
- Perception of and engagement with Patient Access (Intervention group only), which contained items from the baseline questionnaire modified to reflect having had access to their records
- Computer literacy was assessed using a questionnaire modified from the “My diabetes, my way” survey to assess types, frequency, and experience of computer/internet use
- PHWSUQ (Perceived Health Web Site Usability Questionnaire; intervention group only) to assess satisfaction, ease of use and usefulness of the intervention [19].

Detailed description of the questionnaires used is available in the Supplementary Materials.

Finally, for the intervention group only, data relating to frequency of logins to their records were collected.

Procedures

Upon enrolment, participants completed the consent form and baseline questionnaires in the following order: GAD-7, PHQ-9, PAM-13, CFQ-R, PEPPI, computer literacy and ‘perceptions of and intention to engage with Patient Access’. Participants were then randomised into either the intervention or control group. Those in the intervention group were instructed in how to gain access and the functions of Patient Access explained to them. After 26 (+/-1) weeks, participants completed the follow-up questionnaires (GAD-7, PHQ-9, PAM-13, CFQ-R, PEPPI, computer literacy). Those in the intervention group also completed the end of intervention ‘Perception of Patient Access and their engagement’ questionnaire and PHWSUQ. Following successful completion of the questionnaires, participants in the control group were granted access to their EHR if they expressed interest.

Statistical Analysis

An *a priori* sample size calculation was performed using the following formula, assuming a 2-sided 5% significance level, a standardised effect size of 0.6, 80% power, and a drop-out rate of 10%. The calculation indicated that 100 participants would be required, allocated to group on a 1 intervention: 1 control, resulting 50 individuals being recruited to the intervention (given online access to their own secondary care EHR) and 50 people to the control group (no access to their secondary care EHR).

Descriptive statistics were produced for computer literacy. Data are expressed as number or median [interquartile range; IQR] as appropriate. For proportions a Fisher's exact test was used, and for measures a Mann-Whitney U test was used for between subjects. No correction for multiplicity was applied. P <0.05 was used as a guide to significance and all computations used IBM SPSS v26.0 or higher (IMP, Armonk, New York). Usage patterns were derived from the system audit trail which logs when users log in to the system.

Results

Participants characteristics at baseline

Three hundred and fifty people met the inclusion criteria. In total, 102 patients were recruited, 51 in each group. An extra individual was recruited to each group to account for two people who dropped out shortly after consent and randomisation respectively. Baseline characteristics are shown in Table 1.

Groups were similar for age (intervention: 27.5 (IQR 14.0) years vs. control 27 (IQR 15.0) years, P =.960) and sex distribution (intervention 27 males, control 32 males, P =.316).

At baseline, there was no difference between groups for levels of anxiety (GAD-7) or depression (PHQ-9), knowledge, skills and confidence a person with CF has in managing their healthcare (PAM-13), their level of trust in and interactions with their healthcare professionals (PEPPI), the three-symptom QoL scales (weight, digestion and respiratory), and seven of the nine QoL (CFQ-R) domains (physical, role/school, vitality, emotion, social, body image, eating, treatment burden, health perceptions; Table 1). Those in the intervention group had higher levels of health perceptions and social functioning (P =.042 and P =.0008 respectively). Computer literacy was similar across groups (Table 2).

Table 1. Participant characteristics for the intervention and control group (median and IQR unless otherwise stated)

	Baseline			**Follow up**		
	Active group	**Control group**	***P***	**Active group**	**Control group**	***P***
Anxiety level (GAD)	4.0 (5.0)	3.0 (7.0)	>0.99	3.0 (5.0)	5.0 (5.0)	>0.99
QoL Physical Functioning (CFQ-R)	62.50 (51.04)	45.83 (62.50)	.369	60.42 (65.63)	50.00 (62.50)	.481
QoL Vitality (CFQ-R)	50.0 (35.42)	41.67 (25.0)	.763	54.17 (41.67)	41.67 (41.67)	.350
QoL Emotional Functioning (CFQ-R)	73.33 (26.67)	66.67 (93.33)	.169	86.67 (38.33)	66.67 (43.33)	.222
QoL Social Functioning (CFQ-R)	72.22 (22.22)	61.11 (33.33)	.0008	66.67 (27.78)	61.11 (36.11)	.650
QoL Role Functioning (CFQ-R)	75.00 (33.33)	66.67 (33.33)	.152	75.00 (41.67)	75.00 (45.83)	.377
QoL Body Image (CFQ-R)	66.67 (55.56)	66.67 (44.44)	.290	77.78 (33.33)	66.67 (44.44)	.250
QoL Eating Disturbances (CFQ-R)	100 (22.22)	88.89 (22.22)	.303	88.89 (22.22)	100.0 (33.33)	.532
QoL Treatment burden (CFQ-R)	55.56 (25.00)	55.56 (33.33)	.807	55.56 (33.33)	55.56 (38.89)	.332
QoL Respiratory Symptoms (CFQ-R)	55.56 (29.17)	61.11 (27.78)	.738	63.89 (33.33)	55.56 (38.39)	.895
QoL Health Perceptions (CFQ-R)	61.11 (33.33)	44.44 (44.44)	.042	55.56 (44.44)	55.56 (38.89)	.789
QoL Weight (CFQ-R)	83.33 (66.67)	66.67 (66.67)	.127	100.0 (58.33)	66.67 (66.67)	.201
QoL Digestion (CFQ-R)	88.89 (22.22)	88.89 (33.33)	.683	88.89 (3.33)	88.89 (33.33)	.387
Depression level (PHQ)	4.0 (6.0)	6.0 (8.0)	.170	3.0 (7.8)	7.0 (10.5)	.053
PAM-13	65.47 (17.53)	65.47 (19.20)	.237	66.65 (17.11)	60.63 (19.36)	.05
PEPPI	46.00 (10.00)	44.00 (10.00)	.264	49.00 (9.0)	47.00 (8.0)	.379

Table 2. Assessment of computer skills for the intervention and control group

		Baseline		Follow up	
		Active	Control	Active	Control
How would you describe your computer skills? [1] (n)	Poor	0	2	0	3
	Moderate	2	2	3	3
	Average	14	11	10	9
	Good	13	13	15	15
	Very Good	21	23	17	16
Which of the following devices do you own? [1] (n)	Desktop computer	13	10	14	13
	Laptop computer	23	23	33	30
	"Internet-ready" Smart phone	46	49	40	43
	Computer tablet e.g., iPad	35	32	28	25
How often do you use these devices? [1] (n)	Everyday	48	47	44	45
	Several times a week	0	3	1	0
	Several times a month	2	0	0	1
	Less than monthly	0	1	0	0

[1.] One active participant did not complete the question at baseline

At baseline, 96% of those assigned to the intervention and 92% of the control group agreed that Patient Access was a good idea (Table 3). In terms of access, 90% of the intervention group and 84% of the controls thought that patients have a right to see all consultations (rather than healthcare professionals only sharing what they think is appropriate) and the majority of each group thought that having access would improve the patient-healthcare relationship (94% intervention, 86% control). Reasons for wanting access to their records were because they were curious (58% intervention, 66% control), they wanted to see test results (80% intervention, 72% control), they wanted to know about their health (88% intervention, 80% control) and they have a right to see what's in their record (46% intervention, 60% control). Over half of the individuals gave no particular reason for not wanting to access their record (56% intervention, 54% control), whereas the most popular specific reasons were worrying about the privacy of information (12% intervention, 16% control) and because they were afraid about finding something negative about their health which they were not aware about (12% intervention, 16% control).

Over 50% of patients in each group thought that they might show or discuss their records with other people (76% intervention, 54% control) such as their partner (80% intervention, 56% control) or family friend/ relative (72% intervention, 64% control).

Prior to being randomised, the majority agreed (reporting either somewhat agreed and agreed) that they plan to use and access their records for the intervention period (94% intervention, 74% control), that having access would help them understand their health and medical conditions (94% intervention, 84% control), they would remember their care plan better (96% intervention, 88% control), feel more control of their health care (96% intervention, 80% control), and that learning how to use Patient Access would be easy for them (86% intervention, 82% control) because they had the resources (94% intervention, 88% control). The majority also disagreed (either somewhat disagreed and disagreed) that as a result of having access, they would worry more (78% intervention, 70% control), be concerned about privacy (80% intervention, 74% control), or security (74% intervention, 68% control), information would be more confusing than helpful (82% intervention, 72% control), and it would make the doctor's job more difficult (70% intervention, 70% control).

Follow-up

In total, 91 patients completed the six-month study. No differences in age or sex were observed across the two groups considering only those who completed the study (intervention n=45, median age = 27.5 (IQR 12.0) years, 22 males; control group n=46, median age = 27.0 (IQR 15.0) years, 29 males, *P*=.174).

There was no evidence of an effect of Patient Access on levels of anxiety (GAD-7) or depression

(PHQ-9), confidence in managing healthcare (PAM-13), their level of trust in healthcare professionals (PEPPI), computer literacy, the three symptom QoL scales, and eight QoL (CFQ-R) domains (Table 1).

Table 3. Perceptions of and intention to engage with Patient Access for both intervention and control group

			Intervention (n)	Control (n)	*P*
1	In general, making electronic healthcare records available to people with CF (i.e., having Patient Access) is a good idea?[1]	Disagree	0	0	.743
		Somewhat disagree	0	0	
		Somewhat agree	2	3	
		Agree	48	46	
		Don’t know	0	1	
2	How much access should patients have to consultations?[1]	A patient has a right to see them all	45	42	.672
		Healthcare professionals should only share what they think is appropriate	5	8	
3	Why might you like to be able to read your electronic healthcare records (tick/cross all that apply)?[1]	I am curious	29	33	
		I have the right to see what’s in my medical record	23	30	
		I want to see the diagnosis/ test results	40	36	
		I want to check the notes for accuracy	11	10	
		I want to know about my health	44	40	
		Other	9	1	
4	Why might you NOT like to be able to access your electronic healthcare records (tick/cross all that apply)?[2]	I don’t think it would be useful	0	0	
		I do not use the internet very much	0	0	
		I worry about the privacy of information	6	8	
		I do not need to see test results	0	1	
		I do not want to think about my health any more than I have to	1	8	
		I am afraid I will find out something bad about my health that I didn’t know	6	8	
		I do not need to see what healthcare professionals wrote about my visit	2	0	
		No particular reason	28	27	
		Other	2	4	
5	Do you think you might show or discuss your electronic healthcare records with other people?[1]	Yes	38	27	.131
		No	4	10	
		Don’t know	8	13	
6	With whom do you think you might share your electronic healthcare records (tick/cross all that apply)?[3]	Partner	40	28	
		Family friend or relative	36	32	
		Friend	11	8	
		Doctor (outside of cystic fibrosis)	20	19	
		Nurse or Healthcare professional (outside of cystic fibrosis)	16	11	
		Someone else	5	2	
7	Having access to my electronic healthcare record would improve the patient-healthcare professional relationship?[1]	Agree	47	43	.536
		Disagree	3	6	
		Don’t know	0	1	
8	I would better understand my health and medical conditions[1]	Disagree	1	1	.480
		Somewhat disagree	2	3	
		Somewhat agree	15	14	
		Agree	32	28	
		Don’t know	0	4	
9	I would better remember the plan for my care[1]	Disagree	1	2	.690
		Somewhat disagree	0	2	
		Somewhat agree	10	11	

		Agree	38	33	
		Don’t know	1	2	
10	I would feel more in control of my health care[1]	Disagree	1	4	.275
		Somewhat disagree	1	4	
		Somewhat agree	11	9	
		Agree	37	31	
		Don’t know	0	2	
11	I would worry more[1]	Disagree	25	22	.698
		Somewhat disagree	14	13	
		Somewhat agree	5	8	
		Agree	0	2	
		Don’t know	6	5	
12	I would be concerned about my privacy[1]	Disagree	30	25	.603
		Somewhat disagree	10	12	
		Somewhat agree	10	10	
		Agree	0	1	
		Don’t know	0	2	
13	I would be concerned about security of my record[1]	Disagree	28	22	.528
		Somewhat disagree	9	12	
		Somewhat agree	13	13	
		Agree	0	1	
		Don’t know	0	2	
14	The information would be more confusing than helpful[1]	Disagree	25	21	.753
		Somewhat disagree	16	15	
		Somewhat agree	5	5	
		Agree	1	1	
		Don’t know	3	8	
15	It could make my doctor’s job more difficult[1]	Disagree	17	21	.599
		Somewhat disagree	18	14	
		Somewhat agree	9	5	
		Agree	0	1	
		Don’t know	6	9	
16	Learning how to use and access to my electronic healthcare record will be easy for me[6]	Strongly disagree	2	2	.997
		Disagree	1	1	
		Neither agree or disagree	4	5	
		Agree	19	18	
		Strongly agree	24	23	
17	I have the resources necessary to use and have access to my electronic healthcare record (e.g., the internet) [6]	Strongly disagree	3	1	.156
		Disagree	0	0	
		Neither agree or disagree	0	4	
		Agree	10	8	
		Strongly agree	37	36	
18	I plan to use and access to my electronic healthcare record in the next 6 months[6]	Strongly disagree	2	2	.021
		Disagree	0	2	
		Neither agree or disagree	1	8	
		Agree	17	7	
		Strongly agree	30	30	

In the active group, 98% agreed that access was still a good idea and want to continue having access respectively (Table 4). At baseline, patients planned to use and access their records over the 6-month intervention (88%), and did so because they were curious (56%), wanted to see test results (58%) and know about their health (40%), they have a right to see what's in their record (36%) remember what happened at a clinic visit (27%), be sure they understood what the health professional said (22%) and know what the professional was thinking (13%). Over the six-month intervention, eight people did not log into Patient Access at all. Reasons for not doing so were because they had forgotten they had access (n=3), they did not need to see test results (n=2), no particular reason (n=3), and due to worry about the privacy of information (n=1).

Patient Access scored 86% for satisfaction, 82% for ease of use and 80% for usefulness. The median number of logins over the study period was nine (range 1 to 205). For those who did use Patient Access, patients agreed that accessing their record was easy (90%), they understood their CF better (85%), felt more in control of their health (83%), and that information was easy to understand (80%) and more helpful than confusing (88%). There were no privacy or security concerns in 93% and 88% of cases, respectively. Reading the consultations did not impact the way 62.5% felt about healthcare professionals, 22% felt much better, and 15% hadn't considered if their feelings had changed. Seven patients contacted the CF Unit to discuss something in their record, with four people wanting an explanation of a test result, one patient wanted to report something they thought was an error, and two patients cited another reason not provided on the questionnaire. All were satisfied with the healthcare professional's response. Two-thirds of patients (69%) showed, discussed, or shared their record with other people, with the majority reporting sharing it with their partner (54%) or family member (59%).

Table 4. Perceptions of and engagement with Patient Access (intervention group only)

			(n)
1	In general, making electronic healthcare records available to people with CF (i.e., having Patient Access) is a good idea? **3 people not answer**	Disagree	0
		Somewhat disagree	0
		Somewhat agree	2
		Agree	39

		Don't know	1
2	Did you log in and access your electronic healthcare record at any point during the past 6 months? **4 people not answer**	No	8
		Yes	33
3	Why might you like to be able to read your electronic healthcare records (tick/cross all that apply)?	I was curious	25
		I have the right to see what's in my medical record	16
		I wanted to see the diagnosis/ test results	26
		I wanted to know what my health professional was thinking	6
		I wanted to check my record for accuracy	5
		I wanted to be sure I understood what the health professional said	10
		I wanted to remember what happened in the visit	12
		I wanted to know about my health	18
		No particular reason	0
		Other	3
4	Why did you not access your electronic healthcare records (tick/cross all that apply)?	I didn't think it would be useful	0
		I do not use the internet very much	0
		I thought reading the record would make me nervous or anxious	0
		I do not want to think about my health more than I have to	0
		I am afraid I will find out something bad about my health that I didn't know	0
		I do not need to see what healthcare professionals wrote about my visit	0
		I forgot I could access my healthcare records online	3
		I worry about the privacy of information	1
		I do not need to see test results	2
		No particular reason	3
		Other	3
5	How easy was it to understand your healthcare records? **5 people not answer**	Very difficult	0
		Somewhat difficult	3
		Someway easy	12
		Very easy	20
		Don't know	5
6	Did you ever contact the CF unit about something in your healthcare record? **6 people not answer**	Yes	5
		No, I did not feel any need to	32
		I considered it, but decided not to	1
		Don't know/ don't remember	0
7	(If applicable) Why did you decide to contact your healthcare professional about something in your healthcare records **38 people not answer**	I wanted an explanation, for example of a test result	4
		I wanted something removed from my record	0
		I wanted to report something I thought was an error in my record	1
		I wanted to discuss something I disagreed with	0
		Another reason	2
8	Were you satisfied with the healthcare professional's response to your request? **38 people not answer**	Yes	7
		Somewhat	0
		No	0
9	Did you show, discuss, or share your healthcare record with other people? **6 people not answer**	Yes	27
		No	11
		Don't know/ don't remember	1
10	With whom do you show/ discuss/share your healthcare records? **6 people not answer**	My partner	21
		A family friend or relative	23
		A friend	4
		A doctor (outside of cystic fibrosis care)	3
		A nurse or healthcare professional (outside of cystic fibrosis care)	2
		Someone else	2
11	I would like to continue having access to my electronic healthcare record. **5 people not answer**	Yes	39
		No	1
12	I understand my health and medical	Disagree	0

	conditions better? **5 people not answer**	Somewhat disagree	2
		Somewhat agree	8
		Agree	26
		Don't know	4
13	I remember to plan for my care better **5 people not answer**	Disagree	1
		Somewhat disagree	3
		Somewhat agree	11
		Agree	21
		Don't know	4
		Don't know	3
14	I feel more in control of my health care **5 people not answer**	Disagree	0
		Somewhat disagree	6
		Somewhat agree	7
		Agree	26
		Don't know	1
15	I am concerned about my privacy **5 people not answer**	Disagree	26
		Somewhat disagree	11
		Somewhat agree	2
		Agree	0
		Don't know	1
16	I am concerned about security of my record **5 people not answer**	Disagree	26
		Somewhat disagree	9
		Somewhat agree	4
		Agree	0
		Don't know	1
17	I felt offended **5 people not answer**	Disagree	34
		Somewhat disagree	3
		Somewhat agree	2
		Agree	0
		Don't know	1
18	Did reading your electronic healthcare records, specifically the consultations, change the way you feel about healthcare professionals? **5 people not answer**	Yes, felt much worse	0
		Yes, felt much better	9
		No	25
		Don't know	6
19	(At the start of the study) I planned to use and access to my electronic healthcare record in the next 6 months **5 people not answer**	Strongly disagree	0
		Disagree	0
		Neither agree or disagree	5
		Agree	6
		Strongly agree	29

Discussion

Principal findings

In contrast to primary care, secondary care is in the early stage of offering full online access. This is the first study to provide secure access of secondary care records in cystic fibrosis (CF) which has incorporated the feedback about which aspects of their electronic healthcare record (EHR) people with CF wish to access and priorities for development [20].

Over the next few years, there is likely to be significant change in the sharing of medical information between patients and their health care providers. This transference of key information will be bidirectional and include clinical and physiological data collected on individual mobile devices within the home and work environment. In the UK, secure access to personal health records is now well established in primary care. However, access to secondary care records remains limited, due in part to the underinvestment in hospital IT infrastructure and the presence of multiple legacy systems. A key driving force for the expansion of online access is the need to deliver health information transparency, improve health care, quality of records and empower patients to co-manage their own health [21-23].

The changes in digital information exchange of personal medical information has the potential of increasing patient anxiety and may alter the way health care professionals record clinical information due to anxiety about various aspects of privacy, confidentiality, security, patient safety and potentially increased phone calls and or text communications [24]. However, several studies suggest that online access to medical records can result in significant benefits and either reduce or have no effect on patient anxiety [24–27]. Positive effects can include greater patient empowerment, ownership, and improved knowledge of the underlying conditions [24–27]. This was reflected in our study with patients perceiving that online access aided them to better understand their condition, plan for their care better and feel more in control of their health, while providing medical information which was relatively easy to understand and proved more helpful than confusing.

In contrary to the literature [28], levels of anxiety were not increased in our population and may reflect the chronic nature of the disease and the regular and close communication with a familiar multidisciplinary team.

Although all patients had relatively high activation levels (knowledge, skills, and confidence in managing their own health and care) at baseline, and were similar between groups, the results from the PAM-13 questionnaire suggest that having access to their EHR may help sustain and reinforce this. At follow-up, those in the control group had significantly lower activation levels than the intervention group. This supports the literature showing that Patient Access can empower individuals in managing their own health [1, 24, 26].

Research suggests that uptake of Patient Access is affected by privacy and security concerns [2, 29]. In our cohort this was true for one participant in the intervention group who never accessed their record for this reason. Nevertheless, the opportunity to access their records was positively received by the vast majority of the patients who completed the study. In addition, the percentage of people who had privacy and security concerns respectively decreased over the six months (20% and 26% vs. 4% and 9%).

On average, participants in the intervention group accessed their records more than once a month, which suggests that information contained in their EHR may need to be accessed outside of their clinic visit, and the convenience reduces the need for the patient to contact the CF Unit. Increased workload is cited in the literature as a concern by healthcare professionals in patient's having access [3]. Seven patients contacted the CF Unit during the intervention in relation to their records. Although the method of communication (telephone, text, email, face-to-face) or impact on the healthcare professional's workload is unknown, it is positive that only a relatively small percentage of patients made contact and all patients were satisfied with the professional's response.

The level of trust in, and interactions with, their healthcare professionals and levels of self-efficacy (confidence) in self-care and self-management did not change for the majority of those with access. For those that had considered the impact of reading consultations, 22% said they felt much better towards health care professionals afterwards, therefore enhancing patient-provider communication. However, it is unknown if healthcare professionals altered their consultation writing style knowing patients would now be able to view them [30].

Implications for clinical practice

The use of online access to EHR is likely to vary between individuals with uptake being influenced by accessibility, digital literacy, health condition and age of the user. Previous studies have reported improved patient engagement following the introduction of online access to EHR, although the design and function of the portal can be perceived as non-patient centric and inadequate by users [31]. In the present study, patients gave a high score for satisfaction, with ease of use and usefulness slightly lower, suggesting that improvement in usability and functions may be needed. All but one patient agreed that Patient Access was a good idea and wished to continue with access after the six months. Since the end of the intervention, access to EHR has been granted to all adult patients with CF at the Leeds CF unit who wish to have this resource.

Conclusions

Our results suggest that increased patient information sharing through Patient Access to EHR is beneficial and desirable to patients. There was no evidence of an effect of Patient Access on levels of anxiety and QoL but improved subjective understanding, engagement, and control in the management of their CF. Prospective studies are needed to investigate the long-term effect of such interventions on objective health outcomes and how we can improve the functionality of such application from the patient perspective.

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Patient and public involvement in research: Previous research sought patient feedback regarding which aspects of their EHR people with CF wish to access, and their priorities for development [20]. This was incorporated into the design of this study. People with CF were also involved in the design of this study, and were asked to assess the burden of questionnaire completion.

Abbreviations:

CF: cystic fibrosis
CFQ-R: Cystic Fibrosis Questionnaire-Revised
EHR: electronic healthcare record
GAD-7: Generalised Anxiety Disorder-7
IQR: interquartile range
PAM-13: Patient Activation Measure-13
PEPPI: patient and provider perceived efficacy in patient-physician interaction
PHQ-9: Patient Health Questionnaire-9
PHWSUQ: Perceived Health Web Site Usability Questionnaire
QoL: quality of life

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Supplementary Files

Multimedia Appendixes

Detailed description of questionnaires.
URL: http://asset.jmir.pub/assets/3401457d81732c453dfd40630d0a3424.docx