

Your views and preferences for access to the Leeds CF unit's electronic healthcare record

From October 2015 to March 2016, we conducted the first UK study to examine your views and preferences to help us develop personalised access to the Leeds CF unit's electronic healthcare record.

There were 2 objectives of this study:

- (1) To identify your views on the tools and functions that require development for personalised access to the electronic healthcare record
- (2) To identify priorities regarding what you want from the electronic healthcare record.

A total of 201 patients (106 were males) completed the questionnaire. People with CF ranged from 17-58 years old (median age was 29 years) and had a mean body mass index (BMI) of 23.5 kg/m². For those who participated, they attend routine two monthly appointments and were noted to have a wide range of lung function scores, ranging from 15% to 120%, and the number of hospital admissions within the previous year ranged from 0–8 (median number was 1).

Your views about personalised access to your electronic health record

You were asked about your views regarding personalised access to your electronic healthcare record across four topics, and answered using a 6-point rating scale: very important (1); important (2); slightly important (3); ordinary (4); not important (5); very unimportant (6).

The topics were:

- (1) What functions of the electronic healthcare record do you see as valuable to have
- (2) What functions of the electronic healthcare record would you like to have access to
- (3) What information would you like to send to your electronic healthcare record
- (4) What types of communication and feedback do you wish to include in your electronic healthcare record, including communication with clinicians, your experience, comments on errors or missing information, and future wishes such as living wills and advanced directives.

You were also asked to rank 15 functions in the order of importance from 1 to 15 to inform what you consider to be priorities and how we develop access to the electronic healthcare record.

(1) What functions of the electronic healthcare record do you see as valuable to have?

You placed functions which were related towards information that helped in your day-to-day management such as lung function, weight, sputum microbiology, blood results and medication lists (see Table below). This was supported by your high ratings and preferences for accessing similar information. You placed lower ratings on access to information and knowledge portals.

Item that might have value	Important/very important	Quite important/ordinary	Not important/very unimportant
Weight chart	164 (96.5%)	28 (2.5%)	8 (4%)
Lung function	192(95.5%)	5 (2.5%)	2 (1%)
CRP	165 (82.1%)	30 (14.9%)	4 (2%)
Blood glucose	120 (59.7%)	68 (33.8%)	10 (5%)
List of medications	178 (88.6%)	18 (9%)	3 (1.5%)
Latest sputum microbiology	175 (87.1%)	22 (10.9%)	2 (1%)
Blood results	175 (87.1%)	21(10.4%)	3 (1.5%)
Allergies	143 (77.1%)	45 (22.4%)	11 (5.5%)
Bone scan results	116 (57.7%)	74 (36.8%)	8 (4%)
Procedure dates	149 (74.1%)	48 (23.9%)	1 (0.5%)
Alert for repeat tests	146 (72.6%)	48 (23.9%)	4 (2%)
Alert for overdue tests	147 (73.1%)	44 (21.9%)	5 (2.5%)
Access to summary information	132 (65.7%)	58 (28.9%)	8 (4%)
Links to knowledge sites and portals	51 (25.4%)	108 (53.7%)	39 (19.4%)

CRP, C reactive protein; EHR, electronic health record.

(2) What functions of the electronic healthcare record would you like to have access to?

You most wanted to access to measures regarding lung function, blood results, weight and sputum microbiology, changes in and list of medications and access to appointment reminders and consultation summaries (see Figure 1 below).

Although more than 50% of you regarded each category as very important/important, vaccination information, genetic mutation, type and dates of intravenous antibiotic treatments and tracking of admissions and referral on to other departments were considered important by fewer of you.

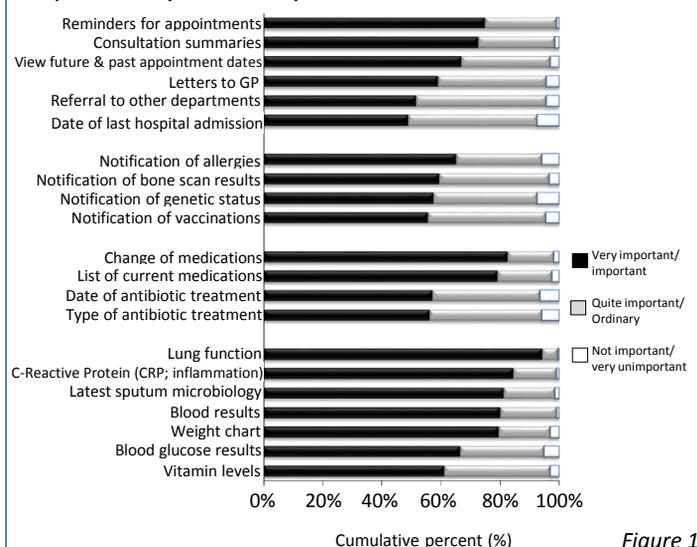


Figure 1

(3) What information would you like to send to your electronic healthcare record?

Types of information and requests that you would like to send to your record was split into the four subcategories:

1. Information generated by you
2. Treatment and prescriptions
3. Physiological measures (lung function, weight etc.)
4. Appointment scheduling information.

Most of you (83%) regarded the function of sending prescription requests as important/very important (see figure 2 below), supported by similar ratings for wanting to access your current list of medications (78%) and changes in medications (82%). Fewer of you (40%) regarded the sending of information relating to food, exercise, mood and quality-of-life (QoL) measures as an important function.

60% of you said that completing a previsit clinic interview to highlight concerns prior to your appointment was very important/important, although 50% or less of you considered completing information about food intake and exercise, quality of life (QoL), mood and pain before your appointment as important.

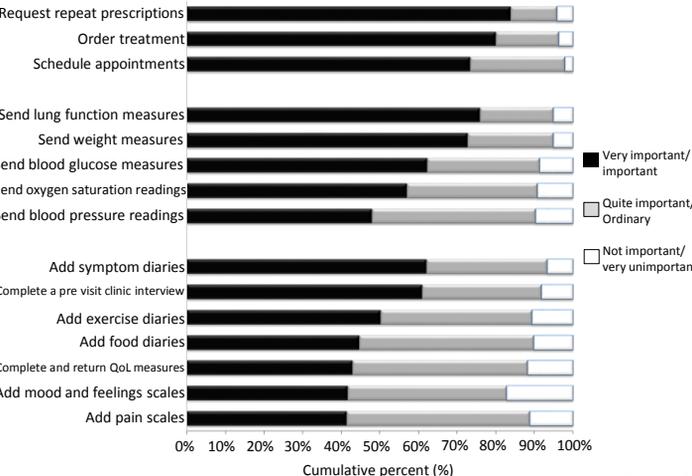


Figure 2

(4) What types of communication and feedback do you wish to include in your electronic healthcare record?

More than 80% of you regarded email contact with the clinicians as high in importance (see figure 3 below). Feedback on drugs and treatment was also important as was sending questions to inform the basis of your next clinic appointment. Your longer-term care informed by advanced directives, feedback of your experience of care and organ donor wishes were more diverse in response.

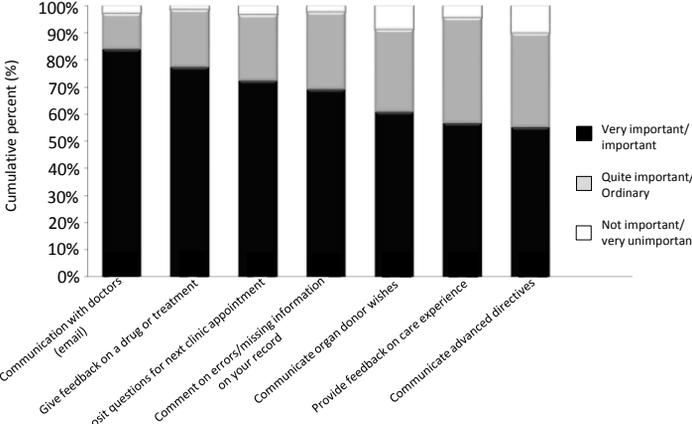


Figure 3

What functions do you think are high priority in viewing your electronic healthcare record?

For this question, you had to rank various functions from 1 (most important) to 15 (least important). Direct access to clinical measures was considered the most important as was access to list of medications (see figure 4 below). In contrast, the ability to comment on experience of care and to comment on errors or missing information were ranked lowest.

With increasing age, you were less likely to consider it very important to send a food/enzyme diary to your electronic healthcare record, compared to not important/very unimportant. Similarly, for pain diaries, and exercise diaries, you were less likely to respond that this was important compared to unimportant with increasing age.

Age had little impact on how you rated and ranked responses, with the exception of repeat prescription requests where those of you who were older than 50 years ranked this significantly lower (and therefore of greater importance) than people who were younger.

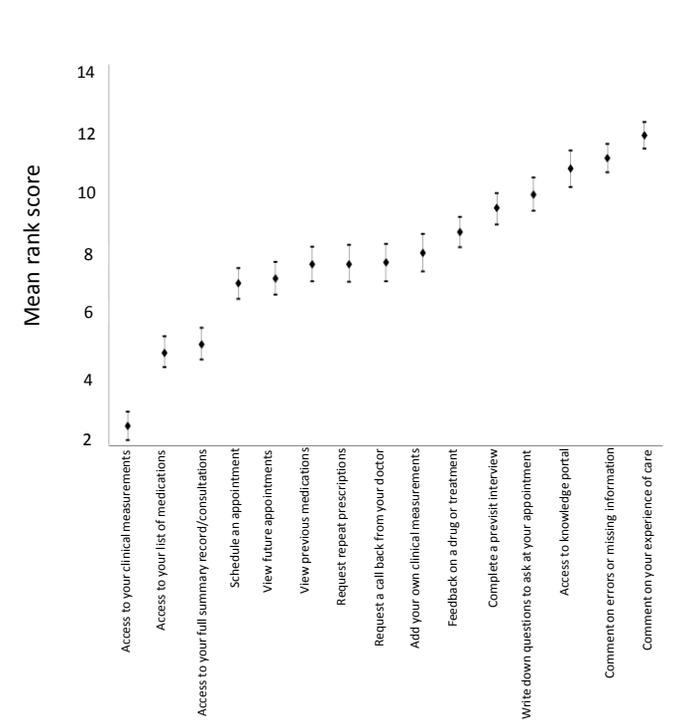


Figure 4

You have told us what you want, so what are we doing now?

We have taken on board your views and preferences regarding what you want to use the electronic healthcare record for, and what you consider as important. We are currently implementing these as part of a study which will be starting this year! This study will allow a number of you to have access to your electronic record as part of a pilot study which will run for 6 months.