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What functionality do patients want from an electronic clinical record (ECR)

Background

Personalised online access to health care records has been piloted in the UK but not adopted beyond requesting repeat prescriptions and appointments within primary care. In hospital care, evaluation has been more limited, due to poorer implementation of ECR. At the CF regional centre, Leeds, a comprehensive ECR for hospital care was developed in 2007, using CF as a chronic disease model. New planned, functionalities include full patient access to their ECR and sharing of a personalised patient generated record.

The objectives were:

1. To identify patient views on the tools and functionality requiring development for personalised access to their hospital ECR and
2. To identify patient led priorities for functional development.

Methods

A cross-sectional, self-complete questionnaire survey was administered to 201 patients who were consecutive attendees at the regional adult cystic fibrosis (CF) centre in Leeds, UK.

Study participants were invited to take part in the study by the specialist research nurse as they attended routine out-patient clinic appointments or ended their in-patient care, each at a time of clinical stability.

Patients were asked their views within four key areas:

- Functionality considered valuable within the ECR
- Functions of the ECR that patients would like to have access to
- The information patients wished to send to their ECR
- The communication and feedback patients wished to input into their ECR; including communication with clinicians, patient experience, comments on errors or omissions, and future wishes such as living wills and advanced directives

Finally, and to aid in future focus of priority, respondents were asked to rank 15 functions in order of priority.

Ethics approval was granted by the National Research Ethics Service London and Hampstead REC Committee [REC No: 15/LO/1428]

Results

Of 204 patients invited to participate in the study, a total of 201 patients consented to complete the questionnaire [106 (52.7%) male]. Median age of subjects was 29 years (range 17-58 years) and median number of hospital admissions in the previous year was 1 (range 0-8).

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Fig. 1: Function patients considered valuable within the ECR

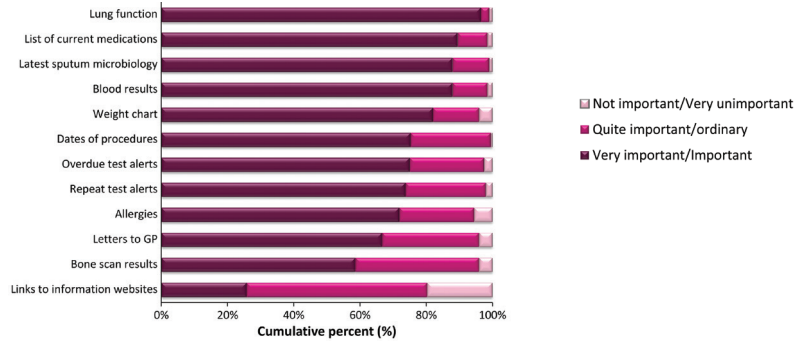


Fig. 2: Patients access wishes to ECR

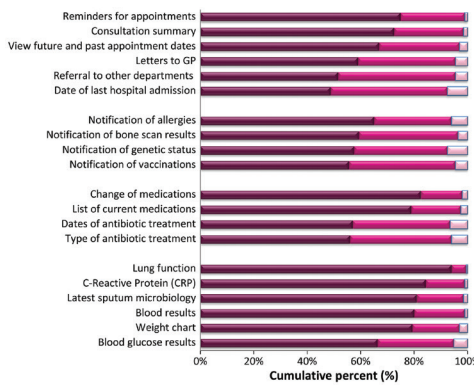


Fig 3: Patient preferences for information they wish to send to their ECR

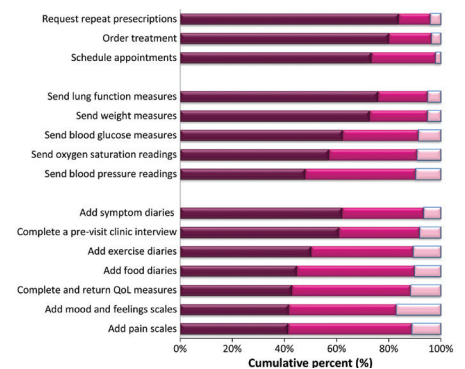


Fig 4: How patients wanted to communicate through their ECR

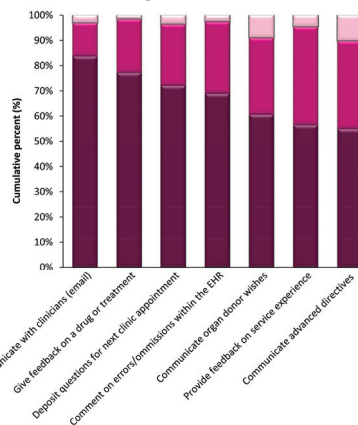
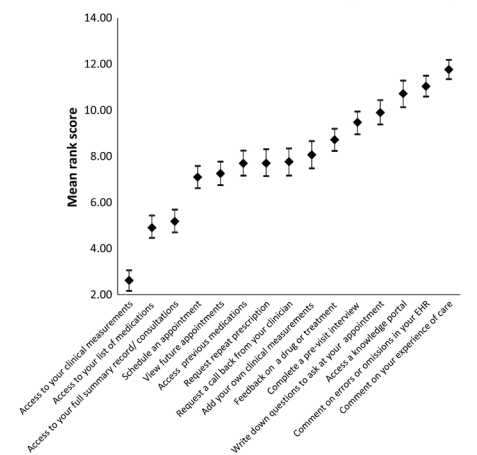


Fig 5 Ranking of functions that patients requested within the ECR (Lower numbers = higher ranking)



*Figure contents indicate Mean (Confidence interval) for each measure

Conclusions

Patients want extensive personal access to their hospital ECR, placing high importance on the viewing of practical clinical measures and medication management. These influence routine day to day care and are priorities for development

This study has enabled us to establish those functions most important for patients. It has informed the preliminary design of an integrated hospital healthcare record for future testing and evaluation in a population with chronic disease