

ORIGINAL ARTICLE

# Assessing effectiveness and patient perceptions of a novel electronic medical record for the management of inflammatory bowel disease

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## Key words

delivery of care, electronic medical records, gastroenterology, immunology, microbiology and inflammatory bowel diseases.

Accepted for publication 25 July 2021.

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Crohn's Colitis Care (CCCare) is a novel IBD-specific electronic medical record intended to improve IBD care is effective and acceptable to patients. We found it effective at capturing important IBD data and very acceptable to IBD patients.

**Declaration of conflict of interest:** Jane M Andrews is the Board Chair of Crohn's Colitis Cure—a not-for-profit IBD charity, which owns the software described herein; Susan J Connor is on the Board of Crohn's Colitis Cure. Patricia Kaazan, Tracy Li, Warren Seow, Jana Bednarz, Watson Ng, Astrid-Jane Williams, and Joseph L Pipicella have no COI.

**Author contribution:** Patricia Kaazan was involved with the conception and design of the study, data acquisition, analysis and interpretation of data, and the initial and final drafting of manuscript. Tracy Li was involved in data acquisition. Warren Seow was involved in data acquisition. Jana Bednarz was involved in statistical design and interpretation and draft review. Joseph L Pipicella assisted in regulatory/IRB/IEC communication, participant recruitment, and data storage. Krupa Krishnaprasad was involved in data acquisition for patient portal survey. Watson Ng was involved in patient recruitment and draft review. Astrid-Jane Williams was involved in patient recruitment, conception and design, and draft review. Susan J Connor was involved in patient recruitment, conception and design, and draft review. Jane M Andrews was involved in conception and design for the study and supervising senior.

## Abstract

**Background and Aim:** There is an increasing prevalence of chronic disease worldwide, resulting in multiple management challenges. Inflammatory bowel disease (IBD) is an exemplar chronic disease requiring coordinated longitudinal care. We propose that Crohn's Colitis Care (CCCare), a novel IBD-specific, structured electronic medical record is effective at improving data capture and is acceptable to patients.

**Methods:** A comparison was made between IBD-data completeness in usual records and CCCare. CCCare's acceptability to patients was assessed in two independent IBD patient cohorts and included:

- Overall ratings of acceptability.
- Factors associated with pre-exposure acceptability ratings.
- Whether exposure and security concerns influenced acceptability ratings.
- Direct patient feedback through CCCare's patient portal.

**Results:** In all cases reviewed, there was data gain using structured CCCare fields compared with IBD documentation in usual medical records. The overall acceptability in the combined cohort ( $n = 310$ ) was very high. More than three-quarters of patients rated acceptability as  $>7$  of 10. Self-reported information technology (IT) literacy positively associated with acceptability. Exposure had a small positive affect on acceptability, whereas security concerns had little impact on acceptability. Patient portal feedback revealed that most patients are very likely to recommend CCCare to others ( $8.56 \pm 2.2$  [out of 10]).

**Conclusion:** CCCare is effective in supporting more complete IBD-specific data capture compared with usual medical records. It is highly acceptable to patients, especially those with reasonable IT literacy. Patient concerns about privacy and security of electronic medical records (EMRs) did not significantly affect acceptability.

## Introduction

There is an increase in prevalence of chronic disease worldwide,<sup>1</sup> with consequent socioeconomic, financial, and management challenges requiring a consistent, longitudinal healthcare approach.

At least half of the Australian population suffer from a chronic disease<sup>2</sup> and although a management platform applicable to a broad range of conditions has been provided by the National Strategic Framework for chronic conditions,<sup>3</sup> it is also important to address disease-specific issues through the use of tools such as disease-specific electronic medical records (EMRs), which may help address management challenges.

Inflammatory bowel disease (IBD) is an exemplar chronic disease as it requires lifelong care, has high associated costs, and is amenable to successful management with relevant clinical and financial gains from proactive care.<sup>4</sup> A dedicated IBD service quantitatively and qualitatively improves patient outcomes in less than 18 months<sup>5</sup> and the challenge is then to upscale this approach to allow its delivery elsewhere.

A chronic care model significantly decreases costs and healthcare utilization in patients with IBD.<sup>4</sup> With Australia having one of the highest rates of IBD in the world,<sup>6</sup> improved management may result in noticeable community gains.

IBD is a chronic relapsing condition of the gastrointestinal tract with onset of symptoms generally between 12 and 40 years of age. It impairs quality of life<sup>7</sup> and psychological well-being<sup>8</sup> and is associated with high rates of hospitalization and surgery. The inaugural Crohn's and Colitis Australia National IBD audit conducted across 71 hospitals highlighted that patient care in this field is generally poor and inconsistent, with only one hospital meeting the published standard for multidisciplinary care.<sup>9</sup> Most identified shortfalls related a lack of a dedicated IBD service, inadequate data collection, and poor documentation.

The utility of usual medical records—whether electronic or paper—vary depending on the user. They often lack completeness, miss crucial disease-specific features, are illegible, do not provide intelligent alerts, and/or are difficult to access across all contexts in which they are required. Due to the lack of customized disease-relevant fields, generic hospital records are of limited benefit in supporting optimal IBD care as they often fail to capture important data such as weight, smoking status, previous IBD drug reactions, and specific, relevant comorbidities.<sup>10</sup>

Crohn's Colitis Care (CCCare) is a novel IBD-specific EMR launched across multiple hospital-based IBD specialist clinics in Australia and New Zealand since 2018.<sup>11</sup> It was designed by IBD clinicians from the Australian and New Zealand IBD Consortium (ANZIBDC), funded by an Australian charity (Crohn's Colitis Cure, [www.C-C-C.org](http://www.C-C-C.org)) and built by Stratos Technology Partners (Christchurch, NZ). It has two portals: clinician portal and a patient portal.

The clinician portal is the main portal for CCCare. There are structured sections for history, assessment, and management plan. Patient-reported outcomes are co-completed by clinicians and patients during virtual or face-to-face assessments.

The patient portal can be used to send questionnaires to patients. This happens 2 weeks prior to a scheduled visit and seeks information regarding their overall health status (vaccinations, hospital admissions, surgery) and updates about changes in general practitioner, usual adherence to IBD medications along

with a free text area for specific issues. Mental health and quality-of-life surveys can be separately emailed to patients as desired within each unit with results automatically populated into the mental health section of the EMR. Notifications to review any returning patient questionnaires and surveys are sent to the responsible consultant specialist.

CCCare's overarching objectives are as follows:

- Support optimal IBD practice by ensuring documentation is complete, readily available, and easily accessible, aiming to reduce variation in care through structured record keeping and display.
- Facilitate real-time audit and benchmarking across centers by sending non-identified data to a clinical quality registry.
- Support national collaborative research through linkage to a research database and biobanking facility for consenting patients through its research module.

We propose this e-health tool has important implications for IBD care, and more broadly, that similar disease-specific EMRs may also be useful in the management of other chronic conditions.

## Aims

We aimed to:

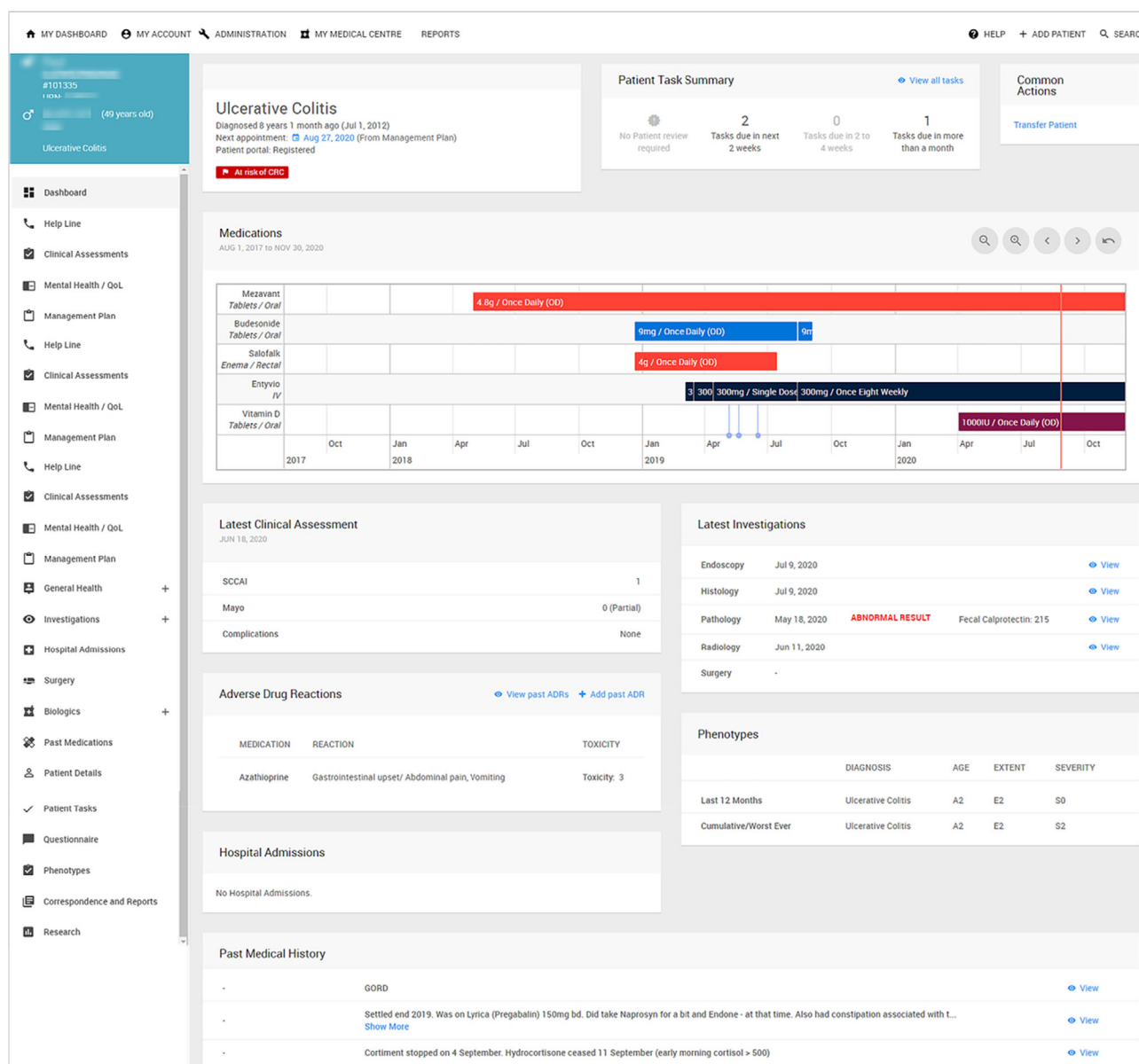
Compare IBD-data completeness between generic medical records and CCCare. Assess patient's acceptability, perceptions, and concerns in relation to CCCare. Explore whether any factors associated with acceptability pre-exposure to CCCare, and the effect exposure and/or security concerns have on acceptability. Analyze patient feedback through CCCare's online patient portal, quantitatively to assess acceptability and qualitatively taking comments on board.

## Methods

Comparison between IBD-data completeness in usual records and CCCare: We compared the completeness of IBD-specific data between pre-existing medical records (discharge summaries, clinic letters, radiology, and laboratory results available on hospital eMR) and CCCare. During active on-boarding of patients to the new eMR, a convenience sample of patients at two tertiary Australian hospitals with dedicated IBD services, the Royal Adelaide Hospital (RAH) ( $n = 50$ ) and Liverpool Hospital (LVH) ( $n = 25$ ), with an encounter in the fourth quarters of 2018 and 2019, respectively, was assessed.

During CCCare implementation, patients with upcoming clinic appointments had their usual EMR reviewed by a dedicated medical officer at each site. Available IBD-specific data were pre-entered into CCCare's structured fields (Fig. 1). Data revealed by this process to be absent from the pre-existing medical record were sought directly from the patient, alternative medical record sources, or by contacting previously visited health facilities. Patients were interviewed by telephone or face-to-face. The extent of data differential between medical records and CCCare was quantified according to the number of CCCare fields that remained unpopulated after usual medical record review, requiring proactive data retrieval.

**Perceptions, acceptability, and factors potentially associated with acceptability.** Patient acceptability of CCCare was assessed with standardized paper-based questionnaires (see Appendices S1 and S2) administered to a convenience



**Figure 1** Representative image of structured Crohn's Colitis Care fields.

sample of IBD patients presenting to an outpatient clinic (RAH or LVH). The pre-exposure cohort of patients completed the questionnaire prior to CCCare exposure in the first and second quarter of 2019 for RAH and LVH, respectively; and the post-exposure cohort completed the questionnaire after receiving care supported by CCCare. These two cohorts were independent (unmatched). The combined cohort refers to both pre- and post-exposure cohorts.

The questionnaire sought patients' perceptions of potential benefits and risks of CCCare using 10-point numeric rating scales, where 0 was "extremely unacceptable" and 10 was "extremely acceptable."

Items scored on the 10-point scale were treated as continuous data, with responses indicated as being between two interval points (e.g. "6 to 7") and being taken to be the mid-point (e.g. "6.5").

Additional data collected only in the pre-exposure cohort included self-assessed information technology (IT) literacy, use of email and social media, and opt-out status with respect to My Health Record, an Australian national online database of personal medical information managed by the federal government as an indicator of comfort with IT security and privacy.

**Patient portal feedback.** Those onboarded onto CCCare were sent an email with a link to the patient portal, where in addition to clinical and demographic data they were asked two questions: one regarding the likelihood they would recommend CCCare to others on a scale of 0–10 (0 being "not likely" and 10 being "extremely likely") and the second sought qualitative sought comments or concerns feedback in a free text field.

**Table 1** Data differential between usual medical records and Crohn's Colitis Care

| Type of data (n)              | Subclasses                      | Number of patients with data gain (%) |     |
|-------------------------------|---------------------------------|---------------------------------------|-----|
| Demographic (73/73)           | Ethnicity                       | 54                                    | 74% |
|                               | Education                       | 53                                    | 73% |
|                               | Occupation                      | 46                                    | 63% |
|                               | Family history                  | 38                                    | 52% |
| IBD-specific (51/73)          | Montreal                        | 41                                    | 56% |
|                               | Disease flare                   | 6                                     | 8%  |
|                               | Compliance                      | 5                                     | 7%  |
|                               | Weight loss                     | 1                                     | 1%  |
|                               | Missed endoscopy                | 1                                     | 1%  |
| Lifestyle 35/73)              | Alcohol                         | 25                                    | 34% |
|                               | Smoking                         | 15                                    | 21% |
| Endoscopy (21/73)             | Rural hospitals                 | 4                                     | 5%  |
|                               | Private facilities              | 8                                     | 11% |
|                               | Pediatric hospital              | 3                                     | 4%  |
|                               | Public Hospital                 | 6                                     | 8%  |
| Surgery (7/73)                | Private surgery                 | 5                                     | 7%  |
|                               | Interstate                      | 2                                     | 3%  |
| Adverse drug reaction (13/73) | IBD drugs adverse drug reaction | 8                                     | 11% |
|                               | Malignancies                    | 5                                     | 7%  |
| Radiology                     |                                 | 11                                    | 15% |

*n*, number of patients with data gain.

**Statistical analysis.** Responses that were unclear or unanswered were assumed to be missing. Continuous variables were reported using means and standard deviations, whereas categorical variables were handled with frequencies and percentages.

Multivariable linear regression was used to assess whether exposure to the software or the level of participants' privacy concerns influenced their acceptability of CCCare. Treatment location (RAH or LVH) was included as an adjustment factor. The level of concern regarding privacy and security of EMRs was a summary measure based on the five relevant questionnaire items, derived using principal components factor analysis. This summary score had a possible range of 0–50.

An exploratory analysis of additional factors that might have been associated with acceptability among the pre-exposure cohort was also performed. The effects of gender, IT literacy, opt-out status with respect to My Health Record, and overall level of concern regarding privacy and security of EMRs on acceptability were investigated using multivariable linear regression, controlling for location. Age group was omitted due to collinearity with IT literacy.

The adequacy of regression models was assessed by visual inspection of residuals. All analyses were conducted using Stata (Version 15, StataCorp, College Station, Texas, USA). The level of statistical significance was set at 0.05.

**Ethics approval.** The questionnaire component of the study was approved by the South Western Sydney Local Health District Human Research Ethics Committee (2019/ETH09751), as was the data comparison component (2020/ETH01541). The questionnaire was undertaken at the RAH primarily to assess consumer engagement with the software and was regarded as a part of ongoing quality assurance and quality improvement of the RAH IBD service. This was discussed with the Central

Adelaide Local Health Human Research Ethics Committee who waived the need for a low-risk human research ethics application. At the RAH, the data comparison component was approved as a quality improvement project. All patients gave verbal consent and willingly provided details needed to complete their CCCare record.

## Results

**Data differential between CCCare and pre-existing medical record.** A review of the records of 75 patients being onboarded to CCCare was completed (50 from the RAH and 25 from LVH). Two patients from the RAH requested to have their data deleted from CCCare and excluded from the analysis, citing privacy concerns, leaving 73 patients for the analysis. In every case, there was a data gap in the usual medical records that required proactive data retrieval to complete the structured fields in CCCare. The major gain was related to demographic data (73/73 = 100% of patients). Other data gains pertained to factors specific to IBD (disease distribution, disease activity, adherence to treatment), lifestyle, surveillance colonoscopy, surgery, adverse drug reactions, and radiology (Table 1).

During this initial usage period, any software-related deficiencies were noted and used to guide software enhancements. Examples included optimizing sections relating to documentation of comorbidities and adverse drug reactions unrelated to IBD.

## Perceptions, acceptability, and factors potentially associated with acceptability

**Overall acceptability.** Of the 210 participants surveyed about acceptability pre-exposure, 200 had complete data (95%). In the post-exposure survey cohort, there were 119 respondents, 110 of whom had complete data (92%). Therefore, 310 respondents

**Table 2** Summary statistics for questionnaire items in overall cohort and by exposure group (mean  $\pm$  SD)

| Questionnaire item                                                                                                                                                            | Pre-exposure cohort ( <i>n</i> = 200) | Post-exposure cohort ( <i>n</i> = 110) | Combined cohort ( <i>n</i> = 310) |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------|----------------------------------------|-----------------------------------|
| Patient's perceptions                                                                                                                                                         |                                       |                                        |                                   |
| How important is your doctor having all the information about your disease, treatment, admissions, test results, and hotline discussions in one place, available at any time? | 9.1 $\pm$ 1.7                         | 9.6 $\pm$ 0.9                          | 9.2 $\pm$ 1.5                     |
| How important is being handed a summary letter at the end of your specialist appointment with an updated care plan?                                                           | 8.4 $\pm$ 2.2                         | 8.8 $\pm$ 1.5                          | 8.5 $\pm$ 2.0                     |
| How important is ability to travel around Australia and receive consistent care at other inflammatory bowel disease (IBD) centers with immediate access to your IBD record?   | 8.5 $\pm$ 2.2                         | 8.8 $\pm$ 2.2                          | 8.6 $\pm$ 2.2                     |
| How important is being able to input data yourself regarding your current symptoms?                                                                                           | 7.8 $\pm$ 2.5                         | 8.1 $\pm$ 2.2                          | 7.9 $\pm$ 2.4                     |
| How important is knowing your doctor has electronic prompts to alert to "danger" signs and cancer surveillance reminders?                                                     | 8.8 $\pm$ 1.7                         | 9.0 $\pm$ 1.7                          | 8.9 $\pm$ 1.7                     |
| How important is being confident your doctor is meeting acceptable care standards in IBD?                                                                                     | 9.2 $\pm$ 1.4                         | 9.5 $\pm$ 1.0                          | 9.3 $\pm$ 1.3                     |
| Patient's security concerns                                                                                                                                                   |                                       |                                        |                                   |
| Level of concern regarding privacy and security of your information                                                                                                           | 6.9 $\pm$ 3.2                         | 7.3 $\pm$ 3.1                          | 7.0 $\pm$ 3.1                     |
| Level of concern regarding use of de-identified data for audit and research purposes                                                                                          | 5.8 $\pm$ 3.5                         | 5.7 $\pm$ 3.7                          | 5.7 $\pm$ 3.6                     |
| Level of concern regarding linkage with other electronic databases or "on selling" of information                                                                             | 7.0 $\pm$ 3.0                         | 7.3 $\pm$ 3.3                          | 7.1 $\pm$ 3.1                     |
| Level of concern regarding lack of control over which health care professional can access your data                                                                           | 6.6 $\pm$ 3.0                         | 6.8 $\pm$ 3.1                          | 6.7 $\pm$ 3.1                     |
| Level of concern regarding potential for data loss                                                                                                                            | 7.2 $\pm$ 2.9                         | 7.4 $\pm$ 2.7                          | 7.3 $\pm$ 2.9                     |
| Level of concern lack of interface with other electronic medical records such as your GP's software                                                                           | 6.8 $\pm$ 2.9                         | 6.7 $\pm$ 3.1                          | 6.8 $\pm$ 2.9                     |
| Patient's general acceptability                                                                                                                                               |                                       |                                        |                                   |
| How comfortable are you having an electronic record of your IBD and treatment created by your care providers                                                                  | 7.9 $\pm$ 2.3                         | 8.6 $\pm$ 1.9                          | 8.2 $\pm$ 2.2                     |
| How willing would you be to fill in questionnaires about your IBD directly into an electronic record using a tablet while waiting for your clinic appointment?                | 7.3 $\pm$ 2.6                         | 8.0 $\pm$ 2.4                          | 7.6 $\pm$ 2.6                     |
| How acceptable do you find the idea of an electronic medical record made specifically for IBD?                                                                                | 8.2 $\pm$ 2.2                         | 8.9 $\pm$ 1.7                          | 8.4 $\pm$ 2.1                     |

All items were measured on a 10-point numeric rating scale.

**Table 3** Multivariable linear regression on effect of exposure on acceptability

| Variable                                                                   | Coefficient ( $\beta$ ) | SE   | (95% CI)      | <i>P</i> value |
|----------------------------------------------------------------------------|-------------------------|------|---------------|----------------|
| (Intercept)                                                                | 7.37                    | 0.45 |               |                |
| Cohort (post-exposure vs pre-exposure)                                     | 0.84                    | 0.22 | (0.40, 1.29)  | <0.0001        |
| Overall level of concern regarding privacy and security of EMRs (per unit) | 0.01                    | 0.01 | (−0.01, 0.03) | 0.459          |
| Location (Liverpool vs RAH)                                                | 0.67                    | 0.23 | (0.21, 1.12)  | 0.004          |

Linear regression results—effect of exposure on acceptability. The coefficient gives the average change in acceptability score associated with that variable.

95% CI, 95% confidence interval for regression coefficient; EMRs, electronic medical records; SE, standard error; RAH, Royal Adelaide Hospital.

were included in the combined cohort for analysis. The overall level of acceptability was very high in both cohorts. The mean acceptability in the combined cohort was  $8.4 \pm 2.1$ , with ratings of  $8.2 \pm 2.2$  for the pre-exposure group and  $8.9 \pm 1.7$  for the post-exposure group. More than three-quarters of participants

(241/310 = 78%) rated acceptability as 8 out of 10 or greater. Summary statistics for questionnaire items are given in Table 2.

**Effect of exposure and level of concern on acceptability.** Controlling for hospital location, a linear regression model

**Table 4** Demographic characteristics

| Characteristic                        | Location                                            |        |                                                         |        |                                                                  |        |
|---------------------------------------|-----------------------------------------------------|--------|---------------------------------------------------------|--------|------------------------------------------------------------------|--------|
|                                       | Liverpool Hospital<br>( <i>n</i> = 160 respondents) |        | Royal Adelaide Hospital<br>( <i>n</i> = 50 respondents) |        | Overall (both locations combined;<br><i>n</i> = 210 respondents) |        |
|                                       | Freq.                                               | (%)    | Freq.                                                   | (%)    | Freq.                                                            | (%)    |
| Gender                                |                                                     |        |                                                         |        |                                                                  |        |
| Male                                  | 81                                                  | (50.6) | 21                                                      | (42.0) | 102                                                              | (48.5) |
| Female                                | 79                                                  | (49.3) | 29                                                      | (58.0) | 108                                                              | (51.4) |
| Age group                             |                                                     |        |                                                         |        |                                                                  |        |
| 25 years or under                     | 30                                                  | (18.7) | 11                                                      | (22.0) | 41                                                               | (19.5) |
| 26–35 years                           | 34                                                  | (21.2) | 13                                                      | (26.0) | 47                                                               | (22.3) |
| 36–45 years                           | 38                                                  | (23.7) | 6                                                       | (12.0) | 44                                                               | (20.9) |
| 46–55 years                           | 23                                                  | (14.3) | 9                                                       | (18.0) | 32                                                               | (15.2) |
| 56–65 years                           | 27                                                  | (16.8) | 6                                                       | (12.0) | 33                                                               | (15.7) |
| 66–75 years                           | 8                                                   | (5.0)  | 5                                                       | (10.0) | 13                                                               | (6.1)  |
| Routine use of email                  |                                                     |        |                                                         |        |                                                                  |        |
| Yes                                   | 130                                                 | (81.2) | 48                                                      | (96.0) | 178                                                              | (84.7) |
| No                                    | 30                                                  | (18.7) | 2                                                       | (4.0)  | 32                                                               | (15.2) |
| Routine use of social media           |                                                     |        |                                                         |        |                                                                  |        |
| Yes                                   | 115                                                 | (71.8) | 48                                                      | (84.0) | 157                                                              | (74.7) |
| No                                    | 43                                                  | (26.8) | 2                                                       | (16.0) | 51                                                               | (24.2) |
| Missing                               | 2                                                   | (1.2)  | 0                                                       | (0.0)  | 2                                                                | (0.9)  |
| Opted out of MyHealth record          |                                                     |        |                                                         |        |                                                                  |        |
| Yes, opted out                        | 27                                                  | (16.8) | 17                                                      | (34.0) | 44                                                               | (20.9) |
| No, did not opt out or unsure         | 120                                                 | (75.0) | 32                                                      | (64.0) | 152                                                              | (72.3) |
| Missing                               | 13                                                  | (8.13) | 1                                                       | (2.0)  | 14                                                               | (6.6)  |
| General practitioner contact for plan |                                                     |        |                                                         |        |                                                                  |        |
| Yes                                   | 43                                                  | (26.8) | 20                                                      | (40.0) | 63                                                               | (30.0) |
| No                                    | 108                                                 | (67.5) | 30                                                      | (60.0) | 138                                                              | (65.7) |
| Unsure                                | 1                                                   | (0.6)  | 0                                                       | (0.0)  | 1                                                                | (0.4)  |
| Missing or N/A                        | 8                                                   | (5.0)  | 0                                                       | (0.0)  | 8                                                                | (3.8)  |

indicated a small but significant effect of software exposure on patient acceptability ( $P < 0.0001$ ), with acceptability 0.8 units higher on average among those in the post-exposure cohort relative to the pre-exposure cohort (95% confidence interval [CI] 0.4, 1.3).

The average overall level of concern regarding privacy and security of EMRs was similar between exposure cohorts and although moderately high, its adjusted effect on acceptability was negligible (Table 3).

**Effect of demographic and other factors.** Demographic characteristics of participants in the pre-exposure cohort, by location (RAH or LVH) and overall are reported in Table 4. Mean self-rated IT literacy (out of 10) across all respondents was  $7.4 \pm 2.4$ , indicating an overall high level. Mean IT literacy decreased with increasing age group (Table 5).

There were no significant relationships between acceptability and any of the factors including gender, treatment location, or level of concern regarding privacy and security. However, self-reported IT literacy and acceptability were positively associated, with an average increase in acceptability of 0.3 units for every one-unit increase in IT literacy (95% CI 0.07, 0.44;  $P = 0.007$ ). Conversely, acceptability was 0.8 units lower among those who had opted out of My Health Record compared

**Table 5** Average information technology literacy by age group

| Age group           | <i>n</i> | Information technology literacy<br>(mean $\pm$ SD) |
|---------------------|----------|----------------------------------------------------|
| 25 years or younger | 35       | $8.7 \pm 1.2$                                      |
| 26–35 years         | 44       | $8.1 \pm 2.4$                                      |
| 36–45 years         | 39       | $8.0 \pm 1.8$                                      |
| 46–55 years         | 28       | $7.2 \pm 2.2$                                      |
| 56 years or older   | 39       | $5.9 \pm 2.8$                                      |

*n*, number of patients.

with those who had not (95% CI  $-1.54$ ,  $0.01$ ;  $P = 0.053$ ) (Table 6).

**Patient portal feedback.** A total of 287 of 312 (92%) patients provided a score for the survey question about recommending CCCare to others. The mean likelihood of recommending CCCare to others was  $8.5 \pm 2.2$  across both hospitals. Over half of all patients ( $154/287 = 53\%$ ) gave the highest possible score (10/10), whereas 6 of 287 (2%) patients gave the lowest possible score (0/10).

**Table 6** Multivariable linear regression of factors affecting acceptability in the pre-exposure cohort

| Variable                                            | Coefficient ( $\beta$ ) | Standard error | (95% CI)      | P value |
|-----------------------------------------------------|-------------------------|----------------|---------------|---------|
| (Intercept)                                         | 5.17                    | 1.05           |               |         |
| Gender (female vs male)                             | −0.27                   | 0.31           | (−0.87, 0.34) | 0.382   |
| Level of information technology literacy (per unit) | 0.26                    | 0.09           | (0.07, 0.44)  | 0.007   |
| Opted out of MyHealth record (no/unsure vs yes)     | 0.76                    | 0.39           | (−0.01, 1.54) | 0.053   |
| Location (Liverpool vs Royal Adelaide Hospital)     | 0.53                    | 0.35           | (−0.17, 1.23) | 0.136   |

Linear regression results—factors associated with acceptability (pre-exposure cohort). The coefficient gives the average change in acceptability score associated with that variable. Adjusted for location (Royal Adelaide Hospital or Liverpool Hospital).

95% CI, 95% confidence interval for regression coefficient.

A total of 22 of 312 (7%) patients provided software-related qualitative feedback. Common themes of concern related to the novelty and limited experience with the software (12 patients), lack of tools to capture important information such as comorbidities, ostomy-related data, managing GP details, and technical issues pertaining to some patients receiving multiple automated survey invitations.

## Discussion

CCCare is a novel IBD-specific structured electronic medical record intended to improve IBD care. In this study, we observed that the structured fields in CCCare enabled more comprehensive and consistent capture of relevant data and enhances delivery of care with readily available information at each clinic/ review.

It is of interest that a large gain in data related to social determinants of health was achieved. These data are crucial to identify patients with unmet “basic needs” and “high risk groups” and should be well documented, especially in chronic disease setting.

Although demographic data gain related to ethnicity have little effect on direct patient care, race and ethnicity<sup>12</sup> have an impact on inflammatory bowel disease. These data are important to build acceptable approaches to chronic disease care<sup>13</sup> and to enhance clinical research such as understanding the pathophysiology of IBD and different IBD phenotypes in different ethnical groups.

Our results are consistent with the results of the inaugural Crohn's and Colitis Australia National IBD audit, which described generally poor IBD documentation based on a review of 1440 inpatient records in 52 hospitals (10). Moreover, CCCare shows a practical way to redress this previous deficiency.

Disease-specific EMRs increase the quality of healthcare services as well as physician's satisfaction<sup>1</sup>. Implementing such systems requires good patient acceptability and engagement with healthcare providers especially as people with IBD play a crucial and pro-active role in self-management (adherence to medications, visits to infusion centres, psychological health, activities of daily living etc). The fact that overall acceptability ratings in both the questionnaires and the patient portals were very high and align with providers acceptability<sup>1</sup> facilitate the implementation of CCCare through bidirectional (patients and providers) understanding of the software goals and importance in providing optimal IBD care, improved documentation and patient-provider e-communication. The qualitative feedback in patient portal was

minimal with only few concerns expressed, further confirming patient acceptability.

Interestingly, while the overall level of concern about privacy and cybersecurity was relatively high among respondents this did not appear to influence acceptability.

This may indicate that the potential perceived benefits of CCCare outweigh patient concerns and potential risks from information leak. It is unsurprising to have a modest positive association between self-reported IT literacy and baseline acceptability and a lower acceptability among respondents who opted out of the national My Health Record.

One of the main strengths of our study is its focus on IBD patients' own perceptions of CCCare to guide clinicians through the development and implementation of the software. This synergy among patient input, digital technology, and healthcare expertise provides innovative solutions and will change the direction in which health care evolves. To our best knowledge, only one patient who was approached declined to participate in the questionnaire. This high participation rate might suggest that the study itself was regarded positively by patients who are ready and willing to participate in healthcare co-design.

In terms of limitations, a sample size calculation for estimating the mean level of acceptability and the effect of exposure on acceptability was not performed at the outset of this study. Nevertheless, the participation rate was very high in our cohort of patients, which suggests reasonable representativeness and therefore generalizability for the target population.

## Conclusion

The IBD-specific EMR, CCCare is highly acceptable and yields substantial gain of data essential for optimal IBD care in comparison to usual medical records. The high patient acceptability observed in our IBD cohorts provides evidence for the utility of disease-specific medical records. Similar disease-specific record-management systems may be beneficial in other complex chronic diseases to augment the quality of care and support clinical decisions.

## Acknowledgments

Dr Reme Mountifield who designed the pre- and post-acceptability questionnaires and Inflammatory Bowel Disease Nurses at Liverpool and Royal Adelaide Hospitals.

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## Supporting information

Additional supporting information may be found in the online version of this article at the publisher's website:

**Appendix S1.** Post-CCCare Questionnaire.

**Appendix S2.** Pre-CCCare Questionnaire.