Data Article

Knowledge translation dataset: An e-health intervention for pregnancy in inflammatory bowel disease

Reed T. Sutton a, Kelsey Wierstra a, Vivian W. Huang a,b,*

a Department of Medicine, University of Alberta, Edmonton, Canada
b Department of Medicine, University of Toronto, Toronto, Canada

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A B S T R A C T
This article presents data collected from a cohort of patients with inflammatory bowel disease, who expressed interest in family planning and reproductive health in their clinical context. They were randomized (1:1, text-only vs. multimedia content) to access an online e-health portal containing educational information on the topic. The data collected includes baseline demographics, medication history, reproductive history, as well as standardized, validated questionnaires on knowledge (‘CCPKnow’), reproductive concerns, beliefs about medications (‘BMQ’), and medication adherence (‘MARS-5’). These questionnaires were administered prior to the intervention, immediately after accessing the materials, and a minimum of 6 months later (without re-accessing the online material). Two publications have been generated from analysis and aggregation of the CCPKnow data (‘Pregnancy-related Concerns and Pregnancy-Related Beliefs and Concerns of Inflammatory Bowel Disease Patients are Modified After Accessing e-Health Portal’ (Sutton et al., in press), “Innovative Online Educational Portal Improves Disease-Specific Reproductive Knowledge Among Patients With Inflammatory Bowel Disease” (Sutton et al., 2018) however this is an extensive dataset that could be analyzed or combined with others’ datasets for further insights.

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* Correspondence to: University of Alberta, Zeidler Ledcor Center, 8540 112th Street NW, Edmonton, Alberta, Canada T6G 2X8.
E-mail address: vwhuang@ualberta.ca (V.W. Huang).

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Specifications table

| Subject area         | Medicine and dentistry |
|----------------------|------------------------|
| More specific subject area | 1. Inflammatory Bowel Disease  |
|                      | 2. Reproductive Health |
| Type of data         | Table, Figures, Raw Spreadsheet |
| How data was acquired| Online questionnaires + Website Analytics (WordPress) |
| Data format          | Raw and Tabulated |
| Experimental factors | No pre-treatment of data. |
| Experimental features| Randomization to text-only or multimedia e-health portal. Pre-, post-, 6+ months post-intervention questionnaires. |
| Data source location | Alberta, Canada (Primarily Edmonton, 53.5444°N, 113.4909°W) |
| Data accessibility   | Dataset published on Mendeley Data: https://data.mendeley.com/datasets/g223h3p8gy/1 |
| Related research articles | • Sutton R, Wierstra K, Bal J, et al. Pregnancy-related Beliefs and Concerns of Inflammatory Bowel Disease Patients are Modified After Accessing e-Health Portal. Patient Education and Counseling. 2019; (in press) [1]. |
|                      | • Wierstra K, Sutton R, Bal J, et al. Innovative Online Educational Portal Improves Disease-Specific Reproductive Knowledge Among Patients With Inflammatory Bowel Disease. Inflamm Bowel Dis. 2018;24(12):2483–2493. doi:10.1093/ibd/izy1612. |

Value of the data

- CCPKnow, MARS-5, and BMQ are validated questionnaires, and so this data provides a benchmark for comparison of patient populations from other centers, or contrast to populations from different demographics.
- The data is extensive, containing disease history and patient demographics, information on user’s technology preferences, methods of learning, and more.
- These data can be utilized by researchers with interest in preconception and pregnancy in inflammatory bowel disease patient populations, combined with others’ datasets, and analyzed for further insights.

1. Data

The data collected at baseline includes demographics, DOB (converted to birth year to protect PII), highest level of education, employment, income, family history, languages, marital status, and extensive reproductive history including children, current pregnancy, pregnancy outcomes and health, future and current family plans. Inflammatory Bowel Disease history was also collected including family history of IBD, diagnosis, year diagnosed, previous and current medications, specialist access, discussion of reproductive topics in IBD, and sources of pregnancy in IBD information accessed. All of this data is included in Appendix A.

Standardized, validated questionnaires on knowledge (‘CCPKnow’), reproductive concerns, beliefs about medications (‘BMQ’), and medication adherence (‘MARS-5’) were also collected at pre-intervention, post-intervention, and 6+ months later. They are detailed below and included in Appendix B.

1. Patient reproductive concerns: Six IBD-specific reproductive concern questions were asked (adapted from Marri et al.) [3,4]. Participants responded ‘yes’ or ‘no’ to each statement.
2. MARS-5: Self-reported adherence assessment utilizing a 5 statement questionnaire evaluating non-adherent medication taking behaviors [5]. Each statement is scored on a 5-point Likert scale, ranging from 1 = always to 5 = never.

3. BMQ IBD S18: The validated BMQ questionnaire, a version specific to IBD, was used to measure beliefs that influenced adherence to medications. Questions from the BMQ are classified as “specific” (personal beliefs), further subdivided into necessity and concerns scales [6]. Participants ranked statements from each scale on a Likert spectrum (1 = strongly disagree, 5 = strongly agree). This particular version of the BMQ included 8 necessity statements and 9 concerns statements.

4. CCPKnow: 17 item validated score used to measure IBD-specific reproductive knowledge [7]. Correct answers to the questions (5 options each question) are usually summed to form a total score, and typically categorized into levels as follows:

i. poor (0–7),
ii. adequate (8–10)
iii. good (11–13)
iv. very good (14–17)

Feedback questions were asked regarding the intervention itself at post-intervention and 6 months later. The questions are included in Appendix C. Finally, analytics data on the usage and access time for specific pages and users was pulled from the portal, and is included in the raw datasets.

2. Experimental design, materials, and methods

2.1. Design

A prospective randomized intervention study was conducted. Patients were invited to access an online e-health portal for reproductive health information in the context of inflammatory bowel disease. Recruitment methods have been described [1,2]. Upon enrollment, patients completed the pre-intervention questionnaire (Appendices A and B), and were randomized (1:1) to receive access to either a text-only version of the portal content, or a multimedia version containing the same text content supplemented by videos, animated diagrams, slideshow, and self-testing quizzes. Patients were given 60 day access to the portal’s content, before completing the post-intervention questionnaire (Appendices B and C). Six months later they completed the same questionnaires again (Appendices B and C).

2.2. Educational content

The portal’s education content (the ‘intervention’) was drafted by expert systematic literature review on topics previously found to be of interest to this patient population [4]. Literature up to May 2014 was included. The content was aggregated into five modules:

1. I have IBD, can I become pregnant?
   (http://pregnancy.ibdclinic.ca/information/ibd-can-i-get-pregnant/)
2. I have IBD, will my child have IBD?
   (http://pregnancy.ibdclinic.ca/information/will-my-child-have-ibd/)
3. I have IBD, could surgery affect my ability to become pregnant?
   (http://pregnancy.ibdclinic.ca/information/ibd-surgery-affect-ability-become-pregnant/)
4. I have IBD, how does IBD affect pregnancy?
   (http://pregnancy.ibdclinic.ca/information/how-does-ibd-affect-pregnancy/)
Table 1
Demographics and medical information for participants at three study time points, pre-intervention, post-intervention, and 6+ months post-intervention.

| Category                        | Pre-intervention Completers (n = 101) | Post-intervention Completers (n = 78) | 6-month study completers (n = 37) |
|---------------------------------|---------------------------------------|--------------------------------------|----------------------------------|
|                                 | No. (% of total)                      | No. (% of total)                     | No. (% of total)                 |
| Age at prestudy, y              |                                       |                                      |                                  |
| 18–24                           | 24 (23.8)                             | 15 (19.2)                            | 7 (18.9)                         |
| 25–29                           | 32 (31.7)                             | 29 (37.2)                            | 11 (29.7)                        |
| 30–34                           | 28 (27.7)                             | 21 (26.9)                            | 12 (32.4)                        |
| 35–39                           | 12 (11.9)                             | 10 (12.8)                            | 5 (13.5)                         |
| 40–45                           | 5 (5.0)                               | 3 (3.8)                              | 2 (5.4)                          |
| Sex                             |                                       |                                      |                                  |
| Male                            | 18 (17.8)                             | 15 (19.2)                            | 7 (18.9)                         |
| Female                          | 83 (82.2)                             | 63 (80.8)                            | 30 (81.1)                        |
| Marital status                  |                                       |                                      |                                  |
| Single, never married           | 33 (32.7)                             | 22 (28.2)                            | 14 (37.8)                        |
| Divorced                        | 3 (3.0)                               | 3 (3.8)                              | 0 (0)                            |
| Partnered                       | 65 (64.4)                             | 53 (67.9)                            | 23 (62.2)                        |
| 1st language                    |                                       |                                      |                                  |
| English                         | 92 (91.1)                             | 71 (91.0)                            | 32 (86.5)                        |
| Income (n = 77)                 |                                       |                                      |                                  |
| Less than $20,000               | 11 (11.2)                             | 8 (10.4)                             | 5 (13.5)                         |
| $20,000 to $29,999              | 6 (6.1)                               | 3 (3.9)                              | 1 (2.7)                          |
| $40,000 to $69,999              | 25 (25.5)                             | 23 (29.9)                            | 11 (29.7)                        |
| $70,000 to $99,999              | 53 (54.1)                             | 41 (53.2)                            | 20 (54.1)                        |
| $100,000 or more                | 3 (3.1)                               | 2 (2.6)                              | 0 (0)                            |
| Education                       |                                       |                                      |                                  |
| Grade 12                        | 10 (9.9)                              | 9 (11.5)                             | 4 (10.8)                         |
| Some postsecondary              | 22 (21.8)                             | 15 (19.2)                            | 4 (10.8)                         |
| Bachelor's degree               | 33 (32.7)                             | 28 (35.9)                            | 17 (45.9)                        |
| Graduate degree                 | 21 (20.8)                             | 14 (17.9)                            | 9 (24.3)                         |
| Technical/trade school degree   | 15 (14.9)                             | 12 (15.4)                            | 3 (8.1)                          |
| Employment                      |                                       |                                      |                                  |
| Unemployed                      | 9 (8.9)                               | 8 (10.3)                             | 4 (10.8)                         |
| Part-time                       | 22 (21.8)                             | 15 (19.2)                            | 11 (29.7)                        |
| Full-time                       | 63 (62.4)                             | 49 (62.8)                            | 20 (54.1)                        |
| Stay-at-home mom                | 7 (6.9)                               | 6 (7.7)                              | 2 (5.4)                          |
| Type of IBD                     |                                       |                                      |                                  |
| Crohn's disease                 | 69 (68.3)                             | 54 (69.2)                            | 25 (67.6)                        |
| Ulcerative colitis              | 29 (28.7)                             | 21 (26.9)                            | 10 (27)                          |
| Indeterminate                   | 3 (3.0)                               | 3 (3.8)                              | 2 (5.4)                          |
| Reproductive history            |                                       |                                      |                                  |
| Have biological children        | 26 (25.7)                             | 19 (24.4)                            | 8 (21.6)                         |
| Currently pregnant              | 11 (10.9)                             | 5 (6.4)                              | 1 (2.7)                          |
| Ever been pregnant              | 27 (26.7)                             | 19 (24.4)                            | 9 (24.3)                         |
| Medication history              |                                       |                                      |                                  |
| Sulfasalazine                   | 12 (11.9)                             | 10 (12.8)                            | 6 (16.2)                         |
| Mesalamine/5-ASA                | 83 (82.2)                             | 67 (85.9)                            | 31 (83.8)                        |
| Budesonide                      | 20 (19.8)                             | 17 (21.8)                            | 8 (21.6)                         |
| Steroids                        | 82 (81.2)                             | 63 (80.8)                            | 31 (83.8)                        |
| Methotrexate                    | 15 (14.9)                             | 12 (15.4)                            | 9 (24.3)                         |
| Azathioprine/mercaptопurine      | 72 (71.3)                             | 55 (70.5)                            | 27 (73)                          |
5. I have IBD, how does IBD affect delivery, postpartum, and breastfeeding? (http://pregnancy.ibdclinic.ca/information/ibd-affect-delivery-postpartum-breastfeeding/)?

**Please note that the content at the above links may have been updated since being used in the described study.**

2.3. Setting, participant characteristics

Described previously, participants were 18–45 year old male and female IBD patients known to the IBD Clinic (University of Alberta Hospital, Edmonton, AB, Canada). The IBD Clinic serves patients from all over Alberta, and from surrounding provinces. The demographics have been tabulated for participants completing each of the three study time points (Table 1).
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Ethics approval

The study, including data collection procedures, was approved by the University of Alberta Health Research Ethics Board (Pro00047498).

Transparency document. Supplementary material

Transparency document associated with this article can be found in the online version at https://doi.org/10.1016/j.dib.2018.12.085.

References

[1] R. Sutton, K. Wierstra, J. Bal, et al. Pregnancy-related Beliefs and Concerns of Inflammatory Bowel Disease Patients are Modified After Accessing e-Health Portal, Patient Educ Counseling, 2019. (In press).
[2] K. Wierstra, R. Sutton, J. Bal, et al., Innovative online educational portal improves disease-specific reproductive knowledge among patients with inflammatory bowel disease, Inflamm. Bowel Dis. 24 (12) (2018) 2483–2493. https://doi.org/10.1093/ibd/izy161.
[3] S.R. Marri, C. Ahn, A.L. Buchman, Voluntary childlessness is increased in women with inflammatory bowel disease, Inflamm. Bowel Dis. 13 (5) (2007) 591–599. https://doi.org/10.1002/ibd.20082.
[4] V. Huang, Reproductive Knowledge Specific to Inflammatory Bowel Disease Among Women with IBD and Physicians Who Treat Women with IBD, 2014.
[5] R. Horne, R. Parham, R. Driscoll, A. Robinson, Patient’s attitudes to medicines and adherence to maintenance treatment in inflammatory bowel disease, Inflamm. Bowel Dis. 15 (6) (2009) 837–844. https://doi.org/10.1002/ibd.20846.
[6] R. Horne, J. Weinman, M. Hankins, The beliefs about medicines questionnaire: the development and evaluation of a new method for assessing the cognitive representation of medication, Psychol. Health 14 (1) (1999) 1–24. https://doi.org/10.1080/08870449908407311.
[7] C.P. Selinger, J. Eaden, W. Selby, et al., Patients’ knowledge of pregnancy-related issues in inflammatory bowel disease and validation of a novel assessment tool (’CCPKnow’), Aliment. Pharmacol. Ther. 36 (1) (2012) 57–67. https://doi.org/10.1111/j.1365-2036.2012.05130.x.