

User Guide for sparc_summary() Function

Crohn’s and Colitis Foundation

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Overview

Sparc_summary() is a function that reads in SPARC data from IBD Plexus. It finds the medications the participant is prescribed from the electronic medical record, patient reported case report forms and Smartform, lists other Smartform data fields, calculates diagnosis, phenotype, disease, and endoscopy scores and lists the encounter id or hist id at a specific ("index") date.

Requirements

- R Version 4.0.2 or above
- The following R packages are required and can be installed using install.packages("package name")
 - reshape2
 - tidyverse
 - lubridate
 - DT
 - readxl
 - openxlsx
- datadir = the directory where the unzipped SPARC site data from IBD Plexus is saved
 - .csv and .txt format are acceptable
 - If multiple extracts are saved in the same folder, the most recent files will be selected
- Index_info = a data frame with DEIDENTIFIED_MASTER_PATIENT_ID and a variable named index_date.
 - The default index_date is the DATE_OF_CONSENT
- Filename = the name of the output file.
 - Must be in .xlsx format
 - The default is SPARC_SITE_SUMMARY.xlsx
- Index_range = the number of days to look out from index date.
 - The default is 14 days
 - For example, to see Smartform values and scores within +/- 30 days of enrollment, the index_range = "30".
- Emr_codes = the codes to search through in the extract
 - Default is an empty vector
 - Usually an ICD10 code
 - For example, to search for Ankylosing spondylitis of multiple sites in spine and Ankylosing spondylitis of unspecified sites in spine, emr_codes = c("M45.0", "M45.9").
- MED_CODES.csv = a file that has the medications of interest saved in the working directory
 - MEDICATION_NAME= the medication of interest and includes the generic and brand names
 - Med_type = the medication class (i.e. Biologic, Antibiotic, etc)
 - New_med_name = the generic name of the drug
- EIM_CODES.csv = a file that has the codes for the EIMS in the Smartform saved in the working directory
 - EIM_DX = the Extraintestinal manifestation of interest as it appears on the Smartform
 - Coding = if the code associated with the code is Yes/No or Unknown
 - DIAG_CONCEPT_CODE = the code associated with the EIM in the Smartform

Output Table

The output file “SPARC_SUMMARY.xlsx” includes the following columns. If more than the DEIDENTIFIED_MASTER_PATIENT_ID and index_date is in the index_info data.frame, those columns will be included as well. Unless otherwise specified, the closest value to the index date is used if there are multiple reported values within the index range.

<i>Column Header</i>	<i>Derived Variable (Y/N)</i>	<i>DDM Table</i>	<i>DDM Data Source</i>	<i>Other DDM Filters</i>	<i>DDM Variable</i>	<i>Notes</i>
DEIDENTIFIED_MASTER_PATIENT_ID	N	Demographics	ECRF_SP ARC		DEIDENTIFIED_MASTER_PATIENT_ID	
INDEX_DATE	Y					A date of interest specified by the user.
DATE_OF_CONSENT	N	Demographics	ECRF_SP ARC		DATE_OF_CONSENT	
DATE_OF_CONSENT_WITHDRAWN	N	Demographics	ECRF_SP ARC		DATE_OF_CONSENT_WITHDRAWN	
BIRTH_YEAR	N	Demographics	ECRF_SP ARC		BIRTH_YEAR	
GENDER	N	Demographics	ECRF_SP ARC		GENDER	
ETHNICITY	N	Demographics	EMR		ETHNICITY	
RACE	N	Demographics	EMR		RACE	
DIAGNOSIS	N	Diagnosis	SF_SPARC > ECRF_SP ARC	DIAG_CONCEPT_NAME equals Crohn’s Disease, Ulcerative Colitis or IBD Unclassified. For SF only, DIAG_STATUS_CONCEPT_CODE equals Yes.	DIAG_CONCEPT_NAME	Chose diagnosis reported closest to index date from SF first, then ECRF. Use ECRF_QORUS if consented to both studies.
DIAGNOSIS_DATE	N	Diagnosis	SF_SPARC	DIAG_CONCEPT_NAME equals Crohn’s Disease, Ulcerative Colitis, IBD Unclassified or Inflammatory Bowel Disease.	DIAGNOSIS_DATE	

CROHN'S DISEASE PHENOTYPE	N	Observations	SF_SPAR_C	For Crohn's Disease patients only. OBS_TEST_CONCEPT_NAME equals "Crohn's Disease Phenotype".	DESCRIPTIVE_SYMP_TEST_RESULTS	Inflammatory, non-penetrating, non-stricturing phenotype can be pulled backward. All phenotypes can be pulled forward to the next reported phenotype.
IBD MANIFESTATIONS - ABDOMINAL ABSCESS, FISTULA, OR OTHER PENETRATING COMPLICATION PHENOTYPE - ANAL STRICTURE	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - DUODENAL STRICTURE	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - ENTEROCUTANEOUS FISTULA	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - ENTEROENTERIC FISTULA	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - ENTEROVESICAL FISTULA	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - ESOPHAGEAL STRICTURE	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - GASTRIC STRICTURE	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - ILEAL STRICTURE	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - INTRA-ABDOMINAL ABSCESS	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - JEJUNAL STRICTURE	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - LEFT COLONIC STRICTURE	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - OTHER FISTULA	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - RECTAL STRICTURE	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - RIGHT COLONIC STRICTURE	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
PHENOTYPE - TRANSVERSE COLONIC STRICTURE	N	Observations	SF_SPAR_C	For Crohn's Disease patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
EXTENT OF MACROSCOPIC ULCERATIVE COLITIS	N	Observations	SF_SPAR_C	For Ulcerative Colitis patients only. OBS_TEST_CONCEPT_NAME equals "Extent of	DESCRIPTIVE_SYMP_TEST_RESULTS	Ulcerative proctitis (rectum only) can be pulled backward. All phenotypes can be pulled forward to the next reported phenotype.

				Macroscopic Ulcerative Colitis"		
EXTENT OF MACROSCOPIC IBD UNCLASSIFIED	N	Observations	SF_SPAR C	For IBD unclassified patients only. OBS_TEST_CONCEPT_NAME equals "Extent of Macroscopic IBD Unclassified"	DESCRIPTIVE_SYMP_TEST_RESULTS	Ulcerative proctitis (rectum only) can be pulled backward. All phenotypes can be pulled forward to the next reported phenotype.
HISTORY OF HOSPITALIZATION FOR SEVERE ULCERATIVE COLITIS	N	Observations	SF_SPAR C	For Ulcerative Colitis patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
HISTORY OF HOSPITALIZATION FOR SEVERE IBD UNCLASSIFIED	N	Observations	SF_SPAR C	For IBD Unclassified patients only.	DESCRIPTIVE_SYMP_TEST_RESULTS	
ANAL PHENOTYPE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	Involved sites since disease onset for Crohn's Disease
DUODENAL PHENOTYPE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	Involved sites since disease onset for Crohn's Disease
ESOPHAGEAL PHENOTYPE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	Involved sites since disease onset for Crohn's Disease
GASTRIC PHENOTYPE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	Involved sites since disease onset for Crohn's Disease
ILEAL PHENOTYPE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	Involved sites since disease onset for Crohn's Disease
JEJUNAL PHENOTYPE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	Involved sites since disease onset for Crohn's Disease
LEFT COLONIC PHENOTYPE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	Involved sites since disease onset for Crohn's Disease
RECTAL PHENOTYPE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	Involved sites since disease onset for Crohn's Disease
RIGHT COLONIC PHENOTYPE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	Involved sites since disease onset for Crohn's Disease
TRANSVERSE COLONIC PHENOTYPE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	Involved sites since disease onset for Crohn's Disease
PERIANAL FISTULA	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	History of Perianal Disease for Crohn's Disease
ANAL CANAL STRICTURE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	History of Perianal Disease for Crohn's Disease
ANAL CANAL ULCER	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	History of Perianal Disease for Crohn's Disease
ANAL FISSURE	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	History of Perianal Disease for Crohn's Disease
LARGE SKIN TAGS	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	History of Perianal Disease for Crohn's Disease
PERIANAL ABCESS	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	History of Perianal Disease for Crohn's Disease

PERIANAL FISTULA - COMPLEX FISTULA	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	History of Perianal Disease for Crohn's Disease
RECTOVAGINAL FISTULA	N	Observations	SF_SPAR C		DESCRIPTIVE_SYMP_TEST_RESULTS	History of Perianal Disease for Crohn's Disease
NUMBER OF IBD SURGERIES	N	Procedures	SF_SPAR C	PROC_CONCEPT_NAME = IBD Surgeries	PHYSICIAN_NOTES_PROC_AVAIL	If 0 surgeries reported greater than the index range after the index date, then pulled back.
YEAR OF FIRST IBD SURGERY	N	Procedures	SF_SPAR C	PROC_CONCEPT_NAME = IBD Surgeries	PROC_START_DATE	Year the same as or before the index date
YEAR OF MOST RECENT IBD SURGERY	N	Procedures	SF_SPAR C	PROC_CONCEPT_NAME = IBD Surgeries	PROC_END_DATE	Year the same as or before the index date
ESOPHAGEAL SURGERY	N	Procedures	SF_SPAR C		PHYSICIAN_NOTES_PROC_AVAIL	
GASTRODUODENAL SURGERY	N	Procedures	SF_SPAR C		PHYSICIAN_NOTES_PROC_AVAIL	
SMALL BOWEL RESECTION	N	Procedures	SF_SPAR C		PHYSICIAN_NOTES_PROC_AVAIL	
SMALL BOWEL RESECTION - DUODENUM	N	Procedures	SF_SPAR C		PROC_STATUS_CONCEPT_CODE	
SMALL BOWEL RESECTION - ILEUM	N	Procedures	SF_SPAR C		PROC_STATUS_CONCEPT_CODE	
SMALL BOWEL RESECTION - JEJUNUM	N	Procedures	SF_SPAR C		PROC_STATUS_CONCEPT_CODE	
COLON RESECTION	N	Procedures	SF_SPAR C		PHYSICIAN_NOTES_PROC_AVAIL	
COLON RESECTION - CECUM	N	Procedures	SF_SPAR C		PROC_STATUS_CONCEPT_CODE	
COLON RESECTION - RECTUM	N	Procedures	SF_SPAR C		PROC_STATUS_CONCEPT_CODE	
COLON RESECTION - SIGMOID	N	Procedures	SF_SPAR C		PROC_STATUS_CONCEPT_CODE	
COMPLETE COLECTOMY	N	Procedures	SF_SPAR C	PROC_CONCEPT_NAME = Complete Colectomy	PROC_STATUS_CONCEPT_CODE	
YEAR OF COMPLETE COLECTOMY	N	Procedures	SF_SPAR C	PROC_CONCEPT_NAME = Complete Colectomy	PROC_START_DATE	
INDICATION FOR TOTAL COLECTOMY	N	Procedures	SF_SPAR C	PROC_CONCEPT_NAME = Complete Colectomy	INDICATION	
ILEOSTOMY/COLOSTOMY	N	Procedures	SF_SPAR C		PHYSICIAN_NOTES_PROC_AVAIL and PROC_STATUS_CONCEPT_NAME	

J-POUCH	N	Procedures	SF_SPARC	PHYSICIAN_NOTES_PROC_AVAIL and PROC_STATUS_CONCEPT_NAME							
STRICTUROPLASTY	N	Procedures	SF_SPARC	PHYSICIAN_NOTES_PROC_AVAIL and PROC_STATUS_CONCEPT_NAME							
PHYSIOLOGICAL SHORT GUT SYNDROME	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME							
TOBACCO USE WITHIN LAST 3 MONTHS	N	Observations	SF_SPARC	DESCRIPTIVE_SYMP_TEST_RESULTS							
TOBACCO USE WITHIN LAST 7 DAYS	N	Observations	SF_SPARC	DESCRIPTIVE_SYMP_TEST_RESULTS							
ORAL NARCOTIC INTAKE WITHIN LAST 30 DAYS	N	Observations	SF_SPARC	DESCRIPTIVE_SYMP_TEST_RESULTS							
ORAL NARCOTIC INTAKE WITHIN LAST 7 DAYS	N	Observations	SF_SPARC	DESCRIPTIVE_SYMP_TEST_RESULTS							
APHTHOUS ULCER	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME	Extraintestinal Manifestation						
ERYTHEMA NODOSUM	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME	Extraintestinal Manifestation						
IBD - ASSOCIATED ARTHROPATHY	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME	Extraintestinal Manifestation						
IRITIS/UVEITIS	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME	Extraintestinal Manifestation						
PRIMARY SCLEROSING CHOLANGITIS	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME	Extraintestinal Manifestation						
PYODERMA GANGRENOSUM	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME	Extraintestinal Manifestation						
THROMBOTIC COMPLICATIONS	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME	Extraintestinal Manifestation						
INTESTINAL DYSPLASIA	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME	Cancer History						
MALIGNANT NEOPLASM OF COLON, UNSPECIFIED	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME	Cancer History						
PERSONAL HISTORY OF CERVICAL DYSPLASIA	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME	Cancer History						
SKIN CANCER	N	Diagnosis	SF_SPARC	DIAG_STATUS_CONCEPT_NAME	Cancer History						
ABDOMINAL.PAIN.SCORE	N	Observations	SF_SPARC; ECRF_SPARC	FOR SF, OBS_TEST_CONCEPT_NAME equals Abdominal Pain-Pain Scale; For	DESCRIPTIVE_SYMP_TEST_RESULTS Use to calculate A for sCDAI equation. <table><tr><td>DESCRIPTIVE_SYMP_TEST_RESULTS</td><td>A</td></tr><tr><td>None</td><td>0</td></tr><tr><td>Mild</td><td>1</td></tr></table>	DESCRIPTIVE_SYMP_TEST_RESULTS	A	None	0	Mild	1
DESCRIPTIVE_SYMP_TEST_RESULTS	A										
None	0										
Mild	1										

				ECRF, OBS_TEST_CONCEPT_N AME equals Abdominal Pain		<table><tr><td>Moderate</td><td>2</td></tr><tr><td>Severe</td><td>3</td></tr></table>	Moderate	2	Severe	3		
Moderate	2											
Severe	3											
DAILY.BM	N	Observations	SF_SPARC; ECRF_SPARC	FOR SF, OBS_TEST_CONCEPT_N AME equals Current Average Number of Daily Bowel Movements or Current Maximum Number of Daily Bowel Movements. For ECRF, OBS_TEST_CONCEPT_N AME equals Current Average Number of Daily Bowel Movements or Current Average Number of Daily Liquid Bowel Movements. For ECRF, if OBS_TEST_RESULT_DATE before August 1, 2018 use Current Average Number of Daily Bowel Movements.	TEST_RESULT_NUMERIC; DESCRIPTIVE_SYMP_TEST_RESULTS	This is <i>B</i> for the sCDAl equation. This is N/A for anyone with an ostomy. 20+ was treated as 20 in the sCDAl equation.						
DAILY.BM.VERSION	Y					<div>Refers to the question used to determine the daily.bm variable in the sCDAl equation.</div> <table><tr><td>1</td><td>Current Average Number of Daily Bowel Movements</td></tr><tr><td>2</td><td>Current Average Number of Daily Liquid Bowel Movements</td></tr><tr><td>3</td><td>Current Maximum Number of Daily Bowel Movements</td></tr></table>	1	Current Average Number of Daily Bowel Movements	2	Current Average Number of Daily Liquid Bowel Movements	3	Current Maximum Number of Daily Bowel Movements
1	Current Average Number of Daily Bowel Movements											
2	Current Average Number of Daily Liquid Bowel Movements											
3	Current Maximum Number of Daily Bowel Movements											
GENERAL.WELL.BEING.SCORE	N	Observations	SF_SPARC; ECRF_SPARC	FOR SF, OBS_TEST_CONCEPT_N AME equals Constitutional - General	DESCRIPTIVE_SYMP_TEST_RESULTS	<div>Use to calculate <i>G</i> for sCDAl equation.</div> <table><tr><td>DESCRIPTIVE_SYMP_TEST_RESULTS</td><td>G</td></tr><tr><td>Generally well</td><td>0</td></tr></table>	DESCRIPTIVE_SYMP_TEST_RESULTS	G	Generally well	0		
DESCRIPTIVE_SYMP_TEST_RESULTS	G											
Generally well	0											

				Well-Being; For ECRF, OBS_TEST_CONCEPT_N AME equals General Well-Being		<table><tr><td>Slightly under par</td><td>1</td></tr><tr><td>Poor</td><td>2</td></tr><tr><td>Very poor</td><td>3</td></tr><tr><td>Terrible</td><td>4</td></tr></table>	Slightly under par	1	Poor	2	Very poor	3	Terrible	4				
Slightly under par	1																	
Poor	2																	
Very poor	3																	
Terrible	4																	
SCDAI.DATE	N	Observations	SF_SPARC; ECRF_SPARC		OBS_TEST_RESULT_DATE													
SCDAI.SCORE ¹	Y	[Calculated]	SF_SPARC; ECRF_SPARC			Crohn's Disease Only. Only use SF or ECRF to calculate; Do not combine from multiple sources to calculate. If one variable is missing from equation, leave blank for that source. $sCDAI = 44 + (2 \times 7 \times B) + (5 \times 7 \times A) + (7 \times 7 \times G)$												
SCDAI.SOURCE	Y		SF_SPARC; ECRF_SPARC			If SF variables used, then put SF, if ECRF variables used then put ECRF.												
GLOBAL.ASSESSMENT.SCORE	N	Observations	SF_SPARC	OBS_TEST_CONCEPT_N AME equals Physician's Global Assessment of Current Disease Status	DESCRIPTIVE_SYMP_TEST_RESULTS	<table><tr><td colspan="2">This is <i>T</i> for the UCDAI.9.SCORE.</td></tr><tr><td>DESCRIPTIVE_SYMP_TEST_RESULTS</td><td>T</td></tr><tr><td>Quiescent</td><td>0</td></tr><tr><td>Mild</td><td>1</td></tr><tr><td>Moderate</td><td>2</td></tr><tr><td>Severe</td><td>3</td></tr></table>	This is <i>T</i> for the UCDAI.9.SCORE.		DESCRIPTIVE_SYMP_TEST_RESULTS	T	Quiescent	0	Mild	1	Moderate	2	Severe	3
This is <i>T</i> for the UCDAI.9.SCORE.																		
DESCRIPTIVE_SYMP_TEST_RESULTS	T																	
Quiescent	0																	
Mild	1																	
Moderate	2																	
Severe	3																	
RECTAL.BLEEDING.SCORE	Y	Observations	SF_SPARC; ECRF_SPARC;	FOR SF, OBS_TEST_CONCEPT_NAME Blood in Stool – Recent Change in Rectal Bleeding Amount . For ECRF, OBS_TEST_CONCEPT_NAME equals Blood in Stool and/or Blood Passed Alone	DESCRIPTIVE_SYMP_TEST_RESULTS	<table><tr><td colspan="2">If from both sources at baseline separate by semicolon. This is <i>R</i> for the UCDAI.6 & UCDAI.9 SCORE.</td></tr><tr><td>DESCRIPTIVE_SYMP_TEST_RESULTS</td><td>R</td></tr><tr><td>None; No blood seen</td><td>0</td></tr><tr><td>Visible blood in stool less than half the time; Blood less than 50% of the time</td><td>1</td></tr><tr><td>Visible blood in stool half the time or more; Blood 50% or more of the time</td><td>2</td></tr><tr><td>Passing blood alone; ECRF: Blood Passed Alone = Yes</td><td>3</td></tr></table>	If from both sources at baseline separate by semicolon. This is <i>R</i> for the UCDAI.6 & UCDAI.9 SCORE.		DESCRIPTIVE_SYMP_TEST_RESULTS	R	None; No blood seen	0	Visible blood in stool less than half the time; Blood less than 50% of the time	1	Visible blood in stool half the time or more; Blood 50% or more of the time	2	Passing blood alone; ECRF: Blood Passed Alone = Yes	3
If from both sources at baseline separate by semicolon. This is <i>R</i> for the UCDAI.6 & UCDAI.9 SCORE.																		
DESCRIPTIVE_SYMP_TEST_RESULTS	R																	
None; No blood seen	0																	
Visible blood in stool less than half the time; Blood less than 50% of the time	1																	
Visible blood in stool half the time or more; Blood 50% or more of the time	2																	
Passing blood alone; ECRF: Blood Passed Alone = Yes	3																	

¹ Henao MP, Bewtra M, Osterman MT, Aberra FN, Scott FI, Lichtenstein GR, Kraschnewski J, Lewis JD. Measurement of Inflammatory Bowel Disease Symptoms: Reliability of an Abbreviated Approach to Data Collection. Inflamm Bowel Dis. 2015 Oct;21(10):2262-71. doi: 10.1097/MIB.0000000000000496. PMID: 26193348; PMCID: PMC4567473.

STOOL.FREQ.SCORE	N	Observations	SF_SPARC; ECRF_SPARC;	FOR SF, OBS_TEST_CONCEPT_NAME equals Recent Change in Daily Stool Frequency. For ECRF, OBS_TEST_CONCEPT_NAME equals Recent Change in Daily Stool Frequency	DESCRIPTIVE_SYMP_TEST_RESULTS	If from both sources at baseline separate by semicolon. This is S for the UCDAI.6 & UCDAI.9 SCORE.										
						<table><tr><td>DESCRIPTIVE_SYMP_TEST_RESULTS</td><td>S</td></tr><tr><td>Normal</td><td>0</td></tr><tr><td>1-2 stools/day more than normal</td><td>1</td></tr><tr><td>3-4 stools/day more than normal</td><td>2</td></tr><tr><td>>4 stools/day more than normal; 5 or more stools per day more than normal</td><td>3</td></tr></table>	DESCRIPTIVE_SYMP_TEST_RESULTS	S	Normal	0	1-2 stools/day more than normal	1	3-4 stools/day more than normal	2	>4 stools/day more than normal; 5 or more stools per day more than normal	3
	DESCRIPTIVE_SYMP_TEST_RESULTS	S														
	Normal	0														
	1-2 stools/day more than normal	1														
3-4 stools/day more than normal	2															
>4 stools/day more than normal; 5 or more stools per day more than normal	3															
UCDAI.6.SCORE	Y	[Calculated]				Ulcerative Colitis Only. Only use SF or ECRF to calculate; Do not combine from multiple sources to calculate. If one variable is missing from equation, leave blank for that source.										
UCDAI.9.SCORE	Y	[Calculated]				$UCDAI.6.SCORE = S + R$ Ulcerative Colitis Only. Only use SF or ECRF to calculate; Do not combine from multiple sources to calculate. If one variable is missing from equation, leave blank for that source.										
UCDAI.9.SCORE						$UCDAI.9.SCORE = S + R + T$										
UCDAI.DATE	N	Observations	SF_SPARC; ECRF_SPARC		OBS_TEST_RESULT_DATE											
UCDAI.SOURCE	Y		SF_SPARC; ECRF_SPARC			If SF variables used, then put SF, if ECRF variables used then put ECRF.										
ILEUM	N	Procedures	ECRF_SPARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION											
DESCENDING COLON	N	Procedures	ECRF_SPARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION											
LEFT COLON	N	Procedures	ECRF_SPARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION											

RECTUM	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION	
RIGHT COLON	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION	
SIGMOID COLON	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION	
TRANSVERSE COLON	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION	
SES_SCORE	Y	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	SES.CD_Subscore	Sum of SES.CD_Subscore from each location from same colonoscopy. If segment is “Not reached” then treated as 0. For Crohn’s Disease patients only.
SES.DATE	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	PROC_START_DATE	Date of colonoscopy with SES scoring.
MAX_EXTENT_ACTIVE_DISEASE	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	MAX_EXTENT_ACTIVE_DISEASE	Units = cm
MAYO_ENDOSCOPY_SCORE²	Y	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	MAYO_ENDOSCOPIC_SUBSCORE	Maximum MAYO_ENDOSCOPIC_SUBSCORE from each location from same colonoscopy. For Ulcerative Colitis patients only.
MODIFIED_MAYO_SCORE²	Y	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	MAYO_ENDOSCOPIC_SUBSCORE	Sum of MAYO_ENDOSCOPIC_SUBSCORE from each location from same colonoscopy. For Ulcerative Colitis patients only.
EXTENDED_MODIFIED_MAYO_SCORE²	Y	[Calculated]				$EMS = \frac{MODIFIED_MAYO_SCORE}{MAX_EXTENT_ACTIVE_DISEASE/10}$

² Triana Lobatón, Talat Bessissow, Gert De Hertogh, Bart Lemmens, Chelsea Maedler, Gert Van Assche, Séverine Vermeire, Raf Bisschops, Paul Rutgeerts, Alain Bitton, Waqqas Afif, Victoria Marcus, Marc Ferrante, The Modified Mayo Endoscopic Score (MMES): A New Index for the Assessment of Extension and Severity of Endoscopic Activity in Ulcerative Colitis Patients, *Journal of Crohn's and Colitis*, Volume 9, Issue 10, October 2015, Pages 846–852, <https://doi.org/10.1093/ecco-jcc/jjv111>

MODIFIED_MAYO_ENDOSCOPIC_SCORE²	Y	[Calculated]				<i>Modified Mayo Endoscopic Score</i> <i>EMS</i> $= \frac{\text{Number of Segments with Active Disease}}{\text{Number of Segments}}$	
MES.DATE	N	Procedures	ECRF_SPARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	PROC_START_DATE	Date of colonoscopy with Mayo Scoring.	
ABDOMINAL.PAIN.SCORE	N	Observations	SF_SPARC; ECRF_SPARC	FOR SF, OBS_TEST_CONCEPT_NAME equals Abdominal Pain-Pain Scale; For ECRF, OBS_TEST_CONCEPT_NAME equals Abdominal Pain	DESCRIPTIVE_SYMP_TEST_RESULTS	Use to calculate A for sCDAI equation.	
						DESCRIPTIVE_SYMP_TEST_RESULTS	A
						None	0
						Mild	1
						Moderate	2
DAILY.BM	N	Observations	SF_SPARC; ECRF_SPARC	FOR SF, OBS_TEST_CONCEPT_NAME equals Current Average Number of Daily Bowel Movements or Current Maximum Number of Daily Bowel Movements. For ECRF, OBS_TEST_CONCEPT_NAME equals Current Average Number of Daily Bowel Movements or Current Average Number of Daily Liquid Bowel Movements. For ECRF, if OBS_TEST_RESULT_DATE before August 1, 2018 use Current Average Number of Daily Bowel Movements.	TEST_RESULT_NUMERIC; DESCRIPTIVE_SYMP_TEST_RESULTS	This is B for the sCDAI equation. This is N/A for anyone with an ostomy. 20+ was treated as 20 in the sCDAI equation.	
DAILY.BM.VERSION	Y					Refers to the question used to determine the daily.bm variable in the sCDAI equation.	
						1	Current Average Number of Daily Bowel Movements

GENERAL.WELL.BEING.SCORE						2	Current Average Number of Daily Liquid Bowel Movements
						3	Current Maximum Number of Daily Bowel Movements
	N	Observations	SF_SPARC; ECRF_SPARC	FOR SF, OBS_TEST_CONCEPT_N AME equals Constitutional - General Well-Being; For ECRF, OBS_TEST_CONCEPT_N AME equals General Well-Being	DESCRIPTIVE_SYMP_TEST_RESULTS	Use to calculate <i>G</i> for sCDAI equation.	
						DESCRIPTIVE_SYMP_TEST_RESULTS	<i>G</i>
						Generally well	0
						Slightly under par	1
						Poor	2
						Very poor	3
						Terrible	4
	SCDAI.DATE	N	Observations	SF_SPARC; ECRF_SPARC	OBS_TEST_RESULT_DATE		
SCDAI.SCORE³	Y	[Calculated]	SF_SPARC; ECRF_SPARC			Crohn's Disease Only. Only use SF or ECRF to calculate; Do not combine from multiple sources to calculate. If one variable is missing from equation, leave blank for that source. $sCDAI = 44 + (2 \times 7 \times B) + (5 \times 7 \times A) + (7 \times 7 \times G)$	
SCDAI.SOURCE	Y		SF_SPARC; ECRF_SPARC			If SF variables used, then put SF, if ECRF variables used then put ECRF.	
GLOBAL.ASSESSMENT.SCORE	N	Observations	SF_SPARC	OBS_TEST_CONCEPT_N AME equals Physician's Global Assessment of Current Disease Status	DESCRIPTIVE_SYMP_TEST_RESULTS	This is <i>T</i> for the UCDAl.9.SCORE.	
						DESCRIPTIVE_SYMP_TEST_RESULTS	<i>T</i>
RECTAL.BLEEDING.SCORE						Quiescent	0
						Mild	1
						Moderate	2
						Severe	3
RECTAL.BLEEDING.SCORE	Y	Observations	SF_SPARC;	FOR SF, OBS_TEST_CONCEPT_NAME Blood in Stool - Recent	DESCRIPTIVE_SYMP_TEST_RESULTS	If from both sources at baseline separate by semicolon. This is <i>R</i> for the UCDAl.6 & UCDAl.9 SCORE.	

³ Henao MP, Bewtra M, Osterman MT, Aberra FN, Scott FI, Lichtenstein GR, Kraschnewski J, Lewis JD. Measurement of Inflammatory Bowel Disease Symptoms: Reliability of an Abbreviated Approach to Data Collection. Inflamm Bowel Dis. 2015 Oct;21(10):2262-71. doi: 10.1097/MIB.0000000000000496. PMID: 26193348; PMCID: PMC4567473.

			ECRF_SP ARC;	Change in Rectal Bleeding Amount • For ECRF, OBS_TEST_CONCEPT _NAME equals Blood in Stool and/or Blood Passed Alone		<table><tr><th>DESCRIPTIVE_SYMP_TEST_RESULTS</th><th>R</th></tr><tr><td>None; No blood seen</td><td>0</td></tr><tr><td>Visible blood in stool less than half the time; Blood less than 50% of the time</td><td>1</td></tr><tr><td>Visible blood in stool h alf the time or more; Bl ood 50% or more of the time</td><td>2</td></tr><tr><td>Passing blood alone; ECRF: Blood Passed Alone = Yes</td><td>3</td></tr></table>	DESCRIPTIVE_SYMP_TEST_RESULTS	R	None; No blood seen	0	Visible blood in stool less than half the time; Blood less than 50% of the time	1	Visible blood in stool h alf the time or more; Bl ood 50% or more of the time	2	Passing blood alone; ECRF: Blood Passed Alone = Yes	3
DESCRIPTIVE_SYMP_TEST_RESULTS	R															
None; No blood seen	0															
Visible blood in stool less than half the time; Blood less than 50% of the time	1															
Visible blood in stool h alf the time or more; Bl ood 50% or more of the time	2															
Passing blood alone; ECRF: Blood Passed Alone = Yes	3															
STOOL.FREQ.SCORE	N	Observati ons	SF_SPAR C; ECRF_SP ARC;	FOR SF, OBS_TEST_CONCEPT _NAME equals Recent Change in Daily Stool Frequency. For ECRF, OBS_TEST_CONCEPT _NAME equals Recent Change in Daily Stool Frequency	DESCRIPTIVE_SYMP_TEST _RESULTS	If from both sources at baseline separate by semicolon. This is S for the UCDAI.6 & UCDAI.9 SCORE. <table><tr><th>DESCRIPTIVE_SYMP_TEST_RESULTS</th><th>S</th></tr><tr><td>Normal</td><td>0</td></tr><tr><td>1-2 stools/day more than normal</td><td>1</td></tr><tr><td>3-4 stools/day more than normal</td><td>2</td></tr><tr><td>>4 stools/day more than normal; 5 or more stools per day more than normal</td><td>3</td></tr></table>	DESCRIPTIVE_SYMP_TEST_RESULTS	S	Normal	0	1-2 stools/day more than normal	1	3-4 stools/day more than normal	2	>4 stools/day more than normal; 5 or more stools per day more than normal	3
DESCRIPTIVE_SYMP_TEST_RESULTS	S															
Normal	0															
1-2 stools/day more than normal	1															
3-4 stools/day more than normal	2															
>4 stools/day more than normal; 5 or more stools per day more than normal	3															
UCDAI.6.SCORE	Y	[Calculat ed]				Ulcerative Colitis Only. Only use SF or ECRF to calculate; Do not combine from multiple sources to calculate. If one variable is missing from equation, leave blank for that source. $UCDAI.6.SCORE = S + R$										
UCDAI.9.SCORE	Y	[Calculat ed]				Ulcerative Colitis Only. Only use SF or ECRF to calculate; Do not combine from multiple sources to calculate. If one variable is missing from equation, leave blank for that source. $UCDAI.9.SCORE = S + R + T$										
UCDAI.DATE	N	Observati ons	SF_SPAR C; ECRF_SP ARC		OBS_TEST_RESULT_DATE											
UCDAI.SOURCE	Y		SF_SPAR C; ECRF_SP ARC			If SF variables used, then put SF, if ECRF variables used then put ECRF.										

ILEUM	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION	
DESCENDING COLON	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION	
LEFT COLON	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION	
RECTUM	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION	
RIGHT COLON	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION	
SIGMOID COLON	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION	
TRANSVERSE COLON	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	LOCATION	
SES_SCORE	Y	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	SES.CD_Subscore	Sum of SES.CD_Subscore from each location from same colonoscopy. If segment is "Not reached" then treated as 0. For Crohn's Disease patients only.
SES.DATE	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	PROC_START_DATE	Date of colonoscopy with SES scoring.
MAX_EXTENT_ACTIVE_DISEASE	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	MAX_EXTENT_ACTIVE_DISEASE	Units = cm

MAYO_ENDOSCOPY_SCORE⁴	Y	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	MAYO_ENDOSCOPIC_SUBSCORE	Maximum MAYO_ENDOSCOPIC_SUBSCORE from each location from same colonoscopy. For Ulcerative Colitis patients only.
MODIFIED_MAYO_SCORE²	Y	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	MAYO_ENDOSCOPIC_SUBSCORE	Sum of MAYO_ENDOSCOPIC_SUBSCORE from each location from same colonoscopy. For Ulcerative Colitis patients only.
EXTENDED_MODIFIED_MAYO_SCORE²	Y	[Calculated]				$EMS = \frac{MODIFIED_MAYO_SCORE}{MAX_EXTENT_ACTIVE_DISEASE/10}$
MODIFIED_MAYO_ENDOSCOPIC_SCORE²	Y	[Calculated]				$Modified\ Mayo\ Endoscopic\ Score = \frac{EMS}{Number\ of\ Segments\ with\ Active\ Disease}$
MES.DATE	N	Procedures	ECRF_SP ARC	PROC_CONCEPT_NAME equals Colonoscopy/Sigmoidoscopy	PROC_START_DATE	Date of colonoscopy with Mayo Scoring.

⁴ Triana Lobatón, Talat Bessissow, Gert De Hertogh, Bart Lemmens, Chelsea Maedler, Gert Van Assche, Séverine Vermeire, Raf Bisschops, Paul Rutgeerts, Alain Bitton, Waqqas Afif, Victoria Marcus, Marc Ferrante, The Modified Mayo Endoscopic Score (MMES): A New Index for the Assessment of Extension and Severity of Endoscopic Activity in Ulcerative Colitis Patients, *Journal of Crohn's and Colitis*, Volume 9, Issue 10, October 2015, Pages 846–852, <https://doi.org/10.1093/ecco-jcc/jjv111>

OSTOMY	N	Procedures & Observations	SF_SPARC, ECRF_SPARC	For SF, PROC_CONCEPT_NAME equals Ileostomy/colostomy ; For ECRF, OBS_TEST_CONCEPT_NAME equals Baseline Number of Daily Bowel Movements or Current Average Number of Daily Bowel Movements or Recent Change in Daily Stool Frequency or Current Average Number of Daily Liquid Bowel Movements equals Not applicable, I have an ostomy	DESCRIPTIVE_SYMP_TEST_RESULTS	Only populated for those missing sCDAI or UCDAI scores.
NO_IBD_MEDICATION_AT_ENROLLMENT	Y	Observations	ECRF_SPARC	OBS_TEST_CONCEPT_NAME == "Are you currently taking any medication for your IBD?" & DESCRIPTIVE_SYMP_TEST_RESULTS == "No"		1 = First Survey with Are you Currently Taking Any Medication = NO) Does not include antibiotics/probiotics within +/- index range of the date of consent; 0 = Question not available or did not answer No
NO_IBD_MEDICATION_AT_INDEX	Y	Prescription	ECRF_SPARC & EMR	See XXX_EMR[1] and XXX_ECRF for logic on determining is a		If no medications are found at the index date +/- index range, then this is 1

BIOLOGIC_AT_INDEX_CONFIDENCE

Y

Prescription

ECRF_SPARC & EMR

participant was on a medication at the index date for each source respectively

Rank of confidence in choice of Biologic at index date. The lowest score (green) indicates high confidence in the choice, while a higher score (orange) indicates less confidence.

Rank	Logic
1	EMR and ECRF_SPARC agree that patient on medication at index
2	ECRF_SPARC says on medication or possibly on medication and no EMR information for this medication
3	EMR says on medication or possibly on medication and no ECRF_SPARC information for this medication
4	EMR and ECRF_SPARC both agree that Possibly on Medication (Index <
5	EMR and ECRF_SPARC both agree that individual "Possibly on Medication (Index Performed <= 12 Months After Last Reported Medication)" or "Possibly on Medication (Index Performed > 1 Year After Last Reported Medication)" or "Possibly on Medication (Index Performed <= 6 Months After Last Reported Medication)"
6	EMR says possibly on medication and ECRF_SPARC says yes on medication

BIOLOGIC_AT_INDEX

					7	EMR says yes on medication and ECRF_SPARC says possibly on medication
					8	EMR says not on medication but ECRF_SPARC says yes or possibly on medication
					9	EMR says yes or possibly on medication but ECRF_SPARC says no
Y	Prescription	ECRF_SPARC & EMR	See XXX_EMR and XXX_ECRF for logic on determining if a participant was on a medication at the index date for each source respectively			The biologic that the patient is predicted to be on at the index date. For EMR, if two biologics reported at the same time, chose the most recently prescribed. For ECRF, if two biologics reported at the same time, chose the most recently reported

XXX_SF	N	Prescriptions	SF_SPAR C	MEDICATION_NAME	MEDICATION_ADMINISTRATED_CODE	Reports of "Never" used medication after index_date can be pulled backward. Otherwise only data up until the index date was used.
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XXX_ECRF	Y	Prescriptions; Observations	ECRF_SP ARC	In the observation table, OBS_TEST_CONCEPT_NAME equals "In the last 90 days, have you had any changes in your Medication(s)?" & DESCRIPTIVE_SYMPTEST_RESULTS == "No"	The status of the medication using the ECRF source. If a patient reported no changes to medication in the past 90 days, then the previously entered medication data can be pulled forward to that survey encounter. This column reflects if the index date is within the MED_START_DATE and MED_END_DATE before the MED_START_DATE or after the MED_END_DATE. For the "Possibly" categories, the time between patient reported being on the medication and the index date is captured in the following groups (<=3 months, <= 6 months, <= 12 months & > 1 year).
XXX_EMR	Y	Prescriptions	EMR		The status of the medication using the EMR source. For each medication, the most recently prescribed was picked.
XXX_STATUS	Y		EMR & ECRF		Summary based on both sources Yes = patient on medication

					Possible = patient possibly on medication
					Contradicts = ECRF_SPARC and EMR sources disagree
					No = patient not on medication
XXX_LOADING_DATE_ECRF	Y	Prescriptions	ECRF	MED_START_DATE	For biologics only, the first date the medication was reported in the ECRF
XXX_LOADING_DATE_EMR	Y	Prescriptions	EMR	MED_START_DATE	For biologics only, the date the medication was first prescribed in the EMR.