ANNEX

Annex I. Search strategy

EMBASE Ovid Embase

1 exp patient satisfaction/

2 satisfaction.ti,ab.

3 satisfied.ti,ab.

4 patient experience.ti.

5 patients experience.ti.

6 participant experience.ti.

7 participants experience.ti.

8 preference*.ti.

9 discomfort.ti,ab.

10 burdensome.ti,ab.

11 acceptab*.ti.

12 willing*.ti.

13 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12

14 exp screening/

15 exp early diagnosis/

16 screening.ti,ab.

17 early detection.ti.

18 14 or 15 or 16 or 17

19 exp colorectal cancer/

20 exp colonoscopy/

21 colorectal.ti.

22 f?ecal occult blood test.ti,ab.

23 f?ecal immunochemical test.ti,ab.

24 stool.ti,ab.

25 FOBT.ti,ab.

26 gFOBT.ti,ab.

27 colonoscop*.ti,ab.

28 colonography.ti,ab.

29 sigmoidoscopy.ti,ab.

30 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29

31 13 and 18 and 30

32 exp psychometry/

33 exp patient health questionnaire/

34 exp validation study/

35 questionnaire*.ti,ab.

36 psychometr*.ti,ab.

37 measure.ti,ab.

38 measures.ti,ab.

39 instrument*.ti,ab.

40 tool.ti,ab.

41 tools.ti,ab.

42 item.ti,ab.

43 items.ti,ab.

44 scale.ti,ab.

45 scales.ti,ab.

46 subscale*.ti,ab.

47 validation.ti,ab.

48 validity.ti,ab.

49 reliability.ti,ab.

50 internal consistency.ti,ab.

51 convergent.ti,ab.

52 discrimina*.ti,ab.

53 construct.ti,ab.

54 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53

55 31 and 54 (608) [hits related to instruments]

56 31 not 55 (610) [hits related to satisfaction as a measurable domain]

MEDLINE (PubMed)

#1 "Patient Satisfaction"[Mesh]

#2 "Patient Acceptance of Health Care"[Majr]

#3 satisfaction[tiab]

#4 satisfied[tiab]

#5 patient experience[tiab]

#6 patients experience[tiab]

#7 participant experience[tiab]

#8 participants experience[tiab]

#9 experience*[ti]

#10 preference*[ti]

#11 discomfort[tiab]

#12 burdensome[tiab]

#13 acceptab*[tiab]

#14 willing*[tiab]

#15 #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14

#16 "Mass Screening"[Mesh]

#17 "Early Detection of Cancer"[Mesh]

#18 screening[tiab]

#19 early detection[ti]

#20 #16 OR #17 OR #18 OR #19

#21 "Colorectal Neoplasms"[Mesh]

#22 "Colonoscopy"[Mesh]

#23 colorectal[ti]

#24 fecal immunochemical test[tiab]

#25 faecal immunochemical test[tiab]

#26 fecal occult blood test[tiab]

#27 stool[tiab]

#28 FOBT[tiab]

#29 gFOBT[tiab]

#30 colonoscop*[tiab]

#31 colonography[tiab]

#32 sigmoidoscopy[tiab]

#33 #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32

#34 #15 AND #20 AND #33

#35 "PSYCHOMETRICS"[Mesh]

#36 "Patient Health Questionnaire"[Mesh]

#37 "Behavior Rating Scale"[Mesh]

#38 "Patient Reported Outcome Measures"[Mesh]

#39 "Validation Studies"[pt]

#40 questionnaire*[tiab]

#41 psychometr*[tiab]

#42 measure[tiab]

#43 measures[tiab]

#44 instrument*[tiab]

#45 tool[tiab]

#46 tools[tiab]

#47 item[tiab]

#48 items[tiab]

#49 scale[tiab]

#50 scales[tiab]

#51 subscale*[tiab]

#52 validation[tiab]

#53 validity[tiab]

#54 reliability[tiab]

#55 internal consistency[tiab]

#56 convergent[tiab]

#57 discrimina*[tiab]

#58 construct[tiab]

#59 #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58

#60 #34 AND #59 780 [hits related to instruments]

#61 #34 NOT #59 1830 [hits related to satisfaction as a measurable domain]

PsycINFO PsycNET

#1 Index Terms: {Satisfaction} OR {Client Satisfaction} OR {Consumer Satisfaction} OR {Job Satisfaction} OR {Life Satisfaction} OR {Marital Satisfaction} OR {Need Satisfaction} OR {Relationship Satisfaction} OR {Role Satisfaction} OR {Sexual Satisfaction}

#2 Title: satisfaction OR Title: satisfied OR Abstract: satisfaction OR Abstract: satisfied

#3 Title: patient experience OR Title: patients experience OR Title: participant experience OR Title: participants experience

#4 Title: preference*

#5 Title: discomfort OR Abstract: discomfort

#6 Title: burdensome OR Abstract: burdensome

#7 Title: acceptab*

#8 Title: willing*

#9 #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8

#10 Index Terms: {Health Screening} OR {Health Promotion}

#11 Title: screening OR Abstract: screening

#12 Title: early detection

#13 #11 OR #12 OR #13

#14 Title: colorectal

#15 Title: "fecal occult blood test" OR Title: "faecal occult blood test" OR Abstract: "fecal occult blood test" OR Abstract: "faecal occult blood test"

#16 Title: "fecal immunochemical test" OR Title: "faecal immunochemical test" OR Abstract: "fecal immunochemical test" OR Abstract: "faecal immunochemical test"

#17 Title: stool OR Abstract: stool

#18 Title: FOBT OR Title: gFOBT OR Abstract: FOBT OR Abstract: gFOBT

#19 Title: colonoscop* OR Title: colonography OR Title: sigmoidoscopy OR Abstract: colonoscop* OR Abstract: colonography OR Abstract: sigmoidoscopy

#20 #14 OR #15 OR #16 OR #17 OR #18 OR #19

#21 #9 AND #13 AND #

#22 Index Terms: {Questionnaires} OR Index Terms: {Test Construction}

#23 Title: questionnaire* OR Abstract: questionnaire*

#24 Title: psychometr* OR Abstract: psychometr*

#25 Title: measure OR Title: measures OR Abstract: measure OR Abstract: measures

#26 Title: instrument* OR Abstract: instrument*

#27 Title: tool OR Title: tools OR Title: item OR Title: items OR Title: subscale* OR Abstract: tool OR Abstract: tools OR Abstract: item OR Abstract: items OR Abstract: subscale*

#28 Title: validation OR Title: validity OR Abstract: validation OR Abstract: validity

#29 Title: reliability OR Abstract: reliability

#30 Title: "internal consistency" OR Abstract: "internal consistency"

#31 Title: convergent OR Abstract: convergent

#32 Abstract: discrimina* OR Abstract: discrimina*

#33 Title: construct OR Abstract: construct

#34 #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33

#35 #21 AND #34 26 [hits related to instruments]

#36 #21 NOT #35 49 [hits related to satisfaction as a measurable domain]

CINAHL EBSCOHost

S1 (MH "Consumer Satisfaction+")

S2 TI satisfaction OR AB satisfaction

S3 TI satisfied OR AB satisfied

S4 TI patient experience OR TI patients experience OR TI participant experience OR TI participants experience

S5 TI preference*

S6 TI discomfort OR AB discomfort

S7 TI burdensome OR AB burdensome

S8 TI acceptab*

S9 TI willing*

S10 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9

S11 (MH "Health Screening+")

S12 TI screening OR AB screening

S13 TI early detection

S14 S11 OR S12 OR S13

S15 (MH "Colorectal Neoplasms+")

S16 (MH "Colonoscopy+")

S17 (MH "Sigmoidoscopy")

S18 TI colorectal

S19 TI faecal occult blood test OR AB faecal occult blood test OR TI fecal occult blood test OR AB fecal occult blood test

S20 TI faecal immunochemical test OR AB faecal immunochemical test OR TI fecal immunochemical test OR AB faecal immunochemical test

S21 TI stool OR AB stool

S22 TI FOBT OR AB FOBT OR TI gFOBT OR AB gFOBT

S23 TI colonoscop* OR AB colonoscop*

S24 TI colonography OR AB colonography

S25 TI sigmoidoscopy OR AB sigmoidoscopy

S26 S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25

S27 S10 AND S14 AND S26

S28 (MH "Psychometrics")

S29 (MH "Questionnaires+")

S30 (MH "Validation Studies")

S31 TI questionnaire* OR AB questionnaire*

S32 TI psychometr* OR AB psychometr*

S33 TI measure OR AB measure OR TI measures OR AB measures

S34 TI instrument* OR AB instrument*

S35 TI tool OR TI tools OR AB tool OR AB tools

S36 TI item OR TI items OR AB item OR AB items

S37 TI scale OR TI scales OR AB scale OR AB scales OR TI subscale* OR AB subscale*

S38 TI validation OR AB validation

S39 TI validity OR AB validity

S40 TI reliability OR AB reliability

S41 TI internal consistency OR AB internal consistency

S42 TI convergent OR AB convergent

S43 TI discrimina* OR AB discrimina*

S44 TI construct OR AB construct

S45 S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44

S46 S27 AND S45 166 [hits related to instruments]

S47 S27 NOT S46 148 [hits related to satisfaction as a measurable domain]

Annex II. Scoring of questionnaires

CollaboRATE: This questionnaire consists of three questions with a score ranging from 0 to 9 for each one. The **Collabo**RATE Score should only be calculated when all three **Collabo**RATE items have been completed for at least 25 clinical encounters for each group of interest. Two scores can be obtained[1]:

a. The CollaboRATE mean score: a continuous variable from 0 to 9. After excluding cases where a response to one or more questions is missing, the mean of the three CollaboRATE responses is calculated for each encounter. Then, the mean of all encounters is calculated. Higher scores represent more shared decision-making.

b. The CollaboRATE top score: a continuous variable from 0 to 100. After excluding cases where a response to one or more of the collaborate questions is missing, each encounter is coded as either "1" if the response to all three collaborate items is 9, or "0" if the response to any of the three CollaboRATE items is less than 9. Then, the percentage of all encounters that are coded as "1" is calculated. Higher scores represent more shared decision-making. This number also corresponds to the proportion of patients for whom there was 'gold standard' shared decision-making.

SDM-Q-9: This instrument consists of nine statements, which can be rated on a six-point scale from "completely disagree" (0) to "completely agree". We will add up all the items to a raw total score between 0 and 45. The authors of SDM-Q-9 suggest the imputation of up to two missing items using the mean of the items that were

[1] Elwyn G, Barr PJ, Grande SW, Thompson R, Walsh T, Ozanne EM. Developing CollaboRATE: A fast and frugal patient-reported measure of shared decision making in clinical encounters. *Patient Educ Couns*. 2013;93(1):102-107. doi:10.1016/j.pec.2013.05.009

filled out to calculate the raw score if required[2]. No total score should be calculated if more than two items are missing. Multiplication of the raw score by 20/9 provides a score forced (transformed) to range from 0 to 100, where 0 indicates the lowest possible level of SDM and 100 indicates the highest extent of SDM.

PATSAT-C33 and OUT-PATSAT7: The instrument consists of four scales, each one with statements that can be rated on a five-point scale from "poor" (1) to "excellent" (5). The raw scores (from 1 to 5) for the individual items within a scale will first be added up, and then, for the multi-item scales, divided by the number of items in the scale. These scale scores will be linearly transformed so that all scales range from 0 to 100, with a higher scale score representing a higher level of satisfaction with care.

[2] Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient Educ Couns*. 2010;80(1):94-99. doi:10.1016/j.pec.2009.09.034

Annex III. Study variables

1. Patient identification number
2. Hospital centre.

Socio-demographic variables

3. Date of birth (dd/mm/yyyy):
4. Gender (F,M):
5. City/town of residence
6. People who live:
    a. Alone
    b. With a partner
    c. With other family members
    d. With other people
    e. In a residential centre
7. Education:
    a. No studies
    b. Primary studies
    c. Secondary studies
    d. High school studies
8. Employment situation:
    a. Working
    b. Retired
    c. Unemployed
    d. Pension beneficiary
9. Last employment:

Clinical variables

10. Symptoms suggesting colorectal cancer:
    a. Change in bowel rhythm
    b. Rectal bleeding
    c. Abdominal pain
    d. Weight loss
    e. Rectal tenesmus
    f. Anal pain
    g. Iron deficiency anaemia
11. Personal history of::
    a. Colorectal cancer
        -Date of diagnosis
    b. Colorectal polyps
    c. Ulcerative colitis
    d. Crohn's disease
    e. Other cancers:
        -which ones and date of diagnosis
12. Comorbidities:
13. Previous diagnostic tests :
    -Colonoscopy. Date.
    -CT-colonography. Date.
    -Barium enema. Date.
    -Sigmoidoscopy. Date.
    -Stool blood test. Date.
14. Past participation in the colorectal cancer screening program.
15. Family history of cancer:
    -Colorectal cancer
        -family member and age at diagnosis
    -For each cancer:
        -family member and age at diagnosis
16. Date of first colonoscopy (dd/mm/yyyy)
17. Centre in which the colonoscopy is performed
18. Number of colonoscopies conducted in the current screening round
    -Date of colonoscopies
19. Reason to repeat the colonoscopy:
    -bad bowel cleansing
    -piecemeal polyp resection
    -other: specify
20. Bowel cleansing preparation used:
    -Moviprep®
    -Bohm®
    -Citrafleet®
    -Lainco®
    -Casenglicol®
    -Enema

-Fosfosoda®
-Klean-Prep®
-Nulitely®
-Pleinvue®

21 Use of other laxative
22 Maximum insertion
23. Bowel cleansing (Boston scale): X-X-X
24. Withdrawal time (in minutes):
25. Additional diagnostic tests and date:
-CT-colonography. Date.
-Barium enema. Date.
-Sigmoidoscopy. Date.
26. Complications of colonoscopy in the first 30 days.
-bleeding
-bowel perforation
-cardio-respiratory complications
-other
27. If any complication, what was the consequence?
-hospital admission <=3 nights
-hospital admission from 4 to 10 nights
-long hospital admission > 10 nights
-admission to ICU >1 night
-surgery
-medical consultation
-death
-permanent disability (specify)
-interrupted colonoscopy due to adverse event
-interventionist radiology due to adverse event
-Repetition of colonoscopy due to adverse event
-respiratory support
-transfusion
28. Final diagnosis of screening:
-Normal colonoscopy
-Hyperplastic or inflammatory polyps.
-High risk lesion
-Intermediate risk lesion
-Low risk lesion
-Polyposis
-Colorectal cancer

Only for colorectal cancer:

29 Pathologic stage (TNM classification)
-If neoadjuvant treatment, identify yp
30. Clinical stage (TNM classification) in case of neoadjuvancy
31. Treatment
-endoscopic resection only
-surgery
-surgery + adjuvant chemotherapy
-surgery + adjuvant radiotherapy
-surgery + chemotherapy + radiotherapy
-neoadjuvant chemo/radiotherapy + surgery
-neoadjuvant chemo/radiotherapy + surgery + adjuvant chemotherapy
-radiotherapy
-chemotherapy
-chemo/radiotherapy

Care process variables

32. Date of faecal blood test analysis.
33. Date of pre-colonoscopy nurse visit
34. Date of first colonoscopy
35. Date of pathology report
36. Date of result-communication visit
In colorectal cancer:
37. Date of presentation to the tumour committee
38. Date of first medical visit after extension study
39. Date of first treatment
40. Treatment centre

Scores of questionnaires (see Annex II)

Annex IV: Statistical analysis

Bivariate analysis:

For categorical variables, we will use cross tables and χ^2 test or F-Fisher when necessary. For quantitative variables, we will use the Student's t-test (or U Mann-Whitney for variables with no normal distribution) to compare means between two groups and the ANOVA test (or Kruskal-Wallis for variables with no normal distribution) to compare means between more than two groups. A two-sided alpha level of 0.05 will be considered statistically significant.

Multivariate analysis:

In addition to the analysis proposed for the main variable, we will also perform a logistic regression analysis to determine which covariates are associated with: 1. Proportion of patients that are satisfied according to the PREM-satisfaction; 2. Rating of shared decision-making according the SDM-Q-9 (ordinal logistic regression); 3. Satisfaction with cancer care according to PATSAT-C33 and OUT-PATSAT7. In all cases, we will consider as covariables those that were statistically significant in the bivariate analysis at p value of <0.10 and those that are not, are relevant from a clinical point of view.

Annex V: Interview topic guide

Topic explored	Example of questions	Question order
General Satisfaction	What do you think about your participation in the CRC screening program? Why?	1
Decision Making	What made you decide to participate in the CRC screening Program?	2
	Did you talk to other people (family, friends, GP, pharmacist) about the possibility of participating in the screening Program? Did that influence your decision?	3
Experience: professional dealing	What did you think about the dealing provided by professionals of the screening program? (pharmacists, nurses, endoscopy professionals)	4
Experience: information received	Did you understand everything that these professionals explained to you?	5
	Do you think you have been able to clarify with the different professionals all the doubts that you have had during your participation in the screening Program?	6
Experience: reaction to positive screening result	What did you think when you knew that the screening test result had been positive?	7
Experience: information received	Remember the time you had the visit with the nurse after knowing that the screening test result had been positive. What did you think of that visit? What did you think of the information the nurse gave you? Did you miss something?	8
	Do you think you could ask anything you wanted? Were you able to clear up any doubts you might have?	9
Decision making	You decided to have the colonoscopy; what was the most influential to decide to do it?	10
Experience: colonoscopy	Think about the day you underwent the colonoscopy. How was that day?	
Experience: information received	Once you know what a colonoscopy is, what information would you like to receive about this procedure?	11
	What do you think of the information you received on your diagnosis and the recommended follow-up? Would you have liked to know anything else?	12
Experience: surveillance	You had a result of (normal colonoscopy/colonoscopy with polyps) and a follow up was recommended to you. What do you think of the recommended follow-up?	13
	Do you remember anything in particular about your participation in the CRC screening program that you have experienced especially badly? And especially good?	14
Experience: waiting times	Is there a time that has been especially long during your participation in the CRC screening program?	15
Closing question	How do you rate your participation in the Program? Has it been as expected?	16