

Kotzur, M., McCowan, C., Macdonald, S., Wyke, S., Gattin, L., Campbell, C., Weller, D., Crighton, E., Steele, R. J.C. and Robb, K. A. (2019) Why colorectal screening fails to achieve the uptake rates of breast and cervical cancer screening: a comparative qualitative study. *BMJ Quality and Safety*, (doi:10.1136/bmjqs-2019-009998).

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.gla.ac.uk/202989/>

Deposited on: 14 November 2019

Why colorectal screening fails to achieve the uptake rates of breast and cervical cancer  
screening: a comparative qualitative study

Marie Kotzur (0000-0001-6921-5075), Colin McCowan (0000-0002-9466-833X), Sara  
Macdonald (0000-0002-5380-6943), Sally Wyke (0000-0002-7509-8247), Lauren Gatting  
(0000-0003-3693-2013), Christine Campbell (0000-0003-4868-0554), David Weller (0000-  
0002-8112-718X), Emilia Crighton (0000-0003-2268-4442), Robert Steele (0000-0003-4248-  
6785), Kathryn Robb (0000-0002-1672-0411)

Marie Kotzur  
Research Associate, Institute of Health and Wellbeing, University of Glasgow, Glasgow  
G120XH, UK

Colin McCowan  
Professor in Health Data Science, School of Medicine, University of St Andrews, St Andrews  
KY16 9TF, UK

Sara Macdonald  
Senior Lecturer, Institute of Health and Wellbeing, University Of Glasgow, Glasgow G12 9LX,  
UK

Sally Wyke  
Interdisciplinary Research Professor, Institute of Health and Wellbeing, University Of  
Glasgow, Glasgow G12 8RS, UK

Lauren Gatting  
PhD student, Institute of Health and Wellbeing, University Of Glasgow, Glasgow G12 0XH,  
UK

Christine Campbell  
Reader, Usher Institute, University of Edinburgh, Edinburgh EH8 9AG, UK

David Weller  
James Mackenzie Professor of General Practice, Usher Institute, University of Edinburgh,  
Edinburgh EH8 9AG, UK

Emilia Crighton  
Head of Health Services, NHS Greater Glasgow and Clyde, Gartnavel Royal Hospital, Glasgow  
G120XH, UK

Robert Steele  
Senior Research Professor, School of Medicine, University of Dundee, Dundee DD14HN, UK

Kathryn Robb

36 Reader, Institute of Health and Wellbeing, University Of Glasgow, Glasgow G120XH, UK  
37 Correspondence concerning this article should be addressed to Kathryn Robb, Institute of  
38 Health and Wellbeing, University of Glasgow, Admin building, 1<sup>st</sup> Floor, 1055 Great Western  
39 Road, Glasgow G12 0XH. Email: [Katie.Robb@glasgow.ac.uk](mailto:Katie.Robb@glasgow.ac.uk)

40

41 **Word count: 4418**

42

## Abstract

**Background:** In Scotland, the uptake of clinic-based breast (72%) and cervical (73%) screening is higher than home-based colorectal screening (~60%). To inform new approaches to increase uptake of colorectal screening, we compared the perceptions of colorectal screening among women with different screening histories.

**Method:** We purposively sampled women with different screening histories to invite to semi-structured interviews: i) participated in all; ii) participated in breast and cervical but not colorectal ('colorectal-specific non-participants'); iii) participated in none. To identify the sample we linked the data for all women eligible for all three screening programmes in Glasgow, Scotland (aged 51-64 years; n=68,324). Interviews covered perceptions of cancer, screening, and screening decisions. Framework Method was used for analysis.

**Results:** Of the 2,924 women invited, 86 expressed an interest, and 59 were interviewed. The three groups' perceptions differed, with the colorectal-specific non-participants expressing that: i) treatment for colorectal cancer is more severe than for breast or cervical cancer; ii) colorectal symptoms are easier to self-detect than breast or cervical symptoms; iii) they worried about completing the test incorrectly; and iv) the colorectal test could be more easily delayed or forgotten than breast or cervical screening.

**Conclusions:** Our comparative approach suggested targets for future interventions to increase colorectal screening uptake including: i) reducing fear of colorectal cancer treatments; ii) increasing awareness that screening is for the asymptomatic; iii) increasing confidence to self-complete the test; and iv) providing a suggested deadline and/or additional reminders.

## BACKGROUND

Colorectal cancer (CRC) is the second leading cause of cancer death worldwide.[1] CRC screening by faecal occult blood test (FOBT) can reduce deaths.[2] In Scotland, since 2007, people aged 50-74 have been mailed a self-complete FOBT every two years as part of the Scottish Bowel Screening Programme. The FOBT requires people to collect two samples from each of three separate bowel motions and to mail their completed kit for processing. Women in Scotland are also invited to attend a pre-arranged appointment for breast screening using mammography and to make an appointment for cervical screening using the Pap smear (Table 1). All three screening tests are offered at no cost to participants through the National Health Service. Uptake of screening is 77% for cervical, 72% for breast but only 59% for colorectal among women aged 50 and over.[3-5] Screening uptake rates show similar patterns in Australia and the US with uptake of CRC screening lagging behind the participation rates of breast and cervical screening.[6, 7]

**Table 1**  
**Invitation procedures in the Scottish cancer screening programmes**

|                     | Screening programme   |  |   |
|---------------------|---|--|---|
|                     | Breast screening by mammography   | Cervical screening by smear test   | CRC screening by faecal occult blood test   |
| Pre-notification    | None  | None   | 2 weeks prior to invitation <sup>a</sup>  |
| Invitation (mailed) | Within 3 years after 50 <sup>th</sup> birthday<br>Until 70 <sup>th</sup> birthday<br>After 70 <sup>th</sup> birthday on request | Before June 2016:<br>After 20 <sup>th</sup> birthday<br>Until 60 <sup>th</sup> birthday<br>From June 2016:<br>After 25 <sup>th</sup> birthday<br>Until 65 <sup>th</sup> birthday | From 50 <sup>th</sup> birthday<br>Until 75 <sup>th</sup> birthday<br>After 75 <sup>th</sup> birthday on request |
| Reminder (mailed)   | Reminder at 3 days following non-attendance   | Reminders at 3 months and at 6 months after the invitation   | Reminder at 6 weeks after the invitation  |
| Screening interval  | Every 3 years   | Aged 25-49: every 3 years<br>Aged 50-64: every 5 years   | Every 2 years   |

Notes. <sup>a</sup>pre-notification letters for CRC screening ceased in February 2015.

79 Reasons for the low uptake of CRC screening include lack of awareness, feeling healthy,  
80 negative views of cancer (fear, fatalism), negative attitudes towards colorectal tests, lack of  
81 motivation including other health concerns, and cultural, gender and socioeconomic  
82 influences.[8-11] Many of these potential barriers also apply to breast and cervical  
83 screening,[12] so it is unclear why CRC screening uptake should remain considerably lower.  
84 There have been few comparisons of barriers across these three screening modalities.[13, 14]  
85 We identified only one study that directly compared barriers to breast, cervical and CRC  
86 screening uptake among women eligible for all three tests.[15] This British self-report survey  
87 of 890 women found that among those who participated in breast and cervical but not  
88 colorectal programmes, 23% reported not liking the idea of CRC screening test and 18% said  
89 they 'haven't got round to it, but intend to take part' as explanations for non-participation in  
90 CRC screening.[15] These explanations relate to both motivational influences such as dislike  
91 of the test, and volitional aspects of 'not getting round to it',[16] the latter being particularly  
92 salient for CRC screening which, unlike breast and cervical screening, is self-completed at  
93 home. Our study adds to those data in three main respects. Firstly, rather than using self-  
94 reported data of screening history, we linked cancer screening uptake data for the breast,  
95 cervical and CRC screening programmes for the complete population of Glasgow, Scotland—  
96 a socioeconomically diverse region with low overall screening uptake. Using this linked  
97 dataset, we identified women with three different screening histories: i) participated in all  
98 programmes; ii) participated in breast and cervical but not colorectal programmes; and iii) did  
99 not participate in any programme. Secondly, we invited women across these three groups to  
100 an individual in-depth interview, rather than a questionnaire, to provide the opportunity for  
101 women to speak at length about their perceptions and experiences of cancer screening.

Thirdly, we organised our findings using the route MAP approach which is a useful tool to summarise the central tenets of multiple models of behaviour change [17]. The MAP describes three routes to behaviour: i) Motivation—strategies that increase and sustain motivation (e.g. information about the behaviour, reassurance); Action-on-motivation—strategies that strengthen and elaborate skills needed to translate motivations into action (e.g. setting behavioural goals, action and coping planning); and Prompted or cued routes—strategies that support behaviour change without the continuous cognitive effort required by the Motivation and Action-on-motivation routes (e.g. prompt, change the environment to facilitate the target behaviour). The MAP approach therefore provides a theoretically informed framework to identify targets for intervention.

The present study was designed to 1) identify why women (who are eligible for all three types of screening) choose to participate in breast and cervical screening but not CRC screening, and 2) gain insight into how CRC screening uptake can achieve the uptake rates of breast and cervical screening.

## **METHODS**

### **Participants and recruitment strategy**

This study was conducted alongside a quantitative study exploring cancer screening uptake among women living in Glasgow, Scotland. Data on screening participation for the breast, cervical and CRC screening programmes were linked for all women aged 20 to 74 (n=430,591) who were registered with NHS Greater Glasgow and Clyde Health Board and invited to screening during the period 2009 to 2013. This linked dataset was used as a sampling frame for the present study to select women who were eligible for breast, cervical and CRC screening

(n=68,324). Because we expected screening experiences to differ by screening history and on socioeconomic position we aimed to interview women in each of six groups (Table 2).

**Table 2**  
**Sampling frame**

|  | Screening behaviour  |  |   |
|--|--|--|---|
|  | Screening participants<br>(screened for breast,<br>cervical and CRC)                   | CRC specific non-participants<br>(screened for breast and<br>cervical, but not CRC)  | Non-participants<br>(not screened for breast,<br>cervical or CRC)                       |
| Living in  |  |  |   |
| Most socioeconomically<br>deprived areas (SIMD <sup>a</sup><br>quintiles 1-2)  | Invited = 119<br>Expressed interest = 13<br>Interviewed = 11<br>Response rate = 10.92% | Invited = 244<br>Expressed interest = 13<br>Interviewed = 9<br>Response rate = 5.33% | Invited = 1,611<br>Expressed interest = 14<br>Interviewed = 10<br>Response rate = 0.87% |
| Least socioeconomically<br>deprived areas (SIMD <sup>a</sup><br>quintiles 4-5) | Invited = 20<br>Expressed interest = 11<br>Interviewed = 10<br>Response rate = 55.00%  | Invited = 159<br>Expressed interest = 14<br>Interviewed = 9<br>Response rate = 8.81% | Invited = 771<br>Expressed interest = 13<br>Interviewed = 10<br>Response rate = 1.69%   |

<sup>a</sup>Scottish Index of Multiple Deprivation

Purposive sampling was used to randomly identify and invite to interview women with three different screening histories: i) women who participated in all programmes (screening participants); ii) women who participated in breast and cervical but not colorectal programmes (CRC-specific non-participants); and iii) women who participated in none (non-participants). The sample was also stratified to obtain a mix of women from areas of high or low socioeconomic deprivation (Table 2). Socioeconomic deprivation was indexed by the Scottish Index of Multiple Deprivation (SIMD), an area-based measure of multiple deprivation linked to each individual's home address.[18] The aim was to obtain approximately ten interviews across the six stratified groups (Table 2). It was anticipated that recruiting non-participants and women living in deprived areas would be more challenging.[19] To ensure we achieved equal numbers of participants across the six groups we significantly oversampled non-participants and women living in deprived areas. In total, 2,924 women were invited (Table 2).

141

142 The research team provided the Glasgow Clinical Research Facility with the sampling frame to  
143 identify 2,924 women of the 68,324 eligible for all three screening tests to be sent invitation  
144 packs. Invitation packs contained a letter inviting women to participate in a study exploring  
145 views on bowel, breast and cervical cancer screening, a participant information sheet, and a  
146 response form with options to indicate interest by email, phone or using a pre-paid envelope  
147 enclosed. Participants were offered £20 for participation and to cover the cost of  
148 refreshments and travel to the interview. Only women responding to the invitation pack were  
149 subsequently identified to the research team. Ethical approval was obtained from the NHS  
150 Health Research Authority (NRES Committee North West – Liverpool Central, REC reference:  
151 4/NW/1300).

152

### 153 **Interview procedure and materials**

154 The interviewer (MK) met with respondents at locations of their choice: home (n = 35), the  
155 University Of Glasgow (n = 15), work (n=3), community centre (n=5), a parish house (n=1). MK  
156 had spoken to the participants by phone prior to the interview, but had no relationship with  
157 them otherwise. MK is female and had previous experience of conducting interviews and  
158 focus groups with women about cancer screening. All participants provided informed consent  
159 before the semi-structured interview started. The interview followed a topic guide and began  
160 with an open question, '*What comes to mind when you think about cancer?*' This was followed  
161 in turn with questions on what comes to mind in relation to bowel, breast and cervical  
162 cancers. The next question asked how they felt about their chances of developing breast,  
163 cervical or CRC. Participants were then asked for their thoughts and feelings about cancer  
164 screening. The interviewer asked, '*What comes to mind when you think about bowel cancer*

*screening?’* with supplementary questions on their understanding of what the test involves and the purpose. This was followed by the same questions in relation to breast and cervical screening. Finally, participants were shown example invitation letters and leaflets and were asked how they felt when they received these and how they decided what to do next. The interviews took place between November 2015 and April 2016, were an average length of 43 minutes, audio recorded and transcribed verbatim.

## **Analysis**

The transcripts were analysed using the Framework Method, which takes a matrix based analytic approach to facilitate rigorous and transparent data management.[20] This approach permitted comparisons of accounts between women with different screening histories and living in different socioeconomic circumstances.

MK, KR and SM read and re-read the data. A mind-mapping process was developed based on the one-sheet-of-paper method.[21] From these mind maps, MK identified themes as the basis of the framework matrix. The themes were organised into the three MAP routes: motivation; action-on-motivation; and prompts.[17] As described by Ritchie and colleagues,[20] the framework matrix was organised in a MS Excel spreadsheet containing one theme per worksheet with sub-themes in the columns. The rows contained individual participants, grouped by screening history and socioeconomic status. The themes and sub-themes within the framework matrix were discussed within the research team. Two researchers (MK and LG) coded the transcript in full and populated the framework matrix with relevant data extracts. They discussed comments and queries using web-based collaboration software (Trello), thus creating an audit trail. MK summarised each theme by comparing patterns within the pre-identified participant categories (screening history and socioeconomic

status) and noting representative data extracts. KR reviewed and discussed the summaries with MK to ensure consistency with the data.

## RESULTS

### Sample characteristics

Of the 2,924 women sent an invitation to participate; 2,629 did not respond, 129 declined, 76 invitations were returned undelivered, four women had died, and 86 expressed an interest in being interviewed of which four were excluded (due to becoming uncontactable, residing primarily outside the UK, or having a stoma). In total, 61 interviews were scheduled and 59 women were interviewed.

Response rates varied considerably across the six groups; 55% of people who had participated in all three programmes, and who lived in the least deprived areas agreed to be interviewed, whereas only 0.9% of people who had participated in none of the programmes and lived in the most deprived areas agreed to be interviewed (Table 2). The respondents' age ranged from 51 to 64 years. The respondents' views varied most commonly by screening participation history (screening participants, CRC-specific non-participants, non-participants), which formed our main comparison category. Comparisons by socioeconomic deprivation did not show clear differences in respondents' views but are highlighted where differences were found.

The results were organised into the three routes of behaviour change described by the MAP approach: motivational challenges to CRC screening; action-on-motivation challenges to CRC screening; and prompts to CRC screening.[17, 22]. The results are summarised in Table 3.

**Table 3****Summary of results identifying unique challenges to colorectal cancer screening in comparison to breast and cervical screening**

|  | Screening participants<br>(screened for breast, cervical and CRC)                          | Screening behaviour<br>CRC specific non-participants<br>(screened for breast and cervical, but not CRC)  | Non-participants<br>(not screened for breast, cervical or CRC)  |
|--|--|--|---|
| <b>Motivational challenges to colorectal screening</b>         |  |  |   |
| Treatment beliefs  | Less negative view of treatment than in other two groups                                   | CRC treatment perceived as more severe than breast or cervical   | Treatment most threatening aspect of cancer   |
| Beliefs about the value of screening                           | Valued screening   | Some questioned value of CRC screening and self-sampling reduced credibility   | Questioned value as intolerable cancer treatment would still be necessary                             |
| Disgust and embarrassment                                      | Acknowledged but overcome  | Frequently discussed as barriers, avoided talking about CRC screening with others  | Frequently discussed as barriers  |
| Symptom beliefs  | Acknowledged screening is for asymptomatic as more treatable at earlier stage of diagnosis | Screening to check existing symptoms, CRC symptoms more visible and detectable reducing need for CRC screening                                     | Screening to check existing symptoms, therefore unnecessary in the absence of symptoms                |
| Comorbidities and previous colorectal investigations           | Comorbidities mentioned less frequently  | Felt less need for CRC screening because of previous colorectal investigations   | Psychological and physical comorbidities made less willing to screen                                  |
| <b>Action-on-motivation challenges to colorectal screening</b> |  |  |   |
| Lack of health professional involvement                        | Acknowledged CRC self-sampling was awkward, but overcome                                   | Worried about completing FOBt incorrectly, CRC burdensome and complicated, disengagement from process possible for breast and cervical but not CRC | Worried about completing FOBt incorrectly, CRC burdensome and complicated                             |
| Colorectal screening requires planning                         | Detailed planning  | Rarely described making plans to screen  | Rarely described making plans to screen   |
| Comorbidities  | Comorbidities mentioned less frequently  | Comorbidities impediments to CRC self-completion   | Comorbidities impediments to CRC self-completion and to a lesser extent breast and cervical screening |
| <b>Prompts to colorectal screening</b>                         |  |  |   |
| Postponing and forgetting                                      | Described using prompts to avoid forgetting  | Lack of appointment time or deadline made CRC more easily delayed or forgotten   | Lack of appointment time or deadline made CRC more easily delayed or forgotten                        |

210 **Motivational challenges to CRC screening**

211 Treatment beliefs

212 CRC-specific non-participants considered CRC treatment to be more severe than breast or  
213 cervical cancer treatment.

214 “I know that breast cancer caught early is really treatable. {...} I think cervical  
215 cancer’s totally curable. {...} I don’t really know that much about the bowel one. I  
216 mean, I know that bowel cancer’s very, very serious. I mean, you can live without  
217 your breasts, you know, you can, you know, have a hysterectomy {...} you cannae  
218 [cannot] really live without the bowels “ (P134, 53 years, CRC-specific non-  
219 participant)

220 Similarly, for non-participants the most threatening aspect of cancer appeared to be its  
221 treatment. They questioned the effectiveness of cancer treatments to reduce mortality and  
222 expressed concern over side effects, such as hair loss, nausea, fatigue, and the quality of life  
223 that patients experienced during and after treatment. These respondents questioned  
224 whether they would accept treatment if they were diagnosed with cancer. Further, non-  
225 participants, mostly from those living in the least deprived areas, did not believe early  
226 detection could help them avoid cancer treatments that would reduce their quality of life.

227 “you just don’t want to think of bowel cancer, and getting colostomies or  
228 whatever. Just the very thought. Sometimes I think I’d rather just not know and  
229 die, rather than be diagnosed with that and having a colostomy. {...} I would rather  
230 just die than go about like that, that’s not living” (P45, 64 years, non-participant)

231 In contrast, the screening participants viewed cancer treatment more positively.

232            “If you are unlucky enough and you lose the whole bowel and you have to have  
233            a colostomy bag then are you not better having that than dying?” (P58, 59 years,  
234            screening participant)

235 Beliefs about the value of CRC screening

236 CRC-specific non-participants questioned the value of CRC screening. These respondents  
237 doubted the efficacy of FOBt after having heard of others who had false negative FOBt results.  
238 They also believed that self-sampling reduced the credibility of CRC screening and completing  
239 the test in their own bathrooms seemed incongruent with the respondents’ schemata for  
240 medical tests.

241            “if somebody [in health care team] had said ... you know, “Come along and sit on  
242            the toilet and we’ll collect your poo,” somehow it would have felt a little bit more  
243            detached, a little bit more kind of clinical {...} they’d probably have worked out  
244            some sort of system that they can do that more easily without needing plastic  
245            bags and God knows what else” (P121, 53 years, CRC-specific non-participant)

246 Disgust and embarrassment

247 The only test described as disgusting was FOBt. CRC-specific and non-participants spoke about  
248 disgust more often than screening participants. Participants’ disgust related to FOBt being a  
249 self-completed test, the involvement of faeces and its association with bowel functions. In  
250 each group, participants described CRC screening to be embarrassing, with embarrassment  
251 relating to handling their faeces, storing the test kit and concern about other people (such as  
252 grandchildren) finding the FOBt kit, or postal workers having to handle the envelopes  
253 containing completed kits. Breast and cervical screening were perceived to be more  
254 acceptable and easier to discuss than CRC screening.

255 “you would think getting your tits out or, you know, opening your legs for some  
256 speculum, you would feel as though both of those things ought to be more  
257 intimate [laughs] but actually, I think it’s probably because the way that we are  
258 brought up not to discuss bowels in this country” (P95, 55 years, CRC-specific non-  
259 participant)

260 CRC-specific non-participants reported talking about cancer screening less often and  
261 specifically avoided talking about CRC screening, which respondents living in more deprived  
262 areas reported as off-limits for discussion. Respondents tended to describe talking about FOBt  
263 as immature, likening it to children laughing about “farts and smells” (P121, 53 years, CRC-  
264 specific non-participant).

265 “you’re told when you’re young [laughs] not tae talk about stuff like that {...}  
266 except for when you’re a boy when all bodily functions are, you know, extremely  
267 funny in your mind” (P134, 53 years, CRC-specific non-participant)

## 268 Symptom beliefs

269 A theme among CRC-specific and non-participants was that they felt they would be  
270 better able to detect CRC symptoms, like indigestion or blood in their faeces than breast  
271 or cervical cancer symptoms. Similarly, non-participants also reported that they would  
272 ‘know’ if they had cancer making screening unnecessary, particularly in the absence of  
273 symptoms.

274 “it [smear test] picks up any issues if you’re not aware of issues {...} I think the  
275 bowel cancer one, you kind of know, most people know what the symptoms would  
276 be and therefore you assume that if you – since it’s easy to see, that you’re okay

277 {...} ‘cos you’re not aware of any symptoms.” (P165, 54 years, CRC-specific non-  
278 participant)

279 Screening participants believed that by the time cancer caused symptoms it would be  
280 advanced and less treatable. In contrast to CRC-specific and non-participants, screening  
281 participants thought they would have difficulty detecting CRC without FOBt.

282 Comorbidities and previous colorectal investigations

283 Some CRC-specific non-participants reported having had colorectal investigations and  
284 therefore felt less need for bowel screening. Non-participants also described how  
285 psychological and physical comorbidities made them less willing to complete screening.  
286 Physical comorbidities meant participants felt unable to cope with the prospect of additional  
287 investigations and/or treatment. Anxiety prevented some non-participants from deciding for  
288 or against cancer screening. A few reported depressive symptoms and thoughts of suicide; in  
289 this context cancer seemed to be an ‘easier’ (or, at least, a blameless) way to die—negating  
290 any perceived need for cancer screening.

#### 291 **Action-on motivation challenges to CRC screening**

292 Lack of health professional involvement

293 CRC-specific non-participants and non-participants expressed worry about completing FOBt  
294 incorrectly without the support of a health professional. This set CRC screening apart from  
295 breast or cervical screening where health professionals conduct the tests.

296 “I suppose it’s different, it’s like a self-kit, you know? ... compared to the other two  
297 are being done by professionals. That’s their job and maybe you just feel like  
298 they’re doing it right.” (P150, 54 years, CRC-specific non-participant)

299 To complete FOBt correctly, CRC-specific non-participants felt they needed to be fully  
300 engaged and 'pay attention'. In contrast, with breast and cervical screening they could  
301 disengage to some extent as the health professional completed these tests for them.

302 "When you go and get a cervical screen you don't have to do anything, you just  
303 turn up. For bowel screening, you've got to go that extra step. {...} you've actually  
304 to make the effort to do it and collect the sample and seal it up and all whatever,  
305 and send it away." (P165, 54 years, CRC-specific non-participant)

306 CRC-specific non-participants described using disengagement during breast or cervical  
307 screening to cope with physical or psychological discomfort, but disengagement to overcome  
308 disgust or displeasure was not possible with self-completed CRC screening.

309 CRC-specific non-participants and non-participants reported CRC screening to be  
310 burdensome. Having to read instructions was considered to be a "hurdle" (P165, 54 years,  
311 CRC-specific non-participant) and FOBt to be complicated and effortful. Having to take three  
312 samples added to FOBt seeming burdensome. In contrast, screening participants rarely  
313 reported that FOBt was time consuming or complicated, but they agreed that taking faecal  
314 samples by themselves was awkward to do.

315 "If somebody was to {...} make it [FOBt] easy for me, I would have done it because  
316 I approve of the principle" (P166, 57 years, CRC-specific non-participant)

317 CRC screening requires planning

318 CRC-specific and non-participants rarely described making plans to do screening. In contrast,  
319 screening participants described detailed planning strategies to overcome practical barriers.  
320 They reported dealing with CRC screening invitations promptly and planned specific days to  
321 do the FOBt. Screening participants living in the least deprived areas also described routines

322 for cleaning after FOBt completion and using gloves and wipes to make FOBt less disgusting  
323 to them.

324 Impact of comorbidities

325 Illnesses and other conditions were an additional challenge to the self-completion of FOBt.  
326 Non-participants most often reported unpredictable bowel movements, diarrhoea, IBS,  
327 coeliac disease, multiple sclerosis and other health conditions as impediments to CRC  
328 screening although such conditions were also mentioned by CRC-specific non-respondents. A  
329 further two respondents with visual impairments reported abandoning half-completed FOBt  
330 kits or waiting for a support worker to organise help with doing FOBt.

331 “I’ve got coeliacs, so, it’s very, very seldom my bowel, my my my toilet is... what’s  
332 the word? Solid. {...} so it’s quite difficult that way. So, maybe once I get the  
333 coeliacs and everything under control then it might be different” (P130, 54 years,  
334 CRC-specific non-participant)

### 335 **Prompts to CRC screening**

336 Postponing and forgetting

337 Unlike breast and cervical screening, CRC screening is completed at home and does not  
338 require an appointed time. CRC-specific and non-participants reported that CRC  
339 screening could be more easily delayed or forgotten than cervical screening which only  
340 required them to make an appointment, and even more easily than breast screening  
341 where the appointment is pre-arranged. Some CRC-specific non-participants and non-  
342 participants living in the least deprived areas explained that they would put their FOBt  
343 invitation to one side and, as a result, forget about it.

344 “if it’s a bowel screening one, yep, put it somewhere and think ‘Yes, I’ll do that’  
345 and then forget about it because it doesn’t have an appointment date. I think if  
346 something has an appointment date, you’re forced to act.” (P165, 54 years, CRC-  
347 specific non-participant)

348 Screening participants living in the least deprived areas described creating CRC screening  
349 reminders: leaving the FOBt material near their bathroom or within their view as a cue.

350 “I just usually take the pack, read the instructions again leave it in the loo until the  
351 next time I have to go {...} I just usually take all the bits in and just leave them there  
352 to remind me what I’ve to do” (P172, 57 years, screening participant)

## 353 **DISCUSSION**

354 Our findings show that women who participated in breast and cervical but not CRC screening  
355 (CRC-specific non-participants) differed in their barriers to CRC screening compared to  
356 screening participants and to a lesser extent, non-participants. CRC-specific non-participants  
357 reported that treatment for CRC was more severe than for breast or cervical cancer, and  
358 colorectal symptoms were easier to detect oneself than breast or cervical symptoms, which  
359 influenced their motivation to complete CRC screening. CRC-specific non-participants also  
360 worried about incorrectly completing the test without the support of a health professional,  
361 and that they felt the home-based CRC screening test could be more easily delayed or  
362 forgotten than breast or cervical screening, which challenged the translation of their  
363 motivation into action.[16]

364

365 A key strength of our study was in achieving a sample of women whose screening histories  
366 were objectively established by linking three cancer screening programmes’ data for the

entire population of Glasgow, Scotland. To our knowledge, this has not previously been done. Among the CRC-specific non-participants and the non-participants the response rate to the invitations to be interviewed was extremely low (0.9-5.3%) reflecting the difficulty of engaging all population groups in research, and the value of the data that has been obtained. The study has limitations; the SIMD measure used to assess socioeconomic deprivation was an area-based measure which offers a relatively blunt assessment and may offer one explanation for the limited number of socioeconomic deprivation differences noted in the analysis. The study focused on women due to the design, and so it is yet to be determined if the same specific CRC challenges apply to men. It is also noted that this study focused on increasing uptake of CRC and does not consider explicitly the role of informed choice principles. Some women make an informed choice not to engage in cancer screening which is entirely appropriate.[23] Our approach does not conflict with the principles of informed choice. For example providing more information reflecting advances in colorectal cancer treatment would increase knowledge.[24] However, interventions to address the identified motivational challenges would aim to improve knowledge and understanding and so support informed choice. The action-on-motivation targets would be aimed at supporting people who intend to screen to put their intentions into action and so would not compromise informed choice.

Understanding why CRC screening fails to achieve the uptake rates of breast and cervical has been explored in one previous self-report, survey study.[15] We are able to expand on the survey's results, as our findings explain that screening participants also dislike the self-completed FOBt, but manage these feelings; our findings show that medical reasons to for non-participation in CRC screening can include comorbidities that impede self-completed CRC screening, but also that women with previous colorectal investigations feel less need for CRC

screening. Other studies have considered the relatively low uptake of CRC in isolation, and while they have identified similar barriers to the present study around, for example, fears about treatment, being asymptomatic, concerns about self-completion[8-11] etc., the present study adds a more nuanced understanding, which informs potential targets for future interventions to increase CRC screening uptake. While it is acknowledged that people are fearful of cancer treatment,[11, 25] the present study identified that women fear of treatments for CRC more than breast or cervical cancer, which may partly explain their reluctance to engage in CRC screening. Similarly, being asymptomatic is a commonly recognised barrier in the screening literature.[8, 26] Surveys have established that awareness of CRC symptoms is low,[27] but it was previously unknown that there may be a misunderstanding that colorectal symptoms are more easily self-detected than breast and cervical symptoms. Furthermore, the present study has illustrated the unique challenges of self-completion of CRC screening in the absence of a health professional, and the greater chance of procrastinating or forgetting the test in the absence of a specified appointment time. We note that similar barriers have been identified for Human Papillomavirus self-sampling for cervical screening.[28, 29]

We have identified potential targets for interventions to increase CRC screening uptake and drafted example policy recommendations (Table 4). For example, to reduce fear and misconceptions of CRC treatments, we recommend a concerted information campaign reflecting advances in CRC treatment and success stories.[30] To increase awareness that CRC screening is for people who are asymptomatic, we recommend a concerted information campaign to reiterate and reinforce existing messages that CRC screening is for the asymptomatic, and symptoms may only appear at an advanced stage. To reduce postponing

415 and forgetting, we recommend providing a further reminder and potentially a suggested  
416 deadline for kit return. It is important to note that Scotland replaced FOBt bowel screening  
417 with Faecal Immunochemical Testing (FIT) in November 2017 and FIT will be introduced in  
418 England and Wales in 2019. FIT requires only one faecal sample and, based on evidence from  
419 pilot studies[31] and the initial months since its introduction in Scotland,[32] it is likely this  
420 easier to complete test will increase uptake. Nonetheless, FIT alone is not sufficient to address  
421 the other identified challenges to CRC screening uptake, and complementary interventions  
422 are recommended.

**Table 4**  
**Potential targets to increase colorectal cancer screening**

| Challenges to successful colorectal cancer screening           | Potential targets to increase CRC screening uptake                                  | Example policy recommendation  |
|--|---|--|
| <b>Motivational challenges to colorectal screening</b>         |   |  |
| Treatment beliefs  | Reduce fear and misconceptions of colorectal cancer treatments                      | Concerted information campaign reflecting advances in colorectal cancer treatment and success stories                        |
| Beliefs about the value of screening                           | Increase credibility of self-sample test  | Concerted information campaign emphasising value of the self-sample test   |
| Disgust and embarrassment                                      | Reduce disgust and embarrassment  | Concerted information campaign modelling people talking about the test to support positive social norms                      |
| Symptom beliefs  | Increase awareness that colorectal screening for asymptomatic                       | Concerted information campaign reiterating that colorectal screening for asymptomatic  |
| Comorbidities and previous colorectal investigations           | Increase support for those with other health priorities                             | Increase awareness within primary care to provide support for colorectal screening among people with other health conditions |
| <b>Action-on-motivation challenges to colorectal screening</b> |   |  |
| Lack of health professional involvement                        | Increase people's confidence to self-complete the test correctly                    | Provide examples of others' experiences of completing the self-sample test to model successful completion                    |
| Colorectal screening requires planning                         | Increase people's ability to plan how, when and where they will complete their test | Provide planning support tool with the self-sample test  |
| Comorbidities  | Increase support for those with other health priorities                             | Increase awareness within primary care to provide support for colorectal screening among people with other health conditions |
| <b>Prompts to colorectal screening</b>                         |   |  |
| Postponing and forgetting                                      | Increase prompts to avoid postponing and forgetting                                 | Provide further reminders<br>Provide a suggested deadline for kit return   |

424

425 This study represents the first step in a process by identifying potential targets to increase

426 CRC screening uptake.[22] It will be necessary to test in a randomised controlled trial whether

an intervention strategy increases uptake by affecting the specified targets.[22] This systematic approach is in line with current best practice guidance on the development of complex interventions,[33, 34] and will build on and expand existing knowledge of effective strategies to improve cancer screening uptake.[35]

## **ADDITIONAL INFORMATION**

### **Ethical approval and consent to participation**

Ethical approval was obtained from the NHS Health Research Authority (NRES Committee North West – Liverpool Central, REC reference: 4/NW/1300). Participants provided informed consent to take part in the study which was performed in accordance with the Declaration of Helsinki.

### **Availability of data and material**

The datasets generated and/or analysed during the current study are available from the corresponding author on request.

### **Conflict of Interest**

The authors declare no conflicts of interest.

### **Funding**

This research was supported by a National Awareness and Early Diagnosis Initiative Grant (C9227/A17676) awarded to co-PIs KR and CMcC. The funder and sponsor had no involvement in the study design, data collection or analysis, or the writing and publication of the report. All researchers involved in this study were independent of the funder and all co-authors had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

### **Acknowledgements**

451 We gratefully acknowledge the Patient Involvement support from Ann Muir and Tom Haswell.

452

## REFERENCES

1. Ferlay J, Ervik M, Lam, F, et al. *Cancer Today (powered by GLOBOCAN 2018)*. IARC CancerBase. Number: 15. Available from <http://publications.iarc.fr/577> [Accessed 26<sup>th</sup> March 2019].
2. Steele RJC, McClements PL, Libby G, et al. Results from the first three rounds of the Scottish demonstration pilot of FOBT screening for colorectal cancer. *Gut* 2009; 58(4): 530—35. Available from: doi:10.1136/gut.2008.162883.
3. Information Services Division. *Scottish Cervical Screening Programme Statistics 2017/18*. 2018. Available from: <https://www.isdscotland.org/Health-Topics/Cancer/Publications/2018-09-04/2018-09-04-Cervical-Screening-Report.pdf> [Accessed 26th March 2019].
4. Information Services Division. *Scottish Breast Screening Programme Statistics 2015/16*. 2017. Available from: <https://www.isdscotland.org/Health-Topics/Cancer/Publications/2017-04-25/2017-04-25-SBSP-Cancer-Report.pdf>. [Accessed 26th March 2019].
5. Information Services Division. *Scottish Bowel Screening Programme Statistics*. 2018. Available from: <https://www.isdscotland.org/Health-Topics/Cancer/Publications/2018-08-07/2018-08-07-Bowel-Screening-Publication-Report.pdf>? [Accessed 27th March 2019].
6. Centers for Disease Control and Prevention. Cancer screening—United States, 2010. *Morbidity and Mortality Weekly Report* 2012; 61(3): 41—5.
7. Australian Institute of Health and Welfare. *National cancer screening programs participation data*. 2019. Available from: <https://www.aihw.gov.au/reports/cancer->

screening/national-cancer-screening-programs-participation/data [Accessed 26th March 2019].

8. Honein-AbouHaidar GN, Kastner M, Vuong V, et al. Systematic review and meta-study synthesis of qualitative studies evaluating facilitators and barriers to participation in colorectal cancer screening. *Cancer Epidemiology and Prevention Biomarkers* 2016; 25: 907—17.
9. Hall N, Rubin G, Dobson C, et al. Attitudes and beliefs of non-participants in a population-based screening programme for colorectal cancer. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy* 2013; 18(5): 1645—57.
10. Jones RM, Woolf SH, Cunningham TD, et al. The relative importance of patient-reported barriers to colorectal cancer screening. *American journal of preventive medicine* 2010; 38(5): 499—5.
11. Chapple A, Ziebland S, Hewitson P, et al. What affects the uptake of screening for bowel cancer using a faecal occult blood test (FOBT): A qualitative study. *Social Science & Medicine* 2008; 66(12): 2425—35.
12. Wardle J, Robb K, Vernon S, et al. Screening for prevention and early diagnosis of cancer. *American psychologist* 2015; 70(2): 119—33. Available from: doi:10.1037/a0037357.
13. Young B, L Bedford L, Kendrick D, et al. Factors influencing the decision to attend screening for cancer in the UK: a meta-ethnography of qualitative research. *Journal of Public Health* 2013; 40(2): 315—39. Available from: 10.1093/pubmed/fdx026
14. Mema SC, Yang H, Vaska M, et al. Integrated cancer screening performance indicators: a systematic review. *PloS one* 2016; 11(8): e0161187.

15. Lo SH, Waller J, Wardle J, et al. Comparing barriers to colorectal cancer screening with barriers to breast and cervical screening: a population-based survey of screening-age women in Great Britain. *Journal of Medical Screening* 2013; 20(2): 73—9. Available from: doi:10.1177/0969141313492508.
16. Schwarzer R. Modeling health behavior change: How to predict and modify the adoption and maintenance of health behaviors. *Applied Psychology* 2008; 57(1): 1—29.
17. Dixon D, Johnston M. *Health Behaviour Change Competency Framework: Competences to deliver interventions to change lifestyle behaviours that affect health*. 2010. Available from: [http://www.healthscotland.com/uploads/documents/4877-Health\\_behaviour\\_change\\_competency\\_framework.pdf](http://www.healthscotland.com/uploads/documents/4877-Health_behaviour_change_competency_framework.pdf). [Accessed 26th March 2019].
18. Scottish Government. *Introducing the Scottish Index of Multiple Deprivation* 2016, Available from: <http://www.gov.scot/Resource/0050/00504809.pdf> [Accessed 26th March 2019].
19. McCaffery K, Wardle J, Nadel M, et al. Socioeconomic variation in participation in colorectal cancer screening. *Journal of Medical Screening* 2002; 9(3): 104—8.
20. Ritchie J, Spencer L, O'Connor W. Carrying out qualitative analysis. In: Ritchie J, Lewis J, editors. *Qualitative research practice: A guide for social science students and researchers*. London: SAGE Publications 2003:219—62.
21. Ziebland S, McPherson A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness). *Medical Education* 2006; 40(5): 405—14. Available from: doi:10.1111/j.1365-2929.2006.02467.x.

22. Sheeran P, Klein WM, Rothman AJ. Health Behavior Change: Moving From Observation to Intervention. *Annual Review of Psychology* 2017; 68(1): 573—600.
23. Jepson RG, Hewison J, Thompson AG, Weller D. How should we measure informed choice? The case of cancer screening. *Journal of medical ethics*. 2005; 31(4): 192-6.
24. Ghanouni A, Renzi C, Meisel SF, Waller J. Common methods of measuring ‘informed choice’ in screening participation: challenges and future directions. *Preventive medicine reports*. 2016; 4: 601-7.
25. Robb KA, Simon AE, Miles A, et al. Public perceptions of cancer: a qualitative study of the balance of positive and negative beliefs *BMJ open* 2014; 4(7), e005434.
26. Power E, Miles A, Von Wagner C, et al. Uptake of colorectal cancer screening: system, provider and individual factors and strategies to improve participation. *Future Oncology* 2009; 5(9): 1371—88.
27. Power E, Simon A, Juszczuk D, Hiom S, Wardle J. Assessing awareness of colorectal cancer symptoms: measure development and results from a population survey in the UK. *BMC cancer*. 2011; 11(1): 366—75.
28. Forrest S, McCaffery K, Waller J, Desai M, Szarewski A, Cadman L, Wardle J. Attitudes to self-sampling for HPV among Indian, Pakistani, African-Caribbean and white British women in Manchester, UK. *Journal of medical screening*. 2004; 11(2): 85-8.
29. Nelson EJ, Maynard BR, Loux T, Fatla J, Gordon R, Arnold LD. The acceptability of self-sampled screening for HPV DNA: a systematic review and meta-analysis. *Sex Transm Infect*. 2017; 93(1): 56-61.
30. McGregor LM, von Wagner C, Vart G, et al. The impact of supplementary narrative-based information on colorectal cancer screening beliefs and intention. *BMC cancer* 2015; 15(1): 162—70.

31. Digby J, McDonald PJ, Strachan JA et al. Use of a faecal immunochemical test narrows current gaps in uptake for sex, age and deprivation in a bowel cancer screening programme. *Journal of Medical Screening* 2013; 20(2), 80—5.
32. Information Services Division. *Scottish Bowel Screening Programme Statistics*. 2019. Available from: <https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-02-05/2019-02-05-Bowel-Screening-Publication-Summary.pdf>? [Accessed 26th March 2019].
33. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: The new Medical Research Council Guidance. *British Medical Journal* 2008; 337: 979—83.
34. Moore GF, Audrey S, Barker M, et al. Process evaluation of complex interventions: Medical Research Council guidance. *British Medical Journal* 2015; 350: h1258.
35. Duffy SW, Myles JP, Maroni R, et al. Rapid review of evaluation of interventions to improve participation in cancer screening services. *Journal of medical screening* 2017; 24(3): 127—45.