Bowel Cancer Screening Intervention Delivered by Community Renewal

Report on Analysis of Returns from the Engagement Team

August 2015

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1. INTRODUCTION

1.1. NHS Greater Glasgow and Clyde has participated in the national bowel cancer screening programme since 1 April 2009. The main objective of the programme is to reduce the overall mortality from colorectal (bowel) cancer in men and women aged between 50–74 years.

1.2. Men and women in this age group are invited to take part in the screening programme and are sent a test kit to their home address every two years. There are variations in completion rates across the Health Board, with men in more deprived areas being the least likely to return a completed test kit.

1.3. In 2014 Community Renewal (with support from the Social Marketing Gateway/SMG) was commissioned to develop, deliver and evaluate an intervention targeting people aged 50 and living in number of disadvantaged areas who should have been sent the kit for the first time shortly after their 50th birthday.

1.4. The intervention involves an experienced contact team from Community Renewal engaging via telephone with people receiving their first invitation for bowel screening around the time the screening kit arrives through the post.

1.5. The contact team staff then use motivational interviewing techniques to:

- Encourage people to complete the screening test;
- Identify and provide further information and, where appropriate, request reissue of kits using the nationally developed information materials and resources, and;
- Gain an understanding of the barriers to completion of bowel screening that people have in order to inform future work.

1.6. SMG's role in the project has been to conduct the qualitative evaluation of the records completed by the Community Renewal contact team following the telephone conversations they have with patients. This has involved SMG working with hand written records supplied by Community Renewal.

1.7. SMG was provided with a total of 417 returns, which were analysed systematically to assess the performance and outcomes of the telephone intervention, and in particular to throw light on the barriers and other factors which appear to be inhibiting patients completing the test.

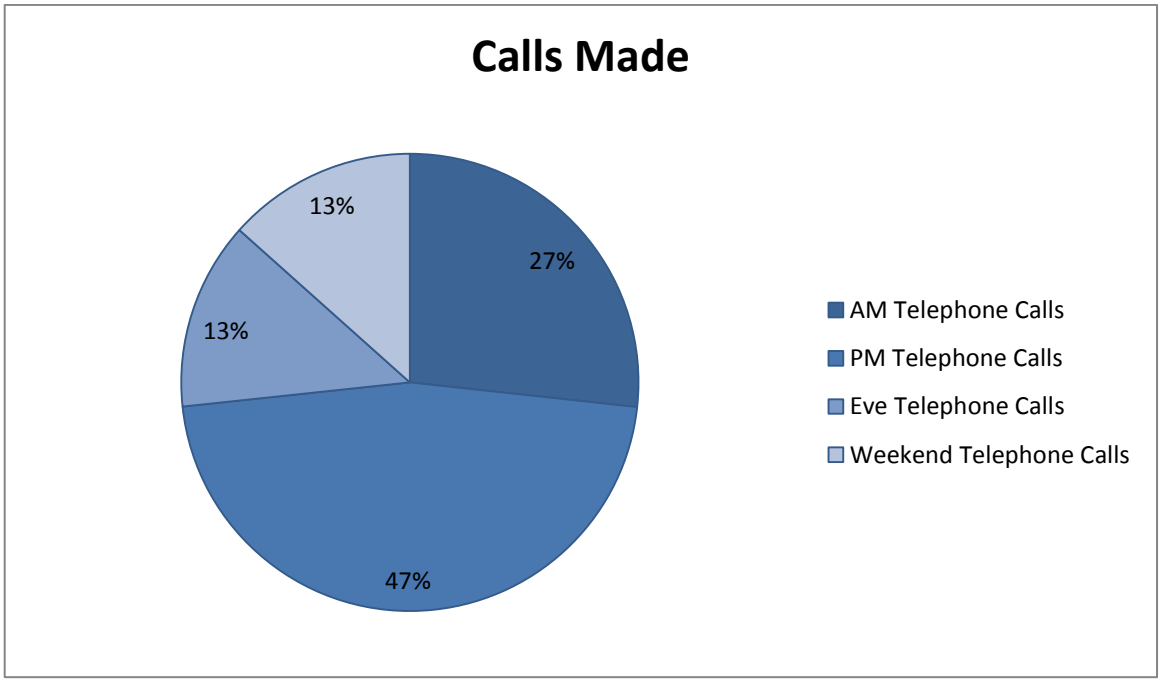
1.8. The following report presents the findings from the qualitative evaluation. It begins by setting out the methodology used by SMG to analyse the written contact records. It then presents a description of how the Community Renewal contact team delivered the intervention. Following this, the main findings are presented.

2. Breakdown of Referrals and Outcomes

Months	No Practices who Engaged with Pilot	No of Patients Referred Each Month	Incorrect Telephone Numbers	Inappropriate Referrals
December	3	124	0	6
January	34	431	31	29
February	39	351	20	18
March	39	281	24	17
April	42	242	40	23
May	43	173	76	9
6 Months	**Total Practices 43**	**1602**	**191**	**102**

Months	Am Telephone Calls	PM Telephone Calls	Eve Telephone Calls	Weekend Telephone Calls
December	13	4	0	0
January	123	183	104	0
February	228	258	10	0
March	64	344	73	104
April	148	284	88	151
May	204	287	113	136
6 Months	**780**	**1360**	**388**	**391**

Total Calls Made	Advised Completed test Prior to Call	Advised Will Complete as Result of Call	Refused to Complete	Refused to Engage on Telephone
2919	113	268	29	7



It should be noted that the afternoon periods of work are the longest therefore reflects the higher volume of calls made

A further breakdown of areas is provided in appendix A

3. EVALUATION METHODOLOGY

1.9. The methodology was largely a desk exercise, working with Community Renewal's hand written records. However, before progressing the desk research, the SMG team met with Community Renewal's contact team to understand how the intervention was delivered. This was very useful as it allowed SMG to:

- Develop a good overview of the role of the contact team and how they handled the telephone conversations with patients;
- Explore what the contact team felt to be the main barriers (or other reasons) that were stopping people completing and returning their test kits
  - NB, this allowed SMG to start thinking about an overall framework of possible barriers that could be used when manually working with the returns;
- Identify lessons learned by the contact team about the best times to phone and how to respond when people presented certain barriers or resistance to the idea of doing the test.

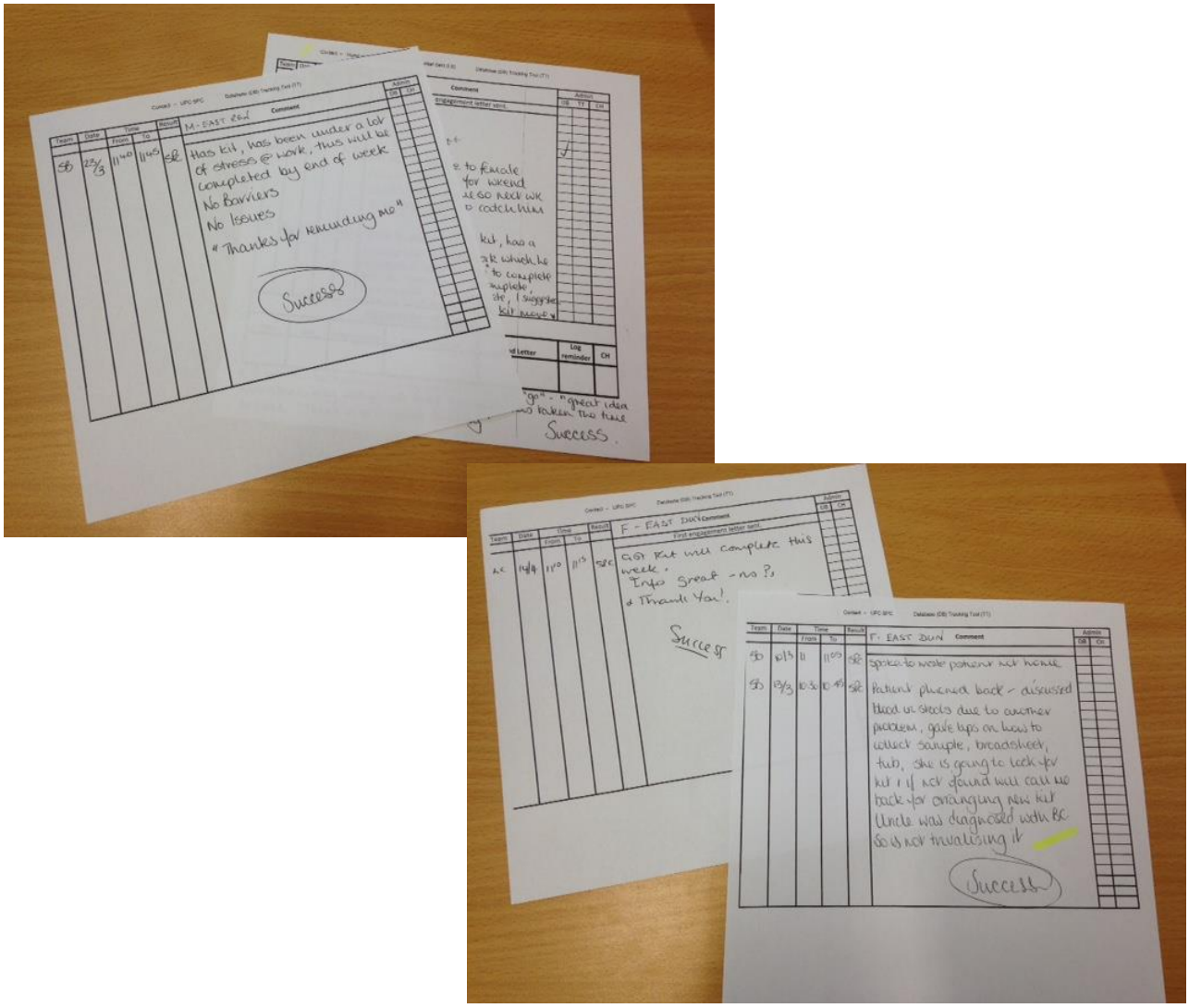
1.10. In terms of the **desk research**, the work was handled in the following stepped way:

- The **first** step was to separate the hard copy returns into those calls deemed to be 'successes' by the contact team and the 'refusals'. 'Successes' were calls where the person was reached on the phone and did not refuse outright to do the test. These accounted for the great majority of calls (93%). Refusals totalled only 29 (7% of all calls where a person was reached). In these cases the contact staff were unable to conduct any constructive or hopeful conversation.
- The **second** step was to divide the successes and refusals by gender. Overall, of the 388 successful calls, some 45% were male and 55% were female. Of the 29 refusals, some 62% were male and 38% were female.
- The **third** step involved going through every 3rd return in each pile and starting to build up a picture of the recurring things that were emerging during the conversations: i.e. in particular, factors that seemed to present barriers or difficulties for people completing the test, but also other interesting things that seemed to be coming up (such as tactics used by the contact team that seemed to work).
- The **fourth** step was to use the information extracted at step 3 to build up an initial framework of potential barriers and other reasons for non-completion of the test. This was provisional at this stage, and was expected to be developed further when revisiting the full set of returns.
- The **fifth** step involved a further dividing up of the full set of records into 4 separate groups (or segments) that emerged as relevant as we were working with the data: i.e. in addition to the refusals, the successes were divided into 3 groups:
  - those that had or were in the process of doing the test when the conversations took place;
  - those that claimed they planned to or would consider doing it; and
  - those that remained unsure.

1.11. Importantly, these segments are distinguished on the basis of their likely '***behaviour'*** in relation to doing or not doing the test.

- The **sixth** step was to revisit the data and work though all 417 returns across each segment to extract information on barriers and on other relevant information emerging in the course of the conversations with contact staff. This information was used to develop and populate the framework of barriers and other reasons for non-completion.
- The **seventh** and final step was to develop a commentary on the above framework, distinguishing the findings by each of the 4 main segments identified.

Figure 1: Examples of hand written contact reports



4. HOW THE INTERVENTION WAS DELIVERED

3.1 Community Renewal's contact team began telephone engagement in December 2014 with a list of telephone numbers of people turning 50 that month received from participating GP practices. Further contact lists were provided in due course, usually on a monthly basis (i.e. with names and telephone numbers of people turning 50 that month). SMG's depth consultation with the Community Renewal contact team points up some useful feedback (see below).

3.2 **Amount and quality of contact data** - Because the contact team began with a limited number of names, they did not phone people up every day, but spread the effort over the month. During the early period of the intervention, the team estimate that they spent about 14 hours a week phoning patients.

3.3 One problem experienced was that quite a few names came without phone numbers. This problem was experienced across all participating GP practices. Also, in some cases where numbers were supplied, on telephoning, the contact team found that they were incorrect. On occasions like this the team would telephone the GP practice to check the number provided was correct and to ascertain of another telephone number was available for the patients, in most cases the telephone provided was the only telephone number recorded for the patient.

3.4 **Timing of phone calls** – The team tried to time their first calls to be slightly after the person's 50th birthday as there was a higher chance that they would have received the kit.

3.5 Based on previous experience, the contact team did not make phone calls before 10am, as people tend to be too busy early in the morning to have a conversation. Saturday mornings tend to be a successful time to call. It is a particularly good time to re-call people who were not in when called previously during the week. The team found that early evening and weekend calls made on a Saturday up until 1pm in the afternoon were the best times to call patients.

3.6 **Success rates** - For every 100 people on the contact list, the contact team estimate that it was common for around 25 not to carry the correct contact details. For the other 75 for whom they had the correct telephone numbers, they felt that they would probably manage to speak to between 20%-40%. So, in other words, for every 100 patient names supplied by the GPs, the contact team might expect to reach between 15 and 30 patients.

3.7 The images below show an example of the monthly chart that the team used to record the outcome of their calls and one of Community Renewal's contact staff at work.

Figure 2: The intervention team at work

3.8 **Handling non-availability** - If people were not available to speak when they were reached on the phone, the contact team's standard protocol would be to ask when would be a good time to call back and to make a note to remind themselves. If the person was still unavailable when they next called, the contact would normally be moved to the list to receive a weekend call.

3.9 **Standard phone call procedure –** the contact team tended to follow a tried and tested approach. While the team has a protocol and a 'talking script' to hand, this was used more as a guide. On the phone, the team's experience is that it is important to adapt to different people and situations and to 'go with the flow' rather than rely on an inflexible script. The contact team pointed to a number of guidelines that tended to govern their telephone work:

- Ask to speak to the named person and say you are calling on behalf of the GP practice
- Ask if it's convenient for them to speak now
- Tell them you've noticed they've had a special birthday recently - "Most people laugh"
- Ask them if they have received the kit
- If yes, ask if they've had a chance to open it and if they have read it through
- If yes, ask if they have any questions or concerns
- At this point many different scenarios can emerge - some people have completed kit, others are planning to do it, but it is also common for people to say they haven't had the time
- Use prompt to help persuade them - e.g. suggest they keep the kit in their bathroom. Very few people keep their kit in their bathroom
- Most calls last about 3-5 minutes, but some can be much longer - e.g. 20mins
- Be prepared for people to go into detail about their personal/medical problems. A wider conversation can therefore develop. Sometimes people don't realise they are being called on behalf of GP, and not by the GP
- When people discuss other health/medical problems, suggest they make an appointment with their doctor
- People may ask about breast cancer screening or a smear test. So, keep information on breast cancer to hand so you are able to tell people when screening will be happening in their area/or remind people they can make their own appointment
- Delivering the service over the phone is a different process than face-to-face. Distance can be a good thing, as people are less embarrassed and can feel more free to talk about things they otherwise might not in a face to face situation
- Peer pressure/persuasion can be a big factor - if friends have had the test they often discuss it in friendship groups.

3.10 **Contact team's reflections -** When the contact team was interviewed by SMG at an advanced stage in their delivery of the intervention, they were able to identify a number of further lessons (or reflections) that might help similar efforts to encourage the uptake of the bowel cancer screening test:

- Don't use a lot of jargon in the conversation, keep the chat simple and friendly
- Don't always stick to the script. Keep a standard introduction. Remember it is an individual you're talking to. Go with the flow
- Know what you're talking about – the contact team had visited the NHS testing centre in Dundee, found out how to work the kit and what happens once it's sent

off. They found out from this that the label is the most important part and were able to pass that information on to people

- Good listening skills are required - sometimes you can identify a barrier just by listening to someone – try and identify “hooks”, state of mind etc. People open up to you, so you need to be able to listen to them
    - When patient expresses ‘yuck factor’ ask if they have thought of using gloves, disposable dish e.g. washed out butter container
    - If patient explains it is in the drawer, keeps forgetting ask them to move to the toilet
    - A patient states that they threw the kit out, ask if they would like another sent
- Rely on gentle persuasion, don't push or force. A simple ‘nudge’ might do it – doing the test has to be their idea, they have to see it as worth it
- Look on it like a friendly chat - people are used to ‘getting advice’ from their GP for being overweight, smoking etc. Use the opposite approach
- If the person has completed the test ask them how it was; ask if they have any suggestions they might have made it easier or better.

5. FINDINGS

4.1 **Overall sample**

Of the total of 417 patients contacted, 192 (46%) were male and 225 (54%) were female.

These patients were subsequently broken down into 4 segments:

- Completers - People who had already completed the test (or were in the process of doing so) when the contact team spoke with them
- Intenders - People who were planning to or thinking about doing the test, including those who may have been helped in this decision as a result of the telephone contact
- Uncertain - People who, despite having a conversation with the contact team were still unsure about completing the test
- Refusers - People who refuse to do the test and who it seems have not been shifted in any way in their view by the telephone contact.

Figures 3 and 4 show how the sample of 417 breaks down according to this segmentation.

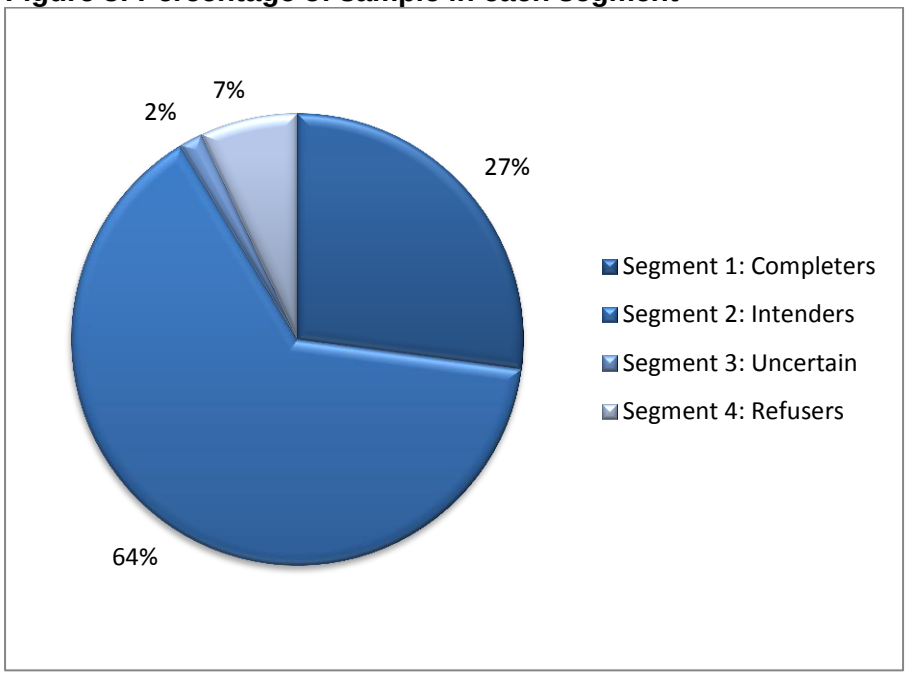
4.2 The largest number of patients fell into segment 2 (Intenders), i.e. those who agreed to complete the screening as a result of being contacted, with 268 patients out of the overall 417 falling into this category.

4.3 This is an encouraging sign for the intervention, indicating a substantial group not already committed to the test who may have been responsive to the encouragement given by the contact team. A note of caution, however, should be made: from the evidence available, SMG is not able to confirm which of these 268 patients actually went on to complete the test following the telephone intervention.

4.4 Segments 1, 2 and 3 all contain a slightly higher number of female patients than males (Figure 4). Interestingly, however, Segment 4 exhibits a higher number of males refusing to participate in the screening than females, with 9% of the overall number of males reached refusing to participate versus only 4% of females. This suggests that in keeping with previous research males appear to be less likely than females to be positively encouraged to participate in the screening.

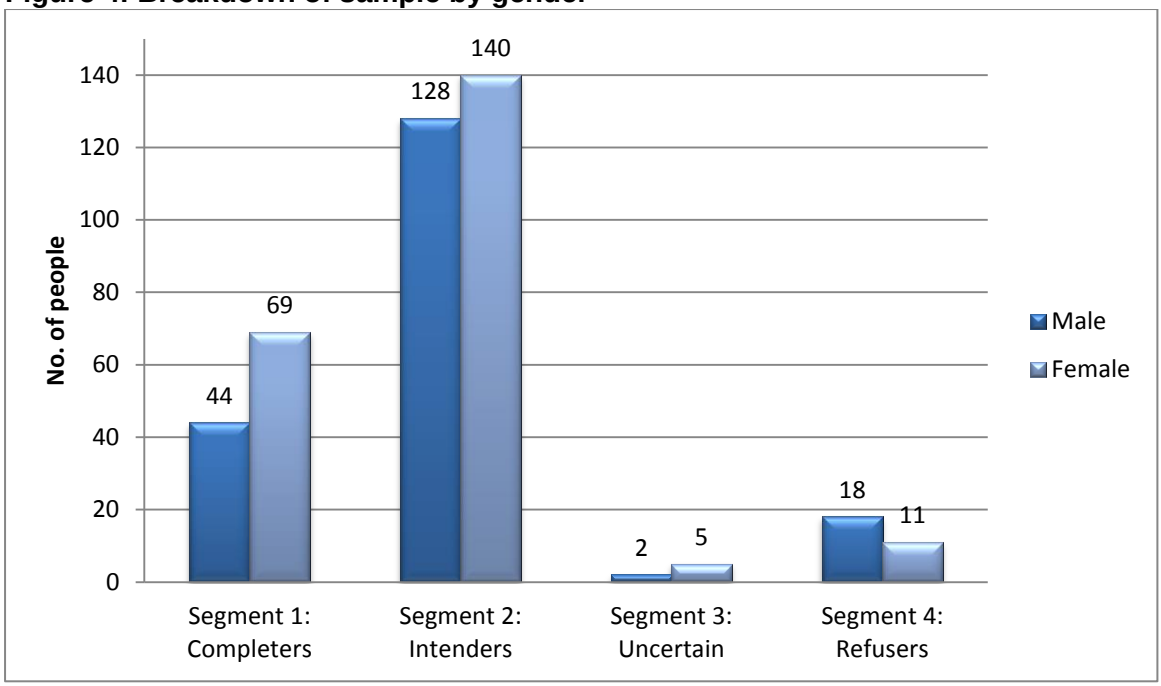
4.5 While each of these segments view and behave differently towards the test, there are both similarities and differences in terms of their experience with the test kit, the concerns or worries they have (or had) and the perceived barriers that inhibit completing the test. The people in each segment may also have responded differently to the telephone intervention: e.g. some may have found the conversation more helpful than others and their attitude to doing the test may have shifted as a result of the chat they had with the contact staff. Similarly, the contact staff had different experiences across different segments. It is these kinds of questions that we will now explore, taking each segment in turn.

Figure 3: Percentage of sample in each segment



Total sample: 417

Figure 4: Breakdown of sample by gender



Total sample: 417

Table 1: Overall analysis of barriers and other reasons for non-completion by segment and gender

	Segment 1: Completers			Segment 2: Intenders			Segment 3: Uncertain			Segment 4: Refusers			
Barriers or other reasons for non-completion	Male	Female	**Total**	Male	Female	**Total**	Male	Female	**Total**	Male	Female	**Total**	**Total**
Too busy			**-**	17	26	**43**		1	**1**		2	**2**	**46**
Not opened kit yet			**-**	24	19	**43**		1	**1**			**-**	**44**
Been unwell			**-**	10	11	**21**	1	3	**4**	2	1	**3**	**28**
Forgot			**-**	15	12	**27**			**-**			**-**	**27**
Lost/misplaced kit			**-**	9	9	**18**			**-**			**-**	**18**
Information unclear	1	3	**4**	4	8	**12**			**-**			**-**	**16**
Disgusted by thought		5	**5**	2	3	**5**		1	**1**		2	**2**	**13**
Not received kit yet			**-**	4	5	**9**		1	**1**	1		**1**	**11**
Doesn't want to, reason unclear/hung up	1		**1**			**-**			**-**	7	2	**9**	**10**
Kit inappropriate/unsuitable		3	**3**		1	**1**			**-**	1		**1**	**5**
Feels healthy			**-**			**-**			**-**	3	2	**5**	**5**
Afraid of outcome			**-**			**-**				2	1	**3**	**3**
Kit damaged			**-**	2		**2**			**-**			**-**	**2**
Other		1	**1**	4	6	**10**	1		**1**	3	1	**4**	**16**
Total no. of people overall (inc. those indicating no barriers/reasons for non-completion)	44	69	**113**	128	140	**268**	2	5	**7**	18	11	***29***	**417**
Total no. barriers/reasons for non-completion given	2	12	14	91	100	191	2	7	9	19	11	30	
Total no. of people experiencing barriers or other difficulties across all groups												**244**	

Key to Table 1

Barrier or other reason for non-completion	Examples of what patients said that was recorded by the contact team
Too busy/competition from other factors	“Not had time to think about it”; “Too stressed and busy at work”; “Been run off my feet - not a good time”
Not received kit yet	Patient had not received a kit through the post by the time of phone call
Not opened kit yet/still to get round to it	“Received my kit but haven’t opened it so don’t know anything about process yet”
Lost/misplaced kit	“Wife didn’t know what it was and threw it out”; “Put it somewhere before I went on holiday and can’t find it now”
Forgot about kit/having to do it	“Vaguely remember receiving it but forgot about it during birthday celebrations”; “Put it away and forgot all about it until this phone call”
Been unwell/in hospital/constipated	“Don’t have regular enough bowel movements”; “Not been well enough to do it”; “Just got out of hospital”
Disgusted by thought/too yucky	“Idea hideous”; “I’m not sending my poo in the post!”; “Couldn’t bring myself to do it”
Afraid of outcome/Fear of result/Denial	“Mother had colonoscopy and was in agony - afraid it might lead to that”; “Would rather not know for any illness”
Information unclear	“The information provided was not sufficient”; “Wasn’t sure how to quantify a ‘smear’”
Kit damaged	Patient accidentally tore barcode; “Kit damaged when received”
Kit inappropriate/unsuitable	“A bit fouttery”; “Afraid kit will open”; “Applicators too flimsy - plastic would be better”
Feels healthy	“Has no problems in that department, feels fit and healthy and you’re not going to change my mind”; “Not interested, I feel fine”
Doesn’t want to/reason unclear/hung up	“Don’t know why, just not wanting to do it”; “Naw yer awright”; “I will under no circumstances be completing the kit, take my name off the list”
Other	“Would have to ask carers to complete and too embarrassed”;

6. Segment 1 – Completers

5.1 Out of the total number of 417 returns, 113 people (28%) had already completed the test when they were contacted by phone: 44 males and 69 females.

5.2 The 'completers' group were largely positive about the test, with 99 patients (88%) seeming to have completed the kit with no apparent concerns or difficulties. The telephone discussions between the contact team and these respondents tended to be fairly short as most patients experienced few or no barriers or other difficulties in fulfilling the test. Indeed, many patients contacted provided some positive feedback regarding the service.

5.3 Recurring themes to emerge from the completers segment include:

- People found the information straightforward and had no problems understanding it
- The physical process of completing the test was easy
- The process is "*not as big a deal as people make it out to be*"
- A number of people felt that perceptions about the test are probably much worse than what it actually involves.

5.4 Out of these themes, the first two (i.e. that people found the information understandable and the test easy to complete) occurred at about the same frequency. Although these run generally in conjunction with one another, it seems prudent to keep them separate as some respondents within the other segments expressed that one applied but not the other (e.g. that the information was useful but that the 'hardware' was unsuitable, or vice-versa).

5.5 Although there were fewer incidences of patients indicating that there were perceptual barriers to overcome, i.e. the test is *"not that big of a deal"*, this is probably a significant theme as it points to a wider barrier that may be important for those who have yet to complete. Clearly a negative perception of the test was not a major challenge for patients within the 'completers' group, but their surprise regarding how easy the kit was to complete indicates that there is possibly a fairly widespread feeling that taking the test could be an uncomfortable or difficult undertaking.

5.6 The behaviour of the respondents within this segment indicates that patients recognised enough benefit to merit completion of the test without outside encouragement. A strong sense of a pragmatic 'can-do' attitude comes across within this group, with a number of respondents acknowledging that doing the test is a pro-active way that you can potentially save your own life.

"Yeah it is a bit disgusting, but if it saves your life then it is worth it."

"Nothing could have put me off doing this"

"It was very straightforward…I'd rather know about these things than let something creep up on me"

"It was no bother at all. You would be foolish not to"

5.7 This idea of 'taking the matter into your own hands' seems to be an important driving force behind this group and appears to be the reason behind many of these patients completing the test.

5.8 Among the 113 patients who had completed the test by the time they were approached by the contact team, a small number (14) indicated that they had had to overcome some challenges. Some 12 of the 14 were females. The challenges were as follows:

- The thought of carrying out the test disgusted them (5)
- The information was insufficient and unclear (4)
- The hardware of the kit was inappropriate for the task (3)
- The patient was not going to complete the test for an unclear reason but later changed their mind (1)
- And one other challenge that has been filed under 'Other' in Table 1:
  - The patient did not complete the test within the correct timescale and therefore requested a second kit themselves prior to being phoned. This has been categorised as 'Other' as it is unclear from the transcript whether this was due to a lack of understanding, a physical inability on the patient's part, or if they forgot they were doing the test after beginning it.

5.9 Out of these 14 patients, the most frequent challenge to overcome was the actual thought of doing the test, which some patients found particularly repulsive.

"It was unpleasant, but I'm glad it's done."

"The idea was hideous"

"The information was very clear and easy to follow, but I did think it's disgusting"

"It was simple and easy, it was just the initial thought"

5.10 Although this was a significant barrier for some patients, for this group this factor did not outweigh the perceived benefit the test would have. Notably, the five patients who perceived this to be a challenge were all female, suggesting that females are possibly more likely to exhibit emotional or attitudinal reactions to the kit, although for these five that was not a strong enough challenge to prevent them from completing the screening.

5.11 The other significant challenges for patients within this group - that the information was insufficient and the kit was inappropriate - are practical rather than perceptual. In spite of a number of people indicating that they did not find the information adequate, they were still able to carry out the test without the need for any assistance or encouragement, suggesting that they were willing to try out the test and figure it out themselves as best they can. One patient in particular displayed motivation to complete the test himself as he stated that when he found the information lacking he went online and watched videos about how to carry out the task.

"Info fantastic, used YouTube to look at videos"

5.12 Three respondents in this group said that they did not find the kit appropriate for the task, with one patient suggesting that the current applicators were too flimsy and that plastic ones would be better. Although they communicated that the kit could be improved, this was not a challenge that that they felt unable to overcome: the kit might have been *'fouttery',* but that was not of great significance.

5.13 Within this group no nudging was necessary by the contact team as all respondents had already completed the kit themselves, however these patients did provide valuable feedback on how the kit worked for them. The most significant feedback indicated that although the kit was workable it could be more appropriate for the task as it is 'flimsy',

and the information, although largely clear, would be more accessible and less daunting if more visuals were incorporated.

7. Segment 2 – Intenders

6.1 Of the 417 returns, 268 patients (64%) said that they would complete the test as a result of the phone call contact. Therefore, almost two-thirds of all patients contacted are people that the intervention seems to have worked well for: it seems very likely that the attitude/s of many in this group towards the screening test were probably altered in a positive way after the short conversation they had with the contact service staff.

6.2 For 77 (29%) of these 268 patients, no particular barriers or other issues towards doing the test can be identified from the contact returns. In these 77 cases the transcripts completed by contact centre staff indicate that upon being phoned the patient agreed to complete the test. The other 191 patients, however, indicated that they had some challenges to overcome before they could complete the test. Again, there were slightly more women than men in this group: 100 females versus 91 males.

6.3 Within this group the two most frequently recurring barriers were *Too busy* and *Not opened kit yet*, with 43 patients appearing in each of these categories. Typical responses indicated that patients were simply too busy at work or just hadn't got around to opening the kit yet.

6.4 Attitudes towards doing the test among this group were, on the whole, fairly positive. It seems that their behaviour prior to being contacted was motivated largely by perceptual indifference towards the test: with the most frequently mentioned reasons for not having done the test being *Too busy* and *Not opened kit yet,* it can be inferred that these patients do not have major attitudinal or emotional barriers to overcome.

6.5 When contacted, many of the patients were somewhat apologetic for not yet having completed the kit and praised the contact team's service for prompting them to do so. For these 43 patients, the telephone engagement was clearly very successful as the small nudge of a phone call which stressed the importance and value of the test seems like it may well be enough to encourage many of them to complete and return the screening kit.

6.6 Additionally, another motivator for this group was peer encouragement. Upon being phoned a number of patients talked about other people they knew who had experienced bowel cancer and indicated that they therefore understood the importance of screening to catch early signs of the disease.

6.7 Nevertheless, without contact being made by the contact team, some of these patients may not have completed the test as it had not been 'front of mind'. Encouragement from the contact team had impressed upon them or reminded them of how important this screening can be.

6.8 One male patient in particular recalled a friend who died of bowel cancer and who had implored him to do the test. After being contacted by the team he intended to start the test that day. In this case the telephone engagement prompted this patient to recognise the value in the screening for himself and seems to have been instrumental in his decision to complete it.

Patient has not completed kit yet, but has read all of the instructions. He said his close friend died of bowel cancer and he had said to him if he had been screened it would have been caught early, so he asked him to do the test. He intends to start today after the call from the team. He very much appreciated the call.

6.9 The male/female split here is notable. Out of all the perceived barriers, there were only three categories in which men outnumbered women: those who had *Not opened their kit yet*, those who had *Forgotten about their kit,* and those who had *Damaged their kit.* Out of all the males in this segment who were considered to have barriers to overcome, 26% had not opened their kit yet, whereas for females the proportion was only 19%. Similarly, the percentage of males who had forgotten about the kit stands at 16%, and for females at 12%, and although 2% of males had a damaged kit to contend with no females experienced the same barrier.

6.10 As other barriers/reasons for non-completion where females exceed males include *Too busy, Disgusted by thought* and *Information unclear*, it seems that females tend to be challenged more by perceptual and emotional barriers, whereas males need to overcome more practical barriers.

6.11 Two patients within this segment, both male, indicated that they had not opened their tests yet as they considered the kit an unwelcome reminder of having turned 50. This barrier was easily overcome by the contact team as these patients had no concerns or fears about the screening itself and simply needed a gentle nudge. However, it raises an interesting point about why patients may not open the kit in the first place.

The patient has still to open the kit. He said he found it "traumatic turning 50" so he put the kit away. He will now go and look it out, read it and get it completed.

6.12 Some 8 patients in this segment - 6 female and 2 male - experienced ***more than one barrier or difficulty*** in completing the test. The gender difference here suggests that females could possibly have more complex concerns about completing the test than males. However, as the percentage of females and males overall who were helped to overcome barriers was similar at 55% and 51% respectively, it may not be the case that having more than one barrier to overcome made it significantly more difficult to nudge those patients into positive action.

6.13 With these patients experiencing several issues, it was mostly commonly a lack of understanding of the information provided, coupled with another barrier such as having misplaced the kit or forgotten about it that made up the challenges they had to surmount. These difficulties seemed to be relatively easily resolved by the contact team as they were able to provide more in depth advice and clear instructions to encourage the patients.

6.14 How did the intervention work for this segment?

The intervention appears to have been most successful for this segment of patients. Hence, this is a group from which we can garner valuable information regarding what might be most effective for encouraging people to who were not already committed to the screening test to participate.

6.15 Those who claim to be *Too busy* to complete the test may require no more than a phone call to encourage them to participate. This seems to be related to the idea of being 'positively pestered' if you were not going to complete the kit; something that the contact team themselves indicated could be a strong motivator for some. For example, the contact team would advise patients that if the kit expired uncompleted they would be sent out another, and if they did not complete that one their GP would be informed. They felt that this was a very effective and appropriate way to encourage those who simply needed a small nudge to complete the kit.

6.16 For those who had not yet opened the kit, a simple phone call from the team in which they explained the process of completing the kit was often adequate to convince patients to engage. For these people it seems that the idea that the test would take a lot of time and effort was putting them off. This was easily overcome by the team explaining the process and highlighting it as being simple and easy.

6.17 A similar approach was taken for those who had forgotten about the kit, found the information unclear, or who had lost of misplaced the kit. The contact team eased concerns about how difficult the kit would be to complete, and for those who found the information unclear the team gave tips and advice on how to collect samples, such as using a takeaway tub or broadsheet newspaper.

6.18 Many of the tips given by the contact team came from patients themselves who had completed the kit or from the team's own knowledge gained when visiting the Dundee centre where they had seen the production of the kit for themselves.

6.19 One of the most common misconceptions patients had was that their three samples had to be collected on three consecutive days, which many people indicated they would be unable to do. When advised this was not the case, some suggested that this should be made be clearer in the information supplied with the kit.

6.20 It was more of a challenge for the contact team to nudge those patients who had other barriers/reasons for non-completion to overcome, such as having been unwell or being repelled at the thought of the test.

6.21 Those who had difficulty with completing the test due to the 'yuck' factor were often convinced by being given practical tips on how to complete in the cleanest and easiest way possible. The contact team found that stressing the value of completing the kit alongside offering advice (such as using gloves and takeaway/butter tubs) often worked. Personal contact over the phone was able to convince some of these patients that completing the test was the right thing to do, whereas prior to the conversation it had been easy for them to dismiss the idea of screening because they saw it as off-putting.

6.22 Some of the patients who cited ill-health as a reason for non-completion were advised on the value of the test and encouraged to participate when they were feeling better. At this point the patients were all very agreeable, with some indicating that if they were not better before the expiry date on the kit they would call and order a new one. However, for most patients who cited ill-health it was constipation that was preventing them doing the test. The contact team were able to solve this problem by telling patients that they could extend the 10-day time frame given by a small amount. Following this advice some of these patients said they were really being left with no excuse.

6.23 This raised an interesting point about patients using ill-health as an excuse when they could have overcome this barrier themselves. While it again highlights the importance

of personal contact, it is not fully clear why these patients were unwilling to participate. It seems possible that it was due to a disgust or feeling that the process would be difficult/time-consuming: reasons that the contact team were able to exert some influence on.

8. Segment 3 – Uncertain

7.1 Out of the 417 patients called, only a small number - 7 (2 males and 5 females) - were still unsure if they would complete the test after the phone conversation.

7.2 One of the males was unsure whether or not he would complete the test as he had various ongoing health issues and was not sure he felt up to completing the test. This patient engaged in a lengthy conversation with the contact team member and, although he was still unsure when the phone call ended, he did show some signs of wanting to complete the test after he was advised on the best way to complete the process.

7.3 The other male was categorised as *Uncertain* as he did not seem to understand who the contact team were or why they were calling him. A new kit was ordered for him by the team. As it was not clear whether or not this man would complete the test or not he has been categorised under *Other* reasons in the *Uncertain* group.

7.4 From the five females, one indicated that she had not had the time to take part. This patient was recorded as being 'not very talkative', merely saying she was considering doing it, but was not entirely decided yet. This patient was difficult to engage with via the telephone and gave 'yes, no and I don't know' answers. The team were unsure whether or not she had been convinced enough to participate.

7.5 Another female patient indicated she had not received the kit, even though the contact team were aware she had already been sent out two. This patient said she was unsure whether or not she would complete the test. The contact team offered information and advice, but it was unclear if this had been enough to convince her. This patient subsequently asked not to be contacted again, so the team were unable to check on the outcome.

7.6 A further two of the five females were unsure if they would take part due to health reasons. One had had a previously diagnosed health issue and had completed a similar test with her GP. As a result, she was unsure whether or not she wished to take part in this screening also.

7.7 The other female who was hesitant to take part due to health reasons had another challenge to overcome in addition to her ill health. Prior to giving constipation as her reason for not taking part, this patient had admitted that she was yet to open the kit, indicating that she had no information on how to complete the test. She was successfully convinced to open her kit and the information was explained to her. It was at this point she cited constipation as another reason for non-participation. When the contact team advised that she would be able to extend the time frame the patient replied *'You're trying hard to convince me and I don't have an excuse now'*. At the end of this call the team left this patient saying she would *'Seriously consider doing the test'*. Although this cannot be considered a fully successful result, the call record suggests a genuine shift had taken place as prior to being contacted she had not opened the kit.

7.8 The final female out of the five also pointed to having multiple difficulties: she found the idea of the test off-putting and also worried that she might not physically be able to complete the test on time. It was clear from the transcript that being *'squeamish at the thought'* was the patient's principal reason for non-participation. However, an additional barrier was that she was constipated and uncertain whether she would be able to complete the test within the time frame. This patient was advised that she could extend the time frame slightly, and she was also given tips on how to best collect her samples in the easiest way possible in order to make the process less traumatic for her. This patient acknowledged the importance of the screening and, although she asked not to be contacted again, said that she *'Hopes she can go through with it'*.

7.9 **Summing up** - Within this segment it seems to have been more challenging for the contact team to shift negative perceptions of the test. Patients were more resolute than patients in the previous segments in not being minded to complete the test. The telephone conversations were successful in the sense that they engaged patients who it seems would definitely not have completed the screening without contact being made. There is now a possibility – but no guarantee - that they might go on to do the test.

9. Segment 4 – Refusals

8.1 Some 29 patients refused to take part in the screening process despite the telephone engagement. This figure amounts to only 7% of those who had not yet completed or started the test by the time of the phone conversations.

8.2 Of these 29 patients, 10 (34%) indicated no clear reason for their lack of interest in taking part. The conversations with these patients tended to be relatively short as they were resolute in their decision in spite of the telephone call. And, even when benefits of the screening could be communicated to them by the contact team, these patients were still not interested in participating.

8.3 Reasons given for non-participation by patients in this segment are set out below:

- 5 patients refused to take part because they felt fully healthy and therefore did not perceive it to be necessary for them. A real attempt was made by the contact team to encourage these patients by explaining that symptoms can go unnoticed and that the screening would still be of benefit. All 5 patients remained steadfastly uninterested.
- 3 patients refused to take part on health grounds as they considered themselves too unwell to complete the test: one patient communicated that he was double-incontinent and on various medications and therefore did not want to participate. He was advised of the new test and agreed to take part when it arrives. Another of the three advised that she was recently out of hospital and in very poor health, and therefore the test was not a priority for her at this point. The third patient said that he had ongoing investigations at the doctor and so had contacted Dundee directly and asked to be locked out of the system.
- 2 patients said that they were too busy to take part in the screening. As this was a barrier that was frequently overcome with patients in Segment 2, it is understood that a similar approach was taken by the contact team, but as the transcripts for

"Patient feels perfectly healthy and doesn't feel the need to complete. I explained the benefits and why you may consider it, if not now, in the future - the patient listened, but was still not interested"

these two refusals are sparse it is unclear why they could not be convinced to reconsider their decision.

- 2 patients refused to take part as they were unable to overcome their revulsion at the thought of carrying out the test. In spite of efforts by the contact team to try and encourage them to engage by explaining the benefits and the best ways to collect samples, neither patient was convinced. One was advised about the new test being rolled out next year and agreed to participate in that when it arrived.
- For 1 patient it was enough of a problem that the kit was inconvenient. This was a challenge for 4 other respondents out of the total 417 contacted experienced, 3 who had already completed the kit by the time they were telephoned and 1 who was successfully encouraged to complete after being given advice from the team. The team were able to convince the 1 patient from Segment 2 to complete by giving her tips on how best to negotiate the kit, and although a similar approach was taken with the patient from Segment 4, they were unable to be persuaded.
- Possibly the most significant barrier for these patients who refused is that 3 would not participate in the screening due to fear of the outcome of the test: 2 males and 1 female. The female patient specifically indicated that she did not want to take part in the screening as it was possible that the results might lead to needing to have a colonoscopy. Her mother had had one and was in agony from it. Fear of potential pain was a challenge this patient could not overcome, even with encouragement from the contact team. The two male patients expressed similar reasons for refusing. One indicated a fear of the outcome, and as worrying brings on seizures he was unwilling to put himself through the test. When the contact team tried to nudge him by suggesting that the test would be able to put his mind at rest he replied *'What will be will be'*. The other male patient displayed told the contact team that he would rather not know if he had a serious illness. Although he had not received the kit by the time he was contacted, on being offered a kit he refused.

"What will be will be"

"I'd rather not know for any illness"

- The other four patients who gave reasons for refusal are filed under *Other*:
  - One patient had previously done the test at the GP's request in December and therefore refused to take part again as there was no need
  - One patient is part of a travelling community and had moved to England, therefore making her ineligible for the screening
  - Two patients seemed not to understand what the phone call was about. For one of the patients, the phone was passed to his wife who said she would try and explain to him.

8.4 Although engagement from the contact team resolved some of the practical issues these patients seemed to have, perceptual issues dominated and the contact team were unable to shift the attitudes and intentions of this segment.

8.5 Two patients refused to participate, saying they would rather remain uninformed of any negative diagnosis regarding their health. There seemed to be an element of 'leaving it to fate' here: the patients were unwilling to be influenced even when informed of the benefits of screening and given advice and tips on how to do the test.

8.6 Overall, for Segment 4 the engagement cannot be regarded as successful and, for some in this group, it is even difficult to ascertain what is actually driving their views and behaviour.

10. CONCLUSIONS

9.1 Our assessment of the bowel cancer screening intervention suggests that, for a very substantial proportion of the patients the contact team managed to engage by telephone, the conversations that took place will have helped clarify information about the screening test and/or remove some of the concerns or worries that they had about completing it.

9.2 While we cannot be sure how may of those who had not yet completed, or who were in the course of completing the test when they spoke to Community Renewal's contact team, will have gone on to actually do it, the evidence is strong that most will be more likely to do the test as a result of the conversation they had with the contact team. Indeed, the great majority of those who had still to complete the test at the time of the conversation left the contact team with the impression that they would complete it.

9.3 While a good number of those reached by the engagement staff had done or were in the process of doing the test, they still represent the minority of patients contacted. Of the majority that had still to do the test, only around 12% remained uncertain or indicated that they would not do the test on conclusion of the telephone chat. The results of our evaluation are, therefore, very encouraging for an intervention of this kind and what might be being achieved by it.

12. CONTACT DETAILS

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13. Appendix

A.

	Referrals	Completed Prior to Call	Will Complete as Result of Call	Refused
Glasgow South	302	22	63	7
Glasgow North East	174	11	34	1
Glasgow North West	270	20	45	10
Renfrewshire	283	23	43	3
East Renfrewshire	145	6	18	0
West Dunbartonshire	112	12	15	4
East Dunbartonshire	136	7	21	0
Inverclyde	180	12	29	4
Totals	1602	113	268	29

This report has been prepared by:

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