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# QUANTITATIVE EVALUATION FINAL REPORT

Liverpool City Council's Inequalities in Bowel Cancer Screening Intervention

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Collaboration for Leadership in Applied Health Research and Care North West Coast









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# Acknowledgements

This report is the work of members of the Liverpool Cancer Inequalities Research Network (LCIRN), a collaboration of university departments and front-line service providers with the aim to understand the pathways to, and take action to reduce, inequalities in cancer outcomes in Liverpool and the surrounding region: https://www.liverpool.ac.uk/nwcrc/lcirn/.

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Appendix 1 lists the individuals and members of each organisation who have been of great assistance to us. The exception being staff from the GP practices and Social Inclusion Team who participated in the study delivery, in order to preserve their anonymity.

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## **Summary**

Between January and July 2017, the Liverpool City Council Public Health Team (LCC PHT) ran a pilot intervention in Riverside, Kensington, and Picton Liverpool Clinical Commissioning Group (LCCG) Neighbourhoods, with the aim of reducing inequalities in bowel cancer screening (BCS) uptake rates. The intervention focused on these three neighbourhoods as they cover relatively deprived communities, some with a high Black, Asian, and Minority Ethnic (BAME) population; both populations with typically low BCS rates.

Two interventions were piloted: A telephone intervention and a face-to-face session in the GP Practice. Both interventions were preceded by a letter from the GP Practice informing patients eligible for inclusion in the study about the interventions and inviting them to take part.

The Telephone Invention consisted of a phone call from GP practice staff or the Social Inclusion Team (SIT) in which the benefits of BCS were explained to the patient and any concerns about taking the test were discussed.

The Face-to-face Intervention consisted of a brief phone call to invite the patient to a session in the GP practice. Information about BCS was delivered face-to-face in an "information session" delivered by GP practice staff or the SIT.

The evaluation consisted of the following elements:

- 1. Data collected through the GP Practice data management system (EMIS) using a predefined template developed by LCCG data managers.
- 2. Monthly returns from each participating GP Practice using an Excel Worksheet developed by the LCC PHT.
- 3. BCS test kit completion data provided by the Midlands and North West BCS Hub directly to EMIS.
- 4. Online questionnaires developed by the University of Liverpool completed by: a sample of patients who either took part in the interventions (Patient Questionnaire) or who did not take part in the interventions (Non-participant Questionnaire), and by staff who took part in delivering the interventions (GP/SIT Questionnaire).

High staff workloads and staff turnover meant that training on delivering the interventions was difficult. Very few people elected to take part in the Face-to-face intervention. There were several other interventions and campaigns to improve uptake of BCS taking place in Liverpool at the same time.

EMIS data proved to be difficult to interpret and was quite different to the monthly returns collected by the LCC PHT. The final evaluation, therefore, is largely based on the BCS completion data from the BCS Hub.

The evaluation data indicated that there may have been a synergistic effect between a Regional BCS Campaign and the IBCS interventions. The data are not robust enough, however, to be confident about this. The questionnaire data indicated the Face-to-face Intervention was not needed as patients said they were prompted to complete the BCS test kit by the invitation letter and initial telephone conversation with the GP Practice.

The pilot study has not provided definitive evidence of the impact of the interventions on uptake of BCS among people living in deprived areas and among BAME groups. It has, however, provided many points of learning that can be taken forward into the development of future interventions to reduce inequalities in BCS uptake rates.

### Introduction

In September 2016, Liverpool City Council Public Health Team (LCC PHT) commissioned The University of Liverpool (UoL) to undertake a quantitative evaluation of the Inequalities in Bowel Cancer Screening Intervention led by the LCC PHT.

The UoL members of the Evaluation Team are:

- Dr Sue Povall, Department of Public Health and Policy, University of Liverpool (UoL) Quantitative Evaluation Lead,
- Dr Pooja Saini, Natural Sciences and Psychology, Liverpool John Moore's University (formerly of Collaborations for Leadership in Applied Health Research and Care North West Coast (CLAHRC NWC) at UoL) Qualitative Evaluation Lead
- Dr Ben Barr, Department of Public Health and Policy, UoL Methodological Adviser

### The Interventions

Between January and July 2017, the LCC Public Health Team ran a pilot intervention in Riverside, Kensington, and Picton Liverpool Clinical Commissioning Group (LCCG) Neighbourhoods, with the aim of increasing access to verbal bowel cancer screening (BCS) information in a variety of languages and, in turn, to improve screening uptake rates. The intervention focused on these three neighbourhoods as they cover relatively deprived communities, some with a high BAME population, both populations with low BCS uptake rates.

Eleven practices took part in the intervention, six took part in a telephone intervention and five took part in a face-to-face intervention (see below) (also referred to as a "Health Promotion Session" or an "Information Session"). The non-participating practices in these LCCG areas continued to receive the usual level of service from the NHS Bowel Cancer Screening Hub (NHS BCSH). The non-participating practices acted as controls for the quantitative evaluation.

LCCG commissioned the SIT of Liverpool Community Health NHS Trust, to support the project by delivering the interventions within practices to people who were not able to or preferred not to speak in English.

There proved to be various challenges in the delivery of these interventions, which had an impact on the evaluation. Next, we describe the intended process for delivery of the interventions. In the next section, we describe the evaluation design. We discuss the challenges faced in the delivery of the intervention and in the evaluation after this.

### Intervention delivery

Each participating practice assigned a dedicated staff member (Practice Advocate) to the intervention. The Practice Advocates were to produce a list of patients aged 60–74 years eligible for the intervention during January – July 2017 (see Appendix 2 for exclusion criteria):

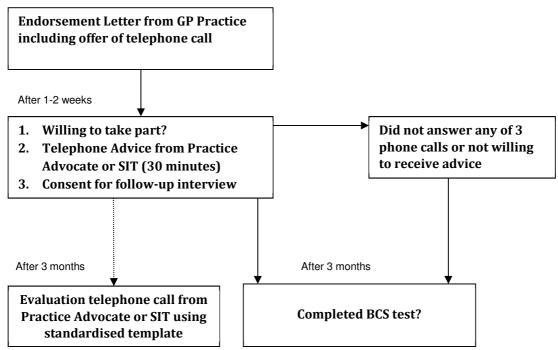
- Patients aged 60 years invited to participate in bowel cancer screening for the first time who had not returned the kit within four weeks of the initial invitation and had been issued a reminder letter (Group 1).
- Patients aged 62 years and over, due for second and subsequent invitations (recall) whose records show that they had not responded to their latest invitation to participate in bowel cancer screening (Group 2).

The practices were to send a letter of endorsement on practice-headed paper signed by the GP, along with an A5 pictorial NHS bowel cancer screening leaflet to patients included in Groups 1 and 2 above.

During the project time, the Practice Advocate or a member of the SIT were to be able to contact the NHS BCSH on behalf of the patients taking part in either intervention to request replacement kits if these had not been received, had been discarded, had been spoiled or if asked to do so by the patient.

### Intervention A: Telephone Information and Advice

Figure 1: Intervention A: Telephone intervention (6 practices)



The endorsement letter from the practice informed the patients that someone from the GP surgery would call them to give the patient the opportunity to discuss the BCS test. Using telephone numbers recorded in local GP registers, either the Practice Advocate or a member of the SIT, were to phone all patients who had not responded to their latest invitation for screening 1-2 weeks after the GP endorsement letter was sent out. They were to make up to three attempts within a period of two weeks (see Figure 1). In the telephone conversation, the Practice Advocate or a member of the SIT were to relay information about BCS and answer patients' questions using a standardised script developed by the LCC Public Health Team. This:

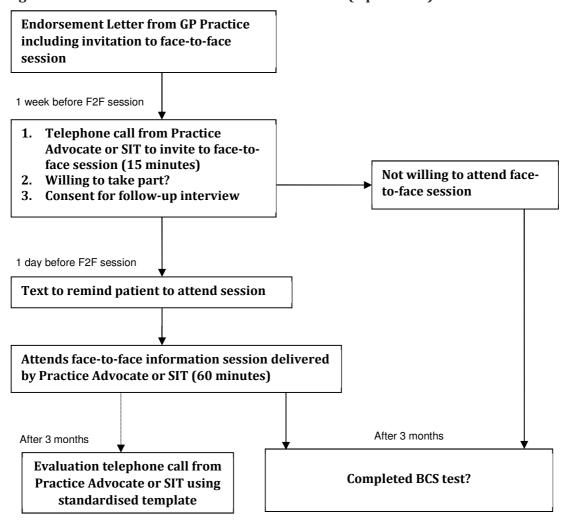
- Introduced the patient to the screening programme
- Explained how to complete the BCS kit and answered any questions
- Informed the patient how to request another test kit if their original kit was spoiled or discarded; checked that the patient had noted down the Freephone number to request a new kit

• Requested consent to a follow-up telephone call using a standardised template to find out about their experience of the intervention and screening process 3 months after their participation in the intervention (Figure 1).

Both the dedicated Practice Advocate and the SIT were to have been given bespoke training from the LCC Public Health Team to undertake this role. The targeted patients were offered the opportunity to opt out at any stage of the intervention.

### Intervention B: Face-to-Face Information Session

Figure 2: Intervention B: Face-to-face intervention (5 practices)



The letter of endorsement by the GP invited patients to attend a group face-to-face health information session at the GP practice premises (see Figure 2). A week before the session was due, either the Practice Advocate or a member of the SIT were to telephone patients to discuss the forthcoming session and confirm their attendance. This:

- Reminded them of the session
- Offered alternative dates in the same or a nearby practice for people unable to attend the session

• Requested consent to a follow-up telephone call using a standardised template to find out about their experience of the intervention and screening process 3 months after their participating in the intervention (Figure 2).

The GP practice were to send a reminder SMS text to those who agreed to attend a face-to-face group session on the day before the session took place.

Face-to-face sessions were to be held monthly by the Practice Advocates or a member of the SIT using a standardised format developed by the LCC Public Health Team. All Practice Advocates and the SIT were to have been given bespoke training from the Public Health team to undertake this role.

Patients attending the face-to-face sessions were to be offered a pictorial guide, verbal advice about the test and three pairs of disposable non-latex gloves to overcome issues related to the unpleasantness of sample collection. Patients were offered the opportunity to opt out at any stage of the intervention.

## The Evaluation Specification

LCC Public Health Team commissioned the Evaluation Team to externally evaluate the impact of the intervention on BCS test completion in Riverside, Kensington, and Picton.

The evaluation had the following research questions:

- 1. Were the completion rates of BCS tests higher, lower or equivalent in the intervention practices (telephone / face-to-face) compared to the comparison practices following the intervention, did this relationship differ between (a) "first time invitees" (Group 1) and "subsequent invitees" (Group 2), (b) between BAME groups and non-BAME groups and (c) between men and women?
- 2. Were the completion rates of BCS tests higher, lower or equivalent in the practices implementing the face-to-face intervention compared to practices implementing the telephone intervention, did this relationship differ between (a) "first time invitees" (Group 1) and "subsequent invitees" (Group 2), (b) between BAME groups and non-BAME groups and (c) between men and women?
- 3. What are the perspectives of those patients in receipt of the two interventions (telephone and face-to-face) in terms of:
  - a. Process
  - b. Level of information given
  - c. Usefulness of information given
  - d. Motivation to complete the bowel cancer screening test?
- 4. What are the strengths and challenges of implementing the interventions from the perspectives of the participating General Practices and the SIT?

### Data Collection

### Research questions 1 & 2

LCCG developed a template (Appendix 3) for the GP data management system, EMIS, to support data entry for this study. The template was developed with input from the Evaluation Team. The eleven practices participating in the interventions were required

to support data analysis by completing this template for the patients they identified as eligible for the interventions, and who were invited to take part. Patients who were ineligible to take part in the study (see Appendix 2) were to be marked as such on EMIS. It was hoped that the use of an EMIS template would ensure data quality and negate the need to clean the data prior to aggregation.

All practices in the study areas used EMIS and had data sharing agreements in place with LCCG. A data sharing agreement between LCCG and UoL was agreed prior to the commencement of the interventions, with an end date of 31 October 2017. It was agreed that LCCG would send the Evaluation Team aggregated data to avoid issues with patient data confidentiality. Appendix 4 lists the data items to be provided to the Evaluation Team by LCCG. The Evaluation Team were to analyse these data and produce a summary for this report.

### Research question 3

The Evaluation Team developed a Patient Questionnaire using a free-to-use online tool, KoBoToolbox, to explore patient experiences of the intervention (Appendix 6). The SIT offered feedback on drafts of the questionnaire and were instrumental in refining the questions and language used. The questionnaire could be used online or offline, anticipating difficulties the SIT may experience connecting to the internet in GP practices. Practice Advocates or a member of the SIT were to telephone patients, who had given consent to be contacted, approximately three months after the intervention took place and to complete the questionnaire with the patient's responses to the questions. Data to be collected included: the patient's experience of the invitation to take part, the intervention and the BCS processes, whether or not they completed the kit and the reasons for non-participation among those not completing the test kit. The Evaluation Team agreed to collate, clean and analyse the data from these interviews, and produce a summary for this report.

### Research question 4

The Evaluation Team developed a GP/SIT Questionnaire using KoBoToolbox to explore the experiences the Practice Advocates and members of the SIT in delivering the interventions, e.g. what worked well and what could be improved (Appendix 7). The Evaluation Team agreed to collate, clean and analyse the data from these interviews, and produce a summary for this report.

# Challenges with intervention delivery

Difficulties in arranging times for training on the intervention and EMIS template led to a delay in the start of the intervention.

High staff turnover and busy work schedules meant that training delivered by the LCC Public Health Team on how to run the interventions and use the EMIS template was lost. This resulted in the interventions being poorly understood by some Advocates. There were differences across the practices in the numbers of interventions delivered, with some practices struggling to find the time to deliver the interventions at all. There was some confusion about how the face-to-face sessions were to be delivered and by whom.

The intervention period was extended by a month in response to these difficulties.

The SIT were used sporadically, even in practices where there were high numbers of BAME patients. These practices developed other means for delivering the interventions

with their patients who preferred to speak in their own language, e.g. using a translation service or not following up on the initial GP letter.

The number and consistency of these issues informed the decision to conduct a qualitative process evaluation that is reported separately.

In addition, the face-to-face intervention was rarely taken up, discussed later.

A number of interventions to increase uptake of BCS within Liverpool were active at the time of the intervention period, including a North West Regional Campaign at bus stops, etc., in January – March 2017. Anecdotally, the Practice Advocates reported an increase in BCS test returns as a result of the Regional Campaign. It was hoped that the use of comparator data would control for the influence of this campaign, although there is the possibility of synergistic effects between the Regional Campaign and the study interventions.

## Challenges with evaluation data collection

The data collection changed in a number of ways:

- Initially, few Practice Advocates were recording their activity on the interventions using the GP EMIS System. Taher Qassim, LCC Public Health Team lead on the project, therefore, initiated data collection through an Excel Spreadsheet (Appendix 5). The spreadsheet asked the participating GP practices to record, monthly: the number of eligible patients identified through searches, the number of letters sent to patients, the number of interventions delivered (note "health promotion session" refers to the face-to-face intervention), and the number of times the SIT were asked to help. It became apparent that the Practice Advocates were interpreting these categories differently and the data recorded represented different things. Time pressures in the practices meant that it was difficult, sometimes, to get these figures from each participating practice.
- The face-to-face intervention was almost entirely not delivered (only 4 patients took part). Patients, were either prompted to complete the BCS test as a result of the GP letter and invitation phone call, or did not want to come into the GP practice for a session. This meant that the Patient Questionnaires could not be completed by GP Practices enrolled in the face-to-face intervention. Practice Advocates from these practices asked for a way to complete the questionnaires for patients who declined to participate. Therefore, we developed a "Non-participant Questionnaire" to be used with patients who were eligible to take part, who had been approached to take part and who declined to take part in the interventions.
- GP Practice time constraints meant that it was not possible for the Practice Advocates / SIT to follow-up with all patients taking part in the interventions to fill in the Patient / Non-participant Questionnaires. Therefore, we chose to ask GP Practices to follow-up with 20 patients each. The choice of patient to follow-up with was at the discretion of the GP Practice Advocates. This sample, therefore, cannot be considered to be representative of all patients invited to take part in the interventions.

# The Evaluation Findings

The challenges described above meant that there was limited information to work with in the Quantitative Evaluation. We were not able to answer most of the research questions listed in The Evaluation Specification.

The three sources of information included in the findings are:

- 1. Data collected via the GP EMIS system,
- 2. Data collected via the LCC Excel spreadsheet, and
- 3. Data collected through the online surveys with patients/non-participants and staff.

In all cases, the data are not robust, and any findings from these data should be interpreted with caution.

### 1. FMIS Data

As the study progressed it became apparent that very few of the intervention GP practices were using the LCCG EMIS template. High staff turnover meant that training on the template was frequently lost. Work pressures meant that some staff struggled to implement the interventions and to record data from them.

Delays in the completion of the study data on EMIS meant that the original data sharing agreements with the intervention practices expired. Only 7 of the 11 intervention practices returned renewed data sharing agreements. Six of these were included in the EMIS data sent to the Evaluation Team for analysis.

LCCG extracted anonymised patient level, rather than aggregate, data for these 6 practices from EMIS using the template and sent these data to the UoL. This was useful because, on inspection of these data, it quickly became apparent that the template codes had been used for other purposes and that all six practices had data in EMIS for both the telephone and face-to-face interventions, when each practice should have done only one of the interventions (4 telephone and 2 face-to-face). It was not possible to determine from these data which patients received which intervention. In addition, patients included in these data often had multiple EMIS template records, making these difficult to interpret. The data seemed to indicate that very few of the participants in the interventions went on to complete the BCS test. The UoL Evaluation Team did not have the resources to clean these data. As a result, we were not able to use the patient level data collected via the template in our analyses.

Instead, LCCG extracted summary level data for the intervention practices and the control practices from the BCS test completion information sent to the GP Practices from the NHS BCSH and recorded on the EMIS system. These data included the number of practices in each group, total practice population for each group, the number of patients eligible for BCS, the number of patients invited to take part in BCS, the number of patients invited to screening who did not complete the test, the number of patients invited to screening who did complete the test (see Table 1).

From the other sources of data, we know that hardly any patients (10) took up the invitation for the face-to-face intervention. We understand that for some patients contacted receiving the invitation phone call was enough to precipitate action on their part. Consequently, this group could be considered to have received a version of the

telephone intervention and we grouped the data from both interventions together for the analyses (see Table 1).

Table1: BCS test completions, 1 Jan - 30 Oct 2017, Riverside, Kensington, Picton Source: NHS BCSH, extracted by LCCG from EMIS

|  | Number<br>of GP<br>practices | Practice<br>population | Patients<br>Eligible<br>for BCS | Eligible as<br>% of<br>practice<br>population | Patients<br>Invited<br>for BCS | Invited<br>as % of<br>eligible | Invited and completed | Completed<br>as % of<br>invited |
|--|------------------------------|------------------------|---------------------------------|---|--------------------------------|--------------------------------|-----------------------|---------------------------------|
| Intervention<br>practices -<br>Telephone | 6                            | 38781                  | 6541                            | 16.87%  | 5399                           | 82.54%                         | 1324                  | 24.52%                          |
| Intervention practices - Group session   | 5                            | 34708                  | 5365                            | 15.46%  | 4594                           | 85.63%                         | 1116                  | 24.29%                          |
| Intervention practices - All             | 11                           | 73489                  | 11906                           | 16.20%  | 9993                           | 83.93%                         | 2440                  | 24.42%                          |
| Control practices                        | 7                            | 43330                  | 5666                            | 13.08%  | 5015                           | 88.51%                         | 1048                  | 20.90%                          |

Findings from these data indicate that, during the study period (Jan – October 2017, allowing for three months for NHS BCSH data to be loaded on the EMIS system following a BCS test):

- As a percentage of practice population, more people were eligible to take part in BCS in the intervention practices (16%) than in the control practices (13%).
- As a percentage of practice population eligible to take part in BCS, fewer people were invited to take part in screening in the intervention practices (84%) than in the control practices (88.5%).
- As a percentage of practice population invited to take part in BCS, more people completed a BCS test in the intervention practices (24.42%) compared to the control practices (20.90%).
- Chi Squared test of significance shows a statistically significant association between the number of patients completing / not completing BCS and whether the practice was an intervention or control practice. The higher numbers of completed BCS tests during the study period in the intervention practices are highly unlikely to have occurred by chance (p<0.001).
- This does not mean that the higher proportion of patients completing the BCS test in intervention practices was due to the intervention. To properly test this hypothesis, we would need to look at whether or not there was a higher proportion of test completions in the intervention practices, compared to the control practices, in the 6 months before the intervention period to see if there was a change in patterns of test completion during the study period. That is, did the patterns of BCS test completions in the intervention and control practices change as a result of the intervention.
- LCCG provided a breakdown by month of BCS test completions for intervention and control practices during the study period (January October 2017) (Table 2).

The differences in BCS test completions between intervention and control practices across these months is statistically significant (p<0.003), as measured by Chi Squared test of significance, and are therefore unlikely to have occurred by chance. However, this significant difference is removed when the first three months of the intervention are NOT included in the analyses. The North West Regional BCS Campaign took place in January – March 2017, indicating that the differences in the first three month largely explain the statistical significance of the results over the whole period. There were increases in BCS test completions in February to April in the intervention practices and in March for the control practices. It is possible that the prolonged increase in test returns in the intervention practices, compared to the control practices, is a synergistic effect between the IBCS intervention and the Regional Campaign. We tested whether the differences in BCS completions between intervention and control practices observed during January - March for statistical significance using a Chi Squared test of significance. This indicated that the differences observed are statistically significant (p<0.05), indicating that the difference are unlikely to have occurred by chance. If the Regional Campaign had had an equal effect across intervention and control practices, we might expect no significant difference in the test completions for the two groups in this time period. It is possible, therefore, that these differences indicate a positive interaction between the IBCS interventions and the Regional BCS Campaign.

Table 2: Monthly breakdown of BCS test completions: Jan – Oct 2017, Riverside, Kensington, Picton. Source: NHS BCSH, extracted by LCCG from EMIS.

|  |                     |                     | Number of BCS test completions Jan – Oct 2017 |     |     |     |     |     |     |     |     |     |
|--|---------------------|---------------------|---|-----|-----|-----|-----|-----|-----|-----|-----|-----|
|  | Number of practices | Practice population | Jan   | Feb | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct |
| Intervention<br>practices -<br>Telephone | 6                   | 38781               | 123   | 159 | 163 | 145 | 100 | 157 | 128 | 112 | 133 | 125 |
| Intervention practices - Group session   | 5                   | 34708               | 94  | 133 | 151 | 118 | 95  | 141 | 114 | 86  | 99  | 119 |
| Intervention<br>practices -<br>Total     | 11                  | 73489               | 217   | 292 | 314 | 263 | 195 | 298 | 242 | 198 | 232 | 244 |
| Control practices                        | 7                   | 43330               | 86  | 80  | 129 | 91  | 108 | 118 | 118 | 91  | 106 | 121 |

## 2. LCC Excel Spreadsheet – intervention practice monthly returns

These data were not completed in the same way by each of the GP practices. For example, some practices appear to have included all 60 and 62+ year olds in the Age Group Search boxes, and others only the eligible patients. This made it hard to compare what each practice had done for the interventions. Comparisons with EMIS data, which we know were not accurate, revealed inconsistencies in the two sets of data. For some practices the data from these two data collections methods were very similar, for others they were

very different. It became apparent that some practices had been more systematic and rigorous in their approach to collecting data than others.

What these data do show are:

- Very few face-to-face interventions took place (10).
- Many more telephone interventions happened (527).
- The Social Inclusion Team was rarely called upon to deliver an intervention.
- Numbers of interventions completed were inconsistent across practices, probably reflecting varying job pressures for the GP staff and staff turnover.

### 3. Patient and GP/SIT Questionnaires

We designed three online questionnaires using KoBoToolbox:

- i) Patient Questionnaire (Appendix 6; the face-to-face intervention is referred to as "information session"): To see how they had found the intervention and the BCS processes.
- ii) Non-Participant Questionnaire (Appendix 8; the face-to-face intervention is referred to as "information session"): As very few patients took part in the face-to-face sessions, we developed a questionnaire to capture the views of patients who chose not to take part in the interventions.

**Table 3: Patient / Non-Participant Questionnaire completions by GP practice** 

| GP Practice               | Patient<br>Questionnaire | Non-Participant<br>Questionnaire | Totals |
|---------------------------|--------------------------|----------------------------------|--------|
| Telephone Intervention    |                          |                                  |        |
| Practice 1                | 20                       | -                                | 20     |
| Practice 2                | 13                       | 7                                | 20     |
| Practice 3                | 1                        | -                                | 1      |
| Practice 4                | -                        | 19                               | 19     |
| Practice 5                | 1                        | -                                | 1      |
| Practice 6                | 13                       | 4                                | 17     |
| Totals                    | 48                       | 30                               | 78     |
| Face-to-face Intervention |                          |                                  |        |
| Practice 7                | -                        | 20                               | 20     |
| Practice 8 - withdrew     | -                        | -                                | -      |
| Practice 9                | -                        | 20                               | 20     |
| Practice 10               | -                        | 19                               | 19     |
| Practice 11               | -                        | 19                               | 19     |
| Practice 12               | -                        | -                                | -      |
| Totals                    | 0                        | 78                               | 78     |
| Grand total               | 48                       | 108                              | 156    |

Initially, we planned for the GP practices / SIT to call all patients receiving an intervention and who agreed to be followed up three months after they had had the intervention. Because of time pressures, this was reduced to 20 patients / non-

participants per practice. The number of Patient / Non-Participant Questionnaires completed varied by GP practice (Table 3). The GP Practice Advocates chose whom to call. As such, the sample may be biased and we cannot presume the responses reflect the experiences of all patients in receipt, or not, of the interventions.

iii) A GP staff / Social Inclusion Team Questionnaire (Appendix 7): the intention for this questionnaire was to understand how the staff delivering the interventions had experienced the process and what recommendations they would make for future practice. 4 Practice Advocates (out of a possible 11) and 5 SIT members completed this questionnaire. As the SIT did not deliver many interventions, their greater number of responses may bias the findings.

We received additional funds to do a qualitative process evaluation of the interventions to understand better how the delivery of similar interventions could be improved in the future. The qualitative evaluation has superseded this GP / SIT Questionnaire.

### Key findings from the questionnaires:

### Participating Patient Questionnaires

- 48 people completed these questionnaires. All of the respondents took part in the telephone intervention.
- More women than men completed the questionnaire (63%).
- More questionnaires were completed by people 62 years and older than 60 years (81%).
- Most of the respondents were white British (69%) [Asian 10%, Black 8%, Chinese 4%, Irish 4%, White Other 4%].
- Most had English as their first language (90%).
- 90% of patients were happy to receive a letter from their GP about BCS.
- 69% of patients found the contents of the letter useful or extremely useful.
- Patients felt that: i) bowel cancer had been explained to them (71%); ii) the benefits of doing the test were also explained (79%); and, (iii) how to order a new test had been explained (77%).
- 65% said they had an opportunity to ask a question and of those 81% were happy with the answers.
- 62.5% felt the telephone script could not be improved.
- Of the three people who spoke in their own language, all found it helpful or very helpful.
- 40% indicated that talking to someone had encouraged them to take the BCS test.
- 37.5% of those completing the questionnaire went on to complete the BCS test. Of those, 79% said they would encourage others to complete the test.
- The most commonly cited reasons for not taking the test was because they did not want to (43%) or because they forgot (17%). Other reasons for not taking the test included:
  - o They were still undecided about taking it (3 people).
  - They were embarrassed to do the test (3 people).
  - They had other priorities at the moment (3 people).

### Non-Participant Questionnaires:

- 28% of the respondents (30 people) had been invited to take part in the telephone intervention, 72% in the face-to-face session (78 people).
- Telephone intervention (30 people):
  - $\circ$  Equal numbers of women (47%) and men (53%) completed the questionnaire.
  - More questionnaires were completed by people 62 years and older than 60 years (73%).
  - o Most of the respondents were white British (80%) [Asian 7%, Black 3%, Chinese 3%, Other 7%].
  - o All had English as their first language.
  - o Most were happy to receive a letter from the GP about BCS (70%).
  - Most (50%) were neutral about whether or not they found the letter useful;
     27% found the letter useful or very useful.
  - Of those who did not want to take part in the telephone call: 20% had already taken the test, 10% ordered the kit when they got the letter, most (60% 18 people) did not want to take part because:
    - They were not interested (9 people),
    - They will think about it in the future (3 people)
    - They are too busy (2 people),
    - They don't like tests (1 person),
    - They felt OK (1 person),
    - "It's my business I hate being chased about things I've made my mind up about" (1 person),
    - They don't want to say (1 person).
- Face-to-face session (78 people):
  - $\circ$  Equal numbers of women (54%) and men (46%) completed the questionnaire.
  - More questionnaires were completed by people 62 years and older than 60 (68%).
  - o Most of the respondents were white British (79.5%).
  - o 87% had English as their first language.
  - o Most were happy to receive a letter from the GP about BCS (77%).
  - o 31.5% found the letter useful or very useful.
  - Of those who did not want to take part in the face-to-face session: 27% said the telephone call was enough to prompt them to take the test, 11.5% were unable to attend the surgery, 10% did not want to attend the surgery, most (40%, 31 people) did not want to take part because:
    - They declined to give a reason (10 people),
    - They don't want to take the test (9 people)
    - They are not sure about taking the test (4 people),
    - The patient is in a care home and not able/ willing to take the test (2 people),
    - They have already taken the test (1 person),
    - They already know about BCS (1 person),
    - They do not trust the test (1 person),
    - They do not want to take the test at the moment (1 person).
    - They are currently having treatment for cancer (1 person),
    - They are awaiting a colonoscopy for existing symptoms (1 person).

- The following additional comments were made:
  - "appointment at surgery is difficult to arrange as working, a telephone call or letter would suffice"
  - 5 people had taken the test
  - 4 people were waiting on a test kit
  - One person was housebound.

### GP Staff / Social Inclusion Team survey:

- The responses for this survey were few, and mainly from the Social Inclusion Team who did not have a large role in delivering the intervention.
- The responses are inconclusive. A couple of respondents did comment that they thought that the phone call was enough to prompt patients to take the BCS test, and that the face-to-face session was not needed. The one GP advocate that used the SIT to deliver interventions found their help very useful.
- These questions will be explored in more detail through the qualitative evaluation.

### Conclusion

The implementation of the interventions and the data gathering for the quantitative evaluation have met with many challenges. The quality of the data mean that we cannot state with certainty whether or not the interventions have had an impact on the uptake of BCS in the study areas of Riverside, Kensington and Picton LCCG Neighbourhoods.

It is clear that the face-to-face intervention was not taken up as expected. Sometimes, the initial contact to arrange the face-to-face meeting was enough to prompt someone to take the BCS test.

The data from the NHS BCSH extracted by LCCG from EMIS indicates that proportionally more BCS tests were completed in the intervention practices during January – October 2017 than in the control practices. This difference is statistically significant and therefore unlikely to have occurred by chance. Most of this difference appears to have occurred in months January – March 2017 when a North West Regional BCS Campaign took place. Differences in BCS completions between intervention and control practices during these months are statistically significant. This may indicate a synergistic effect between the Regional BCS Campaign and the Inequalities in BCS Interventions. We cannot say definitively that is the case, however.

The EMIS data were not of sufficient quality to allow us to examine whether or not there were differences in uptake of BCS tests in the intervention practices and the control practices by gender, age group and ethnicity.

The responses to the Patient and Non-Participant Questionnaires indicate that the interventions have prompted some people to complete the BCS test or to ask for a new test kit. The telephone intervention was favourably received amongst those responding to the survey. It is clear from both surveys that there are people who do not want to take the BCS test, whether or not they have received the intervention.

This study has highlighted several areas of learning that would improve the delivery and evaluation of a similar intervention in the future:

1. The face-to-face intervention is not needed.

- 2. Staff delivering the telephone intervention need to be allocated to that task specifically. The intervention is too time consuming to add to already busy workloads. This might also minimise the disruption caused by staff turnover.
- 3. Data collection for the evaluation needs to be separate from the general data management of the practice. If EMIS is used, the template should have its own unique codes to avoid contamination from other patient data.
- 4. BCS test completion data should be gathered before the intervention starts for both intervention and control practices in order to determine the baseline against which any changes in uptake of BCS can be measured (using a difference in difference analysis).

# Appendix 1: Contributors to study and evaluation design

### **BAME Panel Advisory Group:**

Saiga Ahmed, Dorcas Akeju, Jahanara Miah, Naheed Tahir

Cancer Research UK: Louise Roberts

# Collaboration for Leadership in Applied Health Research and Care North West Coast:

Rumona Dickson, Gareth Jones, Lesley Harper

### **Liverpool City Council, Public Health Team:**

Joan Brookman, Emer Coffey, Ian Cunning, Sandra Davies, Richard Jones, Sarah Jones, Shane Knott, Alexis Macherianakis (now PH Consultant), Jo McCullagh (now PH Trainee), Sue Miller, Paula Parvulescu, Martin Smith

### **Liverpool Clinical Commissioning Group:**

Laura Buckels, Lisa Jones, Gemma Melia, Dianna Osayande, Gayle Rooke, Michelle Timoney

Midlands and North West Bowel Cancer Screening Hub: Dionne Trivedi

### NHS England - North (Cheshire and Merseyside):

Julie Byrne, Marie Coughlin, Pauline Jones, Daniel Seddon

### **Primary Care:**

Katy Gardner (Macmillan GP), Cathy Hubbert (Macmillan GP), Kerry Lloyds, Emma Sutton, GP Staff Leads in Kensington, Picton, and Riverside LCCG Neighbourhood

**Public Representative**: Tony Murphy

**Social Inclusion Team**, Merseycare NHS Foundation Trust – formerly part of Liverpool Community Health

# Appendix 2: Exclusion Criteria

| Exclusion  | EMIS Read Code |
|--|----------------|
| Malignant neoplasm of colon                          | B13            |
| Malignant neoplasm of sigmoid colon                  | B133           |
| Malignant neoplasm of colon NOS                      | B13z           |
| Malignant neoplasm of ascending colon                | B136           |
| Malignant neoplasm of transverse colon               | B131           |
| Malignant neoplasm of descending colon               | B132           |
| Malignant neoplasm of hepatic flexure of colon       | B130           |
| Malignant neoplasm of other specified sites of colon | B13y           |
| Malignant neoplasm of splenic flexure of colon       | B137           |
| Malignant neoplasm, overlapping lesion of colon      | B138           |
| Secondary malignant neoplasm of colon                | B5750          |
| Carcinoma in situ of ascending colon                 | B8036          |
| Carcinoma in situ of colon                           | B803           |
| Carcinoma in situ of colon NOS                       | B803z          |
| Carcinoma in situ of descending colon                | B8032          |
| Carcinoma in situ of hepatic flexure of colon        | B8030          |
| Carcinoma in situ of sigmoid colon                   | B8033          |
| Carcinoma in situ of splenic flexure of colon        | B8037          |
| Carcinoma in situ of transverse colon                | B8031          |

# Appendix 3: EMIS Template

# $\underline{BCS}$

| <u>A</u> ] | LL patient taking part in the study   |
|------------|---|
|            | Patient in local Bowel Cancer Screening Study (9Q2 - Patient in local study)  |
| <u>Pa</u>  | atients eligible to be included in the study - Age 60 years   |
| _<br>      | BCS kit sent to patients (9NC3 - Letter sent to patient)  |
|            | BCS Test completed (EMISNQBO52 - Bowel frequency chart completed)   |
| ВС         | S Test result  Georgia 686A - BCSP faecal occult blood test normal  Georgia 686B - BCSP faecal occult blood test abnormal  Georgia 6867 - BCSP faecal occult blood testing kit spoilt |
| <u>Pa</u>  | atients eligible to be included in the study - Age 62 years   |
|            | BCS kit sent to patient (8C1F - Bowel care)   |
|            | BCS Test Completed (9DB2 - Misc. cert completed)  |
| ВС         | S test result  418 - Lab. test result normal  419 - Lab. test result abnormal  411 - Laboratory test not necessary  |
| <u>Pa</u>  | atients included in the study interventions   |
|            | Letter sent to patient by GP (9NC3 - Letter sent to patient)  |
| □<br>opt   | Patient failed to respond to letter (9Nj1 - Patient failed to respond to appointment :-in letter)   |

# Phone call intervention 1st Call ☐ 1st Telephone call to patient (9b0n - Telephone call to a patient)

| □ Time of Call □ Length of call  Telephone encounter 1 □ Patient did not answer □ Patient agreed to test □ Patient did not agree to test □ Patient is undecided | • • • • • |       |  |
|---|-----------|-------|--|
| □ Length of call  Telephone encounter 1 □ Patient did not answer □ Patient agreed to test □ Patient did not agree to test □ Patient is undecided                |           | Time  |  |
| <ul> <li>□ Patient did not answer</li> <li>□ Patient agreed to test</li> <li>□ Patient did not agree to test</li> <li>□ Patient is undecided</li> </ul>         |           | Lengt |  |
|   | Te]       |       | Patient did not answer Patient agreed to test Patient did not agree to test Patient is undecided |

# Phone call intervention 2nd Call

|     | 2nd Telephone call to patient (9O32 - Second patient "call")   |
|-----|--|
|     | Time of Call   |
|     | Length of call   |
| Tel | ephone encounter 2  Patient did not answer  Patient agreed to test  Patient did not agree to test  Patient undecided |

# Phone call intervention 3rd Call

| 3rd Telephone call to patients (9O33 - Third patient "call") |
|--|
| Time of call   |
| Length of call   |
|  |

Telephone encounter 3

□ Patient did not answer

| □ Patient agreed to do test □ Patient did not agree to do test □ Patient is undecided   |
|---|
| Group session intervention  |
| □ SMS message sent to patient (EMISNQSM1 - SMS message sent to patient)   |
| □ Patient invited to attend Intervention session (EMISNQIN269 - Intervention session type: Open group)  |
| □ Patient attended (8BK2 - Attended expert patients programme)  |
| ☐ Group session (EMISNQIN265 - Intervention session type: Closed group)   |
| ☐ One-to one support session (EMISNQIN266 - Intervention session type: One-to one support)  |
| Outcomes (intervention only)  |
| Patient ordered new kit  Patient ordered new kit- NO  Patient ordered new kit - SELF  Patient ordered new kit - GP Staff  Patient ordered new kit - SI Team |
| Test Completed  Test completed - YES  Test completed - NO   |
| Patients sent a BCS kit  Patients sent a BCS kit - YES  Patients sent a BCS kit - NO  |
| If yes, test results  Test - Normal Test - Abnormal Test - spoilt   |

Quantitative Evaluation of the Inequalities in Bowel Cancer Screening Intervention: Final Report

# Appendix 4: LCCG Data to be provided to the Evaluation Team

### Data required for Research Questions 1 & 2

### For each intervention practice:

- A. The number of people eligible for a BCS test (i.e. prior to being invited for the intervention) between the dates of 1st January 2017 31st July 2017.
- B. Out of A the number who did not return a kit within four weeks of the initial invitation.
- C. Out of B the number of people who were sent an endorsement letter from GP Practice.
- D. Out of C the number of people telephoned by Advocate to provide advice (telephone intervention practices).
- E. Out of D the number of people provided with telephone advice by an Advocate (telephone intervention practices).
- F. Out of D the number of people who did not answer any of 3 phone calls or not willing to receive advice (telephone intervention practices).
- G. Out of B the number of people telephoned by an Advocate to invite to face-to-face session (face to face intervention practices).
- H. Out of G the number attending a face-to-face information session delivered by Advocate
- I. Out of G the number who did not answer any of 3 phone calls or not willing to attend face-to-face session.
- J. Out of B the number returning a kit by the 31st October 2017
- K. Out of E the number returning a kit by the 31st October 2017
- L. Out of F the number returning a kit by the 31st October 2017
- M. Out of H the number returning a kit by the 31st October 2017
- N. Out of I the number returning a kit by the 31st October 2017

Each of the data items above should be additionally disaggregated by the following groups

- (a) "first time invitees" (Group 1) and "subsequent invitees" (Group 2),
- (b) BAME groups and non-BAME groups and
- (c) men and women.

### For each comparison practice:

- A. The number of people eligible for a BCS test between the dates of  $1^{st}$  January  $2017 31^{st}$  July 2017.
- B. Out of A the number who did not return a kit within four weeks of the initial invitation.
- C. Out of B the number returning a kit by the 31st October 2017.

Each of the data items above should be additionally disaggregated by the following groups

- (a) "first time invitees" (Group 1) and "subsequent invitees" (Group 2),
- (b) BAME groups and non-BAME groups and
- (c) men and women.

In addition, data were to be provided giving bowel cancer screening uptake rates, as provided by the Hub for each GP practice since the beginning of the programme, up to the latest data available.

# Appendix 5: LCC data collection forms

|                   | Monthly Update, Telephone Intervention           |                    |                     |                        |                                  |               |  |  |  |  |
|-------------------|--|--------------------|---------------------|------------------------|----------------------------------|---------------|--|--|--|--|
| Inequalities & Bo | Inequalities & Bowel Cancer Screening Month 2017 |                    |                     |                        |                                  |               |  |  |  |  |
|                   |  | Age Grou           | up Search           |                        |                                  |               |  |  |  |  |
| Practice Name     | Code   | Number 60<br>years | Number 62+<br>years | Number<br>Letters Sent | Number<br>Patients<br>Telephoned | SIT<br>Needed |  |  |  |  |
|                   |  |                    |                     |                        |                                  |               |  |  |  |  |
|                   |  |                    |                     |                        |                                  |               |  |  |  |  |
|                   |  |                    |                     |                        |                                  |               |  |  |  |  |
|                   |  |                    |                     |                        |                                  |               |  |  |  |  |
|                   |  |                    |                     |                        |                                  |               |  |  |  |  |
|                   |  |                    |                     |                        |                                  |               |  |  |  |  |

|                   | Monthly Update, Health Promotion Session |                    |                     |                        |                                  |               |  |  |  |  |
|-------------------|--|--------------------|---------------------|------------------------|----------------------------------|---------------|--|--|--|--|
| Inequalities & Bo | wel Canc                                 | er Screening       |                     |                        | Month 2017                       |               |  |  |  |  |
|                   |  | Age Grou           | up Search           |                        |                                  |               |  |  |  |  |
| Practice Name     | Code                                     | Number 60<br>years | Number 62+<br>years | Number<br>Letters Sent | Number<br>Patients HP<br>Session | SIT<br>Needed |  |  |  |  |
|                   |  |                    |                     |                        |                                  |               |  |  |  |  |
|                   |  |                    |                     |                        |                                  |               |  |  |  |  |
|                   |  |                    |                     |                        |                                  |               |  |  |  |  |
|                   |  |                    |                     |                        |                                  |               |  |  |  |  |
|                   |  |                    |                     |                        |                                  |               |  |  |  |  |

# Appendix 6: Patient Questionnaire

<u>Demographic Information</u> (to be completed by the SIT / GP Practice)

Gender

Age

Ethnicity

Language

**GP** Practice

\*\*INTRODUCTION\*\*: Thank you for agreeing to take part in this interview. You have recently taken part in either a phone call or information session to discuss the benefits of completing a bowel health screening test. We would like to know what your experiences were so that we can improve the process for people in the future. This information will only be used by the evaluation team. You do not have to answer these questions if you do not want to. We can stop the interview at any time if that is what you want to do.

### Opening questions

- 1) Were you happy to receive a letter from your GP about bowel screening?
- Why not? (if not)
- 2) How useful was the information in the letter (on a scale from 1 to 5)?
- 3) Were you invited to take part in: Telephone Intervention / Information Session

### **Telephone Intervention**

- 4) Did the person on the phone explain the risks of developing bowel cancer?
- 5) Did they explain the benefits of the test?
- 6) Did they explain how to use the test?
- 7) Did they explain how to order a new test?
- 8) Did you have the opportunity to ask questions?

Were you happy with the answers?

Why not? (if not)

9) Could the phone call be improved in any way?

In what ways? (if yes)

10) Was it helpful to be able to speak in your own language (on a scale from 1 to 5)? (If did not speak in English)

### **Information Session**

11) Did the invitation phone call give you enough information about the session?

Why not? (if not)

12) Were you offered a text message / phone call reminder?

Did you receive one? (if yes)

Was it useful in reminding you to attend the information session? (if received a reminder)

Why not? (if not)

13) Did you attend the information session?

Did you attend: (one-to-one or group)

Why not? (if did not attend)

Please give the reason you did not attend the information session (if "other")

- 14) Did the person at the information session explain the risks of developing bowel cancer?
- 15) Did they explain the benefits of the test?
- 16) Did they explain how to use the test?
- 17) Did they explain how to order a new test?
- 18) Did you have the opportunity to ask questions?

Were you happy with the answers? (if yes)

Why not? (if not happy with the answers)

19) Could the information session be improved in any way?

In what ways (if yes)

20) Was it helpful to be able to speak in your own language (on a scale from 1 to 5)? (if did not speak in English)

### **Closing questions**

- 21) Did talking to someone encourage you to take the test?
- 22) Did you complete the test?

How likely are you to encourage other people to do it as well (on a scale of 1 to 5)? (if yes)

Why not? (if no)

Please specify (if "other")

23) Anything else you would like to add?

# Appendix 7: GP/SIT Questionnaire

\*\*INTRODUCTION\*\*: Thank you for agreeing to take part in this survey. You have recently helped to deliver an intervention to decrease inequalities in the uptake of bowel cancer screening. We would like to know what your experiences were so that we can improve the process in the future. This information will only be used by the evaluation team. You do not have to answer these questions if you do not want to. You can end the survey at any time if that is what you want to do.

### Overview

- 1) Do you work for (GP / SIT):
- 2) How long were you involved with this intervention?

### **Training**

3) How well did you feel you were prepared for your role in the project (on a scale of 1 to 5)? How would you improve the training/preparation?

### Telephone call

4) Did the script for the phone call intervention cover everything you needed to say? How would you improve this script?

### **Information session**

5) Did the materials for the information sessions include everything you needed?

How could these materials be improved?

### Contacting the Social Inclusion Team (If GP Practice Advocate)

6) Did you ask the Social Inclusion Team to deliver interventions to non-English speakers? Please comment on your collaboration with the Social Inclusion Team

#### Workload

7) Was the workload for this project manageable for you?

How could the workload be improved?

### Patient response

8) Do you think the intervention(s) encouraged patients to participate in bowel cancer screening?

What do you think encouraged them to take the BCS test?

### Benefits to staff of taking part in the intervention

9) Did taking part in this intervention have any benefits for either your GP Practice / SIT or for you personally?

### Please explain

### Final questions

- 10) Overall, what do you think worked well?
- 11) Overall, what do you think could be improved?
- 12) Is there anything else you would like to add?

# Appendix 8: Non-Participant Questionnaire

### <u>Demographic Information (to be completed by the SIT / GP Practice)</u>

Gender

Age

Ethnicity

Language

**GP** Practice

\*\*INTRODUCTION\*\*: Thank you for agreeing to take part in this interview. You have recently been invited to take part in either a phone call or information session to discuss the benefits of completing a bowel health screening test. You did not want to take part and we would like to know why that was so that we can improve the way we contact people in the future. This information will only be used by the evaluation team. You do not have to answer these questions if you do not want to. We can stop the interview at any time if that is what you want to do.

### Opening questions

- 1) Were you happy to receive a letter from your GP about bowel screening? Why not? (If not)
- 2) How useful was the information in the letter (on a scale from 1 to 5)?
- 3) Were you invited to take part in: Telephone Intervention / Information Session

### **Telephone Intervention**

4) You did not want to take part in the telephone call. Why was that?

### Information session

5) You did not want to take part in the face-to-face session. Why was that?

### **Closing questions**

6) Anything else you would like to add?