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Community Bowel Screening Volunteers (CBSV) Project: Outcomes and Impact of the Pilot Phase

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1. Executive Summary

The Community Bowel Screening Volunteers Project increases bowel screening uptake by at least 6.5% and specifically targets communities that are more deprived, with the lowest bowel screening rates.

Since the project was first launched in November 2016, 25 volunteers have been involved in making 3,052 calls to bowel screening non-responders from GP practices in Stockport, Trafford and Wigan. The project has exceeded initial expectations and targets, with the following outcomes observed:

1. 1,162 conversations have been held with bowel screening non-responders aged 60-74 to encourage them to get involved in bowel screening and ask if they would like a new kit ordered for them.
2. 812 of these conversations have resulted in a positive outcome, i.e. with the patient giving consent to have a new kit sent to them with the intention of completing it.
3. This means that 70% of those people that volunteers speak to respond positively.
4. Of those people that are sent a new screening kit, 33% have gone on to complete it, 13% did not complete their new kit and 54% are still within the 14 week window they are given to complete their kit at the time of gathering the data, so their response is currently unknown.
5. Across participating GP practices, we have seen a bowel screening uptake increase of, on average, 6.5% as a direct result of the project.
6. Of those who have gone on to complete their kit, there have been 4 cases of abnormal screening results.
7. Two of these people who had abnormal results have gone to colonoscopy and had suspicious, potentially pre-cancerous polyps removed. The other two people went to colonoscopy but no further action was needed.

If the project were to continue in its current form with its current resources, the following results would be expected on an annual basis, based on the conversion rates in the pilot phase:

- 1,277 kits being completed
- 16 people having high risk polyps removed
- 3 cases annually of cancer being diagnosed and treated early

After the success of the pilot phase, Beating Bowel Cancer is looking to scale the project up. In addition to the annual figures above, funding of £70,000 would pay for project expansion,



including a new Volunteer Manager, which would be able to deliver the following results based on the outcomes data in this report:

- 2,555 kits being completed
- 32 more people having high risk polyps removed
- 5 further cases annually of cancer being diagnosed and treated early

2. Context: Bowel cancer prevalence and the importance of early diagnosis

Bowel cancer is the second biggest cancer killer and the fourth most common cancer type registered in the UK, with 41,300 new cases diagnosed in the UK in 2014. This equates to 110 new patients diagnosed every day. Regarding mortality, 15,900 people died of bowel cancer in 2014 in the UK, which means that every day 44 people die of bowel cancer.

When comparing bowel cancer survival rates with other European countries, the UK performs poorly (Independent Cancer Taskforce, 2015). However, if diagnosed at an early stage, bowel cancer can be treated very successfully in 97% of cases. In spite of this, bowel cancer remains the UK's second biggest cancer killer, claiming a life every half an hour.

The primary way to ensure that bowel cancer is caught early is for individuals to take part in the National Bowel Cancer Screening Programme for people aged 60-74; however currently only 58% of people do this nationally and only 53% across Greater Manchester. In some communities participation is lower than 40%. This means that there are many people who are not being diagnosed as early as they could be and therefore reducing their chances of successful treatment.

Recommendation 10 of the Independent Cancer Taskforce (2015) states that: *“NHS England should incentivise GPs to take responsibility for driving increased uptake of FIT and bowel scope in their populations, with an ambition of achieving 75% uptake in all CCGs by 2020”*. The Greater Manchester Cancer Strategy mirrors this target, stating: *“We aim to achieve bowel cancer screening uptake of 75% by 2020, for both the FIT programme and the bowel scope programme for 55 year old people.”* The welcome introduction of the FIT programme to replace FOBt is predicted to make a significant impact on screening rates (approximately an 8-10% potential increase). With the current screening rates in Greater Manchester at 53%, the introduction of FIT might optimistically take this up to around 63%; however there is



still a way to go to reach the target of 75% by 2020, with some populations with low uptake requiring greater attention. Further investment in projects that look to increase bowel screening is therefore essential to meet this target and to tackle inequalities in bowel cancer screening uptake and diagnosis.

There is a strong socio-economic gradient in relation to bowel screening uptake (Von Wagner *et al*, 2011), with people in more deprived areas significantly less likely to partake in screening. This trend is also observed in the strong correlation between the deprivation levels of the population of a GP Practice area and the level of bowel screening uptake.

3. Project methodology

3.1 Beating Bowel Cancer's approach

Bowel screening uptake has been proven in peer-reviewed studies to increase when those who have not responded to the invitation for screening are contacted directly to have a conversation about the importance of screening (Shankleman *et al*; 2014). Volunteers work alongside GP practice staff in their surgery, providing the resources needed to phone people who are aged 60-74 and have not yet completed their screening test.

Volunteers travel to the GP practice they are matched with (not their own GP practice to reduce the chances of identifying patients) and call patients from the practice. They look to have a non-pressured conversation regarding the screening programme, the importance of completing the test and the process involved. If the patient gives consent, they then get resent a new screening kit to complete. This is ordered on their behalf by the GP practice.

No information leaves the premises and volunteers do not need access to the practice database – only a prepared list of names, addresses and phone numbers to contact. All governance, liability and confidentiality issues have been fully considered and are being managed by Beating Bowel Cancer in partnership with the GP Practices.

3.2 Participating GP practices



There are three areas in Greater Manchester that Beating Bowel Cancer has been partnering with on this project: Stockport, Wigan and Trafford. Partnerships with individuals within Public Health, Councils and CCGs in these areas have been key to the success of the project, as well as when recruiting GP practices.

Within each of these three areas, the lowest performing practices in relation to bowel screening were identified. These were invariably closely linked to the deprivation levels of the practice populations. These GP practices were approached and asked if they would like to be included in the project, with the majority replying positively. Cancer Research UK facilitators were also key in developing partnerships with GP practices and there has been significant mutual benefit in working alongside them and their Practice Cancer Champion programme.

There were some cases where GP practices whose screening rates were not the lowest in the area heard about the project and proactively approached Beating Bowel Cancer wanting to get involved. When this happened we were able to allow those practices to be involved. Therefore some practices had higher screening rate base levels than others, but the majority had particularly low screening rates.

3.3 Bowel Screening Volunteers

Our volunteers are selected on the basis of having the right key communication skills and of being personable, engaging and reliable with an appropriate phone manner and a strong respect for confidentiality. They are trained to be respectful of the reasons people might have for not getting involved in bowel screening.

They receive all the training necessary from Beating Bowel Cancer, covered in a half day of training. This includes becoming familiar with a phone script and practicing making calls. The charity's Regional Manager supports and manages the volunteers, including offering out of pocket expenses.

4. Methodology for data gathering

All of the participating GP practices who had been operational with the project for 4 months or more were included in the data gathering exercise. Those practices that got involved more



recently than this were not included as the majority of the patients contacted and sent a new kit in these practices would still not have had the 14 week window allowed to complete it. There were therefore 12 practices in total, with 4 practices from each of the three project areas (Stockport, Trafford and Wigan) being included in the data set.

Meetings were set up with these 12 practices with the aim of gathering the following data set from each practice:

- Total number of patients who have been sent a new kit as a result of a call from a volunteer
- Of those patients who have been sent a new kit, how many of them have gone ahead and completed their screening kit?
 - How many have still not done so after 14 weeks and therefore have again been coded as a non-responder?
 - How many of them have nothing yet on their record as they are still within the 14 week window of potential completion?
- Of those who have completed their screening kit, how many results are normal and how many abnormal?
- Of those that were abnormal, has the patient gone to colonoscopy after being invited and if so, what was the outcome?

Results from each practice were compiled. Averages and rates were calculated. Within this report no individual GP practice data is shared to ensure confidentiality. Individual practice analysis will be shared with individual practices.

5. Volunteer recruitment, support and retention

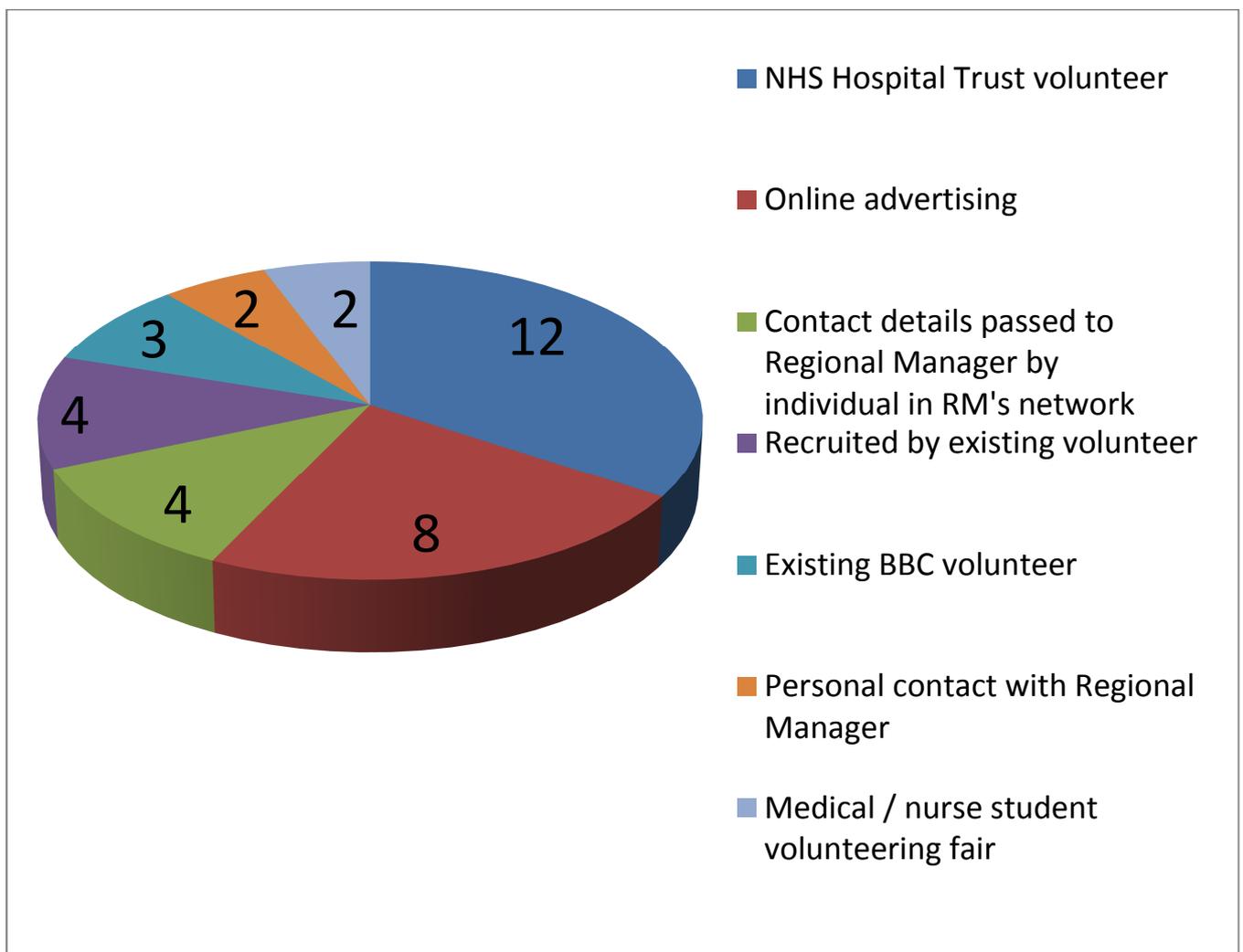
There have been a number of different approaches that have been tried to attract the right volunteers to come and serve on the project. Some have proved more fruitful than others. The two most successful recruitment methods have been online recruitment and recruiting



volunteers via NHS Foundation Trust volunteering centres. These recruitment methods have not just produced a good quantity of volunteers, but the quality of volunteer and the appropriateness for the role has also been high.

5.1 Volunteer recruitment

The table below shows the range of ways in which volunteers were recruited for the project and how many volunteers were recruited by each method.





Overall, there has been a very positive response to the volunteering opportunity and if we were to expand into other CCG areas with the project, volunteer recruitment would not be expected to be a problem.

The starting point when the project first began was to approach any volunteers in the relevant areas who were already volunteering for Beating Bowel Cancer in other capacities. The numbers of existing volunteers provided a good starting point for volunteer recruitment.

The three areas (Trafford, Wigan and Stockport) then had slightly different recruitment strategies depending on the opportunities that arose, as follows.

Trafford recruitment in brief

A strong partnership was established with the volunteering organisation 'Thrive' in Trafford. Their main method of recruitment is online advertising via the 'Do-It' website, which proved very successful in attracting volunteers.

In addition to this a good partnership was established with St Mary's Royal Infirmary Volunteering Centre. They have hundreds of volunteers who serve in different roles across the hospital site. The opportunity was shared with these volunteers, and this led to 5 volunteers being trained.

Wigan recruitment in brief

In Wigan a high number of volunteers were recruited without proactively trying to! This came about due to word of mouth, people in the Regional Manager's network taking about the project and existing volunteers recruiting people they know.

Via an existing volunteer, the Volunteering Centre of Wigan's NHS Royal Albert Edward Infirmary also shared the opportunity, which led to 7 further volunteers being trained.

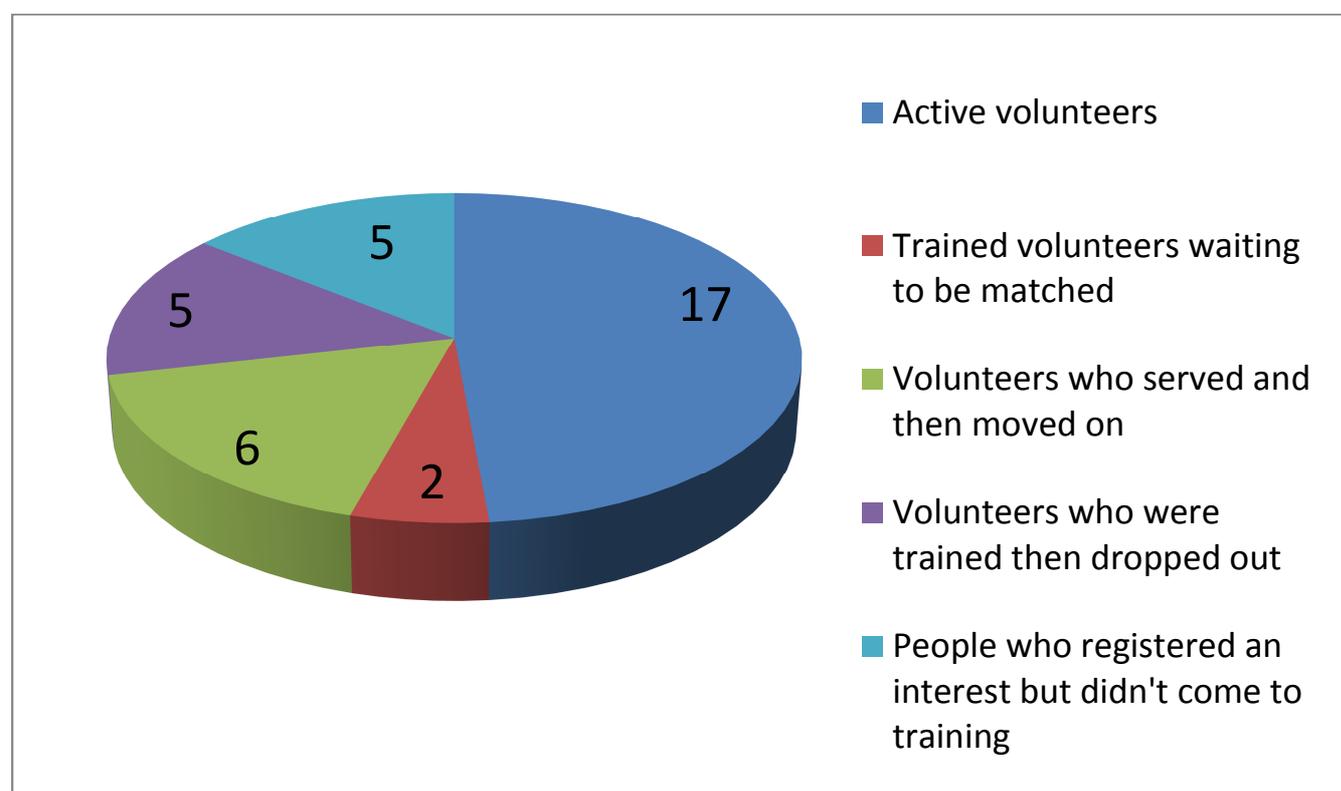
Stockport recruitment in brief

Volunteers were recruited for the Stockport practices by a mix of existing Beating Bowel Cancer volunteers, personal contact with the Regional Manager and referrals from networks.

5.2 Current volunteer numbers



The table below shows the current numbers of active, trained and previously active volunteers.



The volunteer retention for the project has been better than anticipated, with only 6 of the 23 volunteers who have done at least one volunteering session in a GP practice needing to move on. In all 6 cases they have offered an understandable reason for needing to end their volunteering relating to a range of changes in life circumstance. There have been no cases (reported at least) of volunteers ending their volunteering due to negative reasons.

Regarding the 5 volunteers who were trained and then dropped out, this occurred for two reasons. First, again because life circumstances changed; and secondly because after the training session it was apparent that they were not suited to the role. The length of time they needed to wait to be matched with a GP practice might also have been a factor, although this was not explicitly stated.

As, in most cases, volunteers are first recruited and then GP practices found to match them with, some volunteers occasionally have to wait longer than is ideal to be matched with a



practice. Regular communication has kept most volunteers engaged when this happens and expectations are set around these time frames in the training. However, on reflection, it might be better to recruit the GP practices first, and then recruit volunteers, so that people are not left waiting for practices to confirm involvement.

6. Current calling rates

Below are the current figures for the number of volunteer calls and conversations. It should be stressed that these figures are for all participating practices, not just those who were involved in the data gathering exercise. This includes data for all participating areas together.

No. of sessions	No. attempted contacts	No. spoken with	Rate of successful attempted contacts	No. of patients resent kit after giving consent	No. of patients said would not complete the kit	Rate of people spoken with who gave consent to resend kit
94	3052	1162	38%	812	350	70%

The first column shows the total number of volunteer sessions completed to date (as of 23rd August 2017). The second column shows the total number of times a volunteer has dialled a number in an attempt to contact a patient, whatever the outcome. The third column shows the number of patients our volunteers have had a conversation with and the fourth shows the rate of successful attempted contacts (so for every call that is attempted, a volunteer has a 38% chance of getting through).

Of the 1162 patients that have been spoken to at the time of writing, 812 have resulted in a positive conversation where the individual who was a previous non-responder has given consent to have a new kit sent to them with the intention of completing it. This leaves another 350 who, after having the conversation, still decided not to participate. This means that of those previous non-responders who had a conversation with one of our volunteers, 70% decided to opt in to bowel screening.



7. Expected outcomes

According to Logan et al (2011), as well as information from the National Bowel Screening Programme, of those people who complete the FOBt screening kit, 1 person in 50 will receive an abnormal result and therefore be invited to colonoscopy.

Logan *et al* (2011) also reveals the following rates for those who go through to have a colonoscopy as a result of an abnormal screening kit result:

- 9.7% of the population who had colonoscopies had a cancer detected
- 36% of the population who had colonoscopies had a high risk adenoma detected

We can therefore calculate the figure for early detection of cancer and suspicious polyps per screening kit completed as follows:

- 50 would need to be screened (*for 1 in 50 being found with an abnormal test*) $\times 10.3$ (*for the proportion of people who have a colonoscopy who have a cancer detected, 1/9.7%*) = On average we can expect **515 people to be screened for every cancer detected**
- 50 (*for 1 in 50 being found with an abnormal test*) $\times 2.78$ (*for 1 in 3 people who had colonoscopies who have a high risk adenoma detected, 1/36%*) = On average we can expect to need **139 people screened for every high risk adenoma detected**

So in summary we could say that for every 515 screening kits completed, we can expect one life to be saved from cancer and 3 people to have a high risk adenoma detected and removed, which might well have saved their life from cancer.

8. Outcomes

8.1 Abnormal results and high risk polyp removal



The actual rates seen in this project have been higher than the expected outcomes. With the information gathered to date (which only includes GP practices that have been active for more than 4 months, rather than all participating GP practices) we have seen:

- **161 screening kits completed after being resent a kit following a conversation with a volunteer**
- **4 abnormal results**
- **2 of these abnormal results went to colonoscopy and no further action was needed**
- **2 of these abnormal results went to colonoscopy and had potentially cancerous high risk adenomas removed**

These outcomes therefore exceed the expected rate of polyp removal (although the numbers here are relatively small). This might be explained by the population that volunteers are calling potentially going longer before having polyps detected and removed due to their previous non-participation. For example, if a volunteer encourages an individual over 70 to take the screening test for the first time, they have a higher chance of needing polyps removed or cancer being found than someone who is opting in for the first time at 60 years of age. The fact that the communities targeted are in more deprived areas is also likely to be a factor.

8.2 Rates of screening kit completion

From the 12 GP practices in the data set, 489 new kits were sent out as a result of a volunteer conversation. (Note that the total number of new kits sent out for the project to date for all GP practices, including both those in the data set and those that are not, is 812.) This is shown in the table below.

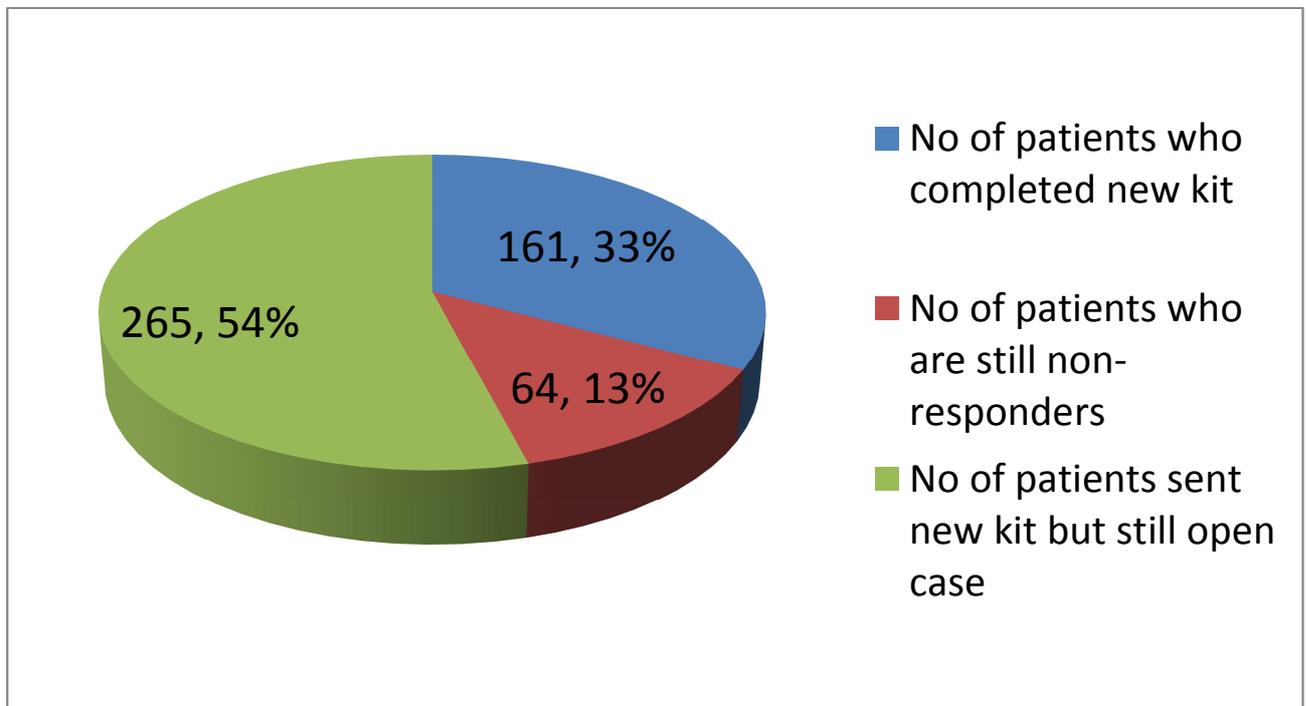


No of patients resent kit to	No of patients who completed new kit	No of patients who are still non-responders	No of patients sent new kit but still open case
489	161	64	265

Of these 489 kits that were sent to patients, 161 of them were completed with the 14 weeks window. 64 patients had still not completed their kits after being resent them and had been coded by the Screening Hub as non-responders once again as the 14 week window had passed. 265 patients had been sent a new kit, but had not yet completed it and were still within the 14 week window before they are coded as non-responders, so their final status is not yet know.

These figures are shown as percentages of the total number of patients who were resent a kit in the graph below.

Rates of screening kit completion when sent a new kit after a conversation with a volunteer



There are still therefore a significant number of patients whose status is unknown. This will include a variety of patients in relation to how recently they were sent their screening kit, with some of them being sent it just a few days ago and others potentially receiving it up to 13 weeks ago. There therefore still remains a significant question mark over the total completion rate; however the rate of at least 33% already represents a higher rate than anticipated and a higher rate than other comparative previous projects. For example, a recent similar project in Luton, part of the ACE project (ACE Bowel Screening Cluster, 2017), saw GP practice staff calling bowel screening non-responders. In this case, 55% of patients contacted gave consent for a new kit to be sent to them (compared to 70% for this project) and 14% of these returned a completed kit (compared to at least 33% in this project).

One potential reason for this could be found in the quality of our volunteers and the calls they are making. Our volunteers receive extensive training and support. A number of them also have personal experiences of bowel cancer, making their calls potentially more persuasive and personal. They are also focused solely on the task of calling people to have conversations about bowel cancer screening, are motivated to do so and have the time to have longer conversations whenever necessary.



Conversion rates

The table below shows the conversion rates for the contact that volunteers had with patients. From the practices in the data set, there were 2,164 occasions where a volunteer attempted to contact a bowel screening non-responder, and they successfully got through to them 36% of the time, having 772 conversations about the importance of bowel screening.

No of attempted contacts	➔ Conversion rate	Total no spoken with	➔ Conversion rate	No of patients resent kit to	➔ Conversion rate	No of patients who completed new kit
2164	36%	772	63%	489	33%	161

From these 772 conversations, 63% resulted in a patient responding positively and giving consent to have a new kit sent to them (note that the total % for all practices both included in the data gathering exercise and those that were not was significantly higher, at 70%). This resulted in 489 kits being sent out to patients, 33% of which were completed. This meant that 161 previous non-responders took part in screening as a result of a conversation with a volunteer.

The additional conversion rates below show the following:

- Every time a volunteer picks up the phone, they have a 7% chance that action will lead to a screening kit being completed
- Every time a volunteer has a conversation with a patient about bowel screening, there is a 21% chance this will result in a kit being completed
- Every time a volunteer receives consent and arranges a new kit to be sent out to a previous non-responders, there is a 33% chance the kit will be completed



No of attempted contacts	➔ Conversion rate	Total no spoken with	➔ Conversion rate	No of patients resent kit to	➔ Conversion rate	No of patients who completed new kit
2164	36%	772	63%	489	33%	161
2164	➔ 7%			➔		161
		772	➔ 21%		➔	161
				489	33%	161

9. Subsequent impact on GP practice screening rates

Based on these figures, calculations have been made to demonstrate the resulting increase in GP practice screening rates. As the project has been running for different lengths of time for different practices, calculations were made to estimate the impact of involvement across the whole of a 12 month period, based on the practice's figures. This was also needed for comparison with current bowel screening uptake levels, which are presented as annual figures.

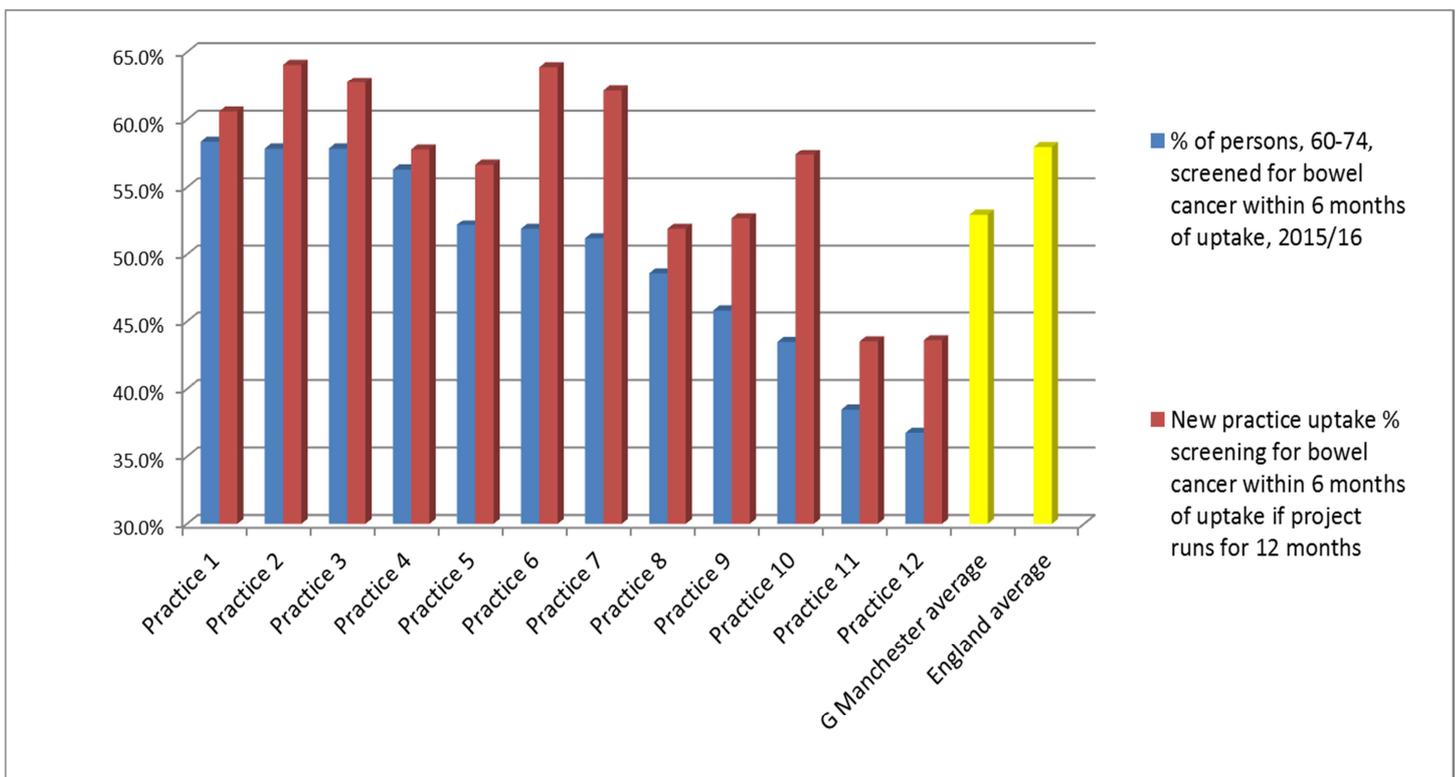
The data showed that, across the 12 GP practices involved in the data set, we would expect on average to see an **increase of 6.5% to their bowel screening rate**. The range between practices is wide, ranging from 1.5% at the practice that saw the smallest increase, to 13.9% for the practice that saw the highest.

Before our involvement, 8 of the 12 participating GP practices were below the Greater Manchester average and all but one of them was below the England average. Once the project has been running for a year, only 4 of the GP practices will be below the Greater Manchester average and 5 practices will be above the England average.



The table below shows, in blue, the 2015/16 bowel screening uptake for each practice. Next to this, in red, is the expected new practice bowel screening uptake after the project has been running for 12 months in each practice. The Greater Manchester and England averages are shown in yellow.

Graph showing expected bowel screening % increase for participating GP practices



The table above shows that every GP practice that participated in the project has seen a significant increase in their bowel screening rates, with some seeing far higher gains than others. We will be looking into the reasons for this, learning from those that have seen the highest increases and sharing best practice. We believe there are three key factors for the variation: firstly the effectiveness of the individual volunteer at each practice and the frequency with which they are doing volunteering sessions; secondly the level of engagement of the GP practice staff supporting the volunteer; thirdly the demographics of the practice in question, with areas of higher deprivation presenting a harder challenge to

volunteers, but also potentially having the most to gain from a low base rate of bowel screening.



10. Cost benefit analysis and the case for expansion

10.1 Current annual reach of the Community Bowel Screening Volunteers Project

With the structure and management of the project as it currently operates, with the Regional Manager (North West) managing all aspects of the project, the maximum number of volunteers (and therefore also GP practices) is 25.

Volunteers are encouraged to do a session every other week. Factoring in breaks and holidays, a reasonable assumption is that a volunteer does a session every 3 weeks.

And at the moment we are seeing 8.6 positive outcome conversations (so resulting in a new kit being ordered) per volunteering session. Therefore,

- On this basis each volunteer will do 17 sessions per year
- Each session results in 8.6 new kits on average being sent out
- So each volunteer will result in 146 kits being sent each year (17 x 8.6)
- So if 25 volunteers are active across the year **we can expect to order 3,650 new screening kits** (25 volunteers x 146 kits per volunteer across the year)
- From the data gathered we know that we can expect at least 35% of these kits to be completed
- We can therefore expect **an annual return of 1277 kits being completed**
- From the rates seen so far from the project in relation to polyps detected and removed at colonoscopy (1 person who has suspicious polyps removed for every 80 kits completed), we can expect to see **16 people having high risk polyps removed annually as a result of the project**



- From Logan et al (2011), we can expect to find one cancer detected for every 500 people screened. We would therefore expect to see **3 cases annually of cancer being diagnosed and treated early as a result of volunteer contact**

10.2 The case for expansion

The figures above are based on the project continuing as it currently operates, with the Regional Manager running all aspects of the project.

However, this model is very replicable, and with additional funding the project could expand significantly. For example one Volunteer Manager role based in the North West could recruit, manage and support at least 50 new volunteers. Two such managers could support 100 volunteers etc.

With funding for just one Volunteer Manager, the expected resulting impact and outcomes would be as follows:

- So if 50 new volunteers are active across the year **we can expect to order 7,300 new screening kits** (50 volunteers x 146 kits per volunteer across the year)
- From the data gathered we know that we can expect at least 35% of these kits to be completed
- We can therefore expect **an annual return of 2,555 further kits being completed**
- From the rates seen so far from the project in relation to polyps detected and removed at colonoscopy (1 person who has suspicious polyps removed for every 80 kits completed), we can expect to see **32 people having high risk polyps removed annually as a result of the project**
- From Logan et al (2011), we can expect to find one cancer detected for every 500 people screened. We would therefore expect to see **5 cases annually of cancer being diagnosed and treated early as a result of volunteer contact**



- **Screening rates in participating GP practices to increase by an average of at least 6.5%**

The realisation of these outcomes would be a significant step towards achieving the Greater Manchester Cancer Strategy and Independent Cancer Taskforce targets of reaching 75% bowel screening uptake by 2020. By targeting those GP practices that have the lowest screening uptakes, the project can also play a significant role in reducing health inequalities and decreasing the bowel screening gap between more affluent areas and areas of high deprivation.

10.3 The costs of expansion

Beating Bowel Cancer has produced a budget for the expansion of the Community Bowel Screening Volunteers Project, based on the recruitment of a new Volunteer Manager and associated support. The total for this is £70,000 on an annual basis.

Therefore, for £70,000 per year:

- 2555 more people will be screened
- 32 people will have high risk polyps removed that may stop them getting cancer before it has the chance to develop
- 5 people will have their cancer diagnosed and treated at an early stage, vastly increasing their chances of success treatment

10.4 Savings for the NHS

The cost for the NHS of treating bowel cancer at Stage 1 is, on average, £3,373. To treat at stage 4 is on average £12,519 (Incisive Health, 2014). Therefore each time the project enables an early diagnosis of cancer it potentially saves the NHS £9,147.

If the project were to expand in line with the plans outlined, 5 cancers would be diagnosed at early stage. 32 high risk polyps would also be removed. Evidence suggests that approximately 25% of adenomas (high risk polyps) result in cancer at the site of the



adenoma (Amersi, Agustin and Clifford, 2005). Therefore, if 32 high risk polyps are detected and removed, this is likely to result in another 8 cancers being prevented before they had a chance to develop.

So just for these 5 cancers that are caught early and 8 cancers prevented by removal of polyps, a **direct saving of £118,911 for the NHS** could be realised. The cost of the expansion of the project (£70,000) is therefore more than made up for by the direct savings associated with the resulting early diagnosis.



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