Pilot Project

Improving uptake of bowel and cervical screening at Portslade Health Centre: a primary care and voluntary sector partnership

"This project has been fantastic and the results speak for themselves. It has brought capacity to our stretched system and has enabled us to really focus on cancer screening. This work is nothing short of life-saving."

Dr Rowan Brown, Clinical Director, West Hove PCN

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Introduction

Act on Cancer Together is a voluntary sector partnership in Brighton and Hove, commissioned through Brighton and Hove public health, NHS Sussex and facilitate earlier diagnosis of cancer in the local population, and increased access to cancer support, particularly among groups facing health inequalities. Voluntary sector partner the Hangleton and Knoll Project (HKP) deliver community development and youth work in areas of deprivation in the west of the city, and have led this pilot project in partnership with their local primary care network (PCN); West Hove, with whom they had previously established a close working relationship through their shared drive to reduce health inequalities in the area. The aim of the pilot was to increase patient engagement with, and uptake of, bowel and cervical screening programmes.

Joanna Martindale, Chief Executive of HKP, met with Dr Rowan Brown, clinical director of West Hove PCN, to consider different models of working that could improve screening rates. The pilot model that they came up with involved HKP's Act on Cancer Together Coordinator engaging in a 3-month secondment at Portslade Health Centre (PHC). This secondment was decided upon to overcome the barriers inherent in data sharing between the NHS and a voluntary sector organisation. The coordinator would telephone patients who had either not returned a bowel screening test, or not attended cervical screening, during the requisite uptake period. It was decided to contact non responders of the Bowel Cancer Screening Programme (BCSP) first, as Faecal Immunochemical Test (FIT) kits could easily be ordered and this did not rely on availability of appointments. While the coordinator worked on that initial set of calls, the practice created capacity in their cervical screening clinics for the coordinator to be able to directly book appointments with non-attenders when they began that round of calls.

Activities

1. Induction/IT training and mandatory training for the GP practice.
2. Identification of patient cohort – reports were run from practice data to create lists of patients that had not responded to the screening invitations.
3. Development of appropriate scripts and offers of support for both bowel and cervical cancer screening.
4. Non-responders to the bowel cancer screening programme were then contacted directly by telephone to encourage take up and explore fears/barriers.
5. If a patient did not answer the call then a text was sent inviting them to participate in the programme, with details of how to contact the local screening hub and a link for further information. If it was not possible to contact a patient by phone or text then a letter or email was sent.
6. Telephone calls also offer tailored support from HKP to address barriers identified if necessary; e.g. translated materials, transport to an appointment, etc.
7. When the full patient list had been completed, the coordinator moved onto cervical screening. The same method was followed but this time the coordinator was able to book people in for cervical screening appointments at the practice there and then.
8. An audit of the responses was taken to establish response rate and if further follow up was required.
9. Follow up calls were made to relevant patients and further results noted.

Approach

A gentle, non-judgemental approach was adopted when contacting patients via telephone to talk about the screening programmes. The calls sought to provide a space to explore the barriers/concerns about participating in the programmes, assess knowledge of the programmes, refer the patient to appropriate resources and provide further advice on the screening programmes . Asking open questions such as "Do you mind me asking your reasons why you don't want to engage with the programme?", "Is there anything that would help persuade you to change your mind?", or "Do you have any concerns or questions that you would like to ask?" was important to give patients an opportunity to explore barriers without being judged, and to explore decision making without overwhelming the patient. At times, viewpoints were gently challenged, with varying degrees of success in creating behaviour change. Understanding the barriers and challenges patients face is essential in being able to offer meaningful support to encourage screening uptake.

Executive summary of outcomes

	Total patients on the list	Patients spoken to directly	% of direct calls that resulted in completed test	Patients texted	% of texts that resulted in completed test	Patients emailed or sent a letter	% of emails/ letters that resulted in completed test
Bowel screening	421	203	27%	147	3%	53	0%

Cervical screening	545	195	30%	241	8%	74	0%

NB The total patients on the list is greater than the number of patients contacted across the four different communication channels. This is due to a combination of factors; inaccurate contact details, inactive patients and others for whom it wasn't appropriate to contact them, for example because they were already undergoing cancer treatment.

Bowel Cancer Screening

Contacts made

Total attempted calls	421
Total patients spoken to at initial call	203
Total patients spoken to at follow up stage	tbc
Total texts sent	147
Total letters/emails sent	53
Total referral to HKP for ongoing support or community activity	4
Total requiring follow up via GP practice	3

Outcomes – screening uptake

Had FIT at home but needed a reminder	48
New FIT ordered for home delivery to patient	99
New FIT ordered for patient to pick up from surgery	8
FITs re-ordered after follow up call	8
FITs completed following initial call	54
FITs completed after follow up call	3
FITs completed following text reminder	5
FITs completed following email or letter	0
Declined taking part	39

Outcomes – clinical

	Tests completed	**Normal result**	**Referred for colonoscopy**
Initial call	54	53	1
Follow up call	3	3	0
Texts	5	5	0
Letters	0	0	0
Total	**62**	**61**	**1**

Common barriers

Barrier	**Explanation**	**Quotes from community members**

Forgetfulness	One of the most cited reasons for not completing FIT kits/engaging with the BCSP was that patients had merely forgotten to complete the test. Many of these patients were appreciative of the reminder and advice about the BCSP and then were keen to do the test as soon as they could.	***"I haven't done the test in 2 years mainly out of laziness but I will do it now. Thank you for the nudge!".*** ***"Thank you for reminding me that I had a test sent to me. I needed the prompting. I will do it this week".***
Health-related overwhelm	A number of patients felt overwhelmed with other health issues that they were dealing with and did not want the stress of having to address a potential health issue such as bowel cancer or even the prospect of going for a colonoscopy/further tests. Several patients with mental health issues felt unable to consider doing the test at the point of the contact. A patient who was due a lung check wanted to deal with this first before considering the BCSP.	***"Biggest concern for me is my eyesight – I am focusing on that and don't want something else to worry about. Anxiety and worry can drive you to an early grave"*** ***"I haven't done it as I have been overwhelmed by other health issues. But now you have called I have been encouraged to do it"***
Lack of awareness about the testing programme	A number of patients had not been aware of being sent a FIT kit and were uncertain/uninformed of the BCSP. Information and advice about the programme was provided repeatedly. Information was provided about how often the kits were posted, what the tests are looking for, how to do the test and return, expiry dates of the kit, how quickly to expect results, what a positive result could mean and how they could get a FIT kit independently if they declined an offer from the coordinator to order one from the hub. Information was also provided to debunk myths and misinformation about the need for screening such as not needing to do the test as they had no symptoms and someone was concerned that	***"I had not considered doing the test in the past, but I will now make more effort to do it now"*** ***"I haven't done the test in the past but I have been discussing this with my wife who has significant health issues in the last year and agreed we should do it"***

	screening might pick up cancer when it doesn't exist.	
Uncertainty/difficulty of how to collect a sample:	A number of patients were unclear as to how to take a stool sample. An explanation of how to collect a sample was provided to these patients who then felt more confident to try. One patient with literacy issues had struggled to understand the instructions to complete the FIT. Advice and instructions were provided over the phone and a follow up phone call agreed . Another patient received advice on how to collect a sample as she disclosed:	**"I have struggled to take a sample due to my weight"**
Fatalistic view of health and	Some patients declined the BCSP citing fatalistic views around getting cancer: One particular patient had given up trying to get an appointment with his GP and as such did not want to address health issues.	***"I have come to terms with my mortality, expectations are not being met. False positives. Only those with money get the treatment that they need"***
negative views of NHS:	Negative views of the NHS and accessing care were also common barriers. One lady felt that she couldn't get an appointment with GP and had given up trying to address her health issues. She was told about the Hangleton and Knoll Project's health forum and referred to HKP E Newsletter for further details of events. She seemed to appreciate having an opportunity to vent her feelings despite still declining the BCSP invite.	***"I have lost all faith in the NHS as nothing is followed up"***
Fear of a cancer diagnosis	Another common barrier was fear of a cancer diagnosis and feeling that they would rather not know. Some patients following a discussion about the positives that an early diagnosis can provide changed their mind.	***"I haven't wanted to know if I had cancer before and I have avoided doing the test. However I will now do it following the information about early diagnosis***"

		"I had forgotten to do the test previously and wanted to avoid the worry. My husband died of bowel cancer and so I would rather not know"
Finding the test unhygienic/unappealing:	A number of patients found the thought of the test unpleasant and had either been putting it off or didn't want to do it for this reason. One patient had not done the test in the past due to embarrassment. He also found the process difficult however with the new type of FIT available he was more motivated to complete.	***"I felt squeamish about doing the test but after seeing it on TV I feel better about it and now will do it"*** ***"I can't be bothered. I do not want to rummage behind and feel that it is unhygienic"***

Some patients also identified that they would discuss completing the FIT test or cervical screening with their spouse/partner – either to reconsider the decision together or provide encouragement to each other do the test together. This is off benefit as uptake potentially can be reinforced in this shared decision making.

Less common barriers

- Issues with post
- Mistaking the FIT kit for a Covid test
- Having irregular bowel habits and so they thought they couldn't do the test
- Stress caused by having to re-do the test which had caused him to disengage with the programme
- Hearing a story about a colonoscopy that had gone wrong which had put them off from engaging with the BCSP
- A painful colonoscopy in the past has put the patient off engaging with the BCSP
- Confusion about when they had completed a FIT and thinking it was not due yet.
- A perception that they lived a healthy lifestyle so would not be affected by BC.
- Several patients declined but would not provide further details on reasons behind their decision.

Bowel screening support case studies
A gentleman in his 60s had limited English and spoke Bengali. He had been a non-responder to the BCSP despite being invited at 3 different times in a 5 year period. During the telephone contact he appeared confused about the BCSP and how the FIT worked. The conversation explored his issues and offered further support with doing the test. He consented to ordering a new FIT kit. Once this was received a further follow up call was made and it was evident that he was still struggling to understand how to do the test. A face-to-face meeting was arranged. The coordinator provided FIT instructions in Bengali and showed the patient a video of someone doing the test in his language to

reinforce the method. This resulted in the man successfully completing the test. He also provided consent to share his details with HKP so he can be informed of other relevant support. He received a a normal result and hopefully will continue to engage with the BCSP.
A patient was called who stated that he had spoiled a previous FIT as he could not see very well and stated the holes are very small to collect a sample. I agreed to order him another test and contact him again. Advice was sought from a GP and the BCSP hub regarding this issue. The hub were able to provide detail on why the previous sample had been refused which was actually in relation to not having written the date on the sample pot. The hub advised the patient to call when he had completed the test to inform them so they could note the date.

Cervical Cancer Screening

Contacts made

Total attempted calls	545
Total patients spoken to	195
Test appointments booked by coordinator	111
Reminder to book given over telephone	54
Text reminders sent	241
Letters/email reminders sent	74
Referrals made to HKP support or community activities	3

Outcomes – screening uptake

	Test completed	Booked but did not attend	Booked but cancelled	Booked but test didn't happen*
Booked by coordinator	48	33	20	4
Booked by patient after telephone reminder	10	3	1	1
Booked by patient after text reminder	21	2	0	3
Booked by patient after email / letter	0	0	0	0
Total	**79**	**38**	**21**	**8**

*NB test didn't happen due to pregnancy or test not due (inaccurate patient data)

Outcomes – clinical

	Tests completed	**Normal result**	**HPV+ 12 month recall**	**Referred for colpo-scopy**	**Awaiting results**
Booked by coordinator	48	44	1	3	0
Booked by patient following call	10	8	0	2	0

Booked by patient following text	21	17	0	2	2
Total	**79**	**69**	**1**	**7**	**2**

Common barriers to cervical screening

Barrier	Explanation	Quotes from people contacted
Access to appointments	One of the main barriers to booking cervical screening that was identified was around work commitments. Patients felt that they could not access smear appointments as they were allocated during the working day. Patients were asked if they could request the time off from work for the appointment – however a number worked in schools and other settings that meant this was not possible. Some patients were able to access early morning appointments. However, there was no appointment provision later in the day/weekends. A number of patients that were called were at work and so couldn't book the smear appointments at the time of the call. Most agreed to call the surgery back at a more convenient time. However, the majority did not call back – reasons for this have not been determined.	
Caring responsibilities	A few women had children and so had to consider childcare when booking the smear appointment. One patient was a single parent with children with special needs. She stated she had no childcare options and had been awaiting a social care assessment for several months and despite having input from the relevant services was still unable to attend due to lack of appropriate childcare provision. Anecdotally she felt lots of other parents in similar position would be facing this barrier. Several patients cited that they had caring responsibilities and so making personal appointments was difficult. During a conversation with one full time carer it was suggested that she speak to her Social Worker about arranging respite care so that she could attend such appointments.	

Fear of procedure	Several patients either held a perception that the smear test would be painful/uncomfortable or had had a previous negative screening experience. One patient had had numerous issues having a smear and had been referred to hospital in the past as the practice nurse had been unable to complete the procedure. She was advised to book a smear at the surgery and to discuss other options with the nurse if they were unable to complete the smear. The smear was completed successfully. One patient disclosed a difficult history with an ex-partner and together with experiencing issues with the position of her cervix which caused her discomfort during the procedure made her reluctant to book an appointment.	**"My last smear was very painful and distressing – I have been putting it off for this reason"** (It was agreed to add this note to the booking and she will raise with the nurse at the appointment.)
Mental health	A number of patients had mental health issues. A patient experiencing anxiety about attending the smear appointment was offered help with getting to the appointment (see case study below). A couple of patients identified that they would benefit from having additional support from family members to attend the appointment. Another patient, when contacted, was in psychiatric hospital, however it was possible to speak to her support worker who agreed to address cervical screening with her on discharge.	
Sexual history	Several patients were uncertain if they required a smear test as they reported to not being sexually active. One patient specifically stating she had not had sex since her last smear test. This particular patient was encouraged to arrange a smear following advice about regarding the risks of cervical cancer.	
Overwhelm	A number of patients either had other physical health issues to manage or personal circumstances, such as divorce/bereavements that meant they felt that they could not address cervical screening at this time**.**	**"I am awaiting tests currently – would rather wait for them and book smear later"** **"I am unwell and scared of the test"**

Less common barriers

- Pregnancy/termination
- Abroad/away
- Perceived as being healthy therefore do not need to be screened
- Uncertainty if full or partial hysterectomy
- Inconvenient time to book smear
- Lack of knowledge/understanding of screening programme
- Menopause – frequent bleeding
- Language barriers

Case study: Cervical screening support
A white female patient in her 40s was contacted who had mental health issues. She described the anxiety she had about attending the cervical screening appointment. It was established that her anxiety was increased by the prospect of having to take a bus to get to the appointment. Consent was gained to refer her to ACT for additional support to attend the appointment. The nature of her anxiety was explored and strategies to reduce the anxiety discussed. She was offered transportation to the appointment, which she accepted as she felt this would greatly improve her likelihood to attend the appointment as the journey would be much quicker via car and avoid using public transport. However, the patient cancelled the appointment due to personal circumstances. She has since felt able to request support from her husband to attend a future appointment. This appointment was re-booked on her behalf.

Lessons learned – successes

- **Removing logistical barriers.** Engagement was more successful when it was clear to the patient that engaging with the screening would not take much time or effort on their part – e.g. the coordinator taking responsibility for ordering the FIT kit or making the cervical screening appointment.
- **Advice and guidance.** Providing advice about how to complete and send back the kits and the timescales involved also appeared to reinforce engagement with the programme.
- **Telephone calls**. Speaking directly with the patient was the most effective method of engaging with patients and improving screening uptake. Texts had some, albeit limited, positive impact on engagement. Letters or emails produced no responses.
- **Being transparent about who was calling**. Using a "soft" telephone that showed the surgery's phone number was helpful in encouraging patients to answer the call.
- **A dual-pronged approach**. Several patients identified that they had recently seen TV campaigns about bowel cancer which in combination with the telephone contact supported their decision to complete the FIT, reducing fear of the test and the potential outcome.
- **Dedicated resource.** Having a coordinator whose sole role was to make these calls, and who couldn't be sidetracked into other practice business (because they weren't a regular member of practice staff), ensured that the calls got made, as practice staff themselves are often pulled into more urgent practice business. The pilot has clearly demonstrated the advantages of having someone from the voluntary sector embedded in a surgery with a clear remit of working solely on cancer screening uptake.
- **Added health promotion benefits.** The calls provided a good opportunity to provide extra health promotion advice. For example, providing information about cancer risk factors and how to reduce the risks in relation to healthy lifestyle advice and what signs and symptoms to look out for.
- **Positive campaign messaging.** This approach in raising hope, delivering positive messaging about cancer screening rather than creating fear seems effective. This has been reflected in the recent ACT cervical screening awareness campaign – focusing on positive messaging that screening can prevent cancer before it starts.
- **Spending more time with patients with complex barriers.** See case studies above. These cases exemplify the importance of having written instructions in an accessible format, and by providing tailored individual support.
- **Partnership working.** With patients with more complex needs it has been helpful to work jointly with either a support worker or carer to provide additional support and encouragement to engage in the screening programmes. Having a trusted person who understood the needs of the individual to encourage participation and to assess if in fact screening was appropriate.

. Lessons learned – challenges

- **Access to appointments.** A number of patients disclosed frustrations around accessing GP appointments. The availability of appointments out of working hours was a common barrier to patients wanting to book cervical screening, indicating a need to increase the provision of appointments.
- **DNAs/continued non response.** The figures demonstrate the need to follow up FIT requests and appointment bookings with further calls to further reduce DNA rates and ensure tests are completed.
- **IT issues.** Due to the part-time and remote nature of the coordinator role, learning IT systems took some time and required support from practice staff and the IT helpdesk.
- **Unclear information about screening processes**. Initial uncertainty around the bowel cancer and screening programmes and timelines both within the surgery and nationally caused some challenges at the outset of the project.
- **Language barriers.** Frequently ethnicity and/or main language spoken was not recorded by the practice and there were challenges to finding out this information.
- **Additional health concerns**. Some patients had complex health needs which required access to advice from medical staff to assess the appropriateness of screening, and at time access to a clinician was limited.
- **Problems with data.** A small number of patients were flagged for screening despite not being due. This may be down to inconsistences with patient records, or lack of clarity around EMIS data.

Next steps for the Act on Cancer Together project

1. Continue learning and refining this delivery model at WellBN GP practice in Brighton and Hove
2. Document a proposed model for contacting non-responder screening patients so that process is clear to worker e.g.establishing how many times a patient is called/texted and action taken if they don't respond, having scripts and "how to" guides available so that induction into the role is clear and transparent
3. Continued development of the support to be offered to patients facing barriers to screening eg: transport, translated materials, chaperone, 1:1 pre appointment to discuss fears/questions.
4. Collaborative work with specialist services, carers, support staff and family members when dealing with individuals in groups experiencing high levels of health inequality.
5. Increased follow up contacts with patients in those groups.
6. Training of GP practice staff on screening programmes and Making Every Contact count; e.g. following up screening during health checks/LD/MH reviews.
7. Deliver training/information sessions to local groups and communities, working with primary care to invite a cohort of patients and staff from GP practices.
8. It is clear that a robust training and support structure must be in place so a streamlined model can be delivered by a worker or volunteer without putting unnecessary demands on already stretched practice staff.
9. Provide leaflets/promotion of screening programmes in waiting rooms.
10. Have a library of accessible/translated and Easy Read information available to provide to patients on screening programmes and cancer awareness.
11. Further review of data around non-responders/screening uptake to look at demographics and longer-term impact of ongoing work.
12. Consider the use of skilled volunteers recruited and supervised by the Act on Cancer Together team to continue this work on a wider scale.

Recommendations for primary care and wider system colleagues

1. Review and implement strategies to address DNA issues – eg send reminder text prior to screening appointment, follow up text/letter to remind to complete FIT
2. Send texts with self-bookable links to patients due cervical screening
3. Work with Brighton and Hove Federation to look at extending access to cervical screening appointments; e.g. accessing women's health clinic at Mile Oak Medical Centre/setting up nervous patient cervical smear clinics
4. Translation of invitation texts and letters in most common languages
5. Work with Act on Cancer Together team to facilitate wider uptake of this work.

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