Applying behavioural insights to increase cancer screening in NE Lincolnshire

A project report by the Behavioural Insights Team

THE BEHAVIOURAL INSIGHTS TEAM

In partnership with Cabinet Office

Local Government Association

NORTH EAST LINCOLNSHIRE COUNCIL
www.nelincs.gov.uk

Contents

Executive summary (1)

Routine cancer screening is an effective way of detecting cancer early when it is easier to treat, leading to better outcomes for people and reduced costs for public services. In England, patients are offered routine bowel and cervical screening, but uptake of these could be improved, particularly amongst people from lower socioeconomic backgrounds. NE Lincs received grant funding from the Local Government Association Behavioural Insights Programme and commissioned the Behavioural Insights Team to increase screening uptake in East and West Marsh wards where it is lower than both the England and the NE Lincs average.

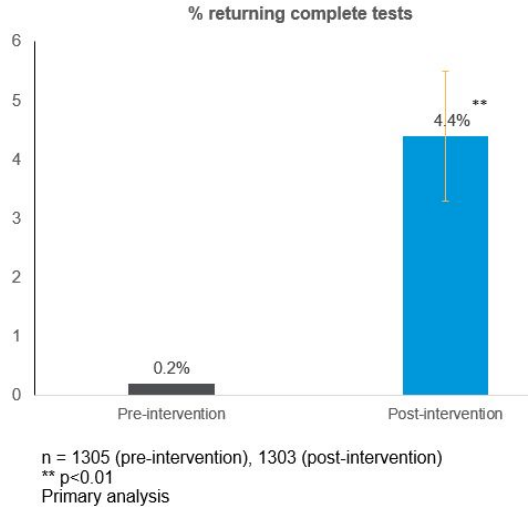
We conducted research with the aim of identifying key barriers to uptake, evidence-based solutions and touchpoints for targeting an intervention at patients. Our review of the academic literature identified a range of barriers such as embarrassment, denial and fatalism, lack of knowledge and awareness, and lack of trust and confidence in being able to navigate the medical system. Many of these barriers were echoed in our interviews with professionals working in NE Lincs.

Although the literature shows that sending reminders can be an effective way of increasing uptake most GPs in NE Lincs did not do so. We decided to test a reminder letter together with two additional behavioural approaches: anticipated regret messaging - asking people to reflect on how they might feel if they got diagnosed too late - and entering people into a lottery if they get screened. The letter was sent by GPs to patients who had not responded to their invite through the national screening programme.

Executive summary (2)

We wanted to send reminder letters to patients who had been invited to the national screening programmes for bowel and cervical cancer. We planned to test the impact using a randomised controlled trial (RCT). We received NHS ethical approval, but Public Health England's cancer screening boards rejected our study design. We were given permission to proceed if we ran a pre-post study (rather than an RCT), focused on one type of cancer and removed the lottery incentives.

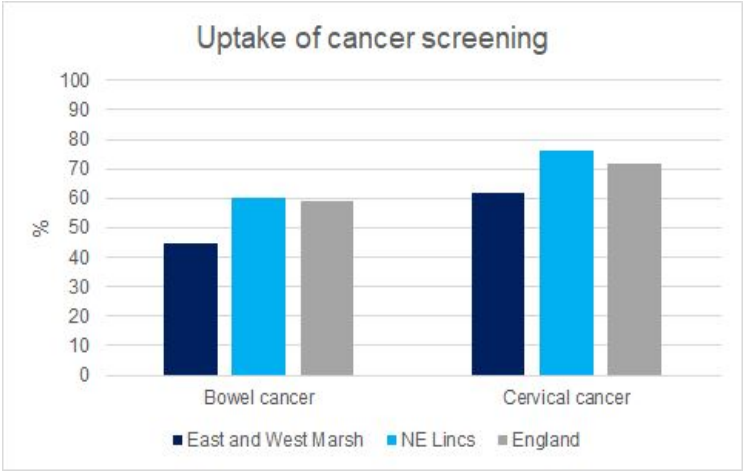
We worked with 5 GP practices to send a reminder letter to all their patients who had been invited to, but not completed, bowel cancer screening between 30 August 2018 and 30 August 2019. Our sample consisted of 1,316 patients. We sent our letters on Monday 11 November and compared the proportion of people returning their kits ten weeks before and after this date. Two patients (0.2%) returned their kits in the pre-intervention period, compared with 54 patients (4.4%) after the letter was sent out; this difference was statistically significant. The significant change in the number of people returning their cancer screening kit combined with the timing of the increase so soon after the letter was sent, suggests the change was due to our intervention rather than chance or other factors. We recommend that NE Lincs Council work with local partners to roll this letter out across all GP practices, and to test other approaches such as lotteries in the future.



Introduction

The challenge

- In England, bowel cancer screening is offered to men and women aged between 60 and 74. Cervical cancer screening is offered to women and transgender men between 25 and 64. Screening helps detect more cancers at an earlier stage when treatment is more effective.[1]
- Bowel and cervical cancer screening uptake is relatively high in North East Lincolnshire but **East and West Marsh wards in Grimsby have lower screening uptake** than the national average. People from lower socioeconomic backgrounds have lower uptake of bowel and cervical cancer screening.[2] East and West Marsh have high levels of deprivation. The lower uptake compared to the rest of NE Lincs is therefore not surprising.
- In March 2018, North East Lincolnshire Council (NE Lincs) commissioned the Behavioural Insights Team (BIT) to design an intervention to increase the uptake of bowel and cervical cancer screening in East and West Marsh. The project was part funded by the Local Government Association (LGA) as part of its behavioural insights programme.



Research overview

The first part of this project involved a range of exploratory research activities in order to better understand the context surrounding screening uptake in NE Lincs. Our aim was to understand the key barriers to uptake, in which population groups, and at what points in the patient journey. We wanted to identify potential behavioural solutions to overcome some of these barriers.

Interviews

We interviewed:

- GP practice managers, family practitioners and the Local GP cancer lead
- Staff at Creating Positive Opportunity (CPO), a local social enterprise, and women at a CPO peer support group
- NHS England - Screening and Immunisation team

Secondary research

- We reviewed the evidence base relevant to bowel and cervical cancer screening uptake. This included screening-specific research as well as more general behavioural science literature.

Data analysis

- We reviewed the number of cases and screening rates in local GP practices to assess the scope for impact and potential for a robust evaluation.

Touchpoint mapping

- We mapped current communication channels with patients to help inform how to target our intervention.

Research findings

The academic literature identifies a number of barriers to screening (1)

Internal barriers

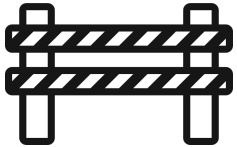
Internal beliefs and feelings [3, 4, 5]

- **Fear:** People can be afraid of experiencing pain or of receiving a positive result.
- **Disgust and embarrassment:** People may feel disgust or embarrassment at the screening procedure. This is particularly the case for bowel screening.
- **Denial and fatalism:** People, particularly those with lack of trust in the health system and confidence in their ability to navigate it, can be in denial despite symptoms. Similarly, people may have a fatalistic attitude and think that the chances of treatment are low. Those in deprived areas are more worried about screening, more fatalistic about cancer and less likely to attend screening.

Intention-action gap (failure to convert intentions into actions) [6, 7]

- **Forgetfulness:** People may simply forget their appointments due to busy lives.
- **Scarcity:** People have a limited mental bandwidth, which is more easily depleted for people experiencing poverty due to financial concerns. This can lead to them ‘tunnel’ and focus on immediate challenges at the expense of acting in their long-term interest.

The academic literature identifies a number of barriers to screening (2)



Other barriers

Social barriers [8]

- **Lack of trust:** People may lack trust in the health system based on previous negative experiences, particularly in deprived communities.
- **Lack of role models:** There may be a lack of role models that normalise cancer screening and make it a positive thing to do, particularly in deprived communities.

Awareness [9]

- **Lack of understanding and knowledge:** People can lack knowledge about the risks of developing cancer, feel low personal risk, and consider the test unnecessary or of no benefit.

External barriers [10]

- **GP access:** Access to GP practices and lack of suitable appointment times can be a challenge.
- **Transport:** Particularly in deprived areas, being able to access GP practices by transport can be a challenge.

These barriers were confirmed by professionals in NE Lincolnshire (1)

- **Educating** people about screening and its benefits is important, as patients receive minimal information on the programmes.
  - This is reflected in the literature: those in deprived areas can be less likely to attend screening because they have a lower knowledge about cancer, lower confidence and self-efficacy and a stronger present bias (i.e. a tendency to overweight immediate demands and costs and undervalue longer-term outcomes).[11]
- **Domestic violence, substance abuse, and unemployment** are relatively high and this can mean families in West and East Marsh do not see healthcare as a priority.
  - The literature shows that patients from lower socioeconomic backgrounds face more stressful situations in their daily lives and have fewer resources to cope with them. They also tend to feel powerless and less supported which makes them less likely to attend cancer screening.[12]
- **Resistance to authority** figures is common, and prior healthcare experiences can mean there is a **lack of trust.**
  - Patients from lower socioeconomic groups can be discouraged from screening by other–health-related beliefs and experiences. For example, they are more likely to have a lack of confidence in dealing with the medical system and to be fatalistic about their health.[13] Given the higher prevalence of cancer in poorer areas, people can ‘get used to’ experiencing cancer - often diagnosed late - as a non-curable condition. Shorter lifespans due to lifestyle and economic hardship contribute to this fatalistic attitude.

These barriers were confirmed by professionals in NE Lincolnshire (2)

- There is a high proportion of **migrant families** in West and East Marsh which can result in additional challenges, especially around language and communication (particularly for Polish and Lithuanian communities).
- Recruitment by phone is problematic, as families are worried about **debt collection calls** and don't answer calls from unrecognised numbers.
- Women often cite **embarrassment and fear of discomfort/pain** as barriers, in addition to a lack of role models to advocate for attending cervical screening.
- There are conflicting feelings of fatalism ("If I have it, I have it") and denial ("It'll never happen to me").
- **Logistical barriers** also exist; for example, if a patient's GP is located on the 'other side' of the river or is not on a bus route, they may be reluctant to attend.

Based on these barriers, practitioners across the system agreed that people need an **additional 'pull'** to encourage screening uptake. In the following section we describe the behavioural approaches we identified.

We identified a number of potential intervention ideas

Timely prompts

- Send behaviourally informed reminders from GP practices e.g. text messages, emails, letters, phone calls, home visits with behavioural framings
- These could be 2 way-communications e.g. “text ‘yes’ to receive a call back to book an appointment”

Incentives

- Offer financial incentives e.g. entering the person into a lottery
- Offer non-financial incentives e.g. Asda vouchers, free bus tickets, pro-social incentive (this has been shown to be effective for breast screening attendance in Australia)

Network nudge

- Encourage individuals who visit practices/attend screening to nudge their friends/family to attend
- Spread behaviour through cancer champions or community groups

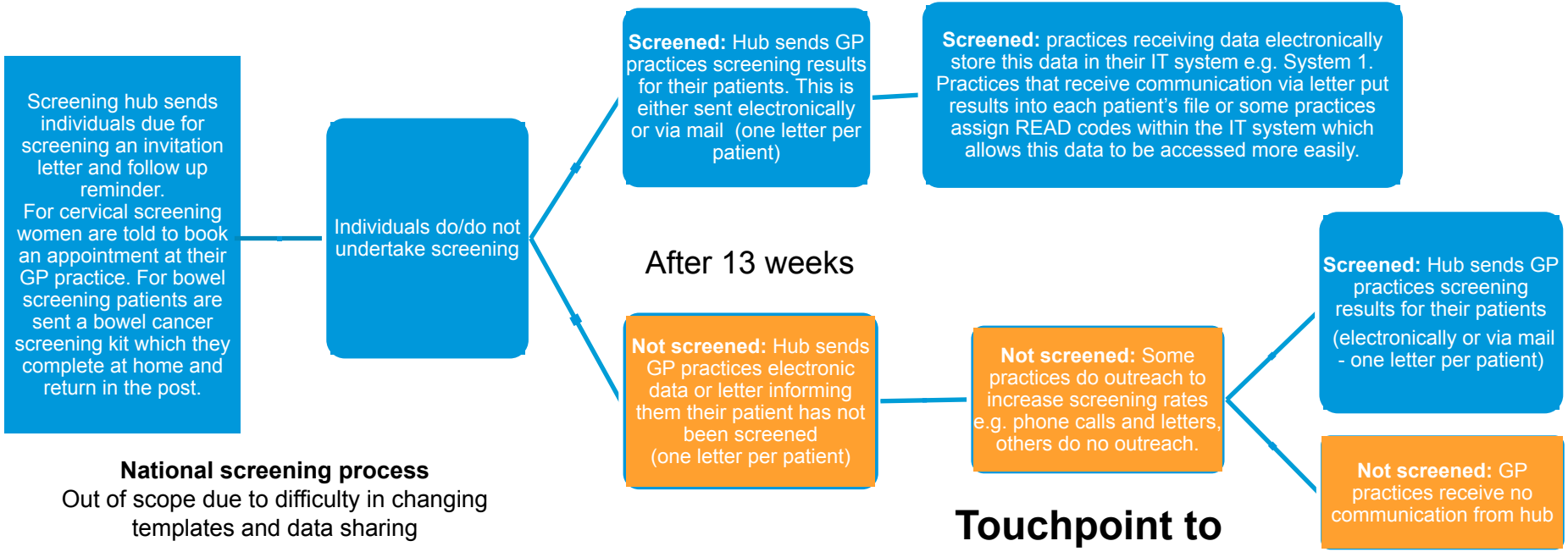
Simplification

- Provide individuals with support to access appointments e.g. practices defaulting individuals into appointments or providing a call back service to book appointments, or volunteers helping to book and organise transport to appointments
- Provide easy read or translated invitations and step by step instructions

Intervention and trial design

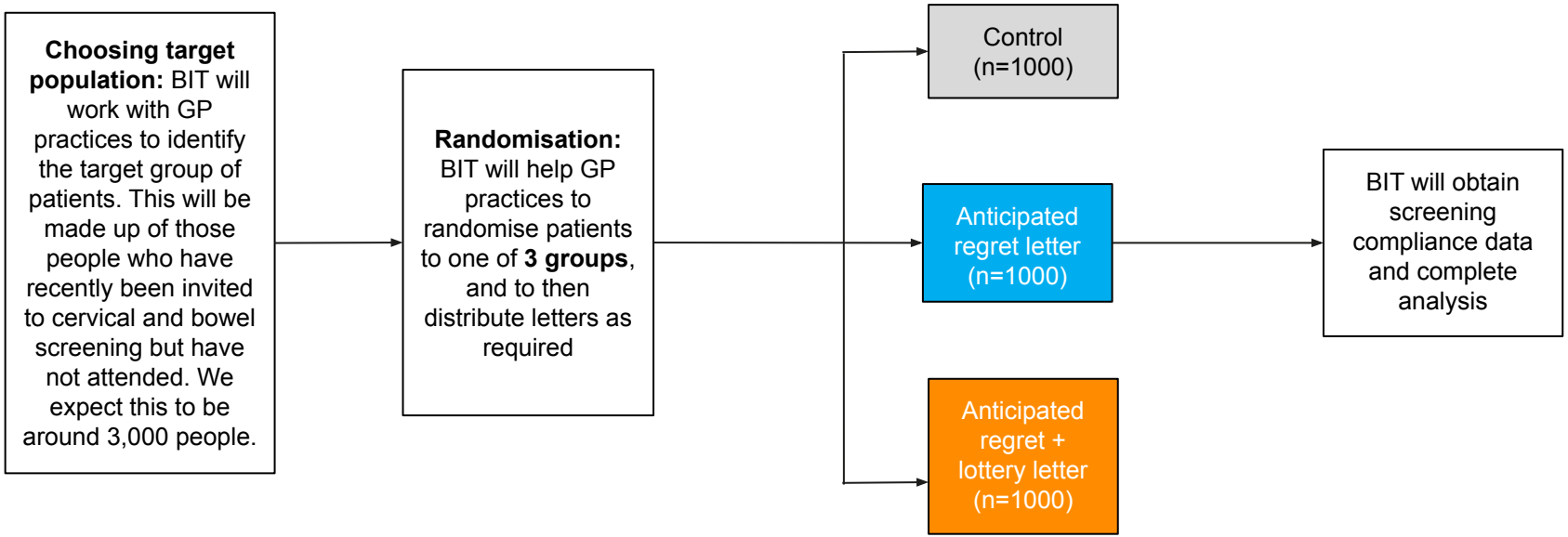
Timeline for national cancer screening programmes

Through the national screening programme all eligible individuals receive the same information from the regional screening hub, but the follow up process with non-attenders varies by GP practice.



We initially designed an RCT testing two different reminder letters on non-attenders of both bowel and cervical screening

Our fieldwork identified that most GP practices did not do any extra follow up with patients who had not responded to the national screening invitations within 13 weeks (‘non-attenders’). We designed an RCT which tested two behaviourally informed reminder letters.



In our reminder letters we wanted to use two behavioral approaches (1)

Loss framing with anticipated regret

Background: The way a risk is framed can have an unexpectedly large effect on how people respond to it. Broadly risks can be framed in one of two ways: a potential benefit of acting (gain framing), or potential cost of failing to act (loss framing). When faced with a risky situation we may be more sensitive to a message stressing the potential losses. There is evidence that **people are more likely to take health-promoting behaviours (such as screening) in response to loss-framed messages** which highlight the potential risks of not acting. **Anticipated regret messaging** prompts people to think about the regret they might feel about having lost the opportunity to avoid a negative outcome (e.g. 'If you were diagnosed late, would you regret not having been screened?'). Combining loss framing and anticipated regret can make a message even more effective.

Example: In an online experiment with Greater Manchester Health and Social Care Partnership, we found that the participants who saw anticipated regret messaging were 8.6% more likely to state they would complete bowel cancer screening, compared to those reading the standard invitation text.[14]

In our reminder letters we wanted to use two behavioral approaches (2)

Lottery

Background: Policymakers often use financial incentives to encourage people to act; for example by offering tax breaks to save for retirement. However, incentives need to be **large enough** to motivate action and this can be a barrier for cash-strapped local authorities. One behavioural approach to addressing this problem is to use lotteries. **Lotteries** tend to be more effective in **changing behaviour**, as people tend to focus more on the size of the prize than their chances of winning it. This may be particularly true of those living in socioeconomically deprived areas.

Example: In a US trial, older male participants were 20% more likely to complete bowel screening when incentivised by a lottery.[15]

Challenges (1)

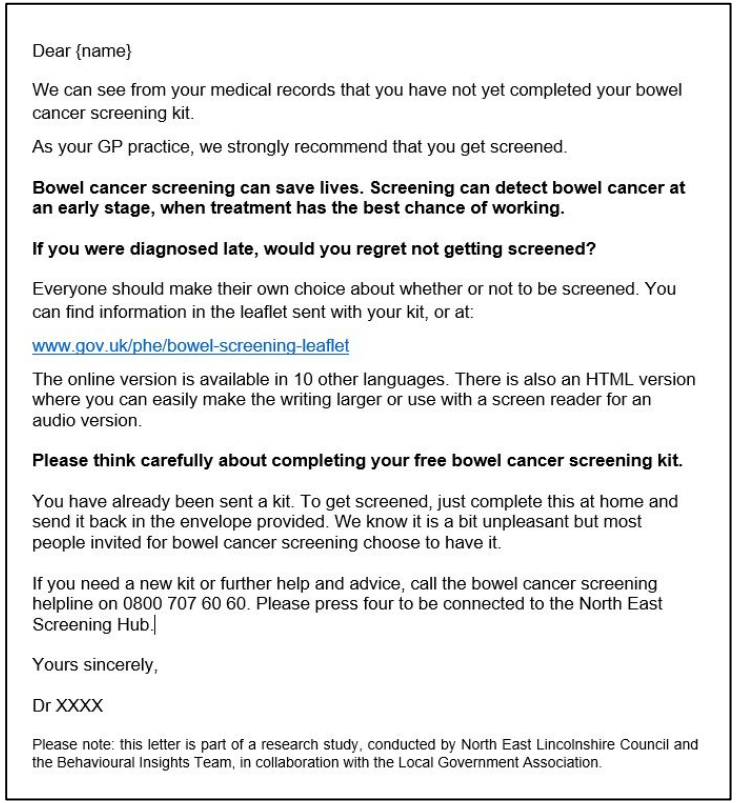
- This was a much more difficult project than we had expected. We initially designed an RCT which included patients who were due to have cervical or bowel cancer screening. We wanted to test two behavioural approaches: anticipated regret and a lottery incentive (see slide 16 for the original trial design). This was mainly due to a lack of clarity about the approval processes needed from NHS and PHE, the interaction with the national cancer screening programmes and the source of the data we needed.
- We knew we had to apply for NHS ethics so once we had our trial design finalised we submitted an application to the Health Research Authority to get ethics approval for our project. We received approval after a round of clarification questions which resulted in minor changes to our intervention letters.
- We then discovered that we also needed to get approval from Public Health England's cancer screening programme boards. We had initially thought our trial was exempt from this because we were not planning on using Screening Hub data (instead getting data direct from GPs). We submitted our application to both the Cervical Screening Programme Research Advisory Committee (CSP RAC) and the Bowel Screening Programme Research Advisory Committee (BSP RAC) and were rejected due to concerns about our study design.

Challenges (2)

- After discussions between Professor Anne Mackie, Director of Screening at PHE, and the LGA, PHE agreed that we could continue the project if we changed the study design and the letter. We focussed on bowel cancer screening, removed the lottery incentive and changed to a pre-post study to measure impact.
- The delays in getting approvals also lead to further delays due to having to restart some of the project management, for example getting back in touch with GP practices to check they were still willing to take part in the project.
- During the early stages of the project we considered using text messages to contact patients. This wasn't possible because the GP practices did not have accurate records of mobile phone numbers and it appeared they did not have permission to use those numbers they had to contact people about cancer screening. For these reasons we decided to send a letter instead.

Intervention letter

- Given the challenges outlined, we were only able to test one version of the reminder letter. The letter had a number of behavioural elements:
    - Simple language with clear next steps and made the process as simple as possible by providing the number of the bowel screening helpline where people could order a new kit if they needed one.
    - An anticipated regret message: “If you were diagnosed late, would you regret not getting screened?”.
    - We emphasised that the GP practice recommended getting screened and highlighted that ‘most people invited for bowel screening choose to have it’ (social norm). We also made it clear that screening is a choice.
    - The letters were printed on headed paper from each GP surgery (trusted messenger).



Dear {name}

We can see from your medical records that you have not yet completed your bowel cancer screening kit.

As your GP practice, we strongly recommend that you get screened.

Bowel cancer screening can save lives. Screening can detect bowel cancer at an early stage, when treatment has the best chance of working.

If you were diagnosed late, would you regret not getting screened?

Everyone should make their own choice about whether or not to be screened. You can find information in the leaflet sent with your kit, or at:

www.gov.uk/phe/bowel-screening-leaflet

The online version is available in 10 other languages. There is also an HTML version where you can easily make the writing larger or use with a screen reader for an audio version.

Please think carefully about completing your free bowel cancer screening kit.

You have already been sent a kit. To get screened, just complete this at home and send it back in the envelope provided. We know it is a bit unpleasant but most people invited for bowel cancer screening choose to have it.

If you need a new kit or further help and advice, call the bowel cancer screening helpline on 0800 707 60 60. Please press four to be connected to the North East Screening Hub.

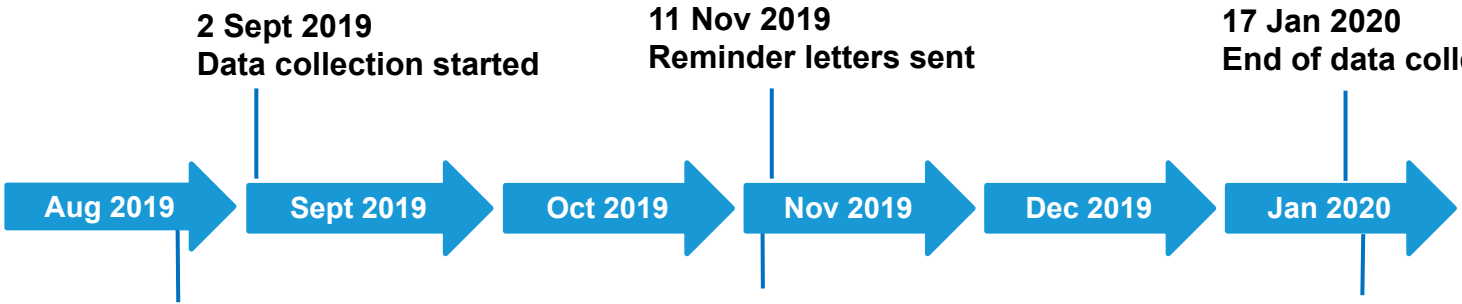
Yours sincerely,

Dr XXXX

Please note: this letter is part of a research study, conducted by North East Lincolnshire Council and the Behavioural Insights Team, in collaboration with the Local Government Association.

Trial design and timelines

We ran a pre-post study comparing the screening rates in our sample during the 10 weeks before and after we sent the letter.



Step 1: Sample identified

At the end of August GP practices ran a report to identify which patients had not completed their bowel screening between 30 August 2018 and 30 August 2019.* People in our sample had received their invitation at various points during this period.

Step 2: Letters sent

GP practices checked if anybody in our sample had returned a screening kit prior to 11 Nov 2019. These people were not sent our intervention letter.

Step 3: Outcome data collected

GP practices shared the outcome data with BIT and BIT completed the analysis.

*In June 2019 NE Lincs started rolling out the new FIT bowel screening kit, which is easier to use and has higher completion rates than the old FOBT kit. People who do not complete their screening are flagged as non-attenders after 13 weeks. We picked 30 August 2019 as the cut off date for our sample as anybody who would have been flagged as a non-attender until this date would definitely have received their invitation before June 2019 and therefore the old kit.

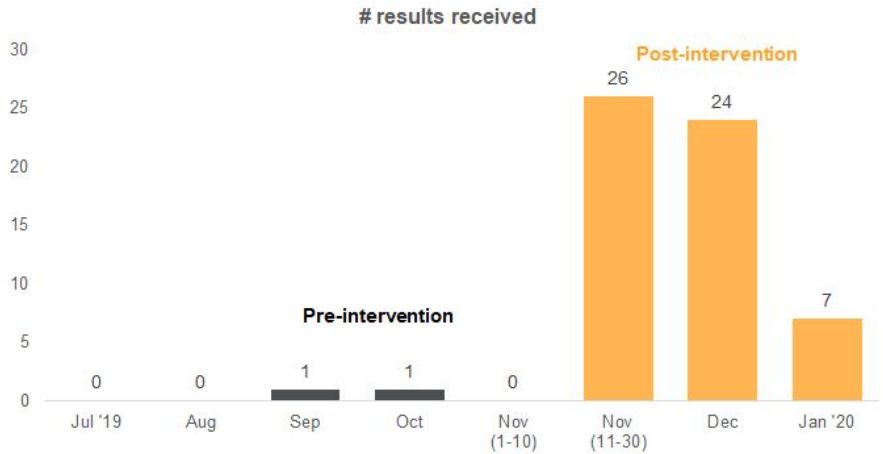
We worked with five GP practices in East and West Marsh wards

Practice	Number of patients flagged as non-attenders*
Roxton	838
Pelham (CV)	271
Dr. Babu	90
Greenlands	59
Pelham (HV)	58
Total	**1,316**

*In June 2019 NE Lincs started rolling out the new FIT bowel screening kit, which is easier to use and has higher completion rates than the old FOBT kit. People who do not complete their screening are flagged as non-attenders after 13 weeks. We picked 30 August 2019 as the cut off date for our sample as anybody who would have been flagged as a non-attender until this date would definitely have received their invitation before June 2019 and therefore the old kit.

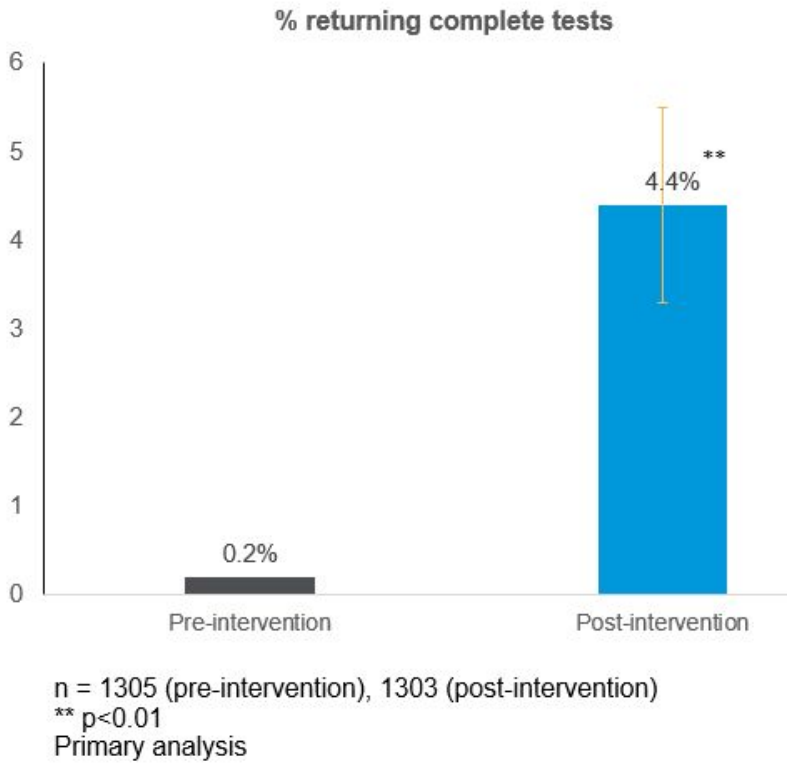
Results and recommendations

There was a sharp increase in kits returned after the reminder letter was sent on 11 November 2019



- As the graph shows there was a substantial increase in the number of patients who sent back their screening kit after the letter was sent.
- The increase in the number of kits being returned was highest in the 6 weeks after the letter was sent and dropped in January.

We observed a sharp increase in results received after the reminder letter was sent on 11 November 2019



n = 1305 (pre-intervention), 1303 (post-intervention)
** p<0.01
Primary analysis

- Two patients (0.2%) from the sample returned their kits in the pre-intervention period, compared to 54 patients (4.4%) after the letter was sent out.
- This difference was statistically significant, which, combined with the timing of the increase, suggests the change was due to our intervention rather than chance or other factors.

Discussion

- As a result of our intervention 52 additional patients were screened.
- The timing and the size of the change in the number of screening kits returned suggests that our intervention worked as intended and that it is a an effective way of increasing uptake of routine cancer screening.
- We therefore recommend NE Lincolnshire Council to work with the local cancer screening lead and GP practices on rolling this letter out.
- We do not know whether the behavioural message (anticipated regret) or simply sending the reminder letter had the most impact. Previous research suggests that anticipated regret is an effective way of increasing health preventative behaviour (such as screening) so we recommend it continues to be included.
- In the future we would recommend that NE Lincolnshire Council test some of the other approaches highlighted in this report to see if they can help increase uptake further.

Lessons learnt

Lessons for future behavioural insights projects

There are several lessons to be learned for future behavioural insights projects in local healthcare systems and the LGA Behavioural Insights Programme more generally.

- **PHE Ethics:** The criteria for which projects require PHE ethics approval were not as clear as they might have been, and we initially thought we did not require this. One learning from this project is to be in touch with PHE as early as possible - alongside the NHS ethics process - to avoid any misunderstandings. In addition, it could be helpful for the LGA to work with PHE to issue guidance on how health trials can be carried out in a local context i.e. outside national screening programmes to allow effective approaches to reduce regional health inequalities.

- **Target a single behaviour/programme:** Individual projects should ideally target a single behaviour or programme to ensure that implementation is feasible. Even when several behaviours are similar (e.g. screening uptake), different organisation structures and processes (e.g. cervical AND bowel screening) make a project much more complicated.

- **Evaluation:** It will often be challenging to conduct RCTs in a local government context, particularly when working in healthcare where ethical approvals are required. Councils and the LGA may want to consider encouraging a greater focus on other evaluation methods such as pre-post or difference-in-difference studies for such projects.

- **Relationships with GPs:** During this project BIT led engagement with the GP practices. To make the project more sustainable it would have been better if the Council had formed and developed those relationships to make it easy to continue contact after the project had finished.

References

References (1)

1. Cancer Research UK (2014). Saving lives, averting costs: An analysis of the financial implications of achieving earlier diagnosis of colorectal, lung and ovarian cancer.

2. Wardle, J., McCaffery, K., Nadel, M., & Atkin, W. (2004). Socioeconomic differences in cancer screening participation: comparing cognitive and psychosocial explanations. *Social science & medicine, 59*(2), 249-261.

3. Jones, R. M., Woolf, S. H., Cunningham, T. D., Johnson, R. E., Krist, A. H., Rothemich, S. F., & Vernon, S. W. (2010). The relative importance of patient-reported barriers to colorectal cancer screening. American journal of preventive medicine, 38(5), 499-507.

4. Senore, C., Inadomi, J., Segnan, N., Bellisario, C., & Hassan, C. (2015). Optimising colorectal cancer screening acceptance: a review. Gut, 64(7), 1158-1177.;

5. Reynolds, L. M., Consedine, N. S., Pizarro, D. A., & Bissett, I. P. (2013). Disgust and behavioral avoidance in colorectal cancer screening and treatment: a systematic review and research agenda. Cancer Nursing, 36(2), 122-130.

6. Von Wagner, C., Good, A., Whitaker, K. L., & Wardle, J. (2011). Psychosocial determinants of socioeconomic inequalities in cancer screening participation: a conceptual framework. Epidemiologic reviews, 33(1), 135-147.

7. Mullainathan, S., & Shafir, E. (2013). Scarcity: Why having too little means so much. Macmillan.

8. Von Wagner, C., Good, A., Whitaker, K. L., & Wardle, J. (2011). Psychosocial determinants of socioeconomic inequalities in cancer screening participation: a conceptual framework. Epidemiologic reviews, 33(1), 135-147.

References (2)

9. Wardle, J., McCaffery, K., Nadel, M., & Atkin, W. (2004). Socioeconomic differences in cancer screening participation: comparing cognitive and psychosocial explanations. *Social science & medicine, 59*(2), 249-261.

10. Von Wagner, C., Good, A., Whitaker, K. L., & Wardle, J. (2011). Psychosocial determinants of socioeconomic inequalities in cancer screening participation: a conceptual framework. Epidemiologic reviews, 33(1), 135-147.

11. Von Wagner, C., Good, A., Whitaker, K. L., & Wardle, J. (2011). Psychosocial determinants of socioeconomic inequalities in cancer screening participation: a conceptual framework. Epidemiologic reviews, 33(1), 135-147.

12. Wardle, J., McCaffery, K., Nadel, M., & Atkin, W. (2004). Socioeconomic differences in cancer screening participation: comparing cognitive and psychosocial explanations. *Social science & medicine, 59*(2), 249-261.

13. Von Wagner, C., Good, A., Whitaker, K. L., & Wardle, J. (2011). Psychosocial determinants of socioeconomic inequalities in cancer screening participation: a conceptual framework. Epidemiologic reviews, 33(1), 135-147.

14. Behavioural Insights Team (2016). Update Report 2015-2016.

15. Kullgren, J. T., Dicks, T. N., Fu, X., Richardson, D., Tzanis, G. L., Tobi, M., & Marcus, S. C. (2014). Financial incentives for completion of fecal occult blood tests among veterans: a 2-stage, pragmatic, cluster, randomized, controlled trial. Annals of internal medicine, 161(10_Supplement), S35-S43.